

# **Survey into Parent and Patient experiences of Selective Dorsal Rhizotomy**

Research Report Prepared for

**WHSSC**

By

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# 1 Introduction

## Background

- 1.1 Support for SDR Wales carried out a survey of parents of patients and patients to provide information from a sample of those who have experienced Selective Dorsal Rhizotomy (SDR). The objective of this survey is to provide supporting information to the WHSSC for the current review being undertaken on the funding of SDR for Welsh patients found suitable for the surgery by neurosurgeons undertaking the surgery in the UK.
- 1.2 The main objectives of this survey are as follows:
  - Provide a demographic of those who have undergone surgery
    - Age
    - Location
    - Where surgery was completed
  - Provide information on the benefits achieved from the surgery for participants in the surgery
  - To understand the complications experienced post surgery
  - To establish the funding arrangements experienced

## 2 Methodology

- 2.1 The survey was uploaded to survey monkey (<https://www.surveymonkey.com/s/J87ZLH9>) and posted to the four facebook pages used by those interested in SDR surgery or who have had SDR. These are <https://www.facebook.com/groups/SDRWales/>  
<https://www.facebook.com/groups/349840758374077/> SDR UK  
<https://www.facebook.com/groups/385434281490178/> SDR Scotland  
<https://www.facebook.com/groups/161839724125/> SDR St. Louis Children's Hospital

A copy of the survey is available in the appendices.

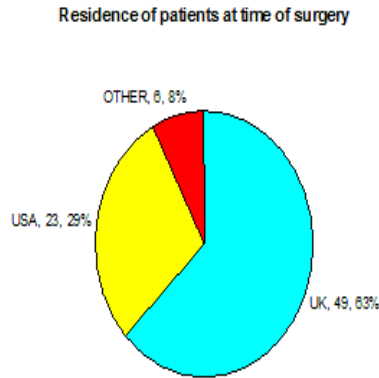
- 2.2 The sample size across these facebook groups was 3,674 as of 11<sup>th</sup> January 2013. This includes a mix of those who have had surgery and those looking into the survey. It also includes duplicates of patients where both parents and indeed grandparents are involved in the groups. The sample figure is therefore inflated due to these factors.

Using the SDR Wales Group we have analysed that 17% of members relate directly to patients who have had SDR surgery. The remainder are duplicate family members or those fundraising for or investigating surgery currently. On this basis, the overall sample size can be reduced from 3,872 to 624 and the response rate was 12.5% (78) of this sample.

There is a 90% confidence rate of an 8.8% error rate based on the response rate and sample size used. On this basis cross tabulation of results is not possible as the sample size would be too small to be statistically accurate.

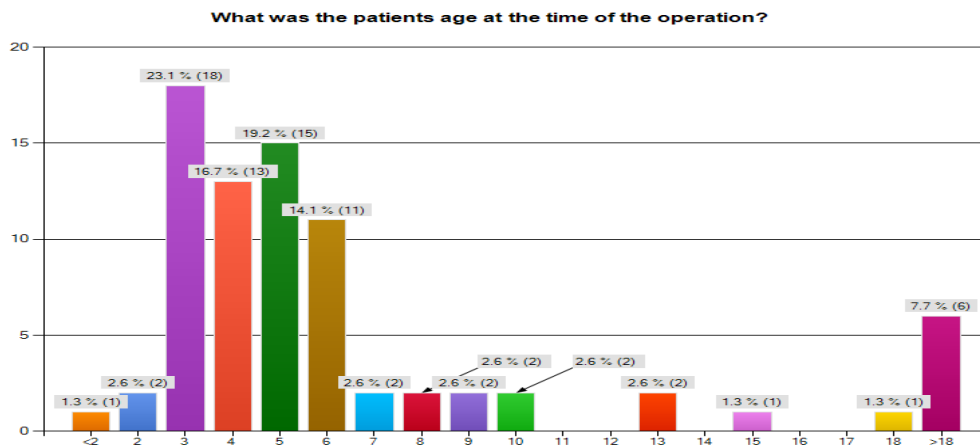
### 3 Demographics

#### 3.1 Residency



63% of respondents were residents within the UK at the time of surgery. 11 respondents were located in Wales (14% of all respondents), 2 in Scotland (3%) and the remainder in England.

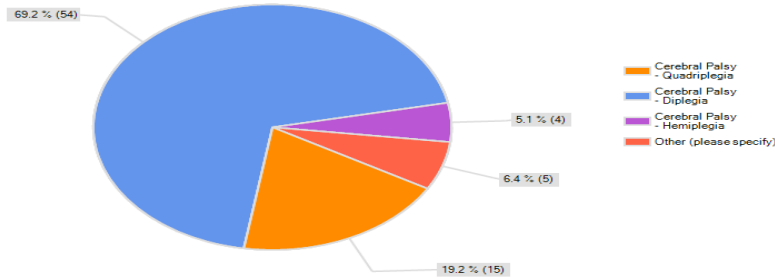
#### 3.2 Age at time of the operation



All respondents answered this question. The current guidelines from NICE advise consideration of surgery for children within the age ranges 3 – 9. This accounted for 81% of respondents of the survey. A small but significant number of respondents underwent surgery over the age of 18. These were completed primarily in the USA where boundaries for consideration are between the age of 2 and 40 (St. Louis Children’s Hospital/Barnes Jewish Age Criteria). One of the respondents over 18 years of age had the surgery completed in the Walton Centre, Liverpool.

### 3.3 Diagnosis

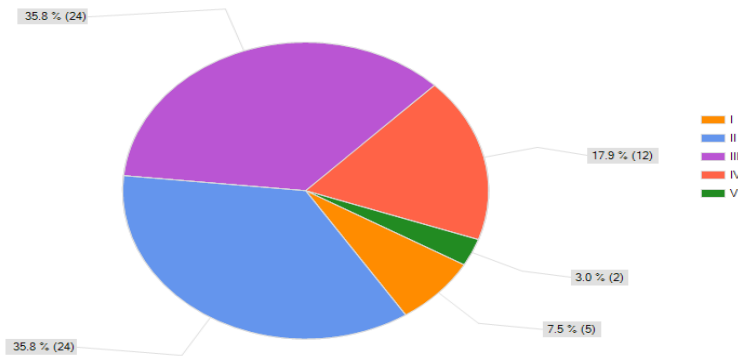
What was the patient's diagnosis prior to Selective Dorsal Rhizotomy?



All respondents answered this question. SDR is primarily used as a treatment for children with Cerebral Palsy – Spastic Diplegia and 69.2% of respondents fell within this category. There were however 18% of patients who are categorised as Cerebral Palsy - quadriplegia.

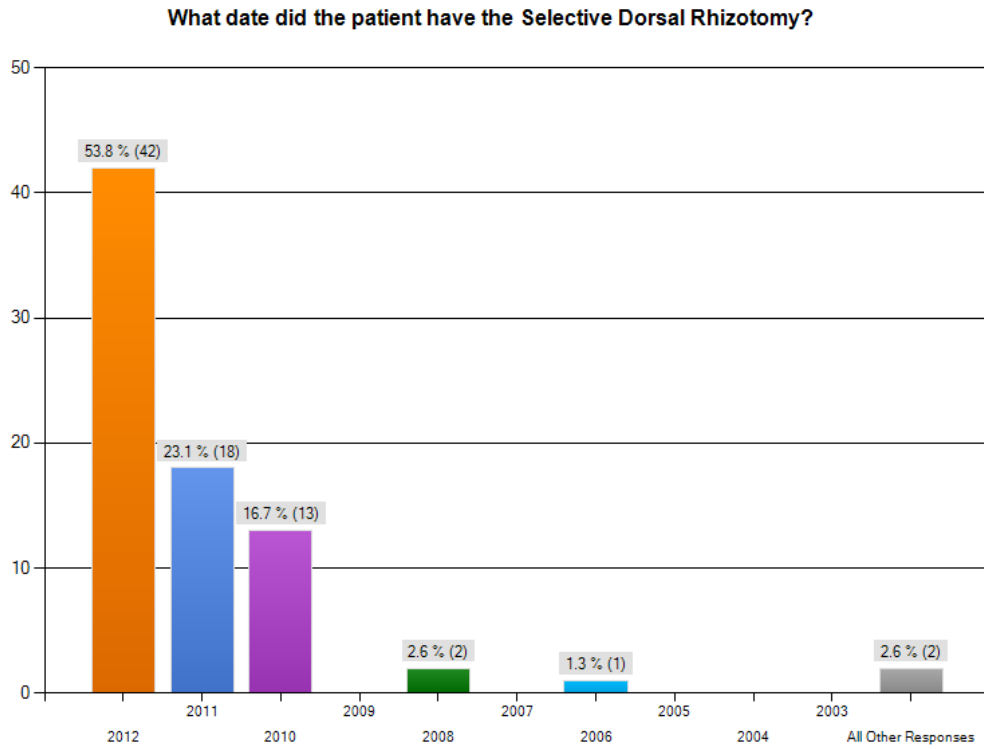
### 3.4 GMFCS

What was the patients Gross Motor Function Score prior to Selective Dorsal Rhizotomy? Explanation of scores can be found here: <http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf>



66 of the 77 respondents completed this question. The recommended categories by NICE for the use of SDR as a treatment for Cerebral Palsy is II and III. (NICE (2012) Spasticity in children and young people with non progressive brain disorders) available online at ([NICE Guidance](#)). Also note NHS Clinical Commissioning Policy: Selective Dorsal Rhizotomy (SDR) December 2012 document in the appendices, which is also available online and provides updated advice. Of the respondents 71.6% fell within the current guidelines. A significant proportion were in the IV category prior to surgery (17.9%) and a small number in the I and V (7.5% and 3%). \_Some individuals had not received a formal analysis of their GMFCS and struggled to answer this question, using a checklist available online for assistance (give link). There may be some error as a result.”

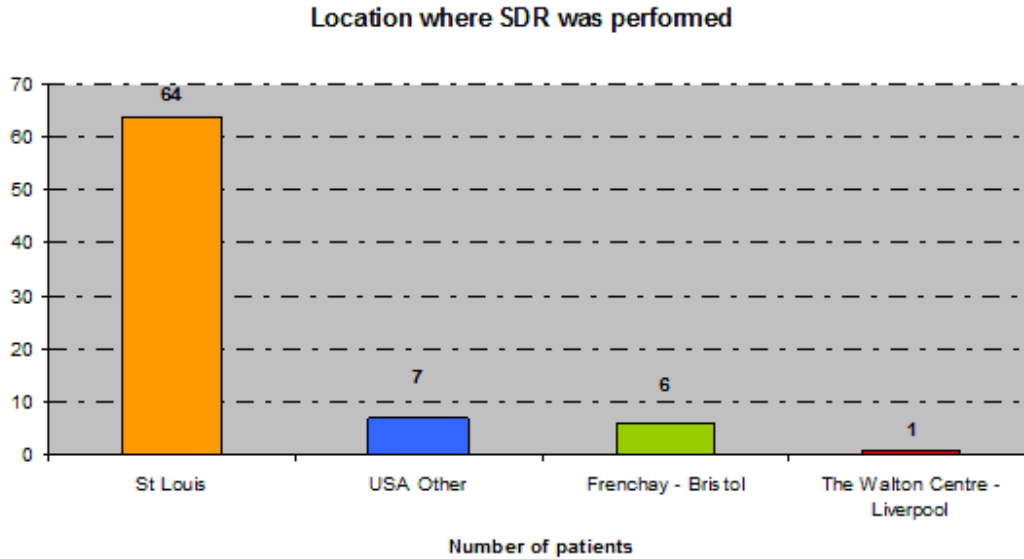
### 3.5 Date of surgery



All respondents answered this question. The data is heavily biased to patients who had the surgery between 2010 and 2012. One of the reasons for this is that the facebook pages concerned were only set up in 2011/2012.

A small number of patients underwent SDR prior to 2000 and a more qualitative review of their experiences will be provided later in this report.

### 3.6 Location of surgery

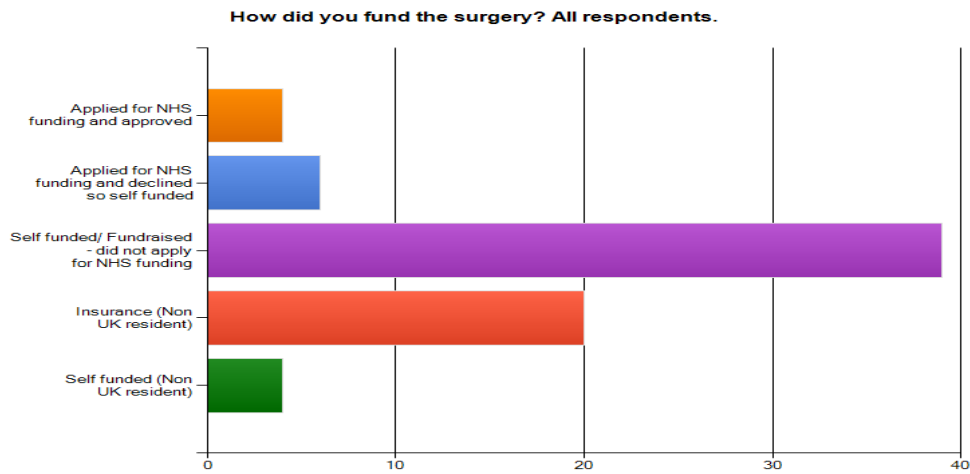


All respondents answered this question. The vast majority of respondents had surgery carried out in St Louis Children's Hospital Missouri, USA. However, given around 30 children have received SDR in Frenchay hospital to date, 6 is a good response rate from this sample, accounting for approx. 20% of all patients who have had surgery at Bristol to date.

St Louis remains the location of choice, although this is primarily due to the availability of surgery and funding arrangements within the UK. SDR has only been available within the UK for one year (2012) and in limited centres. The number of patients having surgery in 2012 who answered this question was 42 of the 78 (54%). If it is further considered that 18 respondents of this 42 were overseas patients and 7 respondents Welsh where no funding is available, this reduces those respondents who would be eligible to apply for funding in the UK in 2012 to 17. Of this 17, 7 had surgery within the UK (41%) and 10 had surgery in St. Louis, USA (59%).



### 3.7 Funding



Of the 78 respondents, 73 answered the question related to funding of the surgery. 24 (33%) of respondents were overseas patients who primarily had the surgery paid for under medical insurance policies.

49 UK respondents answered the question on funding arrangements.

5.6% of respondents applied for NHS funding and were approved. Of the respondents applying for funding this is 40%.

8.3% of respondents applied for funding and were refused. This equates to 60% of all respondents applying for funding. 4 of the 6 respondents declined were from Wales. The decline rate as a proportion of total applicants applying for funding excluding Welsh applicants is 25%. The decline rate for Welsh applicants applying for funding is 100%. This sample size is too small to provide accurate information, however Support4SDR have collated information on funding for English patients and found 50% of those who applied received funding. Anecdotal comments on facebook support groups suggest this is increasing as comments show more and more PCTs are providing funding. What is certain is that no Welsh patients have been approved for funding.

36 patients indicated they self funded and did not approach the NHS. Of these 2 were USA patients who chose the incorrect response for self funding. Of the 34 UK patients who self funded and did not approach the NHS 24% were Welsh patients where funding is not available and 50% were UK patients prior to surgery being available in the UK. Of the remaining 11 respondents who had surgery during 2012, only 1 provided a comment as to why they didn't approach the NHS. "Did ask about funding but told it wouldn't happen".

Anecdotal evidence within the facebook groups indicates similar experiences of other parents when broaching funding with professionals. In addition some parents have decided to go to St. Louis for speed.

### 3.8 Surgery method

Of the 77 respondents, 97% had the limited laminectomy version of the surgery. The 3% had the surgery carried out prior to the limited laminectomy surgery being developed.

## 4 Surgery difficulties and results

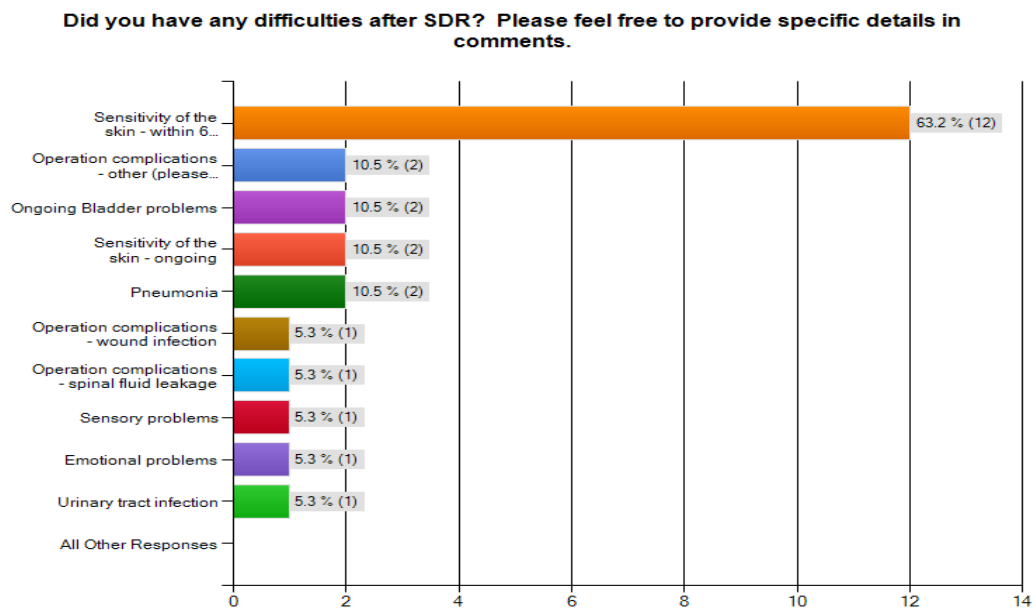
### 4.1 Surgery difficulties

The paragraph below provides information on the complications likely as a result of SDR.

#### “SDR Possible Complications

The dorsal rhizotomy is a long and complex neurosurgical procedure. As in other major neurosurgical procedures, it presents some risks. Paralysis of the legs and bladder, impotence, and sensory loss are the most serious complications. Wound infection and meningitis are also possible, but they are usually controlled with antibiotics. Leakage of the spinal fluid through the wound is another risk.

Abnormal sensitivity of the skin on the feet and legs is relatively common after SDR, but usually resolves within 6 weeks. There is no way to prevent the abnormal sensitivity in the feet. Transient change in bladder control may occur, but this also resolves within a few weeks. A few of our patients have experienced [urinary tract infections](#) and [pneumonia](#).” *St. Louis Childrens.org (2013) “About Selective Dorsal Rhizotomy” (online) (cited 13.01.203) Available from <URL: <http://www.stlouischildrens.org/our-services/center-cerebral-palsy-spasticity/about-selective-dorsal-rhizotomy-sdr>*



19 respondents of the 78 answered this question, 9 of whom only responded to advise they encountered no problems. The sample size therefore for difficulties can be reduced to 10 (13%) of the 78 respondents and there were 25 difficulties raised by these respondents. The analysis of this section is conducted as a proportion of all survey participants to understand the risks attached within the overall sample group.

The most serious complication experienced was spinal fluid leakage and the same patient experienced wound infection. As a proportion of all survey respondents this accounts for 1%. St Louis Hospital advises of more than 2300 patients only 3 experienced spinal fluid leakage, one of which responded to our survey. Of the St. Louis sample, incidences of spinal fluid leakage were less than 1%. *St. Louis Childrens.org (2013) "About Selective Dorsal Rhizotomy" (online) (cited 13.01.2013) Available from <URL: <http://www.stlouischildrens.org/our-services/center-cerebral-palsy-spasticity/about-selective-dorsal-rhizotomy-sdr>*

One respondent noted ongoing sensory issues, which is also listed as a more serious complication. Of the 78 responses to this survey, 2 advised serious complications as a direct result of surgery (3%).

The two other respondents stating operation complications related to complications not specifically related to the surgery itself. One applicant stated problems coming round from the anaesthetic (USA surgery) and the other stated that her son's genitalia was injured on insertion of a catheter plus ongoing bladder problems as a result (UK surgery).

The most commonly experienced problem post surgery was sensitivity of the skin within the first 6 weeks of surgery and this was experienced by 12 (15%) of all survey respondents. Two of these (3%) experienced sensitivity of the skin on an ongoing basis. Other complications which could have been specifically as a result of having the SDR surgery were one report of muscle spasms for a few days post surgery and ongoing bladder problems (2), urinary tract infection (1) and pneumonia (2). Acid reflux (1) was also experienced with this being an ongoing problem not experienced pre surgery. It is not clear if this was as a direct result of surgery.

One additional difficulty was experienced, which does not relate directly to SDR surgery. One patient reported emotional problems relating to the drug Neurontin and once this was stopped the problems ceased.

One of the concerns often raised by professionals in the UK is that SDR can lead to on-going weakness. The question about complications included "on-going increase in weakness" as an option, but this received 0 responses. Whilst these data do not provide evidence of long-term outcome it is important to note that nobody has experienced this problem.

Other potential complications that have not been experienced are:

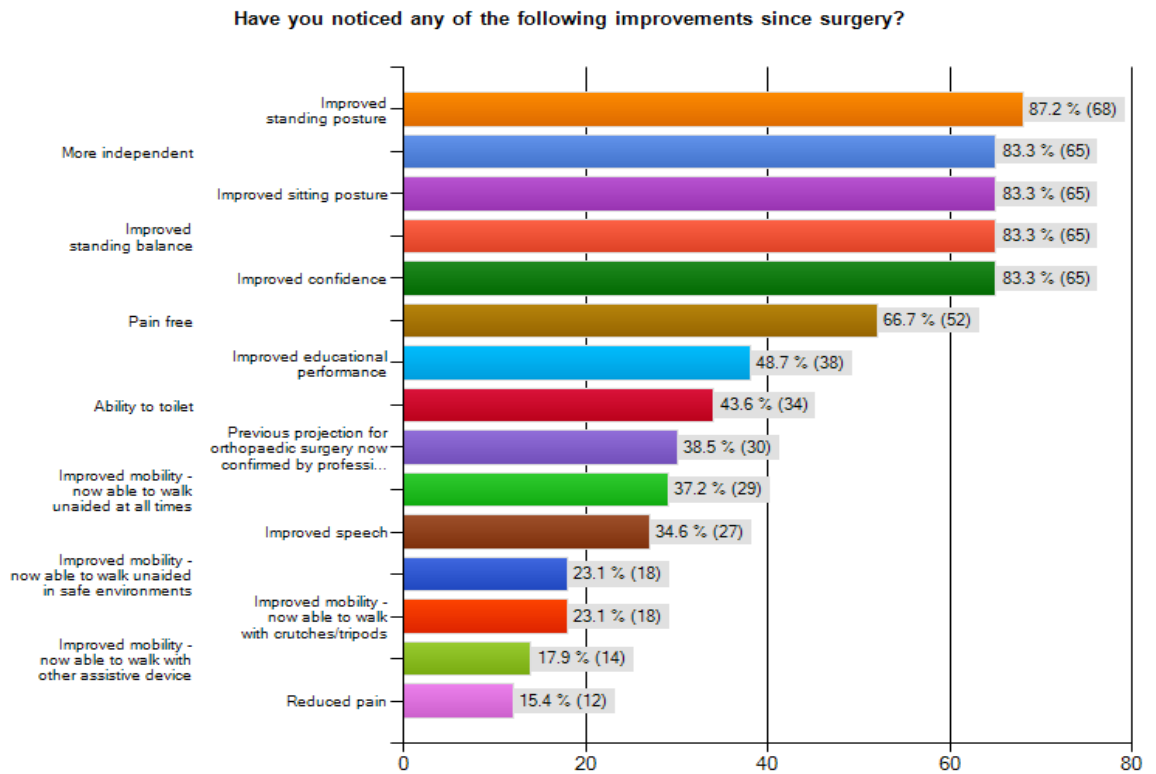
Operation complications - meningitis  
Ongoing increase in weakness  
Weight gain  
Reduced independence  
Reduced mobility  
Reduced confidence  
Scoliosis of the spine  
Orthopaedic surgery resulting from SDR  
Paralysis of the legs  
Impotence  
Spinal fluid collection under the skin  
Anugulation of the spine (kyphosis)  
Unable to carry out required  
physiotherapy

## Survey into Parent and Patient experiences of Selective Dorsal Rhizotomy

An overview of patient comments is provided below. A number of respondents did not tick any of the options for difficulties but completed the text to advise they had experienced no difficulties:

What was the patients age at the time of the operation?	GMFCS Score pre surgery	What date did the patient have the Selective Dorsal Rhizotomy?	What was the patient's diagnosis prior to Selective Dorsal Rhizotomy?	Text of difficulties
3		2006	Cerebral Palsy - Diplegia	no complications/problems at all
4	II	2008	Cerebral Palsy - Diplegia	Feet were mildly sensitive to the touch for about six months post op.
3	II	2011	Cerebral Palsy - Diplegia	Proprioceptive problems more noticeable than previously Actually nothing negative. Only positive. There was the initial weakness, but the rigorous physical therapy post op has my daughter healthier and stronger than ever. Every human being with spastic cerebral palsy should have the opportunity to be free of the chains that bind them(spasticity).
6	II	2012	Other (please specify)	
5	III	2012	Cerebral Palsy - Quadriplegia	Not a single problem noted as of yet and he is 21 weeks post operation. Had very sensitive feet for the few 6 months post op. Now 12months on and all fine now.
6	II	2012	Cerebral Palsy - Diplegia	Prior to surgery, I was highly spastic in my lower extremities, and had a scissor gait, with heels that could not reach the ground. I ambulated with a Kaye Walker, and for longer distances was pushed in a sports stroller. After, I transitioned to forearm crutches and could ambulate independently, though rather uncontrolled in safe environments due to weakness. I became incredibly reliant on my sticks. Which caused problems of its own, and kind of stunted my progress for sometime but I was highly functional on them, so it didn't seem a problem. I had some transient complications related to healing and sensory function as the nerves healed and my brain re-wired itself, but none that were ongoing for more than 6 months or a year at their height and a few years as an occasional recurrence. Any "issues" can also probably be traced to other aspects of growing up as a kid with a disability who has things to overcome as opposed to being directly related to the surgery as well. These included... bladder and bowel issues, and sensitivity of the feet and legs to certain surfaces. The sensitivity issue
3	III	Prior to 2000	Cerebral Palsy - Diplegia	
5	II	2012	Cerebral Palsy - Diplegia	NONE :)
6	III	2011	Cerebral Palsy - Quadriplegia	None of the above
5	II	2012	Cerebral Palsy - Diplegia	In the immediate weeks after surgery there is an increase in pain due to the op. This causes temporary emotional problems and loss of confidence. These had passed within 5-6 weeks after surgery and are considered 'routine'.
4		2011	Other (please specify)	My son got acid reflux after SDR never had it before the operation Dr park said it's nothing to do with the operation but I think different
4	II	2012	Cerebral Palsy - Diplegia	They messed up my sons penis and bladder with the catheter! They did not insert it correctly.....
5	III	2010	Cerebral Palsy - Diplegia	Sensitivity is just tickly legs and feet. Lots of giggling, not a problem at all as he can now walk.
<2	III	2012	Cerebral Palsy - Diplegia	Only side effects were positive. Post surgery, Hari never complained of pain and the effects of surgery have changed Hari's life and our life as a family unit. Hari now sleeps all night, walks unaided and attends mainstream school with no adaption. He can now sit comfortably without needing side support, he is fully toilet trained day and night, can eat solid food, can cross his legs, his speech is now in line with his peers, he can ride a bike, climb a slide.....the list goes on. none of these complications. He strength has increased, not reduced, as has her confidence and toileting control. The physiotherapy and strengthening activities and exercises are hard work, but these are resulting in such noticeable improvements that we all remain motivated so far.
6	IV	2012	Cerebral Palsy - Quadriplegia	
15	III	2012	Cerebral Palsy - Quadriplegia	Muscle spasms for a few nights and pins and needles for a few days
8	IV	2012	Cerebral Palsy - Diplegia	Skin was a bit sensitive initially but no problems at all now
2	III	2012	Other (please specify)	Soles of feet more sensitive/ticklish than before
>18	II	2011	Cerebral Palsy - Diplegia	The emotional problems I faced were a direct result of the Neurontin drug I was on. When I got off of that, that aspect went back to normal. That was not a function of SDR but rather the pain medication. Sensitivity in my hamstrings increased substantially for the first several months. I was very ticklish at first touch (such as during a deep tissue massage), but after that sensations resumed back to normal. My feet were increasingly more ticklish as well. I get a few sharp pains on the bottom of my feet for a few months, but those are "normal" side effects that have passed.
5	III	2011	Cerebral Palsy - Diplegia	Had some difficulty coming out of anesthesia in the few hours immediately after surgery. I don't think this had anything to do with the surgery itself.
5	I	2011	Cerebral Palsy - Hemiplegia	Nothing at all it was very positive experience for us. As soon as our son could walk after sdr he was walking flat footed instead of toe walking
4	III	2011	Cerebral Palsy - Diplegia	His legs were very weak after SDR but within three or four weeks he was back to walking independently but with greatly improved gait and stability.
10	II	2010	Cerebral Palsy - Diplegia	The sensitivity of the skin was only in her feet and she had about 1 week sensitivity in her thighs after SDR. Megan's life has been completely transformed following SDR. It really does scare me to think how Megan would be walking now if she had not of had SDR. My only regret is not finding out about SDR sooner because I know Megan would have benefited even more from SDR if she had been offered SDR around the age of 4. Megan does still have a tilt in her hips which is from spending 7 years leaning forward when she walked up on her toes. After SDR she stood up right for the first time but you can still see her hips are slightly positioned wrongly - this would not have been the case if Megan had been offered SDR at a younger age. The same applies with her feet which now pronate. Many of the kids feet do pronate after SDR but you get far better results on the younger children. Megan has gone from a very high toe walker with feet and legs turning in and would of needed a wheelchair later on in life to a heel to toe walker, feet facing forward and no pain. In my opinion the above questions do
>18	II	Prior to 2000	Cerebral Palsy - Diplegia	I had no side effects.
6	II	2012	Other (please specify)	No negatives only positives. I think it is a shame that not all children with spastic cp are not funded for this procedure.
7	IV	2010	Cerebral Palsy - Diplegia	None we have not had any difficulties.
3	III	2010	Cerebral Palsy - Diplegia	Physiotherapy programme is extremely time consuming and emotional for us as parents and tiring at times

## 4.2 Surgery results



All applicants answered this question and all options received positive responses. The most significant result is the improvement in mobility. 88% of respondents (68) reported some improvement in mobility. Of these, 43% (29) reported the ability to now be able to walk independently without assistance at all times. As a proportion of all respondents this is 37%.

A high proportion of respondents (over 80%) found the following benefits post SDR surgery:

- More independent
- Improved sitting posture
- Improved standing posture
- Improved standing balance
- Improved confidence

## Survey into Parent and Patient experiences of Selective Dorsal Rhizotomy

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67% of respondents reported their child/they were now pain free and a further 15% saw a reduction in pain, meaning 82% of respondents saw an improvement in the pain felt pre-surgery. A basic quality of life without pain is anecdotally one of the primary reasons for parents proceeding with this surgery seen in comments in the facebook pages.

48% reported improvement in educational performance. Removing adults from the responses increases this result to 53%. This is a very high and significant result, which is not easily explained. Some doctors suspect that there may be a neurological reason but reasons given by parents have been the ability of the child to concentrate on studying rather than the effects of spasticity, ability to carry out activities due to improved sitting and standing posture/balance and a new sense of confidence due to achieving more.

44% of respondents reported being able to toilet after surgery whereas prior to surgery toileting was not possible. This improves the quality of life for the child and parent and is one of the unexpected results which parents report on facebook groups that they did not expect. The survey does not distinguish respondents who were already toilet trained prior to surgery and therefore the results are likely to be higher than the indicated 44%.

38% of respondents were advised prior to surgery that orthopaedic surgery would be necessary in the future, but post surgery found this was no longer necessary. This resulted in a financial benefit to the health services concerned for those based in the UK

An overview of parents responses is provided below. Of particular interest for long term results are those who had surgery prior to 2000:

“NO Spasticity at ALL which means that I no longer have to worry about... premature aging, joint deformity, pain, and any number of other things associated with that aspect.”

“Dr. Park performed my SDR in 1990. I am now 42 years old. I walked independently before the SDR and I still do. Before the surgery, I fell at least 20 times a day. Now I fall about twice a month. I am sure I would need crutches or a wheelchair now that I am older if I did not have the SDR. So glad that I did it, wish it was available when I was a child.”

In addition from a personal perspective, as a parent of a child who has had SDR I would like to add my personal perspective:

The primary reason for us to proceed with the surgery, over and above mobility issues, was the fact that our sons hips were dislocating and hip surgery was inevitable. In addition to provide him with reduced pain and some improvement to mobility. We were not expecting miracles.

As a parent whose child could not toilet train prior to surgery, I firmly believe that he trained within a month of surgery as he was able to sit more comfortably and concentrate on the sensation of needing the toilet rather than the spasticity. This is a personal perspective, but the survey results indicate toilet training as a common result indicated by parents.

**Survey into Parent and Patient experiences of Selective Dorsal Rhizotomy**

Respondent comments with patient details:

What was the patients age at the time of the operation?	GMFCS Score pre surgery	What date did the patient have the Selective Dorsal Rhizotomy?	What was the patient's diagnosis prior to Selective Dorsal Rhizotomy?	Text of improvements
3	II	2006	Cerebral Palsy - Diplegia	Basically we bought home a different child!!!!
3	II	2010	Cerebral Palsy - Diplegia	No dribbling. Can perform all activities her friends can.
4	II	2008	Cerebral Palsy - Diplegia	Incredible improvement in physical ability - can now run, play, has learned to snow ski, and is now learning to swim.
4	IV	2011	Cerebral Palsy - Diplegia	Our daughter can now also stand un-aided for approx 2 mins and almost take independent steps!!
4	I	2010	Cerebral Palsy - Diplegia	No longer classed as disabled in the UK and therefore in no receipt of any disability or motability payments
3	III	Prior to 2000	Cerebral Palsy - Diplegia	NO Spasticity at ALL which means that I no longer have to worry about... premature aging, joint deformity, pain, and any number of other things associated with that aspect.
4				Our son's progress since his surgery has been steady. He has transitioned from using a walker prior to SDR to using tripod canes in our home and throughout our community. He has greater endurance, speed, and we are working towards strengthening his muscles even more to aide in his balance. We are now at 10 months post op and still are working towards more progress. We are very grateful that he had this operation.
6	IV	2012	Cerebral Palsy - Diplegia	
6	IV	2011	Cerebral Palsy - Quadriplegia	Huge improvement in sensory area, no longer drools
>18	I	2008	Cerebral Palsy - Diplegia	Can compete and train now at a very high level. Running 5K's and training hard 4x- 5x per week
				Improved range (nhs physio ranges), able to open his legs to get on ride-on toys, toilet (couldn't open his legs prior to push winky down!), his 10 meter walk test as done by nhs physio's to ascertain energy efficiency MASSIVELY improved- pre op Dec 2011 55 steps in 45 seconds, July 2012 7 months post op 28 steps 12 seconds, 19 Dec 2012 1 year exactly post op (sdr20/12/2011), 26 steps 11 seconds-that's a 75% reduction in time taken! Also his resting heartbeat after walking 50 meters returned to normal after 5 minutes, pre-op it was 12 bpm faster-again meaning he is more energy efficient. Ability to gain strength in own muscles, ability to stand (and mobilise) without splints, reduction in orthosis afo-daf0 (meaning easier to get shoes so less expense for nhs!). Ability to run and jump (which I believe the gmfcs classifications is unlikely in cat 2 children).
3	II	2011	Cerebral Palsy - Diplegia	
3		2012	Cerebral Palsy - Quadriplegia	Had severe hyperacusis wore ear defenders 95% of the time hasn't worn them since surgery
6	IV	2012	Cerebral Palsy - Quadriplegia	He only had the operation 4 weeks ago, and we have already noticed these improvements. We are excited about the far greater improvements we may see after 1-2 years of physiotherapy.
8	II	2011	Cerebral Palsy - Diplegia	able to flex foot in a way that allows him to practice bike riding and pedal pressing motion. muscles are looser.
<2	III	2012	Cerebral Palsy - Diplegia	Hari now walks completely unaided, pre sdr could not stand unaided, transfers are much much easier now, and personal care. Our daughter still cannot transfer by herself so at present her independence has not increased a lot, but we are hoping that she will manage independent transfers in time. She is only 7 months post-op. We're waiting for results of her hip x-rays. One hip was 25% uncovered beforehand. We are hoping that this has stabilised - the orthopaedic surgeon did not seem worried about hips at our last appointment post SDR, and confirmed that she would no longer need Botox injections. She is less exhausted all the time and seems more free to move and talk and think. We are all delighted with her progress. She loves being able to walk about with her friends in her walking frame in the playground and along the corridors at school. Although some people suggest that SDR weakens a child, the reverse has been true for our daughter. She is far stronger now than she was. Her legs are looking muscly and more like her friends'. She had giggle incontinence on occasions before SDR, but that is no longer a problem.
6	IV	2012	Cerebral Palsy - Quadriplegia	I would have ticked all them, but they didn't all apply as Brooke had good marks in the others pre-surgery
8	IV	2012	Cerebral Palsy - Diplegia	Increased strength!! I could not stand up from a squatting position. Now I can squat down, pick up my 7 and 5 year old children and stand up with ease. I gained 2" in diameter in my thighs within the first 3 months post op. Ability to stretch. I could not touch my toes for 38 years. Now I can easily wrap my hand completely around the sole of my feet. I could not run for the last 8 years. This past summer I ran a 5k and 2 Warrior Dashes, and finished in the top 1/3rd in all events.
>18	II	2011	Cerebral Palsy - Diplegia	Is a lot more flexible, doesn't tire, can climb stairs correctly & independently, run with longer strides, doesn't toe walk nor toe in on right hand side at all. All of which he couldnt do pre SDR and therefore his confidence is now unbelievable.
5	I	2011	Cerebral Palsy - Hemiplegia	
4	III	2011	Cerebral Palsy - Diplegia	He is able to participate in almost all the activities at school with other children and doesn't just get left behind.
				Dr. Park performed my SDR in 1990. I am now 42 years old. I walked independently before the SDR and I still do. Before the surgery, I fell at least 20 times a day. Now I fall about twice a month. I am sure I would need crutches or a wheelchair now that I am older if I did not have the SDR. So glad that I did it, wish it was available when I was a child.
>18	II	Prior to 2000	Cerebral Palsy - Diplegia	Seb had no educational or speech needs prior to surgery.
3	II	2012	Cerebral Palsy - Hemiplegia	



## 5. Conclusions and recommendations

- The survey findings show that current patient demographics are close to those set out within the criteria for patient selection by NICE. However, positive results have been reported by patients outside this group where they have been selected by a professional in SDR as appropriate for the surgery.
  - The current NICE guidelines are supported, however the surgery should be available outside this demographic if a professional with experience in the surgery finds it an appropriate solution. This would require referral for assessment to be open to all potential patients.
- A high proportion of patients reported benefits post surgery, not all of which were related to mobility. There were also a high proportion of quality of life benefits reported.
  - Improved mobility should not be the only factor in considering the benefits associated with SDR
- A low proportion of difficulties was reported by the sample group. Serious complications were 3% of the sample and most difficulties were short term.
  - The survey results support SDR as a safe surgery, although it is noted that any surgery including orthopaedic surgery presents high risks.
- As the results indicate safety of the surgery and high reported benefits, SDR surgery should be made available to patients in Wales who are selected as appropriate by surgeons undertaking the surgery in the UK.

## Appendices

Questionnaire



SDR Surgery  
Questionnaire 2012/2

Clinical Commissioning Body: Selective Dorsal Rhizotomy (SDR) December 2012



Clinical  
Commissioning Body: