National Institute for Health and Care Excellence

IP1747 Botulinum toxin injections into the urethral sphincter for idiopathic chronic non obstructive urinary retention

IPAC date: 9th March 2023

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1	Consultee 2 NHS professional	1.1	This is an uncommon condition and so the number of women in studies will be low. Transperineal botulinum toxin injections in women with idiopathic chronic non-obstructive urinary retention due to external urethral sphincter dysfunction have been shown to be: 1/ An effective minimally-invasive outpatient treatment -Study 6 cited in the NICE document (Panicker et al. 2016): 10 women; demonstrated significant improvements in flow rate, postvoid residual volumes and Patient Reported Outcome Measures (IPSS) at 1 week, 4 weeks and 10 weeks after the treatment. Acceptable side effects profile -Audit completed in 2022- 11 year follow up study (I am submitting the results of this study to NICE) • 33 women; mean age ±SD 30.2±2.34years • 20 (61%) responders • Number of injection sessions 165 • 15 patients received >1 injection; median interval 112 days (IQR 70) • Number of repeat injections 129; median 3 per responder (range 1-25 injections) 2/ A safe treatment with only mild and transient side effects	Thank you for your comments. The study Panicker 2016 is already included in the evidence overview. Thank you for submitting additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed). Adverse events (i.e, mild pain, incontinence) presented in this study have already been reported in the overview. Efficacy data that has not been published in a peer reviewed journal are not normally selected for presentation to the Committee. Therefore, this study was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.

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			-Study 6 cited in the NICE document (Panicker et al. 2016): no serious side-effects were reported. UTI (n=3 injections), however this was not related to the intervention as the procedure was performed tranperineally and not transurethrally -11 year follow up study: side effects mild and transient: n=19 (11.5% of injections). Stress Incontinece rate 6.7% all injections	
2	Consultee 2 NHS professional	1.1	From a clinical perspective, alternate interventions have significant health and resource consequences such as: - Long-term urethral/suprapubic catheterisation (associated complications include Urethral cleavage, Recurrent urinary tract infection, urosepsis, financial burden to NHS as have to organise to supply catheters, treat UTI's with antibiotics, and arrange for appointments with healthcare professionals inside and outside of hospital for catheter changes every 8-12 weeks, need for both urologist and radiologist to be present in theatre for SPC insertion) -or major Reconstructive abdominal and pelvic surgery eg. Mitrofanoff channel formation (complications include Complications associated with major surgery including DVT, PE, wound infection, Revision surgery for stomal stenosis, Persistent lifetime catheterisation of mitrofanoff channel intermittently, Lifetime follow up for patient with Urologist). Furthermore, expenses should be considered. Intervention- Botulinum toxin (unit price £171.3; 4 injections/year; annual cost- £685.2) Comparator- Intermittent catheterization- the only other alternative treatment (unit price £1.50; 4 catheters/day; annual cost- £2190. However costs escalate with increased UTI risk and need for medical care, antibiotics	Thank you for your comments. IPAC is not looking at comparative effectiveness or cost. IPAC discussed the alternative options available.

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3	Consultee 2 NHS professional	1.1	***Used only in research*** In women with idiopathic chronic non-obstructive urinary retention due to external urethral sphincter dysfunction (otherwise known as Fowler's Syndrome, primary disorder of urethral sphincter relaxation or high tone no-relaxing sphincter), the first line treatment (sacral neuromodulation) is not feasible in several women because of medical/psychological co-morbidities, BMI in the underweight or obese range, lack of availability or patient choice. Urethral sphincter botulinum toxin A injected transperineally following a standardised minimally invasive technique in outpatients has been shown to be effective and safe in follow up studies when offered within a robust governance framework. I would request the panel to make a special arrangements recommendation for this treatment, specifically in the context of women with idiopathic chronic non-obstructive urinary retention due to external urethral sphincter dysfunction.	Thank you for your comments. IPAC considered your comment and amended the recommendation in section 1 to special arrangements for people with external urethral sphincter dysfunction based on lack of alternative options.
4	Consultee 2 NHS professional	1.2	**Further research should ideally be in the form of randomised controlled trials** We explored setting up a Randomised control trial in this group and it was found not to be feasible because: 1. Idiopathic chronic non-obstructive urinary retention covers a broad heterogeneous group of patients who share very little in terms of pathophysiology 2. The group of patients who have responded to botulinum toxin are women with women with evidence for external urethral sphincter dysfunction (Fowler's Syndrome). This is an uncommon condition and therefore recruiting a sufficient number for a trial	Thank you for your comments. IPAC considered comments about a subgroup of patients who would benefit from this procedure and also about feasibility and difficulty of conducting a randomised controlled trial. Section 1 has been amended and the recommendation has been changed to special arrangements for people with external urethral sphincter dysfunction.

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			would be a challenge. 3. Furthermore, Fowler's Syndrome often overlaps with other co-morbidities (joint hypermobility syndrome, psychological co-morbidities, functional disorders, POTS etc.). The presence of these co-morbidities make them unsuitable for participating in an RCT 4. Would struggle with convincing a ethics committee about injecting a placebo into the sphincter of healthy women belonging to the comparator arm of an RCT 5. We were unable to find a potential funder	
5	Consultee 2 NHS professional	2.3	Indeed, a standardised technique has consistently been followed since 2010: The transperineal injection technique involves the following steps: -Application of local anaesthetic (lidocaine) agent periurethrally -Injection of 2% lidocaine periurethrally at the 3 o'clock and 9 o'clock positions -100 units botulinum toxin A diluted in 1 ml of saline injected into the urethral sphincter divided at the 3 o'clock and 9 o'clock positions -Electromyography (EMG) of the urethral sphincter is performed in these women as part of their diagnostic workup and can help to identify the location of the urethral sphincter.	Thank you for your comments. This section of the guidance is intended to be a broad summary of the procedure. **IPAC considered and amended section 2.3 and 2.4 as follows:** Botulinum toxin type A injection into the urethral sphincter for idiopathic chronic non-obstructive urinary retention is usually done as an outpatient procedure with the person awake and lying in the lithotomy position. A local anaesthetic is used on either side of the external meatus. Botulinum toxin type A diluted with normal saline is injected directly into the external urethral sphincter using a syringe needle. A transperineal route (EMG guided) is used in women and a

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				transurethral route (cystoscopy guidance) is used in men. The dose and number of injections used, and the depth and the position of injections on the endoscopic ultrasound, vary and depend on the discretion of the clinician. People a have oral antibiotics for a week. The aim of the procedure is to relax the sphincter muscle and restore voiding function. It may be repeated every few months.
6	Consultee 2 NHS professional	2.3	Comments have been provided in the overview document	Thank you for your comments. See response to comment 5.
7	Consultee 2 NHS professional	2.3, 2.4	A standardised technique has consistently been followed since 2010: The transperineal injection technique involves the following steps: -Application of local anaesthetic (lidocaine) agent periurethrally -Injection of 2% lidocaine periurethrally at the 3 o'clock and 9 o'clock positions -100 units botulinum toxin A diluted in 1 ml of saline injected into the urethral sphincter divided at the 3 o'clock and 9 o'clock positions -Electromyography (EMG) of the urethral sphincter is performed in these women as part of their diagnostic workup and can help to identify the location of the urethral sphincter.	Thank you for your comments. See response to comment 5.
8	Consultee 2 NHS professional	2.3	under EMG, or electrical stimulation and cystoscopy guidance. usually performed either transperineally (EMG guided) or transurethrally (cystoscopy guidance)	Thank you for your comments. See suggested amendments in response to comment 5.
9	Consultee 2	2.3	A local anaesthetic may be used.	Thank you for your comments.

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	NHS professional		is always	See suggested amendments in response to comment 5.
10	Consultee 2 NHS professional	2.4	Incorrect- a catheter is not introduced as part of the procedure	Thank you for your comments. See suggested amendments in response to comment 5.
11	Consultee 2 NHS professional	2.4	Incorrect- no hospital admission required for transperineal injections. This is an outpatient procedure and the patient can leave immediately afterwards	Thank you for your comments. See suggested amendments in response to comment 5.
12	Consultee 5 NHS professional	2.3, 2.4	in the uro-neurology department at UCLH we use EMG guidance we have a standard technique for injections. OnabotulinumtoxinA is injected into the external urethral sphincter as an outpatient procedure by the transperineal approach. In the supine position, 1mL of 2% lidocaine is injected on either side of the external urethral meatus, followed by 100 units of OnabotulinumtoxinA (BotoxTM; Abvie, Irvine, CA, USA), dissolved in 2 mL saline injected transperineally into the striated urethral sphincter divided on either side at the 3 and 9 o'clock position. We do not insert an overnight catheter. The patients are not admitted - it is an outpatient procedure.	Thank you for your comments. **IPAC considered and amended section 2.3 and 2.4 as follows:** Botulinum toxin type A injection into the urethral sphincter for idiopathic chronic non-obstructive urinary retention is usually done as an outpatient procedure with the person awake and lying in the lithotomy position. A local anaesthetic is used on either side of the external meatus. Botulinum toxin type A diluted with normal saline is injected directly into the external urethral sphincter using a syringe needle. A transperineal route is used in women and a transurethral route is used in men. The dose and number of injections used, and the depth and the position of injections on the endoscopic ultrasound, vary and depend on the discretion of the

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				clinician. People a have oral antibiotics for a week. The aim of the procedure is to relax the sphincter muscle and restore voiding function. It may be repeated every few months.
13	Consultee 5 NHS professional	3	I have made some online comments as well. I would also like to submit additional evidence, which is an abstract of a study we recently presented at a conference (ICS conference - Vienna 2022) - BOTULINUM TOXIN INJECTIONS INTO THE URETHRAL SPHINCTER IN WOMEN WITH CHRONIC URINARY RETENTION DUE TO FOWLER'S SYNDROME: A TWO YEAR STUDY DURING THE COVID PANDEMIC Please find the pdf enclosed. experience during Covid pandemic.pdf	Thank you for submitting additional evidence (a conference abstract). Adverse events (i.e, pain, bleeding, incontinence) presented in this study have already been reported in the overview. Efficacy data that have not been published in a peer-reviewed journal article are not normally selected for presentation to the Committee. Therefore, this study was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
14	Consultee 2 NHS professional	3.6	Should be avoided in men as -pathophysiology of nonobstructive urinary retention is poor - efficacy data not convincing Whereas in females with Fowler's Syndrome the efficacy is greater. Please see: - 11 year follow up study data that is being submitted to NICE -Nadeem M, Lindsay J, Pakzad M, Hamid R, Ockrim J, Greenwell	Thank you for your comments. 3.5 currently states that *' Women have the procedure more commonly than men'.* The recently published retrospective study (Nadeem M 2022) has been

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			T. Botulinum toxin A injection to the external urethral sphincter for voiding dysfunction in females: A tertiary center experience. Neurourol Urodyn. 2022 Nov;41(8):1793-1799. doi: 10.1002/nau.25023. Epub 2022 Aug 18. PMID: 35979710.	added to the overview and considered by the committee.
15	Consultee 5 NHS professional	3.6	in the uro-neurology department we perform the procedure only in women with Fowler's syndrome	Thank you for your comments. 3.5 currently states that ***'*** *Women have the procedure more commonly than men'.*
16	Consultee 2 NHS professional	3.7	In the 11 year follow up study of women undergoing transperineal injections (this is being submitted to NICE), women with a higher Urethral Pressure Profile were found to have a better response to treatment. This suggests that it is the group with sphincter overactivity (as evidenced by high urethral pressure profile) that should be offered this treatment Similar result seen in women following transurethral injections (Nadeem M, Lindsay J, Pakzad M, Hamid R, Ockrim J, Greenwell T. Botulinum toxin A injection to the external urethral sphincter for voiding dysfunction in females: A tertiary center experience. Neurourol Urodyn. 2022 Nov;41(8):1793-1799. doi: 10.1002/nau.25023. Epub 2022 Aug 18. PMID: 35979710.)	Thank you for your comments. The recently published retrospective study (Nadeem M 2022) has been added to the overview and considered by the committee. Efficacy data that has not been published in a peer-reviewed journal are not normally selected for presentation to the Committee. Therefore, the additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed) was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
17	Consultee 5 NHS professional	3.7	we confirm sphincter overactivity with UPP and urethral sphincter EMG - only these patients would be suitable candidates for the treatment in our department	Thank you for your comments.

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				Section 3.6 currently states that *'The procedure is most likely to be useful in people with sphincter overactivity'*.
18	Consultee 2 NHS professional	Lay description	Difficulty passing urine or being unable to completely empty the bladder (urinary retention) can happen if the muscle controlling release of urine from the bladder (urethral sphincter) does not relax. Incomplete statement- should read muscle controlling release of urine from the bladder (urethral sphincter) does not relax or the muscle lining the bladder (detrusor) does not contract	Thank you for your comments. **IPAC considered and amended the lay description as follows:** Difficulty passing urine or being unable to completely empty the bladder (urinary retention) can happen if the muscle controlling release of urine from the bladder (urethral sphincter) does not relax or the muscle lining the bladder (detrusor) does not contract.
19	Consultee 5 NHS professional	Description	In our department (Uro-Neurology, UCLH) there is a careful selection of patient suitable for the procedure - patients need to be diagnosed with Fowler's syndrome (high UPP and/or abnormal urethral sphincter EMG showing decelerating bursts).	Thank you for your comments.
20	Consultee 2 NHS professional	Outcomes	Urinary symptom profile missing (please see data being submitted) Bladder diary missing	Thank you for your comments. Thank you for submitting additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed). Efficacy data that has not been published are not normally selected for presentation to the Committee. Therefore, this additional data was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting.

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				IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
21	Consultee 2 NHS professional	Overview evidence assessed	this IP overview is based on 313 patients from Submitting to NICE the results of a 11 year follow up study of women with chronic idiopathic urinary retention undergoing botulinum toxin injections into the sphincter	Thank you for your comments and submitting additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed). Adverse events (i.e, mild pain, incontinence) presented in this study have already been reported in the overview. Efficacy data that has not been published in a peer-reviewed journal are not normally selected for presentation to the Committee. Therefore, this additional data was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
22	Consultee 2 NHS professional	Validity and generalisability	And short period of follow-up Submitting to NICE the results of a 11 year follow up study of women with chronic idiopathic urinary retention who have received transperineal botulinum toxin injections into the sphincter	Thank you for your comments and submitting additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed). Adverse events (i.e, mild pain, incontinence) presented in this study

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				have already been reported in the overview. Efficacy data that has not been published are not normally selected for presentation to the Committee. Therefore, this additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed) was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
23	Consultee 2 NHS professional	Validity and generalisability	*Patients refractory to conventional treatments and with heterogeneous non-neurogenic sphincter functions/causes (DV, DU, and PRES, Fowler's syndrome) were included in the studies.* The IP guidance should be made only for women with idiopathic chronic non-obstructive urinary retention due to external urethral sphincter dysfunction (otherwise known as Fowler's Syndrome, primary disorder of urethral sphincter relaxation or high tone no-relaxing sphincter) In this group, transperineal injections have been shown to be: 1/ An effective minimally-invasive outpatient treatment -Study 6 cited in the NICE document (Panicker et al. 2016): 10 women; demonstrated significant improvements in flow rate, postvoid residual volumes and Patient Reported Outcome Measures (IPSS) at 1 week, 4 weeks and 10 weeks after the treatment.	Thank you for your comments. section 3.5 suggests that 'women have the procedure more commonly than men'. The study Panicker 2016 is already included in the evidence overview. Thank you for submitting additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed). Adverse events (i.e, mild pain, incontinence) presented in this study have already been reported in the overview.

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			-Audit completed in 2022- 11 year follow up study (please find study enclosed) • 33 women; mean age ±SD 30.2±2.34years • 20 (61%) responders • Number of injection sessions 165 • 15 patients received >1 injection; median interval 112 days (IQR 70) • Number of repeat injections 129; median 3 per responder (range 1-25 injections) 2/ A safe treatment with only mild and transient side effects -Study 6 cited in the NICE document (Panicker et al. 2016): no serious side-effects were reported. UTI (n=3 injections), however this was not related to the intervention as the procedure was performed tranperineally and not transurethrally -11 year follow up study: side effects mild and transient: n=19 (11.5% of injections). Stress Incontinece rate 6.7% all injections	Efficacy data that has not been published in a peer-reviewed journal are not normally selected for presentation to the Committee. Therefore, the study was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
24	Consultee 2 NHS professional	Validity and generalisability	*There is no standardised treatment protocol. botulinum injections were diluted with saline but the dose, number of injections, sites and depth of injection given varied across studies and in some studies repeat urethral injections were given.* Transperineal injections follows a standardised technique that has consistently been followed since 2010 in Uroneurology: The transperineal injection technique involves the following steps: -Application of local anaesthetic (lidocaine) agent periurethrally -Injection of 2% lidocaine periurethrally at the 3 o'clock and 9 o'clock positions -100 units botulinum toxin A diluted in 1 ml of saline injected into the urethral sphincter divided at the 3 o'clock and 9 o'clock positions -Electromyography (EMG) of the urethral sphincter is performed in these women as part of their diagnostic workup and can help to	Thank you for your comments. The procedure has been described in section 2 of the guidance. Included studies in the overview reported different doses and number of injections. So the statement under 'validity and generalisability' in the overview is reasonable. The study Panicker 2016 is already included in the evidence overview. Thank you for submitting additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed).

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			identify the location of the urethral sphincter. The outcomes using this technique are provided in -Study 6 cited in the NICE document (Panicker et al. 2016) -11 year follow up study (being submitted along with this consultation)	Adverse events (i.e, mild pain, incontinence) presented in this study have already been reported in the overview. Efficacy data that has not been published in a peer-reviewed journal are not normally selected for presentation to the Committee. Therefore, this study not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
25	Consultee 2 NHS professional	Validity and generalisability	1 small study was from the UK. Another UK study (11 year follow up study) is being submitted to NICE	Thank you for your comments. The study Panicker 2016 is already included in the evidence overview. Thank you for submitting additional evidence (a retrospective case series with 11 year follow-up that is not peer-reviewed). Adverse events (i.e, mild pain, incontinence) presented in this study have already been reported in the overview. Efficacy data that has not been published in a peer-reviewed journal are not normally selected for presentation to the Committee. Therefore, this study

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				was not included in the overview. However, the committee considered this study in their deliberations in part 2 of the committee meeting. IPAC may review the guidance upon publication of new evidence in peer reviewed journals.
26	Consultee 1 Patient	Patient commentary 3.4	At all points of my care, the department has always ensured that I have been made fully aware of current managements available to help me safely and efficiently manage the symptoms of my Fowlers syndrome. The botulinum toxin injections have been for many years the best option for the management of my condition. The injections administered under clinical conditions, and with the utmost professionalism always allow the urethral sphincter to relax accordingly and effectively for me to be able to have a normal urine flow, avoiding full urinary retention, and the dangerous infections that have resulted in the past, even on one occasion leading to serious sepsis. To support the ongoing research and efficiency of the implementation of the Botulinum toxin injection I always complete a bladder diary and other supporting documents of one month prior to the injections to show the deterioration of the condition without the injections, and also documents for one month post injections to show the massive improvement in how efficiently the injections help the condition. As outlined in 3.4, I have always filled in the aforementioned supportive documentary evidence in the form of the bladder diaries, which clearly shows how without the injections there is an increased urinary retention, leading to urinary tract infections and an overall deterioration of the condition. In the supportive documentation there is also evidence to support how once injections have been carried out in a clinical setting, the	Thank you for your comment. The Committee discussed your experiences in their deliberations.

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			improvement of the condition is clear to see. I have also submitted a testimonial supportive letter to the department in the past to ensure that this clinical care continues into the future and is never withdrawn for patients such as myself. As a patient with Fowlers Syndrome, my cause being idiopathic, the injections of Botulinum toxin type A procedure being carried out currently every 3 months with excellent effectiveness improving not only my quality of life, but saving me from potential life threatening infections.	
27	Consultee 6 NHS professional	3.4 Patient commentary	[redacted] wishes to attach this patient testimonial to their submission. To whom it may concern, I am writing this testimonial letter in support of the services supplied by Professor [redacted] and his team at the department of Uro-neurology at the National Hospital of Neurology and Neurosurgery at queens square in London. I have a rare condition called Fowlers Syndrome. My condition was diagnosed at the National Hospital by Professor Fowler in 2009 following the EMG test. It was such a massive relief that finally someone could tell me what was happening with my body, and why I had extremely bad retention of urine, and as a consequence a lot of infections (both kidney and bladder). I even experienced one bad infection that had pushed me into sepsis. Once the diagnosis was received the trial of Botox injections to the primary detrusor muscle was suggested. I started the treatment, and have been receiving these injections for many years. The difference in my quality of life has been tremendous over the years. I can now carry out my work without constant	Thank you for your comment. The Committee discussed your views and experiences in their deliberations.

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			sickness, and care for my family without being constantly debilitated by infection and retention. The Botox injections at London are now carried out every three months. The procedure is always carried out with the upmost professionalism and thought for patient dignity and consideration of ensuring the procedure is pain free. The months after my injections I feel 'normal', and not dragged down by my condition, which the alternative without the injections is ISC (intermittent self catheterisation). This of course can lead to high risk of infection, and then the cycle of infection and hospital admissions begins again. I have always and will continue to supply supportive documentary evidence in the written form of bladder diaries and other assessment documents. These documents clearly show how without the injections the high levels of urinary retention that result and consequent awful infections. On the documents they also support post injections the massive improvement in urinary flow, reduction of painful bladder spasms, improvement in quality of life and no need to carry out ISC. I have been under the care of Professor [redacted] and his team for many years now and it may sound dramatic to say that the work that they carry out in London is a 'lifesaver', but in my eyes and those of the others suffering with this debilitating and disabling condition, it truly is lifesaving. I honestly could not do without the service they provide. The ongoing support that the team also provide through ensuring the care is always excellent and most importantly with the patients well-being and quality of life at the forefront of the care that they provide.	

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			Emailed comments\Dr Sarah Wright\Hospital Letter.docx	
28	Consultee 3 Patient	Patient commentary	Botox In my sphincter has been life changing I've gone from having to Catheterise 5 times a day to pee to not having to do it at all. It has virtually eradicated me having to be an inpatient on Iv anti biotics because of infections. I now get an occasional infection every few years. I also used to be in hospital every other day because I could get a Cathater into my bladder, I couldn't tolerate a superapubic catheter or Aa standard Cathater because the pain was that severe . I am now in hospital for a few hours every 2ish weeks to be catheterised when I am in spasm in an acute stage. To go from every other day to every few weeks is amazing. I have no side effects no incontience nothing. Would be absolutely devastated if my Botox stopped!	Thank you for your comment. The Committee discussed your views and experiences in their deliberations.
29	Consultee 4 Patient	Patient commentary	I have been receiving the botox injections for a number of years now as I suffer with Fowler's Syndrome. Prior to having the injections I struggled on a daily basis, which involved self catharising frequently throughout the day. As a result I became very conscious and anxious about my condition. I would also suffer with frequent UTI's as a result of the regular catharisation. The botox injections has made a big difference in how much I am able to now pass urine on my own throughout the day, therefore reducing the number of times I have to self catharise, therefore reducing the number of urine infections. It has really made a difference to me in managing my condition better compared to prior to receiving the injections. I am finding I am less anxious in general with regards to Fowler's Syndrome. As I have been receiving the injections over a number of years I find receiving the injections a simple procedure and the team	Thank you for your comment. The Committee discussed your views and experiences in their deliberations.

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			have always made me feel at ease.	
30	BSUG Consultee 7		No comments to add	Thank you.

"Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees."