

## Using intermittent self-catheters: experiences of people with neurological damage to their spinal cord

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## **Abstract**

### *Purpose.*

The aim of this study was to investigate the experiences of using intermittent self-catheters among people with neurological damage to their spinal cord. This study sought to highlight the impact of using specific intermittent self-catheters on users' daily lives and to identify key features of product design which affected ease of use.

### *Methods.*

In-depth interviews were conducted with 16 intermittent self-catheter users to elicit their views and experiences of intermittent self-catheter use. Interviewees were purposively sampled, primarily from the spinal cord injury population, via a variety of sources. Transcripts were analysed using the Framework method.

### *Results.*

Key product characteristics which influenced ease of use both inside and outside the home were identified (for example, gauge, rigidity, and packaging); preferences were highly personal. Intermittent self-catheter users were conscious of health consumer issues such as the financial costs, the environmental costs, and the trustworthiness of the manufacturer. Wider self-catheterisation issues such as anxiety, self-image and control over bladder management were also important to interviewees.

### *Conclusions.*

This study provides new information on key issues associated with experiences of intermittent self-catheter use by people living in a community setting who have neurological damage to their spinal cord.

## Background

Populations with neurological damage to the spinal cord may encompass a range of distinct health conditions including spinal cord injury, multiples sclerosis, and spina bifida. Prevalence of spinal cord injury in the US is estimated at 270,000 with 12,000 new cases each year [1], but UK estimates of 40,000 with incidence rates from 720 to 1200 per year [2-3] are less reliable due to non-standardised reporting. Multiple sclerosis in the UK is estimated to affect 100,000 people, but numbers are also limited due to the existence of no official register [4]. Neurological damage to the spinal cord is often accompanied by impaired bladder function requiring catheter-based management as a core feature of day-to-day living [5-8]. Where appropriate, intermittent self-catheters (ISC) are recommended rather than in-dwelling catheters as they are associated with fewer medical complications, a reduced risk of urinary tract infections and fewer days in hospital [9-11]. It is estimated that 90% of people with spinal cord injury in the UK (approx 36,000) use ISCs as their primary method of bladder management [2].

The experiences of people learning to self-catheterise is well documented [12-13] but there is little research exploring the long-term impact of living with self-catheterisation [14-15]. Over 40 different ISC models from a range of manufacturers are currently available, but the impact of different types of ISC on quality of daily life is largely unexplored. ISCs vary across a range of product characteristics that impact on a number of factors including accessibility, independent insertion and risk of urinary tract infections (UTIs), that may influence user preferences and satisfaction [16].

Health-related quality of life (HRQoL) encompasses physical and mental health perceptions and factors that influence those perceptions including: available resources, physical and social environments, and policy and healthcare practices [17-20]. Measures of HRQoL have become important indicators of health status and can be stronger predictors of health outcome compared to

objective measures [21]. User-reported differences between ISCs [22-27] indicate a need to quantify ISC use on HRQoL [28] in order to inform bladder management practices and future product development. Maximisation of HRQoL, rather than cure, is a common goal for people living with chronic health conditions and standardised tools are recommended for its accurate measurement [29]. Qualiveen is an instrument designed to measure the impact of bladder problems on quality of life in people with spinal cord injury, but it does not measure the impact of intermittent catheter use [30]. While Qualiveen is important for informing management of bladder problems it cannot be used to inform strategies for ISC use or new product development. To our knowledge there is no instrument available to measure the impact of intermittent catheter use on the HRQoL of people with spinal cord injury.

A robust qualitative exploration of a topic forms the foundation of rigorously developed HRQoL measures [31-33] and research is needed to explore the lived experiences of those who use ISCs [34]. The aim of this study was therefore to explore the long term experience of ISC use in people with neurological damage to the spinal cord.

## Methods

To explore ISC users' experiences and concerns about ISC use, we chose qualitative in-depth interviews as these allowed flexibility and depth of exploration, capturing users' language, definitions, concerns and priorities.

We aimed to achieve a sample with a range of ISC experiences and considered the competing strategies of targeting users with a range of health conditions ("breadth") versus sampling more extensively within a limited range of health conditions ("depth") [35]. We chose the latter on the basis that this would produce richer, more comprehensive data within the project timeframe. Therefore, we purposively sampled men and women in the four main classifications of spinal cord injury (complete tetraplegia, incomplete tetraplegia, complete paraplegia and incomplete paraplegia). Participants were required to be living in the UK, aged 18+, at least six months post injury, and used intermittent self-catheterisation as their main method of bladder management in the last year. Permission for this study was granted by the Brunel University Research Ethics Committee.

Topics in the interview guide for participants with neurological damage to their spinal cord broadly covered: the interviewee's background, bladder function, recent catheter use, impact on daily routine, health concerns, and feelings about self-catheterisation.

There were considerable challenges in accessing a largely hidden population of people with spinal cord injury who self-catheterise. Potential participants were identified through a national spinal cord injury organisation (Spinal Injuries Scotland) with recruitment information distributed through mailings. A website for the purposes of recruitment was developed and advertised through web links from 'Spinal Injuries Scotland', the 'Spinal Injuries Association' and 'Wandsworth Access' websites. The website was also advertised by poster, internet message boards dedicated to spinal

cord injury and face to face at wheelchair events with recruitment slips. Recruitment also took place using existing participants, where they suggested peers who might wish to be involved in the research.

Given the sensitivity of the topic, face to face interviews took place in the interviewee's home.

Where this was not possible participants were interviewed in relatively private space at their place of work, or a preferred location, to ensure confidentiality. Participants were offered £20 for taking part in the interview. The interviews were conducted by LK over a 12 week period, lasted for approximately one hour and were stored on a digital recorder. Recordings were either transcribed by LK or an outsourced transcription company. Validity of the outsourced transcriptions was verified by LK by replaying the audio recordings and reading transcripts.

Interview transcripts were analysed using the "Framework" method, an analytical approach developed by the UK-based National Centre for Social Research. Framework analysis allows comprehensive and systematic analysis of the data by the research team [36]. The method involves five stages: 1) data familiarisation; 2) identification of a thematic framework using emergent issues, concepts and themes; 3) data indexing according to the thematic framework; 4) charting the data through within-case and between-case comparisons; and 5) data mapping and interpretation. LK led the qualitative analysis using NVIVO computer software, with charting carried on an Excel spreadsheet. All members of the team read the transcripts and discussed interpretation of the data. Coding consistency was checked by GB using independent coding of a sample of transcripts.

## Results

### *Sample characteristics*

The sample consisted of 16 interviewees (characteristics shown in table 1) 13 of which used a wheelchair for day to day living whilst three were able to walk unaided for short distances in familiar environments. All participants managed their own personal care and inserted their own ISC. Fifteen participants were current ISC users and one woman was a recent past user. Duration of ISC use ranged from one to over twenty years.

Four of the eight men, and two of the eight women in the sample did not use ISCs as their sole method of bladder management. Three men also used urinary sheaths whilst the fourth man and two women had a limited capacity to void without any device assistance. Frequency of voiding varied across the sample, however, most participants who solely relied on self-catheterisation to manage their bladder catheterised every three to four hours. Those with more flexible voiding routines were men involved in sporting activities who made use of alternative methods of bladder management such as urinary sheaths. All ISCs were free at the point of use for participants in the study and were obtained through the UK National Health Service.

*Insert table 1 here.*

The physical positions adopted for self-catheterisation varied across the sample. Six of the men catheterised from their wheelchair, one on his bed, and one catheterised while standing. Five women transferred to the toilet (two with gliding seats) for catheterisation, two catheterised from their wheelchairs, and one catheterised on her bed.

### ***Learning to self-catheterise***

Ten participants began self-catheterisation as inpatients in spinal injury units immediately following their injury. The remaining six participants began to self-catheterise as outpatients with previous methods of bladder management including tapping on the abdomen over the bladder to trigger the body's voiding reflexes, wearing a urinary sheath, applying pressure above the pubic bone, or voiding without assistance.

Interviewees' feelings regarding ISC use among those who began to self-catheterise as inpatients and those who began to self-catheterise whilst outpatients were similar. However three of the participants, who began to self-catheterise as outpatients, recalled their initial resentment of experiencing further loss of their functional ability.

Participants were introduced to ISC products through a number of sources including: their Spinal Unit, product samples from manufacturers, and information on the internet and disability magazines. Non specialised health professionals, such as general practitioners or district nurses, were not regarded as useful sources of information on the range of available ISCs, however, participants valued advice from healthcare professionals in spinal injury units; six participants had chosen their current ISC on this recommendation.

Fifteen of the participants had used more than one ISC model, with one participant having tried five different ISCs. Of the 17 ISC models reported, Coloplast's 'Speedicath' was used by 12 people, Astra-tech's 'Lofric' was used by seven people, and Coloplast's female-only product 'Speedicath Compact' was used by five people. Of the 15 currently using ISCs, eight used pre-lubricated catheters, four used catheters where the user adds water for lubrication, one used both a pre-lubricated catheter with a collection bag attached and a pre-lubricated catheter, one person used a dry catheter and



added a gel-based lubricant, and one used a custom-made re-usable silver catheter lubricated with tap water.

### ***ISC product characteristics***

All interviewees talked extensively about the intricacies of ISC use and its effect on aspects of their daily life and well being. Interviewees discussed a number of difficulties and concerns relating to product characteristics:

#### *Gauge*

Six people discussed concerns about the gauge (or diameter) of the catheter. Two men had experienced discomfort during catheter use and had opted for a narrower gauge. Speed of voiding was also important to four participants in terms of minimising the impact self-catheterisation had on their daily life and this influenced their choice of a wider gauge catheter e.g.:

“Most people use a 14 but I’ve got a little bit more sensation...than most so, I don’t want to go for anything bigger. [...] I find a size 12 takes forever” (ISC user 6, Male, age 39).

#### *Rigidity*

Eleven people expressed concern about the rigidity of the catheter in terms of the trade-off between sufficient rigidity to assist insertion and potential damage to the urethra associated with excessive rigidity. Sufficient rigidity was particularly important for four men when guiding the catheter through the urethra: , e.g.:

“If it was a wee bit less pliable, then you wouldn’t have that bending, but then if you made it less pliable it’s maybe not going to find its path, you got to have a wee compromise I suppose you know, so that it will be flexible when it goes in” (ISC user 1, Male, age 51).

### *Length*

Four people were worried about voiding issues related to length of the catheter. Three women and one man were concerned about incomplete voiding due to the length of their catheter and described pushing the catheter in further than recommended in order to ensure complete drainage. Five people expressed frustration with the length of the catheter when trying to void directly into a toilet. One woman who catheterised from her wheelchair thought the short Speedicath Compact was a 'good idea' but impractical as she did not transfer to the toilet in order to void. Four of the six men who catheterised from their wheelchair used an improvised extension to their catheter in order to void directly into the toilet, e.g.:

“Yeah, well obviously because the catheter is only long enough to actually do what it does, it then won't reach the toilet... so what I do, I get a pipe which is either the end of a leg bag pipe or ... night bag pipe that I can actually plug into the catheter [to reach the toilet]” (ISC user 15, Male, 39).

### *Lubrication*

Pre-lubricated ISCs were perceived by six people as having minimal disruptive impact when preparing to catheterise because they were less time consuming and more convenient, particularly when used outside the home.

Fifteen interviewees said that lubrication did not influence the ease of insertion of the catheter once it had been inserted into the urethra. Four interviewees expressed concern about the difficulties of manipulating lubricated catheters and found it difficult to handle some products, e.g.:

“...you open it and it is completely coated from top to bottom and it’s very hard to hold the thing to pass it in when it is as heavily lubricated as that, so that’s why I don’t use them” (ISC user 4, Male, age 47).

#### *Product characteristics and comfort of insertion*

Fifteen out of the 16 interviewees did not experience pain when inserting a catheter. Those with sensation could feel the catheter passing but did not experience any substantial discomfort, e.g.:

“...it’s a minor little sting you get [when inserting an ISC]. It’s very, very slight, it’s not, you get used to it” (ISC user 1, Male, age 51).

One respondent found catheterisation particularly distressing and consequently catheterised only once every two days, partially voiding naturally in the intervening period:

“I get the catheter to about five inches remaining outside and it’s then that I presume that ... is the point at which it has come against my urethra sphincter muscle... that’s where I need to be as relaxed as possible... if I am too rough then it’s painful at the urethra and sphincter muscle” (ISC user 8, Male, age 53).

Three interviewees had experienced bleeding when catheterising, though they were rare occurrences, e.g.:

“..it only ever happened once when I passed one [ISC] and I haemorrhaged quite badly which as you can imagine, I got a bit of a fright” (ISC user 4, Male, age 47)

#### *Packaging*

There are numerous ways in which the packaging of an ISC may impact on the user experience, for example, some ISC packaging is adhesive facilitating hands free preparation of the catheter and some have rings pulls to assist opening packaging. Whilst two women found these features very useful, others found them unnecessary or were unaware they existed. Two participants found the ring pulls to be flimsy, occasionally breaking off during the pulling motion.

...they have got a little ring on them that you can pull, quite often I find that will actually break and not open the packet... (ISC user 15, Male, age 39).

Frustration with product packaging was expressed by participants, for example, of the six women who used a catheter which required a twisting motion to open it, four said they had trouble opening the capsule. Four participants felt the portability of their ISC could be compromised by the packaging as it could burst when in their bag. Poorly designed packaging could result in lubricants leaking and soiling clothes or bags:

...the package itself...if you could make that packaging even more flexible...If that cracks and it leaks then the whole things ruined, ... not to mention the fact that it would leak all over your bag and all over the floor. All over your clothes depending on how you're using it and how you're holding it. (ISC user 3, Male, age 45).

### ***Use of ISCs outside the home***

Participant's homes were largely suitable for routine ISC use, minimising the impact of self-catheterisation on daily life. The impact of ISC use outside the home however (for example in work places and public environments) was clearly substantial and of major concern to study participants. The use of ISCs outside the home changed the environment in which the self-catheterisation took place. Consequently, some interviewees had to self-catheterise in an alternate position (e.g. from

their wheelchair rather than on the toilet or bed), and they had to manage self-catheterisation without the helpful adaptations present in their home (e.g. sliding seats, mirrors). Other concerns included: finding a water supply, using taps with a spray action which made it difficult to add water to the packet, the additional time required for preparation, difficulties in maintaining balance in a wheelchair when filling the ISC packet with water, and maintaining hygiene standards, e.g.:

“It [self-catheterising] can be slightly more awkward in the public domain because, as I mentioned the water supply, and often silly little things like taps, where you push once and you have to keep your hand down on it for the water to come out, some taps are like that and you’re trying to fill [the ISC packet] up and it’s quite awkward, other times, disabled loos the sink is too small, ...it’s ridiculous and so when you actually lay the catheter in there, you know, it’s half out and its dripping all over the floor and whatever so that can be awkward...”

(ISC user 6, Male, age 47)

The problems and limitations of ISC use outside the home impacted on daily life to such an extent that a number of people used alternative catheter models, e.g. pre-lubricated, or chose an alternative method of bladder management altogether, e.g. urinary sheath.

“When I go out, like I say I use sheath drainage, I put a sheath on, plug a leg bag into that and then at least I know then if I don't get my timings right it's not the end of the world, you know, it's, it's er it's still OK, it's still manageable (ISC user 15, Male, 39).

“My biggest problem at the moment, ...is em, even going only every three hours it would be quite difficult for me to get myself completely sterile clean having just dug over a bed in the garden or dealt with a problem with a chicken or something like that...” (ISC user 13,

Female, age 32, living on a farm)

#### *Disclosure and discretion of ISC use*

Disclosure of ISC use to others was a highly personal and important concern. Three participants were reluctant to disclose ISC use even to intimate partners or family whilst four participants were happy to disclose much more widely (e.g. friends, work colleagues, general public). Disclosure was unavoidable in certain circumstances (e.g. to intimate partners, close family, the cleaning lady, work colleagues etc.) because concealment was impractical or impossible.

“I wouldn’t discuss it with them [friends/public]... My daughter knows. My husband knows obviously. My son-in-law knows. ... but that’s really the extent to who I tell. ... my cleaning lady knows...only because she has to help me unpack these wretched boxes!” (ISC user 2, Female, age 59).

“I have lots of accidents at work and things like that, but I’m quite open about it all at work. ... I mean it’s not, it’s not the first time I’ve had to leave work and ... drive up and buy...some clothes but now I keep a change of clothes in the toilet” (ISC user 11, Female, age 60).

Participants who disliked telling others about their ISC use found disclosure difficult even with people close to them:

“I really hate it [telling others about ISC use]...It’s just because you have a disability, erm, and then this is something else on top of it ... my last partner, we went on holiday and things and I had to say that I used this catheter... it’s quite a difficult thing to, to bring up really ...” (ISC user 14, Female, age 40)

“...others ... wouldn’t care [about finding out he uses ISCs] but I do, more probably a vanity thing or whatever” (ISC user 6, Male, age 39).

The ability to be discrete, however, was important to all of our participants as it facilitated control over disclosure. People discussed several aspects of ISC variability that impacted on discretion

including, concealment e.g. size of the ISC and disposability, and branding issues e.g. labelling and packaging.

“Sometimes ...you would like it to come in just a small plain brown wrapper ... the packaging that they’re actually in ... bright green packaging, I mean with a name written all over it” (ISC user 3, Male, age 45).

“Quite often normal loos don’t even have a bin, or if you are at someone’s house you know, not everyone has a bathroom bin, and I don’t want to put my catheters in their bathroom bin [...] I don’t like putting them in other peoples bins” (ISC user 5, Female, age 31).

“It doesn’t look clinical, does it [the catheter]? It looks.... if anyone looked in your bag it could be a lipstick or a mascara” (ISC user 7, Female, age 63).

### ***The ISC user as a health consumer***

#### *Trust*

Four interviewees talked about their trust, or need for confidence, in the ISC products which they used. This trust tended to be related to the design of products (that these ISC designs were effective and non-harmful) and to the product quality (i.e. consistency of product, minimal number of faulty ISCs). In relation to trust, three of these interviewees also talked about their brand loyalty.

“One has to trust the people who design the catheters to make the right decisions for you, because I can’t feel, so you are relying on people who have designed a product that is suitable for you” (ISC user 2, Female, age 59).

“As it goes through the sphincter it’s a little bit rough, it can scratch and causes bleeding which is quite worrying, that’s happened a couple of times. ” (ISC user 6, Male, age 39).

#### *Social responsibility*

Participants in our study discussed social responsibility issues relating to long term ISC use. Ten participants reported that they were concerned about the financial burden which their ISC use put upon the NHS. Two interviewees reported trying to minimise cost through limiting use of pre-lubricated catheters (which they believed to be costly) to outside the home.

“I used to say to my doctor ... I used to ask him how much they cost, I said, ‘Oh well, I’ll just get the, the other ones because they’re awfully expensive.’ He said, ‘Why are you bothering about that?’ I said, ‘Well, it’s the National Health Service that’s having to pay for them’, and I really think that should be taken into account” (ISC user 11, Female, age 60).

Six people were concerned about the environmental impact of disposable ISC products, with one person modifying her choice of ISC on the basis of reduced environmental impact (changed to using a reusable silver ISC).

“They come in a box, within a box, within another box, within a silver bag, within paper wrapping... I don’t think any of these companies have thought of recycling at all!... I don’t have a need to use ready filled catheters in my home life. I feel it would be wasteful.” (ISC user 2, Female, age 59)

“It [the impact of ISC use on the environment] is something I’m conscious of but it’s something that I can’t do anything about. If they come up with a biodegradable catheter that’s as good and as easy to use as this one, I would [use it] but they haven’t” (ISC user 16, Male, age 28).

### ***Wider issues relating to ISC use as a method of bladder management***



Satisfaction in relation to self-catheterisation was reliant on ease of use of the product both inside and outside the home. There were, however, a number of other issues regarding general aspects of self-catheterisation as a method of managing the bladder that were discussed during the course of the interviews. These are outlined below.

### *Anxiety*

Increased or decreased anxiety was expressed by interviewees about a variety of matters relating to ISC use, the most common anxieties relating to the potential of urinary leakage and the long term health effects of ISC use (for instance, effects on kidneys, bladder, and urethra).

“It’s great, because ...for those three or four hours I am not worrying about having to go to the loo. I know I am going to be dry” (ISC user 1, Male, age 51)

“I was staying at somebody else’s house, I’m a bag of nerves because I, erm, I took my sleeping bag with me just in case I had an accident. Erm, so everything you do puts you under stress and you actually make the situation worse yourself” (ISC user 11, Female, age 60).

“I worry about the long term effects” (ISC user 7, Female, age 63).

### *Self-image*

People chose ISCs as their primary method of bladder management for several reasons relating to external perceptions of ‘normality’, for example men and women discussed how their ISC could affect their body-image. Positive effects related to the use of ISCs aiding to maintain a “normal” body-image, as in a body that did not permanently have catheterising equipment attached to it. This allowed them a greater degree of freedom in deciding what they wanted to wear. , e.g.:

“Great, absolutely great, I find it’s absolutely wonderful [...] you can wear dresses and tights and nice underwear and...marvellous. [...] Ok, I’m paralysed, but to all intents and purposes, you know I looked just like anybody else without my clothes on. I didn’t have any extra bits floating around. I think that was very important to me” (ISC user 2, Female, age 59).

Conversely, for two men and two women, ISC use had a negative effect on self-image as it was a further reminder of their physical disability.

#### *Perceived control*

ISC use had the ability to enhance or diminish the amount of bladder control and management that an interviewee had, which in turn enhanced or diminished the amount of control a person had over their lifestyle.

“... we went to a wedding recently and stayed away and I knew that I was safe all night it's, it's liberating. It's really liberating” (ISC user 7, Female, age 63).

“It gives you a lot more freedom and you are able to go out” (ISC user 9, Male, age 32).

“...the bladder management is significantly disruptive to daily living. It is really quite disruptive” (ISC user 8, Male, age 53).

In addition to control over a person’s lifestyle, two participants discussed how their ISC use helped them to take control of their health, particularly in diminishing the likelihood of urinary tract infections.



## Discussion

In this paper we have identified key areas where ISC use impacts on the daily lives of people with neurological damage to the spinal cord living in a community setting. Our population, which predominantly had spinal cord injury, reflected a broad range of physical limitations in both male and female ISC users. As only one participant had a degenerative neurological condition, generalisability remains to be established beyond the spinal cord injury sub-group. Furthermore, this study population proved hard to reach and those volunteering to take part may have reflected those who were comfortable with discussing their bladder management or those who had particular concerns with ISC use. The sample did however express a variety of concerns which are likely to be applicable to the broad population group.

Prior to this study, experience of day to day ISC use had been largely unexplored and our study paid particular attention to users' experiences of current ISC products both inside and outside the home. Many product characteristics, such as gauge, rigidity, lubrication and packaging, had an impact on day to day experiences with catheterisation, influencing perceptions of control over the process and confidence in its efficiency. Additional factors, including concern with discretion and disclosure of ISC use, were particularly pertinent when using ISCs outside of the home in a public context not suitable for the needs of this population. These concerns had a sufficiently profound impact on daily life as to influence both choice of ISC and choice of overall bladder management. Our participants used up to eight ISCs per day costing up to £3.00 per catheter (an estimated population cost of £350 million per year for the NHS). It was therefore not surprising that users' concerns over ISC use included issues around social responsibility, in terms of both cost and environmental impact, which participants felt were not adequately addressed in the range of available products.

Although previous literature has noted possible complications of using ISCs amongst the spinal cord injured population (for example, urinary tract infections and urethral trauma), [37] to date, it has

been not been established how this population deals with day to day challenges of daily catheterisation (for example, using tube extensions on their ISC to void directly into the toilet) . Our findings are consistent with previous research [38] showing differential impact of different modes of bladder management on HRQoL. Several studies have also reported user-perceived impact on day to day living arising from ISC use in a range of populations, particularly outside the home, but our study is the first to examine impact on overall wellbeing specifically in the spinal injury population [11, 38-40]. This was important as they differ from the general population in terms of mobility and demographic profile (tend to be younger).

Our results are consistent with research by Shaw and colleagues, highlighting the impact of ISC use on lifestyle choice and social anxiety [41]. The length of time a person had carried out self-catheterisation however did not influence feelings about ISC use in our study, whereas this was a feature in Shaw et al's population.

Our findings also reflect previously published results on the impact of packaging [11,13,42]. These studies have noted users' worries about inaccessible and indiscrete packaging in diverse populations dissimilar to our population, indicating the pervasive and generalisable impact of these issues across the ISC user spectrum. Descriptive data from a questionnaire [42] has shown respondents to be critical of packaging, however, the authors were unable to find statistically significant differences between ISCs. Given the heavy emphasis of user satisfaction in relation to packaging, this result merits further investigation.

A Cochrane review highlighted financial and environmental issues relating to intermittent catheter use such as the merits of multiple use versus single-use ISCs [27]. Previous research however has been based on fee-paying US populations [40] rather than NHS populations, who do not pay for ISCs. In our study concern was expressed over general NHS burden and the broad environmental impact

of non-recyclable single-use ISCs which may reflect increased global societal awareness of environmental issues.

Lastly, this research found long term ISC users valued trust in the ISC manufacturer. It was important that a manufacturing company was seen to be reliable and trustworthy in the products they provided. As with other consumer products, interviewees also felt comfortable with using known or familiar brands. To our knowledge, individual's views on trust in the ISC manufacturer have not been reported elsewhere.

Overall, participants in this study had highly personal preferences when choosing an ISC and certain product characteristics made self-catheterisation more or less difficult to carry out when inside and outside the home. Particular ISCs made some participants think about their responsibility to wider society as a health consumer. Experiences of self-catheterisation as a method of bladder management sometimes influenced participants' feelings in relation to their anxiety levels, self-image and perceived control of their lifestyle and health. As a number of these issues impact on an individual's overall wellbeing, capturing these preferences using an appropriate standardised measure is essential in order to ensure that future product development incorporates the user perspective.

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## Declarations of interest

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## References

- [1] The National Spinal Cord Injury Statistical Center. Spinal cord injury facts and figures at a glance. Birmingham, Alabama 2012.
- [2] Spinal Injuries Association [Internet]. United Kingdom, Milton Keynes. [Cited 2013 Jan 16] Available from: <http://www.spinal.ac.uk>.
- [3] NHS Clinical Advisory Group. Management of people with spinal cord injury. National Spinal Cord Injury Strategy Board. August 2011
- [4] Multiple Sclerosis Society [Internet]. United Kingdom, London. [Cited 2013 Jan 16] Available from: <http://www.mssociety.org.uk>.
- [5] Fulford S, Coggrave M, Wright L. Bladder and Bowel Management for People With Spinal Cord Injuries. Milton Keynes: Spinal Injuries Association; 2004.
- [6] Bloemen-Vrencken JHA, Post MWM, Hendriks JMS, de Reus ECE, de Witte LP. Health problems of persons with spinal cord injury living in the Netherlands. *Disability and Rehabilitation* 2005;27(22):1381-1389
- [7] Khan F, Pallant JF, Shea TL, Whishaw M. Multiple sclerosis: prevalence and factors impacting bladder and bowel function in an Australian community cohort. *Disability and Rehabilitation* 2009;31(19):1567-1576

[8] Whalley Hammell KR. Perspectives in Rehabilitation. Spinal cord injury rehabilitation research: patient priorities, current deficiencies and potential directions. *Disability and Rehabilitation* 2010;32(14):1209-1218

[9] Cameron AP, Wallner LP, Forchheimer MB, Clemens JQ, Dunn RL, Rodriguez G, Chen D, Horton J 3<sup>rd</sup>, Tate DG. Medical and psychosocial complications associated with method of bladder management after traumatic spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 2011;92:449-56

[10] Cardenas DD, Hooton TM. Urinary tract infection in persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 1995;76:272-80.

[11] Newman DK, Willson MM. Review of intermittent catheterization and current best practices. [Review] *Urologic Nursing* 2011;31(1):12-28

[12] Logan K, Shaw C, Webber I, Samuel S, Broome L. Patients' experiences of learning clean intermittent self-catheterization: a qualitative study, *Journal of Advanced Nursing* 2007;62(1): 32–40

[13] Ramm D, Kane R. A qualitative study exploring the emotional responses of female patients learning to perform clean intermittent self-catheterisation, *Journal of Clinical Nursing* 2011;20:3152-3162

[14] Woodward S, Rew M. Patients' quality of life and clean intermittent self-catheterization. *British Journal of Nursing* 2003;12:1066–74.

[15] Woodbury MG, Hayes KC, Askes HK. Intermittent catheterisation practices following spinal cord injury: A national survey. *Canadian Journal Urology* 2008; 15(3):4065-4071.

[16] Chartier-Kastler E, Denys P. Intermittent catheterization with hydrophilic catheters as a treatment of chronic neurogenic urinary retention. [Review] *Neurourology and Urodynamics* 2011;30(1):21-31.

[17] Kindig DA, Booske BC, Remington PL. Mobilizing Action Toward Community Health (MATCH): metrics, incentives, and partnerships for population health. *Preventing Chronic Disease* 2010;7(4):A68 [http://www.cdc.gov/pcd/issues/2010/jul/10\\_0019.htm](http://www.cdc.gov/pcd/issues/2010/jul/10_0019.htm). Accessed 07.01.2013

[18] Gandek B, Sinclair SJ, Kosinski M, Ware JE Jr. Psychometric evaluation of the SF-36 health survey in Medicare managed care. *Health Care Financing Review* 2004;25(4):5-25.

[19] McHorney C. Health status assessment methods for adults: past accomplishments and future directions. *Annual Review Public Health* 1999; 20:309-35.

[20] Guyatt GH, Feeny DH, Patrick DL. Measuring Health-Related Quality of Life *Annals of Internal Medicine*. 1993;118:622-629.

[21] Dominick KL, Ahern FM, Gold CH, Heller DA. Relationship of health-related quality of life to health care utilization and mortality among older adults. *Aging clinical and experimental research* 2002;14(6):499–508.

[22] Pascoe G, Clovis S. Evaluation of two coated catheters in intermittent self-catheterization.

British Journal of Nursing 2001;10(5):325-9.

[23] Koenen JH, Hoogendoorn P, editors. User evaluation of SpeediCath, the ready to use catheter.

International Continence Society Annual Meeting; 2002 Aug 28-30; Heidelberg; Available from

<http://www.icsoffice.org/>

[24] Koenen JH, Van Kuppevelt D, editors. Comparative randomised cross-over evaluation of a

modern catheter SpeediCath® with conventional catheters LoFric® and EasiCath®. International

Continence Society Annual Meeting; 2005 28 Aug-2 Sept; Montreal; Available from

<http://www.icsoffice.org/>

[25] Leriche A, Charvier K, Bonniaud V, Peyrat L, N'guyen Philippe, Soler J-M, Chapuis A, Egon G.

Comparative study of the acceptability of the SpeediCath Set and Actreen Set catheterization sets in patients performing self-catheterization. *Progres en Urologie* 2006;16(3):347-51.

[26] Litherland AT, Schiotez HA. Patient-perceived discomfort with two coated urinary catheters.

British Journal of Nursing 2007;16(5):284-7.

[27] Moore KN, Fader M, Getliffe KL. Long-term bladder management by intermittent

catheterisation in adults and children (Review). *Cochrane Database of Systematic Reviews* 2007,

Issue 4. The Cochrane Collaboration: John Wiley and Sons, Ltd.

- [28] Hallin P, Sullivan A, Kreuter M. Spinal cord injury and quality of life measures: a review of instrument psychometric quality. *Spinal Cord* 2000;38:509-523.
- [29] Ware JE Jr, Dewey J. Health status and outcome assessment tools. *International Electronic Journal of Health Education* 2000;3:138-148.
- [30] Costa P, Perrouin-Verbe B, Colvez A, Didier JP, Marquis P, Marrel A, Amarenco G, Espirac B, Leriche A. Quality of life in spinal cord injury patients with urinary difficulties: Development and validation of Qualiveen. *European Urology* 2001;39:107-113.
- [31] U.S. Department of Health and Human Services Food and Drug Administration, Center for Drug Evaluation and Research, Center for Biologics Evaluation and Research, Center for Devices and Radiological Health. Guidance for Industry Patient Reported Outcome Measures: Use in medical product development to support labelling claims. 2009
- [32] European Medicines Agency Pre-authorisation Evaluation of Medicines for Human Use. Reflection paper on the regulatory guidance for the use of health-related quality of life (HRQL) measures in the evaluation of medicinal products. 2005.
- [33] Scientific Advisory Committee of the Medical Outcomes Trust. Assessing health status and quality of life instruments: Attributes and review criteria. *Quality of Life Research* 2002;11:193-205
- [34] McConville A. Patients' experiences of clean intermittent catheterisation. *Nursing Times Plus* 2002;98:55-56.

[35] Morse J.M. Determining Sample Size. *Qualitative Health Research* 2000;10(1):3-5.

[36] Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. *Analysing Qualitative Data*. London: Routledge; 1994. p 173-94.

[37] Wyndaele JJ. Complications of intermittent catheterization: their prevention and treatment. *Spinal Cord* 2002;40:536-541

[38] Gardener N, Arnold E, Tophill P, Parker L, Abrams P editors. Quality of life issues for patients with spinal cord injuries requiring bladder management devices – the patients' perspective. International Continence Society Annual Meeting; 2007 20-24 Aug, Rotterdam. Available from <http://www.icsoffice.org/>

[39] Jaquet A, Eiskjaer J, Steffensen K, Laursen BS. Coping with clean intermittent catheterization--experiences from a patient perspective. *Scandinavian Journal of Caring Sciences* 2009;23:660–666

[40] Wilde MH, Brasch J, Zhang Y. A qualitative descriptive study of self-management issues in people with long-term intermittent urinary catheters. *Journal of Advanced Nursing* 2011;67(6):1254-63

[41] Shaw C, Logan CK, Webber I, Broomel L, Samuel S. Effect of clean intermittent self-catheterization on quality of life: a qualitative study. *Journal of Advanced Nursing* 2008;61(6):641–650.

[42] Taskinen S, Fagerholm R, Ruutu M. Patient experience with hydrophilic catheters used in clean intermittent catheterization. *Journal of pediatric urology* 2008;4(5):367-71

**Table 1 Characteristics**

Participant Characteristics	Male: Female
Gender	8:8
Age	
25-34	2:3
35-44	2:1
45-54	4:0
55-64	0:4
Time since injury* (Median, range)	9 yrs, 8mths – 62 yrs
Mobility classification*	
Paraplegic	4:6
Tetraplegic	4:1
Injury severity*	
Complete	2:3
Incomplete	6:4

\* Excludes woman with Spinal Muscular Atrophy