



## Original article

# MS bladder check tool: Development and validation of a patient awareness tool to facilitate timely management of lower urinary tract dysfunction due to multiple sclerosis

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## ABSTRACT

**Background:** Lower urinary tract dysfunction impacts quality of life of people with MS; often, symptoms are 'lived with' or deprioritised by healthcare providers (HCPs). Consequently, patients must be given the skills they need to become confident in managing their illness and enhance their involvement in the process.

**Objective:** To develop and validate a self-assessment tool to help people with MS become more aware of their bladder symptoms and prompt contact with their HCP to facilitate timely management and specialist referral, if required.

**Methods:** The 'MS bladder check tool' was developed by a multidisciplinary panel of specialist advisors. Consensus meetings and pilot testing were conducted to design and evolve the tool into a series of nine questions, using population-appropriate language, and covering all aspects of bladder dysfunction in MS. The tool was then validated by an international, multidisciplinary team of experts.

**Results:** Validity was rated 'excellent' for all questions indicating that the MS bladder check tool is an appropriate method of highlighting bladder problems in people with MS.

**Conclusion:** The MS bladder check tool is simple, easy-to-use, and empowers patients to take charge of their urinary tract health, aiming to improve the management of MS and, ultimately, patient quality of life.

## 1. Introduction

Symptoms of lower urinary tract dysfunction (LUTD) are common in people with multiple sclerosis (MS), and have been reported by 32–96% of individuals, depending on the duration and severity of the disease (Aharony et al., 2017; Panicker, 2020). In people living with MS, frequency is the most prevalent urinary symptom of LUTD (73.5%), followed by urgency (63.9%), incomplete bladder emptying (60.6%), nocturia (54.2%), and incontinence (42.9%) (Al Dandan et al., 2020). LUTD, and symptoms of urgency in particular, negatively impact the

health-related quality of life (HRQoL) of people with MS (Khalaf et al., 2016; Ziadeh et al., 2022). The consequences of living with LUTD are wide-ranging (e.g., social and physical limitations, worry and anxiety, feelings of stigma, fear, sexual disruption, fatigue) and serve to create a sense of loss in the lives of people with MS (Browne et al., 2015).

In MS, the management of LUTD aims, primarily, to improve symptoms and HRQoL and, thereafter, to avoid urological complications, such as urinary tract infections (UTIs), bladder stones and renal impairment, as well as damage to the upper urinary tract (Tornic and Panicker, 2018). However, many cases of LUTD are inadequately

**Abbreviations:** ABSST, Actionable Bladder Symptom and Screening Tool; CBEU, Cytobacteriological Examination of Urine; HCP, healthcare provider; HRQoL, health-related quality of life; LUTD, lower urinary tract dysfunction; MS, multiple sclerosis; OAB, overactive bladder; UTI, urinary tract infections.

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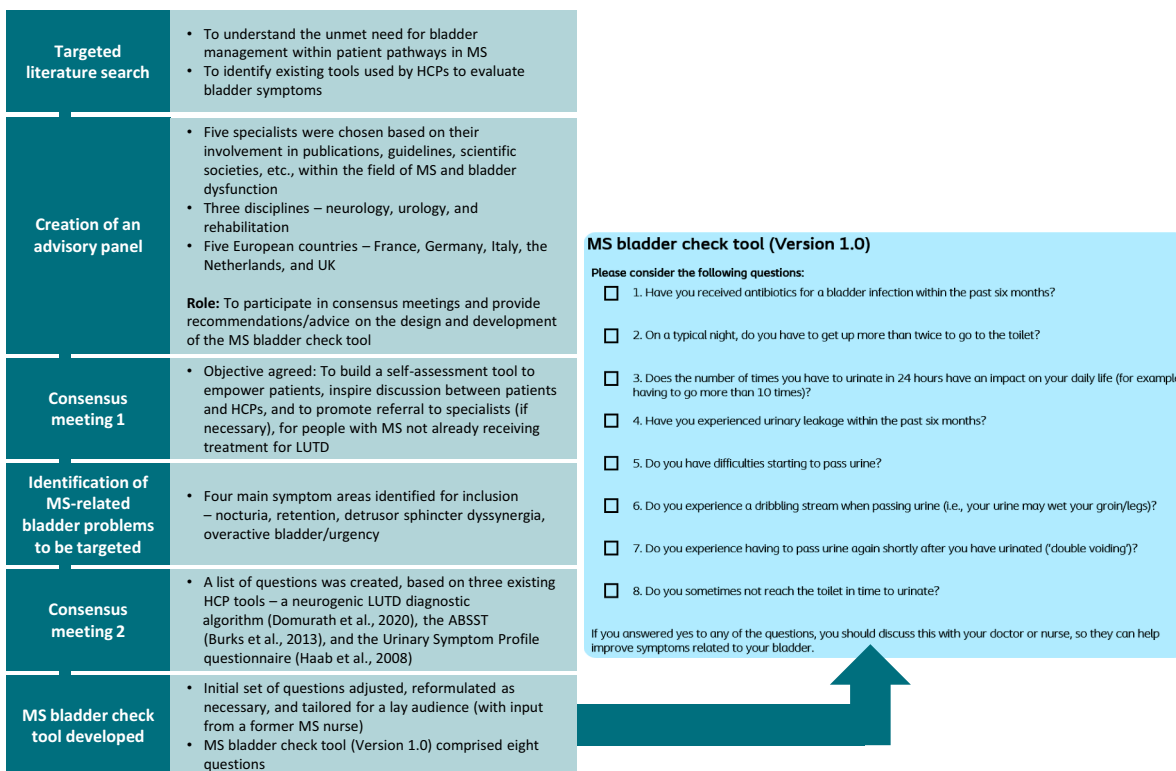
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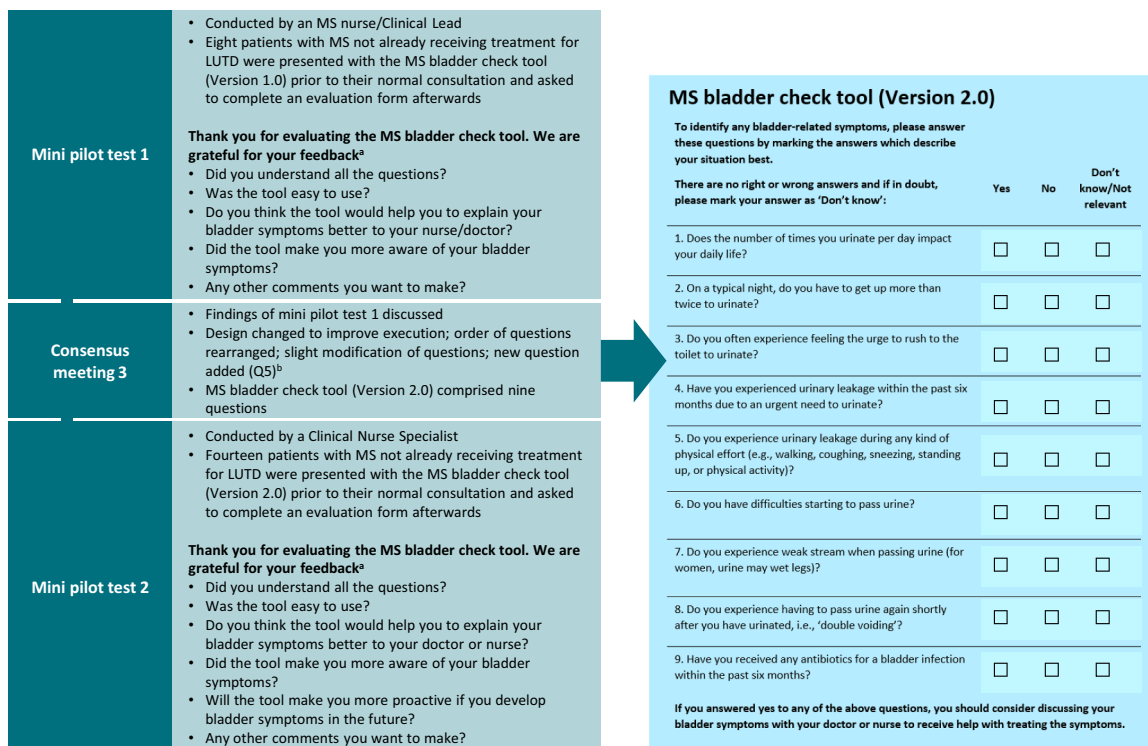
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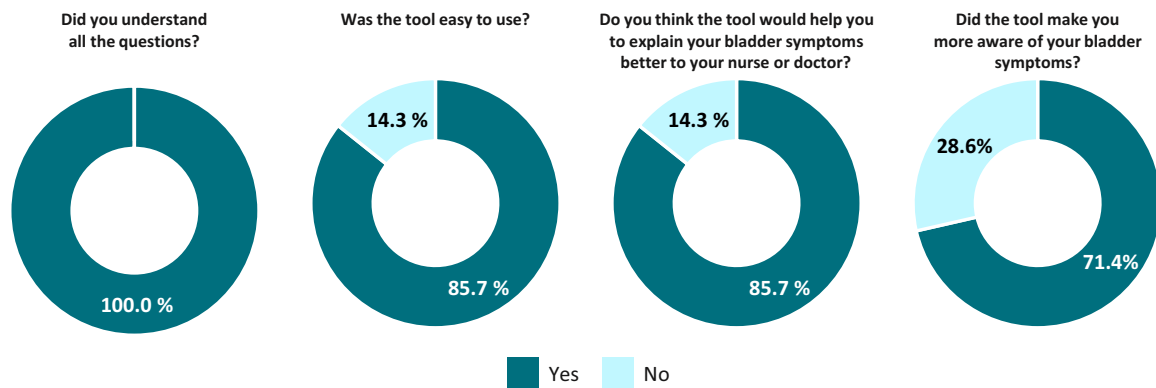
**Fig. 1.** Phase 1: development of the MS bladder check tool (Domurath et al., 2020; Haab et al., 2008). ABSST: Actionable Bladder Symptom and Screening Tool; HCP: healthcare provider; LUTD: lower urinary tract dysfunction.

managed, and referrals to urologists are limited (Mahajan et al., 2010; Rønning and Tornes, 2017; Brucker et al., 2017; Erden et al., 2022), often due to the condition being under-diagnosed. In one patient survey,

only 47.1% of people with MS and urinary symptoms of overactive bladder (OAB) (i.e., frequency, urgency, nocturia, and leakage) were evaluated by a urologist and, of those with more severe OAB symptoms,



**Fig. 2.** Phase 2: mini pilot testing of the MS bladder check tool. <sup>a</sup>Patients were asked to respond to the questions with 'Yes' or 'No' answers; any other comments were provided using free text. <sup>b</sup>New question added to address a problem faced by many women in the target population. LUTD: lower urinary tract dysfunction.

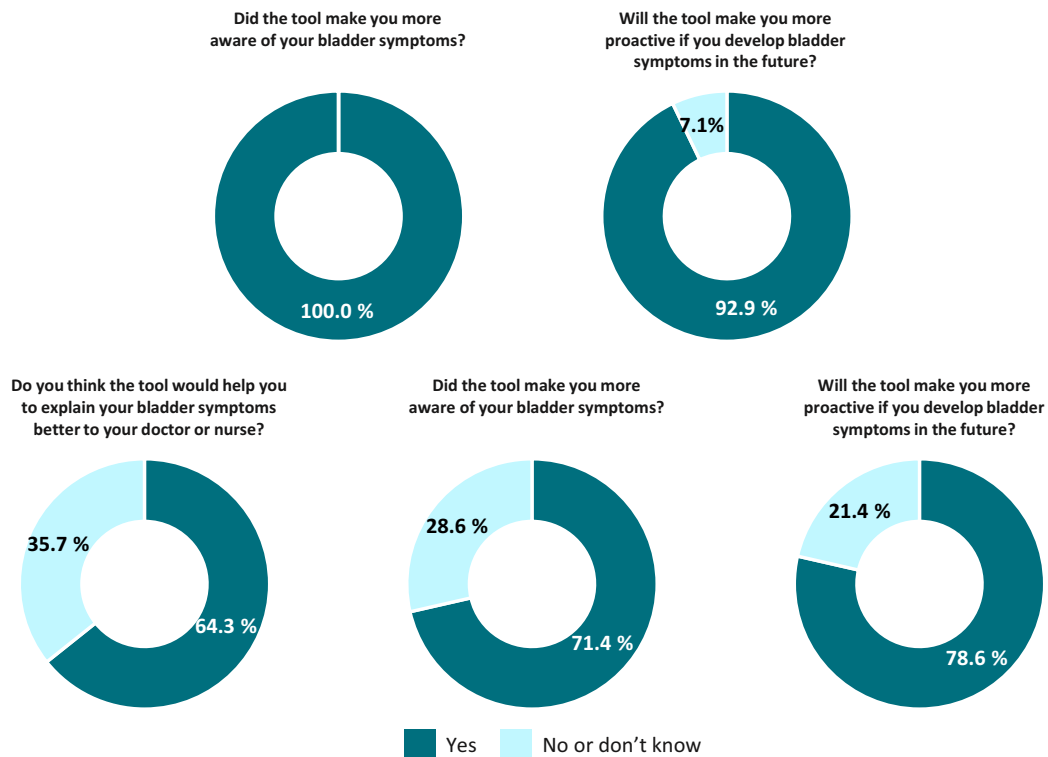


**Fig. 3.** Results of mini pilot test 1 to evaluate the MS bladder check tool (Version 1.0). Responses from seven patients were included; one patient used intermittent catheterisation and was excluded.

only 51.3% received treatment with anticholinergic medication (Mahajan et al., 2010). In a separate study, lack of communication between patients and their healthcare providers (HCPs) was reported as the most common barrier to seeking care for urinary symptoms – doctors did not ask about urinary symptoms, or did not recommend that the patient saw a specialist (Brucker et al., 2017). For people with MS, suboptimal management of LUTD can worsen HRQoL and increase the risk of developing UTIs.

With the rise in patient empowerment, people with MS are now more proactive and aware of their health. However, symptom management is often overshadowed or neglected for various reasons. For example, the advent of disease-modifying treatment focusing on neurological aspects has led to symptom management being deprioritised. In addition, patients are often unaware of the cause of their urinary symptoms and do not deem them of sufficient concern to seek medical advice (Shaw et al., 2001). Often, bladder problems develop gradually and, over time, individuals find ways to compensate, adapting to their ‘new normal’.

Consequently, there is a growing need to enhance patient involvement. By providing individuals with the necessary tools and skills, they can become more confident in managing their own illness. Various calls have been made to place greater emphasis on urinary symptoms in people with MS (Browne et al., 2015; Nortvedt et al., 2007; Nazari et al., 2020), and for the promotion of patient-centred care supported by a biopsychosocial approach (combining biological, psychological, and social factors) (Pétrin et al., 2020). Indeed, early diagnosis and treatment are crucial for the successful management of LUTD, with consequent benefits of improving HRQoL and avoiding urological complications and damage (Tornic and Panicker, 2018; Medina-Polo et al., 2020). Although numerous tools to assess urinary symptoms exist, these instruments, typically, combine patient-reported outcomes (to assess impact on daily life), clinical outcomes (e.g., micturition protocols, symptom checklists) and/or clinical measurements (e.g., post-void residual volume), are tailored for HCPs, and are used infrequently. A few assessment tools, such as the Actionable Bladder Symptom and Screening



**Fig. 4.** Results of mini pilot test 2 to evaluate the MS bladder check tool (Version 2.0). Responses from 14 patients were included.

**Table 1**Expert validation:  $\kappa^*$  values and validity for each question of the MS bladder check tool (Version 2.0).

Question	$\kappa^*$ value	Validity
1. Does the number of times you urinate per day impact your daily life?	1.00	Excellent
2. On a typical night, do you have to get up more than twice to urinate?	0.79	Excellent
3. Do you often experience feeling the urge to rush to the toilet to urinate?	1.00	Excellent
4. Have you experienced urinary leakage within the past six months due to an urgent need to urinate?	0.79	Excellent
5. Do you experience urinary leakage during any kind of physical effort (e.g., walking, coughing, sneezing, standing up, or physical activity)?	0.79	Excellent
6. Do you have difficulties starting to pass urine?	1.00	Excellent
7. Do you experience weak stream when passing urine (for women, urine may wet legs)?	0.79	Excellent
8. Do you experience having to pass urine again shortly after you have urinated (i.e., 'double voiding')?	0.90	Excellent
9. Have you received any antibiotics for a bladder infection within the past six months?	0.66	Good
<b>How relevant is the MS bladder check tool as a whole (Q1–9) for creating awareness of bladder problems in people with MS?</b>	1.00	Excellent

**Table 2**

Comments received on selected questions of the MS bladder check tool (Version 2.0) that resulted in a revision to the wording.

Question	Comment(s)	Revised question
2. On a typical night, do you have to get up more than twice to urinate?	<i>The cut off to define nocturia is more than once and not twice</i>  <i>This is an old definition of nocturia. I suggest rephrasing it on the basis of the ICS 2018 terminology, independently, from the night-time</i>	2. On a typical night, do you have to get up more than <del>twice</del> <b>once</b> to urinate?
5. Do you experience urinary leakage during any kind of physical effort (e.g., walking, coughing, sneezing, standing up, or physical activity)?	<i>Physical activity mentioned twice</i>	5. Do you experience urinary leakage during any kind of physical effort (e.g., walking, coughing, sneezing, or standing up, <del>or physical activity</del> )?
7. Do you experience weak stream when passing urine (for women, urine may wet legs)?	<i>I am not sure, that '(for women, urine may wet legs)' is helpful. Perhaps, this may cause confusion for some patients</i> <i>I suggest removing the sentence in brackets because it may limit the answer to this phenomenon in women. There are several women who experience weak stream without wetting their legs</i>	7. Do you experience weak stream when passing urine ( <del>for women, urine may wet legs</del> )?

Tool (ABSST) for people with MS (Burks et al., 2013) and the Overactive Bladder Questionnaire (Coyne et al., 2002), have been specifically designed to evaluate patient-reported outcomes. However, such tools are used only in the clinic when a patient has presented, and they do not evaluate all aspects of bladder dysfunction that may signal LUTD. Consequently, there is a distinct lack of patient-specific self-assessment tools that can be used before/as a prompt for HCP contact.

The aim of this study was to develop and validate a self-assessment tool to help people with MS become more aware of their bladder symptoms and prompt them to initiate discussions with HCPs to facilitate timely management and referral to a specialist, if required.

## 2. Materials and methods

Development of the 'MS bladder check' tool comprised two phases. In Phase 1, background research was conducted, and discussions with specialist advisors were held to agree on the objective of the work and the aim of the tool (first consensus meeting), and to devise an initial set of questions (second consensus meeting) (Fig. 1).

In Phase 2, the first mini pilot test was conducted on Version 1.0 of the MS bladder check tool, in which the initial questions were evaluated by patients with MS who were not already receiving treatment for LUTDs (described in Fig. 2). The findings are presented in Fig. 3.

Based on the information received, the questions were further refined during the third consensus meeting and an additional question was included; in addition, the design of the tool was changed from using a single check box to the left of each question to using three check boxes to the right of each question representing three possible responses: 'Yes', 'No', and 'Don't know/Not relevant'. Thereafter, the revised MS bladder check tool (i.e., Version 2.0) underwent a second mini pilot test (described in Fig. 2), and the findings are presented in Fig. 4. Compared with the first mini pilot test in which all patients reported bladder problems, some patients in the second test reported no or very few bladder problems. These individuals responded negatively to the question, 'Do you think the tool would help you to explain your bladder symptoms better to your doctor or nurse?', which may explain the more favourable result obtained from the first mini pilot test compared with the second.

To gauge the reliability of the MS bladder check tool, a Cronbach-alpha value was calculated using data from the second mini pilot testing; the value was 0.77, which corresponds to a good level of reliability.

After completion of the mini pilot testing, the MS bladder check tool was subject to expert validation. Invited experts who had agreed to participate in the validation process were provided with digital versions of the MS bladder check tool (Version 2.0), and an accompanying assessment form (see Fig. A.1). Employing the methods outlined in Polit et al. (2007), (Lynn, 1986; Davis, 1992; Polit et al., 2007) for each question, experts selected one of four ratings regarding its relevance: 1. Not relevant; 2. Somewhat relevant; 3. Quite relevant; 4. Highly relevant; experts rating a question 1 or 2 could also provide additional comments. The total number of experts, and the number of experts in agreement (i.e., selecting options 3 or 4), were then used to generate a modified kappa statistic ( $\kappa^*$ ) for each question, to provide a measure of content validity (Polit et al., 2007).  $\kappa^*$  is an index of agreement (Polit et al., 2007) which, in this case, is agreement amongst the experts that the question is relevant. For each question, the values for  $\kappa^*$  were assigned to one of four categories to reflect relevance: excellent ( $\kappa^* > 0.74$ ), good ( $\kappa^* 0.60-0.74$ ), fair ( $\kappa^* 0.40-0.59$ ), or poor ( $\kappa^* < 0.40$ ) (Polit et al., 2007). Furthermore, the overall validity of the tool was assessed by calculating the average scale content validity index (S-CVI/Ave) across the nine questions, as described by Polit et al. (2007); S-CVI/Ave scores  $\geq 0.80$  are recommended for good content validity (Davis, 1992). The findings of the expert validation were discussed during a fourth consensus meeting and, if necessary, questions were revised and the validation process was repeated.

## 3. Results

Fifteen experts were invited to participate in the validation process. Experts were recruited in the order that they responded, and the aim was to engage 6–10 experts. In total, 10 experts agreed to participate, three did not reply, and two cancelled their participation. The expert group comprised three neurologists, five urologists, and two specialists in rehabilitation. Canada, Belgium, Germany, Italy, Norway, Switzerland,

## MS bladder check tool (Version 3.0)

**To identify any bladder-related symptoms, please answer these questions by marking the answers which describe your situation best.**

**There are no right or wrong answers and if in doubt, please mark your answer as ‘Don’t know’:**

	Yes	No	Don’t know/Not relevant
1. Does the number of times you urinate per day impact your daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. On a typical night, do you have to get up more than once to urinate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you often experience feeling the urge to rush to the toilet to urinate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Have you experienced urinary leakage within the past six months due to an urgent need to urinate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you experience urinary leakage during any kind of physical effort (e.g., walking, coughing, sneezing, or standing up)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you have difficulties starting to pass urine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you experience weak stream when passing urine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you experience having to pass urine again shortly after you have urinated, i.e., ‘double voiding’?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Have you received any antibiotics for a bladder infection within the past six months?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If you answered yes to any of the above questions and feel it affects your life, you should consider discussing your bladder symptoms with your doctor or nurse to receive help with treating the symptoms.**

Fig. 5. Validated MS bladder check tool (Version 3.0).

the Netherlands, and the United Kingdom, were represented by one expert from each country and France by two experts. All 10 experts assessed the MS bladder check tool (Version 2.0) using the relevance ratings and provided additional comments on certain questions.

Table 1 presents the  $\kappa^*$  values generated for each question. Validity was ‘excellent’ overall, and for all individual questions, except question 9, which showed ‘good’ validity. (See Table A.1 for the individual relevance ratings of experts.) The S-CVI/Ave for overall tool validity was

0.87 (threshold for good content validity is  $\geq 0.8$ , Davis, 1992).

The fourth consensus meeting discussed the results of the expert validation with a focus on questions where there was disagreement amongst the experts on their relevance. For these questions, comments from experts who selected ratings 1 (not relevant) or 2 (somewhat relevant) were reviewed and discussed. In some cases, the comments were valid and necessitated a revision to the question (Table 2). However, in other cases, the comments focussed on semantics (i.e., a request

Table 3

Second expert validation:  $\kappa^*$  values and validity for each question of the revised MS bladder check tool (Version 3.0).

Question	$\kappa^*$ value	Validity
1. Does the number of times you urinate per day impact your daily life?	1.00	Excellent
2. On a typical night, do you have to get up more than once to urinate?	1.00	Excellent
3. Do you often experience feeling the urge to rush to the toilet to urinate?	0.89	Excellent
4. Have you experienced urinary leakage within the past six months due to an urgent need to urinate?	1.00	Excellent
5. Do you experience urinary leakage during any kind of physical effort (e.g., walking, coughing, sneezing, or standing up)?	0.89	Excellent
6. Do you have difficulties starting to pass urine?	1.00	Excellent
7. Do you experience weak stream when passing urine?	1.00	Excellent
8. Do you experience having to pass urine again shortly after you have urinated (i.e., ‘double voiding’)?	0.89	Excellent
9. Have you received any antibiotics for a bladder infection within the past six months?	0.89	Excellent
<b>How relevant is the MS bladder check tool as a whole (Q1–9) for creating awareness of bladder problems in people with MS?</b>	1.00	Excellent

# MS bladder check

To identify any bladder-related symptoms, please answer these questions by marking the answers which describe your situation best. There are no right or wrong answers and if in doubt, please mark your answer as "Don't know":

		Yes	No	Don't know or not relevant	
1	Does the number of times you urinate per day impact your daily life?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	On a typical night, do you have to get up more than once to urinate?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Do you often experience feeling the urge to rush to the toilet to urinate?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Have you experienced urinary leakage within the past six months due to an urgent need to urinate?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Do you experience urinary leakage during any kind of physical effort (eg. walking, coughing, sneezing or standing)?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Do you have difficulties starting to pass urine?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Do you experience weak stream when passing urine?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Do you experience having to pass urine again shortly after you have urinated, i.e., "double voiding"?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Have you received any antibiotics for a bladder infection within the past six months?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you answered yes to any of the above questions and feel it affects your life, you should consider discussing your bladder symptoms with your doctor or nurse to receive help with treating the symptoms.

Fig. 6. Illustrated version of the revised MS bladder check tool (Version 3.0).

to state 'urinary tract infection' instead of 'bladder infection') or revealed a misunderstanding of the target group by the experts. For example, comments on question 9 included, 'It would be better to ask, "Have you experienced bladder infection symptoms correlated with positive Cytobacteriological Examination of Urine (CBEU) that needed treatment

with antibiotics".' – such a question would not be suitable for a patient population. In these cases, the question was not revised. (See Table A.2 for all comments received from experts.)

Revisions to questions 2, 5, and 7 produced Version 3.0 of the MS bladder check tool (Fig. 5), and prompted a second validation round,

using the same 10 experts as in the first validation and a revised assessment form (see Fig. A.2).

In the second validation round, it was highlighted to the experts that the aim of the tool is to help people with MS become more aware of bladder problems, and that the tool was not designed for HCPs to use in diagnosing such problems in these individuals. In total, nine experts evaluated the MS bladder tool (Version 3.0) in the second validation round (one expert did not respond). Table 3 presents the  $\kappa^*$  values generated for each question. Validity was 'excellent' overall, and for all individual questions. (See Table A.3 for the individual relevance ratings of experts.) The S-CVI/Ave for overall tool validity was 0.95 (threshold for good content validity is  $\geq 0.8$ , Davis, 1992). (See Table A.4 for all comments received from experts.)

Consequently, the MS bladder check tool Version 3.0 is the final validated version. Post-validation, the expert advisors recommended adding illustrations to the final MS bladder check tool, to further promote simplicity and applicability for MS patients who may experience cognitive dysfunction, in addition to their other symptoms. The illustrated version is presented in Fig. 6.

#### 4. Discussion

The MS bladder check tool has been developed for use by people with MS to raise awareness of their bladder symptoms and the effect on daily life, empowering them to initiate discussions with their HCPs, and facilitate timely referral to specialists, if required. In addition, it equips patients with the language they need to address their bladder problems during consultations with nurses and doctors. The tool was developed by a team of expert advisors and has been validated by an international multidisciplinary team of clinical experts representing neurology, urology, and rehabilitation. To our knowledge, the MS bladder check tool is the first self-assessment instrument aimed specifically at people with MS before they have presented to their HCP with symptoms.

Acknowledging that multiple assessment algorithms already exist to support HCPs in the diagnosis, evaluation, and treatment of LUTD in people with MS, the degree of implementation and consistent usage of these tools is limited. Often, HCPs are under considerable time pressure in the clinical setting and, consequently, bladder problems are not always prioritised (Browne et al., 2015). Existing tools can be time-consuming to use and sometimes require specialised equipment; others do not capture the full range of symptoms – the ABSST, for example, requires users to calculate a score from the answers and does not assess urinary retention (Burks et al., 2013). The MS bladder check tool has been developed using language that is appropriate for the general public and has been structured to cover all aspects of bladder disorders in people with MS (nocturia, retention, detrusor sphincter dyssynergia, and overactive bladder/urgency). It is short, easy to use, and has been designed for simplicity as an awareness tool for the so-called 'red flag' symptoms. If a symptom is present and affecting the individual's daily life, they should contact their HCP for help. Consequently, the MS bladder check tool has the potential to refocus HCP attention on bladder symptoms in people with MS when needed. Patient organisations could play a role in disseminating the MS bladder check tool to their members, which would improve the timely management of bladder symptoms and enhance HRQoL for people with MS.

The MS bladder check tool aims to improve the standard-of-care for people with MS by creating awareness, facilitating engagement with patient organisations, and providing support to HCPs in the diagnosis of bladder problems. The tool has wide applicability and could be used in other areas of healthcare where bladder problems may be important but often overlooked symptoms of a neurological condition. The tool could be used for patients with different neurological conditions and at different stages of a patient's journey, serving to identify bladder problems and monitor the development of these symptoms until intervention is required; the tool could also be used to monitor improvement during appropriate management.

A potential limitation of this work is that only a few clinical experts ( $n = 10$ ) were involved in the validation process. However, according to Polit et al. (2007), the minimal acceptable number of experts for content validation is three (Polit et al., 2007). Furthermore, those experts who agreed to take part represented multiple relevant specialties (neurology, urology, and rehabilitation) and different healthcare systems across nine countries, providing a good indication of broad-spectrum validity for the MS bladder check tool. A second potential limitation is that some experts may have misinterpreted the tool as an instrument for HCPs, not for people with MS, which may have affected their ratings of question relevance. However, validity was rated good (one question) or excellent (eight questions) in the first expert validation round, and excellent for all questions in the second validation round; these findings indicate that the MS bladder check tool is an appropriate method of highlighting bladder problems and the effect on daily life in people with MS.

The next step in the development of the MS bladder check tool is to conduct a formal validation study in people with MS. A large pilot study in the UK is planned, which will aim to recruit people with MS who are not receiving treatment for bladder problems. Following successful population validation, the objective is to distribute the MS bladder check tool to people with MS through multiple channels – social media, patient organisations, HCP clinics, etc. In addition, a two-way validated translation of the MS bladder check tool is planned, to allow a wider distribution of the tool to other countries.

#### 5. Conclusions

An MS bladder check tool has been developed and validated by experts. The intention of the tool is not to self-diagnose LUTDs, such as overactive bladder or detrusor sphincter dyssynergia. Rather, the purpose is to raise awareness amongst patients with MS that symptoms of LUTD can occur with this disease; if the symptoms are affecting daily life, this should prompt the individual to have a discussion with their HCP. By empowering patients to take charge of their urinary tract health and ensure a timely referral to a specialist, if required, the MS bladder check tool aims to improve the management of people with MS and, ultimately, their HRQoL.

#### Data availability

All data generated or analysed during this study are included in this published article (and its appendix files).

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#### Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: P. F. has received speaker fees and honoraria for advisory boards from Almirall, Bayer, Biogen Idec, BMS-Celgene, Coloplast A/S, Genzyme, GW Pharma, Hexal, Janssen-Cilag, Novartis, Merck, Roche, Sanofi, Stadapharm, and Teva. None resulted in a conflict of interest. B.B. is a member of the advisory board for Coloplast A/S. G.B. has received funds for a multicentre study from Roche, and for other research projects from H2020 and from the Italian MS Society and its Foundation. J.N.P. is a consultant to Idorsia and Coloplast A/S, has received speaker fees from Allergan, Coloplast A/S, and Novartis, and royalties from Cambridge University Press. V.P. is a consultant to Boston Scientific, Coloplast A/S, Ipsen, and Medtronic. K.B.B. is an employee of Coloplast A/S.

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### Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.msard.2023.105353](https://doi.org/10.1016/j.msard.2023.105353).

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