

8. INTERNATIONAL CONSULTATION ON INCONTINENCE MODULAR QUESTIONNAIRE (ICIQ): QUESTIONNAIRES AND BLADDER DIARY

A. INTERNATIONAL CONSULTATION ON INCONTINENCE MODULAR QUESTIONNAIRE (ICIQ)

The scientific committee which met at the end of the 1st ICI in 1998 supported the idea that a universally applicable questionnaire should be developed, that could be widely applied both in clinical practice and research and should reflect the patients' perspective of their situation.

The hope was expressed that such a questionnaire would be used in different settings and studies and would allow cross-comparisons, for example, between a drug and an operation used for the same condition, in the same way that the IPSS (International Prostate Symptoms Score) has been used.

An ICIQ Advisory Board was formed to steer the development of the ICIQ and met for the first time in 1999. The project's early progress was discussed with the Board and a decision made to extend the concept further and to develop the ICIQ Modular Questionnaire to include assessment of urinary, bowel and vaginal symptoms(1). The first module to be developed was the ICIQ Short Form Questionnaire for urinary incontinence: the ICIQ-UI Short Form (2) (Fig 1). The ICIQ-UI Short Form is now widely used globally and since 2004 its use or further development has been reported in almost 100 publications.

Given the intention to produce an internationally applicable questionnaire, requests were made for translations of the ICIQ-UI Short Form at an early stage, for which the Advisory Board developed a protocol for the production of translations of its modules. The ICIQ modules have been translated into over 40 languages to date across the various modules.

Since the fifth consultation a further two modules have been published and are available for use: the ICIQ Bladder Diary (3,4) and ICIQ-LTCqol(5). The bladder diary is the first fully validated bladder diary, which notably incorporated patient and clinician input during its development. The ICIQ-LTCqol questionnaire provides an assessment of symptoms, impact and bother associated with indwelling catheter use. This brings the total number of available modules to sixteen.

With increasing demand for electronic versions of questionnaires, a study has been conducted by the ICIQ group to evaluate the equivalence of the ICIQ's psychometric properties in alternative formats (6). With equivalence demonstrated, app development for the eICIQ is underway.

www.ICIQ.net provides details of the validation status of the modules under development for urinary symptoms, bowel symptoms and vaginal symptoms and provides information regarding the content of existing modules. Information regarding production of translations and the ICIQ development protocol is also available for those interested in potential collaborations to continue development of the project.

Initial number

ICIQ-UI Short Form

DAY MONTH YEAR

CONFIDENTIAL**Today's date**

Many people leak urine some of the time. We are trying to find out how many people leak urine, and how much this bothers them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

1 Please write in your date of birth:

DAY MONTH YEAR

2 Are you (tick one):Female Male **3 How often do you leak urine? (Tick one box)**

- never 0
about once a week or less often 1
two or three times a week 2
about once a day 3
several times a day 4
all the time 5

4 We would like to know how much urine you think leaks.

How much urine do you usually leak (whether you wear protection or not)?
(Tick one box)

- none 0
a small amount 2
a moderate amount 4
a large amount 6

5 Overall, how much does leaking urine interfere with your everyday life?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

ICIQ score: sum scores 3+4+5 **6 When does urine leak? (Please tick all that apply to you)**

- never – urine does not leak
leaks before you can get to the toilet
leaks when you cough or sneeze
leaks when you are asleep
leaks when you are physically active/exercising
leaks when you have finished urinating and are dressed
leaks for no obvious reason
leaks all the time

Thank you very much for answering these questions.

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Figure 1: ICIQ-UI Short Form

Table 1: Fully validated ICIQ modules and derivation

MODULES AVAILABLE FOR USE	
ICIQ-MLUTS(7) (ICS _{male} Short Form)	Urinary symptoms (male)
ICIQ-FLUTS(8) (BFLUTS Short Form)	Urinary symptoms (female)
ICIQ-VS(9)	Vaginal symptoms and quality of life
ICIQ-B(10,11)	Bowel symptoms and quality of life
ICIQ-UI Short Form(2)	Urinary incontinence short form
ICIQ Bladder diary(3,4)	Bladder events and fluid intake
ICIQ-N(12,13) (ICS _{male} /BFLUTS)	Nocturia symptoms
ICIQ-OAB(12,13) (ICS _{male} /BFLUTS)	Overactive bladder symptoms
ICIQ-MLUTS Long Form(12) (ICS _{male})	Urinary symptoms long form (male)
ICIQ-FLUTS Long Form(13) (BFLUTS)	Urinary symptoms long form (female)
ICIQ-LUTSqol(14) (KHQ)	Urinary symptoms quality of life
ICIQ-Nqol(15) (N-QoL)	Nocturia quality of life
ICIQ-OABqol(16) (OABq)	Overactive bladder quality of life
ICIQ-LTCqol(5)	Long term catheter symptoms and quality of life
ICIQ-MLUTSsex(12) (ICS _{male})	Sexual matters related to urinary symptoms (male)
ICIQ-FLUTSsex(13) (BFLUTS)	Sexual matters related to urinary symptoms (female)

B. ANNEX 1 BLADDER CHARTS AND DIARIES

The ICS defines three types of Bladder Charts and Diaries which can be used to collect data:

MICTURITION TIME CHART

- times of voiding and
- incontinence episodes

FREQUENCY VOLUME CHART

- times of voiding with voided volumes measured,
- incontinence episodes and number of changes of incontinence pads or clothing

BLADDER DIARIES

- the information above, but also
- assessments of urgency,
- degree of leakage (slight, moderate or large) and descriptions of factors leading to symptoms such as stress leakage, eg. running to catch a bus. It is important to assess the individual's fluid intake, remembering that fluid intake includes fluids drunk plus the water content of foods eaten. It is often necessary to explain to a patient with LUTS that it may be important to change the timing of a meal and the type of food eaten, particularly in the evenings, in order to avoid troublesome nocturia.

The recent development and publication of the ICIQ Bladder Diary provides the first fully validated bladder diary that incorporated patient, clinician and statistical

input during its development (3,4). This rigorous development methodology has ensured the provision of a psychometrically robust tool that reflects the key issues from a patient's and clinical perspective to enable the gathering of required information to treat patients with LUTS (Fig 1). The diary is intended to be a standalone tool that provides instructions and an example to guide completion. The diary is intended for completion over three days and fits onto two sides of A4 to optimise administration and completion. Data collected are:

- Fluid intake
- Urine output
- Leakage episodes
- Time of sleep and waking
- Pads used
- Optional bladder sensation scale

The bladder sensation scale is intended to be an interchangeable variable that can be replaced with a more pertinent measure for an intended use, for example, a pain scale. It is advised that any scale used in this manner should be validated.

INSTRUCTIONS FOR USING THE BLADDER DIARY

This diary helps you and us to understand why you get trouble with your bladder. The diary is a very important part of the tests we do, so that we can try to improve you symptoms. On the chart you need to record:

9. When you get out of bed in the morning, show this on the diary by writing 'GOT OUT OF BED'.
10. During the day please enter at the correct time the drinks you have during the day, eg. 8.00am – two cups of coffee (total 400 ml).
11. The time you pass your urine, eg. 7.30am. Do this every time you pass urine throughout the day and night.
12. Each time you pass urine, collect the urine in a measuring jug and record the amount (in mls or fluid ozs) next to the time you passed the urine, eg. 1.30pm/320ml.
13. Each time you pass your urine, please write down how urgent was the need to pass urine:
 - 'O' means it was not urgent.
 - + means I had to go within 10 minutes.
 - ++ means I had to stop what I was doing and go to the toilet.
14. If you leak urine, show this by writing an 'W' on the diary at the time you leaked.
15. If you have a leak, please add 'P' if you have to change a pad and 'C' if you have to change your underclothes or even outer clothes. So if you leak and need to change a pad, please write 'WP' at the time you leaked.
16. If you have a leakage please write in the column called 'Comments' whether you leaked a small amount or a large amount and what you were doing when you leaked, eg. 'leaked small amount when I sneezed three times'.
17. Each time you change a pad or change clothes, please write in the 'Comments' column.
18. When you go to bed at the end of the day show it on the diary - write 'Went to Bed'.

DAY 1 DATE: ____/____/____

Please complete this **3 day** bladder diary. Enter the following in each column against the time. You can change the specified times if you need to. In the time column, please write **BED** when you went to bed and **WOKE** when you woke up.

Drinks Write the amount you had to drink and the type of drink.

Urine output Enter the amount of urine you passed in millilitres (mls) in the urine output column, day and night. Any measuring jug will do. If you passed urine but couldn't measure it, put a tick in this column. If you leaked urine at any time write **LEAK** here.

Bladder sensation Write a description of how your bladder felt when you went to the toilet using these codes

0 - If you had no sensation of needing to pass urine, but passed urine for "social reasons", for example, just before going out, or unsure where the next toilet is.

1 - If you had a normal desire to pass urine and no urgency. "*Urgency*" is different from normal bladder feelings and is the sudden compelling desire to pass urine which is difficult to defer, or a sudden feeling that you need to pass urine and if you don't you will have an accident.

2 - If you had urgency but it had passed away before you went to the toilet.

3 - If you had urgency but managed to get to the toilet, still with urgency, but did not leak urine.

4 - If you had urgency and could not get to the toilet in time so you leaked urine.

Pads If you put on or change a pad put a tick in the pads column.

Here is an example of how to complete the diary:

Time	Drinks		Urine output	Bladder sensation	Pads
	Amount	Type			
6am	WOKE		350ml	2	
7am	300ml	tea			
8am			✓	2	
9am					
10am	cup	water	Leak	3	✓

Time	Drinks		Urine output (mls)	Bladder sensation	Pads
	Amount	Type			
6am					
7am					
8am					
9am					
10am					
11am					
Midday					
1pm					
2pm					
3pm					
4pm					
5pm					
6pm					
7pm					
8pm					
9pm					
10pm					
11pm					
Midnight					
1am					
2am					
3am					
4am					
5am					

Figure 2: ICIQ-Bladder Diary (page 1)

ICIQ-BLADDER DIARY (12/13)

YOUR NAME: _____

DAY 2 DATE: ____/____/____

Time	Drinks		Urine output (mls)	Bladder sensation	Pads
	Amount	Type			
6am					
7am					
8am					
9am					
10am					
11am					
Midday					
1pm					
2pm					
3pm					
4pm					
5pm					
6pm					
7pm					
8pm					
9pm					
10pm					
11pm					
Midnight					
1am					
2am					
3am					
4am					
5am					

DAY 3 DATE: ____/____/____

Time	Drinks		Urine output (mls)	Bladder sensation	Pads
	Amount	Type			
6am					
7am					
8am					
9am					
10am					
11am					
Midday					
1pm					
2pm					
3pm					
4pm					
5pm					
6pm					
7pm					
8pm					
9pm					
10pm					
11pm					
Midnight					
1am					
2am					
3am					
4am					
5am					

Bladder sensation codes

- 0** - No sensation of needing to pass urine, but passed urine for "social reasons"
- 1** - Normal desire to pass urine and no urgency
- 2** - Urgency but it had passed away before you went to the toilet
- 3** - Urgency but managed to get to the toilet, still with urgency, but did not leak urine
- 4** - Urgency and could not get to the toilet in time so you leaked urine

Figure 3: ICIQ-Bladder Diary (page 2)