

Initial number

ICIQ-LTCqol 12/12

CONFIDENTIAL

DAY

MONTH

YEAR

Today's date

Living with a long term catheter

This form can be filled in by a carer, friend or family member, as well as, or instead of by you, but it needs to be your own opinions about your catheter (not theirs). We have used “**you**” to refer to the **person with the catheter** throughout the form – no matter who fills in the form.

Please could you tell us who is answering the questionnaire by ticking the box:

Catheter user ☐ ¹ Carer ☐ ² Family member/friend ☐ ³ Other ☐ ⁴

1. Is the catheter user (tick one):

Female ☐ Male ☐

2. Please write in the catheter user's age:

3. What type of catheter do you currently have? (Tick one box)

urethral (between the legs/into the penis) ☐ 1

supra-pubic (into the abdomen) ☐ 2

Catheter function and concern

4a. Do you have confidence in your catheter equipment (catheter, tubing and bag)? (Tick one box)

never ☐ 4

occasionally ☐ 3

sometimes ☐ 2

most of the time ☐ 1

all of the time ☐ 0

4b. How much does this bother you?

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

5a. Is the possibility of the catheter leaking on your mind? (Tick one box)

never ☐ 0

occasionally ☐ 1

sometimes ☐ 2

most of the time ☐ 3

all of the time ☐ 4

5b. How much does this bother you?

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

6a. Is the possibility of the catheter blocking on your mind? (Tick one box)

- never ☐ 0
occasionally ☐ 1
sometimes ☐ 2
most of the time ☐ 3
all of the time ☐ 4

6b. How much does this bother you?

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

7. How problematic is your catheter? (Tick one box)

- problem free ☐ 0
some problems but I would rather keep it ☐ 1
some problems but I have to keep it ☐ 2
lots of problems ☐ 3

8a. How often do you have 'urine infections' that make you feel unwell or require you to take antibiotics? (Tick one box)

- several times per month ☐ 5
about once a month ☐ 4
once every 2-3 months ☐ 3
a couple of times a year ☐ 2
less than once a year ☐ 1
never ☐ 0

8b. How much does this bother you?

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

9a. Does your catheter cause you to worry about smell? (Tick one box)

- never ☐ 0
occasionally ☐ 1
sometimes ☐ 2
most of the time ☐ 3
all of the time ☐ 4

9b. How much does this bother you?

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

10a. Are you embarrassed by having a catheter? *(Tick one box)*

- never ☐ 0
occasionally ☐ 1
sometimes ☐ 2
most of the time ☐ 3
all of the time ☐ 4

10b. How much does this bother you?

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

11a. Do you feel you have adapted to life with a catheter? *(Tick one box)*

- not at all ☐ 4
not really ☐ 3
somewhat ☐ 2
mostly ☐ 1
completely ☐ 0

11b. How much does this bother you?

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

11c. Please provide further details if you would like

12a. Overall, how much does having a catheter affect your everyday life?

Please ring a number between 0 (overall having a catheter is good) and 10 (overall having a catheter is bad)

0 1 2 3 4 5 6 7 8 9 10
overall good overall bad

Catheter function and concern score: sum scores 4a-12a

Lifestyle impact

13. Does your catheter affect your ability to travel? (Tick one box)

- I don't travel but for other reasons ☐ 5
- I don't travel because of my catheter ☐ 4
- the catheter limits my ability to travel ☐ 3
- the catheter has no effect on my ability to travel ☐ 2
- the catheter has helped my ability to travel ☐ 1

14. Does your catheter affect your social activities (for example, going out for a meal)? (Tick one box)

- I don't take part in social activities but for other reasons ☐ 5
- I don't take part in social activities because of my catheter ☐ 4
- the catheter limits my ability to take part in social activities ☐ 3
- the catheter has no effect on my social activities ☐ 2
- the catheter has helped my ability to take part in social activities ☐ 1

15. Does your catheter affect your ability to go out of the house? (Tick one box)

- I don't go out but for other reasons ☐ 5
- I don't go out because of my catheter ☐ 4
- the catheter limits my ability to go out ☐ 3
- the catheter has no effect on my ability to go out ☐ 2
- the catheter has helped me to go out ☐ 1

Lifestyle impact score: sum scores 13-15

Unscored items

16a. Do you use pads as well as your catheter because of your bladder? (Tick one box)

- never ☐ 0
- occasionally ☐ 1
- sometimes ☐ 2
- most of the time ☐ 3
- all of the time ☐ 4

16b. How much does using pads because of leaks bother you?

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

17a. Does your catheter cause you any pain, discomfort or soreness? (Tick all that apply)

- never ☐ 0
 occasionally ☐ 1
 sometimes ☐ 2
 most of the time ☐ 3
 always ☐ 4

17b. How much does this bother you?

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

18a. Do you experience any bladder spasm (tightening of the bladder when you don't want it to)? (Tick one box)

- never ☐ 0
 occasionally ☐ 1
 sometimes ☐ 2
 most of the time ☐ 3
 always ☐ 4

18b. How much does this bother you?

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

19a. Does having a catheter prevent sexual activity? (Tick one box)

- never ☐ 0
 occasionally ☐ 1
 sometimes ☐ 2
 most of the time ☐ 3
 all of the time ☐ 4
 not applicable ☐ 8
 don't wish to answer ☐ 9

19b. How much does this bother you?

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

20. How does the cost of the following in relation to your catheter impact on your quality of life:

a. Nursing services

b. Consumables for catheter care (garbage bags, cleaning products, odour products)

c. Associated factors for catheter management (food, cranberry juice, catheter friendly clothing, antibiotics, medications in general, vitamins and minerals).

21. What impact has your catheter on your psychological well-being?

22. Has your catheter changed your perception of your body image?

Thank you very much for answering these questions.