

Patient Reported Outcome Measures (PROMs) for Urethral Surgery

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PROM 2

Thank you for completing this questionnaire. The following questions are designed to measure the impact that urethral strictures have on patients' lives.

Some questions may look the same but each one is different. Please take time to read and answer each question carefully, and tick the box that best describes your symptoms over the past 4 weeks.

If you currently have a urethral or suprapubic catheter (a catheter through the lower abdomen), please start at question 10.

1 Is there a delay before you start to urinate?

- Never
- Occasionally
- Sometimes
- Most of the time
- All of the time

2 Would you say that the strength of your urinary stream is...

- Normal
- Occasionally reduced
- Sometimes reduced
- Reduced most of the time
- Reduced all of the time

3 Do you have to strain to continue urinating?

- Never
- Occasionally
- Sometimes
- Most of the time
- All of the time

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4 Do you stop and start more than once while you urinate?

- Never
- Occasionally
- Sometimes
- Most of the time
- All of the time

5 How often do you feel your bladder has not emptied properly after you have urinated?

- Never
- Occasionally
- Sometimes
- Most of the time
- All of the time

6 How often have you had a slight wetting of your pants a few minutes after you had finished urinating and had dressed yourself?

- Never
- Occasionally
- Sometimes
- Most of the time
- All of the time

7 Can you prevent this dribbling from happening by pressing or 'milking' the penis, or squeezing it between your legs?

- Yes
- No

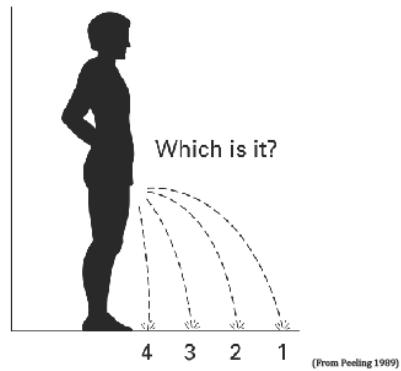
8 Overall, how much do your urinary symptoms interfere with your life?

- Not at all
- A little
- Somewhat
- A lot

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PROM 3

9 Please ring the number that corresponds with the strength of your urinary stream over the past month.



- 10 Do you get penile erections?
- Yes, with normal rigidity
 - Yes, with moderately reduced rigidity
 - Yes, with severely reduced rigidity
 - No, erection not possible
- 11 Do you have ejaculation of semen?
- Yes, normal quantity
 - Yes, moderately reduced quantity
 - Yes, severely reduced quantity
 - No, no ejaculation occurs
- 13 Do you have pain or discomfort during ejaculation of semen?
- No
 - Yes, slight pain/discomfort
 - Yes, moderate pain/discomfort
 - Yes, severe pain/discomfort

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14 If you have an erection does the head or top of the penis swell up like the rest of the penis?

- Yes
- No

15 Have you noticed any numbness of the penis or scrotum over the past month?

- Yes
- No

16 Overall, how much do your sexual symptoms interfere with your life?

- Not at all
- A little
- Somewhat
- A lot

17 Are you satisfied with the outcome of your operation?

- Yes, very satisfied
- Yes, satisfied
- No, unsatisfied
- No, very unsatisfied

18 If you were unsatisfied or very unsatisfied is that because...

- The urinary condition did not improve
- The urinary condition improved but there was some other problem
- The urinary condition did not improve and there was some other problem as well

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PROM 4

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

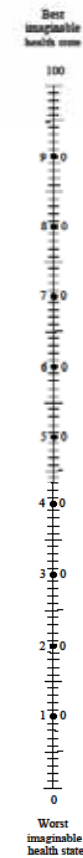
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

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To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own
health state
today



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But Does It Work?

- Reliability
 - Validity
- Acceptability
- Interpretability
 - Feasibility

Reliability

- Internal consistency
 - Do all the questions test the same issue?
 - Cronbach's alphas
- Test-retest reliability
 - Are the answers consistent?
 - Correlation coefficients

Validity

- **Content validity**
 - Are we asking the important questions?
 - Interviews with experts and patients
- **Criterion validity**
 - How does the PROM compare with gold standards?
 - Compare with flow rates and urethrograms
- **Construct validity**
 - Are we addressing a specific issue and only that issue?
 - Consistency, correlation, differentiation
- **Responsiveness**
 - Ability to detect change with time
 - Test before and after

- **Acceptability**

- Will it be used and used properly?
- Completeness

- **Interpretability**

- Can it be used generally?
- Trial

- **Feasibility**

- Time, energy and resources?
- Trial

Testing

- 88 patients Pre-Op
- 55 of these 4-6 months Post-Op
-
- 45 patients Pre-Op Test-Retest
- 45 patients Post-Op Test-Retest
-
- 35 patient interviews for content validity
- 25 patients' flow rates and urethrograms (pre- and post-op) compared with PROM scores for criterion validity
- 55 patients tested for responsiveness

So Does It Work?

Yes

But

Coding

Coding – Stricture Disease

N35 Urethral stricture

Excludes: postprocedural urethral stricture ([N99.1](#))

N35.0 Post-traumatic urethral stricture

Stricture of urethra as a sequela of:

- childbirth
- injury

N35.1 Postinfective urethral stricture, not elsewhere classified

N35.8 Other urethral stricture

N35.9 Urethral stricture, unspecified

Pinhole meatus NOS

Coding – Stricture Treatment

M76.1	Therapeutic endoscopic operations on urethra,	Endoscopic extirpation of lesion of urethra	
M76.2	Therapeutic endoscopic operations on urethra,	Endoscopic removal of foreign body from urethra	
M76.3	Therapeutic endoscopic operations on urethra,	Optical urethrotomy	
M76.4	Therapeutic endoscopic operations on urethra,	Endoscopic dilation of urethra	
M76.5	Endoscopic destruction of urethral valves		
M76.6	Endoscopic insertion of urethral stent		
M76.7	Endoscopic removal of urethral stent		
M76.8	Therapeutic endoscopic operations on urethra,	Other specified	
M76.9	Therapeutic endoscopic operations on urethra,	Unspecified	
M77.1	Diagnostic endoscopic examination of urethra,	Diagnostic endoscopic examination of urethra and biopsy of lesion of urethra	
M77.8	Diagnostic endoscopic examination of urethra,	Other specified	
M77.9	Diagnostic endoscopic examination of urethra,	Unspecified	
M79.1	Other operations on urethra,	Bouginate of urethra	
M79.2	Other operations on urethra,	Dilation of urethra nec	
M79.3	Other operations on urethra,	Calibration of urethra	
M79.4	Other operations on urethra,	Internal urethrotomy nec	
M79.5	Urethrography ascending and descending		
M79.6	Urethrography ascending NEC		
M79.7	Urethrography descending NEC		
M79.8	Other operations on urethra,	Other specified	
			M73.1 Repair of urethra, Repair of hypospadias
			M73.2 Repair of urethra, Repair of epispadias
			M73.3 Repair of urethra, Closure of fistula of urethra
			M73.4 Repair of urethra, Reconstruction of urethra
			M73.5 Repair of urethra, Pull through of urethra
			M73.6 Repair of urethra, Urethroplasty nec
			M73.7 Repair of rupture of urethra NEC
			M73.8 Repair of urethra, Other specified
			M73.9 Repair of urethra, Unspecified

Does It Work?

No

Salvage Hypospadias

How to make it work

Same process as for PROMs

Process

- Identify the factors
 - **Validate**
- Categorise and prioritise them
 - **Validate**
- Quantify them
 - **Validate**

Possible List of Factors

- Small glans
- Traumatic soft tissue loss
- No dartos
- No spongiosum
- Previous graft or flap requiring excision
- Significant chordee
- Stricture in previous urethroplasty >3cm
- Associated lichen sclerosus
- Original site of meatus
- Small penis
- Large fistula or multiple fistulae
- Scarred penile shaft
- Associated bulbar stricture
- Associated peno-scrotal transposition
- Associated obesity

Process

- Identify the factors
 - **Validate**
- Categorise and prioritise them
 - **Validate**
- Quantify them
 - **Validate**

Salvage Hypospadias

- Anatomical factors
- Factors related to previous surgery
 - Co-morbidities

Process

- Identify the factors
 - **Validate**
- Categorise and prioritise them
 - **Validate**
- Quantify them
 - **Validate**

An Example

First Order Problem

Distal (1)

Intermediate (3)

Proximal (6)



Second Order Problem

Persistent chordee $>60^\circ$ (4)
Shallow glans cleft (2)
Deficient dartos (2)



Third Order Problem

Lichen sclerosus Grade 3 (3)

Severity - 14 or Grade 2/3