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Treatment decision-making among men with lower urinary tract symptoms: A qualitative study of men's experiences with recommendations for patient- centred practice

Dr Lucy E. Selman PhD^{1, 2}

Ms Clare Clement MSc¹

Dr Cynthia A. Ochieng PhD²

Dr Amanda L. Lewis PhD^{1, 2}

Prof Christopher Chapple MD, FRCS³

Prof Paul Abrams MD, FRCS⁴

Prof Marcus J. Drake DM (Oxon.), FRCS^{4, 5}

Dr Jeremy Horwood PhD¹

¹ Bristol Randomised Trials Collaboration, Bristol Trials Centre, Bristol Medical School, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol BS8 2PS, U.K.

² Population Health Sciences, Bristol Medical School, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol BS8 2PS, U.K.

³ Sheffield Teaching Hospitals NHS Foundation Trust, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF, U.K.

⁴ Bristol Urological Institute, Southmead Hospital, Level 3 Learning and Research Building, Bristol BS10 5NB, U.K.

⁵ Translational Health Science, Bristol Medical School, University of Bristol, 69 St Michael's Hill, Bristol BS2 8DZ, U.K.

Corresponding author: Dr Lucy Selman, Bristol Medical School, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol BS8 2PS, U.K. Email lucy.selman@bristol.ac.uk Tel. +44 (0)117 3314570, Fax +44 (0)117 92 87325

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Abstract

Aims: To inform and guide patient-centred care for men with lower urinary tract symptoms (LUTS), by providing in-depth qualitative evidence regarding men's perspectives on treatment decision-making for LUTS.

Methods: Interview study of men recruited from 26 English urology departments. Purposive sampling captured, surgical/non-surgical treatment decisions, and diversity in demographics and symptom burden, in men who had urodynamics and those who did not. After diagnostic assessments, men were interviewed either pre-treatment, or after LUTS surgery. Thematic analysis was conducted. Participants' descriptions of how LUTS treatment decisions were made were categorised as patient-led, doctor-led, or shared.

Results: 41 men participated (25 pre-treatment, 16 post-surgery), ages 52-89. 20/41 described the treatment decision as shared with their consultant, 14 as doctor-led, and 7 as patient-led. There was no obvious association between treatment decision-making style and patients' satisfaction with either clinicians' role in their decision or their treatment decision. Incomplete or rushed discussions and misperceptions of LUTS and its treatment were reported, indicating a risk of suboptimal decision-making support by clinicians. As well as clinician opinion, men's treatment decision-making was influenced by the results of urological assessments, comparing current symptoms with possible side-effects of surgery, and others' experiences and opinions.

Conclusions: Men with LUTS report and prefer different kinds of decision-making support from their clinicians, who must tailor their input to patients' preferences and needs. Patients' treatment decision-making involves multiple factors and can be challenging, and areas of inadequate clinician support were identified. Recommendations for patient-centred consultations about LUTS treatment are presented.

MeSH keywords: Decision Making; Lower Urinary Tract Symptoms; Patient-Centered Care; Patient Preference; Qualitative Research; Transurethral Resection of Prostate; Urodynamics; Urologic Surgical Procedures, Male

Introduction

A patient-centred approach that elicits and incorporates patient values, preferences and circumstances is now recognised as an essential complement to evidence-based urology¹. Policy guidance^{2,3} for the treatment of male lower urinary tract symptoms (LUTS) recommends patient-centred, collaborative care which considers patients' individual needs and preferences. The benefits of a patient-centred approach include improved patient recall, understanding and adherence to treatment⁴.

Existing policy guidance, however, does not specify how urologists should achieve patient-centredness, and there is little evidence to inform practice. Studies in prostate cancer suggest that urological care often fails to be patient-centred: patients' personal values are not consistently central to treatment decisions⁵ and patients are not always fully informed about treatment options⁶ and risks⁷. Research into treatment-decision-making has provided useful data to help improve prostate cancer care⁸; however, there is a dearth of evidence to inform treatment decision-making in other fields of urology. In particular, little is known about men with LUTS not associated with cancer, despite its high prevalence⁹. LUTS can significantly impact quality of life⁹, and as prevalence and severity increase with age, LUTS management is an increasing priority given demographic ageing. To help inform clinical practice and education in urology, evidence of how patients engage in LUTS treatment decision-making is crucial.

We aimed to investigate men's perspectives on treatment decision-making for LUTS, the role of clinicians in supporting this decision, and factors influencing men's choice of treatment. Data reported are from the large qualitative study nested within the Urodynamics for Prostate Surgery: Randomised Evaluation of Assessment Methods

(UPSTREAM) randomised controlled trial. UPSTREAM aimed to determine the effect of urodynamic testing on symptoms and rates of bladder outlet obstruction surgery in men with bothersome LUTS seeking further treatment¹⁰. Men (n=820) were randomised to either a routine diagnostic test pathway as detailed by NICE (medical history, digital rectal examination, symptom score, bladder diary, uroflowmetry and urinalysis) or routine tests plus urodynamics.

Materials and Methods

Study design: In-depth semi-structured interviews with UPSTREAM participants. Qualitative methods are the most appropriate means to understand patients' experiences of key medical events such as treatment decision-making. We adhere to international guidelines in study conduct and reporting¹¹. Methodology is summarised here and detailed elsewhere¹².

Trial inclusion criteria: men with bothersome LUTS seeking further treatment for their symptoms, which may include surgery. Exclusion criteria: inability to pass urine without a catheter; neurological disease; active treatment/surveillance for prostate/bladder cancer; previous prostate surgery; not medically fit for surgery; unable to complete outcome assessments.

Sampling and recruitment: Purposive sampling captured diversity in trial arm, site, age, ethnicity, socio-economic status, baseline total International Prostate Symptom Score (IPSS)¹³ and treatment type (surgery vs. non-invasive treatment). Socio-economic status was estimated using the Index of Multiple Deprivation Decile¹⁴; we sampled across three deprivation categories (high, deciles 1-4; medium 5-7; low 8-10). Baseline total IPSS was

categorised as: ≥ 20 = high symptom burden, ≤ 19 = low¹³. Analysis was conducted in parallel with data collection, with recruitment continuing until data indicated saturation.

To capture variation along the treatment pathway, patients were recruited for interview either 1-8 weeks post-consultation where their treatment had been decided, or 6 weeks-4 months post-LUTS surgery.

Data collection: Interviews were conducted face-to-face or by telephone in 2017 by experienced qualitative health researchers (LS/CO). Interview topic guides were developed by the research team, including patient representatives, based on the study aims and literature, and included: treatment decision-making process and outcome, patient and clinician involvement and roles in decision-making, patient preferences regarding treatment, impact of assessments on treatment decision-making, and views of surgery for LUTS. Topic guides were piloted with four men with LUTS (data not included in analysis) and refined prior to use. With informed consent, interviews were audio-recorded and transcribed verbatim.

Analysis: Thematic analyses identified salient issues across the dataset¹⁵. Team members (LS, JH, CO) used line-by-line coding to independently construct draft coding frames, based on three transcripts. We combined deductive coding, based on the aims of the study, and inductive coding, identifying themes within the data. Draft coding frames were discussed and integrated to achieve coding consensus and maximise rigour. LS/CO applied the refined coding frame to the transcripts. Finally, LS applied Charles' typology of decision-making¹⁶ to participants' descriptions of their LUTS treatment decision-making, categorising them as patient-led, doctor-led, or shared. LS used charting to identify patterns in the data and drafted an analytical narrative, refined with CC/JH. Data were analysed in NVivo V10 (QSR

International Ltd) and Excel. Data extracts are tagged with a unique participant ID: 'PT' (pre-treatment) denotes men interviewed after their treatment decision but prior to any planned surgery; 'PS' denotes men interviewed post-surgery.

Results

Forty-one men participated (25 pre-treatment, 16 post-surgery), age range 52-89 (Table 1). Fifteen had a high baseline symptom burden.

INSERT TABLE 1

There were three main themes: 1) Patient and clinician control over LUTS treatment decision-making; 2) Patient satisfaction with treatment decision-making; 3) Factors influencing men's treatment decision-making.

1. Patient and clinician control over LUTS treatment decision-making

Men's perspectives on their LUTS treatment decision encompassed the range of approaches in Charles' typology (Table 2). Overall, 20/41 described the decision as shared with their clinician(s), 14 as doctor-led, 7 as patient-led.

INSERT TABLE 2

Shared decision-making was characterised by patients and clinicians discussing assessment results and treatment options and agreeing a course of action together. It included the opportunity for patients to reflect, and potentially disagree with the consultant or express an alternative view(Quote (Q1), Table 3 – supplementary file). Some men who described shared decision-making had conducted their own research into the options available, side-effects and recovery times. One decided he preferred laser surgery, which his consultant supported(Q2).

Men who described the decision as doctor-led deferred to clinical expertise and felt the treatment decision was the clinician's(Q3). In contrast, patient-led decision-making was evident when participants stressed that the decision was theirs and that they had directed the decision process. Some clinicians reportedly encouraged this approach(Q4); e.g. by not offering a specific recommendation despite severe/worsening symptoms(Q5). One man described why directing the treatment decision was crucial for him(Q6), stressing the importance of written information and telephone support for decision-making(Q7).

Of the 13 men who decided on conservative treatment, 8 reported that the decision was doctor-led and 5 that the decision was shared. Of 28 men who decided on surgery, 7 described a patient-led decision, 6 doctor-led and 15 shared. Thus descriptions of doctor-led decision-making were more common among men receiving conservative, non-surgical treatment for their LUTS, while patient-led decision-making was more common when opting for surgery.

There was no association between the deprivation category of a patient's postcode and decision-making approach. Participants who described doctor-led decision-making tended to be older (mean 72.2, standard deviation (SD) 8.40) than those describing either shared (mean 67.0, SD 9.00) or patient-led decision-making (mean 66.6, SD 7.55).

2. Patient satisfaction with treatment decision-making

Data in this theme related to both satisfaction with the clinicians' role in/support with the treatment decision and satisfaction with the treatment decision itself.

There was no obvious association between the treatment decision-making approach a patient described (i.e. whether patient-/doctor-led or shared), and their satisfaction with

clinicians' role in their decision. For the seven men who described patient-led decision-making, this approach was in line with their preferences and no objections were expressed(Q8). Similarly, none of the men who described doctor-led decision-making objected to how the treatment decision had been reached; in fact, most expressed the view that they relied on clinicians' expertise in this regard (Table 2). However, two men reporting doctor-led decision-making said they had not had much time to discuss treatment options; one said no-one had ever discussed the option of surgery with him(Q10).

Most, but not all, men who described shared decision-making were satisfied with the support they received from their clinicians: some reported insufficient time to discuss the decision(Q9) or felt like they had no choice but to have surgery, as it was the last treatment on offer.

All except one of the men with a decision for conservative treatment were satisfied with the decision; one man had not yet received his medication and so didn't yet have a view. Three out of 13 men reported that they were glad surgery wasn't needed(Q11) (MrPT16 commented that he thought surgery sometimes *'makes things worse'*). Of the 16 post-surgery patients, 15 were satisfied with their treatment, while one man questioned if he had made the right decision. Of the 12 pre-treatment patients listed for surgery, five were having second thoughts or were still considering their options(Q12);these five described shared or patient-led decision-making (Table 3).

3. Factors influencing men's treatment decision-making

a. Clinician opinion

While men reporting doctor-led decision-making were most likely to describe clinician opinion as the primary factor in their treatment decision-making, clinician opinion was also a key factor for those who described patient-led or shared decision-making(Q13, Q14).

Some participants had already decided they wanted surgery, due to the impact of LUTS on their lives. These men perceived clinicians as gate-keepers: the decision to opt for surgery could not proceed without their clinician's support. However, clinician opinion still influenced their final decision(Q15).

Some participants listened to clinician opinion but considered other factors more important in their decision-making. A minority had already decided that they did not want surgery due to possible risks and side-effects.

b. LUTS assessments including urodynamics

The results of clinical assessments played a crucial role for patients, providing information and reassurance: assessments answered questions, helped them understand their condition and confirmed whether they had a problem which could be treated(Q16, Q17).

Urodynamics was valued for its accuracy, e.g. in showing whether the bladder outlet was obstructed(Q18, Q19).

Assessment results influenced treatment decision-making to varying extents. For some men, the assessments were essential to both their clinicians' and their own decision-making process; e.g. validating what was suspected and/or providing a rationale for a treatment pathway(Q20, Q21). Others reported that although assessments were helpful to clinicians, they hadn't personally found them helpful: either because the participant was happy to defer interpretation of assessments and treatment decision-making, or because the

participant already wanted surgery, but felt his consultant needed convincing evidence(Q22, Q23).

Five patients said assessments had not helped with the treatment decision at all: they already knew they wanted surgery, perceived consultants as already decided on surgery, or said test results were inconclusive/uninformative(Q24, 25). Three men were unsure if assessment results had helped treatment decision-making, because either the consultant led the decision-making, or their medication had not been changed(Q26).

c. Current symptoms versus possible side effects of surgery

Men described weighing up the impact of their symptoms on their quality of life with the risks of undergoing surgery and possible side-effects, especially incontinence and sexual dysfunction. This could make the treatment decision difficult(Q27). For two men, misplaced concern about getting cancer, if they didn't have surgery, also influenced their decision-making(Q28).

Due to their symptoms' impact, and the ineffectiveness of non-invasive treatments(Q29), some men had a preference for surgery prior to discussing treatment with their consultant. A preference one way or the other was not related to symptom type or severity: two men with low total IPSS could not live with their symptoms and wanted surgery, and two with high scores preferred not to have surgery. One man decided on conservative treatment despite his high symptom burden and consultant's recommendation of surgery as he felt he was too young to risk sexual dysfunction(Q30). Another highly symptomatic patient decided not to have surgery despite being listed for it, because he had adapted to his symptoms and didn't want to risk post-operative catheterisation.

Surgical intrusiveness was an important consideration for some, due to side effects and recovery time. One man wanted a less intrusive surgery not yet available in the UK(Q31). Two patients listed for surgery had read in a newspaper about a non-invasive treatment ('Urolift'). They thought it sounded preferable to surgery owing to reduced side-effects and wanted to discuss it with their consultants(Q32).

d. Other people's experiences and opinions

Participants reflected on the experiences of peers when deciding about treatment. One described how his brother, who had prostate cancer, had a painful surgical procedure, which made him averse to surgery unless essential. In contrast, another man listed for surgery reported that surgery had helped his father with similar symptoms, and he had recovered without '*too many problems*' (MrPT14). Experiences of side-effects also played a role(Q33). Family members (usually spouse or children) played an important role in decision-making for some, providing their opinion or support(Q34, Q35).

Discussion

This study presents the first in-depth investigation of treatment decision-making among men with LUTS. We found that while shared decision-making was the most common approach, doctor-led and patient-led approaches were also described. There was no apparent relationship between decision-making approach and patient satisfaction with the decision-making process. This highlights the important point that being patient-centred does not necessarily mean implementing a shared approach to decision-making: some patients prefer their doctor to guide some of their medical decisions¹⁷. We found that men reporting doctor-led decision-making tended to be older, reflecting findings of other studies^{18,19}, but no evident association with social deprivation.

Proportionally, more men with a decision for surgery described it as patient-led or shared, compared with men with a decision of conservative management (none of whom reported a patient-led decision). Several possible hypotheses might explain this. First, clinicians may be less likely to direct a decision for surgery due to surgery's inherent risks. Second, it may be only when the invasive option of surgery is on the table, that some patients engage with the decision and it becomes shared. Until then, patients may see the decision as out of their hands or relatively low-stakes. Third, when a patient has a preference for surgery they may be more motivated to engage with the decision.

We found evidence of clinicians and patients negotiating treatment decisions between them and of patients disagreeing with clinicians' recommendations. This is in contrast to a prostate cancer study in which patients' treatment preferences did not predict receipt of active treatment versus surveillance⁵. However, we also found evidence that clinicians' decision-making support can fall far short of delivering patient-centred discussion, consistent with previous studies in prostate cancer^{5,7}. Patients described rushed or incomplete discussions of treatment options and assessment results and their implications, as well as misperceptions about LUTS and its treatment. Two men wanted surgery as they erroneously believed it could prevent cancer; this highlights the need to explore patients' understanding of their condition and treatment preferences and provide accurate information to correct misperceptions.

Four factors influenced men's treatment decision-making: clinician opinion, results of urological assessments, weighing up current symptoms against possible side-effects of surgery, and others' experiences and opinions. Most participants reported that assessment results were useful in treatment decision-making, providing a rationale for treatment; this

reflects our previous finding that urodynamics is largely acceptable and valuable to patients¹². As in other urological studies²⁰, clinicians' opinions and patients' perceptions of surgery's invasiveness, risks (especially of incontinence and sexual dysfunction²¹) and recovery time were important considerations. Unlike in a qualitative study in prostate cancer²², relatives played a supportive role rather than determining men's decision, perhaps due to the perceived higher stakes in cancer treatment decision-making.

Some men reported a treatment preference prior to their assessments or consultant's recommendation, based on their ability to cope with and adapt to their symptoms and their personal surgery 'risk assessment'. Wanting surgery, or deciding not to have it despite a clinician's recommendation, was not associated with symptom severity or type.

Study strengths include providing an in-depth understanding of men's perspectives and experiences; recruitment of a large, diverse sample in terms of age, symptom burden and treatment decision; and attaining data saturation. A limitation is that the sample was predominantly White British, and perspectives on treatment decision-making may vary by culture¹⁹. Participants had consented to a trial in which there was a 50% chance of randomisation to urodynamics; this should be considered in interpreting findings: patients with a strong preference for directing their own treatment might not have consented to participate in the trial. Finally, recall biases may affect men's memories of decision-making.

Our findings have clinical implications. LUTS treatment decision-making is multi-dimensional and potentially complex and challenging for patients. Our finding that urologists' treatment recommendations play a central role in men's decision-making underscores the importance of expertise in the presentation and discussion of treatment options²³. Our finding that decision-making support can be inadequate suggests that to meet policy

recommendations^{2,3} urologists require training in how to support patient-centred decision-making⁷; existing resources in the UK include those by e-Learning for Healthcare²⁴.

Based on study findings, we present key components of a patient-centred approach to supporting LUTS treatment decision-making (Box 1). While some form part of a standard urological consultation, others require additional attention and time for in-depth discussions. While not all urologists will have time for longer consultations, our recommendations may help clinicians use their time more efficiently.

Providing men with clear, consistent and accurate information about treatment options for LUTS is a key requirement in decision-making support. Refining and improving information leaflets and enabling more time for patients to consider and ask questions about the information is therefore crucial (this could be a nurse-led process and/or conducted with groups of patients facing similar treatment decisions). In our study we found no evidence of decision aids being used, but these might be useful²⁵⁻²⁷. Among men with LUTS due to benign prostatic hyperplasia, online decision aids have been found to support more well-informed and value congruent treatment decisions²⁷, and to help patients to confirm their initial treatment preference and support them in forming a treatment preference if they did not have an initial preference²⁶. Decision aids must address not only medical factors of importance to patients (e.g. recovery, side-effects), but also personal factors that may be crucial to their decision, such as how they weigh the risks and possible benefits of treatments.

INSERT BOX 1

Future research is needed to assess the impact and effects of using LUTS decision aids in different contexts (e.g. within outpatient consultations versus a man reading a decision aid

at home prior to a consultation), and to identify which features of the decision-making process and associated support increase decision confidence/satisfaction or decrease decisional regret among men with LUTS. An adequately powered quantitative survey design could be used for the latter, as well as to examine potential associations between patient satisfaction, treatment adherence and improvement in LUTS. This qualitative study also suggests several hypotheses which could be tested quantitatively, e.g. that a preference for surgery is not associated with symptom severity or type, or that patient satisfaction depends not on the style of decision-making but rather congruence between patient's preferred support and the clinician's input. Finally, cultural factors including ethnic background are likely to play an important role in men's treatment decision-making, and exploring the role of culture should be a priority in future research in this area.

Conclusions

Men with LUTS report and prefer different kinds of decision-making support from their clinicians, who must tailor their input to patients' preferences and needs. Patients' treatment decision-making involves multiple factors and can be challenging, and clinicians' support may fail to meet an adequate standard. Following our recommendations will help clinicians to provide support for treatment decision-making which is consistent and structured, as well as patient-centred, flexible and individualised.

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Figure legends

Table 1: Participant characteristics

Table 2: Participants' descriptions of LUTS treatment decision-making

Box 1: Guidelines for optimal LUTS treatment consultations

Supplementary file (online): Table 3: Data extracts by theme (cross-referenced)

Table 1: Participant characteristics

	Pre-treatment patients (n=25)	Post-surgery patients (n=16)
Age group		
51-55	1	1
56-60	1	3
61-65	7	2
66-70	7	3
71-75	6	2
76-80	2	3
81-85	1	0
86-90	0	2
Urodynamics received		
Yes	17	8
No	8	8
Treatment decision		
Conservative	13	N/A
Surgery	12	16
Time since surgery (days)		
Median	N/A	91.5
Range		48-463
Geographical region (England)		
South West	8	6
South East	6	4
London	1	2
East of England	3	1
East Midlands	0	1
West Midlands	2	0
Yorkshire and the Humber	0	1
North West	3	0
North East	1	1
Deprivation decile¹⁴		
High (1-4)	11	4
Medium (5-7)	9	9
Low (8-10)	5	3
IPSS symptom burden (baseline)¹³		
High (≥ 20)	8	7
Low (≤ 19)	17	9
Ethnicity (self-reported)		
White British	23	12
Asian/British Asian	1	1
White American	0	1
Iranian	0	1
Afro-Caribbean	0	1
Not given	1	0

IPSS = International Prostate Symptom Score

Table 2: Participants' descriptions of LUTS treatment decision-making

Decision-making type	Described by:		Exemplifying quotations
	Pre-treatment patients (n, treatment decision)	Post-surgery patients (n)	
Doctor-led	11 (8 conservative ^a , 3 surgery)	3	<i>I look on doctors like mechanics. They know best [laughs]. They fix my car; they can fix me. MrPT11</i> <i>I'm not a surgeon or a urinary expert, "You're the expert." I said, "You're the expert. If you're saying that needs to be done, I'm happy to go with that."... I'm not going to second guess... She was the surgeon, not me... she's done a lot of training to get that far. More than I have on it, so... I was more than happy to go [ahead], if that's what she said needed to be done. MrPT14</i>
Shared	11 (5 conservative, 6 surgery) ^b	9	<i>Actually, they can't tell you, but they would probably recommend it to a certain extent, but you've got to make your own decision. But, yeah, they all supported me. Fantastic, to be honest. MrPS5</i>
Patient-led	3 (3 surgery) ^c	4	<i>You know, they give you all the information... but you still have to make that decision yourself and you just have to sit and... you have to sit on your own thinking about, you know, the consequences of what you're undertaking, you know... it's still my decision. MrPT1</i> <i>We talked through very openly what the options were, how the process worked, what the chance of issues, what were the side effects, what may happen, what does the percentages say about this can happen, that can happen during this process. How effective is it? You know, how many people does it not work for? How many people are left with an issue which is worse than it was before? We went through all of them and I basically came up with the decision well it's not worth it. I will continue with what I've got which I have control of... Without risking potentially needing to be catheterised constantly... It's my choice. But it was well explained. MrPT25</i>

^a One patient said if his consultant had recommended surgery he would not have agreed to it as he did not consider his symptoms severe enough;

^b One of the patients receiving conservative treatment had previously rejected the recommendation of surgery; one of the patients listed for surgery said he was still unsure, and another was having second thoughts and wanted to discuss with his surgeon an alternative technique ('urolift');

^c Although still listed for surgery, one patient had changed his mind at the time of the interview and the two others were unsure whether they still wanted surgery.

Box 1: Guidelines for optimal LUTS treatment consultations

Components of consultation	Topics for discussion and example questions
A. Discuss and acknowledge patient experience, understanding, values	<ol style="list-style-type: none"> 1. Experience and impact of LUTS e.g. quality of life, adaptation to symptoms, burden of key symptom(s). <ul style="list-style-type: none"> • “How do your symptoms effect you and your life? Which of your symptoms bothers you most?” • An acronym suggested by Weston et al. 2001²⁸ is: FIFE: Feelings (“What emotions have your experiences given rise to?”), Ideas (“What do you think is causing this?”), Function (“How has this affected your work? Relationships? Hobbies? Self-care?”), and Expectations (“What are you hoping to leave here with?”) 2. Patients’ understanding of their condition and treatment options, goals for treatment, what they are contemplating in terms of treatment and why. <ul style="list-style-type: none"> • “What is your understanding of your urinary tract condition? What is your understanding of your treatment options?” • “Tell me what matters most to you for this decision?²⁹ What do you most want from your treatment? What are your current thoughts about future treatment? What’s the main reason you would prefer to have treatment X?” • “I hear you saying that what is most important to you is... I understand that you wish to avoid the following things...”²⁹
B. Elicit patient preferences	<ol style="list-style-type: none"> 3. Preferences for patient and clinician involvement in treatment decision-making. 4. Preferences and attitudes regarding the type, quantity and format of information regarding their treatment options (e.g. topics of importance to them, level of detail, online resources/leaflets/decision aids, written or spoken, face-to-face or by phone/email).
C. Provide information and support, tailored to and congruent with 1-4	<ol style="list-style-type: none"> 5. Provide the results of assessments promptly, in sufficient detail for the patient, and in an appropriate context (e.g. not hurriedly and before the patient has dressed¹²); interpret the test results and discuss implications for treatment. 6. Check patients’ understanding of their assessment results and implications. <ul style="list-style-type: none"> • “What is your understanding of your test results? What do you think they mean for your treatment options?”

	<ol style="list-style-type: none">7. Discuss additional factors which might influence patients' decision-making e.g. beliefs about cancer, other people's experiences; correct any misperceptions e.g. regarding cancer risk.8. Offer available information materials (e.g. leaflets, decision aids, online resources) and discuss these fully and in an unbiased way (in person or by phone), based on patient preferences.<ul style="list-style-type: none">• "Let's compare the possible options..."³⁰9. Align yourself with patients' goals, values, attitudes and preferences, and offer treatment recommendations on that basis.<ul style="list-style-type: none">• "Would it be helpful for me to offer a recommendation?" "From what you've told me about what's most important to you, I recommend..."; "How does that sound to you?"²⁹10. Allow time for in-depth discussions and questions, and for patients and families to consider information before making a decision.11. Provide opportunities for patients to revisit the treatment decision and ask more questions – complex decisions require re-evaluation; patient preferences and goals may change; patients may have new questions or doubts.
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Supplementary file (online)

Table 3: Data extracts by theme (cross-referenced)

<p>Patient and clinician control over LUTS treatment decision-making</p>	<p>Q1: <i>They give me the letter and say 'read it and then give us a ring in two weeks' time to let us know your decision' so you've got plenty of time to read the letter and you know, decide whether you want it done or not, yeah. They're good like that, yeah.</i> MrPT2 [shared decision]</p>
	<p>Q2: <i>I'd already read up about it and realised that the side effects of the laser were much lower than the old technique. I hoped that they could do that, so I asked him about it and he then said... he's doing the laser all the time now... the recovery time was much less, you know. I was clear as to what that meant and when he said that was the way he was going, was thinking, as well, then it was an open door... I was really pleased that we'd got a decision and it was a decision we were both in align[ment] with.</i> MrPT22 [shared decision]</p>
	<p>Q3: <i>It depends on doctor, if doctor say I [should have] surgery, I have to go... it is the doctors, they had to make a decision, not me. If they said, well you need operation then I have to make a decision, yes or no.</i> MrPT2 [doctor-led decision]</p>
	<p>Q4: <i>The young – he were a young doctor – he explained what had happened, and then after he explained what I'd been doing, or how it had worked. And then he said to me, 'Go away, discuss it with your wife'. 'Cause there is some side effects. He said, 'Not every people get these side effects. You've got a 96% chance it does work, but you do get the odd one in a hundred that might, you know, it might not work, and you might have this problem, you might have that problem. Go away with your wife, discuss it, and then it's up to you whether you want it doing or not'. Which I did.</i> MrPS11 [patient-led decision]</p>
	<p>Q5: MrPS16: <i>I had to go and see him beginning of the year and he says, 'Operation or do you want trial medication?' I says, 'No I'll have operation this time. Get it over and done with.'</i> Interviewer: <i>And did your surgeon recommend that you have surgery?</i> MrPS16: <i>No, he asked whether I wanted medication or operation.</i> I: <i>Okay right so you had the choice?</i> MrPS16: <i>Yeah, I had the choice.</i> I: <i>Right. Okay. And did he or she give you a recommendation as to what you should have?</i></p>

	<p>MrPS16: <i>No. Not as I can remember... Just put 'operation' down on the sheet and that was about the end of it.</i> [patient-led decision]</p> <p>Q6: <i>The issue is in all of this, do you have enough information? Are you happy that the information is contextually correct and appropriate? Are you then happy that you've got the opportunity to make an informed decision? Yes. And there's no imposition by anybody... Well informed and then regardless of what happens, I am at ease with that situation... Being at ease with the decision is very important. 'Cause the alternative is to be uncertain: Have I made the right decision? What if this? What if that? And that sort of stuff is stressful.</i> MrPT25 [patient-led decision]</p> <p>Q7: <i>This is where the written information in your hand as you're leaving that consultation is important because... There is some people that will not be able to handle the information. They won't hear it. They'll physically hear it, but it will not process [it]... it's in one ear and out the other... They need to take away things that they can sit and read and contemplate and then crucially, my recommendation would be there is a helpline associated with that unit which gives people the chance to call somebody like a nursing sister who knows what the hell's going on, to just say could you just explain this one little thing the Consultant said to me about? And that would be a good thing to do. Yes. Because it gives people the chance to reflect on what they've been told.</i> MrPT25 [patient-led decision]</p>
<p>Patient satisfaction with treatment decision-making</p>	<p>Q8:</p> <p>MrPS14: <i>I think the final decision was really out of my hands, they decided to go ahead with it when I agreed.</i></p> <p>...</p> <p>Interviewer: <i>So do you feel like it was a shared decision that you made with um, the clinical team, or was it more that they made the decision and then you just agreed with it or..?</i></p> <p>MrPS14: <i>I think they made the decision on what they found and I agreed to it.</i></p> <p>I: <i>Okay and was that okay with you?</i></p> <p>MrPS14: <i>Yeah, yeah oh yeah... I don't have any problems.</i></p> <p>[doctor-led decision]</p> <p>Q9:</p> <p>Interviewer: <i>And how much support with the decision did you get from the clinical team?</i></p> <p>MrPS1: <i>Er, what for making the decision?</i></p> <p>I: <i>Yes, did you feel supported?</i></p>

MrPS1: *Um I suppose yes, yeah I did in a way, because we did talk about it for quite a bit, but it was, I mean it was, because you only got to see them really a couple of times to make the decision, I suppose the decision – it was made a bit quickly, but I mean in the end it turned out that it was the right decision.*

[shared decision]

Q10:

Interviewer: *When surgery was suggested, erm, did you get further information about the kind of, erm, risks of having the surgery, or was it just, like, “We can do surgery. Do you want to have it?”*

MrPT11: *Well, I mean – any badness wasn’t explained to me, no... If there is [any], I’ve yet to hear it.*

I: *Okay. How much information were you given about the surgery?*

MrPT11: *Er, [the consultant] told me there was two types of surgery that had to be done. Like I say, the nurse said, “He can’t have that one, because he’s got AF.” So he said, “Well, we can do the laser one.”*

I: *Mm-hmm.*

MrPT11: *Er – I might have suggested then, if I remember rightly, I might have said, er, “Am I going to finish up incontinent?” And I believe he said no. Er – I asked him how long it would take, and he just said, “Not long, really.” The guy who I was talking to, as far as I know, he’s not the one who does it. It’s somebody else... But, er – I believe I did ask him regarding incontinence, and he said, “No, it doesn’t happen.” But then again, like I say, I read an article. And that’s what made me ask again to the nurse. She’s going to get details and let me know. But, regarding any after-effects, I don’t think anything was said to me about that.*

[Doctor-led decision]

Q11:

Interviewer: *And – so how do you feel about the decision to put you on the medication?*

MrPT8: *Erm, yes, I’m happy with that. Erm, certainly, the consultant did say to me, “One option we have is to operate.” And I presume he was referring to removing the prostate or something of that nature. And I said well, I really didn’t think I needed to have such a drastic solution at this stage. And he sort of, er, I think agreed with that. He did seem slightly disappointed [laughs]. You know, I certainly didn’t feel the situation, the symptoms I had and the way I felt about it all was such that I needed that sort of intervention. I was quite happy to try another drug, and, erm, I’ve started that now, and as I said to you, that seems to be working quite well. [shared decision, conservative]*

Q12:

You reach a point, err in the process, where you can deal with it even though you know it’s impacting on you, and the concern is that the older you get the worse it will be. So I don’t know... I think it’s hard. I think it’s very hard. I mean, you know, I’ve been

		<i>given the ultimatum that that's the only thing and I've said, "Yeah, let's go ahead," but I'm not really happy about going ahead if I'm honest. Yeah, I need a lot of reassurance really. And erm, it's all well and good saying "Oh, come on. Man up," and all that, but I don't think it works that way. MrPT1 [patient-led decision, listed for surgery]</i>
Factors influencing men's treatment decision-making	Clinician opinion	Q13: Interviewer: <i>Okay and before his input did you have a preference?</i> MrPT22: <i>Oh 100% yes... I wanted the laser treatment.</i>
		Q14: <i>I listened to the advice of the doctor, and I thought that the advice that they were giving me was good enough to have it done. MrPS11</i>
		Q15: <i>I think I'd decided pretty much before [the assessments] anyway. I, I thought, well, you know, after two or three years of not getting anywhere with medication, erm – that I needed to do something about it, so I was pleased to be... told, "Yes, that's definitely what you need."... I'd have changed my mind if [the doctor] said it wasn't necessary, but yes, I felt [surgery] seemed to be the best option. MrPT10</i>
	LUTS assessments including urodynamics	Q16: <i>The results meant that I didn't have a problem that I thought, you know, we originally thought we had, because they wondered if I had a narrowing of the tube through the, through the prostate because of the enlargement. But there was no narrowing, and it was perfectly all right. MrPT7, routine care</i>
		Q17: <i>[The assessments] answered questions for the nurse and the consultant and then they could explain to me the implication of the results... if I hadn't been producing the flow that I was, you know, they said that would warrant a lot more investigation than the results that we have, which were quite satisfactory. Mr PT20, UDS</i>
Q18: <i>It [UDS test] decided me... it determined if I'm having the operation or not. They said, 'You have got a blockage. I would suggest having this operation'. Well, that more or less made my mind up to go through with it, when I'd had that urodynamics... that was the final straw, yes. When I had that done, I decided then I was going to have it done. MrPS11, UDS</i>		
Q19: <i>It meant, meant that there's nothing else wrong with me, or any concerns... and that I just have to live with it really. MrPT6, UDS</i>		

		<p>Q20: Interviewer: <i>Do you think the results of the assessments that you did helped make the decision for which treatment you'd get?</i> MrPT16, non-invasive: <i>Oh, yes, yes, yes... For both [clinician and patient], I think, because, I mean, although they weren't pleasant, you feel as though at least everybody's had a go, and they've done as much as they can. And I think when [consultant] sort of turned round and sort of said, 'Well, that confirms everything'... and he's not made any secrets of what he thought, so you knew what he was talking about.</i></p> <p>Q21: <i>I didn't realise that I had a flow rate problem until I had this flow test done.</i> MrPT13, UDS</p> <p>Q22: <i>I guess it proved what I already knew. So I suppose it was for the doctor, I guess they needed more evidence than me saying my flow is not as strong as it used to be.</i> MrPT14, routine care</p> <p>Q23: <i>I probably had the idea that [surgery] was the correct way to go before [urodynamics], basically from what was happening to me, but then [urodynamics] validated it and therefore, you know, both the Consultant and myself were on the same path then.</i> MrPT22, UDS</p> <p>Q24: Interviewer: <i>Do you think the results of your test, the test that you did, do you think those helped make the decision for surgery?</i> MrPT3, routine care: <i>No. The results, not really. My symptoms, as I know them, convinced me that something needed to be done. Erm, the fact that we want to get on with our lives and get it sorted, hopefully. And, erm, we realised there was no other way, really, because the fact that it has gone on for five months, now, every day, the smell, and we're going to carry on like the rest of our days, might as well have something done to try and remove that.</i></p> <p>Q25: <i>I mean nothing else was gonna work anyway, so it was a question of, did I put up with this, or do I have the operation. It was either have it or put up with the problems which would increase, and I wasn't prepared to do that.</i> MrPS9, UDS</p> <p>Q26: Interviewer: <i>Did you think that the results of the assessments helped you make the decision to take medication instead of surgery?</i></p>
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		<p>MrPT2, UDS: <i>Well, I not make the decision myself, the doctor, it's up to the doctor. If the doctor say 'You stay on the medicine,' I stay on the medicine.</i></p> <p>I: <i>And do you think that the results of the assessment then made the doctor decide that medication was better than surgery in this case?</i></p> <p>MrPT2, UDS: <i>Well, he had to make a decision and he said, 'Yes, you should take medicine.'</i></p>
	<p>Current symptoms versus possible side effects of surgery</p>	<p>Q27: <i>After I came out [of meeting with consultant] I felt numb and waited for a few days, I felt quite numb you know, 'cause it will change me forever so... MrPT15</i></p> <p>Q28: <i>I suppose I could have said, "I don't want [surgery]," you know, but my mind was made up before I went... "If they say I'm going to need an operation, well, I'm going to have an operation."... Like I said earlier, er – not having it could end up in a worse result, if you know what I'm saying... I don't want to finish up like my father did [his father died of prostate cancer] [laughs]. It's just one thing ticked off that you won't have to worry about. MrPT11</i></p> <p>Q29: <i>My mind was made up before I went, and everything started: "If they say I'm going to need an operation, well, I'm going to have an operation." MrPT11</i></p> <p>Q30: <i>An erection, to a man, is being a man. MrPT9</i></p> <p>Q31: <i>I've been given the ultimatum that that's the only thing and I've said, "Yeah, let's go ahead," but I'm not really happy about going ahead if I'm honest. MrPT1</i></p> <p>Q32: <i>[There's] a new technique available which is suitable for most men, where it would improve the quality of life and minimum side effects. A new treatment called urolift... that would save all the bleeding, blood transfusions or anything else... I've only just read that little bit from the paper... They're a private hospital, so obviously it's going to cost money. Whether it's gonna become available on the National Health is a different matter, isn't it? It's the cost... They don't keep you in overnight... it should be a day surgery thing... I would be more inclined to go for that than the surgery thing and maybe needing a blood transfusion... It won't make you incontinent or anything else... surely that's got to be easier than surgery and all the side effects with that. MrPT4</i></p>

	Others' experiences and opinions	<p>Q33: <i>To be with a [colostomy] bag, that would be not a good thing. Because I've been there before with a son of mine that had a colostomy through Hirschsprung's disease... I know what living with a colostomy was, so I know what having a bag at the side of your body carrying urine and stuff is [like], so I wasn't too keen on doing that. So as we are at the moment, we're dealing with it. MrPT25</i></p>
		<p>Q34: <i>Well, she, she, she encouraged me. I mean I didn't need encouragement, I was, I was quite keen to have it done but she, she was um she agreed with me that it, it needed to be sorted out, yeah. MrPS12</i></p>
		<p>Q35: <i>[I discussed it] with my children I did and, erm, one of them, my younger son, he went with me to [consultant's] appointment and we decided to go ahead. MrPS15</i></p>