









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

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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:** An interview study of men recruited from 26 English urology departments. Purposive sampling captured surgical/nonsurgical 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:** A total of 41 men participated (25 pre-treatment, 16 post-surgery), ages 52–89. Twenty out of 41 described the treatment decision as shared with their consultant, 14 as doctor-led, and seven 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

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factors and can be challenging, and areas of inadequate clinician support were identified. Recommendations for patient-centred consultations about LUTS treatment are presented.

#### KEYWORDS

decision making, lower urinary tract symptoms, patient-centred care, patient preference, qualitative research, transurethral resection of prostate, urodynamics, urologic surgical procedures, male

## 1 | INTRODUCTION

A patient-centred approach that elicits and incorporates patient values, preferences and circumstances is now recognised as an essential complement to evidence-based urology.<sup>1</sup> Policy guidance<sup>2,3</sup> for the treatment of male lower urinary tract symptoms (LUTS) recommends patient-centred, collaborative care that considers patients' individual needs and preferences. The benefits of a patient-centred approach include improved patient recall, understanding and adherence to treatment.<sup>4</sup>

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 decisions<sup>5</sup> and patients are not always fully informed about treatment options<sup>6</sup> and risks.<sup>7</sup> Research into treatment-decision-making has provided useful data to help improve prostate cancer care<sup>8</sup>; 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 prevalence.<sup>9</sup> LUTS can significantly impact quality of life,<sup>9</sup> 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 treatment.<sup>10</sup> 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.

## 2 | MATERIALS AND METHODS

### 2.1 | 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 reporting.<sup>11</sup> Methodology is summarised here and detailed elsewhere.<sup>12</sup> 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.

### 2.2 | Sampling and recruitment

Purposive sampling captured diversity in trial arm, site, age, ethnicity, socio-economic status, baseline total International Prostate Symptom Score (IPSS)<sup>13</sup> and treatment type (surgery vs. non-invasive treatment). Socio-economic status was estimated using the Index of Multiple Deprivation Decile<sup>14</sup>; we sampled across three deprivation categories (high, deciles 1–4; medium 5–7; low 8–10). Baseline total IPSS was categorised as:  $\geq 20$  = high symptom burden,  $\leq 19$  = low.<sup>13</sup> The 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.

## 2.3 | 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 the analysis) and refined before use. With informed consent, interviews were audio-recorded and transcribed verbatim.

## 2.4 | Analysis

Thematic analyses identified salient issues across the data set.<sup>15</sup> 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-making<sup>16</sup> 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 before any planned surgery; 'PS' denotes men interviewed post-surgery.

## 3 | RESULTS

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

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.

**TABLE 1** Participant characteristics

	Pretreatment 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 decile <sup>14</sup>		
High (1–4)	11	4
Medium (5–7)	9	9
Low (8–10)	5	3
IPSS symptom burden (baseline) <sup>13</sup>		
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

Abbreviation: IPSS, International Prostate Symptom Score.

### 3.1 | 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.

Shared decision-making was characterised by patients and clinicians discussing assessment results and treatment options and agreeing on 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 S3—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); for example, 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).

**TABLE 2** Participants' descriptions of LUTS treatment decision-making

Decision-making type	Described by:		Exemplifying quotations
	Pretreatment patients (n, treatment decision)	Post-surgery patients (n)	
Doctor-led	11 (8 conservative <sup>a</sup> , 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) <sup>b</sup>	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) <sup>c</sup>	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>

<sup>a</sup>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.

<sup>b</sup>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').

<sup>c</sup>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.

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).

### 3.2 | 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 was not 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 pretreatment 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 S3).

## 3.3 | Factors influencing men's treatment decision-making

### 3.3.1 | 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.

### 3.3.2 | 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 that could be treated (Q16, Q17). Urodynamics was valued for its accuracy, for example, 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 had not 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).

### 3.3.3 | 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 noninvasive treatments (Q29), some men had a preference for surgery before 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 did not 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).

### 3.3.4 | 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).

## 4 | 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 the 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 decisions.<sup>17</sup> We found that men reporting doctor-led decision-making tended to be older, reflecting findings of other studies,<sup>18,19</sup> 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 surveillance.<sup>5</sup> 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.<sup>5,7</sup> 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 patients.<sup>12</sup> As in other urological studies,<sup>20</sup> clinicians' opinions and patients' perceptions of surgery's invasiveness, risks (especially of incontinence and sexual dysfunction<sup>21</sup>) and recovery time were important considerations. Unlike in a qualitative study in prostate cancer,<sup>22</sup> 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 before 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 culture.<sup>19</sup> 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 options.<sup>23</sup> Our finding that decision-making support can be inadequate suggests that to meet policy recommendations<sup>2,3</sup> urologists require training in how to support patient-centred decision-making<sup>7</sup>; existing resources in the United Kingdom include those by e-Learning for Healthcare.<sup>24</sup>

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 useful.<sup>28-30</sup> Among men with LUTS due to benign prostatic hyperplasia, online decision aids have been found to support more well-informed and value congruent treatment decisions,<sup>30</sup> 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 preference.<sup>29</sup> 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.

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 before 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; for example, 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 this should be a priority in future research.

## 5 | 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

**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

1. Experience and impact of LUTS e.g. quality of life, adaptation to symptoms, burden of key symptom(s).
  - “How do your symptoms effect you and your life? Which of your symptoms bothers you most?”
  - An acronym suggested by Weston et al.<sup>25</sup> 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.
  - “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?<sup>26</sup> 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...”<sup>27</sup>

B. Elicit patient preferences

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

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 dressed<sup>12</sup>); interpret the test results and discuss implications for treatment.
6. Check patients’ understanding of their assessment results and implications.
  - “What is your understanding of your test results? What do you think they mean for your treatment options?”
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.
  - “Let’s compare the possible options...”<sup>26</sup>
9. Align yourself with patients’ goals, values, attitudes and preferences, and offer treatment recommendations on that basis.
  - “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?”<sup>27</sup>
10. 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.



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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## CONFLICT OF INTERESTS

Lucy E. Selman certifies that all conflicts of interest, including specific financial interests and relationships and affiliations relevant to the subject matter or materials discussed in the manuscript (e.g. employment/affiliation, grants or funding, consultancies, honoraria, stock ownership or options, expert testimony, royalties, or patents filed, received, or pending), are the following: Abrams reports being a consultant for Astellas and Ipsen and a speaker for Astellas, Pfizer and Sun Pharma. Chapple reports being an author for Allergan; a grant, scientific study/trial, researcher, author, meeting participant, speaker and consultant/advisor for Astellas Pharma; a consultant/advisor for: Bayer Schering Parma AG, Ferring, Galvani Bioelectronics (GSK), Pierre Fabre, Taris Biomedical, Urovant Sciences and Symimetics, including patent; a researcher and scientific study/trial for Ipsen; and meeting participant and speaker for Pfizer. Drake reports being on associated advisory boards; a speaker (including for Pfizer); an active researcher and grant-holder in this field; and receives nonfinancial support from Allergan, Astellas, Ferring. Horwood, Drake, Chapple and Abrams were co-applicants of the UPSTREAM trial, thus received grant funding. Selman, Lewis, Clement and Ochieng were funded by the UPSTREAM grant.

## ETHICAL APPROVAL

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## AUTHOR CONTRIBUTIONS

Lucy Selman had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* Jeremy Horwood, Lucy E. Selman, Marcus J. Drake and Amanda L. Lewis. *Acquisition of data:* Cynthia A. Ochieng and Lucy E. Selman. *Analysis and interpretation of data:* Lucy E. Selman, Jeremy Horwood, Clare Clement and Cynthia A. Ochieng. *Drafting of the manuscript:* Lucy E. Selman. *Critical revision of the manuscript for important intellectual content:* Jeremy Horwood, Lucy E. Selman, Marcus J. Drake, Amanda L. Lewis, Cynthia A. Ochieng, Clare Clement, Christopher Chapple and Paul Abrams. *Obtaining funding:* Marcus J. Drake, Jeremy Horwood, Christopher Chapple and Paul Abrams. *Supervision:* Jeremy Horwood.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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