

# BMJ Open Management of erectile dysfunction after prostate cancer treatment: cross-sectional surveys of the perceptions and experiences of patients and healthcare professionals in the UK

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## ABSTRACT

**Objectives** Erectile dysfunction (ED) is known to be a common consequence of radical treatment for prostate cancer (PCa) but is often under-reported and undertreated. This study aimed to explore how ED in patients with PCa is managed in real-life clinical practice, from the perspective of patients and healthcare professionals (HCPs).

**Design and setting** This is a UK-wide cross-sectional survey of men with ED after treatment for PCa which covered assessment and discussion of erectile function, provision of supportive care and satisfaction with management. Parallel surveys of primary and secondary HCPs were also conducted.

**Results** Responses were received from 546 men with ED after PCa treatment, 167 primary (general practitioners and practice nurses) and 94 secondary care HCPs (urologists and urology clinical nurse specialists). Survey findings revealed inadequate management of ED in primary care, particularly underprescribing of effective management options. A fifth of men (21%) were not offered any ED management, and a similar proportion (23%) were not satisfied with the way HCPs addressed their ED concerns. There was poor communication between HCPs and men, including failure to initiate discussions about ED and/or involve partners, with 12% of men not told that ED was a risk factor of PCa treatment. These issues seemed to reflect poor access to effective ED management or services and lack of primary HCP confidence in managing ED, as well as confusion over the roles and responsibilities among both HCPs and men.

**Conclusions** This study confirms the need for better support for men from HCPs and more tailored and timely access to effective ED management after treatment for PCa. A clearly defined pathway is required for the discussion and management of ED, starting from the planning stage of PCa treatment. Improved adherence to ED management guidelines and better education and training for primary care HCPs are areas of priority.

## INTRODUCTION

In 2018, 1.28 million men were diagnosed with prostate cancer worldwide, which represented 13% of all cancers diagnosed in men.<sup>1,2</sup> In the UK, prostate cancer is the most

## Strengths and limitations of this study

- This is the first UK study to survey the perceptions and experiences of men with erectile dysfunction after prostate cancer treatment and therefore adds considerable knowledge to the field.
- Also surveying primary and secondary healthcare professionals on the same topics revealed additional unique challenges in management coordination for these men.
- Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received.
- The survey sample contained a higher proportion of younger patients than the prostate cancer population as a whole, and compliance with erectile dysfunction treatment was not explored.
- The surveys were conducted before the availability of generic/over-the counter sildenafil and generic tadalafil.

common cancer in men, with over 56 000 new cases diagnosed in 2018.<sup>3</sup> Risk factors for prostate cancer include increasing age,<sup>4</sup> a family history of the disease in a first-degree relative,<sup>5–7</sup> body weight<sup>8</sup> and ethnicity—one in four black men will be diagnosed with prostate cancer in their lifetime in England, twice the risk of white men (one in eight).<sup>9</sup>

Radical treatments for prostate cancer include radical prostatectomy (RP), external beam radiotherapy (EBRT), brachytherapy, high-intensity focused ultrasound and androgen deprivation therapy (ADT).<sup>10–11</sup> Active surveillance is also offered as an option to men with low-risk, and sometimes intermediate-risk, localised prostate cancer.<sup>10</sup>

While effective in prolonging survival, these treatments commonly induce erectile dysfunction (ED).<sup>13–15</sup> The UK-wide Life After Prostate Cancer Diagnosis (LAPCD) study,



examining patient-reported outcomes of over 30 000 prostate cancer survivors at 18–42 months after diagnosis, recently reported that 81% of patients described their overall sexual function as poor or very poor.<sup>16</sup> By comparison, the prevalence of poor sexual function in the general population of men aged 60 and over is 33%.<sup>17</sup>

Typically, ED, accompanied by gradual structural changes in the penis, develops over a few months and up to 2–3 years after treatment and may be permanent. ADT may also cause loss of sexual interest, as well as more general symptoms such as fatigue, low mood, weight gain and decreased muscle mass. ED has been linked to loss of self-esteem and depression<sup>18</sup> and can significantly impair quality of life for both men and their partners.<sup>13 14 16 19</sup>

A wide range of treatments are available for the management of ED, including oral phosphodiesterase type 5 inhibitors (PDE5is), intracavernosal injections (ICI), intraurethral suppositories or ointment (alprostadil), vacuum erection devices (VED), and penile implants.<sup>10 11 20</sup> Nevertheless, ED remains an under-reported and often undertreated condition.<sup>21–24</sup> The LAPCD study reported that only 44% of men were offered intervention(s) to help with sexual function, such as medications, devices or specialist services.<sup>16</sup> A recent review from a high-volume centre suggested that despite the advancements in surgical technique and postoperative care, erectile function (EF) outcomes after RP have not improved over the last decade, and more efforts are needed to improve patients' care after RP.<sup>25</sup>

To address healthcare professionals' (HCP) concerns that no UK guidelines were available for the management of ED in patients with prostate cancer, specific consensus guidelines for treating ED after prostatectomy<sup>13</sup> or radiotherapy/ADT<sup>14</sup> have been developed. These guidelines emphasise the importance of proactive early sexual rehabilitation postprostatectomy, including patient education and pharmacological intervention, to minimise treatment-induced penile changes and to actively manage the impact of loss of sexual desire and delayed ED postradiotherapy/ADT on men and their partners.

The aim of this study was to explore how ED after prostate cancer treatment is experienced, assessed and managed in a publicly funded healthcare system, from the perspectives of both patients and HCPs. We conducted a UK-wide survey of men with ED after prostate cancer treatment and parallel surveys of primary and secondary HCPs, including general practitioners (GPs), practice nurses, urologists and urology clinical nurse specialists (CNS).

## METHODS

### Study design and participants

An online cross-sectional survey of men experiencing ED after prostate cancer treatment was conducted between August 2014 and March 2015. The survey consisted of a maximum of 48 questions and participants were told it would take 10–15 min to complete. Survey questions

(online supplementary file 1) explored the assessment and discussion of EF with HCPs and satisfaction with ED management. To recruit participants, a hyperlink to the open online survey was widely disseminated through Prostate Cancer UK's communication channels, including electronic newsletters and social media. Paper versions of the survey were also provided on request, and these results were manually entered into the data set.

Online cross-sectional surveys of GPs, practice nurses, urologists and urology CNS were conducted between October 2014 and January 2015. The primary care survey consisted of a maximum of 16 questions, and the secondary care survey consisted of a maximum of 18 questions. All participants were told it would take 10 min to complete. Survey questions (online supplementary file 1) explored confidence regarding knowledge of prostate cancer and ED (primary HCPs only), discussions about potential side effects of prostate cancer treatment, how EF is assessed, the involvement of partners, ED management options, and roles and responsibilities. Participants were invited via Doctors.net.uk and Nursing in Practice access panels, weighted on gender, age and location to be representative of the respective HCP populations.

Questions for both surveys were coproduced and piloted with men living with and after prostate cancer and HCPs, through virtual working groups and face-to-face workshops. Before beginning each survey, participants were informed of the approximate length of time to complete the survey, the purpose of the study, that their responses would be confidential and not used for any other purposes beyond this research study, and the contact details of the study team. Where appropriate, the online survey platform randomised the order that response options for a question were displayed in order to reduce bias. Only completed questionnaires were included in the final data set.

A Strengthening the Reporting of Observational Studies in Epidemiology checklist is provided in online supplementary file 2.

### Statistical analysis

Data were analysed based on the number and percentage of respondents to each question. For the survey of men with ED after prostate cancer treatment, responses were grouped and analysed by type of prostate cancer treatment received. HCP data were already split by profession at the time of data collection. Data were then pooled to compare between professions.

### Patient and public involvement statement

The Prostate Cancer UK 'Policy & Campaigns Forum', consisting of men living with and after prostate cancer, initially raised the issues around ED after prostate cancer treatment as a suggested area of work for Prostate Cancer UK to focus on. The Forum members were subsequently involved in the planning of the study, including development of the research questions and survey design.

**Table 1** Characteristics of survey respondents with erectile dysfunction after prostate cancer treatment (n=546)

<b>Country</b>	
England	400 (73%)
Scotland	106 (19%)
Wales	37 (7%)
Northern Ireland	3 (1%)
<b>Total</b>	<b>546 (100%)</b>
<b>Age (year)</b>	
<50	9 (2%)
50–59	118 (22%)
60–69	280 (51%)
70–79	120 (22%)
≥80	19 (3%)
<b>Total</b>	<b>546 (100%)</b>
<b>Sexual orientation</b>	
Heterosexual	513 (94%)
Gay	17 (3%)
Bisexual	13 (2%)
<b>Total</b>	<b>543 (100%)</b>
<b>Relationship status</b>	
Married/civil partnership	422 (78%)
Have a partner, but not living together	34 (6%)
Do not currently have a partner	36 (7%)
Living with partner but not married/in civil partnership	31 (6%)
Widowed	21 (4%)
<b>Total</b>	<b>544 (100%)</b>
<b>Years since first treatment for prostate cancer</b>	
20 and above	3 (1%)
15–19	21 (4%)
10–14	55 (10%)
5–9	181 (33%)
0–4	286 (52%)
<b>Total</b>	<b>546 (100%)</b>
<b>Number of prostate cancer treatments received</b>	
1	356 (66%)
2	160 (30%)
3	26 (5%)
<b>Total</b>	<b>542 (100%)</b>

Percentages have been rounded to whole numbers.

## RESULTS

### Survey of men with ED after prostate cancer treatment

#### Respondent characteristics

Complete responses from 561 men with ED after prostate cancer were received (a self-selecting convenience sample). Responses from 15 men who had not received treatment in the UK were excluded, leaving a total of

546 respondents for analysis (table 1). The number of responses per question ranged from 408 to 546 (75%–100% response rate) due to respondents selecting they did not know the answer or that the question did not apply to them.

The mean respondent age was 65 years, with half (n=280/546; 51%) of the study sample aged between 60 and 69 years (table 1). Approximately half (n=286/546; 52%) of respondents had received their initial treatment for prostate cancer in the last 4 years. This sample closely resembles the prevalence data set of all patients with prostate cancer alive in England at the end of 2015, which shows 50% living 0–5 years, 33% 5–10 years, 16% 10–15 years and 5% 15–21 years after diagnosis.<sup>26</sup> The majority (n=356/542; 66%) of respondents had received only one treatment for prostate cancer, while 30% (n=160) received two and 5% (n=26) three. The most common treatment was RP (n=310/546; 57%), either alone (n=258; 47%) or in combination with other treatment(s) (n=52; 10%). A quarter of patients (n=137/546; 25%) received EBRT, and one-third (n=182; 33%) received ADT (online supplementary file 3).

#### Men's experiences prior to prostate cancer treatment

Almost three-quarters of respondents (n=401/546; 73%) indicated that they had 'always'/'almost always' been able to get and keep an erection before their prostate cancer treatment, with only 2% (n=10) stating they were not sexually active before treatment (table 2).

Over one-third (n=191/525; 36%) reported that their consultant was the first HCP to question them about their EF before treatment, while another third (n=182; 35%) reported that no one had asked about this (table 2). Less than 10% (n=48/546; 9%) of respondents had completed a pretreatment standard questionnaire, such as the Sexual Health Inventory for Men (SHIM)<sup>27</sup> or the International Index of Erectile Function (IIEF).<sup>28</sup> Men who were to undergo prostatectomy were more likely to be asked to complete a questionnaire, compared with men who were to receive radiotherapy with ADT (14% vs 6%, respectively).

Most respondents (n=447/546; 82%) were told by their doctor or nurse that ED might be a side effect of their treatment; however, 12% (n=68) were not told this information. This information was more likely to be given to men before a prostatectomy, compared with radiotherapy and ADT (91% vs 74%, respectively) (table 2). For respondents with a partner (n=473), 70% (n=332) said their partners were involved in these discussions with their HCPs. The knowledge of possibly experiencing erection difficulties influenced the choice of prostate cancer treatment for 13% (n=74/546) of men.

#### Men's experiences after prostate cancer treatment

Following prostate cancer treatment, half (n=229/437; 52%) of men were asked about their EF by their HCP within 3 months (table 3), most commonly by their consultant, and this rose to 69% (n=156) in the group that had a prostatectomy. However, 29% (n=127) of all respondents said they had not been asked by any HCP

**Table 2** Men's experiences prior to prostate cancer treatment**How often were you (the patient) able to get and keep an erection before prostate cancer treatment? (n=546)**

	Total	Surgery	RT+ADT	Other
Almost always/always	401 (73)	205 (79)	75 (64)	121 (71)
Most times (>50%)	64 (12)	21 (8)	18 (15)	25 (15)
Sometimes (<50%)	54 (10)	26 (10)	13 (11)	15 (9)
Almost never/never	14 (3)	4 (2)	7 (6)	3 (2)
No sexual activity	10 (2)	1 (0)	3 (3)	6 (4)
Unsure	3 (1)	1 (0)	2 (2)	0 (0)
Total (% of total)	546 (100)	258 (47)	118 (22)	170 (31)

**Who asked the first questions about your (the patient's) erections before treatment? (n=525)**

	Total	Surgery	RT+ADT	Other
Your consultant	191 (36)	123 (49)	22 (20)	46 (28)
Your general practitioner	14 (3)	6 (2)	2 (2)	6 (4)
Your nurse	35 (7)	17 (7)	9 (8)	9 (5)
Your partner	4 (1)	1 (0)	0 (0)	3 (2)
You (the patient)	99 (19)	47 (19)	19 (17)	33 (20)
No one	182 (35)	55 (22)	60 (54)	67 (41)
Total (% of total)	525 (100)	249 (47)	112 (21)	164 (31)

**Did your (the patient's) doctor or nurse tell you (the patient) that erectile dysfunction might be a side effect of treatment? (n=546)**

	Total	Surgery	RT+ADT	Other
Yes	447 (82)	235 (91)	87 (74)	125 (74)
No	68 (12)	11 (4)	21 (18)	36 (21)
Unsure	28 (5)	10 (4)	9 (8)	9 (5)
Erectile dysfunction not a side effect of the treatment I had	3 (1)	2 (1)	1 (1)	0 (0)
Total (% of total)	546 (100)	258 (47)	118 (22)	170 (31)

Percentages in brackets are a percentage of each column, unless otherwise stated.

'Other': all men who received a treatment other than 'surgery' or 'RT+ADT'.

'Total': all men who took part in the survey and reported erectile dysfunction following treatment.

'Surgery': men whose only radical treatment was radical prostatectomy.

'RT+ADT': men who only had radiotherapy (external beam radiotherapy and/or brachytherapy) plus ADT. ADT, androgen deprivation therapy; RT, radiotherapy.

about EF following prostate cancer treatment (table 3). Almost a quarter (n=123/489; 23%) of men were not satisfied with the way HCPs addressed their EF concerns.

#### Treatment for ED

Two-fifths of men (n=199/503; 40%) said they were offered ED treatment within 3 months of their prostate cancer treatment, with a further 19% (n=94) being offered treatment within 4–6 months. A fifth of men (n=110; 22%) said they were not offered any treatment (table 3). Treatment was most commonly offered by a consultant (n=230/516; 45%) and usually in a urology department (n=181/503; 36%), GP surgery (n=120; 24%) or ED clinic (n=89; 18%).

ED management options men received for ED are shown in online supplementary file 4 (n=521)—most commonly men were offered three options (n=122/521;

29%). The most common treatments offered were sildenafil 25, 50 or 100mg (16%, 20%, 17%), VED (33%), tadalafil 5, 10 or 20mg (21%, 14%, 29%), and pelvic floor exercises (20%), mostly on National Health Service (NHS) prescription. The most common treatments prescribed privately were also PDE5is and VED.

When asked whether they had any difficulty or delays in getting access to ED treatment, a quarter (n=103/431; 25%) indicated experiencing such problems. These included issues with supply and availability, such as 'restricted availability due to limited prescriptions', 'pharmacies lacking stock', 'cost' and 'HCPs not being helpful/willing to prescribe/lacking knowledge'.

#### Monitoring of ED treatment

Over three-quarters of respondents (n=374/484; 77%) said they were not asked to complete a questionnaire

**Table 3** Men's experiences after prostate cancer treatment

**How soon after prostate cancer treatment, if at all, did the consultant, GP or nurse ask whether your ability to get or keep an erection had been affected? (n=437)**

	Total	Surgery	RT+ADT	Other
≤3 months	229 (52)	156 (69)	29 (33)	44 (35)
4–6 months	59 (14)	34 (15)	7 (8)	18 (14)
7–12 months	16 (4)	5 (2)	4 (5)	7 (6)
>12 months	6 (1)	1 (<1)	1 (1)	4 (3)
Not at all	127 (29)	29 (13)	46 (53)	52 (42)
Total (% of total)	437 (100)	225 (51)	87 (20)	125 (29)

**How long after prostate cancer treatment, if at all, were you offered treatment to help you get or keep an erection? (n=503)**

	Total	Surgery	RT+ADT	Other
<3 months	199 (40)	128 (54)	24 (23)	47 (29)
4–6 months	94 (19)	53 (22)	12 (11)	29 (18)
7–12 months	38 (8)	20 (8)	6 (6)	12 (8)
>12 months	28 (6)	8 (3)	12 (11)	8 (5)
Unsure	34 (7)	10 (4)	9 (8)	15 (9)
Not at all	110 (22)	18 (8)	43 (41)	49 (30)
Total (% of total)	503 (100)	237 (47)	106 (21)	160 (32)

Percentages in brackets are a percentage of each column, unless otherwise stated.

'Other': all men who received a treatment other than 'surgery' or 'RT+ADT'.

'Total': all men who took part in the survey and reported erectile dysfunction following treatment.

'Surgery': men whose only radical treatment was radical prostatectomy.

'RT+ADT': men who only had radiotherapy (external beam radiotherapy and/or brachytherapy) plus ADT.

ADT, androgen deprivation therapy; GP, general practitioner; RT, radiotherapy.

about their erections, such as the SHIM or IIEF, during ED treatment. When asked whether their prescribed ED treatment met their needs, only 32% (n=128/402) said 'yes', while 51% (n=204) said 'no' and 17% (n=70) were 'unsure'. Approximately half of the respondents (n=298/546; 55%) reported having access to a CNS, with the remainder saying they did not have access or were uncertain.

### Survey of primary and secondary HCPs

#### Respondent characteristics

Complete responses from 282 HCPs were received. Twenty-one responses were excluded from the analysis due to duplicate entries, leaving a total of 261 HCPs in the analysis (115 GPs, 52 practice nurses (4 of whom were nurse practitioners/advanced nurse practitioners), 50 urologists and 44 urology CNS) (table 4).

#### Knowledge and confidence in ED management within primary care

GPs and practice nurses were asked how confident they were that their knowledge of prostate cancer, ED and treatment options for ED was sufficiently comprehensive and up-to-date to support men with prostate cancer. Most GPs indicated their knowledge as 'satisfactory'/'confident'/'very confident' for prostate cancer (n=98/115; 85%), for ED (n=104; 90%) and for treatment options for ED (n=108; 94%), compared with 48% (n=25/52),

34% (n=18) and 32% (n=17) of practice nurses, respectively, with the remainder stating they were 'apprehensive' or 'extremely unconfident' (figure 1). When asked what would help to improve their confidence, the most common responses were 'training/education' and 'further information/literature/online resources'.

#### Discussions about ED

Only 26% of GPs (n=30/115) and 32% of practice nurses (n=16/51) said they 'usually'/'always' initiated a discussion about ED with men after prostate cancer treatment, with 29% (n=33) and 38% (n=19) saying they 'rarely' or 'never' did so, respectively. This varied by gender for GPs, with 20% of male GPs (n=13/64) saying they 'never'/'rarely' initiated a discussion, compared with 44% of female GPs (n=17/39). The most common reasons GPs gave for not initiating a discussion about ED were that it 'wasn't a priority topic' or that 'the patient initiated the discussion'. However, 32% of GPs (n=37/115) said that men 'rarely'/'never' initiated a discussion about ED with them, while 25% of practice nurses (n=13/51) said the same. For GPs, this question varied less by gender than the previous question, with 33% of male GPs (n=21/64) saying patients 'never'/'rarely' initiated a discussion with them, compared with 41% of female GPs (n=16/39).

**Table 4** Characteristics of primary and secondary healthcare professionals survey respondents (n=261)

	General practitioners	Practice nurses	Urologists	Urology clinical nurse specialists
<b>Country</b>				
England	97 (84%)	45 (91%)	41 (82%)	38 (86%)
Scotland	10 (9%)	0 (0%)	4 (8%)	2 (5%)
Wales	5 (4%)	4 (6%)	4 (8%)	3 (7%)
Northern Ireland	3 (3%)	3 (3%)	1 (2%)	1 (2%)
<b>Total</b>	<b>115 (100%)</b>	<b>52 (100%)</b>	<b>50 (100%)</b>	<b>44 (100%)</b>
<b>Gender</b>				
Male	64 (62%)	Not asked	40 (80%)	Not asked
Female	39 (38%)		10 (20%)	
<b>Total</b>	<b>103 (100%)</b>		<b>50 (100%)</b>	
<b>Age (years)</b>				
Under 30	1 (1%)	Not asked	3 (6%)	Not asked
30–39	42 (41%)		19 (38%)	
40–49	35 (35%)		20 (40%)	
50–59	21 (20%)		8 (16%)	
60 or over	4 (4%)		0 (0%)	
<b>Total</b>	<b>103 (100%)</b>		<b>50 (100%)</b>	
<b>Average number of patients with prostate cancer seen per month</b>				
0–9	85 (74%)	46 (90%)	3 (6%)	Not asked
10–19	11 (10%)	0	16 (32%)	
20–29	8 (7%)	0	10 (20%)	
30–39	10 (9%)	5 (10%)	10 (20%)	
40–49	0 (0%)	0	3 (6%)	
50–59	0 (0%)	0	2 (4%)	
60–69	0 (0%)	0	2 (4%)	
70–79	0 (0%)	0	0 (0%)	
80–89	1 (1%)	0	2 (4%)	
90–100	0 (0%)	0	2 (4%)	
<b>Total</b>	<b>115 (100%)</b>	<b>51 (100%)</b>	<b>50 (100%)</b>	

Percentages have been rounded to whole numbers.

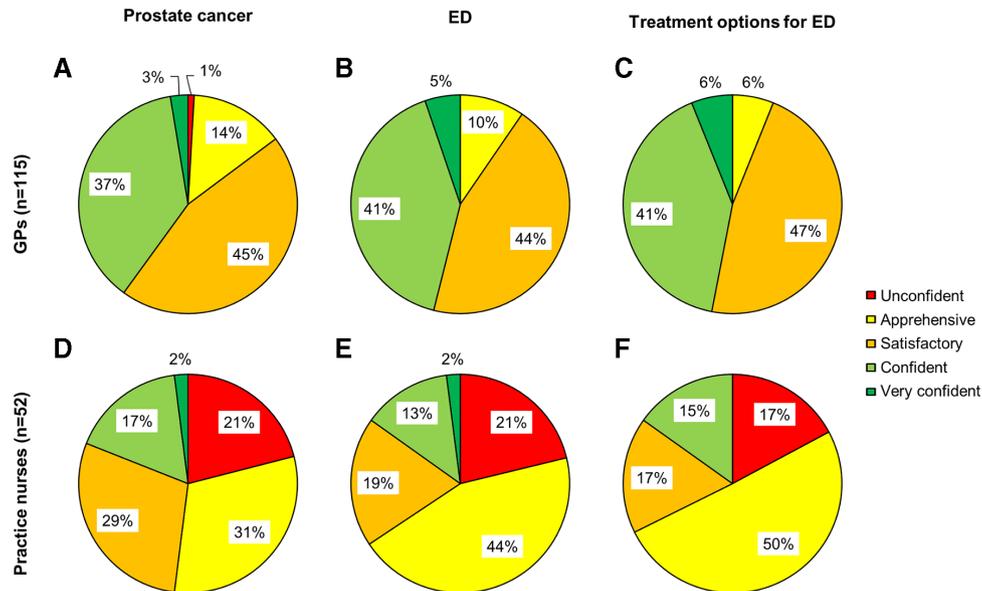
When secondary care HCPs were asked who was the most likely to initiate a discussion about ED, the majority of urologists (n=33/50; 61%) identified themselves, while for non-ED specialist CNS (n=34) the most common first choice was the patient (n=12; 35%), followed closely by the urologist or urology/uro-oncology CNS (both n=11; 32%). A fifth of urologists (n=10/50; 20%) said that the duration of ADT would affect their decision whether to discuss ED with the patient, with the conversation more likely to take place for men on long-term ADT.

Involvement of partners in discussions about ED appeared to be more common in secondary care. Of the urologists, 40% (n=20/50) vs only 13% of GPs (n=15/115) said they 'usually'/'always' involved men's partners in such discussions, while 24% of urologists (n=12/50) vs

60% of GPs (n=70/115) said they 'rarely'/'never' did so. Among the nurses surveyed, 65% of CNS (n=28/43) said they involved partners, compared with only 12% of practice nurses (n=6/51).

#### Assessment of EF in secondary care

The majority of CNS (34/44; 77%) and urologists (40/50; 80%) said they 'usually'/'always' performed a verbal baseline assessment of EF before treatment, with only 8% of urologists (n=4) saying they 'never'/'rarely' did this. Standardised questionnaires were used less frequently than verbal assessments by both urologists and CNS. Of the urologists 30% (n=15/50) indicated that there were some patient groups they chose not to assess for baseline EF, for example if they were very elderly, had advanced



**Figure 1** Level of confidence among (A–C) GPs and (D–F) practice nurses that their knowledge of prostate cancer, ED and treatment options for ED is sufficiently comprehensive/up-to-date to support men with prostate cancer. GPs were asked two separate questions about comprehensive knowledge and up-to-date knowledge. The data shown are for comprehensive knowledge. Practice nurses were asked a single question about comprehensive/up-to-date knowledge. ED, erectile dysfunction; GPs, general practitioners.

disease or did not wish to be assessed. Other factors such as lifestyle, medication, comorbidities and relationships were also often included in the EF assessment.

### Roles and responsibilities

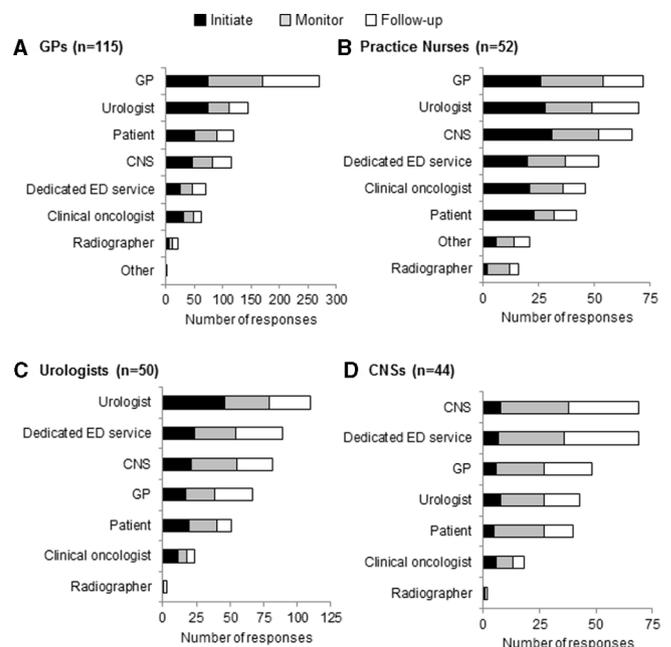
Primary and secondary care HCPs were asked which HCPs or services they perceived as being involved in initiating, monitoring and following up on treatment for ED. The pattern of responses differed considerably between different HCP types, as shown in figure 2. GPs and urologists had the most prominent role according to GPs and practice nurses, whereas urologists and CNS identified themselves and dedicated ED services as playing the major roles. CNS identified themselves as having a greater focus on monitoring and follow-up, rather than on management initiation.

### Management of ED

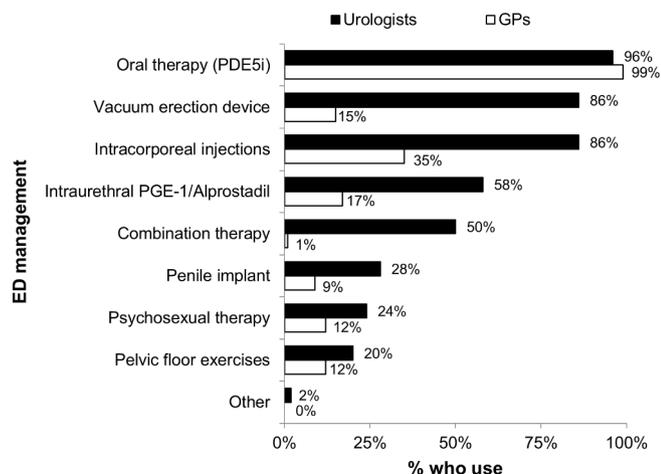
In primary care, 39% of GPs (n=44/115) said that they ‘usually’/‘always’ prescribed pharmacological management for men with ED after prostate cancer treatment, while 51% (n=59) said ‘sometimes’ and 11% (n=12) ‘rarely’/‘never’ did. Only 23% of practice nurses (n=12/52) said that they offered ED management.

A large majority of GPs (n=104/111; 94%) and urologists (42/50; 84%) used oral therapy (PDE5is) as their first-line treatment for ED in patients with prostate cancer. The PDE5i most commonly prescribed by GPs was sildenafil (93%), whereas urologists most commonly prescribed tadalafil (96%). Most GPs prescribed a dose of four tablets per month; only 38% of GPs, compared with 69% of urologists, prescribed daily low-dose (5 mg) tadalafil (the only daily PDE5i licensed for daily use).

GPs were much less likely than urologists to use second-line or third-line treatments, including VED (15% vs 86%), intracorporeal injections (35% vs 86%), intraurethral prostaglandin E1 /alprostadil (17% vs 58%), penile implants (9% vs 28%), combination therapy (1% vs 50%),



**Figure 2** Roles and responsibilities of HCPs for the initiation, monitoring and follow-up of an ED management strategy according to (A) GPs, (B) practice nurses, (C) urologists and (D) CNS. HCPs could select more than one option from initiate (black), monitor (grey) or follow-up (white). ED, erectile dysfunction; GP, general practitioner; HCPs, healthcare professionals; CNS, clinical nurse specialist.



**Figure 3** ED management strategies used after prostate cancer treatment by GPs (n=115) and urologists (n=50). Healthcare professionals could select more than one option. ED, erectile dysfunction; GPs, general practitioners; PDE5i, phosphodiesterase type 5 inhibitor; PGE-1, prostaglandin E1.

psychosexual therapy (12% vs 24%) and pelvic floor exercises (12% vs 20%) (figure 3). A common reason for this would be that GPs would refer the patient to secondary or specialist care for these treatments. However, 41% of GPs (n=47/115) said they ‘rarely’/‘never’ refer men with ED after prostate cancer treatment to secondary or specialist care.

#### Access to treatments

Treatments reported to be inaccessible to some GPs included penile implants (n=74/115; 64%), ICI (n=51; 44%) and VEDs (n=48; 42%). Common reasons given were that these treatments were ‘restricted to secondary care’, ‘not prescribed on the NHS’ or there was ‘a lack of training or expertise in their use’. Treatment access was less of an issue among secondary care HCPs: 56% of urologists (n=28) said that all ED treatments, including psychosexual therapy, were available to their patients.

## DISCUSSION

Our survey of men explored the experiences of ED management after being treated for prostate cancer. In parallel surveys, we examined the knowledge and experience of primary and secondary HCPs in assessing such patients and their management strategies. Our findings indicated that, despite being at high risk from treatment-induced ED, many men were not treated according to recognised/available ED treatment guidelines available at the time of this study<sup>20 29</sup> and many were dissatisfied with their ED management. There was also an apparent mismatch between patient and HCP views on how post-treatment ED is managed in practice. It seems likely that, to some extent, HCPs’ responses may have reflected their ‘ideal’ management rather than what actually took place in practice.

## Management of ED in primary care

In particular, there seemed to be inadequate management of ED in primary care, including failure to implement early and structured strategies, combination ED management strategies and, in some instances, any ED treatment at all. These issues seemed to reflect restricted access to treatments and services and lack of confidence in managing ED. This suggests a need for better targeted training and education, particularly for practice nurses. Many GPs see relatively few patients with prostate cancer, whereas practice nurses encounter men with ED more frequently, presumably when administering ADT injections or providing care for concomitant conditions, such as diabetes. In the UK there has been minimal undergraduate/postgraduate education in sexual medicine and human sexuality.<sup>30 31</sup> We also found a lack of assessment of EF before and after prostate cancer treatment, with low usage of formal/validated measurement instruments (eg, IIEF, SHIM and so on) and no routine structured evaluation of ED management efficacy.

## Communication between HCPs and patients

Communication between HCPs and patients was limited, with failures to initiate discussions about ED and/or involve partners in discussions. It was particularly worrying that 12% of men said they were not told that ED was a risk of prostate cancer treatment. Communication barriers between patients and HCPs are known to be a key factor in the under-reporting, and consequent under-treatment, of ED.<sup>21 22</sup> Understandably, HCPs may be hesitant to enquire into the personal aspects of men’s lives, which may explain why, in this study, female GPs were less likely to initiate a conversation about ED after prostate cancer treatment than male GPs. In addition, patients themselves may be too embarrassed to raise the issue,<sup>32 33</sup> believe that ED is an inevitable result of ageing and/or not know which HCP to ask for help.<sup>22</sup> Factors such as advanced patient age may deter GPs from enquiring about sexual activity.<sup>34 35</sup>

Although the men in our survey were not young (average age 65 years, with 25% aged  $\geq 70$  years), it was clear from their survey responses that sexual activity was still important to them. Other reports suggest that many men wish to continue sexual activity into their eighth and ninth decades.<sup>36 37</sup> Data from the diabetes setting have found patient embarrassment to be the most common reason for under-reporting of ED.<sup>32</sup> In male patients aged  $>30$  years attending their physician, a brief patient questionnaire on EF was found to be an excellent aid for patients and physicians to prompt discussion about ED.<sup>21</sup> Patient reactions to the questionnaire included relief that the issue had been broached and the knowledge that help was available for ED. The Cancer Care Review (CCR), carried out by the GP or practice nurse within 6 months of the practice being notified an individual has a cancer diagnosis, is a component of the Recovery Package.<sup>38</sup> The CCR is a useful opportunity to discuss side effects of treatment, as part of a wider discussion. Despite the

availability of CCR templates and guidance, CCRs are not always conducted in a systematic and consistent manner, leading to variability in patient care and experience.<sup>39</sup>

As disease surveillance after treatment for prostate cancer generally occurs from 6 weeks post-treatment at 3-monthly intervals for at least 12 months in the UK,<sup>10</sup> it was disappointing that there were delays in initiating ED management within secondary care and poor communication within primary care. The necessary focus on disease surveillance in oncology clinics may result in low prioritisation of sexual difficulties. An observational study found that patients with prostate cancer were more likely to initiate a discussion about sexual function in the urology clinic than in the clinical oncology clinic (22% vs 4%), but nevertheless sexual concerns were not discussed at all in almost 50% of visits.<sup>40</sup>

### Differences between HCP opinions

Importantly, we found considerable differences between HCP opinions regarding lead roles in the initiation, monitoring and follow-up of ED management; such confusion could easily lead to inadequate management and contradictory advice, as was evident from the men's survey results. These findings may reflect financial considerations and, in the case of nurses, whether or not they have a prescribing role. The increased role of primary care in the follow-up of patients with prostate cancer<sup>41</sup> requires unified management guidelines and support from Clinical Commissioning Groups regarding GP prescribing of relevant treatments with local guidelines and shared care protocols. While urologists and specialist ED clinics were most commonly identified as being responsible for prescribing ED treatment, this management route inevitably leads to delays, due to the need for specialist referral and limited access to specialist ED clinics.

Specific consensus guidelines for treating ED after prostate surgery<sup>13</sup> and radiotherapy/ADT<sup>14</sup> have been developed. These guidelines emphasise the importance of proactive early ED management, including patient education and pharmacological intervention, to minimise treatment-induced penile changes and the impact that loss of sexual desire and delayed ED may have on men and their partners.<sup>13 14 42-44</sup> The guidelines recommend daily and/or on-demand PDE5is as first-line treatment for patients who have undergone nerve-sparing prostatectomy.<sup>13</sup> PDE5is should be offered early after surgery, within the first month.<sup>44 45</sup> VEDs, alone or in combination with other modalities, may be used if other treatments have proved ineffective.

### Access to treatments and specialist services

The finding in this study that many GPs did not prescribe treatments for ED is a matter for concern. Surprisingly, 44% of urologists did not have access to all ED treatments, despite the National Institute for Health and Care Excellence guidance.<sup>10</sup> NHS prescribing of PDE5is is often limited to once-weekly use, which may not adequately support men's needs or specialist sexual rehabilitation

programme aims.<sup>46</sup> 'Stinting' on effective treatments such as PDE5is can be a false economy, potentially resulting in treatment failure and the need for expensive secondary referrals.<sup>23 24</sup> It is hoped that the recent availability of reduced cost generic sildenafil and tadalafil, and the lifting of restrictions on its daily use, will allow more men with ED to receive early treatment.

Lack of access to specialist ED services is known to be a challenge for effective ED management, with support from nurses being identified as a significant factor impacting patient outcomes. Sexual counselling is known to contribute to better efficacy, patient acceptance of and compliance with other prescribed treatments for ED,<sup>13</sup> but was rarely offered in our survey. The National Prostate Cancer Audit (NPCA) 2014 annual report included results of an organisational audit of prostate cancer services in England and Wales. The audit showed 'sexual function services' to be available in 90% of NHS Trusts in England and hospitals in Wales.<sup>47</sup> However, at the time, these data were inconsistent with findings from Freedom of Information requests submitted by Prostate Cancer UK<sup>48</sup> in 2015 to 235 NHS health authorities across the UK to determine the availability of services (ED clinics, psychosexual clinics and counselling/sexual therapy) and treatments (daily low-dose tadalafil, VEDs and penile implant surgery) for men with ED after prostate cancer treatment. These results indicated poor availability of ED clinics, with only 51% of areas stating they offered this service, with wide geographical variation.<sup>48</sup> The NPCA repeated their organisational audit in 2016/2017 and 2018/2019 and reported that 'sexual function services' were available in 100% of NHS Trusts in England and Health Boards in Wales, either provided on site or by the specialist multidisciplinary team site.<sup>49 50</sup> Despite the published availability of support services, this does not necessarily translate through to men being offered intervention(s), accepting these interventions(s) or that these interventions are helpful. Although not yet proven to be effective, novel support approaches have been developed in a bid to tackle this problem, such as the Movember Foundation's TrueNTH initiative online self-management programme, which provides personalised self-management strategies to help improve sexual well-being after prostate cancer.<sup>51</sup>

### Limitations of the study

Limitations of this study include those inherent to surveys, particularly those dependent on retrospective recall of medical treatments and services offered or received. Men and HCP surveys were conducted separately and some response options differed between surveys, limiting direct comparisons. While HCPs generally answered all questions, many of the men's survey questions were not answered and there were many 'unsure'/'don't know' or 'not applicable' responses. Men received a wide range of prostate cancer treatments—approximately half had undergone surgery (57%)—but we were unable to determine how many had undergone nerve-sparing



prostatectomy, since this question was not asked. Compliance with ED treatment was not explored and data on ethnicity were not collected. We did not conduct a separate analysis of data from gay and bisexual men, due to the small sample size, although recent data suggest that this group may have additional support needs than do heterosexual men.<sup>52</sup> For the survey of men with prostate cancer, a 'convenience sample' was collected, which may limit generalisability of our results. The split by time since diagnosis was representative of all men living with and after prostate cancer in England as of 2015; however, the men in this study were younger than the prostate cancer population as a whole, with 25% aged 70 and over in this study, compared with 75% in the prostate cancer population.<sup>26</sup> This is most likely explained by the use of online resources to recruit men into the study. As already noted, the surveys were conducted before the availability of generic and over-the-counter sildenafil and generic tadalafil.

## CONCLUSIONS

In conclusion, our survey of men experiencing ED after prostate cancer treatment has confirmed findings in other published reports indicating that men living after prostate cancer treatment need better support from HCPs and more tailored and timely access to effective ED management. Results highlighted a lack of consensus over roles and responsibilities among HCPs: there needs to be a clearly defined pathway for discussion and management of ED, starting from the planning stage of prostate cancer treatment.

There is an urgent need for better education regarding ED management to be offered to primary care, particularly regarding the importance of early sexual rehabilitation, and for more high-quality evidence to support the recovery of sexual function following prostate cancer treatment.

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consenting to be part of the study and were informed that their responses would be confidential and not used for any other purposes beyond this research study.

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