Perceptions and recall of treatment for prostate cancer: A survey of two populations

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A B S T R A C T

Background: The complexity of prostate cancer care can impact on patient understanding and participation in shared decision-making. This study used a survey-based approach to investigate patients' recall of their prostate cancer treatment, and more broadly, to understand the perceptions of patients and the general population of prostate cancer treatment.

Method: The survey was completed by 236 patients with prostate cancer (PCa cohort) and 240 participants from the general population of Australia (GenPop cohort). Free-text comments from both cohorts were analysed using content analysis. The PCa cohort reported which treatments and image-guidance related procedures they had received. These patient-reports were compared to medical records and analysed using proportion agreement, kappa statistics and regression analysis.

Results: 135 (57%) PCa and 99 (41%) GenPop respondents provided at least one comment. Five major themes were identified by both cohorts: sharing experiences of treatment; preferences insights and reflections; mindsets; general commentary on the survey; and factors missing from the survey. There was overall good treatment recall amongst the PCa cohort, with proportions of correct recall ranging from 97.3% for chemotherapy to 66.8% for hormone therapy. There was a tendency for younger patients (<70 years old) to recall their hormone treatment more correctly.

Conclusion: Participant comments suggest the complexity of prostate cancer diagnosis and treatment, and the varying perceptions and experiences of participants with prostate cancer. Patients' recall overall was good for both treatment and image-guidance related procedures/approaches, however the poorer recall of hormone therapy requires further investigation.

Introduction

Value-based healthcare is at the core of service delivery, with emphasis on appropriate care to achieve patients' personal goals [1]. Balancing clinically desirable outcomes with outcomes that matter to patients is recognised as critical [2]. Value-based frameworks within radiation oncology encourage the incorporation of patient-centred and safety-focused processes [3–4]. However, to achieve this patient-centred, value-based radiation oncology care, the perspectives of patients need to be understood.

A cancer diagnosis can be a fraught time for an individual as there is a great deal of information to digest and challenging treatment decisions to be made [5]. The move to patient-centred care is predicated on the clinician explaining complex treatments and procedures to an individual so they can understand. However, low health literacy is reported in 60% of adult Australians and 89% of US adults, making explanation a challenging task and affecting the patient's ability to make health decisions, potentially leading to poorer health outcomes [6–9].

Ability to recall medical information is linked to greater health literacy. [10]. Recall ability has implications for shared decision-making as patients must understand the clinical information to make an informed decision [8]. Radiation oncologists have reported employing many techniques to address the observed variation in health literacy of their patients, including tailoring the level of detail to the individual patient, using visual aids, repeating information, and asking the patient to paraphrase information [9]. Patients' correct recall of health conditions and treatment is also important for patient-centred care, particularly when providing health history to new clinicians as the accuracy of recall may influence healthcare offered [11–12]. Furthermore, recall is important for researchers investigating patient-reported outcomes or experience as patients' recall ability may introduce variances [13–14].

This present study builds upon two previous studies [15–16]. The first study captured the perspectives and preferences of 22 prostate cancer patients regarding image-guidance related procedures (fiducial markers versus transperineal ultrasound) via semi-structured interviews [15]. Participants reported image-guidance procedures were tolerable and recognised the importance for increased accuracy, however despite having experienced both fiducial marker insertion, and transperineal ultrasound prostate monitoring during radiation therapy, 45% of participants could not identify which image-guidance method they preferred [15]. The second study, a discrete choice experiment (DCE) survey, was undertaken to elicit preferences regarding image-guidance related procedures in the patient population and members of the Australian general population [16]. The DCE found that both patients and general population valued pain, cost, and accuracy, with differences in preferences in three groups of respondents: one group focussed on clinical efficacy in the attributes of accuracy and side effects, and two other groups focused more on process-related attributes of pain and cost [16].

The aim of this study was to gain a better insight on participant's perspectives on treatment and image-guidance related procedures in prostate cancer radiation therapy by analysing free-text comments given on the larger survey [16]. This information will contribute to value-based radiation oncology by exploring patient and general population's insights around prostate image-guidance related procedures and radiation therapy. A secondary aim was to evaluate patients' recall of prior treatments they received for their prostate cancer, a separate component of the larger survey. This will provide information on potential improvements for information provision in prostate cancer radiation therapy.

Methods

The survey included a discrete choice experiment (DCE), free-text follow-up questions pertaining to the DCE, and treatment recall questions (as applicable) were purposively designed. 1200 patients presenting to a regional cancer centre with a prostate cancer diagnosis between 2009 and 2019 were invited to participate in the survey through a letter of invitation (from herein: "PCa cohort"). All invited patients had a consultation with a Radiation Oncologist, but not all underwent a radiation oncology treatment. This broad invitation was intended to maximise the range of perspectives captured from PCa cohort participants, not just limited to radiation oncology. Standardly, a patient was referred in the public setting to both a urologist and radiation oncologist to make an informed decision regarding their treatment options. No changes to standard information provision were made in the invitation period. Further contextual information about the treatment centre can be found in Supplementary materials.

A cohort from the Australian population completed the online survey, facilitated through an online survey panel (from herein: "GenPop cohort") in addition to the PCa cohort. A GenPop cohort allowed comparison with the target population (i.e. the PCa cohort) to establish if differences in preferences and perspectives existed from those with the lived experience of prostate cancer. Eligibility for participation included

having or having had a prostate; and over the age of 18 years. Limits on participation numbers were placed on age groups and location (state or territory) to ensure a broad representative sample. The GenPop survey was open to participants until the target sample size (calculated at 200 to power the DCE) was reached. Further DCE methods and findings are reported elsewhere [16]. Fig. 1 illustrates the overall survey, and which sections each cohort took part in. The survey was hosted online through SurveyEngine (Berlin, Germany), or a paper copy was available to the PCa cohort on request with the aim of maximising completion rate.

In follow-up questions to the DCE portion of the survey, there were several questions allowing optional free-text responses, as summarised in Table 1. Non-meaningful free-text responses were removed including "no" responses (when asked if they wanted to provide any further information), or where a random string of characters was added.

The final part of the survey was presented to the PCa cohort only, and was optional. PCa cohort participants could choose to identify themselves for comparison of responses against their medical record, and provided treatment details, including details of image-guidance related procedures if they reported receiving external beam radiation therapy (EBRT). A short lay description was given for each item (Table 2). One investigator (AB) independently reviewed the medical records to retrieve participant's treatment details. Any unclear documentation in the medical record was discussed with another investigator (AT) for ratification. Retrieved medical record data was then compared to the respondent's answers. Correct recall was defined as the correct identification by the patient of a particular treatment/procedure received, as verified by the medical record. No other recall factor (such as timing or order of treatment/s) was considered in this study.

Institutional ethics approval was granted (HREC/2019/QTHS/ 55905 and H7929). Consent was implied by participant completion of the survey. After extensive development through literature review, expert panel review and qualitative results [15], the survey was piloted following ethics approval and prior to the main rollout, with only minor
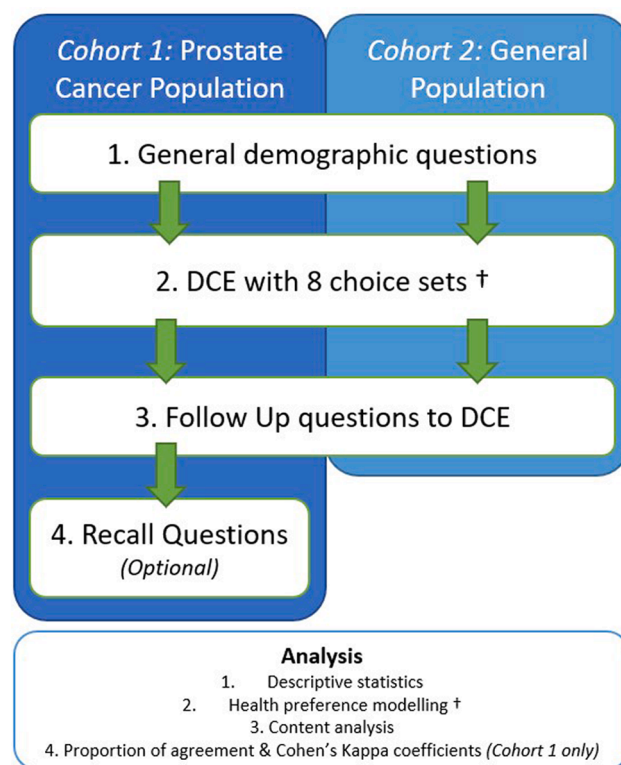

Fig. 1. Schematic overview of the survey, including which parts each cohort completed †*Note: Discrete Choice Experiment (DCE) results reported separately* [16].

Table 1

Free-text questions, context and number of responses.

Free-text optional question	Context of question in survey	Total number of comments
Q1. Please provide any comments you wish to make	Followed Likert-type scales to rate clarity and understanding of the DCE	181
Q2. Are there any factors you would consider that we are missing?	Followed a question where participants rated the importance of the various DCE attributes for image-guidance preferences including. pain, cost, side effects, accuracy, additional time and additional appointments	115
Q3. Do you have anything else you would like to tell the researchers about the survey, or the imaging options presented?	Final question of the survey	103

DCE: Discrete Choice Experiment.

Table 2

Questions and descriptors for treatment and image-guidance related procedures.

Question	Multiple Choice Answers	Descriptors provided
What treatment did you have for your prostate cancer? (*please select all that apply*)	Hormones	*Injections of hormones to help shrink the cancer, usually via a needle into abdomen but can also be through tablets*
	Surgery	*Usually to remove the prostate (prostatectomy)*
	Radiation therapy	*External radiation delivered by a specific machine at a dedicated Radiation Oncology clinic, usually involving a daily treatment session over a number of weeks*
	Brachytherapy	*Internal radiation, either through insertion of radioactive beads which remain in your prostate, or radioactive sources that are inserted to deliver the radiation for a few minutes then removed.*
	Chemotherapy	*Drug/s given to treat the cancer, most often in the case where the cancer has spread outside of the prostate*
	Other _____ Not sure	
As part of your radiation therapy preparation or treatment, did you have any of the following procedures. If unsure of the procedures, hover over to see a short description. (*please select all that apply*)	Gold seed fiducial markers	*Small gold beads (usually 3) are inserted into your prostate using ultrasound guidance, usually with the probe in your back passage. This may be while you were awake or asleep and occurs before your treatment course commences. These are used to locate your prostate every day for radiation therapy treatment.*
	Clarity ultrasound monitoring	*An external ultrasound probe sits against your skin during the radiation simulation/planning CT and every day for treatment, alerting treatment staff if your prostate moves*
	Other _____ Not sure	

Note. This portion of the survey was presented to the PCa cohort only. The survey utilised "Clarity" for transperineal ultrasound, as this was the terminology commonly used with patients at the department.

wording updates to improve clarity and comprehension [16–17]. Responses to the pilot and main survey were combined for analysis.

Analysis

Demographics were summarised using descriptive statistics. Summative content analysis of free-text survey comments was undertaken, with coding completed by two investigators (AB and LA), with discussion until consensus was reached [18]. Proportions of comments were calculated against the themes and subthemes, for both PCa and GenPop cohorts.

Concordance between the self-report by the PCa cohort and the medical record for each treatment modality and image-guidance related procedure was calculated through proportion of agreement and Cohen's Kappa coefficients. Level of agreement was categorised using Altman's method as: 0.75–1.0 = excellent; 0.60–0.74 = good; 0.40–0.59 = fair, and 0.0–0.39 = poor [19]. Following the initial concordance analysis, the cohort was stratified into two groups for sub-analysis, based on the number of years since treatment (Subgroup 1: less than or equal to 5 years since treatment; Subgroup 2: >5 years since treatment), allowing for a possible effect of time on recall.

A logistic regression model was used to analyse trends in the demographics of participants' recall. A-priori demographic and clinical characteristics of time since treatment, age at survey completion and education levels were included in the model. A separate model included all demographic categories except for ethnicity and language spoken, as these two demographic categories had insufficient numbers of responses. Odds ratios were calculated from model coefficients. All statistical analyses were performed using R 3.6.1 [20]. A p-value of < 0.05 was considered significant.

Results

Respondents and demographics

There were 236 respondents from the PCa cohort and 240 from the GenPop cohort. All participants identified as male. 135 (57%) PCa cohort and 99 (41%) GenPop cohort respondents provided comments in at least one of the free-text questions. 226 out of 236 from the PCa cohort (96%) voluntarily gave their ID, permitting comparison of their medical records to their recall survey responses. Of those, 221 respondents had sufficient details to allow for comparison. The mean age of respondents was 75.8 ± 7.1 years, and the mean time from primary treatment in the PCa cohort was 6 years (range 0 to 18). Table 3 summarises the demographics of the cohorts.

Content analysis

Five main themes were developed from content analysis of the free-text feedback: Factors considered by the respondents to be missing from the DCE attributes regarding image-guidance related preferences; patients sharing the experiences of treatment; insights and reflections pertaining to image-guidance related preferences; general commentary on the survey; and mindsets. Fig. 2 summarises the major and sub-themes with illustrative quotes, with complete results of the content analysis in Supplementary material.

Factors missing from the DCE and general commentary on the survey comments were mostly in response to specific questions (i.e. Questions 2 and 3, Table 2). Respondents from both cohorts identified missing factors including treatment outcome and logistics such as travel, however the frequency of all suggested missing factors was low (1.4 to 5.6%). There was a mix of positive and negative feedback (as perceived by the coders) regarding the survey from both cohorts, with more positive responses provided by the GenPop cohort (39.4% vs 2.3% of PCa) and more negative responses provided by the PCa cohort (13% vs 9.9% of GenPop).

Table 3

Demographics of respondents, including free-text and recall survey components.

	GenPop Cohort		PCa Cohort			
	Free-text responders n=99		Free-text responders n=135		Recall responders n=221	
Demographics	n	%	n	%	n	%
Age						
18-29	20	20	-	-		
30-39	24	24	-	-		
40-49	14	14	-	-		
50-59	12	12	1	0.8	1	0.5
60-69	14	14	18	13.7	43	19.5
70-79	10	10	69	52.7	115	52.0
80+	3	3	45	34.4	59	26.7
Did not answer	2	2	2	1.5	3	1.4
Relationship status						
Single, never married	13	18.3	5	3.8	9	4.1
Married or domestic partnership	47	66.2	96	73.3	158	71.5
Widowed	2	2.8	12	9.2	24	10.9
Divorced or separated	4	5.6	16	12.2	28	12.7
Prefer not to say	-	-	-	-	1	0.5
Did not answer	5	7.0	2	1.5	1	0.5
Employment status						
Full-time employment	32	45.1	12	9.2	17	7.7
Part-time employment	11	15.5	1	0.8	2	0.9
Casual	6	8.5		0.0	1	0.5
Retired	18	25.4	115	87.8	195	88.2
Unemployed	2	2.8		0.0	3	1.4
Prefer not to say					2	0.9
Did not answer	2	2.8	3	2.3	1	0.5
Level of education						
Less than high school	32	45.1	12	9.2	26	11.8
High school (or equivalent)	11	15.5	1	0.8	82	37.1
Apprenticeship, TAFE or tech school	6	8.5	-	-	80	36.2
Undergraduate degree	18	25.4	115	87.8	26	11.8
Postgraduate degree	2	2.8		0.0	2	0.9
Prefer not to say	-	-	-	-	4	1.8
Did not answer	2	2.8	3	2.3	1	0.5
Annual household income						
≤ $39,999	16	22.5	58	44.3	114	51.6
$40,000–$79,999	25	35.2	31	23.7	52	23.5
$80,000–$149,999	15	21.1	14	10.7	17	7.7
≥ $150,000	9	12.7	2	1.5	4	1.8
Unknown	6	8.5	26	19.8	34	15.4
Ethnicity†						
Aboriginal and Torres Strait Islander	2	2.8	1	0.8	1	0.5
Aboriginal	2	2.8	1	0.8	2	0.9
Torres Strait Islander	0	0.0	0	0.0	0	0.0
Non-Indigenous	65	91.5	121	92.4	211	95.5
Did not answer	2	2.8	8	6.1	7	3.2
Born						
Australia	44	62.0	92	70.2	165	74.7
Other	24	33.8	34	26.0	52	23.5
Did not answer	3	4.2	5	3.8	4	1.8
Language						
English	64	90.1	126	96.2	214	96.8
Other	5	7.0	2	1.5	4	1.8
Did not answer	2	2.8	3	2.3	3	1.4
Health State†						
Excellent	15	21.1	8	6.1	12	5.4
Very Good	22	31.0	31	23.7	50	22.6
Good	20	28.2	51	38.9	91	41.2
Fair	7	9.9	32	24.4	53	24.0
Poor	5	7.0	4	3.1	12	5.4
Did not answer	2	2.8	5	3.8	3	1.4
Year of primary treatment						
Prior to 2010					28	12.3
2010-2014					94	41.4
2015-2019					102	44.9
Currently on treatment					2	0.9
Refused any treatment					1	0.5
PCa Staging						
T1					44	19.4
T2					112	49.3

Table 3 (continued)

	GenPop Cohort		PCa Cohort			
	Free-text responders n=99		Free-text responders n=135		Recall responders n=221	
Demographics	n	%	n	%	n	%
T3					58	25.5
T4					4	1.8
Tx					4	1.8
Not recorded					5	2.2

The majority of the PCa cohort (83.1%) provided comments on their experiences of treatment. This included reflections on their decision-making during the diagnosis phase (7.6%); their treatment experiences (13.7%) and reporting of side effects (28.3%) and outcomes (3%). Some respondents commented on specific aspects of their treatment journey including pain associated with gold seed insertion (1.5%) and the bladder/bowel filling requirements for EBRT (6.1%). Compliments regarding their treatment were given by 22.9% of the PCa cohort respondents.

12.3% of the PCa cohort and 22.4% of the GenPop cohort commented on the choices made in responding to the DCE. Comments were given about the DCE attributes of pain and cost (aggregated total 4.5% for PCa, 11% for GenPop), and other factors including treatment success (0.8% PCa, 2.8% GenPop), claustrophobia (0.8% PCa), specialist recommendations (1.5% PCa), avoiding insertion (2.3% PCa, 1.4% GenPop), and opting for no treatment (0.8% PCa, 1.4% GenPop). However, there were low frequencies for each of these suggested factors (0.8 to 7.0%).

Recall analysis

Overall, the PCa cohort could recall their treatment regimen with "fair" accuracy, with correct recall proportions ranging from 97.3% for chemotherapy to 66.8% for hormones. The proportion with correct recall for image-guidance related procedure was 87.3% for transperineal ultrasound (TPUS) and 91.4% fiducial markers (FMs). Table 4 summarises the proportions of correct and incorrect recall for each category with the corresponding Kappa statistic, including sub-analysis by year of treatment. The K indicated excellent agreement for surgery (0.81) and FMs (0.83), indicating correct recall; good agreement for brachytherapy (0.65), fair agreement for EBRT (0.41), chemotherapy (0.49) and TPUS (0.49), and poor agreement for hormones (0.35).

Sub-analysis showed recall rates were more correct for surgery and chemotherapy in the group treated <5 years previously. However, there were improved correct recall rates for FMs and TPUS for the group treated >5 years previously. There was no significant time-related difference in participants' recall for hormones and brachytherapy, however the group treated <5 years previously had better recall.

In evaluating PCa cohort demographic trends (Table 5), only age was significantly associated with recall of hormones with younger respondents having better recall (OR = 0.3, 95% CI 0.11–0.74 for < 70 years of age), and year of treatment was significantly associated with recall of TPUS, with treatment > 5 years ago showing better recall (OR = 4.51, 95% CI 1.64–14.56).

The overall count of incorrect recall (i.e. counting each incorrectly identified treatment/procedure per respondent) and free-text comments was tabulated (Supplementary Table S2). Overall, there was no significant difference with recall rates based and comments given.

Discussion

This study analysed free-text comments from participants in a larger study to understand the participants' perceptions of prostate cancer
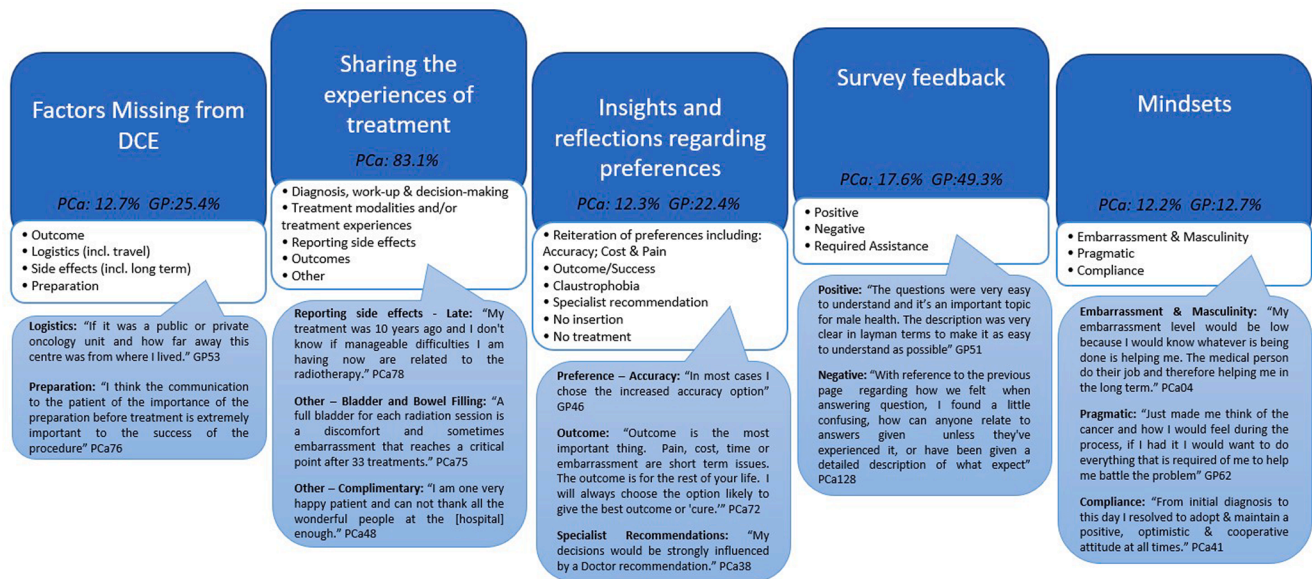
Fig. 2. Themes and Sub-themes arising from free-text comments. Note: Themes are displayed in the dark blue boxes, with corresponding content-analysis frequency for overall theme. PCa refers to the Prostate Cancer cohort; and GP refers to the General Population cohort. Subthemes are displayed in the white boxes, with illustrative quotes in the light blue boxes. Further breakdown of the subtheme content analysis can be found in Supplementary materials. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

Table 4
Proportions of observed recall, including treatment timing sub-analysis.

Clinical Records		Patient Identification				Comparison of Treatment timing						
		All recall respondents n = 221				≤5 years n = 99			>5 years n = 122			
		No %	Yes %	Accuracy (CI)	Cohen's Kappa	No %	Yes %	Cohen's Kappa	No %	Yes %	Cohen's Kappa	p-value
Hormones	No %	27.73	*6.36*	0.67	0.35	24.24	*5.05*	0.39	30.58	*7.44*	0.32	0.11
	Yes %	*26.82*	39.09	(0.60–0.73)	(0.23–0.47)	*25.25*	45.45	(0.21–0.57)	*28.10*	33.88	(0.15–0.48)	
					p < 0.001			p < 0.001			P < 0.001	
Surgery	No %	70.91	*6.36*	0.93	0.81	66.67	*7.07*	0.83	74.38	*5.79*	0.78	<0.01
	Yes %	*0.91*	21.82	(0.89–0.96)	(0.72–0.90)	*0.00*	26.26	(0.71–0.95)	*1.65*	18.18	(0.65–0.92)	
					p < 0.001			p < 0.001			P < 0.001	
EBRT	No %	1.82	*0.91*	0.94	0.41	1.01	*1.01*	0.15	2.48	*0.83*	0.58	0.09
	Yes %	*5.00*	92.27	(0.90–0.97)	(0.10–0.72)	*8.08*	89.90	(-0.37–0.68)	*2.48*	94.21	(0.18–0.98)	
					p = 0.02			p = 0.298			P = 0.03	
Brachytherapy	No %	93.64	*3.18*	0.97	0.65	92.93	*4.04*	0.58	94.21	*2.48*	0.71	0.86
	Yes %	*0.00*	3.18	(0.94–0.99)	(0.40–0.91)	*0.00*	3.03	(0.18–0.98)	*0.00*	3.31	(0.39–1.03)	
					p = 0.001			p = 0.03			P = 0.008	
Chemotherapy	No	95.91	*2.73*	0.97	0.49	96.97	*1.01*	0.79	95.04	*4.13*	0.28	0.01
	Yes	*0.00*	1.36	(0.94–0.99)	(0.09–0.89)	*0.00*	2.02	(0.39–1.19)	*0.00*	0.83	(-0.34–0.89)	
					p = 0.04			p = 0.036			P = 0.228	
Fiducial Markers	No %	51.82	*2.27*	0.91	0.83	45.45	*0.00*	0.82	57.02	*4.13*	0.83	<0.01
	Yes %	*6.36*	39.55	(0.87–0.95)	(0.75–0.90)	*9.09*	45.45	(0.71–0.93)	*4.13*	34.71	(0.72–0.93)	
					p < 0.001			p < 0.001			P < 0.001	
TPUS	No %	79.09	*7.27*	0.87	0.49	62.63	*7.07*	0.52	92.56	*7.44*	NA	<0.01
	Yes %	*5.45*	8.18	(0.82–0.91)	(0.31–0.67)	*12.12*	18.18	(0.33–0.72)	*0.00*	0.00		
					p < 0.001			p < 0.001				

Incorrect proportions are *italicised*. Cohen's Kappa. 0.75–1.0 = excellent; 0.60–0.74 = good; 0.40–0.59 = fair, and 0.0–0.39 = poor [48].

treatment. Additionally, recall by the PCa cohort of their prostate cancer treatment was analysed.

The free-text comments provided demonstrate the varied experiences of the PCa cohort, as well as the different perceptions and preferences in both the PCa cohort and GenPop cohort, with good engagement from both cohorts as demonstrated by the majority of respondents leaving at least one comment. Apart from direct responses specific to the survey (that is, missing factors and specific feedback relating to the survey), most free-text comments from both cohorts were un-prompted. This engagement indicates both a willingness of the PCa cohort to share their experiences and an interest from the general population, and serves to further contextualise the DCE survey [16]. There is

an increasing emphasis on analysing free-text responses given by survey participants [21–23]. Two studies in the oncology setting analysing free-text comments provided additional information on aspects including side effects, treatment outcomes, needs, emotions and experiences [24–25]. These aspects were mirrored in our study from both cohorts, but particularly the PCa cohort.

The PCa cohort in our study recounted experiences associated with EBRT including fiducial insertion and preparation. The comments regarding bladder and bowel filling treatment requirements suggests that preparation makes an impression on the patient. This impression may reflect that this preparation is the most active participation required of the patient during treatment delivery, thereby making it

Table 5
Odds Ratios calculated through Regression Analysis.

Demographic	OR (95% CI)				
	Hormones	**Surgery**	**EBRT**	**Fiducial Markers**	**TPUS**
Age					
<70	0.30	0.36	1.779	0.64	0.37
Base. ≥ 70	(0.11–0.74)*	(0.02–1.95)	(0.36–6.93)	(0.10–2.53)	(0.06–1.42)
Time since treatment					
>5 years	0.73	1.26	2.949	1.73	4.51
Base. ≤ 5 years	(0.38–1.37)	(0.38–4.22)	(0.79–14.08)	(0.57–5.48)	(1.64–14.56)*
Level of education					
≥ Undergraduate	0.49	0.682	0.781	1.30	1.54
Base. < than Undergraduate	(0.15–1.37)	(0.04–3.85)	(0.04–4.65)	(0.19–5.33)	(0.32–5.56)

* $p < 0.05$.

more memorable. The necessity of preparation is reported as a significant cause of distress, with the timing of preparations and lack of instructions contributing to distress, and lack of understanding of the purpose leading to non-compliance [26–27]. [27] With adaptive radiation therapy developments, further evaluation of the necessity of strict preparations when adapting to daily anatomy would be of benefit, given the negative impact reported by respondents [28].

PCa cohort compliments to the staff were more numerous than any other aspect recounted of their treatment (22.9%). This suggests a high level of rapport with the treating team, implying the way patients are treated by staff is just as important to the patient, if not more so, than the treatment/ procedures. Previous radiation therapy studies corroborate the importance of rapport and trust with the health care providers, including oncologists, therapists, and nurses [28–30].

The recounting of side effects (ranging from nil to long-term side effects impacting quality of life) indicates the varied and lasting impact of treatment toxicity on patients. Geographical differences in patient perceptions around prostate radiation therapy side effects have been reported, with regional/remote patients expressing an acceptance of side effects rather than a process to improve as expressed by metropolitan men [31]. This difference was reflected in our study, with regional PCa cohort reporting on the presence of side effects more so than a desire for improvement of the side effects, however some respondents did express regret at the side effects experienced. Previous studies indicate not all patients feel informed about the possible severity of side effects, highlighting a further opportunity for improvement [30]. The GenPop cohort provided comments around the potential impacts of treatment including side effects, suggesting that even without the lived experience of prostate cancer and treatment, the impact of treatment was considered important in the hypothetical scenario addressed.

The desire to follow doctor recommendations found in the present study supports our earlier finding that patients utilise the clinician agency to guide their treatment decisions [15]. The decision to undergo radiation therapy was reported to be "agreeing with the radiation oncologists' recommendation" rather than a personal choice, recognising the trust in the medical professional [30,31,32–33]. Of note, the pragmatic "gotta do" sentiment was reflected in both cohorts in this study, confirming previous findings of a pragmatic approach to treating the prostate cancer [15]. Additionally, the necessity of treatment and procedures overriding potential associated embarrassment was commented on by both PCa and GenPop cohorts. A positive frame of mind in approaching radiation therapy has also been reported, mirroring our results [29].

Good recall of their treatment/s was indicated in the majority of the PCa cohort. However, the recall of hormone treatment was incorrect in 33.2% of respondents, including 26% stating they had not received hormone therapy where the clinical records indicated they had. The Kappa statistic for EBRT and chemotherapy indicated fair agreement. However, the overall proportion of incorrect recall was lower: EBRT and chemotherapy at 5.9% and 2.7% respectively, whereas it was 7.3% for surgery. Kappa's limitations are recognised where observed proportions

are high, making it a conservative measure [32–33]. Differences in levels of recall amongst cancer populations has been reported previously [34–38]. [37] Recall agreement for patients with prostate cancer was good to excellent for surgery, brachytherapy, and radiation therapy but only fair for hormone treatment [38]. As with our present study, there was no specific change in information provided to the prostate cancer population, thus capturing general recall [38].

The PCa cohort overall had high recall receiving radiation therapy (including EBRT and brachytherapy), however were less accurate recalling specific image-guidance related procedures. Lower accuracy in the recall of image-guidance related procedure may indicate that patients focus on the overall treatment rather than individual components or aspects of treatment. While it may not be as crucial that patients recall their image-guidance related procedures compared to their treatment/s, less recall of image-guidance related procedures may suggest the purpose of these procedures may not be understood by all patients.

Time may introduce additional recall bias for patients treated >5 years previously. Unsurprisingly, treatment recency sub-analysis (<5 and >5 years) demonstrated patients treated more recently were more accurate in their recall. Patients treated more recently, however, tended to recall TPUS incorrectly, indicating they had TPUS when they had not. However, this recall value was associated with a wide confidence interval indicating large variances. Patients' recall of TPUS may be confused by the term "ultrasound" which is used during both biopsy and treatment as suggested in our previous study which found that patients often confused the external probe of TPUS with the internal probe of the biopsy and insertion procedures [15].

Younger patients tended to recall their hormone treatment more accurately, suggesting age is a contributor to the poorer recall of hormone treatment in older patients. There is a known link between hormonal therapy and mild cognitive impairment, however exploring this further was beyond the scope of this study [39–40]. There may also be an element of older patients choosing to take a more passive role in their health care, as found in the study investigating decision-making in choosing active surveillance for prostate cancer [41]. Patient education levels have also been demonstrated to influence certainty in prostate cancer patients, showing patients with a lower level of education tending to report higher levels of uncertainty [42]. However, our results did not find a significant recall difference based on education.

Lower levels of recall agreement for hormone treatment have been previously reported. Level of agreement increased when limiting to patients who only had hormone treatment, as opposed to when used alongside radiation therapy and/or surgery [38]. This may be due to hormone treatment being a more "passive" treatment, and the hormone injection not recognised as a separate treatment in their whole treatment regimen. Hormone terminology has been found to be confusing, with "chemical castration", "hormonal therapy" and "androgen deprivation therapy" incorrectly described and not recognised as synonymous by study participants [43]. Additionally, the side effects of hormone therapy were not known by a majority of PCa patients and their partners [44]. This may explain the low recall findings of our study, with some

patients not understanding they were on hormones.

Our results indicate that overall, recall of PCa treatment was reasonable. However, as recall is indicative of patient understanding, our results suggest there is opportunity for further improvement, particularly in the areas of hormone treatment. Improvements could be facilitated through use of decision aides which have demonstrated decreased treatment regret, however these aides need the flexibility to accommodate the differences in information needs [45–47]. Further work is required to understand the patient's decision-making processes at the time of initial consultations with specialists, including the immediate recall of treatment option details. While not all radiation oncology departments have multiple image-guidance procedures/techniques to offer an individual choice to a patient, it is ultimately up to the patient to consent to procedures such as fiducial marker insertion.

Conclusion

Overall, our recall and free-text findings further illuminate the complexities of PCa treatment pathways, with individuals having different experiences and reporting various levels of needs and satisfaction with treatment and related procedures. Incorporating the patient perspective and preferences into future research and clinical developments can ensure increased agency and participation by the patients. Our findings inform areas for improvement to improve patient experience. Further education and research into hormone therapy understanding is recommended.

Data sharing statement

Research data are stored in an institutional repository and will be shared upon request to the corresponding author.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.tipsro.2022.10.001.

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