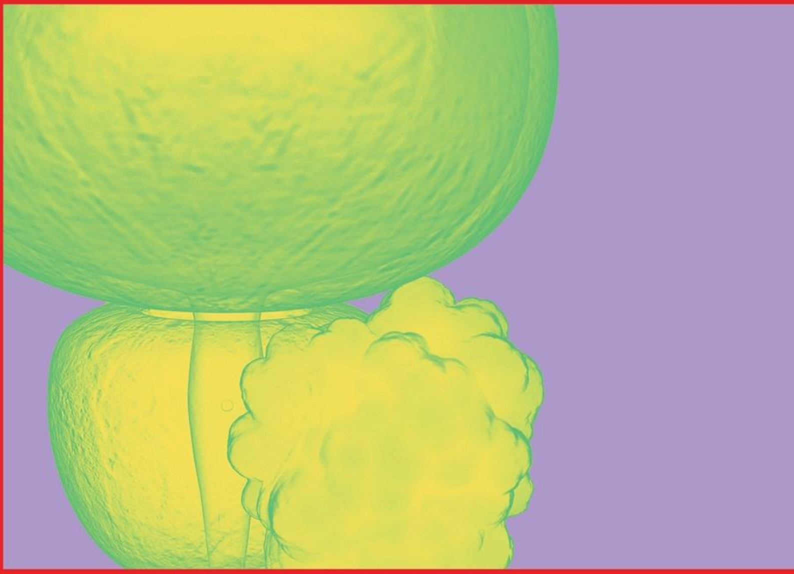
Quantitative short report

Prostate Cancer

Patient Experience – Australia & New Zealand



Johnson&Johnson

Janssen-Cilag Pty Ltd. ABN 47 000 129 975. 1-5 Khartoum Road, Macquarie Park NSW 2113.
Ph: 1800 226 334. CP-450544. Date of preparation: May 2024

Acknowledgements

Johnson & Johnson, Prostate Cancer Foundation of Australia and Community and Patient Preference Research (CaPPRe) would like to thank the individuals who generously gave their time and shared their experiences of Prostate Cancer.

This report was prepared by CaPPRe and authored by Dr Simon Fifer, Laurie Axford, Rose Wilson and Declan Munro.

Funding for this study was provided by Johnson & Johnson.

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Background

At Johnson & Johnson, we are leading where medicine is going. Our unwavering commitment to patient centricity is clearly demonstrated in our investment in collaborative research to understand the needs and priorities of patients. Through collaboration with Patient Organisations, Healthcare Professionals and research organisation Community and Patient Preference Research (CaPPRe) we conducted groundbreaking research with people living with Prostate Cancer to quantify and map their experiences during their overall healthcare journey. By working across the health ecosystem and consistently focussing on understanding the priorities and unmet needs of patients in Australia, Johnson & Johnson aim to revolutionize the future of healthcare, delivering consistently exceptional experiences that truly empower and support patients.

The results of this quantitative stage, in which participants completed a Best Worst Scaling (BWS) task, generating a patient experience index score (PEI), will be used to understand the patient experience and identify areas of potential improvement, with the aim of providing a consistently exceptional experience. The PEI takes into account both satisfaction and importance, thus providing guidance on areas of the pathway that could be targeted to maximise patient satisfaction - that is, areas that are important to patients, but have lower levels of satisfaction.

Research Aim

To develop a thorough understanding of the patient experience within prostate cancer.

Study Objectives

- Identify what is important to patients along the healthcare pathway
- Identify how satisfied patients are with the different areas of treatment and care
- Explore patient beliefs on how prostate cancer healthcare could be improved

Our Approach

Methodology

The Survey

Participants completed an online survey which included:

- BWS task
- Socio-demographic questions
- Questions around treatment status and care received

Best Worst Scaling (BWS)

The BWS task used to measure the importance and satisfaction of the different aspects of the healthcare pathway was defined by a master list of 11 ‘Moments that Matter’ (MTM). The MTM were identified from qualitative research conducted with patients and secondary research from Janssen ANZ. A summary of the MTM can be found in Table 1 and on the dashboard information tab (see page 15 for more information).

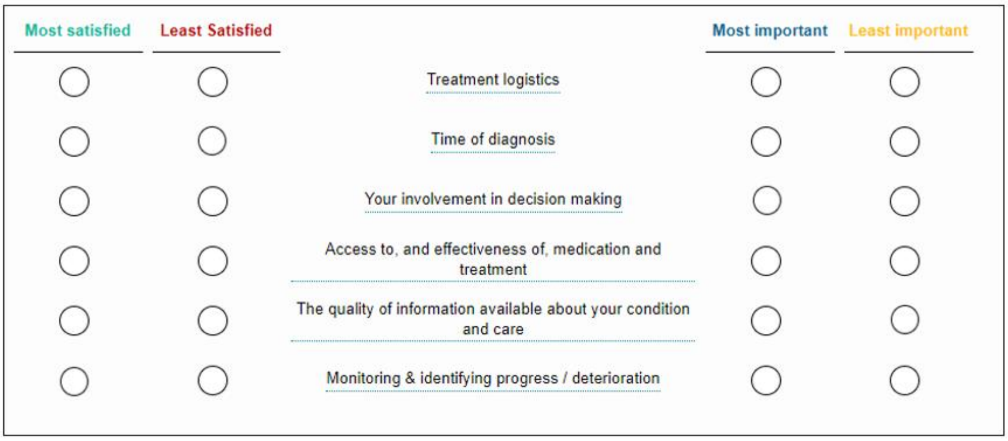
Table 1. PEI MTM and descriptions

	MTM	Description
1	**Time to diagnosis**	• The length of time from developing symptoms through to being diagnosed – whatever this looked like for you.
2	**The quality of information available about your condition and care**	• Having clear, concise, relevant information in a format that works for you (e.g., provided to you by your healthcare team/online/Apps/podcasts).
3	**Your involvement in decision making**	• How involved you are in decisions about your treatment and care, e.g., when selecting specific medication and/or when developing a treatment plan.
4	**The quality of your healthcare team – access to your key healthcare professional/s, consistency of care, and their communication with you and between each other**	• Suitable access to your key healthcare professional (e.g., urologist/oncologist), at regular intervals that you feel are most beneficial to you, or in acute situations where urgent access is required. • Being able to see the same trusted healthcare professional/s on-going for your treatment and care. • How well your needs are met in any interactions with your healthcare team (including doctors, nurses, care coordinators). • The extent to which different members of your healthcare team (e.g., GP / urologist / oncologist / radiation oncologist / physiotherapist / nurses and/or other allied health team) communicate with each other about your condition and care. They may be healthcare professionals within the same service or in different services.
5	**Treatment logistics**	• The broad impact that following a treatment and care plan has on you, i.e., day-to-day difficulties of arranging and attending treatment sessions.
6	**Access to, and effectiveness of, medication**	• Your access to medication for your condition. • How effective the medication prescribed by your healthcare professional/s is in treating your condition.

7	**Side effects of medication**	- Side-effects you may experience from medication prescribed by your healthcare professional/s.
8	**Monitoring & identifying progress/deterioration**	- The ability to monitor day-to-day and long-term changes in your physical and overall wellbeing, for yourself, and by your healthcare professionals (e.g., pain / fatigue / urinary function / sexual function) and adjustments to treatment and care based on this.
9	**Access to other treatments/services (including a care coordinator), to support physical health, mental health, overall wellbeing (holistic approach)**	- A care coordinator, who is assigned to you, to help you navigate the healthcare system and offer emotional support and guidance; this could be a prostate cancer nurse / prostate cancer navigator / clinical nurse specialist or social worker / peer support worker. - Other allied health services could include access to a dietitian/exercise physiologist/occupational therapist/physiotherapist. - Complementary treatments could include acupuncture, massages, and over-the-counter medications such as vitamins and fish oil.
10	**Support for your 'support person'**	- Information/websites specifically for significant others (e.g., spouse, partner, friend etc) and support groups where family members/friends can talk with others in similar situations.
11	**Prostate cancer related costs**	- The overall impact that having prostate cancer has on your financial wellbeing, e.g., how much you are out-of-pocket, and the impact of loss of income.

The MTM were systematically divided into 11 sets of 6 according to an experimental design, resulting in a BWS exercise containing 11 scenarios. For each scenario, participants were asked to consider the 6 displayed MTM (i.e., participants were shown 6 of the 11 MTM at any one time) and select the best and worst MTM across two dimensions: satisfaction and importance.

An example of a scenario is shown in Figure 1 below. Data collected detailed how important each MTM was to an individual, as well as how satisfied they were with each MTM.



Most satisfied	Least Satisfied		Most important	Least important
○	○	Treatment logistics	○	○
○	○	Time of diagnosis	○	○
○	○	Your involvement in decision making	○	○
○	○	Access to, and effectiveness of, medication and treatment	○	○
○	○	The quality of information available about your condition and care	○	○
○	○	Monitoring & identifying progress / deterioration	○	○

Figure 1. Screenshot of the BWS task.

The BWS exercise yielded scores reflecting the relative hierarchy of each MTM vs another MTM. The **BWS scores** were calculated for each MTM by subtracting the number of times it was chosen as worst (least satisfied/important) from the number of times it was chosen as best (most satisfied/important), divided by the number of times it was shown throughout the task.

Furthermore, the BWS scores are mapped onto a scale ranging from 0 (“Not satisfied at all”/”Not important at all”) to 10 (“Completely satisfied”/”Extremely important”) describing the level of satisfaction and importance. These **rescaled scores** allow direct inference of how satisfied/important each individual MTM is, rather than just their relative ranking.

BWS scores range from -1 to 1 and represent the relative ranking (ordering) of the MTM.

- A **negative** score indicates the domain was chosen as ***worst* more often than *best***
- A **positive** score indicates the domain was chosen as ***best* more often than *worst***
- A **zero** score indicates the domain was chosen as ***best* and *worst* an equal number of times** OR was **never chosen**.

Rescaled scores range from 0 to 10 and represent the individual **level of satisfaction and importance** experienced. The scale was labelled at each extreme as follows:

- 0 = “Not satisfied at all”/”Not important at all”
- 10 = “Completely satisfied”/”Extremely important”

Patient Experience Index (PEI)

Standard BWS scores cannot be used to build an index that is comparable between groups of participants because the scores represent a relative ranking. CaPPRe have developed a new method to convert these scores from relative to absolute measures which can be combined to form an index (PEI). An index was built to measure the overall satisfaction of the health experience for the treatment of prostate cancer in ANZ. The PEI is a combined score of the 11 MTM, accounting for both satisfaction and importance, and ranges from 0 to 100.

Participants

Patients were recruited through a panel company and with assistance from patient support groups, Prostate Cancer Foundation Australia and Prostate Cancer Foundation of New Zealand. Patients were compensated for their time and contribution.

All participants provided consent to participate prior to completing the survey and were able to withdraw at any time without penalty or prejudice, including prior to commencing the survey and during survey completion.

Data was collected between 23rd November 2022 to 21st March 2023.

The Findings

Demographic Characteristics

The demographic characteristics of the participants are displayed in Table 2. Of the 45 patients who participated in this research, 35 were citizens or permanent residents of Australia, and 10 were citizens or permanent residents of NZ, at the time of research (i.e., n= 35 Australian patients; n= 10 NZ patients). For ethnicity (where ethnicity is a measure of which ethnic group the patient identifies with) most identified as Australian (62.2%) or New Zealander (17.8%).

Nearly half the total sample were aged between 71-80 (44.4%), and just over 40% were aged between 51-70. Less than 5% of the sample were between the ages of 18-50 (4.4%). Just over a third (34.0%) of the participants reported that they were working at the time of research (either full-time, part-time, or casual). 44% of the participants lived in metro areas; 56% in regional / rural areas.

Table 2. Basic demographic

Demographic characteristic	Patient (N=45) N (%)
Age	
18-29	0 (0.0)
31-40	1 (2.2)
41-50	1 (2.2)
51-60	6 (13.3)
61-70	13 (28.9)
71-80	20 (44.4)
81 or older	4 (8.9)
Occupational status	
Working (full-time)	7 (15.9)
Working (part-time)	7 (15.9)
Working (casual)	1 (2.2)
Student	0 (0.0)
Not working	1 (2.2)
Retired	28 (63.6)
Country of Residence	
Australia	35 (77.8)
New Zealand	10 (22.2)
Ethnicity	
Australian	28 (62.2)
New Zealander	8 (17.8)
Māori	1 (2.2)
European	7 (15.6)
North American	1 (2.2)
Location	
Metro/city	20 (44.4)
Regional	20 (44.4)
Rural	5 (11.1)

Treatment characteristics

Treatment profiles for patients are shown in Table 3. Just under half were on treatment (at the time the study was conducted) or had received treatment for prostate cancer in the past (48.9%). The most common treatments/therapies patients had undertaken were, surgery (50.0%), hormone therapy (45.5%) and radiation therapy (40.9%).

When asked about the mode of administration for their prostate cancer treatment, most patients reported having taken oral medication (81.8%) with less than a quarter having experienced treatment administered via an intravenous infusion (22.7%).

Table 3. Basic treatment characteristics

Treatment characteristic	N (%)
Treatment experience (N=45)	
Currently taking medication to treat prostate cancer	9 (20.0)
Not currently taking medication for prostate cancer but have in the past	13 (28.9)
Have never taken medication to treat prostate cancer	23 (48.9)
Other	1 (2.2)
Treatment/Therapy options (N=22)	
Surgery	11 (50.0)
Radiation Therapy	9 (40.9)
Hormone Therapy	10 (45.5)
Chemotherapy	5 (22.7)
Immunotherapy	2 (9.1)
Targeted Therapy	3 (13.6)
Other	1 (4.5)
Treatment mode of administration (N=22)	
Oral (swallowed by mouth in pill or tablet form)	18 (81.8)
Intravenous infusion	5 (22.7)
Other (i.e., intramuscular injections)	6 (27.3)

Abbreviations: N – sample size.

Characteristics Of Care

Treatment setting

Participants were treated across public and private settings; with nearly half (46.7%) reporting having been treated in a private setting, and approximately one quarter (24.4%) having been treated in a public setting (Figure 2).

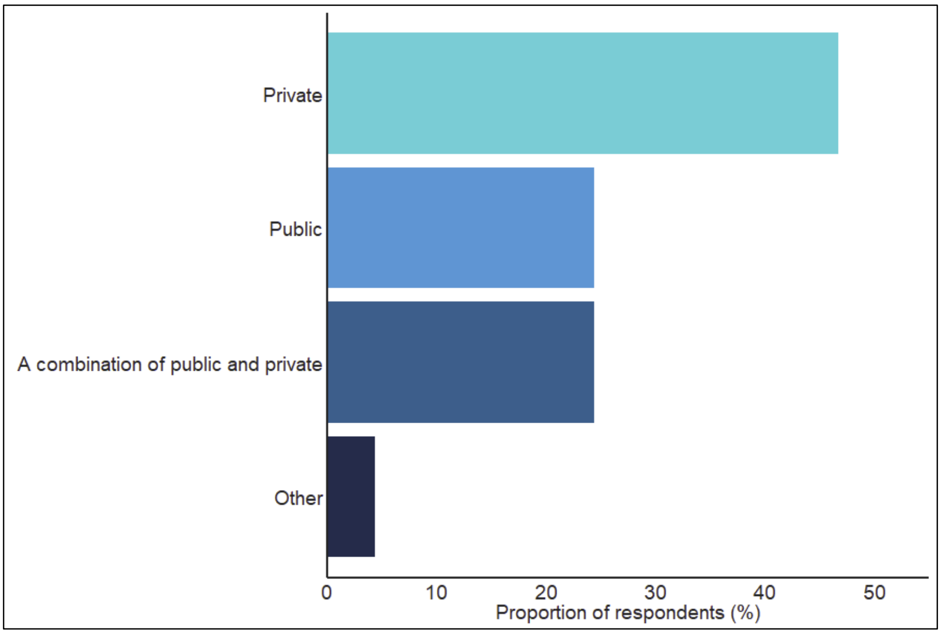


Figure 2. Treatment setting

Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with an average of A$1004 annually. This was followed by 'visits to healthcare professionals and 'costs of complementary treatments' with an average annual amount of $956 and $507, respectively. Please note for the purposes of this graph NZ dollars were converted to Australian dollars.

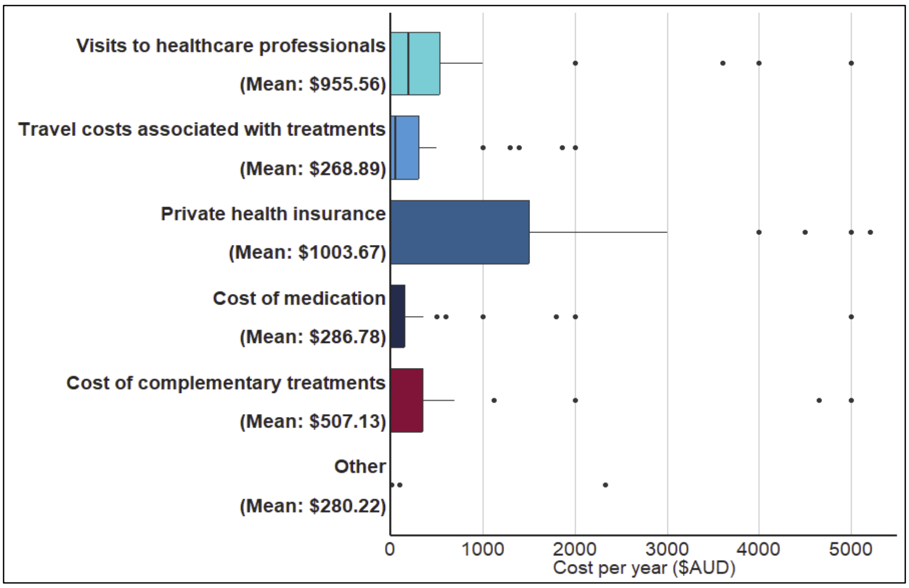


Figure 3. Treatment and care costs

Services Experienced

Over half of respondents have made use of mainstream medical services e.g., treatment/prescription/appointment reminders (51.1%), and just under a quarter of respondents were supported by patient advocacy groups (22.2%). Less than 9% of participants had a care coordinator (8.9%).

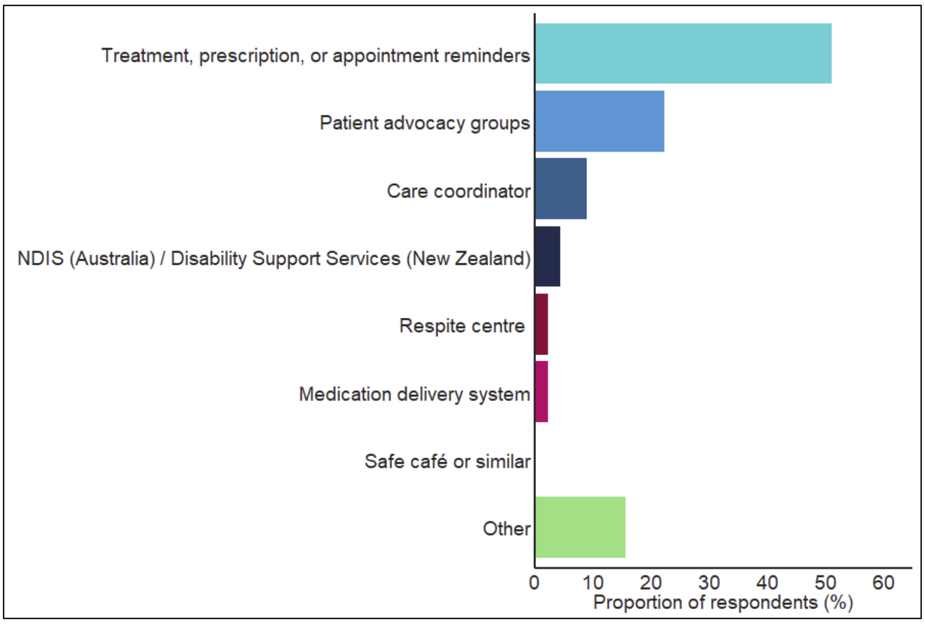


Figure 4. Services experienced

Importance & Satisfaction

PEI: patients

The PEI for patients with prostate cancer, a measure of overall satisfaction, that accounts for the relative importance of each aspect of the healthcare pathway, is displayed in Table 4. The overall median PEI score was 64.02.

The median PEI score for participants from Australia (65.70) was higher than the median PEI score for participants from NZ (55.29). Future research could explore the reasons behind the discrepancy between the two PEI scores, although the NZ sample size is small, which should be taken into consideration.

In addition to this, future research could use the PEI to assess shifts in satisfaction and importance ratings, especially if programs are implemented to address specific patient groups. Please see the prostate cancer PEI dashboard (link on page 15) for subgroups scores, e.g., by basic demographics.

Table 4. Patient PEI score

	Total Sample (n=45)	**Australia** (n=35)	**New Zealand** (n=10)
Mean	62.93	66.57	50.20
Median	64.02	65.70	55.29
Std. deviation	16.53	14.15	18.63

Importance and Satisfaction Quadrant

The drivers of PEI can be examined more closely in the “quadrant map” that plots the BWS importance scores against the BWS satisfaction scores for each MTM. This acts as a visual aid in comparing how patients prioritise/rank the 11 MTM in terms of satisfaction and importance simultaneously.

Figure 5 shows the quadrant map for patients. MTM located further towards the right along the x-axis represent higher satisfaction relative to the other MTM, and MTM higher up along the y-axis represent higher importance relative to the other MTM. MTM in the upper left quadrant are rated high on importance but low on satisfaction.

Noticeably, there are no MTM in the upper left quadrant, meaning there are no MTM rated high on importance but low on satisfaction, suggesting these patients are largely satisfied with the aspects of treatment and care that are important to them.

‘Disease related cost’, ‘Treatment logistics’, ‘Support for support person’, ‘Side effects of medication’ and ‘Access to other treatments/services’ had negative satisfaction scores, but their importance scores were also negative, indicating lower priority. On the other hand, ‘Healthcare team quality’, ‘Effectiveness and Access to medication’, ‘Involvement in decision making’, ‘Time to diagnosis’, ‘Monitoring and identifying progress/deterioration’ and ‘Information quality’ had positive important scores, however their satisfaction scores were also positive indicating that overall patients are satisfied with these high priority MTMs in both Australia and NZ.

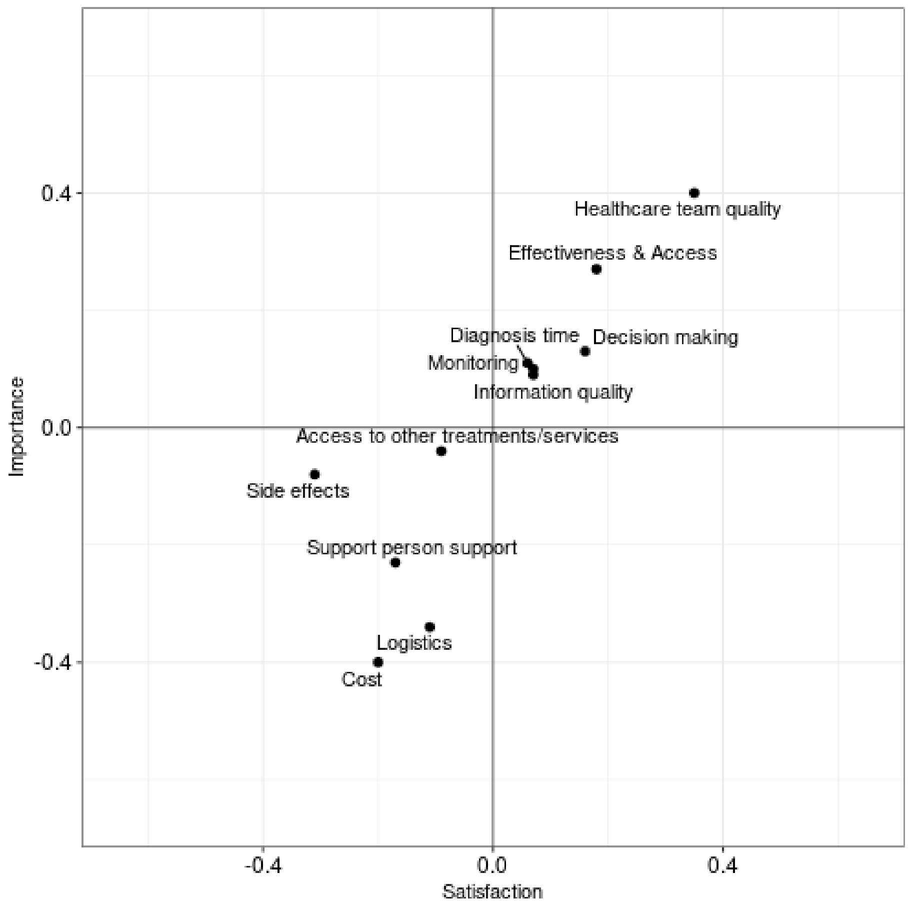


Figure 5. Rescaled importance and satisfaction

Rescaled Importance and Satisfaction

Figure 6 displays the rescaled importance and satisfaction scores. The rescaled values directly correspond to the level of satisfaction and importance stated between “Not satisfied at all”/”Not important at all” (0) and “Completely satisfied”/”Extremely important” (10). The magnitude of the satisfaction and importance can be compared to identify differences between the level of satisfaction and importance of each domain. The MTM have been ordered from top to bottom by importance level, i.e., the most important domain appears at the top of the figure.

Patients found all MTM to be at least somewhat important with none scoring less than 5 out of 10. Three MTM, ‘Healthcare team quality’ (8.18), ‘Effectiveness & Access of Medication’ (7.58), and ‘Involvement in decision making’ (7.27), appear to be especially important, on average. ‘Prostate cancer related costs’ (4.93), ‘Treatment logistics’ (5.26) and ‘Support person support’ (5.52) appeared to be the least important, on average.

Patients were least satisfied with ‘Side effects’ (5.02) and ‘Support person support’ (5.54), ‘Prostate cancer related costs’ (5.67) and ‘Access to other treatments/services’ (5.76) following close behind.

Satisfaction levels were lower than importance levels for most MTM (8 out of 11). The largest gaps between importance and satisfaction were found in ‘Side effects’, ‘Effectiveness & Access to medication’ and ‘Time to diagnosis’, although overall satisfaction for ‘Healthcare team quality’ was relatively high (7.32).

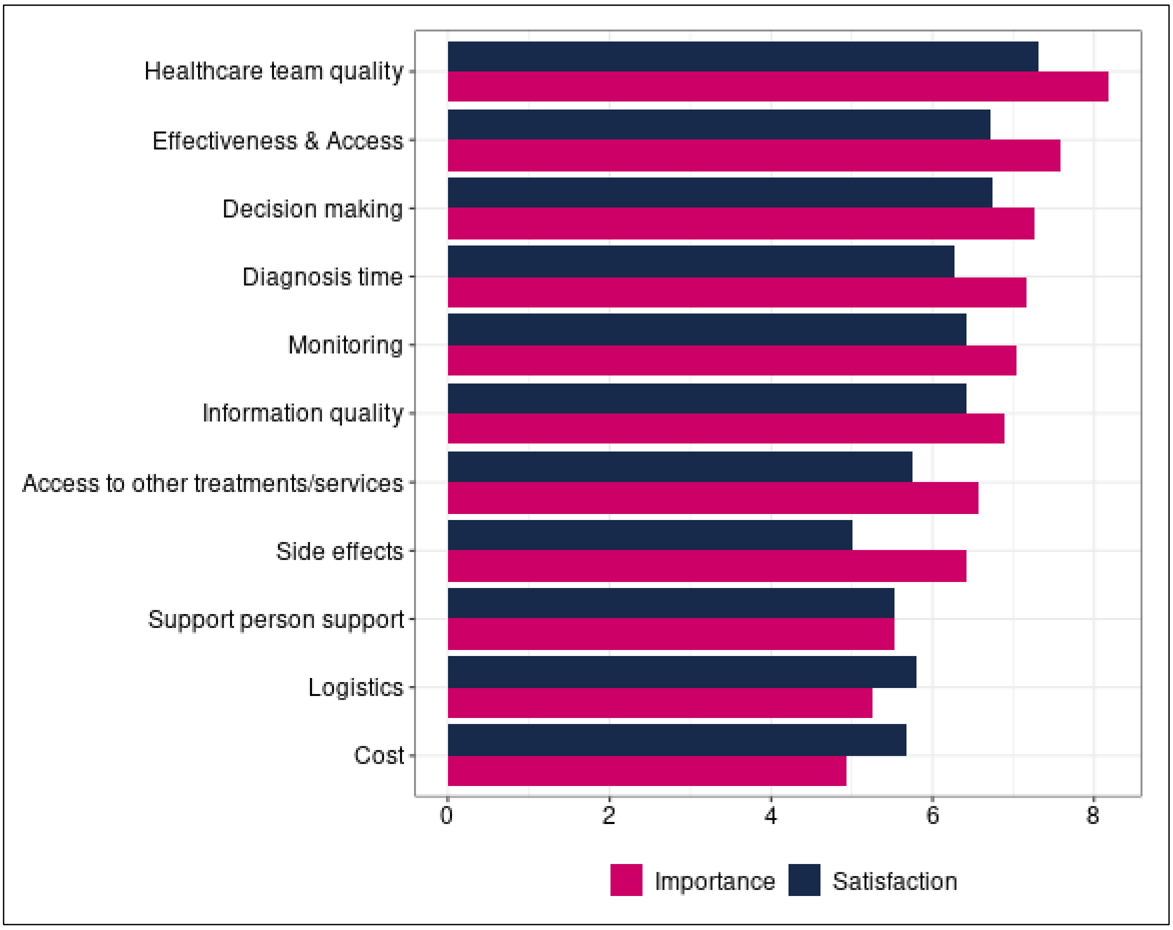


Figure 6. Rescaled importance and satisfaction

Most/Least Important MTM

Figure 7 illustrates the MTM that were most important to patients, however for which they were least satisfied, combining the top 4 of each most important/least satisfied domain for each participant; ‘Side effects’, ‘Effectiveness & Access of medication’, ‘Information quality’ and ‘Healthcare team quality’ came out top.

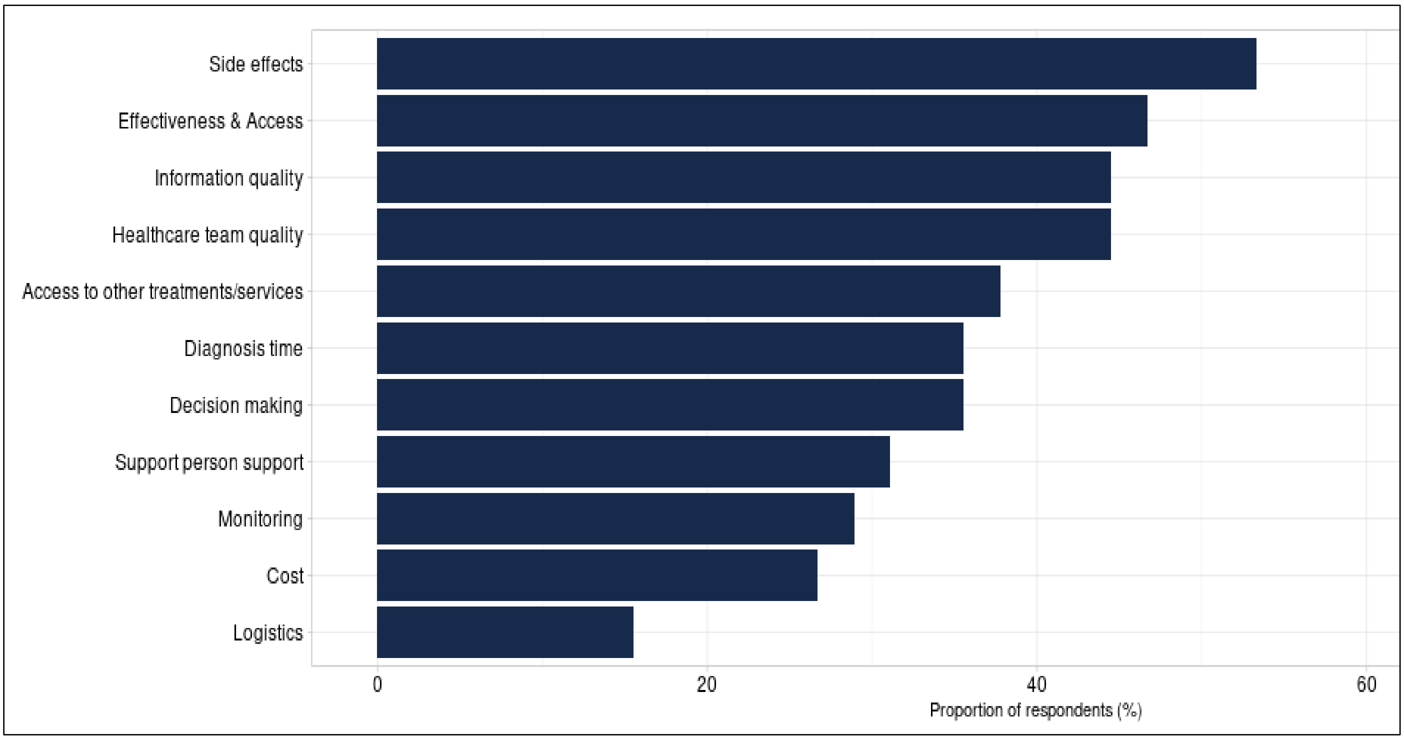


Figure 7. Top 4 least satisfied and most important MTM

Improvements in satisfaction in ‘Side effects’, ‘Effectiveness & Access of medication’, ‘Information quality’ and ‘Healthcare team quality’ (via implementation of successful program / system changes, or improvement in medication effectiveness / side effect profiles) would be likely to increase the PEI given they were rated as being the most important MTM by patients.

Conclusion

Findings from this research suggest a mix of medication and healthcare MTM could be targeted to increase patient satisfaction, particularly if the areas targeted for change are also those which patients consider to be most important within the treatment and healthcare pathway.

Potential MTM To Target

Least Satisfied / Most Important

- Side effects
- Effectiveness & Access of medication
- Information quality
- Healthcare team quality

Biggest gaps between Satisfaction and Importance

- Side effects
- Diagnosis time
- Effectiveness & Access of medication

Patient ideas on what could be done to improve these areas of dissatisfaction:

Side effects of medication / treatment

An overarching theme for the MTM was dissatisfaction around the lack of information patients had been provided by their healthcare professionals on side effects associated with medication/treatment. Some patients commented on the need for more ‘warning’ regarding common side effects, while others reported not having been made aware of the severity of side effects and how this could impact them.

Patients requested more information on the variety and severity of side effects by their healthcare professionals. Some expressed the importance of patient advocacy groups playing a more active role in explaining side effect management strategies.

Effectiveness & Access of medication

Ten patients were not satisfied with how well medications/treatments had worked/or were working to prevent symptoms associated with prostate cancer. A few patients reported their treatments had caused them to feel unwell, therefore reducing their quality of life.

Patients in NZ reported that gaining access to medication/treatments had been problematic, and suggestions were made around the need for government and health authorities to work towards ensuring medication/treatments are accessible to NZ patients, especially if these medications are already available in other countries. Patients suggested Pharmac do more to better fund prostate cancer medication/treatments.

Information quality

Patients from Australia expressed the need for more awareness concerning prostate cancer, and a greater understanding of how it impacts people living with the condition. One patient suggested raising more awareness on the impact of prostate cancer on patients, carers and the community through provision of information in public spaces, such as pharmacies and healthcare practices.

Three patients in Australia suggested more mandatory communications between patients and their nurses and/or healthcare professionals where in-depth information can be passed on to patients. Reasons for dissatisfaction within this MTM came from the lack of information specialists provided to patients, including guiding individuals towards the right resources to find quality and relevant information around prostate cancer. One patient from NZ stated that they had sourced the vast majority of their prostate cancer related information, with minimal assistance from their specialists/doctors.

Healthcare team quality

There was dissatisfaction around the lack of empathy provided by healthcare professionals towards patients; six patients suggested that healthcare professionals showed minimal interest towards individual needs, feelings and emotion. Patients asked for more support and a genuine desire from their healthcare professionals to listen.

Two patients from NZ expressed their concerns around finding healthcare professionals in general, especially in the public system. These patients asked for a general improvement in the NZ public healthcare system.

Patients residing in both Australia and NZ reported a lack of integration and communication within their healthcare team and suggested the need for more ‘systemic coordination’. Patients suggested healthcare professionals send reports to GPs and pharmacists after each consultation, e.g., via phone apps such as ‘My Health Record’ in Australia, and ‘Manage My Health’ in NZ.

Time to diagnosis

Patients reported having little knowledge of prostate cancer prior to diagnosis which was believed to have contributed to a delay in diagnosis.

Three patients reported having experienced a significant delay in receiving a biopsy referral post cancer detection, where suggestions were made around having an easier/faster referral process without needing to go through multiple follow up appointments in between. One patient from NZ stated that if their prostate cancer had been diagnosed earlier, the disease would most likely have been curable.