Quantitative short report

Non-Small Cell Lung Cancer:

Patient Experience – Australia

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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 Non-Small Cell Cell Lung Cancer (NSCLC) 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 patients complete the 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 NSCLC patient experience

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 NSCLC healthcare could be improved

Our approach

Methodology

The Survey

Participants completed an online survey which included:

- Best Worst Scaling (BWS) task
- Socio-demographic questions
- Questions around treatment status and care received

Best Worst Scaling (BWS)

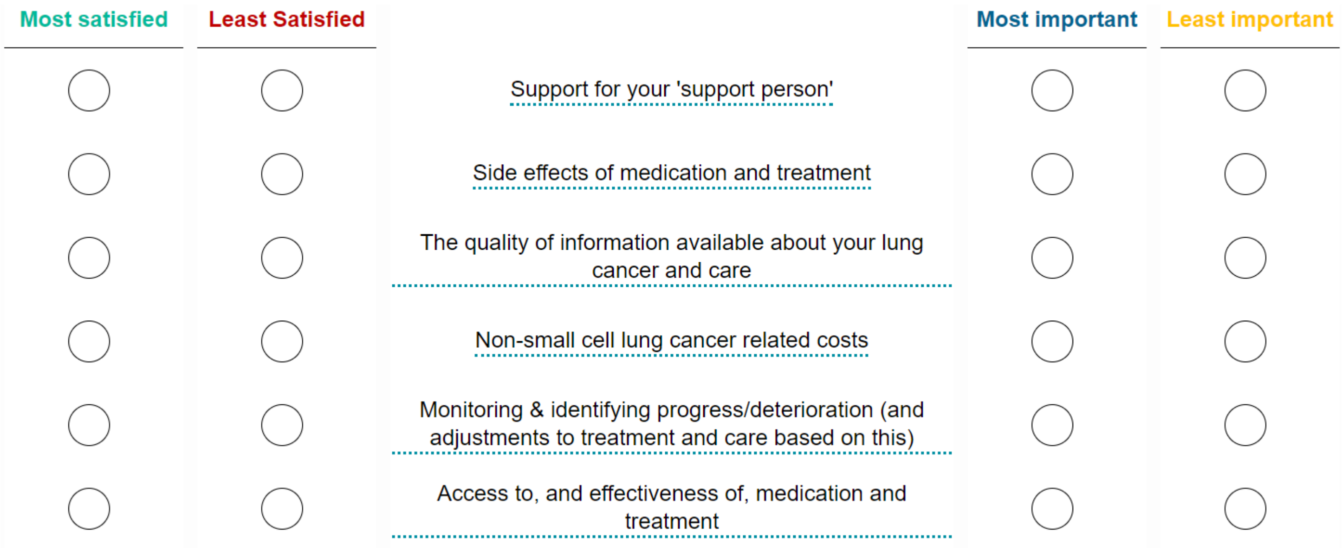
The BWS task used to measure the importance and satisfaction of the different aspects of the healthcare pathway was defined by a master list of 11 domains, or ‘moments that matter’ (MTM). The MTM were identified from qualitative research conducted with patients and secondary research from Janssen ANZ. A summary of the MTM can be found in Figure 1 and on the dashboard info tab (see page 19 for more information).

	MTM	Description
1	**Time to diagnosis**	• The length of time from developing symptoms or first consulting with your initial healthcare team (e.g., GP, emergency department, nurse), through to being diagnosed – whatever this looked like for you.
2	**The quality of information available about your lung cancer and care**	• Having clear, concise, relevant information in a format that meets your needs or expectations (e.g., provided to you by your healthcare team/online/social media).
3	**Your involvement in decision making**	• How involved you are in decisions about your treatment and care, and how much your healthcare team values your input – for example, 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., respiratory physician/ oncologist) at regular intervals that you feel are most beneficial to you where urgent access is required. • How well your needs are met in any interactions with your healthcare team (including doctors, nurses, care coordinators). • Having a healthcare team that knows my history so my treatment can be optimised. • The extent to which your healthcare team (e.g., respiratory physician/ oncologist/ GP/ clinical nurse specialist/ psychologist) communicate with each other about your lung cancer and care. They may be healthcare professionals within the same service or in different services.
5	**Treatment logistics**	• The broad impact that following treatment requirements has on your whole life.
6	**Access to, and effectiveness of, medication**	• Your access to medication and treatment for your lung cancer.

		- The effectiveness of your medication/treatment for your lung cancer.
7	**Side effects of medication and treatment**	- Side effects you may experience from medication and treatment prescribed by your healthcare professional/s.
8	**Monitoring & identifying progress/deterioration** (and adjustments to treatment and care based on this)	- 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) 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 guide you through the healthcare system and offer emotional support; this could be a lung cancer specialist nurse / clinical nurse specialist / peer support worker. - Other allied health services could include seeing a psychologist or a dietitian, or social worker. - Complementary treatments could include acupuncture, hypnosis, mind-body therapies.
10	**Support for your 'support person'**	- Information / websites / support groups specifically for significant others (e.g., spouse, partner, parent, sibling, friend, child etc) and support groups where family members/friends can talk with others in similar situations.
11	**NSCLC-related costs**	- The overall impact that having NSCLC has on your financial wellbeing, e.g., how much you are out-of-pocket, and the impact of loss of income.

Figure 1. PEI MTM and descriptions

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 2 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
○	○	Support for your 'support person'	○	○
○	○	Side effects of medication and treatment	○	○
○	○	The quality of information available about your lung cancer and care	○	○
○	○	Non-small cell lung cancer related costs	○	○
○	○	Monitoring & identifying progress/deterioration (and adjustments to treatment and care based on this)	○	○
○	○	Access to, and effectiveness of, medication and treatment	○	○

Figure 2. Screenshot of 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.

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

- A **negative** score indicates the MTM was chosen as ***worst* more often than *best***
- A **positive** score indicates the MTM was chosen as ***best* more often than *worst***
- A **zero** score indicates the MTM 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, such as the index (PEI) which can be compared between participants. An index was built to measure the overall satisfaction of the health experience for the treatment of NSCLC in ANZ. The PEI is a combined score of the 11 BWS MTM, accounting for both satisfaction and importance, and ranges from 0 to 100.

Participants – Australian NSCLC Patients

Patients were recruited through the patient support group, Lung Foundation Australia along with a panel company. 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 16-Oct-2023 and 13-Feb-2024.

The findings

Demographic characteristics

Demographic characteristic	Patient (N=30)

	N (%)
Gender	
Male	12 (40)
Female	18 (60)
Non-binary/gender fluid/self-described	0 (0)
Prefer not to answer	0 (0)
Age	
18-30	0 (0)
31-40	3 (10)
41-50	6 (20)
51-60	6 (20)
61-70	8 (26.67)
71-80	7 (23.33)
81 or older	0 (0)
Prefer not to answer	0 (0)
Occupational status	
Working (full-time)	7 (23.33)
Working (part-time)	5 (16.67)
Working (casual)	0 (0)
Student	0 (0)
Not working	4 (13.33)
Home duties and/or caring responsibilities	1 (3.33)
Retired	12 (40)
Other	1 (3.33)
Prefer not to answer	0 (0)
Ethnicity	
Australian	24 (80)
Indigenous Australian or Torres Strait Islander	0 (0)
New Zealander	1 (3.33)
Māori	0 (0)
Samoan	0 (0)
Tongan	0 (0)
Cook Islander	0 (0)
Niuean	0 (0)
Fijian	0 (0)
Other Pacific	0 (0)
Pacific Islander	1 (3.33)
Asian	1 (3.33)
Indian	0 (0)
Middle Eastern	0 (0)
European	2 (6.67)
North American	0 (0)
South American	0 (0)
African	0 (0)
Other	1 (3.33)
Prefer not to answer	0 (0)
Location	
Metro/city	18 (60)
Regional	12 (40)

Rural	0 (0)

Abbreviations: N – sample size.

Table 1.Basic demographic characteristics of patients

The characteristics of the participants are displayed in Table 1. Nearly more than half of NSCLC patients identified as female (60%). The majority were aged 61 to 80 years old (50%), with 40% in the 41-60 age categories. Almost half of participants were retired (40%), or reported to be working, in some capacity (40%). Participants were split approximately two thirds vs. a third between metro and regional/rural areas (60% vs. 40%, respectively).

Disease and treatment characteristics

Disease and treatment characteristics for participants are shown in Table 2. Majority of NSCLC patients have undergone biomarker/genomic/molecular testing (70%). Approximately one third of patients tested positive for EGFR mutation, which was the most common, followed by ALK (17.7%) and PD-L1 (14.7%). Of those who tested positive for EGFR, close to half were unsure of the EGFR mutation they identified with (40%), while approximately one third identified with Exon 19 (30%). Participants were diagnosed with NSCLC ranging from Stage 0 to Stage IV, with Stage IV being the most common (30%) followed by Stage I to III equally (20% equally).

Close to two thirds of participants were currently taking medication (60%) while almost one quarter have never taken medication (23%). The most common treatment was chemotherapy (29.2%), followed by radiation therapy (25%) and immunotherapy (20.8%).

Disease and treatment characteristic	Patient N (%)
Testing status N=30	
Yes, undergone biomarker/genomic/molecular testing	21 (70)
No	3 (10)
Don’t know	6 (20)
EGFR status (multi)	
EGFR	10 (29.4)
ALK	6 (17.7)
ROS-1	4 (11.8)
PD-L1	5 (14.7)
KRAS	1 (2.9)
HER02	2 (5.9)
NTRK	1 (2.9)
BRAF V600E	1 (2.9)
Other	0 (0)
Don’t know	4 (11.8)
EGFR mutation(s) identified with	
Exon 17	0 (0)
Exon 18	1 (10)
Exon 19	3 (30)
Exon 20	0 (0)
Exon 21 / L858R	2 (20)
T790M mutation	0 (0)
Other	0 (0)
Don’t know	4 (40)
Lung cancer stage	
Stage 0	3 (10)
Stage I	6 (20)

Stage II	6 (20)
Stage III	6 (20)
Stage IV	9 (30)
Don’t know	0 (0)
Treatment status	
Currently taking medication	18 (60)
Not currently taking medication, but have in the past	3 (10)
Never taken medication	7 (23)
Other	2 (7)
Don't know/unsure	0 (0)
Treatment experience (multi)	
Surgery	7 (14.6)
Chemotherapy	14 (29.2)
Radiation therapy	12 (25)
Immunotherapy	10 (20.8)
Laser therapy	0 (0)
Endoscopic stent placement	0 (0)
Other	5 (10.4)
Don't know/unsure	0 (0)

Abbreviations: N – sample size.

Table 2 .Basic disease and treatment characteristics

Characteristics of Care

Treatment Setting

Almost half of participants were treated in a private setting (46.7%). Approximately a quarter (26.7% and 23.3%) reported having been treated in a public setting exclusively and combination of public/private setting respectively.

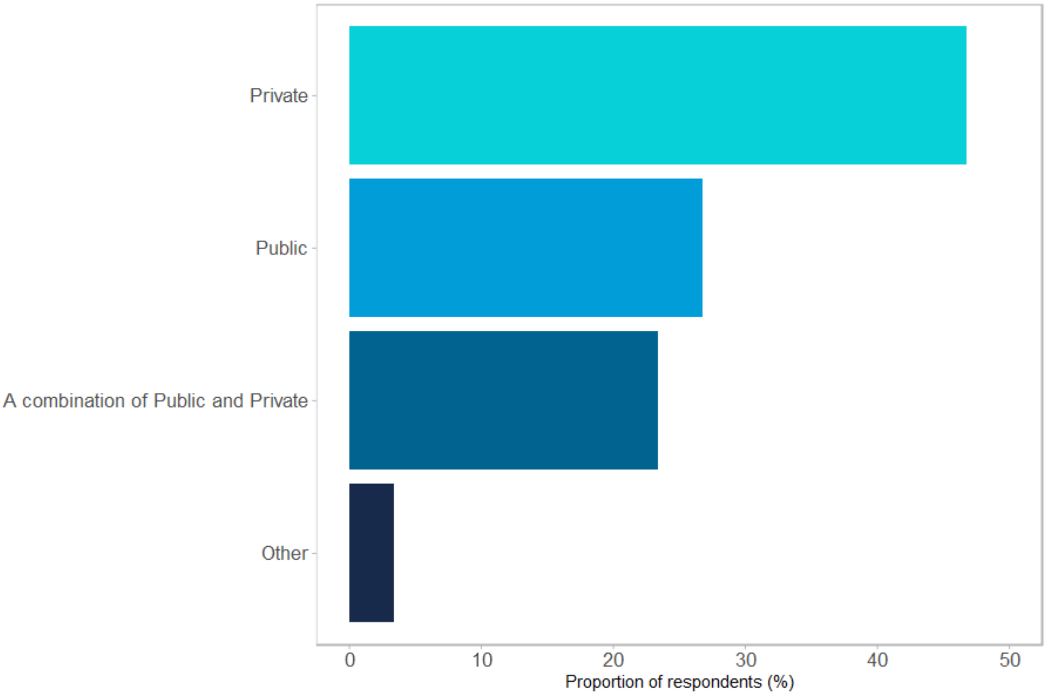


Figure 3. Treatment setting

Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with a mean of $3,067 annually.

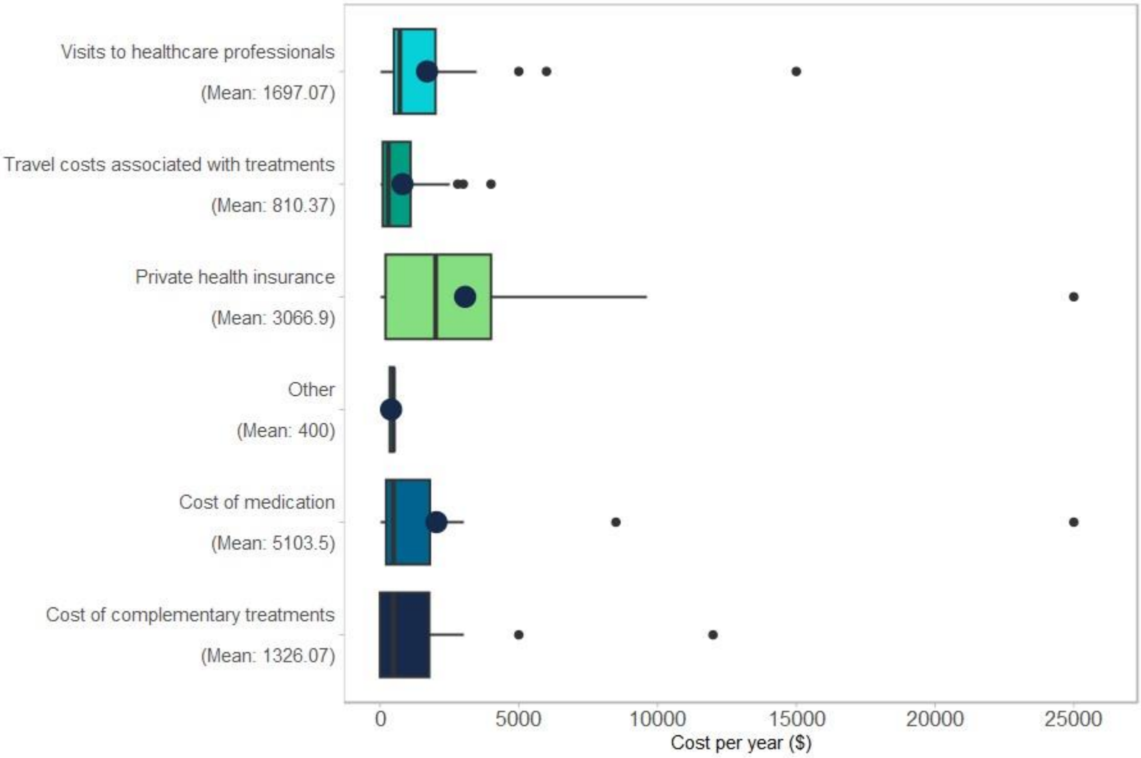


Figure 4. Treatment and care costs

Services Experienced

More than half of participants made use of mainstream medical services e.g., treatment/prescription/appointment reminders (56.7%), and almost half of participants were supported by patient advocacy groups (46.7%). 16.7% of participants made use of a medication delivery system.

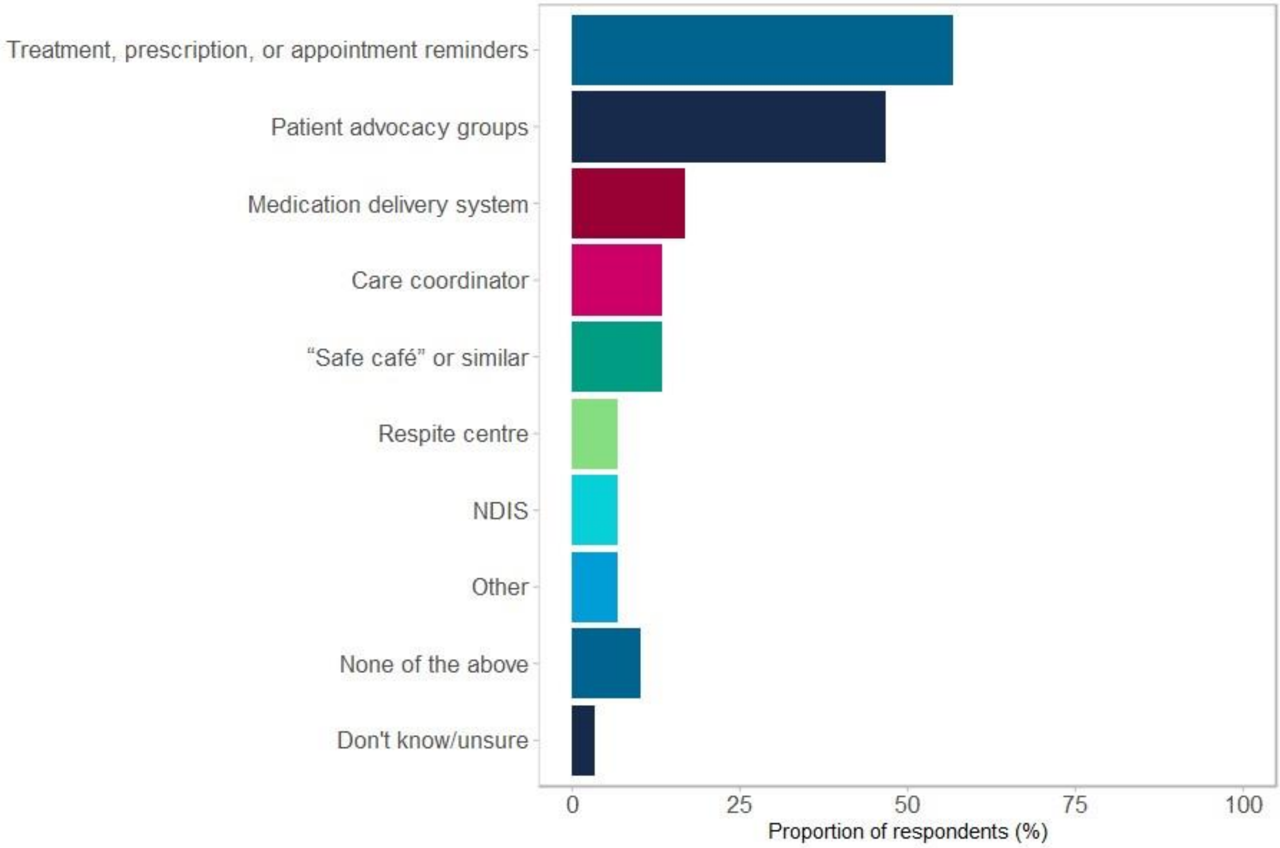


Figure 5. Services experienced

Importance & Satisfaction

PEI

The PEI for NSCLC patients is displayed in Table 3. The PEI represents the overall satisfaction accounting for the relative importance of each aspect of the healthcare pathway. 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 NSCLC PEI dashboard (link on page 16) for subgroups scores, e.g., by basic demographics (see ‘Subgroup analysis’ tab).

	Mean	Median	Std. deviation
Patient Experience Index (N=30)	63.91	68.06	17.37

Table 3. Patient Experience Index score

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 NSCLC patients prioritise/rank the 11 MTM in terms of satisfaction and importance simultaneously.

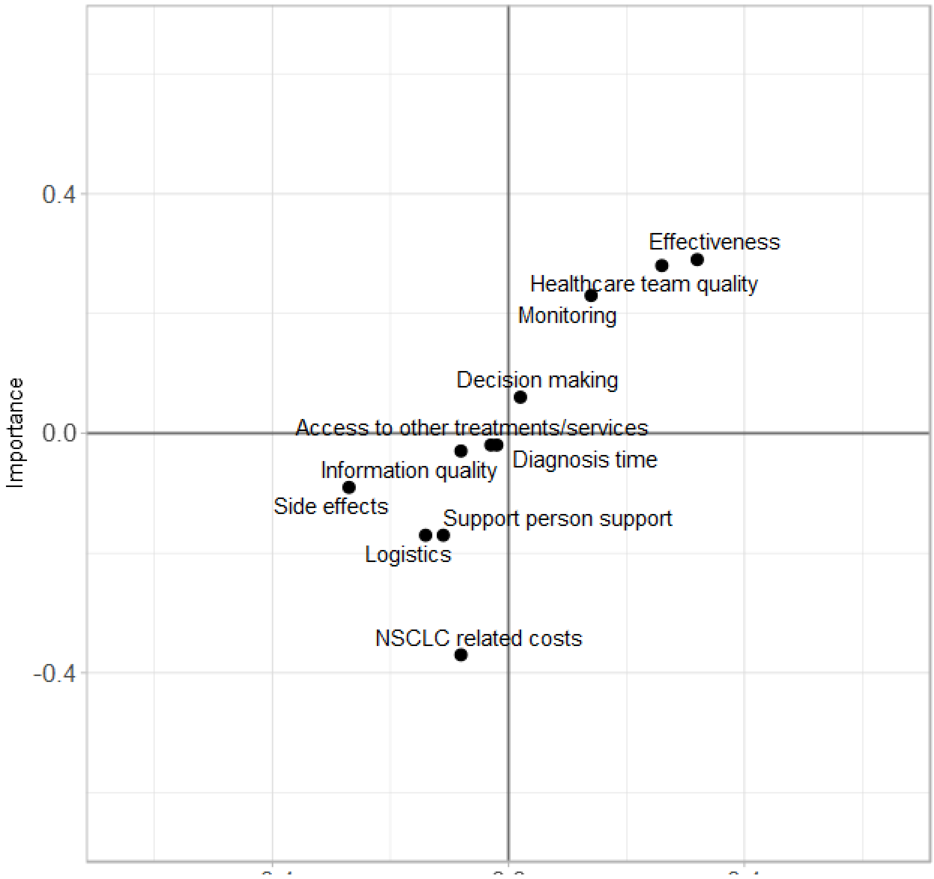


Figure 6. BWS quadrant map

Figure 6 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. 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 the aspects of treatment and care that are most important to them. *Support person support, Access to other treatments/services, Diagnosis time, Information quality, Side effects, Logistics, Support person support,* and *NSCLC related costs* do have negative satisfaction scores, but their importance scores are also negative, indicating lower priority compared to other MTM, namely *Effectiveness, Healthcare team quality* and *Monitoring.*

Rescaled importance and satisfaction

Figure 7 displays the rescaled importance and satisfaction scores for NSCLC patients. 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 MTM. The MTM have been ordered from top to bottom by importance level, i.e., the most important MTM 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* (8.44), *Effectiveness & Access* (8.38), and *Monitoring* (8.27), appear to be especially important, on average. *Decision making* (7.75), *Diagnosis time* (7.36), *Access to other treatments/services* (7.29), *Side effects* (7.22)*,* and *Information quality* (7.2) also scored highly.

Patients were least satisfied with *Side effects* (5.17), *Support person support* (5.59) and *Logistics* (5.8). Satisfaction levels were lower than importance levels on all MTM except *NSCLC-related costs*. The biggest gaps between importance and satisfaction were in *Side effects, Decision making* and *Monitoring* (in order of gap size).

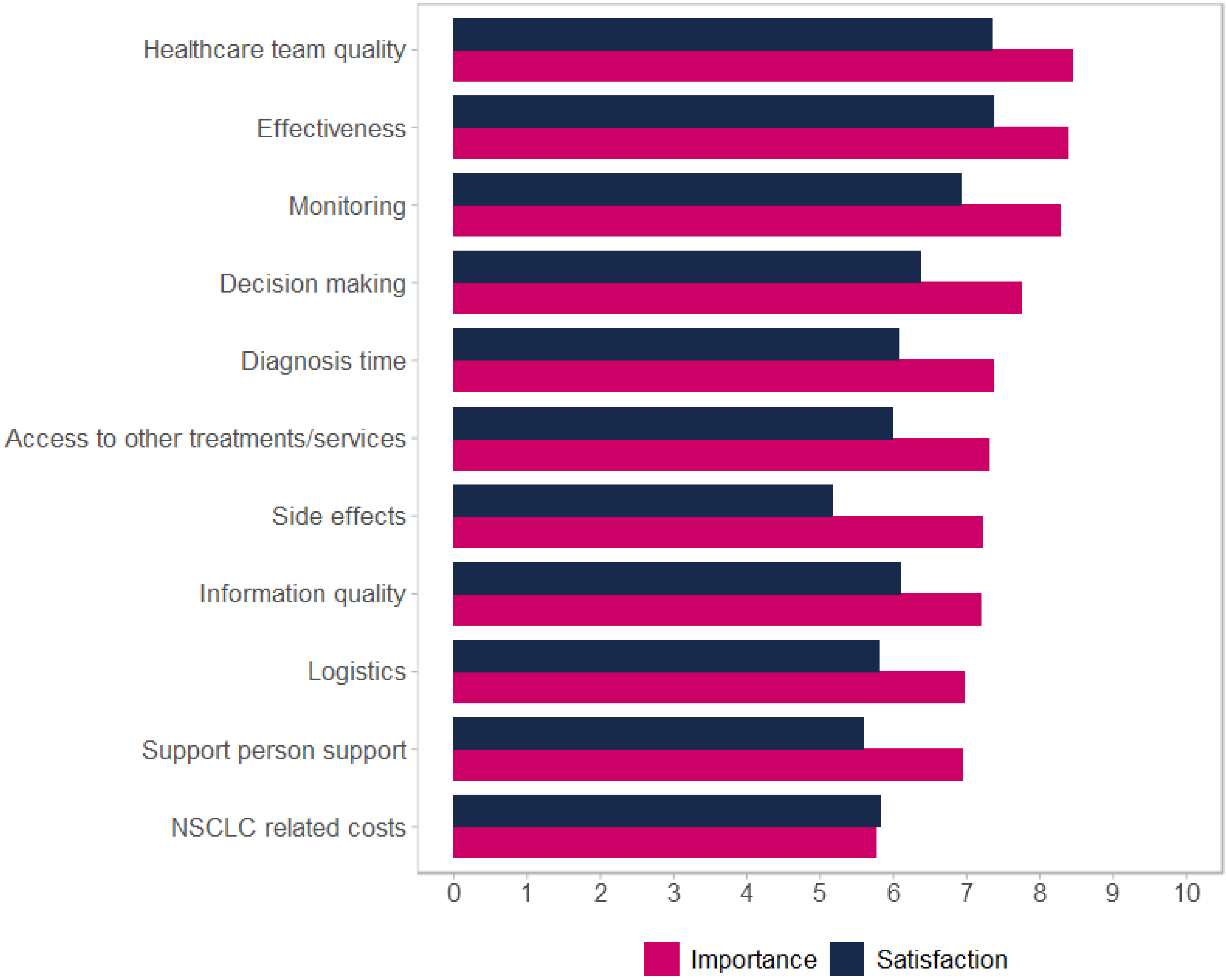


Figure 7. Rescaled importance and satisfaction

Top 4 MTMs commonly identified as least satisfied but most important

Figure 8 shows the MTM that were most commonly regarded by each participant as most important but least satisfied with. The top 4 were *Side effects, Support person support, Access to other treatments/services* and

Healthcare team quality. Improvements in satisfaction of these MTM (via implementation of successful program/ system changes, or improvement in medication effectiveness) may increase the PEI.

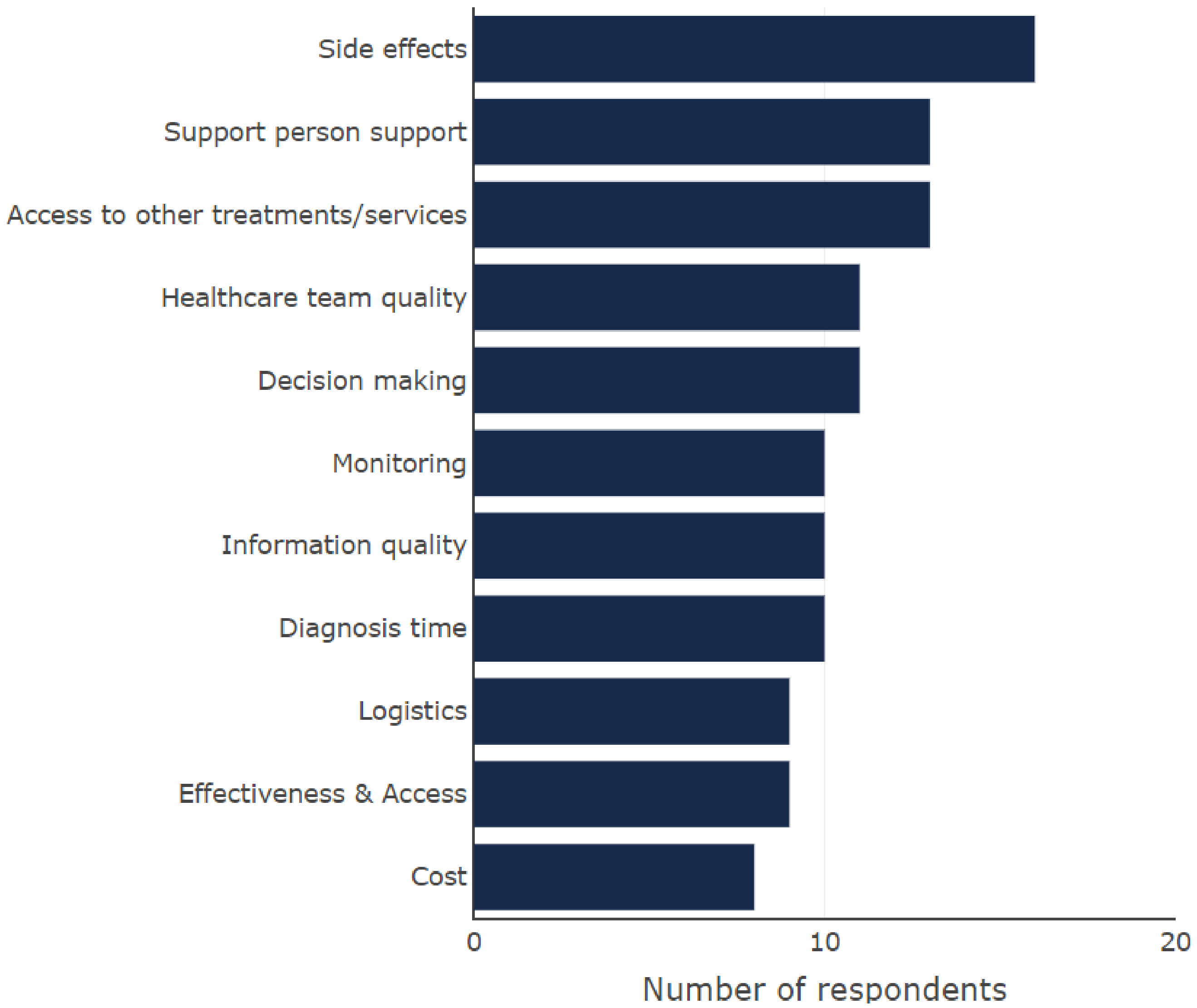


Figure 8. Top 4 least satisfied and most important MTM

Conclusion

Findings from this research suggest a mix of side effects, support for support person, access to other treatments/services, and healthcare team quality 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

Top 4 MTMS commonly identified as least satisfied but most important

- Side effects
- Support for support person
- Access to other treatments/services
- Healthcare team quality

Biggest gaps between satisfaction and importance

- Side effects
- Decision making
- Monitoring

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

Side effects

Patients were most dissatisfied with the impact of side-effects from medication and/or treatment on their day-to-day lives. Several patients expressed frustration on how side effects have prevented them from doing things they enjoy and to function independently. Patients' suggestions for improvement include having better information on side effects (e.g., being clear on what side effects there are in treatment discussions, providing examples of the side effect and the full extent of their impact) so patients know what to expect and are well-prepared to manage them. Other suggestions include investing more in cancer research, specifically on treatments/medications, and clinical trials, so patients can have more treatment choice.

Support for support person

Most participants who had this MTM in their top 4 for high importance/low satisfaction were not satisfied with the emotional/psychological support available for their support person (e.g., peer support, counselling), citing the support was not provided for their support person. Sideas for improvement include, establishing regular check-ins with support people, offering counselling services as required and raising awareness of other support services/resources (e.g. patient advocacy groups, websites, helplines).

Access to other treatments/services

Participants who had this MTM in their top 4 for high importance/low satisfaction were mostly dissatisfied with the level of support to help with lifestyle changes (e.g., diet, exercise, sleep, smoking cessation). Patient suggestions for improvement include, increasing the awareness of support services (e.g., regular check-ins with patients and providing contact information of relevant support services, providing written information on support as not all had received this). Patients also highlighted the need to improve the quality of support services (e.g., having more experienced carers in allied services or subsidising support services).