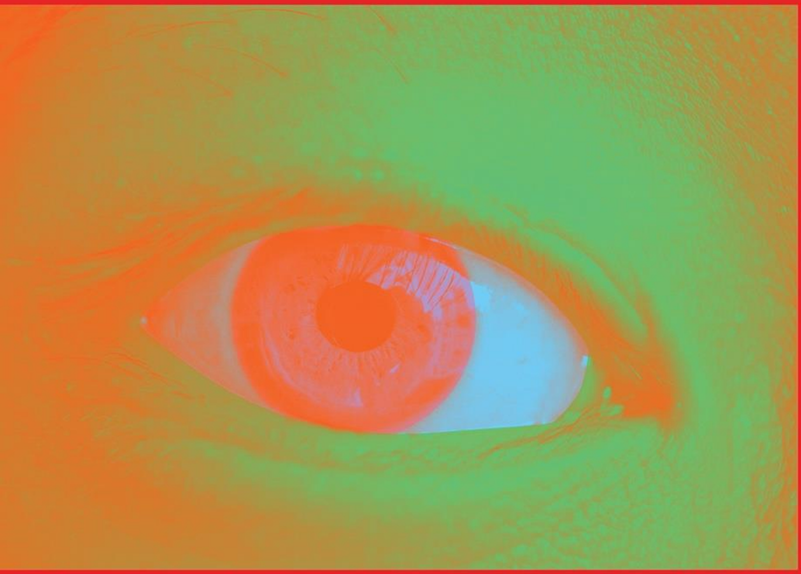
Quantitative short report



Treatment Resistant Depression:

Patient Experience – Australia

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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 Treatment Resistant Depression 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 second, quantitative stage, in which patients complete the BWS, will be used to understand the patient experience and identify areas of potential improvement, with the aim of providing a consistently exceptional experience. The HEI 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 Treatment Resistant Depression (TRD) 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 IBD 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 15 domains. The domains were identified from qualitative research conducted with patients and secondary research from Janssen ANZ then refined during a stakeholder workshop. A summary of the domains can be found in Figure 1 and on the dashboard info tab (see page 15 for more information).

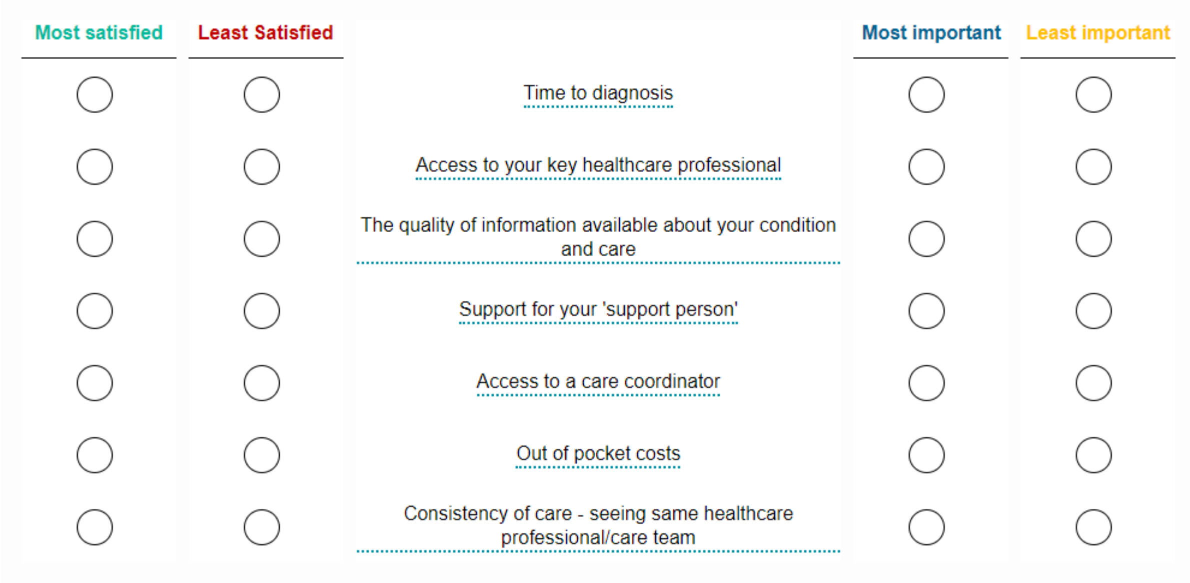
	DOMAIN	Description
1	**The quality of information available about your condition and care**	Having clear, concise, relevant information in a format that works for you (e.g., provided to you by your healthcare team/online/Apps/podcasts).
2	**Your involvement in decision making**	How involved you are in decisions about your treatment and care, e.g., when selecting specific medication and/or when developing a treatment plan.
3	**Quality of your interactions with your healthcare team**	How well your needs are met in any interactions with your healthcare team (including doctors, nurses, care coordinators).
4	**Communication between different members of your healthcare team**	The extent to which different members of your healthcare team (e.g., GPs, psychiatrists, psychologists) communicate with each other about your condition and care. They may be healthcare professionals within the same service or in different services.
5	**Access to medication**	Your access to medication for your condition.
6	**Side effects of medication**	Side effects you may experience from medication prescribed by your HCP.
7	**Effectiveness of medication**	How effective the medication prescribed by your HCP is in treating your condition.
8	**Burden of 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.
9	**Access to other treatments/services (holistic approach)**	Other treatments could include talking therapies, complementary treatments (e.g., electroconvulsive therapy, transcranial magnetic stimulation) and management strategies for increased wellness (e.g., access to dietitians/physiotherapists/occupational therapists).
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	**Out of pocket costs**	This may include specialist fees (i.e., if not covered or gap payments) medication costs or for alternative treatments, transport/parking costs.
12	**Access to a care coordinator**	Someone who is assigned to you (e.g., social worker or peer support worker) to help you navigate the healthcare system and offer emotional support and guidance.

13	**Consistency of care - seeing same healthcare professional/care team**	Being able to see the same trusted healthcare professional/s on-going for your treatment and care.
14	**Access to your key healthcare professional/s**	Suitable access to your key healthcare professional (e.g., psychologists, psychiatrist), i.e., at regular intervals that you feel are most beneficial to you or in acute situations where urgent access is required.
15	**Time to diagnosis**	The length of time from developing symptoms through to being diagnosed – whatever this looked like for you.

Figure 1. HEI domains and descriptions

The domains were systematically divided into 15 sets of 7 according to an experimental design, resulting in a BWS exercise containing 15 scenarios. For each scenario, participants were asked to consider the 7 displayed domains (i.e., participants were shown 7 of the 15 domains at any one time) and select the best and worst domains across two dimensions: satisfaction and importance. An example of a scenario is shown in

Figure 2. Screenshot of BWS task 2 below. Data collected detailed how important each domain was to an individual, as well as how satisfied they were with each domain.



Most satisfied	Least Satisfied		Most important	Least important
○	○	Time to diagnosis	○	○
○	○	Access to your key healthcare professional	○	○
○	○	The quality of information available about your condition and care	○	○
○	○	Support for your 'support person'	○	○
○	○	Access to a care coordinator	○	○
○	○	Out of pocket costs	○	○
○	○	Consistency of care - seeing same healthcare professional/care team	○	○

Figure 2. Screenshot of BWS task

The BWS exercise yielded scores reflecting the relative hierarchy of each domain vs another domain. The **BWS scores** were calculated for each domain 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 domain 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 domains.

- 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”

Health Experience Index (HEI)

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 (HEI). An index was built to measure the overall satisfaction of the health experience for the treatment of TRD in ANZ. The HEI is a combined score of the 15 BWS domains, accounting for both satisfaction and importance, and ranges from 0 to 100.

Participants

Patients were recruited through the patient support group, Lived Experience Australia, and a healthcare panel. 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 21-Sep-2021 and 11-Nov-2021.

The findings

Demographic characteristics

Demographic characteristic	Patient (N=64) N (%)
Gender	
Female	45 (70.31)
Male	15 (23.44)
Non-binary/gender fluid	3 (4.69)
Prefer to self-describe	1 (1.56)
Age	
18-30	11 (17.19)
31-40	15 (23.44)
41-50	17 (26.56)
51-60	10 (15.63)
61-70	10 (15.63)
71-80	1 (1.56)
81 or older	0 (0)
Occupational status	
Working (full-time or part-time)	24 (37.5)
Working (part-time)	10 (15.63)
Working (casual)	4 (6.25)
Student	1 (1.56)
Not working	9 (14.06)
Home duties and/or caring responsibilities	4 (6.25)
Retired	6 (9.38)
Other	6 (9.38)
Ethnicity	
Australian	26 (40.63)
Indigenous Australian or Torres Strait Islander	1 (1.56)
New Zealander	24 (37.5)
Māori	2 (3.13)
Asian	3 (4.69)
Indian	1 (1.56)
European	3 (4.69)
North American	1 (1.56)
Other	2 (3.13)
Prefer not to answer	1 (1.56)
Location	
Metro/city	42 (65.63)
Regional	20 (31.25)
Rural	2 (3.13)

Abbreviations: N – sample size.

Table 1. Basic demographic characteristics of patients

The characteristics of the patient participants are displayed in Table 1. The majority were female (70%), there was a relatively even age distribution; half of participants (50%) were aged 31-50, but both younger and older groups were represented. Over one-third of participants were working full-time (37.5%). Roughly two-thirds of participants (66%) lived in metro areas, the remaining third lived in predominantly regional areas (31%).

Note, for Australia sample size was 34, for New Zealand 30, this donates country of residence. Ethnicity is a measure of which ethnic group the patient identifies with; most identified as Australian (41%) or New Zealander (38%).

Treatment Characteristics

Treatment profiles for patients are shown in Table 2. The majority of patients (94%) have been living with TRD for longer than 3 years. Patients have taken approximately 4 antidepressants (these must have been taken for at least 6 weeks).

Treatment characteristic	Patient (N=64)
Time since diagnosis	
Last 3 years	4 (6.25%)
Longer than 3 years	60 (93.75)
No. antidepressants taken for at least 6 weeks	4 (median)

Abbreviations: N – sample size.

Table 2. Basic treatment characteristics

Characteristics of Care

HCP involved in treatment

The majority of patients were seeing a GP as part of their care (86%), a little under half were seeing a psychologist (42%), and a similar number were seeing a psychiatrist (45%). 18 patients were seeing both a psychologist and psychiatrist.

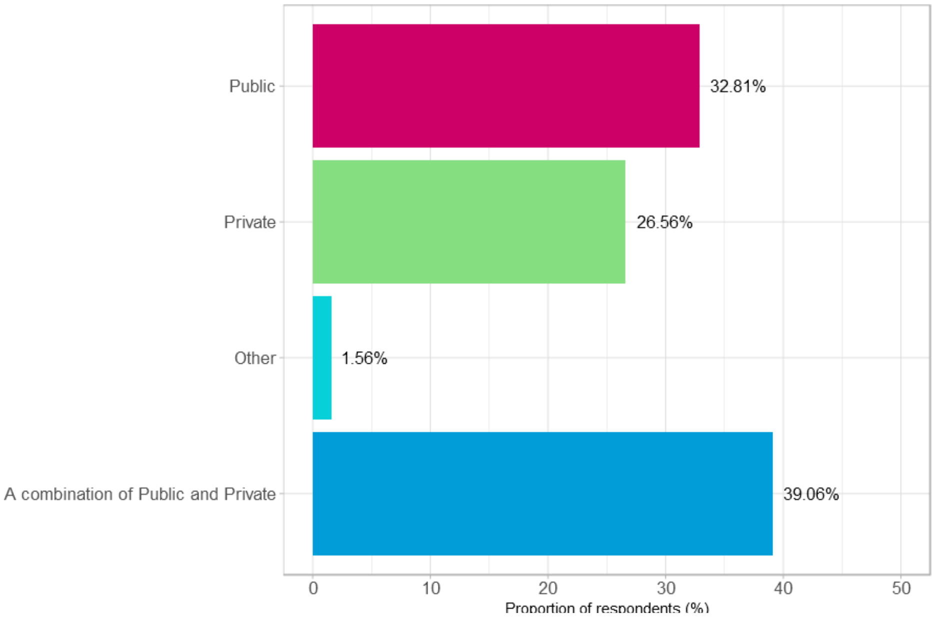


Figure 3. HCP involved in treatment

Treatment Setting

Over a third of patients (39%) received treatment through both the public and private healthcare systems. Of those who were in one system only slightly more were treated in the public system (33% vs. 27%).

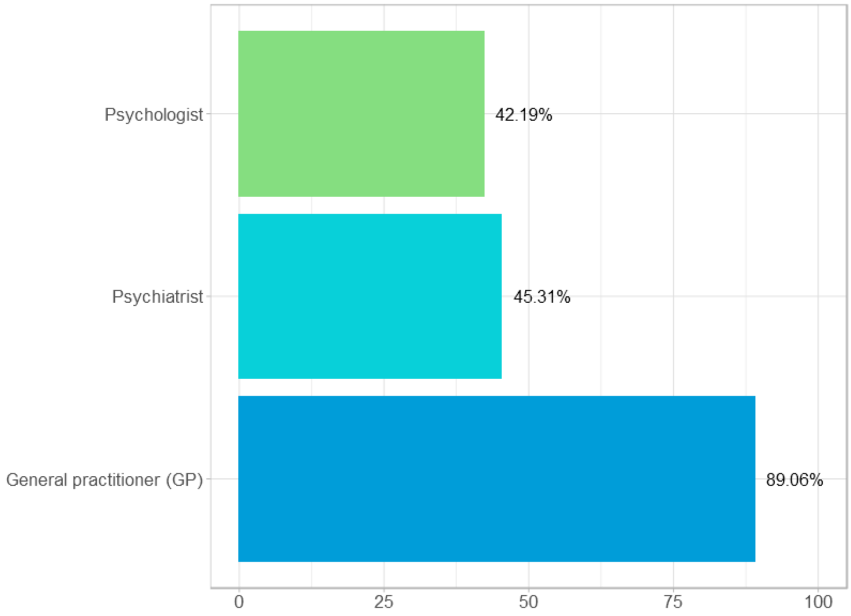


Figure 4. Treatment setting

Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with an average of $1077 annually, this was followed by the cost of seeing HCPs, at an average of $991 annually.

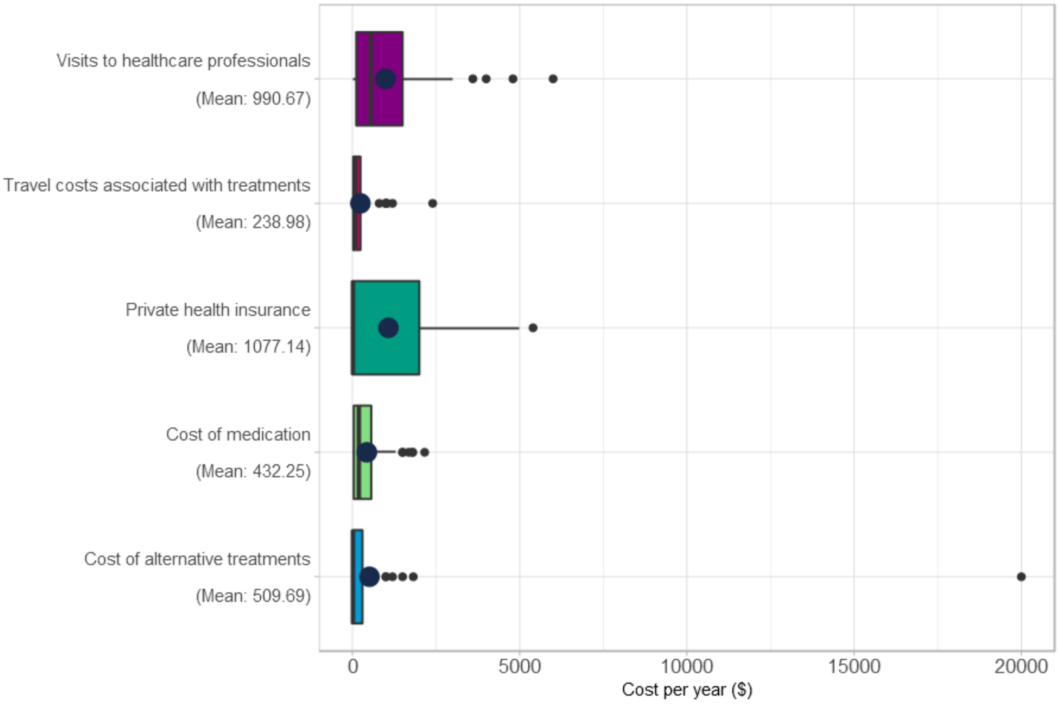


Figure 5. Treatment and care costs

Services Experienced

Five Australian patients were supported by the National Disability Insurance Scheme (NDIS), whilst 6 New Zealanders were supported by Disability Support Services. 13 patients across both countries had access to a care coordinator. Patients had been hospitalized an average of 4.5 times.

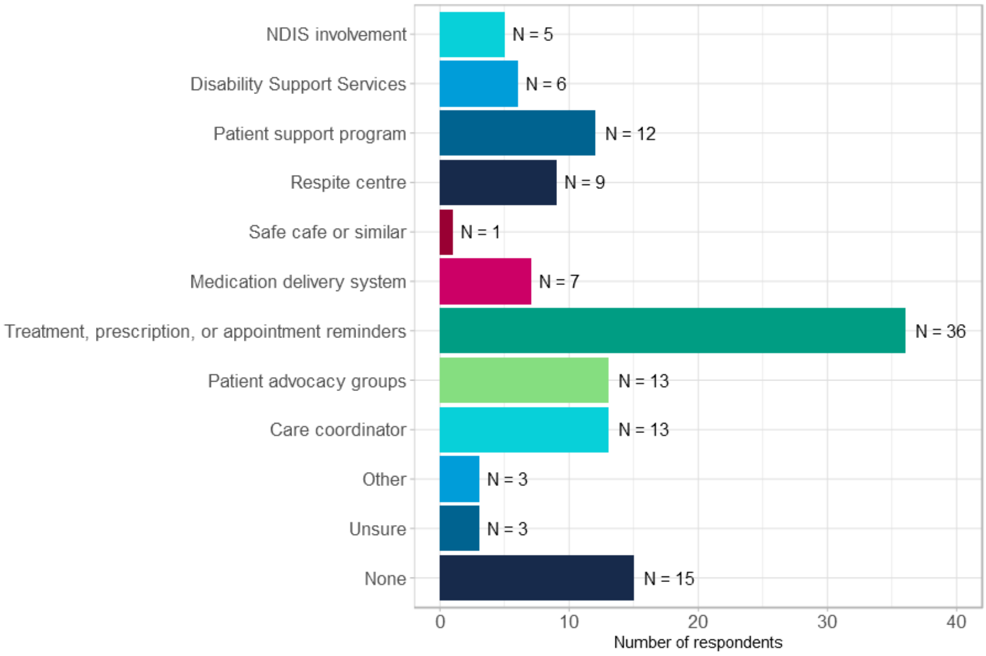


Figure 6. Services experienced

Importance & Satisfaction

HEI: Patients

The HEI for patients with TRD, a measure of overall satisfaction, that accounts for the relative importance of each aspect of the healthcare pathway, is displayed in Table 3. Future research could use the HEI to assess shifts in satisfaction and importance ratings, especially if programs are implemented to address specific patient groups. Please see the TRD HEI dashboard (link on page 15) for subgroups scores, e.g., by country/basic demographics.

	Mean	Median	Std. deviation
Health Experience Index	50.54	51.3	16.08

Table 3. Patient HEI score

Importance and satisfaction quadrant

The drivers of HEI can be examined more closely in the “quadrant map” that plots the BWS importance scores against the BWS satisfaction scores for each domain. This acts as a visual aid in comparing how patients prioritise/rank the 15 domains in terms of satisfaction and importance simultaneously.

Figure 7 shows the quadrant map for patients. Domains located further towards the right along the x-axis represent higher satisfaction relative to the other domains, and domains higher up along the y-axis represent higher importance relative to the other domains. Domains in the upper left quadrant (*Effectiveness/Side effects/Communication*) are rated high on importance but low on satisfaction. Improvements in satisfaction in these domains may result in considerable improvements in overall satisfaction. While *Cost/Care-coordinator access/Support person support/other treatment* have negative satisfaction scores, their importance scores are also negative indicating lower priority compared to other domains, especially *Consistency of Care/Interaction quality/Decision involvement/Medication access.*

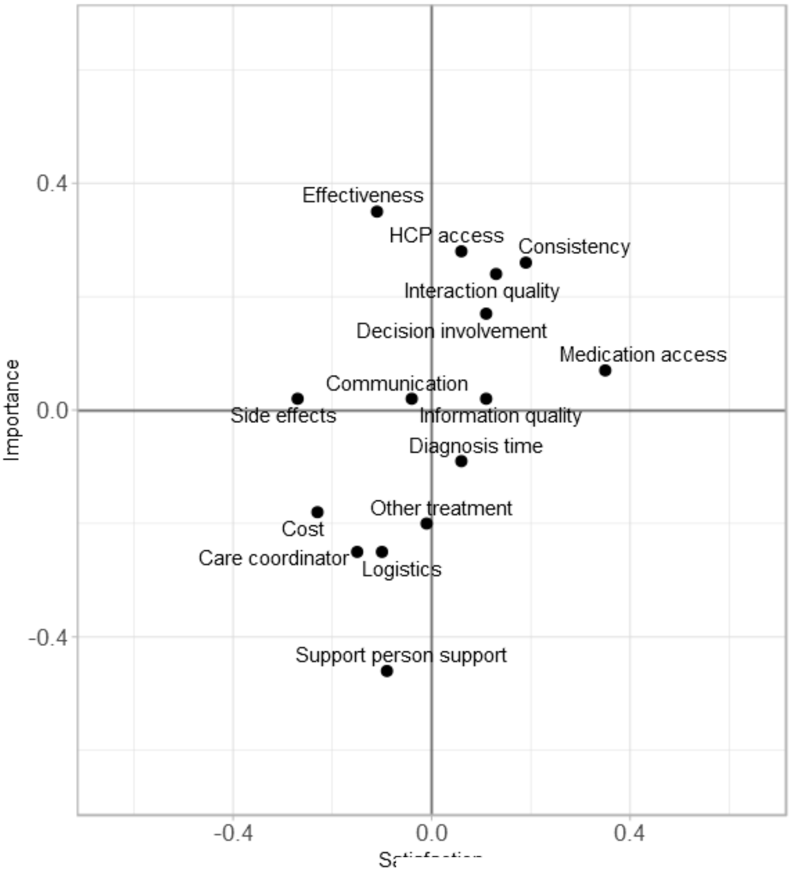


Figure 7. BWS quadrant map

Rescaled importance and satisfaction: patients

Figure 8 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 domains have been ordered from top to bottom by importance level, i.e., the most important domain appears at the top of the figure.

Overall patients found most domains to be at least somewhat important with only *Support person support* (4.2) scoring less than 5 out of 10. Three domains, *Effectiveness* (7.97), *HCP access* (7.58) and *Consistency* (7.54), appear to be especially important on average. *Interaction quality* (7.27) and *Decision involvement* (7.04) were also particularly important for patients.

Patients were least satisfied with *Side effects* (3.95) and *Cost* (4.11), with *Care Coordinator, Effectiveness* (4.45) *and Logistics* (4.68) following close behind. Satisfaction levels were lower than importance levels in all domains except *Support person support,* with particularly big gaps between importance and satisfaction in *Effectiveness, HCP access, Consistency, and Side effects*. Figure 9 illustrates the domains that were most important to patients, but that they were least satisfied with, combining the top 4 of each most important/least satisfied domain for each participant; *Effectiveness, Side effects* and *HCP access* came out on top.

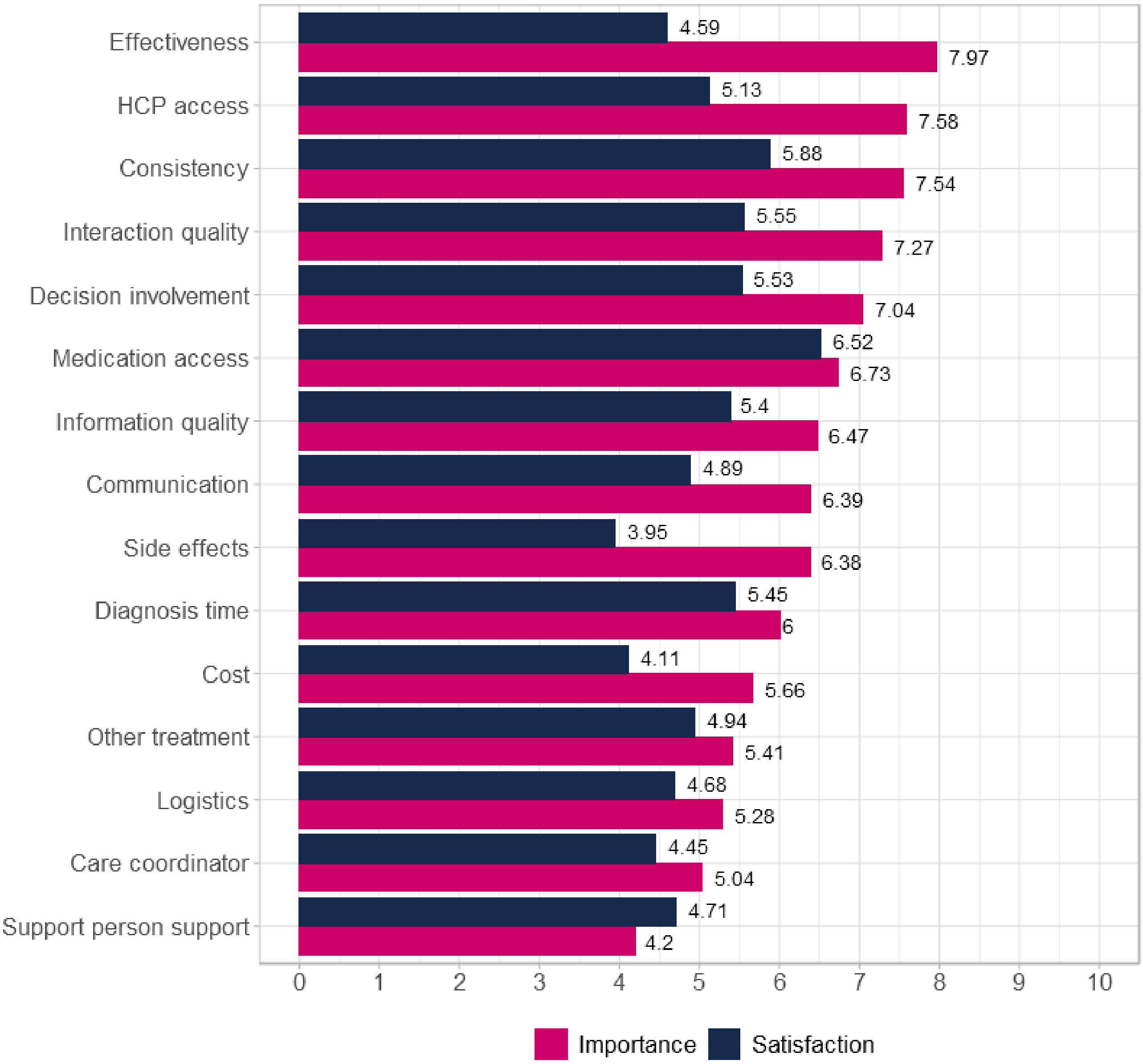


Figure 8. Rescaled importance and satisfaction

Improvements in satisfaction in *Effectiveness, HCP access, Consistency* (via implementation of successful program/ system changes, or improvement in medication effectiveness) would increase the HEI given they were rated as being the most important domains by patients. *Side effects* was not nominated as one of the most important domains, but it was still important, and improvements here could also increase the HEI.

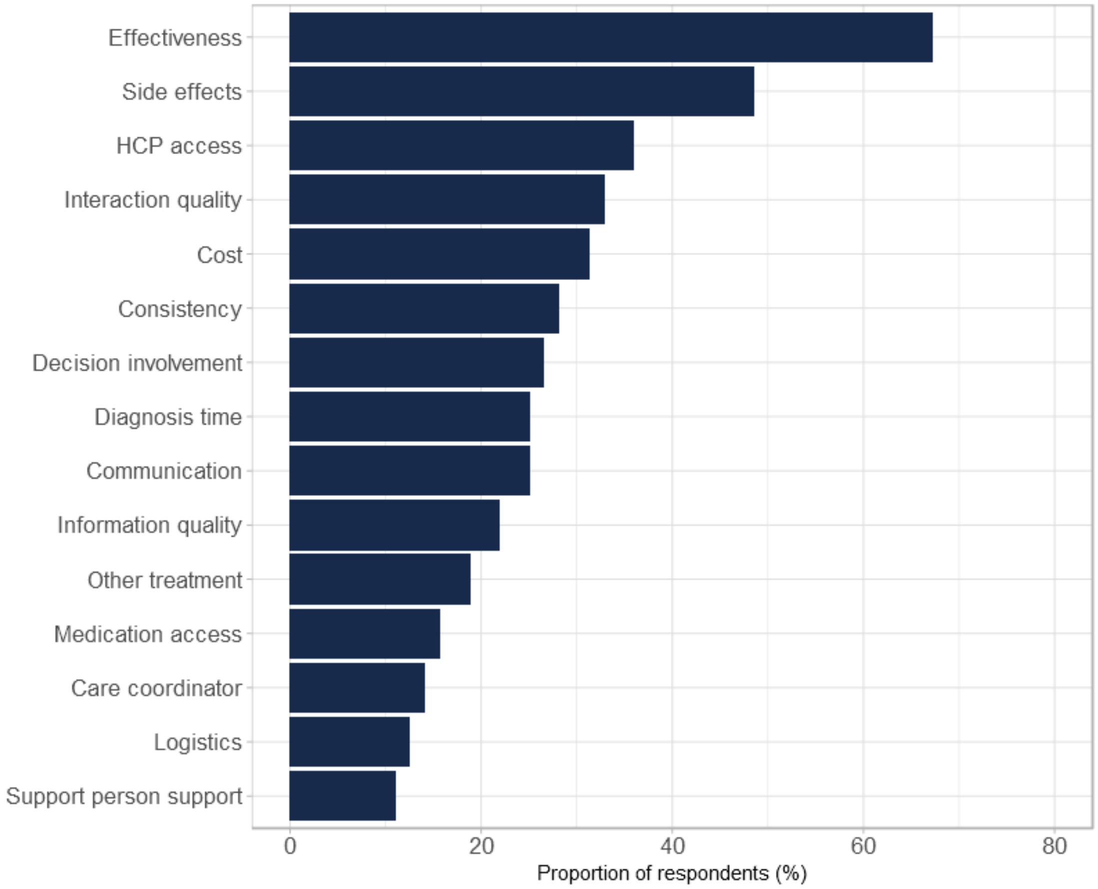


Figure 9. Top 4 least satisfied and most important domains

Conclusion

Findings from this research, combined with those from the stage one qualitative research, suggest a mix of medication and healthcare domains 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 domains to target

Least satisfied/most important

- Effectiveness of medication
- Side effects of medication
- Patient access to key HCPs

Biggest gaps between satisfaction and importance

- Effectiveness of medication
- Patient access to key HCPs
- Consistency of care - seeing same healthcare professional/care team
- Side effects of medication

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

Effectiveness of medication

More research into treatments was a common suggestion, along with treating the patient more holistically, so medication is just one element of the treatment, and alternative and supplementary therapies are discussed and considered. Other suggestions included genetic testing to ascertain which medications could be more effective for different people, and a more structured testing process to understand how well medications are actually working, or not.

Side effects of medication

Better communication from the HCPs prescribing the medication on the potential side effects; many patients felt they received little to no information on this. Patients also called for more understanding and empathy from their doctors when it came to the impact of side effects.

Patient access to key HCPs

There was an overriding call for an increase in the number of HCPs in the workforce, so patients can access a HCP on a regular basis, but also ad hoc in times of crisis/acute episodes.

Consistency of care - seeing same healthcare professional/care team

Staff shortages were reported as the main issue here; patients want to see more HCP in the system, and for them to stay in roles for longer periods.