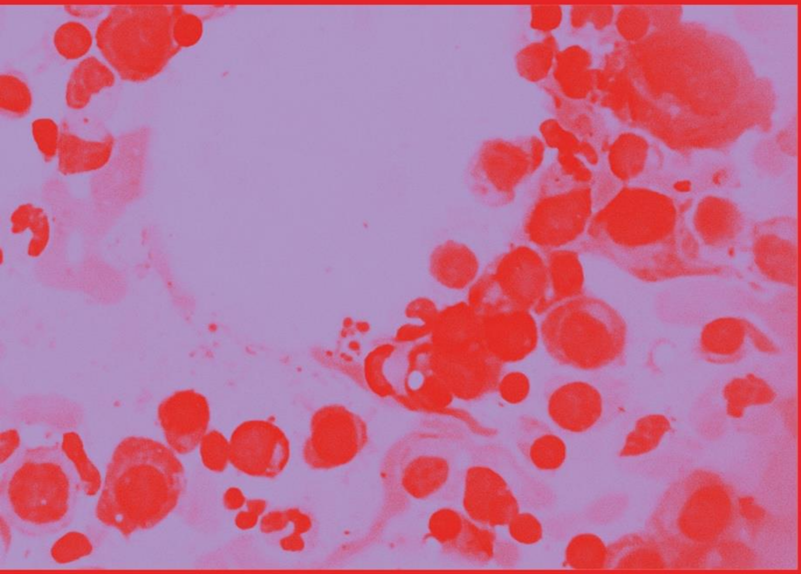
Quantitative short report



Multiple Myeloma

Patient Experience – Australia & New Zealand

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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 Multiple Myeloma 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, 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 Multiple Myeloma (MM) 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 MM 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).

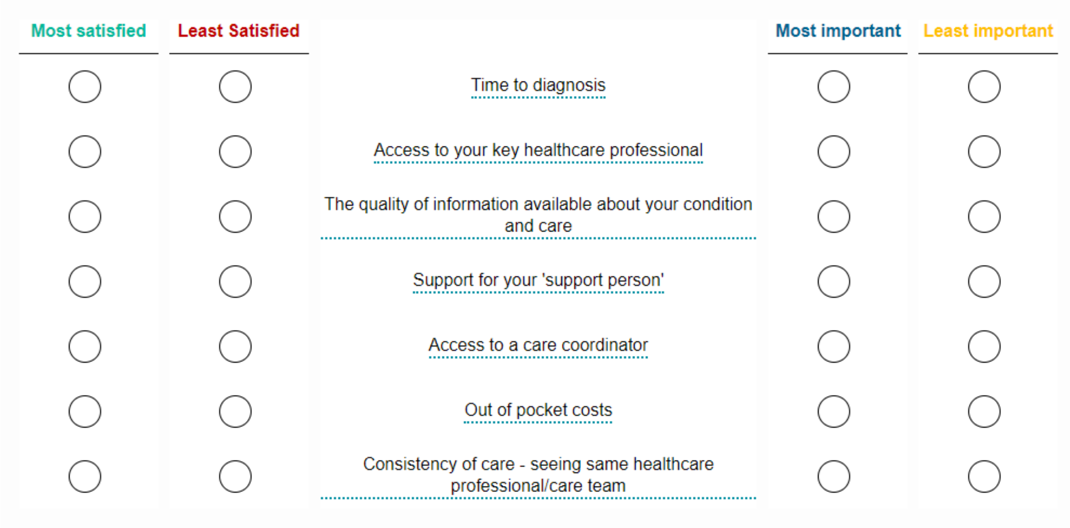
	DOMAIN	Description
1	**The quality of information available about your condition and care**	Having clear, concise, relevant information in a format that works for you (e.g., provided to you by your healthcare team/online/Apps/podcasts).
2	**Your involvement in decision making**	How involved you are in 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, haematologists, other specialists, pharmacists, care co-ordinators, nurses) 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 consultations, appointments, treatment sessions.
9	**Access to other treatments/services (holistic approach)**	Other treatments/services could include psychologists, exercise physiologists, physiotherapists, dieticians, support organisations (e.g., Myeloma Australia).
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., haematology nurse/specialist nurse or care-co-ordinator) 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., haematologist, clinical nurse specialist), 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

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 MM 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 groups, Myeloma Australia and Leukaemia & Blood NZ, as well as 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 07-Oct-2021 and 03-Dec-2021.

The findings

Demographic characteristics

Demographic characteristic	Patient (N=62) N (%)
Gender	
Female	30 (48)
Male	32 (51)
Non-binary/gender fluid	0 (0)
Age	
18-40	0 (0)
41-50	3 (4.84)
51-60	16 (25.81)
61-70	25 (40.32)
71-80	16 (25.81)
81 or older	2 (3.23)
Occupational status	
Working (full-time)	9 (14.52)
Working (part-time)	8 (12.90)
Working (casual)	1 (1.61)
Not working	4 (6.451)
Retired	36 (58.06)
Other	4 (6.45)
Ethnicity	
Australian	29 (46.77)
New Zealander	25 (40.32)
Pacific Islander	2 (3.23)
Middle Eastern	1 (1.61)
European	2 (3.23)
North American	2 (3.23)
Other	1 (1.61)
Location	
Metro/city	41 (66.13)
Regional	18 (29.03)
Rural	3(4.84)

Abbreviations: N – sample size.

Table 1. Basic demographic characteristics of patients

The characteristics of the participants are displayed in Table 1. Just over half of participants were male (48% female vs. 51% males). Two thirds were aged between 51 and 70 years old (66%), both younger and older groups were represented. Less than a third were working (either full-time or part-time) (27%). Roughly two-thirds of participants (66%) lived in metro areas, the remaining third lived in predominantly regional areas (29%).

Note, for Australia sample size was 33, for New Zealand 29, this denotes country of residence. Ethnicity is a measure of which ethnic group the patient identifies with; most identified as Australian (47%) or New Zealander (40%).

Treatment characteristics

Treatment profiles for patients are shown in Table 2. Two thirds of patients (66%) had received one or two lines of treatment. The majority of patients had received a stem cell transplant (75%), around half (51%) had not experienced a relapse.

Treatment characteristic	Patient (N=62) N (%)
Lines of treatment	
1 line of treatment	28 (45.16)
2 lines of treatment	13 (20.97)
3 or more lines of treatment	19 (30.65)
No treatment	1 (1.61)
Don’t know/unsure	1 (1.61)
Relapses	
0 relapses	34 (50.94)
1 relapse	12 (11.18)
2 relapses	6 (5.59)
3 relapses	1 (0.93)
4 relapses	2 (1.86)
5 relapses	0 (0)
6 relapses	1 (0.93)
Don't know/unsure	6 (11.32)
Stem cell transplant	
Stem cell transplant	46 (74.19)
No stem cell transplant	16 (25.81)

Abbreviations: N – sample size.

Table 2. Basic treatment characteristics

Characteristics of Care

Treatment setting

The majority of patients received treatment through the public healthcare system (70%), with only a small amount (11%) receiving treatment solely through the private system.

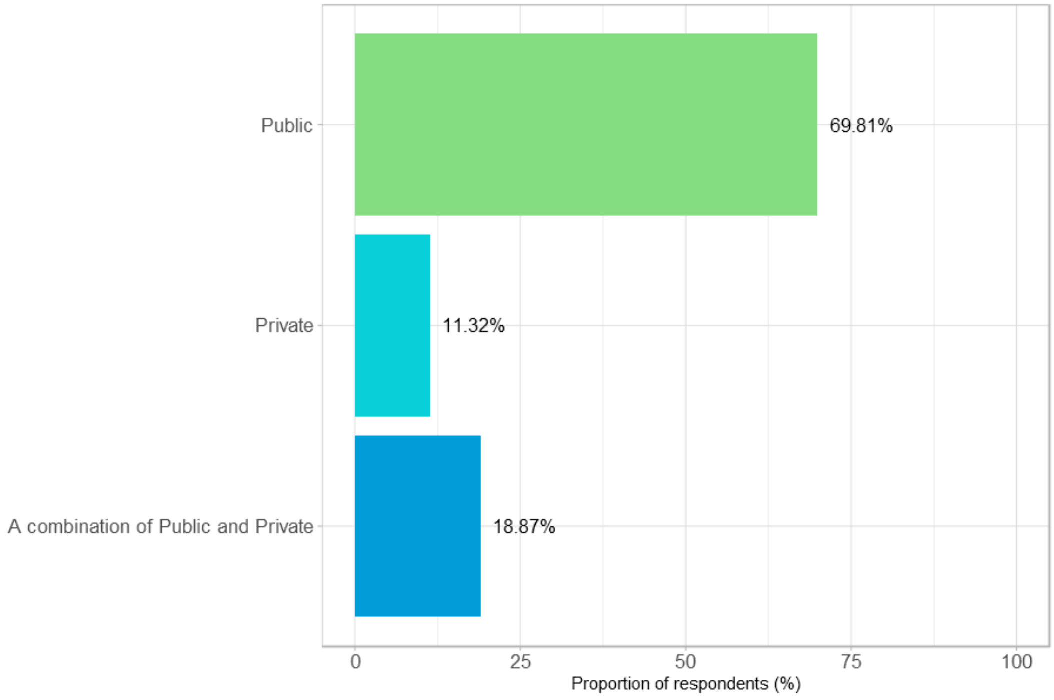


Figure 3. Treatment setting

Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with an average of $2164 annually. All other costs (visits to HCPs/ travel/ medication/ complementary treatments) were similar – ranging from $400 to $580.

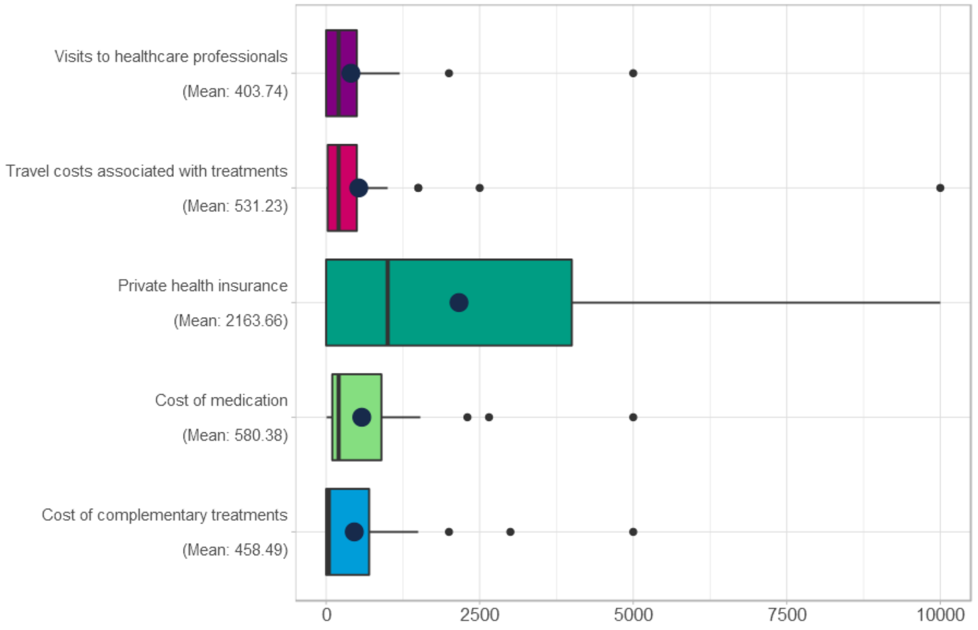


Figure 4. Treatment and care costs

Services experienced

None of the patients were supported by the National Disability Insurance Scheme (NDIS), whilst 3 New Zealanders received help from Disability Support Services. 29 patients across both countries had access to a care coordinator. Around 60% had been involved with/had experience with a patient advocacy

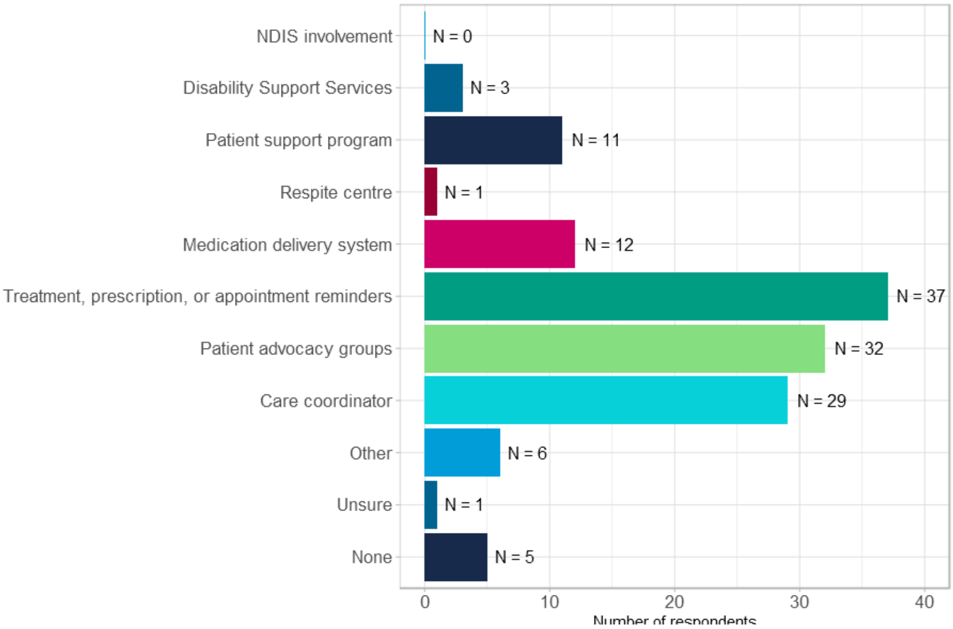


Figure 5. Services experienced

Importance & satisfaction

HEI: patients

The HEI for patients with MM, 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 MM HEI dashboard (link on page 15) for subgroups scores, e.g., by country/basic demographics.

	Mean	Median	Std. deviation
Health Experience Index	62.96	63.13	11.70

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.

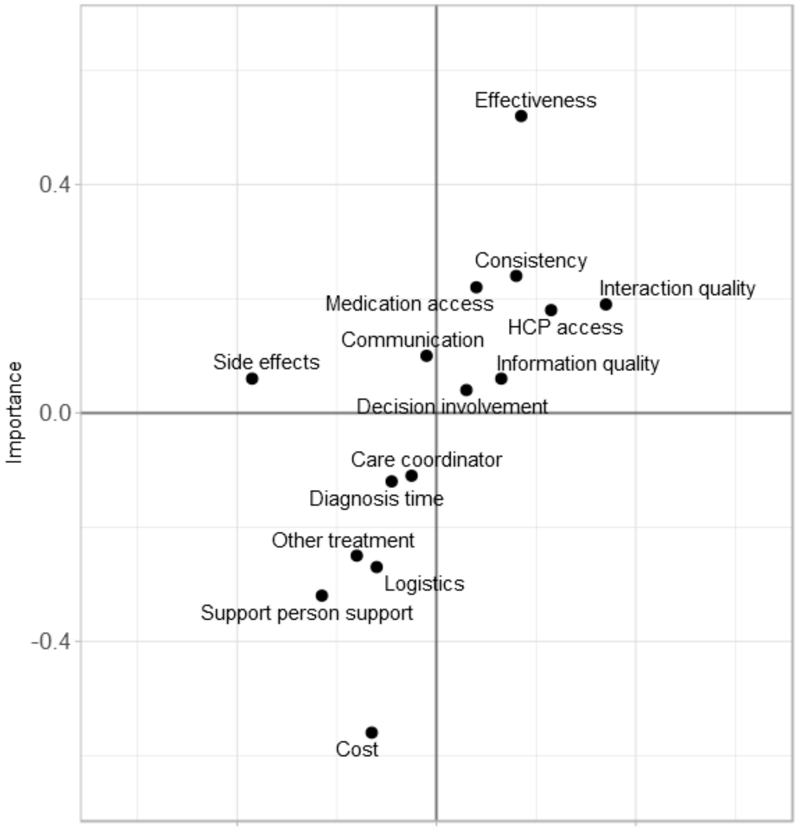


Figure 6. BWS quadrant map

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 (*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 *Care coordinator/Diagnosis time/Other treatment (holistic approach)/Logistics/ Support person support/Cost* have negative satisfaction scores, their importance scores are also negative indicating lower priority compared to other domains, namely *Effectiveness (of medication)/Consistency of Care/Interaction quality/Information quality/Decision involvement.*

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 *Other treatment* (4.97) *Support person support* (4.88) and Cost (3.66) scoring less than 5 out of 10. Five domains, *Effectiveness* (8.57), *Medication access* (7.52), *Consistency* (7.29), *HCP Access* (7.06) and *Interaction quality* (7.02), appear to be especially important on average. *Communication* (6.63), *Information quality* (6.6), *Decision involvement* (6.44) and *Side-effects* (6.4) were also important for patients.

Patients were least satisfied with *Side effects* (4.46) and *Support person Support* (5.28), with *Other treatment* (5.45) *and Cost* (5.6) following close behind. Satisfaction levels were lower than importance levels for just over half the domains. There are particularly big gaps between importance and satisfaction in *Effectiveness and Side effects,* although overall satisfaction for *Effectiveness* is relatively high (6.86). Satisfaction is also lower than importance for *Consistency, Medication Access, Communication and HCP Access.*

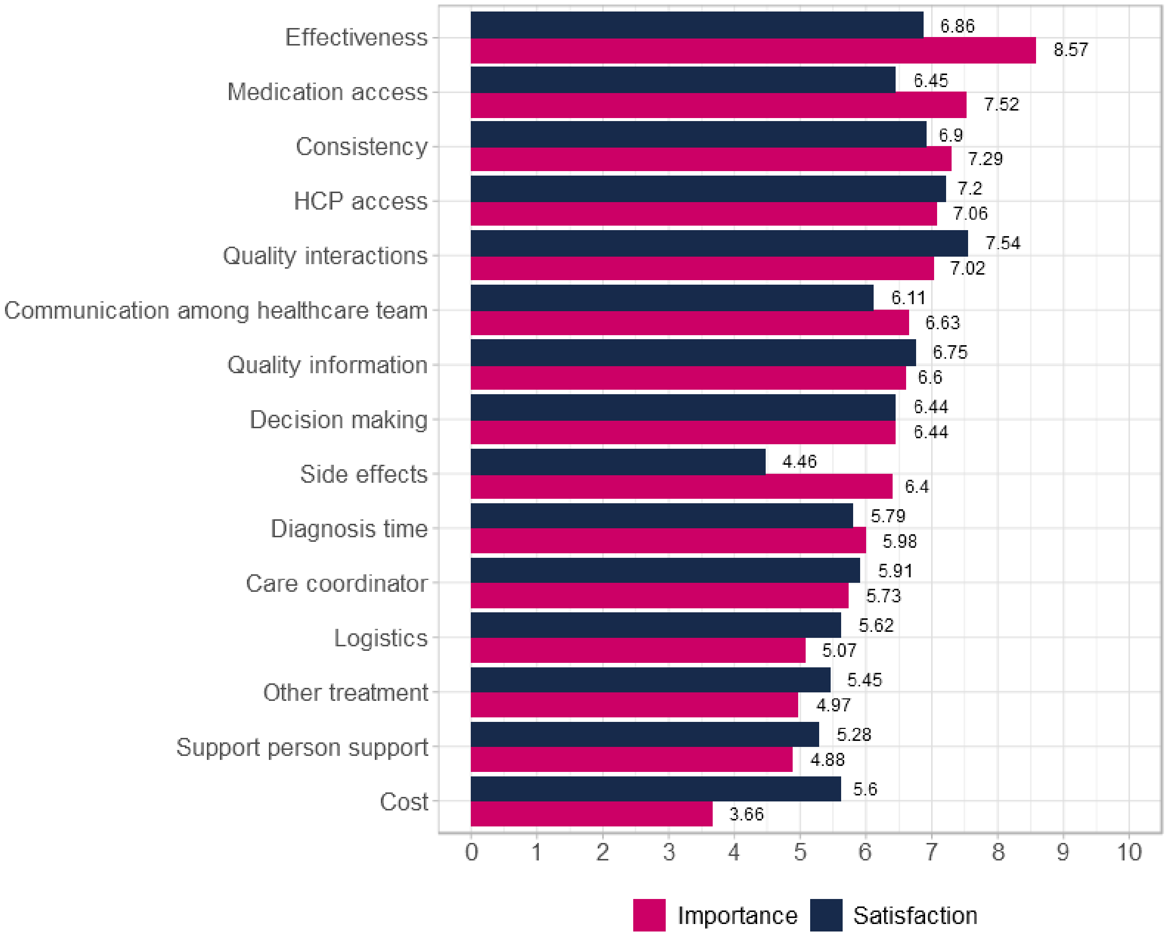


Figure 7. Rescaled importance and satisfaction

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; *Side effects, Effectiveness,* and *Medication access* came out on top.

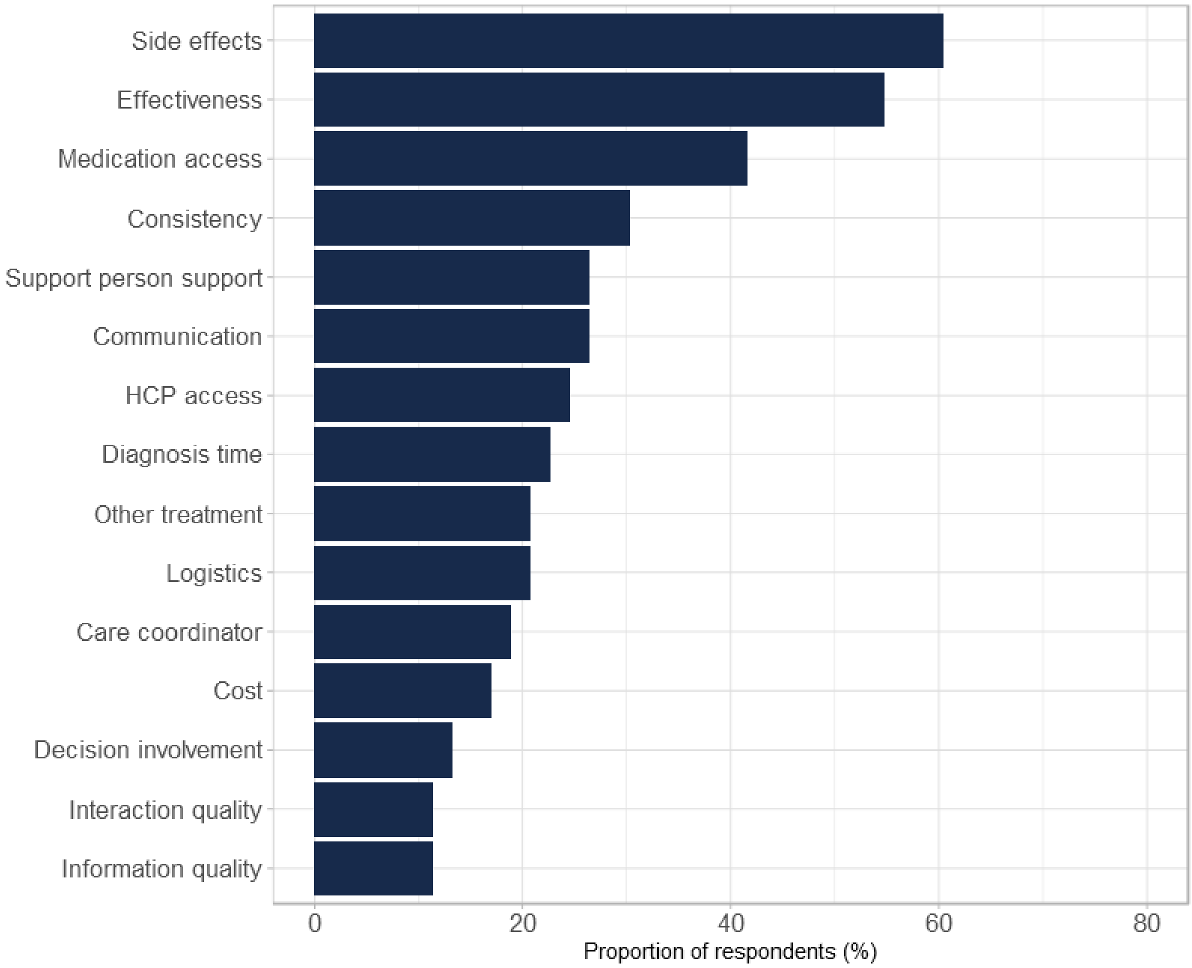


Figure 8. Top 4 least satisfied and most important domains

Improvements in satisfaction in *Effectiveness*, *Consistency*, *Medication access*, *Interaction quality*, and *HCP Access* (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 the gap between importance and satisfaction is large, so improvements here could also increase the HEI.

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

- Side effects of medication
- Effectiveness of medication
- Medication access

Biggest gaps between satisfaction and importance

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

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 an expansion on the funding for treatments and research. Better access to clinical trials in NZ was also called for, along with a more holistic approach to treatment to compliment medication.

Side effects of medication

Patients would, understandably, like treatments with fewer or no side-effects but they are realistic about what is achievable, and suggest more help with managing side-effects, e.g., ways to cope with fatigue and weight gain. Several mentioned the timing and order of medication they take making a difference to how they experience side effects, and they felt more could be done to get those things in alignment so as to reduce the impact of side effects.

Medication access

Patients in NZ report that their options are more limited than patients in other countries and they call for increased Pharmac funding and less of a delay between Government (Medsafe) approval and treatment availability.

Patient access to key HCPs

Several patients raised the need for better out of hours communication. One spoke about the importance of reallocating resources across the country (Australia), so regional, rural and remote areas are better served.

Consistency of care

Ideally, patients would like to see the same specialist and nurses, on-going, and suggest more funding in order to prevent high turnover of staff. A couple suggest the appointment scheduling could be improved, to help with consistency when seeing a specialist.

Communication between HCPs

Suggestions for improvement include granted access to centralised systems for all HCPs; scheduled GP and haematologist patient catch-up conversations (e.g., quarterly or half yearly); the allocation of a case manager who could be central point of call for everything.