Quantitative short report

Psoriatic Arthritis:

Patient Experience – Australia

Janssen-Cilag Pty Ltd. ABN 47 000 129 975. 1-5 Khartoum Road, Macquarie Park NSW 2113.
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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 Psoriatic Arthritis 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 task, 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 PsA 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 psoriatic arthritis 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)

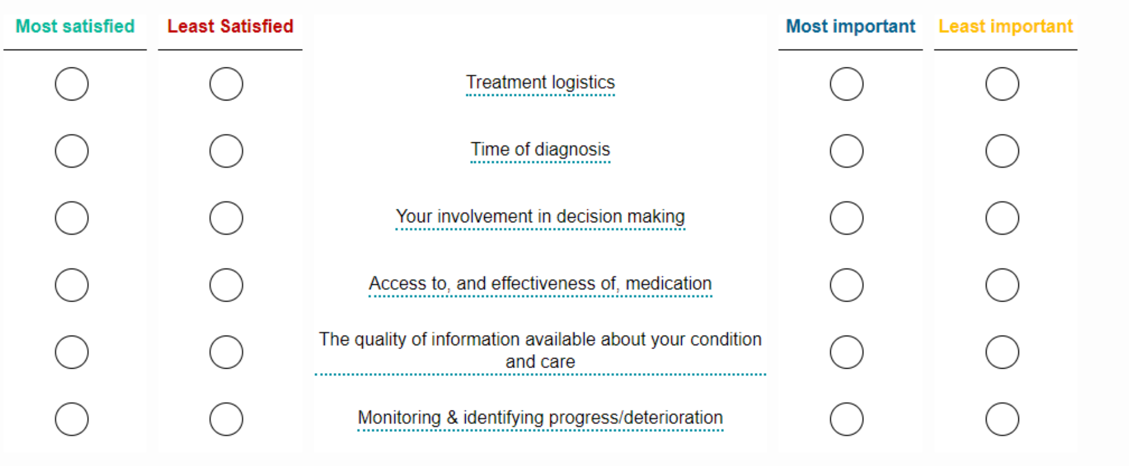
The BWS task used to measure the importance and satisfaction of the different aspects of the healthcare pathway was defined by a master list of 11 domains, or 'moments that matter' (MTM). The MTM were identified from qualitative research conducted with patients and secondary research from Janssen ANZ. A summary of the MTM can be found in Figure 1 and on the dashboard info tab (see page 14 for more information).

	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., rheumatologist and dermatologists), 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., rheumatologist/GP/clinical nurse specialist) 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) 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)**	- Other services could include seeing a psychologist or exercise physiologist. Complementary treatments could include massage, balneotherapy and management strategies for increased wellness (e.g., access to dietitian/exercise physiologist/occupational therapists). - Having 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.
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	**Psoriatic Arthritis-related costs**	- The overall impact that having Psoriatic Arthritis has on your financial wellbeing, e.g., how much you are out-of-pocket, and the impact of loss of income.

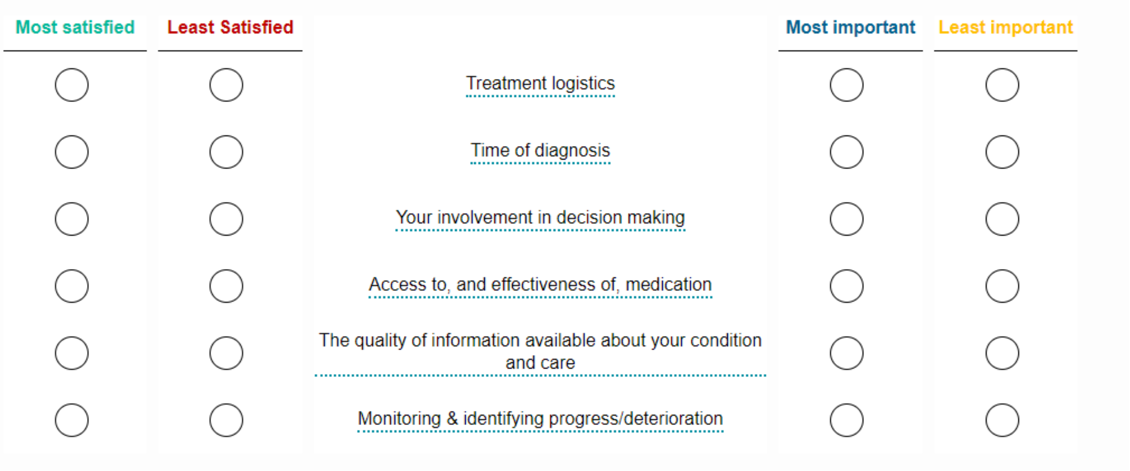
Figure 1. PEI MTM and descriptions

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 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	○	○
○	○	The quality of information available about your condition and care	○	○
○	○	Monitoring & identifying progress/deterioration	○	○

Figure 2. Screenshot of BWS task



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

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”

Health 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 PsA 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

Patients were recruited through a panel company and with help from the patient support group, CreakyJoints. 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 12-May-2022 and 14-June-2022.

The findings

Demographic characteristics

Table 1. Basic demographic characteristics of patients

Demographic characteristic	Patient (N=53) N (%)
Gender	
Female	16 (30.19)
Male	30 (56.6)
Non-binary/gender fluid	0 (0)
Prefer not to answer	7 (13.21)
Age	
18-29	2 (3.77)
30-39	5 (9.43)
40-49	18 (33.96)
50-59	8 (15.09)
60-69	15 (28.3)
70-79	3 (5.66)
80 or older	1 (1.89)
Prefer not to answer	1 (1.89)
Occupational status	
Working (full-time)	16 (30.19)
Working (part-time)	9 (16.98)
Working (casual)	3 (5.66)
Student	0 (0)
Not working	7 (13.21)
Home duties and/or caring responsibilities	2 (3.77)
Retired	9 (16.98)
Other	2 (3.77)
Prefer not to answer	5 (9.43)
Ethnicity	
Australian	45 (84.91)
Cook Islander	1 (1.89)
Asian	2 (3.77)
European	4 (7.55)
Other	1 (1.89)
Location	
Metro/city	35 (66.04)
Regional	11 (20.75)
Rural	7 (13.21)

Abbreviations: N – sample size.

The characteristics of the participants are displayed in Table 1. Over half of participants identified as male (57%). The majority were aged over 49 (83%), with a third in the 50-59 age category. Over half were working (53%), either full-time, part-time, or casually. Participants were split two third vs. a third between metro and rural/regional areas (66% vs. 34% respectively).

Disease and treatment characteristics

Disease and treatment profiles for patients are shown in Table 2. Almost half of participants were in the 'long-term/active/progressed' PsA stage (49%). The majority report taking medication, at the time of the survey (81%).

Treatment characteristic	Patient (N=53) N (%)
PsA stage	
Pre-clinical	3 (5.66)
Early stage	10 (18.87)
Long-term/active/progressed	26 (49.06)
Remission/minimal disease activity	3 (5.66)
Other	1 (1.89)
Don't know	10 (18.87)
Medication status	
Currently taking medication to treat PsA	43 (81.13)
Not currently taking medication to treat PsA	7 (13.21)
Never taken medication for PsA	1 (1.89)
Don't know/unsure	2 (3.77)
Administration type – ever taken (muti-selection question)	
Oral (swallowed by mouth in pill or tablet form)	44 (88)
Injection under the skin	25 (50)
Intravenous infusion	6 (12)
Other	0 (0)
Don't know/unsure	3 (6)

Abbreviations: N – sample size.

Table 2. Basic disease and treatment characteristics

Characteristics of Care

Treatment Setting

Participants were treated across public and private settings; with third (34%) reporting having been treated in a combination of public/private settings. 42% of participants reported being treated in private settings.

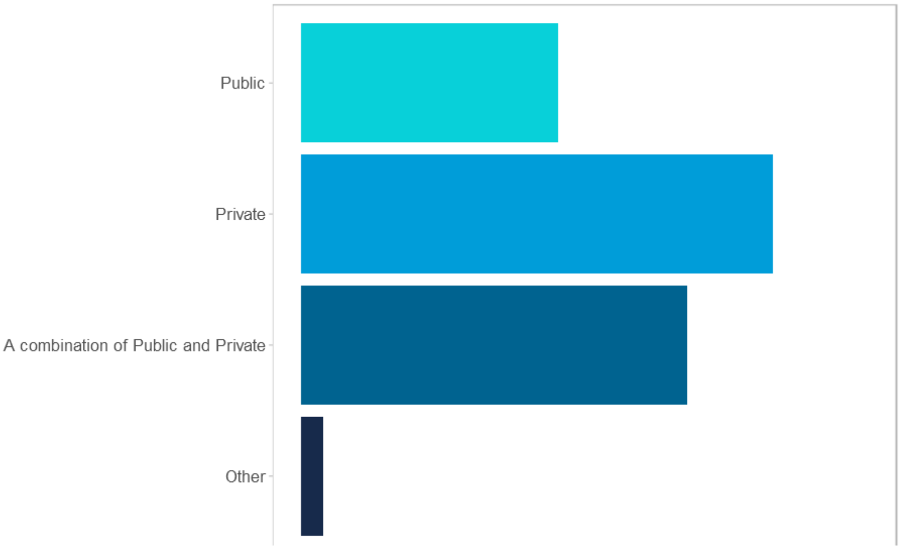

Figure 3. Treatment setting

Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with a mean of $5,584 annually.

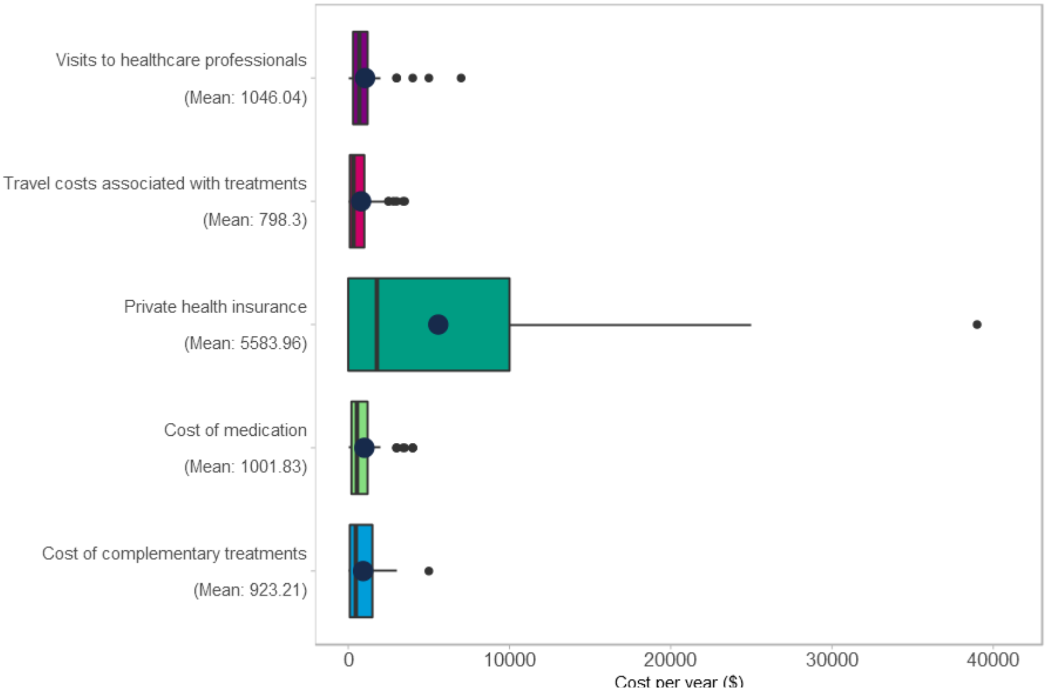

Figure 4. Treatment and care costs

Services Experienced

Several participants (18) have made use of mainstream medical services, e.g., treatment/prescription/ appointment reminders.
10 participants have been involved with/have experience with a patient advocacy group.

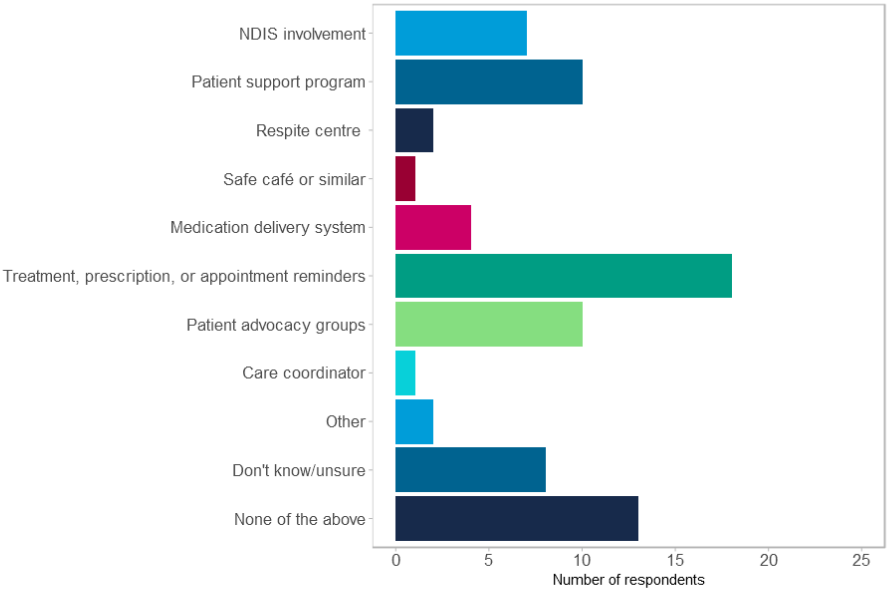

Figure 5. Services experienced

Importance & Satisfaction

PEI: Patients

The PEI for patients with PsA, 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 PEI to assess shifts in satisfaction and importance ratings, especially if programs are implemented to address specific patient groups. Please see the PsA PEI dashboard (link on page 14) for subgroups scores, e.g., by basic demographics.

Table 3. Patient Experience Index score

	Mean	Median	Std. deviation
Patient Experience Index	68.40	70.02	20.71

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 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. The MTM in the upper left quadrant (*Access to other treatment/services*) is rated high on importance but low on satisfaction. Improvements in satisfaction in this MTM may result in considerable improvements in overall satisfaction. While *Side effects, Cost, Diagnosis time, logistics, Support person support* have negative satisfaction scores, their importance scores are also negative indicating lower priority compared to other MTM, namely *Healthcare team quality, Effectiveness, Monitoring, Information quality.*

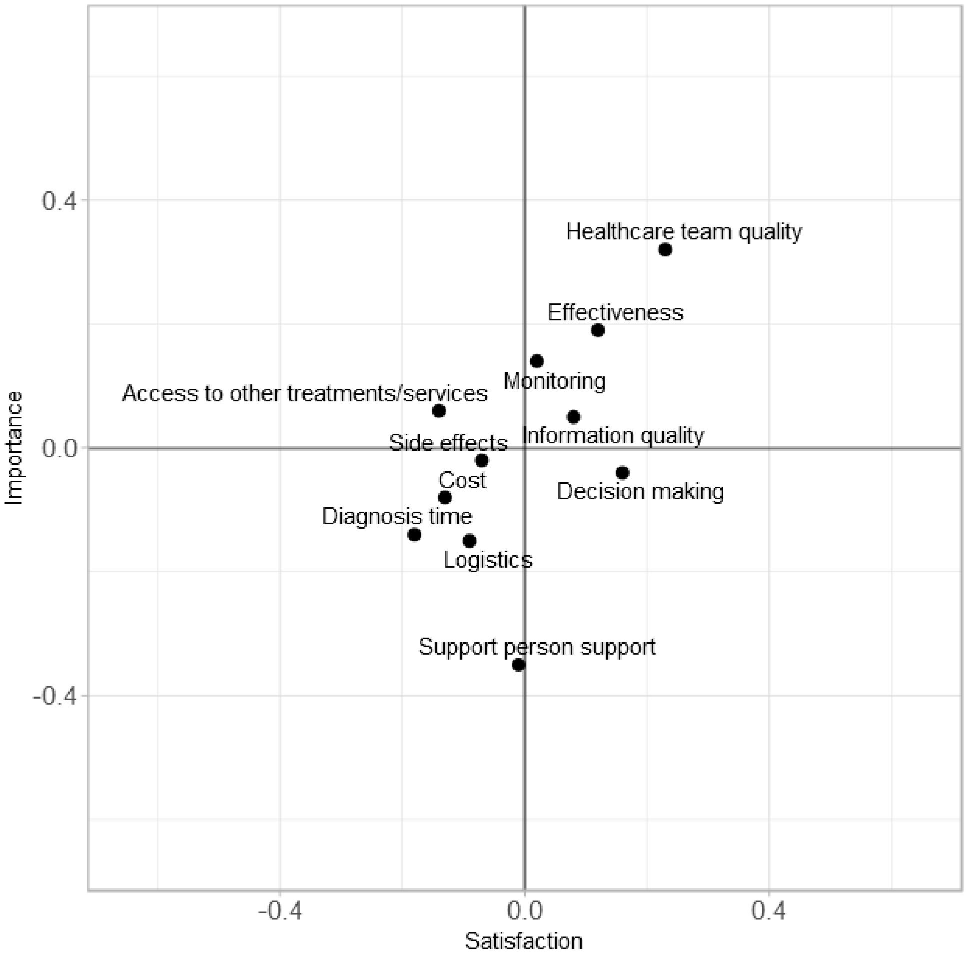

Figure 6. BWS quadrant map

Rescaled importance and satisfaction: patients

Figure 7 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 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. Four MTM, *Healthcare team quality* (8.73), *Effectiveness* (8.52), *Monitoring* (8.32), and *Information quality* (8.13), appear to be especially important, on average. With the exception of *Support person support* (6.6), the other MTM did also score highly; *Side effects* (7.88), *Access to other treatments and services* (7.81), *Decision making* (7.8), *Cost* (7.77), *Diagnosis time* (7.67), and *Logistics* (7.51).

Patients were least satisfied with *Access to other treatments/services* (6.26) and *Diagnosis time* (6.27), with *Cost* (6.52) and *Side effects* (6.6) following close behind. Satisfaction levels were lower than importance levels all MTM except *Support person support*. The biggest gaps are between importance and satisfaction in *Monitoring, Access to other treatments/services* and *Healthcare team quality.*

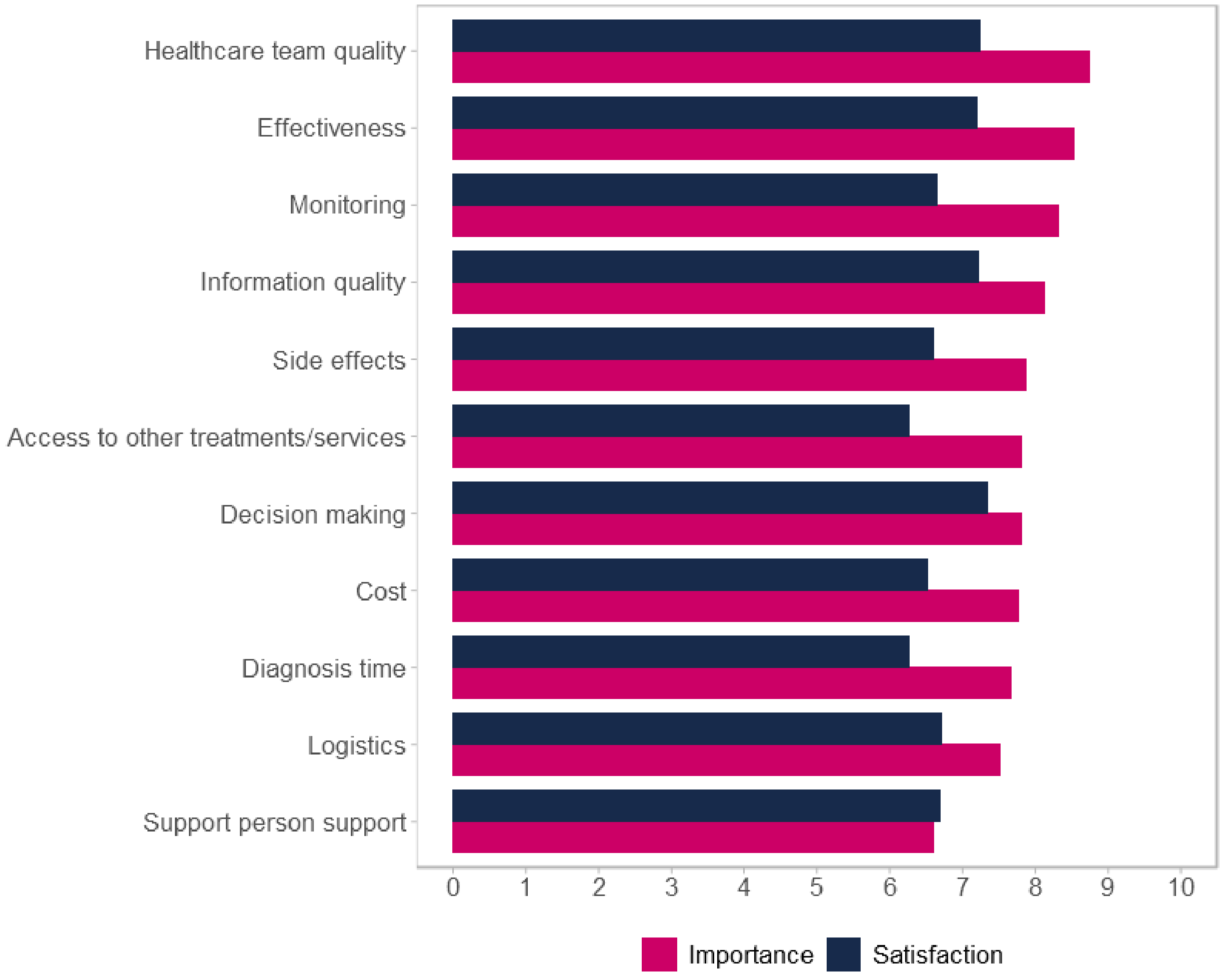

Figure 7. Rescaled importance and satisfaction

Figure 7. Rescaled importance and satisfaction

Figure 8 shows 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; *Access to other treatments/services, Monitoring, Cost* and *Diagnosis time* came out on top. Improvements in satisfaction of these MTM (via implementation of successful program/ system changes, or improvement in medication effectiveness) may increase the PEI.

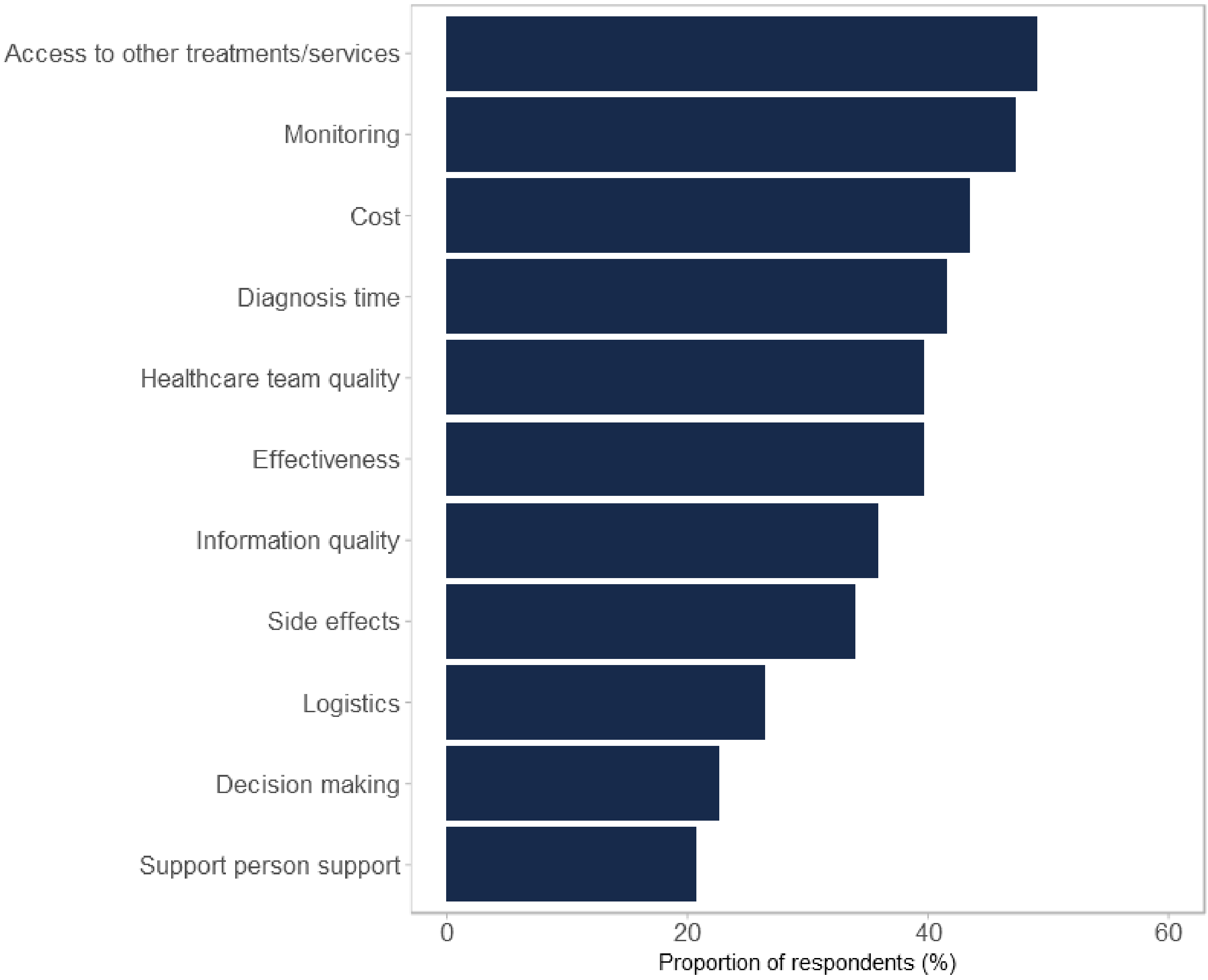

Figure 8. Top 4 least satisfied and most important MTM

Conclusion

Findings from this research, combined with those from the stage one qualitative 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

- Healthcare team quality
- Access to other treatment/services
- Side effects
- Information quality

Biggest gaps between satisfaction and importance

- Monitoring
- Access to other treatments/services
- Healthcare team quality

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

Healthcare team quality

Suggestions were wide ranging but there was a focus on improvements in access to HCPs (e.g., access to consistent care, ability to access a HCP during severe flare-ups) along with consistent care and better communication between treating HCP (e.g., communication between the rheumatologists and the GPs). Some patients suggested that healthcare professionals need to be more caring, compassionate, and understanding as they felt they can lack empathy.

Side effects

Patients would like to receive transparent and up to date information on side effects of medications. Some suggested receiving support along the way from HCPs on how to deal with side effects.

Information quality

Patients would like to have access to information that is more specific to their condition, current information is often generalised. Patients desire more direction on where they can find information on their disease area, e.g., signposting to websites. Some suggested having more accessible written information, e.g., pamphlets/information sheets that can be picked up at the doctors and pharmacies.

Monitoring

Patients would like to track and monitor their own progress and/or deterioration; they would like help and support with this, including how to make changes to improve physical health and mental wellbeing. Some would like tools to be recommended to them (e.g., Apps) to assist with monitoring their own health.

Access to other treatments/services

Patient’s call for Increased access to complementary treatments/services/therapies and care coordinators, as well as better information on how to access these services. Several patients report having to research and access complementary treatments and services themselves, which they then have to self-fund.