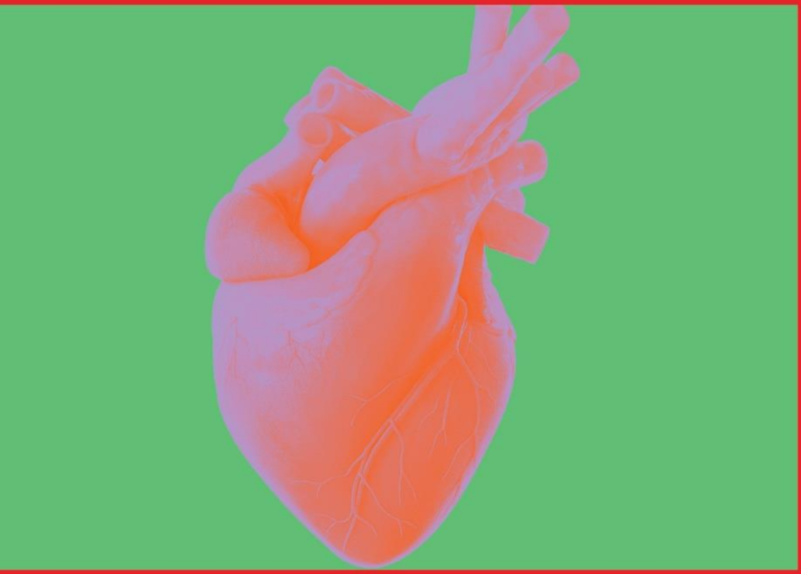
Quantitative short report



# Pulmonary Arterial Hypertension:

## Patient Experience – Australia

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# Acknowledgements

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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 PAH 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 PAH 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 PAH 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. The domains were identified from qualitative research conducted with patients and secondary research from Janssen ANZ. 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** | **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 – including, 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., cardiologist/pulmonologist), at regular intervals that you feel are most beneficial to you or in acute situations where urgent access is required.<br>• Being able to see the same trusted healthcare professional/s on-going for your treatment and care.<br>• How well your needs are met in any interactions with your healthcare team (including doctors, nurses, care coordinators).<br>• The extent to which different members of your healthcare team (e.g., cardiologist/pulmonologist/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.<br>• 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., blood pressure/weight/mood/pressure in arteries) 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 prescribed exercise, talking therapies, and management strategies for increased wellness (e.g., access to dietitians/physiotherapists/occupational therapists/psychologists).<br>- 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 | **Pulmonary arterial hypertension related costs** | - The overall impact that having pulmonary arterial hypertension has on your financial wellbeing, e.g., how much you are out-of-pocket, and the impact of loss of income |

*Figure 1. HEI domains and descriptions*

The domains 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 domains (i.e., participants were shown 6 of the 11 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 |
|---|---|---|---|---|
| ○ | ○ | 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*

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 PAH in ANZ. The HEI is a combined score of the 11 BWS domains, accounting for both satisfaction and importance, and ranges from 0 to 100.

## Participants

Patients were recruited through the patient support group, PHAA. 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 18-Nov-2021 and 26-Dec-2021.

# The findings

## Demographic characteristics

*Table 1. Basic demographic characteristics of patients*

| Demographic characteristic | Patient (N=39) N (%) |
|---|---|
| **Gender** | |
| Female | 36 (92.5) |
| Male | 3 (7.5) |
| **Age** | |
| 18-30 | 3 (7.69) |
| 31-40 | 7 (17.95) |
| 41-50 | 11 (28.21) |
| 51-60 | 6 (15.38) |
| 61-70 | 5 (12.82) |
| 71-80 | 7 (17.95) |
| 81 or older | 0 (0) |
| **Occupational status** | |
| Working (full-time) | 9 (23.08) |
| Working (part-time) | 7 (17.94) |
| Not working | 4 (10.26) |
| Home duties and/or caring responsibilities | 4 (10.26) |
| Retired | 11 (28.21) |
| Other | 4 (10.26) |
| **Ethnicity** | |
| Australian | 28 (71.80) |
| New Zealander | 3 (7.69) |
| Indigenous Australian or Torres Strait Islander | 1 (2.56) |
| Asian | 1 (2.56) |
| Indian | 1 (2.56) |
| European | 5 (2.56) |
| Other | 0 (0) |
| **Location** | |
| Metro/city | 17 (43.59) |
| Regional | 11 (28.21) |
| Rural | 11 (28.21) |

*Abbreviations: N – sample size.*

The characteristics of the participants are displayed in Table 1. PAH affects more females than males and the majority of participants were female (92.5%). Participants spanned age categories 18-30 through to 71-80, the largest category represented was 41-50 (28%). Over a third of participants were working, either full-time or part-time (41%). Participants were split between metro and rural/regional areas (44% vs. 56% respectively).

### Treatment Characteristics

Treatment profiles for patients are shown in Table 2. Whilst nearly half of participants were unsure of the stage of their PAH (46%), those that were able to report this were spread relatively evenly across stages 1 – 4. Nearly two-thirds of participants reported that their PAH was idiopathic (62%).

*Table 2. Basic treatment characteristics*

| Treatment characteristic | Patient (N=39) N (%) |
|---|---|
| PAH stage | |
| Functional Class 1 | 5 (12.82) |
| Functional Class 2 | 7 (17.95) |
| Functional Class 3 | 5 (12.82) |
| Functional Class 4 | 4 (10.26) |
| Don't Know | 18 (46.15) |
| PAH subtype | |
| Congenital Heart Disease PAH | 6 (15.38) |
| Connective Tissue Disease PAH | 5 (12.82) |
| Heritable PAH | 1 (2.56) |
| Idiopathic PAH | 24 (61.54) |
| Paediatric PAH | 1 (2.56) |
| Other | 2 (5.13) |

*Abbreviations: N – sample size.*

## Characteristics of Care

### Treatment Setting

Over half of patients received treatment through the public system (54%). Less than a fifth were treated through the private system only (18%).

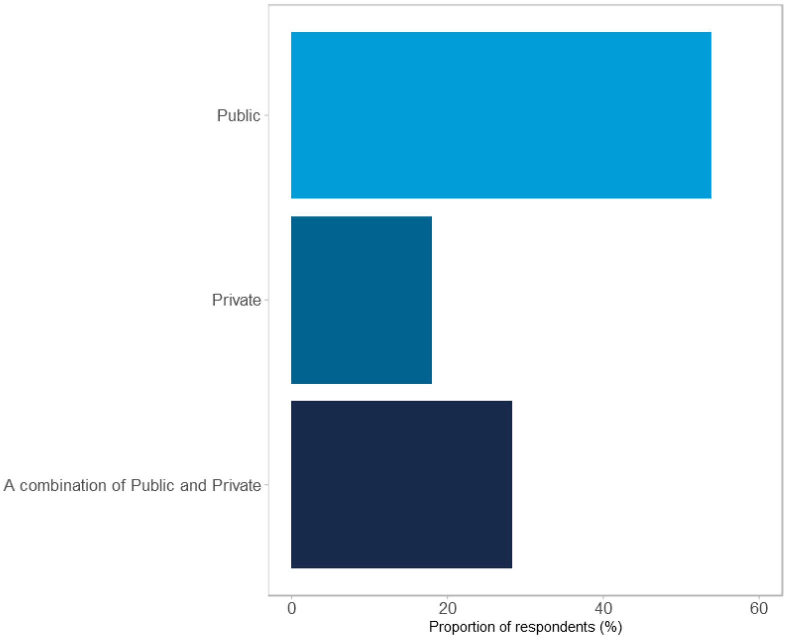

*Figure 3. Treatment setting*

## Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with an average of $1888 annually. This was followed by the cost of medication at $1599 annually.

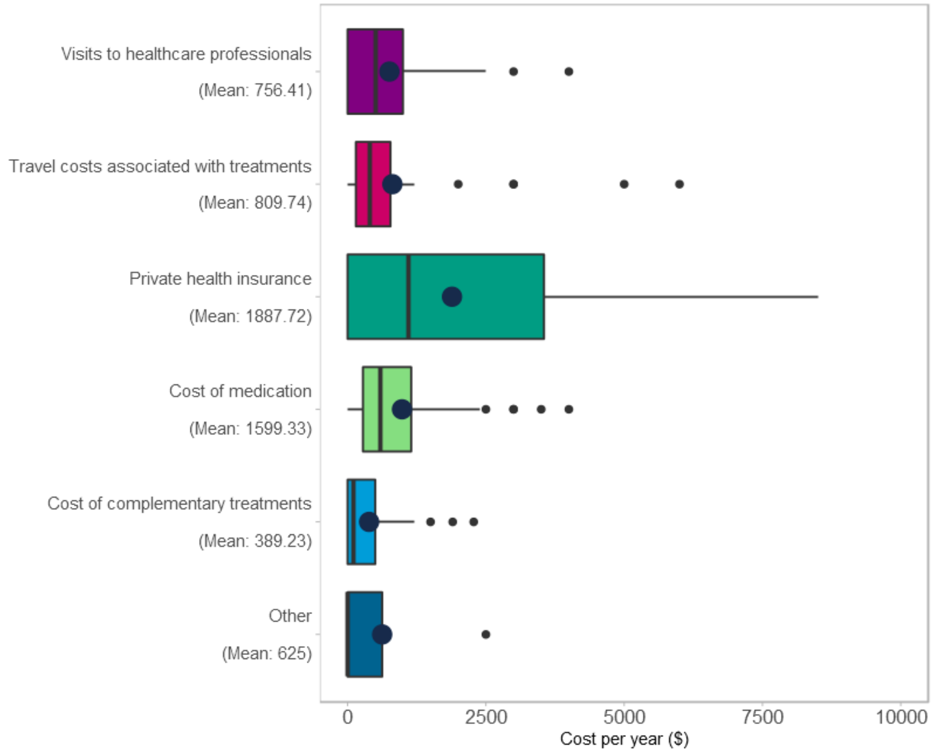

*Figure 4. Treatment and care costs*

## Services Experienced

Many participants have made use of mainstream medical services, e.g., 29 participants have used medication delivery; 18 have used reminder services. Over a third (14 participants) have been involved with/had experience with a patient advocacy group (36%). However, other services were not widely used/experienced within this patient group.

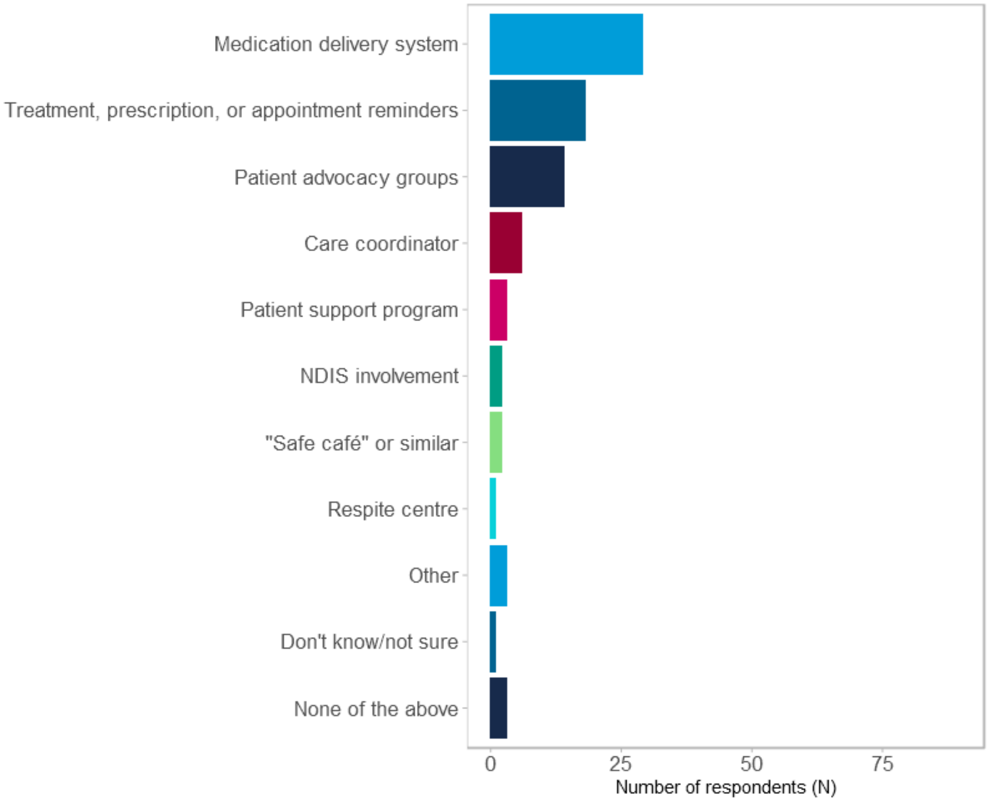

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*Figure 5. Services experienced*

# Importance & Satisfaction

## HEI: Patients

The HEI for patients with PAH, 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 PAH HEI dashboard (link on page 14) for subgroups scores, e.g., by basic demographics.

*Table 3. Table 3. Patient HEI score*

| | Mean | Median | Std. deviation |
|---|---|---|---|
| **Health Experience Index** | 63.32 | 63.20 | 18.30 |

## 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 11 domains in terms of satisfaction and importance simultaneously.

Figure 6 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. The domain in the upper left quadrant (*Access to other treatment/services*) is rated high on importance but low on satisfaction. Improvements in satisfaction in this domain may result in considerable improvements in overall satisfaction. While *Information quality/Time to diagnosis/Side effects/Logistics/Support person support* have negative satisfaction scores, their importance scores are also negative indicating lower priority compared to other domains, namely *Healthcare team quality/Effectiveness/Monitoring/ Access to other treatment/services.*

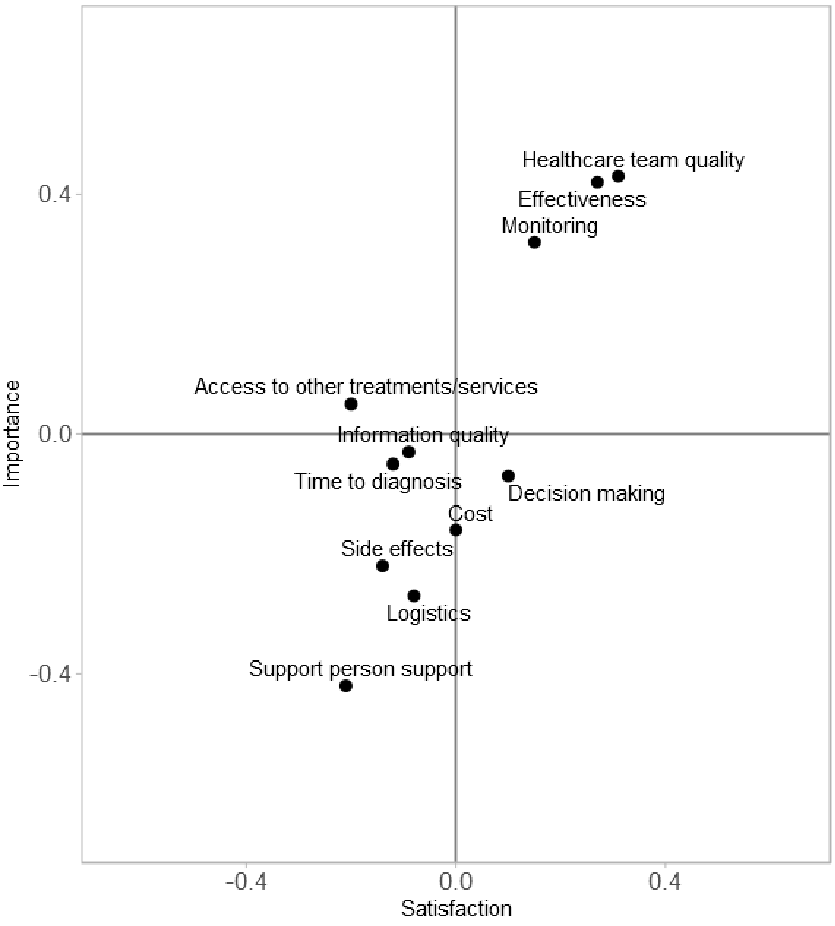

*Figure 6. BWS quadrant map*

## 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 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.

All domains were at least somewhat important to patients; *Effectiveness* (8.9), *Healthcare team quality* (8.89), *Monitoring* (8.49), *Access to other treatment/services* (7.63) *and Information quality (7.38)* appear to be especially important, on average. Followed closely by *Decision making* (7.37) and *Time to diagnosis* (7.36).

Patients were least satisfied with *Access to other treatment/services* (5.53), *Support person support* (5.63) and *Time to diagnosis* (5.9) following close behind. The biggest gap between importance and satisfaction was in *Access to other treatment/services,* there were also noticeable gaps between importance and satisfaction in *Effectiveness, Healthcare team quality, Time to diagnosis* and *Monitoring.*

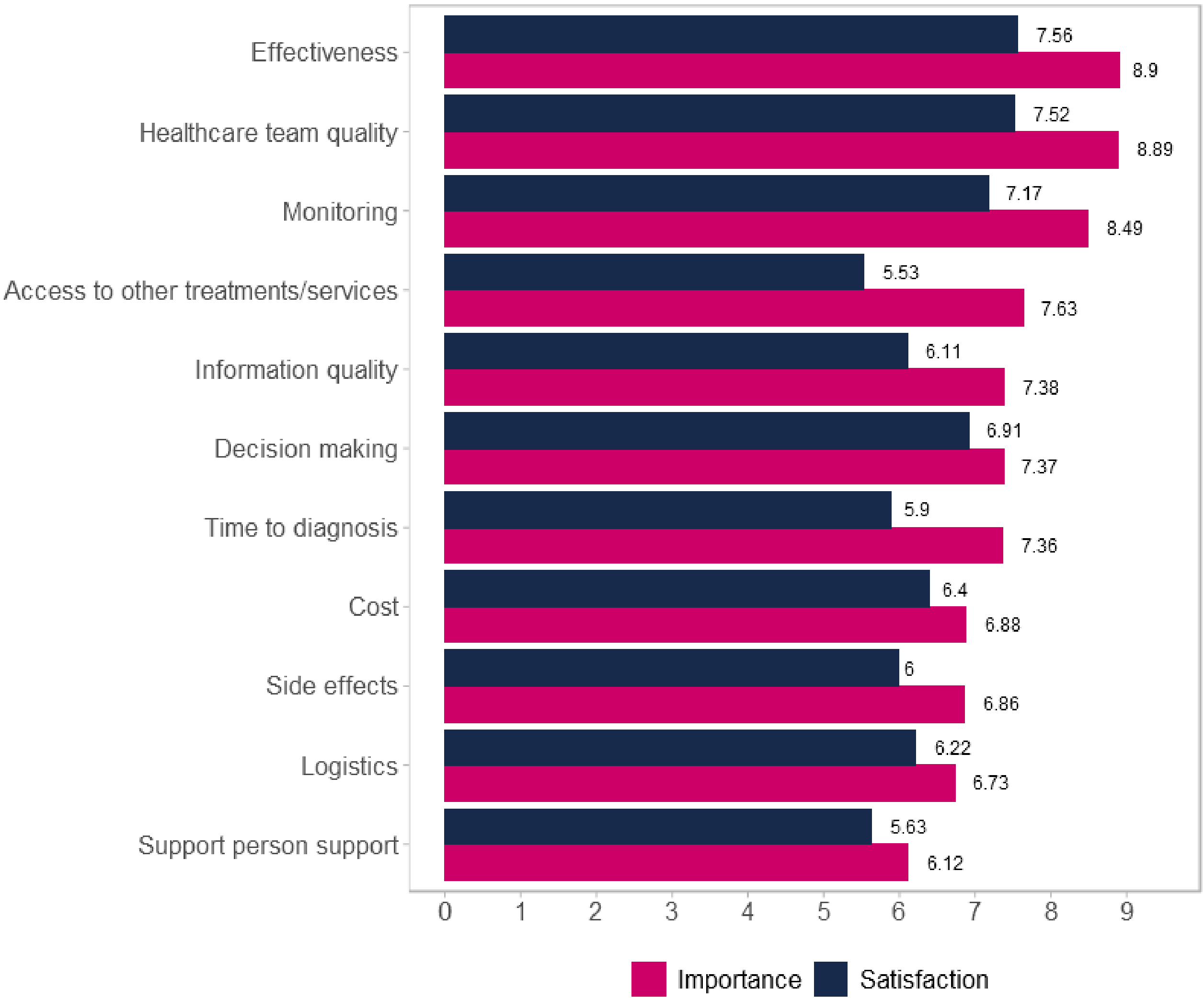

*Figure 7. Rescaled importance and satisfaction*

Figure 8 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; *Access to other treatment/services, Time to diagnosis, Information quality* and *Healthcare team quality* came out on top. Improvements in satisfaction in these domains, along with *Effectiveness* and *Monitoring* (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.

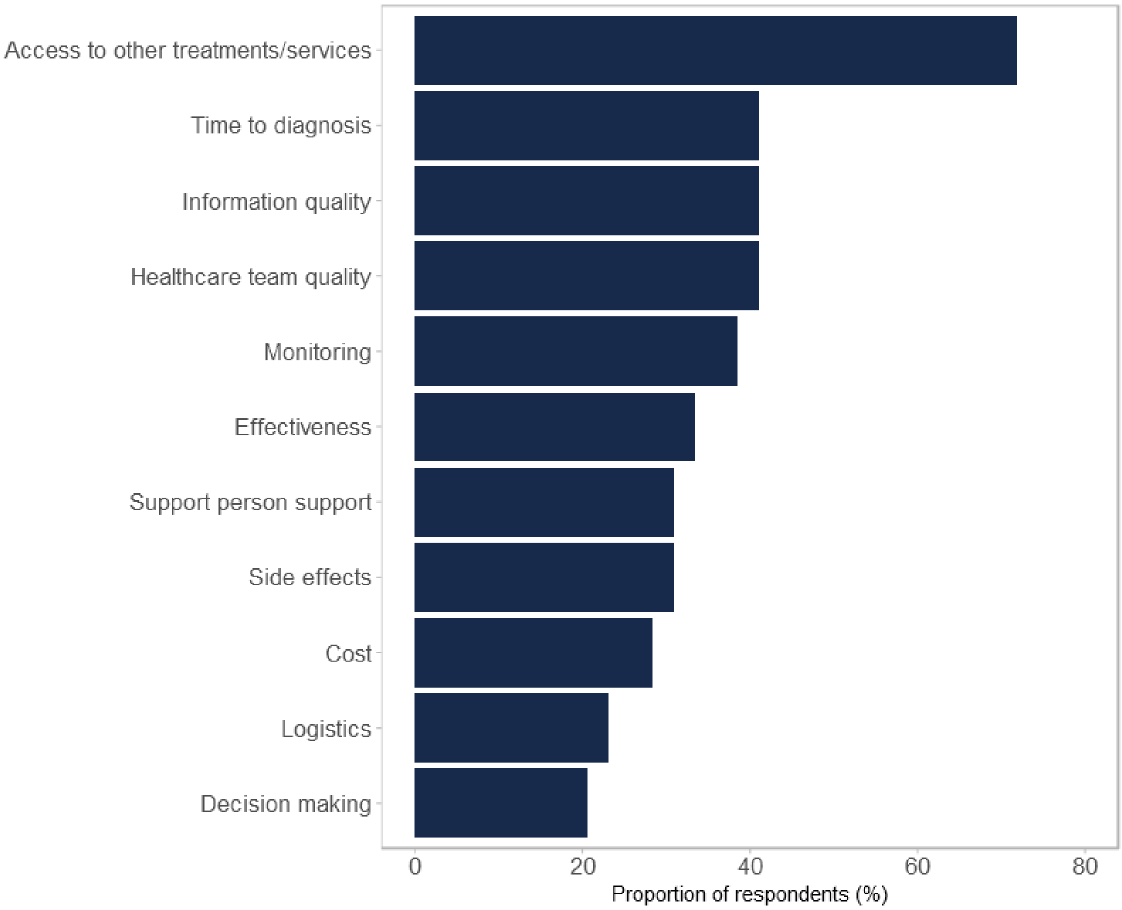

*Figure 8. Top 4 least satisfied and most important domains*

# 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

- Access to other treatment/services
- Time to diagnosis
- Information quality
- Healthcare team quality

### Biggest gaps between satisfaction and importance

- Access to other treatment/services
- Effectiveness
- Healthcare team quality
- Time to diagnosis
- Monitoring

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

### Access to other treatments/services

Increased mental health support, along with referrals/signposting on where to get mental health support. Several report struggling to navigate the heath system and would like more help with this, e.g., through a care-coordinator. Patients would like access to holistic services and advice, e.g., for diet/sleep/exercise, or at least more information provided to them by healthcare professionals (HCPs) on these areas.

### Time to Diagnosis

Raise awareness of the disease by improving HCP knowledge of signs and symptoms.

### Information quality

Patients would like to receive clear, trustworthy, current information on the condition, particularly at diagnosis. Some suggest signposting to support groups and relevant organisations would be helpful, along with HCPs spending more time with patients to explain the condition and treatments more fully.

### Healthcare team quality

Suggestions were wide ranging but centred on improvements in access to HCPs (e.g., more scheduled regular contact) along with consistent care and better communication between treating HCPs (e.g., consultants sharing results with GPs).

### Effectiveness

Aside from simply increasing the effectiveness treatments available, patients called for better access to clinical trials.

## Monitoring

There is a need for more information on how patients can track and monitor their own progress and/or deterioration. Some patients would also like to be given tools (e.g., Apps) to assist with monitoring their own health.