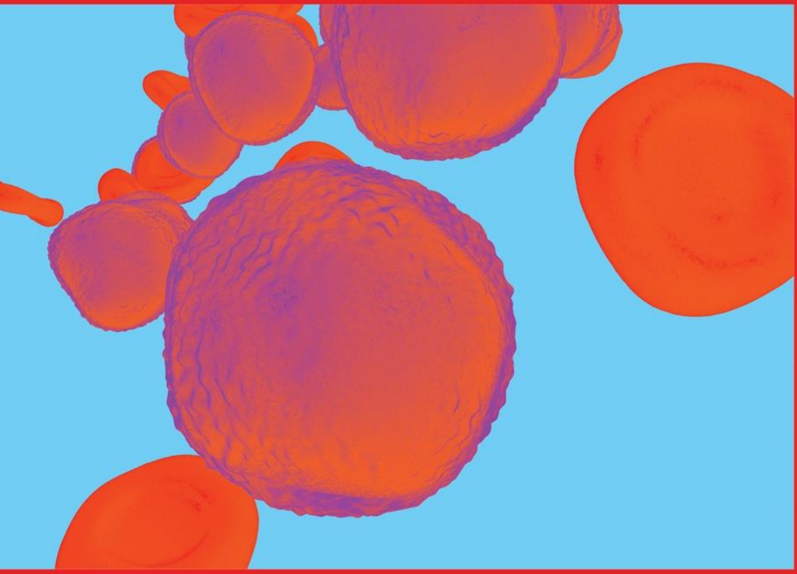
Quantitative short report



Chronic Lymphocytic Leukemia

Patient Experience – Australia

Johnson&Johnson

Janssen-Cilag Pty Ltd. ABN 47 000 129 975. 1-5 Khartoum Road, Macquarie Park NSW 2113.
Ph: 1800 226 334. CP-450275. Date of preparation: May 2024

Acknowledgements

Johnson & Johnson, Lymphoma Australia and Community and Patient Preference Research (CaPPRe) would like to thank the individuals who generously gave their time and shared their experiences of chronic lymphocytic leukaemia (CLL).

This report was prepared by CaPPRe and authored by Dr Simon Fifer, Laurie Axford, Rose Wilson and Ellie Morris.

Funding for this study was provided by Johnson & Johnson.

Contents

Table of tables

Table of figures

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 chronic lymphocytic leukaemia (CLL) 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 CLL 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 CLL 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).

	Moments that Matter	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., haematologist), 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., haematologist/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 acupuncture, massage, mind-body techniques, and management strategies for increased wellness (e.g., access to dietitians/physiotherapists/occupational therapists/psychologists). • 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	**CLL-related costs**	• he overall impact that having CLL 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
○	○	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 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 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 CLL 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 treatment experienced patients

Patients were recruited through panel companies, a health social network, and with help from the patient support group, Lymphoma Australia. 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 15-July-2022 and 21-November-2022.

The findings

Demographic characteristics

Demographic characteristic	Patient (N=25)
	N (%)
Gender	
Male	16 (64)
Female	9 (36)
Non-binary/gender fluid	0
Prefer not to answer	0
Age	
18-30	0
31-40	3 (12)
41-50	5 (20)
51-60	1 (4)
61-70	10 (40)
71-80	5 (20)
81 or older	1 (4)
Prefer not to answer	0
Occupational status	
Working (full-time)	6 (24)
Working (part-time)	2 (8)
Working (casual)	1 (4)
Student	0
Not working	1 (4)
Home duties and/or caring responsibilities	0
Retired	13 (52)
Other	2 (8)
Prefer not to answer	0
Ethnicity	
Australian	21 (84)
Cook Islander	
Asian	1 (4)
European	2 (8)
Other	
Prefer not to answer	1 (4)
Location	
Metro/city	16 (64)
Regional	8 (32)
Rural	1 (4)

Table 1.Basic demographic characteristics of patients

Abbreviations: N – sample size.

The characteristics of the participants are displayed in Table 1. Nearly two-thirds of CLL patients who have treatment experience, identified as male (64%), representative of the fact CLL is more common in men. The majority were aged 40 or older (88%), with 40% in the 60-69 age category. Over half of participants were retired (52%), and over a third of participants reported to be working, in some capacity (36%). Participants were split two thirds vs. a third between metro and regional/rural areas (64% vs. 36%, respectively).

Disease and treatment characteristics

Disease and treatment profiles for patients are shown in Table 2. 28% were receiving 1st line treatment; 32% 2nd line; with none on 3rd or 4th line.

Slightly more participants reported having experience receiving the targeted therapy (80%) compared to the chemoimmunotherapy approach (68%).

Treatment characteristic	Patient N (%)
Treatment stage N=25	
1st-line treatment	7 (28)
Not currently on treatment due to achieving remission / minimal disease activity from 1st-line treatment	4 (16)
2nd-line treatment	8 (32)
Not currently on treatment due to achieving remission / minimal disease activity from 2nd-line treatment	2 (8)
3rd or 4th -line treatment	0
Not currently on treatment due to achieving remission / minimal disease activity from 3rd or 4th-line treatment	1 (4)
Other (please specify)	3 (12)*
Treatment regime	
Chemoimmunotherapy	17 (68)
Targeted therapy	20 (80)
Don't know/unsure	0
Treatment experience	
Oral (swallowed by mouth in pill or tablet form)	20 (80)
Injection under the skin	5 (20)
Intravenous infusion	19 (76)
Other	1 (4)
Don't know/unsure	0

Table 2 .Basic disease and treatment characteristics

Abbreviations: N – sample size.

** Other (please specify): responses included being on maintenance therapy; not being on treatment due to lack of tolerability*

Characteristics of Care

Treatment Setting

The number of participants treated in exclusively public or private settings was even (36%). Over a quarter (28%) reported having been treated in a combination of public/private settings.

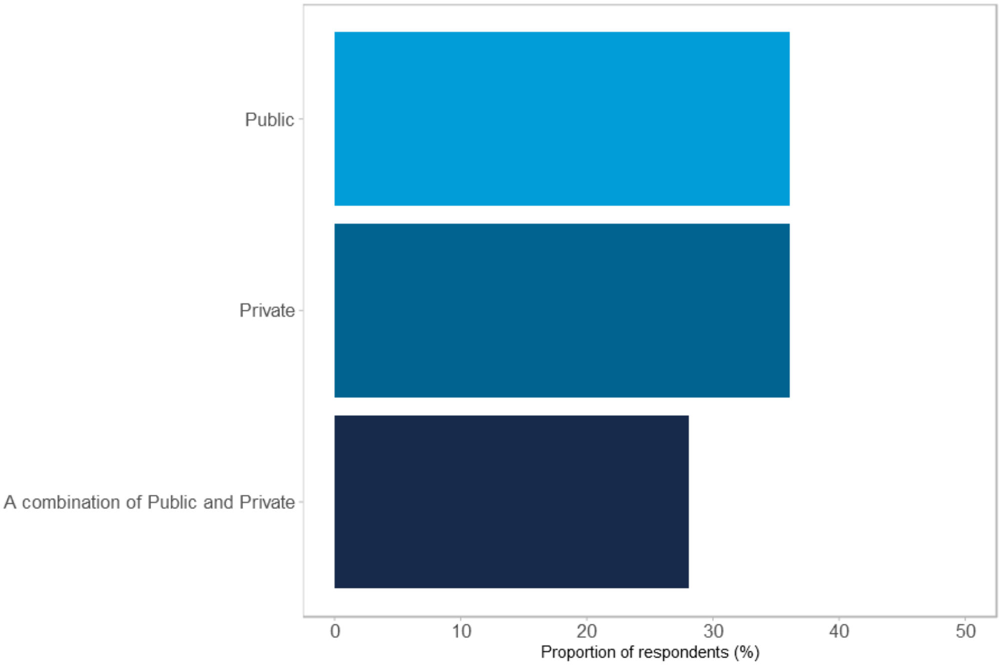


Figure 3. Treatment setting

Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with a mean of $3,147 annually.

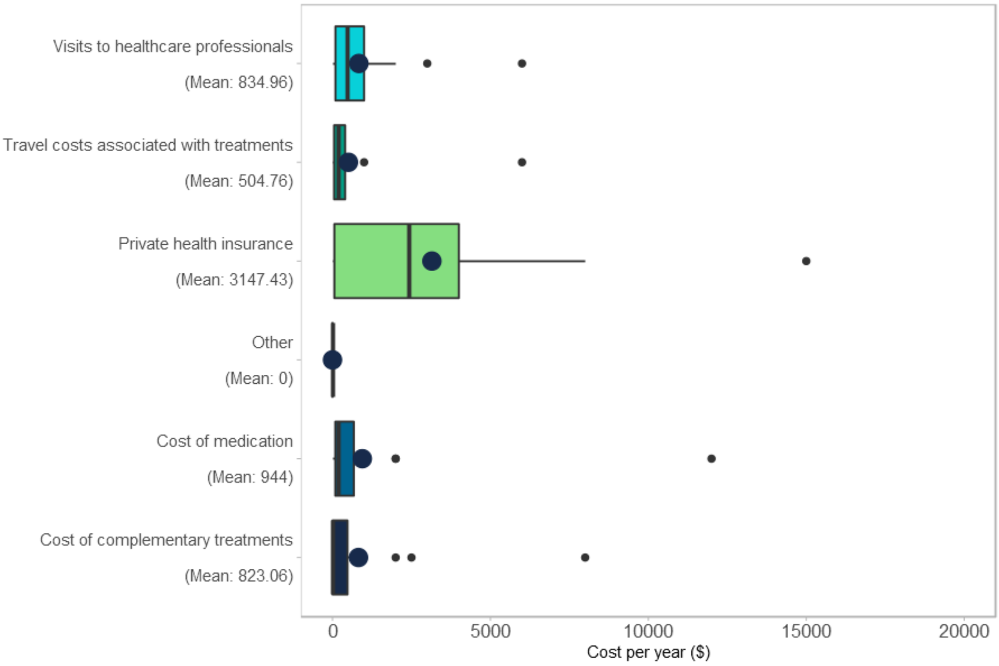


Figure 4. Treatment and care costs

Services Experienced

Nearly two-thirds of participants were supported by patient support organisations (64%) and just over half of the respondents have made use of mainstream medical services e.g., treatment/prescription/appointment reminders (52%). 8% of participants have a care coordinator.

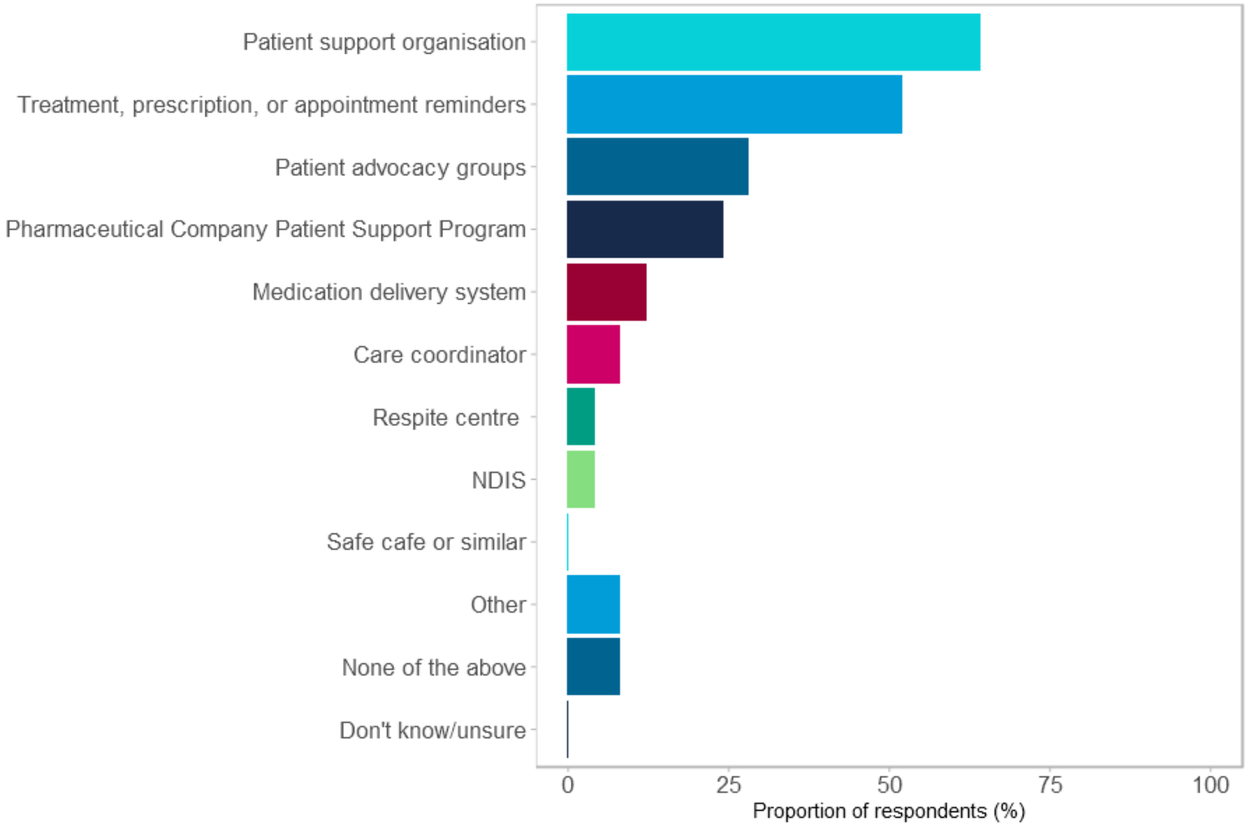


Figure 5. Services experienced

Importance & Satisfaction

PEI

The PEI for CLL patients with treatment experience, 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 CLL PEI dashboard (link on page 19) for subgroups scores, e.g., by basic demographics.

	Mean	Median	Std. deviation
Patient Experience Index (N=25)	65.97	66.18	14.02

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 CLL patients with treatment experience 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. 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 with the aspects of treatment and care that are important to them. *Support person support, Access to other treatments/services, Side effects, Logistics, Decision making,* and *Diagnosis time* 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.*

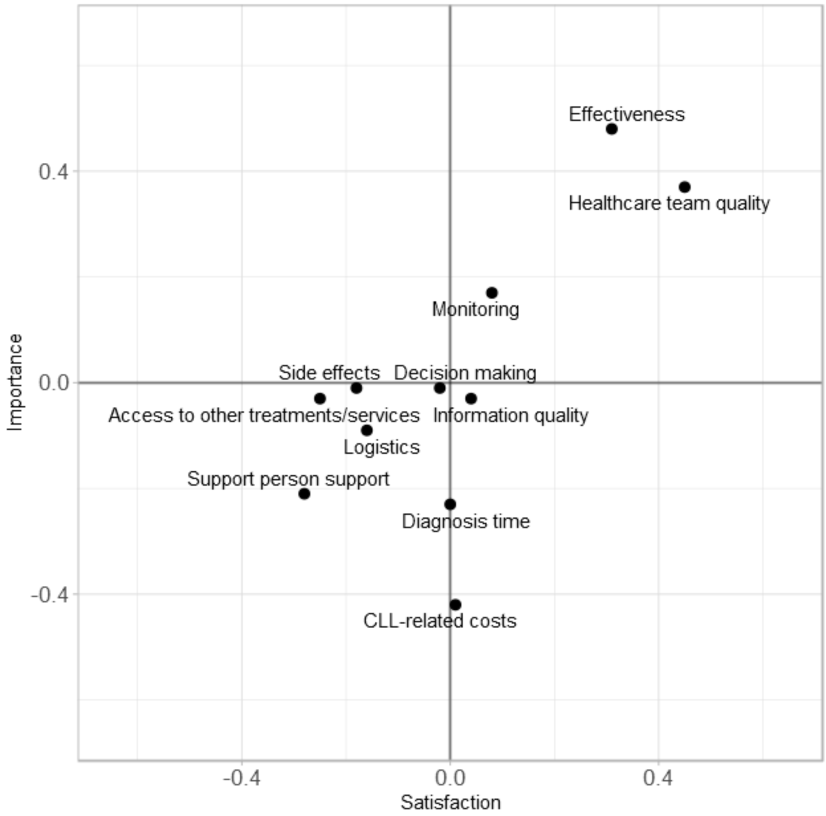


Figure 6. BWS quadrant map

Rescaled importance and satisfaction

Figure 7 displays the rescaled importance and satisfaction scores for CLL patients with treatment experience. 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, *Effectiveness* (8.98), *Healthcare team quality* (8.07), and *Monitoring* (7.63), appear to be especially important, on average. *Decision making* (7.10), *Side effects* (6.93), *Access to other treatments/services* (6.77) and *Information quality* (6.75) also scored highly.

Treatment experienced patients were least satisfied with *Support person support* (5.28), *Access to other treatments/services* (5.44), *Side effects* (5.74) and *Logistics* (5.77). Satisfaction levels were lower than importance levels on all MTM except *Diagnosis time* and *CLL-related costs*. The biggest gaps between importance and satisfaction were in *Effectiveness, Monitoring* and *Access to other treatments/services*.

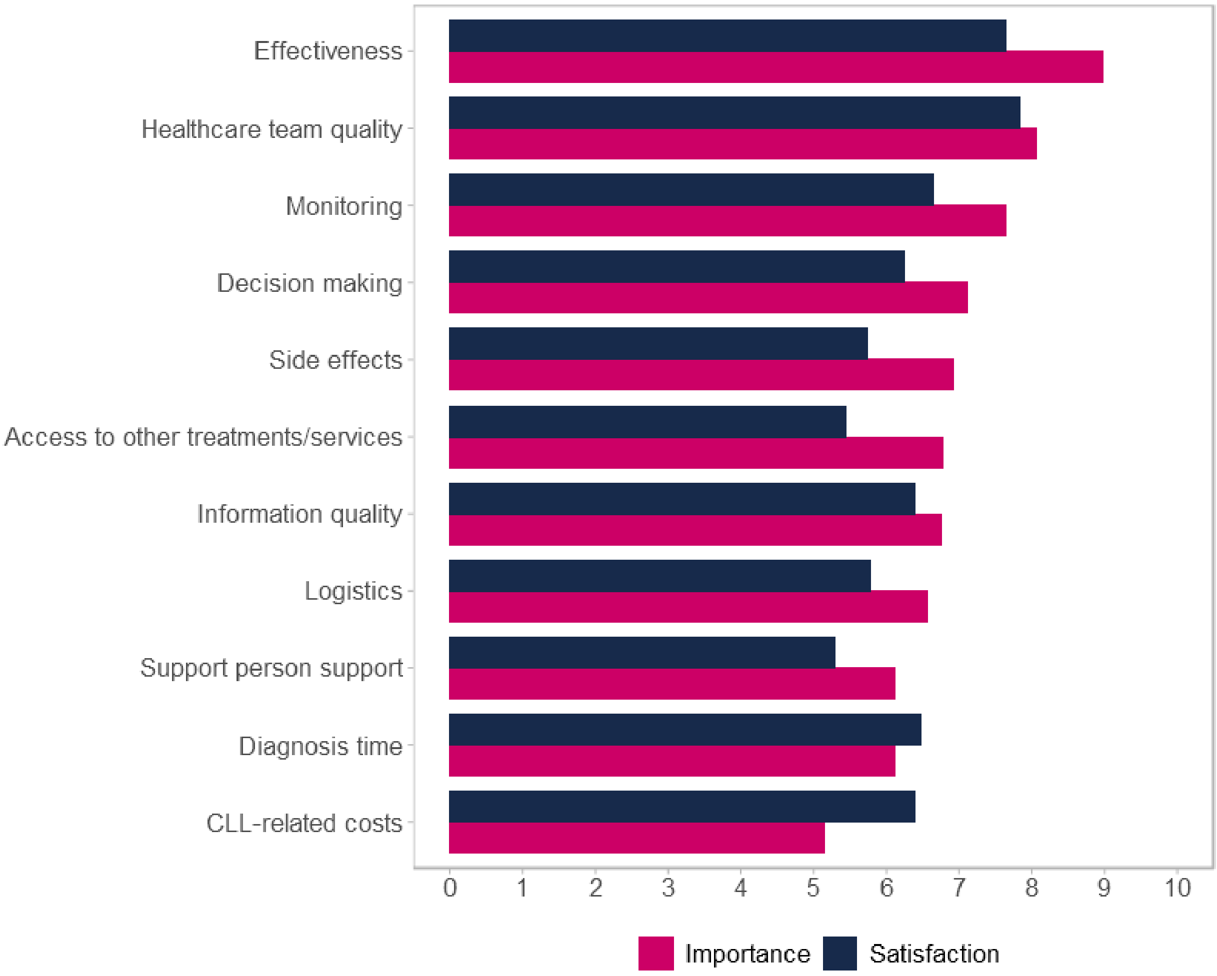


Figure 7. Rescaled importance and satisfaction

Conclusion

Findings from this 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

- Access to, and effectiveness of, medication (Effectiveness)
- Support for support person
- Access to other treatments/services
- Monitoring & identifying progress/deterioration

Biggest gaps between satisfaction and importance

- Access to, and effectiveness of, medication (Effectiveness)
- Monitoring & identifying progress/deterioration
- Access to other treatments/services

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

Effectiveness

The areas patients were most dissatisfied within this MTM were, access to medication and access to clinical trials. Several patients report that the guidelines around lines of treatment (i.e., when medication can be taken, and the order in which it is prescribed) is restrictive and payment for medications is prohibitive. There was a call for best-fit treatments to be decided by healthcare professionals (HCPs)/patients.

A patient described the difficulty of living with side effects associated with their medication(s) (e.g., fatigue), preventing them from doing certain physical activities and/or tasks which require a fair amount of mental capacity. Patients called for better and more information on side effect management, as they expressed that this currently is not readily available.

Another comment was made in being excluded from a trial due to comorbidities, meaning they did not meet inclusion criteria, which was a source of frustration; they suggested providing more information on why patients do not meet the inclusion criteria.

The distance to the city was perceived as a barrier in taking part in trials by another participant. Several comments were made in that clinical trials were simply not available, or the timings had not worked out. Patients suggested trials should be more widespread, i.e., also conducted in regional areas.

Support for support person

Several participants who had this MTM in their top 4 for high importance/low satisfaction were dissatisfied with the emotional support available for their support person (e.g., peer support, counselling). A few patients mentioned that the COVID-19 pandemic had restricted the emotional support their support person used to receive, and some mentioned the difficulty of their support person feeling ‘included’ due to most consultations taking place online or over the phone. Patients expressed that they were not aware of any existing services for their support person, where one participant suggested a development of a ‘care plan’ designed specifically for their carers.

Monitoring

Participants who had this MTM in their top 4 for high importance/low satisfaction were mostly dissatisfied with the availability of tools to help them track physical or mental health changes. Some patients report that they were not aware of any tools used for monitoring/tracking changes in their physical and mental health (including their overall wellbeing), and they would like an efficient health records system which consists of information that highlights these changes over time.