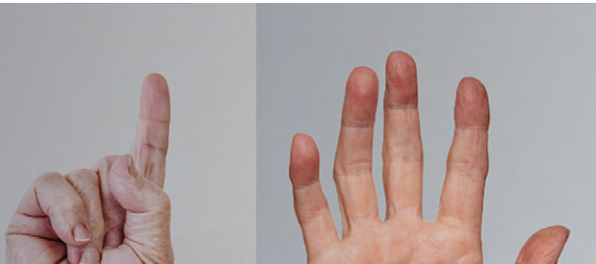


No Patient Like Me

My CLL, my priorities.

Let's talk about what matters to me.



CLL treatment: putting patient priorities at the centre of treatment decisions

Why shared decision-making matters across the CLL treatment journey

White Paper

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Executive summary

In recent years, there have been significant advances in the treatment of CLL. There are now more therapeutic options available than ever before, each with distinct profiles in terms of efficacy, safety, and convenience. As patients live longer with the disease, ensuring they have a voice in treatment decisions is increasingly important.

Every person living with CLL has unique priorities, needs, and goals. These should be reflected in the treatment decision-making process. While physicians assess clinical suitability and expected benefit, patients are best placed to judge what matters most to them, how the burden of treatment can fit into their lives and what trade-offs are acceptable to them.



Shared decision-making is integral to patient-centred care, yet patient involvement in the decision-making process still varies across countries.

Patient education, local protocols, treatment availability and reimbursement, procurement conditions, and access to specialist care all influence how much choice patients can exercise.

Listening to unsolicited online open-forum discussions can reveal what matters to people living with CLL and where treatment conversations could better elicit and consider their individual priorities. As these online discussions occur independently of any research purpose, they provide insight into the concerns and experiences that patients and caregivers chose to discuss in their own words, rather than in response to predefined survey questions. This helps reduce some of the response and framing biases associated with prompted research methods.

Analysis of real-world, unsolicited online open-forum patient and caregiver discussions across five European countries found that patients rarely described being actively involved in treatment decisions.

Where there was patient involvement, it often took the form of self-advocacy, looking for second opinions, questioning recommendations, or navigating access to specialist centres and care pathways. The analysis also showed that the burden of treatment often extended beyond clinical outcomes to physical, emotional, practical, and financial burden during active therapy and treatment-free periods. Together, these findings support a call to action for more structured, two-way treatment conversations between patients and clinicians in which patient priorities are actively elicited and considered, and patients are given a clear picture of their treatment options, related constraints, and likely quality-of-life consequences of the various treatment options throughout their journey. However, it is important to note that online discussions may not reflect the experiences of all patients, and variations in digital access, source availability, and online participation, as well as differences in healthcare systems and cultural norms may limit the interpretation of these findings.



Introduction: Why shared decision-making matters in CLL



Advances in CLL treatment mean patients now have more treatment options with different efficacy, safety and treatment duration and administration profiles, making their involvement in treatment decisions increasingly important.



People living with CLL differ in their priorities, needs, and goals, which should be considered alongside clinical factors in decision-making.



As the treatment landscape evolves and multiple treatment options become available, treatment choice increasingly depends on clinical factors and individual patient preferences and priorities.



Published CLL patient preference studies show that patients and physicians may prioritise treatment attributes differently, highlighting the importance of shared decision-making.

There is no one-size-fits-all approach to treating CLL. Every person living with CLL has unique priorities, needs, and goals. Scientific advances have substantially expanded the range of available treatment options, which differ in their schedules and clinical profiles, giving patients and clinicians more possibilities to consider but also making treatment decisions increasingly complex. As Cancer Patients Europe highlights, for many people with cancer there is no single “right” treatment choice.¹

Notably, patients and healthcare professionals may not always place the same importance on treatment characteristics. A 2022 patient-physician preference study in CLL found that progression-free survival was the most important treatment attribute for haematologists, whereas patients placed the greatest importance on the risk of serious infections.² A multidisciplinary expert opinion in CLL published in 2026 similarly emphasised considering patient-specific factors such as infection history, comorbidities, functional status, and broader psychosocial circumstances, and highlighted patient preferences as integral to treatment decision-making.³

Shared decision-making is increasingly recognised as a central element of person-centred oncology care. Del Carpio et al. (2026) showed that contemporary oncology-specific models of shared decision-making consider factors at multiple levels, including the patient, clinician, treatment, and healthcare system, as well as interpersonal and social factors.⁴

Methodology

This multi-country observational study analysed anonymised, real-world, unsolicited open-forum online discussions posted by patients and caregivers across five European countries.

Relevant patient discussions and treatment-related conversations were identified through large-scale web screening of publicly accessible sources, including patient forums, social media communities, and other disease-specific platforms.

A proprietary AI-powered technology (Semantic Hub)* was used to analyse the discussions and identify relevant themes, including CLL treatments and treatment attributes, patient involvement and self-advocacy in treatment choice, quality-of-life burden, and country-specific patterns in care pathways and decision-making. All findings were reviewed and verified by human analysts. The analysis looked at how prominent different themes were across patient discussions, while also examining the language and context behind them to understand patients' experiences and the trade-offs they described.

Data presented is at an aggregated level only. No individual patients were identified, and any patient examples used in the report were anonymised.

Illustrative patient examples from the study dataset were adapted to reduce the risk of re-identification. Paraphrased examples do not reproduce individual posts verbatim but preserve the meaning and emotional significance of the experiences described. All examples are included solely to illustrate broader patterns identified in the analysis.

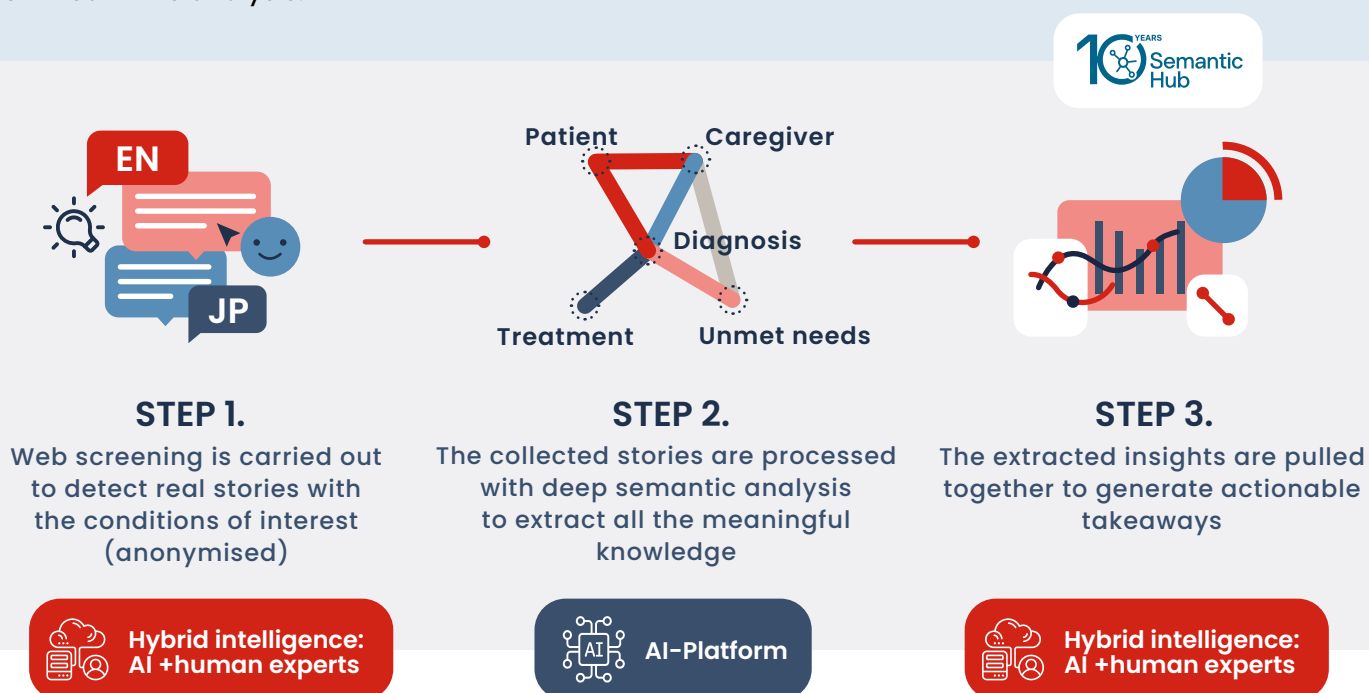


Figure 1. Overview of the AI-supported patient-voice analysis methodology. Anonymised patient stories were identified through web screening, processed using deep semantic analysis, and aggregated to generate actionable insights. Human experts contributed across the workflow to support interpretation and quality control.

*Semantic Hub (<https://semantic-hub.com/>) uses a hybrid AI architecture combining fine-tuned machine-learning models, including large language models, with rule-based and pattern-based modules. Human experts supervise and validate analytical outputs for contextual accuracy and relevance to predefined research questions.



Dataset overview

The analysis was based on anonymised, real-world, unsolicited online discussions from five European countries:

France, Italy, Spain, Germany, and the UK.

The final analytical dataset included **44,451** posts from **2,699** unique authors identified from their posts as people **living with CLL or caregivers of CLL patients***, selected from a larger pool after filtering by diagnosis, country relevance, and the presence of treatment experience or related facts.



Sources included patient forums, charity and disease-specific communities, and other publicly accessible online platforms. Most posts were written by patients, with **caregiver narratives appearing less frequently**.



The dataset covered the period **from January 2020 to December 2025**. While content from the full period was included, the majority of treatment-related discussions were posted after 2023, when online conversations around CLL treatment choice became more frequent.



This white paper also refers to a comparable analysis of **US patient discussions**, comprising **42,516** messages from **4,172 authors**.

*Patient and caregiver roles were determined from the narrative content, based on whether the experience described was the individual's own or that of another person. Percentages were subsequently calculated at the patient level, including patients whose experiences were reported by caregivers. Authors identified on different online platforms were not merged across sources. Within a given author's narratives, information referring to the same patient was linked and analysed as belonging to that patient.

Results

1. Visible patient involvement appears limited



Across the **five European countries**, mentions of explicit patient involvement in treatment choice ranged from **7 to 19%** of patients who discussed a selected therapy.



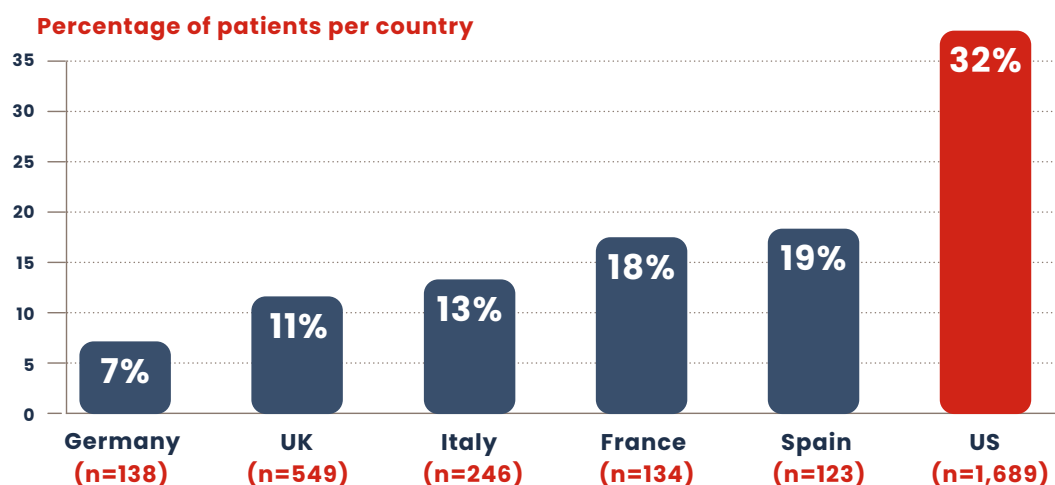
The same analysis applied to the **US** reference dataset found more frequent mentions of involvement, at **32%**.



Published patient-reported studies similarly suggest a gap between patients' desired and experienced levels of involvement.

In real-world unsolicited discussions, only a minority of patients who mentioned a selected therapy also described explicit involvement in treatment choice. Across the five European countries, **the proportion of patients who described being involved in a treatment-choice discussion with their physician ranged from 7% to 19%**. While this analysis is limited to explicit mentions of patient involvement in treatment-choice discussions and may therefore underestimate some forms of shared decision-making, the same approach applied to the **US reference dataset suggests a different pattern**: patient involvement was mentioned more frequently, by **32% of patients** who discussed a selected therapy.

Explicit mentions of involvement in treatment choice within analysed online discussions



Explicit mentions of involvement in treatment-choice discussions among patients mentioning a selected therapy.

Figure 2. Explicit mentions of patient involvement in treatment choice across five European countries and the US reference dataset. Percentages represent the proportion of patients who explicitly mentioned being involved in a treatment-choice discussion with their physician among those who mentioned therapy and treatment process.

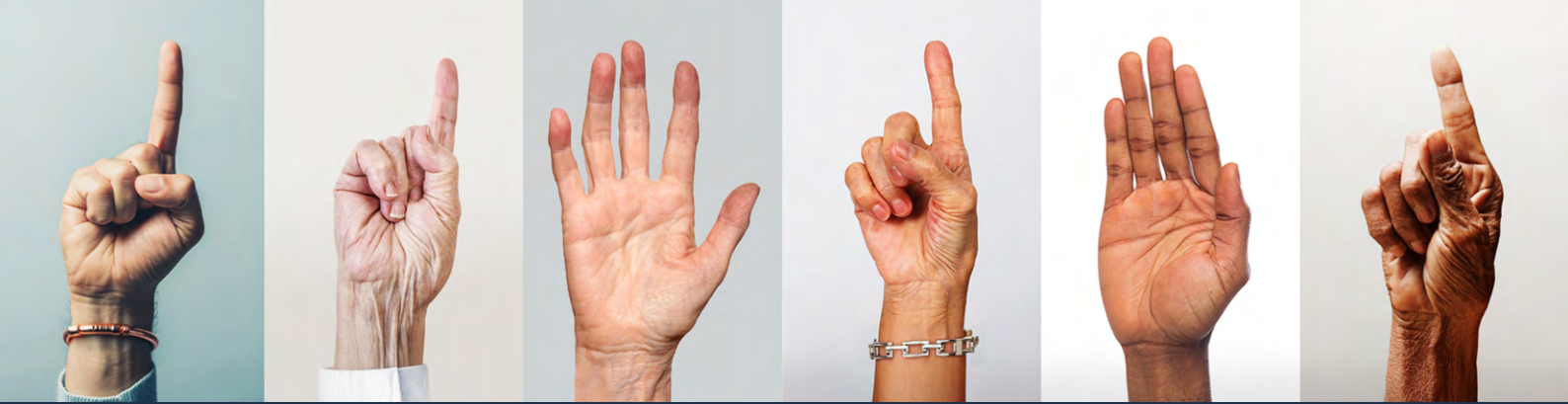


Published patient-reported studies have generally reported higher levels of involvement in treatment decision-making than those observed in our study. For example, the 2024 Lymphoma Coalition Global Patient Survey, which included respondents from **79 countries**, reported that **52% of patients felt as involved in decisions about their care and treatment as they wished to be.**⁵

Similarly, in a 2022 UK qualitative study of patients with chronic haematological cancers, most participants felt that they had been involved to the extent they wanted, although none recalled clinicians formally asking how they wished to participate in the decision-making process.⁶

In addition, a global survey of patients with CLL conducted across 30 countries between 2021 and 2022, with the largest proportion of respondents from the **UK**, found that **52% of patients who had initiated treatment reported not being offered a choice of treatment options.**⁷





Direct comparisons between these studies and our findings should be interpreted with caution because of important differences in study design, methodology, patient populations, geographic representation, and the measures used to assess patient involvement. In particular, **variations in how shared decision-making and patient participation were defined and evaluated may contribute to the higher levels of reported involvement** in these studies compared with the **19% observed in our cohort**.

Nevertheless, despite reporting more favourable levels of involvement than our study, these findings **still highlight meaningful gaps in patient participation and indicate substantial opportunities to further improve shared decision-making in the care of patients with CLL**.

The higher level of explicit involvement observed in the US reference dataset is consistent with earlier US patient-reported evidence. **In the 2018 CLL Society survey of 1,147 patients, 83% of respondents rated their own views as influential in treatment decision-making, while 73% of treated respondents reported having been offered more than one treatment option.⁸**



However, treatment decision-making occurs within different healthcare contexts in the US and Europe. In the US, discussions may more frequently incorporate considerations such as insurance coverage, out-of-pocket costs, and reimbursement, potentially increasing patients' awareness of treatment choices. By contrast, in many European healthcare systems, treatment costs are largely managed by the healthcare system and are less visible to patients, which may influence how treatment options and decision-making are experienced and reported.

2. Patients want to be involved in treatment decisions



Patient involvement was often described as requiring an active role.



Published evidence suggests that many patients want the opportunity to discuss treatment benefits, risks, and outcomes with their doctor.

This analysis of online discussions showed that patients had to be forthcoming in order to be involved in their treatment decision-making. Patient accounts included examples of having to take a proactive role to make their concerns and preferences heard. This included seeking second opinions, questioning recommendations, researching alternatives, choosing expert centres, and asking for further explanations or treatment adjustments.



Self-advocacy was discussed particularly openly in the **UK patient communities**, where patients directly encouraged one another to take a more active role:

"Advocate for yourself and do not be afraid to ask questions or challenge a recommendation if you do not understand why it is right for you"

"I expected my care team to work together in my interests... When that did not happen, I felt I had to speak up for myself."

Some patients reported receiving little guidance or support from their healthcare team and feeling that they had to manage their treatment journey themselves. In more extreme cases, patients described being prepared to refuse treatment until the proposed approach had been adequately explained. Others reported that active questioning ultimately led to clearer information:

"After I raised my concerns and asked more questions, I finally received a treatment plan that felt clear and considered"



German patient discussions showed similar examples. Patients described difficult conversations about treatment complications, independently researching alternatives, and bringing their own suggestions to their haematologists. In some cases, seeking advice from more than one specialist resulted in different recommendations, adding another layer of complexity for the patient.



French patients also described the need to prepare and take the initiative in communication with clinicians:

"I felt I needed to gather enough information before I could have a meaningful conversation with my doctor"



Italian patient discussions suggest that some patients had to create opportunities for involvement themselves: by asking numerous questions, seeking additional information, pushing for further investigations, obtaining second opinions, changing treatment centres, or directly declining a proposed treatment. Patients also encouraged one another to seek additional specialist advice:

"Keep asking questions, and consider another specialist opinion if you are still not comfortable with the proposed treatment"



Spanish patients similarly described examples of necessary self-advocacy, including challenging information recorded in their medical notes, requesting an appropriate route of administration, directly refusing to continue treatment, and independently seeking a second opinion.

However, not all patients have the confidence or emotional resources needed to actively self-advocate. Some patients mentioned feeling uncomfortable requesting further input:

"I was worried that asking for another opinion might create tension with the doctors looking after me"



As a result, the patients whose priorities ultimately become visible may disproportionately be those willing and able to speak up. **Yet, in the 2022 UK study of patients with chronic haematological cancers, most participants wanted “to be given the opportunity to discuss treatment benefits, risks and outcomes with their doctor.”⁶**

In the 2024 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL, **93% of patients considered it important that their doctor ask how much they wanted to be involved in decisions about their care and treatment, while 70% reported not being given more than one treatment option before their current or most recent treatment.⁵**



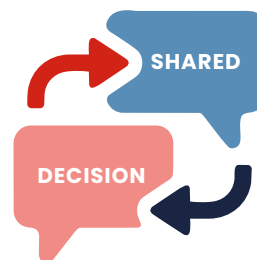
Patients want a genuine opportunity to understand the available options, discuss relevant trade-offs, and have their priorities reflected in the final decision. Shared decision-making should not require patients to challenge recommendations or navigate the healthcare system alone before their concerns are heard. Treatment conversations should proactively create space for questions, explain available options, elicit patient preferences and ensure that they are considered in treatment planning.

3. What “choice” means may vary by healthcare system



Meaningful patient choice may depend not only on the treatments available, but also on access to specialist care, local protocols, and the structure of the healthcare system.

Shared decision-making in CLL should take into account the different treatment options available, each with their own product attributes, and how these may align with patient priorities. Shared decision-making may also be shaped by country- and system-specific factors. In some contexts, patient involvement may mean choosing a care pathway, seeking access to a specialist centre, or navigating which treatments are locally available, rather than choosing freely between all clinically appropriate regimens. In the analysed discussions, such **system-level constraints emerged** particularly clearly in **Italy and Spain**.



In Italy, treatment choice often appeared to involve **choosing a centre or specialist as much as choosing between treatment regimens**, since not every centre has the same experience, infrastructure, or practical capacity to initiate and monitor every available treatment. **Local routines and resources may therefore shape which options are actually offered and how readily they can be started and followed up.** When the proposed approach did not align with their preferences, some patients sought a second opinion or transferred to another centre in the hope of accessing a different treatment strategy. As a result, the care pathway itself may become an important lever of patient choice.

Patients described changing hospitals, seeking specialist advice, and travelling considerable distances when they were not convinced by the proposed approach or wanted access to a different treatment strategy. In one case, a family sought advice at a specialist centre in another region after questioning the treatment initially proposed. Another patient mentioned transferring to a different hospital:

"I eventually left the care pathway I was in and moved to another hospital. I now feel much more confident in the care I receive there"



In Spain, access and system-level factors also appeared to shape treatment choice. Regional protocols, local treatment availability, and the perceived expertise of the treating centre influenced which options were considered or offered. **Patients sometimes expressed concern that treatment choice could be constrained by cost, procurement practices, budget considerations, or local availability, prompting some to seek second opinions or travel to larger cities.** The public-private divide was also relevant: some patients were diagnosed in private hospitals but continued their long-term treatment within the public system. For some families, overcoming these limitations required considerable effort and travel. In one case, a caregiver travelled a considerable distance to obtain a second opinion from a more experienced specialist after disagreeing with the local recommendation.



These findings suggest that the challenge extends beyond communication between patients and clinicians. Even where clinicians are willing to accommodate individual priorities, the options they can offer may be limited. Meaningful shared decision-making therefore requires transparent discussion of these constraints and, where appropriate, consideration of alternative pathways, specialist advice, or referral to another centre.

4. Why patient involvement matters: treatment choice may have consequences beyond therapeutic effect



The best care recognises the whole patient:

treatment decisions should consider not only clinical outcomes, but also how different options may fit into the patient's life.

Treatment choice in CLL is not only a clinical decision: it is also a decision about how treatment may shape a patient's life during therapy and beyond. Different approaches may affect daily functioning, emotional well-being, hospital and monitoring burden, recovery expectations, independence, and the ability to preserve normal routines.

These quality-of-life consequences form part of the trade-offs patients may consider when deciding what treatment burden is acceptable and which outcomes matter most to them. Hester et al. found that many patients' main goal was **"to live normally and with the lowest impact possible through the CLL and its therapy."**⁹ However, what constitutes the lowest impact may differ between patients. In this present study, some patients perceived the least burdensome approach as one that minimised disruption to normal life while providing reassurance that the disease remained under control. Others were willing to accept a more intensive treatment burden if it offered a clear endpoint. The same treatment characteristic may therefore represent a benefit, an acceptable trade-off, or a burden for different patients.



Clinical evidence can establish which options are medically appropriate, but it cannot fully determine how the practical and emotional consequences of each option will fit into an individual patient's life. Patient involvement is therefore essential not only in selecting a treatment, but also in anticipating and addressing the quality-of-life burden that may follow from that decision. **The following sections examine how these consequences were reflected in patients' experiences during and after treatment.**

5. Quality of life burden across the patient journey



Patients mentioned challenges across a wide range of areas, including daily functioning, emotional well-being, treatment burden, and the ability to maintain normal life



Patients report significant burden even after treatment completion

In this study, quality-of-life issues during active treatment were analysed among 1,110 patients who discussed their experiences online. Patients described challenges across multiple and often overlapping areas, including physical functioning, emotional well-being, treatment-management burden, work, finances, and the ability to maintain normal life. Physical suffering and disease management were the most prominent domains overall, but the findings show that the burden of treatment extended considerably beyond side effects alone.

Multiple quality-of-life domains were discussed during treatment

Predominant quality-of-life areas mentioned by patients during treatment, by country (%)

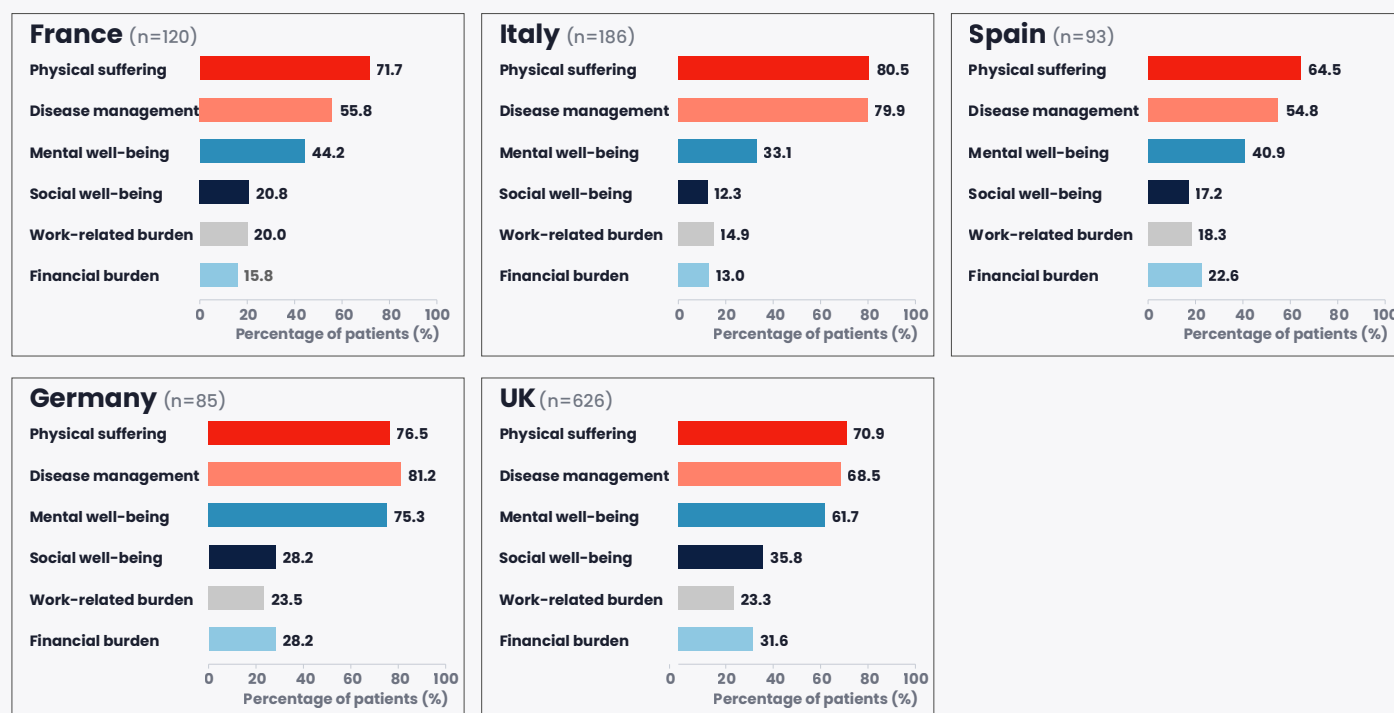
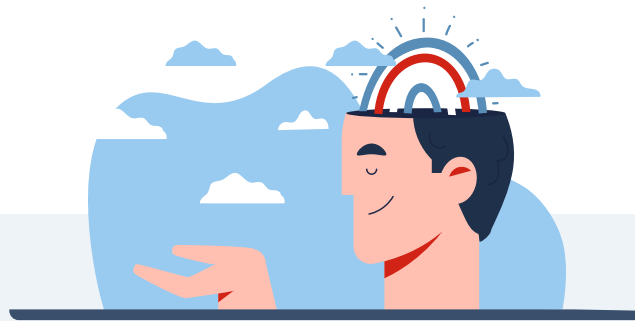


Figure 3. Quality-of-life domains identified in patient discussions during CLL treatment, by country. Percentages indicate the proportion of analysed authors in each country whose discussions were coded to the relevant domain. They do not estimate population prevalence or symptom severity. Authors could be assigned to more than one domain.

The categories shown in Figure 3 capture different dimensions of the treatment experience. Physical suffering included fatigue, low energy, pain, treatment-related symptoms, reduced mobility, and difficulty carrying out everyday activities. Disease management referred to the practical and cognitive work of living with treatment, including treatment administration, hospital and pharmacy visits, monitoring requirements, and continuing concerns about whether treatment was working. **Patients also described being unable to travel as one of the consequences of this burden, due to treatment schedules, hospital visits, infection risk, and the practical challenges of managing medication away from home.** For some, this loss of freedom was a particularly visible way in which treatment affected normal life and independence.



Mental well-being covered treatment-related anxiety, persistent fears, uncertainty, and the emotional strain of living with and managing CLL. Social well-being reflected the effects of treatment on relationships, social participation, independence, and the ability to continue ordinary activities. Work-related burden included reduced capacity to work, the need for sick leave, and concerns about whether symptoms would allow patients to remain in employment. Financial burden included loss of income, as well as concerns about insurance, benefits, sick-leave arrangements, and the financial and administrative consequences of CLL and its treatment.

Although the overall pattern was broadly consistent, the relative prominence of individual domains varied. Physical suffering and disease-management burden were particularly dominant in Italy, whereas mental well-being was more prominent in Germany and the UK. Some practical experiences also differed: French patients more often described the **time and travel burden of day-hospital care and pharmacy logistics**; Italian discussions included the burden of collecting hospital-issued medication and the potential value of home delivery; Spanish patients mentioned **painful infusions and long hours in hospital**; German and UK patients highlighted **repeated visits and monitoring requirements**.

The end of active treatment did not necessarily mark the end of this burden. **Patient discussions showed that some challenges continued into treatment-free periods.**

Some burdens may continue treatment-free periods

Common quality-of-life themes identified during post-treatment intervals

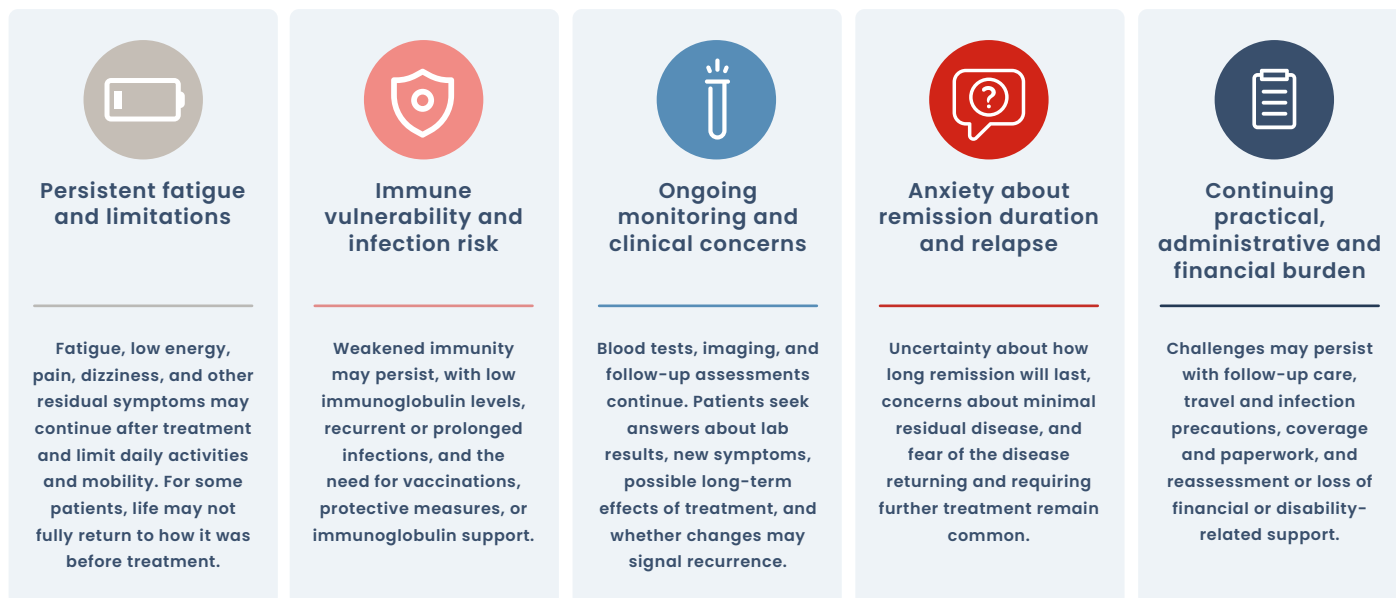
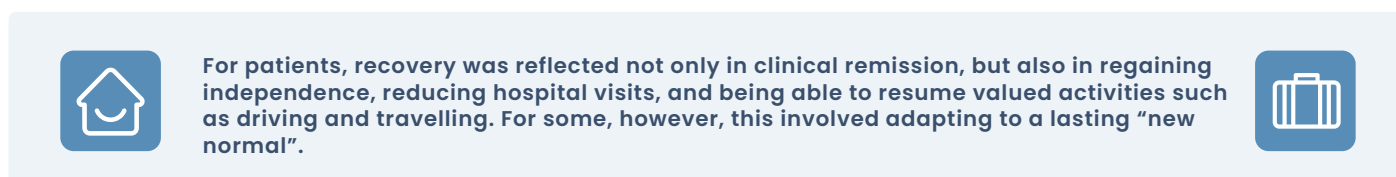


Figure 4. Common quality-of-life challenges during treatment-free intervals



Across all five countries, patients described a similar set of challenges during treatment-free periods, including persistent fatigue and functional limitations, immune vulnerability, continued monitoring, uncertainty about remission, and practical or financial burden. Many of these experiences were unexpected, particularly where patients had anticipated that treatment completion would bring a rapid return to normal life.



Patient experiences illustrate how this burden differed in form across countries. In the **UK**, some patients described a lasting change in functioning and the need to adapt expectations:

After treatment, I realised that life was not simply going back to how it had been. I had to adapt to a different level of energy and independence”.



In Germany, post-treatment discussions often focused on new clinical findings and questions about whether they might be treatment-related:

"All my immunoglobulin levels are normal except gamma-Ig, which has continued to decline since treatment ended."



A patient from **France** described achieving clinical remission alongside continued immune fragility and treatment-related burden:

"The disease is in remission, but I still have significant immune problems and recurring infections that require ongoing supportive treatment."



Italian patients similarly reported persistent symptoms and functional limitations:

"Even walking short distances has become difficult. The fatigue is severe, and I often feel that I have almost no energy."



A patient from **Spain** described the uncertainty that can remain even during remission:

"No one can tell me whether this remission will be brief or last for many years"

These experiences reinforce that patients value outcomes beyond clinical response alone. Fifer et al. (2024) found that patients' long-term treatment goals included being physically healthy, living a long life, spending time with family and friends, and avoiding hospitalisation.¹⁰ At the same time, patients may continue to experience anxiety about whether the disease remains under control, how long remission will last, and what new symptoms or test results might mean. **Treatment success should therefore also be considered in terms of whether patients can recover functioning,** regain independence, maintain relationships and valued activities, feel reassured about disease control, and live with less physical and emotional disruption from both CLL and its treatment.



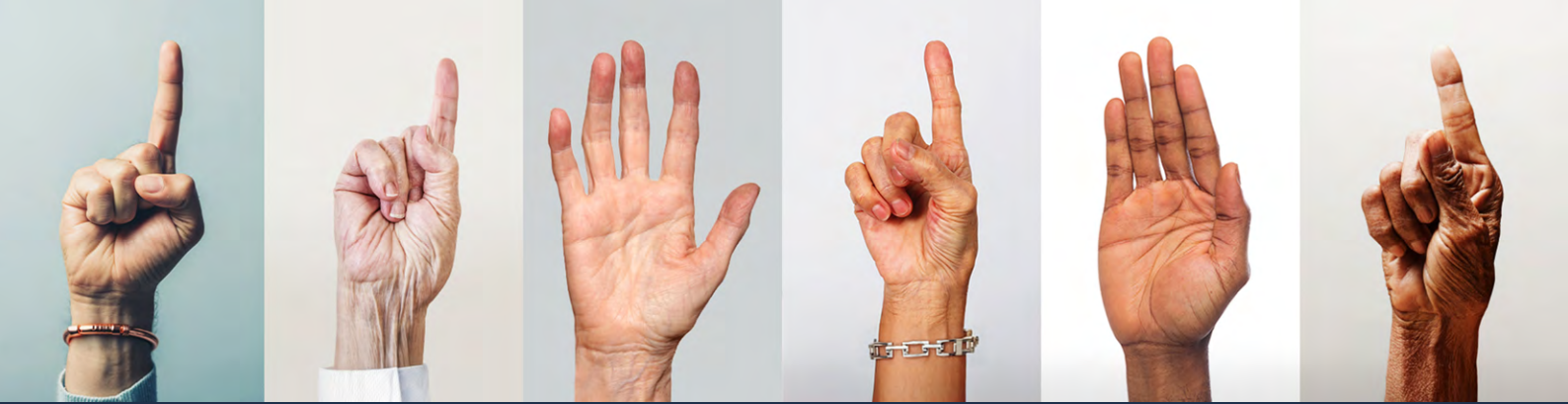
Closing implication and call to action

Listening to unsolicited online open-forum discussions provides a view of patients' real-world experiences, from making treatment decisions, through living with treatment, to dealing with its effects after therapy has ended. These findings should, however, be interpreted with caution: online discussions may not reflect the experiences of all patients, and cross-country differences may also partly reflect variation in digital access, source availability, and online participation, as well as differences in healthcare systems and cultural norms.

Overall, these discussions make clear that understanding available options, weighing their consequences, anticipating quality-of-life impact, and navigating the healthcare system should not become an additional burden placed on patients who are already living with a serious and demanding disease.

Clinical suitability helps define which treatment options are possible. Meaningful shared decision-making helps determine which of those options is right for the individual patient. The best care recognises the whole patient: what matters to them, which burdens and uncertainties they are willing to accept, and how treatment may fit into their life. Patient priorities should be considered alongside clinical evidence in the treatment decision. Where options are limited, patients should also understand why, what alternatives exist, and whether another opinion or care pathway might better meet their needs.

Shared decision-making in CLL must move from principle to routine practice. Del Carpio et al. (2026) identified four common elements across oncology-specific shared decision-making models: exchanging information, discussing alternatives, eliciting patient values and preferences, and making a decision.⁴ In CLL, putting these principles into practice means creating structured, open, two-way treatment conversations that give patients the information and opportunity they need to participate at the level that is right for them.



For the clinical community, this means going beyond explaining treatment options to ensure patients see the full picture of their treatment journey: what each option may mean during active treatment, throughout treatment-free periods, and in the event of possible relapse and further treatment. The relevant benefits, burdens, uncertainties, and trade-offs should be discussed early enough to inform the decision, rather than only as they arise. **Priorities should be actively elicited and revisited as circumstances or treatment goals change.**

For the patient community, this means feeling confident and empowered to voice goals, concerns, daily-life needs, and preferences so that treatment decisions reflect not only clinical benefit, but the realities of living with CLL.

As CLL treatment continues to advance, shared decision-making must advance with it, moving beyond simply offering choices towards a deeper understanding of what matters to each individual patient.



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White Paper

