



Global CLL Community Insights

How Stakeholders Can Collaborate to Improve Care



abbvie





About This Report

GLOBAL CLL COMMUNITY INSIGHTS:

How Stakeholders Can Collaborate To Improve Care highlights needs related to emotional wellbeing and communication with healthcare providers, especially around treatment decisions, for those living with chronic lymphocytic leukemia (CLL) and their care partners. This report is intended to help improve dialogue and increase shared decision-making in CLL.

Global CLL Community Insights leverages academic research, global and local patient surveys and solutions sourced from 18 countries all over the world.*

This report was developed and funded by AbbVie, in partnership with CLLAN (CLL Advocates Network), leveraging insights from the global CLL patient and care partner community.

*Australia, Brazil, Canada, Colombia, Czech Republic, Denmark, Estonia, Lithuania, France, Germany, Ireland, Italy, Poland, Slovakia, Spain, Switzerland, Taiwan and United Kingdom

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Introduction

Chronic lymphocytic leukemia (CLL) is a chronic cancer – **it grows slowly, and there is no cure, but there are treatments to help control the disease.**¹

People with CLL typically **live at least 10 years after diagnosis** — but this can vary from months to decades.²

The disease itself, and therapies currently available to treat it, **can have physical and emotional side effects as well as an impact on everyday life.**



Approximately

1/3 of people
with CLL will never require treatment,³ and will instead undergo “active monitoring,”

which means patients won’t receive any treatments, but their health and disease are monitored through regular visits. They will continue to remain untreated as long as they do not have any symptoms and there is no evidence that their disease is progressing.⁴

In the 2023 Global Leukemia Experience Survey (conducted by CLLAN, CML and ALAN global patient advocacy groups and collecting over 2,000 patient and care partner responses from 60 countries),

45% (n=309)
of CLL patients

who had been placed on “active monitoring” answered that they were **very confident about recognizing the symptoms of disease progression.**⁵



However, whether on active monitoring or treatment, **CLL must be surveilled and managed throughout the rest of a patient’s life.**

The experience of living with CLL varies, and **the possibility of reoccurrence continues throughout a patient’s lifetime.**

Physical and Emotional Impact on Patients

Acknowledging the impact of CLL on both the physical and emotional health of patients as a chronic and incurable cancer.

FOR PATIENTS

CLL can have **tremendous emotional impact** on the person who has been diagnosed, as well as their loved ones.

FOR HEALTHCARE PROVIDERS

it is important to address this **emotional turmoil that patients experience** not only at initial presentation of their diagnosis, but also throughout their entire life with CLL.

THE PHYSICAL

A CLL diagnosis can be riddled with uncertainty regarding prognosis and treatment, as the disease varies from one person to the next and no two journeys are the same. However, there are common symptoms that patients may experience:



According to the CLL Society, a patient advocacy group based in the U.S., **fatigue is one of the most common symptoms of CLL but is also frequently overlooked and underreported.**⁶



People with CLL are found to be more **prone to infection**,¹ and therefore more susceptible to communicable diseases, like COVID-19.⁸ CLL patients are also prone to anemia – due to overgrowing white blood cells crowding out red blood cells – as well as bleeding or bruising.⁹



A 2024 Global Patient Survey on Lymphomas & CLL conducted by the Lymphoma Coalition, which received responses from over 11,000 patients and care partners from 79 countries (22% of respondents were living with CLL), found that up to **66% of people with CLL reported fatigue as a side effect of their treatment.**⁷



In addition to the physical symptoms that are part of the disease presentation, CLL treatments' **side effects can also impact a patient's physical wellness and everyday activities.**⁷

“[Caregivers] don’t realize that taking care of themselves is taking better care of their family member: caregivers with their resting needs, leisure, satisfied emotional support will be able to have more energy and mobilize their physical and psychological resources in the care of the sick much more and better.”

- How to support the Hematological patient's caregivers, Agrupación Española de entidades de Lucha Contra la Leucemia y Enfermedades de la Sangre (AELCLÉS)

Physical and Emotional Impact on Patients

THE EMOTIONAL

People living with hematological cancers are likely to report they have experienced emotional side effects of the disease.⁷ These are some unique attributes of hematological cancers that impact a patient’s wellbeing:



In the 2023 Global Leukemia Experience Survey, **66%** (n=1,273) of patients diagnosed with a blood cancer reported that since diagnosis, **they feel anxious^A more frequently.**⁵



Overall, **one in 10 patients** (10%, n=195) **reported the symptoms and/or side effects they experienced had a moderate to severe impact on their quality of life** (scoring 16 or above out of 36).⁵



The survey found **CLL also affected patients financially**, with **30%** (n=743) reporting CLL has had an **overall negative impact since diagnosis, and socially**



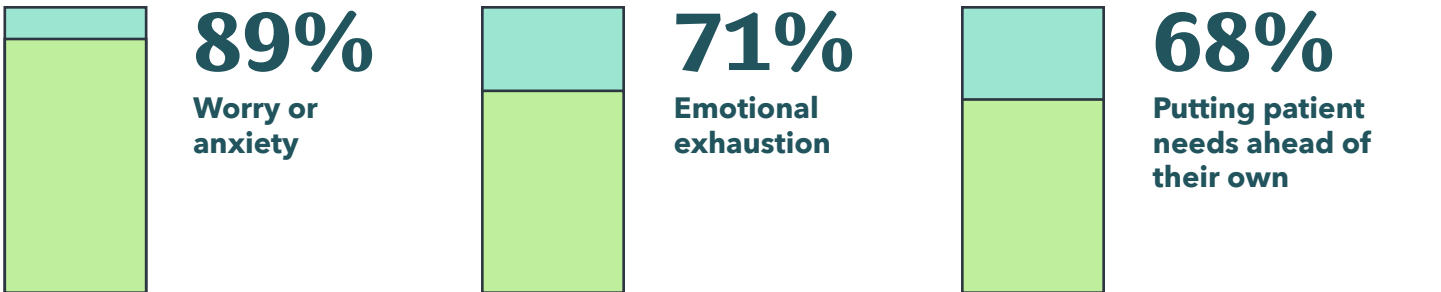
46% (n=4,237) of patients in the 2024 Global Patient Survey on Lymphomas & CLL **responded that they were afraid of relapse and that their disease would progress.**⁷



22% of patients reporting CLL impacted their mood “sometimes;” 11% reporting impacts as “very often” and 3% reporting impacts as “always” (n=750).⁵

Altogether, CLL symptoms and treatment side effects can have a substantial impact on a person’s quality of life.⁵

It is also important to address the needs of care partners in terms of both physical and psychological wellness. The majority of care partners (69%, n=375) from the 2023 Global Leukemia Experience Survey **acknowledged that caring for someone with leukemia had a moderate to an extremely large effect on their quality of life.**⁵ A 2020 Canadian survey in partnership with Lymphoma Canada and Lymphoma Coalition, which included over 603 responses from patients (n=540) and care partners (n=63), found that more than two-thirds of CLL care partners reported in the last 12 months through their responses, **they were most affected by:**¹⁰



^A “Feel anxious” refers to patients who reported always, very often or sometimes experiencing general anxiety since their diagnosis.

Collaborating Around the Challenges

Physicians' impact on physical and emotional needs.

Two surveys found that patients view their healthcare providers as the primary source of information about CLL and their options for managing the disease.



The 2024 Global Patient Survey on Lymphomas & CLL found that 67% (n=7,488) of people with lymphoma **prefer to receive information about their disease in conversations with healthcare staff.**⁷



A global survey entitled VOICE (The Virtual Opinions poll Independent Centered on CLL patients' Experience) found that 90% (n=374) of patients **relied on their physicians to answer questions about CLL and its treatments.**¹¹

Expectations for interactions with healthcare providers are also consistent across different countries, based on evidence from three separate surveys:



FRANCE:

In a survey of over 1,000 patients living with CLL from France,

60%

(n=1,294) of patients **ranked their healthcare provider as their preferred source of information.**¹²



AUSTRALIA:

A study of 70 patients diagnosed with CLL participated in a qualitative structured interview and quantitative questionnaire, conducted by the Centre for Community-Driven Research with

57%

(n=40) of **patients reporting an overall positive experience with their provider while navigating their CLL diagnosis.**¹⁴



CANADA:

The previously mentioned 2020 Canadian survey found that

65%

(n=603) of **patients and their care partners reported they always had confidence in the doctors that were treating them.** An additional 31% of patients and care partners reported that they sometimes had confidence.¹³



Collaborating Around the Challenges

CURRENT GAPS IN COMMUNICATION AND EDUCATIONAL NEEDS

Two global patient surveys show respondents may still need more upfront information about CLL and potential treatments, and ongoing education to help them better understand their disease journey:



In the 2023 Global Leukemia Experience Survey, less than half of patients (44%, n=770) **stated that they had been given or directed to written information about leukemia at diagnosis**; patients aged 56-65 (81%, n=410) and 76 and over (84%, n=131) were least likely to receive information.⁵



When it comes to information on clinical trials, **nearly half of respondents** (48%, n=4,632) in the 2024 Global Patient Survey on Lymphomas & CLL **responded that they did not receive any information about clinical trials.**⁷



In the same survey, **46%** (n=3,150) of **patients who experienced fatigue reported their doctor had not provided them with any fatigue related information over the past two years.**⁷



46% (n=4,237) of patients in the 2024 Global Patient Survey on Lymphomas & CLL **responded that they were afraid of relapse and that their disease would progress.**⁷



"I let every doctor know that I want to be informed. Now, I will read anything and everything associated to my medical condition."

I write down questions that I want to ask the doctor for my next appointment, so I don't forget. I find that when you go to your oncology appointments at the clinic, they don't spend very long with you."

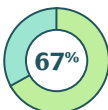
– PEEK Study, Australia¹⁴

Collaborating Around the Challenges

OPEN COMMUNICATION AND EASILY ACCESSIBLE INFORMATION ARE KEY FOR HOLISTIC DISEASE MANAGEMENT



When asked about understanding diagnostic test and results, **only 51%** (n=5,709) of participants surveyed in the 2024 Global Patient Survey on Lymphomas & CLL **noted that these were completely explained in a way they could understand.**⁷



According to the Lymphoma Coalition’s Global Patient Survey on Lymphoma & CLL 2024 Highlights Report, 67% of patients (n=9,233) and 91% (n=1,071) of care partners **said they had experienced emotional effects related to lymphoma in the past six months,**



A majority of patients and care partners (58%, n=603) in the 2023 Global Leukemia Experience Survey **agreed that their doctor was able to partially address the patient’s symptoms,** while only 14% felt their doctor fully addressed symptoms.¹³



only 60% of patients **received recommendations from their medical team on managing their emotional concerns.**



Regarding fatigue specifically, of the 53% (n=2,313) of people who reported fatigue in the 2024 Global Patient Survey on Lymphomas & CLL, **they were not provided with any help from their healthcare team.**⁷

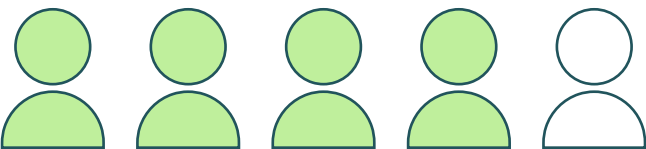


Additionally, only 38% of patients declared that **their doctor greatly understands the impact of lymphoma or CLL on their quality of life.**¹⁵

Additionally, the term “watch and wait” commonly used to describe the period when the patient is not receiving treatments can also be a source of anxiety for some individuals; generally, the expression “active monitoring” is preferred.¹⁶

In fact, following a CLL diagnosis, 79% (n=8,762) of patients and 46% (n=5,123) of care partners in the 2024 Global Patient Survey on Lymphomas & CLL sought information.⁷

4 out of 5
patients



Nearly half
of care partners



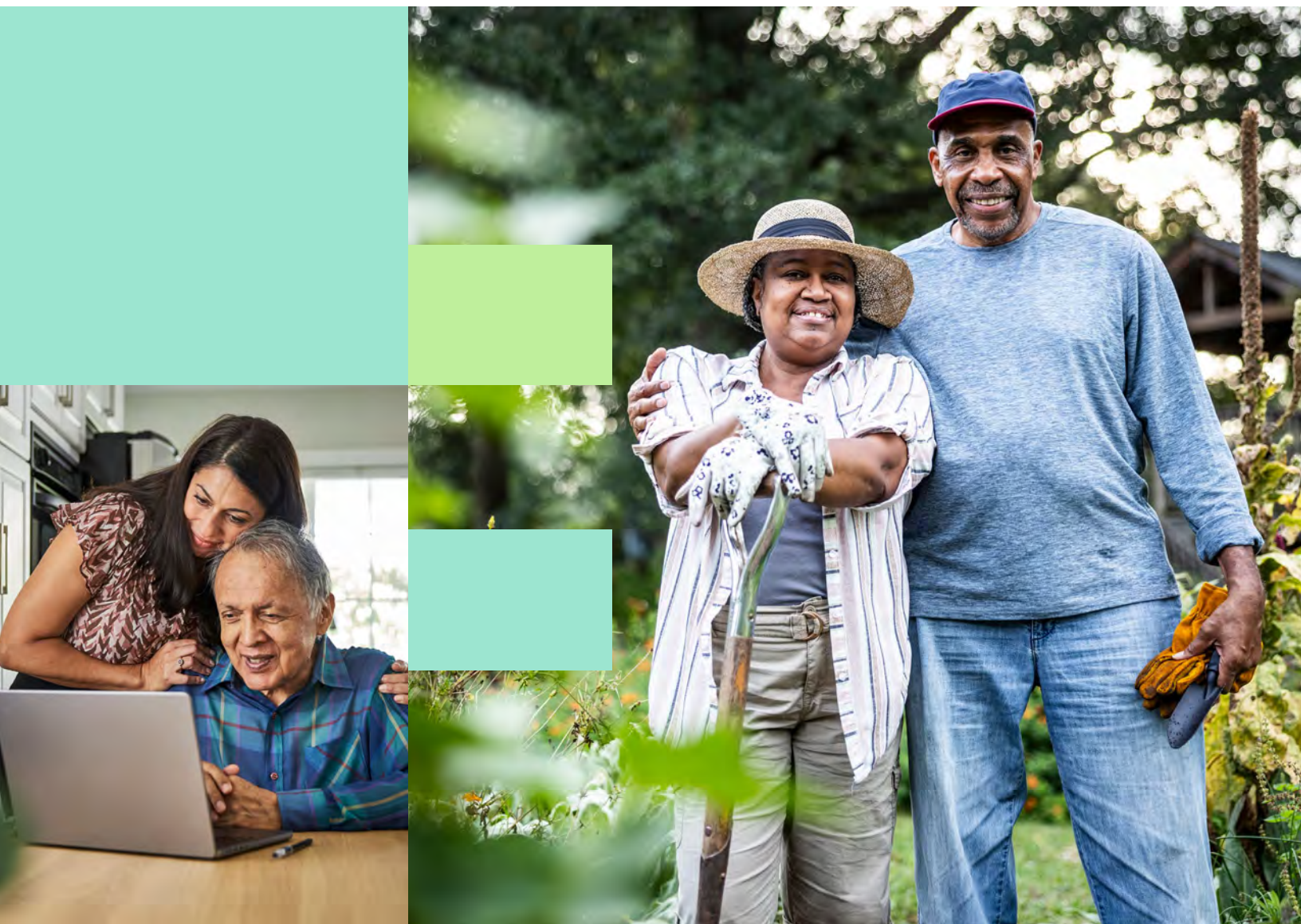
Collaborating Around the Challenges

BRIDGING THE GAPS

As the Global Patient Survey Highlights report 2024 points out, opportunities exist to improve dialogue and collaboration between patients, doctors, nurses and patient organizations and positively impact their experience.

For patients who receive personalized education, this encourages them to be an active participant in decisions about their care and treatment options, which results in better outcomes and overall patient satisfaction.¹⁷ HCPs should also proactively create space for those conversations.

Referring patients to educational resources and support services can also help in bridging some gaps of information. According to the Lymphoma Coalition's Global Patient Survey on Lymphoma & CLL 2024 Highlights Report, **86% (n=11,086) of respondents said they used information from patient organizations**, with websites being the most used resource from an organization.¹⁵



Shared Decision-Making

Embracing shared decision-making for improved quality of life.

According to the same survey from Lymphoma Coalition, when patients are involved in their care and treatment and work together with their healthcare teams to decide on treatment goals and plans, it can improve health outcomes.¹⁵ **While healthcare providers are the technical experts on CLL and treatment options, patients and their care partners are the experts on how the disease affects daily life - and this duality can lead to shared decision-making.** However, there are gaps to address in order to optimize the relationship between a patient and provider.

BEING INVOLVED IN MORE DECISIONS

About half of CLL patients (52%, n=228) from the 2023 Global Leukemia Experience Survey reported they were involved as much as they wanted to be in decisions about their treatment.⁵ **This leaves opportunities to involve more patients in shared decision-making conversations.**

IMPROVING CHOICES IN TREATMENT DECISIONS

76% (n=7,936) of respondents in the 2024 Global Patient Survey on Lymphomas & CLL prefer that they make the decisions, yet **70% (n=5,240) were not given more than one treatment choice before their most recent treatment.**⁷

ACKNOWLEDGING THAT SHARED TREATMENT DECISION-MAKING TRENDS VARY BY COUNTRY:

The 2023 Global Leukemia Experience Survey reveals patients in:



China (45%, n=154) and **Brazil** (43%, n=87) were **most likely to report a choice of treatment options was offered to them.**



The **Netherlands** (79%, n=55) and **Denmark** (74%, n=75) were **most likely to report they were not offered a choice of treatment options.**⁵

DURATION OF TREATMENT AND ACTIVE MONITORING - IMPACT ON QUALITY OF LIFE

As part of shared decision making, duration of treatment may be an important factor to consider when choosing a therapeutic approach. The 2023 Global Leukemia Experience Survey revealed **58% (n=1,124) of patients responded positively to treatment plans that contained treatment-free periods or included stopping treatment altogether.**⁵

An analysis from 20 interviews from a small survey of 229 patients with a self-reported diagnosis of CLL from a discrete-choice experiment (DCE) survey suggested **some patients perceive fixed-duration treatment as an opportunity to be free from medication and restore their sense of being in control.**¹⁸



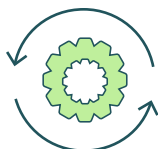
Shared Decision-Making

The same DCE survey also reported that treatment duration is an important factor in choosing a CLL therapy; almost all individuals interviewed (n=17/20) noted that they preferred a treatment with a fixed duration compared with treating to progression.¹⁸

Additional qualitative insights collected from the survey noted that patients have associated the benefit of fixed-duration treatment with:¹⁸



Convenience,
such as ability
to not take a
treatment, having
freedom from
medication and
not having to
refill a medication



**Being more
in control**



**Limited drug
exposure while
off treatment**

Additionally, a recent survey of 123 patients diagnosed with chronic lymphocytic leukemia, mantle cell lymphoma, follicular lymphoma and Waldenström's macroglobulinemia, initiated by Danish hematology patient advocacy group Lyle and conducted by Molecule Consultancy, found that **most participants were satisfied with transitioning to a medicine-free period (47%), with 32% perceiving it as a sign of their health improving.**¹⁹

However, patients who have time off treatment and who are undergoing active monitoring need supportive resources. CLLAN conducted an analysis of the 2023 Global Leukemia Experience Survey data to examine diagnostic pathways, immunity status and treatment decision experiences specifically for people with CLL (846 responses out 2,260 patient responses were from patients with CLL in 30 countries). The analysis found:²⁰



When asked who helps with pain or symptoms while on active monitoring 52% (n=145/280) of **patients responded that they self-manage without help;**

Respondents who did not fully understand the active monitoring strategy may lack adequate support, clear information and education in managing symptoms;



Near half (45%, n=309/689) respondents with CLL were "definitely confident" in their ability to recognize the signs and symptoms of CLL progression.

People need to be educated on how to recognize disease progress and when to reach out to their medical team for advice.

As part of the vulnerabilities of the disease as it relates to infection, **respondents who did not receive clear information about what steps to take to stay healthy and avoid infections reported worse quality of life.**²⁰

Actionable Solutions and Concluding Concepts

Concluding with actionable solutions.

1.

RECOGNIZE AND ADDRESS THAT CHALLENGES GO BEYOND PHYSICAL NEEDS

CLL creates both a physical and emotional burden for patients and their care partners;⁷ **an understanding of these struggles and ability to provide resources to address these challenges as well as improving overall wellness and quality of life for the patient is vital.**

2.

PROACTIVE CARE IS KEY TO IMPROVED OUTCOMES

Patients and their care partners may not understand what symptoms they should report or what steps they need to take to stay healthy and avoid infections. Thus, **healthcare providers should engage with them proactively and communicate in a concise and easy to understand manner to identify their needs, which can be an important step to enhancing their wellbeing and quality of life.**

3.

CREATING A MULTIDISCIPLINARY CARE TEAM THAT PROVIDES A BREADTH OF ONGOING SUPPORT IS CRITICAL TO IMPROVING TREATMENT ADHERENCE AND QUALITY OF LIFE

Both patients and care partners place a great deal of trust on their healthcare providers by counting on them to provide relevant information about CLL and its treatment options. **Building a multidisciplinary care team to include a variety of providers is vital to collaborative care and helps to share the responsibility of care among doctors, nurses, patient advocacy groups and others to improve patient experiences.** For example, a full team can consist of an oncologist, primary care provider, mental health counselor and other professionals to provide support in financial and spiritual areas.²¹ Patient advocacy and community groups can help providers aid their efforts to inform patients and care partners on the disease and available treatment options as well as navigating the emotional roller coaster of the cancer chronicity.

4.

SHARED DECISION-MAKING AND PERSONALIZED TREATMENT PLANS CAN HELP IMPROVE OUTCOMES IN PARTNERSHIP WITH CLEAR COMMUNICATION AND RESOURCES

Encouraging shared decision-making and understanding how a patient would like to be involved, as well as their preferences in terms of treatment goals, can help healthcare providers match the right therapy to each patient, improving the outcomes that matter most to them. For patients undergoing active monitoring, care teams should ensure that educational resources are made available and consistent, clear communication is used to help patients manage their symptoms and track any progression.²⁰



Sampling of Resources and Global Initiatives

Note: The link provided in this section is to a website not under the control and influence of AbbVie.

GLOBAL PATIENT ADVOCACY GROUP RESOURCE



Thank you to the global CLL patient and care partner community for sharing their voices, insights and resources on these important topics.

1. Mayo Clinic. Chronic lymphocytic leukemia. <https://www.mayoclinic.org/diseases-conditions/chronic-lymphocytic-leukemia/symptoms-causes/syc-20352428>. Accessed September 2024.
2. AJMC. Chronic Lymphocytic Leukemia: An Overview of Diagnosis, Prognosis, and Treatment. <https://www.ajmc.com/view/ll-overview-diagnosis-prognosis-treatment>. Accessed September 2024.
3. Shadman, M. Diagnosis and Treatment of Chronic Lymphocytic Leukemia: A Review. JAMA. 2023; Mar 21;329(11):918-932. doi: <https://doi.org/10.1001/jama.2023.1946>
4. Lymphoma Research Foundation. Treatment Options. <https://lymphoma.org/understanding-lymphoma/treatment-planning-and-options/treatments/active-surveillance/>. Accessed September 2024.
5. ALAN, CMLAN, CLLAN and Picker. Global Leukemia Experience Survey 2023 Report. July 2024. <https://acuteleuk.org/wp-content/uploads/2024/10/P-101824-Global-Leukemia-Experience-Survey-2023-Report-FINAL.pdf>
6. CLL Society. Cancer-Related Fatigue. <https://cllsociety.org/ll-sll-patient-education-toolkit/cancer-related-fatigue/>. Accessed September 2024.
7. Lymphoma Coalition. 2024 Global Patient Survey on Lymphomas & CLL. <https://lymphomacoalition.org/wp-content/uploads/P-101874-Lymphoma-Coalition-GPS-2024-Global-Report-FINAL-A4-1.pdf>. Accessed October 2024.
8. Ng, et al. Managing and treating COVID-19 in patients with hematological malignancies: a narrative review and expert insights. Clin Exp Med. 2024; 24(1): 119. doi: <https://doi.org/10.1007/s10238-024-01381-5>
9. Penn Medicine. Chronic Lymphocytic Leukemia (CLL). <https://www.pennmedicine.org/cancer/types-of-cancer/leukemia/types-of-leukemia/chronic-lymphocytic-leukemia>. Accessed September 2024.
10. Lymphoma Canada. Key Findings from the 2020 Canadian Lymphoma Report Card. https://www.lymphoma.ca/wp-content/uploads/2021/04/Caregiver-Infographic_WEB.pdf
11. Tam C, Pinilla-Ibarz J, Castillo CG, et al. Results of VOICE: a global survey of disease-specific knowledge and perspectives of real-world patients with CLL. Blood Adv. 2023;7(22):6819-6828. doi: <https://doi.org/10.1182/bloodadvances.2023010879>
12. Lymphoma Coalition. 2022 Global Patient Survey on Lymphomas & CLL. Country Report: France. Lymphoma Coalition 2022 Global Patient Survey on Lymphomas & CLL October 2022. <https://www.ellye.fr/fr/f29905366ae3cbe11a36a36a13b6074e7608c17/LC%20GPS%202022%20France%20Report%20FINAL%20Updated%20Nov%2017.pdf>
13. Lymphoma Canada. The CLL Patient Experience. https://www.lymphoma.ca/wp-content/uploads/2021/04/CLL-ReportCard_SINGLES.pdf. Accessed October 2024.
14. Centre for Community-Driven Research (CCDR). Personal Experience Expectations and Knowledge (PEEK) study: People diagnosed with chronic lymphocytic leukaemia. Volume 3, Issue 2 (2020). https://www.cc-dr.org/wp-content/uploads/V3I2_2020AUCCLL_FULL-REPORT.pdf
15. Lymphoma Coalition. Global Patient Survey on Lymphomas & CLL 2024 Highlights Report. Accessed October 2024. https://lymphomacoalition.org/wp-content/uploads/2024_Global_Patient_Survey_VF_Digital_A4-1.pdf
16. Kyrou, et al. The Looming Cancer: A Qualitative Study on the Experience of Living with Chronic Lymphocytic Leukemia (CLL) before the Initiation of Treatment. European Journal of Cancer Care. 2024; Feb 24. doi: <https://doi.org/10.1155/2024/4034801>
17. Bhattad, et al. Promoting Patient Education and Health Literacy. Cureus. 2022 Jul 27;14(7):e27336. doi: <https://doi.org/10.7759/cureus.27336>
18. Ravelo, et al. Patient Preferences for Fixed Versus Treat-to-Progression Therapies in Chronic Lymphocytic Leukemia. Blood 2023; 142 (Supplement 1): 3706. doi: <https://doi.org/10.1182/blood-2023-174719>
19. Lyle and Molecule Consultancy. Patients' experience of medication-free periods. <https://lyle.dk/patients-oplevelse-af-medicinfrie-perioder/>
20. CLLAN. Insights from the 2023 Global Leukemia Experience Survey: CLL specific findings, unmet needs and recommendations for action. September 2024. <https://www.clldadvocates.net/wp-content/uploads/2025/01/Insights-from-the-2023-Global-Leukemia-Experience-Survey-CLL-specific-findings-unmet-needs-and-recommendations-for-action.pdf>
21. AJMC. Team Effort: Dr Brian Koffman Describes Multidisciplinary Care for Patients With CLL. <https://www.ajmc.com/view/team-effort-dr-brian-koffman-describes-multidisciplinary-care-for-patients-with-ll>. Accessed September 2024.