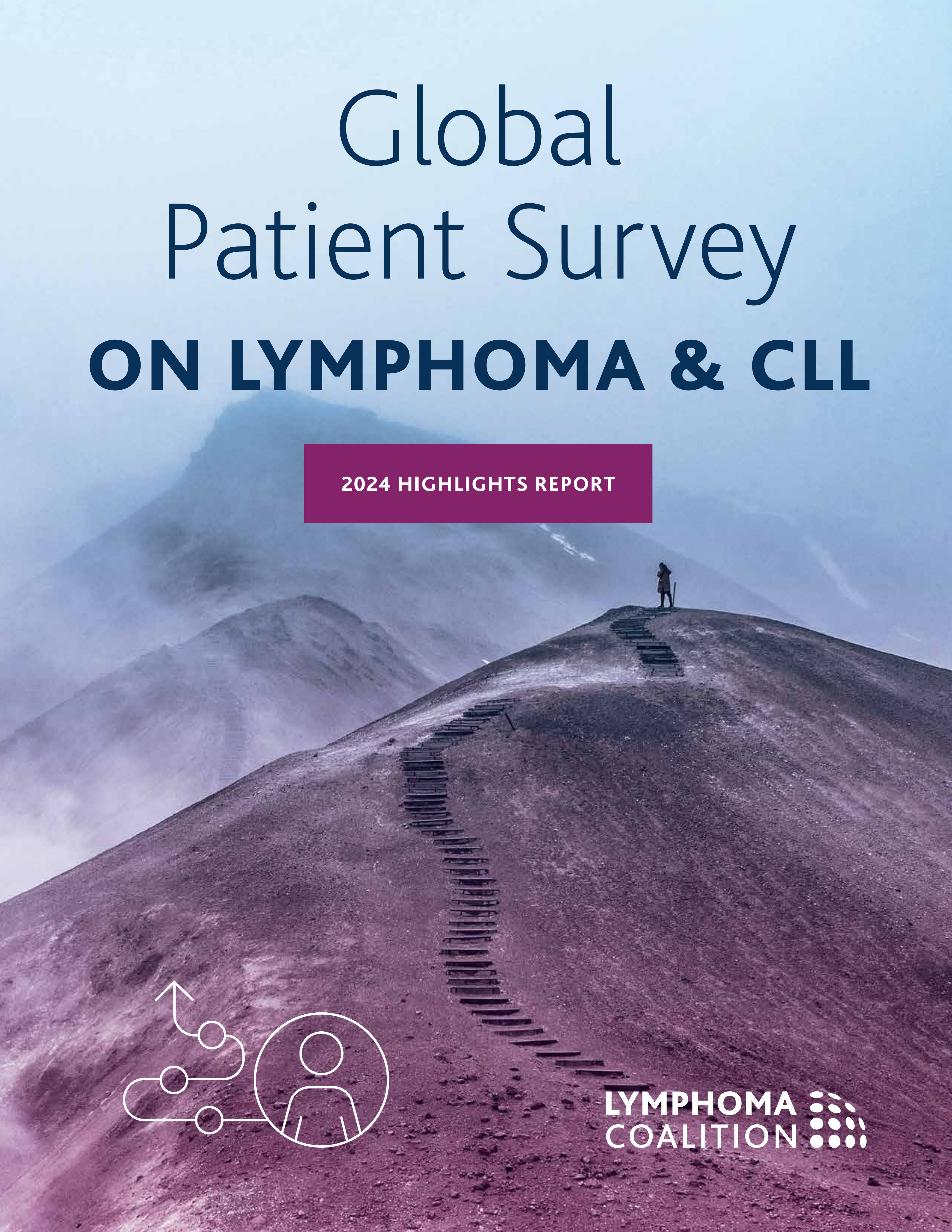
Global Patient Survey ON LYMPHOMA & CLL

2024 HIGHLIGHTS REPORT



LYMPHOMA COALITION

Message from Lymphoma Coalition

We're excited to share the 2024 edition of the Global Patient Survey on Lymphoma & CLL Highlights Report, which features key findings and trends observed in the biennial survey.

Lymphoma Coalition, together with the support of member organisations, was one of the first global patient organisations to survey the experiences of patients and care partners, which has now become a practice across the global cancer community. First launched in 2008, the Global Patient Survey was created to deeply understand the patient experience through the shared insights of people from around the world living with lymphomas, including CLL, and their care partners. Over the years, tens of thousands of people have participated, creating a sustained, long-term body of data.

To do this sophisticated work, Lymphoma Coalition has invested in recruiting a skilled team of people that brings years of research and analytical experience. This allows us to continuously improve and evolve the survey to respond to a changing healthcare landscape and specific member needs. In 2024, the survey underwent extensive review and introduced new topics, which included health literacy and comprehension of medical terms and treatment options. In addition, health-related quality of life and performance status were also assessed, which will allow for the framing of our findings in a more clinical context.

The data generated from the survey puts evidence at the centre of our work – planning and policy development, bridging knowledge gaps and advocating for equitable access to treatment and care across borders. Patient experiences from the survey have served as the foundation of scientific abstracts, publications, reports and the development of resources for those affected by lymphoma. The data findings have anchored successful awareness campaigns and presentations to healthcare professionals and other stakeholders who play a role in patient care.

We invite you to learn more about the patient and care partner experience in the pages ahead. Together we can ensure the voices of patients and care partners are heard and have an impact by helping shape the global lymphoma landscape.

Lorna Warwick

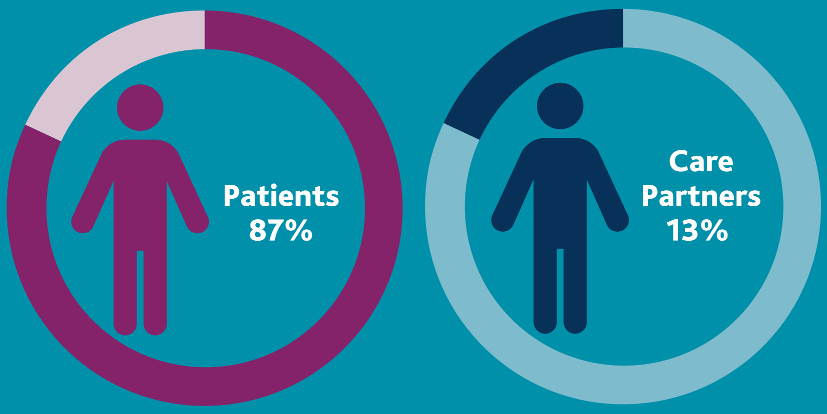
Lorna Warwick
CEO, Lymphoma Coalition

2024 Survey Demographics

In 2024, 11170 people from 79 countries completed the Global Patient Survey on Lymphoma & CLL, which represents a 29% increase over the 2022 survey.

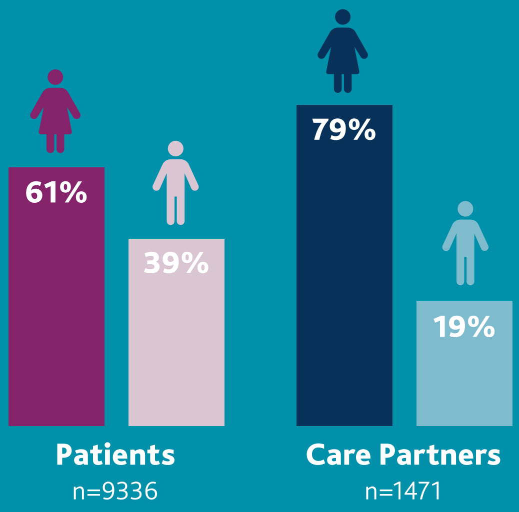
Patients vs Care Partners

The majority of respondents were people living with lymphoma or CLL.



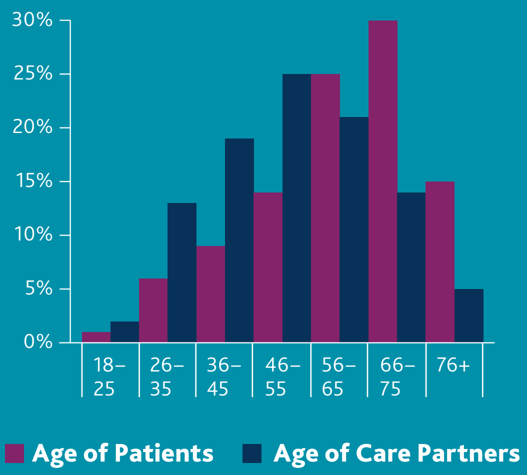
Women vs Men

More women than men – both patients and care partners – completed the survey.



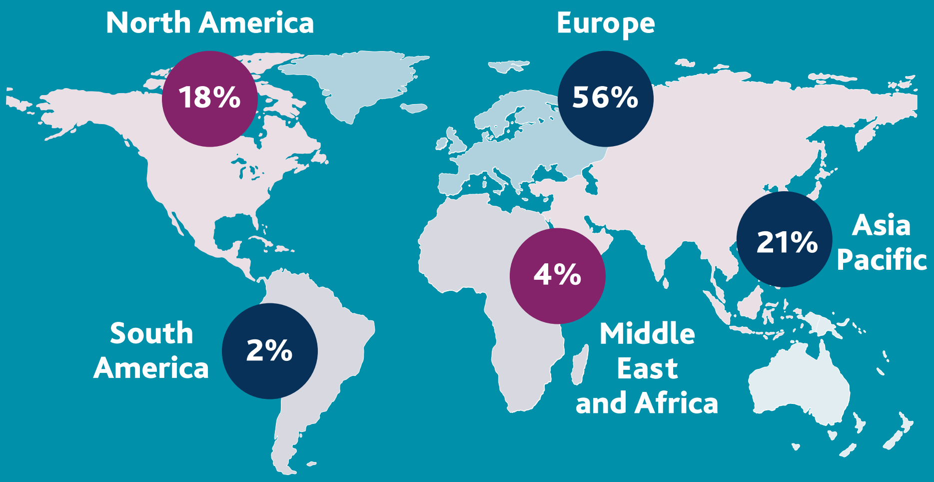
Age

The survey was open to people over 18. Most care partners are middle-aged, while 70% of patients are over 55.



Geographic Breakdown

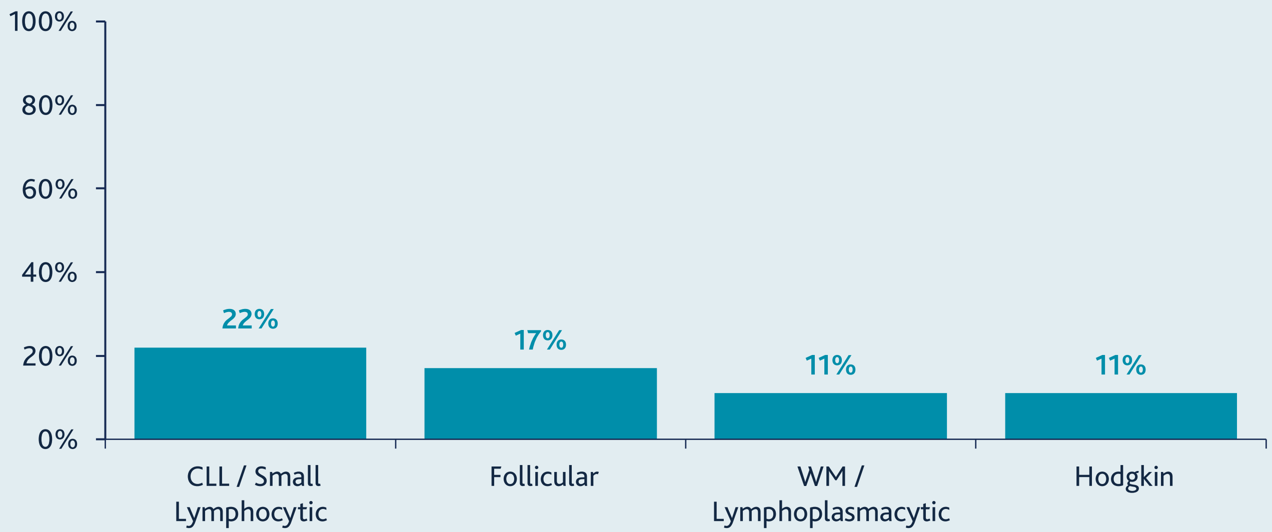
Countries with the most responses included France (17%), the United Kingdom (11%) and the United States (10%).



Diagnosis

The experience a person has at the time of diagnosis with lymphoma or CLL can set the course of how they navigate and participate in their care. This includes how long it takes to receive a diagnosis and its accuracy, and how well this information is shared with the individual.

Most Common Subtypes of Respondents



WM = Waldenstrom Macroglobulinemia

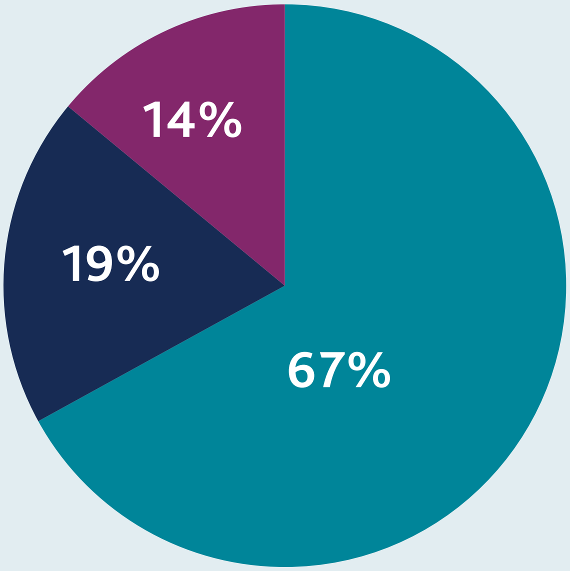
n=11170

According to the survey, most people (68%) received a diagnosis of lymphoma or CLL within three months of first seeking medical care for their symptoms. This establishes a trend of improvement over the findings in 2022 (61%) and 2020 (50%).

Understanding the details of diagnosis is critical to understanding treatment and care options. Similar to 2022, 66% of respondents were told their subtype when they were first diagnosed, while 26% were not and another 8% were unsure.

Global campaigns like *Know Your Subtype* and *We Can't Wait to Track Subtypes* raise awareness about the importance of understanding subtypes.

Misdiagnosis

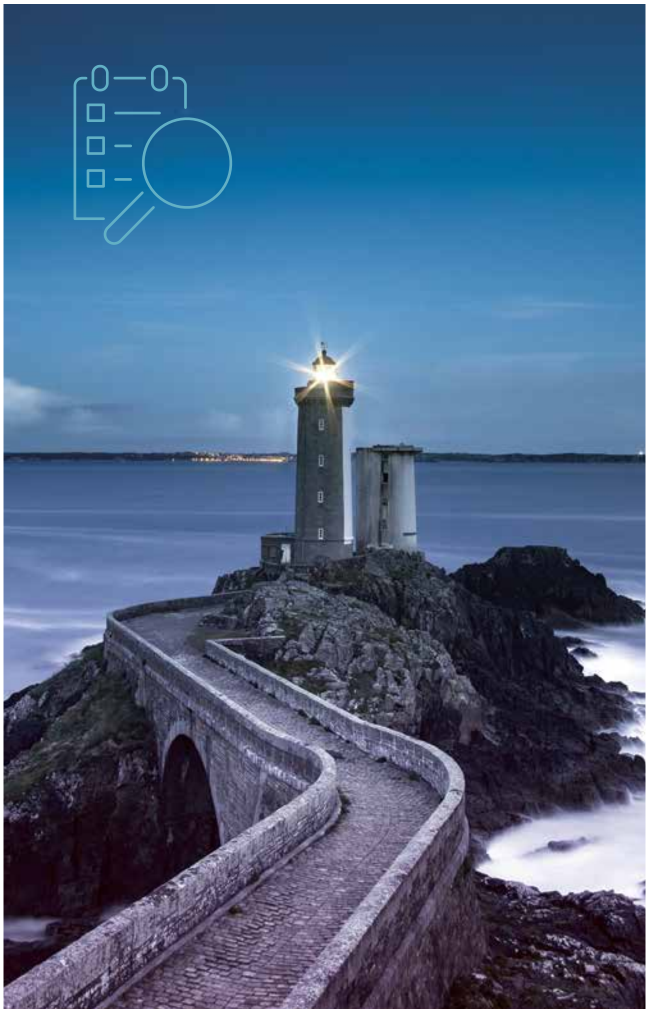


n=11003

One-third of respondents (33%) did not receive a correct first diagnosis.

A correct diagnosis is critical in beginning the right treatment pathway. However, one-third of respondents had one or more incorrect diagnoses before their lymphoma or CLL was confirmed.

Most respondents said they understood the way their diagnostic tests and results were explained. Specifically, 51% said they understood their diagnostic results completely and 37% said yes, to some extent. Only 3% said they didn't understand the results and 6% said they didn't receive any explanation of their diagnostic test results, which means one of every 10 patients is lacking this information.

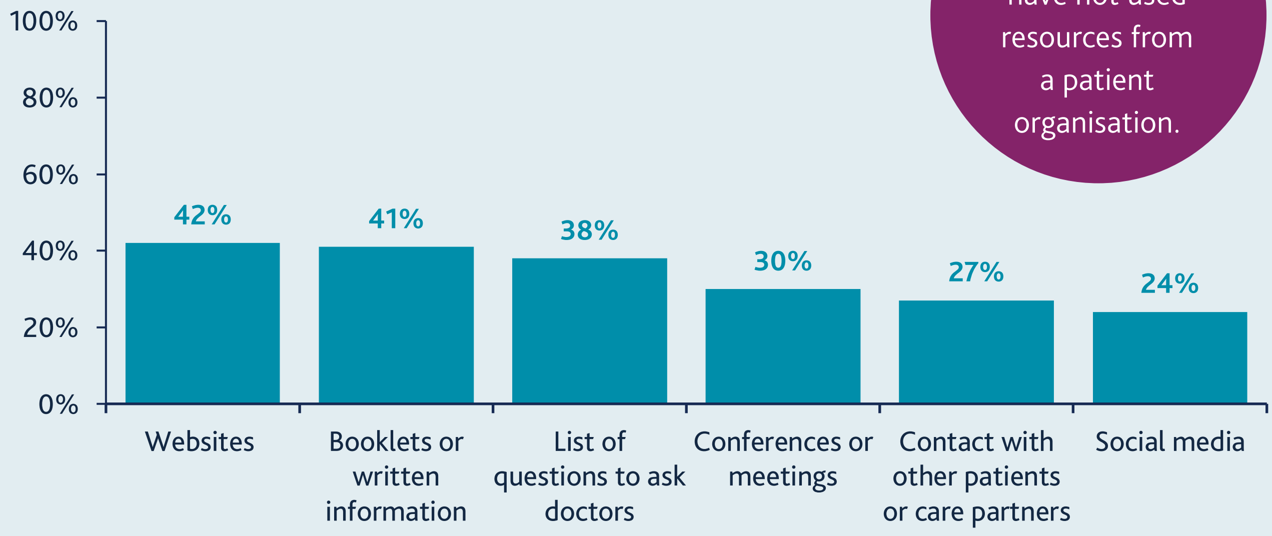


Information Sources

Whether at diagnosis, a change in treatment or when treatment is finished, information needs of people affected by lymphoma and CLL are high. Nearly four out of five (79%) patients and nearly half (46%) of care partners looked for disease or treatment information after diagnosis. Only 5% said no-one looked for additional information beyond what was told to them by their medical team.

Most respondents (67%) said their preferred information source is conversations with their healthcare providers. However, given the increase in demands and decrease in time spent with patients, healthcare providers cannot be expected to provide all the information and support for patients.

Patient Organisation Resources



n=11086

Only 14% of respondents have not used resources from a patient organisation.

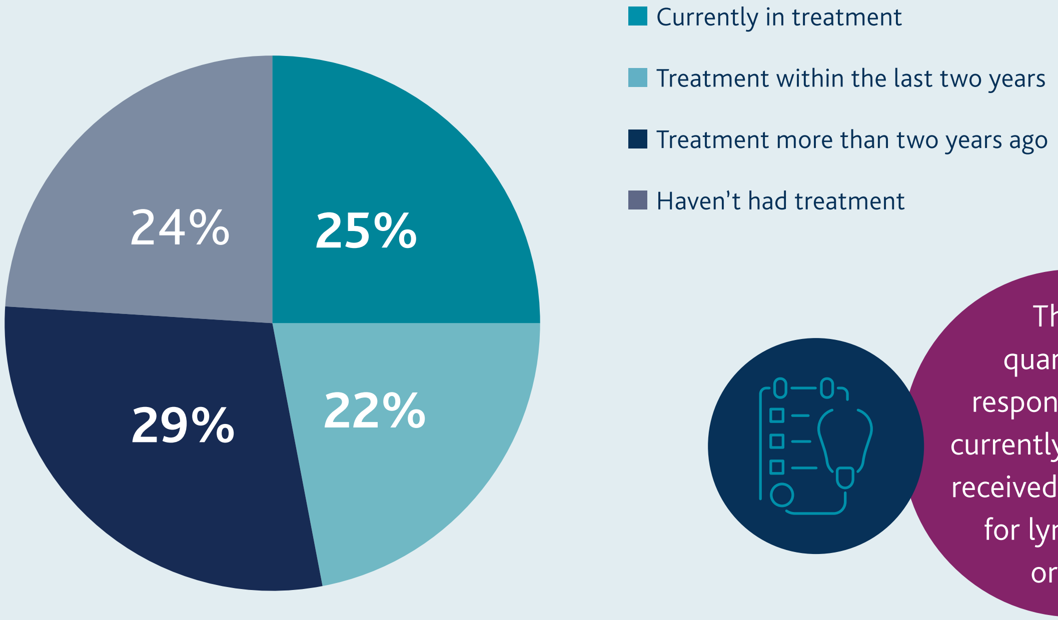
Role of Patient Organisations

Patient organisations are playing an important role in filling the information gap. According to the survey, 86% of respondents said they used information from patient organisations, with websites being the most used resource.

Treatment

Most people with a lymphoma or CLL diagnosis will undergo treatment for their cancer. But because of the many lymphoma subtypes with specific treatment and care needs and due to differences in global and regional standards of care, individuals' treatment experiences can vary substantially.

Treatment Status



n=10333

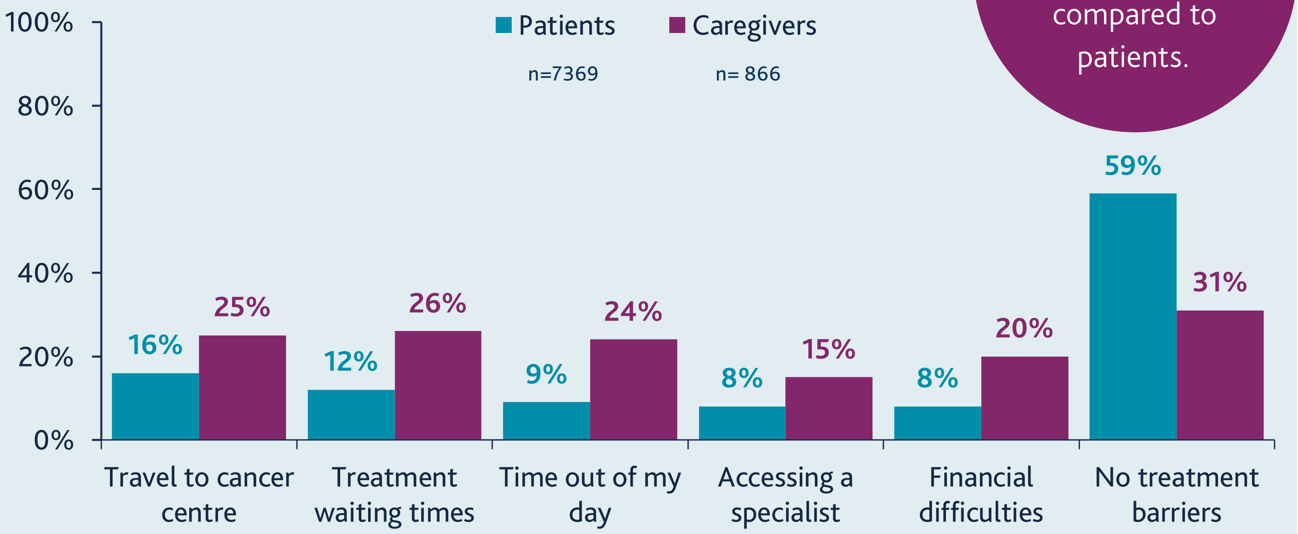
Three-quarters of respondents are currently in or have received treatment for lymphoma or CLL.

When asked about what treatment they are receiving or have received 56% said chemo-immunotherapy, 23% said chemotherapy alone, 23% said immunotherapy alone, 17% said radiation and 16% said steroids. These differences can be explained by different lymphoma subtypes, local access to treatments and the evolution of improved lymphoma care.

Barriers to Treatment

Getting the right treatment at the right time is a cornerstone of excellent cancer care, and it is important to work to reduce any barriers that stand in the way. According to the survey, most patients (59%) said they did not face any barriers to treatment, however when care partners were asked the same question, only 31% felt the same way.

Barriers to Treatment

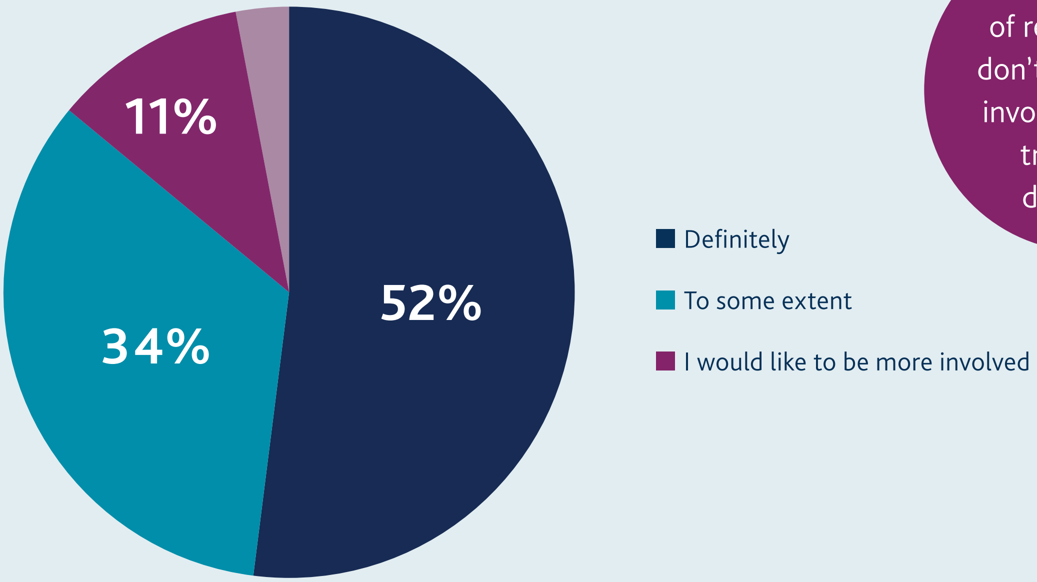


More care partners are experiencing barriers compared to patients.

Shared Decision-Making

When patients are involved in their care and treatment, working together with their healthcare teams to decide on treatment goals and plans, it can improve health outcomes.

Do You Feel as Involved as You Want to Be in Healthcare Decisions?



n=9451

Only 1% of respondents don't want to be involved in their treatment decisions.

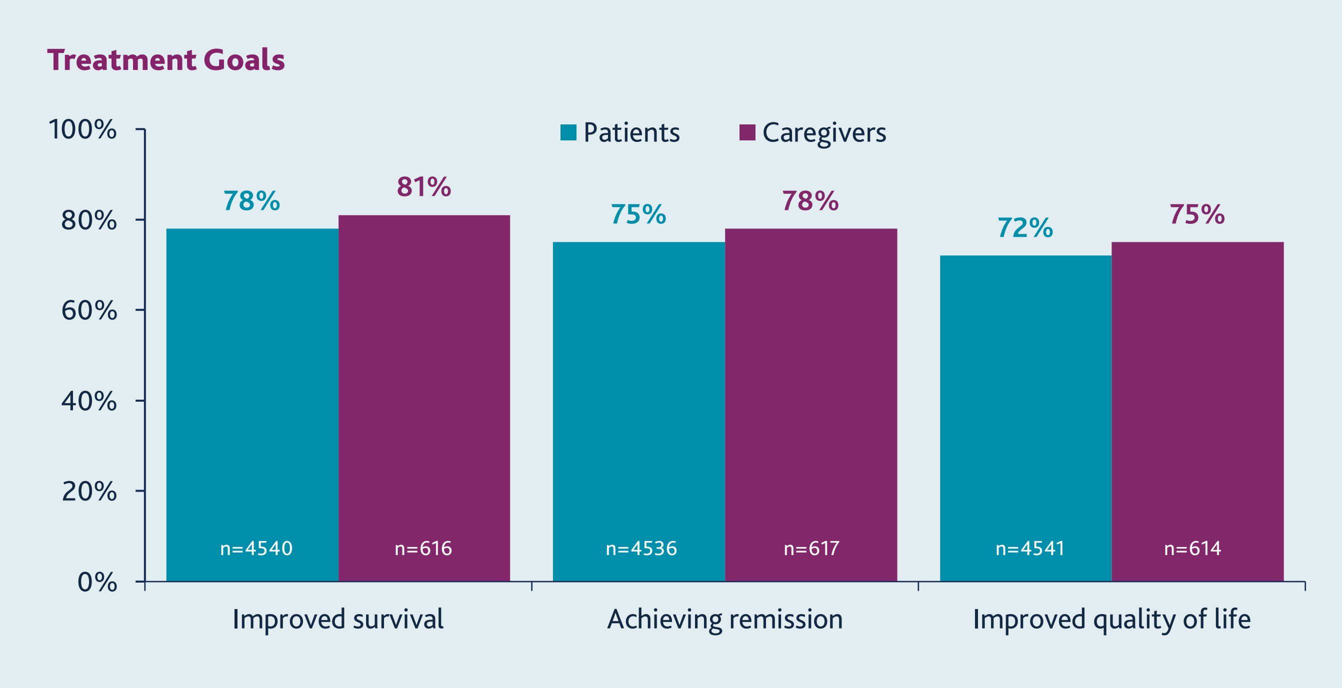
Similar to the survey in 2022, half of respondents (52%) are as involved in their treatment decisions as they would like to be.

The relationship between patients and care teams plays an important role in improving communication and patient involvement.

- 65% of respondents said their doctor encourages questions (always and mostly)
- 75% of respondents said their doctor ensures they understand the answer (always and mostly)
- 86% of respondents said their doctor talks in a kind and sensitive way (always and mostly)

Treatment Goals

When asked about their treatment goals, patients and care partners had similar priorities.



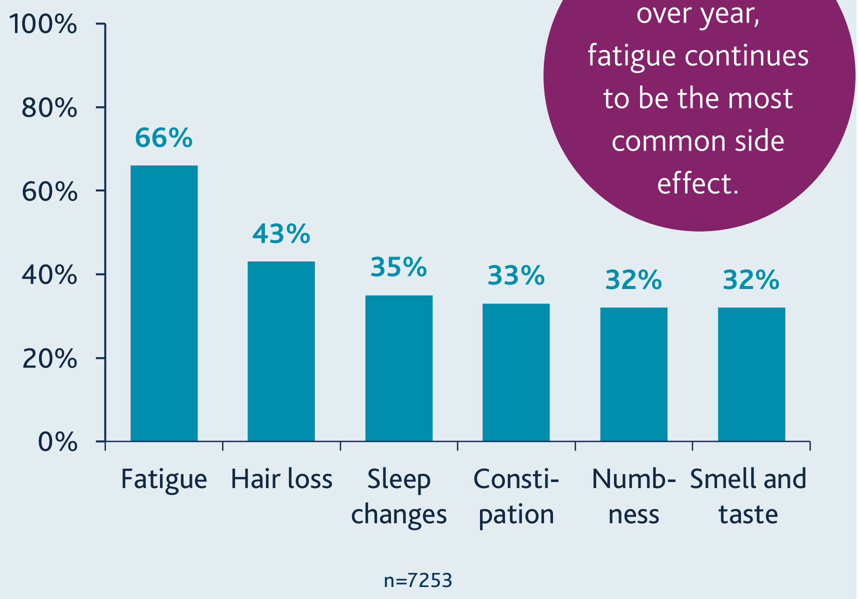
Honest Talk

96% of people said it is important their doctor tells the full truth about the diagnosis or test results when breaking difficult news.

Living with Lymphoma & CLL

There are many ways a lymphoma or CLL diagnosis can affect a person's life. The disease and treatment can result in physical and emotional side effects and have an impact on everyday activities.

Most Common Physical Side Effects



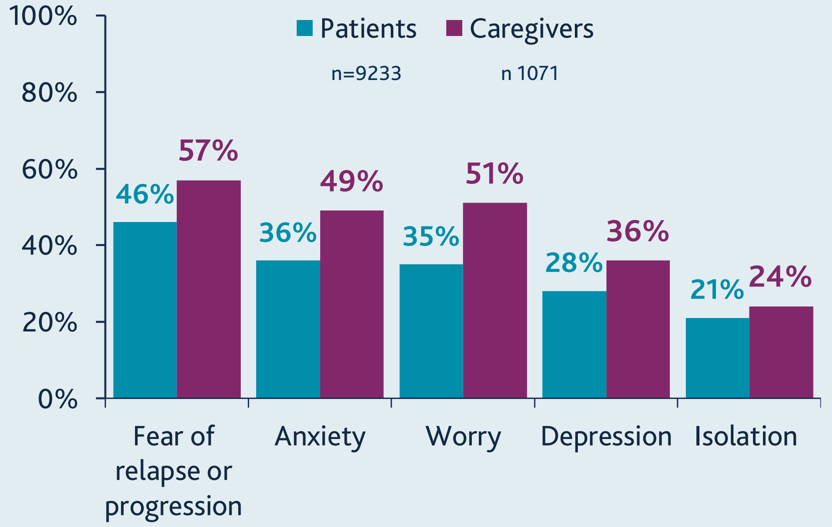
Year over year, fatigue continues to be the most common side effect.

Physical Side Effects

The survey found 94% of patients experienced physical side effects from their treatment.

Fatigue is both a symptom of lymphoma and a side effect of cancer treatment, and it affects many aspects of patients' lives. Yet, 53% of people who reported it were not provided with any help from their healthcare team.

Most Common Emotional Side Effects



Emotional Side Effects

Living with lymphoma or CLL can be hard and affects how many people feel. According to the survey, 67% of patients and 91% of care partners said they had experienced emotional effects related to lymphoma in the past six months.

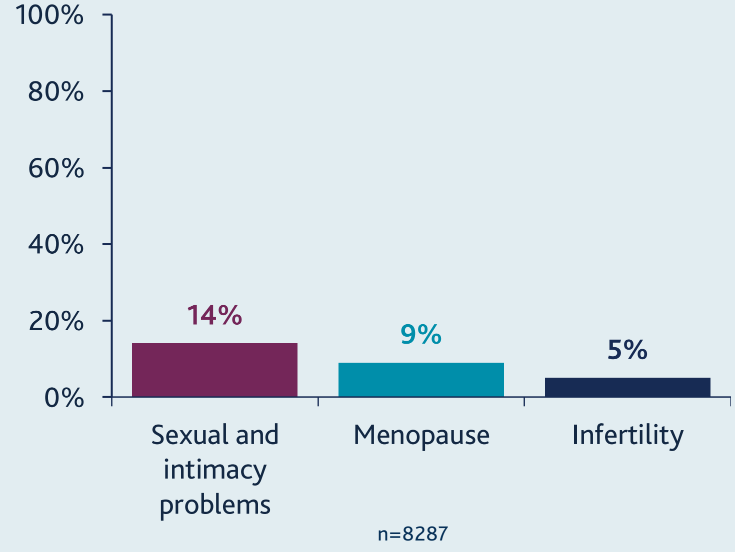
Honest conversations between people with lymphoma and their healthcare team can help address any emotional concerns and connect patients to specialists and resources. Only 60% received recommendations from their medical team on manging their emotional concerns. However, the survey found only half of patients (51%) completely followed through on their doctor's recommendations.

Well-Being

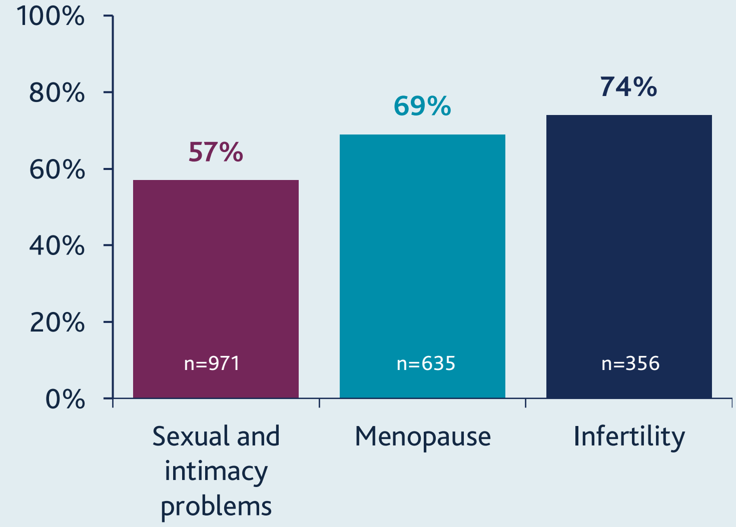
The toll of living with lymphoma can affect people's well-being and make everyday aspects of life challenging. According to the survey, respondents said they were severely or very severely impacted in their inability to do pre-cancer activities (48%), had problems walking (33%), experienced pain and discomfort (32%) and had problems washing or dressing (30%).

When asked about their last doctor's appointment, 37% of respondents said they were definitely asked relevant questions about their quality of life, and 33% said they were asked to some extent. Only 38% felt their doctor fully understood the impact of cancer on the patient's quality of life.

Reported side effects related to treatment

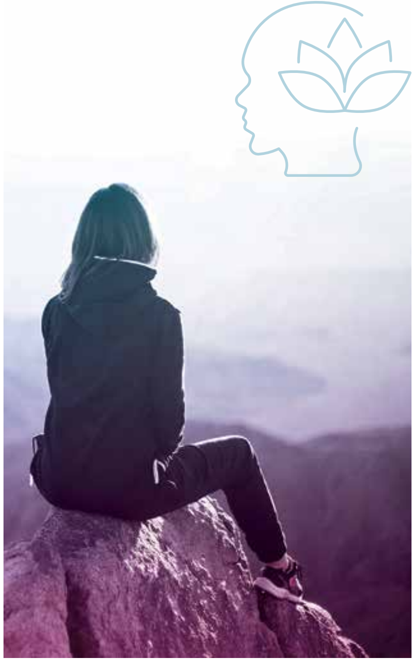


Reported severe or very severe impact



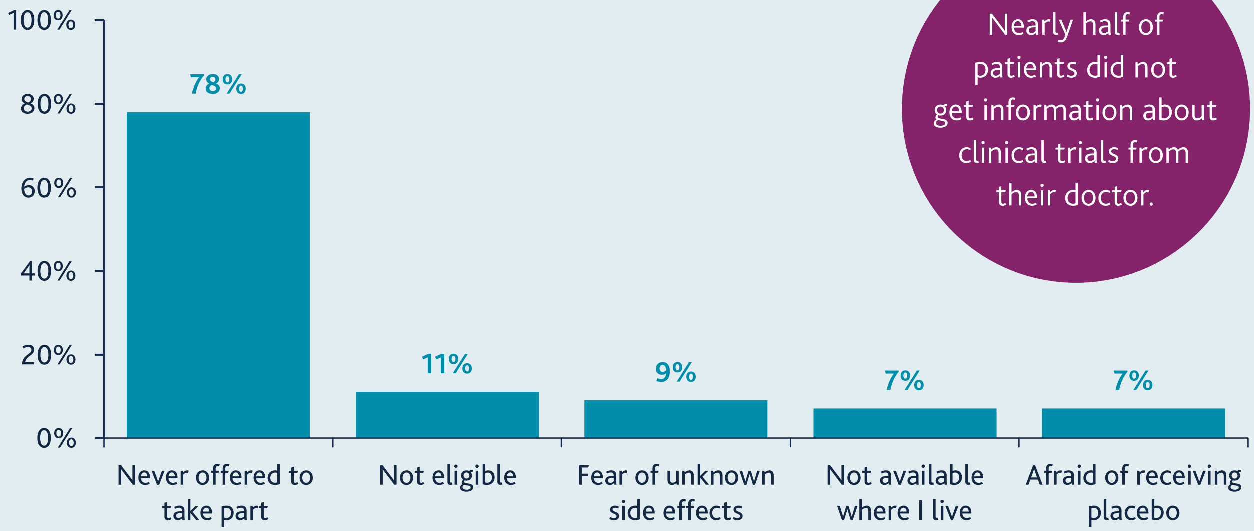
Sexuality, Menopause and Fertility

Lymphoma treatment can also have an impact on people's sexuality and fertility, and can induce menopause. For the first time, the 2024 Global Patient Survey explored these issues. While the number of people affected is relatively low, the survey also revealed these symptoms have a severe or very severe impact and need the attention of healthcare teams.



Clinical Trials

Although 77% of respondents were aware that trials can offer patients better treatment options only 13% had ever participated in a clinical trial. More than half of respondents (59%) said they would likely participate in a clinical trial in the future if they were invited.



Preventing Clinical Trial Participation

n=8287

Nearly half of patients did not get information about clinical trials from their doctor.

While providing information to patients about clinical trials is most important to their participation, there are a variety of variables that may determine if an appropriate clinical trial is available. There are geographic disparities in where trials are offered. In addition, some lymphoma subtypes have more trials, which is often related to the size of the patient population and the current disparity of treatments available.

Supporting Immunocompromised Patients

Having an impaired immune system is called being immunocompromised. However, when that weakened immune system is a result of a medication or treatment, it is called being immunosuppressed. People with lymphoma and CLL can be both immunocompromised and face immunosuppression.

Lymphomas and CLL can cause immunocompromised status in patients even if they are not treated. Also, since cancer treatments can damage healthy cells, lymphoma and CLL patients are immunosuppressed during treatment and for a period after.

In the survey, more than a third of respondents (38%) said they were concerned about being immunocompromised as a result of living with lymphoma or CLL during the past six months. However, significantly fewer respondents are concerned about contracting COVID-19 compared to past surveys (12% in 2024 compared to 76% in 2022).

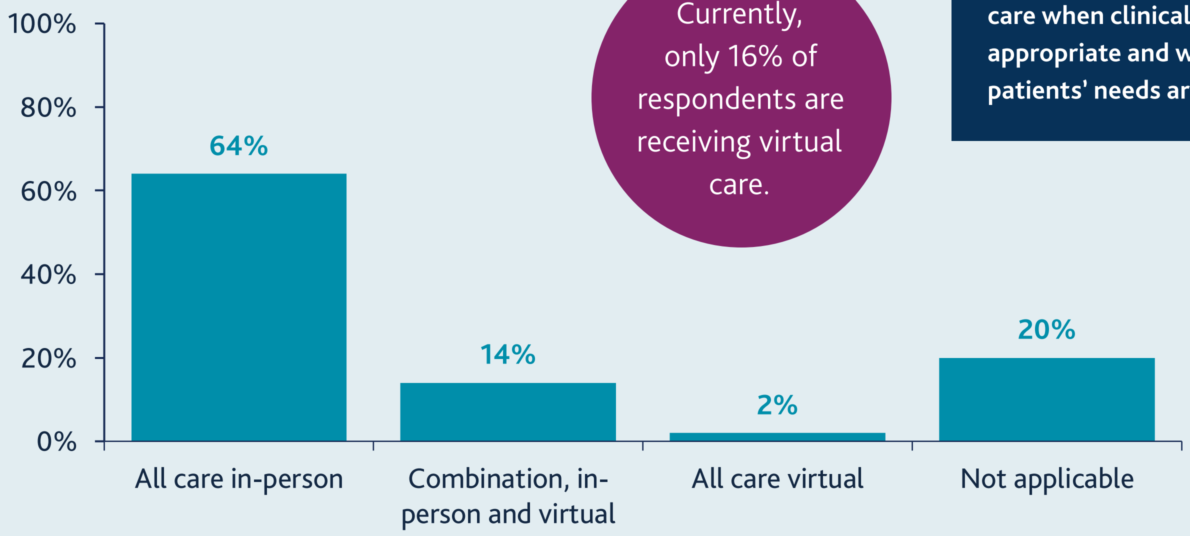
Regardless of the type of infection, when clinically appropriate, telemedicine or virtual care is one of the ways to protect patients from exposures or infections, including COVID-19.

Of those who are receiving virtual care (either in part or completely), the majority are having a positive experience. Specifically, 68% agree their current care is appropriate for some virtual care and 58% agree their health needs are addressed with virtual care. While more than half of respondents (52%) said they would like to use virtual care in the future, only 18% said they prefer it to in-person appointments.

One-third of respondents (35%) said they didn't understand the term immunosuppression.

Living with immunosuppression is a reality for many living with lymphoma and CLL. Advances in virtual care – largely accelerated forward through the COVID-19 pandemic – offer an opportunity to incorporate these technologies into care when clinically appropriate and when patients' needs are met.

Current Virtual Care



Currently, only 16% of respondents are receiving virtual care.

n=9820

Conclusion

The 2024 Global Patient Survey on Lymphoma & CLL uncovers the experiences of patients and care partners when affected by the disease. This highlights report provides a snapshot of key issues and trends uncovered. Some of the issues highlighted in 2024 have been showcased in past years – high levels of fatigue, emotional side effects and lack of information about clinical trials for example. There is an undeniable need to address these issues and improve patient communications.

The survey also showed care partners are greatly affected by the role they play supporting a loved one. It is an undisputably important role, but we also must acknowledge the emotional effects and the impact on their everyday lives and find ways to lessen their burden.

While there is an important role for healthcare teams to partner with patients and care partners to offer the care they need, the responsibility cannot be left to them alone when working in resource-strapped healthcare systems. There lies an opportunity in better understanding the complimentary role of patient organisations and finding ways for patients, doctors, nurses and patient organisations to effectively work together and uncover tangible solutions that drive improved patient experiences. This could include regular referrals to education resources and support services, and partnering on clinical trial creation and promotion, when appropriate.

We acknowledge the many people and organisations that contribute to the success of the Global Patient Survey on Lymphoma & CLL. Thank you to the Lymphoma Coalition research team which oversees the survey development and implementation. We are also grateful to everyone who promotes the survey and drives participation – this includes member organisations, scientific partners, healthcare providers and community alliances. Lastly, and most importantly, thank you to all the patients and care partners who completed the survey and shared their insights.

We are stronger when we work together.

**LYMPHOMA
COALITION**

Lymphoma Coalition (LC) is a worldwide network of patient organisations that support those affected by lymphoma. LC acts as a central hub for reliable and current information, as well as advocating for equitable care globally. Its mission is to enable global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action and advocating for equitable care around the world. Today, there are more than 90 member organisations from over 55 countries.

For more information about Lymphoma Coalition, please visit lymphomacoalition.org

---

The Global Patient Survey on Lymphoma & CLL

The Global Patient Survey on Lymphoma & CLL (GPS) is a biennial survey that aims to deeply understand the patient experience through the shared insights of patients and care partners. The survey explores the impact of treatment and care, information and support needs, and experience with clinical trials.

The data generated from the GPS helps drive planning and policy development, bridge knowledge gaps and advocate for equitable care across borders. The data collected serves as the foundation for scientific abstracts, peer reviewed publications, joint research initiatives, policy papers and international collaborations and presentations.

The survey, which was available in 20 languages, was hosted on a third-party site from 2 February – 15 April 2024, and gathered responses from 11170 people from 79 countries. More information can be found at **lymphomacoalition.org/global-patient-survey**.

The 2026 Global Patient Survey will be open January – March 2026

More details to come at:
lymphomacoalition.org/global-patient-survey.