



# REPORT CARD ON LYMPHOMAS

**SPOTLIGHT ON THE EXPERIENCE OF  
PATIENTS WITH INDOLENT LYMPHOMAS**

**2022**



# About Lymphoma Coalition

Lymphoma Coalition (LC) is a worldwide network of patient organisations with a full or partial focus on providing support to those affected by lymphoma, including chronic lymphocytic leukaemia (CLL).

The need for a central hub of consistent, reliable, and current information was recognized, as well as the need for lymphoma patient organisations to share resources, best practices, and policies and procedures. With this in mind, four lymphoma organisations started LC in 2002 and it incorporated as a not-for-profit organisation in 2010. Today, there are over 80 member organisations from more than 50 countries.

As the organization grew, an additional workstream was added dedicated to advocating for equitable care globally.

LC's current strategy remains focused on ensuring impact within two key pillars: information and advocacy.

**Vision:** Equity in lymphoma outcomes across borders.

**Mission:** Enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

## DISCLAIMER

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Lymphoma Coalition (LC) provides the 2022 Report Card on Lymphomas for general information related to topics relevant to lymphoma worldwide. While LC makes every effort to ensure accuracy, the information contained in the report is taken from various public and private sources. No responsibility can be assumed by LC for the accuracy or timeliness of this information.

## WARNING

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LC's 2022 Report Card on Lymphomas should not be used for the purpose of self-diagnosis, self-treatment or as an alternative to medical care. If you have any concerns arising out of the information contained in this report, you should consult your own physician or medical advisor. If you suspect you have lymphoma, seek professional attention immediately.

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## Objectives

### This report aims to:

- Identify key issues and challenges for patients living with indolent lymphoma, by stage of the patient experience and by subtype
  - Highlight concerns that are consistent throughout the entire indolent patient experience
  - Determine areas where patients require additional care, information, and support.
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# Overview

Lymphomas encompass a wide variety of distinct disease entities.<sup>1</sup> There are more than 80 different subtypes of lymphomas.<sup>2</sup> Depending on the subtype, the disease can be aggressive, progress rapidly, and be considered curable in certain instances, such as diffuse large B-cell lymphoma and classical Hodgkin lymphoma. Others are indolent, generally advance more slowly, and are currently considered incurable for most patients, including follicular lymphoma, marginal zone lymphoma (MZL) and chronic lymphocytic leukaemia (CLL). Some may have both aggressive and indolent variants, like mantle cell lymphoma.

This report focuses specifically on the experience of those diagnosed with an indolent lymphoma, and the challenges living with a chronic cancer brings. Despite the existence of defined care pathways and referral processes, patients' experiences are rarely linear and always unique, which allows space for gaps in support. Through gaining a better understanding of the challenges and issues that patients' face during each phase of their care, LC hopes to bring awareness to and aid in bridging these gaps.

### Key issues include:

- Diagnosis delays;
- Negative impact on patients' quality of life;
- Access to credible, useable information to help them engage in their own care decisions;
- Healthcare systems are not patient-centred and do not reflect the unique needs of patients living with indolent lymphomas, especially those in active monitoring.

The information in this report is largely based on the learnings from the 2022 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL (LC 2022 GPS) which included 4085 patient respondents living with an indolent lymphoma.

**This is comprised of patients with the following diagnoses:**

- Chronic lymphocytic leukaemia (CLL) / small lymphocytic lymphoma (SLL) – 1300 patients (32%).  
*This group is referred to as 'CLL' throughout the report.*
- Cutaneous lymphoma – 518 patients (13%).
- Follicular lymphoma – 1132 patients (28%).
- Marginal zone lymphoma (MZL) – 250 patients (6%).
- Waldenstrom macroglobulinemia (WM) / Lymphoplasmacytic lymphoma (LPL) – 885 patients (22%).  
*This group is referred to as 'WM' throughout the report.*

**The patient experience was also divided into and will be analysed according to the following five stages:**

**Table 1. Stage of patient experience as reported by respondents of LC 2022 GPS**

Stage of patient experience		% of total respondents
1	<b>Active Monitoring (never treated)</b> • Diagnosed and treatment is not yet needed	24%
2	<b>Treatment</b> • Currently in treatment • In maintenance therapy	32%
3	<b>Active Monitoring (post-treatment)</b> • Finished treatment and back in active monitoring	19%
4	<b>Remission</b> • Treatment-free as the lymphoma is in remission	14%
5	<b>Other</b> • Finished or stopped treatment but not in remission • Relapsed or refractory disease but not currently being treated • Palliative	10%

The survey did include 36 patients who are newly diagnosed and are not yet sure of their treatment course. Due to the low number of patients (1% of the total), this category will not be further examined in this report.

Important to note is that this is not a temporal analysis; this report is not following the same group of individuals over time, but rather has used stages to categorise respondents and examine the keys issues within these categorised sample populations.

A full methodology for the LC 2022 GPS is available in [Appendix A](#).

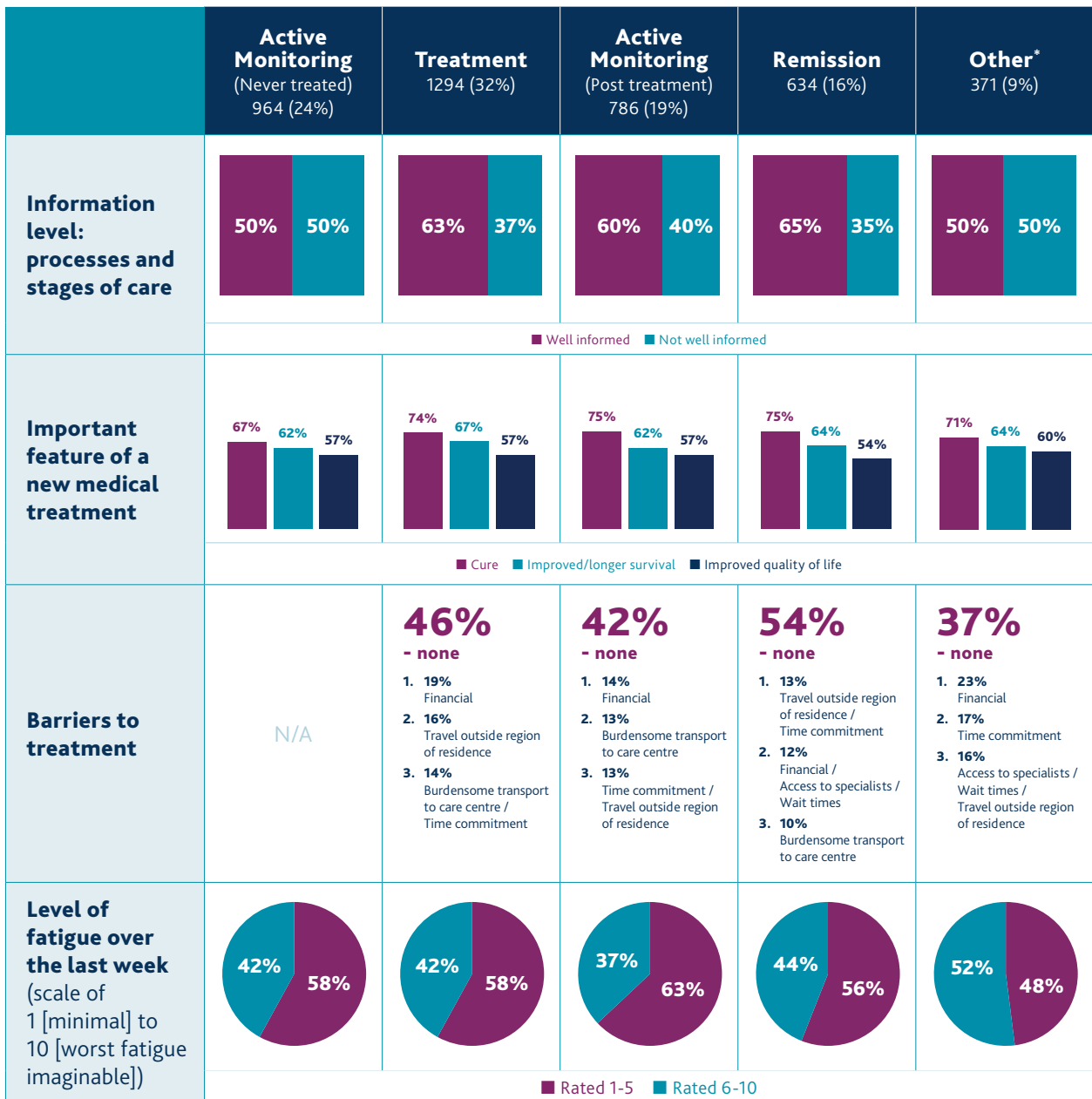
A list of subtypes being examined broken down by stage of experience is available in [Appendix B](#).

# PATIENT EXPERIENCE WITH INDOLENT LYMPHOMA: BY SUBTYPE

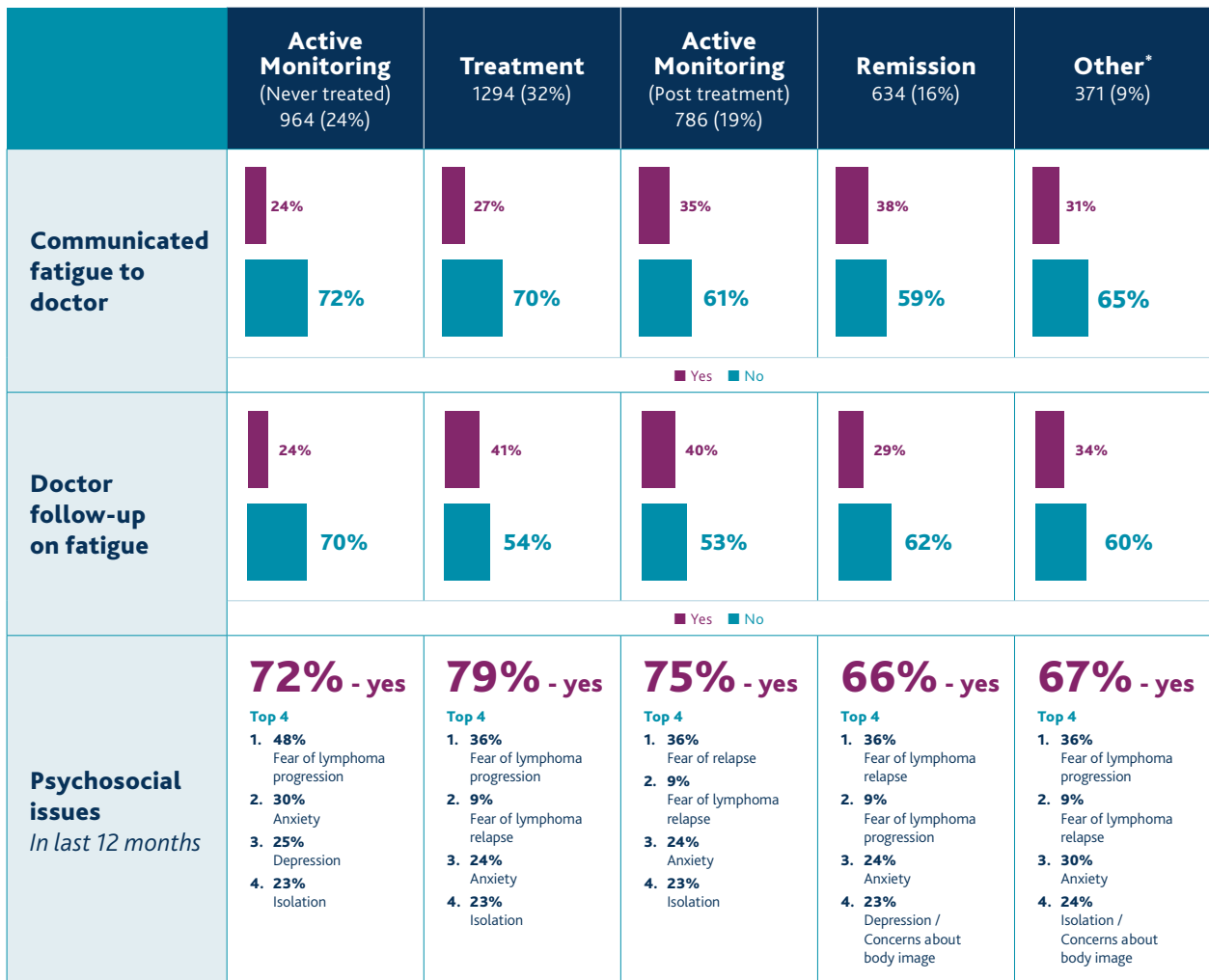
	CLL 1300 (32%)	Cutaneous 518 (12%)	Follicular 1132 (28%)	Marginal Zone 250 (6%)	WM 885 (21%)
<b>Number of doctors visited before being diagnosed</b>					
<b>Information level: diagnostic tests</b>					
	<p>■ Explained and I understand ■ Not explained well or at all ■ Don't know</p>				
<b>Information level: processes and stages of care</b>					
	<p>■ Well informed ■ Not well informed</p>				
<b>Preferred information sources</b>					
	<p>■ Doctor ■ Patient organisation ■ Internet</p>				
<b>Most common symptoms</b>	<p>Fatigue 68%</p> <p>Enlarged lymph nodes 56%</p> <p>Easily bruise or bleed 32%</p>	<p>Skin rashes/lesions 88%</p> <p>Itchy skin 78%</p> <p>Fatigue 56%</p>	<p>Fatigue 65%</p> <p>Enlarged lymph nodes 60%</p> <p>B-symptoms 32%</p>	<p>Fatigue 60%</p> <p>Enlarged lymph nodes 38%</p> <p>Itchy skin 34%</p>	<p>Fatigue 76%</p> <p>Anaemia 53%</p> <p>Easily bruise or bleed 39%</p>
<b>Symptoms alleviated by treatment</b>	<p>Fatigue 39%</p> <p>Enlarged lymph nodes 90%</p> <p>Easily bruise or bleed 30%</p>	<p>Skin rashes/lesions 65%</p> <p>Itchy skin 53%</p> <p>Fatigue 17%</p>	<p>Fatigue 33%</p> <p>Enlarged lymph nodes 87%</p> <p>B-symptoms 70%</p>	<p>Fatigue 16%</p> <p>Enlarged lymph nodes 24%</p> <p>Itchy skin 9%</p>	<p>Fatigue 47%</p> <p>Anaemia 77%</p> <p>Easily bruise or bleed 23%</p>

	CLL 1300 (32%)	Cutaneous 518 (12%)	Follicular 1132 (28%)	Marginal Zone 250 (6%)	WM 885 (21%)
<b>Frequent side effects of treatment</b>	Fatigue <b>62%</b> Diarrhoea <b>30%</b> Bruising & Bleeding <b>38%</b>	Fatigue <b>51%</b> Skin, hair & nails <b>37%</b> Hair loss <b>30%</b>	Fatigue <b>72%</b> Hair loss <b>55%</b> Sleep changes <b>44%</b>	Fatigue <b>64%</b> Hair loss <b>48%</b> Sleep changes <b>35%</b>	Fatigue <b>66%</b> Peripheral neuropathy <b>37%</b> Bruising & Bleeding <b>37%</b>
<b>Symptoms / side effects' impact on quality of life</b>	<b>63%</b> / <b>52%</b>	<b>42%</b> / <b>41%</b>	<b>64%</b> / <b>57%</b>	<b>61%</b> / <b>58%</b>	<b>56%</b> / <b>44%</b>
	■ Negative impact on everyday activities people my age can do ■ Negative impact on social life				
<b>Involvement in decision-making about care</b>					
	■ Yes, definitely ■ Yes, to some extent ■ No, I would like to be ■ No, & not interested				
<b>Given choice of more than one treatment option</b>					
	■ Yes ■ No ■ Other				
<b>Clinical trial participation</b>	<b>31%</b> / <b>69%</b>	<b>14%</b> / <b>86%</b>	<b>13%</b> / <b>87%</b>	<b>10%</b> / <b>90%</b>	<b>13%</b> / <b>87%</b>
	■ Yes ■ No				
<b>Psychosocial issues</b> <i>In last 12 months</i>	<b>70% - yes</b> <b>Top 4</b> 1. <b>36%</b> Fear of lymphoma progression 2. <b>9%</b> Fear of relapse 3. <b>24%</b> Isolation 4. <b>23%</b> Depression	<b>78% - yes</b> <b>Top 4</b> 1. <b>56%</b> Fear of lymphoma progression 2. <b>40%</b> Body image 3. <b>30%</b> Anxiety 4. <b>27%</b> Depression	<b>81% - yes</b> <b>Top 4</b> 1. <b>47%</b> Fear of relapse 2. <b>44%</b> Fear of lymphoma progression 3. <b>36%</b> Anxiety 4. <b>25%</b> Isolation	<b>86% - yes</b> <b>Top 4</b> 1. <b>51%</b> Fear of lymphoma progression 2. <b>44%</b> Fear of relapse 3. <b>36%</b> Anxiety 4. <b>31%</b> Isolation	<b>68% - yes</b> <b>Top 4</b> 1. <b>36%</b> Fear of lymphoma progression 2. <b>25%</b> Isolation 3. <b>24%</b> Anxiety 4. <b>22%</b> Depression

# PATIENT EXPERIENCE WITH INDOLENT LYMPHOMA: BY STAGE







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\*Other - including those who have finished or stopped treatment but are not in remission, those who have relapsed or refractory disease but not being treated, and those deemed palliative.

Good communication with healthcare professionals is key to an optimal patient experience.

Patients should feel confident voicing all their concerns to their doctor and letting their doctor know if they have not received a satisfactory answer or adequate support.

# Key Issues and Challenges at Each Stage of the Patient Experience

## DIAGNOSIS

Lymphomas often present a diagnostic challenge and there are no screening programs to help with prompt or early diagnosis. This challenge is further complicated by the fact that lymphomas are a mixed group of cancers that have a variety of clinical presentations. Long time to diagnosis can result in increased patient anxiety and may impact the patient's survival and quality of life.<sup>3,4</sup>

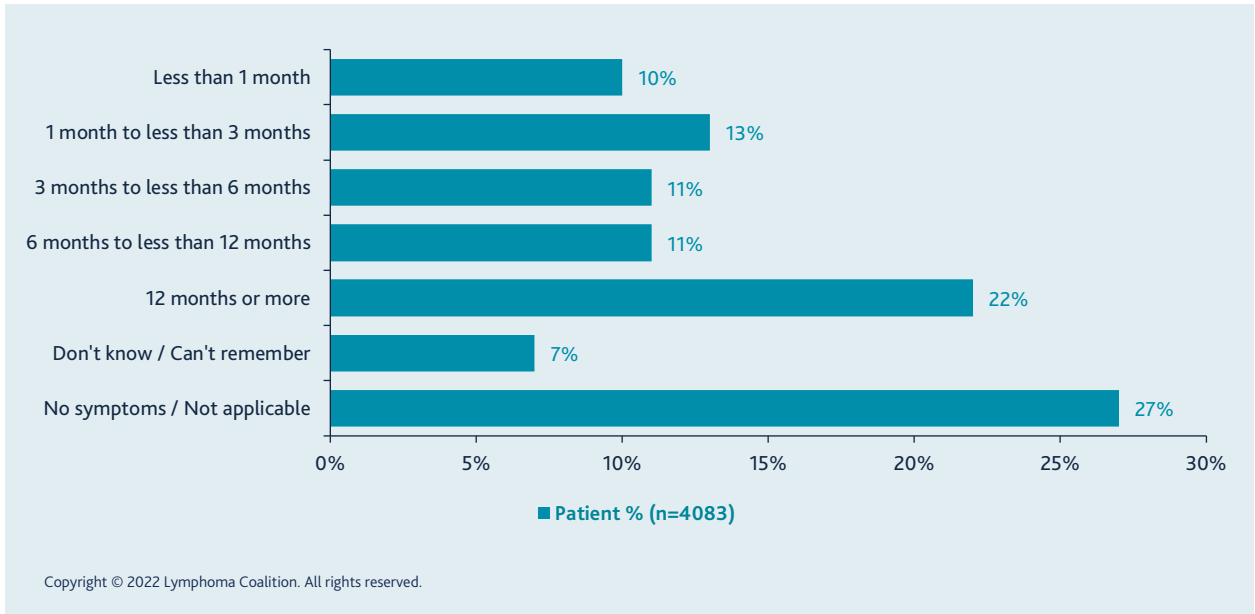
For example, because indolent lymphomas are slow growing, some patients may not develop any noticeable symptoms, which was true for 27% of patients who responded to the LC 2022 GPS (see Figure 1). For others, symptoms can be non-specific and vague (such as fever and lethargy), potentially leading to patients delaying seeking care. Symptoms can affect patients' lives in many ways and patients may try practical ways to cope with the symptoms (e.g., taking a bath to relieve severe itching, napping or sleeping more when tired, or propping up with extra pillows to relieve breathlessness) before seeking healthcare.<sup>4,5</sup>

For those that had symptomatic disease, the top symptoms negatively impacting patients were:

- Fatigue (67%)
- Enlarged lymph nodes (44%)
- Itchy skin (34%)
- B-symptoms (fever, chills, night sweats and weight loss) (30%)
- Skin rashes/lesions (27%)

**Almost a quarter of patients with indolent lymphoma who responded to the survey had symptoms for a year or more before they sought help from a medical professional. This of course means a prolonged time to diagnosis.**

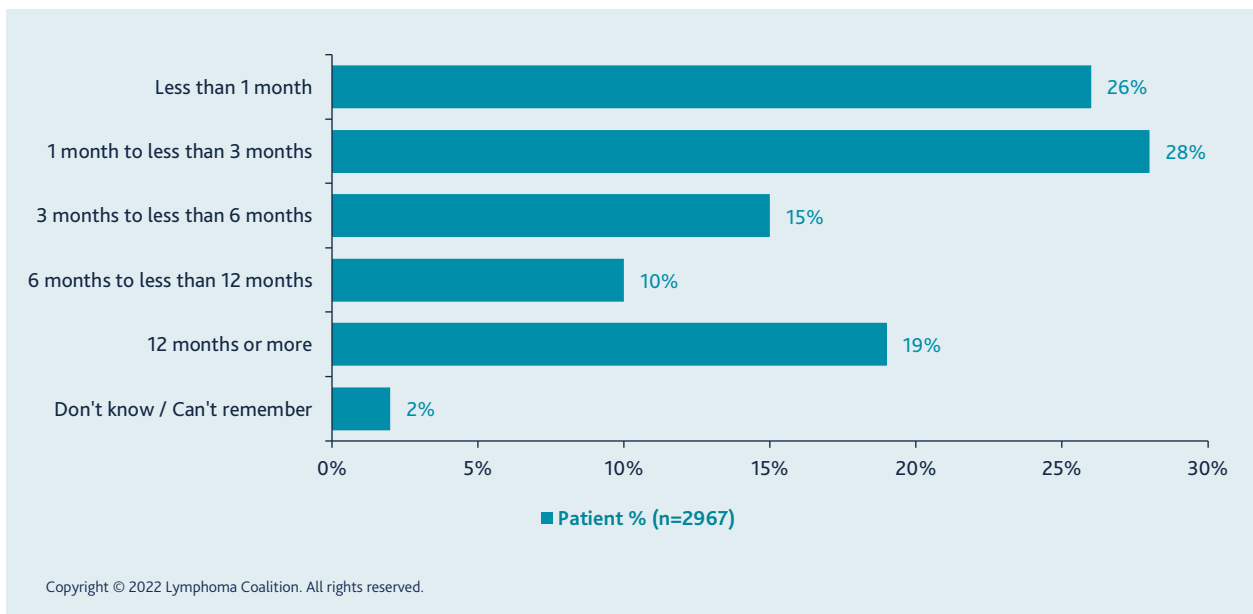
**Figure 1. How long were you experiencing symptoms for before seeking medical care**



**Once a patient makes it to a doctor, it can still take a considerable amount of time to diagnose lymphoma. About half of patients with indolent lymphoma (54%) were diagnosed within three months, but for one in five patients, it took a year or more (Figure 2).**

Those with cutaneous lymphoma were more likely to have a long time to diagnosis, with it taking a year or more for almost half of these patients to discover they had lymphoma. Two-thirds were given a wrong diagnosis in that time and 78% received treatment for the wrong illness. 20% of patients with WM also reported it taking a year or more to be diagnosed. This points to the need for continuing physician education on the signs and symptoms of rare subtypes.

**Figure 2. Overall, how long did it take from the first appointment with the family doctor or seeking medical care about the symptoms to first getting diagnosed with lymphoma or CLL?**



A qualitative study that examined patients' experiences before lymphoma and myeloma diagnosis described participants who had vague symptoms (such as fever or lethargy) or misattributed their symptoms to other illnesses experienced more diagnostic delays and had a chaotic diagnostic pathway including consulting various healthcare professionals, often many times, as symptoms persisted/progressed.<sup>6</sup> On average, patients with indolent lymphomas saw two healthcare professionals about their symptoms before receiving their diagnosis. The total number of healthcare professionals consulted varied across subtypes.

**About a third of patients with CLL (30%) only saw one doctor for their symptoms before they found out they had cancer while patients with cutaneous lymphoma saw four or more. Having to navigate through multiple doctors before receiving a diagnosis also contributes to time delays.**

Patient response to a diagnosis of lymphoma varies. Some feel disbelief initially and then shock as they come to terms with their diagnosis, while others feel relieved that their symptoms have been acknowledged, have been associated with an illness and care can commence.<sup>7</sup>

**Communication with healthcare professionals is key as patients will use this information to make sense of their unfolding situation.** Many patients struggle with a lack of understanding as they may have never heard about lymphoma before, and more specifically their subtype.

## ACTIVE MONITORING

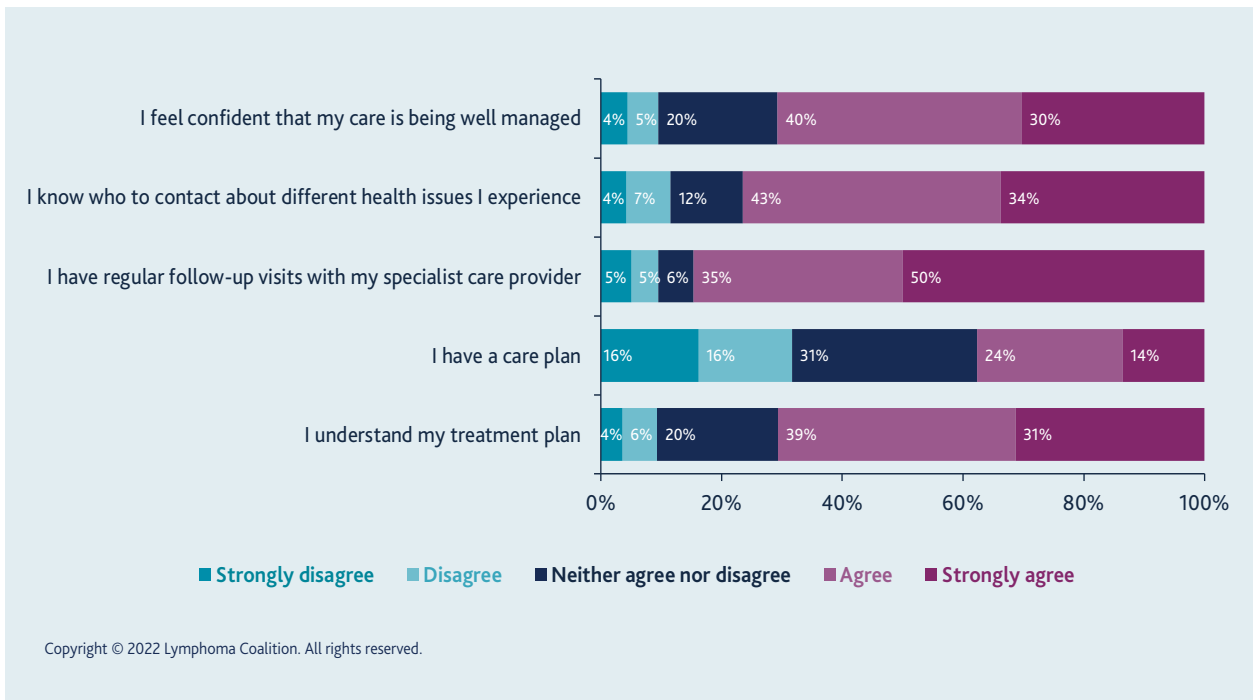
To be diagnosed with cancer and not receive treatment right away counters general public messaging about optimal cancer care. It may even be more confusing if a clear explanation is not given that this is a validated part of the patient care pathway. Half of patients at this stage say they do not feel well informed about the processes and stages of care. Although it may seem that because patients do not require immediate treatment they do not need support, findings from the LC 2022 GPS contradict this perception.

**Active monitoring can elicit distress as it may seem a risky or passive approach to a very serious disease.**

It is likely these patients require a great deal of reassurance that their symptoms are being tracked and treatment will begin when necessary.

While most patients say practical aspects of their care are being addressed (e.g. regular appointments with their specialist, knowing who to contact about health issues), they struggle with believing there is a cancer care plan for them, with only a third of patients in active monitoring (38%) agreeing they have one in place. Despite this, most have confidence in their doctor and believe their care is being well managed.

**Figure 3. In thinking about your cancer care right now, please indicate how much you agree or disagree with the following statements:**



The data does reveal gaps in care which might contribute to why more patients responded with 'agree' instead of 'strongly agree' to these questions. An example of this is patients dealing with fatigue. Those in active monitoring are most likely to talk about their fatigue with their doctor (72%), yet 70% said there was no follow-up by their doctor at subsequent visits.

## TREATMENT

Quality of life (QoL) is an individual's assessment of one's life at any time relative to one's previous state or prior experiences. Health-related QoL is multidimensional, relating to a state of daily physical, psychological, sexual, and social/family functioning.<sup>8</sup>

**Haematological cancers have been found to have a negative impact on overall QoL and health related QoL.<sup>9</sup>**

A variety of factors have been shown to impact QoL of a patient living with lymphoma, such as the physical symptoms associated with the underlying lymphoma, the stage of the lymphoma, the type of treatments administered, the presence of comorbid conditions, and the emotional and social state of the patient.<sup>8,9,10,11</sup>

Treatment options for lymphoma may include chemotherapy, immunotherapy, targeted therapy, radiotherapy, stem cell transplantation, CAR T-cell therapy, skin-directed therapies (for cutaneous lymphoma), or a combination of these treatments. These treatments come with significant short- and long-term effects like fatigue, cytopenia, cognitive impairments, peripheral neuropathies, sexual difficulties, muscle wasting and pain. The side effects impact greatly on the patient's QoL, with some patients experiencing them for a long period of time after treatment has ended.<sup>12</sup>

Completion of successful treatment that puts indolent lymphoma into remission or relieves symptoms does not necessarily translate to a better quality of life for patients if they are still dealing with symptoms and side effects, in some cases for up to eight or more years after treatment ends. As well, due to the nature of these indolent subtypes where the cancer returns, patients often undergo multiple lines of therapy over time, resulting in a higher, accumulated side effect burden. It is key that patients receive support and ongoing management of these issues.

The most frequently reported side effects of treatment by patients with an indolent lymphoma are shown below.

- Fatigue 65%
- Changes in sleep patterns 34%
- Hair loss 31%
- Constipation 31%
- Nausea and vomiting 29%

**Fatigue was consistently the most experienced side effect across all subtypes.** There is a lot of variation in other commonly reported side effects, aligning with the therapies used to treat different subtypes. Where chemoimmunotherapy is used, more people report hair loss and sleep changes (like follicular and marginal zone lymphoma). Newer targeted therapies' toxicities can include bruising and bleeding, and this side effect is reported more often by patients living with CLL or WM. Patients with cutaneous lymphoma spoke to the skin problems resulting from skin-directed treatment.

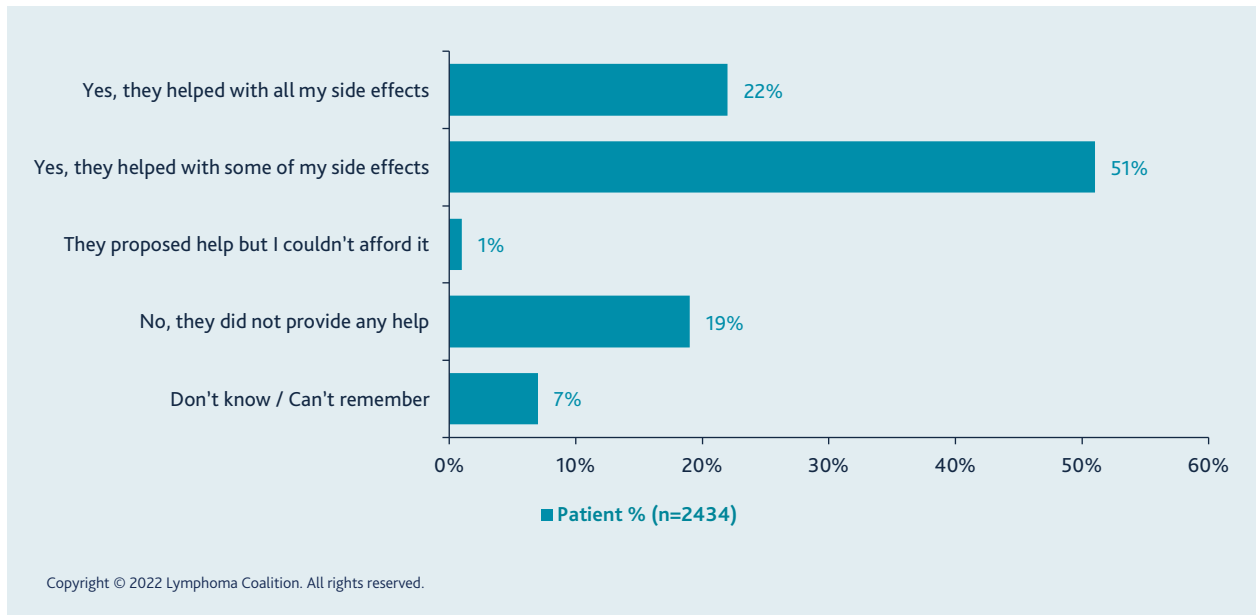
While all toxicities are unpleasant, some cause more problems for patients than others. The side effects that affected the wellbeing of patients living with an indolent lymphoma the most are as follows (listed in order ranked, with #1 having the greatest impact on wellbeing):

1. Fatigue
2. Nausea and vomiting
3. Infections (neutropenia)
4. Hair loss
5. Changes in sleep pattern/trouble sleeping

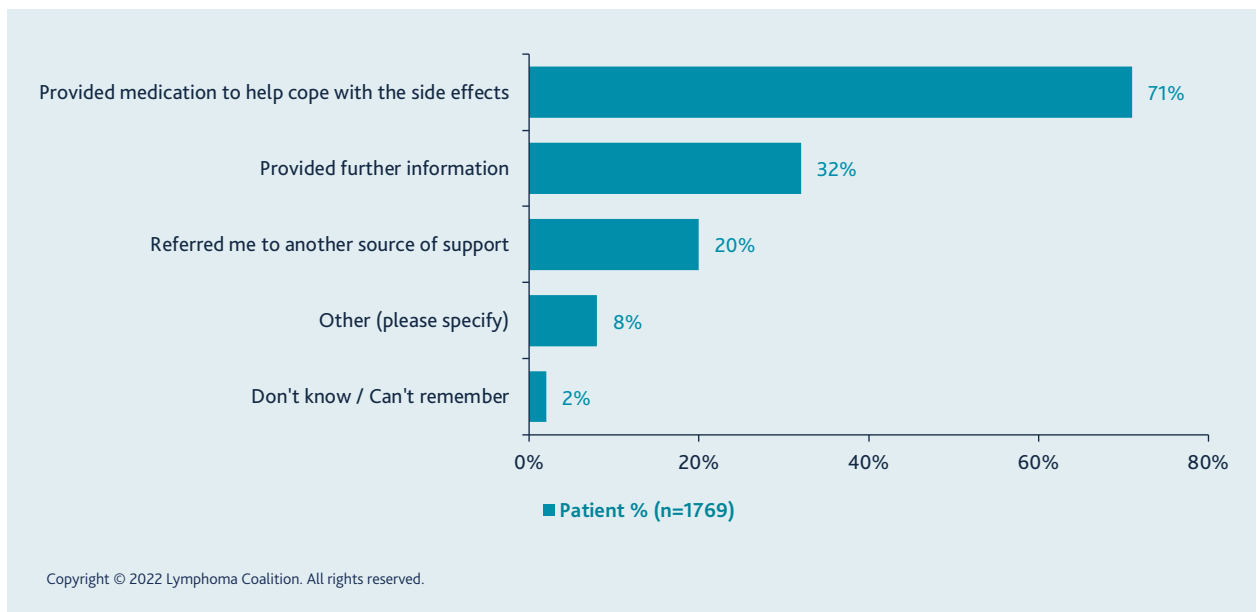
Fatigue was ranked highly across all subtypes, proving again how debilitating cancer-related fatigue can be.

While almost three-quarters of patients say doctors were able to help with some or all of their side effects, 19% said they did not help at all. For those that were helped, most often the doctor prescribed medication (71%), with 31% providing further information and only 20% referred to other sources of support.

**Figure 4. Was your doctor or other members of your medical team able to help you alleviate or cope with the side effects of the lymphoma or CLL treatment?**



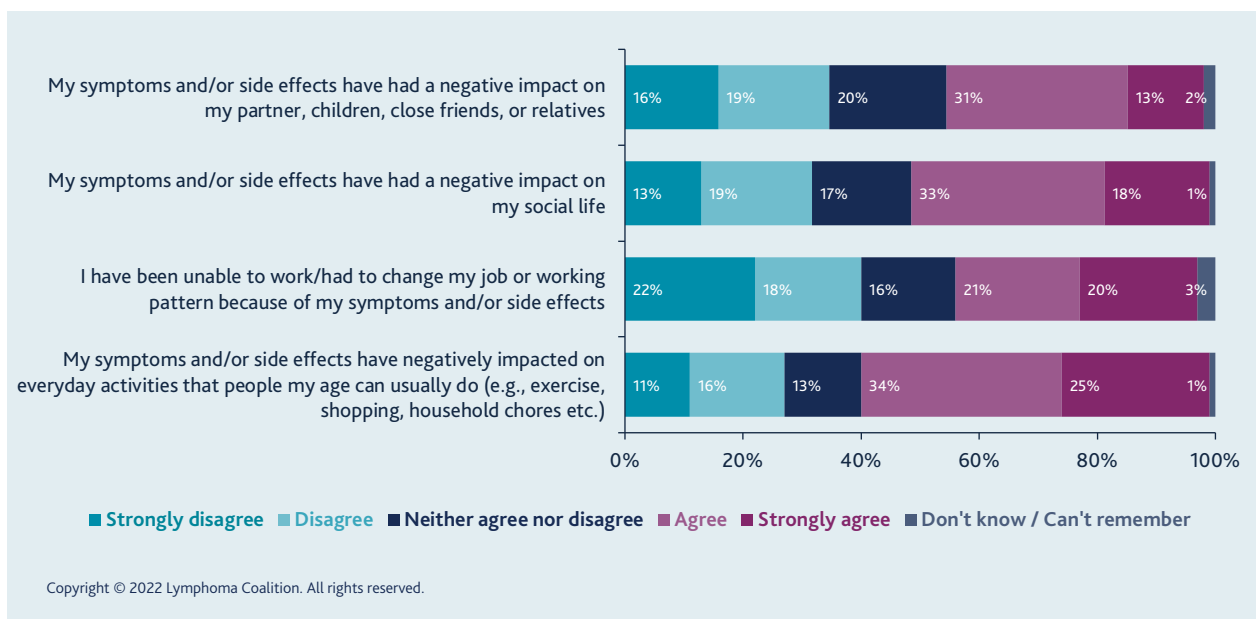
**Figure 5. What specifically did the doctor do to help?**



While 65% believe their treatment was chosen to minimize the impact of possible side effects on their lifestyle and/or favourite activities - an important feature of a treatment where cure is not possible - symptoms and side effects are having a significant impact on quality of life.

Three out of every five patients living with an indolent lymphoma agree symptoms and side effects have negatively impacted their everyday life and half say they have had a negative impact on their social life. 43% say these issues have also impacted their family, close friends, and relatives.

**Figure 6. Thinking about your lymphoma symptoms and/or treatment side effects, to what extent, if at all, do you agree or disagree with each of the following statements?**





Patients were asked if they experienced any barriers to receiving care.

**Over half of patients (52%) faced some kind of barrier or difficulty accessing treatment. What makes this more concerning is it a significant increase over the LC 2020 GPS global rate of 30%.**

There is no one barrier that is accounting for this difference, but rather several issues becoming more problematic. Difficulties can be grouped into financial concerns (financial difficulties, income impact, paying for childcare and travel); access (to treatments, to a specialist, and the logistical problems of getting to care facilities); and practical concerns (the time it takes to get treatment, administrative burden, language). Some of the problems were heightened by the COVID-19 pandemic and its impact on healthcare systems.

**Table 3: What, if anything, has made getting treatment more difficult?**

Finance	Access	Travel	Practical Concerns
Financial difficulties (17%)	Access to specialist (11%)	Traveling outside of region (15%)	Time out of day-to-day life (14%)
Could not give up work/job (8%)	Access to most up-to-date treatment (11%)	Burdensome transport to treatment centre (13%)	Difficulties with administrative tasks (paperwork) (8%)
Paying for childcare (1%)	Treatment waiting times (9%)	Accommodation (5%)	Language barriers (1%)

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As indolent lymphomas are incurable for most, there is a need for new and better treatments, both to ideally bring about a cure but also new therapy options to extend life for patients that have exhausted all their currently available choices. Lymphoma is an area of cancer with significant active research. Within indolent lymphomas, follicular lymphoma currently has the most clinical trial activity, followed by CLL. However, CLL has the most trials that are specific to CLL itself, as many trials include multiple subtypes.

**Table 4: Number of Clinical Trials per Indolent Subtype**

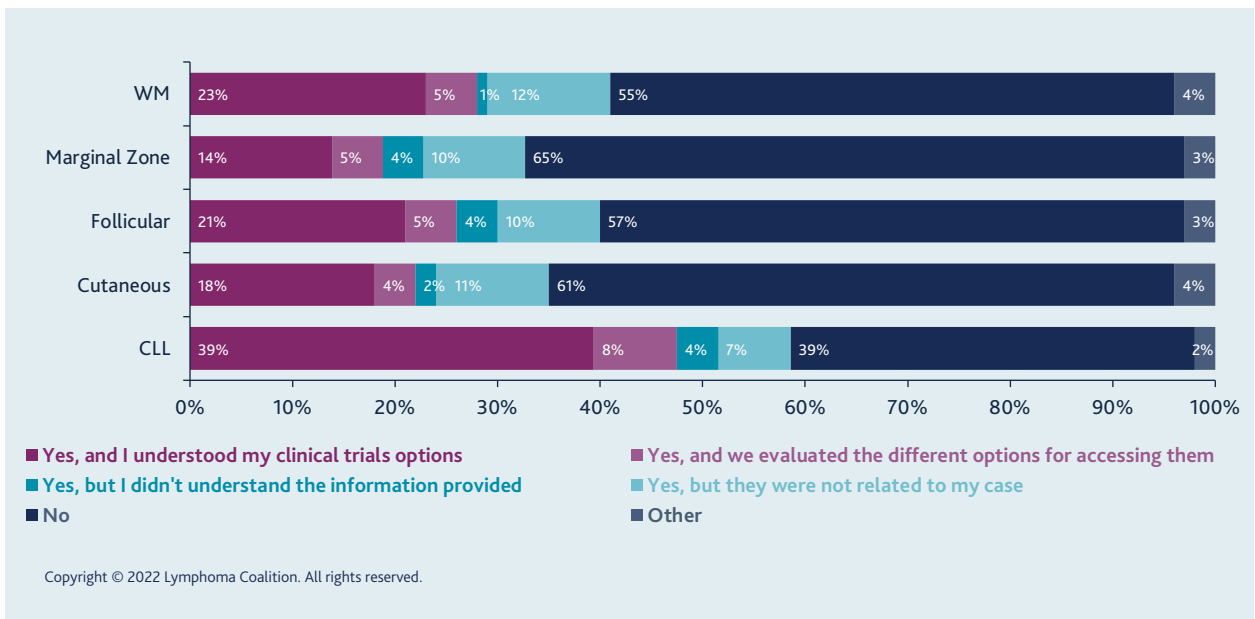
Sub-type	Phase I*	Phase II	Phase III	Total	Trials that are Subtype Specific (%)
Follicular	33	290	42	365	20%
CLL	21	232	37	290	51%
Cutaneous	3	94	3	100	24%
Marginal Zone	6	171	14	191	8%
Waldenstrom Macroglobulinemia	4	95	10	109	13%

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Clinical trials can provide patients with access to the best treatments. 69% of patients indicated they were aware of this, but a quarter were not, leaving room for better education on the advantages of participating in a trial.

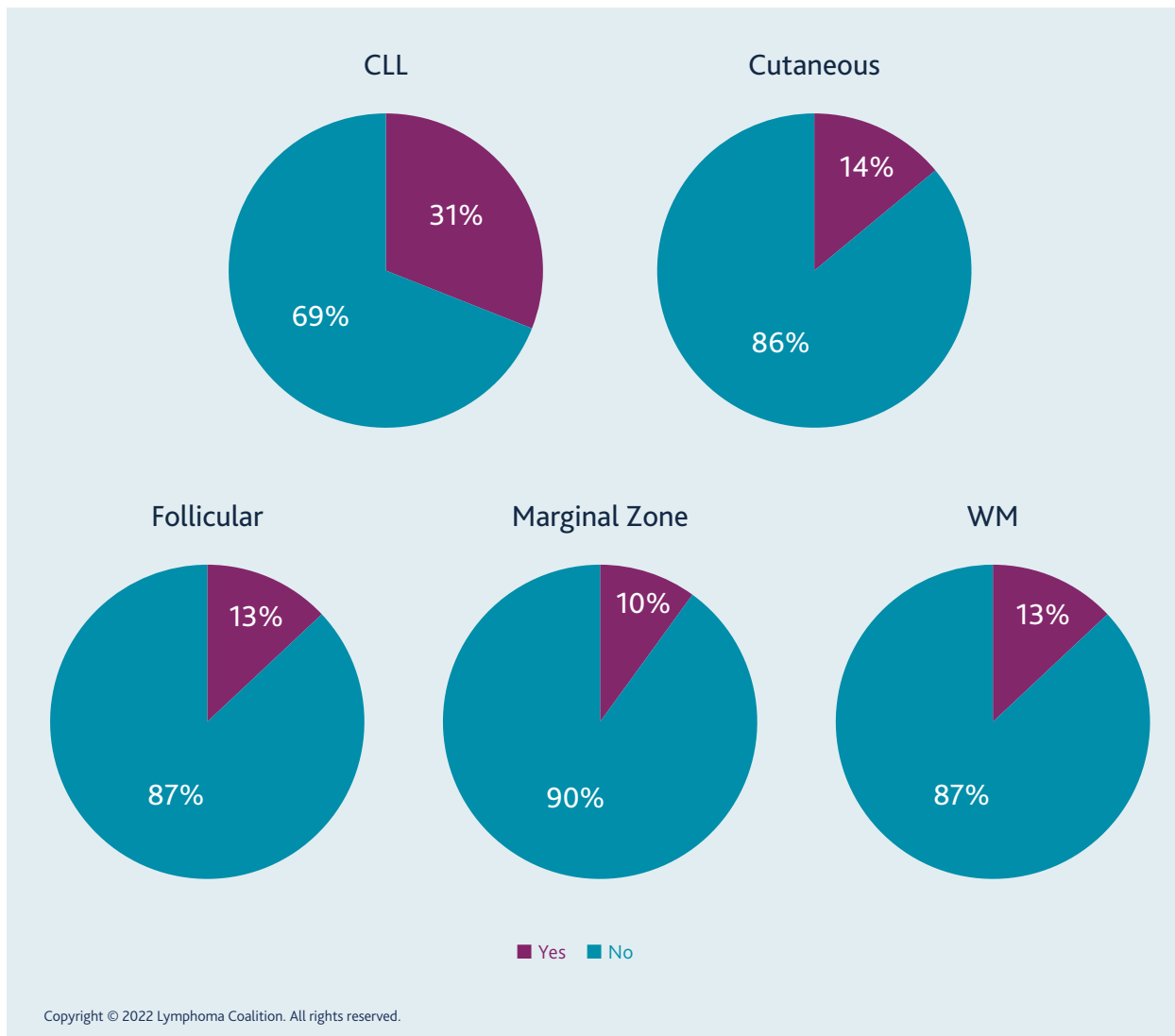
Half of patients (53%) did not receive any information on clinical trials from their specialist. Those diagnosed with CLL were more likely to receive this type of information (58%), which does correlate with the fact there are currently more CLL-specific trials than other indolent subtypes. However, the information was not always presented in an understandable way and was not always applicable to the patient's situation.

**Figure 7. During your meetings with your lymphoma or CLL doctor, did you receive any information about clinical trials? (by subtype)**



**Overall, only 17% of patients with indolent disease have been in a trial.** Again, the results by subtype are reflective of the number of CLL-specific clinical trials, with patients with this subtype being more likely to have participated in one (31%). The other subtypes had clinical trial participation of 10% - 14%.

**Figure 8. Have you ever been in a clinical trial?**



When we examine what would prevent patients from participating in a clinical trial, most of the reasons provided are related to the practical aspects of participation – never being presented with an opportunity (57%), not being eligible or selected (27%), lack of clinical trials where they live (23%), geographical access (23%), etc. Other reasons for not participating are related to fears that education may be able to address i.e. fear of potential side effects (31%), fear of receiving a placebo (23%), not wanting to be experimented on (9%), etc.

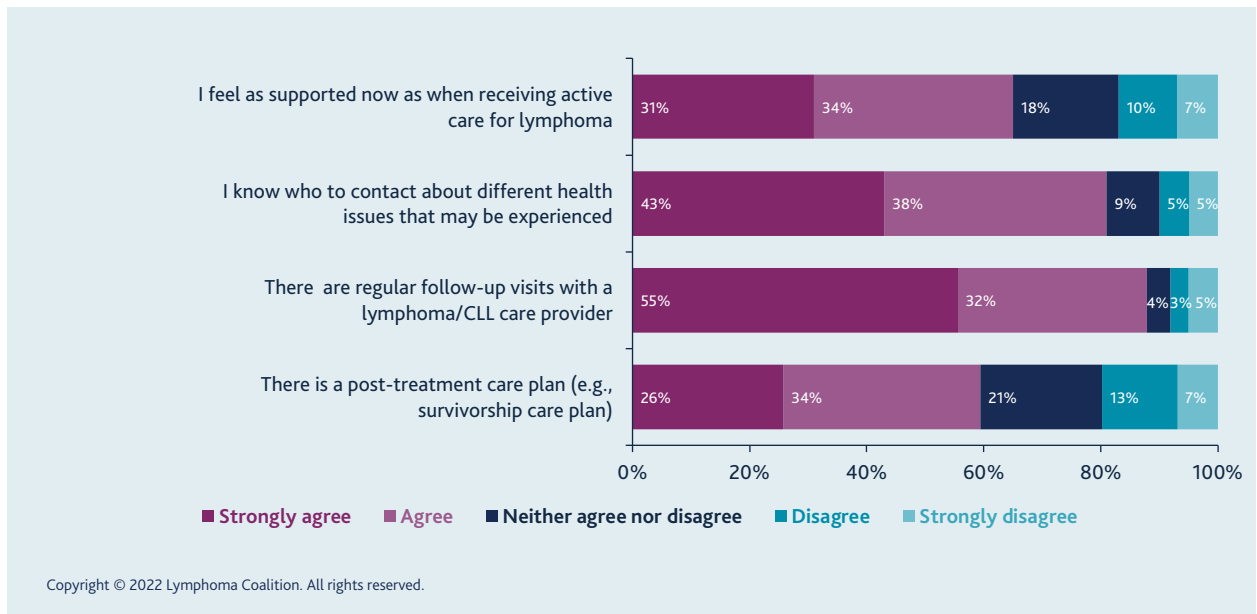
**More needs to be done to ensure that patients living with an indolent lymphoma have access to quality care and opportunities to participate in clinical trials and that this access is given without undue financial and logistical stress for the patients and their families.**

## REMISSION

Remission can also be challenging for patients as they move out of active treatment and adapt to this new phase in their care. Patients with indolent lymphoma who had indicated they were in remission were asked a series of questions about their cancer care support experience as they transitioned into survivorship.

Like those in active monitoring, 40% of those in remission struggle to believe there is a post-treatment care plan or a survivorship plan in place for them. In addition, a third (35%) do not feel as well supported as they did when receiving treatment.

**Figure 9. In thinking about the transition from cancer care into survivorship, please indicate how much you agree or disagree with the following statement**



Being in remission does not, unfortunately, mean a cessation of side effects. They can continue to be an issue long after treatment is completed and continue to negatively impact a patients' quality of life. **Almost 70% of patients with indolent lymphoma in remission said they were still experiencing cancer-related fatigue.** Out of this group, 44% rated their fatigue over the last week as significant. Three out of every five patients are communicating their fatigue to their doctor, but only 29% say their doctor follows up on it.

As well, two-thirds of those in remission indicated continuing psychosocial issues, with 47% reporting a fear of lymphoma progression, 34% a fear of lymphoma relapse, 31% anxiety, 26% isolation and another 26% concerns about body image.

Care needs to be integrated so that patients in remission are supported by a seamless system that ensures their physical, medical and emotional issues are addressed. Patients need support developing a new 'normal' that incorporates the cancer experience into their lives, allowing them to focus on their health positively.

# Common Issues Throughout the Lymphoma Patient Experience

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Patient-centeredness is a key part of providing high-quality cancer care as it takes into consideration the goals and expectations of patients and their families, as well as responding to the patient's physical and emotional concerns.

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## LIVING WITH A CHRONIC CANCER

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Patients with cutaneous lymphoma, follicular lymphoma, CLL and WM were asked to describe their experience living with a chronic cancer. Almost two-thirds (64%) of patients reported that they focus on living their lives and try not to dwell on their disease, and that they were content if they had a good quality of life (59%).

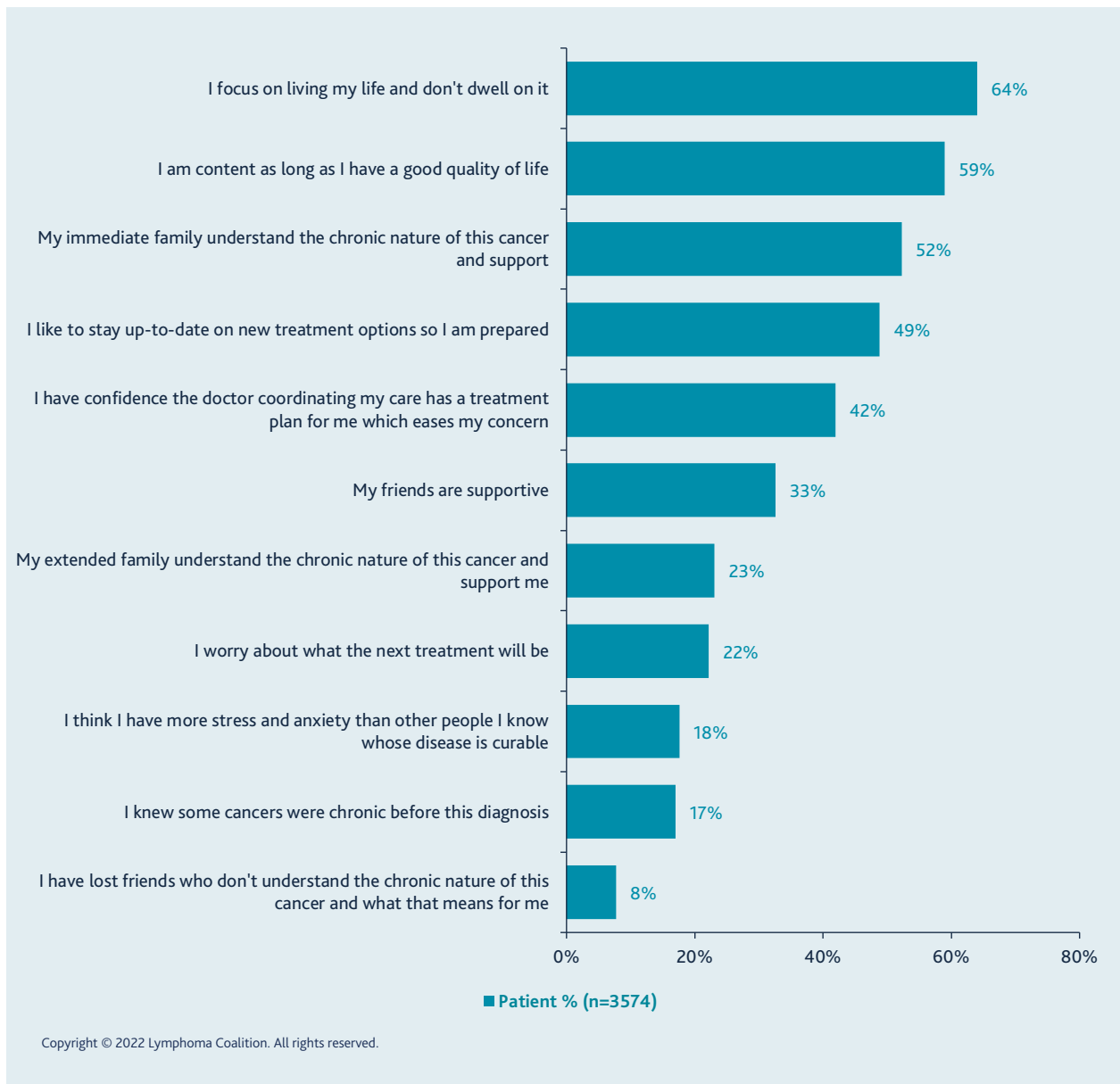
**There are issues that can make this situation more difficult. Many patients living with an indolent lymphoma are struggling with their loved ones understanding the chronic nature of their cancer and their support needs.**

About half say their immediate family understand and provide support, only a quarter say their extended family is supportive, and a mere third report their friends are supportive. Approximately 1 in every 10 patients say they have lost friends due to their diagnosis.

Half of patients say they try to stay up to date on new therapies, so when they do need treatment again, they are prepared and knowledgeable about their options. But one in five admits they are worried about what that next treatment will be.

**Importantly, only 17% indicated they knew cancers could be chronic before they were diagnosed with one, reinforcing the need for good communication, credible information, and solid support for patients as they adapt to their diagnosis.**

**Figure 10. Which of the following statements reflects how you feel about your experience living with a chronic cancer?**



Patients living with an indolent lymphoma were asked to rank outcomes of a new treatment in

It is important to note this becomes more important as a patient advances through their patient experience (67% of those who have never been treated rank this as important while 74% of those in treatment and 75% of those in active monitoring post-treatment or in remission rank it important). If a new treatment is not life-extending, it should improve survival (65%).

Patients rated improving their quality of life (57%) and reducing the side effect burden (52%) as the most important feature of a treatment after its curative value.

**Table 2. What, if any, of the following would you consider to be an important feature of a new medical treatment for lymphoma or CLL? (by patients' lymphoma experience)**

	Active monitoring (never been treated)	Treatment	Active monitoring (post-treatment)	Remission	Other*
A cure	67%	74%	75%	75%	71%
Improved/longer survival	62%	65%	67%	64%	64%
Bring about a remission or response	45%	52%	53%	54%	54%
Improved quality of life	57%	59%	57%	52%	60%
Fewer side effects/more tolerable side effects	50%	51%	55%	51%	52%
Reduced long term effects post treatment (e.g. impact on fertility)	21%	19%	22%	18%	22%
Treatment at home versus treatment in clinic	31%	27%	21%	20%	28%
Duration of treatment	23%	24%	21%	20%	20%
A reduced impact on caregiver/family members	21%	15%	16%	13%	15%
Certainty of available treatment data/results	30%	25%	22%	23%	28%

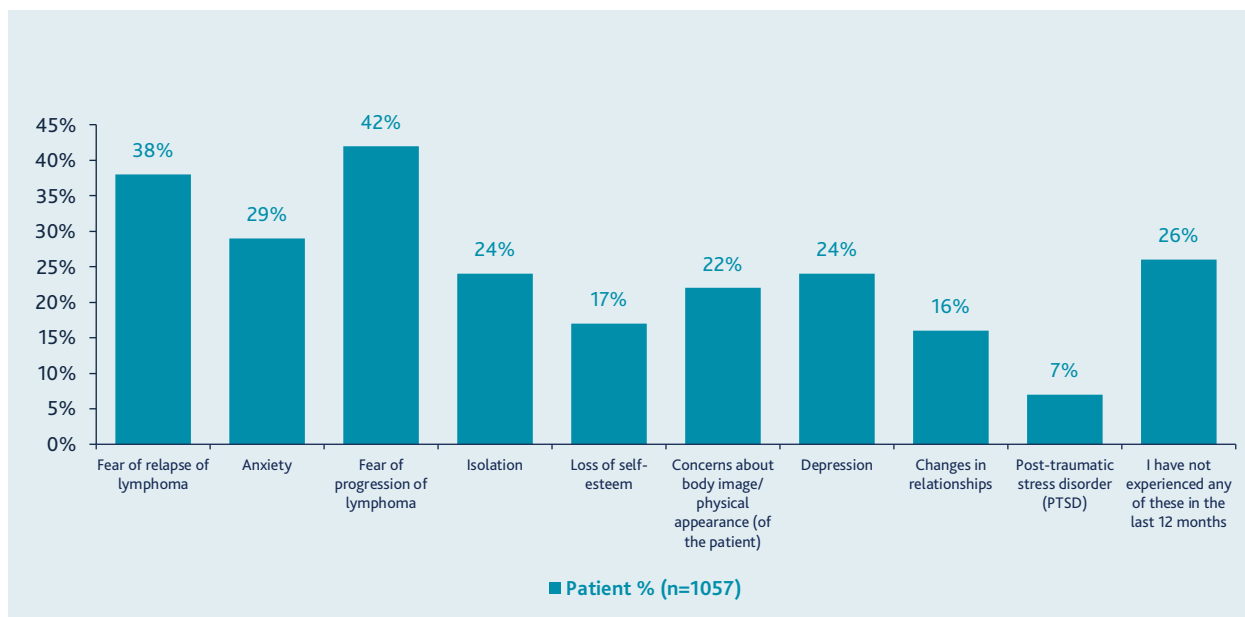
Copyright © 2022 Lymphoma Coalition. All rights reserved. \*Other - including those who have finished or stopped treatment but are not in remission, those who have relapsed or refractory disease but not being treated, and those in palliative.

## PSYCHOSOCIAL EFFECTS

Many patients with lymphoma experience psychosocial issues. The term psychosocial refers to the intersection and interaction of social, cultural, and environmental influences on the mind and behaviour.<sup>13</sup> In lymphoma, it encompasses how a person copes with the change in their health and the new environment they are living in, and how it impacts their daily functioning. Psychosocial issues are often related to uncertainties about the cancer and its treatment, and fear of unknown outcomes.

The LC 2022 GPS data shows that three-quarters of patients living with an indolent lymphoma have experienced psychosocial concerns due to their diagnosis.

**Figure 11. In the last 12 months, have you personally experienced any of the following as a result of the lymphoma diagnosis?**



There is some variability by subtype, ranging from 86% of patients with marginal zone lymphoma having worries or concerns, to 69% of those with WM.

When reviewed by subtype, fear of lymphoma progression is the leading issue for patients with cutaneous lymphoma (56%), marginal zone lymphoma (51%), CLL (36%), and WM (36%). For follicular, fear of relapse is the biggest concern (47%), but this is followed closely by fear of progression (44%). Due to the visible nature of cutaneous lymphoma, it is not surprising that 40% are worried about their physical appearance.



**When examined by stage of patient experience, psychosocial issues are problematic throughout the patient experience for those living with an indolent lymphoma.**

These worries are most reported by those in treatment and those where treatment failed (both 79%), ranging down to two-thirds of those in remission.

Fear of cancer recurrence (when the cancer comes back after a remission), or fear of progression (the cancer growing) is a major issue that patients with cancer experience. This issue is apparent at all stages of the patient experience, speaking profoundly to the temporal reach of this fear. For those in active monitoring and yet to be treated, patients are fearful of the unknown – when the cancer will grow enough to warrant treatment. This was true for half of patients in this stage according to the LC 2022 GPS. For those in treatment, some therapies for indolent lymphomas reduce the amount of cancer and ease symptoms but don't put the disease into remission, and these patients fear their lymphoma will progress, seen in 47% of patients. For those where treatment does achieve a remission, knowing the likelihood of recurrence is high can trigger fear as reported by 31% of survey respondents. **Fear like this has been associated with worsened patient outcomes in areas such as general health status, cognitive, emotional, and social functioning.**<sup>14</sup>

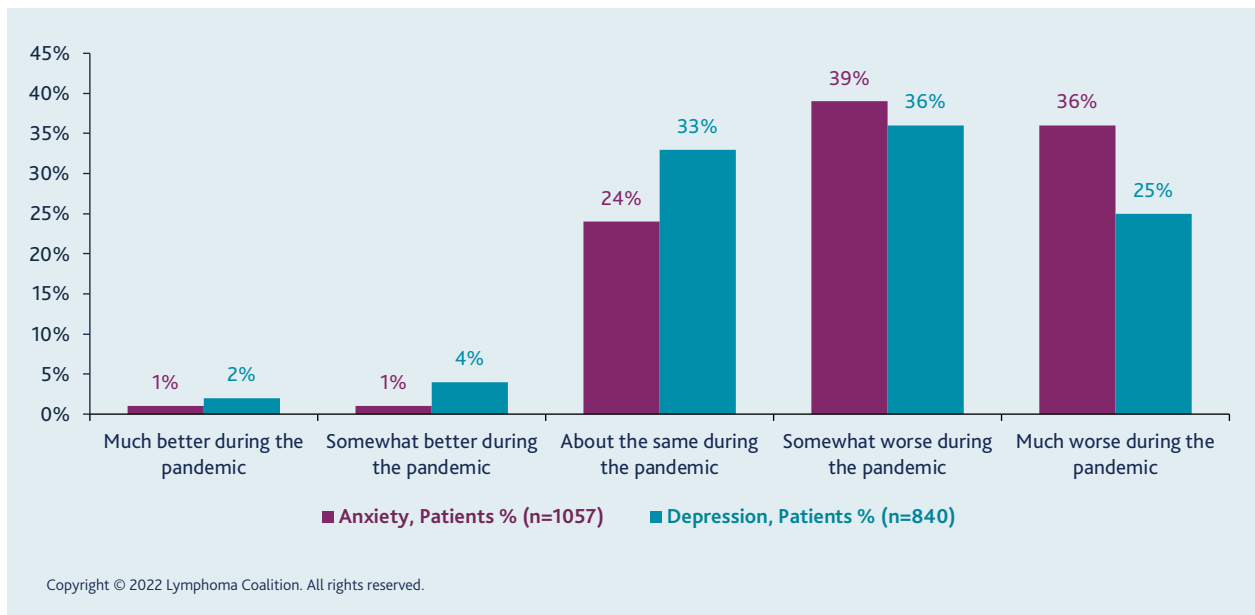
Across comorbidity studies, fear of relapse is consistently reported to be a predictor of overall quality of life, mental health-related quality of life, and physical health-related quality of life (QoL).<sup>15,16</sup> Earlier LC research provided evidence for the correlation of fear of relapse with isolation, depression, and anxiety.<sup>17</sup> Studies also suggest that fear of relapse/recurrence is one of the most frequently cited unmet need among cancer survivors<sup>18</sup>, which is corroborated in this group of patients. Only a quarter of patients fully discussed their fear with their doctor, and another 40% discussed it to some extent. In most cases (60%), the doctor responded by being empathetic, and a third recommended the patient exercise. Unfortunately, only a fifth of patients said their doctor was definitely able to help, and another 56% said they somewhat helped.

Those who experience fear of relapse or fear of progression must be identified, supported, and directed to appropriate resources. Cancer patients should be given opportunities to express these feelings with their health professionals who can give them the help that they need or refer them to resources that can assist in managing these issues. **It is critical for their fear to be recognised, openly discussed, and met with appropriate intervention and support.**

For more on fear of cancer recurrence in patients with lymphoma, please read [LC's report and fact sheets](#).

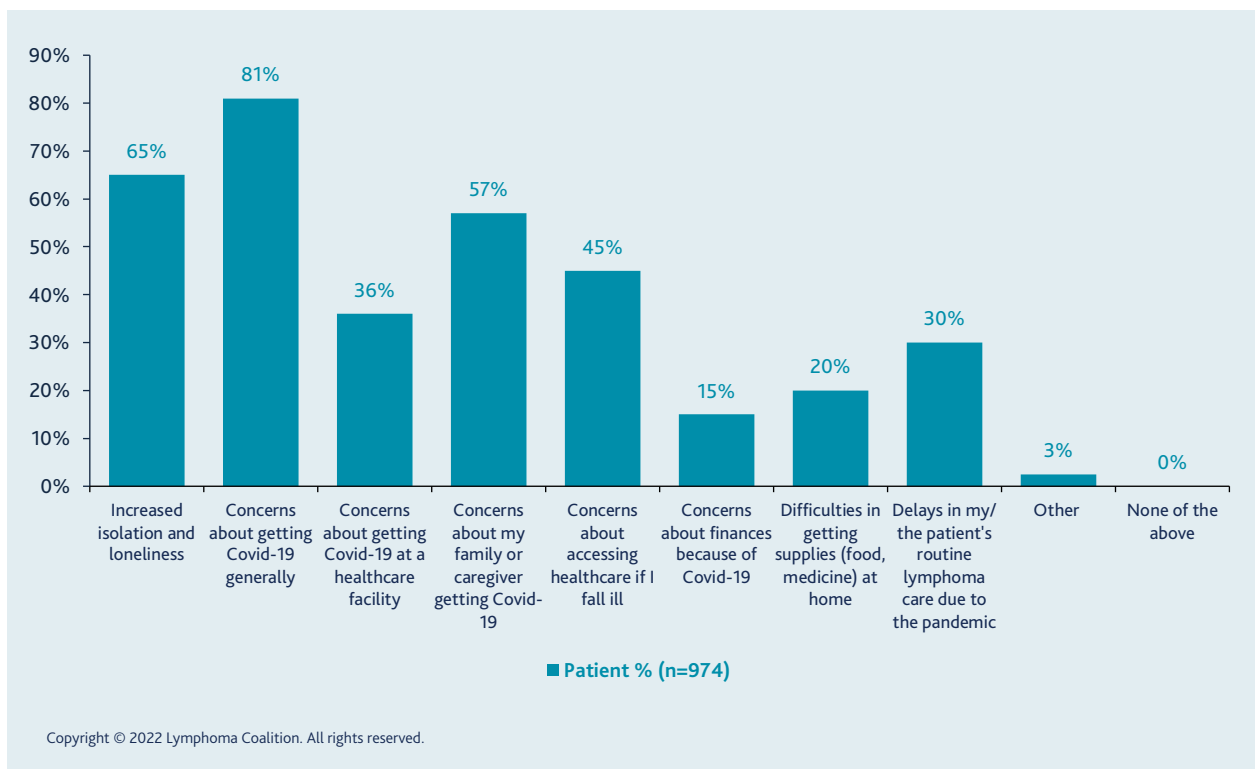
In 2020-2022, patients not only coped with a personal change due to their health status, but they also had to cope with the multidimensional changes brought by the Covid-19 pandemic and their impacts. While the survey results did not show much change in prevalence of anxiety and depression from the LC 2020 GPS to the LC 2022 GPS, they did show an increase in the severity of these issues. **Three-quarters of patients with anxiety said it was worse during the pandemic than before and 61% of those with depression say the same thing.**

**Figure 12. Please describe your levels of anxiety and depression during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.**



Patients were asked what they thought led to the worsening of their concerns. There is a broad spectrum of reasons, but most patients with indolent lymphoma reference their fear of personally contracting Covid-19 (81%) or their family members catching it (57%) and being isolated (65%). The increase in worry is supported by studies showing that immunocompromised patients with indolent lymphoma are more likely to be hospitalised and have worse outcomes from Covid-19.<sup>19</sup> There are also studies showing vaccines are not as effective in these populations.<sup>20</sup>

**Figure 13. Which of the following were contributing factors for the worsened anxiety and/or depression?**



Like fear of relapse and fear of progression, patients do not all speak about their anxiety and depression. About one in five definitely told their doctor, with another 30% talking about it to a limited extent. Similarly, one in five said their doctor definitely helped and just over 50% were helped to some extent. In the case of anxiety and depression, doctors were most likely to prescribe medications (49% and 60% respectively).

It has been shown that patients who have usable and effective coping mechanisms to deal with stress have been shown to have lower levels of depression, anxiety, and symptoms related to the cancer and its treatment.<sup>21</sup> To encourage communication, the emotional impact of a cancer diagnosis needs to be acknowledged at the outset, and the emotional cues from the patient must be recognised and responded to throughout their experience.

**The response of healthcare professionals to a patient's emotional cues has been proven to encourage patients to speak more freely about their feelings.<sup>22</sup>**

Patients need to be supported throughout their care experience and referred to relevant resources by their healthcare providers as needed. This is required not only for physical or medical ailments, but medical professionals should also actively seek to uncover and help with the psychosocial issues that patients may have too. As well, it is imperative there is follow up to ensure any recommended supports are working and helping the patient cope.

**It is important to remember not to neglect the psychosocial needs of patients that may not be undergoing active treatment or having frequent hospital visits, such as patients who are under active monitoring for their lymphoma and patients who have completed treatment and are in remission or back in active monitoring.**

They are more acutely faced with worries about cancer recurrence or cancer progression. These patients may not thoroughly understand what the plan is moving forward when their disease progresses. They may also not have the kind of social support that patients undergoing active treatment have because the impact of their cancer is not as visible to their loved ones, or their social circle believes the impact of lymphoma ceased when treatment ended.<sup>14,12,24</sup>

# FATIGUE

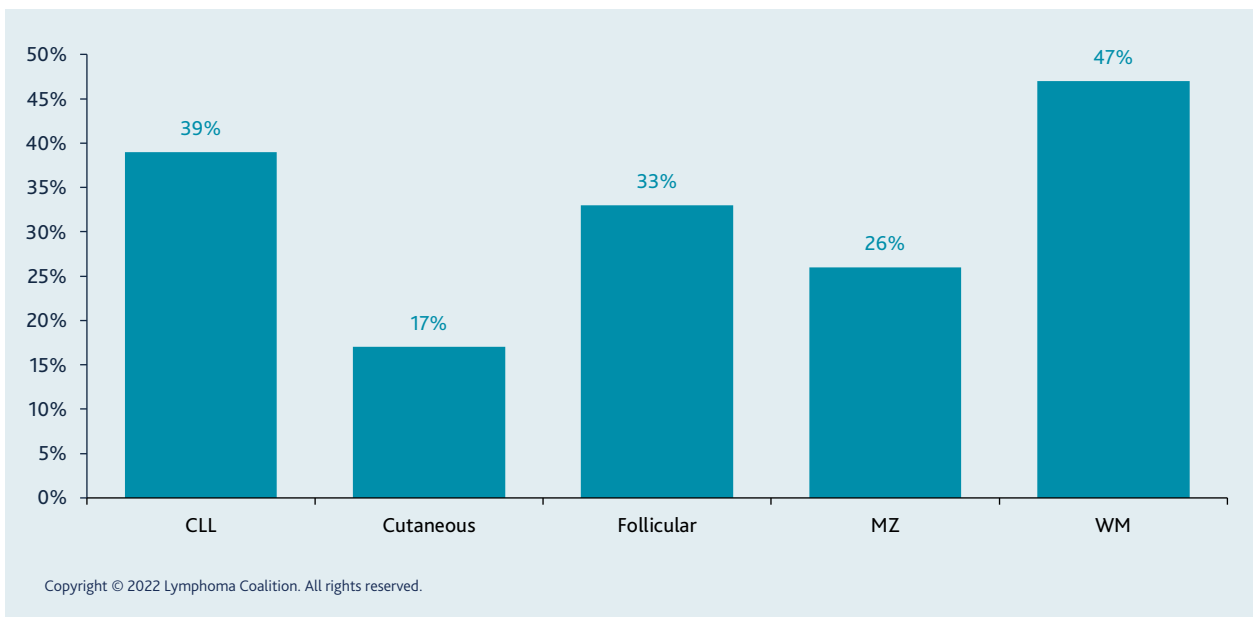
Cancer-related fatigue is often described as paralyzing and can severely impact the lives of those affected. Since fatigue is a symptom of lymphoma itself, as well as a side effect of many of the treatments used to treat it, in many cases, the prevalence of fatigue increases instead of decreases through the patient experience.

Fatigue is the leading symptom affecting quality of life in four out of the five subtypes examined. For those with cutaneous lymphoma, skin rashes and lesions have a bigger impact on quality of life, but fatigue is still mentioned in the top 3 issues they face.

Fatigue is also a top-reported side effect of treatment, and one having a significant impact on wellbeing.

Only 37% of patients say treatment helped alleviate their fatigue. When reviewed by subtype, there is range of responses, with treatment for WM relieving fatigue for almost half of patients, and only 17% of those with cutaneous lymphoma getting relief.

**Figure 14. Has treatment alleviated your fatigue? (only asked to those indicating they had fatigue as a symptom)**

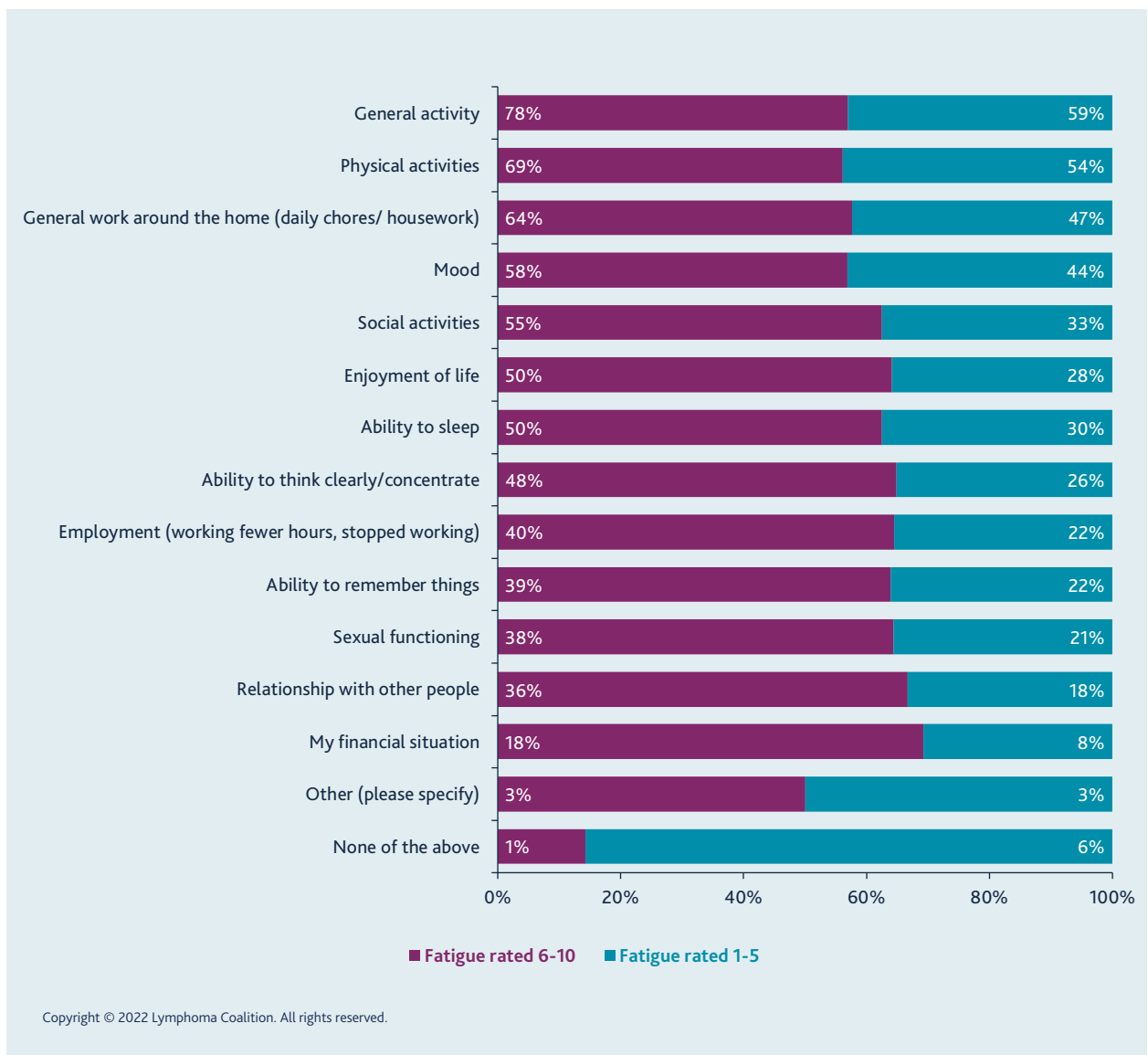


**This highlights the need for research into new therapies that do not include fatigue as a side effect. Treatments should not exacerbate the leading symptom faced by patients living with an indolent lymphoma.**

In the GPS, patients who indicated fatigue was an issue for them were asked to rate their fatigue on a scale of 1 (minimal) to 10 (worst fatigue imaginable) over the last week, following a scale used in clinical practice. 58% rated their fatigue 1-5 and 42% gave it a rating of 6-10.

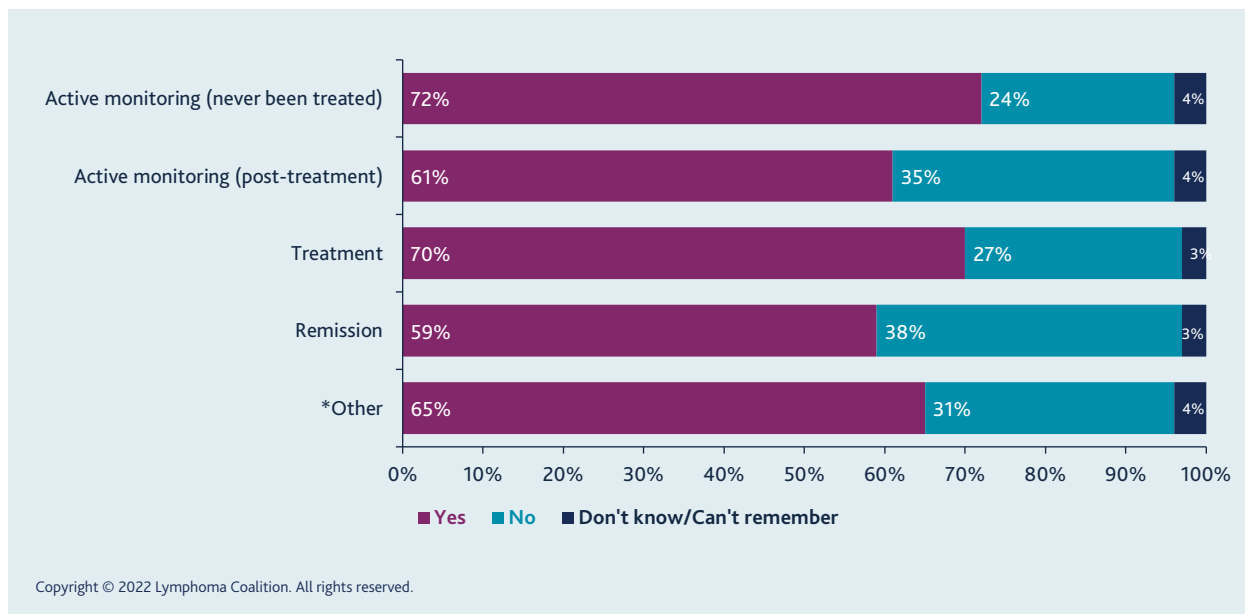
The LC 2022 GPS showed that many of those who experienced fatigue also reported that as a result of it they experienced changes in their lifestyle, independence, ability to work, general activity levels, and ability to care for loved ones among other issues. Those with more severe fatigue experience all of these concerns more frequently.

**Figure 15. Which of the following areas/activities, if any, has your fatigue affected over the last two years?**



Despite the impact fatigue has on their wellbeing, a third of patients have not discussed their fatigue with their doctor. Those later in their disease experience stage were less likely to raise the issue than those in the early stages.

**Figure 16. Have you discussed your fatigue with your doctor over the last two years?**



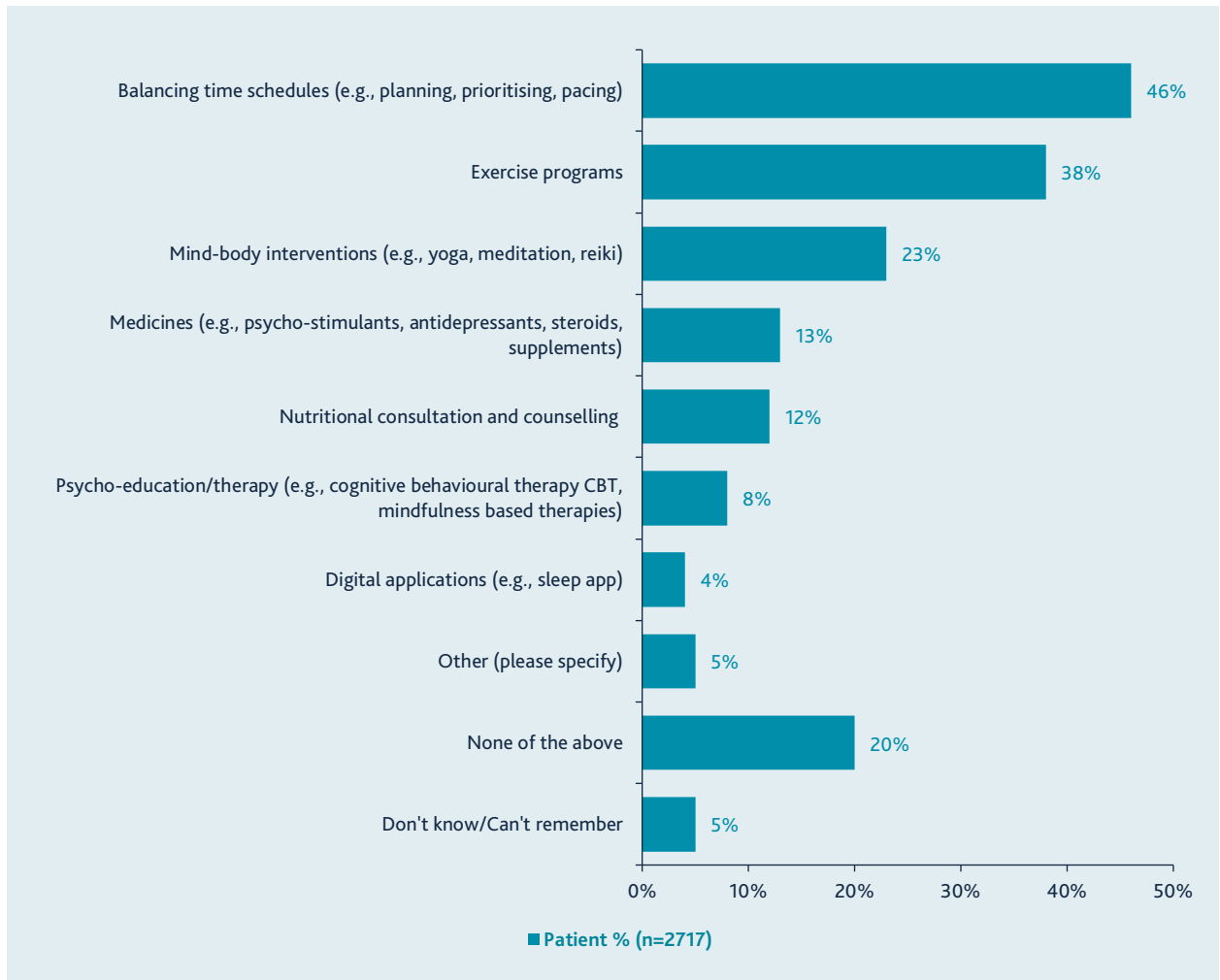
\*Other- including those who have finished or stopped treatment but are not in remission, those who have relapsed or refractory disease but not being treated, and those deemed palliative.

For those that did tell their doctor about their fatigue, 59% said their doctor never followed up, even though cancer-related fatigue guidelines produced by both ESMO<sup>25</sup> and NCCN<sup>26</sup> stress the importance of ongoing monitoring. This was most reported by those who have not yet been treated (70%), but over half of those in treatment or in active monitoring post-treatment also reported a lack of follow up, as did 60% of those in remission and those for whom treatment failed.

What is also concerning is that for 41% of patients who do speak up about their fatigue, their doctor is not providing any resources to help them cope. For doctors who do provide some support, 30% provide information about cancer-related fatigue compared to normal fatigue, or information about the persistence of fatigue after treatment. Only one in every 20 patients were referred to other resources that might help.

Interestingly, there are practical and easy-to-implement tactics patients can employ to help with fatigue. Patients found balancing their time schedules the most helpful way to manage fatigue (46%), followed closely by exercise programs (38%). Patients should be made aware of these tools.

**Figure 17. Have you found any of the following options helpful in managing cancer-related fatigue?**



For more on fatigue, please read [LC's report on cancer-related fatigue](#).

## INFORMATION & HEALTH LITERACY

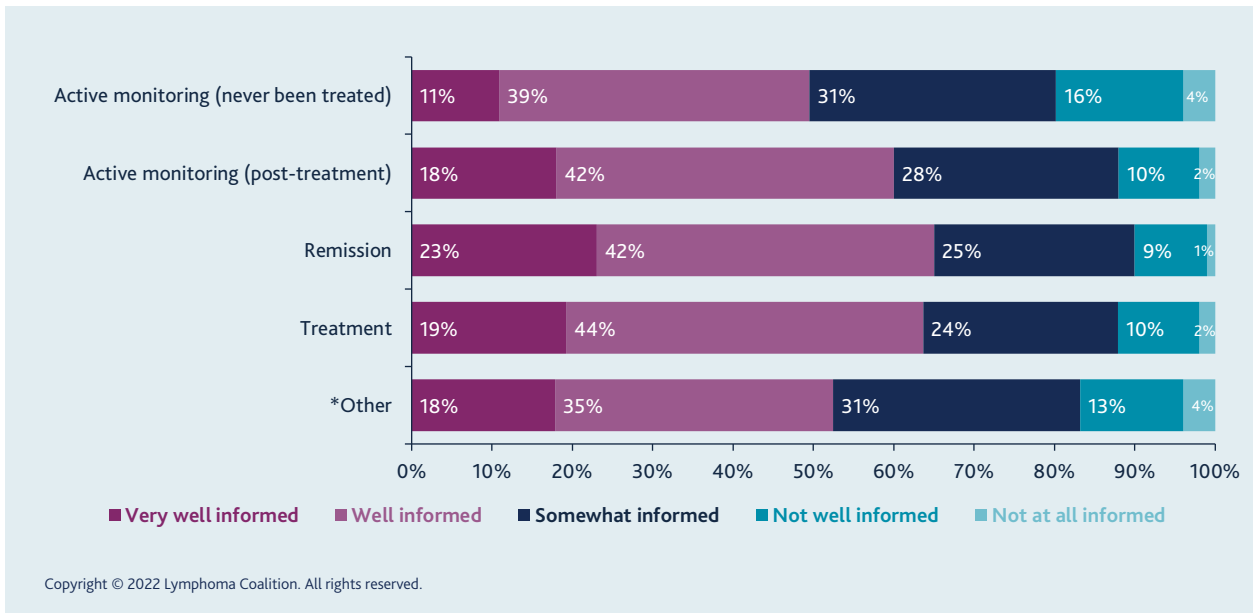
Knowledge is frequently named as the basic requirement needed before patients can fully participate in their own care. For information to be useful to a patient, it needs to be understood and usable. Health literacy encompasses both of these facets. Studies show that people with higher levels of health literacy often experience increased involvement in shared decision-making. Those with low health literacy are more likely to experience poorer health outcomes as well as lower engagement with health services, higher hospital re-admission rates, and a decreased understanding of how to manage complex medication regimes.<sup>27</sup>

Meeting the need for more information right from the beginning is critical as previous LC research showed patients who reported an overall 'adequate' information level also reported a greater understanding of all issues surrounding diagnosis and care after their initial visit to the doctor. Having adequate information was also correlated with a number of positive feelings and outcomes throughout the patient experience.<sup>28</sup>

**Yet, a third of patients living with an indolent lymphoma don't understand their diagnostic tests and results, and 40% of patients report low levels of information related to issues surrounding their subtype and care (e.g., treatment, resources available for support and self-care).**

This is more of an issue for patients in active monitoring – those who have never been treated – where half of patients say they feel poorly informed but it's also an issue for patients whose treatment has failed.

**Figure 18. How informed have you felt about the processes and stages of your healthcare throughout your experience with lymphoma or CLL? (by patients' lymphoma experience stage)**



\*Other- including those who have finished or stopped treatment but are not in remission, those who have relapsed or refractory disease but not being treated, and those in palliative.



Patients with WM were the most informed overall (70%). The rest of the subtypes had about half of patients say they felt well informed.

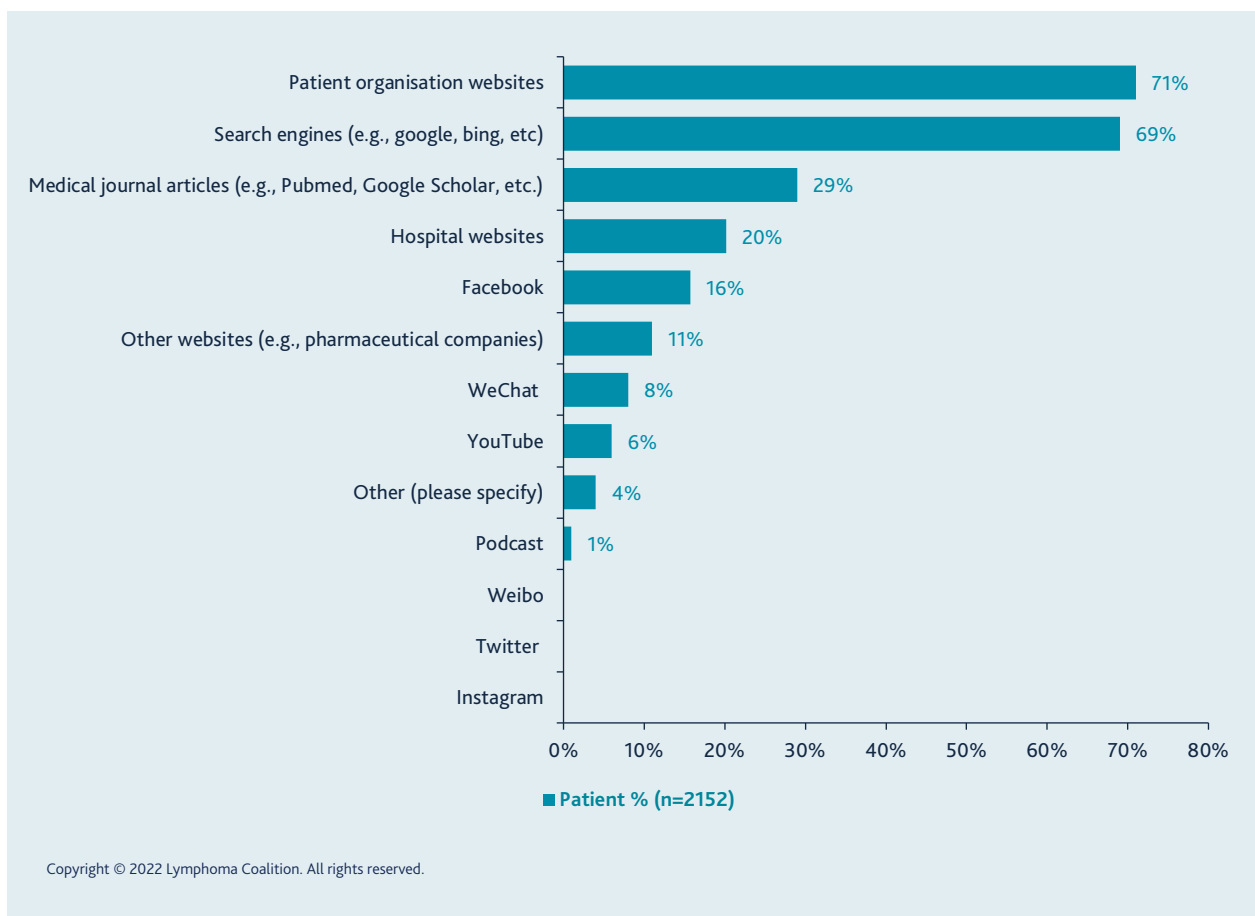
**Only one in every ten patients said they did not seek out additional information over and above what they were provided with by their doctor and medical team.**

Information can come from multiple sources. The leading sources for patients were their doctor (85%), patient organisations (54%), and the internet (53%). These top preferred sources for information are consistent across subtypes and stage of experience.

The preferred method for receiving information is oral information from healthcare providers (56%), websites (56%), and booklets or written information (42%).

Many patients will search for information about their cancer on the internet. **It is important they are directed to credible sources and know their subtype to make sure they find information that applies to their own situation.** A third of patients indicated they were not told or were unsure they were told their subtype when diagnosed. This is especially true for those with CLL and marginal zone lymphoma, where only half of patients were told their subtype (48% and 55% respectively).

**Figure 19. Where on the internet do you usually get your lymphoma or CLL information from?**



## HEALTHCARE INVOLVEMENT & DECISION-MAKING

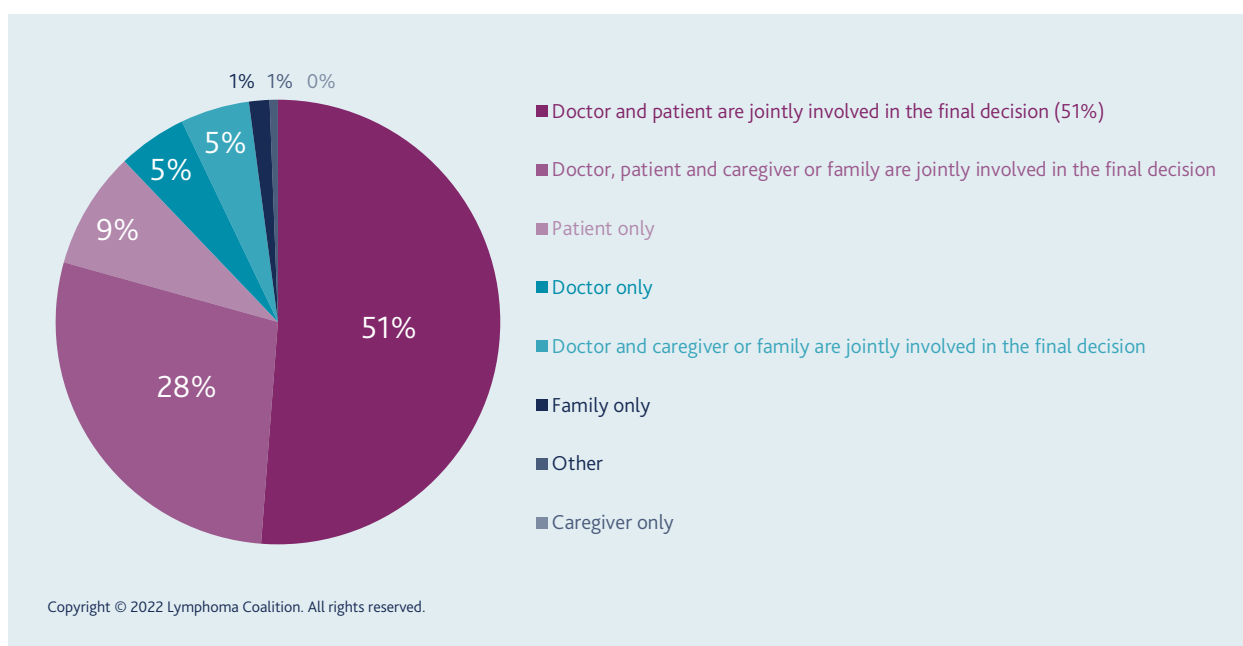
Across health systems, there is an expanding focus on the idea that patients should act as more effective managers of their own healthcare. For this to happen, there must be a shift in culture so that patients are both encouraged and enabled to participate, engage, self-direct, and become empowered. If a patient does not possess the knowledge or confidence in their ability and right to ask questions of a physician or others on their medical team, to take a certain therapy or not, to request further clarification when they do not understand, to feel like they have the right to take up more of the doctor's time, to bring up emotional issues and so on, then they are at risk for a poor patient experience. Patients should feel confident voicing all their concerns to their doctor and letting their doctor know if they have not received a satisfactory answer or adequate support.

Healthcare professionals are the experts on the diseases and treatment options. Patients are the experts on themselves. **Patient-centeredness is a key part of providing high-quality cancer care as it takes into consideration the goals and expectations of patients and their families.** A patient-centred approach by doctors to communicating information has been shown to increase patient confidence and satisfaction with treatment decisions, enhance their trust in the healthcare team, increase treatment adherence, improve health-related quality of life, and improve physical health.<sup>31</sup>

In indolent lymphoma, there are more and more choices for treating patients due to the success of research in recent years. As well, the indolent nature of the disease often allows adequate time to consider options before initiating therapy. Where multiple treatment options exist with variable impact on quality of life, the implementation of a joint treatment decision-making process is essential in facilitating patient care.<sup>29,30</sup>

Most patients indicate they would like a collaborative approach to healthcare decision-making, with over half wanting joint decisions involving patients and their doctors, with a further 28% wanting their caregiver or family involved in the decision as well.

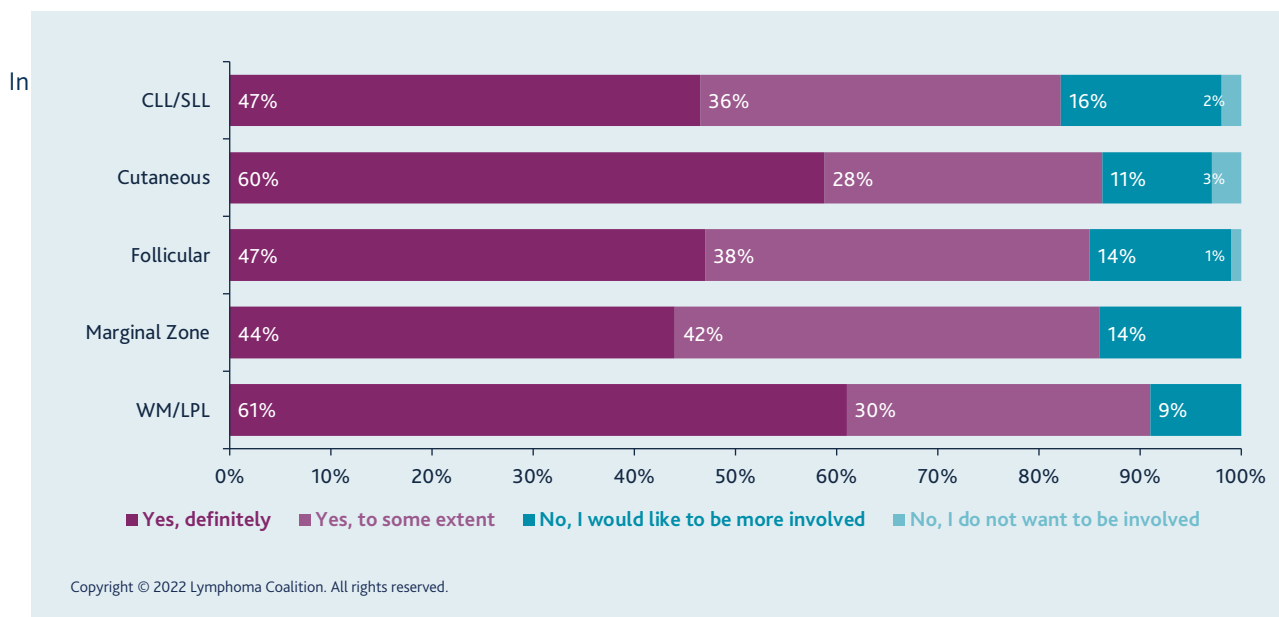
**Figure 20. Who would you like to make the final decision on your healthcare?**



When asked if they are involved as much as they want to be in decisions about their care, the results were very similar across all stages of the patient experience. **Only 1% of patients said they did not want to be involved in these types of decisions.** About half of patients (51%) are definitely involved as much as they want to be, and another half (48%) would like to be more involved.

When the same information is analysed by subtype, those with cutaneous lymphoma or WM are more likely to be satisfied with their current level of involvement, with room for improvement in CLL, follicular and marginal zone lymphomas.

**Figure 21. Do you feel as involved as much as you want to be, in decisions about your care and treatment? (by subtype)**



practice less than a third of patients were given more than one treatment option. Even if patients are not being presented with different treatment options, they should be consulted about their desired outcomes of treatment and understand the potential side effects of the chosen treatment to ensure their preferences are integrated into their care.

The LC 2022 GPS showed some areas where communication is functioning well, and where gaps remain.

**According to patients living with indolent lymphoma, most doctors 'always' do the following:**

- ✓ Allow the patient to express themselves without interrupting (73%)
- ✓ Explain the care plan in a way the patient understands (65%)
- ✓ Communicates with empathy (63%)

**On the other hand, these areas need attention:**

- ✗ About half of doctors (55%) always encourages patients' questions, leaving the onus on the patient to speak up in a significant percentage of cases
- ✗ Less than half of doctors (45%) explore patient preferences and understanding
- ✗ Only 27% of doctors always recommend other resources and support

**Patients also rank the following as important in any doctor/patient relationship.**

- The truth about the diagnosis is conveyed, even though it may be uncomfortable or difficult to hear (78%)
- The patient's goals and concerns about care options are understood and considered (67%)
- Patient preference about the level of information and involvement in decisions about care is met (63%)

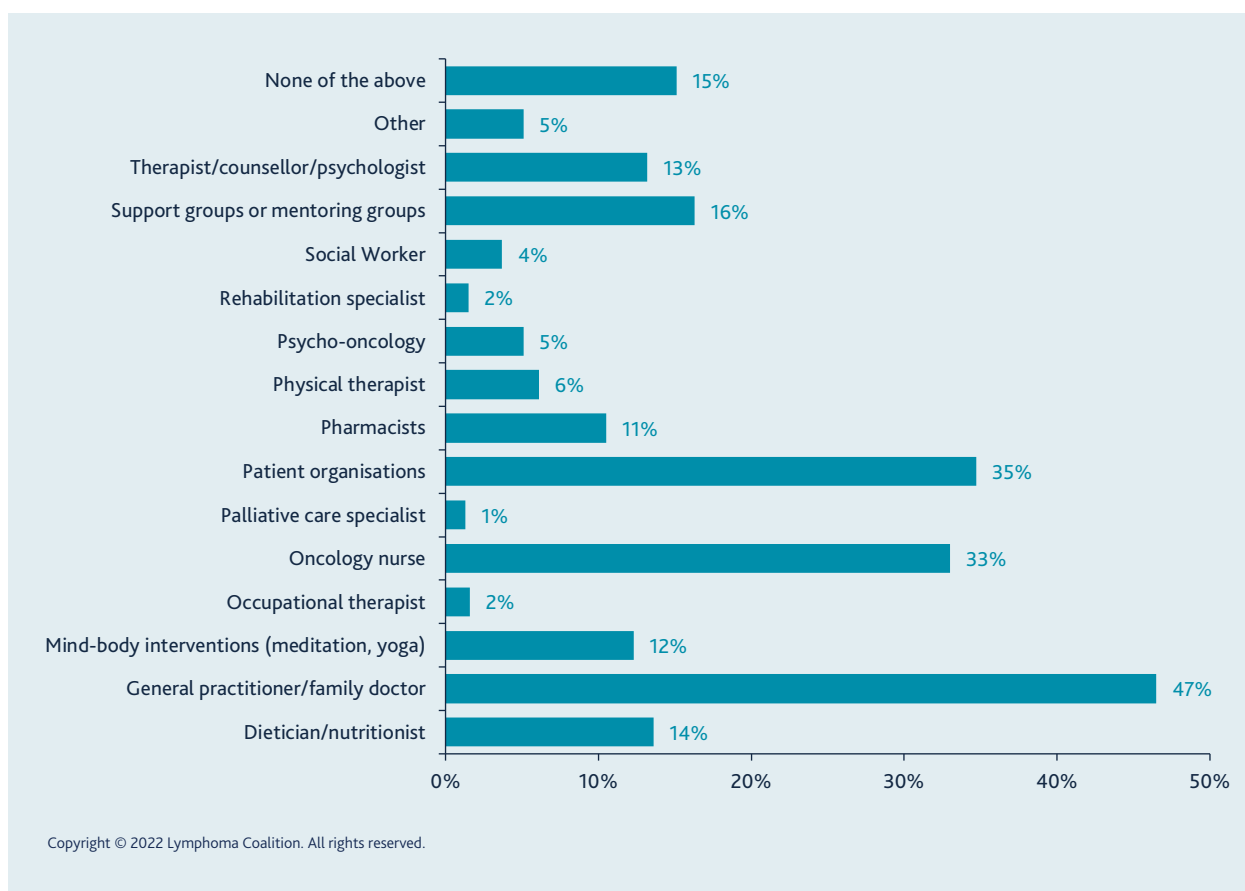
With just over half of doctors (57%) always clearly explaining treatment choices and the risks and benefits associated with each to the patient, there is clearly room for improvement.

## CARE BEYOND THE CANCER CLINIC

Haematology-oncology healthcare professionals cannot be expected to provide all the support that a patient requires. It is important that patients are directed to services that may help. This can include resources available in hospitals, other health services in the community, credible websites or other online resources, and local patient organisations.

Patients with indolent lymphoma were asked who was useful in providing supportive care outside of their specialty physician. Almost half said their family doctor was helpful, followed by patient organisations (35%) and oncology nurses (33%).

**Figure 22. Which of the following, if any, have you found useful in providing supportive care, outside of the specialty physician?**



When asked about the current involvement of their family doctor in their care, 42% said they were involved enough, but 35% would like them more involved. Ideally, 64% of patients living with indolent lymphoma say they would like their family doctor fully involved before, during and after treatment.

Patients that had utilised the services of a patient organisation said they were most likely to use the patient group's website (59%), booklets or written information (47%), webinars (43%) and conferences or other patient meetings (42%).

Over 80% of patients who utilised these services said they were satisfied with the information learned, which is slightly higher than their satisfaction level with information from healthcare professionals (73%).

**Despite patient organisations being a preferred source for information, and one that is highly regarded by those who have accessed services, only 40% of patients are recommended to a patient organisation by their medical team.**

# Conclusions and Recommendations

<b>1</b>	<b>Late diagnosis is an issue, especially for those with rarer subtypes like cutaneous lymphoma and Waldenstrom macroglobulinemia.</b>
<b>1.1</b>	<b>How LC can help:</b> Raise awareness of indolent lymphomas, including CLL, on World Lymphoma Awareness Day and throughout the year.
<b>i</b>	<b>High-Level Plan:</b> Increase awareness across the lymphoma care and treatment pathways by developing and disseminating credible, useable information. This includes working with the Cutaneous Lymphoma Foundation and the International Waldenstrom's Macroglobulinemia Foundation to develop and distribute information specific to these subtypes.
<b>2</b>	<b>Greater efforts are needed to ensure patients have a thorough understanding not only of their diagnosis but also their subtype's characteristics, care pathway, treatment options and potential side effects so they can fully participate in decisions about their care.</b>
<b>2.1</b>	<b>How LC can help:</b> Build an evidence-based framework of systemic patient-centric questions to guide physician-patient communication.
<b>i</b>	<b>High-Level Plan:</b> Promote a patient-centric approach to physician-patient communication by developing questions that ensure patient concerns are addressed, to guide communication and support individual treatment plans. Thought will be given to health literacy issues when developing these tools.
<b>2.2</b>	<b>How LC can help:</b> Anchor health literacy as a key factor of health promotion and quality of life.
<b>i</b>	<b>High-Level Plan:</b> Address health literacy as a barrier to access and an influential factor in determining patient outcomes and quality of life with key stakeholders to help inform position statements, policy development, or shared strategic actions.
<b>2.3</b>	<b>How LC can help:</b> Work with patient organisations to ensure their digital platforms (website) and materials are up to date and medically vetted.
<b>i</b>	<b>High-Level Plan:</b> Consult with and/or advise patient organisations on best practices and governance strategies to help ensure their digital platforms (website) contain updated and evidence-based information. Provide a mechanism for sharing of quality content amongst organisations.

Lymphoma Coalition has a 5-year strategic plan based on two pillars of activity:



**1. Advocacy**








**2. Information**

The following explains actions LC will take to address identified gaps in care for those living with an indolent lymphoma, within these two defined work areas.

<b>3 Issues affecting quality-of-life persist, with fatigue, fear of cancer relapse and fear of cancer progression being the top physical and psychosocial issues for patients.</b>	
<b>3.1</b>	<b>How LC can help:</b> Champion the recognition of fatigue as diminishing patients' quality of life and actively work to introduce active monitoring of fatigue in the lymphoma care pathway.
 	<b>High-Level Plan:</b> Leverage the GPS to increase awareness of fatigue as a symptom and side effect. Support the adoption of active monitoring as outlined in cancer-related fatigue clinical practice guidelines to improve quality of care and inform fatigue management plans. Relevant patient centric information will be widely disseminated to member organisations.
<b>3.2</b>	<b>How LC can help:</b> Connect doctors and patients with local patient organisations to provide support with physical, emotional, and/or practical needs.
	<b>High-Level Plan:</b> Identify patient organisations that offer psychosocial or supportive services to patients with lymphoma, through stakeholder mapping, to support seamless integrated care.
<b>3.3</b>	<b>How LC can help:</b> Support the adjustment and validation of tools for collecting quality of life and Patient-Reported Outcomes (PRO) and/or other patient-centric measurements.
	<b>High-Level Plan:</b> Inform the validation and integration of PROs to help standardize symptom assessment processes and support the use of aggregated data to drive system-wide improvements in the quality of care.
<b>3.4</b>	<b>How LC can help:</b> Create new resources addressing the emotional aspects of a the patient experience.
	<b>High-Level Plan:</b> Review key issues outlined in the GPS, find out what resources are currently available through a mapping exercise, then create resources to fill gaps.



4	<b>Patient experience data is necessary to foster a patient-centred healthcare environment that reflects the unique experiences of those living with an indolent lymphoma.</b>
4.1	<b>How LC can help:</b> Work for the inclusion of the patient perspective across the life cycle of medicine.
	<b>High-Level Plan:</b> Equip member organisations with the knowledge and skills to act locally in support of the inclusion of patient perspectives. For example, offer e-learning opportunities (online seminars) to member organisations who wish to increase their knowledge or understanding of the best practices of regulatory agencies and HTA bodies in their respective region.
4.2	<b>How LC can help:</b> Connect and partner with clinicians and stakeholders to share evidence-based knowledge in support of multidisciplinary, continuous, and participative care.
	<b>High-Level Plan:</b> Highlight the key findings of the GPS and present at the LC Global Summit, external scientific programmes, and/or submit for publication in evidence-based journals.
4.3	<b>How LC can help:</b> Work with stakeholders to remove barriers to clinical trial participation.
 	<b>High-Level Plan:</b> Partner with stakeholders to ensure clinical trials more closely match the real-world patient demographic, and explore options for decentralised trials. At the same time, ensure patient organisations have good information on understanding clinical trials and what participation means for a patient.
4.4	<b>How LC can help:</b> Utilise Community Advisory Boards (CABs) to help build research that examines key areas of shared priorities, interests, and/or concerns.
	<b>High-Level Plan:</b> Host stakeholder dialogues to generate insights, inform or define priorities, and propose strategies to support implementation within national health systems across a broad spectrum of topics including rare cancers. As well, design and deliver enhanced training to CAB members to increase their engagement and support the expansion of the CAB model.

# Appendices

## APPENDIX A: METHODOLOGY

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### Development of the 2022 GPS

The GPS underwent an amendment between 2020 and 2022 to better understand patient and caregiver experiences. The survey was redesigned with consultation between Lymphoma Coalition, member groups and the University of Waterloo Survey Research Centre. The revisions for 2022 included patient- and caregiver-specific questions, expanded questions relating to healthcare information, involvement and decision-making, and new questions about the impacts of Covid-19.

Thematics for the 2022 GPS included the following:

#### Healthcare information and guidance

- Information seeking and provision (at diagnosis and with ongoing care)
- Patient experience of the path to diagnosis
- Preferred sources and methods of receiving information
- Level of satisfaction with information received

#### Effects of lymphoma/CLL, treatment, and side effects

- Symptoms & side effects: lymphoma-related, treatment-related, and psychosocial issues
- Use of biosimilars
- Cancer-related fatigue
- Fear of cancer relapse
- Impact on daily life
- Barriers to treatment, including clinical trials

#### Healthcare support

- Specialist care and supportive care
- Support experience for patients with indolent lymphomas, patients in active monitoring and patients in remission

#### Healthcare involvement and decision-making

- Patients' preferred level of involvement in their care
- The role of the doctor in encouraging participation in care

#### Impact of Covid-19

- Changes to care during the pandemic/lockdown
- Psychosocial effect
- Telemedicine usage

LC member organisations in countries with 100+ responses to the previous survey (LC 2020 GPS) were allowed to add up to five country-specific questions. These were standardised, translated, and asked only to those from that country and reported only in those country-specific reports. Two subtype-specific member groups received a similar opportunity. The survey was cognitively tested by eight patients living with lymphoma and four caregivers, and a few minor text amends were made to improve the survey following this testing. LC recruited the cognitive testers.

## Data Collection

The 2022 GPS went live on 10 February 2022 and was hosted online for nine weeks. There were no time constraints to answer individual survey questions. Respondents could complete the survey at their own pace within the timeframe from the go-live date (10 February 2022) and the hosted end date (14 April 2022). LC created materials to help promote the survey. The engagement and promotion materials for the survey were shared on the LC website and social media properties such as Twitter, Instagram, and Facebook. Promotional materials were also shared with LC member organisations, healthcare professionals, and scientific and community partners across the globe.

LC ensured privacy and confidentiality measures were respected and ensured no participant identifiers were collected. Considerations were taken to ensure that respondents could be as honest as possible without fear of repercussions.

The 2022 GPS was scripted, thoroughly tested, and hosted on a third-party online survey portal, Qualtrics (Provo, UT). The English questions were translated into 18 languages by an approved language translation service using native speakers to translate and proofread. Native-speaking LC members also reviewed the final translations. The survey was published online in the following languages:

- English
- Dutch
- German
- Korean
- Slovak
- Arabic
- Danish
- Hindi
- Lithuanian
- Spanish
- Bulgarian
- Finnish
- Italian
- Portuguese
- Swedish
- Chinese
- French
- Japanese
- Serbian

Respondents could leave survey questions blank if they preferred not to answer.

## Data Cleaning

The data cleaning process included the following steps: all partially completed surveys were kept if Q2=1 (respondents agreed to having their answers recorded) and if the survey had been completed at minimum up to Q47 (i.e., Q47 is completed). A review of surveys that were flagged by Qualtrics as potential bots was also completed prior to data being aggregated.

Data was categorised within Qualtrics before being exported to MS Excel and IBM Statistical Package for the Social Sciences (SPSS) v27 for visualisation into frequency tables and charts. Data were then exported into reports for researcher interpretation and commentary. No statistical analysis was performed; any reported differences cannot assume statistical significance.

Cross-tabulations were used to investigate patterns in care experiences between patient demographics, lymphoma subtype and countries and regions of residence; cross-tabulations were also used to examine patterns between caregiver experiences.

Results were only reported where there were 20 or more survey responses (per question). For any sub-group analyses (e.g., by lymphoma subtype, gender, or age group), data captured was not reported on groups lower than 20. Consideration was given to (i) the data can be misleading and unrepresentative from low numbers, and (ii) it risks individual respondents becoming identifiable.

Some questions were asked only to a subset of respondents and given that there was an option not to answer a particular question, the total number of respondents may fluctuate between questions.

## Data Dissemination

The LC dissemination and data preservation plan ensures best practices and ethical guidelines have been met. All critical data and documentation files produced during the data collection process are stored behind a firewall on the LC's password-protected server.

## APPENDIX B: LIST OF SUBTYPES BY STAGE

**Table B. List of indolent lymphoma subtypes and where they were in their lymphoma experience**

Sub-type	Newly Diagnosed	Active monitoring (never been treated)	Treatment	Active monitoring (post-treatment)	Remission	Other*	Total
<b>CLL**</b>	16 (1%)	529 (41%)	383 (30%)	164 (13%)	121 (9%)	87 (7%)	<b>1300</b>
<b>Cutaneous</b>	8 (2%)	59 (11%)	256 (20%)	73 (14%)	46 (9%)	76 (15%)	<b>159</b>
<b>Follicular</b>	7 (1%)	137 (12%)	313 (24%)	221 (20%)	349 (31%)	105 (9%)	<b>1132</b>
<b>Marginal zone</b>	3 (1%)	40 (16%)	55 (4%)	75 (30%)	49 (20%)	28 (11%)	<b>174</b>
<b>WM**</b>	2 (0%)	199 (23%)	287 (22%)	253 (29%)	69 (8%)	75 (8%)	<b>885</b>
<b>Total</b>	36	964	939	786	634	371	<b>4085</b>

\*Other - including those who have finished or stopped treatment but are not in remission, those who have relapsed or refractory disease but not being treated, and those in palliative.

\*\*CLL includes those diagnosed with Chronic Lymphocytic Leukaemia (CLL) or Small Lymphocytic Lymphoma (SLL); WM includes those diagnosed with Waldenström Macroglobulinemia and Lymphoplasmacytic Lymphoma.

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