2022 Global Patient Survey on Lymphomas & CLL

September 2022

Country Report

UK

Table of Contents

SECTION 1

Overview

Overview

Lymphoma Coalition (LC) is a non-profit organisation comprised of a worldwide network of patient advocacy groups that support those affected by lymphoma, including chronic lymphocytic leukaemia (CLL). LC was formed in 2002, launched its first web-based Global Patient Survey on Lymphomas & CLL (GPS) in 2008 and continues to conduct the GPS every second year. The goal of the GPS is to understand the patient and caregiver experience in lymphomas, including chronic lymphocytic leukaemia (CLL), and the impact of treatment and care. Further, the data generated from the GPS help drive planning and policy, bridge knowledge gaps, and advocate for equitable care across the globe. Additionally, the data serves as the foundation for scientific abstracts, joint research initiatives, policy papers, and other international collaborations and presentations.

In 2022 the GPS was redesigned to include patient and caregiver-specific questions, expanded questions on healthcare information, involvement and decision-making, and new questions on the impact of Covid-19. Member organisations in countries with 100+ responses to the previous survey (LC 2020 GPS) were invited to add up to five additional country-specific questions that addressed their local issues and concerns. Two subtype-specific Member organisations had the same invitation.

The Survey Research Centre (SRC) at the University of Waterloo, Ontario, Canada, was commissioned by LC to run the 2022 GPS on lymphomas and CLL. The survey was available in 19 languages and was promoted by LC patient member organisations, scientific partners, healthcare providers and community alliances.

Respondents

The results in this report present the data from the UK.

The overall number of completed responses is 488 made up of:

434 Patients

54 Caregivers

SECTION 2

Key Findings

Key Findings from Patients

Information, Guidance and Support

Only 21% of patients felt very well informed about the processes and stages of their healthcare

66% of patients ranked booklets and other written information as their top method of receiving information

Outside of their doctor, 51% of patients say their nurse is most useful in providing supportive care

59% would like doctor and patient to jointly make healthcare decisions

Diagnosis and Treatment

62% of patients were told their lymphoma subtype at diagnosis

Only 20% of patients were given more than one treatment option before their current or last therapy for lymphoma

80% of respondents experienced fatigue as a side effect of treatment and 78% as a symptom of lymphoma

65% agree that side effects and symptoms have negatively impacted their everyday activities.

56% of patients reported that nothing had made getting treatment more difficult

56% of respondents indicated they had experienced fear of lymphoma relapse and 43% experienced fear of lymphoma progression

29% of patients received information about clinical trials from their doctor, and only 8% are currently, or have been, in a clinical trial for their lymphoma or CLL

68% of patients reported the top barrier to participating in a clinical trial was ‘never being presented with an opportunity to take part’

COVID-19 - Impact and Experiences

55% of patients reported their anxiety was much worse and 28% said it was somewhat worse during the Covid-19 pandemic.

38% of patients reported their depression was much worse and 30% said it was somewhat worse during the Covid-19 pandemic.

70% of patients experienced changes to their lymphoma care due to COVID-19.

Only 13%% of patients strongly agreed that they preferred telephone consultation or video consultation to face-to-face visit.

'Patient organisations' were identified by 68% of patients as very helpful or helpful sources of information and support during the COVID-19 pandemic.

36% of patients were satisfied with the government's support for the practical needs of the clinically extremely vulnerable during the pandemic

SECTION 3

Background

Background

Lymphoma Coalition

http://www.lymphomacoalition.org/

Lymphoma Coalition (LC) is a non-profit organisation comprising a worldwide network of lymphoma patient groups. LC was established in 2002 and has over 80 member organisations across more than 50 countries. The overarching goal is to facilitate a community of patient organisations and support efforts to help patients with lymphoma, including CLL, receive the care and support needed.

- The LC vision is equity in lymphoma outcomes across borders.
- The LC mission is enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

LC's current strategy is focused on ensuring impact within two pillars: information and advocacy. This is partially achieved through collecting data from the biennial Global Patient Survey (GPS).

Survey Research Centre

http://www.Uwaterloo.ca/src

The Survey Research Centre (SRC) is a cooperative venture between the Department of Statistics and Actuarial Science and the Department of Sociology and Legal Studies at the University of Waterloo. The SRC strives to provide high-quality survey research with full transparency of project conduct. Therefore, the SRC adheres to the standards and protocols developed by the American Association for Public Opinion Research (AAPOR). Final disposition codes are adapted from the AAPOR list of standard codes for telephone and online surveys. In addition, SRC has worked with universities and colleges across Canada and is adept at conducting surveys among vulnerable populations.

Global Patient Survey

LC launched its first web-based Global Patient Survey (GPS) on Lymphomas and CLL in 2008 and has conducted a biennial survey ever since. The survey seeks to understand patient experience with lymphomas, including CLL, and the impact of treatment and care. The GPS is promoted by LC member organisations, scientific partners, healthcare providers and community alliances. Examples of some of LCs partners and alliances include the Hematology Nurses and HealthCare Allied Professionals group (HNHCP), European Hematology Association (EHA), International Lymphoma Epidemiology Consortium (InterLymph), Union for International Cancer Control (UICC), and multidisciplinary healthcare professionals among many others.

The survey responses have provided rich datasets that have fostered a culture of collaboration and knowledge sharing. Patient experiences from the GPS have served as the foundation for scientific abstracts, publications, reports, and the development of various patient resources in addition to highlighting areas for further research. The information collected over the years has been instrumental in advocating for equitable care and evoking change for people affected by lymphomas. The dissemination of data has served to develop successful campaigns and presentations to healthcare professionals and other stakeholders who play a role in the care of patients.

SECTION 4

Methodology

Methodology

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

Healthcare support

Specialist care and supportive care
Support experience for patients with indolent lymphomas, patients in active surveillance 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

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

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

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.

Examples of how the data is used and disseminated:

- LC 2020 GPS Survey Reports (https://lymphomacoalition.org/global-patient-survey/)
- Lymphoma report card (2020 and 2021) (https://lymphomacoalition.org/global-report-card/) and European report (https://lymphomacoalition.org/wp-content/uploads/Report_Lymphoma_Care_In_Europe_VF_A4_Digital.pdf)
- Abstracts and scientific posters (https://lymphomacoalition.org/lymphoma-coalition-research)
- Subtype reports- e.g., CLL (https://lymphomacoalition.org/wp-content/uploads/2022_Lymphoma_Coalition_Report_CLL_VF_A4_Digital.pdf)
- World Lymphoma Awareness Day (WLAD) (https://lymphomacoalition.org/world-lymphoma-awareness-day/)

SECTION 5

Results

Patient Results

434 people living with lymphoma/CLL in the UK responded to the 2022 GPS. The results in this section will report across the following areas:

- ✓ Patient characteristics
- ✓ Diagnostic demographics
- ✓ Treatment demographics
- ✓ Healthcare information and guidance
- ✓ Healthcare support
- ✓ Healthcare involvement and decision making
- ✓ Effects of lymphoma
- ✓ Barriers to treatment
- ✓ Side effects of treatment
- ✓ Fatigue
- ✓ Psychosocial effects
- ✓ Covid-19 and virtual care

Patient Characteristics

- Most responses were from patients aged 65 or older (39%), followed by patients aged 55-64 (36%), with the lowest survey respondents being those under age 35 (6%).

- Almost all patients reported their ethnicity as Caucasian or White at 96%.

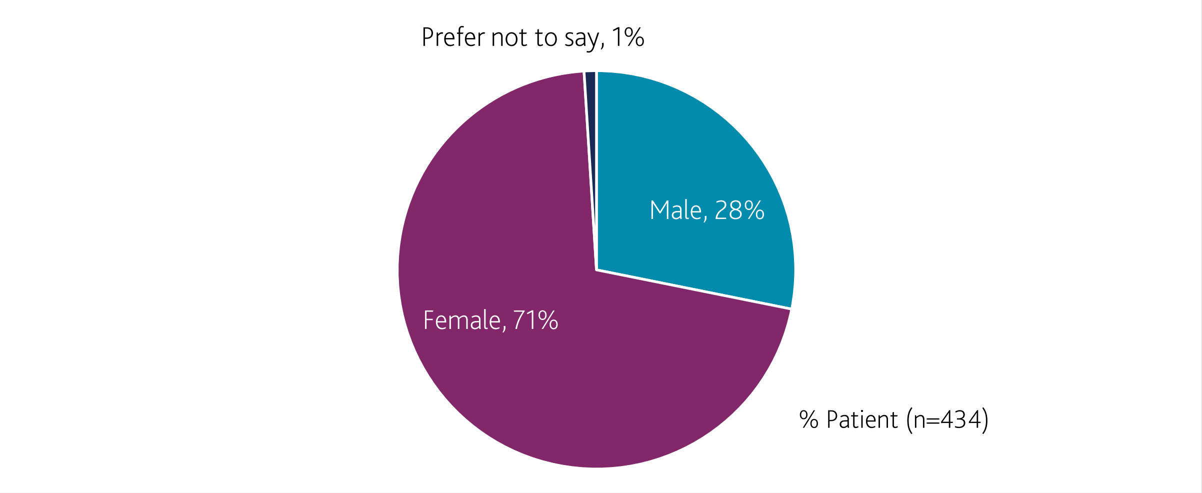
- The overall cohort of patient respondents (434) was mainly female (71%), with most respondents residing in suburbs or residential areas (52%).

- 79% of the overall respondents had completed advanced education, with 58% completing college/university degrees and 21% having completed postgraduate education such as a master's or Ph.D.

- A majority reported they have retired (47%), and a third are still working either full or part-time. 9% of patients were unable to work for health-related reasons.

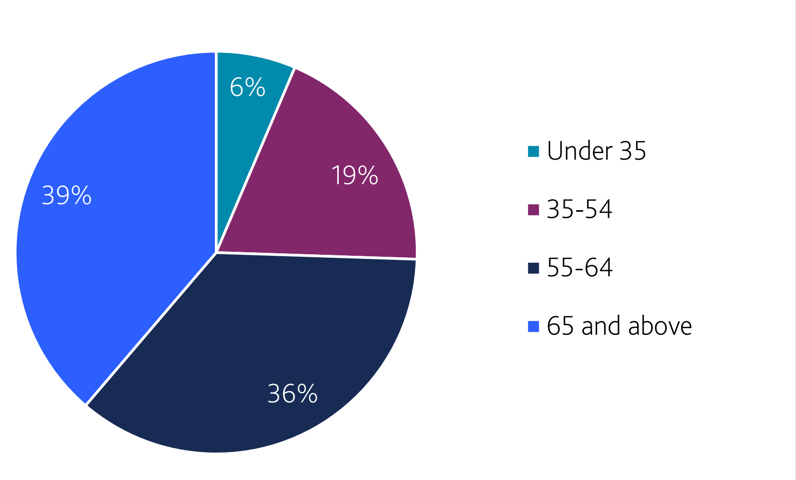
- Figure 1 shows that most respondents are female.

Figure 1. Sex of patient



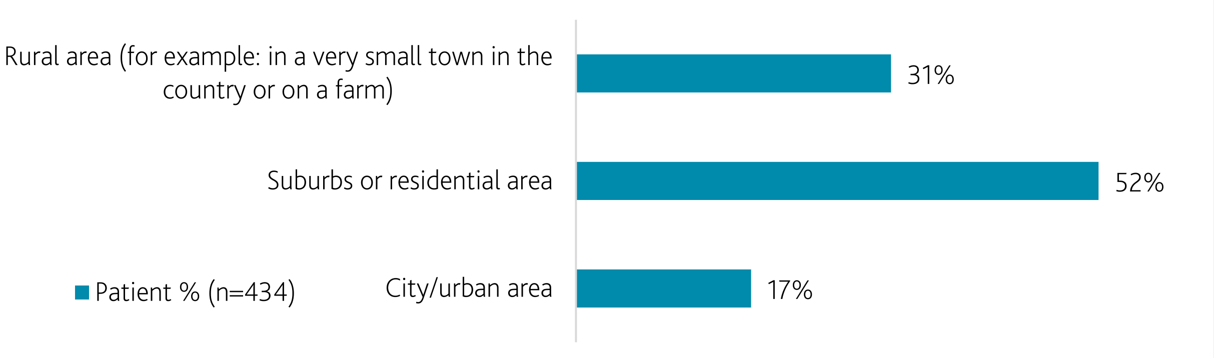
- Figure 2 illustrates that 75% of patients are aged 55 and over.

Figure 2. Age range of respondents



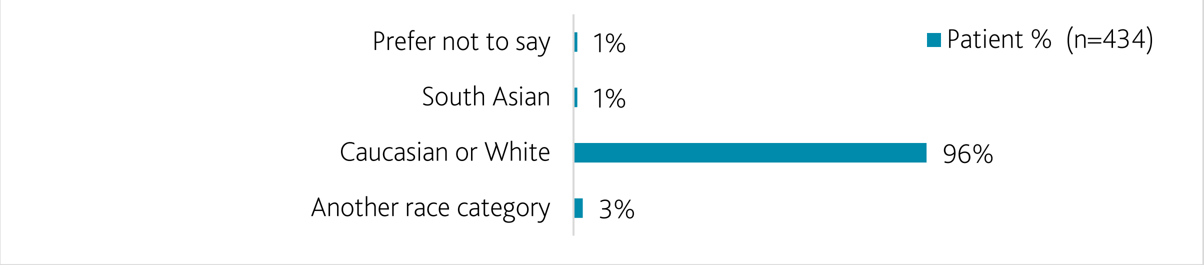
- Figure 3 shows over half of patients live in the suburbs or residential areas.

Figure 3. Which best describes the area you live in?



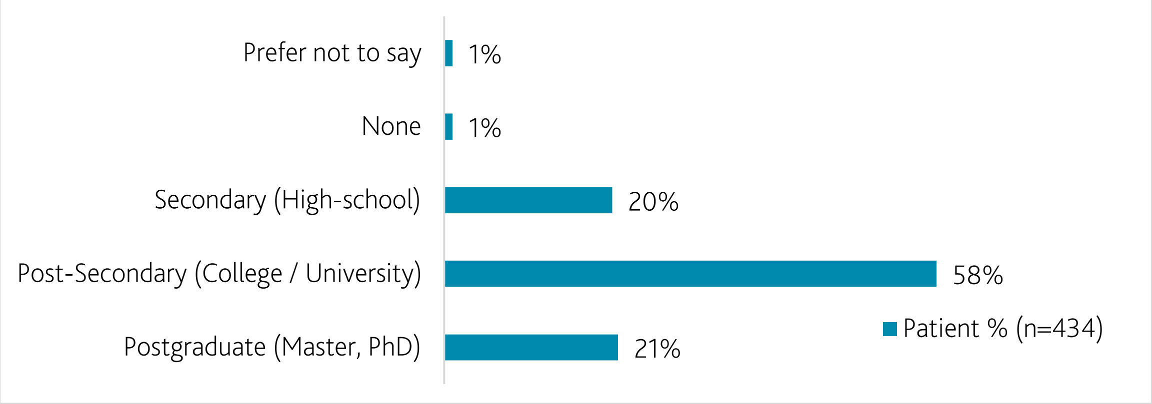
- Figure 4 indicates that almost all patients are ethnically Caucasian or White.

Figure 4. How do you identify your ethnicity?



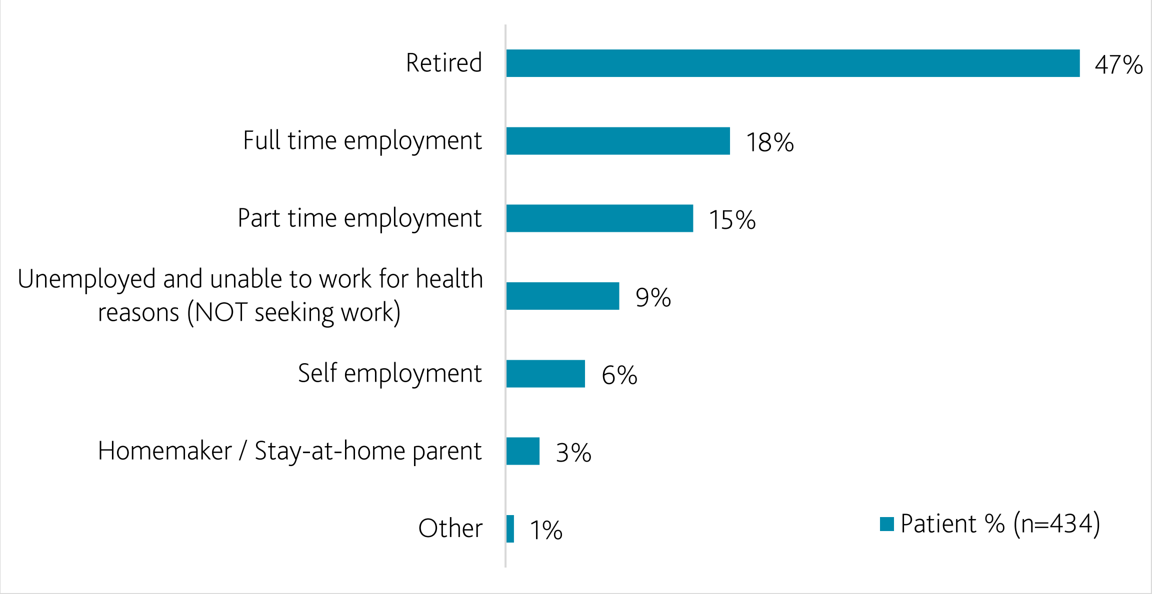
- Figure 5 illustrates that the majority of patients are well educated, having completed a post-secondary or postgraduate education.

Figure 5. What is your highest educational level completed?



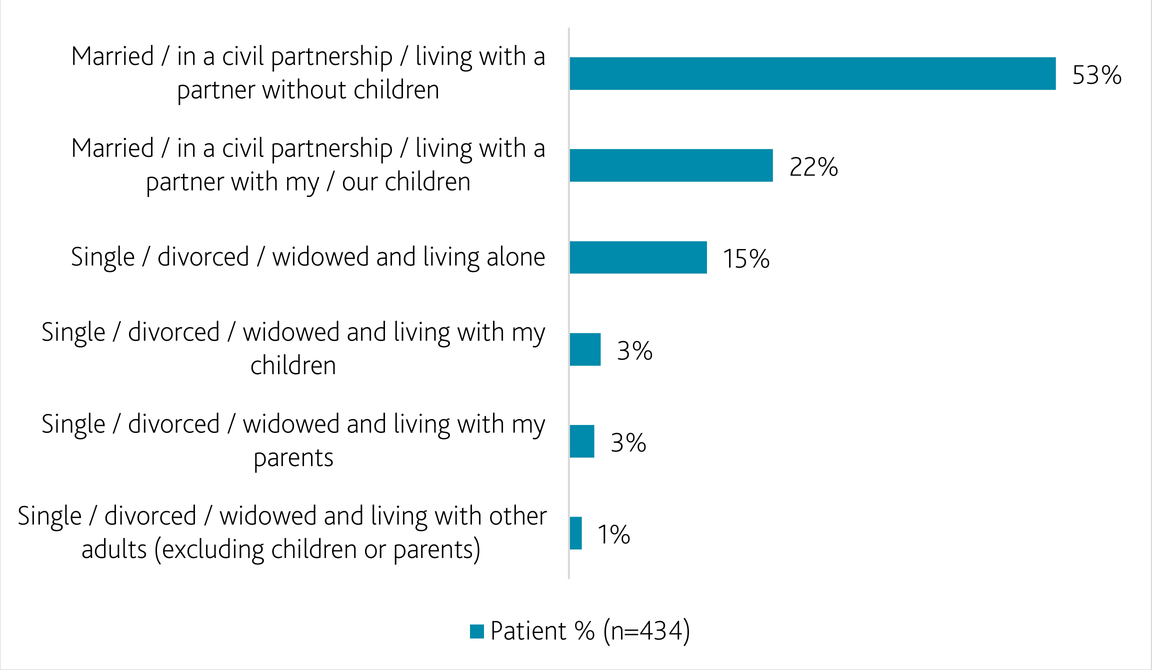
- Figure 6 shows that almost half of patients are retired.

Figure 6. Which of the following best describes your employment status?



- Figure 7 reveals three-quarters of patients live with a partner, 53% with children and 22% without children.

Figure 7. Which of the following best describes your household status?

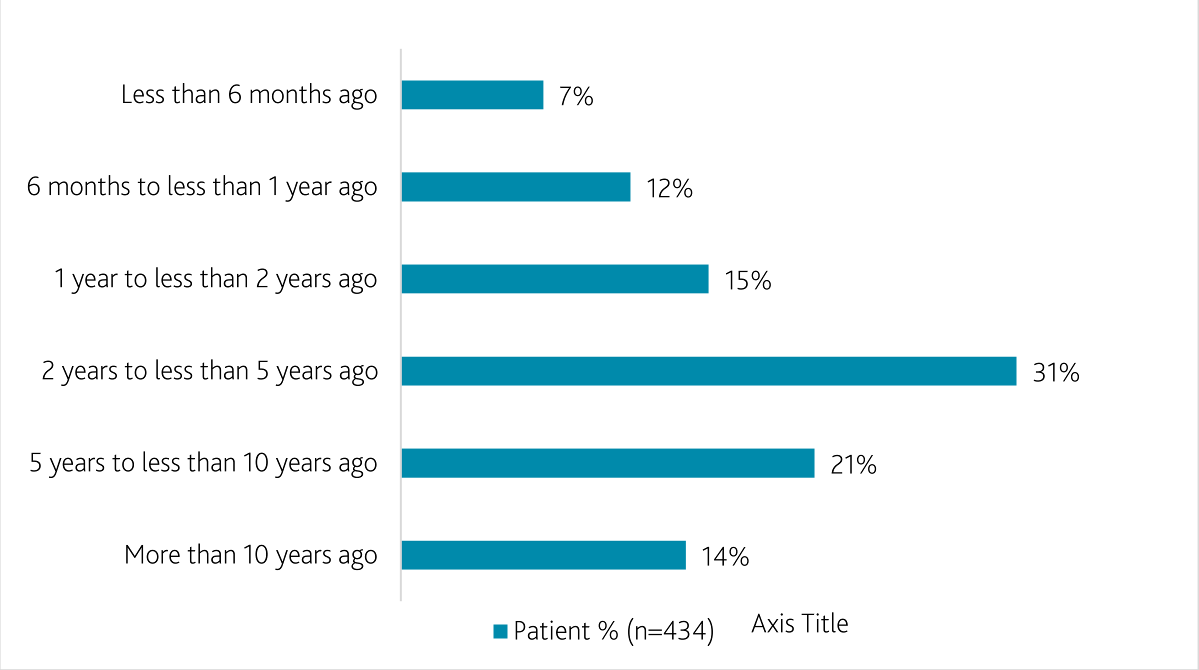


Diagnostic Demographics

- 31% of patients who responded to the survey were diagnosed 2 to 5 years ago.
- Three out of five patients were seen by 3 or more healthcare professionals for their symptoms before receiving their initial diagnosis. A staggering 14% were seen by 5 or more healthcare professionals before receiving a diagnosis.
- A quarter of patients (26%) experienced their symptoms for more than six months before seeking medical care. Just over half of patients (54%) had a diagnosis within three months of their first appointment with their family physician or when they first sought medical care about their symptoms. However, 17% had to wait longer than six months before they received a diagnosis.
- The top five reported subtypes were follicular lymphoma (28%), Waldenstrom's macroglobulinemia (14%), Hodgkin lymphoma (13%), diffuse Large B-Cell lymphoma (13%), and marginal zone lymphoma (7%),

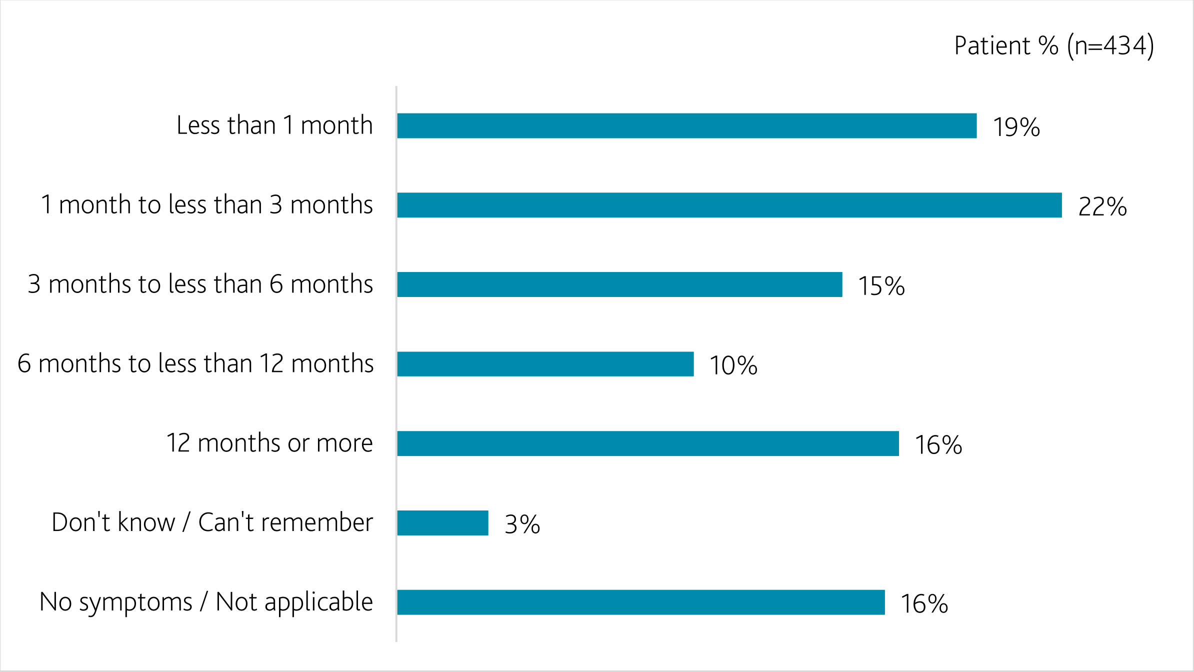
❖ Figure 8 points out that half of respondents were diagnosed with lymphoma or CLL between 2 to 10 years ago.

Figure 8. How long ago were you / the patient diagnosed with lymphoma or CLL?



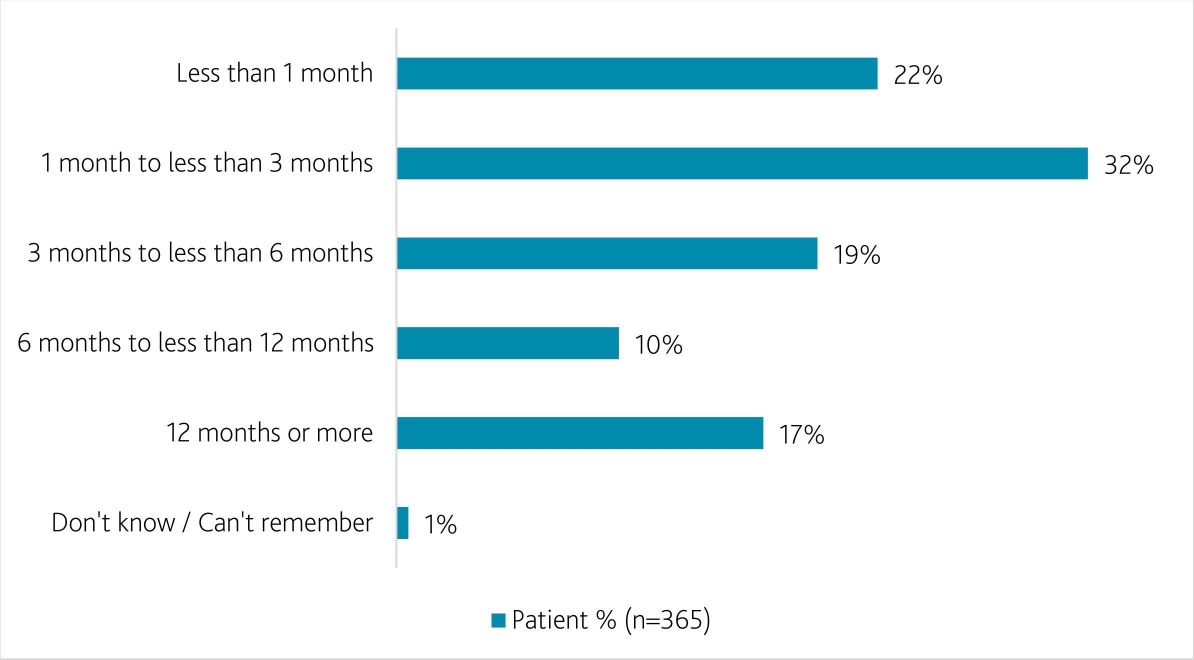
- Figure 9 shows that 16% of patients did not experience lymphoma symptoms before diagnosis.

Figure 9. How long were you originally experiencing lymphoma symptoms for before you went to your primary doctor or sought medical care about these concerns?



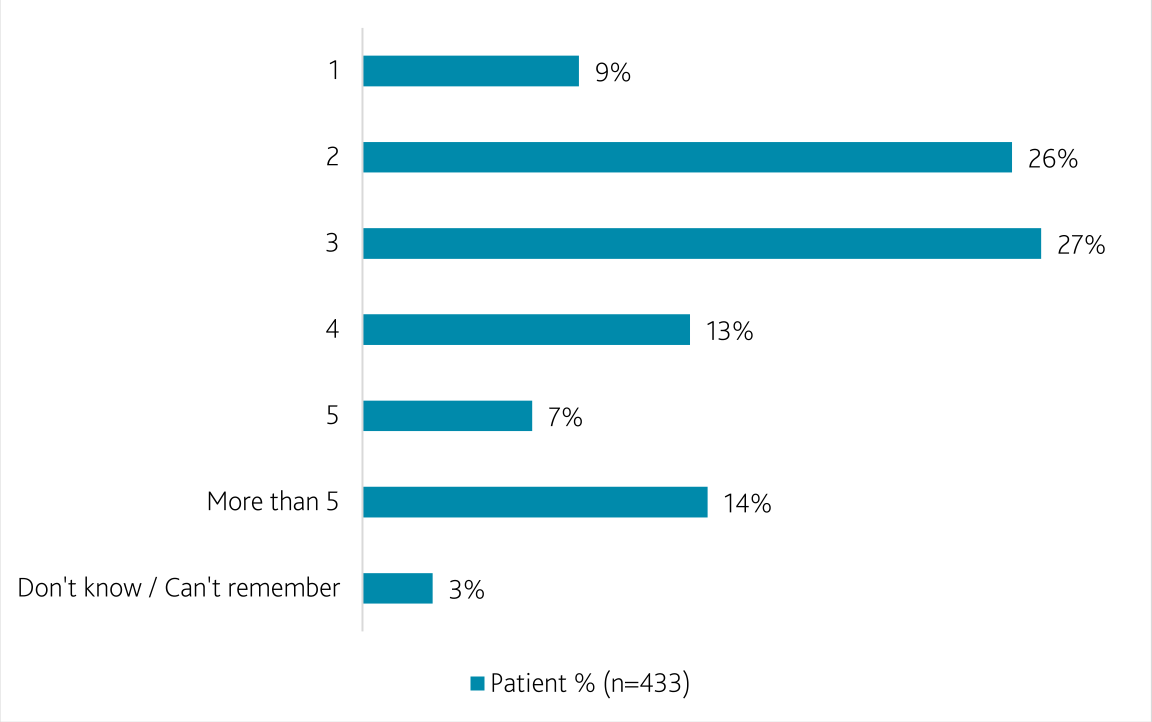
- Figure 10 illustrates that over half of patients (54%) had a diagnosis within 3 months of their first appointment, but 27% were waiting 6 months or more from their initial meeting with their GP.

Figure 10. 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?



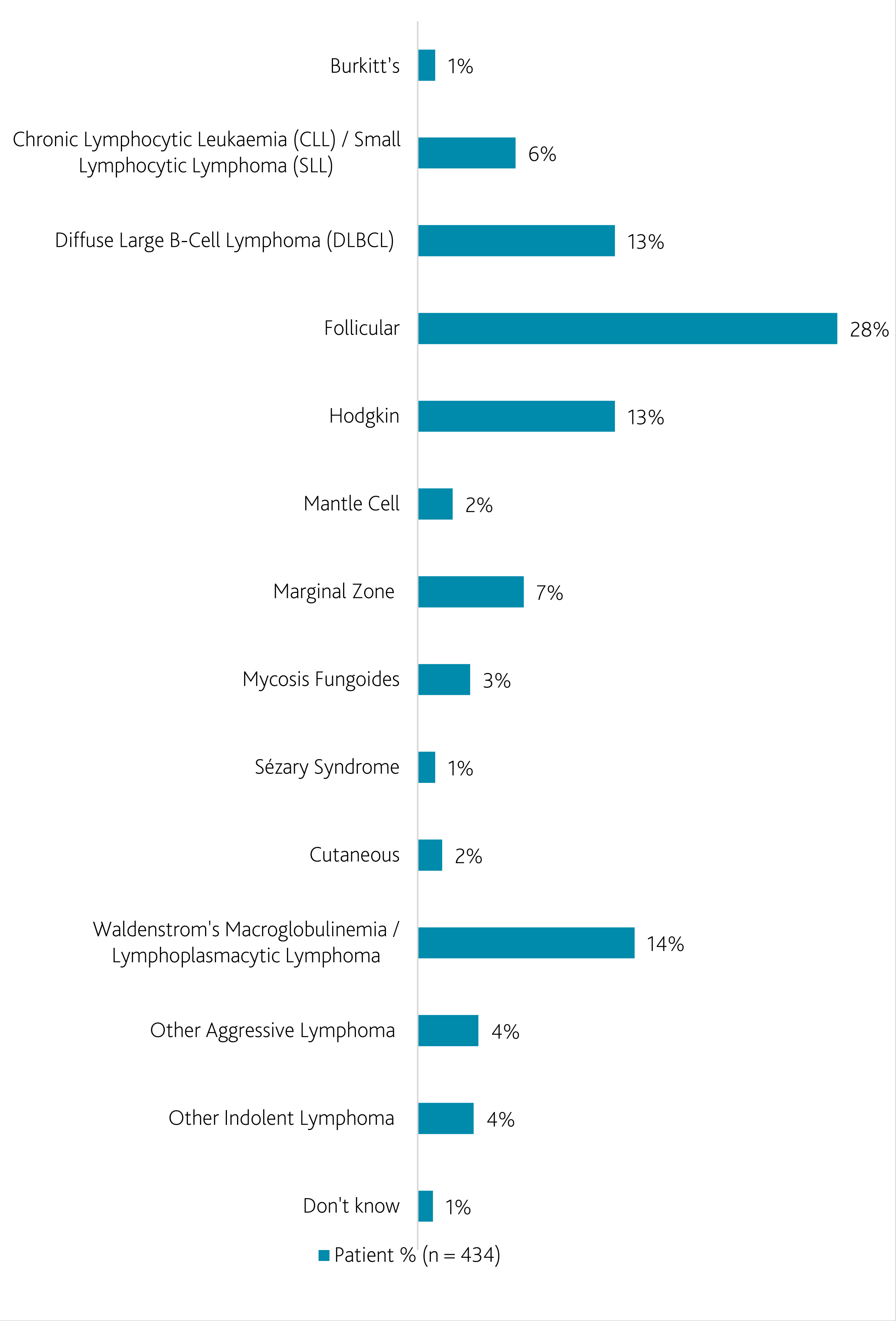
- Figure 11 reveals that 61% of patients saw 3 or more healthcare professions about their symptoms before receiving their current diagnosis.

Figure 11. How many healthcare professionals did you see about your symptoms before receiving the current diagnosis?



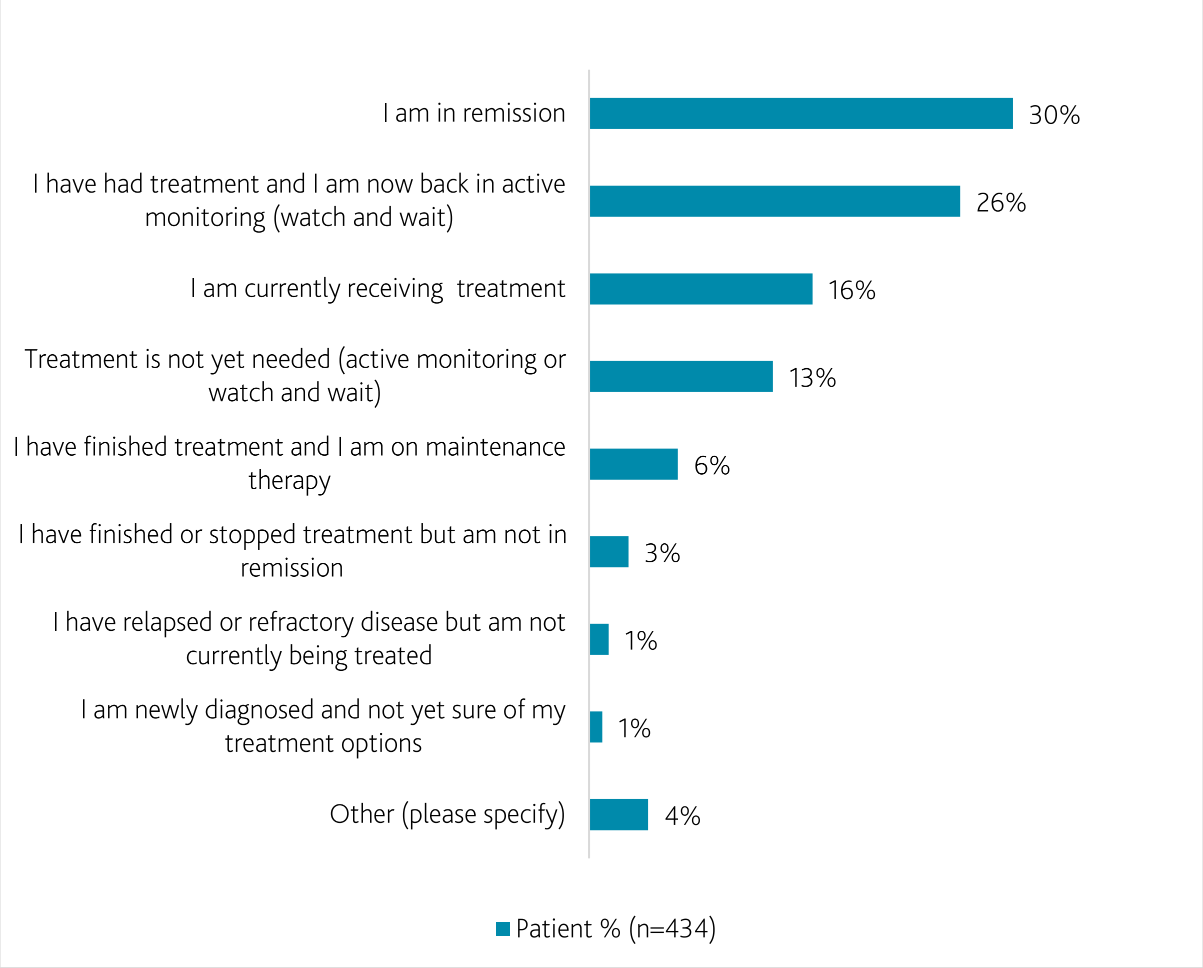
- Figure 12 illustrates that over a quarter of patients have follicular lymphoma.

Figure 12. What subtype of lymphoma do you have / does the patient have?



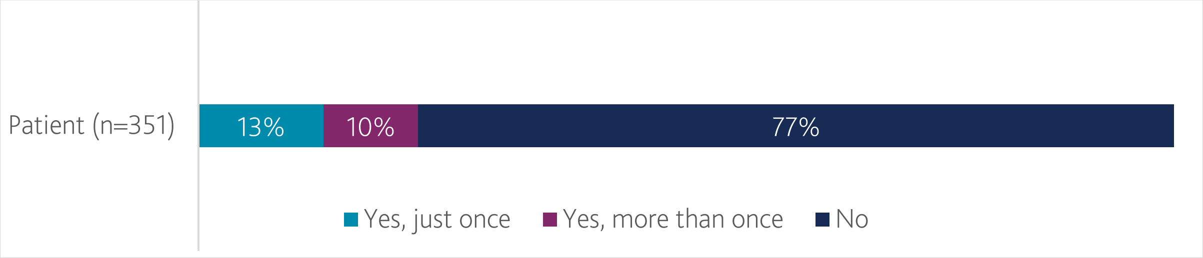
- Figure 13 shows that over half of respondents have received treatment are now in remission, back in active monitoring or treatment has stopped.

Figure 13. What statement best describes where you are in the lymphoma/CLL experience?



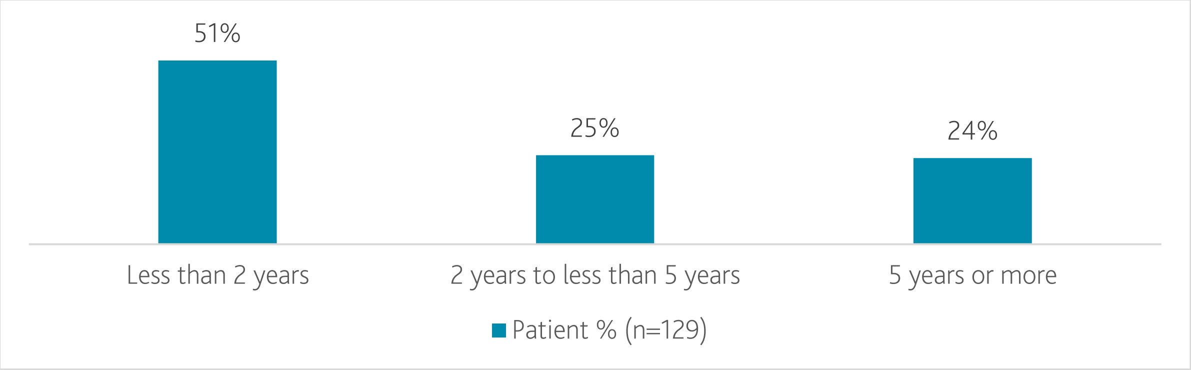
- Figure 14 reveals that for those who have been treated, more than three-quarters of patients have not experienced a lymphoma or CLL relapse. Only asked to those who have received or are receiving treatment.

Figure 14. Has the lymphoma or CLL ever relapsed?



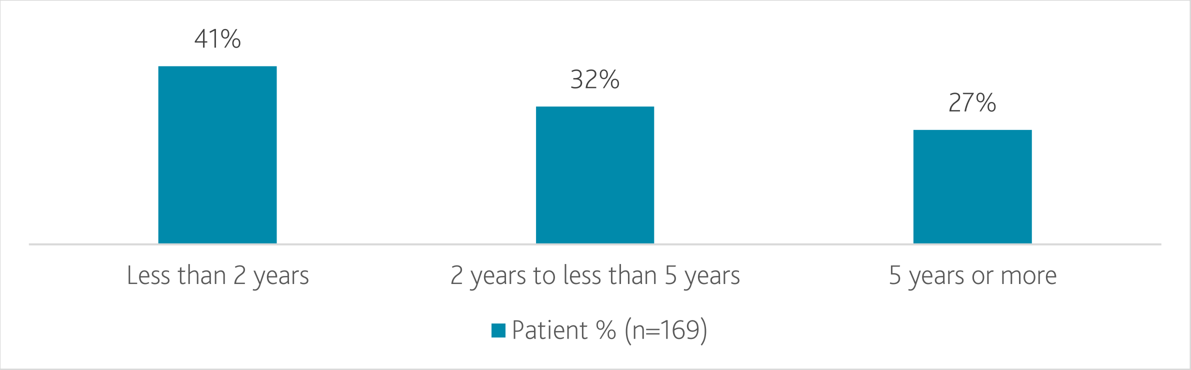
- Figure 15 points out that of those patients who indicated they were in remission, about half had their last treatment within the past 2 years. Only asked to those who selected they were in remission.

Figure 15. You have said that you are in remission, how long has it been since the last treatment?



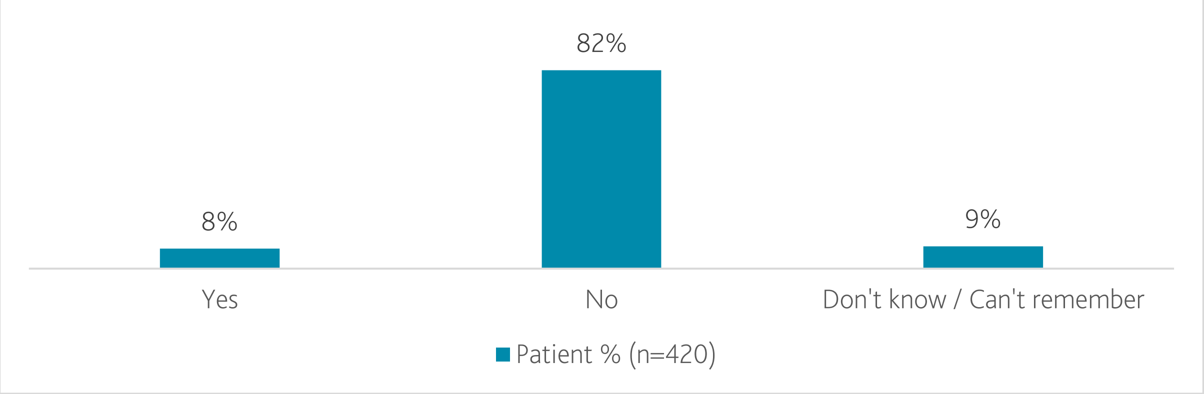
- Figure 16 illustrates that two out of every five patients have been in active monitoring for less than 2 year. Only asked to those who selected they were in active monitoring.

Figure 16. How long have you been in active monitoring (watch and wait)?



- Figure 17 illustrates that most patients have not had the lymphoma or CLL transform

Figure 17. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?



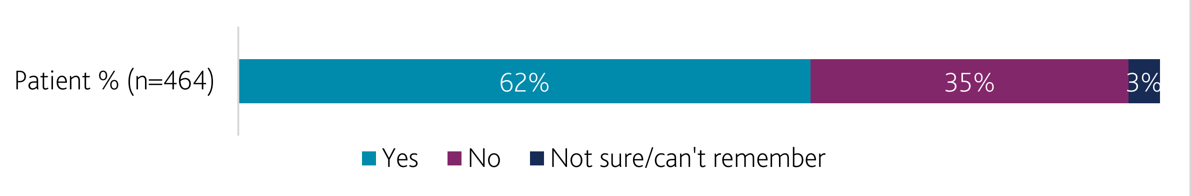
Healthcare Information, Guidance and Support

Previous surveys showed that having 'adequate information' was correlated with more self-reported positive healthcare experiences. Also, patients with adequate information reported better management of their health and healthcare through improved understanding, confidence levels, and communication with healthcare professionals. When a patient has knowledge related to their condition, treatment options, and self-care practices, doctor-patient communication is more fluid, patient experience is improved, and patients are more inclined to be confident in taking a sustained active role in managing their health and condition.

- More than a third of patients were not told their subtype when first diagnosed.
- Only half of patients had their diagnostic tests explained to them well, as a result they could understand the information.
- 93% of patients sought additional information other than what the doctor/ healthcare staff told them. in 66% of cases the patient was searching for information alone. The preferred method of obtaining this information is booklets or written information (66%).
- 12% of patients are not informed or well informed about the processes and stages of their healthcare.
- Patients ranked their top 3 sources for information as 1. Doctor, 2. Nurse, 3. Internet.
- Almost a third of patients didn't receive any contact details or information on patient organisation offerings from their medical team. But 84% of those who connected with them were very satisfied or satisfied with the support from patient organisations.

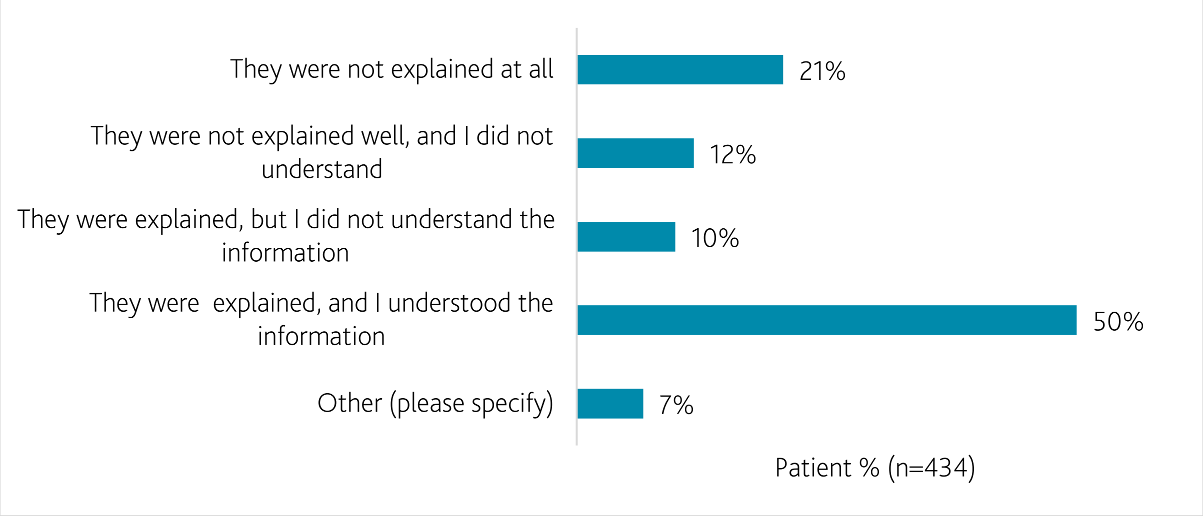
❖ Figure 18 reports that two-thirds of patients were told the lymphoma subtype at diagnosis. This question was only asked to those who were diagnosed less than 2 years from survey time.

Figure 18. When first diagnosed, were you told the lymphoma subtype?



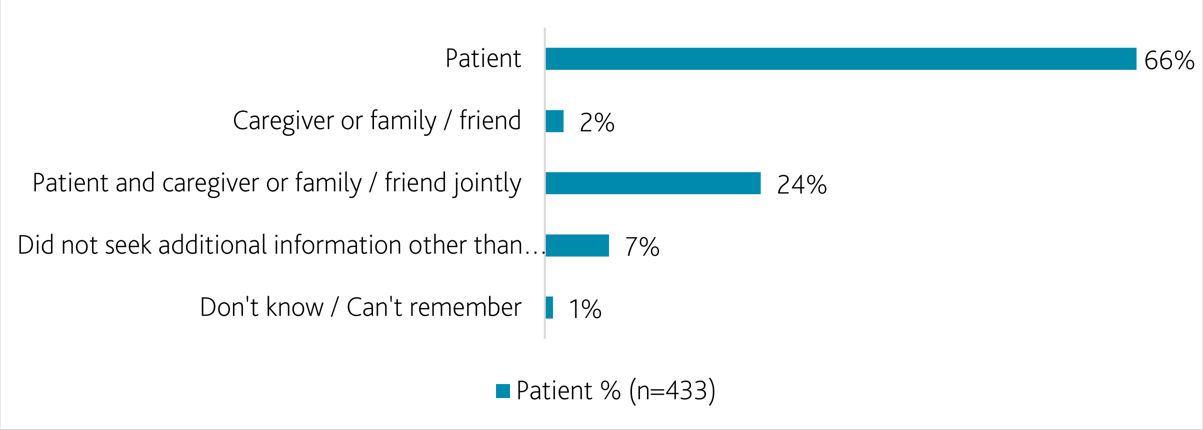
- Figure 19 reveals that 72% of patients had their diagnostic tests and results explained to them, but 22% did not fully understand what was being said. 21% did not receive any explanation at all.

Figure 19. To what extent, if at all, were diagnostic tests and results explained to you (i.e., what blood counts meant, pathology report, molecular testing results, etc.)?



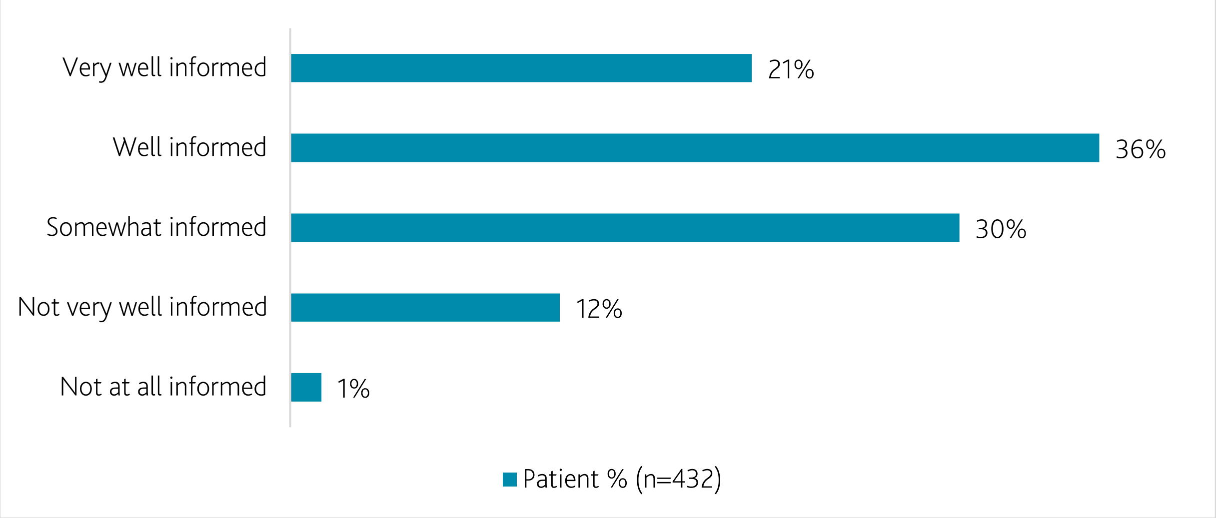
- Figure 20 shows that 66% of patients are seeking out information on their disease alone, while 24% reported that it was the patient and carer jointly. 7% did not seek any additional information other than what their doctor/healthcare staff told them.

Figure 20. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



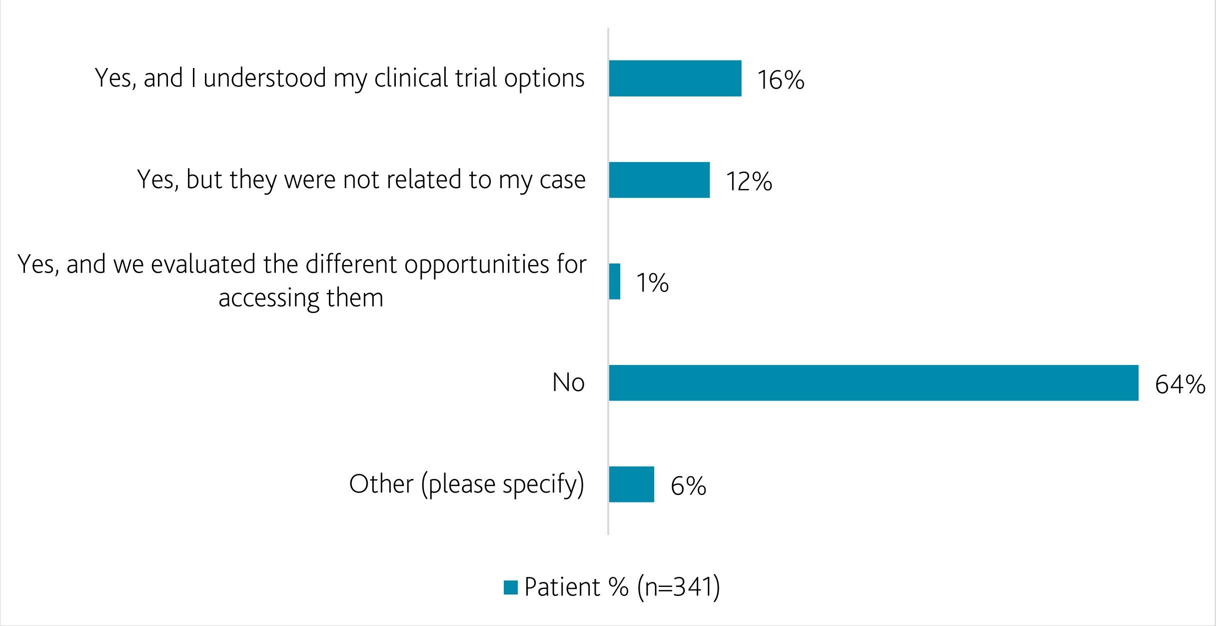
- Figure 21 illustrates that only 21% of patients felt very well informed about the processes and stages of their care and 13% were not well informed or not informed at all.

Figure 21. How informed have you felt about the processes and stages of your/ the patient's healthcare (e.g., diagnosis, treatment, resources available for support and self-care) throughout your experience with lymphoma or CLL?



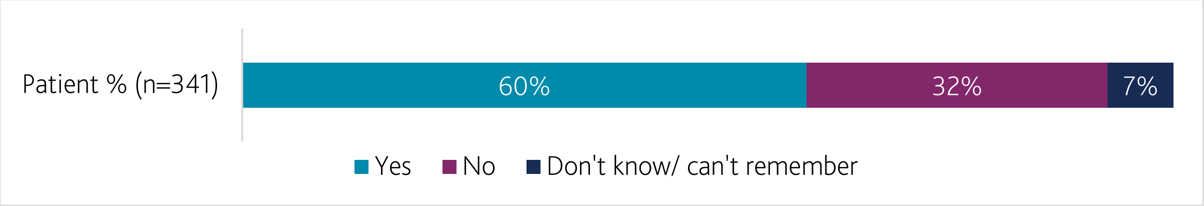
- Figure 22 points out that almost two-thirds of patients did not receive any information about clinical trials

Figure 22. During your meetings with your lymphoma or CLL doctor, did you receive any information about clinical trials?



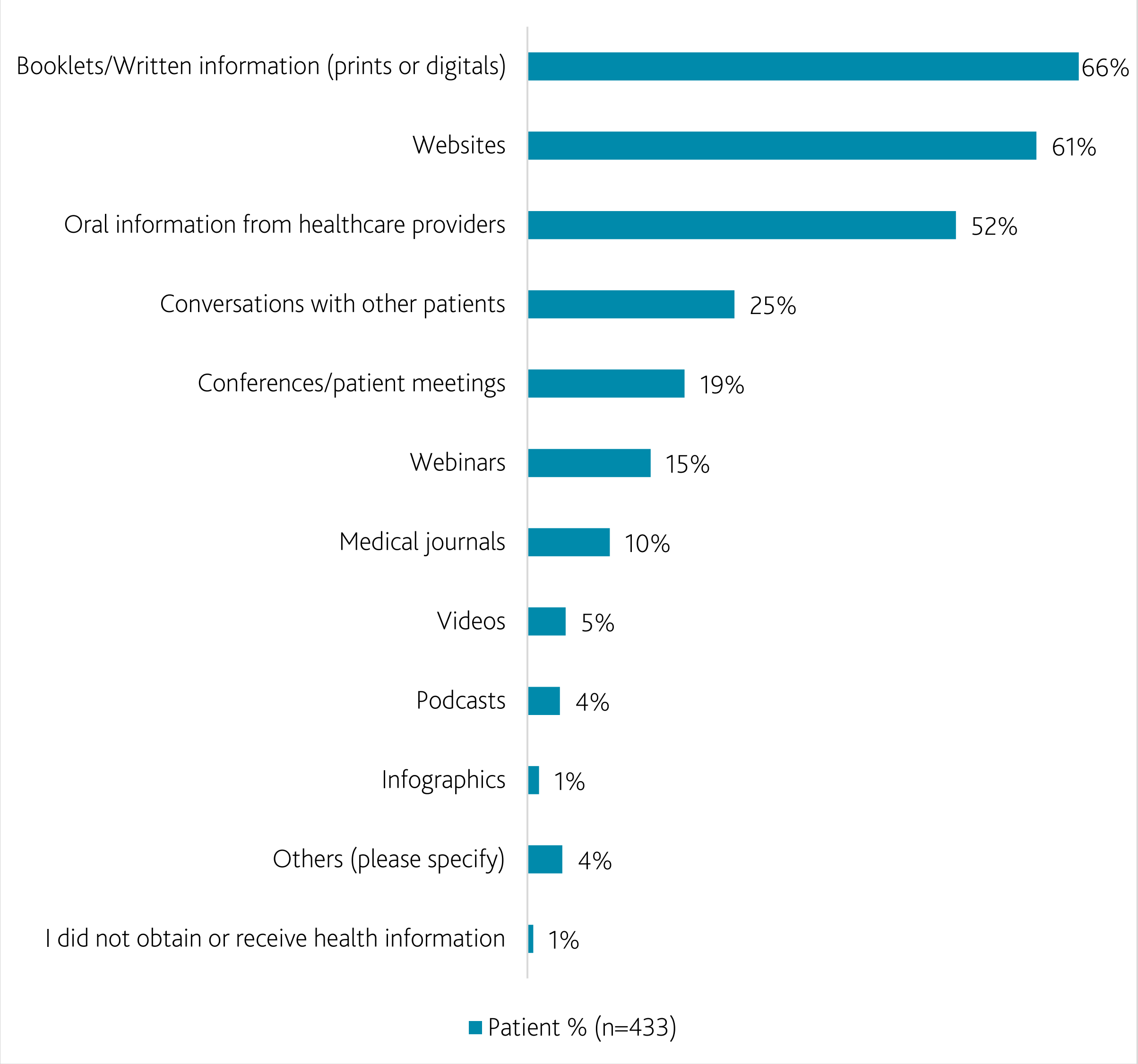
- Figure 23 reports that 60% of patients were aware that a clinical trial can sometimes provide access to the best treatment, but almost a third had no idea.

Figure 23. Were you aware that a clinical trial can sometimes give you access to the best treatment?



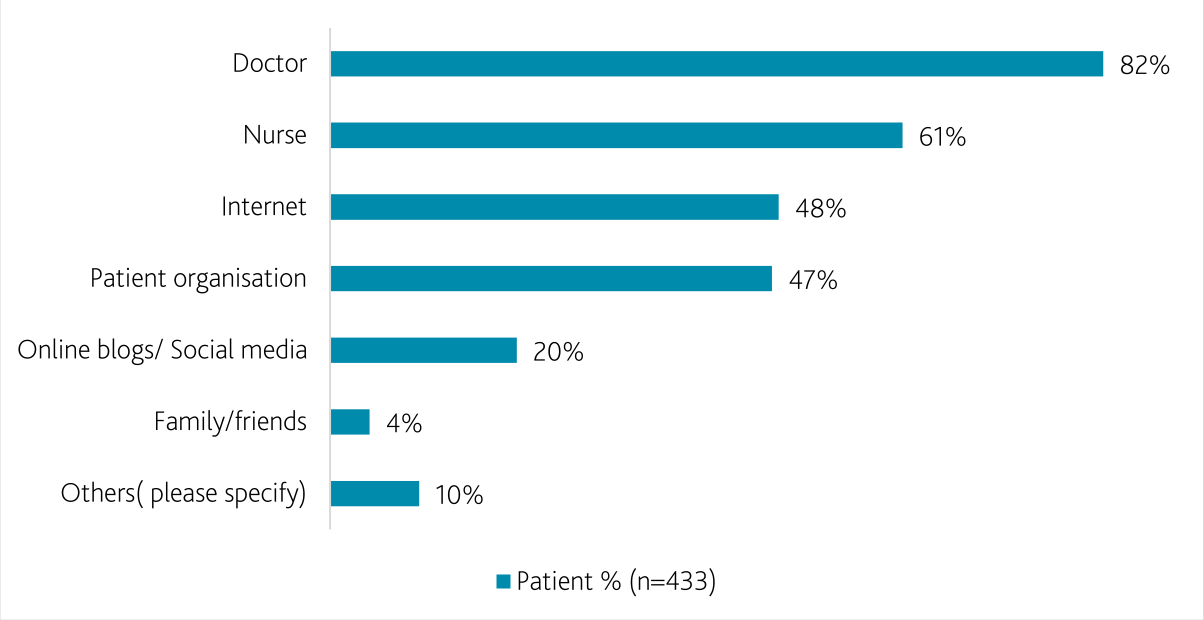
- Figure 24 reveals that two-thirds of patients prefer to get their information from booklets or written health information, followed closely by websites (61%) and oral information from healthcare providers (52%)

Figure 24. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



- Figure 25 shows that over 80% of patients would prefer their disease information come from their doctors, followed by nurses (61%), and the internet (48%) and patient organisations (47%)

Figure 25. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?



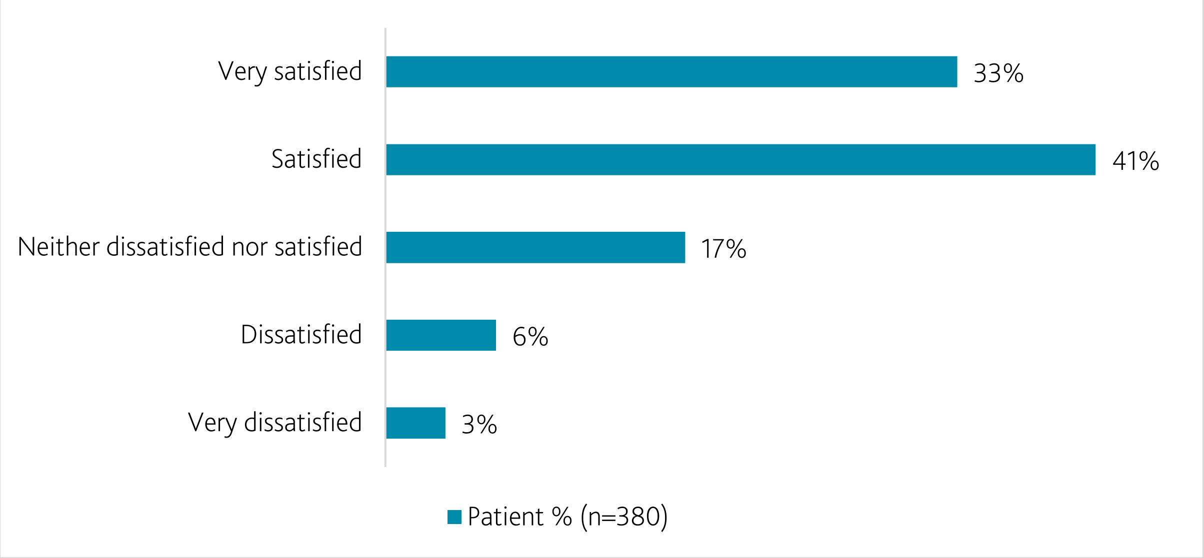
- Table 1 illustrates that 63% of patients rank doctors as their top source of lymphoma or CLL information they would most prefer

Table 1. Rank your top three sources of lymphoma or CLL information that you most prefer.

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	176	**64%**	40	15%	34	13%
Nurse	21	8%	121	**45%**	46	18%
Internet	18	7%	39	14%	71	**28%**
Online blogs/ social media	12	4%	13	5%	19	7%
Family/friends	2	1%	3	1%	5	2%
Patient organisation	36	13%	48	18%	71	**28%**
Others (please specify)	8	3%	7	3%	11	4%
Total	273	100%	271	100%	257	100%

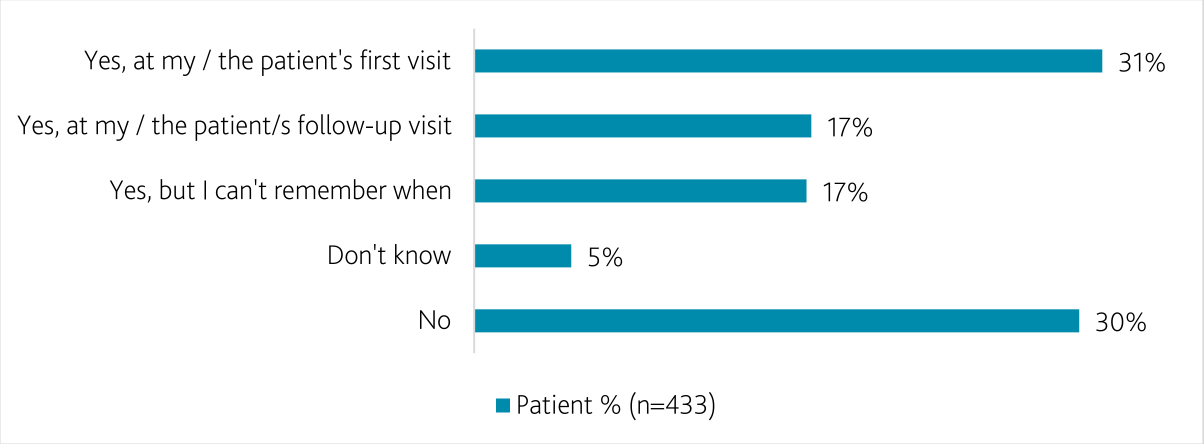
- Figure 26 shows that 74% of patients are satisfied or very satisfied with the information given to them by healthcare providers

Figure 26. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, nurses)?



- Figure 27 illustrates that 30% of patients did not receive any information about patient organisations from their lymphoma or CLL doctor or medical team

Figure 27. Did the lymphoma or CLL doctor or any member of the medical team give you the contact details of a patient organization, a support group and/or information produced by a patient organization?

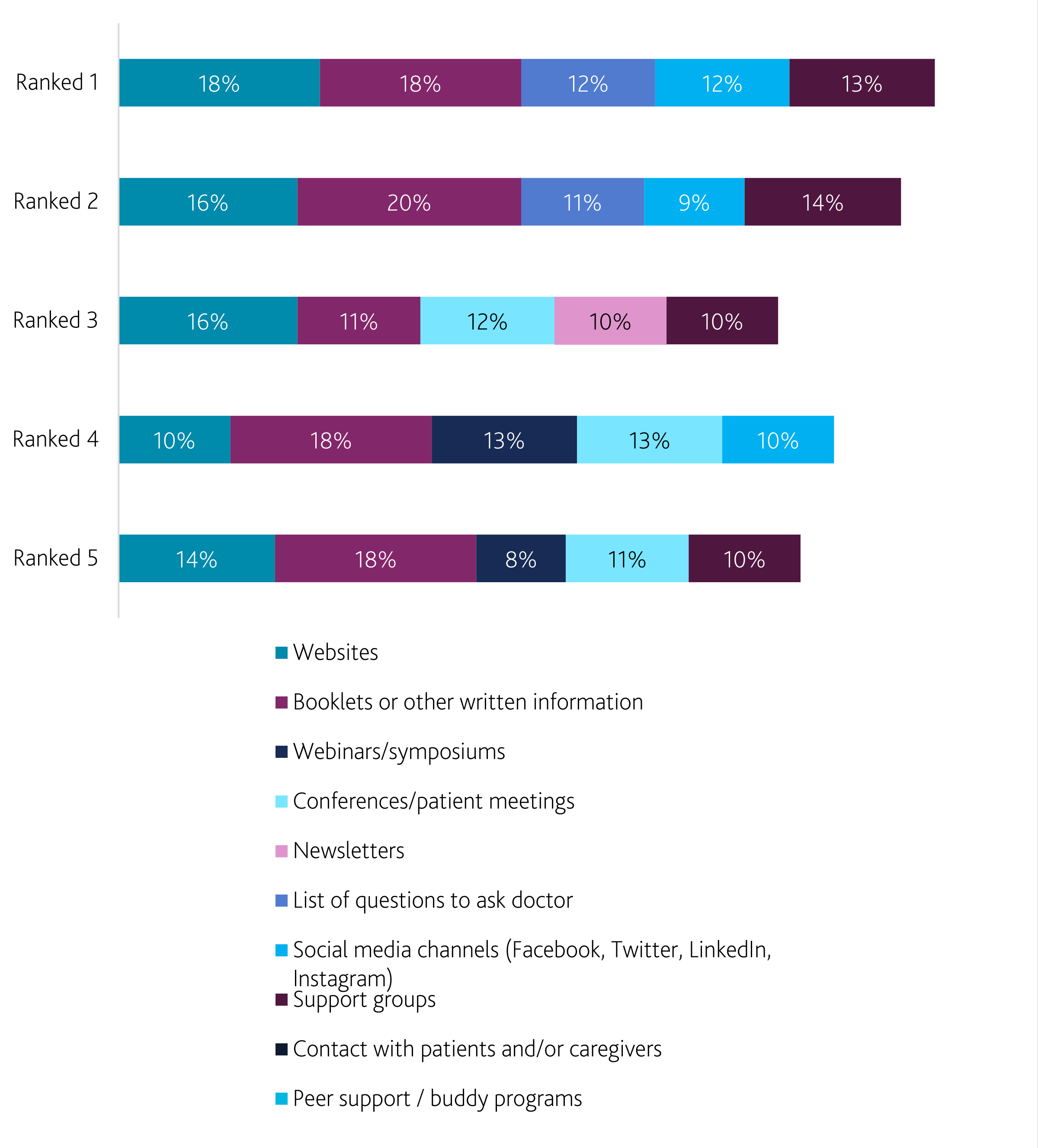


- Figure 28 reveals that most patients (75%) use patient organisation's booklets or written information. However, a significant number of patients are websites (66%), and attending support groups (50%). Only asked to those who indicated they had connected with a patient organisation.

Figure 28. What type of patient organisation information do you use?

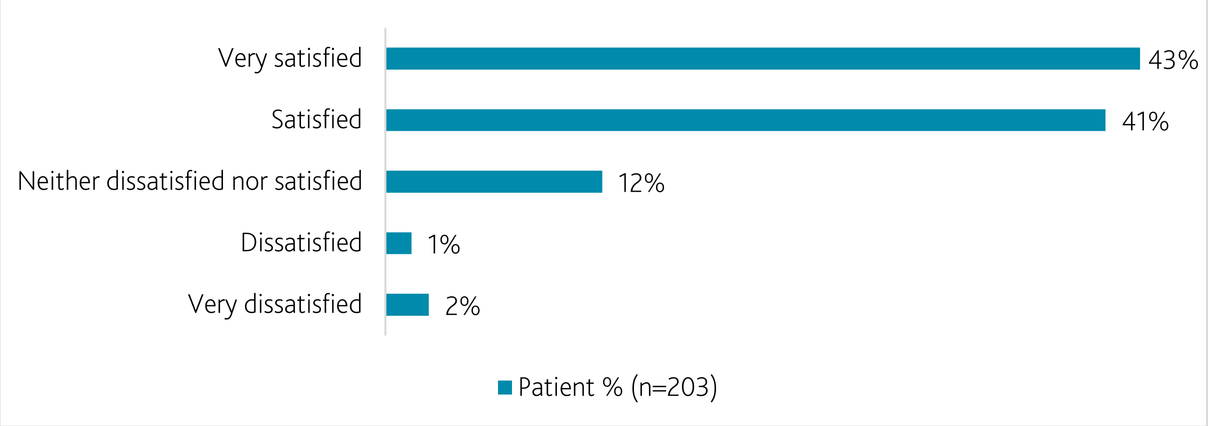
- Figure 29 shows that, when asked to rank information sources from patient organisations, websites and booklets/written information were both ranked #1 by 18% of respondents. Only asked to those who indicated they had connected with a patient organisation.

Figure 29. Top 5 information sources of patient organisations ranked 1-5



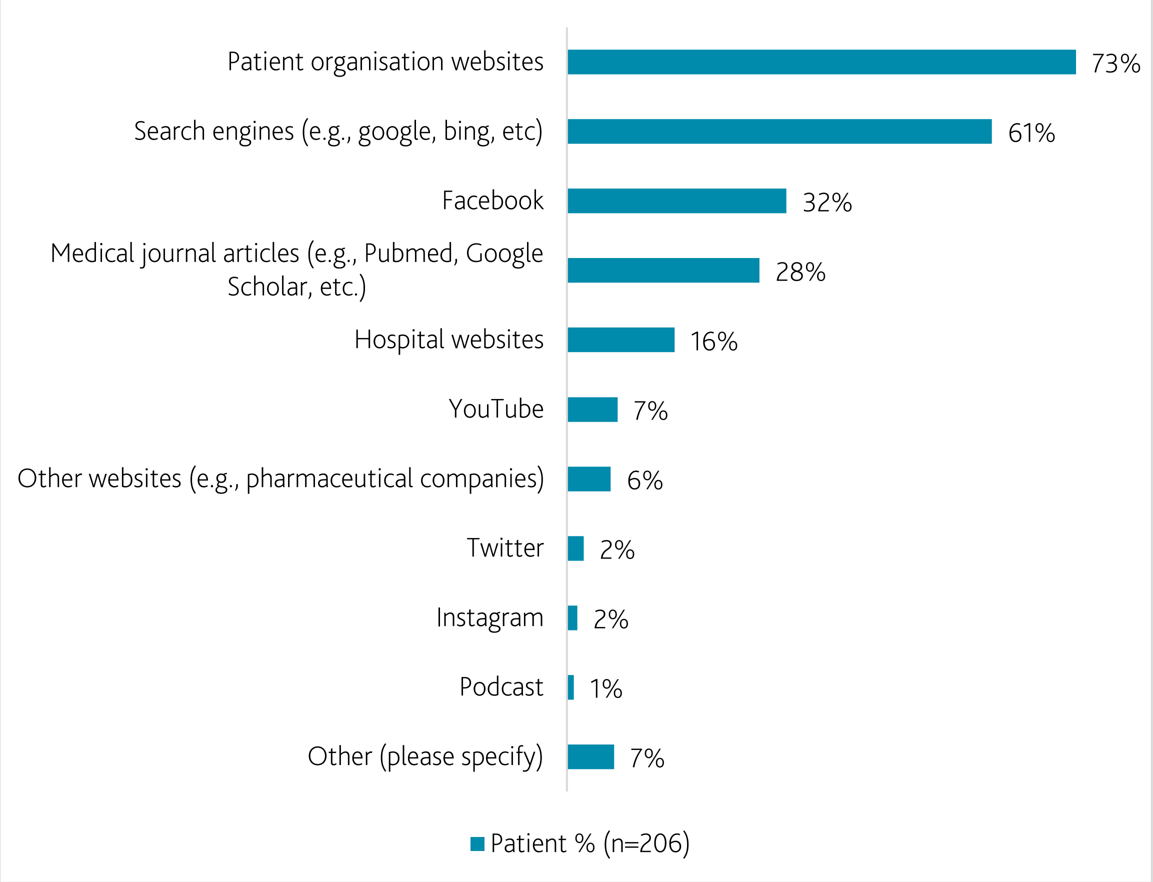
- Figure 30 illustrates that most patients are satisfied with the information given by patient organisations. Only asked to those who indicated they had connected with a patient organisation.

Figure 30. How satisfied or unsatisfied are you with the information given to you by patient organisations?



- Figure 31 reveals that 73% of patients usually get lymphoma or CLL internet-based information from patient organisation websites, followed by search engines (61%). Only asked to those who indicated they used the internet to source information.

Figure 31. Where on the internet do you usually get your lymphoma or CLL information from?



Healthcare Support

In addition to information, patients need support to help them cope with the challenges they face during their experience with lymphoma or CLL. The results in this section includes specific questions for patients with indolent disease, those in remission/survivors and people in active monitoring.

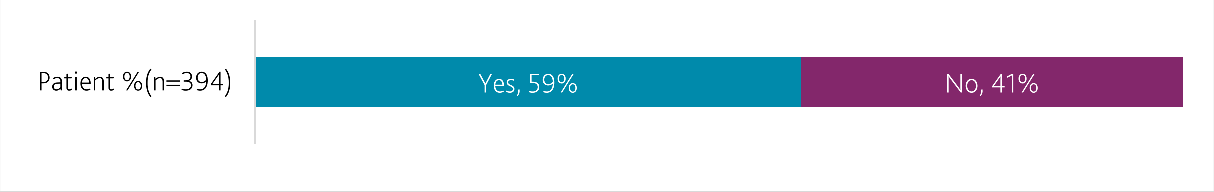
- 91% of patients had seen a specialist (e.g., haematologist, oncologist, dermatologist) for their lymphoma subtype.
- 59% of patients had been seeing the same speciality physician (e.g., haematologist, oncologist, dermatologist) throughout their patient experience.
- Three-quarters of patients did have their health care supported by a cancer care (multidisciplinary) team and/or cancer care coordinator
- 46% of those who had their care supported by a cancer care team, had a dedicated first point of contact

- Figure 32 reports that the majority of patients have seen a specialist for their lymphoma subtype

Figure 32. Have you ever seen a specialist (e.g., haematologist, oncologist, dermatologist) for your lymphoma subtype?

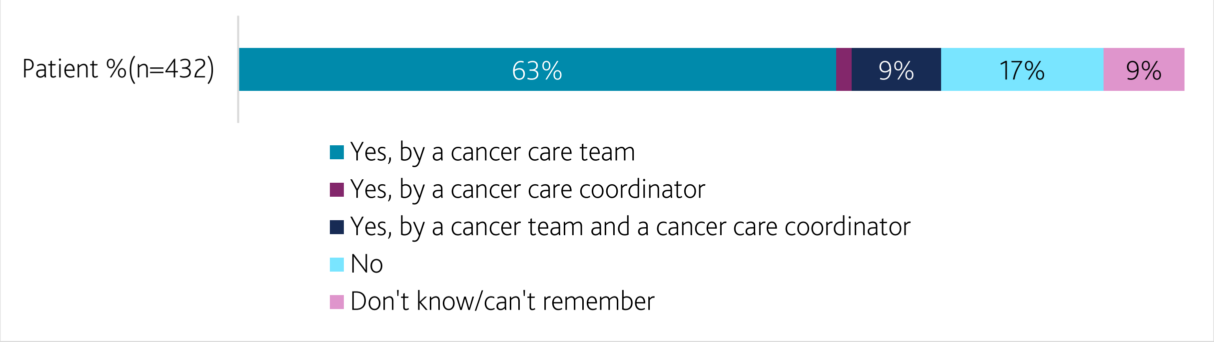
- Figure 33 shows that over half of patients (59%) have been seeing the same specialty physician throughout their patient experience. Only asked to those who indicated they had seen a specialist.

Figure 33. Have you been seeing the same specialty physician (e.g., haematologist, oncologist, dermatologist) throughout your patient experience?



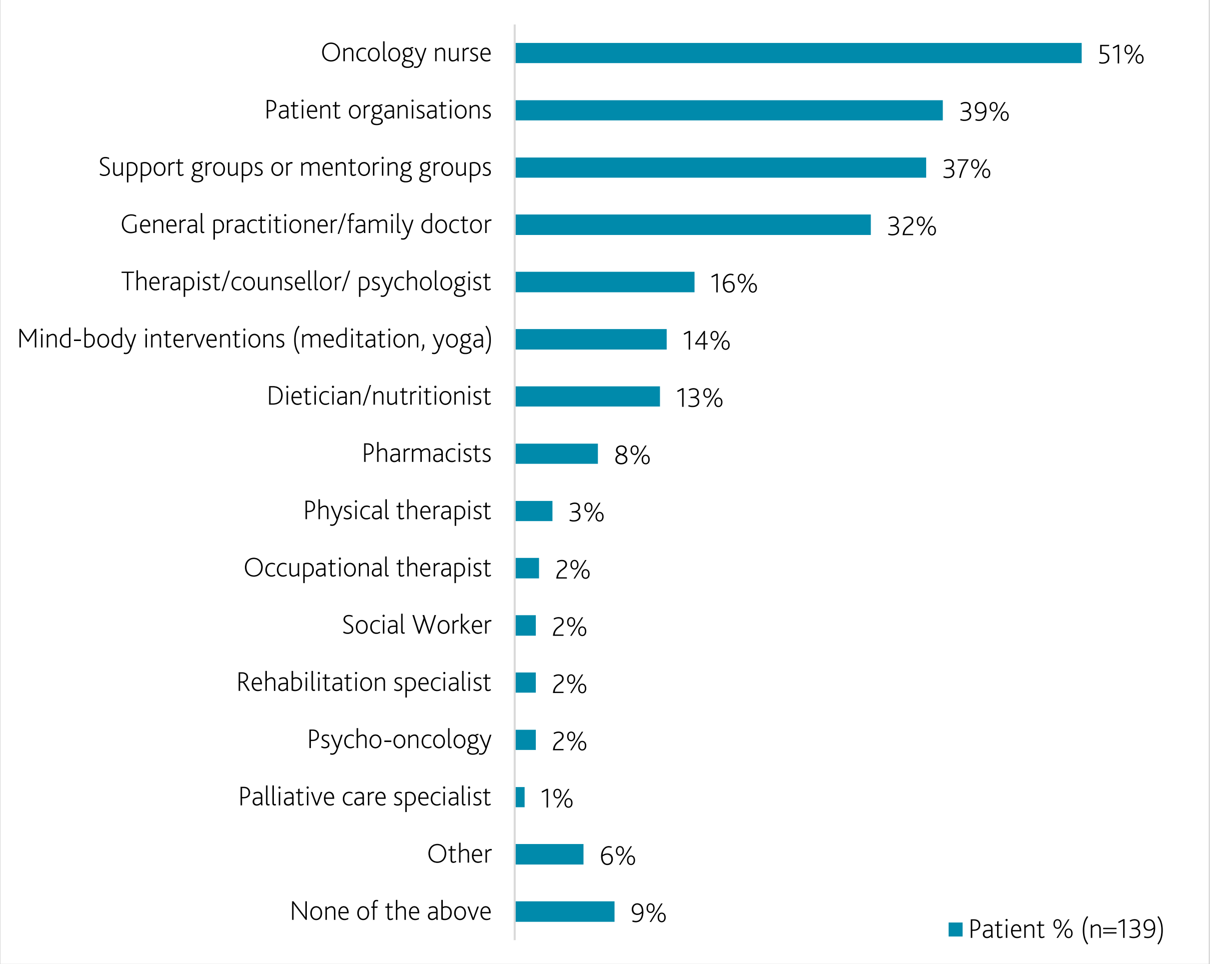
- Figure 34 reveals that 74% of patients did have lymphoma care provided by a cancer team and/or cancer care coordinator

Figure 34. Did/do you have lymphoma care provided by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator?



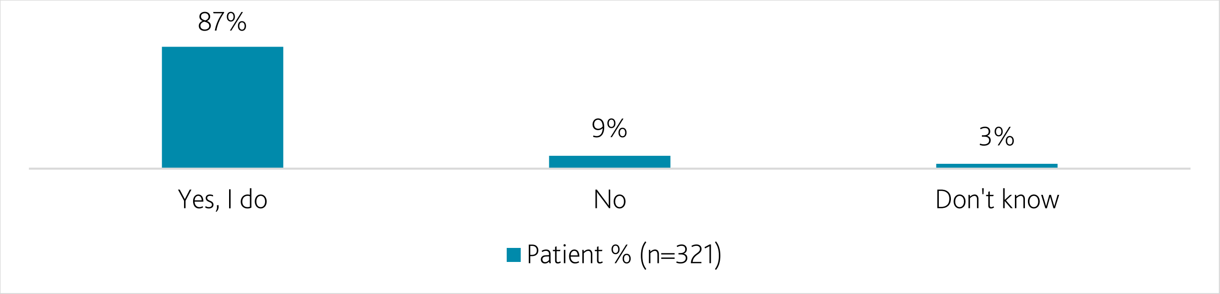
- Figure 35 reveals that about half of patients who reported that they had access to a cancer care team found oncology nurses useful in providing supportive care. Only asked to those who reported they had access to a cancer care team and/or cancer care coordinator.

Figure 35. Which of the following, if any, have you found useful in providing supportive care, outside of the specialty physician?



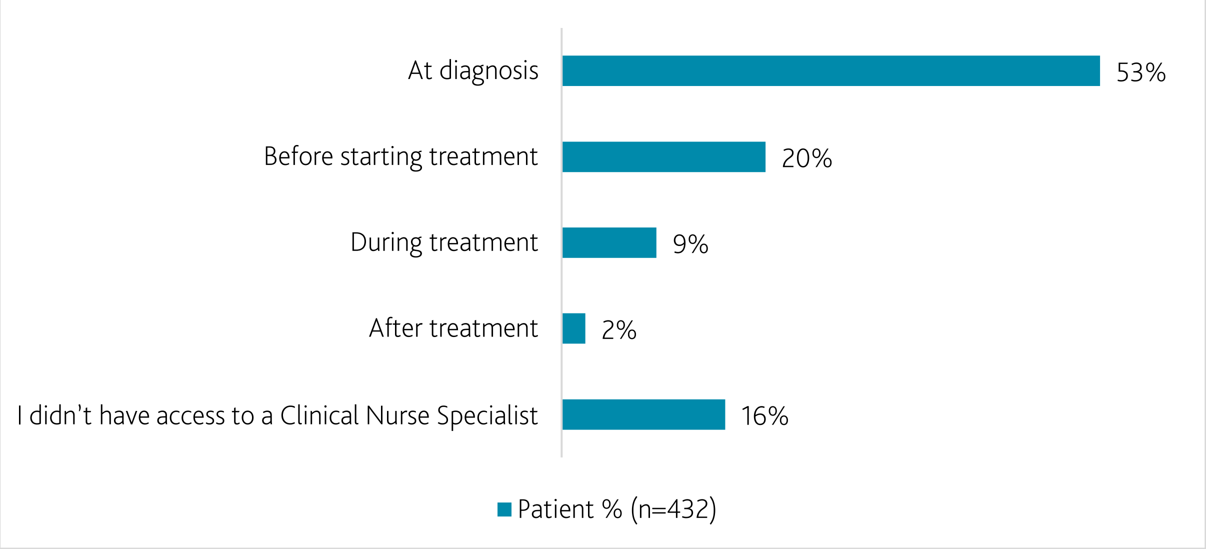
- Figure 36 illustrates that the majority of patients have a dedicated first point of contact within the cancer care team. Only asked to those who reported they had access to a cancer care team and/or cancer care coordinator.

Figure 36. Do you have a dedicated first point of contact within the cancer care team?



- Figure 37 shows half of patients were given access to a Clinical Nurse Specialist at diagnosis. 16% never had a CNS as part of their medical team.

Figure 37. If you were given access to a Clinical Nurse Specialist, when did this access start?

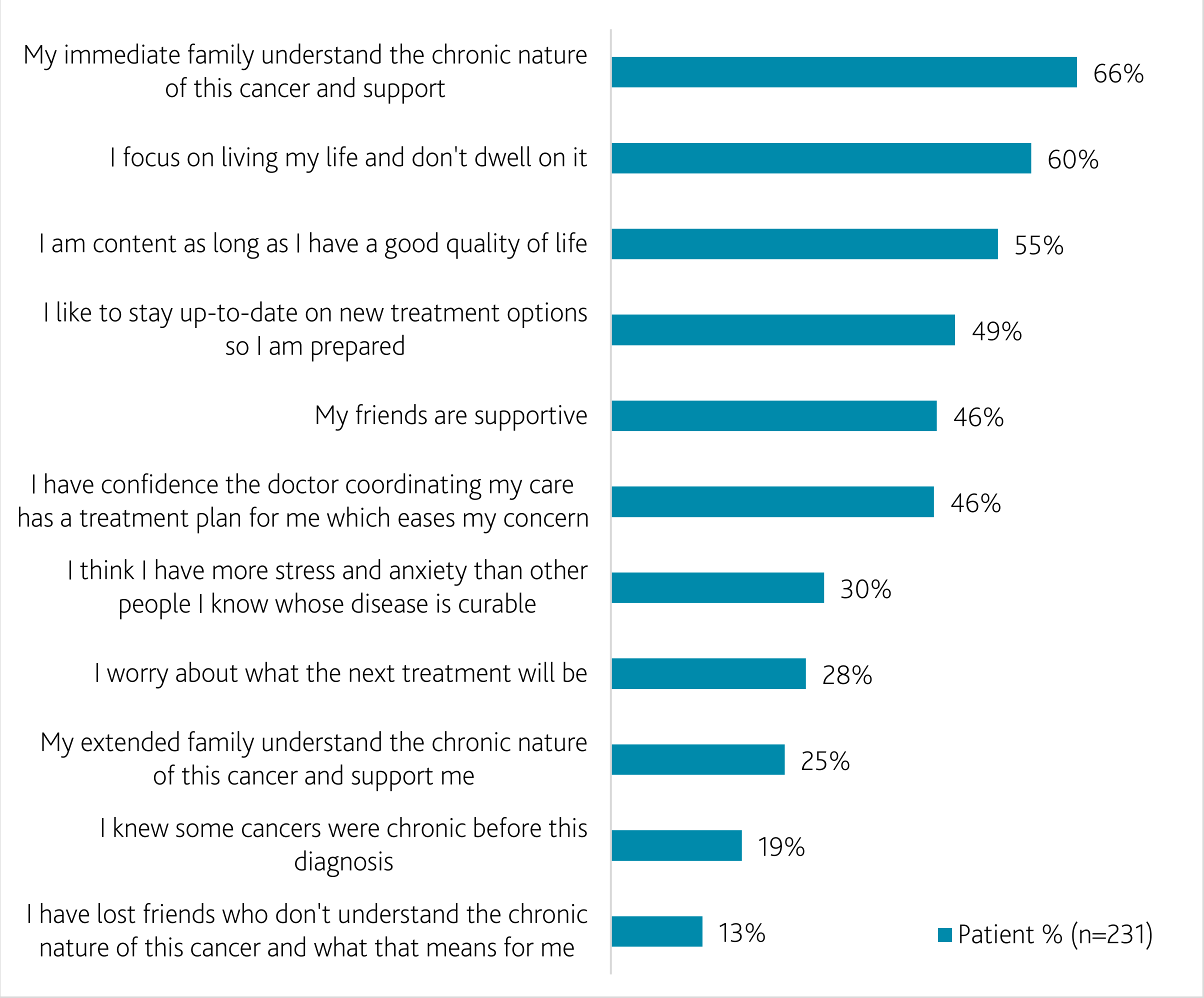


Support Experience of Patients with Indolent Lymphomas

Patients with indolent disease are sometimes overlooked for their support needs when they are not undergoing active treatment or due to having less frequent clinic visits. The results below show some of the support experiences of this patient group. Only asked to those who indicated they were diagnosed with CLL/SLL, cutaneous lymphoma, follicular lymphoma and Waldenstrom's macroglobulinemia.

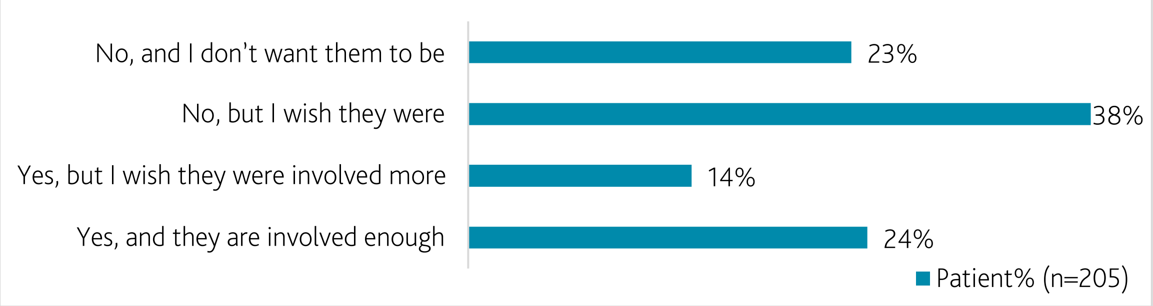
- Figure 38 reports that 66% of patient feel their family understands what having a chronic cancer means. Interestingly, 30% feel they have more stress than a person with a curable cancer.

Figure 38. Which of the following statements reflects how you feel about your experience living with a chronic cancer? Those with cutaneous lymphoma, CLL/SLL, follicular lymphoma and Waldenstrom's macroglobulinemia were asked this question.



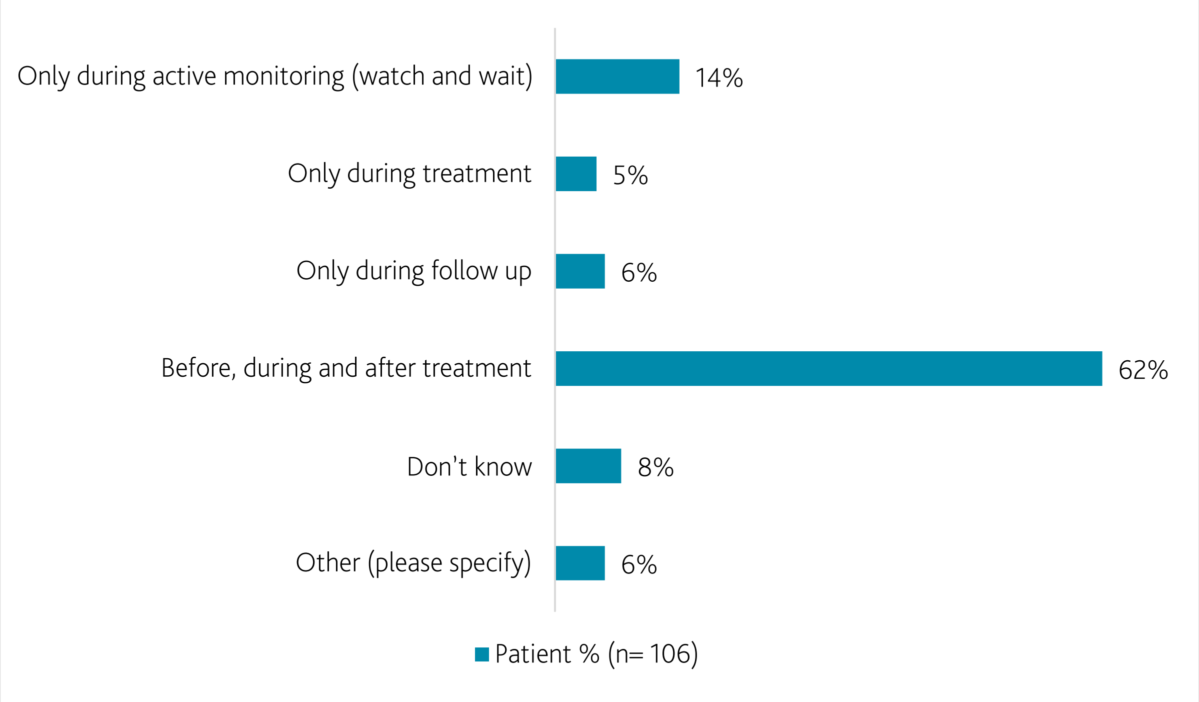
- Figure 39 shows over half of patients would like their family physician to be more involved in their cancer care.

Figure 39. Is your general practitioner / family physician involved in the follow-up care of your lymphoma or CLL?



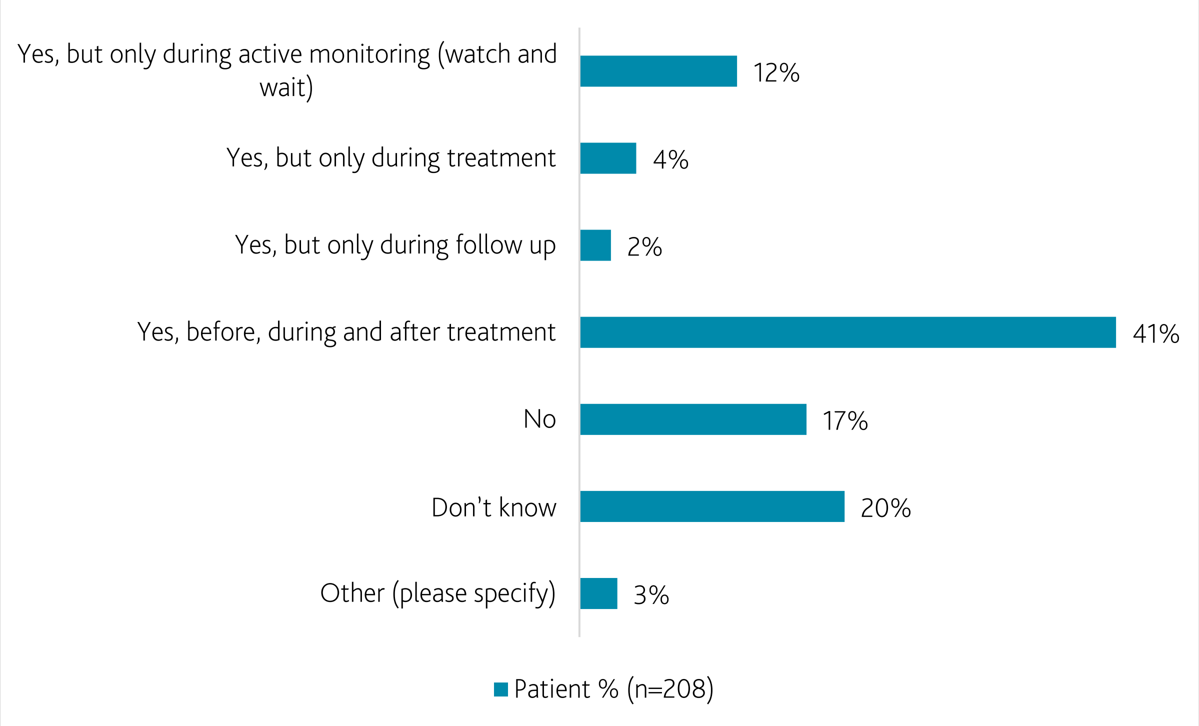
- Figure 40 reports - for those who would like their family physician more involved - 62% would like them to be involved throughout the cancer care continuum, not only for follow-up.

Figure 40. In which areas of care would you like your general practitioner / family physician to be more involved in the follow-up of your disease?



- Figure 41 points out 59% of patients with indolent disease are comfortable using telemonitoring to help with checking their disease status

Figure 41. Are you comfortable with the idea of using telemonitoring or information technology such as apps or wearable devices to monitor you from a distance?

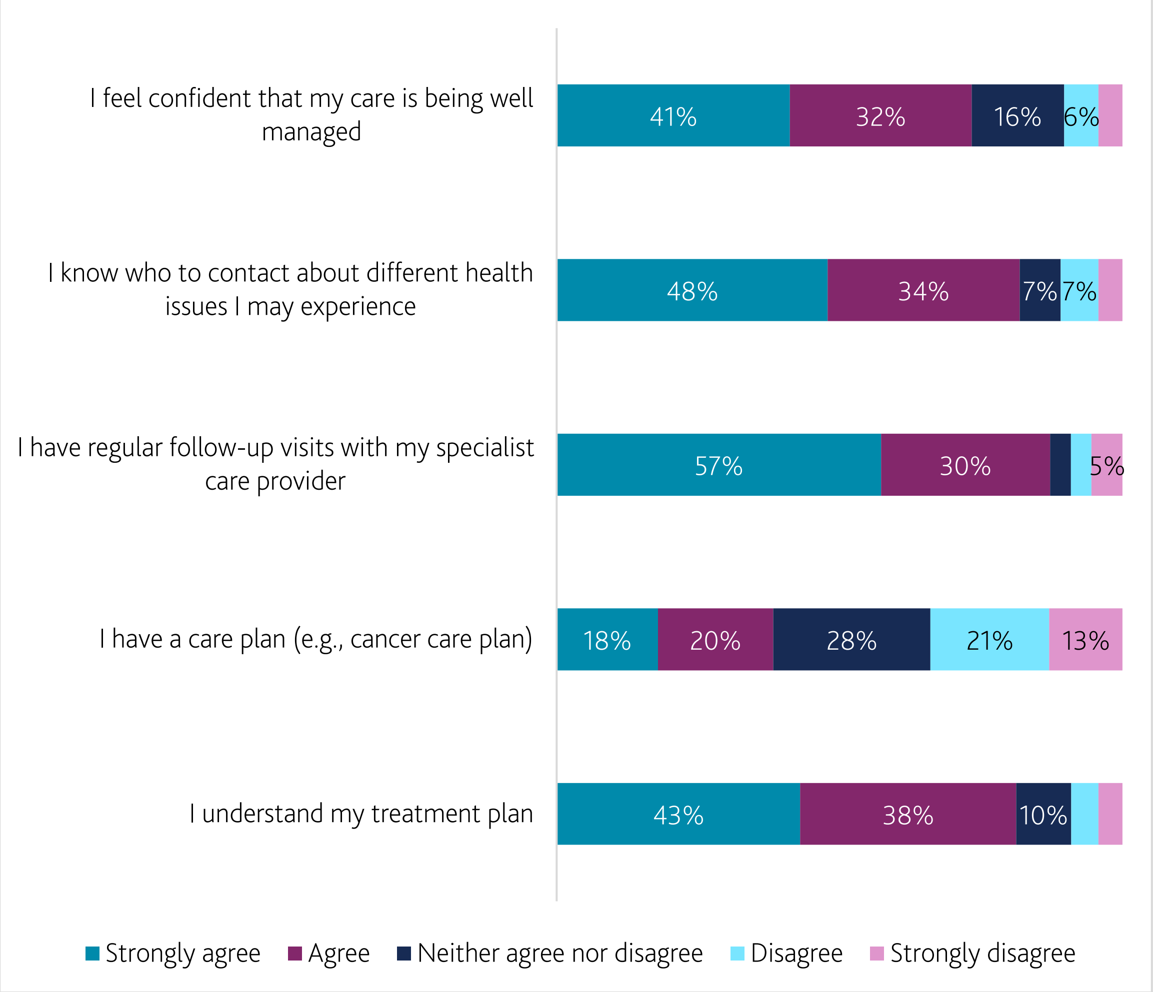


Support Experience of Patients in Active Surveillance

Patients who had indicated they were in active surveillance (including those who never received treatment and those who had been treated and were back in active surveillance) were asked a series of questions about their cancer care support experience.

- Figure 42 reveals that 87% of patients agree they are having regular follow-up visits with their specialist, yet only 38% agree there is a cancer care plan for them. Only asked to those in active monitoring, both those who have never had treatment and those back in active monitoring post-treatment.

Figure 42. You have indicated that you are currently in active monitoring (watch and wait)In thinking about your cancer care right now, please indicate how much you agree and disagree with the following statements.

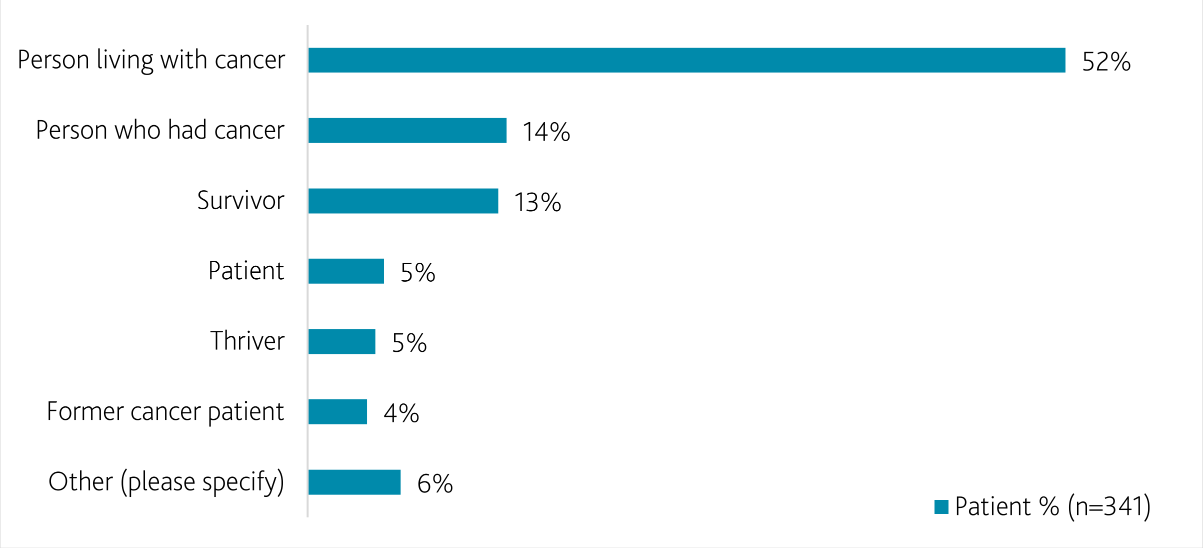


Support Experience of Patients in Remission/ Survivorship

Patients who had indicated they were in remission were asked a series of questions about their cancer care support experience as they transitioned into survivorship. Only asked to those who indicated they were in remission.

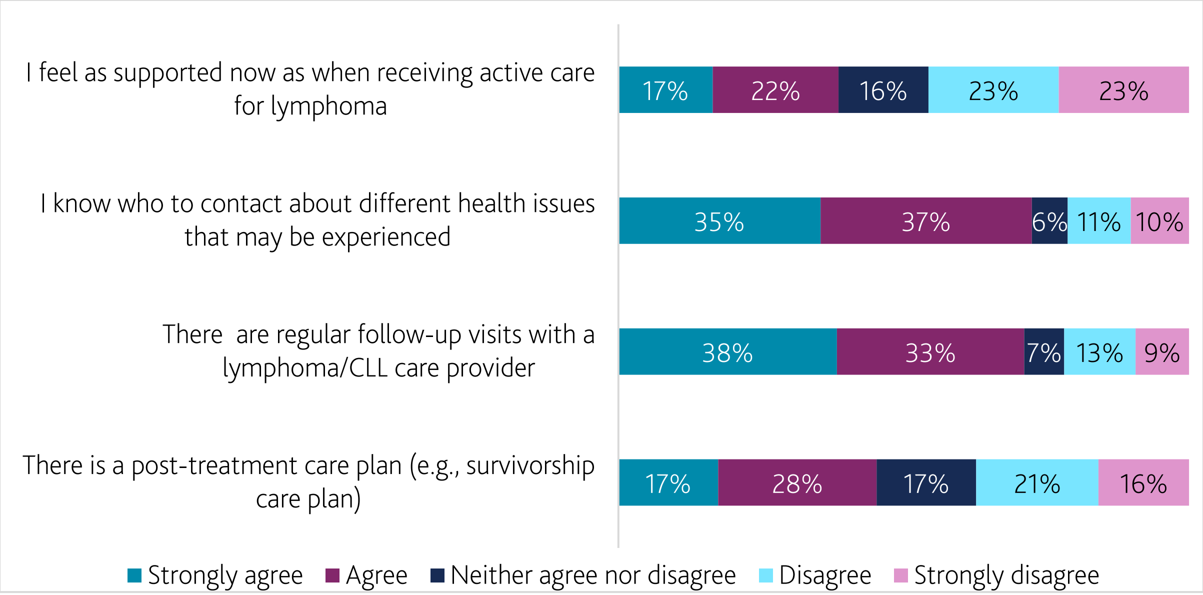
- Figure 43 shows that 52% of patients would describe themselves as a person living with cancer

Figure 43. What term would you use to describe yourself following cancer treatment?



- Figure 44 illustrates that 71% of patients agree or strongly agree that there are regular follow-up visits with a lymphoma/CLL care provider when transitioning from cancer care into survivorship, but 46% do not feel as well supported as they did when receiving active care

Figure 44. In thinking about the transition from cancer care into survivorship, please indicate how much you agree or disagree with the following statements. Only asked to those who indicated they were in remission.



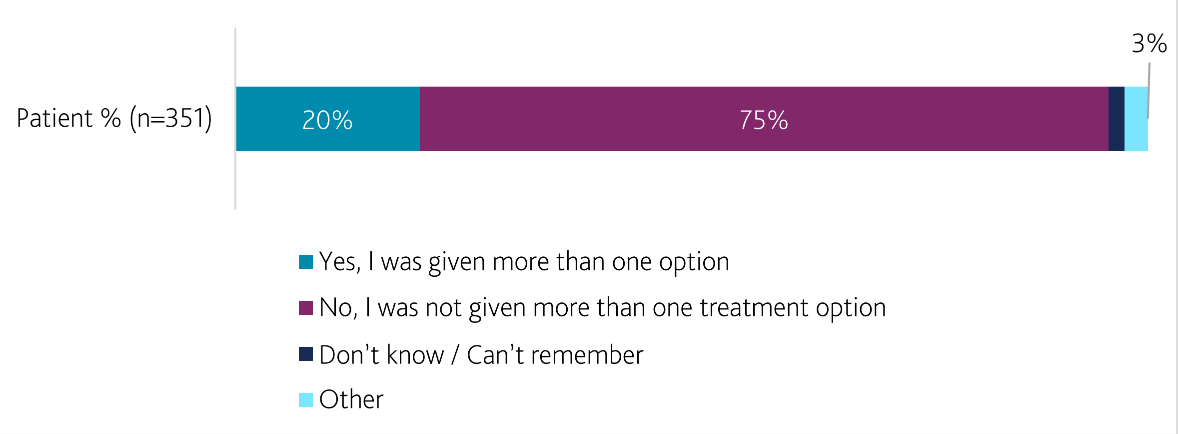
Healthcare Involvement and Decision Making

Patient-centeredness is a key part of providing high-quality cancer care as it takes the goals and expectations of patients and their families into consideration. Patients should be seen by healthcare providers as individuals and not as a diagnosis and doctors should respond to the needs, preferences and concerns of patients and their families. This implies that healthcare providers should ensure a collaborative approach to healthcare decision-making with patients and their families.

- Only 20% of patients were given more than one treatment option before their current or last therapy for lymphoma.
- Half of patients definitely felt as involved as much as they want to be in decisions about their care and treatment.
- 59% of patients would like the doctor and patient to be jointly involved in final decisions about care, with a further 28% wanting their care/family involved as well.
- About three-quarters of patients say their doctor always allows them to express their thoughts without interrupting.
- About half of patients (49%) say their doctor always explores their preferences and understanding when making decisions about care.

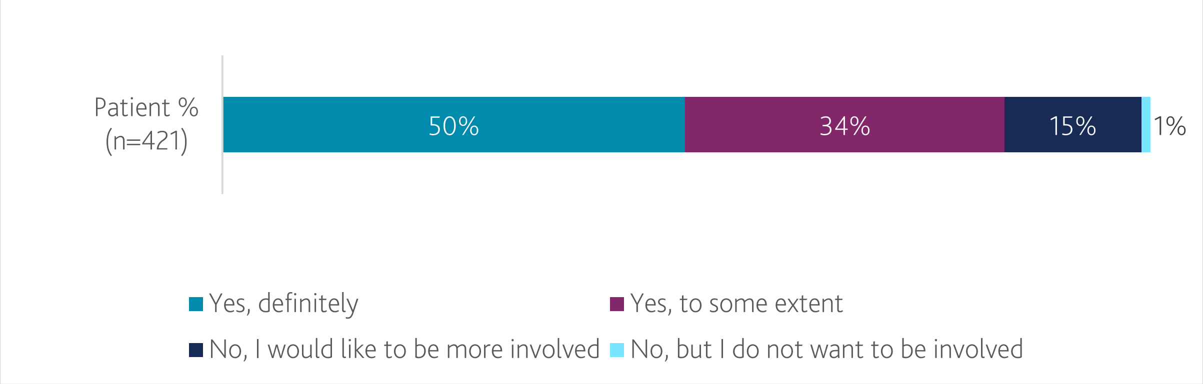
❖ Figure 45 illustrates that 75% of patients were not given more than one treatment option

Figure 45. Were you given more than one treatment option (for instance, different types of chemotherapy regimens to choose from or a choice between a stem cell transplant and a new targeted therapy) before your current or last therapy for lymphoma?



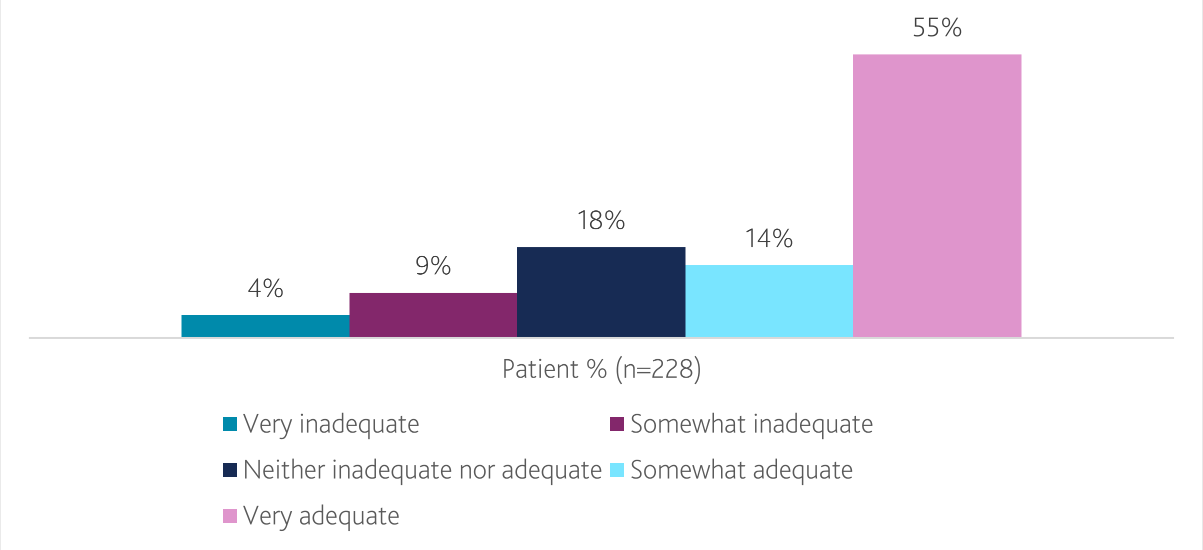
- Figure 46 reveals that 50% of patients definitely feel that they are as involved as much as they want to be in decisions about their care and treatment

Figure 46. Do you feel as involved as much as you want to be, in decisions about your care and treatment?



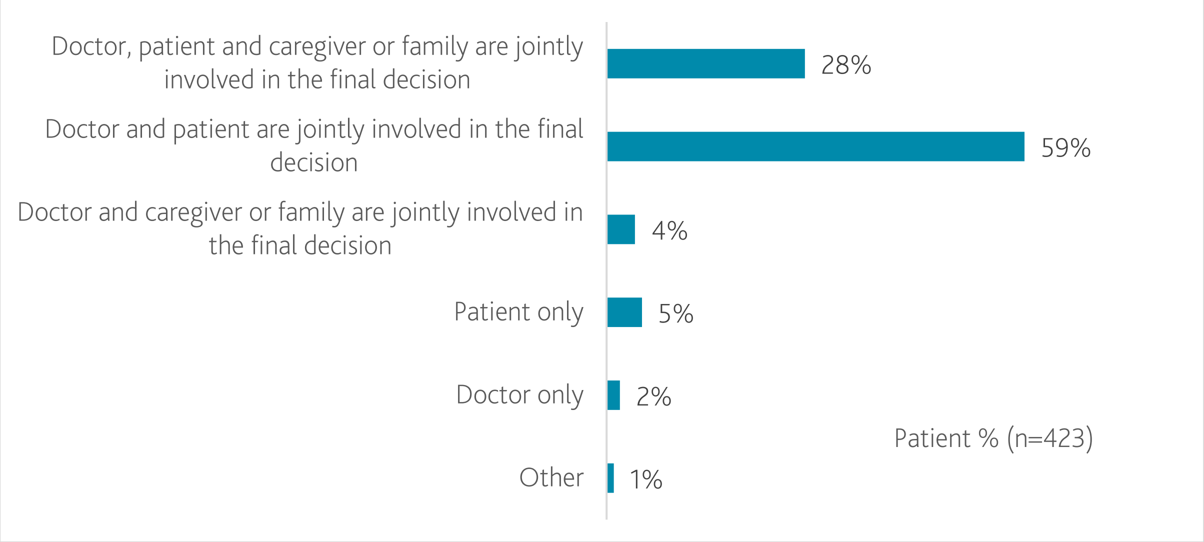
- Figure 47 illustrates that 55% of patients feel that they had very adequate amount of time to think about treatment before the treatment decision was made. Only asked to those who had been treated.

Figure 47. Regarding your current treatment (or last treatment if you are no longer in treatment) how adequate was the amount of time you were given to think about your treatment before the treatment decision was made?



- Figure 48 illustrates that 59% of patients would like the doctor and patient to be jointly involved in the final decision on their healthcare

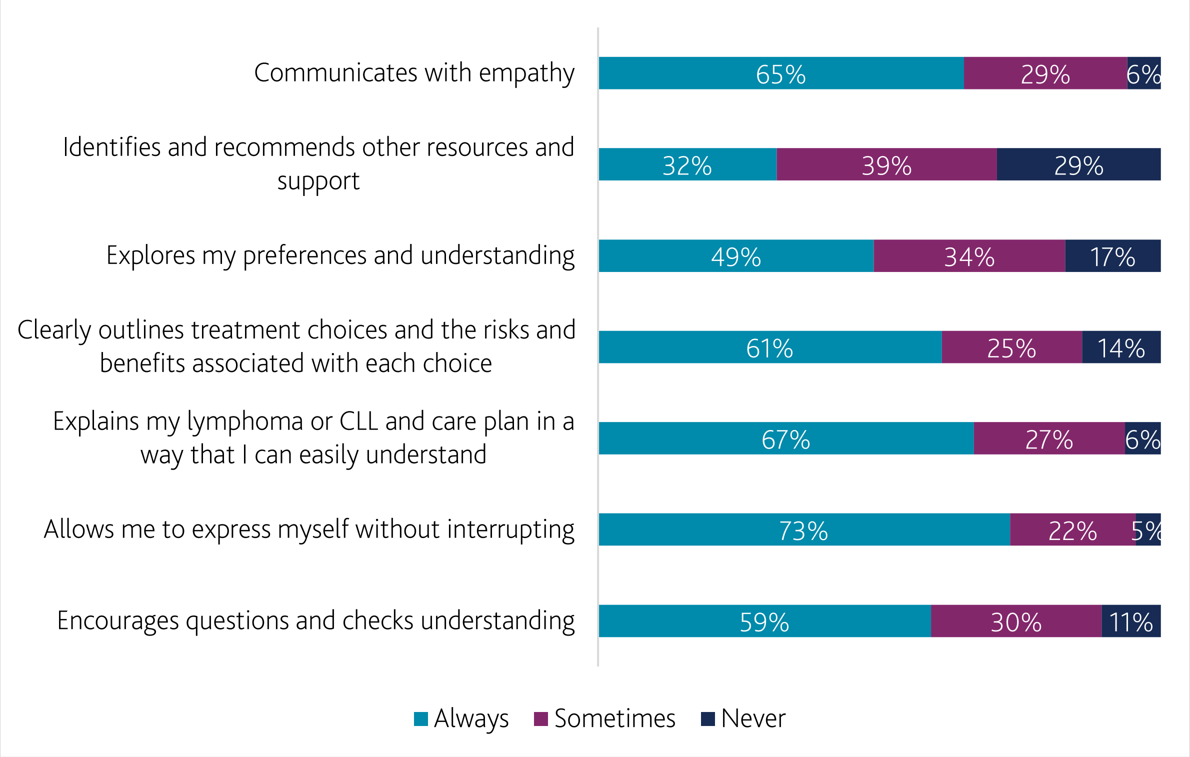
Figure 48. Who would you like to make the final decision on your healthcare?



Patients were asked a series of questions about what their doctors do to encourage participation in decision-making about their care and factors they consider important in interactions with their doctors.

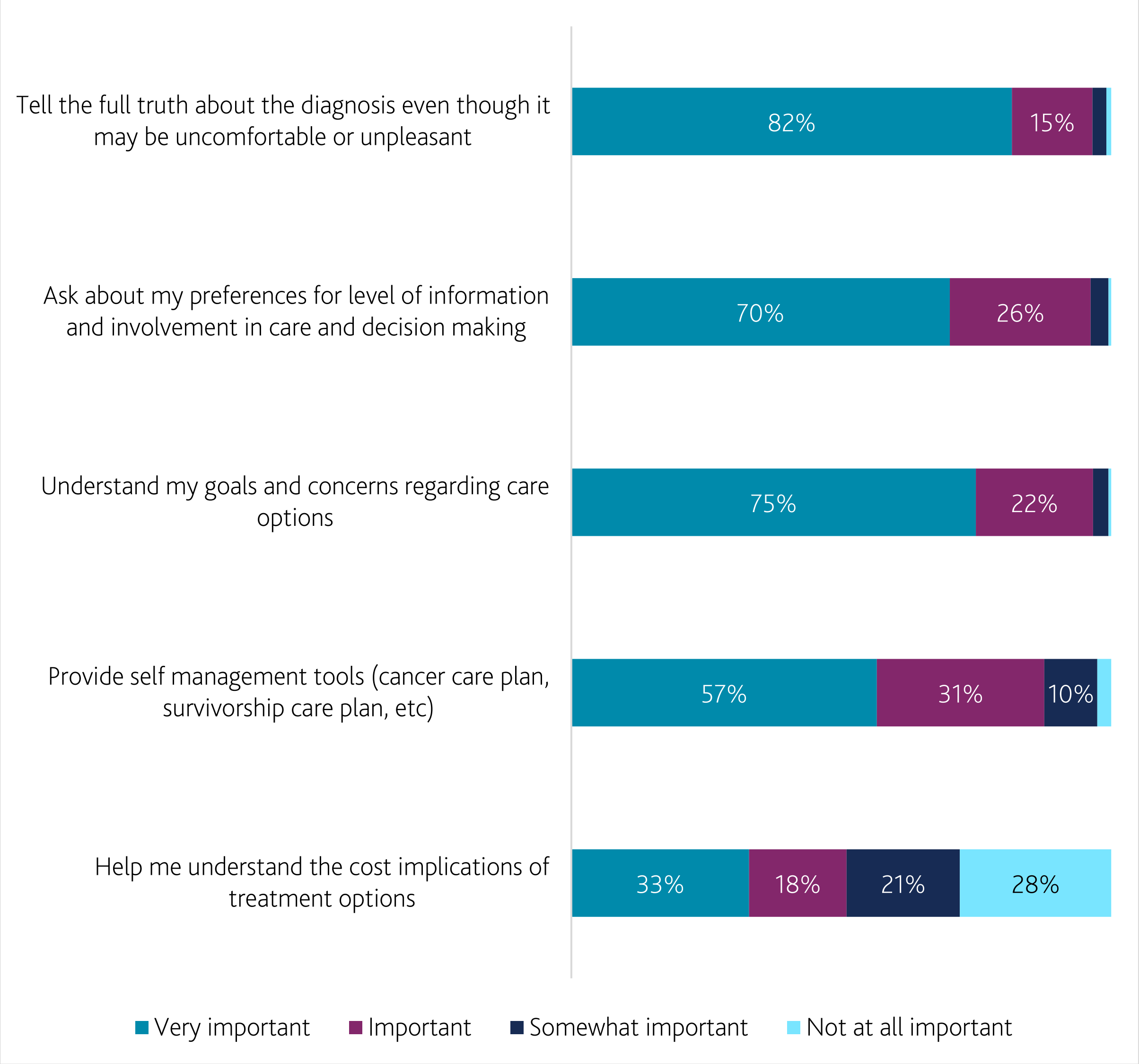
- Figure 49 shows the two biggest gaps identified are 17% of patients said their doctor never explored their preferences and understanding and 29% said their doctor never identified or recommended other resources and support.

Figure 49. Does your doctor do any of the following to encourage participation in decision-making about your care?



- Figure 50 explains that 72% of patients feel that it is very important to have the lymphoma or CLL doctor tell the full truth about the diagnosis even though it may be uncomfortable or unpleasant. Less important are the cost implications of treatment.

Figure 50. How important or unimportant is it to you to have the lymphoma or CLL doctor…



Effects of Lymphoma/CLL

To fully understand patient experience in regard to the effects of lymphoma, consideration must be given to all of the interactions within a patient's life not only those aspects that are treatment related. Important to consider are the symptoms of lymphoma itself.

- Table 2 describes that over three-quarters of patients have experienced fatigue due to lymphoma/CLL

Table 2. Below is a list of symptoms that affect some people with lymphoma/CLL. Which, if any, have affected you?

Effects of Lymphoma	n	%	Treatment alleviated symptoms*
Abdominal swelling	98	23%	65%
Anaemia	111	26%	71%
Bone pain	124	29%	48%
Cold agglutinin disease	7	2%	100%
Cryoglobulinaemia	3	1%	67%
Easily bruised or bleed	115	27%	21%
Enlarged lymph nodes/ abnormal painless swelling(s) on the body	211	50%	78%
Fatigue	329	**78%**	34%
Fever, chills, night sweats and weight loss (B-symptoms)	169	40%	71%
Frequent or repeated infections	100	24%	41%
Headaches	85	20%	30%
Hyperviscosity syndrome	9	2%	71%
Itchy skin	186	44%	47%
Pain	99	24%	44%
Shortness of breath	158	37%	53%
Skin rashes/lesions	99	24%	48%
Other (please specify)	62	15%	59%
No symptoms	12	3%	16%

*only asked to those who reported the symptom

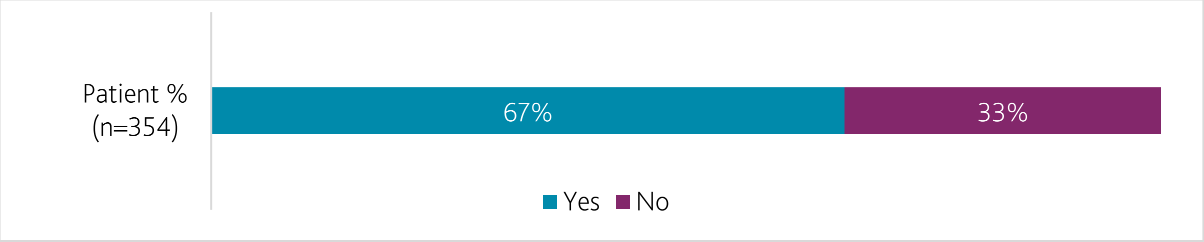
Lymphoma and CLL Treatments

This section deals with questions that were only asked to patients currently on treatment or those who had previously received treatment for their lymphoma, including CLL, which accounted for 82% of respondents. Of that group, 67% had treatment within the last 2 years.

- 65% the patients who had ever received or were receiving treatment were receiving their first treatment.
- Only 8% of patients had been in a clinical trial.
- 5% of patients were interested in information about the effect of their treatment on fertility but were not given such information.
- 22% of patients agree and 24% strongly agree that their treatment was chosen to minimize the impact of possible side effects on lifestyle and/or favourite activities.
- 84% of respondents are hoping new treatments bring about a cure, followed by 77% hoping for longer survival.

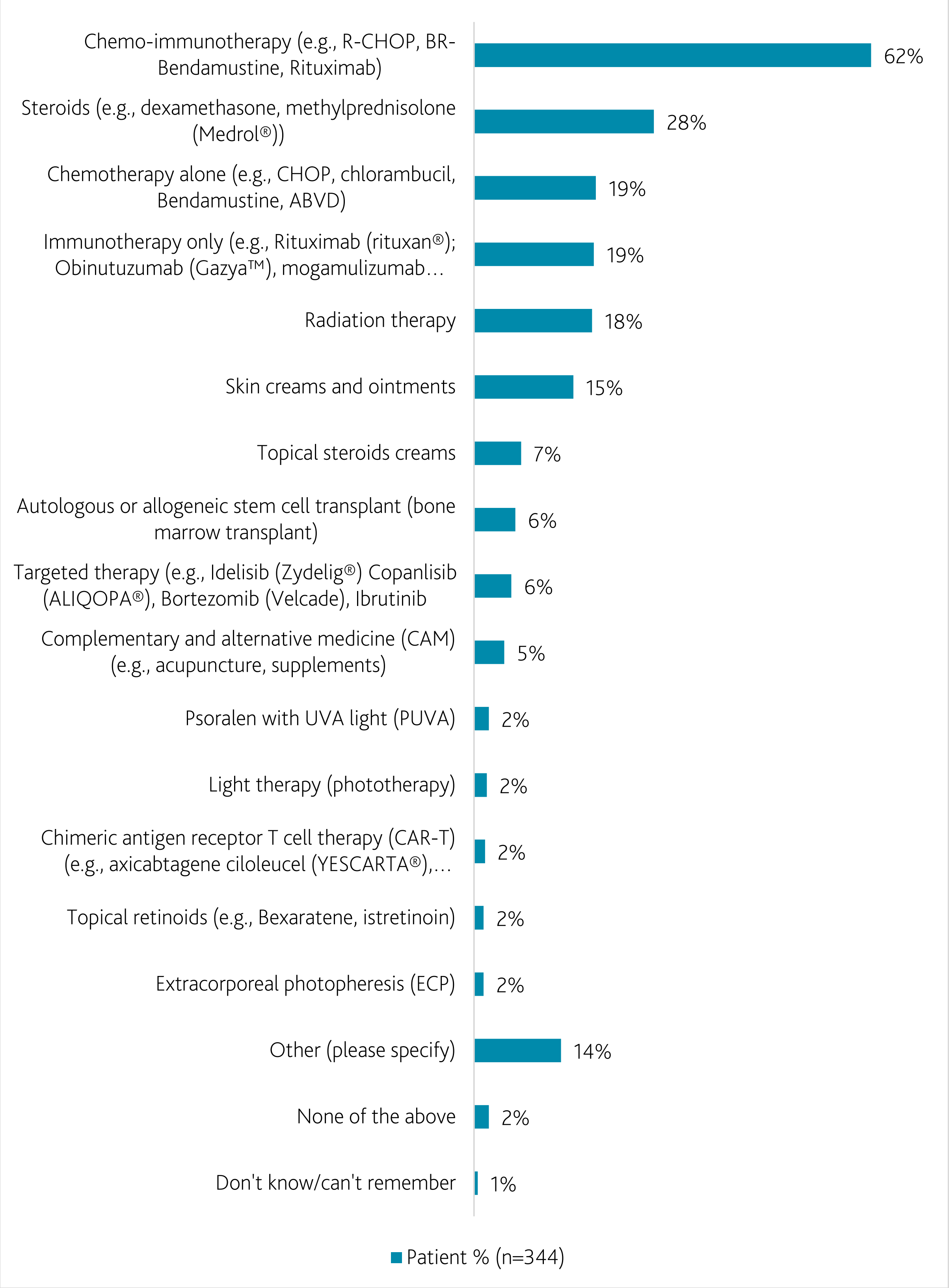
❖ Figure 51 illustrates that two-thirds of respondents have received medical treatment for their lymphoma or CLL. Only asked to those who have received treatment.

Figure 51. Have you received or are you receiving any medical treatment (e.g., chemotherapy, radiation) for your lymphoma or CLL within the last 2 years?



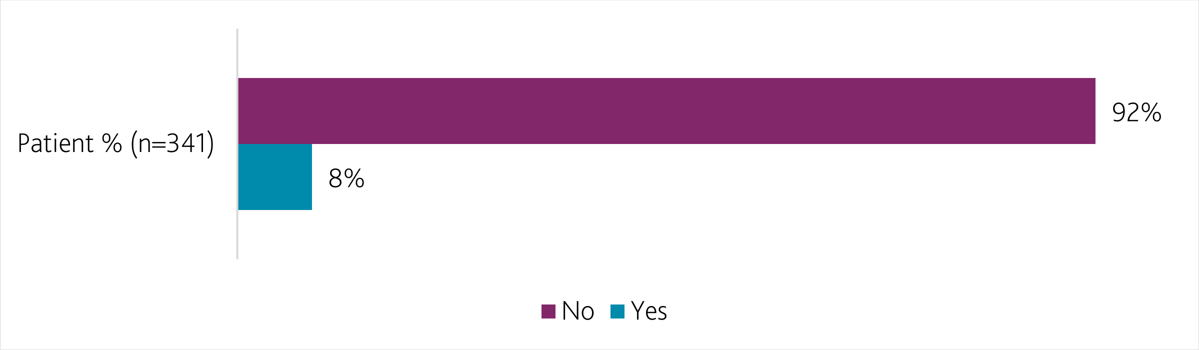
- Figure 52 describes the types of treatments patients have had, with 3 in every 5 patients having received chemo-immunotherapy. Only asked to those who have received treatment.

Figure 52. Which of the following treatment options, if any do you receive currently, or have ever received in the past?



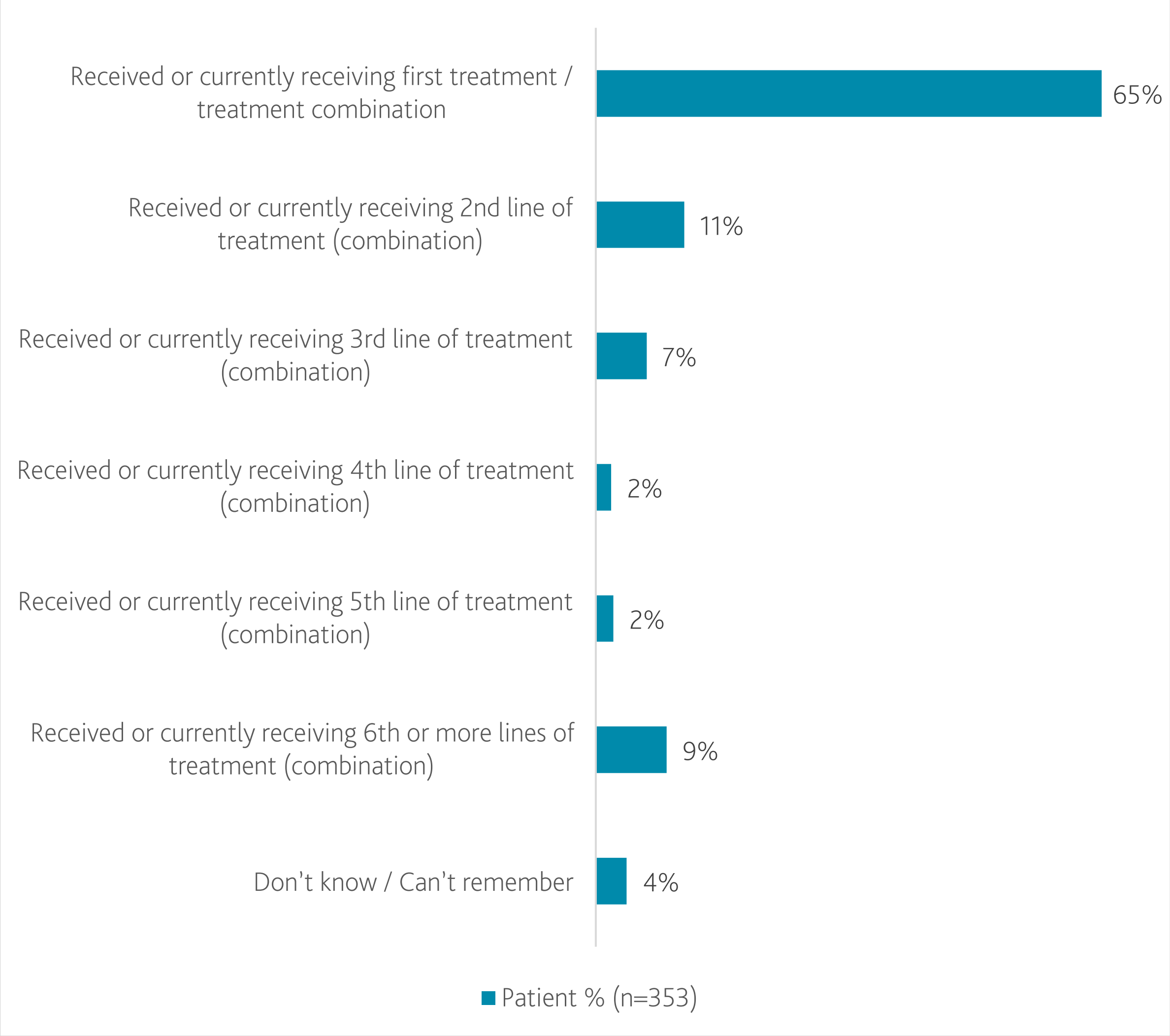
- Figure 53 reveals that only 8% of patients have been in a clinical trial for lymphoma. Only asked to those who have received treatment.

Figure 53. Are you currently, or have you ever been in a clinical trial for your lymphoma?



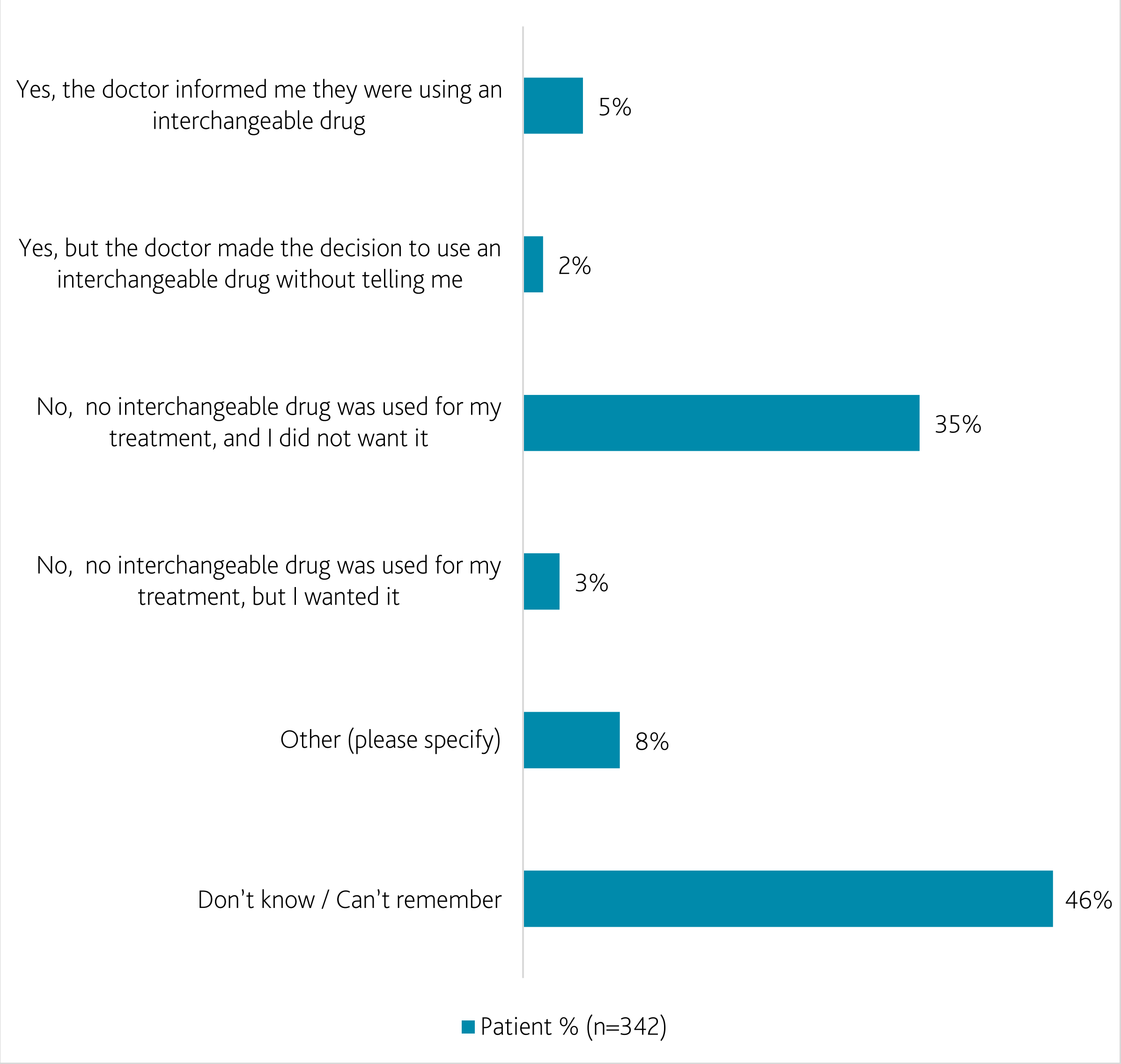
- Figure 54 shows most patients have received or are currently receiving their first treatment/treatment combination. Only asked to those who have received treatment.

Figure 54. How many lines of treatment have you/the patient received to date for lymphoma?



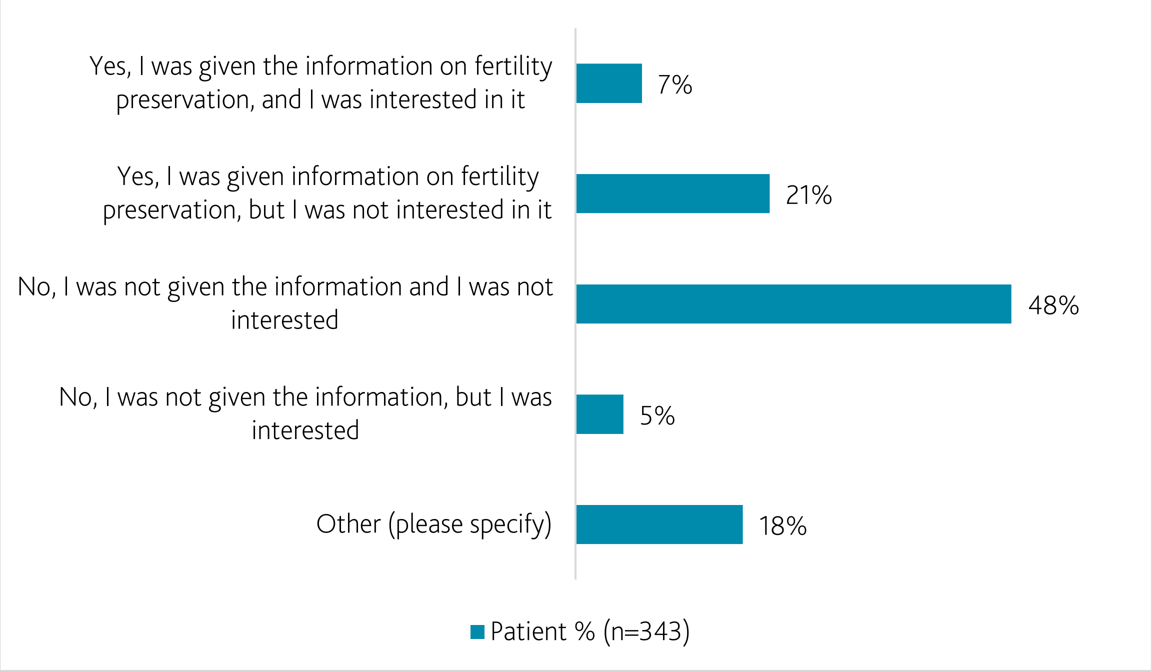
- Figure 55 illustrates that 35% of patients did not use an interchangeable drug for their treatment and did not want it, but almost half of respondents don't know or can't remember if an interchangeable drug was used. Only asked to those who have received treatment.

Figure 55. Were interchangeable/equivalent (e.g., generic, biosimilars, pharmaceutical equivalents), used during your treatment?



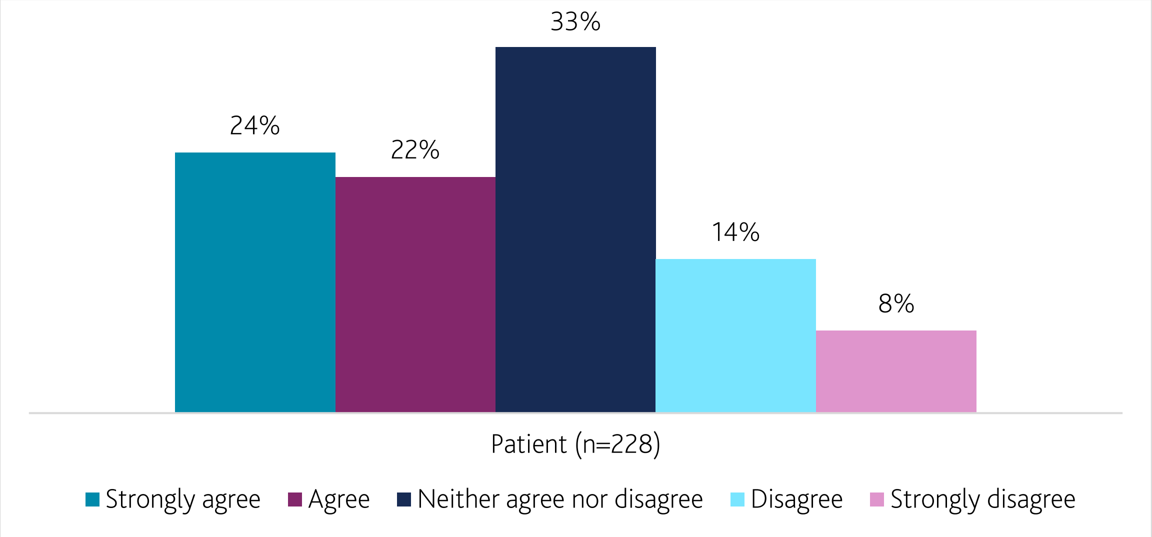
- Figure 56 reveals 5% of patients were not given information about treatment side effects on fertility but they were interested in such information. Only asked to those who have received treatment.

Figure 56. Did your medical team give you any information about treatment side effects on fertility and about fertility preservation opportunities prior to treatment?



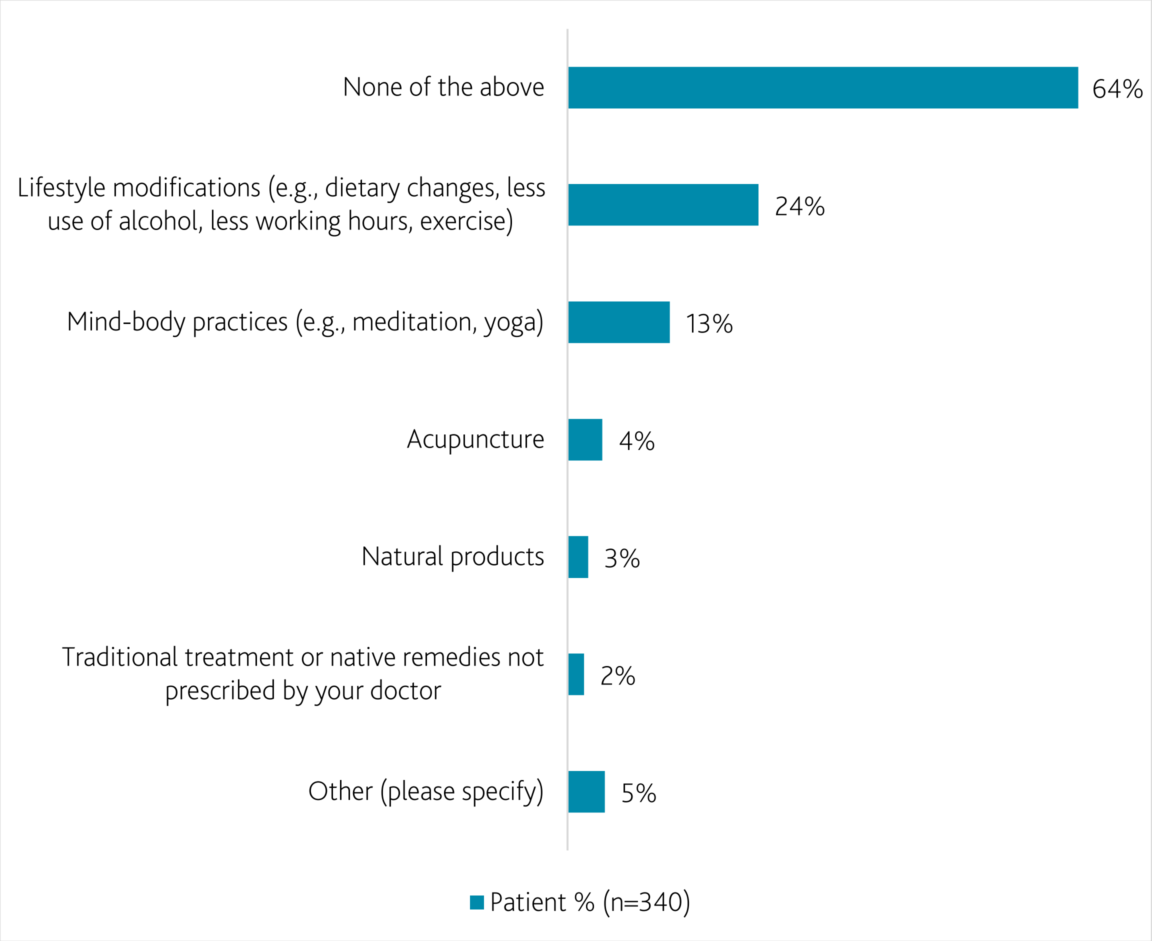
- Figure 57 points out that almost half of patients agree or strongly agree that treatment was chosen to minimize the impact of possible side effects on their lifestyle and/or favourite activities. Only asked to those who have received treatment.

Figure 57. How much do you agree or disagree that your treatment was chosen to minimize the impact of possible side effects on your lifestyle and /or favourite activities?



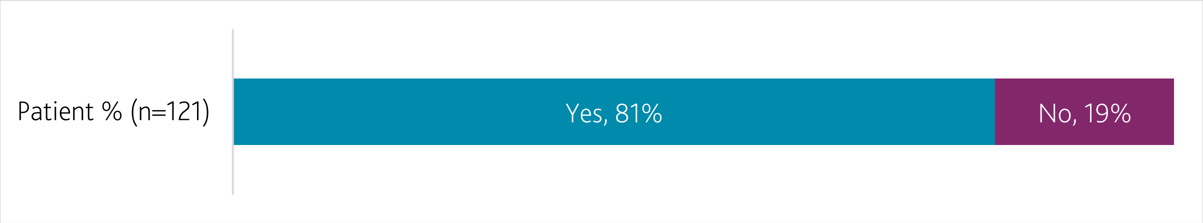
- Figure 58 details that 64% of patients have not used any of the following practices alongside conventional cancer treatments. Only asked to those who have received treatment.

Figure 58. During your experience so far with lymphoma or CLL, were any of following used alongside conventional cancer treatments?



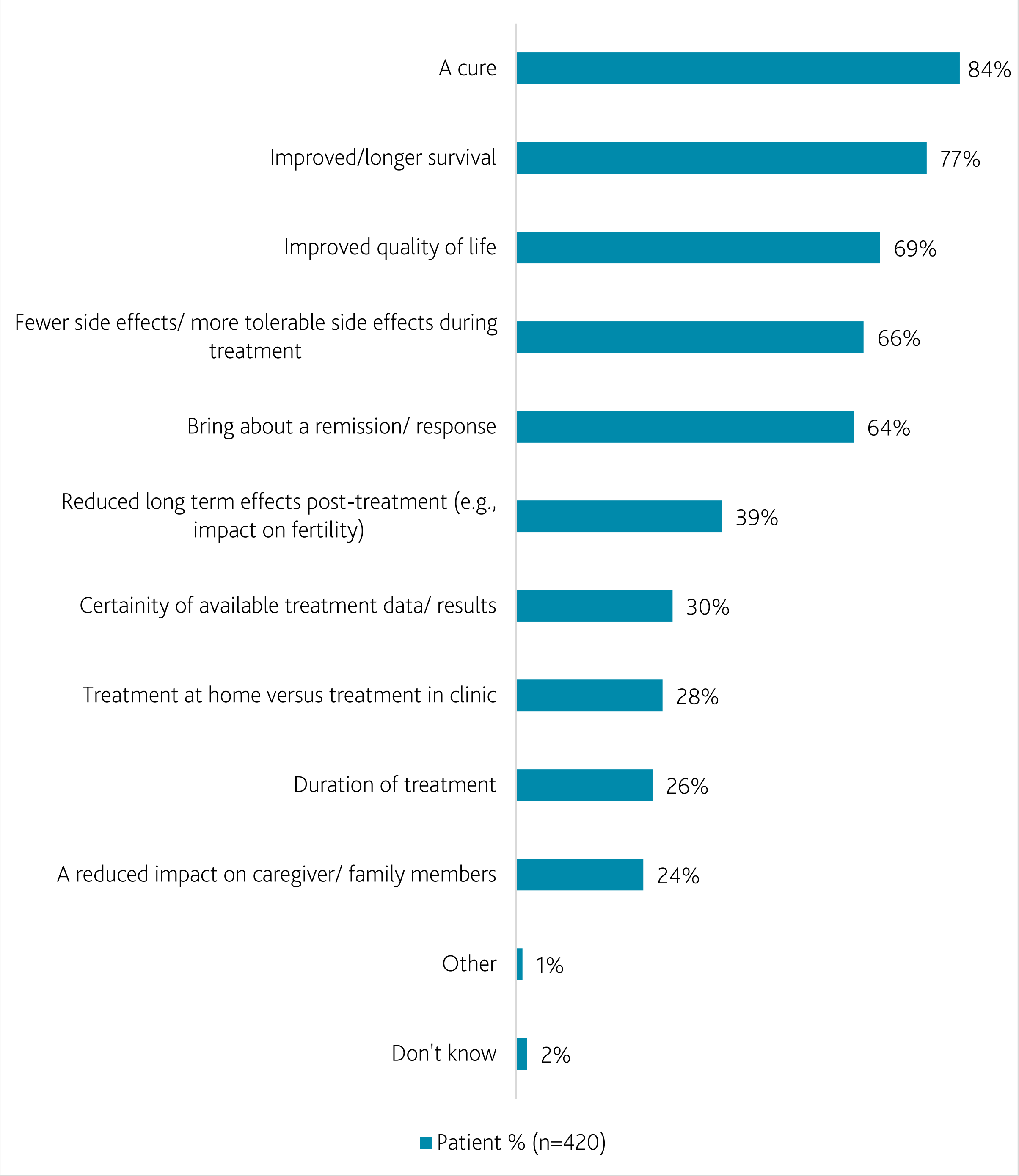
- Figure 59 illustrates that most patients told their lymphoma or CLL doctor or another member of their medical team that they were applying lifestyle modification(s)/treatment(s)/product(s). Only asked to those who used these types of remedies alongside conventional cancer treatment.

Figure 59. Did you tell your lymphoma or CLL doctor or another member of your medical team that you were using/ applying these lifestyle modification(s)/ treatment(s)/ product(s)?



- Figure 60 reveals that 84% of patients consider a cure to be an important feature of a new medical treatment for lymphoma or CLL, followed closely by improved or longer survival (77%)

Figure 60. What, if any, of the following would you consider to be an important feature of a new medical treatment for lymphoma or CLL?



- Table 3 illustrates that 74% of patients rank having a cure as a top feature of a new medical treatment for lymphoma or CLL

Table 3. Please rank your top three features of a new medical treatment for lymphoma or CLL

	#1		#2		#3	
	n	%	n	%	n	%
A cure	258	**74%**	5	1%	26	8%
Improved/ longer survival	25	7%	189	**55%**	45	13%
Bring about a remission/ response	18	5%	55	16%	94	**28%**
Improved quality of life	20	6%	42	12%	63	19%
Fewer side effects/ more tolerable side effects during treatment	12	3%	28	8%	56	17%
Reduced long-term effects post-treatment (e.g., impact on fertility)	5	1%	10	3%	23	7%
Treatment at home versus treatment in the clinic	2	1%	6	2%	9	3%
Duration of treatment	2	1%	0	0%	4	1%
A reduced impact on caregiver/family members	1	0%	4	1%	8	2%
Certainty of available treatment data/results	5	1%	3	1%	8	2%

Barriers to Treatment

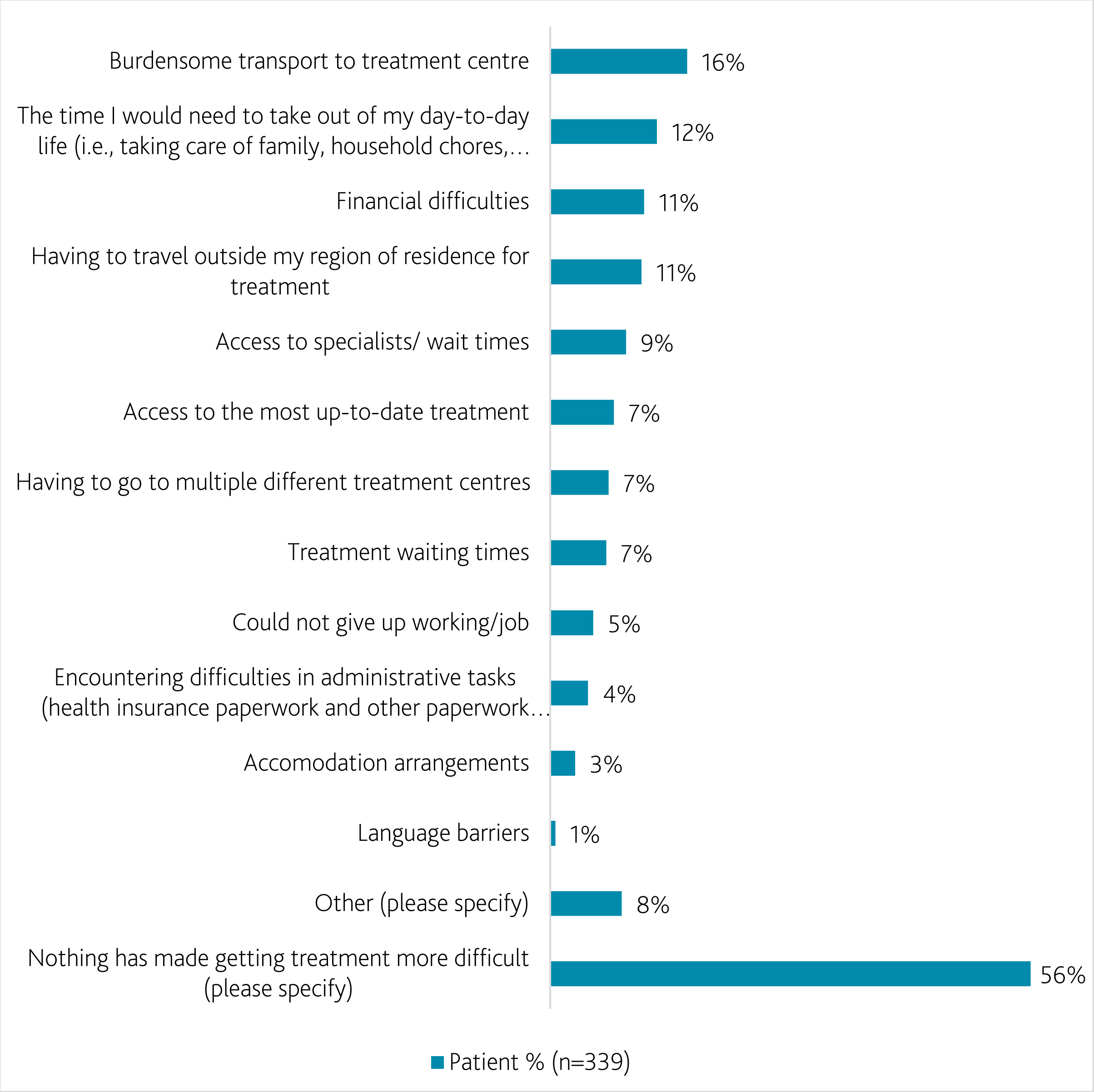
Barriers to standard therapy and access to clinical trials remain essential topics to examine. In previous surveys, financial issues have been the most reported barrier to receiving treatment.

Clinical trials may provide an option for patients facing disease progression who have exhausted all traditional therapies in their country to access novel treatments. Similarly, clinical trials can provide an opportunity for patients to access treatments that would otherwise be cost-prohibitive.

- Over half of patients from the UK reported not having any barriers to receiving treatment (56%).
- 16% reported burdensome travel to the treatment centre was a barrier, and 11% referred to having to travel outside of their region of residence to get treatment.
- 68% of patients said never being presented with an opportunity to take part is the top reason they have not participated in a clinical trial.

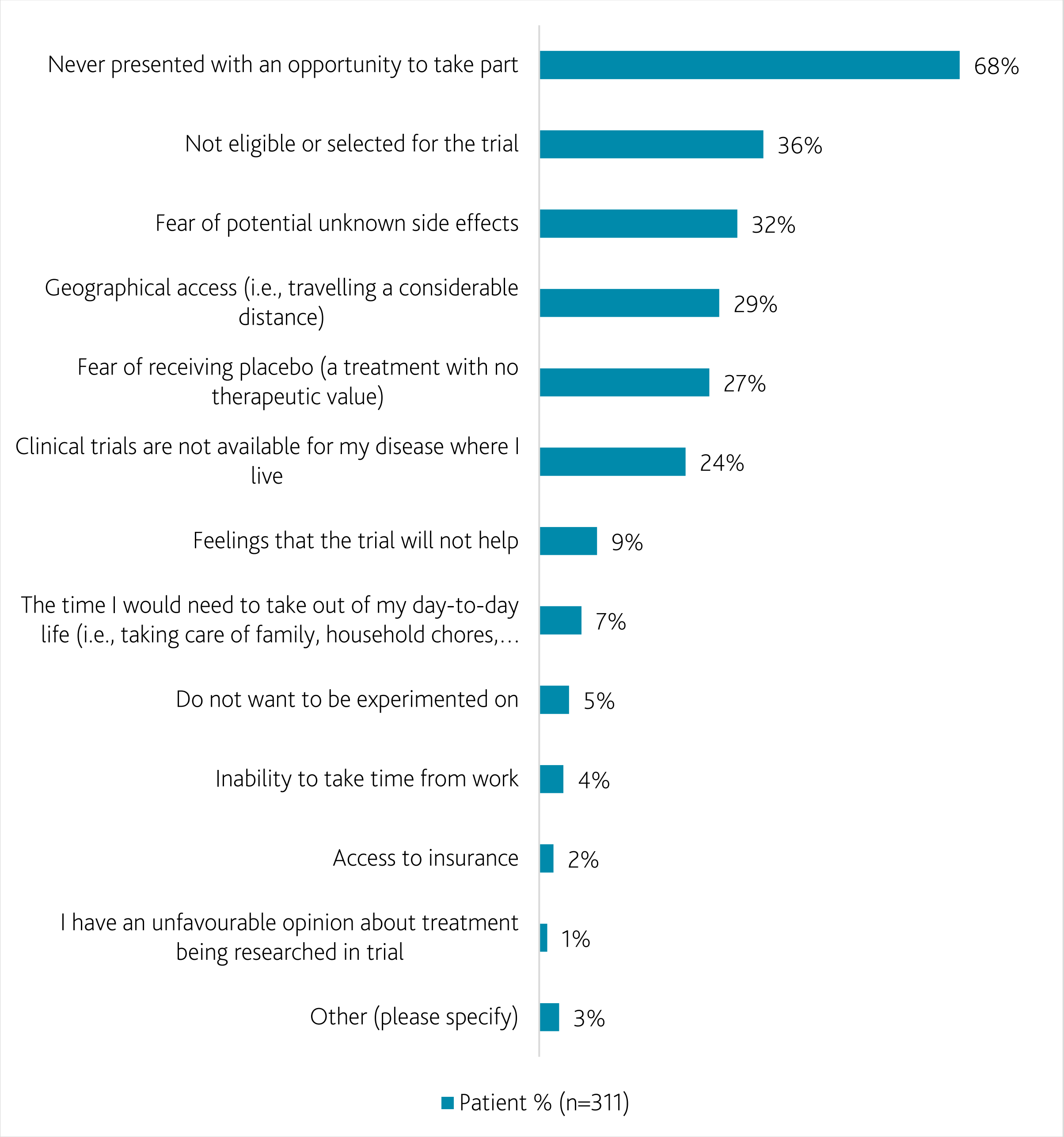
- Figure 61 illustrates that 56% of patients feel that nothing has made getting treatment more difficult. Only asked to those who have received treatment.

Figure 61. What, if anything, has made getting treatment more difficult?



- Figure 62 explains that seven out of 10 patients were never presented with an opportunity to take part in a clinical trial. Only asked to those who have received treatment.

Figure 62. What, if anything, would prevent you from participating in a clinical trial?



Side Effects of Treatment

Patients receiving treatment for their lymphoma/CLL are affected by a range of treatment-related side effects.

- The most common side effects are:
    - Fatigue (80%)
    - Hair loss (63%)
    - Constipation (56%)
    - Changes in sleeping pattens (i.e., trouble sleeping, etc.) (53%)

- The side effects that affected patients' wellbeing the most (ranked 1st) were:
    - Hair loss
    - Infections (neutropenia)
    - Constipation

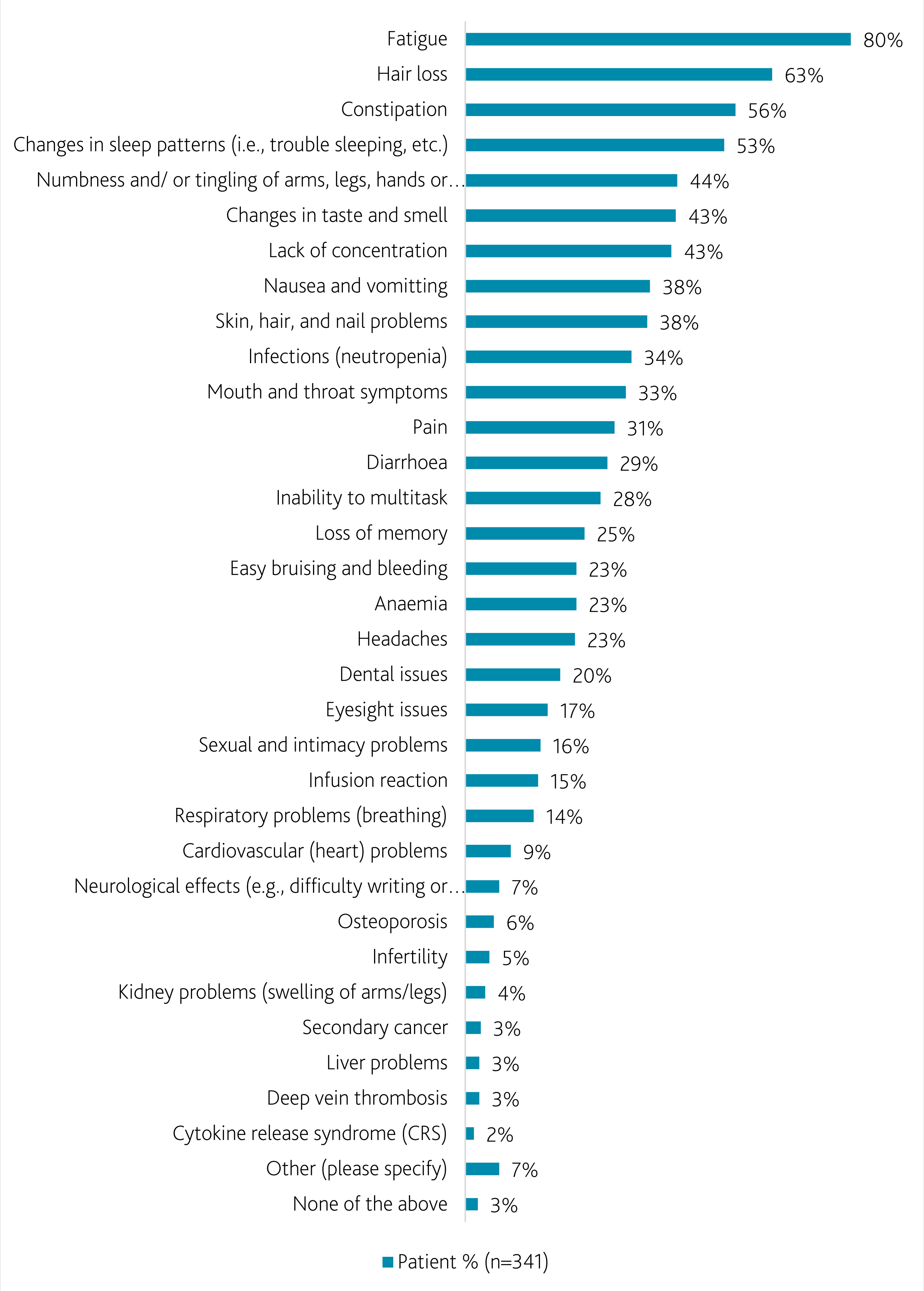
- 76% of patients who were affected by hair loss and 72% of those affected by constipation experienced these side effects for less than 1 year.

- 37% of those affected by changes to sleep patterns were affected for under a year, but 22% continued to be affects for 1 to 2 years, 25% for 2 to 5 years, and 16% for more than 5 years.

- 29% of patients who were affected by fatigue experienced these side effects for less than 1 year, with the rest continuing to experience fatigue longer term (23% - 1 to 2 years, 27% - 2 to 5 years, 9% - 5 to 8 years, 12% more than 8 years).

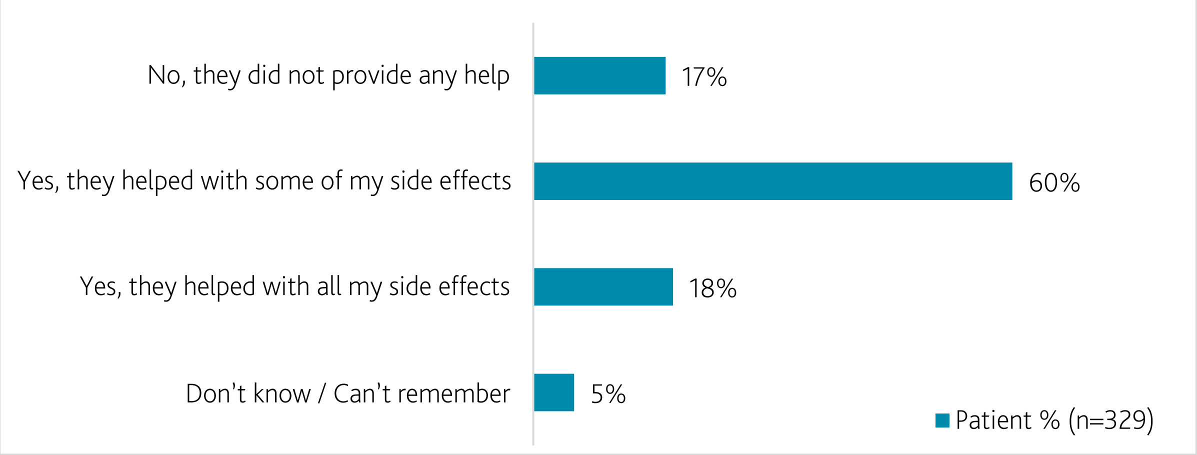
- Figure 63 shows 80% of patients experienced fatigue as a side effect. Only asked to those who have received treatment.

Figure 63. Which of the following side effects, if any, have you been affected by (Highlighted the side effects that affected patients the most)?



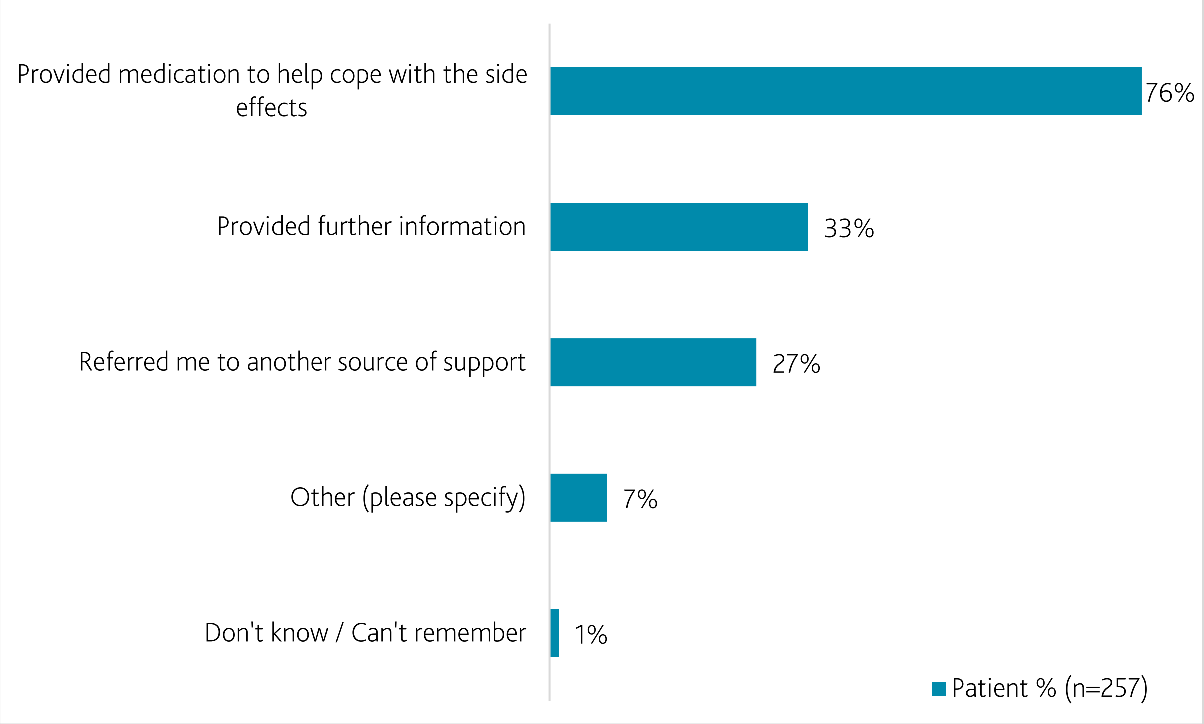
- Figure 64 shows that 78% of patients felt that their doctor or other members of their medical team was able to help alleviate or cope with some or all of their side effects. Only asked to those who said they had side effects.

Figure 64. 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 65 illustrates that 76% of the patient's doctor provided medication to help cope with the side effects. Only asked to those that said the doctor helped with their side effects.

Figure 65. What specifically did the doctor do to help?

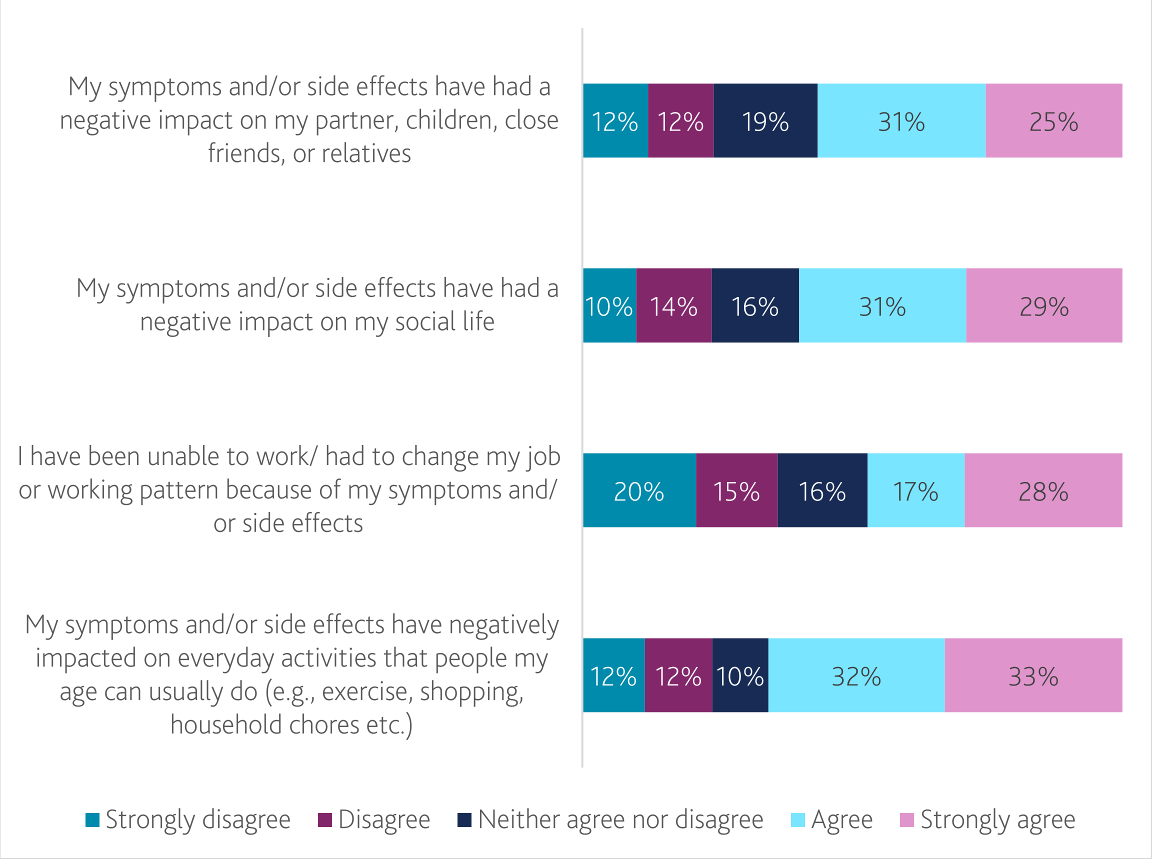


Impact of lymphoma or CLL symptoms and treatment side effects on quality of life

The side effects and symptoms of lymphoma and CLL profoundly impact patients' quality of life.

- Figure 66 shows that 65% of patients strongly agree or agree that their symptoms and/or side effects have negatively impacted on everyday activities. Only asked to those who said they had symptoms from their disease or side effects from treatment.

Figure 66. 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?



Fatigue

Fatigue was the leading physical symptom affecting the quality of life reported by respondents to the LC 2020 Global Patient Survey, regardless of whether the patient was newly diagnosed, in treatment, had relapsed disease or was in remission. However, patients were not being educated about fatigue or directed to further information/support by their doctors. Healthcare professionals have been challenged in their efforts to assess and help their patients manage cancer-related fatigue because of various patient-related, professional, and systematic barriers.

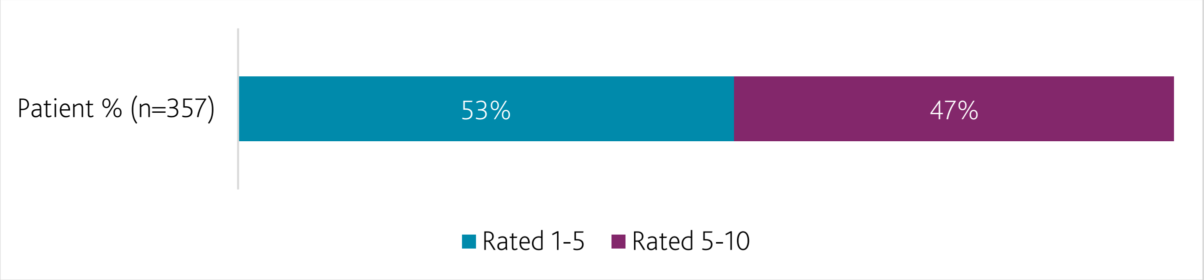
This section of the report only includes responses from patients who reported that they had fatigue either as a symptom of lymphoma (78%) and/or as a side effect of treatment (80%).

- 43% of patients didn't discuss their fatigue with their doctor over the last two years.
- 30% of patients were provided strategies (e.g. physical activity) to manage their fatigue by their doctor and 52% of patients found balancing schedules helpul and the best way to manage their cancer related fatigue.
- 39% of patients were followed up for their cancer related fatigue by their doctor.

Patients with fatigue were asked to rate the severity of their fatigue over the last week on a scale of 1-10 (1 representing minimal fatigue, and 10 being the worse fatigue imaginable). Only asked to those who reported they had fatigue.

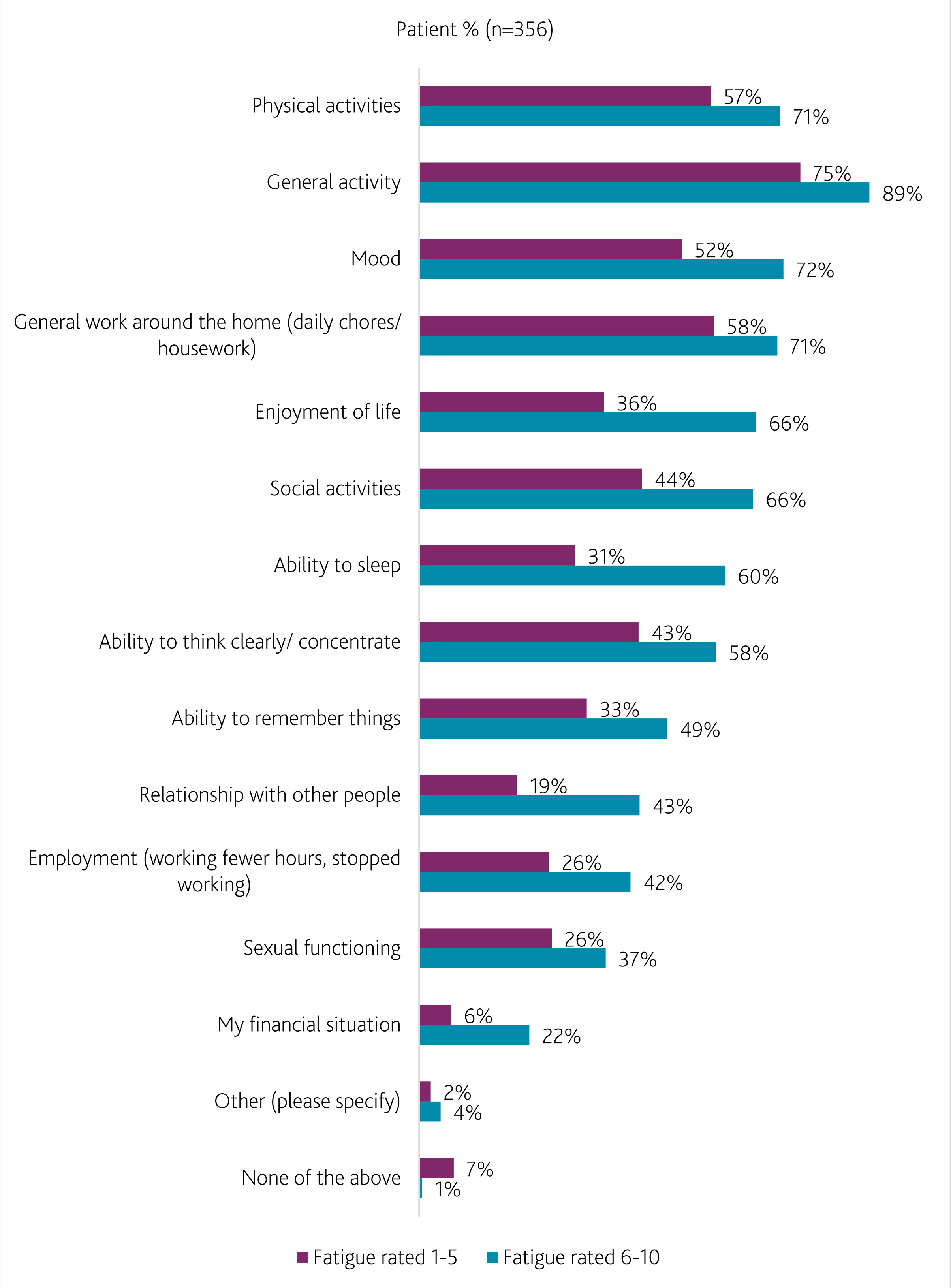
❖ Figure 67 illustrates that 53% of patients report minimal fatigue

Figure 67. Patients were asked to rate their level of fatigue on a scale of one (minimal fatigue) to 10 (worst fatigue imaginable).



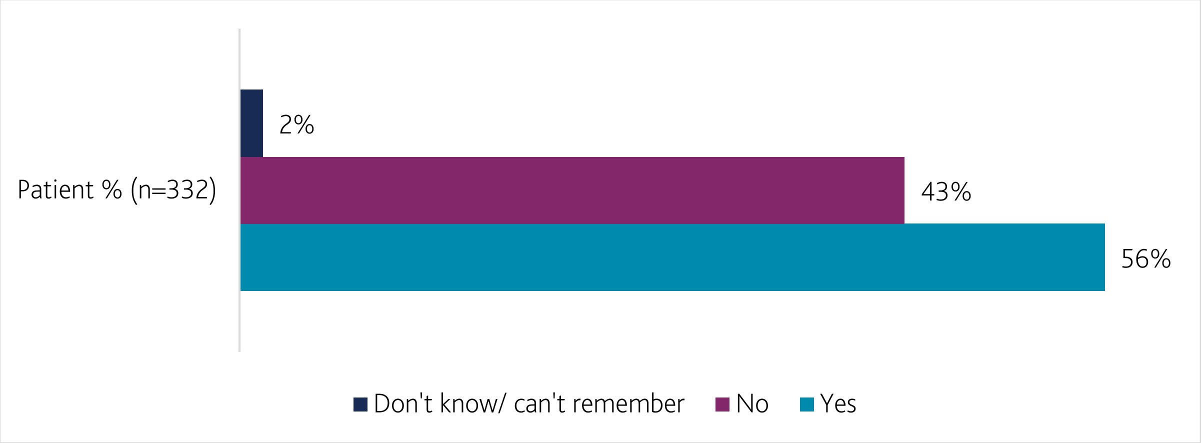
- Figure 68 reveals patients with fatigue state it affects many aspects of their lives regardless of their fatigue rating. However, overall, people with a higher rating of fatigue (6-10) faced a greater impact on their lives. Only asked to those who reported they had fatigue.

Figure 68. Which of the following areas/ activities, if any, has your fatigue affected over the last two years?



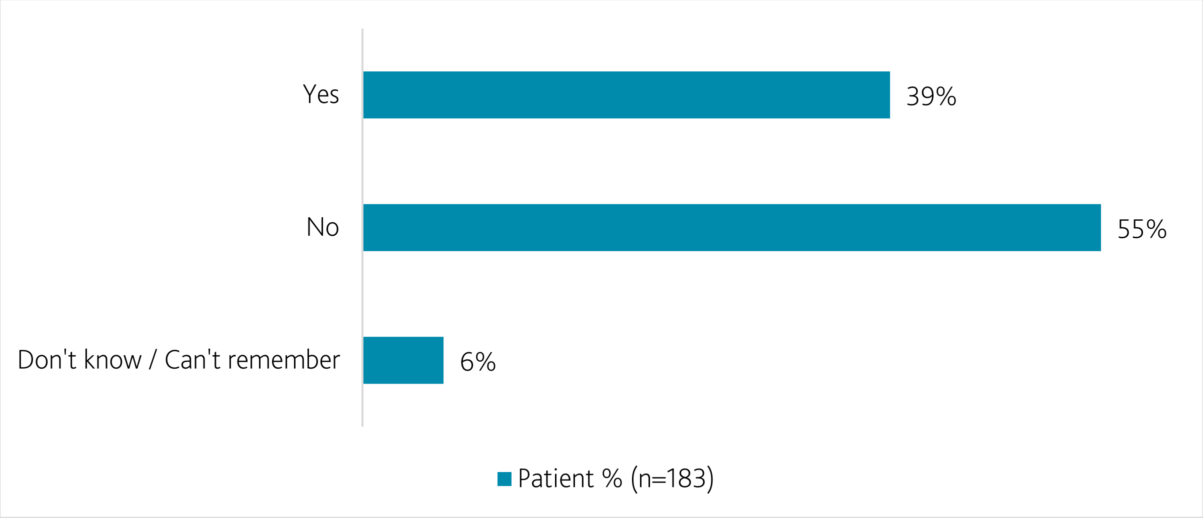
- Figure 69 reveals over half of patients have discussed their fatigue with their doctor over the last two years. Only asked to those who reported they had fatigue.

Figure 69. Have you discussed your fatigue with your doctor over the last two years?



- Figure 70 shows that 55% of patients did not receive follow up from their doctor about the fatigue they were experiencing. Only asked to those who reported they had discussed their fatigue with their doctor.

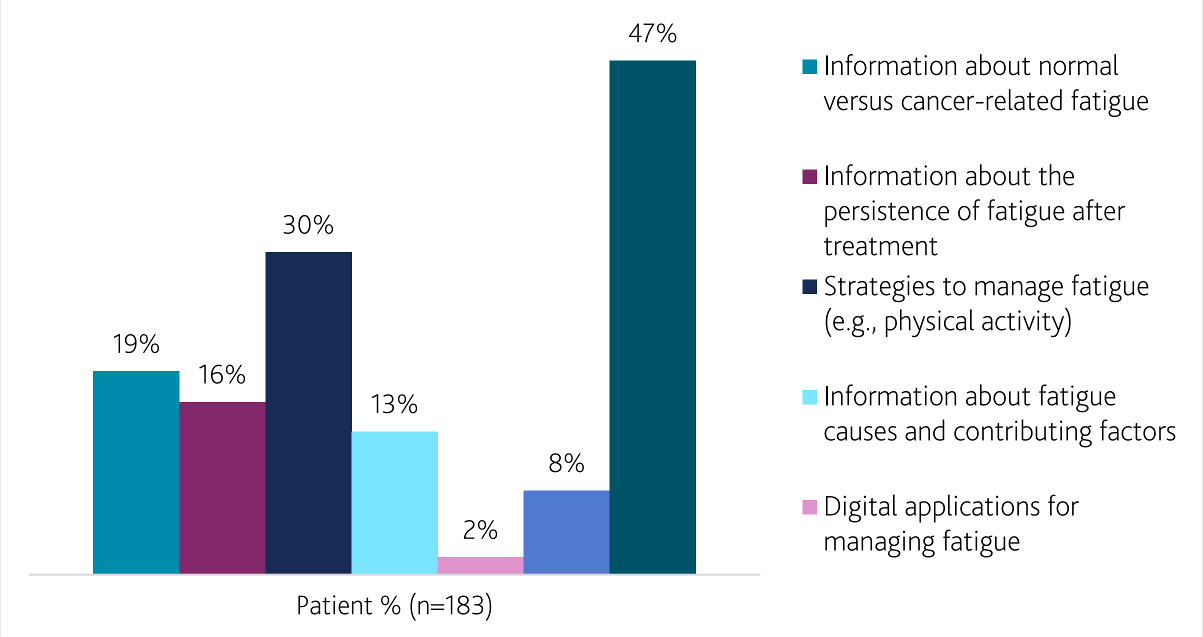
Figure 70. Did your doctor follow up with you about the fatigue you were experiencing?



Patients who discussed their fatigue with their doctor (n=332) were also asked what type of information they received from their doctor.

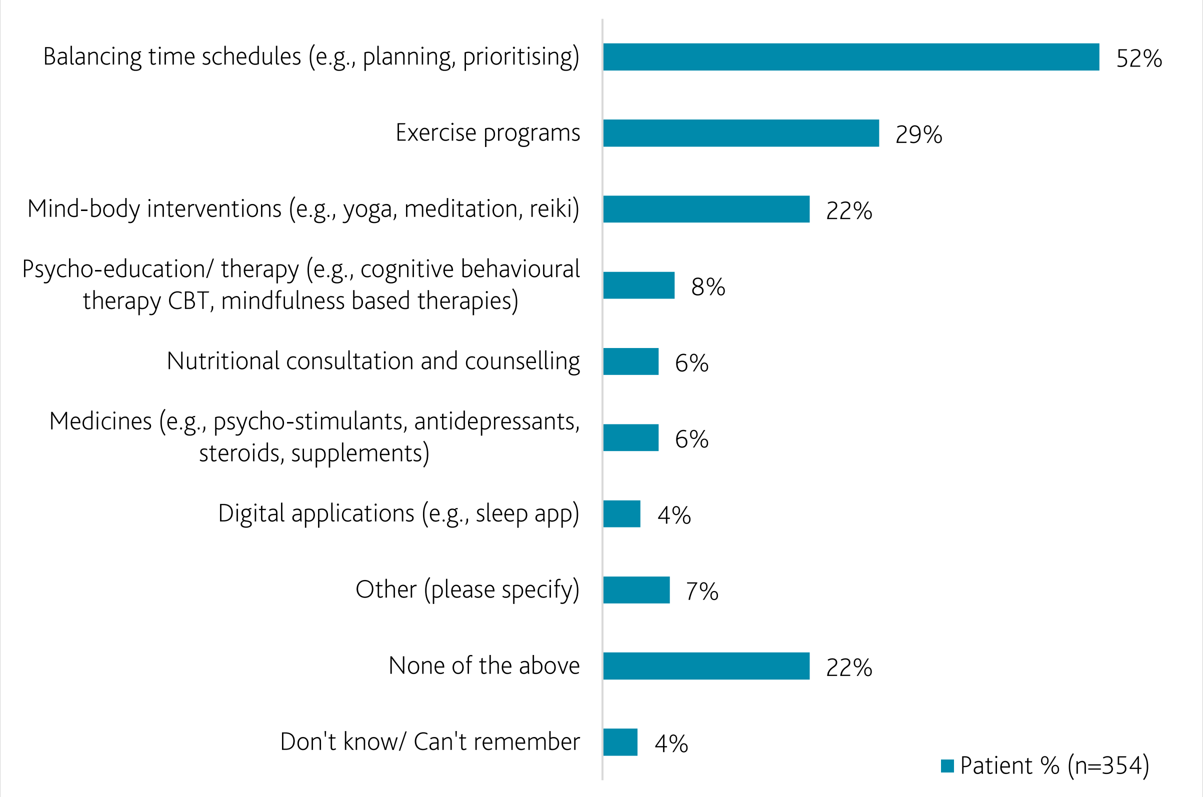
- Figure 71 illustrates that almost half of patients were not provided with information on cancer-related fatigue from their doctor . Only asked to those who reported they had discussed their fatigue with their doctor.

Figure 71. Which information types did your doctor provide you with?



- Figure 72 reveals that about half of patients found that balancing time schedules was helpful in managing their fatigue. Only asked to those who reported they had fatigue.

Figure 72. Have you found any of the following options helpful in managing cancer-related fatigue?



Psychosocial Effects of Lymphoma

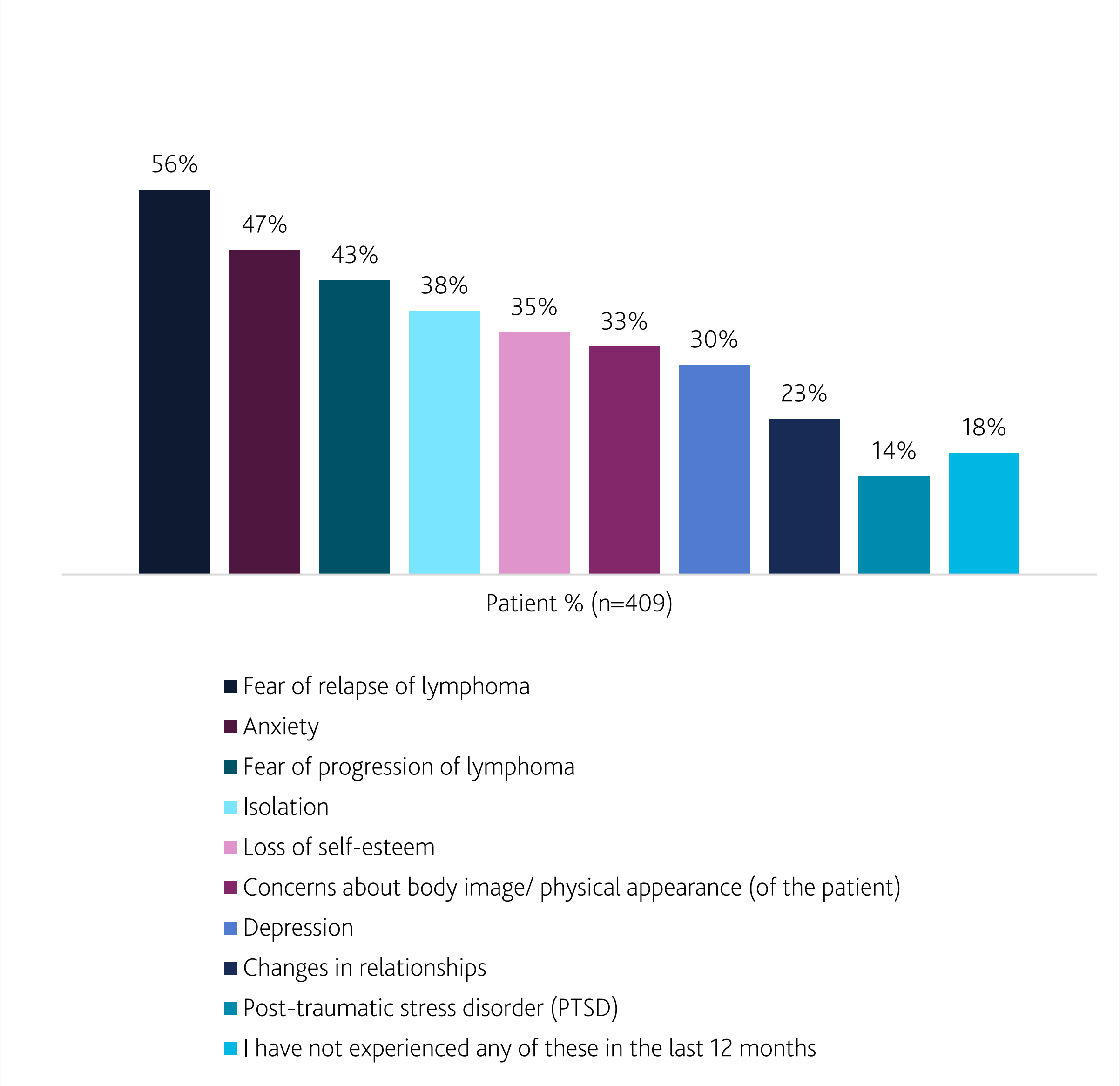
This section reports on the emotional and social effects of lymphoma and its treatment, specifically fear of lymphoma progression, fear of cancer relapse, and experiences impacting mental and emotional health.

The questions exploring psychosocial effects in the 2022 GPS resulted from highlighted data within the previous surveys (2018 & 2020 LC GPS), showing that fear of cancer relapse, depression, and anxiety were the most commonly reported psychosocial issues. Additionally, the 2022 survey explored the fear of lymphoma progression to capture the experience of those in active surveillance who 'watch and wait' for their lymphoma's growth status.

- 82% of patients experienced some kind of psychosocial issue over the last year.
- Over half of the patients who are in treatment/ had treatment or in remission reported a fear of cancer relapse (56%) and fear of lymphoma progression (43%) as their biggest worries or concerns, but only 1 in 5 patients talked about their fears with their doctor.
- Other psychosocial effects experienced in the last 12 months included anxiety (47%), Isolation (38%), and loss of self-esteem (35%).
- The most provided approach by doctors to help patients cope with their fear was the empathic/ understanding approach (58% & 63%).
- For two-thirds of patients, doctors did not follow up on these issues.

- Figure 73 discloses that 56% of patients have experienced fear of relapse of lymphoma and a further 43% are fearful their lymphoma will progress.

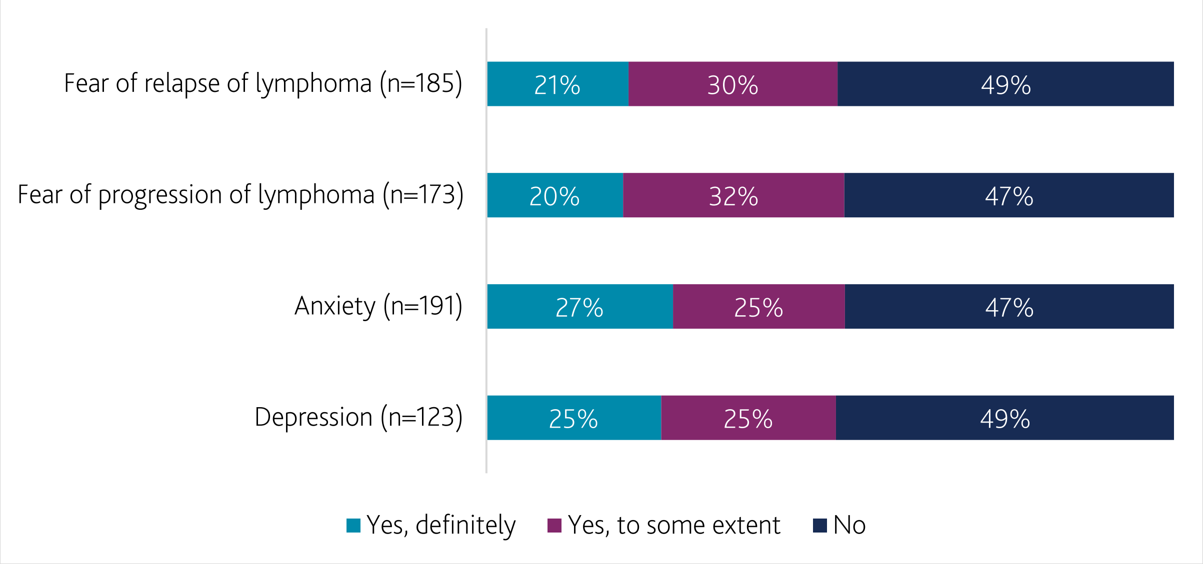
Figure 73. In the last 12 months, have you personally experienced any of the following as a result of the lymphoma diagnosis?



The next questions only focused on the top 4 psychosocial issues identified by patients globally: fear of relapse of lymphoma, fear of progression of lymphoma, anxiety and depression.

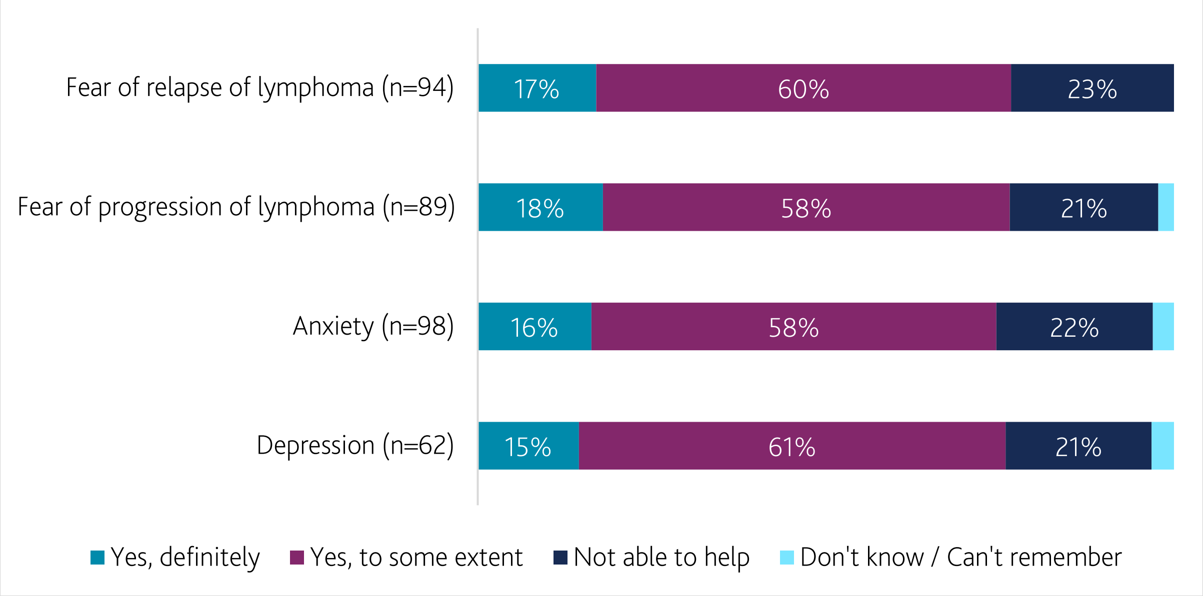
- Figure 74 reveals that about half of patients have not discussed any of their concerns with a doctor. Only asked to those who indicated they were affected by at least one of the following: fear of relapse, fear of progression of lymphoma, anxiety, and depression.

Figure 74. For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with a doctor?



- Figure 75 shows that when patients did discuss these issues with their doctor, in most case the doctor was able to help fully or to some extent. Only asked to those who indicated they were affected by at least one of the following: fear of relapse, fear of progression of lymphoma, anxiety, and depression.

Figure 75. For each of the worries or concerns that you discussed with your doctor, please indicate how much, if at all, the doctor was able to help.



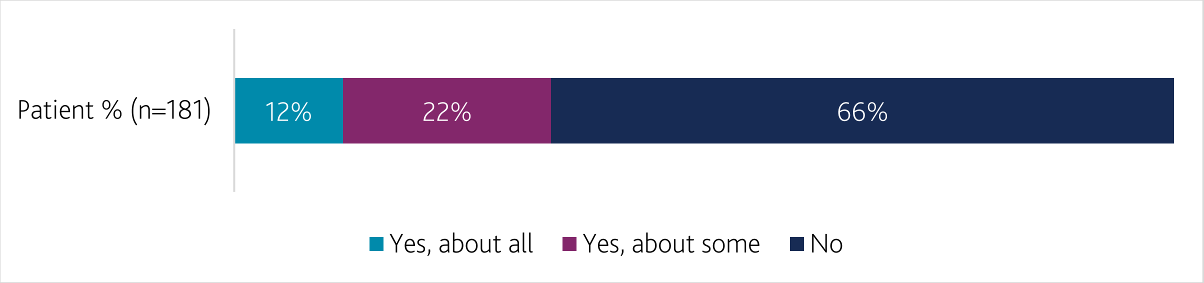
- Table 4 illustrates that regardless of the specific psychosocial issue, the most common types of help offered or recommended was an understanding approach from doctors. Only asked to those who indicated they were affected by at least one of the following: fear of relapse, fear of progression of lymphoma, anxiety, and depression.

Table 4. What type of help were you provided with?

Help offered	For Depression	For Anxiety	For Fear of progression of lymphoma	For Fear of relapse of lymphoma
Medication to help cope with this worry or concern	**53%**	41%	8%	3%
Further written or verbal information	15%	12%	17%	11%
The empathetic/ understanding approach of my doctor when I told him/ her	34%	**52%**	**58%**	**63%**
Patient organisation or patient support group	17%	26%	29%	31%
Referral to other sources of support (e.g., social worker, therapist, counselling)	49%	40%	17%	18%
Exercise	19%	16%	15%	18%
Participation of family/ caregiver in providing support	9%	14%	15%	17%
The empathetic/ understanding approach of my nurse when I told him/ her	17%	26%	24%	25%
Eating a healthy diet	15%	18%	18%	21%
Other	4%	3%	9%	10%

- Figure 76 reveals that in most cases doctors did not follow up about psychosocial issues

Figure 76. Did your doctor follow up with you about the psychosocial issues you were experiencing?



COVID-19 and Virtual Care

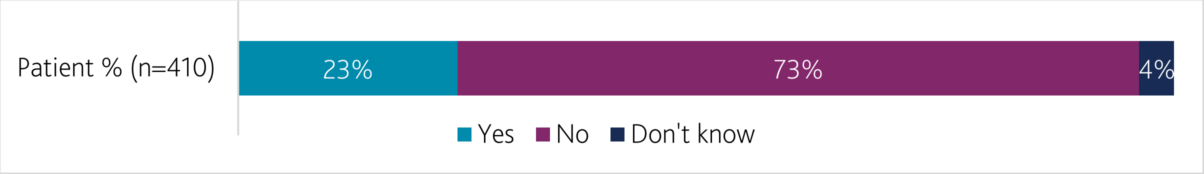
The previous two years of the Covid-19 pandemic (December 2019 to December 2021) have impacted many areas of patients' lives, notably impacting emotional well-being and experiences with fatigue.

Several patients also experienced changes in their care, including switching to telemedicine.

- 89% of patients consider themselves at high risk for contracting COVID-19 and experiencing severe illness from it.
- 55% of patients reported that their anxiety was much worse and 38% of patients reported that their depression was much worse during the Covid-19 pandemic.
- 12% of patients avoided or delayed seeking medical attention due to the pandemic.
- Two-thirds of patients (67%) strongly disagreed/disagreed that they preferred telephone consultation (TC) or video consultation (VC) to face-to-face visits, while only 13% strongly agreed/agreed that they preferred it.
- 53% of patients strongly disagreed/disagreed that they would like to continue to use TC/VC even after the pandemic is over.

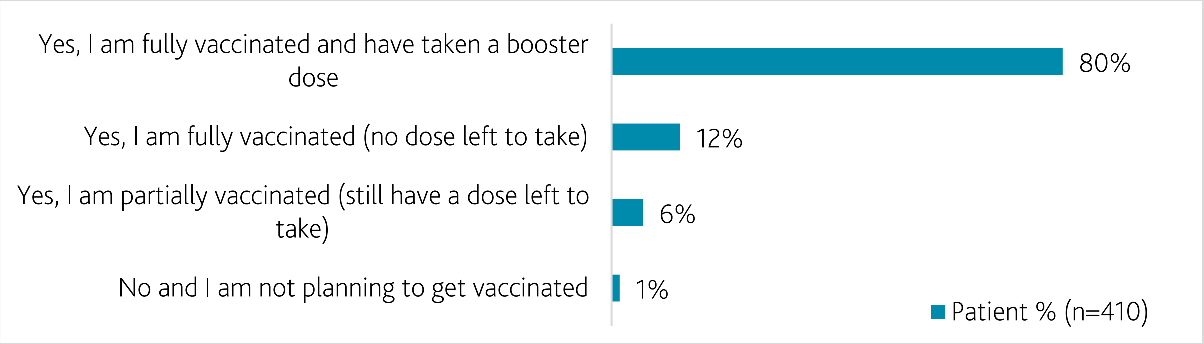
❖ Figure 77 shows about three-quarters of patients have not contracted Covid-19 at any point

Figure 77. Have you contracted Covid-19, now or at any point?



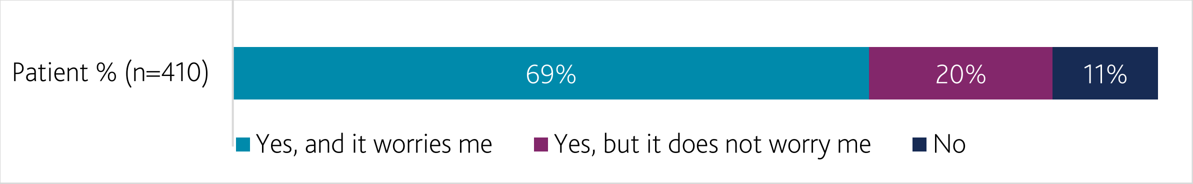
❖ Figure 78 illustrates that 92% of patients are fully vaccinated

Figure 78. Have you, or are you planning to get the Covid-19 vaccine?



- Figure 79 shows that 89% of patients consider themselves as high risk of contracting Covid-19, but 20% are not worried about it

Figure 79. Do you consider yourself at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?

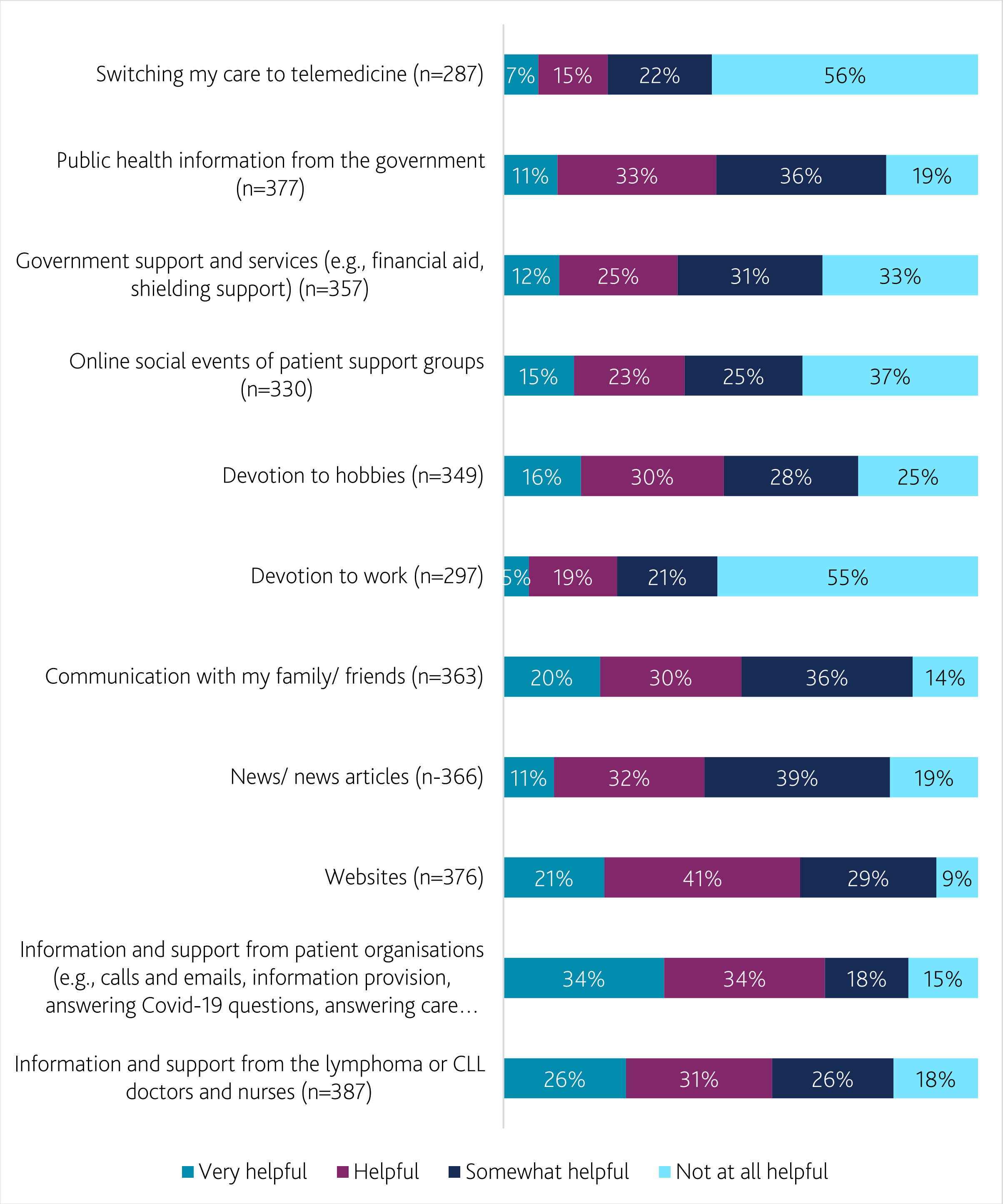


- Figure 80 shows that 88% of patients did not avoid or delay seeking medical attention for their lymphoma or CLL during the Covid-19 pandemic

Figure 80. Did you avoid or delay seeking medical attention for your lymphoma or CLL during the Covid-19 pandemic?

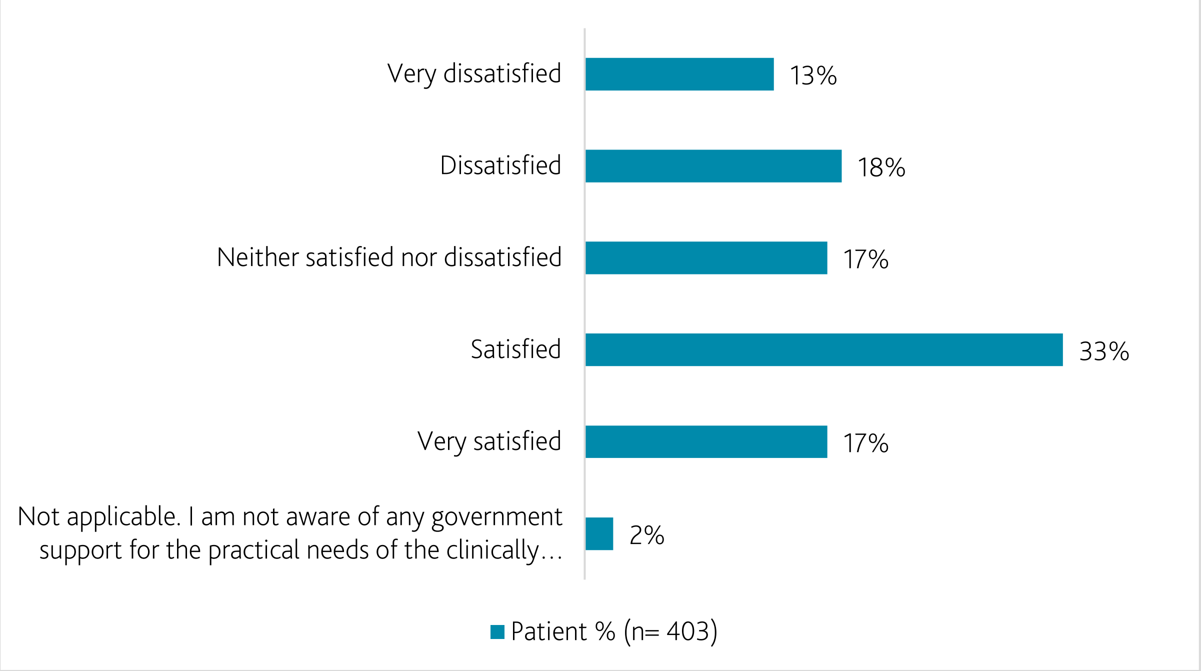
- Figure 81 illustrates that 56% of patients found that switching care to telemedicine was not helpful in providing support for lymphoma or CLL during the COVID-19 pandemic

Figure 81. Please indicate how helpful, if at all, the following have been in providing support regarding lymphoma or CLL and the impact of COVID-19 pandemic.



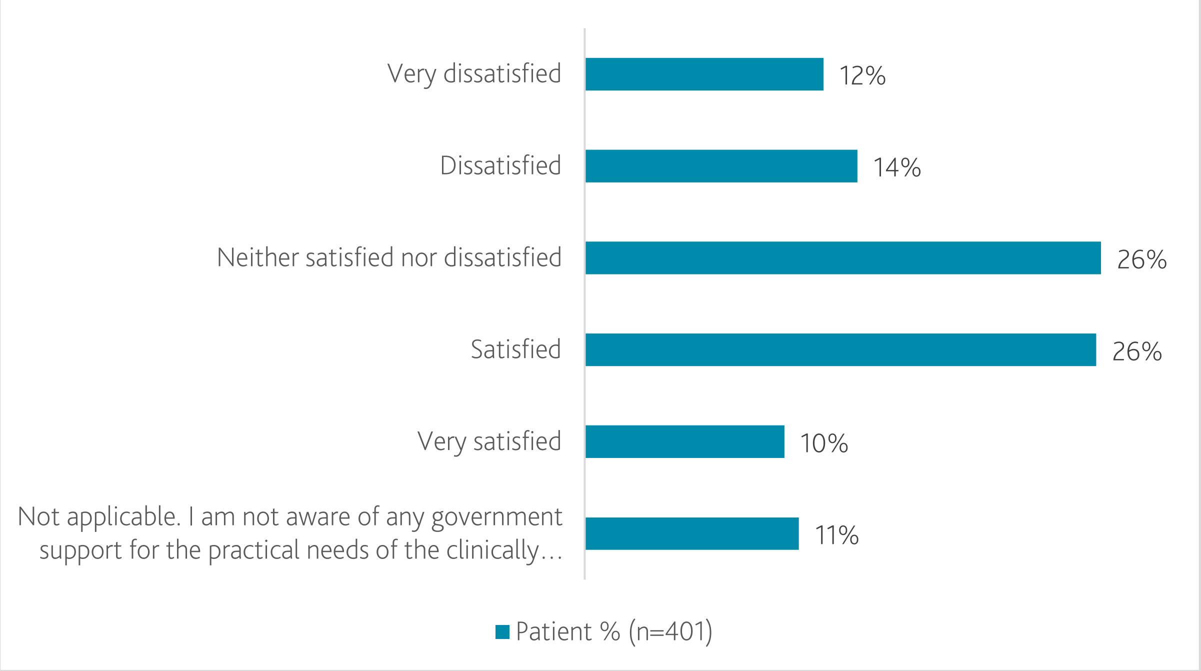
- Figure 82 shows half of patients were either satisfied or very satisfied with the information provided by the government during the pandemic.

Figure 82. How satisfied or dissatisfied are you with the information provided by the government for the clinically extremely vulnerable patients during the pandemic (e.g., information on how to manage your healthcare)?



- Figure 83 reveals a third of patients were either satisfied or very satisfied with the practical support provided by the government during the pandemic.

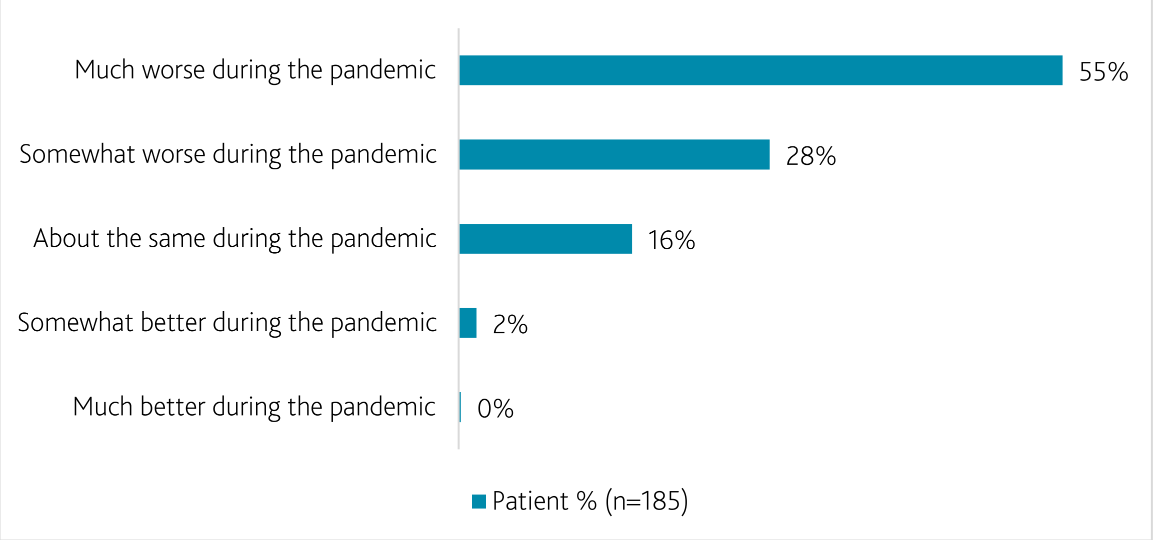
Figure 83. How satisfied or dissatisfied are you with the government's support for the practical needs of the clinically extremely vulnerable during the pandemic (e.g., furlough, supporting conversations with your employer)?



Patients who reported having anxiety (as a psychosocial issue) were asked how the Covid-19 pandemic affected their anxiety level.

- Figure 84 reveals that 55% of patients felt that their level of anxiety was much worse during the pandemic compared to before the pandemic. Only asked to those who indicated they had anxiety.

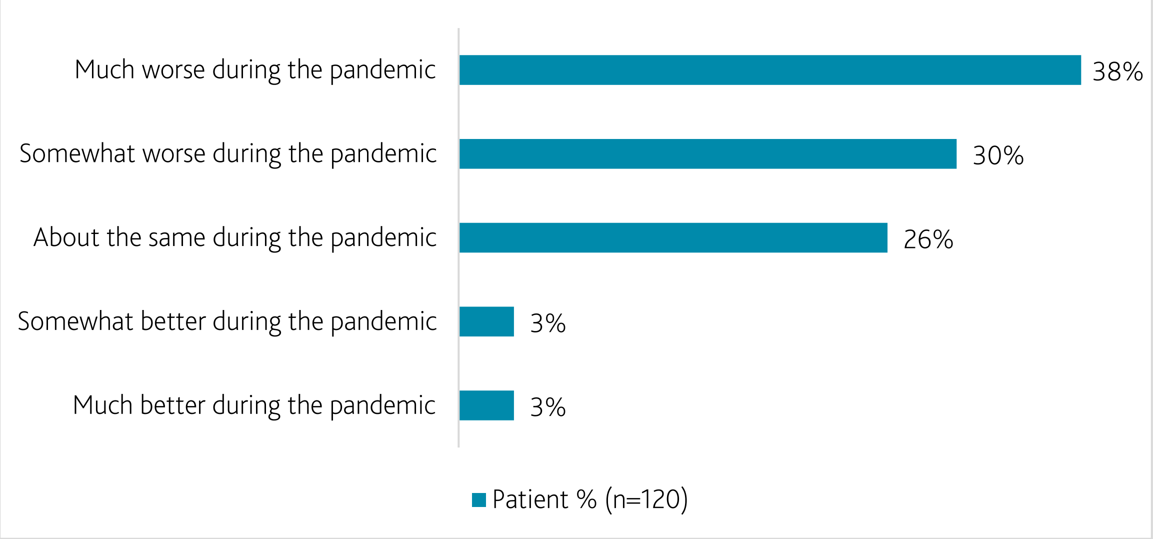
Figure 84. Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.



Patients who reported that they had experienced depression (as a psychosocial issue) were also asked how the Covid-19 pandemic affected their level of depression.

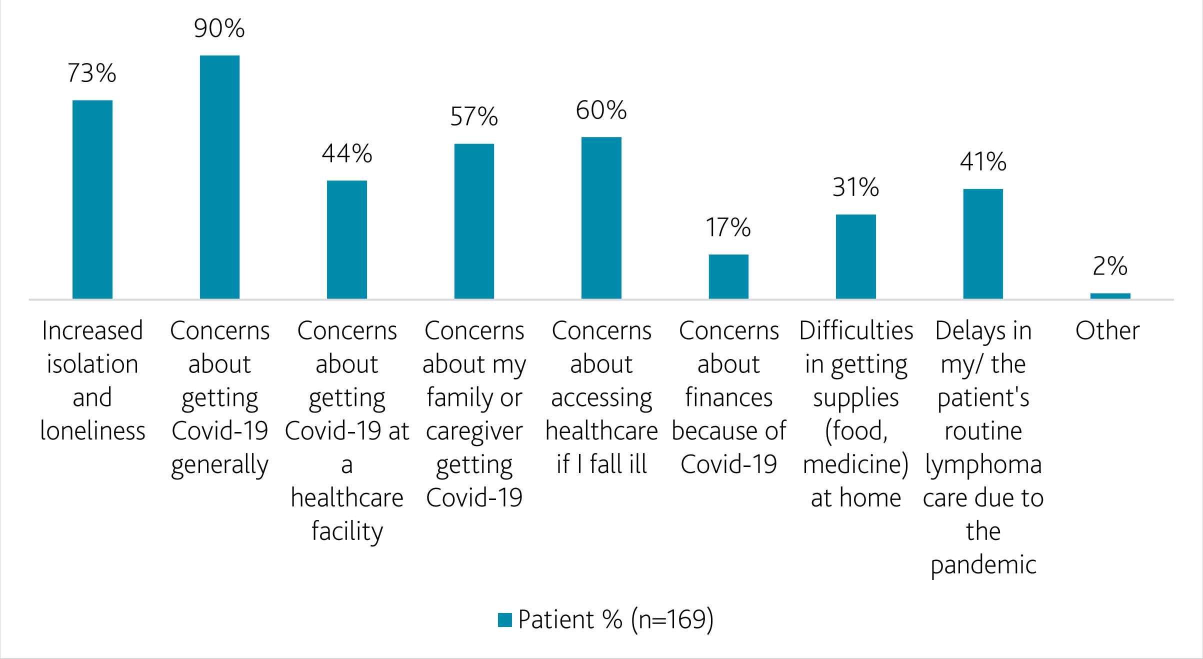
- Figure 85 illustrates that 38% of patients felt that their level of depression during the COVID-19 pandemic was much worse compared to before the COVID-19 pandemic. Only asked to those who indicated they had depression.

Figure 85. Please describe your level of depression during the COVID-19 pandemic, compared to your level of depression before the COVID-19 pandemic.



- Figure 86 illustrates 90% of patients felt their concerns about getting Covid-19 in general was contributing to their worsened level of anxiety and/or depression, followed closely by increased isolation and loneliness (73%). Only asked to those who said they had anxiety or depression that was worse during the pandemic.

Figure 86. Which of the following were contributing factors for the worsened anxiety and/ or depression?

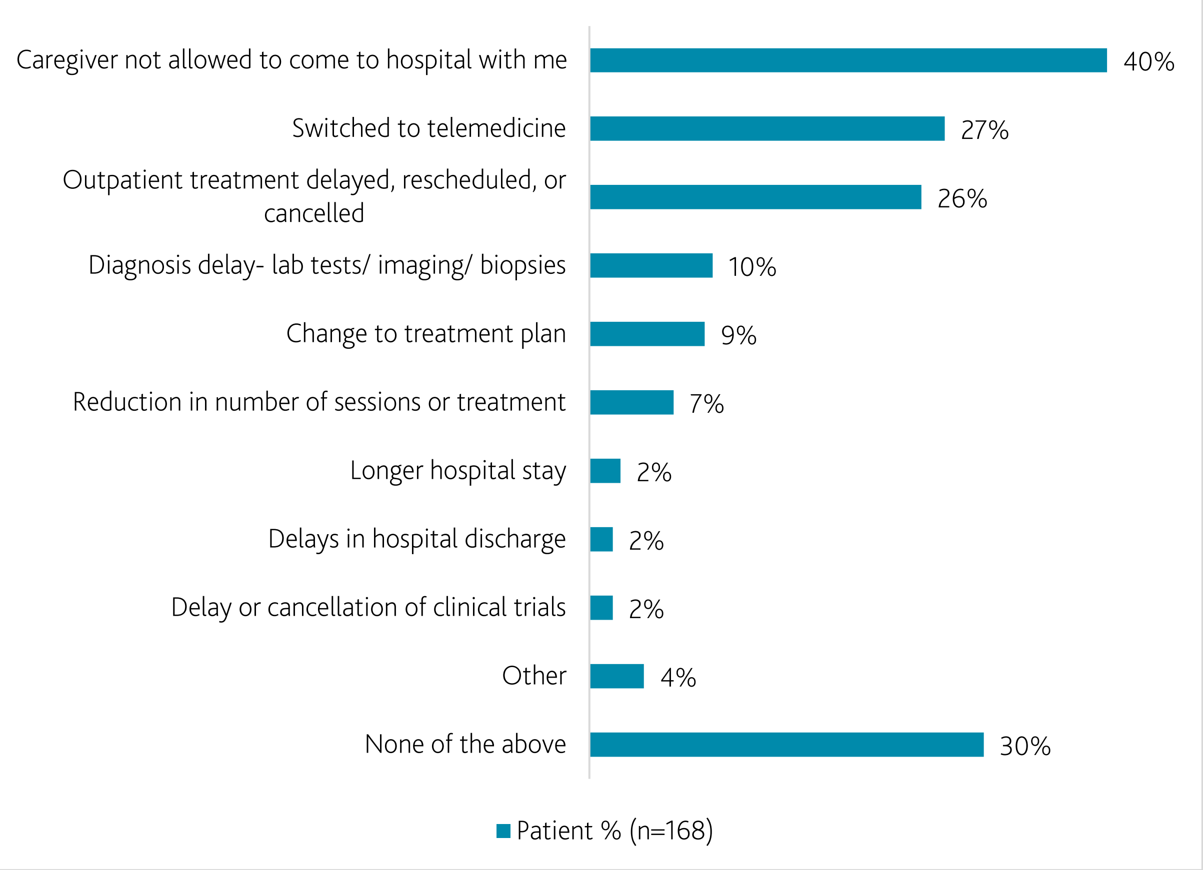


- Figure 87 shows that 58% of patients were not scheduled to receive treatment for lymphoma or CLL when Covid-19 restriction was an issue in their community

Figure 87. Were you scheduled to receive treatment for your lymphoma or CLL when Covid-19 restriction was an issue in your community?

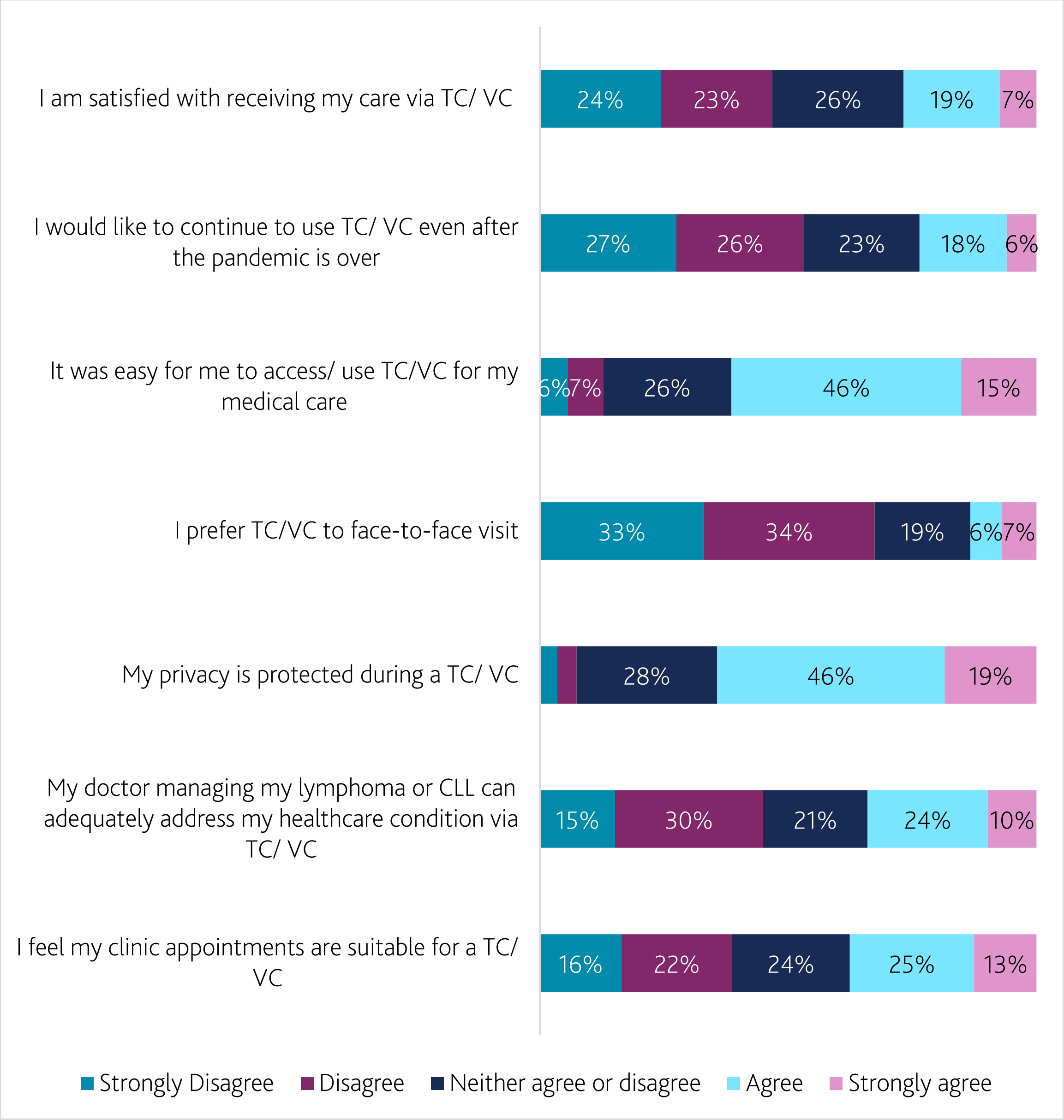
- **Figure 88 illustrates** 70% of patients experienced changes to care due to the COVID-19 restrictions. 40% of patients reported that their caregivers were not allowed to come into the hospital with them, while 26% had their outpatient treatment delayed, rescheduled, or cancelled. 7% of the patients experienced a reduction in their treatment sessions. 27% of patients had their care switched to telemedicine. Only asked to those who received treatment during Covid-19 restriction in their community.

Figure 88. Did you experience any of the following changes to your care due to Covid-19?



- Figure 89 shows that 65% of patients agree that their privacy was protected during a telephone consultation or video consultation but 67% prefer face-to-face consultations. Only asked to those who reported that their care had switched to telemedicine (use of telephone consultation (TC) or video consultation (VC)) were asked about their experience.

Figure 89. Regarding your use of telemedicine (Telephone consultation (TC) or video consultation (VC)), how much do you agree or disagree with the following statements?



Caregiver Results

Family and informal caregivers (known here as caregivers) are unpaid care providers giving support to lymphoma patients. The support they provide can be substantial in scope, intensity and duration and considered an extension of the patient's healthcare team. However, given that most caregivers did not plan to be in their circumstances or trained to provide support, they may feel unequipped or unsupported.

54 was the total number of people caring for patients living with lymphoma/CLL who responded to the survey. The results in this section will be reported across the following areas:

- ✓ Caregiver characteristics
- ✓ Caregiver healthcare information experience,
- ✓ Healthcare decision-making
- ✓ Impact of COVID-19 on healthcare experience

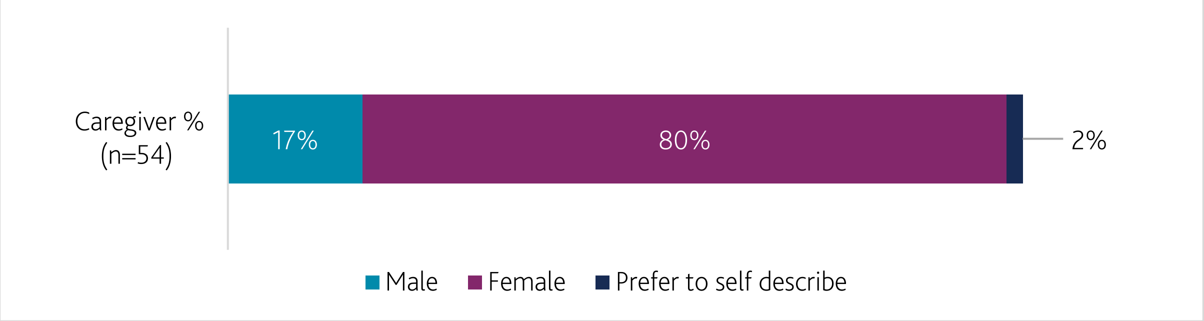
Data is only shared for questions where there were at least 20 responses to the question.

Caregiver Characteristics

- 54 carers responded to the survey, with 63% of the respondents residing in suburban or residential areas. Most carers (80%) were female.
- 85% of all carers are providing support to their spouse / partner.

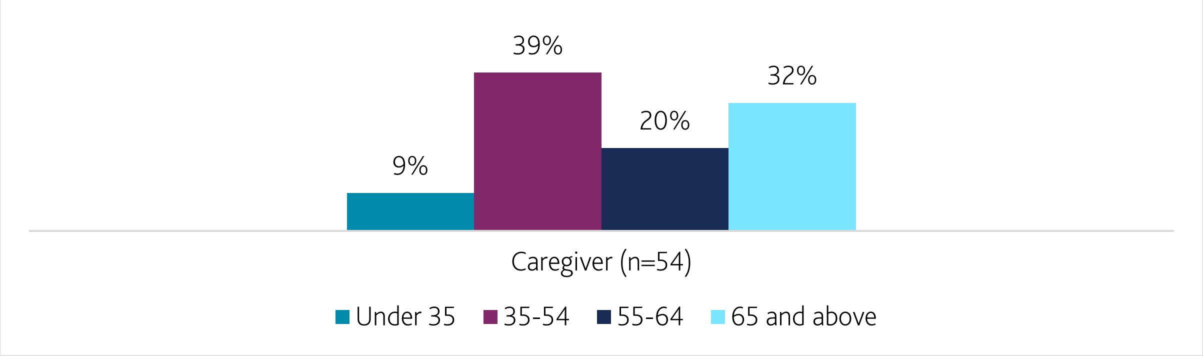
❖ Figure 90 explains the majority of carer respondents are female

Figure 90. Gender of the caregiver



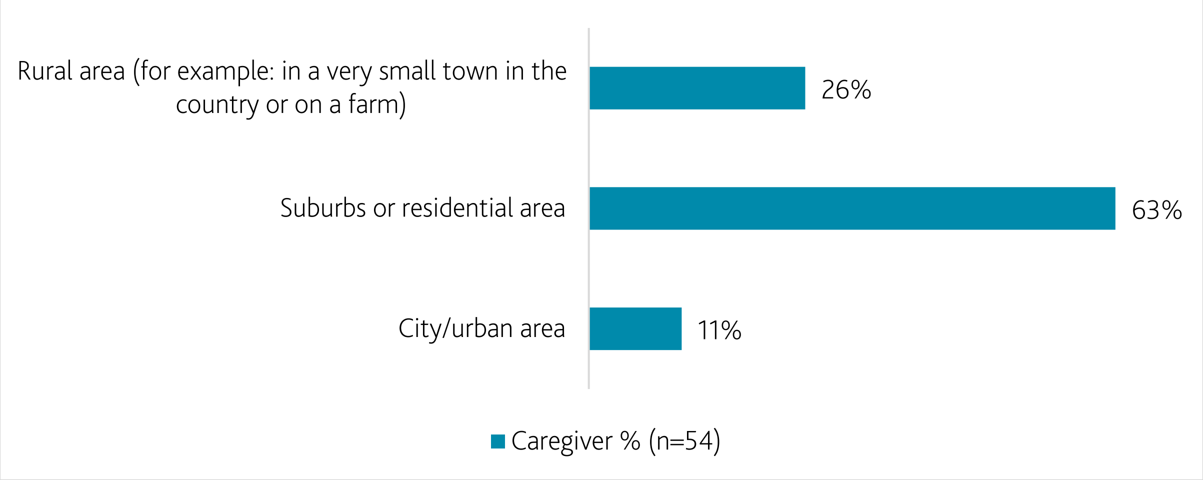
- Figure 91 illustrates that just over a third of caregivers are between the ages of 35 to 54, with another third aged 65 and older

Figure 91. Age range of caregivers



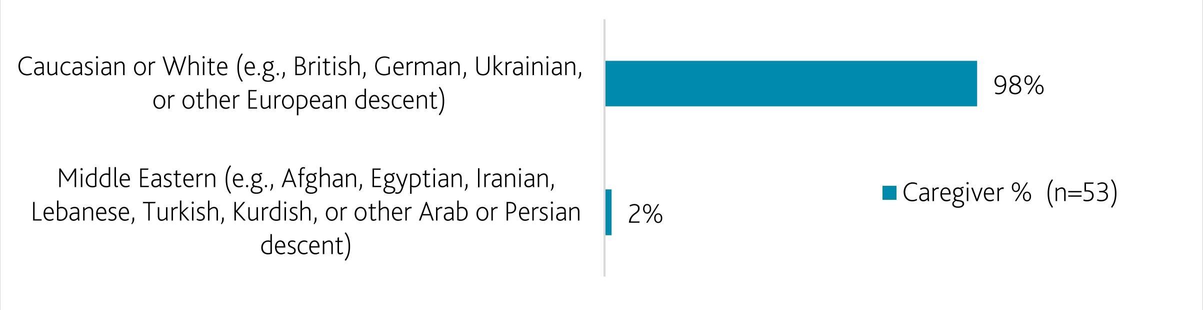
- Figure 92 illustrates that almost two-thirds of carers live in the suburbs or a residential area

Figure 92. Which best describes the area you live in?



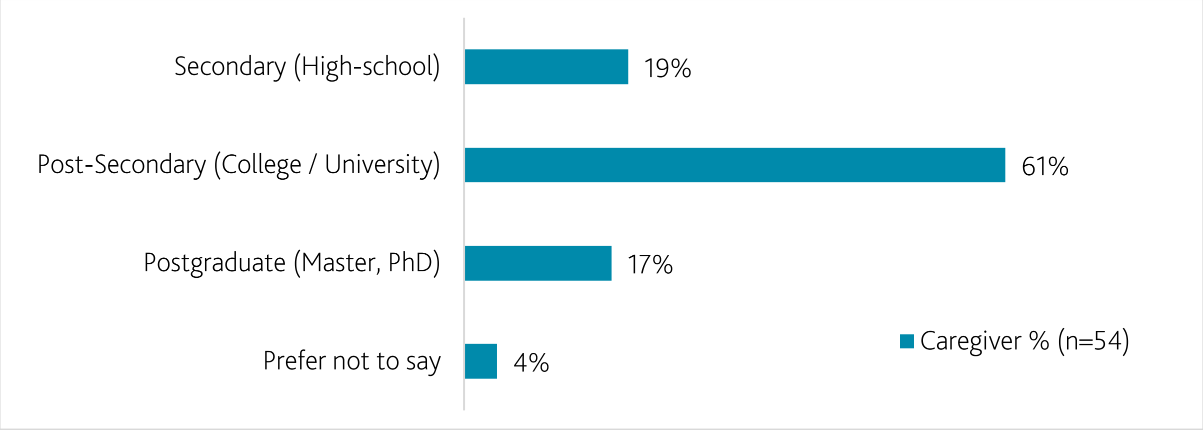
- Figure 93 shows that almost all carers are Caucasian

Figure 93. How do you identify your ethnicity?



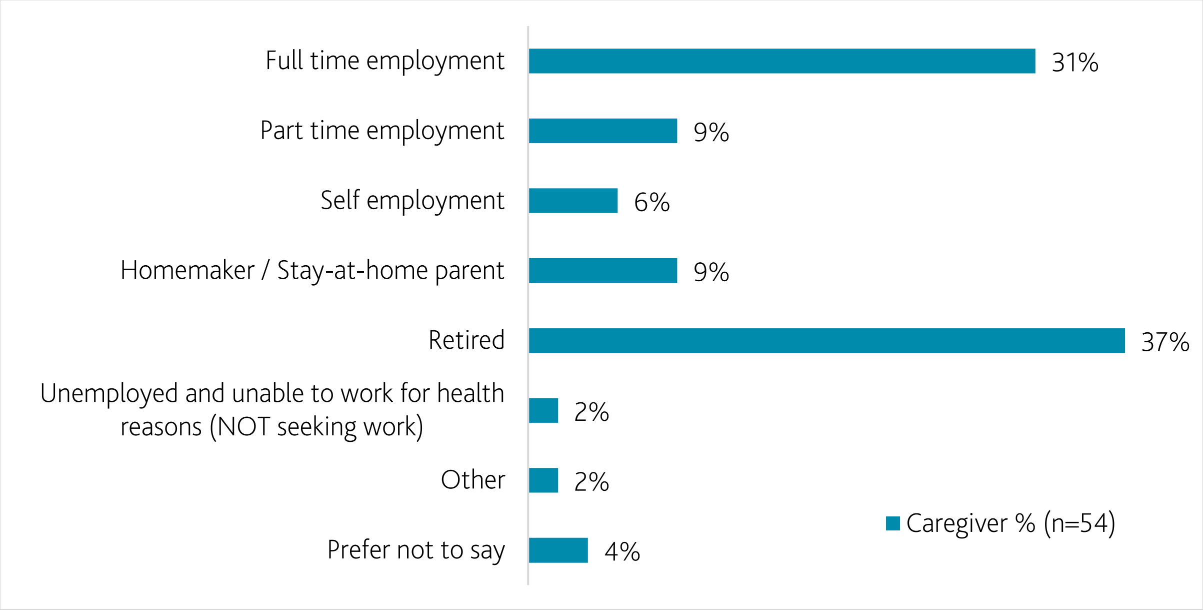
- Figure 94 reveals that 78% of carers have completed a post-secondary or postgraduate education

Figure 94. What is your highest educational level completed?



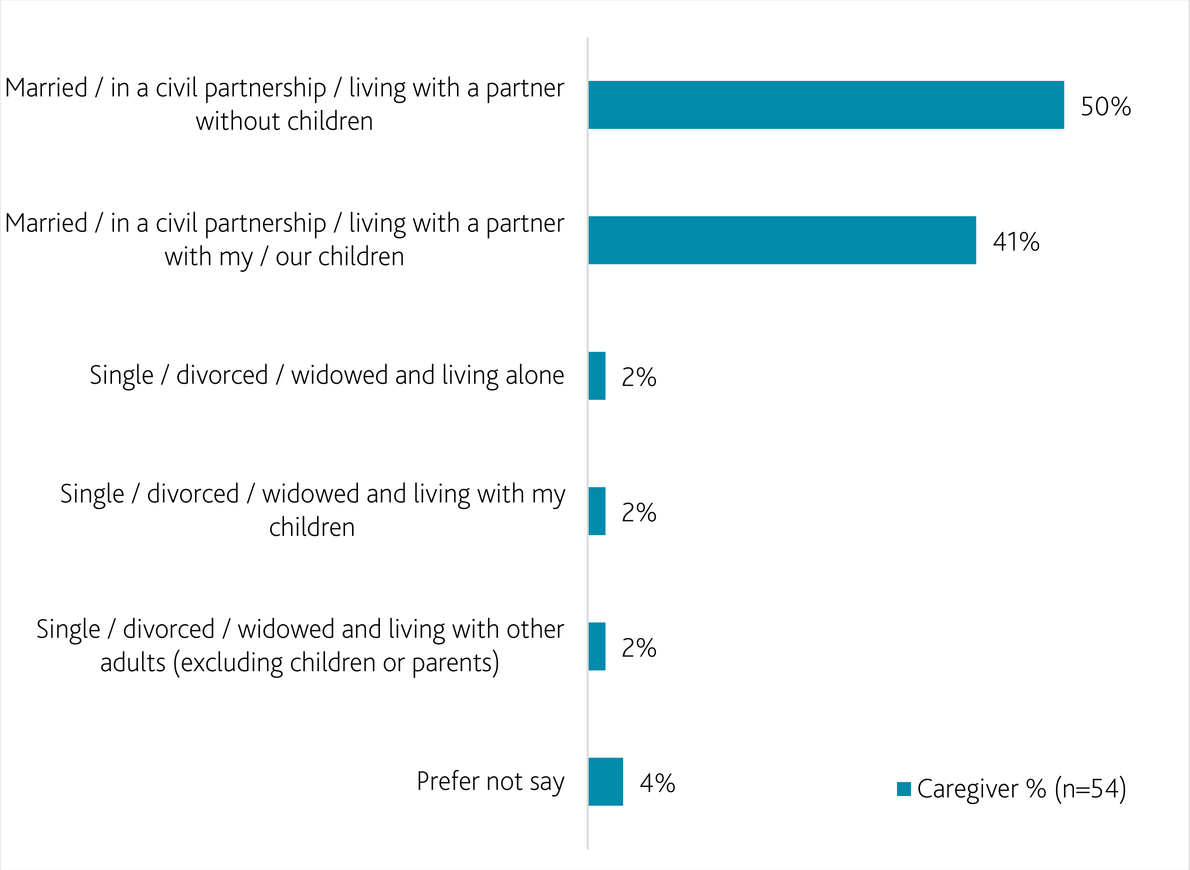
- Figure 95 illustrates that over a third of carers are retired

Figure 95. Which of the following best describes your employment status?



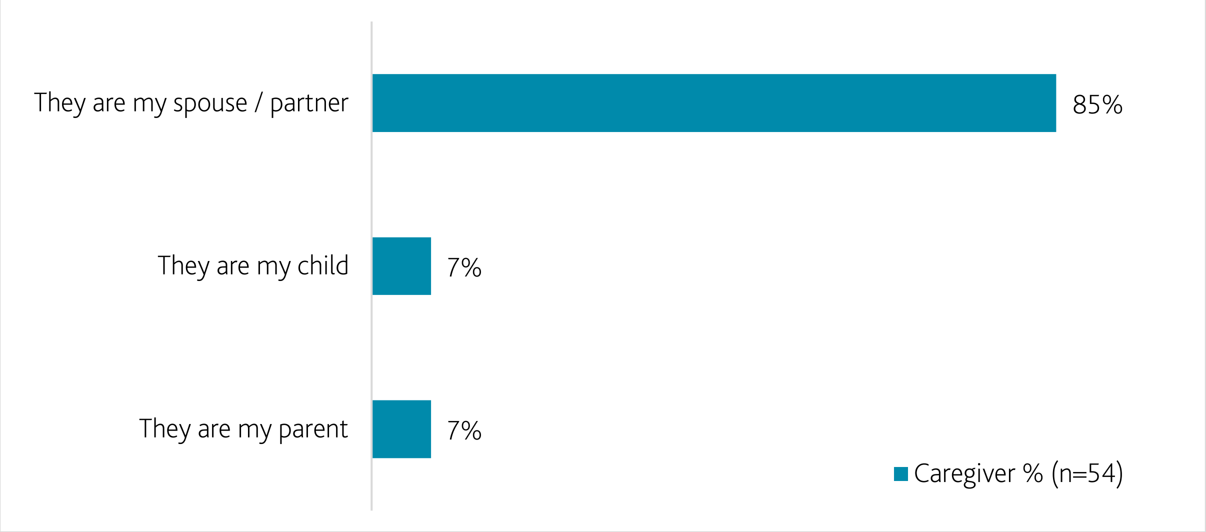
- Figure 96 reveals that 90% of carers live with a partner, 50% without children and 41% with children

Figure 96. Which of the following best describes your household status?



- Figure 97 illustrates most carers are providing care and support to their spouse/partner

Figure 97. What is your relationship to the person you are providing care and support to?

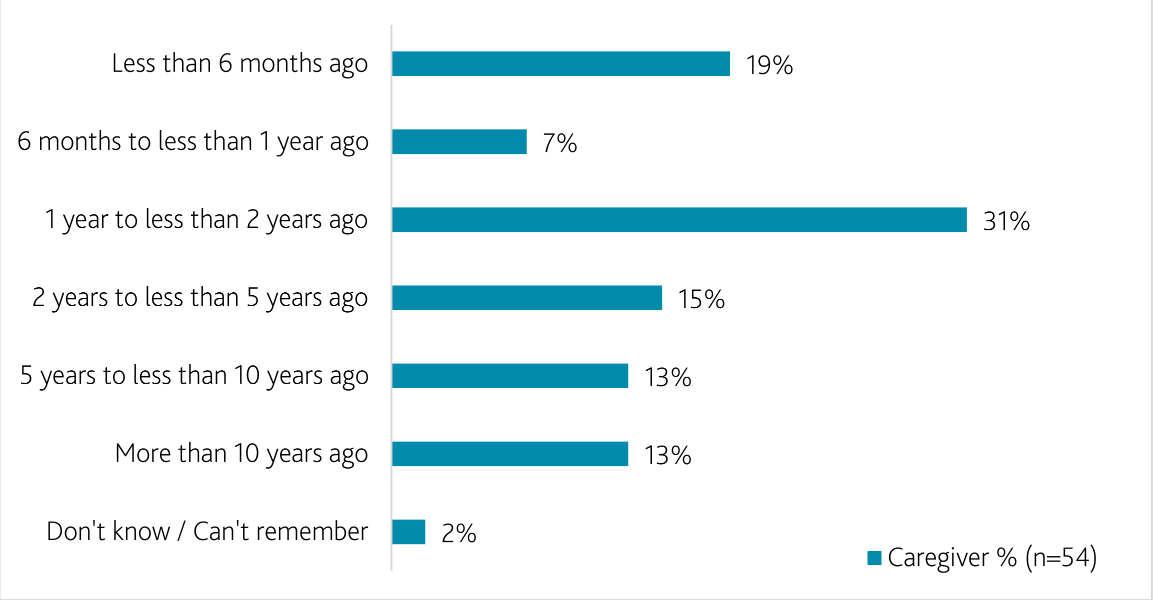


Diagnostic Demographics

- More than half have been providing support for less than 2 years.
- Most carers reported they were providing care for patients with Diffuse Large B-Cell Lymphoma (22%), followed by other aggressive lymphomas (15%).

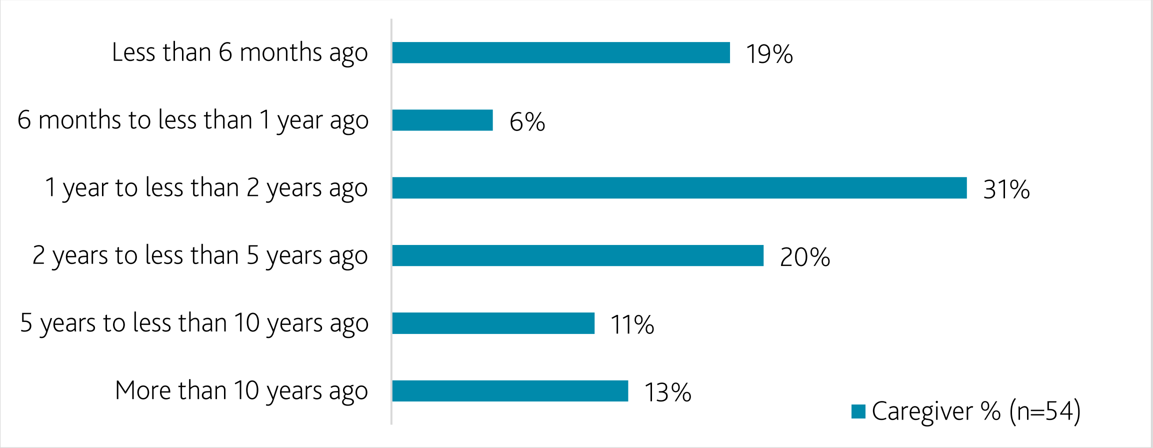
❖ Figure 98 reports that 57% of carers have patients that have been diagnosed with lymphoma or CLL within the last 2 years

Figure 98. How long ago were you / the patient diagnosed with lymphoma or CLL?



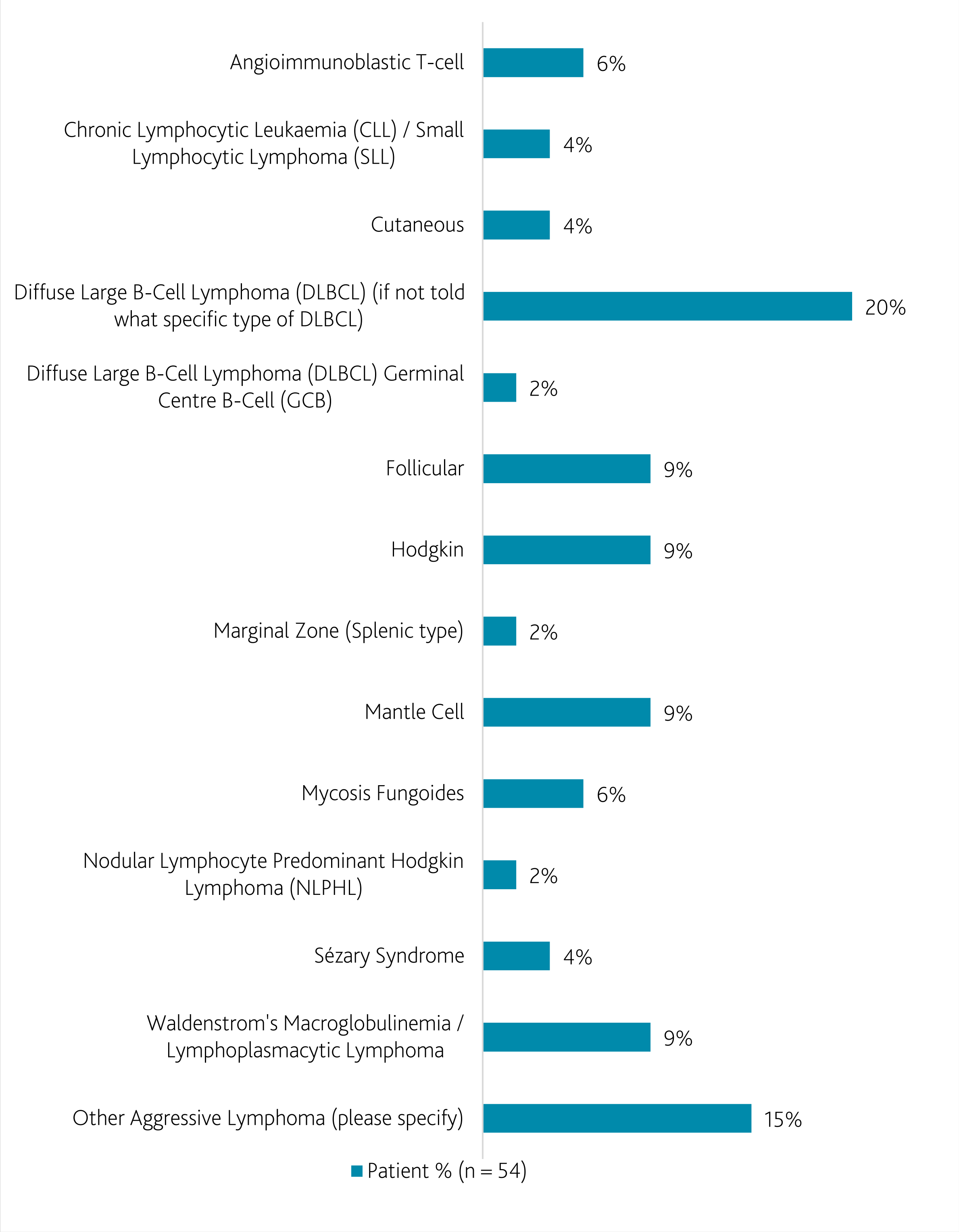
❖ Figure 99 illustrates that about a third of caregivers have been providing cancer-related care and support for between 1 to 2 years

Figure 99. How long have you been providing cancer-related care and support to the person with lymphoma or CLL?



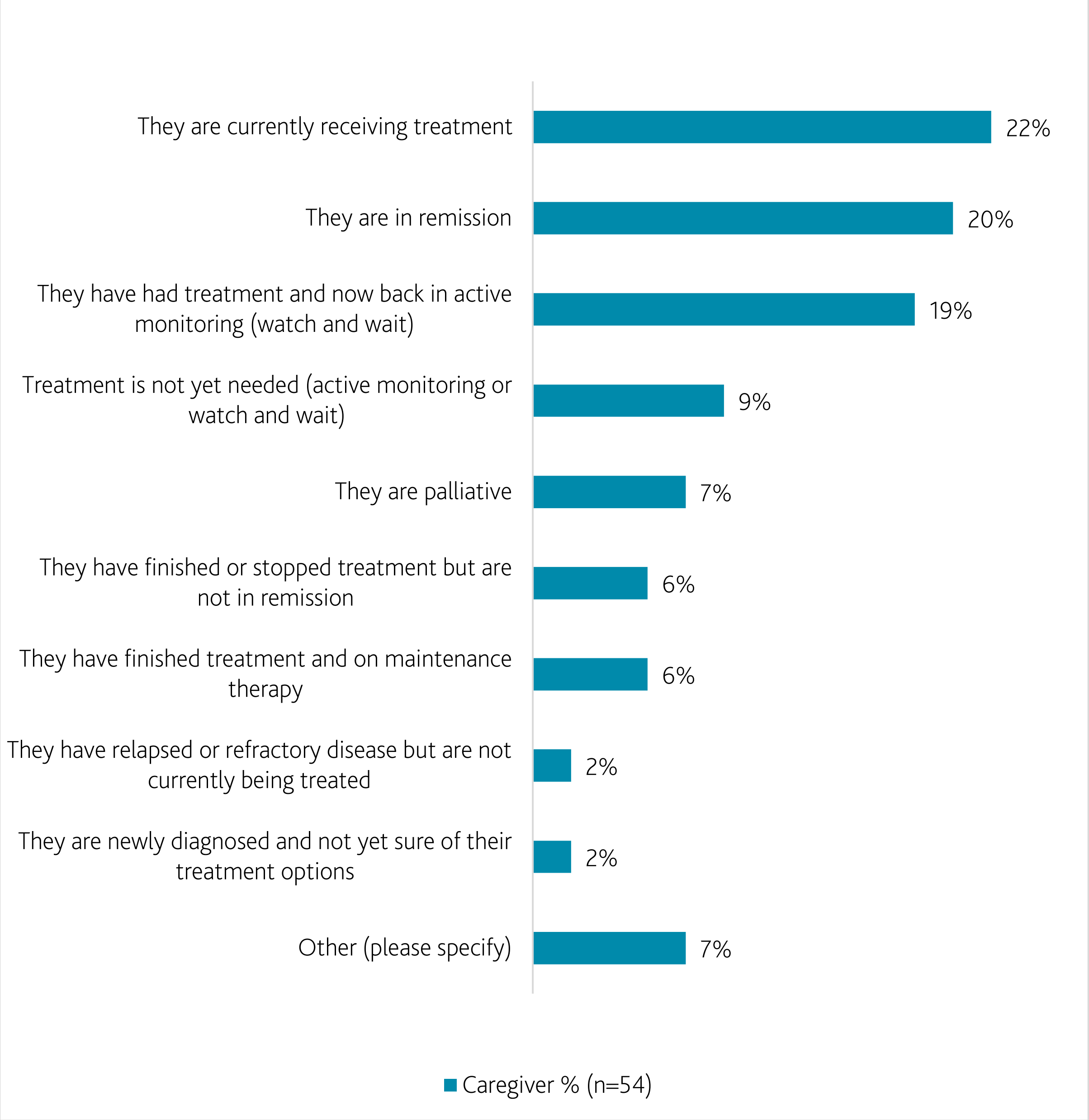
- Figure 100 illustrates that 22% of carer's patients have diffuse large B-cell lymphoma (DLBCL)

Figure 100. What subtype of lymphoma do you have / does the patient have?



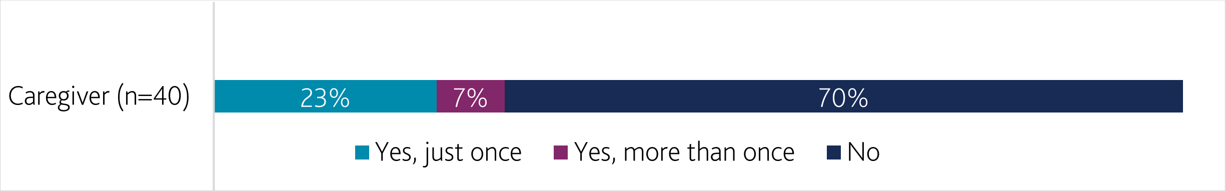
- Figure 101 shows that 22% of carers are caring for patients that are currently receiving treatment, with another 45% caring for patients whose treatment has stopped (with a variety of outcomes).

Figure 101. What statement best describes where the person you care for is in the lymphoma or CLL experience?



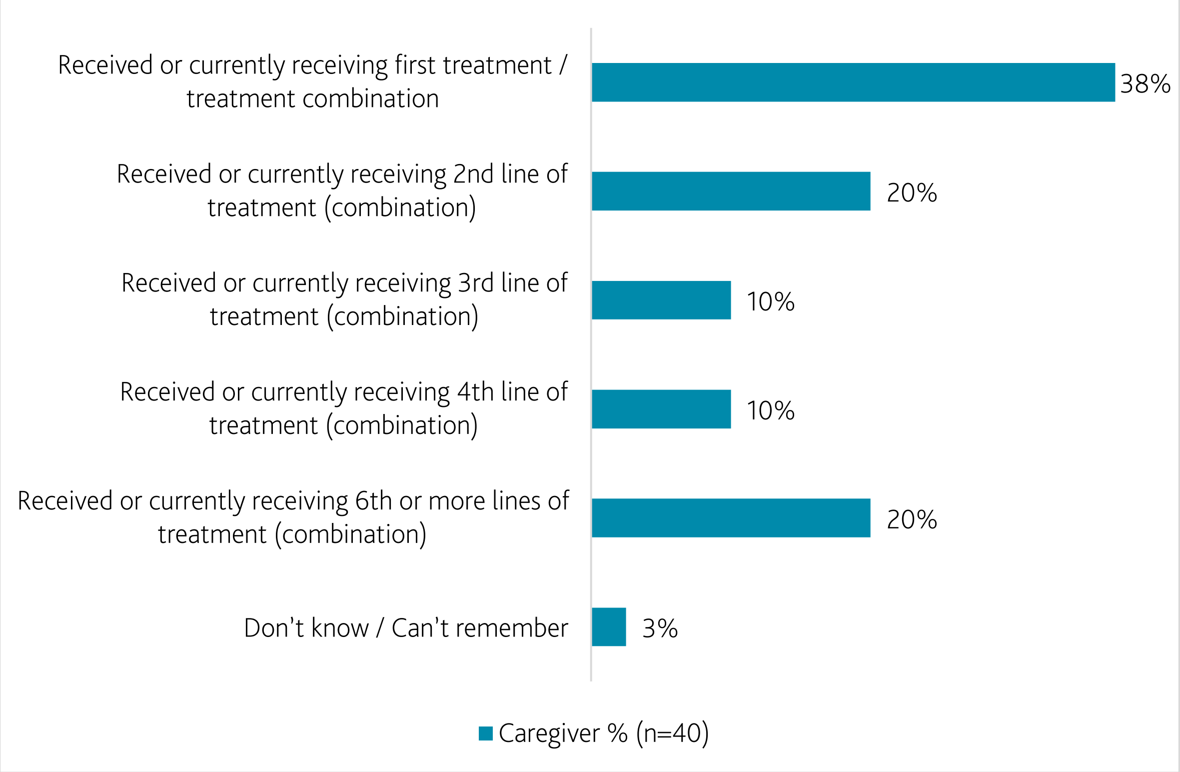
- Figure 102 points out that most carer's patients have not had their lymphoma or CLL relapse. Only asked to caregivers who said their patient had received treatment.

Figure 102. Has the lymphoma or CLL ever relapsed?



- Figure 103 illustrates that 38% of caregivers report that their patient has received their first treatment/treatment combination. Only asked to caregivers who said their patient had received treatment.

Figure 103. How many lines of treatment have you/the patient received to date for lymphoma?



- Figure 104 shows that most have patients whose lymphoma or CLL has not transformed

Figure 104. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?

Healthcare Information

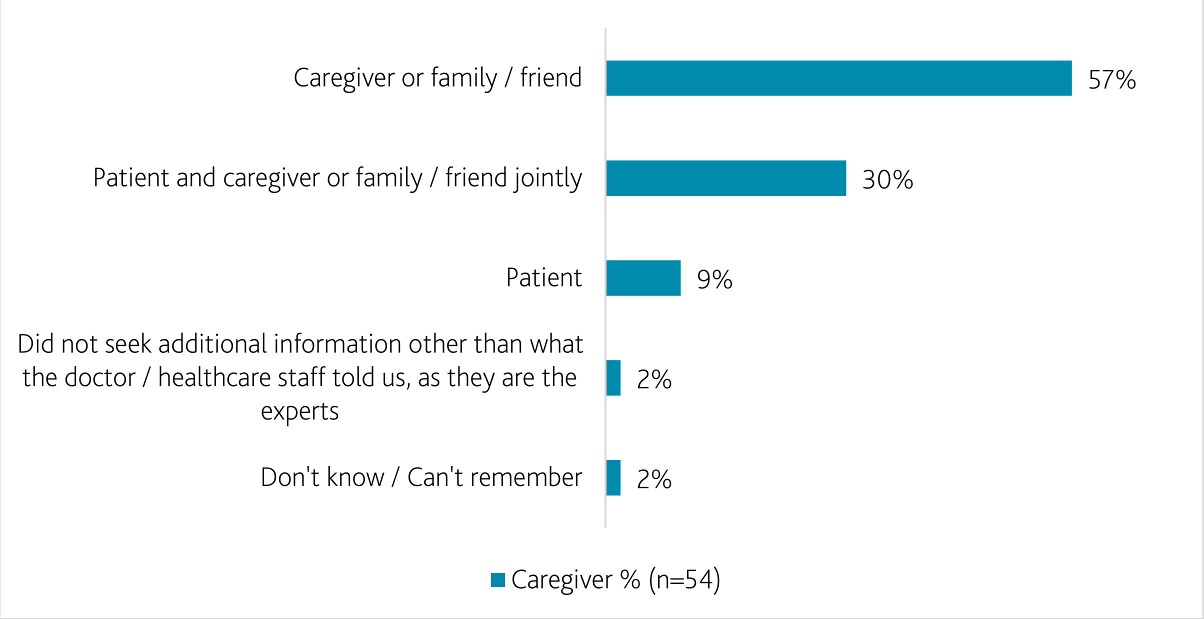
- Over half of carers (57%) stated that they were seeking out information and details about the disease and potential treatment options by themselves, following the patient's lymphoma or CLL diagnosis.

- 54% of carers reported being well informed, or very well informed about the processes and stages of the patient's healthcare.

- Carers preferred methods of getting information on lymphoma and CLL are websites (65%), followed by booklets or written information, and then oral information from healthcare providers (54%).

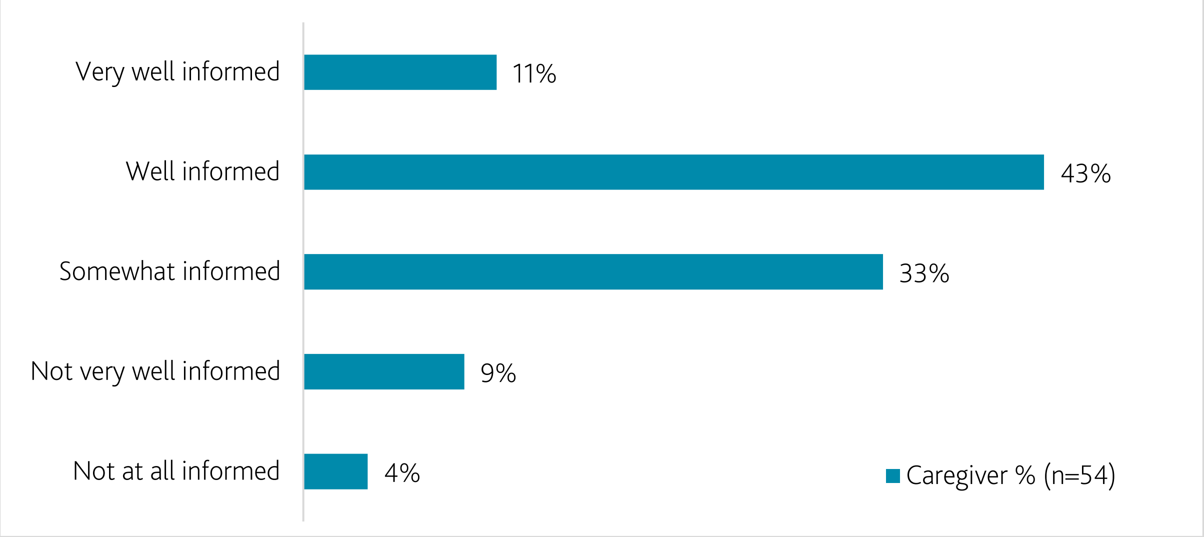
❖ Figure 105 describes that 87% of caregivers were seeking out information and details about the disease and potential treatments, either alone or with the patient.

Figure 105. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



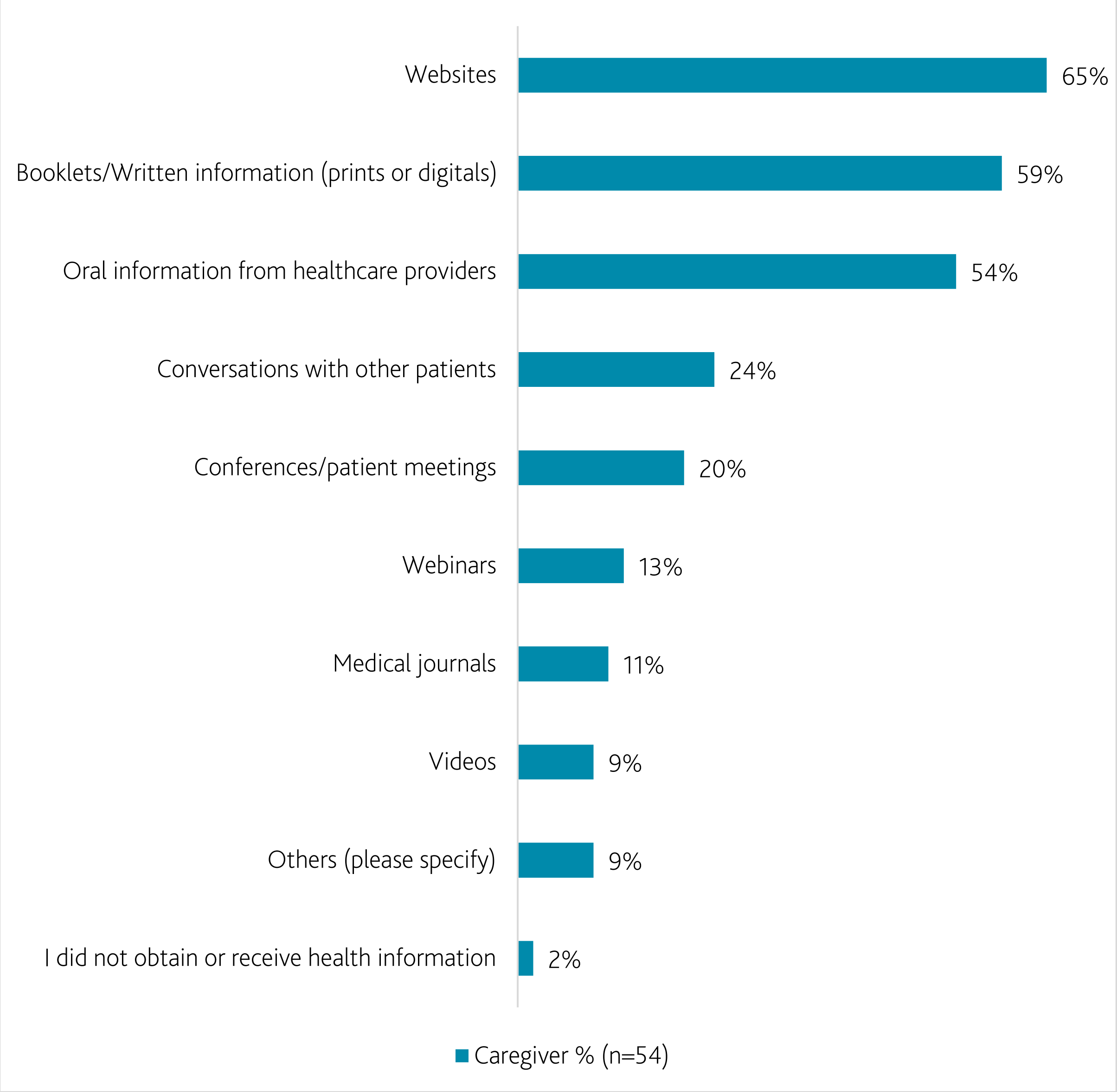
- Figure 106 reveals that 13% of carers felt not very well informed or not informed at all about the processes and stages of their patient's healthcare

Figure 106. How informed have you felt about the processes and stages of your/ the patient's healthcare (e.g., diagnosis, treatment, resources available for support and self-care) throughout your experience with lymphoma or CLL?



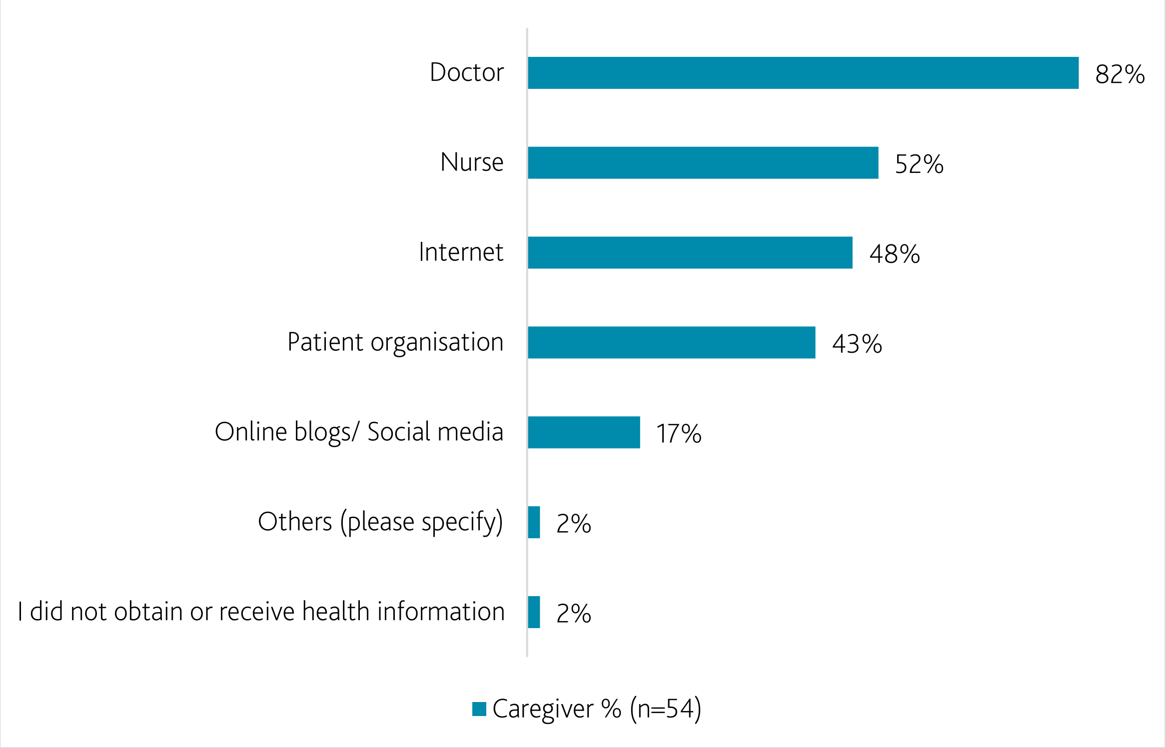
- Figure 107 explains that 65% of caregivers prefer websites as their method for obtaining or receiving health information about lymphoma or CLL, followed by written materials (59%) and oral information from healthcare providers (54%)

Figure 107. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



- Figure 108 reveals that 82% of carers prefer doctors as their source of lymphoma or CLL information, followed by nurses (52%) and the internet (48%)

Figure 108. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?



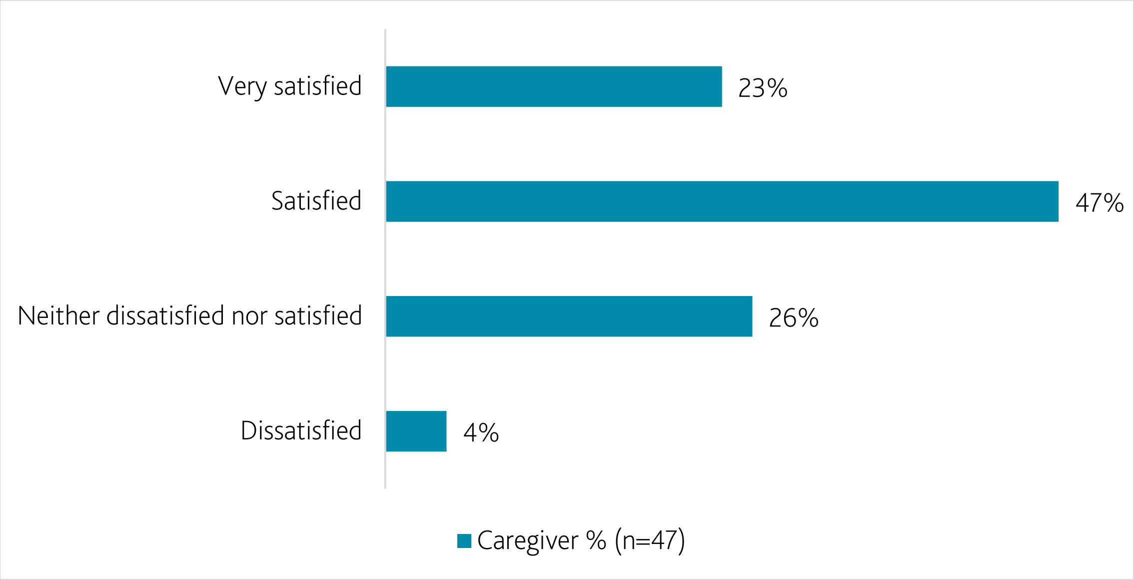
- Table 5 illustrates that 51% of caregivers rank doctors as their number 1 source of lymphoma or CLL information

Table 5. Rank your top three sources of lymphoma or CLL information that you most prefer.

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	15	**56%**	2	7%	7	27%
Nurse	1	4%	12	**44%**	4	15%
Internet	6	22%	7	26%	8	**31%**
Online blogs/ social media	1	4%	1	4%	4	15%
Family/friends	0	0%	0	0%	0	0%
Patient organisation	4	15%	5	19%	3	12%
Others (please specify)	0	0%	0	0%	0	0%
Total	27	100%	27	100%	26	100%

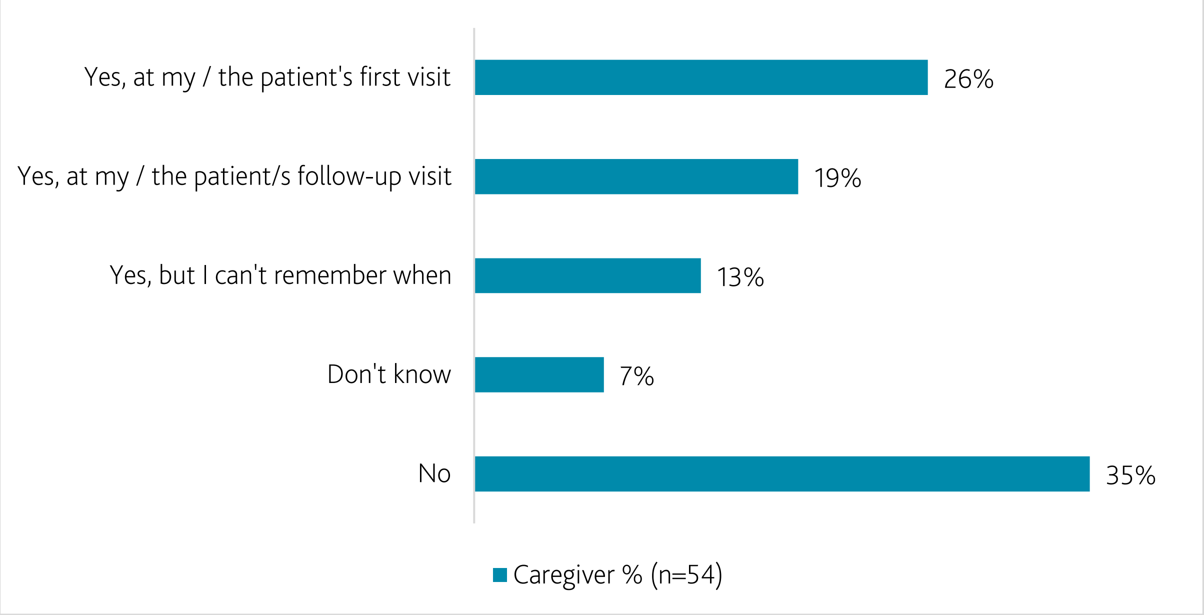
- Figure 109 shows that 70% of carers are satisfied or very satisfied with the information given to them by healthcare providers. Only asked to those who indicated doctors as an information source.

Figure 109. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, and nurses)?



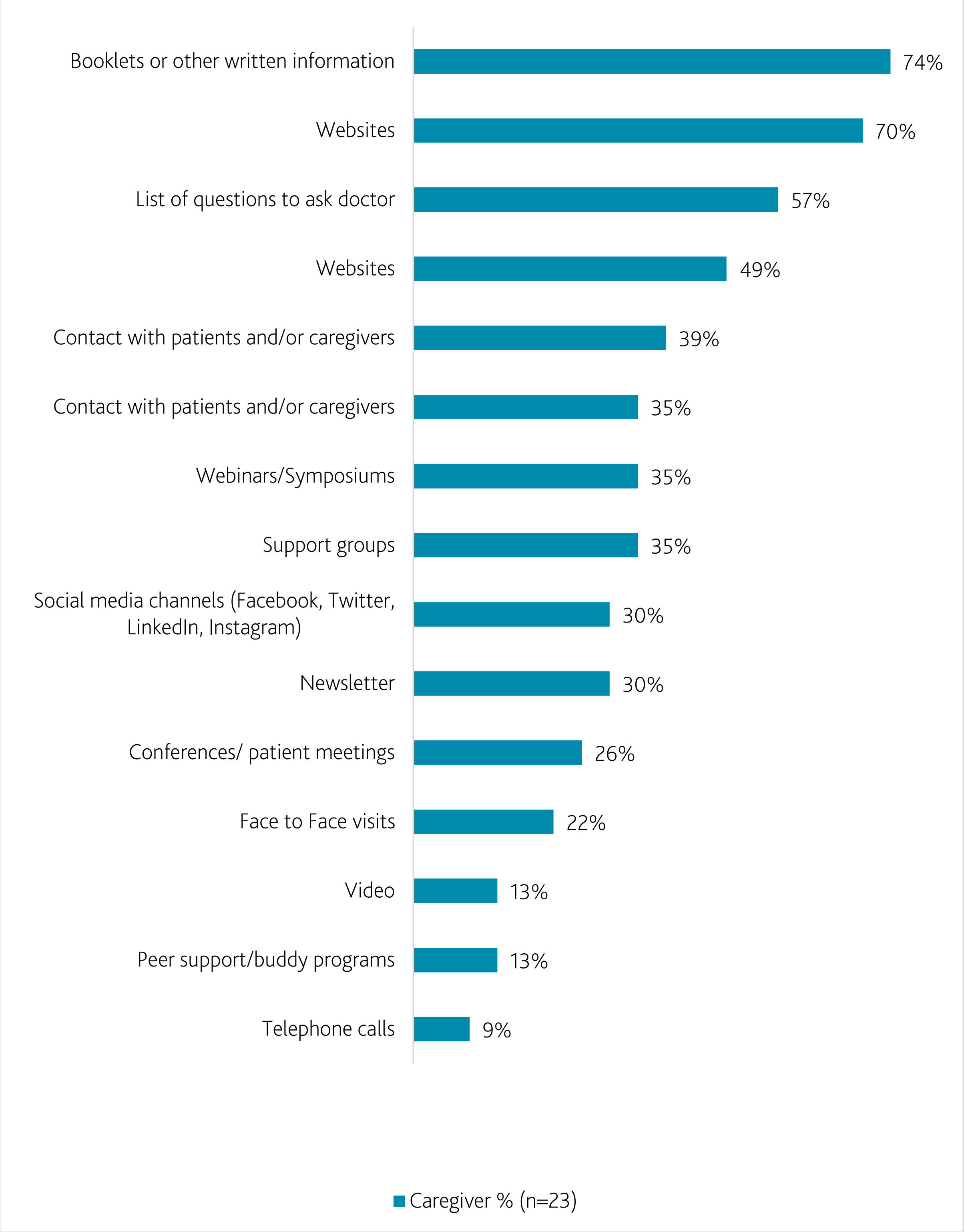
- Figure 110 reports that about a third (35%) of carers did not receive contact details or information concerning patient organisations from their medical team

Figure 110. Did the lymphoma or CLL doctor or any member of the medical team give you the contact details of a patient organisation, a support group and/or information produced by a patient organisation?



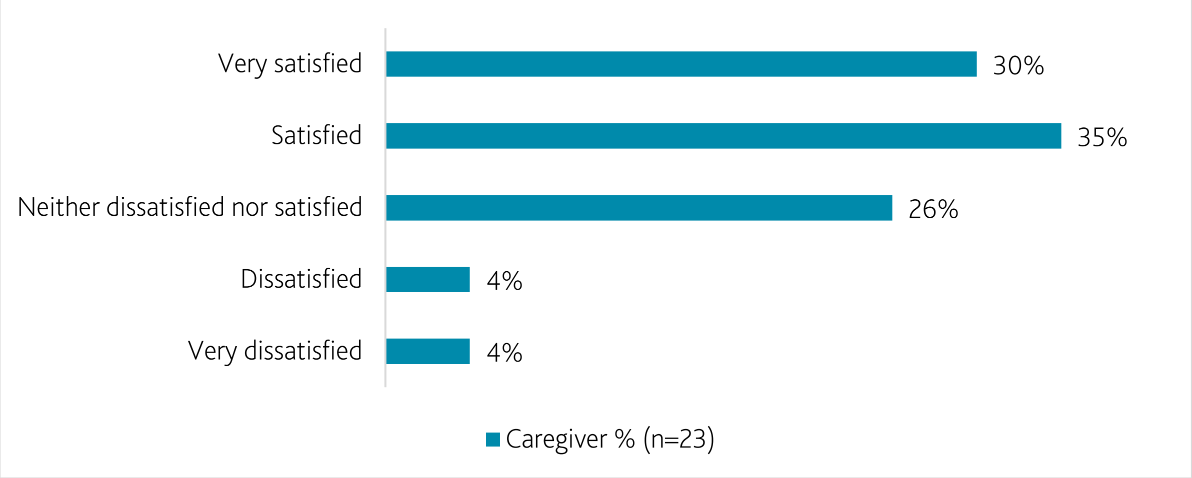
- Figure 111 reveals that three-quarters of carers prefer booklets or written information, followed closely by websites (70%) from patient organisations. Only asked to those who selected patient organisations as a preferred source of information.

Figure 111. What type of patient organisation information do you use (ranked sources)?



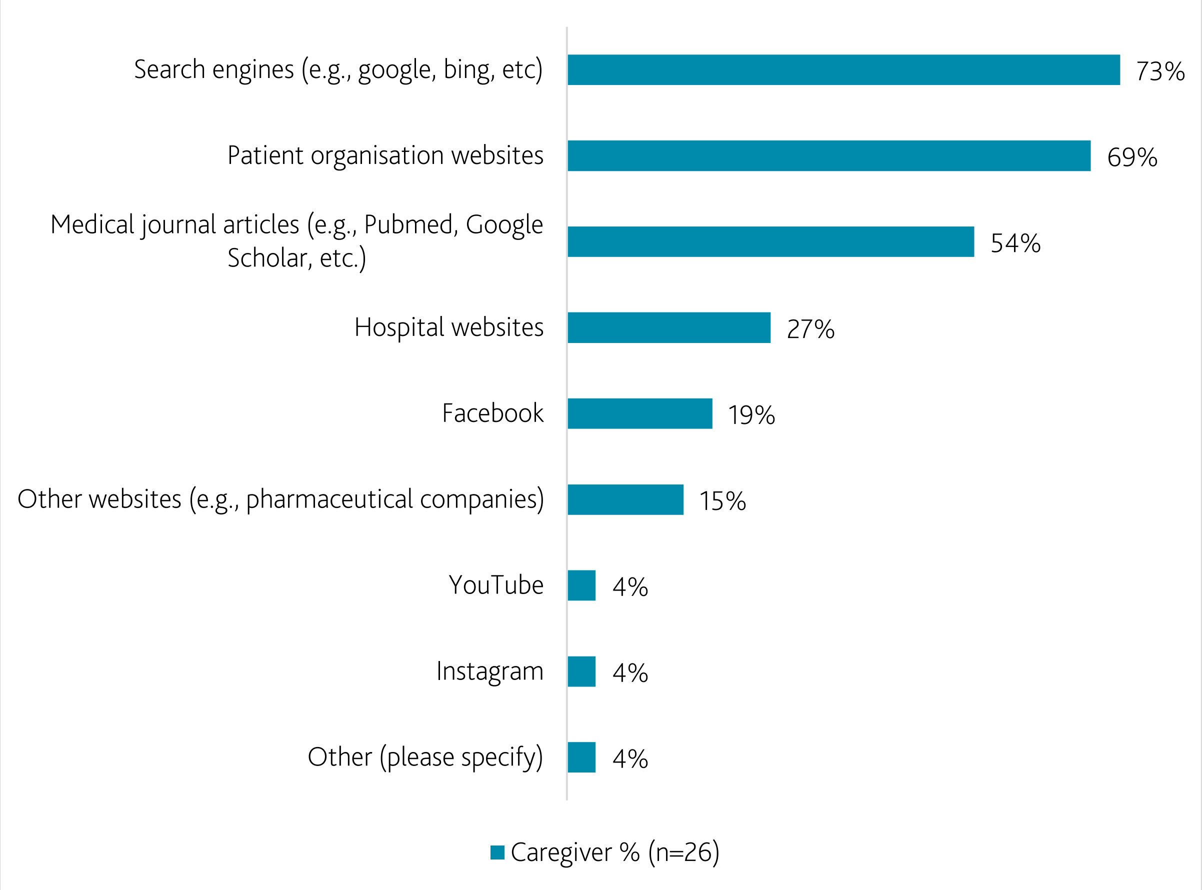
- Figure 112 illustrates that 65% of carers are satisfied or very satisfied with the information provided by patient organisations. Only asked to those who selected patient organisations as a preferred source of information.

Figure 112. How satisfied or unsatisfied are you with the information given to you by patient organisations?



- Figure 113 reveals that 73% of carers use search engines on the internet to get lymphoma or CLL information, followed by patient organisation websites (69%). Only asked to those who selected the internet as a preferred source of information.

Figure 113. Where on the internet do you usually get your lymphoma or CLL information from?

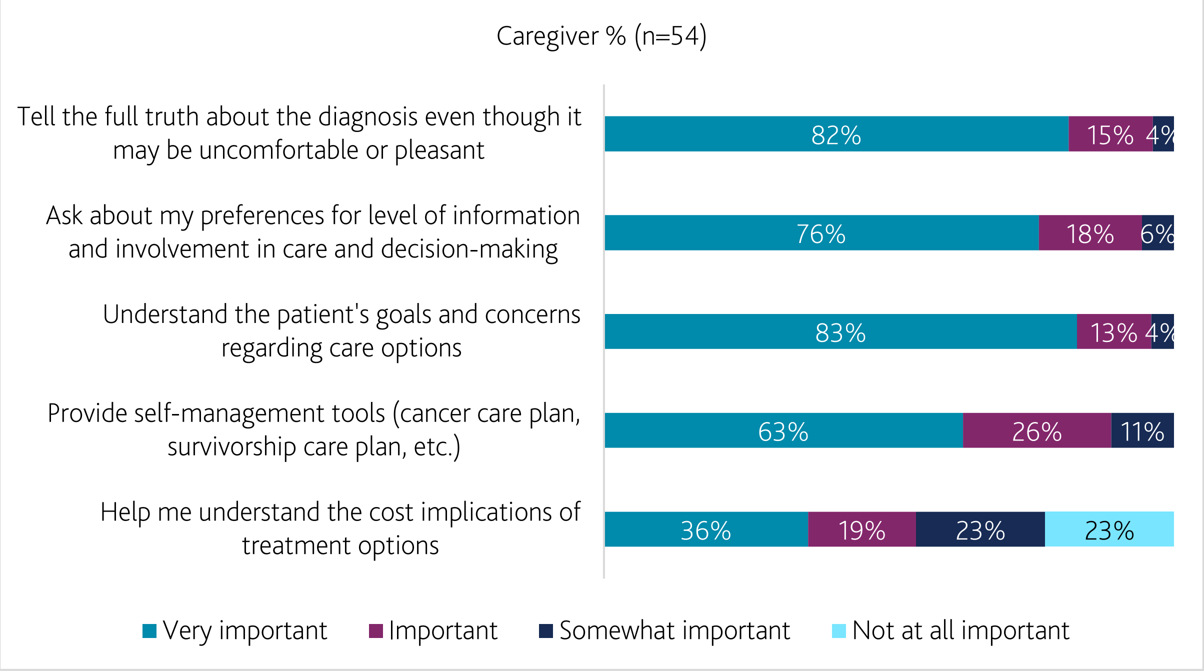


Healthcare Involvement and Decision Making

- For 82% of carers, it is important or very important that the lymphoma doctor tell them the full truth about the diagnosis even though it may be uncomfortable or unpleasant.
- For 83% of caregivers, it is important or very important that doctors ask them about their preferences for their level of information and involvement in care and decision making.
- 59% of carers think that doctors, patients and caregiver or family should be jointly involved the final decision about a patient's healthcare.

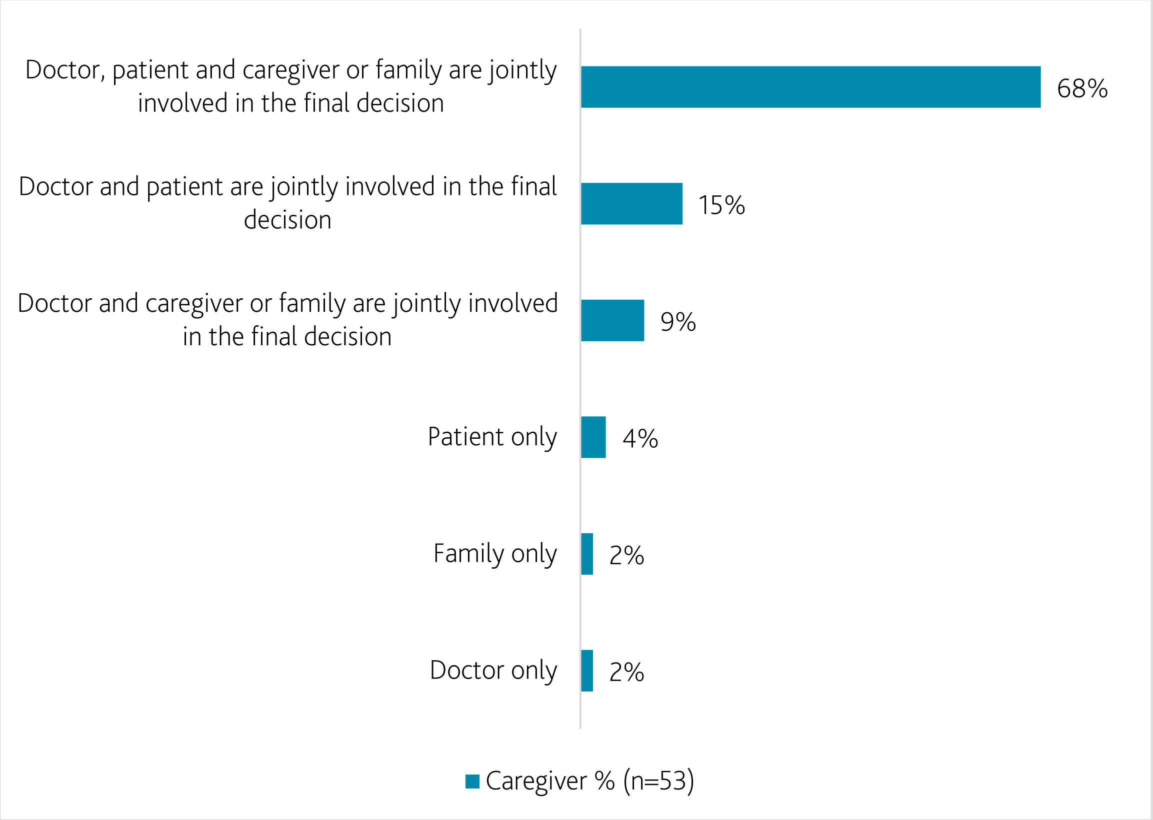
❖ Figure 114 reveals that 69% of carers felt that it is very important for the lymphoma or CLL doctor to understand their goals and concerns regarding care options.

Figure 114. How important or unimportant is it to you to have the lymphoma or CLL doctor…



- Figure 115 illustrates that 59% of caregivers felt that the doctor, patient and caregiver or family should be jointly involved in the final decision on healthcare.

Figure 115. Who would you like to make the final decision on the patient's healthcare?

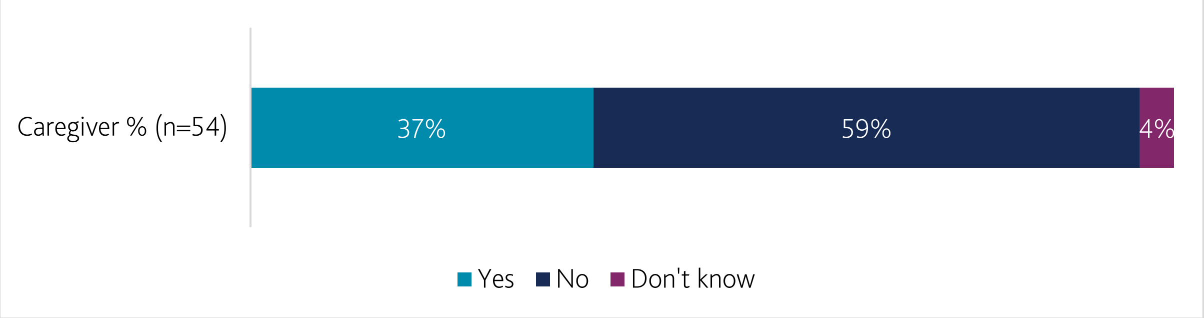


COVID-19 Concerns and Virtual Care

- 37% of carers had contracted Covid-19, at some point before or during the survey
- 74% of carers had been fully vaccinated and taken a booster dose, while 6% were not vaccinated and not planning to get vaccinated
- 72% of carers considered the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19, and that it worried them

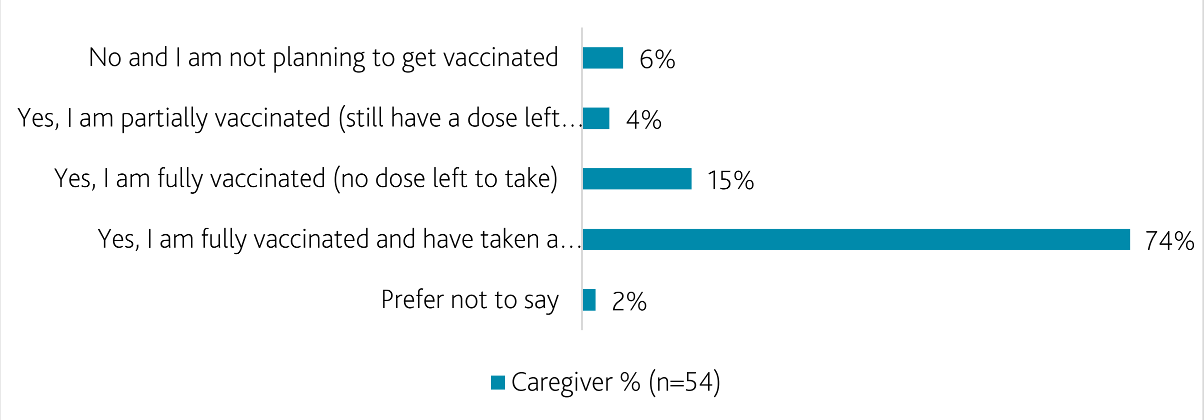
❖ Figure 116 illustrates that 85% of carers have not contracted Covid-19 at any point

Figure 116. Have you contracted Covid-19, now or at any point?



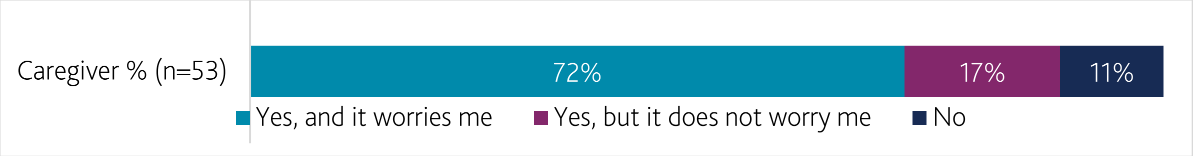
❖ Figure 117 illustrates that 74% of caregivers are fully vaccinated and have taken a booster dose

Figure 117. Have you, or are you planning to get the COVID-19 vaccine?



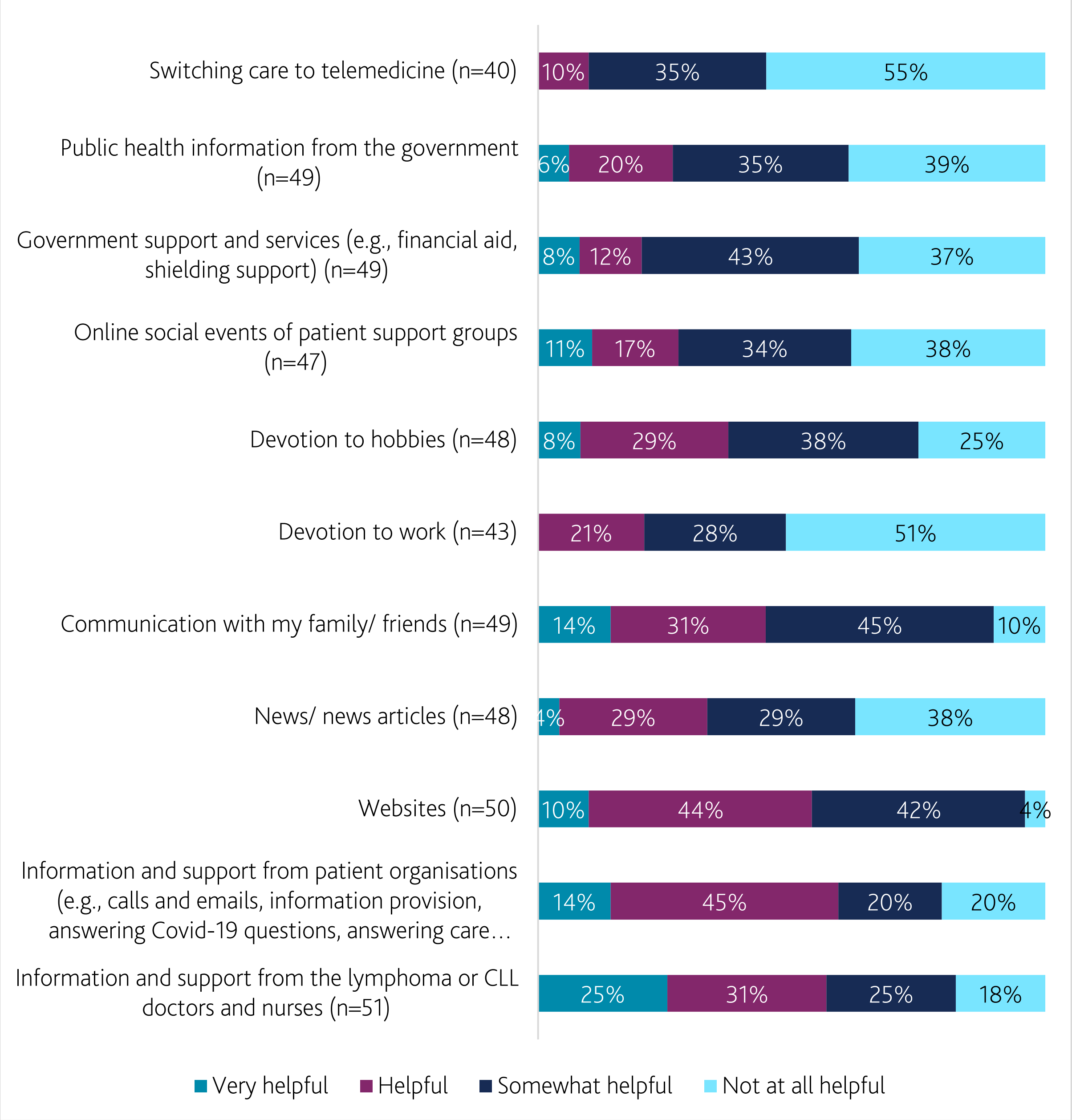
- Figure 118 illustrates that 72% of carers consider their patient as high risk for contracting COVID-19 and it worries them

Figure 118. Do you consider the patient at high risk for contracting COVID-19 and experiencing severe illness from COVID-19?



- Figure 119 illustrates that 56% of caregivers felt that information and support from doctors and nurses has been helpful in providing support regarding lymphoma or CLL

Figure 119. Please indicate how helpful, if at all, the following have been in providing support regarding lymphoma or CLL and the impact of COVID-19 pandemic.



List of Figures