



2022 Global Patient Survey on Lymphomas & CLL

October 2022

Country Report

Belgium

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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 Belgium.

The overall number of completed responses was **267**, made up of:

238 Patients



29 Caregivers



SECTION 2

Key Findings



Key Findings from Patients

Information, Guidance and Support



78% of patients felt well or very well informed about the processes and stages of their healthcare.



92% of patients reported doctors as their preferred source of information.



65% of patients would like doctors, and patients jointly involved in making healthcare decisions.



28% say the doctor never recommends other resources and support.

Diagnosis and Treatment



54% of patients were told their lymphoma subtype at diagnosis.



Only 26% of patients were given more than one treatment option before their current or last therapy for lymphoma.



71% of respondents experienced fatigue as a symptom of lymphoma and 78% experienced it as a side effect of treatment.



43% of patients indicated they had experienced fear of lymphoma relapse and 34% experienced fear of lymphoma progression.



68% of patients reported nothing had made getting treatment more difficult.



10% of patients reported time they would need to take out of their day-to-day life was a barrier preventing them from receiving treatment.



52% of patients received information about clinical trials from their doctor, yet only 29% of patients were in or had been in a clinical trial for their lymphoma or CLL.



25% of patients reported the top barrier to participating in a clinical trial was 'fear of unknown side effects.'

COVID-19 - Impact and Experiences



38% patients reported their depression was somewhat worse during the Covid-19 pandemic, and 18% said it was much worse.



37% of patients reported their anxiety was somewhat worse during the Covid-19 pandemic and 22% said it was much worse.



44% of patients experienced changes to their lymphoma care due to Covid-19.



Only 3% of patients strongly agreed and 3% agreed that they preferred telephone consultation or video consultation to face-to-face visit.



Patient organisations were identified by 59% of patients as very helpful or helpful sources of information and support during the COVID-19 pandemic.



78% of patients found doctors & nurses very helpful or helpful sources of information and support during the pandemic.

Key Findings from Caregivers



48% of caregivers felt well or very well informed about the processes and stages of the patient's healthcare.



97% of caregivers reported doctors as their preferred source of information.



34% of caregivers think that for the final decision about a patient's healthcare should involve, the doctor, and patient.



80% of caregivers report seeking out additional information about the patient's diagnosis, above what they were told by the medical team.

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

238 people living with lymphoma/CLL 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

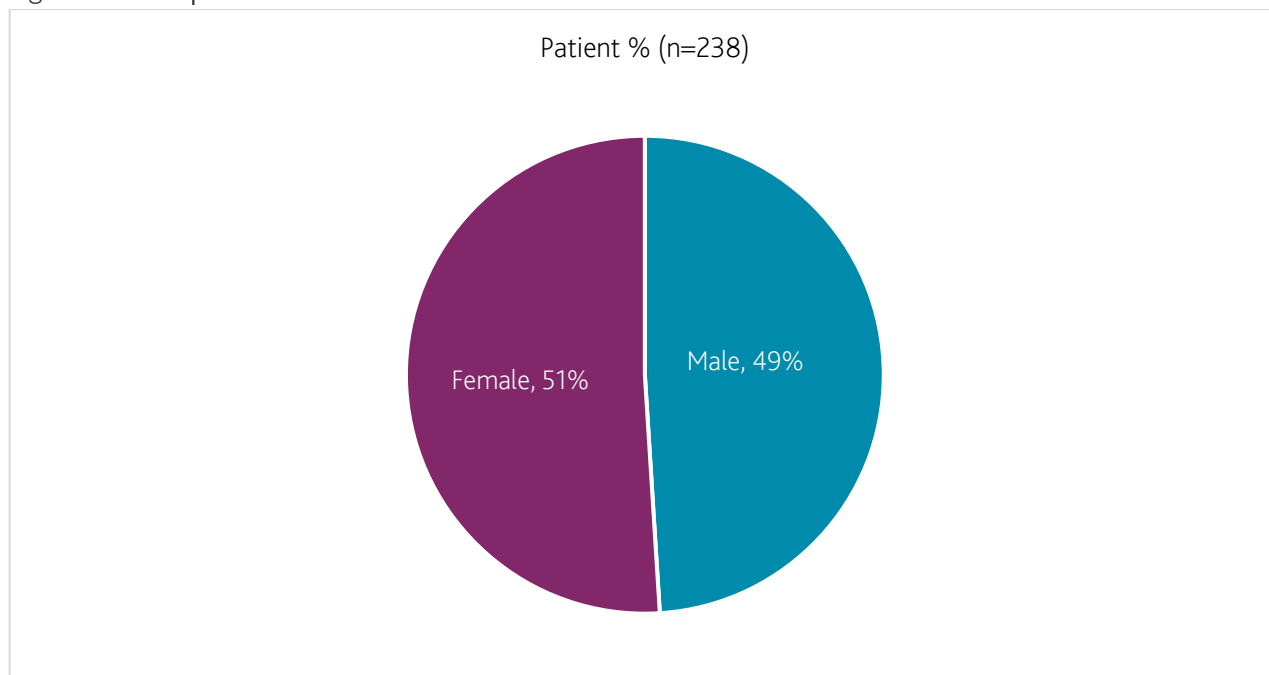
Patient Characteristics



- Most responses were from patients aged 65+ (40%), followed by patients 55-64 (33%), with the lowest survey respondents age group 18-34 (7%).
- 81% of patients reported their ethnicity as Caucasian or white.
- The overall cohort of patient respondents (238) represented 51% female and 49% male, with most respondents residing in rural areas (42%).
- Nearly half (49%) of respondents completed post-secondary education (college/university), with a high rate (18%) having completed postgraduate education such as a master's or Ph.D.
- A majority reported they are retired (45%), and 18% continue with full-time employment. Only 3% of patients were unable to work for health-related reasons.

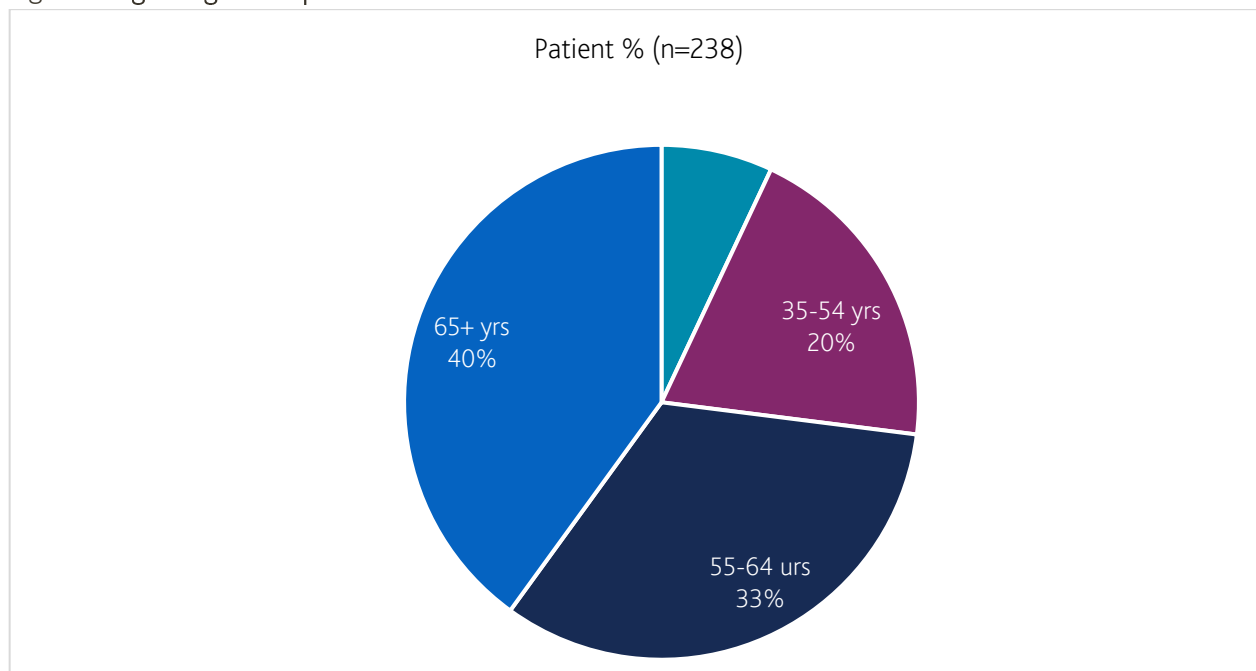
❖ Figure 1 shows a slightly higher response from female patients.

Figure 1. Sex of patient



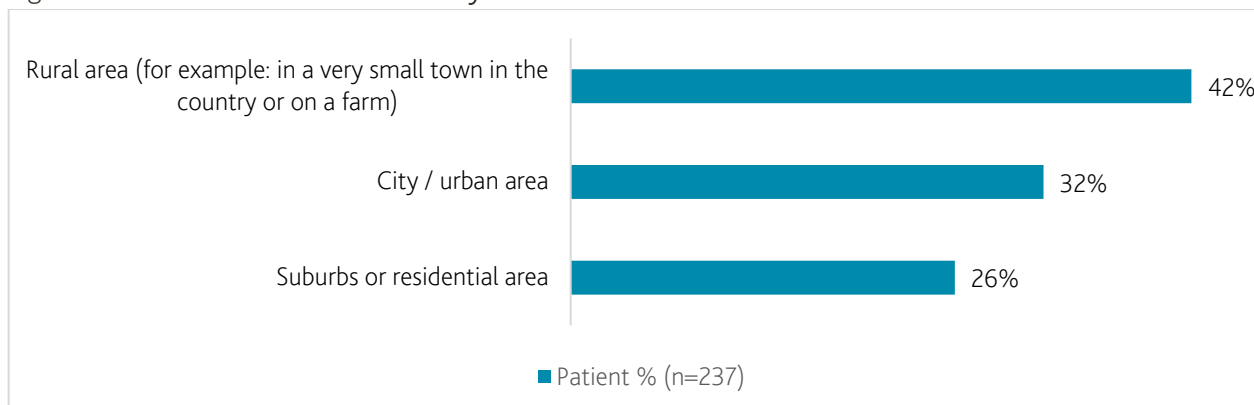
❖ Figure 2 illustrates that 40% of patients are aged 65 or older.

Figure 2. Age range of respondents



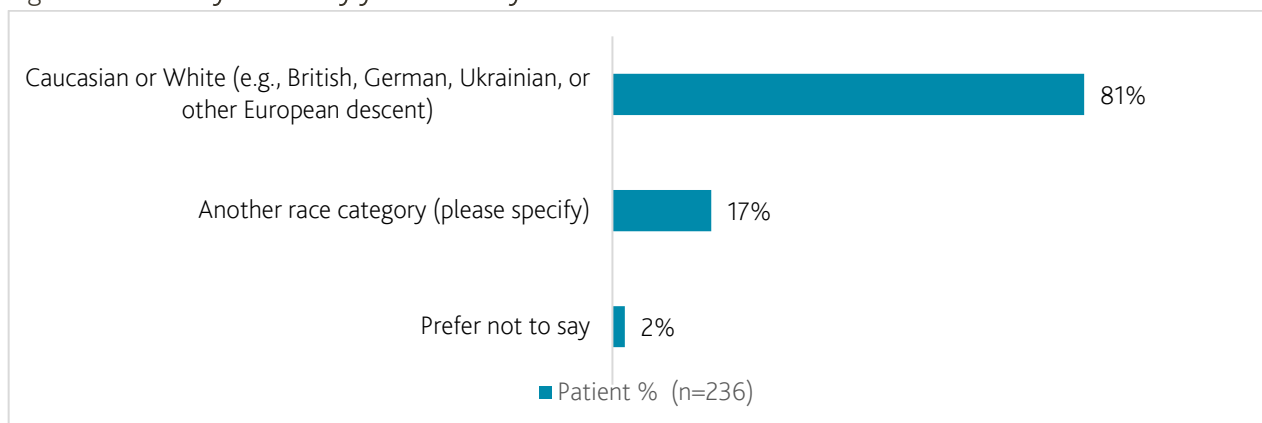
❖ Figure 3 shows 42% of respondents live in rural areas.

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



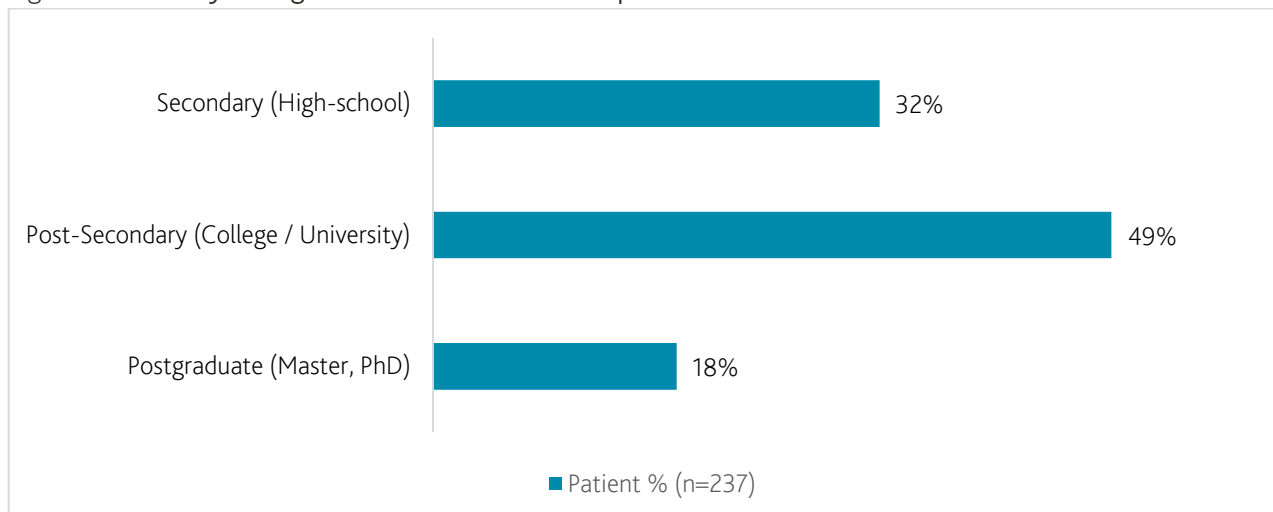
❖ Figure 4 indicates most patients identify as Caucasian.

Figure 4. How do you identify your ethnicity?



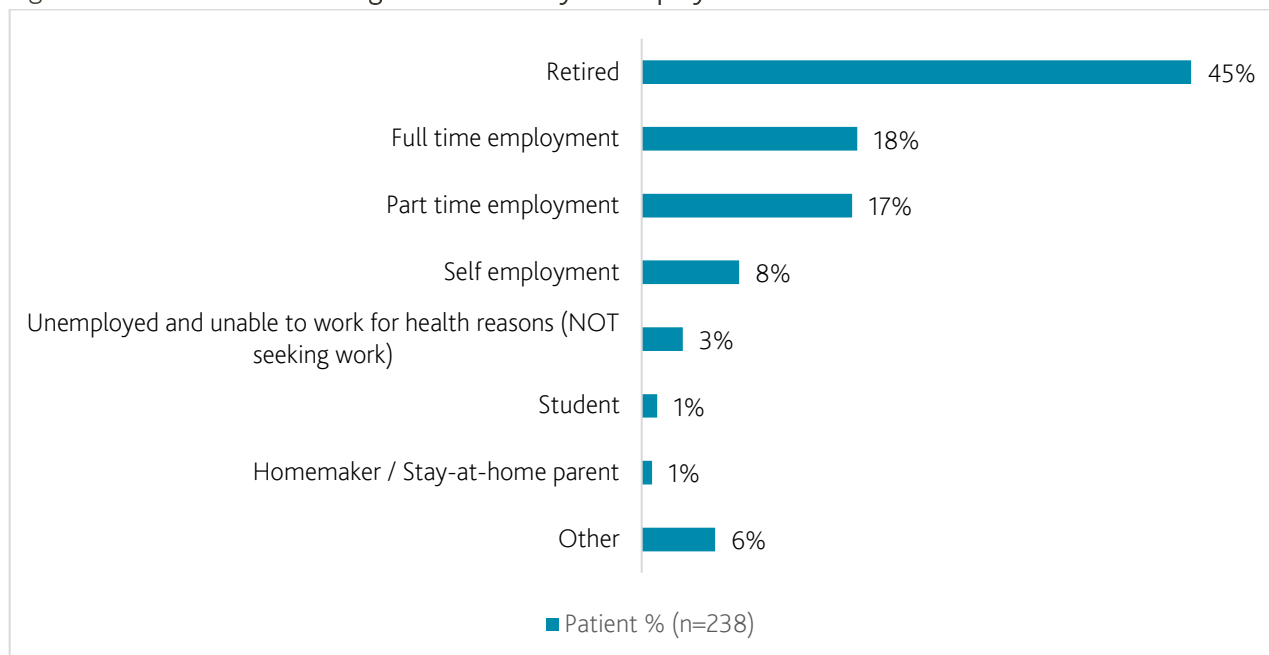
❖ Figure 5 illustrates the majority of patients have completed post-secondary education or higher (67%).

Figure 5. What is your highest educational level completed?



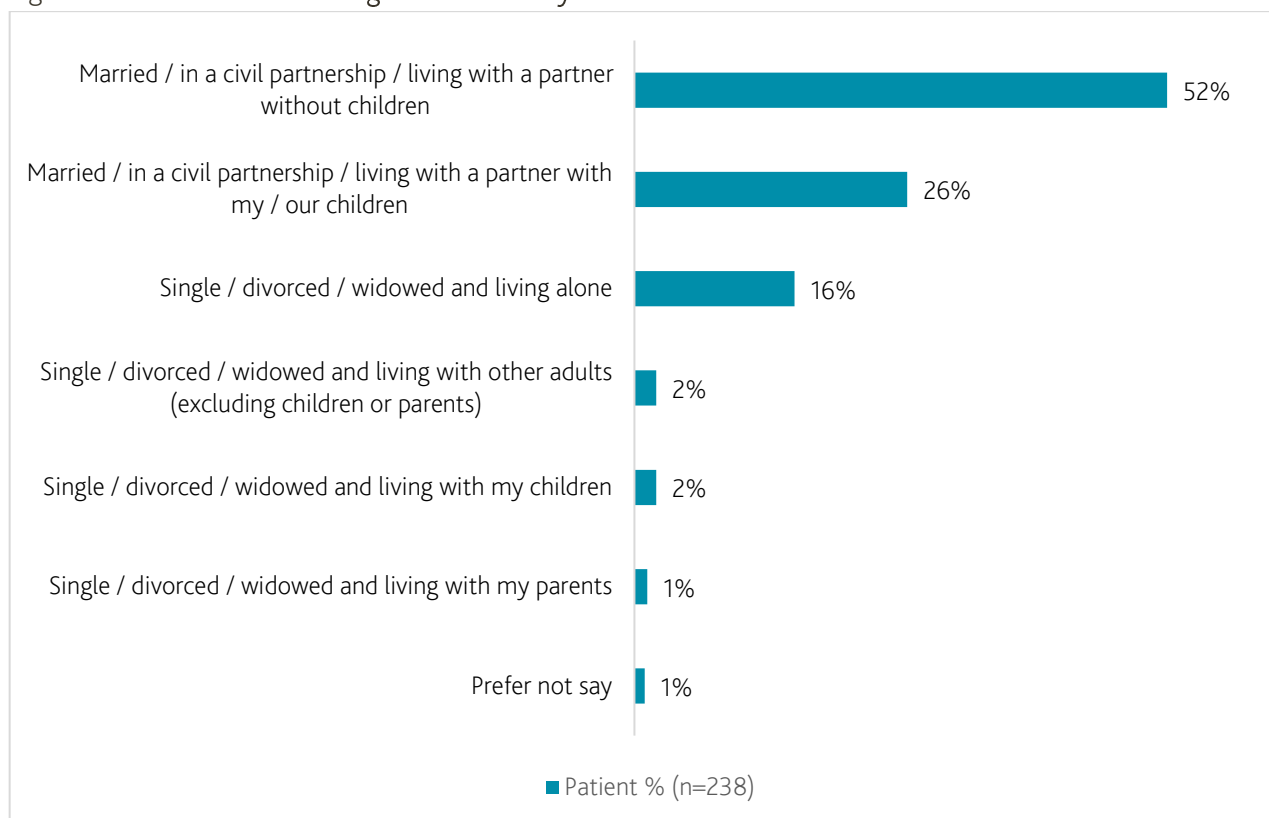
- ❖ Figure 6 shows most patients are retired. Equal numbers of patients reported being employed either full time or part time (about 17% each).

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



- ❖ Figure 7 reveals over 70% of patients live with a partner, either with or without children.

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



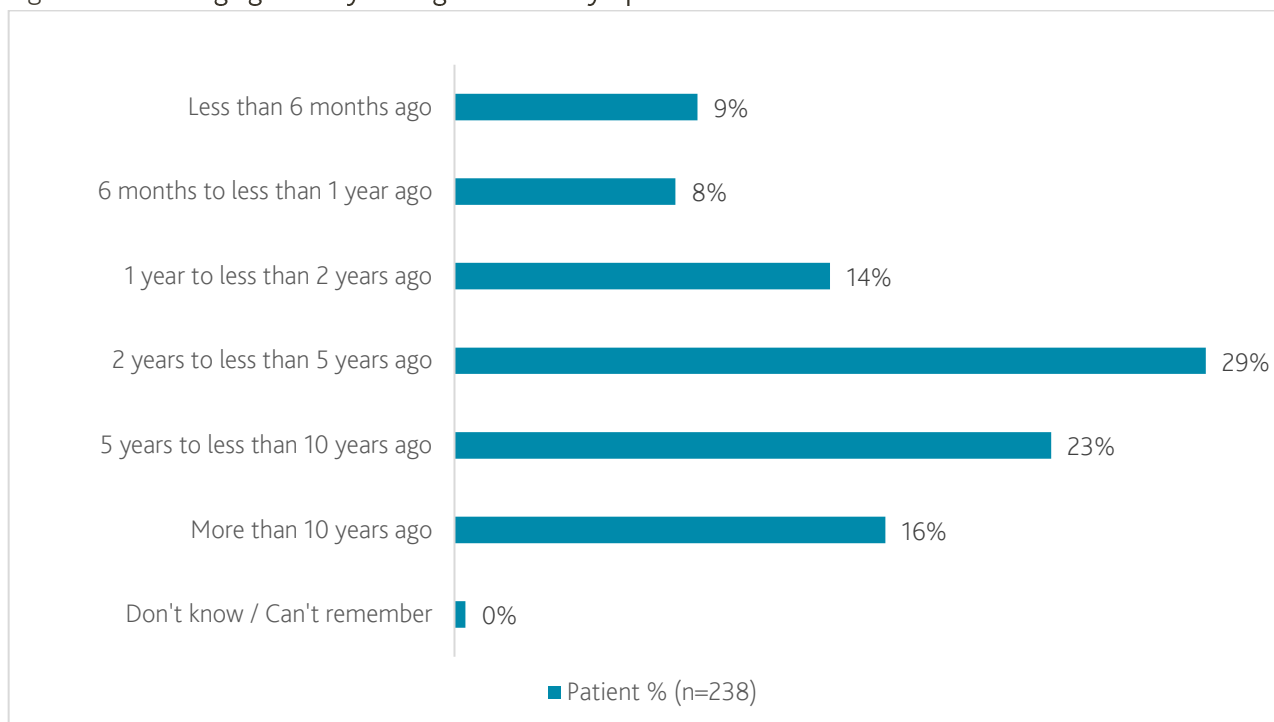
Diagnostic Demographics



- 29% of patients who responded to the survey were diagnosed 2 to less than 5 years ago.
- 68% of patients were seen by two or more healthcare professionals for their symptoms before receiving their initial diagnosis. Only 4% were seen by five or more healthcare professionals before receiving a diagnosis.
- Over a fifth of patients (22%) experienced their symptoms for more than six months before seeking medical care. Over two-thirds (70%) of patients 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, over 15% had to wait longer than six months from when they met with their family physician or sought care for their symptoms before they received a diagnosis.
- The top five reported subtypes were Chronic Lymphocytic Leukaemia (CLL) / Small Lymphocytic Lymphoma (SLL) (23%), Diffuse Large B-Cell Lymphoma (DLBCL) (16%), Follicular (13%), Hodgkin (12%), and Mantle Cell (7%),

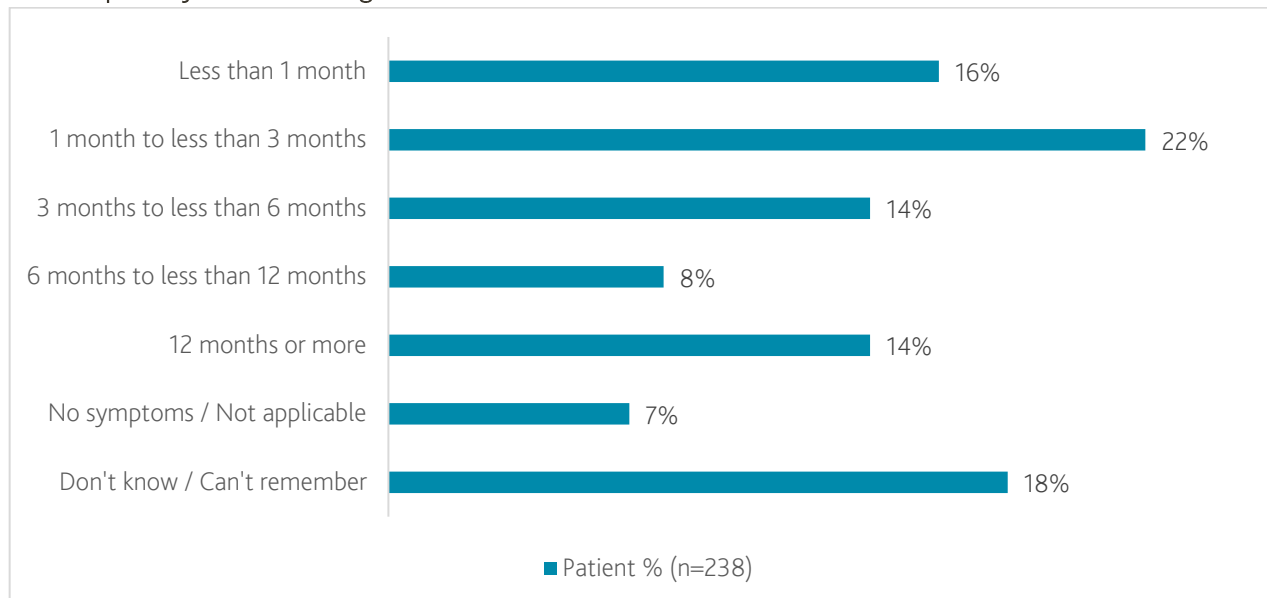
❖ Figure 8 reveals 29% of patients have been diagnosed with lymphoma or CLL 2 to less than 5 years ago.

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



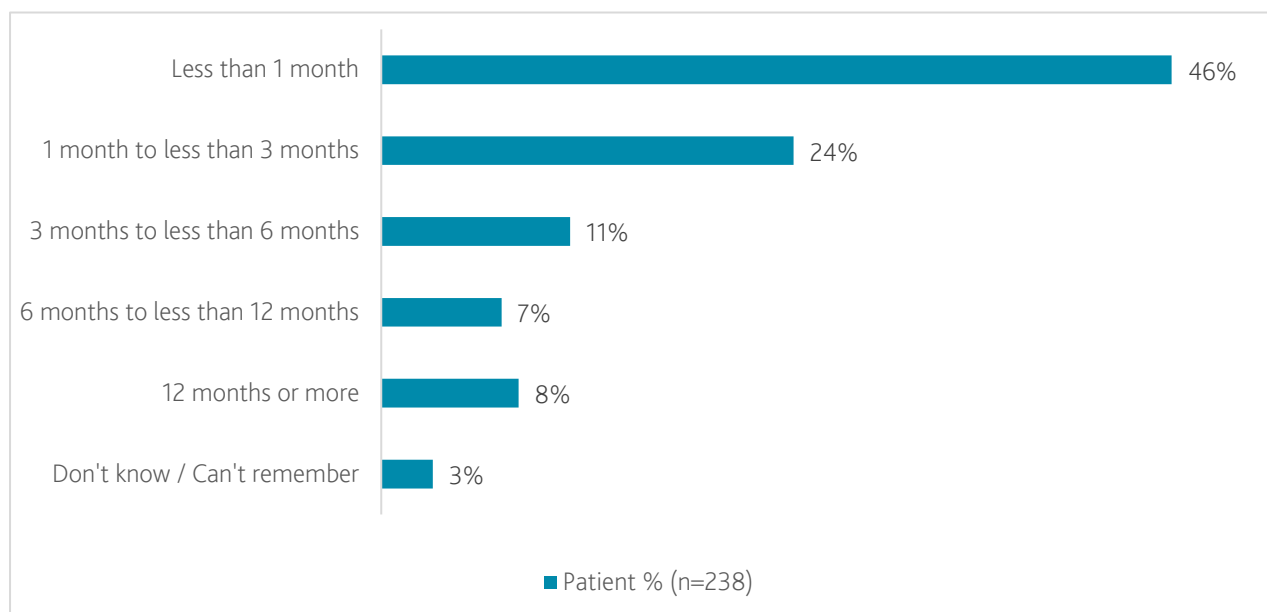
- ❖ Figure 9 shows there is a lot of variation in how long patients reported waiting to seek medical care about the symptoms they were experiencing. In addition, 18% of patients reported not having any symptoms.

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?



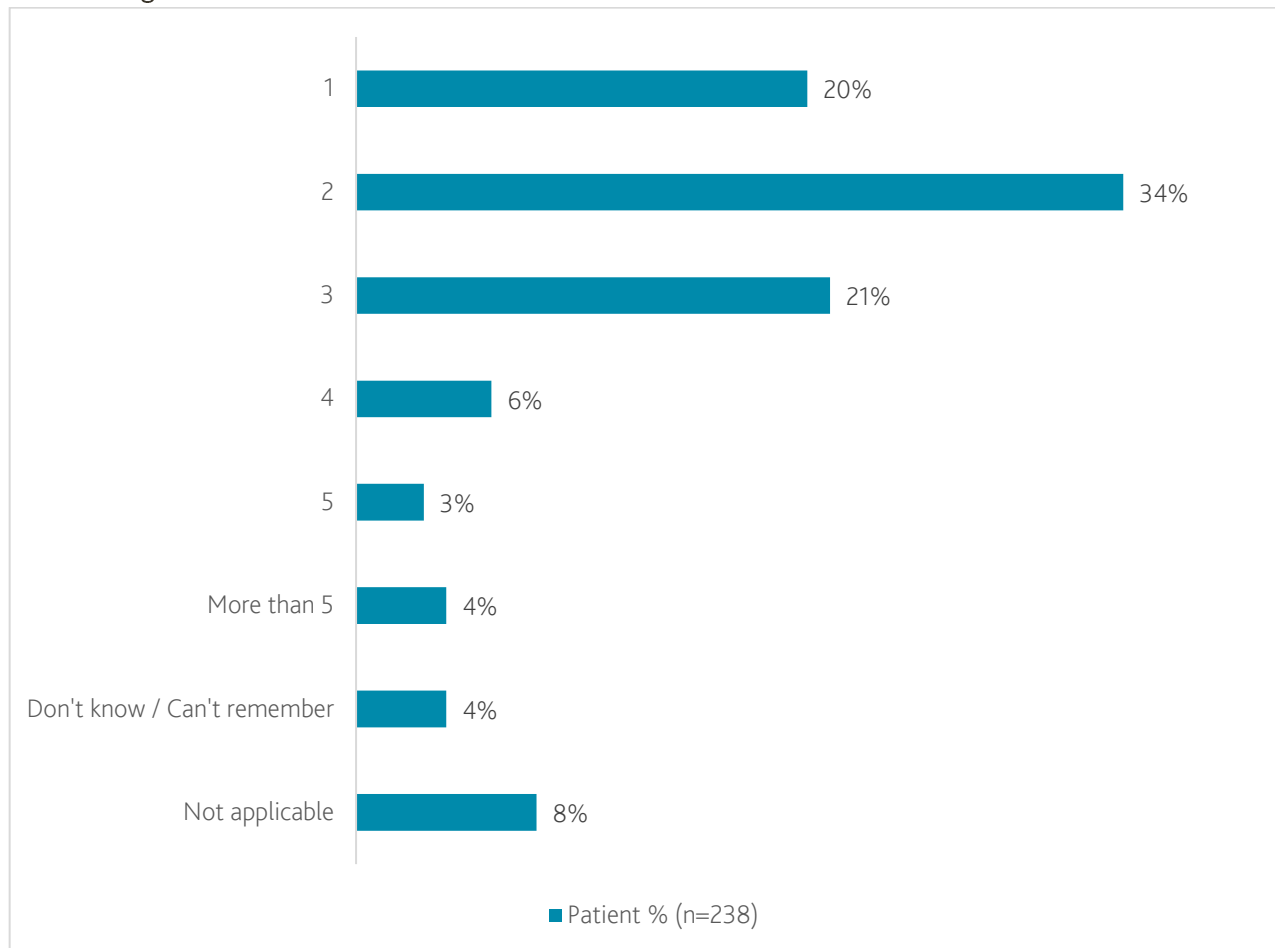
- ❖ Figure 10 illustrates 70% of patients had a diagnosis within 3 months of their first appointment, but 8% waited a year or more.

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?



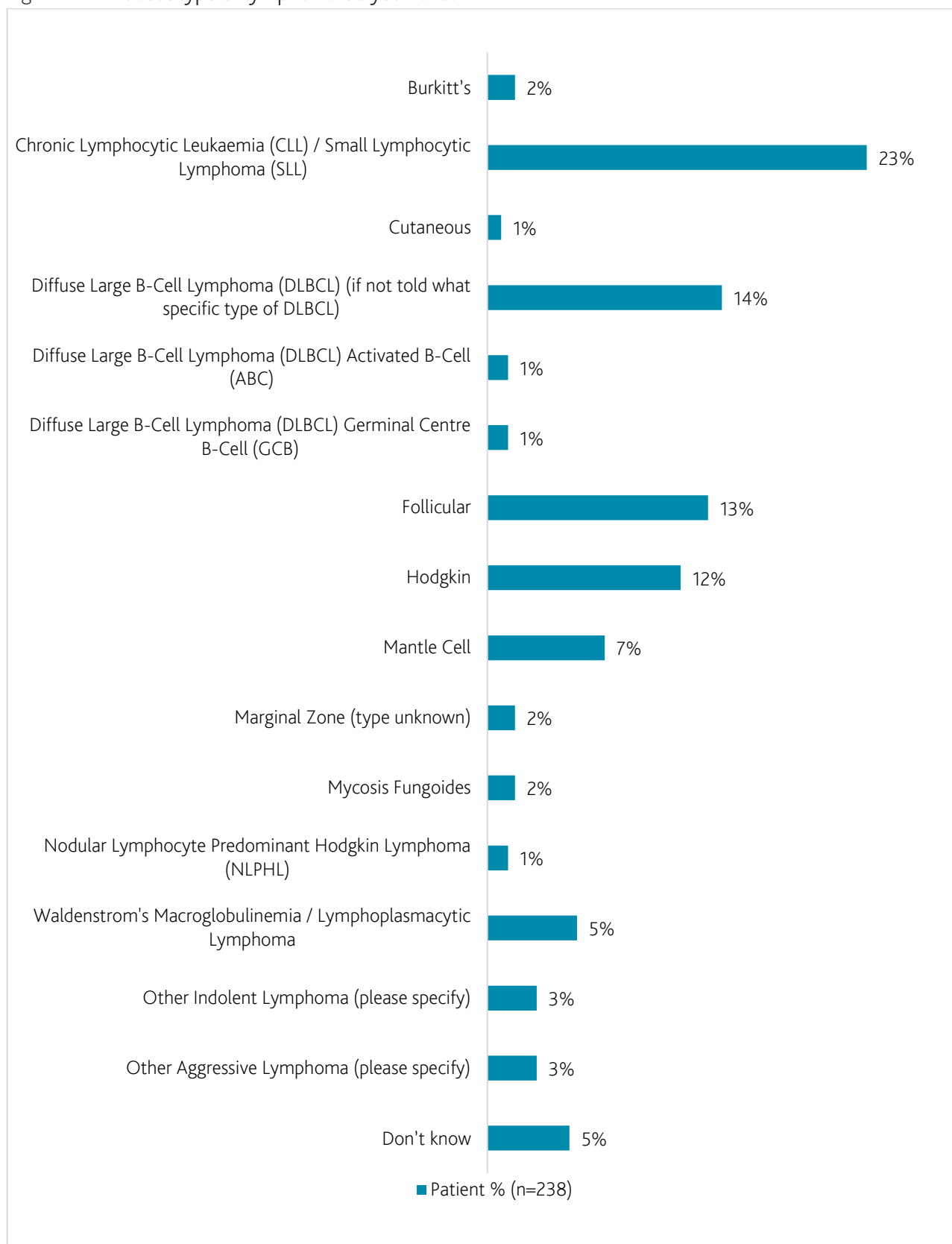
- ❖ Figure 11 reveals a third of patients saw 2 healthcare professionals before receiving their current diagnosis.

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



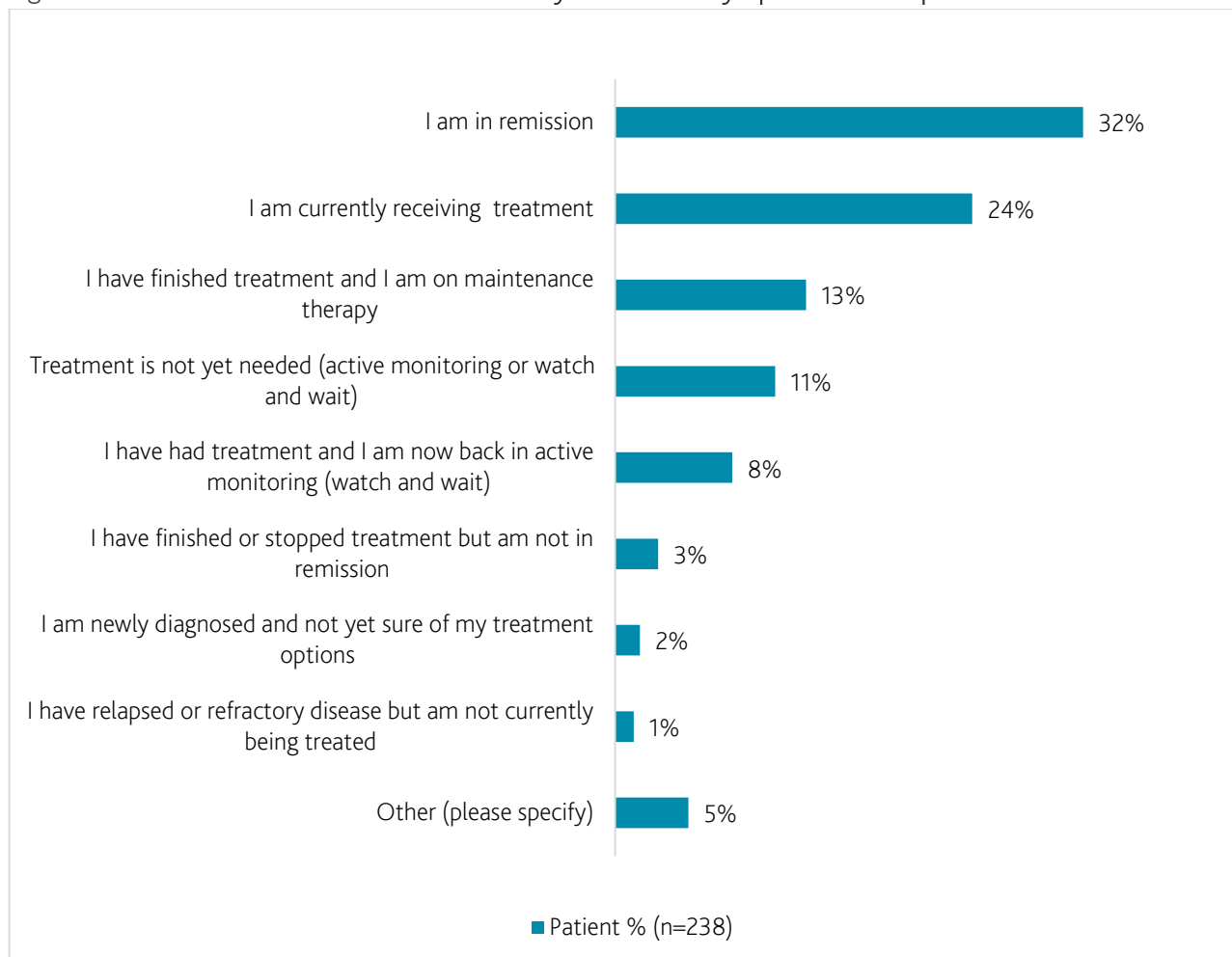
- ❖ Figure 12 illustrates almost a quarter of patients have Chronic Lymphocytic Leukaemia (CLL) / Small Lymphocytic Lymphoma (SLL)

Figure 12. What subtype of lymphoma do you have?



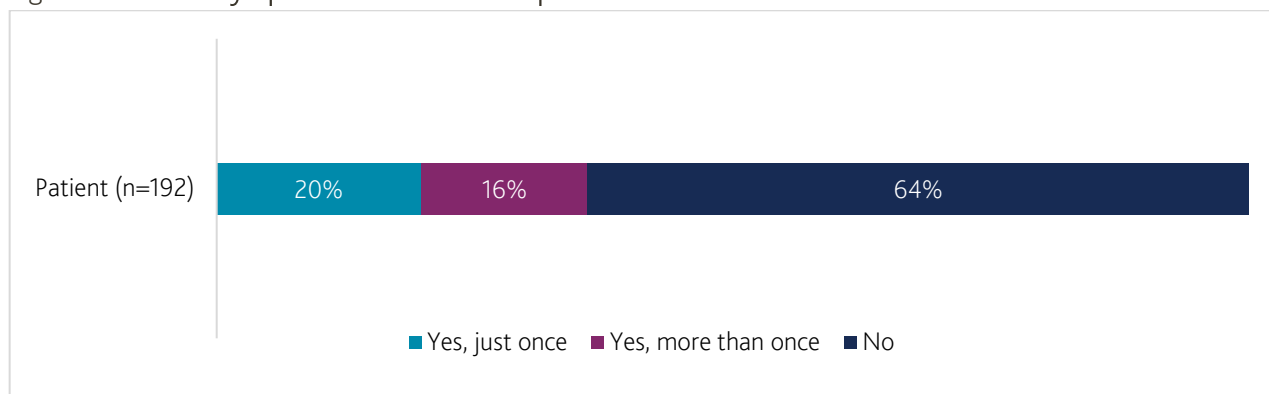
❖ Figure 13 shows nearly a third of patients are in remission.

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



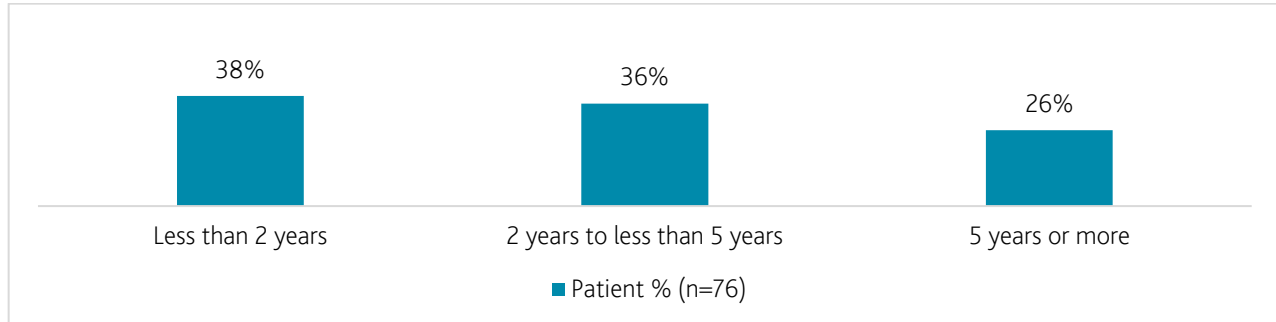
❖ Figure 14 illustrates that 64% of patients who have been treated have not experienced a relapse of their lymphoma or CLL. *Only asked to those who have received or are receiving treatment.*

Figure 14. Has the lymphoma or CLL ever relapsed?



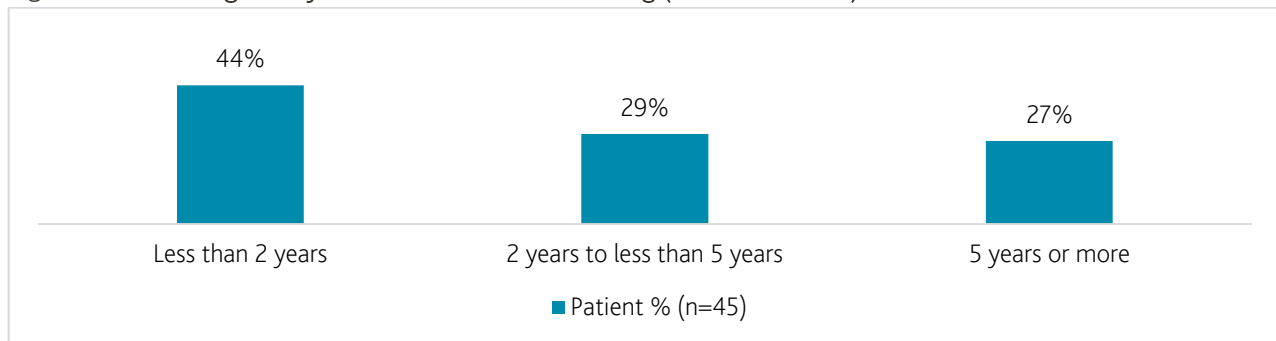
- ❖ Figure 15 explains when patients indicating they were in remission were asked how long they have been treatment-free, similar amounts said less than 2 years and 2-5 yrs. *Only asked to those who selected they were in remission.*

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



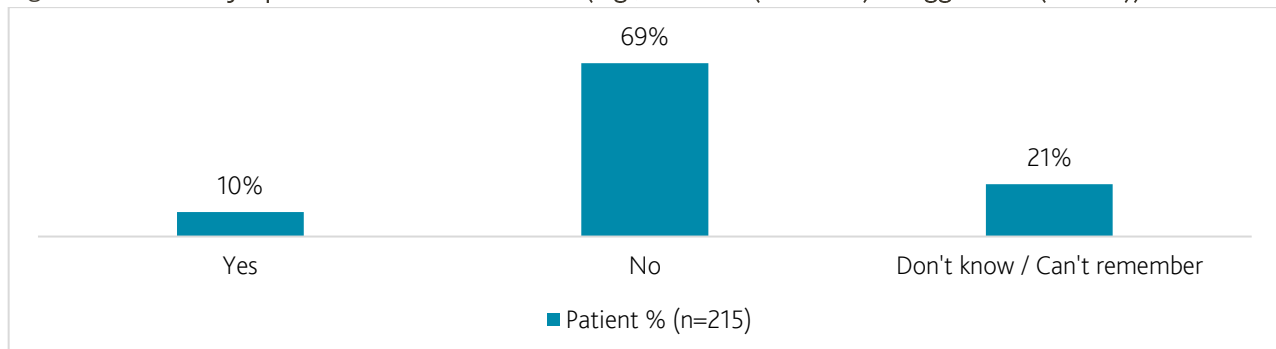
- ❖ Figure 16 shows when patients in active surveillance were asked how long they had been monitoring, 44% said less than 2 years. *Only asked to those who selected they were in active monitoring.*

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



- ❖ Figure 17 depicts over two-thirds of 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 and Guidance

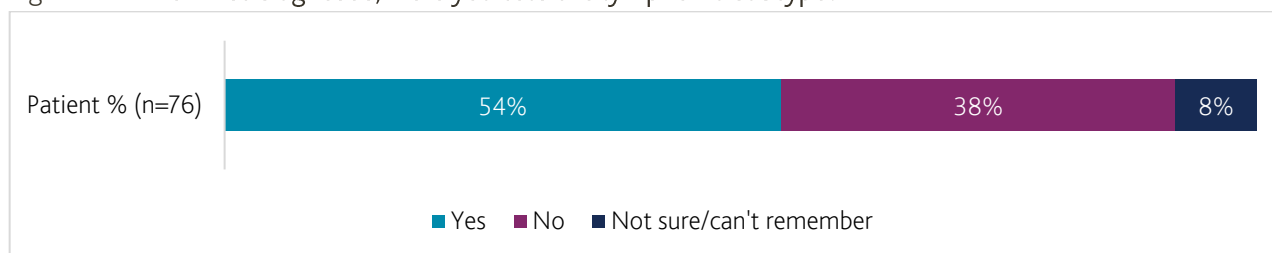
Previous surveys showed that having 'adequate information' was correlated with more self-reported positive healthcare experiences. Also, patients with adequate information reported better management of their health and healthcare through improved understanding, confidence levels, and communication with 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.



- About half (54%) were told their subtype at diagnosis.
- A quarter of patients did not seek additional information other than what the doctor/healthcare staff told them.
- For those who were seeking out information and details about their disease and potential treatment following their diagnosis, 45% said it was the patient doing this and the preferred method of obtaining this information for nearly two-thirds of the patients was via oral information from healthcare providers.
- Nearly three-quarters of patients (73%) felt the results they had received about their disease and diagnostic tests were explained well and they understood.
- Only 5% of patients indicated they did not feel well informed about the processes and stages of their health.
- Over half of patients did not receive details for a patient organisation, a support group, and/or information produced by a patient organisation from their healthcare team. But 87% of those who received information from patient organisations were very satisfied or satisfied with the information.

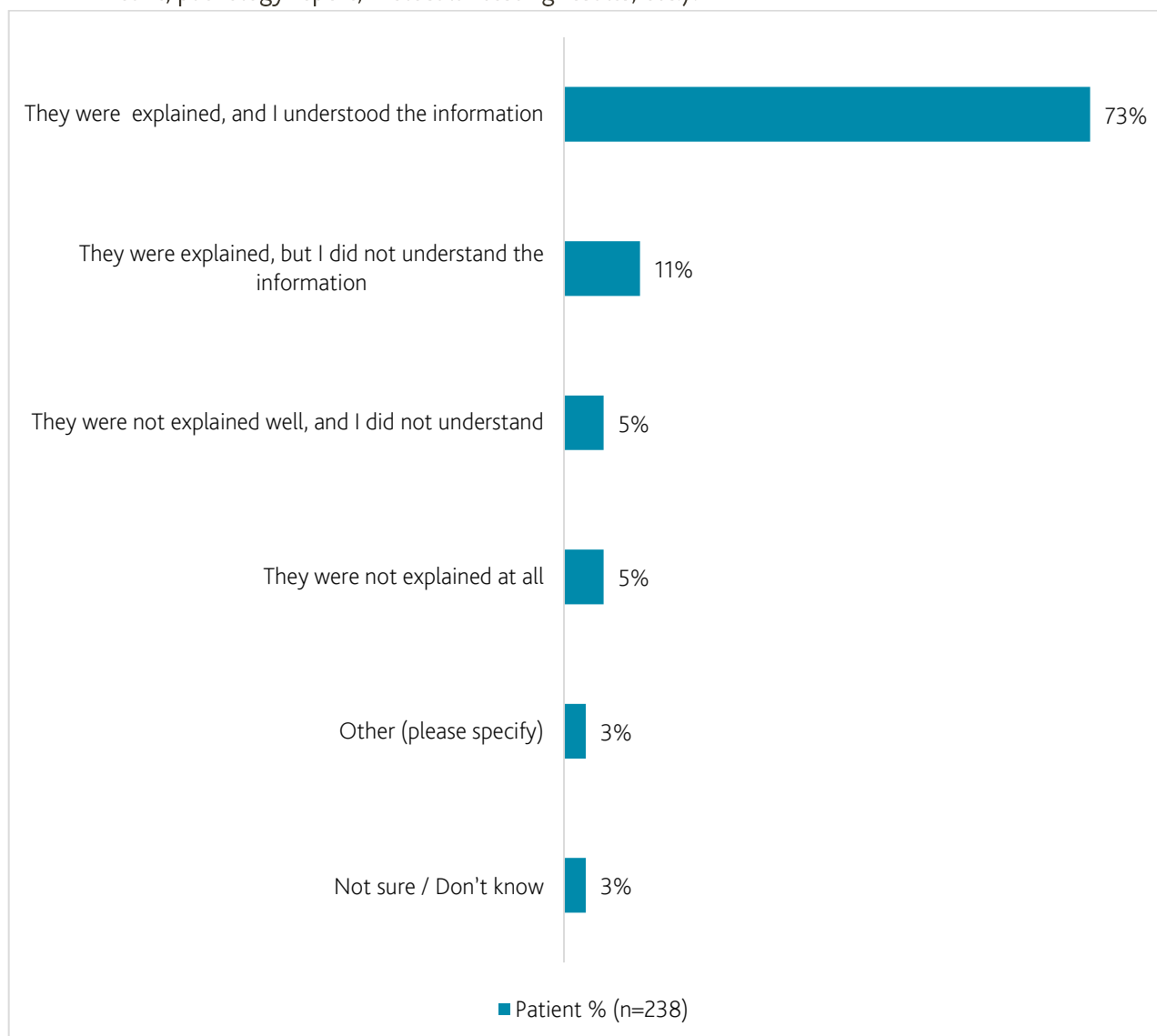
- ❖ Figure 18 illustrates 54% of the patients were told their lymphoma subtype when first diagnosed. This question was only asked to those who were diagnosed less than 2 years from survey time.

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



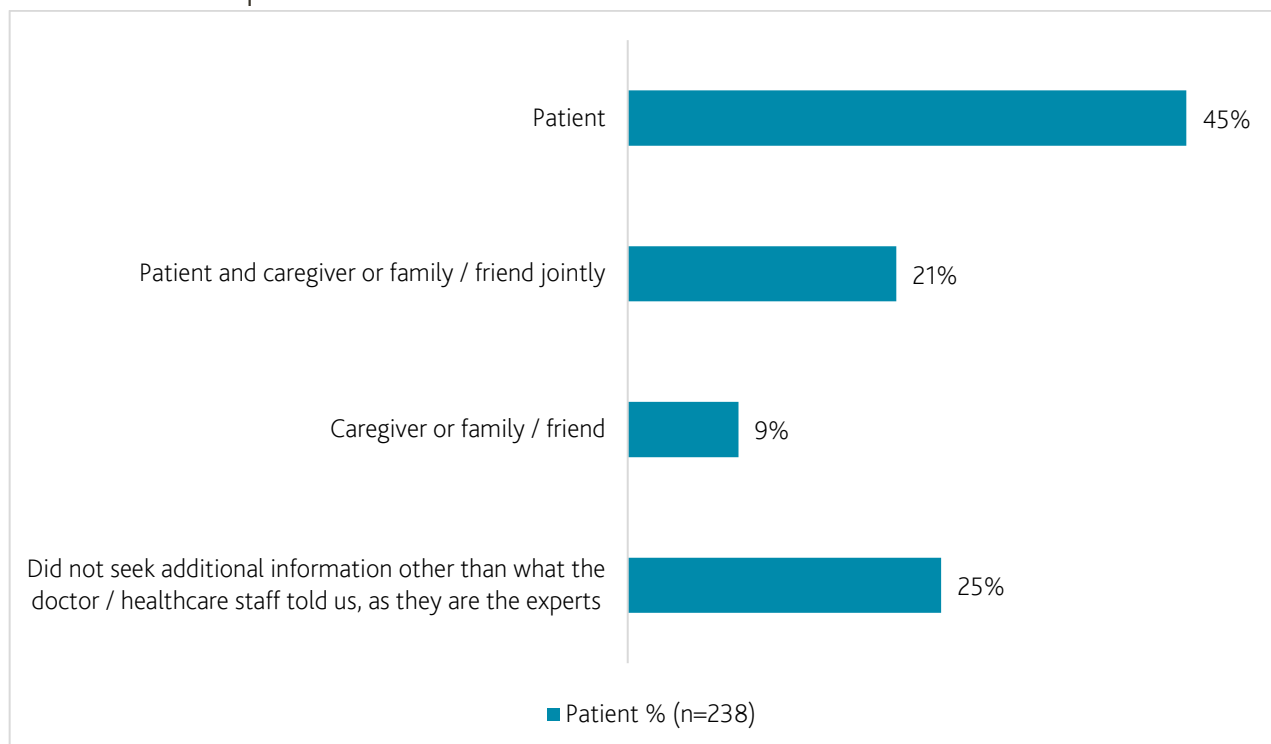
- ❖ Figure 19 reveals nearly three-quarters of patients had their diagnostic tests and results explained to them and understood the information

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.)?



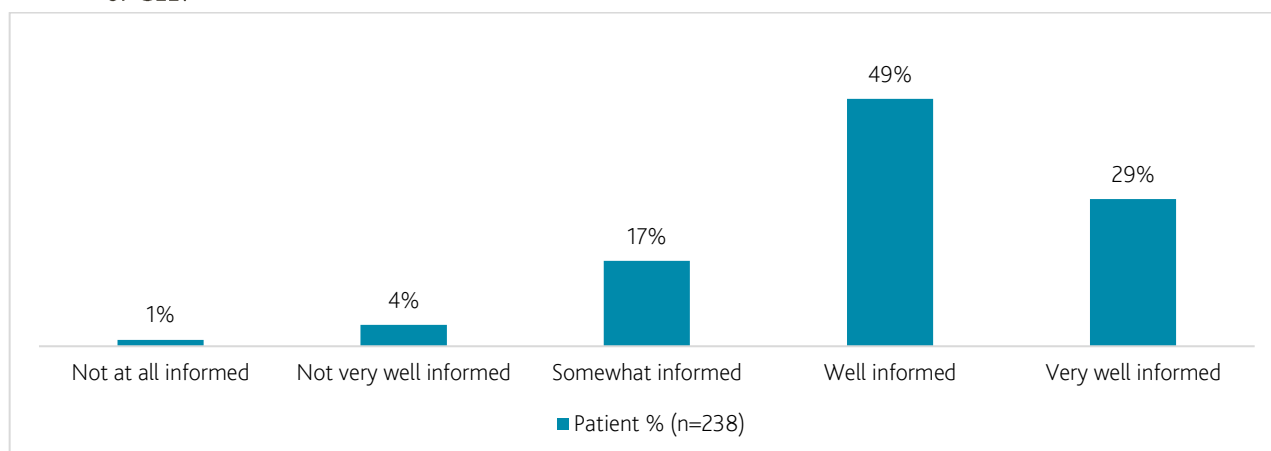
- ❖ Figure 20 shows 66% of patients sought out information and details about the disease and potential treatments. 45% of patients do this alone and 21% do it with a caregiver, family, or friend. 25% reported that they did not seek information other than what their doctor told them.

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



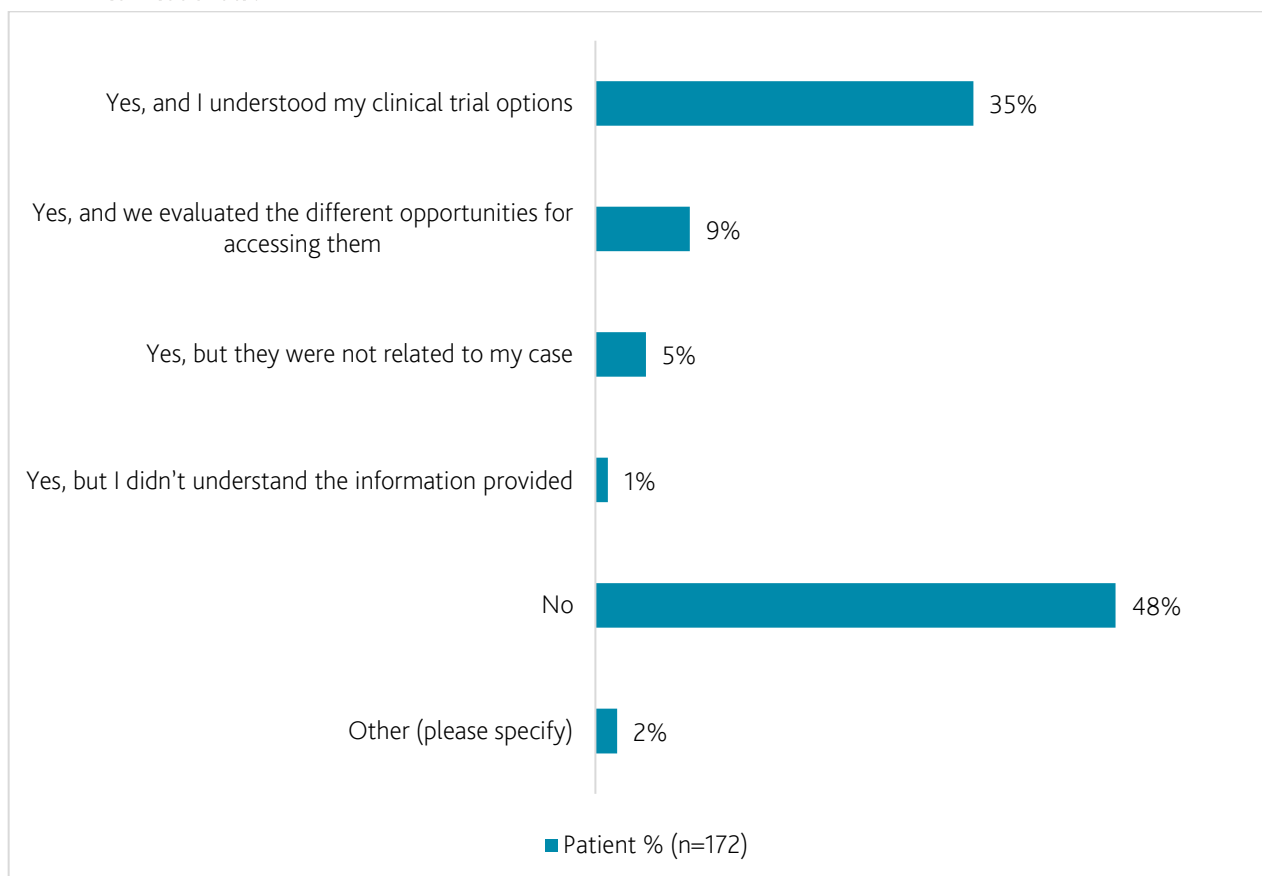
- ❖ Figure 21 illustrates only 5% of patients felt they were not well informed about the processes and stages of their healthcare throughout their experience

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



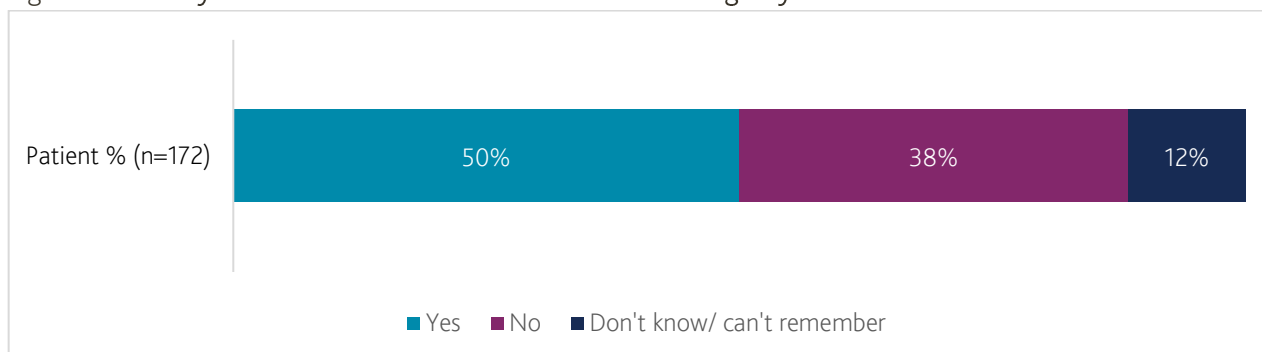
- ❖ Figure 22 reveals half of patients did not receive any information about clinical trials

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



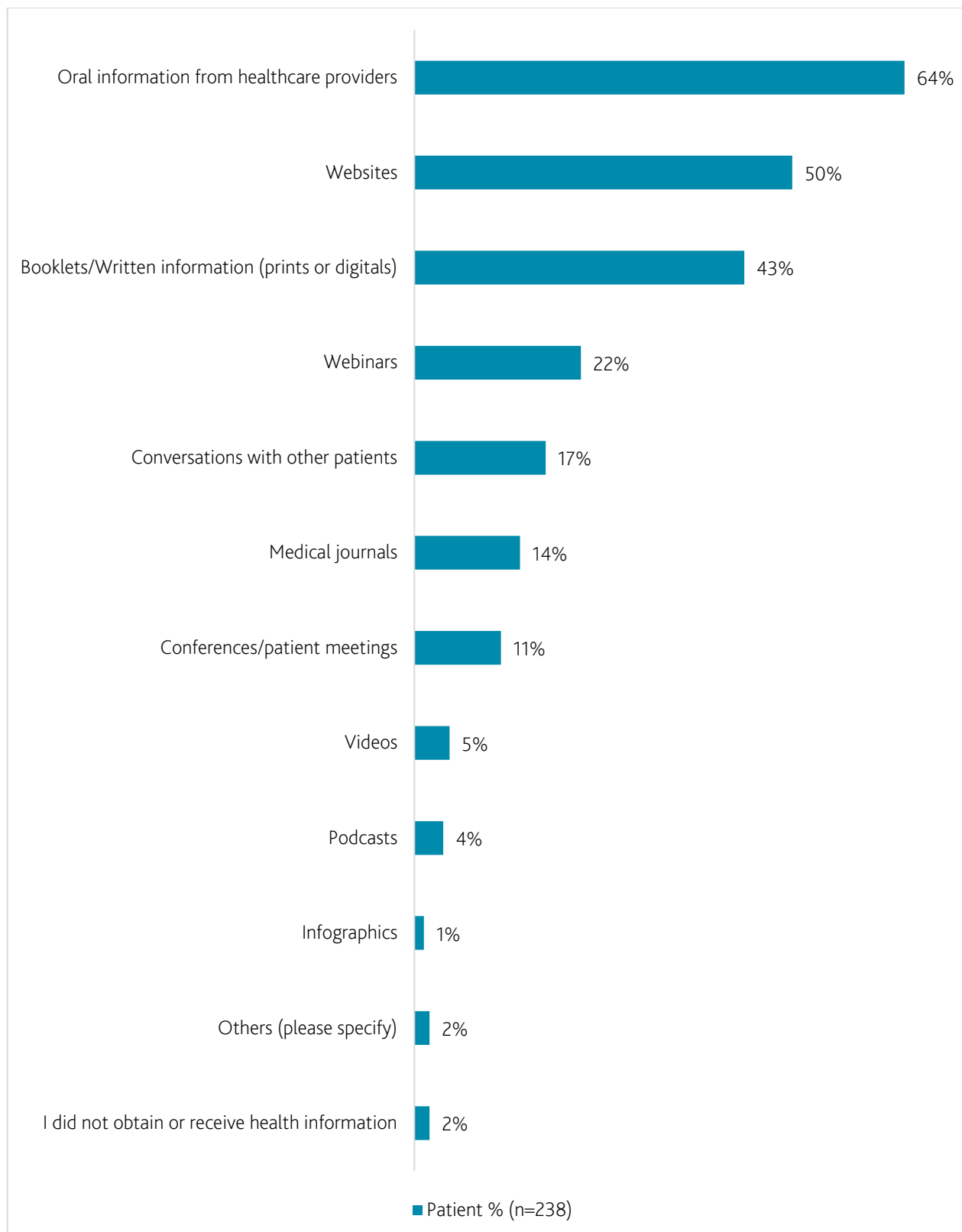
- ❖ Figure 23 shows when asked about clinical trials, half of respondents said they were aware that a clinical trial can sometimes provide access to the best treatment

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



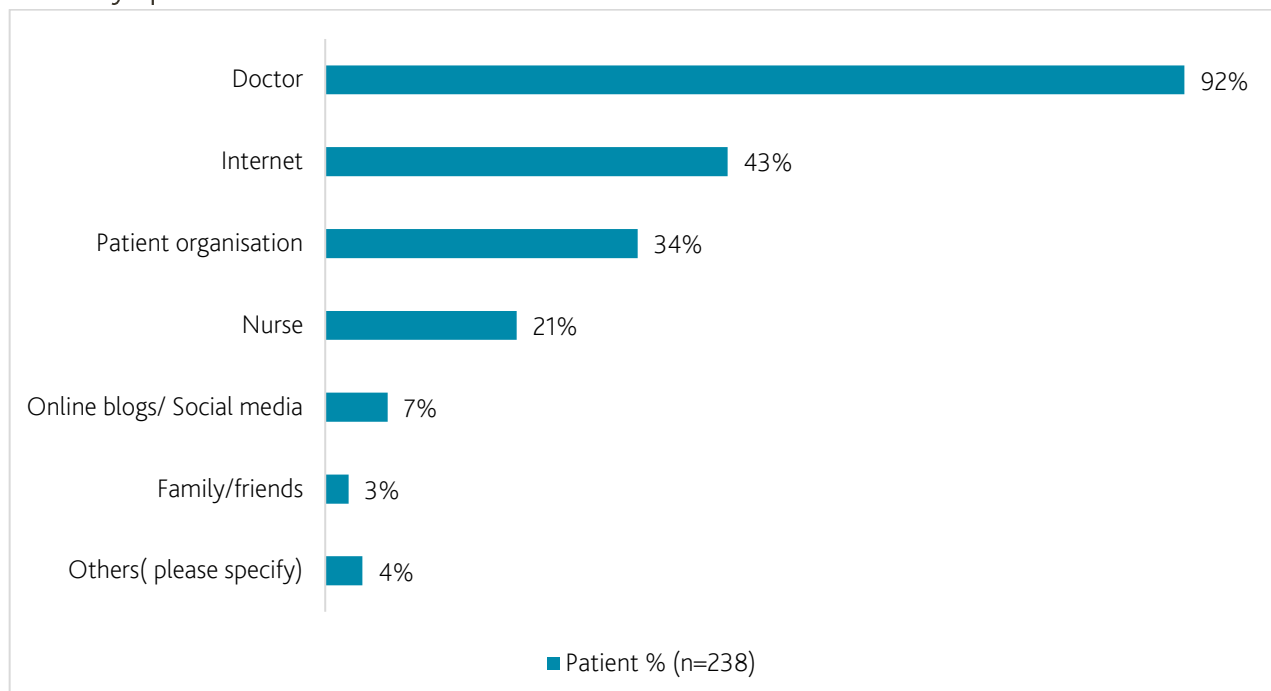
- ❖ Figure 24 reveals when patients were asked about receiving health information about lymphoma or CLL, the preferred methods were oral information from healthcare providers (64%), websites (50%), and booklets or written information 43%).

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



- ❖ Figure 25 shows patients preferred sources for information about lymphoma CLL included doctor (92%), internet (43%), and patient organisations (34%).

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



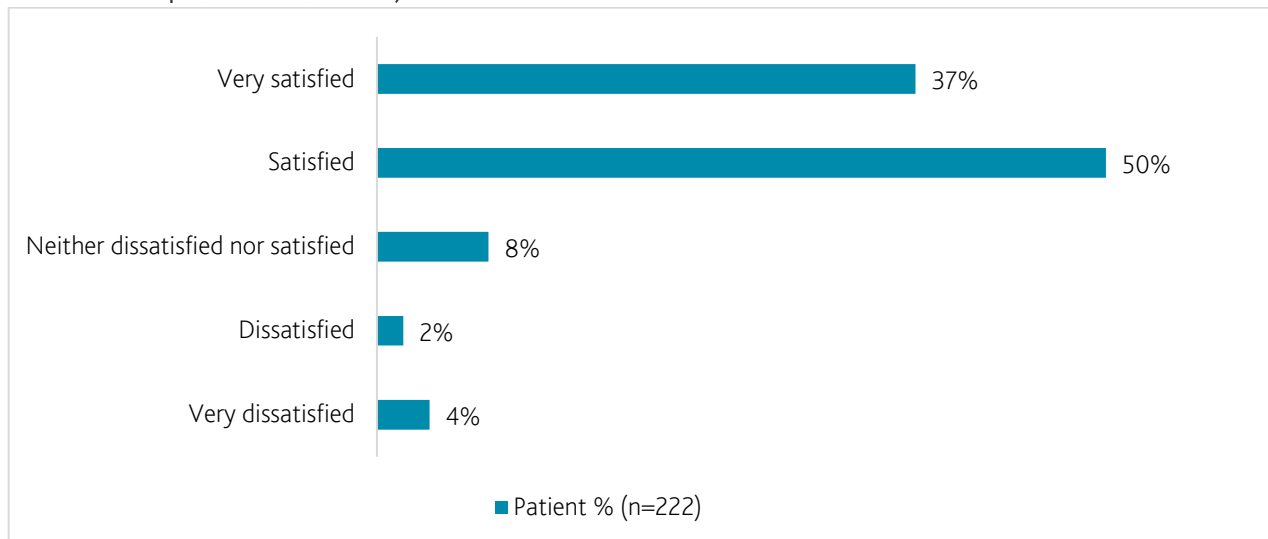
- ❖ Table 1 illustrates when patients were asked to rank their preferred source of lymphoma or CLL information, 86% cited doctors as their top choice.

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

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	61	86%	4	6%	3	4%
Nurse	0	0%	26	37%	8	11%
Internet	5	7%	10	14%	31	44%
Online blogs/social media	0	0%	4	6%	4	6%
Family/friends	0	0%	3	4%	2	3%
Patient organisation	5	7%	24	34%	21	30%
Others (please specify)	0	0%	0	0%	2	3%
Total	71	100%	71	100%	71	100%

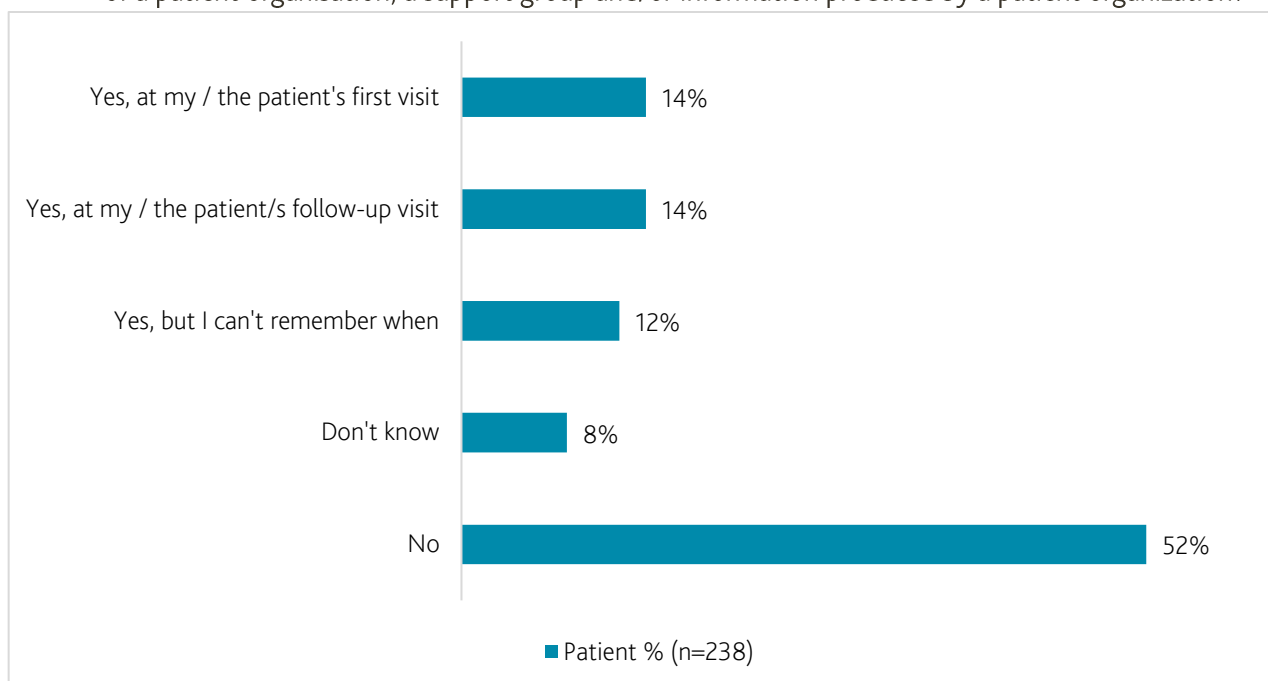
- ❖ Figure 26 reveals overall, 87% of patients indicated they were satisfied or very satisfied with the information given to them by their healthcare team.

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



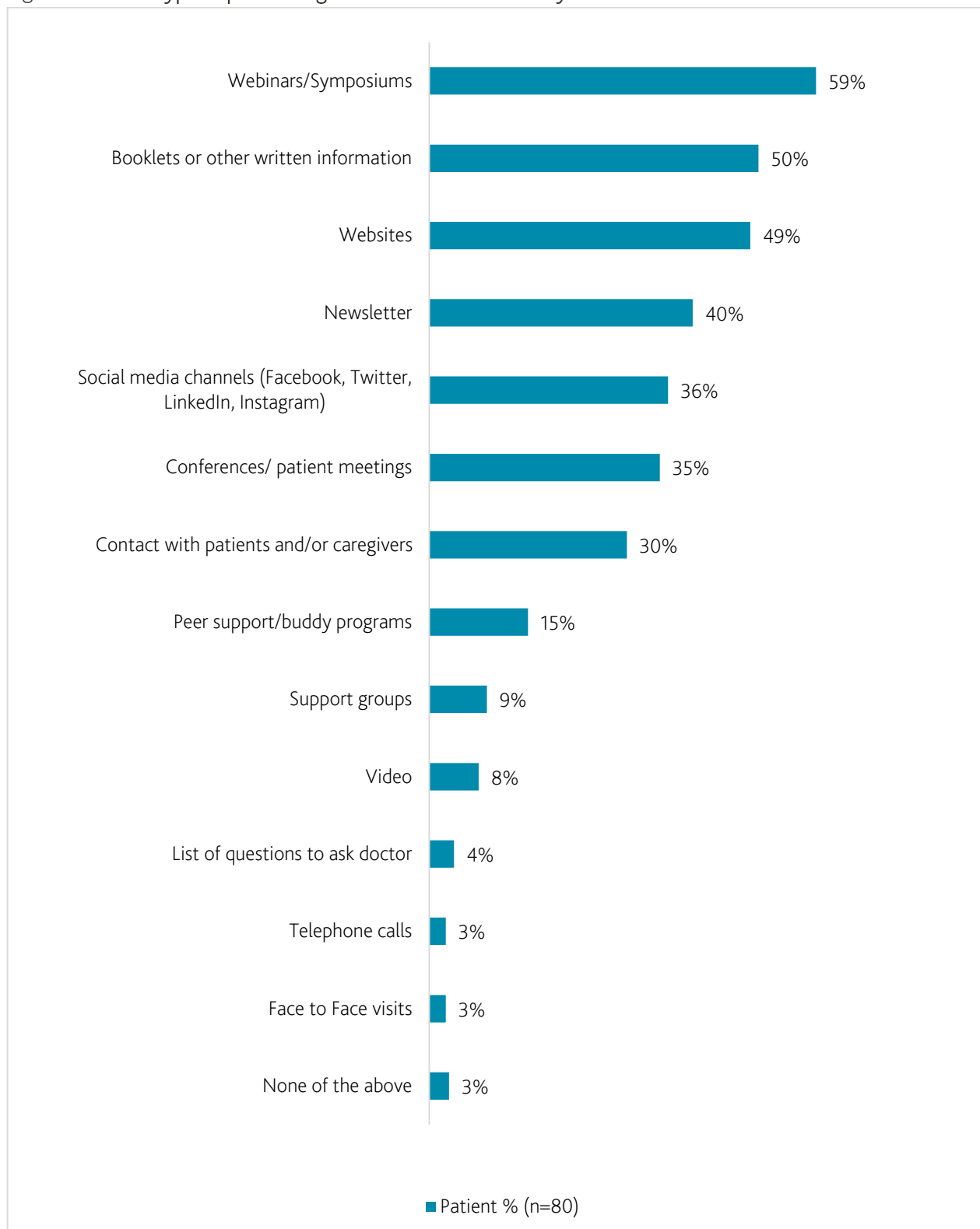
- ❖ Figure 27 illustrates half of patients did not receive any information about patient organisations from their lymphoma or CLL doctor or medical team

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



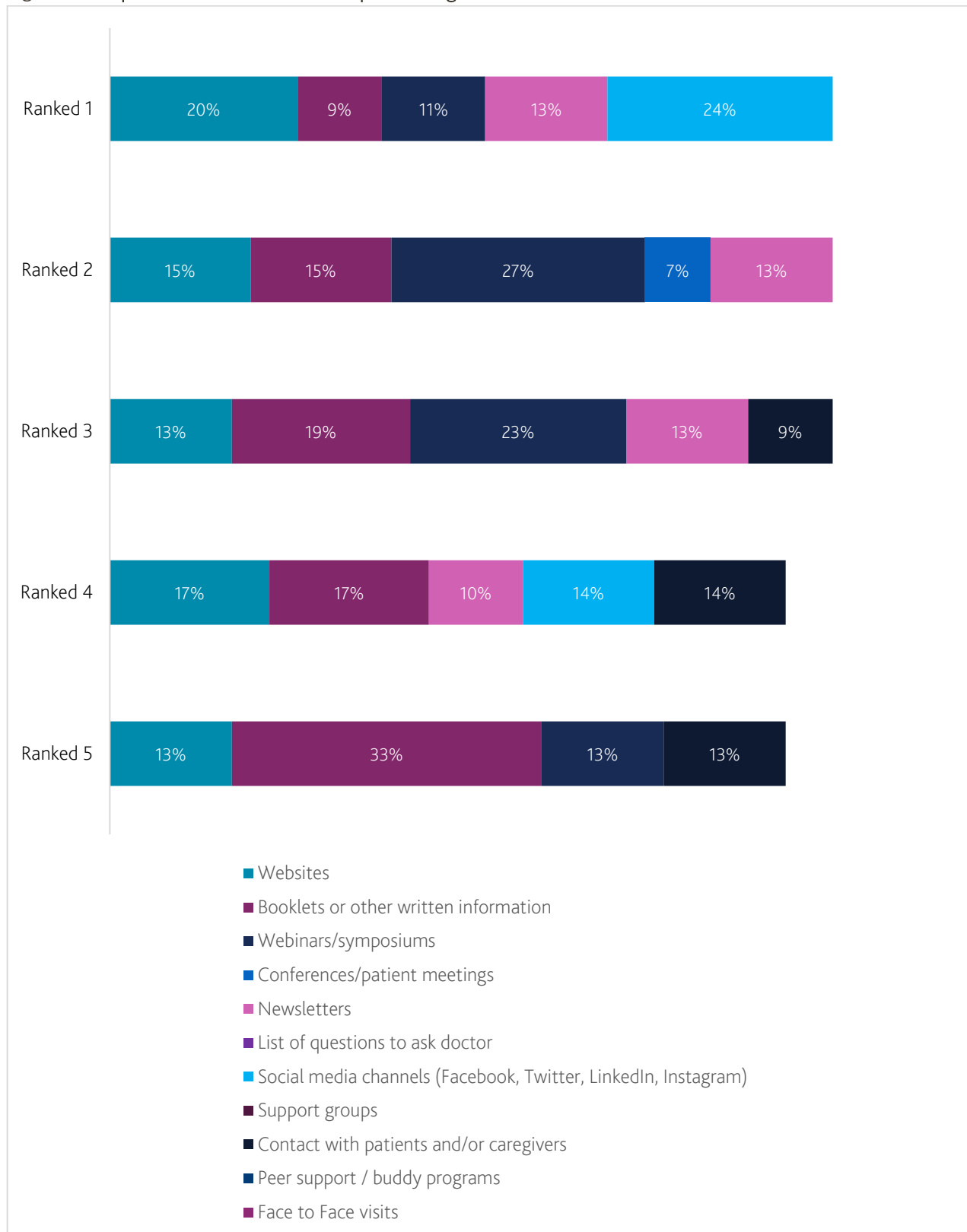
- ❖ Figure 28 reveals the top patient organisation information used is webinars/symposium (59%). However, a number of patients are accessing booklets or written information (50%), websites (9%) and newsletters (40%). *Only asked to those who indicated they had connected with a patient organisation.*

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



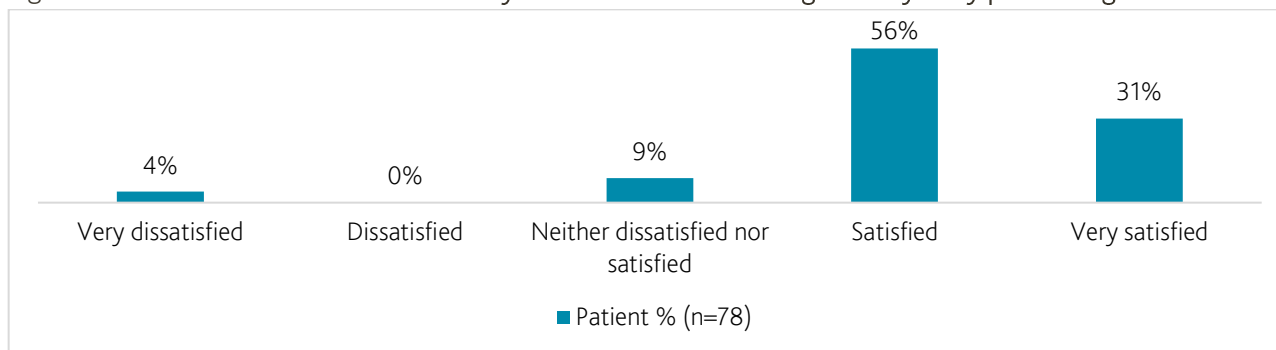
- ❖ Figure 29 shows when asked what their top information source from a patient organisation was, more people ranked social media channels as their top choice (24%), followed by websites (20%). *Only asked to those who indicated they had connected with a patient organisation.*

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



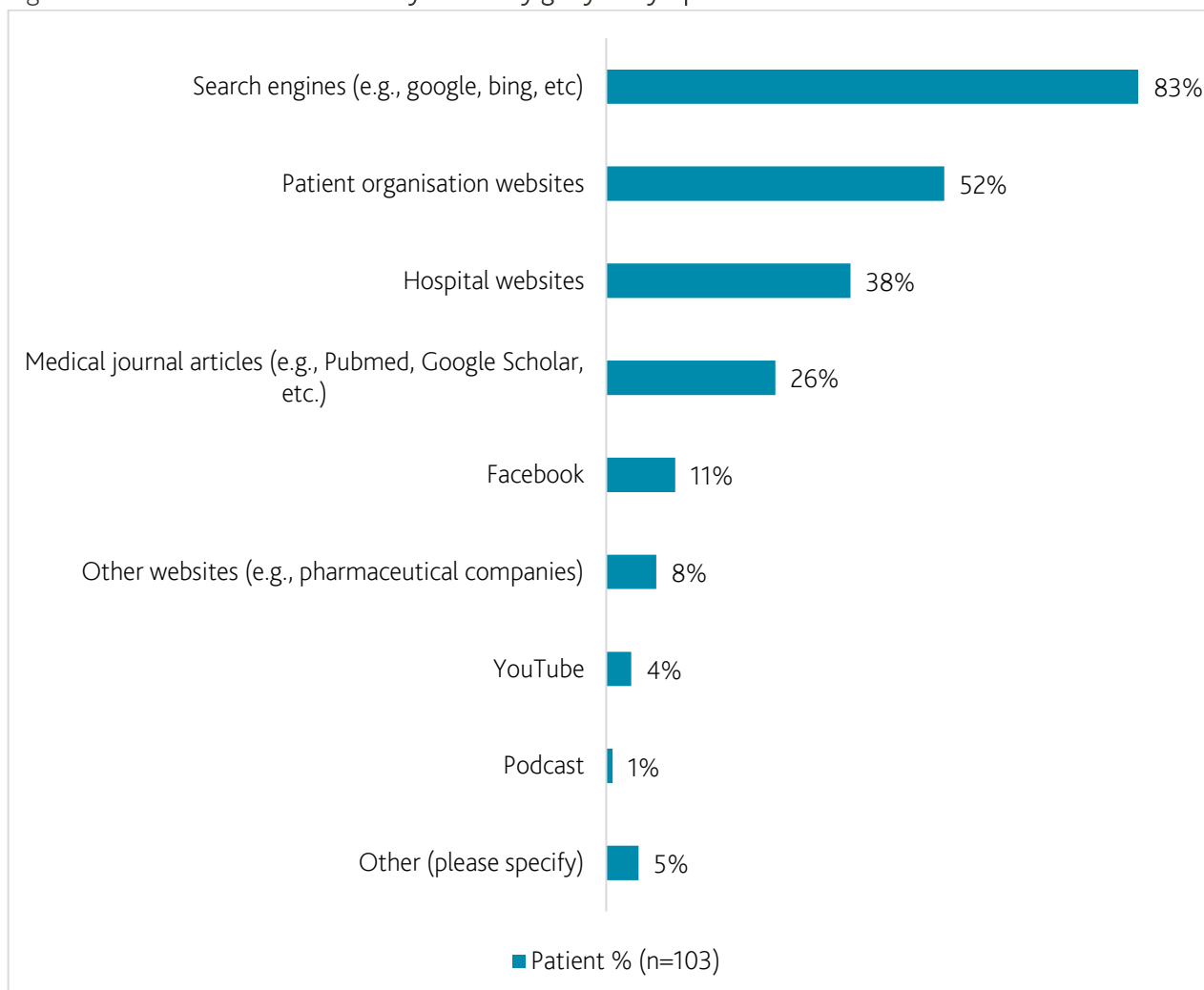
- ❖ Figure 30 reveals 87% of patients were satisfied or very satisfied with the information given by patient organisations. *Only asked to those who indicated they had connected with a patient organisation.*

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



- ❖ Figure 31 explains when on the internet, patients most often get lymphoma or CLL information from search engines (83%) and patient organisations (52%). *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?



Country-Specific Question

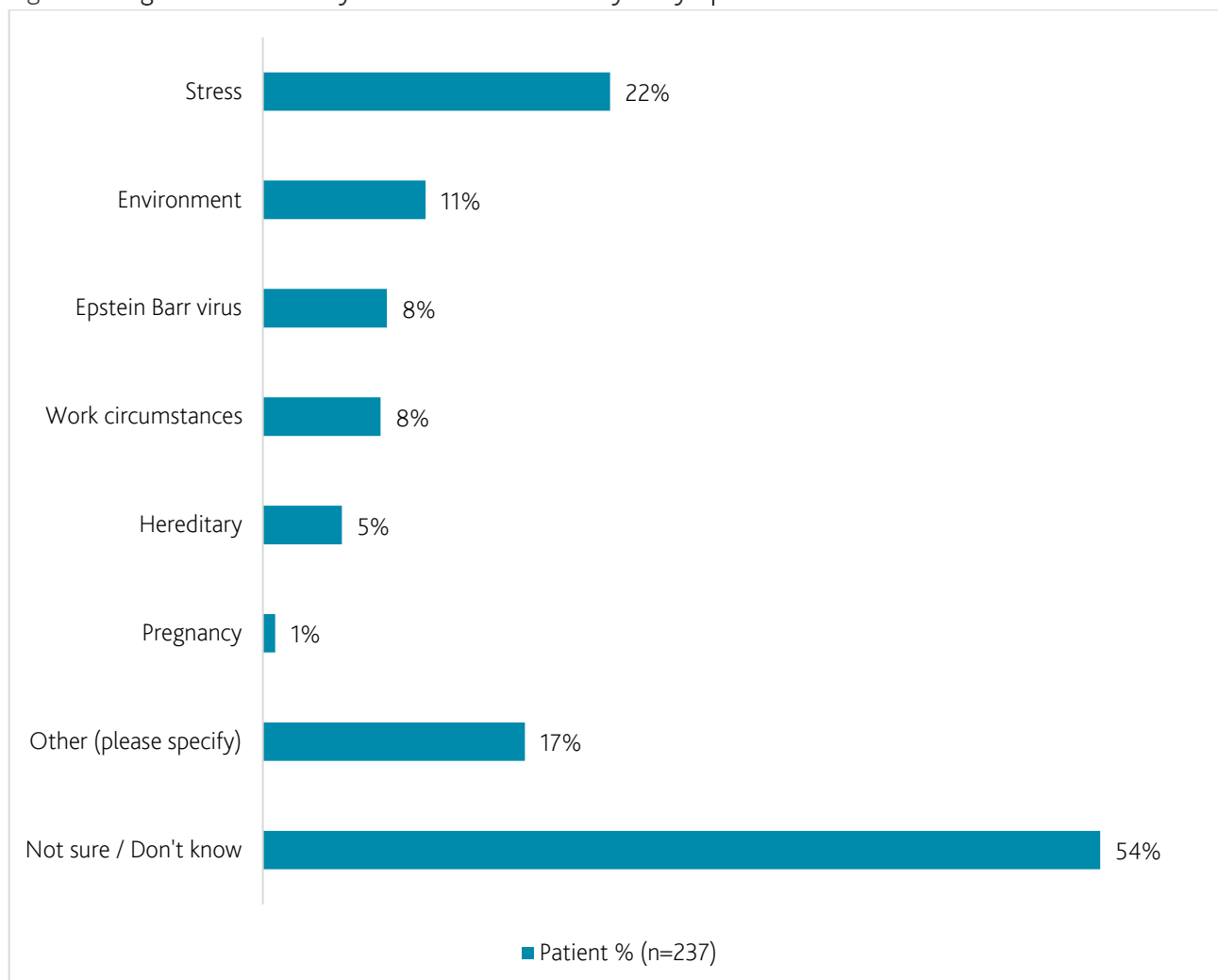
Patients from Belgium were asked what they thought was the cause of their lymphoma.



- Over half of patients were unsure what caused their lymphoma..
- Stress was the highest reported speculated cause (22%), followed by environment (11%) and Epstein Barr virus (8%).

❖ Figure 32 reveals an almost even split between those who believe they know what caused their lymphomas and those that don't.

Figure 32. Figure 32. What do you think is the cause of your lymphoma?



Healthcare Support

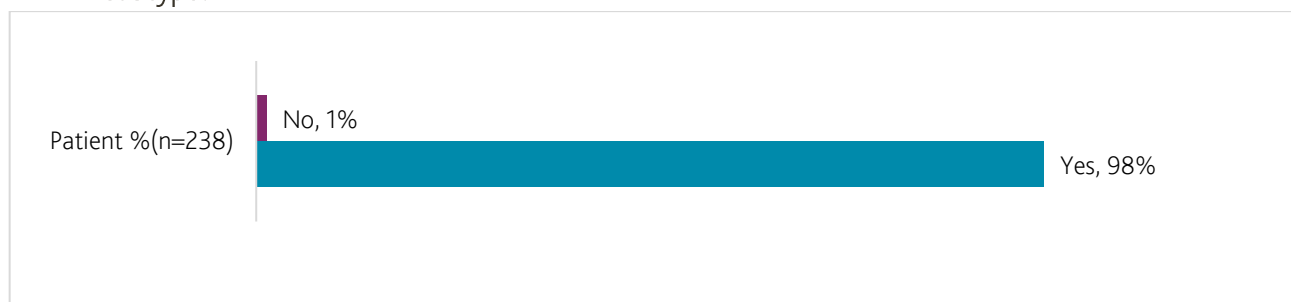
In addition to information, patients need support to help them cope with the challenges they face during their experience with lymphoma or CLL. The results in this section includes specific questions for patients with indolent disease, those in remission/survivors and people in active monitoring.



- Almost half of patients had seen a specialist (e.g., haematologist, oncologist, dermatologist) for their lymphoma subtype.
- The majority of patients had been seeing the same speciality physician (e.g., haematologist, oncologist, dermatologist) throughout their patient experience.
- Most patients did not have their healthcare supported by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator.
- Over two-thirds of those who had their care supported by a cancer care team, had a dedicated first point of contact

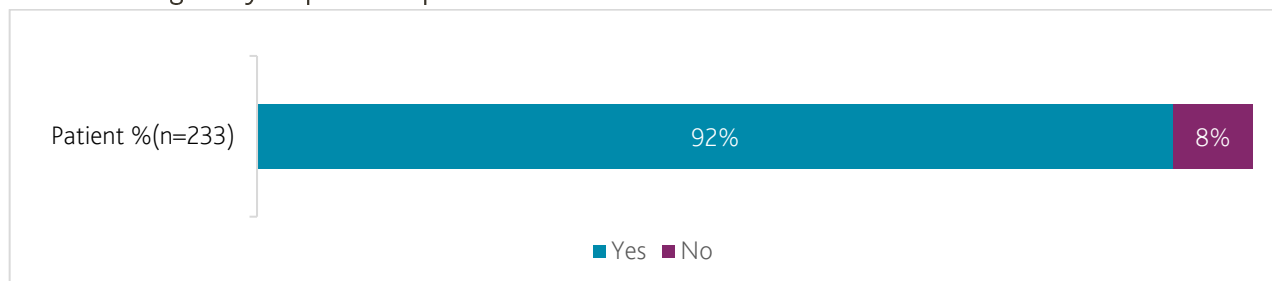
❖ Figure 33 shows almost all had seen a specialist for their lymphoma subtype.

Figure 33. Have you ever seen a specialist (e.g., haematologist, oncologist, dermatologist) for your lymphoma subtype?



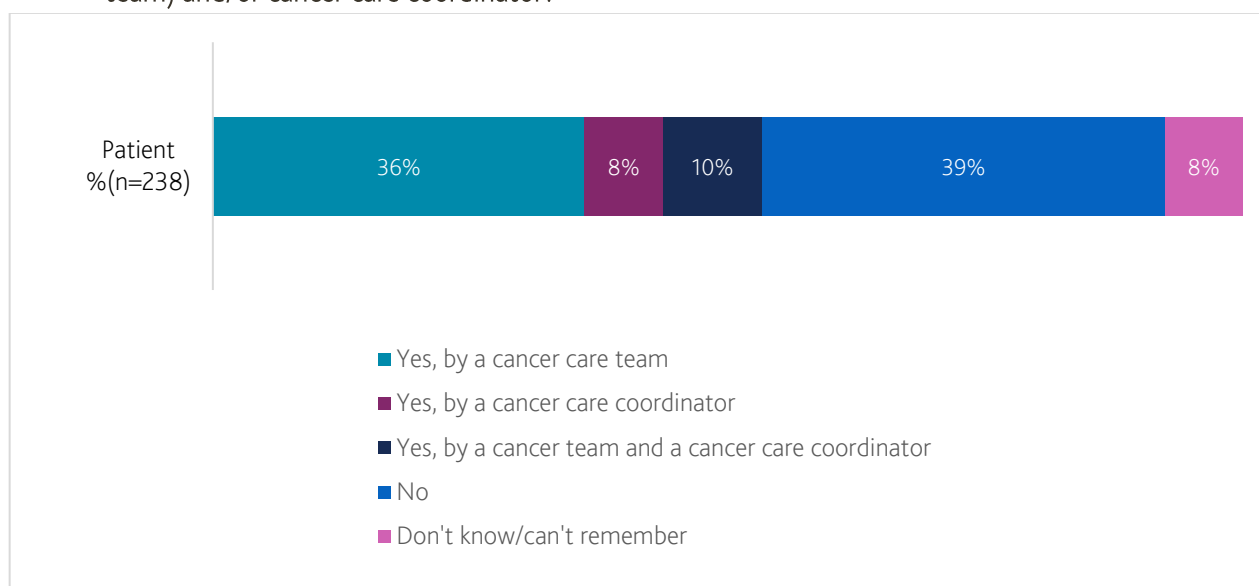
- ❖ Figure 34 reveals of those who did see a specialists, 8% did not see the same specialty physician throughout their patient experience. *Only asked to those who indicated they had seen a specialist.*

Figure 34. Have you been seeing the same specialty physician (e.g., haematologist, oncologist, dermatologist) throughout your patient experience?



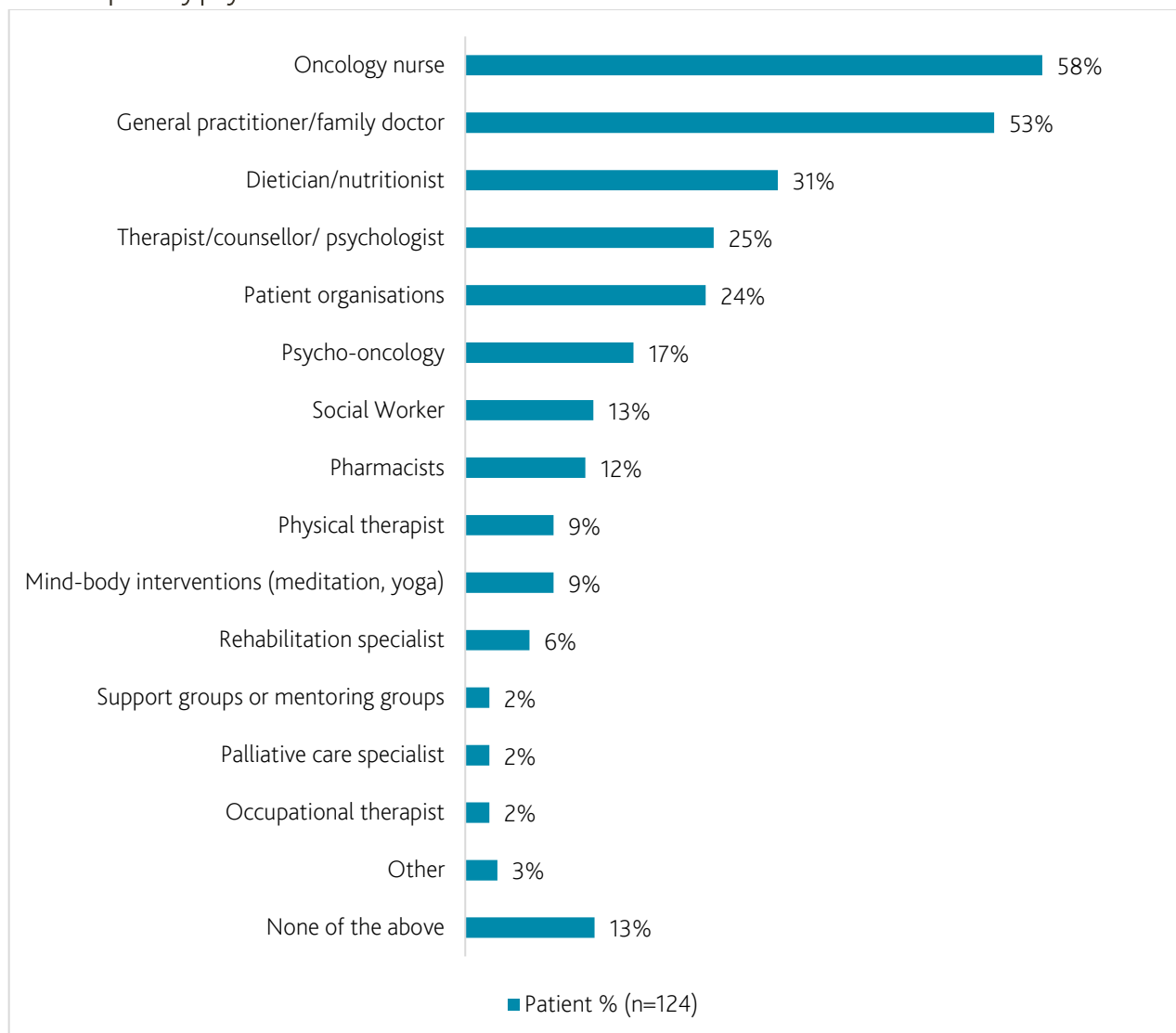
- ❖ Figure 35 illustrates that 39% of patients did not have their lymphoma care provided by a cancer team or coordinator.

Figure 35. Did/do you have lymphoma care provided by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator?



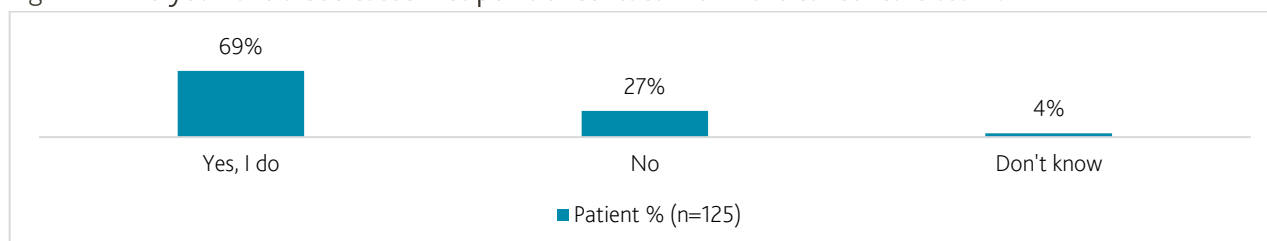
- ❖ Figure 36 reveals of those who had access to a cancer care team, 58% said oncology nurses were useful in providing supportive care, followed by general practitioners (53%), and dietitians (31%). *Only asked to those who reported they had access to a cancer care team and/or cancer care coordinator.*

Figure 36. Which of the following, if any, have you found useful in providing supportive care, outside of the specialty physician?



- ❖ Figure 37 shows of those who had access to a cancer care team, 69% of patients have a dedicated first point of contact within the team. *Only asked to those who reported they had access to a cancer care team and/or cancer care coordinator.*

Figure 37. Do you have a dedicated first point of contact within the cancer care team?

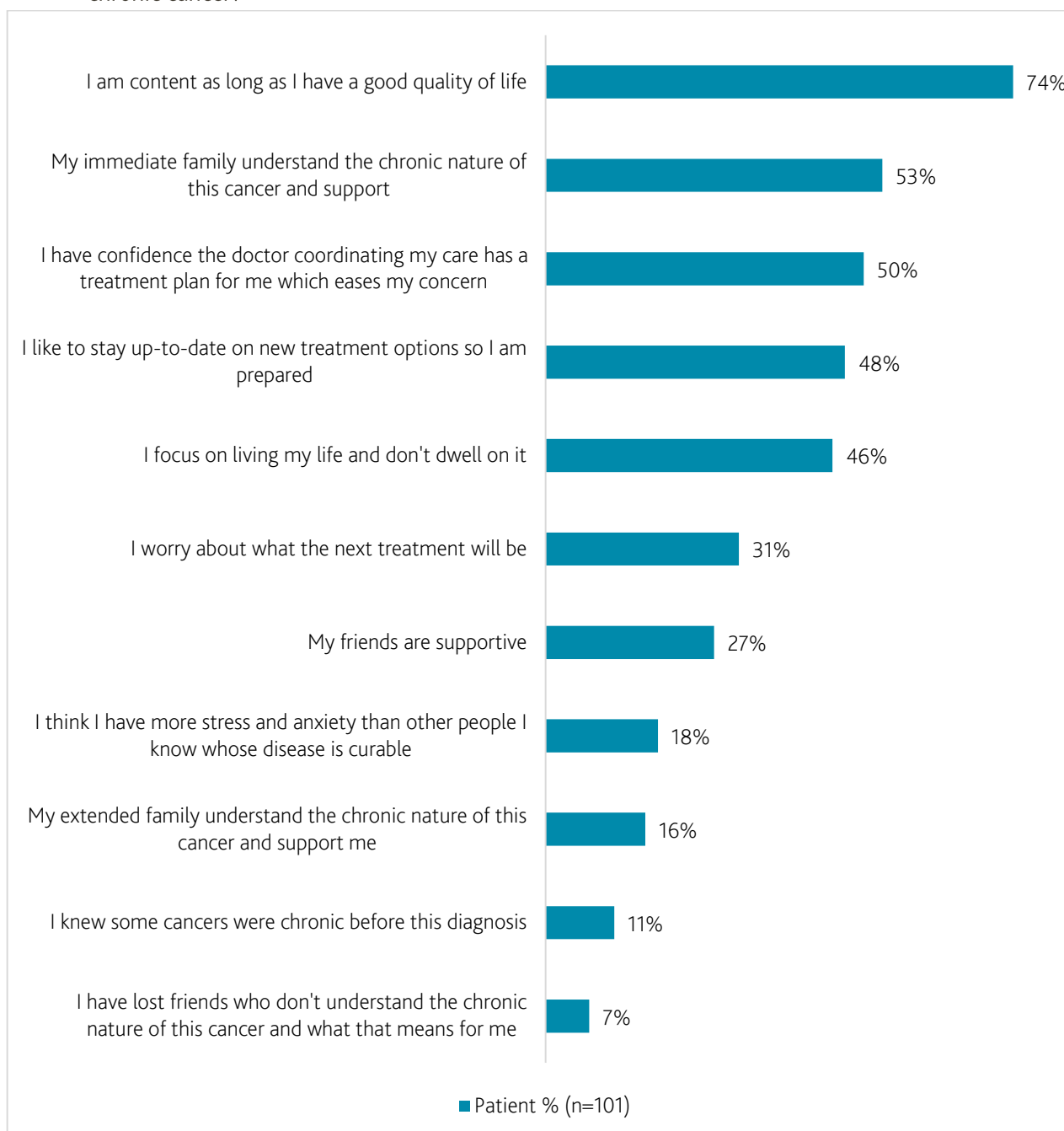


Support Experience of Patients with Indolent Lymphomas

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 reveals that when asked about living with a chronic cancer, 74% of patients say they are content as long as they have a good quality of life.

Figure 38. Which of the following statements reflects how you feel about your experience living with a chronic cancer?

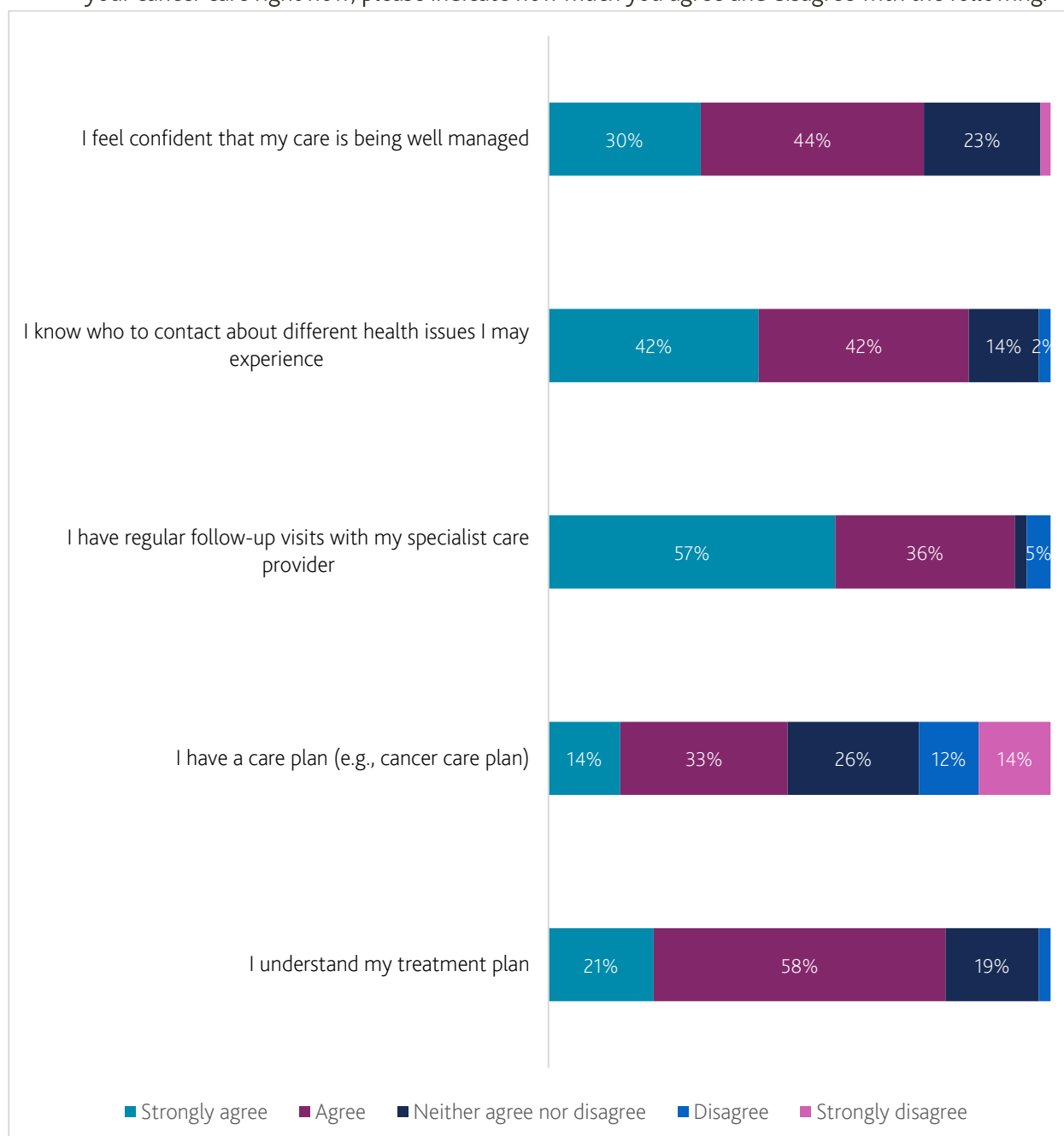


Support Experience of Patients in Active Surveillance

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 39 illustrates that overall, 93% of patients have regular follow-up visits with their specialist care provider. 47% of patients strongly agree or agree they have a cancer care plan. *Only asked to those in active monitoring, both those who have never had treatment and those back in active monitoring post-treatment.*

Figure 39. 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.

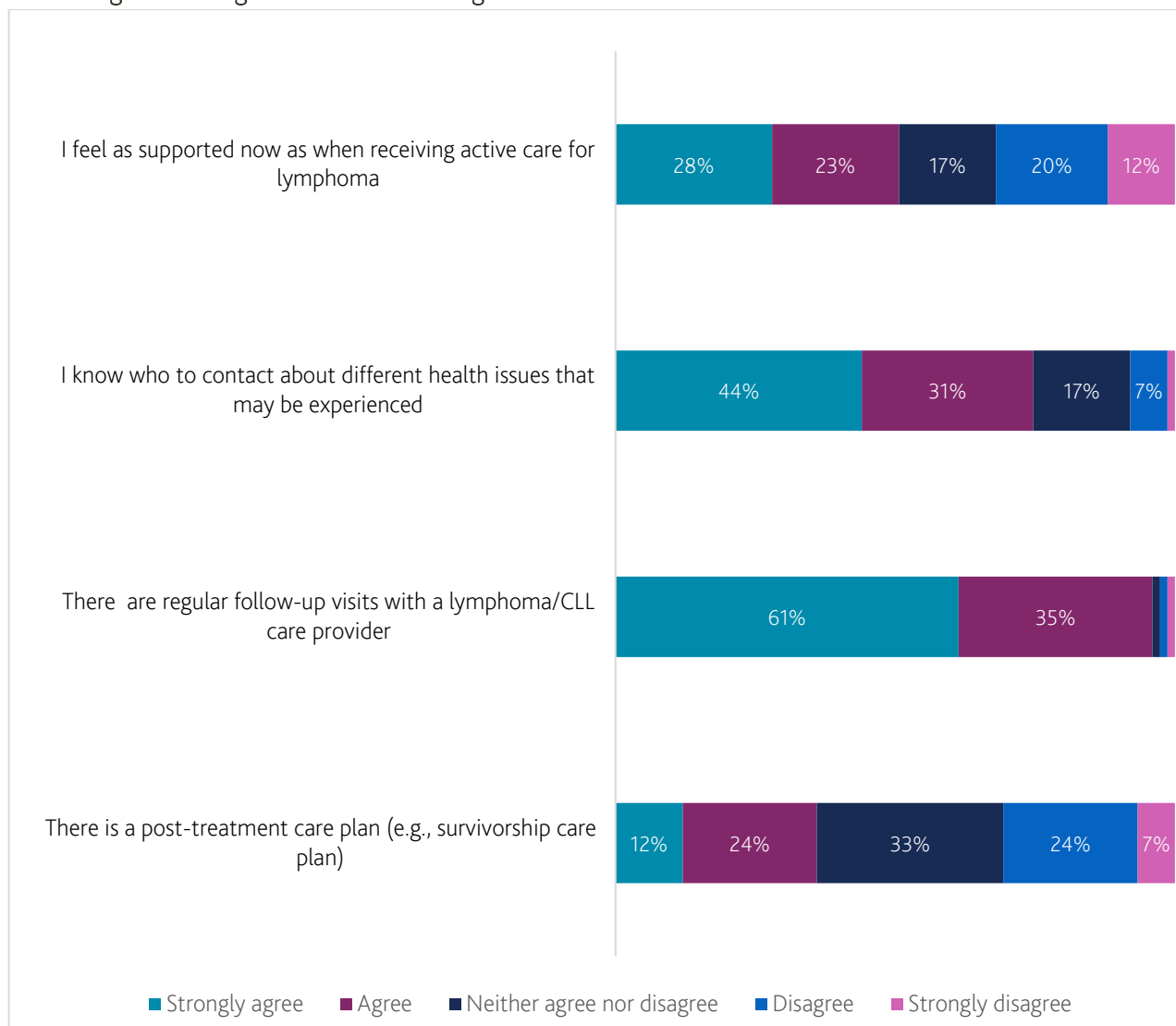


Support Experience of Patients in Remission/ Survivorship

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.

- ❖ Figure 40 shows that overall, 61% of patients in remission strongly agree that they have regular follow-up visits with a lymphoma/CLL care provider. 36% believe they have a cancer care plan. *Only asked to those who indicated they were in remission.*

Figure 40. In thinking about the transition from cancer care into survivorship, please indicate how much you agree or disagree with the following statement



Healthcare Involvement and Decision-Making

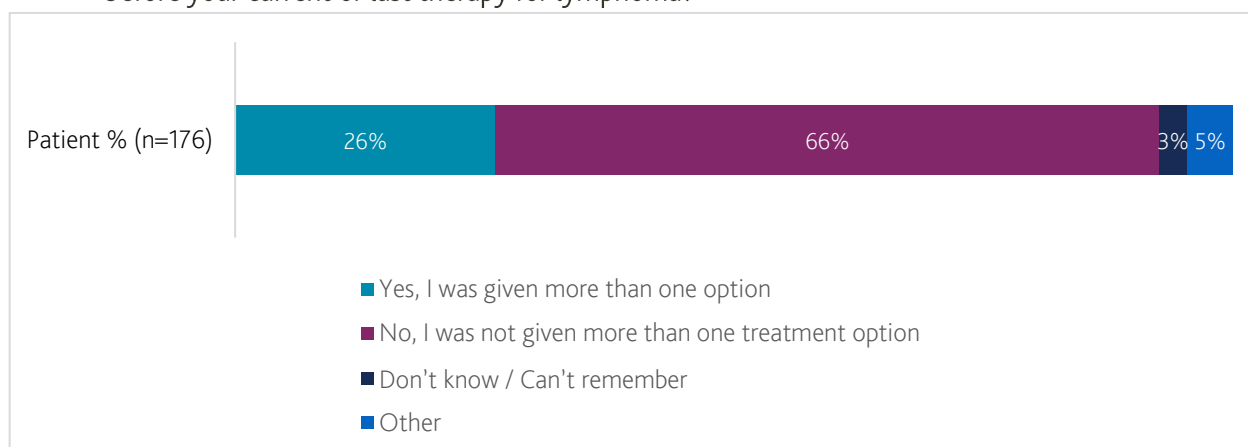
Patient-centeredness is a key part of providing high-quality cancer care as it takes the goals and expectations of patients and their families into consideration. Patients should be seen by healthcare providers as individuals and not as a diagnosis and doctors should respond to the needs, preferences 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 26% of patients were given more than one treatment option before their current or last therapy for lymphoma.
- 86% of patients felt as involved as much as they want to be in decisions about their care and treatment.
- Nearly two-thirds of patients would like the doctor and patient to be involved in final decisions about care.
- 28% of patients say their doctor never identifies and recommends other resources and support.

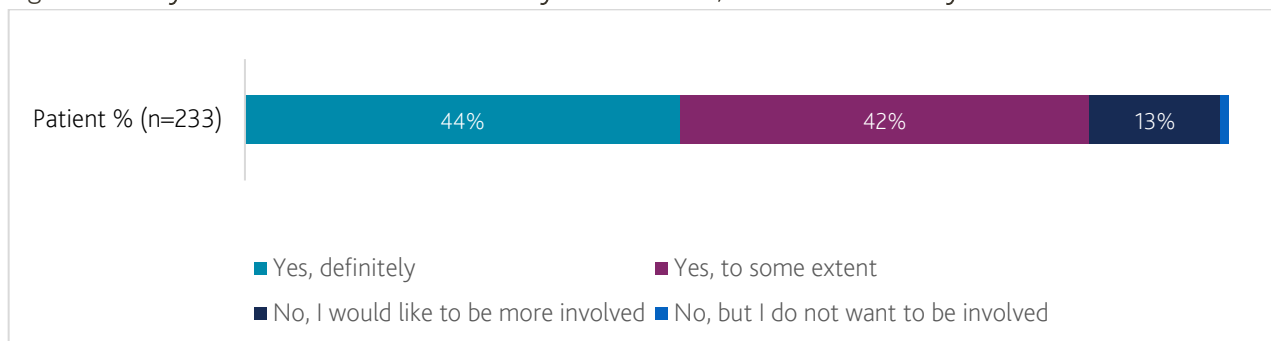
❖ Figure 41 reveals two-thirds of patients were not given more than one treatment option before their current or last therapy for lymphoma or CLL. **Only asked to those who had been treated.**

Figure 41. 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?



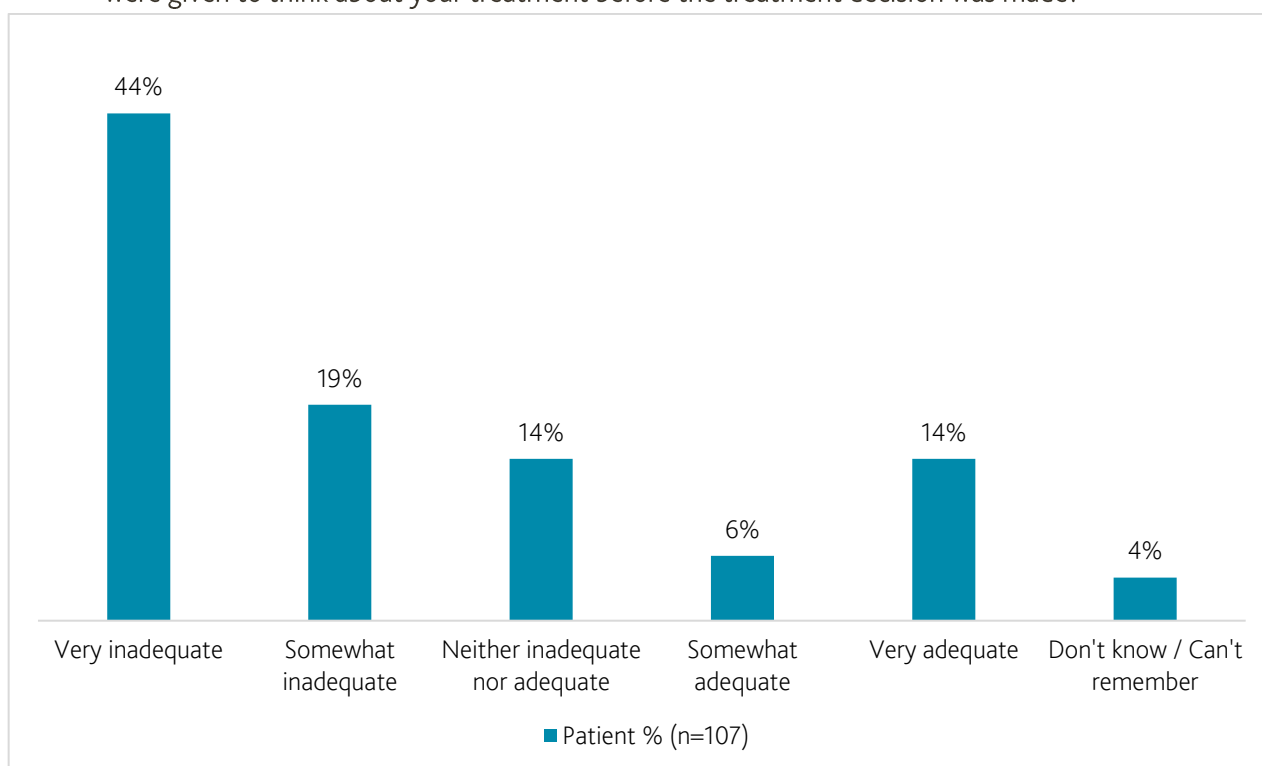
- ❖ Figure 42 explains 44% said they were involved as much as they wanted to be in decisions about care and treatment.

Figure 42. Do you feel as involved as much as you want to be, in decisions about your care and treatment?



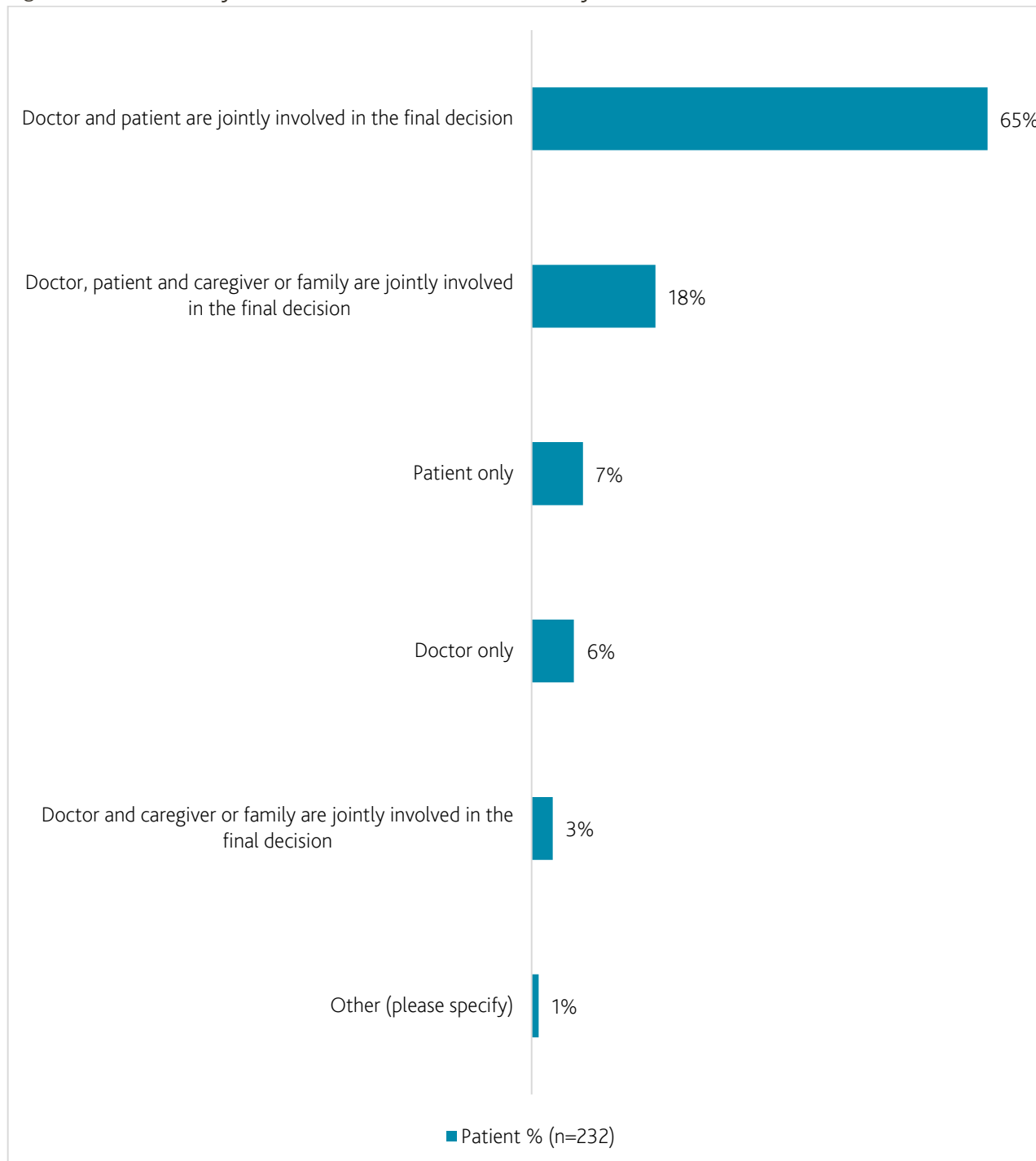
- ❖ Figure 43 reveals 63% of patients said the amount of time to think about treatment was inadequate. *Only asked to those who had been treated.*

Figure 43. Regarding your current treatment or last treatment, how adequate was the amount of time you were given to think about your treatment before the treatment decision was made?



- ❖ Figure 44 shows when asked about healthcare decision making, there was an overwhelming preference for collaboration. The majority (65%) included the doctor and the patient in the decision, and 18% included the caregiver or family as well.

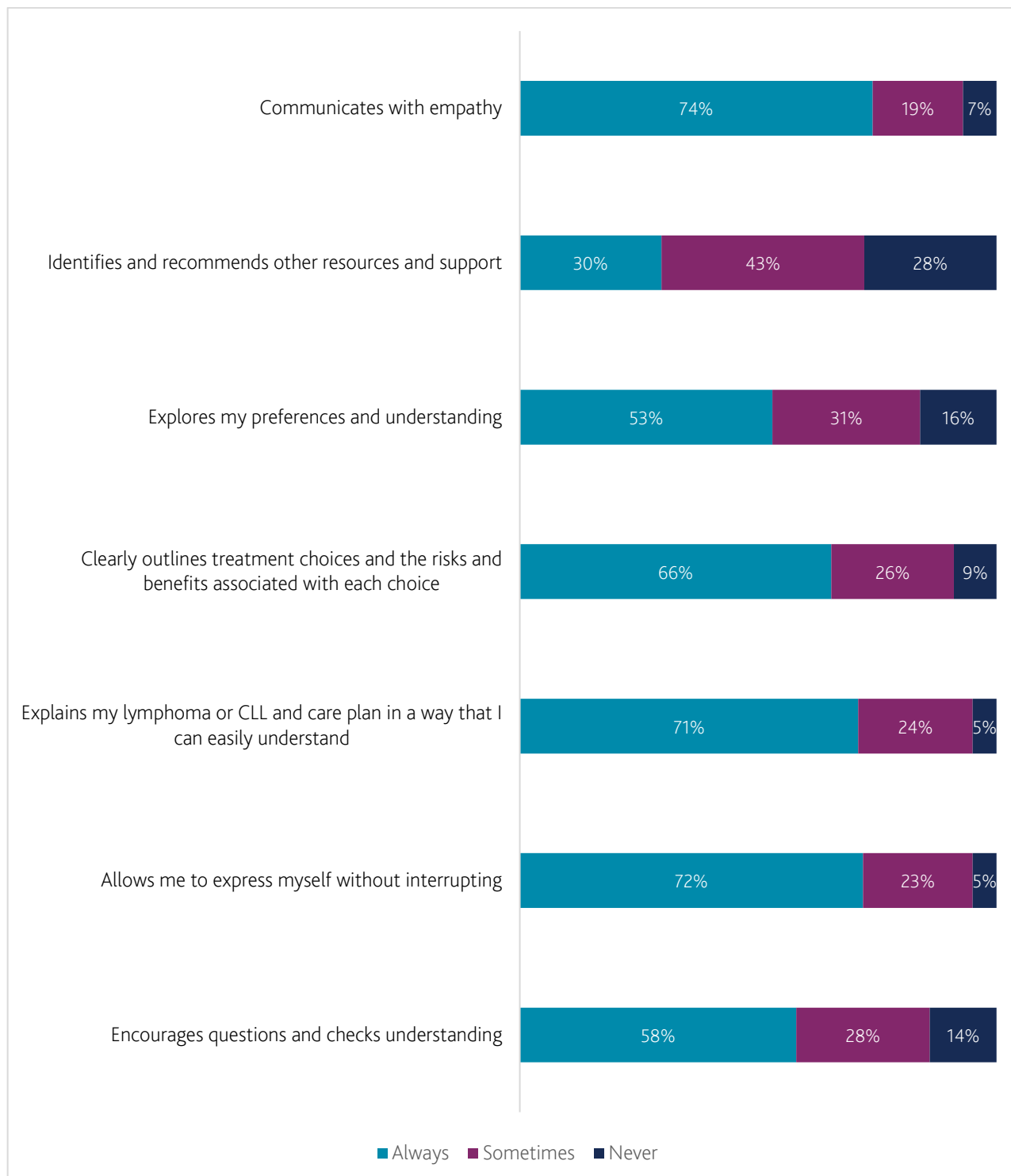
Figure 44. Who would you like to make the final decision on your healthcare?



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 45 illustrates the two biggest gaps identified are 28% of patients said their doctor never identifies and recommends other sources and support and 16% said their doctor never explores their preferences and understanding.

Figure 45. Does your doctor do any of the following to encourage participation in decision-making about your care?



- ❖ Figure 46 reveals that when asked about the importance of information from the specialist physician, telling the truth (84%) and understanding patient goals and concerns about treatment (68%) were ranked most important.

Figure 46. 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 fatigue was the most reported symptom of lymphoma or CLL (71%). Treatment alleviated fatigue for 20% of those affected by it.

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

Effects of Lymphoma	Number of respondents (n)	%	Treatment alleviated symptoms*
Abdominal swelling	29	13%	57%
Anaemia	51	22%	53%
Bone pain	61	26%	35%
Cold agglutinin disease	3	1%	0%
Cryoglobulinemia	1	0%	0%
Easily bruised or bleed	52	23%	26%
Enlarged lymph nodes/ abnormal painless swelling(s) on the body	118	51%	90%
Fatigue	164	71%	20%
Fever, chills, night sweats and weight loss (B-symptoms)	92	40%	64%
Frequent or repeated infections	30	13%	45%
Headaches	55	24%	28%
Hyperviscosity syndrome	2	1%	50%
Itchy skin	58	25%	54%
Pain	33	14%	41%
Shortness of breath	66	29%	31%
Skin rashes/lesions	40	17%	45%
Other (please specify)	35	15%	44%
No symptoms	5	2%	14%

*only asked to those who reported the symptom

Lymphoma and CLL Treatments

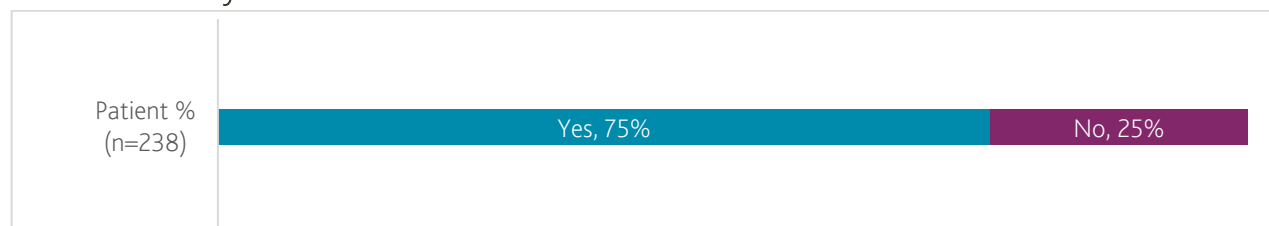
This section deals with questions that were only asked to patients currently on treatment or those who had previously received treatment for their lymphoma, including CLL, which accounted for 75% of respondents. Of that group, 62% had treatment within the last 2 years.



- 61% who had ever received or received treatment had first line, while 11% received their second line of treatment
- 29% of patients had been in a clinical trial
- 9% of patients were interested in information about the effect of their treatment on fertility, but they were not given such information
- 28% of patients agree and 36% strongly agree that their treatment was chosen to minimize the impact of possible side effects on lifestyle and/or favourite activities

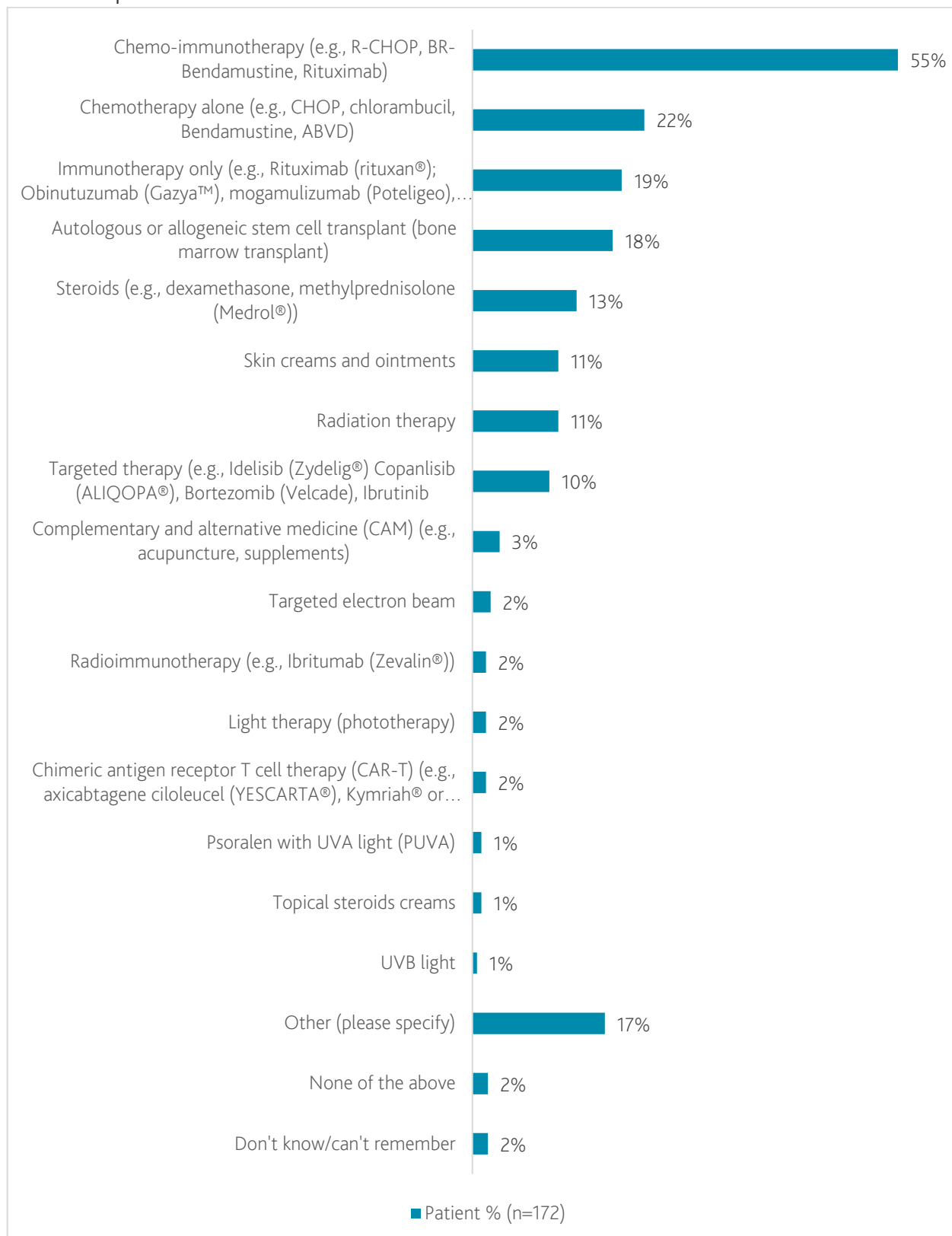
❖ Figure 47 illustrates three-quarters of patients are receiving or have received medical treatment for their lymphoma or CLL in the last 2 years. **Only asked to those who have received treatment.**

Figure 47. Did you receive a medical treatment (e.g., chemotherapy, radiation) for lymphoma or CLL within the last 2 years?



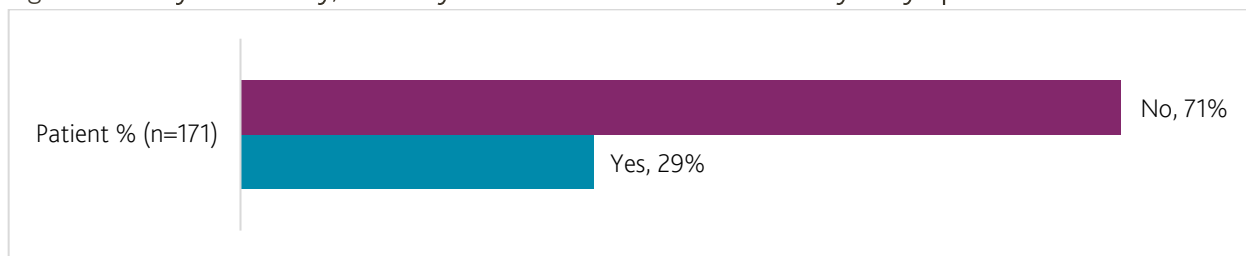
- ❖ Figure 48 shows that 55% of patients are currently receiving, or have received, chemoimmunotherapy. Only asked to those who have received treatment.

Figure 48. Which of the following treatment options, if any do you receive currently, or have ever received in the past?



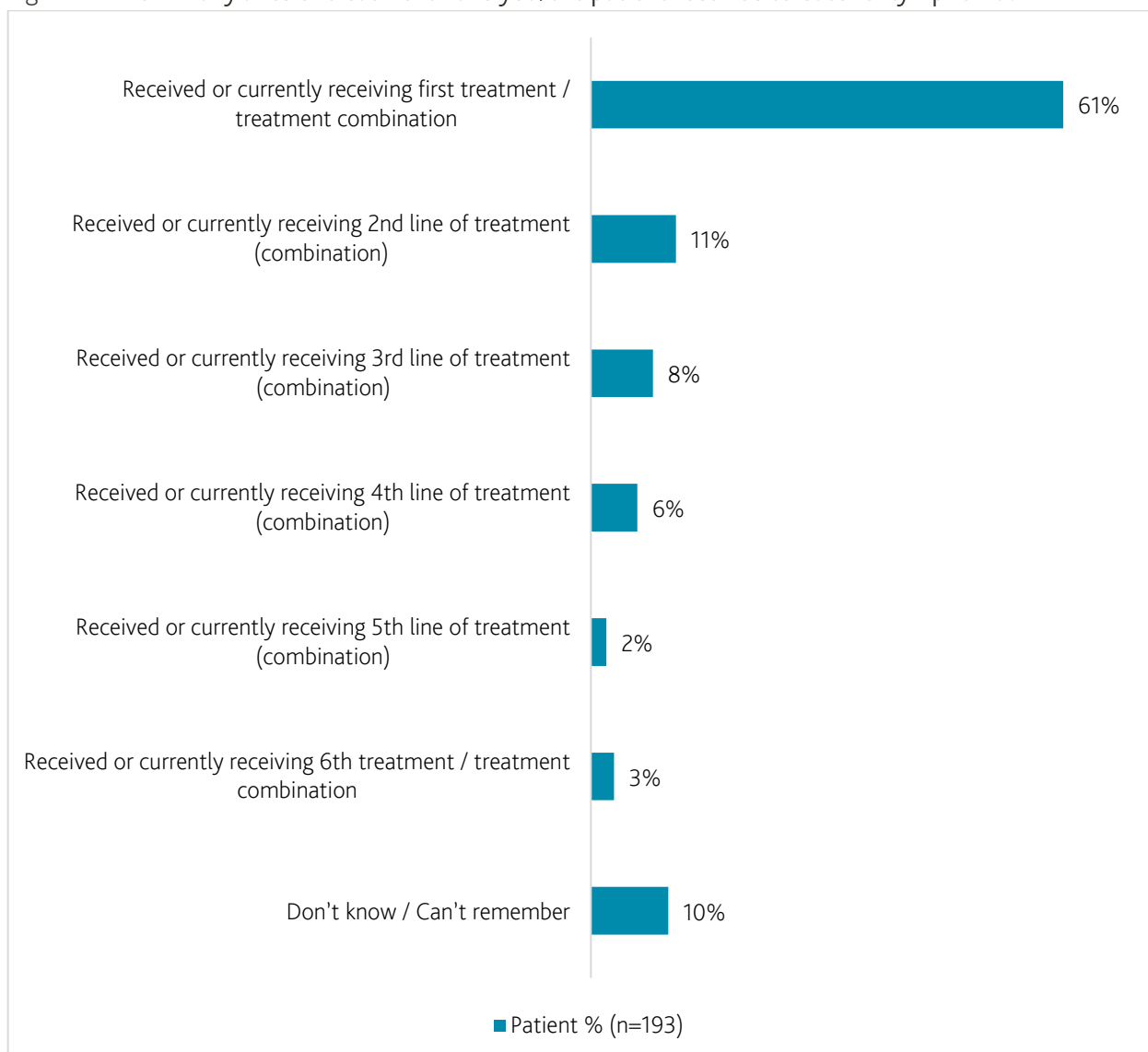
- ❖ Figure 49 reveals 29% of patients have been in a clinical trial for lymphoma. *Only asked to those who have received treatment.*

Figure 49. Are you currently, or have you ever been in a clinical trial for your lymphoma?



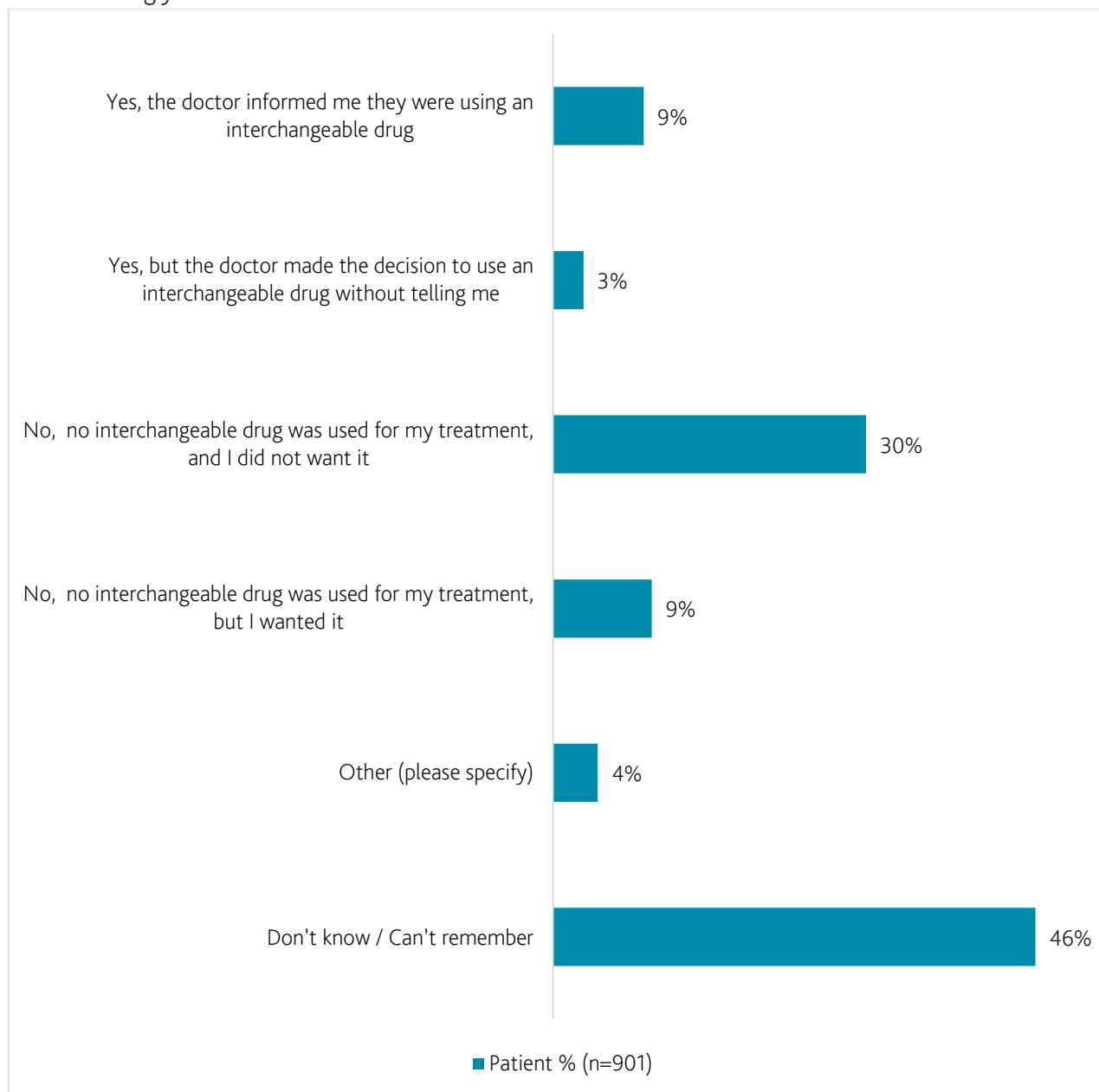
- ❖ Figure 50 shows 61% patients have received or are receiving their first line of treatment or treatment combination. *Only asked to those who have received treatment.*

Figure 50. How many lines of treatment have you/the patient received to date for lymphoma?



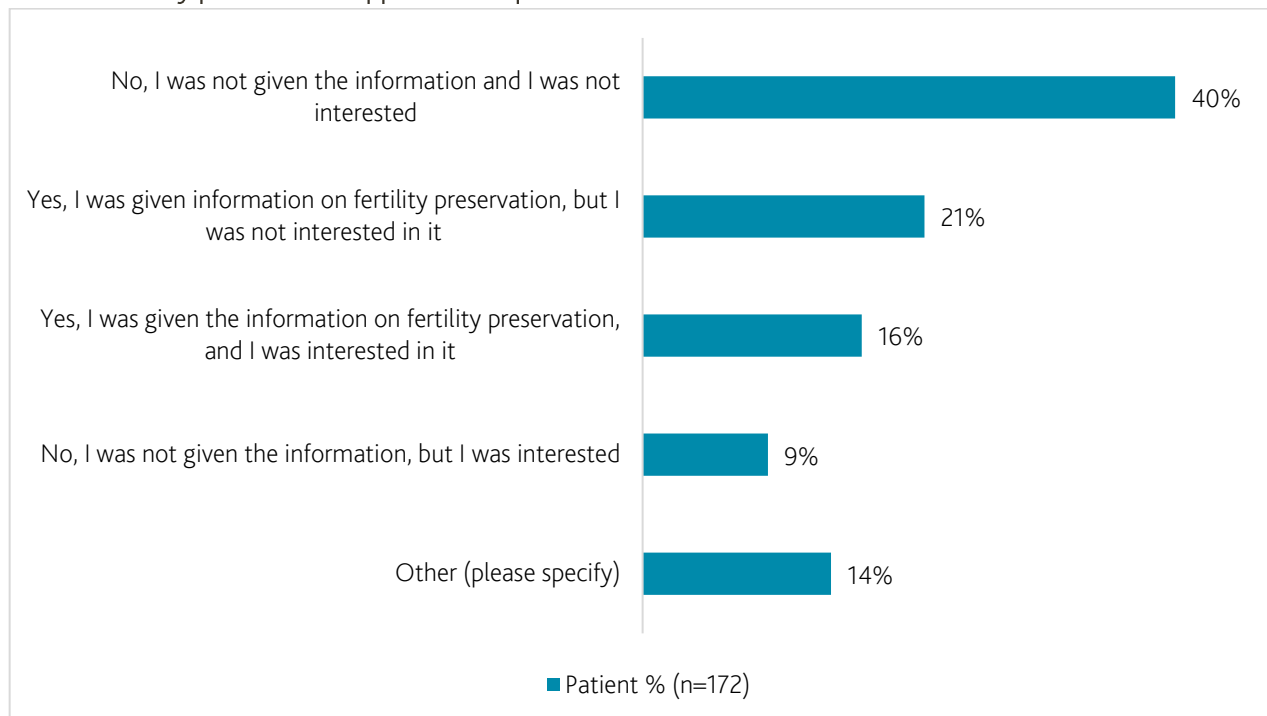
- ❖ Figure 51 illustrates an interchangeable drug was used in the treatment of 12% of patients, but 3% were not told about the decision. 46% of patients did not know if an interchangeable drug had been used or not. **Only asked to those who have received treatment.**

Figure 51. Were interchangeable/equivalent drugs (e.g., generic, biosimilars, pharmaceutical equivalents), used during your treatment?



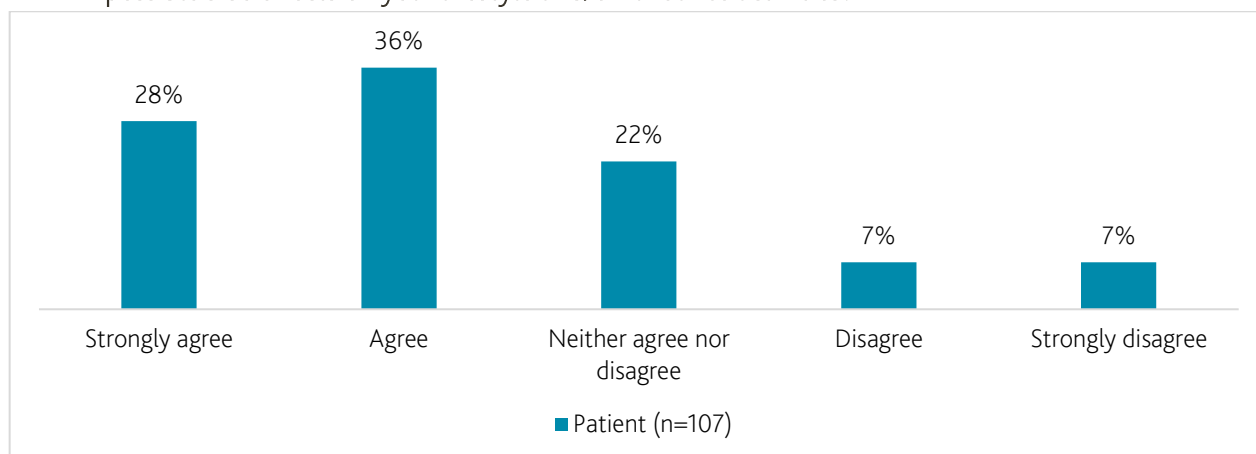
- ❖ Figure 52 reveals a quarter of patients were interested in information about fertility, but 9% were not given such information. *Only asked to those who have received treatment.*

Figure 52. Did your medical team give you any information about treatment side effects on fertility and about fertility preservation opportunities prior to treatment?



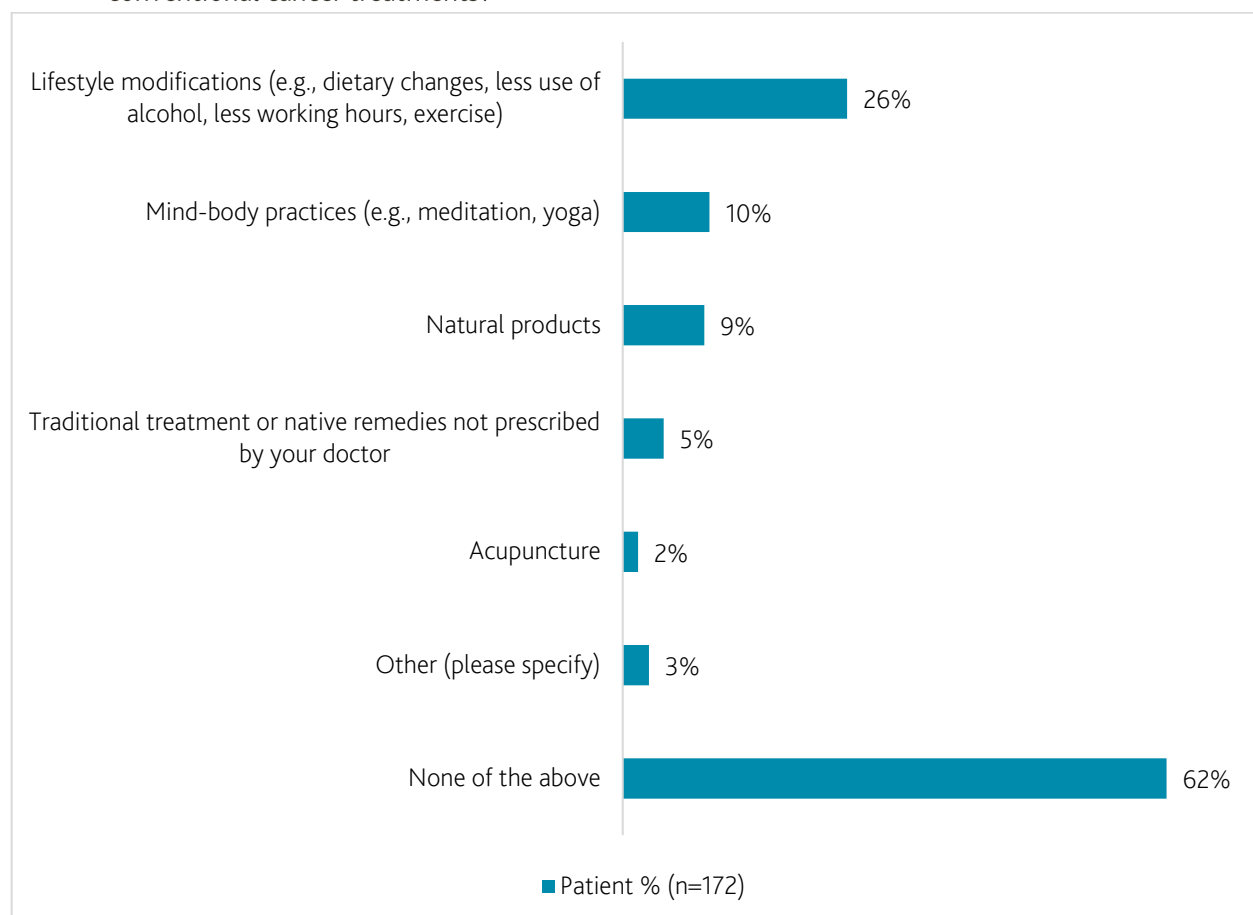
- ❖ Figure 53 illustrates that nearly two-thirds of patients agree or strongly agree that treatment was chosen to minimize the impact of possible side effects on their lifestyle and/or favourite activities. *Only asked to those who have received treatment.*

Figure 53. 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?



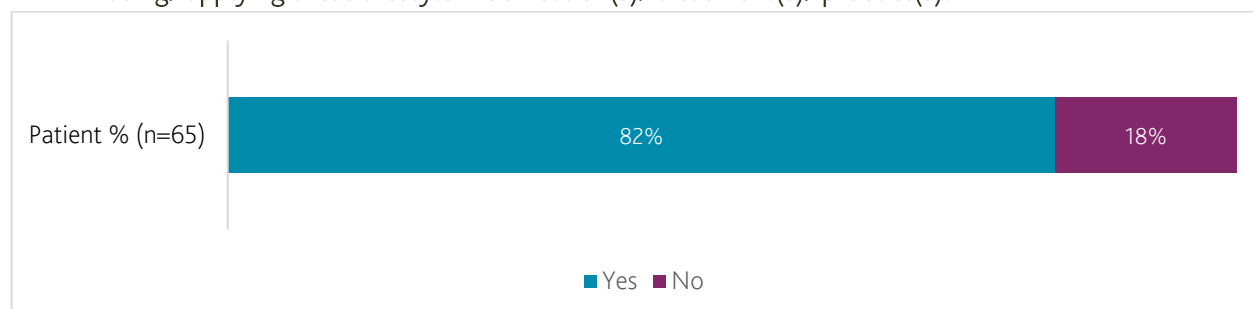
- ❖ Figure 54 reveals that 62% of patients had not used any of the following treatments alongside conventional cancer treatments. *Only asked to those who have received treatment.*

Figure 54. During your experience so far with lymphoma or CLL, were any of following used alongside conventional cancer treatments?



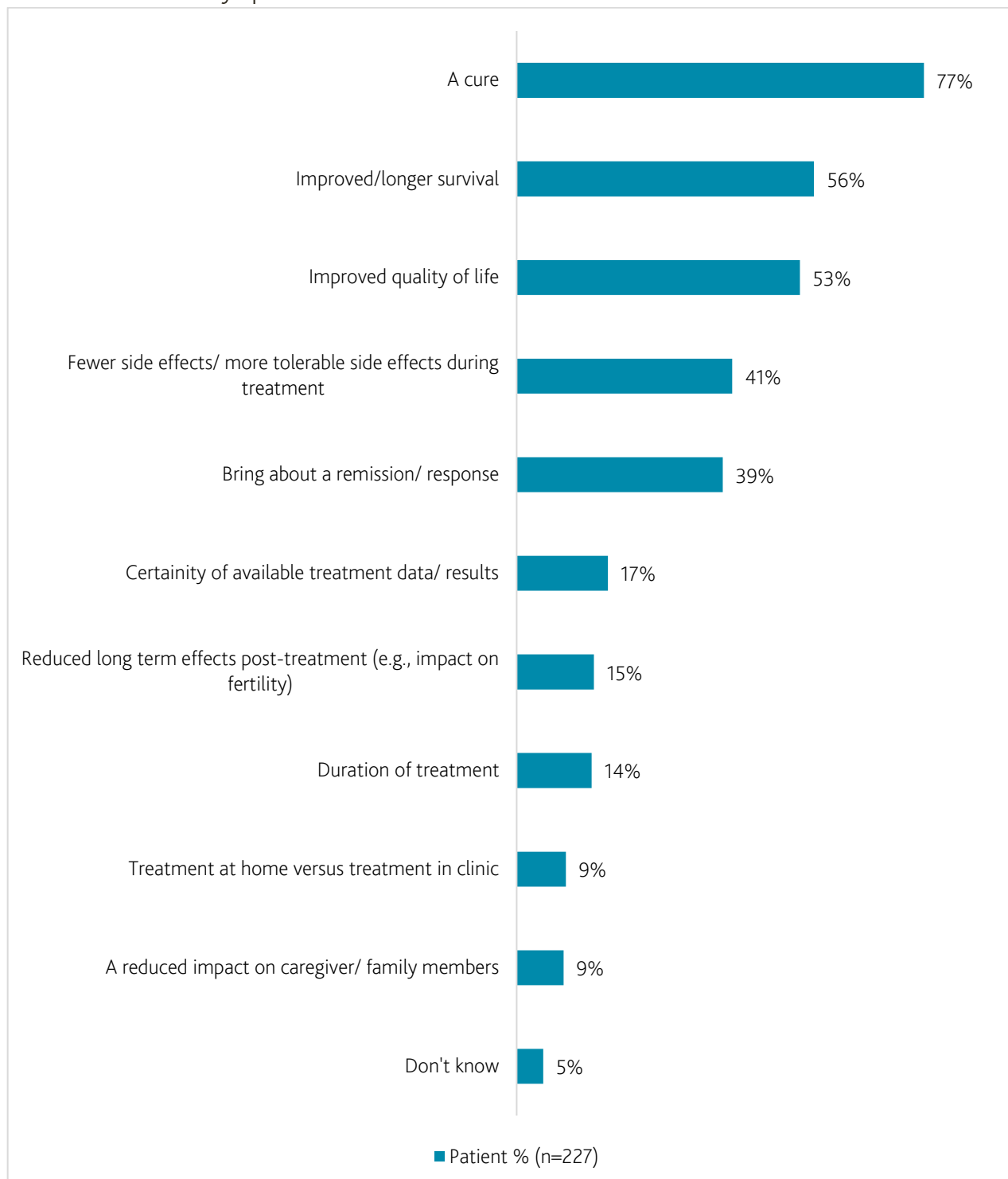
- ❖ Figure 55 explains of those who applied lifestyle modifications, treatments, or products, 82% told their lymphoma or CLL doctor about it. *Only asked to those who used these types of remedies alongside conventional cancer treatment.*

Figure 55. 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 56 reveals when asked about important features of a new medical treatment for lymphoma or CLL, patients said a cure (77%), improved/longer survival (56%), and improved quality of life (53%).

Figure 56. 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 69% of patients rank 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	96	69%	8	6%	16	12%
Improved/ longer survival	9	6%	53	38%	21	15%
Bring about a remission/ response	8	6%	24	17%	22	16%
Improved quality of life	14	10%	25	18%	25	18%
Fewer side effects/more tolerable side effects during treatment	6	4%	16	12%	21	15%
Reduced long-term effects post-treatment (e.g., impact on fertility)	3	2%	4	3%	9	7%
Treatment at home versus treatment in the clinic	2	1%	2	1%	5	4%
Duration of treatment	1	1%	2	1%	5	4%
A reduced impact on caregiver/family members	1	1%	1	1%	4	3%
Certainty of available treatment data/results	0	0%	4	3%	9	7%

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.

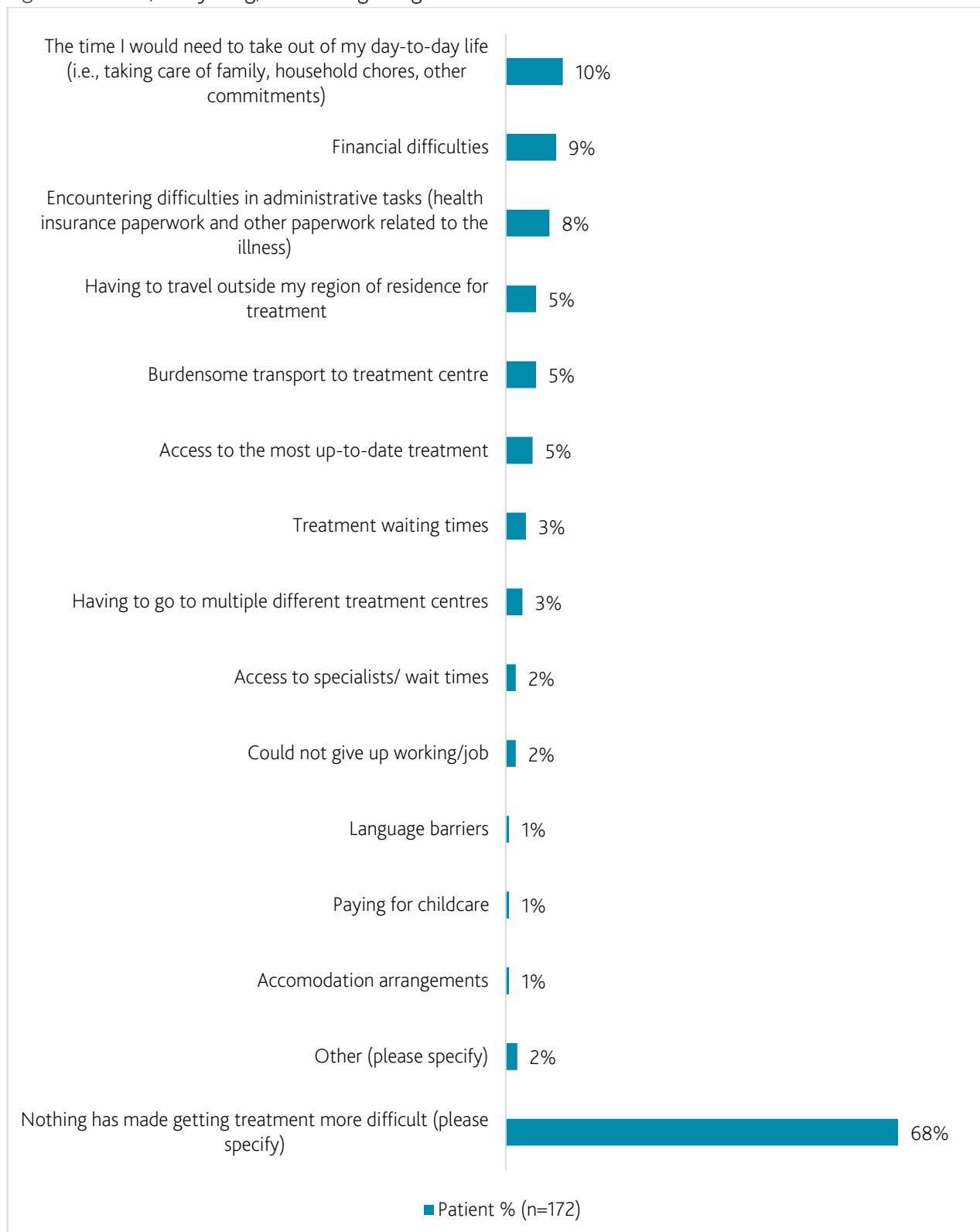
Clinical trials may provide an option for patients facing disease progression who have exhausted all traditional therapies in their country to access novel treatments. Similarly, clinical trials can provide an opportunity for patients to access treatments that would otherwise be cost-prohibitive.



- Two-thirds (68%) reported not having any barriers to receiving treatment.
- 10% of patients reported they were prevented from receiving treatment because of time they would need to take out of their day-to-day life.
- 9% patients indicated financial difficulties made receiving treatment difficult.
- A quarter of patients said they would not participate in a clinical trial due to fear of potential unknown side effects.

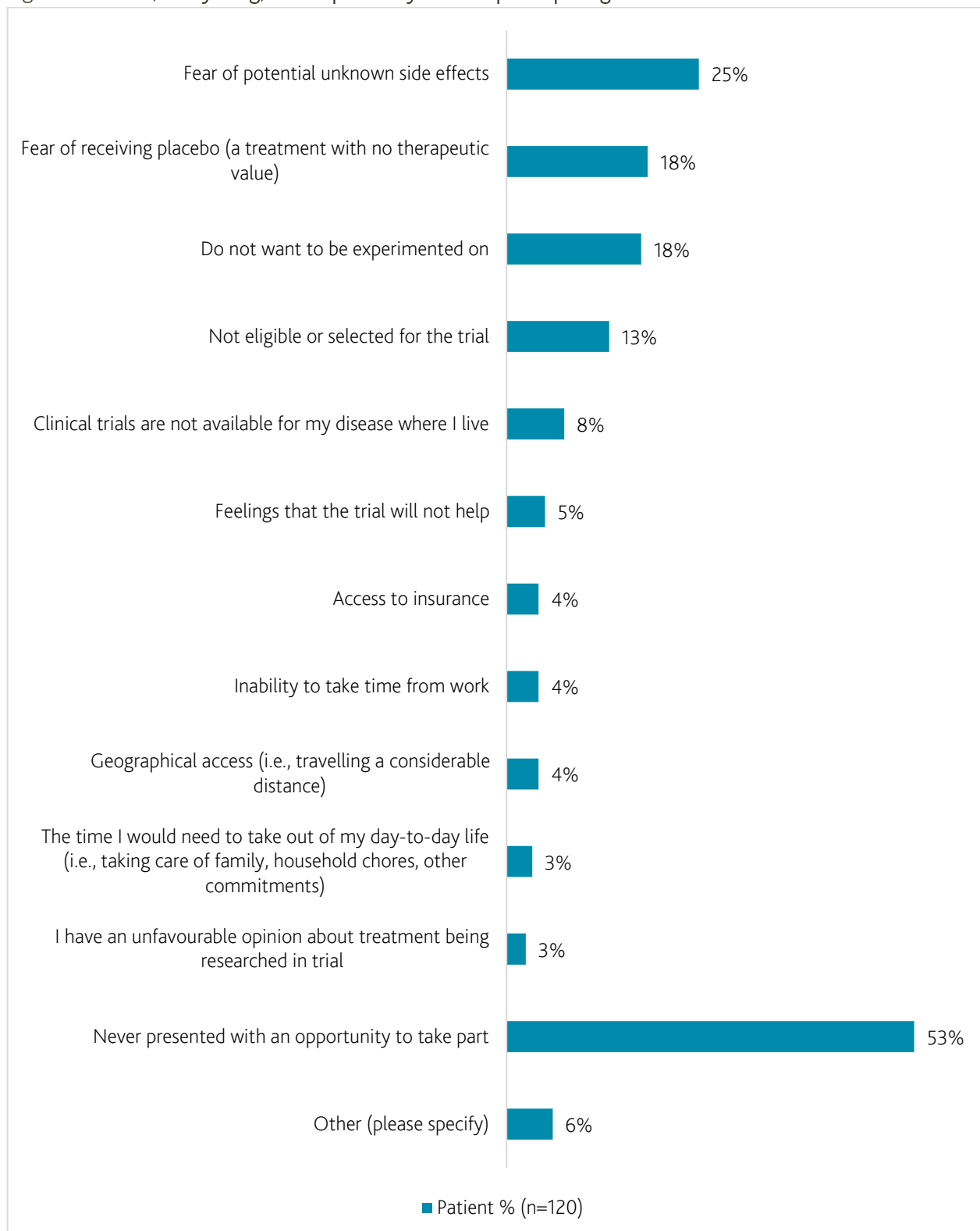
- ❖ Figure 57 reveals that 68% of patients feel that nothing has made getting treatment more difficult. *Only asked to those who have received treatment.*

Figure 57. What, if anything, has made getting treatment more difficult?



- ❖ Figure 58 explains a quarter of patients were afraid of potential unknown side effects. Only asked to those who have received treatment.

Figure 58. What, if anything, would prevent you from participating in a clinical trial?



Side Effects of Treatment

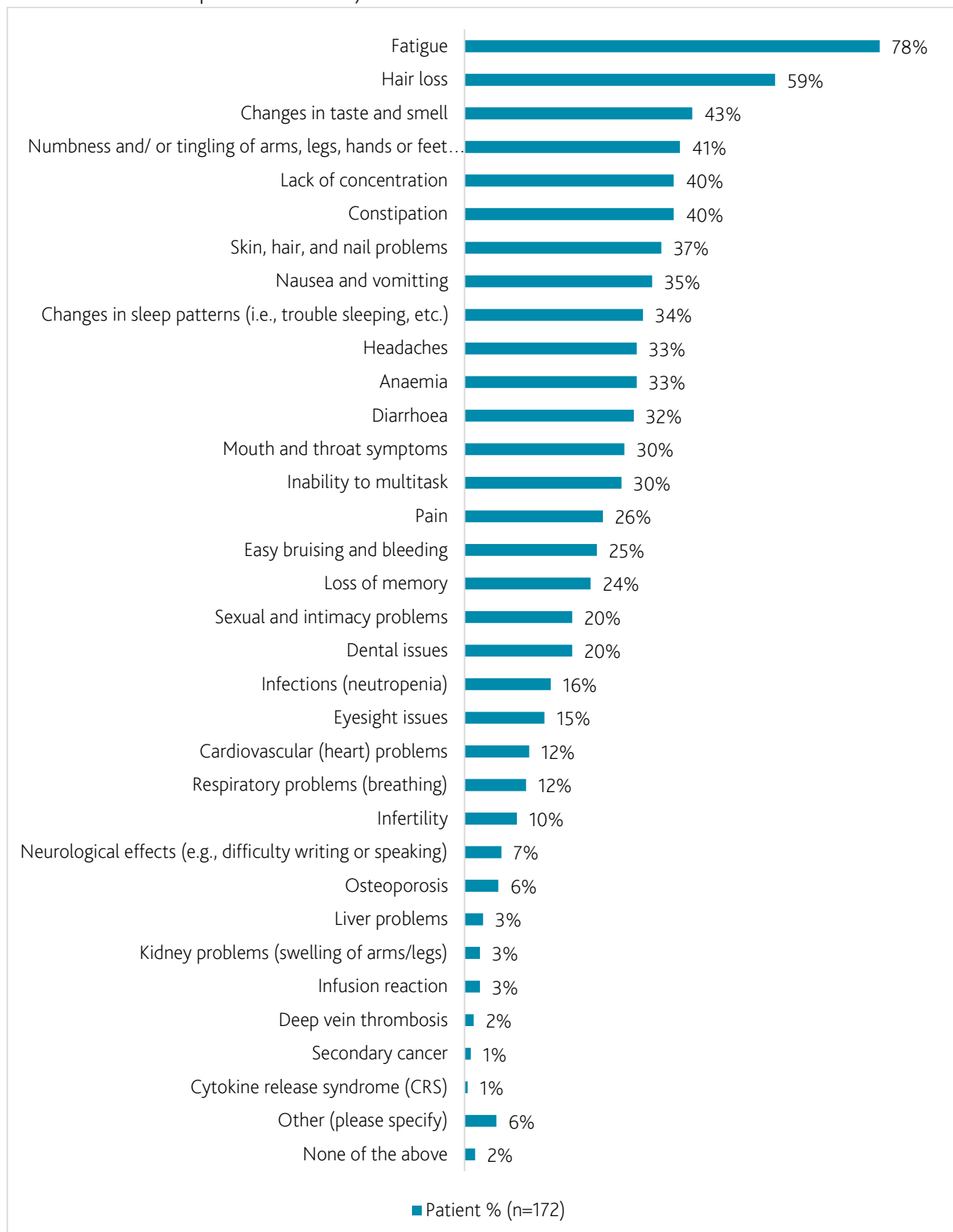
Patients receiving treatment for their lymphoma/CLL are affected by a range of treatment-related side effects.



- The most frequent side effects are:
 - Fatigue (78%)
 - Hair loss (59%)
 - Changes in taste and smell (43%)
 - Numbness and / or tingling of arms, legs, hands, or feet (41%)
 - Lack of concentration (40%)
- The side effects that affected patients' wellbeing the most (ranked 1st) were:
 - Fatigue
 - Changes in taste and smell
 - Hair loss
- 38% of patients who were affected by changes in taste and smell and 76% of those affected by hair loss experienced these side effects for less than 1 year.
- 73% of patients who were affected by fatigue experienced these side effects for less than five years.
- 49% of patient said their medical team helped them with some of their side effects, and 34% said they were helped with all of them.

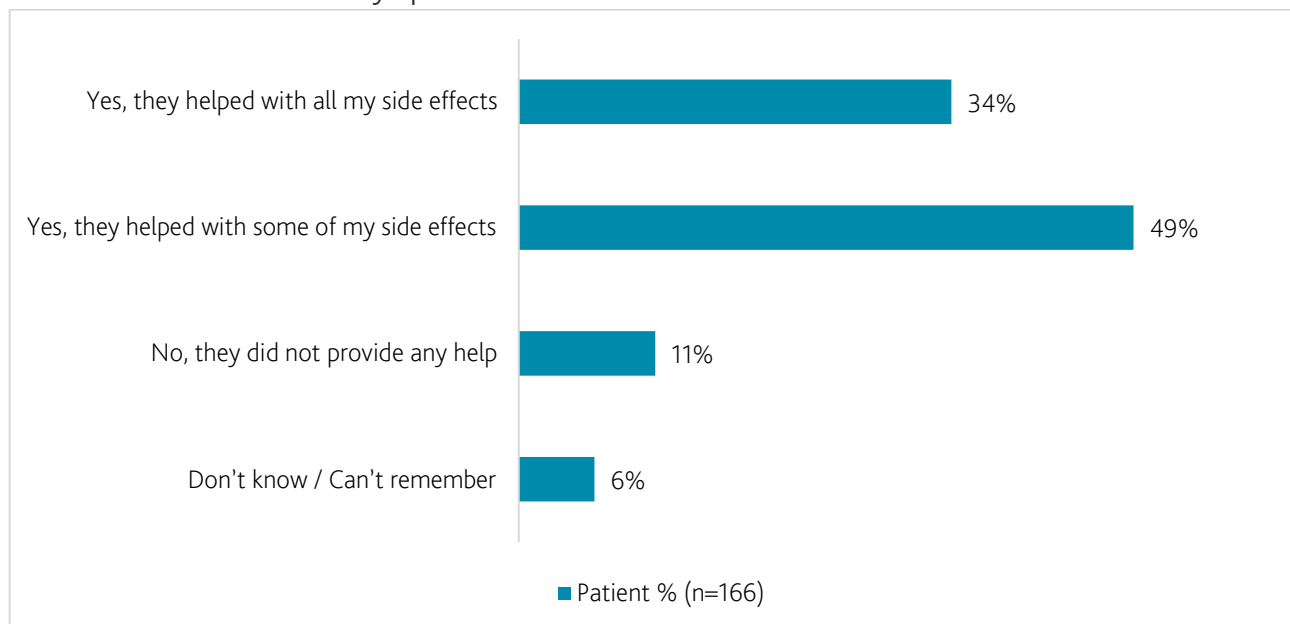
- ❖ Figure 59 shows the most commonly experienced side effects included fatigue (78%), hair loss (59%), and changes in taste and smell (43%). *Only asked to those who have received treatment.*

Figure 59. Which of the following side effects, if any, have you been affected by (highlighted the side effects that affected patients the most)?



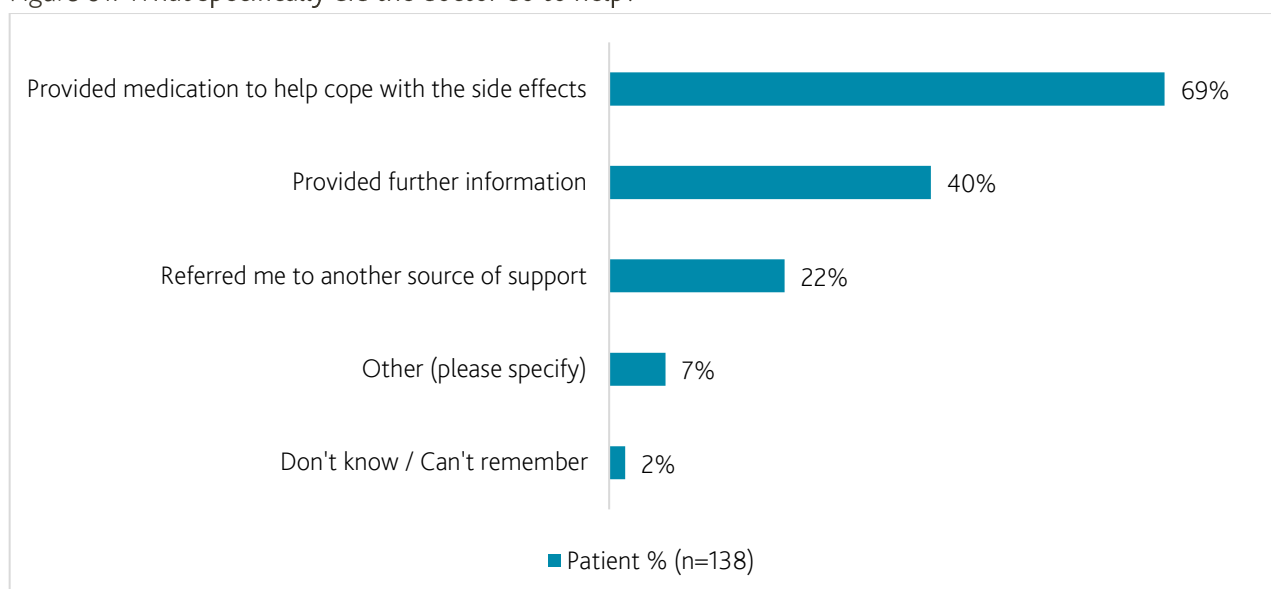
- ❖ Figure 60 shows 83% of patients said their medical team helped them with some (49%) or all (34%) of their side effects. *Only asked to those who said they had side effects.*

Figure 60. 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 61 explains medication was the top reported method (69%) of help from doctors to manage side effects, followed by information (40%) and referral to other support (22%). *Only asked to those that said the doctor helped with their side effects.*

Figure 61. What specifically did the doctor do to help?

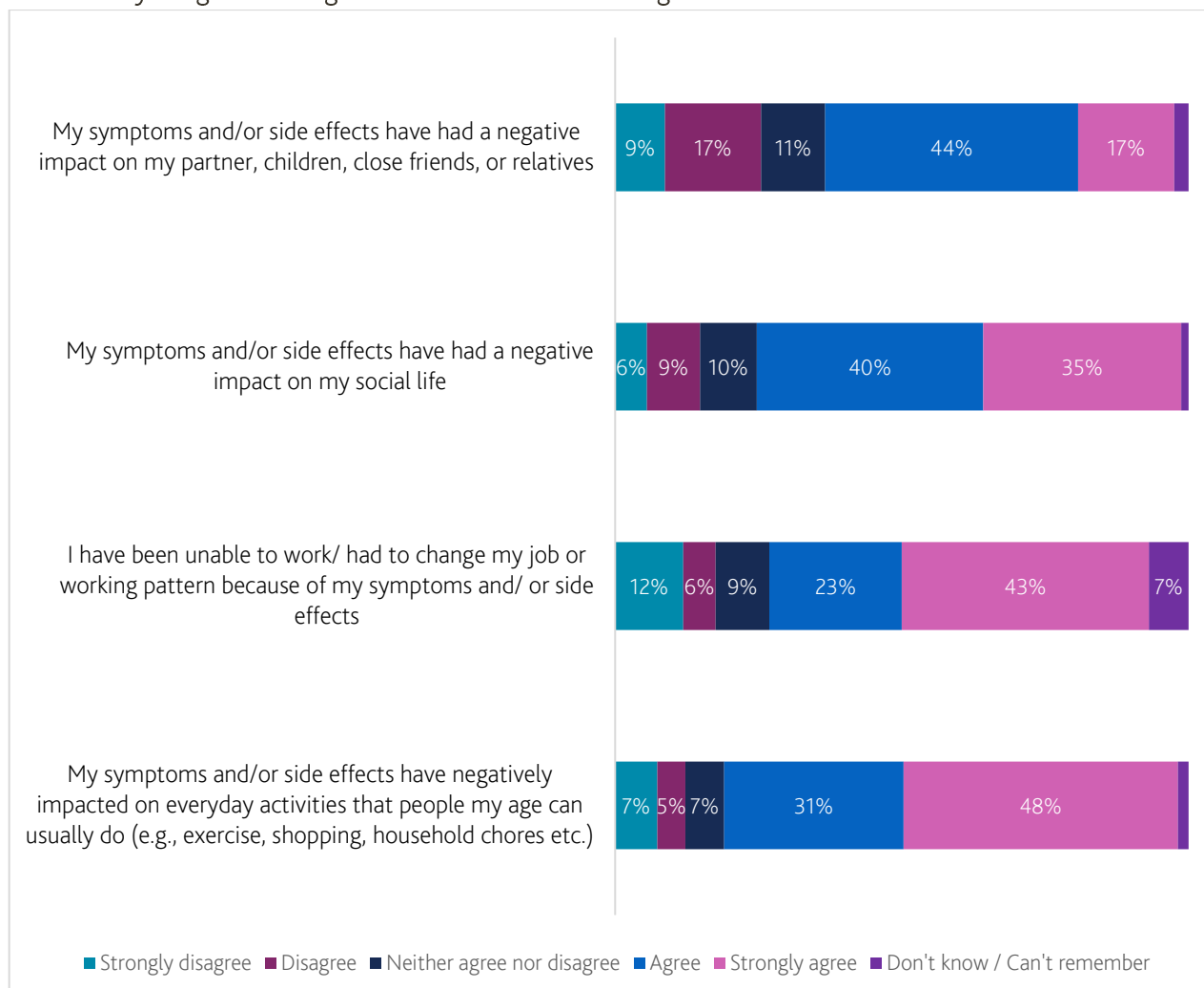


Impact of Lymphoma or CLL Symptoms and Treatment Side Effects on Quality of Life

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

- ❖ Figure 62 shows when asked about their symptoms and/or side effects, the majority of patients said they are negatively affecting many aspects of their lives. *Only asked to those who said they had symptoms from their disease or side effects from treatment.*

Figure 62. 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 (71% of all respondents) and/or as a side effect of treatment (78%).

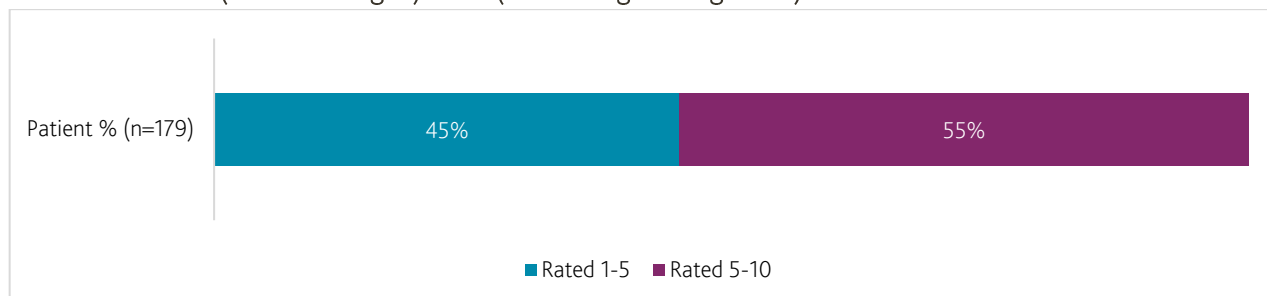


- 14% of patients didn't discuss their fatigue with their doctor over the last two years.
- 26% of patients were not provided any information to help with fatigue.
- 58% reported that they found exercise programs helpful in managing cancer-related fatigue.
- 51% of patients had a follow-up with their doctor for their cancer-related fatigue.

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).

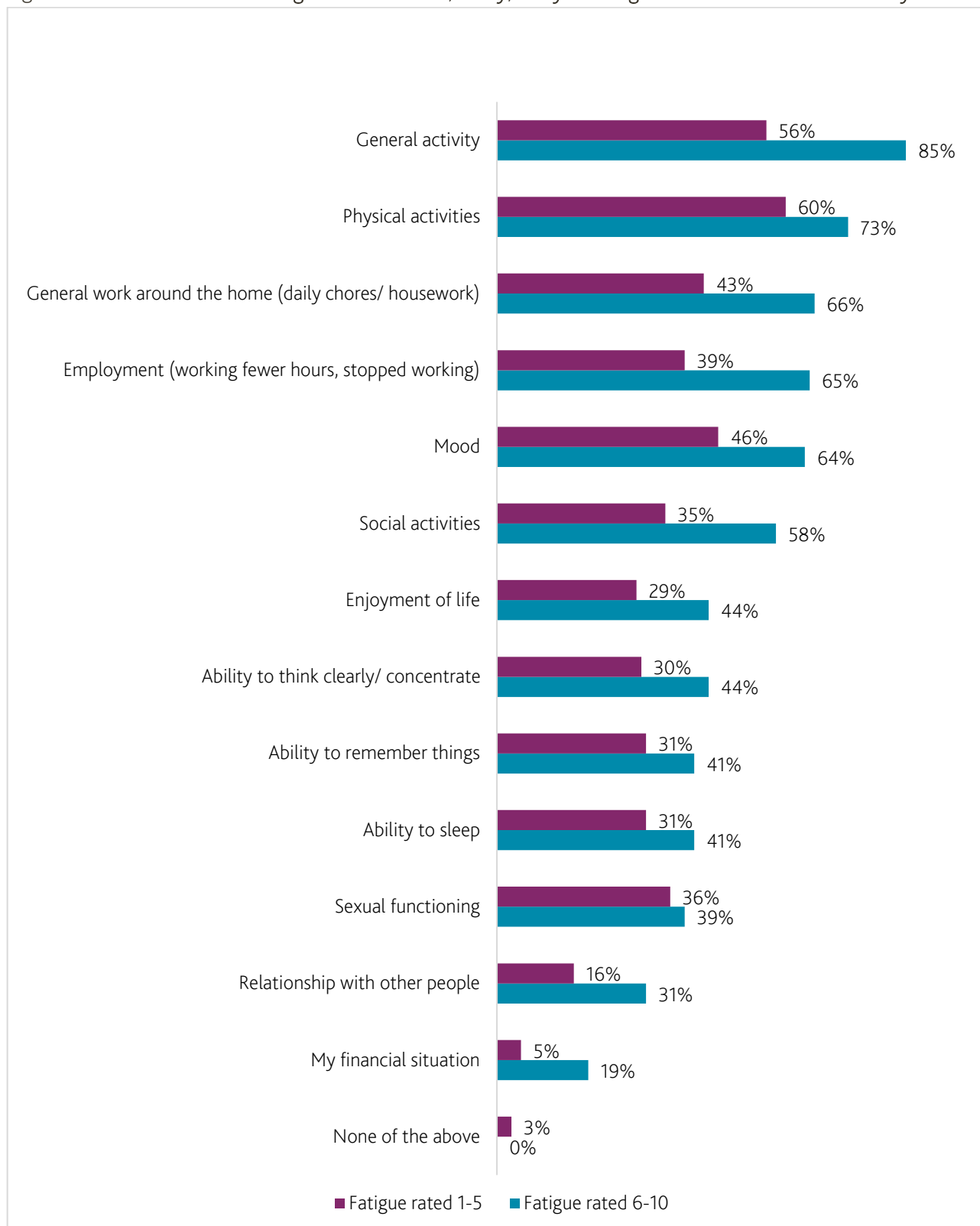
❖ Figure 63 illustrates 45% of patients reporting low and 55% high levels of fatigue over the last week.
Only asked to those who reported they had fatigue.

Figure 63. Patients were asked to rate their level of fatigue over the last one week (of taking the survey) on a scale of 1 (minimal fatigue) to 10 (worst fatigue imaginable).



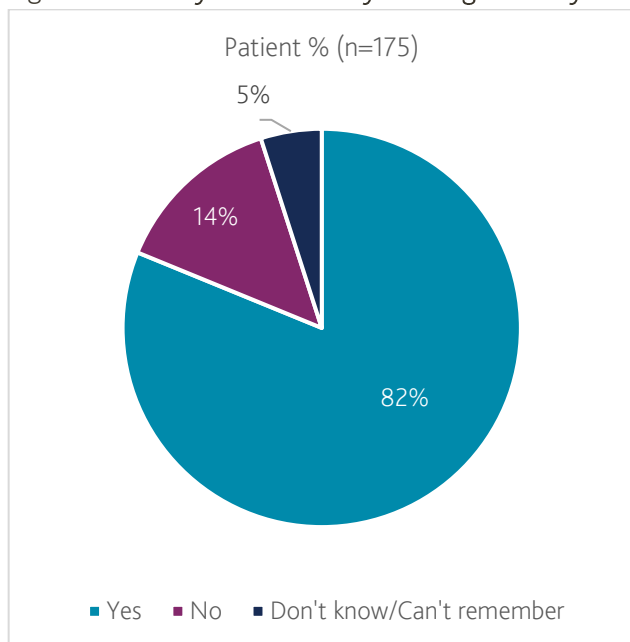
- ❖ Figure 64 illustrates patients with fatigue state it affects many aspects of their lives regardless of their fatigue rating. However, overall, people with a higher rating of fatigue (6-10) faced a greater impact on their lives. *Only asked to those who reported they had fatigue.*

Figure 64. Which of the following areas/ activities, if any, has your fatigue affected over the last two years?



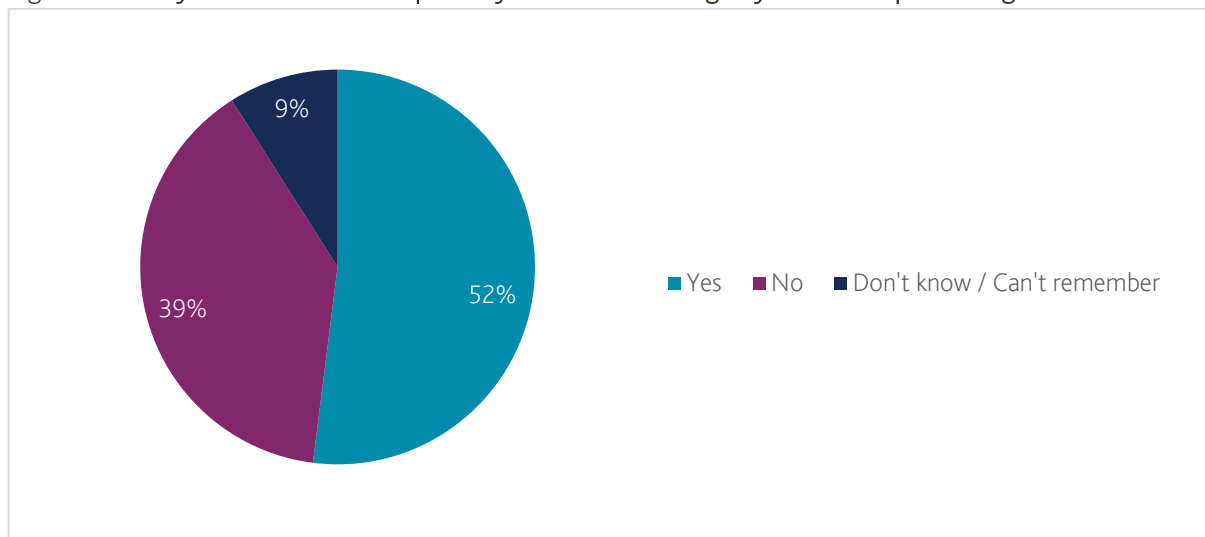
- ❖ Figure 65 reveals 82% of patients experiencing fatigue have discussed it with their doctor over the past two years. *Only asked to those who reported they had fatigue.*

Figure 65. Have you discussed your fatigue with your doctor over the last two years?



- ❖ Figure 66 shows half of patients experiencing fatigue said their doctor followed up about it (52%). *Only asked to those who reported they had discussed their fatigue with their doctor.*

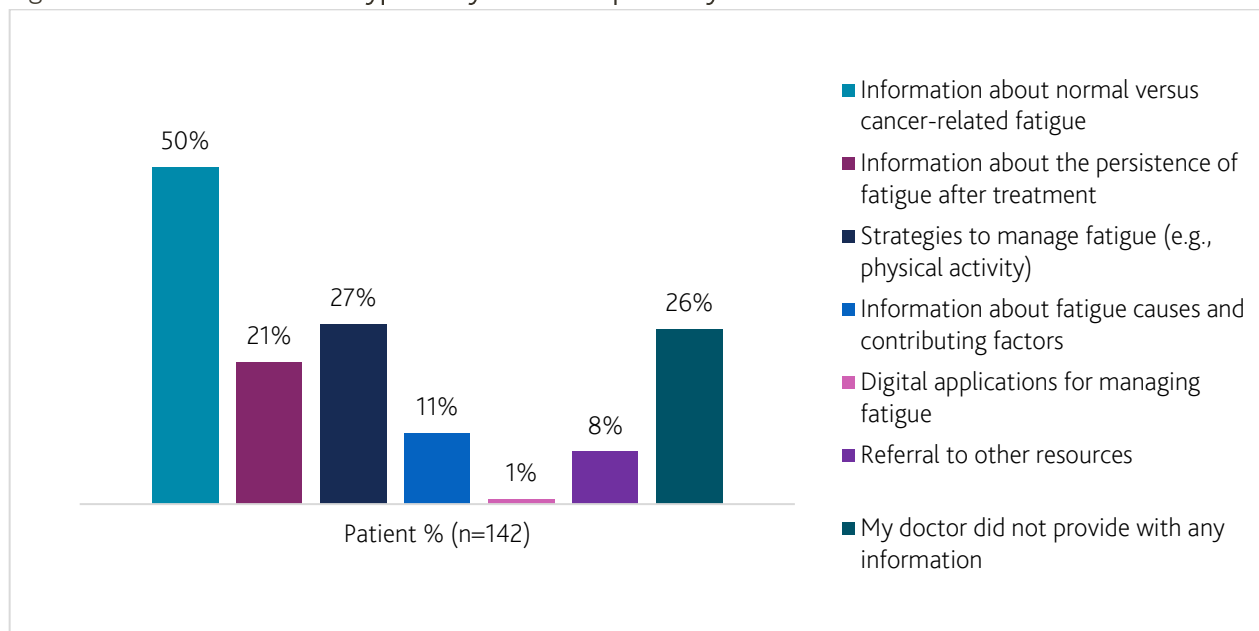
Figure 66. Did your doctor follow up with you about the fatigue you were experiencing?



Patients who discussed their fatigue with their doctor (n=143) were also asked what type of information they received from their doctor

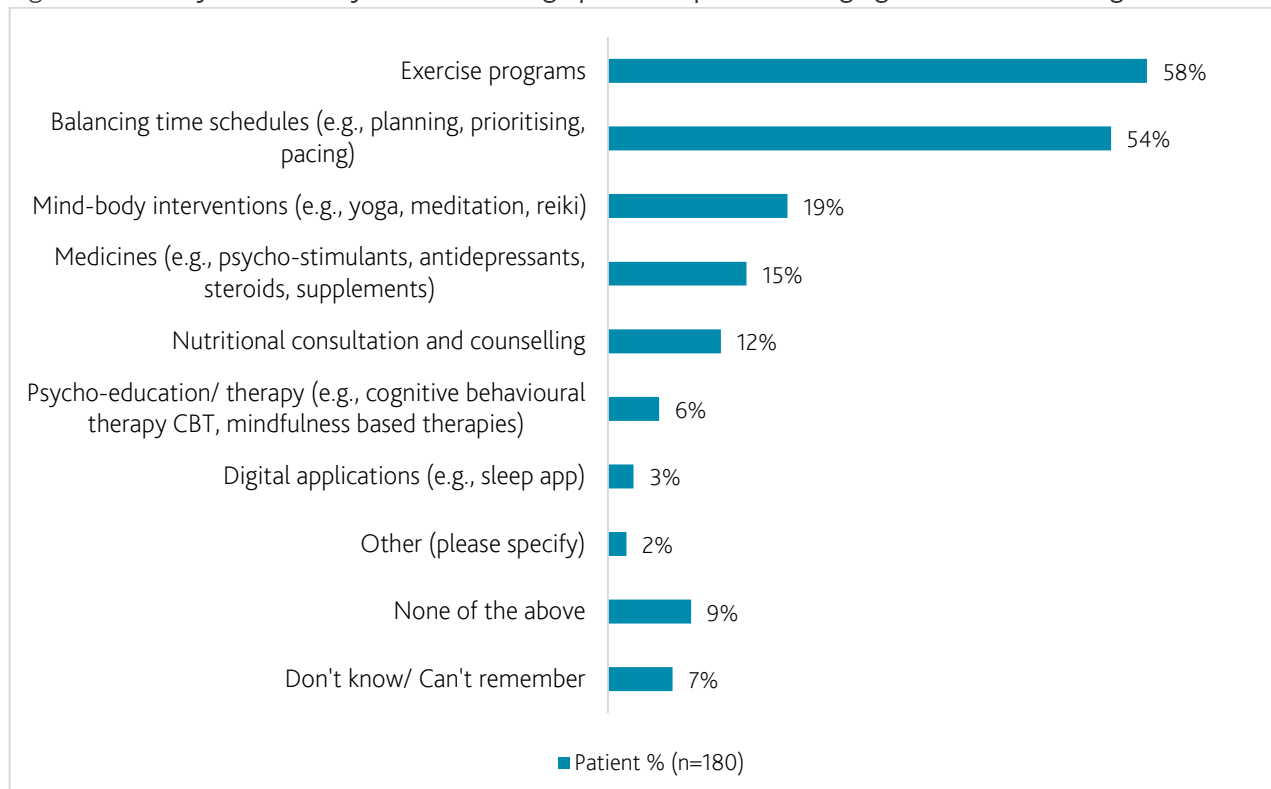
- ❖ Figure 67 illustrates that 74% of patients received some type of information about their fatigue from their doctor. *Only asked to those who reported they had discussed their fatigue with their doctor.*

Figure 67. Which information types did your doctor provide you with?



- ❖ Figure 68 reveals 58% of patients found exercise helpful in managing cancer-related fatigue, and 4% found balancing time schedules helpful. *Only asked to those who reported they had fatigue.*

Figure 68. 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.

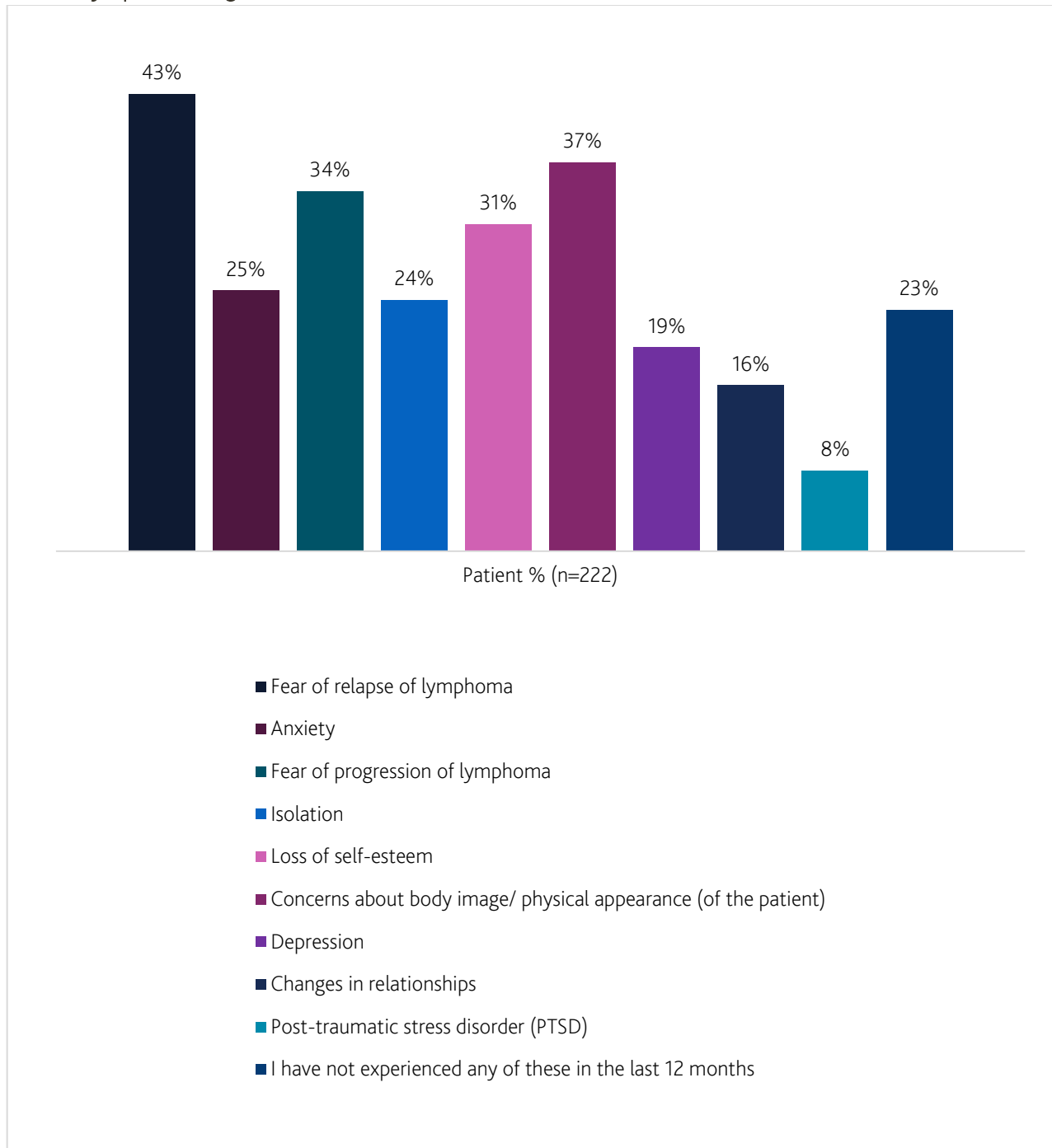
The questions exploring psychosocial effects in the 2022 GPS resulted from highlighted data within the previous surveys (2018 & 2020 LC GPS), showing that fear of cancer relapse, depression, and anxiety were the most commonly reported psychosocial issues. Additionally, the 2022 survey explored the fear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



- 77% of patients indicated they had psychosocial concerns over the last year.
- 43% of those who were in treatment/had had treatment or were in remission reported a fear of relapse of lymphoma and 34% reported fear of progression of lymphoma as their biggest worries or concerns. But only two out of every five of these patients definitely talked about their fears with their doctor.
- Other psychosocial effects experienced in the last 12 months included body image concerns (37%), loss of self-esteem (31%), and anxiety (25%).
- The most provided approach by doctors to help patients cope with depression was medication (56%), and the empathetic / understanding approach for anxiety (55%).
- The empathetic / understanding approach was the most common tactic used by doctors to help patients cope with fear of lymphoma progression (67%) and fear of cancer relapse (56%).

- ❖ Figure 69 discloses when asked about psychosocial effects resulting from their lymphoma diagnoses, the top issues reported by patients were fear of relapse (43%), body image concerns (37%) and fear of progression (34%).

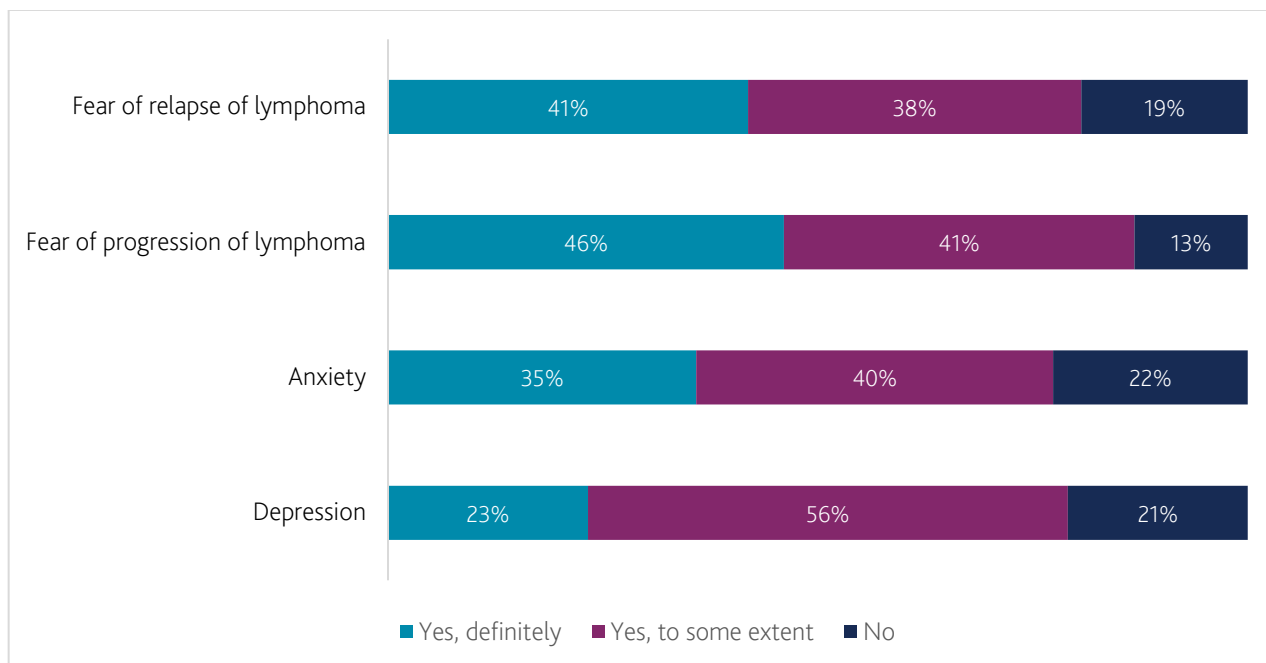
Figure 69. In the last 12 months, have you personally experienced any of the following as a result of the lymphoma diagnosis?



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.

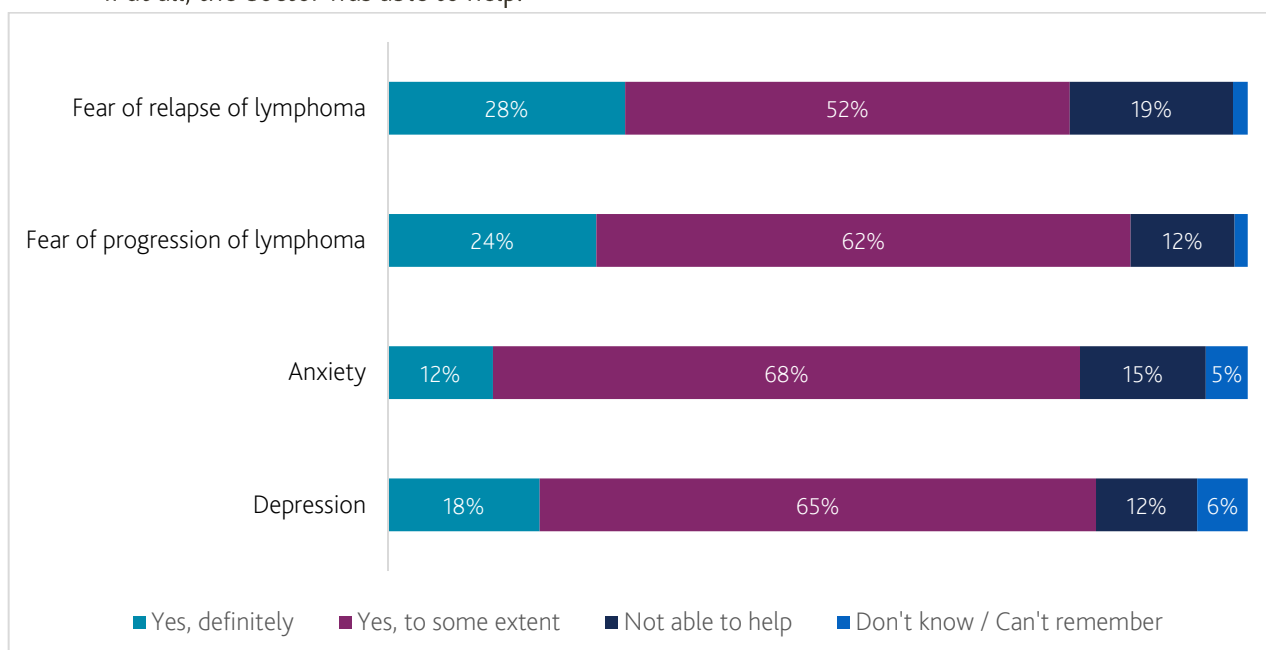
- ❖ Figure 70 reveals that patients are more likely to discuss their fear with a doctor than their depression. Only asked to those who indicated they were affected by at least one of the following: fear of relapse, fear of progression of lymphoma, anxiety, and depression.

Figure 70. For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with a doctor?



- ❖ Figure 71 shows that when patients did discuss these issues with their doctor, in most cases the doctor was able to help fully or to some extent. Only asked to those that discussed their fear of relapse, fear of progression of lymphoma, anxiety and/or depression with their doctor.

Figure 71. 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.



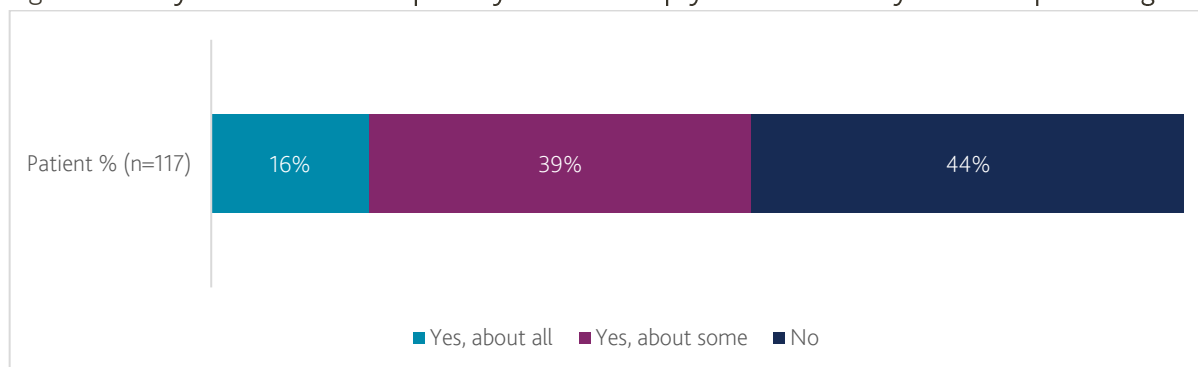
- ❖ Table 4 illustrates regardless of the specific psychosocial issue, the most common types of help offered or recommended were **help**, **help**, and **help**. Only asked to those that discussed their fear of relapse, fear of progression of lymphoma, anxiety and/or depression with their doctor.

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

Help offered	Depression	Anxiety	Fear of progression of lymphoma	Fear of relapse of lymphoma
Medication to help cope with this worry or concern	56%	42%	9%	18%
Further written or verbal information	11%	9%	18%	16%
The empathetic/ understanding approach of my doctor when I told him/ her	59%	55%	67%	56%
Patient organisation or patient support group	19%	9%	24%	20%
Referral to other sources of support (e.g., social worker, therapist, counselling)	41%	36%	7%	7%
Exercise	44%	48%	33%	33%
Participation of family/ caregiver in providing support	15%	33%	35%	29%
The empathetic/ understanding approach of my nurse when I told him/ her	26%	24%	9%	13%
Eating a healthy diet	15%	6%	5%	7%
Other	4%	3%	4%	4%

- ❖ Figure 72 reveals that 44% of patients reported their doctors did not follow up on the psychosocial issues

Figure 72. 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.

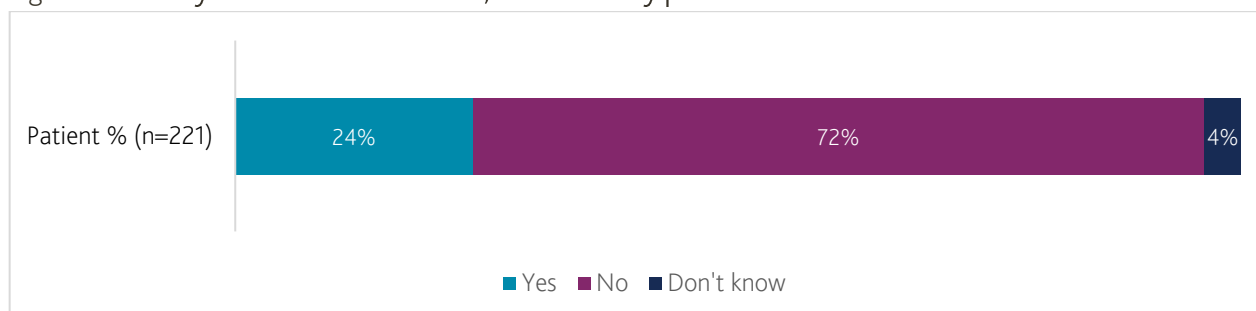
Several patients also experienced changes in their care, including switching to telemedicine.



- 79% of patients consider themselves at high risk for contracting Covid-19 and experiencing severe illness from it, and it worries 49% of them.
- 22% of patients reported that their anxiety was much worse and 37% said it was worse during the Covid-19 pandemic.
- 18% of patients reported that their depression was much worse and 38% said it worse during the Covid-19 pandemic.
- 6% of patients avoided or delayed seeking medical attention due to the pandemic.
- The most frequently reported change to care due to Covid-19 restriction was caregiver not allowed to come to hospital with patient (24%), followed by treatment delays (17%). 56% had no change to their care.
- 75% strongly disagreed/disagreed that they preferred tele-conference (TC)/ video conference (VC) to face-to-face visits, while only 6% strongly agreed/agreed that they preferred it.
- 52% of patients strongly disagreed/disagreed that they would like to continue to use TC/VC even after the pandemic is over.

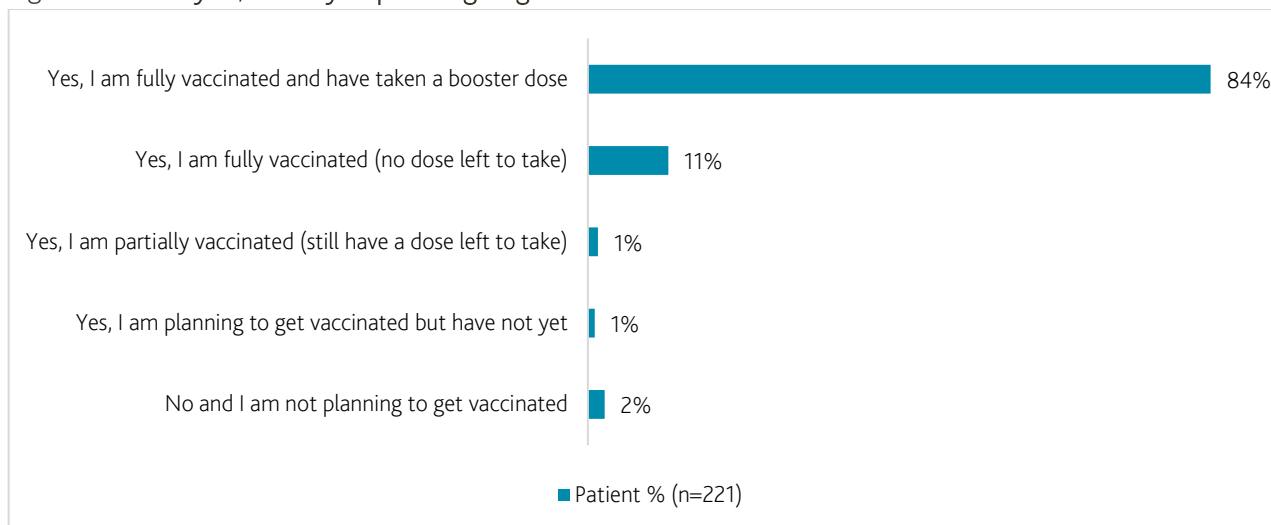
❖ Figure 73 shows 72% of patients have not contracted Covid-19.

Figure 73. Have you contracted Covid-19, now or at any point?



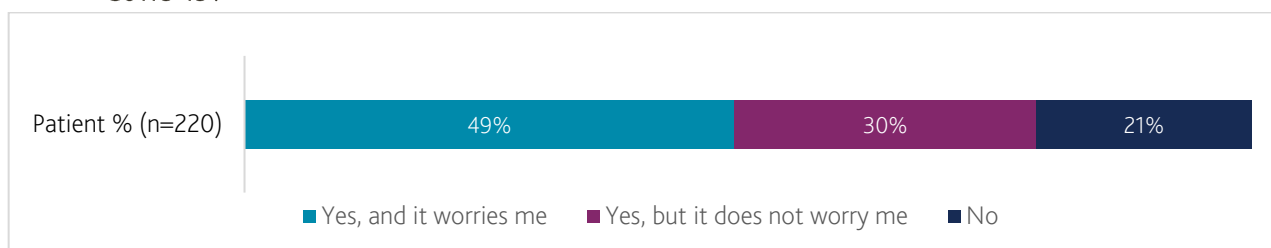
- ❖ Figure 74 illustrates that 5% of patients are fully vaccinated, and 84% have also taken a booster dose.

Figure 74. Have you, or are you planning to get the Covid-19 vaccine?



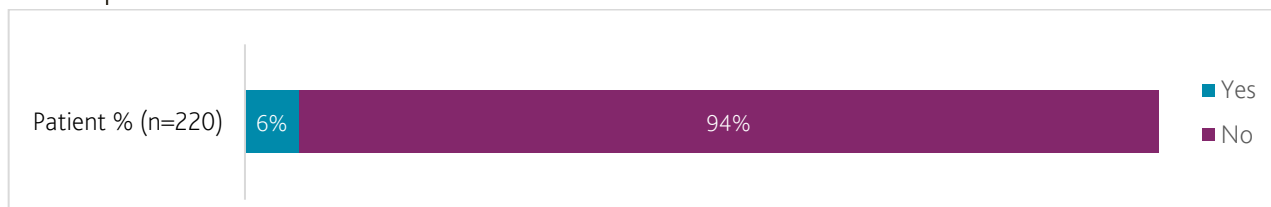
- ❖ Figure 75 shows that 79% of patients consider themselves as high risk of contracting Covid-19 and it worries 49% of them.

Figure 75. Do you consider yourself at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?



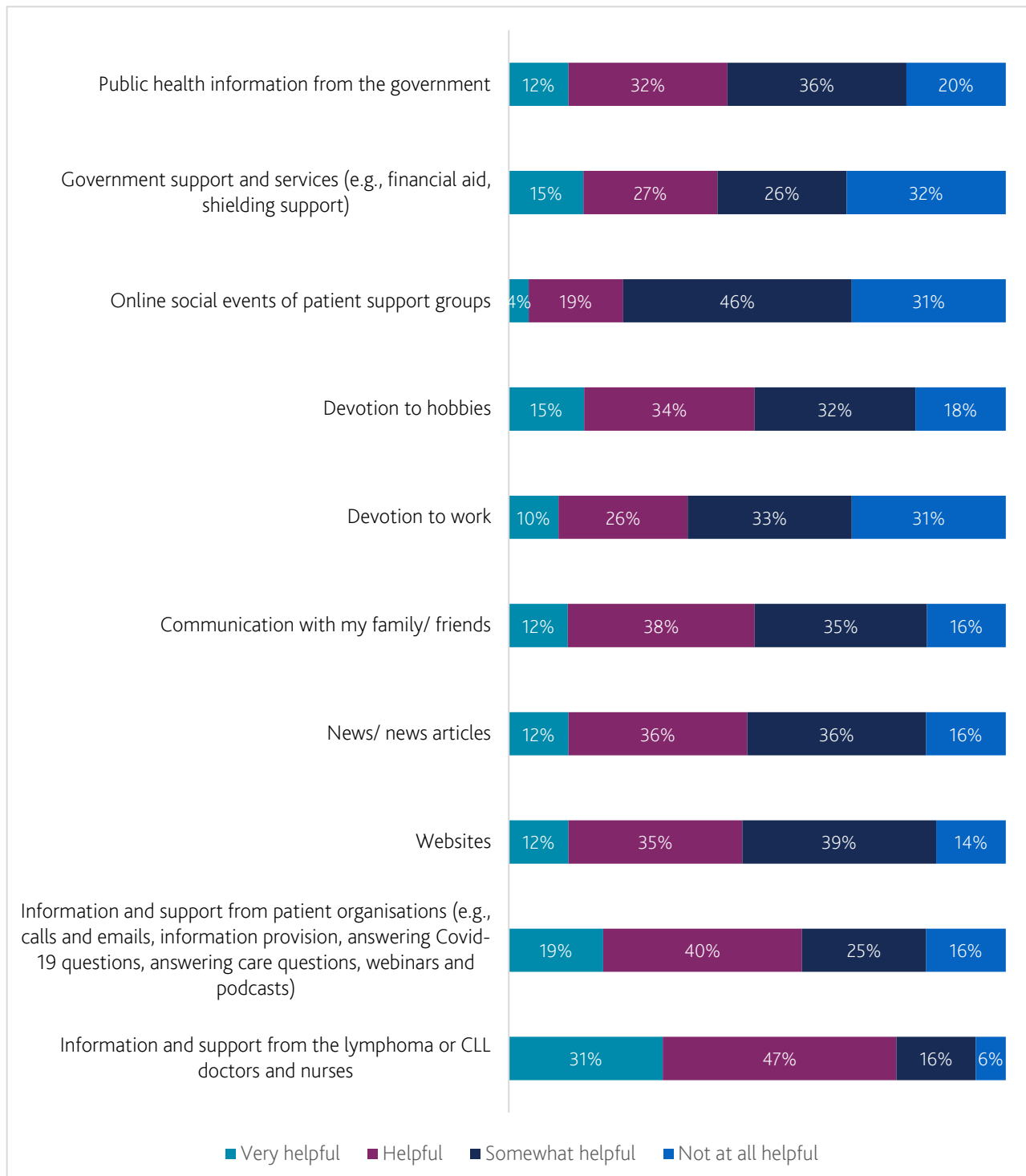
- ❖ Figure 76 reveals 6% of patients avoided or delayed seeking medical attention for their lymphoma or CLL during the Covid-19 pandemic.

Figure 76. Did you avoid or delay seeking medical attention for your lymphoma or CLL during the Covid-19 pandemic?



- ❖ Figure 77 illustrates that 32% of patients said government support was not helpful in providing support for lymphoma or CLL during the Covid-19 pandemic. What was helpful was doctors and nurses (78%), and patient organisations (59%).

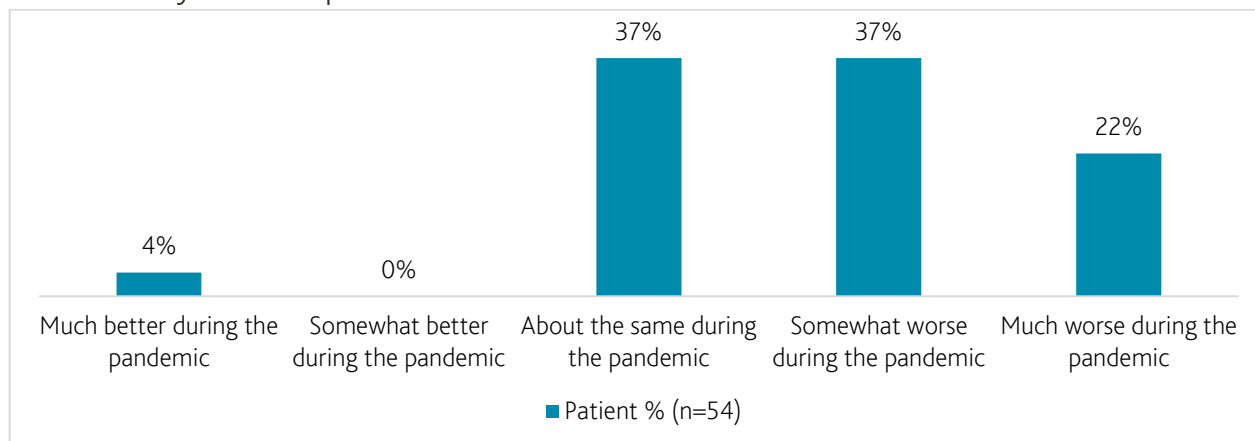
Figure 77. Please indicate how helpful, if at all, the following have been in providing support regarding lymphoma or CLL and the impact of Covid-19 pandemic.



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

- ❖ Figure 78 reveals that 59% of patients felt their level of anxiety was worse during the pandemic. *Only asked to those who indicated they had anxiety.*

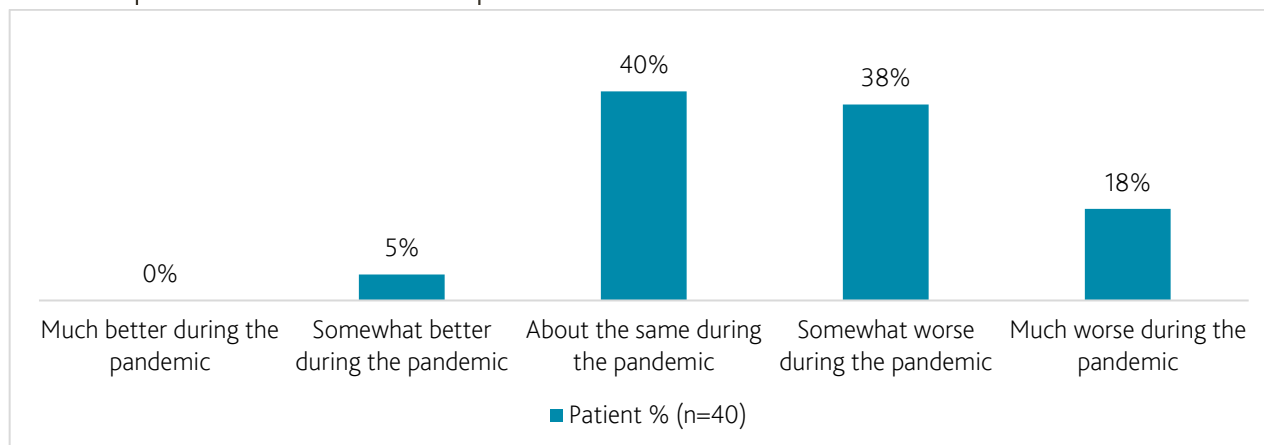
Figure 78. Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.



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.

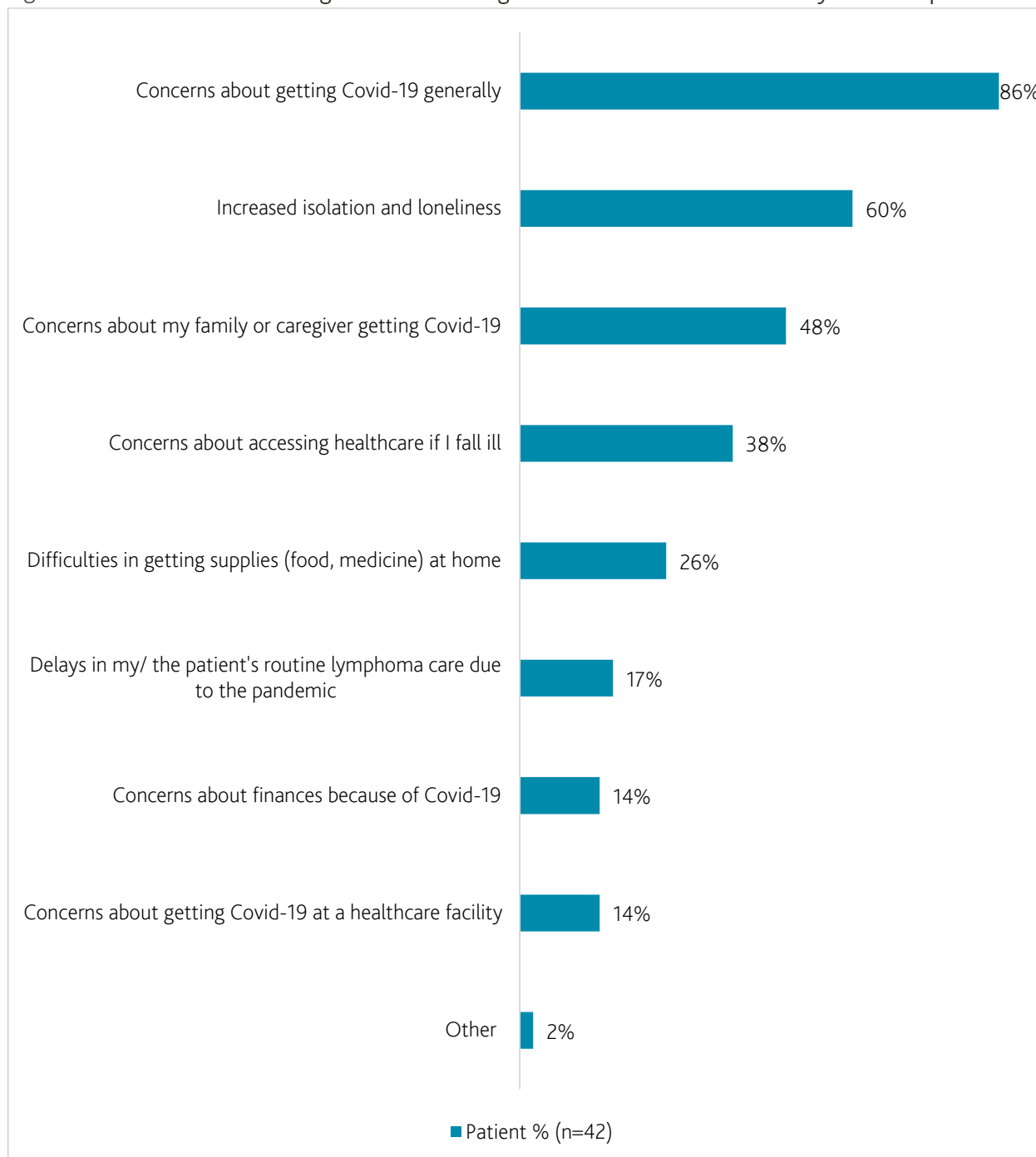
- ❖ Figure 79 shows that 56% of patients felt that their level of depression was worse during the Covid-19 pandemic. *Only asked to those who indicated they had depression.*

Figure 79. Please describe your level of depression during the Covid-19 pandemic, compared to your level of depression before the Covid-19 pandemic.



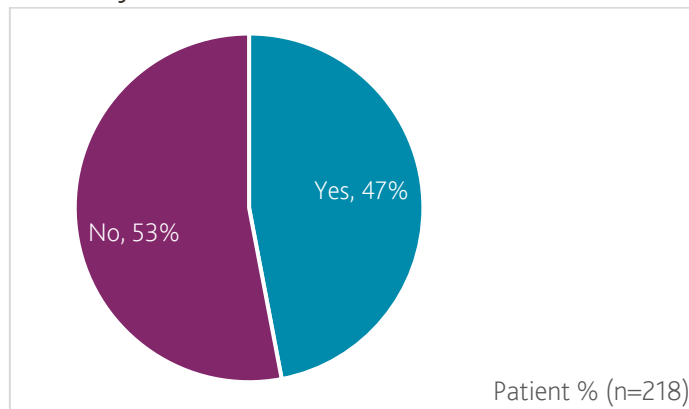
- ❖ Figure 80 illustrates that 86% of patients felt concerns about getting Covid-19 generally was contributing to their worsened level of anxiety and/or depression, followed by isolation and loneliness (60%). Only asked to those who said they had anxiety or depression that was worse during the pandemic.

Figure 80. Which of the following were contributing factors for the worsened anxiety and/or depression?



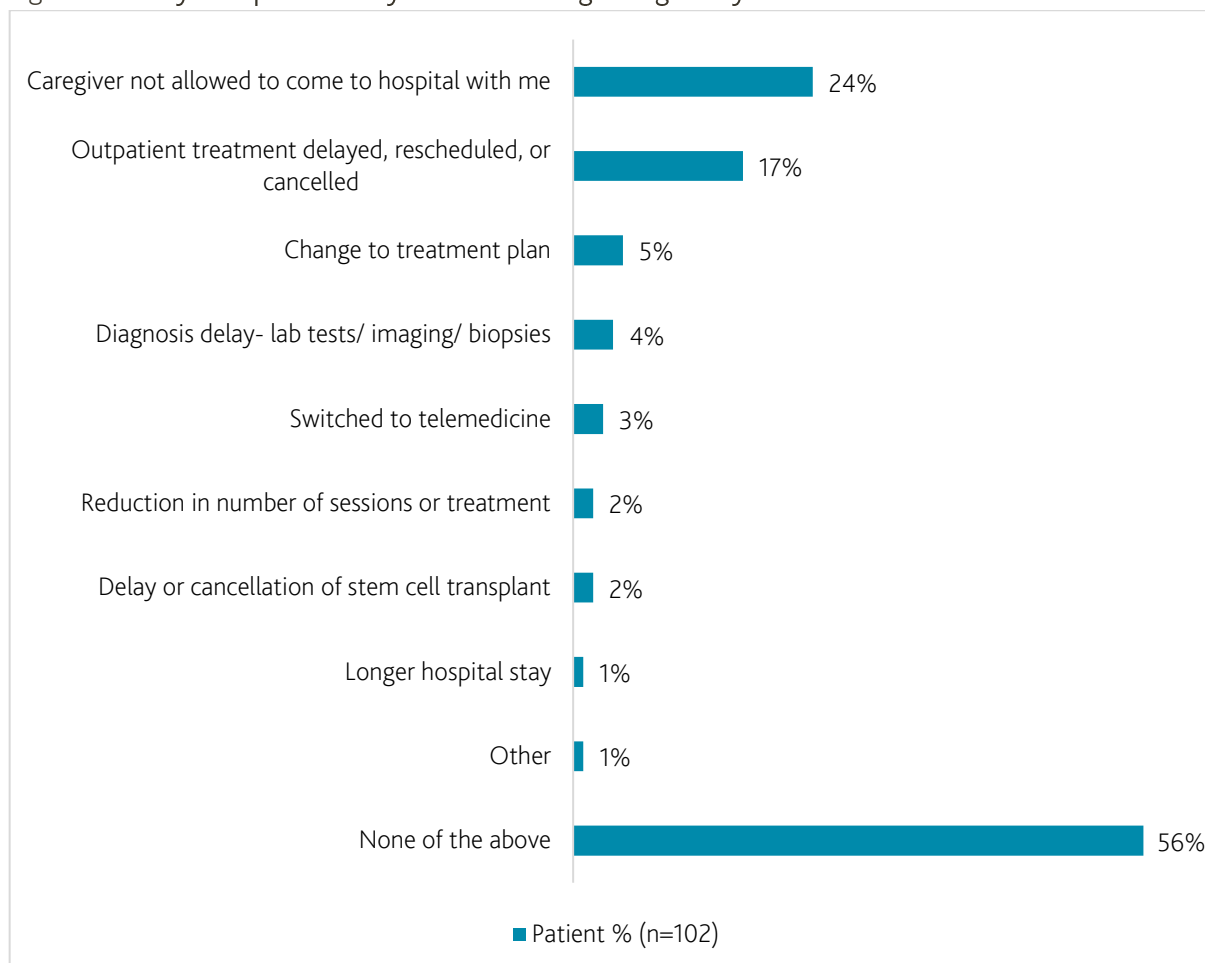
- ❖ Figure 81 shows nearly half of patients were scheduled to receive treatment for lymphoma or CLL when Covid-19 restrictions were an issue in their community.

Figure 81. Were you scheduled to receive treatment for your lymphoma or CLL when Covid-19 restriction was an issue in your community?



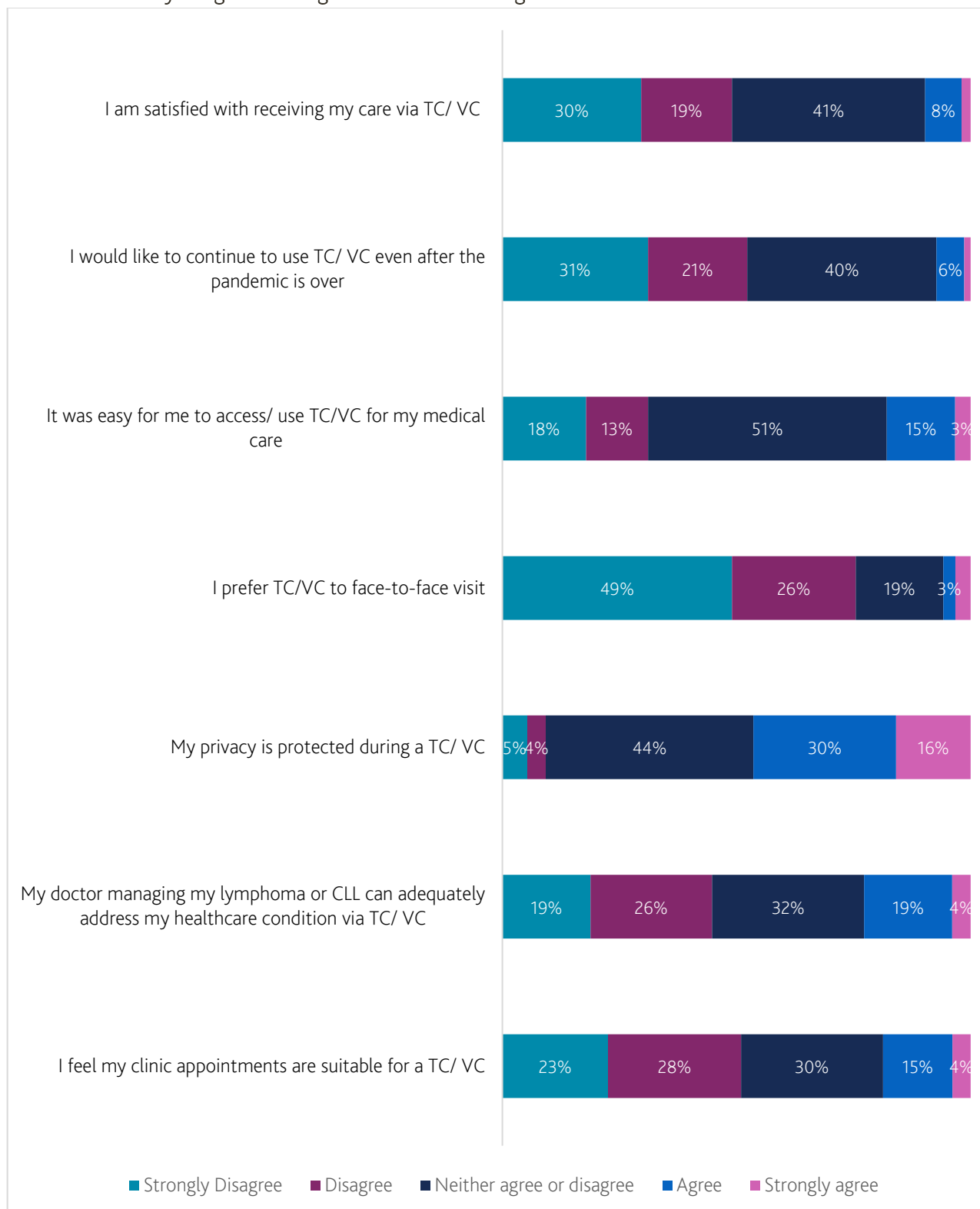
- ❖ Figure 82 explains that 56% of patients experienced no changes to care due to the COVID-19 restrictions. Of those who faced changes (44%), 24% reported their caregiver was not allowed to come to the hospital with them, while 17% reported outpatient treatment delayed, rescheduled, or cancelled.. *Only asked to those who received treatment during Covid-19 restriction in their community.*

Figure 82. Did you experience any of the following changes to your care due to Covid-19?



- ❖ Figure 83 illustrates 75% of patients 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 83. 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.

29 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

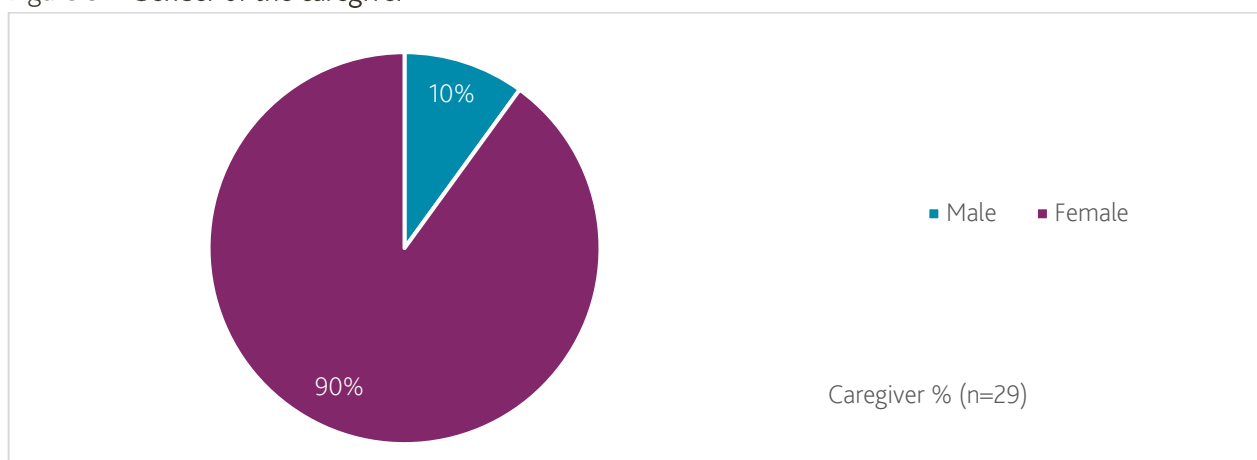
Caregiver Characteristics



- 29 caregivers responded to the survey, with 38% of the respondents residing in rural areas. Most caregivers (90%) were female.
- 55% of all caregivers provide support to their spouse/partner, 24% care for their child, and 10% for their parent.

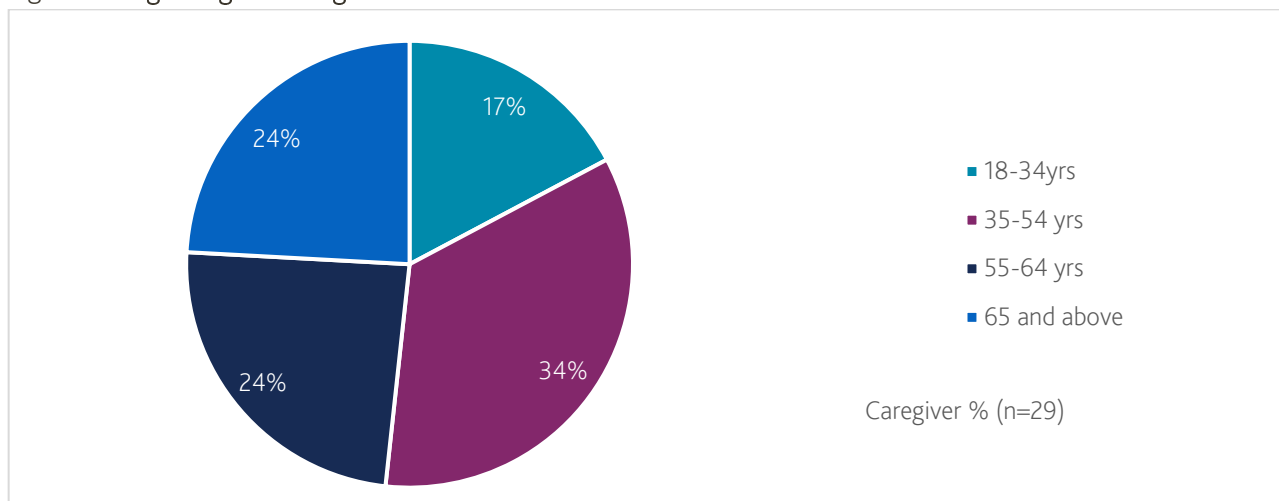
❖ Figure 84 explains most caregivers are female.

Figure 84. Gender of the caregiver



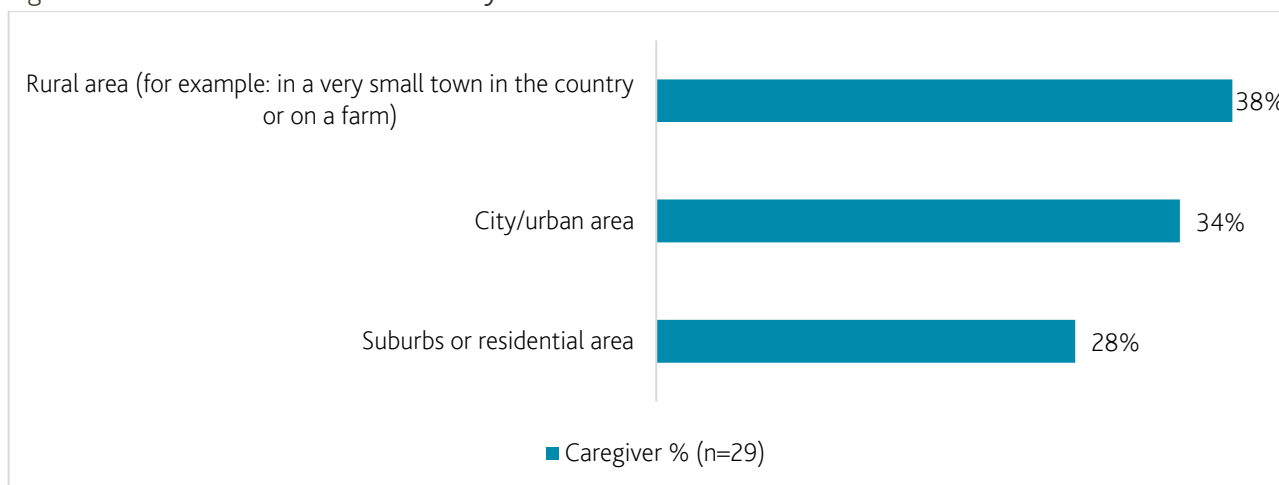
- ❖ Figure 85 shows 34% of caregivers are age 55-64 and another 24% each are age 55-64 and age 65 and above.

Figure 85. Age range of caregivers



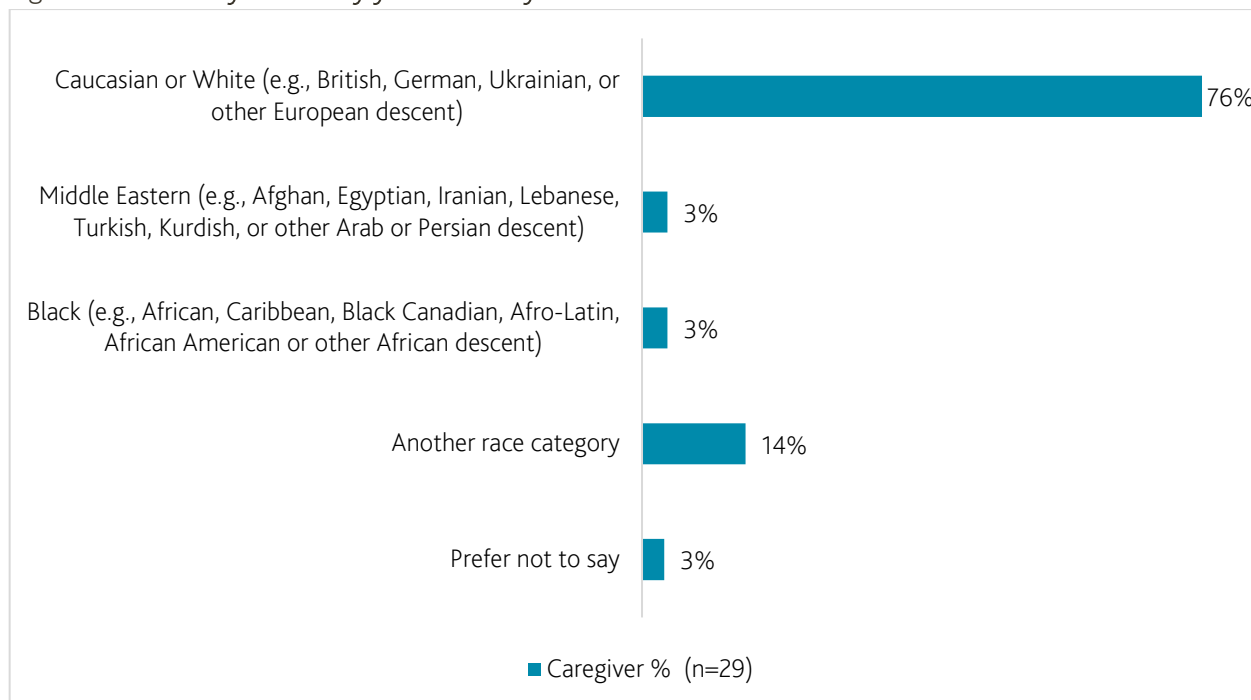
- ❖ Figure 86 describes how 38% of caregivers live in rural areas.

Figure 86. Which best describes the area you live in?



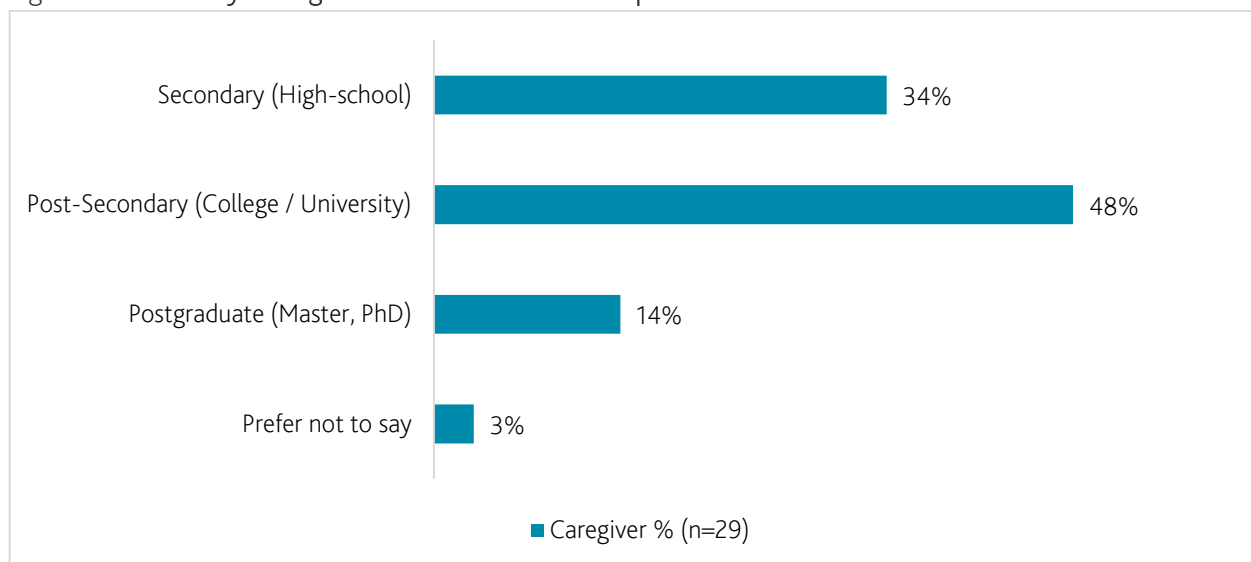
❖ Figure 87 illustrates 76% of caregivers identify as Caucasian.

Figure 87. How do you identify your ethnicity?



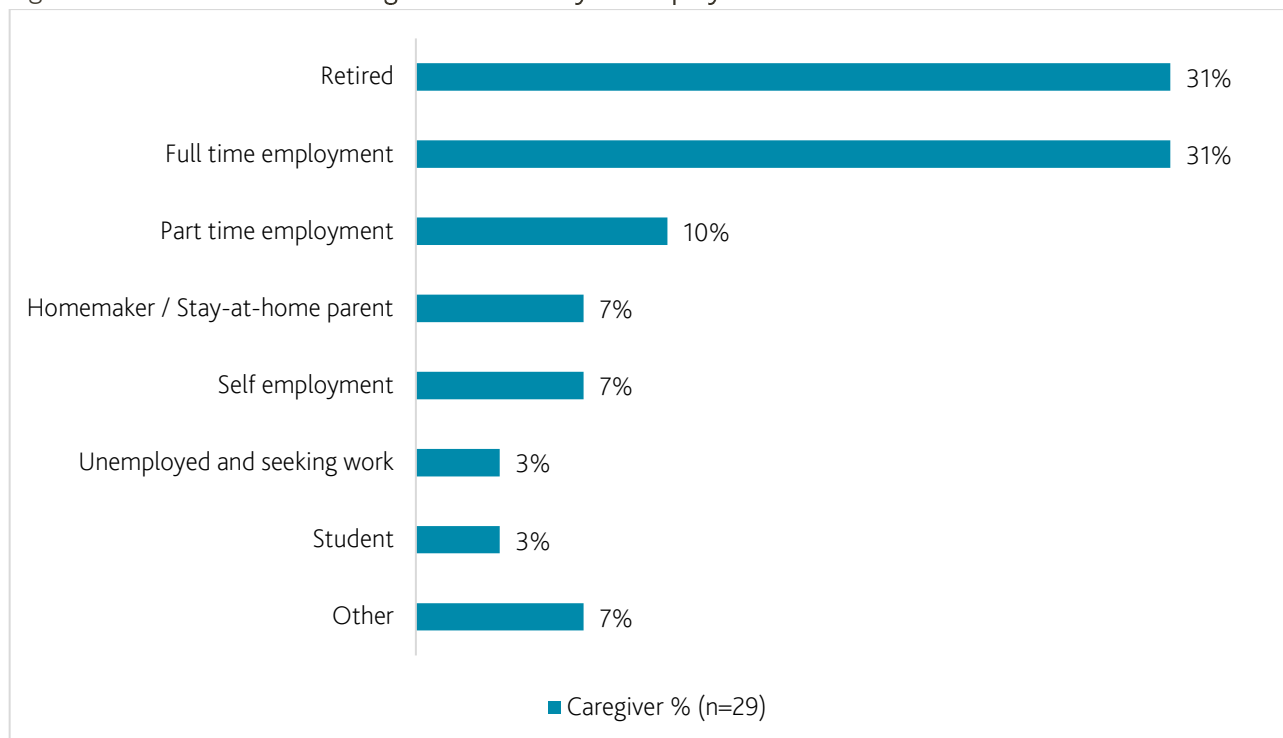
❖ Figure 88 shows 62% of caregivers have completed advanced education.

Figure 88. What is your highest educational level completed?



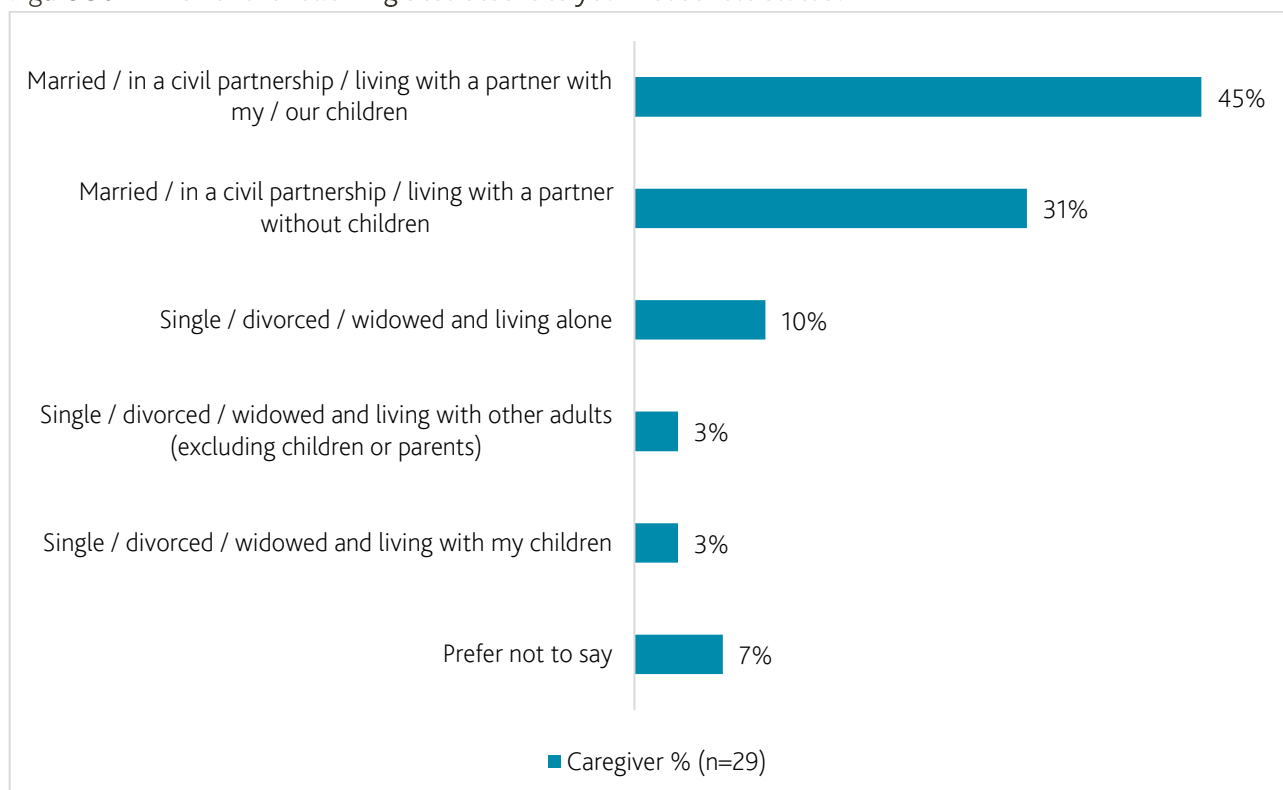
❖ Figure 89 illustrates 31% of caregivers are retired and 31% are employed full time.

Figure 89. Which of the following best describes your employment status?



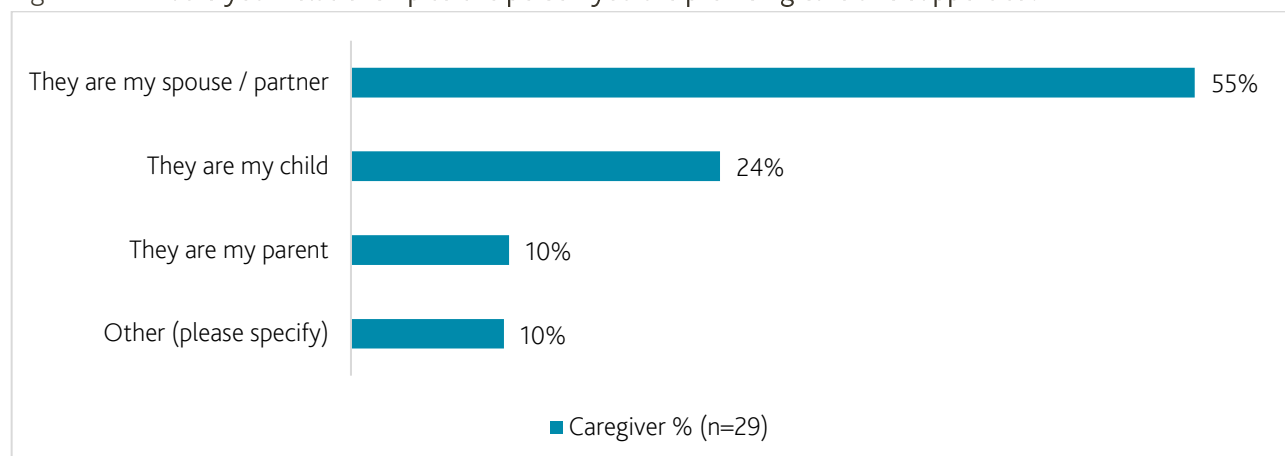
❖ Figure 90 reveals 76% of caregivers are living with a partner, 45% with children as well.

Figure 90. Which of the following best describes your household status?



- ❖ Figure 91 illustrates 55% of caregivers are providing care and support to their spouse, 24% to their child and 10% to a parent.

Figure 91. What is your relationship to the person you are providing care and support to?



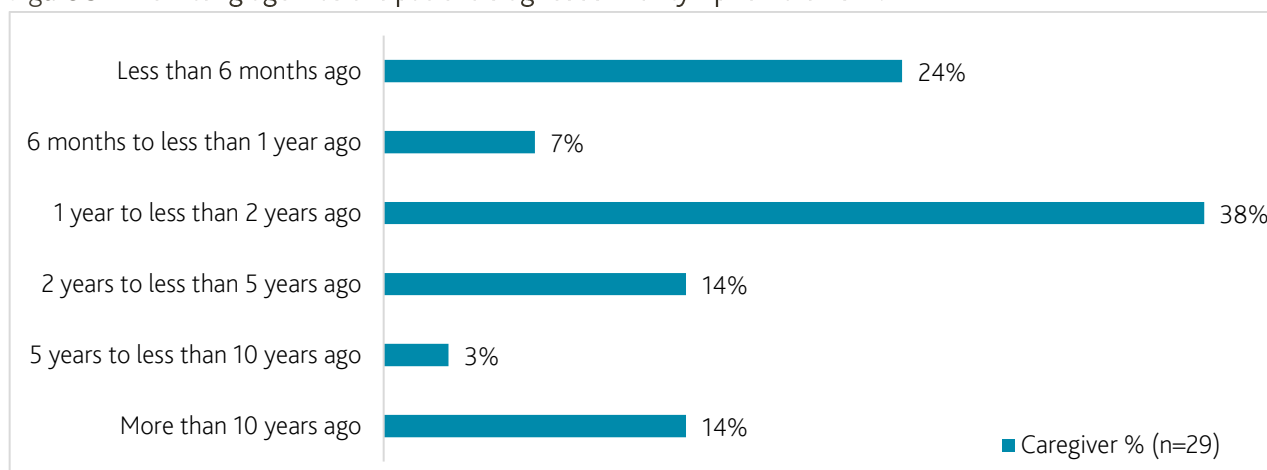
Diagnostic Demographics



- 34% of caregivers have been providing help for 1-2 years.
- Most caregivers reported they were providing care for patients with subtype (x%), followed by subtype (x%), then subtype (x%).

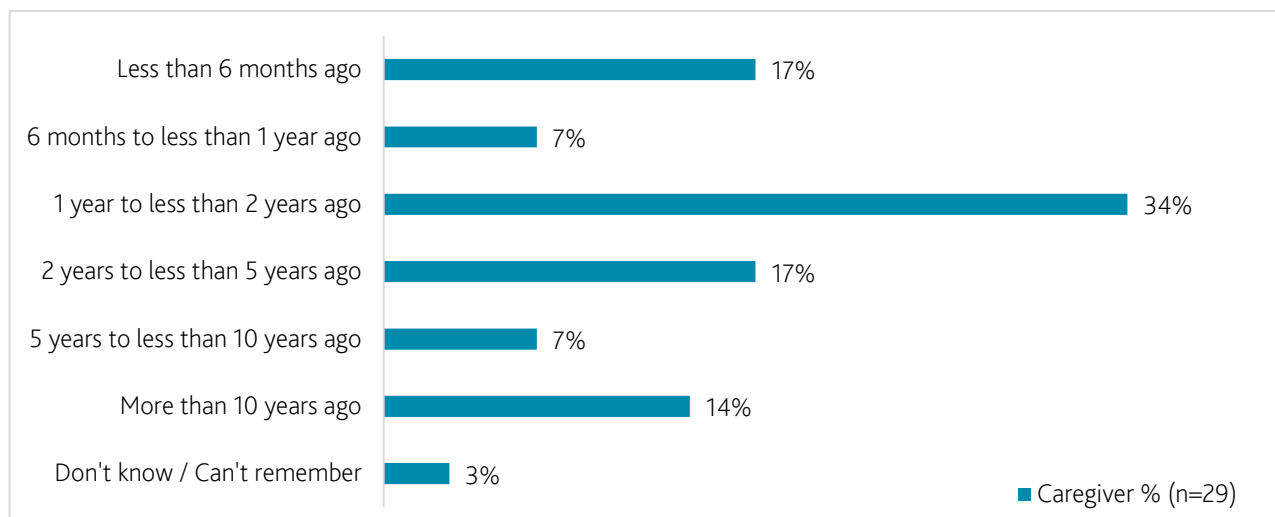
❖ Figure 92 reports that 38% are providing care to a patient who was diagnosed with lymphoma or CLL 1-2 years ago.

Figure 92. How long ago was the patient diagnosed with lymphoma or CLL?



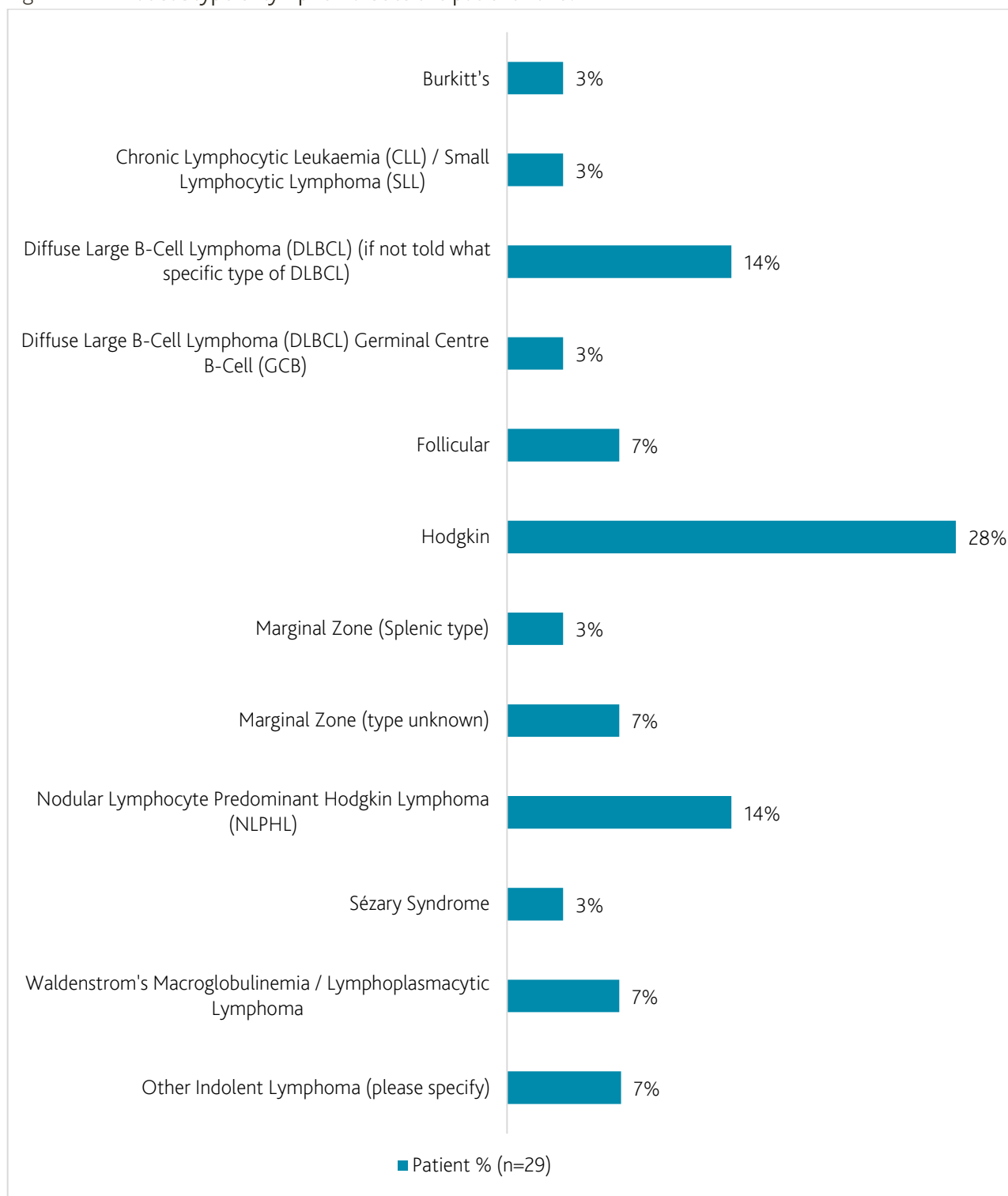
❖ Figure 93 shows 34% of caregivers have been providing cancer-related care and support for 1-2 years.

Figure 93. How long have you been providing cancer-related care and support to the person with lymphoma or CLL?



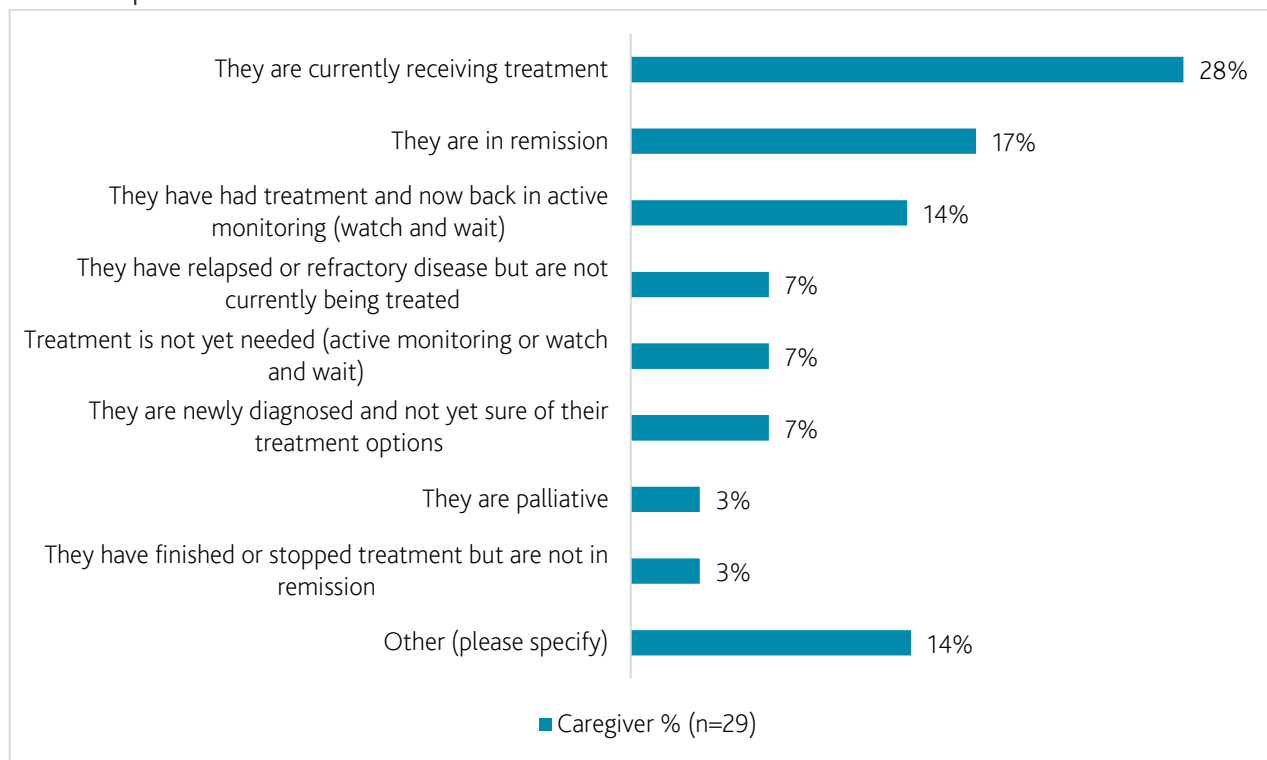
- ❖ Figure 94 illustrates when caregivers were asked about the patient they care for, the most commonly reported lymphoma subtypes included classic Hodgkin (28%), DLBCL (17%), and NLPHL (14%).

Figure 94. What subtype of lymphoma does the patient have?



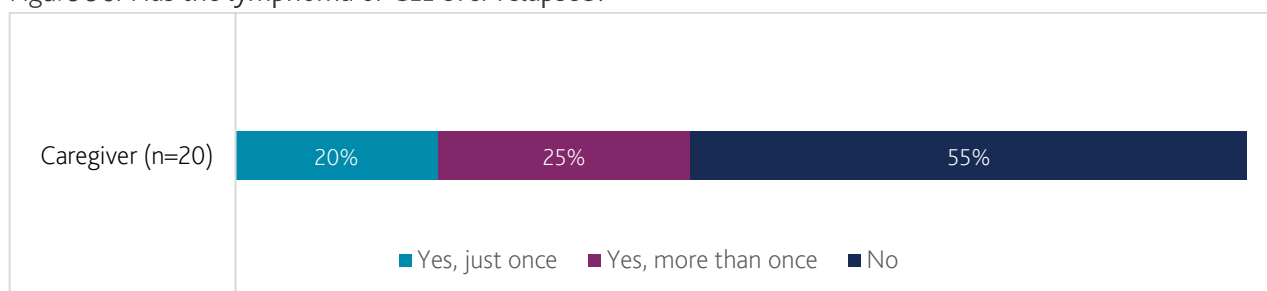
- ❖ Figure 95 shows 28% of caregivers are caring for patients that are currently in treatment and 17% are currently in remission.

Figure 95. What statement best describes where the person you care for is in the lymphoma or CLL experience?



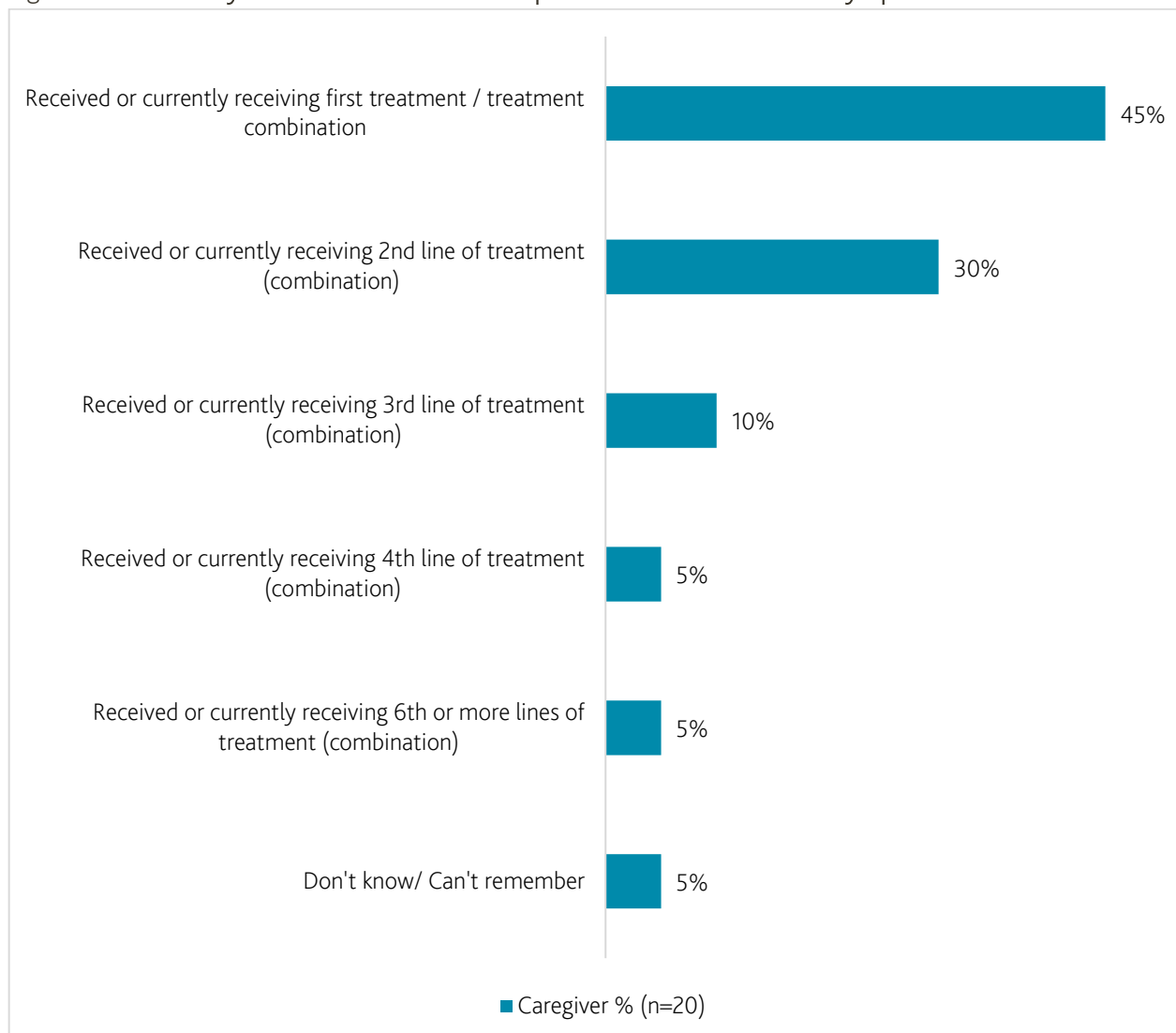
- ❖ Figure 96 points out that 55% of caregiver's patients have not had their lymphoma or CLL relapse. *Only asked to caregivers who said their patient had received treatment.*

Figure 96. Has the lymphoma or CLL ever relapsed?



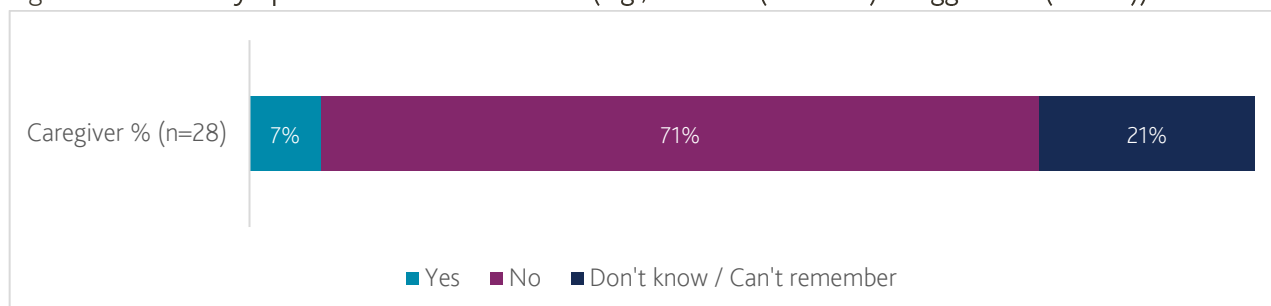
- ❖ Figure 97 illustrates that 45% of caregivers report the patient they help care for is receiving their first line of treatment or treatment combination. **Only asked to caregivers who said their patient had received treatment.**

Figure 97. How many lines of treatment has the patient received to date for lymphoma?



- ❖ Figure 98 shows 71% of caregivers said the lymphoma of patient they care for has not transformed.

Figure 98. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?



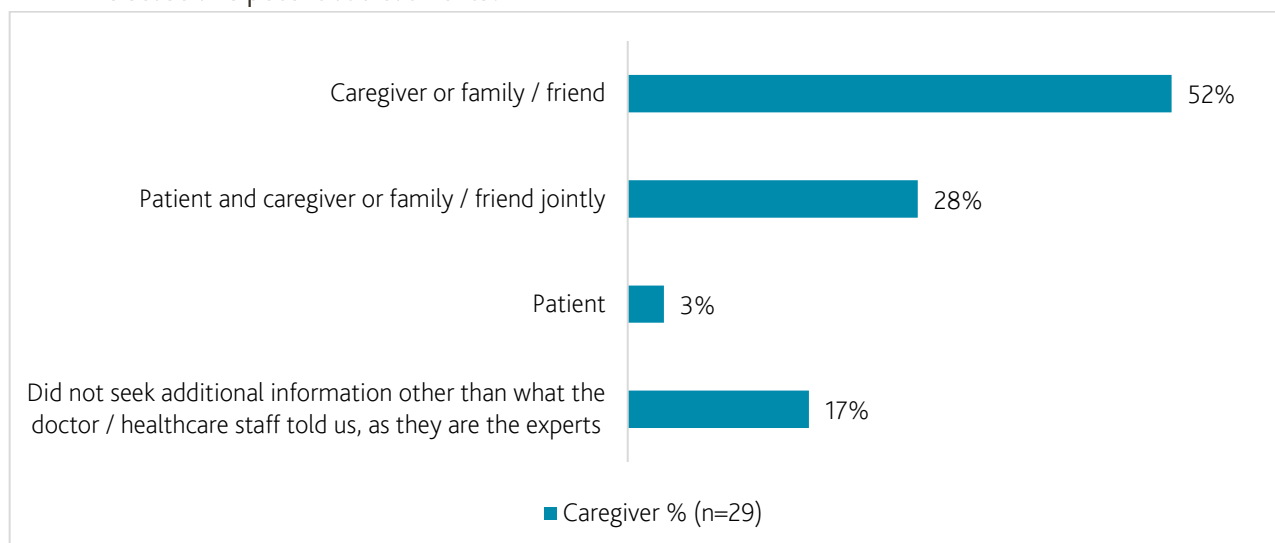
Healthcare Information



- 83% of caregivers report seeking out additional information about the patient's diagnosis, above what they were told by the medical team.
- 48% of caregivers reported being well informed, or very well informed about the processes and stages of the patient's healthcare. 17% felt ill-informed.
- Caregivers preferred sources of information on lymphoma and CLL are doctors (97%), followed by internet (59%), and patient organisations (55%).

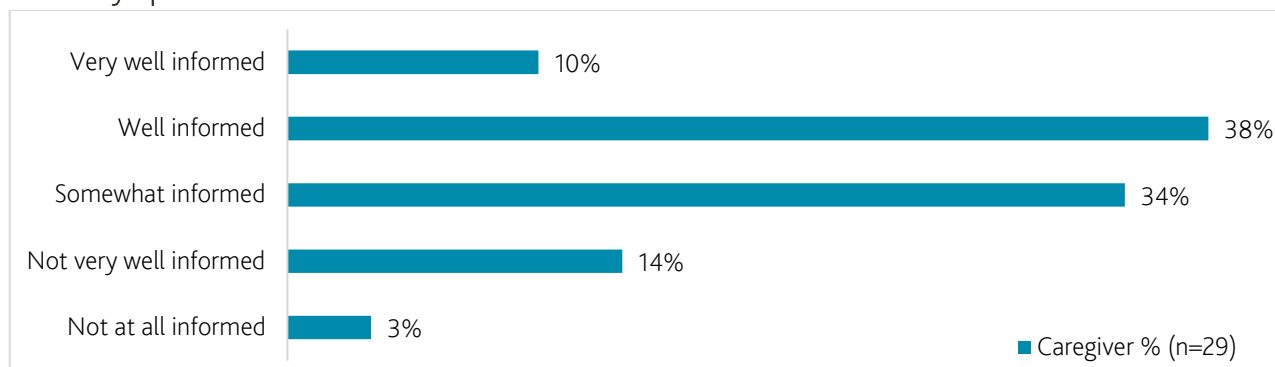
❖ Figure 99 says half of caregivers said they sought out information about the disease and treatment following diagnosis, and 28% said they did it jointly with the patient.

Figure 99. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



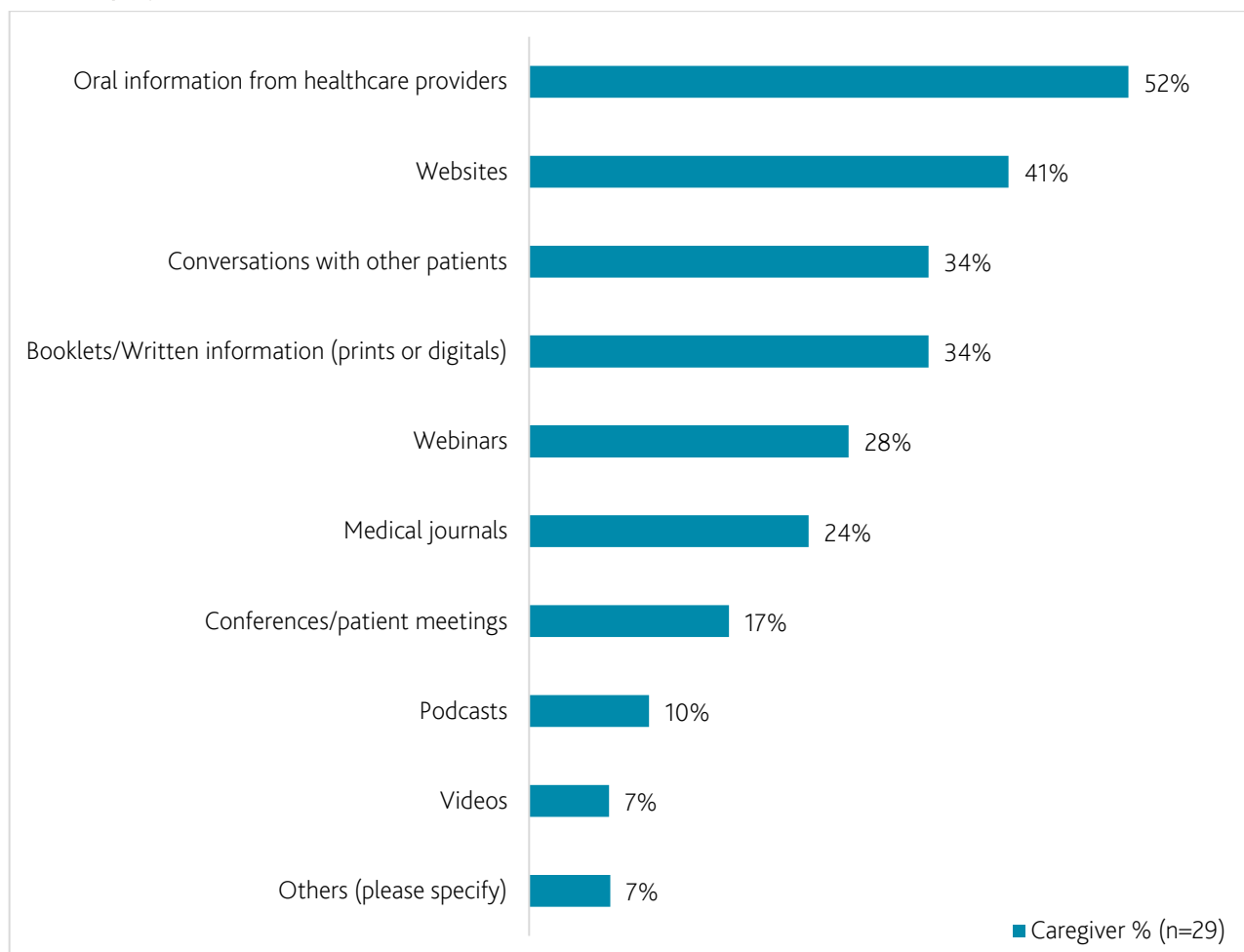
- ❖ Figure 100 reveals 17% of caregivers felt not at all or not very well informed about the process and stages of the patient's healthcare.

Figure 100. 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?



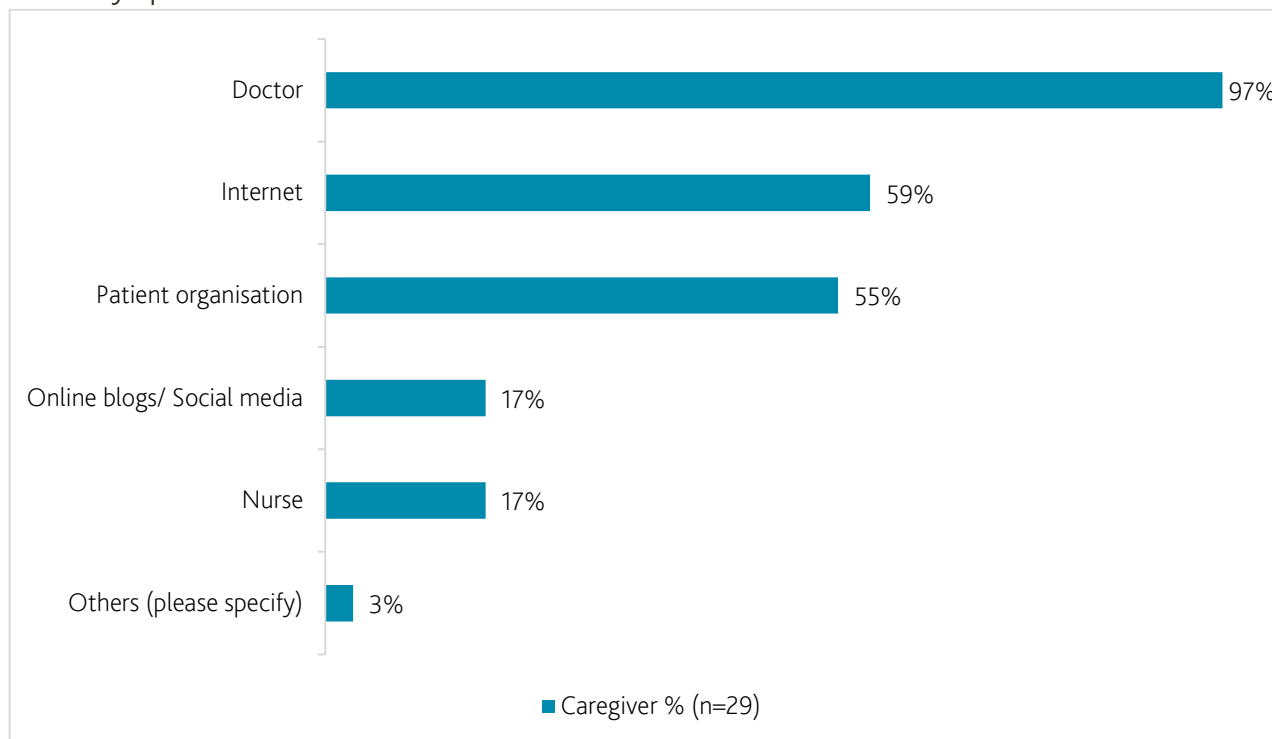
- ❖ Figure 101 explains 52% of caregivers prefer oral information from healthcare professionals to obtain information about lymphoma or CLL, followed by websites (41%).

Figure 101. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



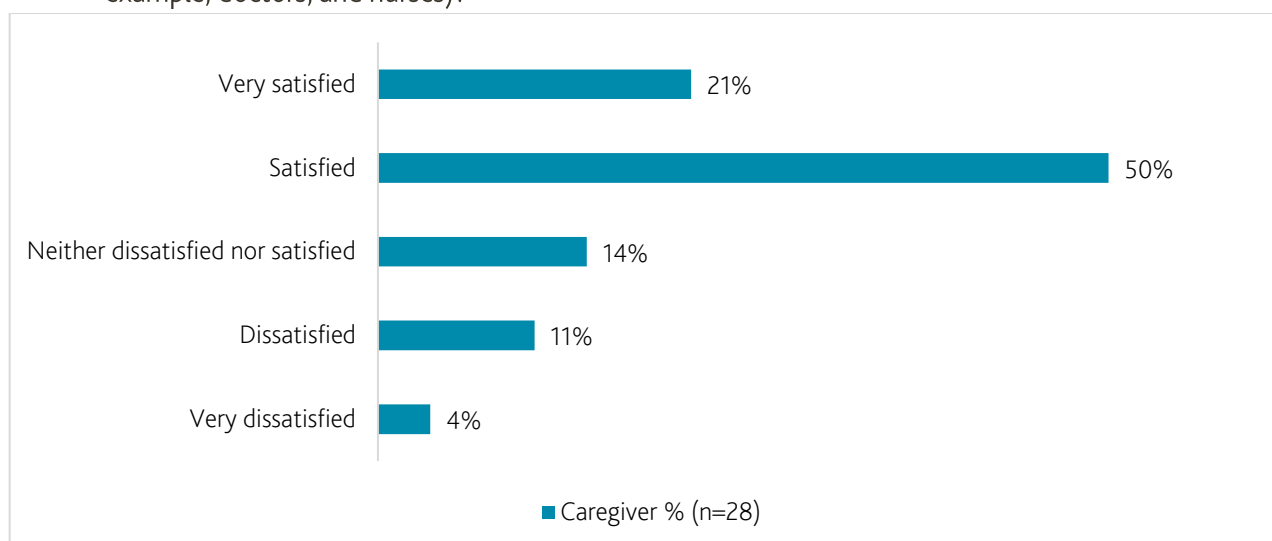
- ❖ Figure 102 reveals caregivers reported their preferred sources for lymphoma or CLL information as doctor (97%), followed by internet (59%) and patient organisation (55%).

Figure 102. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?



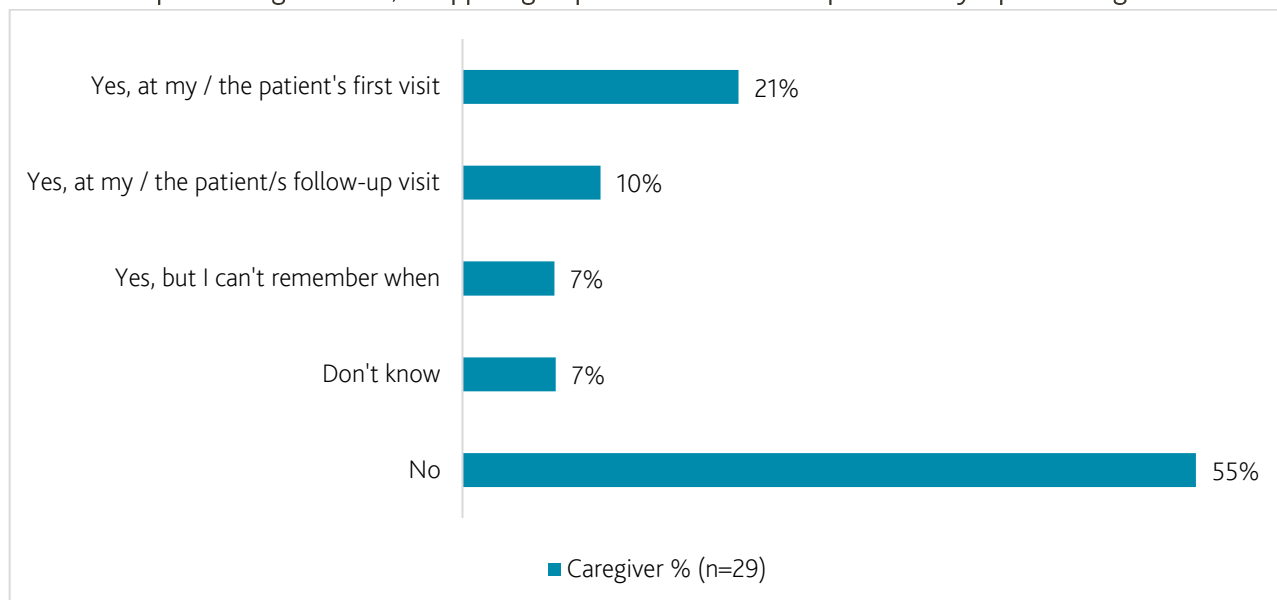
- ❖ Figure 103 shows 71% of caregivers were satisfied (50%) or very satisfied (21%) with the information from healthcare providers. *Only asked to those who indicated doctors as an information source.*

Figure 103. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, and nurses)?



- ❖ Figure 104 illustrates 55% of caregivers did not receive patient organisation information from their patient's medical team.

Figure 104. 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?



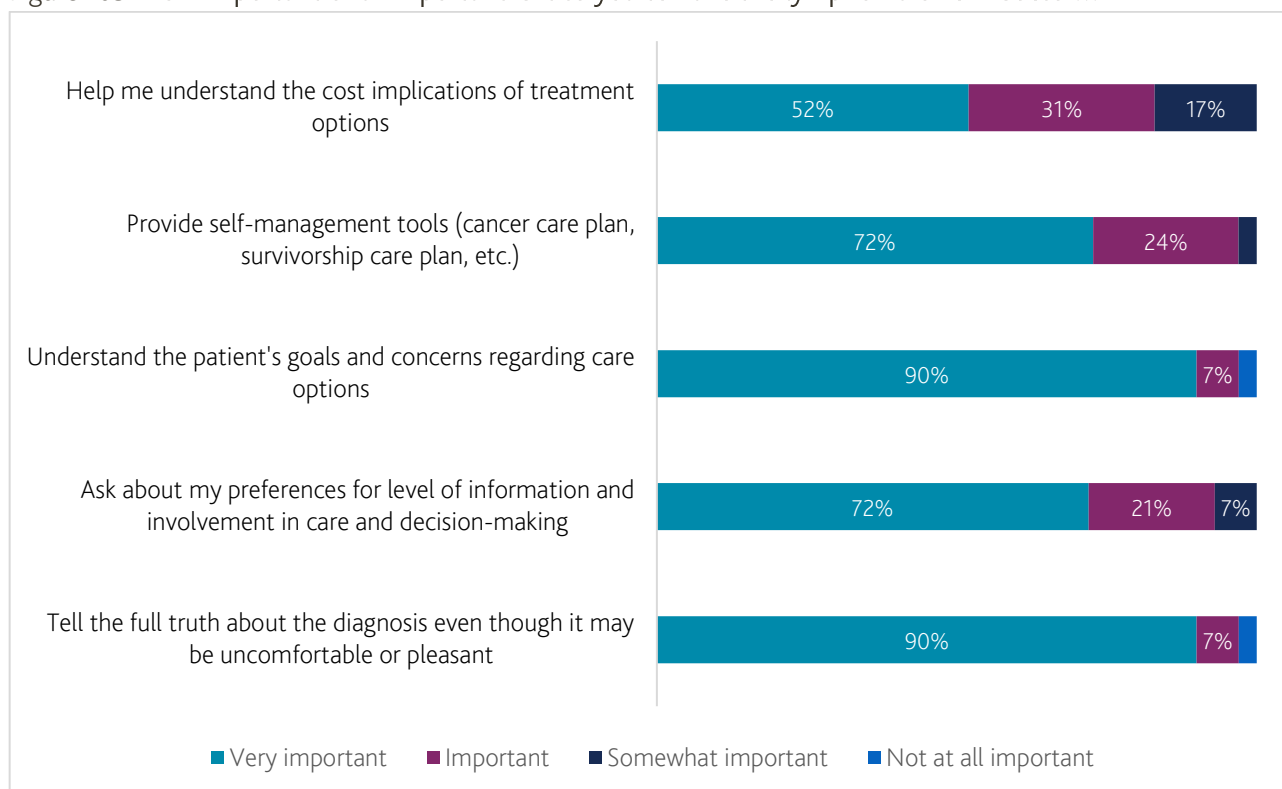
Healthcare Involvement and Decision-Making



- For 97% of caregivers, it is important or very important that the lymphoma doctor tell the full truth.
- For 97% of caregivers, it is important or very important to know that doctors understands the patients goals and concerns about treatment.
- 34% of caregivers think that for the final decision about a patient's healthcare, the patient and doctor should be involved.

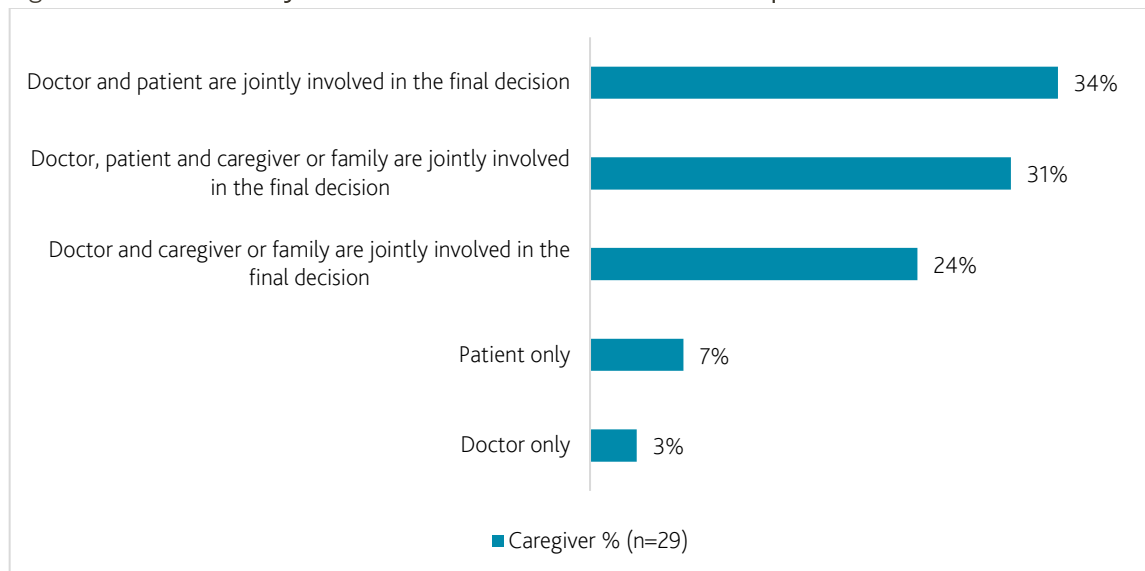
❖ Figure 105 reveals caregivers said all the factors listed were important to receive from the doctor.

Figure 105. How important or unimportant is it to you to have the lymphoma or CLL doctor...



- ❖ Figure 106 reveals, when asked about healthcare decision-making, there was a preference for collaboration. 31% included the doctor, patient and caregiver or family in the decision, and 34% included the doctor and patient.

Figure 106. Who would you like to make the final decision on the patient's healthcare?



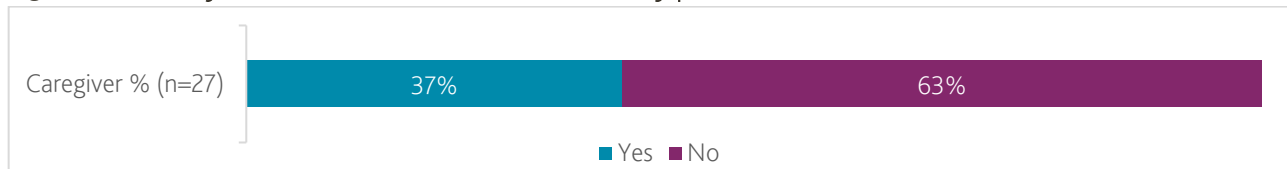
Covid-19 Concerns and Virtual Care



- 88% of caregivers had been fully vaccinated, with 81% having taken a booster dose, while 7% were not vaccinated and not planning to get vaccinated
- 81% of caregivers considered the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19, and it worried 70% of them.

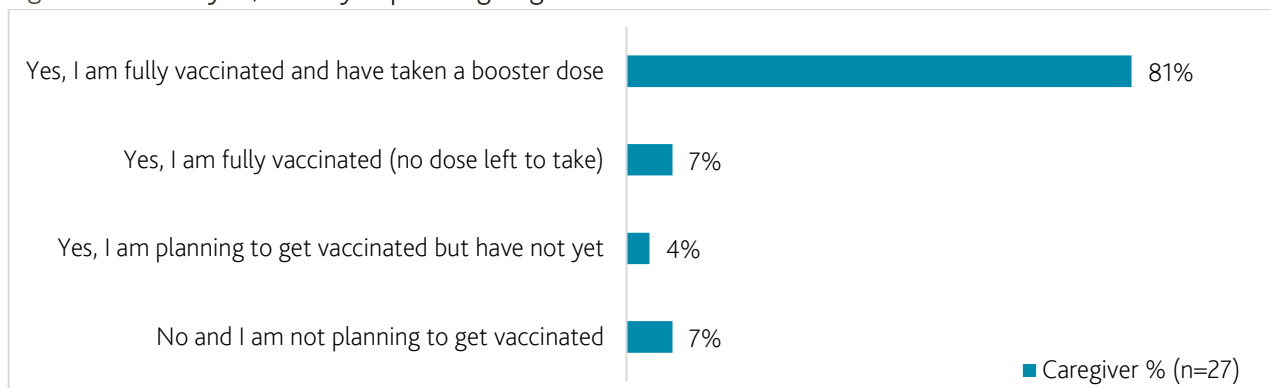
❖ Figure 107 reveals 37% of caregivers had contracted Covid-19 at any point

Figure 107. Have you contracted Covid-19, now or at any point?



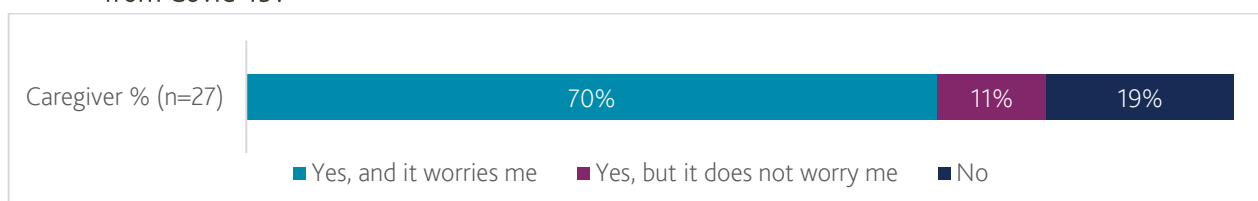
❖ Figure 108 shows 88% of caregivers had been fully vaccinated, with 81% having taken a booster dose.

Figure 108. Have you, or are you planning to get the Covid-19 vaccine?



❖ Figure 109 shows 81% of caregivers consider their patients as high risk for contracting Covid-19, and it worries 70% of them.

Figure 109. Do you consider the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?



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