



2022 Global Patient Survey on Lymphomas & CLL

November 2022

Country Report

Bulgaria

Table of Contents

Overview	4
Key Findings from Patients.....	6
Key Findings from Caregivers.....	7
Background	9
Lymphoma Coalition.....	9
Survey Research Centre.....	9
Global Patient Survey.....	9
Methodology.....	11
Development of the 2022 GPS.....	11
Data Collection	12
Data Cleaning.....	12
Data Dissemination	13
Patient Results.....	15
Patient Characteristics	15
Diagnostic Demographics	19
Healthcare Information and Guidance.....	25
Healthcare Support.....	34
Healthcare Involvement and Decision Making.....	40
Effects of Lymphoma/CLL.....	45
Lymphoma and CLL Treatments	46
Barriers to Treatment	53
Side Effects of Treatment.....	56
Fatigue.....	60
Psychosocial Effects of Lymphoma.....	64
Covid-19 and Virtual Care.....	68
Caregiver Results.....	75
Caregiver Characteristics.....	75
Diagnostic Demographics	79
Healthcare Information.....	83
Healthcare Involvement and Decision Making.....	89
Covid-19 Concerns and Virtual Care.....	91
List of Figures.....	93

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 CLL, and the impact of treatment and care. 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 serve 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 Bulgaria.

The overall number of completed responses was **210**, made up of:

161 Patients



49 Caregivers



SECTION 2

Key Findings



Key Findings from Patients

Information, Guidance and Support



33% of patients felt well or very well informed about the processes and stages of their healthcare.



85% of patients reported doctors as their preferred source of information.



52% of patients would like doctors, and patients jointly involved in making healthcare decisions.



43% say the doctor did not identify and recommend other resources and supports when making decisions about care.

Diagnosis and Treatment



65% 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.



64% of respondents experienced fatigue as a symptom of lymphoma and 68% experienced it as a side effect of treatment.



60% of patients indicated they had experienced fear of lymphoma relapse and 41% experienced fear of lymphoma progression.



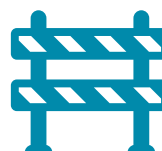
32% of patients reported nothing had made getting treatment more difficult.



37% of patients reported having to travel outside of their region of residence for treatment was a barrier preventing them from receiving treatment.



22% of patients received information about clinical trials from their doctor, yet only 5% of patients were in or had been in a clinical trial for their lymphoma or CLL.



54% 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



33% patients reported their depression was somewhat worse during the Covid-19 pandemic, and 39% said it was much worse.



31% of patients reported their anxiety was somewhat worse during the Covid-19 pandemic and 51% said it was much worse.



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



Only 7% of patients strongly agreed and 16% agreed that they preferred telephone consultation or video consultation to face-to-face visit.



Patient organisations were identified by 42% of patients as very helpful or helpful sources of information and support during the COVID-19 pandemic.



45% of patients found doctors & nurses very helpful or helpful sources of information and support during the pandemic.

Key Findings from Caregivers



39% of caregivers felt well or very well informed about the processes and stages of the patient's healthcare.



94% of caregivers reported doctors as their preferred source of information.



65% of caregivers think that for the final decision about a patient's healthcare should involve, the doctor, patient and caregiver or family.



84% of caregivers report seeking out additional information about the patient's diagnosis, above what they were told by the medical team.

SECTION 3

Background



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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 (HNNHCP), 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



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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.

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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. Promotion materials were also shared with LC member organisation networks, 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 subgroup 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.

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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

LC dissemination and data preservation plan ensure 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 server a 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



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Patient Results

161 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

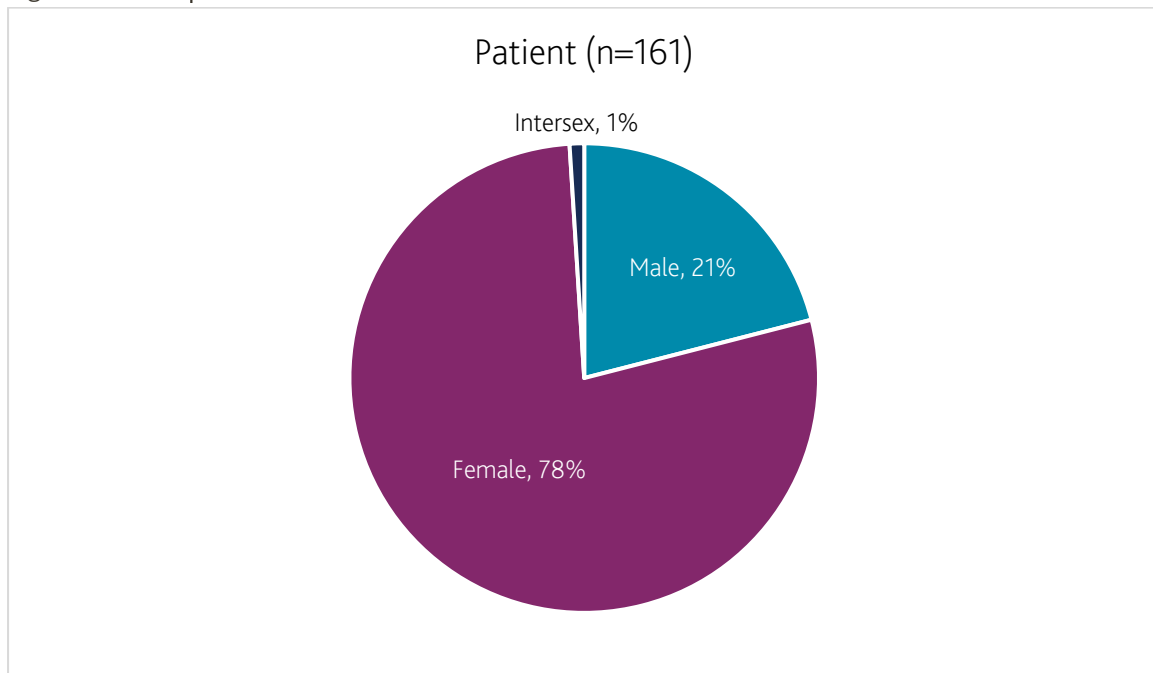


- Most responses were from patients aged 35-54 (52%), followed by patients aged 55-64 (20%), with the lowest survey respondents being 65 or older (10%).
- Patients who reported their ethnicity as Caucasian or White represented the largest cohort at 70%.
- The overall cohort of patient respondents (161) represented 78% female and 22% male, with most respondents residing in city or urban areas (77%).
- Nearly half (42%) of the overall respondents completed post-secondary education (college/university), with a high rate (24%) having completed postgraduate education such as a master's or Ph.D.
- A majority reported they have full-time employment (60%), and 15% are retired. Only 3% of patients were unable to work for health-related reasons.

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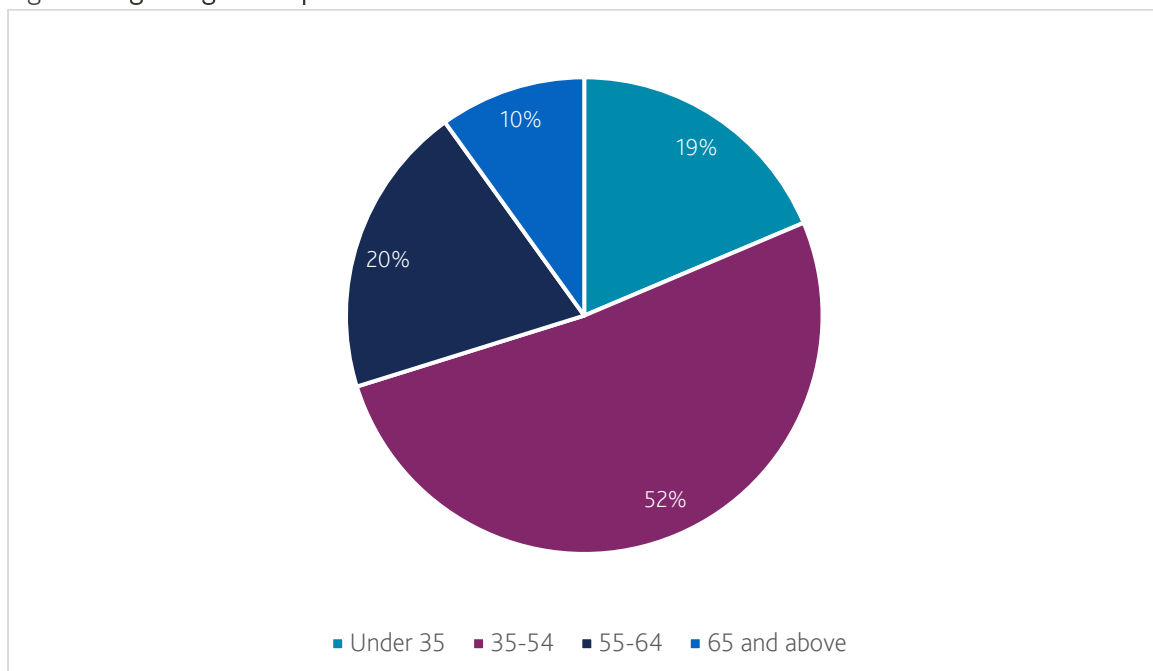
- ❖ Figure 1 shows three-quarters of respondents are female patients.

Figure 1. Sex of patient



- ❖ Figure 2 illustrates that over half (52%) of patients are ages 35-54.

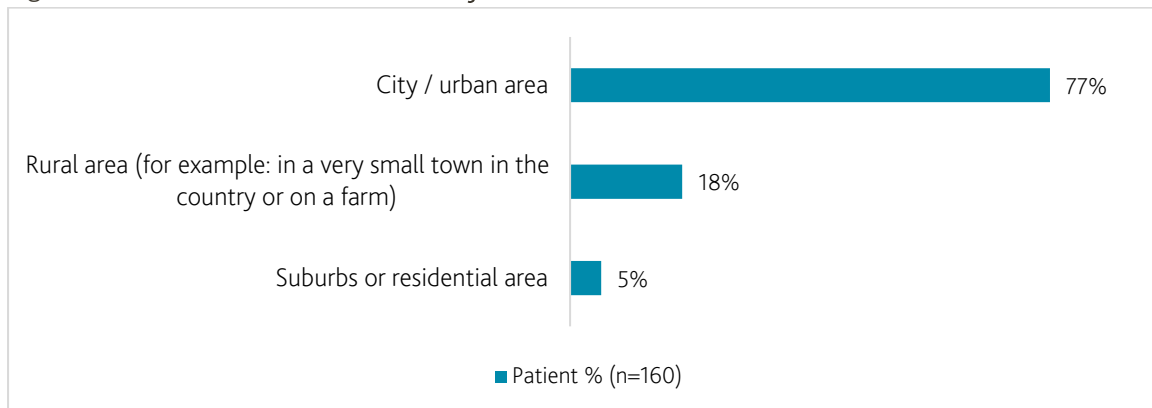
Figure 2. Age range of respondents



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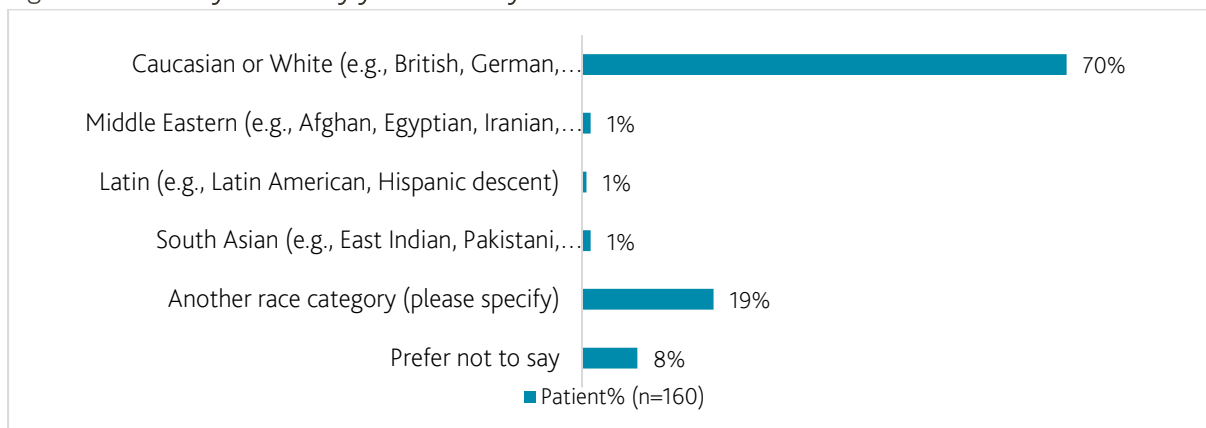
- ❖ Figure 3 shows three quarters of patients live in city / urban areas.

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



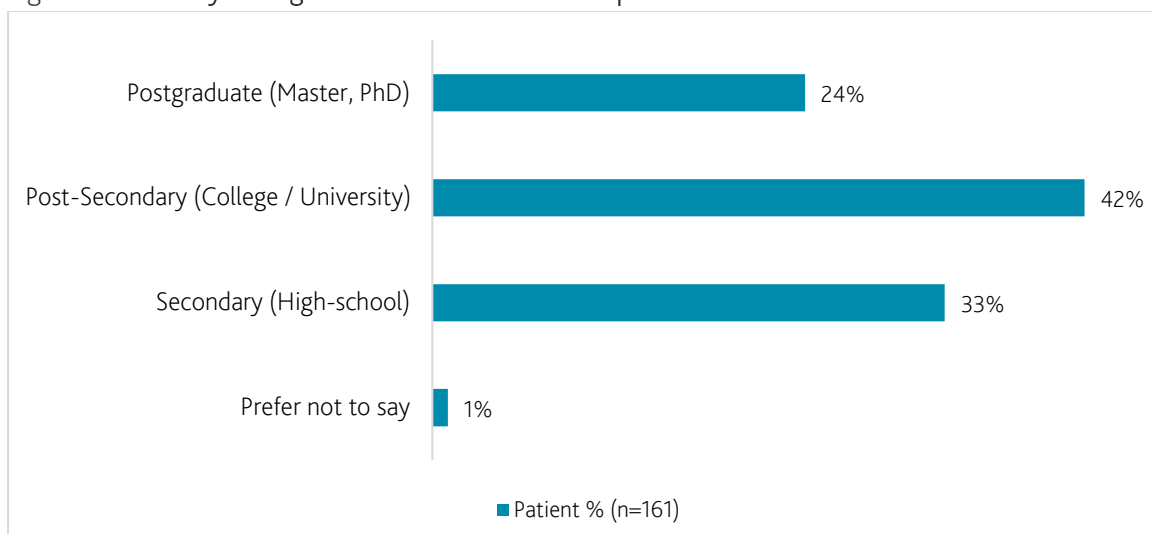
- ❖ Figure 4 indicates almost three-quarters of patients identify as Caucasian or White.

Figure 4. How do you identify your ethnicity?



- ❖ Figure 5 illustrates that 42% of patients have completed post-secondary education.

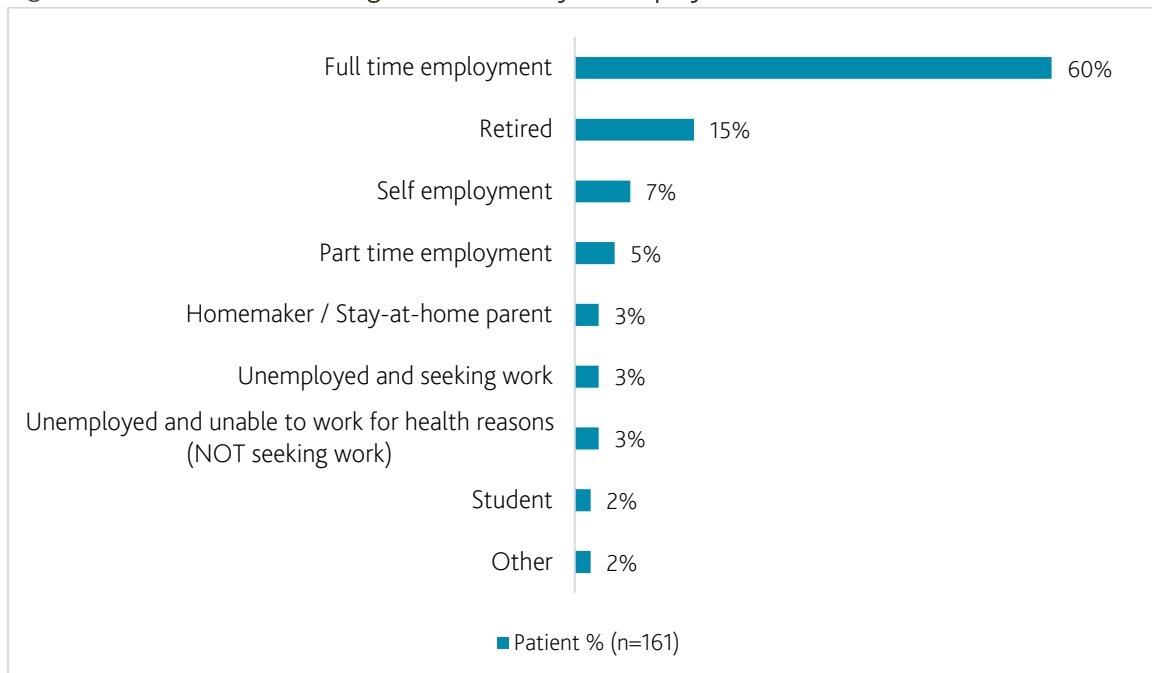
Figure 5. What is your highest educational level completed?



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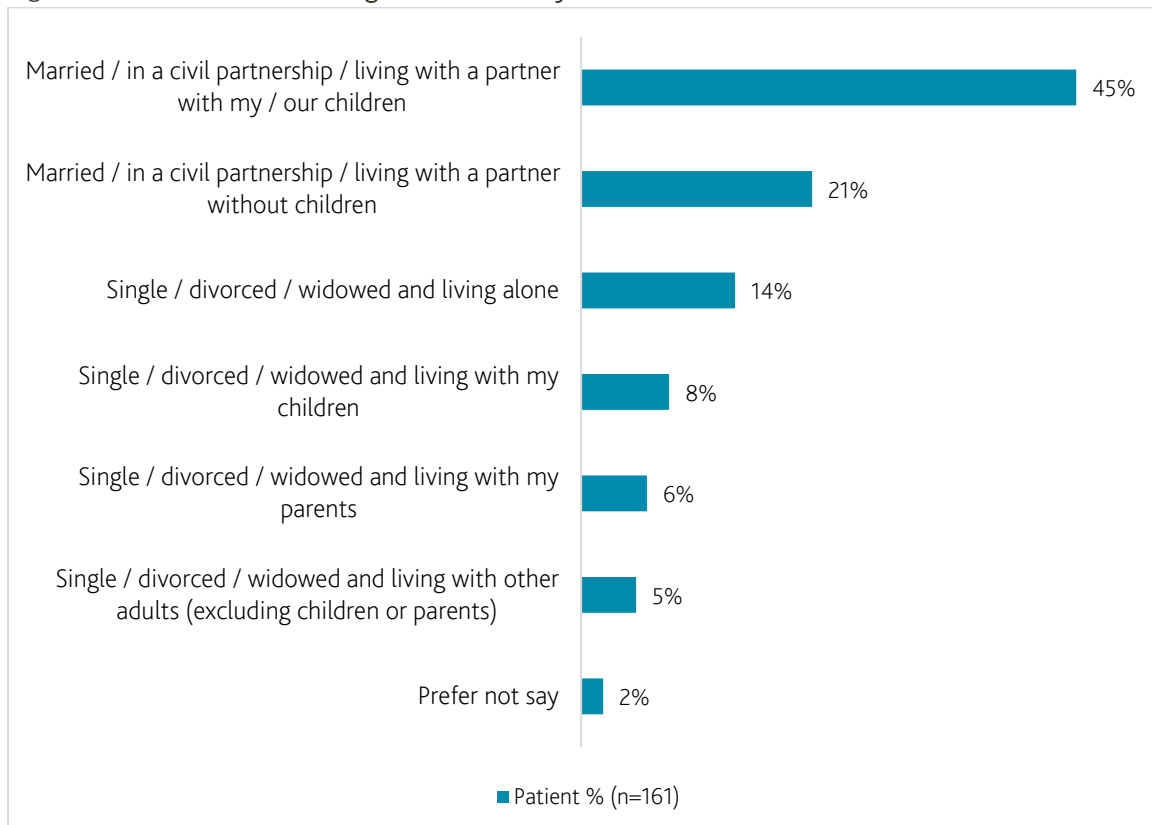
❖ Figure 6 shows almost two-thirds (60%) of patients have full-time employment.

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



❖ Figure 7 reveals that 45% of patients have a partner and children.

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



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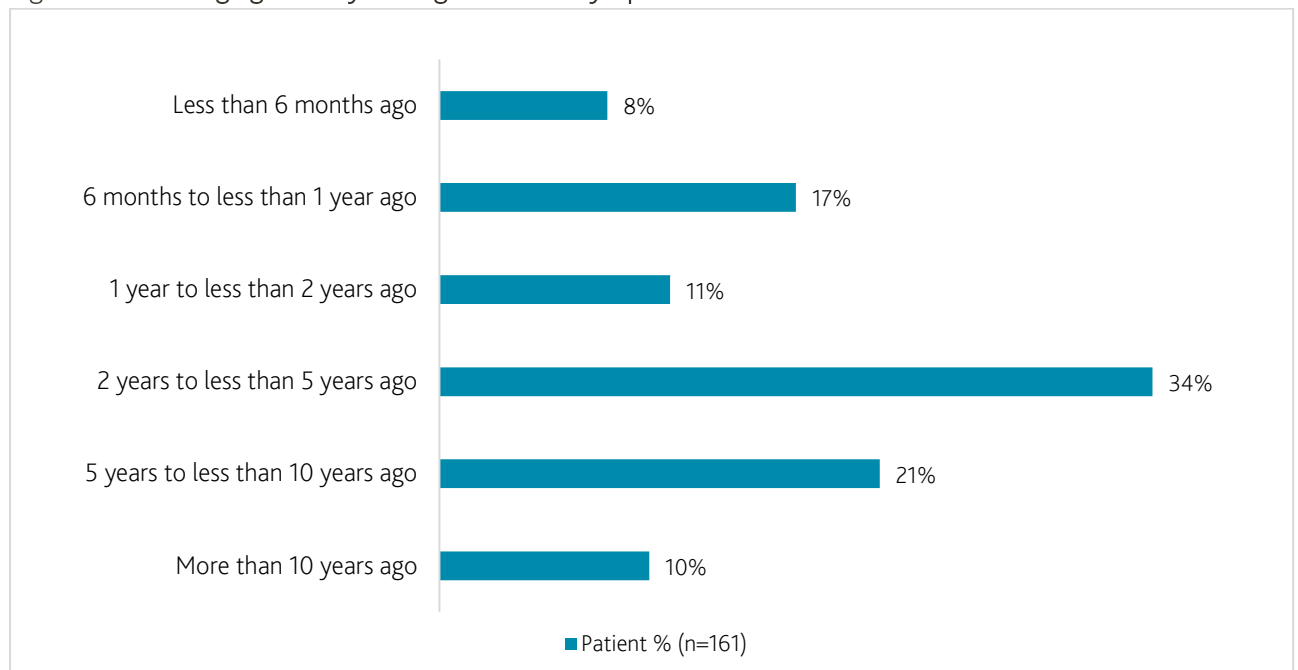
Diagnostic Demographics



- 34% of patients who responded to the survey were diagnosed 2 to less than 5 years ago.
- 86% of patients were seen by two or more healthcare professionals for their symptoms before receiving their initial diagnosis. A staggering 23% were seen by five or more healthcare professionals before receiving a diagnosis.
- A quarter of patients (23%) experienced their symptoms for more than six months before seeking medical care. 59% 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, 18% 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 Follicular lymphoma (23%), Hodgkin lymphoma (15%), Diffuse Large B-Cell Lymphoma (no specific type) (14%), Chronic Lymphocytic Leukaemia (CLL) / Small Lymphocytic Lymphoma (11%), and Mantle Cell Lymphoma (7%),

❖ Figure 8 reveals a third of patients have been diagnosed with lymphoma or CLL between 2 to 5 years ago.

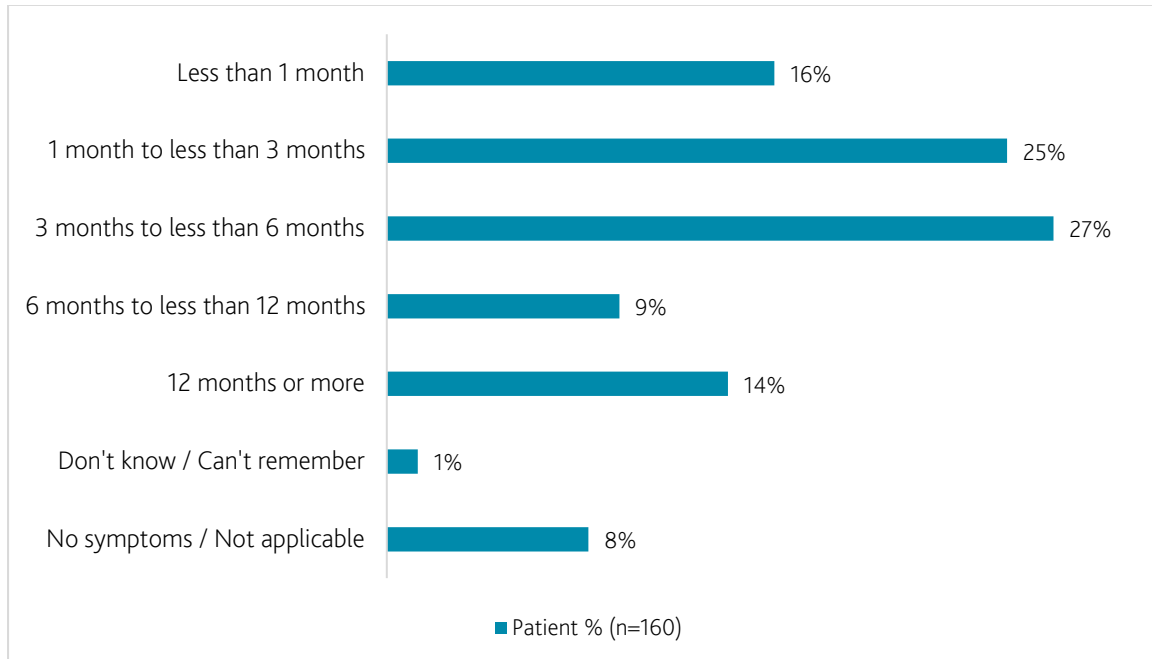
Figure 8. How long ago were you diagnosed with lymphoma or CLL?



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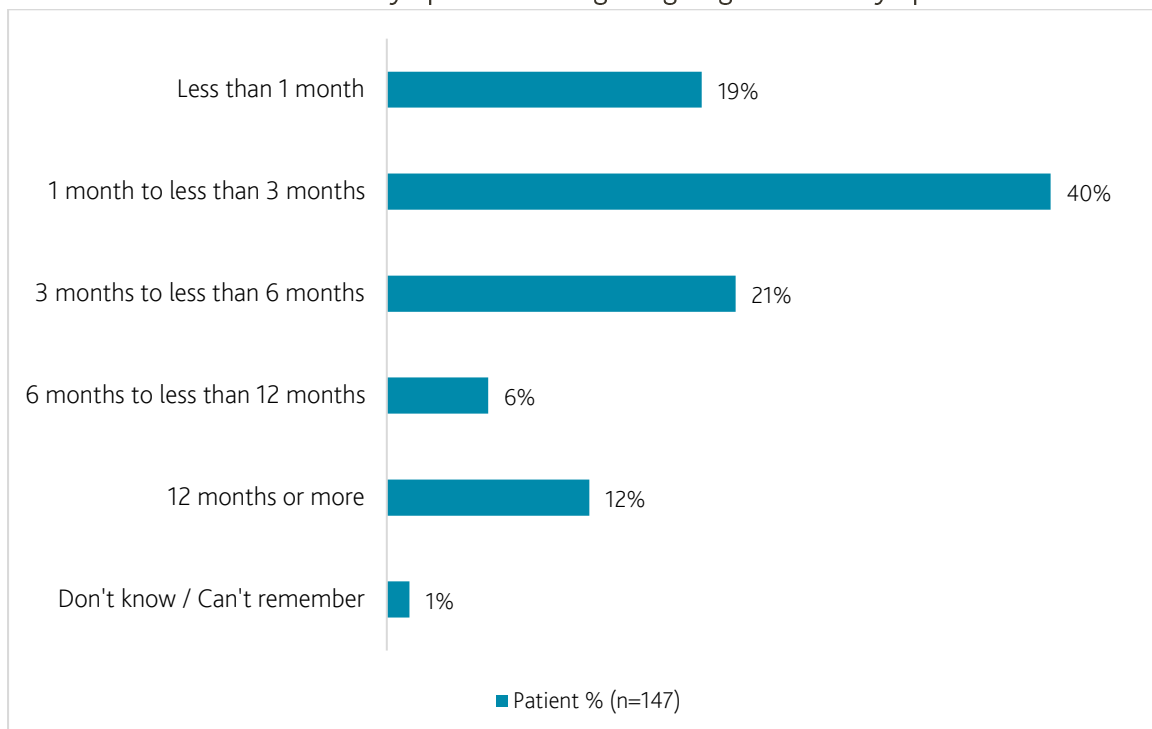
- ❖ Figure 9 shows that 8% of patients did not experience any symptoms of lymphoma.

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 over half (59%) patients had a diagnosis within 3 months of their first appointment, but 18% were waiting 6 months or more from their initial GP meeting.

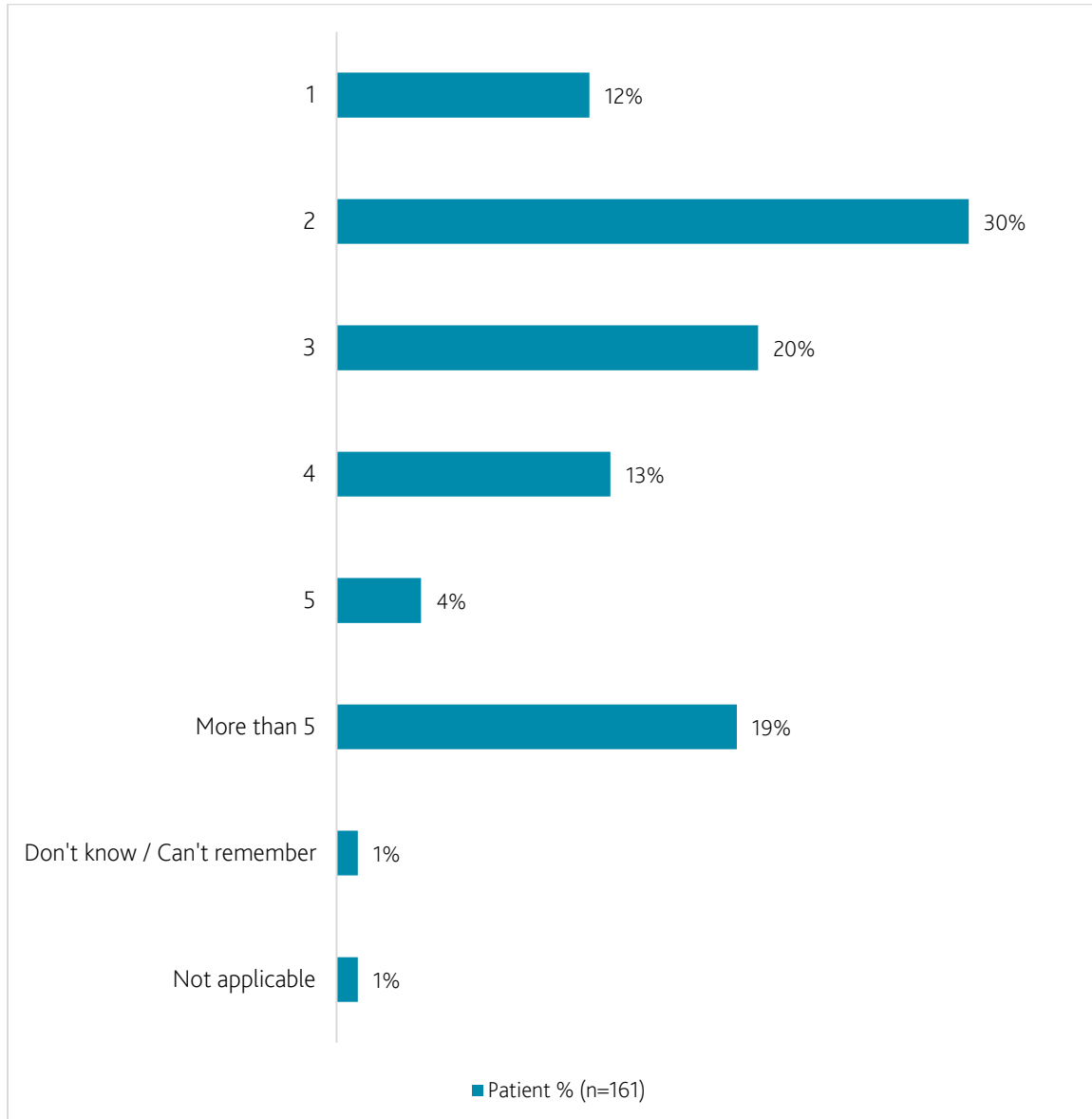
Figure 10. Overall, how long did it take from the first appointment with the family doctor or seeking medical care about the symptoms to first getting diagnosed with lymphoma or CLL?



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- ❖ Figure 11 reveals nearly a fifth of patients saw more than 5 healthcare professionals about their symptoms before receiving their current diagnosis.

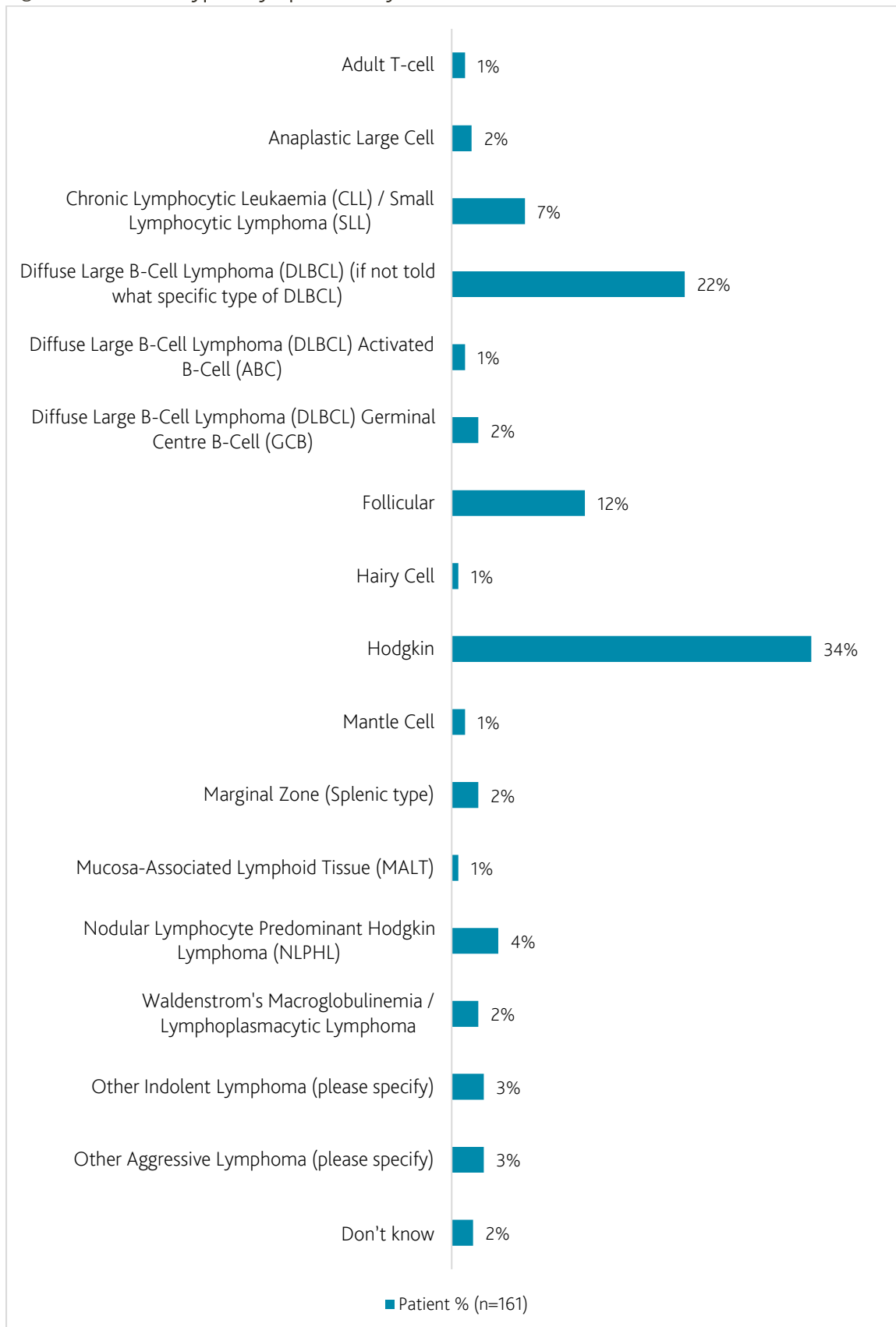
Figure 11. How many healthcare professionals did you see about your symptoms before receiving the current diagnosis?



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❖ Figure 12 illustrates that a third of patients have Hodgkin lymphoma.

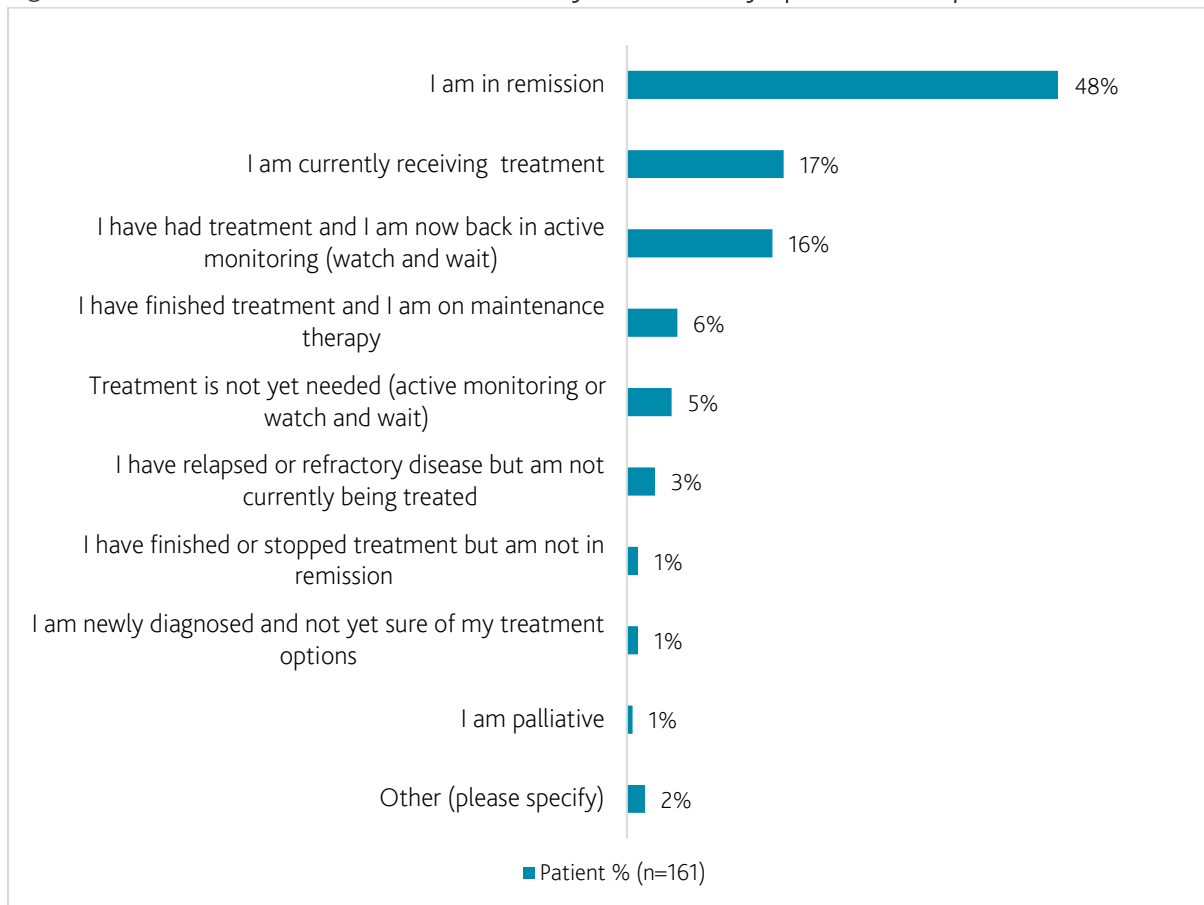
Figure 12. What subtype of lymphoma do you have?



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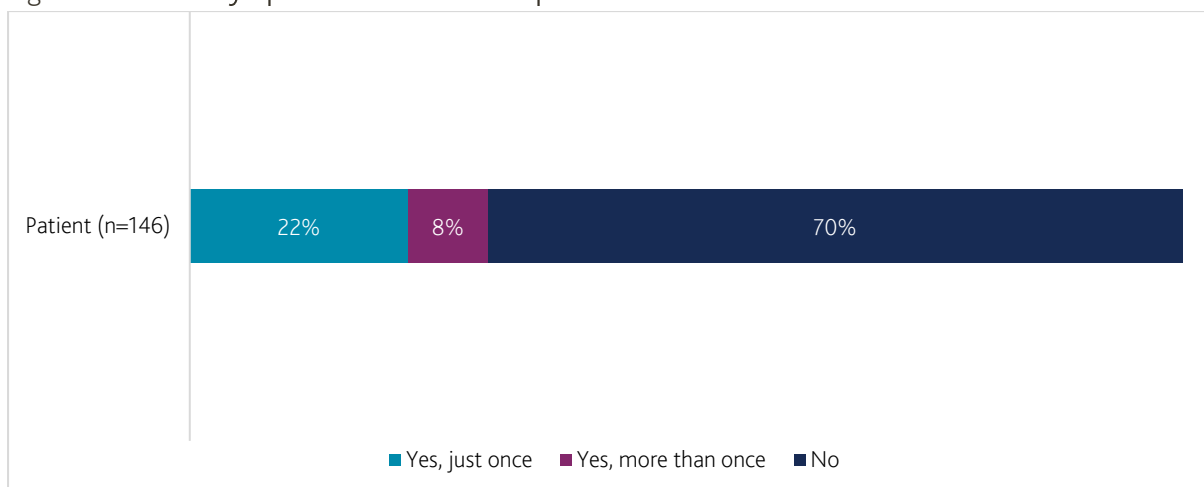
- ❖ Figure 13 shows almost half of patients are in remission.

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



- ❖ Figure 14 illustrates that 70% of patients have not experienced a lymphoma or CLL relapse. **Only asked to those who have received or are receiving treatment.**

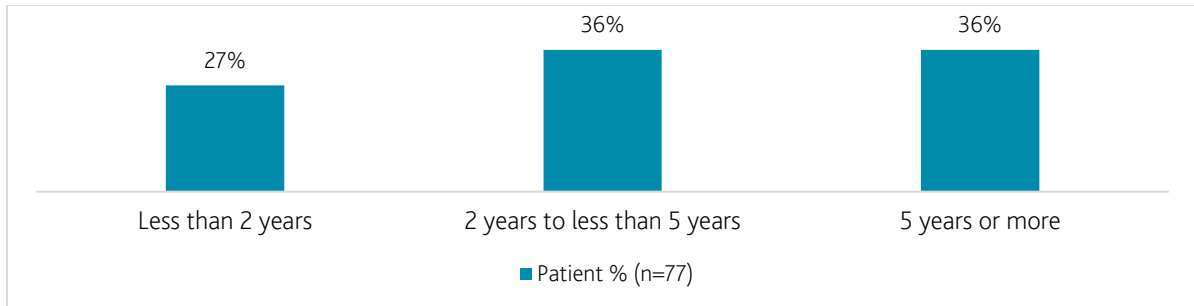
Figure 14. Has the lymphoma or CLL ever relapsed?



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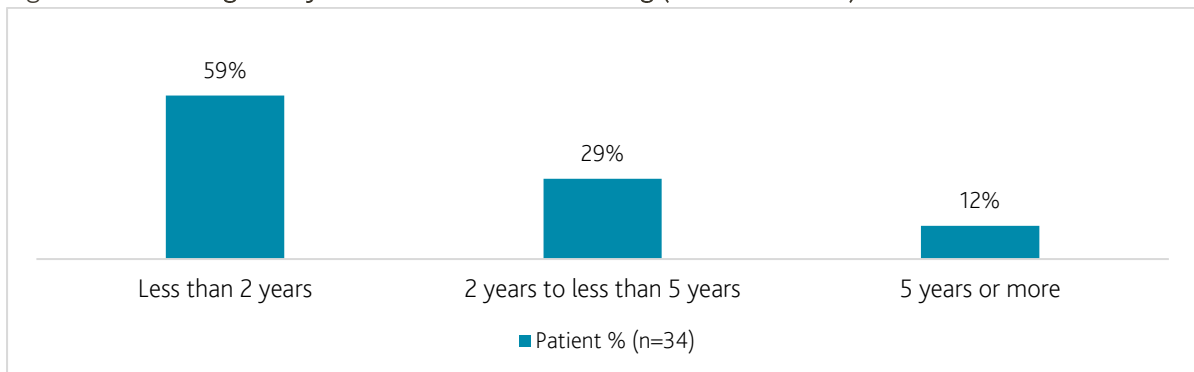
- ❖ Figure 15 explains that almost three-quarters of patients in remission had their last treatment more than 2 years ago. *Only asked to those who selected they were in remission.*

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



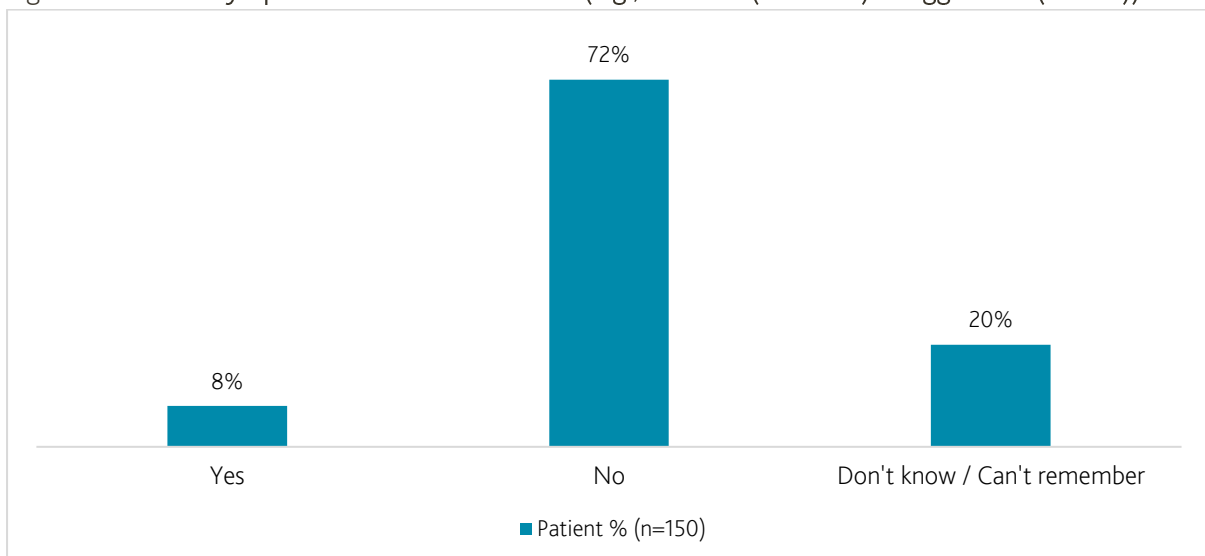
- ❖ Figure 16 shows that over half of patients have been in active monitoring for less than 2 years. *Only asked to those who selected they were in active monitoring.*

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



- ❖ Figure 17 depicts 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))?



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Healthcare Information and Guidance

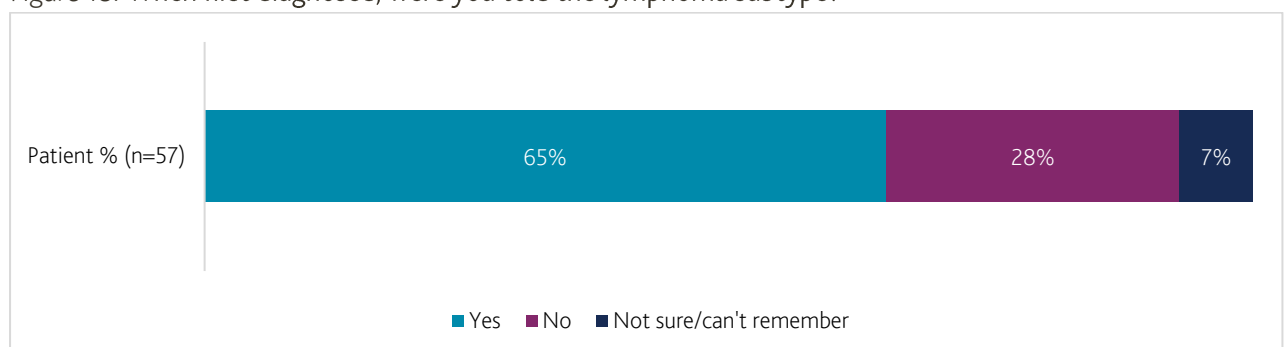
Previous surveys showed that having 'adequate information' was correlated with more self-reported positive healthcare experiences. Also, patients with adequate information reported better management of their health and healthcare through improved understanding, confidence levels, and communication with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



- 50% of patients reported that they were seeking out information and details about their disease and potential treatment following their diagnosis and the preferred method of obtaining this information for over half of the patients (59%) was via websites.
- Nearly half of the patients (41%) felt the results they had received about their disease and diagnostic tests were explained, and they understood the explanations.
- 14% of the patients did not seek additional information other than what the doctor/ healthcare staff told them (as the doctors are the experts).
- 16% of patients were not informed at all and 19% were not very well informed about the processes and stages of their health.
- 81% of the patients did not receive any contact details of a patient organisation, a support group, and/or information produced by a patient organisation. But 72% of those who received information from patient organisations were very satisfied or satisfied with the information.

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

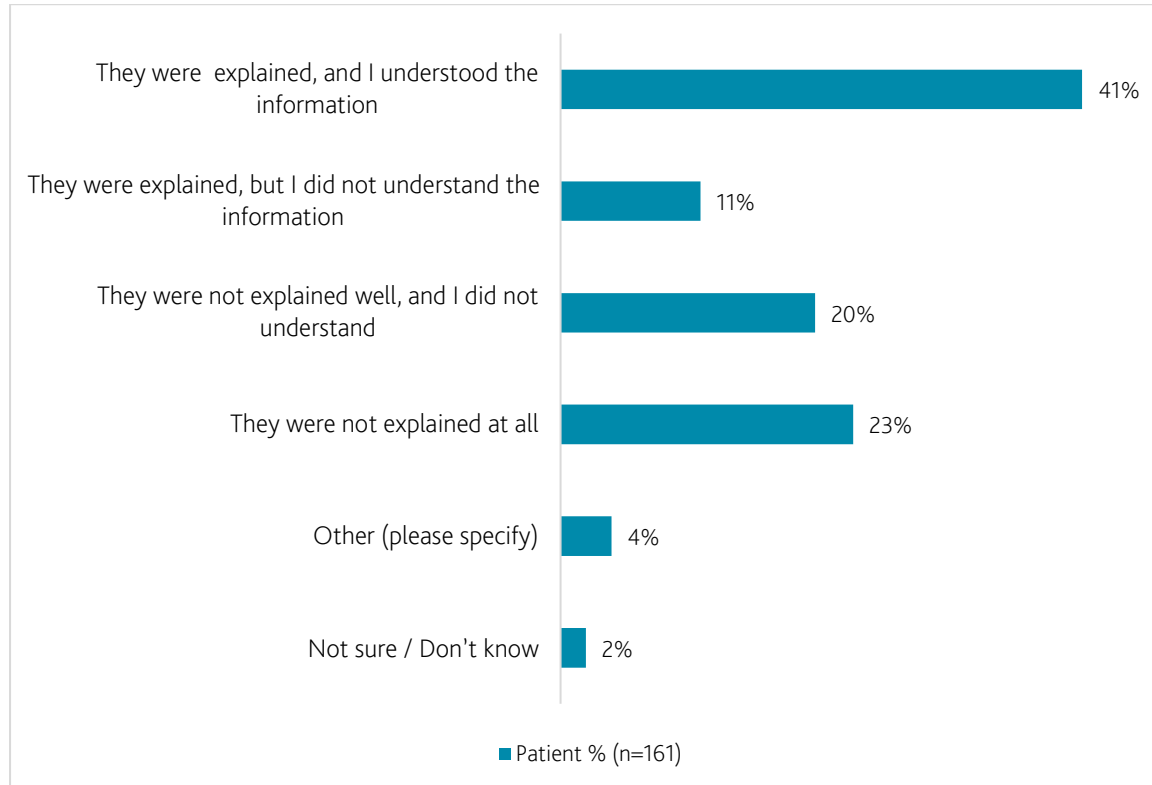
Figure 18. When first diagnosed, were you told the lymphoma subtype?



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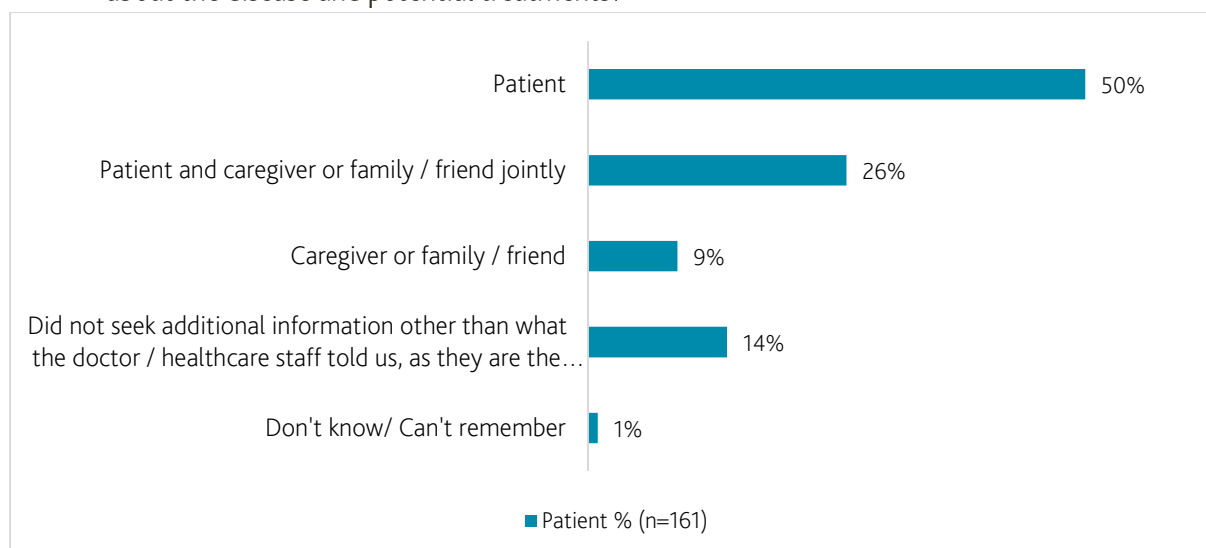
- ❖ Figure 19 reveals 72% of patients had their diagnostic tests and results explained to them but only 41% understood the information.

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 50% of patients said it was the patient alone who was seeking out the information and details about the disease and potential treatments, after their diagnosis, while 26% reported that it was the patient and caregiver jointly.

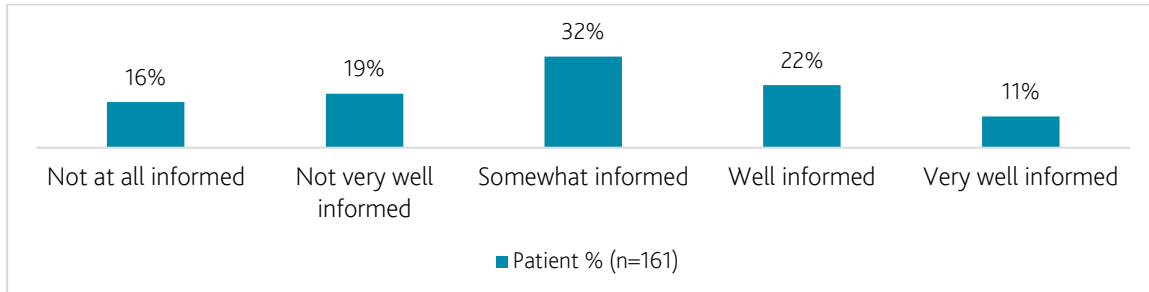
Figure 20. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



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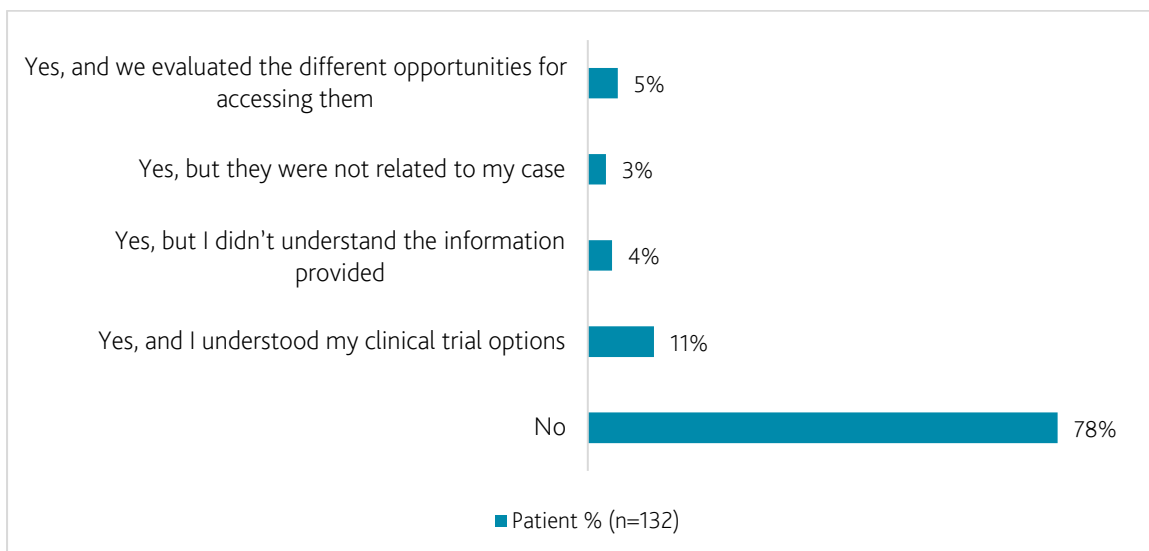
- ❖ Figure 21 illustrates that only 11% of patients felt very well informed and 22% felt well informed about the processes and stages of their healthcare throughout their experience.

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?



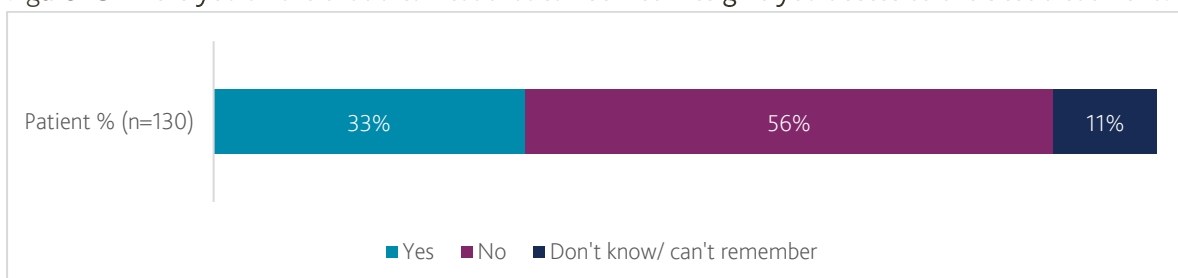
- ❖ Figure 22 reveals that over three-quarters (78%) of patients did not receive any information about clinical trials.

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



- ❖ Figure 23 shows that 59% of patients were aware that a clinical trial can sometimes provide access to the best treatment.

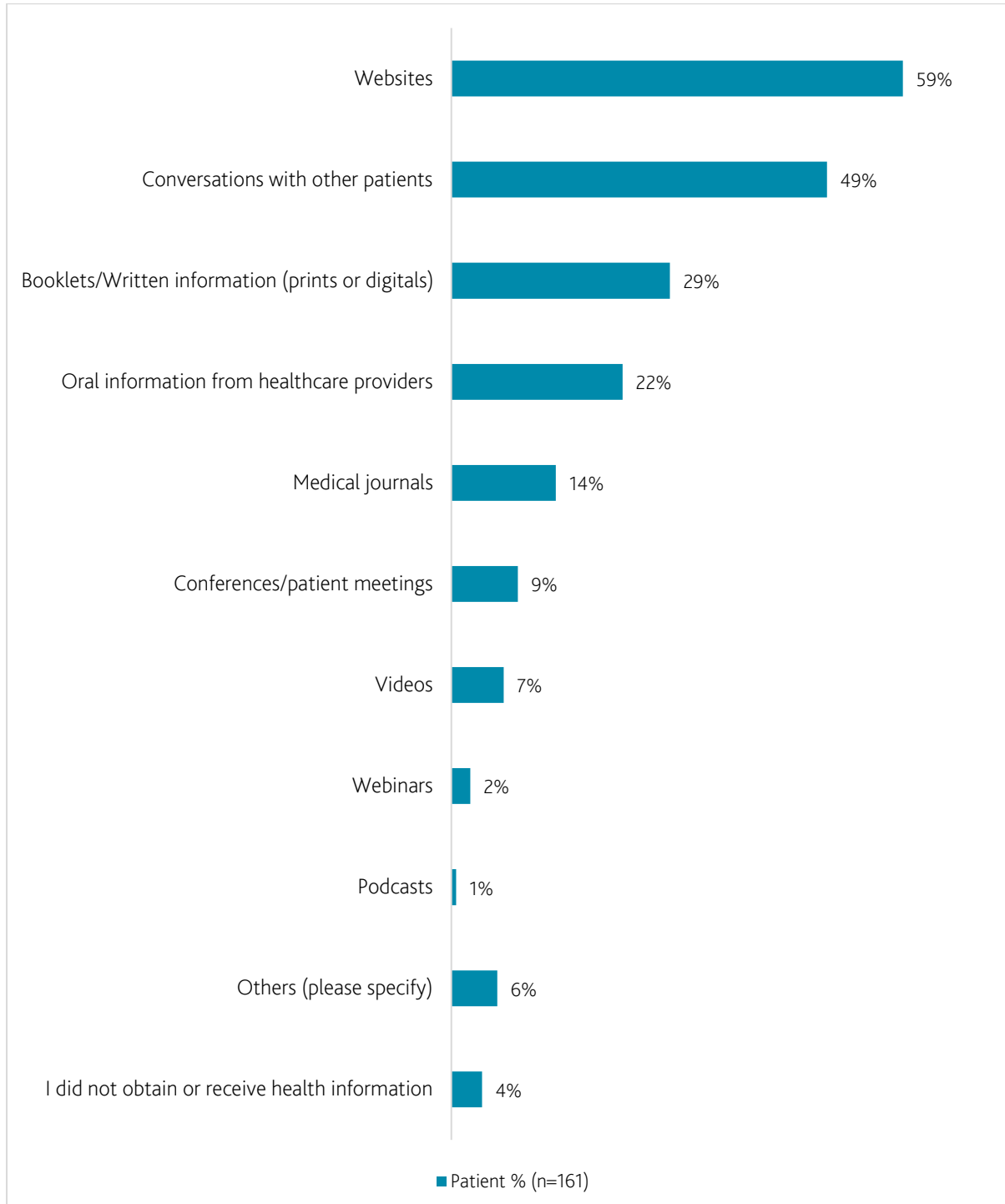
Figure 23. Were you aware that a clinical trial can sometimes give you access to the best treatment?



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- ❖ Figure 24 reveals 59% of patients preferred obtaining or receiving health information through websites and 49% from conversations with other patients.

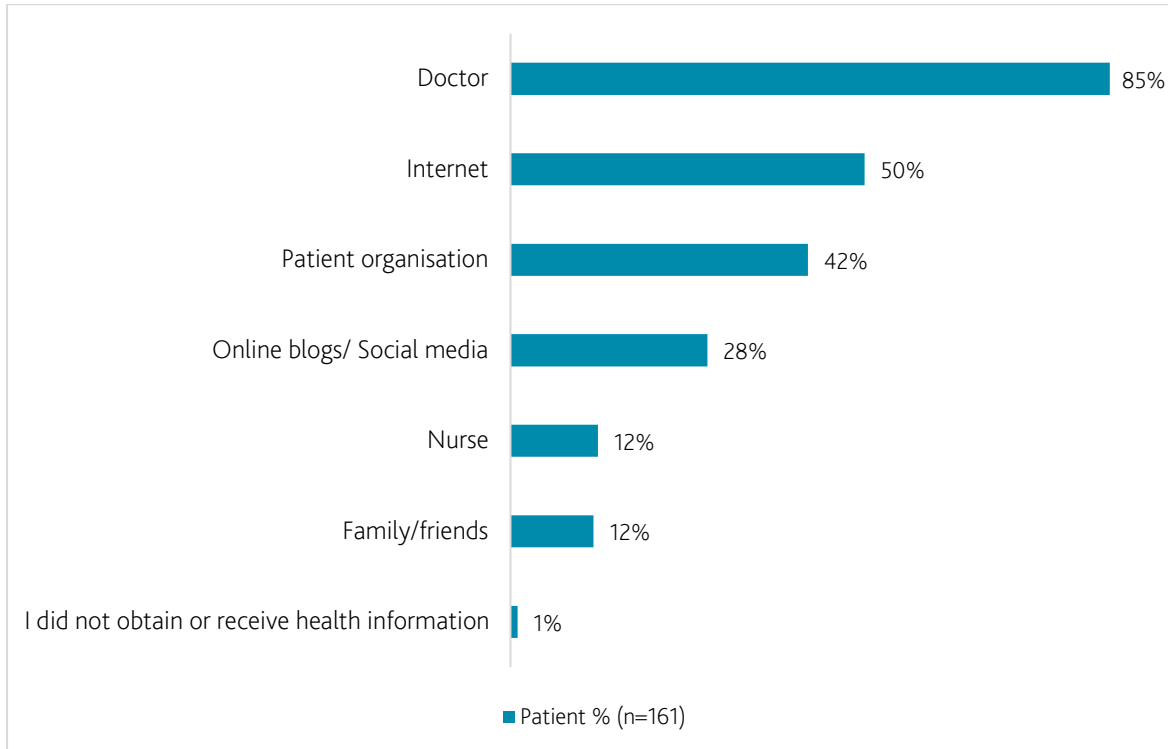
Figure 24. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



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- ❖ Figure 25 shows that the majority (85%) of patients preferred doctors followed by the internet (50%) as their source for lymphoma or CLL information.

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 59% of patients ranked doctors as their top source of lymphoma or CLL information.

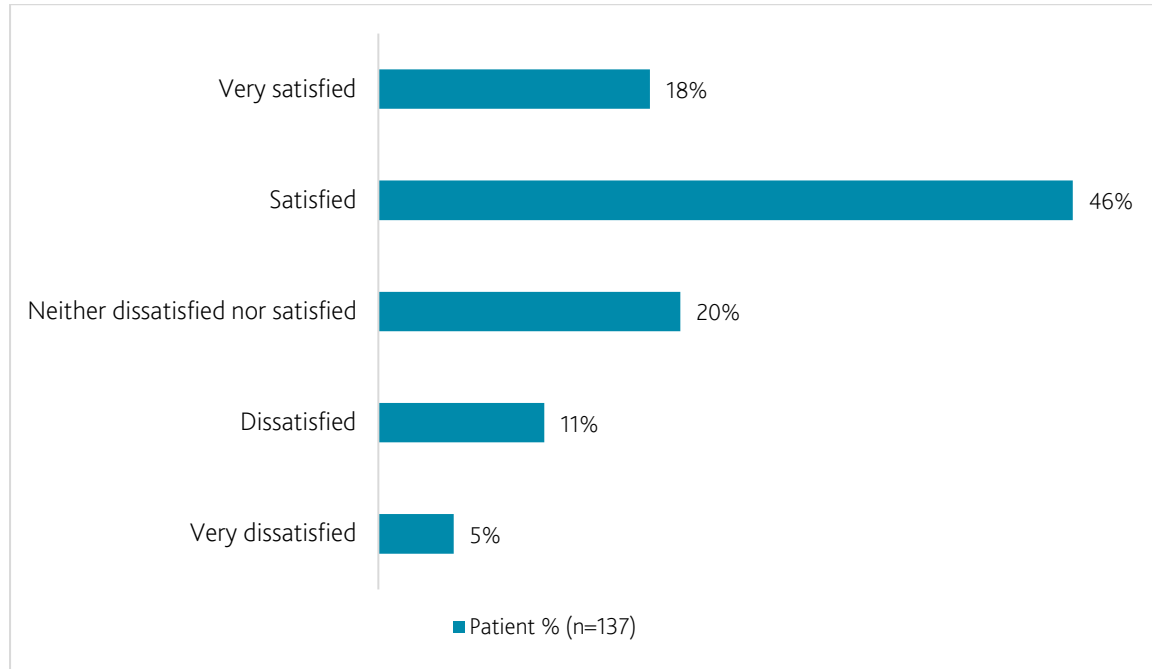
Table 1. Rank your top three sources of lymphoma or CLL information that you most prefer.

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	44	59%	8	12%	18	28%
Nurse	2	3%	8	12%	1	2%
Internet	16	21%	13	19%	19	29%
Online blogs/ social media	6	8%	6	9%	12	18%
Family/friends	1	1%	7	10%	3	5%
Patient organisation	6	8%	25	37%	12	18%
Others (please specify)	0	0%	0	0%	0	0%
Total	75	100%	67	100%	65	100%

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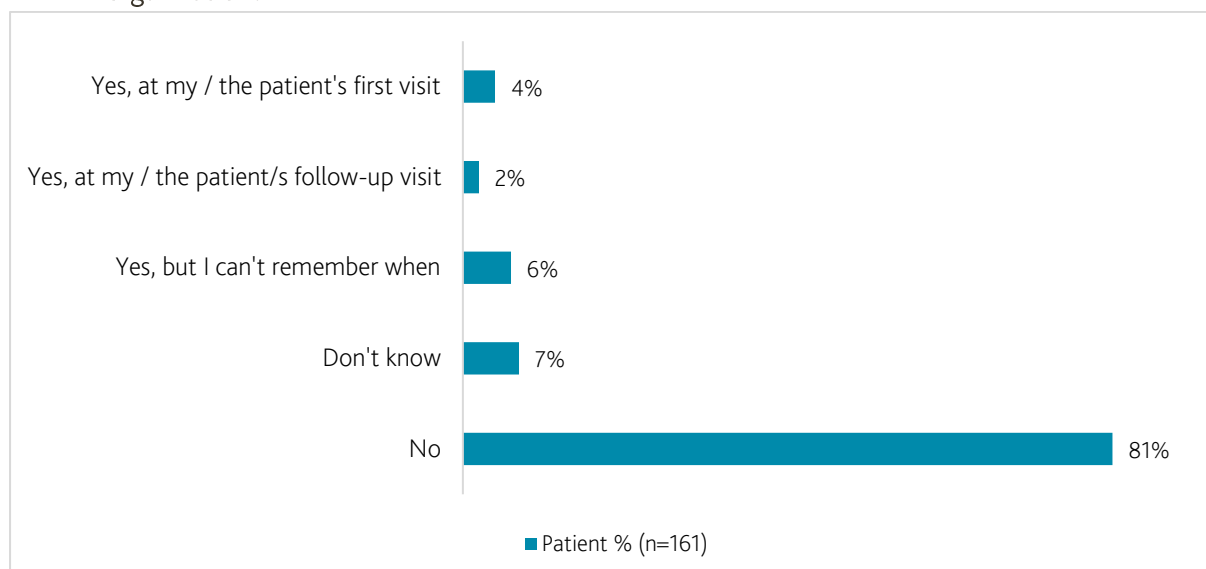
- ❖ Figure 26 reveals 64% of patients were very satisfied/satisfied with the information given to them by healthcare providers.

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 over three-quarters (81%) of patients did not receive any information about patient organisations from their lymphoma or CLL doctor or medical team.

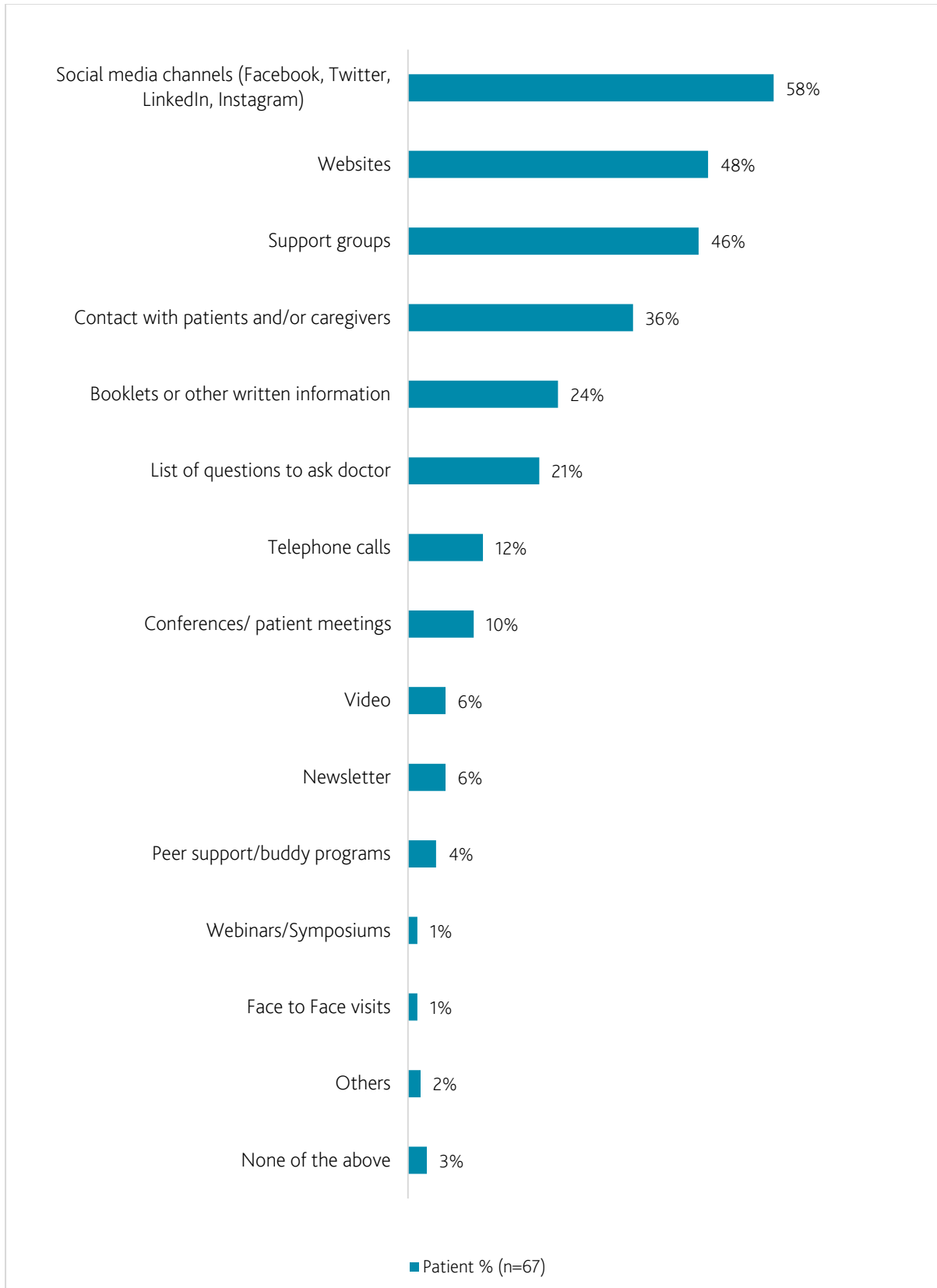
Figure 27. Did the lymphoma or CLL doctor or any member of the medical team give you the contact details of a patient organisation, a support group and/or information produced by a patient organization?



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- ❖ Figure 28 describes that almost half of patients used patient organisation social media channels.
Only asked to those who indicated they had connected with a patient organisation.

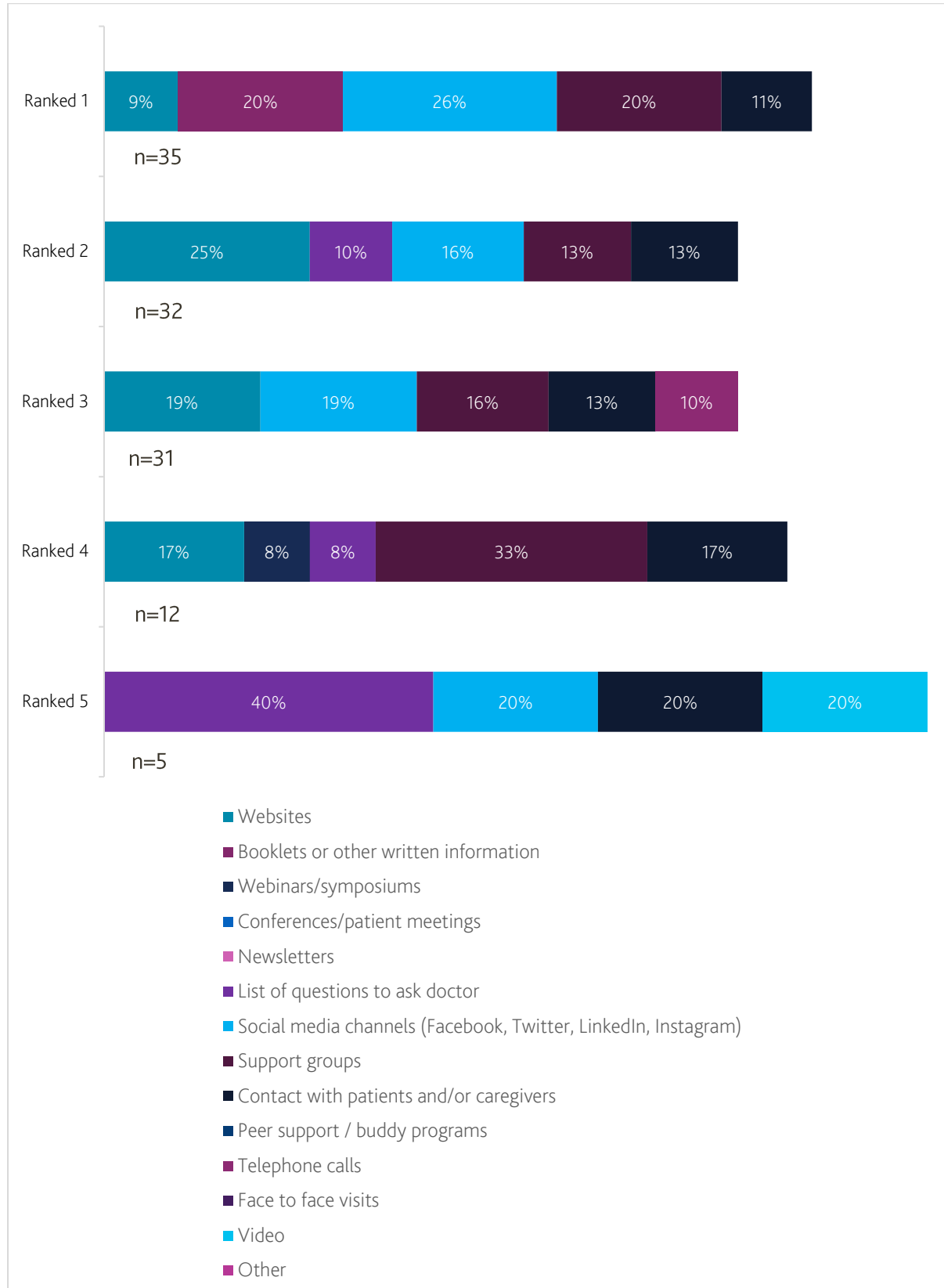
Figure 28. What type of patient organisation information do you use?



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- ❖ Figure 29 illustrates that 26% of patients ranked social media channels as their top information source produced by patient organisations. *Only asked to those who indicated they had connected with a patient organisation.*

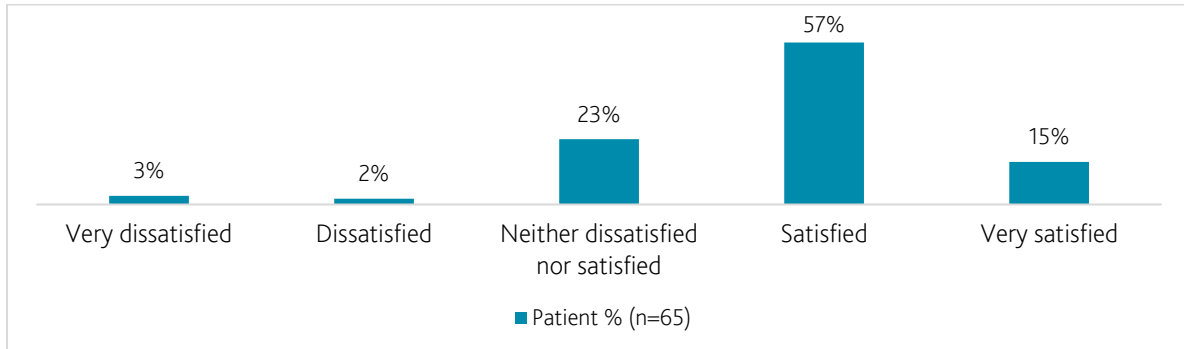
Figure 29. Top 5 information sources of patient organisations ranked 1-5



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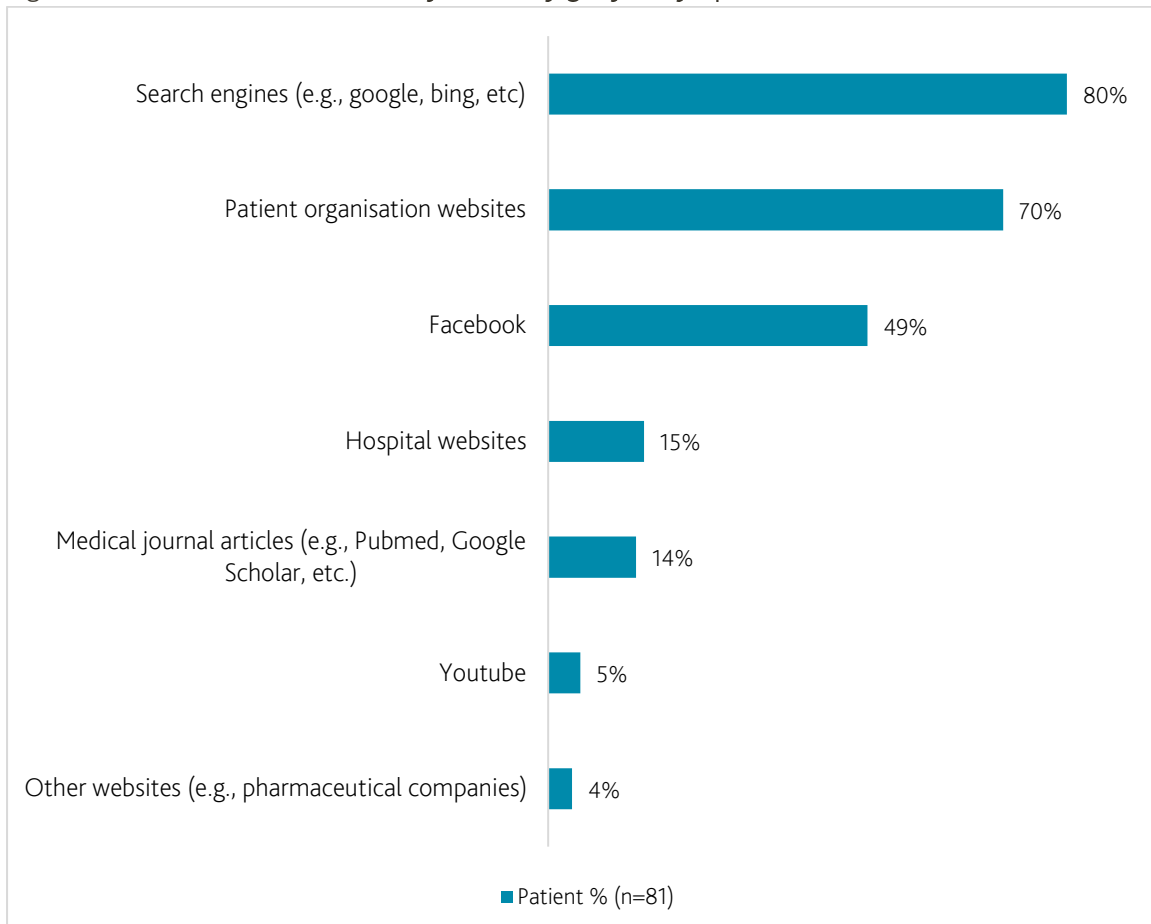
- ❖ Figure 30 reveals that 72% of patients were satisfied or very satisfied with the information given by patient organisations. *Only asked to those who indicated they had connected with a patient organisation.*

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



- ❖ Figure 31 explains that 80% of patients usually get lymphoma or CLL information from search engines, followed by patient organization websites (70%). *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?



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Healthcare Support

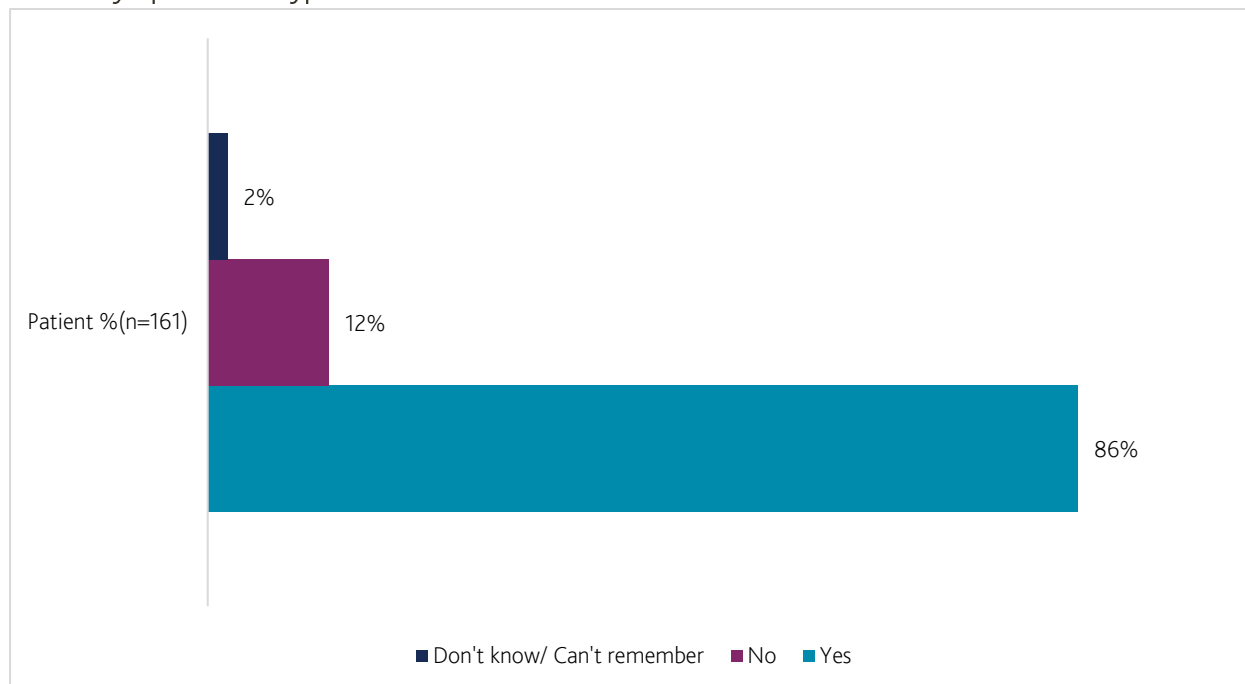
In addition to information, patients need support to help them cope with the challenges they face during their experience with lymphoma or CLL. The results in this section includes specific questions for patients with indolent disease, those in remission/survivors and people in active monitoring.



- 86% of patients had seen a specialist (e.g., haematologist, oncologist, dermatologist) for their lymphoma subtype.
- 63% of patients had been seeing the same speciality physician (e.g., haematologist, oncologist, dermatologist) throughout their patient experience.
- 36% of patients did not have their health care supported by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator.
- 54% of those who had their care supported by a cancer care team, had a dedicated first point of contact.

❖ Figure 32 shows that most patients had seen a specialist for their lymphoma subtype.

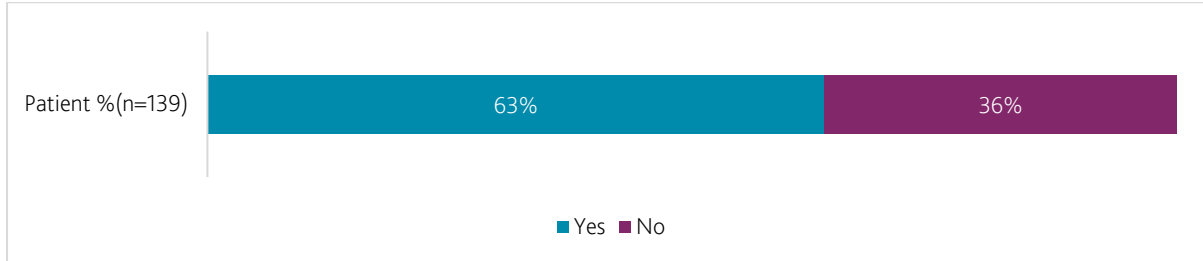
Figure 32. Have you ever seen a specialist (e.g., haematologist, oncologist, dermatologist) for your lymphoma subtype?



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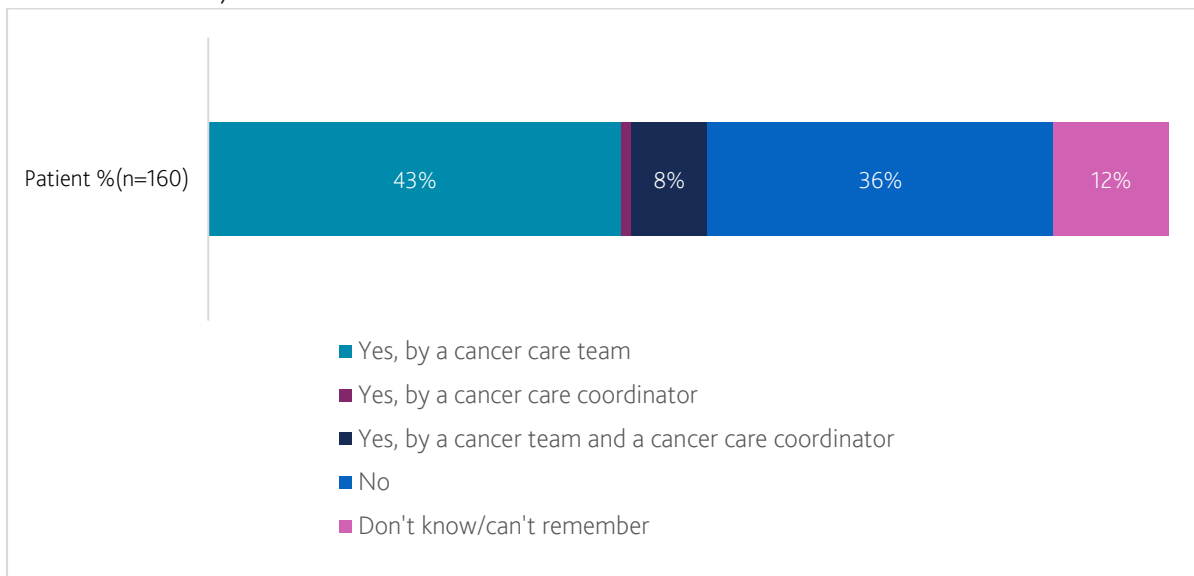
- ❖ Figure 33 reveals that 63% of patients had been seeing the same specialty physician throughout their patient experience. *Only asked to those who indicated they had seen a specialist.*

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



- ❖ Figure 34 illustrates that 36% of patients did not have their lymphoma care provided by a cancer team or coordinator.

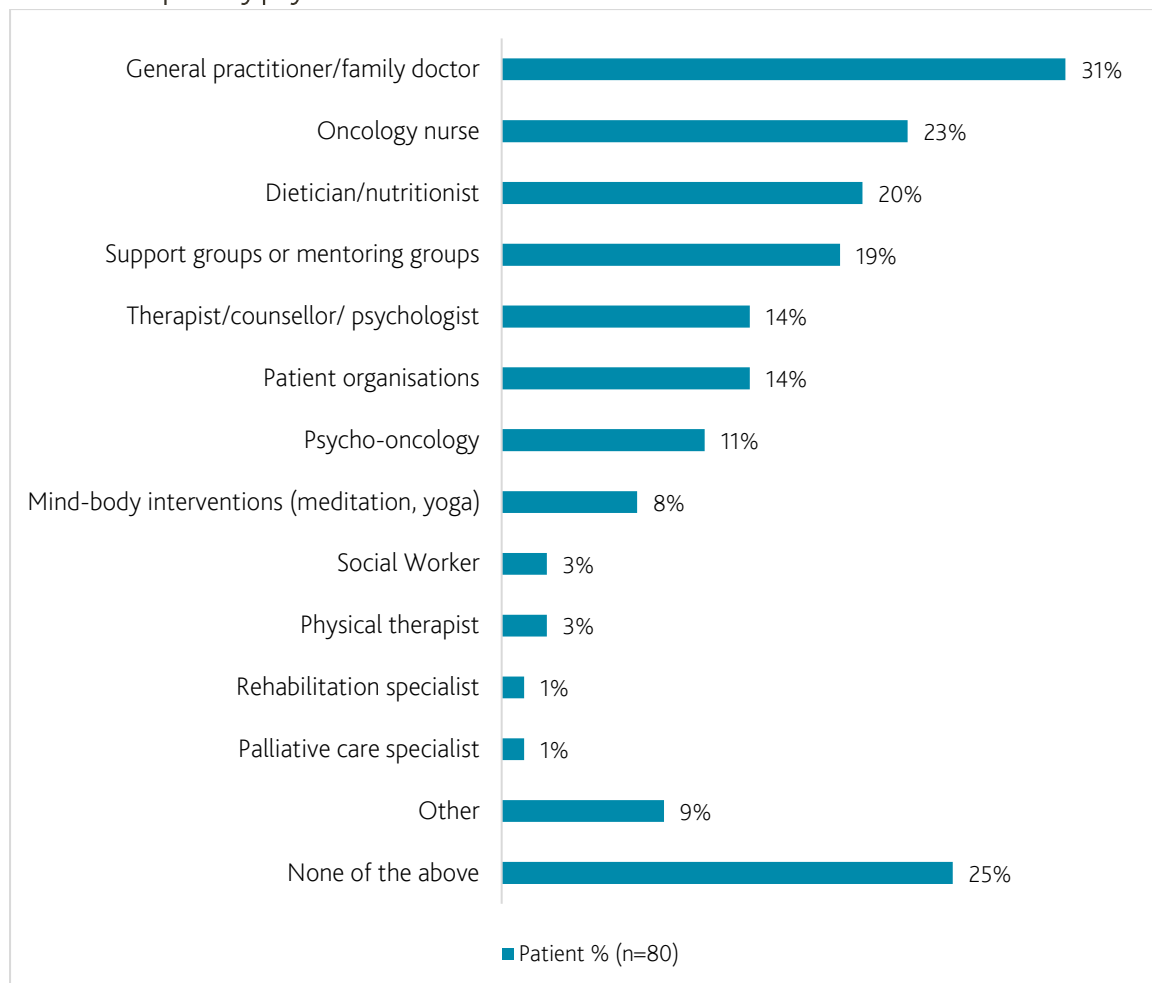
Figure 34. Did/do you have lymphoma care provided by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator?



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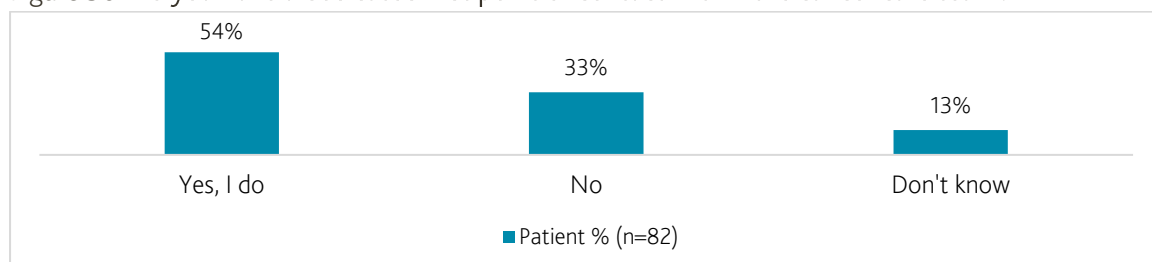
- ❖ Figure 35 reveals that 31% who reported that they had access to a cancer care team found general practitioners / family doctors useful in providing supportive care outside of their speciality physician. In addition, 23% of patients found oncology nurse's useful in providing supportive care. *Only 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 shows half 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?



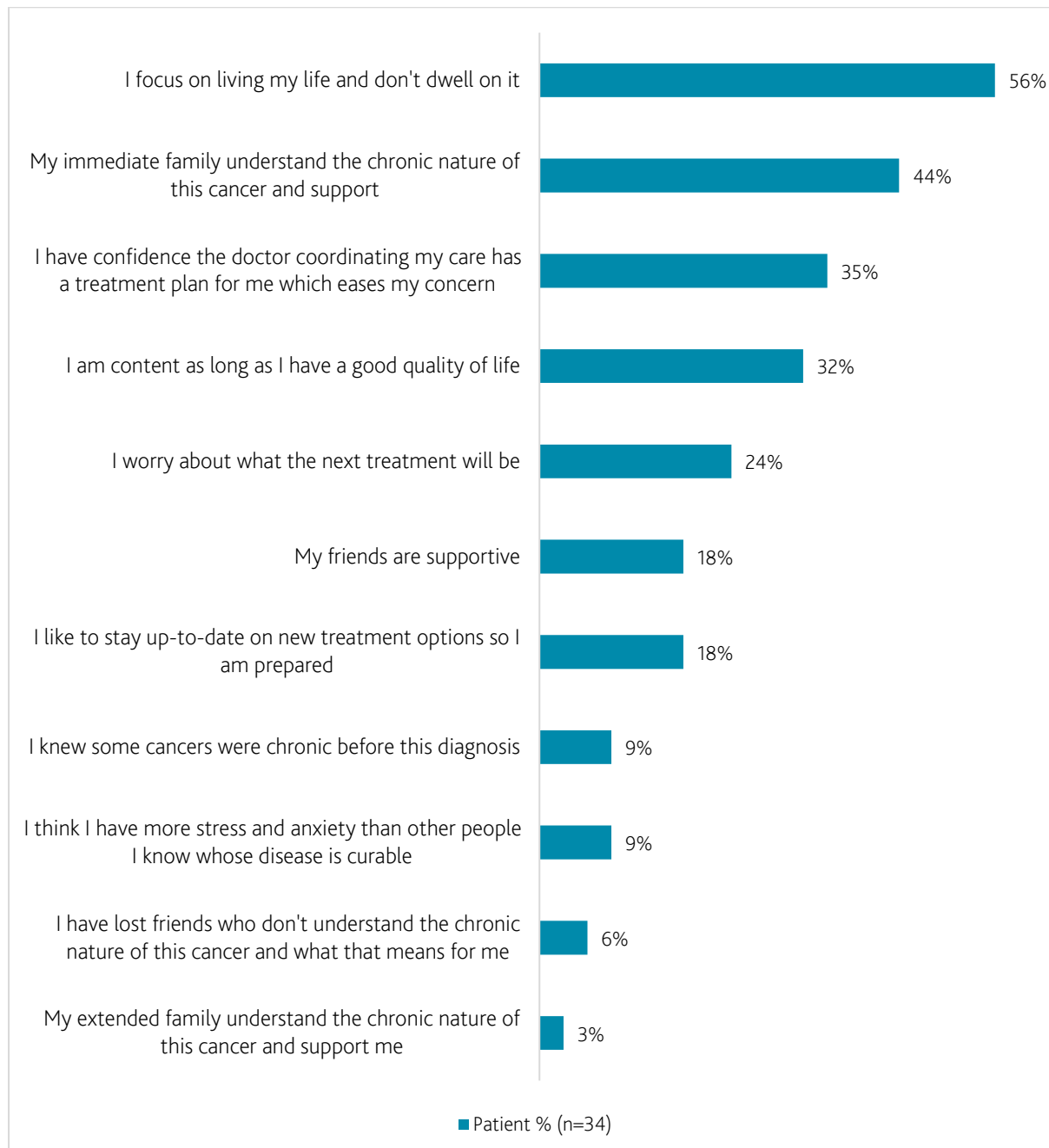
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Support Experience of Patients with Indolent Lymphomas

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 37 reveals that 56% of patients with an indolent form of lymphoma focus on living their life and don't dwell on it.

Figure 37. Which of the following statements reflects how you feel about your experience living with a chronic cancer?



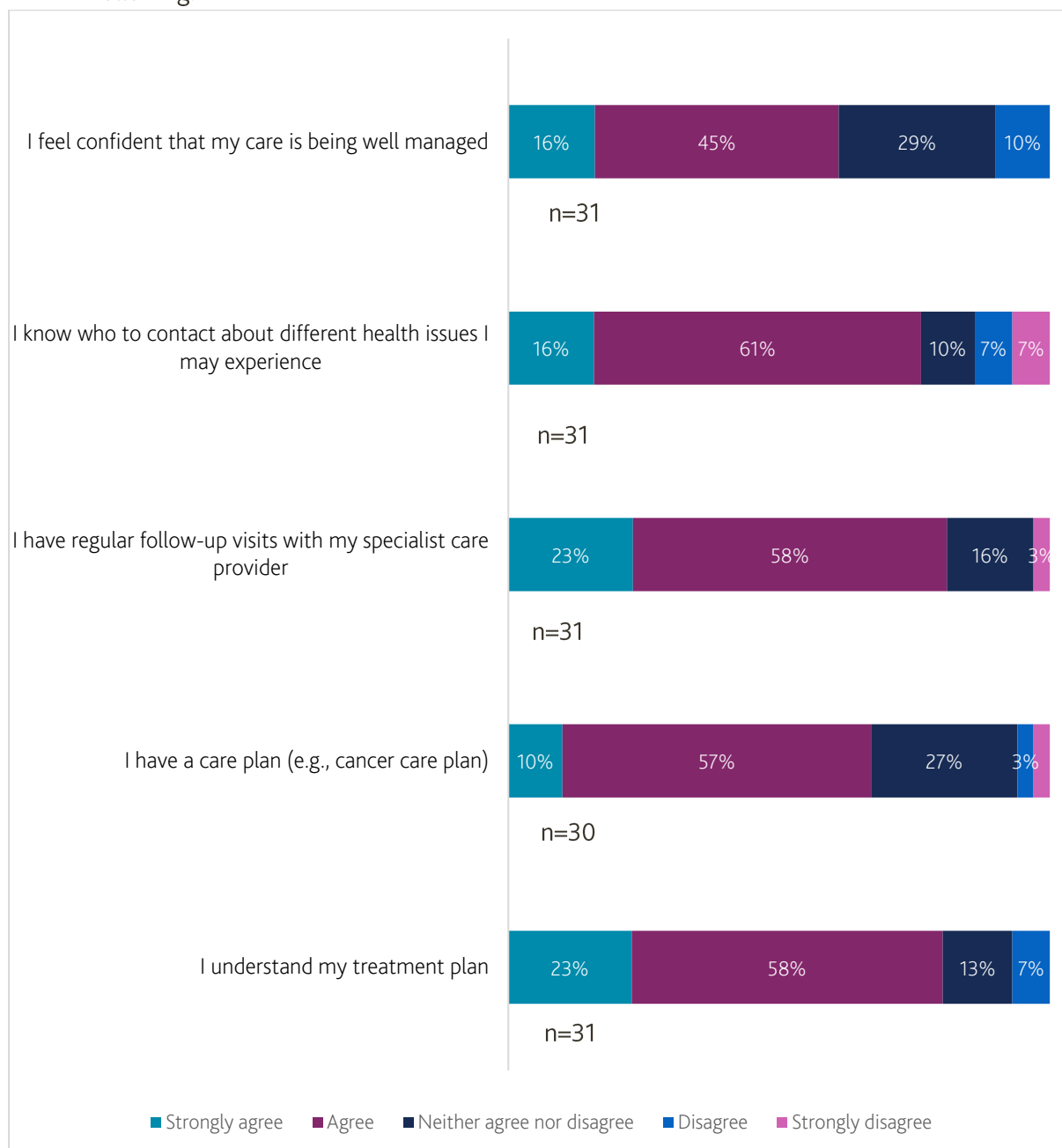
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Support Experience of Patients in Active Surveillance

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 38 illustrates that 81% of patients in active monitoring strongly agree or agree that they understand their treatment plan. *Only asked to those in active monitoring, both those who have never had treatment and those back in active monitoring post-treatment.*

Figure 38. 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.



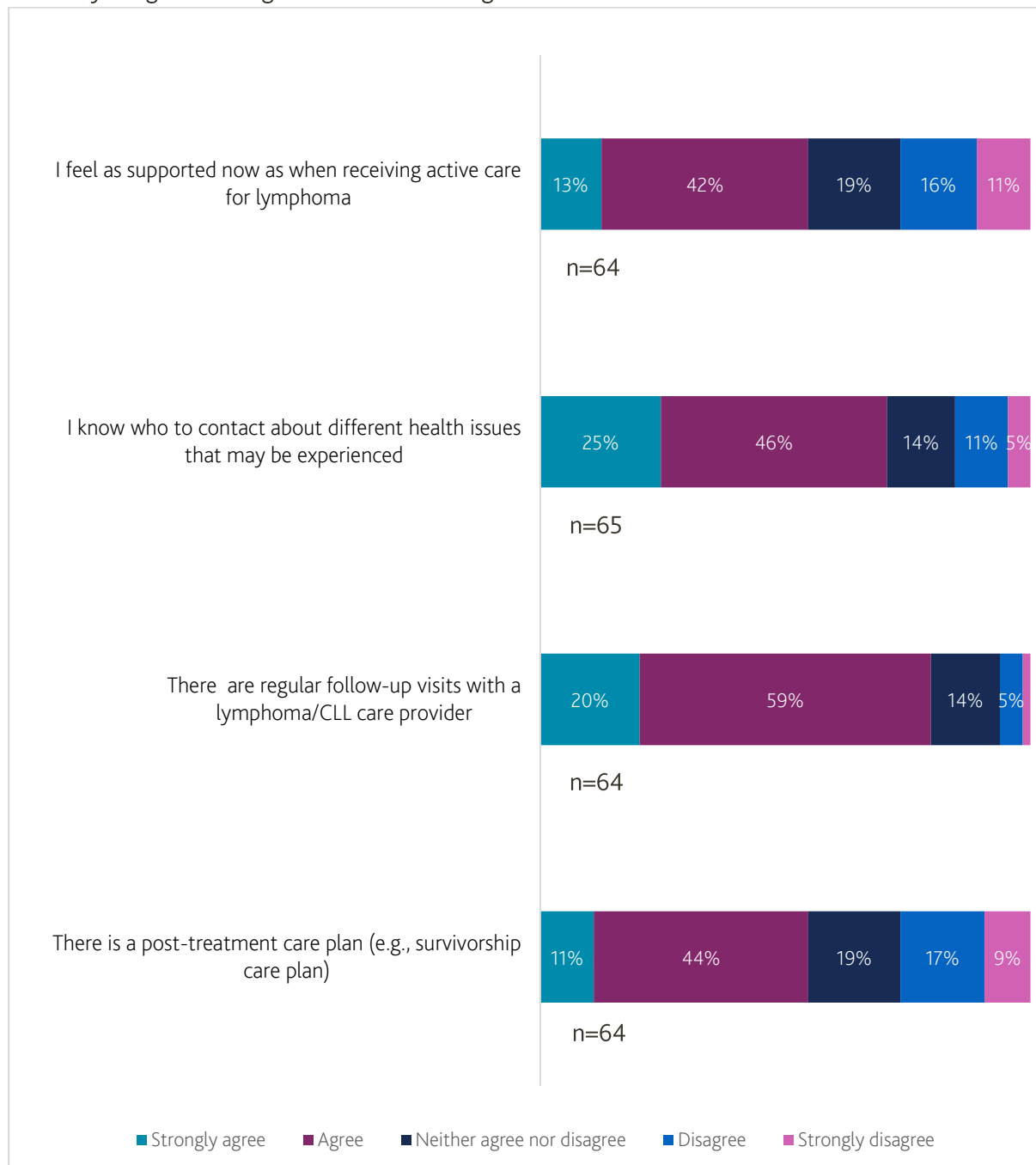
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Support Experience of Patients in Remission/ Survivorship

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 39 shows that 71% of patients in remission strongly agree or agree that they know who to contact about different health issues they may experience. *Only asked to those who indicated they were in remission.*

Figure 39. In thinking about the transition from cancer care into survivorship, please indicate how much you agree or disagree with the following statement.



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Healthcare Involvement and Decision Making

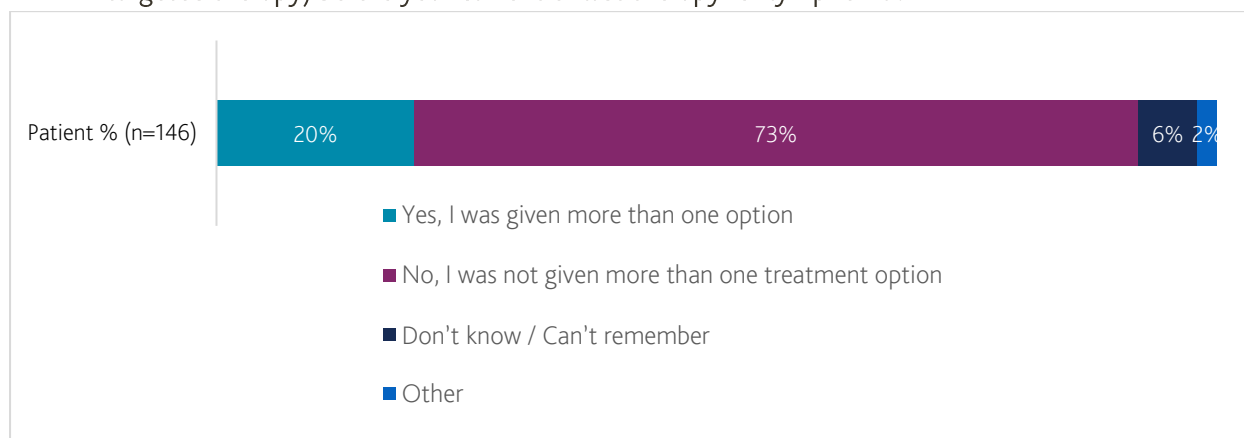
Patient-centeredness is a key part of providing high-quality cancer care as it takes the goals and expectations of patients and their families into consideration. Patients should be seen by healthcare providers as individuals and not as a diagnosis and doctors should respond to the needs, preferences 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.
- 34% of patients definitely felt as involved as much as they want to be in decisions about their care and treatment.
- 52% of patients would like the doctor and patient to be jointly involved in final decisions about care.
- 43% of patients say their doctor never identifies and recommends other resources and support.

❖ Figure 40 reveals that almost three-quarters of patients were not given more than one treatment option. **Only asked to those who had been treated.**

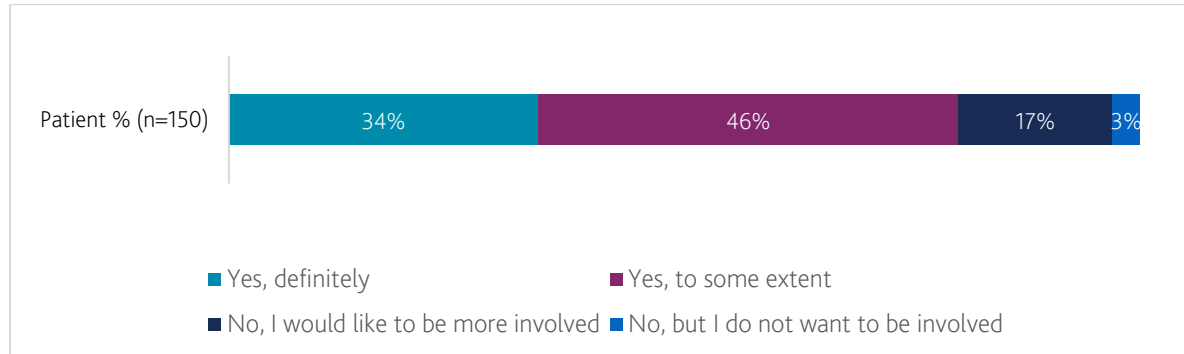
Figure 40. Were you given more than one treatment option (for instance, different types of chemotherapy regimens to choose from or a choice between a stem cell transplant and a new targeted therapy) before your current or last therapy for lymphoma?



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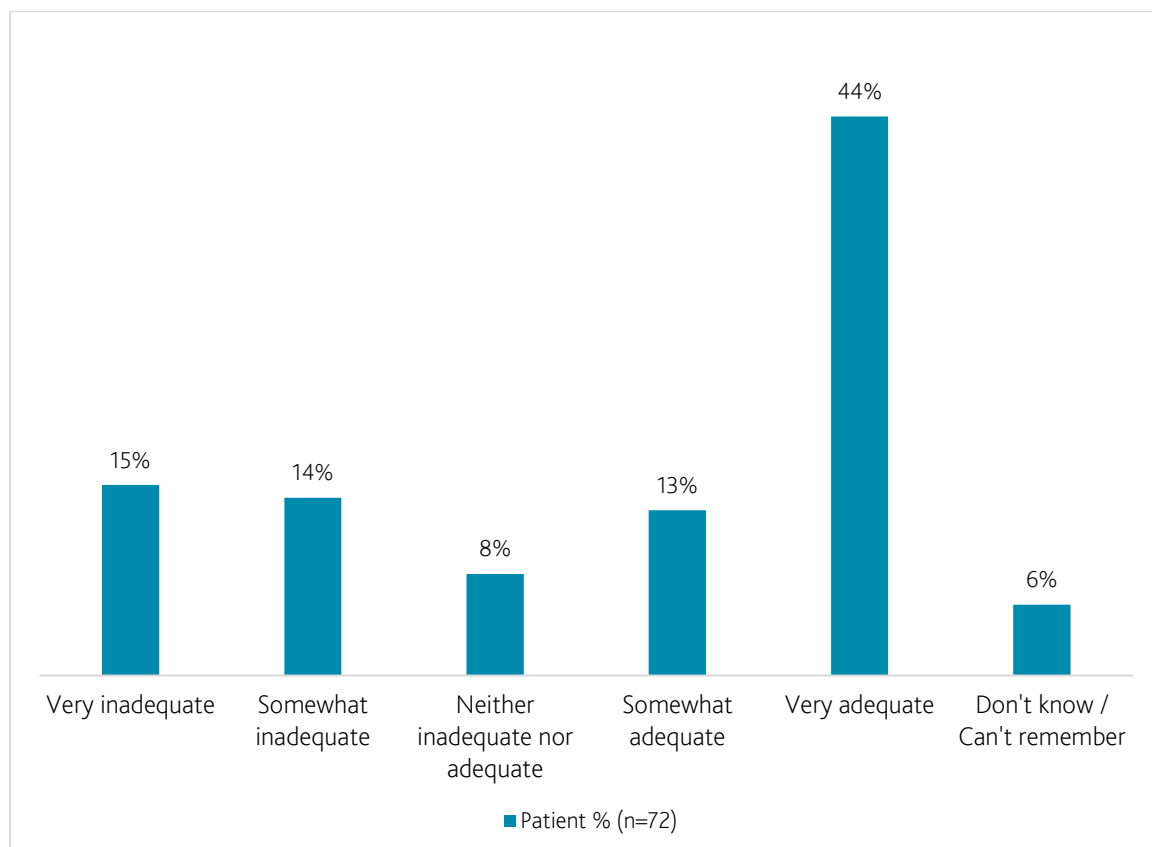
- ❖ Figure 41 explains that 34% of patients definitely felt that they were involved as much as they wanted to be in decisions about their care and treatment.

Figure 41. Do you feel as involved as much as you want to be, in decisions about your care and treatment?



- ❖ Figure 42 reveals that 44% of patients felt they had a very adequate amount of time to think about treatment before the treatment decision was made. *Only asked to those who had been treated.*

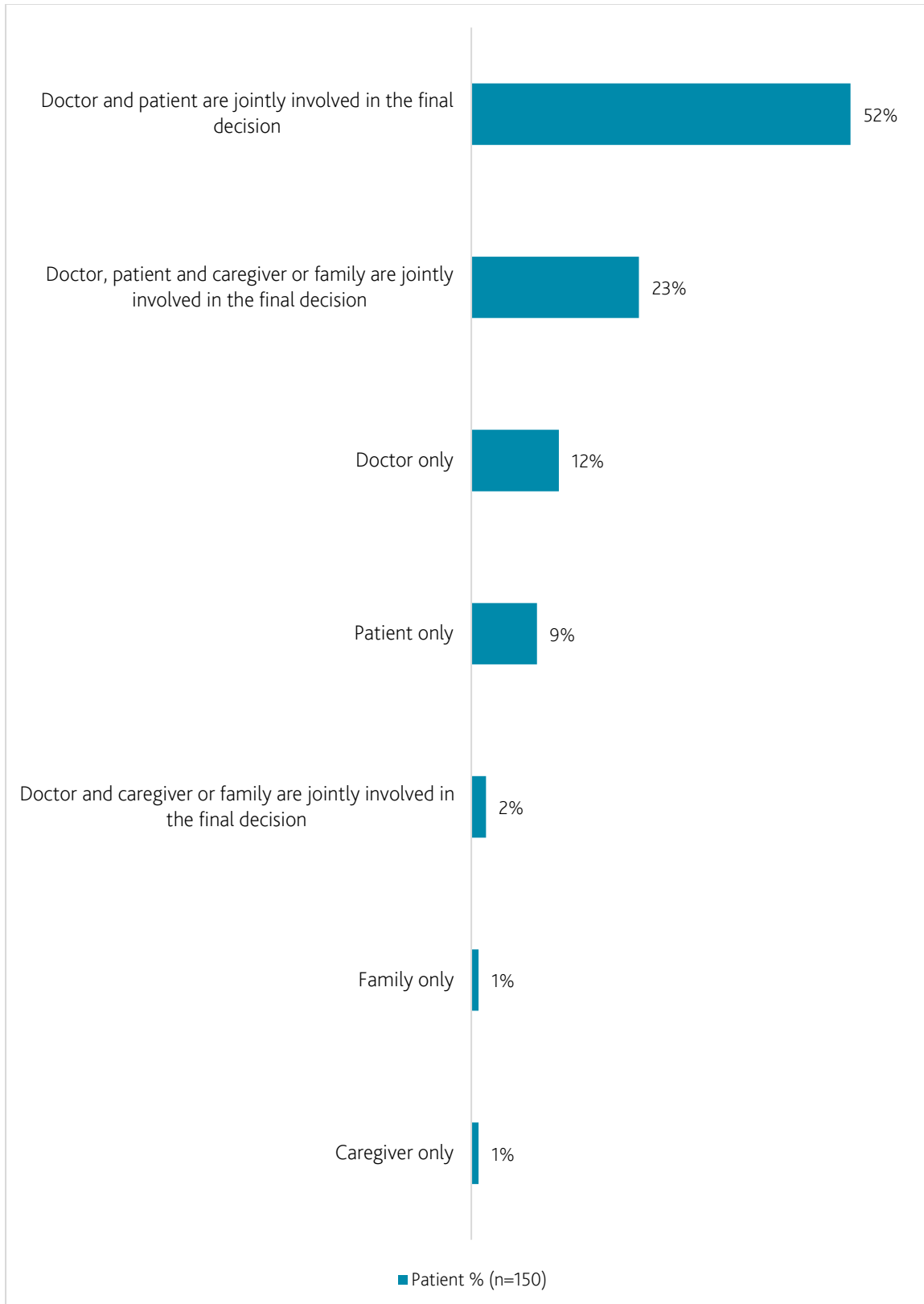
Figure 42. Regarding your current treatment (or last treatment) if you are no longer in treatment) how adequate was the amount of time you were given to think about your treatment before the treatment decision was made?



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- ❖ Figure 43 shows that 52% of patients would like the doctor and patient to be jointly involved in the final decision on the patient's healthcare.

Figure 43. Who would you like to make the final decision on your healthcare?

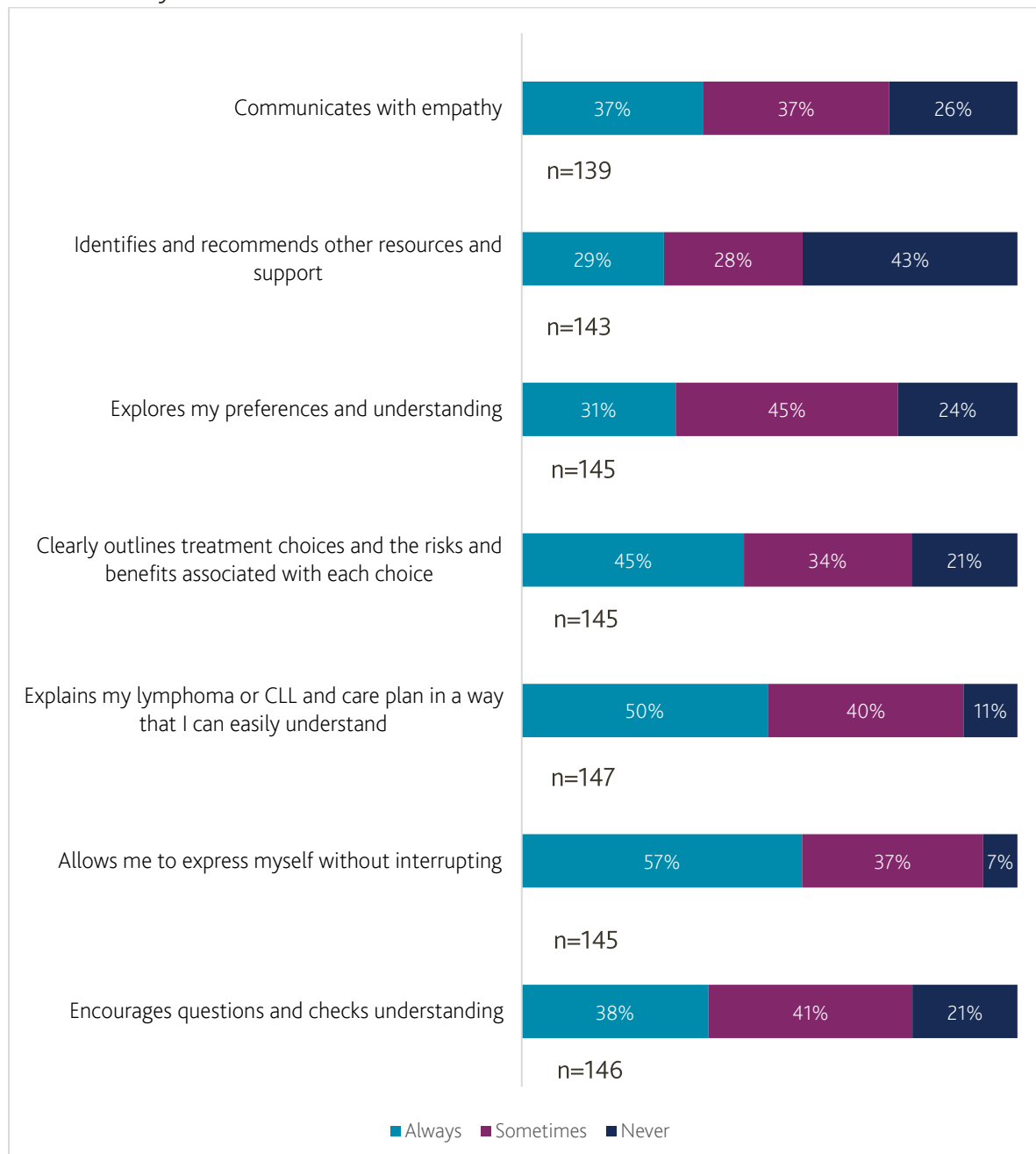


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Patients were asked a series of questions about what their doctors do to encourage participation in decision-making about their care and factors they consider important in interactions with their doctors.

- ❖ Figure 44 illustrates that 57% of patients feel that their doctor always allows them to express themselves without interrupting, and 50% feel that their doctor always explains their lymphoma or CLL and care plan in a way that they can easily understand.

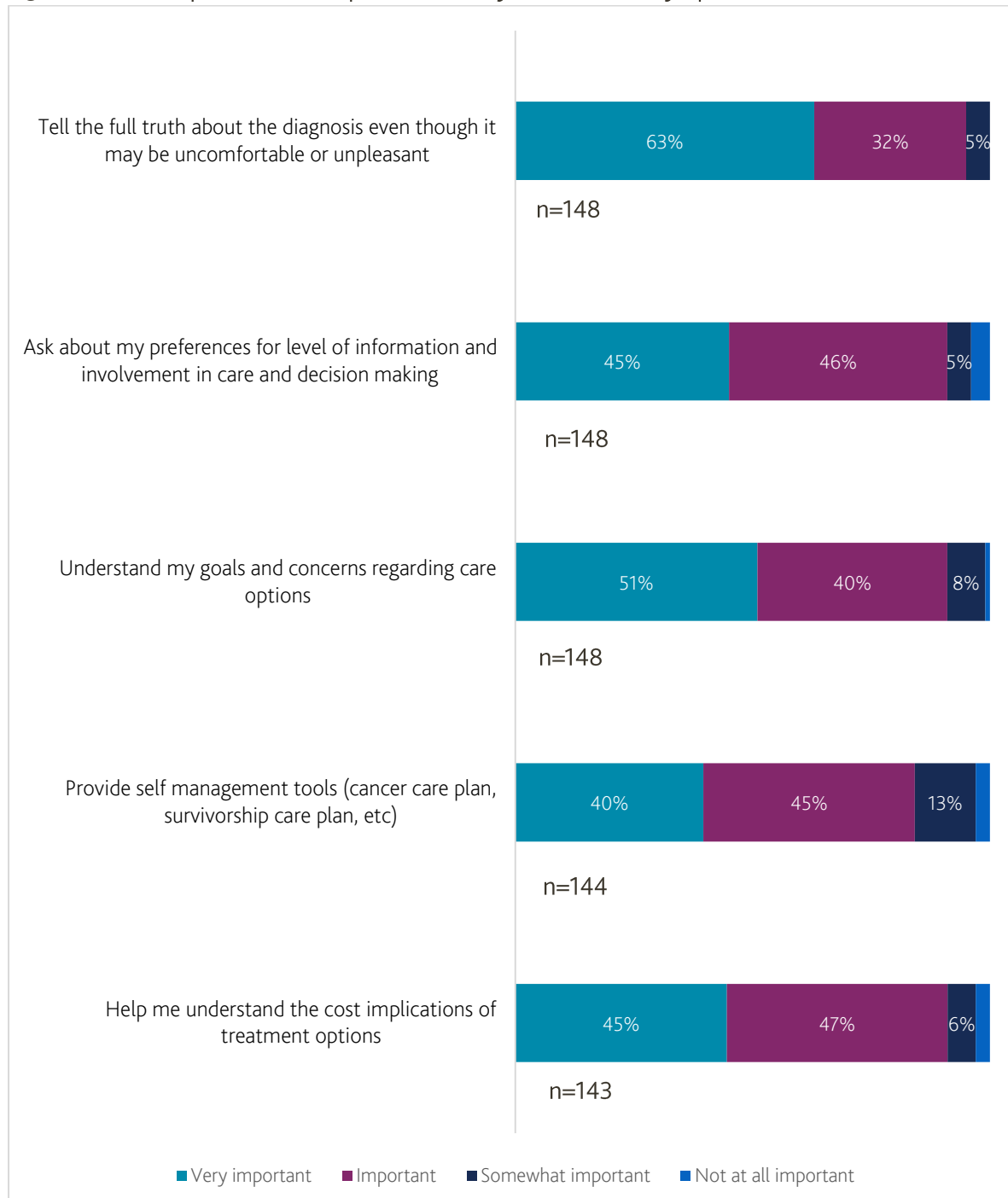
Figure 44. Does your doctor do any of the following to encourage participation in decision-making about your care?



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- ❖ Figure 45 reveals that 63% 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 and 51% highlight the importance of understanding their goals and concerns regarding care options.

Figure 45. How important or unimportant is it to you to have the lymphoma or CLL doctor...



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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 that almost two-thirds of patients 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	Number of respondents (n)	%	Treatment alleviated symptoms*
Abdominal swelling	21	14%	39%
Anaemia	26	18%	70%
Bone pain	44	30%	50%
Cold agglutinin disease	2	1%	50%
Cryoglobulinemia	0	0%	0%
Easily bruised or bleed	12	8%	55%
Enlarged lymph nodes/ abnormal painless swelling(s) on the body	67	46%	85%
Fatigue	93	64%	60%
Fever, chills, night sweats and weight loss (B-symptoms)	61	42%	78%
Frequent or repeated infections	17	12%	27%
Headaches	28	19%	62%
Hyperviscosity syndrome	1	1%	0%
Itchy skin	50	34%	79%
Pain	16	11%	60%
Shortness of breath	29	20%	69%
Skin rashes/lesions	17	12%	67%
Other (please specify)	23	16%	96%
No symptoms	9	6%	6%

*only asked to those who reported the symptom

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Lymphoma and CLL Treatments

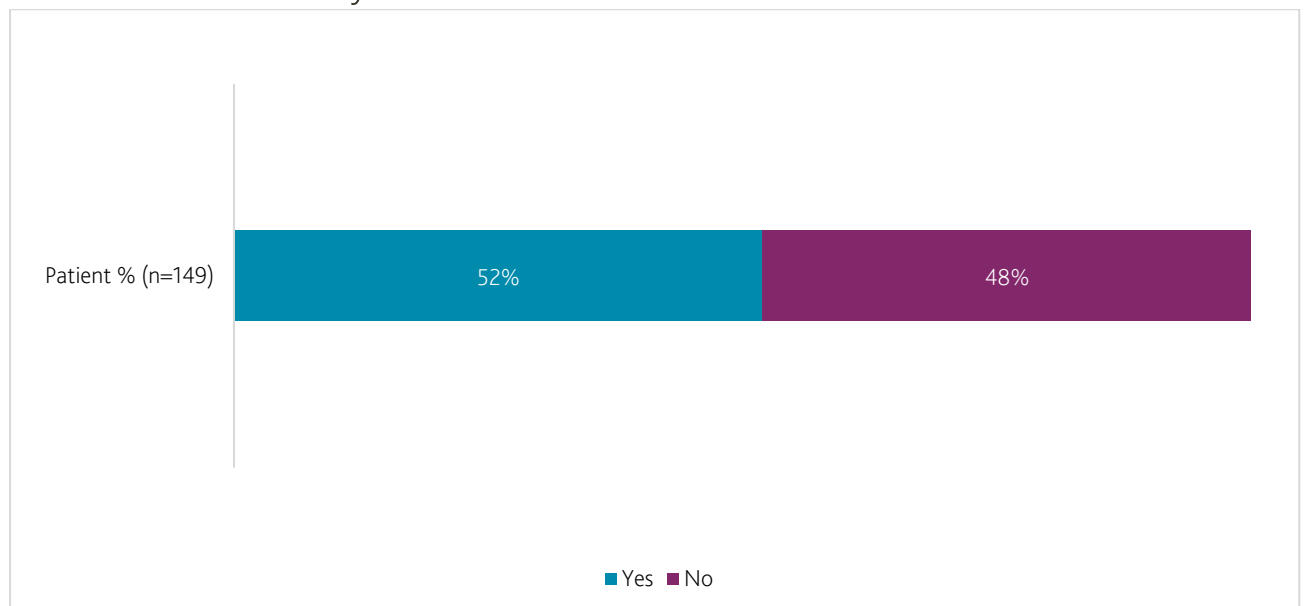
This section deals with questions that were only asked to patients currently on treatment or those who had previously received treatment for their lymphoma, including CLL, which accounted for 93% of respondents. Of that group, 52% had treatment within the last 2 years.



- Two-thirds of the patients (64%) who had ever received or received treatment were receiving their first treatment, while 15% received their 2nd line of treatment.
- 5% of patients had been in a clinical trial.
- 48% of patients were not given information about the effect of their treatment on fertility, but 22% were interested in it.
- 54% of patients agree and 18% strongly agree that their treatment was chosen to minimize the impact of possible side effects on lifestyle and/or favourite activities.

❖ Figure 46 illustrates that over half of patients are receiving or have received medical treatment for their lymphoma or CLL within the last 2 years. *Only asked to those who have received treatment.*

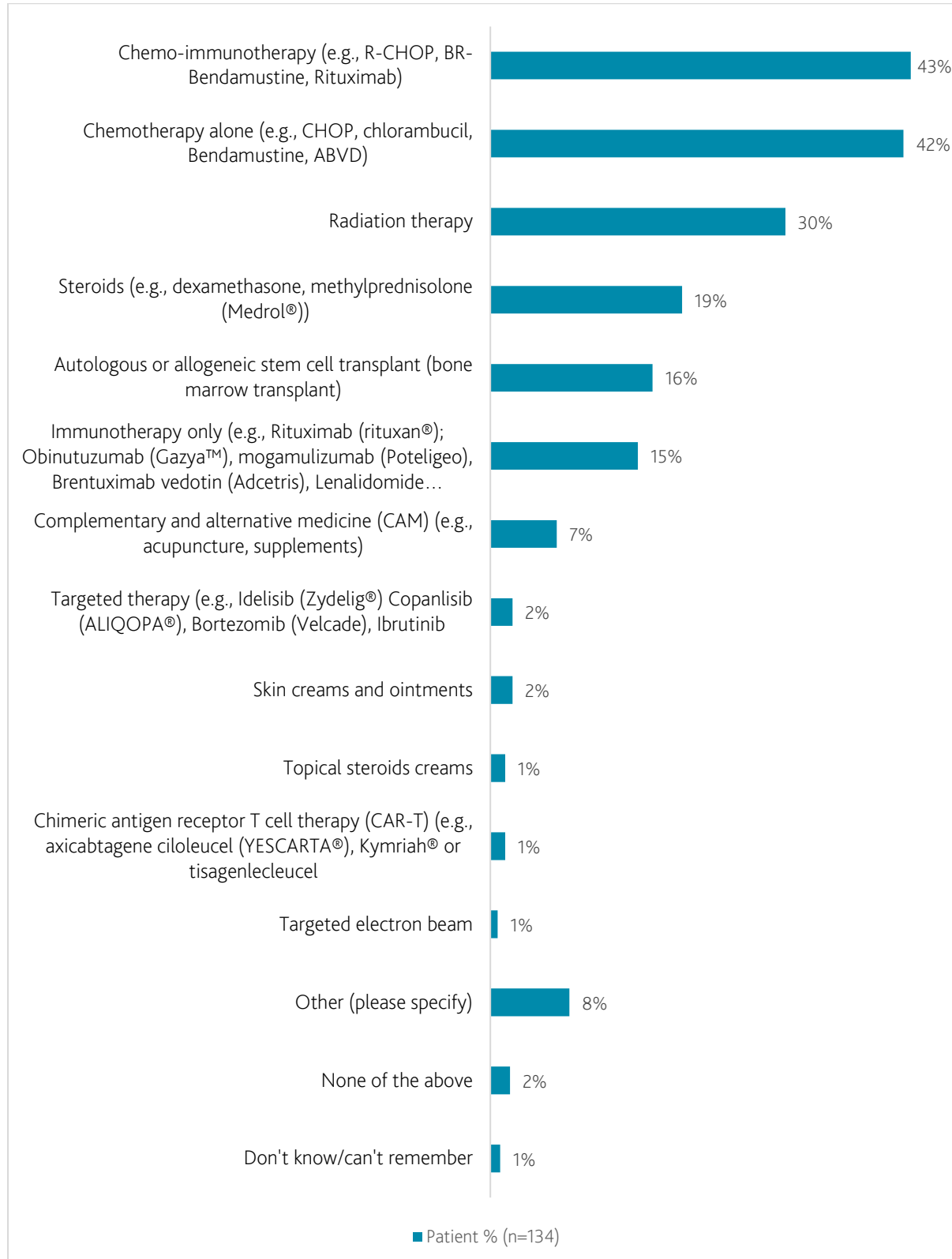
Figure 46. Did you receive a medical treatment (e.g., chemotherapy, radiation) for your lymphoma or CLL within the last 2 years?



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- ❖ Figure 47 shows that almost half (43%) of patients are currently receiving, or have received, chemo-immunotherapy. **Only asked to those who have received treatment.**

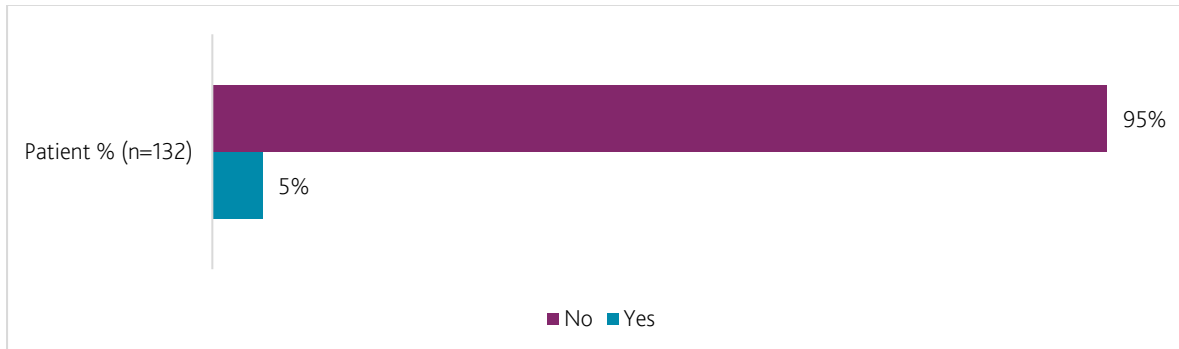
Figure 47. Which of the following treatment options, if any do you receive currently, or have ever received in the past?



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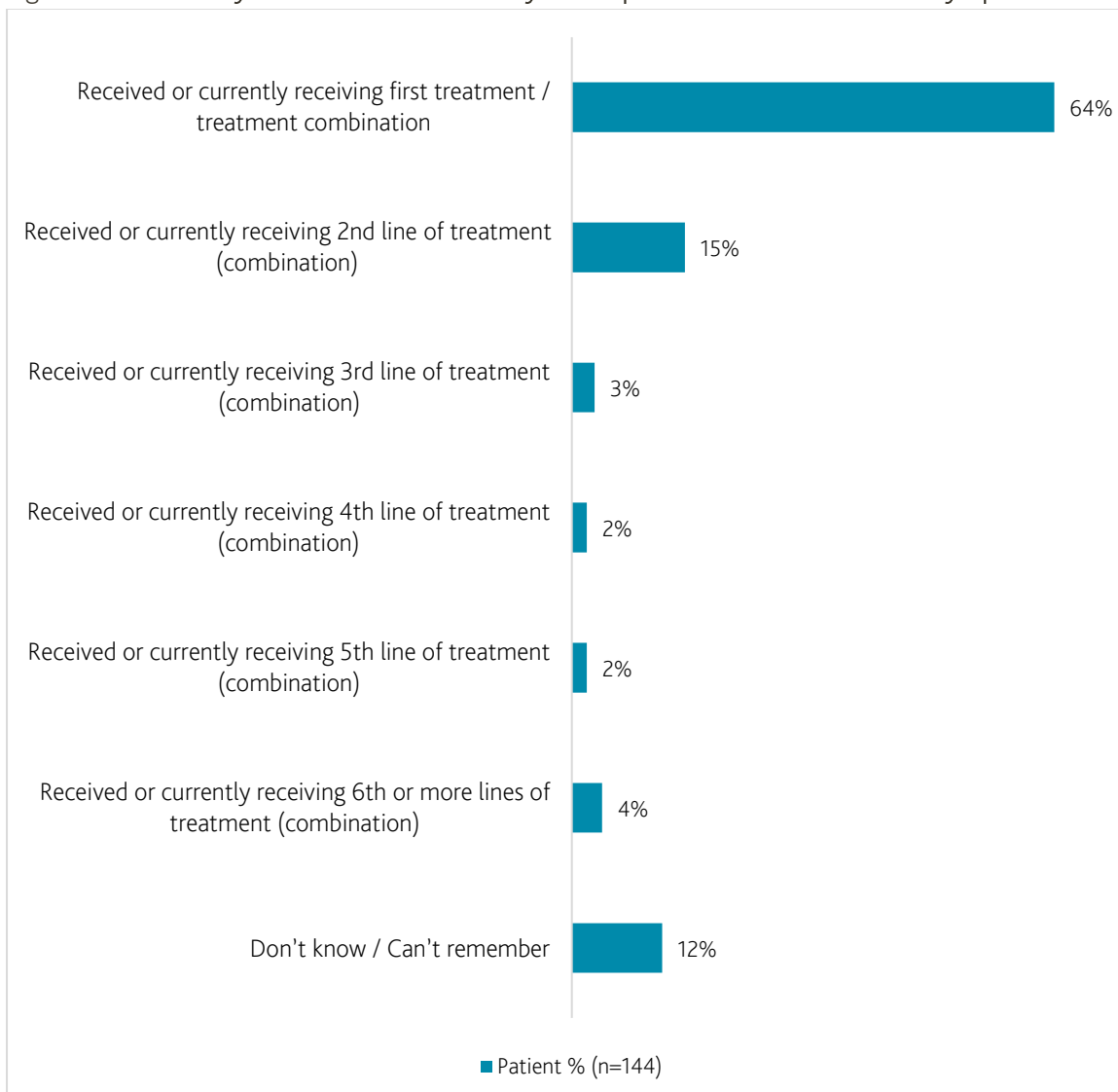
- ❖ Figure 48 reveals that 95% of patients have not been in a clinical trial for lymphoma. *Only asked to those who have received treatment.*

Figure 48. Are you currently, or have you ever been in a clinical trial for your lymphoma?



- ❖ Figure 49 shows two-thirds of patients have received or are currently receiving their first treatment/treatment combination. *Only asked to those who have received treatment.*

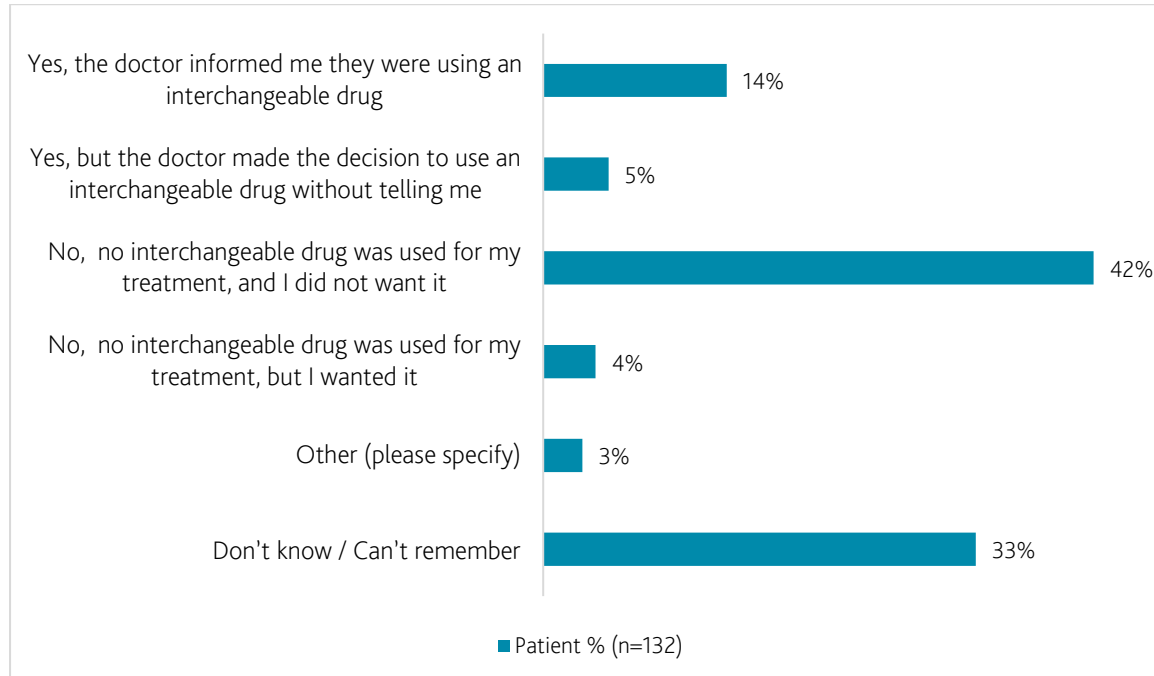
Figure 49. How many lines of treatment have you/the patient received to date for lymphoma?



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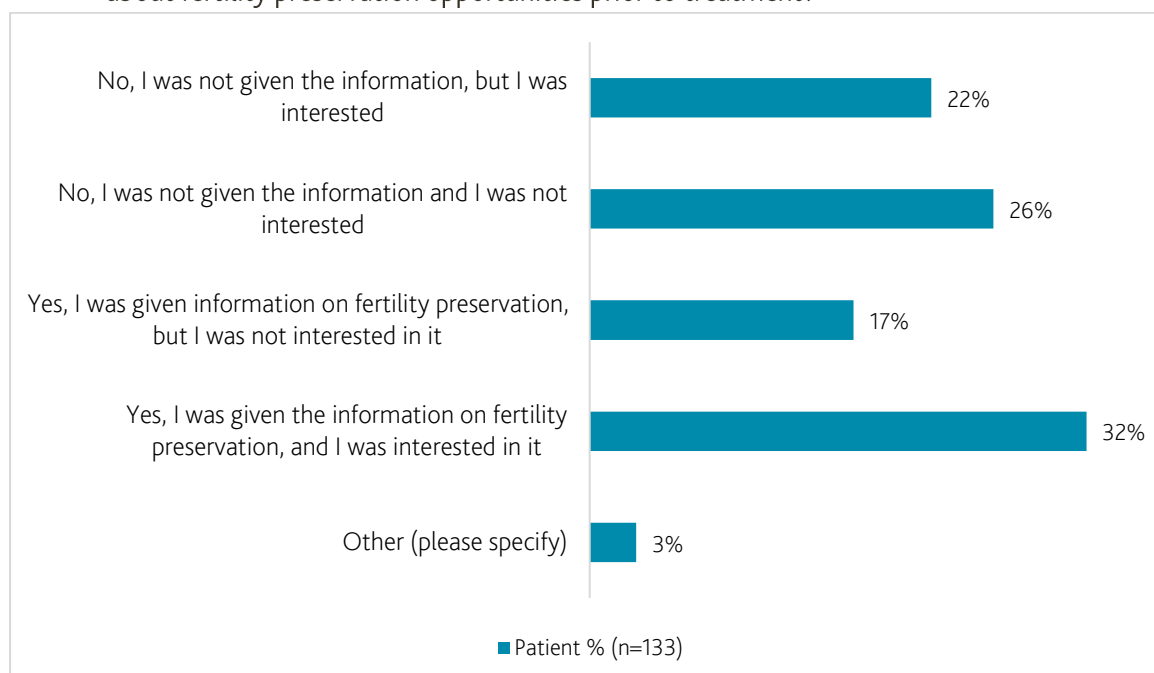
- ❖ Figure 50 illustrates that an interchangeable drug was used in the treatment of 19% of patients but 5% were not told of the decision. *Only asked to those who have received treatment.*

Figure 50. Were interchangeable/equivalent (e.g., generic, biosimilars, pharmaceutical equivalents), used during your treatment?



- ❖ Figure 51 reveals 32% of patients were interested in information about the effect of their treatment on fertility, and they were given such information. *Only asked to those who have received treatment.*

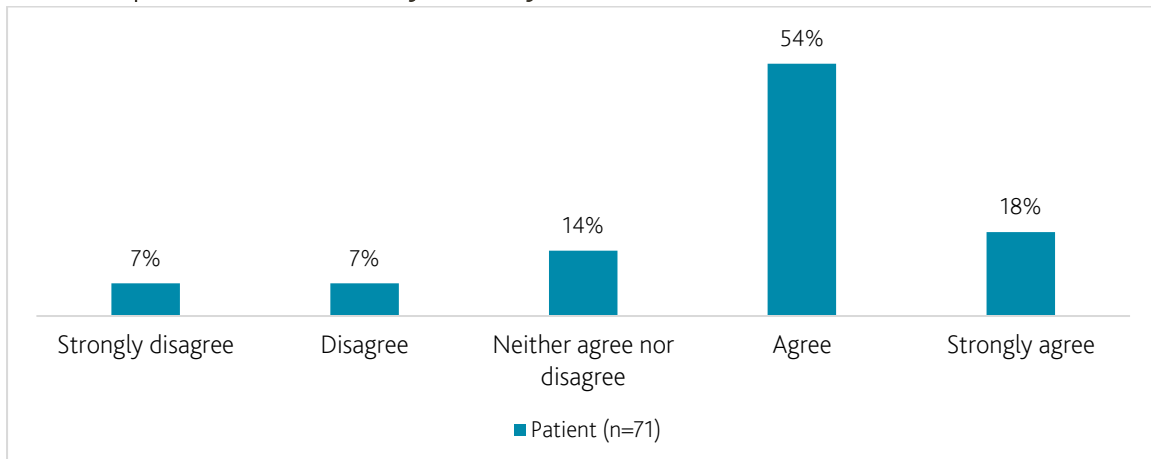
Figure 51. Did your medical team give you any information about treatment side effects on fertility and about fertility preservation opportunities prior to treatment?



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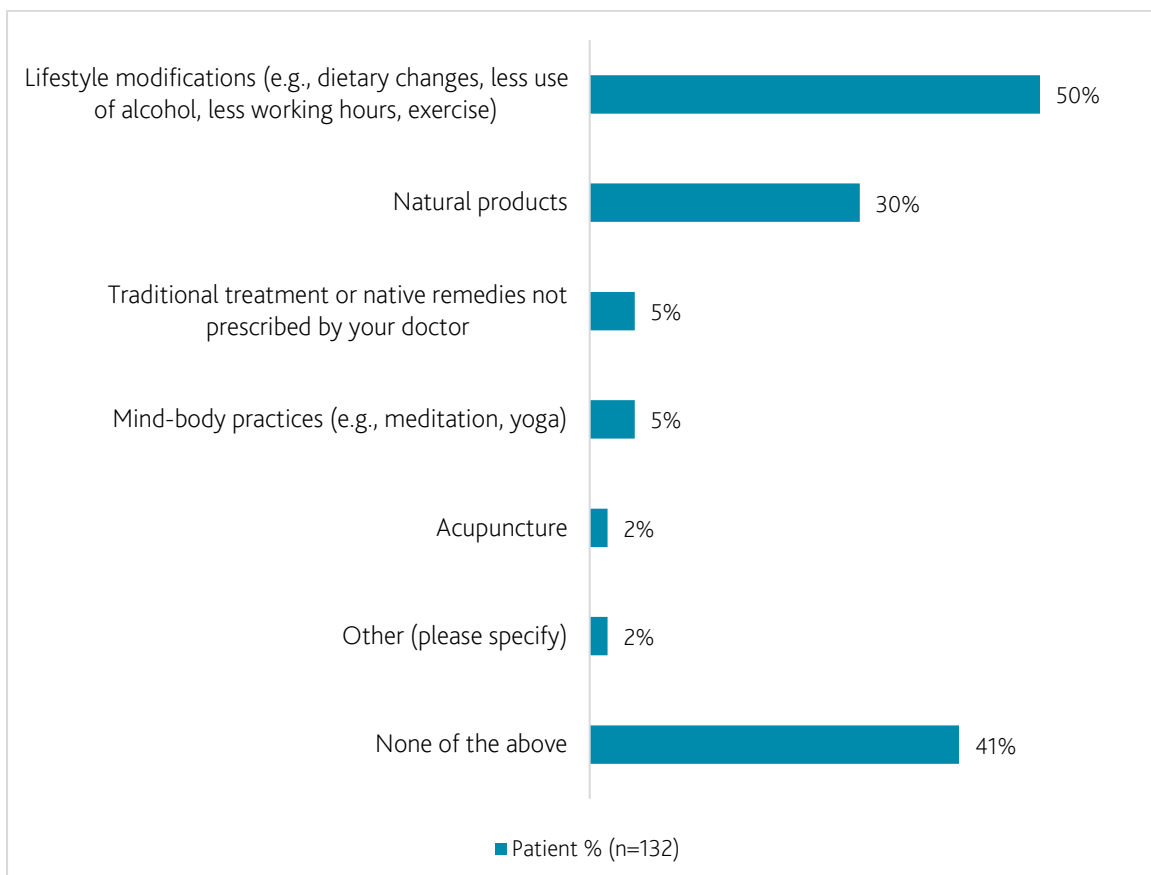
- ❖ Figure 52 illustrates that three-quarters (72%) of patients agree or strongly agree that treatment was chosen to minimize the impact of possible side effects on their lifestyle and/or favourite activities. *Only asked to those who have received treatment.*

Figure 52. 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 53 reveals that 41% of patients have not used any of the following alongside conventional cancer treatments. *Only asked to those who have received treatment.*

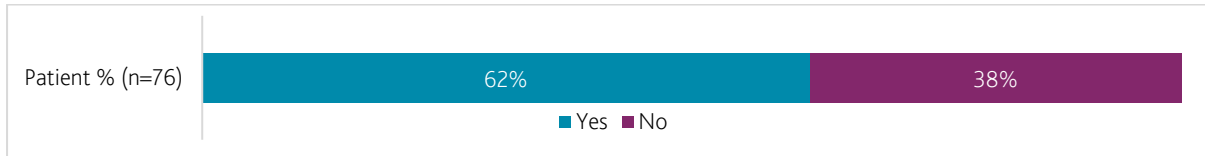
Figure 53. During your experience so far with lymphoma or CLL, were any of following used alongside conventional cancer treatments?



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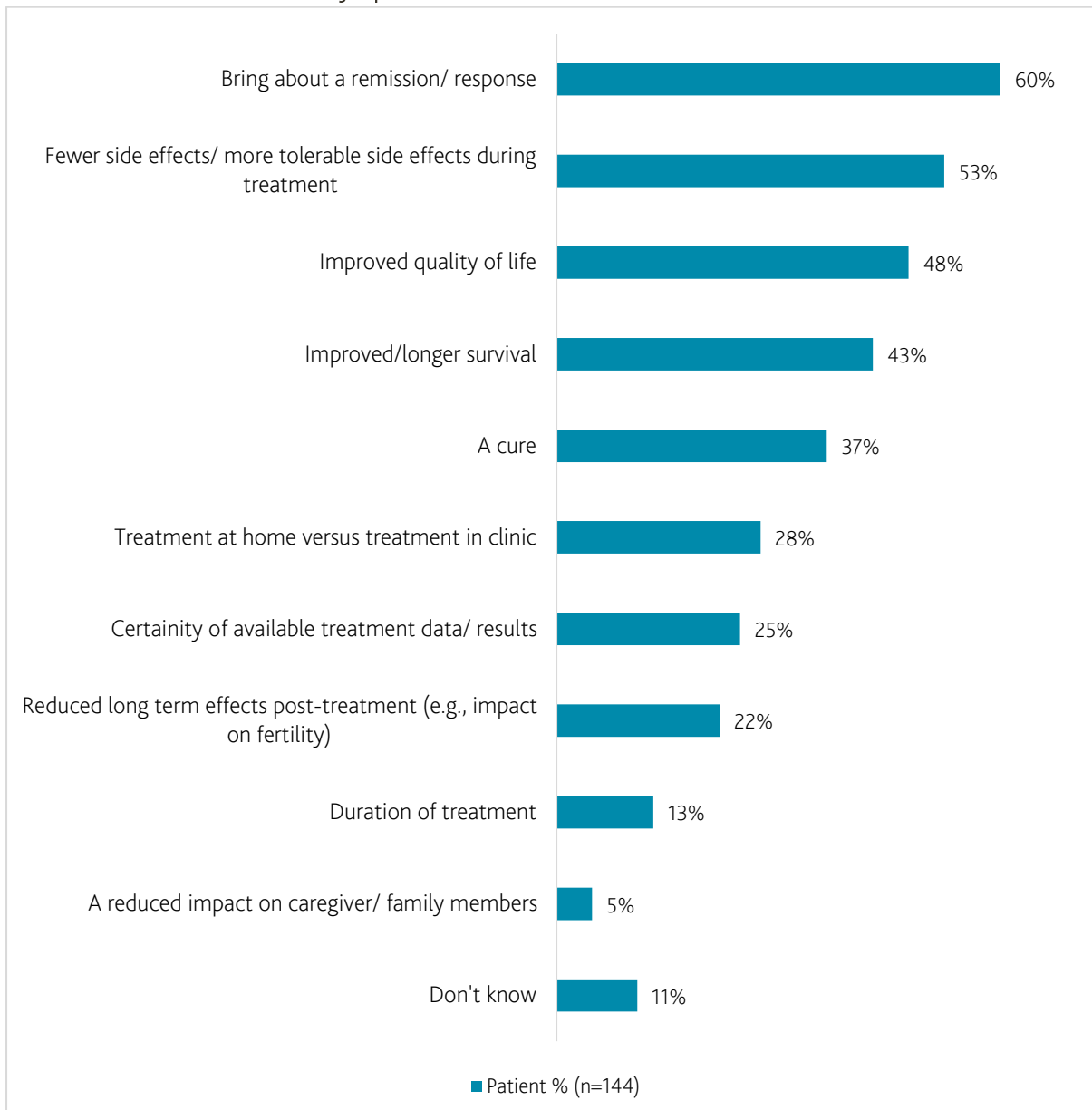
- ❖ Figure 54 explains that 83% of patients told their lymphoma or CLL doctor or another member of their medical team that they were applying lifestyle modification(s)/treatment(s)/product(s). *Only asked to those who used these types of remedies alongside conventional cancer treatment.*

Figure 54. 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 55 reveals 60% of patients consider bringing about a remission/ response to be an important feature of a new medical treatment for lymphoma or CLL.

Figure 55. What, if any, of the following would you consider to be an important feature of a new medical treatment for lymphoma or CLL?



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- ❖ Table 3 illustrates that 26% of patients rank bring about a remission/response 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	21	24%	4	5%	7	9%
Improved/ longer survival	18	20%	19	24%	6	8%
Bring about a remission/ response	23	26%	21	26%	17	22%
Improved quality of life	7	8%	14	18%	11	14%
Fewer side effects/ more tolerable side effects during treatment	8	9%	10	13%	17	22%
Reduced long-term effects post-treatment (e.g., impact on fertility)	1	1%	1	1%	7	9%
Treatment at home versus treatment in the clinic	3	3%	4	5%	6	8%
Duration of treatment	2	2%	3	4%	2	3%
A reduced impact on caregiver/family members	1	1%	1	1%	0	0%
Certainty of available treatment data/results	5	6%	3	4%	5	6%
Total	89	100%	80	100%	78	100%

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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.

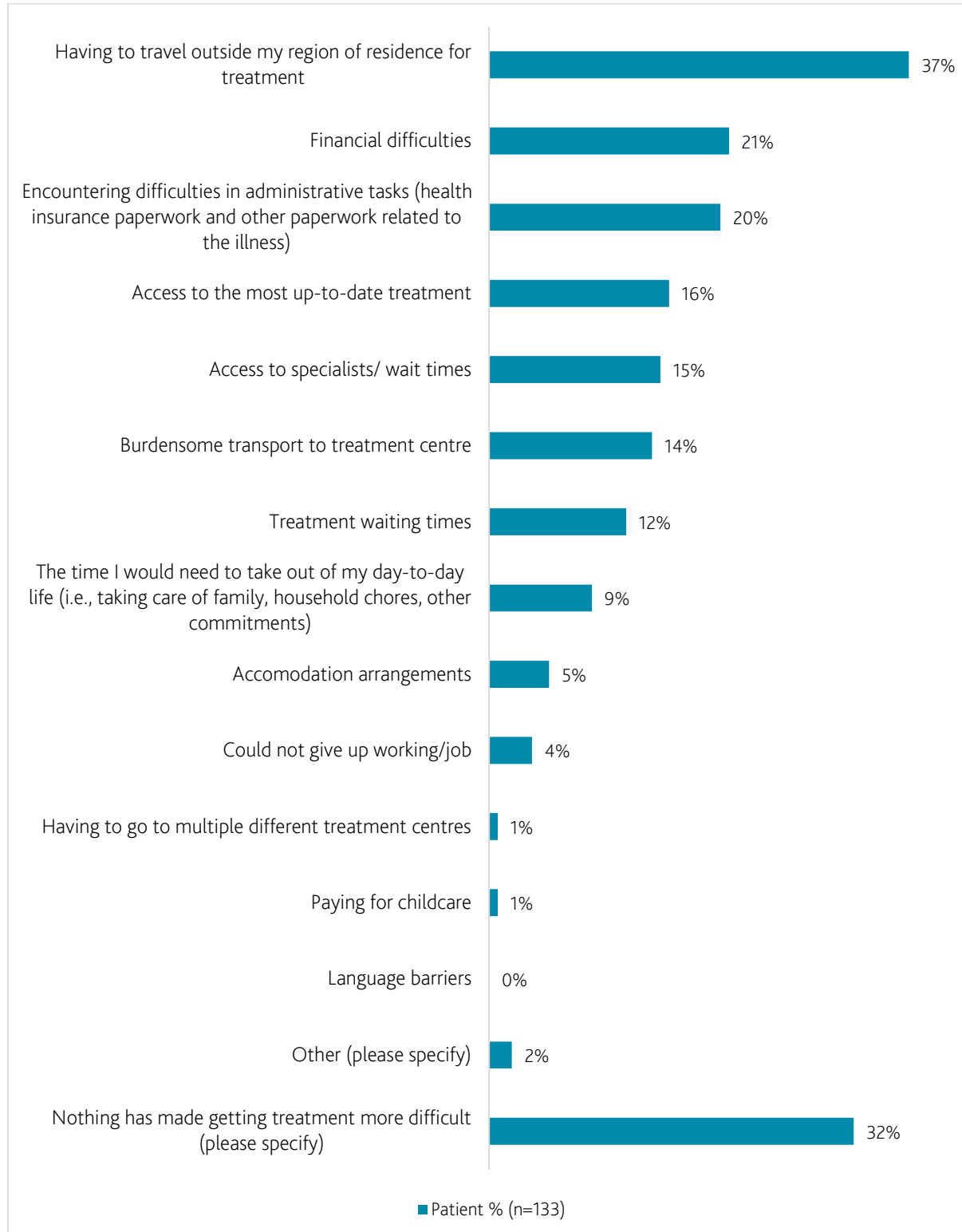


- 32% patients from Bulgaria reported not having any barriers to receiving treatment.
- One-fifth of patients reported they were prevented from receiving treatment by financial difficulties (21%).
- 37% indicated having to travel outside of their region made receiving treatment difficult.
- 54% of patients said never being presented with an opportunity to take part in a clinical trial is the top reason they have not participated in one.

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- ❖ Figure 56 reveals that 32% of patients feel that nothing has made getting treatment more difficult, meaning the majority are experiencing difficulties. *Only asked to those who have received treatment.*

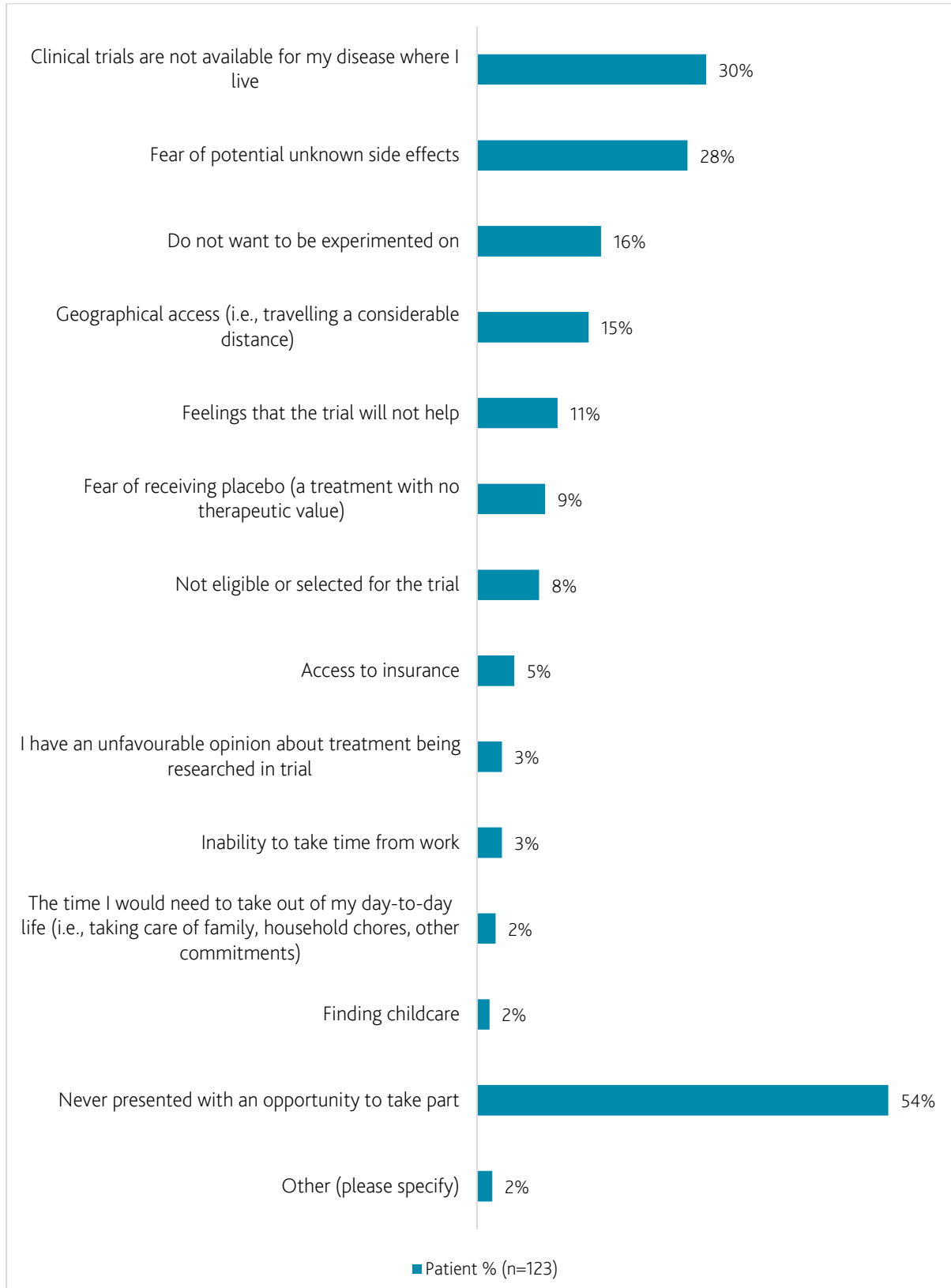
Figure 56. What, if anything, has made getting treatment more difficult?



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- ❖ Figure 57 explains that for almost a third of patients, the fact that clinical trials are not available for their disease where they live which is what prevented them from participating. *Only asked to those who have received treatment.*

Figure 57. What, if anything, would prevent you from participating in a clinical trial?



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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:
 - Hair loss reported by 80%
 - Fatigue was reported by 68%
 - Nausea and vomiting reported by 43%
 - Numbness/tingling of arms, legs, hands, or feet reported by 39%
 - Changes in taste and smell reported by 36%

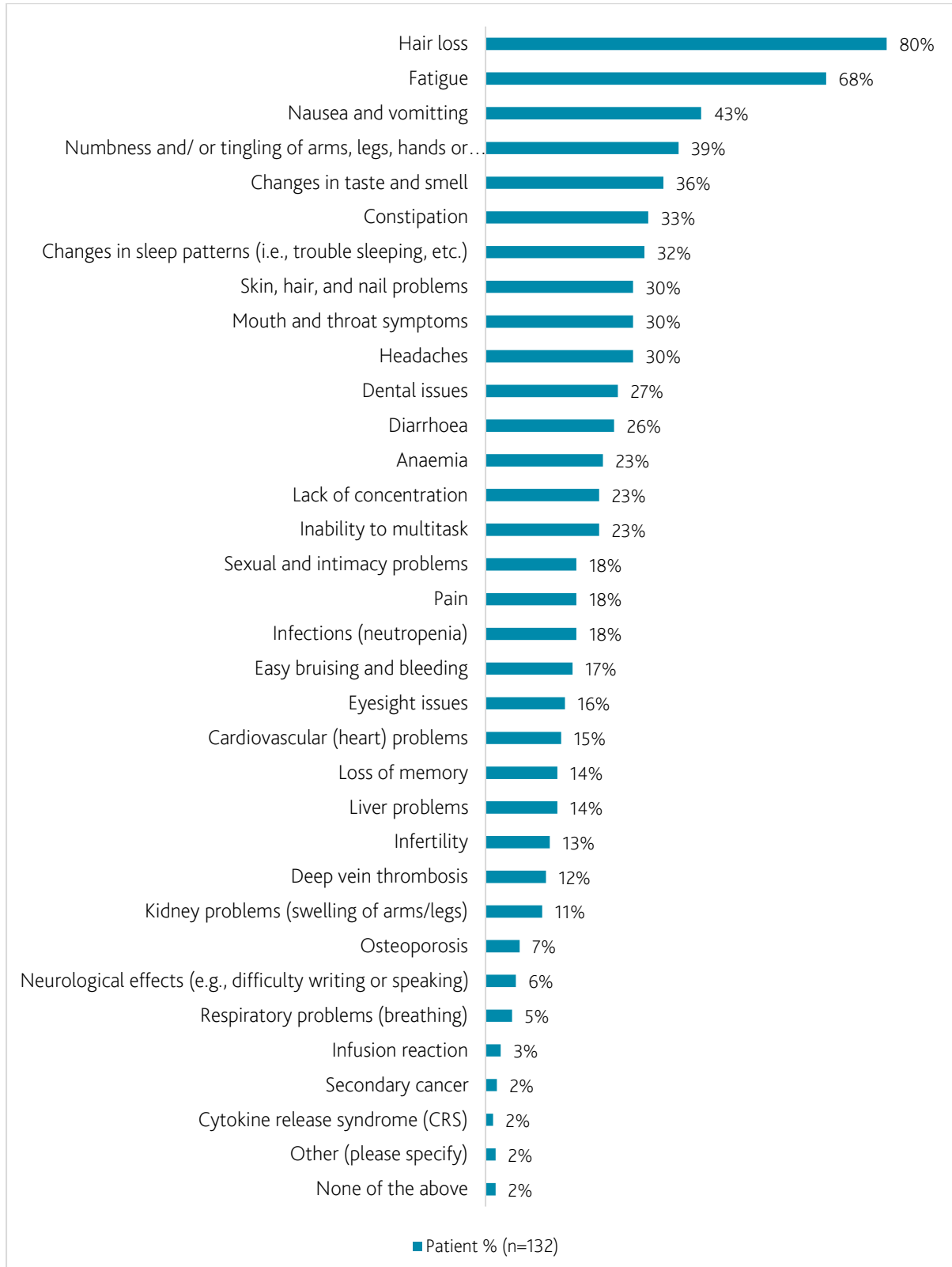
See figure 58 for a full list of reported side effects from treatment.

- The side effects that affected patients' wellbeing the most (ranked 1st) were:
 - Hair loss– 13% (n=15)
 - Nausea and vomiting – 9% (n=10)
 - Fatigue – 8% (n=9)
- 78% of patients who were affected by hair loss and 75% of those affected by nausea and vomiting experienced these side effects for less than 1 year.
- 79% of patients who were affected by fatigue experienced these side effects for less than five years.

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- ❖ Figure 58 shows that 80% of patients experience hair loss as a side effect. *Only asked to those who have received treatment.*

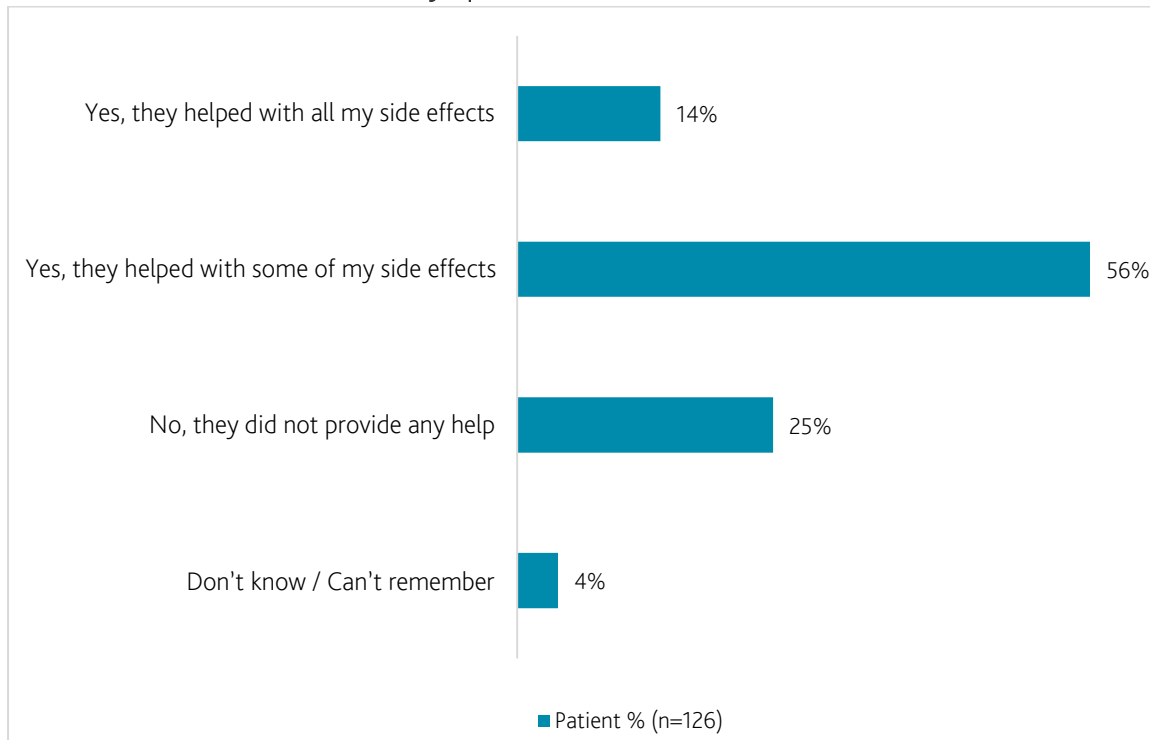
Figure 58. Which of the following side effects, if any, have you been affected by (Highlighted the side effects that affected patients the most)?



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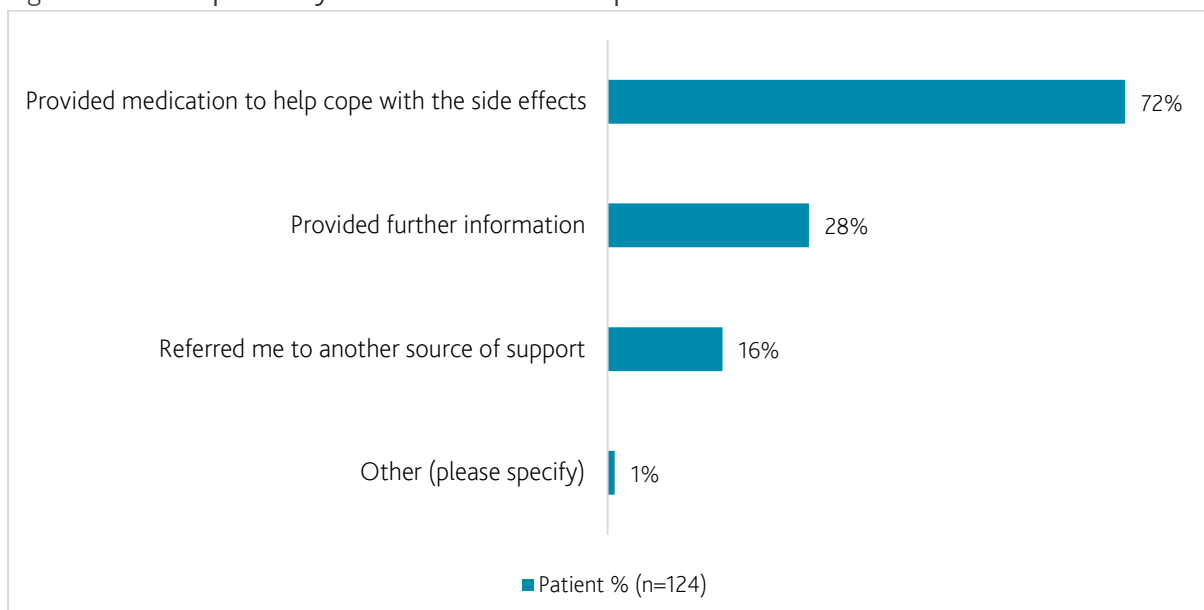
- ❖ Figure 59 shows only 14% of patients felt their doctor or other members of their medical team was able to help alleviate or cope with all their side effects. *Only asked to those who said they had side effects.*

Figure 59. 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 60 explains that in most cases the doctor provided medication to help cope with the side effects. *Only asked to those that said the doctor helped with their side effects.*

Figure 60. What specifically did the doctor do to help?



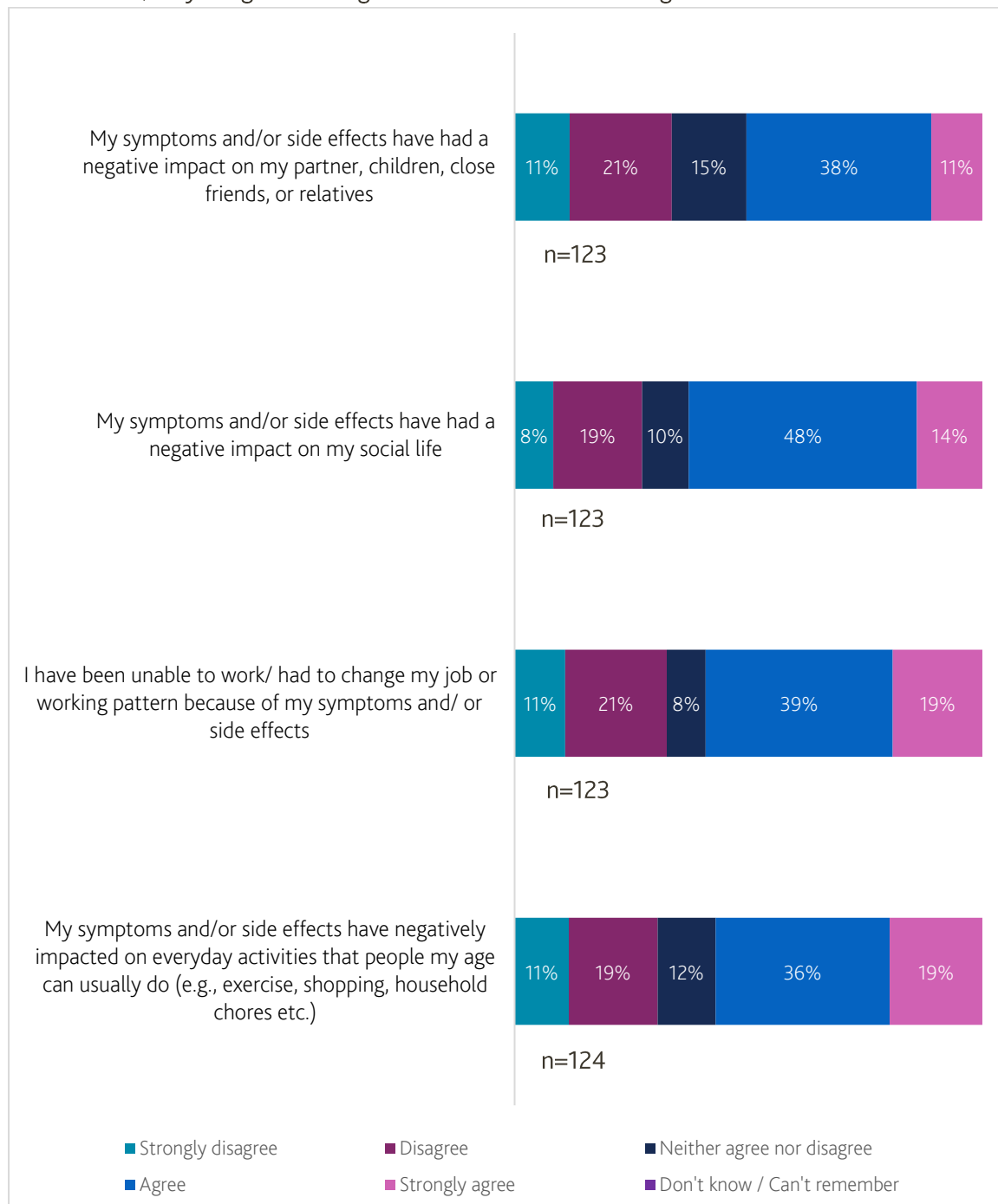
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Impact of lymphoma or CLL symptoms and treatment side effects on quality of life

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

- ❖ Figure 61 shows that 62% of patients strongly agree or agree that their symptoms and/or side effects have negatively impacted their social lives. *Only asked to those who said they had symptoms from their disease or side effects from treatment.*

Figure 61. 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?



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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 (64% of all respondents) and/or as a side effect of treatment (68%).

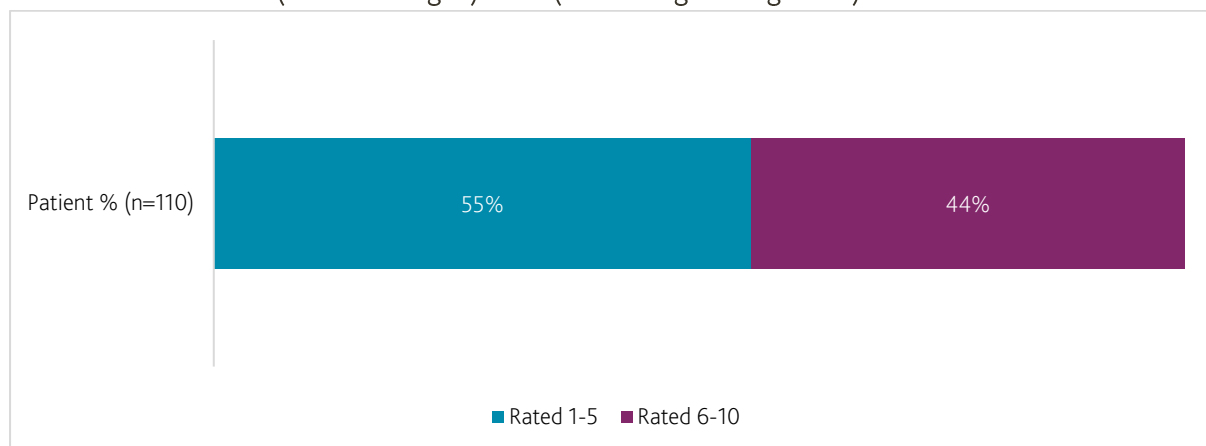


- 56% of patients didn't discuss their fatigue with their doctor over the last two years.
- 23% of patients were not provided any information to help with fatigue.
- Over a third of patients (40%) reported that they found balancing time schedules helpful in managing cancer-related fatigue.
- 51% of patients 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).

❖ Figure 62 illustrates that 55% of patients report minimal fatigue over the last week. *Only asked to those who reported they had fatigue.*

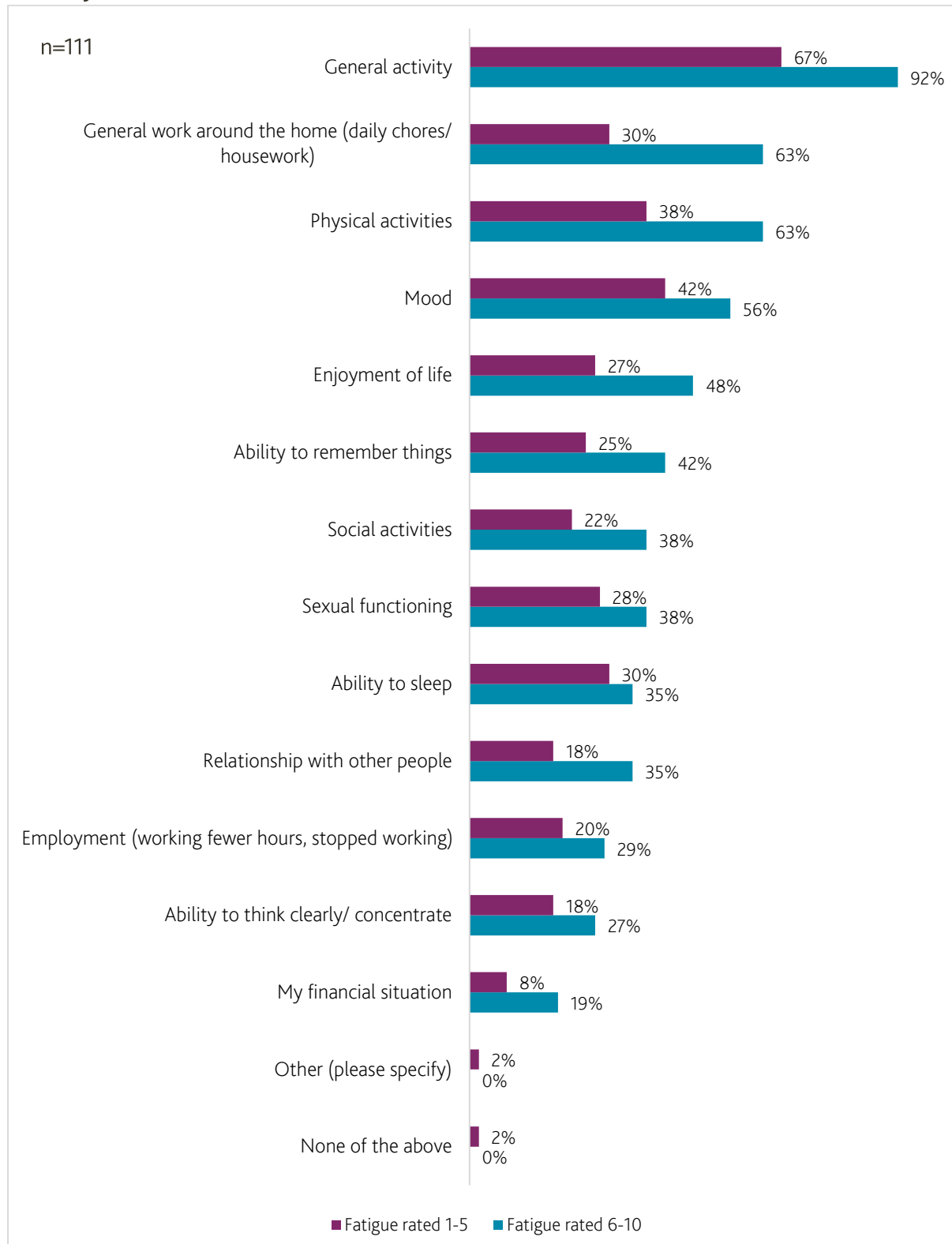
Figure 62. Patients were asked to rate their level of fatigue over the last one week (of taking the survey) on a scale of 1 (minimal fatigue) to 10 (worst fatigue imaginable).



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- ❖ Figure 63 illustrates that almost all (92%) of patients who reported rating their fatigue between 6-10 felt that fatigue has affected their general activity over the last two years, and this was also an issue for over two-thirds of patients with minimal fatigue. *Only asked to those who reported they had fatigue.*

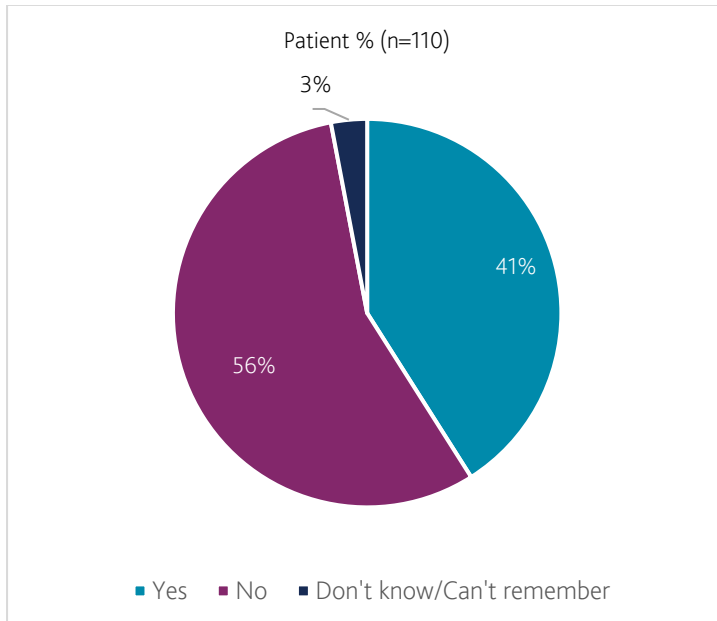
Figure 63. Which of the following areas/ activities, if any, has your fatigue affected over the last two years?



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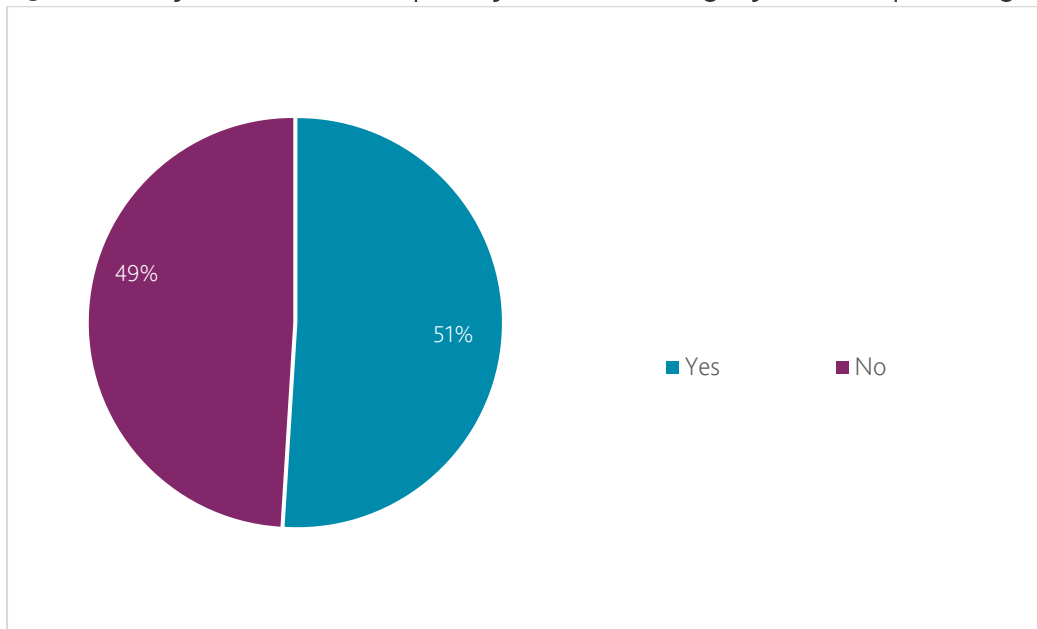
- ❖ Figure 64 reveals over half of patients have not discussed their fatigue with their doctor over the last two years. *Only asked to those who reported they had fatigue.*

Figure 64. Have you discussed your fatigue with your doctor over the last two years?



- ❖ Figure 65 shows that in the case of 49% of patients, doctors did not follow up about the fatigue the patients were experiencing. *Only asked to those who reported they had discussed their fatigue with their doctor.*

Figure 65. Did your doctor follow up with you about the fatigue you were experiencing?

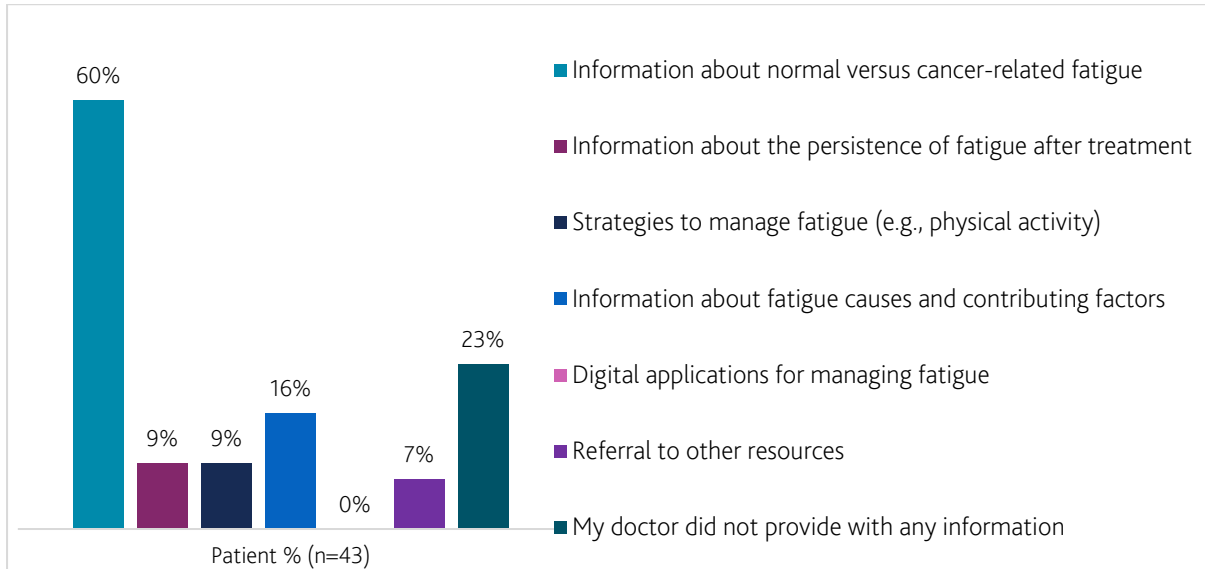


Patients who discussed their fatigue with their doctor (n=45) were also asked what type of information they received from their doctor

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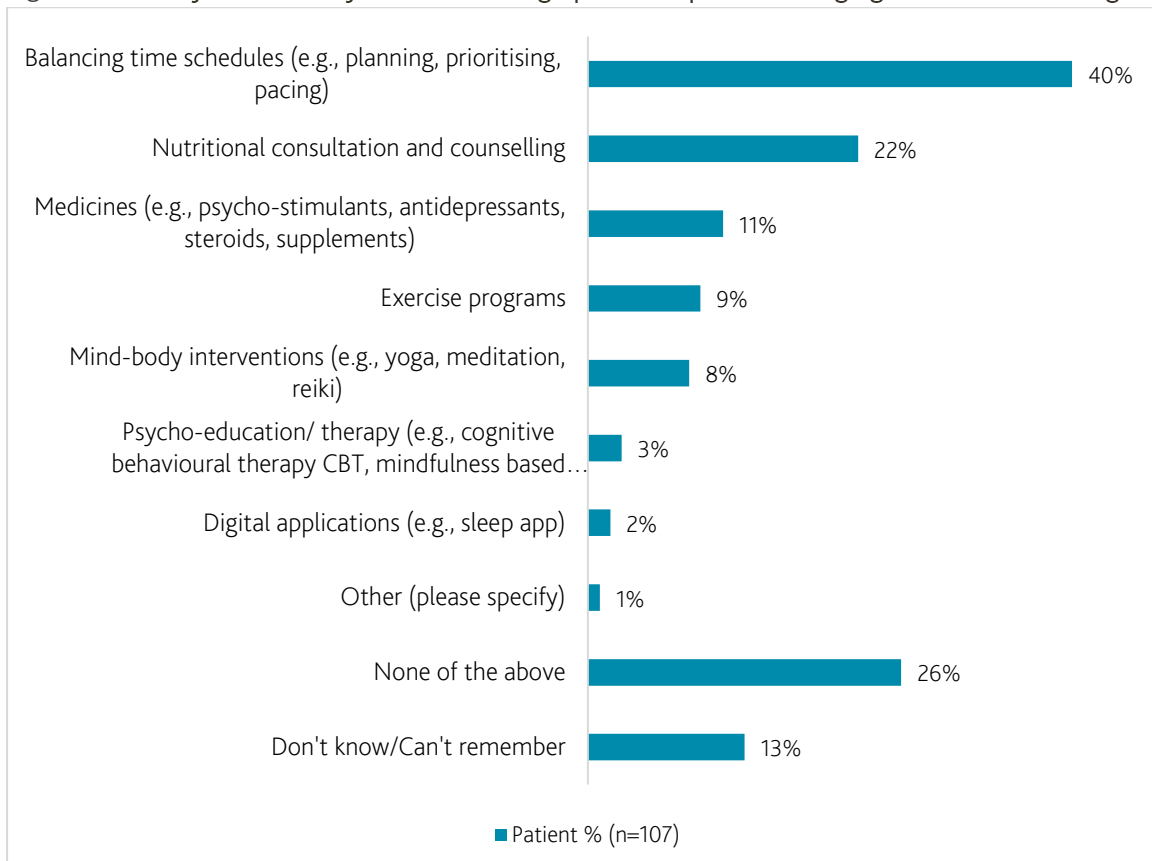
- ❖ Figure 66 illustrates that 23% of patients were not provided with information about their fatigue from their doctor. *Only asked to those who reported they had discussed their fatigue with their doctor.*

Figure 66. Which information types did your doctor provide you with?



- ❖ Figure 67 reveals 62% of patients found exercise programs helpful in managing cancer-related fatigue. *Only asked to those who reported they had fatigue.*

Figure 67. Have you found any of the following options helpful in managing cancer-related fatigue?



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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.

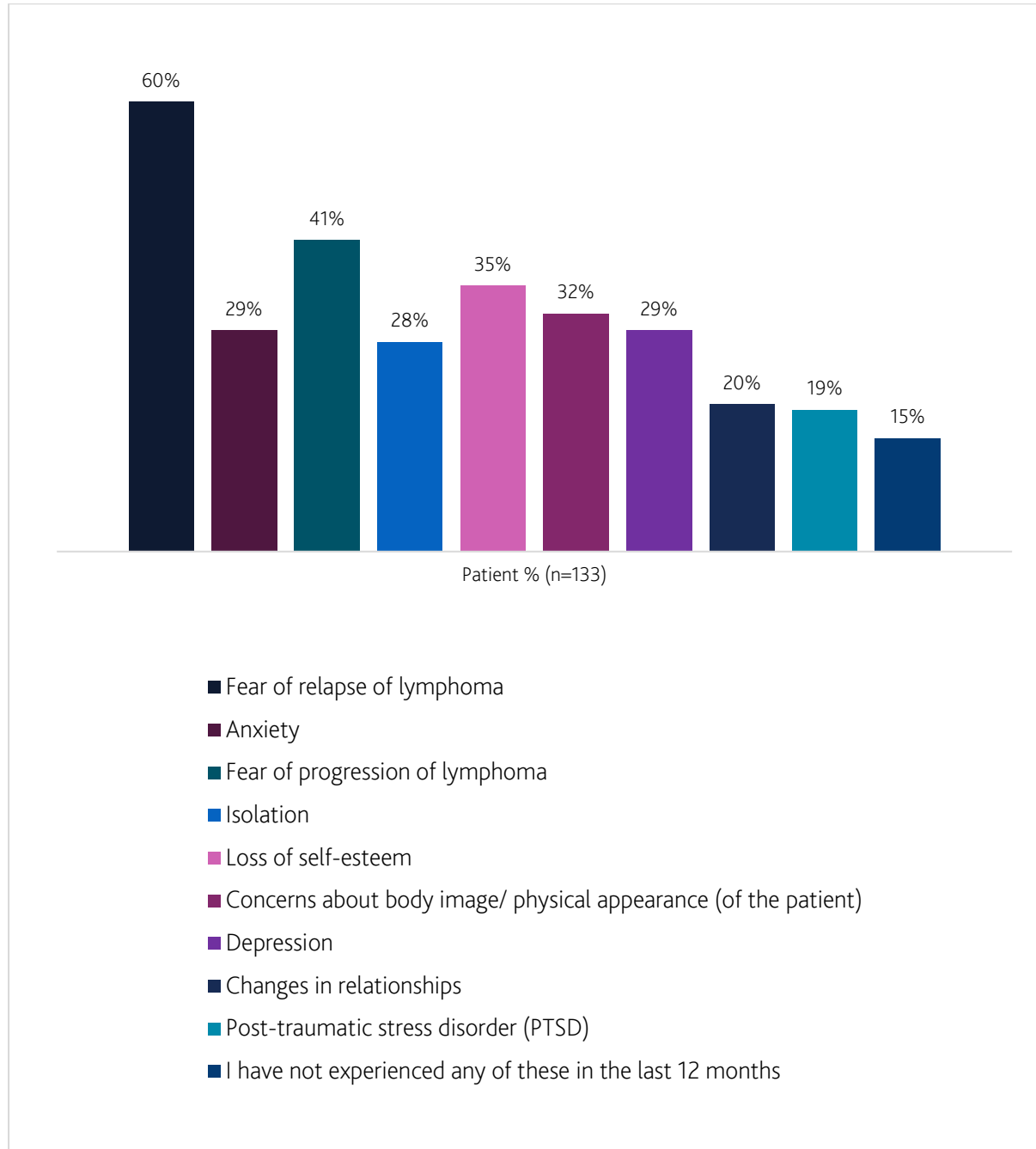


- Almost two-thirds of the patients who were in treatment/ had had treatment or were in remission reported a fear of relapse of lymphoma (60%) and almost half (41%) reported fear of progression of lymphoma as their biggest worries or concerns.
- Only 40% of patients discussed their fear of progression of lymphoma with their doctor. An even smaller proportion (27%) definitely discussed their fear of relapse of lymphoma with their doctor.
- The most provided approach by doctors to help patients cope with depression was the empathetic / understanding approach (44%), which was the same for fear of progression (54%) and fear of relapse (44%).
- The most provided approach by doctors to help patients cope with anxiety was participation of family/ caregiver in providing support (71%).

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- ❖ Figure 68 discloses 60% of patients have experienced fear of relapse of lymphoma and a further 41% are fearful their lymphoma will progress.

Figure 68. In the last 12 months, have you personally experienced any of the following as a result of the lymphoma diagnosis?

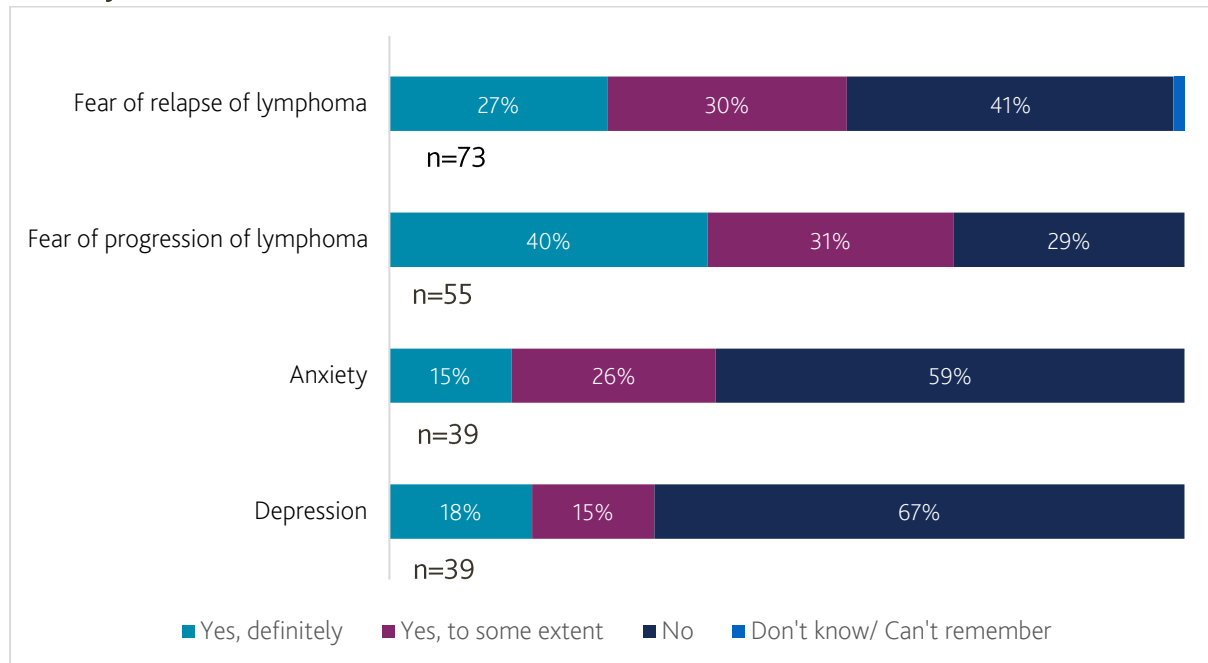


The next questions only focused on the top 4 psychosocial issues identified by patients globally: fear of relapse of lymphoma, fear of progression of lymphoma, anxiety, and depression.

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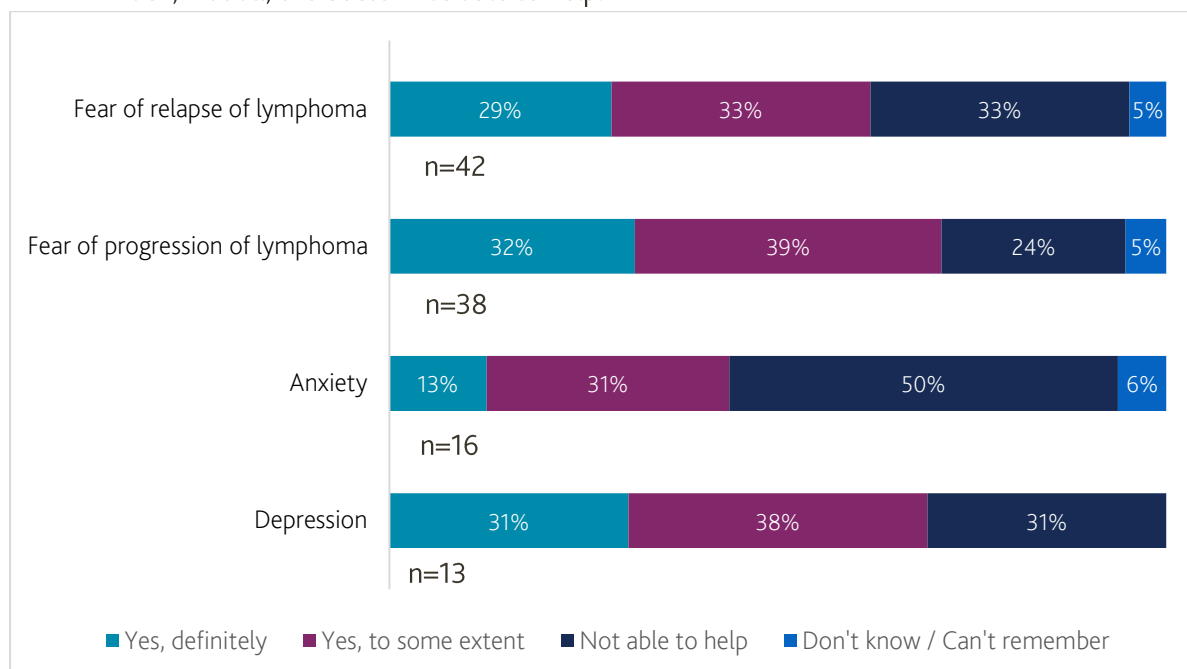
- ❖ Figure 69 reveals that patients are more likely to discuss their fear with a doctor than their anxiety and depression. *Only asked to those who indicated they were affected by at least one of the following: fear of relapse, fear of progression of lymphoma, anxiety, and depression.*

Figure 69. For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with a doctor?



- ❖ Figure 70 shows that when patients did discuss these issues with their doctor, in almost half of the 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 70. 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.



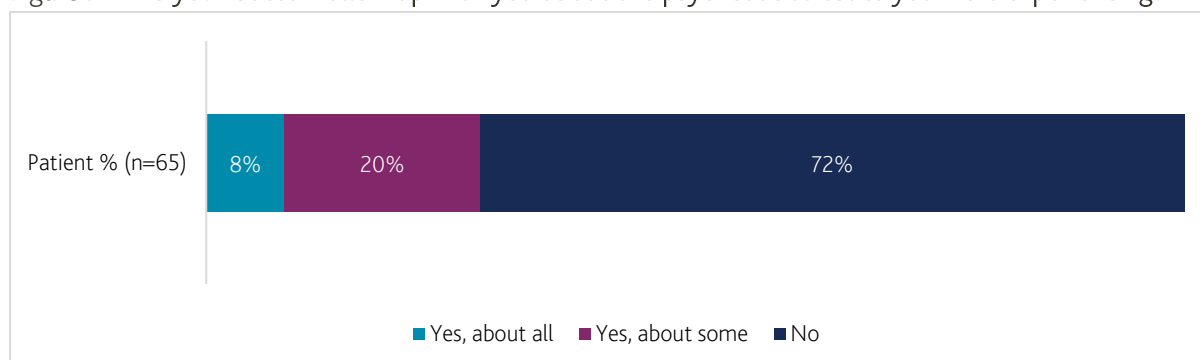
- ❖ Table 4 illustrates that doctors were most likely to provide an empathetic/understanding approach regarding these issues other than for anxiety in which case participation of family/caregiver in providing support was most often provided. *Only asked to those that discussed their fear of relapse, fear of progression of lymphoma, anxiety and/or depression with their doctor.*

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

Help offered	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	22%	14%	0%	0%
Further written or verbal information	22%	29%	22%	19%
The empathetic/ understanding approach of my doctor when I told him/ her	44%	14%	44%	54%
Patient organisation or patient support group	11%	14%	19%	12%
Referral to other sources of support (e.g., social worker, therapist, counselling)	11%	14%	0%	0%
Exercise	11%	14%	15%	19%
Participation of family/ caregiver in providing support	22%	71%	22%	27%
The empathetic/ understanding approach of my nurse when I told him/ her	11%	14%	7%	4%
Eating a healthy diet	11%	29%	15%	19%
Other	0%	0%	4%	8%

- ❖ Figure 71 reveals that most patients reported that their doctors did not follow up on the psychosocial issues.

Figure 71. Did your doctor follow up with you about the psychosocial issues you were experiencing?



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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.

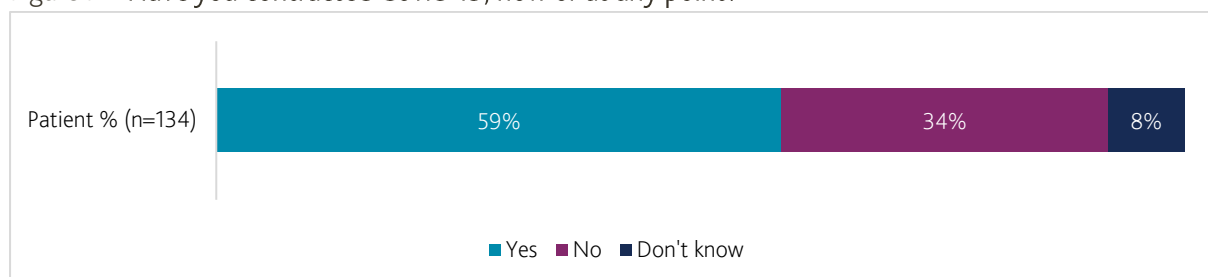
Several patients also experienced changes in their care, including switching to telemedicine.



- 51% of patients reported that their anxiety was much worse and 39% of patients reported that their depression was much worse during the Covid-19 pandemic.
- 76% of patients consider themselves at high risk for contracting Covid-19 and experiencing severe illness from it, and it worries 50% of them.
- 39% of patients reported that their depression was much worse and 33% said it worse during the Covid-19 pandemic.
- The most frequently reported change to care due to Covid-19 restriction was outpatient treatment delay, rescheduled, or cancelled (25%), followed by caregiver not allowed to come to the hospital with patient (16%), followed by change to treatment plan (16%).
- 22% of patients avoided or delayed seeking medical attention due to the pandemic.
- Over half of patients (59%) strongly disagreed/disagreed that they preferred TC/VC to face-to-face visits, while only 23% strongly agreed/agreed that they preferred it.
- 47% of patients strongly disagreed/disagreed that they would like to continue to use TC/VC even after the pandemic is over.

❖ Figure 72 shows over half of patients have contracted Covid-19 at any point.

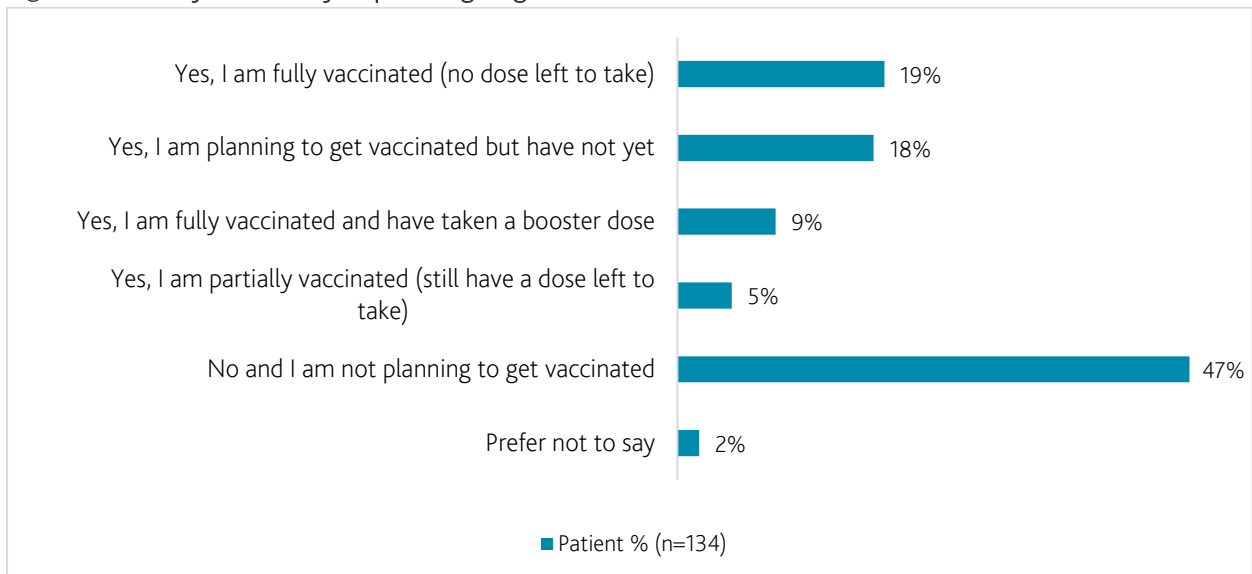
Figure 72. Have you contracted Covid-19, now or at any point?



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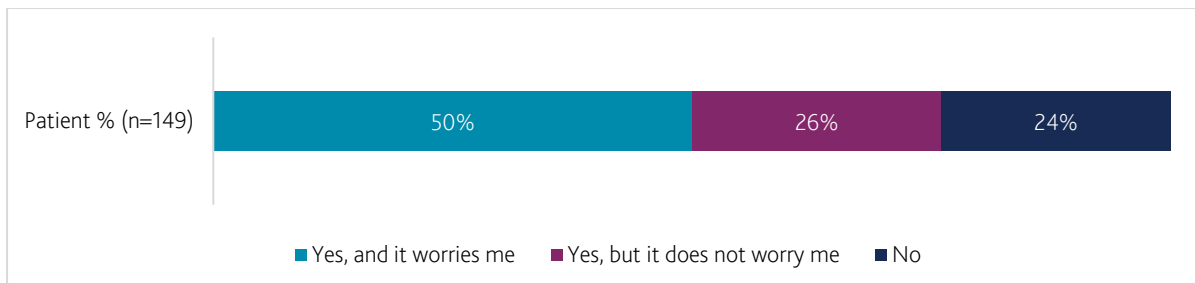
- ❖ Figure 73 illustrates that 47% of patients are not planning to get vaccinated.

Figure 73. Have you, or are you planning to get the Covid-19 vaccine?



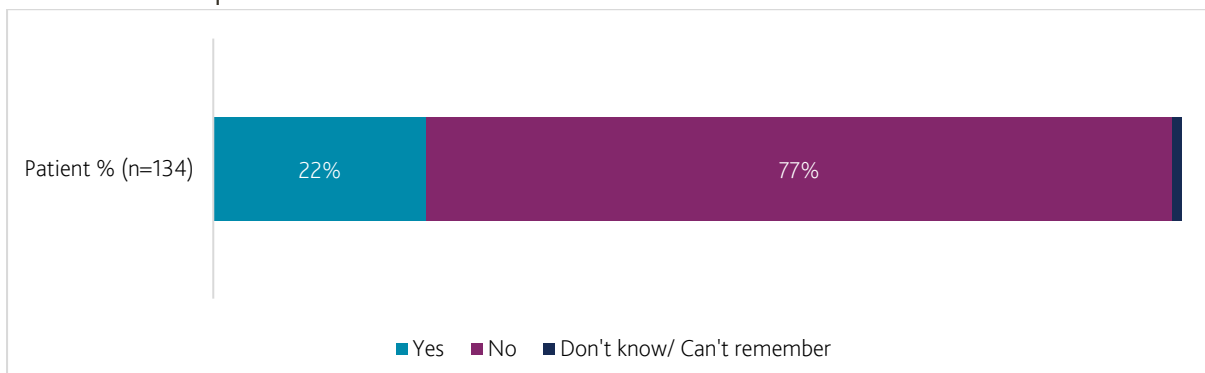
- ❖ Figure 74 shows that half of patients consider themselves as high risk of contracting Covid-19 and it worries them.

Figure 74. Do you consider yourself at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?



- ❖ Figure 75 reveals 22% of patients avoided or delayed seeking medical attention for their lymphoma or CLL during the Covid-19 pandemic.

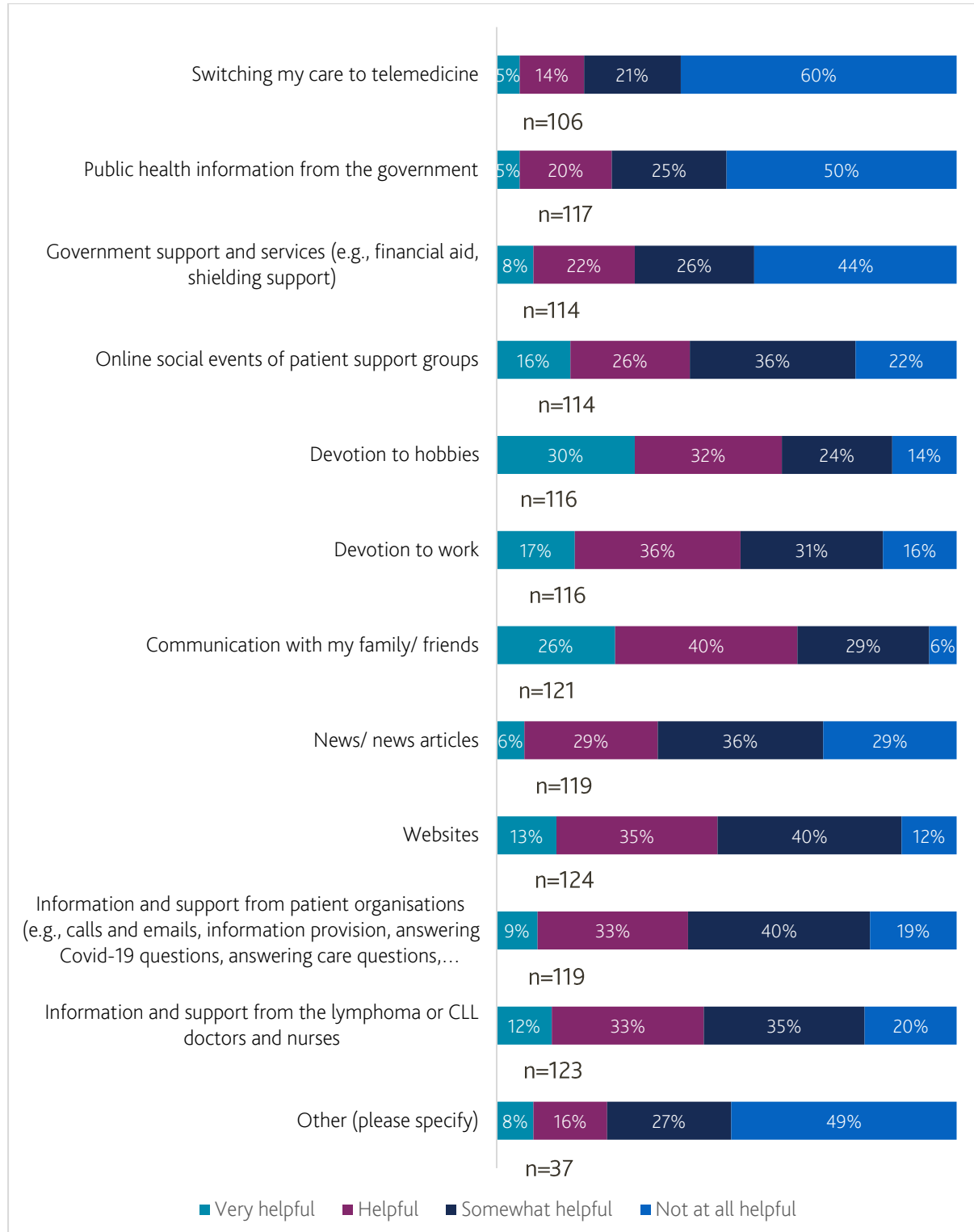
Figure 75. Did you avoid or delay seeking medical attention for your lymphoma or CLL during the Covid-19 pandemic?



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- ❖ Figure 76 divulges that 60% of patients said switching care to telemedicine has been not helpful in providing support for lymphoma or CLL during the Covid-19 pandemic.

Figure 76. 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.

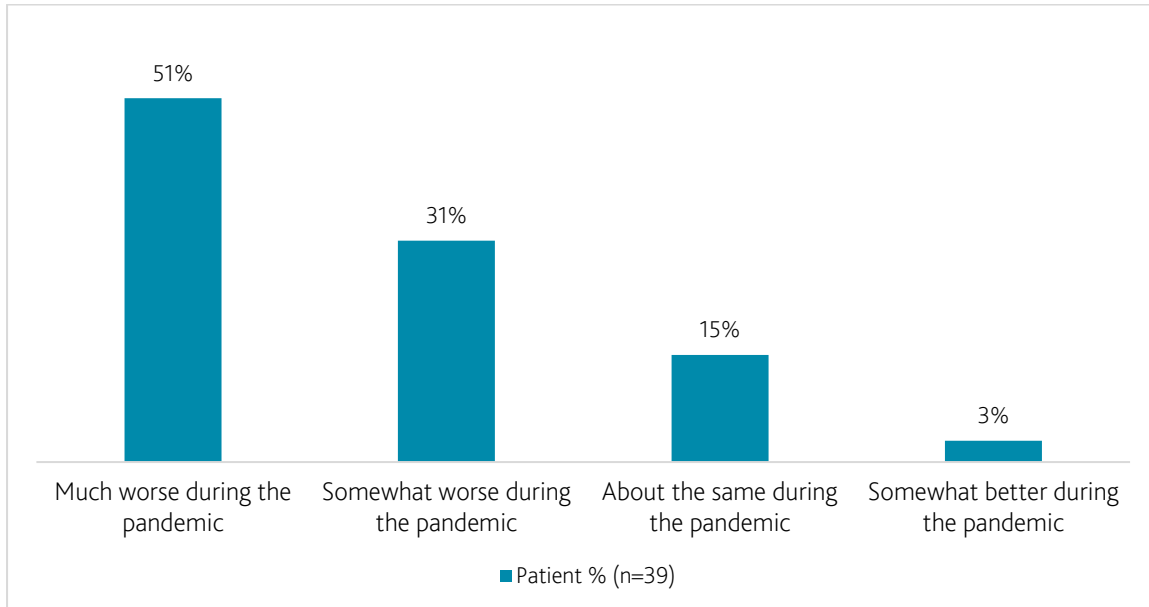


Patients who reported having anxiety (as a psychosocial issue) were asked how the Covid-19 pandemic affected their anxiety level.

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- ❖ Figure 77 reveals that just over half 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.*

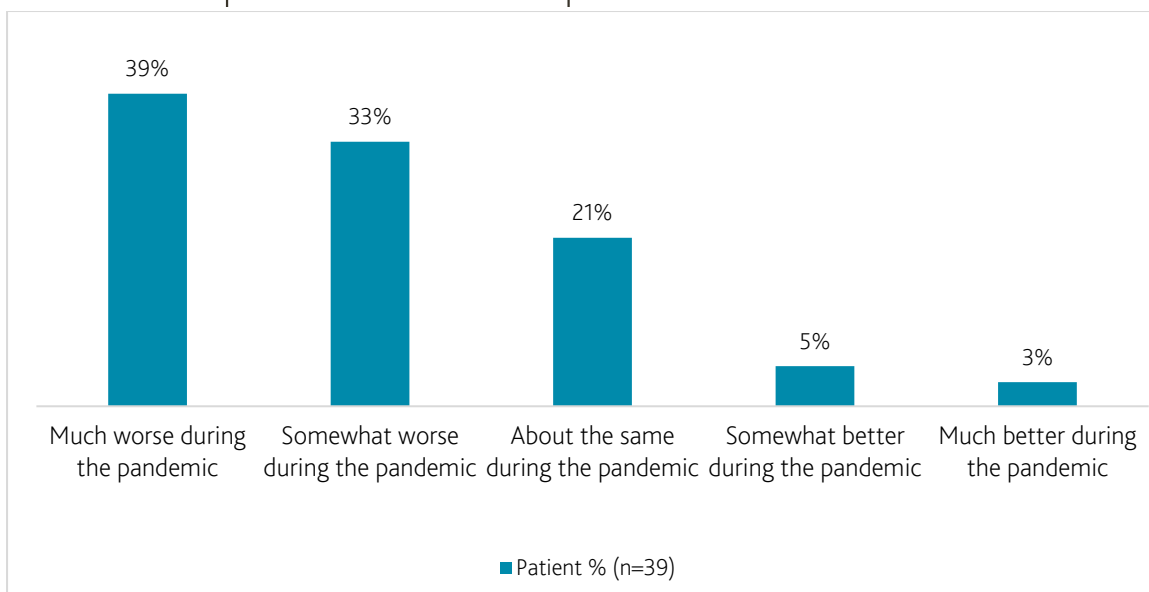
Figure 77. Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.



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 78 shows that 39% 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.*

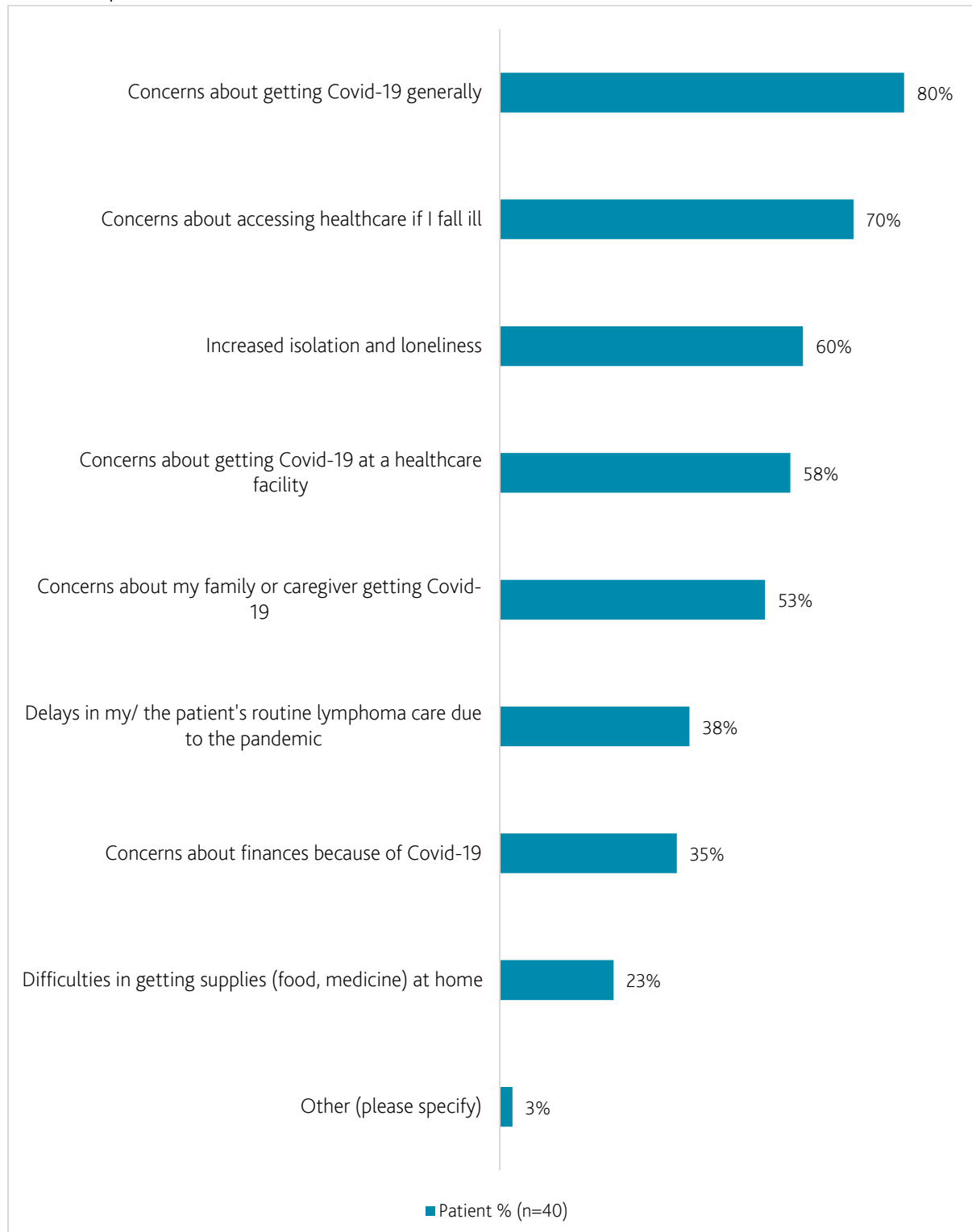
Figure 78. Please describe your level of depression during the Covid-19 pandemic, compared to your level of depression before the Covid-19 pandemic.



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- ❖ Figure 79 illustrates that 80% of patients felt that concerns about getting Covid-19 generally was contributing factors to their worsened level of anxiety and/or depression, followed closely by concerns about accessing care if they fell ill. *Only asked to those who said they had anxiety or depression that was worse during the pandemic.*

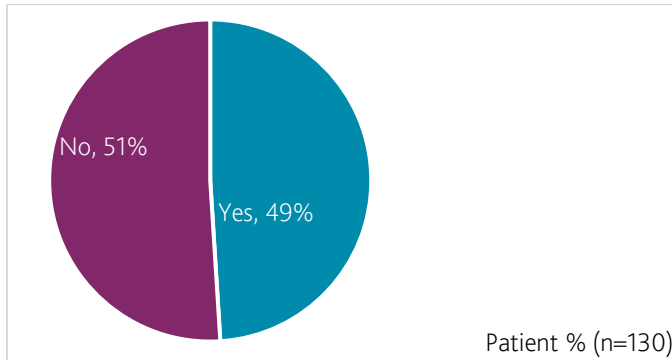
Figure 79. Which of the following were contributing factors for the worsened anxiety and/ or depression?



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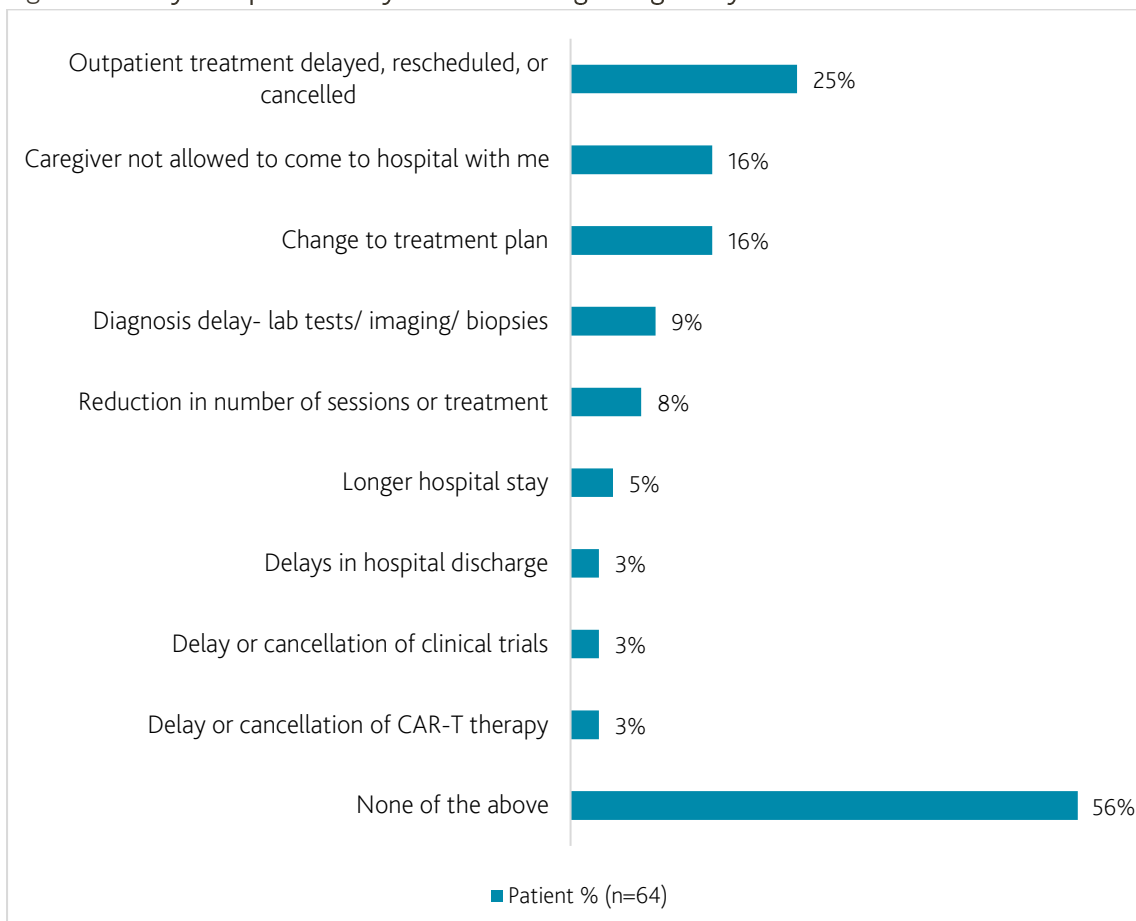
- ❖ Figure 80 shows half of patients were scheduled to receive treatment for lymphoma or CLL when Covid-19 restriction was an issue in their community.

Figure 80. Were you scheduled to receive treatment for your lymphoma or CLL when Covid-19 restriction was an issue in your community?



- ❖ Figure 81 explains that 44% of patients experienced changes to care due to the COVID-19 restrictions. 25% of patients reported outpatient treatment delayed, rescheduled, or cancelled, while 16% reported their caregiver was not allowed to come to the hospital with them. 16% of the patients experienced changes to their treatment plan. 9% of patients experienced a diagnosis delay (lab tests, imaging, biopsies). *Only asked to those who received treatment during Covid-19 restriction in their community.*

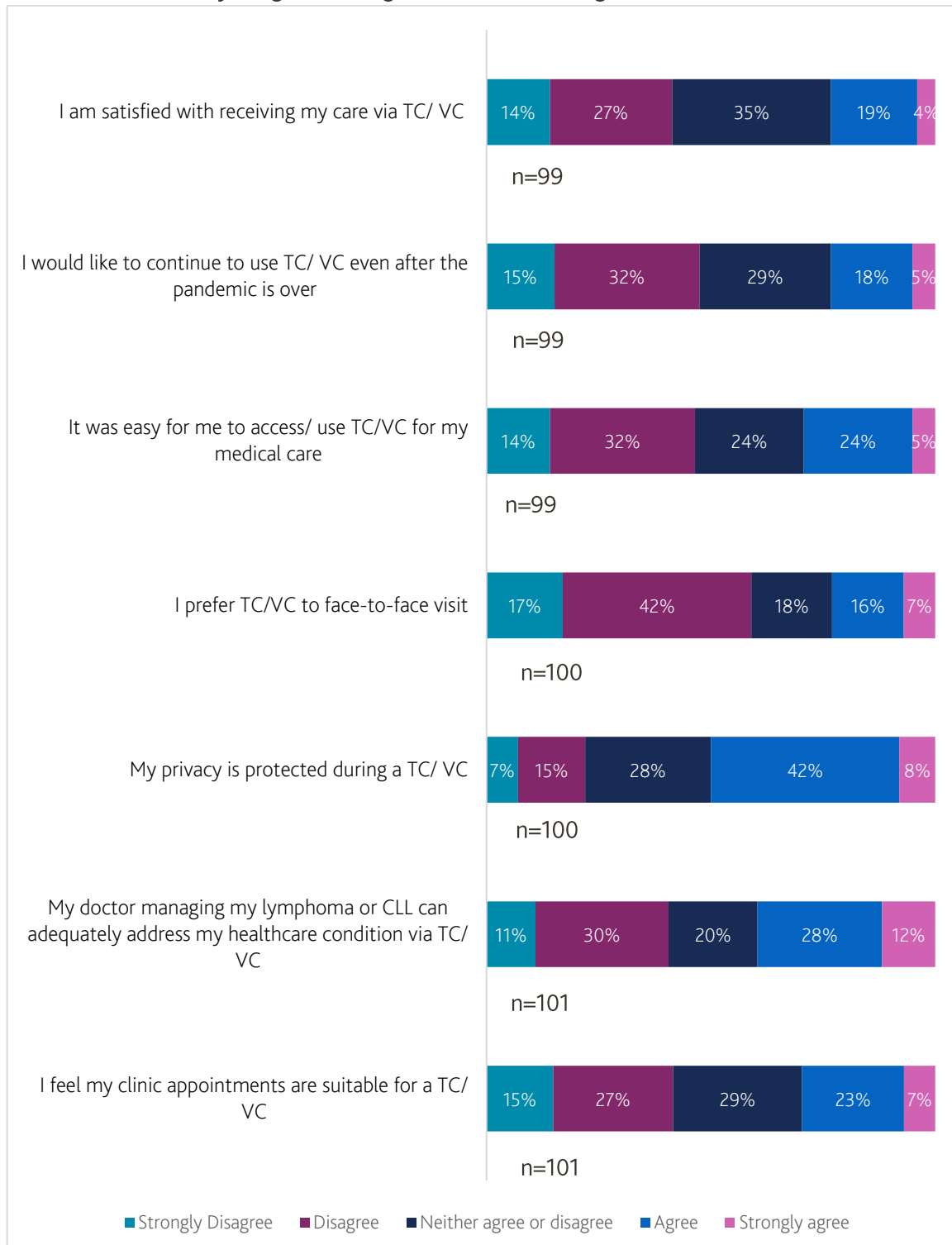
Figure 81. Did you experience any of the following changes to your care due to Covid-19?



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- ❖ Figure 82 illustrates that 50% of patients agree or strongly agree that their privacy is protected during a TC/VC, yet 59% 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 82. Regarding your use of telemedicine (Telephone consultation (TC) or video consultation (VC), how much do you agree or disagree with the following statements?



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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.

49 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

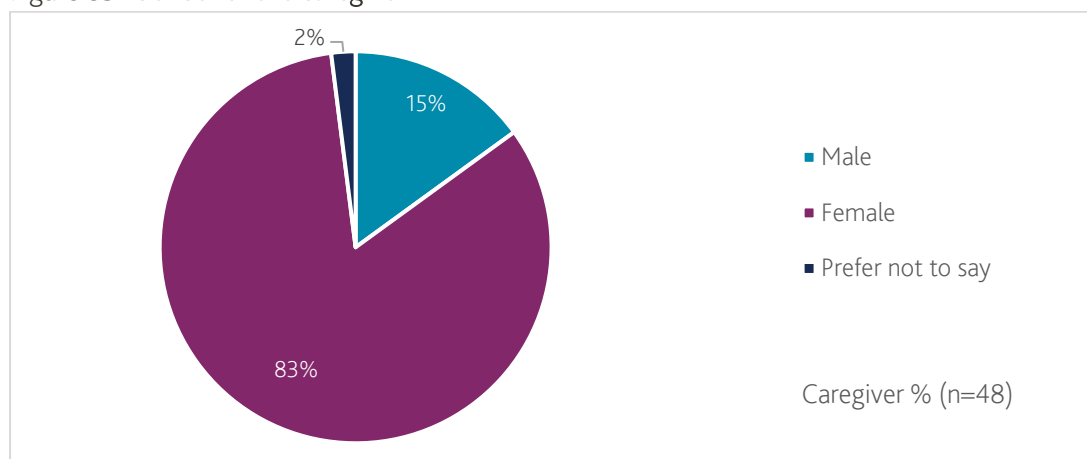
Caregiver Characteristics



- 49 caregivers responded to the survey, with two-thirds of the respondents residing in city/urban areas (90%). Most caregivers (83%) were female.
- 47% of all caregivers are providing support to their spouse/ partner, 18% cared for their parent, and 18% for their child.

❖ Figure 83 explains that 83% of caregivers are female.

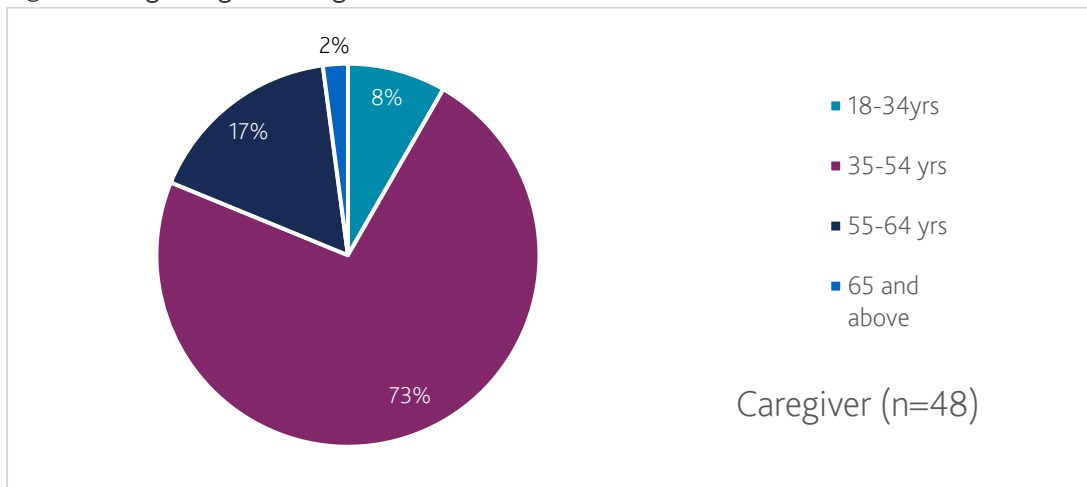
Figure 83. Gender of the caregiver



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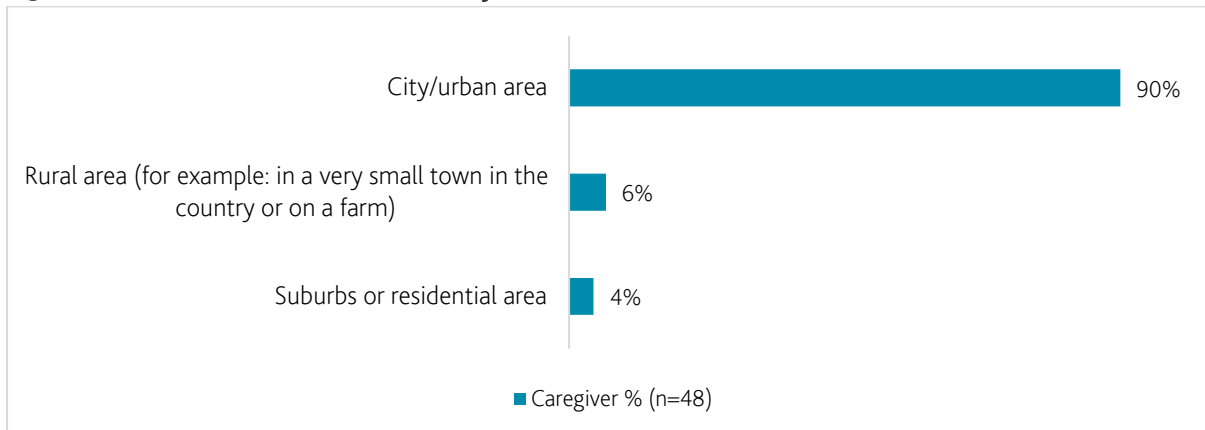
- ❖ Figure 84 illustrates that more than half of caregivers are between the ages of 35 and 54.

Figure 84. Age range of caregivers



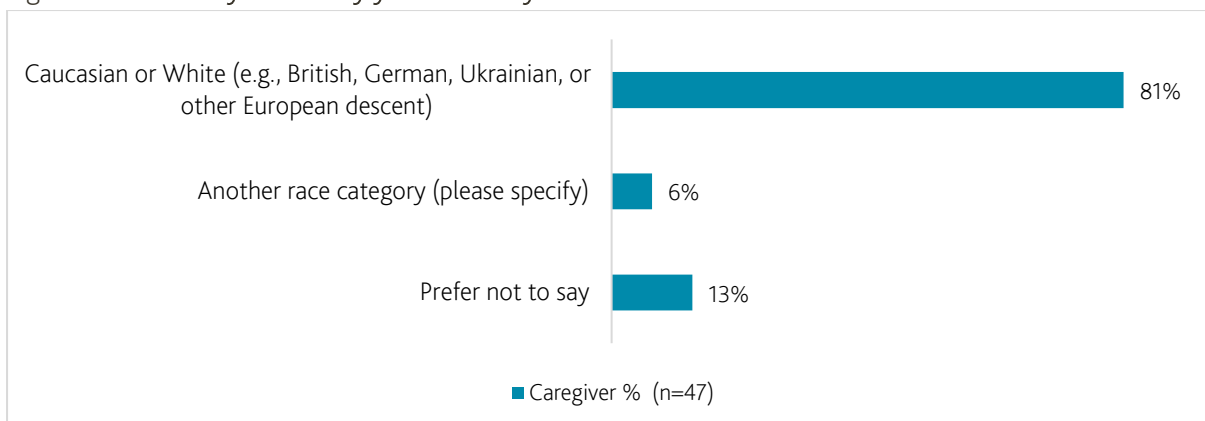
- ❖ Figure 85 depicts that 90% of caregivers live in a city/urban area.

Figure 85. Which best describes the area you live in?



- ❖ Figure 86 illustrates that almost all caregivers are Caucasian or White.

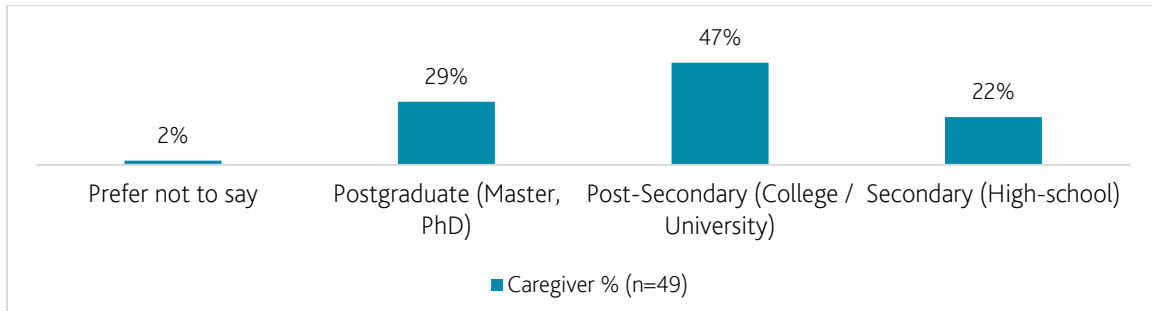
Figure 86. How do you identify your ethnicity?



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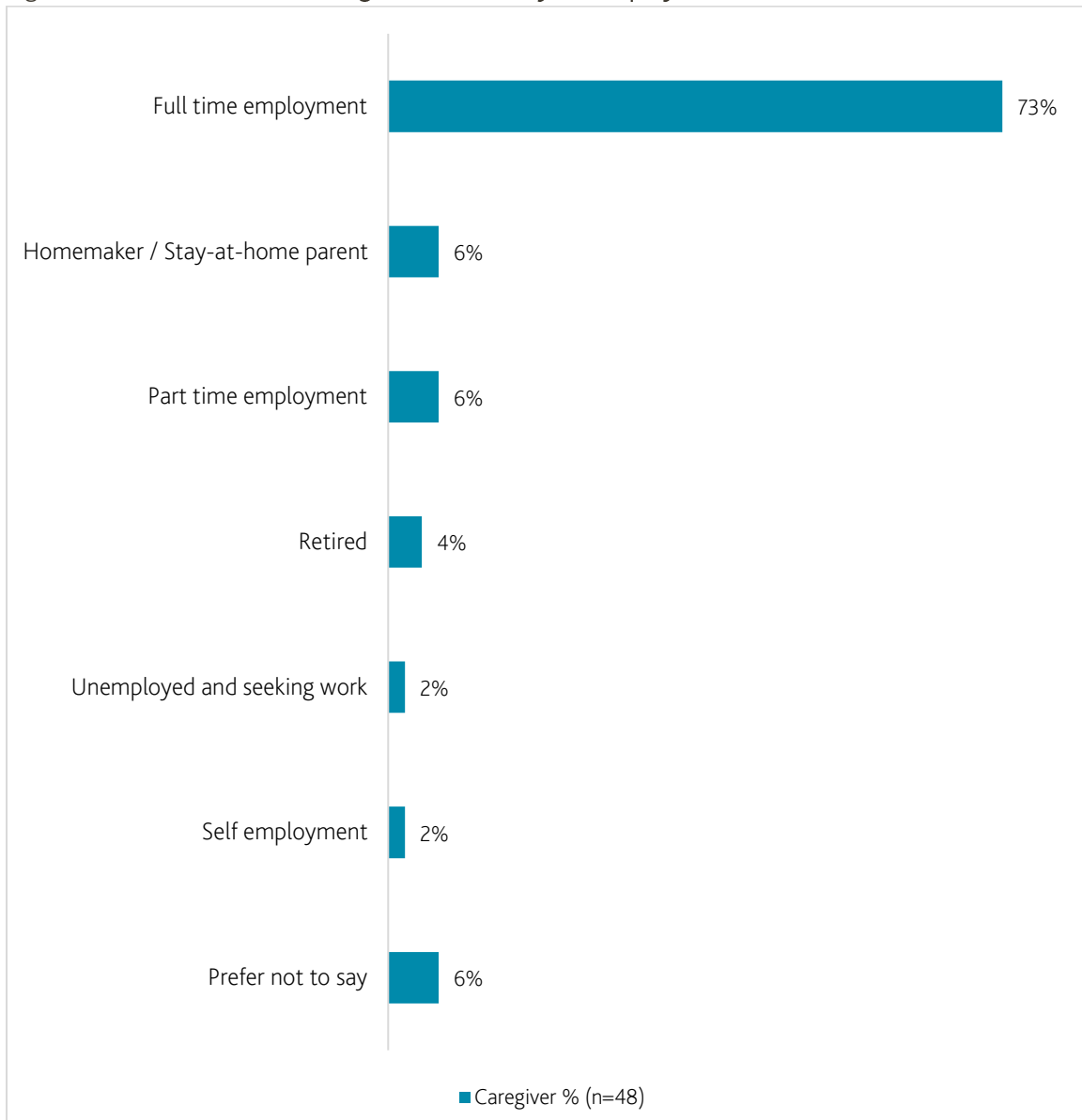
- ❖ Figure 87 shows that 47% of caregivers have completed post-Secondary education and a high rate (29%) completed Postgraduate program (Master, PhD).

Figure 87. What is your highest educational level completed?



- ❖ Figure 88 illustrates that 73% of caregivers are employed full time.

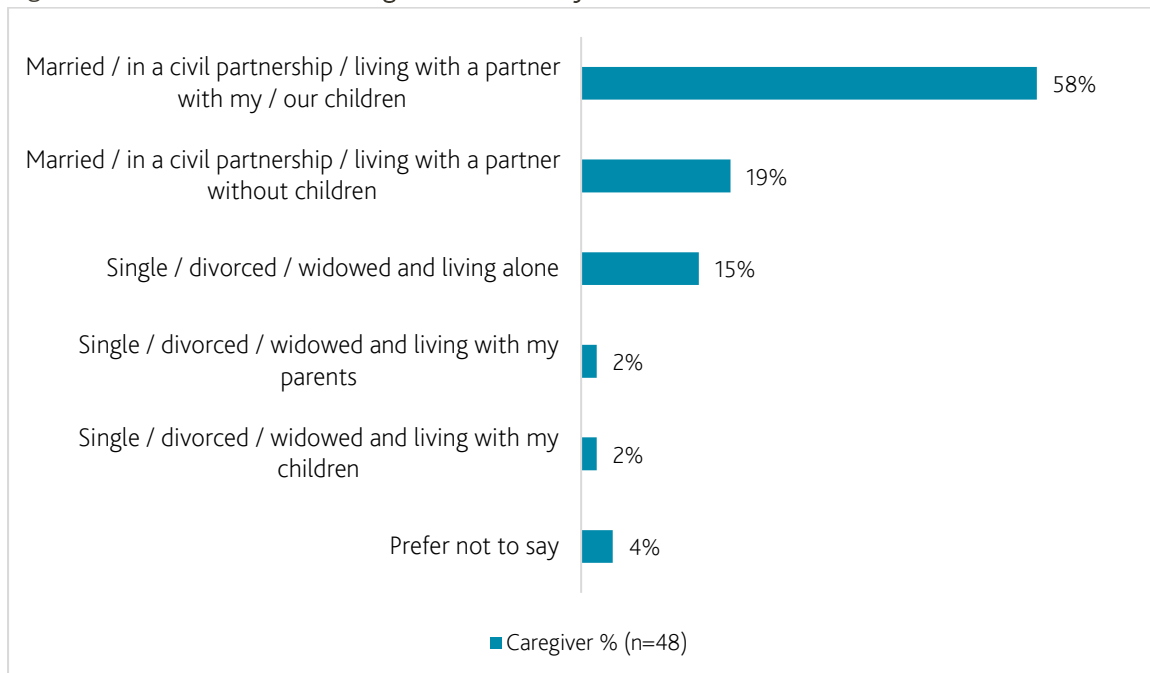
Figure 88. Which of the following best describes your employment status?



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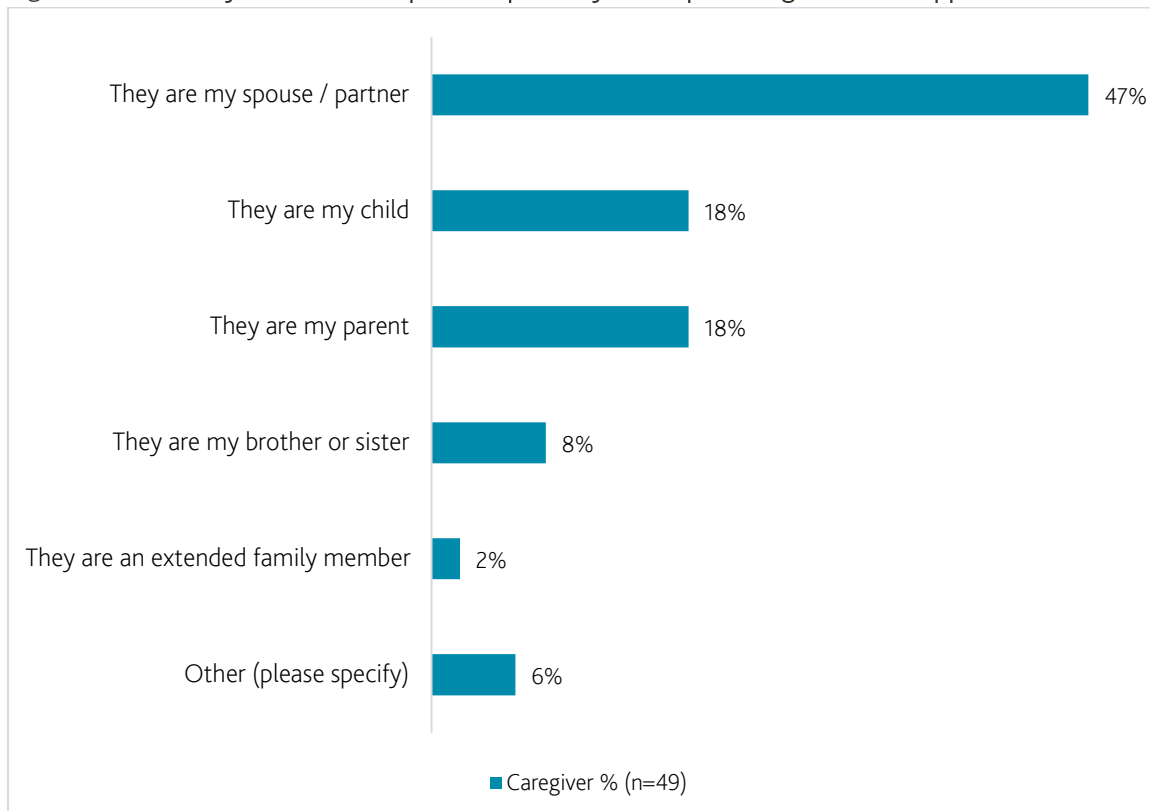
- ❖ Figure 89 reveals that over half (58%) of caregivers have a partner and children.

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



- ❖ Figure 90 illustrates that 47% of caregivers are providing care and support to their spouse/partner.

Figure 90. What is your relationship to the person you are providing care and support to?



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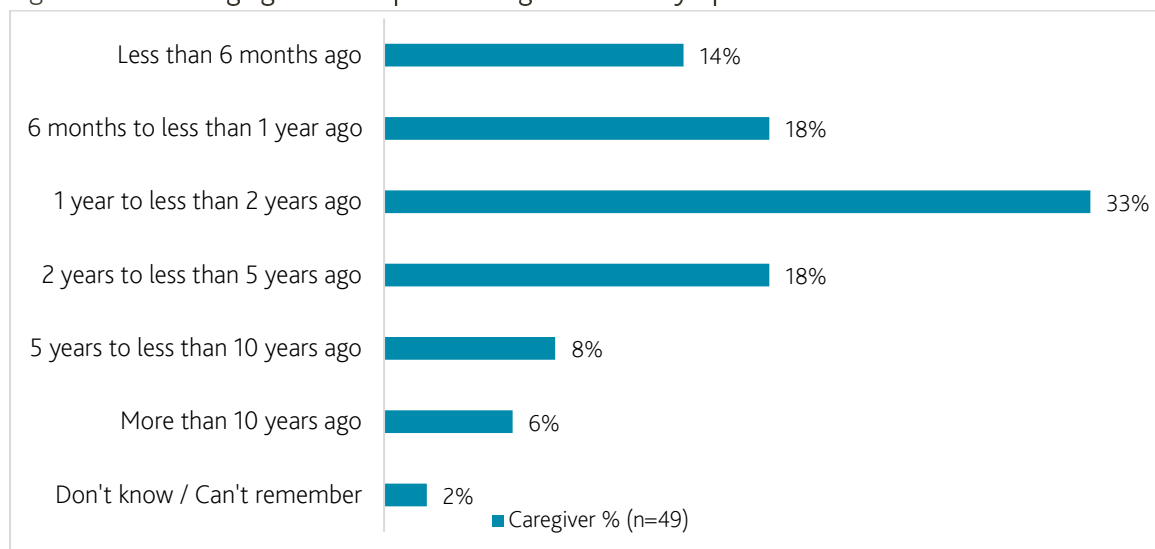
Diagnostic Demographics



- 25% of caregivers have been providing help for 1 year to less than 2 years ago.
- Most caregivers reported they were providing care for patients with Hodgkin lymphoma (45%), followed by Diffuse Large B-Cell Lymphoma (DLBCL) (nonspecific type) (18%), then Follicular lymphoma (10%).

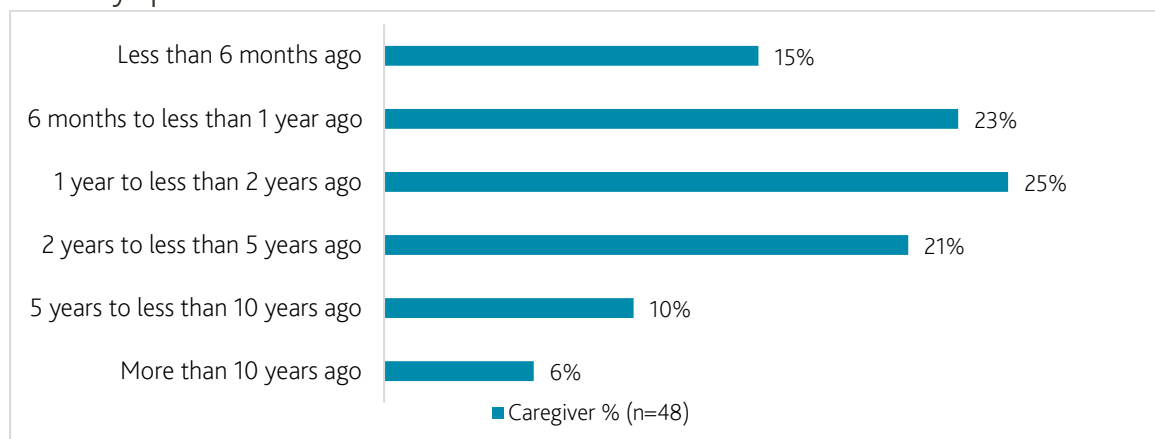
- ❖ Figure 91 reports that 33% are providing care to a patient who was diagnosed with lymphoma or CLL 1 year to less than 2 years ago.

Figure 91. How long ago was the patient diagnosed with lymphoma or CLL?



- ❖ Figure 92 illustrates that most caregivers have been providing cancer-related care and support for less than 5 years.

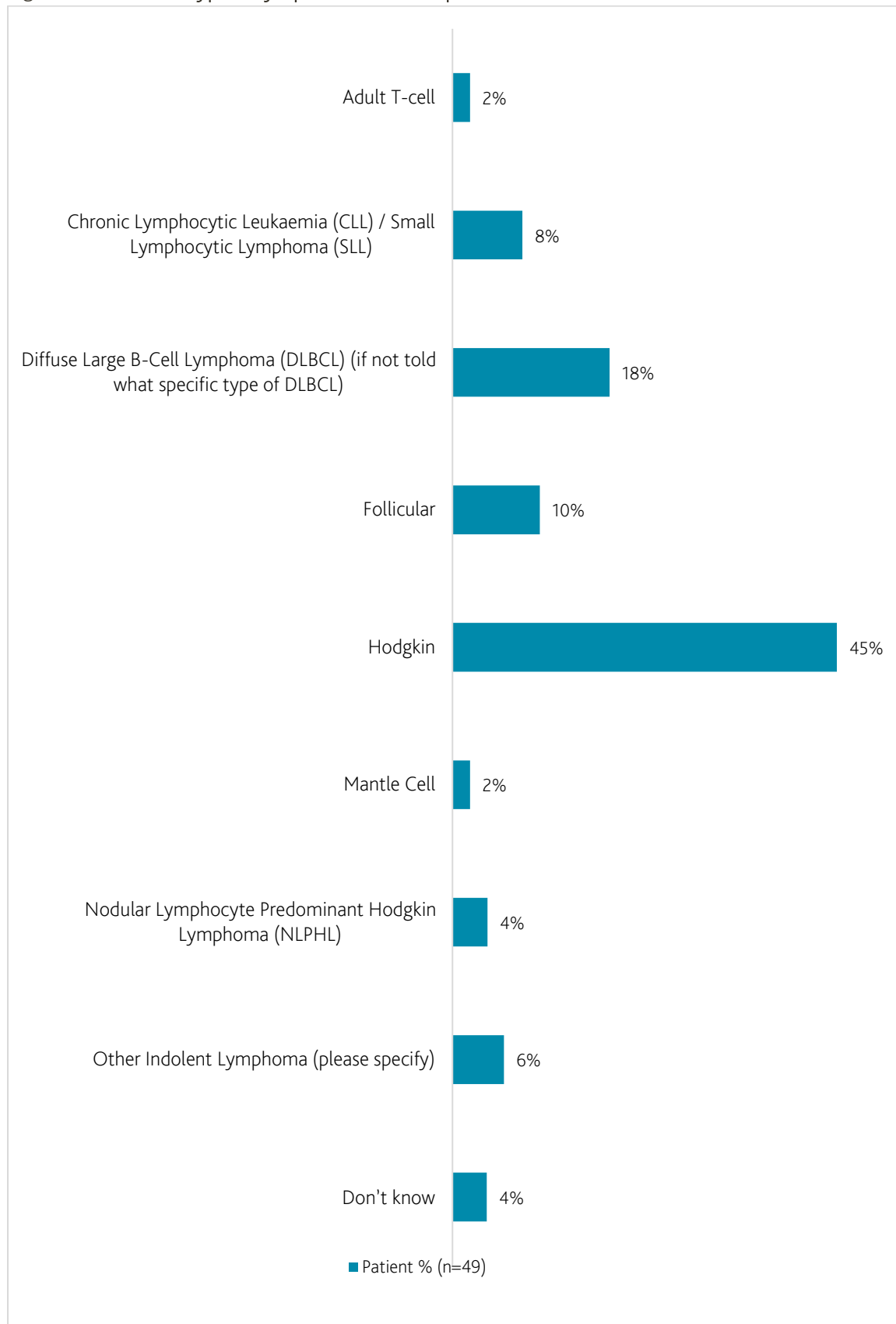
Figure 92. How long have you been providing cancer-related care and support to the person with lymphoma or CLL?



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❖ Figure 93 illustrates that almost half of caregiver's patients have Hodgkin lymphoma.

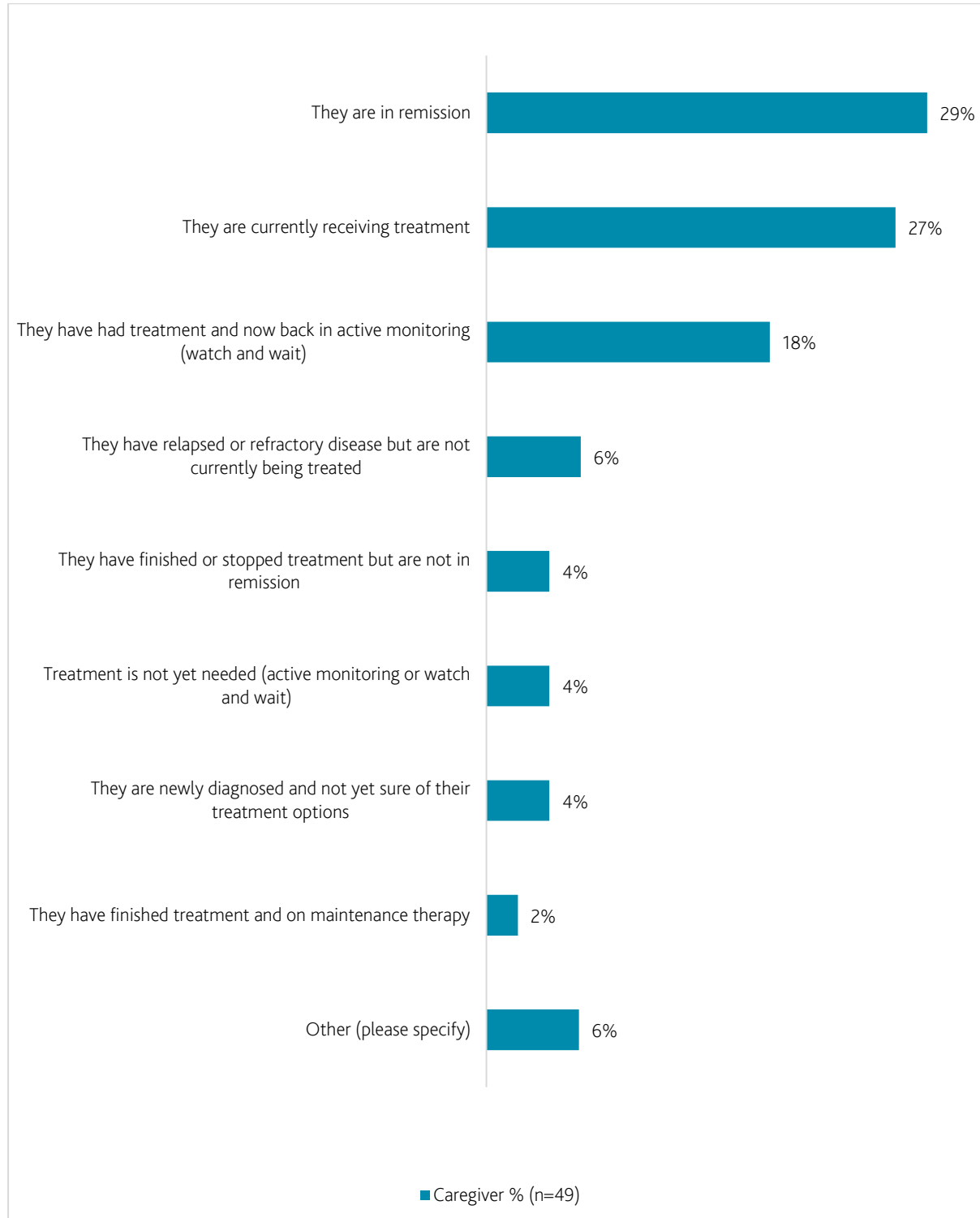
Figure 93. What subtype of lymphoma does the patient have?



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- ❖ Figure 94 shows that 29% of caregivers are caring for patients that are currently in remission and a similar percentage (27%) are currently receiving treatment.

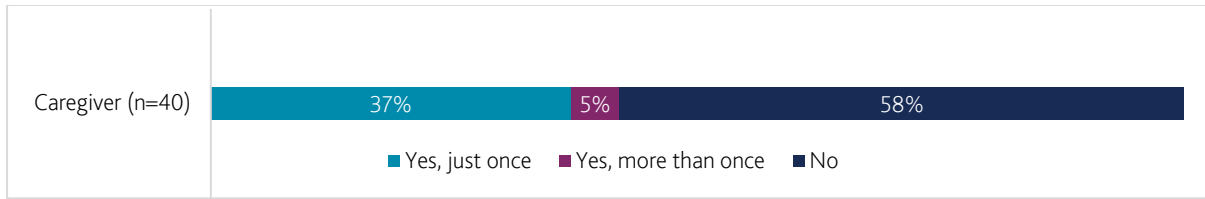
Figure 94. What statement best describes where the person you care for is in the lymphoma or CLL experience?



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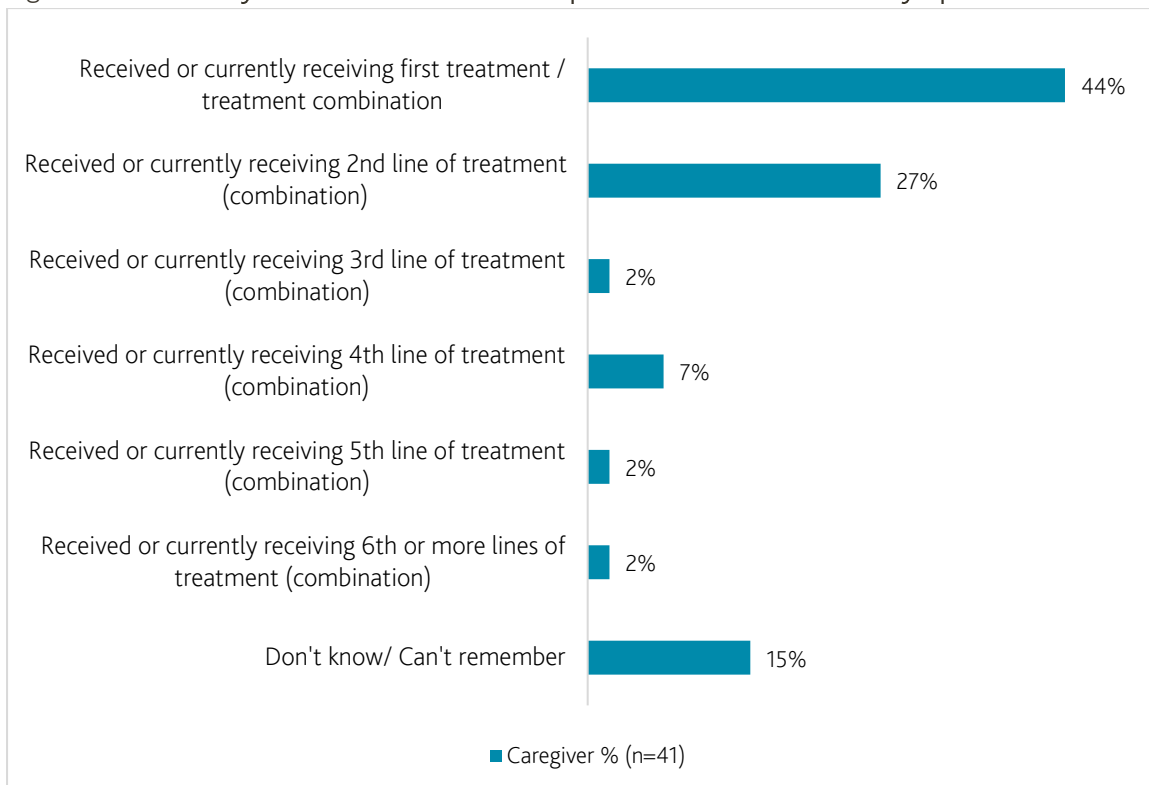
- ❖ Figure 95 points out that over half (58%) caregiver's patients have not had their lymphoma or CLL relapse. *Only asked to caregivers who said their patient had received treatment.*

Figure 95. Has the lymphoma or CLL ever relapsed?



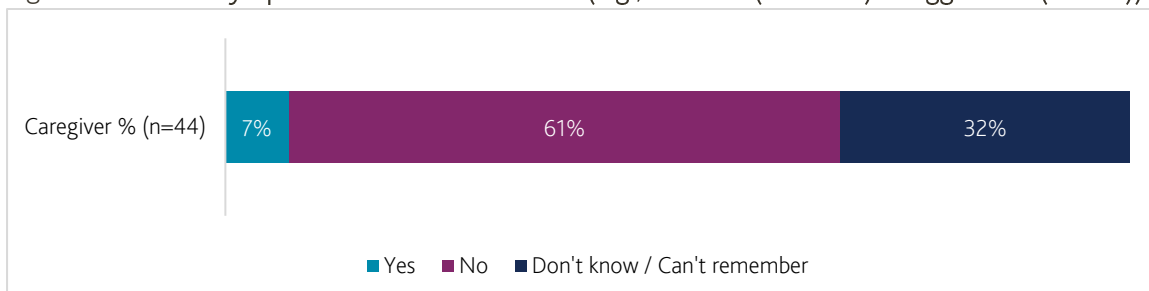
- ❖ Figure 96 illustrates that almost half (44%) of caregivers report that their patient has received their first treatment/treatment combination. *Only asked to caregivers who said their patient had received treatment.*

Figure 96. How many lines of treatment has the patient received to date for lymphoma?



- ❖ Figure 97 shows that most caregivers have patients whose lymphoma or CLL has not transformed.

Figure 97. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?



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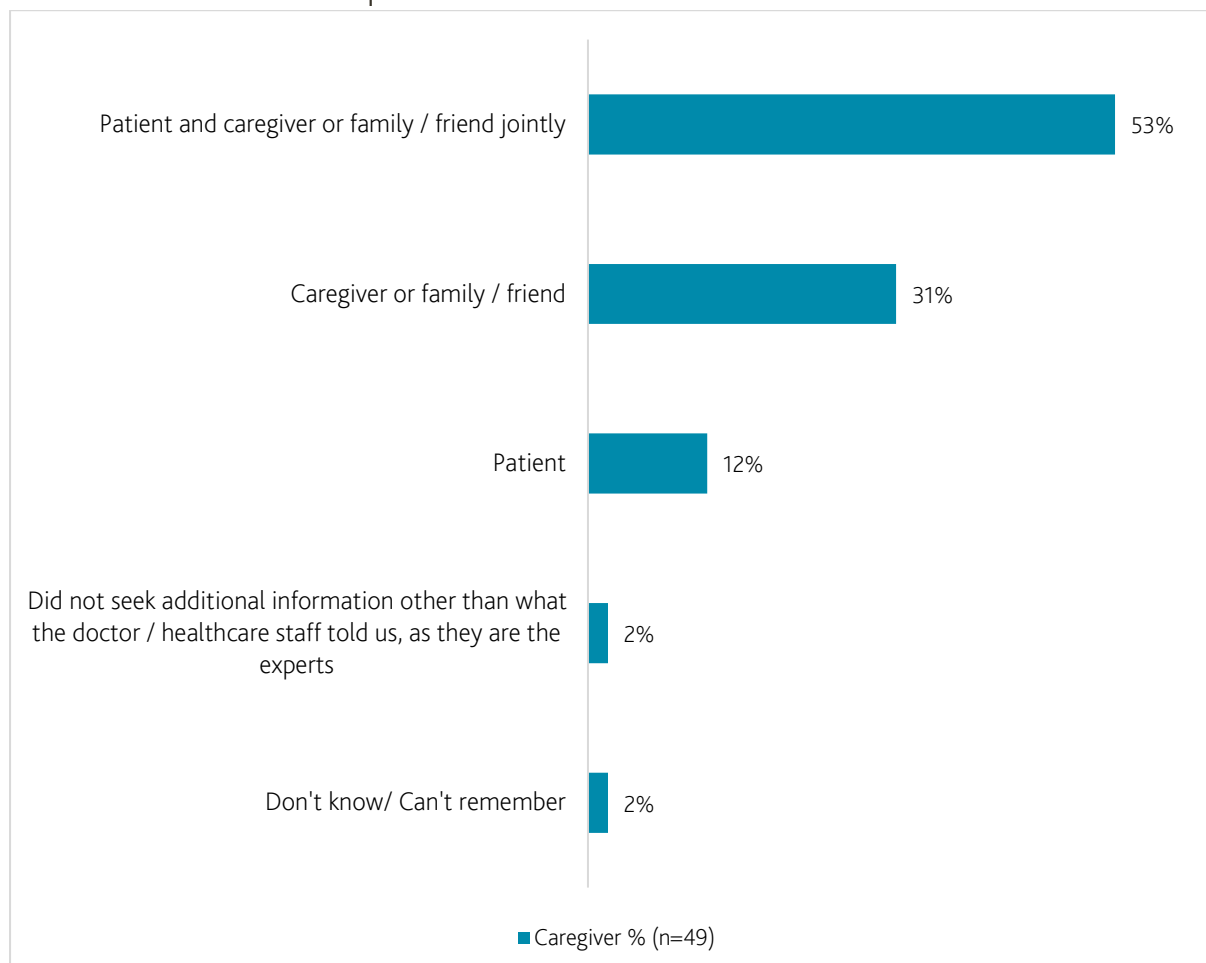
Healthcare Information



- 98% of caregivers report seeking out additional information about the patient's diagnosis, above what they were told by the medical team.
- 39% of caregivers reported being well informed, or very well informed about the processes and stages of the patient's healthcare. 8% felt not at all informed.
- Caregivers preferred sources of information on lymphoma and CLL are doctors (94%), followed by the internet (63%), and patient organization (54%).

❖ Figure 98 illustrates that 53% of caregivers say the patient and caregiver were jointly seeking out information and details about the disease and potential treatments.

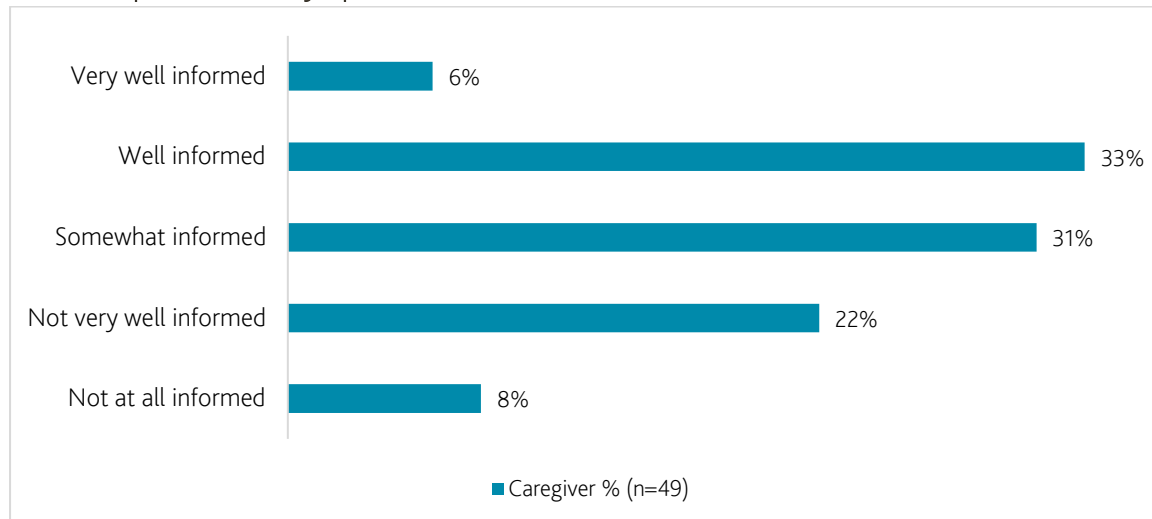
Figure 98. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



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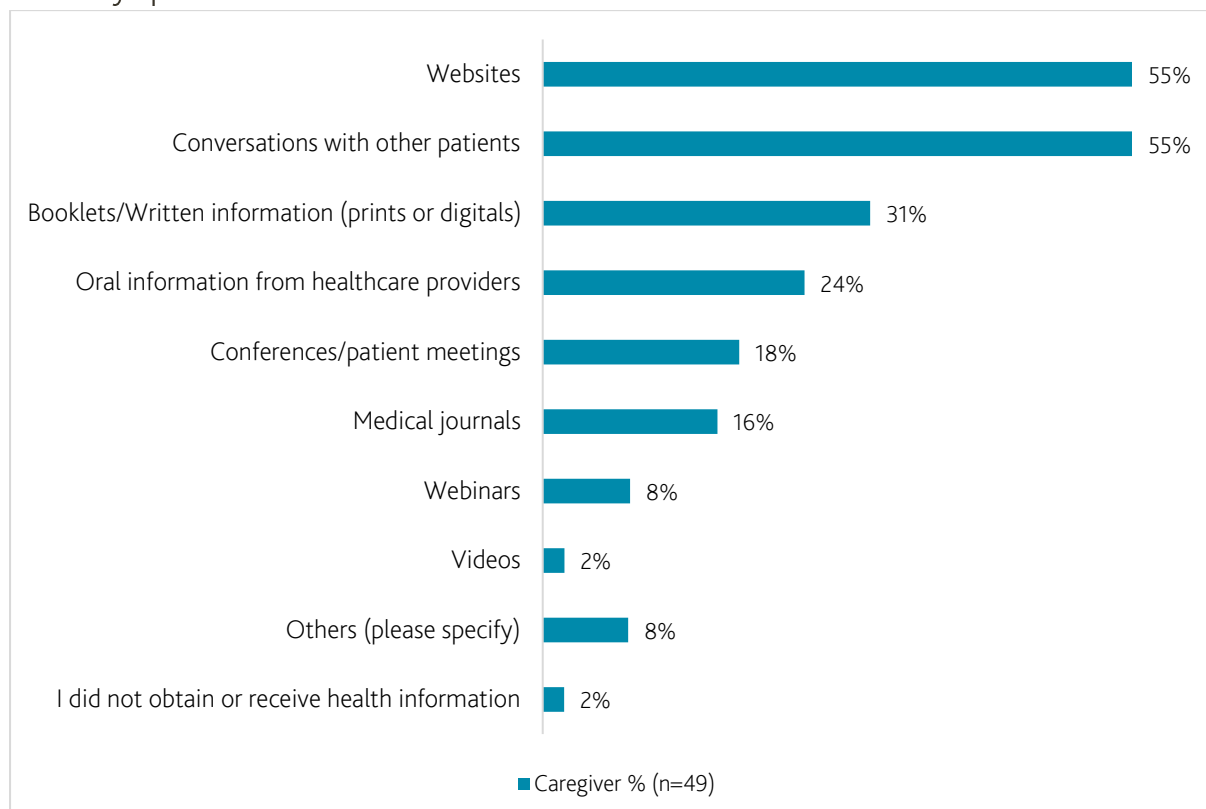
- ❖ Figure 99 reveals that 8% of caregivers felt not at all or not very well informed about the processes and stages of their patient's healthcare.

Figure 99. 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 100 explains that 55% of caregivers prefer websites and the same percent prefer conversations with other patients as their method for obtaining or receiving health information about lymphoma or CLL, followed by booklets/ written information (31%).

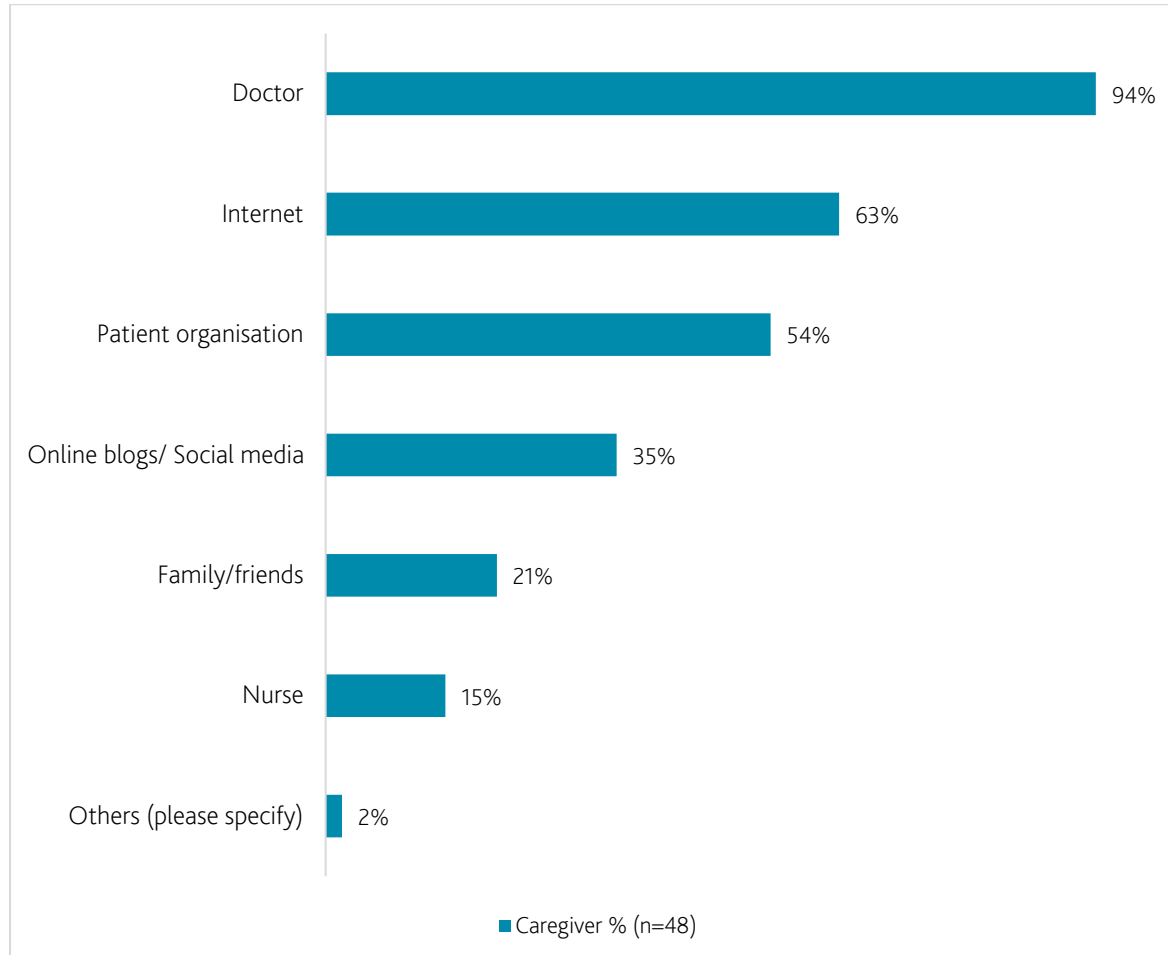
Figure 100. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



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- ❖ Figure 101 reveals that 94% of caregivers chose doctors as their preferred source of lymphoma or CLL information, followed by the internet (63%) and patient organisations (54%).

Figure 101. 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 64% of caregivers rank doctors as their number 1 source of lymphoma or CLL information.

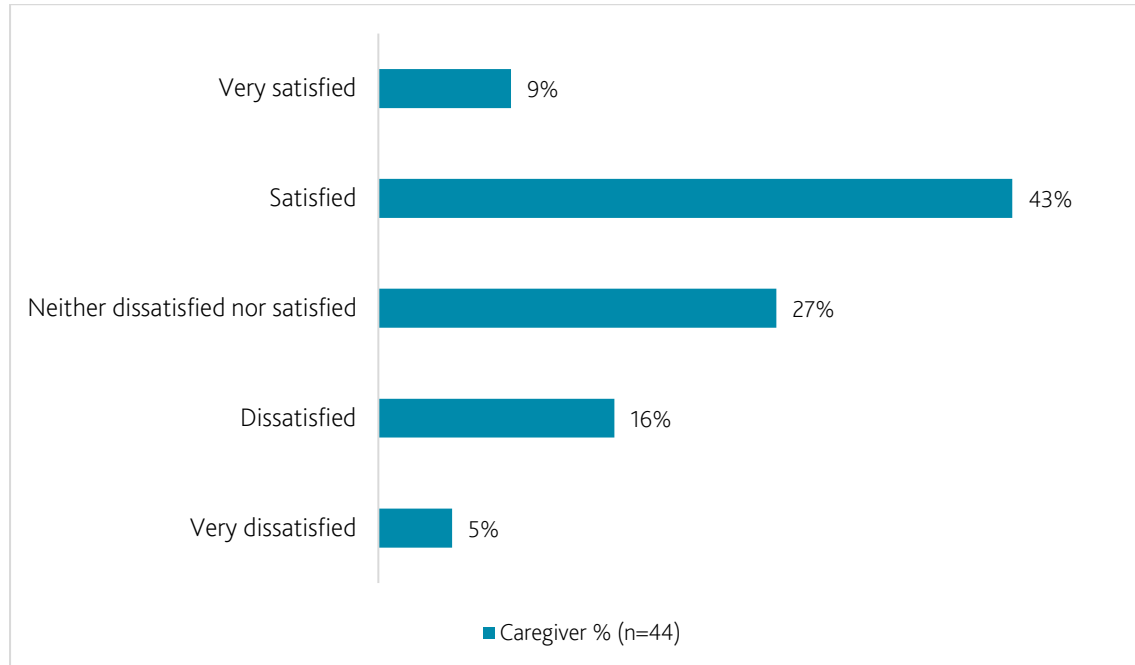
Table 5. Rank your top three sources of lymphoma or CLL information that you most prefer.

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	18	64%	4	15%	4	15%
Nurse	0	0%	2	7%	2	7%
Internet	6	21%	6	22%	11	41%
Online blogs/ social media	3	11%	3	11%	2	7%
Family/friends	0	0%	1	4%	2	7%
Patient organisation	1	4%	11	41%	6	22%
Total	28	100%	27	100%	27	100%

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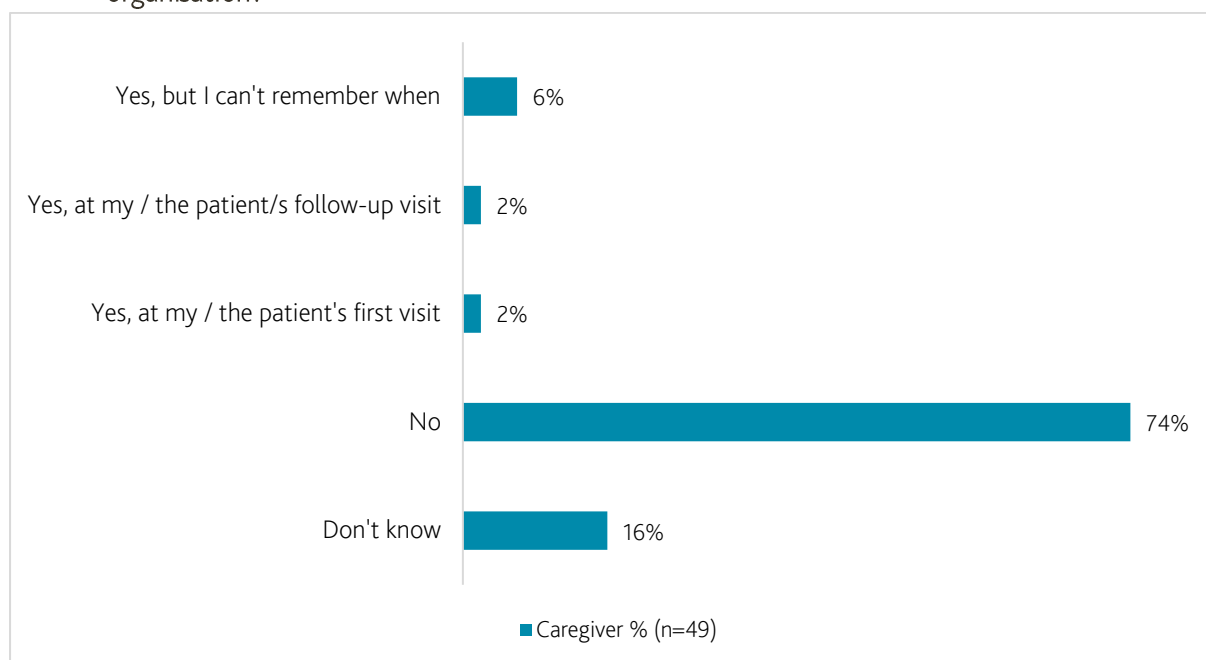
- ❖ Figure 102 shows that 43% of caregivers were satisfied with the information given by healthcare providers. *Only asked to those who indicated doctors as an information source.*

Figure 102. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, and nurses)?



- ❖ Figure 103 illustrates that almost three-quarters of caregivers did not receive patient organisation contact details or information from their patient's doctor.

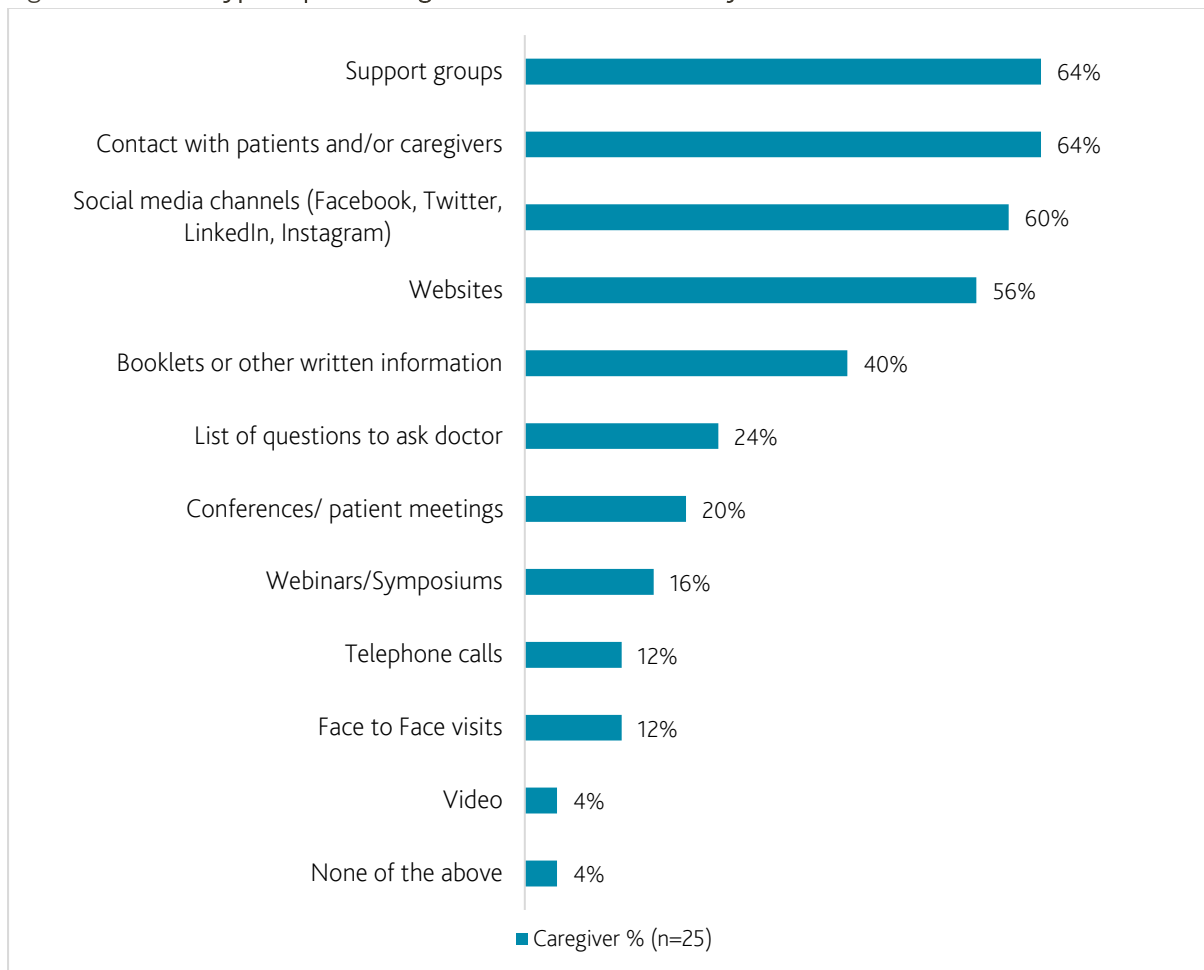
Figure 103. Did the lymphoma or CLL doctor or any member of the medical team give you the contact details of a patient organisation, a support group and/or information produced by a patient organisation?



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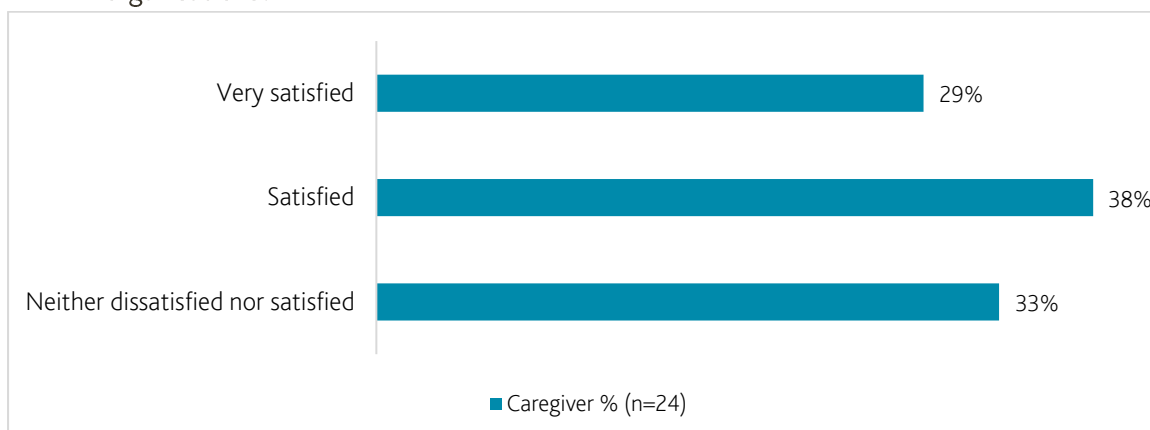
- ❖ Figure 104 reveals that almost two-thirds of caregivers use patient organisations' support groups. *Only asked to those who selected patient organisations as a preferred source of information.*

Figure 104. What type of patient organisation information do you use?



- ❖ Figure 105 illustrates that over a quarter of caregivers were satisfied with the information provided by patient organisations. *Only asked to those who selected patient organisations as a preferred source of information.*

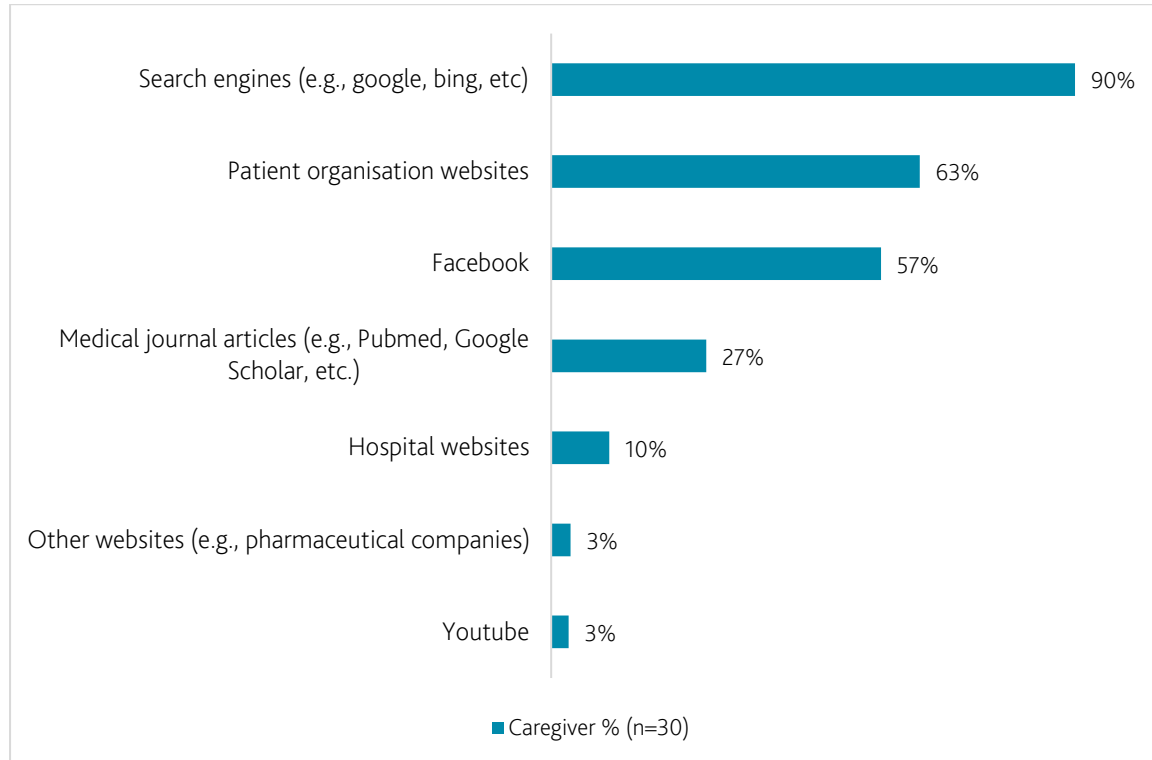
Figure 105. How satisfied or unsatisfied are you with the information given to you by patient organisations?



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- ❖ Figure 106 reveals that 90% of caregivers, when searching for lymphoma or CLL information on the internet, use search engines. *Only asked to those who selected the internet as a preferred source of information.*

Figure 106. Where on the internet do you usually get your lymphoma or CLL information from?



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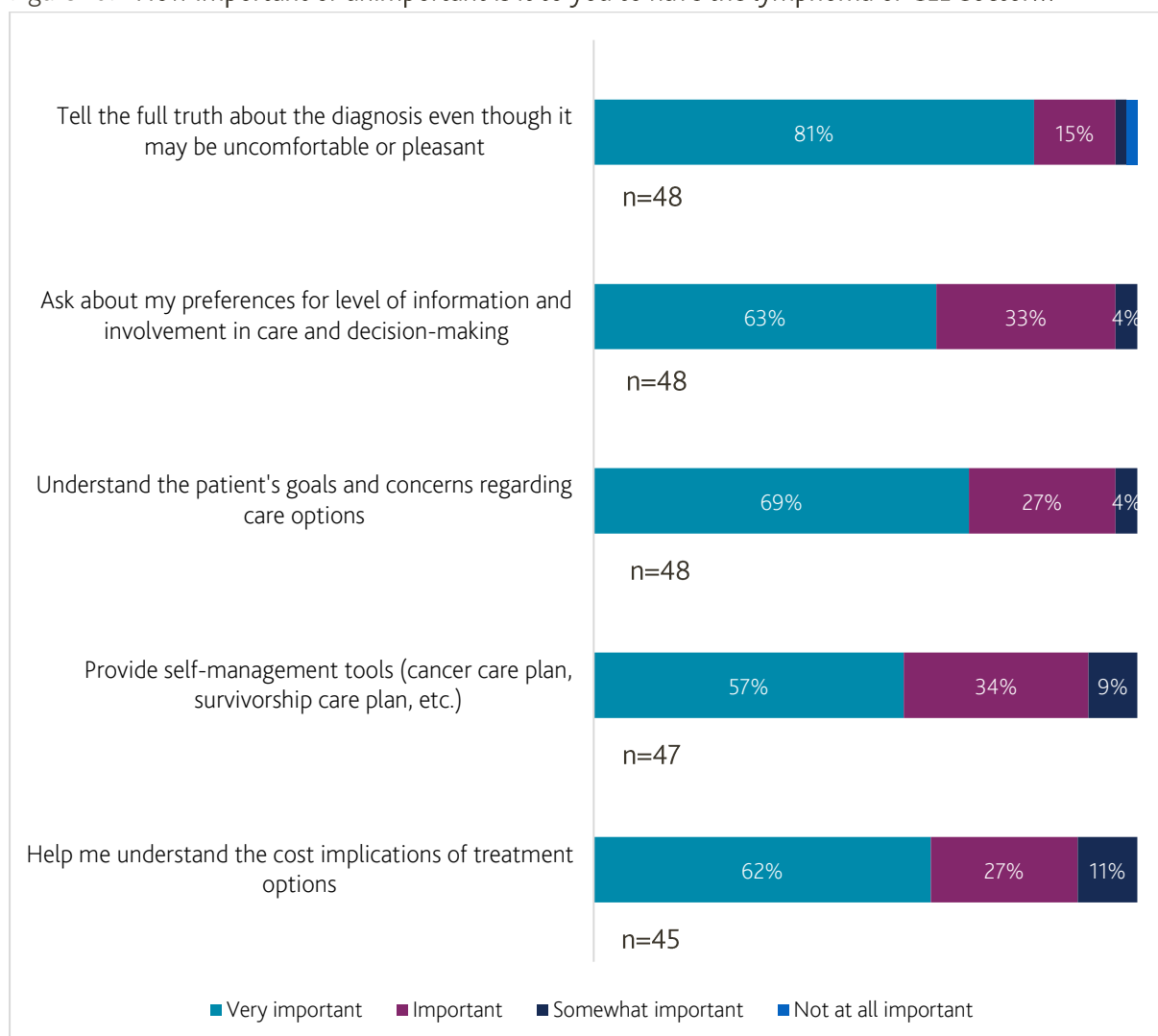
Healthcare Involvement and Decision Making



- For 89% of caregivers, it is important or very important that the lymphoma doctor help them understand the cost implications of treatment options.
- For 96% of caregivers, it is important or very important to know that doctors tell the full truth about the diagnosis even though it may be uncomfortable or unpleasant.
- 65% of caregivers think that for the final decision about a patient's healthcare, doctor, patient and caregiver or family should be involved in the final decision.

❖ Figure 107 illustrates that the majority of caregivers felt that all the factors listed were very important/ important for the doctor to do.

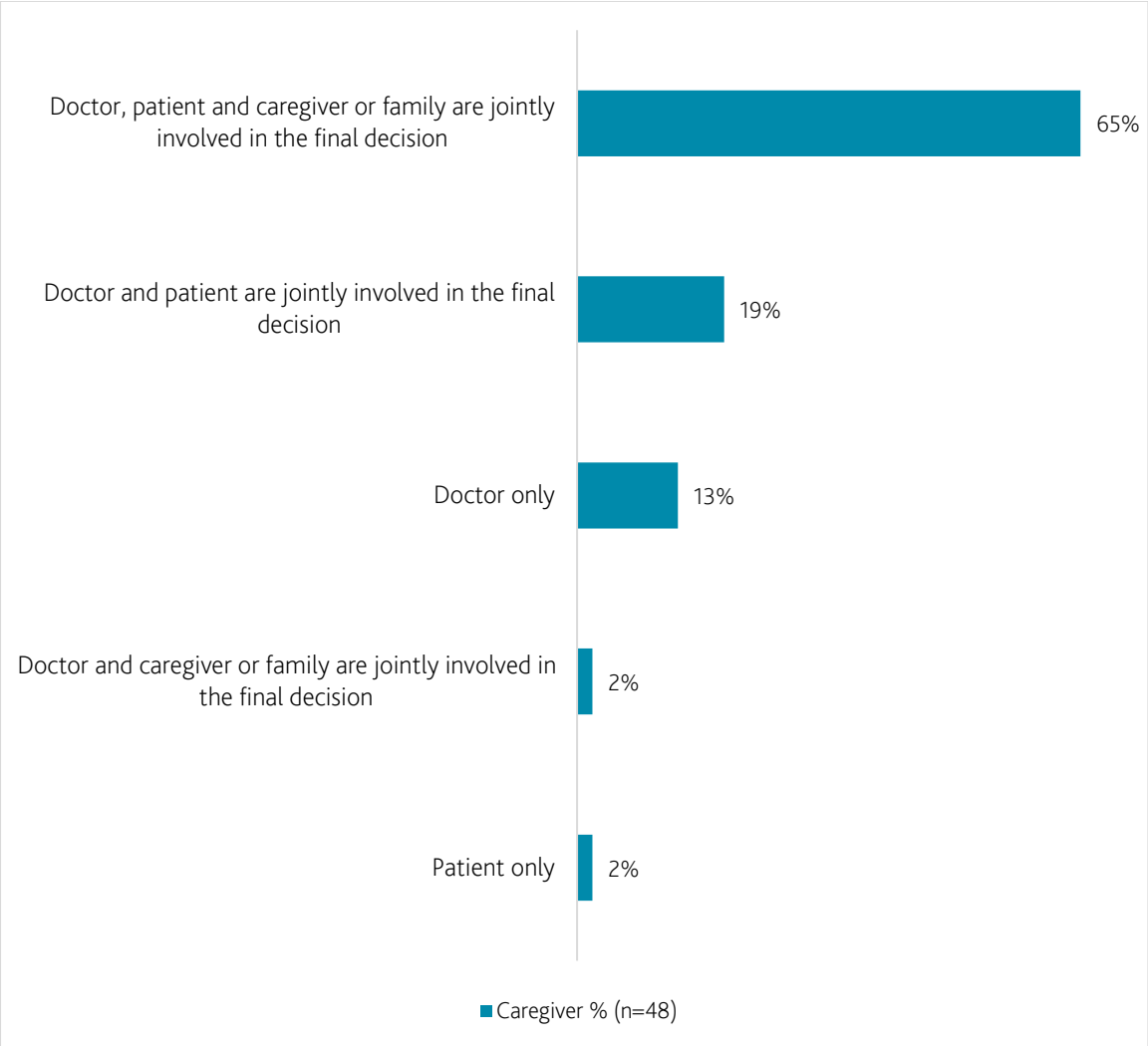
Figure 107. How important or unimportant is it to you to have the lymphoma or CLL doctor...



GPS 2022: Country Report - Bulgaria

- ❖ Figure 108 reveals that 65% of caregivers felt that the doctor, patient and caregiver or family should be involved in the final decision on the patient's healthcare.

Figure 108. Who would you like to make the final decision on the patient's healthcare?



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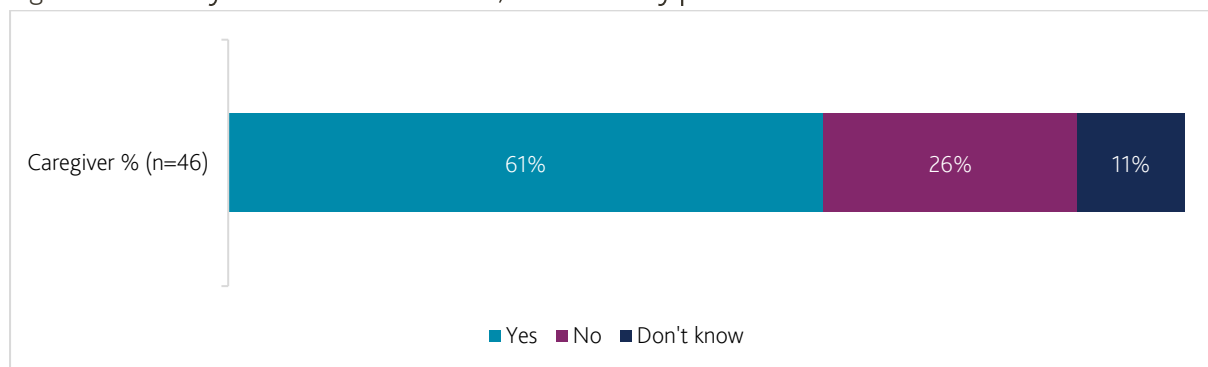
Covid-19 Concerns and Virtual Care



- 61% of caregivers had contracted Covid-19, at some point before or during the survey.
- 20% of caregivers had been fully vaccinated and taken a booster dose, while 35% were not vaccinated and not planning to get vaccinated.
- 78% of caregivers considered the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19, and that it worried them.

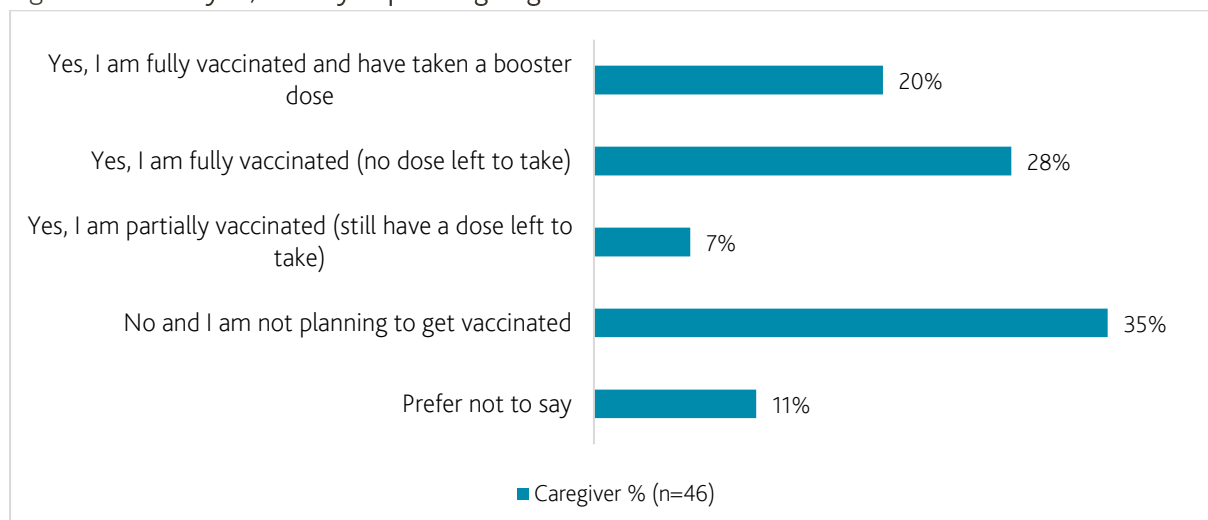
- ❖ Figure 109 reveals that almost two-thirds (61%) of the caregivers had contracted Covid-19 at any point.

Figure 109. Have you contracted Covid-19, now or at any point?



- ❖ Figure 110 shows that over a third of caregivers were not vaccinated and not planning on getting vaccinated.

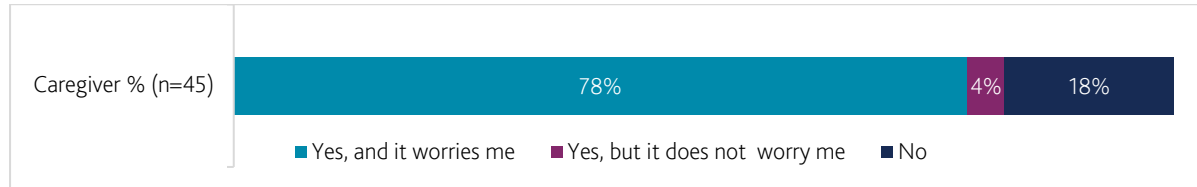
Figure 110. Have you, or are you planning to get the Covid-19 vaccine?



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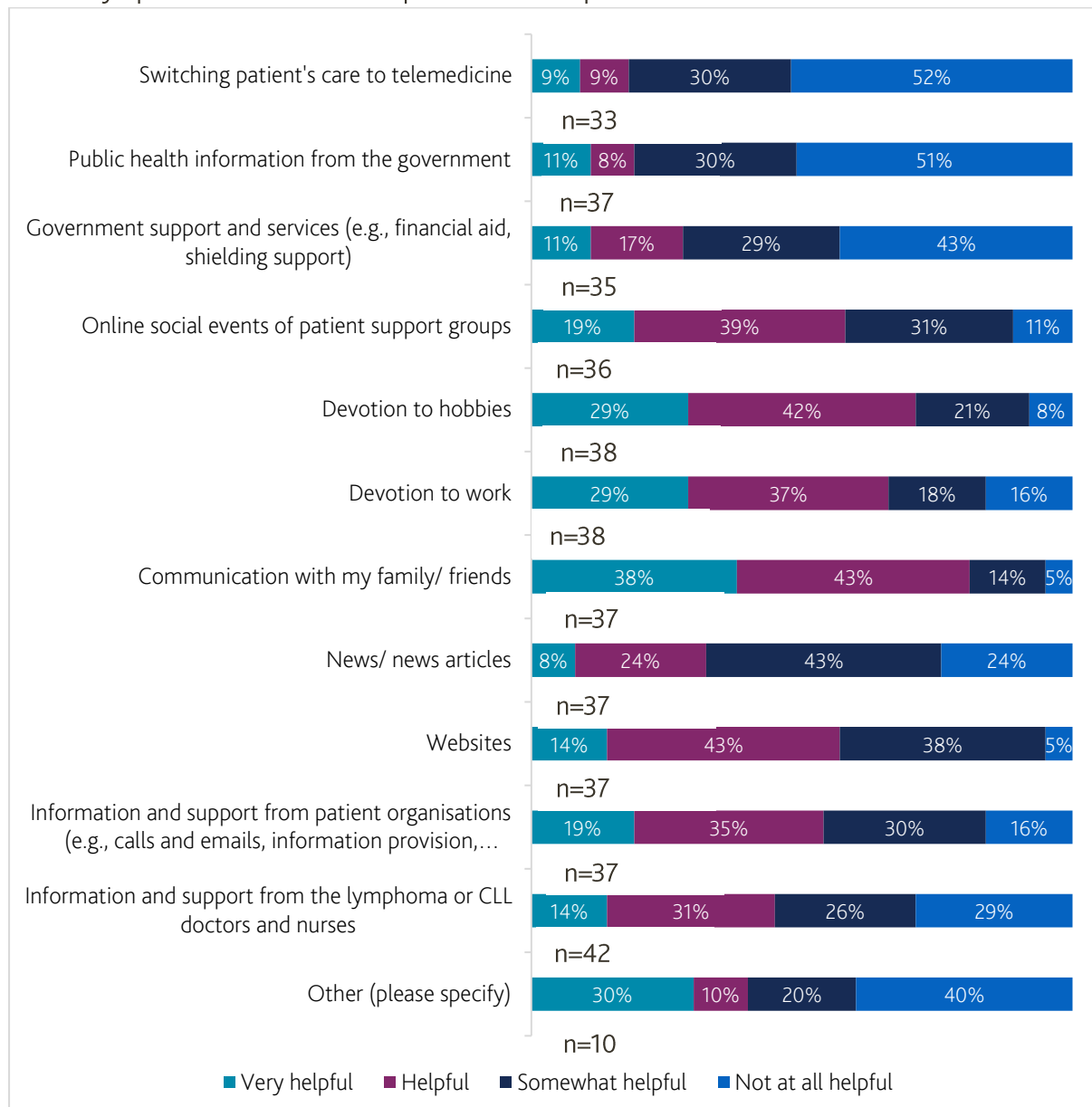
- ❖ Figure 111 shows two-thirds of caregivers considered their patients as high risk for contracting Covid-19, and it worries them.

Figure 111. Do you consider the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?



- ❖ Figure 112 illustrates that 81% of caregivers felt that communication with family and friends have been helpful/very helpful in providing support regarding the impact of Covid-19 lymphoma or CLL.

Figure 112. 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

Figure 1. Sex of patient.....	16
Figure 2. Age range of respondents	16
Figure 3. Which best describes the area you live in?	17
Figure 4. How do you identify your ethnicity?.....	17
Figure 5. What is your highest educational level completed?.....	17
Figure 6. Which of the following best describes your employment status?.....	18
Figure 7. Which of the following best describes your household status?	18
Figure 8. How long ago were you diagnosed with lymphoma or CLL?	19
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?.....	20
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?	20
Figure 11. How many healthcare professionals did you see about your symptoms before receiving the current diagnosis?	21
Figure 12. What subtype of lymphoma do you have?	22
Figure 13. What statement best describes where you are in the lymphoma/CLL experience?	23
Figure 14. Has the lymphoma or CLL ever relapsed?.....	23
Figure 15. You have said that you are in remission, how long has it been since the last treatment?	24
Figure 16. How long have you been in active monitoring (watch and wait)?.....	24
Figure 17. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?.....	24
Figure 18. When first diagnosed, were you told the lymphoma subtype?.....	25
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.)?	26
Figure 20. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?	26
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?	27
Figure 22. During your meetings with your lymphoma or CLL doctor, did you receive any information about clinical trials?	27
Figure 23. Were you aware that a clinical trial can sometimes give you access to the best treatment?	27
Figure 24. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?	28
Figure 25. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?.....	29
Figure 26. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, nurses)?	30
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?	30
Figure 28. What type of patient organisation information do you use?	31
Figure 29. Top 5 information sources of patient organisations ranked 1-5.....	32
Figure 30. How satisfied or unsatisfied are you with the information given to you by patient organisations?.....	33
Figure 31. Where on the internet do you usually get your lymphoma or CLL information from?.....	33

GPS 2022: Country Report - Bulgaria

Figure 32. Have you ever seen a specialist (e.g., haematologist, oncologist, dermatologist) for your lymphoma subtype?	34
Figure 33. Have you been seeing the same specialty physician (e.g., haematologist, oncologist, dermatologist) throughout your patient experience?	35
Figure 34. Did/do you have lymphoma care provided by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator?	35
Figure 35. Which of the following, if any, have you found useful in providing supportive care, outside of the specialty physician?	36
Figure 36. Do you have a dedicated first point of contact within the cancer care team?	36
Figure 37. Which of the following statements reflects how you feel about your experience living with a chronic cancer?	37
Figure 38. 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.	38
Figure 39. In thinking about the transition from cancer care into survivorship, please indicate how much you agree or disagree with the following statement	39
Figure 40. 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?	40
Figure 41. Do you feel as involved as much as you want to be, in decisions about your care and treatment?	41
Figure 42. 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?	41
Figure 43. Who would you like to make the final decision on your healthcare?	42
Figure 44. Does your doctor do any of the following to encourage participation in decision-making about your care?	43
Figure 45. How important or unimportant is it to you to have the lymphoma or CLL doctor?	44
Figure 46. Did you receive a medical treatment (e.g., chemotherapy, radiation) for lymphoma or CLL within the last 2 years?	46
Figure 47. Which of the following treatment options, if any do you receive currently, or have ever received in the past?	47
Figure 48. Are you currently, or have you ever been in a clinical trial for your lymphoma?	48
Figure 49. How many lines of treatment have you/the patient received to date for lymphoma?	48
Figure 50. Were interchangeable/equivalent drugs (e.g., generic, biosimilars, pharmaceutical equivalents), used during your treatment?	49
Figure 51. Did your medical team give you any information about treatment side effects on fertility and about fertility preservation opportunities prior to treatment?	49
Figure 52. 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?	50
Figure 53. During your experience so far with lymphoma or CLL, were any of following used alongside conventional cancer treatments?	50
Figure 54. 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)?	51
Figure 55. What, if any, of the following would you consider to be an important feature of a new medical treatment for lymphoma or CLL?	51
Figure 56. What, if anything, has made getting treatment more difficult?	54

GPS 2022: Country Report - Bulgaria

Figure 57. What, if anything, would prevent you from participating in a clinical trial?.....	55
Figure 58. Which of the following side effects, if any, have you been affected by (highlighted the side effects that affected patients the most)?.....	57
Figure 59. 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?	58
Figure 60. What specifically did the doctor do to help?	58
Figure 61. 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?	59
Figure 62. 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).....	60
Figure 63. Which of the following areas/ activities, if any, has your fatigue affected over the last two years?.....	61
Figure 64. Have you discussed your fatigue with your doctor over the last two years?.....	62
Figure 65. Did your doctor follow up with you about the fatigue you were experiencing?.....	62
Figure 66. Which information types did your doctor provide you with?	63
Figure 67. Have you found any of the following options helpful in managing cancer-related fatigue?...63	
Figure 68. In the last 12 months, have you personally experienced any of the following as a result of the lymphoma diagnosis?	65
Figure 69. For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with a doctor?	66
Figure 70. 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.....	66
Figure 71. Did your doctor follow up with you about the psychosocial issues you were experiencing? ..67	
Figure 72. Have you contracted Covid-19, now or at any point?	68
Figure 73. Have you, or are you planning to get the Covid-19 vaccine?	69
Figure 74. Do you consider yourself at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?.....	69
Figure 75. Did you avoid or delay seeking medical attention for your lymphoma or CLL during the Covid-19 pandemic?	69
Figure 76. 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.....	70
Figure 77. Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.....	71
Figure 78. Please describe your level of depression during the Covid-19 pandemic, compared to your level of depression before the Covid-19 pandemic.	71
Figure 79. Which of the following were contributing factors for the worsened anxiety and/or depression?	72
Figure 80. Were you scheduled to receive treatment for your lymphoma or CLL when Covid-19 restriction was an issue in your community?.....	73
Figure 81. Did you experience any of the following changes to your care due to Covid-19?	73
Figure 82. Regarding your use of telemedicine (telephone consultation (TC) or video consultation (VC)), how much do you agree or disagree with the following statements?	74
Figure 83. Gender of the caregiver	75
Figure 84. Age range of caregivers.....	76
Figure 85. Which best describes the area you live in?	76
Figure 86. How do you identify your ethnicity?.....	76

GPS 2022: Country Report - Bulgaria

Figure 87. What is your highest educational level completed?.....	77
Figure 88. Which of the following best describes your employment status?	77
Figure 89. Which of the following best describes your household status?.....	78
Figure 90. What is your relationship to the person you are providing care and support to?	78
Figure 91. How long ago was the patient diagnosed with lymphoma or CLL?.....	79
Figure 92. How long have you been providing cancer-related care and support to the person with lymphoma or CLL?	79
Figure 93. What subtype of lymphoma does the patient have?	80
Figure 94. What statement best describes where the person you care for is in the lymphoma or CLL experience?	81
Figure 95. Has the lymphoma or CLL ever relapsed?	82
Figure 96. How many lines of treatment has the patient received to date for lymphoma?	82
Figure 97. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))? ...	82
Figure 98. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?	83
Figure 99. 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?.....	84
Figure 100. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?	84
Figure 101. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?.....	85
Figure 102. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, and nurses)?	86
Figure 103. 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?	86
Figure 104. What type of patient organisation information do you use?	87
Figure 105. How satisfied or unsatisfied are you with the information given to you by patient organisations?	87
Figure 106. Where on the internet do you usually get your lymphoma or CLL information from?	88
Figure 107. How important or unimportant is it to you to have the lymphoma or CLL doctor... ..	89
Figure 108. Who would you like to make the final decision on the patient's healthcare?.....	90
Figure 109. Have you contracted Covid-19, now or at any point?.....	91
Figure 110. Have you, or are you planning to get the Covid-19 vaccine?.....	91
Figure 111. Do you consider the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?	92
Figure 112. 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.....	92