LYMPHOMA COALITION

2022 Global Patient Survey on Lymphomas & CLL

October 2022

Country Report

France

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SECTION 1

Overview

Overview

Lymphoma Coalition (LC) is a non-profit organisation comprised of a worldwide network of patient advocacy groups that support those affected by lymphoma, including chronic lymphocytic leukaemia (CLL). LC was formed in 2002, launched its first web-based Global Patient Survey on Lymphomas & CLL (GPS) in 2008 and continues to conduct the GPS every second year. The goal of the GPS is to understand the patient and caregiver experience in lymphomas, including 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 France.

The overall number of completed responses was 1398, made up of:

1294 Patients

104 Caregivers

SECTION 2

Key Findings

Key Findings from Patients

Information, Guidance and Support

63% of patients felt well or very well informed about the processes and stages of their healthcare.

60% of patients reported doctors as their preferred source of information.

48% of patents would like doctors, and patients jointly involved in making healthcare decisions.

21% say the doctor did not explore the patient's preferences or understanding when making decisions about care.

Diagnosis and Treatment

53% of patients were told their lymphoma subtype at diagnosis.

Only 19% of patients were given more than one treatment option before their current or last therapy for lymphoma.

[redacted].

48% of patients indicated they had experienced fear of lymphoma relapse and 37% experienced fear of lymphoma progression.

60% of patients reported nothing had made getting treatment more difficult.

[redacted].

[redacted].

61% 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

32% patients reported their depression was somewhat worse during the Covid-19 pandemic, and 14% said it was much worse.

31% of patients reported their anxiety was somewhat worse during the Covid-19 pandemic and 26% said it was much worse.

47% of patients experienced changes to their lymphoma care due to Covid-19.

Only 4% of patients strongly agreed and 4% agreed that they preferred telephone consultation or video consultation to face-to-face visit.

Patient organisations were identified by 64% of patients as very helpful or helpful sources of information and support during the COVID-19 pandemic.

67% of patients found doctors & nurses very helpful or helpful sources of information and support during the pandemic.

Key Findings from Caregivers

60% of caregivers felt well or very well informed about the processes and stages of the patient's healthcare.

76% of caregivers reported doctors as their preferred source of information.

63% of caregivers think that for the final decision about a patient's healthcare should involve, the doctor, patient and caregiver or family.

79% of caregivers report seeking out additional information about the patient's diagnosis, above what they were told by the medical team.

SECTION 3

Background

Background

Lymphoma Coalition

http://www.lymphomacoalition.org/

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

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

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

Survey Research Centre

http://www.Uwaterloo.ca/src

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

Global Patient Survey

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

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

SECTION 4

Methodology

Methodology

Development of the 2022 GPS

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

Thematics for the 2022 GPS included the following:

Healthcare information and guidance

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

Healthcare support

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

Healthcare involvement and decision-making

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

Effects of lymphoma/CLL, treatment, and side effects

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

Impact of Covid-19

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

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

Data Collection

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

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

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

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

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

Data Cleaning

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

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

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

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

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

Data Dissemination

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

Examples of how the data is used and disseminated:

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

SECTION 5

Results

Patient Results

1294 people living with lymphoma/CLL responded to the 2022 GPS. The results in this section will report across the following areas:

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

Patient Characteristics

- Most responses were from patients aged 65 and above (55%), followed by patients 55-64 years old (23%), with the lowest survey respondents being 18-34 years old (4%).

- 80% of patients reported their ethnicity as Caucasian.

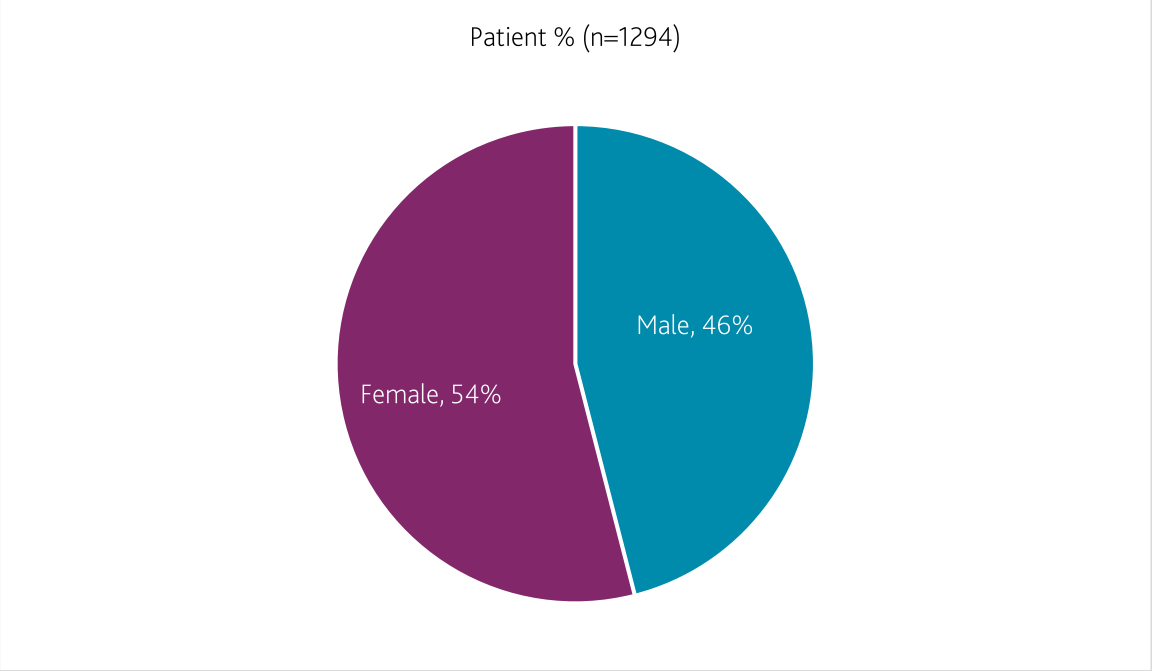
- The overall cohort of patient respondents (1294) represented 54% female and 46% male, with most respondents residing in rural areas (39%).

- Just over one-third (39%) of respondents completed post-secondary education (college/university), with a high rate (25%) having completed postgraduate education such as a master's or Ph.D.

- A majority reported they are retired (59%), and 22% are employed full-time. 4% of patients were unable to work for health-related reasons.

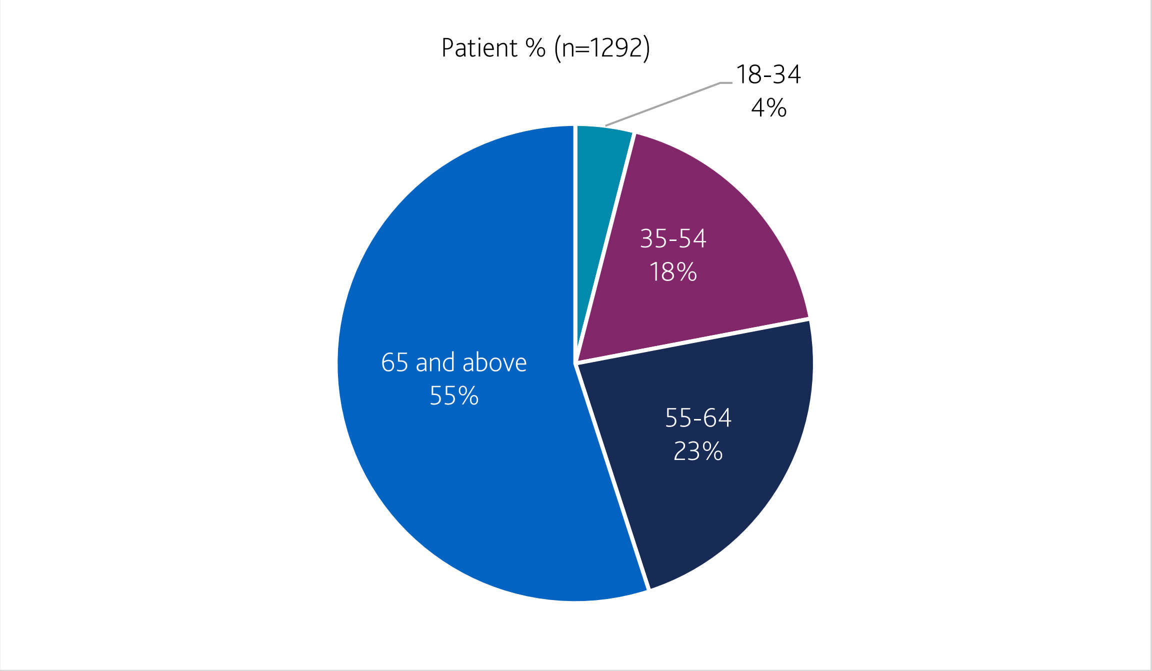
- Figure 1 shows a slightly higher response from female patients.

Figure 1. Sex of patient



- Figure 2 illustrates that more than half (55%) of patients are 65 and above.

Figure 2. Age range of respondents



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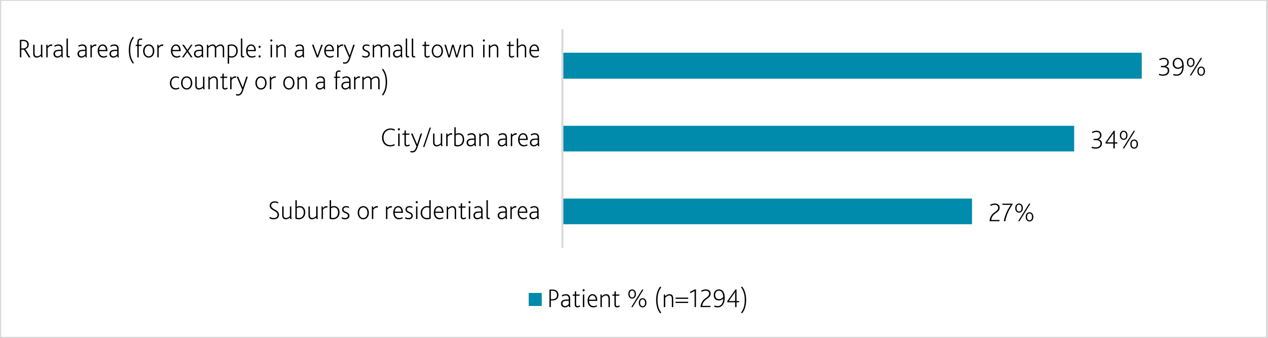
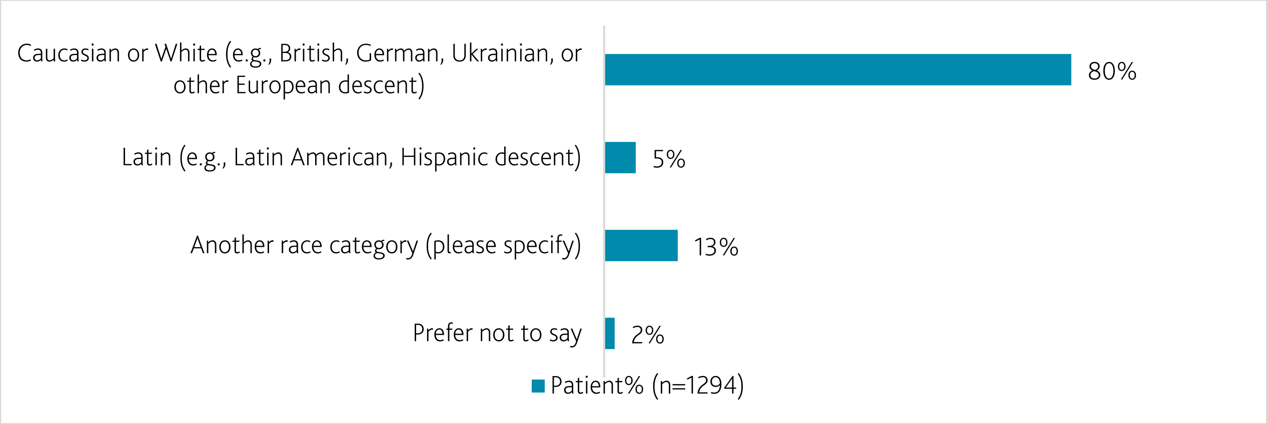
- Figure 3 shows respondents are slightly more likely to live in rural areas.

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



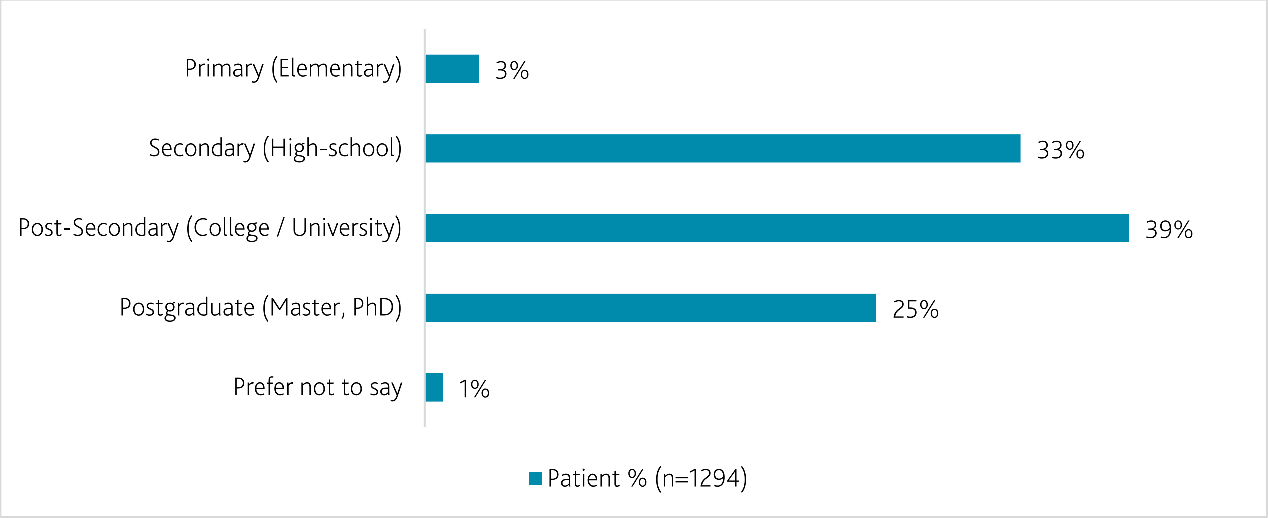
- Figure 4 indicates most patients identify as Caucasian.

Figure 4. How do you identify your ethnicity?



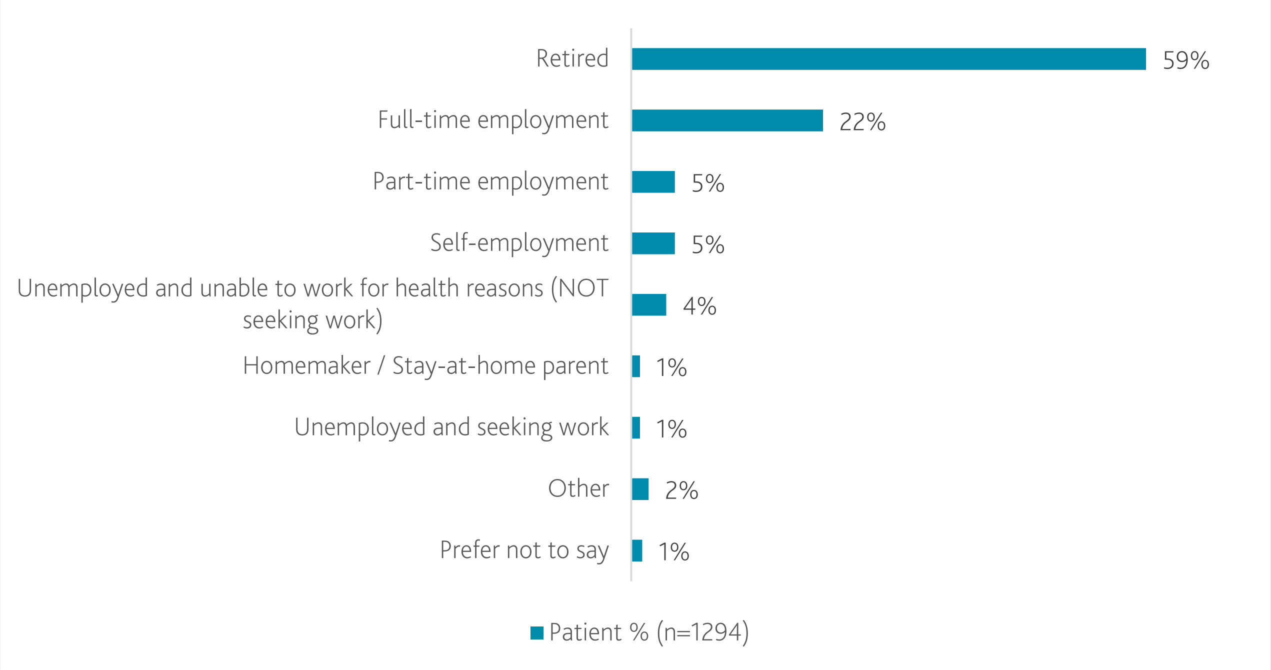
- Figure 5 illustrates the majority of patients have completed post-secondary education or higher (64%).

Figure 5. What is your highest educational level completed?



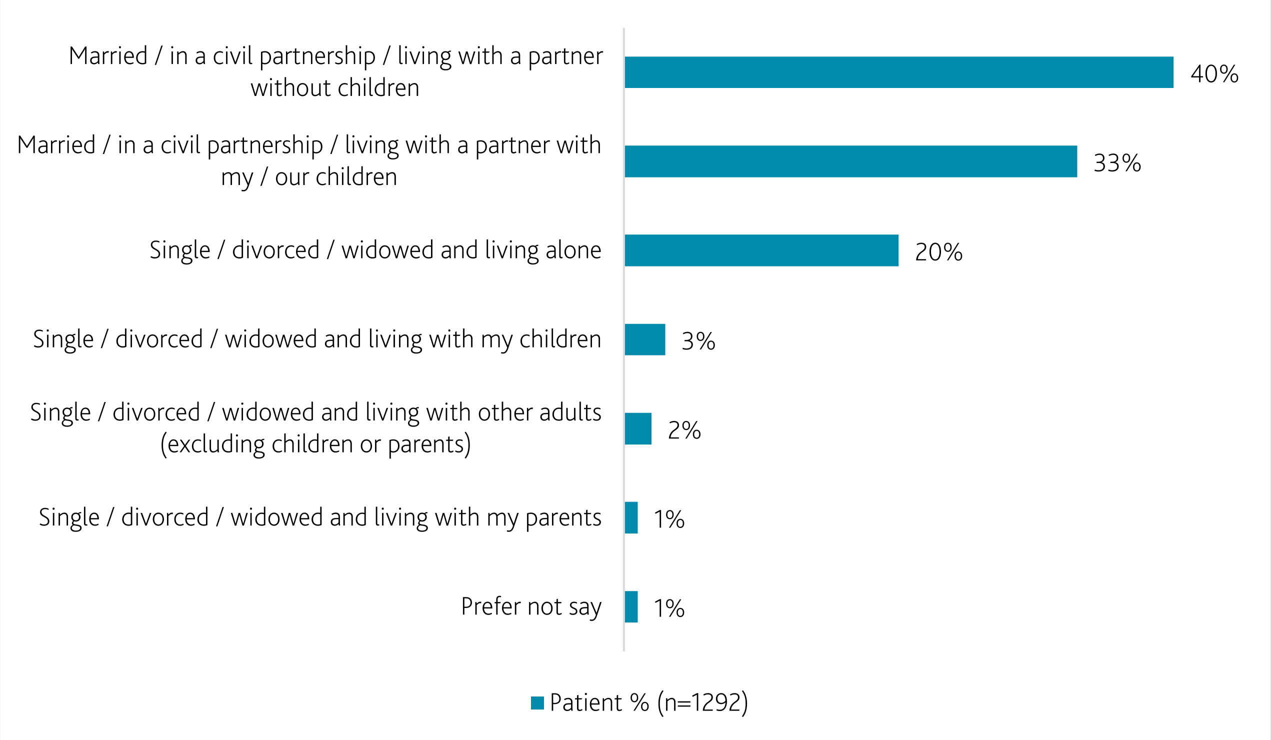
- Figure 6 shows over half (59%) of patients are retired.

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



- Figure 7 reveals 73% of patients live with a partner; most without children in the home.

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



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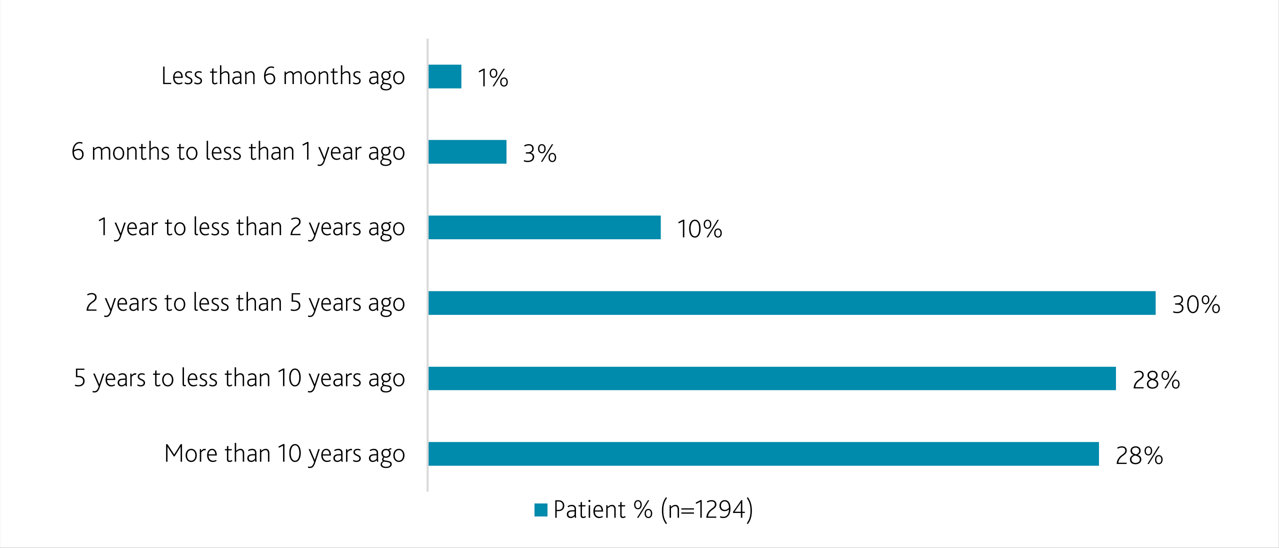
Diagnostic Demographics

- 56% of patients who responded to the survey were diagnosed 5+ years ago.
- 30% of patients were seen by three or more healthcare professionals for their symptoms before receiving their initial diagnosis, with 5% seen by five or more.
- Almost a quarter of patients (22%) experienced their symptoms for more than six months before seeking medical care.
- 58% 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, 22% had to wait longer than six months from when they met with their family physician or sought care for their symptoms before they received a diagnosis.
- The top five reported subtypes were chronic lymphocytic leukaemia (CLL) / small lymphocytic lymphoma (37%), follicular lymphoma (15%), diffuse large B-Cell lymphoma (11%), Waldenstrom's macroglobulinemia (8%), and Hodgkin 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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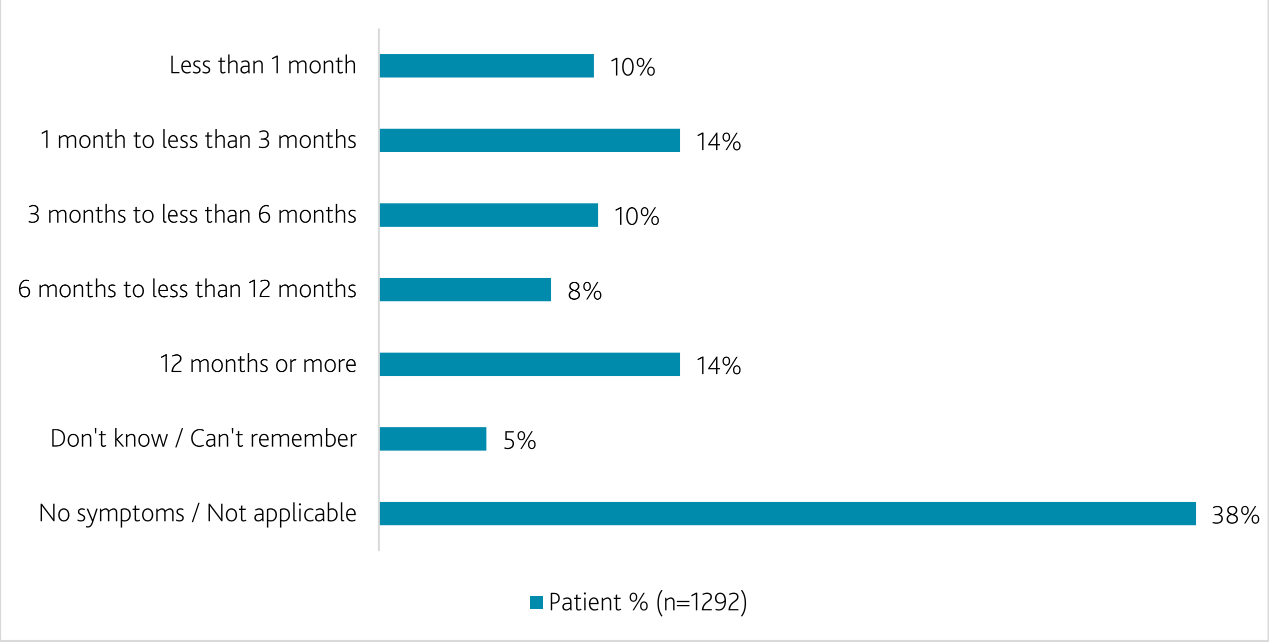
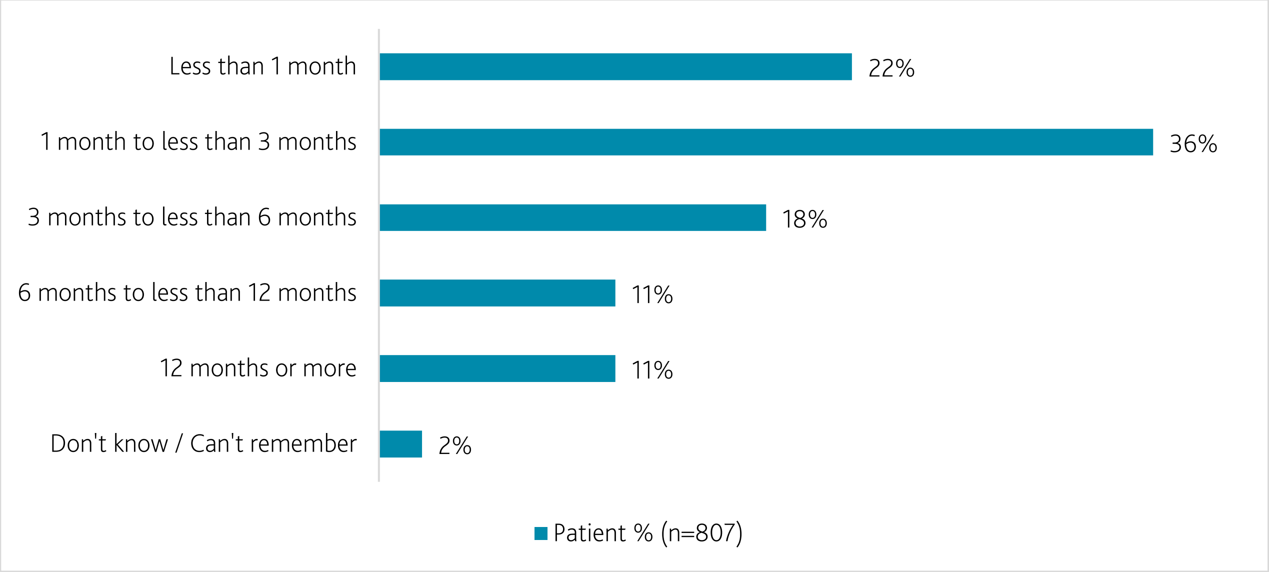
- Figure 9 shows there is a lot of variation in how long patients reported waiting to seek medical care about the symptoms they were experiencing. In addition, 38% of patients reported not having any symptoms.

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



- Figure 10 illustrates over half (58%) of patients had a diagnosis within 3 months of their first appointment, but 22% waited 6 months or more.

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



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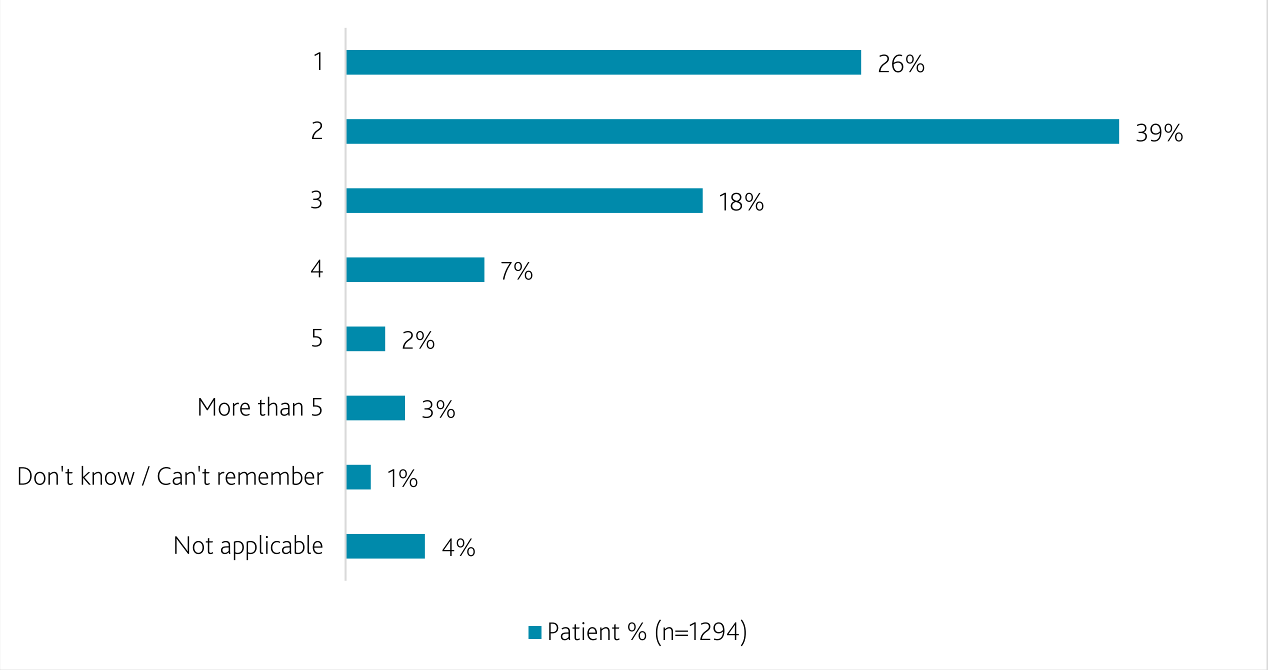
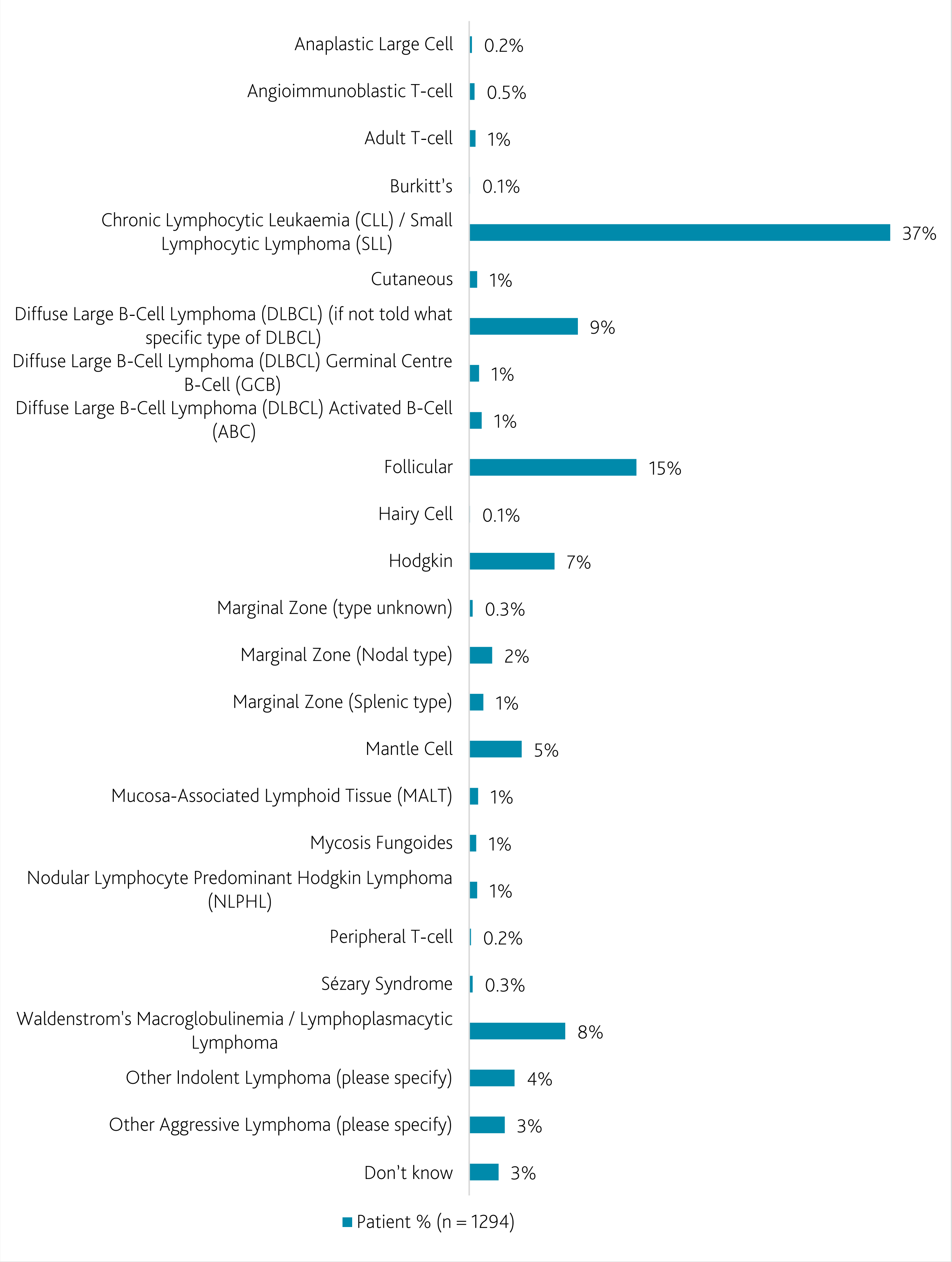
- Figure 11 reveals almost 40% patients saw 2 healthcare professionals before receiving their current diagnosis.

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



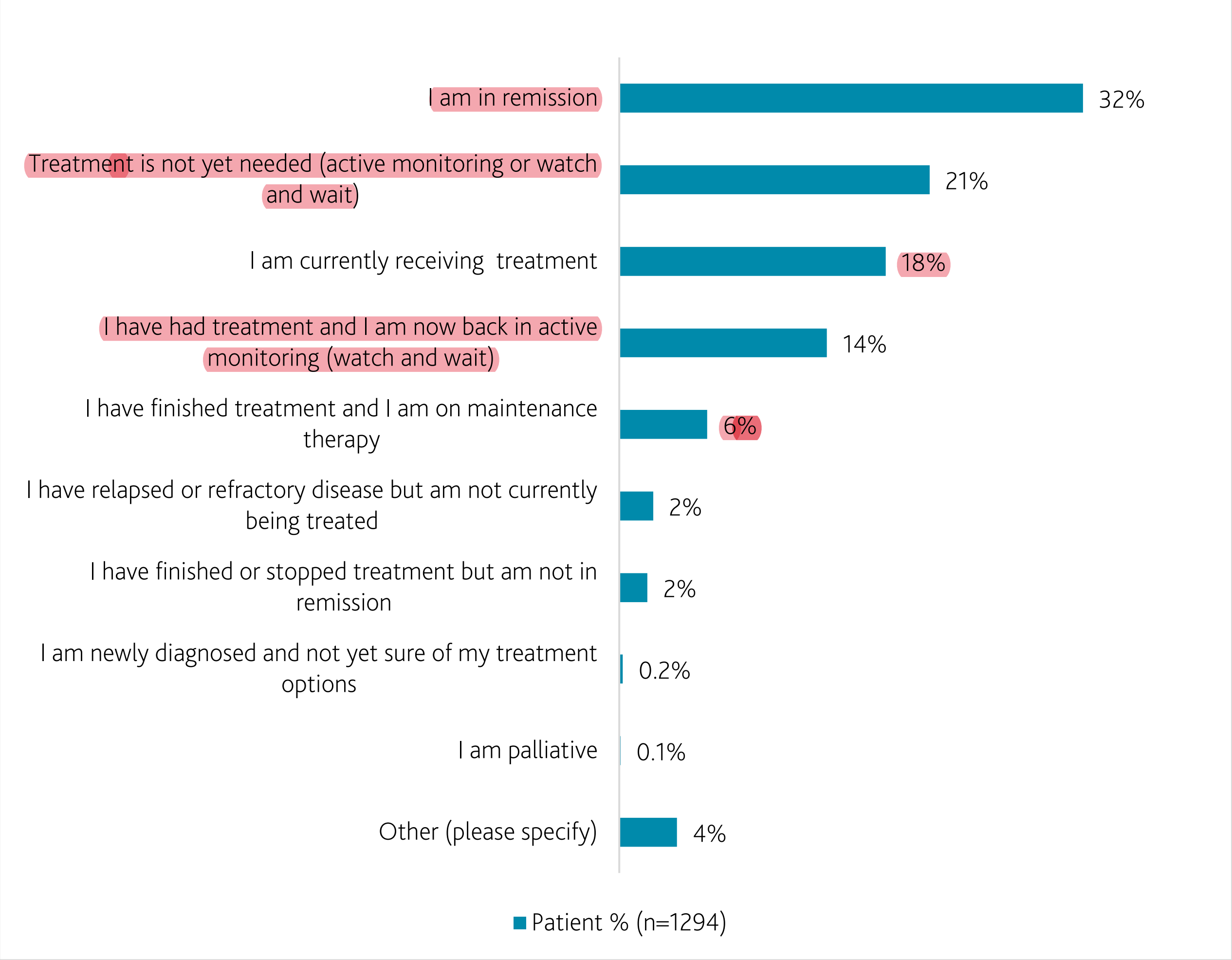
- Figure 12 illustrates that over a third of respondents were diagnosed with CLL/SLL.

Figure 12. What subtype of lymphoma do you have?



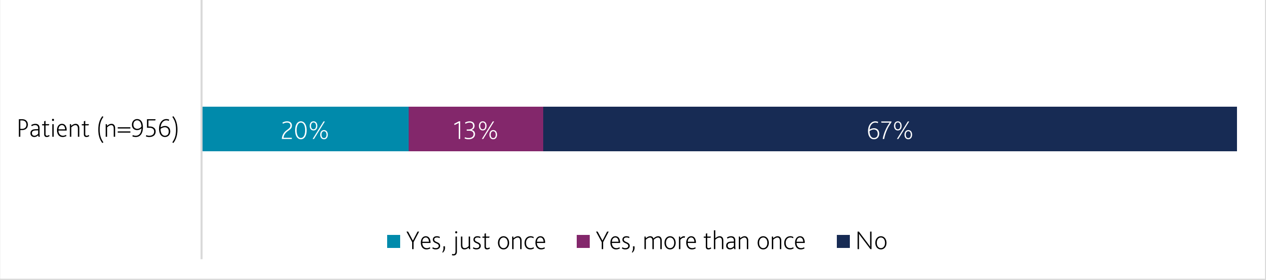
- Figure 13 shows a third (32%) of patients are in remission.

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



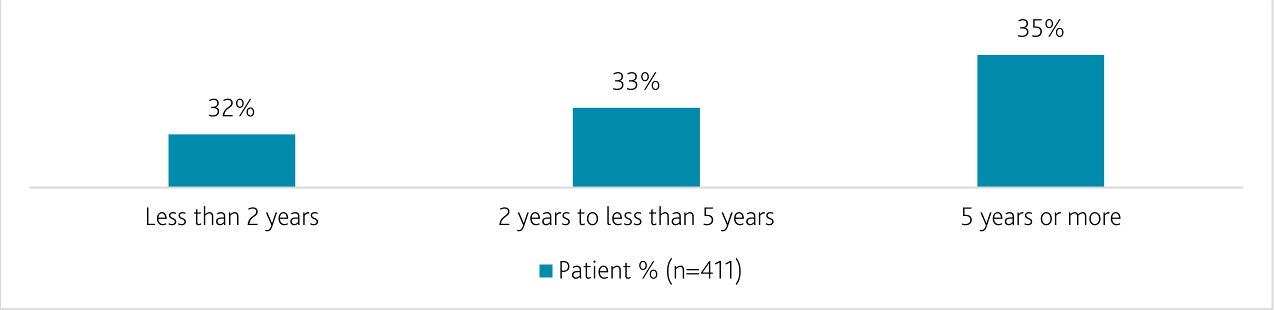
- Figure 14 illustrates that two-thirds of patients who have been treated have not experienced a relapse of their lymphoma or CLL. Only asked to those who have received or are receiving treatment.

Figure 14. Has the lymphoma or CLL ever relapsed?



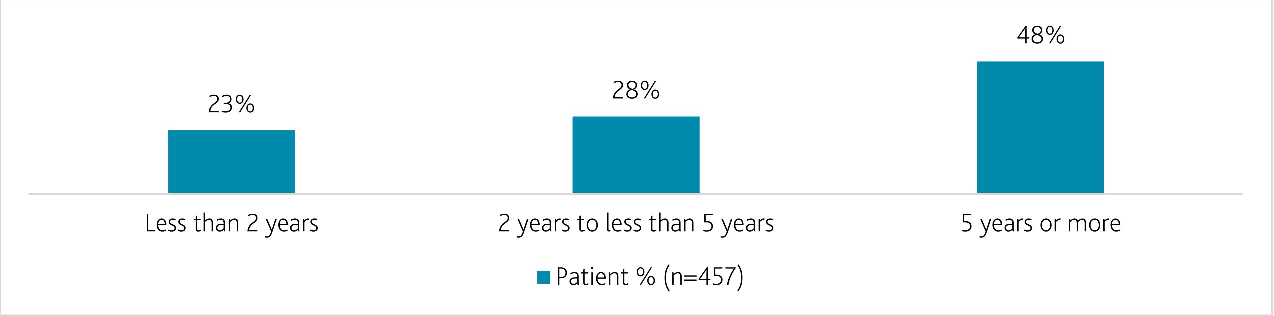
- Figure 15 explains when patients indicating they were in remission were asked how long they have been treatment-free, there is almost an even split between the options provided. Only asked to those who selected they were in remission.

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



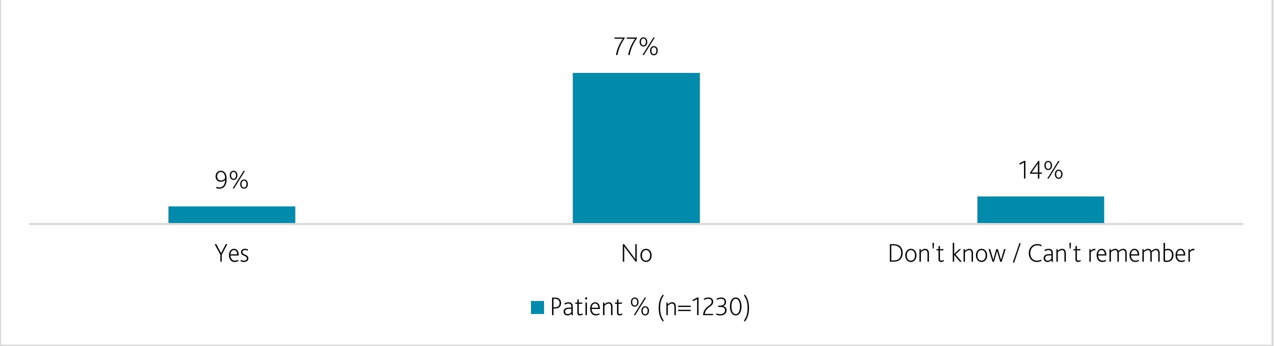
- Figure 16 shows when patients in active surveillance were asked how long they had been monitoring, the majority (48%) said 5 years or more. Only asked to those who selected they were in active monitoring.

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))?



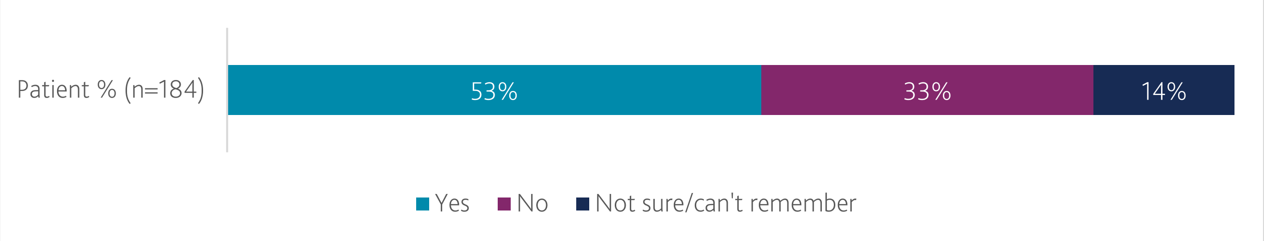
Healthcare Information and Guidance

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.

- Half of patients (53%) were told their subtype at diagnosis.
- 21% of the patients did not seek additional information other than what the doctor/ healthcare staff told them.
- For those who were seeking out information and details about their disease and potential treatment following their diagnosis, 62% said it was the patients doing this alone and the preferred method of obtaining this information for over half of the patients (60%) was via oral information from healthcare providers.
- Two-thirds of the patients (65%) felt the results they had received about their disease and diagnostic tests were explained well, and they understood the explanations.
- 35% of patients indicated they did not feel well informed about the processes and stages of their health.
- 56% did not receive details for a patient organisation, a support group, and/or information produced by a patient organisation from their healthcare team. But 76% of those who received information from patient organisations were very satisfied or satisfied with the information.

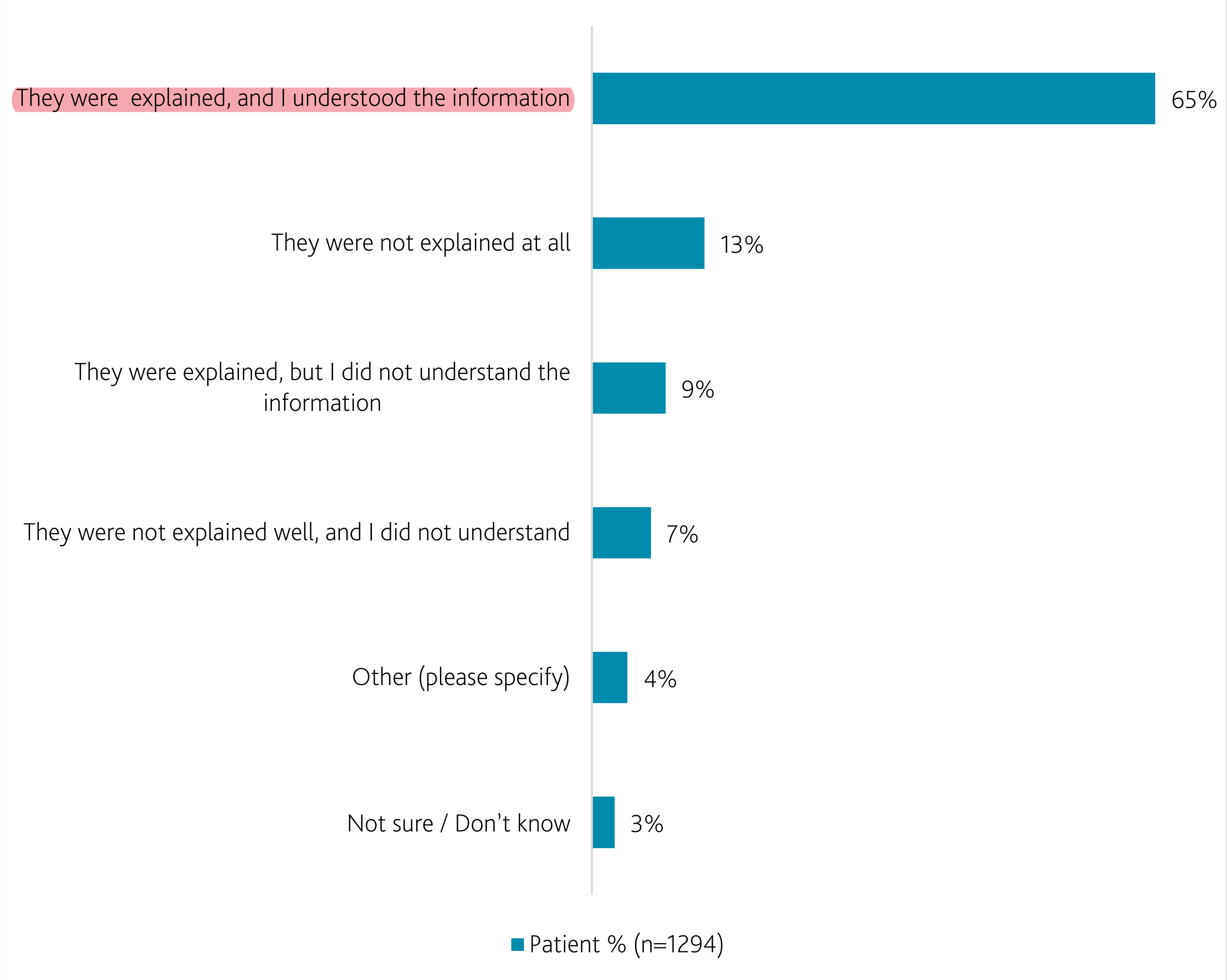
- Figure 18 illustrates that over half of the patients were told their lymphoma subtype when first diagnosed. This question was only asked to those who were diagnosed less than 2 years from survey time.

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



- Figure 19 reveals 81% of patients had their diagnostic tests and results explained to them but only 65% 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.)?



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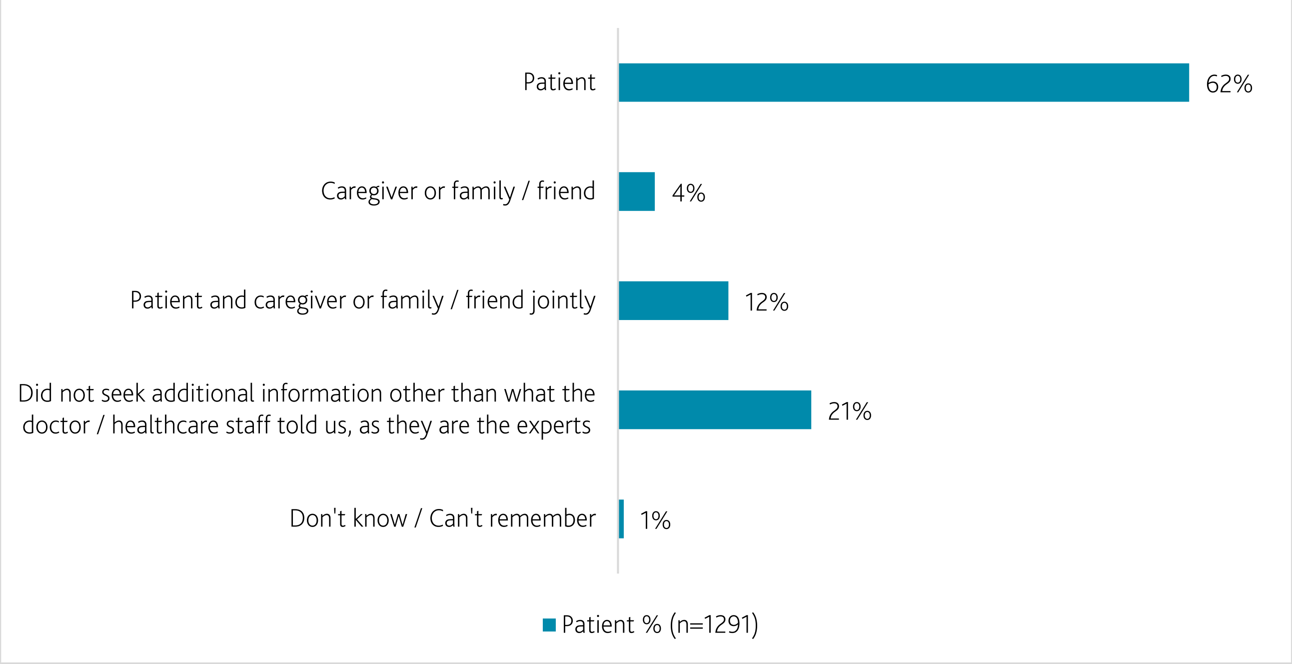
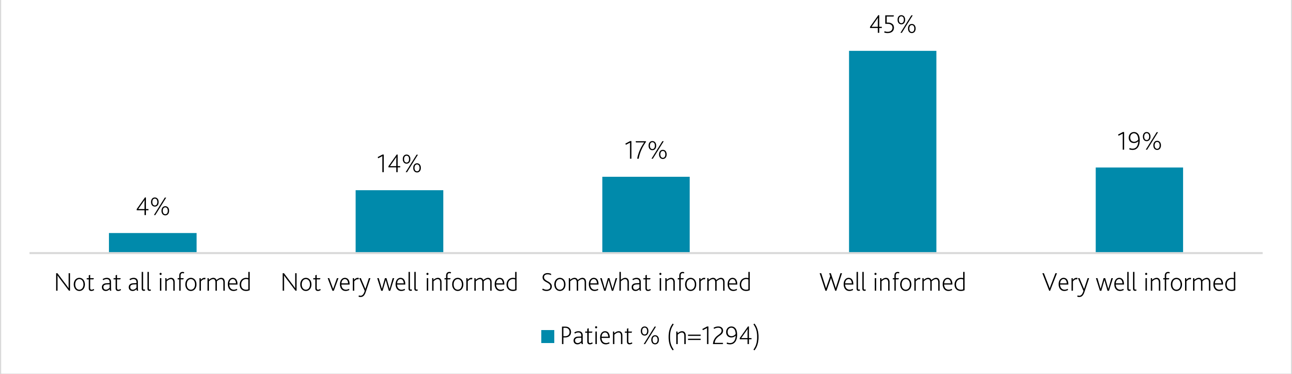
- Figure 20 shows the majority of patients sought out information and details about the disease and potential treatments. 62% of patients do this alone and 12% do it with a caregiver, family, or friend. 21% reported that they did not seek information other than what their doctor told them.

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



- Figure 21 illustrates a third of patients felt they were not well informed about the processes and stages of their healthcare throughout their experience

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



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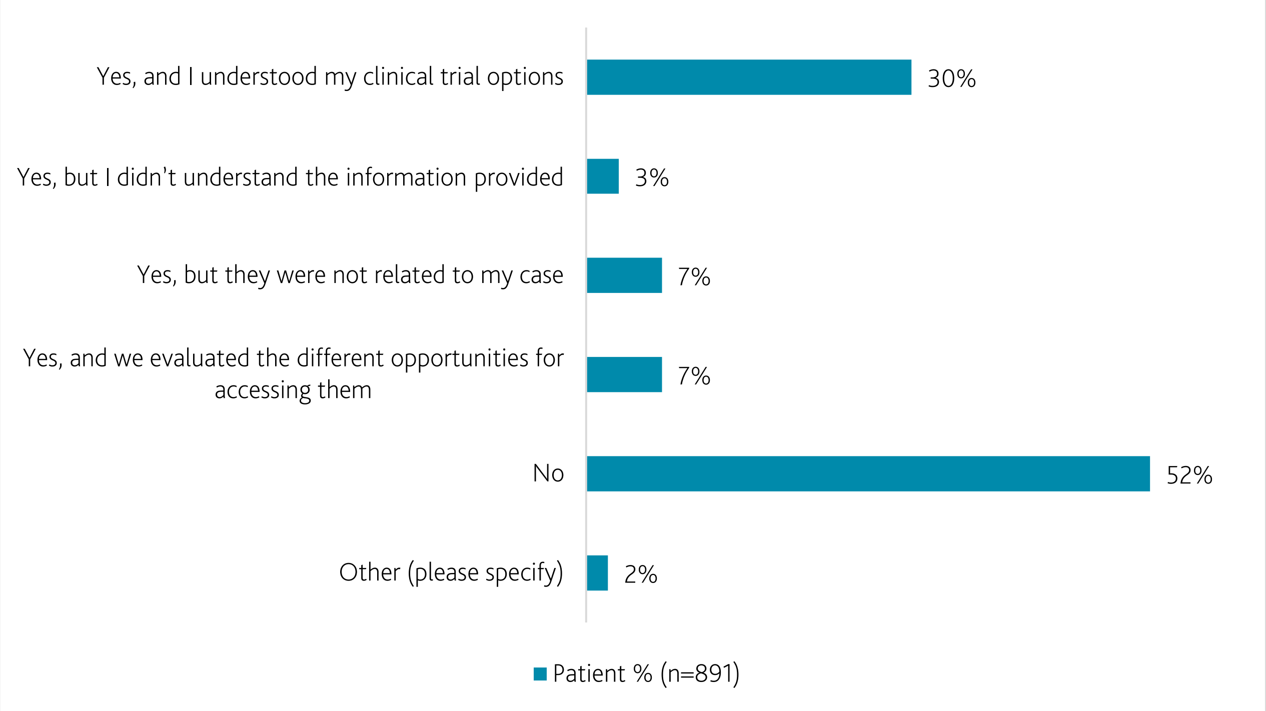
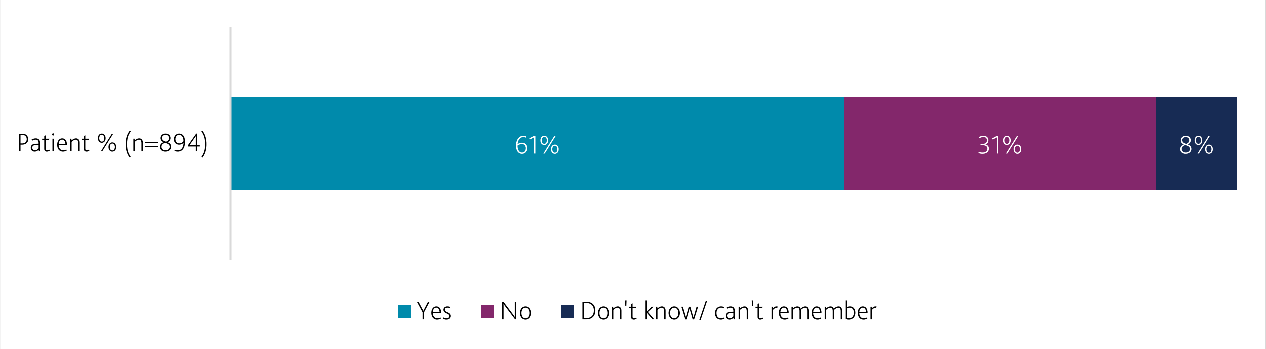
- Figure 22 reveals half of patients did not receive any information about clinical trials

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



- Figure 23 shows when asked about clinical trials, 61% of respondents said they were aware that a clinical trial can sometimes provide access to the best treatment

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



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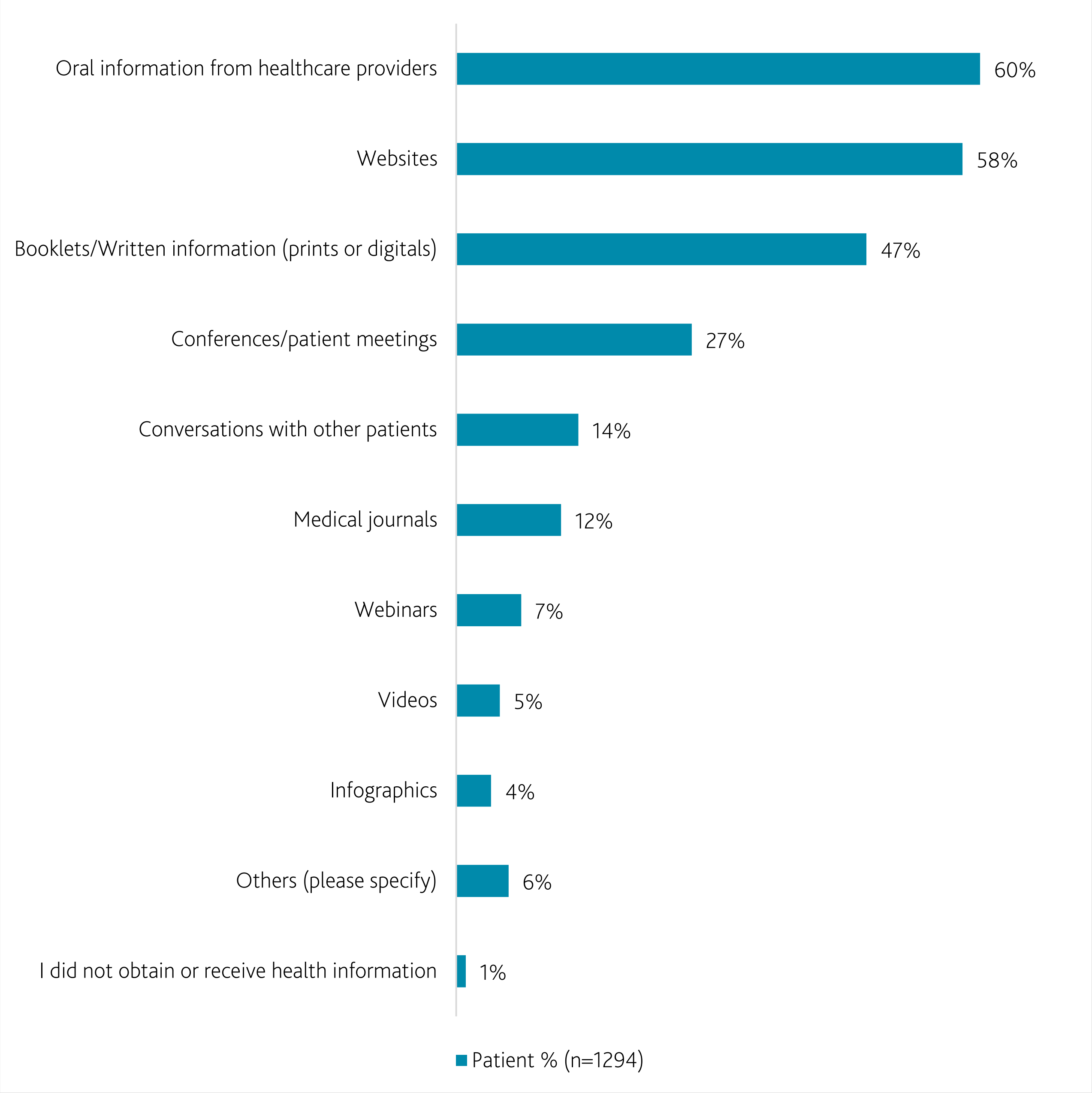
- Figure 24 reveals when patients were asked about receiving health information about lymphoma or CLL, the preferred methods were oral information from healthcare providers (60%), websites (58%), and booklets or written information (47%).

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



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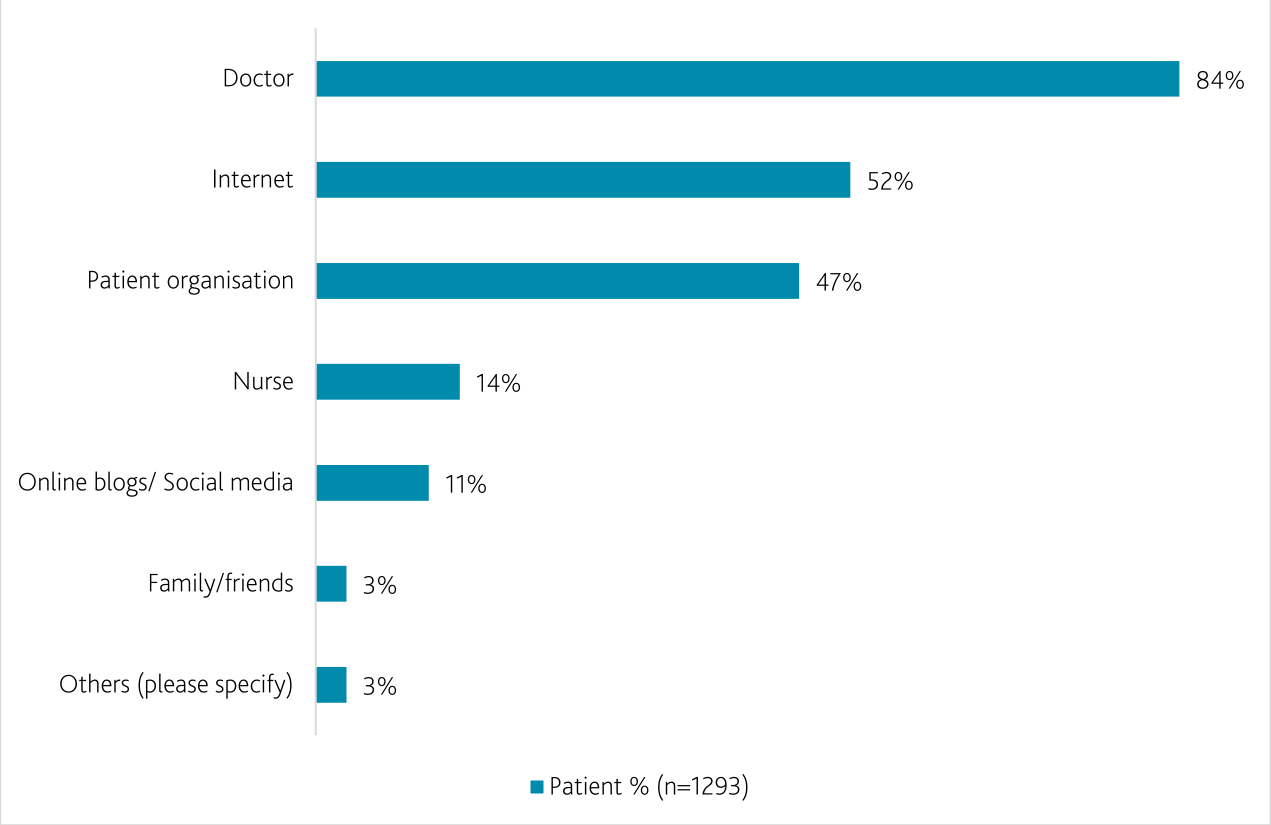
- Figure 25 shows patients preferred sources for information about lymphoma CLL included doctors (84%), the internet (52%), and patient organisations (47%).

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



- Table 1 illustrates when patients were asked to rank their preferred source of lymphoma or CLL information, most patients (68%) cited doctors as their top choice.

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

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	295	68%	73	17%	37	9%
Nurse	10	2%	76	18%	32	8%
Internet	39	9%	102	24%	187	45%
Online blogs/social media	17	4%	20	5%	43	10%
Family/friends	3	1%	10	2%	10	2%
Patient organisation	64	15%	140	33%	102	25%
Others (please specify)	4	1%	4	1%	3	1%
Total	**432**	100%	425	100%	414	100%

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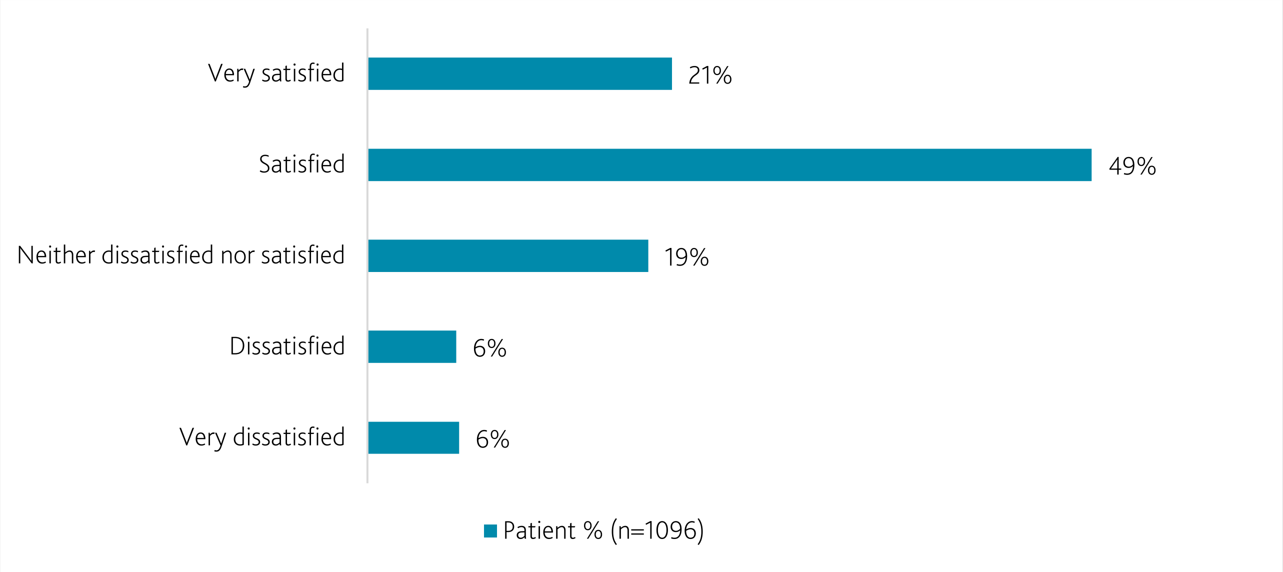
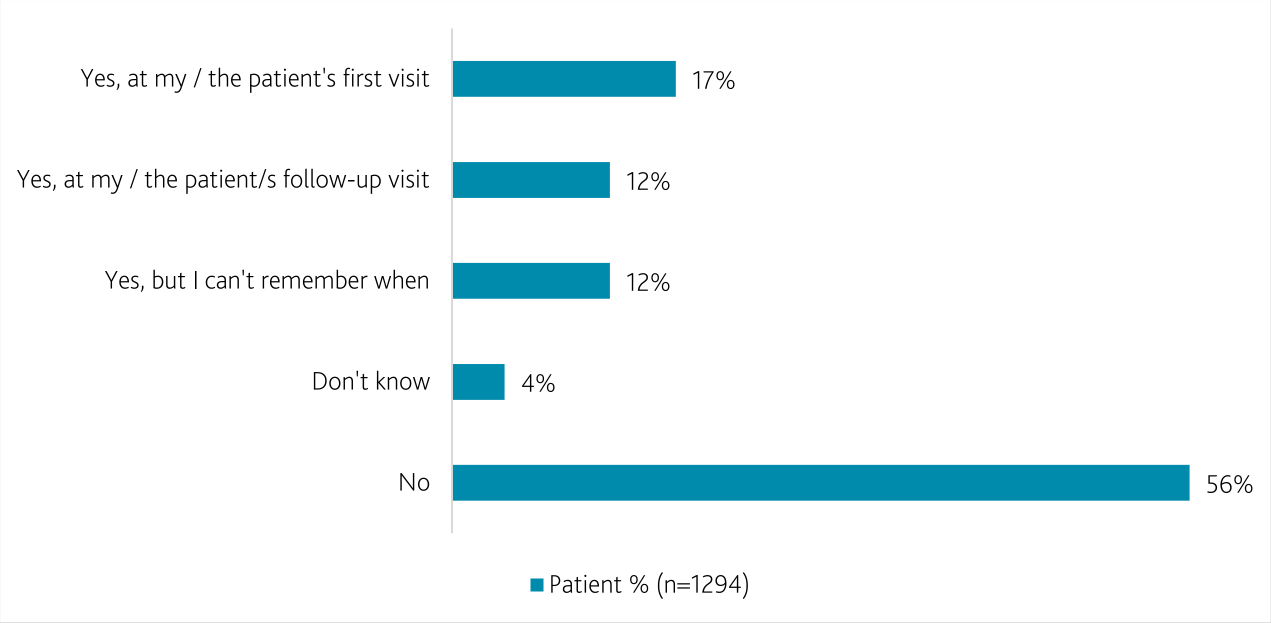
- Figure 26 reveals overall, the majority patients indicated they were satisfied with the information given to them by their healthcare team.

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



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

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



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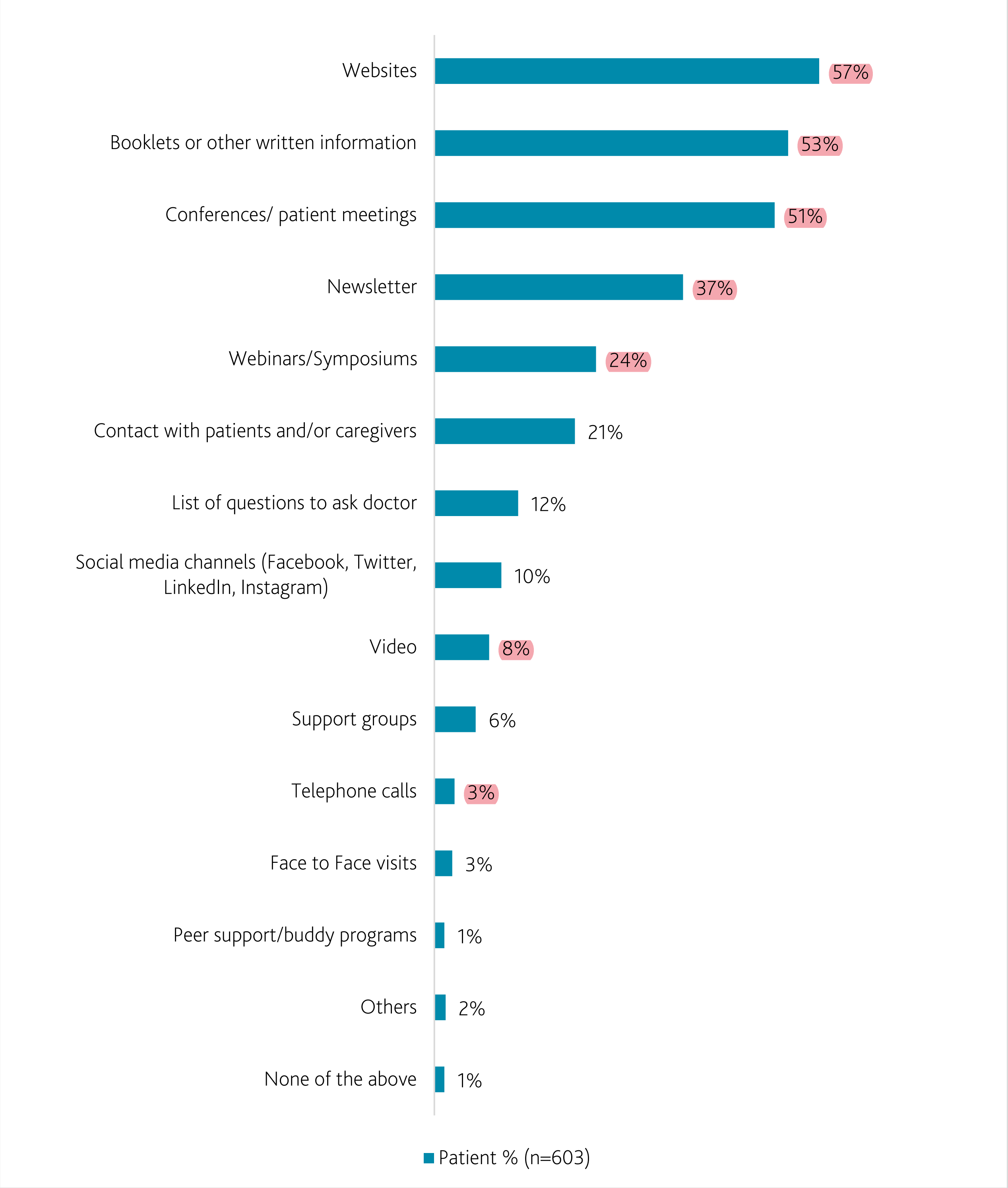
- Figure 28 reveals the top patient organisation information used is websites (57%). However, a significant number of patients are accessing booklets or written information (53%), attending conferences or patient meetings (51%) and reading newsletters (37%). Only asked to those who indicated they had connected with a patient organisation.

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



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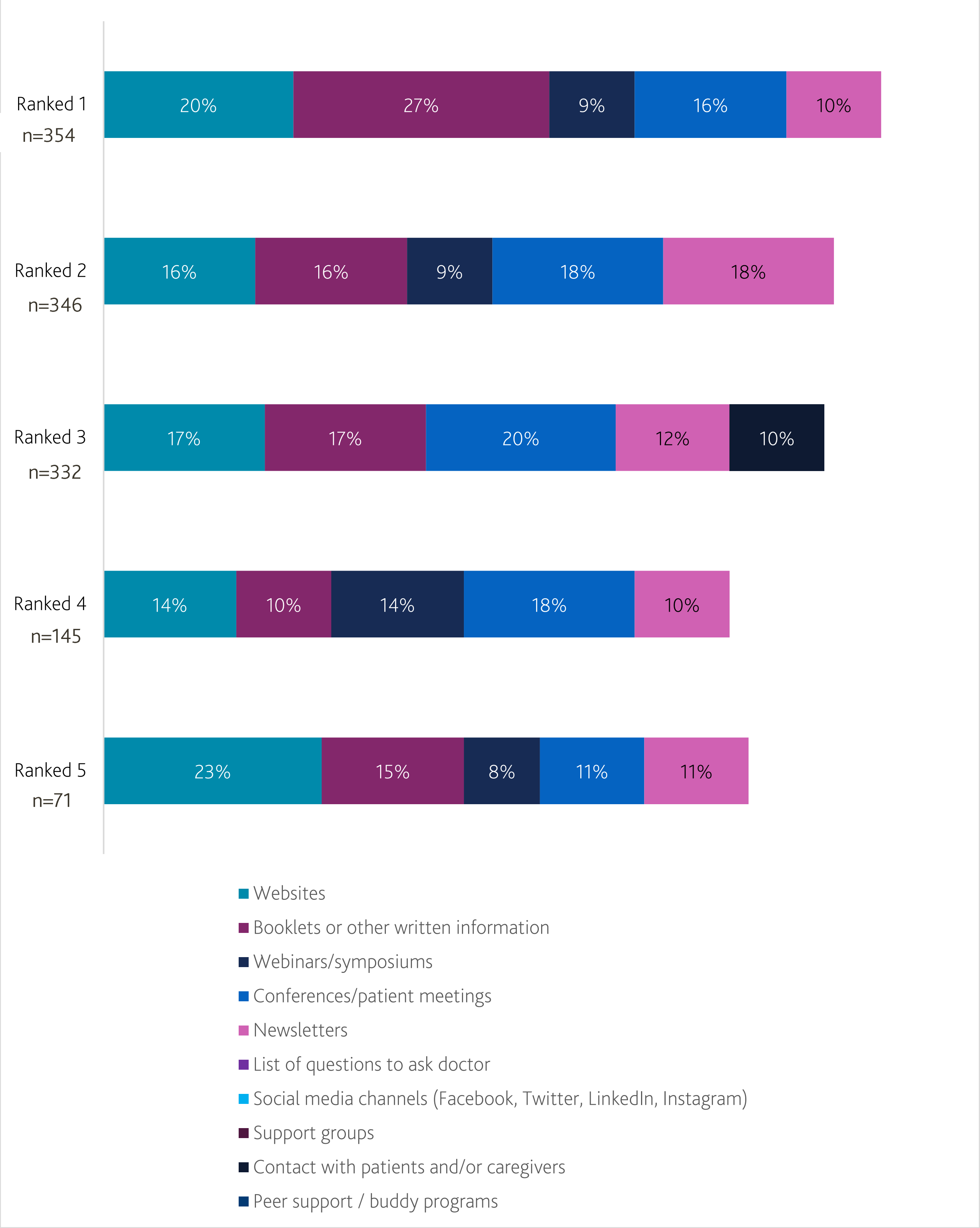
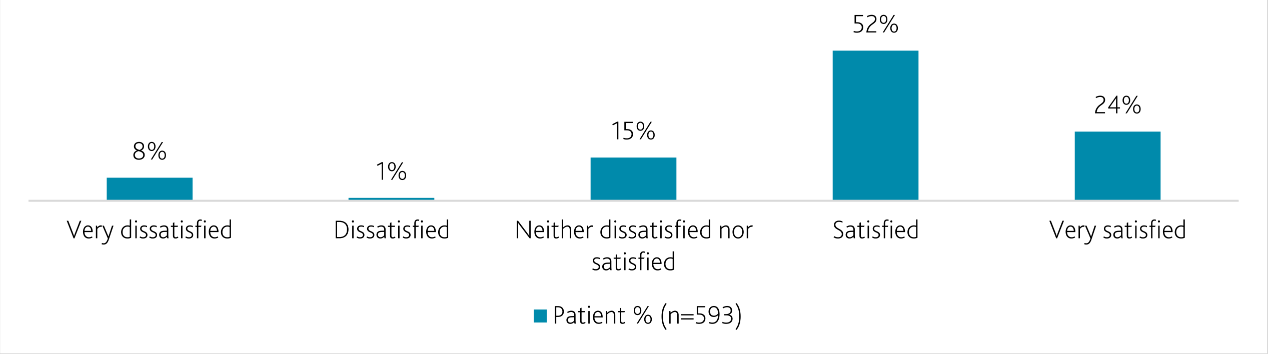
- Figure 29 shows when asked what they top information source from a patient organisation was, more people ranked booklets and written information as their top choice (27%) than they did websites (20%), even though more people had used websites. Only asked to those who indicated they had connected with a patient organisation.

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



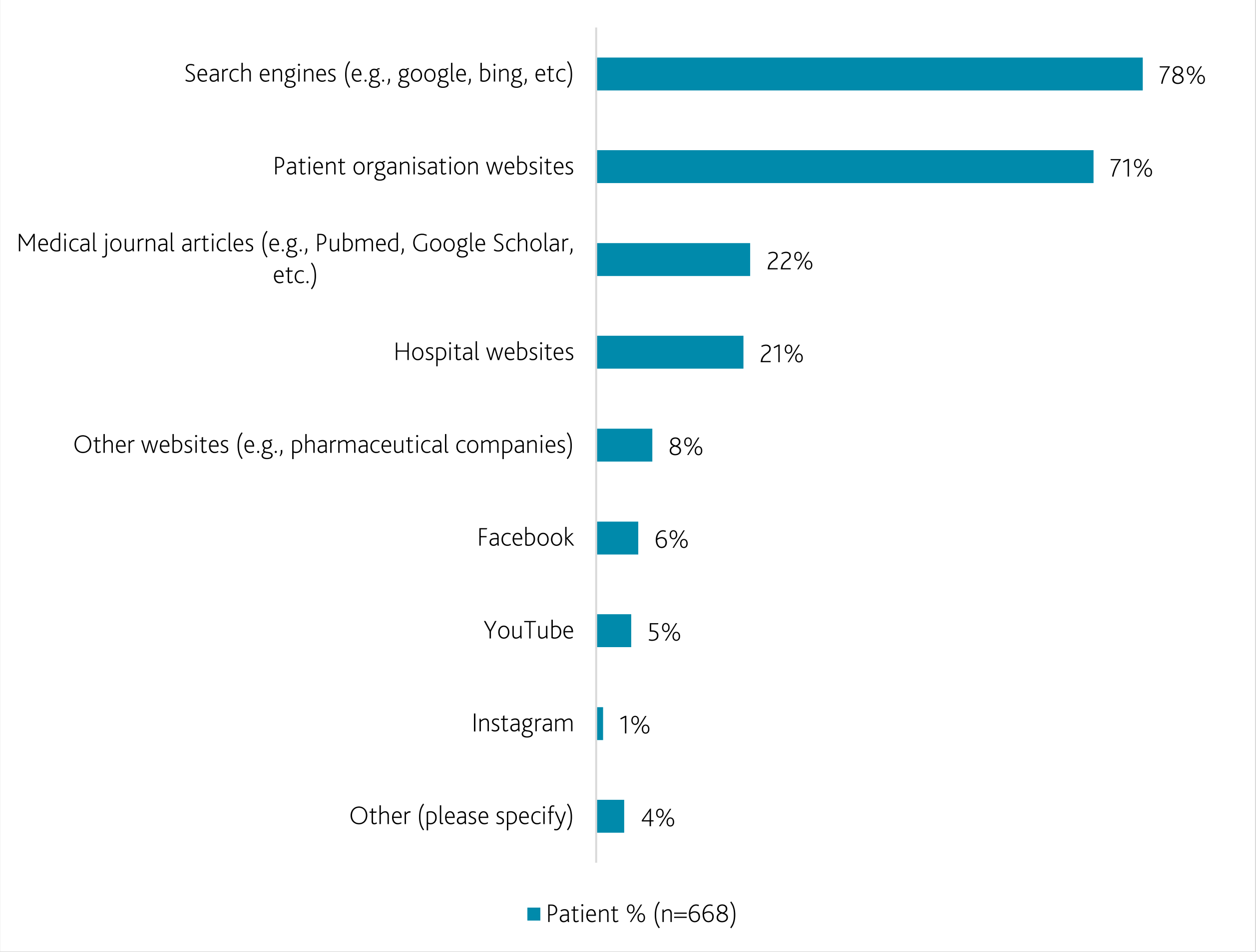
- Figure 30 reveals 76% of patients were satisfied or very satisfied with the information given by patient organisations. Only asked to those who indicated they had connected with a patient organisation.

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



- Figure 31 explains when on the internet, patients most often get lymphoma or CLL information from search engines (78%) and patient organization sites (71%). 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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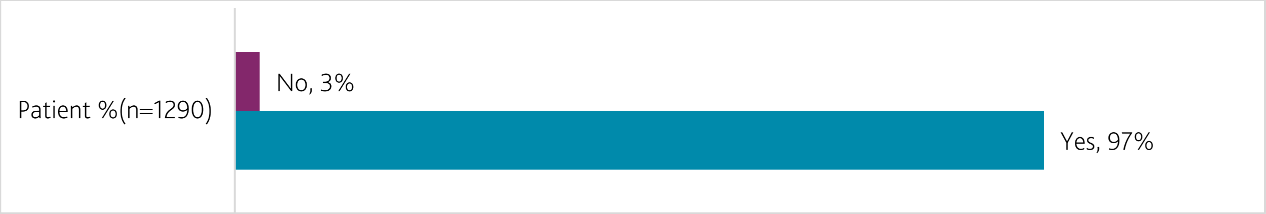
Healthcare Support

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.

- 97% of patients had seen a specialist (e.g., haematologist, oncologist, dermatologist) for their lymphoma subtype.
- 77% of patients had been seeing the same speciality physician (e.g., haematologist, oncologist, dermatologist) throughout their patient experience.
- 20% of patients did not have their healthcare supported by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator.

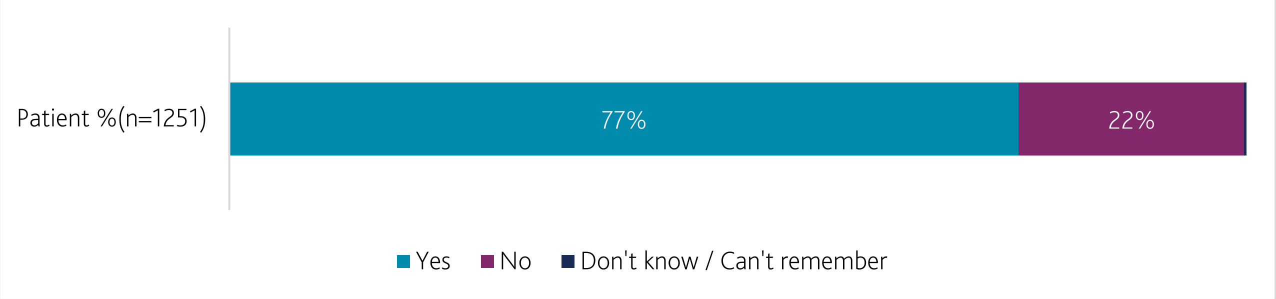
❖ Figure 32 shows the majority of patients (97%) had seen a specialist for their lymphoma subtype.

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



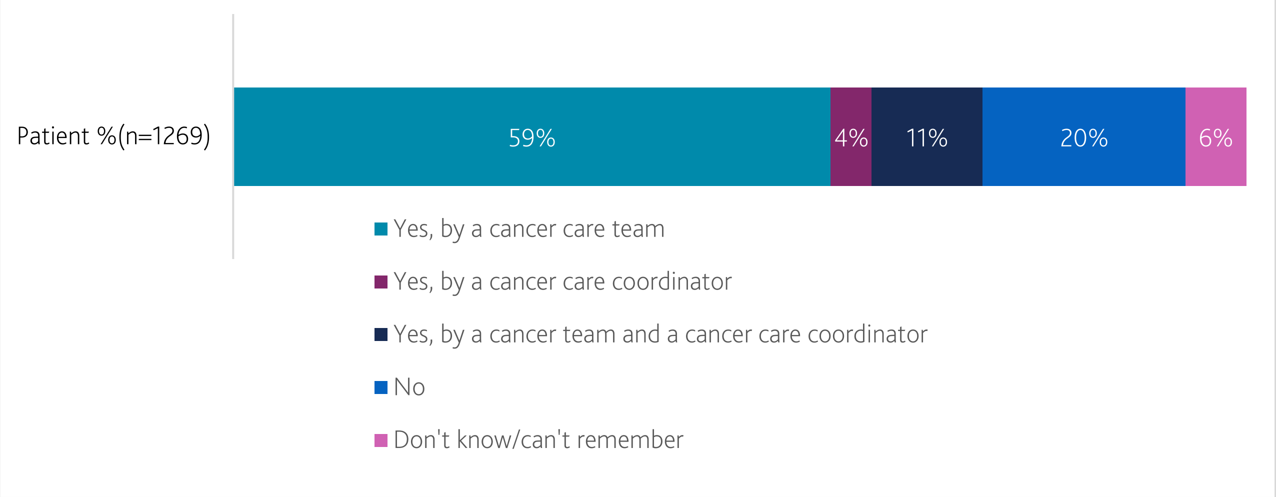
- Figure 33 reveals of those who did see a specialists, nearly one-quarter (22%) did not see the same specialty physician throughout their patient experience. Only asked to those who indicated they had seen a specialist.

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



- Figure 34 illustrates that three-quarters of patients had their lymphoma care provided by a cancer team

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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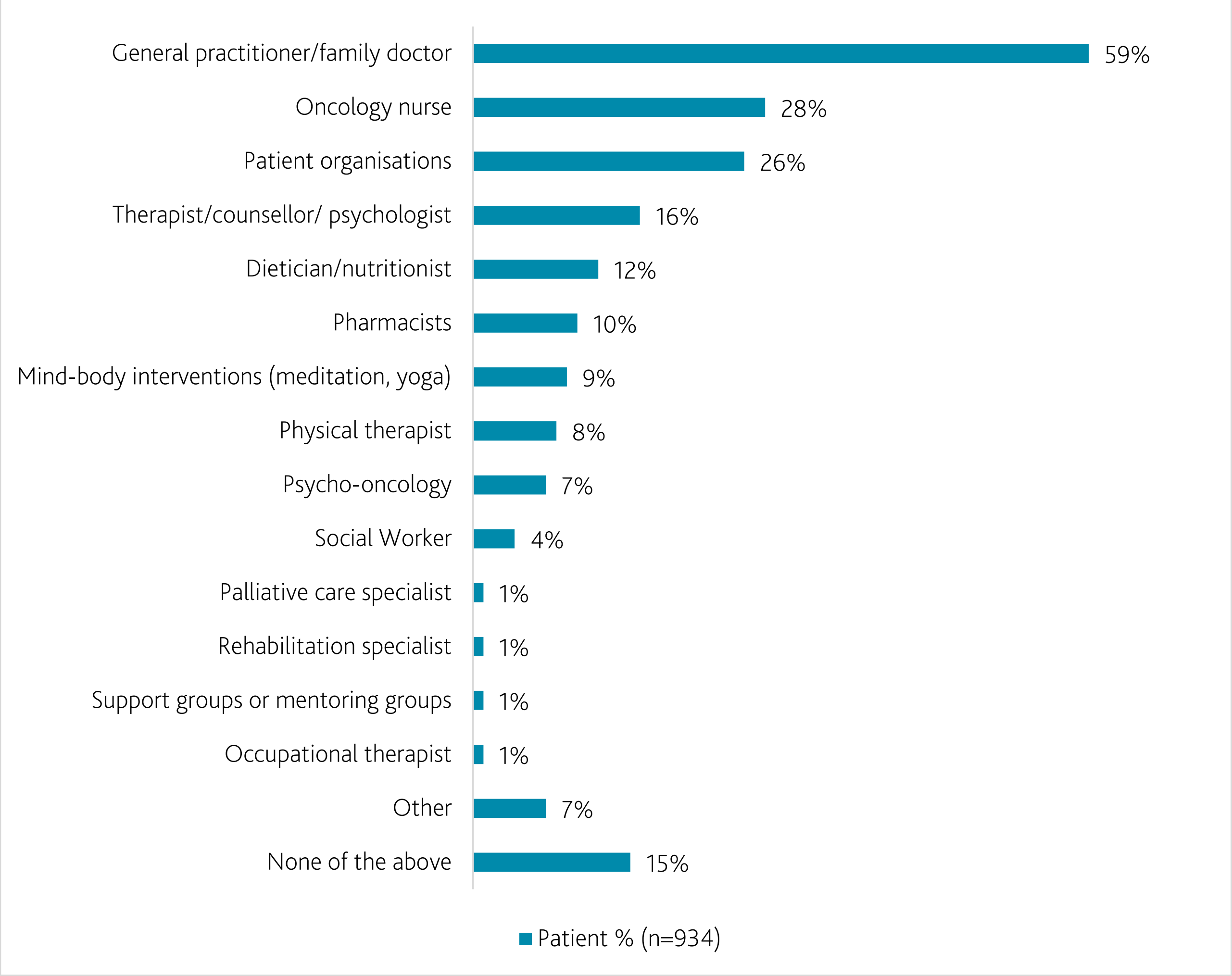
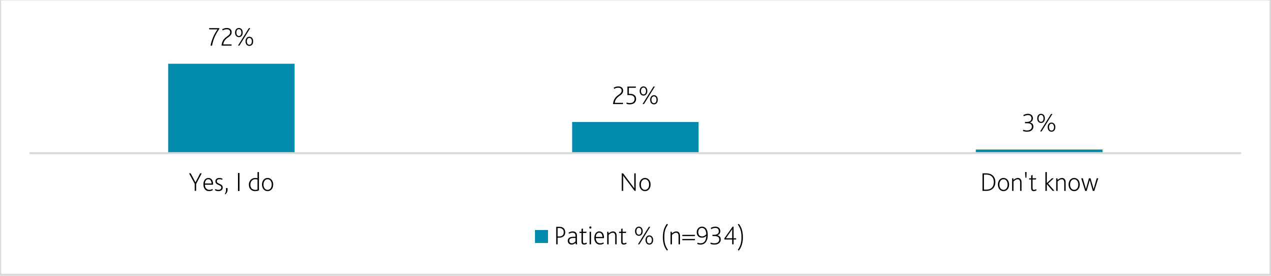
- Figure 35 reveals of those who had access to a cancer care team, 59% said general practitioners were useful in providing supportive care, followed by oncology nurses (28%), and patient organisations (26%). Only asked to those who reported they had access to a cancer care team and/or cancer care coordinator.

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



- Figure 36 shows of those who had access to a cancer care team, 72% of patients have a dedicated first point of contact within the team. Only asked to those who reported they had access to a cancer care team and/or cancer care coordinator.

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

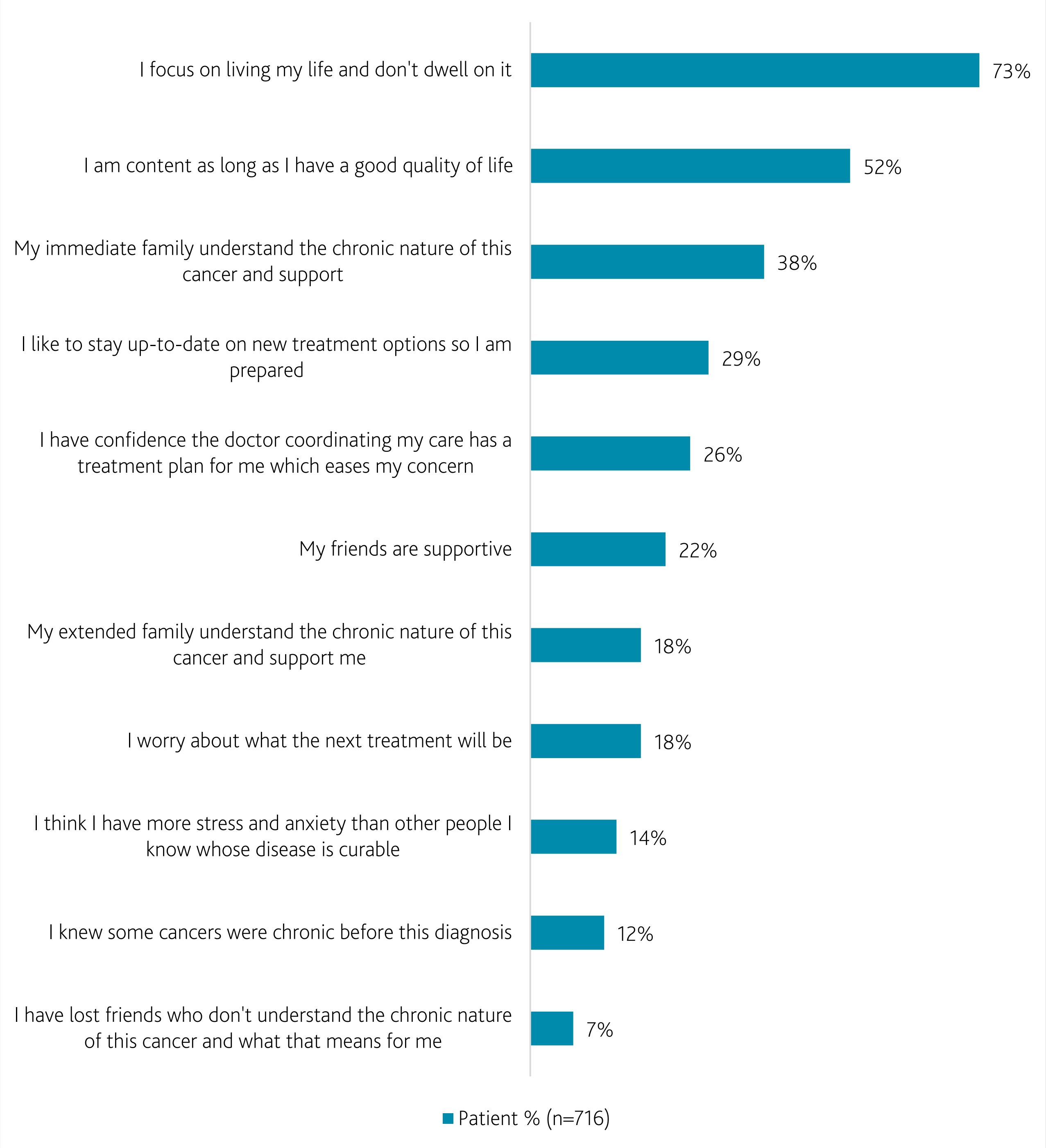


Support Experience of Patients with Indolent Lymphomas

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

- Figure 37 reveals that when asked about living with a chronic cancer, three-quarters of patients say they 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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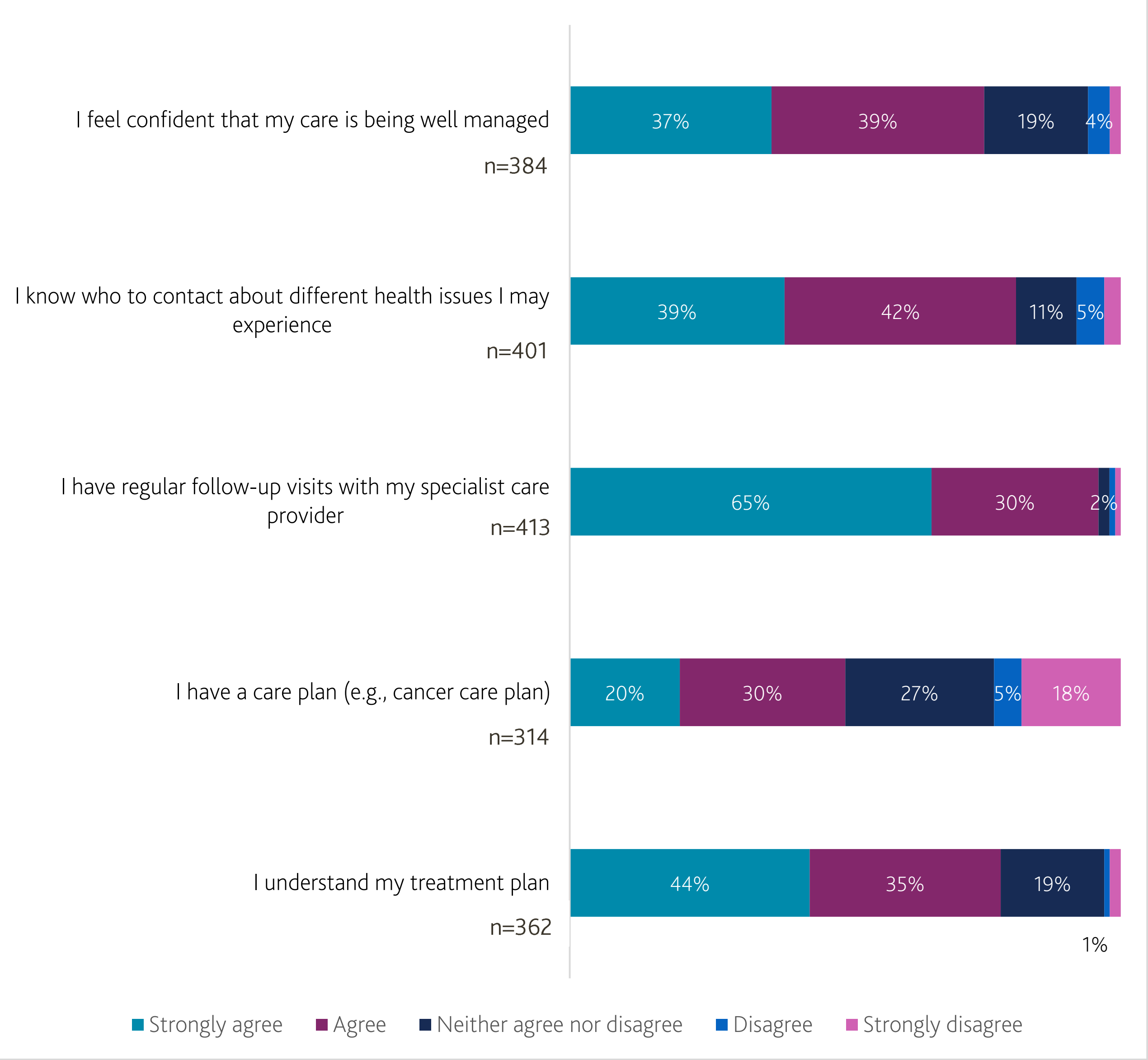
Support Experience of Patients in Active Surveillance

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 overall, the majority of patients are seeing their specialist regularly, understand their treatment plan, are confident their care is being well managed, and know who to contact about issues. Only half of patients strongly agree or agree that they have a 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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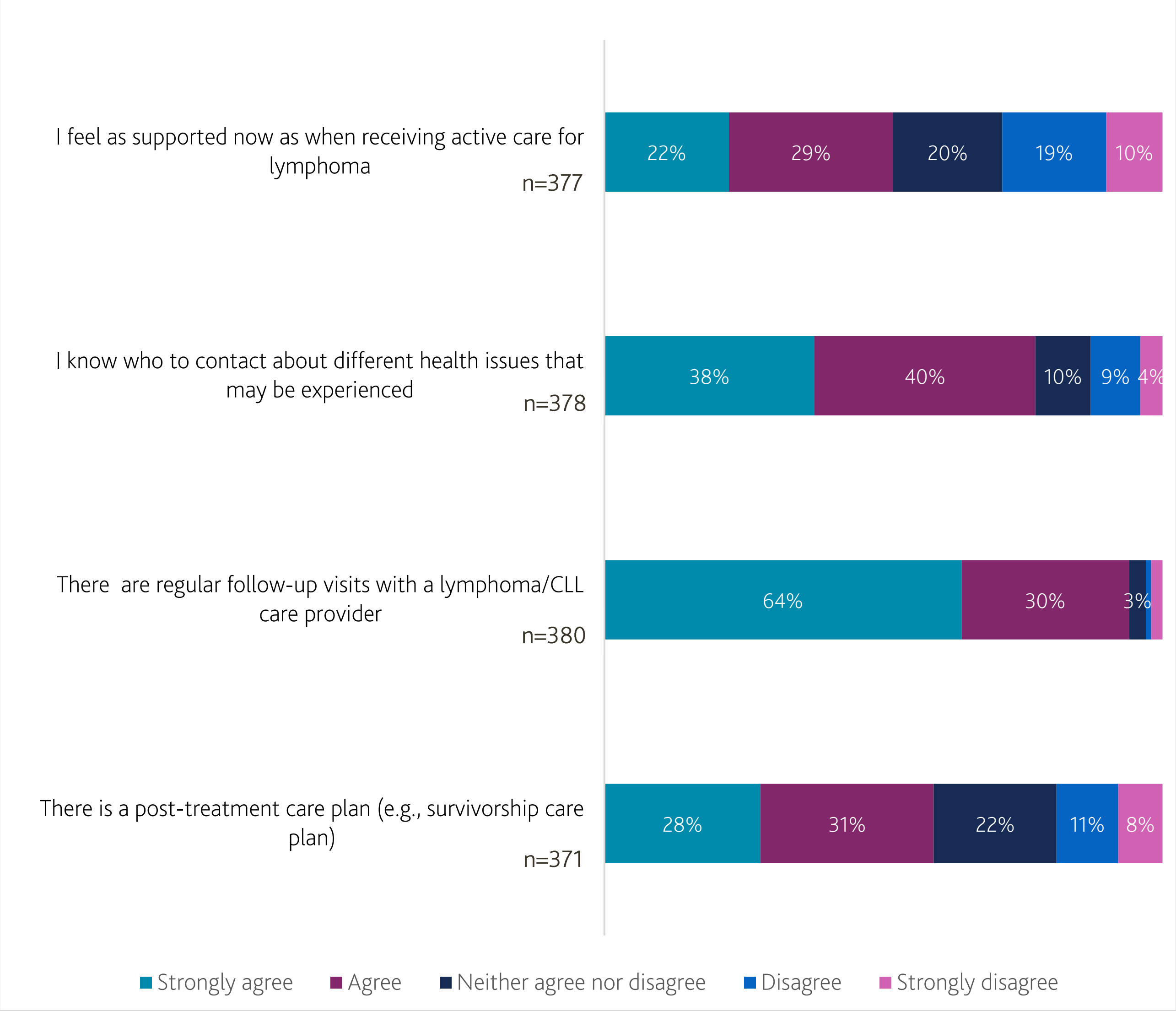
Support Experience of Patients in Remission/Survivorship

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 overall, the majority of this group of patients have follow-up visits, have a treatment plan, and know who to contact for health issues. Half feel as supported now as when they were in active care. 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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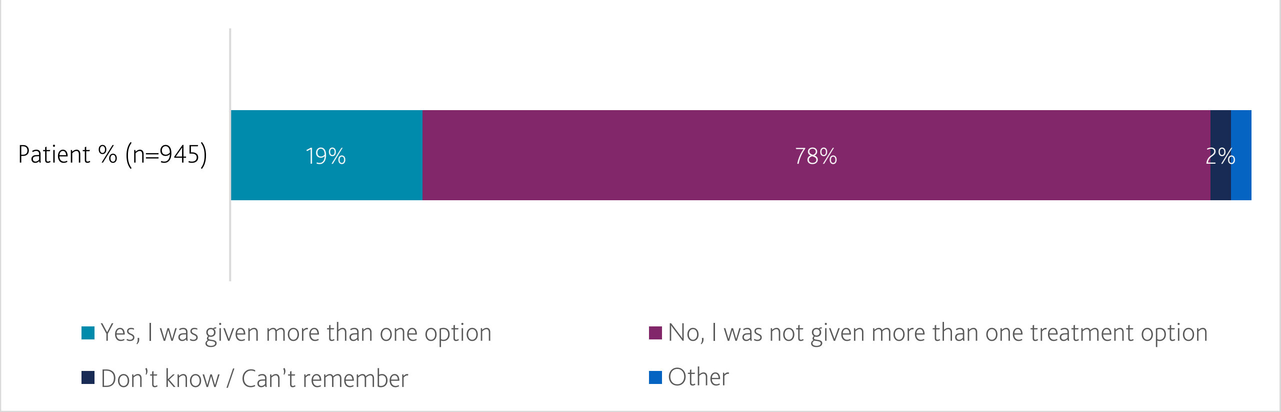
Healthcare Involvement and Decision-Making

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 19% of patients were given more than one treatment option before their current or last therapy for lymphoma.
- 36% of patients definitely felt as involved as much as they want to be in decisions about their care and treatment.
- 48% of patients would like the doctor and patient to be involved in final decisions about care.
- 21% of patients say their doctor never explores their preferences and understanding when making decisions about care.

❖ Figure 40 reveals more than three-quarters of patients were not given more than one treatment option before their current or last therapy for lymphoma or CLL. Only asked to those who had been treated.

Figure 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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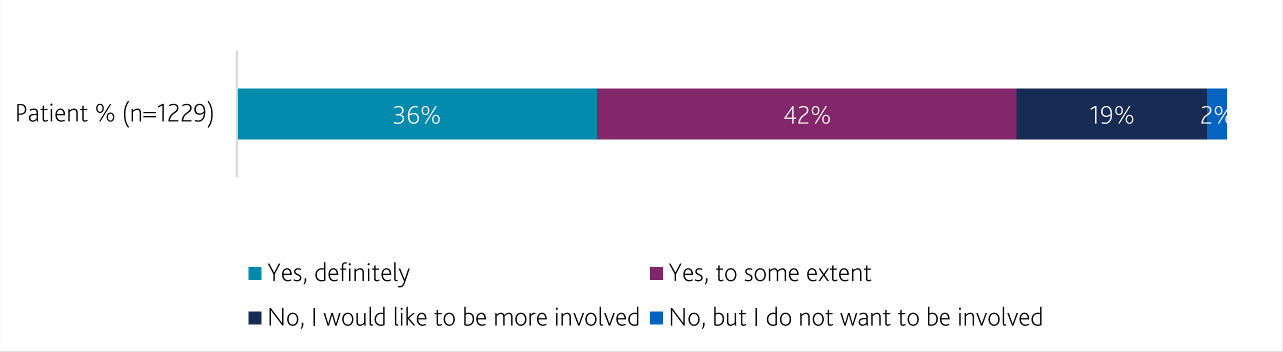
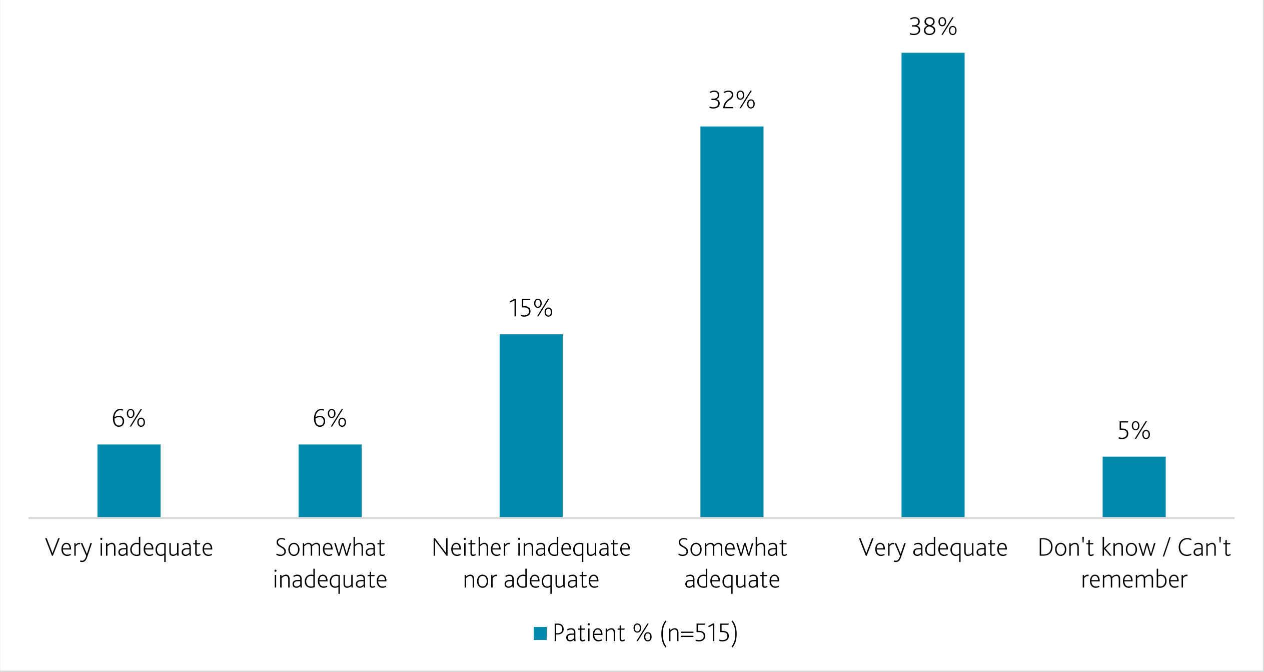
- Figure 41 explains the majority of patients (78%) said they were involved as much as they wanted to be in decisions about care and treatment.

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



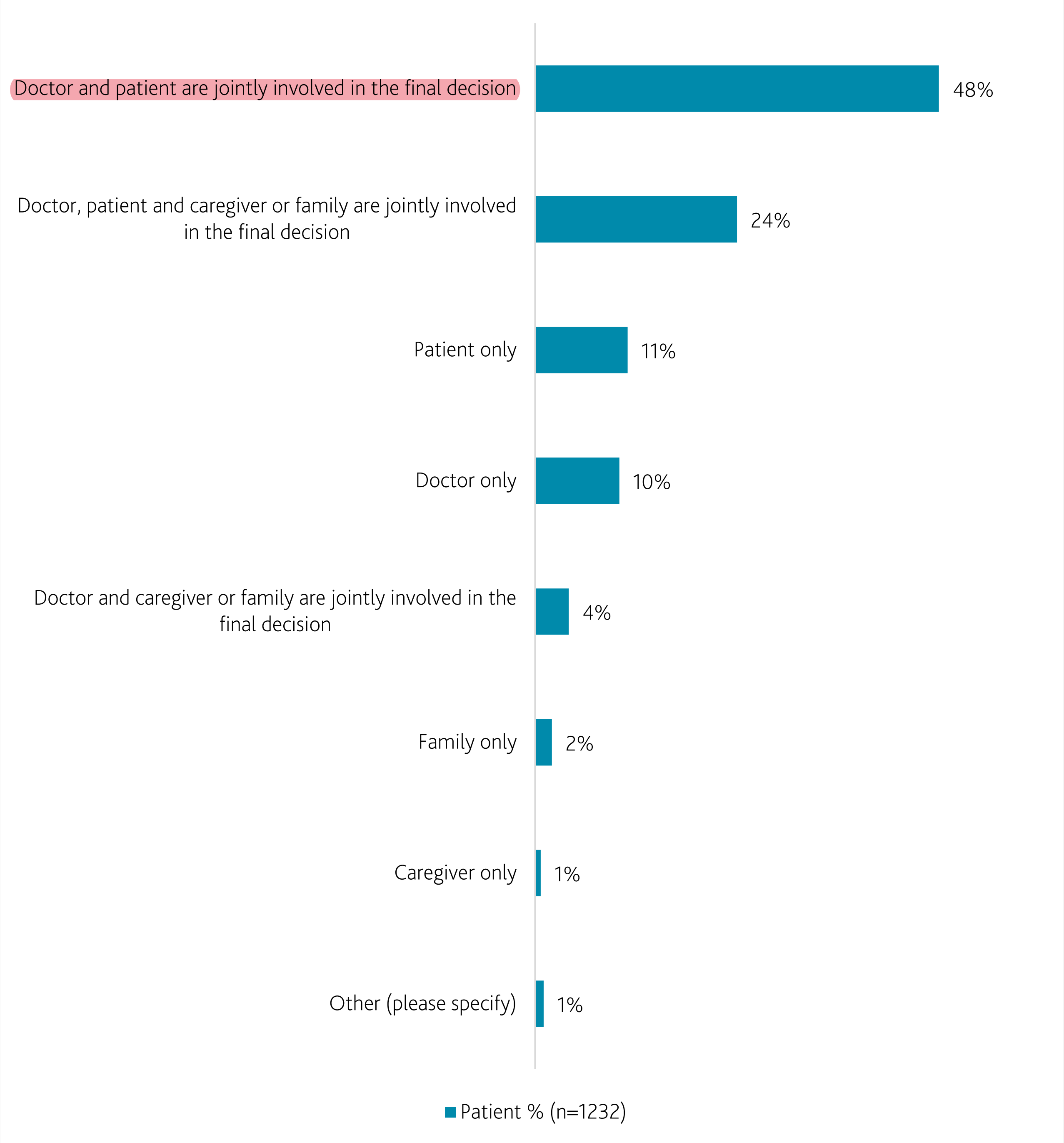
- Figure 42 reveals only 12% of patients said the amount of time to think about treatment was inadequate. Only asked to those who had been treated.

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?



- Figure 43 shows when asked about healthcare decision making, there was an overwhelming preference for collaboration. The majority (48%) included the doctor and patient in the decision, and 24% included the doctor, patient and caregiver or family.

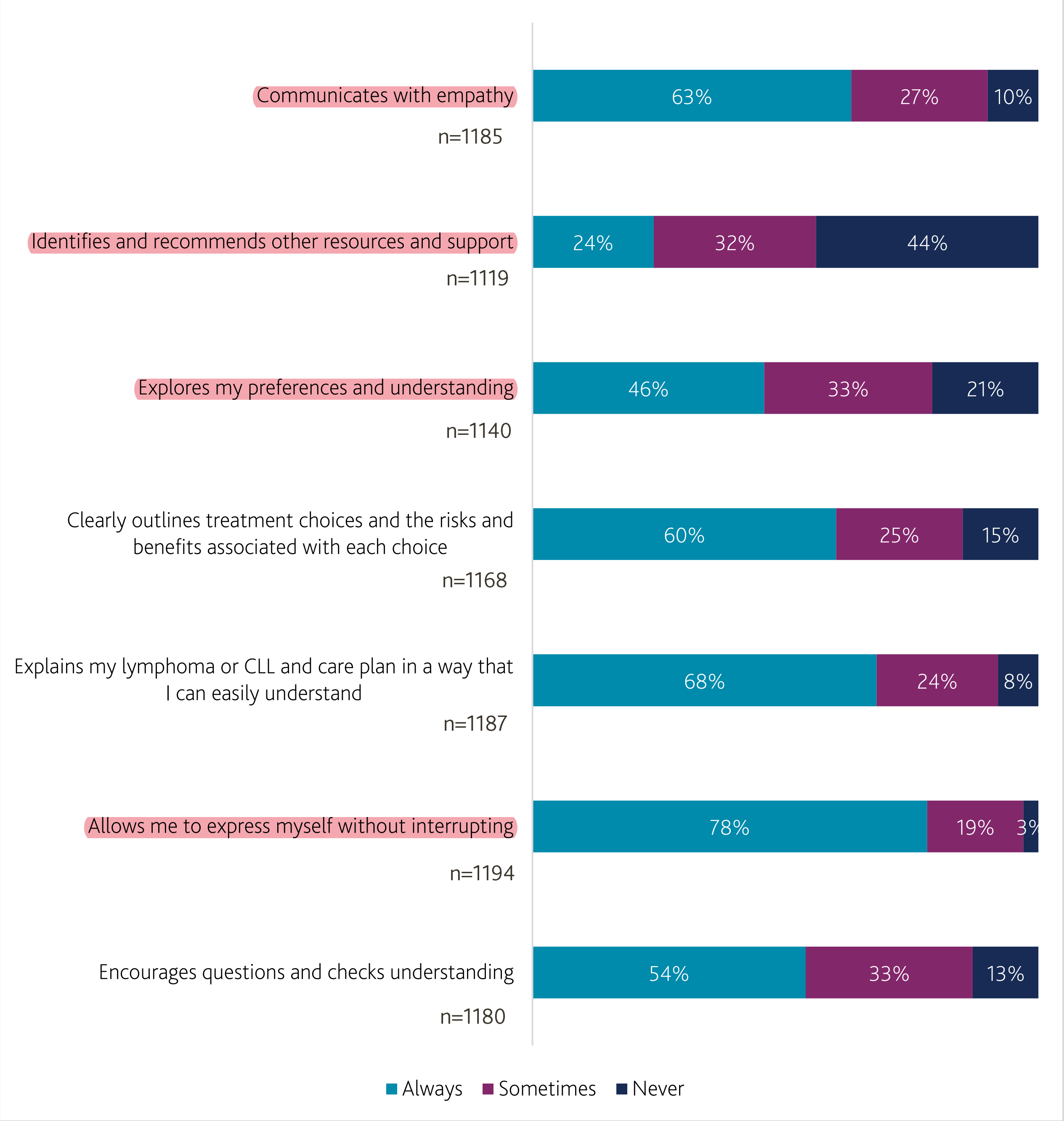
Figure 43. Who would you like to make the final decision on your healthcare?



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

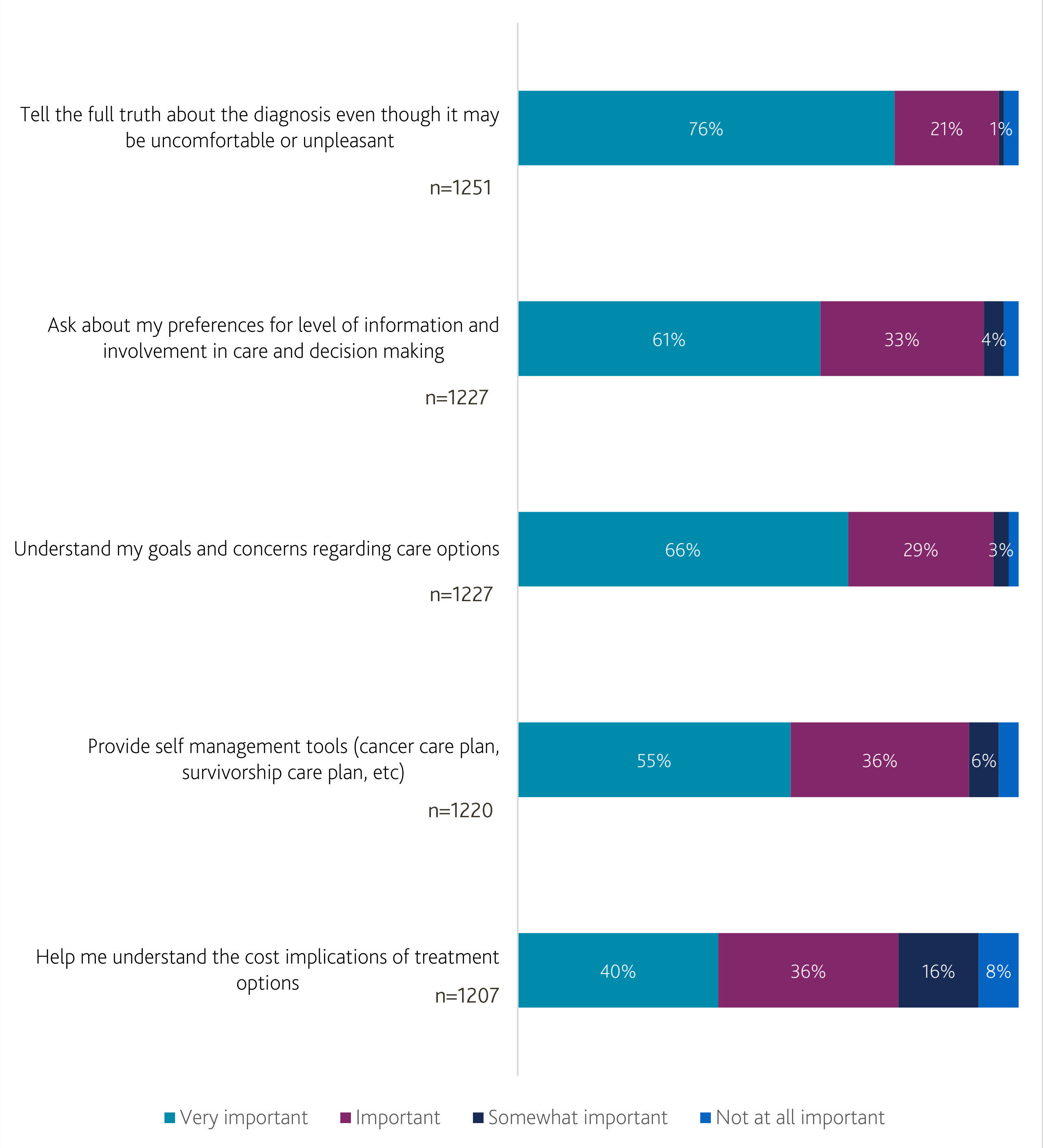
- ❖ Figure 44 illustrates the two biggest gaps identified are 21% of patients said their doctor never explored their preferences and understanding and 44% said their doctor never identified or recommended other resources and support.

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



- Figure 45 reveals that when asked about the importance of information from the specialist physician, the full truth about the diagnosis (76%) and understanding the patient's goals and concerns about care options (66%) were ranked most important.

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 fatigue was the most reported symptom of lymphoma or CLL (69%). Treatment alleviated fatigue for only 32% of those affected by it.

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

Effects of Lymphoma	Number of respondents (n)	%	Treatment alleviated symptoms*
Abdominal swelling	177	14%	44%
Anaemia	297	24%	64%
Bone pain	270	22%	37%
Cold agglutinin disease	15	1%	39%
Cryoglobulinemia	16	1%	43%
Easily bruised or bleed	271	22%	26%
Enlarged lymph nodes/abnormal painless swelling(s) on the body	599	49%	91%
Fatigue	851	69%	32%
Fever, chills, night sweats and weight loss (B-symptoms)	415	34%	67%
Frequent or repeated infections	205	17%	46%
Headaches	192	16%	38%
Hyperviscosity syndrome	18	2%	59%
Itchy skin	332	27%	49%
Pain	223	18%	45%
Shortness of breath	420	34%	42%
Skin rashes/lesions	203	17%	48%
Other (please specify)	154	13%	57%
No symptoms	83	7%	12%

*only asked to those who reported the symptom

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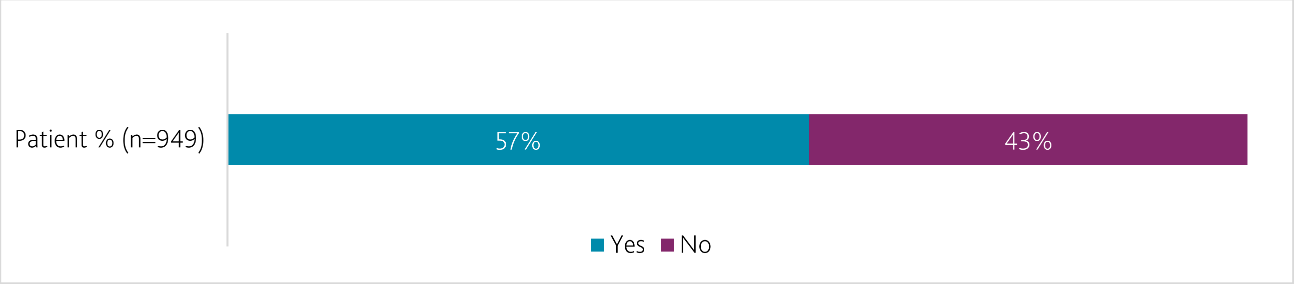
Lymphoma and CLL Treatments

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 74% of respondents. Of that group, 57% had treatment within the last 2 years.

- Half of the patients (51%) who had ever received or received treatment had first-line treatment only, while 19% received their 2nd line of treatment.
- A quarter (25%) of patients had been in a clinical trial
- 12% of patients were interested in information about the effect of their treatment on fertility, but they were not given such information
- 36% of patients agree and 21% strongly agree that their treatment was chosen to minimize the impact of possible side effects on lifestyle and/or favourite activities

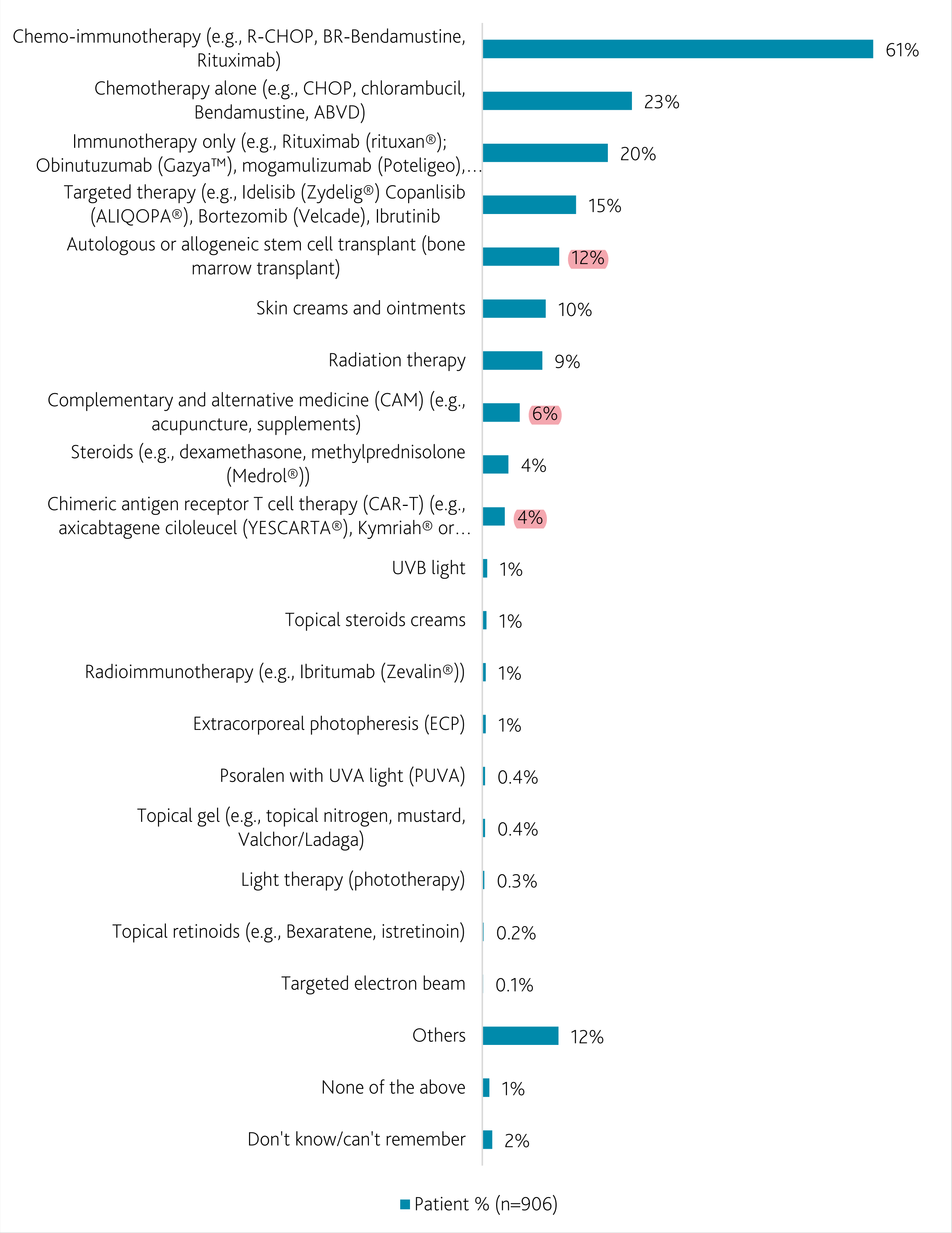
❖ Figure 46 illustrates that over half of patients are receiving or have received medical treatment for their lymphoma or CLL in the last 2 years. Only asked to those who have received treatment.

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



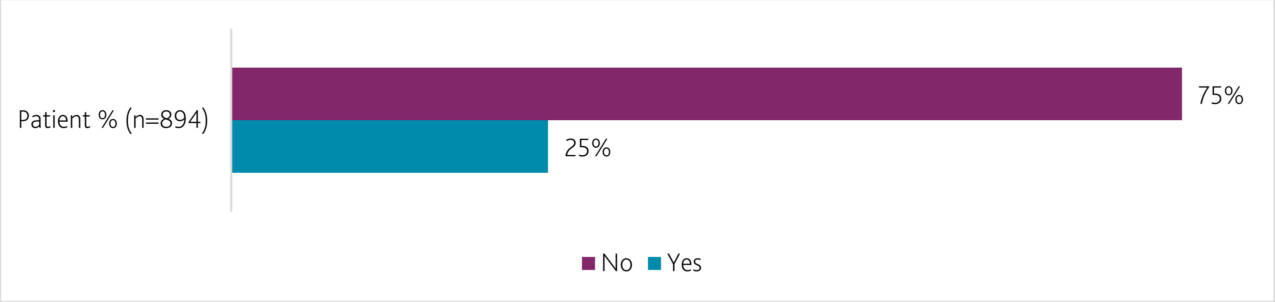
- Figure 47 shows that almost two-thirds of patients are currently receiving, or have received, chemo-immunotherapy. Only asked to those who have received treatment.

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



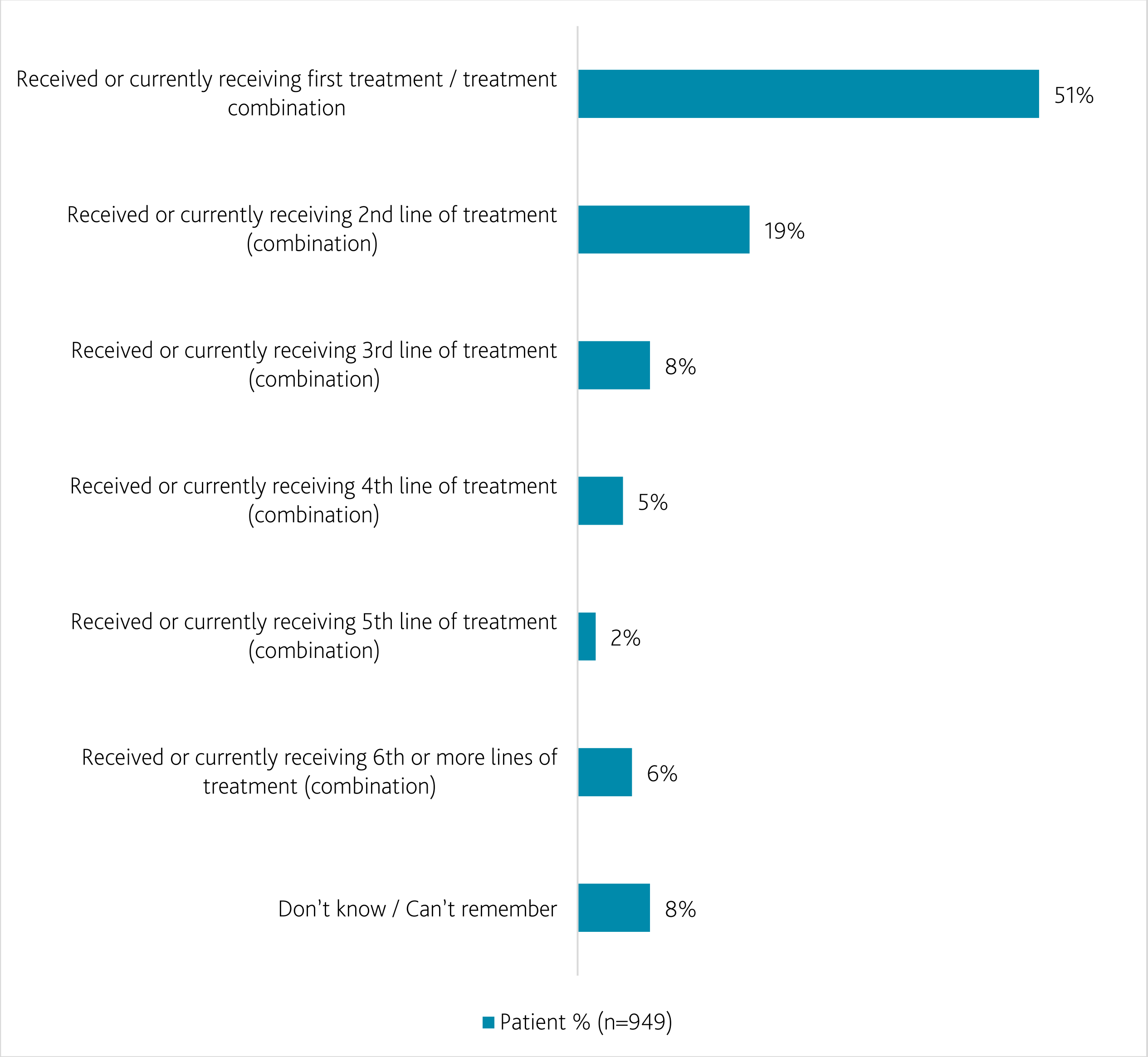
- Figure 48 reveals that only a quarter of patients have been in a clinical trial for lymphoma. Only asked to those who have received treatment.

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



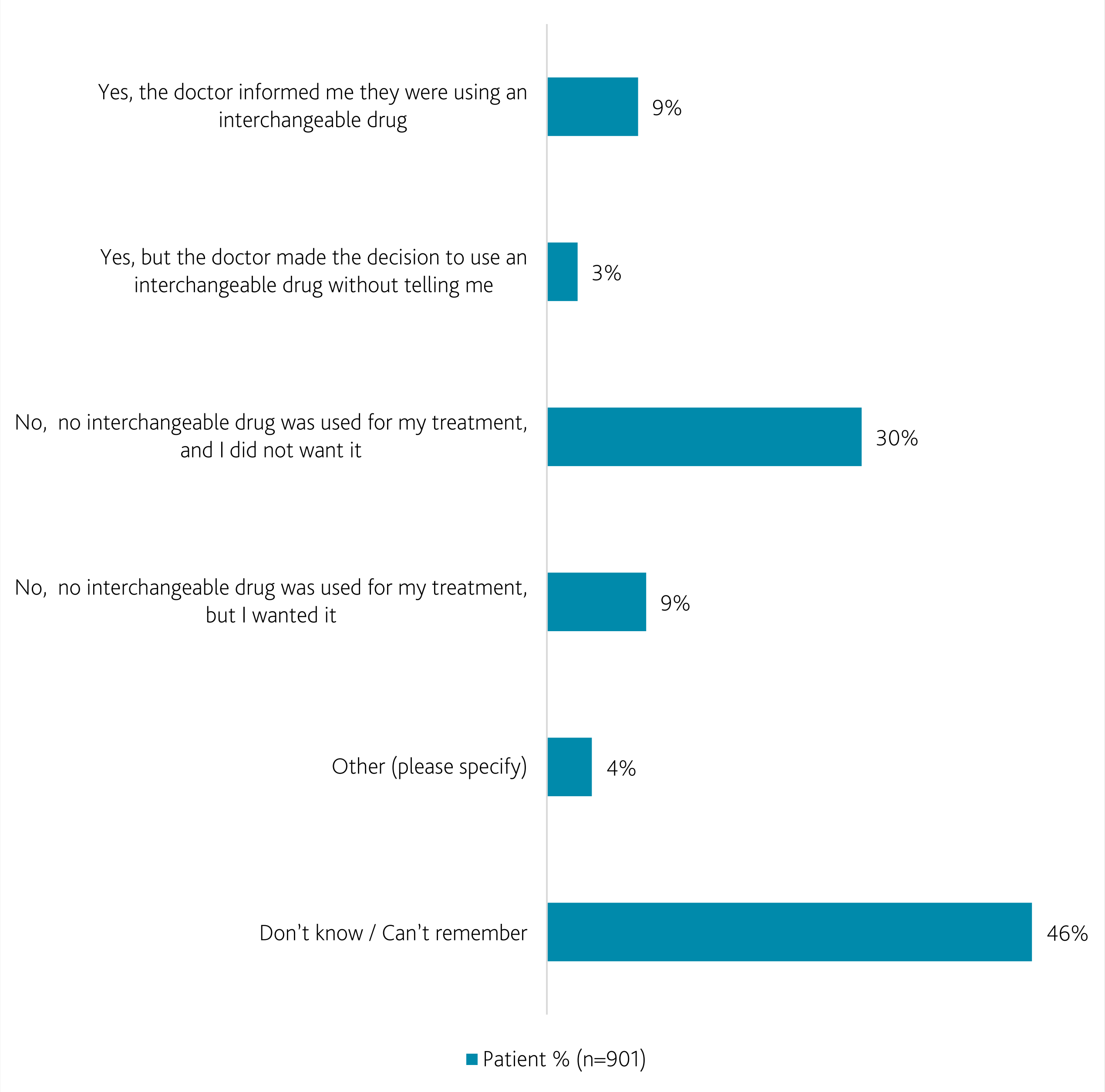
- Figure 49 shows half of patients have received or are receiving their first line of treatment or treatment combination. Only asked to those who have received treatment.

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



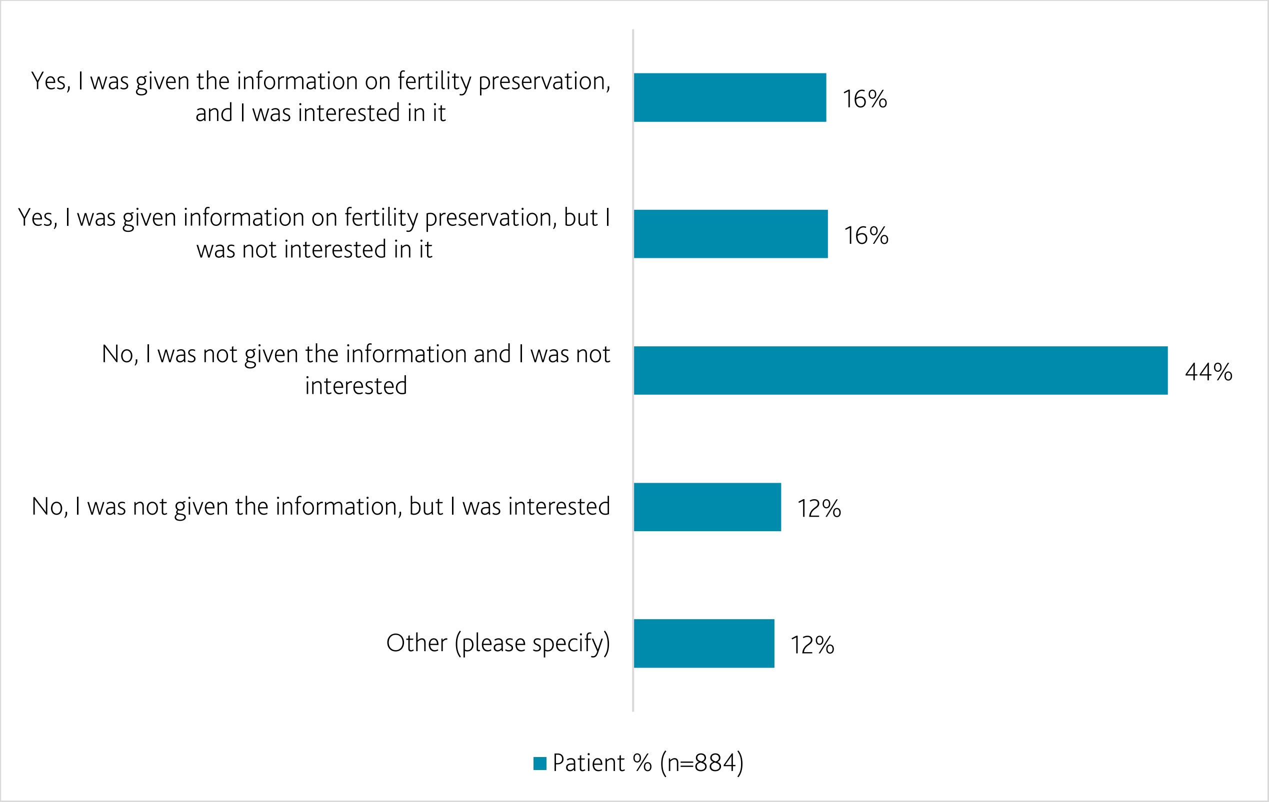
- Figure 50 illustrates an interchangeable drug was used in the treatment of 12% of patients, but 3% were not told about the decision. Almost half of patients did not know if an interchangeable drug had been used or not. Only asked to those who have received treatment.

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



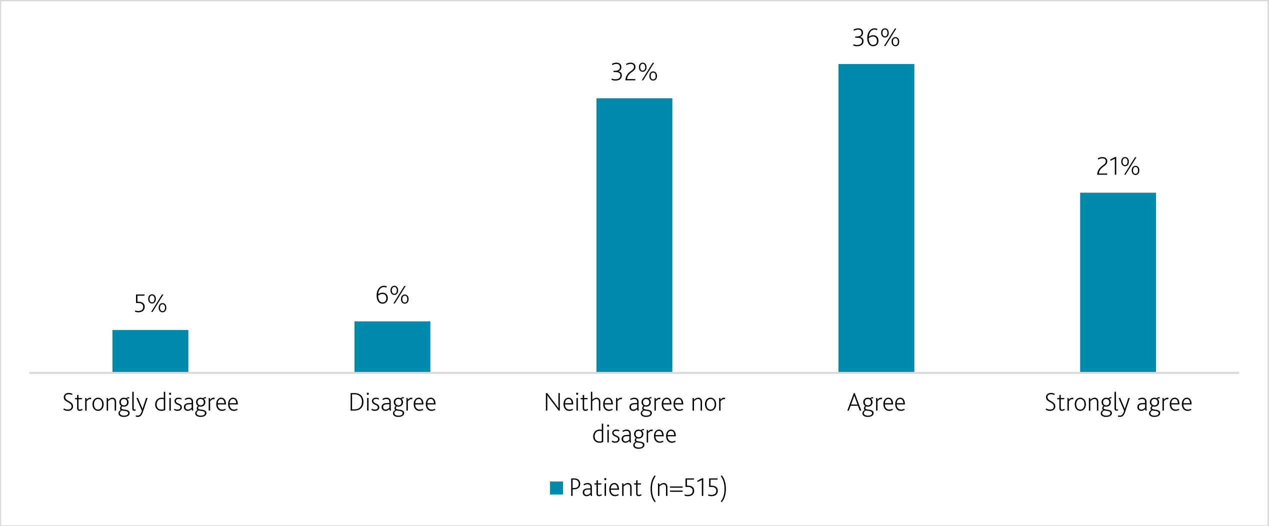
- Figure 51 reveals 28% of patients were interested in information about fertility, but 12% were not given such information. Only asked to those who have received treatment.

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



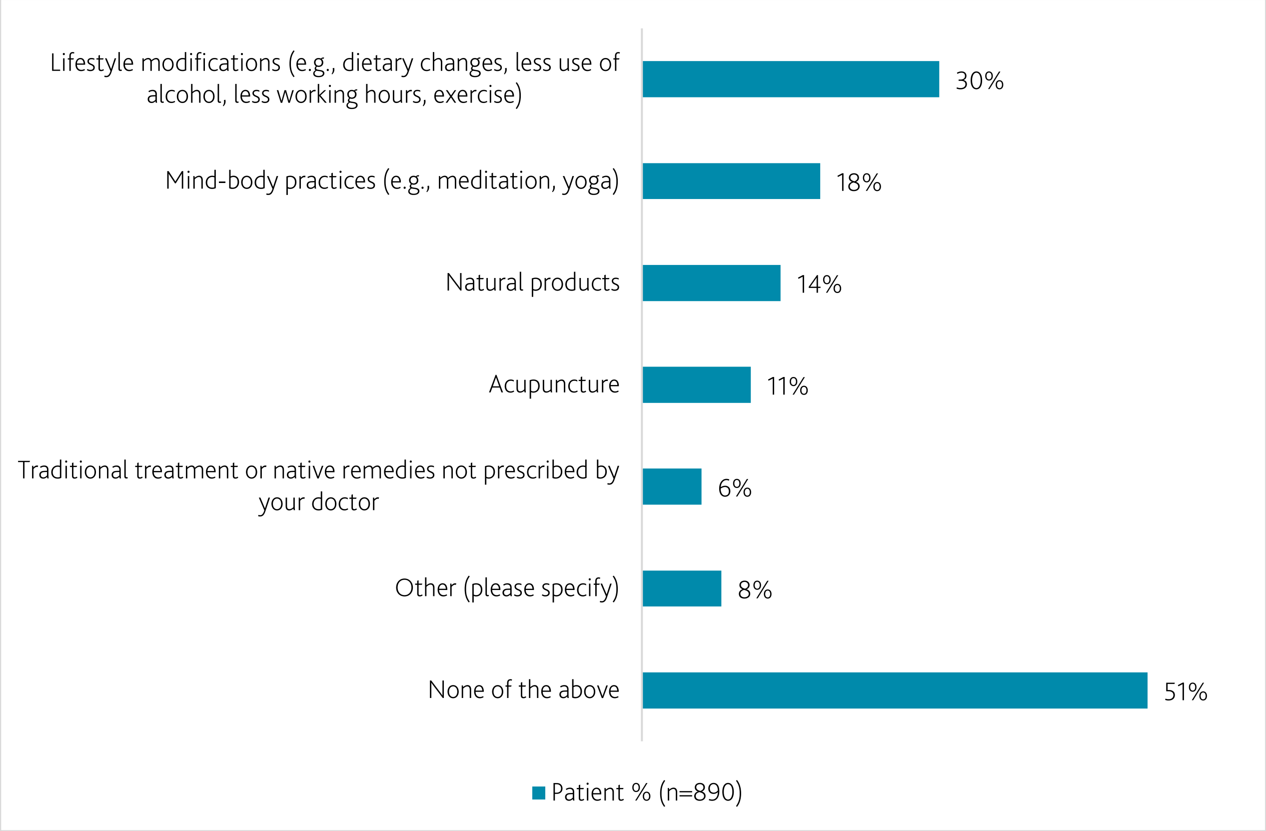
- Figure 52 illustrates that 57% of patients agree or strongly agree that treatment was chosen to minimize the impact of possible side effects on their lifestyle and/or favourite activities. Only asked to those who have received treatment.

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?



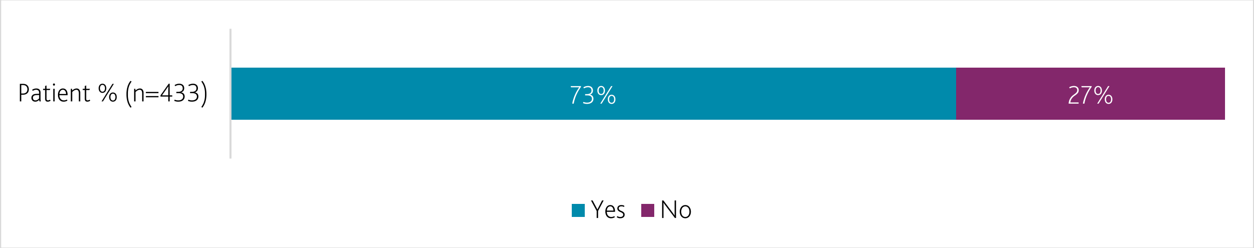
- Figure 53 reveals that 30% of patients made lifestyle modifications alongside their conventional cancer treatment, and 18% used mind-body practices. Only asked to those who have received treatment.

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



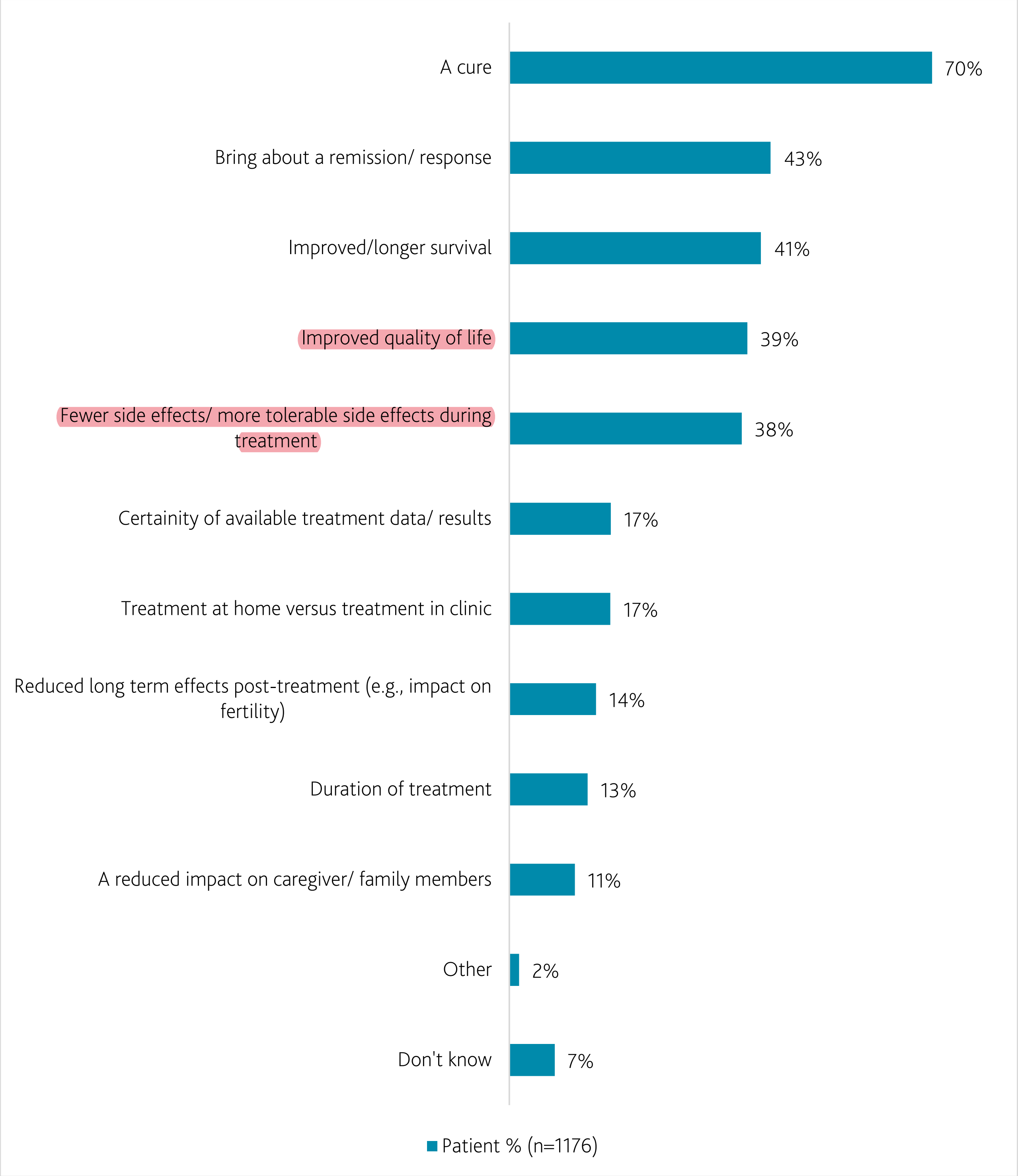
- Figure 54 explains of those who applied lifestyle modifications, treatments or products, three-quarters told their lymphoma or CLL doctor about it. Only asked to those who used these types of remedies alongside conventional cancer treatment.

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 when asked about important features of a new medical treatment for lymphoma or CLL, patients said a cure (70%), bring about a remission (43%), and improved or longer survival (41%).

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 67% of patients rank having a cure as a top feature of a new medical treatment for lymphoma or CLL

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

	#1		#2		#3	
	n	%	n	%	n	%
A cure	390	67%	22	4%	57	10%
Improved/ longer survival	46	8%	180	32%	57	10%
Bring about a remission/ response	46	8%	137	24%	108	20%
Improved quality of life	34	6%	81	14%	93	17%
Fewer side effects/more tolerable side effects during treatment	30	5%	87	15%	103	19%
Reduced long-term effects post-treatment (e.g., impact on fertility)	4	1%	23	5%	33	6%
Treatment at home versus treatment in the clinic	10	2%	16	3%	34	6%
Duration of treatment	11	2%	8	1%	16	3%
A reduced impact on caregiver/family members	5	1%	6	1%	19	3%
Certainty of available treatment data/results	10	2%	6	1%	34	6%

Barriers to Treatment

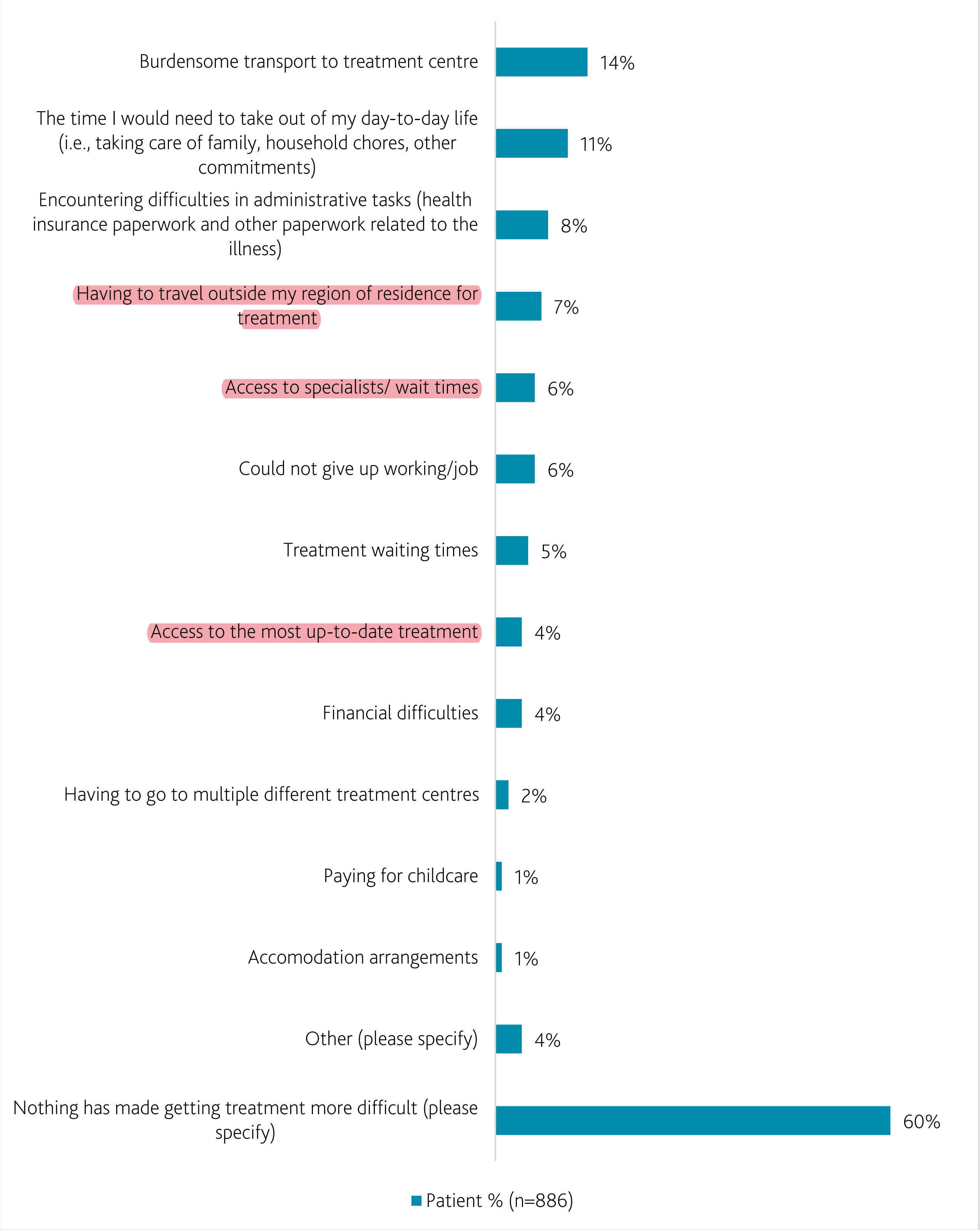
Barriers to standard therapy and access to clinical trials remain essential topics to examine. In previous surveys, financial issues have been the most reported barrier to receiving treatment.

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.

- The majority of patients (60%) from France reported not having any barriers to receiving treatment.
- 14% of patients reported they were prevented from receiving treatment because of burdensome transport to the treatment centre.
- One out of every ten patients indicated having to take time out of their day-to-day life made receiving treatment difficult.
- 61% of patients said never being presented with the opportunity to take part in a clinical trial is the top reason they have not participated in one.

- Figure 56 reveals that 60% of patients feel that nothing has made getting treatment more difficult. Only asked to those who have received treatment.

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



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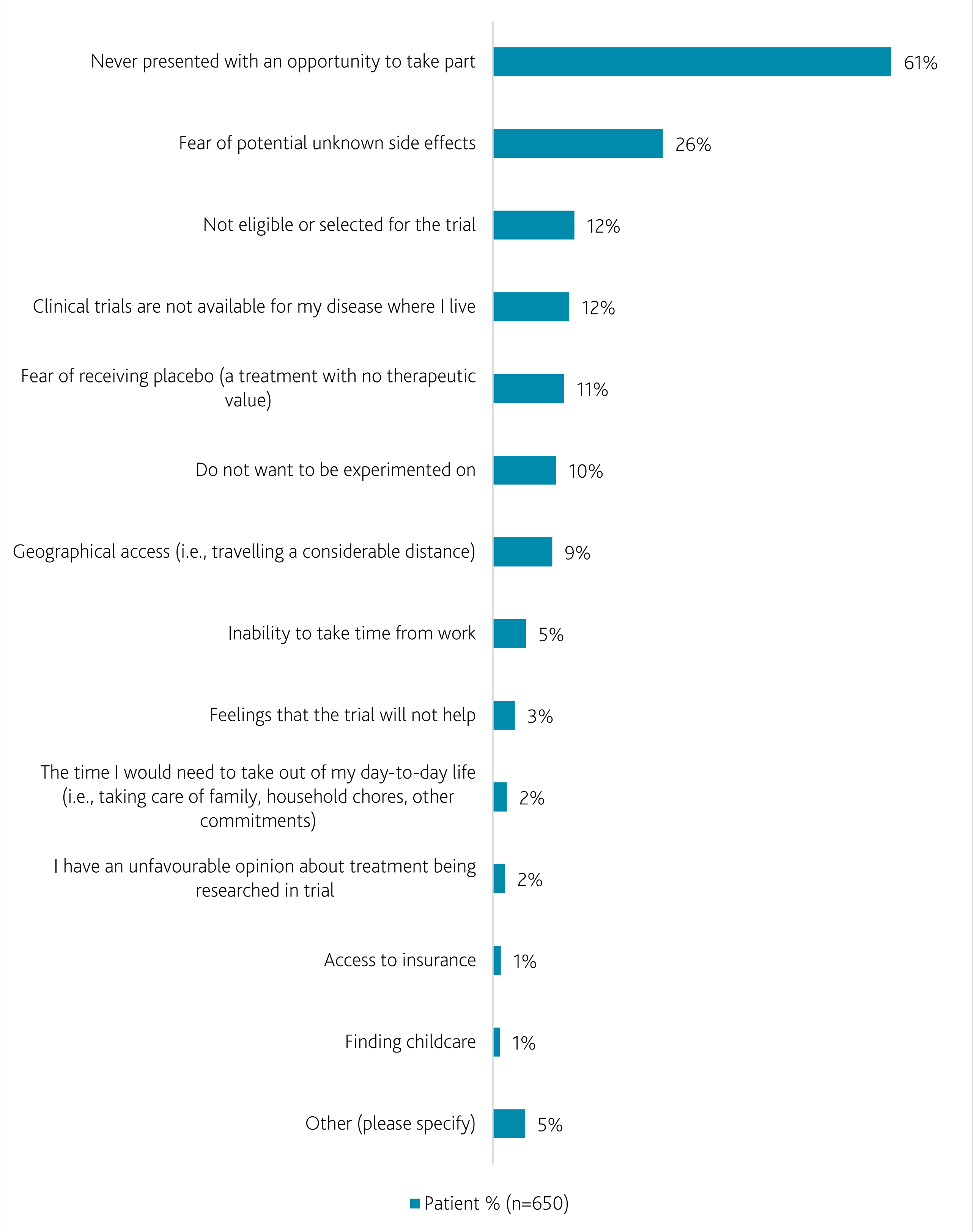
- Figure 57 explains almost two-thirds of patients (61%) were never presented with the opportunity to take part in a clinical trial. Only asked to those who have received treatment.

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:
    - Fatigue (76%)
    - Hair loss (49%)
    - Nausea and vomiting (45%)
    - Anaemia (35%)
    - Skin, hair, and nail problems (34%)

- The side effects that affected patients' wellbeing the most (ranked 1st) were:
    - Fatigue
    - Nausea and vomiting
    - Hair loss

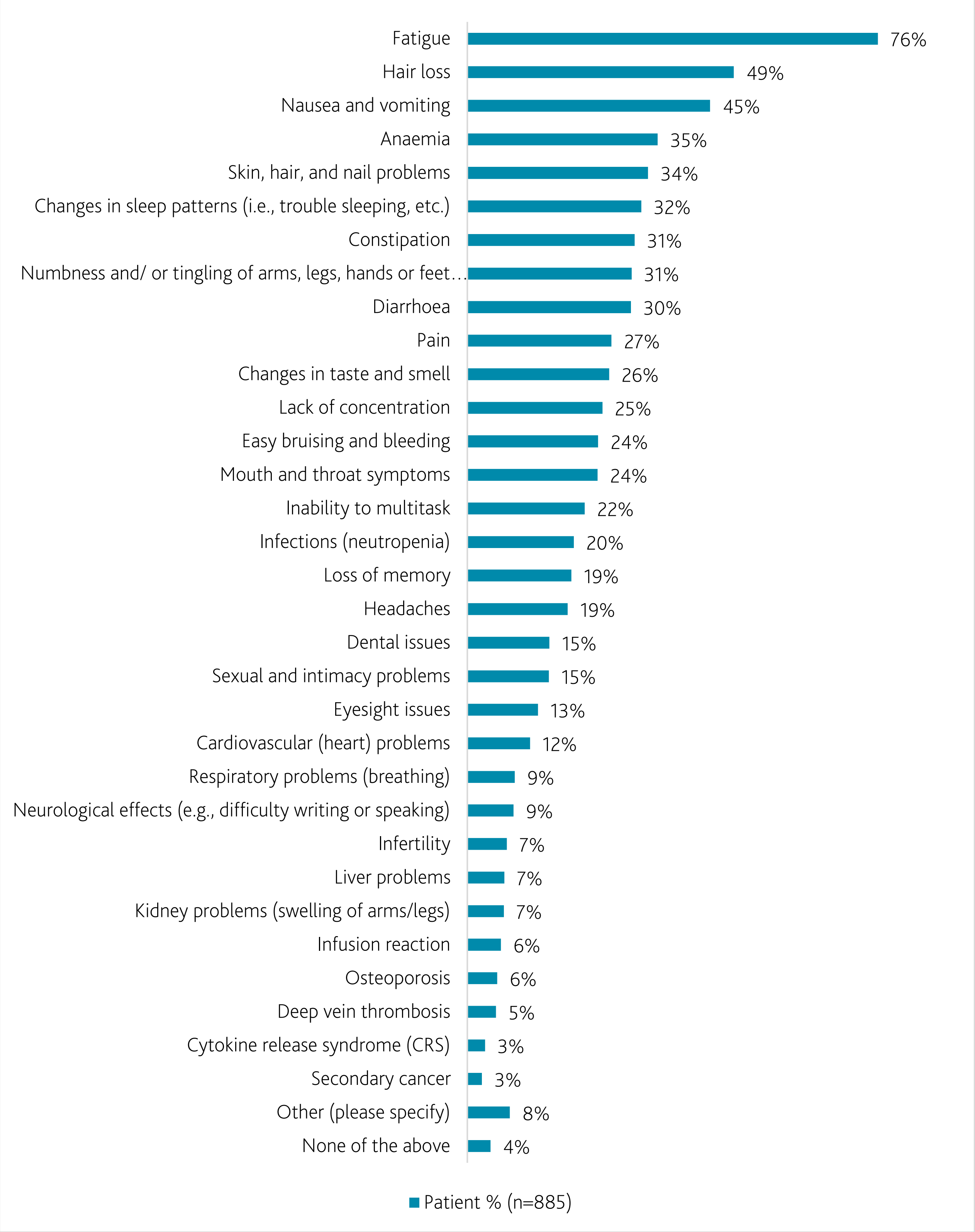
- 91% of patients who were affected by nausea and vomiting and 67% of those affected by hair loss experienced these side effects for less than 1 year.

- 70% of patients who were affected by fatigue experienced these side effects for less than five years.

- Half of patient said their medical team helped them with some of their side effects, and a quarter said they were helped with all of them.

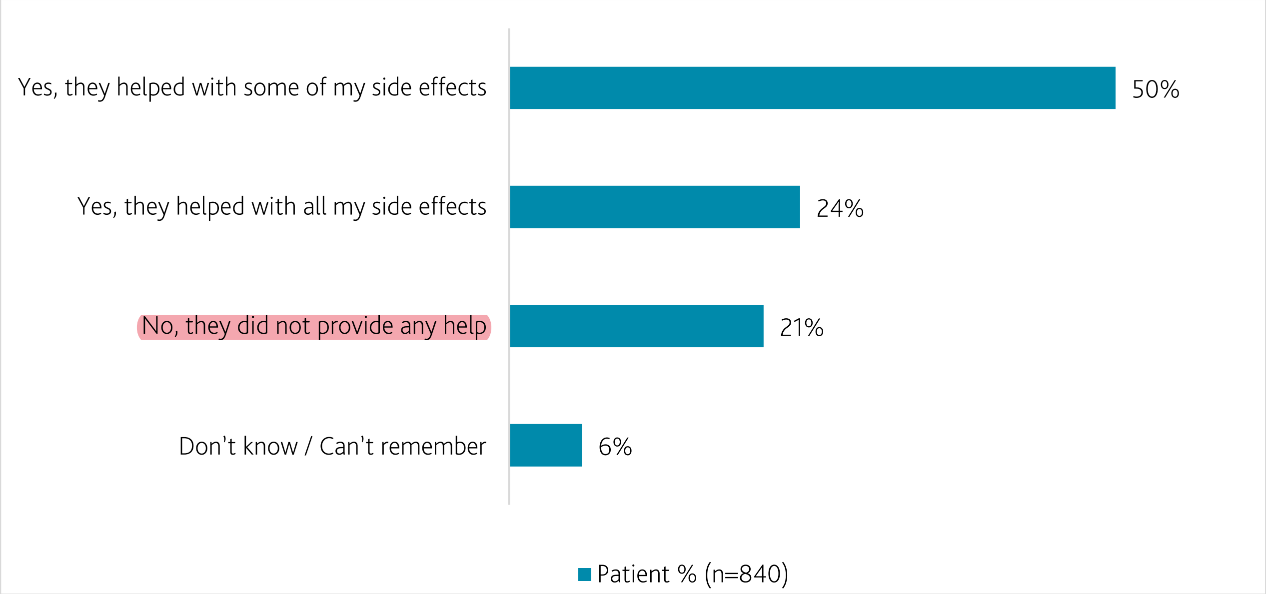
- Figure 58 shows the most commonly experienced side effects included fatigue (76%), hair loss (49%), and nausea and vomiting (45%). Only asked to those who have received treatment.

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



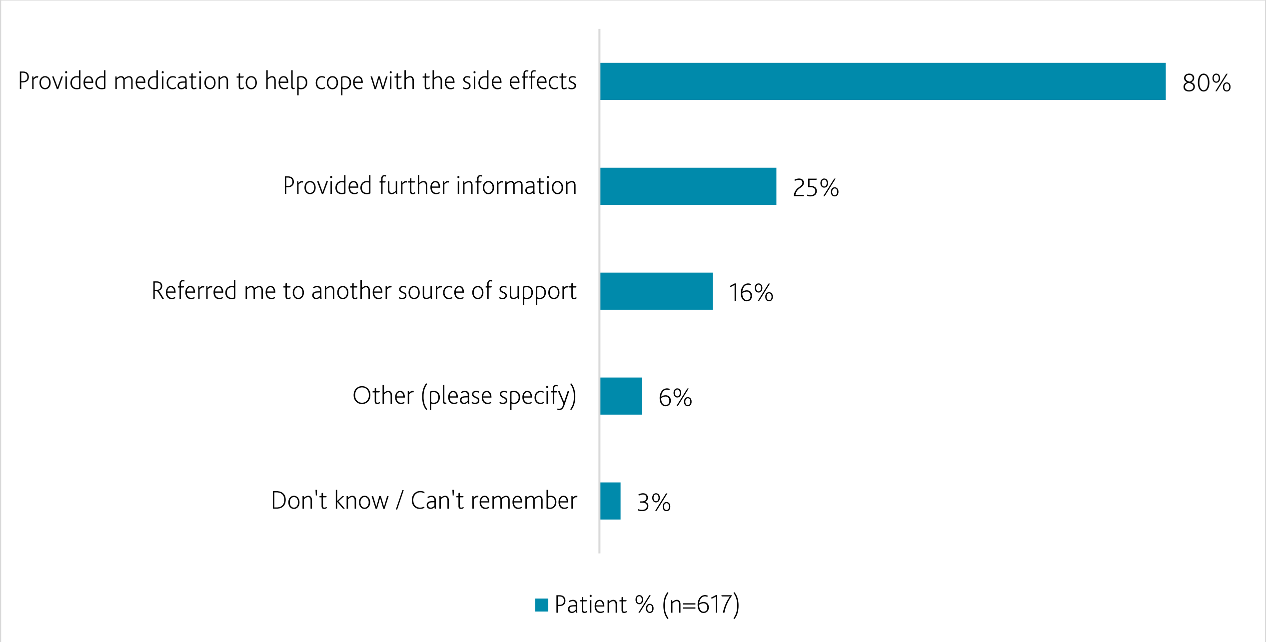
- Figure 59 shows the majority of patients said their medical team helped them with some (50%) or all (24%) of their side effects. Only asked to those who said they had side effects.

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 medication was the top reported method (80%) of help from doctors to manage side effects, followed by providing additional information (25%) and referring to another source of support (16%). Only asked to those that said the doctor helped with their side effects.

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

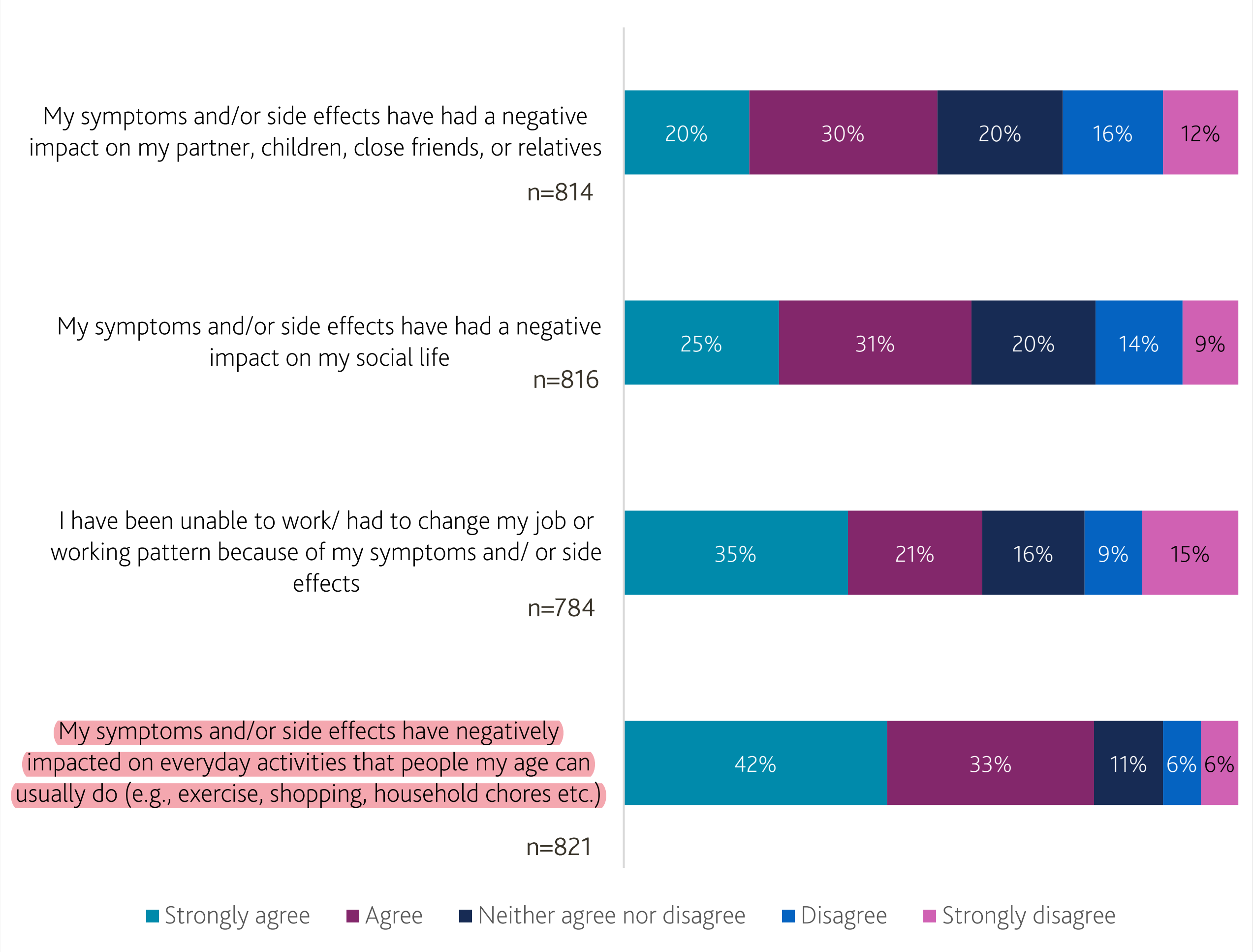


Impact of Lymphoma or CLL Symptoms and Treatment Side Effects on Quality of Life

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

- Figure 61 shows when asked about their symptoms and/or side effects, the majority of patients said they are negatively affecting many aspects of their lives. Only asked to those who said they had symptoms from their disease or side effects from treatment.

Figure 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?



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.

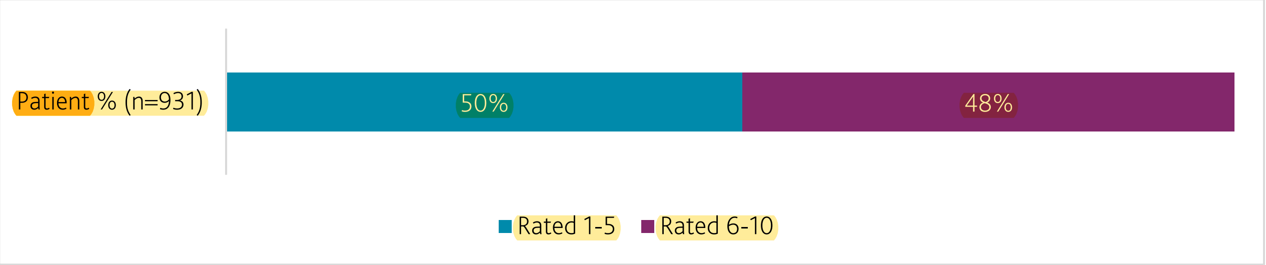
This section of the report only includes responses from patients who reported that they had fatigue either as a symptom of lymphoma (69%) and/or as a side effect of treatment (76%).

- 23% of patients didn't discuss their fatigue with their doctor over the last two years.
- 35% of patients were not provided any information to help with fatigue.
- Just over one-third of patients (36%) reported that they found balancing time schedules helpful in managing cancer-related fatigue.
- 16% of patients had a follow-up with their doctor for their cancer-related fatigue.

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

❖ Figure 62 illustrates an almost even split of patients reporting low and high levels of 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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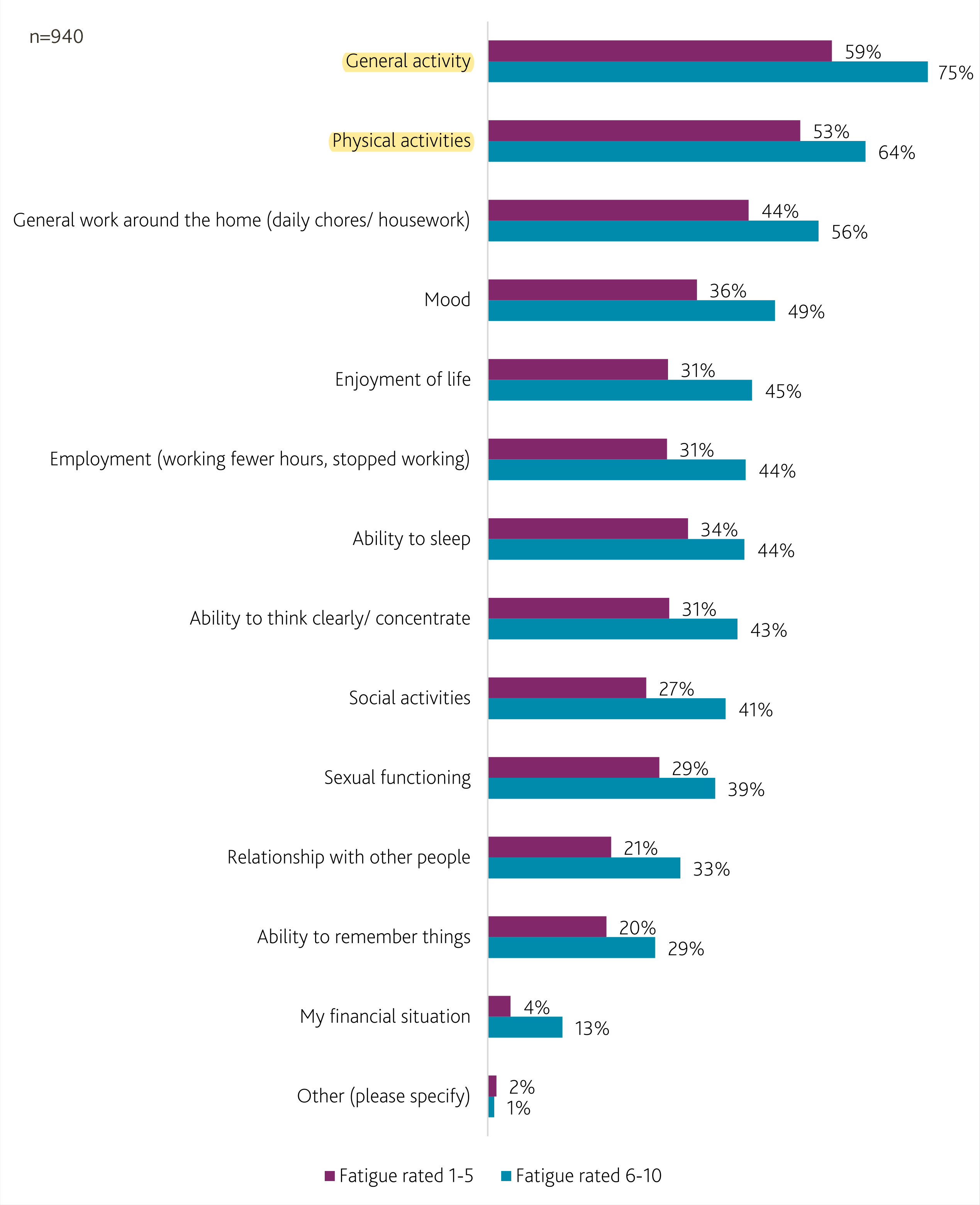
- Figure 63 illustrates patients with fatigue state it affects many aspects of their lives regardless of their fatigue rating. However, overall, people with a higher rating of fatigue (6-10) faced a greater impact on their lives. Only asked to those who reported they had fatigue.

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



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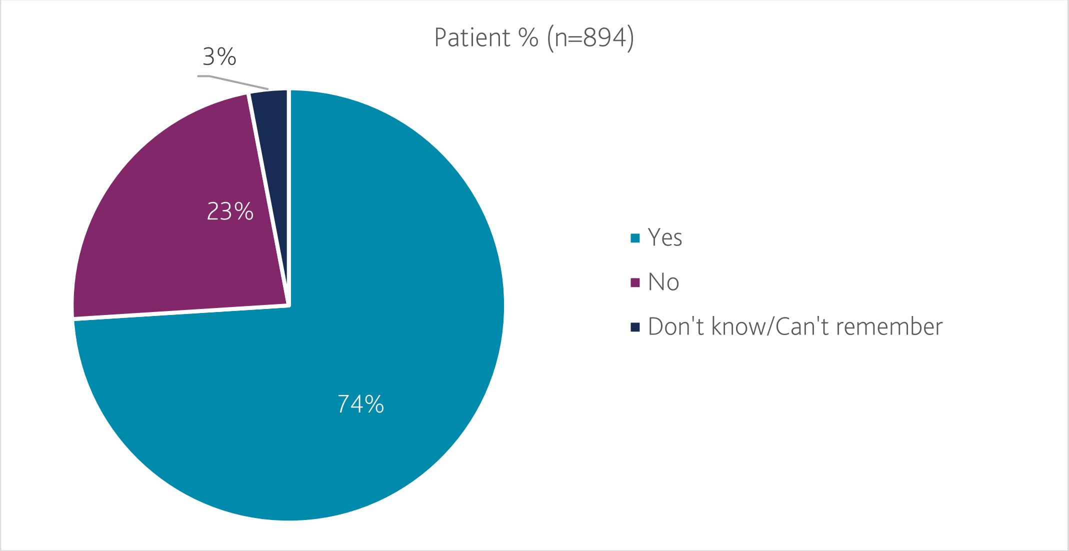
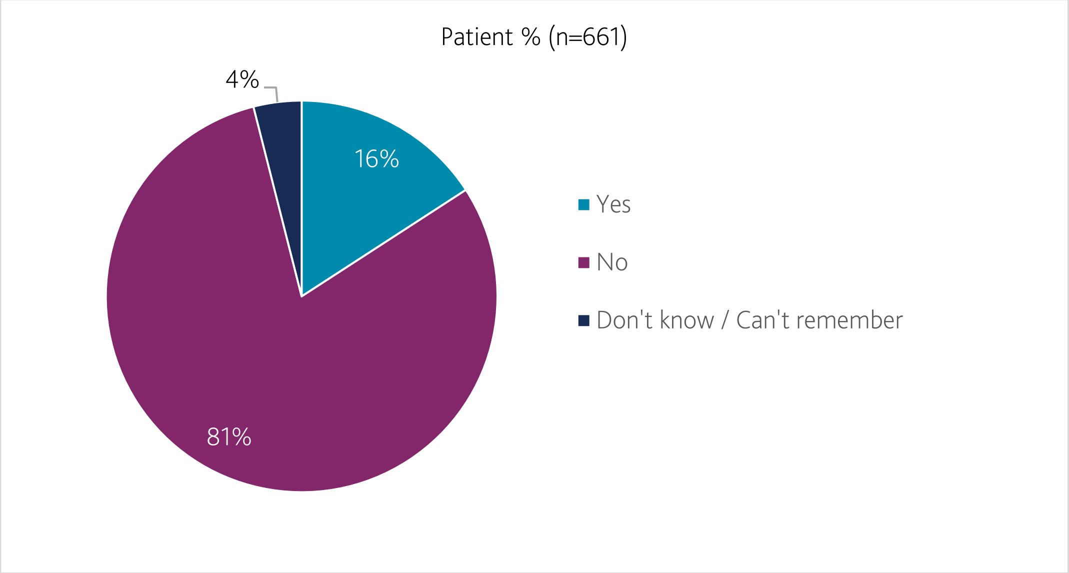
- Figure 64 reveals three-quarters of patients experiencing fatigue (74%) have discussed it with their doctor over the past two years.. Only asked to those who reported they had fatigue.

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



- Figure 65 shows most patients experiencing fatigue said their doctor did not follow up about it (81%). 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=661) were also asked what type of information they received from their doctor

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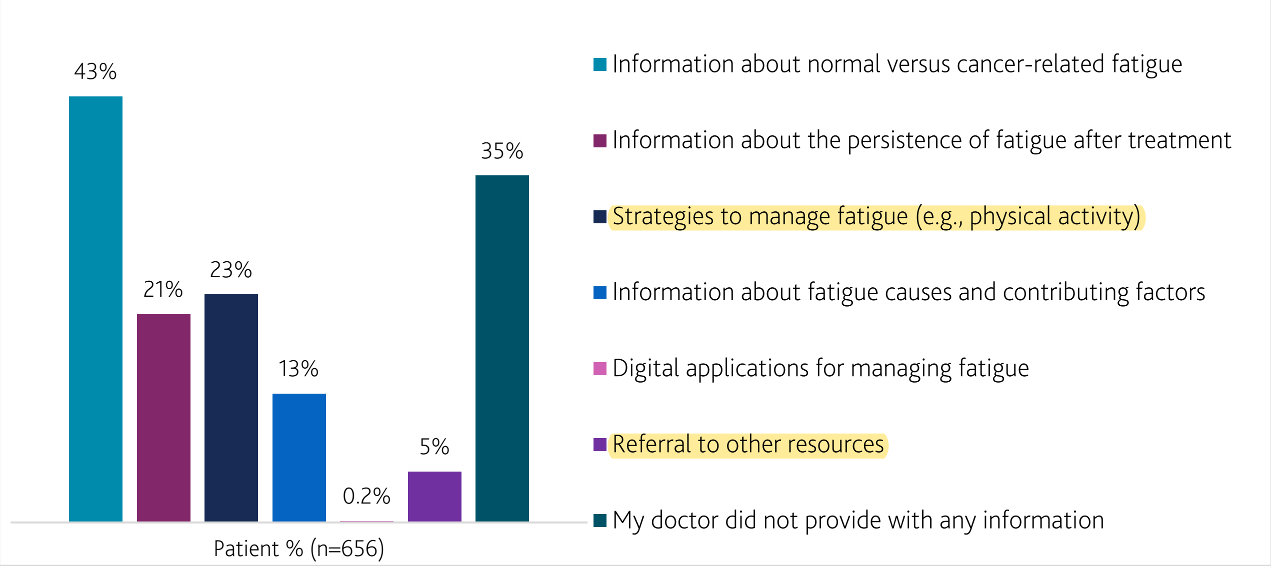
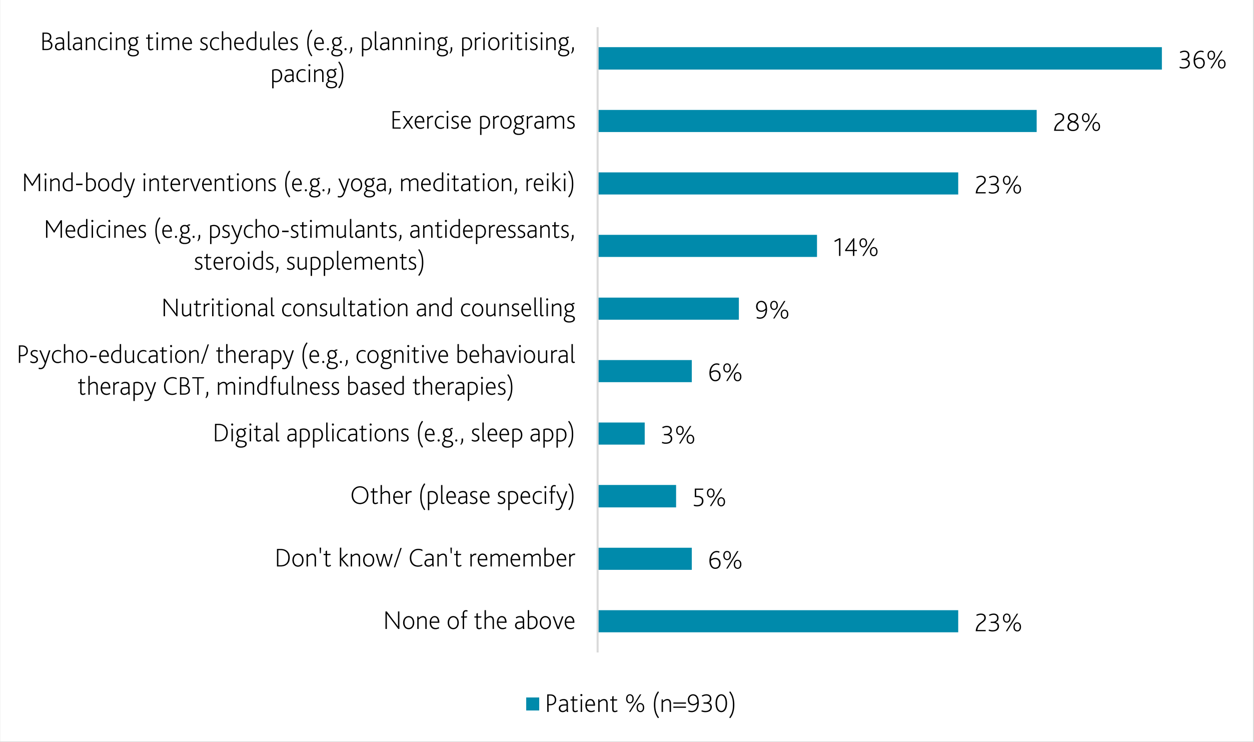
- Figure 66 illustrates that 65% of patients received some type of information about their fatigue from their doctor. Only asked to those who reported they had discussed their fatigue with their doctor.

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



- Figure 67 reveals 36% of patients found balancing schedules helpful in managing cancer-related fatigue, and 28% found exercise programs helpful. 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 half of patients (48%) who were in treatment/had had treatment or were in remission reported a fear of relapse of lymphoma and over one-third (37%) reported fear of progression of lymphoma as their biggest worries or concerns. But only about one-third of these patients definitely talked about their fears with their doctor.

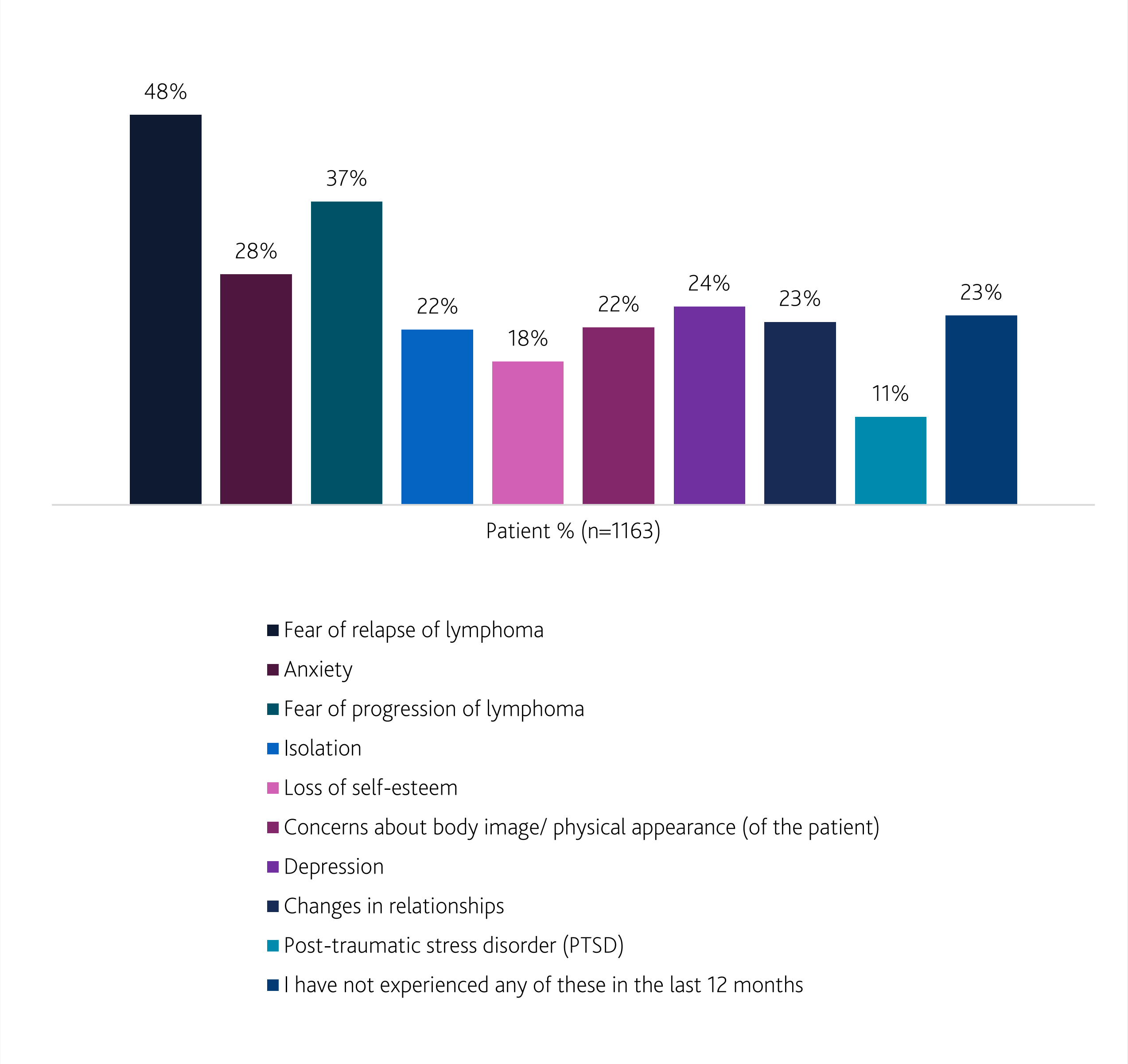
- Other psychosocial effects experienced in the last 12 months included changes in relationships (23%), concerns about body image / physical appearance (22%), Isolation (22%).

- The most provided approach by doctors to help patients cope with depression was medication (70%), which was the same for anxiety (64%).

- An empathetic / understanding approach was the most common tactic used by doctors to help patients cope with fear of lymphoma progression (47%) and fear of cancer relapse (55%).

- Figure 68 discloses when asked about psychosocial effects resulting from their lymphoma diagnoses, the top issues reported by patients were fear of relapse of lymphoma (48%), fear of progression of lymphoma (37%) and anxiety (28%).

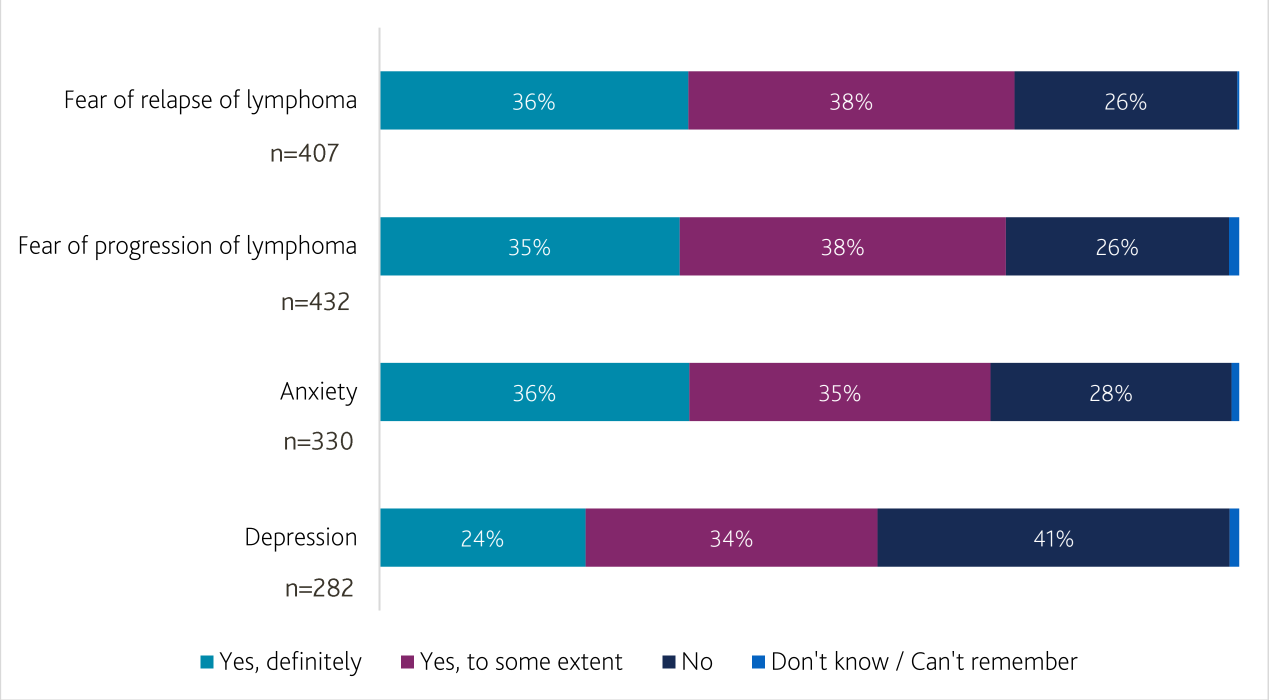
Figure 68. In the last 12 months, have you personally experienced any of the following as a result of the lymphoma diagnosis?



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.

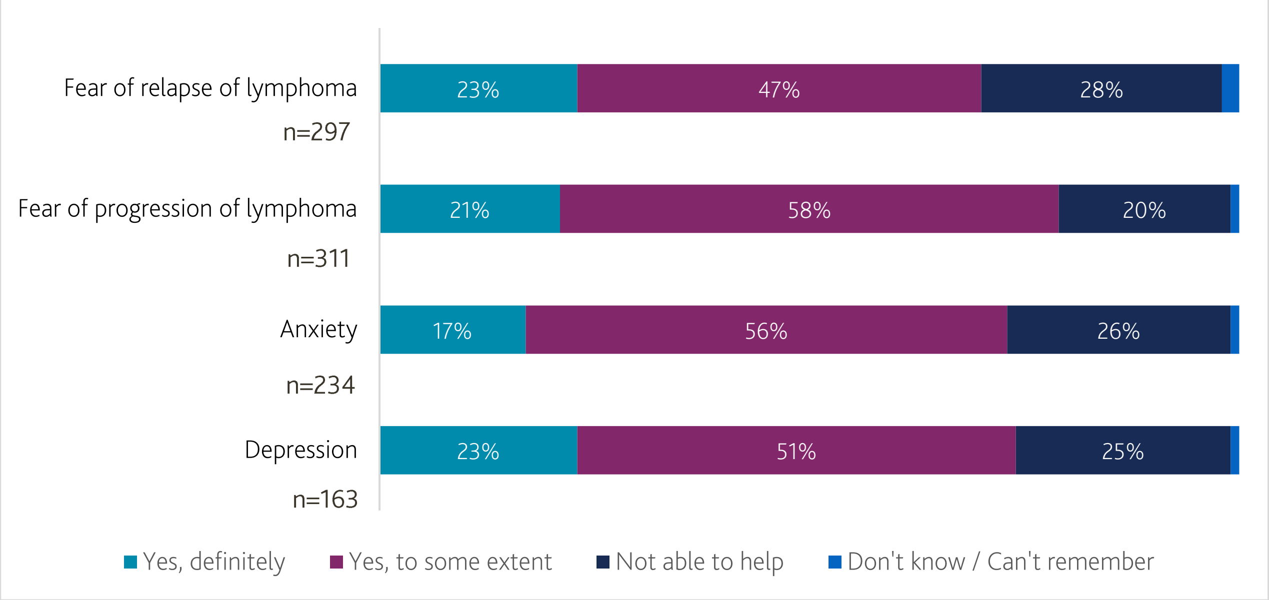
- Figure 69 reveals that patients are more likely to discuss their fear and anxiety with a doctor than their depression. Only asked to those who indicated they were affected by at least one of the following: fear of relapse, fear of progression of lymphoma, anxiety, and depression.

Figure 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 most cases the doctor was able to help fully or to some extent. Only asked to those that discussed their fear of relapse, fear of progression of lymphoma, anxiety and/or depression with their doctor.

Figure 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.



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- Table 4 illustrates regardless of the specific psychosocial issue, the most common types of help offered or recommended were and understanding approach from doctors, exercise, and participation of family/ caregiver in providing support. Only asked to those that discussed their fear of relapse, fear of progression of lymphoma, anxiety and/or depression with their doctor.

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

Help offered	Depression	Anxiety	Fear of progression of lymphoma	Fear of relapse of lymphoma
Medication to help cope with this worry or concern	70%	64%	16%	15%
Further written or verbal information	12%	13%	26%	21%
The empathetic/ understanding approach of my doctor when I told him/ her	42%	43%	47%	55%
Patient organisation or patient support group	17%	17%	24%	18%
Referral to other sources of support (e.g., social worker, therapist, counselling)	29%	21%	8%	10%
Exercise	36%	36%	44%	36%
Participation of family/ caregiver in providing support	28%	33%	28%	24%
The empathetic/ understanding approach of my nurse when I told him/ her	13%	16%	12%	12%
Eating a healthy diet	12%	13%	17%	15%
Other	8%	4%	4%	4%

- Figure 71 reveals that three-quarters of patients reported 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?

Covid-19 and Virtual Care

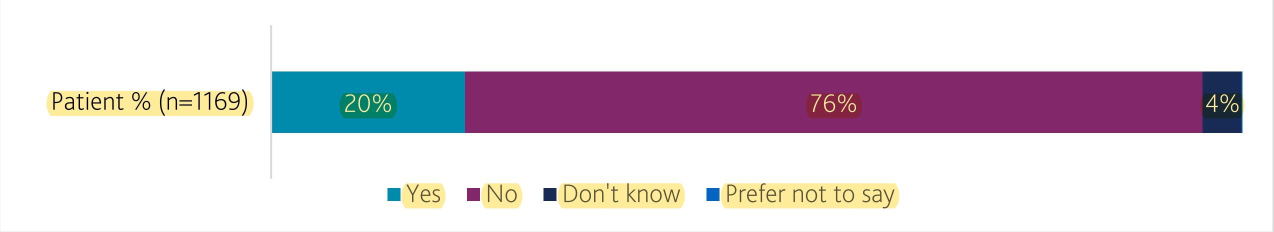
The previous two years of the Covid-19 pandemic (December 2019 to December 2021) have impacted many areas of patients' lives, notably impacting emotional well-being and experiences with fatigue.

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

- 68% of patients consider themselves at high risk for contracting Covid-19 and experiencing severe illness from it, and it worries 42% of them.
- 26% of patients reported that their anxiety was much worse and 31% said it worse during the Covid-19 pandemic.
- 14% of patients reported that their depression was much worse and 32% said it worse during the Covid-19 pandemic.
- 19% of patients avoided or delayed seeking medical attention due to the pandemic.
- The most frequently reported change to care due to Covid-19 restriction was caregivers not being allowed to come to the hospital with the patient (23%), followed by delayed, rescheduled, or cancelled outpatient treatment (12%), followed by being switched to telemedicine (9%).
- Three-quarters of patients (75%) strongly disagreed/disagreed that they preferred tele-conference (TC)/ video conference (VC) to face-to-face visits, while only 8% strongly agreed/agreed that they preferred it.

❖ Figure 72 shows three-quarters of patients have not contracted Covid-19.

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



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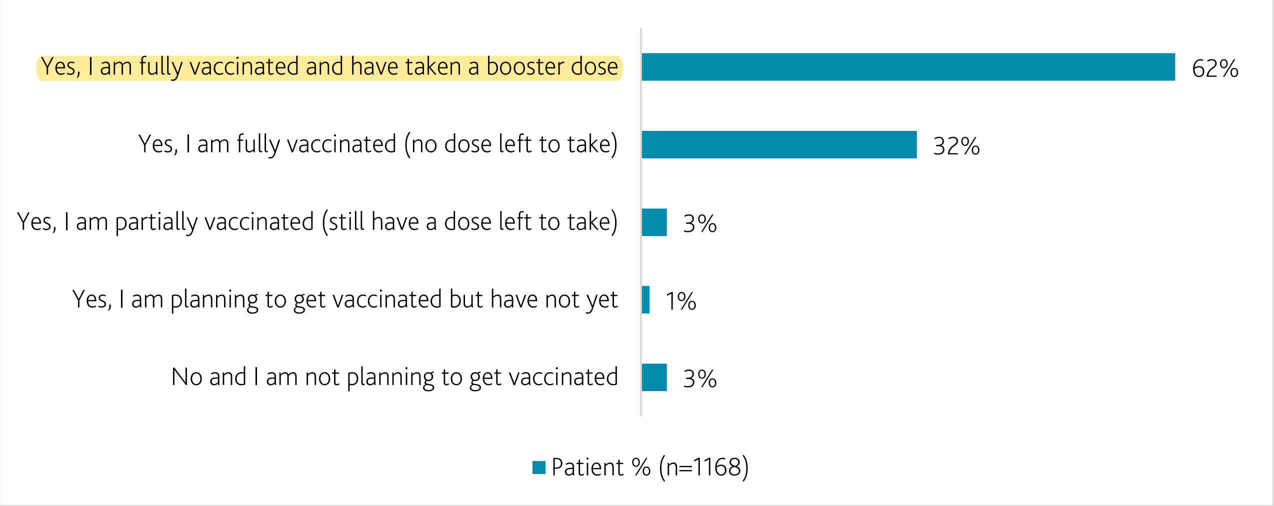
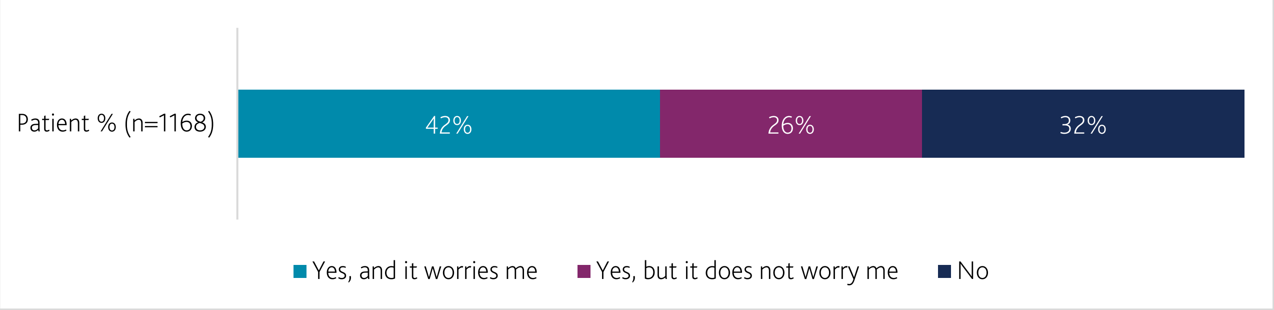
- Figure 73 illustrates that 94% of patients are fully vaccinated, and most have taken a booster dose.

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



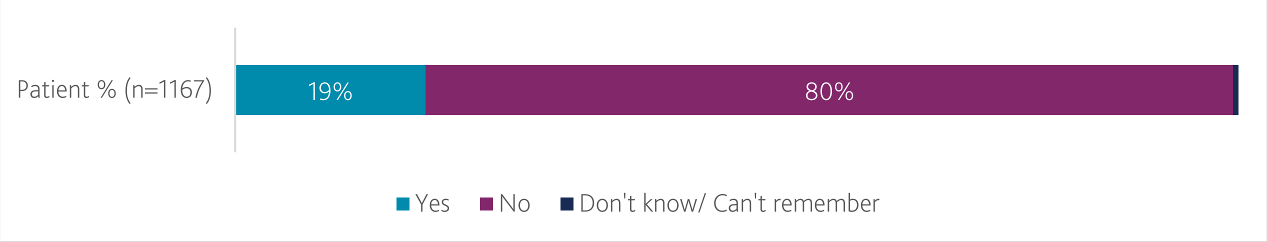
- Figure 74 shows that 68% of patients consider themselves as high risk of contracting Covid-19 and it worries 42% of them.

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



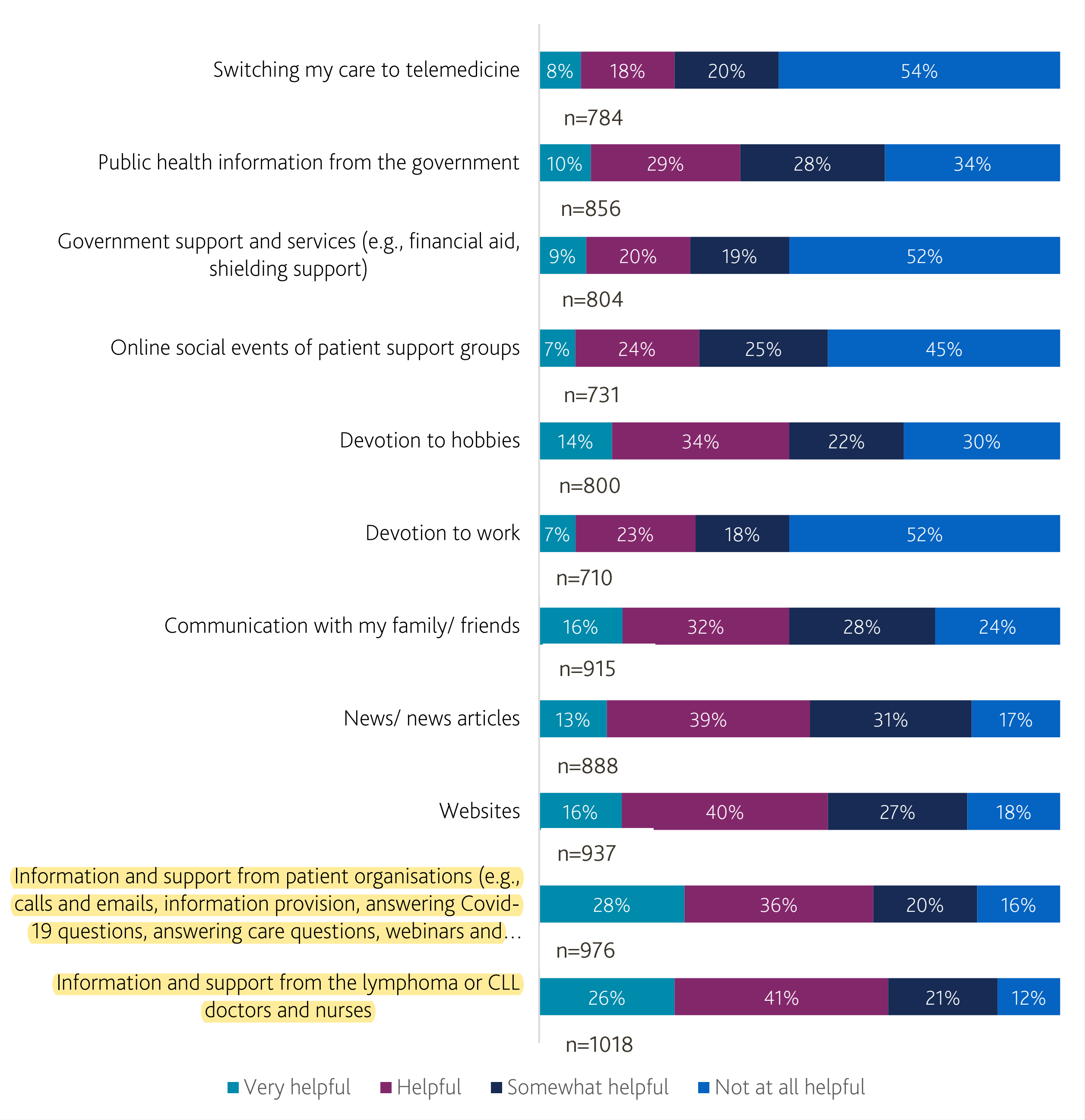
- Figure 75 reveals one in five patients avoided or delayed seeking medical attention for their lymphoma or CLL during the Covid-19 pandemic.

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



- Figure 76 illustrates that 54% of patients said switching care to telemedicine has been not helpful in providing support for lymphoma or CLL during the Covid-19 pandemic. What was helpful was information from doctors and nurses (67%), and patient organisations (64%).

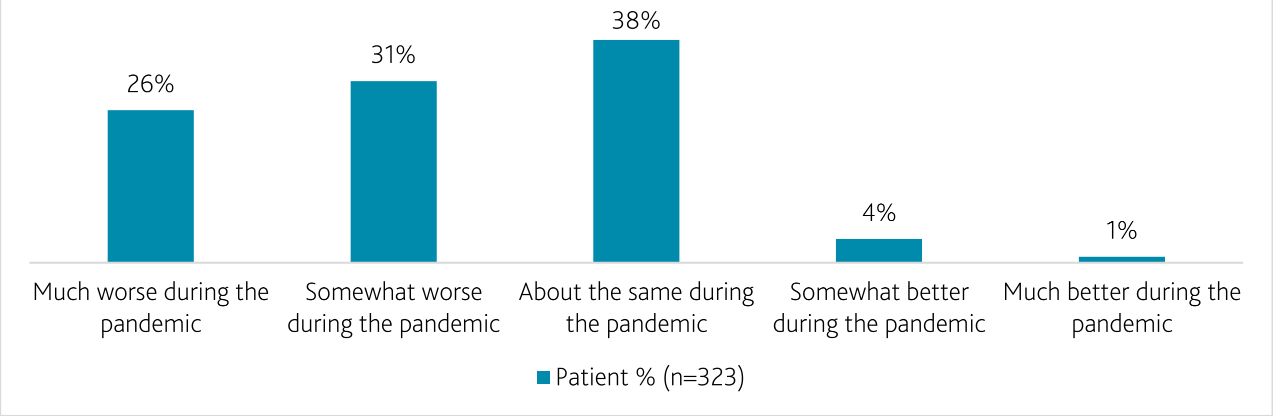
Figure 76. Please indicate how helpful, if at all, the following have been in providing support regarding lymphoma or CLL and the impact of Covid-19 pandemic.



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

- Figure 77 reveals that over half of patients (57%) felt their level of anxiety was worse during the pandemic. Only asked to those who indicated they had anxiety.

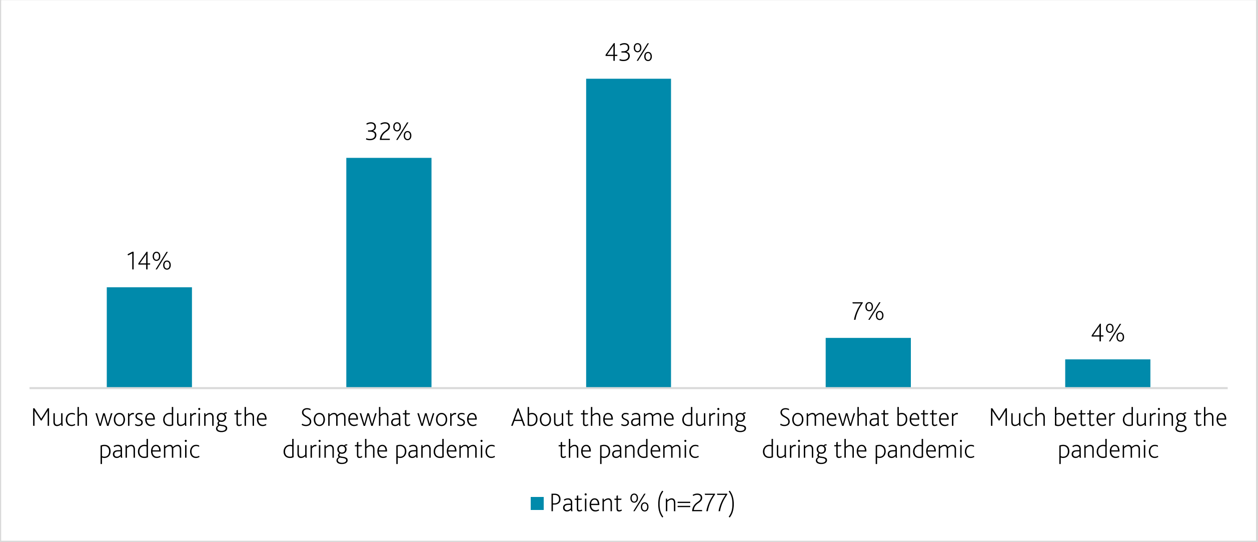
Figure 77. Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.



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 nearly half (46%) of patients felt that their level of depression was worse during the Covid-19 pandemic. Only asked to those who indicated they had depression.

Figure 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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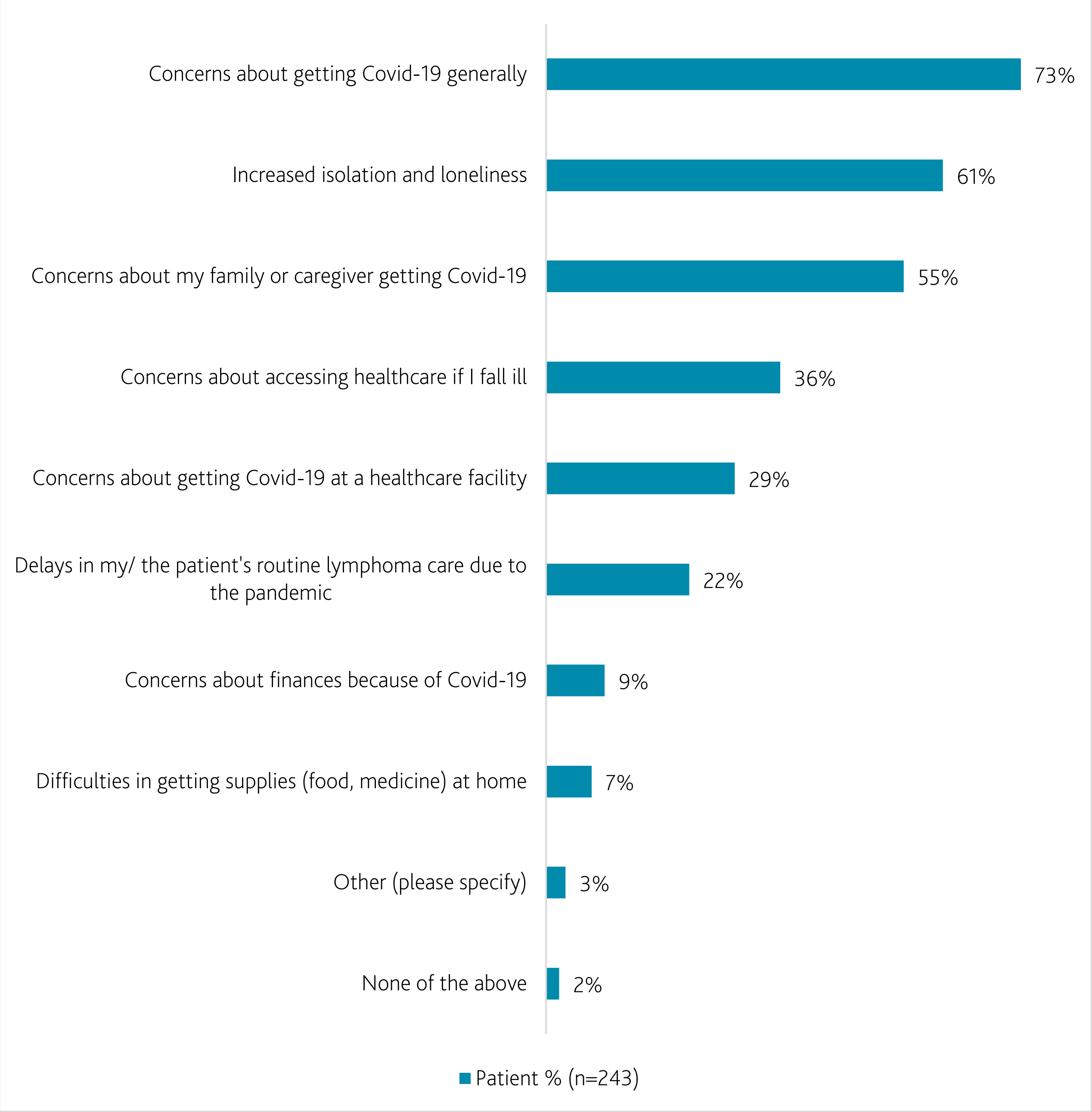
- Figure 79 illustrates that 73% of patients felt their concerns about getting Covid-19 in general was contributing to their worsened level of anxiety and/or depression, followed closely by increased isolation and loneliness (61%). Only asked to those who said they had anxiety or depression that was worse during the pandemic.

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



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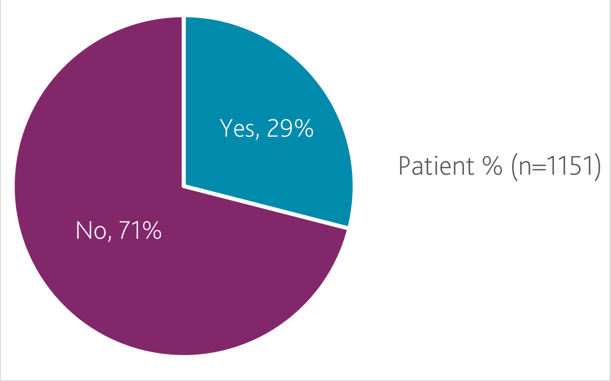
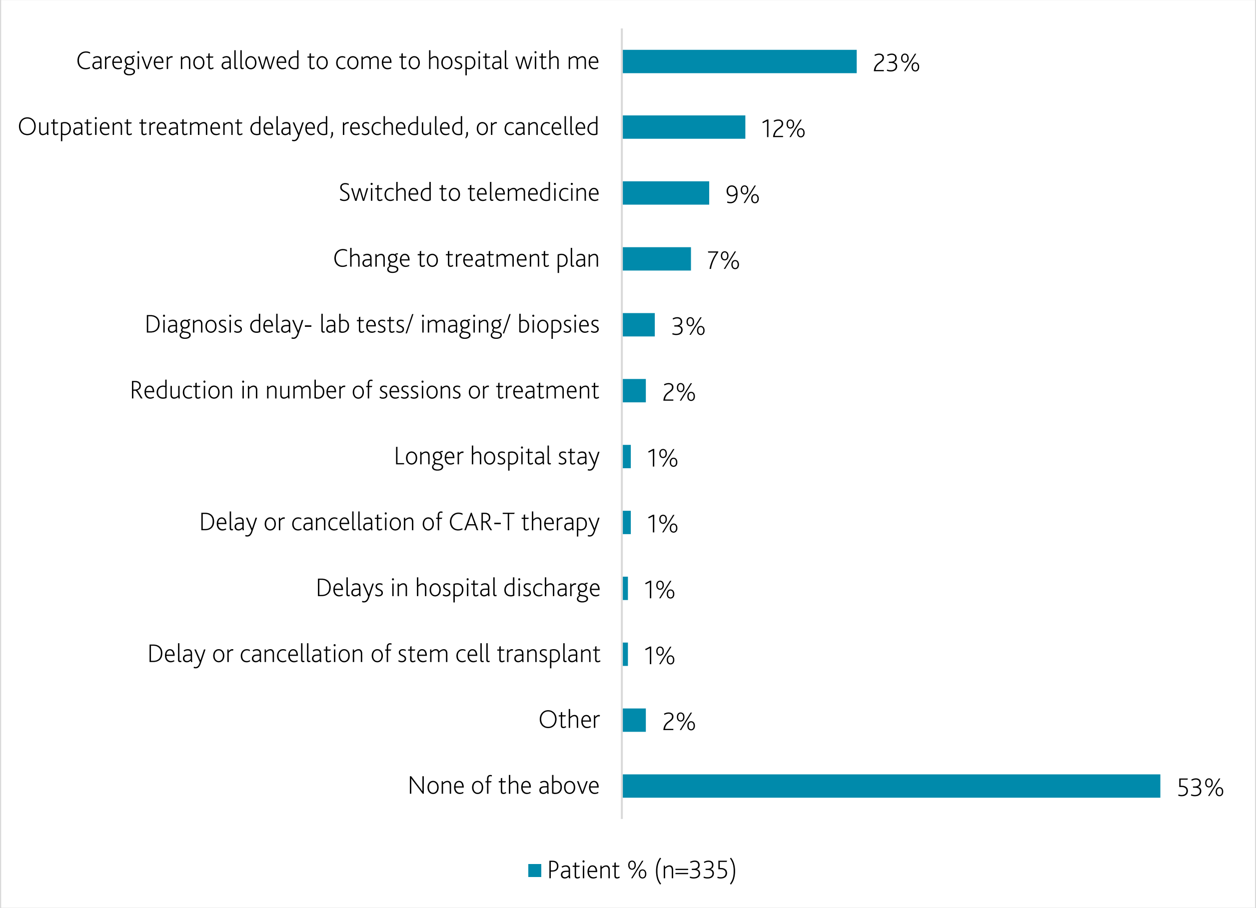
- Figure 80 shows just under a third of patients were scheduled to receive treatment for lymphoma or CLL when Covid-19 restrictions were an issue in their community.

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



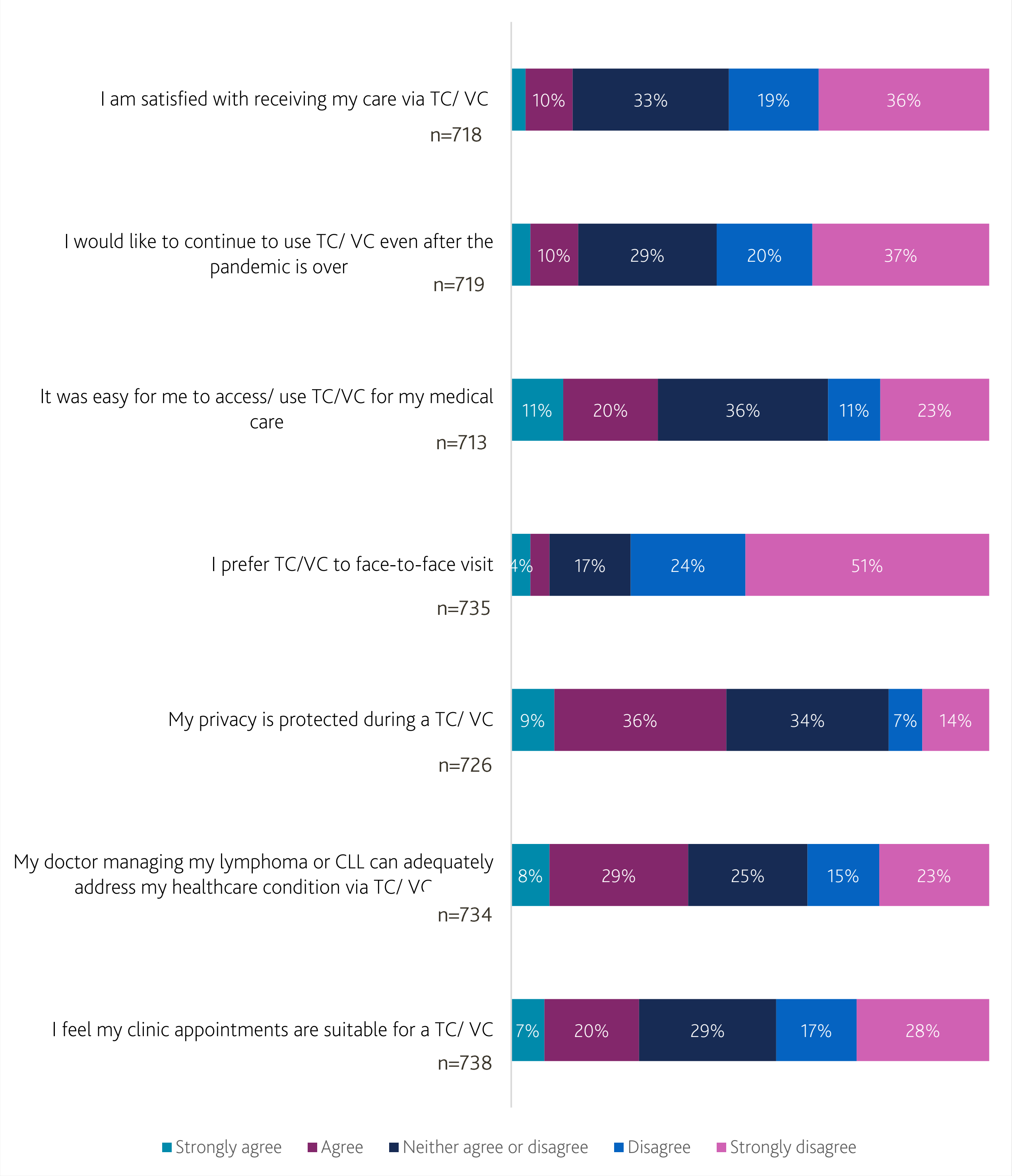
- Figure 81 explains that 53% of patients experienced no changes to care due to the COVID-19 restrictions. 23% reported their caregiver was not allowed to come to the hospital with them while 12% of patients reported outpatient treatment delayed, rescheduled, or cancelled. 9% reported they switched to telemedicine. 7% of the patients experienced changes to their treatment plan. 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?



- Figure 82 illustrates three-quarters of patients (75%) 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.

104 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:

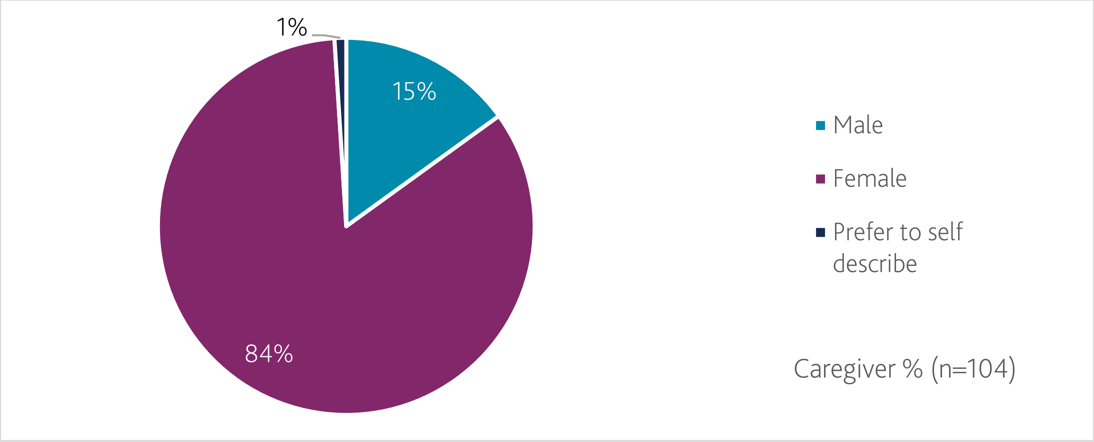
- ✓ Caregiver characteristics
- ✓ Caregiver healthcare information experience
- ✓ Healthcare decision-making
- ✓ Impact of Covid-19 on healthcare experience

Caregiver Characteristics

- 104 caregivers responded to the survey, with 40% of the respondents residing in rural areas. Most caregivers (84%) were female.
- 62% of all caregivers provide support to their spouse / partner, 20% care for their child, and 10% for their parent.

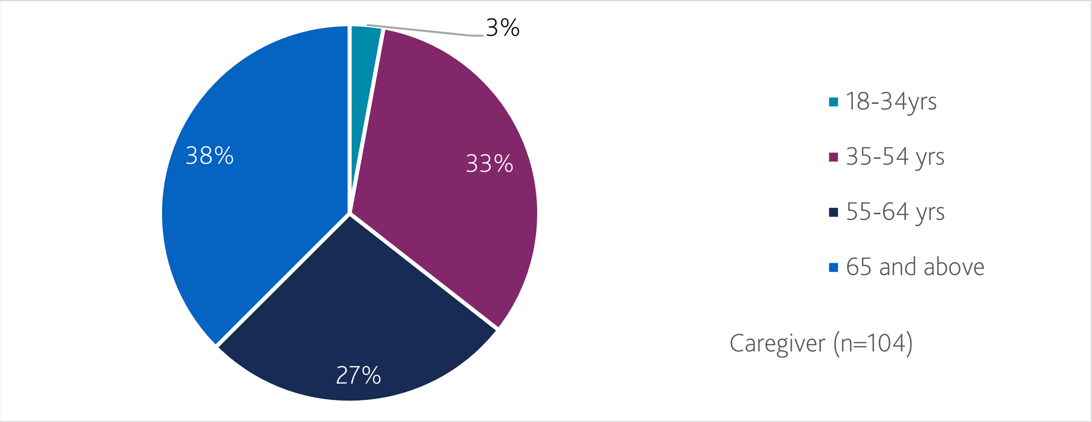
❖ Figure 83 explains the majority (84%) of caregivers are female.

Figure 83. Gender of the caregiver



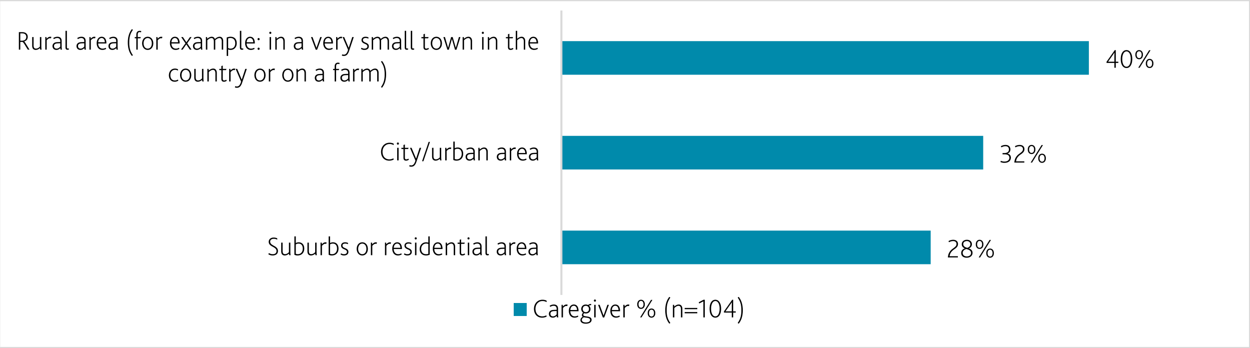
- Figure 84 shows one-third of caregivers are between the ages of 35 and 54 and another third are aged 65 and over.

Figure 84. Age range of caregivers



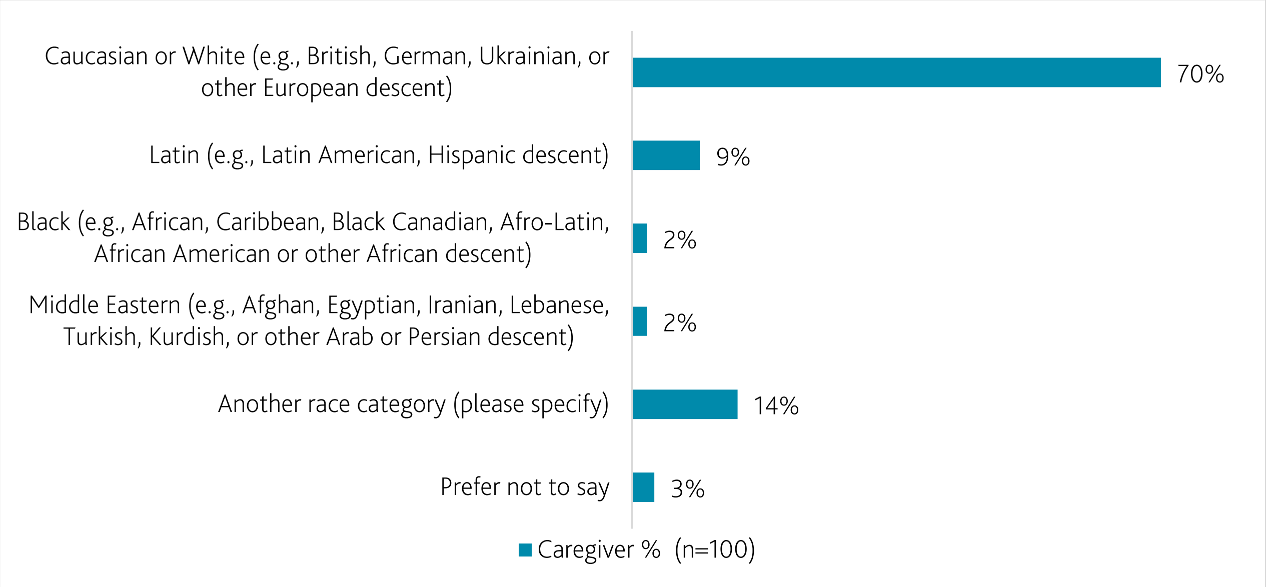
- Figure 85 describes how 40% of caregivers live in rural areas.

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



- Figure 86 illustrates 70% of caregivers identify as Caucasian.

Figure 86. How do you identify your ethnicity?



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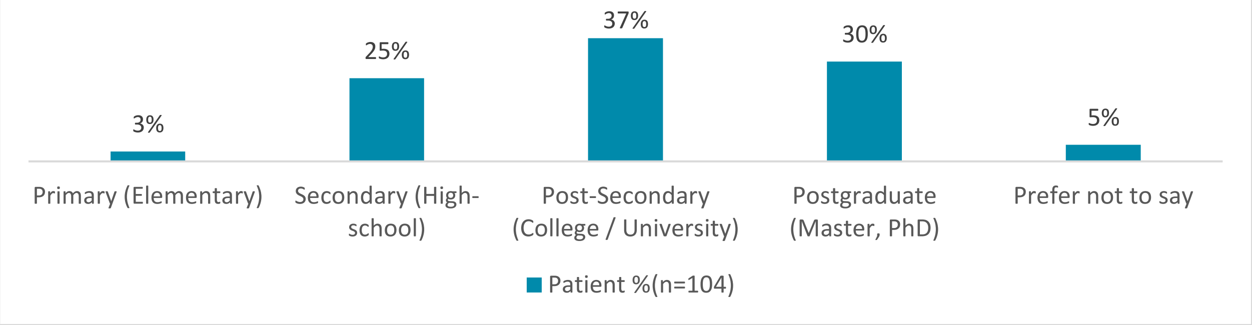
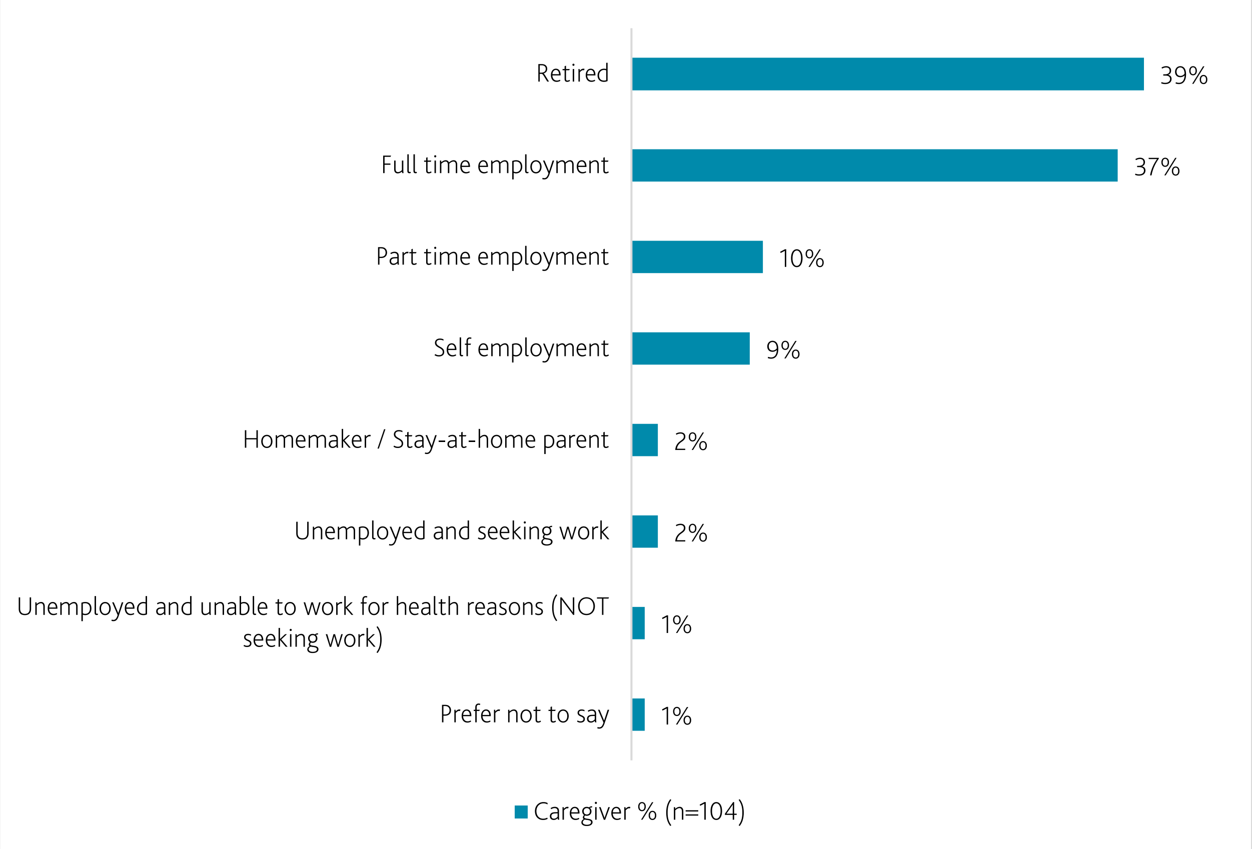
- Figure 87 shows 68% of caregivers have completed post-secondary education or higher.

Figure 87. What is your highest educational level completed?



- Figure 88 illustrates 39% of caregivers are retired and a similar amount (37%) are working full-time.

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



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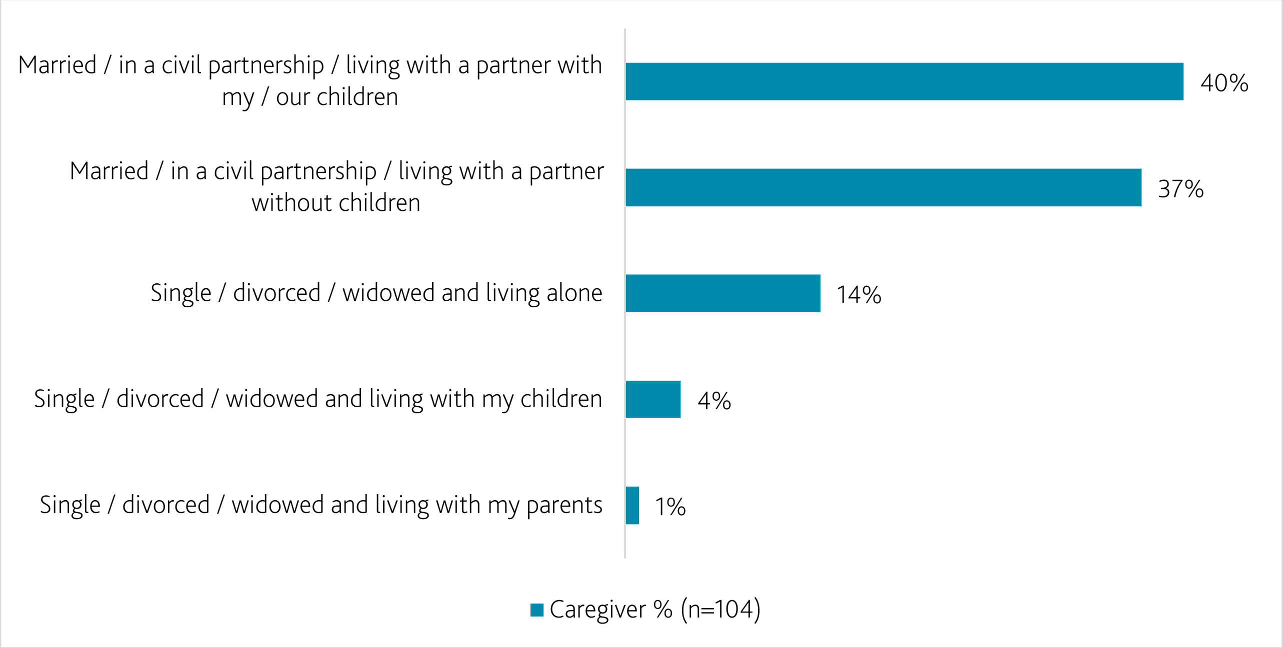
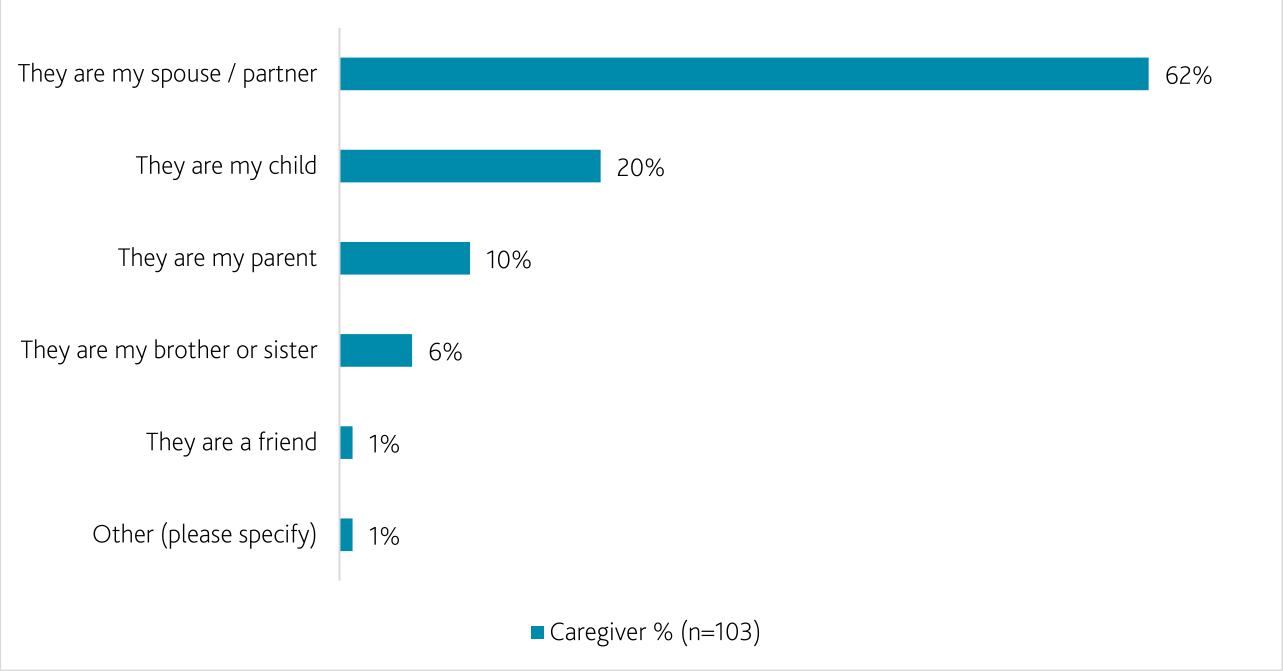
- Figure 89 reveals the majority of caregivers (77%) live with a partner, with 40% also having children living with them.

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



- Figure 90 illustrates 62% of caregivers are providing care and support to their spouse or partner, 20% to a child and 10% to a parent.

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



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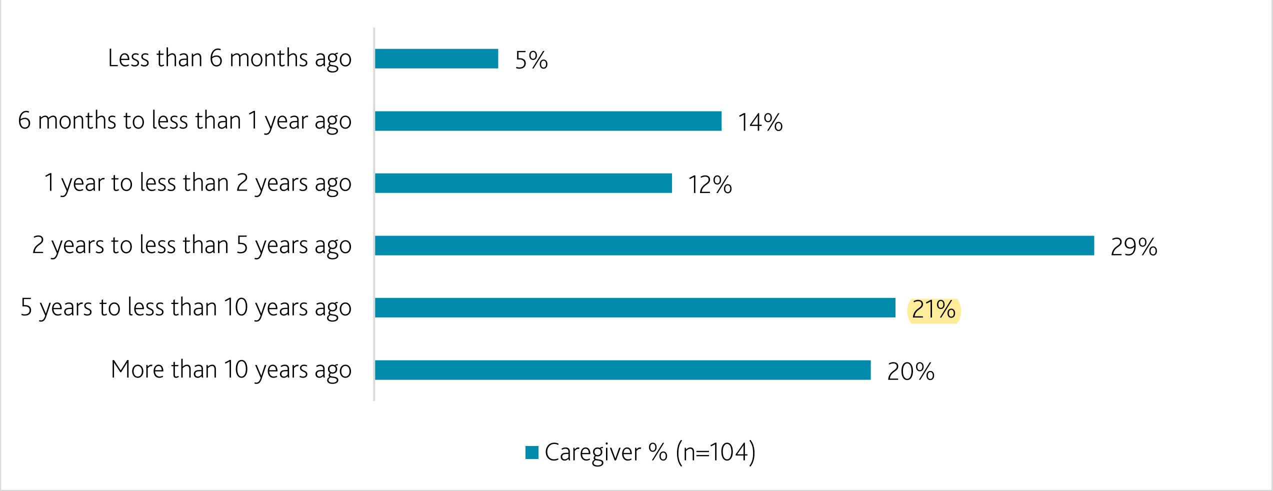
Diagnostic Demographics

- Two out of every five caregivers have been providing help for 5 years or more.
- Most caregivers reported they were providing care for patients with chronic lymphocytic leukaemia (CLL) / small lymphocytic lymphoma (SLL) (25%), followed by diffuse large B-cell lymphoma (22%), then Hodgkin lymphoma (14%).

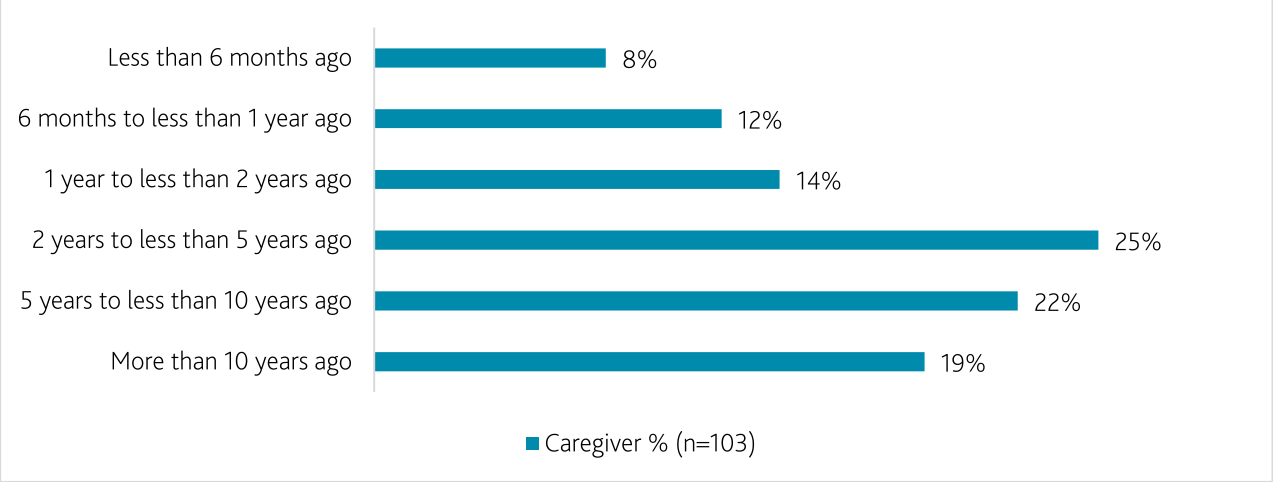
❖ Figure 91 reports that 29% are providing care to a patient who was diagnosed with lymphoma or CLL 2 to 5 years ago.

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



❖ Figure 92 shows a quarter of caregivers have been providing cancer-related care and support for 2 to 5 years, and 41% have been doing so for more 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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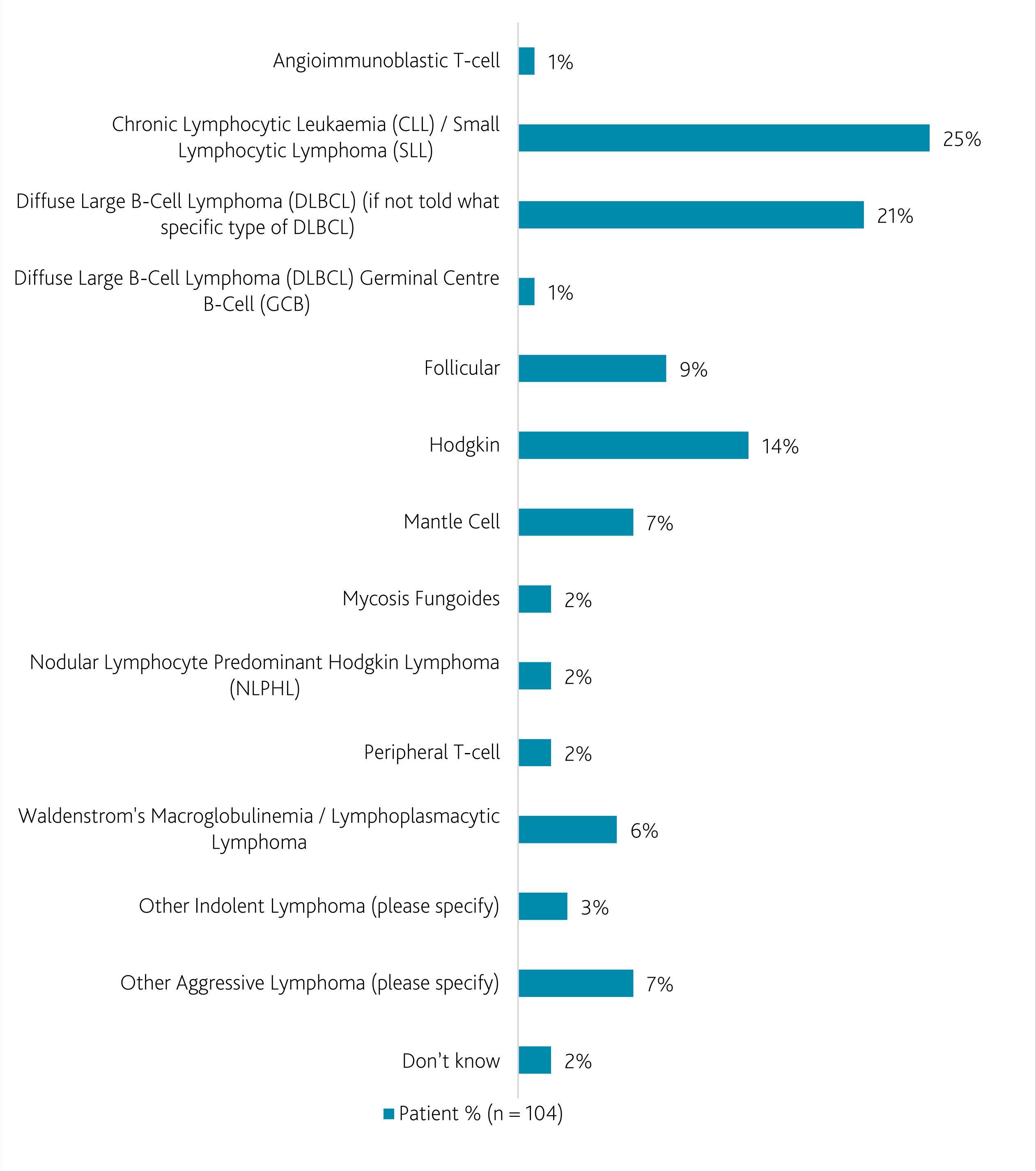
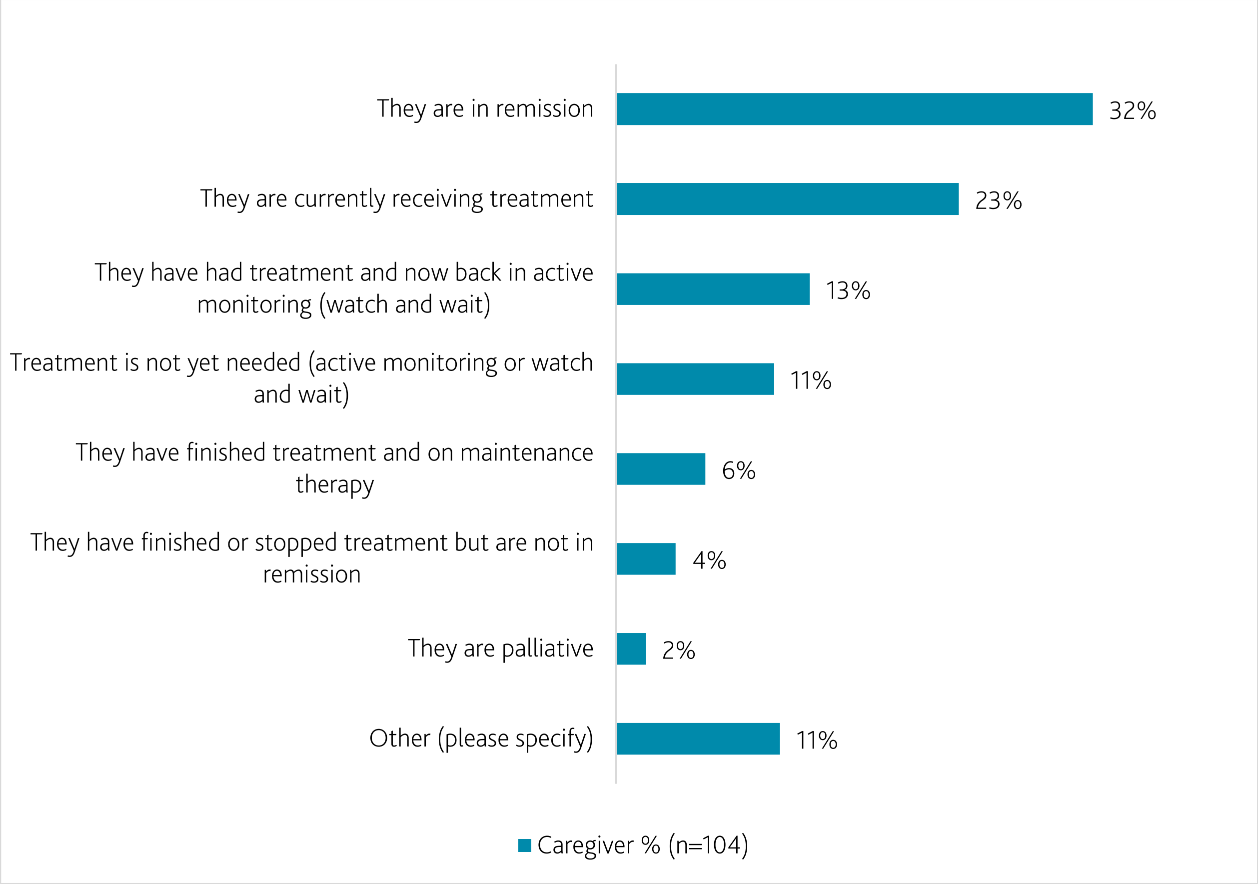
- Figure 93 illustrates when caregivers were asked about the patient they care for, the most commonly reported lymphoma subtypes included CLL (25%), DLBCL (22%), and Hodgkin lymphoma (14%).

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



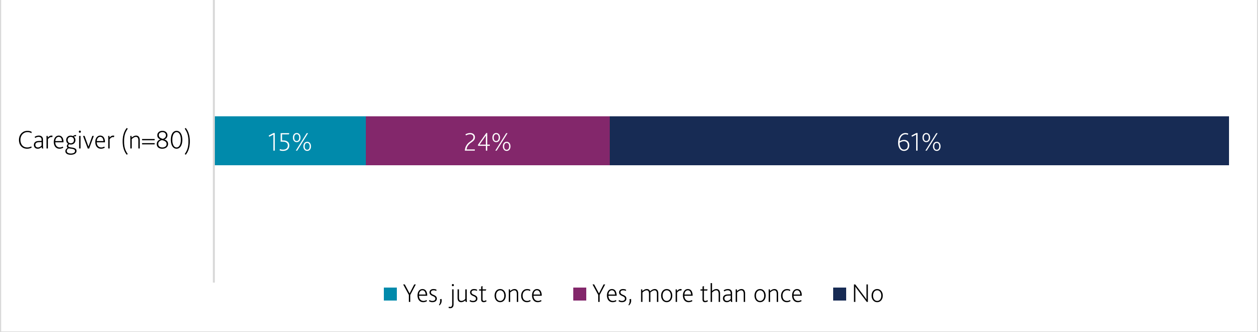
- Figure 94 shows a third (32%) of caregivers are caring for patients that are currently in remission and a quarter (23%) are currently receiving treatment.

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



- Figure 95 points out that most (61%) 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?



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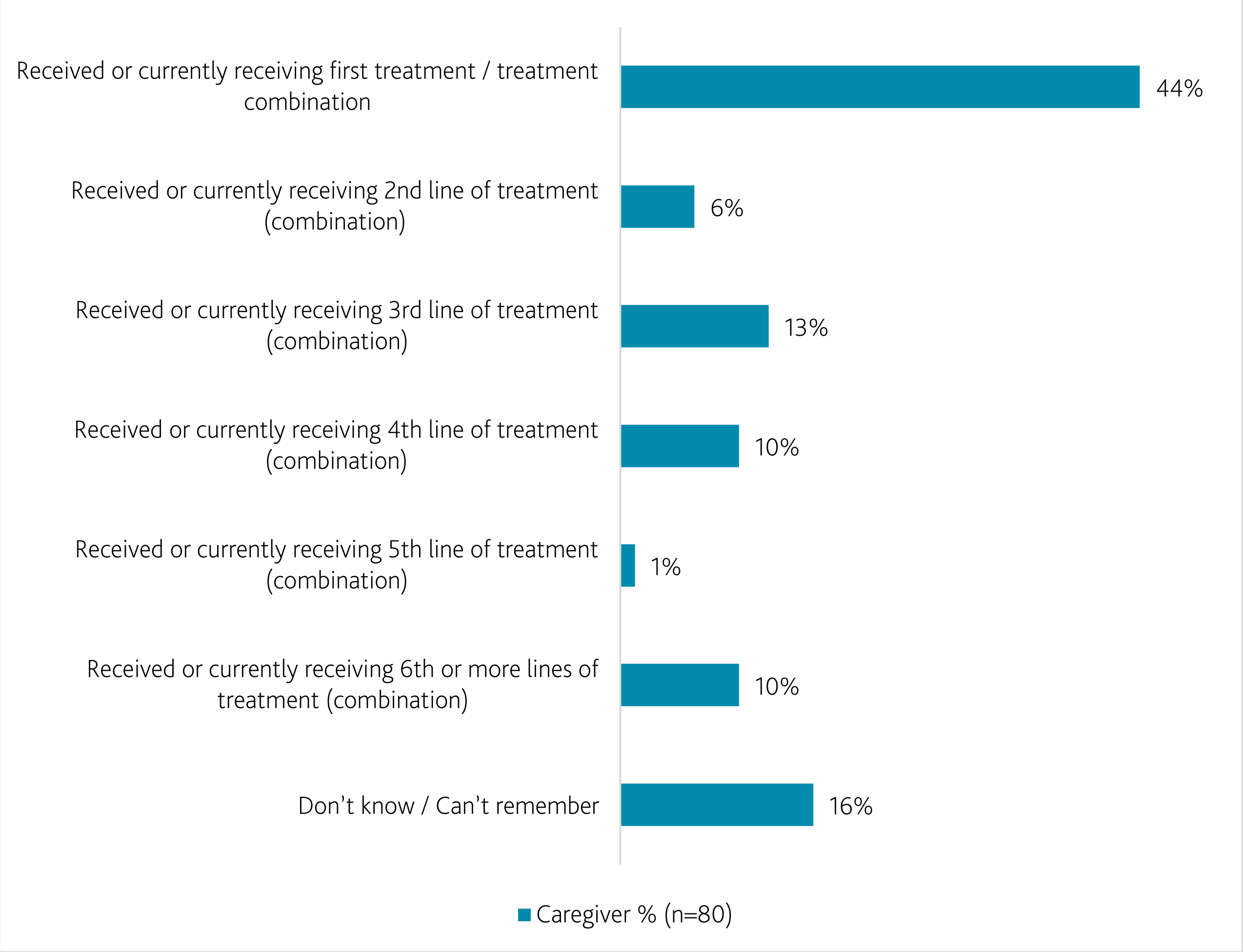
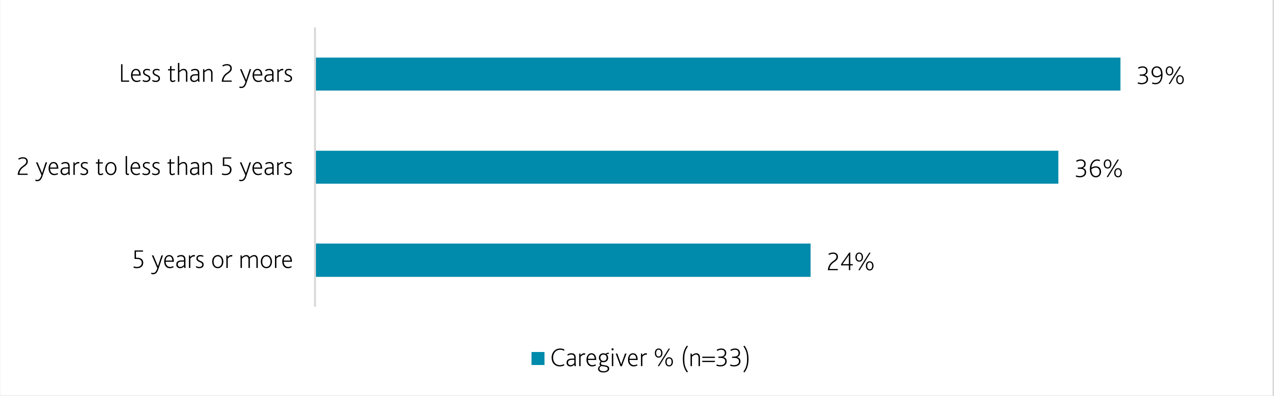
- Figure 96 illustrates that almost half of caregivers (44%) report the patient they help care for is receiving their first line of treatment or treatment combination. Only asked to caregivers who said their patient had received treatment.

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



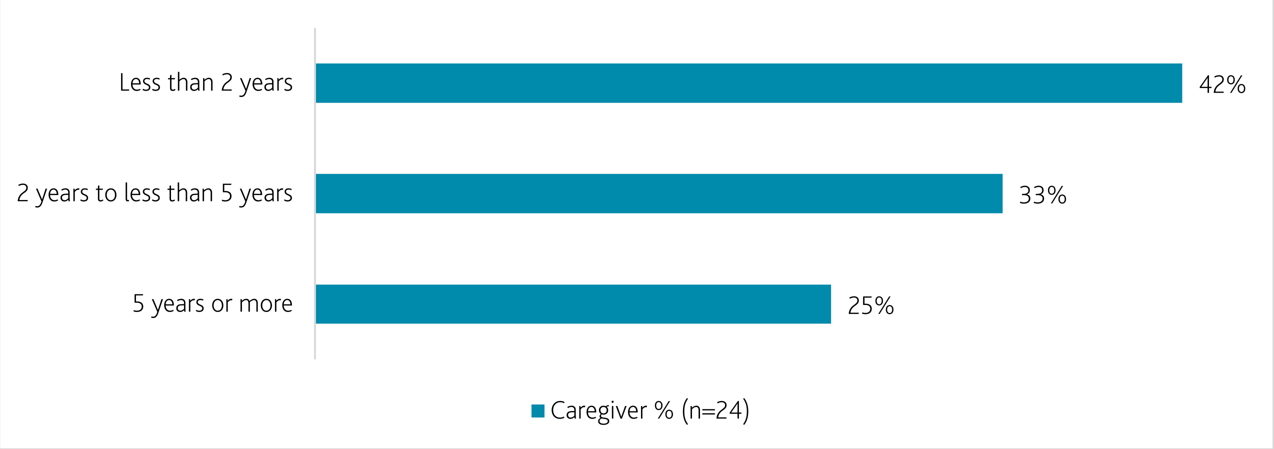
- Figure 97 reveals of the caregivers who said the patient they care for is in remission, 39% said the last treatment was less than 2 years ago, and 36% said it was between 2 and 5 years ago. Only asked to caregivers who said their patient was in remission.

Figure 97. You have said that the patient is in remission, how long has it been since the last treatment?



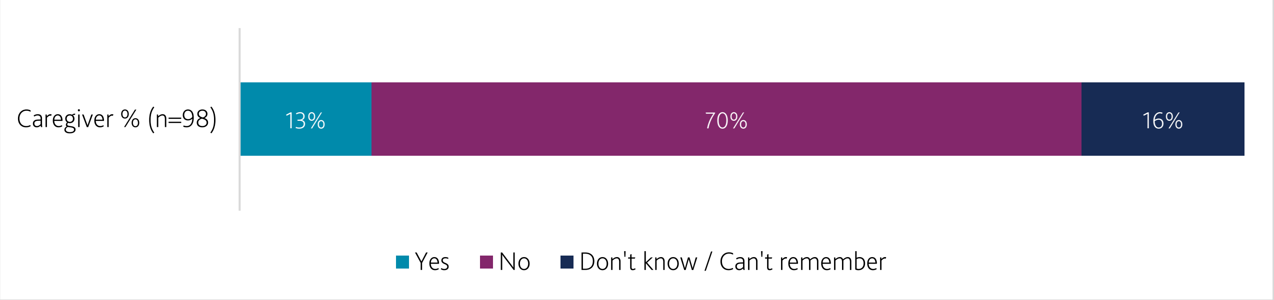
- Figure 98 illustrates of the caregivers who said the patient they care for is in active monitoring, the majority (42%) said it had been for less than 2 years. Only asked to caregivers who said their patient was in active monitoring.

Figure 98. How long has the patient been in active monitoring (watch and wait)?



- Figure 99 shows the majority of caregivers (70%) said the lymphoma of patient they care for has not transformed.

Figure 99. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?



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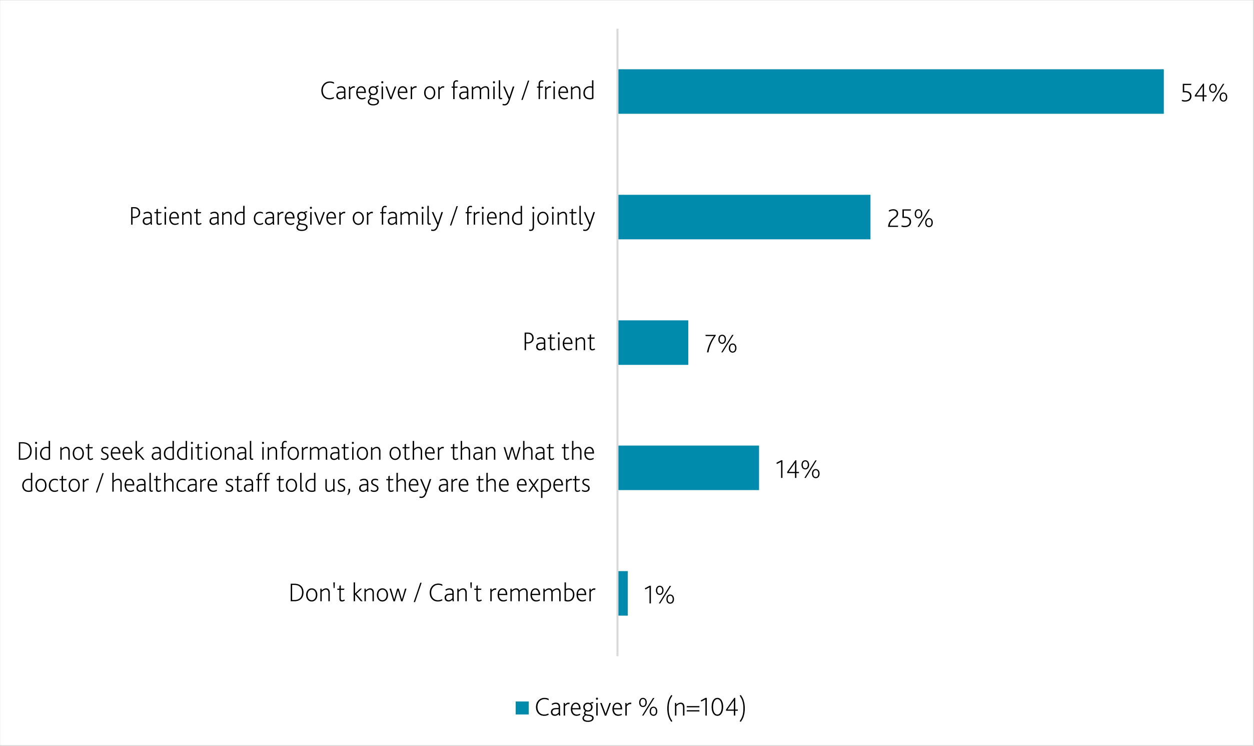
Healthcare Information

- 79% of caregivers report seeking out additional information about the patient's diagnosis, above what they were told by the medical team.
- 60% of caregivers reported being well informed, or very well informed about the processes and stages of the patient's healthcare. 23% felt ill-informed.
- Caregivers preferred sources of information on lymphoma and CLL are oral information from healthcare providers (60%), followed by websites (56%), and booklets / written information (39%).

❖ Figure 100 says half of caregivers (54%) said they sought out information about the disease and treatment following diagnosis, and a quarter (25%) said they did it jointly with the patient.

Figure 100. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



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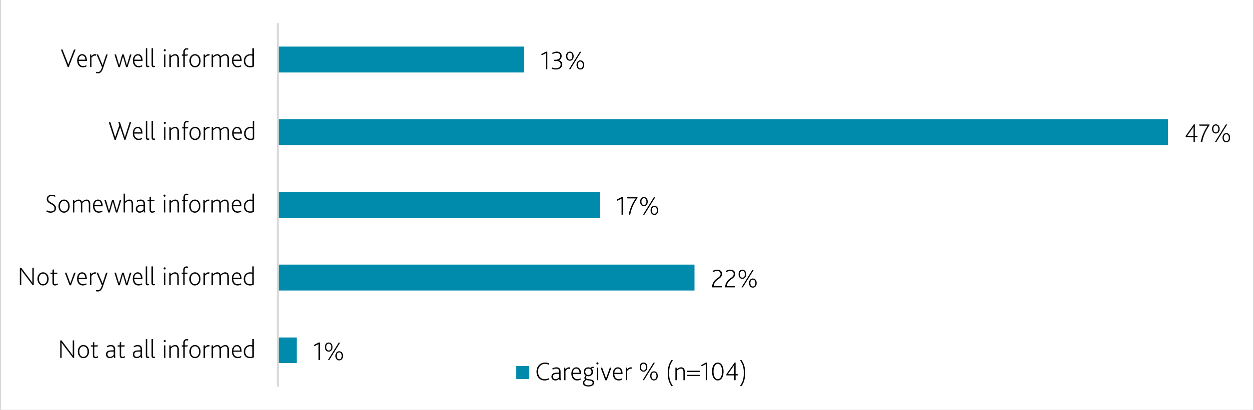
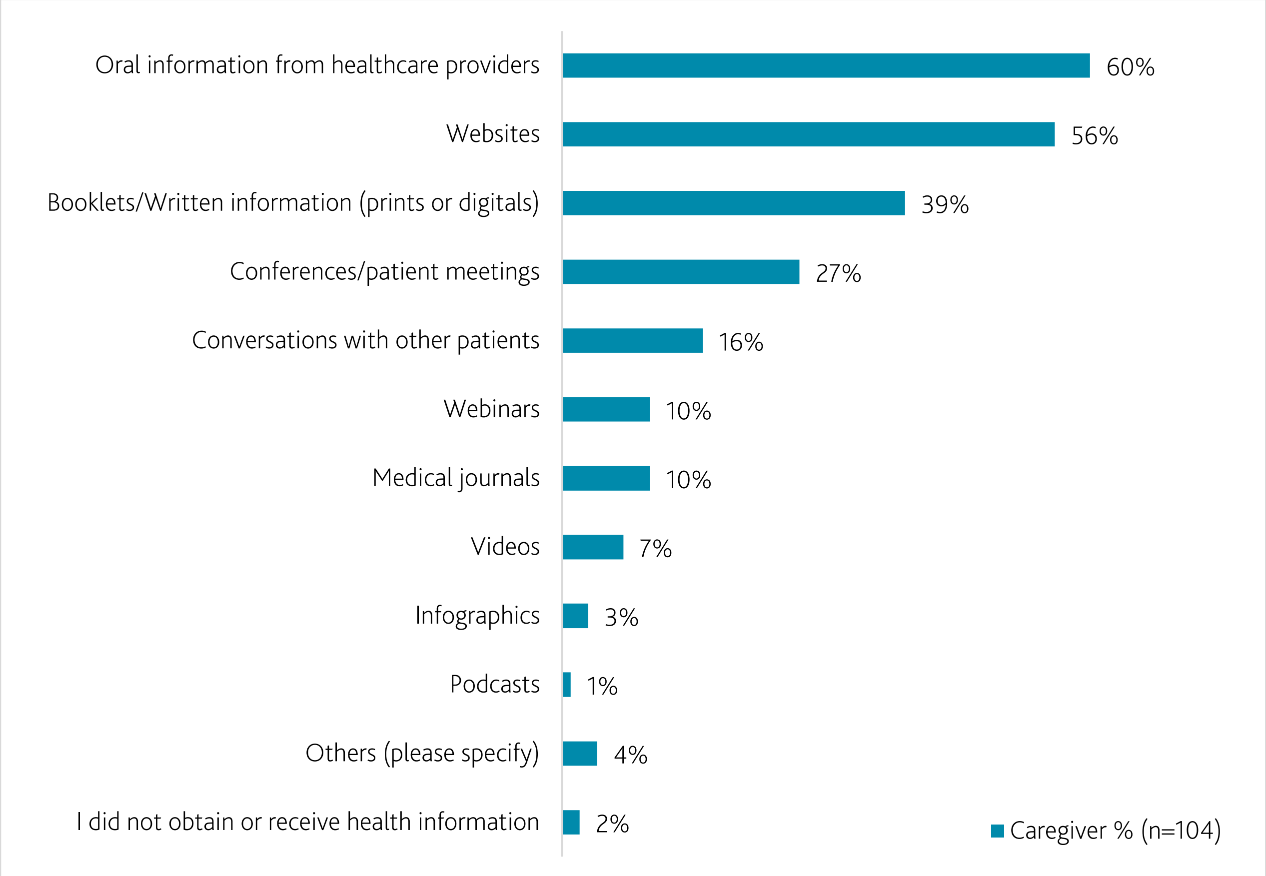
- Figure 101 reveals a quarter (23%) of caregivers felt not at all or not very well informed about the process and stages of the patient's healthcare.

Figure 101. 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?



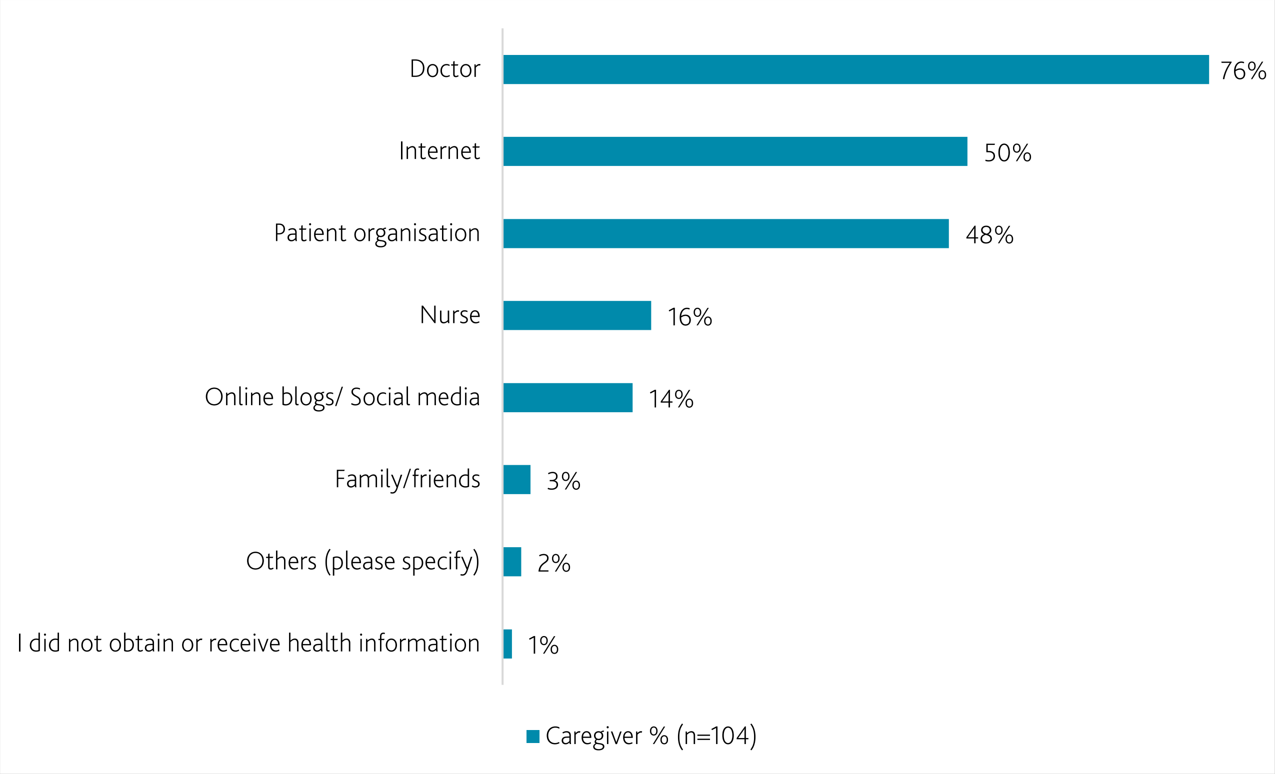
- Figure 102 explains the majority of caregivers prefer receiving oral information from healthcare professionals (60%) to source information about lymphoma or CLL, followed closely by websites (56%), and booklets or other written information (39%).

Figure 102. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



- Figure 103 reveals caregivers reported their preferred sources for lymphoma or CLL information as doctors (76%), followed by the internet (50%) and patient organisations (48%).

Figure 103. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?



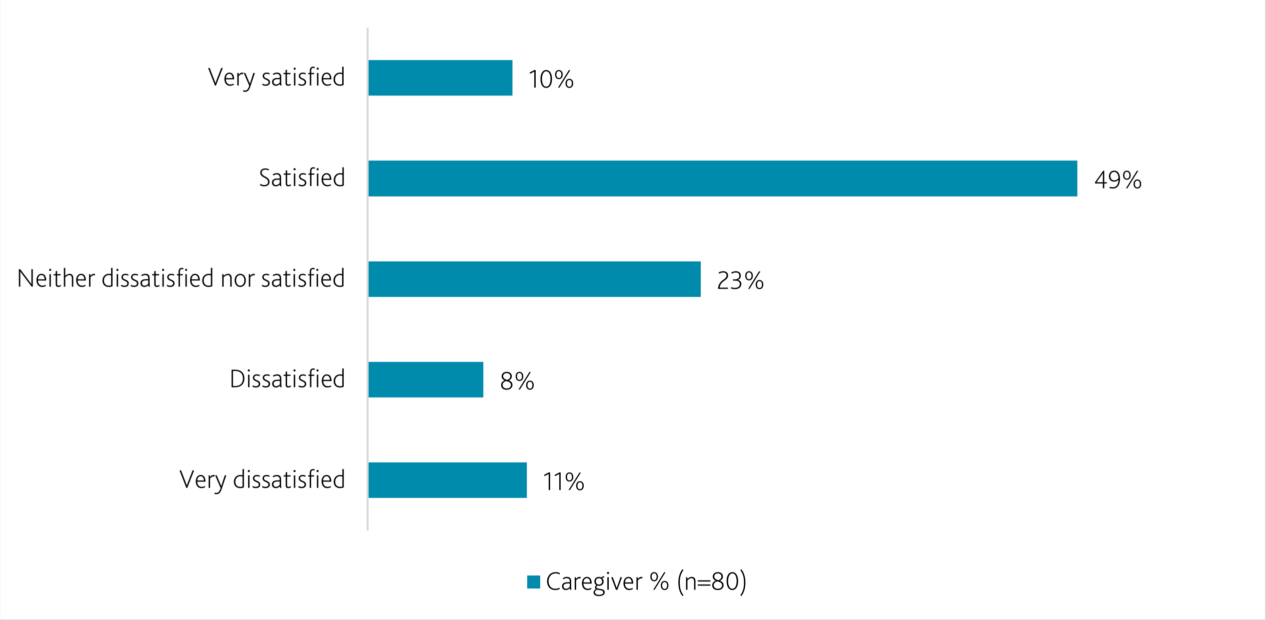
- Table 5 illustrates 64% of caregivers rank doctors as their number 1 source of lymphoma or CLL information, the internet ranked #2, and patient organisations ranked #3.

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

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	25	**64%**	5	13%	6	16%
Nurse	0	0%	10	26%	3	8%
Internet	3	8%	14	**37%**	7	19%
Online blogs/ social media	1	2%	2	5%	7	19%
Family/friends	0	0%	1	3%	1	3%
Patient organisation	10	26%	6	16%	13	**35%**
Others (please specify)	0	0%	0	0%	0	0%
Total	39	100%	38	100%	37	100%

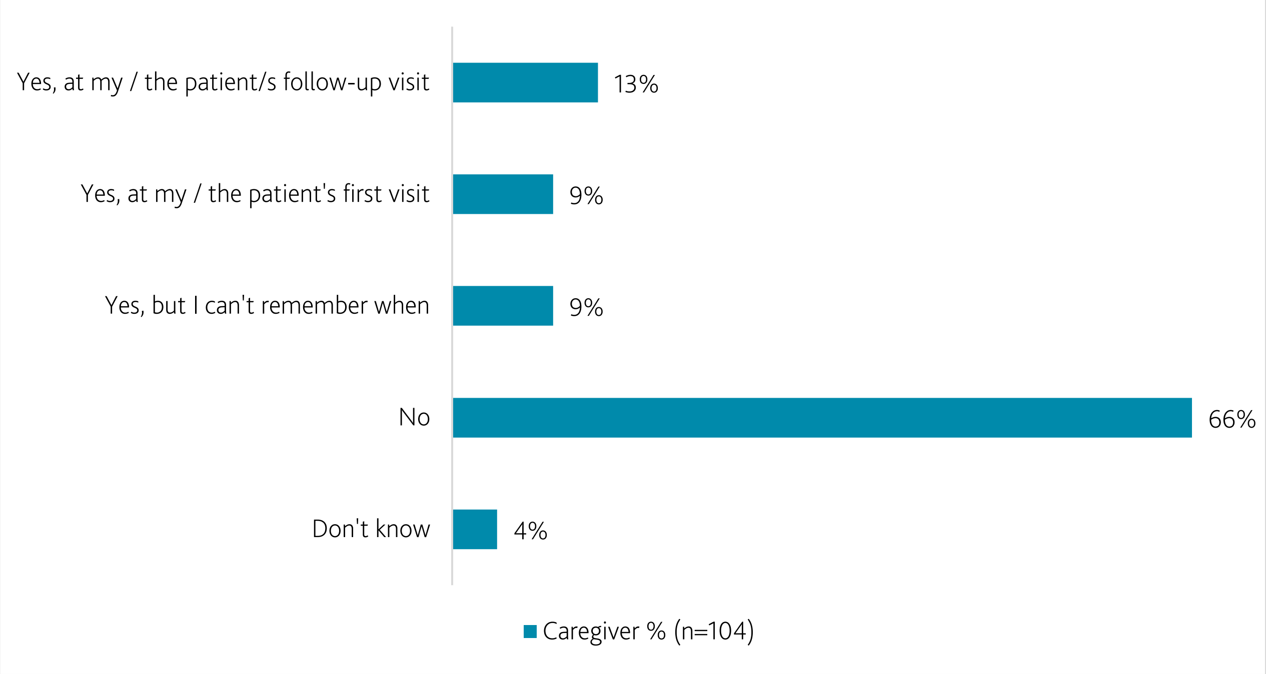
- Figure 104 shows the majority of caregivers were satisfied (49%) or very satisfied (10%) with the information from healthcare providers. Only asked to those who indicated doctors as an information source.

Figure 104. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, and nurses)?



- Figure 105 illustrates two-thirds of caregivers did not receive patient organisation information from their patient's medical team.

Figure 105. 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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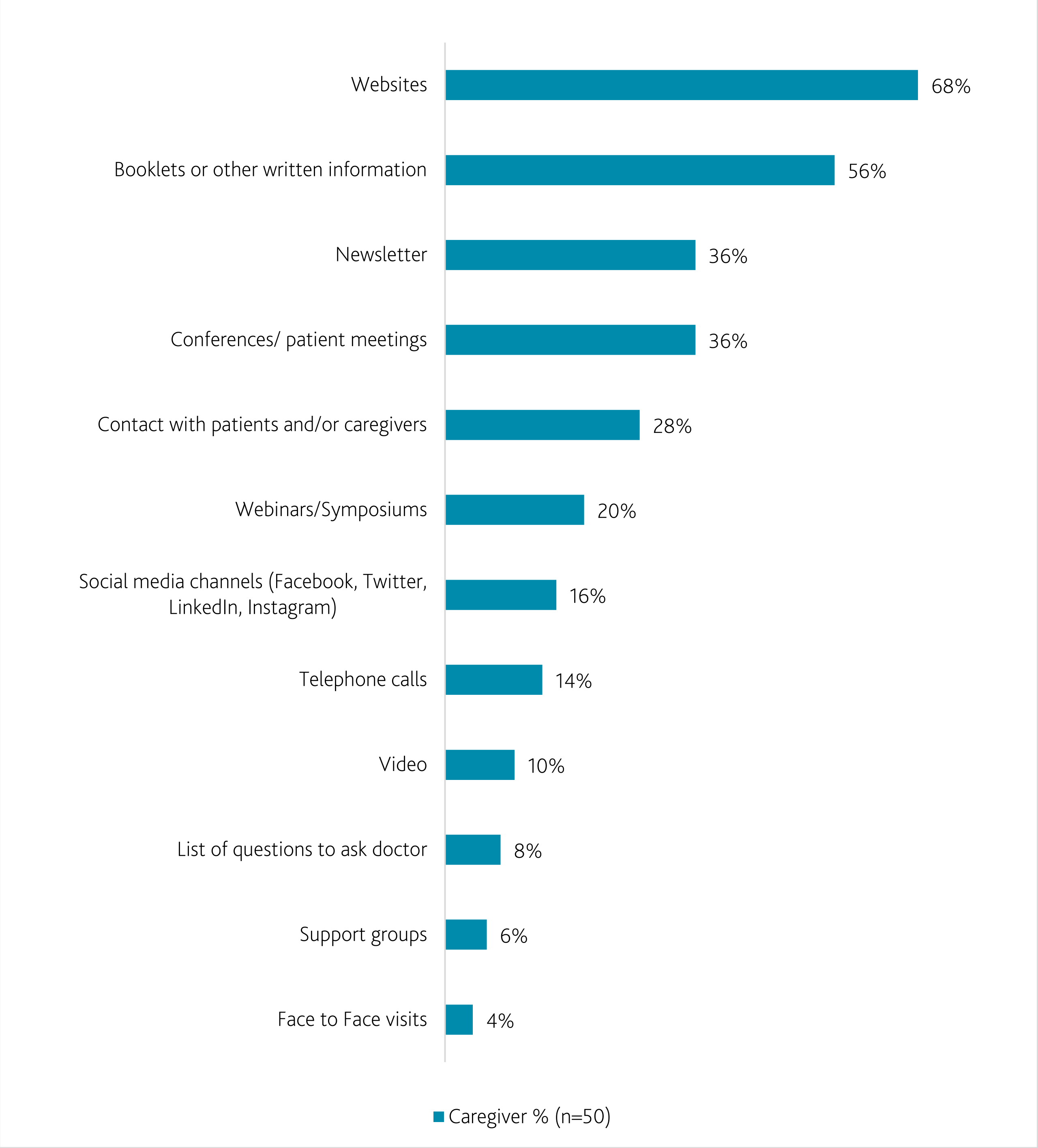
- Figure 106 reveals of the caregivers who said they preferred patient organisations as a source of lymphoma or CLL information, 68% said they used the organisations' websites, followed by booklets or written information (56%). Only asked to those who selected patient organisations as a preferred source of information.

Figure 106. What type of patient organisation information do you use?



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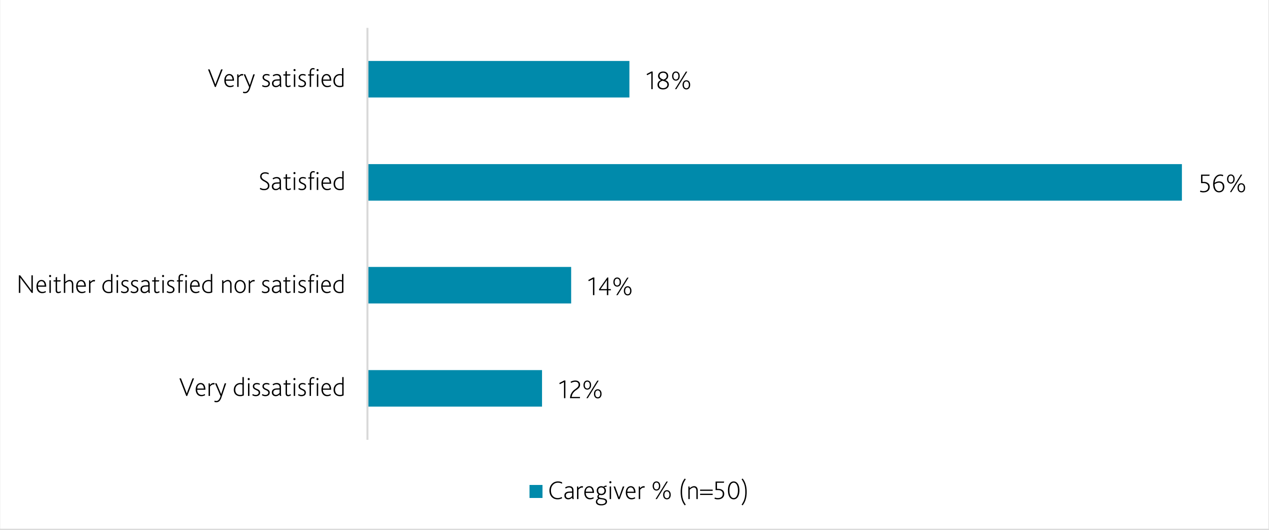
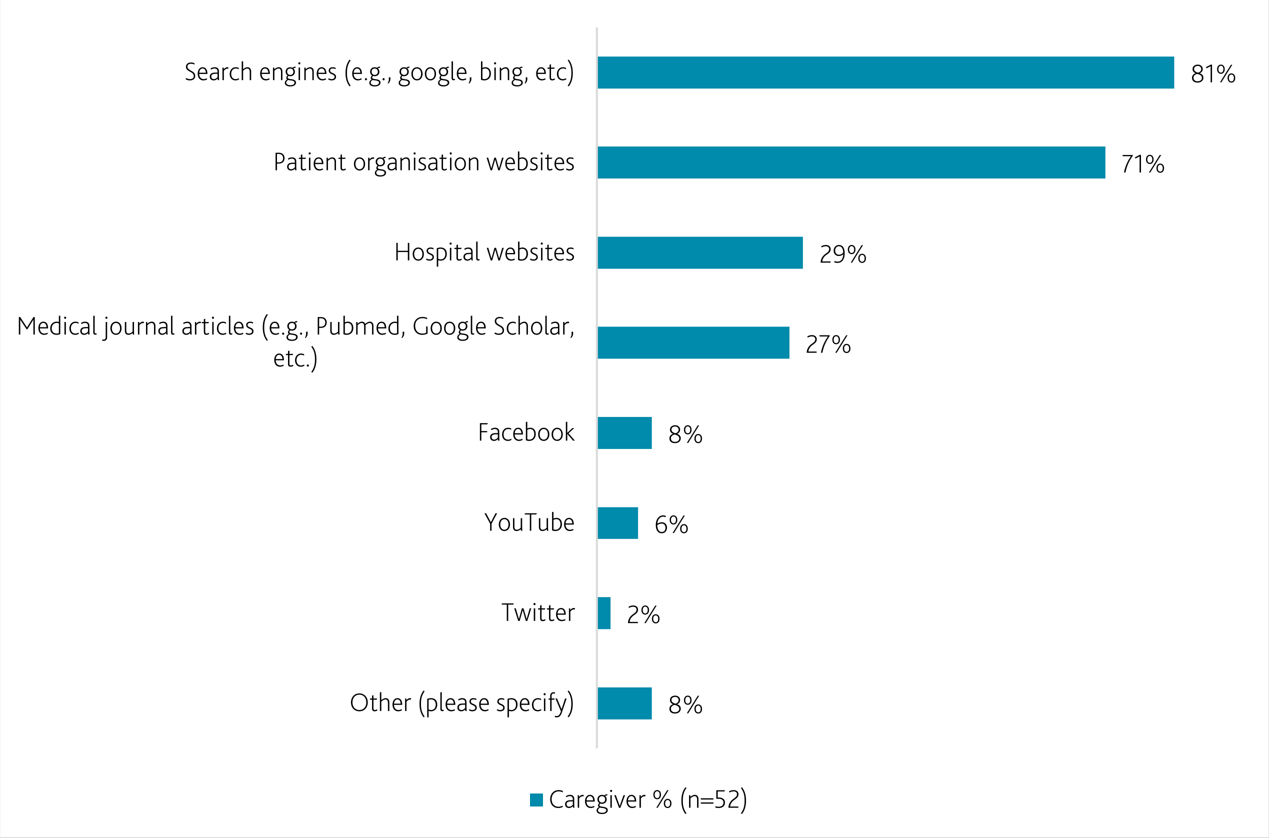
- Figure 107 illustrates three-quarters of caregivers (74%) were satisfied / very satisfied with the information provided by patient organisations. Only asked to those who selected patient organisations as a preferred source of information.

Figure 107. How satisfied or unsatisfied are you with the information given to you by patient organisations?



- Figure 108 reveals when asked about online sources for information about lymphoma or CLL, caregivers said they use search engines (81%), patient organisation websites (71%), and hospital websites (29%). Only asked to those who selected the internet as a preferred source of information.

Figure 108. Where on the internet do you usually get your lymphoma or CLL information from?



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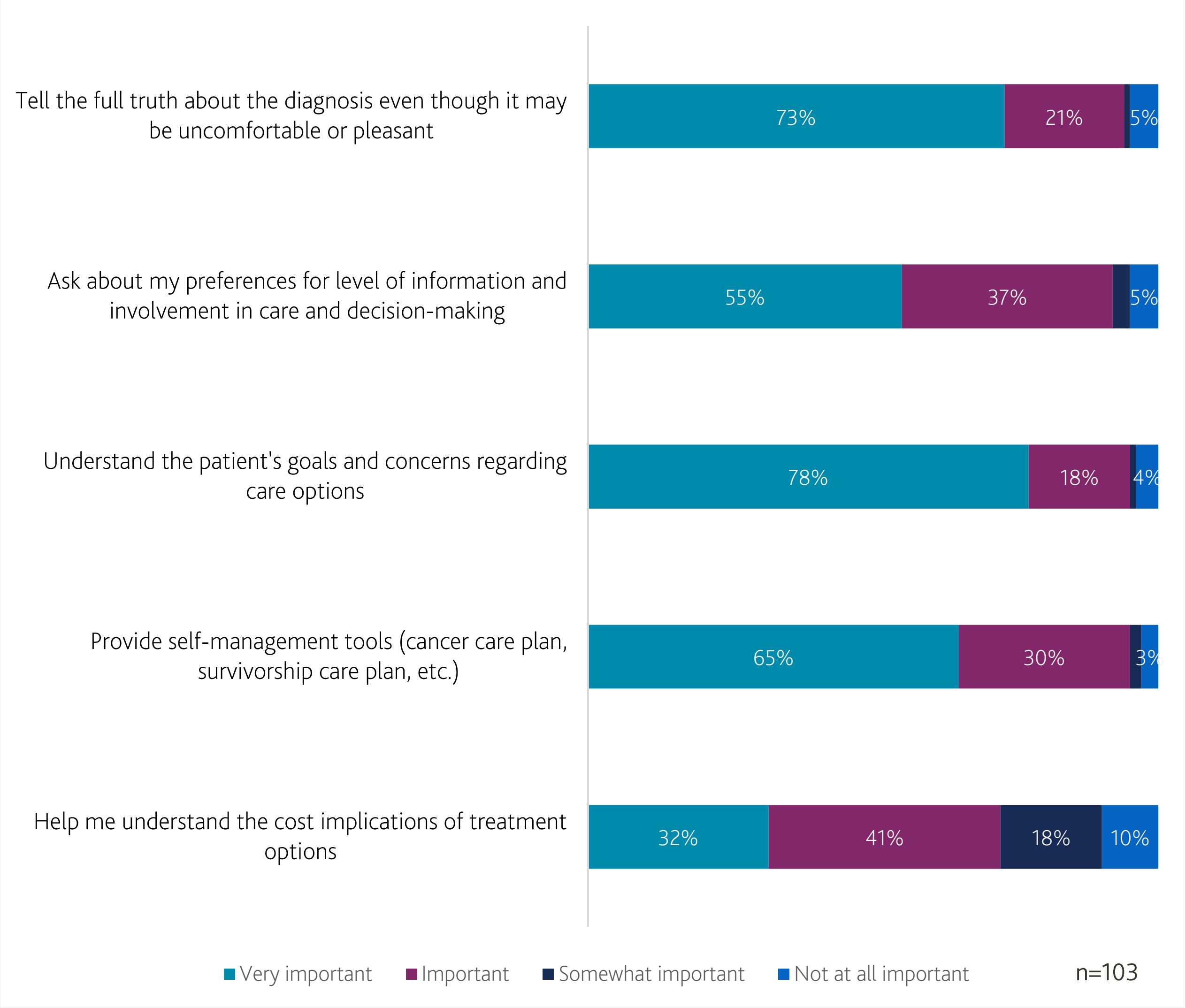
Healthcare Involvement and Decision-Making

- For 96% of caregivers, it is important or very important that the lymphoma doctor understand the patient's goals and concerns regarding care options..
- For 94% 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.
- 63% of caregivers think that for the final decision about a patient's healthcare, the doctor, patient, and caregiver or family should be involved.

❖ Figure 109 reveals caregivers said all the factors listed were important to receive from the doctor..

Figure 109. How important or unimportant is it to you to have the lymphoma or CLL doctor…



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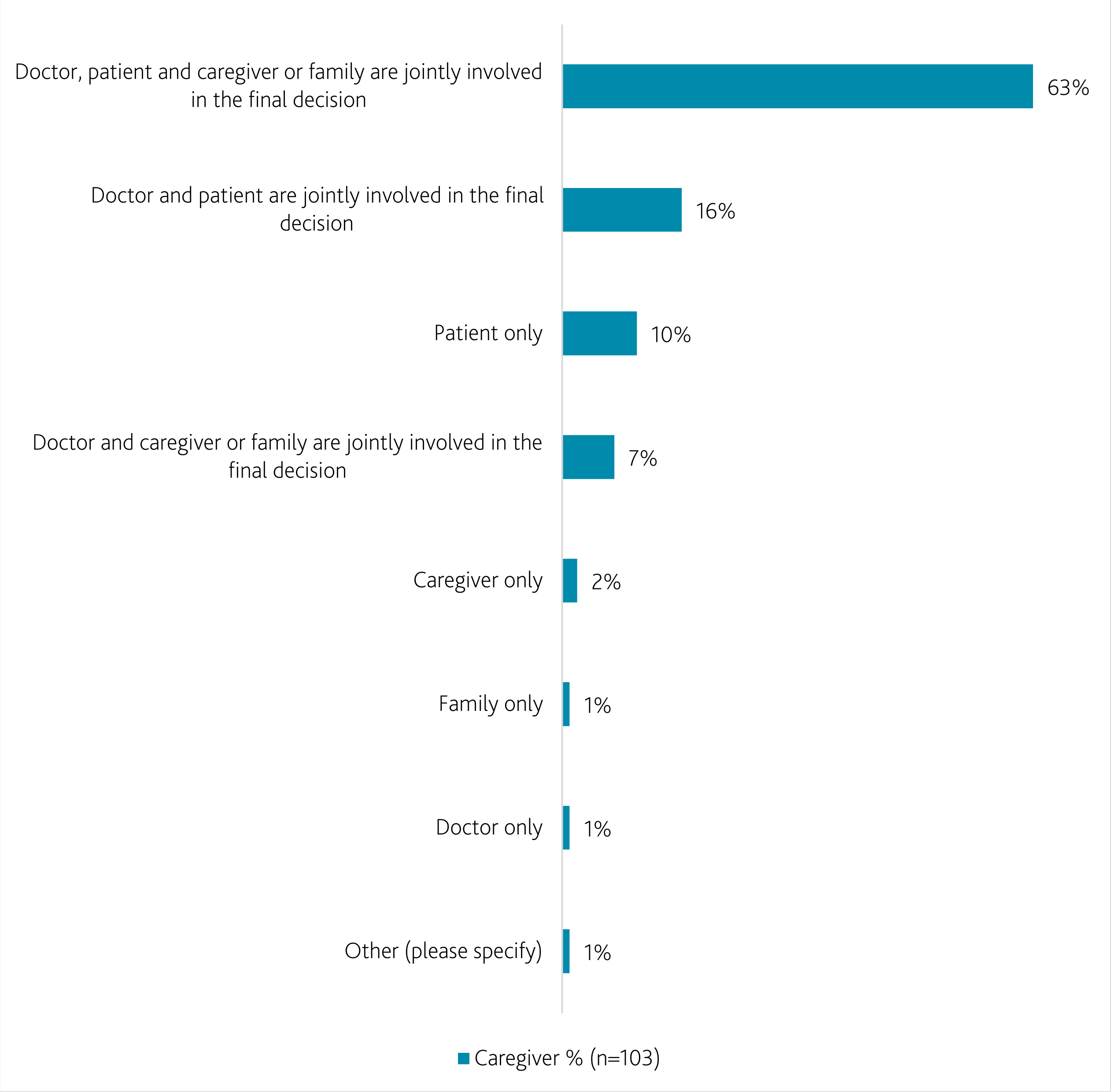
- Figure 110 reveals, when asked about healthcare decision-making, there was an overwhelming preference for collaboration. The majority (63%) included the doctor, patient and caregiver or family in the decision, and 16% included the doctor and patient.

Figure 110. Who would you like to make the final decision on the patient's healthcare?



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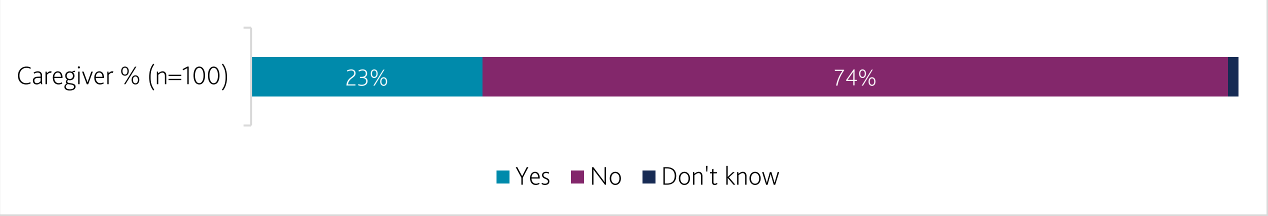
Covid-19 Concerns and Virtual Care

- 91% of caregivers had been fully vaccinated, with 52% having taken a booster dose, while only 1% were not vaccinated and not planning to get vaccinated
- 87% of caregivers considered the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19, and it worried three-quarters (76%) of them.
- Only 25% of caregivers found switching the patient's care to telemedicine helpful.

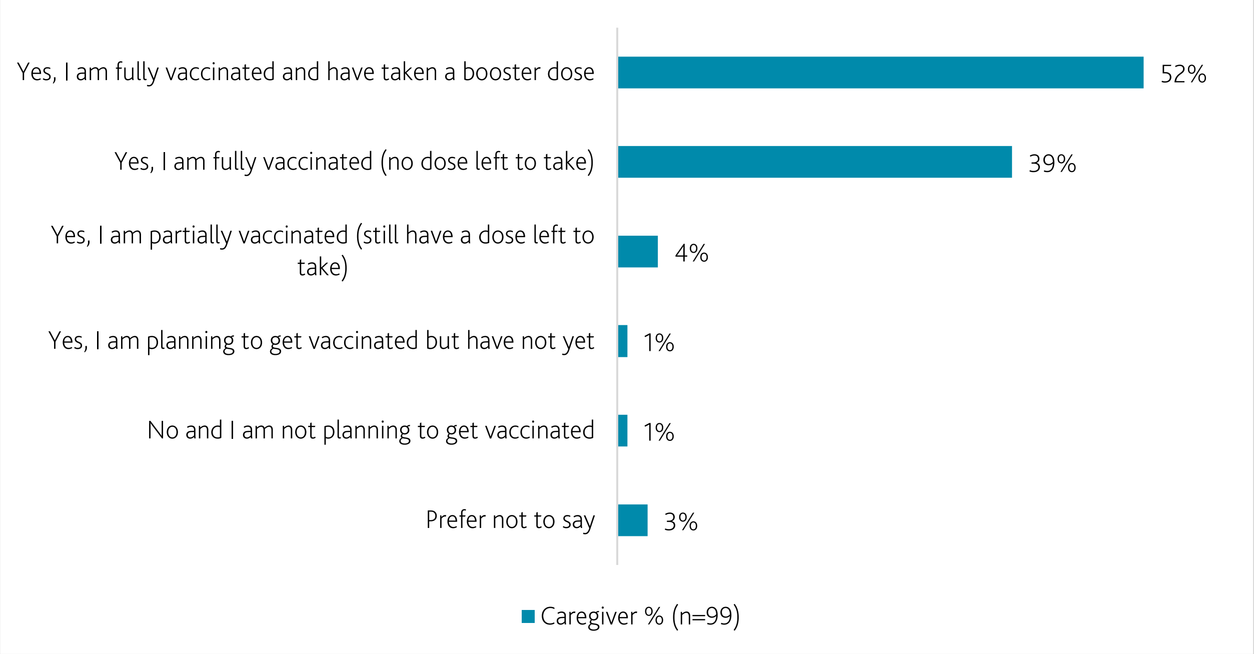
❖ Figure 111 reveals almost a quarter of the caregivers had contracted Covid-19 at any point

Figure 111. Have you contracted Covid-19, now or at any point?



❖ Figure 112 shows 91% of caregivers had been fully vaccinated, with 52% having taken a booster dose.

Figure 112. Have you, or are you planning to get the Covid-19 vaccine?



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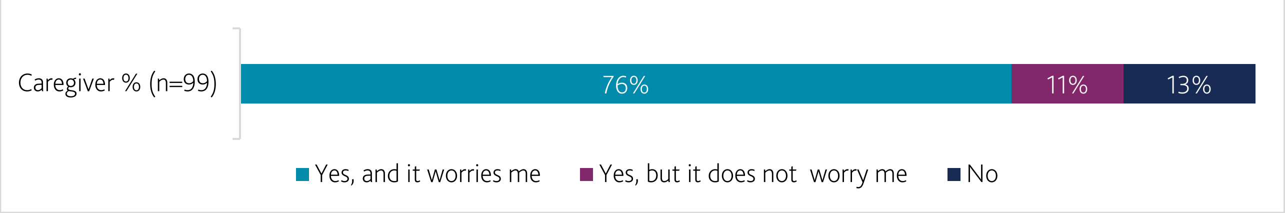
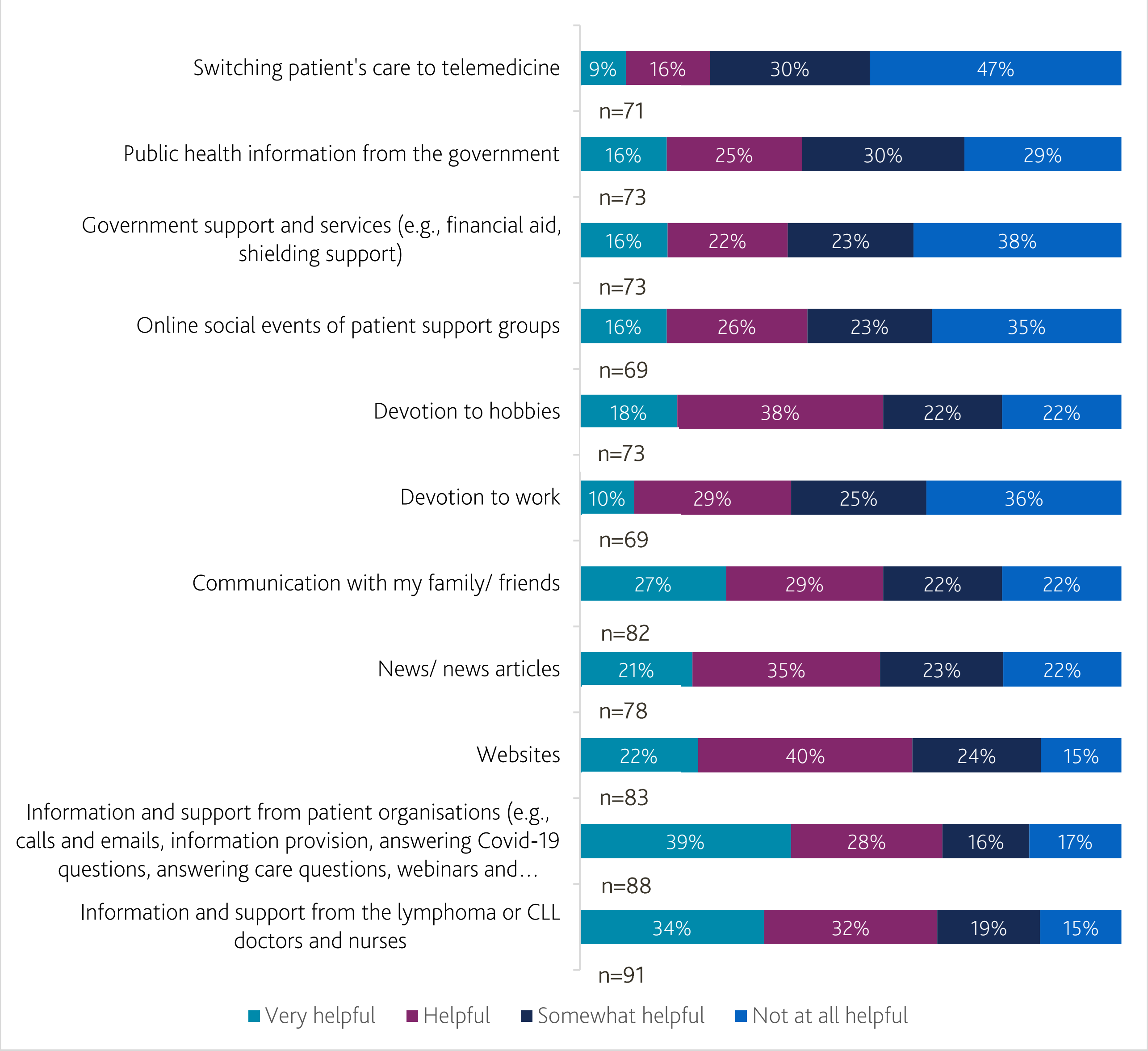
- Figure 113 shows three-quarters of caregivers (76%) consider their patients as high risk for contracting Covid-19, and it worries them

Figure 113. Do you consider the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?



- Figure 114 illustrates most caregivers (67%) found information and support from patient organisations to be helpful or very helpful in providing support regarding lymphoma or CLL and the impact of Covid-19.

Figure 114. 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.



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