



# 2022 Global Patient Survey on Lymphomas & CLL

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November 2022

Global Report

## Table of Contents

Executive Summary.....	4
Key findings.....	6
Background .....	9
Lymphoma Coalition.....	9
Survey Research Centre.....	9
Background on Global Patient Survey.....	9
Methodology.....	11
Overview and Development of the 2022 GPS .....	11
Data Collection .....	12
Data Cleaning.....	12
Data Dissemination .....	13
Patient Results.....	15
Patient Characteristics .....	15
Diagnostic Demographics .....	21
Healthcare Information and Guidance.....	28
Healthcare Support.....	38
Healthcare Involvement and Decision Making.....	45
Effects of Lymphoma/CLL.....	50
Treatment and Side-Effects .....	52
Barriers to Treatment .....	61
Side Effects .....	64
Fatigue.....	68
Psychosocial Effects of Lymphoma.....	72
Covid-19 and Virtual Care.....	76
Caregiver Results.....	84
Caregiver Characteristics.....	84
Diagnostic Demographics .....	90
Healthcare Information.....	96
Healthcare Involvement and Decision Making.....	102
Covid-19 Concerns and Virtual Care.....	104

SECTION 1

## Executive Summary



### Executive Summary

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

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

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

### Respondents

The results in this report present the data from all worldwide respondents.

The overall number of completed responses was **8637**, made up of:

**7113** Patients



**1524** Caregivers



SECTION 2

## Key Findings



## Key findings

### Patient Information, Guidance and Support



66% of patients were told their lymphoma subtype at diagnosis.



Only 18% of patients felt very well informed about the processes and stages of their healthcare.



Only 29% of patients were given more than one treatment option before their current or last therapy for lymphoma



56% of patients reported oral information from healthcare providers as their preferred source of information.

### Effects of Diagnosis and Treatment



67% of respondents experienced fatigue as a side effect of lymphoma treatment.



50% of patients indicated they had experienced fear of lymphoma relapse and 47% experienced fear of lymphoma progression.



55% of patients reported the top barrier to participating in a clinical trial was 'never being presented with an opportunity to take part'.



93% of patients from the Philippines and 77% in India reported that financial difficulties were barriers preventing them from receiving treatment.



44% of patients received information about clinical trials from their doctor and 16% of patients were in or had been in a clinical trial for their lymphoma or CLL.



36% of patients reported that nothing had made getting treatment more difficult.

### COVID-19 - Impact and Experiences



58% of patients experienced changes to their lymphoma care due to COVID-19.



36% of patients reported their anxiety was much worse and 33% said it was somewhat worse during the Covid-19 pandemic.



'Patient organisations' and 'doctors and nurses' were each identified by 61% of patients as very helpful or helpful sources of information and support during the COVID-19 pandemic.



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

## SECTION 3

# Background





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### Background

#### Lymphoma Coalition

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 patient member organisations across more than 50 countries. The overarching goal is to facilitate a community of patient organisations supporting 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, which is partially achieved through collecting data from the biennial Global Patient Survey (GPS).

<http://www.lymphomacoalition.org/>

#### Survey Research Centre

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.

<http://www.Uwaterloo.ca/src>

#### Background on 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 patient 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 lymphoma. The dissemination of data has served to develop successful campaigns and presentations to healthcare professionals and other stakeholders who play a role in the care of patients.

SECTION 4

## Methodology



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### Methodology

#### Overview and Development of the 2022 GPS

The GPS underwent an amendment between 2020 and 2022 to better understand the patient and caregiver experiences. The survey was redesigned with consultation between the Lymphoma Coalition, patient members groups and the University of Waterloo Survey Research Centre. The revisions for 2022 included patient and caregiver-specific questions, expanded on 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:

#### 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, treatment experience and side effects of treatment:

- 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 on healthcare and experiences relating to COVID-19, including

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

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

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### Data Collection

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

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

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

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

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

### Data Cleaning

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

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

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

Results were only reported where there were 20 or more survey responses (per question). For any subgroup analyses (e.g., by lymphoma subtype, gender, or age group), data captured was not reported on

## GPS 2022: Global Report

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

LC dissemination and data preservation plan ensure best practices and ethical guidelines have been met. All critical data and documentation files produced during the data collection process are stored behind a security system, on the LC server a password protected server.

Examples of how the data is used and disseminated:

- LC 2020 GPS Survey Reports (<https://lymphomacoalition.org/global-patient-survey/>)
- Lymphoma report card (2020 and 2021) (<https://lymphomacoalition.org/global-report-card/>) and European report ([https://lymphomacoalition.org/wp-content/uploads/Report\\_Lymphoma\\_Care\\_In\\_Europe\\_VF\\_A4\\_Digital.pdf](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](https://lymphomacoalition.org/wp-content/uploads/2022_Lymphoma_Coalition_Report_CLL_VF_A4_Digital.pdf))
- World Lymphoma Awareness Day (WLAD) (<https://lymphomacoalition.org/world-lymphoma-awareness-day/>)

SECTION 5

## Results



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### Patient Results

**7113** 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
- ✓ Patient information and guidance
- ✓ Healthcare support
- ✓ Patient involvement in healthcare and decision making
- ✓ Physical effects of diagnosis and treatment
- ✓ Effects of lymphoma
- ✓ Effects of treatment
- ✓ Fatigue
- ✓ Psychosocial effects, including fear of cancer relapse
- ✓ Barriers to treatment
- ✓ Impact of Covid-19: changes to healthcare and telemedicine experience

#### Patient Characteristics



- Most responses were from patients over the age of 65 years (38%), followed by patients ranging from ages between 35 and 54 years (26%), with the lowest survey respondents age group between 18 and 34 years old (12%).
- Patients who reported their ethnicity as Caucasian or White represented the largest cohort at 65%, followed by East Asian (Chinese, Korean, Japanese, Taiwanese, or other East Asian descent) at 19%.
- The overall cohort of patient respondents (7113) represented 58% female and 42% male, with most respondents residing in city/urban areas (43%).
- Nearly half (49%) of the overall respondents completed post-secondary education (college/university), with a high rate (21%) having completed postgraduate education such as a master's or Ph.D.
- A majority reported they are now retired (42%), and 28% continue with full-time employment. Only 6% of patients were unable to work for health-related reasons.

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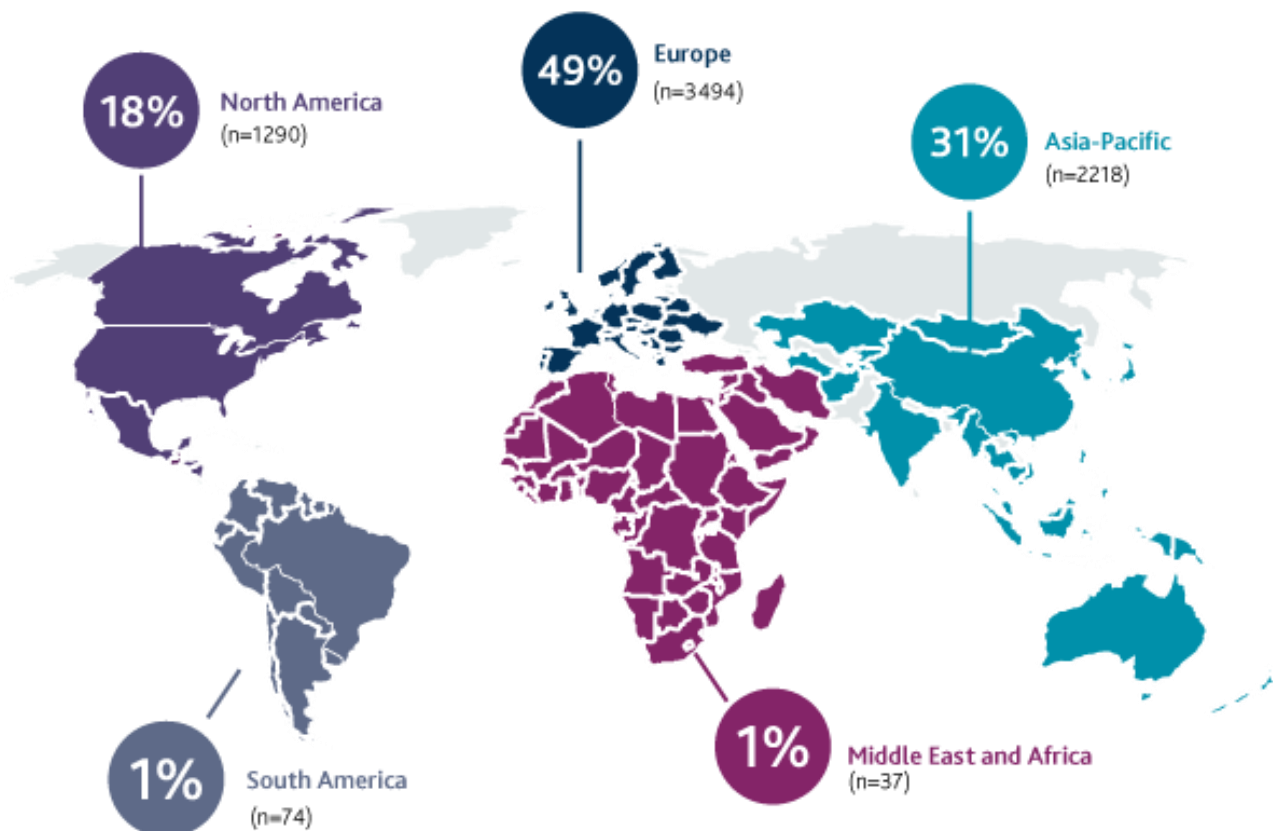
Patients responding to the 2022 GPS expanded across 72 countries.

The top four country responses were:

1. France (18%)
2. China (15%)
3. United States of America (13%)
4. Italy (7%)

18 countries had over 100+ responses to the 2022 GPS.

The global regional distribution of where patients responded from is:

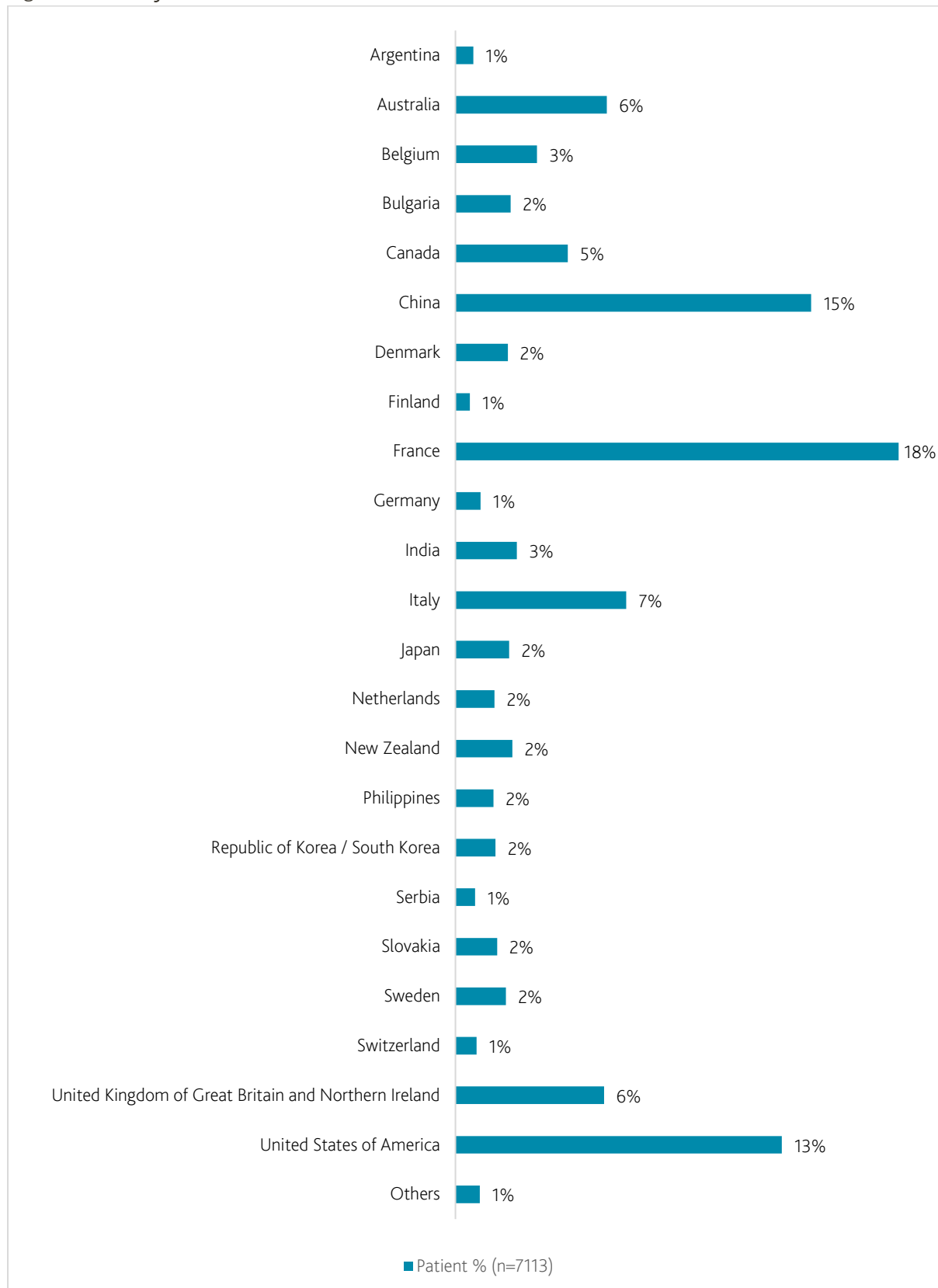




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❖ Figure 1 illustrates that 18% of patients are from France

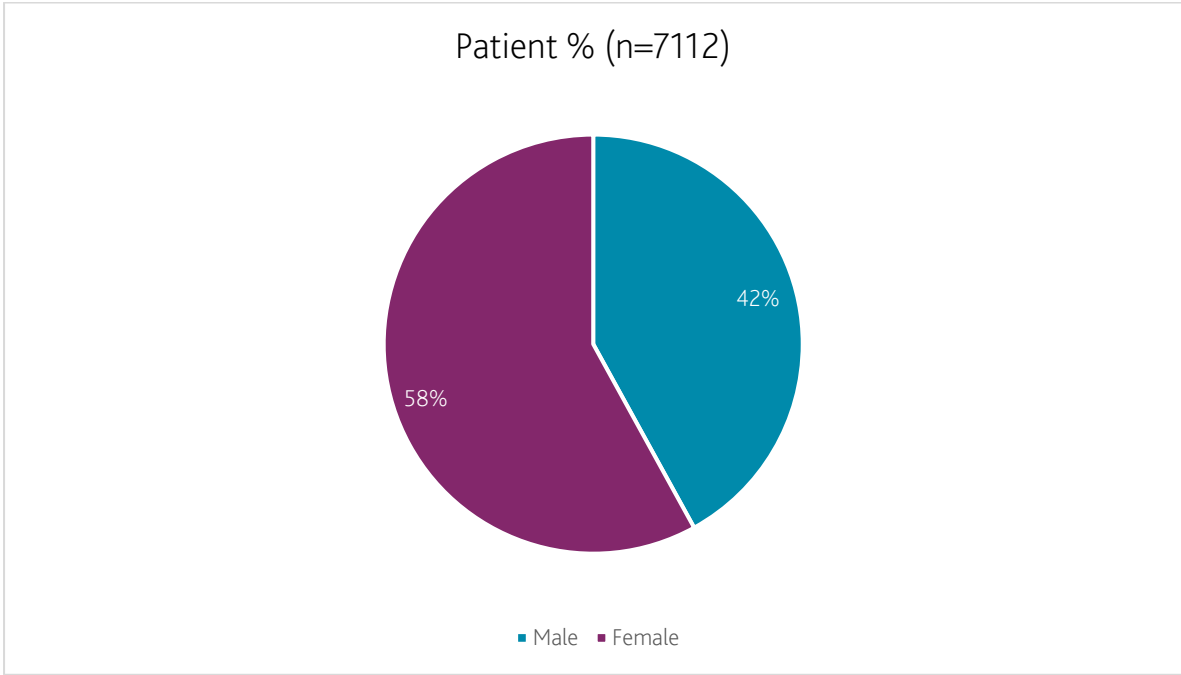
Figure 1. Country of Residence



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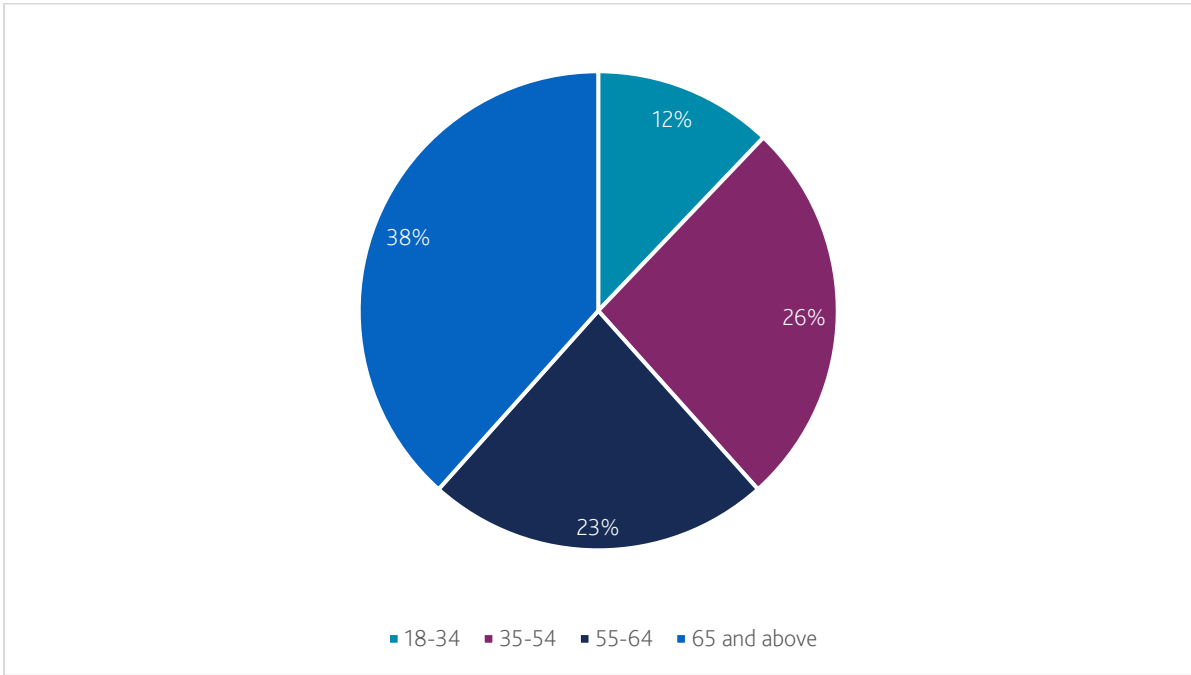
❖ Figure 2 illustrates that 58% of patients are female

Figure 2. Sex of patient



❖ Figure 3 illustrates that 38% of patients are age 65 years and above

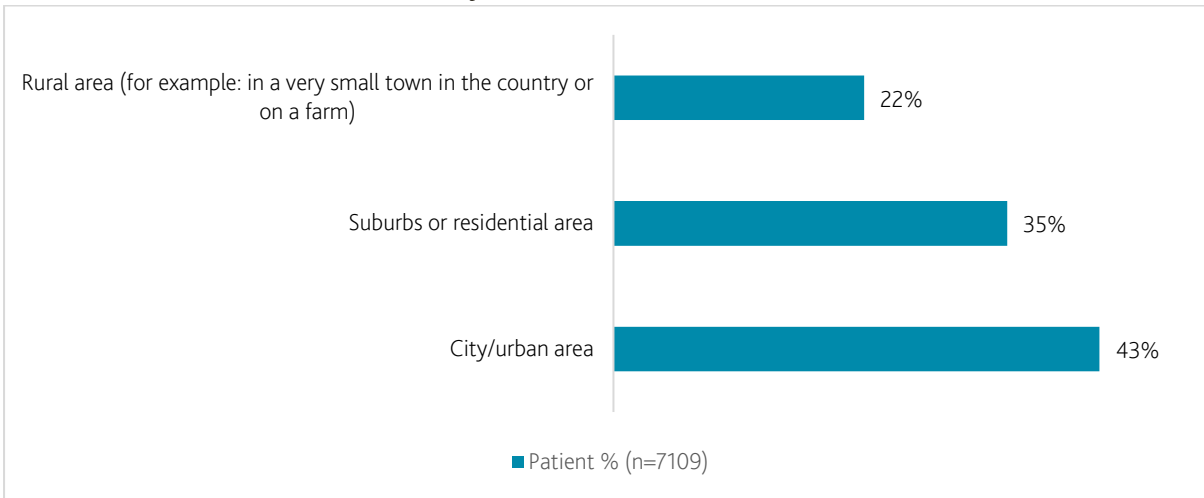
Figure 3. Age range of respondents



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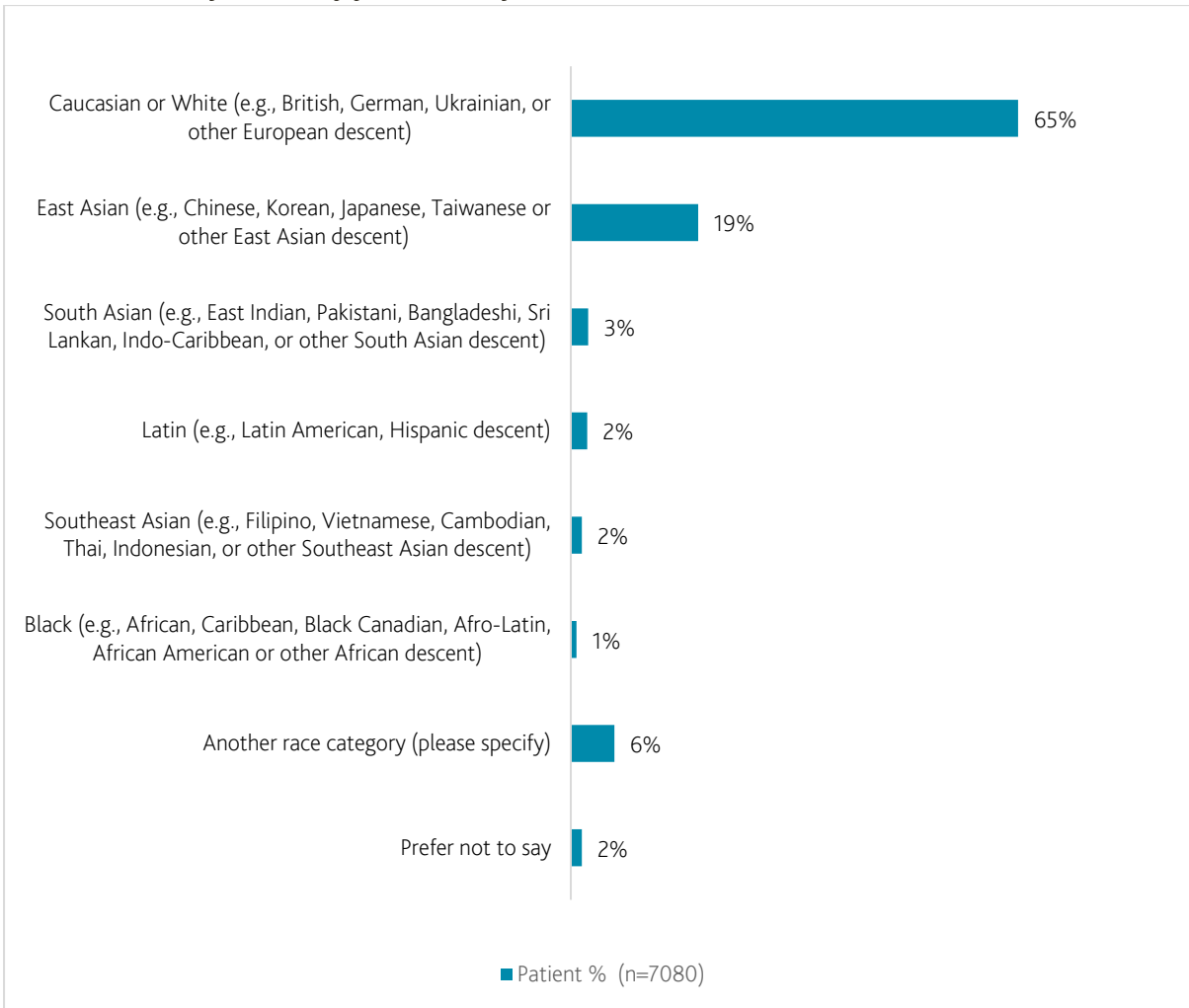
❖ Figure 4 illustrates that 43% of patients live in city/urban areas

Figure 4. Which best describes the area you live in?



❖ Figure 5 illustrates that 65% of patients identify ethnically as Caucasian or White

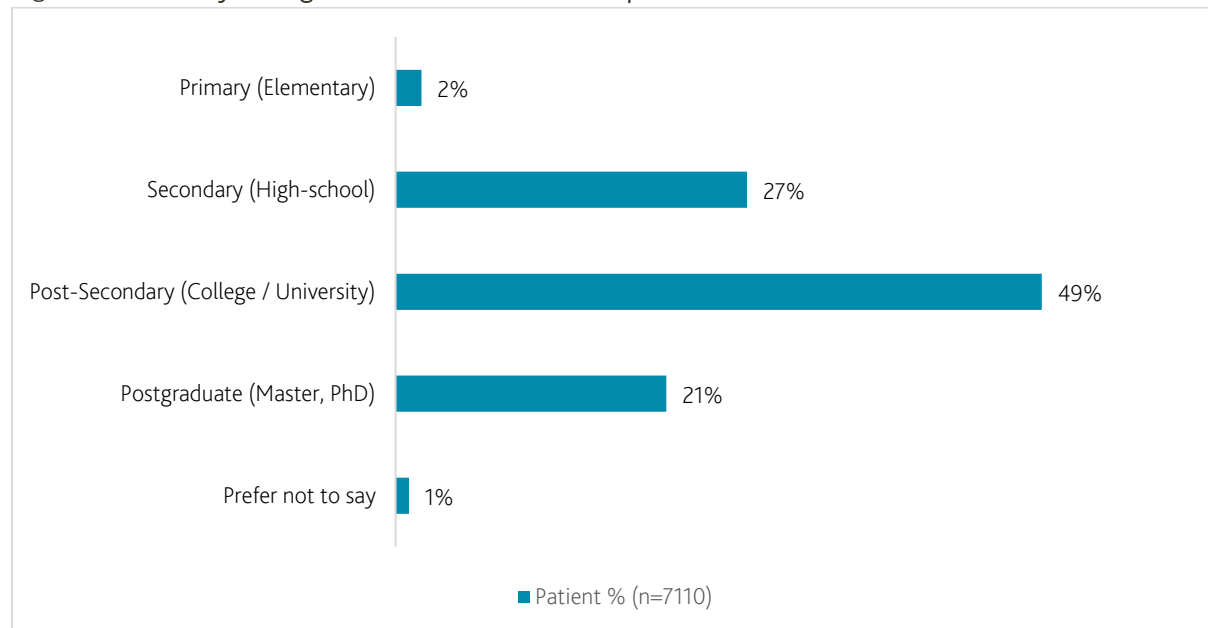
Figure 5. How do you identify your ethnicity?



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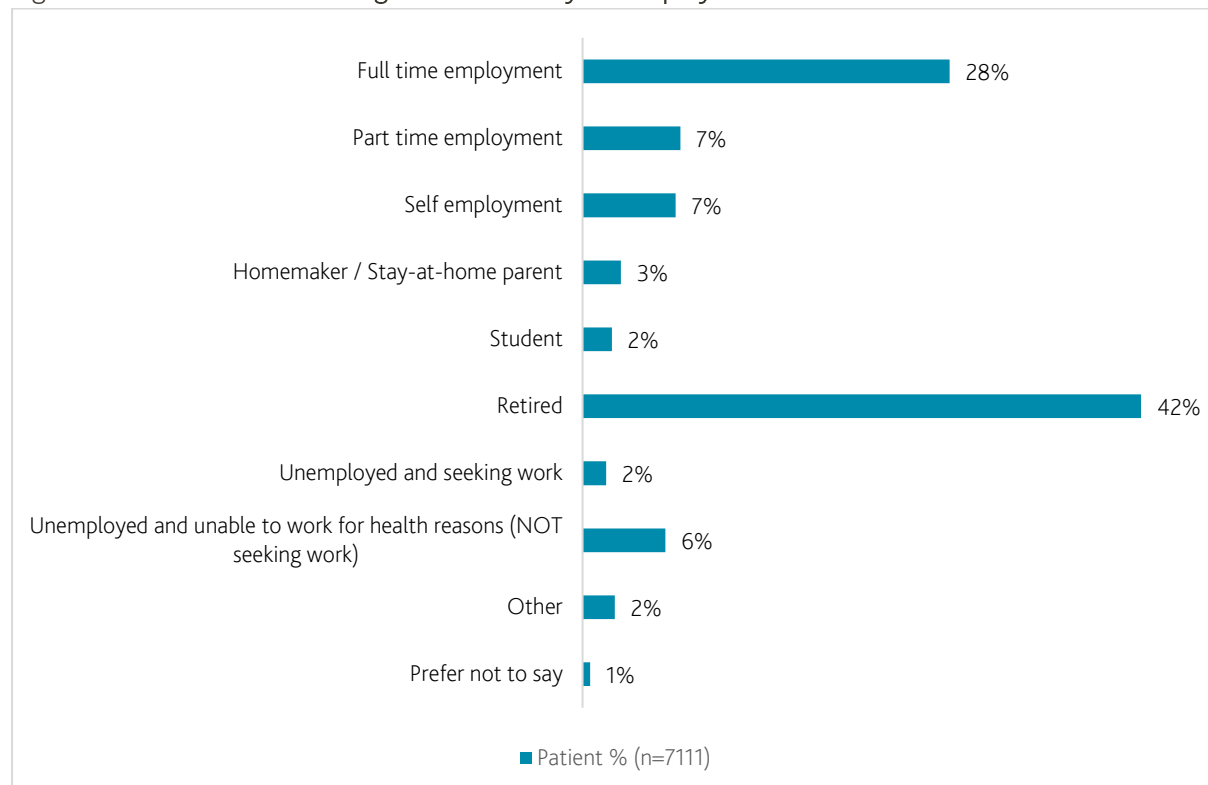
❖ Figure 6 illustrates that 49% of patients have completed a post-secondary education

Figure 6. What is your highest educational level completed?



❖ Figure 7 illustrates that 42% of patients are retired

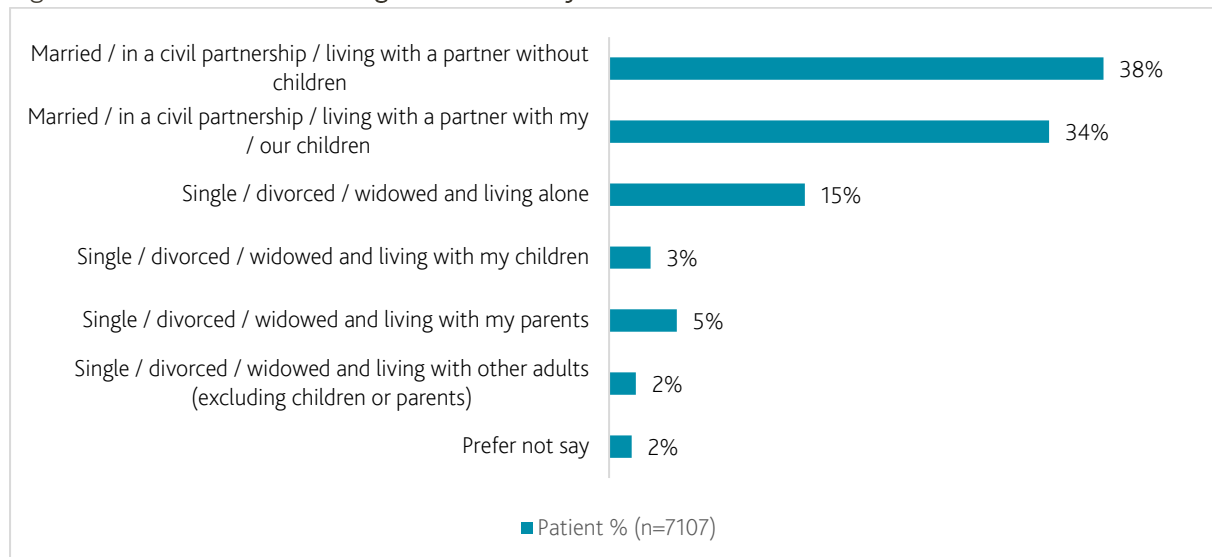
Figure 7. Which of the following best describes your employment status?



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- ❖ Figure 8 illustrates that 38% of patients are married/in a civil partnership/living with a partner without children

Figure 8. Which of the following best describes your household status?



## Diagnostic Demographics

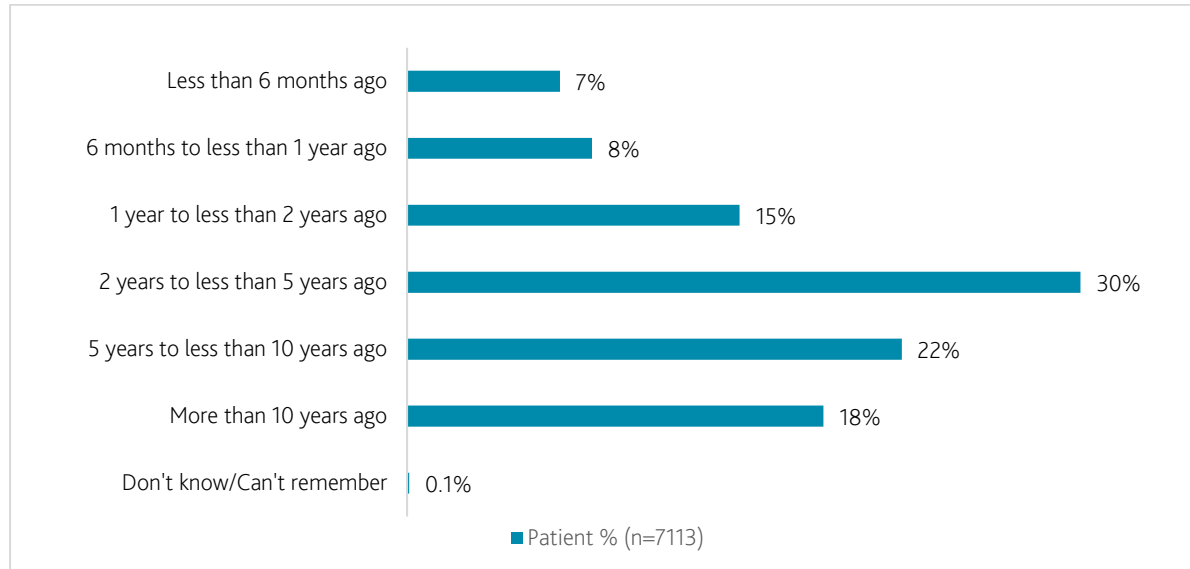


- 70% of patients who responded to the survey were diagnosed over two years ago.
- Over half of the patients (60%) felt like the results they had received about their disease and diagnostic tests were explained, and they understood the explanations.
- 76% of patients were seen by two or more healthcare professionals for their symptoms before receiving their initial diagnosis. A staggering 12% were seen by five or more healthcare professionals before receiving a diagnosis.
- Over a quarter of patients (28%) experienced their symptoms for more than six months before seeking medical care. The majority (61%) of patients had a diagnosis within three months of their first appointment with their family physician or when they first sought medical care about their symptoms. However, over 20% had to wait longer than six months from when they met with their family physician or sought care for their symptoms before they received a diagnosis.
- The top five reported subtypes were chronic lymphocytic leukaemia (CLL)/small lymphocytic lymphoma (SLL) (18%), follicular lymphoma (16%), diffuse large B-cell lymphoma (DLBCL) (all subtypes) (14%), Waldenstrom's macroglobulinemia (WM)/lymphoplasmacytic lymphoma (LPL) (12%) and Hodgkin lymphoma (12%)

## GPS 2022: Global Report

- ❖ Figure 9 illustrates that 30% of patients have been diagnosed with lymphoma or CLL between 2 to less than 5 years ago

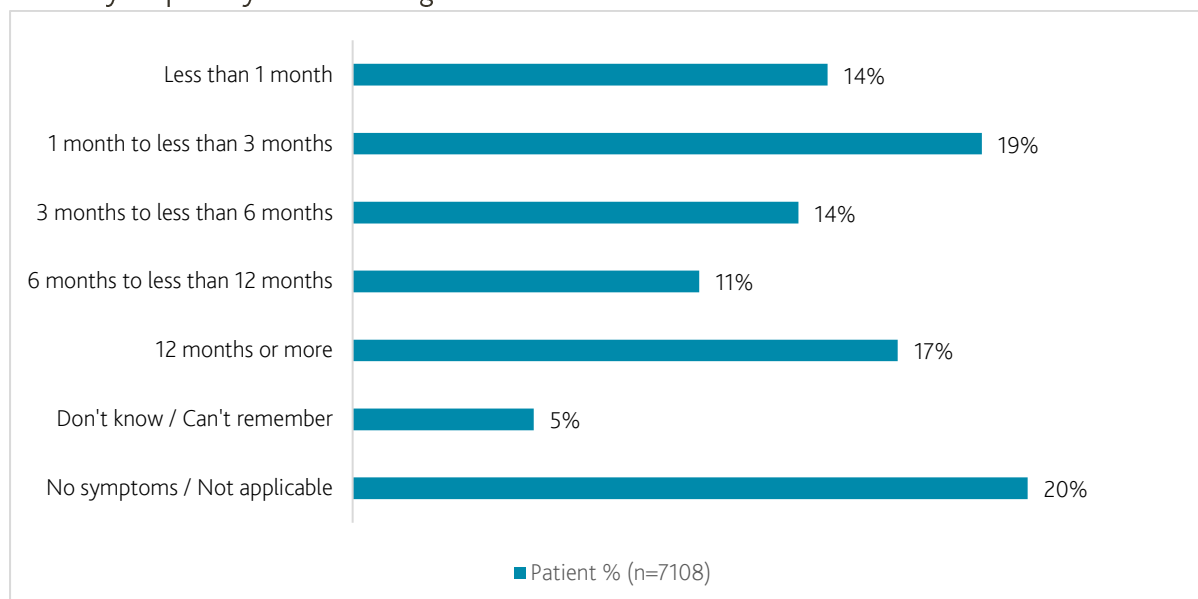
Figure 9. How long ago were you diagnosed with lymphoma or CLL?



76% of patients saw at least two healthcare professionals for their symptoms before receiving their diagnosis. In addition, 12% of patients saw five or more healthcare professionals before diagnosis.

- ❖ Figure 10 illustrates that 33% of patients experienced lymphoma symptoms for less than 3 months before seeking medical care

Figure 10. How long were you originally experiencing lymphoma symptoms for before you went to your primary doctor or sought medical care about these concerns?



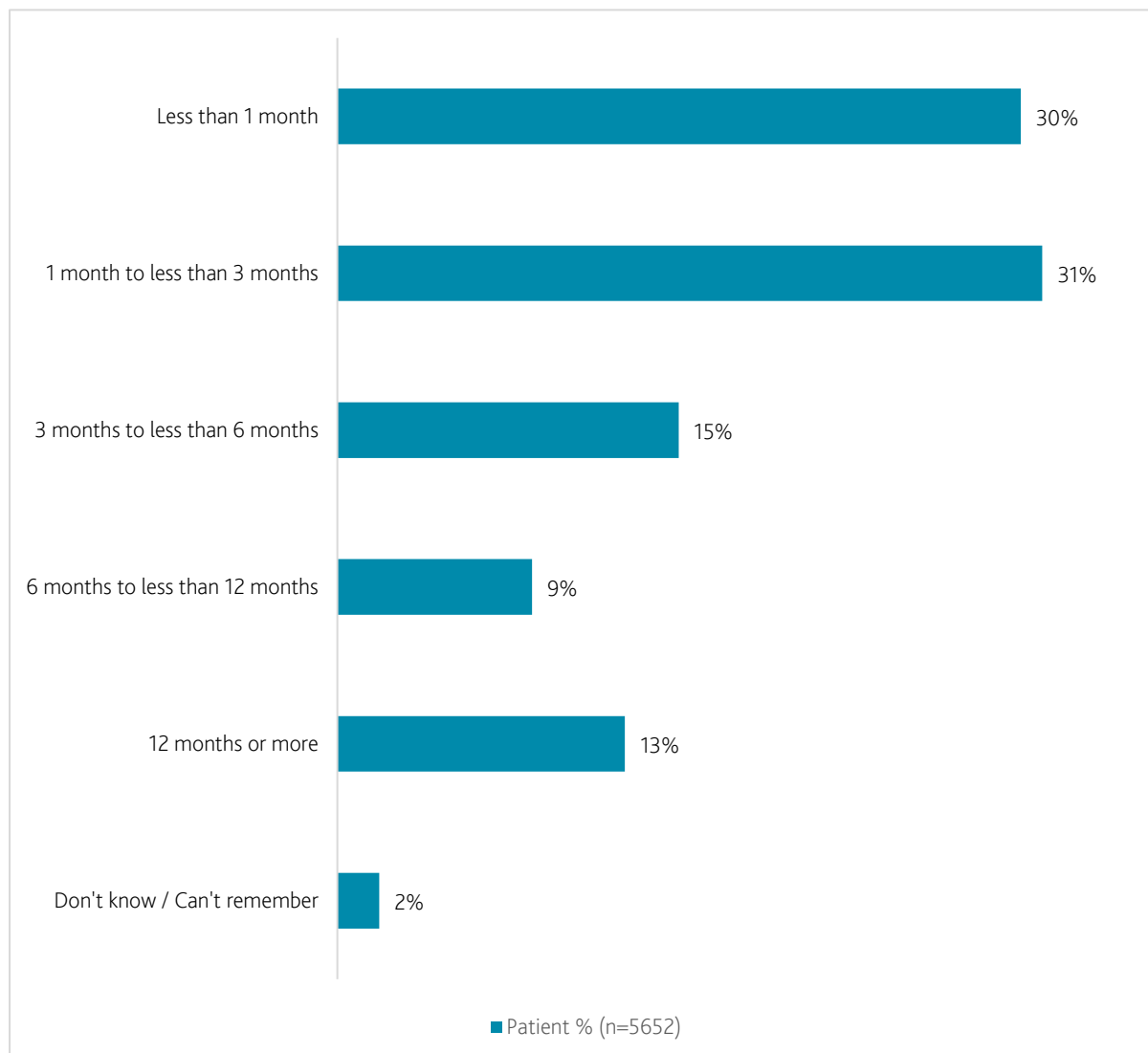
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Below shows how long patients reported waiting between their first GP appointment about their symptoms to getting a diagnosis. Most (61%) patients had a diagnosis within 1 month to less than 3 months of their first appointment. However, 22% were waiting 6 months or more from their initial meeting with their GP.

Over a third of patients with cutaneous lymphoma (39%), and half of patients with mycosis fungoides (50%) and Sézary syndrome (50%) reported that it took more than 12 months to receive a diagnosis;

- ❖ Figure 11 illustrates that 31% of patients took between 1 to 3 months to get diagnosed with lymphoma or CLL after their first appointment seeking medical care about symptoms

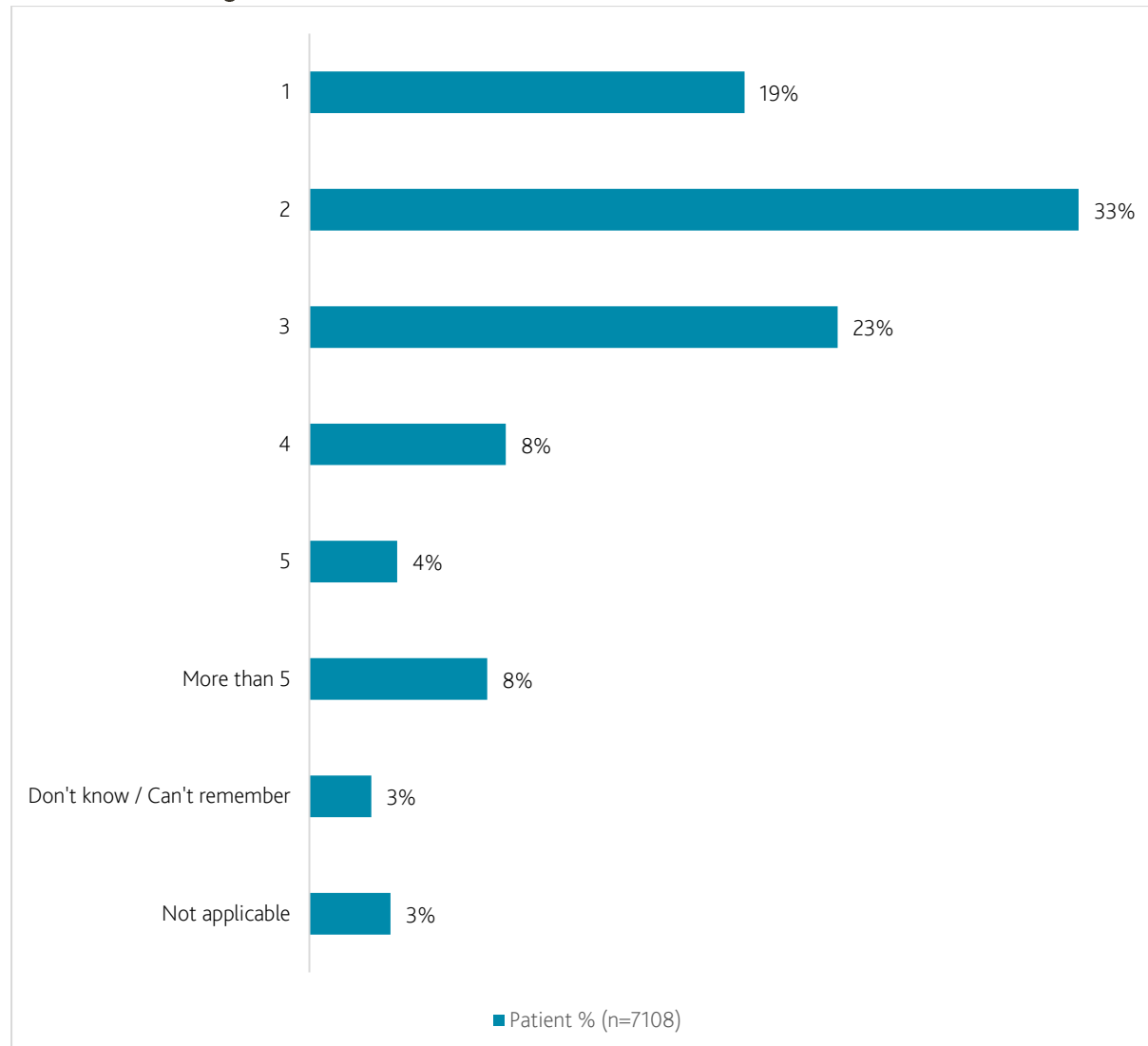
Figure 11. Overall, how long did it take from the first appointment with the family doctor or seeking medical care about the symptoms to first getting diagnosed with lymphoma or CLL?



## GPS 2022: Global Report

- ❖ Figure 12 illustrates that 33% of patients saw 2 healthcare professions about their symptoms before receiving their current diagnosis

Figure 12. How many healthcare professionals did you see about your symptoms before receiving the current diagnosis?

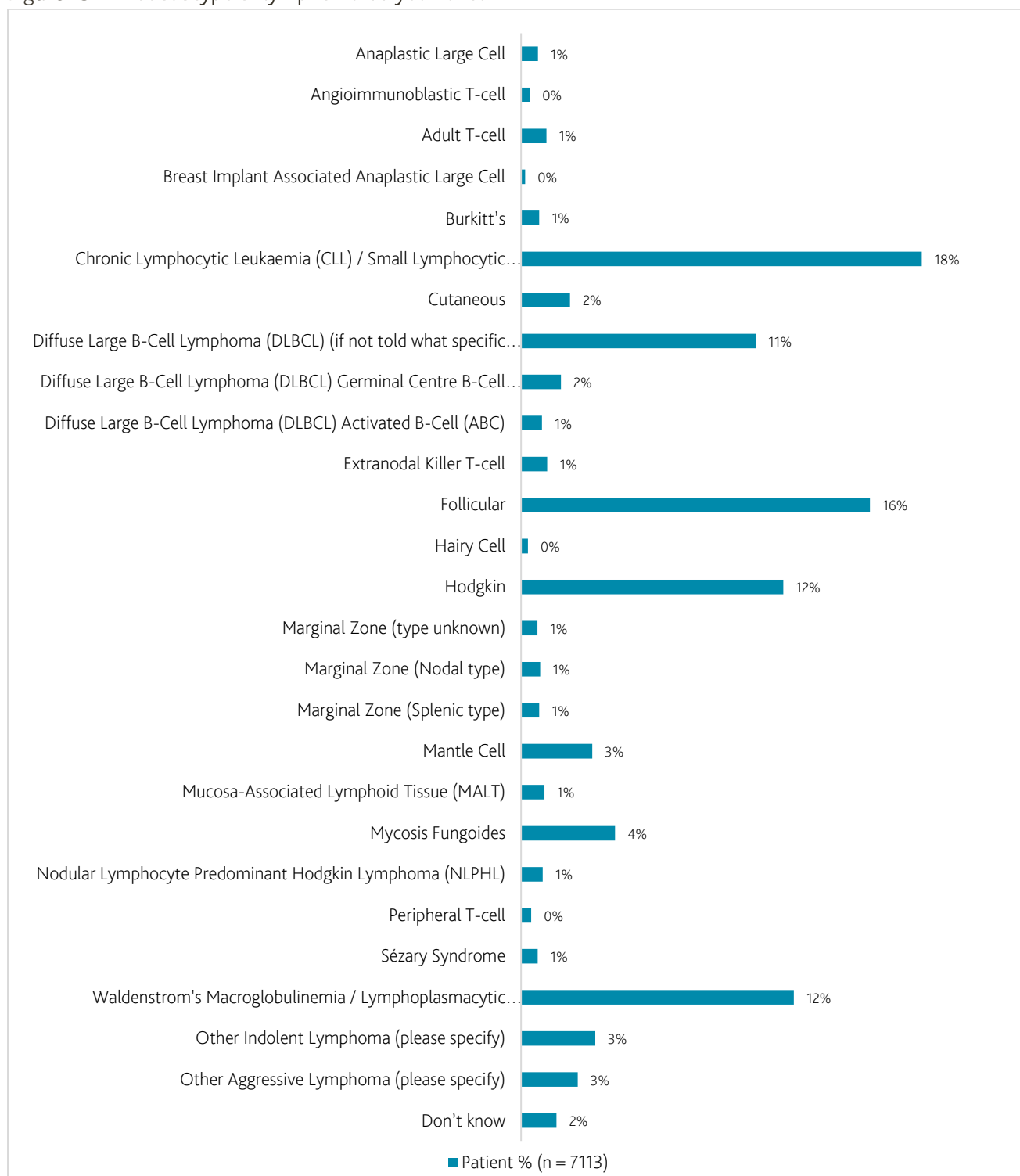


Across the world regions, the average number of healthcare professionals that patients had to see about their symptoms before diagnosis was made was: Asia-2, Europe-2, Middle East and Africa-3, North America-2, and South America -3.



- ❖ Figure 13 illustrates that 18% of patients have Chronic Lymphocytic Leukaemia (CLL) / Small Lymphocytic Lymphoma (SLL)

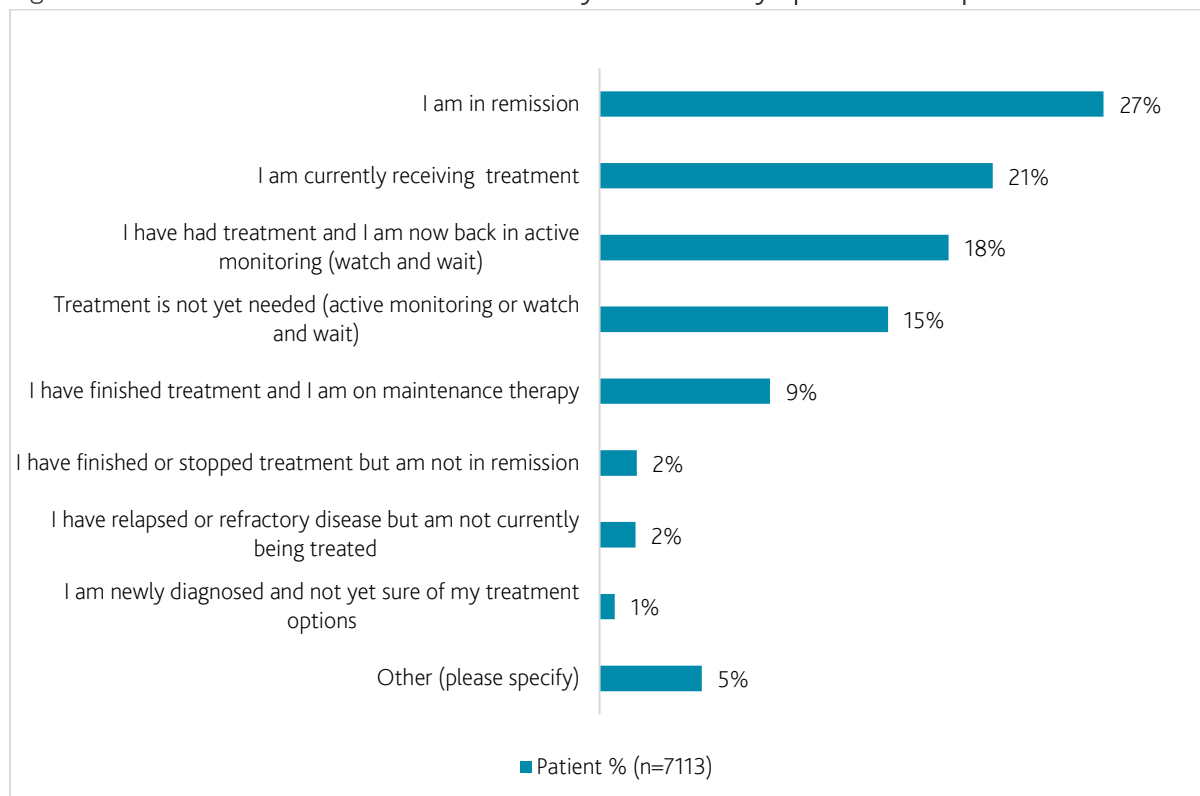
Figure 13. What subtype of lymphoma do you have?



Survey participants were also asked about the stage of their lymphoma care pathway. 15% of patients report that treatment is not yet needed (active surveillance), 21% are currently in treatment, 18% have had treatment and are now back in active surveillance. 9% have finished treatment and are on maintenance therapy, and 27% of patients report that they are in remission.

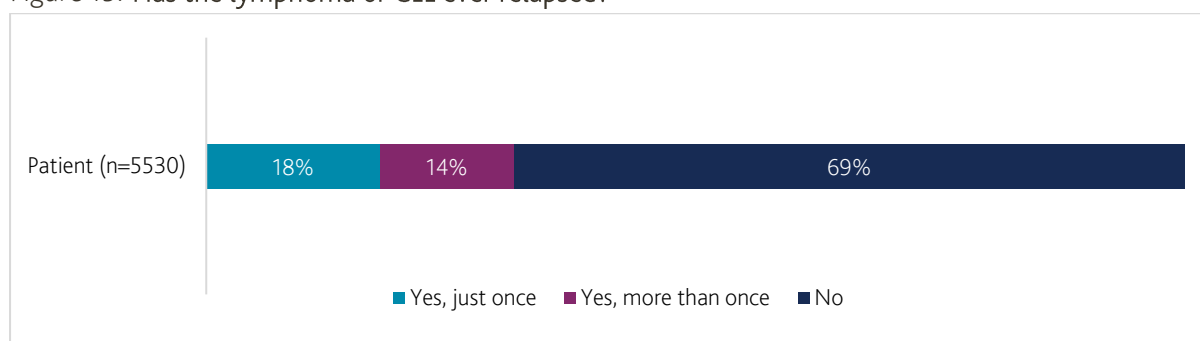
❖ Figure 14 illustrates that 27% of patients are in remission

Figure 14. What statement best describes where you are in the lymphoma/CLL experience?



❖ Figure 15 illustrates that 69% of patients have not had the lymphoma or CLL relapse

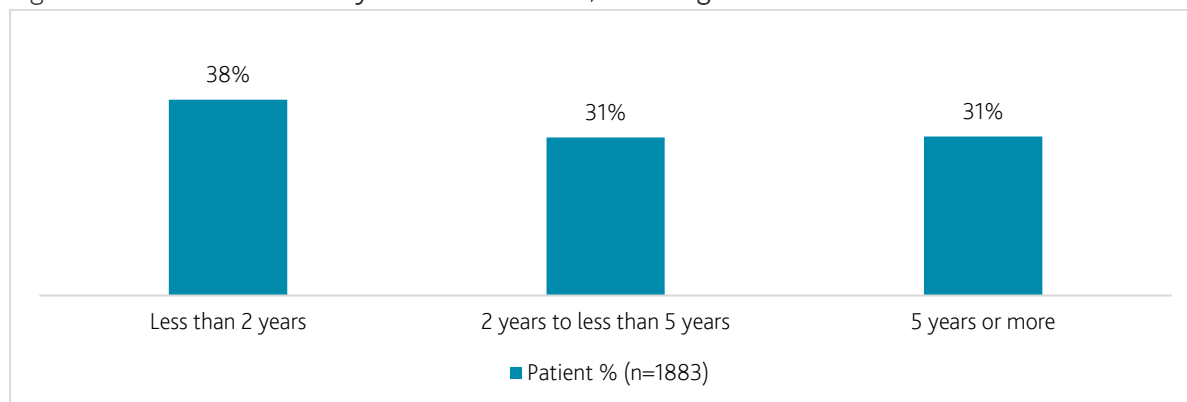
Figure 15. Has the lymphoma or CLL ever relapsed?



- Patients indicating, they were in remission were asked how long they have been treatment free. The majority in remission for less than 2 years (38%).
- Patients in active surveillance were asked how long they had been monitored for; the majority had been in active surveillance for less than 2 years (39%).
- Patients who were receiving/had ever received treatment, those on maintenance therapy, and those in remission were asked:
  - whether their lymphoma/CLL has ever relapsed- 18% had experienced a relapse once, while 14% had more than once.
  - whether their lymphoma/CLL has ever transformed- only 8% has experienced a lymphoma transformation.

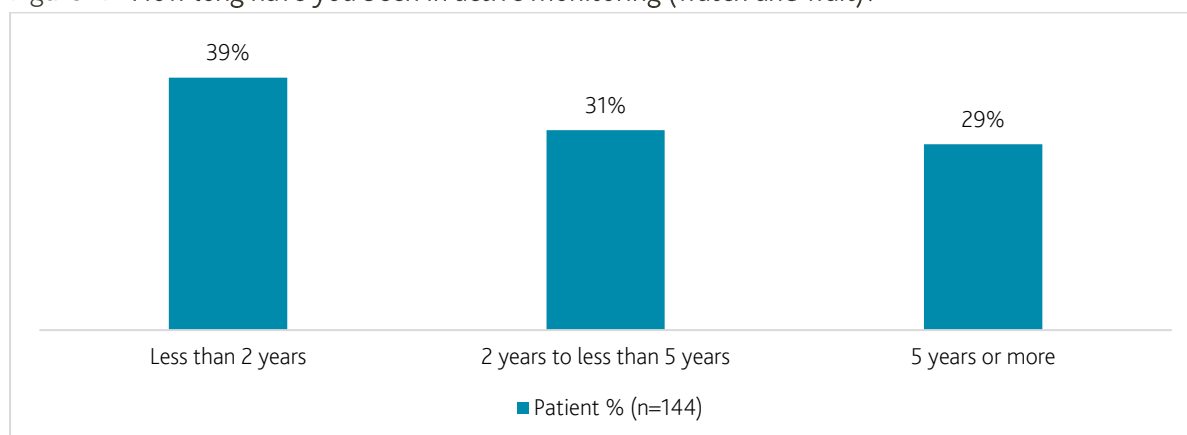
- ❖ Figure 16 illustrates that 38% of patients in remission had their last treatment within the past 2 years

Figure 16. You have said that you are in remission, how long has it been since the last treatment?



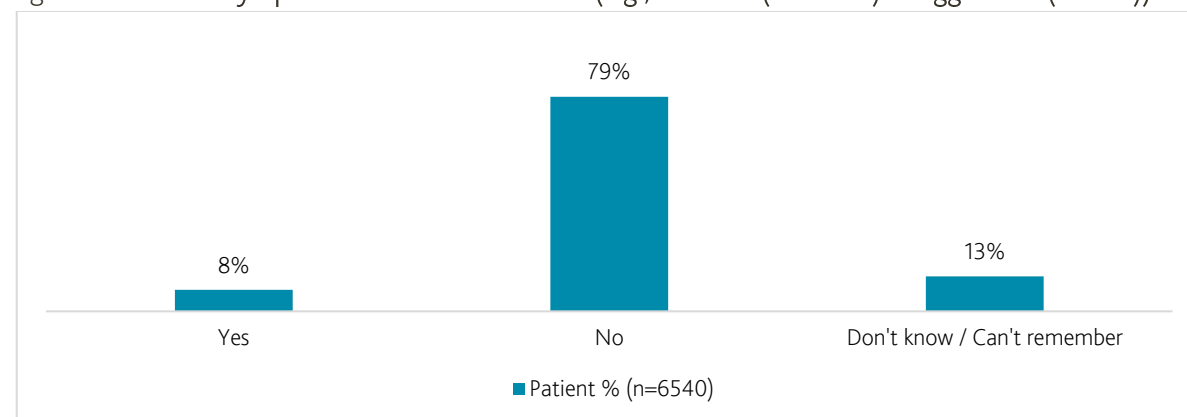
- ❖ Figure 17 illustrates that 39% of patients have been in active monitoring for 5 years or more

Figure 17. How long have you been in active monitoring (watch and wait)?



- ❖ Figure 18 illustrates that 79% of patients have not had the lymphoma or CLL transform

Figure 18. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?



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### Healthcare Information and Guidance

Previous surveys showed that having 'adequate information' was correlated with more self-reported positive healthcare experiences. Patients with adequate information reported bettered management of their health and healthcare through improved understanding, confidence levels, and communication with healthcare professionals. When a patient has knowledge surrounding 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.

This section therefore focuses on survey results relating to the patient experience with information at diagnosis; information obtained from healthcare providers, patient organisations and the internet.

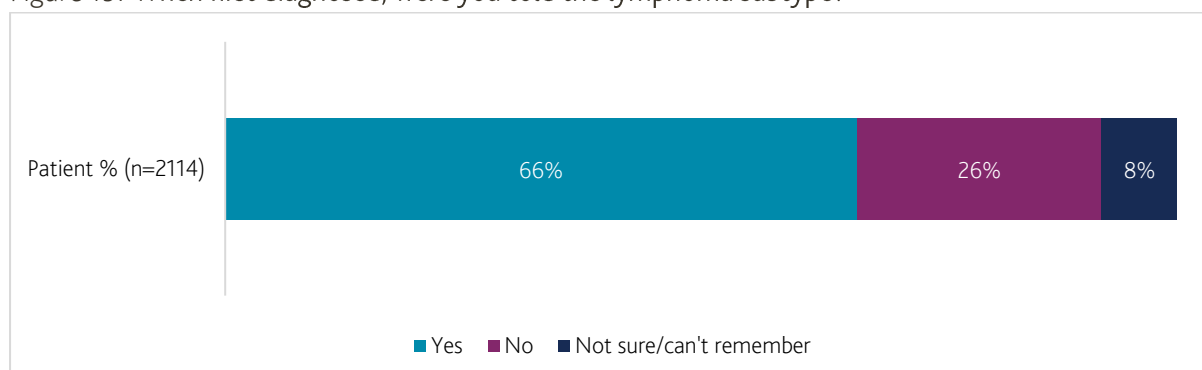
A summary of the findings from this section is displayed in Box 1 below.



- 86% of the patients and/or caregivers were seeking out information and details about their disease and potential treatment and their preferred method of obtaining this information is oral information from healthcare providers (56%).
- 13% of the patients did not seek additional information other than what the doctor/ healthcare staff told them, as they are the experts.
- 15% of patients were not informed or not very well informed about the processes and stages of their health.
- 52% of the patients did not receive any contact details of a patient organisation, a support group, and/or information produced by a patient organisation. But 81% of those who received the information were very satisfied or satisfied with the information.

❖ Figure 19 illustrates that 66% of patients were told the lymphoma subtype when first diagnosed

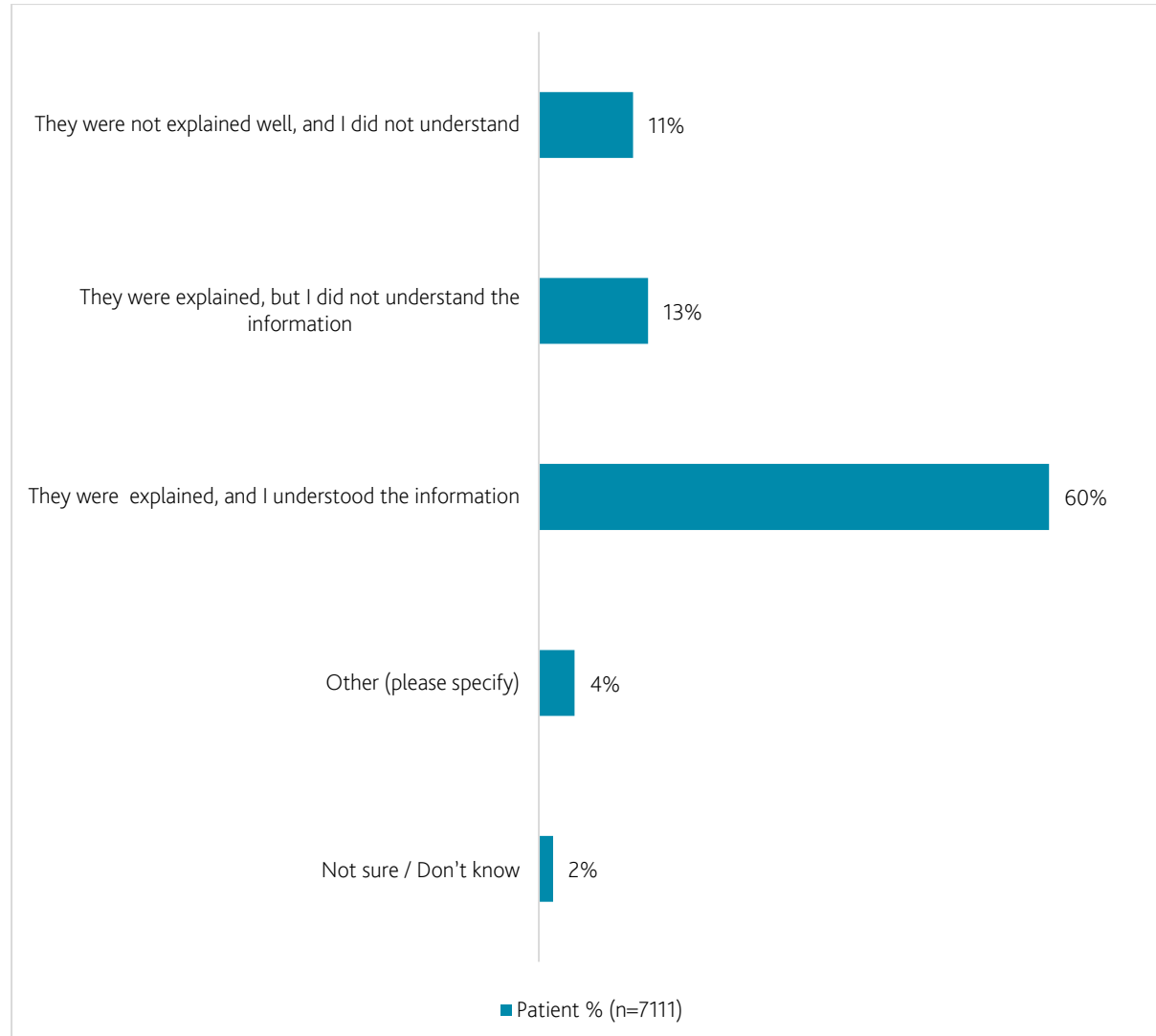
Figure 19. When first diagnosed, were you told the lymphoma subtype?



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- ❖ Figure 20 illustrates that 60% of patients had their diagnostic tests and results explained to them and they understood the information

Figure 20. 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.)?

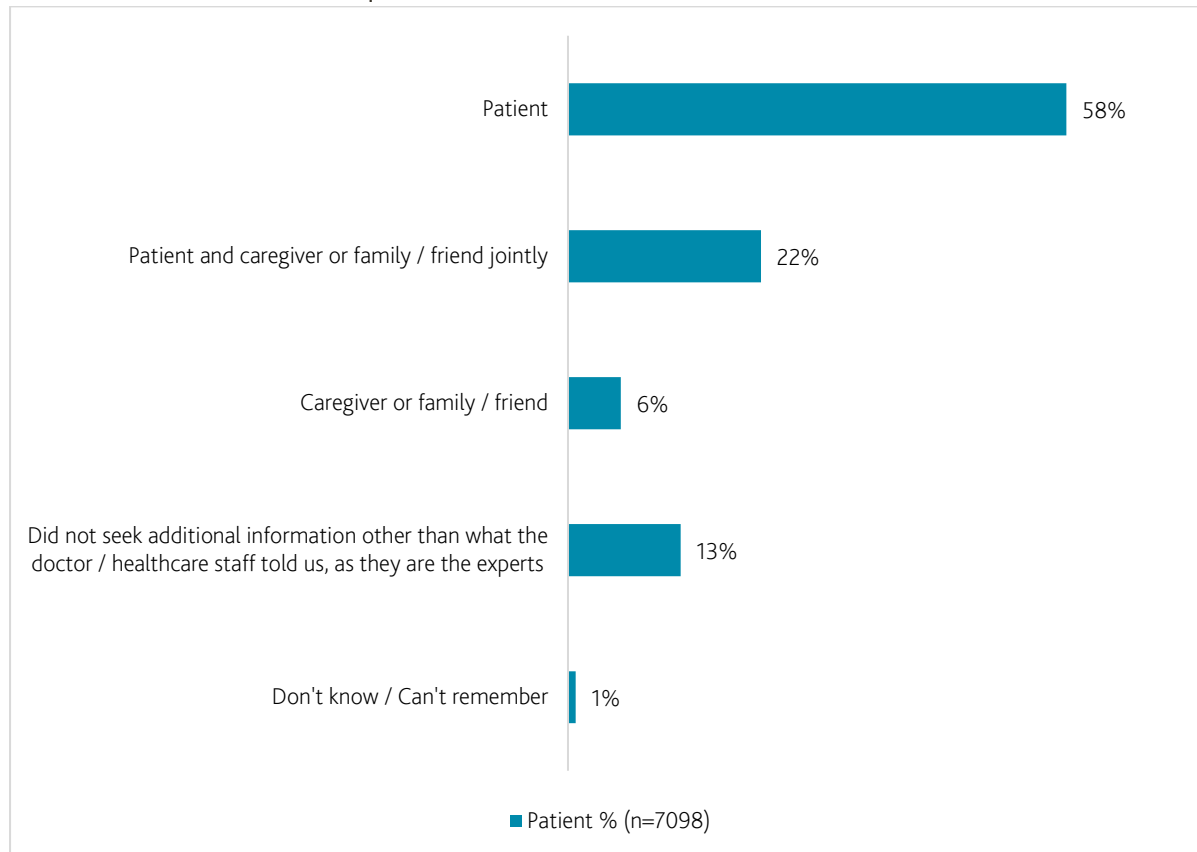


Understanding of diagnostic tests and procedures was more prevalent with increasing age across the age groups. A higher proportion of 65yrs+ (68%) reported that their diagnostic tests and results were explained to them, and they understood the information compared to the other age groups.

## GPS 2022: Global Report

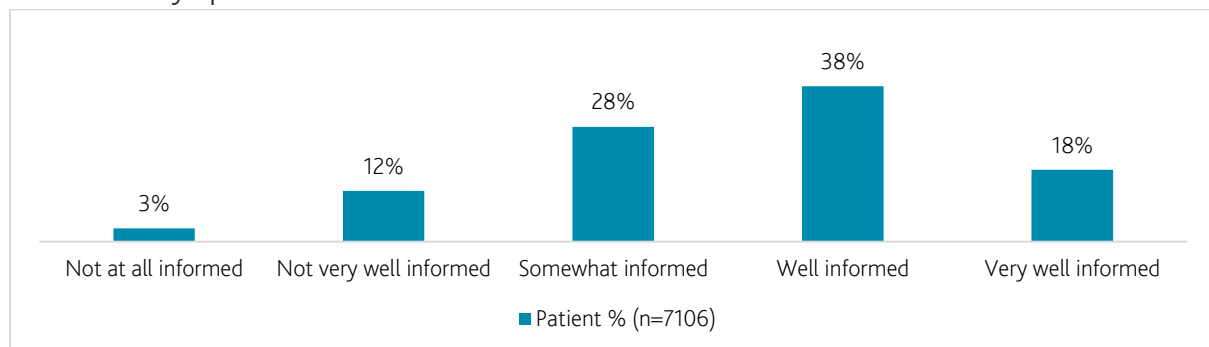
- ❖ Figure 21 illustrates that 58% of patients reported that it was the patient alone who was seeking out the information and details about the disease and potential treatments, after their diagnosis, while 22% reported that it was the patient and caregiver jointly.

Figure 21. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



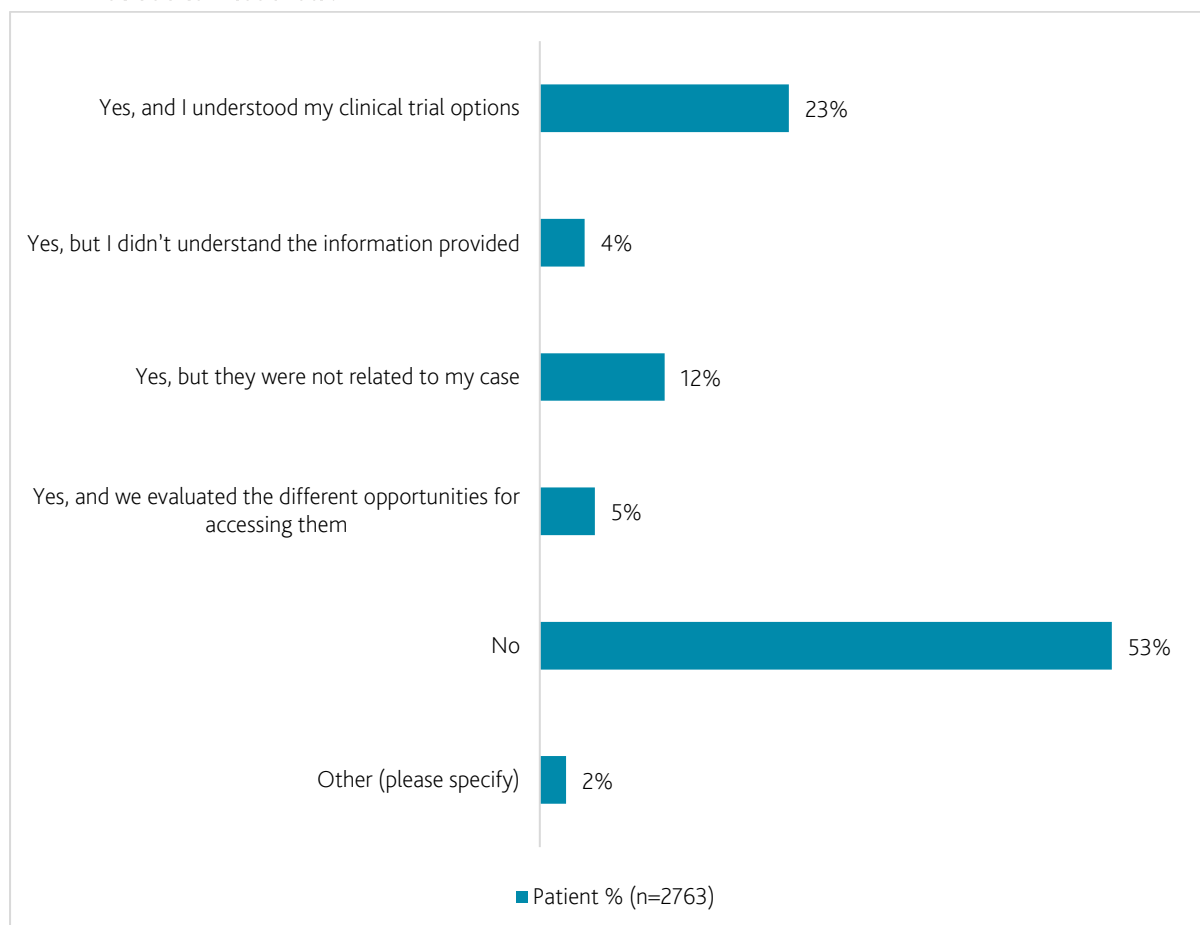
- ❖ Figure 22 illustrates that 18% of patients felt very well informed and 38% felt well informed about the processes and stages of their healthcare throughout their experience

Figure 22. How informed have you felt about the processes and stages of your healthcare (e.g., diagnosis, treatment, resources available for support and self-care) throughout your experience with lymphoma or CLL?



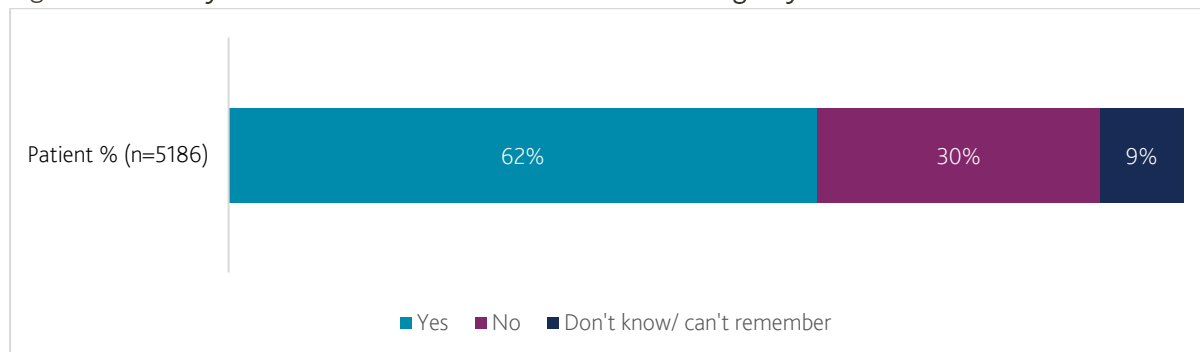
- ❖ Figure 23 illustrates that 53% of patients did not receive any information about clinical trials

Figure 23. During your meetings with your lymphoma or CLL doctor, did you receive any information about clinical trials?



- ❖ Figure 24 illustrates that 62% of patients were aware that a clinical trial can sometimes provide access to the best treatment

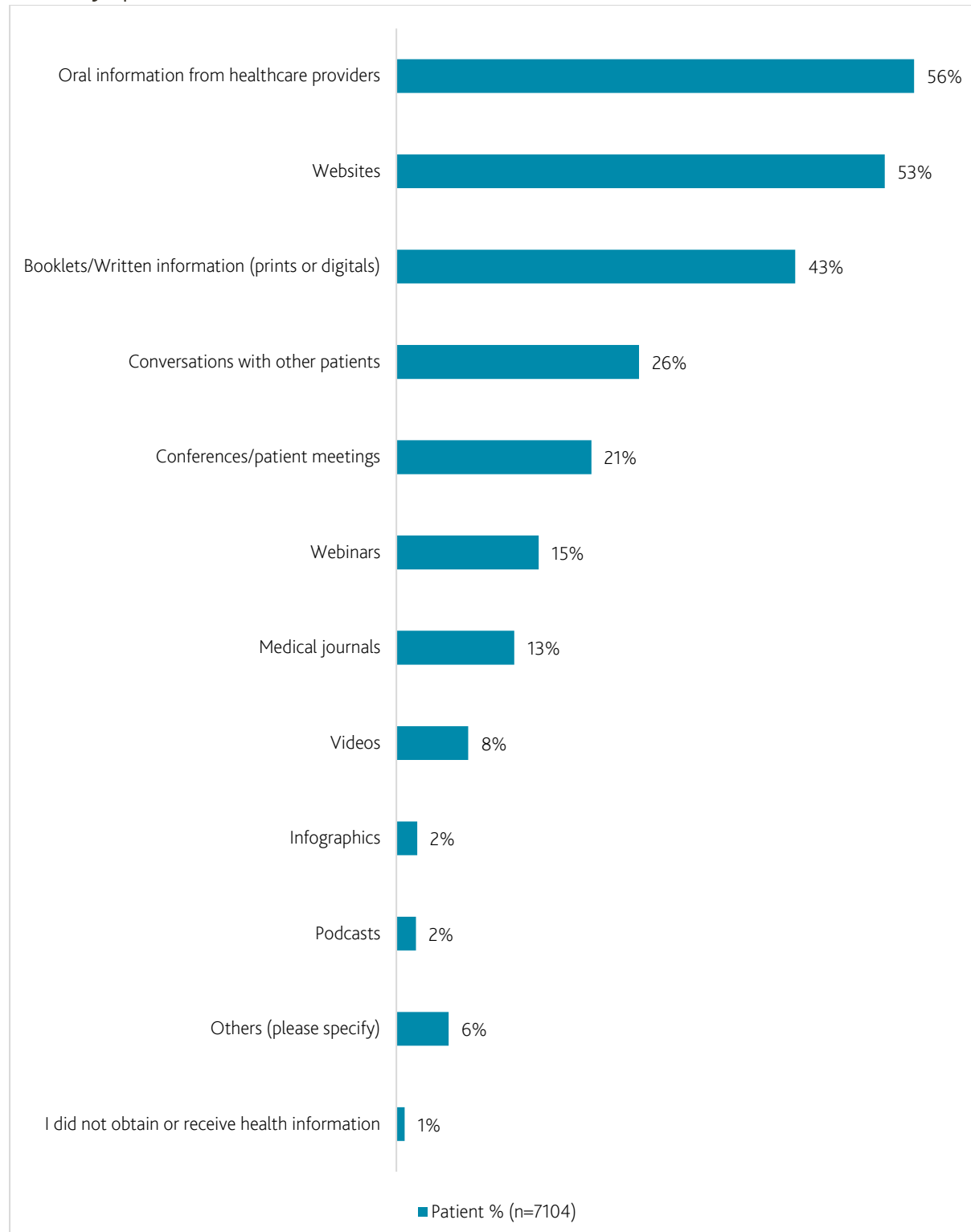
Figure 24. Were you aware that a clinical trial can sometimes give you access to the best treatment?



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- ❖ Figure 25 illustrates that 56% of patients preferred obtaining or receiving health information through oral information from healthcare providers

Figure 25. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?

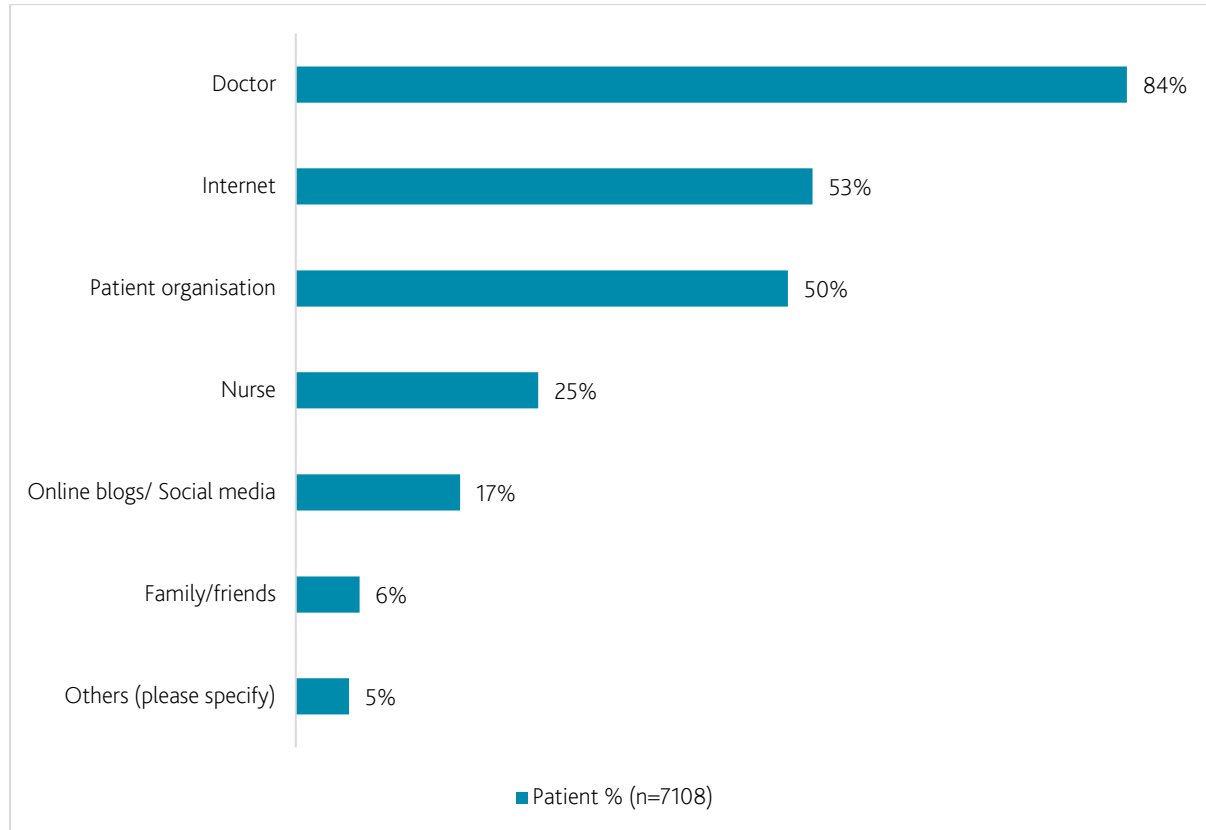




## GPS 2022: Global Report

- ❖ Figure 26 illustrates that 84% of patients preferred doctors as their source for lymphoma or CLL information

Figure 26. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?



- ❖ Table 1 illustrates that 63% of patients ranked doctors as their top source of lymphoma or CLL information

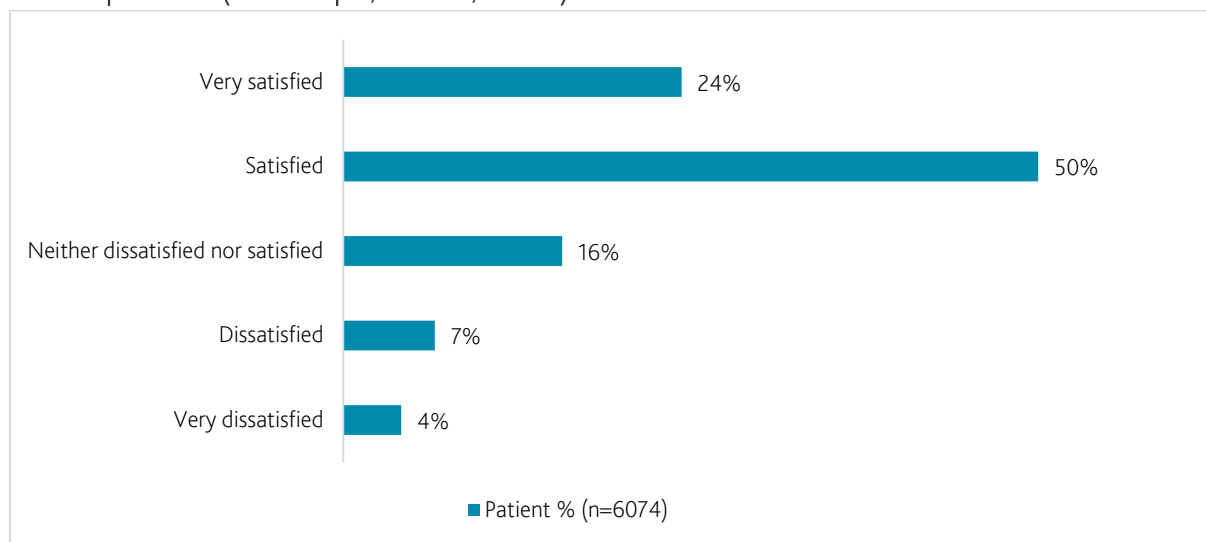
Table 1. Rank your top three sources of lymphoma or CLL information that you most prefer.

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	2123	63%	477	15%	508	16%
Nurse	91	3%	759	23%	279	9%
Internet	451	13%	723	22%	1037	33%
Online blogs/ social media	127	4%	199	6%	317	10%
Family/friends	32	1%	89	3%	102	3%
Patient organisation	463	14%	909	28%	863	27%
Others (please specify)	68	2%	80	2%	64	2%
<b>Total</b>	<b>3355</b>	<b>100%</b>	<b>3236</b>	<b>100%</b>	<b>3170</b>	<b>100%</b>

Satisfaction level of patients with the health information provided by healthcare providers increased with age range, with more patients aged 65yrs and older being very satisfied with the health information provided by their healthcare providers.

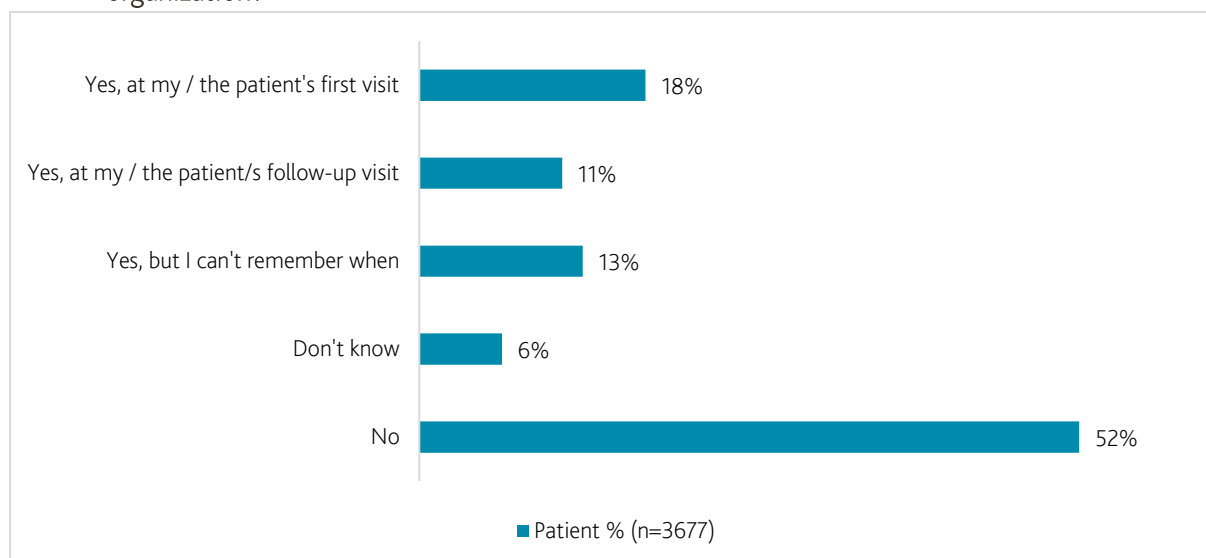
- ❖ Figure 27 illustrates that only 24% of patients were very satisfied with the information given to them by healthcare providers

Figure 27. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, nurses)?



- ❖ Figure 28 illustrates that 52% of patients did not receive details about a patient organization, a support group and/or information produced by a patient organization

Figure 28. Did the lymphoma or CLL doctor or any member of the medical team give you the contact details of a patient organization, a support group and/or information produced by a patient organization?

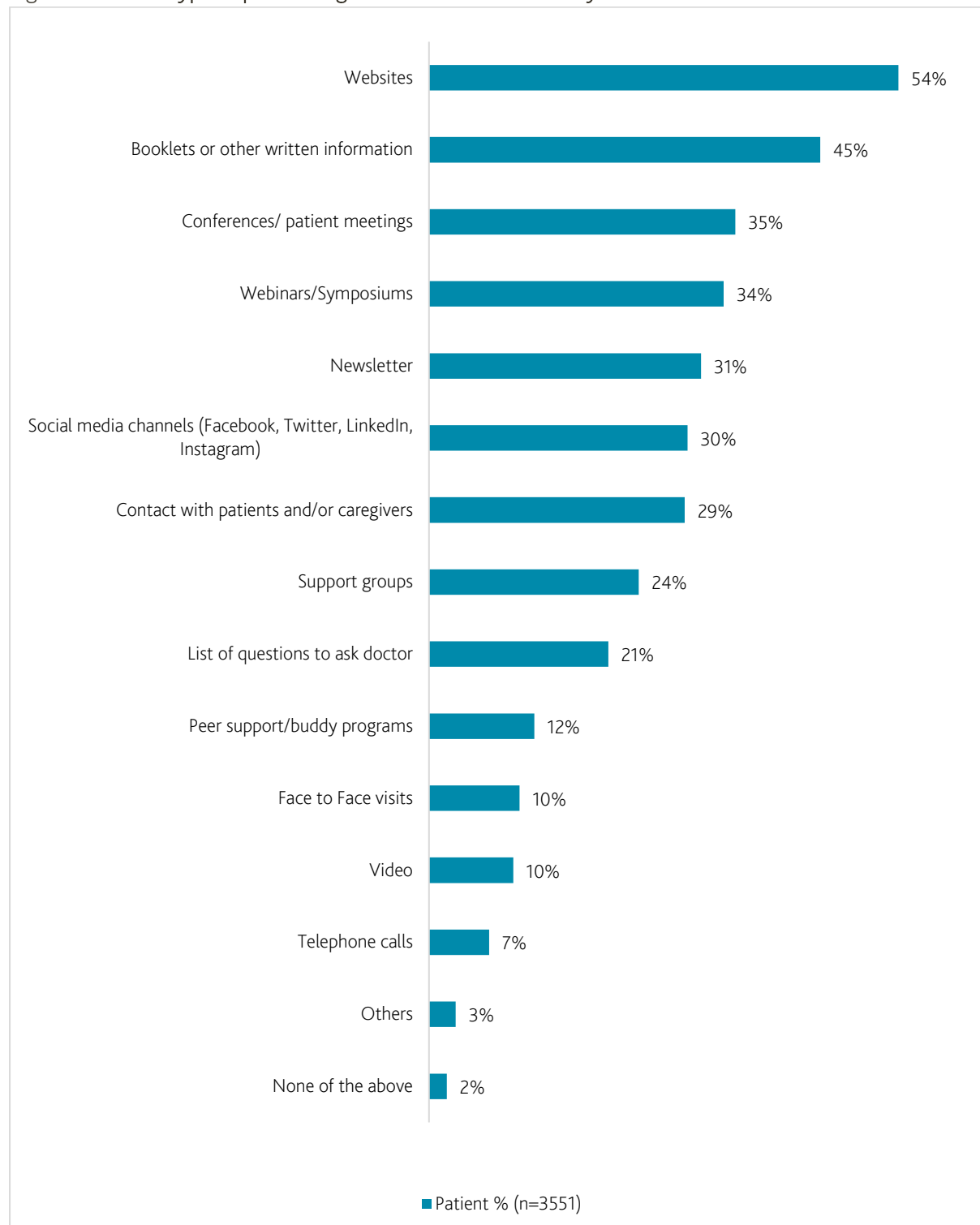


## GPS 2022: Global Report

Patients were asked about the type of patient organisation information they use- the organisation's website was the top reported one (54%), followed by booklets or other written information (45%), conferences/ patient meetings (35%) and webinars/ symposiums (34%).

❖ Figure 29 illustrates that 54% of patients used patient organisation websites

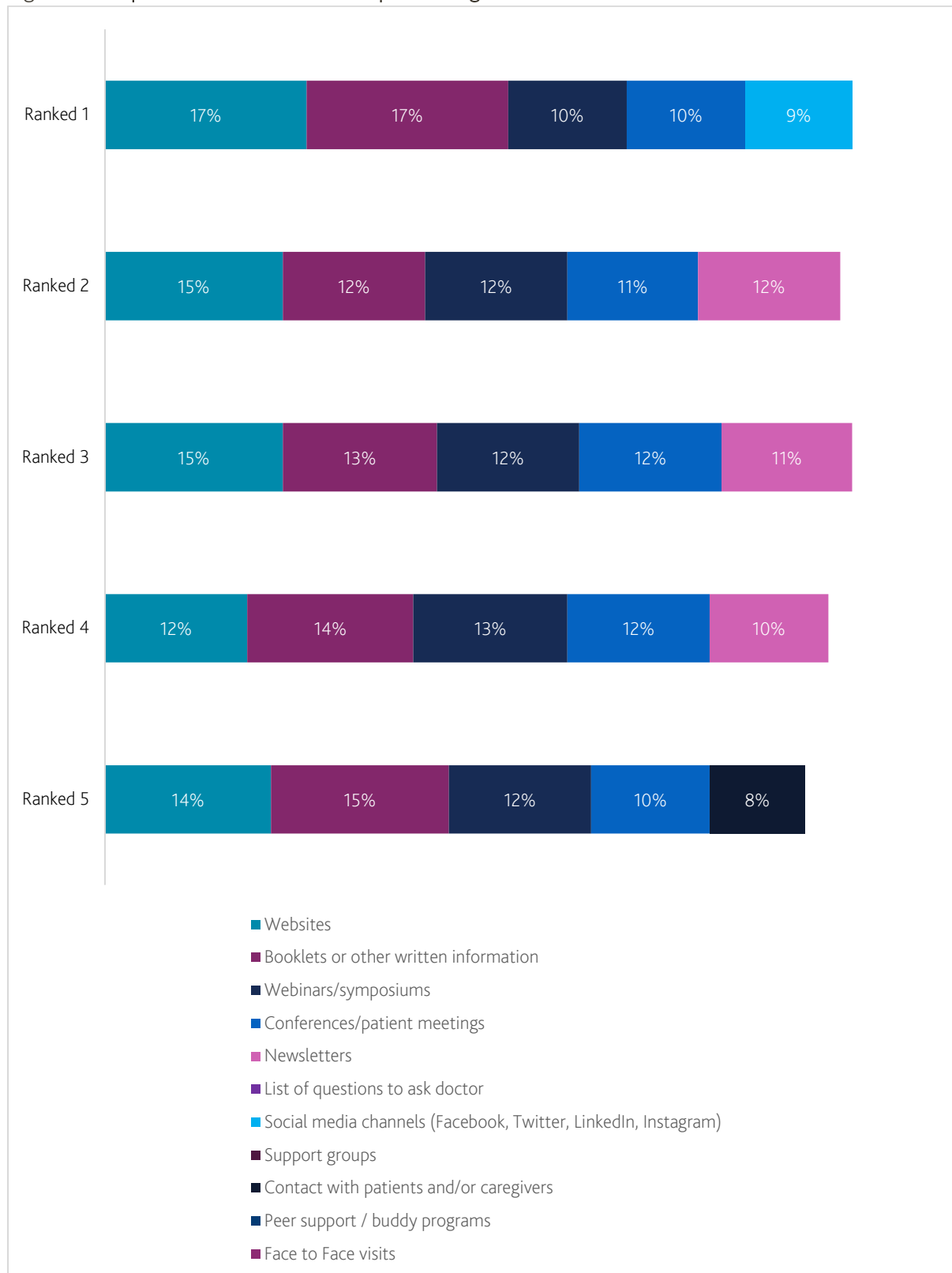
Figure 29. What type of patient organisation information do you use?



## GPS 2022: Global Report

- ❖ Figure 30 illustrates that 34% of patients ranked either websites or booklets and other written information as their top information source of patient organisations

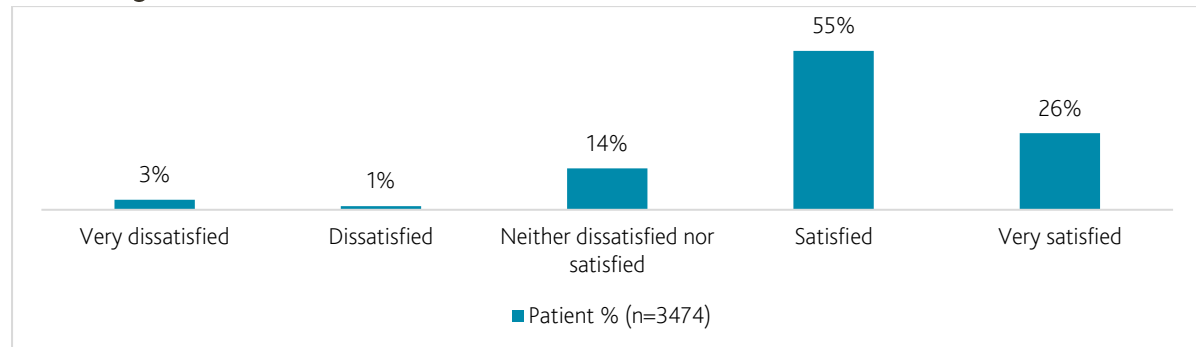
Figure 30. Top 5 information sources of patient organisations ranked 1-5



## GPS 2022: Global Report

- ❖ Figure 31 illustrates that 55% of patients were satisfied with the information given by patient organisations

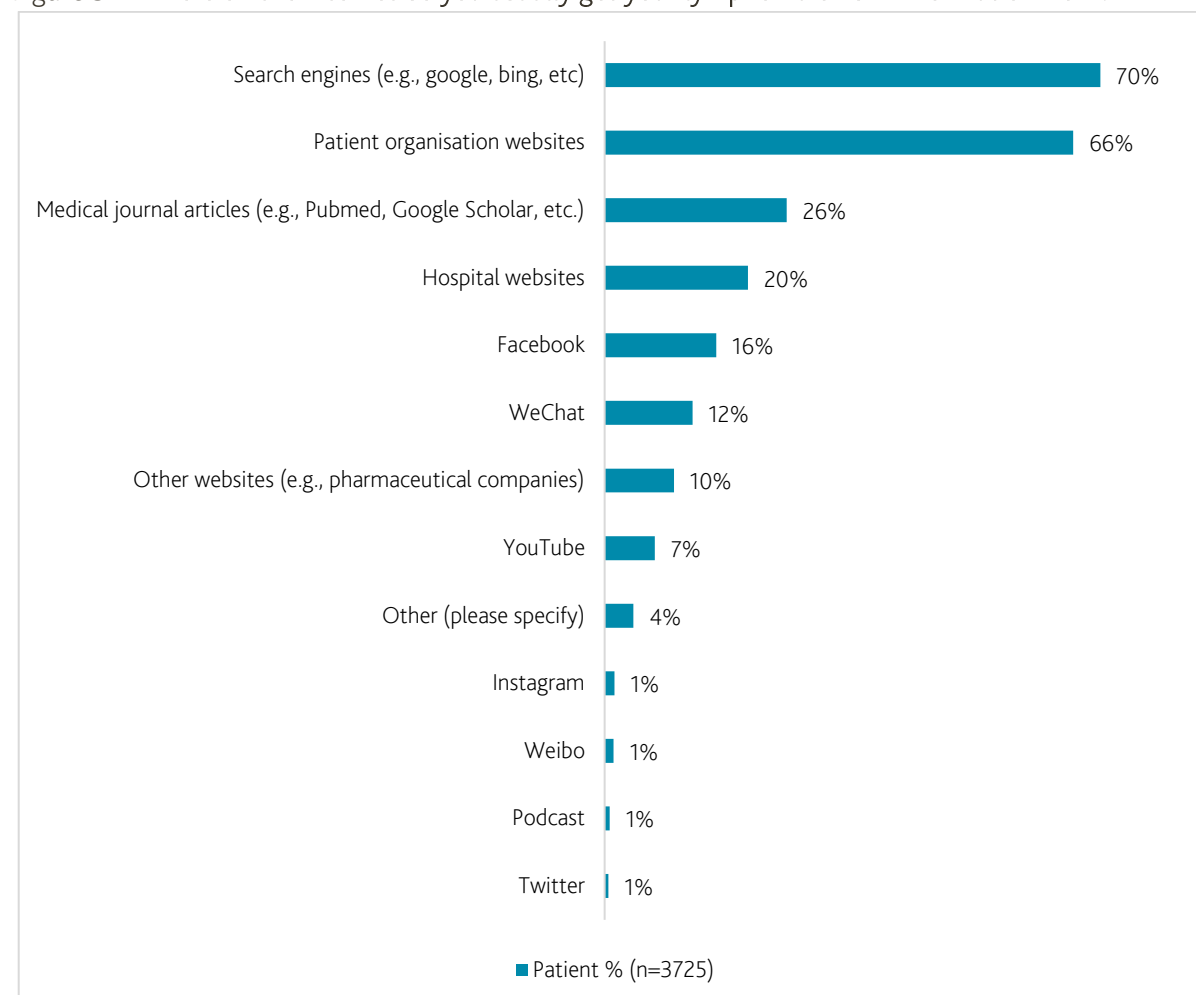
Figure 31. How satisfied or unsatisfied are you with the information given to you by patient organisations?



Below shows the common places on the internet that lymphoma or CLL patients get lymphoma or CLL information from.

- ❖ Figure 32 illustrates that 70% of patients usually get lymphoma or CLL information from search engines on the internet

Figure 32. Where on the internet do you usually get your lymphoma or CLL information from?



## GPS 2022: Global Report

### Healthcare Support

In addition to information, patients need support to help them cope with the challenges they face during their care processes. Clear information, communication and support for self-care are important aspects of person-centred care.

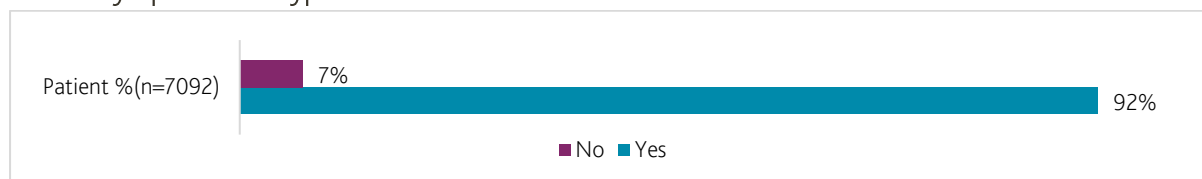
This results in this section focus on the support experiences of patients (including segments specific to patients with indolent diseases, those in remission/survivors and those in active surveillance care)



- 92% of patients had seen a specialist (e.g., haematologist, oncologist, dermatologist) for their lymphoma subtype.
- 73% of patients had been seeing the same speciality physician (e.g. haematologist, oncologist, dermatologist) throughout their patient experience.
- 42% of patients did not have their health care supported by a cancer care team (multidisciplinary cancer care team) and/or cancer care coordinator
- 73% of those who had their care supported by a cancer care team, had a dedicated first point of contact

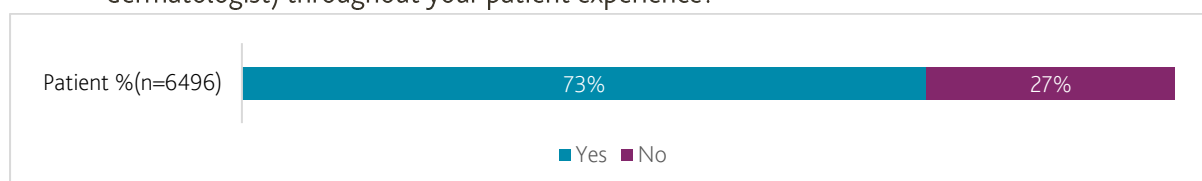
❖ Figure 33 illustrates that 92% of patients had seen a specialist for their lymphoma subtype

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



❖ Figure 34 illustrates that 73% of patients had been seeing the same specialty physician throughout their patient experience

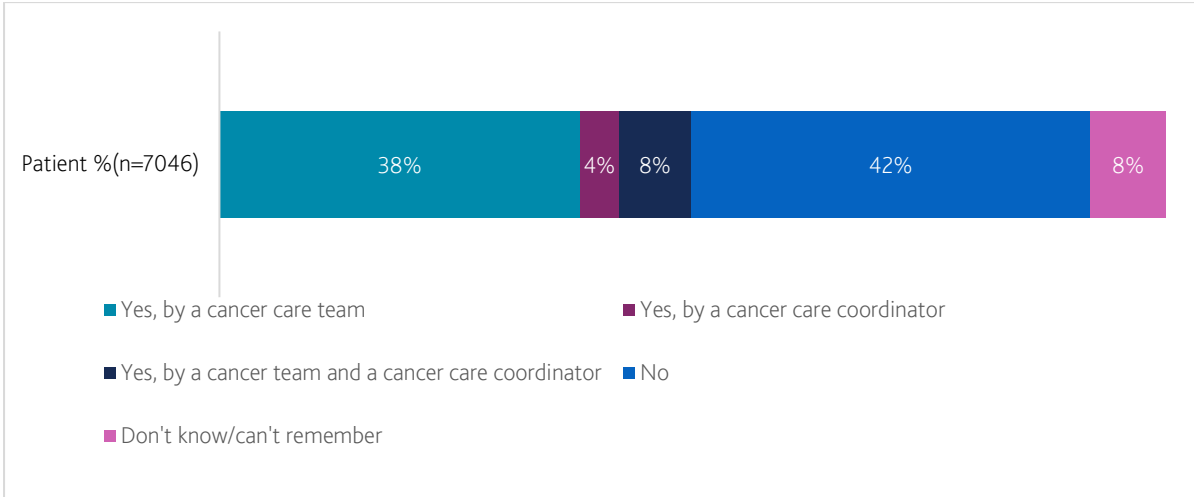
Figure 34. Have you been seeing the same specialty physician (e.g., haematologist, oncologist, dermatologist) throughout your patient experience?



GPS 2022: Global Report

- ❖ Figure 35 illustrates that 42% of patients did not have lymphoma care provided by a cancer team or coordinator

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



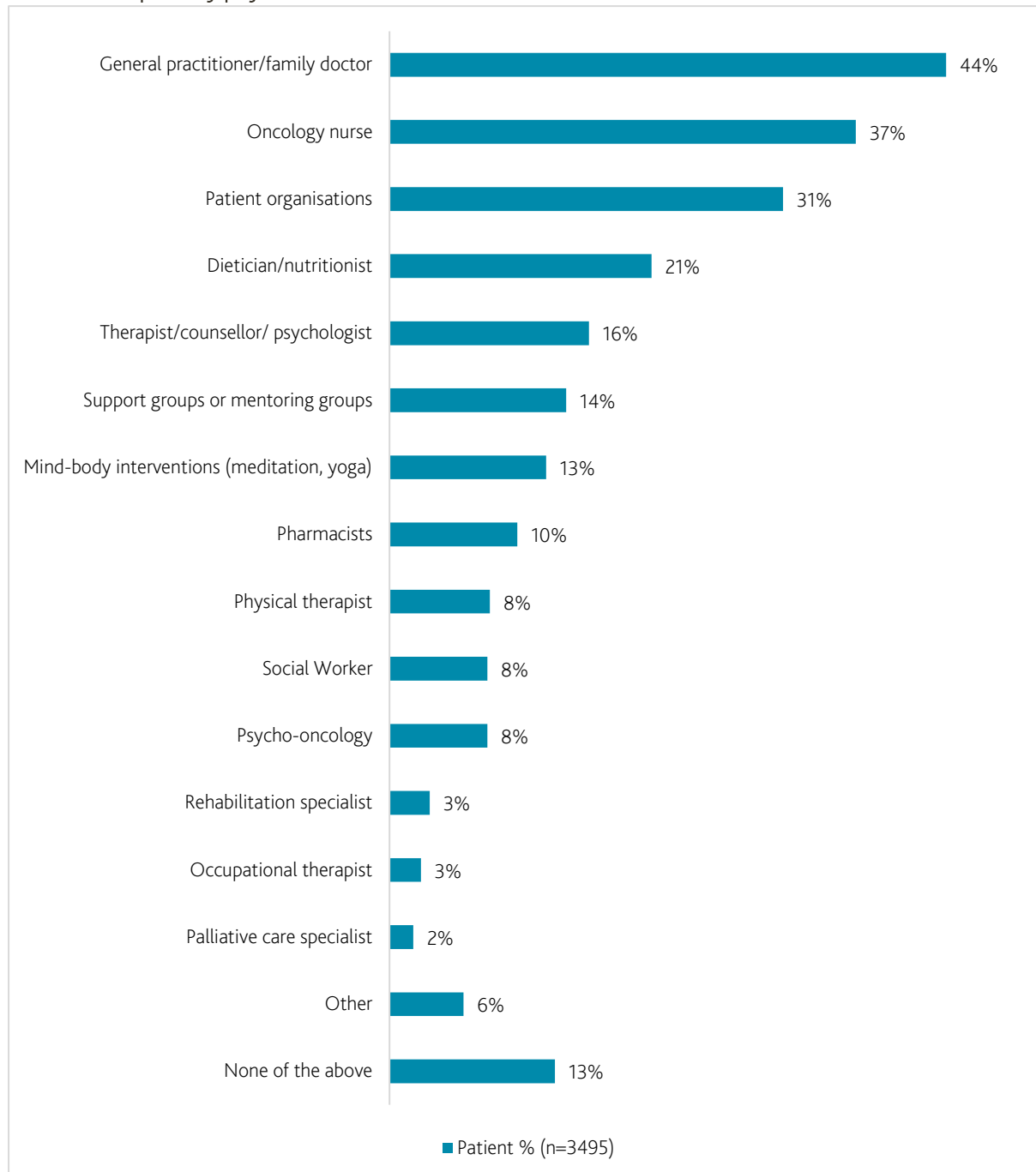
The proportion of patients with lymphoma or CLL who did not have their lymphoma care provided by a cancer care team (multidisciplinary cancer care team) varied across the regions: Asia-Pacific- 60%, North America-46%, Europe-29%, Middle East and Africa- 36%, and South America-41%.

## GPS 2022: Global Report

44% of patients who reported that they had access to a cancer care team found their general practitioner/family doctor useful in providing supportive care outside of their speciality physician. In addition, 31% of patients found patient organisations useful in providing supportive care.

- ❖ Figure 36 illustrates that 44% of patients found general practitioners/family doctors useful in providing supportive care, outside of the specialty physician

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

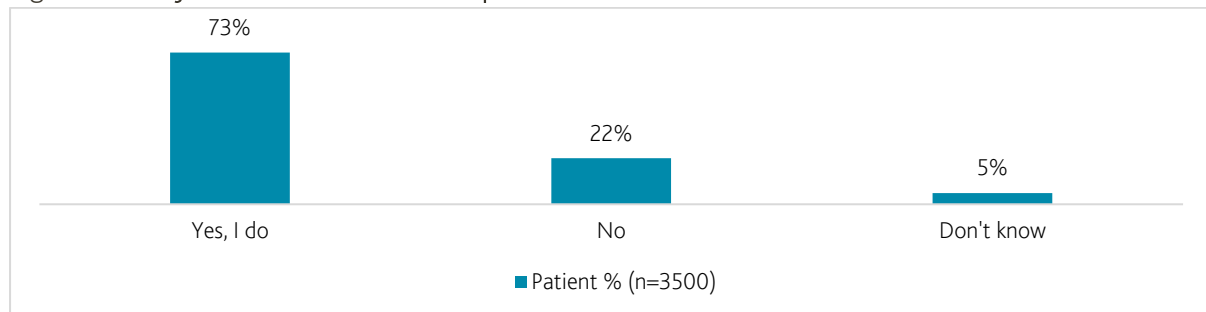




## GPS 2022: Global Report

- ❖ Figure 37 illustrates that 73% of patients have a dedicated first point of contact within the cancer care team

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



### Support Experience of Patients with Indolent Lymphomas

Patients with indolent disease are sometimes overlooked for their support needs when they are not undergoing active treatment or due to having less frequent clinic visits. The results below show some of the support experiences of this patient group.

Patients with CLL/SLL, follicular lymphoma and Waldenstrom's macroglobulinemia were asked how much involvement their general practitioner (GP)/family physician had in their care. 42% reported that their GP was adequately involved in their care, while 20% reported that their GP was not involved in their care but that they wished that they were.

For the patients who reported that their GP was involved in their care, when asked which areas/aspects of their care they would want their GP to be more involved in, 64% reported before, during and after treatment. Only 8% reported that they would like their GP to be involved only during follow up.

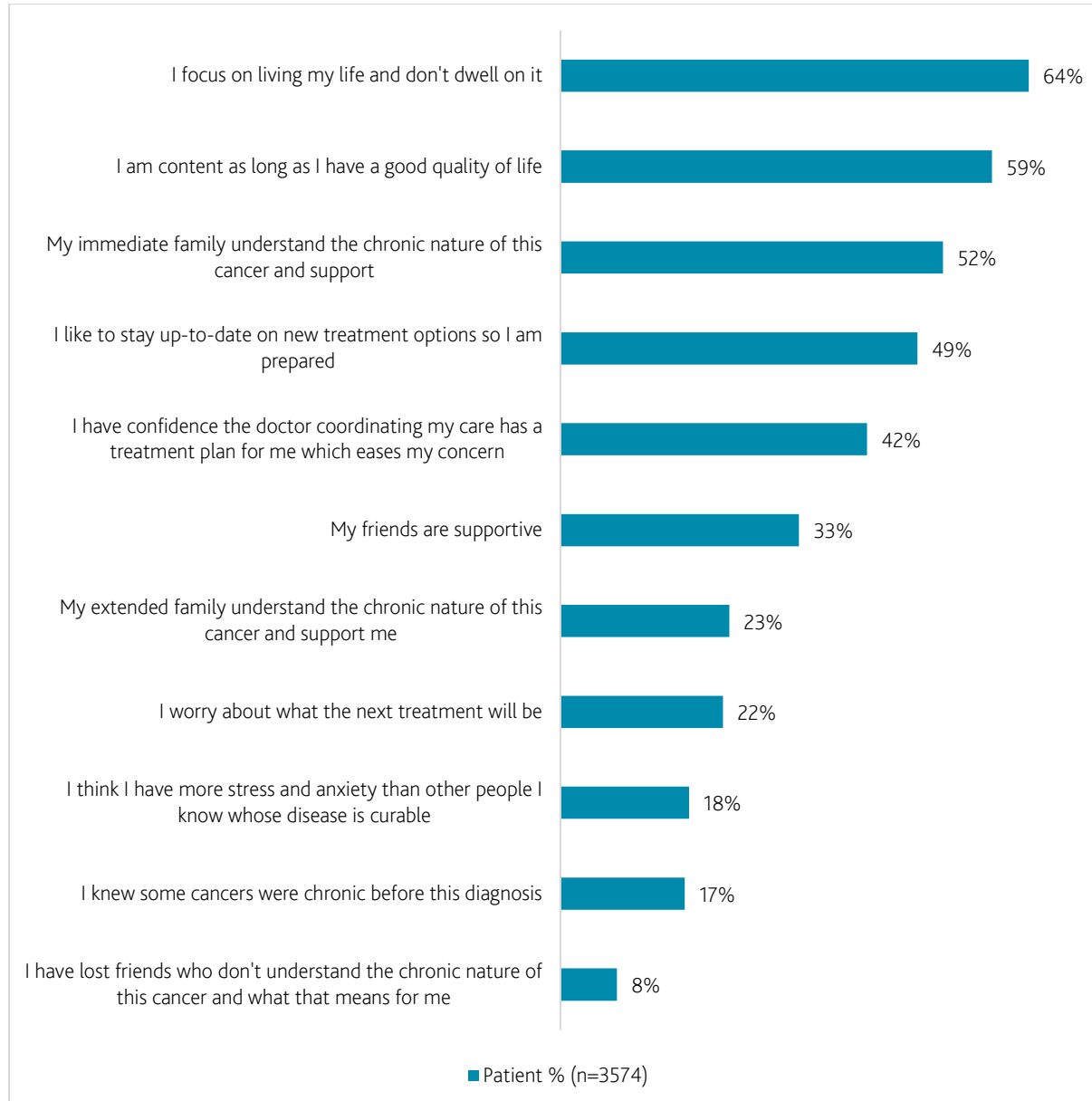
With the development and use of monitoring devices in healthcare, patients with CLL/SLL, follicular lymphoma and Waldenstrom's macroglobulinemia were asked if they were comfortable with the idea of using telemonitoring or information technology such as applications (apps) or wearable devices to monitor them from a distance. 19% of patients were not comfortable with the idea. On the other hand, 36% of patients were comfortable using them before, during and after treatment.

Patients with cutaneous lymphoma (including Sézary syndrome and mycosis fungoides), follicular lymphoma, CLL/SLL and Waldenstrom's macroglobulinemia were also asked to describe their experience living with chronic lymphoma. Almost two-thirds (64%) of patients reported that they focused on living their lives and not dwelling on their disease. Only about half of patients (52%) reported that their immediate family understood the chronic nature of their cancer and their support needs. 18% of patients think they have more stress and anxiety than other patients whose diseases are curable.

## GPS 2022: Global Report

- ❖ Figure 38 illustrates that 64% of patients were focused on living life and did not dwell on living with chronic cancer

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



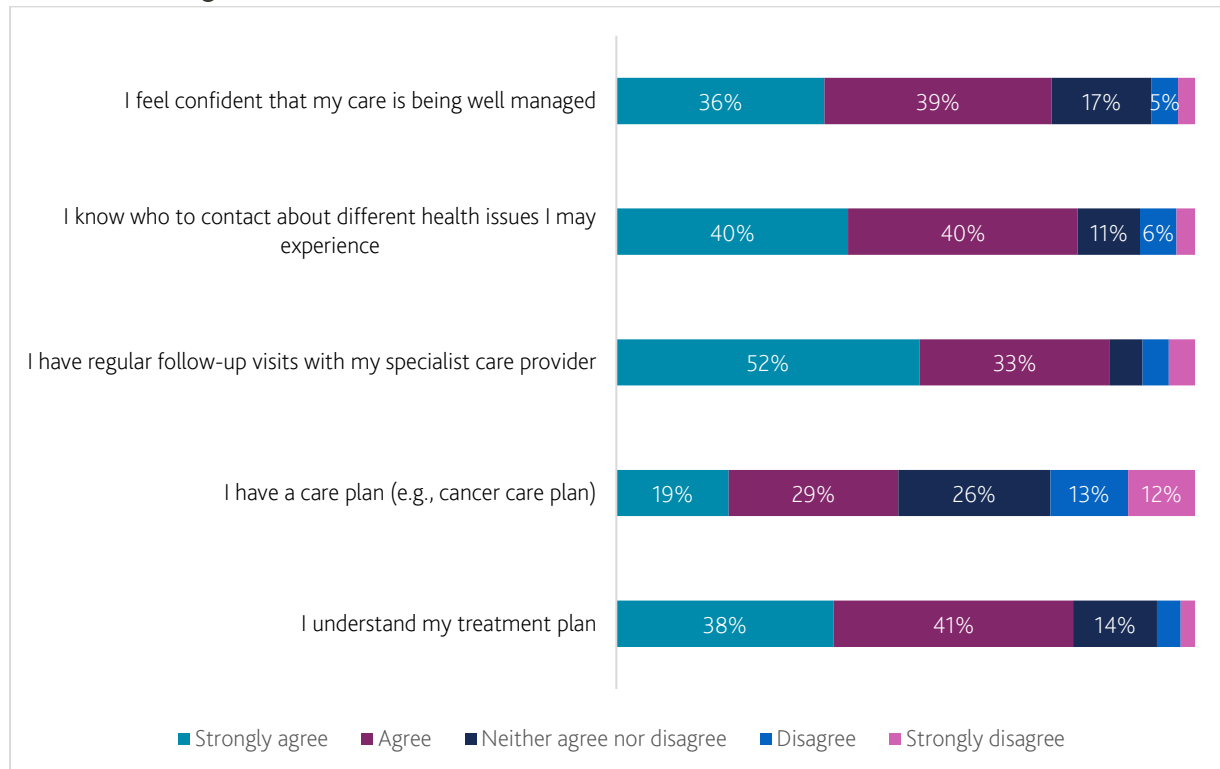
### Support Experience of Patients in Active Surveillance

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

## GPS 2022: Global Report

- ❖ Figure 39 illustrates that 52% of patients strongly agree that they have regular follow-up visits with their specialist care provider

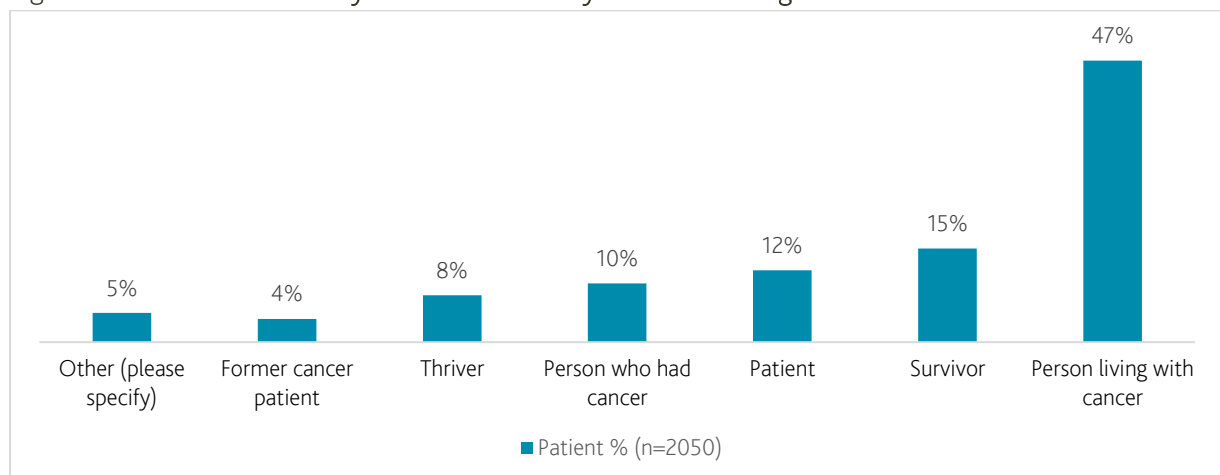
Figure 39. You have indicated that you are currently in active monitoring (watch and wait). In thinking about your cancer care right now, please indicate how much you agree and disagree with the following statements.



Patients who had received or were receiving medical treatment were asked if there was a term they would use to describe themselves. *(This question was specific to patient respondents who answered the survey in English to limit the possibility of misinterpretation of the options given in the question).*

- ❖ Figure 40 illustrates that 47% of patients would describe themselves as a person living with cancer

Figure 40. What term would you use to describe yourself following cancer treatment?



## GPS 2022: Global Report

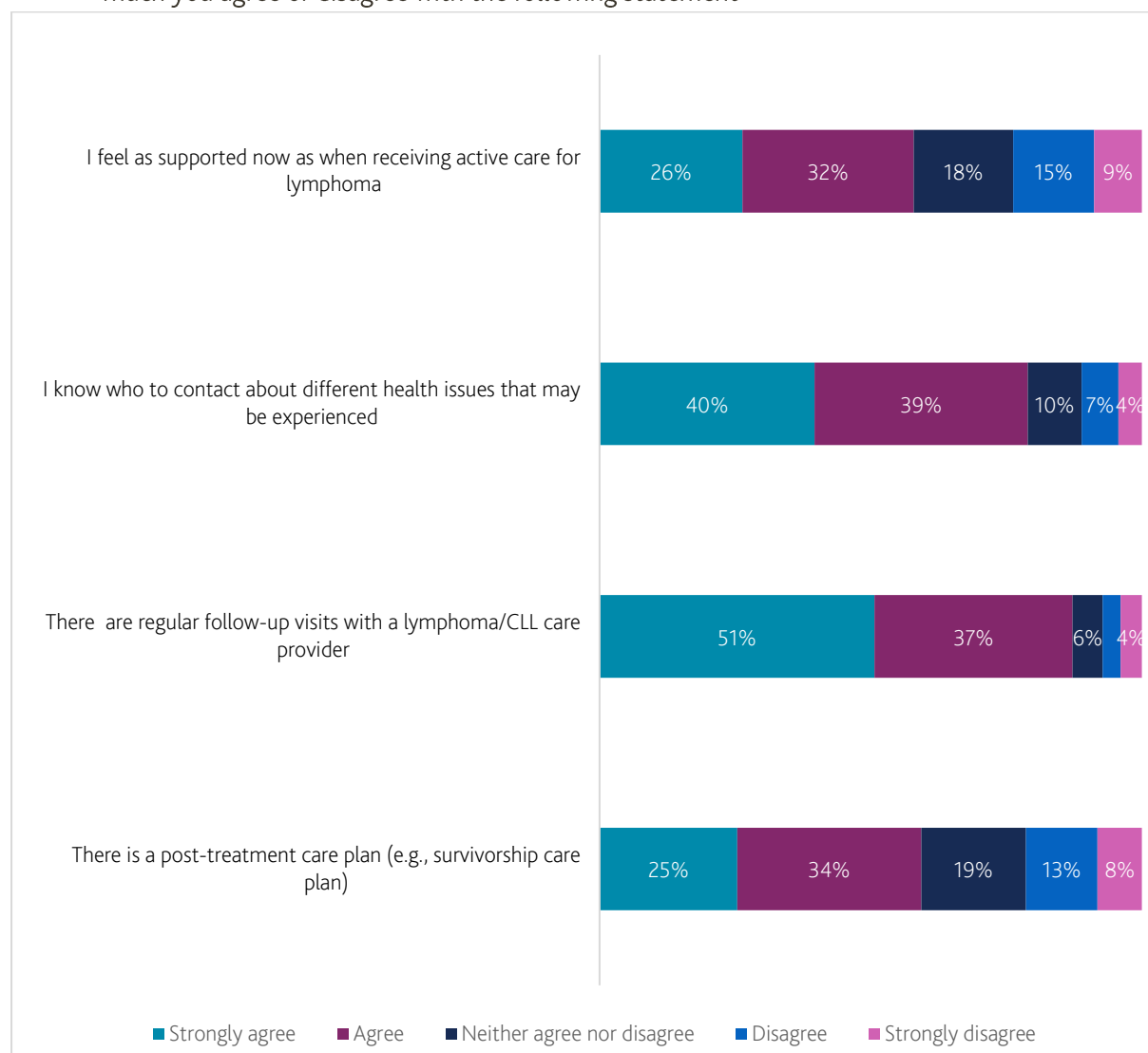
### Support Experience of Patients in Remission/ Survivorship

Patients in remission (who had transitioned out of cancer care into survivorship) were also asked a series of questions about their support experience and the results are shown below.

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, and the results are shown below.

- ❖ Figure 41 illustrates that 51% of patients strongly agree that they had regular follow-up visits with a lymphoma/CLL care provider when transitioning from cancer care into survivorship

Figure 41. In thinking about the transition from cancer care into survivorship, please indicate how much you agree or disagree with the following statement



Healthcare Involvement and Decision Making

Patient-centeredness is a key part of providing high-quality cancer care as it takes into consideration the goals and expectations of patients and their families. Patients should be seen by healthcare providers as individuals and not just 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.

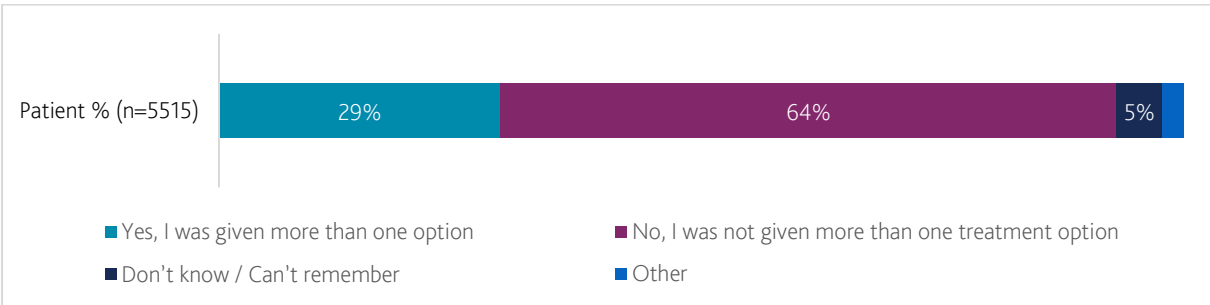
The results below show the experiences that patients with lymphoma or CLL had with healthcare involvement and decision-making.



- Only 29% of patients were given more than one treatment option before their current or last therapy for lymphoma.
- Only 50% of patients definitely felt as involved as much as they want to be in decisions about their care and treatment.

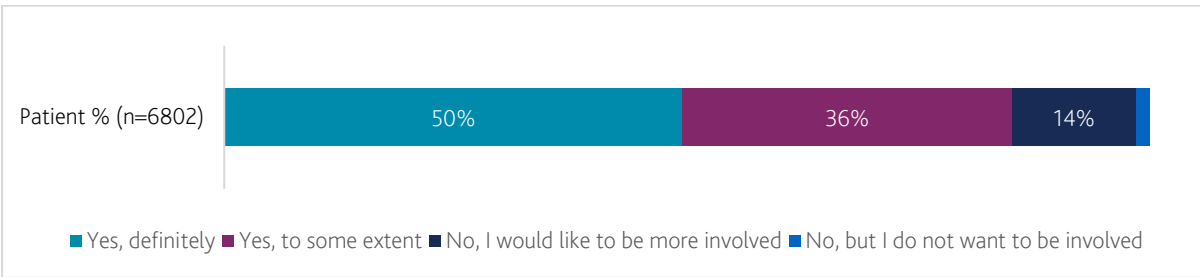
❖ Figure 42 illustrates that 64% of patients were not given more than one treatment option

Figure 42. Were you given more than one treatment option (for instance, different types of chemotherapy regimens to choose from or a choice between a stem cell transplant and a new targeted therapy) before your current or last therapy for lymphoma?



❖ Figure 43 illustrates that 50% of patients definitely felt that they were as involved as much as they want to be in decisions about their care and treatment

Figure 43. Do you feel as involved as much as you want to be, in decisions about your care and treatment?

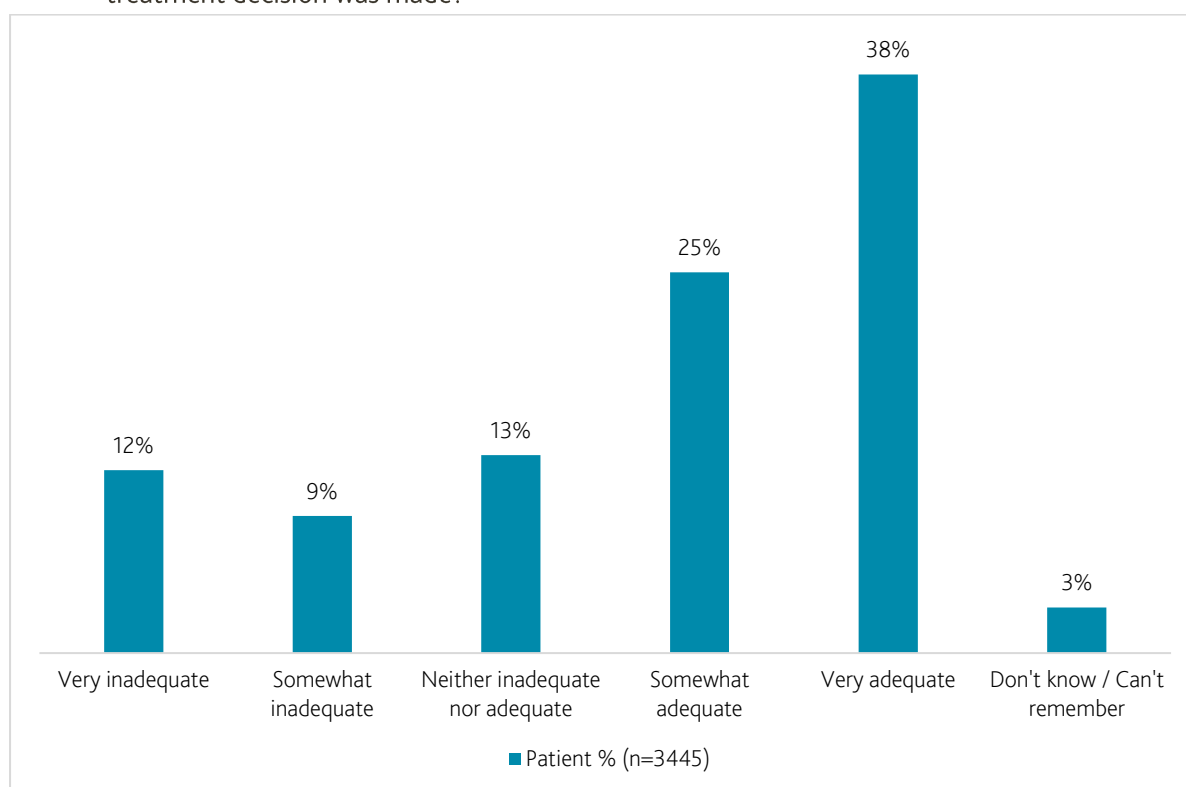


Patients with the following lymphoma subtypes were more prevalent in reporting that they definitely felt involved in their care (as much as they wanted to be): cutaneous lymphoma (64%), mycosis fungoides (57%), Sézary syndrome (65%), Waldenstrom's macroglobulinemia (61%) and DLBCL (germinal centre B-cell) (62%), and most of these patients resided in North America (67%).

When patients were asked if they were given adequate time to think about their treatment before their treatment decision was made, only 38% reported that the time given was very adequate, while 12% reported that it was very inadequate.

- ❖ Figure 44 illustrates that 38% of patients feel that they had very adequate amount of time to think about treatment before the treatment decision was made

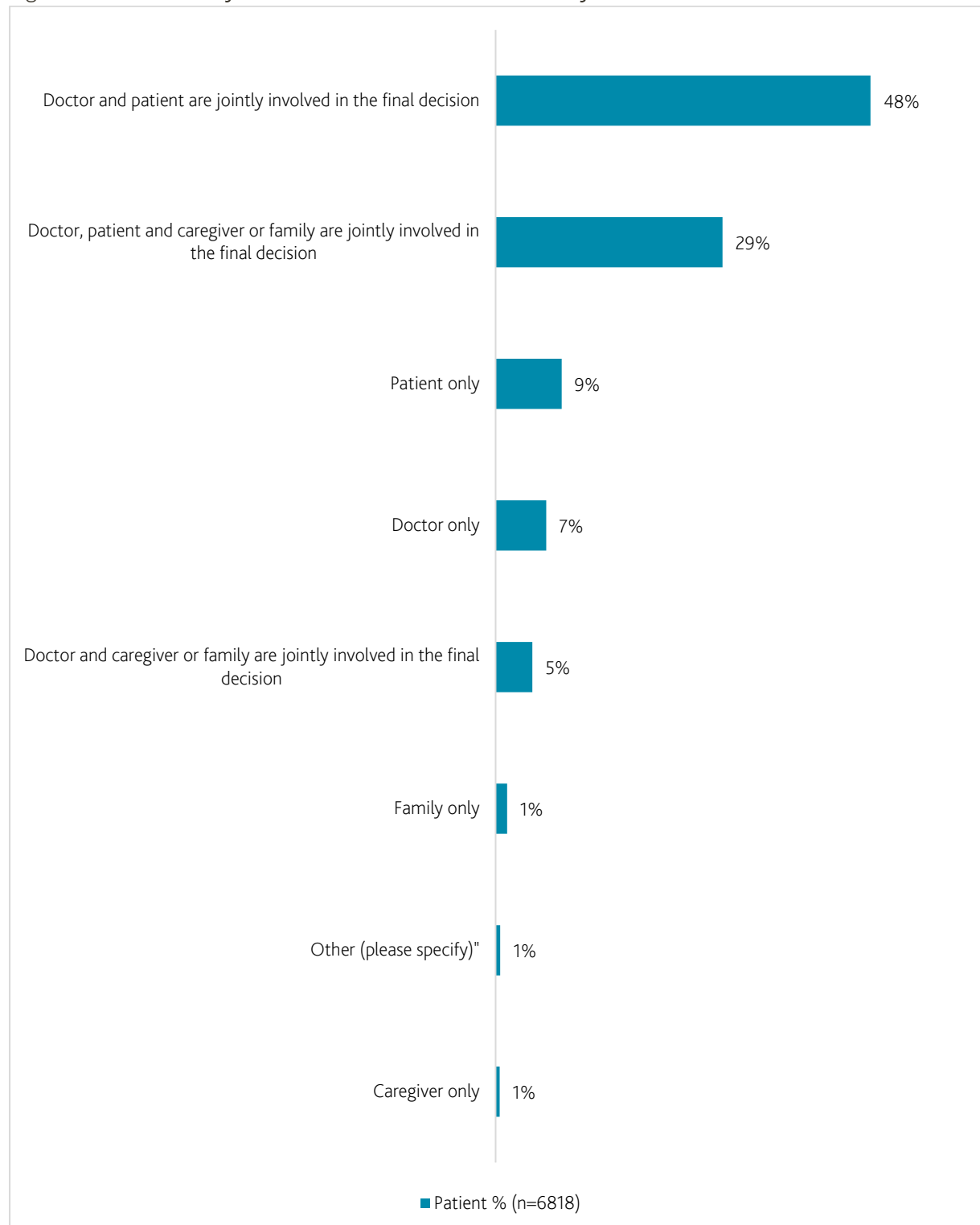
Figure 44. Regarding your current treatment (or last treatment) if you are no longer in treatment) how adequate was the amount of time you were given to think about your treatment before the treatment decision was made?



When asked whom they would like to make the final decision on their healthcare, almost half of the patients (48%) reported that they would like the doctor and patient to be jointly involved in making the final decision. 7% reported that they wanted only the doctor to make the final decision while 9% reported patient only.

- ❖ Figure 45 illustrates that 48% of patients would like the doctor and patient to be jointly involved in the final decision on their healthcare

Figure 45. Who would you like to make the final decision on your healthcare?

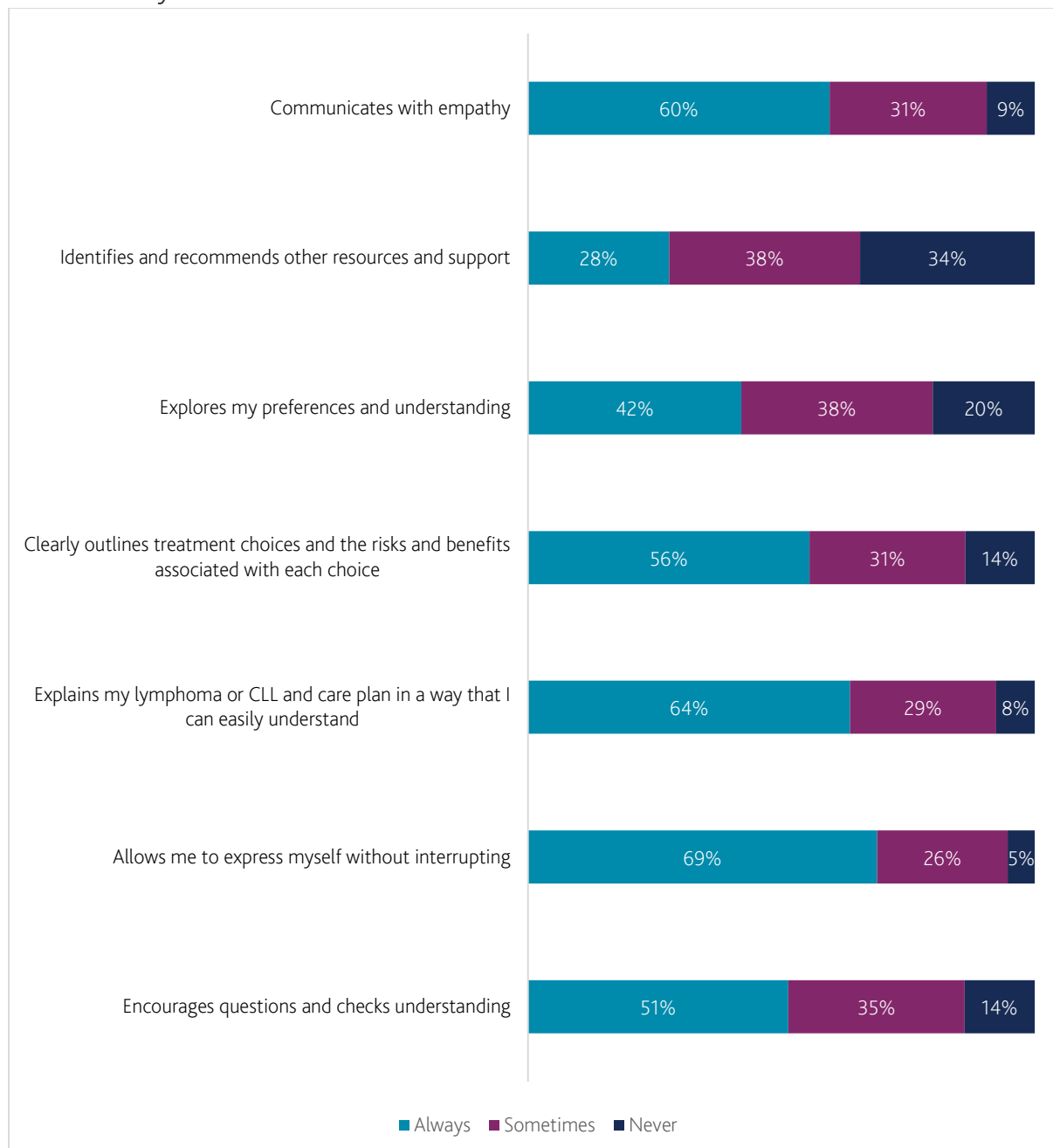


## GPS 2022: Global Report

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 46 illustrates that 69% of patients feel that their doctor always allows them to express themselves without interrupting

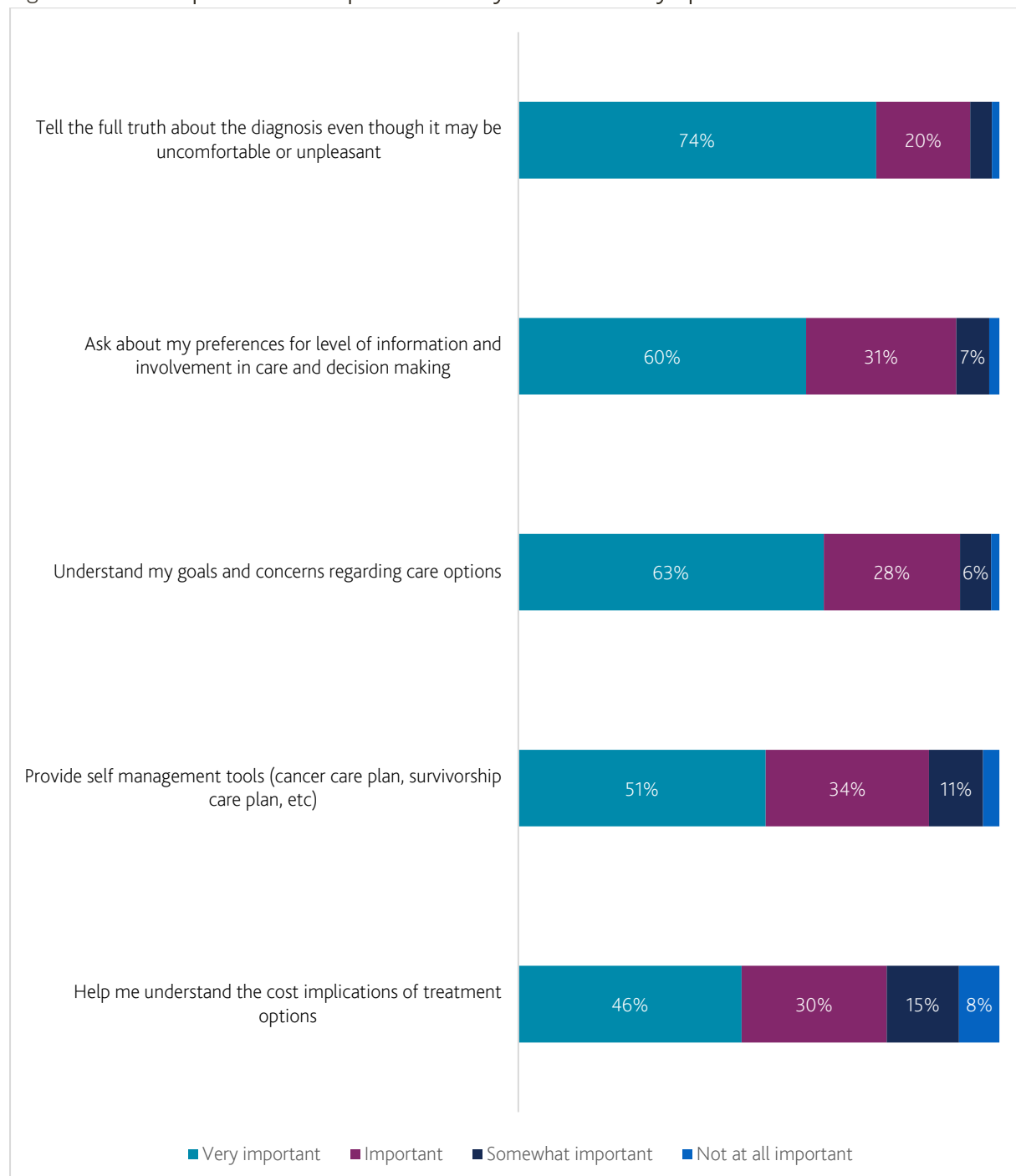
Figure 46. Does your doctor do any of the following to encourage participation in decision-making about your care?





- ❖ Figure 47 illustrates that 74% of patients feel that it is very important to have the lymphoma or CLL doctor tell the full truth about the diagnosis even though it may be uncomfortable or unpleasant

Figure 47. How important or unimportant is it to you to have the lymphoma or CLL doctor?



## GPS 2022: Global Report

### Effects of Lymphoma/CLL

To fully understand patient experience regarding the effects of lymphoma, including CLL, consideration must be given to all the interactions within a patient's life, such as the symptoms and side effects of the disease, emotional and social effects, or financial implications. This section of the report details the physical effects of lymphoma, treatment experience and side effects of treatment.

In previous LC Global Patient Surveys, cancer-related fatigue (CRF) was the leading physical symptom affecting the quality of life reported by respondents, regardless of whether the patient was newly diagnosed, in treatment, or had relapsed disease was in remission. However, the survey data reflects that patients were not being educated about their fatigue or directed to further information/support by their doctors. Like previous years, fatigue remains the top reported symptom and side effect in the 2022 GPS.



- Fatigue was the most reported symptom of lymphoma, including CLL (66%).
- Fatigue was also the most reported side effect from treatment (67%)
- Over half of the patients (57%) who had ever received or received treatment were receiving their first treatment, while 16% received their 2nd line of treatment.
- Only 16% of patients had been in a clinical trial
- 10% of patients were interested in information about the effect of their treatment on fertility but they were not given such information
- 40% of patients agree and 23% strongly agree that their treatment was chosen to minimize the impact of possible side effects on lifestyle and/or favourite activities

Some symptoms reported by patients result from their lymphoma rather than the medications used to treat it. However, these symptoms can be exacerbated by medications. The top symptoms that impact patients negatively were fatigue, enlarged lymph nodes, abnormal painless swelling(s) on the body and B-symptoms (fever, chills, night sweats and weight loss).

❖ Table 2 illustrates that 66% of patients have experienced fatigue with lymphoma/CLL

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

Effects of Lymphoma	Number of respondents (n)	%	Treatment alleviated symptoms*
Abdominal swelling	1072	16%	55%
Anaemia	1664	25%	66%
Bone pain	1483	22%	47%
Cold agglutinin disease	92	1%	36%
Cryoglobulinemia	67	1%	28%
Easily bruised or bleed	1424	21%	28%
Enlarged lymph nodes/ abnormal painless swelling(s)	3059	45%	84%
Fatigue	4474	66%	40%
Fever, chills, night sweats and weight loss (B-symptoms)	2376	35%	73%
Frequent or repeated infections	1026	15%	49%
Headaches	1290	19%	42%
Hyperviscosity syndrome	157	2%	74%
Itchy skin	2337	39%	53%
Pain	1338	20%	47%
Shortness of breath	1858	28%	48%
Skin rashes/lesions	1615	24%	52%
Other (please specify)	835	12%	56%
No symptoms	363	5%	13%

\*only asked to those who reported the symptom

GPS 2022: Global Report

Treatment and Side-Effects

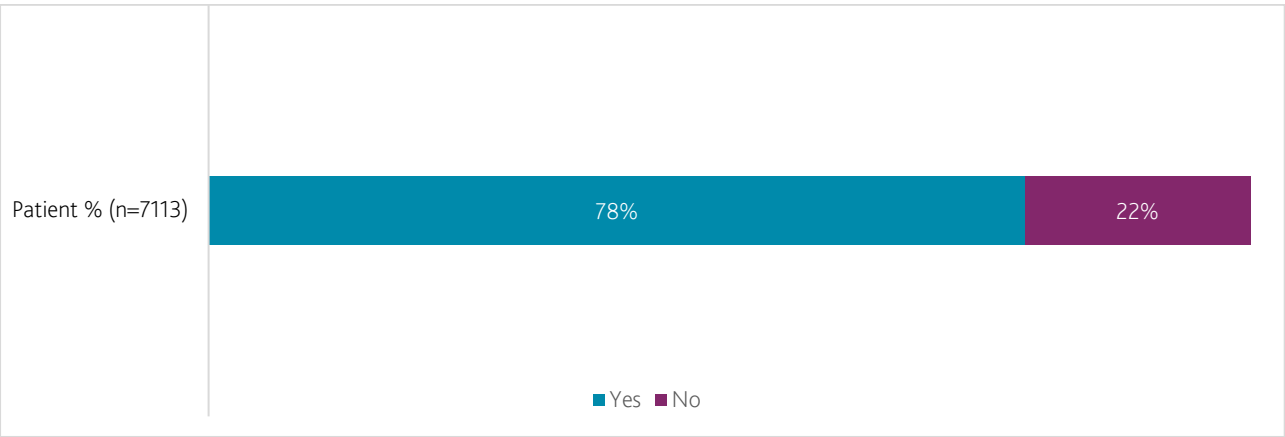
This section deals with questions only asked to patients currently on treatment or those who have ever had treatment for their lymphoma, including CLL.

5577 (78%) patients reported they had received or were receiving medical treatment and 65% of them had received those treatments within the last 2 years (from survey time).

Patients who had received their treatment within the last 2 years (from survey time) were asked if they were given an adequate amount of time to think about their treatment before the treatment decision was made, and only 38% reported that the time given to them was very adequate.

- ❖ Figure 48 illustrates that 78% of patients are receiving medical treatment for their lymphoma or CLL

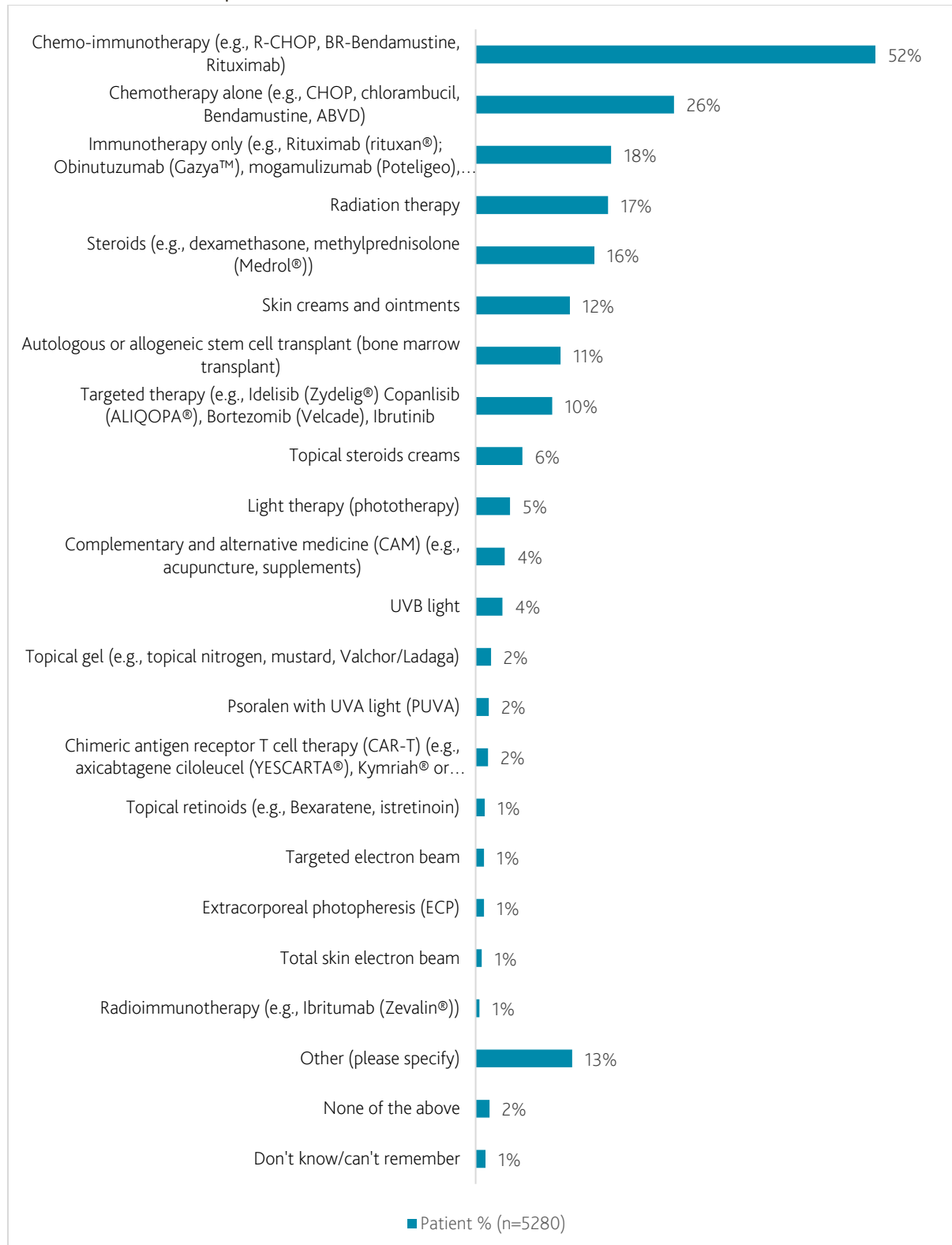
Figure 48. Have you received or are you receiving any medical treatment (e.g., chemotherapy, radiation) for your lymphoma or CLL?



## GPS 2022: Global Report

- ❖ Figure 49 illustrates that 52% of patients are currently receiving, or have received chemo-immunotherapy

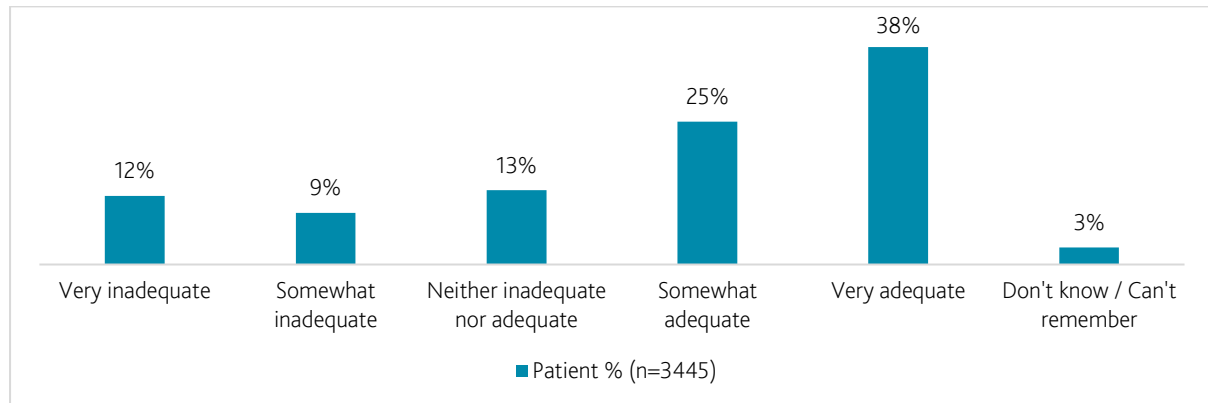
Figure 49. Which of the following treatment options, if any do you receive currently, or have ever received in the past?



## GPS 2022: Global Report

- ❖ Figure 50 illustrates that 38% of patients felt that they had very adequate amount of time to think about their treatment before the treatment decision was made

Figure 50. Regarding your current treatment (or last treatment if you are no longer in treatment), how adequate was the amount of time you were given to think about your treatment before the treatment decision was made?

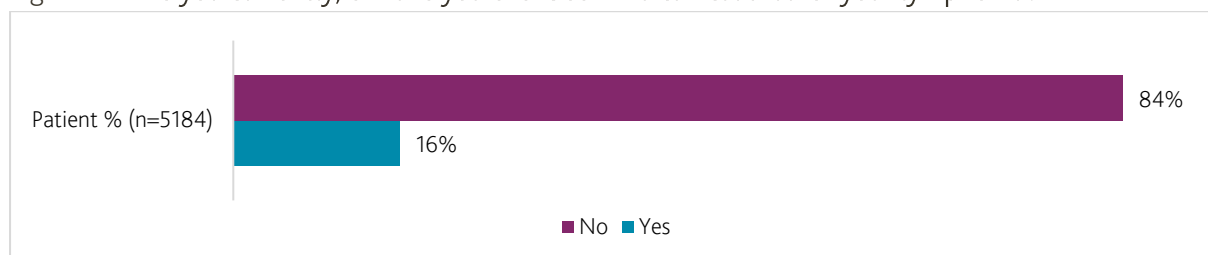


- A large proportion of patients (90%) with breast implant-associated anaplastic large cell (BIA-ALC) lymphomas, Hodgkin lymphoma (81%) and Peripheral T-cell (73%) have received chemotherapy alone.
- A large proportion of patients with diffuse large B-cell lymphoma (DLBCL) (all subtypes ranging from 76%-86%), follicular lymphoma (78%), marginal zone lymphomas (all subtypes ranging from 66% to 76%) and mantle cell lymphomas have received chemo-immunotherapy (e.g., R-CHOP, BR-bendamustine rituximab).
- The following treatments were specific to cutaneous lymphoma subtypes: extracorporeal photopheresis (ECP), light therapy, skin creams, targeted electron beam, total skin electron beam, topical gel, topical retinoids, topical steroid creams, PUVA and UVB light. Only 16% of patients had been or were currently in a clinical trial.

The following countries (amongst countries with 100+ responses to the 2022 GPS) had the highest proportion of patients that had been/or were in a clinical trial: Denmark (30%), Belgium (29%) and France (25%), while the United Kingdom (8%), the Philippines (6%) and Bulgaria (5%) had the least proportions.

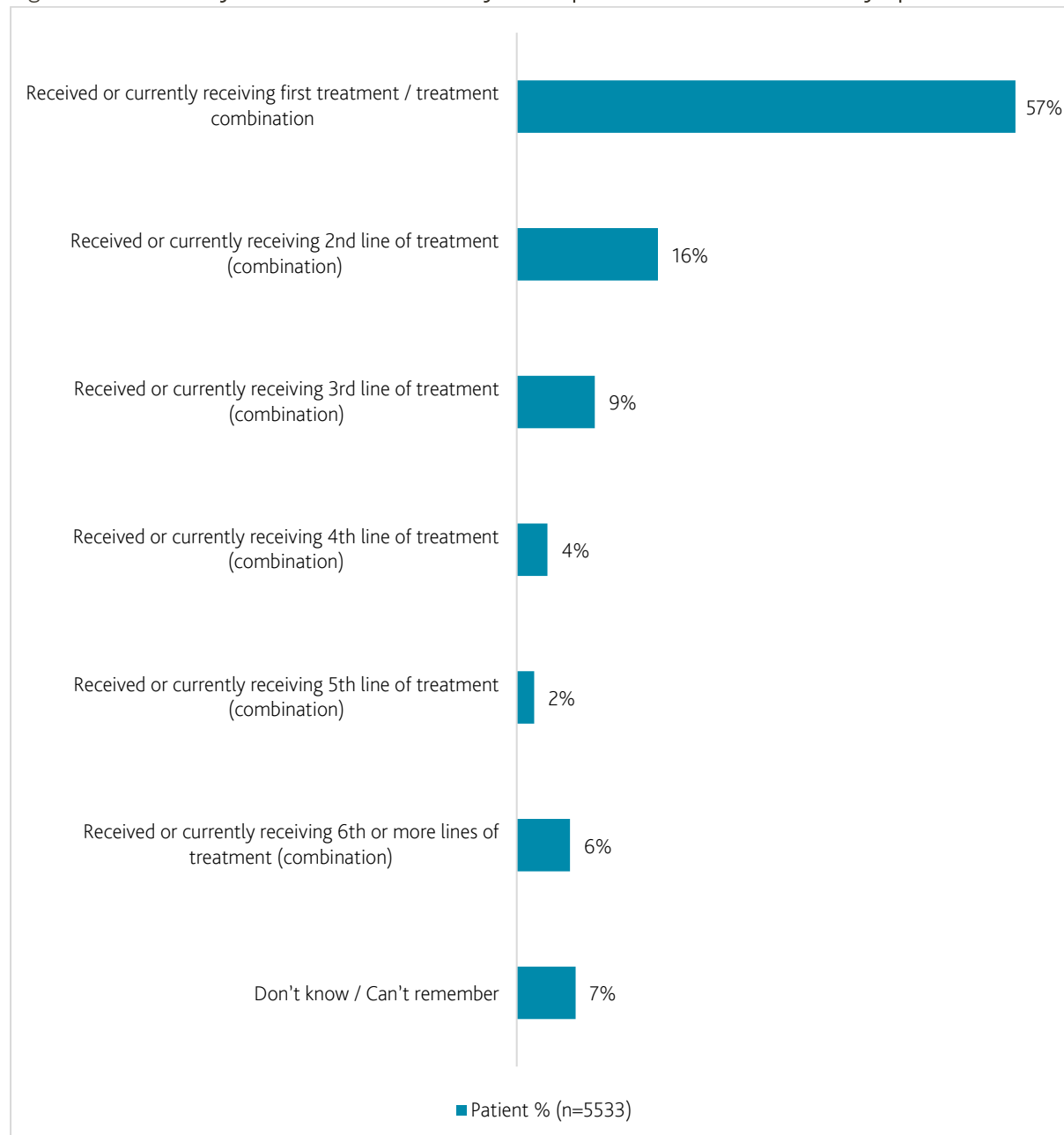
- ❖ Figure 51 illustrates that 84% of patients have not been in a clinical trial for lymphoma

Figure 51. Are you currently, or have you ever been in a clinical trial for your lymphoma?



- ❖ Figure 52 illustrates that 57% of patients have received or are currently receiving their first treatment/treatment combination

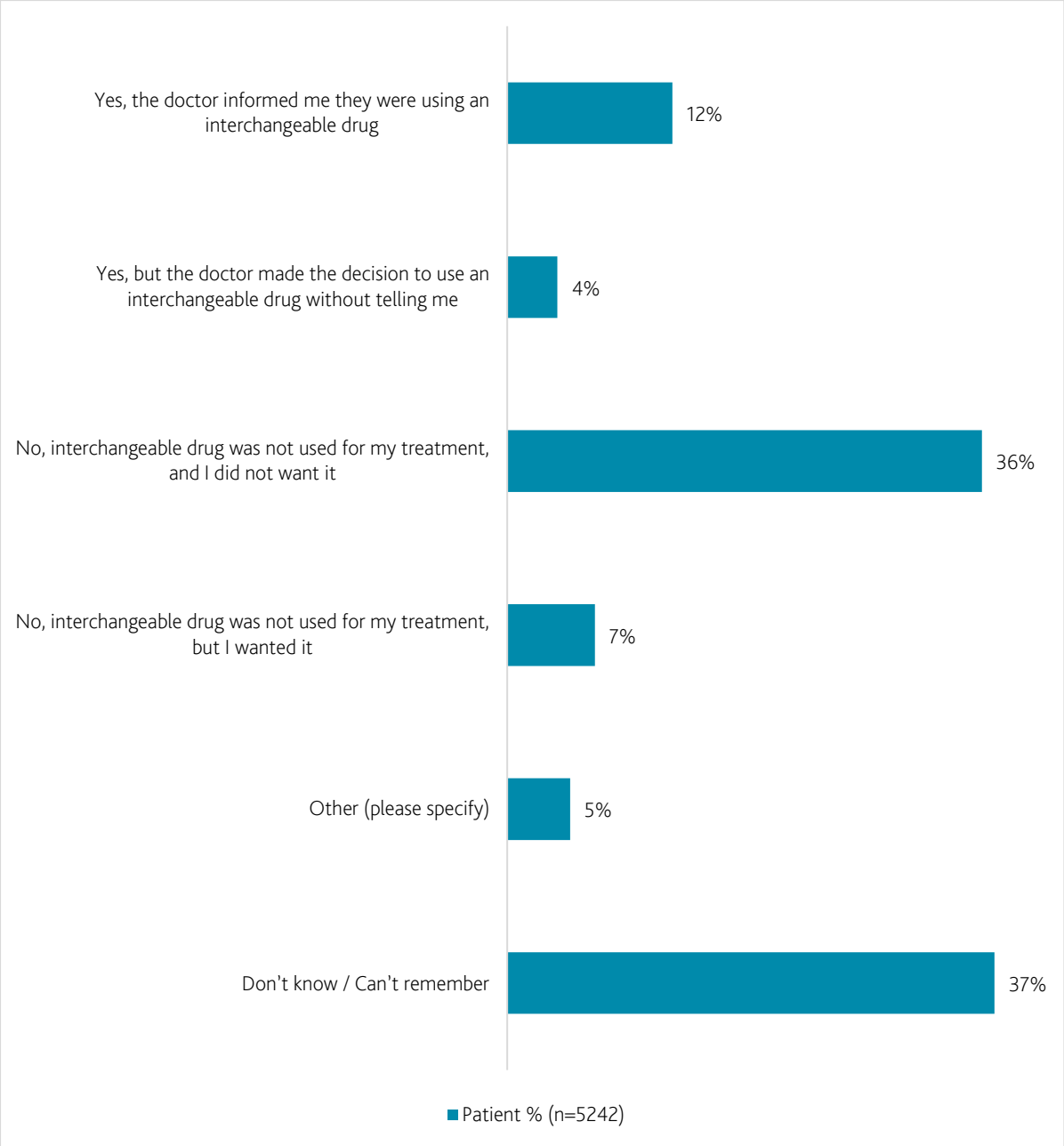
Figure 52. How many lines of treatment have you/the patient received to date for lymphoma?



GPS 2022: Global Report

❖ Figure 53 illustrates that 36% of patients did not use an interchangeable drug for their treatment and did not want it

Figure 53. Were interchangeable/equivalent (e.g., generic, biosimilars, pharmaceutical equivalents), used during your treatment?



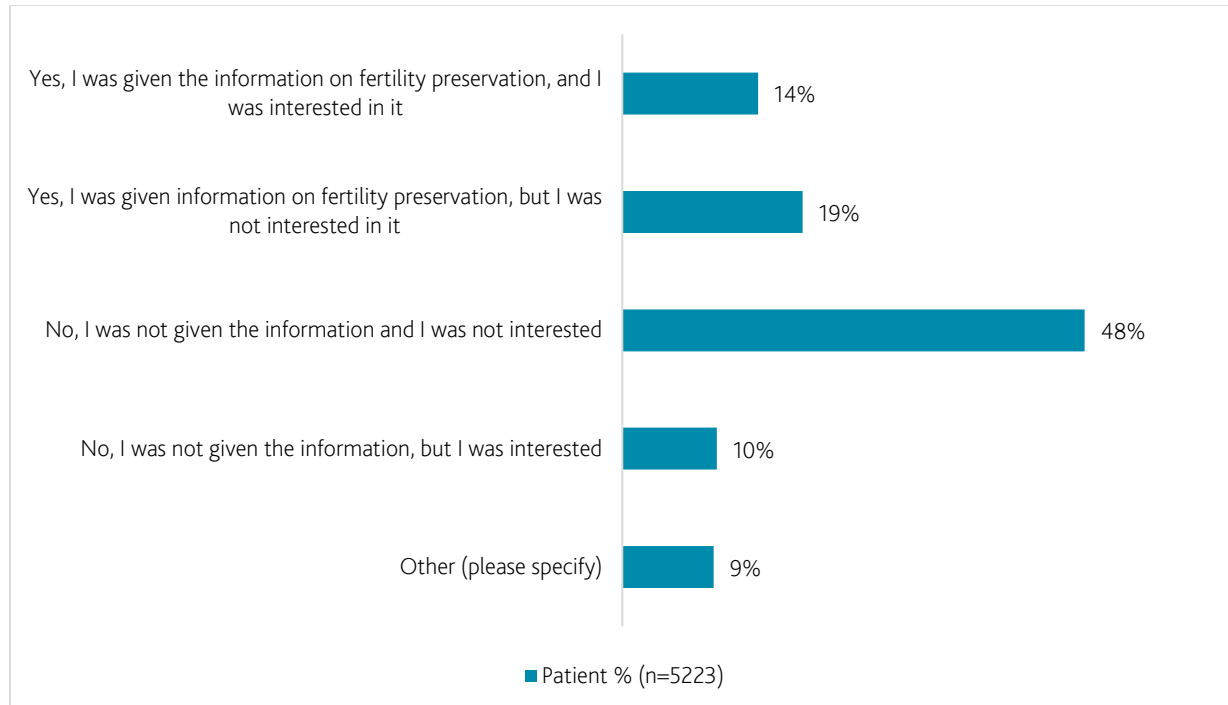
A higher proportion of patients in Asia-Pacific (25%) and in the Middle East and Africa (24%) reported the usage of an interchangeable drug/biosimilar compared to patients residing in Europe (12%), North America (12%) and South America (7%).



## GPS 2022: Global Report

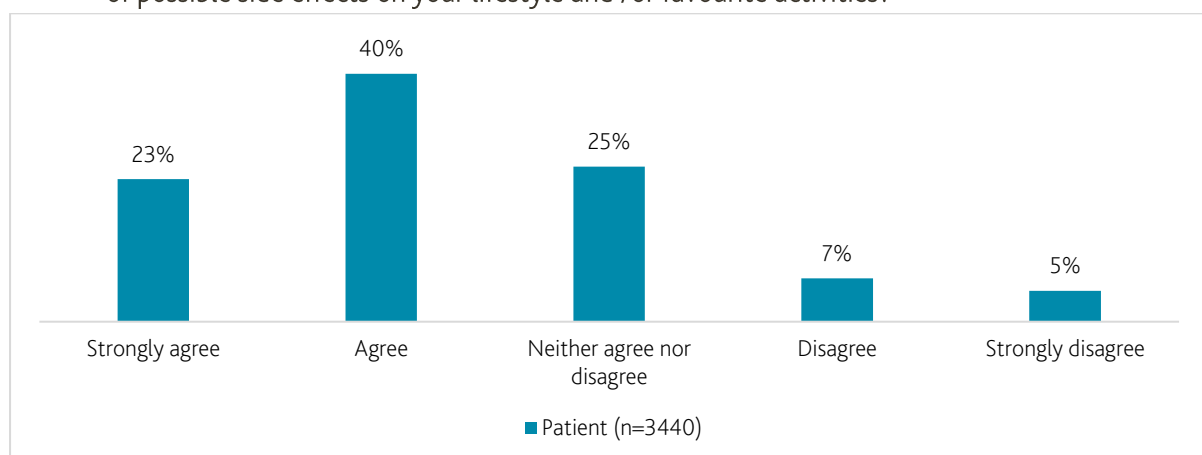
- ❖ Figure 54 illustrates 10% of patients were interested in information about the effect of their treatment on fertility but they were not given such information

Figure 54. Did your medical team give you any information about treatment side effects on fertility and about fertility preservation opportunities prior to treatment?



- ❖ Figure 55 illustrates that 40% of patients agree and 23% strongly agree that treatment was chosen to minimize the impact of possible side effects on lifestyle and/or favourite activities

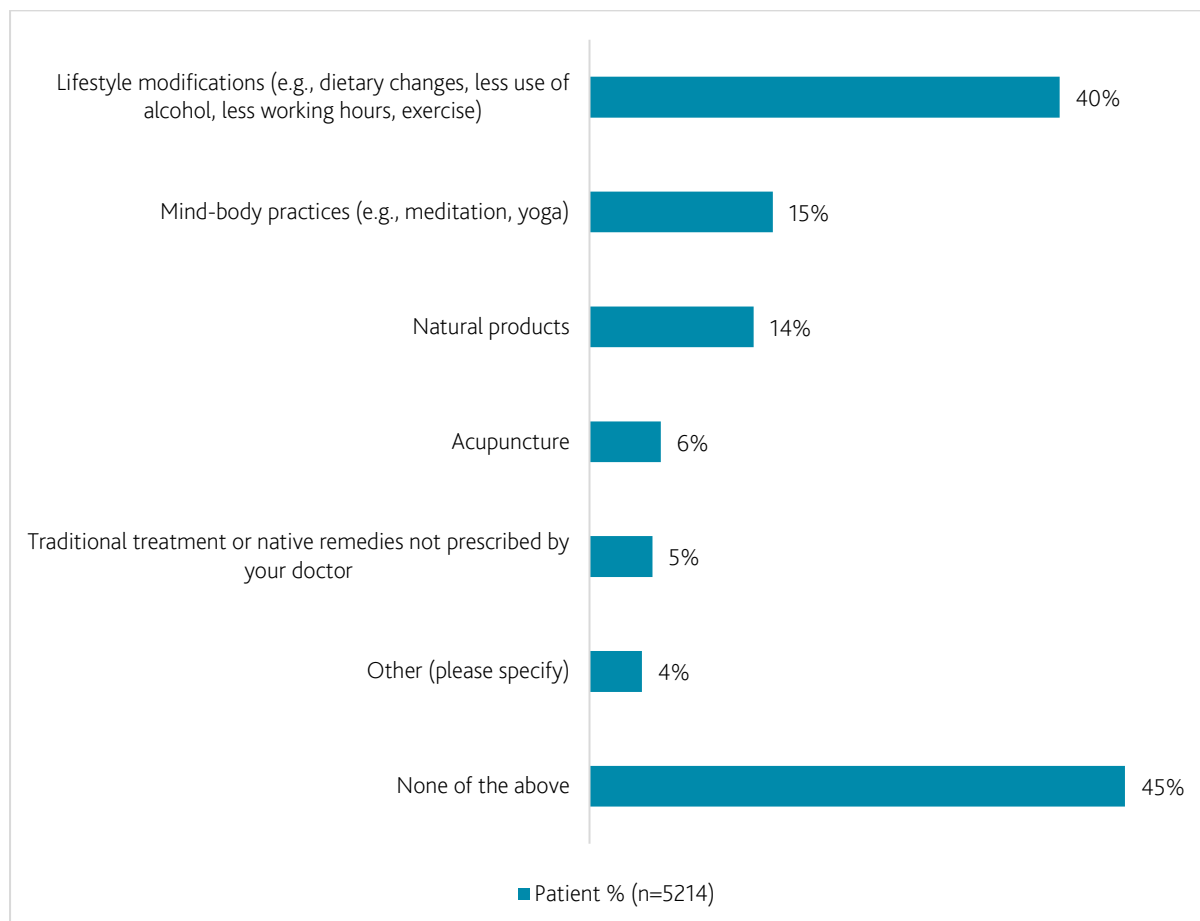
Figure 55. How much do you agree or disagree that your treatment was chosen to minimize the impact of possible side effects on your lifestyle and /or favourite activities?



Patients were asked if they used some form of treatment/product/ lifestyle modification alongside conventional treatments - 40% of patients reported using lifestyle modifications such as dietary changes and exercise while, 5% used traditional treatment/native remedies. A quarter of patients (27%) who reported using some form of treatment/product/ lifestyle modification alongside conventional treatments did not tell their lymphoma or CLL doctor about it.

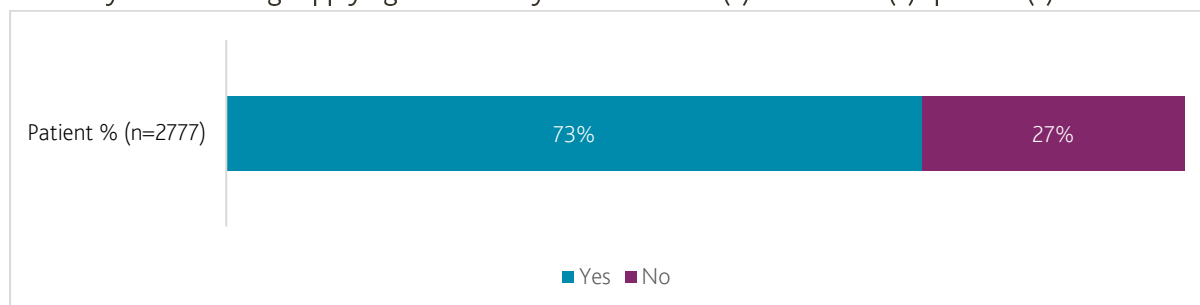
- ❖ Figure 56 illustrates that 45% of patients have not used any of the following treatments alongside conventional cancer treatments

Figure 56. During your experience so far with lymphoma or CLL, were any of following used alongside conventional cancer treatments?



- ❖ Figure 57 illustrates that 73% of patients told their lymphoma or CLL doctor or another member of their medical team that they were applying lifestyle modification(s)/treatment(s)/product(s)

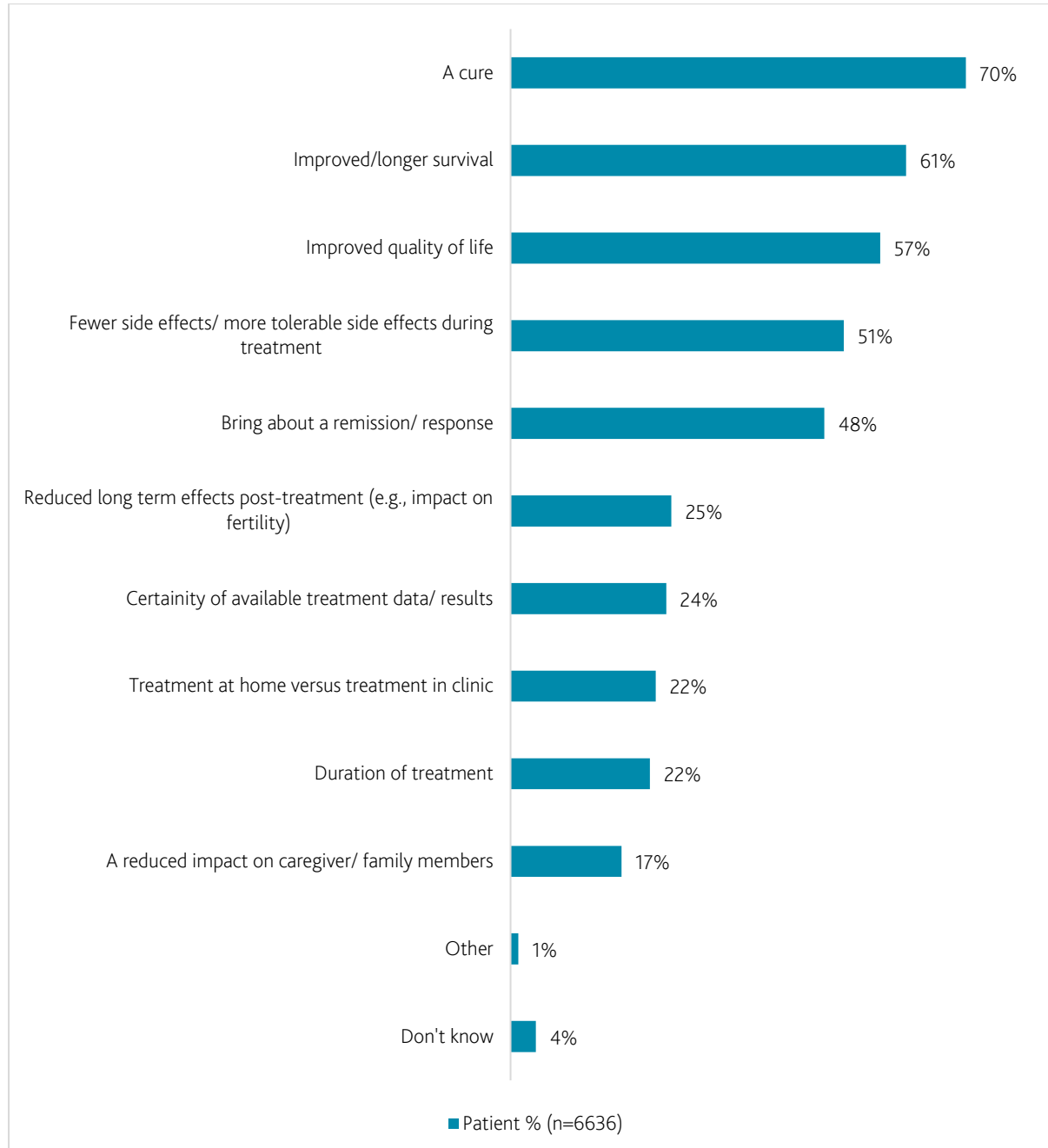
Figure 57. Did you tell your lymphoma or CLL doctor or another member of your medical team that you were using/ applying these lifestyle modification(s)/ treatment(s)/ product(s)?



## GPS 2022: Global Report

- ❖ Figure 58 illustrates that 70% of patients consider a cure to be an important feature of a new medical treatment for lymphoma or CLL

Figure 58. What, if any, of the following would you consider to be an important feature of a new medical treatment for lymphoma or CLL?



A higher proportion of younger patients (aged 18-35 yrs) considered an improved quality of life (64%), reduced long term effects post treatment (47%), duration of treatment (28%) and reduced impact on caregivers/family members (22%) as important features of a new treatment compared to patients in the older age groups.

## GPS 2022: Global Report

- ❖ Table 3 illustrates that 58% 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	2601	58%	170	4%	483	11%
Improved/ longer survival	551	12%	1723	40%	541	13%
Bring about a remission/ response	353	8%	751	18%	860	20%
Improved quality of life	354	8%	712	17%	747	18%
Fewer side effects/ more tolerable side effects during treatment	252	6%	519	12%	735	17%
Reduced long-term effects post-treatment (e.g., impact on fertility)	77	2%	149	3%	207	5%
Treatment at home versus treatment in the clinic	64	1%	98	2%	187	4%
Duration of treatment	61	1%	57	1%	144	3%
A reduced impact on caregiver/family members	42	1%	52	1%	127	3%
Certainty of available treatment data/results	94	2%	56	1%	175	4%

## GPS 2022: Global Report

### 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 a way for patients facing disease progression who have exhausted all traditional therapies in their country. Similarly, clinical trials can provide an opportunity for patients to access treatments that would otherwise be cost-prohibitive. The 2022 Global Patient Survey asked specific questions about challenges or limitations patients faced around accessing clinical trials.



- A third of patients in the survey (36%) reported not having any barriers to receiving treatment.
- 29% of patients reported they were prevented from receiving treatment by financial difficulties
- 55% of patients have never been given the opportunity to participate in a clinical trial.

There has been a notable increase in the barriers patients face with access to treatment. In 2022, 36% of patients (worldwide) reported not having any barriers to receiving treatment. This is in contrast to the 2020 report where 70% of the patients (worldwide) reported not having barriers to receiving treatment.

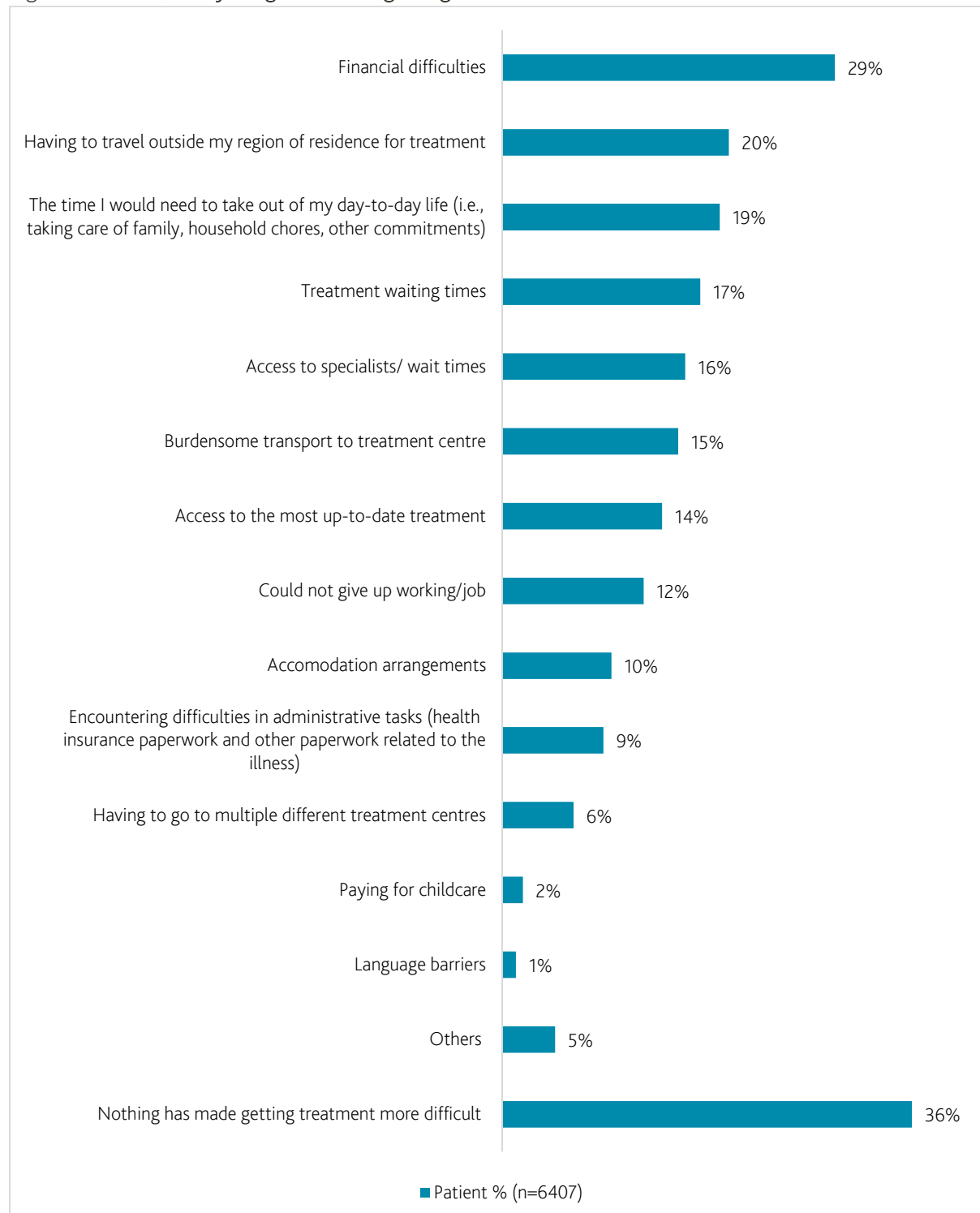
Disparities continue to exist in how patients with lymphoma and CLL experience barriers to treatment. Financial difficulties were reported by most patients in the Philippines (93%), India (77%) and China (66%) while only a few patients reported it in France (4%), Italy (4%) and Denmark (1%).

All barriers, except for the barriers involving transportation (i.e., 'burdensome transport to the treatment centres', 'having to travel outside the region of residence for treatment' and 'having to go to multiple treatment centres'), were experienced by a higher proportion of patients in the urban areas than those in the rural and suburban areas. Those residing in suburban areas were the highest in reporting that they experienced no barriers to care.

When asked to select from a list of potential barriers to treatment, 36% of patients reported that nothing had prevented them from receiving treatment. 29% of patients reported they were prevented from receiving treatment by financial difficulties.

- ❖ Figure 59 illustrates that 36% of patients feel that nothing has made getting treatment more difficult

Figure 59. What, if anything, has made getting treatment more difficult?

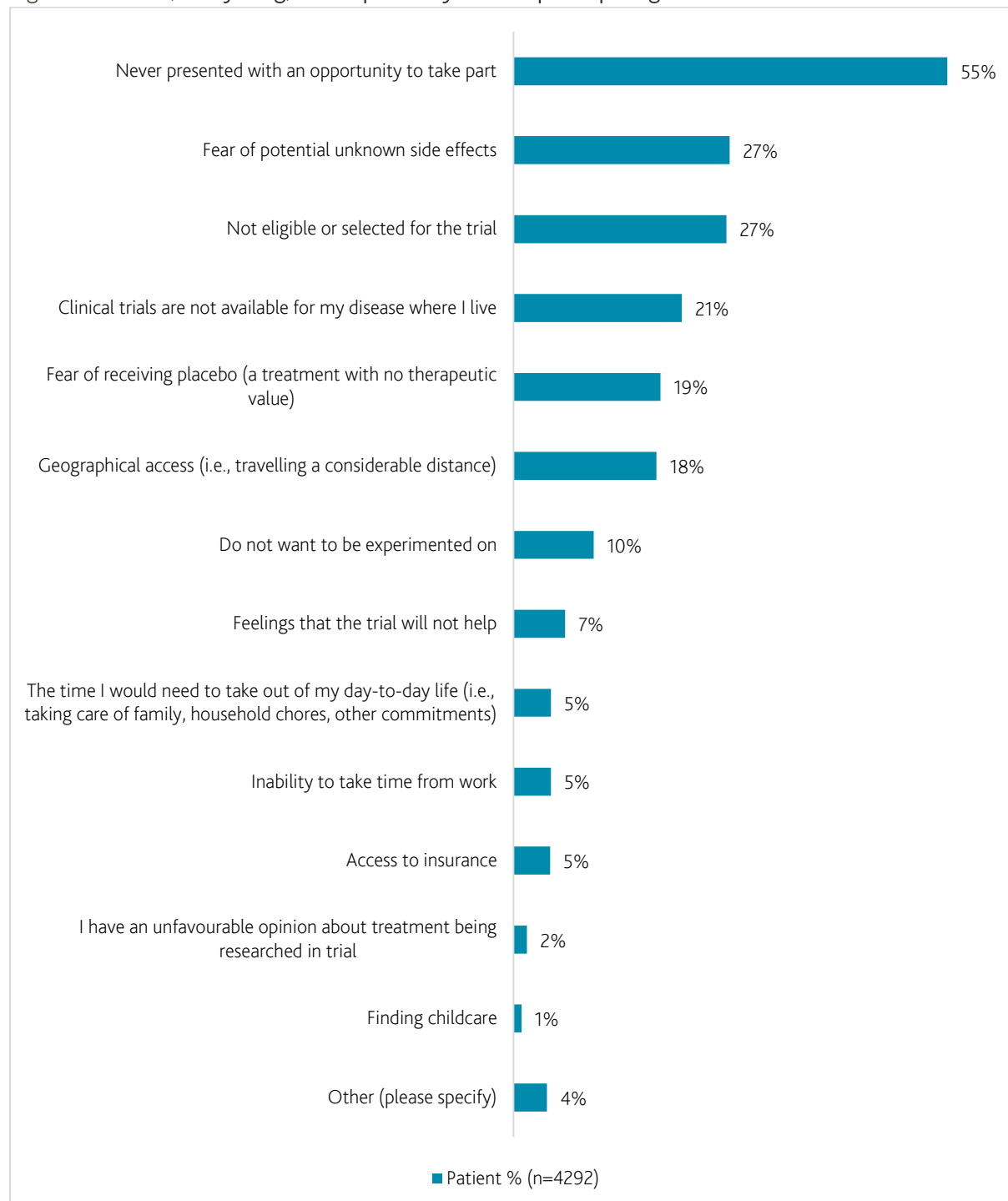


## GPS 2022: Global Report

Patients were asked if anything had prevented them from participating in a clinical trial. The results are shown below.

Figure 60 illustrates that 55% of patients were never presented with an opportunity to take part in a clinical trial

Figure 60. What, if anything, would prevent you from participating in a clinical trial?



## GPS 2022: Global Report

### Side Effects

Patients receiving treatment for their lymphoma/CLL are affected by a range of treatment-related side effects; the most frequent are shown below. See figure 61 for a full list of reported side effects from treatment.

- Fatigue reported by 67%
- Hair loss was reported by 52%
- Constipation reported by 39%
- Nausea and vomiting were reported by 38%
- Changes in sleep patterns reported by 37%

The side effects that affected patients the most (ranked 1st) were:

- Fatigue – 18% (n=728)
- Hair loss – 10% (n=409)
- Nausea and vomiting – 8% (n=337)

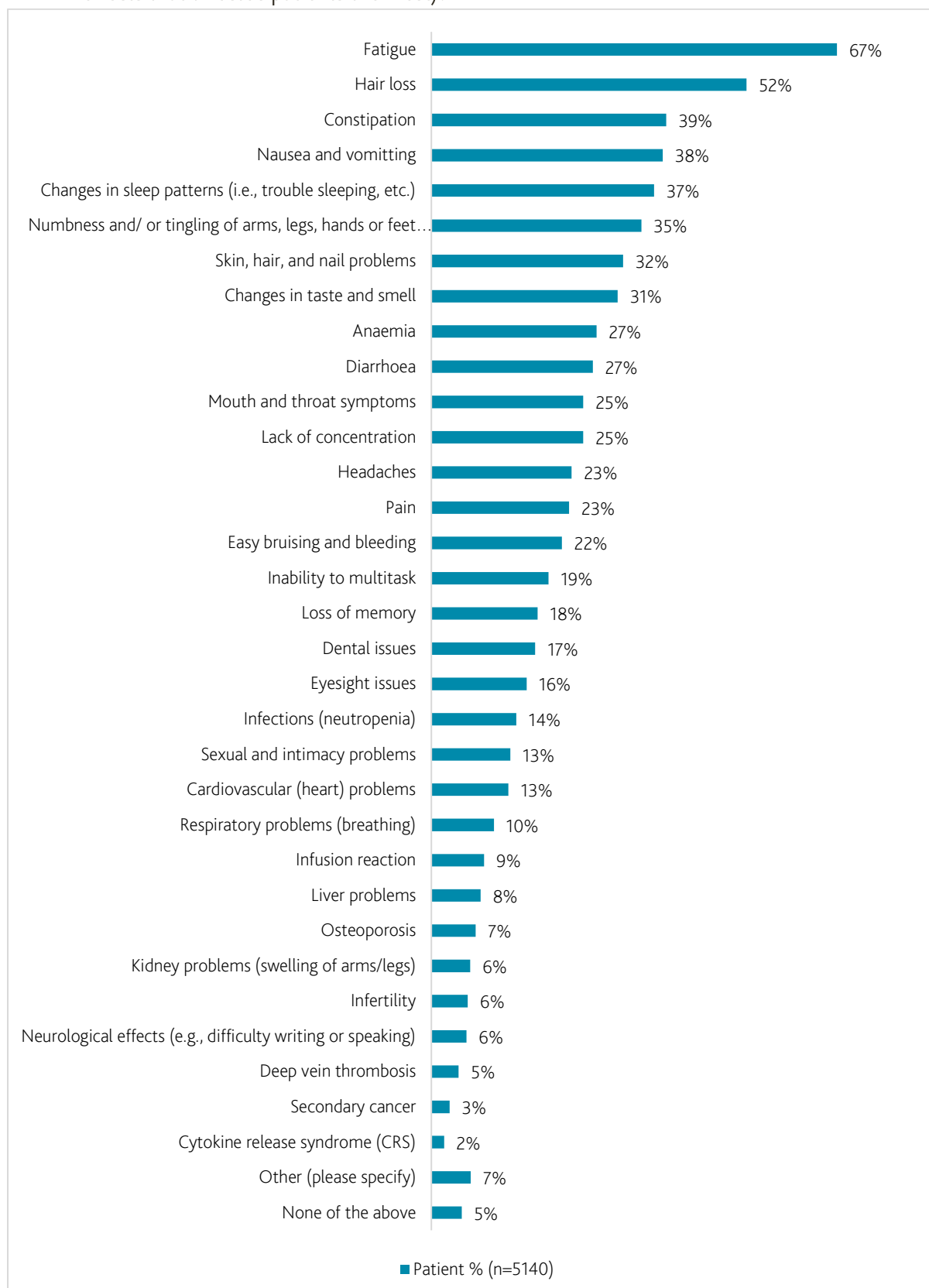
75% of those affected by fatigue experienced these side effects for under 5 years.

90% of those affected by hair loss and 84% by nausea and vomiting experienced these side effects for under 2 years.



❖ Figure 61 illustrates that 67% of patients experience fatigue as a side effect

Figure 61. Which of the following side effects, if any, have you been affected by (Highlighted the side effects that affected patients the most)?



## GPS 2022: Global Report

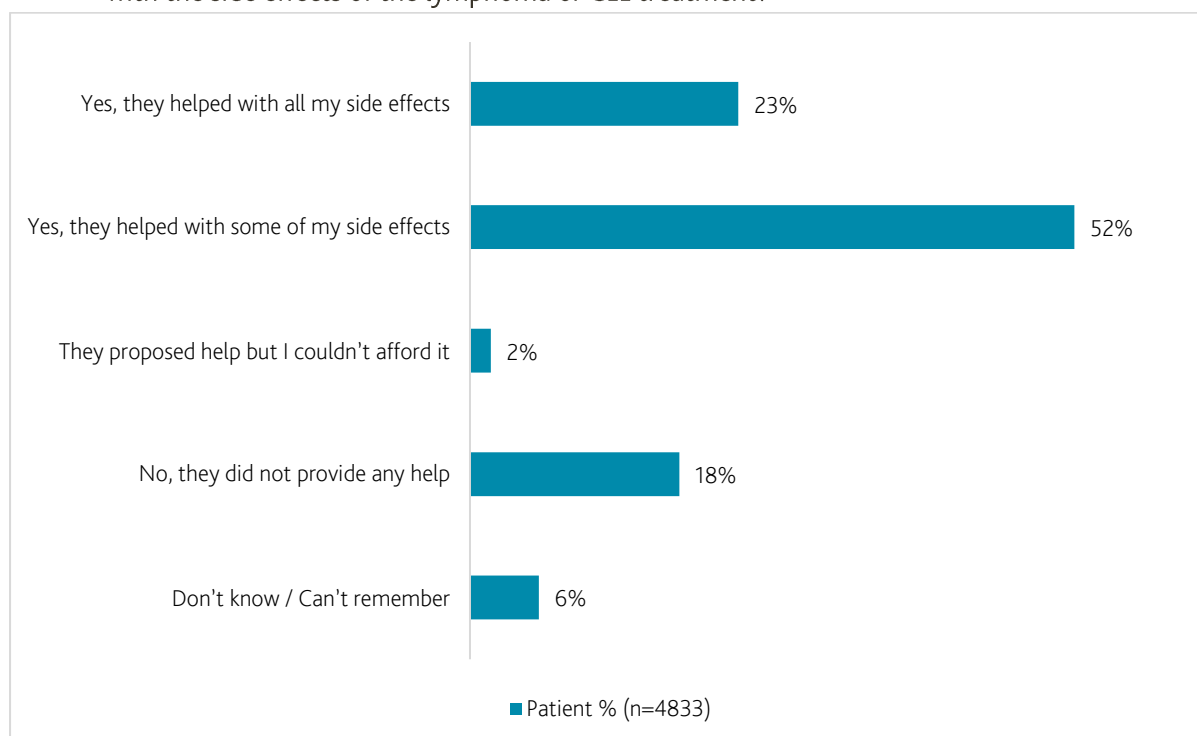
23% of patients experiencing side effects reported that their doctor/medical team helped them with all their side effects while 18% reported that their doctor/ medical team did not provide any help with their side effects.

Patients residing in the following countries were the highest in reporting that their doctor/ medical team did not provide them with any help for their side effects: Bulgaria (28%), Japan (27%) and Australia (23%).

Patients who received CAR-T therapy (4%) and ECP (6%) were the least to report that their doctor/medical team did not provide them with any help for their side effects while patients that received UVB light (24%), light therapy (phototherapy) (21%) and complementary and alternative medicine (CAM) (21%) were the most to report that they did not receive any help.

- ❖ Figure 62 illustrates that 52% of patients felt that their doctor or other members of their medical team was able to help alleviate or cope with some of their side effects

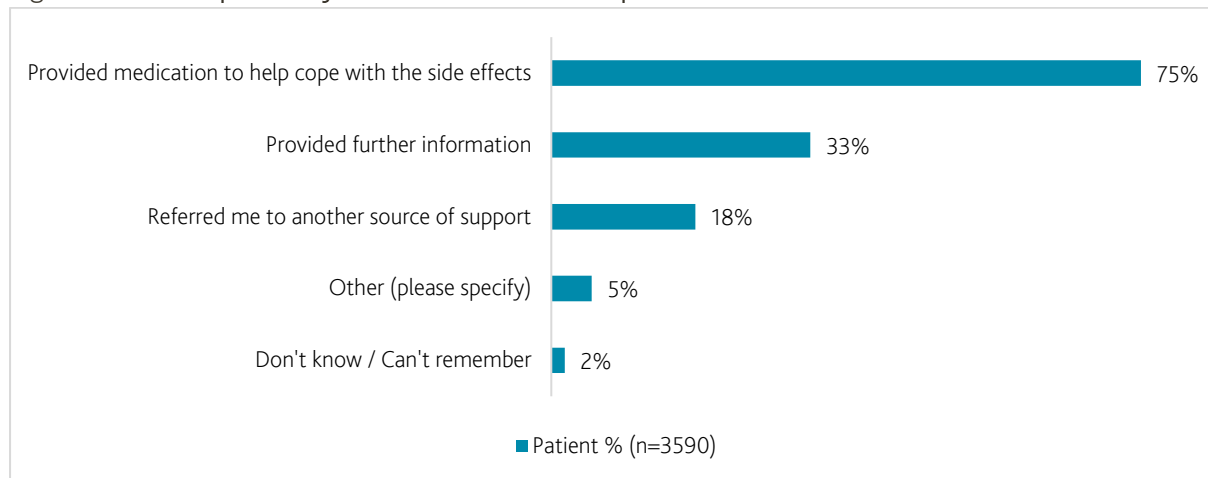
Figure 62. Was your doctor or other members of your medical team able to help you alleviate or cope with the side effects of the lymphoma or CLL treatment?



Medication was the top reported help (75%) provided by doctors for side effects, followed by provision of further information (33%) and referral to another source of support (18%).

- ❖ Figure 63 illustrates that 75% of the patient's doctor provided medication to help cope with the side effects

Figure 63. What specifically did the doctor do to help?

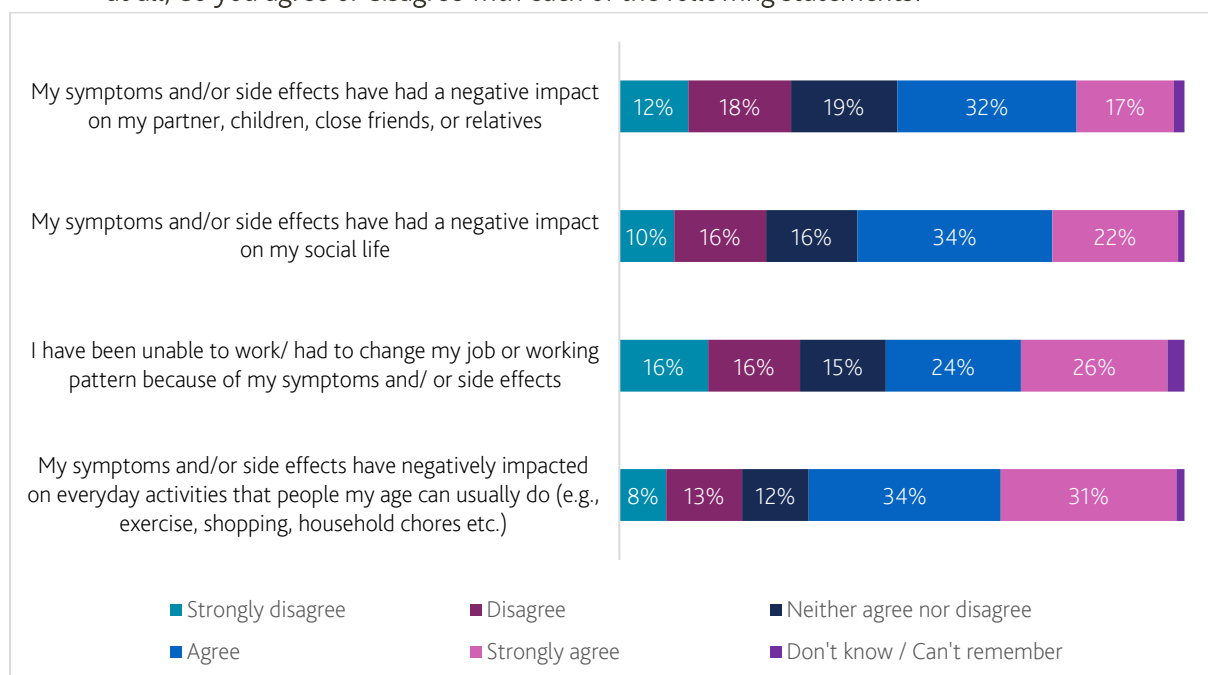


The side effects and symptoms of lymphoma and CLL profoundly impact patients' quality of life. The data reflects that 65% of patients strongly agreed/agreed that their symptoms/ side effects negatively impacted their activities of daily living (ADL), and over half (56%) of patients strongly agreed/agreed that their social lives had been negatively impacted.

The symptoms and side effects also negatively impact family life (49%) and work/employment ability (50%).

Figure 64 illustrates that 34% of patients agree that their symptoms and/or side effects have negatively impacted their everyday activities and social life.

Figure 64. 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?



## GPS 2022: Global Report

### 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 their 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 includes only responses from patients who reported that they had fatigue either as a symptom of lymphoma (66% of all respondents) and/or as a side effect of treatment (67%).



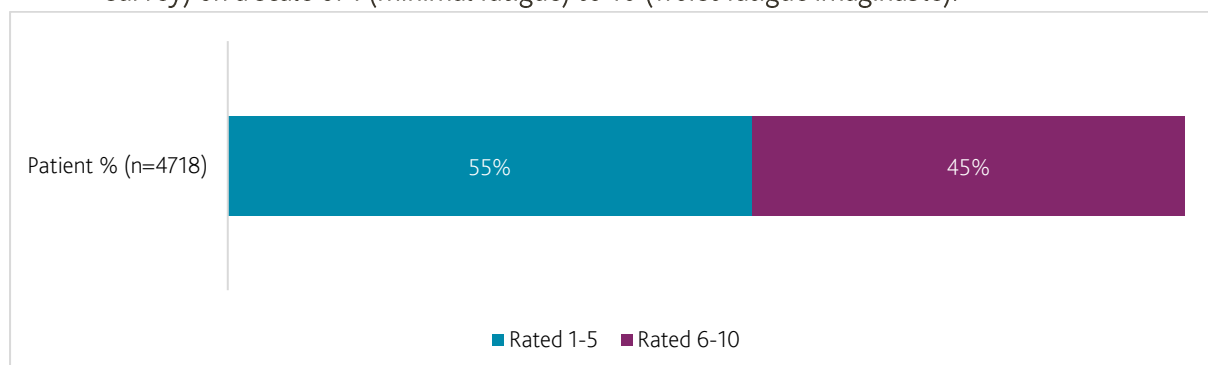
- 34% of patients didn't discuss their fatigue with their doctor over the last two years.
- 28% of patients were provided strategies (e.g. physical activity) to manage their fatigue by their doctor and 39% of patients found exercise programs helpful and the best way to manage their cancer-related fatigue.
- 36% of patients were followed up for their cancer-related fatigue by their doctor.

Patients with fatigue were asked to rate the severity of their fatigue on a scale of 1-10 (1 representing minimal fatigue, and 10 being the worse fatigue imaginable). Overall, 45% of patients reported their fatigue level over the last week (from when they took the survey) was six or above.

Patients stated that their fatigue had affected various aspects of their life over the last two years (from the survey time). Below is the impact of fatigue by the fatigue rating levels (1-5) and (6-10). The two groups' top areas/activities affected by fatigue were general and physical activities. More patients with a fatigue rating of 6-10 reported that they felt the impact of fatigue on all the areas examined than patients with a fatigue rating of 1-5, except for the effect on the ability to remember things.

❖ Figure 65 illustrates that 55% of patients report minimal fatigue

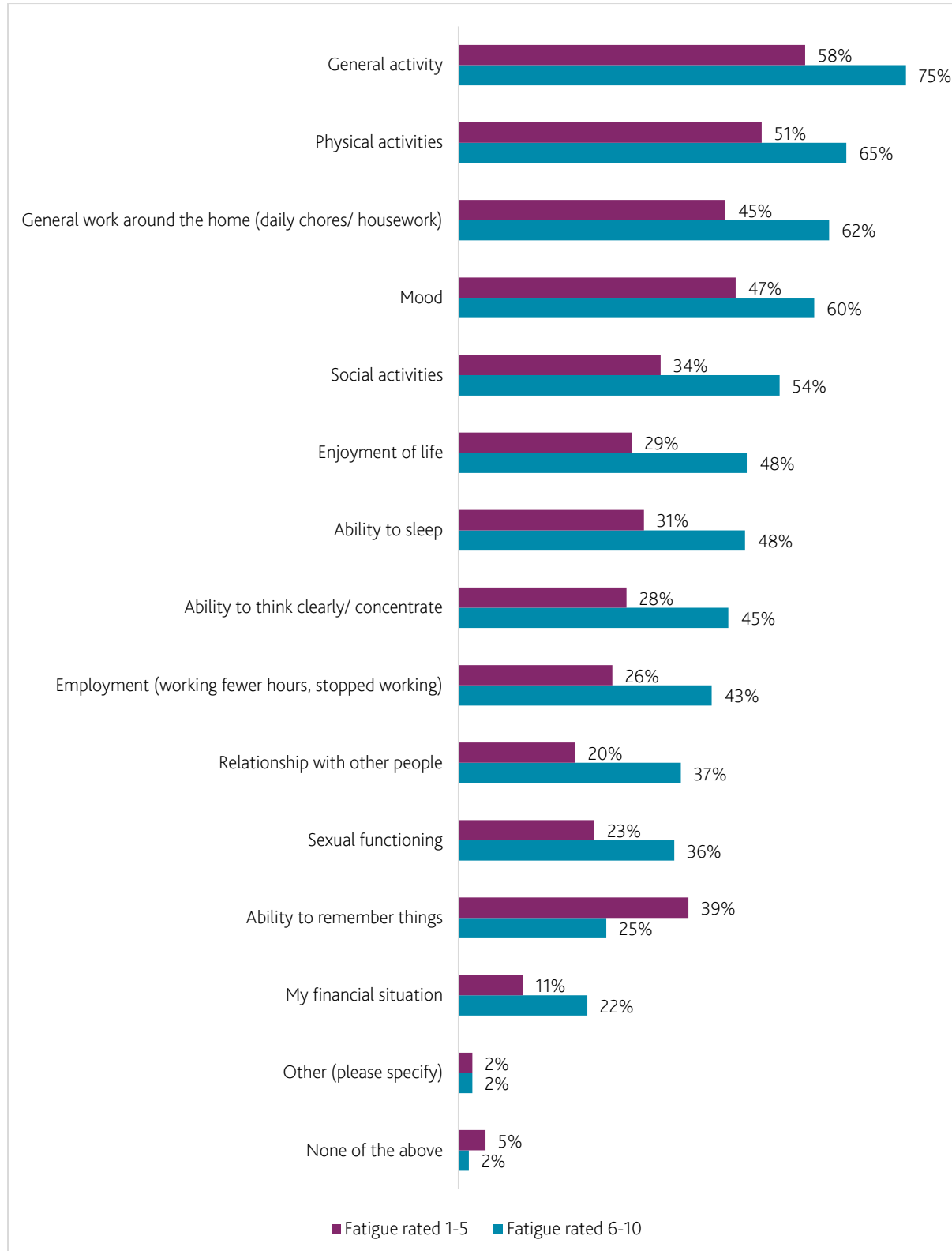
Figure 65. Patients were asked to rate their level of fatigue over the last one week (of taking the survey) on a scale of 1 (minimal fatigue) to 10 (worst fatigue imaginable).



## GPS 2022: Global Report

- ❖ Figure 66 illustrates that 75% of patients who reported rating their fatigue between 6-10 felt that fatigue has affected their general activity over the last two years

Figure 66. Which of the following areas/ activities, if any, has your fatigue affected over the last two years?

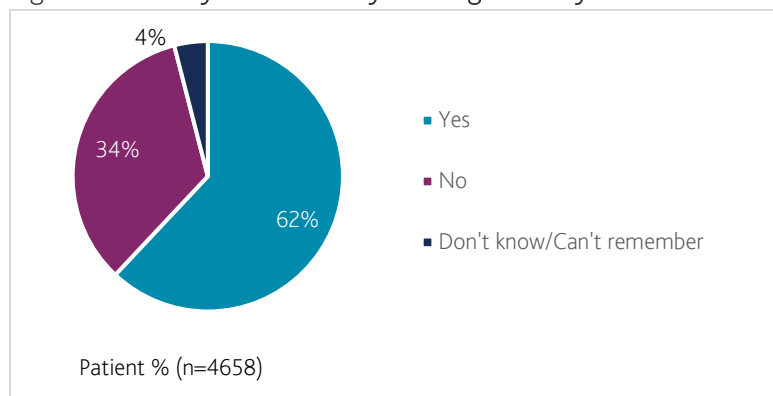


The middle-age groups (35-64 yrs) had the highest proportion of patients that felt the effect of fatigue on their ability to think clearly (41%), ability to remember things (35%) and ability to sleep (42%), while the effect of fatigue on mood was most prevalent in patients in the 18-34 yrs group (72%). The effect of fatigue on physical activities was highest in the 65yrs+ age group (60%).

62% of patients discussed their fatigue with their doctor over the last two years while, 34% had not. Of those who discussed with their doctor, 58% were not followed up by their doctor.

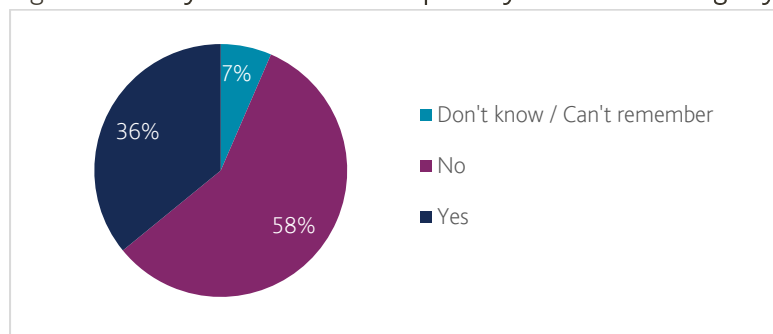
- ❖ Figure 67 illustrates that 62% of patients have discussed their fatigue with their doctor over the last two years

Figure 67. Have you discussed your fatigue with your doctor over the last two years?



- ❖ Figure 68 illustrates that 58% of patients were not followed up about the fatigue they were experiencing

Figure 68. Did your doctor follow up with you about the fatigue you were experiencing?

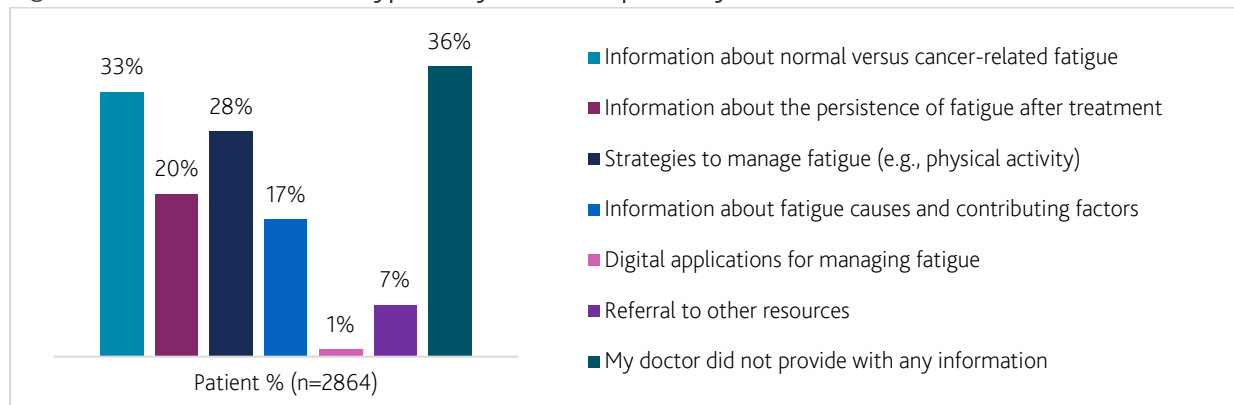


Patients who discussed their fatigue with their doctor were also asked what type of information they received from their doctor. Notably, 36% of patients reported that the doctor did not act after discussing their fatigue. However, a third of the patients (33%) stated that information about normal versus cancer-related fatigue was given, and about a quarter (28%) were given information on strategies to manage fatigue.

## GPS 2022: Global Report

- ❖ Figure 69 illustrates that 36% of patients were not provided with information from their doctor

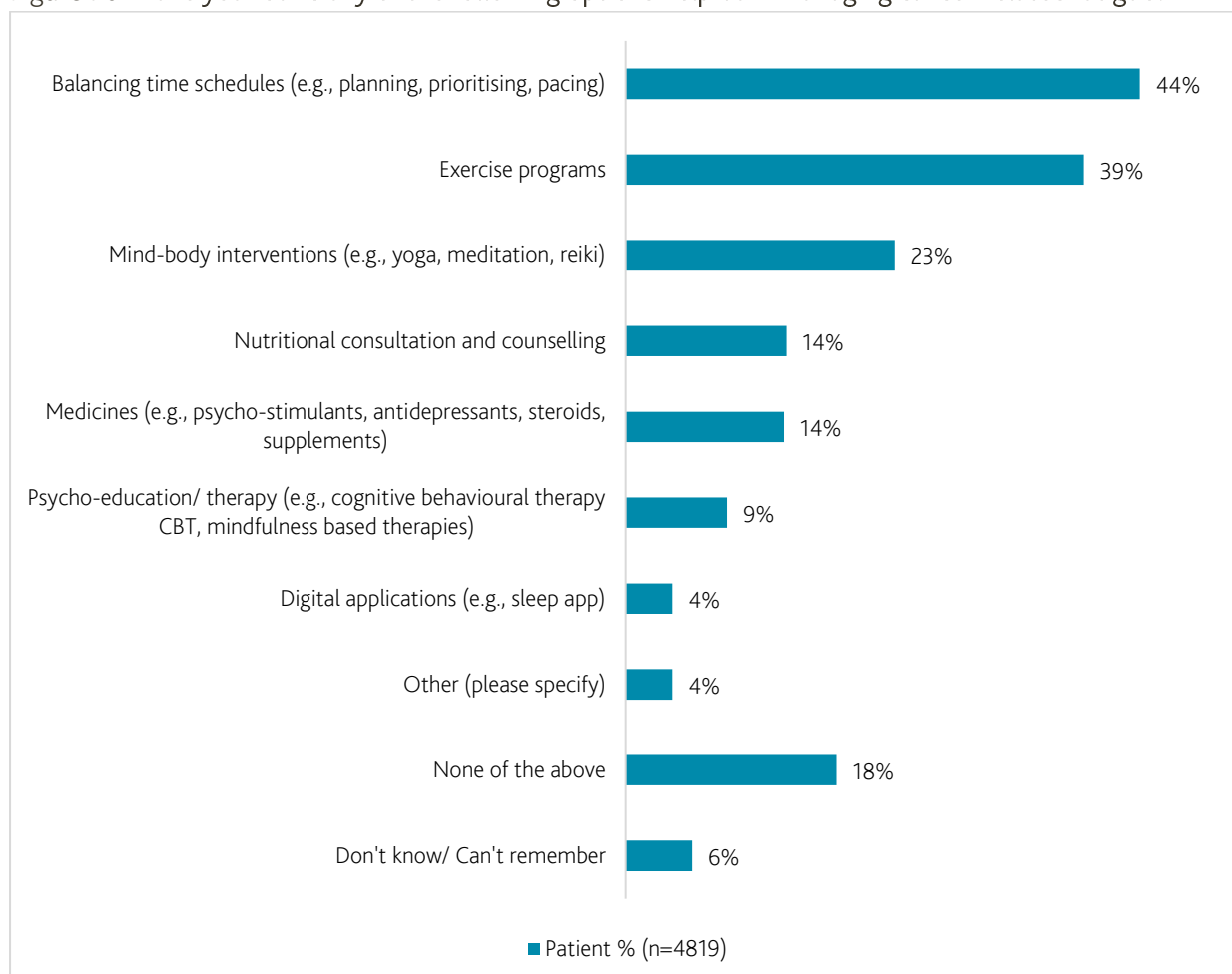
Figure 69. Which information types did your doctor provide you with?



Coping mechanisms that patients used to help with their fatigue over the last two years, with the top ones include: balancing time schedules (44%), exercise programs (39%) and mind-body interventions (23%).

- ❖ Figure 70 illustrates that 44% of patients found that balancing time schedules was helpful in managing cancer-related fatigue

Figure 70. Have you found any of the following options helpful in managing cancer-related fatigue?



## GPS 2022: Global Report

### Psychosocial Effects of Lymphoma

The 2022 GPS reports on the effects of lymphoma and treatment, particularly on fear of lymphoma progression, 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 during treatment. Additionally, the 2022 survey explored the fear of lymphoma progression to capture the experience of those in active surveillance who had been left to 'watch and wait' for their lymphoma's growth status.

The 2022 GPS data indicates that patients' biggest worries or concerns (whether on treatment finished treatment or in remission) is the fear of their cancer relapsing (50%), followed by fear of lymphoma progression (47%). The previous survey (2020 GPS) indicated that 60% of patients in remission experienced fear of cancer relapse after treatment. Feelings of anxiety, depression and isolation are consistently reported as being associated with the fear of relapse and progression.



Half of the patients who were in treatment/ had had treatment or in remission reported fear of cancer relapse (50%) and fear of progression (47%) as their biggest worries or concerns, but just a third (32%) of these patients talked about their fears with their doctor.

- The most provided approach by doctors to help patients cope with depression was medication (55%) but for anxiety, the empathic/ understanding approach was the most provided way (53%).
- The most provided approach by doctors to help patients cope with fear of lymphoma progression (55%) and fear of cancer relapse (59%) was also the empathetic/ understanding approach of the doctor.

Patients with lymphoma were asked what psychosocial effects they had experienced in the last 12 months. The most reported responses were:

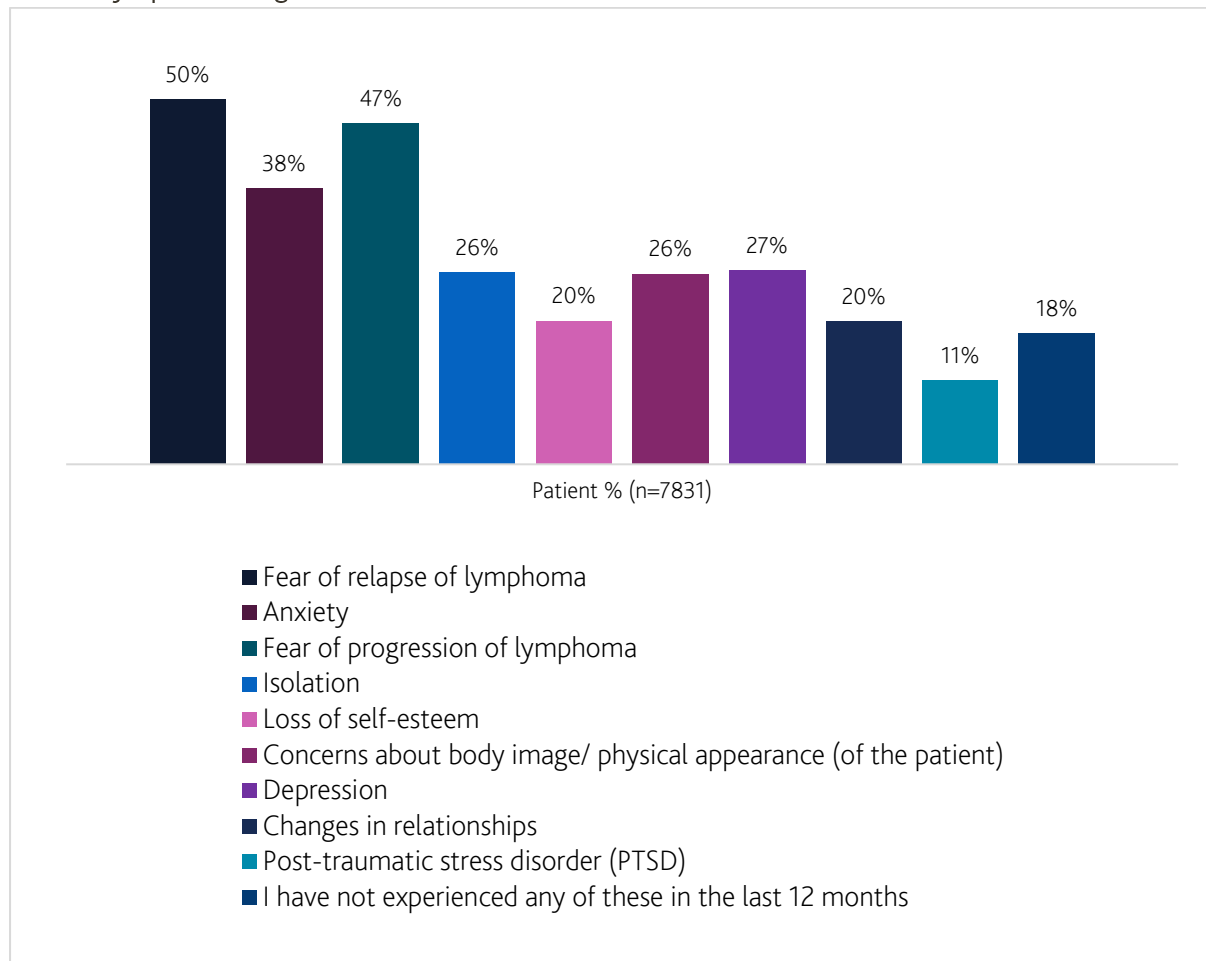
- Fear of relapse of lymphoma (experienced by 50% of patients)
- Fear of progression of lymphoma (experienced by 47% of patients)
- Anxiety (experienced by 32% of patients)



## GPS 2022: Global Report

❖ Figure 71 illustrates that 50% of patients have experienced fear of relapse of lymphoma

Figure 71. In the last 12 months, have you personally experienced any of the following as a result of the lymphoma diagnosis?



The experiencing of these psychosocial effects varied by lymphoma subtypes. Patients with extranodal killer T-cell had the highest proportion of experiencing anxiety (62%), fear of progression (65%) and fear of relapse (82%) respectively. Patients with BIA-ALC were most prevalent in reporting loss of self-esteem (72%), isolation (88%) and changes in relationships (50%), while patients with Waldenstrom's macroglobulinemia (31%), CLL (27%) and cutaneous lymphomas (all subtypes ranging from 19-22%) had the highest prevalence of not experiencing any psychosocial issues.

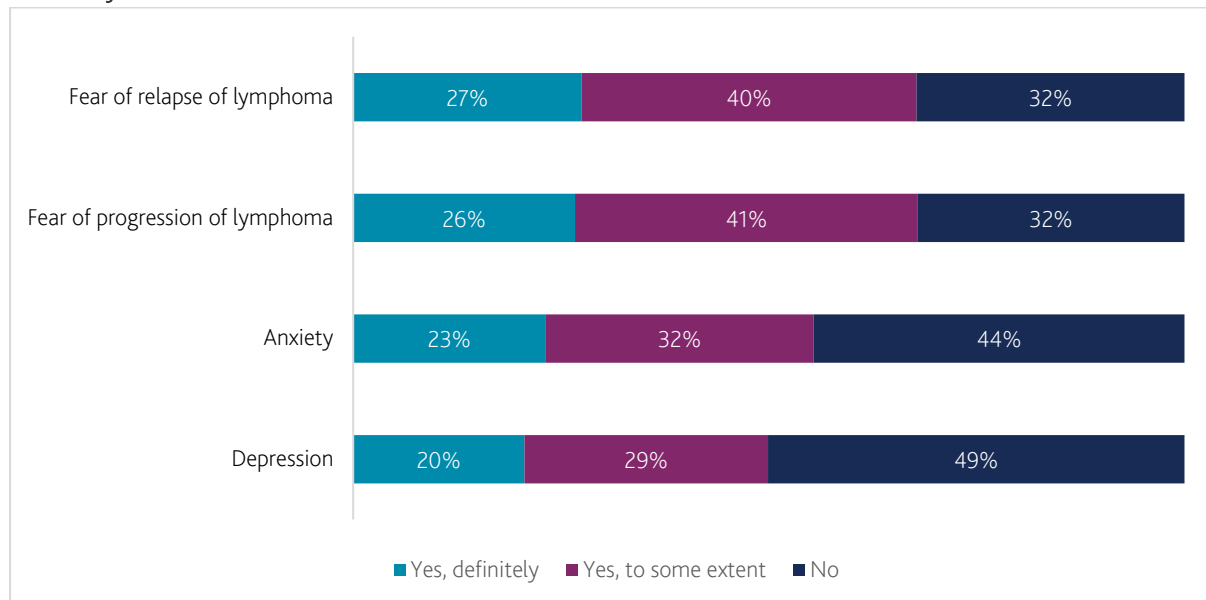
From this point on, the LC 2022 GPS questions focused on the top four psychosocial issues- fear of lymphoma relapse, fear of progression of lymphoma, anxiety, and depression. Therefore, the data below reflects only these four issues.

67% of patients who feared their disease progressing or the relapse of their cancer fully discussed their fears with their doctors or to some extent. In comparison, about 50% of patients with anxiety and depression discussed their issues with their doctor.

## GPS 2022: Global Report

- ❖ Figure 72 illustrates that 67% of patients have discussed their fear of progression of lymphoma with a doctor

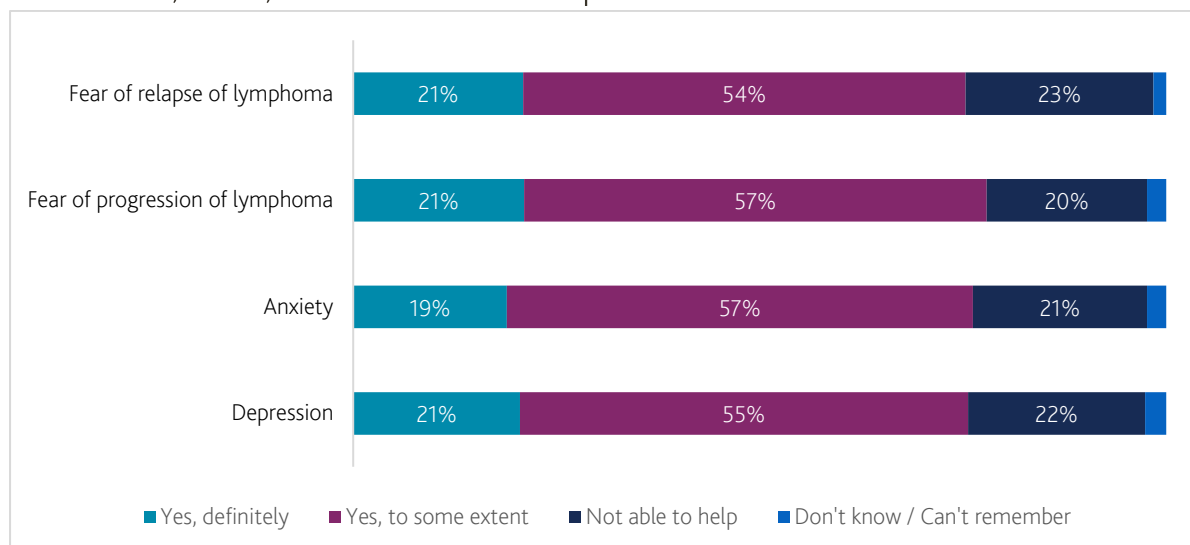
Figure 72. For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with a doctor?



More patients in the youngest age group (18-34yrs) did not discuss their depression (57%) and anxiety (52%) with their doctors compared to the older age groups.

- ❖ Figure 73 illustrates that 75% of patients felt that their doctor was able to help with their fear of progression of lymphoma fully or to some extent

Figure 73. 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.



## GPS 2022: Global Report

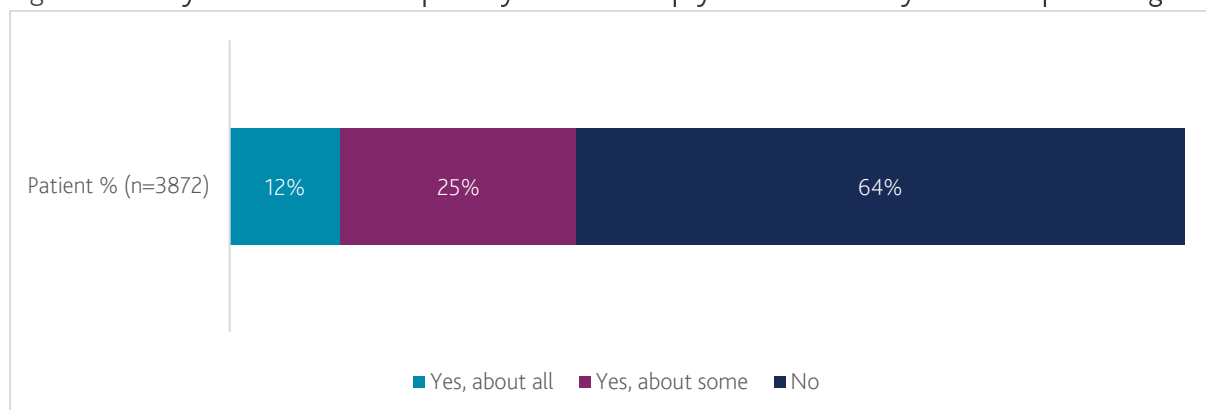
- ❖ Table 4 illustrates that 59% of patients were provided with the empathetic/understanding approach of their doctor to help with their fear of relapse of lymphoma

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

Help offered	For Depression	For Anxiety	For Fear of progression of lymphoma	For Fear of relapse of lymphoma
Medication to help cope with this worry or concern	55%	43%	17%	13%
Further written or verbal information	13%	15%	20%	19%
The empathetic/ understanding approach of my doctor when I told him/ her	50%	53%	55%	59%
Patient organisation or patient support group	19%	24%	31%	24%
Referral to other sources of support (e.g., social worker, therapist, counselling)	31%	25%	12%	12%
Exercise	34%	35%	31%	34%
Participation of family/ caregiver in providing support	23%	31%	30%	24%
The empathetic/ understanding approach of my nurse when I told him/ her	16%	18%	14%	13%
Eating a healthy diet	25%	26%	30%	28%
Other	4%	4%	4%	5%

- ❖ Figure 74 illustrates that 64% of doctors did not follow up on the psychosocial issues

Figure 74. Did your doctor follow up with you about the psychosocial issues you were experiencing?



## GPS 2022: Global Report

### 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 psychosocial well-being and experiences with fatigue.

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

This section of the 2022 GPS examines the impact of the Covid-19 pandemic and lockdown period on the healthcare experiences of patients with lymphoma.



- Three-quarter (73%) of patients were generally concerned about getting Covid-19.
- Over half of patients (58%) faced increased isolation and loneliness.
- 55% of patients were concerned about their family or caregiver getting Covid-19.
- 17% of patients avoided or delayed seeking medical attention due to the pandemic.
- Over half of patients (54%) strongly disagreed/disagreed that they preferred TC/VC to face-to-face visits, while only 21% strongly agreed/agreed that they preferred it.
- 43% of patients strongly disagreed/disagreed that they would like to continue to use TC/VC even after the pandemic is over.

### Covid-19 experience

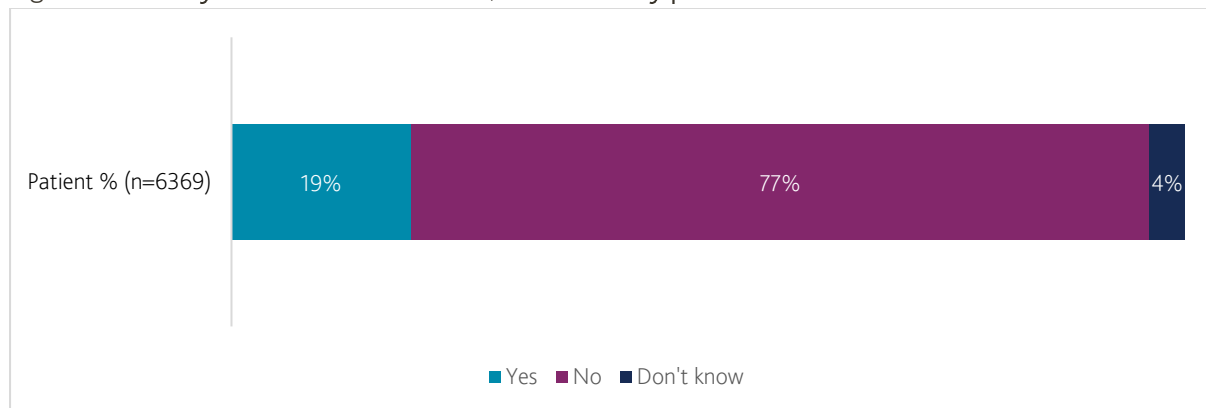
- 19% of patients had contracted Covid-19 at some point before/during the survey
- 59% had been fully vaccinated and taken a booster dose, and a further 17% are fully vaccinated to the extent currently available to them.
- 12% were not planning to get vaccinated
- 51% of patients consider themselves at high risk for contracting Covid-19 and experiencing severe illness from it and it worries them.
- Only 16% avoided or delayed seeking medical attention for their lymphoma or CLL during the Covid-19 pandemic

Patients residing in South America gave the highest reports of outpatient treatment delay, rescheduling or cancellation due to Covid-19 (38%), while those in Europe experienced these delays or cancellations the least (19%). Patients residing in South America also had the highest proportion of patients that reported changes to their treatment plan (17%), diagnosis delay (10%), delays in hospital discharge (14%) and longer hospital stays (14%) due to Covid-19.

The regions with the highest proportion of patients reporting a switch to telemedicine due to Covid-19 were North America (31%) and South America (28%), while patients in the Middle East and Africa were the least (9%) to report a switch.

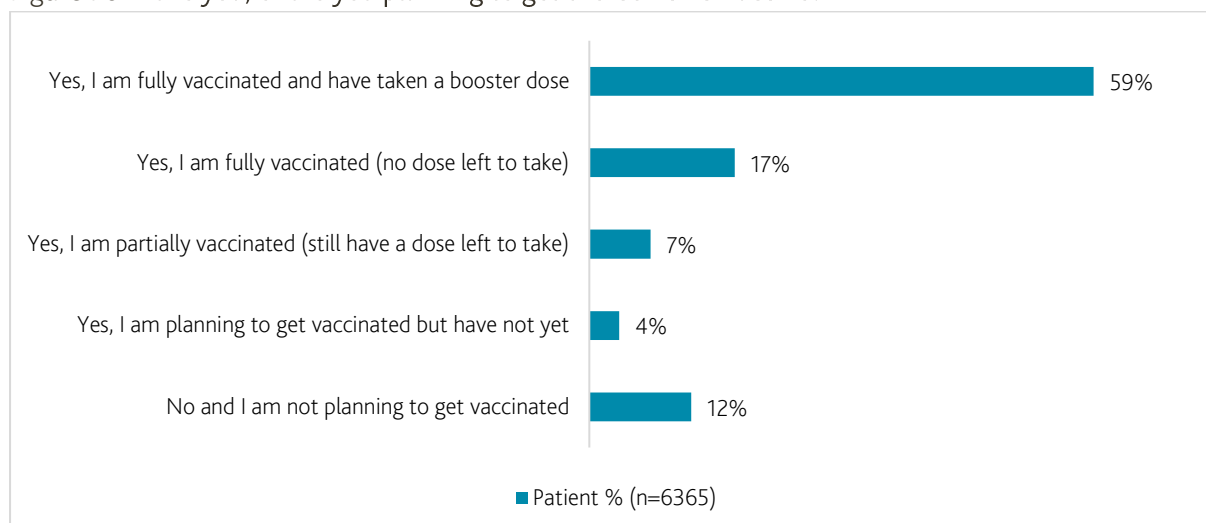
- ❖ Figure 75 illustrates that 77% of patients have not contracted Covid-19 at any point

Figure 75. Have you contracted Covid-19, now or at any point?



- ❖ Figure 76 illustrates that 59% of patients are fully vaccinated and have taken a booster dose

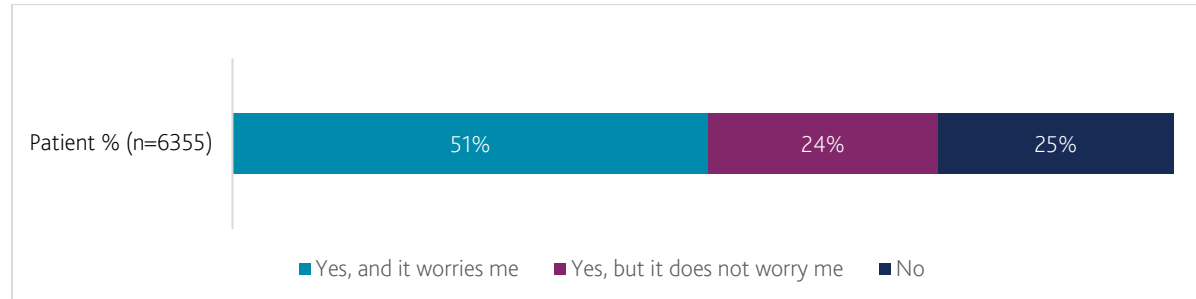
Figure 76. Have you, or are you planning to get the Covid-19 vaccine?



## GPS 2022: Global Report

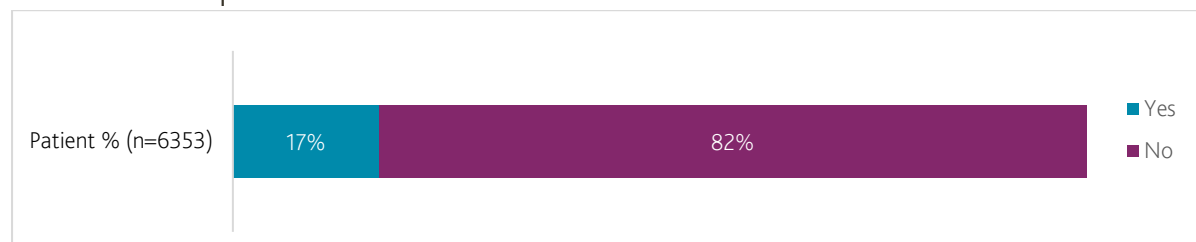
- ❖ Figure 77 illustrates that 51% of patients consider themselves as high risk of contracting Covid-19 and it worries them

Figure 77. Do you consider yourself at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?



- ❖ Figure 78 illustrates that 82% of patients did not avoid or delay seeking medical attention for their lymphoma or CLL during the Covid-19 pandemic

Figure 78. Did you avoid or delay seeking medical attention for your lymphoma or CLL during the Covid-19 pandemic?

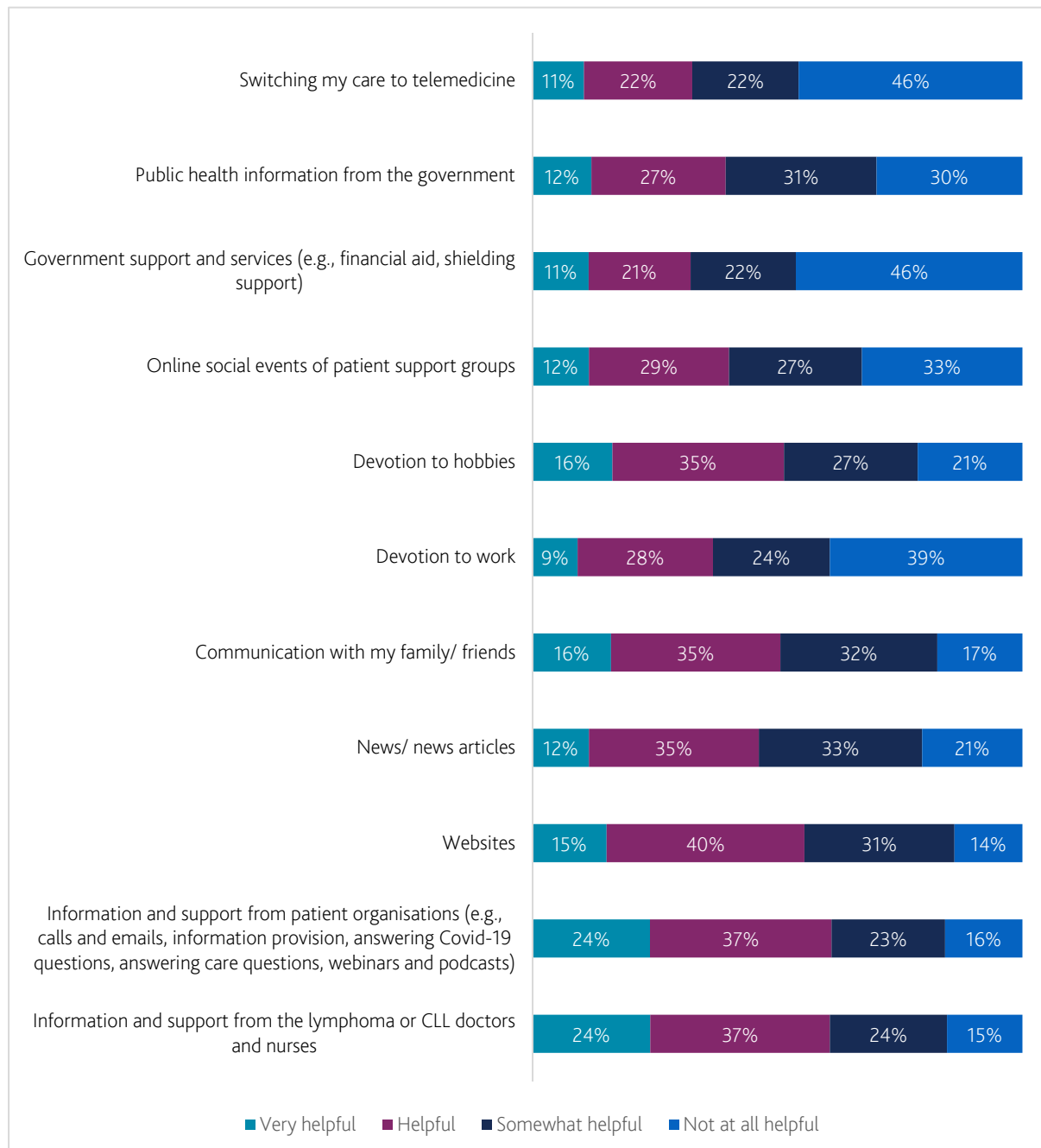


The results below show how helpful certain factors were in supporting lymphoma or CLL patients during the Covid-19 pandemic. Information and support from patient organisations and doctors and nurses were the top reported support that patients found very useful

## GPS 2022: Global Report

- ❖ Figure 79 illustrates that 46% of patients found that switching to telemedicine and government support and services have both been not helpful in providing support for lymphoma or CLL during the Covid-19 pandemic

Figure 79. 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.

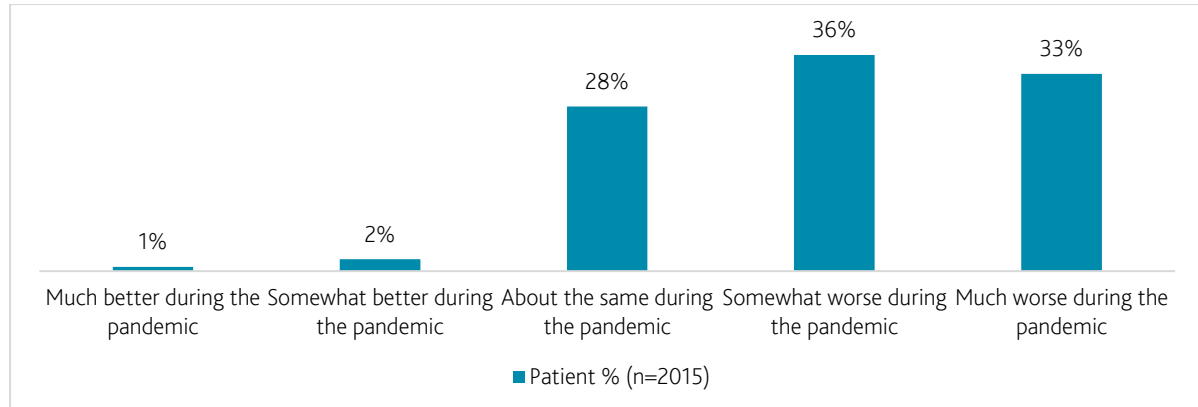


Patients who reported having anxiety (as a psychosocial issue) were asked how the Covid-19 pandemic affected their anxiety level- 69% of them stated that their anxiety level was somewhat worse/ much worse during the pandemic, and 28% stated that it was about the same level.

## GPS 2022: Global Report

- ❖ Figure 80 illustrates that 36% of patients felt that their level of anxiety was somewhat worse during the pandemic compared to before the pandemic

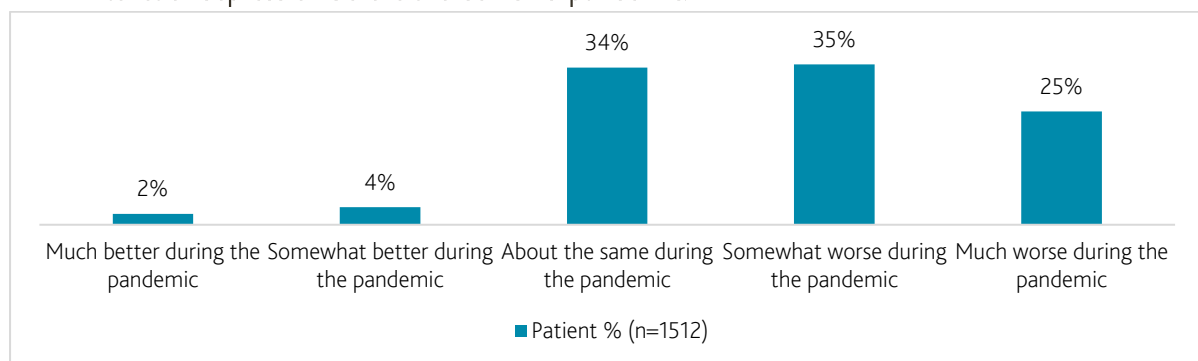
Figure 80. Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.



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- 60% of them stated that their level of depression was somewhat worse/ much worse during the pandemic, while 34% stated that it was about the same level.

- ❖ Figure 81 illustrates that 35% of patients felt that their level of depression during the Covid-19 pandemic was somewhat worse compared to before the Covid-19 pandemic

Figure 81. Please describe your level of depression during the Covid-19 pandemic, compared to your level of depression before the Covid-19 pandemic.



Patients who reported their anxiety or depression levels had worsened during the COVID-19 pandemic, reported their top stressors as:

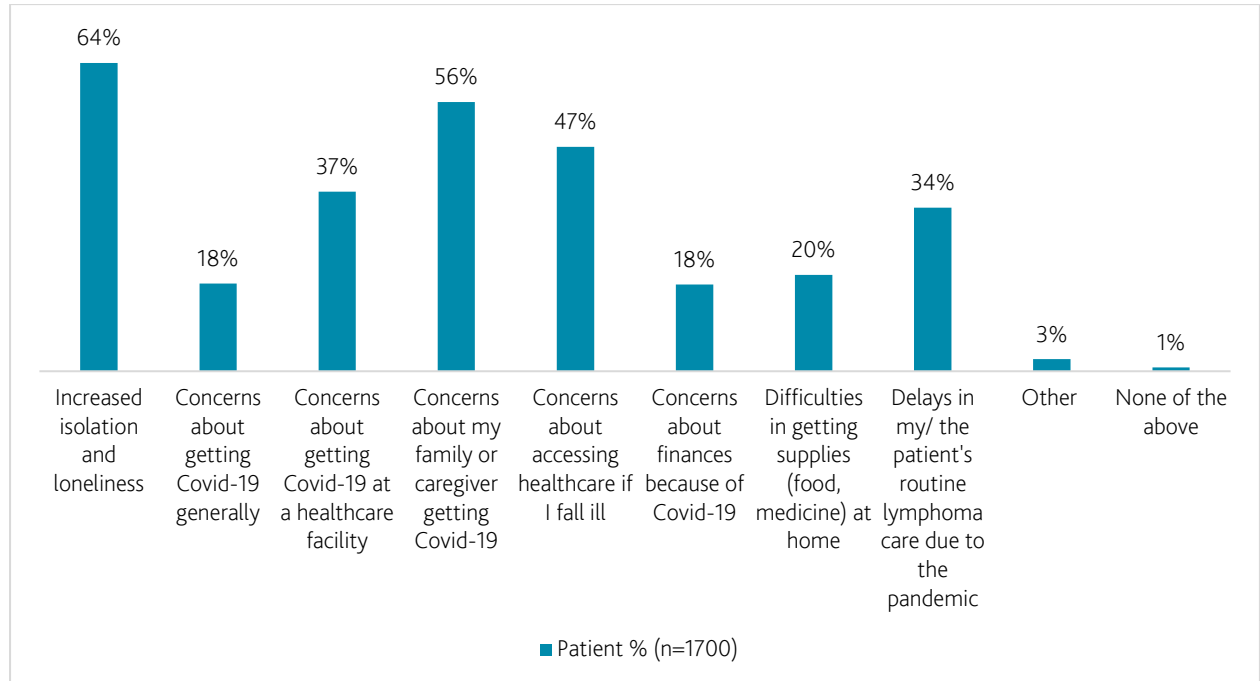
- Increased isolation and loneliness (experienced by 64% of patients)
- Concerns about family or caregiver getting Covid-19 (experienced by 56% of patients)
- Concerns about healthcare should they fall ill (experienced by 47% of patients)



## GPS 2022: Global Report

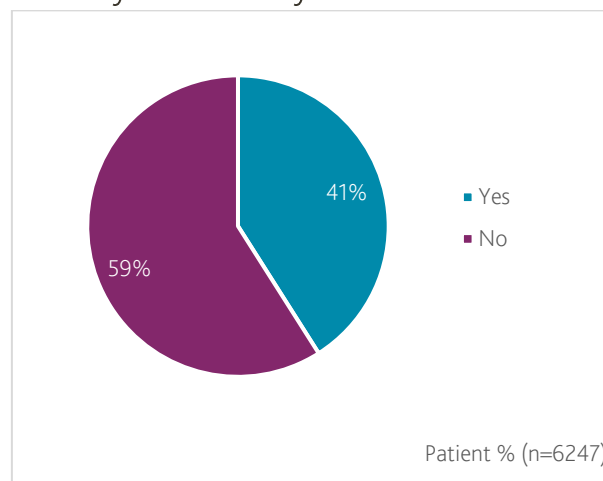
- ❖ Figure 82 illustrates that 64% of patients felt that increased isolation and loneliness were contributing factors to their worsened level of anxiety and/or depression

Figure 82. Which of the following were contributing factors for the worsened anxiety and/ or depression?



- ❖ Figure 83 illustrates that 41% of patients were scheduled to receive treatment for lymphoma or CLL when Covid-19 restriction was an issue in their community

Figure 83. Were you scheduled to receive treatment for your lymphoma or CLL when Covid-19 restriction was an issue in your community?

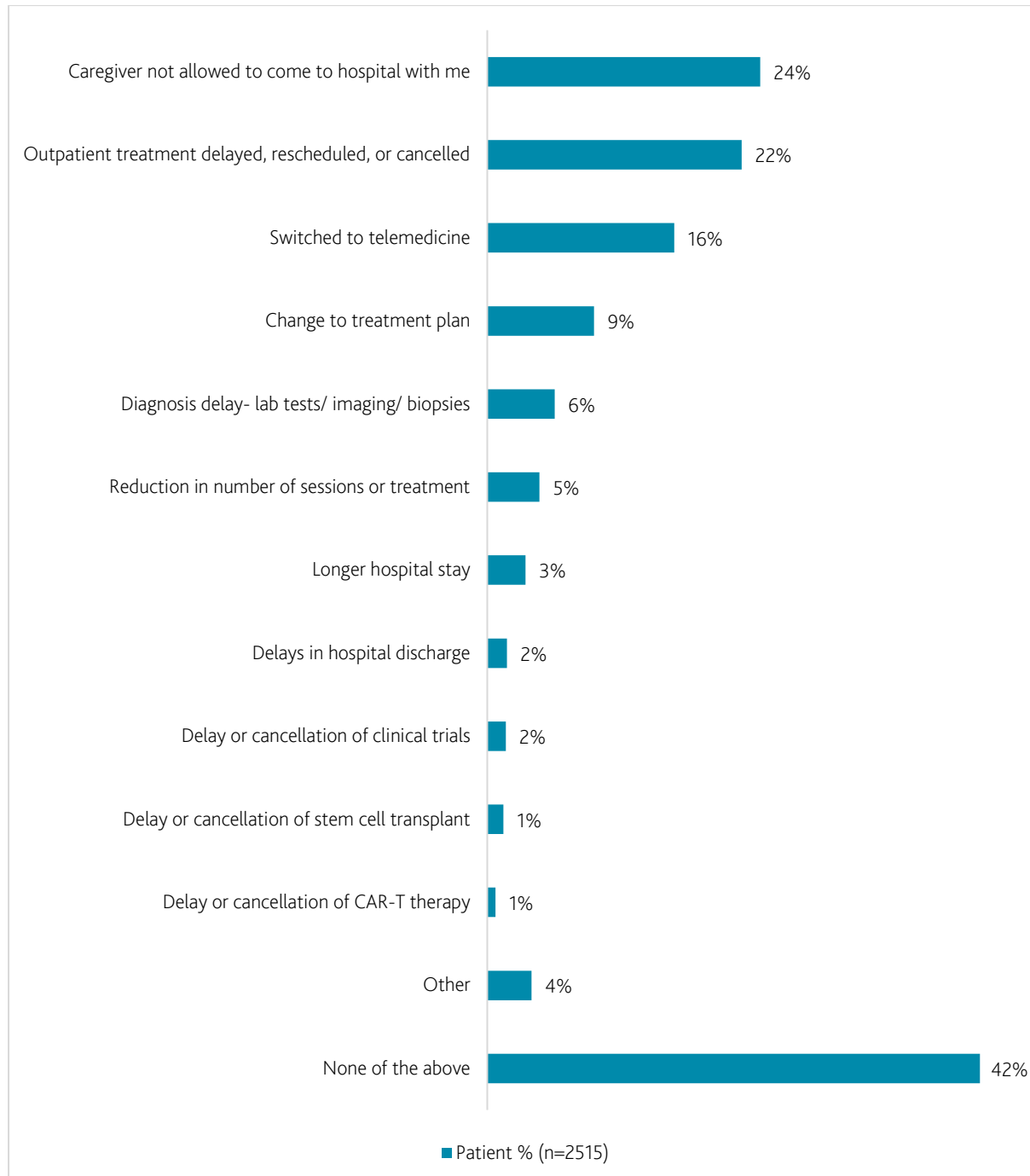


58% of patients experienced changes to care due to the COVID-19 restrictions. 24% of patients reported that their caregivers were not allowed to come into the hospital with them, while 22% had their outpatient treatment delayed, rescheduled, or cancelled. 5% of the patients experienced a reduction in their treatment sessions. 16% of patients had their care switched to telemedicine.

## GPS 2022: Global Report

- ❖ Figure 84 illustrates that 42% of patients did not experience any changes to their care due to Covid-19

Figure 84. Did you experience any of the following changes to your care due to Covid-19?

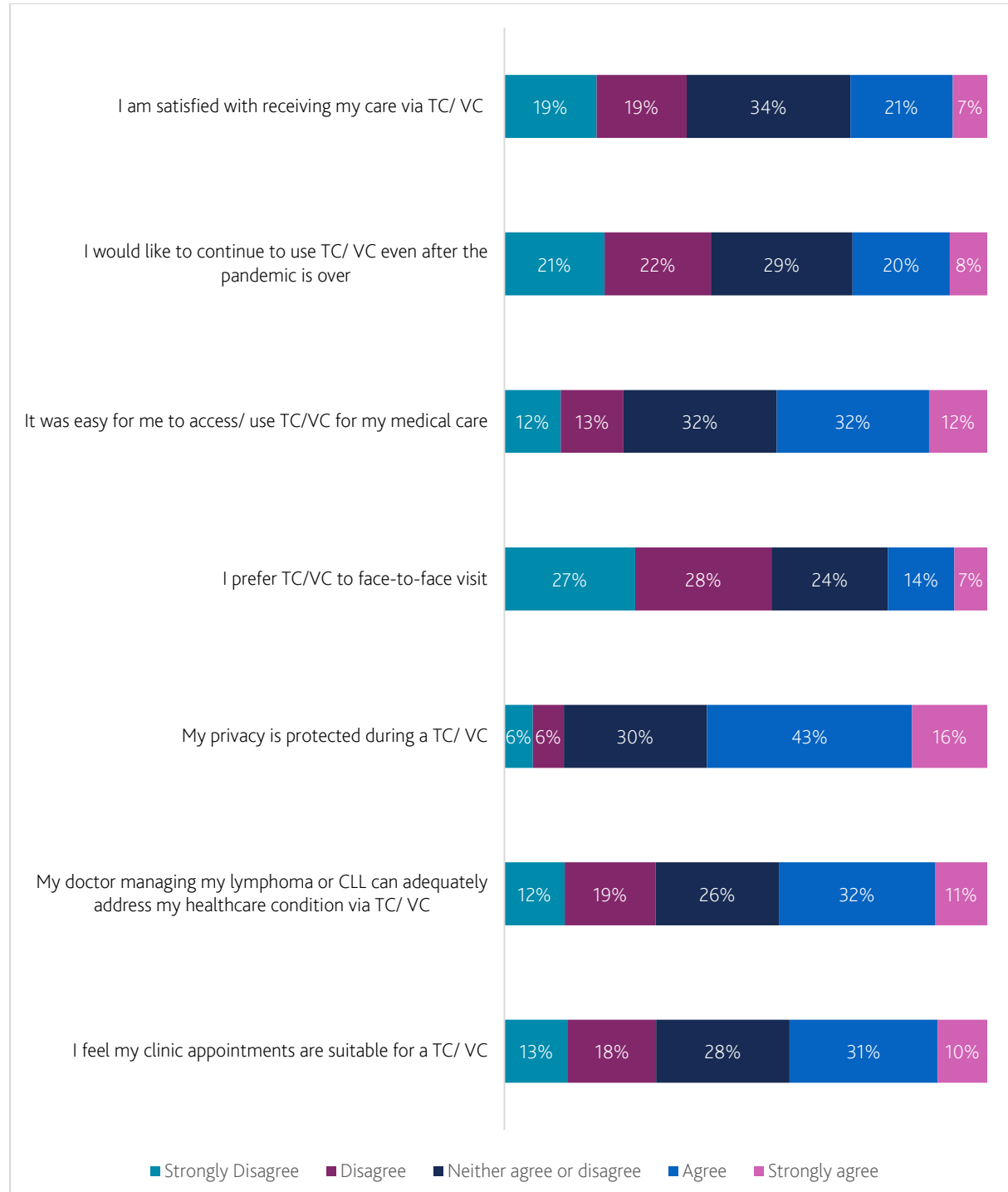


Patients who reported that their care had switched to telemedicine (use of telephone consultation (TC) or video consultation (VC)) were asked about their experience with it.

## GPS 2022: Global Report

- ❖ Figure 85 illustrates that 43% of patients agree that their privacy was protected during a telephone consultation or video consultation

Figure 85. Regarding your use of telemedicine (Telephone consultation (TC) or video consultation (VC), how much do you agree or disagree with the following statements?



## GPS 2022: Global Report

### Caregiver Results

Family and informal caregivers (caregivers) are unpaid care providers providing support to lymphoma patients and the support they provide can be substantial in scope, intensity and duration and considered an extension of the patient's health care 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. Therefore, this survey sought to understand caregivers' support and decision-making experience.

**1524** 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

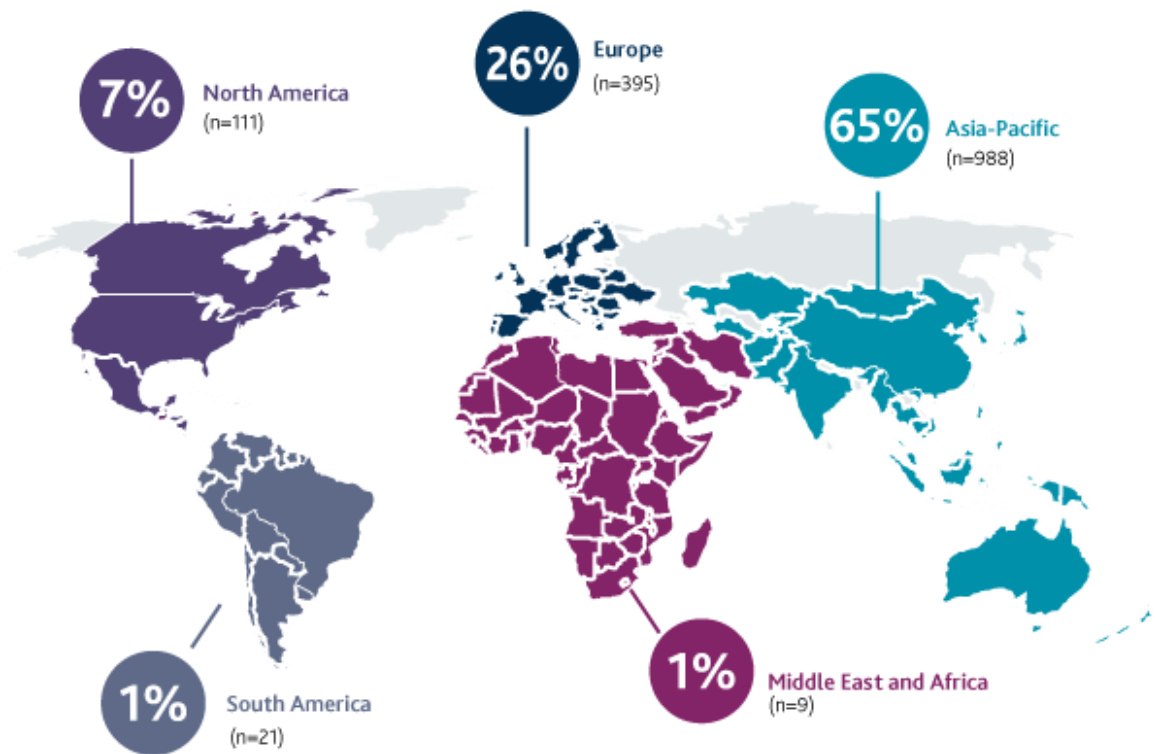
### Caregiver Characteristics



- 1524 caregivers responded to the survey, with half of the respondents residing in China (52%). Most caregivers (71%) were female.
- 43% of all caregivers identified as their spouse or partner, 29% cared for their parent, and 18% for their child.
- Most caregivers reported they were providing care for patients with diffuse large B-cell (15%), followed by Hodgkin lymphoma (13%), then chronic lymphocytic leukaemia (CLL)/small lymphocytic lymphoma (SLL) 11%.
- 80% of caregivers reported being somewhat informed, well informed, or very well informed about the processes and stages of the patient's healthcare.
- Caregivers preferred sources of information on lymphoma and CLL are from doctors (79%), followed by internet searches (64%) and then patient organisations (60%).

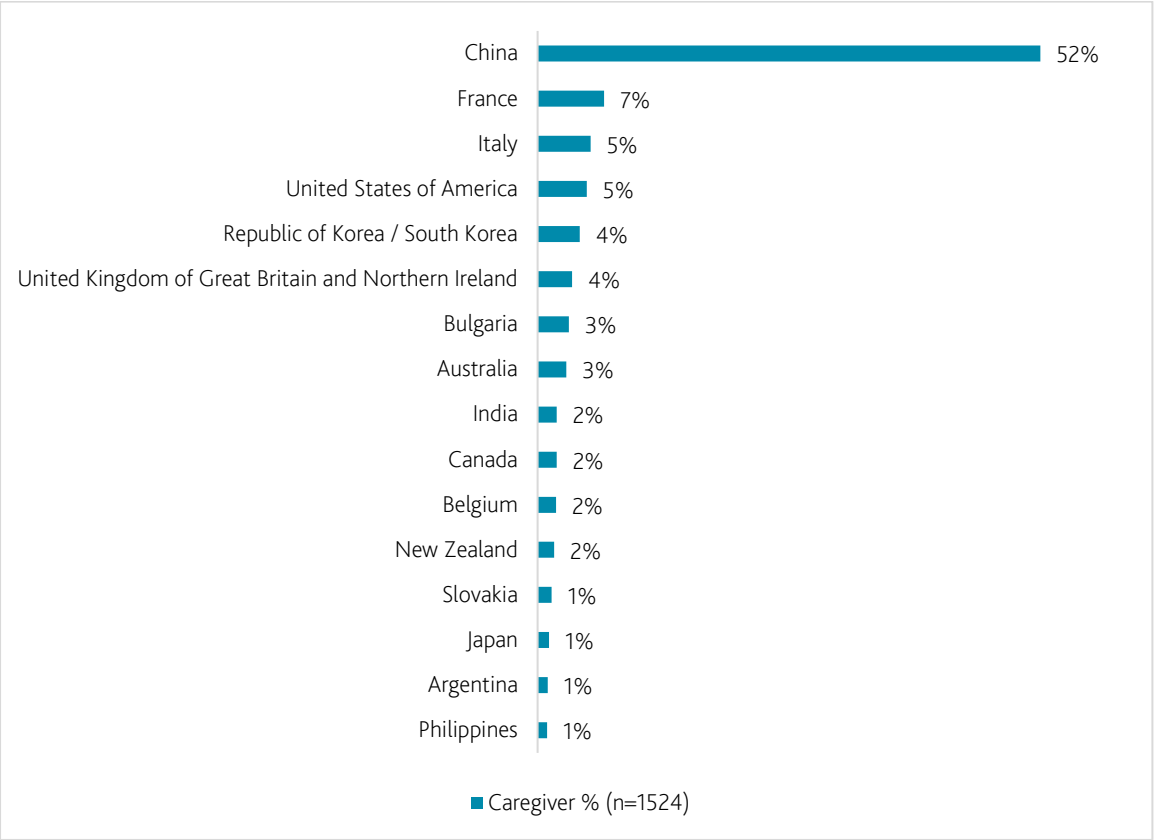
GPS 2022: Global Report

The global regional distribution of where caregivers responded from is:



❖ Figure 86 illustrates that 52% of caregivers are from China

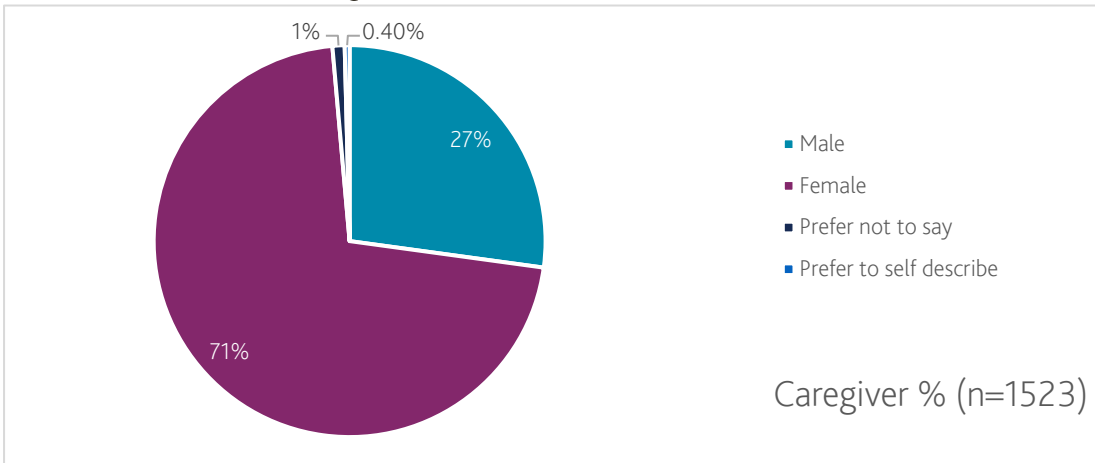
Figure 86. Country of residence



GPS 2022: Global Report

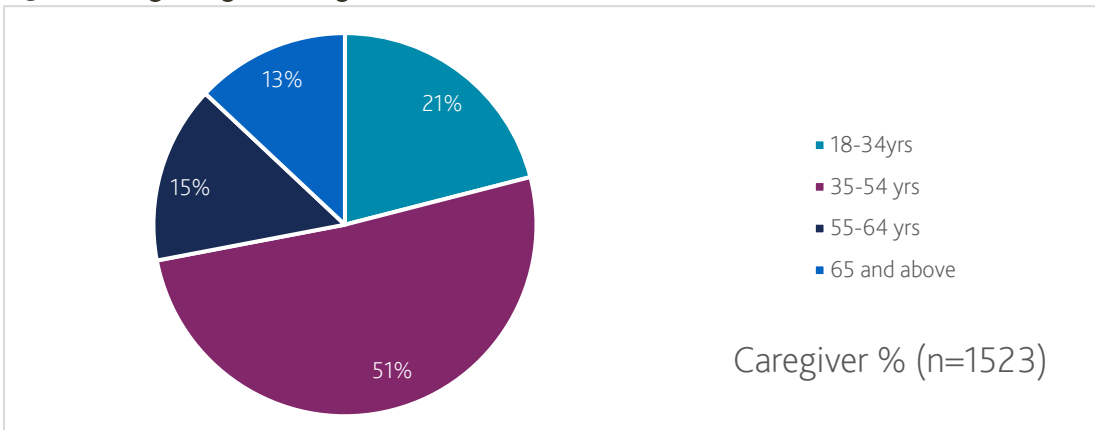
❖ Figure 87 illustrates that 71% of caregivers are female

Figure 87. Gender of the caregiver



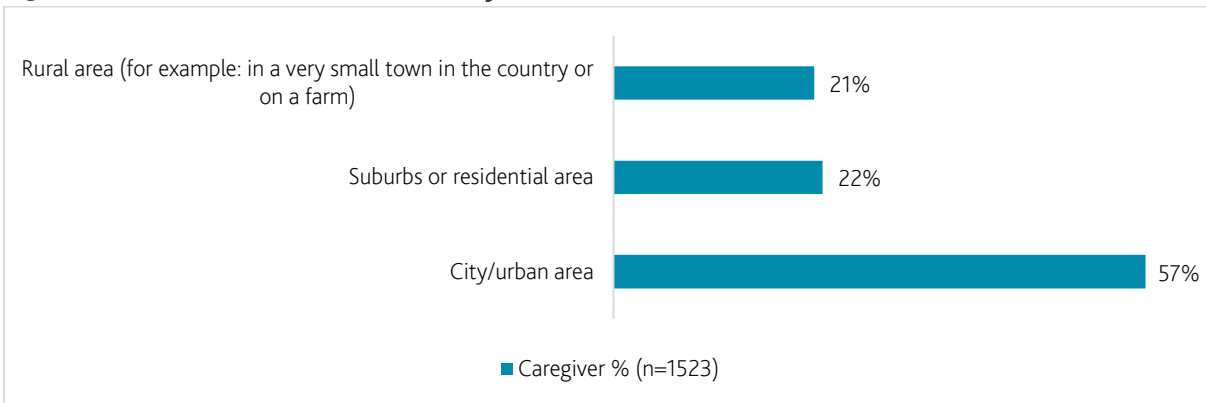
❖ Figure 88 illustrates that 51% of caregivers are between the ages of 35 to 54 years

Figure 88. Age range of caregivers



❖ Figure 89 illustrates that 57% of caregivers live in a city/urban area

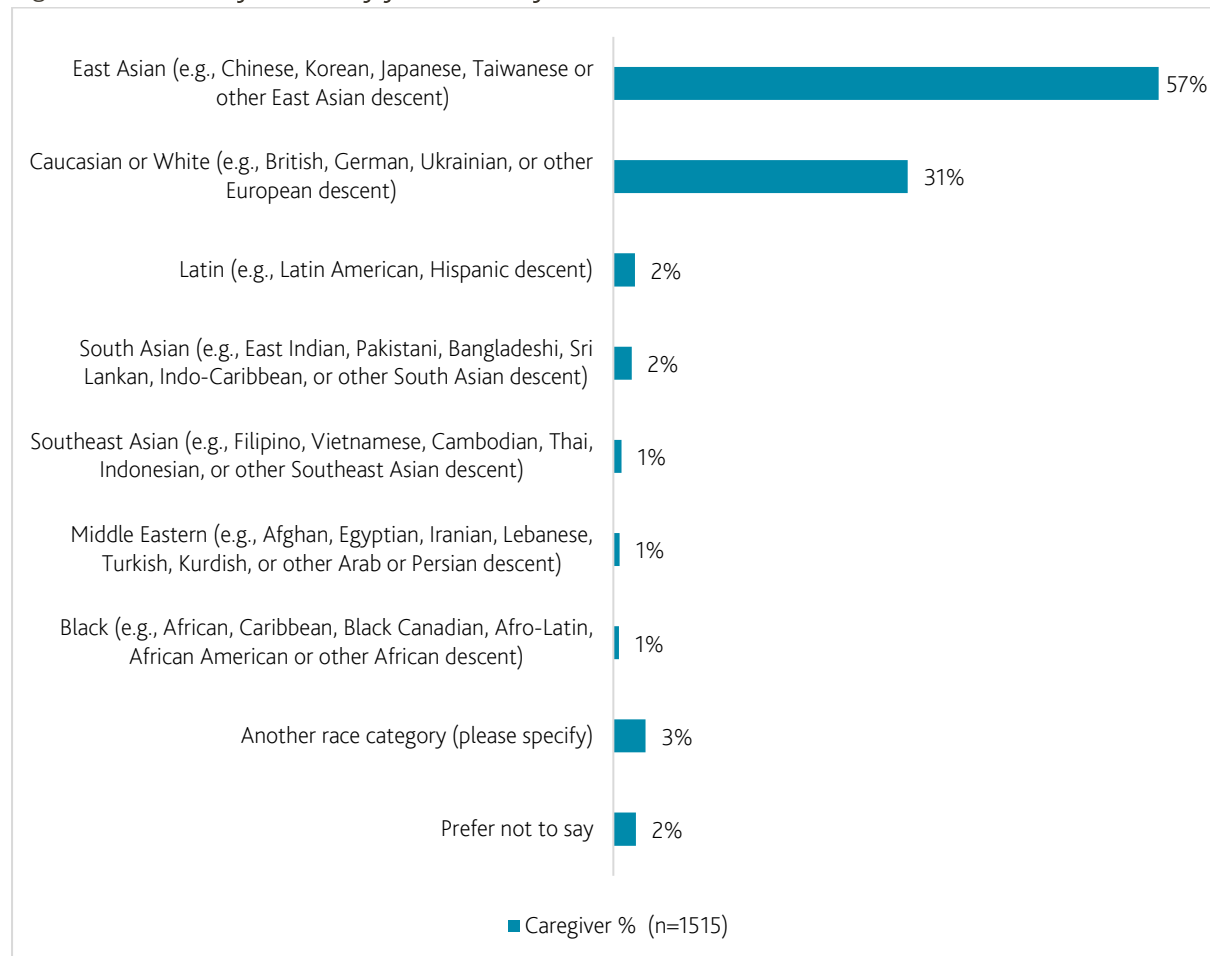
Figure 89. Which best describes the area you live in?



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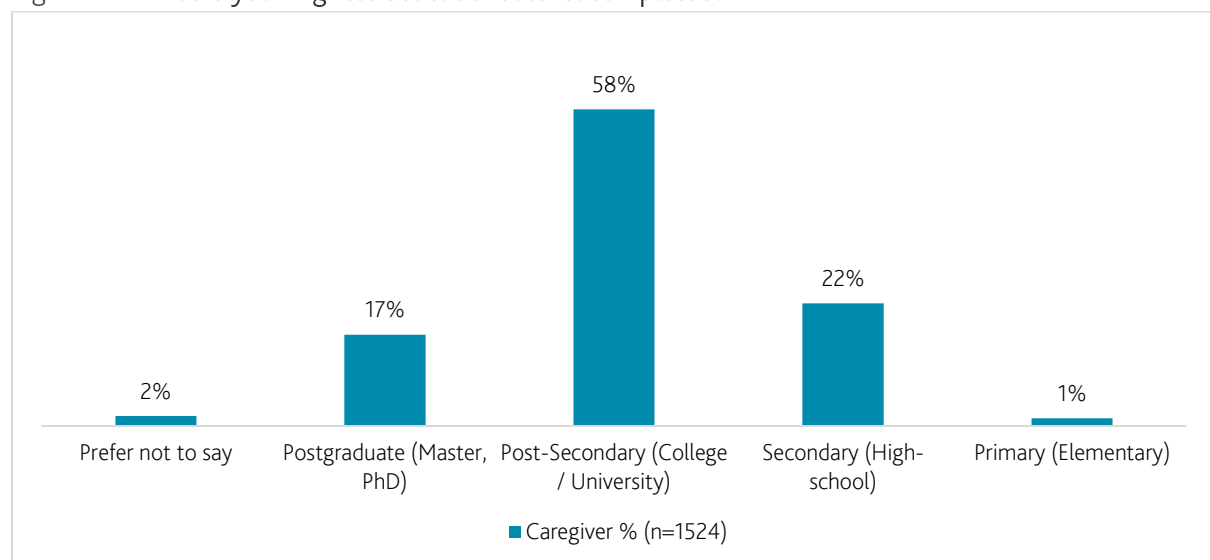
❖ Figure 90 illustrates that 57% of caregivers are East Asian

Figure 90. How do you identify your ethnicity?



❖ Figure 91 illustrates that 58% of caregivers have completed a post-secondary education

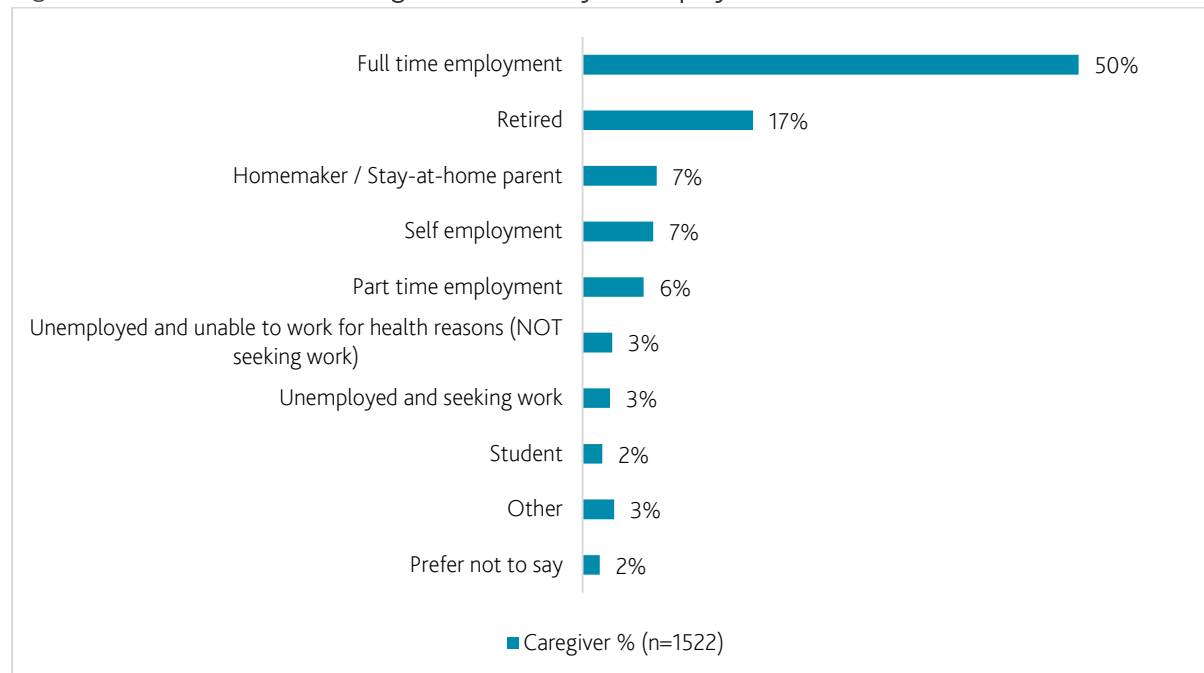
Figure 91. What is your highest educational level completed?



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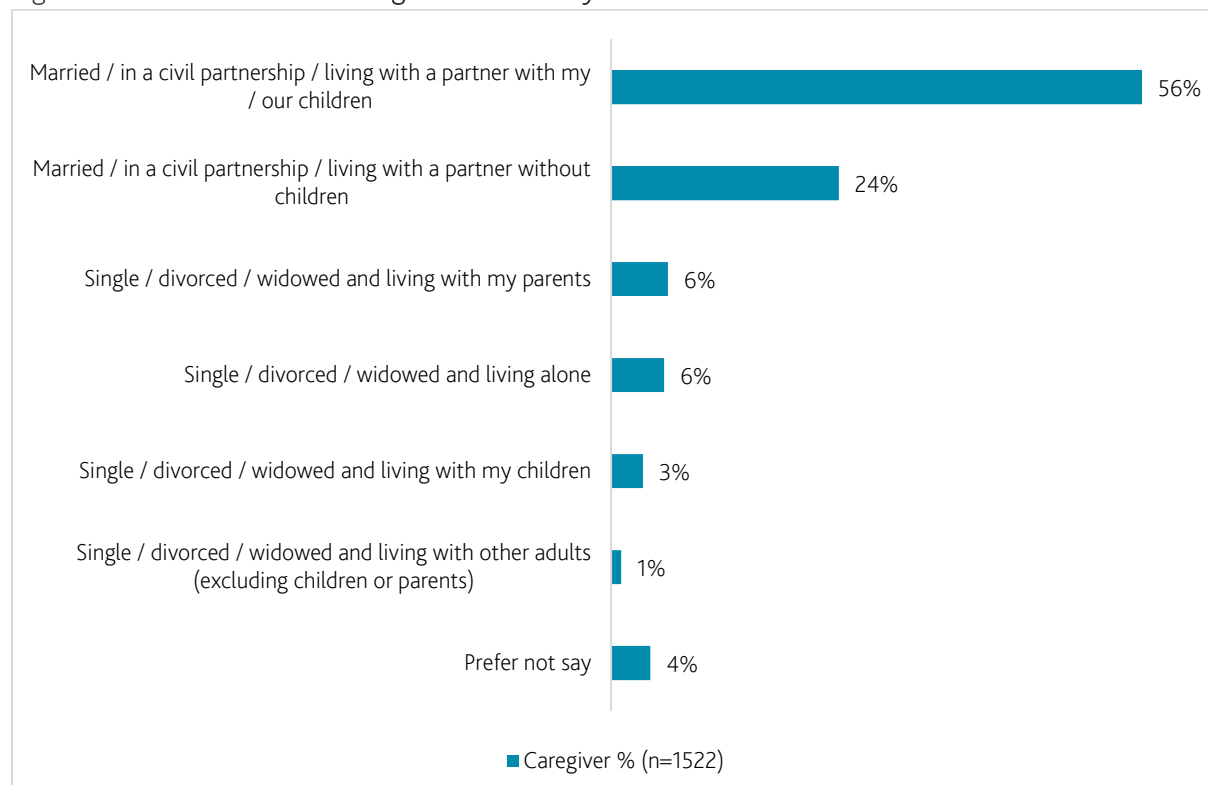
- ❖ Figure 92 illustrates that 50% of caregivers are employed full-time

Figure 92. Which of the following best describes your employment status?



- ❖ Figure 93 illustrates that 56% of caregivers are married/in a civil partnership/living with a partner with their children

Figure 93. Which of the following best describes your household status?



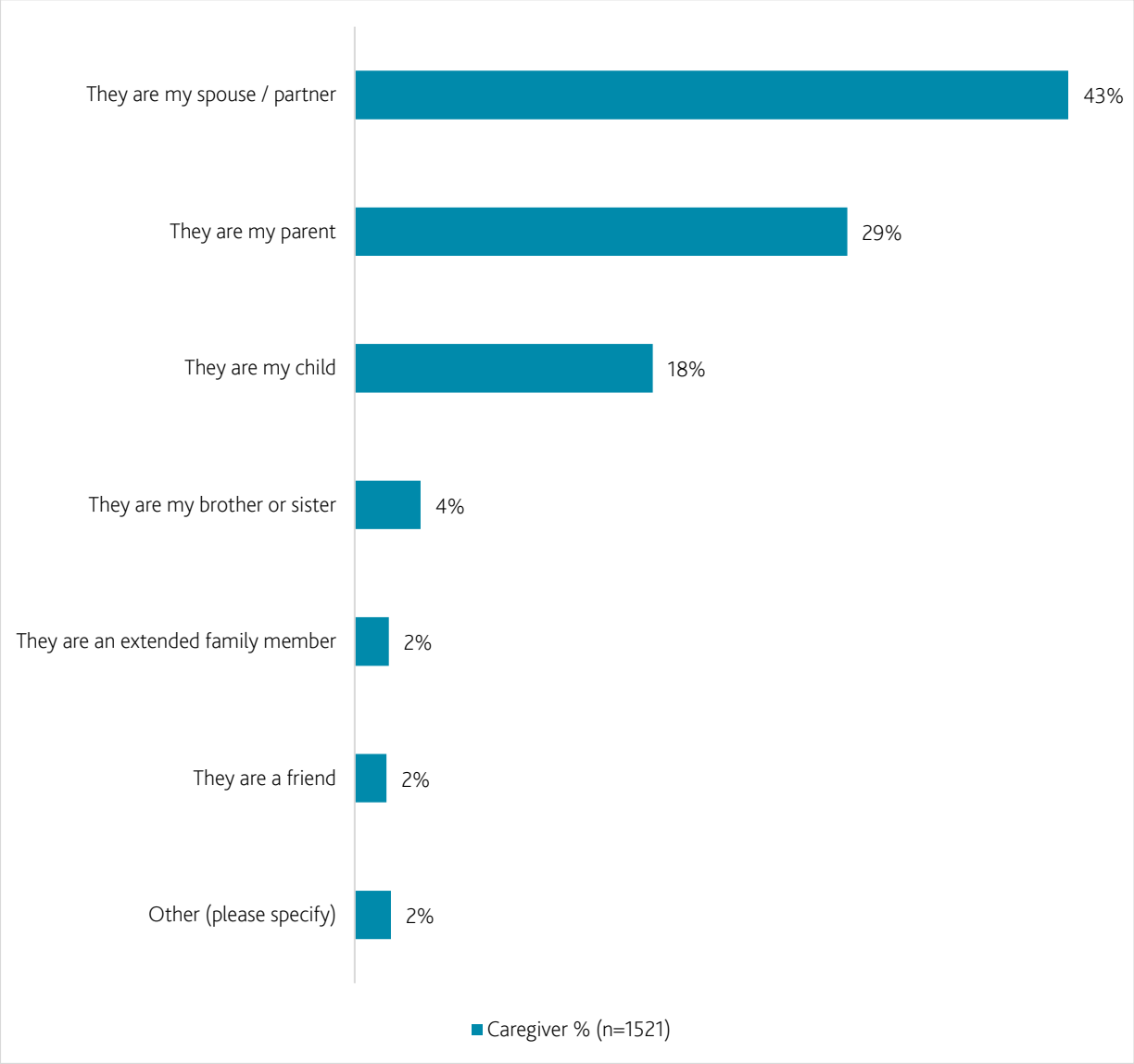


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Caregivers were asked to identify their relationship with the person they are providing care and support to; 43% of caregivers are a spouse/partner and 29% are caring for their parent.

❖ Figure 94 illustrates that 43% of caregivers are providing care and support to their spouse/partner

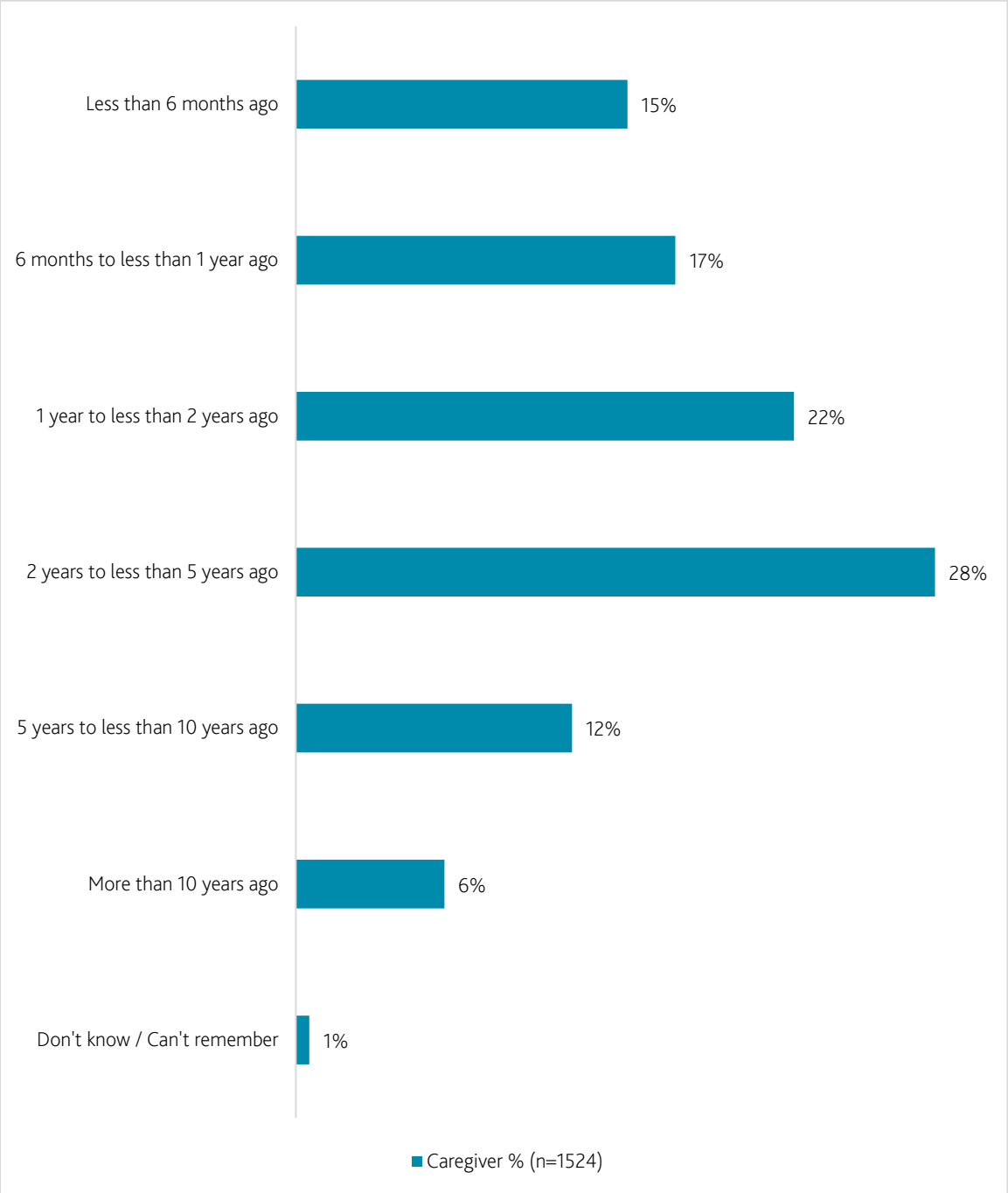
Figure 94. What is your relationship to the person you are providing care and support to?



Diagnostic Demographics

- ❖ Figure 95 illustrates that 28% of caregivers have patients that have been diagnosed with lymphoma or CLL between 2 to 5 years ago

Figure 95. How long ago was the patient diagnosed with lymphoma or CLL?

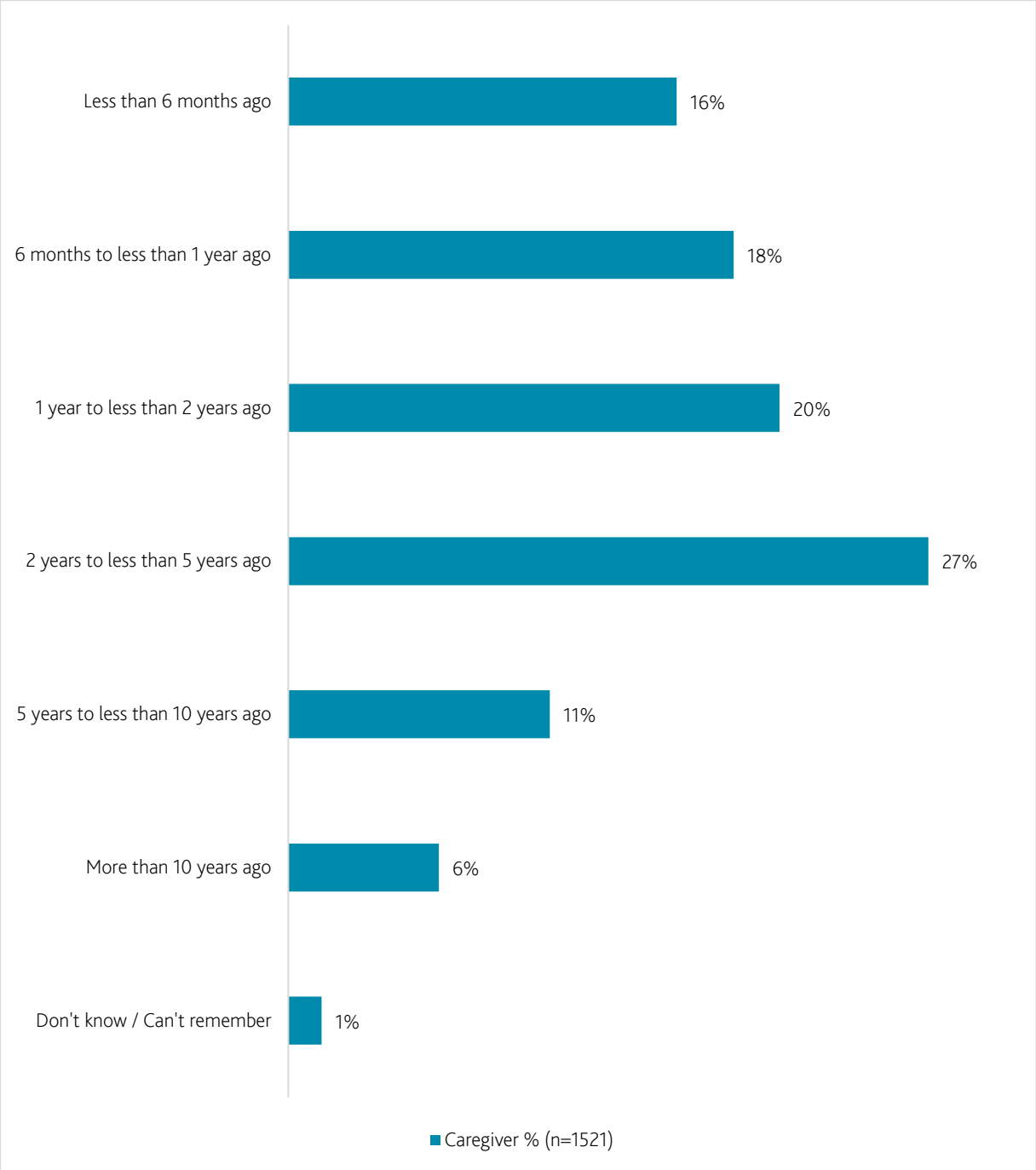


About half of caregivers who responded have only been providing care and support for less than 2 years. Nearly a quarter (27%) of caregivers stated they had been providing care for 2 to less than 5 years (as of survey time).

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- ❖ Figure 96 illustrates that 27% of caregivers have been providing cancer-related care and support between 2 to 5 years

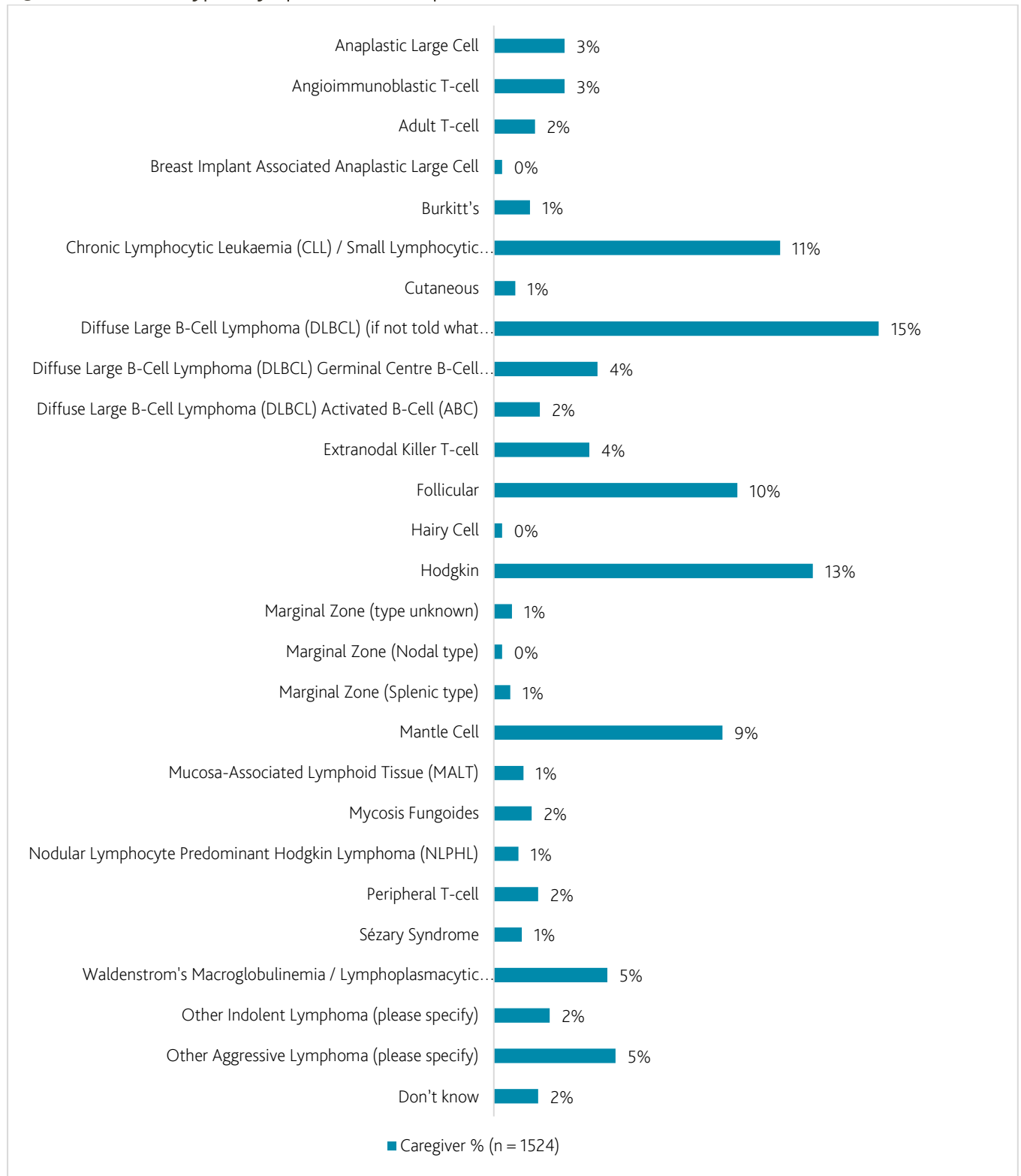
Figure 96. How long have you been providing cancer-related care and support to the person with lymphoma or CLL?



The main three lymphoma subtypes of the patients that caregivers are providing care and support were DLBCL (subtype unknown) (15%), Hodgkin lymphoma (13%), and CLL/SLL (11%).

❖ Figure 97 illustrates that 15% of caregiver's patients have diffuse large B-cell lymphoma (DLBCL)

Figure 97. What subtype of lymphoma does the patient have?

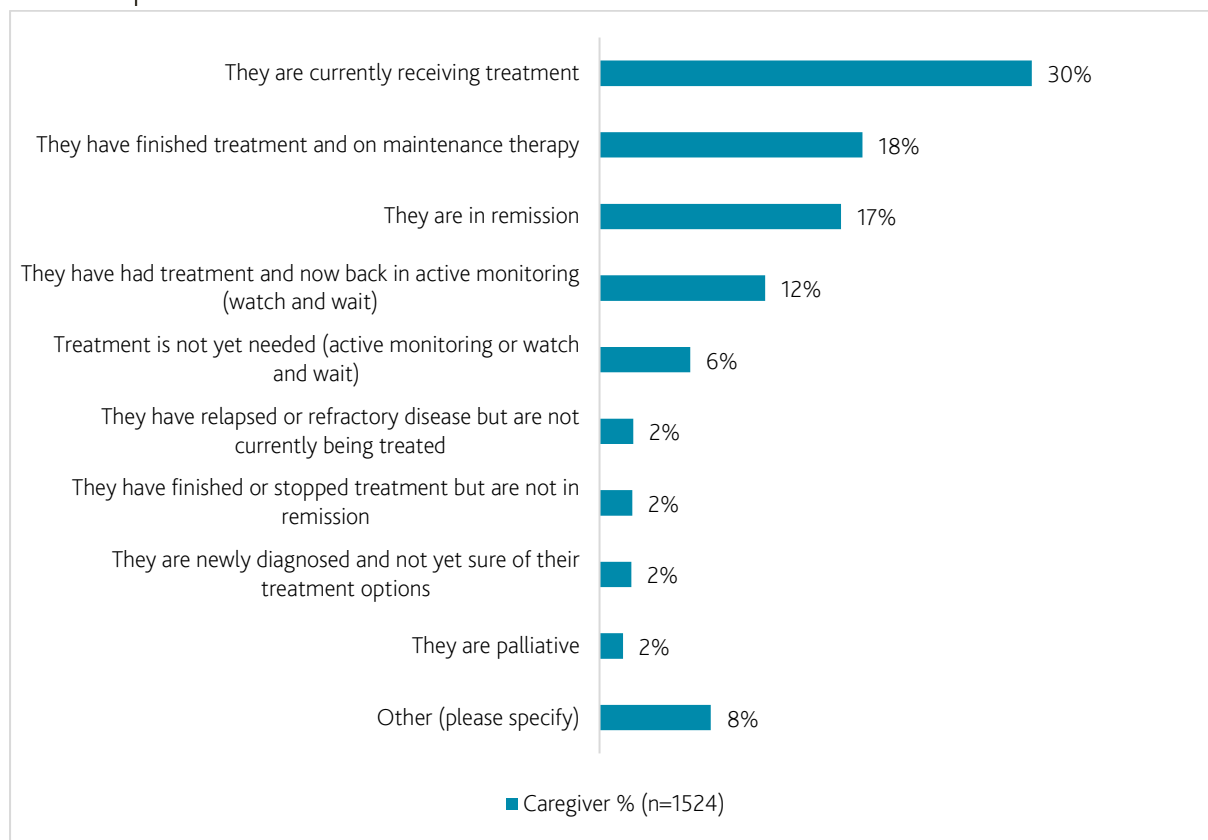


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Below displays the stage of the care pathway of patients the caregivers were providing care and support for. About a third (30%) of all caregivers support somebody currently in treatment.

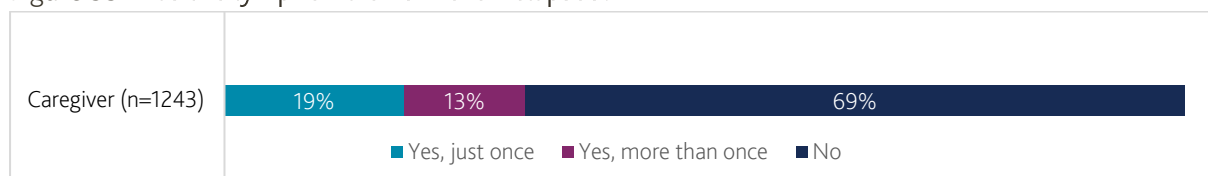
- 57% of patients being cared for, who had been in remission were in remission for less than 2 years; 28% for 2 to less than 5 years 15% for 5 years or more
  - 60% of patients in active monitoring, being cared for, had been in active monitoring for less than 2yrs; 20% for 2 to less than 5 years and 11% for 5 years or more
  - 32% of the patients being cared for had experienced a relapse- 19%, just once and 13% more than once
  - 11% of patients being cared for had experienced their lymphoma or CLL transform (e.g., from indolent (e.g., follicular) to aggressive (e.g. DLBCL).
- ❖ Figure 98 illustrates that 30% of caregivers are caring for patients that are currently receiving treatment

Figure 98. What statement best describes where the person you care for is in the lymphoma or CLL experience?



- ❖ Figure 99 illustrates that 69% of caregiver's patients have not had their lymphoma or CLL relapse

Figure 99. Has the lymphoma or CLL ever relapsed?

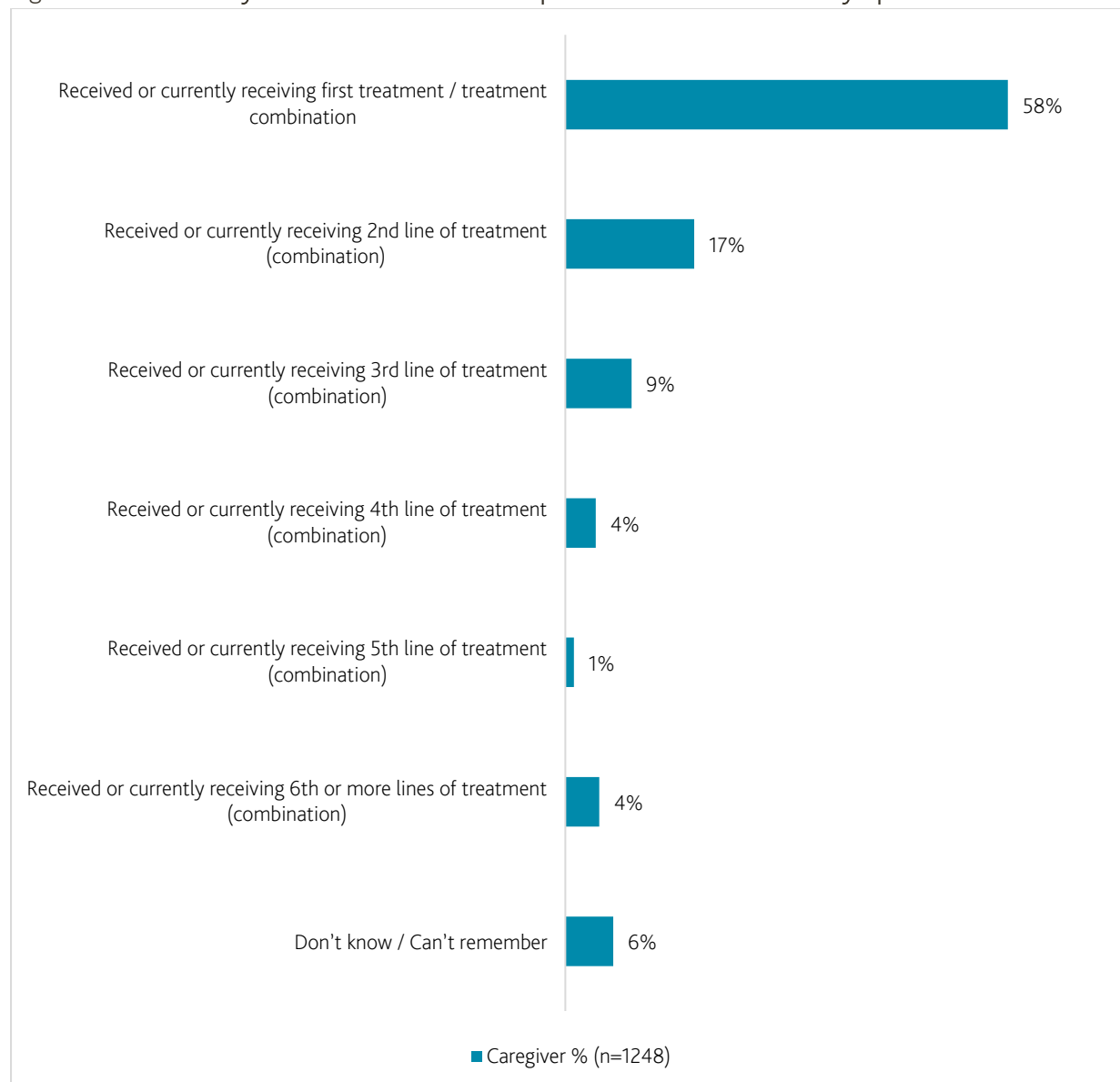


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58% of caregivers provided care to patients who had received or were currently receiving their first treatment/ treatment combination, while 35% of the caregivers provided care to patients who had received or were receiving the 2nd line or more of treatment.

Figure 100 illustrates that 58% of caregivers report that their patient has received their first treatment/treatment combination

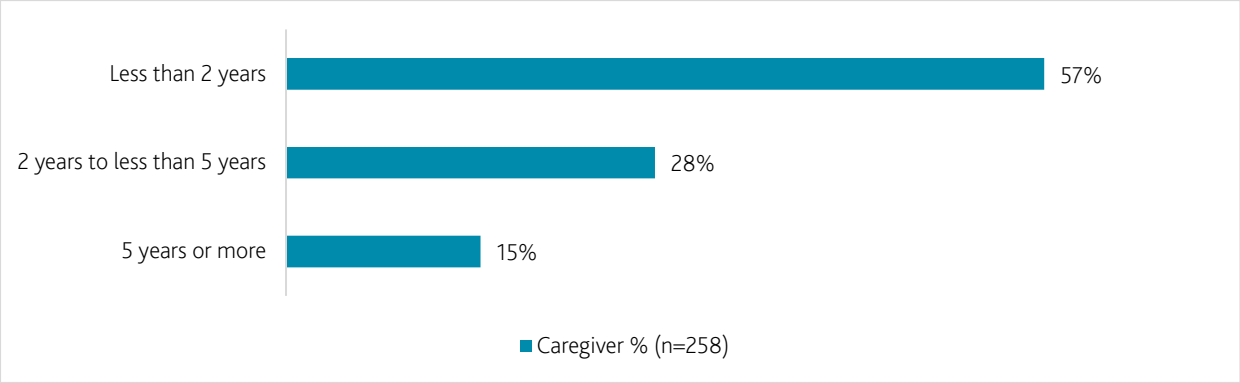
Figure 100. How many lines of treatment has the patient received to date for lymphoma?



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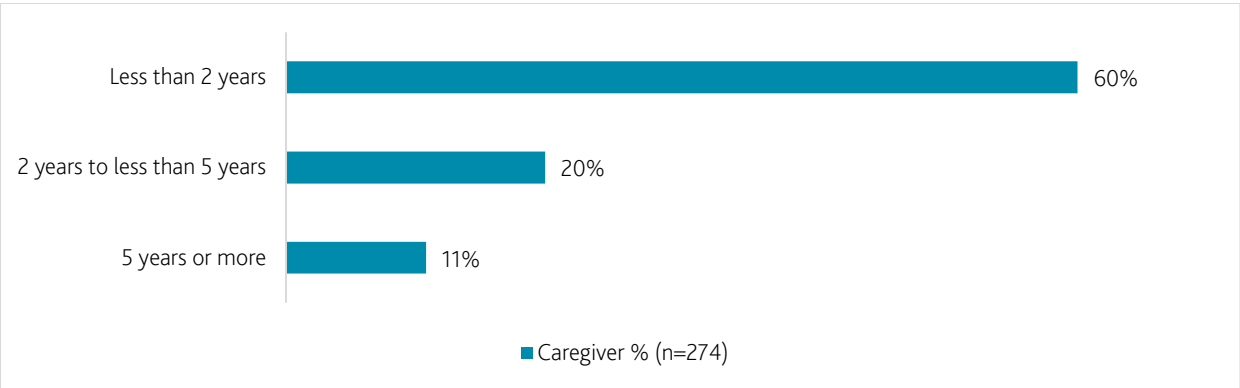
- ❖ Figure 101 illustrates that 57% of caregivers reported that the last treatment for their patient in remission was less than 2 years ago

Figure 101. You have said that the patient is in remission, how long has it been since the last treatment?



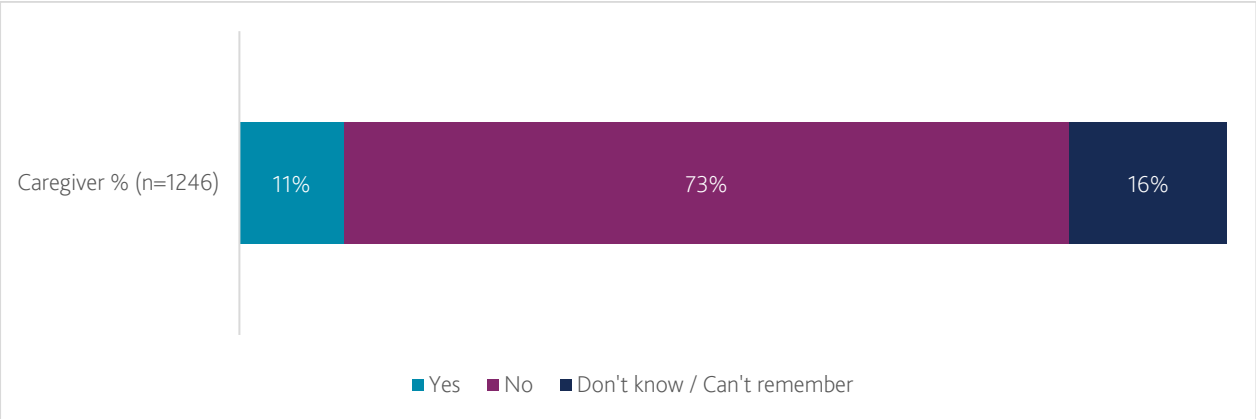
- ❖ Figure 102 illustrates that 60% of caregivers had patients that had been in active monitoring for less than 2 years

Figure 102. How long has the patient been in active monitoring (watch and wait)?



- ❖ Figure 103 illustrates that 73% of caregivers have patients whose lymphoma or CLL has not transformed

Figure 103. Has the lymphoma or CLL transformed (e.g., indolent (follicular) to aggressive (DLBCL))?



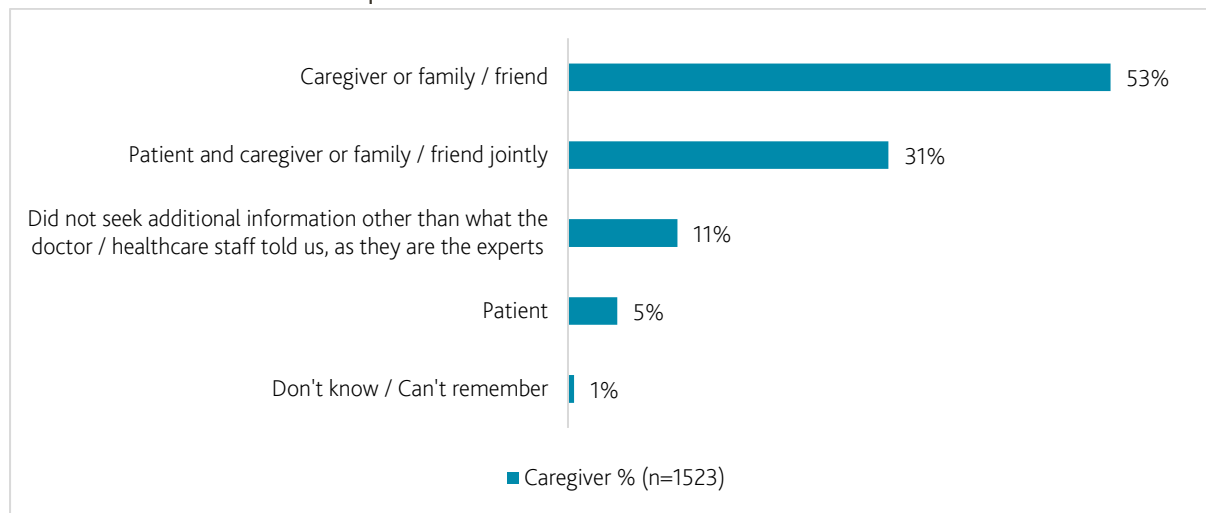
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### Healthcare Information

Over half of caregivers (53%) stated that they were seeking out information and details about the disease and potential treatment options alone, following the patient's lymphoma or CLL diagnosis.

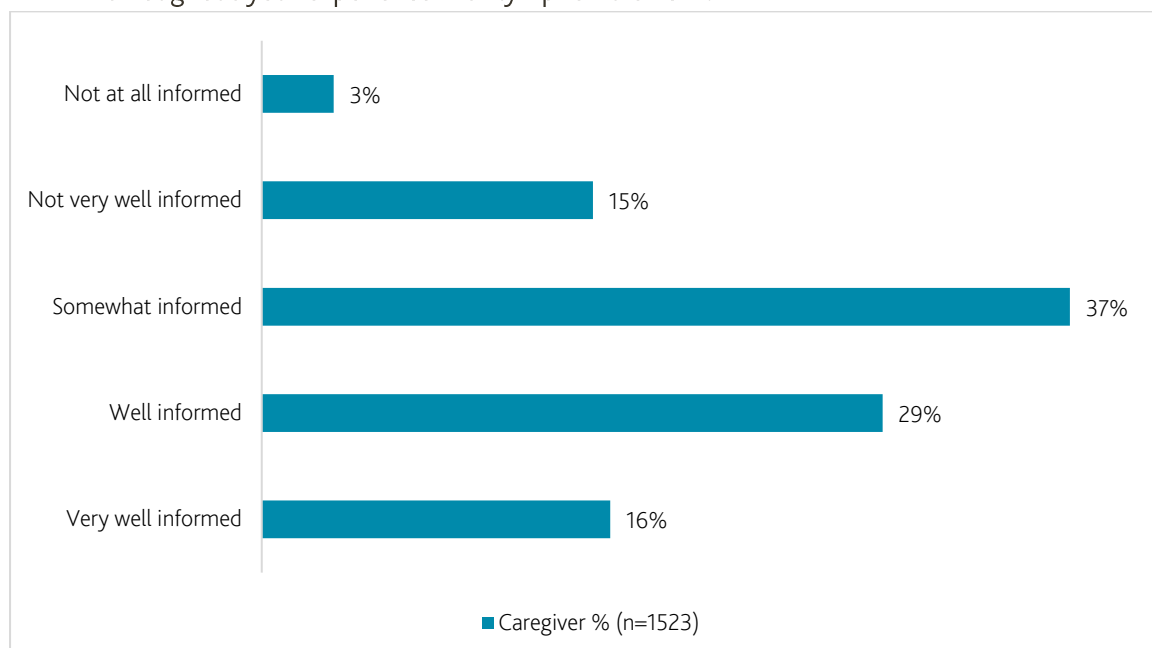
- ❖ Figure 104 illustrates that 53% of caregivers were seeking out information and details about the disease and potential treatments

Figure 104. Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



- ❖ Figure 105 illustrates that 37% of caregivers felt somewhat informed about the processes and stages of their patient's healthcare

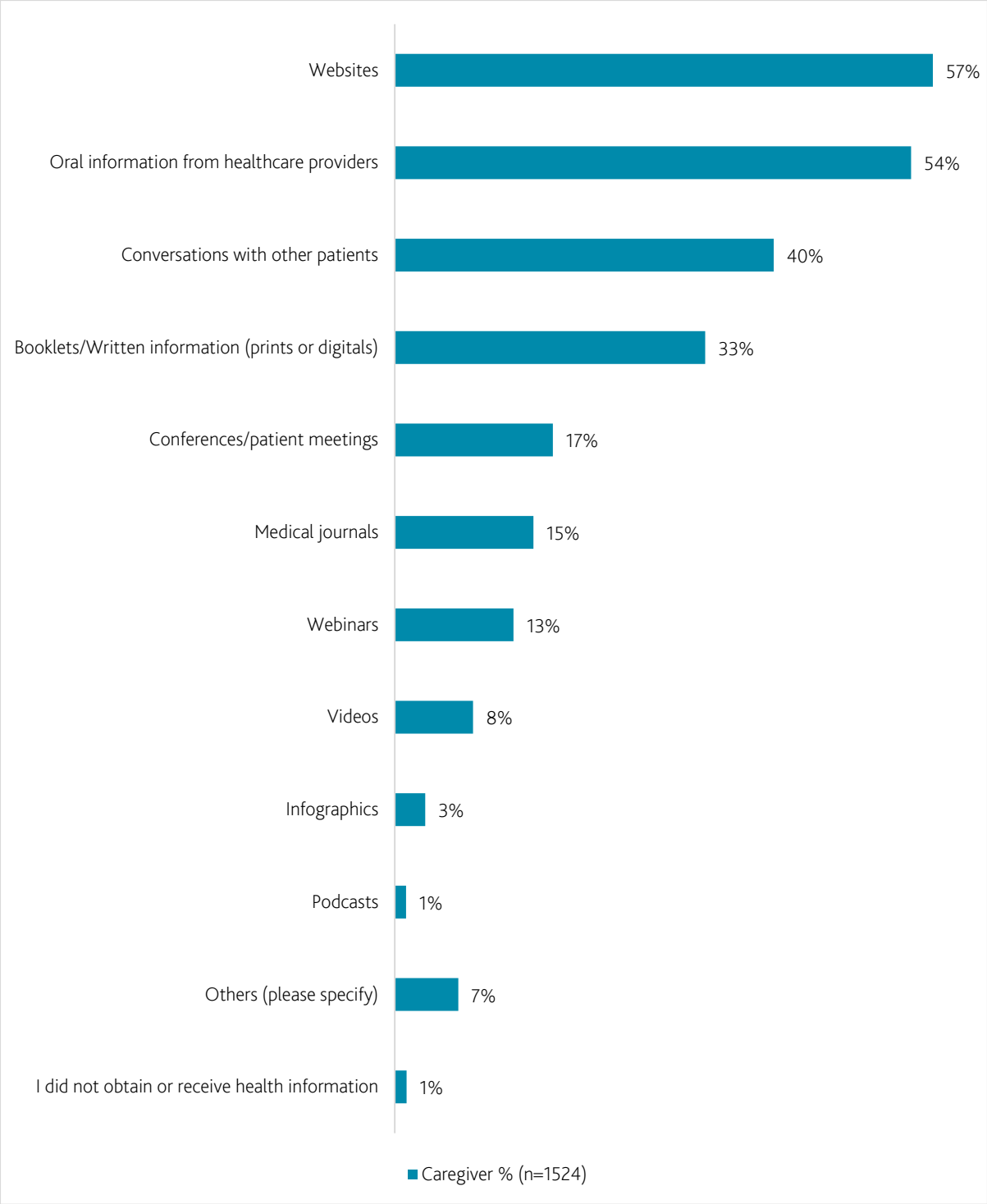
Figure 105. How informed have you felt about the processes and stages of your/ the patient's healthcare (e.g., diagnosis, treatment, resources available for support and self-care) throughout your experience with lymphoma or CLL?





❖ Figure 106 illustrates that 57% of caregivers prefer websites as their method for obtaining or receiving health information about lymphoma or CLL

Figure 106. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?

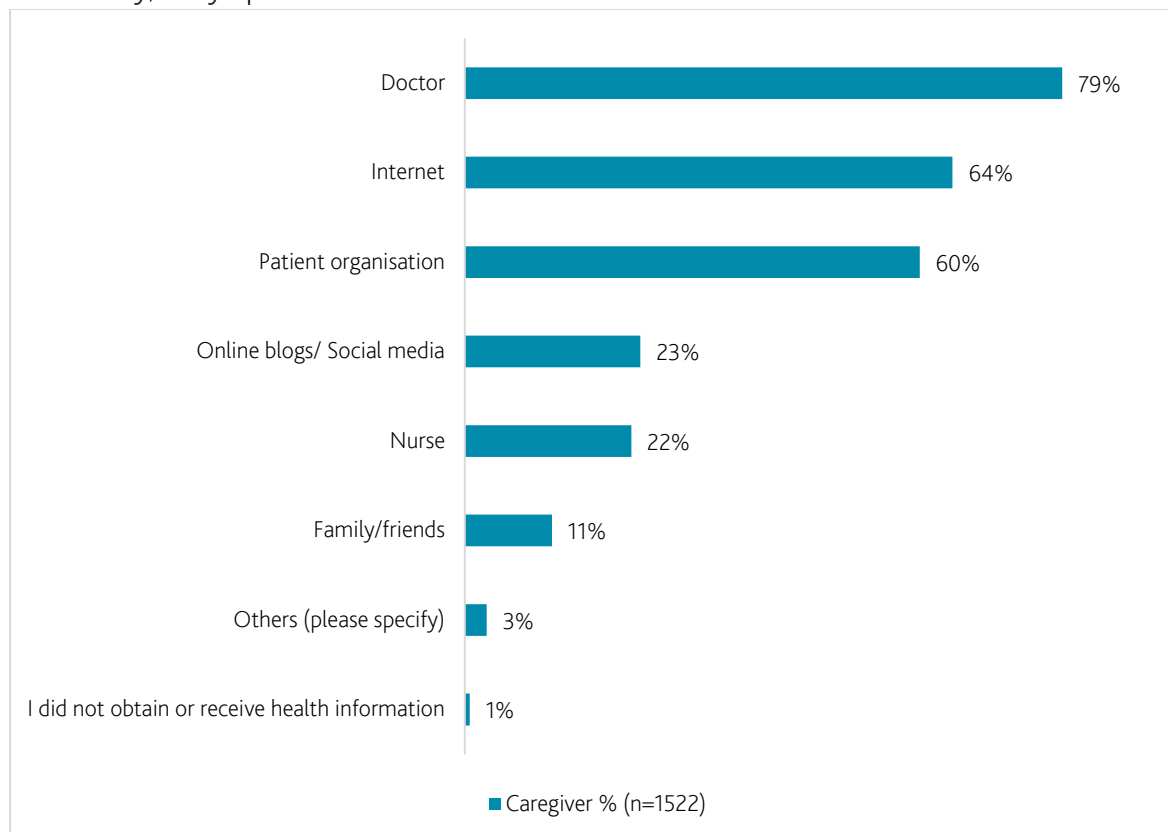


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Their top information source ranked 1st is doctors (51%), top source ranked 2nd is internet (28%) and the top source ranked 3rd is patient organization (30%).

- ❖ Figure 107 illustrates that 79% of caregivers chose doctors as their preferred source of lymphoma or CLL information

Figure 107. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?



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

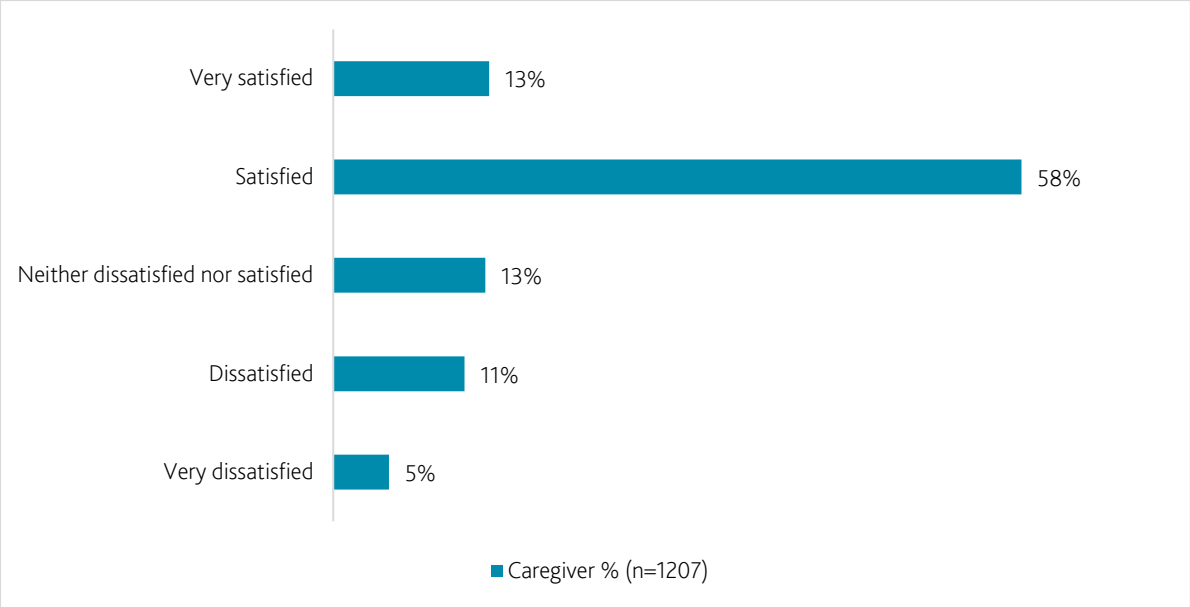
Table 5. Rank your top three sources of lymphoma or CLL information that you most prefer.

	#1		#2		#3	
	n	%	n	%	n	%
Doctor	437	51%	139	17%	167	21%
Nurse	13	2%	125	15%	37	5%
Internet	184	21%	232	28%	210	27%
Online blogs/ social media	32	4%	78	10%	88	11%
Family/friends	8	1%	25	3%	45	6%
Patient organisation	184	21%	210	26%	241	30%
Others (please specify)	7	1%	7	1%	4	1%
<b>Total</b>	<b>865</b>	<b>100%</b>	<b>816</b>	<b>100%</b>	<b>792</b>	<b>100%</b>

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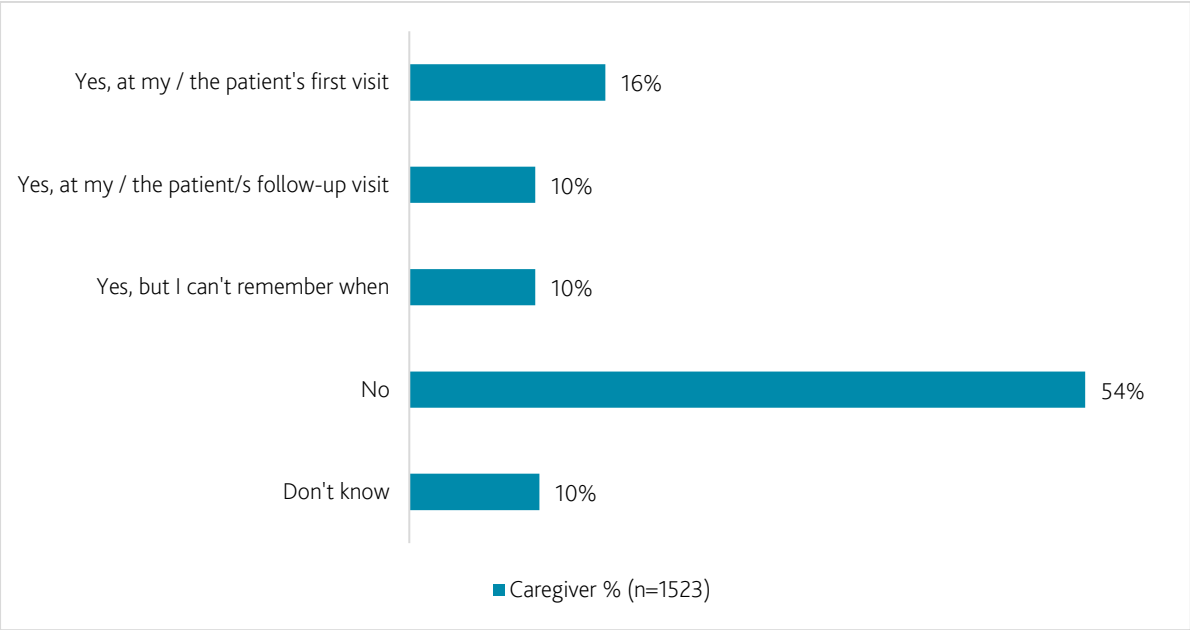
- ❖ Figure 108 illustrates that 58% of caregivers were satisfied with the information given by healthcare providers

Figure 108. How satisfied or unsatisfied are you with the information given to you by healthcare providers (for example, doctors, and nurses)?



- ❖ Figure 109 illustrates that 54% of caregivers did not receive contact details of a patient organisation, a support group and/or information produced by a patient organisation from their patient's doctor.

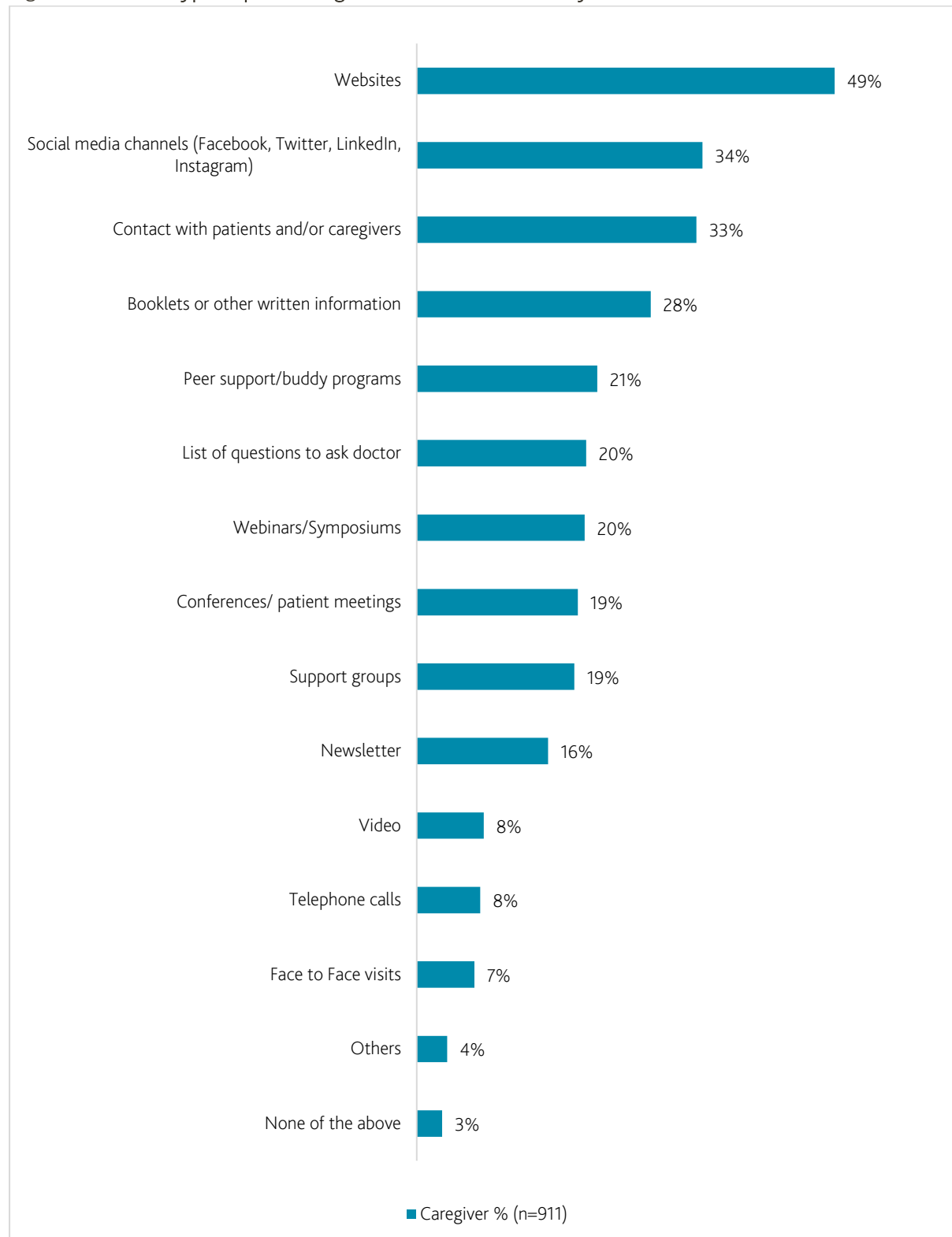
Figure 109. Did the lymphoma or CLL doctor or any member of the medical team give you the contact details of a patient organisation, a support group and/or information produced by a patient organisation?



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❖ Figure 110 illustrates that 49% of caregivers use patient organisations' websites

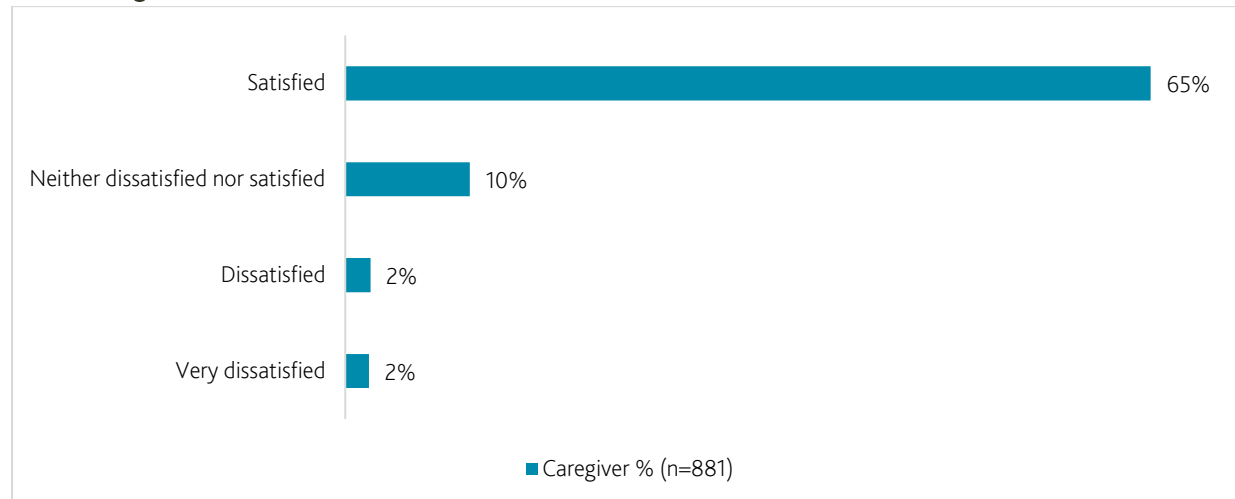
Figure 110. What type of patient organisation information do you use?



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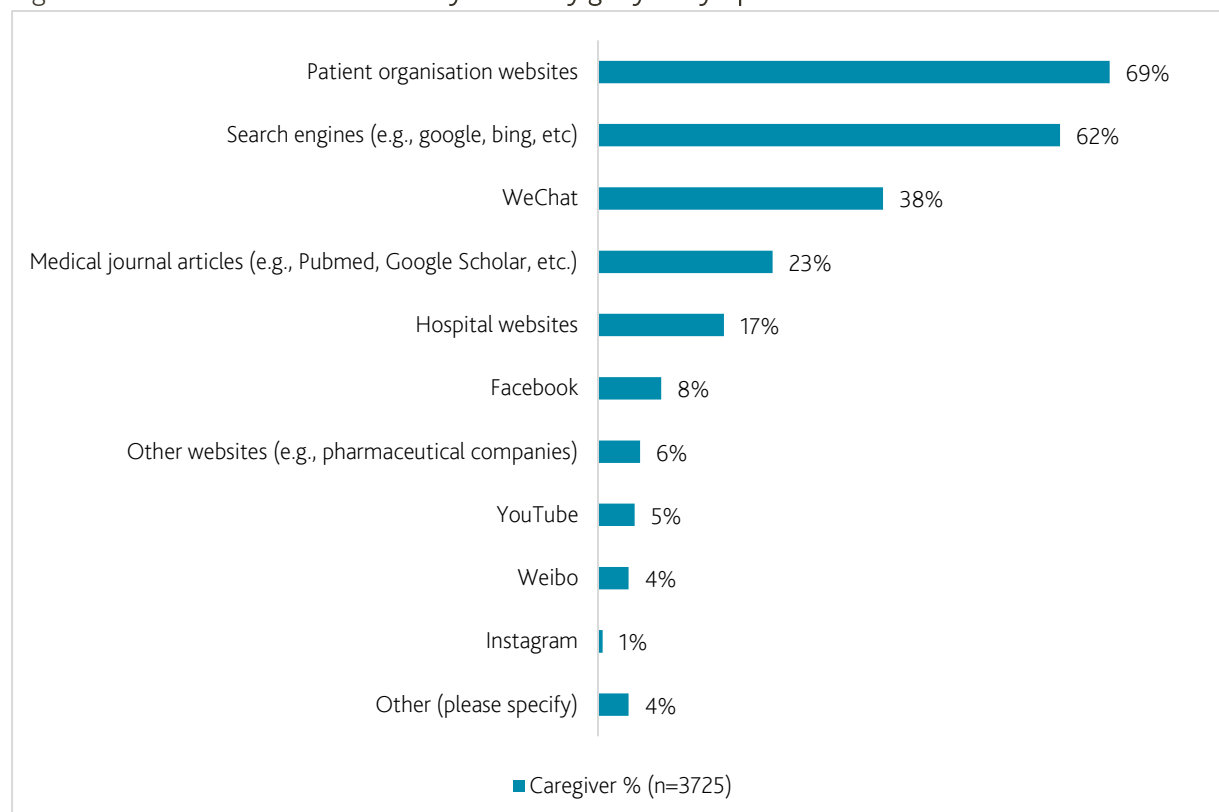
- ❖ Figure 111 illustrates that 65% of caregivers were satisfied with the information provided by patient organisations

Figure 111. How satisfied or unsatisfied are you with the information given to you by patient organisations?



- ❖ Figure 112 illustrates that 69% of caregivers use patient organisation websites on the internet to get lymphoma or CLL information

Figure 112. Where on the internet do you usually get your lymphoma or CLL information from?



Websites (17%), social media channels (13%), and booklets or other written information (13%) were the top sources of information ranked 1.

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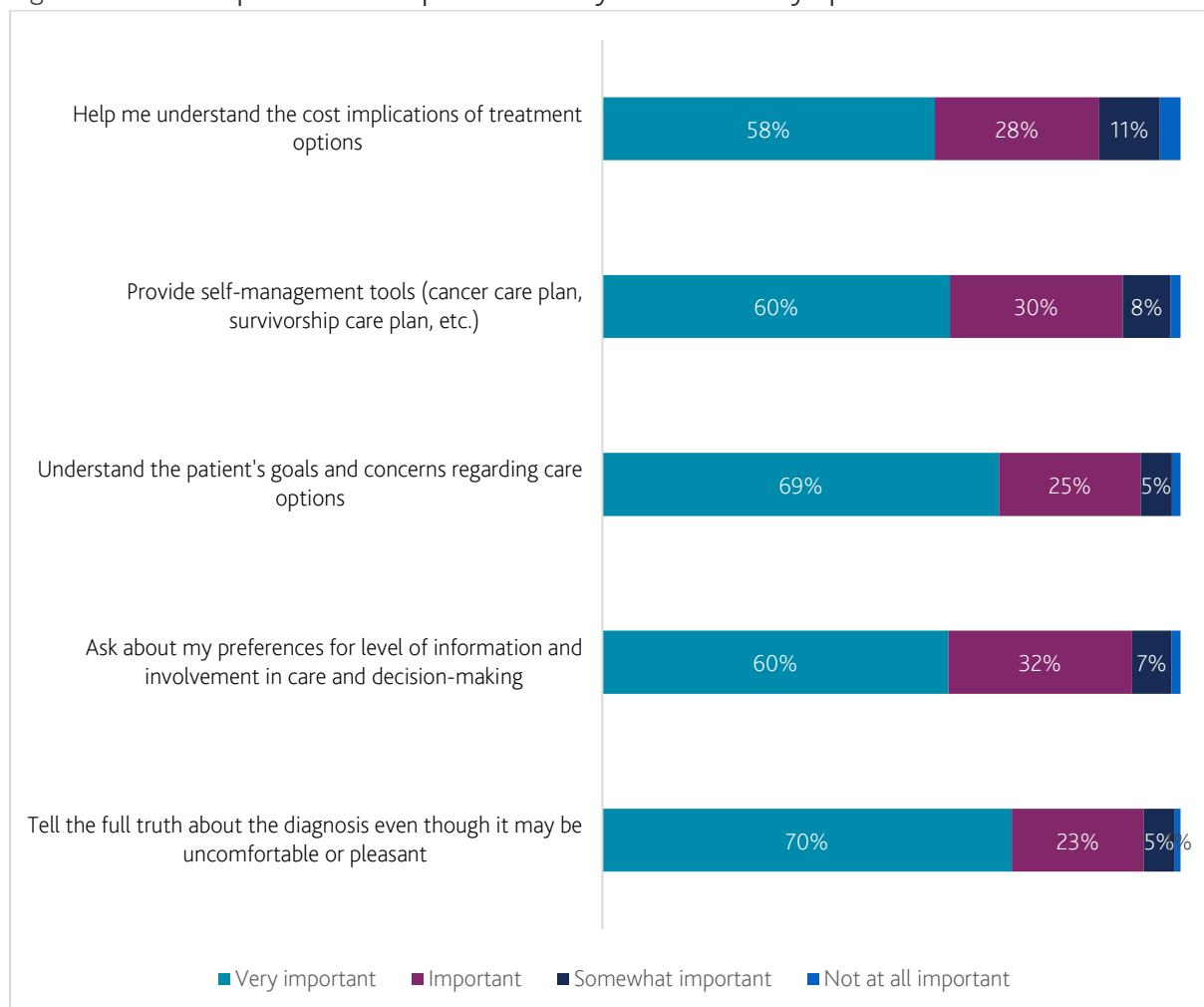
### Healthcare Involvement and Decision Making



- For 93% of caregivers, it is important or very important that the lymphoma doctor tell them the full truth about the diagnosis even though it may be uncomfortable or unpleasant.
- For 92% of caregivers, it is important or very important to know that doctors ask them about their preferences for the level of information and involvement in care and decision making.
- 59% of caregivers think that for the final decision about a patient's healthcare, doctors, patients and caregiver or family are jointly should be involved in the final decision.

❖ Figure 113 illustrates that 69% of caregivers felt that it is very important for the lymphoma or CLL doctor to understand their goals and concerns regarding care options.

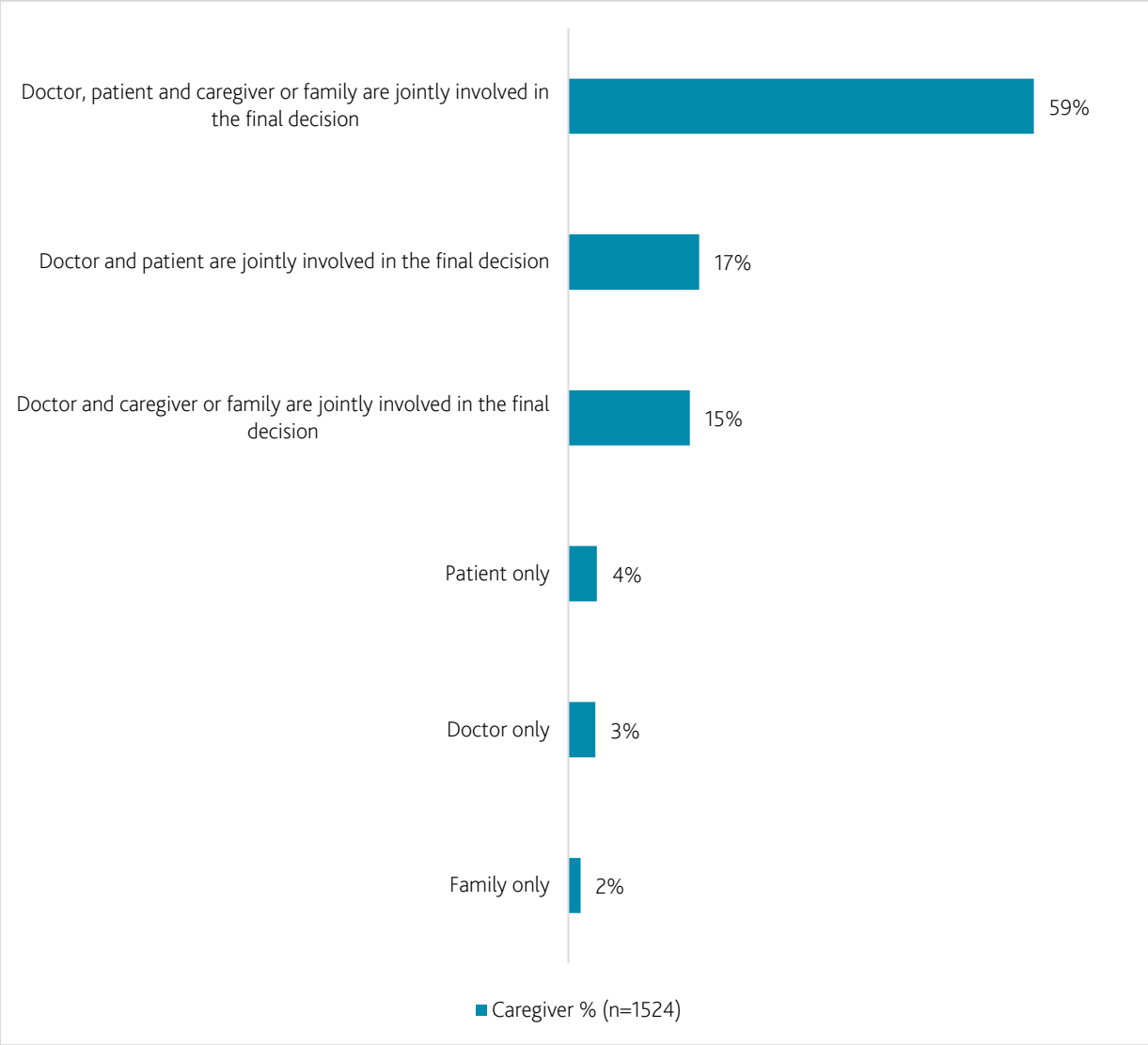
Figure 113. How important or unimportant is it to you to have the lymphoma or CLL doctor?



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- ❖ Figure 114 illustrates that 59% of caregivers felt that the doctor, patient and caregiver or family should be jointly involved in the final decision on healthcare.

Figure 114. Who would you like to make the final decision on the patient's healthcare?



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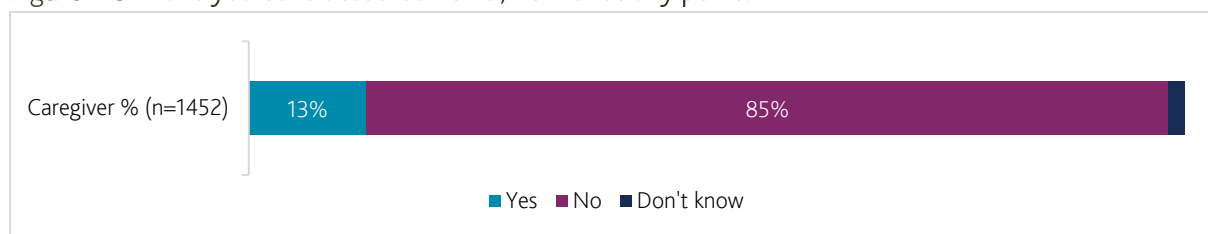
### Covid-19 Concerns and Virtual Care



- 13% of caregivers had contracted Covid-19, at some point before or during the survey
- 42% of caregivers had been fully vaccinated and taken a booster dose, while 18% were not vaccinated and not planning to get vaccinated
- 69% of caregivers considered the patient at high risk for contracting Covid-19 and experiencing illness from Covid-19, and that it worries them

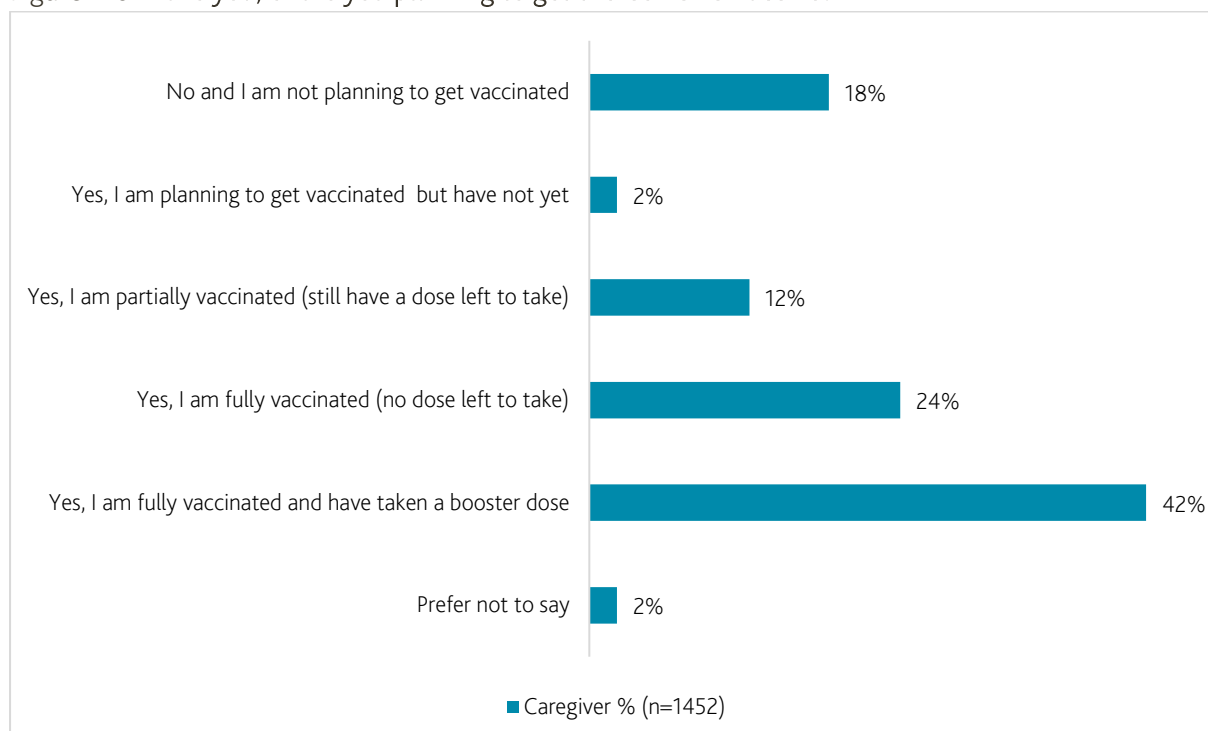
❖ Figure 115 illustrates that 85% of caregivers had not contracted Covid-19 at any point

Figure 115. Have you contracted Covid-19, now or at any point?



❖ Figure 116 illustrates that 42% of caregivers were fully vaccinated and had taken a booster dose

Figure 116. Have you, or are you planning to get the Covid-19 vaccine?

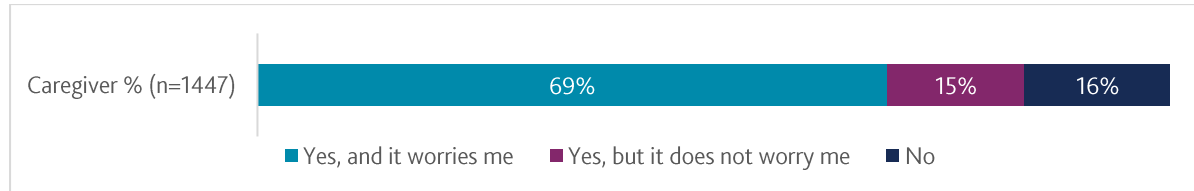




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- ❖ Figure 117 illustrates that 69% of caregivers considered their patients as high risk for contracting Covid-19 and it worries them

Figure 117. Do you consider the patient at high risk for contracting Covid-19 and experiencing severe illness from Covid-19?



- ❖ Figure 118 illustrates that 40% of caregivers felt that devotion to hobbies has been helpful in providing support regarding the impact of Covid-19 lymphoma or CLL

Figure 118. 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.

