

# Lymphoma Coalition

## 2020 Global Patient Survey on Lymphomas & CLL

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A report prepared for Lymphoma  
Coalition  
by Picker Institute Europe

July 2020

Regional Report

Asia-Pacific

# Lymphoma Coalition

Lymphoma Coalition (LC) is a world-wide network of lymphoma patient groups. LC was formed in 2002 and was incorporated as a not-for-profit organisation in 2010. Today, there are 83 member organisations from 52 countries.

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.

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## Picker

Picker is an international charity dedicated to ensuring the highest quality health and social care for all, always. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

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SECTION 1

## Executive Summary





## Executive Summary

Lymphoma Coalition (LC) is a non-profit organisation comprising of a world-wide network of lymphoma patient groups. LC acts as a central hub for credible, current information that is used by member groups to support patients in receiving high quality, care, and support. LC carries out research on the experience of those affected by lymphoma to highlight and bridge gaps in knowledge.

Picker is a leading international healthcare charity who carry out research to understand individuals' needs and their experiences of care. Picker were commissioned by LC to run their 2020 biennial Global Patient Survey (GPS) on Lymphomas and CLL.

In 2008, LC launched its first GPS (web-based). It has been conducted every two years since. The survey seeks to understand patient experience in lymphomas as well as the impact of treatment and care. LC and its global members use results to ensure patient voices are heard, to drive planning, actions, and support.

The survey was extensively redeveloped for 2020 and contained both a patient and caregiver version. It was available in 19 languages and was promoted via LC member organisations, scientific partners, community alliances (e.g. HNHCP, EHA, INTERLYMPH), and healthcare professionals, as well as via the LC social media and web properties.

## Results

The results in this report present the data for the Asia-Pacific region including Australia, China, Hong Kong, India, Indonesia, Japan, Lao People's Democratic Republic, Malaysia, Nepal, New Zealand, North Korea, Philippines, Singapore, South Korea, Tonga, Turkey, and Vanuatu.

Overall number of completed responses **4,744** made up of:



**3,021** Patients



**1,723** Caregivers

## Demographics

The demography of survey respondents is displayed in Figures 1-4:

Figure 1: Sex of patients

Please describe your experience with lymphoma, including CLL.  
3021 Responses



Figure 2: Gender of caregivers

Please describe your experience with lymphoma, including CLL.  
1723 Responses

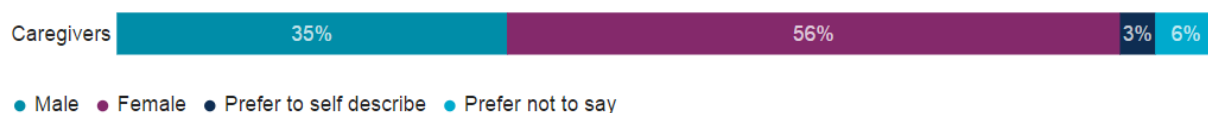


Figure 3: Age of patients and caregivers

Please describe your experience with lymphoma, including CLL.  
4740 Responses

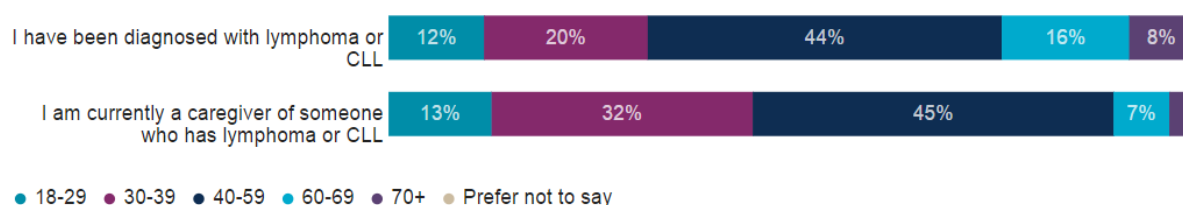
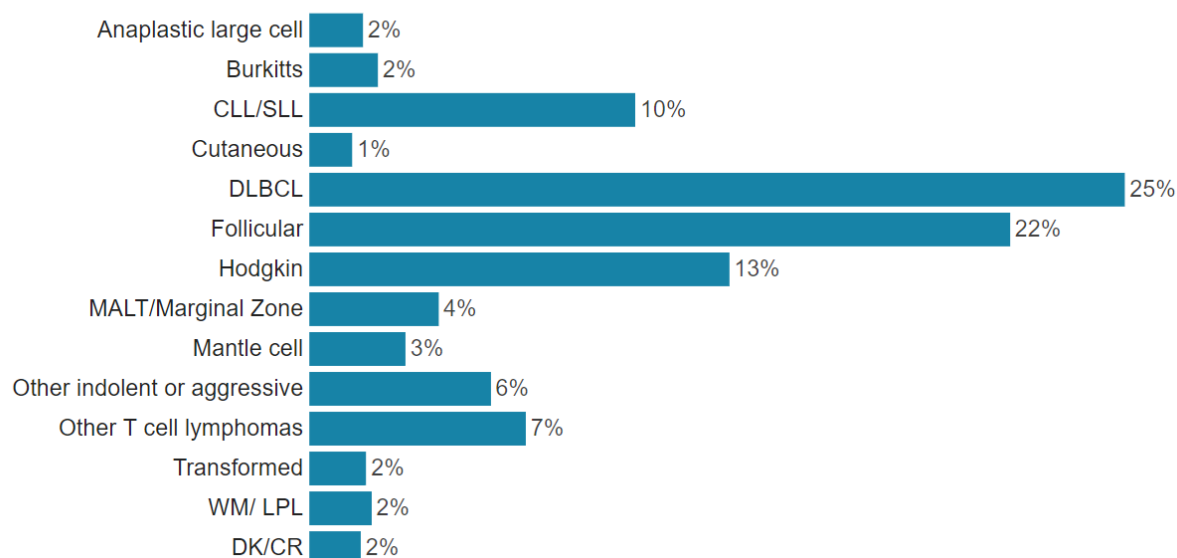


Figure 4: Subtype by patients and caregivers

Patient subtype (grouped)

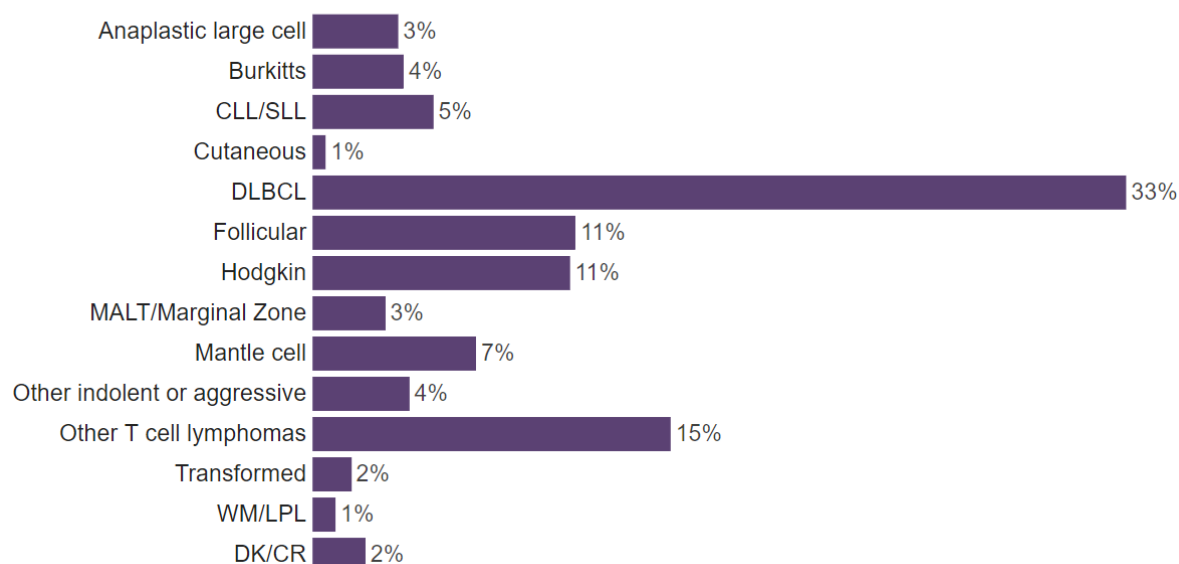
3021 Responses



*Abbreviations: CLL/SLL- chronic lymphocytic leukaemia/small lymphocytic lymphoma; DLBCL- diffuse large B cell lymphoma; MALT- mucosa associated lymphoid tissue; WM/LPL- Waldenström's macroglobulinaemia/lymphoplasmacytic lymphoma; DK/CR- don't know/can't remember*

Caregiver subtype (grouped)

1723 Responses



*Abbreviations: CLL/SLL- chronic lymphocytic leukaemia/small lymphocytic lymphoma; DLBCL- diffuse large B cell lymphoma; MALT- mucosa associated lymphoid tissue; WM/LPL- Waldenström's macroglobulinaemia/lymphoplasmacytic lymphoma; DK/CR- don't know/can't remember*

Some key findings from the patient survey are as follows:

## Patient information, guidance, and support



74% of patients were told their lymphoma subtype at diagnosis.



Only 28% strongly agree that they have good conversations with their doctor about care and treatment plans.



Only 37% of patients were informed and completely understood how to manage side effects of treatment.



49% are definitely involved as much as they want to be in decisions about their care and treatment.



48% of patients felt they were not given enough information around the time of diagnosis.



68% of patients reported they needed more information about treatment options.

## Effects of diagnosis and treatment



Fatigue was the most commonly reported **symptom of lymphoma/CLL** (54%).



Hair loss was the most commonly reported **side effect of treatment** (72%).



Over half of patients (52%) agree or strongly agree that their treatment-related side effects negatively impact on everyday activities people their age can normally do.



50% of patients indicated they had experienced fear of cancer relapse as a result of their lymphoma diagnosis.



Only 35% of patients who discussed their fear of cancer relapse with their doctor, reported that the doctor was definitely able to help.



45% of patients use exercise programs to help them with their fear of cancer relapse.

## Barriers to treatment



30% of patients reported that financial difficulties have prevented them from receiving treatment.



41% of patients reported that never being presented with an opportunity to take part was a barrier to being in a clinical trial.



Patients living in suburban areas were less likely to report that financial difficulties prevented them from receiving treatment (13%) than patients living in urban (32%) or rural areas (42%).



Only 12% of patients are currently, or have been, in a clinical trial for their lymphoma or CLL.

More detailed findings from the survey can be found in the main report, and full frequency tables showing detailed responses to each survey question are available separately.

SECTION 2

## Background



## Background

Lymphoma Coalition (LC) is a non-profit organisation comprising of a world-wide network of lymphoma patient groups. Today, there are 83 member organisations from 52 countries. Its purpose is to create a level playing field of credible and current information around the world and to facilitate a community of lymphoma patient organisations to support efforts in helping patients with lymphoma receive the care and support needed<sup>1</sup>.

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.

Picker were commissioned by LC to run their 2020 biennial Global Patient Survey (GPS) on lymphomas and CLL.

Picker is an international charity dedicated to ensuring the highest quality health and social care for all, always. We conduct research to understand patient care needs and experiences, and are here to:

- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

Our expertise covers all stages of research from design, sampling and questionnaire development to execution, analysis, and reporting. Our Principles of Person-Centred Care are an internationally recognised quality improvement framework that we use to produce actionable, insightful results. We empower our partners to act upon their results to deliver the highest quality person centred care for all, always.

## What is the Global Patient Survey?

LC launched its first Global Patient Survey (web-based) on lymphomas and CLL in 2008. Since then, it has been conducted every two years. The survey seeks to understand patient experience in lymphomas as well as the impact of treatment and care, and LC and its global members use results to ensure patient voices are heard and to drive planning, actions, and support.

The last Global Patient Survey went live in January 2018 and closed in March 2018. It was available online in 19 languages. It was hosted on a third-party portal (Question Pro). The Institute of Applied Biosciences at The Centre for Research and Technology Hellas (INAB | CERTH), Thessaloniki, Greece,

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<sup>1</sup> <https://www.lymphomacoalition.org/news-and-events9/world-lymphoma-awareness-day-2019>

performed the analysis and wrote the reports. Overall, 6631 patients responded from all over the world.

The data was used in the following abstracts, reports, and campaigns, as well as in many presentations to healthcare professionals and others who play a role in the care of people affected by lymphoma:

- LC (2018) Global Survey Reports<sup>2</sup>
- LC Healthcare Matters Reports and Subtype Reports<sup>3</sup>
- Abstracts<sup>4</sup> (Dren, Warwick & Bamigbola, 2019; Bamigbola, Dren, & Warwick, 2019; Warwick, Dren & Bamigbola 2019; Dren, Warwick, Van Rassel, Moysiadis, Karamanidou, & Xochelli 2018).
- Scientific Posters (Appendix 1)
- World Lymphoma Awareness Day (WLAD)<sup>5</sup>

In addition, the survey results were instrumental to the development of the LC 5-year strategic plan.

This report outlines the methods and results from the 2020 survey, overseen by Picker on behalf of LC.

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<sup>2</sup> <https://www.lymphomacoalition.org/global-information/global-patient-survey/2018>

<sup>3</sup> <https://www.lymphomacoalition.org/global-information/feature-articles/healthcare-matters:https://www.lymphomacoalition.org/lymphomas/lymphoma-subtypes/subtype-reports/dlbcl-report>

<sup>4</sup> Dren, N., Warwick L. & Bamigbola, O. (2019). A cross-sectional study examining the effects of patient information level on healthcare experience in 2 patient populations: Extranodal natural killer t-cell lymphoma (ENKTL) and Waldenstrom Macroglobulinemia (WM). *Blood*, 134(Suppl 1), 3422; Bamigbola, O., Dren, N. & Warwick, L. (2019). A cross-sectional study of unmet needs of lymphoma patients in patient-doctor communication: Follicular lymphoma (FL) and diffuse large B-cell lymphoma (DLBCL); *Blood*, 134(Suppl 1), 4718. Warwick, L. E., Dren, N. M. & Bamigbola, O. A. (2019). A cross-sectional study examining how knowledge of lymphoma subtype affects the patient experience. *Hematological Oncology*, 37(S2), 543-544; Dren, N., Warwick, L., Van Rassel, K., Moysiadis, T., Karamanidou, C., & Xochelli, A. (2018). Correlation of lymphoma patient information level with healthcare experience. *Blood*, 132(Suppl 1), 4782.

<sup>5</sup> <https://www.lymphomacoalition.org/news-and-events9/world-lymphoma-awareness-day-2019>



SECTION 3

## Methodology



# Methodology



## Survey 2020 Development and Launch

The survey underwent significant amendment between 2018 and 2020. It was redesigned via consultation between Picker, LC, and its members. The survey included the following themes:

- Patient information, guidance, and support, including:
  - Information provision (at diagnosis and with ongoing care)
  - Patient experience of diagnosis
  - Patient understanding of their condition and treatment
  - Patient confidence
  - Health behaviours and costs to healthcare system
  - Healthcare decision-making
  - Communication with healthcare professionals
- Symptoms of diagnosis and treatment, including :
  - Side effects: lymphoma-related, treatment-related, and psychosocial issues
  - Cancer-related fatigue
  - Fear of cancer relapse
  - Impact on daily life
- Barriers to treatment

The survey also asked about demographics such as gender/sex and age, as well as time since diagnosis and lymphoma type.

In addition to the patient survey, a caregiver version of the survey was made available. This focused on caregiver experiences of information provision and support, psychosocial issues including fear of relapse, and communication with healthcare professionals, as well as the impact caring has on their lives.

The survey 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. The final translations were also reviewed by native-speaking LC members. The survey was published online in the following languages:

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

Countries who had 100+ responses to the 2018 survey were given the opportunity to add up to 5 country-specific questions. These were standardised and translated and asked only to those from that

country, as well as reported only in those country specific reports. The survey was cognitively tested by two respondents living with lymphoma, and a number of minor text amends were made to improve the survey following this. The cognitive testers were recruited by LC. Materials to promote the survey were created by LC and shared via the LC web and social properties, member organisation networks, healthcare professionals and other scientific and community alliance partners (e.g. EHA, HNHCP, INTERLYMPH).

The survey was published and made live on 13 January 2020 and was hosted online until 13 March 2020.

The survey fieldwork timing was close to the coronavirus pandemic, mainly the outbreak in Asia was happening during fieldwork, with it emerging in Europe towards the very end of fieldwork. This might have influenced response rates, and there may have also been an impact on how people responded to the survey questions. The worldwide pandemic and government restrictions are likely to influence people's perceptions – for example of the available healthcare, how it is delivered, interactions with healthcare professionals, etc.

## Analysis and Reporting

The data were categorised and visualised into frequency tables and charts within Qualtrics, before being explored into reports for researcher interpretation and commentary. No statistical analysis was performed and therefore any reported differences cannot assume statistical significance. Cross-tabulations investigated patterns in care experiences between patient demographics; treatment type and lymphoma subtype; treatment payment source by country or region; and effects of lymphoma treatment. Cross-tabulations were also used to investigate patterns between caregiver experience and treatment type, subtype, stage of treatment and relationship to patient.

Where there were over 100 patient responses from a particular country, a country-specific report was written. This was the case for 18 countries. Missing data has been removed from the base sizes before reporting. For the demographic information, both patients and caregivers data are shown side by side. When reporting on the main survey the patients and caregivers data has been reported in different sub-sections. Country specific questions are only shown in the country specific reports.

Please note that results are only reported where there are 20 or more survey responses (per question). For any sub-group analyses (e.g. by lymphoma subtype, gender, or age group), data is not reported on groups lower than 20 since (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 to ensure only applicable questions were presented. Furthermore, respondents had the ability to leave questions blank if they preferred not to answer. This means that the total number of respondents may fluctuate between questions. Rounding of percentages means that sometimes the total for a single-response question will be just below or just above 100%.

Please note that an anomaly was identified in patient data for South Korea (n=145 patients). For certain questions, especially questions relating to patient-doctor communication, there is a very high response for 'don't know/can't remember'. Korea Blood Disease and Cancer Association (KBDCA)

provided valuable insights about this. In Korea, many patients with lymphoma will visit large hospitals in Seoul where there is an excess of patients relative to number of doctors. Patients may only have a short time to speak with their physician, and so may not know or remember if they were informed of certain things (recall bias). Additionally, to reach more patients, KBDCA provided doctors with paper versions of the survey to administer to their patients with lymphoma. Given that physicians delivered the questionnaire directly to the patient, there was likely some response bias where patients felt uncomfortable choosing a negative response and chose rather to report 'don't know/can't remember'. This is in line with Korean culture which is sensitive to courtesy. The sample size of South Korean patients is small (n=145) compared to the total sample size of Asia-Pacific patients analysed in this report (n=3,021). However, it is worth noting this anomaly due to any potential influence it may have.

Please note the following abbreviations: CLL/SLL- chronic lymphocytic leukaemia/small lymphocytic lymphoma; DLBCL- diffuse large B cell lymphoma; MALT/MZ - mucosa associated lymphoid tissue/marginal zone; WM/LPL- Waldenström's macroglobulinaemia/lymphoplasmacytic lymphoma; DK/CR- don't know/can't remember.

SECTION 4

## Respondent Demographics



## Respondent Demographics



The results in this report are presenting the data for the Asia-Pacific region including Australia, China, Hong Kong, India, Israel, Japan, Lao People's Democratic Republic, Malaysia, New Zealand, Philippines, South Korea, and Vanuatu.

A total of 3,021 responded to the patient survey and 1,723 to the caregiver survey.

The top five countries by response number were China, Australia, New Zealand, Japan, and India – see Figure 1.

**Figure 1: Countries with 100 or more respondents (patients + caregivers)**

Responses per country  
4744 Responses



Demographic characteristics of survey respondents are detailed below. Figure 2 (a&b) displays respondent sex/gender, Figure 3 shows age group, Figure 4 presents their household status and Figure 5 presents their employment status. Figure 6 displays the area of residence of the respondents.

**Figure 2a: Sex of patients**

Please describe your experience with lymphoma, including CLL.  
3021 Responses



Figure 2b: Gender of caregivers

Please describe your experience with lymphoma, including CLL.  
1723 Responses



Figure 3: Age range of respondents

Please describe your experience with lymphoma, including CLL.  
4740 Responses

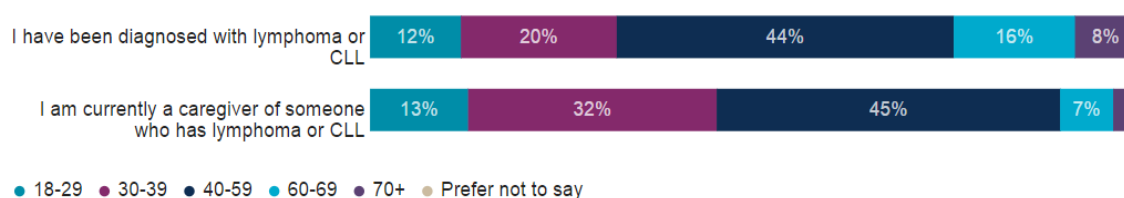


Figure 4: Household status of respondents (patients + caregivers)

Which of the following best describes your household status?  
4744 Responses

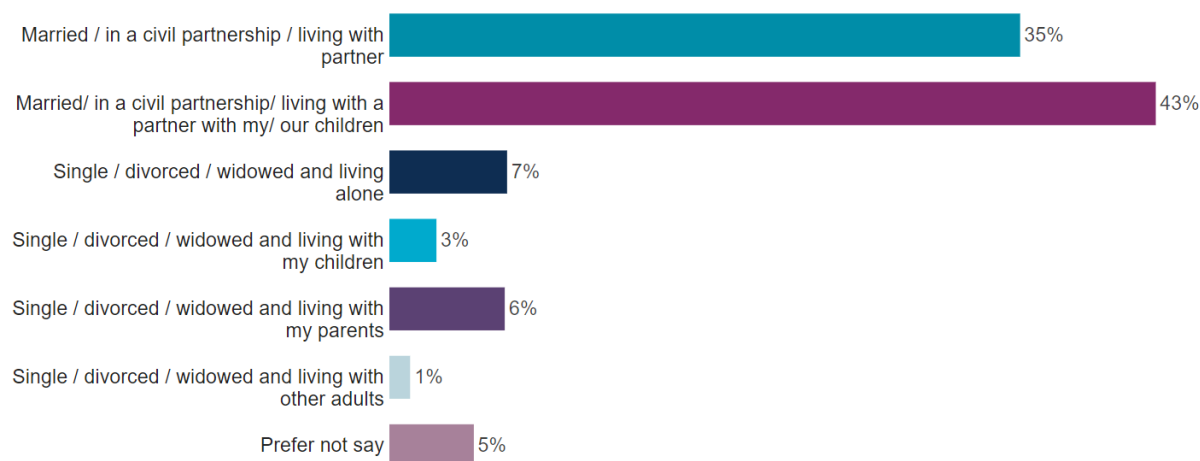


Figure 5: Employment status of respondents

Which of the following best describes your employment status?

4744 Responses

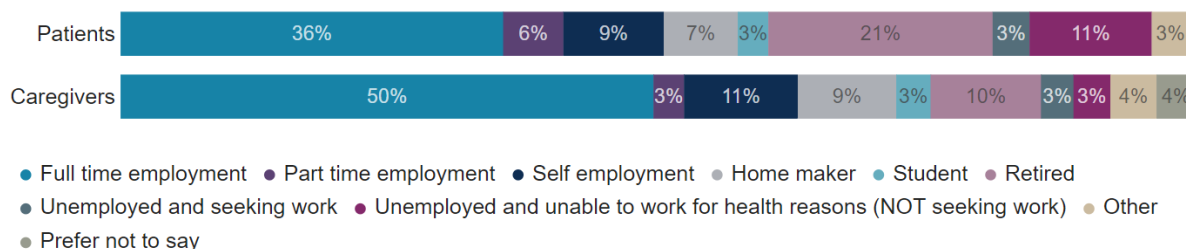
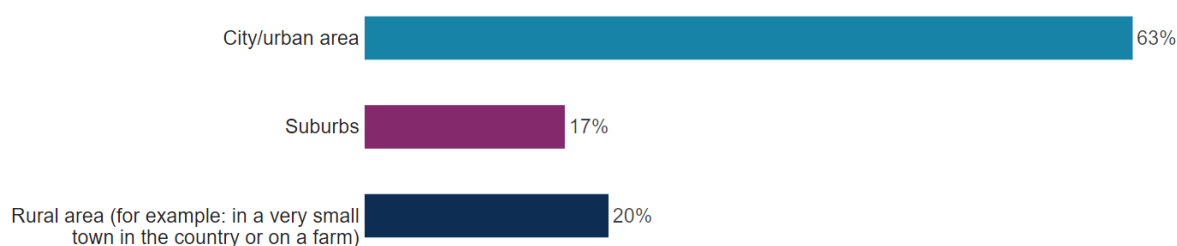


Figure 6: Area of residence of respondents (patients+ caregivers)

Which best describes the area you live in?

4744 Responses





## SECTION 5

### Results

- I. Patient Survey
- II. Caregiver Survey



## Results I. Patient Survey

This section outlines results from the patient survey. The caregiver survey data is reported in a later section of the results.

3,021 people living with lymphoma/CLL responded to the survey. The results in this section will be reported across the following areas:

- Diagnostic demographics
- Treatment demographics
- Patient information, guidance, and support
- Side effects of diagnosis and treatment
  - Effects of lymphoma
  - Effects of treatment, including fatigue
  - Psychosocial effects, including fear of cancer relapse
- Barriers to treatment

### Diagnostic Demographics

The top five countries by patient response number were China, Australia, New Zealand, Japan, and South Korea- see Figure 7.

Figure 7: Countries with 100 or more patient respondents

Responses per country  
3021 Responses



Patients were asked how long ago they were diagnosed with lymphoma or CLL, and the results are displayed in Figure 8. Over half of patients (54%) were diagnosed less than two years ago.

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

Length of time since diagnosis  
3021 Responses

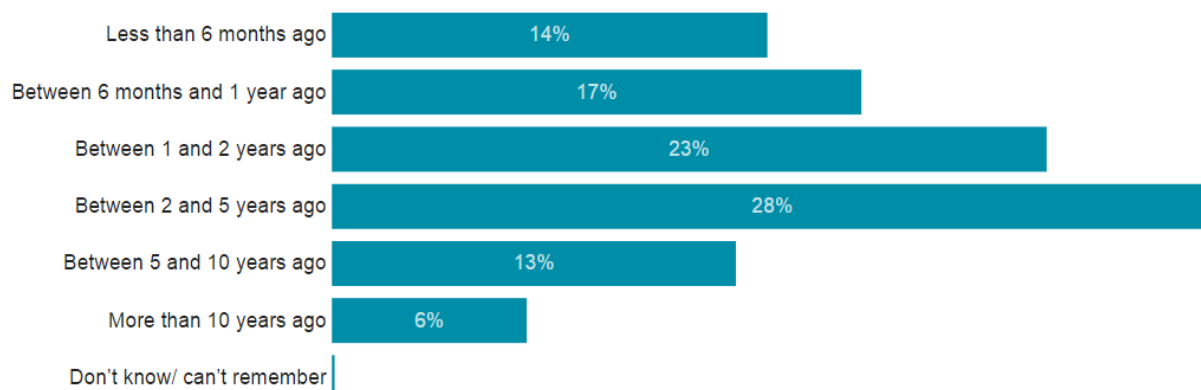


Figure 9 below shows how long patients reported waiting between their first GP appointment about their symptoms to getting a diagnosis. The majority (55%) of patients had a diagnosis within less than three months of their first appointment. However, 19% were waiting six months or more from their initial meeting with their GP.

Figure 9: How long was it since the first appointment with your GP about the symptoms you were experiencing to getting a diagnosis?

How long was it from the first appointment with your GP about the symptoms you were experiencing to getting a diagnosis of lymphoma or CLL?  
3021 Responses

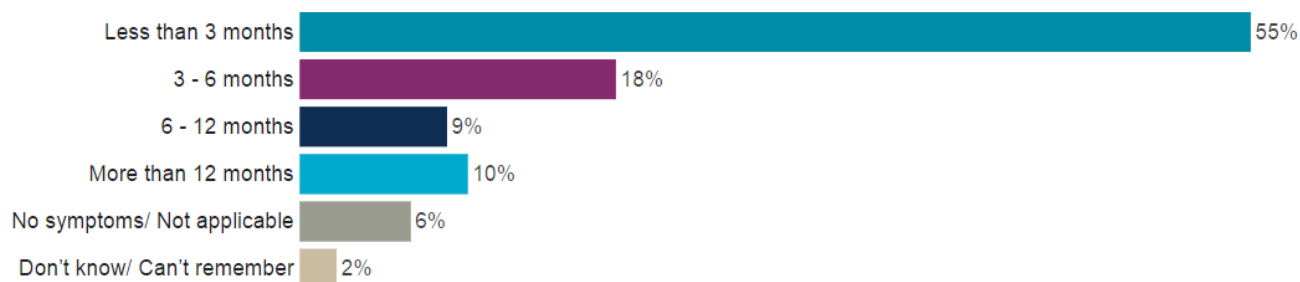


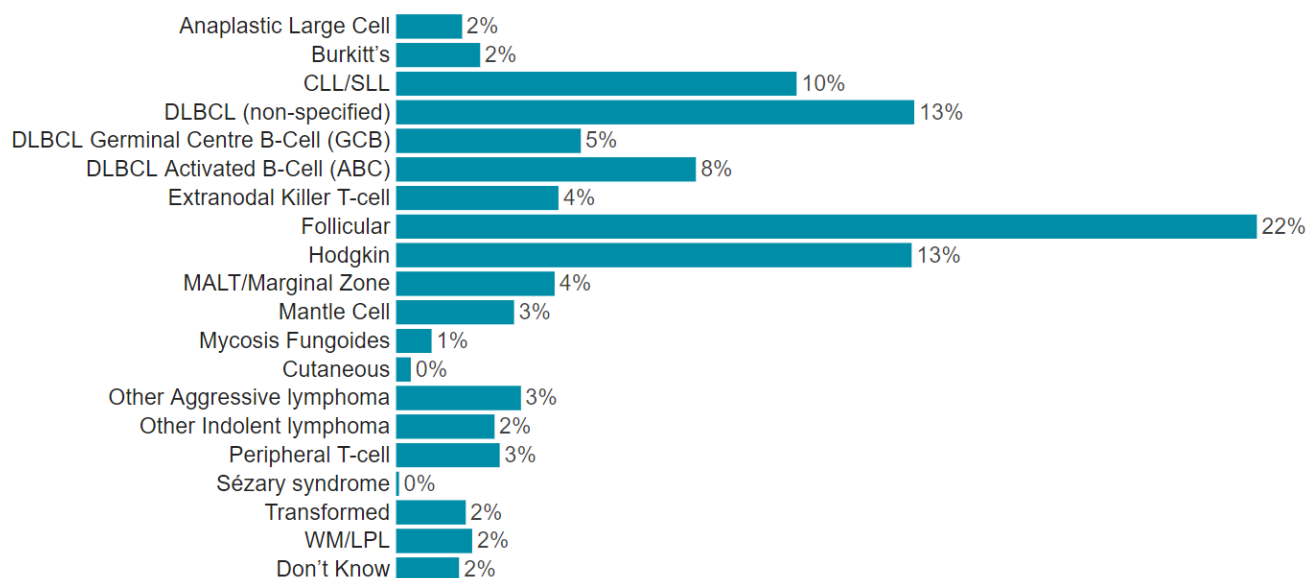
Figure 10 below shows respondent lymphoma subtype. The most common subtypes reported are:

- 22% Follicular lymphoma
- 13% Diffuse large B cell lymphoma (DLBCL not told specific type)
- 13% Hodgkin lymphoma

Figure 10: What subtype of lymphoma do you have?

What subtype of lymphoma do you have?

3021 Responses



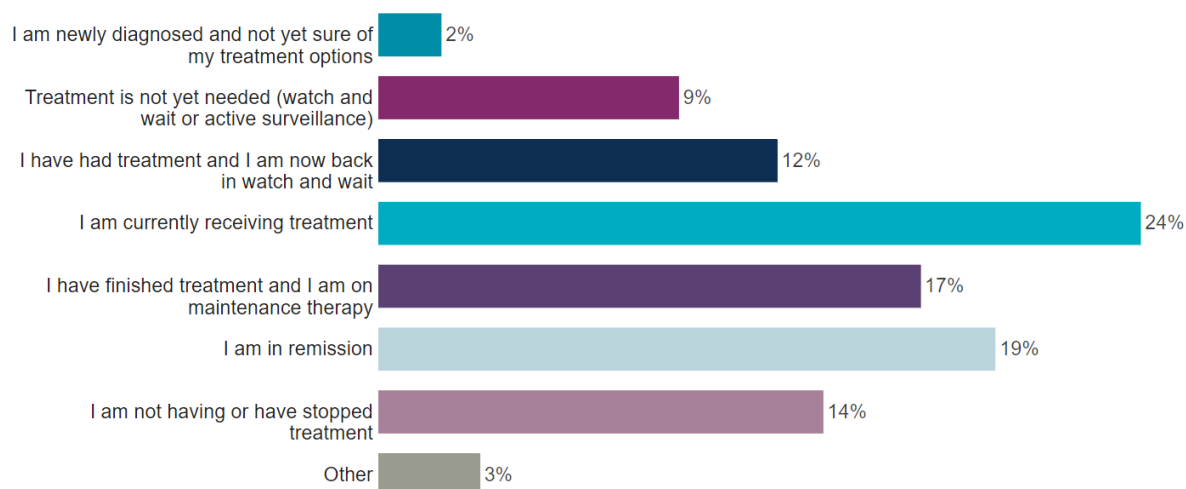
Hodgkin lymphoma was the most commonly reported lymphoma subtype in patients aged 18-29 (33%) and 30-39 (23%). For patients aged 40-59 (28%) and 60-69 (26%), the largest proportion had a diagnosis of follicular lymphoma. Patients aged 70 or over most commonly reported having a diagnosis of CLL/SLL (23%).

Survey participants were also asked about the stage of their lymphoma care pathway, and their responses are displayed in Figure 11.

24% of patients are currently in treatment, 19% of patients report that they are in remission, 17% have finished treatment and are on maintenance therapy, 14% are not having or have stopped treatment, 12% have had treatment and are now back in watch and wait, and 9% of patients report that treatment is not yet needed (watch and wait) - see Figure 11.

**Figure 11: What statement best describes where you are in the lymphoma/ CLL experience?**

What statement best describes where you are in your lymphoma/CLL experience?  
3021 Responses



A subset of patients were asked further questions depending on the stage of their lymphoma care pathway. Results to these questions are available in the frequency tables (see Appendix 2), and include the following:

- Patients indicating they are in remission were asked how long they have been treatment free;
- Those in watch and wait/ active surveillance were asked how long they had been in watch and wait for;
- All 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;
  - Whether their lymphoma/CLL has ever transformed.

## Treatment Demographics

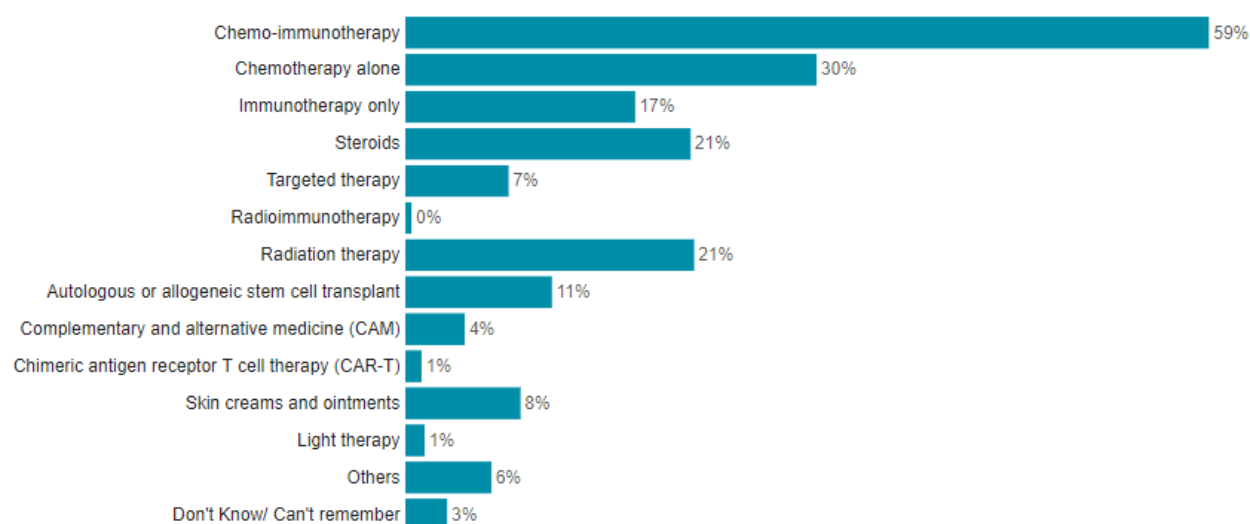
### Treatment Options

The following questions were only asked to patients who were currently on treatment or those who have ever had treatment for their lymphoma.

2348 patients reported the different treatments they are on/ or have ever been on, these can be seen in Figure 12 below.

**Figure 12: Which of the following treatment options do you receive currently, or have ever received in the past?**

Which of the following treatments do you receive currently, or have ever received in the past?  
2348 Responses



Subtype comparisons revealed that a larger proportion of patients with DLBCL (all types) received chemo-immunotherapy (83%) compared to other treatments. A greater proportion of patients with follicular lymphoma (79%) have also received chemo-immunotherapy compared to other treatments.

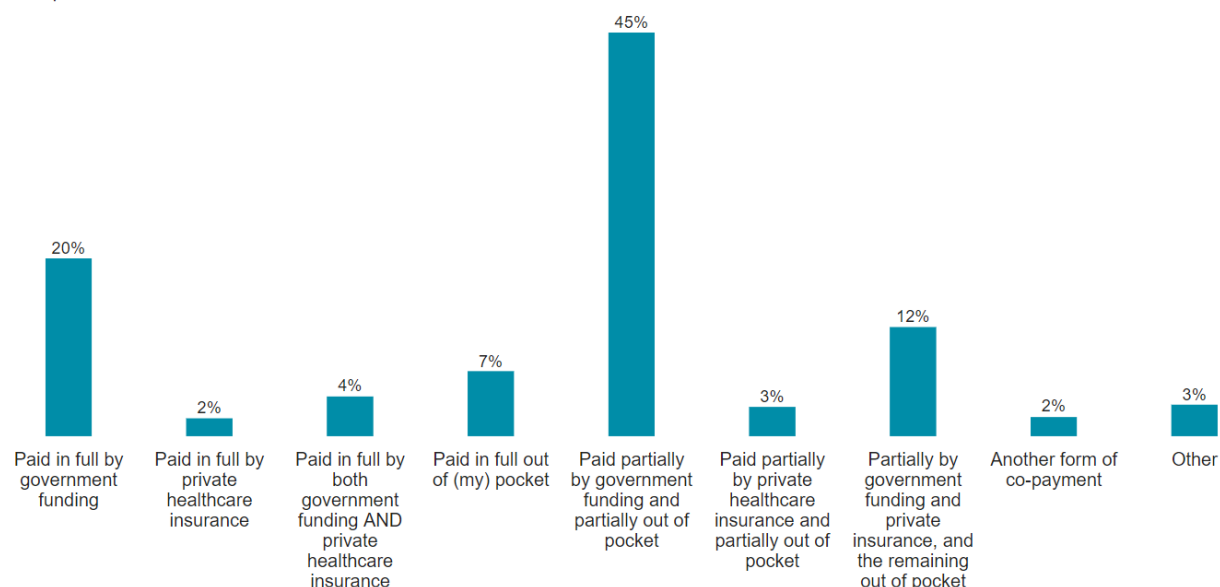
Half of patients with other T-cell lymphomas (51%) have received chemotherapy alone. The most commonly reported treatment by patients with Hodgkin lymphoma was chemotherapy alone (83%).

Additional survey questions were asked about treatments including how these were administered. Results for these questions are available in the frequency tables (see Appendix 2).

In regard to payment of treatment, almost half of patients (45%) selected that their chemotherapy/immunotherapy/chemo-immunotherapy is paid for partially by government funding and partially out-of-pocket - see Figure 13.

Figure 13: Who pays for your chemo-immunotherapy, your chemotherapy (only) or your immunotherapy (only) treatments?

Who pays for the chemo-immunotherapy/ chemotherapy alone or the immunotherapy only?  
2066 Responses



39% of patients reported that targeted treatment is paid for partially by government funding and partially out-of-pocket, and 30% report it is paid for in full out-of-pocket.

77% of patients reported that complementary and alternative medicine (CAM) is paid for in full out of their own pocket.

Only 12% of patients are currently or have previously been in a clinical trial for their lymphoma or CLL.

## Patient Information, Guidance and Support

The previous LC (2018) Global Patient Survey 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.

In the previous LC (2018) Global Patient Survey, it was evident that many patients left their initial diagnosis meeting with a poor understanding of many aspects of their treatment and care plan going forward. This can negatively impact many areas of their patient experience (i.e. communication with the doctor, adherence to treatment, psychosocial issues). Access to credible timely information is an important aspect to a successful patient experience.

Clear information, communication and support for self-care are important aspects of person-centred care<sup>6</sup>. This section therefore focuses on survey results relating to these areas of care.

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



- 85% of patients reported that it was clear they had been given a diagnosis of cancer when receiving their lymphoma diagnosis. 74% of patients reported they were told their lymphoma subtype at diagnosis.
- Patients were asked how they felt about the amount of information they received upon diagnosis – 48% were not given enough information. 68% of patients reported they needed more information about treatment options, and 57% required more information about the side effects from treatment.
- 92% and 86% felt that they had enough support from family/friends and from doctors, respectively. However, almost a quarter of patients (23%) felt that they did not get enough financial support.
- Almost half (48%) of patients agree or strongly agree that they feel overwhelmed by managing their health and condition.
- 28% of patients report being 'not very' or 'not at all' confident in managing their health problems day-to-day. Additionally, 39% agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help.

<sup>6</sup> <https://www.picker.org/about-us/picker-principles-of-person-centred-care/>



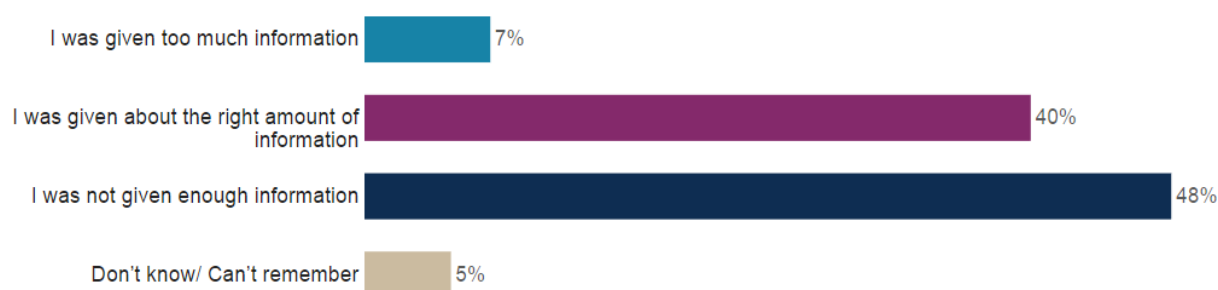
## Diagnosis

Patients were asked about their experience of receiving a lymphoma diagnosis. Those diagnosed in the last two years were asked whether it was clear they had been given a diagnosis of cancer, 85% of patients said yes. Furthermore, 74% of patients reported they were told their lymphoma subtype at diagnosis.

Patients were asked how they felt about the amount of information they received upon diagnosis – 48% were not given enough information – see Figure 14.

**Figure 14: How do you feel about the amount of information you were given around the time you were first diagnosed with lymphoma?**

How do you feel about the amount of information you were given around the time you were first diagnosed with lymphoma?  
2992 Responses



A smaller proportion of the older group aged 70+ (25%) reported not receiving enough information at diagnosis compared to the other age groups; 18-29 years (45%), 30-39 years (53%), 40-59 years (52%), and 60-69 years (44%).

Those who had been diagnosed within the last two years were asked whether they were given and understood information relating to their diagnosis and care plans. Less than 40% of patients had been given and completely understood all of the categories of information examined. Less than a third (31%) of patients were given and completely understood information on the different medical treatment options, including active surveillance (watch and wait). Only 39% of patients were provided with information on and completely understood the process and stages of care. And 37% reported they received information on and completely understood how to manage side effects of treatment. See Figure 15 for more details.

Figure 15: When first diagnosed, were you given enough information on the following:

When you were first diagnosed, were you given information on the different medical treatment options, including active surveillance (watch and wait)?

1590 Responses



When you were first diagnosed, were you given information on the process and stages of your care?

1501 Responses



When you were first diagnosed, were you given information on how to manage side effects of treatment?

1352 Responses



- Yes, and I completely understood
- Yes, and I understood a little
- Yes, but I did not understand
- No, I was not given this information
- Don't know/ Can't remember

## Patient Knowledge and Experience

61% of patients had the greatest need for information within the first month following diagnosis.

When asked about information needs:

- 68% of patients reported they needed more information about treatment options;
- 57% required more information about the side effects from treatment;
- 55% needed more information about diagnosis and what it means;
- 42% required more information about support for self-care;
- 35% of patients needed more information about psychological support/counselling;
- 23% required more information about support for their families.

67% of those with DLBCL (all types) needed additional information about treatment options. This was true for 70% of patients with follicular lymphoma and Hodgkin lymphoma. Table 1 displays the number of patients selecting each information need, by lymphoma subtype.

Age comparisons revealed that 70%–78% of patients aged 18–59 needed more information on treatment options, compared to 63% of 60–69-year-olds, and 43% of patients aged 70 or over. A higher proportion of males needed more information on treatment options (72%) than females (65%), and a higher proportion of females needed information on psychological support or counselling (39%) than males (30%).

Table 1: Which if any, have you needed information about, by lymphoma subtype.

	Which of the following, if any, have you needed more information about?																	
	Diagnosis and what it means		Treatment options		Support for self-care		Psychological support/ counselling		Support for my family		Side effects from treatment		Fertility		I have not needed more information		Total	
Anaplastic large cell	59%	29	78%	38	49%	24	41%	20	27%	13	61%	30	27%	13	2%	1	49	
Burkitts	48%	30	67%	42	40%	25	37%	23	30%	19	59%	37	30%	19	5%	3	63	
CLL/SLL	50%	152	59%	181	32%	98	27%	83	19%	59	48%	146	4%	12	9%	27	305	
Cutaneous	50%	20	70%	28	23%	9	23%	9	18%	7	43%	17	15%	6	8%	3	40	
DLBCL	57%	430	67%	507	49%	367	37%	280	25%	191	60%	450	17%	127	6%	43	756	
Follicular	55%	353	70%	451	38%	242	33%	216	19%	120	53%	341	9%	56	7%	48	645	
Hodgkin	50%	193	70%	273	43%	169	42%	165	26%	101	67%	261	30%	118	5%	19	389	
Mantle cell	52%	47	72%	65	43%	39	30%	27	21%	19	67%	60	6%	5	4%	4	90	
MALT/MZ	60%	71	78%	93	48%	57	39%	47	27%	32	55%	65	10%	12	2%	2	119	
Other indolent or aggressive	56%	94	68%	114	40%	67	34%	56	24%	40	54%	91	17%	29	6%	10	167	
Other T cell lymphomas	57%	114	76%	151	48%	95	35%	69	29%	57	63%	125	18%	36	5%	10	199	
Transformed	47%	25	62%	33	47%	25	28%	15	25%	13	62%	33	11%	6	4%	2	53	
WML/LPL	71%	41	59%	34	19%	11	17%	10	16%	9	57%	33	2%	1	10%	6	58	
Don't know/can't remember	58%	26	62%	28	51%	23	36%	16	29%	13	51%	23	9%	4	7%	3	45	

When asked to select their top three places to go for information about their healthcare, 72% said 'doctor' and 15% said 'websites' was their top place to go. Table 2 displays the number of patients selecting each source of information within their top three choices.

Table 2: Since getting your diagnosis, when you have a need for information about your healthcare, which of the following are the top places you go to first for information? You may select up to 3.

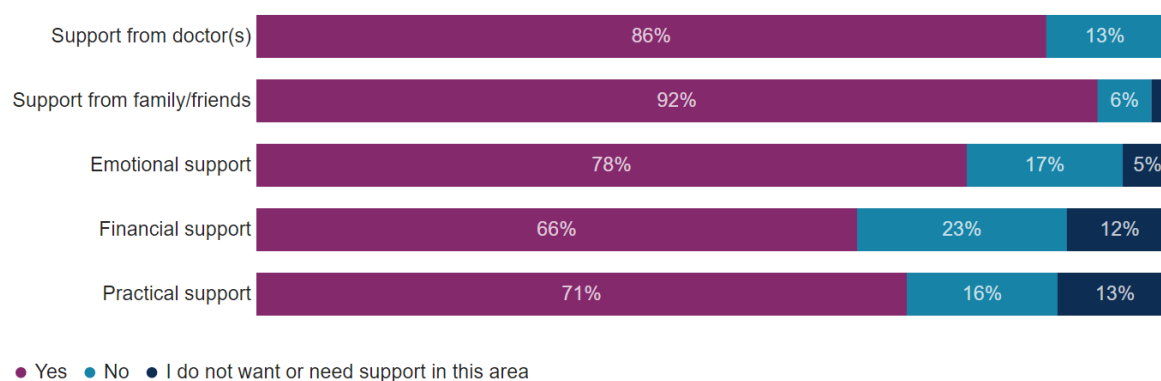
**Since getting your diagnosis, when you have a need for information about your healthcare, which of the following are the top three places you go to first for information? Please select your top choices starting with your first choice.**

	1		2		3	
Doctor	72%	2131	14%	405	8%	223
Nurse	3%	87	21%	613	7%	186
Websites	15%	448	26%	745	28%	751
Online blogs/social media	1%	31	4%	124	8%	211
Family/friends	1%	28	5%	150	8%	225
Patient organisation	7%	208	28%	812	37%	995
Other	0%	10	0%	13	4%	99
Total	100%	2943	100%	2862	100%	2690

Figure 16 displays whether patients felt they had received enough support in key areas of patient experience. 92% and 86% felt that they had enough support from family/friends and from doctors, respectively. However, 23% felt that they did not get enough financial support.

Figure 16: In general, have you received enough support throughout your patient experience in the following areas?

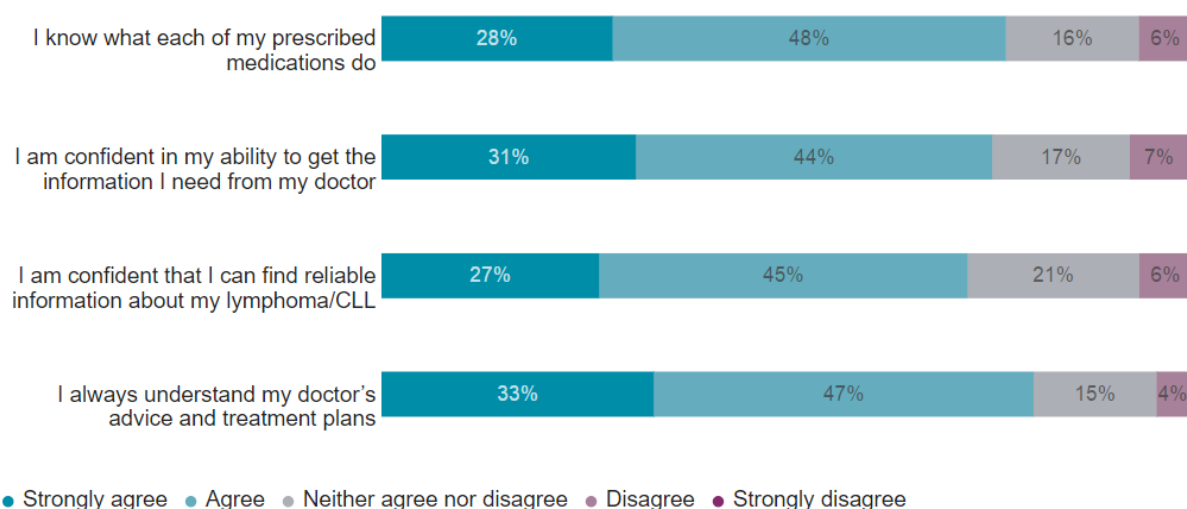
In general, have you received enough support throughout your patient experience in the following areas?  
2890 Responses



Over 70% of patients agree or strongly agree that they know what each of their prescribed medications do, that they are confident in their ability to get the information they need from their doctor, that they are confident they can find reliable information about their lymphoma/CLL, and that they always understand their doctors' advice and treatment plans - see Figure 17.

Figure 17: Thinking about your knowledge and experience of lymphoma/CLL, please indicate how much you agree or disagree with each statement:

Thinking about your knowledge and experience of lymphoma, please indicate how much you agree or disagree with each statement:  
2839 Responses



Of those patients who needed more information on treatment options, 77% also agree or strongly agree that they always understand their doctor's advice and treatment plans, compared to 94% of patients who did not have the need for any additional information.

Of those patients who needed more information on side effects from treatment, 70% also agree or strongly agree that they are confident in their ability to get the information they need from their doctor, compared to 93% of patients who did not have the need for any additional information.

Just 35% of patients who did not feel supported by their doctors throughout their patient experience agree or strongly agree that they are confident in their ability to get the information they need from their doctor. This is in comparison to 84% of patients who did feel they had enough support from their doctors. Furthermore, 46% of those who did not feel supported by their doctor, agree, or strongly agree that they always understand their doctors' advice, in comparison to 87% of those who did feel supported.

Patients who reported feeling 'very' or 'fairly' confident in managing their health problems day-to-day consistently agree or strongly agree more to each of the above statements (shown in Figure 17) than those who reported feeling 'not very' or 'not at all' confident.

Figure 18 indicates that overall, 68% of patients reported they always have confidence and trust in the doctors treating them- with a further 29% agreeing 'sometimes'.

**Figure 18: Do you have confidence and trust in the doctors treating you?**

Do you have confidence and trust in the doctors treating you?  
2769 Responses



Of 1570 (56%) patients who have seen nurses for their lymphoma care over the last year, 48% definitely feel comfortable asking nurses questions about their lymphoma/CLL (Figure 19), and 48% always have confidence and trust in the information they are given (Figure 20).

**Figure 19: Do you feel comfortable asking nurses questions about your lymphoma/CLL?**

Do you feel comfortable asking nurses questions about your lymphoma/CLL?  
1570 Responses



**Figure 20: Do you have confidence and trust in the information you get from the nurses?**

Do you have confidence and trust in the information you get from the nurses?  
1569 Responses



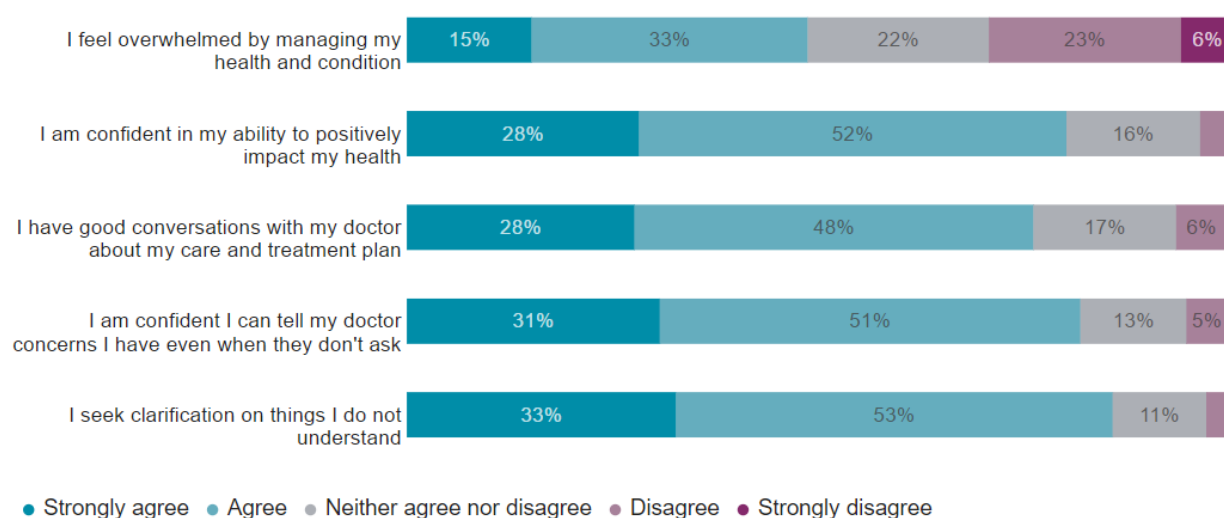
## Healthcare Decision Making

Patients were asked a series of questions about the role they play in making decisions about their healthcare – see Figure 21. 86% of patients agree or strongly agree that they seek clarification on

things they do not understand, and 82% agree or strongly agree that they are confident they can tell their doctor their concerns. However, almost half (48%) of patients agree or strongly agree that they feel overwhelmed by managing their health and condition.

**Figure 21: Thinking about your role in making decisions about your healthcare, please indicate how much you agree or disagree with each statement:**

Thinking about your role in making decisions about your healthcare, please indicate how much you agree or disagree with each statement:  
2835 Responses



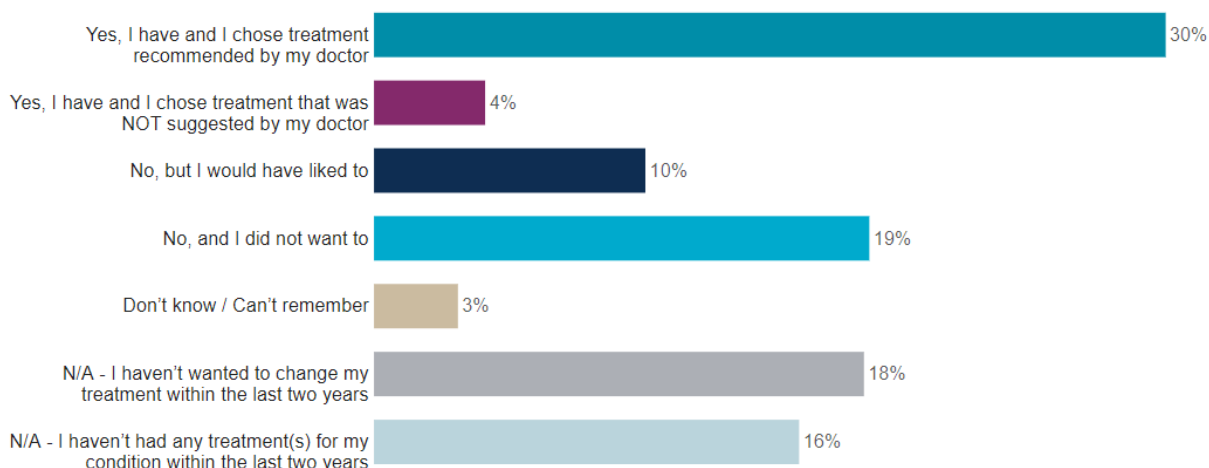
66% of patients who did not feel they had enough support from their doctor throughout their patient experience also agree or strongly agree that they are confident in their ability to positively impact their health. This is in comparison to 83% of those who did feel supported by their doctor. Additionally, just 35% of those who did not feel supported by their doctor also agree or strongly agree that they have good conversations with their doctor about their care and treatment plan, compared to 84% of patients who felt supported.

49% of patients reported they are definitely involved as much as they want to be in decisions about their care and treatment; 41% reported they are involved to some extent. 9% reported they are not involved but would like to be, and 2% reported they are not involved but do not want to be.

34% of patients who were receiving treatment or had received treatment in the past reported they had talked to their doctor about wanting to change their treatment to better meet their needs within the last two years. See Figure 22.

**Figure 22: Have you talked to your doctor about wanting to change your treatment to better meet your needs, within the last 2 years?**

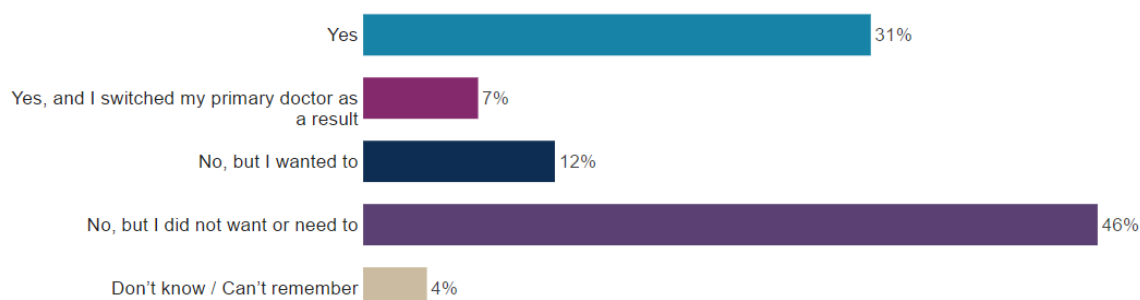
Have you talked to your doctor about wanting to change your treatment to better meet your needs, within the last 2 years?  
2429 Responses



31% of patients got a second opinion about their most recent treatment, however only 7% patients got a second opinion and changed their primary doctor as a result. 12% wanted to get a second opinion but did not, and 46% felt they did not want or need to get a second opinion- see Figure 23.

**Figure 23: Thinking about your most recent treatment, did you get a second opinion about your treatment options?**

Thinking about your most recent treatment, did you get a second opinion about your treatment options?  
816 Responses



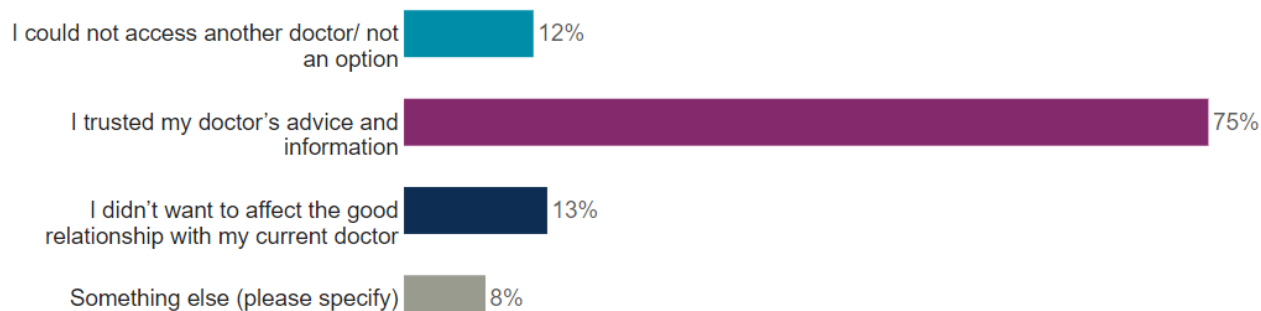
Of those patients who did not get a second opinion (see Figure 24):

- 75% said it was because they trusted their doctors' advice and information
- 13% said it was because they did not want to affect the good relationship with their current doctor
- 12% said it was because they could not access another doctor/it was not an option



Figure 24: What was the reason for not getting a second opinion?

What was the reason for not getting a second opinion?  
466 Responses

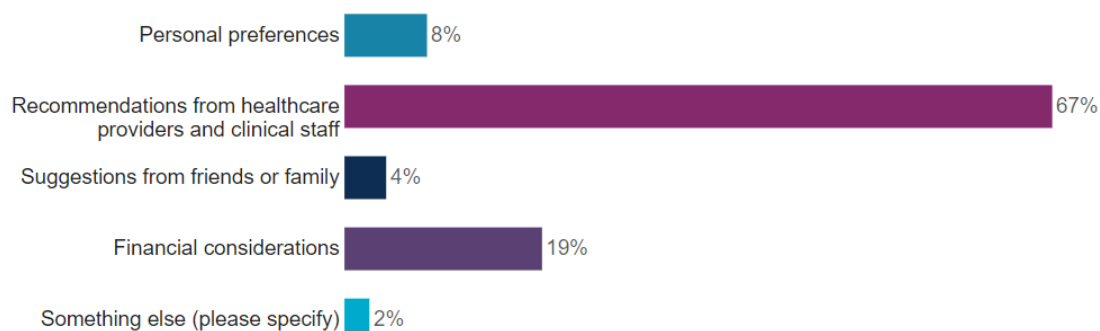


When patients were asked what they are most influenced by when making healthcare decisions, the top answers were (see Figure 25):

- 67% said recommendations from healthcare providers and clinical staff
- 19% were most influenced by financial considerations; and
- 8% were influenced by personal preferences.

Figure 25: What influences your healthcare decisions the most?

What influences your healthcare decisions the most?  
2815 Responses



When asked about the importance of a range of outcomes (see Table 3), 67% of patients ranked 'a cure' as having the most importance to them, and 22% said 'quality of life' was the most important.



Table 3: Please rate these outcomes in order of importance to you, where 1 is most important to you and 7 is least important to you. If you don't have an 'Other (please specify)' please rank as number 7.

2639 Responses

**Please rate these outcomes in order of importance to you, where 1 is most important to you and 7 is least important to you? If you don't have an 'Other (please specify)' please rank as number 7.**

	1		2		3		4		5		6		7	
A cure	67%	1760	15%	398	8%	201	4%	113	3%	76	3%	70	1%	21
Quality of life	22%	590	44%	1172	15%	401	11%	284	5%	130	2%	53	0%	9
Fewer side effects to tolerate	4%	96	26%	688	46%	1211	17%	446	6%	149	2%	42	0%	7
Treatment at home versus treatment in clinic	1%	23	3%	71	8%	216	23%	619	36%	962	25%	657	3%	91
Duration of treatment	2%	52	8%	223	18%	479	36%	957	28%	733	7%	178	1%	17
What's best for my caregiver	2%	55	2%	55	4%	110	7%	191	21%	563	59%	1565	4%	100
Other (Please specify)	2%	63	1%	32	1%	21	1%	29	1%	26	3%	74	91%	2394

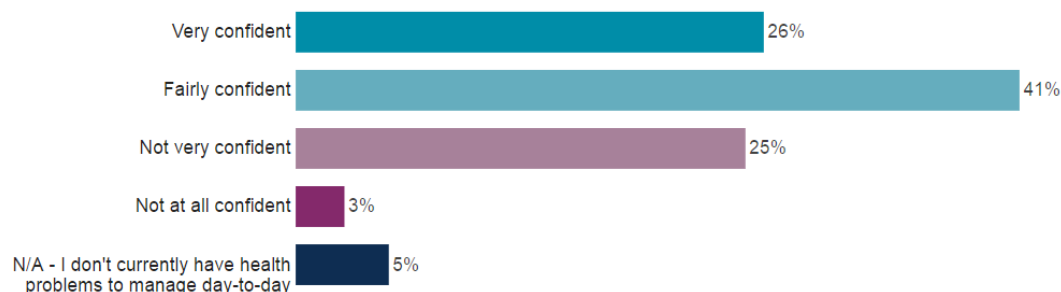
## Health Behaviours

26% of patients are 'very confident' about managing their health problems day-to-day, and 41% report they are 'fairly confident'. However 28% are 'not very' or 'not at all' confident. The full data can be seen in Figure 26.

Figure 26: How confident are you that you can manage your health problems day-to-day?

How confident are you that you can manage your health problems day-to-day?

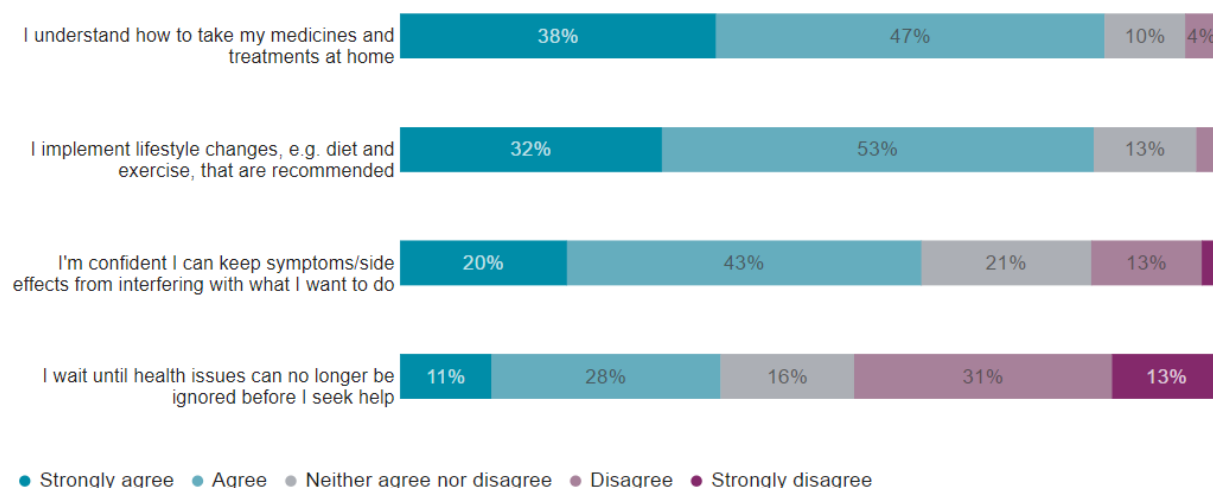
2696 Responses



Patients were asked a series of questions about how they manage their day-to-day condition. Over 60% agree or strongly agree that they understand how to take their medicines and treatments at home, that they implement recommended lifestyle changes, and that they are confident they can keep symptoms/side effects from interfering with what they want to do. However, 39% agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help. See Figure 27 for full details.

Figure 27: Thinking about how you manage your condition day-to-day, how much do you agree or disagree with the following statements?

Thinking about how you manage your condition day-to-day, how much do you agree or disagree with the following statements?  
2754 Responses



A larger proportion of males (69%) than females (59%) agree or strongly agree that they are confident they can keep symptoms/ side effects from interfering with what they want to do.

Patients who reported feeling 'very' or 'fairly' confident managing their health problems consistently agree or strongly agree more in all the statements displayed in Figure 27, compared to those who report feeling 'not very' or 'not at all' confident.

## Physical and Medical Side Effect of Diagnosis and Treatment

In understanding people's experiences of healthcare conditions, it is important to consider the symptoms and side effects of the condition and associated treatment, including the impact it has upon a person's daily life.

In the LC (2018) Global Patient Survey, cancer related fatigue was the leading physical symptom affecting quality of life reported by respondents, 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. The LC (2018) Global Patient Survey showed that changes in relationships and anxiety were the most commonly reported psychosocial issues during treatment. The survey also indicated that 43% of respondents experienced fear of cancer relapse (FCR) during treatment and 72% experienced FCR after treatment. Fear of relapse was associated with feelings of anxiety, depression, and isolation. However, these feelings were not frequently discussed with the doctor, and this was a common finding in all countries.

A consistent finding in all analysis was that patients reported they were more likely to communicate their physical and medical difficulties than their psychosocial difficulties with their doctors.

The LC (2020) Global Patient Survey reports on effects of lymphoma and treatment with particular emphasis on: fatigue, fear of cancer relapse, changes in relationships and mental health difficulties.



- The symptoms of lymphoma/CLL most reported to affect patients were fatigue (54%), abnormal painless swellings/enlarged lymph nodes (39%), and B-symptoms (33%).
- Almost half (49%) of patients report that their lymphoma/CLL symptoms have negatively impacted their social life.
- The side effects of treatments most reported to affect patients were hair loss (72%), fatigue (61%), and nausea and vomiting (55%).
- 59% of patients had definitely discussed treatment side effects with their doctor. Of these patients, only 27% reported that the doctor was definitely able to help.
- 31% of patients who did not discuss their treatment side effects with their doctor reported this was because they thought they could handle it on their own.

## Effects of Lymphoma/CLL

Some symptoms that patients experience are effects of lymphoma/CLL itself, rather than the medications used to treat it. However, these symptoms can be exacerbated by medications. The symptoms most reported to affect patients were fatigue (54%), abnormal painless swellings/enlarged lymph nodes (39%), and B-symptoms (33%) - see Table 4.

Table 4: Below are a list of symptoms that affect some people with lymphoma/CLL. Which, if any, have affected you?

2781 Responses

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

Fatigue	54%	1508
Frequent or repeated infections	13%	358
Headaches	15%	419
Shortness of breath	18%	507
Easily bruised or bleed	14%	401
Skin rashes/lesions	22%	611
Fever, chills, night sweats and weight loss (B-symptoms)	33%	918
Abnormal painless swelling(s) on the body/enlarged lymph nodes	39%	1088
Pain	25%	706
Anaemia	17%	463
No symptoms	13%	361
Other (please specify)	10%	283
Total		2781

Table 5 indicates the length of time that respondents have experienced symptoms. 50% or more of patients who are affected by B-symptoms, pain, abnormal painless swelling/enlarged lymph nodes, or shortness of breath report it has affected them for under a year. 12% of those affected by fatigue have experienced this symptom for more than five years.

Table 5: You have indicated that you have been affected by the symptoms shown below, for each symptom that has affected you, please indicate how long you have had this symptom for:

2353 Responses

You have indicated that you have been affected by the symptoms shown below, for each symptom that has affected you, please indicate how long you have had this symptom for:

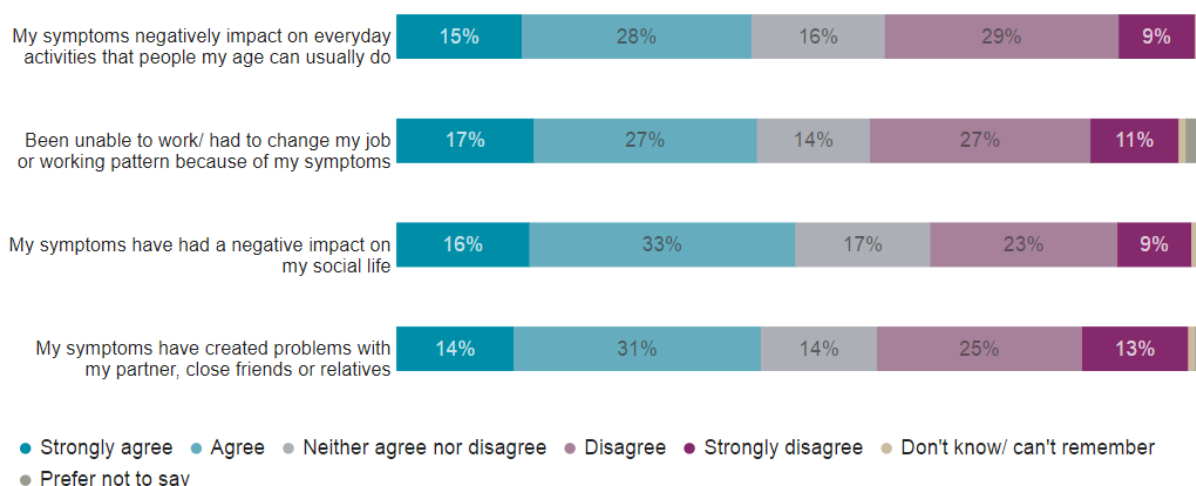
	Under a year		1-2 years		2-5 years		5-8 years		More than 8 years		Don't know/ can't remember		Total
Fever, chills, night sweats and weight loss (B-symptoms)	59%	543	17%	154	9%	85	2%	21	3%	26	9%	84	913
Pain	57%	396	19%	134	10%	67	3%	24	3%	21	8%	56	698
Fatigue	38%	565	24%	366	18%	272	6%	86	6%	89	8%	125	1503
Abnormal painless swelling(s) on the body/ enlarged lymph nodes	52%	558	18%	198	16%	171	4%	42	3%	30	8%	82	1081
Shortness of breath	50%	252	25%	124	13%	67	3%	15	4%	20	5%	26	504
Skin rashes/ lesions	46%	277	22%	134	16%	98	4%	24	6%	38	6%	35	606
Frequent or repeated infections	36%	128	24%	85	17%	59	6%	22	7%	25	10%	34	353
Anaemia	44%	199	23%	107	12%	56	2%	11	7%	31	12%	53	457
Headaches	47%	193	20%	83	12%	49	5%	22	6%	26	10%	41	414
Easily bruised or bleed	29%	117	26%	103	20%	81	7%	26	8%	33	10%	38	398

Figure 28 presents respondent views on the effects of their lymphoma/CLL symptoms. Roughly half (49%) of patients agree or strongly agree that their lymphoma/CLL symptoms have had a negative impact on their social life.

Figure 28: Thinking about the symptoms of lymphoma/CLL that affect you, to what extent, if at all, do you agree or disagree with each of the following statements? (Please select one option on each row):

Thinking about the symptoms of lymphoma/CLL that affect you, to what extent do you agree or disagree with the following:

2386 Responses

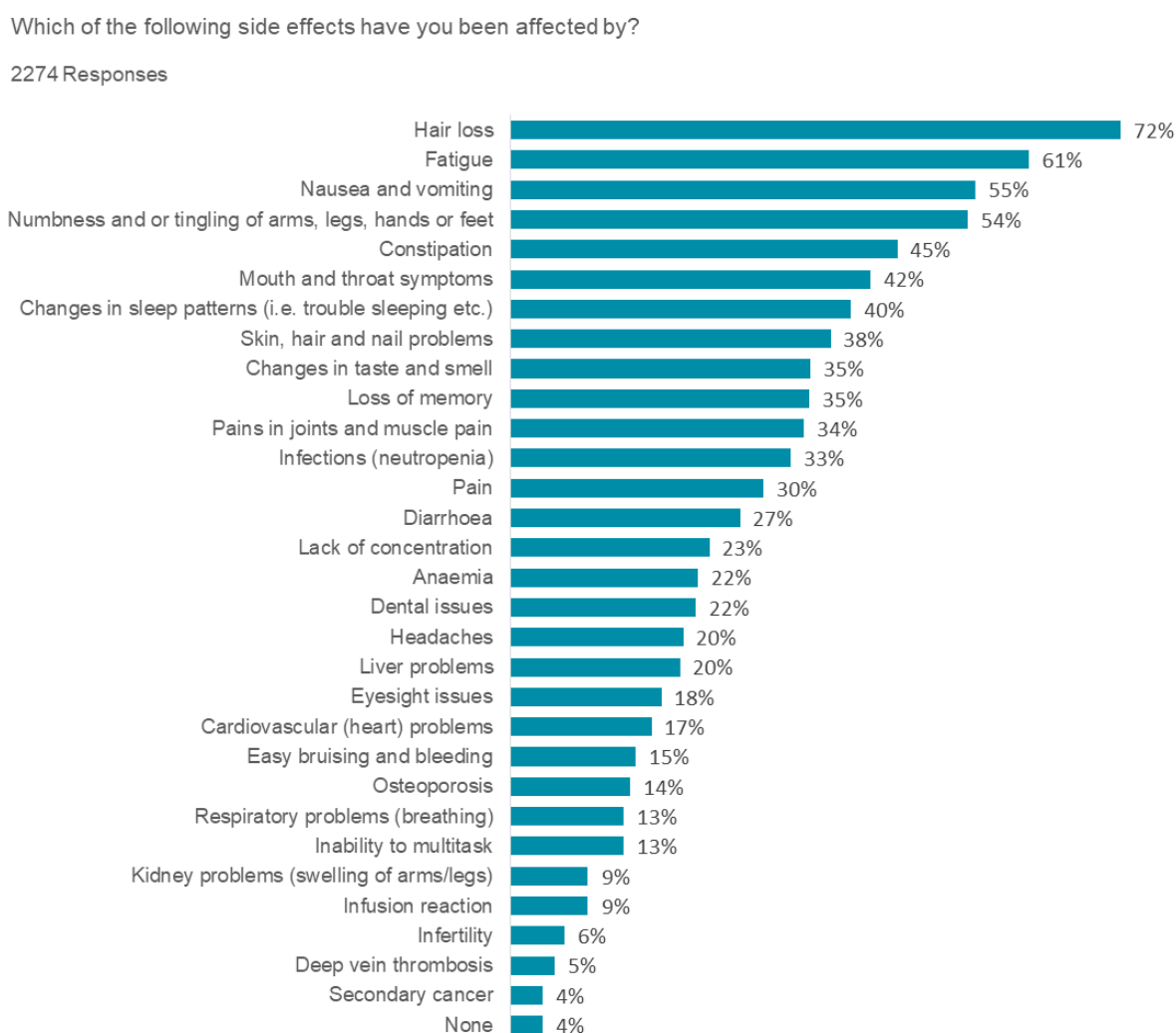


## Effects of Lymphoma/CLL Treatment

Patients who are receiving treatment for their lymphoma/CLL are affected by a range of treatment-related side effects, the most frequently are shown below. See Figure 29 for full list of reported side effects from treatment.

- Hair loss reported by 72%
- Fatigue reported by 61%
- Nausea and vomiting reported by 55%

Figure 29: Thinking now about your side effects from treatment: Which of the following side effects have you been affected by?



Patients were asked to think about all of the treatment-related side effects that affected them and to rank the top three from 1 (most affected by) to 3 (least affected by). The side effects that affected people the most (ranked 1) are:

- 18% (n=344) report that hair loss affects them the most
- 14% (n=269) report that nausea and vomiting affects them the most
- 12% (n=227) report that fatigue affects them the most

76% of those affected by hair loss and 83% of those affected by nausea and vomiting, reported that it has affected them for under a year. 22% of patients who reported fatigue affects them most report that they have been affected by fatigue for two to five years.

Figure 30 displays whether patients discussed treatment side effects with their doctor. Figure 31 displays if their doctor was able to help. 59% of patients had definitely discussed treatment side effects with their doctor. Of these patients, only 27% reported that the doctor was definitely able to help.

**Figure 30: You said you experienced side effects, did you discuss them with your doctor?**

You said you experienced side effects of treatment, did you discuss them with your doctor?

2168 Responses



● Yes, definitely ● Yes, to some extent ● No ● Don't know/ can't remember

**Figure 31: Was the doctor able to help with the side effects?**

Was the doctor able to help with the side effects?

1982 Responses



● Yes, definitely ● Yes, to some extent ● No ● Don't know/ can't remember

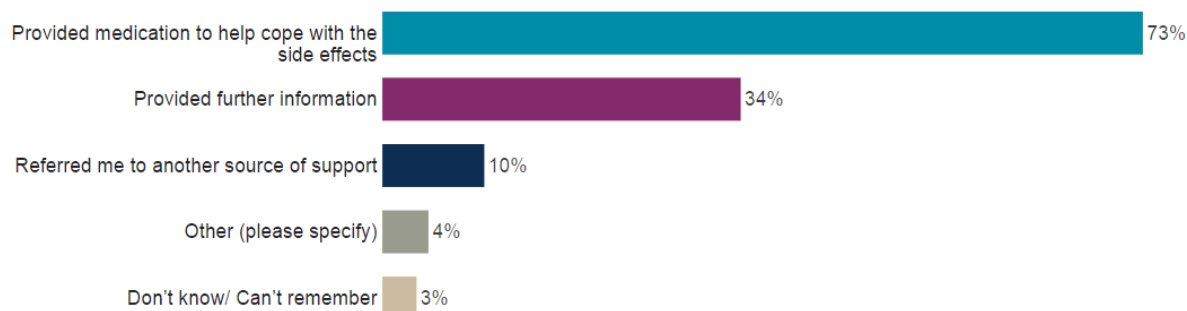
Of those who said their doctor was able to help with treatment side effects (see Figure 32):

- 73% said the doctor helped by providing medication to help cope with the side effects
- 34% said the doctor helped by providing further information

**Figure 32: What specifically did the doctor do to help?**

What specifically did the doctor do to help?

1647 Responses



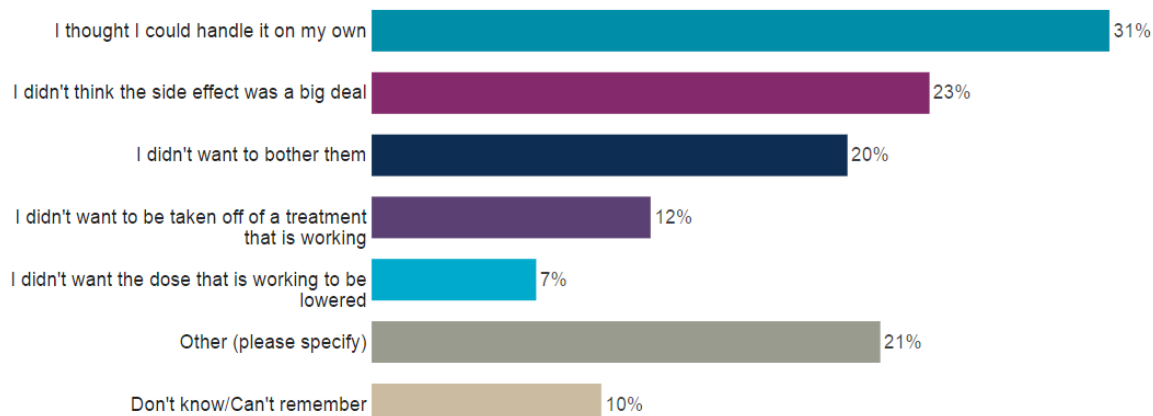
Those who have experienced treatment-related side effects and who did not discuss them with their doctor reported the reasons why (Figure 33). For 31% the reason was they thought they could handle it on their own.



Figure 33: Why have you not discussed these side effects that you have been experiencing with your doctor?

Why have you not discussed these side effects that you have been experiencing with your doctor?

146 Responses

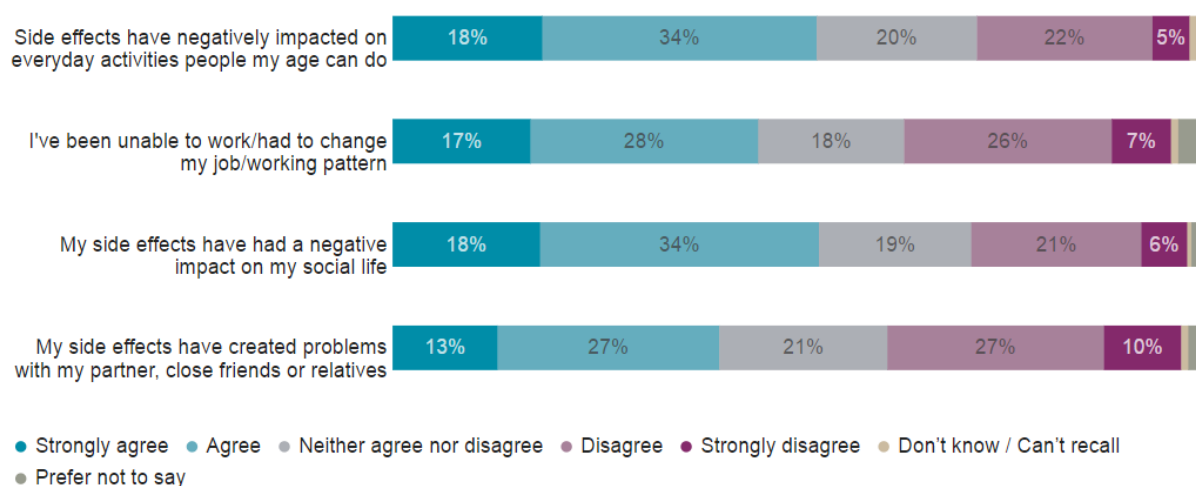


Regarding the treatment side effects that affected patients, 52% of patients agree or strongly agree that their side effects have negatively impacted on everyday activities people their age can do, and 52% agree/strongly agree that their side effects have had a negative impact on their social life - see Figure 34.

Figure 34: Thinking about the side-effects of medication that affect you, to what extent, if at all, do you agree or disagree with each of the following statements? (Please select one option on each row):

Thinking about the side effects of medication that affect you, to what extent, if at all, do you agree or disagree with each of the following statements:

2146 Responses





## Fatigue

Fatigue was the leading physical symptom affecting quality of life reported by respondents to the LC (2018) 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.



- 34% of patients reported their fatigue levels over the last week were six or above (one = minimal fatigue to ten = worse fatigue imaginable).
- 54% of patients have discussed their fatigue with their doctor over the last two years and 39% have not. Of those who discussed their fatigue, almost a quarter (23%) reported that the doctor took no action after their discussion, and 38% reported that the doctor never followed up about their fatigue.
- The main reason patients reported as not having discussed their fatigue with their doctor was that they did not think anything could help (35%).
- The top reported coping mechanisms patients have used to help with their fatigue over the last two years are balancing time schedules (46%) and exercise programs (40%).

In the LC (2020) Global Patient Survey, patients with lymphoma were asked to rate their level of fatigue on a scale of one = minimal fatigue to ten = worse fatigue imaginable. 34% of patients reported their fatigue levels over the last week were six or above. These patients stated that their fatigue affects the following areas/activities over the last two years:

- General activity (reported by 69% of patients with a fatigue rating of six or more)
- Mood (reported by 65% of patients with a fatigue rating of six or more)
- Physical activities (reported by 61% of patients with a fatigue rating of six or more)

Table 6 indicates the extent to which fatigue has affected various areas of life over the last two years, by age group.

63% of those aged 18-29, and 58% of patients aged 30-39 reported that their fatigue has affected their mood over the last two years. Patients aged 40-59 were more likely to report that their fatigue has affected their general activity (48%) and their mood (48%) compared to other areas or activities. 59% of those aged 60 or over reported that their fatigue has affected their general activity over the last two years. Additionally, 59% of patients aged 70+ reported that their fatigue has affected their physical activities.

Table 6: Which of the following areas/ activities has your fatigue affected over the last two years?

Which of the following areas/ activities has your fatigue affected over the last two years?																
	Not known		18-29		30-39		40-59		60-69		70+		Prefer not to say		Total	
My fatigue hasn't affected any areas of my life over the last two years	0%	0	9%	18	10%	34	15%	115	14%	40	16%	25	0%	0	13%	232
General activity	100%	1	51%	106	53%	178	48%	379	59%	172	59%	91	100%	1	52%	928
Mood	100%	1	63%	131	58%	193	48%	374	43%	127	37%	57	100%	1	50%	884
Employment (working fewer hours, stopped working)	100%	1	37%	77	42%	140	35%	276	19%	56	7%	11	0%	0	32%	561
General work around the home (daily chores/housework)	100%	1	26%	55	41%	138	43%	340	48%	141	47%	72	100%	1	42%	748
Relationships with other people	100%	1	30%	62	23%	77	20%	157	18%	53	17%	26	0%	0	21%	376
Social activities	100%	1	47%	98	39%	129	37%	294	35%	103	33%	51	100%	1	38%	677
Physical activities	100%	1	45%	94	43%	142	44%	344	51%	150	59%	90	100%	1	46%	822
My financial situation	100%	1	25%	53	29%	96	24%	189	15%	43	5%	7	0%	0	22%	389
Enjoyment of life	100%	1	41%	86	36%	121	35%	279	35%	102	37%	56	0%	0	36%	645
Ability to think clearly/concentrate	100%	1	39%	82	38%	128	34%	265	32%	94	29%	44	0%	0	35%	614
Ability to remember things	100%	1	26%	55	32%	107	29%	226	28%	83	29%	44	0%	0	29%	516
Ability to sleep	100%	1	31%	65	38%	127	40%	316	35%	102	39%	59	0%	0	38%	670

Figure 35 shows that 54% of patients have discussed their fatigue with their doctor over the last two years and 39% have not.

Figure 35: Have you discussed your fatigue with your doctor over the last two years?

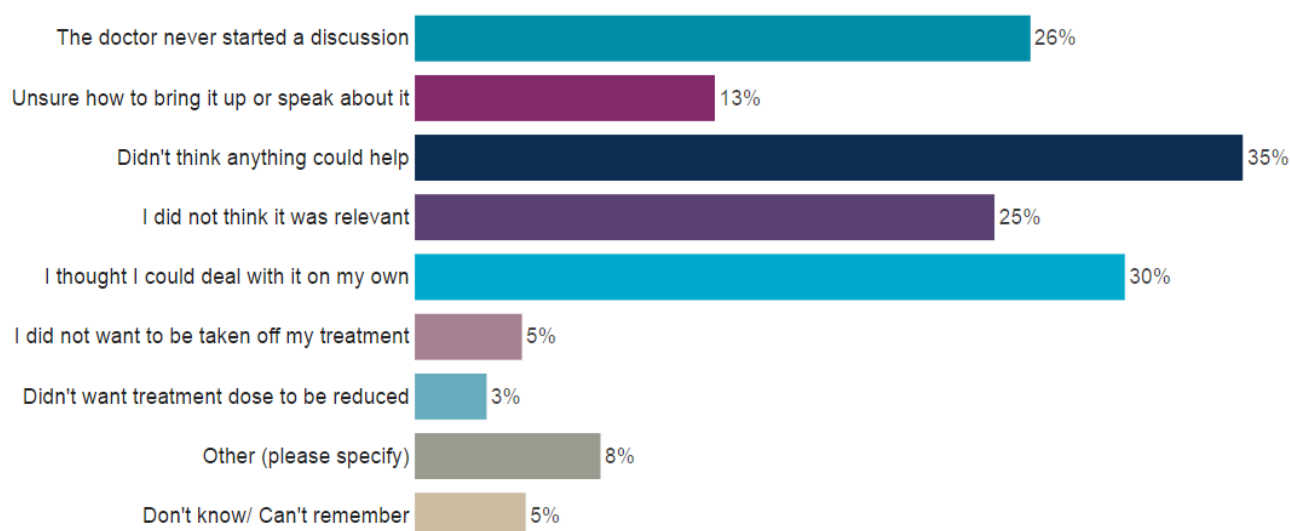
Have you discussed your fatigue with your doctor over the last two years?  
1542 Responses



The main reason patients reported as not having discussed their fatigue with their doctor was that they did not think anything could help (35%). See Figure 36 for full data.

Figure 36: Why have you not discussed your fatigue with your doctor?

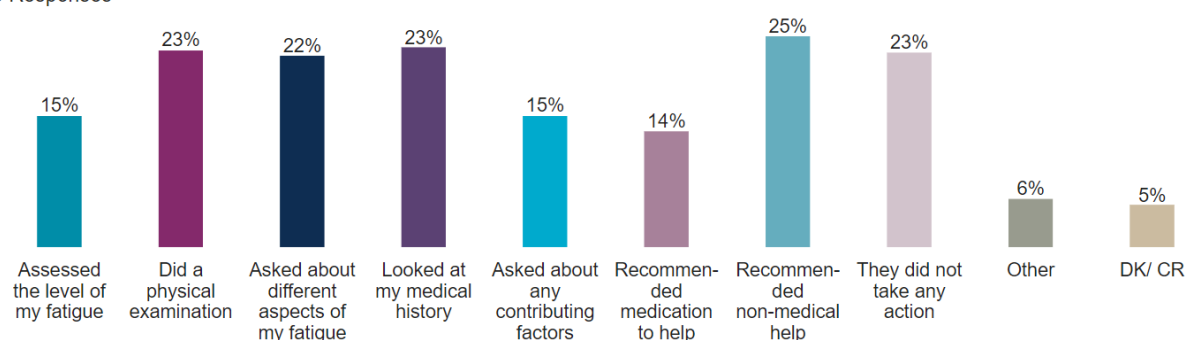
Why have you not discussed your fatigue with your doctor?  
596 Responses



Patients who discussed fatigue with their doctor were asked how their doctor helped with their fatigue. Responses are displayed in Figure 37. Less than a quarter of patients reported that the doctor did a physical examination (23%) or looked at their medical history (23%). Further, 23% reported that the doctor did not take any action after they discussed their fatigue.

Figure 37: What did the doctor do after you discussed your fatigue?

What did the doctor do after you discussed your fatigue?  
833 Responses

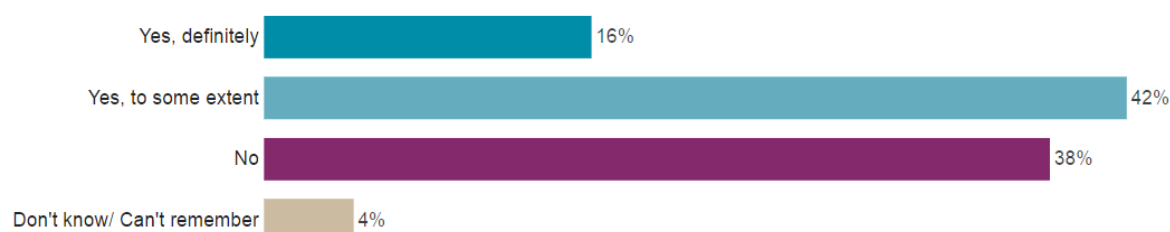


Patients who had discussed fatigue with a doctor were asked whether their doctor followed up with them about their fatigue (Figure 38), and:

- 16% said 'Yes, definitely'
- 42% said 'Yes, to some extent'
- 38% said 'No'

Figure 38: Did your doctor follow-up with you about the fatigue you were experiencing?

Did your doctor follow-up with you about the fatigue you were experiencing?  
833 Responses



Patients were asked whether they spoke to anyone else (other than a doctor) about their fatigue, and 63% reported that they also spoke to family and friends. See Figure 39.

Figure 39: Did you speak to anybody else to help you with your fatigue?

Did you speak to anybody else to help you with your fatigue?  
1525 Responses

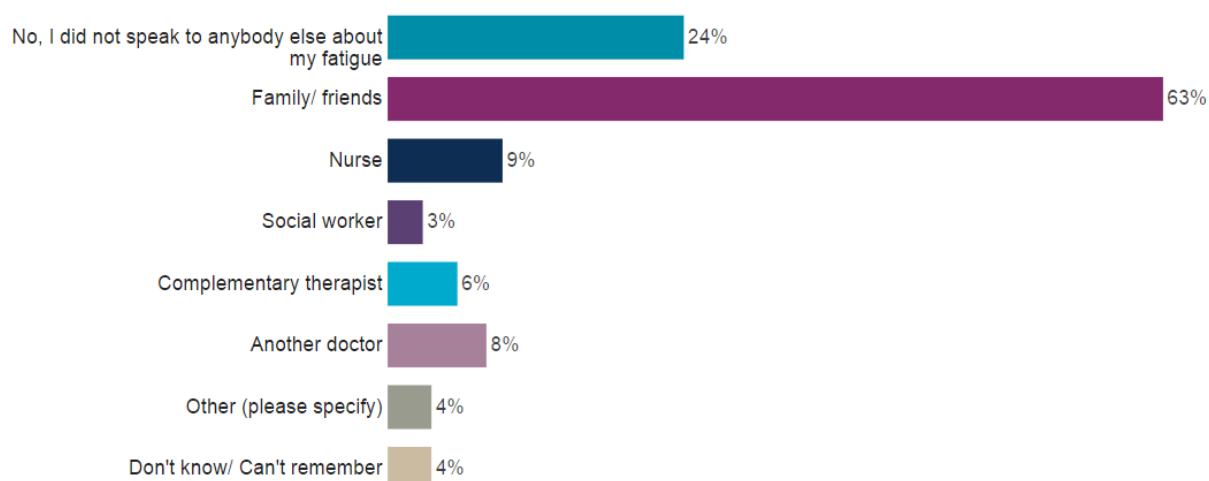
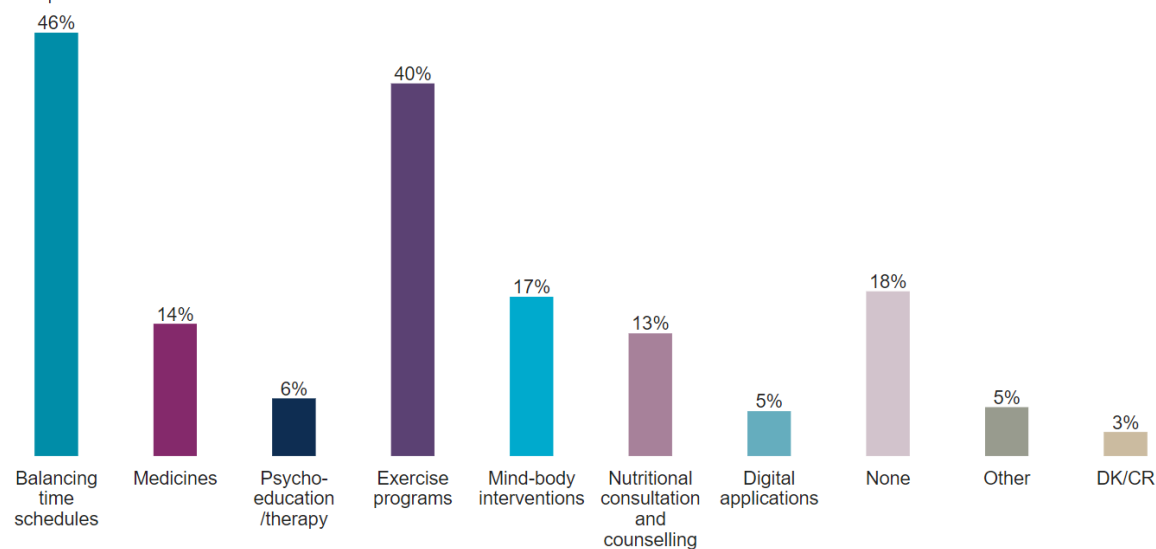


Figure 40 displays that the top reported coping mechanisms patients have used to help with their fatigue over the last two years are balancing time schedules (46%) and exercise programs (40%).

Figure 40: What coping mechanisms have you used to help with your fatigue over the last two years?

What coping mechanisms have you used to help with your fatigue over the last two years?

1757 Responses



## Psychosocial Effects of Lymphoma/CLL and its Treatment

The previous LC (2018) Global Patient Survey showed that patients were much more likely to communicate their physical/medical issues than their psychosocial issues with their doctors. When patients did report raising emotional concerns, only the minority reported that the doctor was able to help. Questions were added to the LC (2020) Global Patient Survey to further investigate this issue in order to bridge this two-way communication gap.



- The most commonly reported psychosocial effects experienced were fear of cancer relapse (50%), fear of progression of the lymphoma (41%), and anxiety (39%).
- Patients were more likely to discuss their depression (32%) or anxiety (36%) with the doctor than their changes in relationships (19%).
- Of those who reported not discussing their changes in relationships, anxiety, and/or depression with their doctor, the main reasons reported were that they thought they could handle on their own (43-46%) and they did not want to bother their doctor (34-37%).
- Less than a third of patients who discussed their depression, anxiety or changes in relationships reported that the doctor followed up with them about any of these issues.
- When asked who else they had spoken to regarding their worries or concerns, in many cases, patients reported that they had spoken with their family and friends for help.

Patients with lymphoma were asked what psychosocial effects they had experienced in the last 12 months (Table 7). The most commonly reported responses were:

- 50% of patients experienced fear of cancer relapse
- 41% of patients experienced fear of progression of the lymphoma
- 39% of patients experienced anxiety

Table 7: In the last 12 months, have you experienced any of the following as a result of your lymphoma diagnosis?

2565 Responses

**In the last 12 months, have you experienced any of following as a result of your lymphoma diagnosis?**

Loss of self-esteem	30%	757
Concerns about body image/physical appearance	30%	757
Changes in relationships	19%	491
Isolation	19%	482
Depression	38%	964
Anxiety	39%	998
Fear of relapse	50%	1271
Fear of progression of the lymphoma	41%	1044
I have not experienced any of these in the last 12 months	15%	395
Don't know/ can't remember	2%	64
Total		2565

A larger proportion of patients in watch and wait (treatment not yet needed) reported a fear of progression of the lymphoma (57%), compared to those who were in remission (26%) or on maintenance therapy (38%).

47% of newly diagnosed patients who are not yet sure of treatment options reported experiencing anxiety, compared to those who have had treatment and are back in watch and wait (30%), patients who are in remission (35%), or for those in watch and wait where treatment not yet needed (39%).

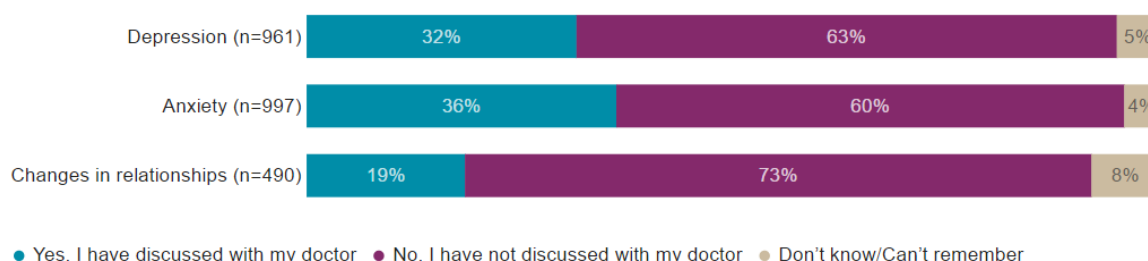
Patients who reported not receiving enough information around the time of diagnosis consistently reported higher proportions of experiencing the psychosocial effects listed in Table 7, compared to those who had received enough information. Furthermore, those who reported being affected by fatigue consistently reported higher proportions of experiencing the psychosocial effects listed in Table 7 compared to those who had not suffered from fatigue.

From this point on, the LC (2020) Global Patient Survey questions focused on three psychosocial issues that were determined to be significant in the LC (2018) GPS: changes in relationships, anxiety, and depression. The data below reflects only these three issues.

Figure 41 presents the percentage of patients who discussed their changes in relationships, anxiety, and/or depression with their doctor. Patients were more likely to discuss their depression (32%) or anxiety (36%) with the doctor than their changes in relationships (19%).

**Figure 41: For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with your doctor?**

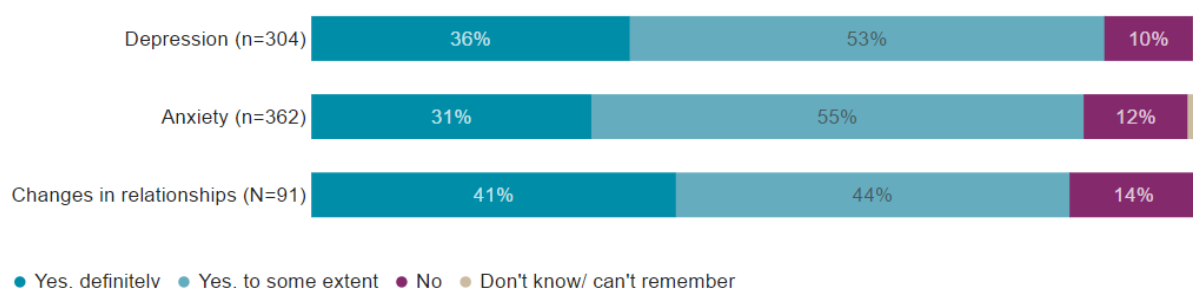
For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with your doctor?



Those who discussed these psychosocial worries or concerns with their doctor were asked whether the doctor was able to help (see Figure 42) and what information or support they were provided with (Table 8).

**Figure 42: For each worry or concern that you discussed with your doctor, please indicate if the doctor was able to help?**

For each worry or concern that you discussed with your doctor, please indicate if the doctor was able to help?



For those who experienced depression or anxiety, the majority (43% and 42%, respectively) were given further written or verbal information to help them cope. Additionally, approximately one third of patients (35% and 32% respectively) were given medication to help them cope. Those who reported changes in relationships were mainly given further written or verbal information (44%) – see Table 8.



Table 8: What type of information or support were you provided with?

For each worry or concern that you have experienced, what type of information or support were you provided with?

Depression											
Medication to help cope with this worry or concern		Further written or verbal information		Information on coping mechanisms		Signposting to another source of support		Other		Don't know/Can't remember	
35%	94	43%	113	32%	86	22%	57	7%	19	6%	16
											265

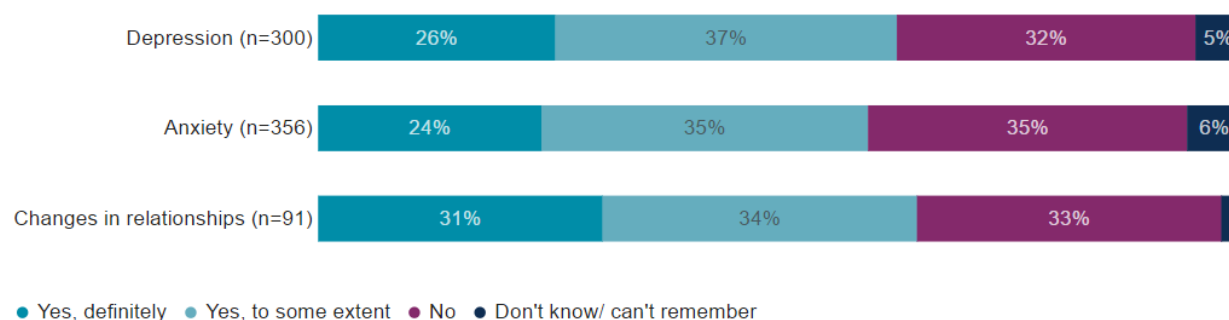
Anxiety											
Medication to help cope with this worry or concern		Further written or verbal information		Information on coping mechanisms		Signposting to another source of support		Other		Don't know/Can't remember	
32%	98	42%	130	34%	103	17%	53	7%	20	8%	24
											306

Changes in relationships											
Medication to help cope with this worry or concern		Further written or verbal information		Information on coping mechanisms		Signposting to another source of support		Other		Don't know/Can't remember	
22%	17	44%	34	35%	27	21%	16	10%	8	10%	8
											77

Of those who discussed these psychosocial issues, only about a quarter of patients reported that the doctor followed up about their depression (26%) or anxiety (24%), and only 31% reported that the doctor followed up about their changes in relationships.

Figure 43: For each worry or concern that you discussed with you doctor, please indicate if your doctor followed-up with you about these worries that you were experiencing?

For each worry or concern that you discussed with you doctor, please indicate if your doctor followed-up with you about these worries that you were experiencing?



Of those who reported not discussing their changes in relationships, anxiety, and/or depression with their doctor, the main reasons reported (see Table 9) were:

- They thought they could handle it on their own (43-46%)
- They did not want to bother the doctor (34-37%)

Table 9: For each worry or concern that you have experienced, please indicate what were your reasons for not discussing it with your doctor?

For each worry or concern that you have experienced, please indicate what were your reasons for not discussing it with your doctor?

Depression														
I thought I could handle it on my own		Didn't think it was a big deal		Didn't want to bother them		Didn't want the dose that is working to be lowered		Didn't want to be taken off of a treatment that is working		Other (please specify)		Don't know/ can't remember		Total
43%	263	16%	97	36%	221	5%	32	11%	68	11%	66	7%	43	606

Anxiety														
I thought I could handle it on my own		Didn't think it was a big deal		Didn't want to bother them		Didn't want the dose that is working to be lowered		Didn't want to be taken off of a treatment that is working		Other (please specify)		Don't know/ can't remember		Total
46%	275	15%	86	37%	220	5%	27	10%	57	11%	63	5%	28	592

Changes in relationships														
I thought I could handle it on my own		Didn't think it was a big deal		Didn't want to bother them		Didn't want the dose that is working to be lowered		Didn't want to be taken off of a treatment that is working		Other (please specify)		Don't know/ can't remember		Total
45%	163	19%	69	34%	123	4%	16	8%	30	11%	38	6%	20	359

When asked who else they had spoken to regarding their worries or concerns (besides a doctor), in many cases, patients reported that they had spoken with their family and friends for help. See Table 10 below for a breakdown of responses for all psychosocial concerns (not only depression, anxiety, and changes in relationships).

Table 10: For each worry or concern that you have experienced, please indicate who else you have spoken with to help you with these worries or concerns?

For each worry or concern that you have experienced, please indicate who else you have spoken with to help you with these worries or concerns?

Loss of self-esteem																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		Don't know/ can't remember		Total
36%	265	58%	427	5%	39	4%	31	5%	34	6%	46	2%	18	4%	27	733
Concerns about body image/physical appearance																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		Don't know/ can't remember		Total
28%	209	64%	473	7%	54	3%	21	3%	22	5%	35	2%	17	5%	36	741
Changes in relationships																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		Don't know/ can't remember		Total
33%	158	54%	261	7%	32	7%	32	5%	25	4%	18	3%	13	7%	34	479
Isolation																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		Don't know/ can't remember		Total
49%	231	38%	177	3%	16	4%	18	4%	21	3%	16	2%	11	8%	38	468
Depression																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		Don't know/ can't remember		Total
34%	313	56%	518	5%	43	3%	27	5%	44	6%	55	3%	27	4%	40	929
Anxiety																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		Don't know/ can't remember		Total
32%	308	58%	557	5%	45	4%	39	5%	46	8%	82	3%	27	3%	32	966
Fear of progression of the lymphoma																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		Don't know/ can't remember		Total
32%	325	57%	581	9%	88	4%	37	4%	43	11%	114	3%	31	4%	45	1017

## Fear of Cancer Relapse

Year after year, fear of cancer relapse is the top reported psychosocial issue in the LC Global Patient Survey; however, there is still too little conversation in the healthcare community as well as between patients and doctors about this issue. Communication between patients and healthcare providers – including oncologists, haematologists, other doctors, nurses, and allied healthcare professionals – can have an important impact on a patient's psychosocial well-being and help reduce fear of relapse.



- 50% of patients reported that they experienced a fear of cancer relapse in the last 12 months, and 53% have discussed their fear of relapse with their doctor.
- Of those who discussed fear of relapse with their doctor, only 35% of patients reported their doctor was definitely able to help. Further, only 25% reported that the doctor definitely followed up about their fear of relapse, while a third (33%) reported that the doctor did not follow up.
- A third of patients (34%) who experience fear of relapse have difficulty making plans for the future as a result.
- 29% of patients reported that they are not using any coping mechanisms to help with their fear of relapse. 45% reported they are using exercise programs.

In the LC (2020) Global Patient Survey, 50% of patients reported that they experienced a fear of cancer relapse in the last 12 months, and 53% have discussed their fear of relapse with their doctor.

Of those who have discussed fear of relapse with their doctor, only 35% of patients reported their doctor was definitely able to help (Figure 44).

**Figure 44: For each worry or concern that you discussed with your doctor about fear of relapse, please indicate if the doctor was able to help?**

For fear of relapse, please indicate if the doctor was able to help

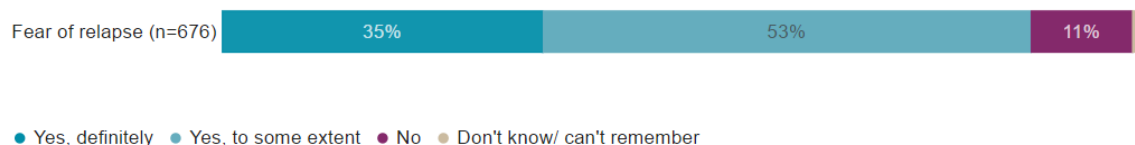
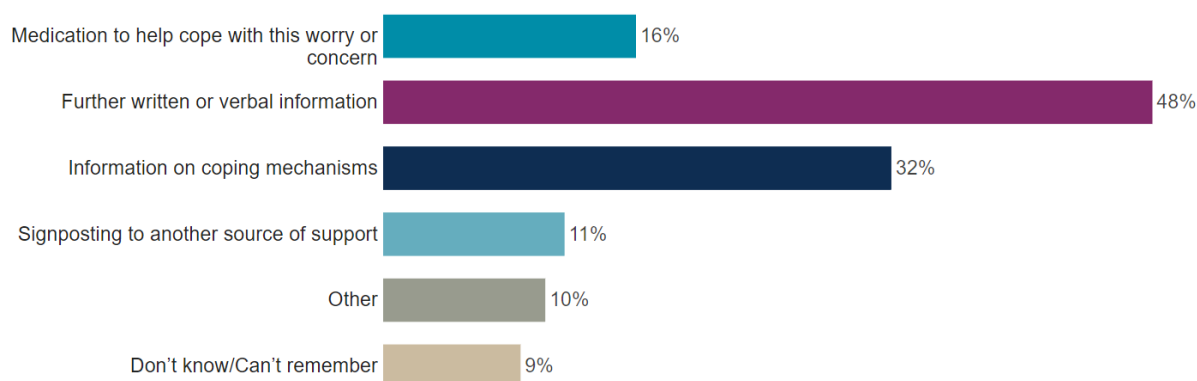


Figure 45 displays the type of information or support patients were provided with by their doctor to help with fear of relapse. Most patients (48%) reported that further written information or verbal information was provided.

**Figure 45: For fear of relapse, what type of information or support were you provided with?**

For fear of relapse, what type of information or support were you provided with?  
583 Responses



Only 25% of patients who discussed fear of relapse with their doctor reported that their doctor definitely followed up with them about it, while a third (33%) reported that the doctor did not follow up. See Figure 46.

**Figure 46: For fear of relapse, please indicate if your doctor followed-up with you about these worries that you were experiencing?**

For fear of relapse, please indicate if your doctor followed-up with you about these worries that you were experiencing?  
669 Responses



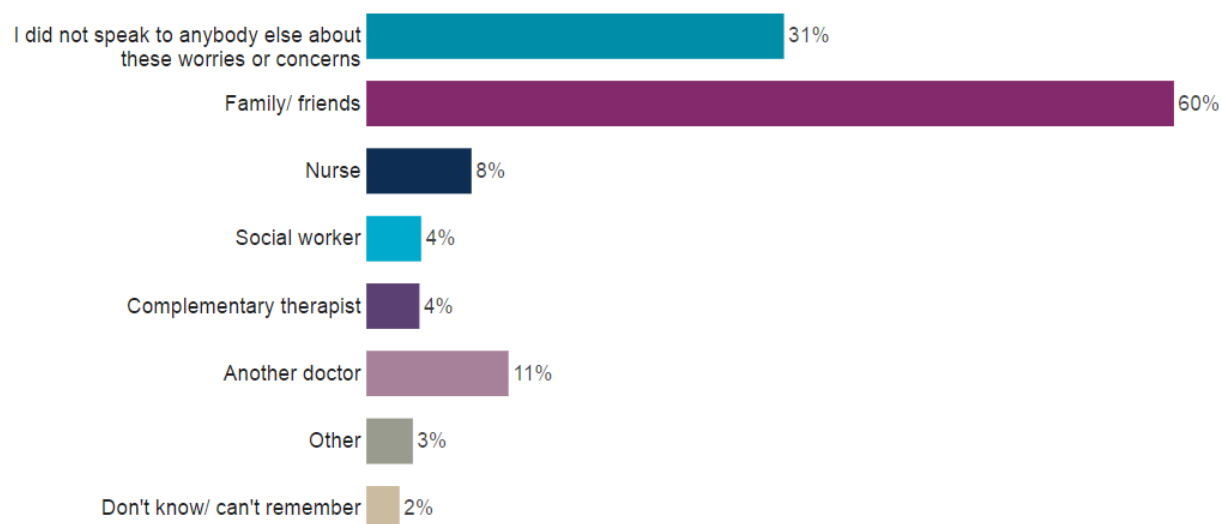
Of those patients who did not discuss fear of relapse with their doctor, 34% reported this was because they did not want to bother their doctor.

The majority of patients (60%) reported they have also spoken to family and friends about their fear of relapse, see Figure 47.

Figure 47: For each worry or concern that you have experienced, please indicate who else you have spoken with to help you with these worries or concerns?

For **fear of relapse**, please indicate who else you have spoken with to help you with these worries or concerns?

1237 Responses

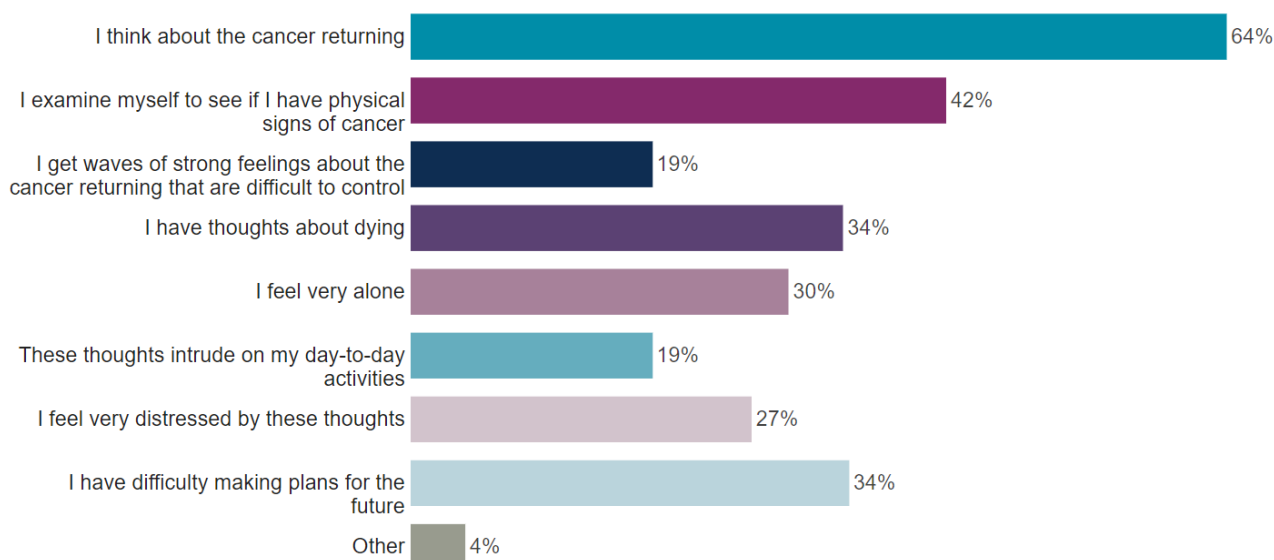


64% of patients who reported experiencing fear of relapse also reported that they think about the cancer returning, and 42% examine themselves to see if they have physical signs of cancer. Additionally, just over a third of patients think about dying (34%) and have difficulty making plans for the future (34%) because of their fear of relapse. See Figure 48.

Figure 48: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?

You have indicated that you have experienced a fear of relapse, which of the following have you experienced?

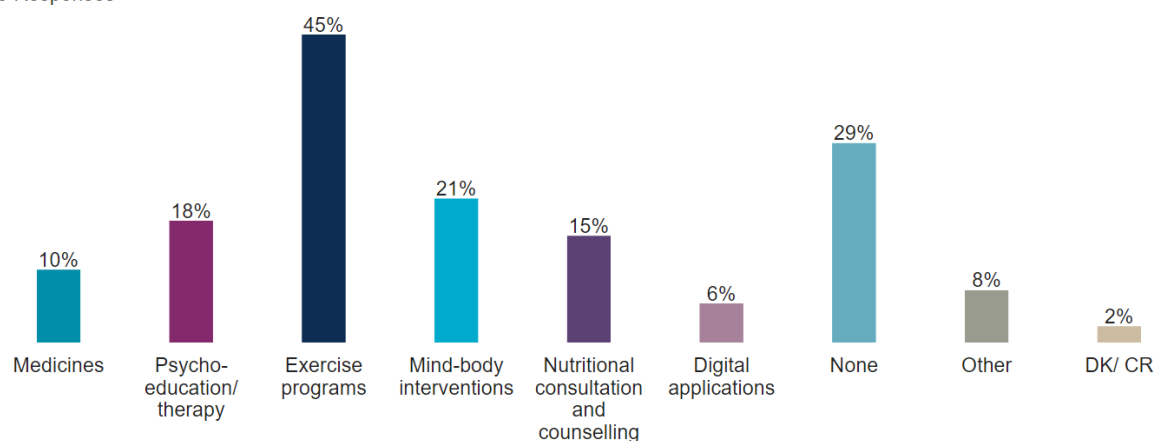
653 Responses



29% of patients reported that they are not using any coping mechanisms to help with their fear of relapse. 45% reported they are using exercise programs. See Figure 49.

**Figure 49: What coping mechanisms are you using to help with your fear of relapse?**

What coping mechanisms are you using to help with your fear of relapse?  
1233 Responses



## Barriers to Treatment

In previous surveys, financial issues have been the most reported barrier to receiving treatment. This continues to be an important topic to examine. As clinical trials provide a way for patients with limited options to obtain new treatments or access treatments that would otherwise be cost-prohibitive, in the LC (2020) Global Patient Survey questions were also asked about barriers to accessing clinical trials.



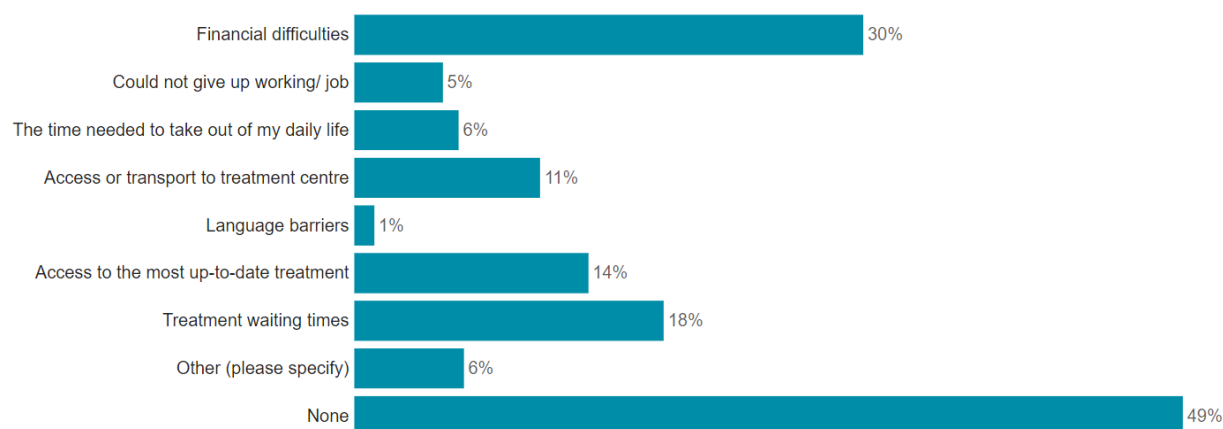
- 49% of patients reported that no barriers had prevented them from receiving treatment. However, 30% of patients reported they were prevented from receiving treatment by financial difficulties.
- 41% of patients reported that never being presented with an opportunity to take part was a barrier to being in a clinical trial.

When asked to select from a list of potential barriers to treatment, 49% of patients selected that “none” have prevented them from receiving treatment (see Figure 50). 30% of patients reported they were prevented from receiving treatment by financial difficulties. 18% reported that treatment waiting times prevented them from receiving treatment, and 14% reported not being able to access the most up-to-date treatment as a barrier.

Of those that reported no barriers to treatment, 78% also reported that they are ‘fairly’ or ‘very’ confident they can manage their health problems day-to-day. Patients living in suburban areas were less likely to report that financial difficulties prevented them from receiving treatment (13%) compared to those living in city/ urban areas (32%) or rural areas (42%).

**Figure 50: Have any of the following prevented you from receiving treatment?**

Have any of the following prevented you from receiving your treatment?  
2257 Responses



41% of patients found that never being presented with an opportunity to take part was a barrier to participating in a clinical trial.



## Results II. Caregiver survey

In past surveys, caregivers completed the same survey as patients, giving their unique insight on the patient's experience. While important data was learned this way, many new therapies are taken at home or rely on caregiver support for ideal management, placing extra burden on the caregiver themselves. Given the psychosocial impact of caring for a person with cancer, this survey seeks to further understand the experiences of those acting as a caregiver for someone with lymphoma/CLL.

1,723 was the total number of people caring for somebody living with lymphoma/CLL that responded to the survey. The results in this section will be reported across the following areas:

- Caregiver demographics
- Caregiver information, guidance, and support
- Impact of caring

### Caregiver Demographics

1,723 caregivers participated in the survey. A large proportion of respondents were caregivers from China (see Figure 51).

Figure 51: Caregivers by Country

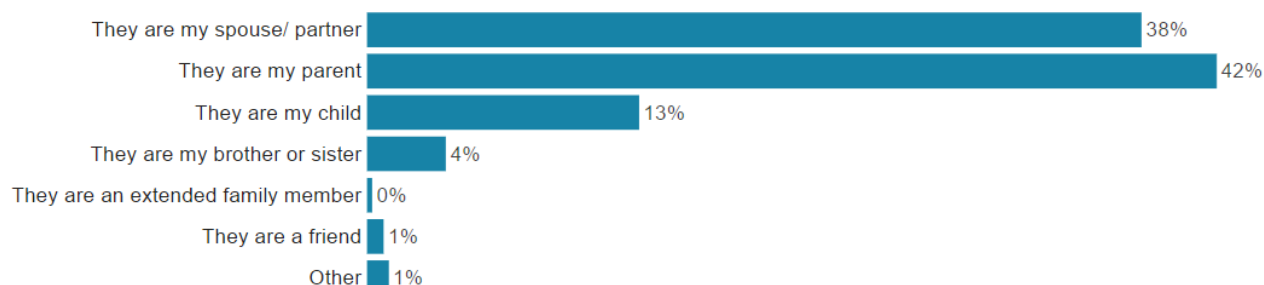
Responses per country  
1723 Responses



Caregivers were asked to identify their relationship to the person they are providing care and support to. 42% of caregivers are caring for their parent, and 38% of caregivers are a spouse/partner. Figure 52 displays the full results.

Figure 52: What is your relationship to the person you are providing care and support to?

What is your relationship to the person you are providing care and support to?  
1723 Responses



About half (54%) of caregivers use the term 'caregiver' when thinking about themselves and the care/support they provide.

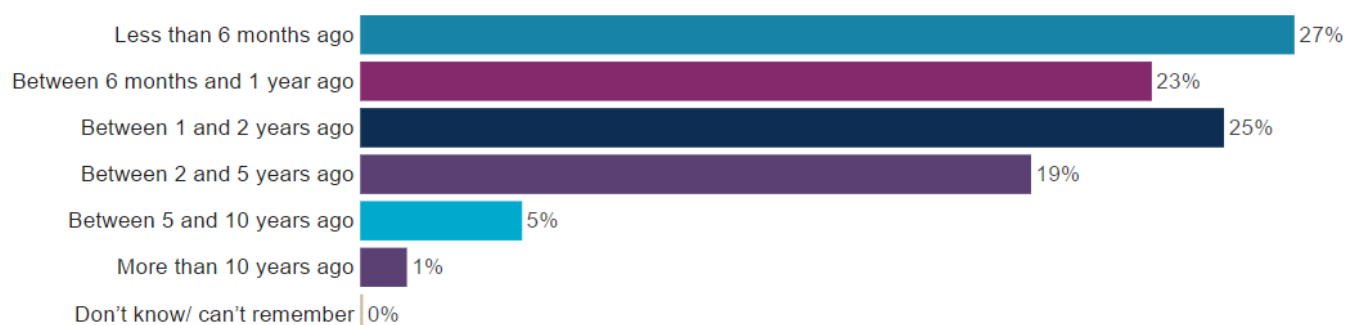
When caregivers were asked the about the support that they provide:

- 80% responded 'accompanying the patient with lymphoma/CLL to appointments'
- 70% said 'looking for information'
- 69% reported 'emotional support' talking and listening'

Caregivers were asked how long ago the person they provide care for was diagnosed. Figure 53 displays the results. Three quarters of caregivers (75%) were providing care and support to someone who received their diagnosis less than two years ago.

Figure 53: Length of time since diagnosis

How long ago was the person you care for diagnosed with lymphoma or CLL?  
1723 Responses

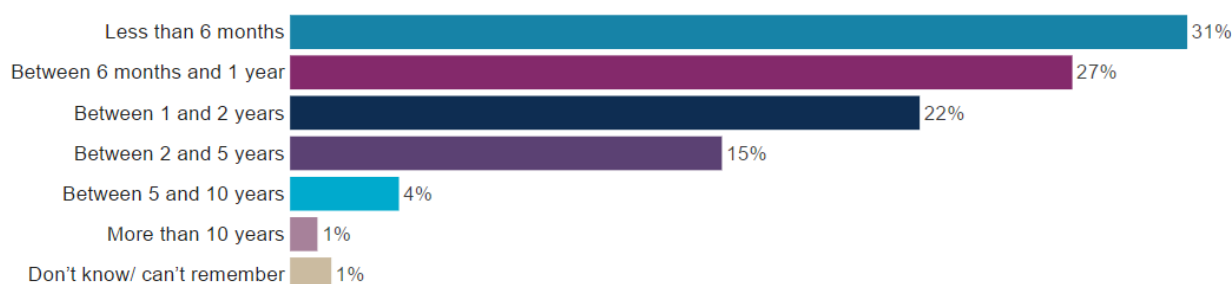


Over half of caregivers (58%) who responded have only been providing care and support for a year or less, see Figure 54 below.

Figure 54: How long have you been providing care and support to the person with lymphoma or CLL?

How long have you been providing care and support to the person with lymphoma or CLL?

1723 Responses



The main lymphoma subtypes of the patients that caregivers are providing care and support are DLBCL activated B-cell (13%) and DLBCL (not told specific type) (12%), follicular lymphoma (11%), and Hodgkin lymphoma (11%). Figure 55 displays the lymphoma subtype for all patients who caregivers are supporting.

Figure 55: What subtype of lymphoma/CLL does/did the person you care for have?

What subtype of lymphoma does/did the person you care for have?

1723 Responses

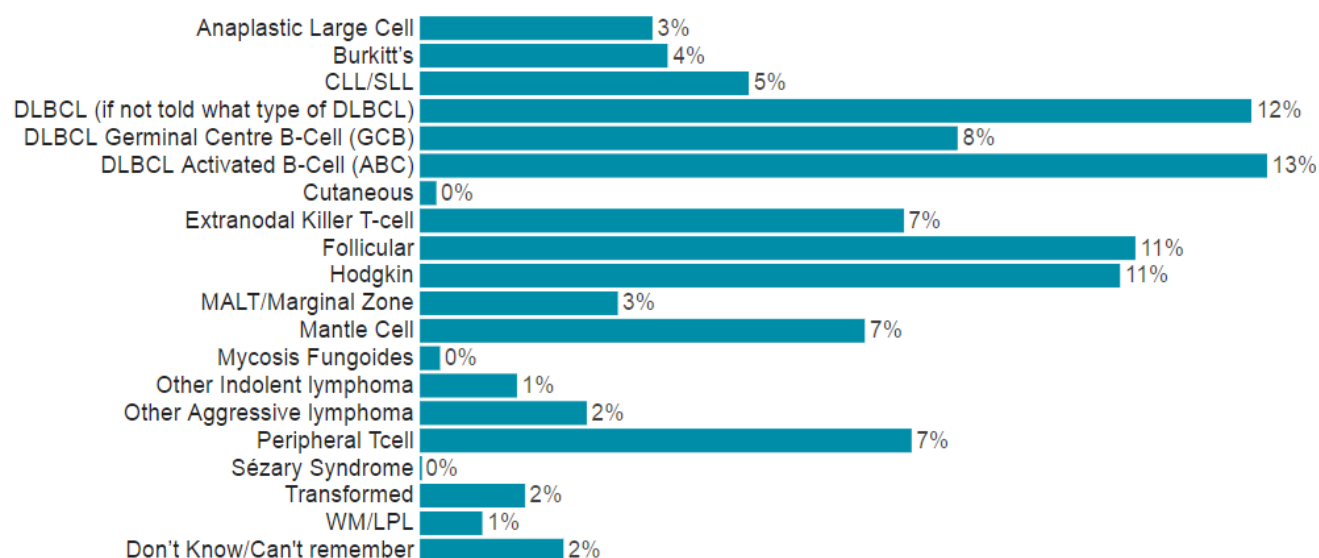
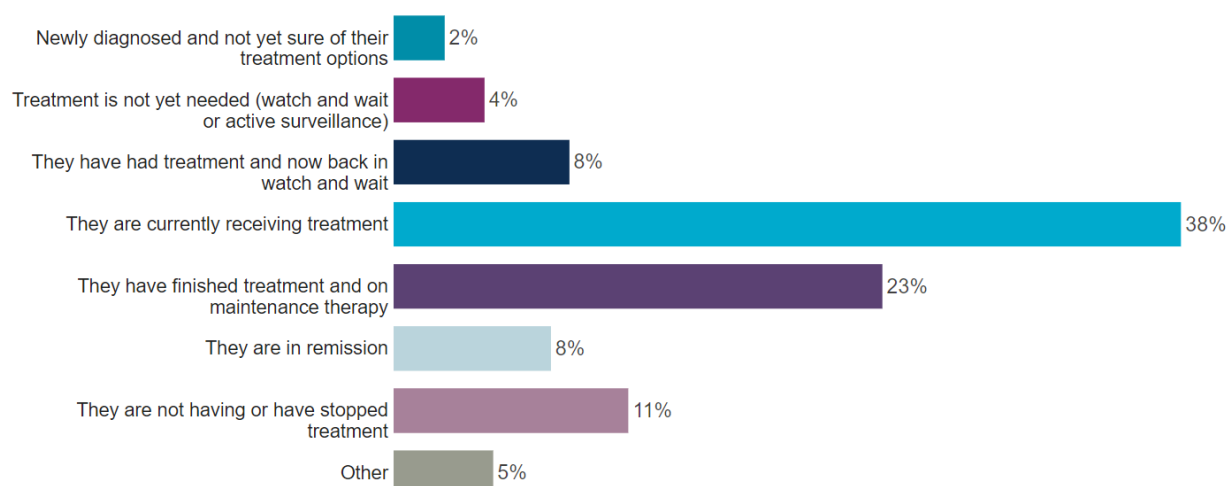


Figure 56 displays the stage of the care pathway of the patients the caregivers are providing care and support for. 38% of all caregivers are supporting somebody currently in treatment.

**Figure 56: What statement best describes where the person you care for is in the lymphoma or CLL experience?**

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

1723 Responses



Of those caregivers who reported the person they care for is in remission, 72% of respondents said they have been in remission for less than two years, and 24% for between two and five years.

For caregivers of patients in watch and wait, 78% of respondents reported they have been in watch and wait for less than two years, and 13% for between two and five years.

24% of caregivers reported that the lymphoma/CLL of the person they care for has relapsed, and 7% reported that it has transformed.

## Caregiver Information, Guidance and Support



- When asked to select their top three places to go for information, 72% of caregivers said 'doctor' was their top place to go.
- The majority of caregivers (57%) were the ones seeking out information and details about the disease and potential treatments on behalf of the patient.
- Only 39% of caregivers report they definitely felt assisted/ supported and understood by healthcare staff in their caregiving role.

When asked to select their top three places to go for information, 72% of caregivers said 'doctor' was their top place to go (see Table 11 for more details).

Table 11: When you have a need for information about the healthcare of the person you care for, which of the following are the top places you go to first for information? You may select up to 3.

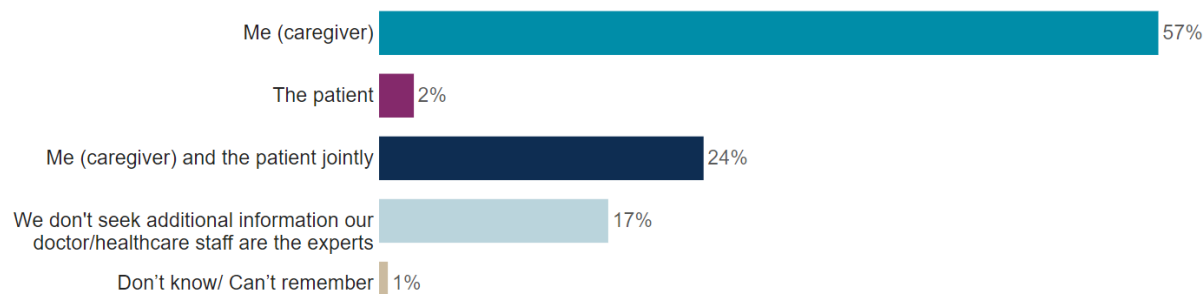
**When you have a need for information about the healthcare of the person you care for, which of the following do you go to first for information? Please rank your top choices starting with your first choice.**

	1		2		3	
Doctor	72%	1156	15%	224	10%	142
Nurse	1%	11	13%	194	5%	75
Websites	12%	189	27%	419	34%	479
Online blogs/social media	0%	7	2%	26	4%	53
Family/friends	2%	35	6%	86	10%	136
Patient organisation	13%	204	38%	584	35%	495
Other	0%	1	0%	6	3%	47
Total	100%	1603	100%	1539	100%	1427

Figure 57 indicates who was seeking out information and details about the disease and potential treatments (the patient with lymphoma, the caregiver, or both). The majority (57%) reported it was them, the caregiver, seeking information.

**Figure 57: Following the diagnosis, who was seeking out information and details about the disease and potential treatments?**

Following the diagnosis, who was seeking out information and details about the disease and potential treatments?  
1604 Responses



When caregivers were asked how long ago they last saw a healthcare provider with or for the person they provide care and support to:

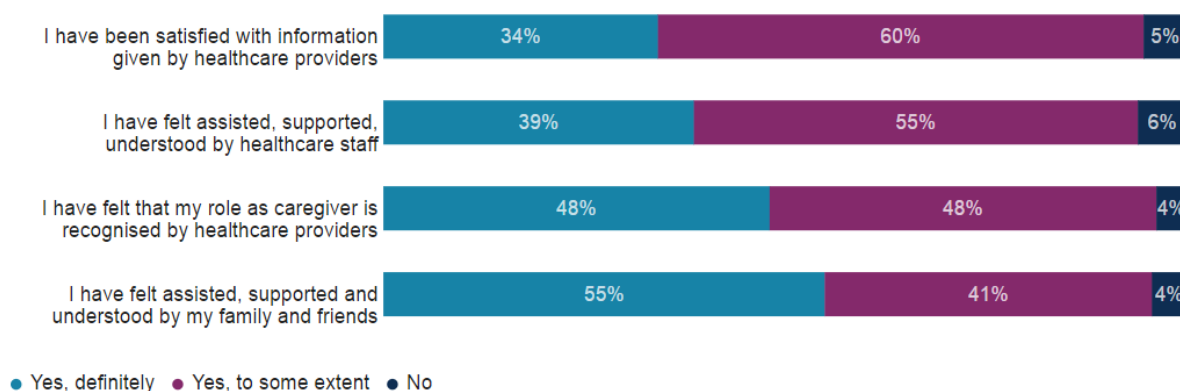
- 69% said less than six months ago
- 12% said between six months and one year ago
- 12% said more than one year ago
- 3% said they have never seen a healthcare provider
- 4% do not know or cannot remember

Caregivers who had seen a healthcare provider with/for the person they provide care for anytime in the last year were asked to think about how supported and recognised they felt in their caregiving role.

Figure 58 displays the extent to which caregivers report feeling supported and recognised. Only half of caregivers (55%) report they definitely felt assisted/ supported and understood by their family and friends, and only 39% felt assisted/supported and understood by healthcare staff.

**Figure 58: Thinking about the person you provide care and support to, please read the following statements and indicate the extent to which they occur.**

Thinking about the person you provide care and support to, please read the following statements and indicate the extent to which they occur.  
1189 Responses



## Impact of Caregiving



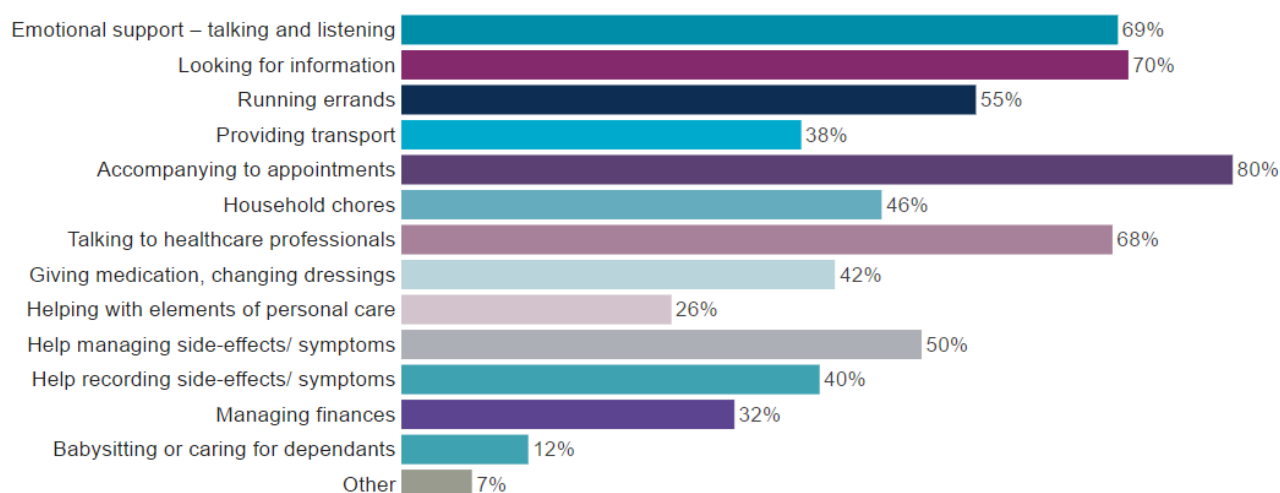
- Accompanying patients to appointments (80%) and looking for information (70%) were the most commonly reported aspects of caring.
- 47% of caregivers reported financial support as the hardest type of care and support to provide. Additionally, when asked which areas of their lives have been most impacted by their caregiver role, the area of life most selected was 'financial' (65%).
- 93% of caregivers reported they have been affected by fear of relapse. Almost half (48%) of caregivers feel very distressed by their thoughts surrounding fear of relapse, and 42% have difficulty making plans for the future.

Caregivers were asked to think about the different aspects of the care and support that they provide to somebody with lymphoma/CLL. Accompanying patients to appointments (80%) and looking for information (70%) were the most commonly reported aspects. Figure 59 displays the results for all types of care provided by the caregivers who responded.

Figure 59: Below are some elements of 'caring' that others providing care and support to somebody with lymphoma/CLL have mentioned. Please select what type(s) of care that you provide

Below are some elements of 'caring' that others providing care and support to somebody with lymphoma/CLL have mentioned. Please select what type(s) of care that you provide.

1585 Responses



Caregivers were asked which type of care and support they find the hardest to provide:

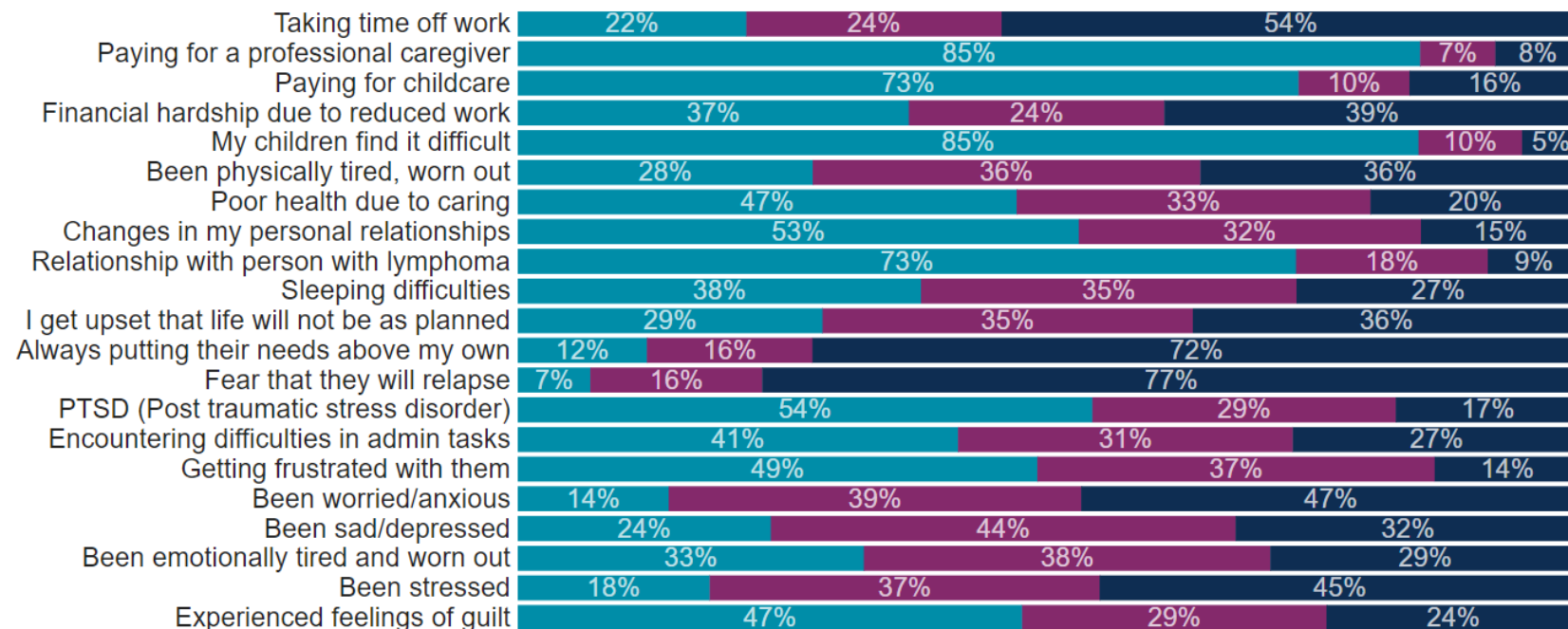
- 47% reported financial support
- 25% reported emotional support
- 9% reported practical support
- 5% reported physical support
- 14% do not know or cannot remember

Caregivers rated the frequency with which some aspects of providing care and support to somebody with lymphoma/CLL had affected them over the last 12 months – see Figure 60. 77% often or always fear that the cancer of the person they care for will relapse, and 72% often or always put the needs of the patient above their own. 54% are often or always affected by the need to take time off work.

Figure 60: In the past 12 months, to what extent do each of the following issues affect you as a caregiver?

In the past 12 months, to what extent have each of the following issues affected you as a caregiver?

1502 Responses



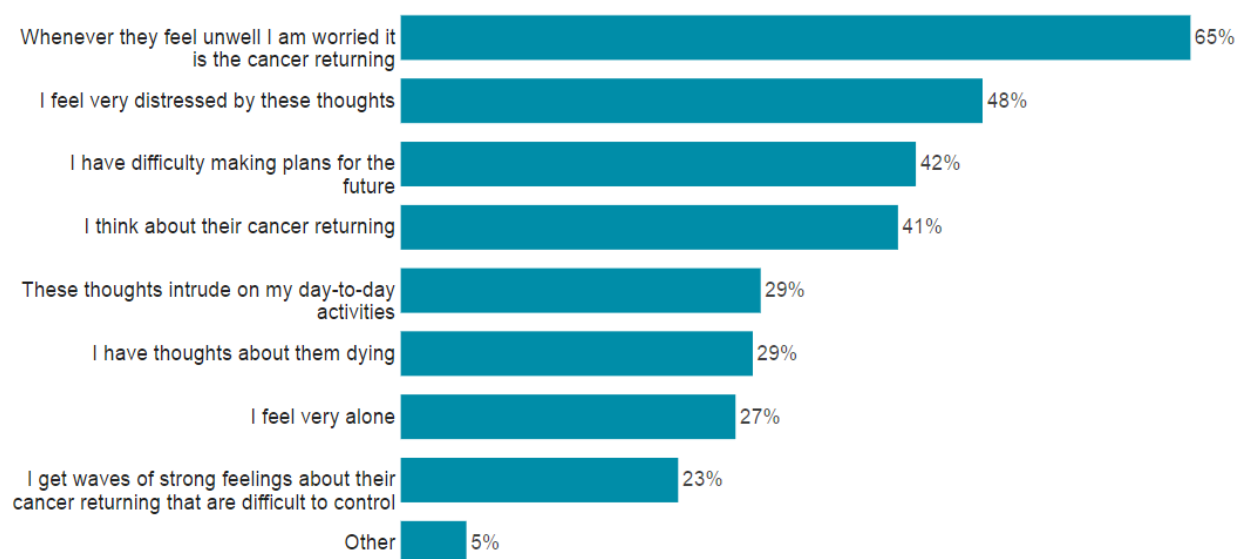
● Never/rarely ● Sometimes ● Often/always



93% of caregivers reported they have been affected by fear of relapse (often/always + sometimes). Regarding their fear of relapse, 65% of caregivers reported they have experienced worrying the cancer is returning whenever the person they support feels unwell – see Figure 61. Almost half (48%) of caregivers feel very distressed by their thoughts surrounding fear of relapse, and 42% have difficulty making plans for the future.

**Figure 61: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?**

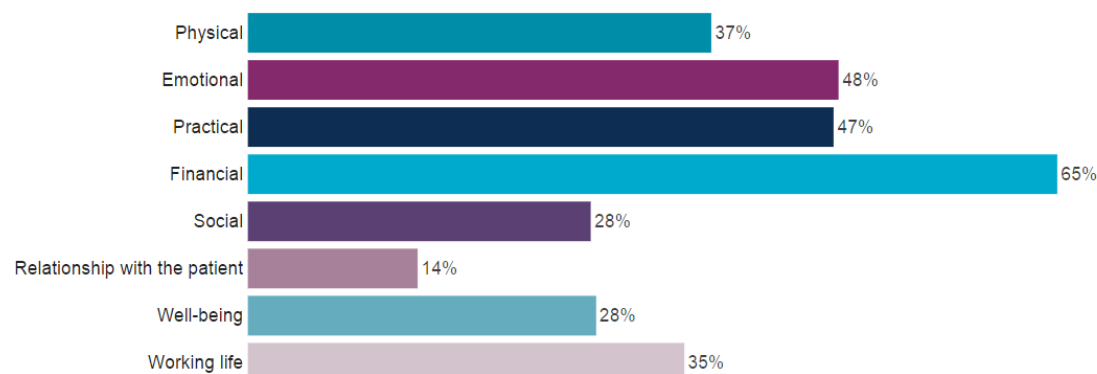
You have indicated that you have experienced a fear of relapse, which of the following have you experienced?  
936 Responses



When asked which areas of their lives have been most impacted by caring or supporting somebody with lymphoma/CLL, the area of life most selected by caregivers was 'financial' (65%). See Figure 62.

**Figure 62: Which of the following areas of your life have been impacted most by caring for or supporting somebody with lymphoma/CLL?**

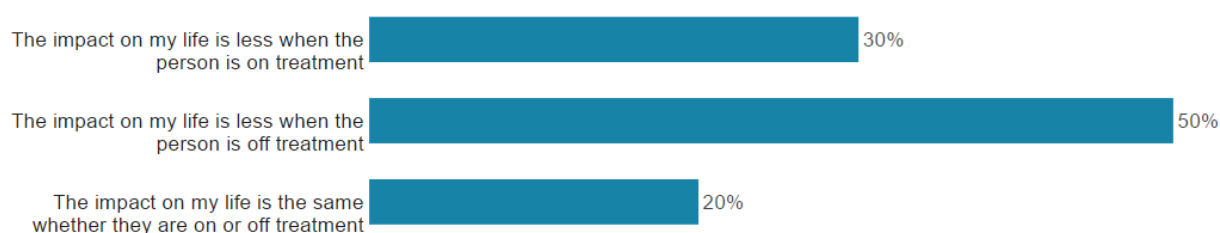
Which of the following areas of your life have been impacted most by caring for or supporting somebody with lymphoma/CLL?  
1500 Responses



Caregivers were asked whether the impact of caregiving on their lives is influenced by whether or not the person they care for is on treatment (see Figure 63). 50% said the impact is less when the person is off treatment, and 30% indicated that the impact on their life is greater when the person is on treatment.

**Figure 63: Thinking about the areas of your life that are affected by providing this care or support, does this impact your life in different ways depending on whether the person with lymphoma/CLL is on/off treatment?**

Thinking about the areas of your life that are affected by providing this care or support, does this impact your life in different ways depending on whether the person with lymphoma/CLL is on/off treatment?  
1489 Responses



# Appendices

## Appendix 1

The data from the Global Patient Survey 2018 were used for the following abstracts/ posters.

#2035

### Comparative Analysis of CLL and DLBCL Patients' Level of Understanding After Initial Doctor's Appointment

L. E. Warwick<sup>1</sup>; O. A. Bamigbola, MB/BS, MSc(Epid)<sup>2</sup>; N.M. Dren, B.Sc., MPH<sup>2</sup>



<sup>1</sup>Chief Executive Officer, Lymphoma Coalition, Mississauga, ON, Canada; <sup>2</sup>Research, Lymphoma Coalition, Mississauga, ON, Canada



**1) INTRODUCTION**  
For chronic lymphocytic leukaemia (CLL), the treatment landscape has changed dramatically in the last few years. The standard of care is regularly being updated due to ongoing outcomes of clinical trials investigating new therapies. However, this fast-evolving landscape complicates CLL patients' understanding of the best treatment option for them. Education on coping strategies to manage side effects is another key issue, especially for patients on long-term continuous therapies.

This study presents a unique look at how CLL patients are feeling in this complicated therapeutic landscape, by comparing their level of understanding of key issues after their initial doctor's appointment with that of diffuse large B-cell lymphoma (DLBCL) patients (given that DLBCL has a more established standard of care), using the Lymphoma Coalition's (LC) 2018 Global Patient Survey (GPS) on lymphomas and CLL. In addition, this study examined doctor-patient communication and support surrounding side effect management.

#### 2) METHODOLOGY

**Study Design**  
• This study is a sub-analysis of the 2018 LC GPS, which is a biennial online global survey of patients with lymphomas including CLL.  
• The survey was hosted on a third-party portal from January-March 2018 in 19 languages.

#### Participants

- Globally, 6631 participants took part (70+ countries).
- There were 595 CLL and 1478 DLBCL respondents.

#### Statistical Analysis

- Raw data was entered, merged, and cleaned in IBM SPSS v21.
- Demographic comparison of respondent subgroups (CLL vs DLBCL) was completed.
- Comparison of the subgroup of respondents who reported either having the 'most understanding' or the 'least understanding' to questions relating to their level of understanding of key issues after their initial doctor's appointment was completed.
- Respondents' response to whether their doctors were able to help them manage their treatment side-effects was charted and compared.
- Differences in proportions were tested with chi-square tests (p<0.05) and odds ratio with 95% CI.

#### 3) RESULTS

CLL and DLBCL respondents differed in the distribution of age, sex, and residence (all p values <0.05) (table 1).

Table 1. Socio-demographic distribution of respondents

	CLL count (% N=595)	DLBCL count (% N=1478)	X <sup>2</sup> (p-value)
<b>Age</b>			244 (<0.001)
18-24	7(1)	155(10)	
25-30	28(5)	223(15)	
31-35	213(36)	509(34)	
36-40	213(36)	509(34)	
41-45	213(36)	509(34)	
46-50	213(36)	509(34)	
51-55	115(19)	117(8)	
<b>Sex</b>			8.6 (<0.01)
Male	306(51)	667(45)	
Female	278(47)	803(54)	
<b>Residence</b>			35.3 (<0.001)
Rural	116(20)	345(24)	
Suburban	171(29)	234(17)	
Urban	308(51)	899(61)	

The DLBCL subgroup had more respondents in the younger age group (18-30 yrs age group-combined) compared to CLL respondents (32% vs 5%). The CLL group had more than twice the proportion of older respondents (>40 years) than the DLBCL group (13% vs 8%).

CLL respondents had more males (51%) whilst DLBCL respondents had a lower male proportion (45%). One-fifth (20%) of CLL respondents and 24% of DLBCL respondents resided in rural areas (table 1).

#### 3) RESULTS CONT.

Analysis of the level of understanding of key issues after their initial doctor's appointment showed that compared to DLBCL respondents, CLL respondents were more likely to have less understanding for all the issues analysed (table 2).

Of statistical significance, CLL respondents who started treatment right away were twice as likely as DLBCL respondents to have less understanding of their initial treatment and its potential side effects (OR=2.25 and 2.54 respectively).

	CLL Count (%)	DLBCL Count (%)	OR (95% CI)
Understanding of diagnosis	187 (31%)	222 (15%)	OR=1.10 (0.82-1.47)
Understanding of initial treatment (for those who started right away)	187 (31%)	222 (15%)	OR=2.25 (1.42-3.58)
Understanding of potential side effects	187 (31%)	222 (15%)	OR=2.54 (1.62-4.21)
Understanding of side effects management	187 (31%)	222 (15%)	OR=1.12 (0.82-1.53)
Understanding the different treatment options	187 (31%)	222 (15%)	OR=1.17 (0.82-1.67)
Understanding of the different processes and stages of care	187 (31%)	222 (15%)	OR=1.12 (0.82-1.53)

CLL respondents were more likely to have less understanding about side effect management, the different treatment options and the various processes and stages of their care compared to DLBCL respondents (ORs=1.9, 1.5 and 1.8 respectively) (table 2).

Importantly, more CLL respondents felt that their doctors were unable to help them manage their treatment side effects (13%), or felt only somewhat helped (31%) compared to DLBCL respondents (7% & 23%, respectively) (figure 1).

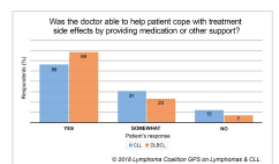


Figure 1. Respondents' feeling about their doctor's ability to help with treatment side effects.

#### 4) CONCLUSIONS

It is clear from this exploratory analysis that CLL patients are leaving their initial doctor's appointment with less clarity than the DLBCL patients. CLL patients also feel they are not receiving enough help from their doctors in coping with treatment side effects. LC will assess the impact of the possible confounding effects of the sociodemographic factors in future studies.

A global approach to regularly updating recommended CLL treatment standards and making them easily accessible will help both the clinicians and patients. LC also believes that continuous effort should be made to inform and educate lymphoma patients adequately and appropriately at all points of clinical contact.

#### 5) CONTACT

To contact the abstract group with questions and/or comments, please email: [natalie@lymphomacoalition.org](mailto:natalie@lymphomacoalition.org) or [lorne@lymphomacoalition.org](mailto:lorne@lymphomacoalition.org)

## Correlation of Lymphoma Patient Information Level with Healthcare Experience

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<sup>1</sup>Lymphoma Coalition, Mississauga, Canada; <sup>2</sup>Institute of Applied Biosciences, Centre for Research and Technology Hellas, Thessaloniki, Greece

### 1) INTRODUCTION & OBJECTIVES

Across recent health reform research, there is growing advocacy and awareness surrounding the idea that patients should act as more effective managers of their health and healthcare. Knowledge dissemination is regularly named as a preliminary requirement for this shift in attitude and behaviours. In 2017, the Lymphoma Coalition (LC) conducted a mixed methods investigation to determine if evidence exists pointing to better outcomes for more informed patients. A key theme was identified, where a patient has knowledge surrounding their condition, they are more inclined to be confident in sustaining an active patient role, they ask more questions and their patient experience is improved.

To continue this investigation, the LC utilised the 2018 Global Patient Survey (GPS) on lymphomas and CLL to further explore patient awareness and understanding, sources and level of information, support from healthcare professionals, and the impact this has on the patient experience.

### 2) METHODS

**Study Design**  
• Online global survey (2018 LC GPS) of patients with lymphomas (including CLL).  
• Hosted on a third-party portal from January 2018 to March 2018 in 19 languages.  
• Question topics: patient information and support, fear of relapse, fatigue, living with side effects, and barriers to care.

**Participants**  
• The survey was advertised through the social media of 65+ lymphoma-related patient organisations, Lymphoma Hub, scientific partners, INTERLYMPH, and HCPs.  
• 6631 participants took part from all over the world (70+ countries).

**Statistical Analysis**  
• A minimum completion threshold (Total M 0.70) was defined in order to eliminate partially completed surveys. Additional data sanitation was completed.  
• Descriptive statistics were performed for all questions of the survey. Associations between factors were examined through cross-tabulations and chi-square tests (p<0.05).  
• All statistical analyses were performed by a third-party scientific research institute with IBM SPSS v21.

### 3) RESULTS

#### 3.1 Levels of Understanding

The impact of perceived information level (Figure 1) was reflected in respondent's understanding of the medical aspects of their lymphoma, diagnosis and care (Table 1, Figures 2(a) & (b)).

	Adequate Information (% N=595)	Somewhat/Adequate Information (% N=1478)
Diagnosis	74	73
Characteristics of the particular subtype	54	27
Different medical treatment options	64	26
Initial treatment & extent of care	54	26
Potential side effects of treatment options	60	24
Side effect management	60	23
Phases and stages of care	55	23
Active surveillance (watch and wait), if applicable	71	26

Figure 1. Level of information respondents perceived they had overall.

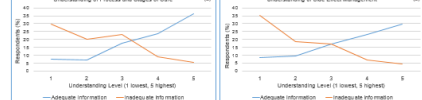


Figure 2(a) Respondents' understanding of the process and stages of their care and (b) side effect management after their initial visit with their doctor based on perceived information level.

#### 3.2 Respondent Feelings

Adequately informed respondents felt more confident in determining the need for medical care vs. handling a health problem on their own (85%) compared to somewhat (35%) and inadequately (22%) informed respondents. Similar trends were observed across the majority of feeling categories (Figure 3). 'Most days', adequately informed respondents reported experiencing low levels of negative feelings (out of control, fearful) and inadequately informed respondents reported experiencing low levels of positive feelings (in control, mentally/physically strong).

Figure 3. Respondents' feelings most days according to perceived information level.

### 3.3 Doctor-Patient Communication



Figure 4. Respondents' communication with the doctor based on perceived information level.

Across all categories, improved communication was reported by those with adequate information (Figure 4). Additionally, the general reporting of physical, medical, and psychosocial side effects was statistically dependent on the information level variable.

### 4) CONCLUSION

Having a perceived adequate information level was correlated with more self-reported positive healthcare experiences. Patients with adequate information reported better management of their health and healthcare through improved understanding, confidence levels, and communication. Therefore, access to credible timely information is an important aspect to a successful patient experience. These results present implications for both patient outcomes (health behaviours, health status) and costs to the healthcare system.

### ACKNOWLEDGEMENTS

Special thanks to all patients and the LC member organisations who offered their insight and support as well as to the many other organisations, pharmaceutical companies, medical professionals, pharmacists and individuals who generously shared their knowledge, resources and understanding for this project.

\*Disclosure: For authors, there are no relationships to disclose.

## A Cross-Sectional Study Examining the Effects of Patient Information Level on Healthcare Experience in 2 Patient Populations: Extranodal Natural Killer T-Cell Lymphoma (ENKTL) and Waldenstrom Macroglobulinemia (WM)



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### 1) INTRODUCTION

In 2018, the Lymphoma Coalition (LC) analysed data from the 2018 LC Global Patient Survey (GPS) on Lymphomas and CLL and determined that 'adequately informed' patients reported more positive healthcare experiences.

To further assess this correlation, the LC compared 2 patient subpopulations: Extranodal Natural Killer T-cell lymphoma (ENKTL) patients, and Waldenstrom Macroglobulinemia (WM) patients. Both rare subtypes present complicated disease landscapes for patients to navigate as they are difficult to understand, treat, and manage. However, 2018 LC GPS results indicated that across all lymphoma subtypes (14 analysed), ENKTL patients reported being the **least informed** and WM patients the **most informed**. The LC compared how this affected patient understanding, patient-doctor communication, and psychosocial side effects.

### 2) METHODOLOGY

#### Study Design

- This study is a sub-analysis of the 2018 LC GPS, which is a biennial online global survey of patients with lymphomas including CLL.
- Hosted on a third-party portal from January-March 2018 in 19 languages.

#### Respondents

- Globally, there were 6631 patient respondents from 70+ countries.
- There were 177 ENKTL and 764 WM respondents.

#### Statistical Analysis

- Raw data was entered, merged, and cleaned in IBM SPSS v21.
- Demographic comparison of respondent subgroups (ENKTL vs WM patients) was completed.
- Comparison of the subgroup of patients who reported either having the 'most' or the 'least' understanding of key issues surrounding diagnosis and care was completed.
- Comparison of the subgroup of patients who reported either 'yes' or 'somewhat/no' to questions about patient-doctor communication was completed.
- The prevalence of psychosocial issues during and after treatment was compared.
- Differences in proportions were tested using chi-square tests ( $p < 0.05$ ) and odds ratios with 95% CI.

### 3) RESULTS

The ENKTL subgroup had the highest proportion of inadequately informed patients (35%), and the lowest proportion of adequately informed patients (13%). The WM subgroup had the highest proportion of adequately informed patients (57%) and the lowest proportion of inadequately informed patients (9%). Both subtypes used the same primary information sources (doctor & website) and sought information in the same timespan (immediately upon diagnosis).

### 3.1) RESULTS CONT.

ENKTL and WM patients differed significantly in distribution of age, sex, and residence (all  $p$  values  $< 0.05$ ) (table 1). The majority (97%) of ENKTL patients lived in Asia, while the majority (72%) of WM patients lived in North America (NA).

Table 1. Socio-demographic distribution of patients

	ENKTL Count (%)	WM Count (%)	X <sup>2</sup> (p-value)
Age			
18-29	40 (23)	1 (0)	505.9 ( $p < 0.0001$ )
30-39	41 (24)	2 (0)	
40-49	121 (69)	22 (3)	
50-59	11 (6)	152 (19)	
60-69	11 (6)	152 (19)	
70+	7 (4)	302 (39)	
Sex			5.5 ( $p = 0.0186$ )
Male	122 (69)	410 (53)	
Female	55 (31)	354 (47)	
Residence			81.1 ( $p < 0.0001$ )
Rural	43 (25)	156 (20)	
Suburban	152 (88)	259 (34)	
Urban	29 (16)	344 (46)	

Analysis of level of understanding of key issues after patient's initial doctor's appointment showed that compared to WM patients, ENKTL patients were nearly twice as likely to have less understanding of their diagnosis, initial treatment, and different treatment options (OR=1.94, 1.99, 1.84 respectively) (table 2).

Table 2. Patients' level of understanding of key issues after their initial doctor's visit

	Subtype	Patients with the least understanding Count (%)	Patients with the most understanding Count (%)	OR (95% CI)	p-value
Understanding of diagnosis	ENKTL	14 (8)	12 (2)	OR=1.94 (95% CI 1.27-2.94)	$p < 0.0020$
	WM	155 (20)	360 (47)		
Understanding of initial treatment (for those who started right away)	ENKTL	57 (41)	50 (37)	OR=1.99 (95% CI 1.29-3.05)	$p < 0.0018$
	WM	147 (20)	256 (33)		
Understanding of different treatment options	ENKTL	67 (51)	38 (29)	OR=1.84 (95% CI 1.19-2.83)	$p < 0.0058$
	WM	200 (28)	277 (37)		
Understanding of side effect management	ENKTL	53 (39)	38 (29)	OR=1.27 (95% CI 0.80-2.00)	$p = 0.0084$
	WM	242 (33)	220 (29)		
Understanding of the different processes and stages of care	ENKTL	49 (35)	51 (39)	OR=1.16 (95% CI 0.75-1.78)	$p = 0.0005$
	WM	222 (30)	267 (35)		

Analysis of patient-doctor communication showed that compared to WM patients, ENKTL patients were more likely to not (somewhat/not) communicate all the issues analysed (table 3). ENKTL patients were twice as likely as WM patients to not communicate medical issues (OR=2.20) and to not seek clarification on things they did not understand (OR=2.88). ENKTL patients were 4 times as likely as WM patients to not feel confident voicing concerns (OR=4.43).

Disclosure: For all authors, there are no relationships to disclose.

### 3.2) RESULTS CONT.

Table 3. Patient communication of key issues with the doctor

	Subtype	No (Somewhat + No) Count (%)	Yes Count (%)	OR (95% CI)	p-value
Communicated medical issues to the doctor	ENKTL	19 (28)	51 (72)	OR=2.20 (95% CI 1.23-3.91)	$p < 0.0076$
	WM	70 (14)	479 (86)		
Communicated emotional issues to the doctor	ENKTL	46 (71)	19 (29)	OR=1.26 (95% CI 0.75-2.19)	$p = 0.0089$
	WM	200 (28)	141 (19)		
Sought clarification on things they did not understand	ENKTL	13 (28)	35 (72)	OR=2.88 (95% CI 1.51-5.50)	$p < 0.0019$
	WM	60 (13)	439 (87)		
Felt confident voicing concerns to the doctor	ENKTL	30 (48)	24 (42)	OR=4.43 (95% CI 2.56-7.73)	$p < 0.0001$
	WM	121 (28)	309 (72)		

Compared to WM patients, the reported prevalence of all psychosocial issues (both during and after treatment) was higher for ENKTL patients (figure 1a & b).

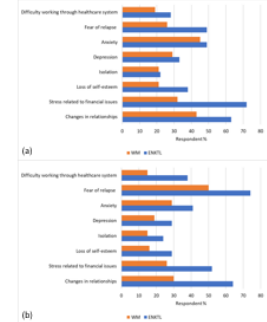


Figure 1. Psychosocial issues reported by patients (a) during and (b) after treatment

### 4) CONCLUSIONS

Compared to ENKTL patients (least informed subgroup in the GPS), WM patients (most informed) reported improved understanding and patient-doctor communication, and lesser prevalence of psychosocial issues. In the future, LC plans to investigate the potential confounding effects of demographic factors and cultural factors (Asia vs NA).

## A Cross-Sectional Study of Unmet Needs of Lymphoma Patients in Patient-Doctor Communication: Follicular Lymphoma (FL) and Diffuse Large B-Cell Lymphoma (DLBCL)



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### 1) INTRODUCTION

The complexity of the lymphoma experience and the myriads of side effects from treatments makes patient-centricity a cornerstone for the care of lymphoma patients. Communication with clinicians is a significant component of this.

This study describes the experiences and unmet needs in patient-doctor communication of patients (FL and DLBCL) using the Lymphoma Coalition (LC) 2018 Global Patient Survey (GPS) on Lymphomas and CLL.

### 2) METHODOLOGY

#### Study Design

- This study is a sub-analysis of the 2018 LC GPS, which is a biennial online global survey of patients with lymphomas including CLL.
- Hosted on a third-party portal from January-March 2018 in 19 languages.

#### Respondents

- Globally, there were 6631 patient respondents from 70+ countries.
- There were 937 FL and 1478 DLBCL respondents.

#### Statistical Analysis

- Raw data was entered, merged, and cleaned in IBM SPSS v21.
- Demographic comparison of respondent subgroups (FL vs DLBCL patients) was completed.
- Questions relating to patient-doctor experiences and perceptions were examined. Descriptive analysis was performed.
- Differences in proportions were tested using chi-square tests ( $p < 0.05$ ) and odds ratios with 95% CI.

### 3) RESULTS

FL and DLBCL patients differed in the distribution of age, sex, and residence (all  $p$  values  $< 0.05$ ) (table 1).

Table 1. Demographic distribution of Follicular lymphoma (FL) and Diffuse large B-cell lymphoma (DLBCL)

	FL count (%)	DLBCL count (%)	X <sup>2</sup> (p-value)
Age			
18-29	27(3)	155(10)	93.83 ( $p < 0.001$ )
30-39	129(14)	323(22)	
40-49	466(50)	599(41)	
50-59	251(27)	277(19)	
60-69	60(6)	117(8)	
Sex			11.58 ( $p < 0.001$ )
Male	558(59)	667(45)	
Female	579(62)	803(55)	
Residence			24.98 ( $p < 0.001$ )
Rural	191(20)	345(24)	
Suburban	240(26)	254(17)	
Urban	502(54)	879(59)	

Two-thirds of both groups (FL-65%, DLBCL-68%) would have liked more information and support at their initial diagnosis. Despite this need, less than half of patients felt their doctors encouraged discussion (FL-39%, DLBCL-45%) and only 23% of FL and 43% of DLBCL patients were referred to further support (figure 1).

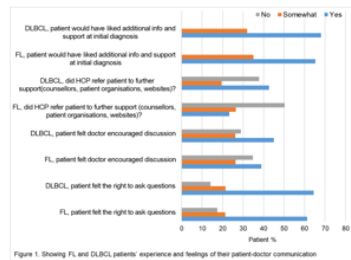


Figure 1. Showing FL and DLBCL patients' experience and feelings of their patient-doctor communication

### 3.1) RESULTS CONT.

Most patients (FL-70%, DLBCL-77%) reported communicating their medical/physical issues to their doctors compared to the low level of communication of emotional issues in both groups (FL-41%, DLBCL-38%).

For those who communicated issues, less than half of them felt helped by their doctors for physical issues (FL-40%, DLBCL-47%) and less still for emotional issues (FL-31%, DLBCL-42%).

Patients' unmet need for help with fatigue, fear of cancer relapse (FOR) and side effects were also examined. Fewer patients felt the doctor helped with issues of fatigue (FL-33%, DLBCL-43%) and FOR (FL-33%, DLBCL-40%) compared to helping with treatment side effects (52%-FL, 69%-DLBCL).

### 4) CONCLUSIONS

- The results show that FL and DLBCL patients would like more information and support than what is currently provided by their doctors.
- Doctors are more likely to address physical and medical aspects of care.
- A large gap exists regarding communication surrounding the emotional/psychosocial issues that lymphoma patients' experience.
- LC advocates for improved communication between doctors and patients. The existing gaps in communication prevent care from being truly patient-centered.

Disclosure: For all authors there are no relationships to disclose.

## Appendix 2

Frequency tables – supplied separately

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