

# Lymphoma Coalition

## 2020 Global Patient Survey on Lymphomas & CLL

---

A report prepared for Lymphoma  
Coalition  
by Picker Institute Europe

July 2020

Country Report

UK

## 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.

Lymphoma Coalition  
8 Stavebank Road N, Unit 401  
Mississauga ON L5G 2T4  
Website: <https://www.lymphomacoalition.org/>

## 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.

Picker Institute Europe  
Buxton Court, 3 West Way  
Oxford, OX2 0JB  
England

Email: [info@pickereurope.ac.uk](mailto:info@pickereurope.ac.uk)  
Website: [www.picker.org](http://www.picker.org)

Registered Charity in England and Wales: 1081688  
Registered Charity in Scotland: SC045048  
Company Limited by Registered Guarantee No 3908160

Picker Institute Europe has UKAS accredited certification for ISO20252: 2012 (GB08/74322) and ISO27001:2013 (GB10/80275). We comply with Data Protection Laws including the General Data Protection Regulation, the Data Protection Act 2018 and the Market Research Society's (MRS) Code of Conduct.

## Contents

Executive Summary	5
Background	12
What is the Global Patient Survey?	12
Methodology	15
Survey 2020 Development and Launch	15
Analysis and Reporting	16
Respondent Demographics	19
Results I. Patient Survey	22
Diagnostic Demographics	22
Treatment Demographics	25
Treatment Options	25
Patient Information, Guidance and Support	27
Diagnosis	28
Patient Knowledge and Experience	29
Healthcare Decision Making	32
Health Behaviours	35
Physical and Medical Side Effects of Diagnosis and Treatment	37
Effects of Lymphoma/CLL	37
Effects of Lymphoma/CLL Treatment	39
Fatigue	43
Psychosocial Effects of Lymphoma/CLL and its Treatment	48
Fear of Cancer Relapse	53
Barriers to Treatment	56
Results – II. Caregiver Survey	58
Caregiver Demographics	58
Caregiver Information, Guidance and Support	61
Impact of Caregiving	63
Appendices	68

SECTION 1

## Executive Summary



## Executive Summary

Lymphoma Coalition (LC) is a non-profit organisation comprising 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 respondents from the United Kingdom.

Overall number of completed responses **743** made up of:



**679** Patients



**64** 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.  
679 Responses



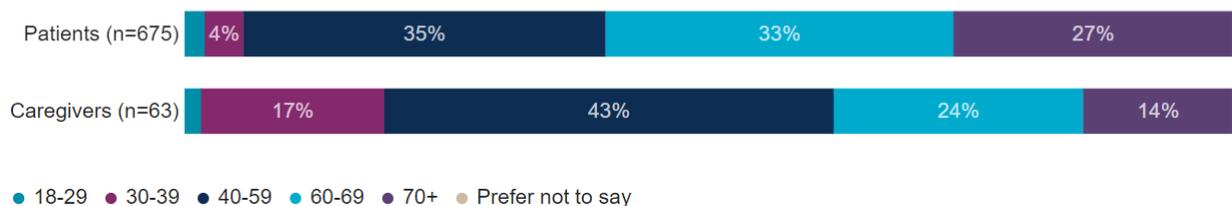
**Figure 2: Gender of caregivers**

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



**Figure 3: Age of patients and caregivers**

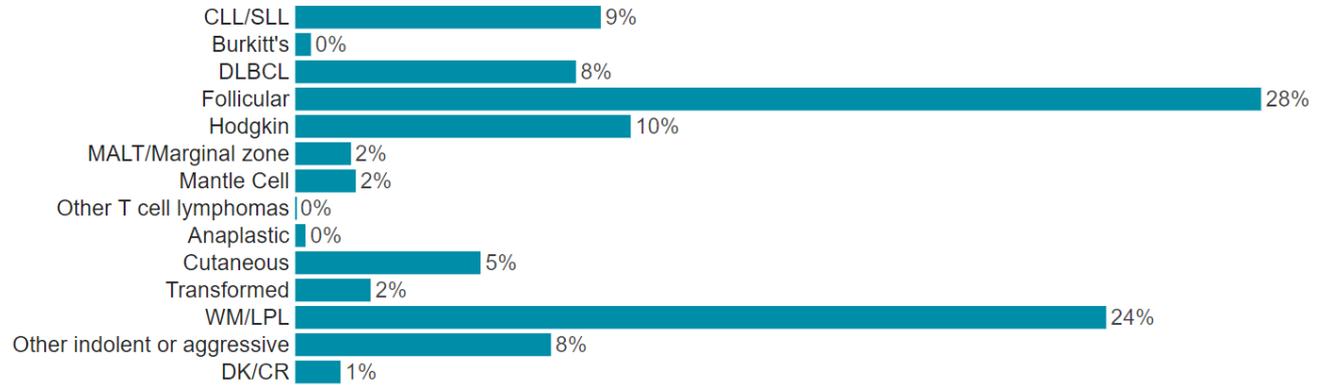
Please describe your experience with lymphoma, including CLL.  
738 Responses



**Figure 4: Subtype by patients and caregivers**

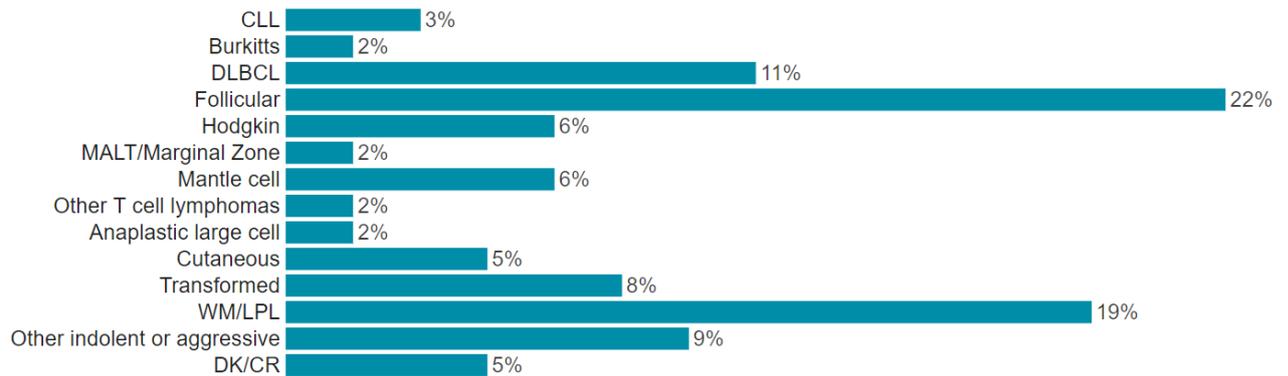
**Patient subtype (grouped)**

679 Responses



**Caregiver subtypes (grouped)**

64 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



70% of patients were told their lymphoma subtype at diagnosis.



Only 32% agree strongly that they have good conversations with their doctor about care and treatment plans.



52% of patients were informed and completely understood how to manage side effects of treatment.



57% are definitely involved as much as they want to be in decisions about their care and treatment.



47% were given access to a clinical nurse specialist at diagnosis.



57% had the greatest need for information within the first month after diagnosis.

## Effects of diagnosis and treatment



76% of patients chose fatigue as the **symptom of lymphoma/CLL** which affects them the most.



79% of patients chose fatigue as the **side effect of treatment** which affects them the most.



Almost two thirds of patients (63%) have discussed their fatigue with their doctor over the last two years. 48% say the doctor did not follow up with them.



56% of patients say their lymphoma/CLL symptoms have negatively impacted their ability to undertake everyday activities people their age can do.



44% of patients had experienced a fear of progression of their lymphoma, and 40% had experienced a fear of cancer relapse.



33% of patients use exercise programs to help them with their fear of cancer relapse.

## Barriers to treatment



83% of respondents reported that there were no barriers that have prevented them from receiving treatment.



54% of respondents reported that not being presented with an opportunity to participate in a clinical trial was the biggest barrier to being in a clinical trial.



Only 9% of patients are currently, or have ever 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,

---

<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.

---

<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 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 respondents from the United Kingdom.

A total of 679 responded to the patient survey and 64 to the caregiver survey. **Caution should be taken in the interpretation of caregiver data given the low number of respondents.**

Demographic characteristics of survey respondents are detailed below. Figure 1 (a&b) displays respondent sex/gender, Figure 2 shows age group, Figure 3 presents their household status and Figure 4 presents their employment status. Figure 5 shows the area of residence of the respondents.

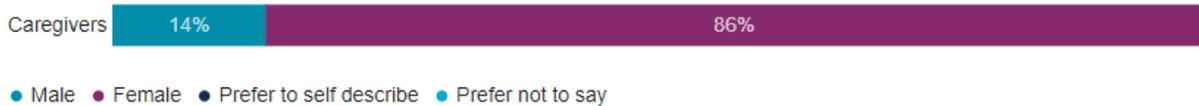
**Figure 1a: Sex of patients**

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



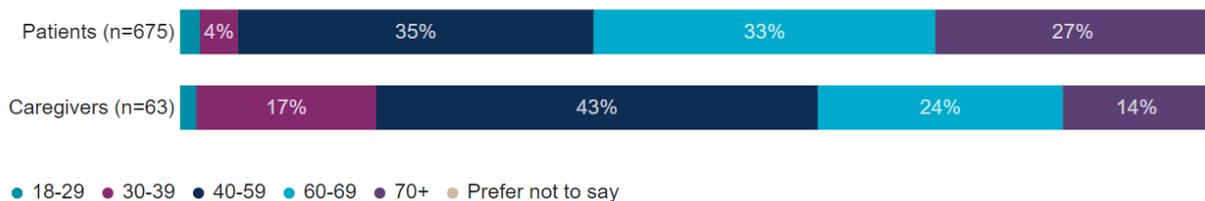
**Figure 1b: Gender of caregivers**

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



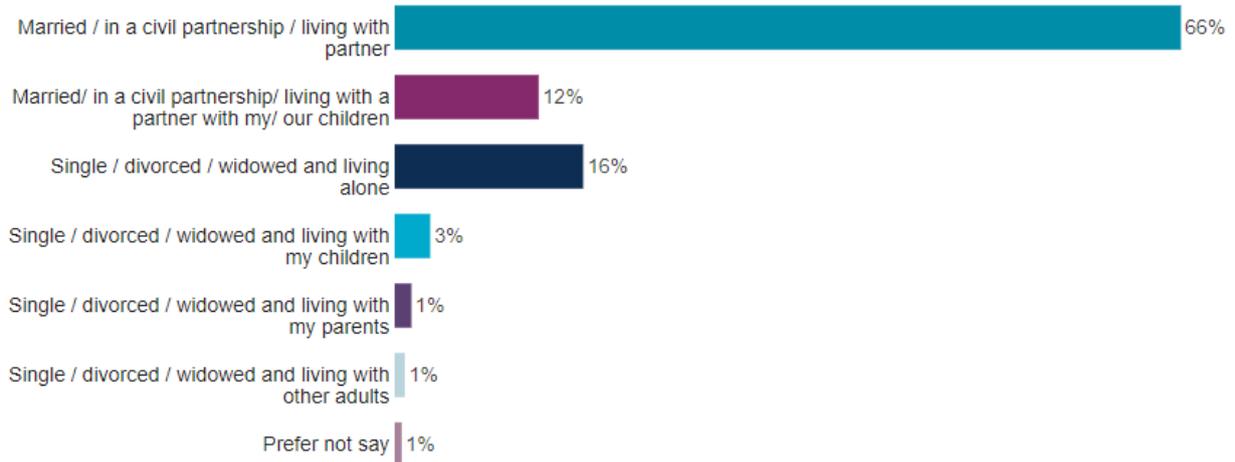
**Figure 2: Age range of respondents**

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



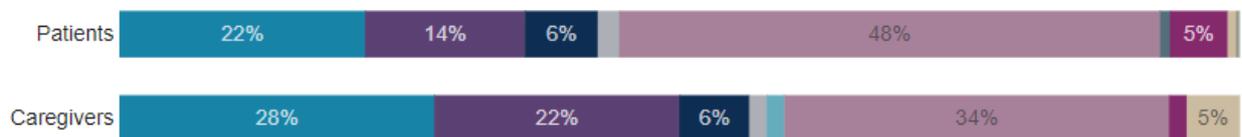
**Figure 3: Household status of respondents (patients + caregivers)**

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



**Figure 4: Employment status of respondents**

Which of the following best describes your employment status?



- Full time employment
- Part time employment
- Self employment
- Home maker
- Student
- Retired
- Unemployed and seeking work
- Unemployed and unable to work for health reasons (NOT seeking work)
- Other
- Prefer not to say

**Figure 5: Area of residence of respondents (patients + caregivers)**

Which best describes the area you live in?  
743 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.

679 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

Patients were asked how long ago they were diagnosed with lymphoma or CLL, and the results are displayed in Figure 6. The majority of patients were diagnosed over two years ago (74%).

**Figure 6: How long ago were you diagnosed with lymphoma or CLL?**

Length of time since diagnosis  
679 Responses

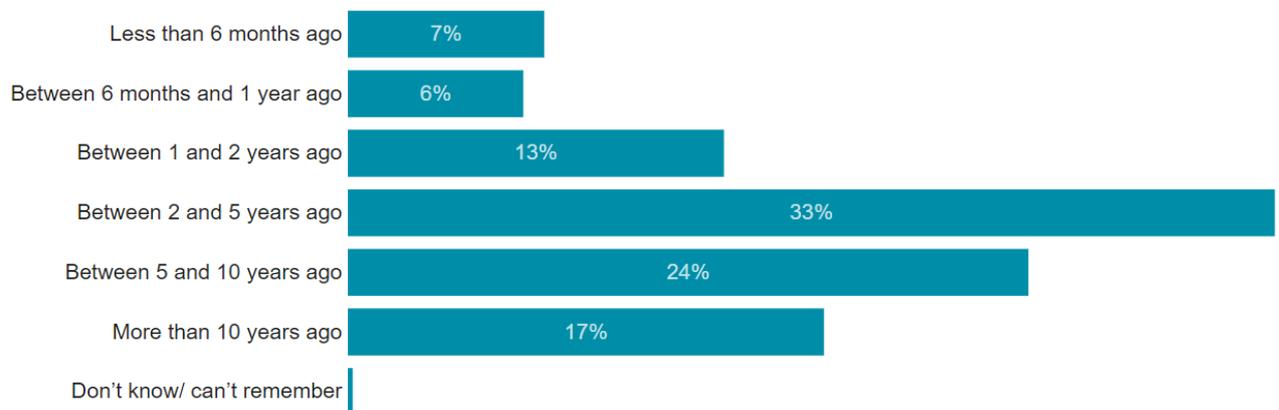


Figure 7 below shows how long patients reported waiting between their first GP appointment about their symptoms to getting a diagnosis. Almost half (47%) of patients had a diagnosis within three months of their first appointment. However, 28% were waiting six months or more from their initial meeting with their GP.

There were no notable differences in the proportion of patients receiving a diagnosis in less than three months across different age groups. When looking at where patients live, over half of patients from city/urban areas and rural areas received a diagnosis in less than three months (54%,53%,

respectively) after their first GP appointment; however, less than half (37%) of patients from suburban areas received a diagnosis in less than three months.

**Figure 7: 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?  
679 Responses

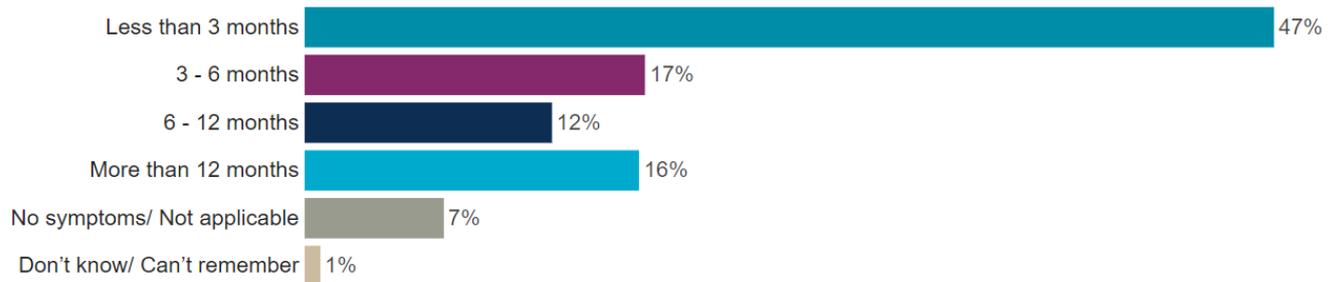


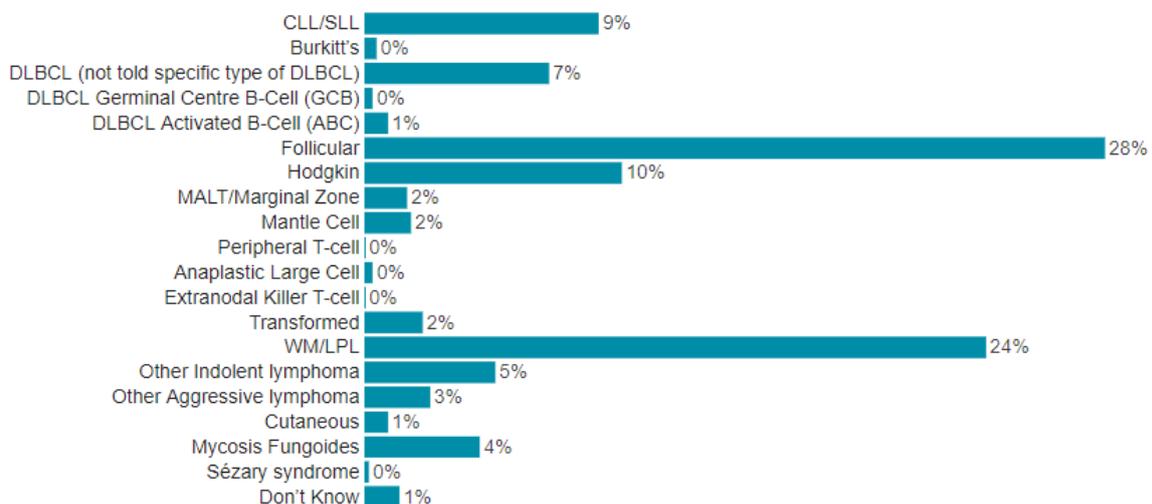
Figure 8 below shows respondent lymphoma subtype. The most common subtypes reported are:

- 28% Follicular lymphoma
- 24% Waldenström’s macroglobulinaemia (WM)/ lymphoplasmacytic lymphoma (LPL)
- 10% Hodgkin lymphoma

There were no notable differences in terms of the proportion of lymphoma subtypes across different age groups and sex. When investigating how long it takes to get a diagnosis of lymphoma, there were no differences (compared to the total UK patient population) for two common subtypes, follicular lymphoma and Hodgkin lymphoma. However, for the patients for whom it took more than 12 months to be diagnosed, 34% of them had the subtype WM/LPL, compared to 24% at total level.

**Figure 8: What subtype of lymphoma do you have?**

What subtype of lymphoma do you have?  
679 Responses

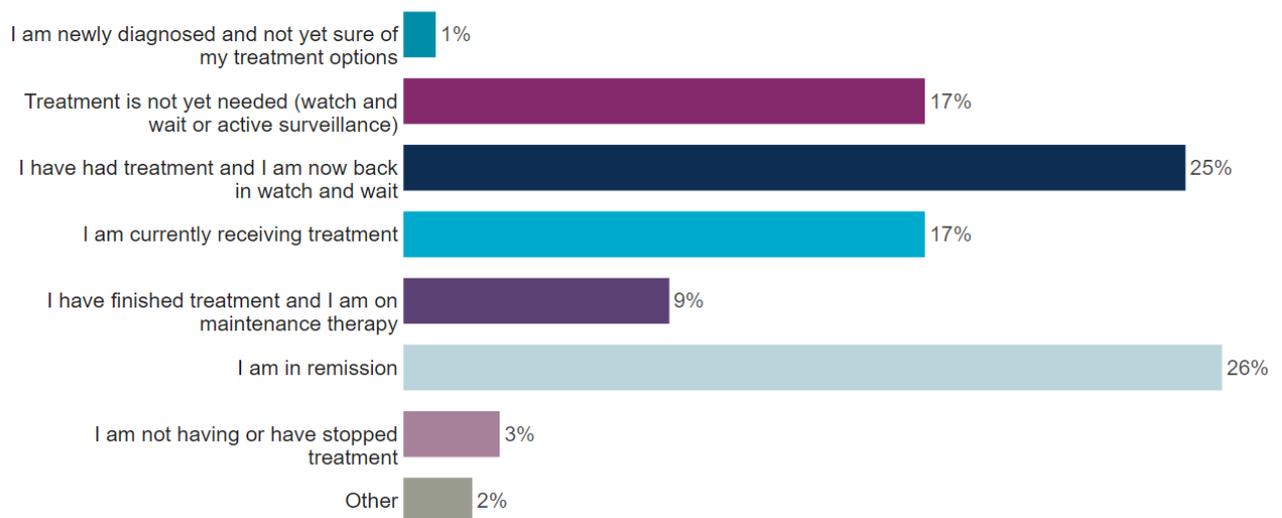


Survey participants were also asked about the stage of their lymphoma care pathway, and their responses are displayed in Figure 9.

17% of patients report that treatment is not yet needed (watch and wait), 17% are currently in treatment, 25% have had treatment and are now back in watch and wait. 9% have finished treatment and are on maintenance therapy, and 26% of patients report that they are in remission.

**Figure 9: What statement best describes where you are in the lymphoma/ CLL experience?**

What statement best describes where you are in your lymphoma/CLL experience?  
679 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

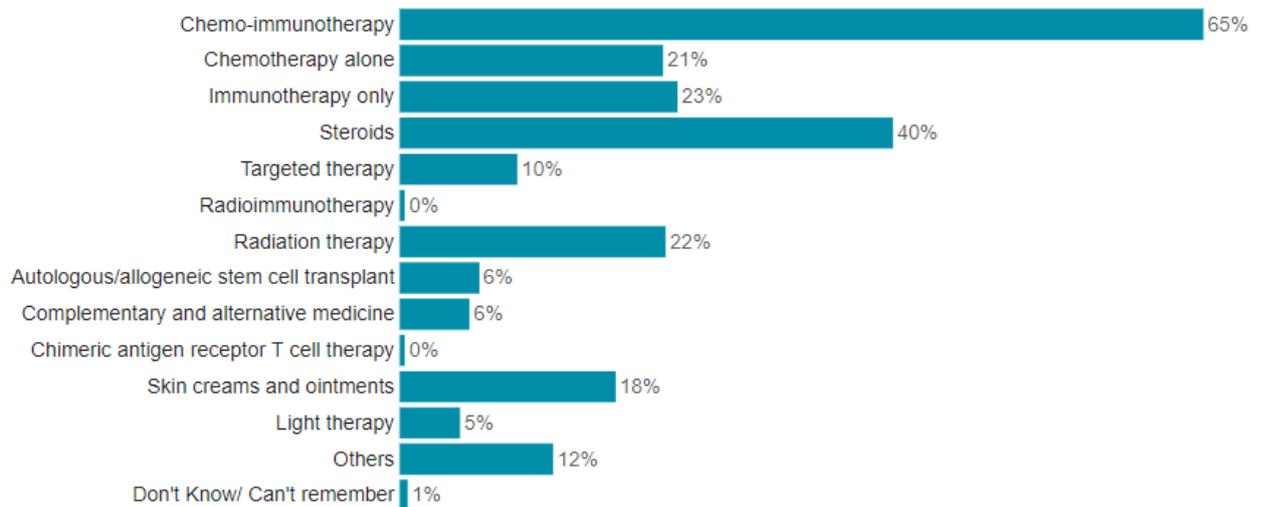
### Treatment Options

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

514 patients reported the different treatments they are on/or have ever been on, these can be seen in Figure 10 below:

**Figure 10: 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?  
514 Responses



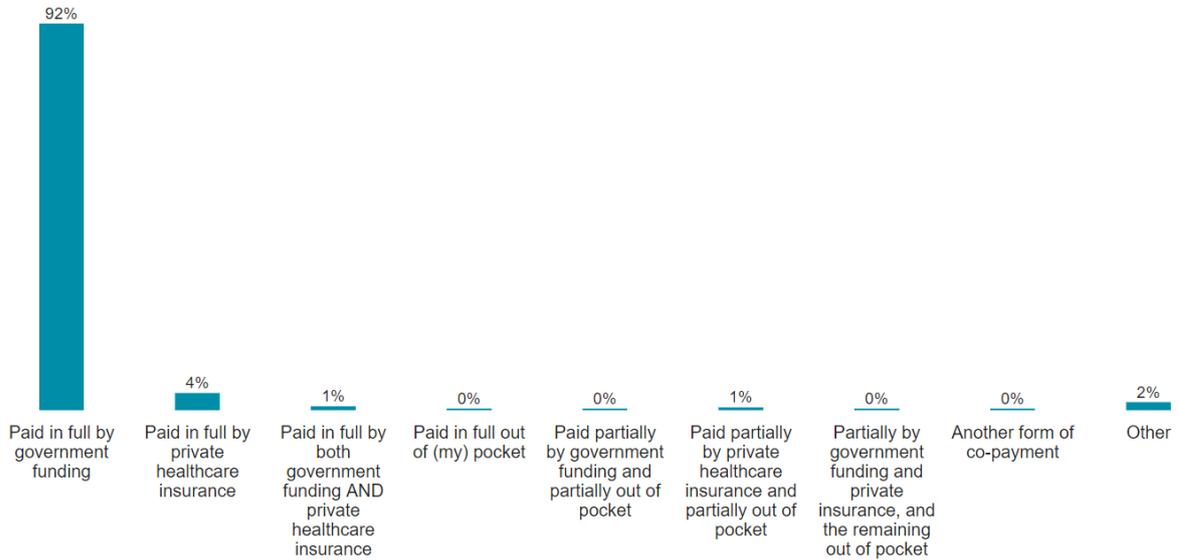
- The majority (80%, n= 149) of patients with follicular lymphoma received chemo-immunotherapy.
- 74% (n=120) of patients with WM/ LPL lymphoma received chemo-immunotherapy. Half (51%) of them also received steroids.

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, the majority of patients selected that their chemotherapy/ immunotherapy/chemo-immunotherapy is paid for in full by government funding (92%) – see Figure 11.

**Figure 11: 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?  
442 Responses

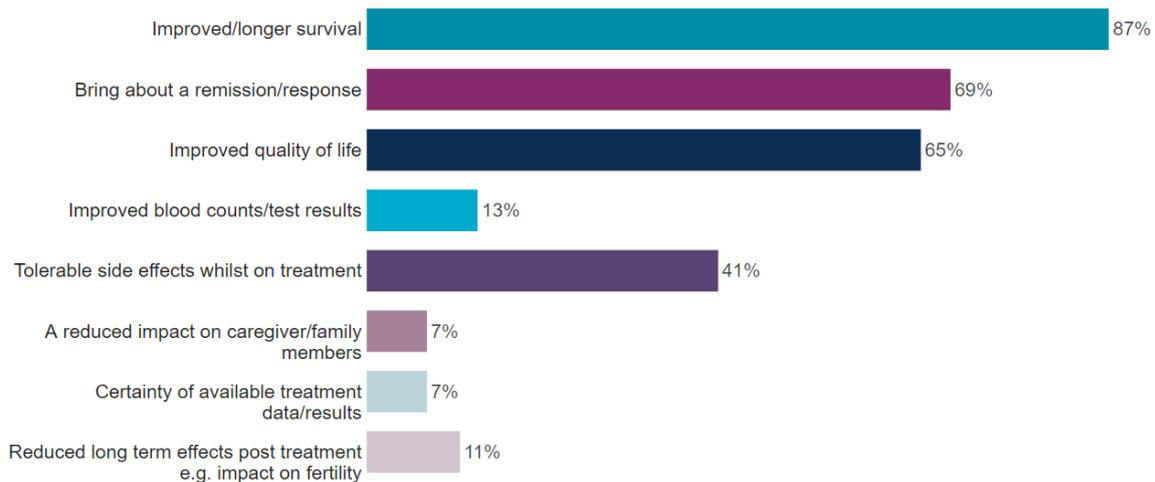


Targeted treatment is also largely paid for in full by government funding (83%, n=40). The results were very different for complementary alternative medicine, whereby 57% of patients reported that it is paid for in full out of their own pocket, 14% report it is paid for in full by the government, and 21% selected ‘other’ as the means of payment.

Patients were asked what they would consider to be important features of a new treatment, and the responses are shown in Figure 12 below. The majority (87%) of patients reported that improved/ longer survival would be an important feature of new treatments. Just 11% reported reduced long term effects post treatment as being important.

**Figure 12: What would you consider to be an important feature of a new treatments?**

What would you consider to be an important feature of a new treatment?  
570 Responses



Only 9% of patients are currently or have previously been in a clinical trial for 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 better 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.



- The majority of patients (88%) reported it was clear they had been given a diagnosis of cancer, and 70% of patients reported they were told their lymphoma subtype.
- 30% of patients were not given enough information at diagnosis, and patients had the greatest need for information within the first month after diagnosis (57%).
- Almost half of patients (47%) were given access to a clinical nurse specialist at diagnosis.
- 34% of patients did not get enough emotional support, and 29% did not get enough financial support throughout their patient experience.
- Over a quarter (26%) of patients agree or strongly agree that they feel overwhelmed by managing their health and condition, and 33% agree or strongly agree that they would wait until health issues could no longer be ignored before they seek help.

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

## Diagnosis

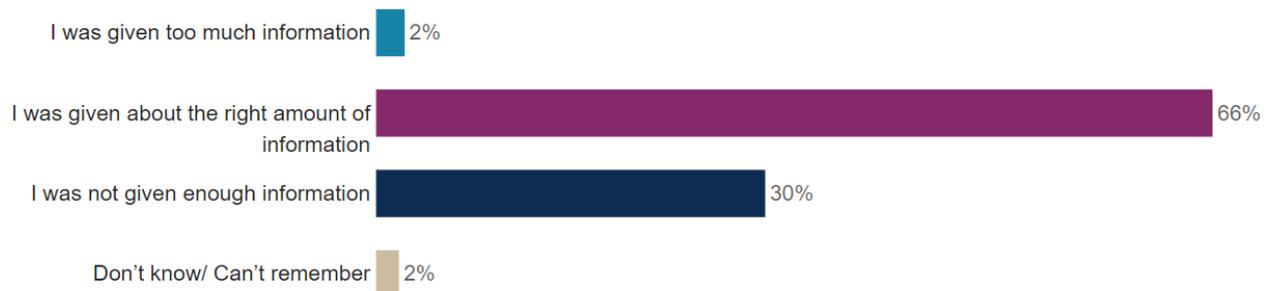
Patients were asked about their experience of receiving a lymphoma diagnosis. Those diagnosed within the last two years (n=178), were asked whether it was clear they had been given a diagnosis of cancer, 88% of patients said yes. Furthermore, 70% of patients reported they were told their lymphoma subtype at diagnosis.

Patients were asked how they felt about the amount of information they received upon diagnosis – 30% were not given enough information. See Figure 13 for overall response.

When asked about the amount of information patients received, there were no differences by age group. There were some differences by sex; 74% of male patients compared to 60% of female patients felt that they were given the right amount of information around the time they were first diagnosed with lymphoma.

**Figure 13: 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?  
676 Responses



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 – see Figure 14. 51% of patients were given and completely understood information on the different medical treatment options, including active surveillance (watch and wait). 55% of patients were provided with information on and completely understood the process and stages of care. And 52% reported they received information on and completely understood how to manage side effects of treatment.

**Figure 14: 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)?

178 Responses



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

167 Responses



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

130 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

Patients had the greatest need for information within the first month after diagnosis (57%).

When asked about information needs:

- 53% needed more information about diagnosis and what it means;
- 46% of patients reported they needed more information about treatment options;
- 43% wanted more information on the side effects from treatment;
- 38% of patients needed more information about psychological support/counselling;
- 25% required more information about support for self-care.

Table 1 displays the number of patients selecting each information need, by lymphoma subtype. Take care interpreting data when number of responses for a particular subtype is less than 20. The table shows that 55% of those with follicular lymphoma and 52% of those with WM/LPL had the greatest need for more information about 'diagnosis and what it means'. 58% of those with Hodgkin lymphoma needed further information about 'side effects from treatment'.

**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	50%	1	50%	1	0%	0	100%	2	0%	0	100%	2	50%	1	0%	0	
Burkitts	100%	3	100%	3	0%	0	0%	0	33%	1	100%	3	0%	0	0%	0	3
CLL/SLL	71%	42	54%	32	32%	19	37%	22	19%	11	39%	23	0%	0	2%	1	59
Cutaneous	57%	21	65%	24	38%	14	43%	16	8%	3	46%	17	5%	2	8%	3	37
DLBCL	49%	27	45%	25	40%	22	38%	21	25%	14	64%	35	4%	2	13%	7	55
Follicular	55%	106	41%	78	24%	45	46%	87	18%	35	37%	71	2%	4	16%	30	191
Hodgkin	49%	33	37%	25	31%	21	48%	32	31%	21	58%	39	24%	16	7%	5	67
Mantle cell	42%	5	75%	9	17%	2	42%	5	33%	4	42%	5	0%	0	0%	0	12
MALT/MZ	55%	6	36%	4	36%	4	45%	5	18%	2	55%	6	9%	1	18%	2	11
Other indolent or aggressive	37%	19	39%	20	24%	12	35%	18	8%	4	35%	18	4%	2	20%	10	51
Transformed	40%	6	40%	6	20%	3	40%	6	7%	1	53%	8	7%	1	20%	3	15
WM/LPL	52%	84	51%	83	14%	23	23%	38	5%	8	37%	60	1%	2	20%	33	162
Don't know/can't remember	44%	4	33%	3	22%	2	22%	2	11%	1	44%	4	0%	0	22%	2	9

When asked to select their top three places to go for information, 41% of patients said ‘doctor’ was their top choice. 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.**

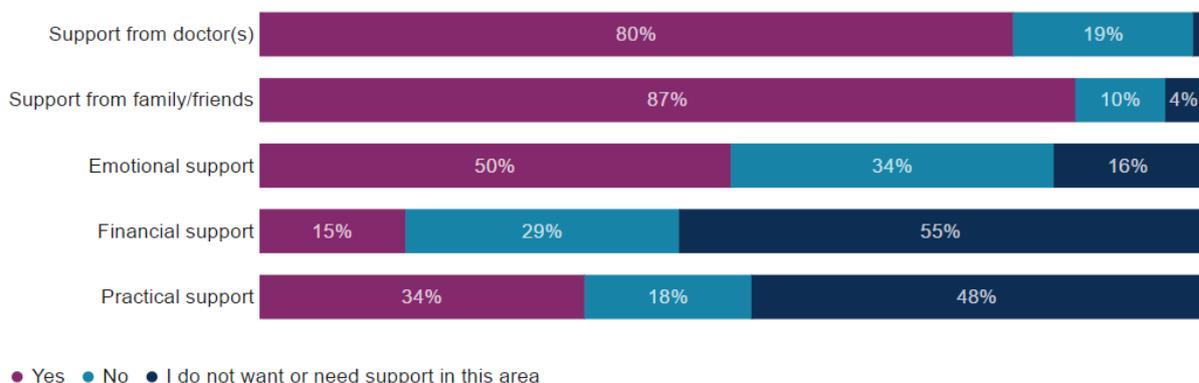
**662 Responses**

	1		2		3	
Doctor	41%	273	26%	168	19%	114
Nurse	17%	110	28%	179	15%	90
Websites	26%	173	22%	143	27%	160
Online blogs/social media	4%	25	7%	44	12%	70
Family/friends	0%	3	0%	3	3%	18
Patient organisation	10%	67	17%	109	22%	132
Other	2%	11	1%	4	3%	15
Total	100%	662	100%	650	100%	599

Figure 15 displays whether patients felt they had received enough support in key areas of patient experience. 87% and 80% felt that they had enough support from family/friends and from doctors, respectively. However, 34% of patients did not get enough emotional support, and 29% did not get enough financial support.

**Figure 15: 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?  
655 Responses

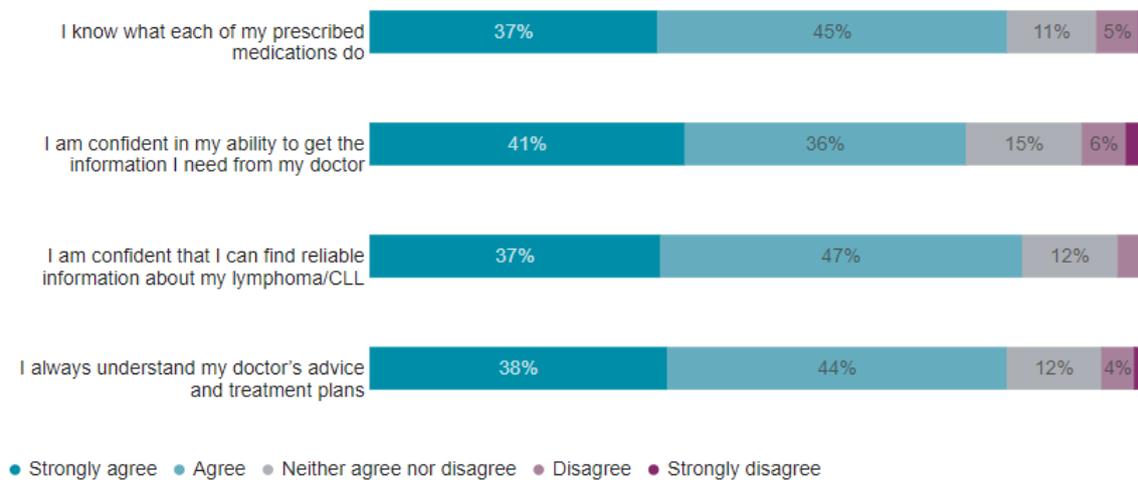


Gender comparisons reveal that a higher proportion of females felt unsupported emotionally (43%), financially (32%) and practically (21%), compared to males (21%, 24% and 13% respectively).

84% reported that they either agree or strongly agree that they are confident that they can find reliable information about their lymphoma/ CLL, and 82% reported that they either agree or strongly agree that they know what each of their prescribed medications do – see Figure 16.

**Figure 16: 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:  
651 Responses



Area comparisons reveal that a higher proportion of patients living in rural areas agree or strongly agree that they are confident in their ability to get the information they need from their doctor (83%) compared to those living in city/urban areas (75%) and suburban areas (72%).

Overall, 64% of patients reported they always have confidence and trust in the doctors treating them, with a further 32% agreeing ‘sometimes’ – see Figure 17.

**Figure 17: Do you have confidence and trust in the doctors treating you?**

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



Of the 54% patients (n=353) who have seen nurses for their lymphoma care over the last year, 75% definitely feel comfortable asking nurses questions about their lymphoma/CLL, and 65% always have confidence and trust in the information they are given – see Figures 18 and 19.

**Figure 18: Do you feel comfortable asking nurses questions about your lymphoma/CLL?**

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



**Figure 19: 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?  
353 Responses



47% of patients in the UK were given access to a clinical nurse specialist at diagnosis:

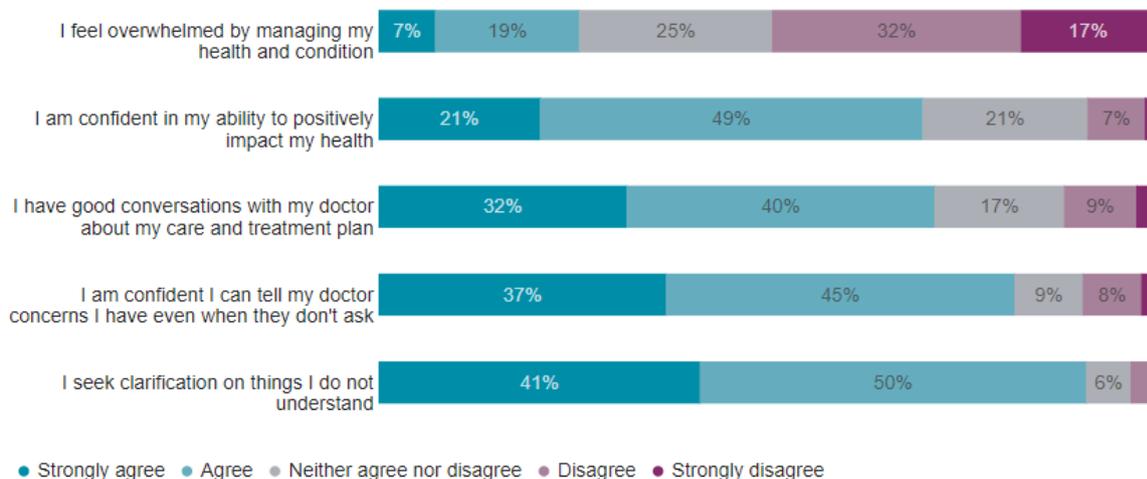
- 28% before starting treatment;
- 23% during treatment;
- 9% after treatment; and
- 20% did not have access to a clinical nurse at all.

### Healthcare Decision Making

Patients were asked a series of questions about the role they play in making decisions about their healthcare – see Figure 20. 91% agree or strongly agree that they seek clarification on things they do not understand. However, over a quarter (26%) agree or strongly agree that they feel overwhelmed by managing their health and condition.

**Figure 20: 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:  
652 Responses



A larger proportion of patients aged 40-59 agreed or strongly agreed that they feel overwhelmed by managing their health and condition (37%) compared to those aged 60-69 (22%) and 70 or over (9%). Furthermore, females were more likely to report feeling overwhelmed by managing their health and condition (32%) compared to males (17%).

57% of patients reported they are definitely involved as much as they want to be in decisions about their care and treatment and 34% report they are involved to some extent. 9% are not involved but would like to be and 1% are not involved, but do not want to be.

Figure 21 shows that 19% of patients had talked to their doctor about wanting to change their treatment to better meet their needs within the last two years.

**Figure 21: 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?  
528 Responses

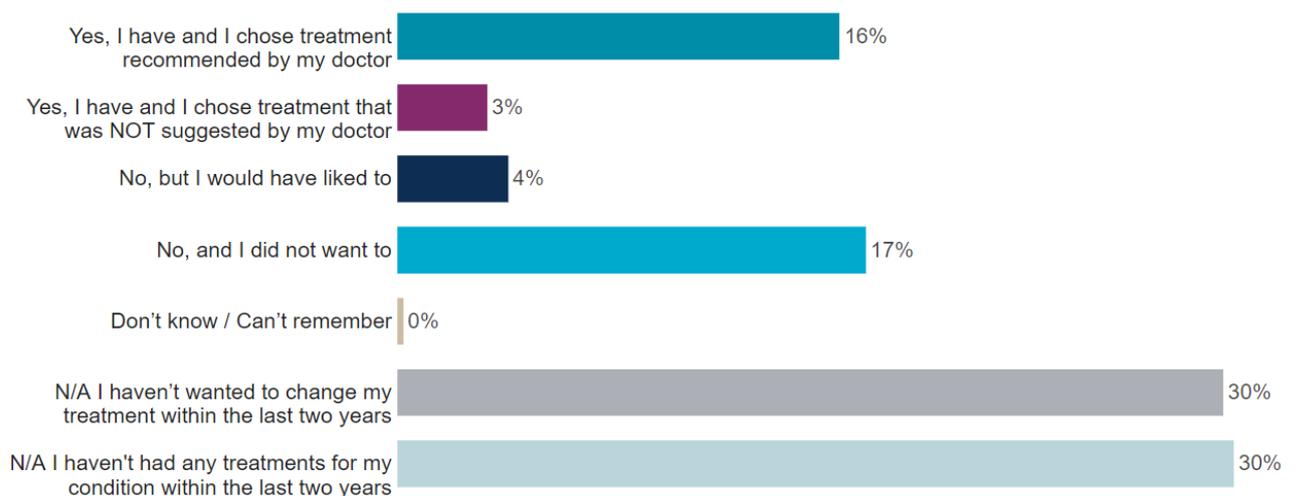
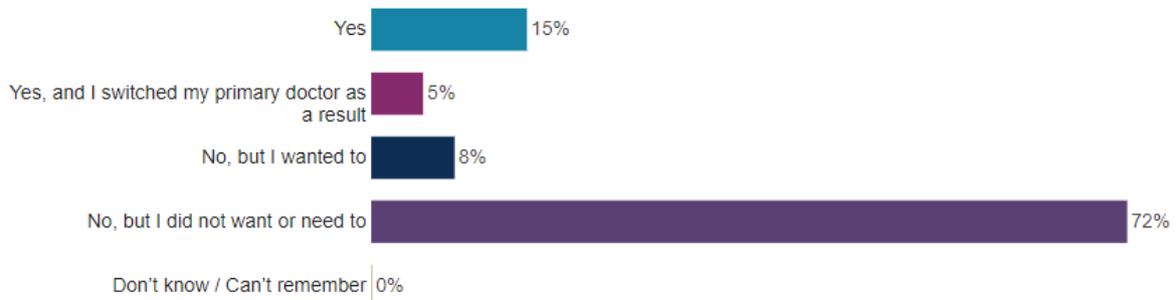


Figure 22 indicates that 20% of patients got a second opinion about their most recent treatment, and 5% changed their primary doctor as a result. 8% wanted to get a second opinion but did not, and 72% felt they did not want or need to get a second opinion.

**Figure 22: 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?  
101 Responses

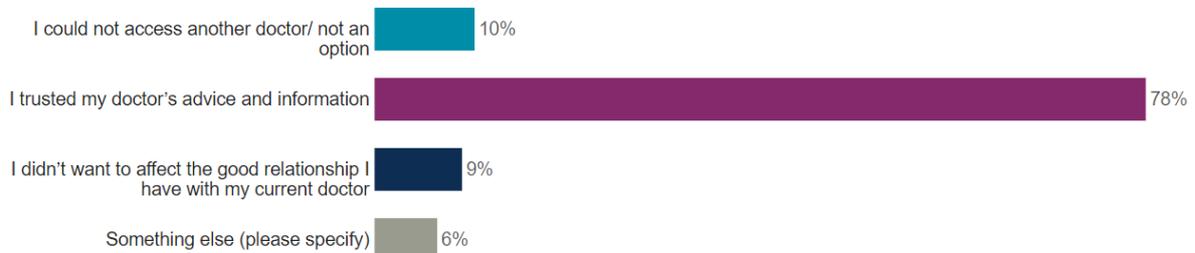


Of those patients who did not get a second opinion (see Figure 23):

- 78% said it was because they trusted their doctors advice and information
- 10% said it was because they could not access another doctor or it was not an option
- 9% said it was because they did not want to affect the good relationship they have with their current doctor

**Figure 23: What was the reason for not getting a second opinion?**

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



When patients were asked what they are most influenced by when making healthcare decisions, the top answers were:

- 77% said recommendations from healthcare providers and clinical staff;
- 19% were most influenced by personal preferences; and
- Only 2% were influenced by financial factors.

Patients were asked to rank the importance of various outcomes – see Table 3. 76% of patients ranked 'a cure' as having the most importance to them, and 'quality of life' was ranked second by 58% of patients.

There were no notable differences by age group and subtype. Cure remains the most important outcome.

**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.**

**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.**

**566 Responses**

	1		2		3		4		5		6		7	
A cure	76%	428	10%	56	6%	34	3%	18	2%	14	2%	12	1%	4
Quality of life	20%	113	58%	328	13%	75	7%	39	1%	8	0%	1	0%	2
Fewer side effects to tolerate	2%	9	24%	137	53%	299	16%	88	5%	27	1%	6	0%	0
Treatment at home versus treatment in clinic	0%	2	2%	12	9%	49	18%	101	37%	209	31%	176	3%	17
Duration of treatment	0%	2	3%	16	14%	80	43%	243	30%	170	9%	49	1%	6
What's best for my caregiver	1%	5	1%	8	4%	22	12%	69	23%	130	53%	299	6%	33
Other	1%	7	2%	9	1%	7	1%	8	1%	8	4%	23	89%	504

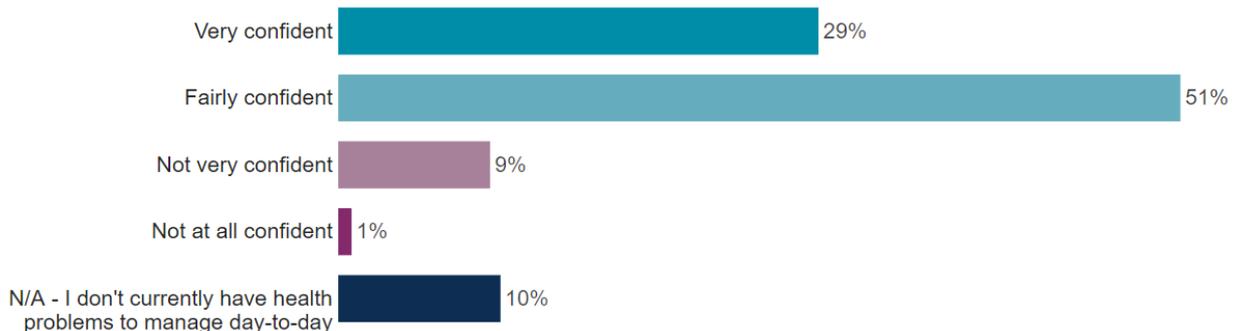
### Health Behaviours

51% of patients report they are 'fairly confident' about managing their health problems day-to-day, however 10% are 'not very' or 'not at all' confident. The full data can be seen in Figure 24.

**Figure 24: 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?

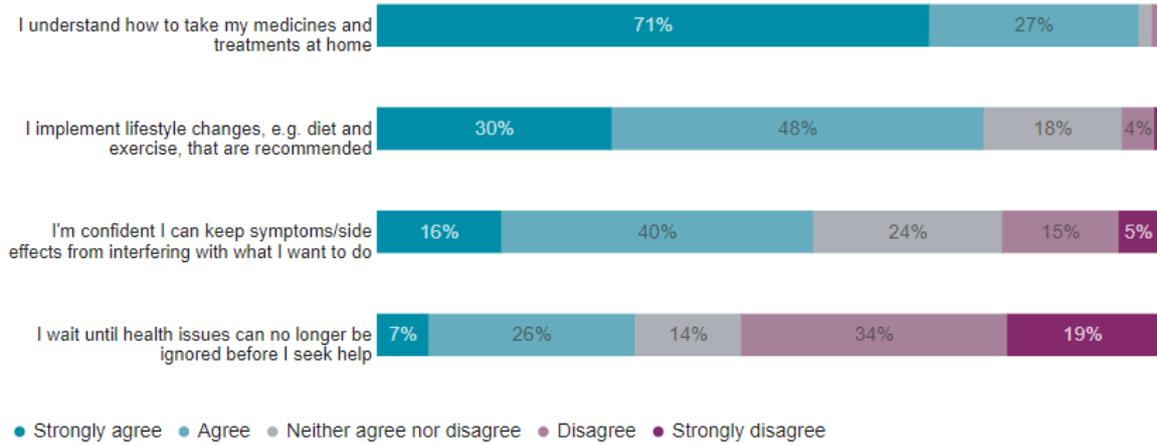
642 Responses



98% agree or strongly agree that they understand how to take their medication and treatments at home; however, 33% agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help – see Figure 25.

**Figure 25: 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?  
631 Responses



## Physical and Medical Side Effects 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 (CRF) 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 2020 survey reports on effects of lymphoma and treatment with particular emphasis on: fatigue, fear of cancer relapse, changes in relationships and mental health difficulties.



- Fatigue was the most reported (76%) symptom experienced due to lymphoma/CLL. Fatigue was also the most reported (79%) treatment related side effect, and 30% of those who experienced fatigue as a result of treatment experienced it for more than 8 years.
- Just over half of patients (56%) agree or strongly agree that their lymphoma symptoms negatively impact on everyday activities that people their age can usually do.
- Only a fifth of patients (19%) who had discussed their treatment-related side effects with their doctor said that the doctor was definitely able to help.
- Just over half of patients who are having or have had treatment agree or strongly agree that their side effects have negatively impacted the everyday activities that people their age can do (57%) and their social life (51%).

### 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 (see Table 4) were fatigue (76%), shortness of breath (35%) and B-symptoms (35%).

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

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

**643 Responses**

Fatigue	76%	486
Frequent or repeated infections	33%	210
Headaches	21%	133
Shortness of breath	35%	228
Easily bruised or bleed	24%	156
Skin rashes/lesions	29%	189
Fever, chills, night sweats and weight loss (B-symptoms)	35%	228
Abnormal painless swelling(s) on the body/enlarged lymph nodes	34%	218
Pain	24%	155
Anaemia	24%	152
No symptoms	8%	52
Other	19%	119
Total	100%	643

Table 5 displays symptoms by how long patients have experienced them. Nearly half of respondents who are affected by B-symptoms or abnormal painless swellings report it has affected them for under a year. 13%-15% of respondents affected by headaches, anaemia, bruising easily, repeated infections, skin rashes and fatigue have been experiencing these side effects for more than eight years. Due to small base sizes of results when broken down by the symptoms and how long the patients have had them, the results cannot be presented by any demographic breaks.

**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:**

**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:**

**580 Responses**

	Under a year		1-2 years		2-5 years		5-8 years		More than 8 years		DK/CR		Total
Fever, chills, night sweats and weight loss (B-symptoms)	47%	106	20%	46	18%	41	3%	7	5%	11	7%	16	227
Pain	36%	56	18%	27	23%	36	8%	13	10%	15	5%	7	154
Fatigue	22%	105	20%	99	30%	147	10%	49	15%	71	3%	14	485
Abnormal painless swelling(s) on the body/ enlarged lymph nodes	43%	94	19%	42	16%	35	5%	10	9%	19	8%	17	217
Shortness of breath	37%	84	25%	56	23%	52	7%	15	6%	14	3%	7	228
Skin rashes/ lesions	28%	52	24%	46	19%	36	11%	21	15%	28	3%	6	189
Frequent or repeated infections	22%	46	21%	45	30%	62	11%	24	13%	27	3%	6	210
Anaemia	34%	51	21%	32	19%	29	7%	11	13%	20	6%	9	152
Headaches	30%	40	18%	24	23%	30	8%	11	14%	18	8%	10	133
Easily bruised or bleed	25%	39	18%	28	23%	35	14%	22	15%	23	5%	8	155

Figure 26 presents respondent views on the effects of their lymphoma/CLL symptoms. 56% reported that they agree or strongly agree that their lymphoma symptoms negatively impact on everyday activities that people their age can usually do.

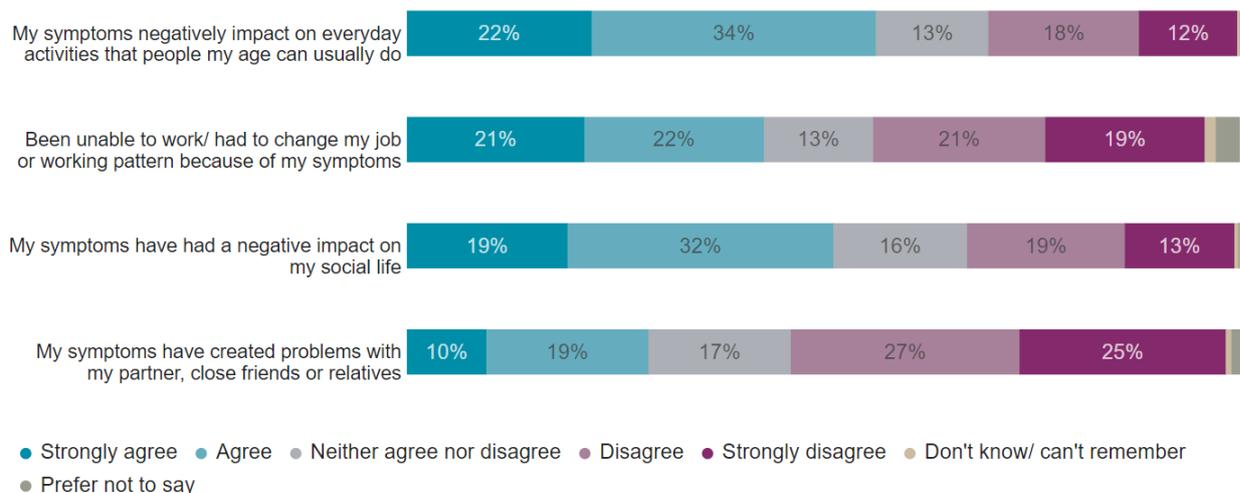
The patients from younger age groups (18-59 years) were affected more by the symptoms of lymphoma, compared to patients from older age groups (60-70+ years). For example, 66% of patients of 18-59 years agreed or strongly agreed that their symptoms had negatively impacted on everyday activities, compared to 50% of patients who were 60-70+ years old.

When looking at patients' household status, single patients generally had a slightly higher proportion of agreement than married patients regarding the impact of symptoms. For example, 59% of single patients agreed or strongly agreed that their lymphoma symptoms had a negative impact on their social life, compared to 49% of the same opinion from married patients.

**Figure 26: 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...

586 Responses



### Effects of Lymphoma/CLL Treatment

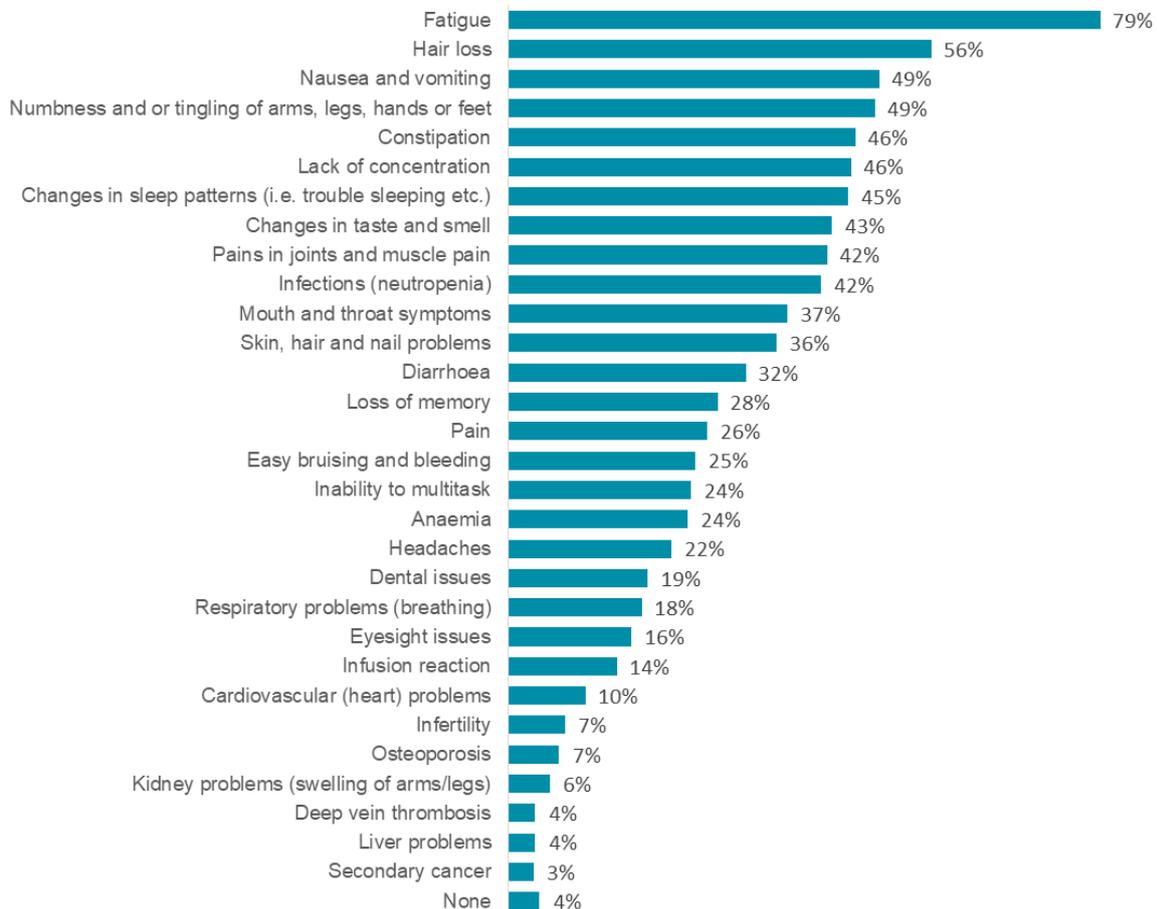
Patients who are receiving treatment for their lymphoma/CLL are affected by a range of treatment-related side effects, the most frequently are shown below (see Figure 27 for full list of reported side effects from treatment):

- Fatigue reported by 79%
- Hair loss reported by 56%
- Nausea and vomiting reported by 49%
- Numbness/tingling of limbs reported by 49%

**Figure 27: Thinking now about your side effects from treatment: Which of the following side effects have you been affected by?**

Which of the following side effects have you been affected by?

507 Responses



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

- 29% (n=124) report that fatigue affects them the most
- 12% (n=53) report that nausea and vomiting affects them the most
- 12% (n=51) report that infections affects them the most
- 7% (n=32) report that hair loss affects them the most
- 4% (n=18) report that numbness/tingling of extremities affects them the most
- 4% (n=17) report that pain affects them the most

30% of patients were affected by fatigue, and 11% were affected by numbness or tingling of extremities for more than eight years. 11% report that they have been experiencing changes in their sleep patterns for between five and eight years.

Figure 28 displays whether patients discussed treatment side effects with their doctor.

**Figure 28: You said you experienced side effects of treatment, did you discuss them with your doctor?**

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

482 Responses



62% responded that they had discussed treatment side effects with their doctor, of those, 19% said that the doctor was definitely able to help with these. A further 57% reported that the doctor was able to help to some extent.

When patients were asked if the doctor was able to help with side effects, there were few variations by age group and sex. For the patients who did not think they were provided with enough information upon diagnosis, 34% did not think the doctor helped with the side effects. This is higher compared to 18% of the same opinion from the patients who thought they were provided with enough information. Causal direction is not implied in this case.

Of those who said their doctor was able to help with treatment side effects:

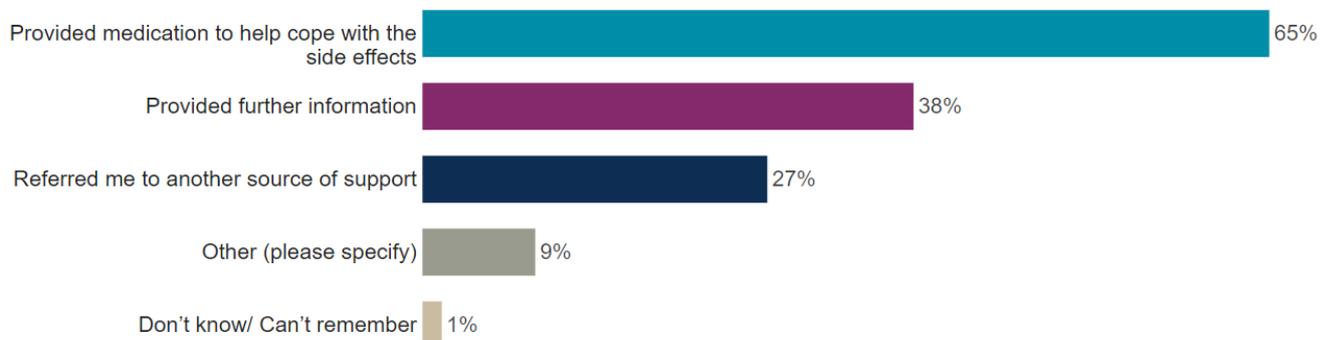
- 65% said the doctor helped by providing medication to help cope
- 38% said the doctor helped by providing further information

See Figure 29 for all response data.

**Figure 29: What specifically did the doctor do to help?**

What specifically did the doctor do to help?

347 Responses



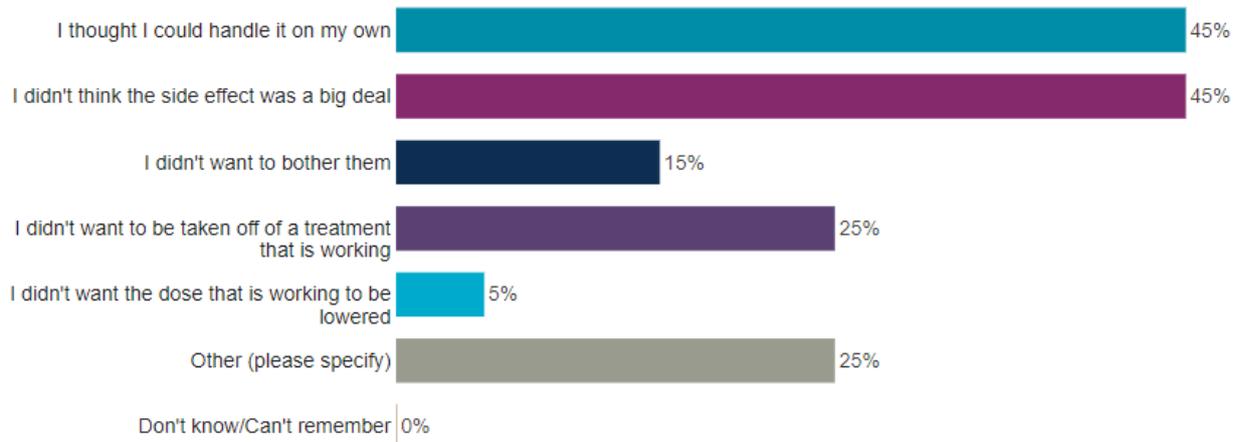
32% of those who have experienced treatment-related side effects and who did not discuss them with their doctor reported the reasons why – see Figure 30 (please take care when interpreting

results, as only 20 patients in total answered this question). Nine patients reported the reason was that they thought they could handle it on their own, and a further nine patients did not think their side effect(s) was a big deal.

Due to low base sizes of this question, the results by demographic subgroup cannot be presented.

**Figure 30: Why have you not discussed these side effects that you have been experiencing with your doctor?**

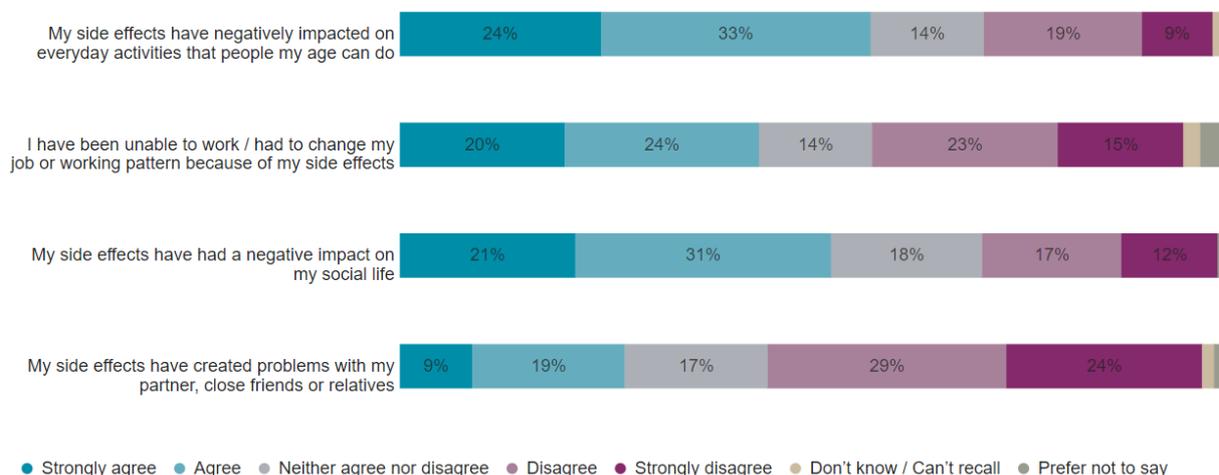
Why have you not discussed these side effects that you have been experiencing with your doctor?  
20 Responses



Regarding the treatment side effects that affected patients, 57% reported that they agree or strongly agree that their side effects have negatively impacted the everyday activities that people their age can do. Similarly 52% agree or strongly agree their side effects have had a negative impact on their social life. However, 53% disagree or strongly disagree that their side effects have created problems with their partner/ close friends or family. See Figure 31 for full details.

**Figure 31: 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:  
478 Responses



● Strongly agree ● Agree ● Neither agree nor disagree ● Disagree ● Strongly disagree ● Don't know / Can't recall ● Prefer not to say

## 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.



- 42% of patients who experience fatigue reported fatigue levels of six or above out of ten (where one = minimal fatigue to ten = worse fatigue imaginable).
- Almost two thirds of patients (63%) have discussed their fatigue with their doctor over the last two years. Patients who reported not discussing their fatigue with their doctor said it was because they thought they could handle it on their own (42%), and that they did not think anything could help (39%).
- 44% of patients report that the doctor did not take any action after they had discussed their fatigue, and almost half of patients (48%) report that the doctor did not follow up with them about the fatigue they were experiencing.

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. 42% 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 85% of patients with a fatigue rating of six or more )
- Physical activity (reported by 79% of patients with a fatigue rating of six or more)
- Social activities (reported by 71% of patients with a fatigue rating of six or more)
- General work around the home (reported by 71% of patients with a fatigue rating of six or more)

See Figure 32 for severity of fatigue broken down by age group. It demonstrates that younger patients were more likely to report a fatigue level of six or more out of ten relative to those aged 60 and above.

**Figure 32: Please rate the severity of your fatigue over the last week on a scale of 1 (minimal fatigue) to 10 (worst fatigue imaginable):**

Level of fatigue by age group



Table 6 displays which areas or activities of a patients life that fatigue has affected over the last two years, broken down by age group. At a total level, general and physical activity were the most commonly reported areas affected by fatigue.

**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?														
	18-29		30-39		40-59		60-69		70+		Not known		Total	
My fatigue hasn't affected any areas of my life over the last two years	10%	1	6%	1	7%	13	14%	23	11%	15	0%	0	10%	53
General activity	80%	8	78%	14	69%	124	66%	109	67%	93	100%	3	68%	351
Mood	90%	9	83%	15	63%	114	46%	76	36%	49	0%	0	51%	263
Employment (working fewer hours, stopped working)	90%	9	67%	12	54%	98	31%	51	4%	5	33%	1	34%	176
General work around the home (daily chores/housework)	70%	7	50%	9	60%	108	48%	79	54%	74	33%	1	54%	278
Relationships with other people	60%	6	56%	10	41%	74	24%	40	17%	24	0%	0	30%	154
Social activities	80%	8	61%	11	58%	105	43%	72	38%	53	33%	1	48%	250
Physical activities	90%	9	56%	10	69%	124	52%	87	58%	80	67%	2	60%	312
My financial situation	50%	5	39%	7	24%	44	14%	23	7%	9	33%	1	17%	89
Enjoyment of life	80%	8	72%	13	49%	89	41%	68	37%	51	100%	3	45%	232
Ability to think clearly/concentrate	90%	9	50%	9	57%	104	44%	73	26%	36	33%	1	45%	232
Ability to remember things	90%	9	56%	10	53%	96	36%	60	30%	41	33%	1	42%	217
Ability to sleep	60%	6	50%	9	51%	93	39%	64	35%	48	33%	1	43%	221

Figure 33 shows that 63% of patients have discussed their fatigue with their doctor over the last two years and 35% have not.

**Figure 33: 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?  
463 Responses

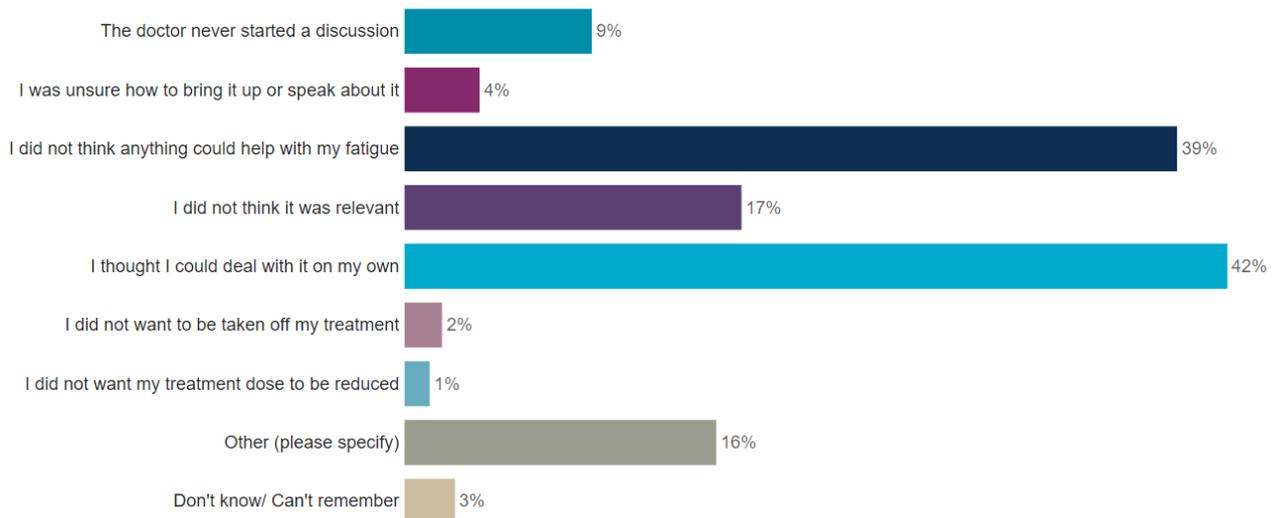


The main reasons patients reported as not having discussed their fatigue with their doctor was they thought they could handle it on their own (42%), and that they did not think anything could help with their fatigue (39%) – see Figure 34.

Due to low base sizes of this question, the results by demographic subgroup cannot be presented.

**Figure 34: Why have you not discussed your fatigue with your doctor?**

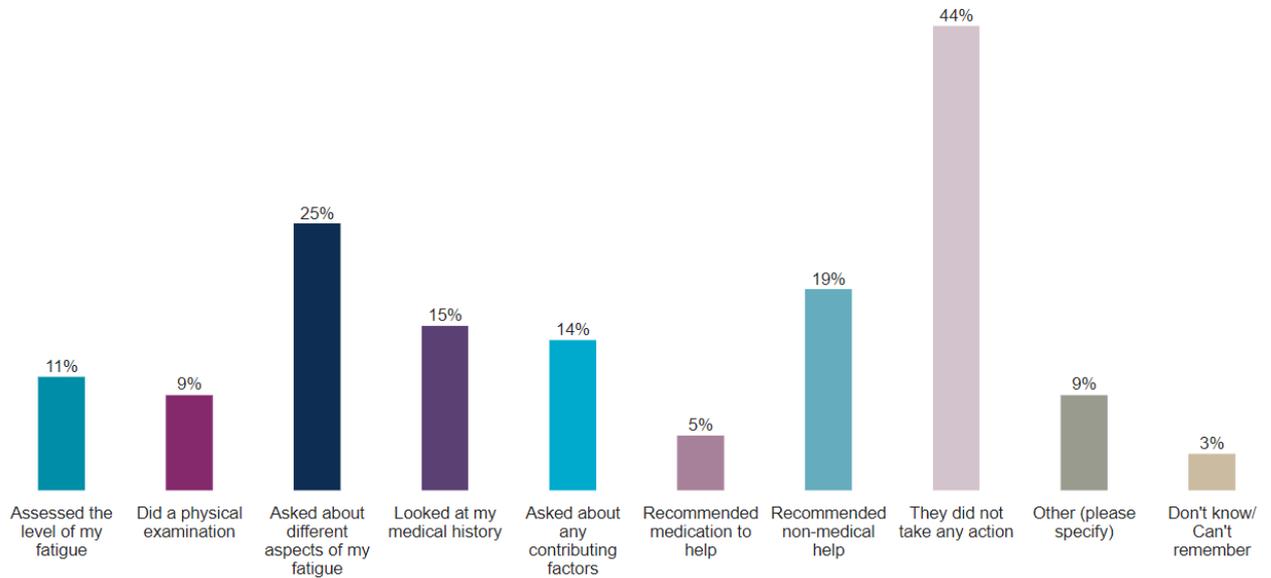
Why have you not discussed your fatigue with your doctor?  
159 Responses



Patients who discussed fatigue with their doctor were asked how their doctor helped with their fatigue. Responses are displayed in Figure 35. Under 20% of patients reported that the doctor did a physical examination (9%) or looked at their medical history (15%). Further, 44% reported that the doctor did not take any action after they had discussed their fatigue.

**Figure 35: What did the doctor do after you discussed your fatigue?**

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

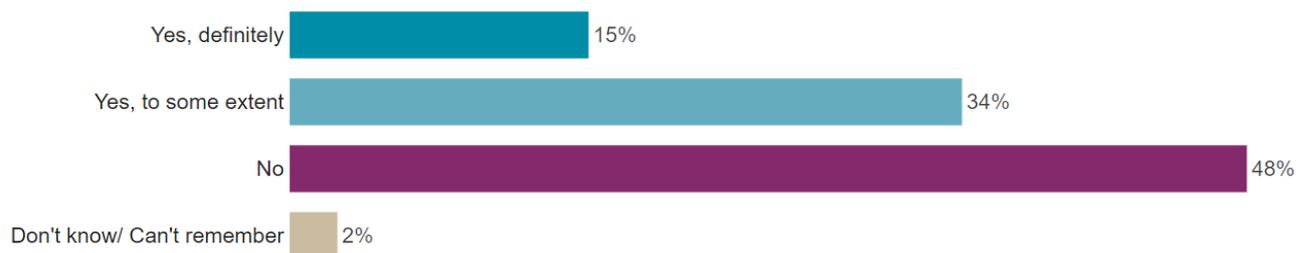


Patients who had discussed fatigue with a doctor were asked whether their doctor followed up with them about their fatigue (see Figure 36), and:

- 15% said 'Yes, definitely'
- 34% said 'Yes, to some extent'
- 48% said 'No'

**Figure 36: 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?  
291 Responses



Patients were asked whether they spoke to anyone else (other than a doctor) about their fatigue, and 57% reported that they also spoke to family/ friends – see Figure 37.

**Figure 37: Did you speak to anybody else to help you with your fatigue?**

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

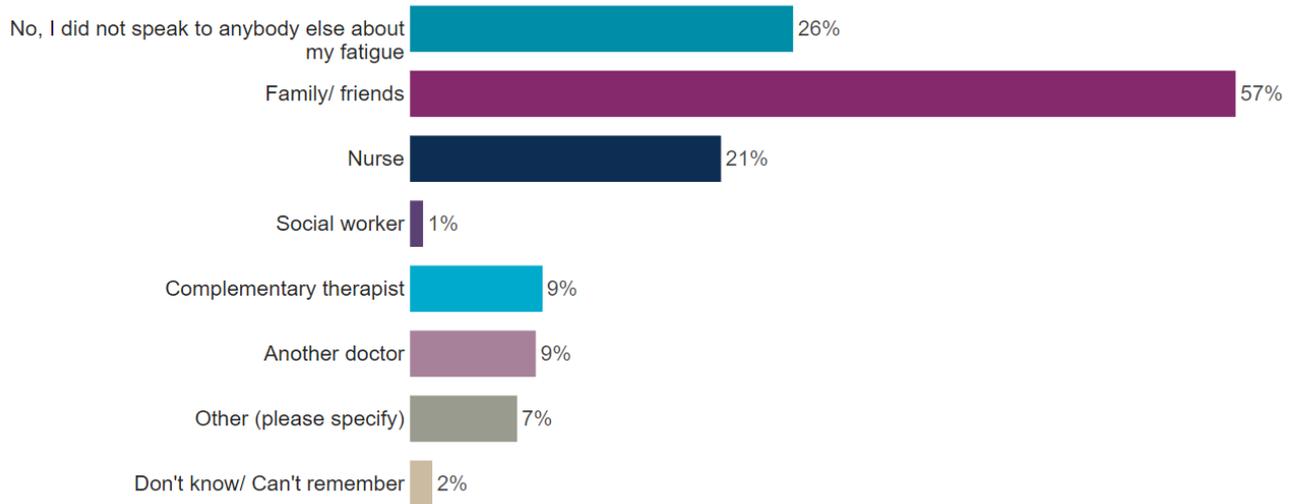
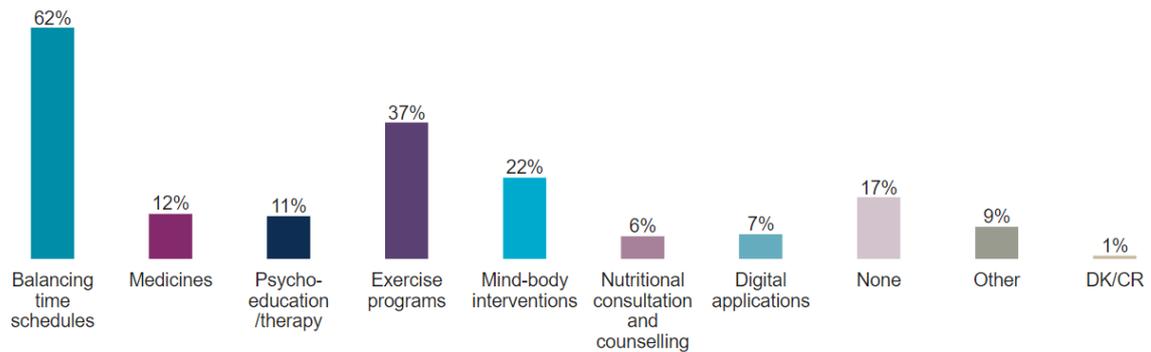


Figure 38 displays the coping mechanisms patients have used to help with their fatigue over the last two years. The most popular selections are balancing time schedules (62%), exercise programs (37%) and mind-body interventions (22%).

**Figure 38: 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?  
515 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.



- Fear of progression of the lymphoma and fear of cancer relapse (experienced by 44% and 40% respectively) were the biggest worries/concerns for patients.
- Less than half of patients who are experiencing anxiety or depression discussed this with their doctor (49% and 42% respectively for anxiety and depression), and only 15% of patients experiencing changes in their relationships discussed it with their doctor.
- Approximately half of those who did not discuss their changes in relationships, anxiety, and/or depression with their doctor say they thought they could handle it on their own (51%, 49% and 53% respectively).

Patients with lymphoma were asked what psychosocial effects they had experienced in the last 12 months as a result of their lymphoma diagnosis (see Table 7). The most commonly reported responses were:

- 44% of patients experienced fear of progression of the lymphoma
- 40% of patients experienced fear of cancer relapse
- 35% of patients experienced anxiety

Looking at what patients experienced as a result of lymphoma diagnosis shows that younger patients had more concerns compared to older patients. For patients who were of 18-59 years, over half of them experienced anxiety (51%), fear of cancer relapse (52%), and fear of progression of the lymphoma (52%). Over 40% of them also experienced loss of self-esteem (43%), concerns about body image/physical appearance (41%) and depression (41%). Only 7% of them stated they did not experience any of these in the last 12 months. For older patients who were over 60 years old, the most commonly reported psychosocial effect they reported was fear of lymphoma progression (39%). 28% of them had not experienced any of these concerns in the last 12 months.

Looking at the results by sex, women had more concerns than men on all aspects. Nearly half of women (49%) experienced fear of progression of the lymphoma, compared to 37% of men. 13% of women did not experience any concerns compared with 31% for men.

There were no notable differences when patients were at different stages of treatment, although there was variation in the results. It is worth noting that when patients were in the stage after treatment and back in 'watch and wait' or the remission stage, they had a higher rate of fear of cancer relapse (52% and 65% respectively) compared to the average.

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

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

**613 Responses**

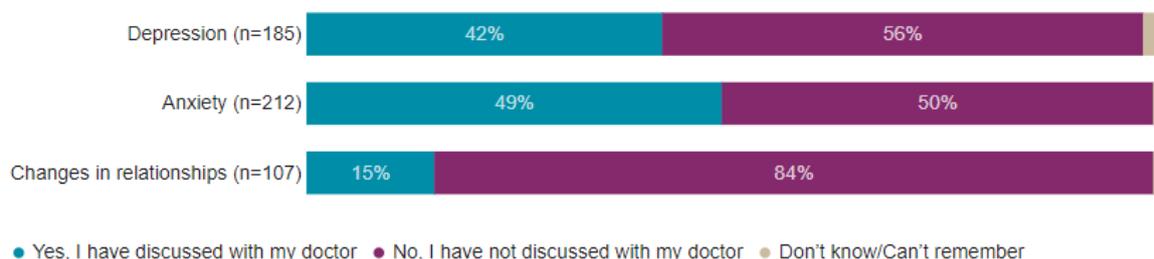
Loss of self-esteem	27%	164
Concerns about body image/physical appearance	28%	172
Changes in relationships	17%	107
Isolation	25%	151
Depression	30%	185
Anxiety	35%	212
Fear of relapse	40%	243
Fear of progression of the lymphoma	44%	270
I have not experienced any of these in the last 12 months	20%	121
Don't know/ can't remember	1%	5
Total	100%	613

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 39 presents the percentage of patients who discussed their changes in relationships, anxiety, and/or depression with their doctor. Less than half of patients reported discussing any of these issues, and patients were more likely to discuss their depression (42%) and anxiety (49%) with their doctor than their changes in relationships (15%).

**Figure 39: 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?

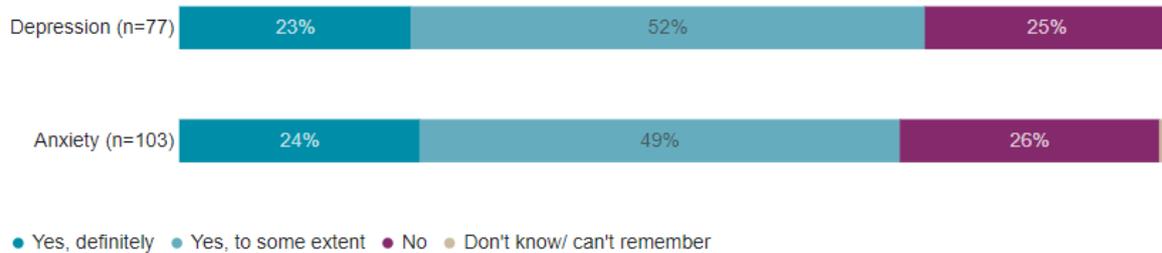


Those who discussed these psychosocial worries or concerns with their doctor were asked whether the doctor was able to help (see Figure 40), and what information or support they were provided with (Table 8).

Due to low base sizes of this question, the results for changes in relationships cannot be presented in Figure 40.

**Figure 40: 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, two thirds (66%) were given medication to help them cope. This was true for 44% of patients reporting anxiety. 43% of patients who experienced changes in relationships were signposted to another source of support. 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	DK/CR	Total						
66%	38	7%	4	22%	13	36%	21	2%	1	3%	2	58

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	DK/CR	Total						
44%	33	20%	15	28%	21	43%	32	5%	4	5%	4	75

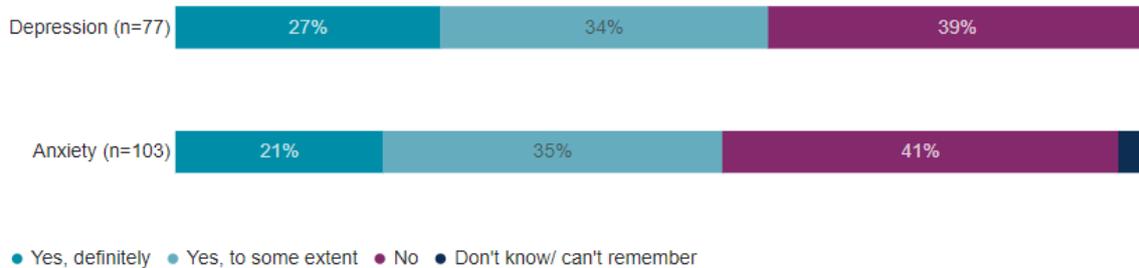
  

Changes in relationships												
Medication to help cope with this worry or concern	Further written or verbal information	Information on coping mechanisms	Signposting to another source of support	Other	DK/CR	Total						
14%	1	14%	1	29%	2	43%	3	14%	1	0%	0	7

Of those who discussed these psychosocial issues with their doctor, only 21% reported that their doctor definitely followed up about anxiety, and 27% reported that their doctor definitely followed up about their depression – see Figure 41.

**Figure 41: For each worry or concern that you discussed with your 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 your doctor, please indicate if your doctor followed-up with you about these worries that you were experiencing?



Of those who reported not discussing these psychosocial issues with their doctor, the main reasons reported were:

- Thought I could handle it on my own (51%, 49% and 53% for changes in relationships, anxiety, and depression respectively)
- Did not want to bother the doctor (30%, 34% and 24% respectively for changes in relationships, anxiety, and depression)
- Did not think it was a big deal (12%, 20% and 14% respectively for changes in relationships, anxiety, and depression)

**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		DK/CR		Total
53%	55	14%	14	24%	25	1%	1	3%	3	17%	18	2%	2	103

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		DK/CR		Total
49%	52	20%	21	34%	36	0%	0	2%	2	20%	21	0%	0	106

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		DK/CR		Total
51%	45	12%	11	30%	27	0%	0	0%	0	12%	11	4%	4	89

When asked who else they had spoken to regarding their worries or concerns (besides the 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 issues experienced, not just changes in relationships, depression and anxiety).

**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		DK/CR		Total
44%	72	43%	70	8%	13	1%	1	12%	20	4%	7	6%	9	4%	6	162

Concerns about body image/physical appearance																
I did not speak to anybody else		Family/friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
40%	67	54%	91	11%	18	1%	1	6%	10	4%	6	4%	6	1%	2	169

Changes in relationships																
I did not speak to anybody else		Family/friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
48%	50	36%	37	7%	7	1%	1	3%	3	5%	5	7%	7	5%	5	104

Isolation																
I did not speak to anybody else		Family/friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
48%	72	38%	57	9%	13	1%	1	7%	10	3%	5	5%	7	2%	3	149

Depression																
I did not speak to anybody else		Family/friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
33%	60	46%	84	13%	23	1%	1	8%	15	17%	31	5%	10	3%	5	182

Anxiety																
I did not speak to anybody else		Family/friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
26%	54	50%	105	14%	30	0%	1	13%	28	16%	34	6%	12	3%	7	210

Fear of progression of the lymphoma																
I did not speak to anybody else		Family/friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
38%	101	48%	129	12%	33	1%	2	4%	11	9%	23	4%	11	2%	6	269

## 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.



- Two-fifths of patients (40%) have experienced a fear of cancer relapse in the last 12 months.
- Almost half of those experiencing fear of relapse (46%) have discussed it with their doctors, with only 24% reporting that the doctor was definitely able to help. Only 21% of those who discussed their fear of relapse reported that the doctor definitely followed up with them about it.
- 41% of patients who experience fear of relapse are not using any coping mechanisms to manage this issue. A third of patients (33%) are using exercise programs as a coping mechanism.

In the LC (2020) Global Patient Survey, 40% of patients reported they experienced a fear of cancer relapse in the last 12 months, and 46% of these have discussed their fear of relapse with their doctor.

Of those who have discussed fear of relapse with their doctor, only 24% of patients reported their doctor was definitely able to help – see Figure 42.

**Figure 42: For the fear of relapse that you discussed with your doctor, please indicate if the doctor was able to help?**

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

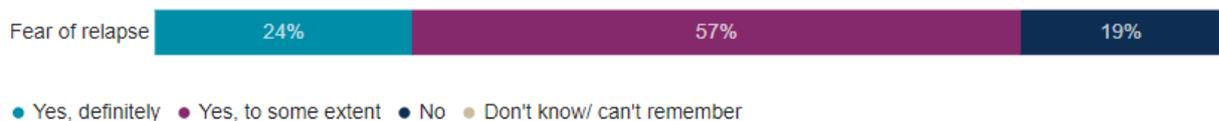
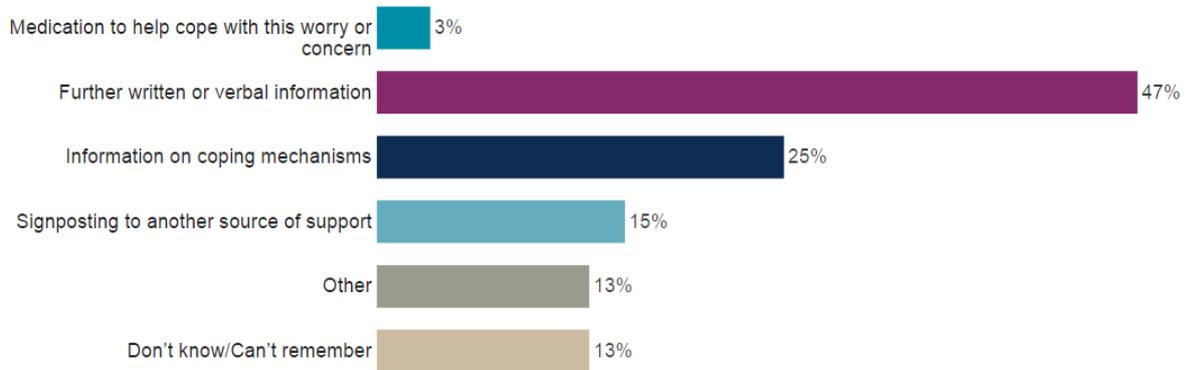


Figure 43 displays the type of information or support patients were provided with by their doctor to help with fear of relapse. Almost half of patients (47%) reported that further written information or verbal information was provided.

**Figure 43: What type of information or support were you provided with, for your fear of relapse?**

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



Only 21% of patients who discussed fear of relapse with their doctor reported that their doctor definitely followed up with them about it, see Figure 44.

**Figure 44: Please indicate if your doctor followed-up with you about the fear of relapse that you were experiencing?**

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

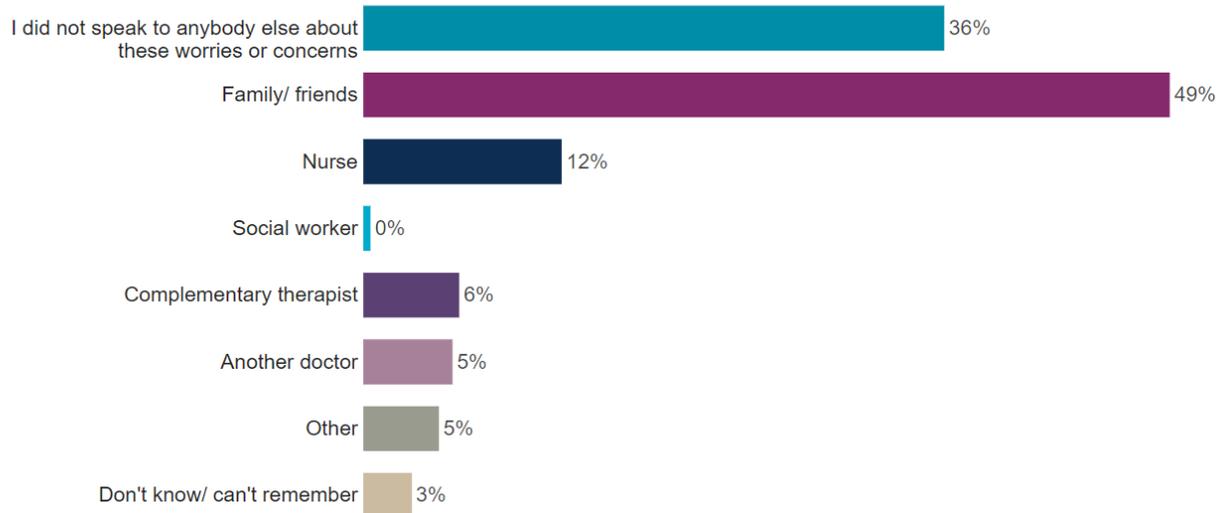


Of those patients who did not discuss fear of relapse with their doctor, 43% reported this was because they thought they could handle it on their own, and 21% reported they did not want to bother their doctor.

Almost half of patients (49%) reported they have also spoken to family and friends about their fear of relapse – see Figure 45.

**Figure 45: For fear of relapse that you have experienced, please indicate who else you have spoken with to help you with these worries or concerns?**

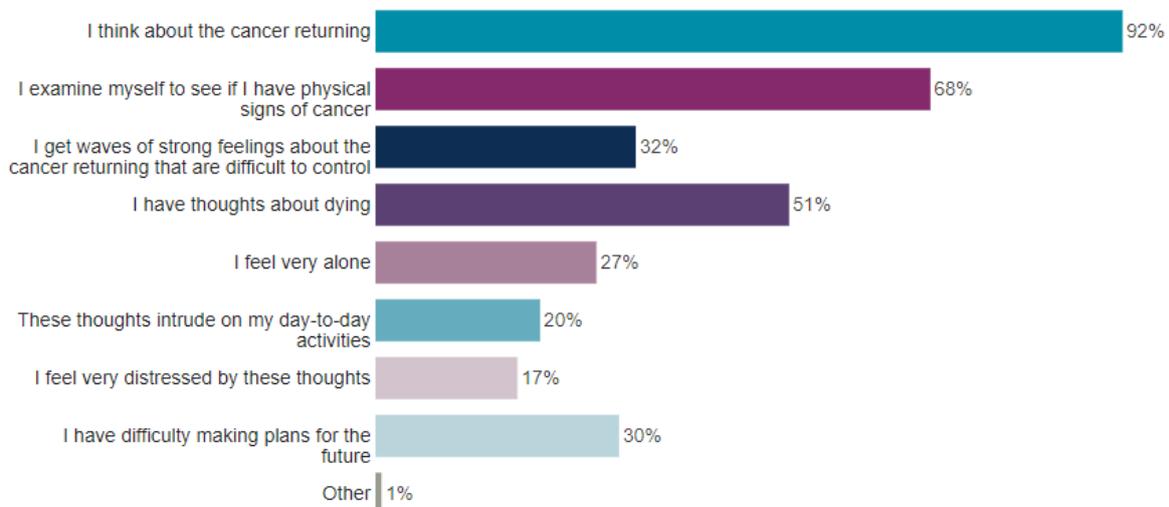
For **fear of relapse**, please indicate who else you have spoken with to help you with these worries or concerns?  
239 Responses



92% of patients who reported experiencing fear of relapse also reported that they think about the cancer returning, and 68% examine themselves to see if they have physical signs of cancer- see Figure 46. Almost a third of patients (30%) have difficulty making plans for the future because of their fear of relapse.

**Figure 46: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?**

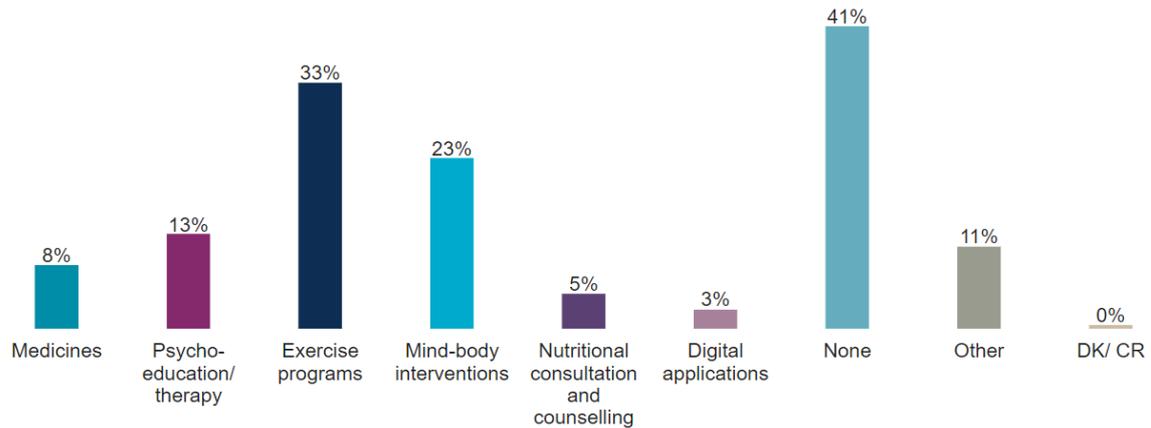
You have indicated that you have experienced a fear of relapse, which of the following have you experienced?  
144 Responses



41% of patients reported that they are not using any coping mechanisms to help with their fear of relapse. 33% reported they are using exercise programs. See Figure 47.

**Figure 47: 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?  
237 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.



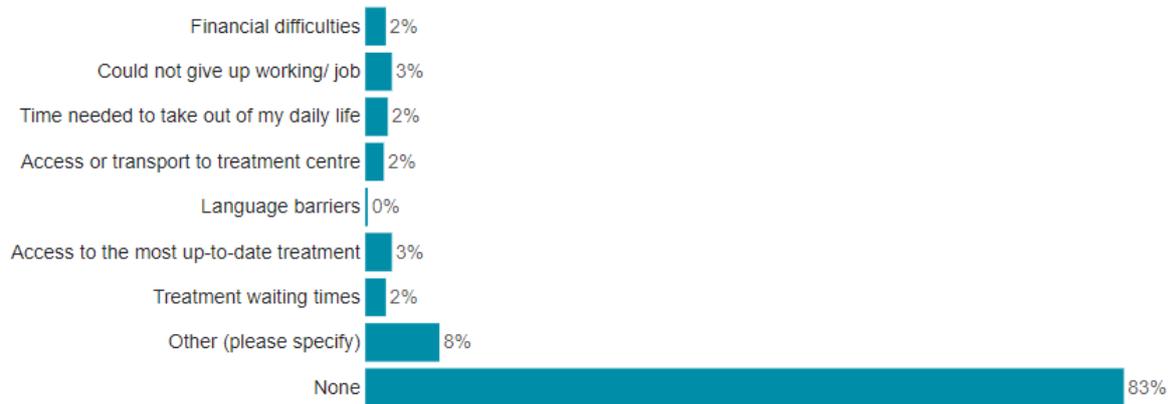
- The majority of patients report there being no barriers to treatment (83%) .
- Just over half of patients (54%) who are having or have had treatment say they have not been presented with an opportunity to participate in a clinical trial, a further 18% say they were not eligible or selected for a trial, and 10% state that clinical trial availability is a barrier.

When asked to select from a list of potential barriers to treatment, 83% of patients selected “none” have prevented them from receiving treatment. 8% of patients reported they were prevented from receiving treatment by ‘other’- see Figure 48.

There were no notable differences in barriers by the areas where patients live. Due to low base sizes, the results cannot be compared within demographic breaks to identify any differences between positive and negative responses.

**Figure 48: Have any of the following prevented you from receiving treatment?**

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



54% of patients found that not having been presented with an opportunity to participate in a trial as the biggest barrier to being in a clinical trial. 18% say they were not eligible or selected for a trial, and 10% state that clinical availability is a barrier.

## 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.

64 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

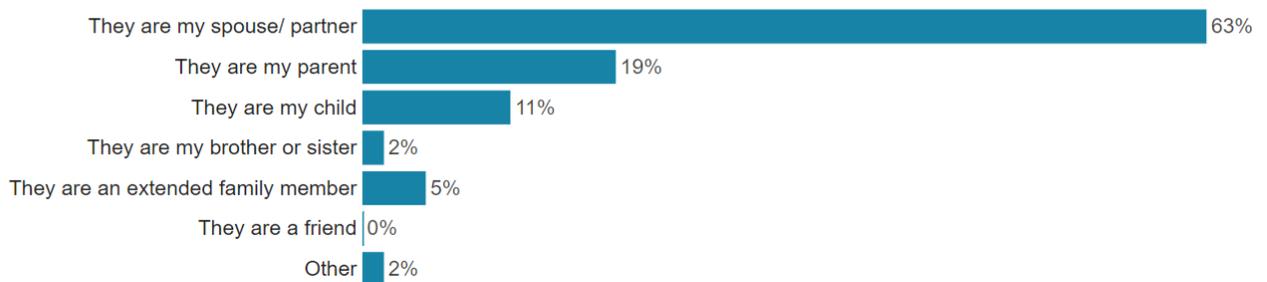
### Caregiver Demographics

64 caregivers participated in the survey.

Caregivers were asked to identify their relationship to the person they are providing care and support to, 63% of caregivers are a spouse/partner and 19% are caring for their parent. Figure 49 displays the full results.

**Figure 49: 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?  
64 Responses



Only 27% of caregivers use the term ‘caregiver’ when thinking about themselves and the care/support they provide.

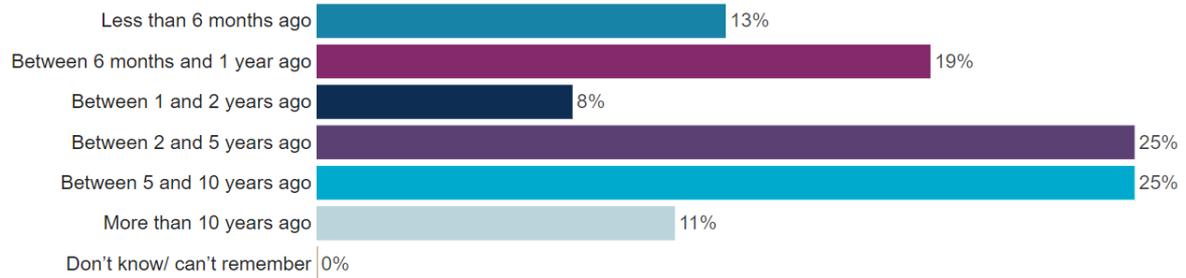
When caregivers were asked the about the support that they provide:

- 95% provide emotional support
- 90% accompany the patient with lymphoma/CLL to appointments
- 79% provide support by looking for information

Caregivers were asked how long ago the person they provide care for was diagnosed, Figure 50 displays the results. The majority of caregivers are caring for someone who received their diagnosis more than two years ago (61%).

**Figure 50: Length of time since diagnosis**

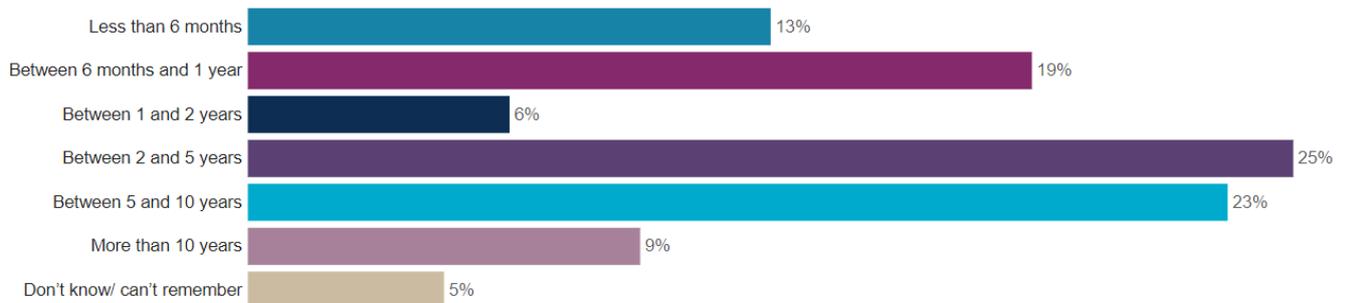
How long ago was the person you care for diagnosed with lymphoma or CLL?  
64 Responses



A third of caregivers (32%) who responded to the survey have been providing care and support for five years or more, see Figure 51 below:

**Figure 51: 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?  
64 Responses



The main lymphoma subtypes of the patients that caregivers are providing care and support are follicular lymphoma (22%) and Waldenström's macroglobulinaemia (WM)/lymphoplasmacytic lymphoma (LPL) (19%). Figure 52 displays the lymphoma subtype for all patients who caregivers are supporting.

**Figure 52: 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?  
64 Responses

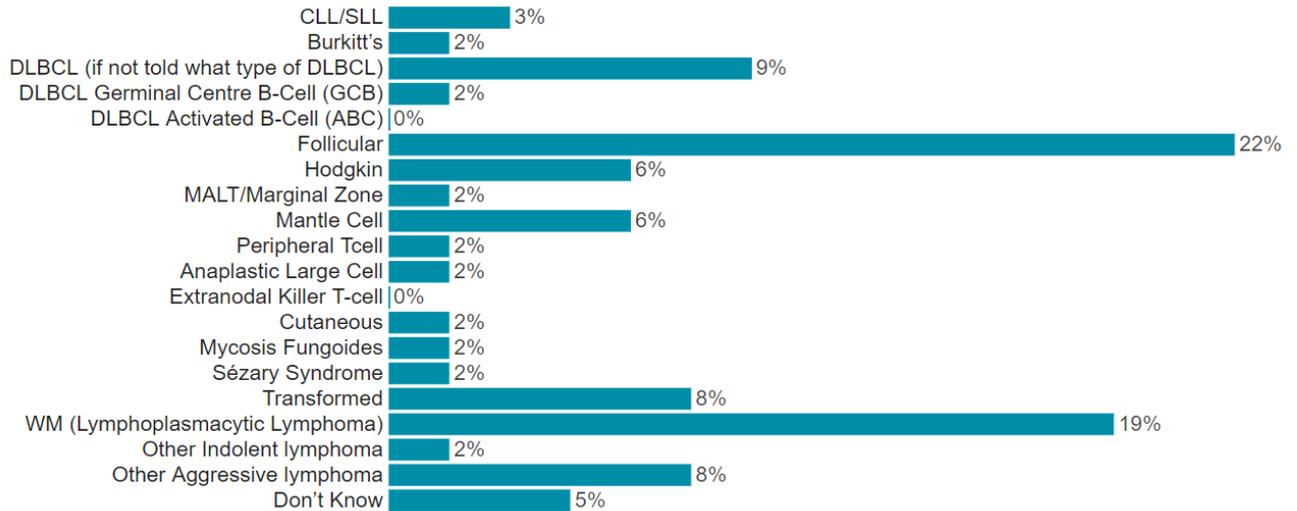
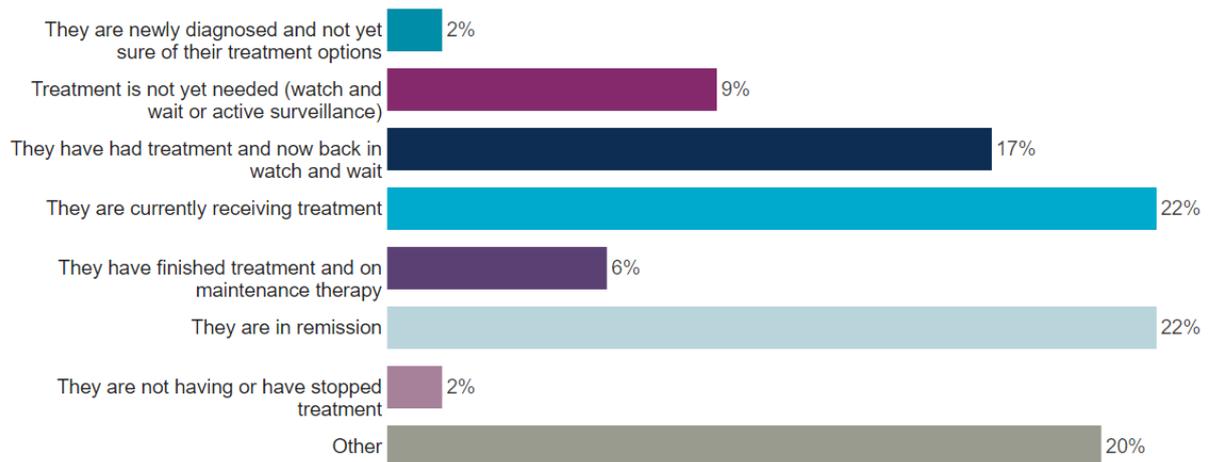


Figure 53 displays the stage of the care pathway of the patients the caregivers are providing care and support for. A fifth (22%) of all caregivers are supporting somebody currently in treatment, and a further 22% care for somebody in remission.

**Figure 53: 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?  
64 Responses



25% of caregivers reported the lymphoma/CLL of the person they care for has relapsed, and 16% reported it has transformed.

## Caregiver Information, Guidance and Support



- Caregivers report playing a large role in gathering information for the patient, 42% seek information alone, and 43% seek information with the patient.
- 53% of caregivers reported that a doctor would be their first place to go for information, should they need it.
- Just over a third (36%) say they have definitely felt supported/assisted/understood by healthcare providers. However, only a quarter (26%) definitely feel their role as caregiver is recognised by healthcare providers.

Table 11 indicates the top places caregivers go for information. When asked to select their top three places to go for information, 53% of caregivers said ‘doctor’ was their top choice.

**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.**

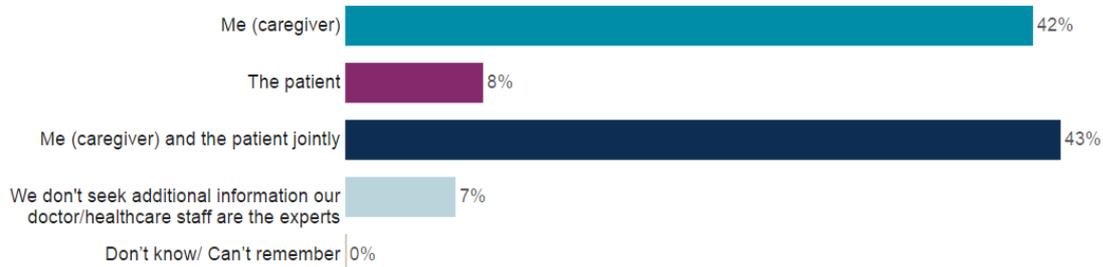
**When you have a need for information about the healthcare of the person you care for, which of the following do you go to first for information? Please rank your top choices starting with your first choice. 60 Responses**

	1		2		3	
Doctor	53%	32	15%	9	14%	8
Nurse	12%	7	27%	16	16%	9
Websites	17%	10	32%	19	25%	14
Online blogs/social media	3%	2	12%	7	7%	4
Family/friends	2%	1	2%	1	4%	2
Patient organisation	12%	7	12%	7	32%	18
Other	2%	1	0%	0	2%	1
<b>Total</b>	<b>100%</b>	<b>60</b>	<b>100%</b>	<b>59</b>	<b>100%</b>	<b>56</b>

Figure 54 indicates who was seeking out information and details about the disease and potential treatments (the patient with lymphoma, the caregiver, or both).

**Figure 54: 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?  
60 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:

- 72% said it was less than six months ago;
- 13% said it was more than one year ago;
- 12% said it was between six months and one year ago.

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. Only about a quarter of caregivers (28%) report they definitely felt assisted/supported and understood by their family and friends, and that their role as a caregiver is recognised by healthcare providers (26%). Figure 55 displays the extent to which caregivers report feeling supported and recognised.

**Figure 55: 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.  
50 Responses



## Impact of Caregiving



- The most common reported elements of caring are emotional support (95%) and accompanying the patient to appointments (90%), with 57% stating that they find emotional support the most difficult to provide.
- 90% of caregivers reported being affected by fear of cancer relapse (often/always + sometimes) and 89% reported feeling worried and/or anxious (often/always + sometimes)
- The areas of caregivers lives most affected are the emotional, social and practical aspects in addition to their own well-being (88%, 47%, 40% and 37% respectively).

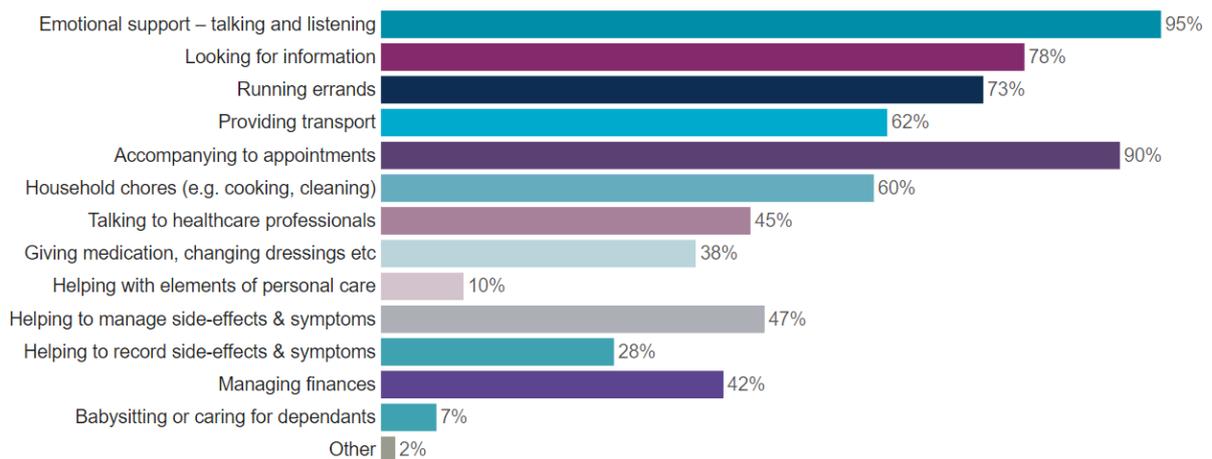
Caregivers were asked to think about the different aspects of the care and support that they provide to somebody with lymphoma/CLL. Providing emotional support (95%) and accompanying patients to appointments (90%) were the most common reported aspects. Figure 56 displays the results for all types of care provided by the caregivers who responded.

Due to low base sizes of this question, the results by demographic subgroup cannot be presented.

**Figure 56: 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.

60 Responses



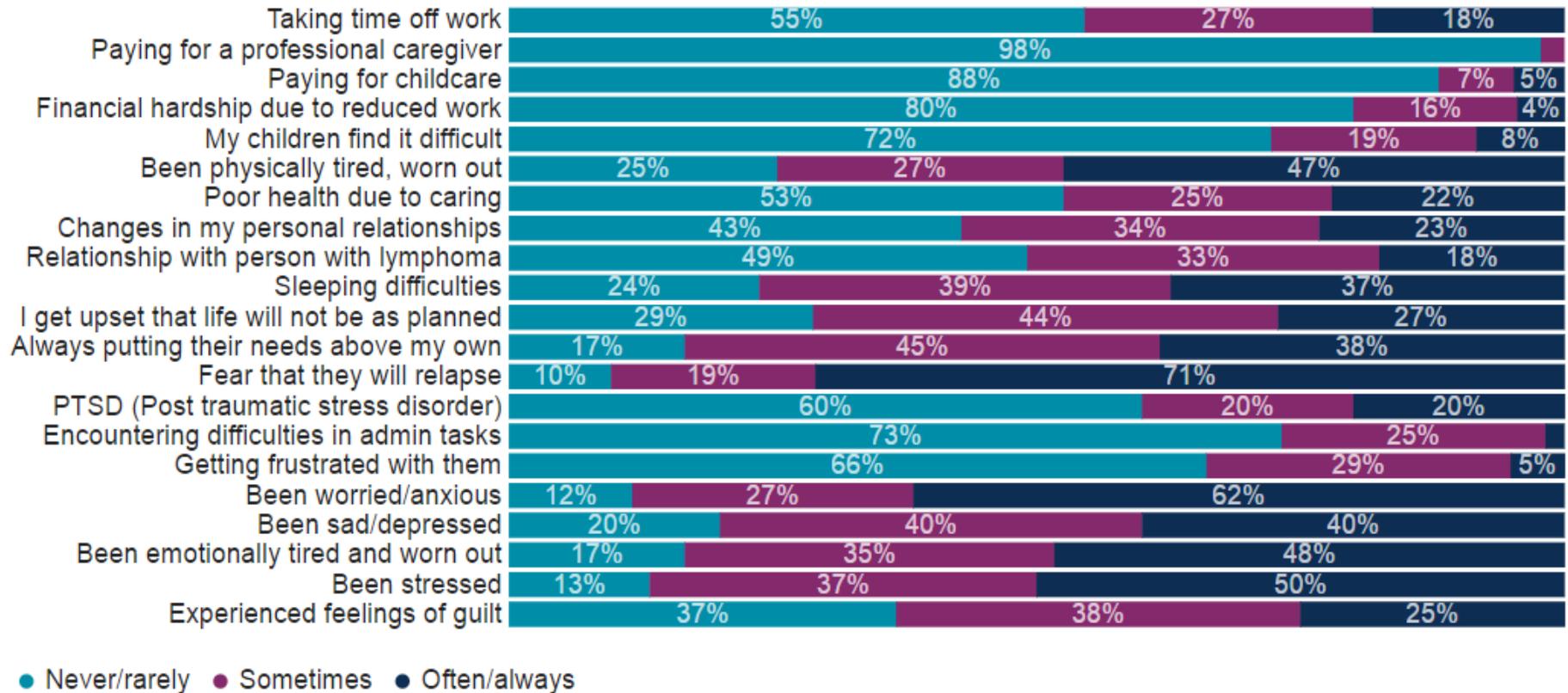
Caregivers were asked which type of care and support they find the hardest to provide:

- 57% reported emotional support
- 8% reported physical support

Caregivers rated the frequency with which some aspects of providing care and support to somebody with lymphoma/CLL had affected them. Figure 57 on the next page displays the extent to which various issues have affected caregivers in the past 12 months. Fear of cancer relapse often/always affected 71% of caregivers. 62% report they are often/always worried or anxious, and half of all caregivers (50%) say they are often/always stressed.

Figure 57: In the past 12 months, to what extent do each of the following issues affect you as a caregiver?

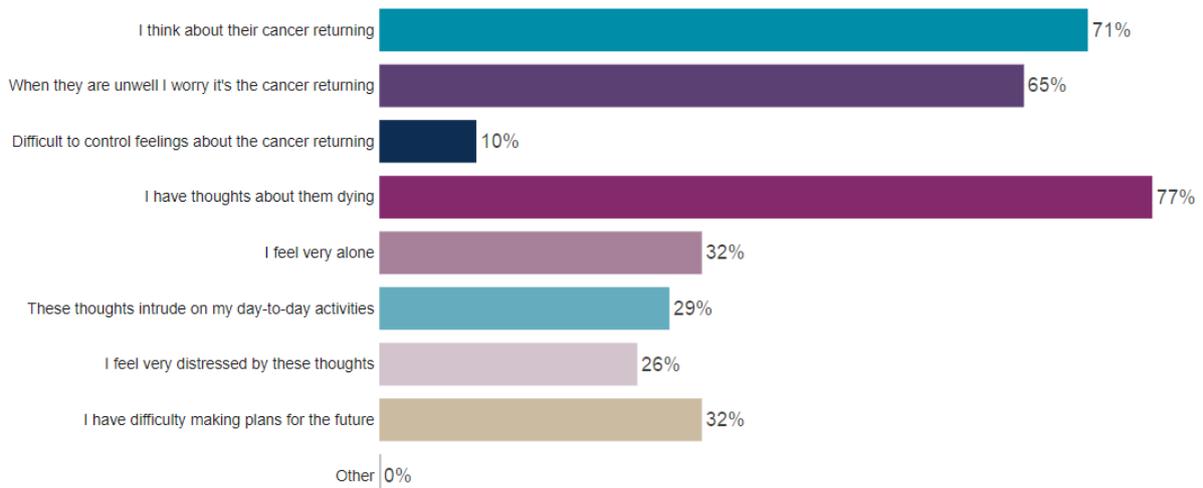
In the past 12 months, to what extent have each of the following issues affected you as a caregiver?  
60 Responses



90% of caregivers reported they have been affected by fear of cancer relapse (often/always + sometimes). Regarding their fear of relapse, 77% of caregivers reported they have experienced thoughts about the patient dying – see Figure 58. Nearly a third of caregivers (32%) have difficulty making plans for the future because of their fear of relapse.

**Figure 58: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?**

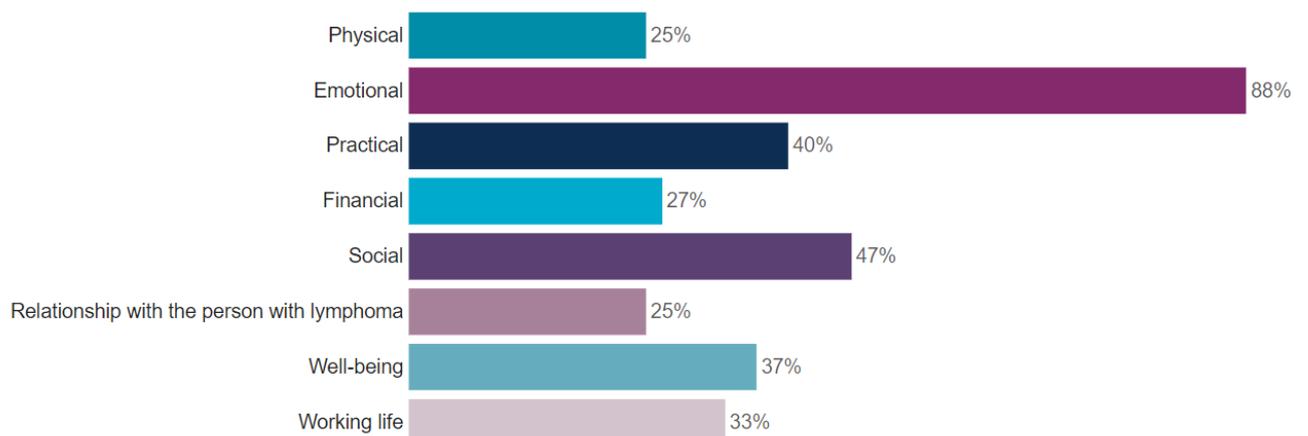
You have indicated that you have experienced a fear of relapse, which of the following have you experienced?  
31 Responses



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 “emotional” (88%) – see Figure 59.

**Figure 59: 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?  
60 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 60). 48% indicated that the impact on their life is less when the person is off treatment, and only 5% felt that the impact was less when the person is on treatment.

**Figure 60: 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?

60 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-moving landscape complicates CLL patients' understanding of the best treatment option for them. Education on ongoing clinical trials and their 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 facing 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 national 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**

- 6631 participants took part (70h countries)
- There were 598 CLL and 4438 DLBCL respondents.

**Statistical Analysis**

- Raw data was entered, merged, and cleaned in IBM SPSS v25.
- 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 checked 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).

	CLL (N=598)	DLBCL (N=4438)	P (p-value)
Age			
18-29	711 (11.9%)	155 (3.5%)	0.0001
30-39	284 (4.7%)	32 (0.7%)	
40-49	111 (1.8%)	89 (2.0%)	
50-59	234 (3.9%)	271 (6.1%)	
60-69	111 (1.8%)	117 (2.6%)	
70+	111 (1.8%)	117 (2.6%)	0.0001
Sex			
Male	336 (56.2%)	667 (14.8%)	0.0001
Female	272 (45.3%)	405 (9.1%)	
Residence			
Rural	18 (3.0%)	34 (0.8%)	0.0001
Suburban	171 (28.3%)	248 (5.6%)	
Urban	298 (49.7%)	405 (9.1%)	

© 2018 Lymphoma Coalition (GPS on Lymphomas & CLL)

The CLL subgroup had more respondents in the younger age group (18-39 yrs age group combined) compared to CLL respondents (32% vs 3%). The CLL group had more than twice the proportion of older respondents (>65 years) than the DLBCL group (49% vs 8%).

CLL respondents had more males (56%) whilst DLBCL respondents had a lower male proportion (14%). One-third (28%) 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=2.23 and 2.14 respectively).

Subject	CLL (N=598)	DLBCL (N=4438)	P (p-value)
Understanding of diagnosis	187 (31.3%)	222 (5.0%)	0.0001
Understanding of initial treatment	142 (23.7%)	158 (3.6%)	0.0001
Understanding of potential side effects	188 (31.4%)	222 (5.0%)	0.0001
Understanding of side effects management	188 (31.4%)	222 (5.0%)	0.0001
Understanding of when to see a doctor	188 (31.4%)	222 (5.0%)	0.0001
Understanding of when to stop treatment	188 (31.4%)	222 (5.0%)	0.0001
Understanding of when to start treatment	188 (31.4%)	222 (5.0%)	0.0001
Understanding of when to stop treatment	188 (31.4%)	222 (5.0%)	0.0001
Understanding of when to start treatment	188 (31.4%)	222 (5.0%)	0.0001

© 2018 Lymphoma Coalition (GPS on Lymphomas & CLL)

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 (OR=1.9, 1.3 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 3).

**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 socio-demographic 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 efforts 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: [research@lymphomacoalition.org](mailto:research@lymphomacoalition.org) or [oma@lymphomacoalition.org](mailto:oma@lymphomacoalition.org)

## Correlation of Lymphoma Patient Information Level with Healthcare Experience

Natalie Dren, BSc, MPH<sup>1</sup>, Lorna Warwick<sup>1</sup>, Karen Van Rassel<sup>1</sup>, Theodoros Moysiadis<sup>2</sup>, Christina Karamanidou, MSc, PhD<sup>2</sup>, Aiki Xochelli, MD, PhD<sup>2</sup>

<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 frequently named as a preliminary requirement for this shift in attitude and behaviour. 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: when 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 85+ 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 sanitisation 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 respondents' understanding of the medical aspects of their lymphoma, diagnosis and care (Table 1, Figures 2(a) & (b)).

Topics Around Diagnosis and Care	Adequate Information (%)	Somewhat Adequate/Inadequate Information (%)
Diagnosis	69	36
Characteristics of the particular subtype	54	27
Different medical treatment options	64	28
Initial treatment if started right away	74	39
Potential side effects of treatment options	66	34
Side effect management	60	26
Process and stages of care	65	32
Active surveillance (watch and wait), if applicable	71	38

**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 (59%) 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).

**3.3 Doctor-Patient Communication**

**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.

**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)**



N. M. Dren, BSc, MPH<sup>1</sup>; L. E. Warwick, BA, B Ed<sup>2</sup>; O. A. Bamigbola MB; BS, MSc (Epid)<sup>2</sup>  
<sup>1</sup>Research, Lymphoma Coalition, Mississauga, ON, Canada; <sup>2</sup>Management, Lymphoma Coalition, Mississauga, ON, Canada



**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 & websites) 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

Age	ENKTL Count (%) N=177	WM Count (%) N=764	X <sup>2</sup> (p-value)
18-29	45 (23)	1 (0)	505.9 (p < 0.0001)
30-39	48 (26)	2 (0)	
40-59	72 (40)	123 (16)	
60-69	13 (8)	332 (44)	
70+	3 (2)	302 (40)	
Sex			5.5 (p = 0.018763)
Male	122 (69)	450 (59)	
Female	55 (31)	305 (41)	
Residence			81.1 (p < 0.0001)
Rural	45 (26)	150 (21)	
Suburban	122 (69)	295 (39)	
Urban	29 (16)	304 (40)	

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)
Understanding of diagnosis	ENKTL 54 (30)	52 (27)	OR=1.94 95% CI 1.27-2.94 P=0.0020
Understanding of initial treatment (for those who started right away)	ENKTL 57 (44)	50 (27)	OR=1.99 95% CI 1.29-3.05 P=0.0019
Understanding different treatment options	ENKTL 67 (38)	38 (20)	OR=1.84 95% CI 1.19-2.83 P= 0.0059
Understanding of side effect management	ENKTL 53 (30)	38 (20)	OR=1.27 95% CI 0.80-2.00 P=0.3086
Understanding of the different processes and stages of care	ENKTL 49 (28)	51 (28)	OR=1.10 95% CI 0.75-1.78 P=0.5105

Analysis of patient-doctor communication showed that compared to WM patients, ENKTL patients were more likely to not (somewhat/no) 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=2.28). 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 or No) Count (%)	Yes Count (%)	OR (95% CI)
Communicated medical issues to the doctor	ENKTL 19 (26)	51 (74)	OR=2.20 95% CI 1.23-3.91 P=0.0074
Communicated emotional issues to the doctor	ENKTL 48 (27)	126 (72)	OR=2.28 95% CI 1.19-4.50 P=0.0168
Sought clarification on things they did not understand	ENKTL 13 (28)	38 (87)	OR=2.25 95% CI 1.10-4.50 P=0.0270
Felt confident voicing concerns to the doctor	ENKTL 30 (88)	24 (69)	OR=4.43 95% CI 2.54-7.73 P < 0.0001

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

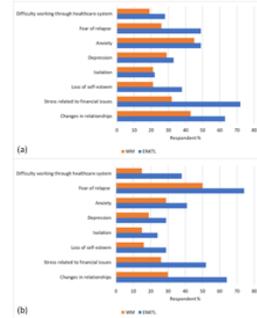


Figure 1. Psychosocial issues reported by patients (a) during and (b) after treatment

**4) CONCLUSIONS**

Compared to ENKTL patients (least informed subtype group 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)**



L. E. Warwick, BA, B Ed<sup>1</sup>; O. A. Bamigbola MB; BS, MSc (Epid)<sup>2</sup>; N. M. Dren, BSc, MPH<sup>2</sup>  
<sup>1</sup>Management, Lymphoma Coalition, Mississauga, ON, Canada; <sup>2</sup>Research, Lymphoma Coalition, Mississauga, ON, Canada



**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)

Age	FL count (%)	DLBCL count (%)	X <sup>2</sup> (p-value)
18-29	27(3)	155(10)	93.83 (p<0.001)
30-39	128(14)	232(22)	
40-59	466(50)	599(41)	
60-69	25(27)	277(19)	
70+	60(6)	117(8)	
Sex			11.58 (p=0.001)
Male	358(38)	667(45)	
Female	578(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).

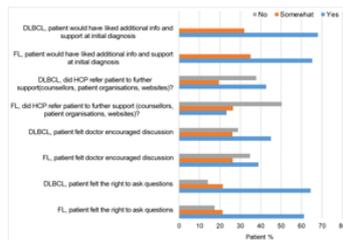


Figure 1. Showing FL and DLBCL patients' experience and feelings of their patient-doctor communication

**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 (62%-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

Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford, OX2 0JB  
England

Tel: 01865 208100  
Fax: 01865 208101

[info@pickereurope.ac.uk](mailto:info@pickereurope.ac.uk)  
[www.picker.org](http://www.picker.org)

Registered Charity in England and Wales: 1081688  
Registered Charity in Scotland: SC045048  
Company Limited by Registered Guarantee No 3908160