

# Lymphoma Coalition

## 2020 Global Patient Survey on Lymphomas & CLL

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A report prepared for Lymphoma  
Coalition  
by Picker Institute Europe

July 2020

Country Report  
Slovakia

## Lymphoma Coalition

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

The LC vision is equity in lymphoma outcomes across borders.

The LC mission is enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

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## Picker

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

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

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## Contents

|  |    |
|--|----|
| Executive Summary  | 4  |
| Background   | 10 |
| What is the Global Patient Survey?                           | 10 |
| Methodology  | 13 |
| Survey 2020 Development and Launch                           | 13 |
| Analysis and Reporting                                       | 14 |
| Respondent Demographics                                      | 17 |
| Results – I. Patient Survey                                  | 20 |
| Diagnostic Demographics                                      | 20 |
| Treatment Demographics                                       | 23 |
| Treatment Options  | 23 |
| Patient Information, Guidance and Support                    | 25 |
| Diagnosis  | 26 |
| Patient Knowledge and Experience                             | 27 |
| Healthcare Decision Making                                   | 30 |
| Health Behaviours  | 33 |
| Physical and Medical Side Effects of Diagnosis and Treatment | 34 |
| Effects of Lymphoma/CLL                                      | 34 |
| Effects of Lymphoma/CLL Treatment                            | 36 |
| Fatigue  | 39 |
| Psychosocial Effects of Lymphoma/CLL and its Treatment       | 43 |
| Fear of Cancer Relapse                                       | 46 |
| Barriers to Treatment  | 49 |
| Results – II. Caregiver Survey                               | 50 |
| Caregiver Demographics                                       | 50 |
| Caregiver Information, Guidance and Support                  | 53 |
| Impact of Caregiving   | 55 |
| Appendices   | 59 |

SECTION 1

## Executive Summary



## Executive Summary

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

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

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

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

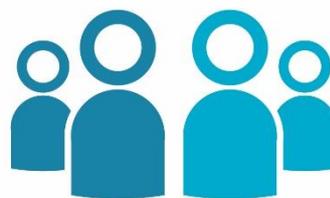
## Results

The results in this report present the data for respondents from Slovakia.

Overall number of completed responses **164** made up of:



**132** Patients



**32** 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.  
132 Responses



**Figure 2: Gender of caregivers**

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



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

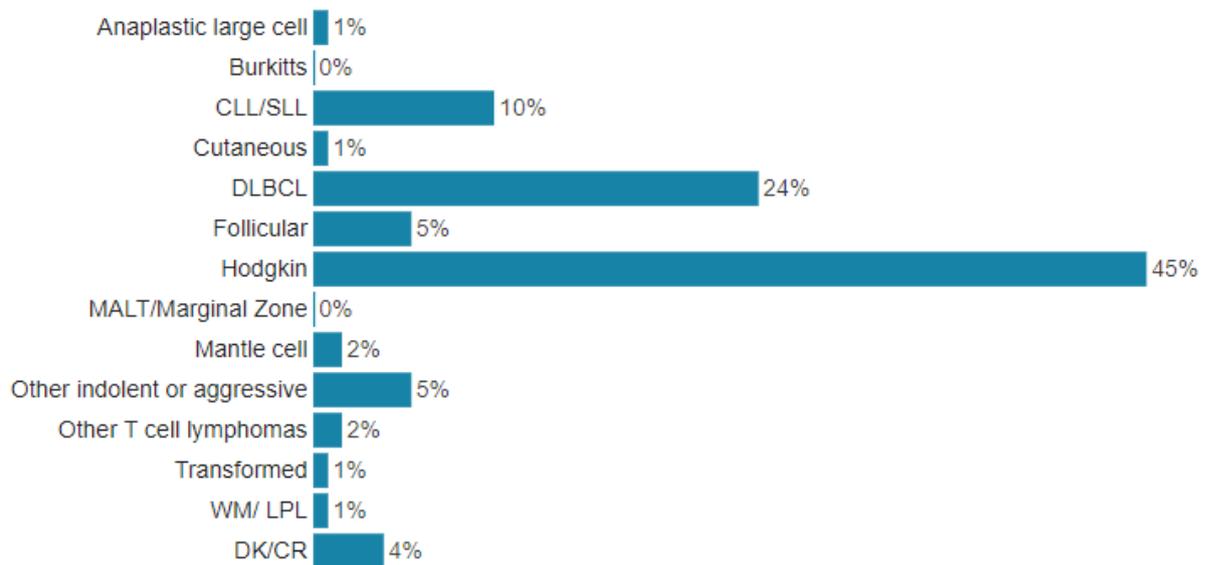
Please describe your experience with lymphoma, including CLL.  
164 Responses



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

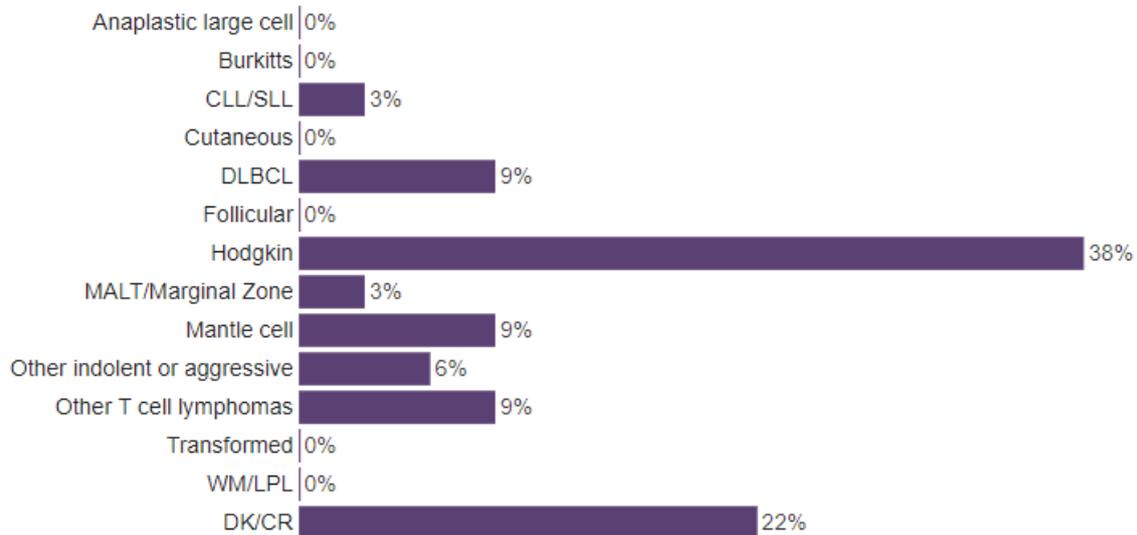
**Patient subtype (grouped)**

132 Responses



**Caregiver subtype (grouped)**

32 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



Less than half of patients (45%) were told their lymphoma subtype at diagnosis.



Only 13% agree strongly that they have good conversations with their doctor about care and treatment plans.



42% were informed and completely understood how to manage side effects of treatment.



Only 23% are definitely involved as much as they want to be in decisions about their care and treatment.



When asked about information needs, 78% of patients reported they needed more information about treatment options.



Nearly half (49%) of patients felt that they did not get enough financial support.

## Effects of diagnosis and treatment



Fatigue was the most commonly reported **symptom of lymphoma** (79%).



Fatigue was the most common **side effect of treatment** (83%).



Of the 54% of patients who discussed their fatigue with their doctor, 18% reported that the doctor did not follow-up with them about their fatigue.



33% of patients have experienced anxiety, and 30% have experienced depression in the last 12 months as a result of their lymphoma diagnosis.



39% of patients indicated they had experienced fear of cancer relapse as a result of their lymphoma diagnosis.



48% of patients do not use any coping mechanisms to help them with their fear of cancer relapse.

## Barriers to treatment



77% of patients reported that nothing has prevented them from receiving treatment. The next most reported barrier to receiving treatment was the time patients would need to take out of their daily lives (11%).



72% of patients reported that never being presented with an opportunity to take part was a barrier to being in a clinical trial.

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

SECTION 2

## Background



## Background

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

The LC vision is equity in lymphoma outcomes across borders.

The LC mission is enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

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

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

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

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

## What is the Global Patient Survey?

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

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

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

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

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

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

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

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

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

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

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

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

SECTION 3

## Methodology



## Methodology



### Survey 2020 Development and Launch

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

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

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

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

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

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

Countries who had 100+ responses to the 2018 survey were given the opportunity to add up to five 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 Slovakia.

A total of 132 responded to the patient survey and 32 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 area of residence (urban or rural).

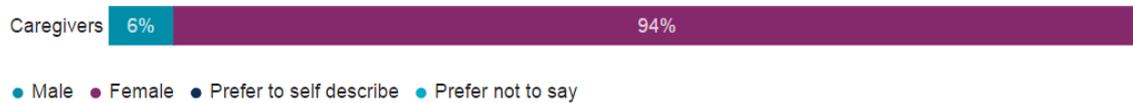
**Figure 1a: Sex of patients**

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



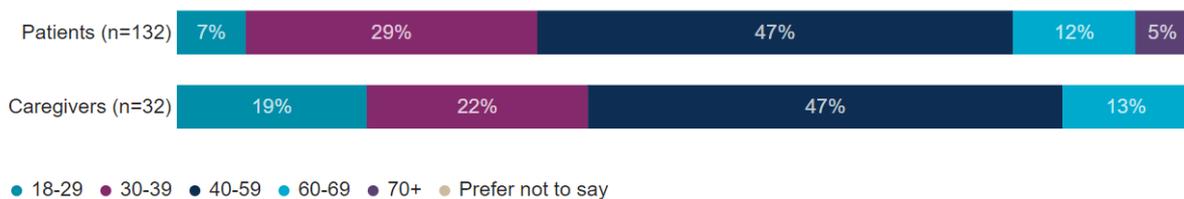
**Figure 1b: Gender of caregivers**

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



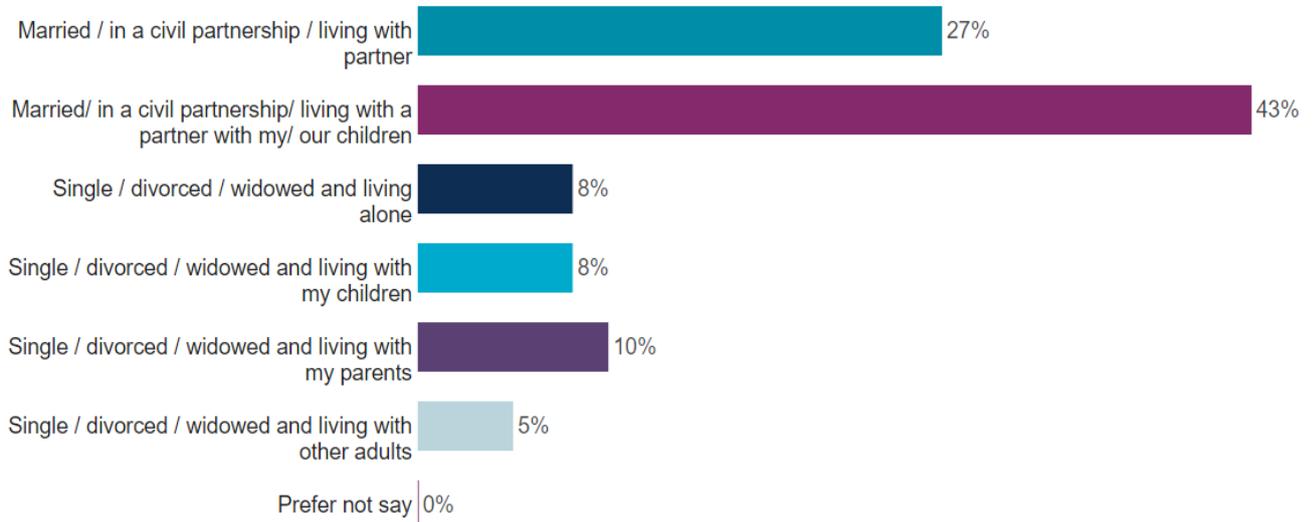
**Figure 2: Age range of respondents**

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



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

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



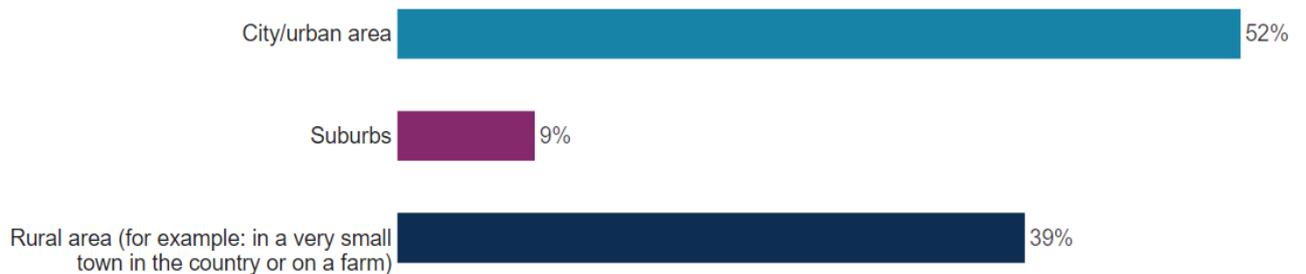
**Figure 4: Employment status of respondents**

Which of the following best describes your employment status?



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

Which best describes the area you live in?  
164 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.

132 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 more than two years ago (70%).

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

Length of time since diagnosis  
132 Responses

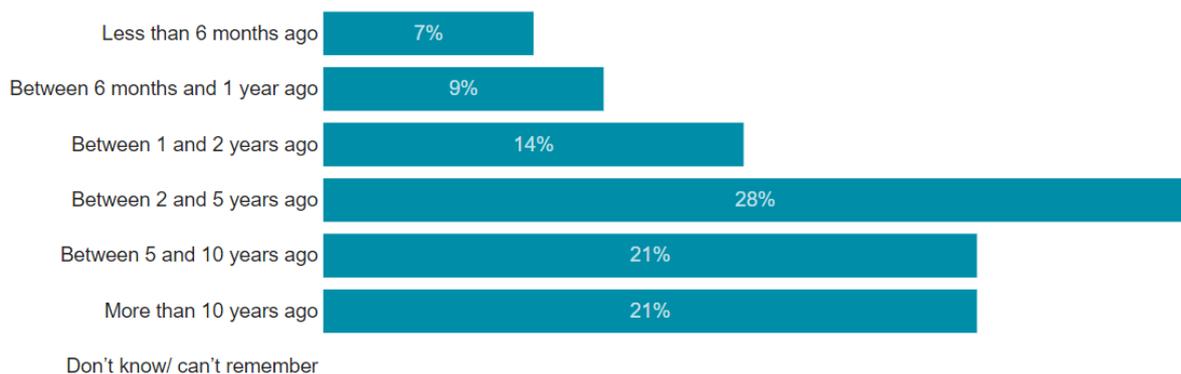


Figure 7 below shows how long patients reported waiting between their first GP appointment about their symptoms to getting a diagnosis. 39% of patients had a diagnosis within less than three months of their first appointment. However, 22% were waiting six months or more from their initial meeting with their GP.

**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?  
132 Responses

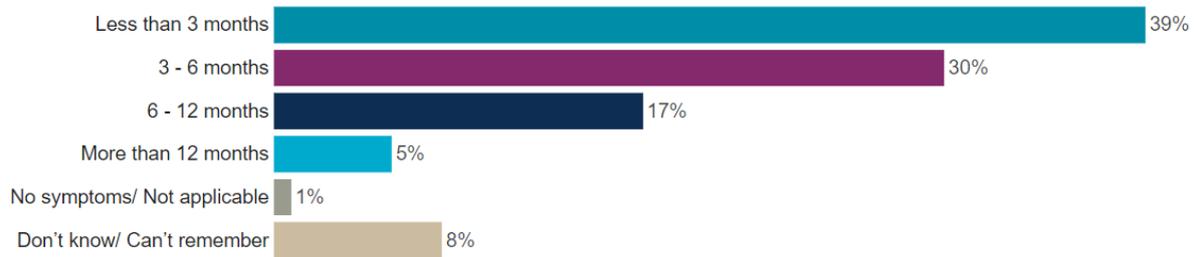
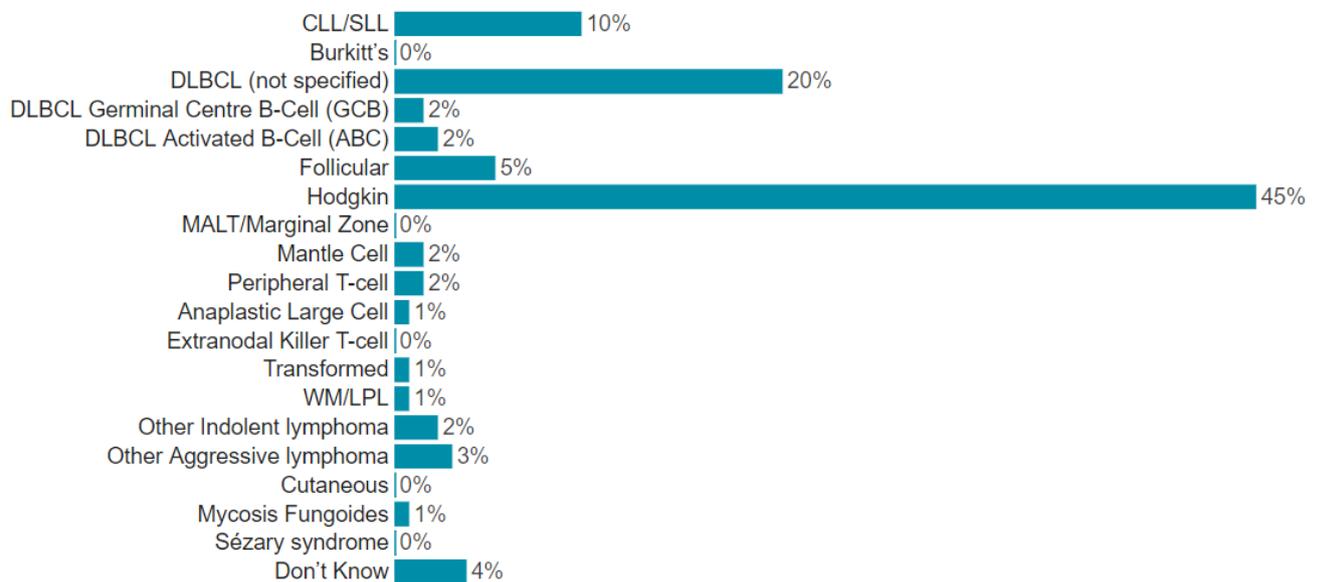


Figure 8 below shows respondent lymphoma subtype. The most common subtypes reported are:

- 45% Hodgkin lymphoma
- 20% Diffuse large B-cell lymphoma (DLBCL) (not specified)
- 10% Chronic lymphocytic leukaemia (CLL)/small lymphocytic lymphoma (SLL)

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

What subtype of lymphoma do you have?  
132 Responses



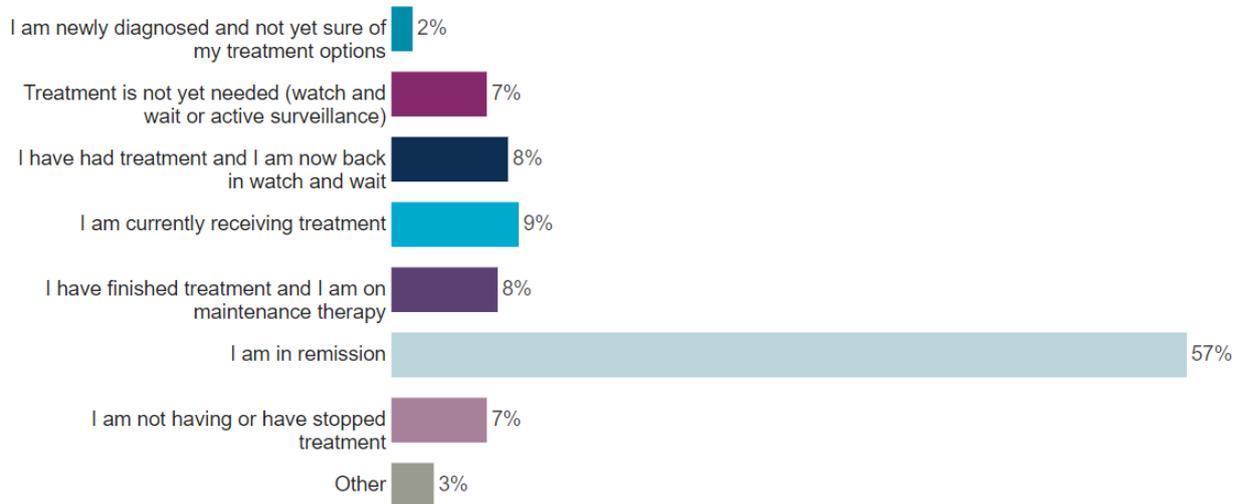
Survey participants were also asked about the stage of their lymphoma care pathway, and their responses are displayed in Figure 9.

7% of patients report that treatment is not yet needed (watch and wait), 9% are currently in treatment, 8% have had treatment and are now back in watch and wait. 8% have finished treatment and are on maintenance therapy, and 57% 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?

132 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

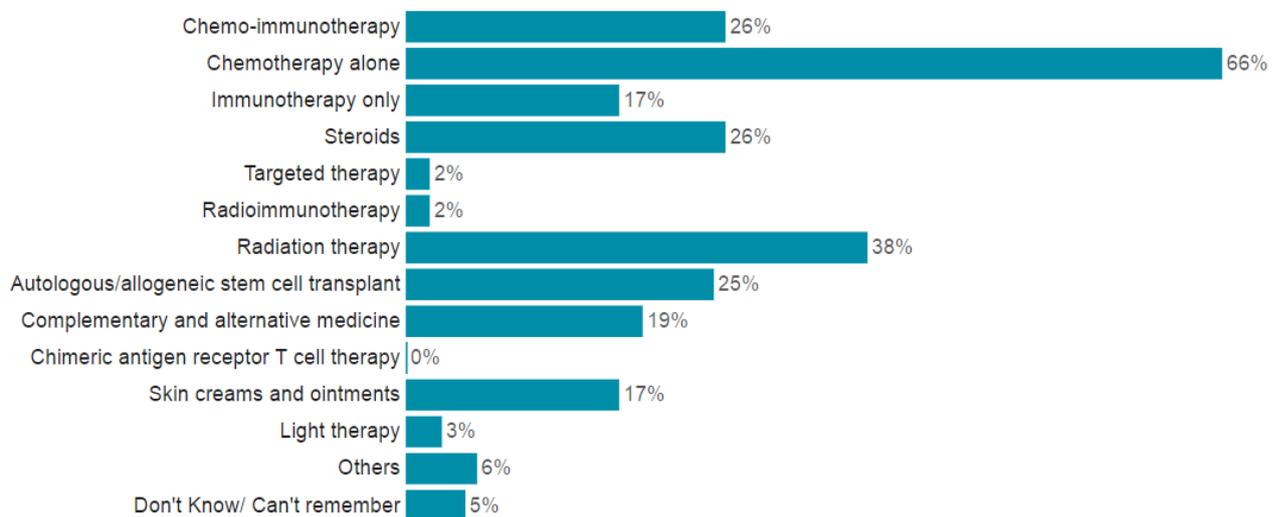
### Treatment Options

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

104 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?  
104 Responses

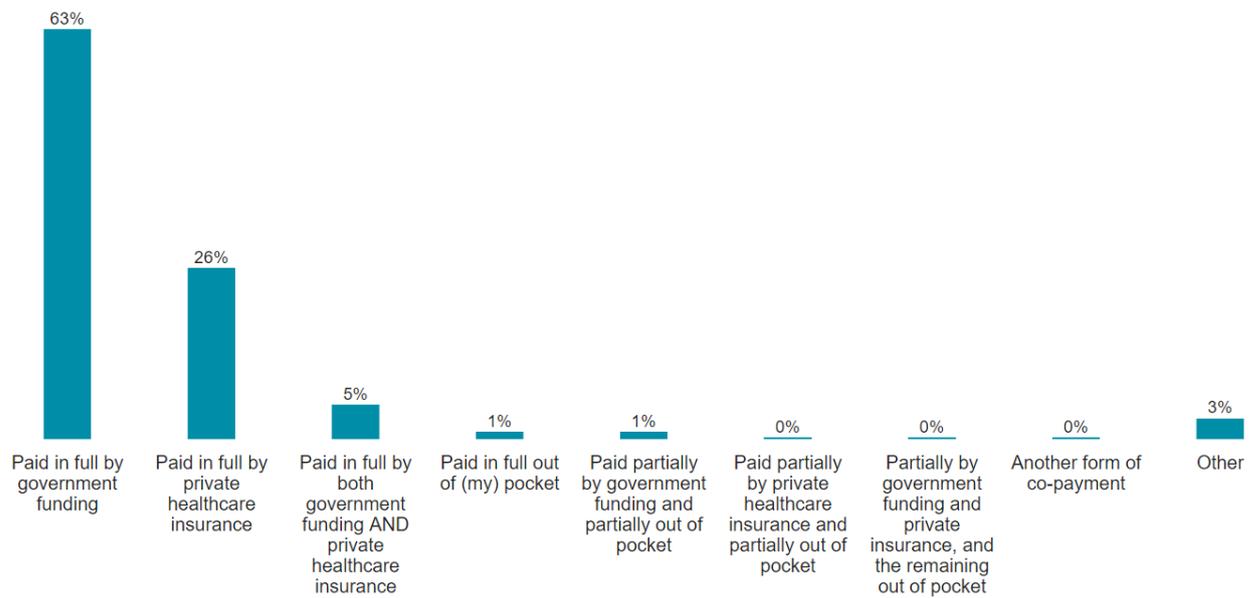


Additional survey questions were asked about treatments including how these were administered. Results for these questions are available in the frequency tables (see Appendix 2).

In regard to payment of treatment, the majority of patients (63%) selected that their chemotherapy/immunotherapy/chemo-immunotherapy is paid in full by government funding – see Figure 11.

**Figure 11: Who pays for your chemo-immunotherapy, your chemotherapy (only) or your immunotherapy (only)?**

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



Complementary and alternative medicine (CAM) is largely paid for in full out of patients' pocket (90% n=18).

Only 13% (n=14) of patients are currently or have previously been in a clinical trial for their lymphoma or CLL.

## Patient Information, Guidance and Support

The previous LC Global Patient Survey (2018) showed that having ‘adequate information’ was correlated with more self-reported positive healthcare experiences. Patients with adequate information reported bettered management of their health and healthcare through improved understanding, confidence levels, and communication with healthcare professionals. When a patient has knowledge surrounding their condition, treatment options, and self-care practices, doctor-patient communication is more fluid, patient experience is improved, and patients are more inclined to be confident in taking a sustained active role in managing their health and condition.

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

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

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



- Less than half (45%) of patients were told their lymphoma subtype at diagnosis, and 34% of patients reported that they did not receive enough information upon diagnosis.
- 78% of patients reported they needed more information about treatment options, and 70% needed more information about diagnosis and what it means.
- 80% of patients ranked ‘doctor’ as the top place they go for information about their healthcare. However, only 13% strongly agree that they have good conversations with their doctor about care and treatment.
- 55% of patients agree or strongly agree that they feel overwhelmed by managing their health and condition. Only 3% of patients report they are ‘very confident’ about managing their health problems day-to-day.
- Nearly half (49%) of patients felt that they did not get enough financial support.

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

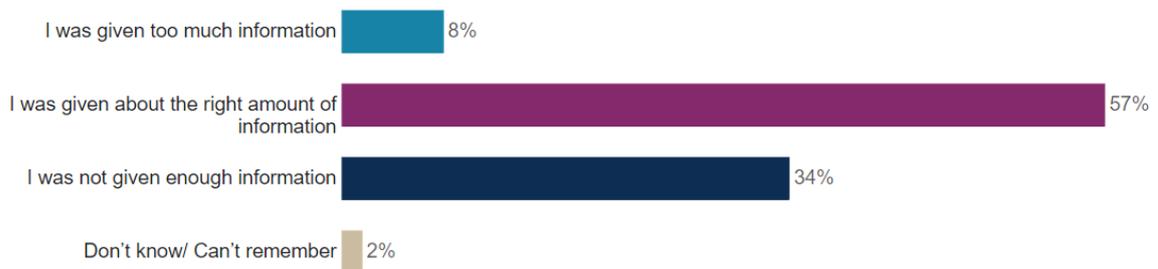
**Diagnosis**

Patients were asked about their experience of receiving a lymphoma diagnosis. Those diagnosed in the last two years were asked whether it was clear they had been given a diagnosis of cancer, 79% of patients said yes. However, only 45% 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 – 34% were not given enough information. See Figure 12 for overall response.

**Figure 12: 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?  
131 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 (Figure 13). Less than 50% of patients had been given and completely understood all of the categories of information examined. 34% of patients were given and completely understood information on the different medical treatment options, including active surveillance (watch and wait). 49% of patients were provided with information on and completely understood the process and stages of care. And 42% reported they received information on and completely understood how to manage side effects of treatment.

**Figure 13: 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)?

38 Responses



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

35 Responses



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

31 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 (63%) within the first month following their diagnosis.

When asked about information needs:

- 78% of patients reported they needed more information about treatment options;
- 70% needed more information about diagnosis and what it means;
- 53% required more information about the side effects from treatment;
- 22% of patients needed more information about psychological support/counselling;
- 20% required more information about support for self-care;
- 20% required more information about support for their families.

Many patients across the different lymphoma subtypes needed more information about their treatment options. Table 1 displays the number of patients selecting each information need, by lymphoma subtype. Please take care interpreting data for subtypes with fewer than 20 respondents.

**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        | 100%  | 1  | 100%              | 1  | 100%                  | 1  | 0%                                | 0  | 100%                  | 1  | 100%                        | 1  | 0%        | 0  | 0%                                 | 0 | 0     | 1 |
| CLL/SLL                      | 69%   | 9  | 69%               | 9  | 31%                   | 4  | 8%                                | 1  | 0%                    | 0  | 0%                          | 0  | 0%        | 0  | 15%                                | 2 | 13    |   |
| Cutaneous                    | 0%  | 0  | 0%                | 0  | 0%                    | 0  | 0%                                | 0  | 0%                    | 0  | 100%                        | 1  | 0%        | 0  | 0%                                 | 0 | 1     |   |
| DLBCL                        | 69%   | 22 | 81%               | 26 | 13%                   | 4  | 19%                               | 6  | 16%                   | 5  | 47%                         | 15 | 16%       | 5  | 6%                                 | 2 | 32    |   |
| Follicular                   | 86%   | 6  | 86%               | 6  | 14%                   | 1  | 0%                                | 0  | 14%                   | 1  | 57%                         | 4  | 0%        | 0  | 0%                                 | 0 | 7     |   |
| Hodgkin                      | 64%   | 38 | 78%               | 46 | 17%                   | 10 | 25%                               | 15 | 22%                   | 13 | 66%                         | 39 | 29%       | 17 | 3%                                 | 2 | 59    |   |
| Mantle cell/MZ               | 100%  | 2  | 100%              | 2  | 100%                  | 2  | 50%                               | 1  | 50%                   | 1  | 100%                        | 2  | 50%       | 1  | 0%                                 | 0 | 2     |   |
| Other indolent or aggressive | 100%  | 7  | 57%               | 4  | 29%                   | 2  | 29%                               | 2  | 14%                   | 1  | 43%                         | 3  | 0%        | 0  | 0%                                 | 0 | 7     |   |
| Other T cell lymphomas       | 100%  | 2  | 100%              | 2  | 0%                    | 0  | 0%                                | 0  | 0%                    | 0  | 0%                          | 0  | 0%        | 0  | 0%                                 | 0 | 2     |   |
| Transformed                  | 100%  | 1  | 100%              | 1  | 0%                    | 0  | 100%                              | 1  | 100%                  | 1  | 100%                        | 1  | 0%        | 0  | 0%                                 | 0 | 1     |   |
| WM/LPL                       | 0%  | 0  | 0%                | 0  | 0%                    | 0  | 0%                                | 0  | 100%                  | 1  | 0%                          | 0  | 0%        | 0  | 0%                                 | 0 | 1     |   |
| Don't know/can't remember    | 80%   | 4  | 100%              | 5  | 40%                   | 2  | 60%                               | 3  | 40%                   | 2  | 60%                         | 3  | 20%       | 1  | 0%                                 | 0 | 5     |   |

When asked to select their top three places to go for information about their healthcare, 80% said ‘doctor’ and 11% said ‘website’ as their top place to go. Table 2 displays the number of patients selecting each source of information within their top three choices.

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

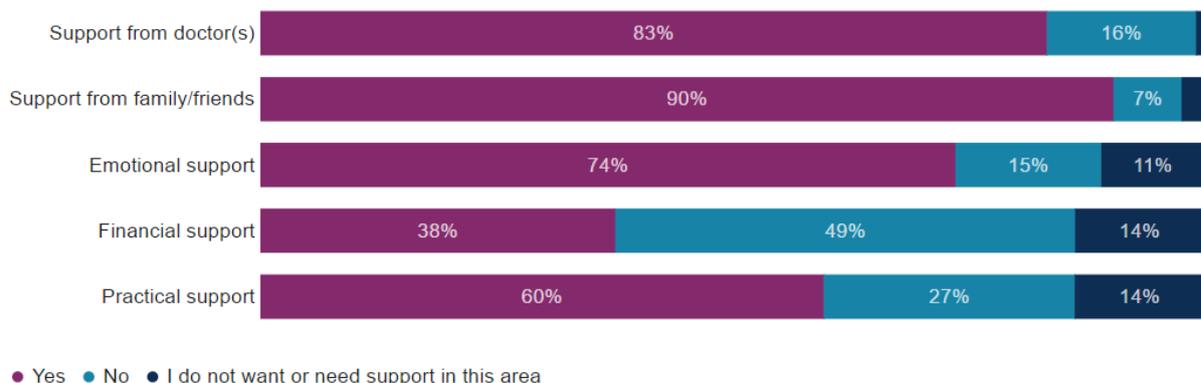
**Since getting your diagnosis, when you have a need for information about your healthcare, which of the following are the top three places you go to first for information? Please select your top choices starting with your first choice.**  
130 Responses

|                           | 1           |            | 2           |            | 3           |            |
|---------------------------|-------------|------------|-------------|------------|-------------|------------|
| Doctor                    | 80%         | 104        | 10%         | 12         | 8%          | 9          |
| Nurse                     | 0%          | 0          | 23%         | 28         | 6%          | 7          |
| Websites                  | 11%         | 14         | 31%         | 38         | 27%         | 30         |
| Online blogs/social media | 5%          | 6          | 10%         | 12         | 16%         | 18         |
| Family/friends            | 1%          | 1          | 8%          | 10         | 7%          | 8          |
| Patient organisation      | 2%          | 3          | 19%         | 23         | 31%         | 34         |
| Other                     | 2%          | 2          | 0%          | 0          | 4%          | 4          |
| <b>Total</b>              | <b>100%</b> | <b>130</b> | <b>100%</b> | <b>123</b> | <b>100%</b> | <b>110</b> |

Figure 14 displays whether patients felt they had received enough support in key areas of patient experience. 90% and 83% felt that they had enough support from family/friends and from doctors, respectively. However, 49% felt that they did not get enough financial support.

**Figure 14: 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?  
128 Responses

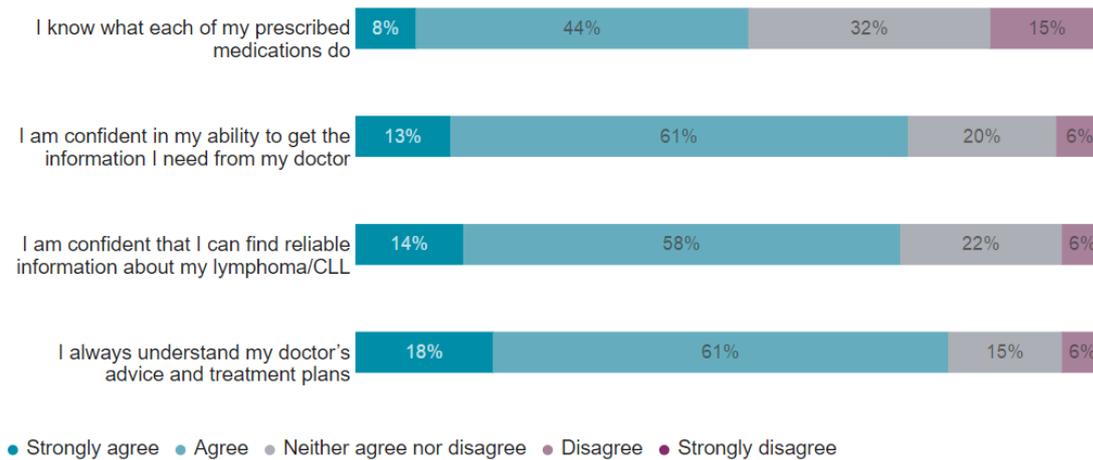


79% either agree or strongly agree that they always understand their doctor’s advice and treatment plans, and 74% agree or strongly agree that they are confident in their ability to get the information

they need from their doctor. However, 15% strongly disagree that they know what each of their prescribed medications do. See Figure 15.

**Figure 15: 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:  
128 Responses



Overall, 73% of patients reported they always have confidence and trust in the doctors treating them – see Figure 16.

**Figure 16: Do you have confidence and trust in the doctors treating you?**

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



Of the 64% of patients who have seen nurses for their lymphoma care over the last year, only 14% definitely feel comfortable asking nurses questions about their lymphoma/CLL (Figure 17), and only 29% always have confidence and trust in the information they are given (Figure 18).

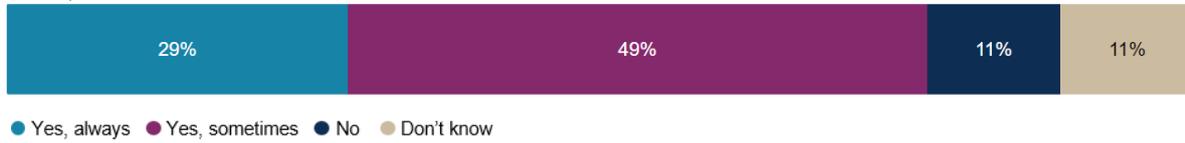
**Figure 17: Do you feel comfortable asking nurses questions about your lymphoma/CLL?**

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



**Figure 18: 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?  
80 Responses

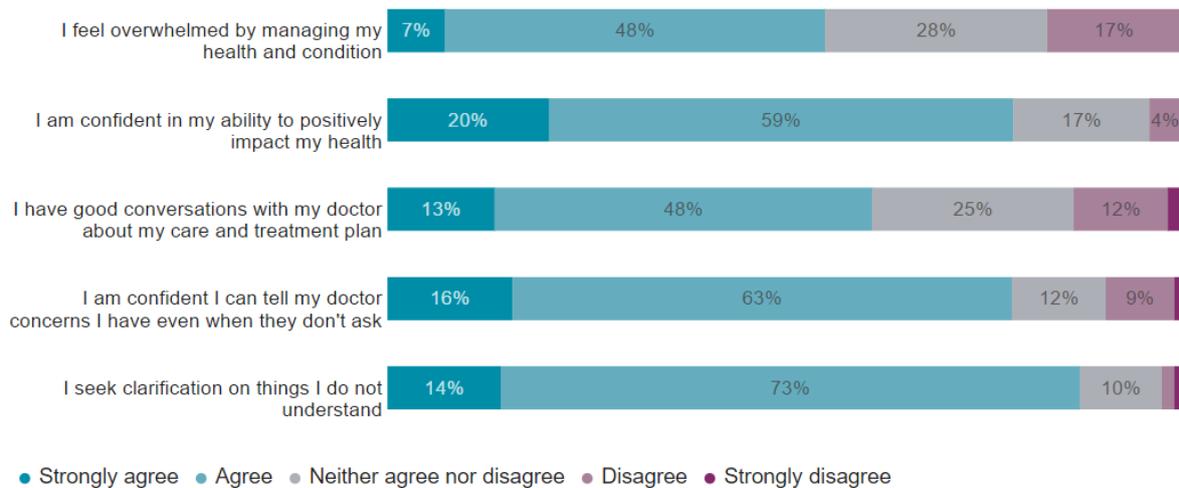


**Healthcare Decision Making**

Patients were asked a series of questions about the role they play in making decisions about their healthcare – see Figure 19. 87% agree or strongly agree that they seek clarification on things they do not understand. However, 55% agree or strongly agree that they feel overwhelmed by managing their health and condition.

**Figure 19: 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:  
128 Responses

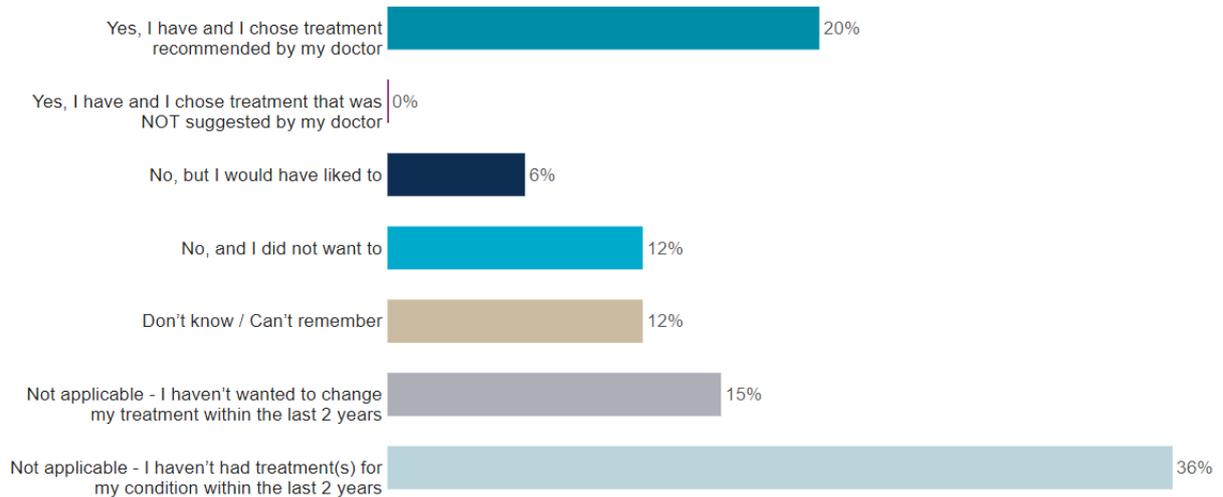


23% of patients reported they are definitely involved as much as they want to be in decisions about their care and treatment. Meanwhile, 58% reported that they are involved to some extent. 15% reported they are not involved but would like to be, and 4% reported they are not involved but do not want to be.

20% of patients who were receiving treatment or had received treatment in the past reported they had talked to their doctor about wanting to change their treatment to better meet their needs within the last two years (see Figure 20). All of these patients chose the treatment recommended by their doctor.

**Figure 20: Have you talked to your doctor about wanting to change your treatment to better meet your needs, within the last 2 years?**

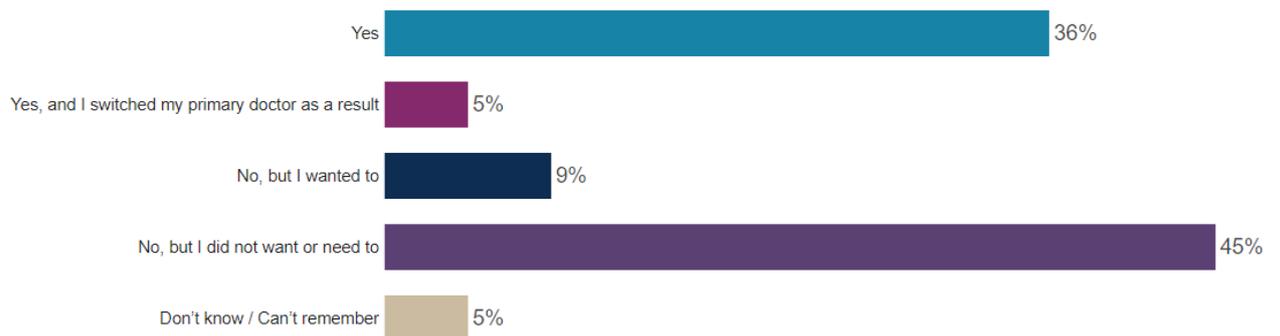
Have you talked to your doctor about wanting to change your treatment to better meet your needs, within the last 2 years?  
112 Responses



41% of patients got a second opinion about their most recent treatment, and 5% changed their primary doctor as a result. 9% wanted to get a second opinion but did not, and 45% felt they did not want or need to get a second opinion. See Figure 21.

**Figure 21: 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?  
22 Responses

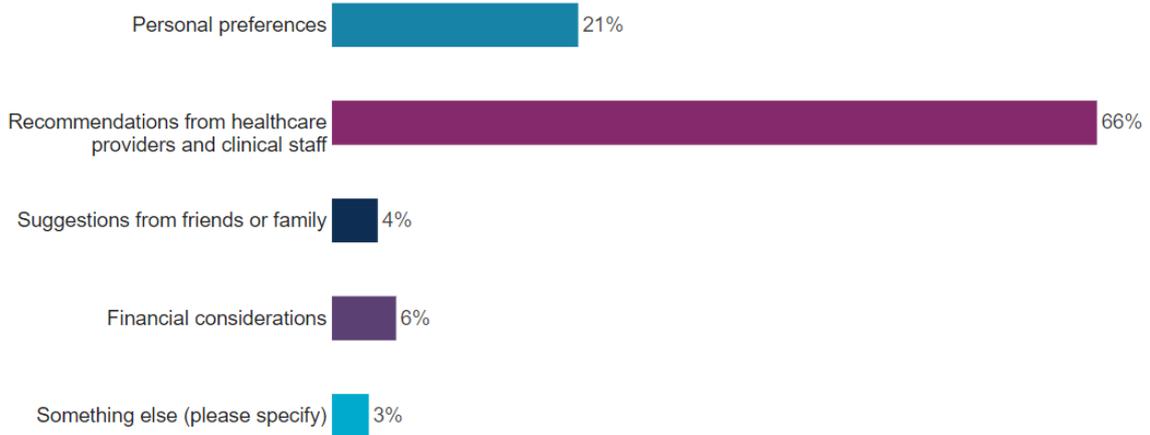


When patients were asked what they are most influenced by when making healthcare decisions, the top answers were (see Figure 22):

- Recommendations from healthcare providers and clinical staff (66%)
- Personal preferences (21%)
- Financial considerations (6%)

**Figure 22: What influences your healthcare decisions the most?**

What influences your healthcare decisions the most?  
127 Responses



When asked about the importance of a range of outcomes, 90% of patients ranked ‘a cure’ as the most important outcome for them (Table 3). 56% of patients ranked ‘quality of life’ as the second 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.**  
116 Responses

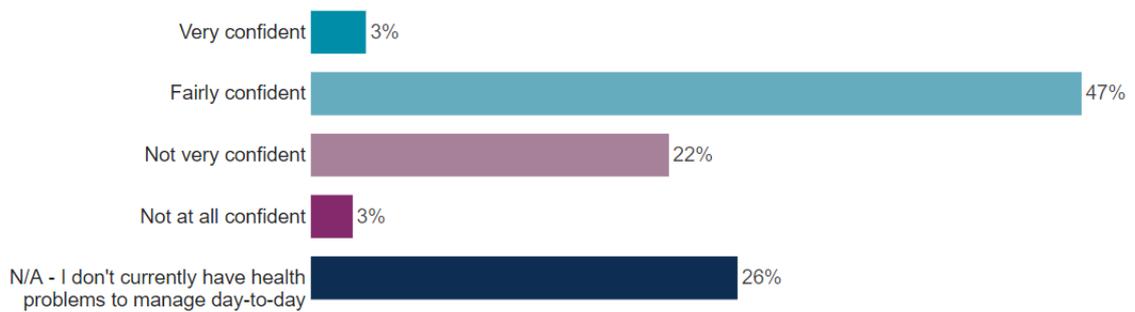
|  | 1   |     | 2   |    | 3   |    | 4   |    | 5   |    | 6   |    | 7   |    |
|--|-----|-----|-----|----|-----|----|-----|----|-----|----|-----|----|-----|----|
| A cure                                       | 90% | 104 | 3%  | 3  | 1%  | 1  | 2%  | 2  | 0%  | 0  | 3%  | 3  | 3%  | 3  |
| Quality of life                              | 7%  | 8   | 56% | 65 | 22% | 26 | 6%  | 7  | 5%  | 6  | 3%  | 3  | 1%  | 1  |
| Fewer side effects to tolerate               | 1%  | 1   | 18% | 21 | 34% | 40 | 29% | 34 | 15% | 17 | 3%  | 3  | 0%  | 0  |
| Treatment at home versus treatment in clinic | 1%  | 1   | 14% | 16 | 20% | 23 | 28% | 32 | 23% | 27 | 9%  | 11 | 5%  | 6  |
| Duration of treatment                        | 0%  | 0   | 4%  | 5  | 18% | 21 | 28% | 33 | 41% | 47 | 9%  | 10 | 0%  | 0  |
| What's best for my caregiver                 | 0%  | 0   | 3%  | 3  | 4%  | 5  | 6%  | 7  | 14% | 16 | 66% | 76 | 8%  | 9  |
| Other  | 2%  | 2   | 3%  | 3  | 0%  | 0  | 1%  | 1  | 3%  | 3  | 9%  | 10 | 84% | 97 |

### Health Behaviours

Only 3% of patients report that they are ‘very confident’ about managing their health problems day-to-day. 47% of patients report they are ‘fairly confident’, however 25% are ‘not very’ or ‘not at all’ confident. The full data can be seen in Figure 23.

**Figure 23: How confident are you that you can manage your health problems day-to-day?**

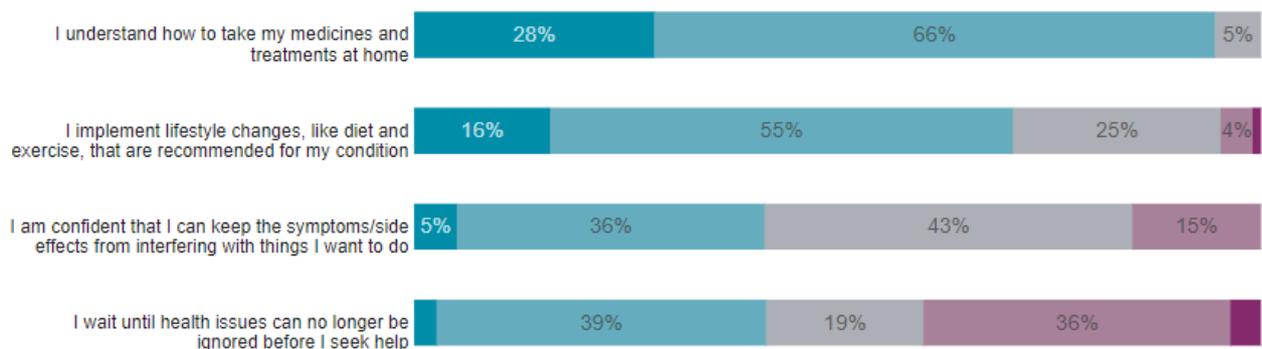
How confident are you that you can manage your health problems day-to-day?  
120 Responses



94% agree or strongly agree that they understand how to take their medicines and treatments at home. However, 42% agree or strongly agree that they wait until health issues can no longer be ignored before they seek help.

**Figure 24: 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?  
116 Responses



● Strongly agree ● Agree ● Neither agree nor disagree ● Disagree ● Strongly disagree

## 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 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 symptom of lymphoma (79%) and was also the most frequently reported side effect of treatment (83%).
- 74% of patients reported that they agree or strongly agree that their lymphoma/CLL symptoms negatively impact on everyday activities that people their age can usually do.
- Regarding treatment side effects, 77% reported that they agree or strongly agree that their side effects have negatively impacted on everyday activities that people their age can usually do.

### Effects of Lymphoma/CLL

Some symptoms that patients experience are effects of lymphoma/CLL itself, rather than the medications used to treat it. However, these symptoms can be exacerbated by medications. The symptoms most reported to affect patients were fatigue (79%), shortness of breath (36%), and B-symptoms (31%). See Table 4.

**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?  
122 Responses**

|  |      |     |
|--|------|-----|
| Fatigue  | 79%  | 96  |
| Frequent or repeated infections                                | 30%  | 36  |
| Headaches  | 26%  | 32  |
| Shortness of breath  | 36%  | 44  |
| Easily bruised or bleed  | 11%  | 14  |
| Skin rashes/lesions  | 18%  | 22  |
| Fever, chills, night sweats and weight loss (B-symptoms)       | 31%  | 38  |
| Abnormal painless swelling(s) on the body/enlarged lymph nodes | 20%  | 24  |
| Pain   | 23%  | 28  |
| Anaemia  | 17%  | 21  |
| No symptoms  | 9%   | 11  |
| Other (please specify)   | 10%  | 12  |
| Total  | 100% | 122 |

Table 5 indicates the length of time that patients have experienced symptoms. Almost two thirds (63%) of patients who are affected by B-symptoms and/or abnormal painless swellings report it has affected them for under a year. 14%-19% of patients affected by bruising easily, anaemia, headaches, and/or fatigue have been experiencing these side effects for more than eight years.

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

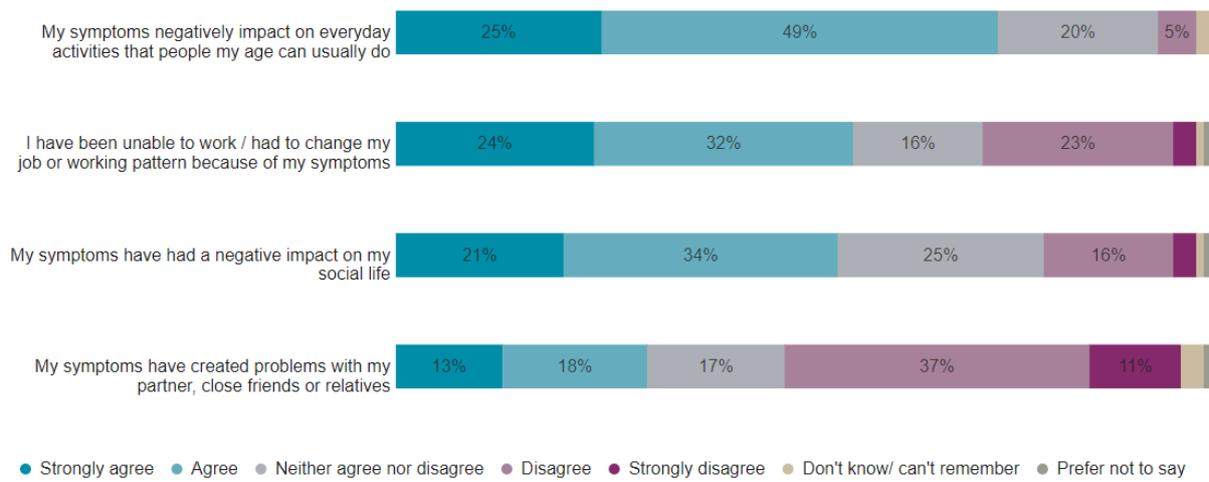
**You have indicated that you have been affected by the symptoms shown below, for each symptom that has affected you, please indicate how long you have had this symptom for:  
111 Responses**

|   | 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)        | 63%          | 24 | 21%       | 8  | 3%        | 1  | 3%        | 1 | 5%                | 2  | 5%    | 2 | 38    |
| Pain  | 46%          | 13 | 18%       | 5  | 25%       | 7  | 0%        | 0 | 7%                | 2  | 4%    | 1 | 28    |
| Fatigue   | 23%          | 22 | 28%       | 27 | 21%       | 20 | 7%        | 7 | 19%               | 18 | 2%    | 2 | 96    |
| Abnormal painless swelling(s) on the body/ enlarged lymph nodes | 63%          | 15 | 17%       | 4  | 13%       | 3  | 4%        | 1 | 4%                | 1  | 0%    | 0 | 24    |
| Shortness of breath   | 39%          | 17 | 23%       | 10 | 23%       | 10 | 11%       | 5 | 5%                | 2  | 0%    | 0 | 44    |
| Skin rashes/ lesions  | 32%          | 7  | 36%       | 8  | 23%       | 5  | 0%        | 0 | 5%                | 1  | 5%    | 1 | 22    |
| Frequent or repeated infections                                 | 33%          | 12 | 22%       | 8  | 28%       | 10 | 8%        | 3 | 8%                | 3  | 0%    | 0 | 36    |
| Anaemia   | 33%          | 7  | 14%       | 3  | 19%       | 4  | 10%       | 2 | 19%               | 4  | 5%    | 1 | 21    |
| Headaches   | 22%          | 7  | 25%       | 8  | 25%       | 8  | 9%        | 3 | 16%               | 5  | 3%    | 1 | 32    |
| Easily bruised or bleed   | 43%          | 6  | 21%       | 3  | 14%       | 2  | 7%        | 1 | 14%               | 2  | 0%    | 0 | 14    |

Figure 25 presents respondent views on the effects of their lymphoma/CLL symptoms. 74% of patients reported that they agree or strongly agree that their symptoms negatively impact on everyday activities that people their age can usually do.

**Figure 25: 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...  
107 Responses



### Effects of Lymphoma/CLL Treatment

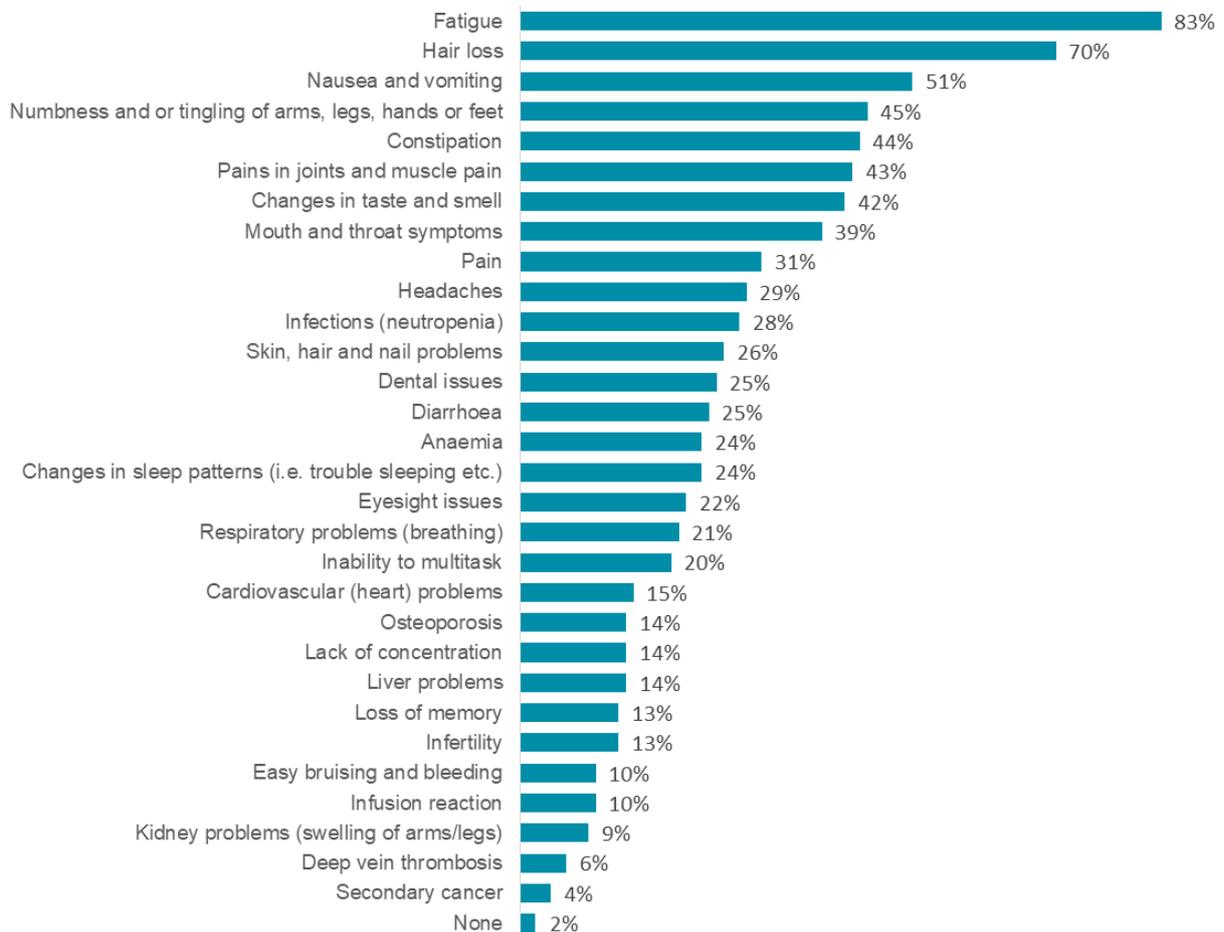
Patients who are receiving treatment for their lymphoma/CLL are affected by a range of treatment-related side effects, the most frequently are shown below, see Figure 26 for full list of reported side effects from treatment.

- Fatigue reported by 83%
- Hair loss reported by 70%
- Nausea and vomiting reported by 51%

**Figure 26: 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?

102 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:

- 24% (n=21) report that fatigue affects them the most
- 21% (n=19) report that nausea and vomiting affects them the most
- 18% (n=16) report that hair loss affects them the most

The treatment-related side effect that affected patients the longest (for five or more years) was fatigue. This was reported by 32% (n=17) of patients.

58% of patients definitely discussed their treatment-related side effects with their doctor – see Figure 27. Figure 28 displays whether the doctor was able to help with these side effects. Only 22% of patients said that the doctor was definitely able to help with treatment side effects, while 59% reported that the doctor was able to help to some extent.

**Figure 27: 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?

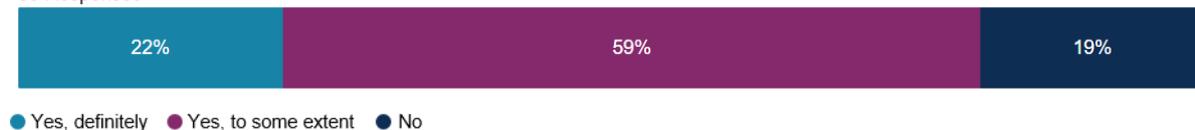
97 Responses



**Figure 28: Was the doctor able to help with the side effects?**

Was the doctor able to help with the side effects?

85 Responses



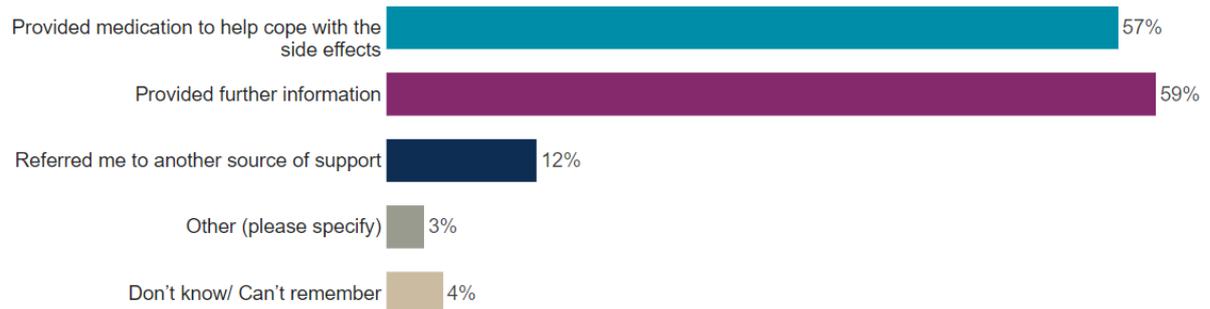
Of those who said their doctor was able to help with treatment side effects (Figure 29):

- 59% said the doctor helped by providing further information
- 57% said the doctor helped by providing medication to help cope with side effects

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

What specifically did the doctor do to help?

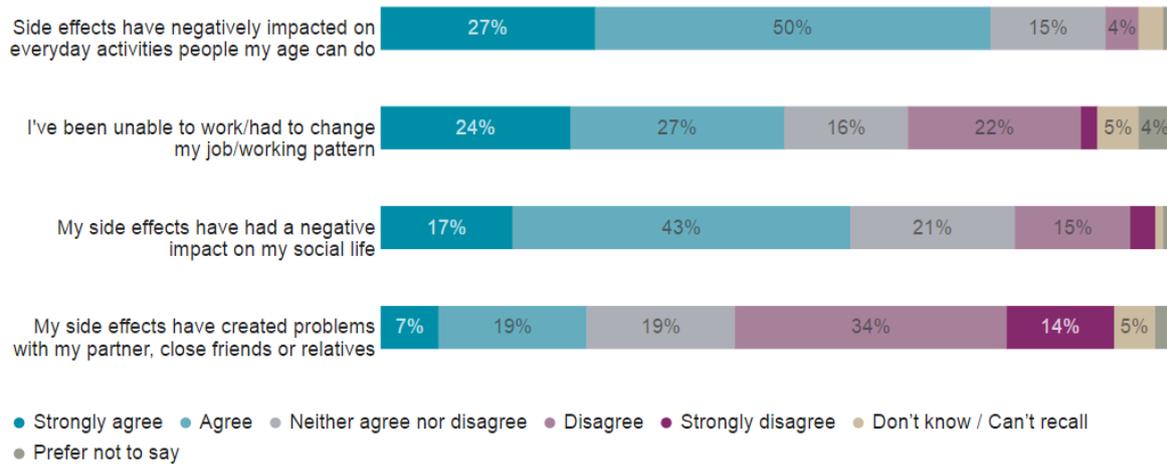
69 Responses



Regarding the treatment side effects that affected patients, 77% reported that they agree or strongly agree that their side effects have negatively impacted on everyday activities that people their age can usually do. Similarly, 60% agree or strongly agree that their side effects have had a negative impact on their social life – see Figure 30.

**Figure 30: 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:  
96 Responses



## Fatigue

Fatigue was the leading physical symptom affecting quality of life reported by respondents to the LC (2018) Global Patient Survey, regardless of whether the patient was newly diagnosed, in treatment, had relapsed disease or was in remission. However, patients were not being educated about their fatigue or directed to further information/support by their doctors. Healthcare professionals have been challenged in their efforts to assess and help their patients manage cancer-related fatigue because of various patient-related, professional, and systematic barriers.



- Over 65% of those who rated their fatigue as a six or above out of ten (where one = minimal and ten = worst imaginable) reported that it affects their physical activities, general work around the home and general activity.
- Of the 54% of patients who discussed their fatigue with their doctor, 18% reported that the doctor did not follow-up with them about their fatigue.
- 40% of patients did not discuss their fatigue with their doctor. The top reported reason for why patients did not discuss their fatigue was that patients did not think it was relevant (46%).

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. 43% of patients reported their fatigue levels over the last week were six or above. These patients stated that their fatigue affected the following areas/activities over the last two years:

- Physical activities (reported by 72% of patients with a fatigue rating of six or more)
- General work around the home (reported by 67% of patients with a fatigue rating of six or more)
- General activity (reported by 65% of patients with a fatigue rating of six or more)

Figure 31 shows that 54% of patients have discussed their fatigue with their doctor over the last two years, and 40% have not.

**Figure 31: Have you discussed your fatigue with your doctor over the last two years?**

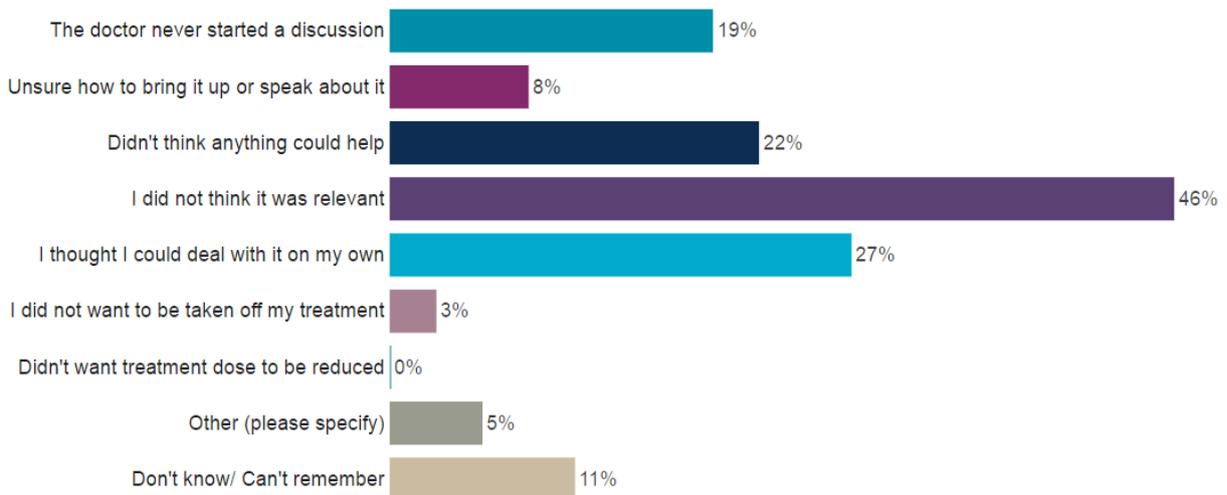
Have you discussed your fatigue with your doctor over the last two years?  
95 Responses



The main reason patients reported as not having discussed their fatigue with their doctor was that they did not think it was relevant (46%) – see Figure 32.

**Figure 32: Why have you not discussed your fatigue with your doctor?**

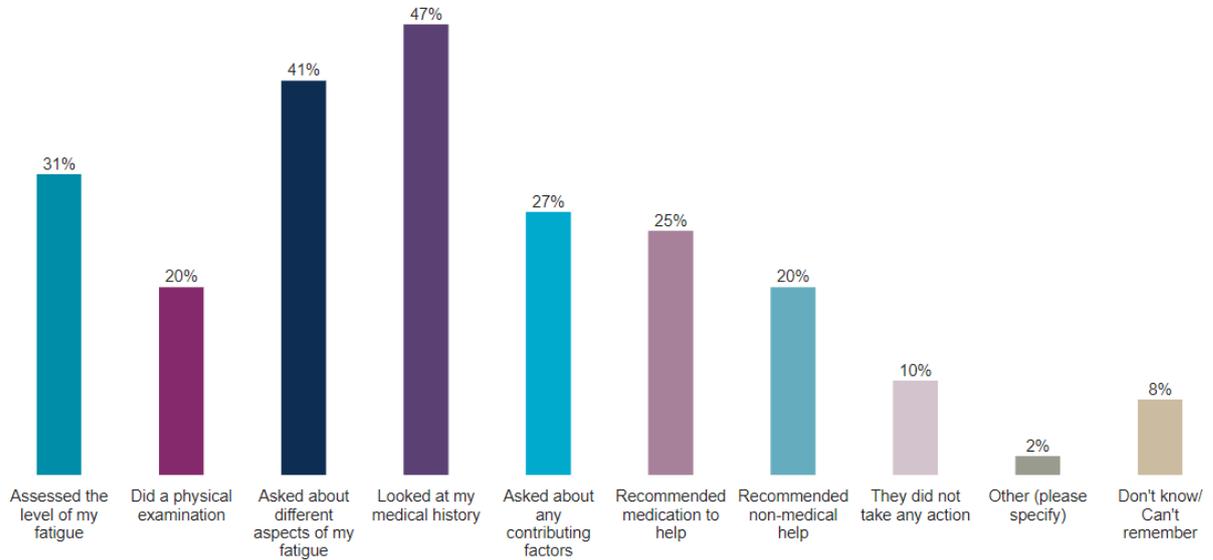
Why have you not discussed your fatigue with your doctor?  
37 Responses



Patients who discussed fatigue with their doctor were asked how their doctor helped with their fatigue. Responses are displayed in Figure 33. Less than half of patients reported that the doctor did a physical examination (20%) or looked at their medical history (47%)

**Figure 33: What did the doctor do after you discussed your fatigue?**

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

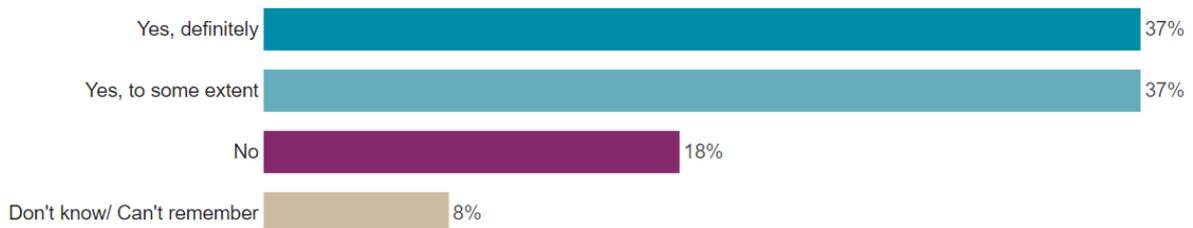


When respondents were asked whether their doctor followed up with them about their fatigue (Figure 34):

- 37% said 'Yes, definitely'
- 37% said 'Yes, to some extent'
- 18% said 'No'

**Figure 34: 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?  
51 Responses



Patients were asked whether they spoke to anyone else (other than a doctor) about their fatigue, and 65% reported that they also spoke to family/friends – see Figure 35

**Figure 35: Did you speak to anybody else to help you with your fatigue?**

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

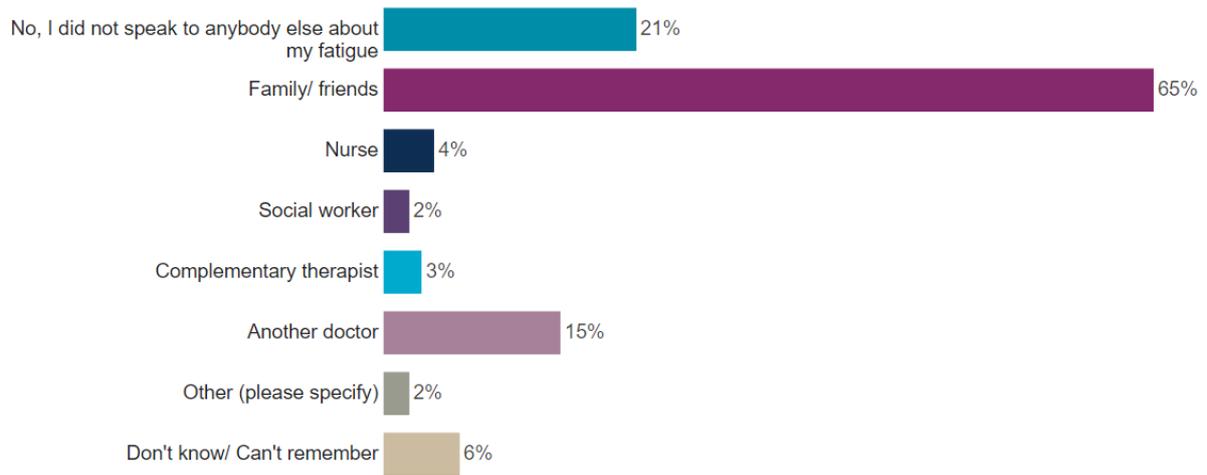
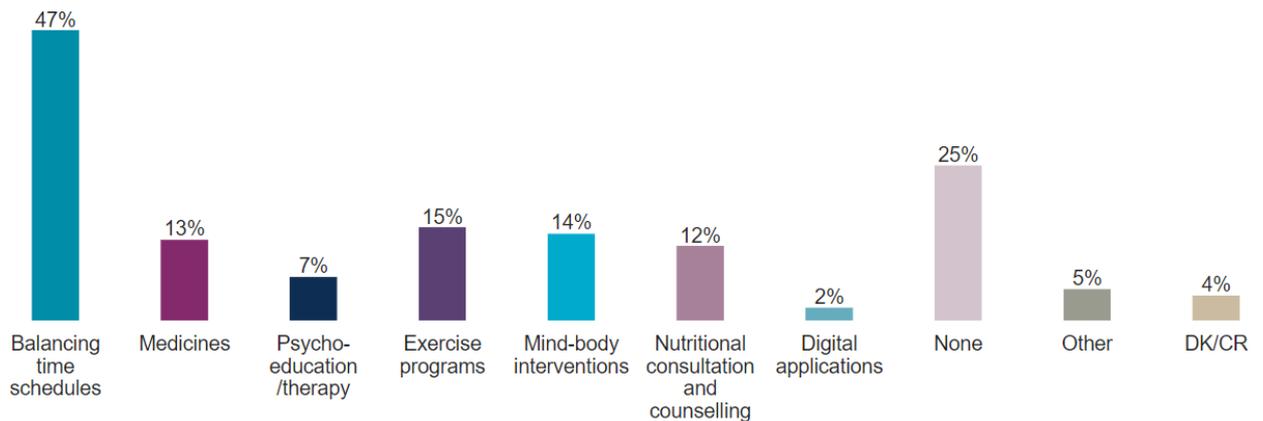


Figure 36 displays that the top reported coping mechanisms patients have used to help with their fatigue over the last two years are balancing time schedules (47%) and exercise programs (15%). Meanwhile, 25% report having used no coping mechanisms.

**Figure 36: 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?  
100 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 2020 LC Global Patient Survey to further investigate this issue in order to bridge this two-way communication gap.



- The most commonly reported psychosocial effects that patients had experienced in the last 12 months included fear of cancer relapse (39%), anxiety (33%) and depression (30%).
- Only 31% of those with anxiety discussed it with their doctor, and only 41% of those with depression discussed it with their doctor.
- Patients experiencing depression or anxiety were more likely to say that they had not discussed this with anybody else other than a doctor (38% and 32% respectively) compared with all other psychosocial effects (14%-26%).

Patients with lymphoma were asked what psychosocial effects they had experienced in the last 12 months – see Table 6. The most commonly reported responses were:

- 39% of patients experienced fear of cancer relapse
- 33% of patients experienced anxiety
- 30% of patients experienced depression

**Table 6: 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?**

**106 Response**

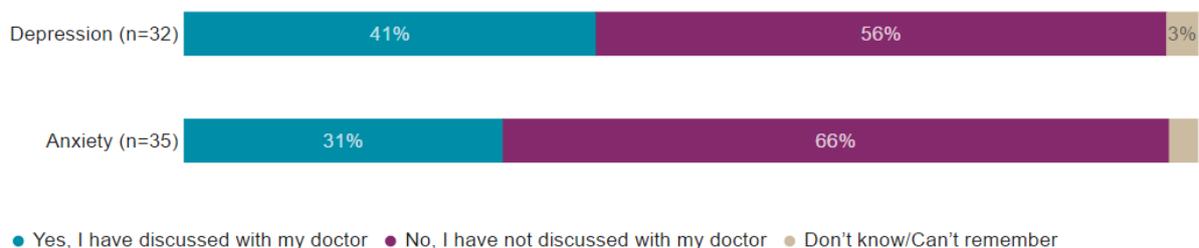
|   |             |            |
|---|-------------|------------|
| Loss of self-esteem                                       | 22%         | 23         |
| Concerns about body image/physical appearance             | 26%         | 28         |
| Changes in relationships                                  | 18%         | 19         |
| Isolation   | 25%         | 26         |
| Depression  | 30%         | 32         |
| Anxiety   | 33%         | 35         |
| Fear of relapse   | 39%         | 41         |
| Fear of progression of the lymphoma                       | 27%         | 29         |
| I have not experienced any of these in the last 12 months | 22%         | 23         |
| Don't know/ can't remember                                | 4%          | 4          |
| <b>Total</b>  | <b>100%</b> | <b>106</b> |

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 anxiety and depression; changes in relationships is not reported due to the low base size (n=19).

Figure 37 presents the percentage of patients who discussed their anxiety, and/or depression with their doctor. Less than half of patients who experienced either issue had discussed it with their doctor.

**Figure 37: 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?



Of those who reported reasons for not discussing their anxiety with their doctor (n=23), the main reason was they thought they could handle it on their own (57%). Reasons for not discussing depression is not reported due to a low sample size (n=18).

When asked who else they had spoken to regarding their worries or concerns (all psychosocial issues included, not just depression, anxiety and changes in relationships), in many cases, patients reported that they had spoken with their family and friends for help. See Table 7 below for a breakdown of responses. Patients experiencing depression or anxiety were more likely to say that they had not discussed this with anybody else other than a doctor (38% and 32% respectively) compared with all other psychosocial effects (14%-26%).

**Table 7: 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 |    |
|                                 | %               | n   | %     | n   | %             | n  | %                       | n  | %              | n   | %     | n  | %     | n  |       |    |
| 22%                             | 5               | 65% | 15    | 13% | 3             | 0% | 0                       | 4% | 1              | 13% | 3     | 0% | 0     | 4% | 1     | 23 |

| 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 |    |
|   | %               | n   | %     | n   | %             | n  | %                       | n  | %              | n  | %     | n  | %     | n  |       |    |
| 19%   | 5               | 74% | 20    | 15% | 4             | 4% | 1                       | 0% | 0              | 4% | 1     | 0% | 0     | 7% | 2     | 27 |

| Isolation                       |                 |     |       |     |               |    |                         |    |                |    |       |    |       |    |       |    |
|---------------------------------|-----------------|-----|-------|-----|---------------|----|-------------------------|----|----------------|----|-------|----|-------|----|-------|----|
| I did not speak to anybody else | Family/ friends |     | Nurse |     | Social worker |    | Complementary therapist |    | Another doctor |    | Other |    | DK/CR |    | Total |    |
|                                 | %               | n   | %     | n   | %             | n  | %                       | n  | %              | n  | %     | n  | %     | n  |       |    |
| 19%                             | 5               | 65% | 17    | 12% | 3             | 0% | 0                       | 0% | 0              | 8% | 2     | 0% | 0     | 8% | 2     | 26 |

| Depression                      |                 |     |       |    |               |    |                         |    |                |     |       |    |       |    |       |    |
|---------------------------------|-----------------|-----|-------|----|---------------|----|-------------------------|----|----------------|-----|-------|----|-------|----|-------|----|
| I did not speak to anybody else | Family/ friends |     | Nurse |    | Social worker |    | Complementary therapist |    | Another doctor |     | Other |    | DK/CR |    | Total |    |
|                                 | %               | n   | %     | n  | %             | n  | %                       | n  | %              | n   | %     | n  | %     | n  |       |    |
| 38%                             | 12              | 50% | 16    | 6% | 2             | 6% | 2                       | 6% | 2              | 19% | 6     | 0% | 0     | 3% | 1     | 32 |

| Anxiety                         |                 |     |       |    |               |    |                         |    |                |     |       |    |       |    |       |    |
|---------------------------------|-----------------|-----|-------|----|---------------|----|-------------------------|----|----------------|-----|-------|----|-------|----|-------|----|
| I did not speak to anybody else | Family/ friends |     | Nurse |    | Social worker |    | Complementary therapist |    | Another doctor |     | Other |    | DK/CR |    | Total |    |
|                                 | %               | n   | %     | n  | %             | n  | %                       | n  | %              | n   | %     | n  | %     | n  |       |    |
| 32%                             | 11              | 53% | 18    | 3% | 1             | 3% | 1                       | 6% | 2              | 15% | 5     | 0% | 0     | 3% | 1     | 34 |

| 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 |    |
|                                     | %               | n   | %     | n   | %             | n  | %                       | n  | %              | n   | %     | n  | %     | n  |       |    |
| 14%                                 | 4               | 76% | 22    | 10% | 3             | 3% | 1                       | 3% | 1              | 14% | 4     | 0% | 0     | 3% | 1     | 29 |

## 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.



- 39% of patients reported experiencing fear of cancer relapse in the last 12 months, and only 41% have discussed their fear of relapse with their doctor.
- 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.
- Nearly half (48%) of patients reported that they are not using any coping mechanisms to help with their fear of relapse.

In the 2020 Global Patient Survey, 39% of patients reported they experienced a fear of cancer relapse in the last 12 months, and only 41% have discussed their fear of relapse with their doctor.

Of those who have discussed fear of relapse with their doctor, only 12% of patients reported their doctor was definitely able to help (Figure 38 – please note only 17 patients responded to the question).

**Figure 38: 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

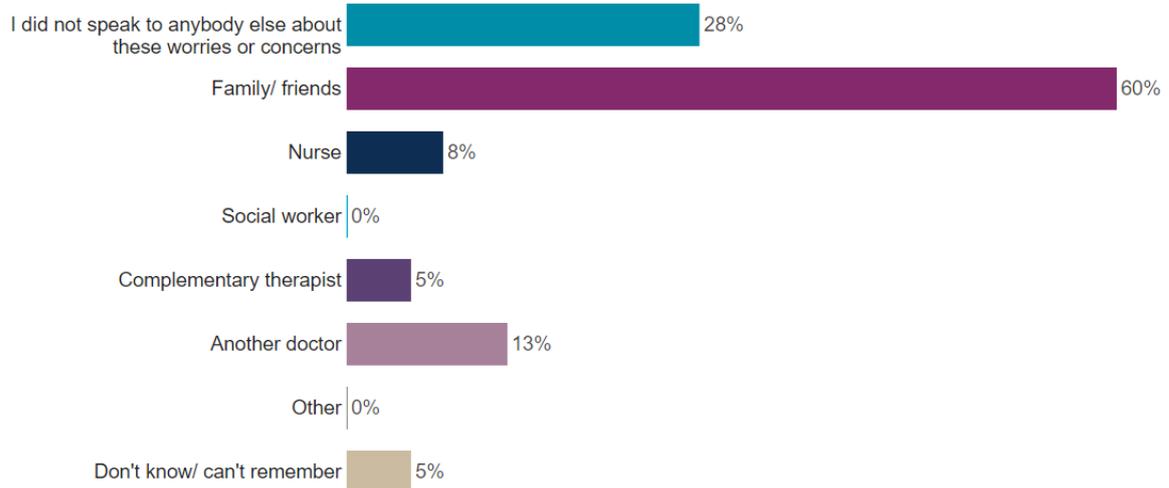


- Yes, definitely
- Yes, to some extent
- No
- Don't know/ can't remember

Almost two thirds of patients (60%) reported they have also spoken to family and friends about their fear of relapse – see Figure 39.

**Figure 39: For the fear of relapse that you have experienced, please indicate who else you have spoken with to help you with these worries or concerns?**

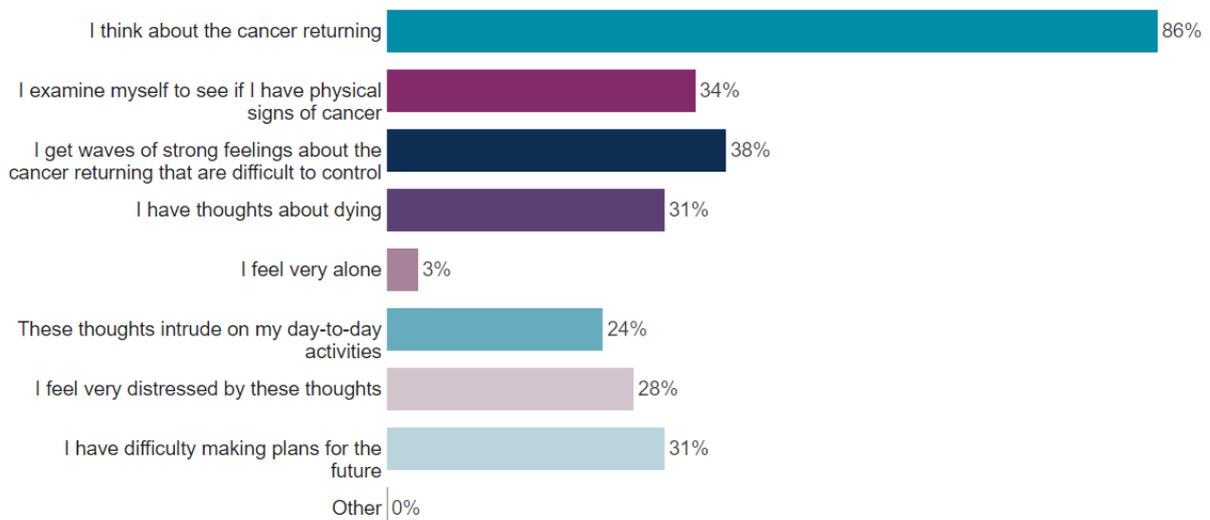
For **fear of relapse**, please indicate who else you have spoken with to help you with these worries or concerns?  
40 Responses



86% of patients who reported experiencing fear of relapse also reported that they think about the cancer returning, and 38% get waves of strong feelings about the cancer returning that are difficult to control (Figure 40). Almost a third of patients (31%) who experience fear of cancer relapse have difficulty making plans for the future as a result.

**Figure 40: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?**

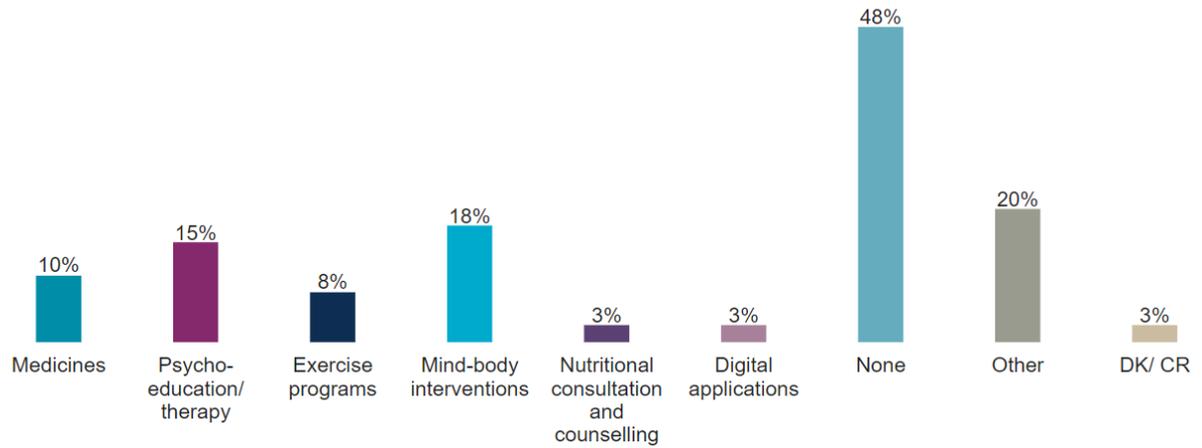
You have indicated that you have experienced a fear of relapse, which of the following have you experienced?  
29 Responses



48% of patients reported that they are not using any coping mechanisms to help with their fear of relapse. 18% reported they are using mind-body interventions – see Figure 41.

**Figure 41: 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?  
40 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 2020 Global Patient Survey questions were also asked about barriers to accessing clinical trials.

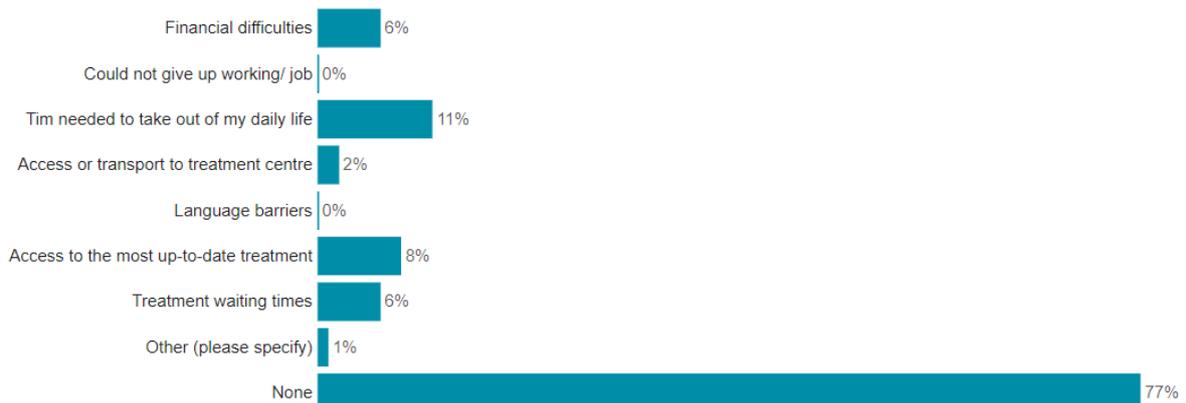


- 77% of patients reported that nothing has prevented them from receiving treatment. The next most reported barrier to receiving treatment was the time patients would need to take out of their daily lives (11%).
- 72% of patients reported that never being presented with an opportunity to take part was a barrier to being in a clinical trial.

When asked to select from a list of potential barriers to treatment, 77% of patients selected that ‘none’ have prevented them from receiving treatment. 11% of patients reported they were prevented from receiving treatment because of the time they would have needed to take out of their daily life – see Figure 42.

**Figure 42: Have any of the following prevented you from receiving treatment?**

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



72% of patients reported that never being presented with an opportunity to take part was a barrier to being in a clinical trial.

## Results – II. Caregiver survey

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

32 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

Please take care interpreting results in this caregiver section due to a low number of respondents (32 overall).

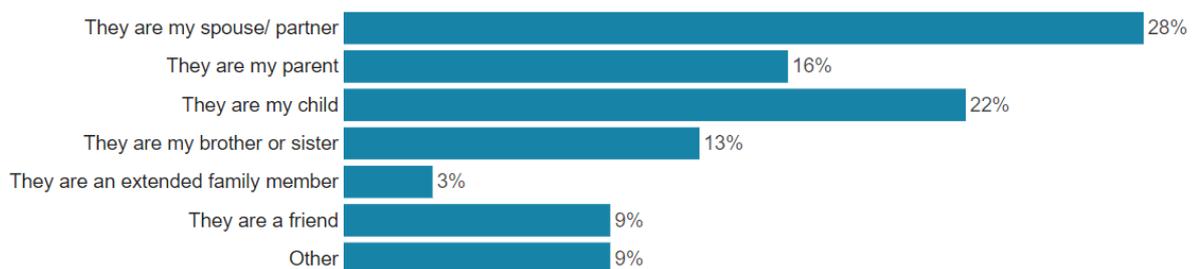
### Caregiver Demographics

Caregivers were asked to identify their relationship to the person they are providing care and support to, 28% of caregivers are a spouse/partner, and 22% are caring for their child. Figure 43 displays the full results.

**Figure 43: 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?

32 Responses



Only 9% of caregivers use the term ‘caregiver’ when thinking about themselves and the care/support they provide.

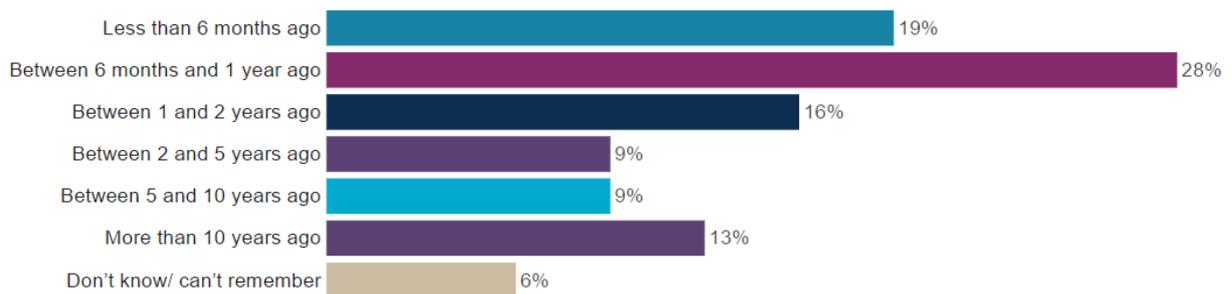
When caregivers were asked the about the support that they provide:

- 78% responded that they provide emotional support, such as talking and listening
- 63% said that they look for information
- 56% responded that they run errands, such as helping with shopping and collecting prescriptions

Caregivers were asked how long ago the person they provide care for was diagnosed; Figure 44 displays the results. Nearly half of caregivers (47%) are caring for someone who received their diagnosis less than one year ago.

**Figure 44: Length of time since diagnosis**

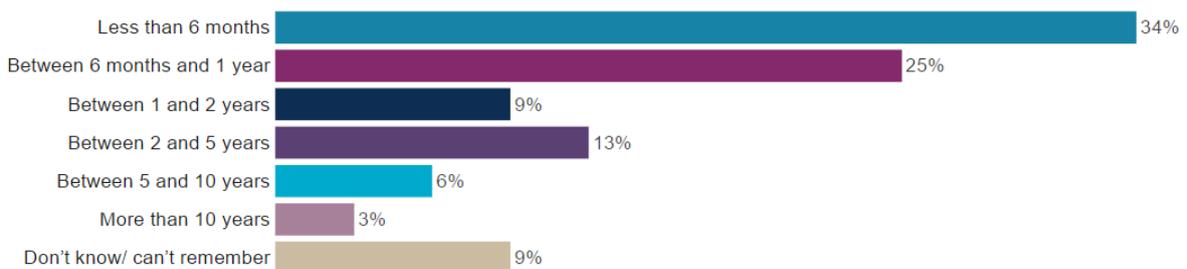
How long ago was the person you care for diagnosed with lymphoma or CLL?  
32 Responses



Over half (59%) of caregivers who responded have only been providing care and support for a year or less, see Figure 45 below:

**Figure 45: 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?  
32 Responses



The most common lymphoma subtype of the patients that caregivers are providing care and support for is Hodgkin lymphoma (reported by 38%). 22% of caregivers are unsure of the lymphoma subtype of the person they are caring for, and 9% report providing care for someone with mantle cell or peripheral T cell lymphoma. Figure 46 displays the lymphoma subtype for all patients who caregivers are supporting.

**Figure 46: What subtype of lymphoma does/did the person you care for have?**

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

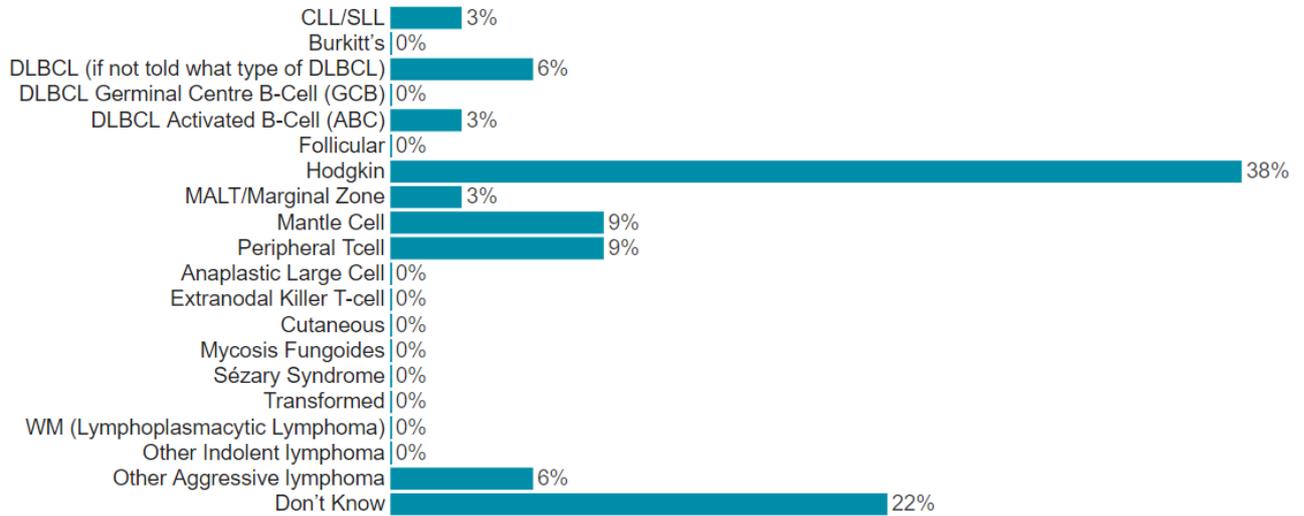
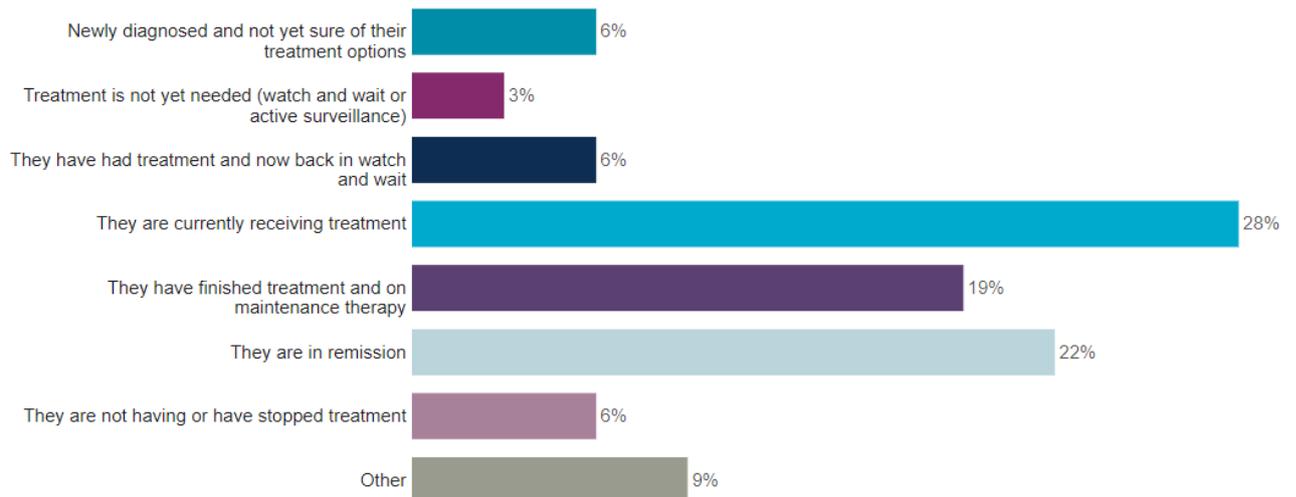


Figure 47 displays the stage of the care pathway of the patients the caregivers are providing care and support for. Over a quarter (28%) of all caregivers are supporting somebody currently in treatment.

**Figure 47: 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?  
32 Responses



20% of caregivers reported the lymphoma/CLL of the person they care for has relapsed, and 12% reported it has transformed.

## Caregiver Information, Guidance and Support



- 75% of caregivers reported that a doctor was their top place to go for information.
- 43% of caregivers report that both they and the patient jointly sought out information about the disease and potential treatments following the diagnosis.
- The majority of caregivers (70%) report they definitely felt assisted/supported and understood by their family and friends; however, a quarter of caregivers (24%) did not feel that their role was recognised by healthcare providers.

When asked to select their top three places to go for information, 75% of caregivers said ‘doctor’ was their top place to go (see Table 8 for more details).

**Table 8: When you have a need for information about the healthcare of the person you care for, which of the following are the top places you go to first for information? You may select up to 3.**

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

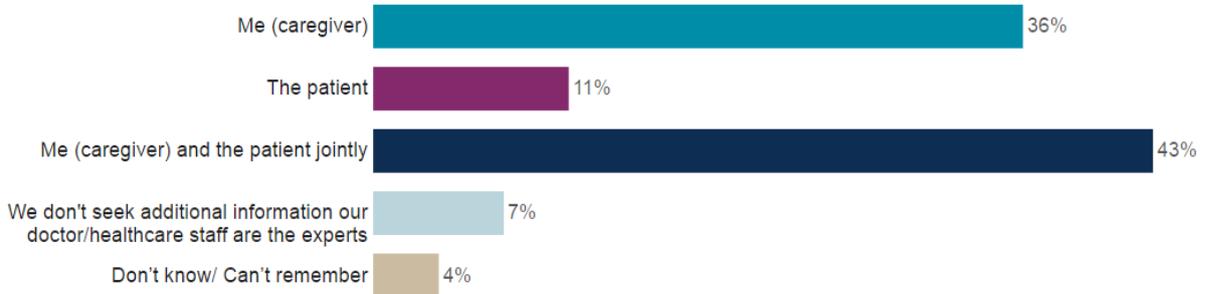
|                           | 1           |           | 2           |           | 3           |           |
|---------------------------|-------------|-----------|-------------|-----------|-------------|-----------|
| Doctor                    | 75%         | 21        | 14%         | 4         | 4%          | 1         |
| Nurse                     | 0%          | 0         | 29%         | 8         | 0%          | 0         |
| Websites                  | 14%         | 4         | 29%         | 8         | 42%         | 10        |
| Online blogs/social media | 0%          | 0         | 14%         | 4         | 13%         | 3         |
| Family/friends            | 11%         | 3         | 0%          | 0         | 17%         | 4         |
| Patient organisation      | 0%          | 0         | 14%         | 4         | 25%         | 6         |
| Other                     | 0%          | 0         | 0%          | 0         | 0%          | 0         |
| <b>Total</b>              | <b>100%</b> | <b>28</b> | <b>100%</b> | <b>28</b> | <b>100%</b> | <b>24</b> |

Figure 48 indicates who was seeking out information and details about the disease and potential treatments (the patient with lymphoma, the caregiver, or both).

**Figure 48: 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?

28 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

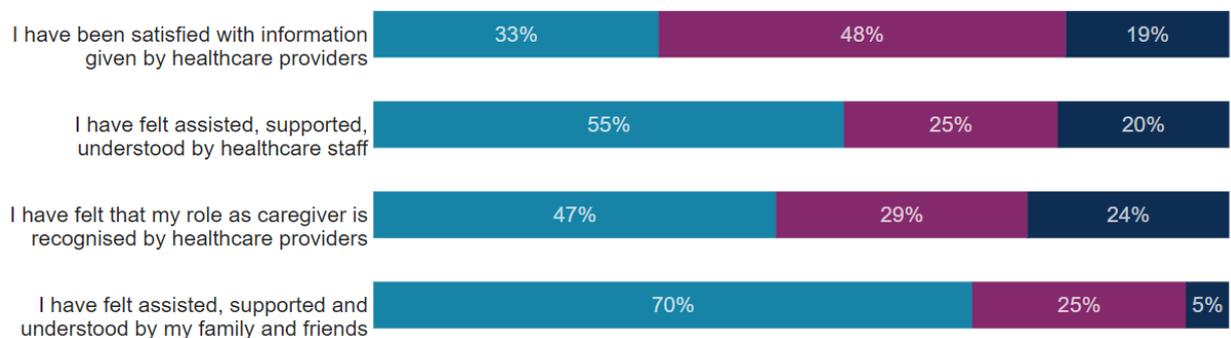
- 65% said less than six months ago
- 19% said between six months and one year ago
- 4% said more than one year ago

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 – see Figure 49. The majority of caregivers (70%) report they definitely felt assisted/supported and understood by their family and friends; however, a quarter of caregivers (24%) did not feel that their role was recognised by healthcare providers.

**Figure 49: 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.

21 Responses



- Yes, definitely
- Yes, to some extent
- No

## Impact of Caregiving



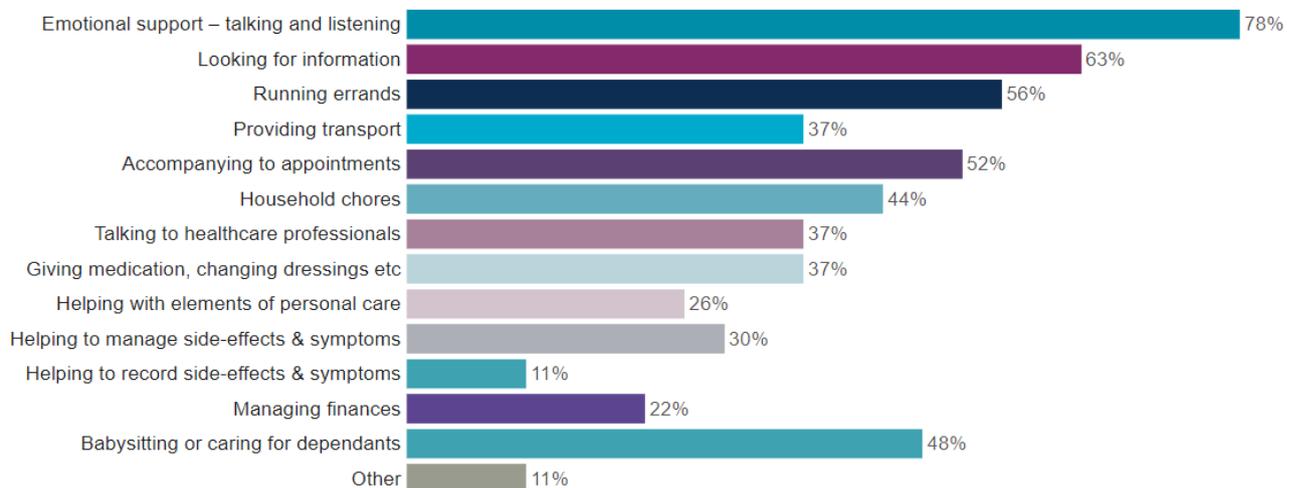
- Over half of caregivers (59%) reported that emotional support was the hardest type of care to provide.
- The top reported issues that have often or always affected caregivers in the last 12 months included fear that the patient will relapse (67%) and putting the needs of the patient before their own (60%).
- Over half (58%) of caregivers indicated that the impact on their life is the same whether the person they care for is on or off treatment.

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 (78%) and looking for information (63%) were the most common reported aspects. Figure 50 displays the results for all types of care provided by the caregivers who responded.

**Figure 50: 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.

27 Responses



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

- 59% reported emotional support
- 15% reported were not sure
- 11% reported practical support

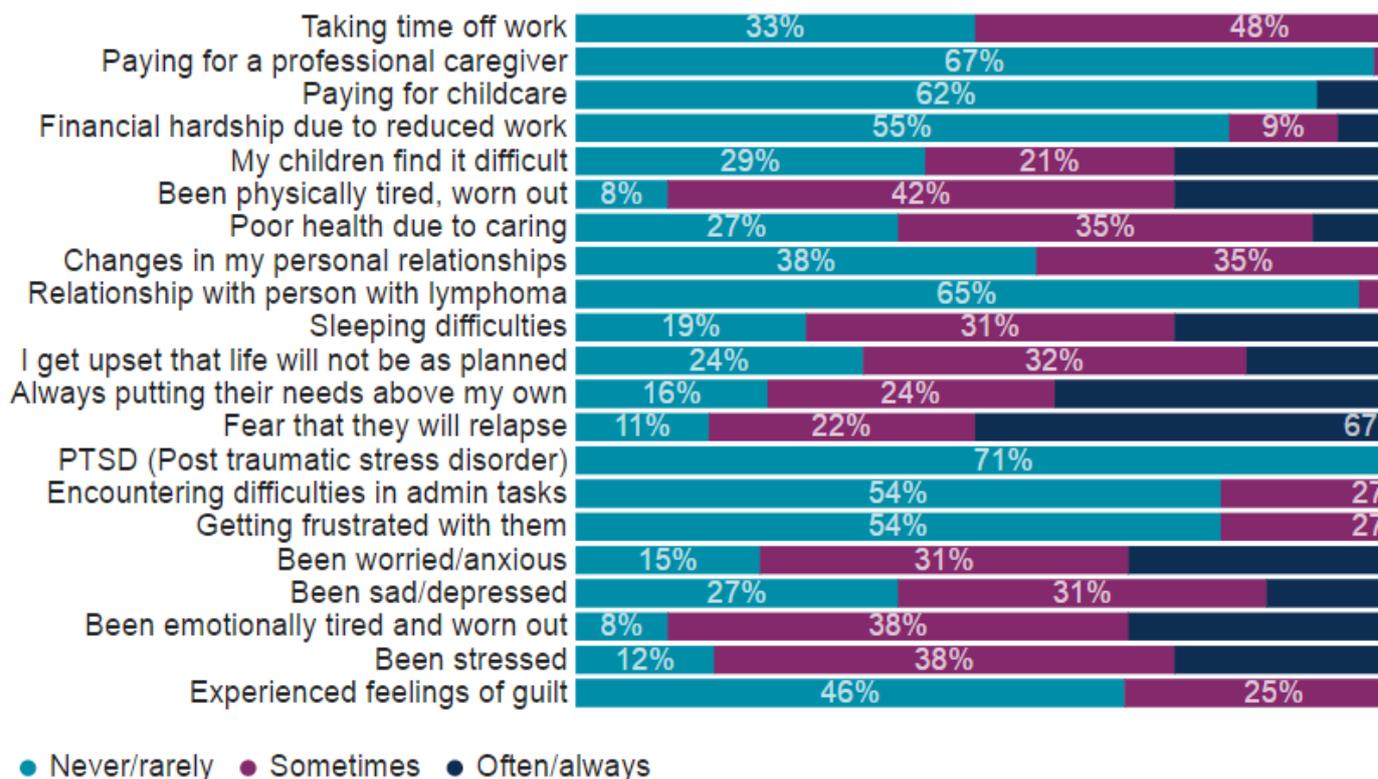
Caregivers rated the extent to which some aspects of providing care and support to somebody with lymphoma/CLL had affected them in the past 12 months – see Figure 51. The top reported issues

included: 'fear that they will relapse' (67% often/always) and 'always putting their needs before my own' (60% often/always).

Figure 51: 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?

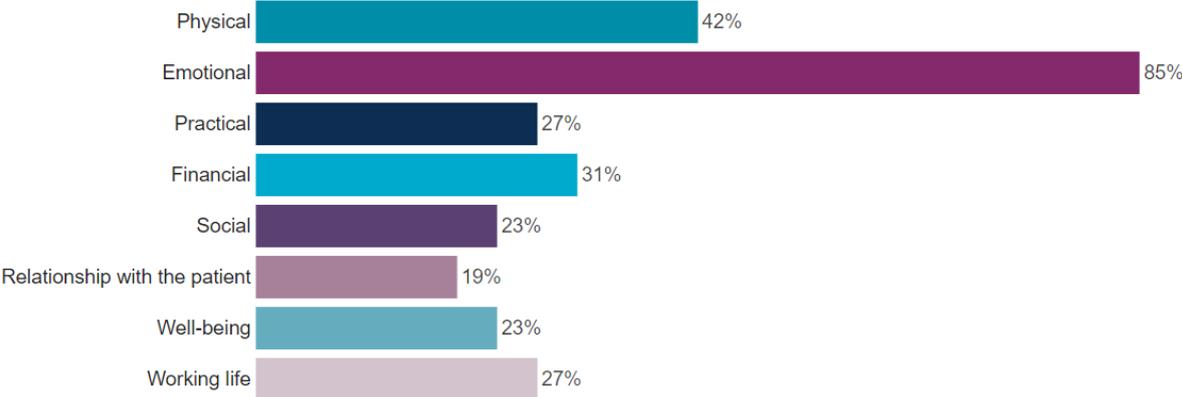
26 Responses



When asked which areas of their life have been most impacted by caring or supporting somebody with lymphoma/CLL, the area of life most selected by caregivers was ‘emotional’ (85%) – see Figure 52.

**Figure 52: Which of the following areas of your life have been impacted most by caring for or supporting somebody with lymphoma/CLL?**

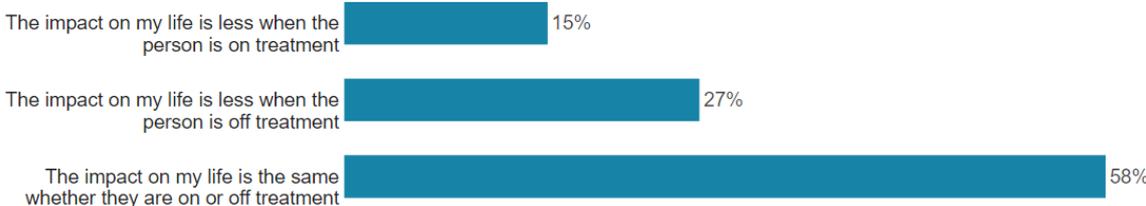
Which of the following areas of your life have been impacted most by caring for or supporting somebody with lymphoma/CLL?  
26 Responses



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 53). 58% indicated that the impact on their life is the same whether the person they care for is on or off treatment.

**Figure 53: 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?  
26 Responses



# Appendices

## Appendix 1

#2035

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

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



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



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

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

**2) METHODOLOGY**  
• This study is a sub-analysis of the 2018 LC GPS, which is a biennial online global survey of patients with lymphomas including CLL.  
• The survey was hosted on a third-party portal from January-March 2018 in 19 languages.  
**Participants**  
• Globally, 6631 participants took part (70+ countries).  
• There were 595 CLL and 1478 DLBCL respondents.

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

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

|           | CLL (n=595) | DLBCL (n=1478) | P-value* |
|-----------|-------------|----------------|----------|
| Age       |             |                |          |
| 18-24     | 7(1)        | 155(10)        | <0.001   |
| 25-39     | 28(4)       | 325(22)        |          |
| 40-49     | 213(36)     | 599(41)        |          |
| 50-59     | 224(38)     | 277(19)        |          |
| 60+       | 311(52)     | 117(8)         |          |
| Sex       |             |                |          |
| Male      | 308(52)     | 657(45)        | 0.001    |
| Female    | 274(46)     | 803(54)        |          |
| Residence |             |                |          |
| Rural     | 198(33)     | 345(23)        | 0.001    |
| Suburban  | 171(29)     | 354(24)        |          |
| Urban     | 286(48)     | 679(46)        |          |

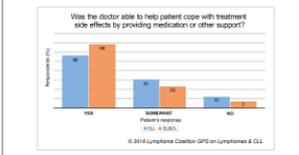
The DLBCL subgroup had more respondents in the age group (18-39 yrs age group-combined) compared to CLL respondents (32% vs 5%). The CLL group had more than twice the proportion of older respondents (>60 years) than the DLBCL group (18% vs 8%).  
CLL respondents had more males (51%) whilst DLBCL respondents had a lower male proportion (42%). One-fifth (20%) of CLL respondents and 24% of DLBCL respondents resided in rural areas (table 1).

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

Of statistical significance, CLL respondents who started treatment right away were twice as likely as DLBCL respondents to have less understanding of their initial treatment and its potential side effects (OR=2.23 and 2.34 respectively).

| Issue   | CLL (n=595) | DLBCL (n=1478) | OR (95% CI)      |
|---|-------------|----------------|------------------|
| Understanding of diagnosis                                  | 187 (31%)   | 223 (15%)      | 2.94 (2.34-3.42) |
| Understanding of initial treatment                          | 148 (25%)   | 182 (12%)      | 2.93 (2.33-3.53) |
| Understanding of the best treatment option (if any)         | 136 (23%)   | 167 (11%)      | 3.00 (2.41-3.80) |
| Understanding of potential side effects                     | 182 (31%)   | 223 (15%)      | 2.94 (2.34-3.42) |
| Understanding of side effects management                    | 148 (25%)   | 182 (12%)      | 2.93 (2.33-3.53) |
| Understanding of the different treatment and stages of care | 187 (31%)   | 223 (15%)      | 2.94 (2.34-3.42) |

CLL respondents were more likely to have less understanding about side effect management, the different treatment options and the various processes and stages of care compared to DLBCL respondents (ORs 1.8, 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 1).



**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 effect 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 effort should be made to inform and educate lymphoma patients adequately and appropriately at all points of clinical contact.

**5) CONTACT**  
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## Correlation of Lymphoma Patient Information Level with Healthcare Experience

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### 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 behaviours. In 2017, the Lymphoma Coalition (LC) conducted a mixed methods investigation to determine if evidence exists pointing to better outcomes for more informed patients. A key theme was identified 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 65+ lymphoma-related patient organizations, 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 respondent's understanding of the medical aspects of their lymphoma, diagnosis and care (Table 1, Figures 2(a) & (b)).

| Topic   | Adequate Information (%) | Somewhat Adequate Information (%) | Inadequate/No Adequate Information (%) |
|---|--------------------------|-----------------------------------|--|
| Diagnosis   | 66                       | 30                                | 4                                      |
| Characteristics of the particular subtype           | 54                       | 27                                | 19                                     |
| Additional medical treatment options                | 64                       | 24                                | 12                                     |
| Initial treatment of starter right away             | 74                       | 19                                | 7                                      |
| Potential side effects of treatment options         | 66                       | 24                                | 10                                     |
| Side effect management                              | 60                       | 29                                | 11                                     |
| Process and stages of care                          | 65                       | 23                                | 12                                     |
| Active surveillance (watch and wait), if applicable | 67                       | 21                                | 12                                     |

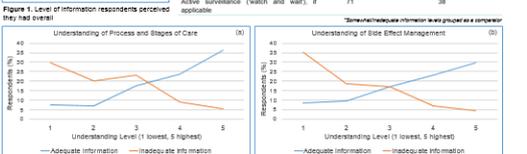
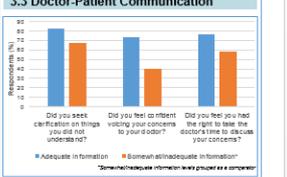


Figure 2 (a) Respondents' understanding of the process and stages of their care and (b) side effect management after their initial visit with their doctor based on perceived information level.

**3.2 Respondent Feelings**  
Adequately informed respondents felt more confident in determining the need for medical care vs. handing 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



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

### 4) CONCLUSION

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

### ACKNOWLEDGEMENTS

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

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



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**1) INTRODUCTION**

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

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

**2) METHODOLOGY**

**Study Design**

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

**Respondents**

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

**Statistical Analysis**

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

**3) RESULTS**

The ENKTL subgroup had the highest proportion of inadequately informed patients (59%), 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.

|                  | ENKTL Count (%) | WM Count (%) | X <sup>2</sup> (p-value) |
|------------------|-----------------|--------------|--------------------------|
| <b>Age</b>       |                 |              | 505.9 (p < 0.00001)      |
| 18-29            | 40 (23)         | 1 (9)        |                          |
| 30-39            | 45 (26)         | 2 (9)        |                          |
| 40-49            | 72 (43)         | 125 (16)     |                          |
| 50-59            | 15 (9)          | 332 (44)     |                          |
| 70+              | 3 (2)           | 302 (40)     | 5.8 (p = 0.016766)       |
| <b>Sex</b>       |                 |              |                          |
| Male             | 122 (69)        | 450 (59)     |                          |
| Female           | 55 (31)         | 308 (41)     | 81.1 (p < 0.00001)       |
| <b>Residence</b> |                 |              |                          |
| Rural            | 45 (26)         | 156 (21)     |                          |
| Suburban         | 102 (59)        | 209 (27)     |                          |
| Urban            | 29 (16)         | 364 (48)     |                          |

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   | 51 (29)   | 52 (37)  | OR=1.94 (95% CI 1.27-2.94) |
|   | WM      | 169 (22)  | 369 (48)                                       | P=0.002                    |
| Understanding of initial treatment (for those who started with any) | ENKTL   | 57 (41)   | 50 (37)  | OR=1.99 (95% CI 1.29-3.05) |
|   | WM      | 147 (20)  | 254 (33)                                       | P=0.001                    |
| Understanding different treatment options                           | ENKTL   | 67 (41)   | 38 (28)  | OR=1.84 (95% CI 1.19-2.83) |
|   | WM      | 209 (28)  | 277 (36)                                       | P=0.009                    |
| Understanding of side effect management                             | ENKTL   | 53 (29)   | 38 (28)  | OR=1.27 (95% CI 0.85-2.00) |
|   | WM      | 242 (41)  | 220 (27)                                       | P=0.105                    |
| Understanding of the different processes and stages of care         | ENKTL   | 49 (28)   | 51 (34)  | OR=1.16 (95% CI 0.75-1.78) |
|   | WM      | 222 (30)  | 287 (38)                                       | P=0.510                    |

Analysis of patient-doctor communication showed that compared to WM patients, ENKTL patients were more likely to not (somehow/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 (don't/want + No) Count (%) | Yes Count (%) | OR (95% CI)                |
|--|---------|--------------------------------|---------------|----------------------------|
| Communicated medical issues to the doctor              | ENKTL   | 19 (24)                        | 51 (76)       | OR=2.20 (95% CI 1.23-3.91) |
|  | WM      | 78 (14)                        | 479 (86)      | P=0.0074                   |
| Communicated emotional issues to the doctor            | ENKTL   | 48 (61)                        | 31 (39)       | OR=2.24 (95% CI 0.70-7.19) |
|  | WM      | 201 (46)                       | 245 (54)      | P=0.469                    |
| Sought clarification on things they did not understand | ENKTL   | 13 (21)                        | 50 (79)       | OR=2.28 (95% CI 1.16-4.50) |
|  | WM      | 68 (11)                        | 439 (87)      | P=0.0179                   |
| Feel confident voicing concerns to the doctor          | ENKTL   | 39 (98)                        | 24 (41)       | OR=4.43 (95% CI 2.04-9.73) |
|  | WM      | 128 (45)                       | 266 (78)      | 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).

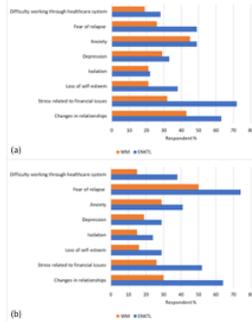


Figure 1. Psychosocial issues reported by patients (a) during and (b) after treatment

**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)**



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**1) INTRODUCTION**

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

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

**2) METHODOLOGY**

**Study Design**

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

**Respondents**

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

**Statistical Analysis**

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

**3) RESULTS**

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

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

|                  | FL count(%) | DLBCL count(%) | X <sup>2</sup> (p-value) |
|------------------|-------------|----------------|--------------------------|
| <b>Age</b>       |             |                | 93.83 (p<0.001)          |
| 18-29            | 27(3)       | 156(10)        |                          |
| 30-39            | 129(14)     | 323(22)        |                          |
| 40-49            | 466(50)     | 599(41)        |                          |
| 50-59            | 251(27)     | 277(19)        |                          |
| 70+              | 60(6)       | 117(8)         |                          |
| <b>Sex</b>       |             |                | 11.58 (p<0.001)          |
| Male             | 358(38)     | 667(45)        |                          |
| Female           | 276(29)     | 803(55)        |                          |
| <b>Residence</b> |             |                | 24.98 (p<0.001)          |
| Rural            | 191(20)     | 345(24)        |                          |
| Suburban         | 240(26)     | 284(17)        |                          |
| Urban            | 502(54)     | 870(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).

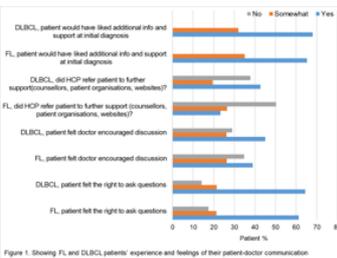


Figure 1. Showing FL and DLBCL patients' experience and feelings of their patient-doctor communication

**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

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