Lymphoma Coalition
2020 Global Patient Survey on Lymphomas & CLL

A report prepared for Lymphoma Coalition by Picker Institute Europe

July 2020
Lymphoma Coalition

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

The LC vision is equity in lymphoma outcomes across borders.

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

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Picker

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

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

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SECTION 1

Executive Summary
Executive Summary

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

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

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

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

Results

Upon analysis of the France data as a whole, it was apparent that the patient population was heavily dominated by patients with chronic lymphocytic leukaemia (CLL)/small lymphocytic lymphoma (SLL) and Waldenström’s macroglobulinaemia (WM)/lymphoplasmacytic lymphoma (LPL). The results in this report therefore present the data for respondents from France with CLL/SLL and WM/LPL to explore this population in more detail.

Overall number of completed responses 826 made up of:

770 Patients
56 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.
770 Responses

<table>
<thead>
<tr>
<th>Patients</th>
<th>59%</th>
<th>41%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intersex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to say</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 2: Gender of caregivers

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

<table>
<thead>
<tr>
<th>Caregivers</th>
<th>39%</th>
<th>61%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer to self describe</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to say</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 3: Age of patients and caregivers

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

<table>
<thead>
<tr>
<th>Patients (n=749)</th>
<th>22%</th>
<th>38%</th>
<th>40%</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-29</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40-59</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to say</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregivers (n=54)</th>
<th>24%</th>
<th>50%</th>
<th>26%</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-29</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40-59</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to say</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 4: Subtype by patients and caregivers

Patient subtype (grouped)
770 Responses

<table>
<thead>
<tr>
<th>CLL/SLL</th>
<th>79%</th>
</tr>
</thead>
<tbody>
<tr>
<td>WM/LPL</td>
<td>21%</td>
</tr>
</tbody>
</table>

Caregiver subtype (grouped)
56 Responses

<table>
<thead>
<tr>
<th>CLL/SLL</th>
<th>68%</th>
</tr>
</thead>
<tbody>
<tr>
<td>WM/LPL</td>
<td>32%</td>
</tr>
</tbody>
</table>

Abbreviations: CLL, chronic lymphocytic leukaemia; SLL, small lymphocytic lymphoma; WM, Waldenström’s macroglobulinaemia; LPL, lymphoplasmacytic lymphoma
Some key findings from the patient survey are as follows:

**Patient information, guidance and support**

- 63% of patients were told their lymphoma subtype at diagnosis.
- Only 39% agree strongly that they have good conversations with their doctor about care and treatment plans.
- 63% were informed and completely understood how to manage side effects of treatment.
- 50% are definitely involved as much as they want to be in decisions about their care and treatment.
- 15% of patients got a second opinion about their most recent treatment, and a further 3% got a second opinion and changed their primary doctor as a result.
- 63% of patients needed more information about diagnosis and what it means.

**Effects of diagnosis and treatment**

- Fatigue was the most commonly reported symptom of lymphoma/CLL (69%).
- Fatigue was the most commonly reported side effect of treatment (70%).
- 64% of patients agree or strongly agree that their treatment side effects have negatively impacted on everyday activities people their age can normally do.
- 37% of patients indicated they had experienced fear of progression of the lymphoma as a result of their lymphoma diagnosis.
- 17% of patients reported experiencing fear of cancer relapse in the last 12 months.
- 52% of patients do not use any coping mechanisms to help them with their fear of cancer relapse.
SECTION 2

Background

87% of patients reported that no barriers have prevented them from receiving treatment.

61% of patients reported that they have never been presented with an opportunity to take part in a clinical trial.

14% of patients are currently, or have been, in a clinical trial for their lymphoma or CLL.

More detailed findings from the survey can be found in the main report, and full frequency tables showing detailed responses to each survey question are available separately.
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.\(^1\)

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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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
- LC Healthcare Matters Reports and Subtype Reports
- Scientific Posters (Appendix 1)
- World Lymphoma Awareness Day (WLAD)

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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https://www.lymphomacoalition.org/lymphomas/lymphoma-subtypes/subtype-reports/dlbcl-report
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
- Arabic
- Bulgarian
- Chinese
- Dutch
- Finnish
- French
- German
- Hindi
- Italian
- Japanese
- Korean
- Lithuanian
- Portuguese
- Punjabi
- Serbian
- Slovak
- Spanish
- Swedish
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, lymphoma 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; 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 France with chronic lymphocytic leukaemia (CLL)/small lymphocytic lymphoma (SLL); or Waldenström’s macroglobulinaemia (WM)/lymphoplasmacytic lymphoma (LPL).

A total of 770 responded to the patient survey and 56 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 displays the area of residence of the respondents.

**Figure 1a: Sex of patients**

Please describe your experience with lymphoma, including CLL.

770 Responses

![Sex of patients chart]

**Figure 1b: Gender of caregivers**

Please describe your experience with lymphoma, including CLL.

56 Responses

![Gender of caregivers chart]

**Figure 2: Age range of respondents**

Please describe your experience with lymphoma, including CLL.

803 Responses

![Age range of respondents chart]
Figure 3: Household status (patients + caregivers)

Which of the following best describes your household status? 826 Responses

- Married / in a civil partnership / living with partner: 71%
- Married / in a civil partnership / living with a partner with my/our children: 9%
- Single / divorced / widowed and living alone: 15%
- Single / divorced / widowed and living with my children: 3%
- Single / divorced / widowed and living with my parents: 0%
- Single / divorced / widowed and living with other adults: 2%
- Prefer not say: 0%

Figure 4: Employment status of respondents

Which of the following best describes your employment status? 826 Responses

<table>
<thead>
<tr>
<th>Category</th>
<th>Patients</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time employment</td>
<td>16%</td>
<td>11%</td>
</tr>
<tr>
<td>Part time employment</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Self employment</td>
<td></td>
<td>9%</td>
</tr>
<tr>
<td>Home maker</td>
<td></td>
<td>3%</td>
</tr>
<tr>
<td>Student</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed and seeking work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed and unable to work for health reasons (NOT seeking work)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not say</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

Which best describes the area you live in? 826 Responses

- City/urban area: 44%
- Suburbs: 14%
- Rural area (for example: in a very small town in the country or on a farm): 42%
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.

770 people living with CLL/SLL or WM/LPL 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 CLL/SLL or WM/LPL, and the results are displayed in Figure 6. The majority of patients (90%) were diagnosed more than two years ago.

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

![Chart showing diagnosis time](chart)

Figure 7 below shows how long patients reported waiting between their first GP appointment about their symptoms to getting a diagnosis. The majority (73%) had a diagnosis within six months of their first appointment. However, 14% 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?

<table>
<thead>
<tr>
<th>Duration</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 3 months</td>
<td>52%</td>
</tr>
<tr>
<td>3 - 6 months</td>
<td>21%</td>
</tr>
<tr>
<td>6 - 12 months</td>
<td>7%</td>
</tr>
<tr>
<td>More than 12 months</td>
<td>7%</td>
</tr>
<tr>
<td>No symptoms/ Not applicable</td>
<td>10%</td>
</tr>
<tr>
<td>Don’t know/ Can’t remember</td>
<td>3%</td>
</tr>
</tbody>
</table>

770 Responses

Figure 8 shows how the majority of patients (79%) in this report have CLL/SLL, whereas about a fifth (21%) were diagnosed with WM/LPL.

Figure 8: What subtype of lymphoma do you have?

<table>
<thead>
<tr>
<th>Type</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLL/SLL</td>
<td>79%</td>
</tr>
<tr>
<td>WM/LPL</td>
<td>21%</td>
</tr>
</tbody>
</table>

770 Responses

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

42% of patients report that treatment is not yet needed (watch and wait), 21% are currently in treatment, 12% have had treatment and are now back in watch and wait. 4% have finished treatment and are on maintenance therapy, and 17% of patients report that they are in remission.
Figure 9: What statement best describes where you are in the lymphoma/CLL experience?

Patients with CLL/ SLL were asked to select which status applies to them, if known. Results are shown below in Figure 10, with the majority (75%) not knowing.

Figure 10: Please select any of the following that you know apply to your CLL or SLL.

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 CLL/SLL or WM/LPL.

413 patients reported the different treatments they are on/ or have ever been on, these can be seen in Figure 11 below.

Figure 11: 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?

413 Responses

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemo-immunotherapy</td>
<td>50%</td>
</tr>
<tr>
<td>Chemotherapy alone</td>
<td>12%</td>
</tr>
<tr>
<td>Immunotherapy only</td>
<td>13%</td>
</tr>
<tr>
<td>Steroids</td>
<td>4%</td>
</tr>
<tr>
<td>Targeted therapy</td>
<td>31%</td>
</tr>
<tr>
<td>Radioimmunotherapy</td>
<td>0%</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>1%</td>
</tr>
<tr>
<td>Autologous or allogeneic stem cell transplant</td>
<td>1%</td>
</tr>
<tr>
<td>Complementary and alternative medicine (CAM)</td>
<td>4%</td>
</tr>
<tr>
<td>Chimeric antigen receptor T cell therapy (CAR-T)</td>
<td>0%</td>
</tr>
<tr>
<td>Skin creams and ointments</td>
<td>8%</td>
</tr>
<tr>
<td>Light therapy</td>
<td>1%</td>
</tr>
<tr>
<td>Others</td>
<td>13%</td>
</tr>
<tr>
<td>Don't Know/ Can't remember</td>
<td>5%</td>
</tr>
</tbody>
</table>

A slightly larger proportion of patients with CLL/SLL (33%) had received targeted therapy than those with WM/LPL (26%).

A greater percentage of patients with WM/LPL (20%) had received immunotherapy than those with CLL/SLL (11%).

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 (89%) selected that their chemotherapy/immunotherapy/chemo-immunotherapy is paid for in full by government funding – see Figure 12.

**Figure 12: Who pays for your chemo-immunotherapy, your chemotherapy (only) or your immunotherapy (only) treatments?**

For those patients who have received targeted therapy, 89% report that it is paid for in full by the government, and 5% report that it is paid for in full by private healthcare insurance. Just 3% report it is paid for by a combination of government funding and healthcare insurance, and a further 3% report some ‘other’ form of funding for targeted therapy.

Only 14% of patients are currently, or have previously been in a clinical trial for their lymphoma or CLL, while 86% are not currently or have never been in a trial.
Patient Information, Guidance and Support

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

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

Clear information, communication and support for self-care are important aspects of person-centred care6. 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.

- 88% of patients reported that it was clear they had been given a diagnosis of cancer when they were told they had lymphoma, and 63% said they were told their lymphoma subtype at diagnosis.
- Most patients were given their diagnosis via face-to-face consultation (84%).
- Almost a quarter (24%) of patients felt that they were not given enough information upon diagnosis. The majority (60%) of patients reported having the greatest need for information within the first month following diagnosis.
- When asked to select their top three places to go for information about their healthcare, 75% reported that ‘doctor’ was their top place to go.
- Nearly a third (32%) of patients felt that they did not get enough emotional support.
- 92% of patients agree or strongly agree that they seek clarification on things they do not understand. However, almost a fifth (18%) agree or strongly agree that they feel overwhelmed by managing their health and condition.
- Almost a quarter of patients (24%) agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help.
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, 88% of patients said yes. Furthermore, 63% of patients reported they were told their lymphoma subtype at diagnosis.

The majority of patients (84%) reported that their diagnosis was announced via face-to-face consultation, 5% reported on the phone, 2% by post or mail, 1% in the hallway, and 8% answered other.

Patients were asked how they felt about the amount of information they received upon diagnosis – 24% were not given enough information. See Figure 13 for overall response.

Figure 13: How do you feel about the amount of information you were given around the time you were first diagnosed with lymphoma?

More females (32%) than males (19%) reported that they were not given enough information at the time of diagnosis.

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. 68% of patients were given and completely understood information on the different medical treatment options, including active surveillance (watch and wait). 59% of patients were provided with information on and completely understood the process and stages of care. And 63% reported they received information on and completely understood how to manage side effects of treatment. See Figure 14 for more details.
Figure 14: When first diagnosed, were you given enough information on the following:

When you were first diagnosed, were you given information on the different medical treatment options, including active surveillance (watch and wait)?
82 Responses
- 68% Yes, and I completely understood
- 26% Yes, and I understood a little
- 6% Yes, but I did not understand
- 6% No, I was not given this information
- 6% Don’t know/Can’t remember

When you were first diagnosed, were you given information on the process and stages of your care?
81 Responses
- 59% Yes, and I completely understood
- 25% Yes, and I understood a little
- 10% Yes, but I did not understand
- 6% No, I was not given this information
- 6% Don’t know/Can’t remember

When you were first diagnosed, were you given information on how to manage side effects of treatment?
27 Responses
- 63% Yes, and I completely understood
- 22% Yes, and I understood a little
- 15% Yes, but I did not understand
- 6% No, I was not given this information
- 6% Don’t know/Can’t remember

When discussing treatment options with their doctor, 8% of patients said they were given information about opportunities for fertility preservation. 87% had not been given this information but did not need it. However, 5% did not receive this information but would have liked to.
Patient Knowledge and Experience

Patients had the greatest need for information within the first month following diagnosis (60%).

When asked about information needs:

- 63% needed more information about diagnosis and what it means;
- 52% of patients reported needing more information about treatment options;
- 31% required more information about the side effects from treatment;
- 15% of patients needed more information about psychological support/counselling;
- 4% required more information about support for their families.

Table 1 displays the number of patients selecting each information need by lymphoma subtype. For both CLL/SLL and WM/LPL patients, the majority of patients (64% and 61% respectively) needed more information about diagnosis and what it means, followed by treatment options (51% and 56% respectively).

**Table 1: Which of the following, if any, have you needed more information about?**

<table>
<thead>
<tr>
<th></th>
<th>CLL/SLL</th>
<th>WM/LPL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis and what it means</td>
<td>64%</td>
<td>61%</td>
</tr>
<tr>
<td>Treatment options</td>
<td>38%</td>
<td>96%</td>
</tr>
<tr>
<td>Support for self-care</td>
<td>51%</td>
<td>56%</td>
</tr>
<tr>
<td>Psychological support/counselling</td>
<td>31%</td>
<td>14%</td>
</tr>
<tr>
<td>Support for my family</td>
<td>15%</td>
<td>14%</td>
</tr>
<tr>
<td>Side effects from treatment</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Fertility</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>I have not needed more information</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>Total</td>
<td>609</td>
<td>158</td>
</tr>
</tbody>
</table>

When asked to select their top three places to go for information about their healthcare, 75% said ‘doctor’ and 14% 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.**

**762 Responses**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>75%</td>
<td>17%</td>
<td>11%</td>
</tr>
<tr>
<td>Nurse</td>
<td>1%</td>
<td>11%</td>
<td>75</td>
</tr>
<tr>
<td>Websites</td>
<td>14%</td>
<td>31%</td>
<td>208</td>
</tr>
<tr>
<td>Online blogs/social media</td>
<td>1%</td>
<td>5%</td>
<td>31</td>
</tr>
<tr>
<td>Family/friends</td>
<td>0%</td>
<td>3%</td>
<td>19</td>
</tr>
<tr>
<td>Patient organisation</td>
<td>10%</td>
<td>31%</td>
<td>211</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>2%</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Figure 15 displays whether patients felt they had received enough support in key areas of patient experience. 78% and 77% felt that they had enough support from their doctor(s) and from family and friends, respectively. However, nearly a third (32%) of patients felt that they did not get enough emotional support.

Figure 15: In general, have you received enough support throughout your patient experience in the following areas?

<table>
<thead>
<tr>
<th>Area</th>
<th>Agree/Strongly Agree</th>
<th>Neutral</th>
<th>Disagree/Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support from doctor(s)</td>
<td>76%</td>
<td>15%</td>
<td>6%</td>
</tr>
<tr>
<td>Support from family/friends</td>
<td>77%</td>
<td>10%</td>
<td>13%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>36%</td>
<td>32%</td>
<td>32%</td>
</tr>
<tr>
<td>Financial support</td>
<td>7%</td>
<td>28%</td>
<td>65%</td>
</tr>
<tr>
<td>Practical support</td>
<td>18%</td>
<td>24%</td>
<td>58%</td>
</tr>
</tbody>
</table>

84% agree or strongly agree that they always understand their doctors’ advice and treatment plans, and 85% agree or strongly agree that they are confident in their ability to get the information they need from their doctor. However, 16% disagree or strongly disagree that they know what each of their prescribed medications do. See Figure 16.
Slightly more males (46%) than females (36%) strongly agreed that they felt confident in their ability to get the information they need from their doctor. Similarly, more males (43%) than females (33%) strongly agreed that they always understand their doctors’ advice and treatment plans.

Differences were also identified between those who felt they were given the right amount of information at diagnosis and those who felt that they were not given enough information. 49% of those who felt that they were given the right amount of information at diagnosis strongly agreed that they were confident in their ability to get the information they needed from their doctor. Meanwhile, only 23% of those who felt that they were not given enough information at diagnosis strongly agreed that they were confident in their ability to get the information they needed from their doctor.

In addition, those who reported feeling ‘very’ confident in managing their health problems day-to-day more often strongly agreed with all four areas presented in Figure 16 compared to those who reported feeling ‘fairly’, ‘not very’ or ‘not at all’ confident.

61% of patients have been seeing the same referring haematologist/oncologist/dermatologist during the whole of their treatment, however 10% have not and have suffered from the turnover of doctors. Just under a third (29%) have not been seeing the same referring haematologist/oncologist/dermatologist but have not suffered from the turnover of doctors.

Figure 17 indicates that overall, 77% of patients reported they always have confidence and trust in the doctors treating them- with a further 21% agreeing ‘sometimes’.
Figure 17: Do you have confidence and trust in the doctors treating you?

<table>
<thead>
<tr>
<th>Yes, always</th>
<th>Yes, sometimes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>77%</td>
<td>21%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Of the 27% of patients (n=203) who have seen nurses for their lymphoma care over the last year, 62% definitely feel comfortable asking nurses questions about their lymphoma/CLL (Figure 18), and 52% always have confidence and trust in the information they are given (Figure 19).

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

<table>
<thead>
<tr>
<th>Yes, definitely</th>
<th>Yes, to some extent</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>62%</td>
<td>30%</td>
<td>4%</td>
<td></td>
</tr>
</tbody>
</table>

Figure 19: Do you have confidence and trust in the information you get from the nurses?

<table>
<thead>
<tr>
<th>Yes, always</th>
<th>Yes, sometimes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>52%</td>
<td>39%</td>
<td>5%</td>
<td></td>
</tr>
</tbody>
</table>

Healthcare Decision Making

Patients were asked a series of questions about the role they play in making decisions about their healthcare – see Figure 20. 92% agree or strongly agree that they seek clarification on things they do not understand. However, 18% agree or strongly agree that they feel overwhelmed by managing their health and condition.
Figure 20: Thinking about your role in making decisions about your healthcare, please indicate how much you agree or disagree with each statement:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel overwhelmed by managing my health and condition</td>
<td>4%</td>
<td>14%</td>
<td>20%</td>
<td>35%</td>
<td>27%</td>
</tr>
<tr>
<td>I am confident in my ability to positively impact my health</td>
<td>29%</td>
<td>40%</td>
<td>17%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>I have good conversations with my doctor about my care and treatment plan</td>
<td>39%</td>
<td>40%</td>
<td>15%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>I am confident that I can tell my doctor concerns I have even when health does not ask</td>
<td>39%</td>
<td>48%</td>
<td>8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I seek clarification on things I do not understand</td>
<td>40%</td>
<td>52%</td>
<td>5%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

64% of those who felt ‘very confident’ in managing their health problems day-to-day strongly agreed that they seek clarification on things they do not understand, compared to 35% of those who are only ‘fairly confident’ in managing their health problems day-to-day.

88% of patients reported they are involved as much as they want to be in decisions about their care and treatment—either definitely or to some extent. 11% reported they are not involved but would like to be, and 2% reported they are not involved but do not want to be.

29% 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 21.
Figure 21: Have you talked to your doctor about wanting to change your treatment to better meet your needs, within the last 2 years?

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

<table>
<thead>
<tr>
<th>Response Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I have and I chose treatment recommended by my doctor</td>
<td>27%</td>
</tr>
<tr>
<td>Yes, I have and I chose treatment that was NOT suggested by my doctor</td>
<td>2%</td>
</tr>
<tr>
<td>No, but I would have liked to</td>
<td>3%</td>
</tr>
<tr>
<td>No, and I did not want to</td>
<td>8%</td>
</tr>
<tr>
<td>Don't know / Can't remember</td>
<td>1%</td>
</tr>
<tr>
<td>N/A - I haven't wanted to change my treatment within the last two years</td>
<td>34%</td>
</tr>
<tr>
<td>N/A - I haven't had any treatment(s) for my condition within the last two years</td>
<td>25%</td>
</tr>
</tbody>
</table>

15% of patients got a second opinion about their most recent treatment, and a further 3% got a second opinion and changed their primary doctor as a result. 13% wanted to get a second opinion but did not, and 66% felt they did not want or need to get a second opinion - see Figure 22.

Figure 22: Thinking about your most recent treatment, did you get a second opinion about your treatment options?

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

<table>
<thead>
<tr>
<th>Response Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15%</td>
</tr>
<tr>
<td>Yes, and I switched my primary doctor as a result</td>
<td>3%</td>
</tr>
<tr>
<td>No, but I wanted to</td>
<td>13%</td>
</tr>
<tr>
<td>No, but I did not want or need to</td>
<td>66%</td>
</tr>
<tr>
<td>Don't know / Can't remember</td>
<td>3%</td>
</tr>
</tbody>
</table>

Of those patients who did not get a second opinion (see Figure 23), the majority (88%) said it was because they trust their doctor’s advice and information.
When patients were asked what they are most influenced by when making healthcare decisions, the top answers were (see Figure 24):

- 73% said recommendations from healthcare providers and clinical staff
- 23% were most influenced by personal preferences

When asked about the importance of a variety outcomes, 52% of patients ranked ‘a cure’ as having the most importance to them, and 34% ranked ‘quality of life’ as the most important outcome – see Table 3.
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.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>A cure</td>
<td>52%</td>
<td>18%</td>
<td>85%</td>
<td>9%</td>
<td>41%</td>
<td>8%</td>
<td>40%</td>
</tr>
<tr>
<td>Quality of life</td>
<td>34%</td>
<td>28%</td>
<td>135%</td>
<td>18%</td>
<td>87%</td>
<td>14%</td>
<td>66%</td>
</tr>
<tr>
<td>Fewer side effects to tolerate</td>
<td>6%</td>
<td>30%</td>
<td>37%</td>
<td>176%</td>
<td>31%</td>
<td>150</td>
<td>13%</td>
</tr>
<tr>
<td>Treatment at home versus treatment in clinic</td>
<td>4%</td>
<td>19%</td>
<td>12%</td>
<td>56%</td>
<td>23%</td>
<td>110</td>
<td>27%</td>
</tr>
<tr>
<td>Duration of treatment</td>
<td>0%</td>
<td>2%</td>
<td>3%</td>
<td>13%</td>
<td>15%</td>
<td>70</td>
<td>29%</td>
</tr>
<tr>
<td>What’s best for my caregiver</td>
<td>1%</td>
<td>4%</td>
<td>3%</td>
<td>13%</td>
<td>5%</td>
<td>22%</td>
<td>8%</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td>2%</td>
<td>8%</td>
<td>1%</td>
<td>4%</td>
<td>0%</td>
<td>2%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Health Behaviours

23% of patients report they are ‘very confident’ about managing their health problems day-to-day, and 53% are ‘fairly confident’. However 7% are ‘not very’ or ‘not at all’ confident. The full data can be seen in Figure 25.

Figure 25: How confident are you that you can manage your health problems day-to-day?

735 Responses

- Very confident: 23%
- Fairly confident: 63%
- Not very confident: 6%
- Not at all confident: 1%
- N/A - I don't currently have health problems to manage day-to-day: 17%
Patients were asked a series of questions about how they manage their day-to-day condition. 96% agree or strongly agree that they understand how to take their medicines and treatments at home. However 24% agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help. See Figure 26 for full details.

**Figure 26: Thinking about how you manage your condition day-to-day, how much do you agree or disagree with the following statements?**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand how to take my medicines and treatments at home</td>
<td>76%</td>
<td>18%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I implement lifestyle changes, like diet and exercise, that are recommended for my condition</td>
<td>35%</td>
<td>46%</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am confident that I can keep the symptoms/side effects from interfering with things I want to do</td>
<td>16%</td>
<td>42%</td>
<td>29%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>I wait until health issues can no longer be ignored before I seek help</td>
<td>7%</td>
<td>17%</td>
<td>18%</td>
<td>30%</td>
<td>29%</td>
</tr>
</tbody>
</table>

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

- The symptoms of lymphoma/CLL most reported to affect patients were fatigue (69%), shortness of breath (33%) and abnormal painless swellings on the body/enlarged lymph nodes (31%).
- 14-32% of patients reported experiencing each symptom of lymphoma/CLL for more than five years.
- The most common treatment-related side effects reported by patients were fatigue (70%), nausea and vomiting (42%), and pains in joints/muscle pain (33%).
- 78% of patients reported that they had definitely discussed their treatment side effects with their doctor. Of those, only 23% said that the doctor was definitely able to help with these.
- 64% of patients agree or strongly agree that their treatment side effects have negatively impacted on everyday activities that people their age can normally 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 (69%), shortness of breath (33%), and abnormal painless swellings on the body/enlarged lymph nodes (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?
746 Responses

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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>69%</td>
<td>515</td>
</tr>
<tr>
<td>Frequent or repeated infections</td>
<td>26%</td>
<td>197</td>
</tr>
<tr>
<td>Headaches</td>
<td>12%</td>
<td>92</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>33%</td>
<td>247</td>
</tr>
<tr>
<td>Easily bruised or bleed</td>
<td>21%</td>
<td>153</td>
</tr>
<tr>
<td>Skin rashes/lesions</td>
<td>19%</td>
<td>141</td>
</tr>
<tr>
<td>Fever, chills, night sweats and weight loss (B-symptoms)</td>
<td>23%</td>
<td>174</td>
</tr>
<tr>
<td>Abnormal painless swelling(s) on the body/enlarged lymph nodes</td>
<td>31%</td>
<td>228</td>
</tr>
<tr>
<td>Pain</td>
<td>16%</td>
<td>119</td>
</tr>
<tr>
<td>Anaemia</td>
<td>20%</td>
<td>146</td>
</tr>
<tr>
<td>No symptoms</td>
<td>17%</td>
<td>129</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>11%</td>
<td>83</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>746</strong></td>
<td></td>
</tr>
</tbody>
</table>

Table 5 indicates the length of time that patients have experienced symptoms. 59% of patients affected by abnormal painless swellings on the body/enlarged lymph nodes have been experiencing these symptoms for less than two years. However, 14-32% of patients reported experiencing all of the symptoms below for more than five years. 30% of those affected by fatigue have been experiencing this symptom for more than five years.
Table 5: You have indicated that you have been affected by the symptoms shown below, for each symptom that has affected you, please indicate how long you have had this symptom for:

603 Responses

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

<table>
<thead>
<tr>
<th>Symptom Description</th>
<th>Under a year</th>
<th>1-2 years</th>
<th>2-5 years</th>
<th>5-8 years</th>
<th>More than 8 years</th>
<th>Don't know/can't remember</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fever, chills, night sweats and weight loss</td>
<td>41%</td>
<td>26%</td>
<td>18%</td>
<td>6%</td>
<td>10%</td>
<td>8%</td>
<td>14%</td>
</tr>
<tr>
<td>Pain</td>
<td>22%</td>
<td>22%</td>
<td>26%</td>
<td>15%</td>
<td>18%</td>
<td>12%</td>
<td>3%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>17%</td>
<td>21%</td>
<td>26%</td>
<td>14%</td>
<td>73%</td>
<td>16%</td>
<td>84%</td>
</tr>
<tr>
<td>Abnormal painful swelling(s) on the body/enlarged lymph nodes</td>
<td>29%</td>
<td>30%</td>
<td>23%</td>
<td>8%</td>
<td>19%</td>
<td>7%</td>
<td>15%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>25%</td>
<td>25%</td>
<td>26%</td>
<td>12%</td>
<td>29%</td>
<td>9%</td>
<td>21%</td>
</tr>
<tr>
<td>Skin rashes/lesions</td>
<td>36%</td>
<td>24%</td>
<td>20%</td>
<td>13%</td>
<td>19%</td>
<td>5%</td>
<td>7%</td>
</tr>
<tr>
<td>Frequent or repeated infections</td>
<td>11%</td>
<td>22%</td>
<td>43%</td>
<td>17%</td>
<td>33%</td>
<td>15%</td>
<td>30%</td>
</tr>
<tr>
<td>Anaemia</td>
<td>38%</td>
<td>22%</td>
<td>32%</td>
<td>12%</td>
<td>17%</td>
<td>11%</td>
<td>16%</td>
</tr>
<tr>
<td>Headaches</td>
<td>18%</td>
<td>24%</td>
<td>22%</td>
<td>8%</td>
<td>7%</td>
<td>20%</td>
<td>18%</td>
</tr>
<tr>
<td>Easily bruised or bleed</td>
<td>25%</td>
<td>20%</td>
<td>30%</td>
<td>10%</td>
<td>16%</td>
<td>11%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Figure 27 presents patient views on the effects of their lymphoma/CLL symptoms. 58% agree or strongly agree that their symptoms negatively impact on everyday activities that people their age can normally do. Almost a quarter (24%) agree or strongly agree that they have been unable to work or had to change their job or working pattern because of their symptoms.

Figure 27: 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...

616 Responses

- My symptoms negatively impact on everyday activities that people my age can usually do
- Been unable to work/had to change my job or working pattern because of my symptoms
- My symptoms have had a negative impact on my social life
- My symptoms have created problems with my partner, close friends or relatives

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know/can't remember
- Prefer not to say
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 28 for full list of reported side effects from treatment.

- Fatigue reported by 70%
- Nausea and vomiting reported by 42%
- Muscle and joints pain reported by 33%

Figure 28: 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?

497 Responses

Fatigue: 70%
Nausea and vomiting: 42%
Pains in joints and muscle pain: 33%
Skin, hair and nail problems: 26%
Diarrhoea: 25%
Easy bruising and bleeding: 24%
Infections (neutropenia): 24%
Anaemia: 23%
Numbness and or tingling of arms, legs, hands or feet: 23%
Changes in sleep patterns (i.e. trouble sleeping etc.): 21%
Lack of concentration: 19%
Changes in taste and smell: 18%
Constipation: 17%
Pain: 16%
Loss of memory: 15%
Inability to multitask: 14%
Mouth and throat symptoms: 12%
Headaches: 12%
Respiratory problems (breathing): 12%
Hair loss: 12%
Eyesight issues: 12%
Cardiovascular (heart) problems: 9%
Infusion reaction: 8%
Dental issues: 8%
Kidney problems (swelling of arms/legs): 7%
Liver problems: 4%
Secondary cancer: 4%
Osteoporosis: 3%
Deep vein thrombosis: 1%
Infertility: 1%
None: 7%

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

- 27% (n=79) report that fatigue affects them the most;
- 24% (n=70) report that nausea and vomiting affects them the most;
- 7% (n=21) report that infections affect them the most;
- 7% (n=20) report that pains in joints and muscle pain affects them the most;
- 7% (n=19) report that anaemia affects them the most.
A quarter of patients (25%) were affected by fatigue and 31% were affected by infections for more than five years.

Figure 29 displays whether patients discussed treatment side effects with their doctor, and whether the doctor was able to help. 78% responded that they had definitely discussed side effects and of those, only 23% said that the doctor was definitely able to help with these. A further 52% reported that the doctor was able to help to some extent.

Figure 29: You said you experienced side effects, did you discuss them with your doctor?
Was the doctor able to help with the side effects?

Of those who said their doctor was able to help with treatment side effects (see Figure 30):
- 66% said the doctor helped by providing medication to help cope with the side effects;
- 36% said the doctor helped by providing further information.

Figure 30: What specifically did the doctor do to help?
Regarding the treatment side effects that affected patients, 64% agree or strongly agree that their side effects have negatively impacted on everyday activities that people their age can do. 36% agree or strongly agree their side effects have had a negative impact on their social life. See Figure 31.

Figure 31: Thinking about the side-effects of medication that affect you, to what extent, if at all, do you agree or disagree with each of the following statements? (Please select one option on each row):

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

- 383 Responses

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree or disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don't know / Can't recall</th>
<th>Prefer not to say</th>
</tr>
</thead>
<tbody>
<tr>
<td>My side effects have negatively impacted on everyday activities</td>
<td>31%</td>
<td>33%</td>
<td>16%</td>
<td>13%</td>
<td>5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have been unable to work / had to change my job or working pattern</td>
<td>15%</td>
<td>15%</td>
<td>17%</td>
<td>20%</td>
<td>10%</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>My side effects have had a negative impact on my social life</td>
<td>13%</td>
<td>23%</td>
<td>20%</td>
<td>26%</td>
<td>16%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My side effects have created problems with my partner, close friends or</td>
<td>9%</td>
<td>9%</td>
<td>16%</td>
<td>38%</td>
<td>28%</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>relatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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.

- Just under half of the patients (46%) reported their fatigue level as six or more out of ten (where one = minimal and 10 = worst imaginable) over the last week.
- 75% of patients have discussed their fatigue with their doctor. However, over a third (36%) of patients who discussed their fatigue reported that the doctor did not take any action, and 48% reported that the doctor did not follow up with them about their fatigue.
- Of those who did not discuss their fatigue with their doctor, 33% reported the reason was that they did not think it was relevant to bring up.
- The top reported coping mechanism patients have used to help with their fatigue over the last two years is balancing time schedules (48%).

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. 46% of patients reported their fatigue levels over the last week were six or above. These patients stated that their fatigue affects the following areas/activities over the last two years:

- Physical activities (reported by 73% of patients with a fatigue rating of six or more);
- General activity (reported by 71% of patients with a fatigue rating of six or more);
- Enjoyment of life (reported by 53% of patients with a fatigue rating of six or more).

See Figure 32 for severity of fatigue broken down by age group. Ages 18-39 have been excluded due to low number of respondents. Figure 32 demonstrates that 40-59 year olds were more likely to report a fatigue level of six or more out of ten relative to those aged 60 and above.
Please rate the severity of your fatigue over the last week on a scale of 1 (minimal fatigue) to 10 (worst fatigue imaginable):

Level of fatigue by age group

<table>
<thead>
<tr>
<th>Age Group</th>
<th>0%</th>
<th>1%</th>
<th>2%</th>
<th>3%</th>
<th>4%</th>
<th>5%</th>
<th>6%</th>
<th>7%</th>
<th>8%</th>
<th>9%</th>
<th>10%</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-59 (n=120)</td>
<td>4%</td>
<td>5%</td>
<td>8%</td>
<td>9%</td>
<td>12%</td>
<td>20%</td>
<td>20%</td>
<td>15%</td>
<td>6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69 (n=188)</td>
<td>4%</td>
<td>7%</td>
<td>8%</td>
<td>12%</td>
<td>16%</td>
<td>12%</td>
<td>16%</td>
<td>13%</td>
<td>9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70+ (n=188)</td>
<td>4%</td>
<td>6%</td>
<td>6%</td>
<td>16%</td>
<td>12%</td>
<td>17%</td>
<td>18%</td>
<td>10%</td>
<td>7%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 6 displays what areas or activities fatigue has affected over the last two years, by age. Data is not shown for younger age groups (18-39) as numbers of respondents was under 20.

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

<table>
<thead>
<tr>
<th>Area/Activity</th>
<th>40-59</th>
<th>60-69</th>
<th>70+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>My fatigue hasn’t affected any areas of my life over the last two years</td>
<td>8%</td>
<td>9%</td>
<td>13%</td>
<td>10%</td>
</tr>
<tr>
<td>General activity</td>
<td>63%</td>
<td>75%</td>
<td>57%</td>
<td>59%</td>
</tr>
<tr>
<td>Mood</td>
<td>43%</td>
<td>52%</td>
<td>42%</td>
<td>48%</td>
</tr>
<tr>
<td>Employment (working fewer hours, stopped working)</td>
<td>51%</td>
<td>61%</td>
<td>11%</td>
<td>42%</td>
</tr>
<tr>
<td>General work around the home (daily chores/housework)</td>
<td>46%</td>
<td>55%</td>
<td>38%</td>
<td>51%</td>
</tr>
<tr>
<td>Relationships with other people</td>
<td>28%</td>
<td>33%</td>
<td>22%</td>
<td>29%</td>
</tr>
<tr>
<td>Social activities</td>
<td>36%</td>
<td>43%</td>
<td>25%</td>
<td>37%</td>
</tr>
<tr>
<td>Physical activities</td>
<td>63%</td>
<td>76%</td>
<td>58%</td>
<td>74%</td>
</tr>
<tr>
<td>My financial situation</td>
<td>13%</td>
<td>15%</td>
<td>4%</td>
<td>14%</td>
</tr>
<tr>
<td>Enjoyment of life</td>
<td>46%</td>
<td>55%</td>
<td>39%</td>
<td>59%</td>
</tr>
<tr>
<td>Ability to think clearly/concentrate</td>
<td>34%</td>
<td>41%</td>
<td>27%</td>
<td>41%</td>
</tr>
<tr>
<td>Ability to remember things</td>
<td>26%</td>
<td>31%</td>
<td>20%</td>
<td>26%</td>
</tr>
<tr>
<td>Ability to sleep</td>
<td>47%</td>
<td>56%</td>
<td>35%</td>
<td>48%</td>
</tr>
</tbody>
</table>

Figure 33 shows that 75% of patients have discussed their fatigue with their doctor over the last two years, and 20% have not.

Figure 33: Have you discussed your fatigue with your doctor over the last two years?

<table>
<thead>
<tr>
<th>Response</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know/Can’t remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>70%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>Don’t know/Can’t remember</td>
<td>5%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Patients who did not discuss fatigue with their doctor were asked why. A third of patients (33%) reported they did not think their fatigue was relevant, 29% thought they could deal with it on their own, and 28% said they did not think there was anything that could help. See Figure 34 for full data.

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

Patients who discussed fatigue with their doctor were asked how their doctor helped with their fatigue. 31% reported they were asked about different aspects of their fatigue. However, less than 20% of patients reported that the doctor did a physical examination (16%) or looked at their medical history (14%), and just over a third (36%) reported the doctor did not take any action. Responses are displayed in Figure 35.

Figure 35: What did the doctor do after you discussed your fatigue?
Patients who had discussed fatigue with a doctor were asked whether their doctor followed up with them about their fatigue (Figure 36), and:

- 13% said ‘Yes, definitely’
- 35% said ‘Yes, to some extent’
- 48% said ‘No’

**Figure 36: Did your doctor follow-up with you about the fatigue you were experiencing?**

Patients were asked whether they spoke to anyone else (other than a doctor) about their fatigue, and 81% reported that they also spoke to family/ friends. See Figure 37.

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

Figure 38 displays that the top reported coping mechanism patients have used to help with their fatigue over the last two years is balancing time schedules (48%). A quarter of patients reported that they do not use any coping mechanisms (25%).
Figure 38: What coping mechanisms have you used to help with your fatigue over the last two years?

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

<table>
<thead>
<tr>
<th>Coping Mechanism</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balancing time schedules</td>
<td>48%</td>
</tr>
<tr>
<td>Medicines</td>
<td>15%</td>
</tr>
<tr>
<td>Psycho-education/therapy</td>
<td>4%</td>
</tr>
<tr>
<td>Exercise programs</td>
<td>15%</td>
</tr>
<tr>
<td>Mind-body interventions</td>
<td>19%</td>
</tr>
<tr>
<td>Nutritional consultation and counselling</td>
<td>7%</td>
</tr>
<tr>
<td>Digital applications</td>
<td>2%</td>
</tr>
<tr>
<td>None</td>
<td>25%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
</tr>
<tr>
<td>DK/CR</td>
<td>2%</td>
</tr>
</tbody>
</table>

505 Responses
Psychosocial Effects of Lymphoma/CLL and its Treatment

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

- Over a third of patients (37%) experienced a fear of progression of the lymphoma in the last 12 months, and around a quarter experienced depression (26%) and anxiety (24%).
- Patients were more likely to discuss their depression (51%) and anxiety (59%) with their doctor than their changes in relationships (29%).
- Only a quarter of those who discussed depression (25%) and anxiety (26%) reported the doctor was definitely able to help. The same was true for just 10% of those who discussed their changes in relationships.
- Under a third of patients who discussed psychosocial issues with the doctor reported that their doctor definitely followed up with them about their changes in relationships (14%), anxiety (26%), and/or depression (30%).

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

- 37% of patients experienced fear of progression of the lymphoma;
- 26% of patients experienced depression;
- 24% of patients experienced anxiety.
Table 7: In the last 12 months, have you experienced any of the following as a result of your lymphoma diagnosis?

704 Responses

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

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of self-esteem</td>
<td>11%</td>
<td>79</td>
</tr>
<tr>
<td>Concerns about body image/physical appearance</td>
<td>15%</td>
<td>104</td>
</tr>
<tr>
<td>Changes in relationships</td>
<td>10%</td>
<td>72</td>
</tr>
<tr>
<td>Isolation</td>
<td>11%</td>
<td>75</td>
</tr>
<tr>
<td>Depression</td>
<td>26%</td>
<td>182</td>
</tr>
<tr>
<td>Anxiety</td>
<td>24%</td>
<td>166</td>
</tr>
<tr>
<td>Fear of relapse</td>
<td>17%</td>
<td>117</td>
</tr>
<tr>
<td>Fear of progression of the lymphoma</td>
<td>37%</td>
<td>262</td>
</tr>
<tr>
<td>I have not experienced any of these in the last 12 months</td>
<td>30%</td>
<td>208</td>
</tr>
<tr>
<td>Don't know/ can't remember</td>
<td>4%</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>704</td>
</tr>
</tbody>
</table>

Those aged 70+ tended to report fewer psychosocial side effects than other age groups, and 40% reported that they had not experienced any of the side effects presented in Table 7 over the last 12 months. In addition, those who reported experiencing fatigue also reported experiencing more psychosocial effects than those who had not reported experiencing fatigue.

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

Figure 39 presents the percentage of patients who discussed their changes in relationships, anxiety, and/or depression with their doctor. 51% of patients who experienced depression and 59% of those who experienced anxiety discussed these effects with their doctor. However, only 29% of those who experienced changes in relationships did the same.

Figure 39: For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with your doctor?

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

- Depression (n=182) 51% 49%
- Anxiety (n=166) 59% 40%
- Changes in relationships (n=72) 29% 68%

- Yes, I have discussed with my doctor  
- No, I have not discussed with my doctor  
- Don’t know/ Can’t remember
Those who discussed these psychosocial worries or concerns with their doctor were asked whether the doctor was able to help (see Figure 40). Although the majority of patients experiencing depression (82%) and anxiety (72%) felt the doctor was able to help (definitely or to some extent), this was only the case for 29% of those experiencing changes in relationships.

Figure 40: For each worry or concern that you discussed with your doctor, please indicate if the doctor was able to help?

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

<table>
<thead>
<tr>
<th>Worry or Concern</th>
<th>Definitely Helped</th>
<th>To Some Extent</th>
<th>No</th>
<th>Don’t Know/Can’t Remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression (n=92)</td>
<td>25%</td>
<td>57%</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td>Anxiety (n=96)</td>
<td>26%</td>
<td>46%</td>
<td>29%</td>
<td></td>
</tr>
<tr>
<td>Changes in relationships (n=21)</td>
<td>10%</td>
<td>19%</td>
<td>71%</td>
<td></td>
</tr>
</tbody>
</table>

- Yes, definitely - Yes, to some extent - No - Don’t know/Can’t remember

Those who reported that they received enough support from doctors also tended to report that the doctor was definitely able to help with their depression, anxiety and changes in relationships compared to those who reported that they did not receive enough support from doctors.

Table 8 indicates what information or support they patients were provided with. The response numbers were low for those with changes in relationships (n=6), therefore are not displayed for this question.

For those who experienced depression or anxiety, the majority (71% and 65% respectively) were given medication to help them cope.

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

<table>
<thead>
<tr>
<th>Worry or Concern</th>
<th>Medication</th>
<th>Further Written or Verbal Information</th>
<th>Information on Coping Mechanisms</th>
<th>Signposting to Another Source of Support</th>
<th>Other</th>
<th>Don’t know/Can’t Remember</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>71%</td>
<td>53%</td>
<td>3%</td>
<td>2%</td>
<td>7%</td>
<td>36%</td>
<td>5</td>
</tr>
<tr>
<td>Anxiety</td>
<td>65%</td>
<td>45%</td>
<td>14%</td>
<td>10%</td>
<td>9%</td>
<td>26%</td>
<td>18</td>
</tr>
</tbody>
</table>

Of those who discussed psychosocial issues with their doctor, under a third reported that their doctor definitely followed up with them about their changes in relationships (14%), anxiety (26%), and/or depression (30%). See Figure 41.
Figure 41: For each worry or concern that you discussed with your doctor, please indicate if your doctor followed-up with you about these worries that you were experiencing?

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

- Depression (n=52)
  - 30% Yes, definitely
  - 30% Yes, to some extent
  - 29% No
  - 29% Don't know/ can't remember

- Anxiety (n=57)
  - 26% Yes, definitely
  - 36% Yes, to some extent
  - 30% No
  - 30% Don't know/ can't remember

- Changes in relationships (n=21)
  - 14% Yes, definitely
  - 10% Yes, to some extent
  - 76% No
  - 76% Don't know/ can't remember

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

- They thought they could handle it on their own (51-63%)
- They did not think it was a big deal (19-28%)

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

<table>
<thead>
<tr>
<th>For each worry or concern that you have experienced, please indicate what were your reasons for not discussing it with your doctor?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Depression</strong></td>
</tr>
<tr>
<td>I thought I could handle it on my own</td>
</tr>
<tr>
<td>60%</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
</tr>
<tr>
<td>I thought I could handle it on my own</td>
</tr>
<tr>
<td>63%</td>
</tr>
<tr>
<td><strong>Changes in relationships</strong></td>
</tr>
<tr>
<td>I thought I could handle it on my own</td>
</tr>
<tr>
<td>51%</td>
</tr>
</tbody>
</table>
When asked who else they had spoken to regarding their worries or concerns (besides a doctor), in many cases, patients reported that they had either spoken with their family and friends for help or that they had not spoken to anyone. See Table 10 below for a breakdown of responses (for all psychosocial issues, not just depression, anxiety and changes in relationships).

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

<table>
<thead>
<tr>
<th>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?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss of self-esteem</strong></td>
</tr>
<tr>
<td><strong>I did not speak to anybody else</strong></td>
</tr>
<tr>
<td>54%</td>
</tr>
</tbody>
</table>

| **Concerns about body image/physical appearance** |
| I did not speak to anybody else | Family/ friends | Nurse | Social worker | Complementary therapist | Another doctor | Other | Don't know/ can't remember | Total |
| 40% | 42% | 50% | 8% | 8% | 0% | 0% | 6% | 6% | 13% | 14% | 1% | 1% | 1% | 104 |

| **Changes in relationships** |
| I did not speak to anybody else | Family/ friends | Nurse | Social worker | Complementary therapist | Another doctor | Other | Don't know/ can't remember | Total |
| 44% | 31% | 49% | 35% | 1% | 1% | 0% | 0% | 18% | 13% | 10% | 7% | 1% | 1% | 1% | 71 |

| **Isolation** |
| I did not speak to anybody else | Family/ friends | Nurse | Social worker | Complementary therapist | Another doctor | Other | Don't know/ can't remember | Total |
| 55% | 40% | 38% | 28% | 1% | 1% | 1% | 1% | 12% | 9% | 1% | 1% | 3% | 2% | 0% | 0% | 73 |

| **Depression** |
| I did not speak to anybody else | Family/ friends | Nurse | Social worker | Complementary therapist | Another doctor | Other | Don't know/ can't remember | Total |
| 31% | 56% | 101% | 3% | 6% | 0% | 0% | 18% | 32% | 18% | 32% | 0% | 0% | 0% | 0% | 181 |

| **Anxiety** |
| I did not speak to anybody else | Family/ friends | Nurse | Social worker | Complementary therapist | Another doctor | Other | Don't know/ can't remember | Total |
| 28% | 47% | 55% | 91% | 2% | 4% | 0% | 0% | 24% | 40% | 18% | 30% | 1% | 0% | 0% | 1% | 1% | 165 |

| **Fear of progression of the lymphoma** |
| I did not speak to anybody else | Family/ friends | Nurse | Social worker | Complementary therapist | Another doctor | Other | Don't know/ can't remember | Total |
| 44% | 113% | 47% | 122% | 3% | 7% | 0% | 1% | 7% | 19% | 17% | 45% | 0% | 1% | 1% | 1% | 2% | 259 |
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.

- 17% of patients reported experiencing fear of cancer relapse in the last 12 months
- While 62% of patients discussed their fear of relapse with their doctor, just under a third (32%) reported the doctor was definitely able to help. Further, only 24% reported that the doctor definitely followed up with them about their fear of relapse.
- Of those patients who did not discuss fear of relapse with their doctor, 53% reported this was because they thought they could handle it on their own.
- The majority (62%) were provided with further written or verbal information to help with their fear of relapse.
- 52% of patients reported that they are not using any coping mechanisms to help with their fear of relapse.

In the LC (2020) Global Patient Survey, 17% of patients reported that they experienced a fear of cancer relapse in the last 12 months.

Given that CLL/SLL and WM/LPL are more indolent (slow-growing) disease types, it is important to note that a further 37% experienced fear of lymphoma progression, which is an overall impact of 54% being fearful of their disease recurring or getting worse. Many patients with indolent lymphomas may never have been in full remission, yet have stable disease and they are still fearful for their future. In the LC (2020) GPS, respondents were only given the option to express further thoughts and impacts of fear of relapse, not fear of progression. All of the data below reflects only fear of relapse.

62% of patients who experienced fear of cancer relapse have discussed it with their doctor. Of those who have discussed fear of relapse with their doctor, only 32% of patients reported their doctor was definitely able to help (Figure 42).
Figure 42: For each worry or concern that you discussed with your doctor about fear of relapse, please indicate if the doctor was able to help?

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

<table>
<thead>
<tr>
<th>Fear of relapse</th>
<th>32%</th>
<th>46%</th>
<th>22%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, definitely</td>
<td>Yes, to some extent</td>
<td>No</td>
<td>Don't know/can't remember</td>
</tr>
</tbody>
</table>

Figure 43 displays the type of information or support patients were provided with by their doctor to help with fear of relapse. 62% of patients reported that further written information or verbal information was provided, whereas 25% were provided with information on coping mechanisms.

Figure 43: For fear of relapse, what type of information or support were you provided with?

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

- Medication to help cope with this worry or concern: 4%
- Further written or verbal information: 62%
- Information on coping mechanisms: 25%
- Signposting to another source of support: 5%
- Other: 5%
- Don't know/Can't remember: 9%

Only 24% of patients who discussed fear of relapse with their doctor reported that their doctor definitely followed up with them about it, see Figure 44.
Figure 44: For fear of relapse, please indicate if your doctor followed-up with you about these worries that you were experiencing?

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

71 Responses

- Yes, definitely: 24%
- Yes, to some extent: 51%
- No: 25%
- Don't know/ can't remember: 0%

Of those patients who did not discuss fear of relapse with their doctor, 53% reported this was because they thought they could handle it on their own, and 14% did not think it was a big deal. 12% did not want to bother their doctor.

Over half of patients (57%) reported they have also spoken to family and friends about their fear of relapse, see Figure 45.

Figure 45: Please indicate who else you have spoken with to help you with your fear of relapse?

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

116 Responses

- I did not speak to anybody else about these worries or concerns: 29%
- Family/ friends: 57%
- Nurse: 3%
- Social worker: 0%
- Complementary therapist: 14%
- Another doctor: 17%
- Other: 2%
- Don't know/ can't remember: 2%

79% of patients who reported experiencing fear of relapse also reported that they think about the cancer returning, and 51% examine themselves to see if they have physical signs of cancer. See Figure 46. An additional 38% have thoughts about dying, and 29% have difficulty making plans for the future because of their fear of relapse.
Figure 46: Fear of relapse, 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?

63 Responses

- I think about the cancer returning: 79%
- I examine myself to see if I have physical signs of cancer: 51%
- I get waves of strong feelings about the cancer returning that are difficult to control: 12%
- I have thoughts about dying: 36%
- I feel very alone: 6%
- These thoughts intrude on my day-to-day activities: 7%
- I feel very distressed by these thoughts: 6%
- I have difficulty making plans for the future: 29%
- Other: 3%

52% of patients reported that they are not using any coping mechanisms to help with their fear of relapse. 23% reported they are using mind-body interventions and 18% use exercise programs. See Figure 47.

Figure 47: What coping mechanisms are you using to help with your fear of relapse?

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

116 Responses
Barriers to Treatment

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

- 87% of patients have not experienced any barriers to receiving treatment.
- 61% of patients have not had an opportunity to take part in a clinical trial.

When asked to select from a list of potential barriers to treatment, 87% of patients selected that ‘none’ have prevented them from receiving treatment (see Figure 48).

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

<table>
<thead>
<tr>
<th>Barriers</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial difficulties</td>
<td>1%</td>
</tr>
<tr>
<td>Could not give up working/ job</td>
<td>0%</td>
</tr>
<tr>
<td>The time needed to take out of my daily life</td>
<td>3%</td>
</tr>
<tr>
<td>Access or transport to treatment centre</td>
<td>0%</td>
</tr>
<tr>
<td>Language barriers</td>
<td>1%</td>
</tr>
<tr>
<td>Access to the most up-to-date treatment</td>
<td>3%</td>
</tr>
<tr>
<td>Treatment waiting times</td>
<td>2%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>4%</td>
</tr>
<tr>
<td>None</td>
<td>67%</td>
</tr>
</tbody>
</table>

Patients were asked to identify any barriers they had experienced to participating in a clinical trial. 61% of patients had never been presented with an opportunity to take part in a clinical trial, 12% were not eligible or selected for a trial, 6% feared the potential unknown side effects of the trial, and 21% answered other causes.
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.

56 was the total number of people caring for somebody living with CLL/SLL or WM/LPL that responded to the survey. The results in this section will be reported across the following areas:

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

Caregiver Demographics

Caregivers were asked to identify their relationship to the person they are providing care and support to, 82% of caregivers are a spouse/partner, and 11% are caring for their parent. Figure 49 displays the full results.

![Figure 49: What is your relationship to the person you are providing care and support to?](image)

Only 25% of caregivers use the term ‘caregiver’ when thinking about themselves and the care/support they provide.

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

- 80% responded emotional support
- 80% said accompanying the patient with lymphoma/CLL to appointments
- 61% responded looking for information
Caregivers were asked how long ago the person they provide care for was diagnosed. Figure 50 displays the results, with the majority of caregivers (82%) providing care for someone diagnosed more than two years ago.

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

The majority of caregivers (71%) who responded have been providing care and support for two or more years, see Figure 51 below:

**Figure 51: How long have you been providing care and support to the person with lymphoma or CLL?**

Figure 52 displays the lymphoma subtype breakdown for all patients who caregivers are supporting. Around two thirds of caregivers (68%) care for someone with CLL/SLL.

**Figure 52: What subtype of lymphoma/CLL does/did the person you care for have?**
Figure 53 displays the stage of the care pathway of the patients the caregivers are providing care and support for. 29% of all caregivers are supporting somebody currently in treatment, and 27% are caring for somebody where treatment is not yet needed (watch and wait).

**Figure 53: What statement best describes where the person you care for is in the lymphoma or CLL experience?**

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

- **Newly diagnosed and not yet sure of their treatment options**: 4%
- **Treatment is not yet needed (watch and wait or active surveillance)**: 27%
- **They have had treatment and now back in watch and wait**: 21%
- **They are currently receiving treatment**: 20%
- **They have finished treatment and on maintenance therapy**: 7%
- **They are in remission**: 11%
- **They are not having or have stopped treatment**: 0%
- **Other**: 2%

34% of caregivers reported the lymphoma/CLL of the person they care for has relapsed, and 8% reported it has transformed.
Caregiver Information, Guidance and Support

- 77% of caregivers reported that ‘doctor’ was their top place to go for information.
- Over half of caregivers (52%) were the ones seeking out information and details about the disease and potential treatments on behalf of the patient.
- Less than a third of caregivers (31%) reported that they definitely felt assisted/supported and understood by healthcare staff.

When asked to select their top three places to go for information, 77% of caregivers said ‘doctor’ and 13% said ‘websites’ was their top place to go (see Table 11 for more details).

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

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>77%</td>
<td>14%</td>
<td>9%</td>
</tr>
<tr>
<td>Nurse</td>
<td>0%</td>
<td>5%</td>
<td>13%</td>
</tr>
<tr>
<td>Websites</td>
<td>13%</td>
<td>42%</td>
<td>25%</td>
</tr>
<tr>
<td>Online blogs/social media</td>
<td>0%</td>
<td>14%</td>
<td>6%</td>
</tr>
<tr>
<td>Family/friends</td>
<td>0%</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Patient organisation</td>
<td>10%</td>
<td>14%</td>
<td>34%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Figure 54 indicates who was seeking out information and details about the disease and potential treatments (the patient with lymphoma, the caregiver, or both). For over half of caregivers (52%), it was themselves seeking information.
Following the diagnosis, who was seeking out information and details about the disease and potential treatments?

48 Responses

- Me (caregiver) 52%
- The patient 8%
- Me (caregiver) and the patient jointly 29%
- We don't seek additional information our doctor/healthcare staff are the experts 13%
- Don't know/ Can't remember 0%

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

- 78% said within the last six months;
- 13% said more than six months 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. Figure 55 display the extent to which caregivers report feeling supported and recognised. Less than half of caregivers reported definitely feeling satisfied, recognised or assisted/supported in their role in any of the categories examined. Just over a third of caregivers (35%) report they definitely felt assisted/ supported and understood by their family and friends, and just under a third (31%) felt definitely assisted, supported and understood by healthcare staff.

Figure 55: Thinking about the person you provide care and support to, please read the following statements and indicate the extent to which they occur.
Impact of Caregiving

- Accompanying patients to appointments (80%) and providing emotional support (80%) were the most commonly reported aspects of care and support that caregivers provide.
- 61% of caregivers reported that they find emotional support the hardest to provide, and 82% report that the area of their life most affected by their caregiving role is ‘emotional’.
- 90% of caregivers reported that they often/always or sometimes fear that the cancer of the patient they care for will relapse.

Caregivers were asked to think about the different aspects of the care and support that they provide to somebody with lymphoma/CLL. Accompanying patients to appointments (80%) and providing emotional support (80%) were the most commonly reported aspects. Figure 56 displays the results for all types of care provided by the caregivers who responded.

Figure 56: Below are some elements of ‘caring’ that others providing care and support to somebody with lymphoma/CLL have mentioned. Please select what type(s) of care that you provide.

Caregivers were asked which type of care and support they find the hardest to provide:
- 61% reported emotional support;
- 7% reported physical support;
- 24% reported they were not sure which aspect of care they found the hardest.
Caregivers rated the frequency with which various aspects of providing care and support to somebody with lymphoma/CLL have affected them over the last 12 months. 75% of caregivers reported that they often or always fear that the cancer of the patient they care for will relapse. 61% report that they are often or always anxious or worried, and 58% report that they often or always put the needs of the patient before their own.
Figure 57: In the past 12 months, to what extent do each of the following issues affect you as a caregiver?

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

44 Responses

- Taking time off work: 88% Never/rarely, 9% Sometimes, 9% Often/always
- Paying for a professional caregiver: 92% Never/rarely, 5% Sometimes, 5% Often/always
- Paying for childcare: 97% Never/rarely, 3% Sometimes, 0% Often/always
- Financial hardship due to reduced work: 92% Never/rarely, 5% Sometimes, 5% Often/always
- My children find it difficult: 47% Never/rarely, 79% Sometimes, 15% Often/always
- Been physically tired, worn out: 36% Never/rarely, 49% Sometimes, 25% Often/always
- Poor health due to caring: 40% Never/rarely, 64% Sometimes, 24% Often/always
- Changes in my personal relationships: 19% Never/rarely, 19% Sometimes, 19% Often/always
- Relationship with person with lymphoma: 40% Never/rarely, 40% Sometimes, 24% Often/always
- Sleeping difficulties: 40% Never/rarely, 40% Sometimes, 24% Often/always
- I get upset that life will not be as planned: 10% Never/rarely, 28% Sometimes, 58% Often/always
- Always putting their needs above my own: 15% Never/rarely, 15% Sometimes, 70% Often/always
- Fear that they will relapse: 10% Never/rarely, 10% Sometimes, 80% Often/always
- PTSD (Post traumatic stress disorder): 15% Never/rarely, 67% Sometimes, 75% Often/always
- Encountering difficulties in admin tasks: 5% Never/rarely, 93% Sometimes, 0% Often/always
- Getting frustrated with them: 7% Never/rarely, 73% Sometimes, 15% Often/always
- Been worried/anxious: 35% Never/rarely, 32% Sometimes, 61% Often/always
- Been sad/depressed: 42% Never/rarely, 42% Sometimes, 23% Often/always
- Been emotionally tired and worn out: 35% Never/rarely, 42% Sometimes, 21% Often/always
- Been stressed: 30% Never/rarely, 35% Sometimes, 35% Often/always
- Experienced feelings of guilt: 84% Never/rarely, 16% Sometimes, 0% Often/always
When asked which areas of their lives have been most impacted by caring or supporting somebody with lymphoma/CLL, the area of life most selected by caregivers was ‘emotional’ (82%). See Figure 58 for full responses.

Figure 58: Which of the following areas of your life have been impacted most by caring for or supporting somebody with lymphoma/CLL?

<table>
<thead>
<tr>
<th>Area</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>33%</td>
</tr>
<tr>
<td>Emotional</td>
<td>82%</td>
</tr>
<tr>
<td>Practical</td>
<td>20%</td>
</tr>
<tr>
<td>Financial</td>
<td>2%</td>
</tr>
<tr>
<td>Social</td>
<td>38%</td>
</tr>
<tr>
<td>Relationship with the patient</td>
<td>22%</td>
</tr>
<tr>
<td>Well-being</td>
<td>31%</td>
</tr>
<tr>
<td>Working life</td>
<td>16%</td>
</tr>
</tbody>
</table>

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 59). 47% indicated that the impact on their life is less when the person is off treatment.

Figure 59: 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?

<table>
<thead>
<tr>
<th>Impact on Life</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The impact on my life is less when the person is on treatment</td>
<td>13%</td>
</tr>
<tr>
<td>The impact on my life is less when the person is off treatment</td>
<td>47%</td>
</tr>
<tr>
<td>The impact on my life is the same whether they are on or off treatment</td>
<td>40%</td>
</tr>
</tbody>
</table>
Appendices

Appendix 1

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

#0253 Comparative Analysis of CLL and DLBCL Patients’ Level of Understanding After Initial Doctor’s Appointment
L. E. Warwick1, O. A. Bamigbola, MB, BS, MSc (Epidemiology), N. M. Dren, B.Sc., MPhil2
1Chief Executive Officer, Lymphoma Coalition, Mississauga, ON, Canada; 2Research, Lymphoma Coalition, Mississauga, ON, Canada

Correlation of Lymphoma Patient Information Level with Healthcare Experience
Nethaka Dren, BSc, MPhil1, Lorna Warwick1, Karen Van Rensel1, Theodore Maynard1, Christina Karamaridou, MSc, PhD2, Albo Kochelli, MD, PhD2
1Lymphoma Coalition, Morristown, Canada; 2Institute of Applied Mathematics, Center for Research and Technology Hellas, Thessaloniki, Greece
A Cross-Sectional Study Examining the Effects of Patient Information Level on Healthcare Experience in 2 Patient Populations: Extramedullary Natural Killer T-Cell Lymphoma (ENTKTL) and Waldenstrom Macroglobulinemia (WM)

N. M. Dean, BSc, MPH,1 L. E. Warwick, BA, B Ed2; O. A. Bamigbola MB; BS, MSc (Epid)1 3
1Research, Lymphoma Coalition, Mississauga, ON, Canada; 2Management, Lymphoma Coalition, Mississauga, ON, Canada

1 INTRODUCTION

The complexity of the lymphoma experience and the myriad of side effects from treatment makes patient education a cornerstone for the care of lymphoma patients. Communication with clinicians is a significant component of this.

This study describes the unmet needs in patient-doctor communication of patients (FL and DLBCL) using the Lymphoma Coalition’s 2016 Global Patient Survey (GPS) on Lymphomas and CLL.

2 METHODOLOGY

Study Design

- The study is a sub-analysis of the 2016 GPS, which is a large-scale, online global survey of patients with lymphoma including CLL.
- Published on the Lymphoma Coalition’s website on January 20, 2016 in 26 languages.

Respondents

- Globally, there were 4617 patient respondents from 70 countries.
- There were 927 FL and 3690 DLBCL respondents.

Statistical Analysis

- Data were analyzed using chi-square tests and odds ratios with 95% CI.
- Differences in proportions were tested using chi-square tests (p<0.05) and odds ratios with 95% CI.

3 RESULTS

3.1 RESULTS CONT.

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

L. E. Warwick, BA, B Ed2; O. A. Bamigbola MB; BS, MSc (Epid)1; N. M. Dean, BSc, MPH1
1Management, Lymphoma Coalition, Mississauga, ON, Canada; 2Research, Lymphoma Coalition, Mississauga, ON, Canada

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- Globally, there were 4617 patient respondents from 70 countries.
- There were 927 FL and 3690 DLBCL respondents.

Statistical Analysis

- Data were analyzed using chi-square tests and odds ratios with 95% CI.
- Differences in proportions were tested using chi-square tests (p<0.05) and odds ratios with 95% CI.

3 RESULTS

3.1 RESULTS CONT.

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 myriad of side effects from treatment makes patient education a cornerstone for the care of lymphoma patients. Communication with clinicians is a significant component of this.

This study describes the unmet needs in patient-doctor communication of patients (FL and DLBCL) using the Lymphoma Coalition’s 2016 Global Patient Survey (GPS) on Lymphomas and CLL.

2 METHODOLOGY

Study Design

- The study is a sub-analysis of the 2016 GPS, which is a large-scale, online global survey of patients with lymphoma including CLL.
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Respondents

- Globally, there were 4617 patient respondents from 70 countries.
- There were 927 FL and 3690 DLBCL respondents.

Statistical Analysis

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3 RESULTS

3.1 RESULTS CONT.
Appendix 2

Frequency tables – supplied separately