Lymphoma Coalition

2020 Global Patient Survey on Lymphomas & CLL

A report prepared for Lymphoma Coalition
by Picker Institute Europe

July 2020

Country Report

France

Lymphoma Coalition

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

The LC vision is equity in lymphoma outcomes across borders.

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

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Picker

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

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

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SECTION 1

Executive Summary

Executive Summary

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

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

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

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

Results

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

Overall number of completed responses 1,747 made up of:

1,577 Patients

170 Caregivers

Demographics

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

Figure 1: Sex of patients

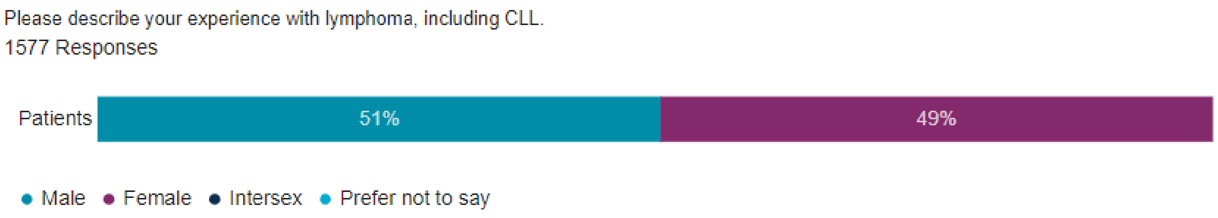


Figure 2: Gender of caregivers

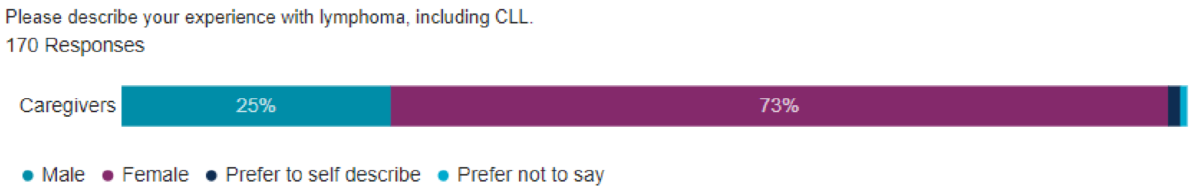


Figure 3: Age of patients and caregivers

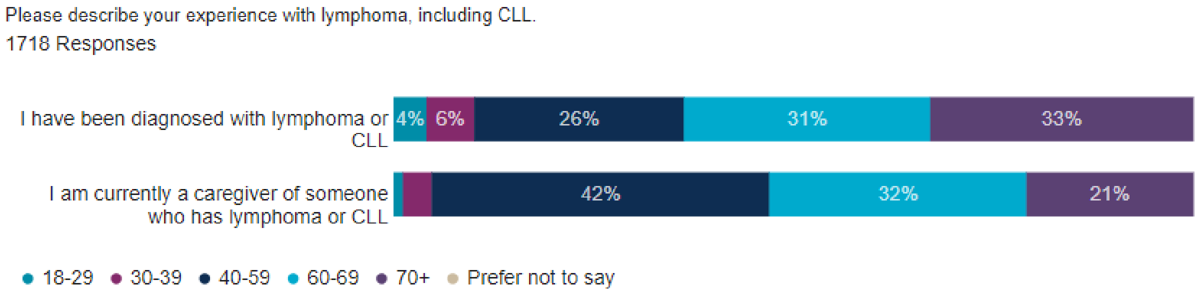
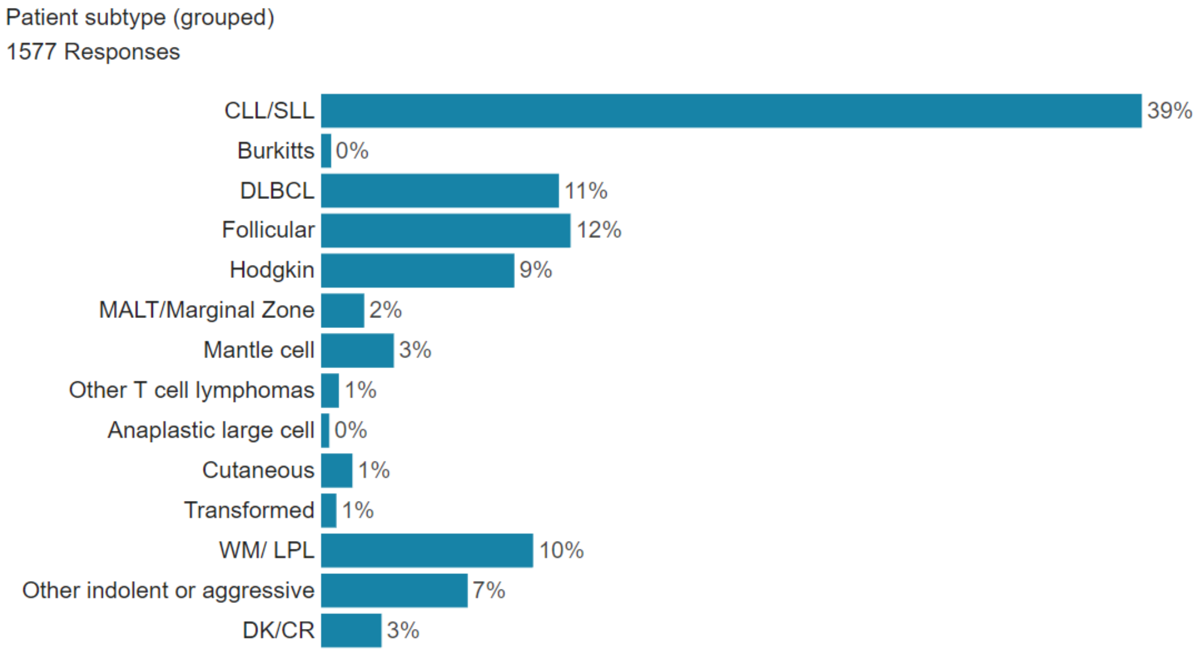
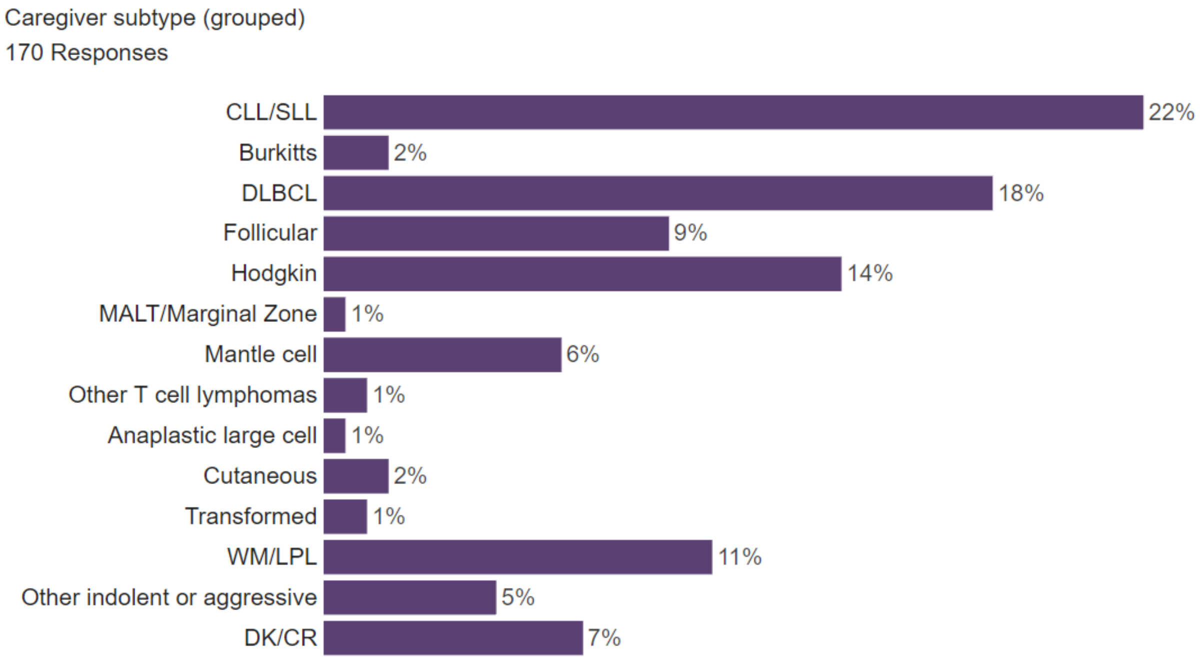


Figure 4: Subtype by patients and caregivers



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



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

Some key findings from the patient survey are as follows:

Patient information, guidance and support

63% were told their lymphoma subtype at diagnosis.

Less than half (41%) agree strongly that they seek clarification on things they do not understand.

Only 39% of patients were given information on and completely understood how to manage side effects of treatment.

46% are definitely involved as much as they want to be in decisions about their care and treatment.

86% of patients were clear that they had been given a diagnosis of cancer at the point of diagnosis

34% of patients felt they had not received enough financial support, 33% did not receive enough emotional support, and 28% did not get enough practical support.

Effects of diagnosis and treatment

Fatigue was the most commonly reported **symptom of lymphoma/CLL** (75%).

40% of patients who experienced fatigue as a **side effect of treatment** said it was the side effect that affects them the most.

35% of patients had experienced fear of cancer relapse and 34% had feared progression of their lymphoma as a result of their diagnosis**.**

22% of patients use mind-body interventions to help them with their fear of cancer relapse.

Barriers to treatment

89% of patients reported that nothing had prevented them from receiving treatment

65% of patients found they have never been presented with an opportunity to take part in a clinical trial.

Only 16% of patients are currently, or have been, in a clinical trial for their lymphoma or CLL.

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

SECTION 2

Background

Background

Lymphoma Coalition (LC) is a non-profit organisation comprising of a world-wide network of lymphoma patient groups. Today, there are 83 member organisations from 52 countries. Its purpose is to create a level playing field of credible and current information around the world and to facilitate a community of lymphoma patient organisations to support efforts in helping patients with lymphoma receive the care and support needed[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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[1] https://www.lymphomacoalition.org/news-and-events9/world-lymphoma-awareness-day-2019

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

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

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

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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[2] https://www.lymphomacoalition.org/global-information/global-patient-survey/2018

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

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

[5] https://www.lymphomacoalition.org/news-and-events9/world-lymphoma-awareness-day-2019

SECTION 3

Methodology

Methodology

Survey 2020 Development and Launch

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

- Patient information, guidance and support, including:
    - Information provision (at diagnosis and with ongoing care)
    - Patient experience of diagnosis
    - Patient understanding of their condition and treatment
    - Patient confidence
    - Health behaviours and costs to healthcare system
    - Healthcare decision-making
    - Communication with healthcare professionals

- Symptoms of diagnosis and treatment, including :
    - Side effects: lymphoma-related, treatment-related, and psychosocial issues
    - Cancer-related fatigue
    - Fear of cancer relapse
    - Impact on daily life

- Barriers to treatment

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

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

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

- English
- 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, 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 numbers of respondents may fluctuate between questions. Rounding of percentages means that sometimes the total for a single-response question will be just below or just above 100%.

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

SECTION 4

Respondent Demographics

Respondent Demographics

The results in this report are presenting the data for respondents from France.

A total of 1577 responded to the patient survey and 170 to the caregiver survey.

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

Figure 1a: Sex of patients

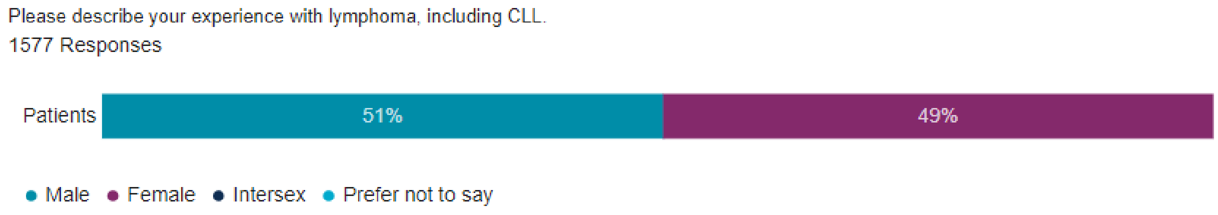


Figure 1b: Gender of caregivers

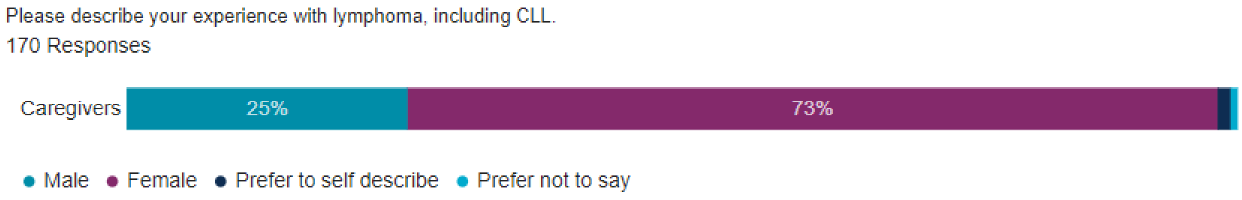


Figure 2: Age range of respondents

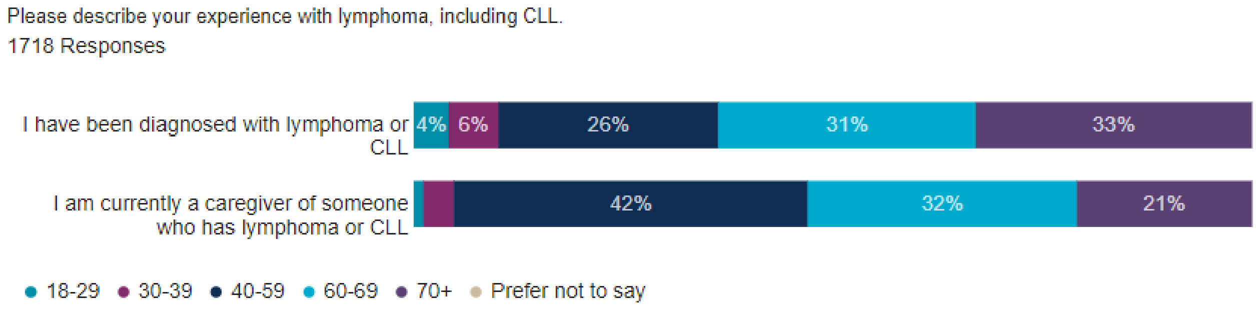


Figure 3: Household status of respondents (patients and caregivers)

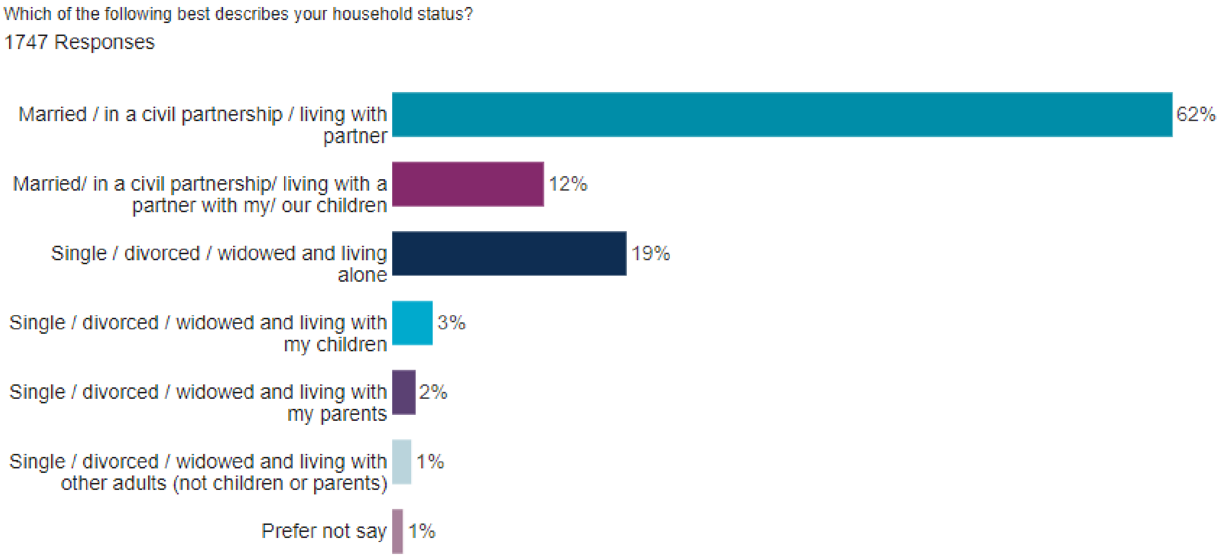


Figure 4: Employment status of respondents

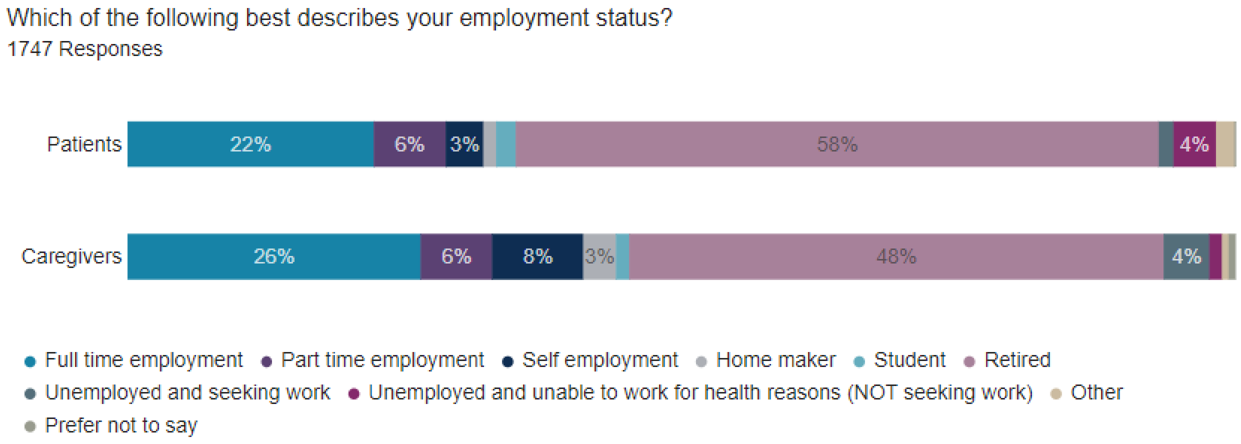
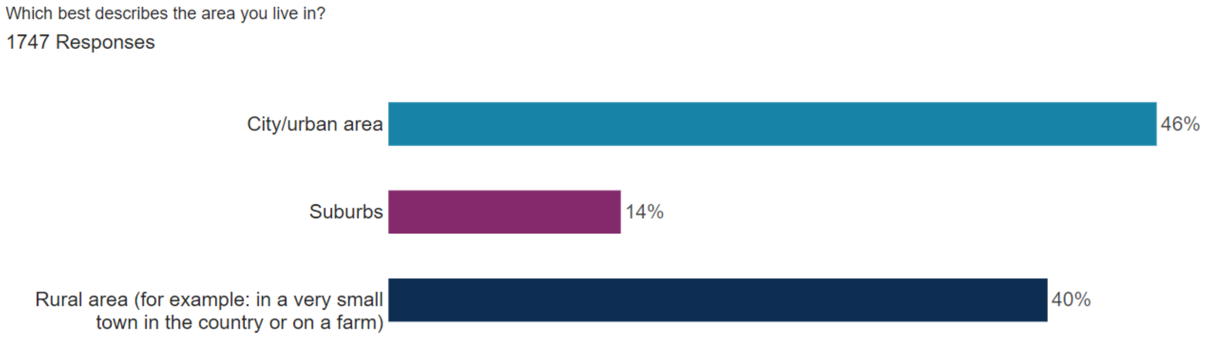


Figure 5: Area of residence of respondents (patients and caregivers)



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.

1577 people living with lymphoma/CLL responded to the survey. The results in this section will be reported across the following areas:

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

Diagnostic Demographics

Patients were asked how long ago they were diagnosed with lymphoma or CLL, and the results are displayed in Figure 6. The majority of patients were diagnosed over two years ago (79%).

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

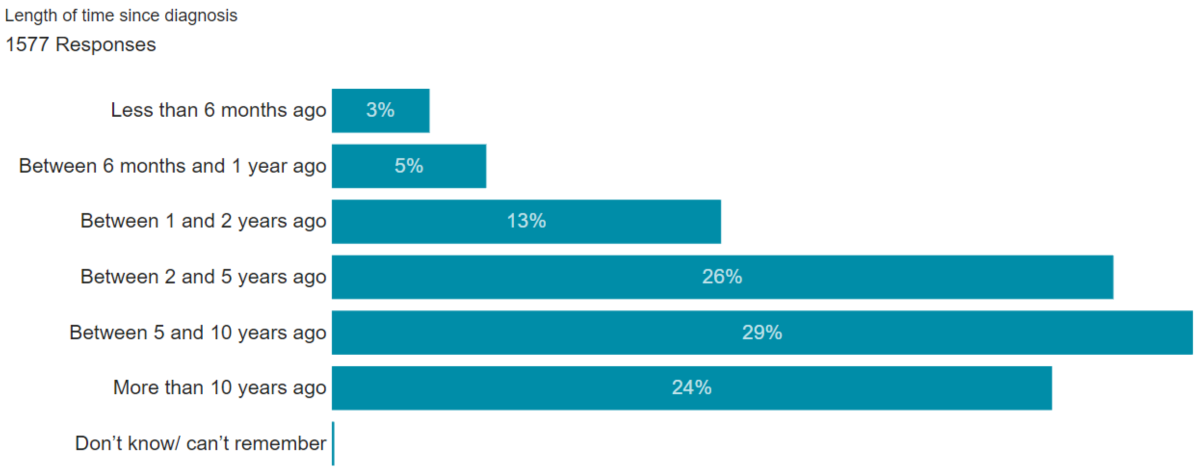


Figure 7 below shows how long patients reported waiting between their first GP appointment about their symptoms to getting a diagnosis. The majority (53%) of patients had a diagnosis within three months of their first appointment. However, 16% were waiting six months or more from their initial meeting 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?

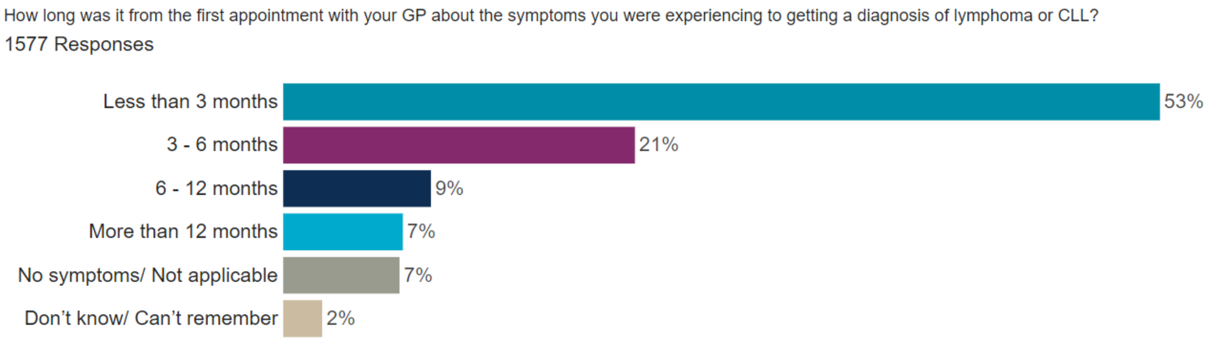
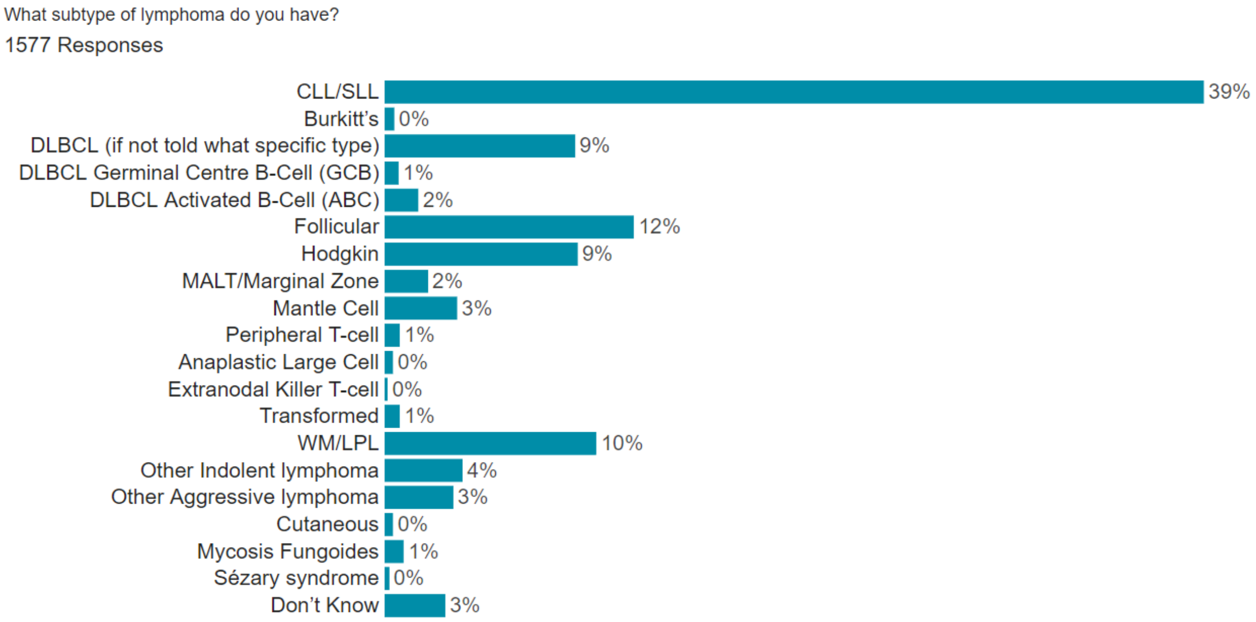


Figure 8 below shows patient lymphoma subtype. The most common subtypes reported are:

- 39% Chronic lymphocytic leukaemia (CLL)/small lymphocytic lymphoma (SLL)
- 12% Follicular lymphoma
- 10% Waldenström's macroglobulinaemia (WM)/lymphoplasmacytic lymphoma (LPL)

Figure 8: What subtype of lymphoma do you have?



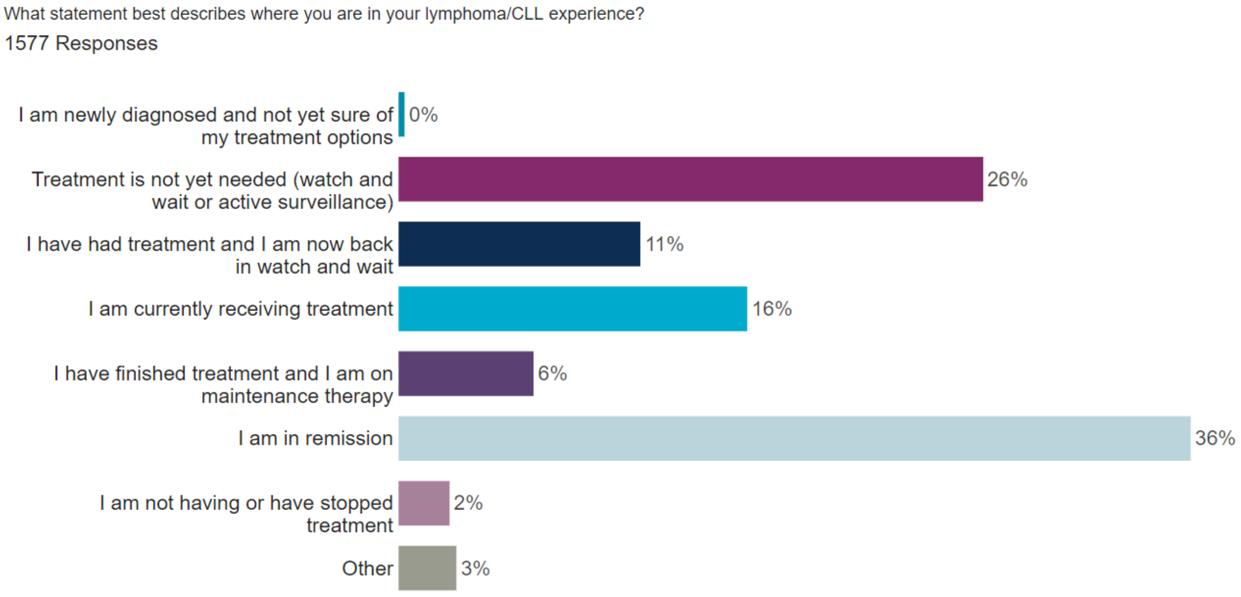
A larger proportion of those aged 40-59, 60-69 and 70 and above had a diagnosis of CLL/SLL (34%-48%) compared to those aged 18-29 (0%) and 30-39 (3%).

A larger proportion of the younger patients aged 18-29 (75%) and 30-39 (45%) had a diagnosis of Hodgkin lymphoma than the older patients aged 40-59, 60-69 and 70+ (1%-9%).

More males reported having a diagnosis of CLL/SLL (44%) than females (34%). More females reported having a diagnosis of Hodgkin lymphoma (14%) than males (4%).

Survey participants were also asked about the stage of their lymphoma care pathway, and their responses are displayed in Figure 9. 36% of patients report that they are in remission. 26% of patients report that treatment is not yet needed (watch and wait), 16% are currently in treatment, 11% have had treatment and are now back in watch and wait. 6% have finished treatment and are on maintenance therapy.

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



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

- Patients indicating they are in remission were asked how long they have been treatment free;
- Those in watch and wait/ active surveillance were asked how long they had been in watch and wait for;
- All patients who were receiving/had ever received treatment, those on maintenance therapy, and those in remission were asked:
  - Whether their lymphoma/CLL has ever relapsed;
  - Whether their lymphoma/CLL has ever transformed.

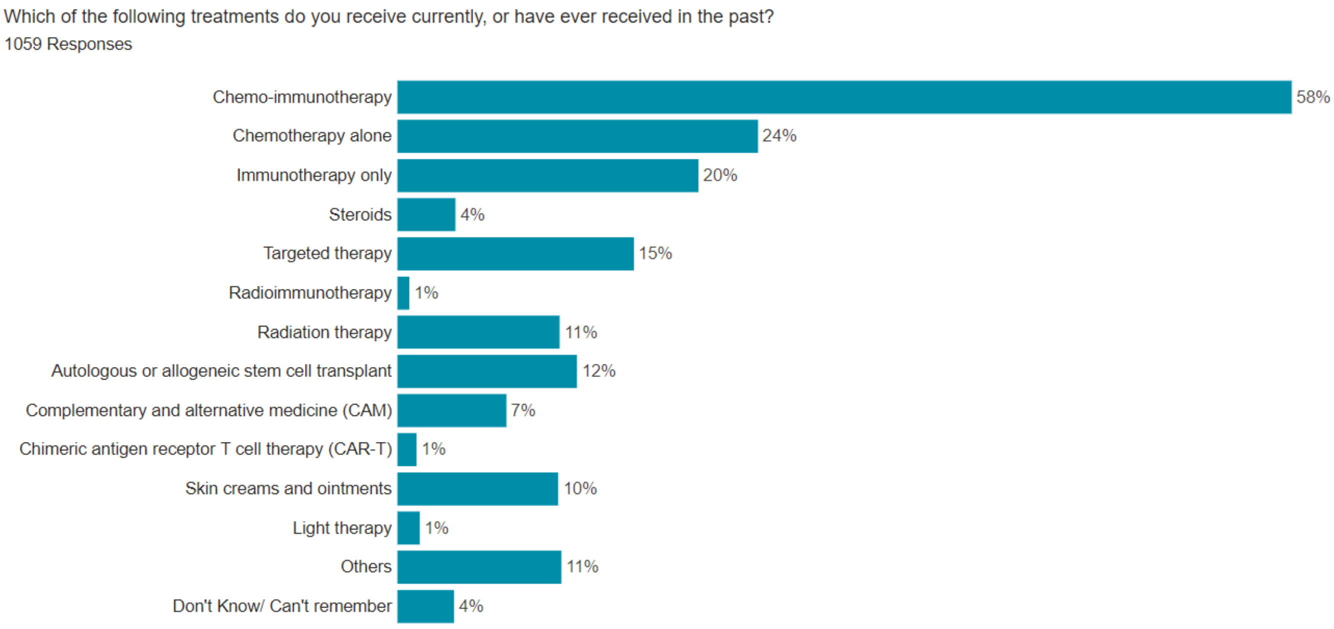
Treatment Demographics

Treatment Options

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

1059 patients reported the different treatments they are on/ or have ever been on. Their responses can be seen in Figure 10 below.

Figure 10: Which of the following treatment options do you receive currently, or have ever received in the past?



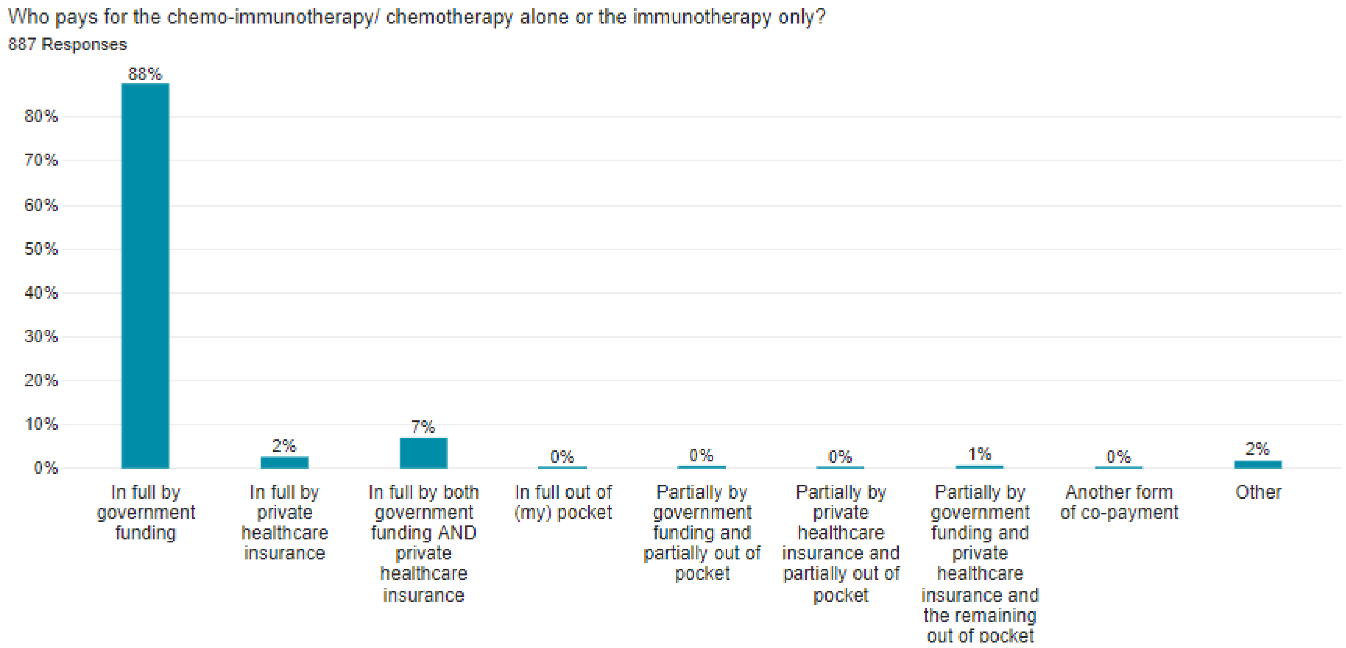
Subtype comparisons reveal that:

- Patients with Hodgkin lymphoma were more likely to report having received chemotherapy alone (86%), compared to any other treatment (1%-42%).
- Patients with follicular lymphoma most commonly reported receiving chemo-immunotherapy (80%) compared to any other treatment (1%-45%).
- Patients with CLL/SLL (33%), WM/LPL (26%) and mantle cell (23%) were more likely to have received targeted therapy than any other subtype (0%-17%).

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 (88%) selected that their chemotherapy/immunotherapy/chemo-immunotherapy is paid for in full by government funding – see Figure 11.

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



Targeted therapy is largely paid for in full by government funding (89%). The results were very different for complementary and alternative medicine, whereby 51% patients reported that it is paid in full out of their pocket.

16% of patients are currently or have previously been in a clinical trial for lymphoma or CLL.

Patient Information, Guidance and Support

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

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

Clear information, communication and support for self-care are important aspects of person-centred care[6]. 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.

- Patients were asked how they felt about the amount of information they received upon diagnosis – 26% were not given enough information. 50% of patients reported they needed more information about treatment options; 61% needed more information about diagnosis and what it means.
- 90% agree or strongly agree that they seek clarification on things they do not understand. 21% of patients report they are 'very confident' about managing their health problems day to day, and a further 54% are 'fairly confident'.
- 34% of patients felt that they did not get enough financial support, and 33% did not get enough emotional support.
- 22% agree or strongly agree that they feel overwhelmed by managing their health and condition, and 27% agree or strongly agree that they would wait until health issues could no longer be ignored before they seek 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, of which 86% of patients said yes. 63% patients reported they were told their lymphoma subtype at diagnosis.

The majority of patients in France (82%) stated that their diagnosis was announced via face to face consultation, 6% were told over the phone, 2% in the hallway, 1% received their diagnosis via post/ mail and 8% said it was something 'other'.

Patients were asked how they felt about the amount of information they received upon diagnosis (see Figure 12). Although over two thirds (70%) felt they were given the right amount of information, 26% were not given enough information.

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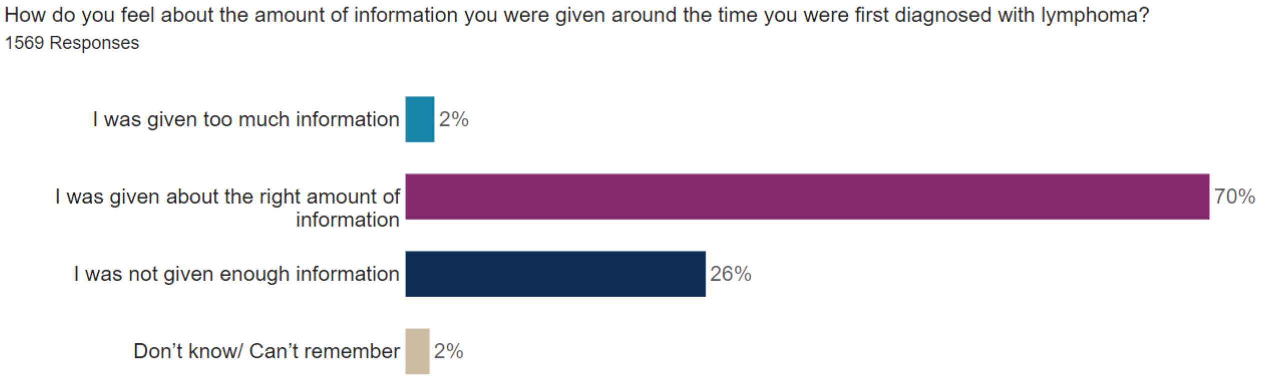
[6] https://www.picker.org/about-us/picker-principles-of-person-centred-care/

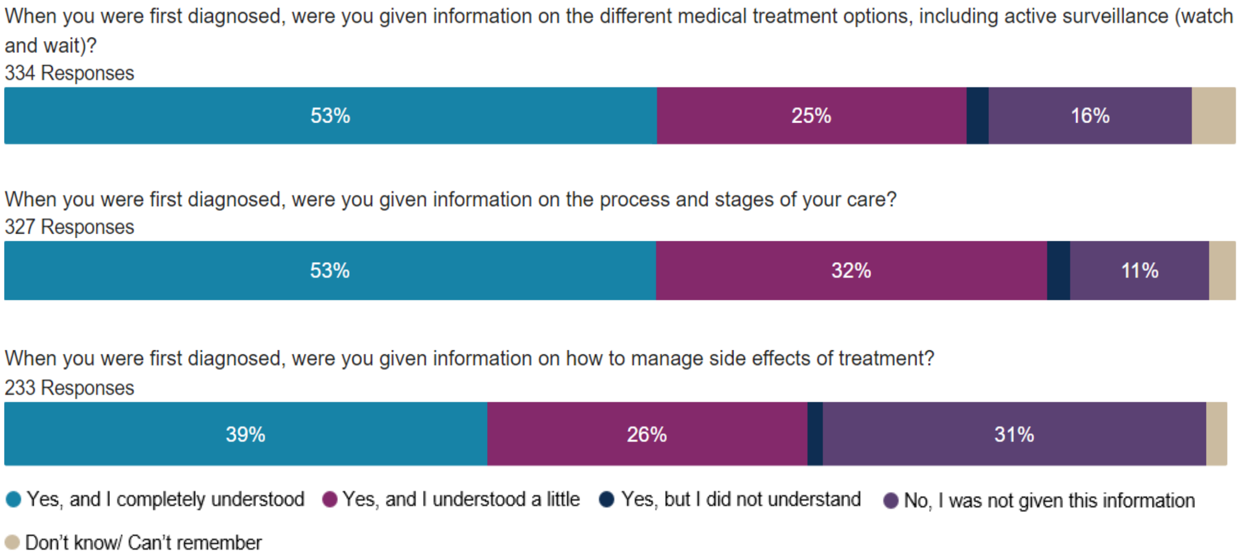
Figure 12: How do you feel about the amount of information you were given around the time you were first diagnosed with lymphoma?



The patients in the younger age groups (18-29: 58%; 30-39: 60%; and 40-59: 64%) were less likely to report being given about the right amount of information around the time of their diagnosis than those in the older age groups (60-69: 72% and 70+: 75%). Additionally, a higher proportion of females reported that they were not given enough information around the time of diagnosis (31%) compared to males (21%).

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 plan. 53% of patients were given and completely understood information on the different medical treatment options, including active surveillance (watch and wait). The same proportion (53%) of patients were provided with information on and completely understood the process and stages of care. Only 39% reported they received information on and completely understood how to manage side effects of treatment, while 31% reported that they were not given this information. See Figure 13 for more details.

Figure 13: When first diagnosed, were you given enough information on the following:



When discussing treatment options with their doctor, 21% of patients said they were given information about opportunities for fertility preservation. 70% had not been given this information but did not need it. However, 9% 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, reported by 61% (n=954) of patients.

When asked about information needs:

- 61% needed more information about diagnosis and what it means;
- 50% of patients reported they needed more information about treatment options;
- 41% required more information about side effects from treatment;
- 21% of patients needed more information about psychological support/counselling; and
- 8% required more information about support for their families.

A larger proportion of younger patients aged 18-29 (44%), 30-39 (42%) and 40-59 (32%) reported needing more information on psychological support/counselling than those in the older age groups: 60-69 (18%) and 70+ (10%). Males were more likely than females to report needing more information on treatment options (55% and 45% respectively).

Table 1 displays the number of patients selecting a range of information needs, by lymphoma subtype. Please be cautious of interpreting results where numbers are small (for example, some subtypes have fewer than 20 responses in total).

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

	Which of the following, if any, have you needed more information about?																
	Diagnosis and what it means		Treatment options		Support for self-care		Psycholog-ical support/ counselling		Support for my family		Side effects from treatment		Fertility		I have not needed more information		Total
Anaplastic large cell	40%	2	40%	2	0%	0	80%	4	20%	1	80%	4	20%	1	0%	0	5
Burkitts	57%	4	57%	4	0%	0	0%	0	29%	2	71%	5	43%	3	0%	0	7
CLL / SLL	64%	387	51%	312	2%	12	15%	93	4%	22	30%	182	1%	6	10%	60	609
Cutaneous	68%	15	64%	14	0%	0	27%	6	0%	0	64%	14	9%	2	5%	1	22
DLBCL	55%	96	40%	70	4%	7	26%	46	12%	21	53%	92	7%	13	13%	22	175
Follicular	58%	107	51%	94	5%	9	24%	45	7%	13	44%	81	4%	7	11%	21	184
Hodgkin	59%	85	48%	69	10%	14	41%	59	24%	34	72%	103	29%	41	2%	3	143
Mantle cell	56%	30	54%	29	0%	0	22%	12	11%	6	43%	23	0%	0	13%	7	54
MALT/MZ	81%	26	56%	18	3%	1	28%	9	6%	2	28%	9	0%	0	3%	1	32
Other indolent or aggressive	66%	71	51%	55	4%	4	23%	25	12%	13	44%	48	5%	5	6%	6	108
Other T cell lymphomas	50%	6	67%	8	0%	0	8%	1	8%	1	67%	8	25%	3	0%	0	12
Transformed	73%	8	55%	6	0%	0	18%	2	0%	0	55%	6	0%	0	9%	1	11
WM/LPL	61%	96	1	88	0	5	0	22	0	7	0	55	0	1	0	14	158
Don't know/can't remember	62%	28	40%	18	4%	2	18%	8	9%	4	24%	11	0%	0	16%	7	45

Table 2 displays the number of patients selecting each source of information within their top 3 choices. When asked to select their top three places to go for information, 73% of patients said ‘doctor’ was their top choice.

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.

1556 Responses

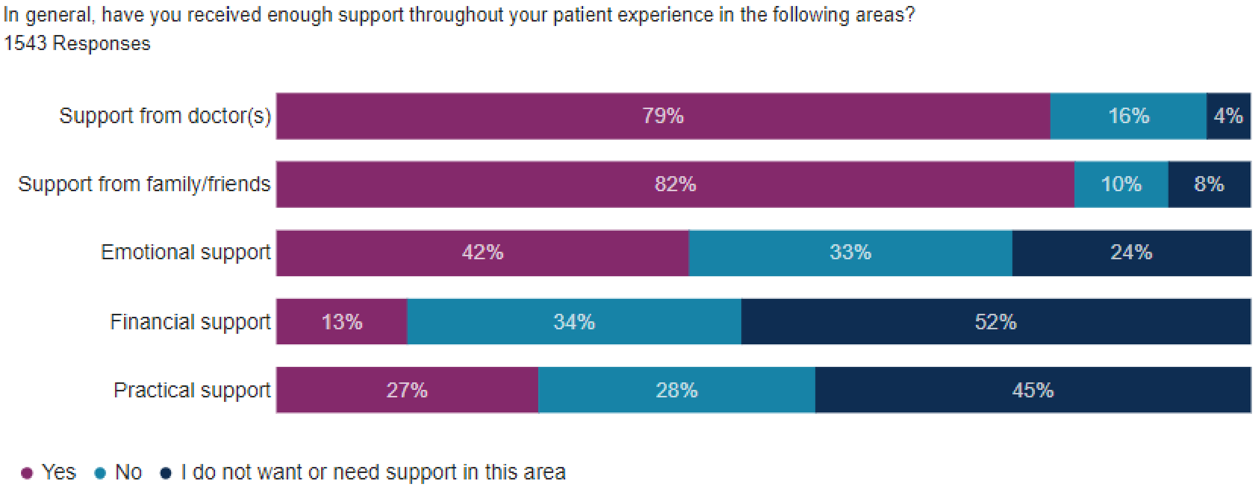
Since getting your diagnosis, when you have a need for information about your healthcare, which of the following are the top three places you go to first for information? Please select your top choices starting with your first choice.

	1		2		3	
Doctor	73%	1141	18%	254	11%	112
Nurse	2%	36	16%	227	5%	51
Websites	15%	231	29%	403	28%	295
Online blogs/social media	2%	28	6%	84	14%	149
Family/friends	1%	10	4%	56	10%	106
Patient organisation	7%	104	24%	335	27%	281
Other	0%	6	2%	22	6%	63
Total	100%	1556	100%	1381	100%	1057

A larger proportion of those with a lower educational level (primary; 91%) reported that a doctor would be the top place they would go for information, compared to those with a secondary (79%), post-secondary (75%) or postgraduate education level (71%).

Figure 14 displays whether patients felt they had received enough support in key areas of patient experience. 82% felt that they had enough support from family/friends, and 79% felt supported by doctors. However, 34% felt that they did not get enough financial support, and 33% did not get enough emotional support.

Figure 14: In general, have you received enough support throughout your patient experience in the following areas?



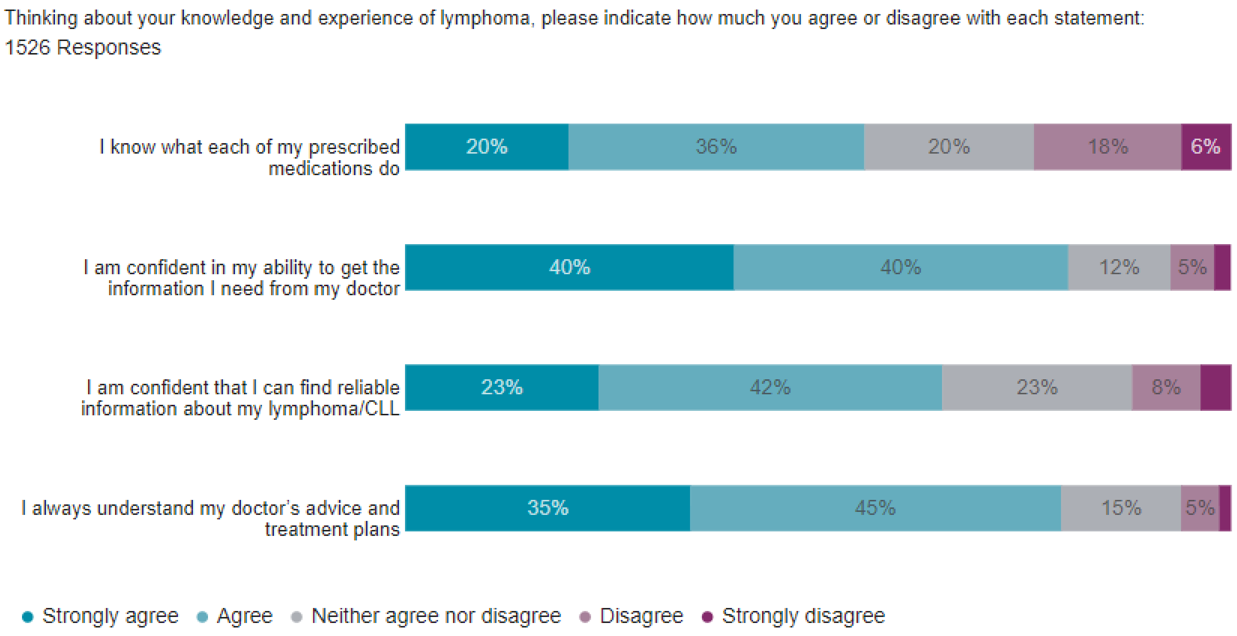
In general, have you received enough support throughout your patient experience in the following areas?

1543 Responses

A larger proportion of females consistently reported not getting enough support in the areas above, than males. A larger proportion of those who stated they were single and living with children reported they did not get enough support from their doctor (25%) than any other household status (9%-19%).

80% of patients reported that they either agree or strongly agree that they are confident in their ability to get the information needed from their doctor, and 80% reported that they either agree or strongly agree that they always understand their doctor's advice and treatment plans. However, 24% disagree or strongly disagree that they know what each of their prescribed medications do. See Figure 15 for full details.

Figure 15: Thinking about your knowledge and experience of lymphoma/CLL, please indicate how much you agree or disagree with each statement:



Males were more likely to agree or strongly agree that they always understand their doctors' advice and treatment plans (83%) than females (76%).

Those who reported receiving about the right amount of information upon diagnosis were more likely to agree or strongly agree that they always understand their doctors advice and treatment plans (86%) compared to those who felt they were given too much (62%) or too little (64%) information.

57% patients have been seeing the same referring haematologist/oncologist/dermatologist during the whole of their treatment.

Overall, 74% patients reported they have confidence and trust in the doctors treating them – see Figure 16.

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

Of the 36% (n=547) of patients who have seen nurses for their lymphoma care over the last year, 69% definitely feel comfortable asking nurses questions about their lymphoma/CLL, and 54% always have confidence and trust in the information they are given – see Figures 17 and 18.

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

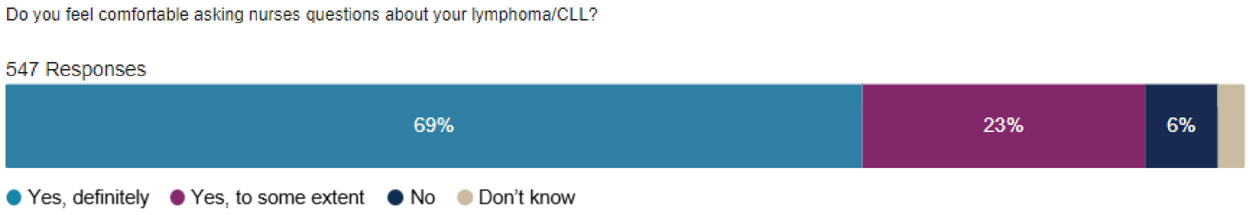
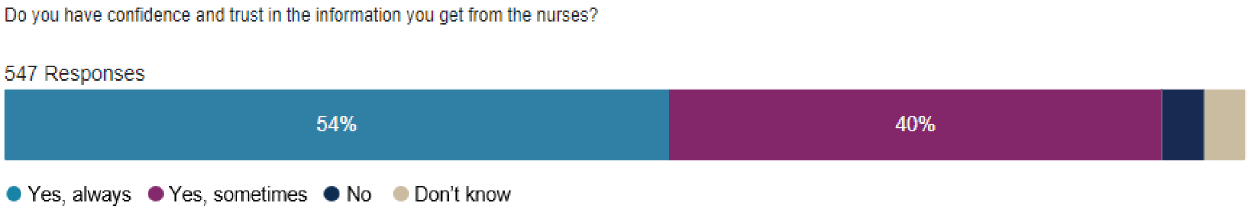


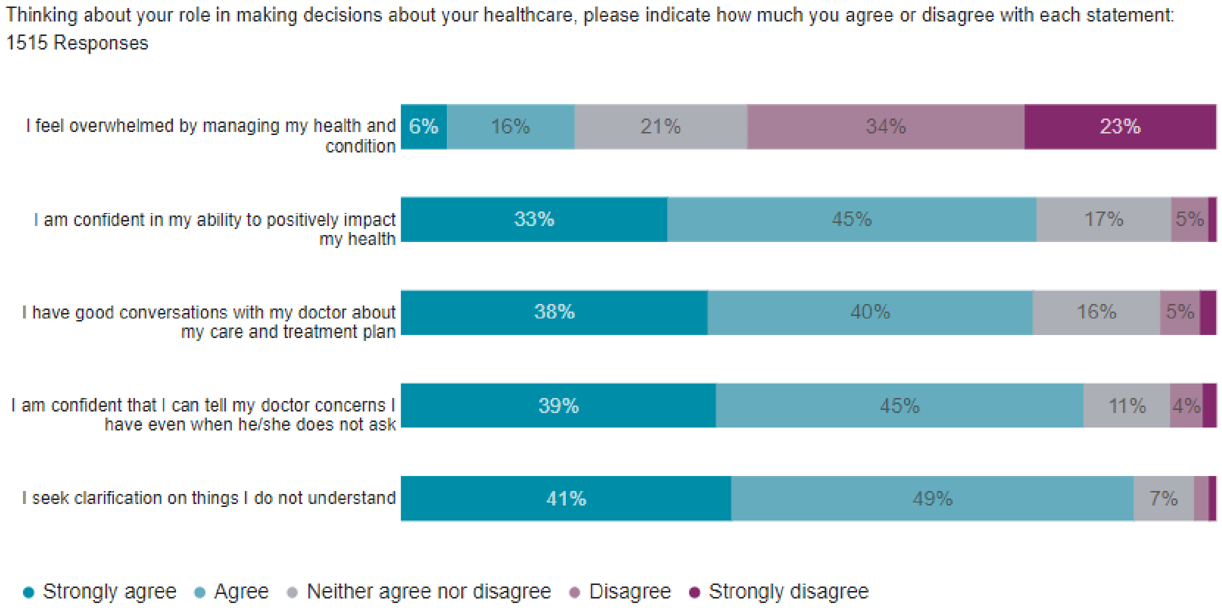
Figure 18: Do you have confidence and trust in the information you get from the nurses?



Healthcare Decision Making

Patients were asked a series of questions about the role they play in making decisions about their healthcare – see Figure 19. 90% agree or strongly agree that they seek clarification on things they do not understand. However, 22% agree or strongly agree that they feel overwhelmed by managing their health and condition.

Figure 19: Thinking about your role in making decisions about your healthcare, please indicate how much you agree or disagree with each statement:



88% of men, compared to 79% of women agree or strongly agree that they are confident that they can tell their doctor concerns they have even if the doctor does not ask.

Just under half (46%) of those who felt they were given too much information around the time of diagnosis agree or strongly agree that they feel overwhelmed by managing their health and condition, compared to those who were given about the right amount of information (18%) and those who were not given enough (28%).

Of those who feel ‘very confident’ in managing their health problems day to day, just 8% also agree or strongly agree that they feel overwhelmed by managing their health and condition. In comparison, 21% of those who feel fairly confident, 52% of those who don’t feel very confident and 69% who are not at all confident report the same.

46% of patients reported they are definitely involved as much as they want to be in decisions about their care and treatment, 40% report they are involved to some extent, 13% report that they are not, but would like to be more involved and 2% said they are not but they do not want to be involved.

24% of patients who were receiving treatment or had received treatment in the past reported they had talked to their doctor about wanting to change treatment to better meet their needs within the last two years – see Figure 20.

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

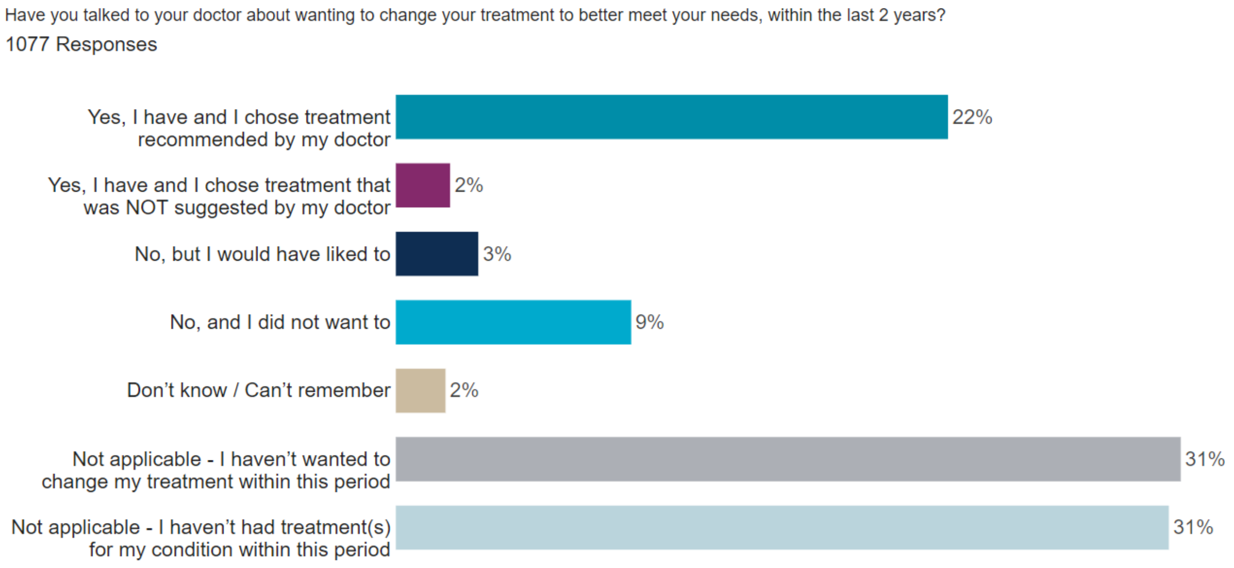
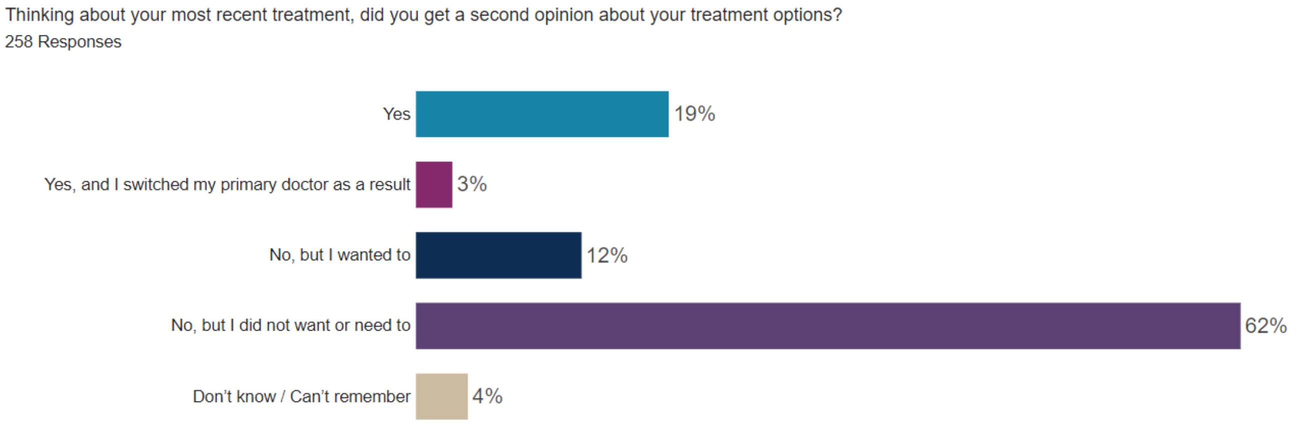


Figure 21 displays information relating to seeking a second opinion about treatment options. 22% of patients got a second opinion about their most recent treatment, but just 3% of patients changed their primary doctor as a result. 12% wanted to get a second opinion but did not, and 62% felt they did not want or need to get a second opinion.

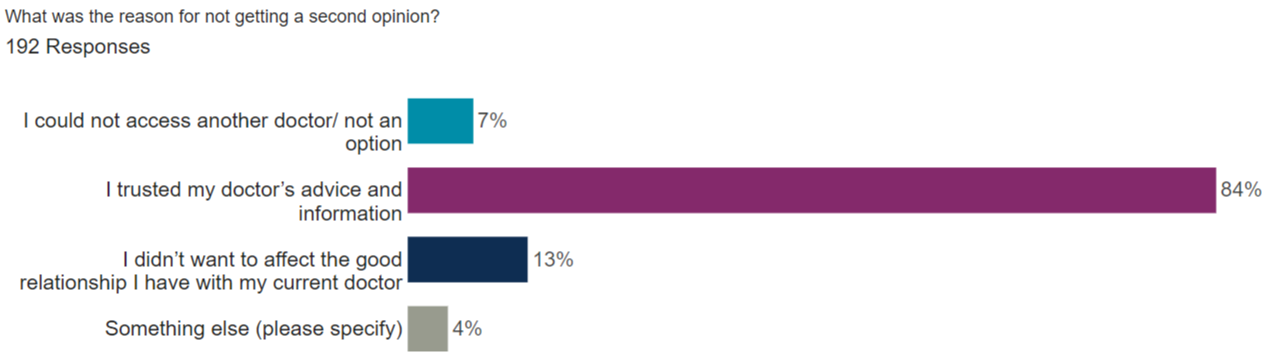
Figure 21: Thinking about your most recent treatment, did you get a second opinion about your treatment options?



Of those patients who did not get a second opinion (see Figure 22):

- 84% said it was because they trusted their doctor's advice and information
- 13% said it was because they did not want to affect the good relationship they have with their current doctor
- 7% said it was because they could not access another doctor/ not an option

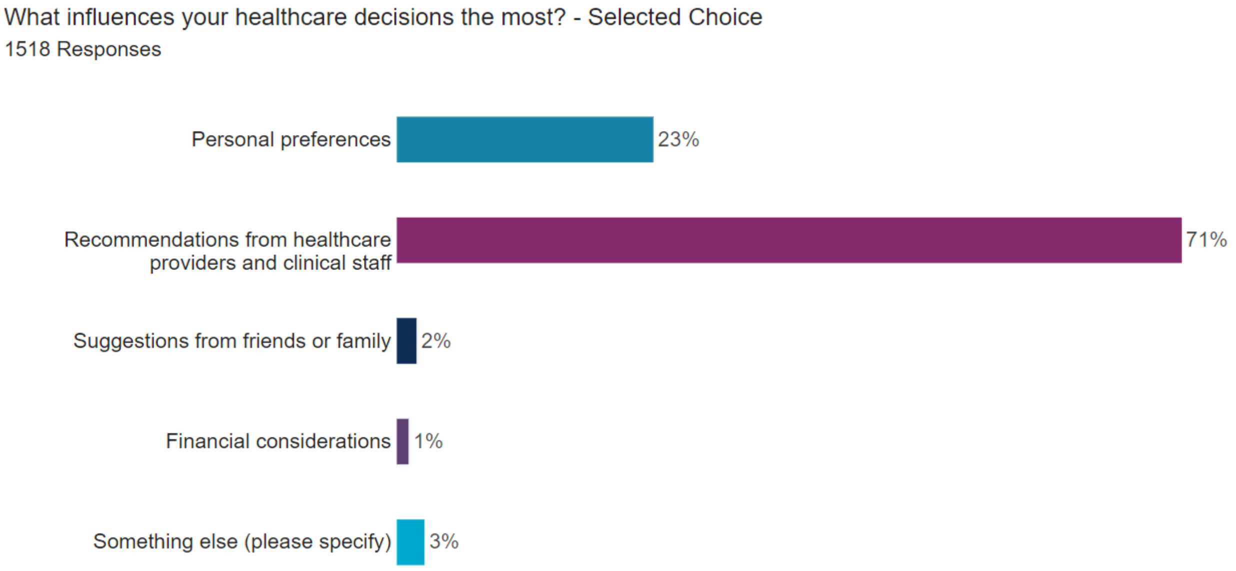
Figure 22: What was the reason for not getting a second opinion?



When patients were asked what they are most influenced by when making healthcare decisions, the top answers were (see Figure 23):

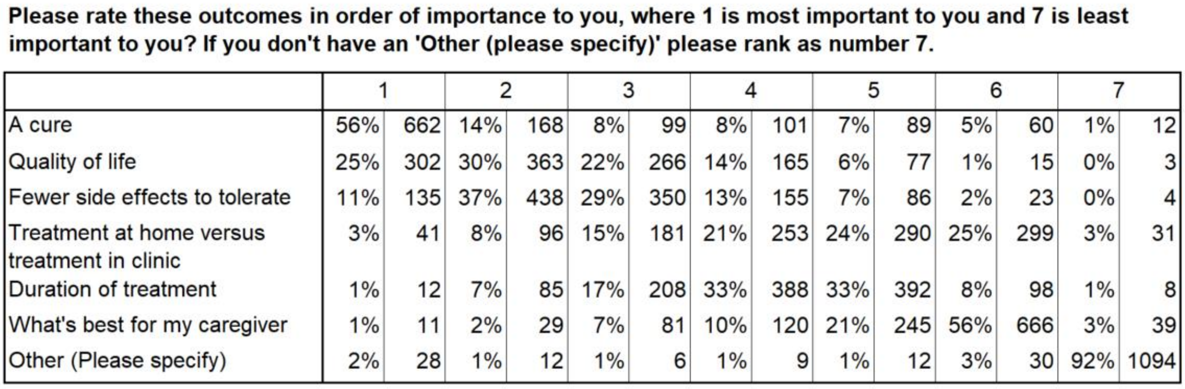
- 71% said they were most influenced by recommendations from healthcare providers and clinical staff;
- 23% were most influenced by personal preferences;
- and 6% were influenced by the other options.

Figure 23: What influences your healthcare decisions the most?



Patients were asked to rate various outcomes in order of importance (see Table 3). 56% of patients ranked a cure as having the most importance to them.

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



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

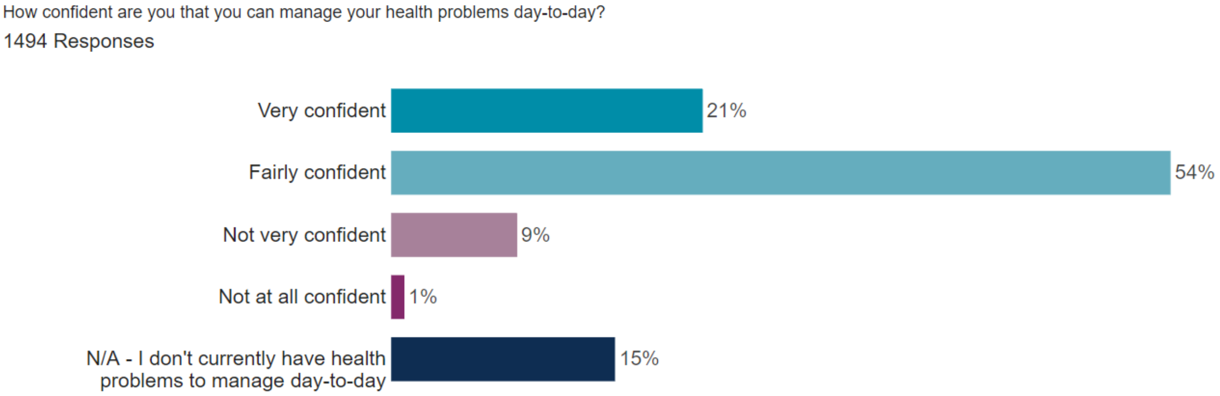
	1		2		3		4		5		6		7	
A cure	56%	662	14%	168	8%	99	8%	101	7%	89	5%	60	1%	12
Quality of life	25%	302	30%	363	22%	266	14%	165	6%	77	1%	15	0%	3
Fewer side effects to tolerate	11%	135	37%	438	29%	350	13%	155	7%	86	2%	23	0%	4
Treatment at home versus treatment in clinic	3%	41	8%	96	15%	181	21%	253	24%	290	25%	299	3%	31
Duration of treatment	1%	12	7%	85	17%	208	33%	388	33%	392	8%	98	1%	8
What's best for my caregiver	1%	11	2%	29	7%	81	10%	120	21%	245	56%	666	3%	39
Other (Please specify)	2%	28	1%	12	1%	6	1%	9	1%	12	3%	30	92%	1094

Those aged 30-39 were more likely to select ‘a cure’ as being most important to them (67%) than any other age group (46%-59%).

Health Behaviours

21% of patients report they are ‘very confident’ and 54% were ‘fairly confident’ about managing their health problems day to day, however 10% are ‘not very’ or ‘not at all’ confident. The full data can be seen in Figure 24.

Figure 24: How confident are you that you can manage your health problems day-to-day?

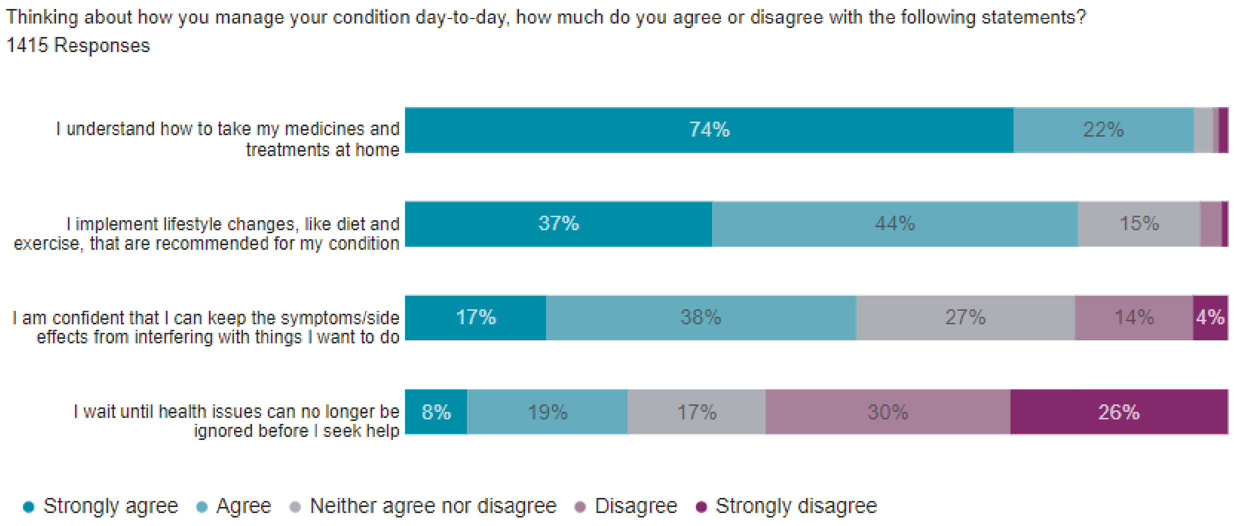


How confident are you that you can manage your health problems day-to-day?

1494 Responses

96% agree or strongly agree that they understand how to take their medicines and treatment at home. However 27% agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help – see Figure 25.

Figure 25: Thinking about how you manage your condition day-to-day, how much do you agree or disagree with the following statements?



Females were less likely to agree or strongly agree that they were confident in keeping the side effects/ symptoms of their condition and treatment from interfering with the things they want to do (48%) than males (61%).

Patients who reported feeling supported by their doctor were more likely to agree or strongly agree that they were confident in keeping the side effects/ symptoms of their condition and treatment from interfering with the things they want to do (58%) compared to those who did not receive enough support from their doctor (38%).

A larger proportion of patients who felt they were given the right amount of information upon diagnosis also agreed or strongly agree that they implement lifestyle changes that are recommended for their condition (84%) compared to those who were given too much (65%) or too little information (79%).

Patients who feel very confident (89%) or fairly confident (82%) in managing their health problems day to day were more likely to agree or strongly agree that they implement lifestyle changes that are recommended for their condition, than those who report feeling not very (65%) or not at all (54%) confident.

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 patients, 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.

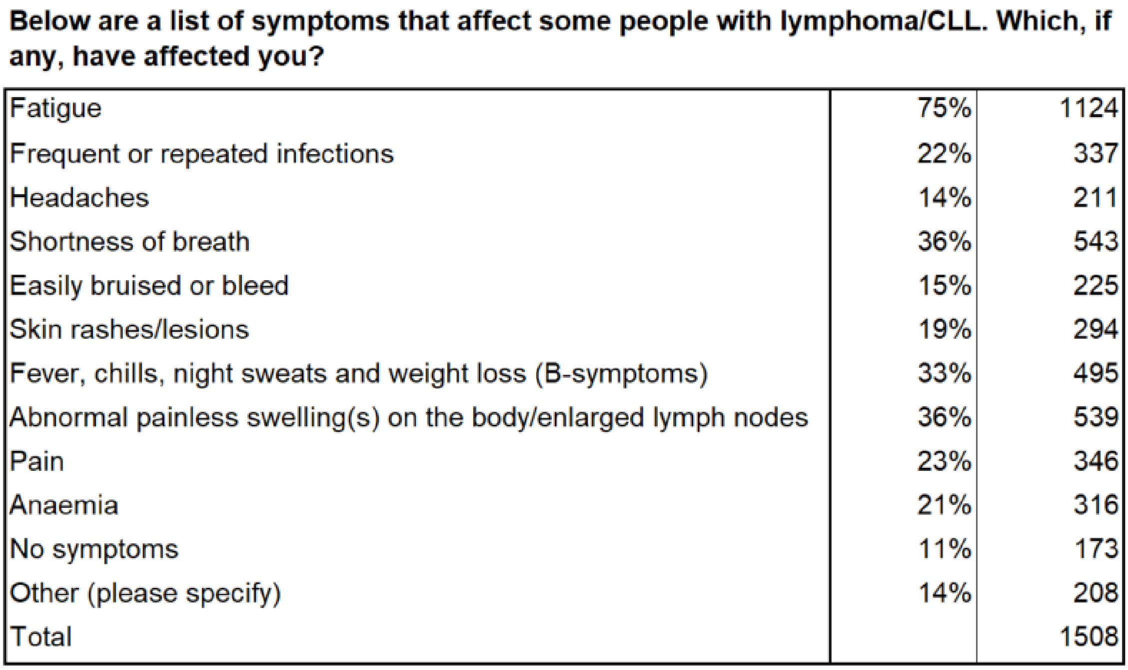
- Fatigue was the most reported symptom of lymphoma amongst all patients (75%). Fatigue was also the most reported treatment-related side effect (80%). 19% of patients were affected by fatigue for more than five years.
- Nausea and vomiting was the treatment-related side effect reported to affect patient's quality of life the most (53%).
- 64% reported that they agree or strongly agree that their lymphoma/CLL symptoms impact on everyday activities people their age can usually do.
- 79% of patients talked to their doctor about their treatment-related side effects, a quarter (23%) reported that the doctor was not able to help with their side effects.

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 (reported by 75% of patients), abnormal painless swelling(s) on the body or enlarged lymph nodes (36%) and shortness of breath (36%) – see Table 4. For all patients regardless of subtype, fatigue was the most reported symptom with between 20%-29% of each patient group experiencing it.

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

1508 Responses



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

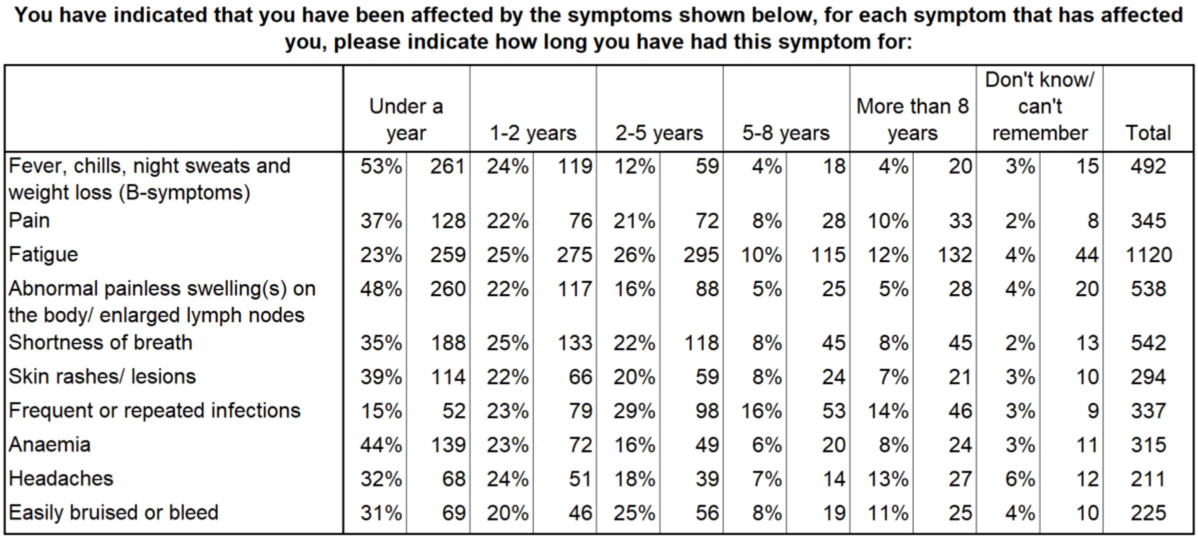
Fatigue	75%	1124
Frequent or repeated infections	22%	337
Headaches	14%	211
Shortness of breath	36%	543
Easily bruised or bleed	15%	225
Skin rashes/lesions	19%	294
Fever, chills, night sweats and weight loss (B-symptoms)	33%	495
Abnormal painless swelling(s) on the body/enlarged lymph nodes	36%	539
Pain	23%	346
Anaemia	21%	316
No symptoms	11%	173
Other (please specify)	14%	208
Total		1508

A larger proportion of patients aged 18-29 (91%) reported experiencing fatigue than all other age groups; 30-39 (83%), 40-59 (82%), 60-69 (70%) and 70+ (70%).

Table 5 displays the length of time that patients have experienced symptoms. Approximately half of patients who are affected by B-symptoms (53%) or abnormal painless swellings (48%) report it has affected them for under a year. 11%-14% of patients affected by pain, headaches, bruising easily, repeated infections, and fatigue have been experiencing these side effects for more than eight years.

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

1314 Responses

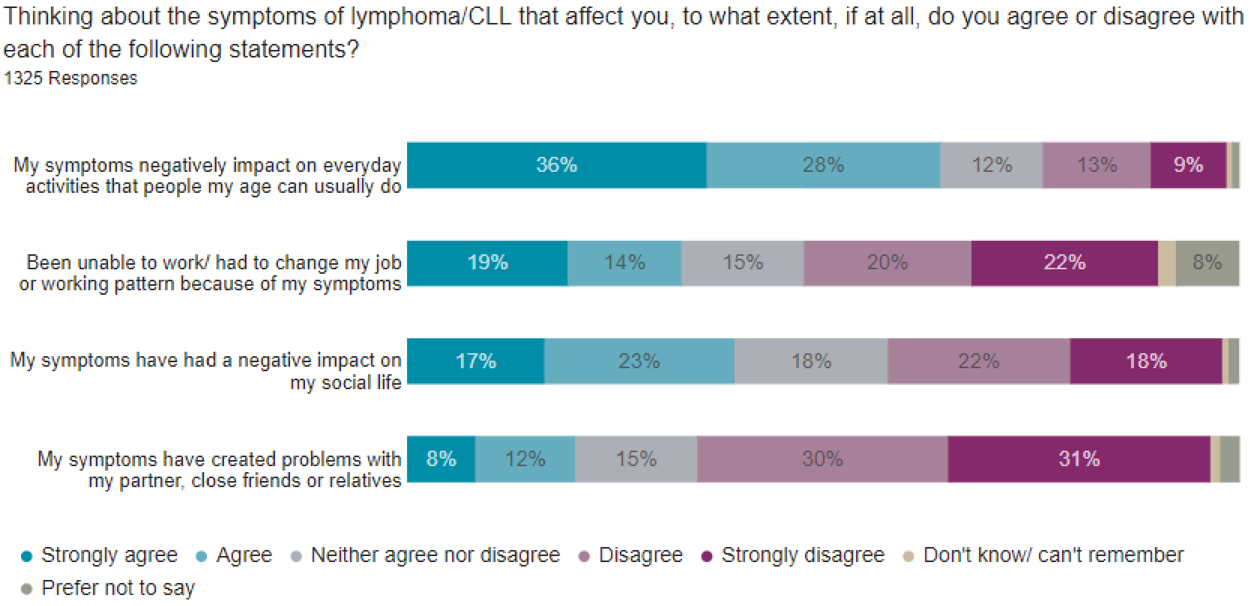


You have indicated that you have been affected by the symptoms shown below, for each symptom that has affected you, please indicate how long you have had this symptom for:

	Under a year		1-2 years		2-5 years		5-8 years		More than 8 years		Don't know/ can't remember		Total
Fever, chills, night sweats and weight loss (B-symptoms)	53%	261	24%	119	12%	59	4%	18	4%	20	3%	15	492
Pain	37%	128	22%	76	21%	72	8%	28	10%	33	2%	8	345
Fatigue	23%	259	25%	275	26%	295	10%	115	12%	132	4%	44	1120
Abnormal painless swelling(s) on the body/ enlarged lymph nodes	48%	260	22%	117	16%	88	5%	25	5%	28	4%	20	538
Shortness of breath	35%	188	25%	133	22%	118	8%	45	8%	45	2%	13	542
Skin rashes/ lesions	39%	114	22%	66	20%	59	8%	24	7%	21	3%	10	294
Frequent or repeated infections	15%	52	23%	79	29%	98	16%	53	14%	46	3%	9	337
Anaemia	44%	139	23%	72	16%	49	6%	20	8%	24	3%	11	315
Headaches	32%	68	24%	51	18%	39	7%	14	13%	27	6%	12	211
Easily bruised or bleed	31%	69	20%	46	25%	56	8%	19	11%	25	4%	10	225

Figure 26 presents patient views on the effects of their lymphoma/CLL symptoms. 64% reported that they agree or strongly agree that their symptoms impact on everyday activities people their age can usually do.

Figure 26: Thinking about the symptoms of lymphoma/CLL that affect you, to what extent, if at all, do you agree or disagree with each of the following statements? (Please select one option on each row):



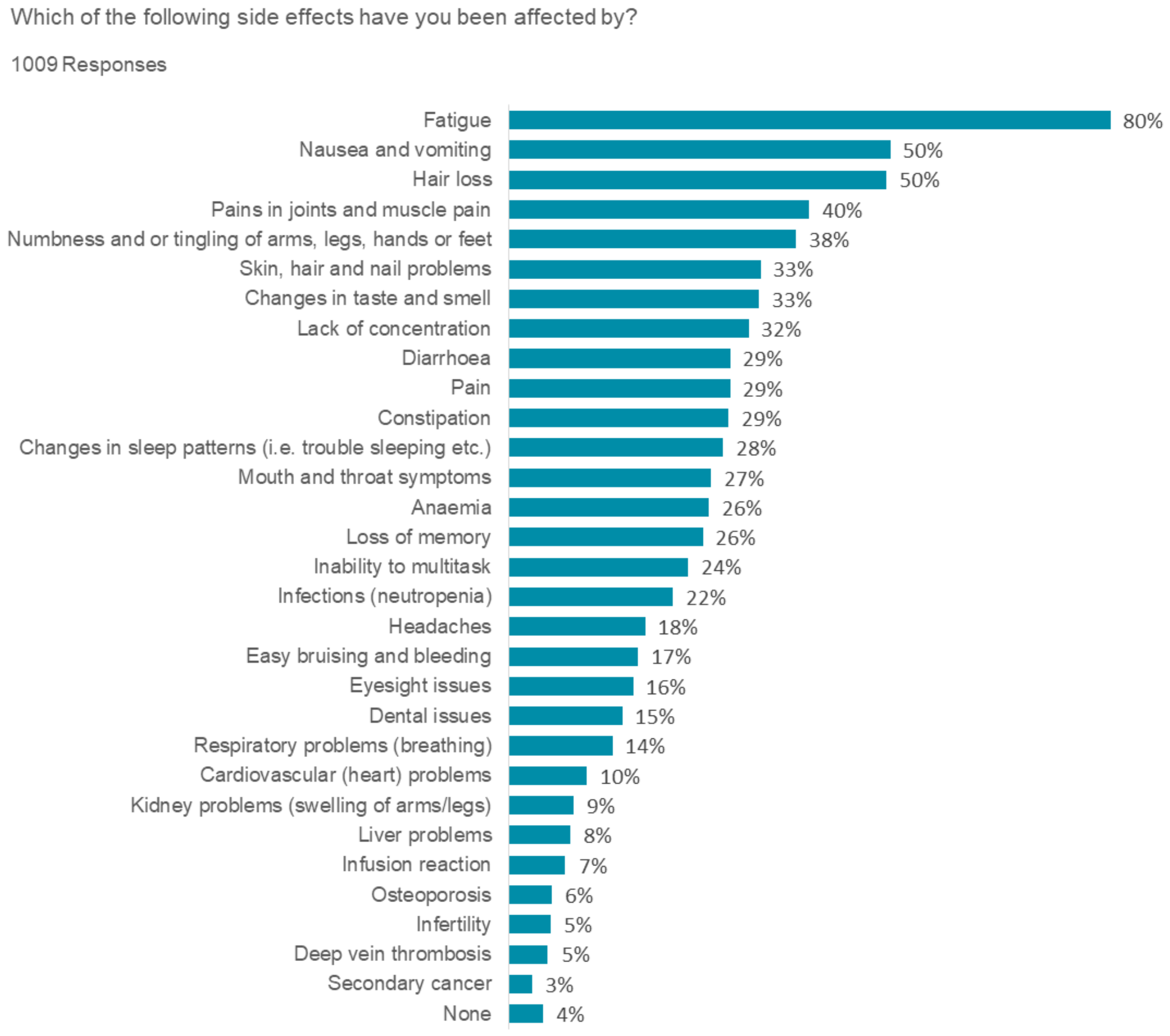
A larger proportion of patients aged 30-39 (42%) agreed or strongly agreed that their symptoms have created problems with their partner, close friends or relatives, compared to any other age group; 18-29 (29%), 40-59 (27%), 60-69 (18%) and 70+ (11%).

Effects of Lymphoma/CLL Treatment

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

- Fatigue reported by 80%
- Hair loss reported by 50%
- Nausea and vomiting reported by 50%

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



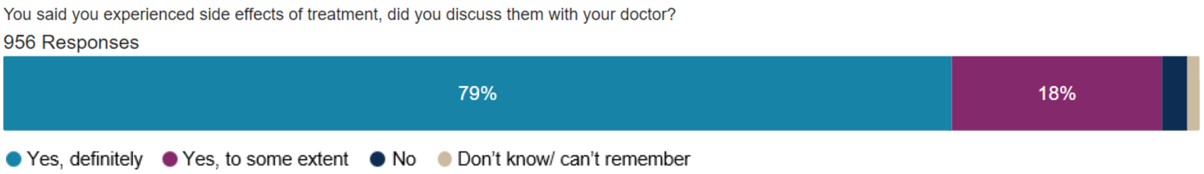
Patients were asked to think about all of the side effects that affected them and to rank the top three from one (most affected by) to three (least affected by). The side effects that affected people the most (ranked one) are:

- 53% report that nausea and vomiting affects them the most
- 50% report that hair loss affects them the most
- 40% report that fatigue affects them the most
- 38% report that infections affect them the most
- 32% report that pains in joints and muscle pain affects them the most

19% of patients were affected by fatigue for more than five years, and 17% of patients were affected by pains in joints and muscle pain for more than five years. 27% of patients were affected by infections for more than five years.

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

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



Of the 97% of patients who discussed side effects with their doctor (either definitely, or to some extent), only 22% said that the doctor was definitely able to help with these. A further 54% reported that the doctor was able to help to some extent. Almost a quarter (23%) felt the doctor was unable to help – see Figure 29.

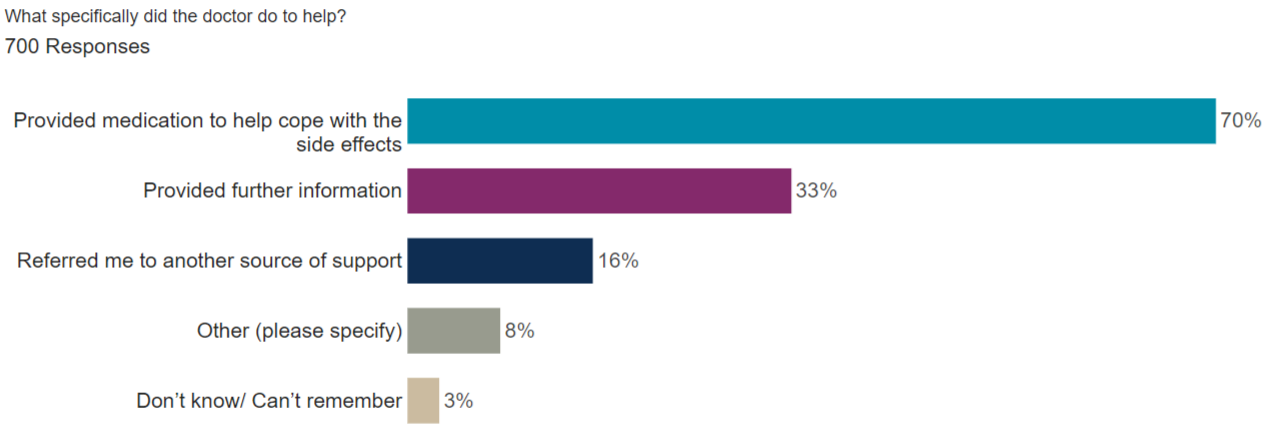
Figure 29: Was the doctor able to help with the side effects?

A larger proportion of patients who reported they were not given enough information upon diagnosis also reported that the doctor was not able to help with their side effects (36%) compared to those who were given the right amount of information (19%) or too much (10%). Additionally, patients who felt 'very' (18%) or 'fairly' (24%) confident in managing their health problems day to day were less likely to report their doctor not being able to help with the side effects, compared to those who felt 'not very' (31%) or 'not at all' confident (43%).

Of those who said their doctor was able to help with treatment side effects (see Figure 30):

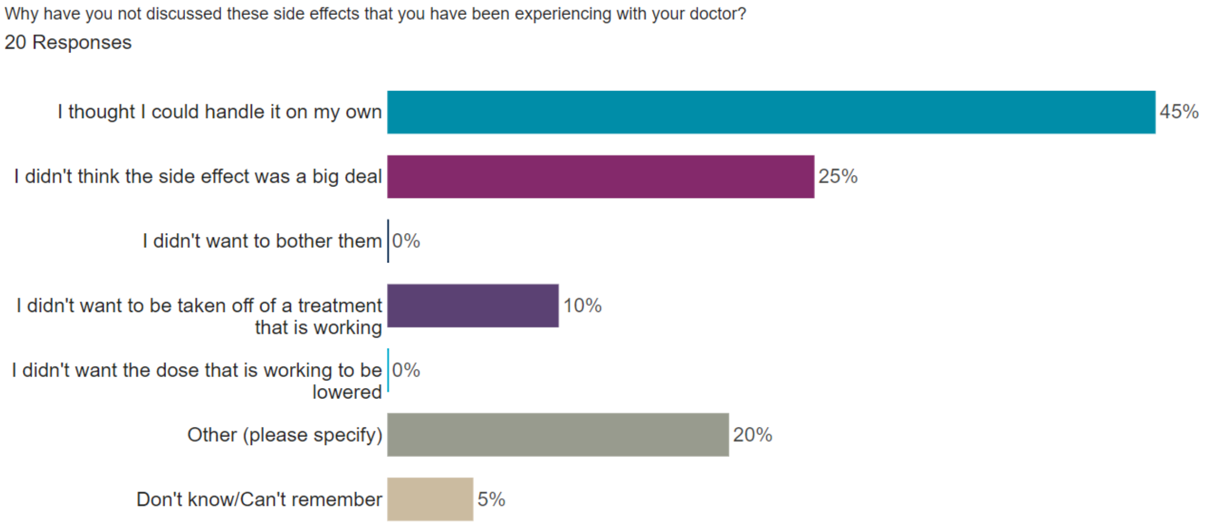
- 70% said the doctor helped by providing medication to help cope with the side effects
- 33% said the doctor helped by providing further information.

Figure 30: What specifically did the doctor do to help?



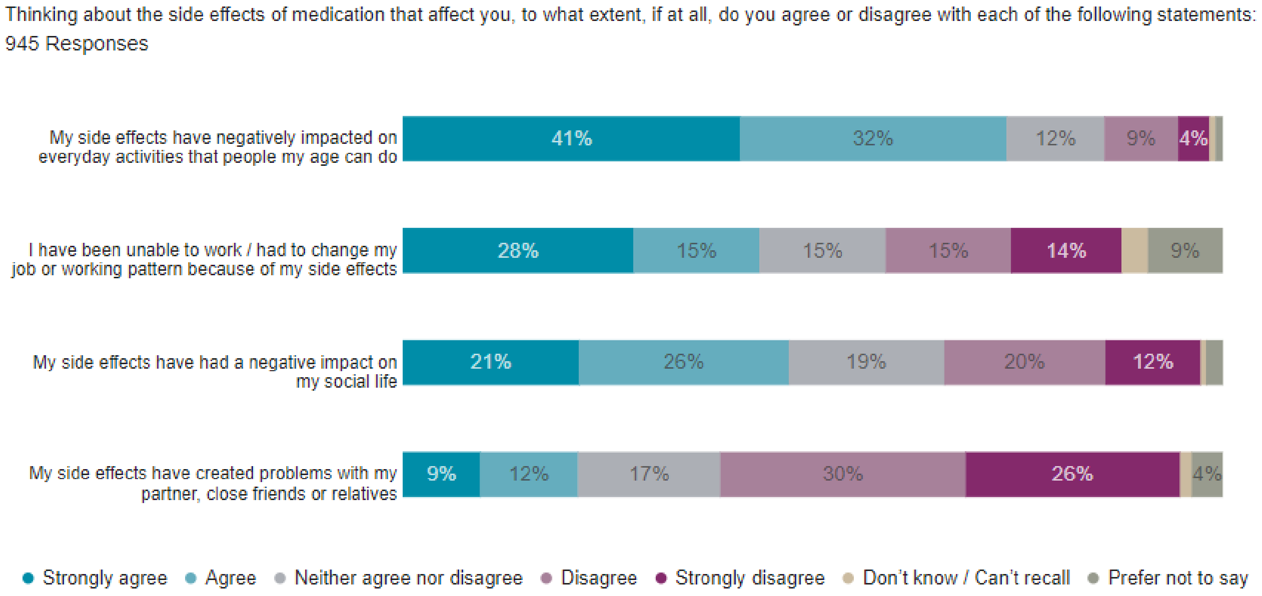
The 2% (n=20) of patients who have experienced treatment-related side effects and who did not discuss them with their doctor reported the reasons why (see Figure 31). For 45%, the reason was that they thought they could handle it on their own, and for 25% the reason was they did not think the side effect was a big deal.

Figure 31: Why have you not discussed these side effects that you have been experiencing with your doctor (interpret the chart with caution due to the low base size of 20 patient respondents)?



Regarding the treatment side effects that affected patients, 74% reported that they agree or strongly agree their side effects have negatively impacted on everyday activities that people their age can do. 47% agree or strongly agree their side effects have had a negative impact on their social life. However, fewer patients (21%) agree or strongly agree that their side effects have created problems with their partner, close friends or relatives. See Figure 32 for full details.

Figure 32: 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):



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.

- Patients who rated their level of fatigue as six or more out of ten reported that their fatigue has affected their physical activity (74%), general activity (72%), and general work around the home (55%).
- 76% patients have discussed their fatigue with their doctor over the last two years; however, 32% reported that the doctor took no action after fatigue was discussed, and only 17% reported that the doctor definitely followed up about their fatigue.
- The main reason patients reported as not having discussed their fatigue with their doctor was they did not think it was relevant (21%).

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% (n=516) 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 activity reported by 74% of patients with a fatigue rating of six or more
- General activity reported by 72% of patients with a fatigue rating of six or more
- General work around home reported by 55% of patients with a fatigue rating of six or more.

Figure 33 displays fatigue ratings by age group.

Figure 33: Please rate the severity of your fatigue over the last week on a scale of 1 (minimal fatigue) to 10 (worst fatigue imaginable):

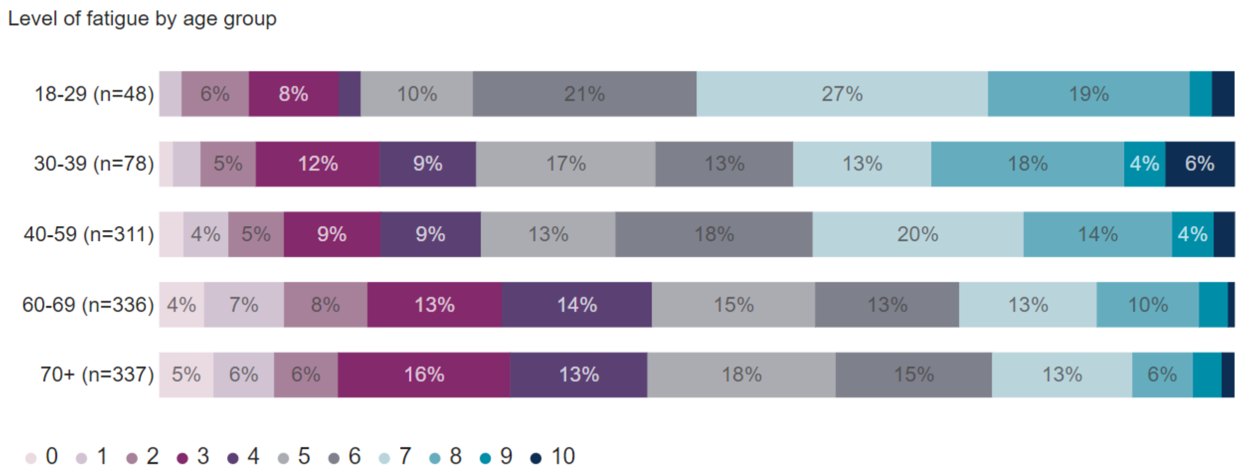
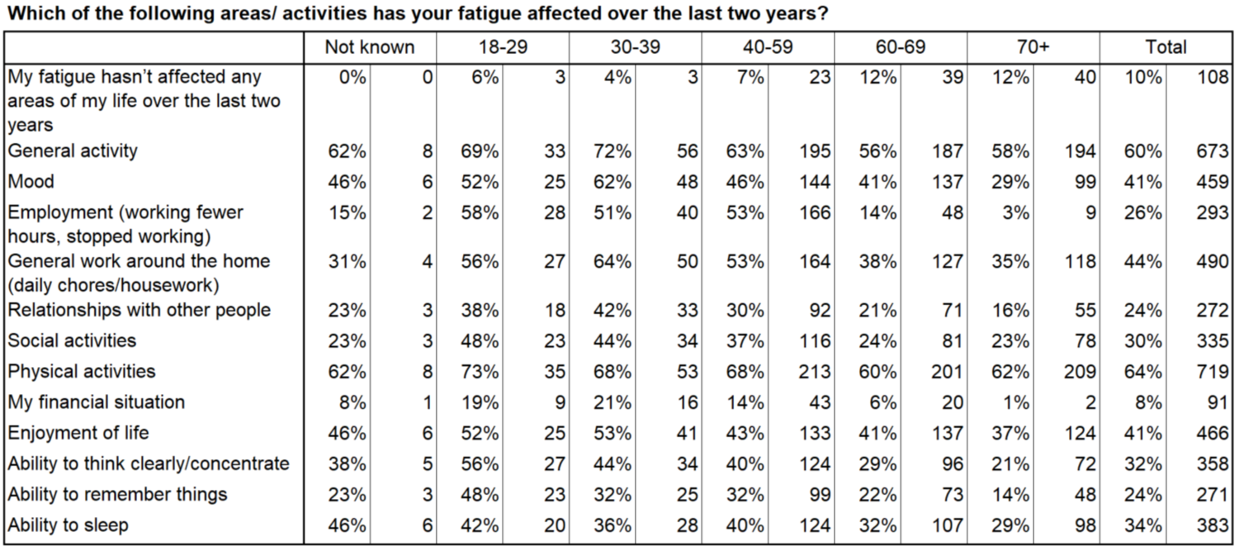


Table 6 shows areas/activities affected by fatigue over the last two years by age. Age comparisons show that a larger proportion of the younger patients (18-29 years) report fatigue has affected their ability to think clearly (56%) and remember things (48%) than those in any other age group (21%-44%) and (14%-32%) respectively.

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

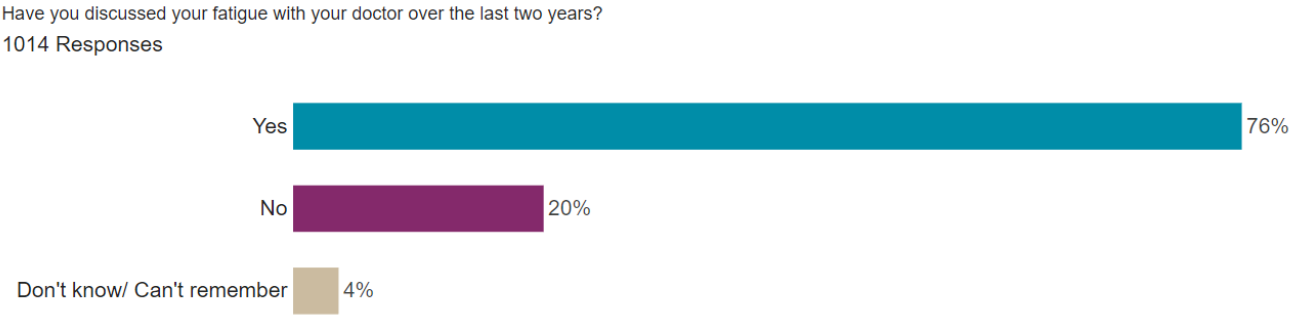


Which of the following areas/ activities has your fatigue affected over the last two years?

	Not known		18-29		30-39		40-59		60-69		70+		Total	
My fatigue hasn't affected any areas of my life over the last two years	0%	0	6%	3	4%	3	7%	23	12%	39	12%	40	10%	108
General activity	62%	8	69%	33	72%	56	63%	195	56%	187	58%	194	60%	673
Mood	46%	6	52%	25	62%	48	46%	144	41%	137	29%	99	41%	459
Employment (working fewer hours, stopped working)	15%	2	58%	28	51%	40	53%	166	14%	48	3%	9	26%	293
General work around the home (daily chores/housework)	31%	4	56%	27	64%	50	53%	164	38%	127	35%	118	44%	490
Relationships with other people	23%	3	38%	18	42%	33	30%	92	21%	71	16%	55	24%	272
Social activities	23%	3	48%	23	44%	34	37%	116	24%	81	23%	78	30%	335
Physical activities	62%	8	73%	35	68%	53	68%	213	60%	201	62%	209	64%	719
My financial situation	8%	1	19%	9	21%	16	14%	43	6%	20	1%	2	8%	91
Enjoyment of life	46%	6	52%	25	53%	41	43%	133	41%	137	37%	124	41%	466
Ability to think clearly/concentrate	38%	5	56%	27	44%	34	40%	124	29%	96	21%	72	32%	358
Ability to remember things	23%	3	48%	23	32%	25	32%	99	22%	73	14%	48	24%	271
Ability to sleep	46%	6	42%	20	36%	28	40%	124	32%	107	29%	98	34%	383

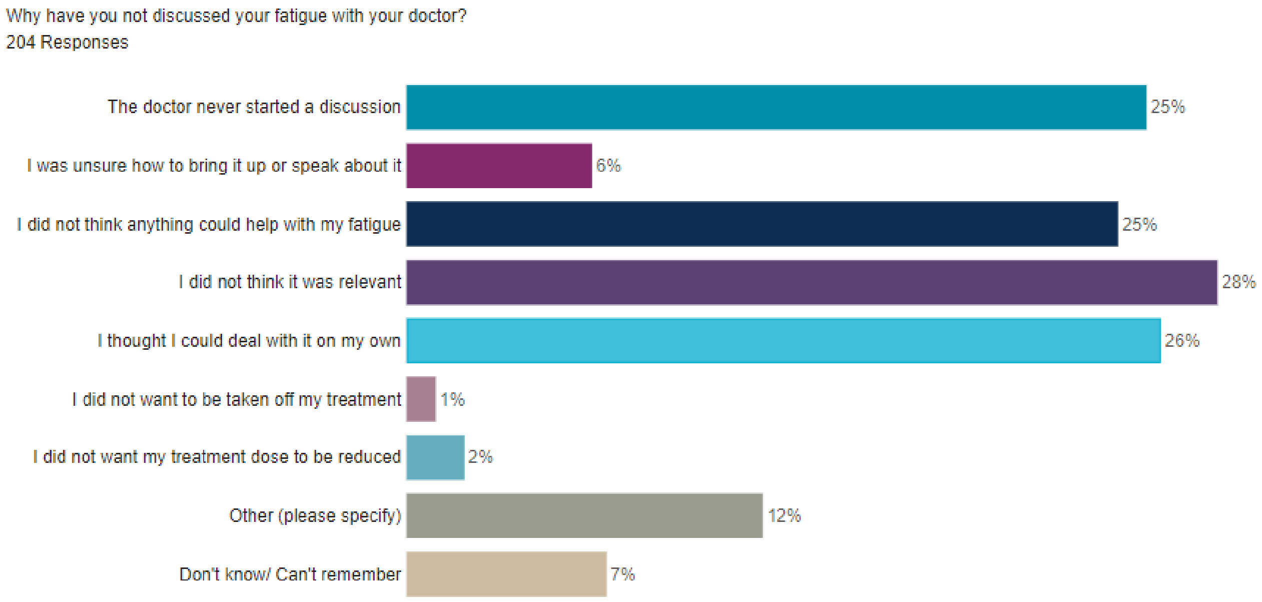
Figure 34 shows that 76% patients have discussed their fatigue with their doctor over the last two years and 20% have not.

Figure 34: Have you discussed your fatigue with your doctor over the last two years?



The main reason patients reported as not having discussed their fatigue with their doctor was they did not think it was relevant (28%), followed closely by they thought they could deal with it on their own (26%) – see Figure 35.

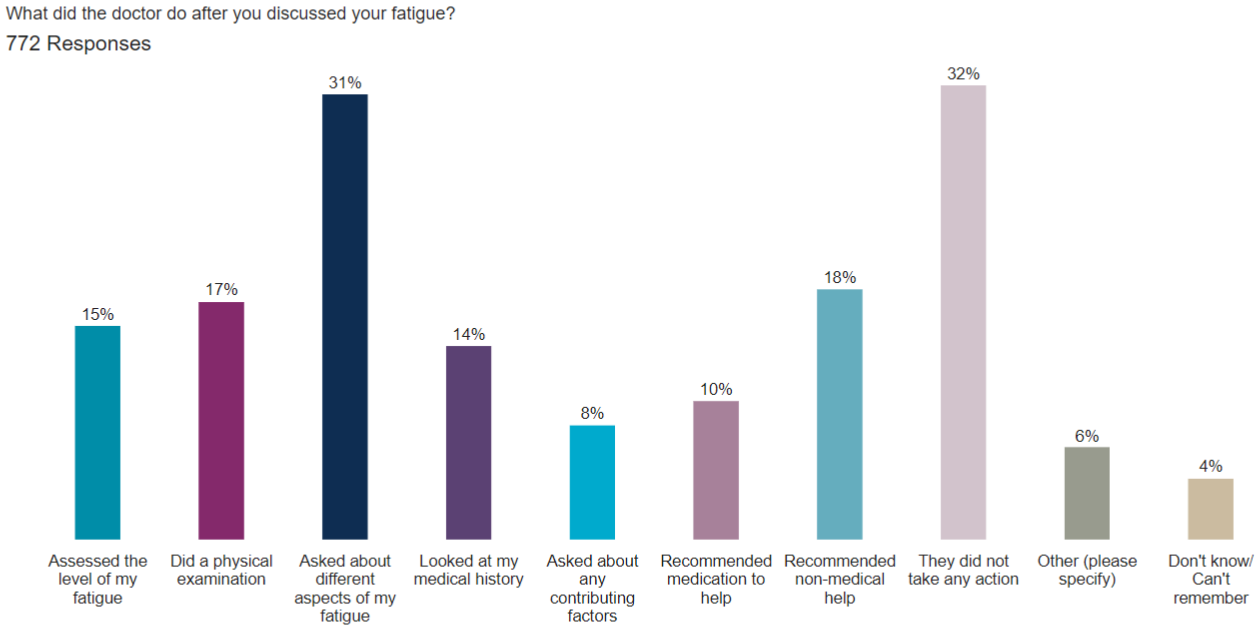
Figure 35: Why have you not discussed your fatigue with your doctor?



A larger proportion of females (32%) reported that they thought they could deal with their fatigue on their own, compared to males (20%).

Patients who discussed fatigue with their doctor were asked how their doctor helped with their fatigue. Less than 20% of patients reported that the doctor did a physical examination (17%) or looked at their medical history (14%). Notably, 32% reported the doctor did not take any action. Responses are displayed in Figure 36.

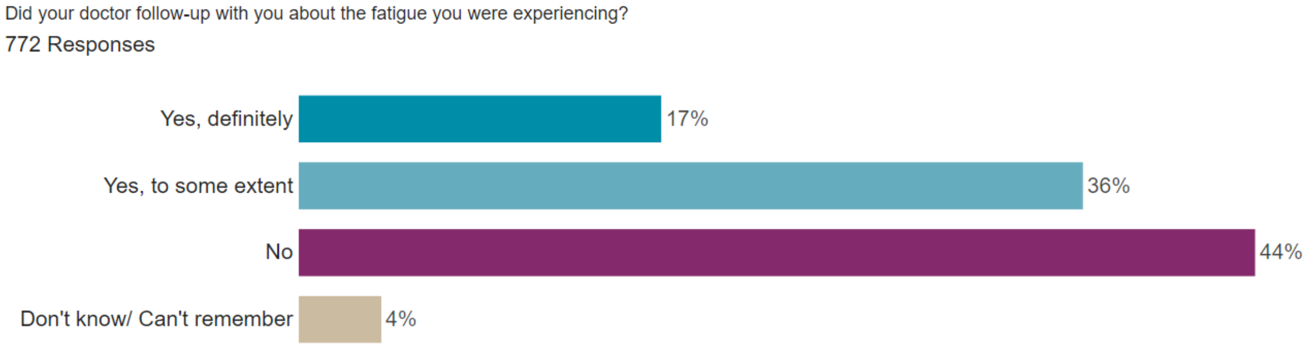
Figure 36: What did the doctor do after you discussed your fatigue?



Patients who had discussed fatigue with a doctor were asked whether their doctor followed up with them about their fatigue (see Figure 37), and:

- 17% said 'Yes, definitely'
- 36% said 'Yes, to some extent'
- 44% said 'No'

Figure 37: 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 (see Figure 38). 81% reported that they also spoke to family and friends.

Figure 38: Did you speak to anybody else to help you with your fatigue?

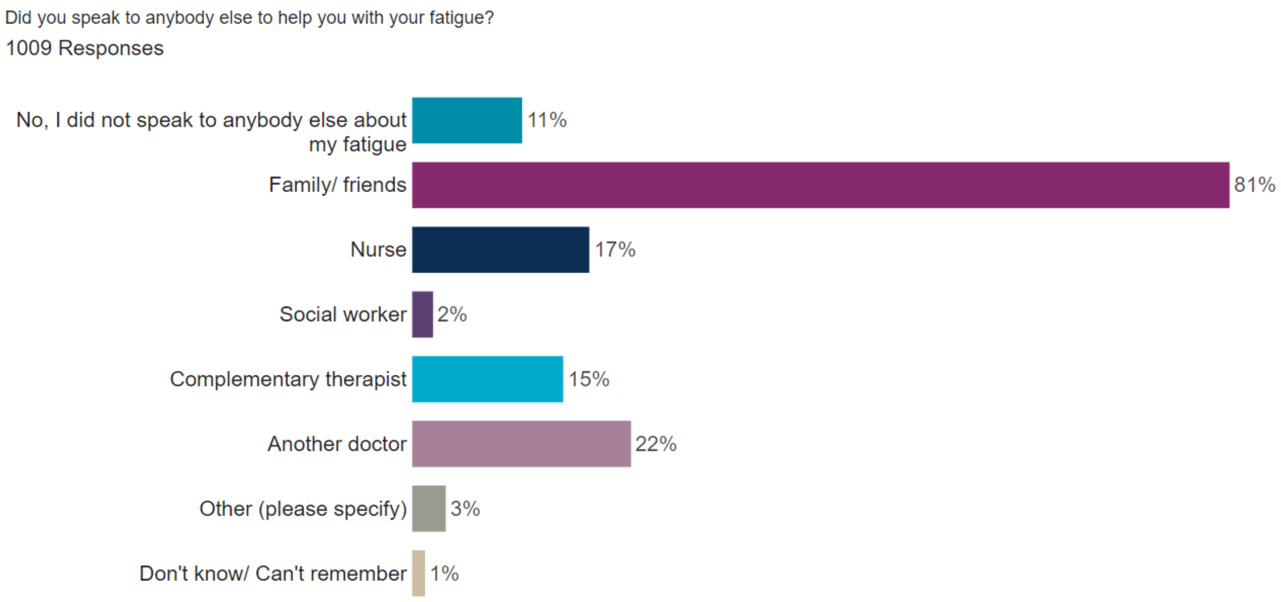
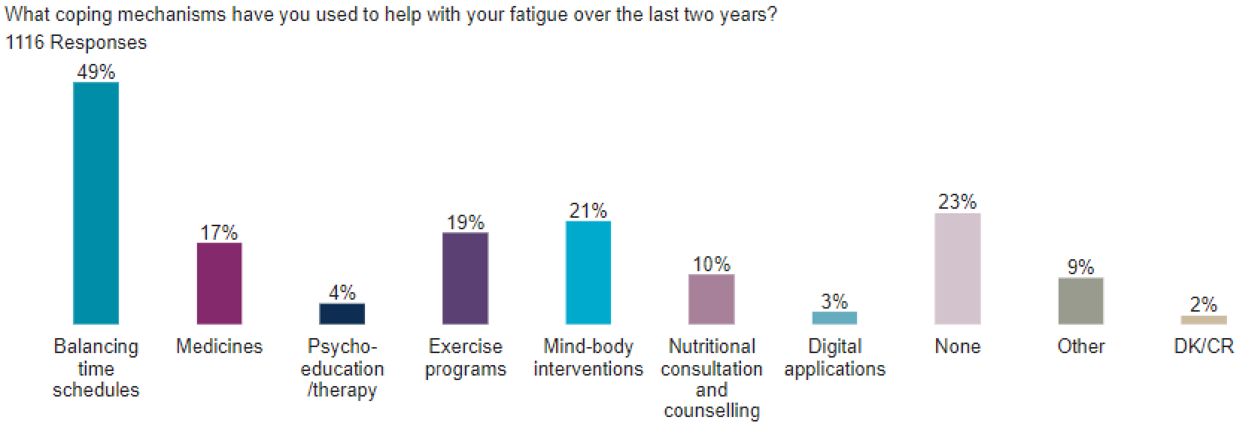


Figure 39 displays that the top reported coping mechanisms patients have used to help with their fatigue over the last two years are balancing their time schedules (49%) and mind-body interventions (21%). 23% reported using no coping mechanisms ('none').

Figure 39: What coping mechanisms have you used to help with your fatigue over the last two years?



Psychosocial Effects of Lymphoma/CLL and its Treatment

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

- Fear of cancer relapse (35%) and fear of progression of the lymphoma (34%) were the most commonly reported psychosocial side effects of lymphoma. Other relevant choices were depression (27%), anxiety (27%), and relationship changes (16%).

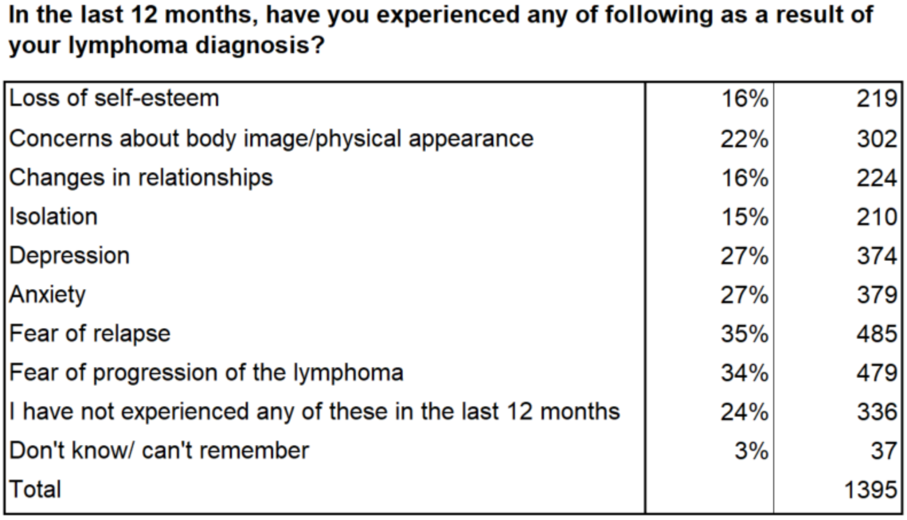
- Patients were less likely to discuss their relationship changes (26%) than their depression (52%) or anxiety (63%) with their doctor.

- Less than 35% of those who discussed their depression, anxiety or changes in relationships felt that the doctor was definitely able to help, with the lowest percentage (19%) reported for changes in relationships.

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

- Fear of cancer relapse, reported by 35% of patients
- Fear of progression of the lymphoma, reported by 34% of patients
- Anxiety, reported by 27% of patients
- Depression, reported by 27% of patients

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



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

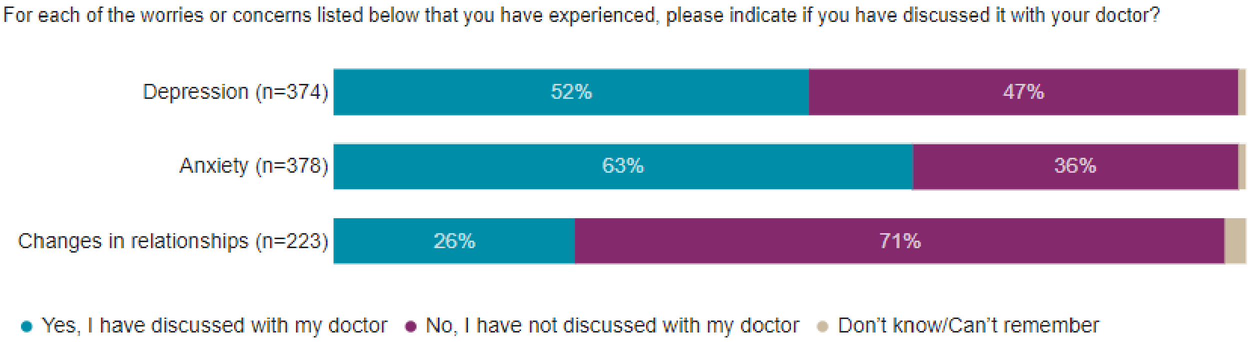
Loss of self-esteem	16%	219
Concerns about body image/physical appearance	22%	302
Changes in relationships	16%	224
Isolation	15%	210
Depression	27%	374
Anxiety	27%	379
Fear of relapse	35%	485
Fear of progression of the lymphoma	34%	479
I have not experienced any of these in the last 12 months	24%	336
Don't know/ can't remember	3%	37
Total		1395

Patients aged 30-39 (32%) were more likely to report feeling isolated than any other age group; 18-29 (23%), 40-59 (21%), 60-69 (11%) and 70+ (10%).

From this point on, the LC (2020) GPS 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.

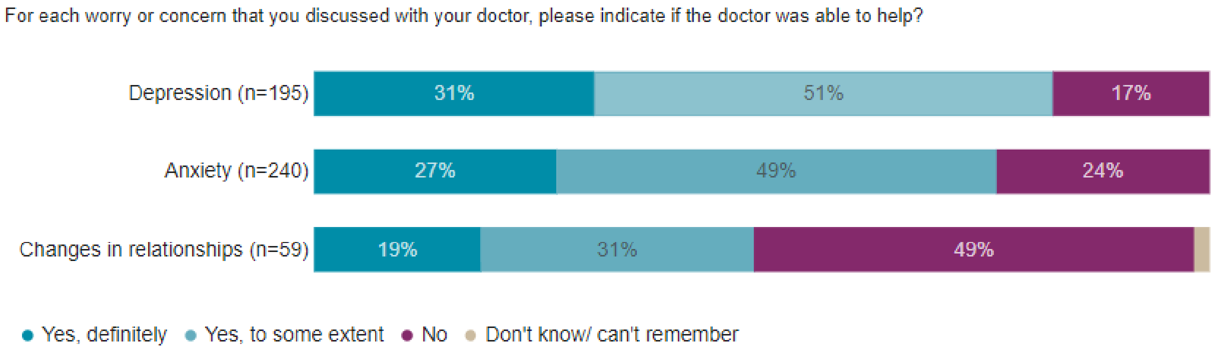
Figure 40 presents the percentage of patients who discussed their changes in relationships, anxiety, and/or depression with their doctor.

Figure 40: For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with your doctor?



Those who discussed these psychosocial worries or concerns with their doctor were asked whether the doctor was able to help (see Figure 41) and what information or support they were provided with (Table 8). Less than 35% of those who discussed their depression, anxiety or changes in relationships felt that the doctor was definitely able to help- with the lowest percentage (19%) reported for changes in relationships.

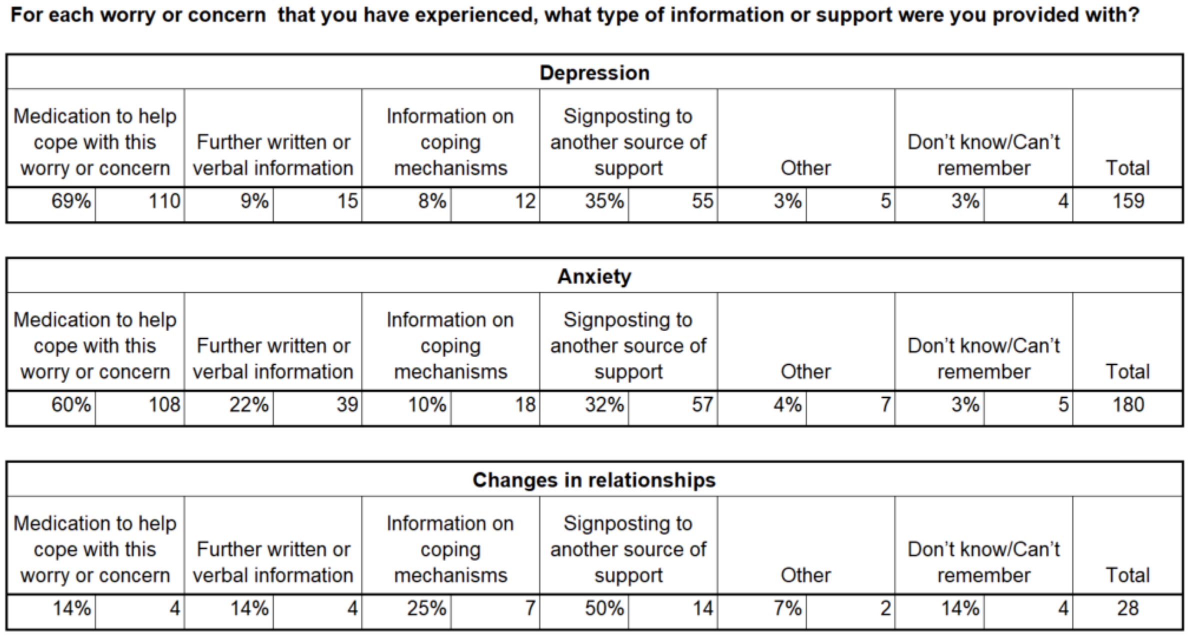
Figure 41: For each worry or concern that you discussed with your doctor, please indicate if the doctor was able to help?



A larger proportion of males reported that the doctor was not able to help with their depression (23%), compared to females (13%).

For those who experienced depression and those experiencing anxiety, the majority (69% and 60% respectively) were given medication to help them cope. Half of those who reported changes in relationships were signposted to another source of support (50%), see Table 8.

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



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

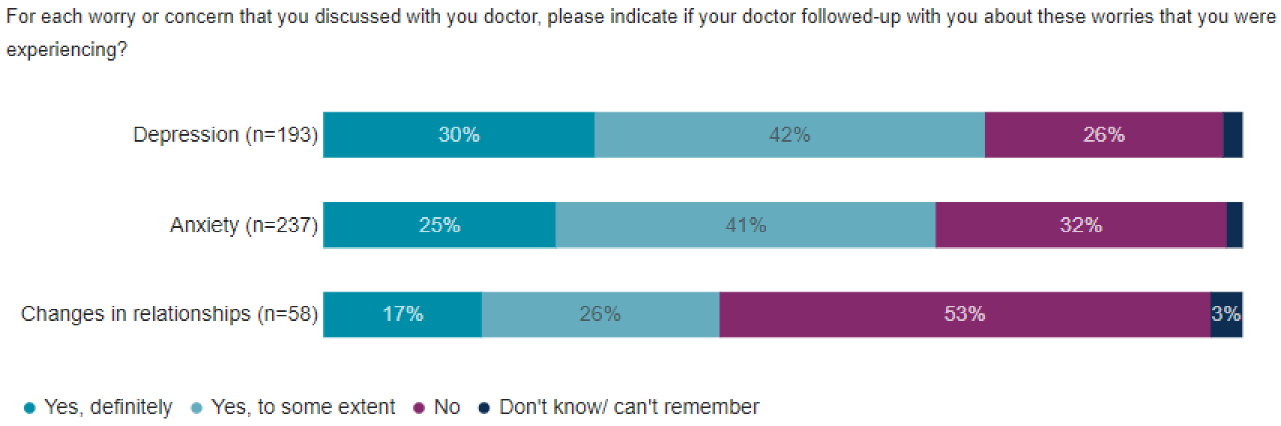
Depression												
Medication to help cope with this worry or concern		Further written or verbal information		Information on coping mechanisms		Signposting to another source of support		Other		Don't know/Can't remember		Total
69%	110	9%	15	8%	12	35%	55	3%	5	3%	4	159

Anxiety												
Medication to help cope with this worry or concern		Further written or verbal information		Information on coping mechanisms		Signposting to another source of support		Other		Don't know/Can't remember		Total
60%	108	22%	39	10%	18	32%	57	4%	7	3%	5	180

Changes in relationships												
Medication to help cope with this worry or concern		Further written or verbal information		Information on coping mechanisms		Signposting to another source of support		Other		Don't know/Can't remember		Total
14%	4	14%	4	25%	7	50%	14	7%	2	14%	4	28

Of those who discussed these psychosocial issues with their doctor, 43% reported their doctor definitely or to some extent followed up with them about their changes in relationships, compared to 67% for those experiencing anxiety, and 72% for depression. Over half (53%) of those who discussed changes in relationships with their doctor said their doctor did not follow up – see Figure 42.

Figure 42: For each worry or concern that you discussed with you doctor, please indicate if your doctor followed-up with you about these worries that you were experiencing?

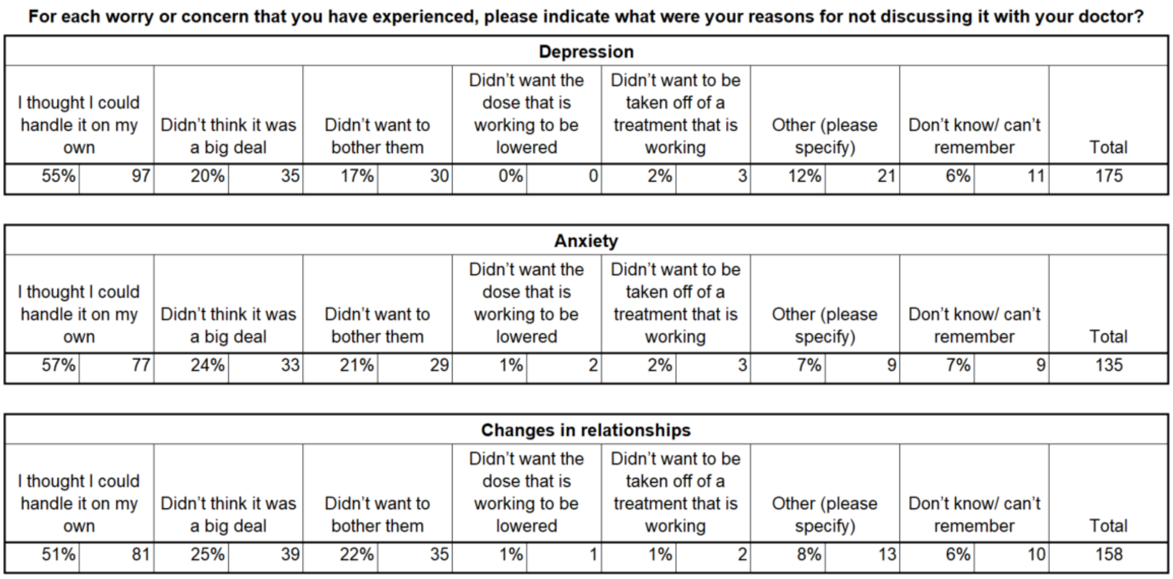


Of those who reported not discussing psychosocial worries or concerns with their doctor, the main reasons reported (see Table 9) were:

- They thought they could handle it on their own (51%, 57% and 55% for those experiencing changes in relationships, anxiety and depression respectively)
- They did not think it was a big deal (35%, 24%, 20% respectively for those experiencing changes in relationships, anxiety and depression)

- They did not want to bother the doctor (22%, 21% and 17% respectively for changes in relationships, anxiety and depression)

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



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

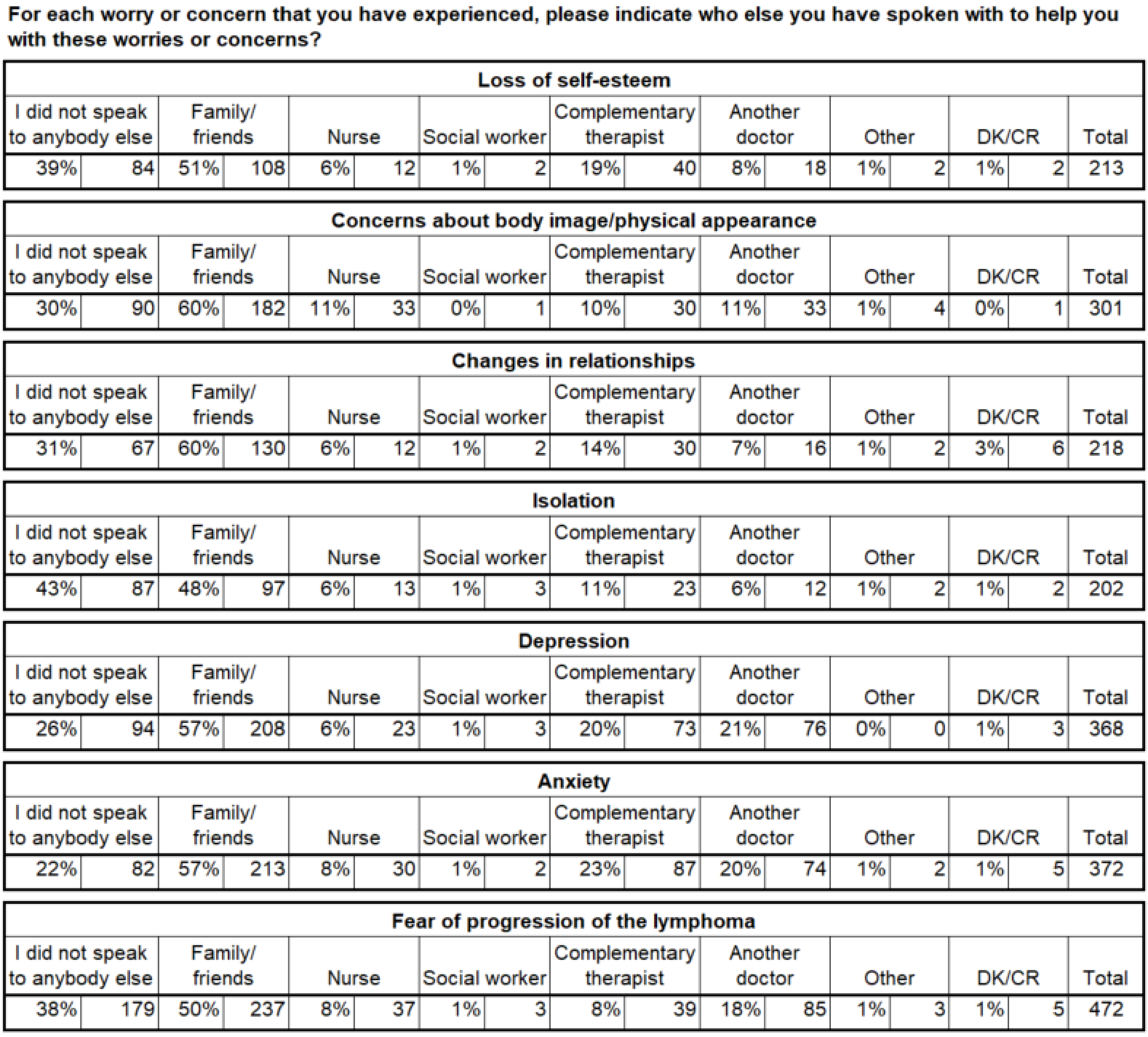
Depression														
I thought I could handle it on my own		Didn't think it was a big deal		Didn't want to bother them		Didn't want the dose that is working to be lowered		Didn't want to be taken off of a treatment that is working		Other (please specify)		Don't know/ can't remember		Total
55%	97	20%	35	17%	30	0%	0	2%	3	12%	21	6%	11	175

Anxiety														
I thought I could handle it on my own		Didn't think it was a big deal		Didn't want to bother them		Didn't want the dose that is working to be lowered		Didn't want to be taken off of a treatment that is working		Other (please specify)		Don't know/ can't remember		Total
57%	77	24%	33	21%	29	1%	2	2%	3	7%	9	7%	9	135

Changes in relationships														
I thought I could handle it on my own		Didn't think it was a big deal		Didn't want to bother them		Didn't want the dose that is working to be lowered		Didn't want to be taken off of a treatment that is working		Other (please specify)		Don't know/ can't remember		Total
51%	81	25%	39	22%	35	1%	1	1%	2	8%	13	6%	10	158

When asked who else they had spoken to regarding their worries or concerns, in most cases, patients reported that they had spoken with their family and friends for help. See Table 10 below for a breakdown of responses (for all psychosocial issues, 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?



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

Loss of self-esteem

I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
39%	84	51%	108	6%	12	1%	2	19%	40	8%	18	1%	2	1%	2	213

Concerns about body image/physical appearance

I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
30%	90	60%	182	11%	33	0%	1	10%	30	11%	33	1%	4	0%	1	301

Changes in relationships

I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
31%	67	60%	130	6%	12	1%	2	14%	30	7%	16	1%	2	3%	6	218

Isolation

I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
43%	87	48%	97	6%	13	1%	3	11%	23	6%	12	1%	2	1%	2	202

Depression

I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
26%	94	57%	208	6%	23	1%	3	20%	73	21%	76	0%	0	1%	3	368

Anxiety

I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
22%	82	57%	213	8%	30	1%	2	23%	87	20%	74	1%	2	1%	5	372

Fear of progression of the lymphoma

I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
38%	179	50%	237	8%	37	1%	3	8%	39	18%	85	1%	3	1%	5	472

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.

- Fear of cancer relapse was reported by 35% of patients and was the most commonly reported psychosocial side effect of lymphoma.
- Of those who discussed fear of relapse with their doctor, only 31% of patients reported their doctor was definitely able to help. Further, only 28% reported that the doctor definitely followed up about their fear of relapse.
- Almost half (45%) of patients who reported experiencing fear of relapse are not using any coping mechanisms to manage this issue.

In the LC 2020 Global Patient Survey, 35% of patients reported they experienced a fear of cancer relapse in the last 12 months, and 60% have discussed their fear of relapse with their doctor.

Of those who have discussed fear of relapse with their doctor, only 31% of patients reported their doctor was definitely able to help, with a further 48% agreeing to some extent (Figure 43).

Figure 43: For your fear of relapse that you discussed with your doctor, please indicate if the doctor was able to help?

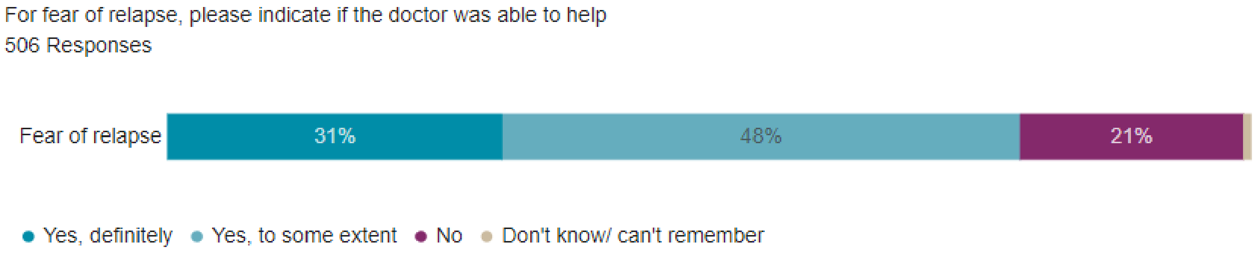
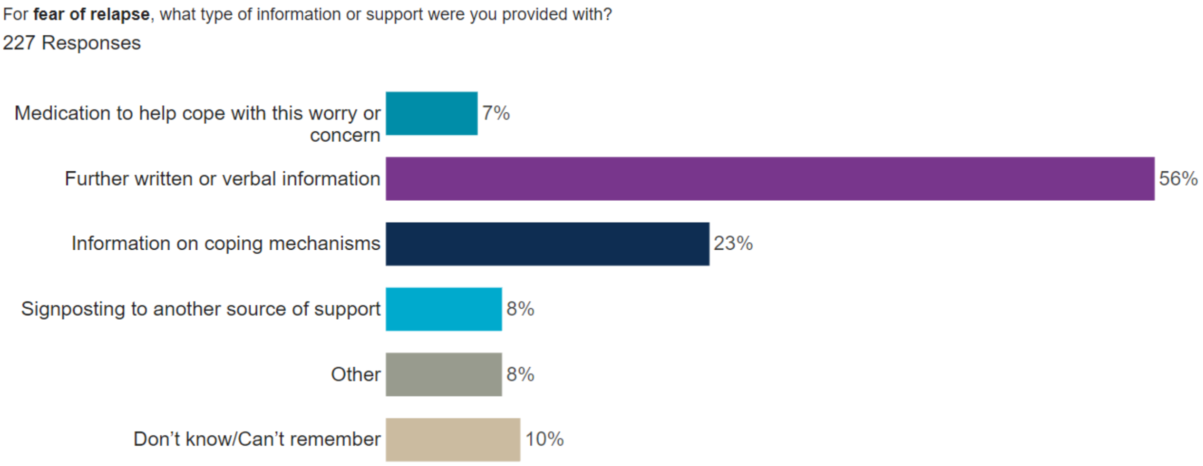


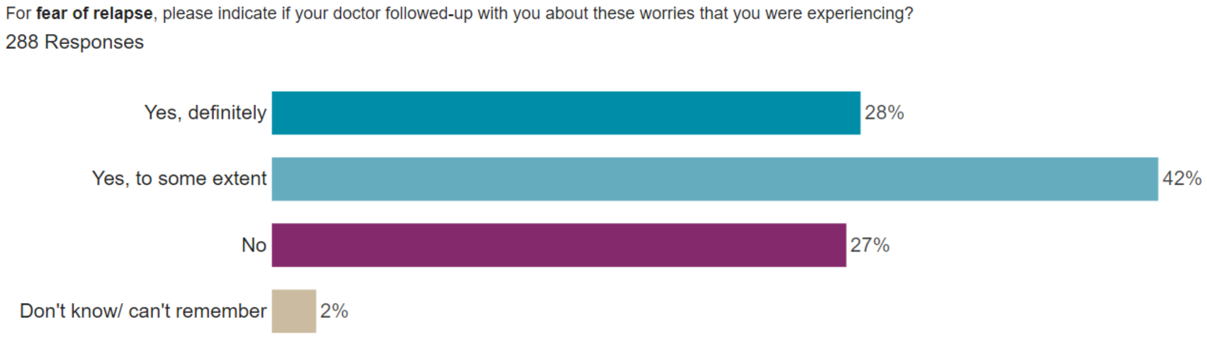
Figure 44 displays the type of information or support patients were provided with by their doctor to help with fear of relapse. Over half of patients (56%) reported that further written information or verbal information was provided.

Figure 44: What type of information or support were you provided with for your fear of relapse?



Only 28% of patients who discussed fear of relapse with their doctor reported that their doctor definitely followed up with them about their fear of relapse, and 27% said they did not follow up – see Figure 45.

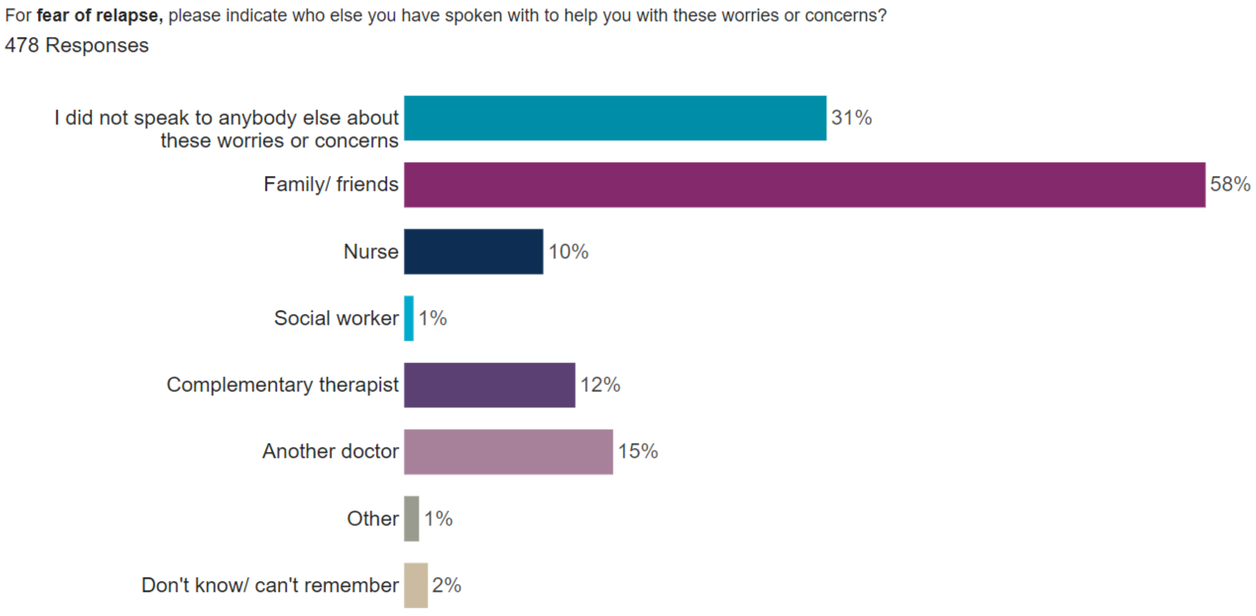
Figure 45: Please indicate if your doctor followed-up with you about your fear of relapse that you were experiencing?



Of those patients who did not discuss fear of relapse with their doctor, 42% reported this was because they thought they could handle it on their own, 16% did not think it was a big deal and 16% did not want to bother the doctor.

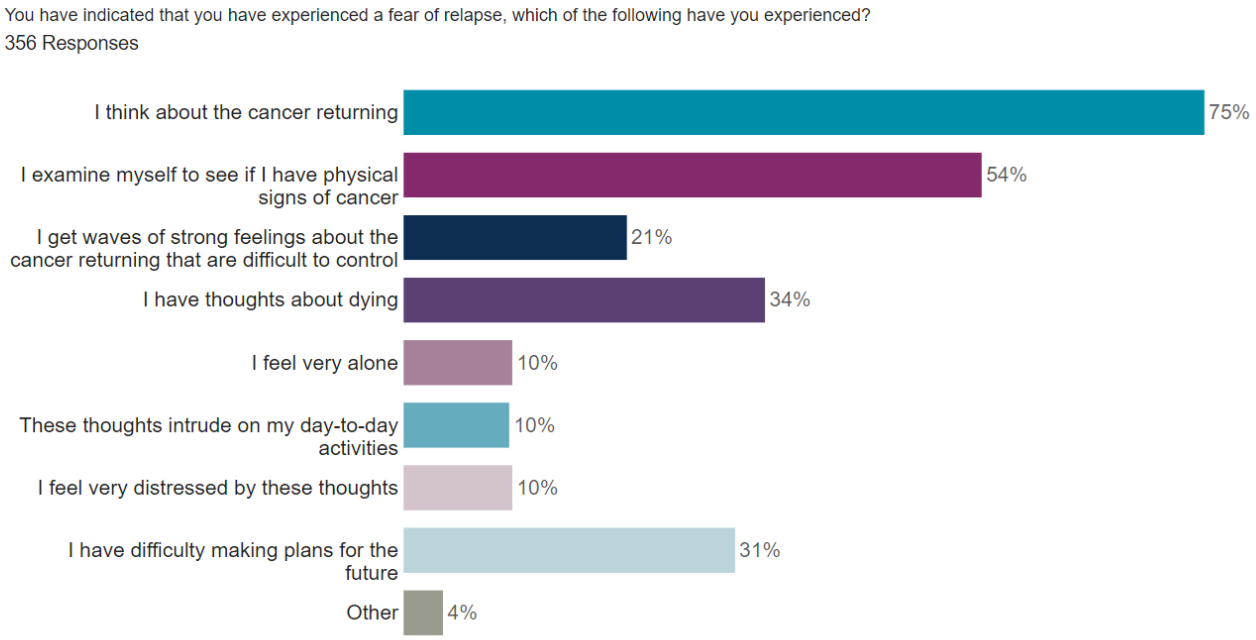
The majority of patients (58%) reported they have also spoken to family and friends about their fear of relapse, whereas 31% reported they had not spoken to anyone else, see Figure 46 for full results.

Figure 46: For fear of relapse, please indicate who else you have spoken with to help you with these worries or concerns?



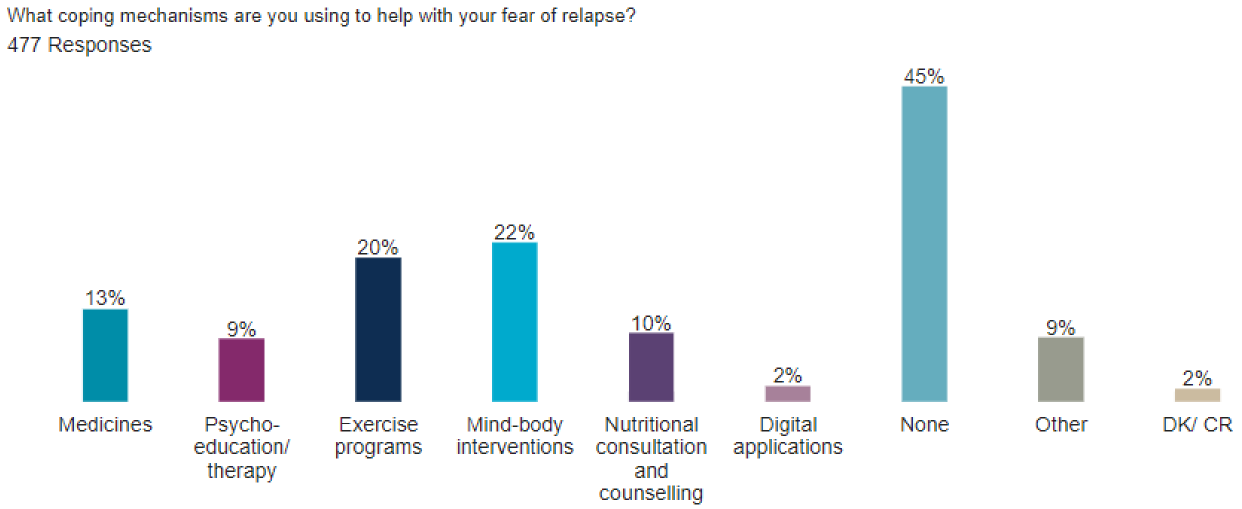
75% of patients who reported experiencing fear of relapse also reported that they think about the cancer returning, and 54% examine themselves to see if they have physical signs of cancer. Almost a third (31%) of patients have difficulty making plans for the future because of their fear of relapse – see Figure 47.

Figure 47: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?



45% of patients reported that they are not using any coping mechanisms to help with their fear of relapse. 22% reported they are using mind body interventions such as yoga. See Figure 48.

Figure 48: What coping mechanisms are you using to help with your fear of relapse?



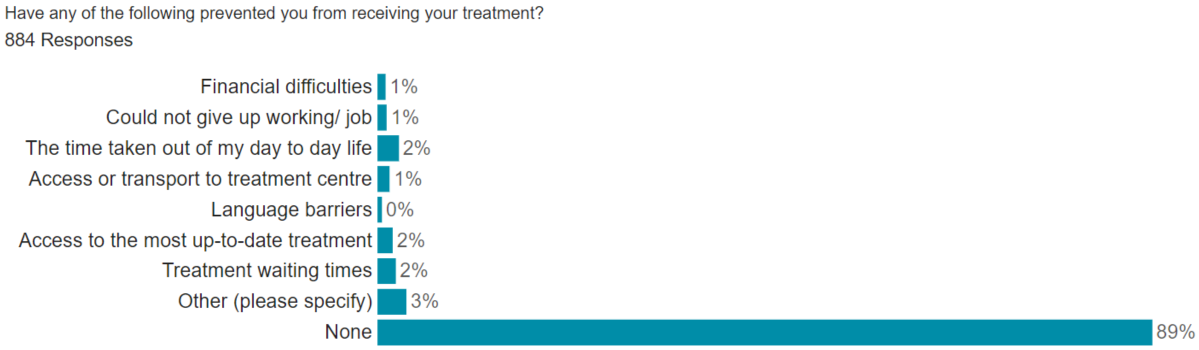
Barriers to Treatment

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.

- When asked to select from a list of potential barriers to treatment, 89% of patients selected "none".
- 65% of patients found they have never been presented with an opportunity to take part as a barrier to being in a clinical trial.

When asked to select from a list of potential barriers to treatment (see Figure 49), 89% of patients selected "none", and 2% of patients reported they were prevented from receiving treatment by treatment waiting times.

Figure 49: Have any of the following prevented you from receiving treatment?



65% of patients reported they have never been presented with an opportunity to take part in a clinical trial.

Results II. Caregiver Survey

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

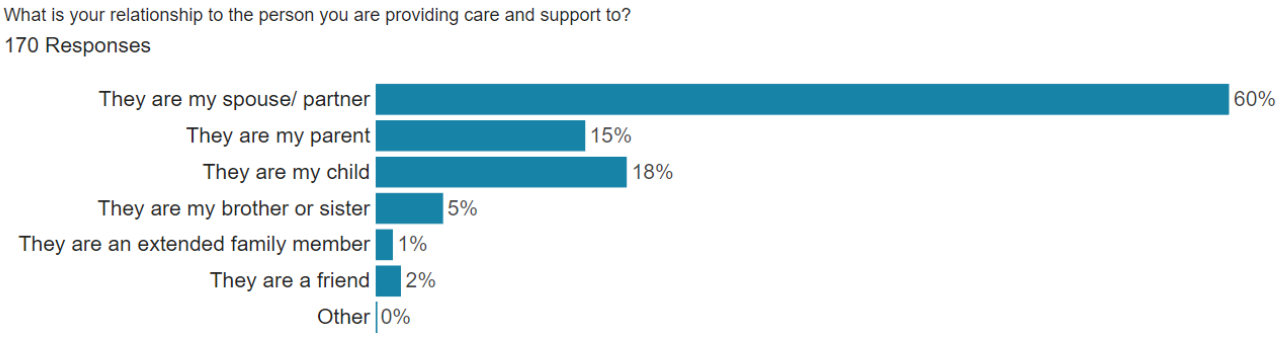
170 was the total number of people caring for somebody living with lymphoma/CLL that responded to the survey. The results in this section will be reported across the following areas:

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

Caregiver Demographics

Caregivers were asked to identify their relationship to the person they are providing care and support to, 60% of caregivers are a spouse/partner, and 18% are caring for their child. Figure 50 displays the full results.

Figure 50: What is your relationship to the person you are providing care and support to?



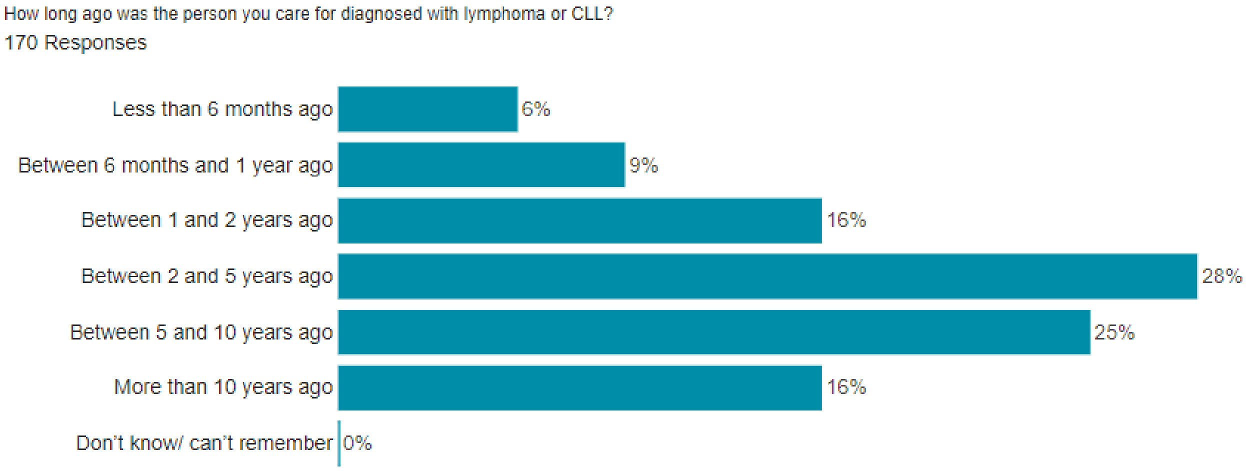
34% of caregivers use the term 'caregiver' when thinking about themselves and the care/support they provide.

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

- 89% responded emotional support – talking and listening
- 83% said accompanying the patient to appointments
- 63% responded looking for information

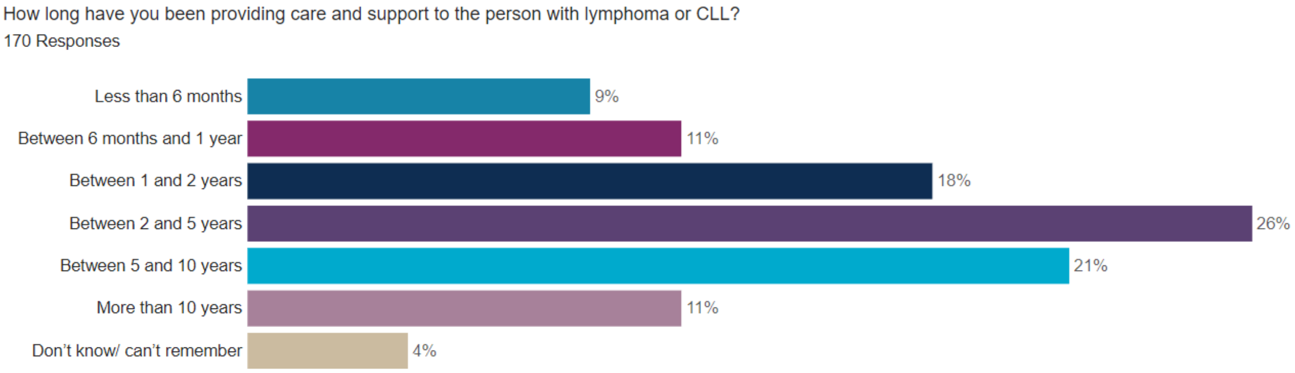
Caregivers were asked how long ago the person they provide care for was diagnosed, with the majority (69%) providing care for someone who was diagnosed over two years ago. Figure 51 displays the full results.

Figure 51: Length of time since diagnosis



Only 20% of caregivers have only been providing care and support for a year or less, see Figure 52 below:

Figure 52: How long have you been providing care and support to the person with lymphoma or CLL?



The main three lymphoma subtypes of the patients that caregivers are providing care and support are CLL/SLL (22%), DLBCL (not told specific type) (14%) and Hodgkin lymphoma (14%). Figure 53 displays the lymphoma subtype for all patients who caregivers are supporting.

Figure 53: What subtype of lymphoma/CLL does/did the person you care for have?

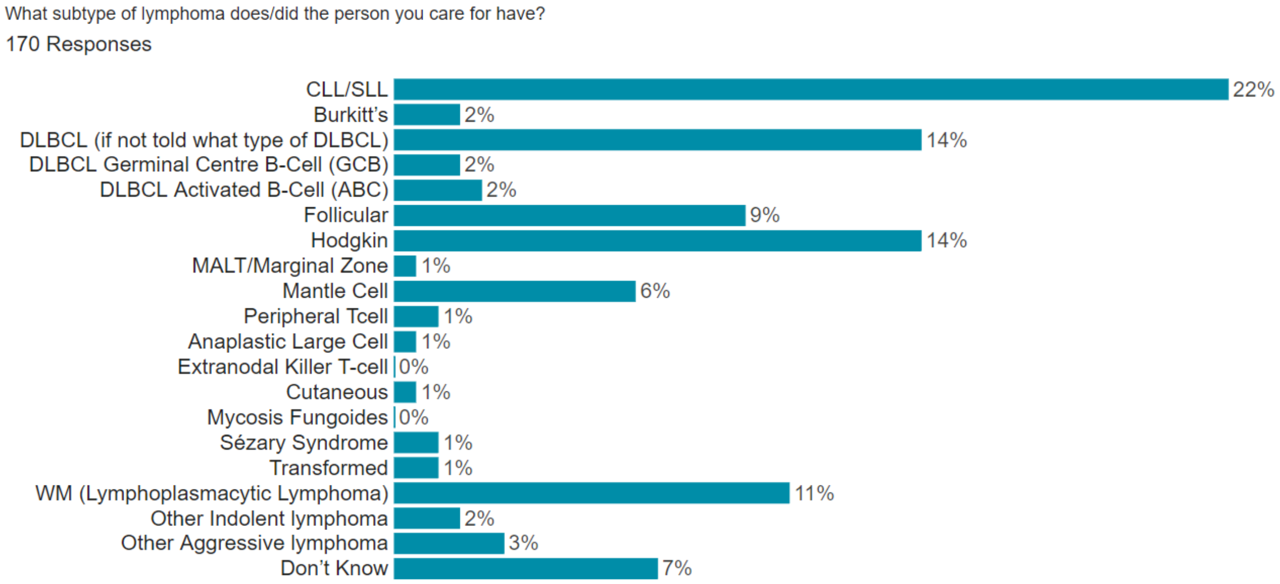
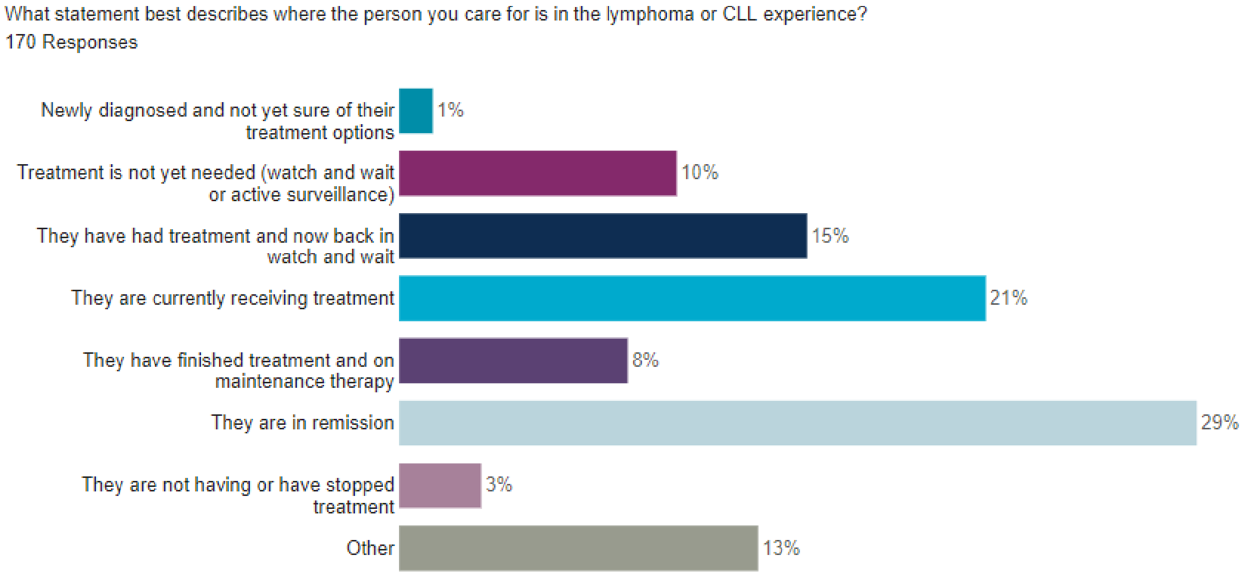


Figure 54 displays the stage of the care pathway of the patients the caregivers are providing care and support for. 29% of all caregivers are supporting somebody currently in remission, and 21% are supporting somebody currently receiving treatment.

Figure 54: What statement best describes where the person you care for is in the lymphoma or CLL experience?



Of those caregivers who reported the person they care for is in remission, over half of caregivers (53%) said they have been in remission for less than two years, and 22% for more than five years.

For caregivers of patients in watch and wait, 41% reported they have been in watch and wait for less than two years.

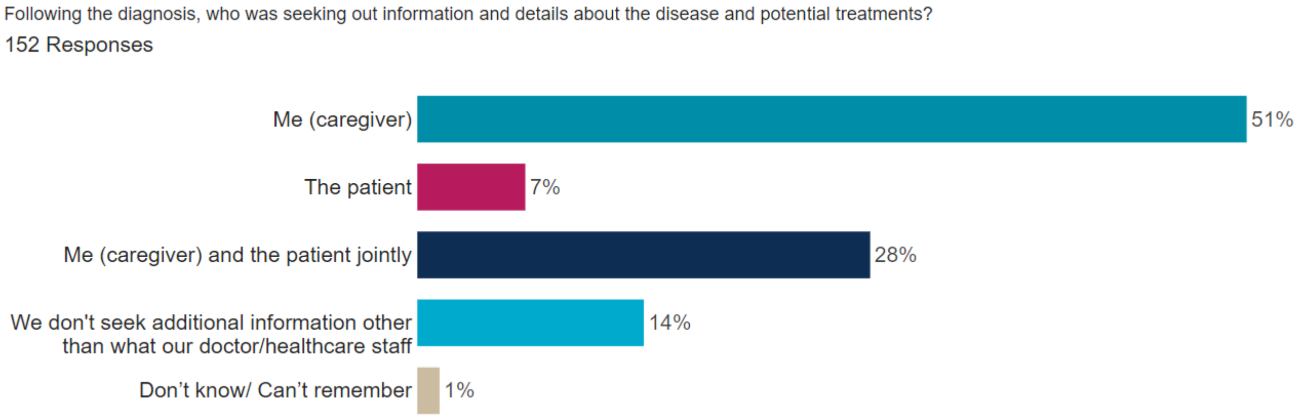
31% of caregivers reported the lymphoma/CLL of the person they care for has relapsed, and 11% reported it has transformed.

Caregiver Information, Guidance and Support

- 73% of caregivers reported 'doctor' as their top place to go for information.
- 51% of caregivers are the ones seeking out information and details about the patient's disease and potential treatments.
- 39% of caregivers said they definitely felt assisted/supported and understood by their family and friends, and 48% felt satisfied with the information received by healthcare staff.

Figure 55 indicates who was seeking out information and details about the disease and potential treatments (the patient with lymphoma, the caregiver, or both). The majority (51%) reported that they were the ones who sought information, and 28% stated that it was both them and the patient who sought information together.

Figure 55: Following the diagnosis, who was seeking out information and details about the disease and potential treatments?



When asked about the top three places they go for information, 73% of caregivers said ‘doctor’ was their top choice (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.
152 Responses

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

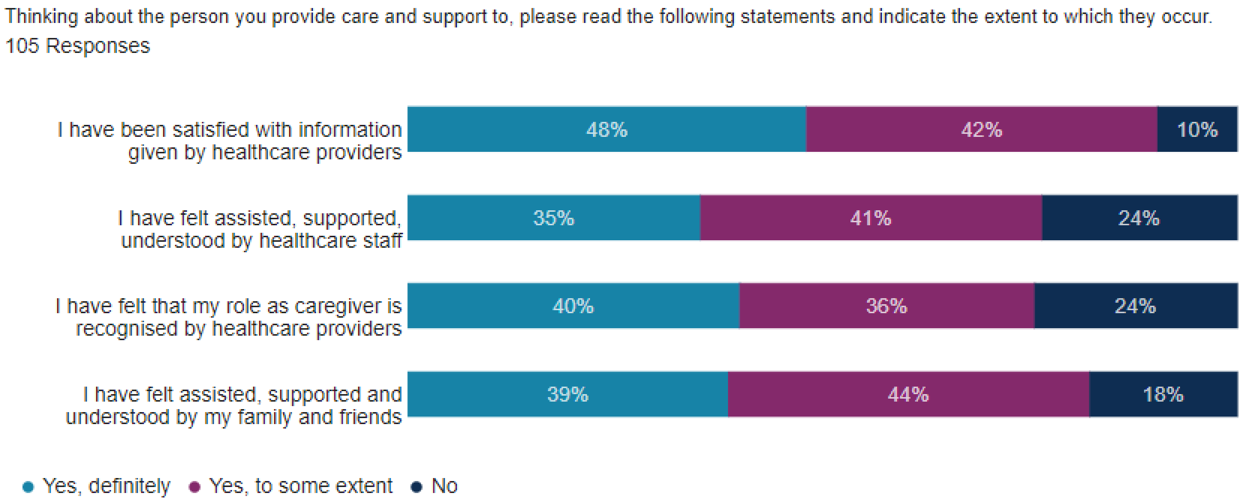
	1		2		3	
Doctor	73%	111	14%	19	14%	15
Nurse	3%	4	21%	30	8%	8
Websites	14%	21	30%	42	30%	31
Online blogs/social media	2%	3	7%	10	12%	12
Family/friends	1%	1	5%	7	6%	6
Patient organisation	8%	12	21%	29	26%	27
Other	0%	0	2%	3	5%	5
Total	100%	152	100%	140	100%	104

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

- 61% said less than six months ago;
- 13% said between six months and one year ago;
- 12% said more than one year ago.

Caregivers who had seen a healthcare provider with/for the person they provide care for anytime in the last year were asked to think about how supported and recognised they felt in their caregiving role – see Figure 56. Over a third of caregivers (39%) report they definitely felt assisted/ supported and understood by their family and friends, and 48% definitely feel satisfied with information given by healthcare providers.

Figure 56: Thinking about the person you provide care and support to, please read the following statements and indicate the extent to which they occur.

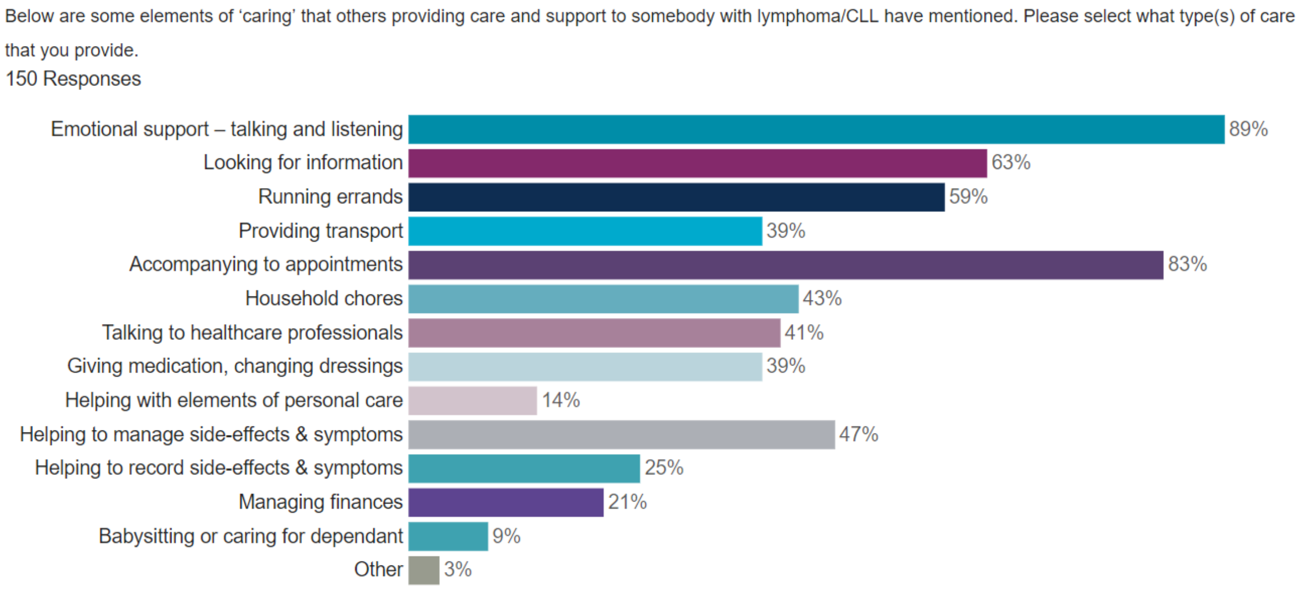


Impact of Caregiving

- Caregivers were asked which type of care and support they find the hardest to provide: 71% reported emotional support; and 7% reported financial support.
- Fear of cancer relapse (79%), putting the patient needs above their own (76%) and being worried or anxious (70%) were the most common issues often or always affecting caregivers in the last 12 months.
- Of those who experienced fear of cancer relapse, almost half (49%) reported having difficulties planning for the future as a result.
- 44% of caregivers said that the impact on their life is less when the person they provide care and support for is off treatment.

Caregivers were asked to think about the different aspects of the care and support that they provide to somebody with lymphoma/CLL. Providing emotional support (89%) and accompanying patients to appointments (83%) were the most commonly reported aspects. Figure 57 displays the results for all types of care provided by the caregivers who responded.

Figure 57: 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

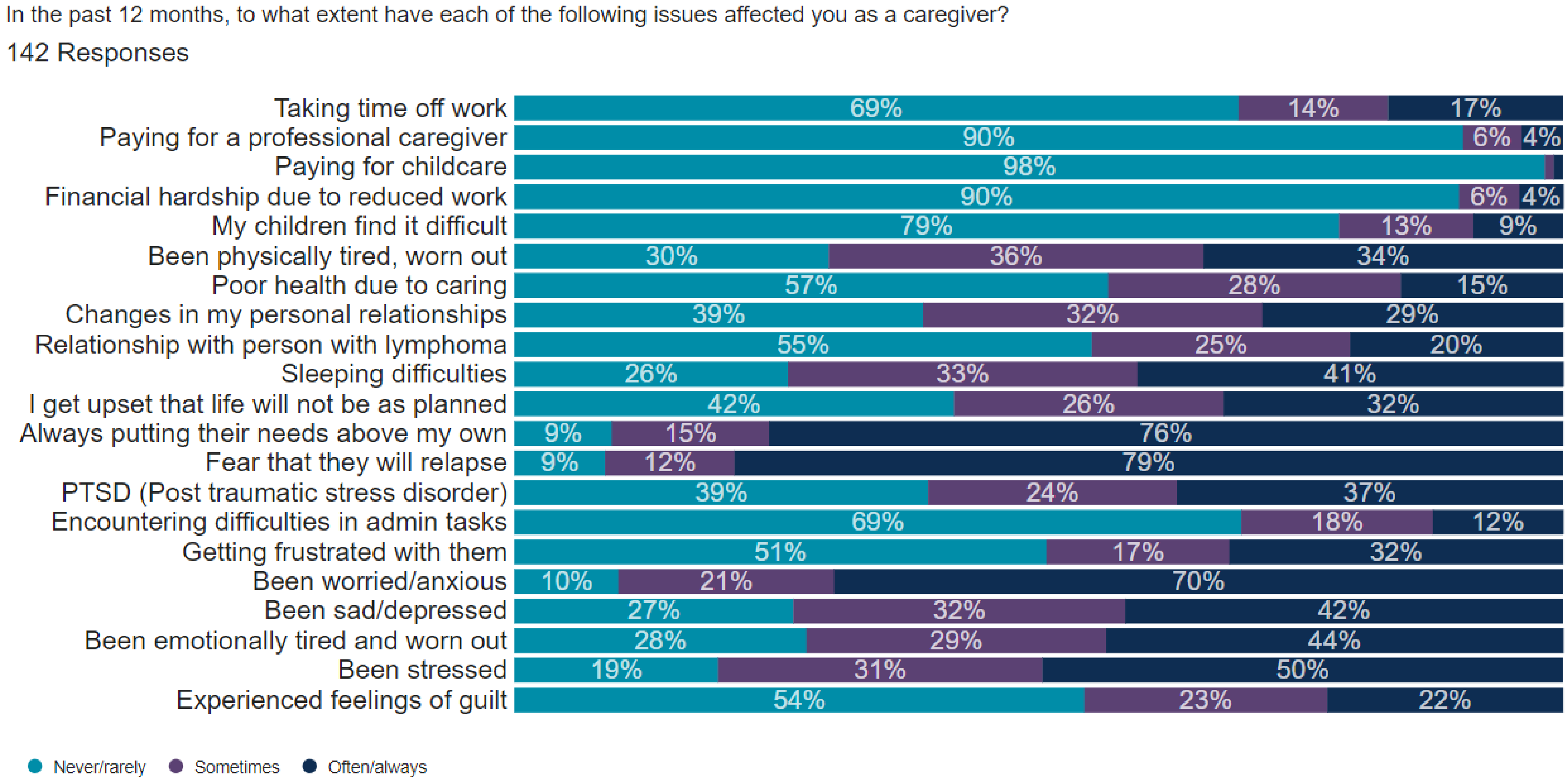


Caregivers were asked which type of care and support they find the hardest to provide:

- 71% reported emotional support
- 7% reported financial support

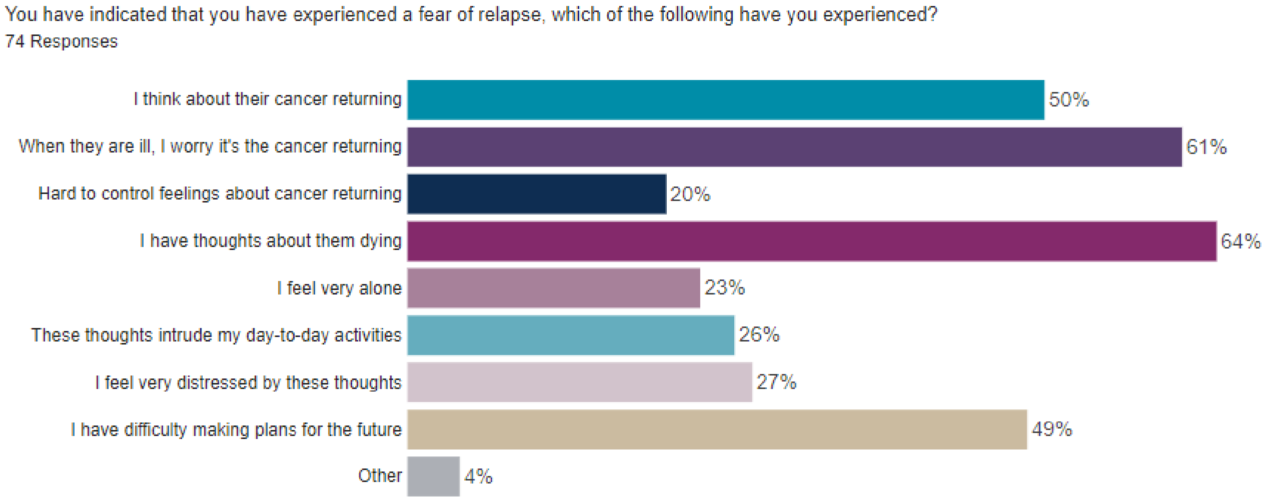
Figure 58 displays the extent to which various issues have affected caregivers in the past 12 months. Fear of cancer relapse (79%), putting the patient needs above their own (76%) and being worried or anxious (70%) were the most common issues often or always affecting caregivers.

Figure 58: In the past 12 months, to what extent do each of the following issues affect you as a caregiver?



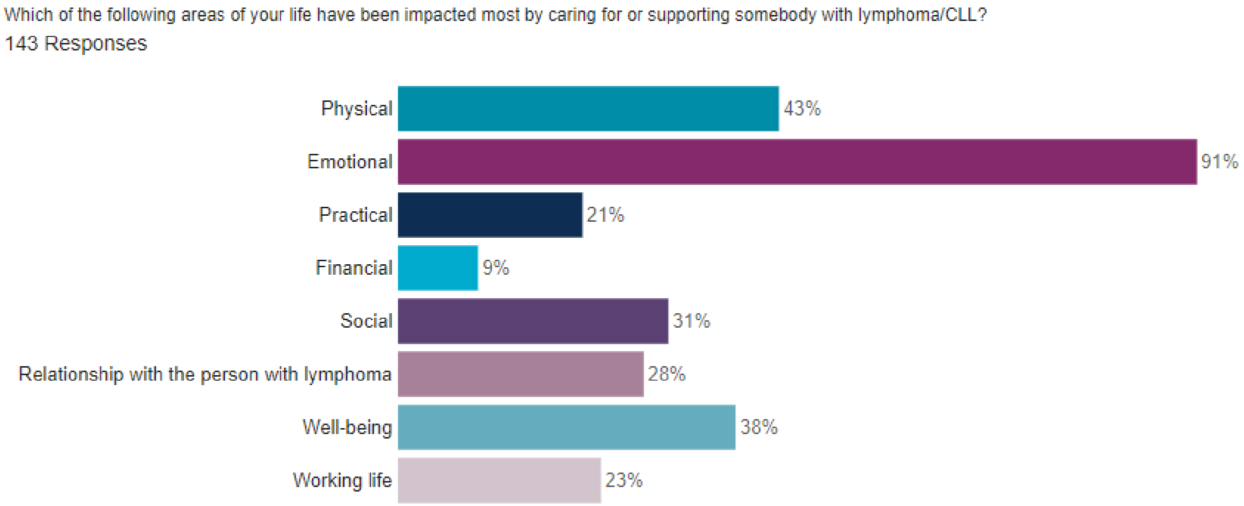
79% of caregivers reported they are often or always affected by fear of cancer relapse. Regarding their fear of relapse, 64% of caregivers reported they have experienced thoughts about the patient dying, and 61% worry the patient's cancer is returning every time they feel unwell. Almost half (49%) have difficulties making plans for the future because of their fear of relapse- a full list of worries can be seen below in Figure 59.

Figure 59: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?



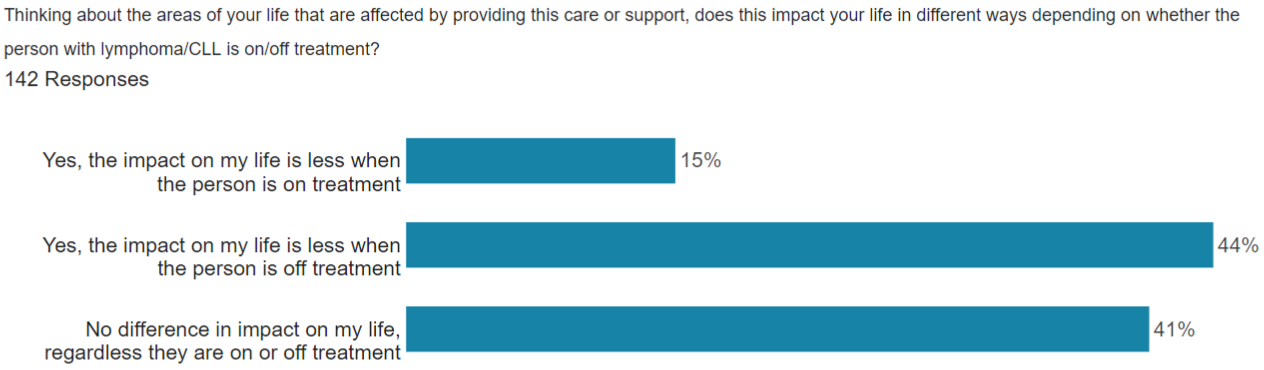
When asked which areas of their lives have been most impacted by caring or supporting somebody with lymphoma/CLL, the area of life most selected by caregivers was "emotional" (91%) – see Figure 60.

Figure 60: Which of the following areas of your life have been impacted most by caring for or supporting somebody with lymphoma/CLL?



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 61). 44% indicated that the impact on their life is lesser when the person is off treatment.

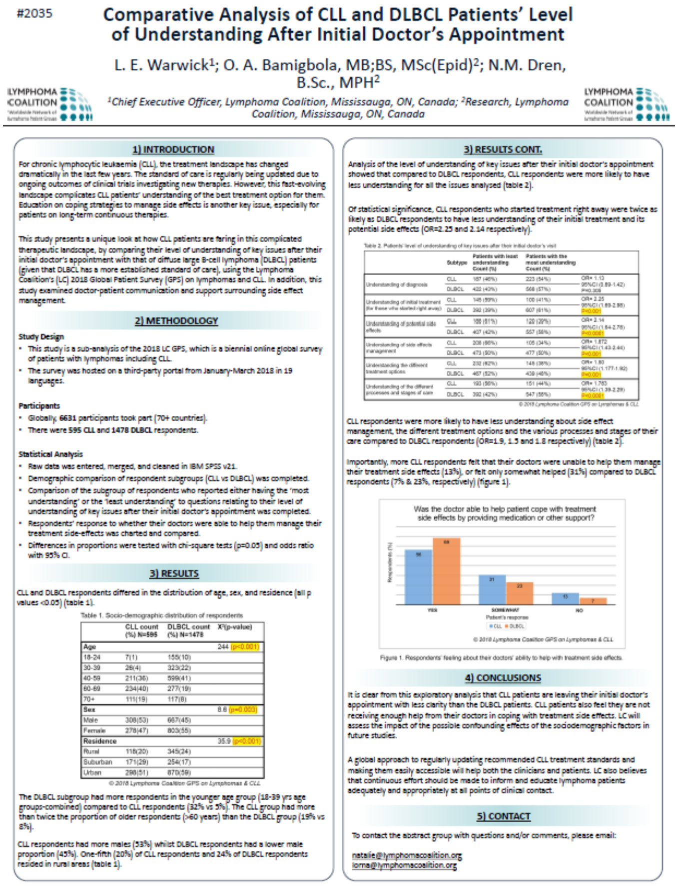
Figure 61: Thinking about the areas of your life that are affected by providing this care or support, does this impact your life in different ways depending on whether the person with lymphoma/CLL is on/off treatment?



Appendix

Appendix 1

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



#2035

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

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1) INTRODUCTION

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

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

2) METHODOLOGY

Study Design

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

Participants

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

Statistical Analysis

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

3) RESULTS

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

Table 1. Socio-demographic distribution of respondents

	CLL count (%) N=595	DLBCL count (%) N=1478	X^2(p-value)
Age			244 (p<0.001)
18-24	7(1)	155(10)	
30-39	26(4)	323(22)	
40-59	211(36)	599(41)	
60-69	234(40)	277(19)	
70+	111(19)	117(8)	
Sex			8.6 (p=0.003)
Male	308(53)	667(45)	
Female	278(47)	803(55)	
Residence			35.9 (p<0.001)
Rural	118(20)	345(24)	
Suburban	171(29)	254(17)	
Urban	298(51)	870(59)	

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The DLBCL subgroup had more respondents in the younger age group (18-39 yrs age groups-combined) compared to CLL respondents (32% vs 5%). The CLL group had more than twice the proportion of older respondents (>60 years) than the DLBCL group (19% vs 8%).

CLL respondents had more males (53%) whilst DLBCL respondents had a lower male proportion (45%). One-fifth (20%) of CLL respondents and 24% of DLBCL respondents resided in rural areas (table 1).

3) RESULTS CONT.

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

Of statistical significance, CLL respondents who started treatment right away were twice as likely as DLBCL respondents to have less understanding of their initial treatment and its potential side effects (OR=2.25 and 2.14 respectively).

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

	Subtype	Patients with least understanding Count (%)	Patients with the most understanding Count (%)	
Understanding of diagnosis	CLL	187 (46%)	223 (54%)	OR= 1.13 95%CI (0.89-1.42) P=0.308
	DLBCL	422 (43%)	568 (57%)	
Understanding of initial treatment (for those who started right away)	CLL	145 (59%)	100 (41%)	OR= 2.25 95%CI (1.69-2.98) P<0.001
	DLBCL	392 (39%)	607 (61%)	
Understanding of potential side effects	CLL	188 (61%)	120 (39%)	OR= 2.14 95%CI (1.64-2.78) P<0.0001
	DLBCL	407 (42%)	557 (58%)	
Understanding of side effects management	CLL	208 (66%)	105 (34%)	OR= 1.872 95%CI (1.43-2.44) P<0.001
	DLBCL	473 (50%)	477 (50%)	
Understanding the different treatment options	CLL	232 (62%)	148 (38%)	OR= 1.50 95%CI (1.177-1.92) P<0.001
	DLBCL	467 (52%)	439 (48%)	
Understanding of the different processes and stages of care	CLL	193 (56%)	151 (44%)	OR= 1.783 95%CI (1.39-2.29) P<0.0001
	DLBCL	392 (42%)	547 (58%)	

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

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

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

4) CONCLUSIONS

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

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

5) CONTACT

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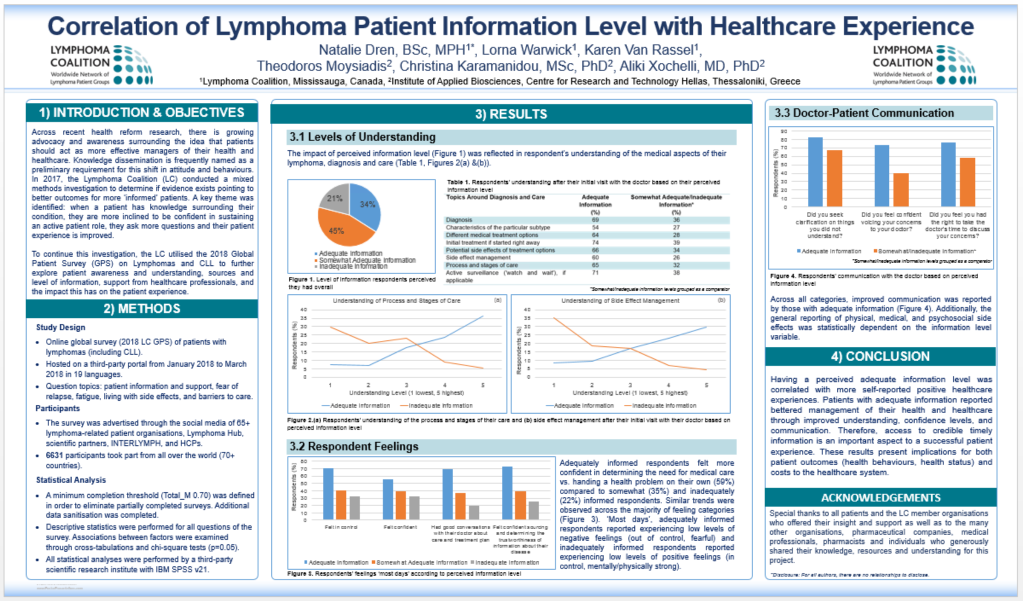

Correlation of Lymphoma Patient Information Level with Healthcare Experience

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1) INTRODUCTION & OBJECTIVES

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

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

2) METHODS

Study Design

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

Participants

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

Statistical Analysis

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

3) RESULTS

3.1 Levels of Understanding

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

Figure 1. Level of information respondents perceived they had overall

Table 1. Respondents' understanding after their initial visit with the doctor based on their perceived information level

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

**Somewhat/inadequate information levels grouped as a comparator*

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

3.2 Respondent Feelings

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

Adequately informed respondents felt more confident in determining the need for medical care vs. handing a health problem on their own (59%) compared to somewhat (35%) and inadequately (22%) informed respondents. Similar trends were observed across the majority of feeling categories (Figure 3). 'Most days', adequately informed respondents reported experiencing low levels of negative feelings (out of control, fearful) and inadequately informed respondents reported experiencing low levels of positive feelings (in control, mentally/physically strong).

3.3 Doctor-Patient Communication

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

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

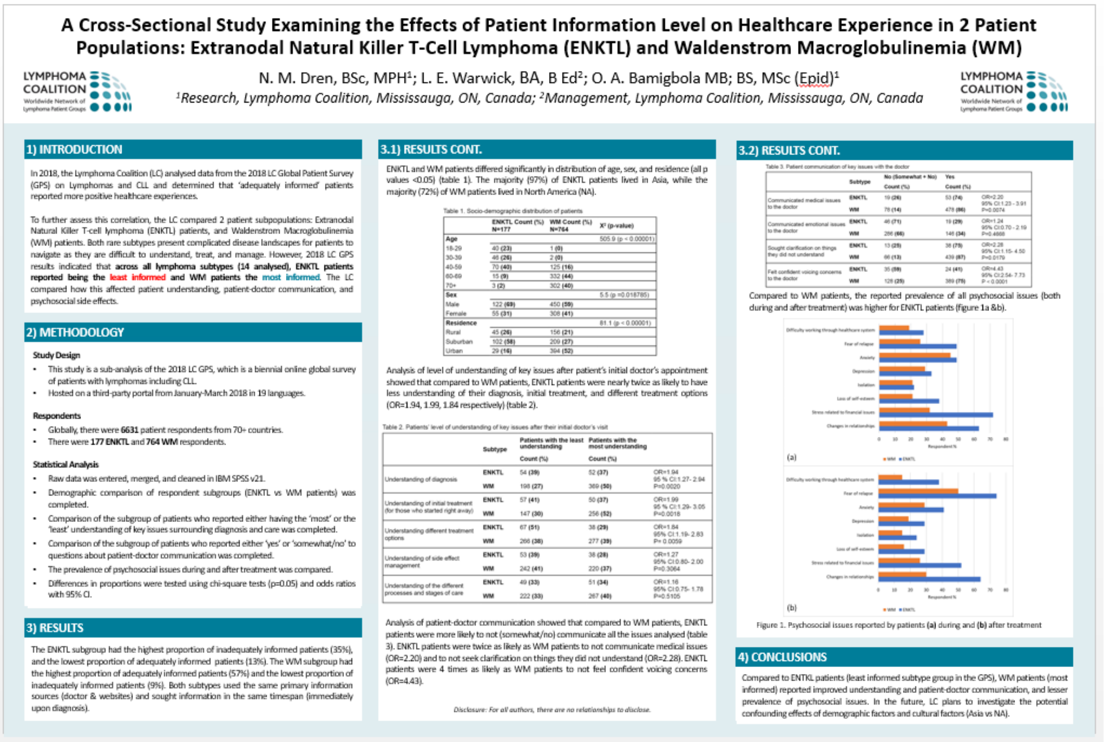
4) CONCLUSION

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

ACKNOWLEDGEMENTS

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

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



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

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1) INTRODUCTION

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

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

2) METHODOLOGY

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

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

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

3) RESULTS

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

3.1) RESULTS CONT.

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

Table 1. Socio-demographic distribution of patients

	ENKTL Count (%) N=177	WM Count (%) N=764	X^2 (p-value)
Age			505.9 (p < 0.00001)
18-29	40 **(23)**	1 **(0)**	
30-39	46 **(26)**	2 **(0)**	
40-59	70 **(40)**	125 **(16)**	
60-69	15 **(9)**	332 **(44)**	
70+	3 **(2)**	302 **(40)**	
Sex			5.5 (p =0.018785)
Male	122 **(69)**	450 **(59)**	
Female	55 **(31)**	308 **(41)**	
Residence			81.1 (p < 0.00001)
Rural	45 **(26)**	156 **(21)**	
Suburban	102 **(58)**	209 **(27)**	
Urban	29 **(16)**	394 **(52)**	

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

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

	Subtype	Patients with the least understanding Count (%)	Patients with the most understanding Count (%)	
Understanding of diagnosis	**ENKTL**	54 **(39)**	52 **(37)**	OR=1.94 95 % CI:1.27- 2.94 P=0.0020
	WM	198 **(27)**	369 **(50)**	
Understanding of initial treatment (for those who started right away)	**ENKTL**	57 **(41)**	50 **(37)**	OR=1.99 95 % CI:1.29- 3.05 P=0.0018
	WM	147 **(30)**	256 **(52)**	
Understanding different treatment options	**ENKTL**	67 **(51)**	38 **(29)**	OR=1.84 95% CI:1.19- 2.83 P= 0.0059
	WM	266 **(38)**	277 **(39)**	
Understanding of side effect management	**ENKTL**	53 **(39)**	38 **(28)**	OR=1.27 95% CI:0.80- 2.00 P=0.3064
	WM	242 **(41)**	220 **(37)**	
Understanding of the different processes and stages of care	**ENKTL**	49 **(33)**	51 **(34)**	OR=1.16 95% CI:0.75- 1.78 P=0.5105
	WM	222 **(33)**	267 **(40)**	

Analysis of patient-doctor communication showed that compared to WM patients, ENKTL patients were more likely to not (somewhat/no) communicate all the issues analysed (table 3). ENKTL patients were twice as likely as WM patients to not communicate medical issues (OR=2.20) and to not seek clarification on things they did not understand (OR=2.28). ENKTL patients were 4 times as likely as WM patients to not feel confident voicing concerns (OR=4.43).

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

3.2) RESULTS CONT.

Table 3. Patient communication of key issues with the doctor

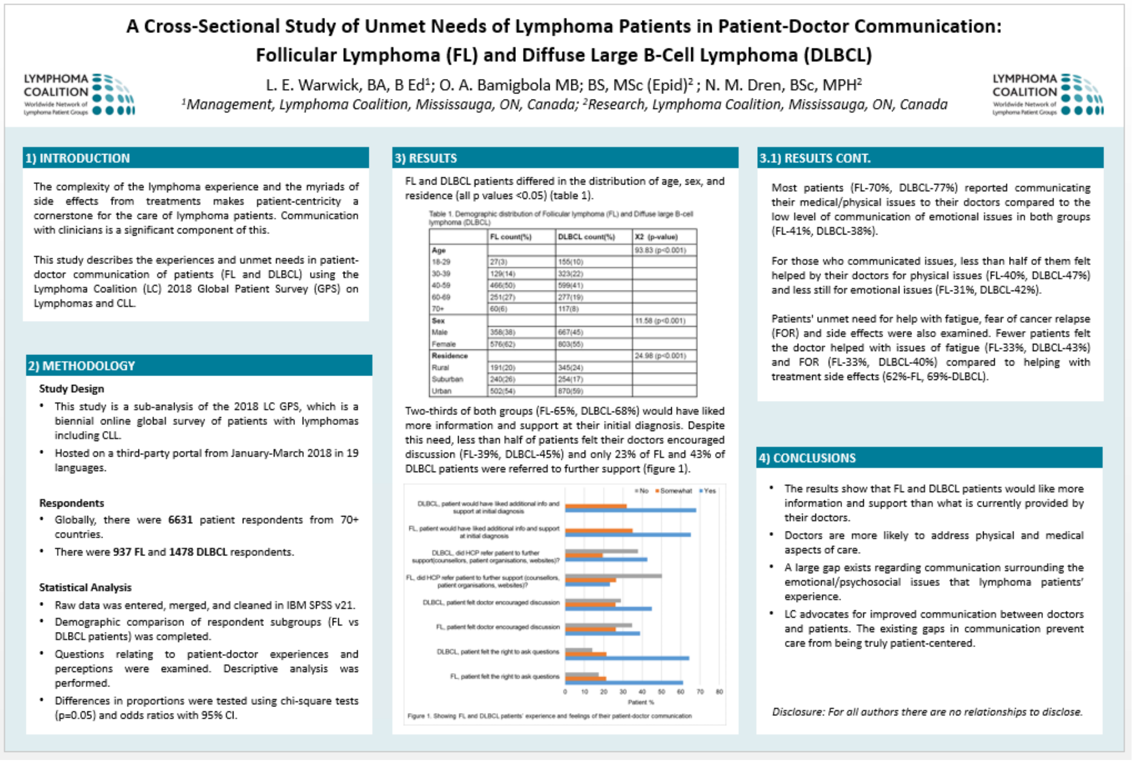
	Subtype	No (Somewhat + No) Count (%)	Yes Count (%)	
Communicated medical issues to the doctor	**ENKTL**	19 **(26)**	53 **(74)**	OR=2.20 95% CI:1.23 - 3.91 P=0.0074
	WM	78 **(14)**	478 **(86)**	
Communicated emotional issues to the doctor	**ENKTL**	46 **(71)**	19 **(29)**	OR=1.24 95% CI:0.70 - 2.19 P=0.4668
	WM	286 **(66)**	146 **(34)**	
Sought clarification on things they did not understand	**ENKTL**	13 **(25)**	38 **(75)**	OR=2.28 95% CI:1.15- 4.50 P=0.0179
	WM	66 **(13)**	439 **(87)**	
Felt confident voicing concerns to the doctor	**ENKTL**	35 **(59)**	24 **(41)**	OR=4.43 95% CI:2.54- 7.73 P < 0.0001
	WM	128 **(25)**	389 **(75)**	

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

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

4) CONCLUSIONS

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



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

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1) INTRODUCTION

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

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

2) METHODOLOGY

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

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

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

3) RESULTS

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

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

	FL count(%)	DLBCL count(%)	X2 (p-value)
Age			93.83 (p<0.001)
18-29	27(3)	155(10)	
30-39	129(14)	323(22)	
40-59	466(50)	599(41)	
60-69	251(27)	277(19)	
70+	60(6)	117(8)	
Sex			11.58 (p<0.001)
Male	358(38)	667(45)	
Female	576(62)	803(55)	
Residence			24.98 (p<0.001)
Rural	191(20)	345(24)	
Suburban	240(26)	254(17)	
Urban	502(54)	870(59)	

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

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

3.1) RESULTS CONT.

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

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

Patients' unmet need for help with fatigue, fear of cancer relapse (FOR) and side effects were also examined. Fewer patients felt the doctor helped with issues of fatigue (FL-33%, DLBCL-43%) and FOR (FL-33%, DLBCL-40%) compared to helping with treatment side effects (62%-FL, 69%-DLBCL).

4) CONCLUSIONS

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

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Appendix 2

Frequency tables – supplied separately.

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