Lymphoma Coalition

2020 Global Patient Survey on Lymphomas & CLL

A report prepared for Lymphoma Coalition
by Picker Institute Europe

July 2020

Country Report

Belgium

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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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 data for Belgium.

Overall number of completed responses 165 made up of:

147 Patients

18 Caregivers

Note: There is no analysis or reporting of the caregivers' data for Belgium, due to only 18 caregivers responding to the survey.

Demographics

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

Figure 1: Sex of patients

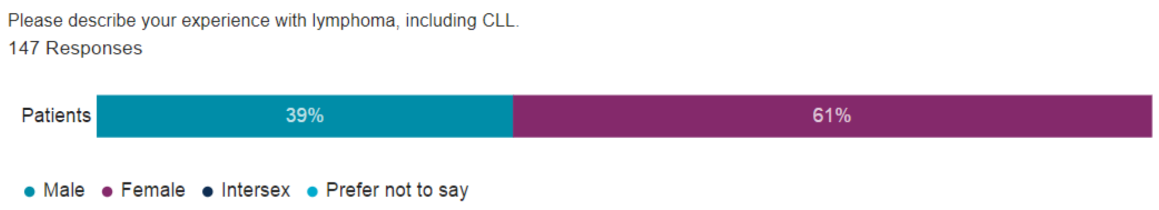


Figure 2: Gender of caregivers

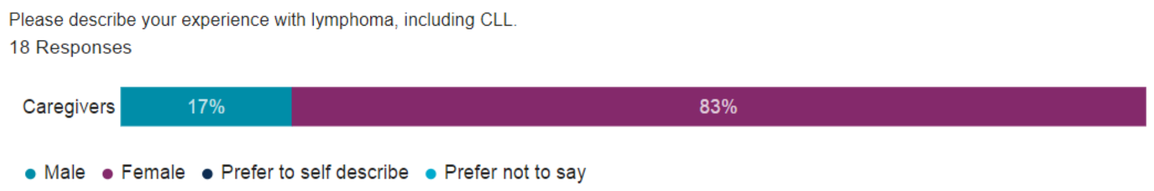


Figure 3: Age of patients and caregivers

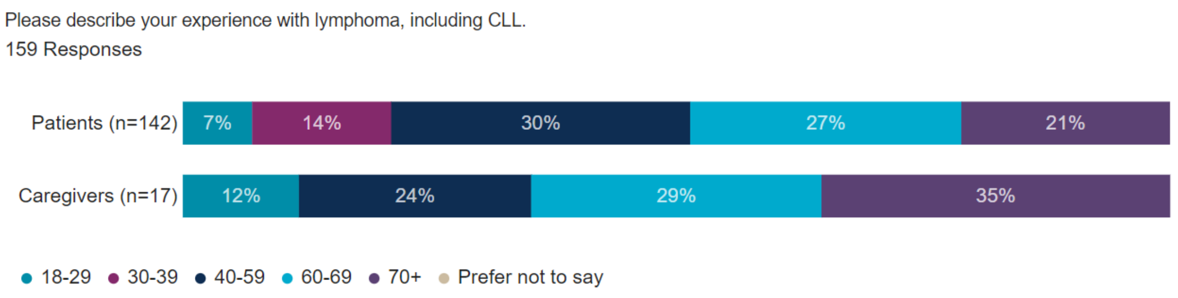
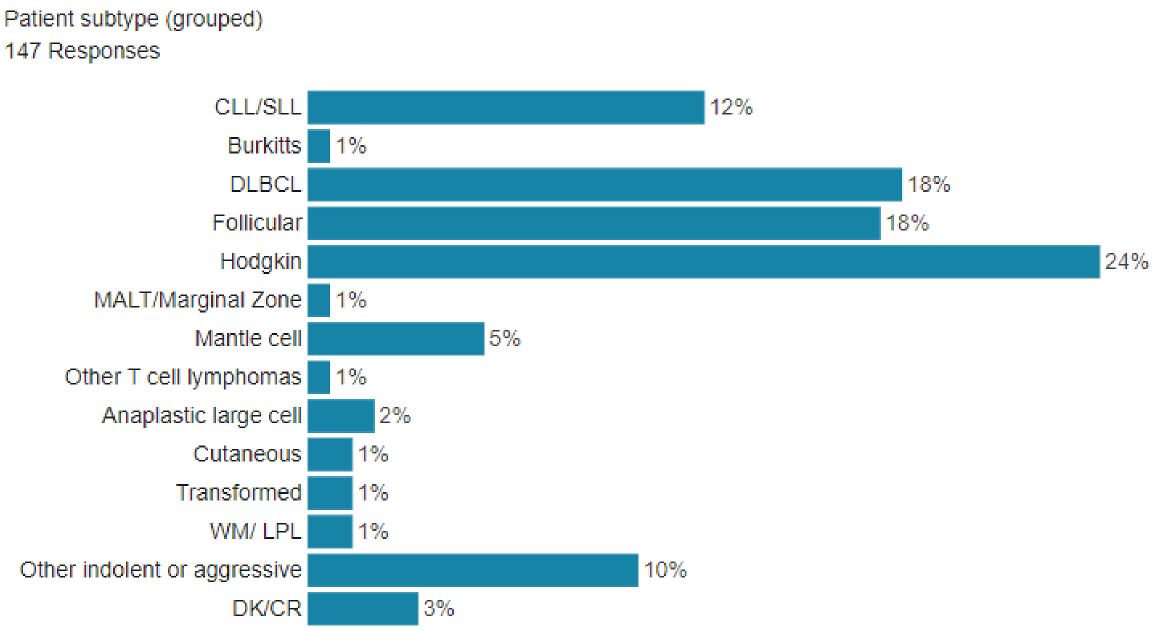
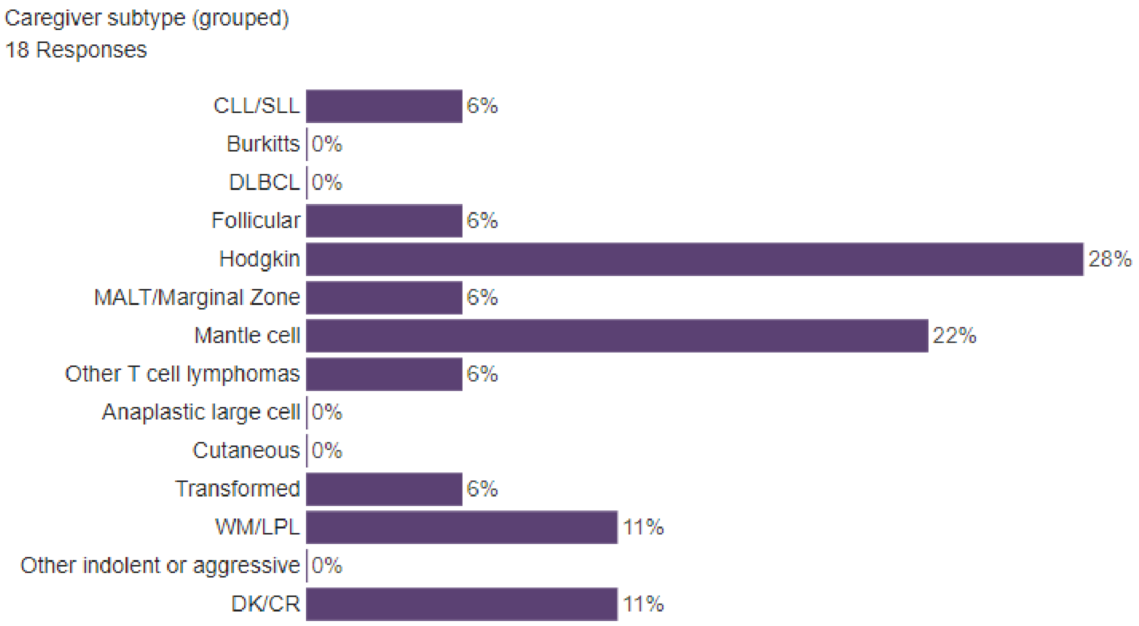


Figure 4: Subtype by patients and caregivers



Abbreviations: CLL/SLL- chronic lymphocytic leukaemia/small lymphocytic lymphoma; DLBCL- diffuse large B cell lymphoma; MALT/MZ - mucosa associated lymphoid tissue/marginal zone; 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/MZ - mucosa associated lymphoid tissue/marginal zone; 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

59% of patients were told their lymphoma subtype at diagnosis.

Only 27% agree strongly that they have good conversations with their doctor about care and treatment plans.

Less than half (48%) of patients were informed and completely understood how to manage side effects of treatment.

39% of patients are definitely involved as much as they want to be in decisions about their care and treatment.

53% of patients needed more information about the side effects of treatment.

23% of patients who were receiving treatment, or had received treatment in the past, had talked to their doctor about wanting to change treatment to better meet their needs within the last two years.

Effects of diagnosis and treatment

Fatigue was the most commonly reported **symptom of lymphoma/CLL** (86%).

90% of patients report fatigue as a **side effect of treatment**.

48% of patients indicated they had experienced a fear of cancer relapse as a result of their lymphoma diagnosis.

17% of patients use mind-body interventions or medication to help them with their fear of cancer relapse.

Only half of patients experiencing anxiety or depression have discussed it with their doctor (53% and 52% respectively).

Barriers to treatment

85% of patients reported that they did not face any barriers to receiving treatment.

48% of patients reported that they have not been presented with an opportunity to participate in a clinical trial.

22% 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

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

Biosciences at The Centre for Research and Technology Hellas (INAB | CERTH), Thessaloniki, Greece, 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 5 country-specific questions. These were standardised and translated and asked only to those from that country, as well as reported only in those country specific reports. The survey was cognitively tested by two respondents living with lymphoma, and a number of minor text amends were made to improve the survey following this. The cognitive testers were recruited by LC. Materials to promote the survey were created by LC and shared via the LC web and social properties, member organisation networks, healthcare professionals and other scientific and community alliance partners (e.g. EHA, HNHCP, INTERLYMPH).

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

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

Analysis and Reporting

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

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

Please note that results are only reported where there are 20 or more survey responses (per question). For any sub-group analyses (e.g. by lymphoma subtype, gender or age group), data is not reported on groups lower than 20 since (i) the data can be misleading and unrepresentative from low numbers; and (ii) it risks individual respondents becoming identifiable.

Some questions were asked only to a subset of respondents to ensure only applicable questions were presented. Furthermore, respondents had the ability to leave questions blank if they preferred not to answer. This means that the total number of respondents may fluctuate between questions.

Rounding of percentages means that sometimes the total for a single-response question will be just below or just above 100%.

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

Note: There is no analysis or reporting of the caregivers' data for Belgium, due to only 18 caregivers responding to the survey.

SECTION 4

Respondent Demographics

Respondent Demographics

The results in this report are presenting data for Belgium.

A total of 147 responded to the patient survey and 18 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, Figure 3 presents their household status and Figure 4 presents their employment status. Figure 5 shows area of residence (urban or rural).

Figure 1a: Sex of patients

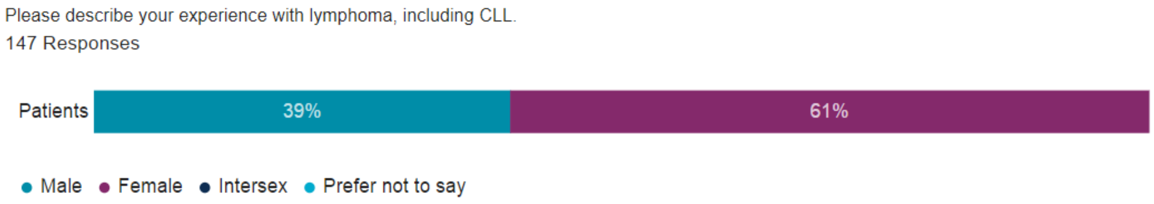


Figure 1b: Gender of caregivers

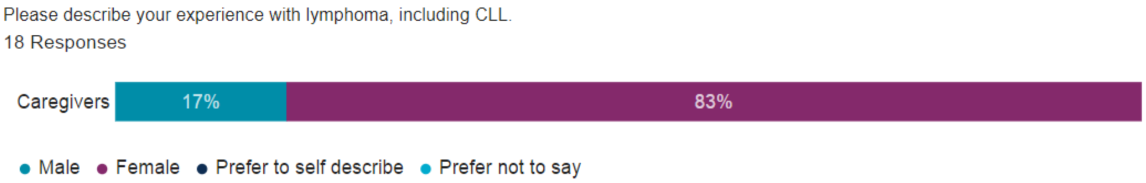


Figure 2: Age range of respondents

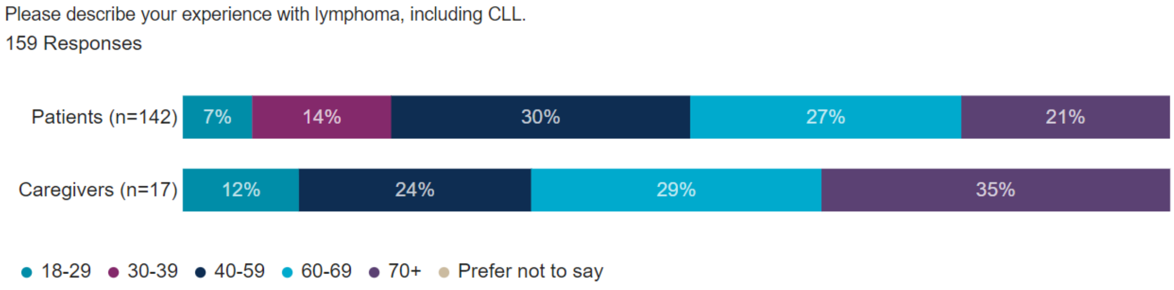


Figure 3: Household status of respondents (patients + caregivers)

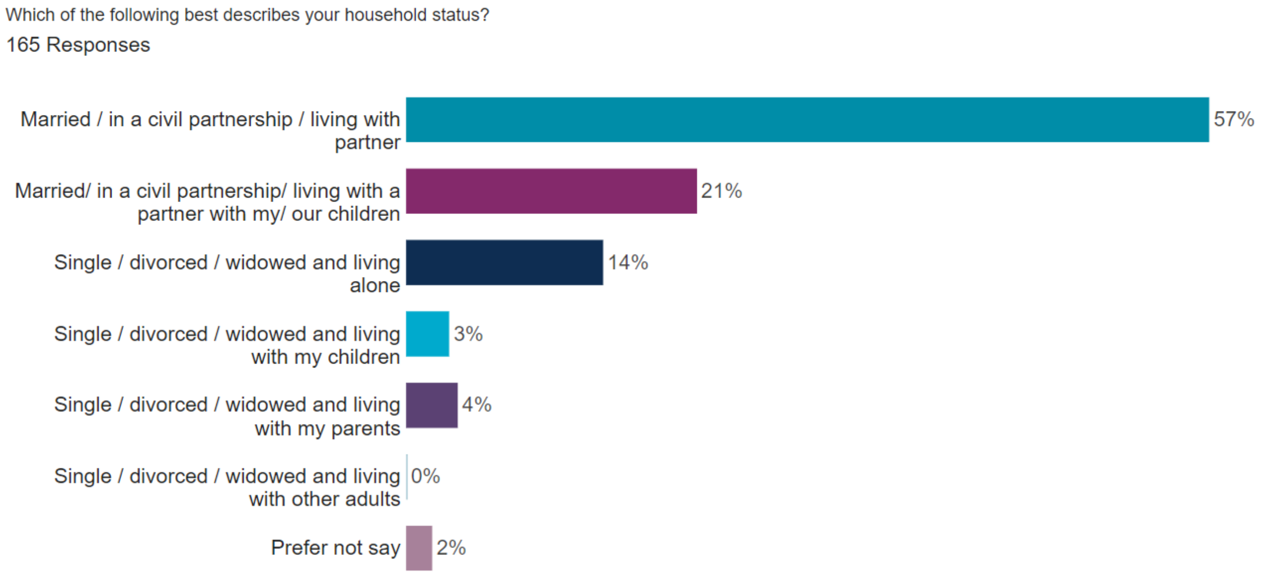


Figure 4: Employment status of respondents

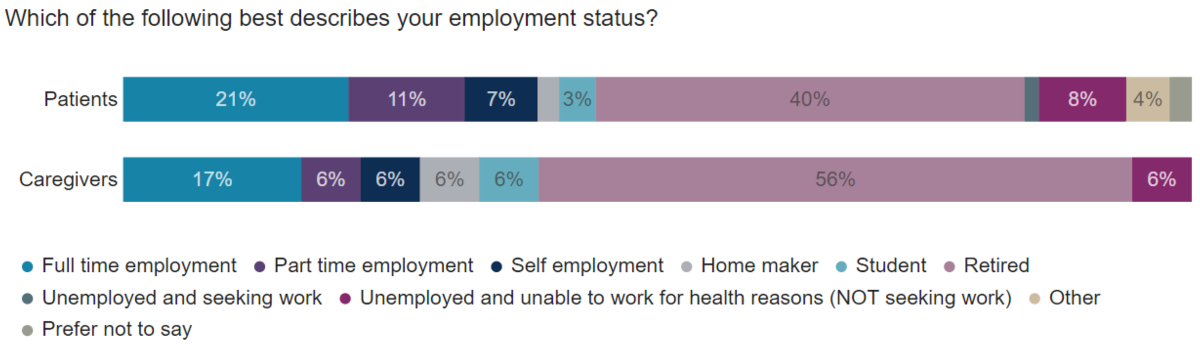


Figure 5: Area of residence of respondents (patients + caregivers)

SECTION 5

Results – Patient Survey

Results – Patient Survey

This section outlines results from the patient survey. There is no caregiver survey data reported due to low numbers (under 20).

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 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.

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

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

Diagnostic Demographics

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

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

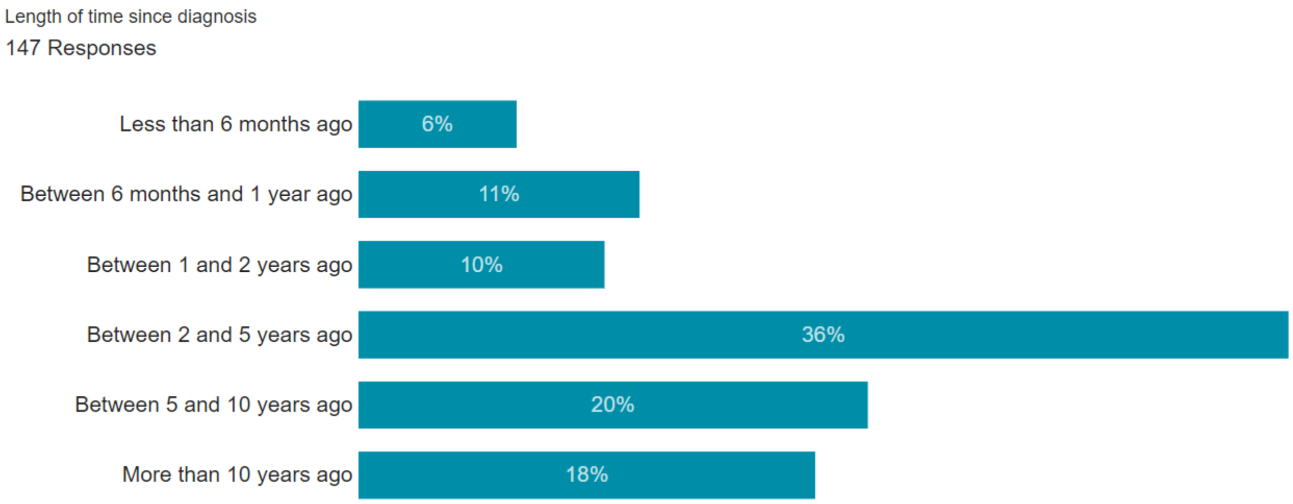


Figure 7 below shows how long patients reported waiting between their first GP appointment about their symptoms to getting a diagnosis. Almost two thirds (62%) of patients had a diagnosis within three months of their first appointment. However, 14% were waiting six months or more from their initial meeting with their GP.

Figure 7: How long was it since the first appointment with your GP about the symptoms you were experiencing to getting a diagnosis?

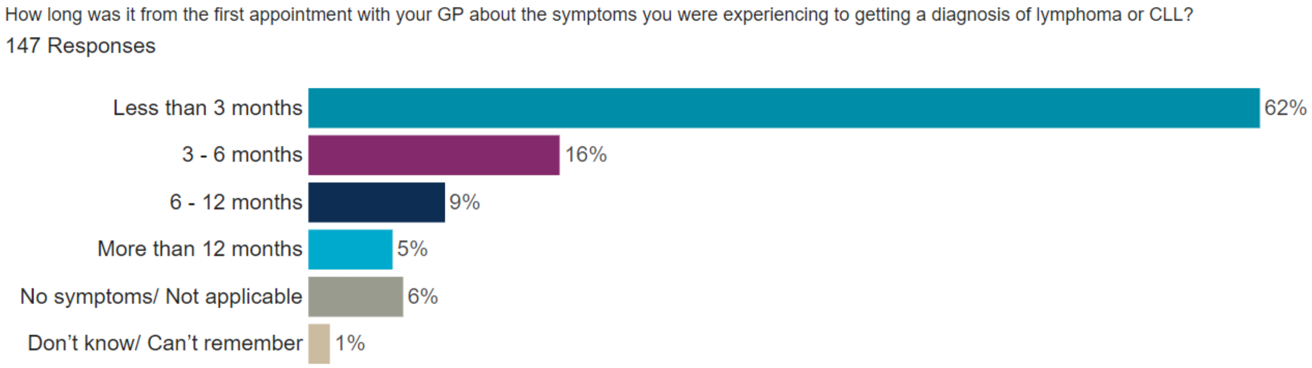
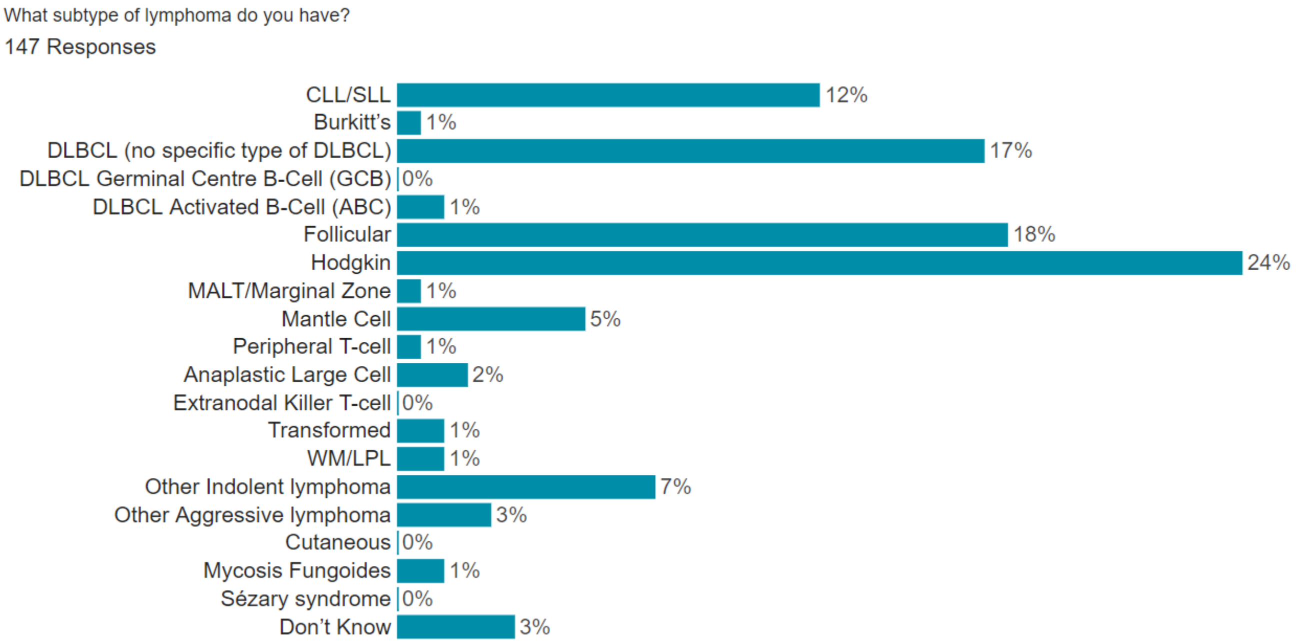


Figure 8 below shows respondent lymphoma subtype. The most common subtypes reported are:

- 24% Hodgkin lymphoma
- 18% Follicular lymphoma
- 17% Diffuse large B-cell lymphoma (not told specific type of DLBCL)

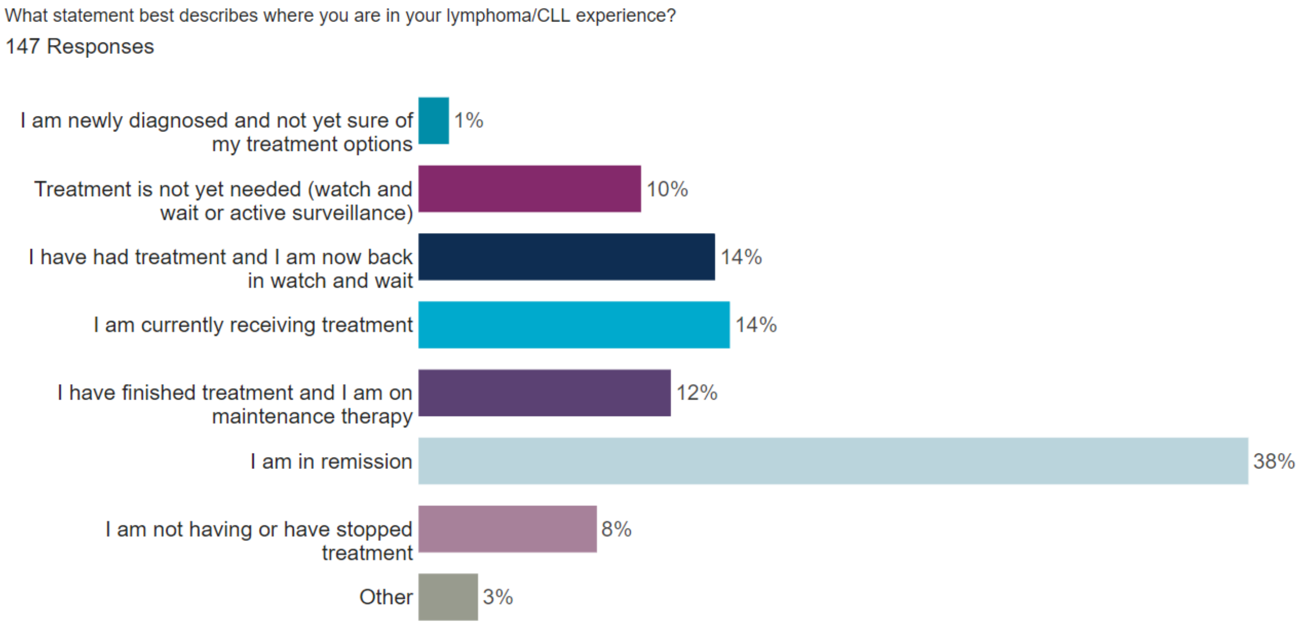
Figure 8: What subtype of lymphoma do you have?



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

10% of patients report that treatment is not yet needed (watch and wait), 14% are currently in treatment, 14% have had treatment and are now back in watch and wait. 12% have finished treatment and are on maintenance therapy, and 38% of patients report that they are in remission.

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.

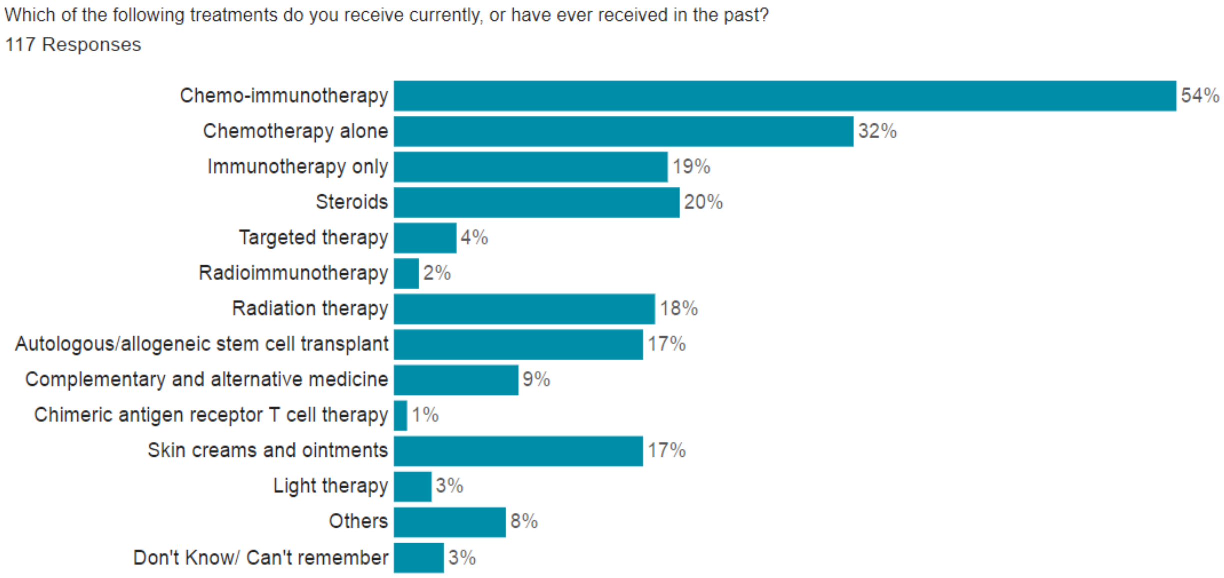
Treatment Demographics

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.

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

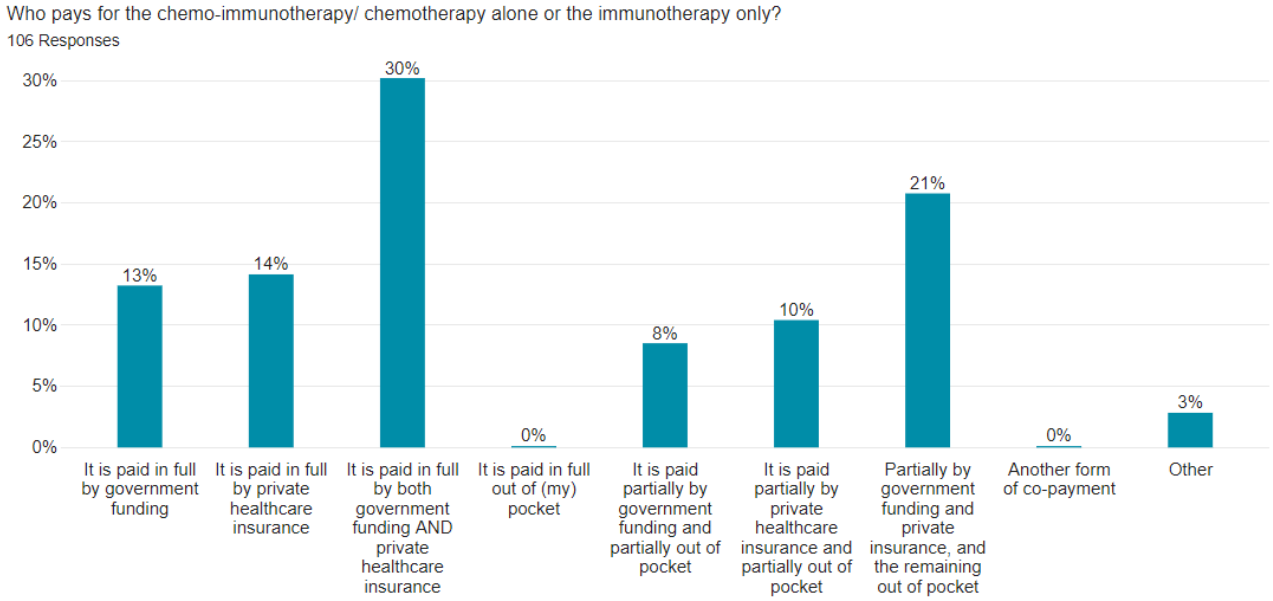
Figure 10: Which of the following treatment options do you receive currently, or have ever received in the past?



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

In regard to payment of treatment, almost a third of patients (30%) selected that their chemotherapy/immunotherapy/chemo-immunotherapy is paid for by in full by both government funding and private healthcare insurance (Figure 11).

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



22% 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.

- 92% of patients diagnosed in the last two years said it was clear they had been given a diagnosis of cancer, and 59% were told their subtype at diagnosis.
- 26% of patients were not given enough information at diagnosis. Just over half of patients (53%) say they needed more information about the side effects of treatment.
- Only 39% of patients are definitely involved as much as they want to be in decisions about their care and treatment.
- 57% agree or strongly agree to feeling overwhelmed by managing their health and condition.
- 48% agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help.

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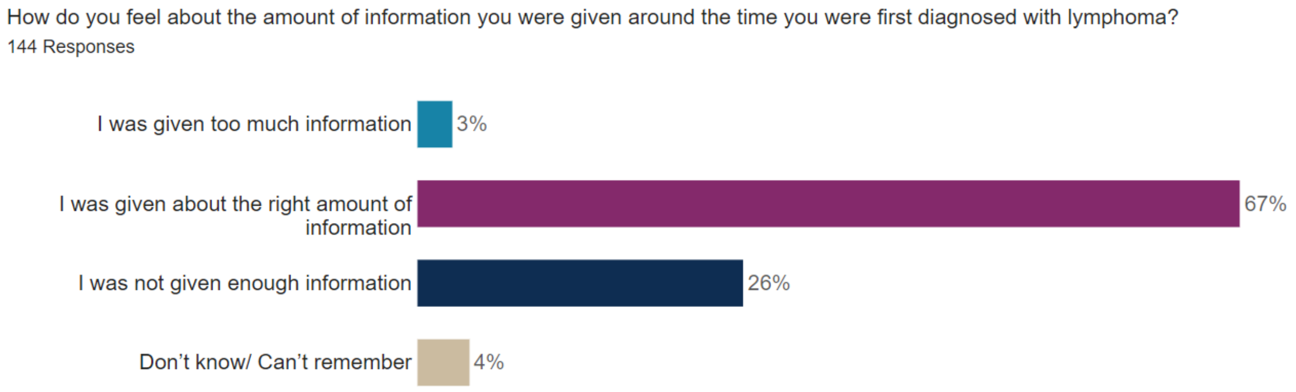
[6] https://www.picker.org/about-us/picker-principles-of-person-centred-care/

Diagnosis

Patients were asked about their experience of receiving a lymphoma diagnosis. Those diagnosed in the last two years were asked whether it was clear they had been given a diagnosis of cancer, 92% of patients said yes. Furthermore, 59% of patients reported they were told their lymphoma subtype at diagnosis.

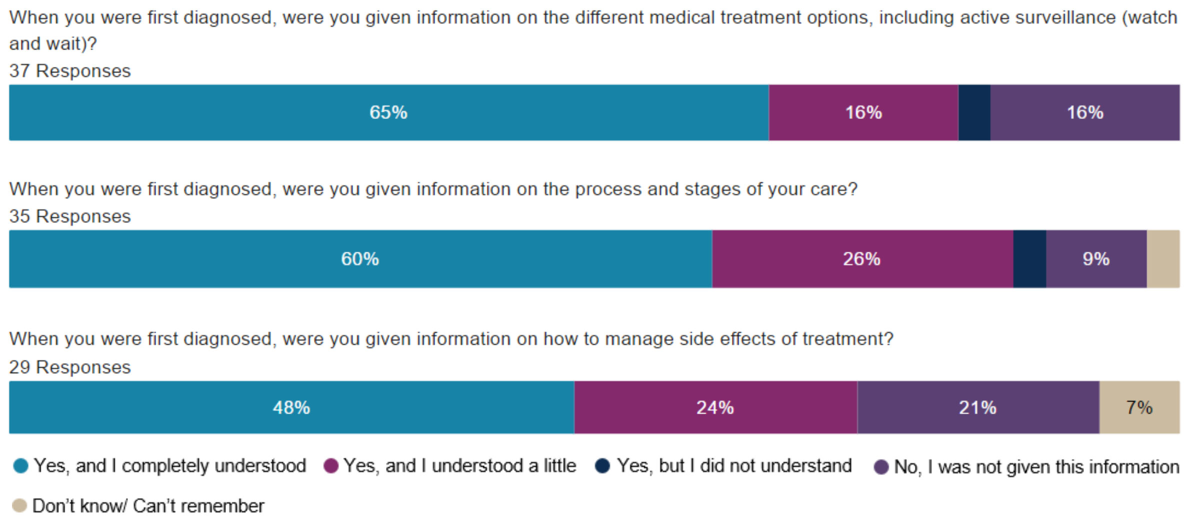
Patients were asked how they felt about the amount of information they received upon diagnosis – 26% were not given enough information. See Figure 12 for overall response.

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



Those who had been diagnosed within the last two years were asked whether they were given and understood information relating to their diagnosis and care plans (see Figure 13). 65% of patients were given and completely understood information on the different medical treatment options, including active surveillance (watch and wait). 60% of patients were provided with information on and completely understood the process and stages of care. And 48% reported they received information on and completely understood how to manage side effects of treatment.

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



Patient Knowledge and Experience

Patients had the greatest need for information within the first month (62%) after diagnosis.

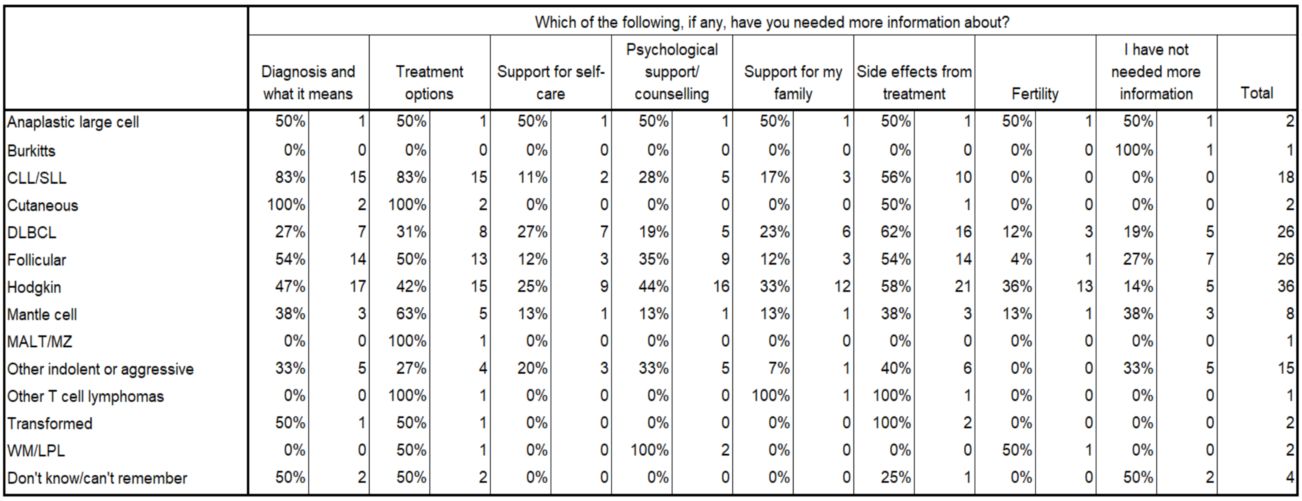
When asked about information needs:

- 53% required more information about the side effects from treatment;
- 48% of patients reported they needed more information about treatment options;
- 47% needed more information about diagnosis and what it means;
- 31% of patients needed more information about psychological support/counselling;
- 19% required more information about support for their families;
- 18% required more information about support for self-care;
- 14% required more information about fertility.

Table 1 displays the number of patients selecting each information need, by lymphoma subtype. Please take care interpreting data for subtypes with fewer than 20 respondents.

58% of those with Hodgkin lymphoma needed more information about side effects of treatment. 54% of those with follicular lymphoma needed more information on diagnosis and what it means.

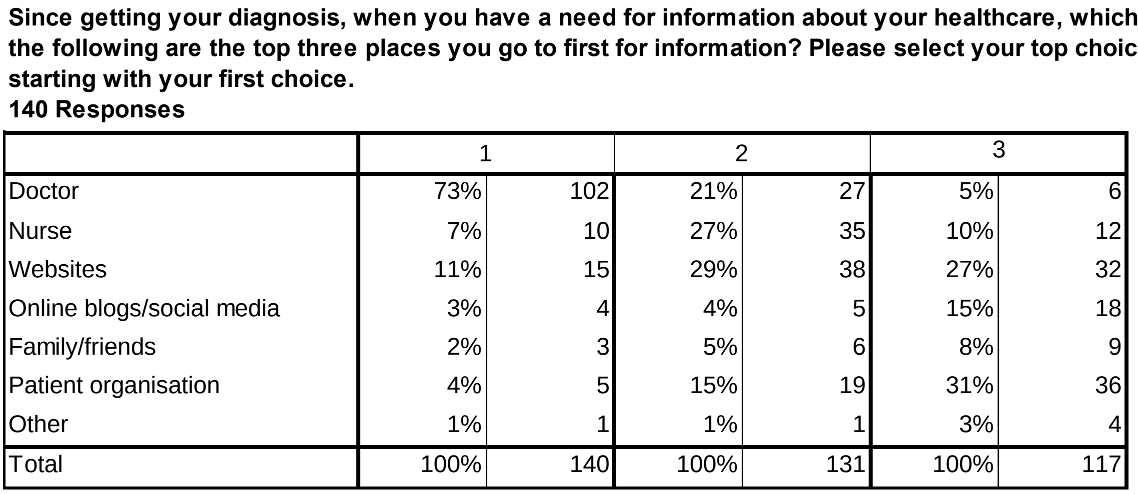
Table 1: Which if any, have you needed information about, by lymphoma subtype.



	Which of the following, if any, have you needed more information about?																
	Diagnosis and what it means		Treatment options		Support for self-care		Psychological support/ counselling		Support for my family		Side effects from treatment		Fertility		I have not needed more information		Total
Anaplastic large cell	50%	1	50%	1	50%	1	50%	1	50%	1	50%	1	50%	1	50%	1	2
Burkitts	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	100%	1	1
CLL/SLL	83%	15	83%	15	11%	2	28%	5	17%	3	56%	10	0%	0	0%	0	18
Cutaneous	100%	2	100%	2	0%	0	0%	0	0%	0	50%	1	0%	0	0%	0	2
DLBCL	27%	7	31%	8	27%	7	19%	5	23%	6	62%	16	12%	3	19%	5	26
Follicular	54%	14	50%	13	12%	3	35%	9	12%	3	54%	14	4%	1	27%	7	26
Hodgkin	47%	17	42%	15	25%	9	44%	16	33%	12	58%	21	36%	13	14%	5	36
Mantle cell	38%	3	63%	5	13%	1	13%	1	13%	1	38%	3	13%	1	38%	3	8
MALT/MZ	0%	0	100%	1	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	1
Other indolent or aggressive	33%	5	27%	4	20%	3	33%	5	7%	1	40%	6	0%	0	33%	5	15
Other T cell lymphomas	0%	0	100%	1	0%	0	0%	0	100%	1	100%	1	0%	0	0%	0	1
Transformed	50%	1	50%	1	0%	0	0%	0	0%	0	100%	2	0%	0	0%	0	2
WM/LPL	0%	0	50%	1	0%	0	100%	2	0%	0	0%	0	50%	1	0%	0	2
Don't know/can't remember	50%	2	50%	2	0%	0	0%	0	0%	0	25%	1	0%	0	50%	2	4

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

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

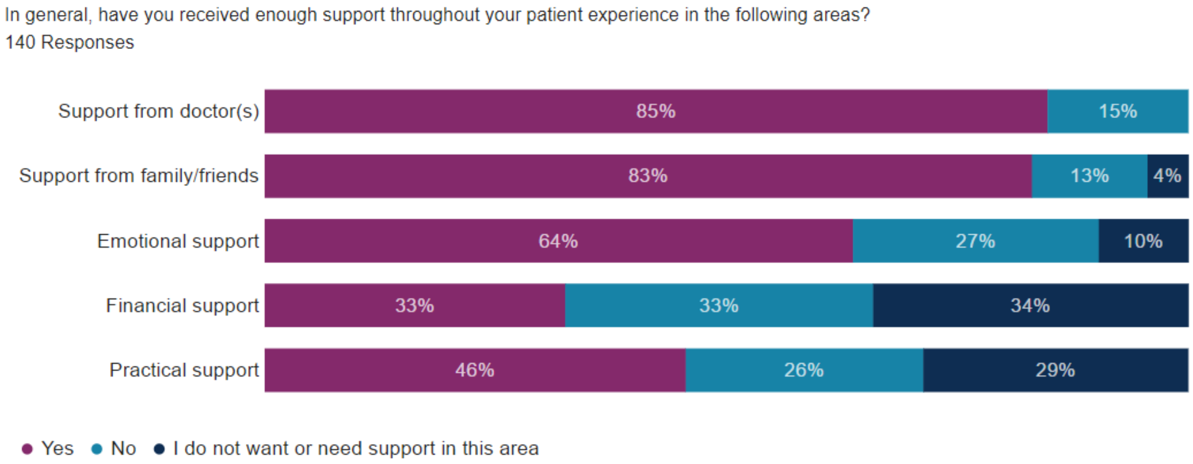


Since getting your diagnosis, when you have a need for information about your healthcare, which of the following are the top three places you go to first for information? Please select your top choices starting with your first choice.
140 Responses

	1		2		3	
Doctor	73%	102	21%	27	5%	6
Nurse	7%	10	27%	35	10%	12
Websites	11%	15	29%	38	27%	32
Online blogs/social media	3%	4	4%	5	15%	18
Family/friends	2%	3	5%	6	8%	9
Patient organisation	4%	5	15%	19	31%	36
Other	1%	1	1%	1	3%	4
Total	100%	140	100%	131	100%	117

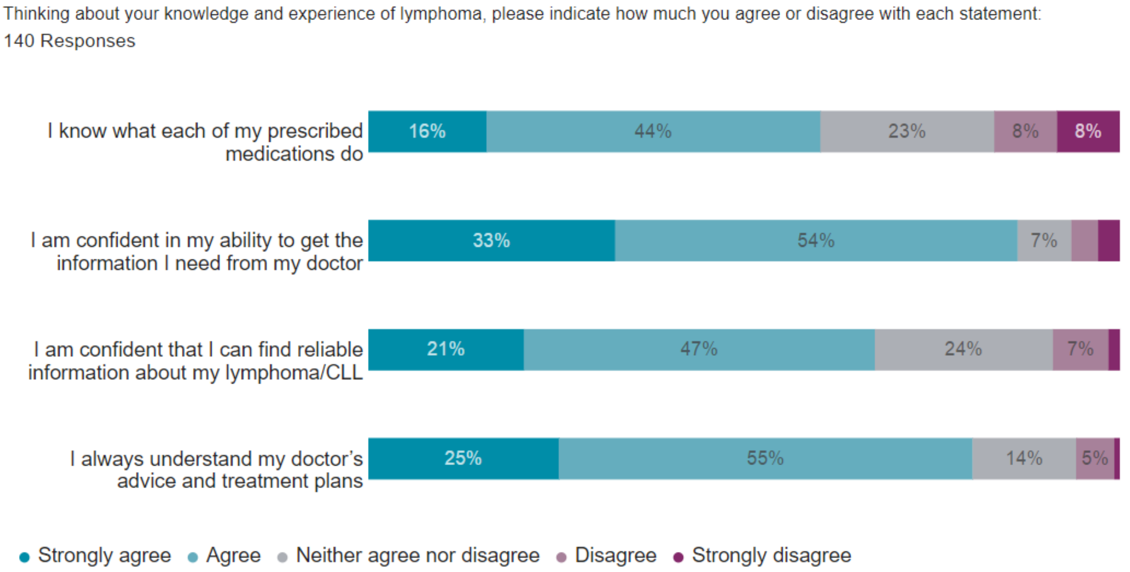
Figure 14 displays whether patients felt they had received enough support in key areas of patient experience. 85% and 83% felt that they had enough support from doctors and from family/ friends respectively. However, 33% felt that they did not get enough financial support.

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



87% agree or strongly agree that they are confident in their ability to get the information they need from their doctor, and 80% agree or strongly agree that they always understand their doctors’ advice and treatment plans. However, 16% disagree or strongly disagree that they know what each of their prescribed medications do, see Figure 15.

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



Overall, 72% of patients reported they always have confidence and trust in the doctors treating them (Figure 16).

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

Of 51% (n=71) of patients who have seen nurses for their lymphoma care over the last year, 68% definitely feel comfortable asking nurses questions about their lymphoma/CLL (see Figure 17) and 55% always have confidence and trust in the information they are given (Figure 18).

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

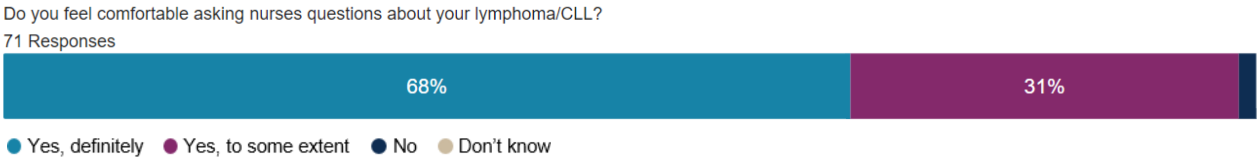
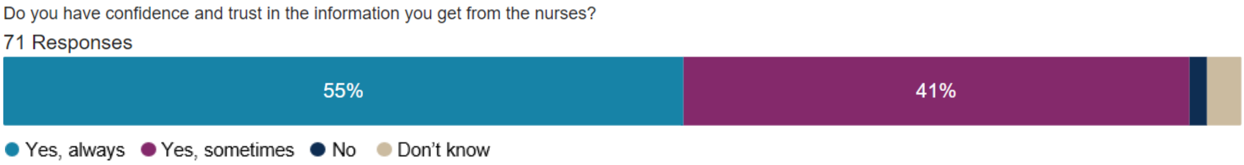


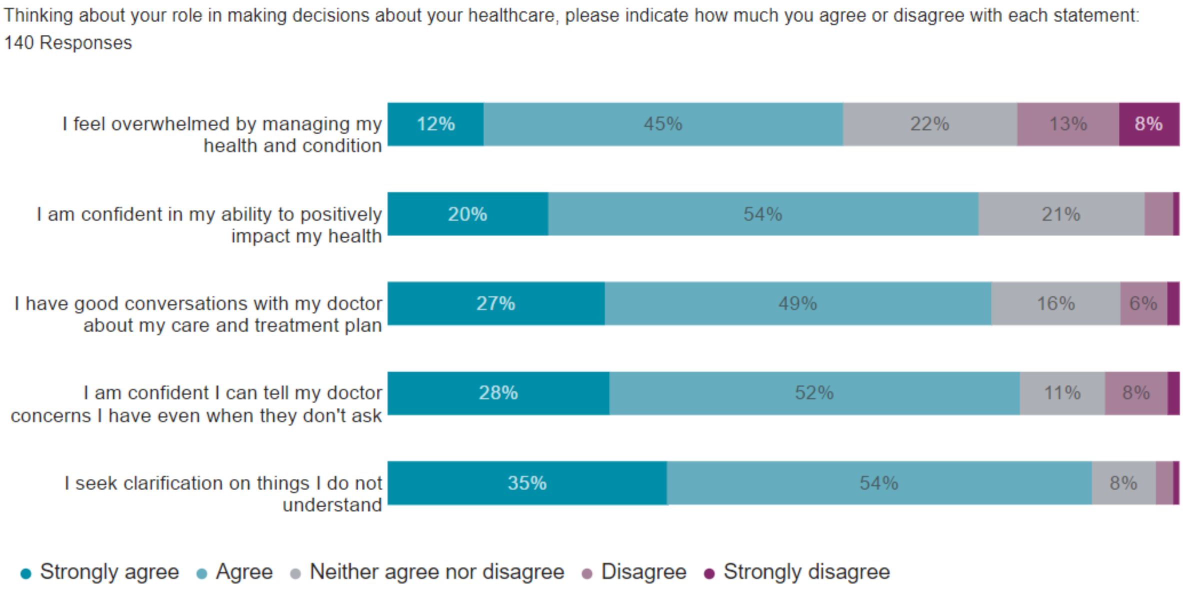
Figure 18: Do you have confidence and trust in the information you get from the nurses?



Healthcare Decision Making

Patients were asked a series of questions about the role they play in making decisions about their healthcare – see Figure 19. 89% agree or strongly agree that they seek clarification on things they do not understand. However, 57% agree or strongly agree to feeling overwhelmed by managing their health and condition.

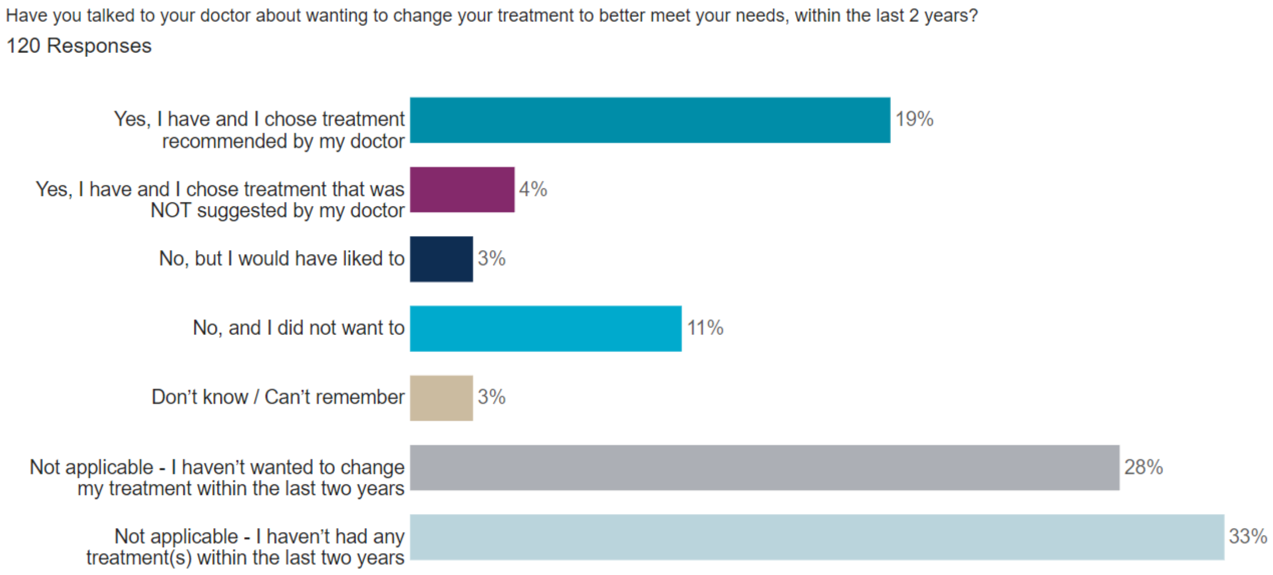
Figure 19: Thinking about your role in making decisions about your healthcare, please indicate how much you agree or disagree with each statement:



39% of patients reported they are definitely involved as much as they want to be in decisions about their care and treatment, and 53% agreed with this to some extent. 8% reported they are not involved but would like to be, and 1% reported no they are not involved but do not want to be.

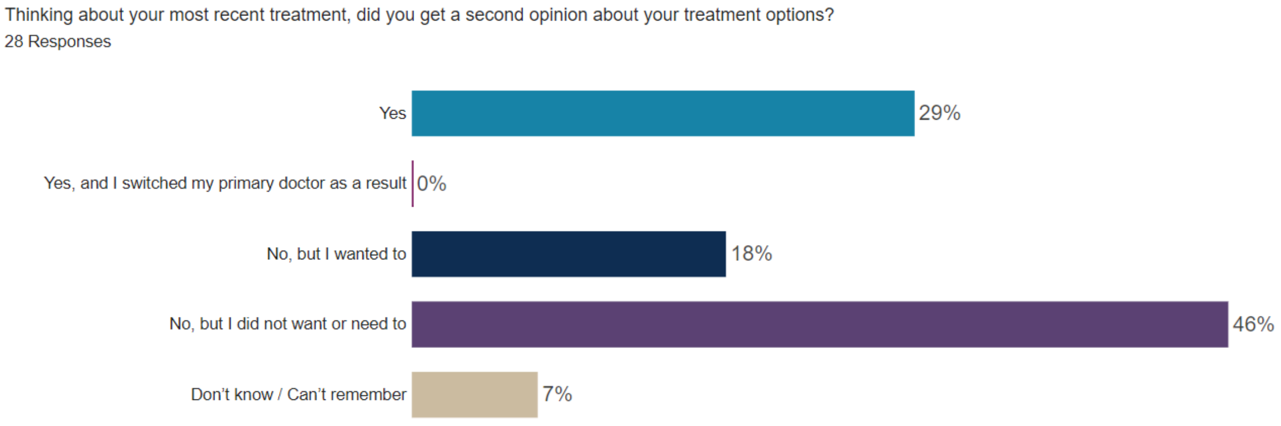
23% of patients who were receiving treatment, or had received treatment in the past, had talked to their doctor about wanting to change treatment to better meet their needs within the last two years, Figure 20.

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



29% of patients got a second opinion about their most recent treatment; however, no patients changed their primary doctor as a result. 18% wanted to get a second opinion but did not, and 46% felt they did not want or need to get a second opinion (Figure 21).

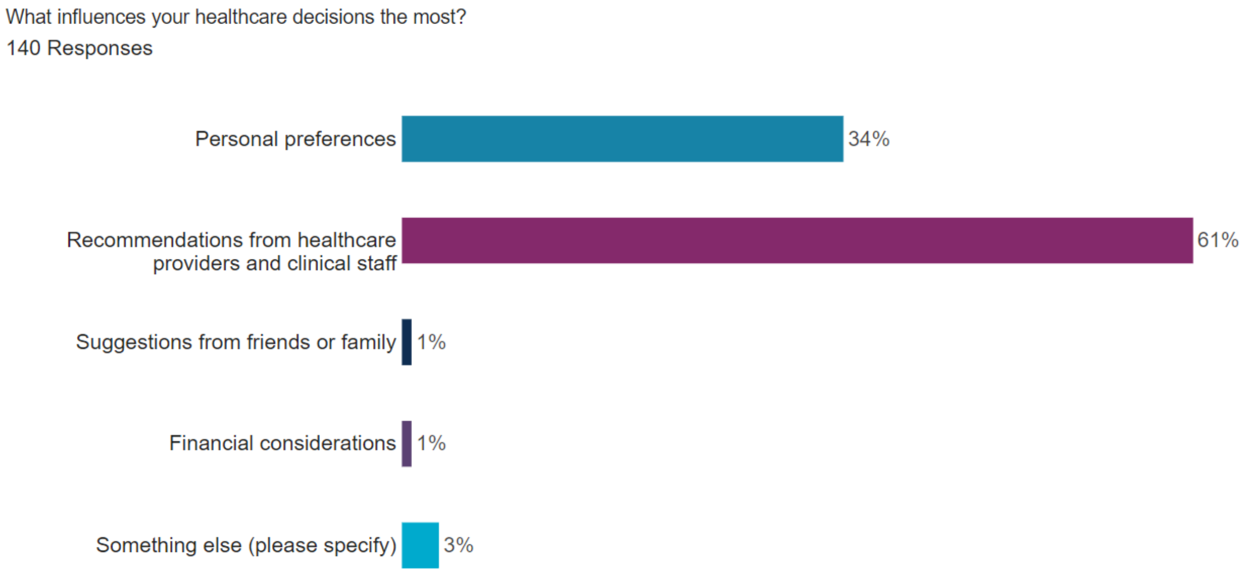
Figure 21: Thinking about your most recent treatment, did you get a second opinion about your treatment options?



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

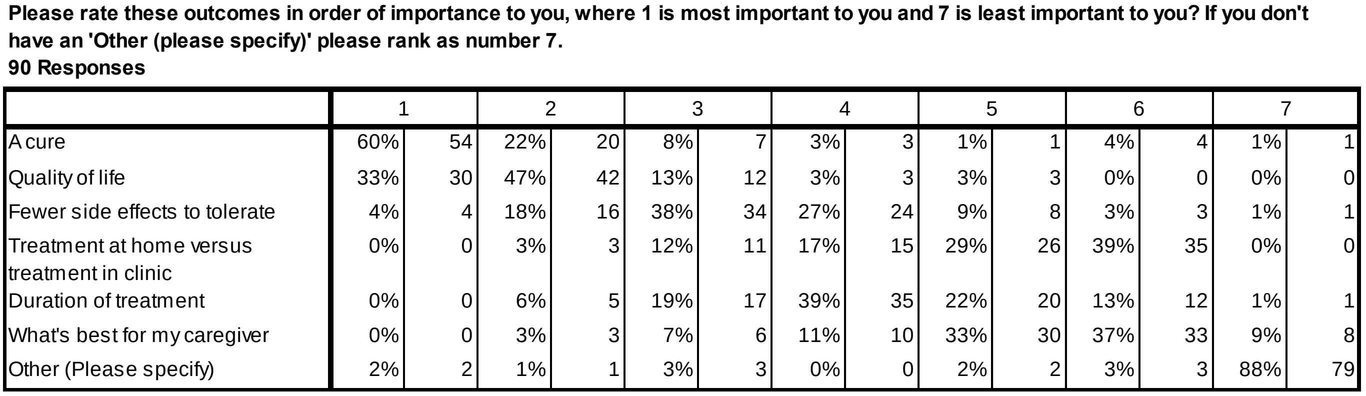
- 61% said recommendations from healthcare providers and clinical staff
- 34% were most influenced by personal preferences

Figure 22: What influences your healthcare decisions the most?



When asked about outcomes, 60% of patients ranked a cure as having the most importance to them, whereas 39% reported treatment at home versus treatment in clinic as being the least important (see Table 3).

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



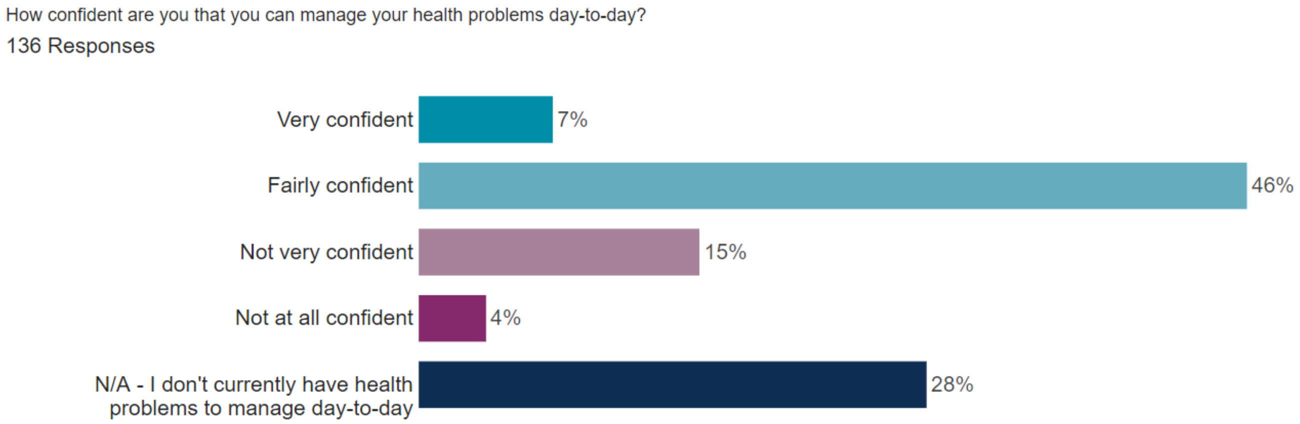
Please rate these outcomes in order of importance to you, where 1 is most important to you and 7 is least important to you? If you don't have an 'Other (please specify)' please rank as number 7.
90 Responses

	1		2		3		4		5		6		7	
A cure	60%	54	22%	20	8%	7	3%	3	1%	1	4%	4	1%	1
Quality of life	33%	30	47%	42	13%	12	3%	3	3%	3	0%	0	0%	0
Fewer side effects to tolerate	4%	4	18%	16	38%	34	27%	24	9%	8	3%	3	1%	1
Treatment at home versus treatment in clinic	0%	0	3%	3	12%	11	17%	15	29%	26	39%	35	0%	0
Duration of treatment	0%	0	6%	5	19%	17	39%	35	22%	20	13%	12	1%	1
What's best for my caregiver	0%	0	3%	3	7%	6	11%	10	33%	30	37%	33	9%	8
Other (Please specify)	2%	2	1%	1	3%	3	0%	0	2%	2	3%	3	88%	79

Health Behaviours

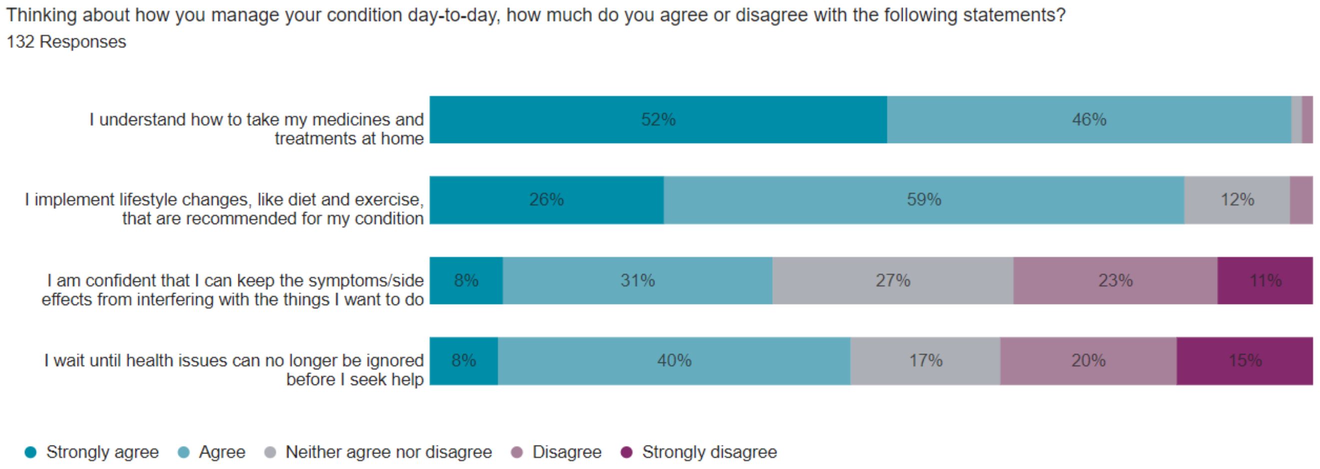
46% of patients report they are ‘fairly confident’ about managing their health problems day to day, however 19% are ‘not very’ or ‘not at all’ confident. The full data can be seen in Figure 23.

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



98% agree or strongly agree that they understand how to take their medicines and treatments at home, however 48% agree or strongly agree that they would wait until health issues could no longer be ignored before they sought help (see Figure 24).

Figure 24: Thinking about how you manage your condition day-to-day, how much do you agree or disagree with the following statements?



Physical and Medical Side Effects of Diagnosis and Treatment

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

In the LC (2018) Global Patient Survey, cancer related fatigue was the leading physical symptom affecting quality of life reported by respondents, regardless of whether the patient was newly diagnosed, in treatment, had relapsed disease or was in remission. However, patients were not being educated about their fatigue or directed to further information/support by their doctors.

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

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

The 2020 survey reports on effects of lymphoma and treatment with particular emphasis on: fatigue, fear of cancer relapse, changes in relationships and mental health difficulties.

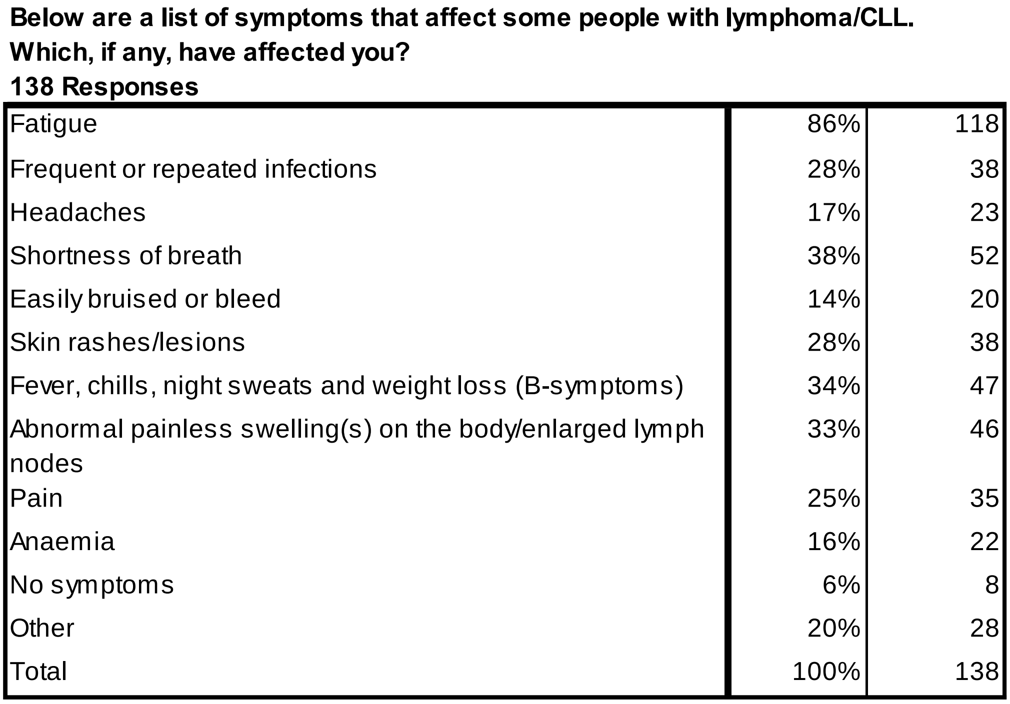
- The marjority of patients (86%) reported fatigue as the most common symptom of their lymphoma/CLL. Fatigue was also the most commonly reported treatment-related side effect (90%).
- 77% reported that they agree or strongly agree that their lymphoma/CLL symptoms negatively impact on everyday activities that people their age can usually do.
- 96% of patients discussed their side effects of treatment with their doctor. 78% report that the doctor gave them medication to help them cope.

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 (86%), shortness of breath (38%) and B-symptoms (fever, chills, night sweats and weight loss) (34%) – see Table 4.

The most common effect across all subtypes was fatigue.

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



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

Fatigue	86%	118
Frequent or repeated infections	28%	38
Headaches	17%	23
Shortness of breath	38%	52
Easily bruised or bleed	14%	20
Skin rashes/lesions	28%	38
Fever, chills, night sweats and weight loss (B-symptoms)	34%	47
Abnormal painless swelling(s) on the body/enlarged lymph nodes	33%	46
Pain	25%	35
Anaemia	16%	22
No symptoms	6%	8
Other	20%	28
Total	100%	138

Table 5 indicates the length of time that respondents have experienced lymphoma/CLL symptoms. Around half of patients who are affected by pain, abnormal painless swellings and B-symptoms report it has affected them for under a year. Of patients affected by repeated infections, anaemia or fatigue, 21%, 18% and 15% respectively have been experiencing these side effects for more than eight years.

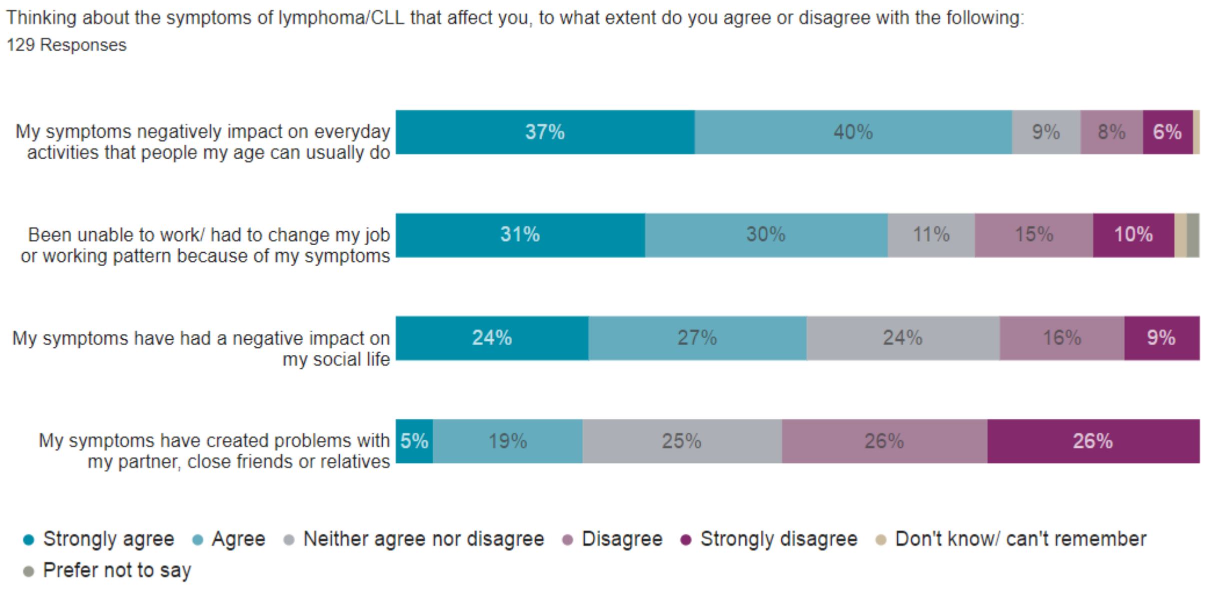
Table 5: You have indicated that you have been affected by the symptoms shown below, for each symptom that has affected you, please indicate how long you have had this symptom for:

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

	Under a year		1-2 years		2-5 years		5-8 years		More than 8 years		DK/CR		Total
Fever, chills, night sweats and weight loss (B-symptoms)	55%	26	13%	6	15%	7	4%	2	4%	2	9%	4	47
Pain	56%	19	12%	4	15%	5	6%	2	9%	3	3%	1	34
Fatigue	20%	23	23%	27	28%	33	9%	10	15%	17	6%	7	117
Abnormal painless swelling(s) on the body/ enlarged lymph nodes	52%	24	17%	8	11%	5	4%	2	7%	3	9%	4	46
Shortness of breath	44%	23	17%	9	25%	13	4%	2	6%	3	4%	2	52
Skin rashes/ lesions	37%	14	34%	13	8%	3	11%	4	8%	3	3%	1	38
Frequent or repeated infections	32%	12	18%	7	21%	8	3%	1	21%	8	5%	2	38
Anaemia	41%	9	14%	3	18%	4	9%	2	18%	4	0%	0	22
Headaches	30%	7	22%	5	13%	3	22%	5	4%	1	9%	2	23
Easily bruised or bleed	30%	6	10%	2	40%	8	15%	3	0%	0	5%	1	20

Figure 25 presents patient views on the effects of their lymphoma/CLL symptoms. 77% agree or strongly agree that their symptoms negatively impact on everyday activities that people their age can usually do.

Figure 25: Thinking about the symptoms of lymphoma/CLL that affect you, to what extent, if at all, do you agree or disagree with each of the following statements? (Please select one option on each row):

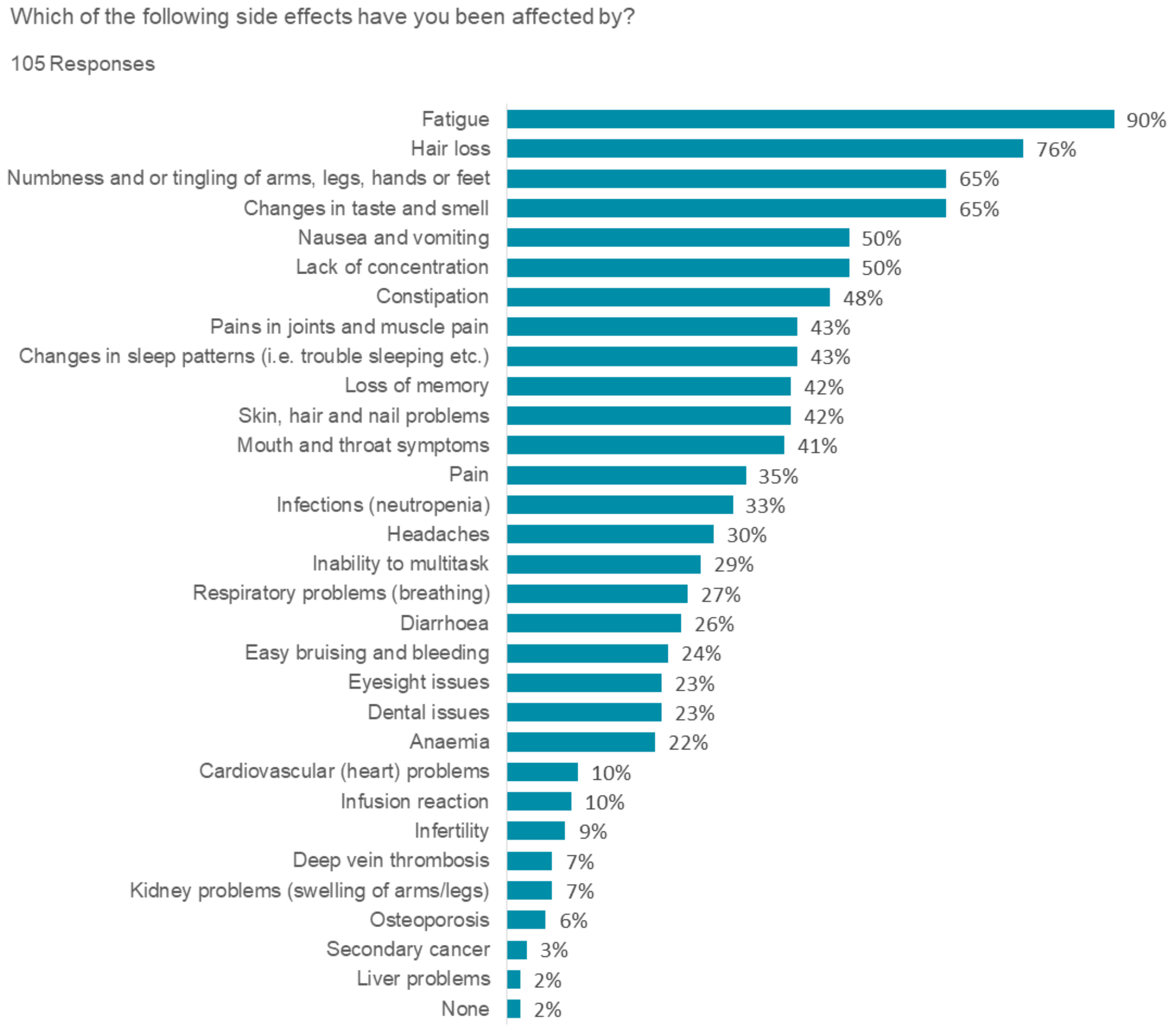

Thinking about the symptoms of lymphoma/CLL that affect you, to what extent do you agree or disagree with the following:
129 Responses

Effects of Lymphoma/CLL Treatment

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

- Fatigue reported by 90%
- Hair loss reported by 76%
- Numbness/tingling of limbs reported by 65%
- Changes in taste and smell by 65%

Figure 26: **Thinking now about your side effects from treatment: Which of the following side effects have you been affected by?**



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

- 42% (n=41) report that fatigue affects them the most
- 14% (n=14) report that hair loss affects them the most
- 9% (n=9) report that nausea and vomiting affects them the most

34% of patients were affected by fatigue for five years or more, while 91% were affected by hair loss and 87% were affected by nausea and vomiting for less than five years.

Figure 27 displays whether patients discussed treatment side effects with their doctor.
96% responded that they had definitely or to some extent discussed these. Of those, 19% said that the doctor was definitely able to help with their treatment side effects, and a further 59% reported that the doctor was able to help to some extent (see Figure 28).

Figure 27: You said you experienced side effects of treatment, did you discuss them with your doctor?

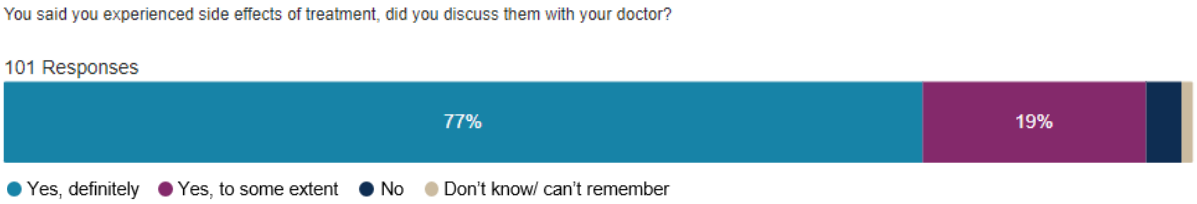
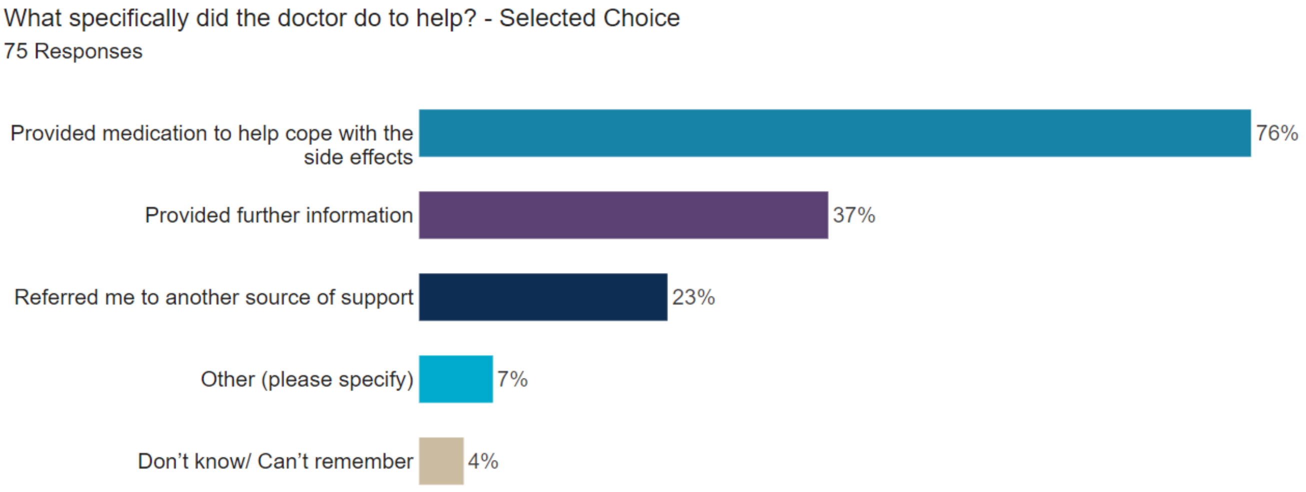


Figure 28: Was the doctor able to help with the side effects?

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

- 76% said the doctor helped by providing medication to help cope with the side effects
- 37% said the doctor helped by providing further information

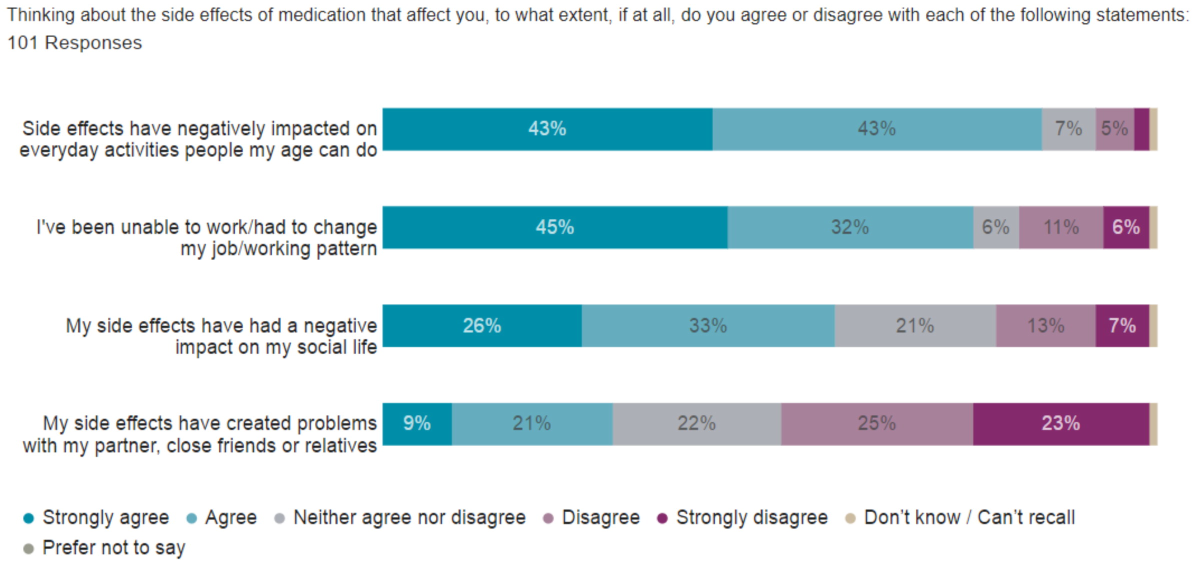
Figure 29: What specifically did the doctor do to help?



Only three respondents reported that they did not discuss their treatment-related side effects with their doctor.

Regarding the treatment side effects that affected patients, 86% agree or strongly agree their side effects negatively impact on everyday activities that people their age can do. Similarly 77% agree or strongly agree they have been unable to work or had to change their job or working pattern because of their side effects. However, 48% disagree or strongly disagree that their side effects have created problems with their partner/ family or close friends (see Figure 30).

Figure 30: Thinking about the side-effects of medication that affect you, to what extent, if at all, do you agree or disagree with each of the following statements? (Please select one option on each row):



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.

- Half of all patients who are experiencing fatigue (50%) report a rating of six or above (where one = minimal, and ten = worst imaginable) in the week they participated in the survey.
- 88% of patients spoke to their doctor about their fatigue, of which 30% report the doctor did not take any action, and 24% report that the doctor did not follow up with them about their fatigue.
- Balancing schedules was the most common coping mechanism for fatigue (48%).

In the LC (2020) Global Patient Survey, patients with lymphoma were asked to rate their level of fatigue on a scale of one = minimal fatigue to ten = worse fatigue imaginable. 50% of patients reported their fatigue levels over the last week were six or above out of ten. These patients stated that their fatigue has affected the following areas/activities over the last two years:

- General activity (reported by 87% of patients with a fatigue rating of six or more)
- Physical activity (reported by 78% of patients with a fatigue rating of six or more)
- General work around the home (reported 76% of patients with a fatigue rating of six or more)

Figure 31 shows that 88% of patients have discussed their fatigue with their doctor over the last two years, and 10% have not.

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

Patients who discussed fatigue with their doctor were asked how their doctor helped with their fatigue. Responses are displayed in Figure 32. Less than one quarter of patients reported that the doctor did a physical examination (13%) or looked at their medical history (20%). Further, 30% reported that the doctor did not take any action.

Figure 32: What did the doctor do after you discussed your fatigue?

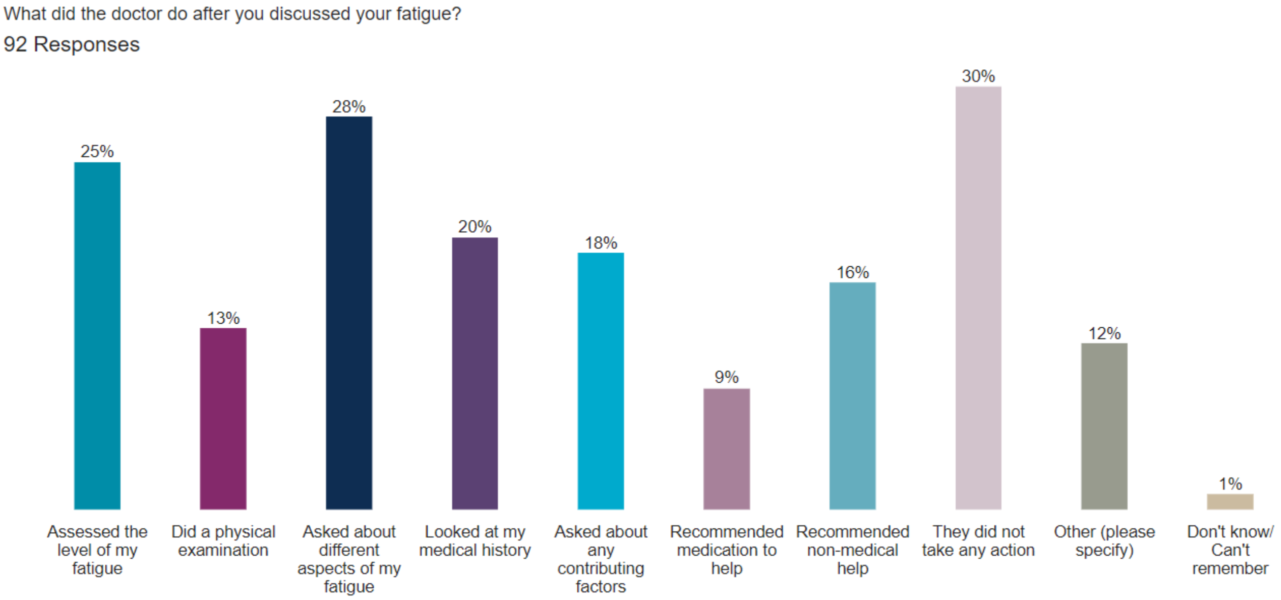
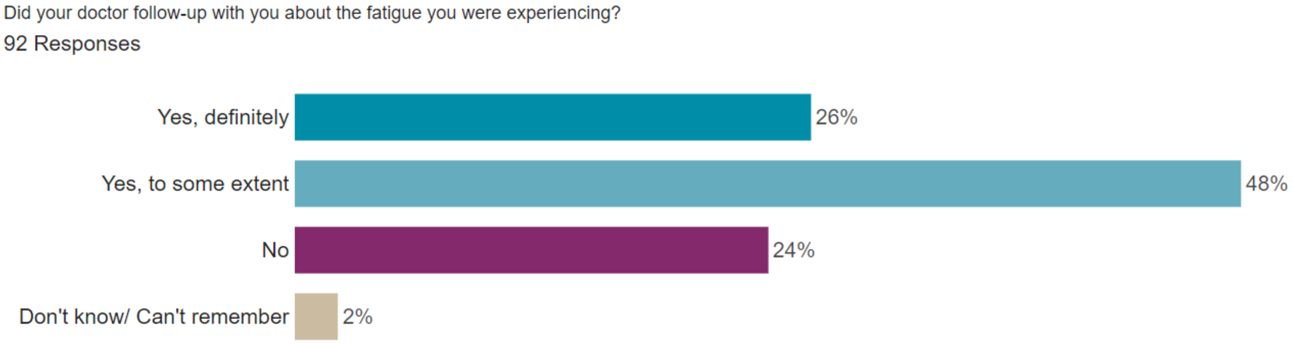


Figure 33 shows patients who had discussed fatigue with a doctor were asked whether their doctor followed up with them about their fatigue, and:

- 26% said 'Yes, definitely'
- 48% said 'Yes, to some extent'
- 24 % said 'No'

Figure 33: Did your doctor follow-up with you about the fatigue you were experiencing?



Patients were asked whether they spoke to anyone else (other than a doctor) about their fatigue, and 65% reported that they also spoke to family and friends (Figure 34).

Figure 34: Did you speak to anybody else to help you with your fatigue?

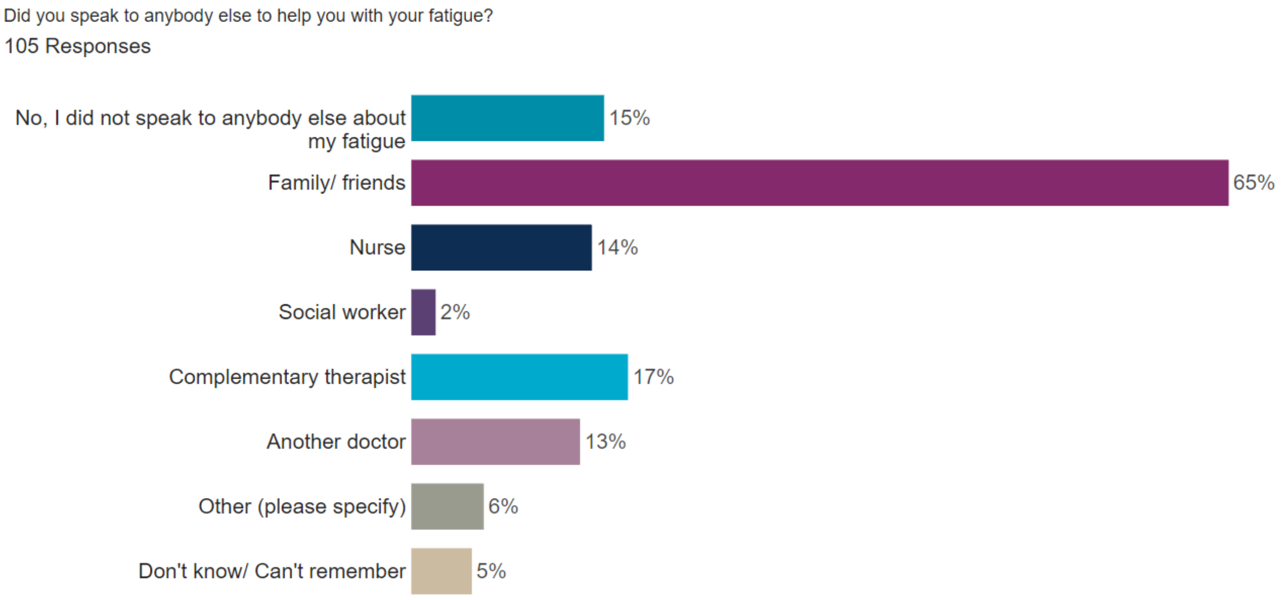
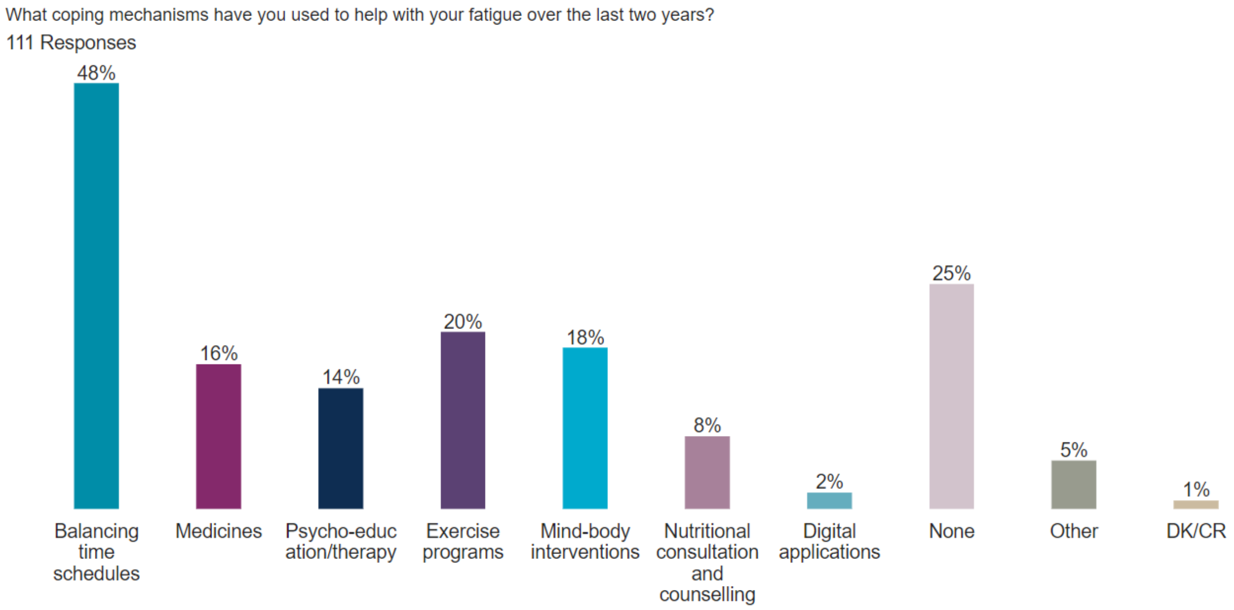


Figure 35 displays that the top reported coping mechanisms patients have used to help with their fatigue over the last two years are balancing time schedules (48%), exercise programmes (20%) and mind-body interventions (18%).

Figure 35: What coping mechanisms have you used to help with your fatigue over the last two years?



Psychosocial Effects of Lymphoma/CLL and its Treatment

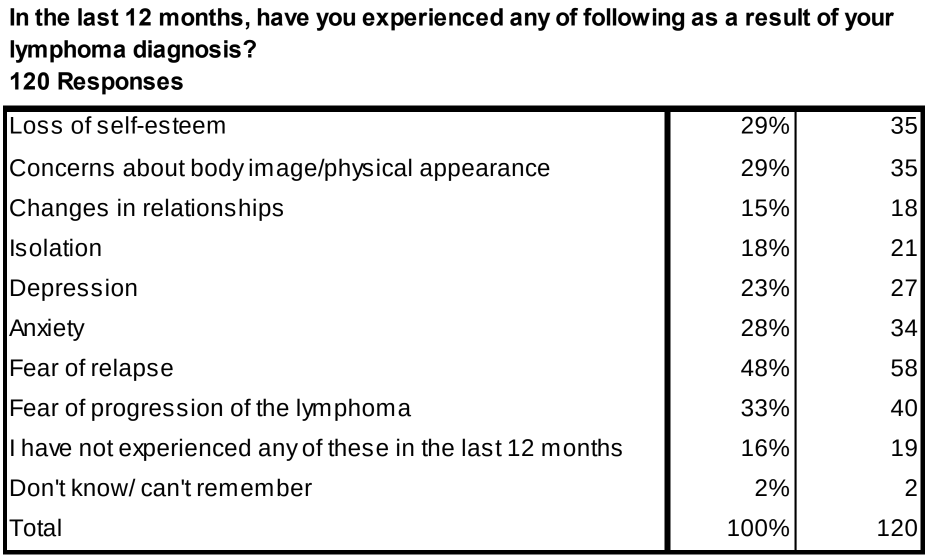
The previous LC (2018) Global Patient Survey showed that patients were much more likely to communicate their physical/medical issues than their psychosocial issues with their doctors. When patients did report raising emotional concerns, only the minority reported that the doctor was able to help. Questions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

- Almost half of all patients (48%) have experienced a fear of cancer relapse in the last 12 months, 33% report a fear of their lymphoma progressing, and 28% have experienced anxiety.
- Only half of all patients experiencing anxiety or depression have discussed it with their doctor (53% and 52% respectively).
- 44% of those who are experiencing anxiety have spoken to a complementary therapist.

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

- 48% of patients experienced fear of cancer relapse
- 33% of patients experienced fear of progression of the lymphoma
- 29% of patients experienced loss of self-esteem and concerns about their physical appearance

Table 6: In the last 12 months, have you experienced any of the following as a result of your lymphoma diagnosis?



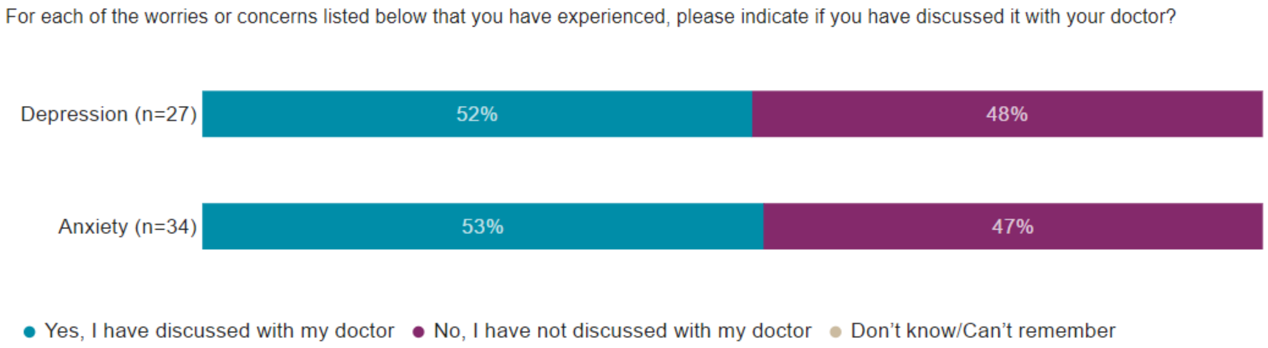
In the last 12 months, have you experienced any of following as a result of your lymphoma diagnosis?
120 Responses

Loss of self-esteem	29%	35
Concerns about body image/physical appearance	29%	35
Changes in relationships	15%	18
Isolation	18%	21
Depression	23%	27
Anxiety	28%	34
Fear of relapse	48%	58
Fear of progression of the lymphoma	33%	40
I have not experienced any of these in the last 12 months	16%	19
Don't know/ can't remember	2%	2
Total	100%	120

From this point on, the LC (2020) Global Patient Survey questions focused on three psychosocial issues that were determined to be significant in the LC (2018) GPS: changes in relationships, anxiety and depression. Due to low the base size of those experiencing changes in relationship (n=18), it is not possible to report this data for some of the questions below.

Figure 36 presents the percentage of patients who discussed their anxiety, and/or depression with their doctor.

Figure 36: For each of the worries or concerns listed below that you have experienced, please indicate if you have discussed it with your doctor?



When asked who else they had spoken to regarding their worries or concerns (besides a doctor), in many cases, patients reported that they had spoken with their family and friends for help. See Table 7 below for a breakdown of responses (for all psychosocial issues, not just changes in relationships, anxiety and depression).

Table 7: For each worry or concern that you have experienced, please indicate who else you have spoken with to help you with these worries or concerns?

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

Loss of self-esteem																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
34%	12	49%	17	9%	3	0%	0	37%	13	9%	3	0%	0	0%	0	35

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
26%	9	69%	24	14%	5	0%	0	23%	8	3%	1	3%	1	0%	0	35

Changes in relationships																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
39%	7	50%	9	6%	1	6%	1	33%	6	11%	2	6%	1	0%	0	18

Isolation																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
38%	8	48%	10	14%	3	0%	0	14%	3	5%	1	0%	0	0%	0	21

Depression																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
19%	5	70%	19	4%	1	0%	0	26%	7	4%	1	0%	0	0%	0	27

Anxiety																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
12%	4	74%	25	12%	4	3%	1	44%	15	12%	4	0%	0	0%	0	34

Fear of progression of the lymphoma																
I did not speak to anybody else		Family/ friends		Nurse		Social worker		Complementary therapist		Another doctor		Other		DK/CR		Total
18%	7	63%	25	10%	4	0%	0	13%	5	15%	6	3%	1	3%	1	40

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.

- Almost half of patients (48%) have experienced a fear of cancer relapse in the last 12 months.
- A quarter of patients (26%) who discussed their fear of relapse with their doctor report that the doctor was unable to help.
- The majority of patients (62%) say they have spoken to family and friends about their fear of cancer relapse, and quarter (24%) have spoken to a complementary therapist. However a fifth of patients (22%) have not spoken to anybody else.

In the 2020 Global Patient Survey, 48% of patients reported they experienced a fear of cancer relapse in the last 12 months, and 59% have discussed their fear of relapse with their doctor.

Of those who have discussed fear of relapse with their doctor, 74% of patients reported their doctor was able to help, either definitely or to some extent (see Figure 37).

Figure 37: For the fear of relapse that you discussed with your doctor, please indicate if the doctor was able to help?

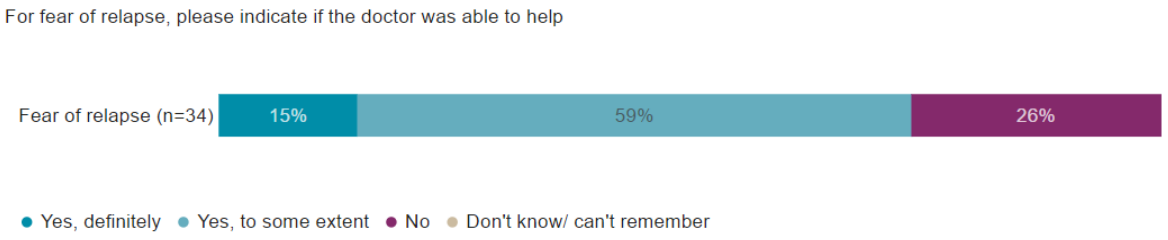
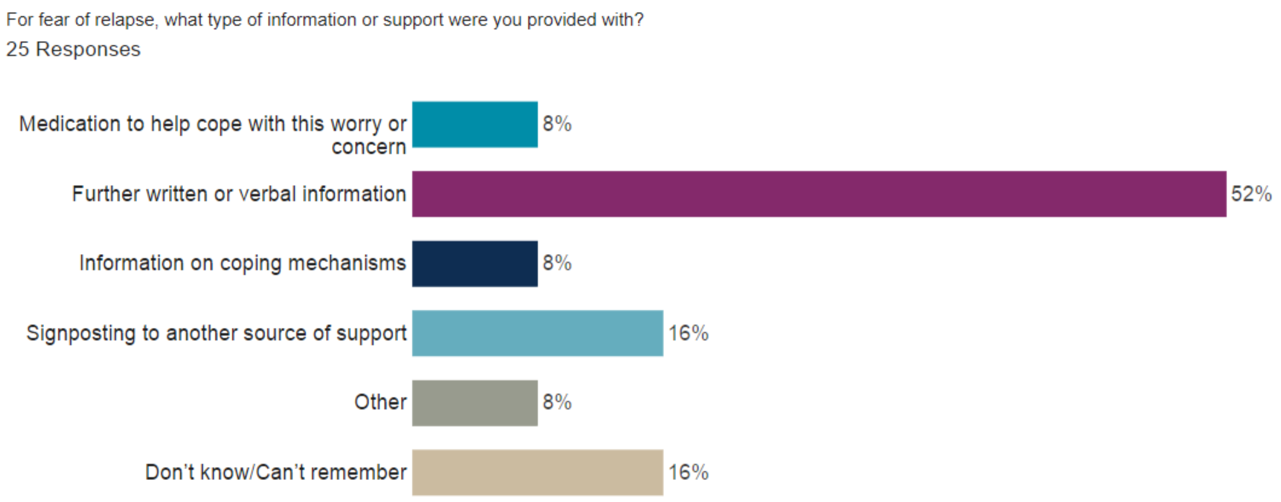


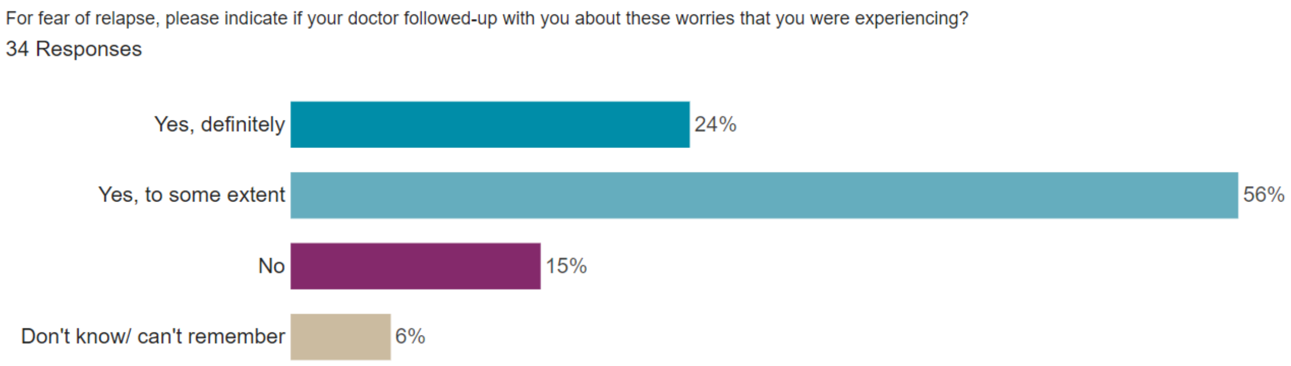
Figure 38 displays the type of information or support patients were provided with by their doctor to help with fear of relapse. Just over half of patients (52%) reported that further written information or verbal information was provided.

Figure 38: What type of information or support were you provided with?



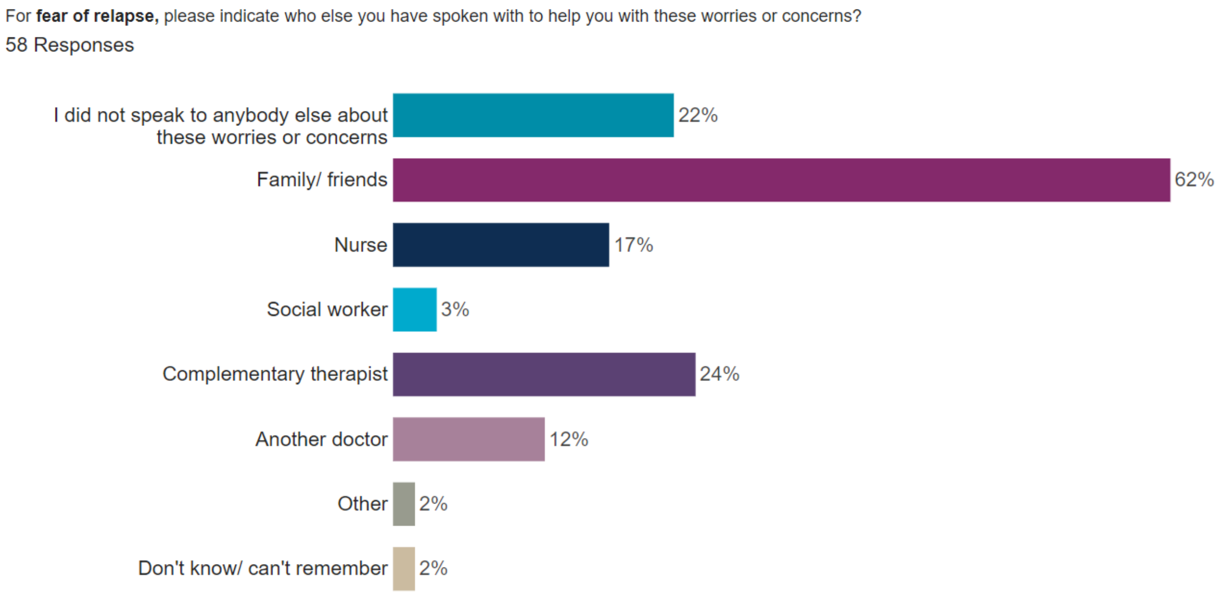
Only a quarter of patients (24%) who discussed fear of relapse with their doctor reported that their doctor definitely followed up with them about it, see Figure 39.

Figure 39: Please indicate if your doctor followed-up with you about the fear of relapse that you were experiencing?



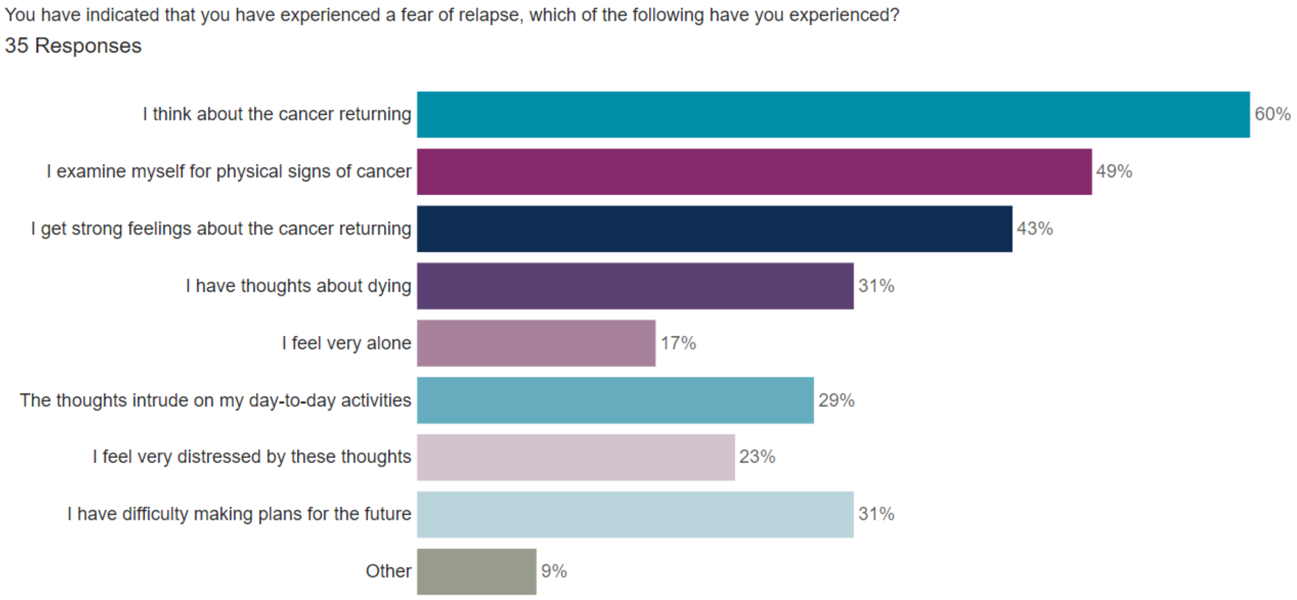
In addition to talking to a doctor, almost two thirds of patients (62%) reported they have also spoken to family and friends about their fear of relapse (Figure 40).

Figure 40: For the fear of relapse that you have experienced, please indicate who else you have spoken with to help you with this concern?



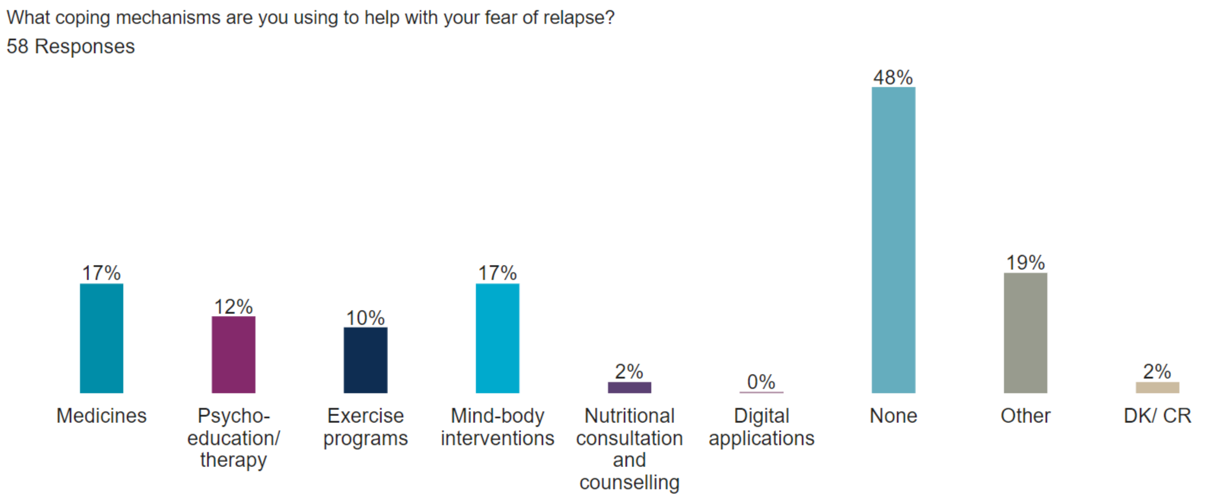
60% of patients who reported experiencing fear of relapse also reported that they think about the cancer returning, and 49% examine themselves to see if they have physical signs of cancer (see Figure 41). Almost a third of patients (31%) reported having difficulty making plans for the future as a result of their fear of relapse.

Figure 41: You have indicated that you have experienced a fear of relapse, which of the following have you experienced?



48% of patients reported that they are not using any coping mechanisms to help with their fear of relapse. 17% reported they are using medicines and mind-body interventions. 19% said they are using other mechanisms to cope with their fear of relapse (Figure 42).

Figure 42: What coping mechanisms are you using to help with your fear of relapse?



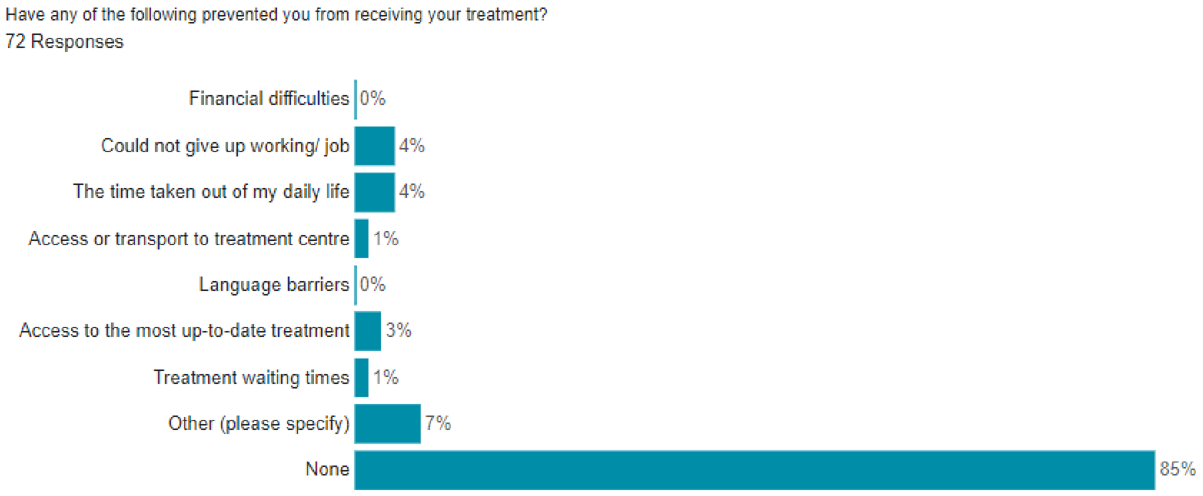
Barriers to Treatment

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.

- 85% of patients report they did not face any barriers to receiving treatment.
- 48% of patients have never been presented with an opportunity to take part in clinical trial.
- 21% say not being eligible or selected has been the biggest barrier to being in a clinical trial.

When asked to select from a list of potential barriers to treatment, 85% of patients said that no barriers have prevented them from receiving treatment. 4% of patients reported they were prevented from receiving treatment by not being able to give up working, and not being able to take time out of their day (Figure 43).

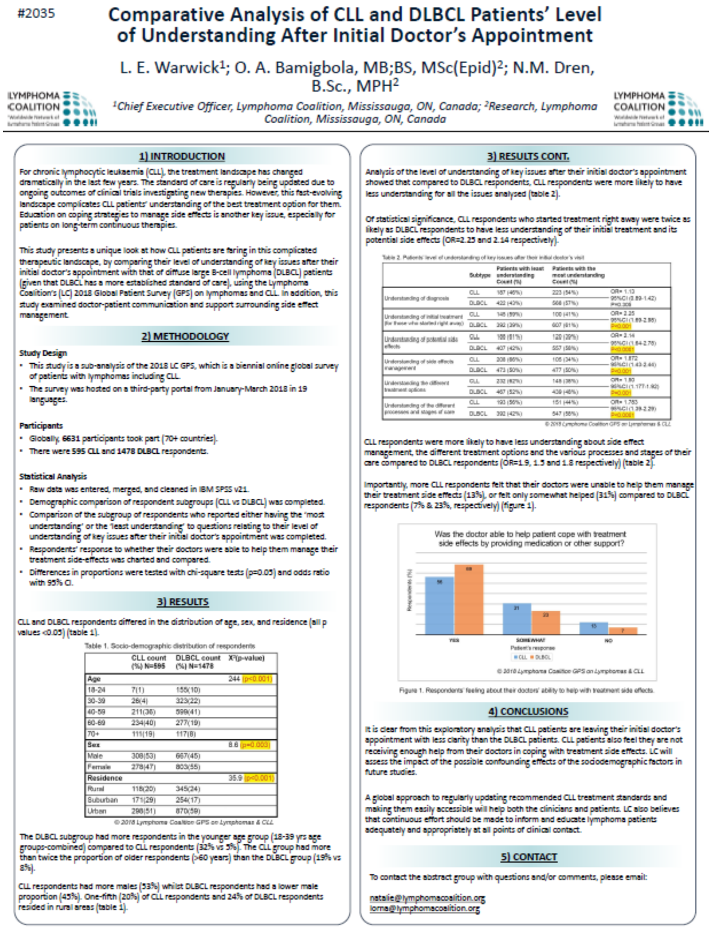
Figure 43: Have any of the following prevented you from receiving treatment?



48% of patients report that they have not been presented with an opportunity to take part in clinical trial, a further 21% say not being eligible or not being selected has been the biggest barrier to being in a clinical trial.

Appendices

Appendix 1



#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=0.309
	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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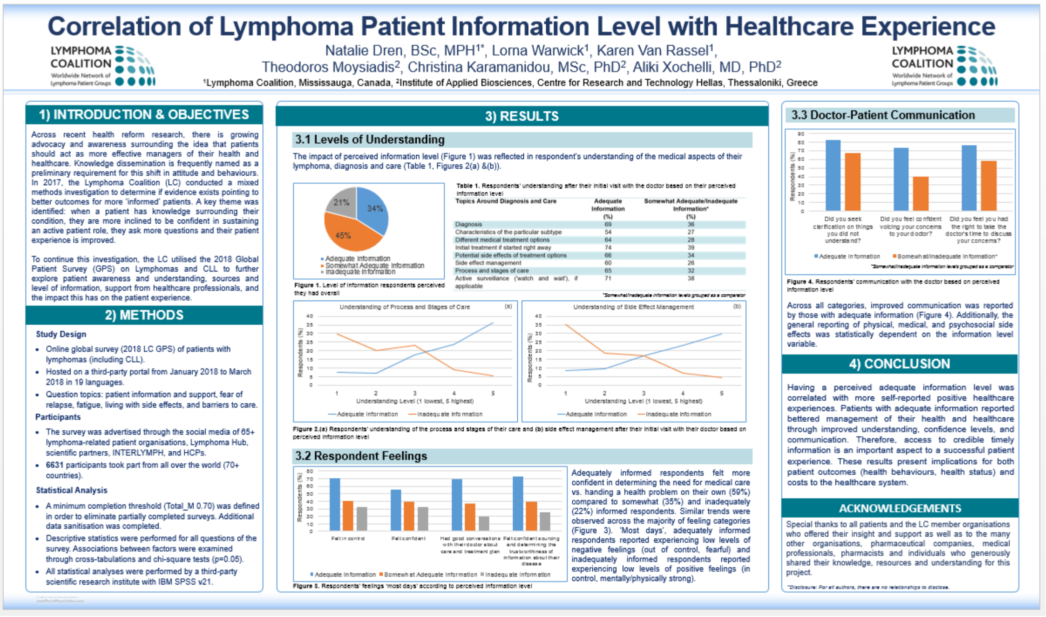

Correlation of Lymphoma Patient Information Level with Healthcare Experience

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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.

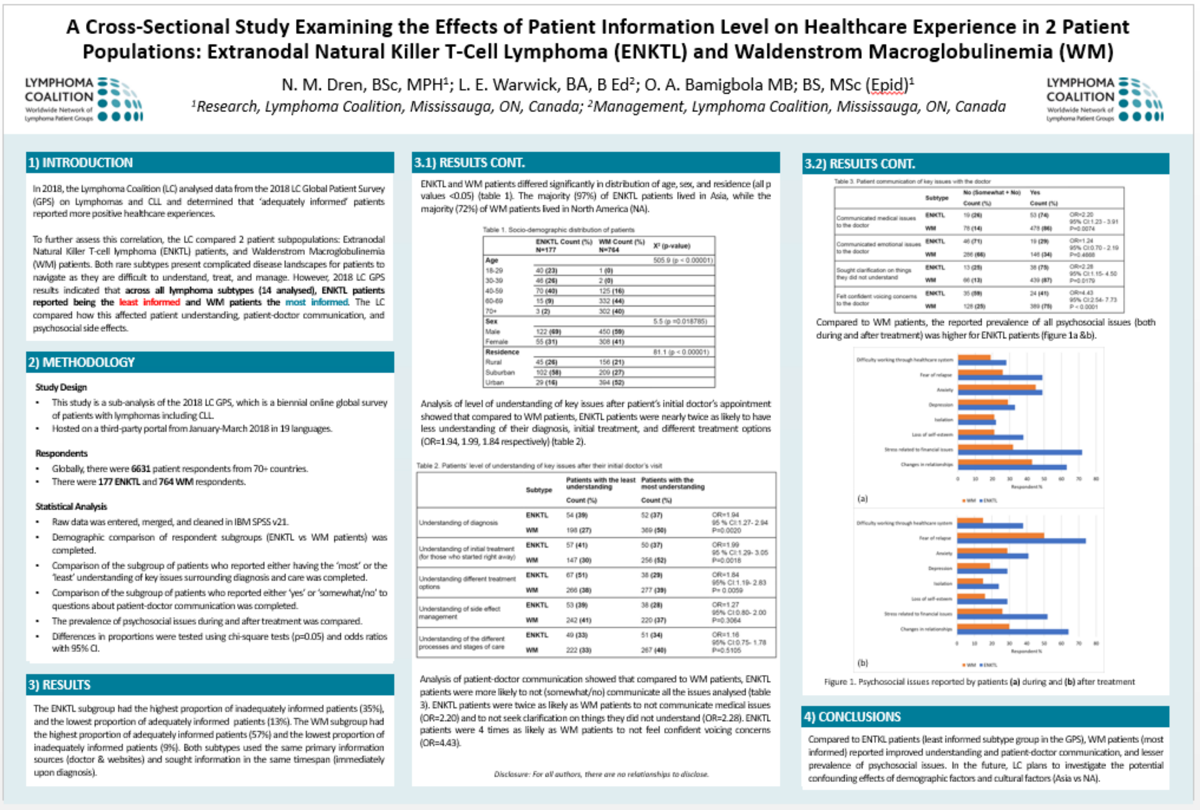
4) CONCLUSION

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

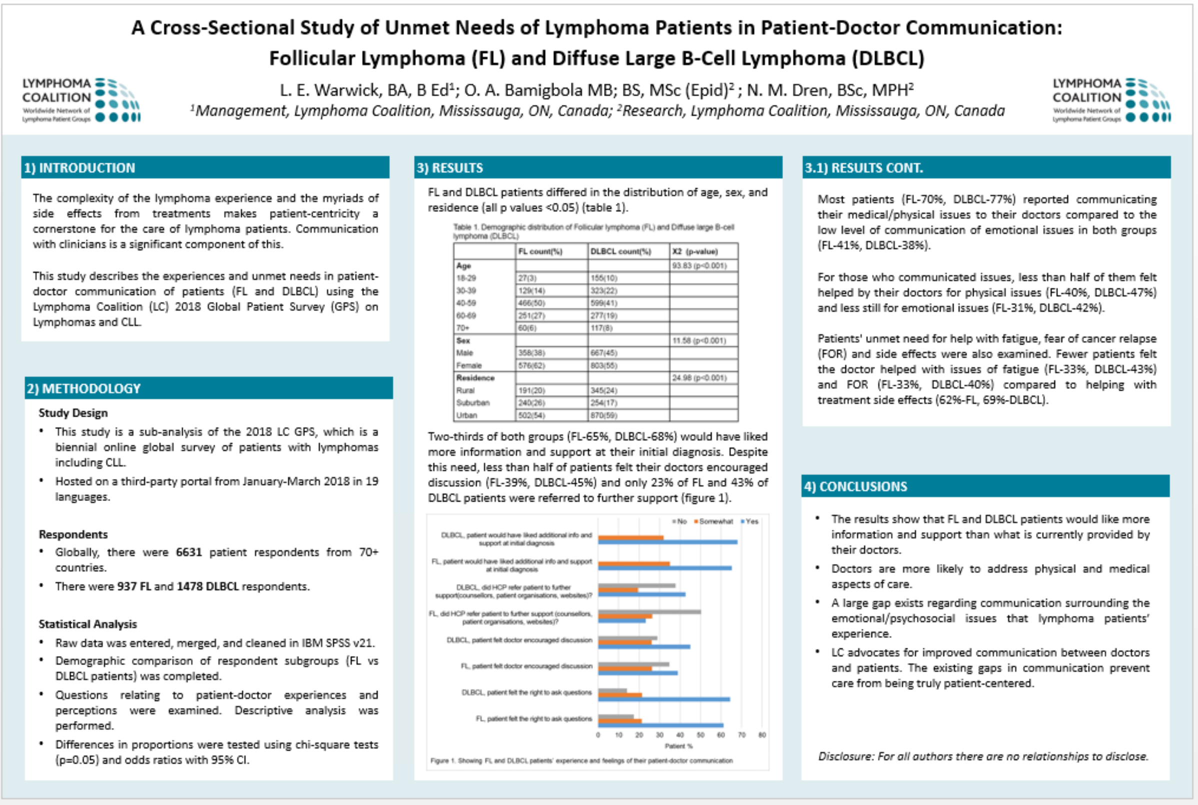
	Subtype	No (Somewhat + No) Count (%)	Yes Count (%)	
Communicated medical issues to the doctor	**ENKTL**	19 **(26)**	53 **(74)**	OR=2.20 95% CI:1.23 - 3.91 P=0.0074
	WM	78 **(14)**	478 **(86)**	
Communicated emotional issues to the doctor	**ENKTL**	46 **(71)**	19 **(29)**	OR=1.24 95% CI:0.70 - 2.19 P=0.4668
	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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