

# 2018

## Global Patient Survey on Lymphomas & CLL

### COUNTRY REPORT



**LYMPHOMA  
COALITION**

Worldwide Network of  
Lymphoma Patient Groups



# SLOVAKIA

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## INTRODUCTION

In early 2008, Lymphoma Coalition (LC) launched its first Global Patient Survey. Since then, LC has established the tradition of launching a global patient survey every two years. Through this survey, patient experience in lymphomas as well as the impact of treatment and care can be better understood, and LC and its global members can bring the patient voice forward.

The 2018 Global Patient Survey went live in January 2018 and closed in March 2018. It was prepared and made available in 19 languages through at least 65 patient organisations' social media, the Lymphoma Hub, scientific partners, INTERLYMPH, and a small portion of the healthcare community. The Institute of Applied Biosciences at CERTH, The Centre for Research and Technology Hellas (INAB | CERTH) performed the analysis and wrote the report.

Overall, 6,631 participants took part from all over the world, demonstrating a marked increase from 4,129 participants in 2016.

## METHODOLOGY

### Survey Development and Launch

Lymphoma Coalition developed the 2018 survey based on the 2016 survey findings and questions, which were modified and expanded as needed. The resulting questions were first reviewed by the LC internal committee, and then sent out to the LC membership for review. The questions were subsequently reviewed by the Institute of Applied Biosciences at CERTH, (INAB | CERTH), which is an external scientific research body. Commentary and feedback from all parties on the English version was analysed, and appropriate revisions and edits were made. The finalised version of the survey contained 29 questions. It was translated into 19 languages by a third-party translation firm. As a final step, translated surveys were sent to LC membership for an opportunity to correct language errors. When the procedure was completed, the survey was launched on a third-party hosting portal. A patient and a caregiver version of the survey were made available. These two surveys were identical in questions and only differed in wording so that a caregiver could answer on behalf of a patient.

### Survey Analysis

In order to perform the analysis, the surveys completed by patients and those completed by caregivers were merged. For example, responses to question 1 completed by patients (Q1 P) and responses to question 1 completed by caregivers (Q1 C) were considered together and analysed as a single group of respondents (Q1 P + Q1 C= Q1 total). The same method was followed for all remaining survey questions.

Descriptive statistics were performed for all questions of the survey. In addition, associations between factors and levels of statistical significance were examined through cross-tabulations and chi-square tests. The level of

significance used for interpretation of findings was p=0.05. All statistical analyses were performed with IBM SPSS v21.

Incomplete responses to the survey were eliminated to enable statistical analysis. For a full account of treating the raw data, performing checks, merging caregiver and patient survey responses as well as elimination of incomplete responses, please see Appendix 1 (page number 44).

## Goals for the 2018 Global Patient Survey

The goal for the 2018 Global Patient Survey was to gather information that will assist LC and its members to begin to understand the patient experience, through examination of the following areas:

- I. Patient Information, Guidance and Support
- II. Fear of Relapse
- III. Fatigue
- IV. Living with Side Effects
- V. Barriers and Impediments

More specifically, the 2018 Global Patient Survey would like to investigate:

- I. Patient awareness and understanding, sources and level of information and support, support from healthcare professionals (HCPS), and the impact this has on the patient experience; how a patient ‘feels’ when they have the information and support they perceive they need;
- II. Trends in patient ‘fear of relapse’ to ensure that patients are getting enough proactive psychosocial support during/after the treatment process;
- III. A variety of fatigue-related issues and demographics, and determine how often patients are communicating these issues to their HCPS;
- IV. Issues around physical/medical/psychosocial side effects; and
- V. Availability and efficacy of services by country and by area (rural/urban), and determine if/how that affects the patient experience (communication, side effects, information-seeking, etc.)

By sharing this information with HCPS, government and the public, LC and its members will be better equipped to educate the lymphoma community and develop advocacy platforms for change, thereby having a positive effect on the lives of lymphoma patients everywhere. This report identifies specific results for the lymphoma population in Slovakia. With this information, LC and Lymfoma Slovensko, the lymphoma patient support group in Slovakia, can be better equipped to serve the needs of their lymphoma community.

## OVERVIEW

*Two hundred and twenty-five (225) respondents from Slovakia took part in the 2018 LC survey. Most respondents were aware of their subtype at the time of the survey. However, 23% found the characteristics of their particular subtype followed by the different medical treatment options, the potential side effects of treatment options and side effect management (21% each) difficult to understand. 41% of respondents in Slovakia wanted additional information and searched for information and support mostly immediately after their diagnosis. The primary sources of information for respondents in Slovakia were doctors and websites. Having adequate information positively influenced feelings such as confidence in determining the trustworthiness of information about their health condition and treatment choices. It also positively impacted respondents' communication with the doctor; for example, feeling like they had the right to take the doctor's time to discuss their concerns.*

*Overall, fatigue, hair loss and muscle weakness were the most frequently reported physical conditions. The most commonly reported medical issues during treatment were stomach-related issues and tingling. Tingling, heart-related issues, and issues with other organs were the most frequent medical issues reported after treatment. Changes in relationships with loved ones, friends or co-workers/social life was the most commonly reported psychosocial issue during treatment, while fear of relapse was common after treatment. In their totality, medical issues, physical conditions and psychosocial issues experienced were diverse and lasted for various lengths of time after treatment.*

*Because of their lymphoma, most respondents in Slovakia had experienced changes in their lifestyle and about half had experienced changes in their independence. Fear of relapse was experienced by respondents during treatment with levels rising significantly after treatment. Respondents' reports of fear of relapse peaked around 2-5 years after treatment, and it was reported by some respondents at 8+ years after treatment. Fear of relapse was associated with feelings of anxiety, depression and isolation, which were rarely discussed with the doctor. Respondents' reports of fatigue peaked immediately following treatment, and it was sometimes reported at 8+ years after treatment. Fatigue affected respondents' independence, but more so their lifestyle, with general activity suffering a large impact.*

*Respondents in Slovakia commonly reported that financials constituted a barrier to treatment, followed by access to treatment centre/prohibitive travel. There were barriers found to be associated with respondents' area of residence. For example, for respondents living in suburban areas, personal support was identified more frequently as a barrier compared to respondents living in urban/rural areas. Respondents' interest in services included treatment information, complementary nutrition/ fitness information, credible website links and downloadable materials. When respondents were asked to rate service types that they had already used, they specified that spiritual support was the service that they found to be most helpful.*

## SURVEY RESULTS

### I) Demographics

A total of 225 individuals from Slovakia answered this year's Global Patient Survey. Of these, 192 (85%) were patients diagnosed with a lymphoma and 33 (15%) were respondents answering on behalf of the patients. From this point forward, both groups will be considered as one and will be referred to as 'respondents'.

#### Respondents Demographic Profile

216 (98%) of respondents said they had never participated in the Global Patient Survey before, while of the 5 (2%) who said they had, some had participated in more than one year so direct correlations could not be made for trending analysis. Four respondents did not respond to this question; therefore, percentages are based on the total number of replies to this question (221).

34% were males, 63% were females and 3% preferred not to answer.

60% of respondents were older than 40 years old.

More specifically:

- 18-29 (14%)
- 30-39 (26%)
- 40-59 (29%)
- 60-69 (24%)
- 70+ (7%)

Regarding the area of residence:

- 55% lived in an urban area
- 9% lived in a suburban area
- 36% lived in a rural area

Responses varied with regards to the level of school completed/highest degree; however, most of the respondents had received some secondary training. In more detail, respondents had completed/acquired:

- Pre-secondary school: 3%
- Some secondary school, no diploma: 13%
- Secondary school diploma or equivalent: 45%
- Some college/university, no diploma/degree: 3%
- College/University diploma/degree: 16%
- Trade/technical/vocational training: 3%

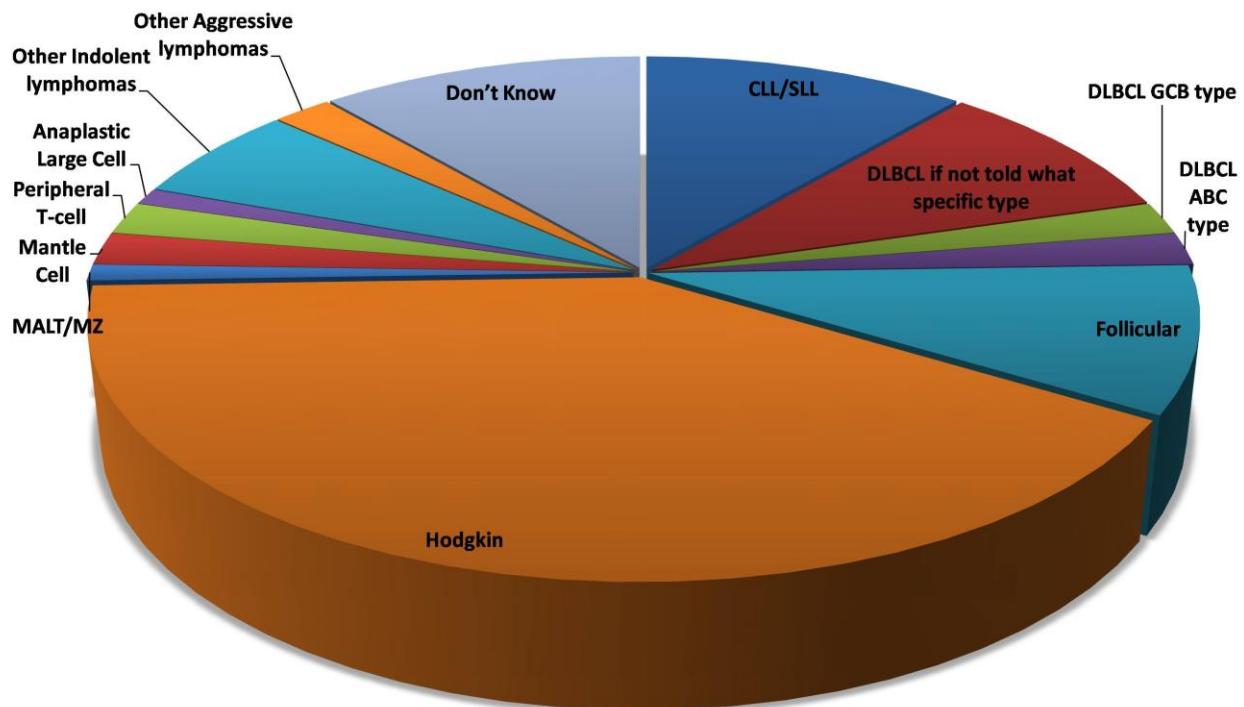
- Master's degree: 14%
- Doctorate degree: 3%

Diagnosis included the following lymphoma subtypes (Table 1) (Figure 1):

**Table 1.** Distribution of lymphoma respondents in Slovakia.

Lymphoma Subtype	% of Lymphoma Respondents
Hodgkin	40
CLL/SLL	11
Don't Know	11
DLBCL if not told what specific type	9
DLBCL GCB type	2
DLBCL ABC type	2
Follicular	9
Other Indolent lymphomas	6
Other Aggressive lymphomas	2
Mantle Cell	2
Peripheral T-cell	2
Anaplastic Large Cell	1
MALT/MZ	1
Burkitt's	1
Cutaneous	1

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**Figure 1.** Distribution of lymphoma respondents in Slovakia.

Abbreviations: CLL, Chronic Lymphocytic Leukemia; SLL, Small Lymphocytic Lymphoma; DLBCL, Diffuse Large B-Cell Lymphoma; GCB, Germinal Centre B-cell; ABC, Activated B-cell

DLBCL lymphoma cases included patients with a DLBCL diagnosis who were not aware of their specific type, and patients belonging to the Germinal Centre (GCB) and Activated B-cell (ABC) DLBCL subtypes. All subtype analysis concerning respondents with a DLBCL diagnosis will refer to those who have not been told their specific subtype as well as those belonging to the Germinal Centre (GCB) or Activated B-cell (ABC) DLBCL subtypes as one group (DLBCL).

Respondents reported their year of diagnosis as:

- 1996-2002: 8%
- 2003-2009: 16%
- 2010-2016: 48%
- 2017: 28%

The stage that best described where the respondent was in their experience:

- 8% were newly diagnosed
- 32% had been diagnosed and were in treatment
- 5% had been diagnosed and have been told treatment is not yet needed
- 11% were in remission and have been treatment free for 2 years or less
- 8% were in remission and have been treatment free for 2 to 5 years
- 18% were in remission and have been treatment free for more than 5 years
- 5% had relapsed for the first time and were in treatment
- 1% had relapsed more than 2 times and were in remission
- 3% had relapsed more than 2 times and were in treatment
- 9% had finished treatment and were in maintenance therapy

## II) Patient Information, Guidance and Support

### LC Objectives:

LC has anecdotal and research-backed insight that the success of the patient may lie in having the right information at the right time. A patient may feel differently depending on how ‘informed’ they feel, and this can translate across many other aspects of their experience (i.e. information/support seeking, communication, side effects). In the LC recent White Paper **“The Knowledge Age: ‘Better’ Outcomes for the ‘Informed Patient?’”**, confidence was a key patient quality behind patients reporting better overall healthcare experiences. We would like to further explore this idea looking at the results from the survey.

### Key Findings:

*Most respondents in Slovakia were aware of their subtype at the time of the survey. However, 23% found the characteristics of their particular subtype followed by the different medical treatment options, the potential side effects of treatment options and side effect management (21% each) difficult to understand. 41% of respondents in Slovakia wanted additional information and searched for information and support mostly immediately after their diagnosis. The primary sources of information for respondents in Slovakia were doctors and websites. Respondents who considered themselves to be adequately informed wanted to overcome the disease and felt in control ‘most days’, they also had good conversations with their doctors. Respondents who were somewhat or inadequately informed also wanted to overcome the disease but felt less in control and did not have good conversations with their doctors as frequently as adequately informed respondents. Adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own, they were also confident in their ability to determine the trustworthiness of information about their health condition and treatment choices. Somewhat adequately and inadequately informed respondents felt less confident in the aforementioned areas. Moreover, compared to respondents with somewhat adequate/inadequate information, respondents with adequate information sought clarification on things they*

*did not understand more frequently, felt more confident voicing their concerns to their doctors, and felt that they had the right to take the doctor's time to discuss their concerns. Most respondents in Slovakia raised questions about side effects during discussions with their doctor and felt that it helped. Respondents' interest in services included treatment information, complementary nutrition/fitness information, credible website links and downloadable materials.*

Most respondents (67%) were made aware of their lymphoma subtype during their initial diagnosis, whereas 14% were not informed and 19% were not sure.

Next, we asked participants to rate on a scale of 1-5 (5 being the highest) their understanding of: (1) their diagnosis, (2) the characteristics of their particular subtype, (3) the different medical options, (4) initial treatment if started right away, (5) the potential side effects of treatment options, (6) side effect management, (7) the process and stages of their care and (8) active surveillance ('watch and wait'), if applicable (Table 2).

Interestingly what respondents in Slovakia had the most difficulty understanding concerned the characteristics of their particular subtype (23%), followed by the different medical treatment options, the potential side effects of treatment options and side effect management (21% each) (responses 1+2).

**Table 2.** Respondents' understanding (1 lowest, 5 highest) after their initial visit to the doctor.

Issues Around Diagnosis and Care	Respondents' Level of Understanding						
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	N/A (%)
Diagnosis	8	8	22	20	36	6	-
Characteristics of the particular subtype	11	12	22	24	19	12	-
Different medical treatment options	13	8	22	22	28	6	1
Initial treatment if started right away	9	8	19	19	37	5	3
Potential side effects of treatment options	11	10	24	17	29	6	3
Side effect management	9	12	27	21	24	7	-
Process and stages of care	8	10	22	21	32	6	1
Active surveillance ('watch and wait'), if applicable	8	8	22	20	36	6	-

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When asked if they would have liked to receive additional medical or associated support information at their initial diagnosis meeting with the doctor:

- 41% would like to receive additional information
- 38% received enough information
- 13% felt overwhelmed and did not want more information as it was too much to take in at the time and,
- 8% did not want additional information.

Respondents were most active in seeking information immediately upon diagnosis (57%) and 1-3 months after the diagnosis (19%). Similarly, they were most active in seeking support immediately upon diagnosis (48%) and

1-3 months after diagnosis (17%). Interestingly 11% of respondents never sought information and 17% of respondents never sought support. (Table 3).

**Table 3.** Respondents' information and support seeking at different time points.

Time Points	Information (%) of Respondents		Support (%) of Respondents
Immediately upon diagnosis	57		48
1-3 months	19		17
3-6 months	5		7
6 months-year	5		4
1 year-onwards	3		7
Never	11		17

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For those who never sought additional information or support, they reported reasons as follows:

- 23% did not want to know/were not interested
- 18% felt they had the support they needed
- 18% felt like they had the level/type of information they needed
- 13% were fearful of what they may find out
- 18% felt like it would not make a difference
- 8% did not want support, wanted to fight this thing on their own
- 2% asked someone (friend, spouse, caregiver etc.) to seek information for them

When asked what level of information they felt they had overall, 62% of respondents felt they had received adequate information, 28% somewhat adequate information and 10% inadequate information. Respondents' associated feelings according to their perceived level of information, adequate, somewhat adequate and inadequate respectively, can be seen in Tables 4, 5, 6 below.

**Table 4.** Feelings experienced by respondents with an adequate information level.

Feelings Experienced with an Adequate Information Level	Associated Frequency of Feelings (%)			
	Most days	Sometimes	Never	N/A
In control	71	27	1	1
Out of control	9	59	29	3
Wanted to get into bed and hide	16	42	41	1
Wanted to overcome this disease	86	11	1	2
Overall fearful	31	50	16	3
Fearful for the future	43	39	18	-
At a loss	14	45	37	4
Confident	45	37	16	2
Felt mentally strong and capable	66	26	4	4

Felt physically strong and capable	48	31	15	6
Had good conversations with my doctor on my care and treatment plan	73	24	1	2
I was confident could determine if I needed to get medical care or if I could handle a health problem myself	40	28	25	7
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	58	33	2	7

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**Table 5.** Feelings experienced by respondents with a somewhat adequate information level.

Feelings Experienced with a Somewhat Adequate Information Level	Associated Frequency of Feelings (%)			
	Most days	Sometimes	Never	N/A
In control	45	52	-	3
Out of control	5	76	17	2
Wanted to get into bed and hide	22	44	29	5
Wanted to overcome this disease	85	11	-	4
Overall fearful	34	58	4	4
Fearful for the future	45	53	1	1
At a loss	19	56	21	4
Confident	23	40	30	7
Felt mentally strong and capable	40	47	11	2
Felt physically strong and capable	23	56	19	2
Had good conversations with my doctor on my care and treatment plan	37	48	7	8
I was confident could determine if I needed to get medical care or if I could handle a health problem myself	19	38	38	5
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	25	59	7	9

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**Table 6.** Feelings experienced by respondents with an inadequate information level.

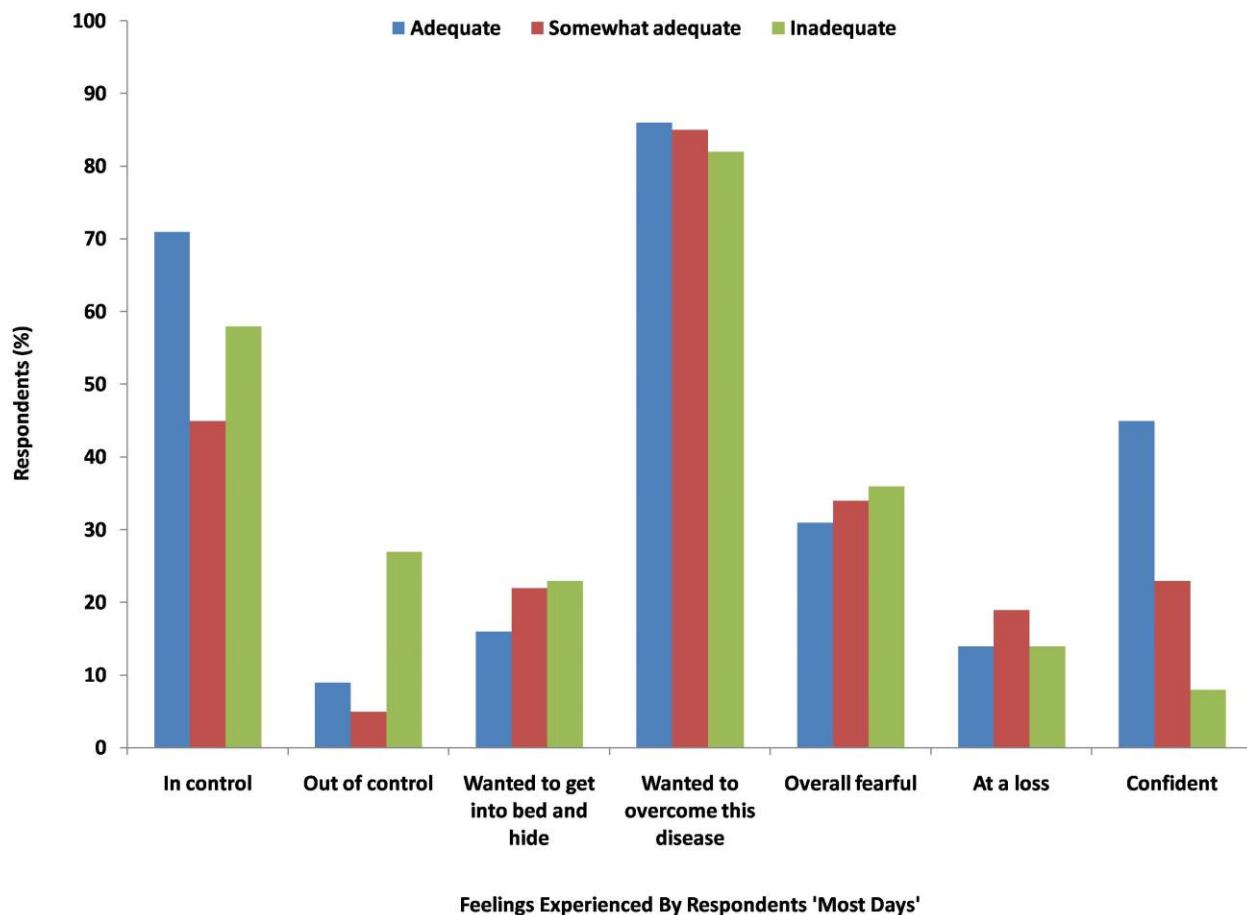
<b>Feelings Experienced with an Inadequate Information Level</b>	<b>Associated Frequency of Feelings (%)</b>			
	<b>Most days</b>	<b>Sometimes</b>	<b>Never</b>	<b>N/A</b>
In control	58	25	-	17
Out of control	27	55	-	18
Wanted to get into bed and hide	23	46	23	8
Wanted to overcome this disease	82	18	-	-
Overall fearful	36	57	7	-
Fearful for the future	44	50	-	6
At a loss	14	57	22	7
Confident	8	67	17	8
Felt mentally strong and capable	31	46	15	8
Felt physically strong and capable	14	29	50	7
Had good conversations with my doctor on my care and treatment plan	17	17	58	8
I was confident could determine if I needed to get medical care or if I could handle a health problem myself	34	58	-	8
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	31	23	38	8

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In analysing what respondents felt ‘most days’ according to their perceived information level, respondents who considered themselves to be adequately informed wanted to overcome the disease (86%), felt in control (71%) and had good conversations with their doctors (73%). Respondents who were somewhat adequately informed wanted to overcome the disease (85%) but felt in control in only 45% of cases and had good conversations with their doctors in 37% of cases. Inadequately informed respondents wanted to overcome the disease most days (82%) but felt in control in 58% of cases and had good conversations with their doctors in only 17% of cases.

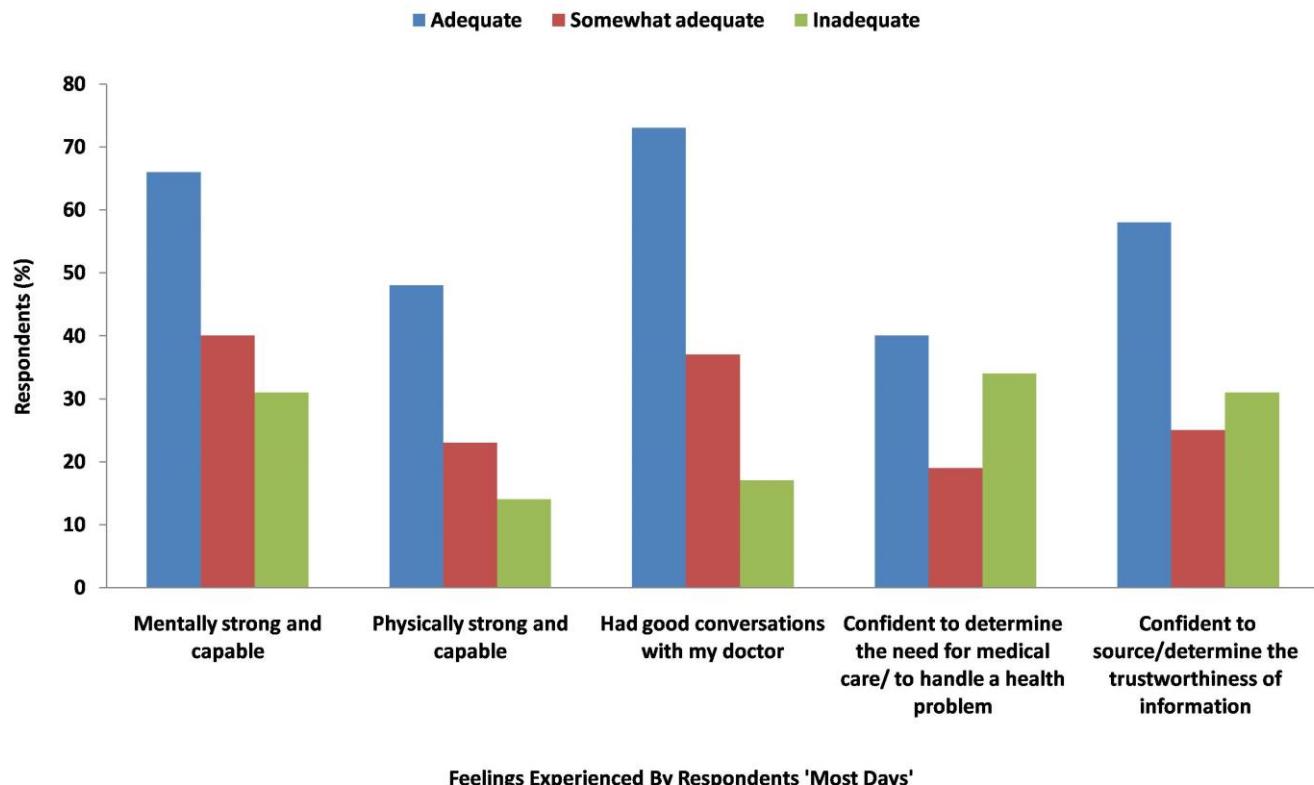
Moreover, ‘most days’, adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own (40%), as well as determine the trustworthiness of information about their health condition and treatment choices (58%). Somewhat adequately informed and inadequately informed respondents, ‘most days’, felt less confident in these same areas (19% and 25%, and 34% and 31% respectively).

The perceived level of information seems to play a significant role with regards to the way respondents are feeling. Please see Figures 2a, 2b below, which provide a graphic comparison among adequately, somewhat adequately and inadequately informed respondents’ feelings.



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**Figure 2a.** Feelings experienced by respondents with different perceived information levels 'most days'.



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**Figure 2b.** Feelings experienced by respondents with different perceived information levels 'most days'.

During their patient experience, respondents' primary sources for information were:

- Doctor 83%
- Websites 58%
- Family/friends 24%
- Online blogs/social media 23%
- Nurse 18%
- Patients organisations 15%
- Other 5%

Table 7 describes respondents' communication with the doctor, and the impact that this communication may have had on the different issues that the respondents faced.

**Table 7.** Communication of topics concerning the patient experience with the doctor.

Communication with Doctor on Topics Concerning the Patient Experience	Responses			
	Yes (%)	Somewhat (%)	No (%)	N/A (%)
Have you communicated any of your physical and/or medical issues to the doctor?	83	13	2	2
Was the doctor able to help?	63	30	4	3
Have you communicated any of your emotional issues to the doctor?	35	19	40	6
Was the doctor able to help?	46	26	15	13
Did you bring forward questions about side effects?	69	15	12	4
Was the doctor able to answer your questions?	69	22	3	6
Was the doctor able to help you cope with your side effects by providing medication or other support?	67	23	4	6
Did you seek clarification on things you did not understand?	70	14	12	4
Was the doctor able to answer your questions?	68	21	4	7
Did you discuss your fear of relapse with your doctor?	39	17	38	6
Do you feel that it helped to alleviate the fear?	32	31	24	13
Did the doctor or nurse refer you to further support you were able to use?	30	15	47	8
Did you feel confident/comfortable voicing your concerns to your doctor?	58	24	10	8
If you experienced fatigue issues, did the doctor or nurse refer you to further support or information that you were able to use?	42	18	31	9
Did you feel you had the right to take the doctor's time to discuss any of the above during your visits?	58	19	14	9

Did the doctor encourage discussion with you on any of the above?	63	19	12	6
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In their totality respondents who felt, at the time of the survey, that they had adequate information also reported that they had a greater understanding of the following issues after the initial visit to the doctor as reflected in Table 8.

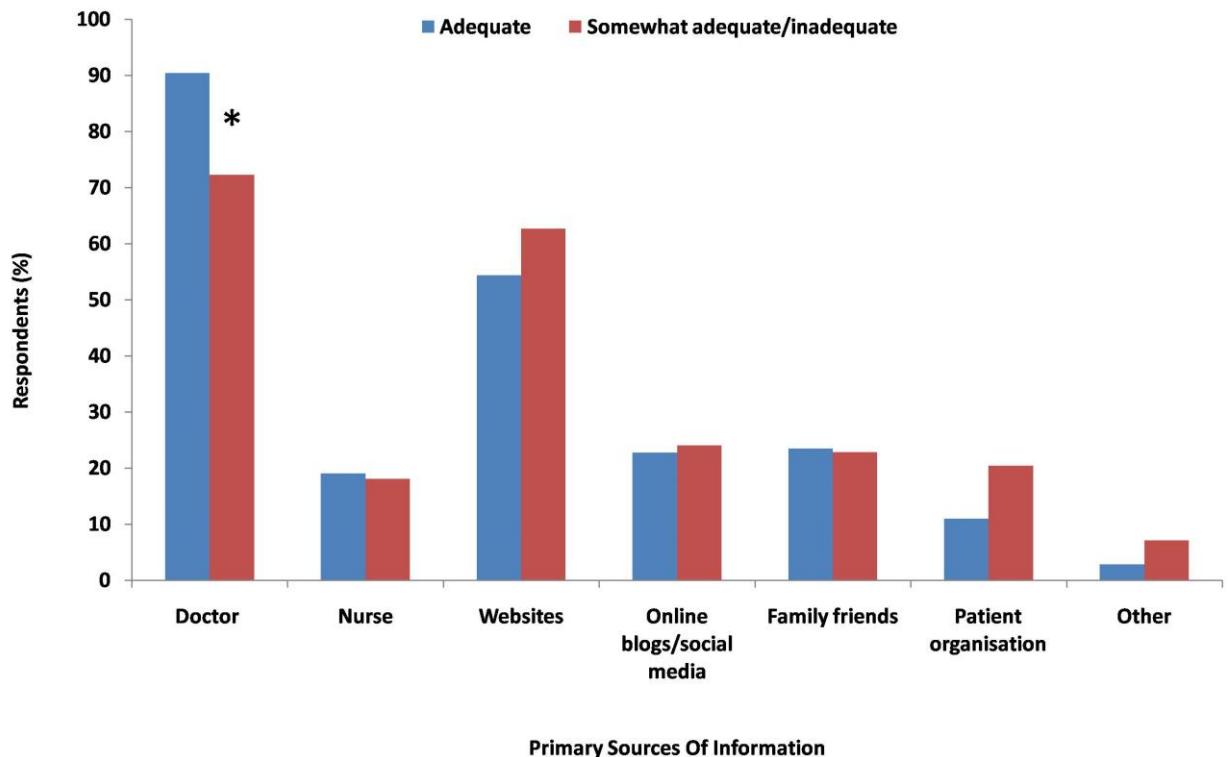
**Table 8.** Respondents' understanding after the initial visit with the doctor based on their perceived level of information.

Topics Around Diagnosis and Care	Adequate Information	Somewhat Adequate/ Inadequate Information*
	(%)	(%)
Diagnosis	72	37
Characteristics of the particular subtype	61	28
Different medical treatment options	69	29
Initial treatment if started right away	76	34
Potential side effects of treatment options	64	25
Side effect management	59	31
Process and stages of care	66	40
Active surveillance ('watch and wait'), if applicable	58	37

\* For the purpose of analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information.

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Figure 3 points to respondents' primary sources of information; those who felt they had received adequate information differed significantly from those who felt they had somewhat adequate/inadequate information regarding their primary sources of information. Those with an adequate information level more frequently reported doctors as their main information source.



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**Figure 3.** Primary sources of information by respondents' perceived level of information.  
The asterisk symbolises statistically significant differences.

Interestingly, no associations could be inferred between perceived level of information and area of residence (Table 9).

**Table 9.** Respondents' perceived level of information based on the area of residence.

Area of Residence	Respondents' Level of Information		
	Adequate (%)	Somewhat Adequate (%)	Inadequate (%)
Rural	55	32	13
Urban	67	25	8
Suburban	55	40	5

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For analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information. Respondents with adequate information sought clarification on things they did not understand more frequently (79%) compared to those with perceived somewhat adequate/inadequate information (57%). Moreover, respondents with adequate information felt more confident voicing their concerns to their doctors (73%) compared to respondents with somewhat adequate/inadequate information (39%).

The impact of the perceived level of information on respondent-reported confidence was higher in respondents who felt they had adequate information. Of these, 45% felt confident most days versus 20% of those who felt they had received somewhat adequate /inadequate information.

58% of respondents with adequate information felt that they had the right to take the doctor's time to discuss their concerns as opposed to 35% of respondents with somewhat adequate/inadequate information.

When asked what barriers had been experienced in receiving lymphoma treatment, respondents who felt they had received somewhat adequate/inadequate information identified barriers more frequently compared to those who felt they had received adequate level of information (Table 10).

Interestingly, experiencing no barriers in receiving lymphoma treatment was the option most reported (37%) by those respondents with a reported adequate information level. Only 17% of the respondents with a somewhat adequate/inadequate level of information reported experiencing no barriers (Table 10).

**Table 10.** Barriers in receiving treatment based on the respondents' perceived level of information.

Barriers in Receiving Treatment	Perceived Level of Information	
	Adequate Information (%)	Somewhat Adequate/Inadequate Information* (%)
Financial	36	63
Access to treatment centre/prohibitive travel	34	73
Access to the most up to date treatment	5	39
Wait time was longer than necessary	16	35
Personal support	0	5
Specialty physician available locally	7	12
Could not give up caregiver role (child, parent, disabled person) while in treatment	6	10
None	37	17

\* For the purpose of analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information.

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When asked about patient services, respondents showed the greatest interest in treatment information (76%) and reported less interest in in-person support groups (46%) and phone-line support (47%) (Table 11).

**Table 11.** Respondents' interest in different services.

Service Type	Interest of Total Respondent Population (%)
Treatment information	76
Complementary nutrition/fitness information	72
Credible website links	72
Downloadable materials	71
Information on patient organisation services	70
Fatigue support	69
Financial support	67
Hard copy materials	67
Patient organisation support	65
Clinical trial options	63
Professional physical support	62
Professional emotional support	61
Support in navigating the insurance system	59
Online chats	57
Live education sessions	55
Phone-line support	47
In person support groups	46

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When compared to the total respondent population, those who felt they had adequate information expressed interest in services in a different order. Their major interest focused on downloadable materials (69%) followed by treatment information (67%), though they also reported less interest in phone-line support (39%) and in-person support groups (40%) (Table 12).

**Table 12.** Interest in different services by respondents with perceived adequate information.

Service Type	Interest of Adequate Information (%)
Downloadable materials	69
Treatment information	67
Complementary nutrition/fitness information	64
Credible website links	64
Information on patient organisation services	63
Financial support	61
Fatigue support	61
Hard copy materials	60
Clinical trial options	59

Support in navigating the insurance system	58
Patient organisation support	56
Professional physical support	56
Professional emotional support	52
Live education sessions	51
Online chats	51
In person support groups	40
Phone-line support	39

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Interest in different patient services was also analysed by subtype. Subtype analysis was restricted only to lymphomas with more than 10 answers in this question to reach significant conclusions.

Respondents with a CLL/SLL diagnosis were mostly interested in hard copy materials (65%), information on patient organisation services (61%), clinical trial options (60%) and fatigue support (60%).

Respondents with a Hodgkin diagnosis were found to be more interested in treatment information (88%) complementary nutrition/fitness information (88%) and credible website links (87%) (Table 13).

**Table 13.** Interest in different services by respondents with different lymphoma diagnosis.

Service Type	CLL/SLL (%)	Hodgkin (%)
Professional physical support	27	74
Professional emotional support	47	75
Information on patient organisation services	61	81
Credible website links	57	87
Patient organisation support	46	77
Phone-line support	44	52
In person support groups	33	62
Online chats	33	78
Live education sessions	50	60
Hard copy materials	65	68
Downloadable materials	53	77
Financial support	50	78
Clinical trial options	60	70
Treatment information	53	88
Complementary nutrition/fitness information	47	88
Support in navigating the insurance system	38	76
Fatigue support	60	77

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In considering different stages of the patient experience, respondents who reported they had relapsed more than two times and were in remission, respondents who reported they had relapsed for the first time and were in treatment and respondents who had been diagnosed and have been told treatment is not yet needed were the most confident in voicing their concerns to their doctor (Table 14).

**Table 14.** Confidence in voicing concerns to the doctor at different stages of the lymphoma experience.

Stages	Responses			
	Yes (%)	Somewhat (%)	No (%)	N/A (%)
Newly diagnosed	44	44	11	1
Diagnosed and currently in treatment	64	19	6	11
Diagnosed and have been told that treatment is not yet needed	75	-	-	25
In remission and treatment free for 2 years or less	47	20	33	-
In remission and treatment free for 2 to 5 years	50	33	8	9
In remission and treatment free for more than 5 years	54	19	12	15
Have relapsed for the first time and currently in treatment	75	25	-	-
Have relapsed more than two times and in remission	83	17	-	-
Have relapsed more than two times and currently in treatment	50	42	8	-
Have finished treatment and currently in maintenance therapy	44	44	11	1
Have transformed	64	19	6	11

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### III) Fear of Relapse

#### LC Objectives:

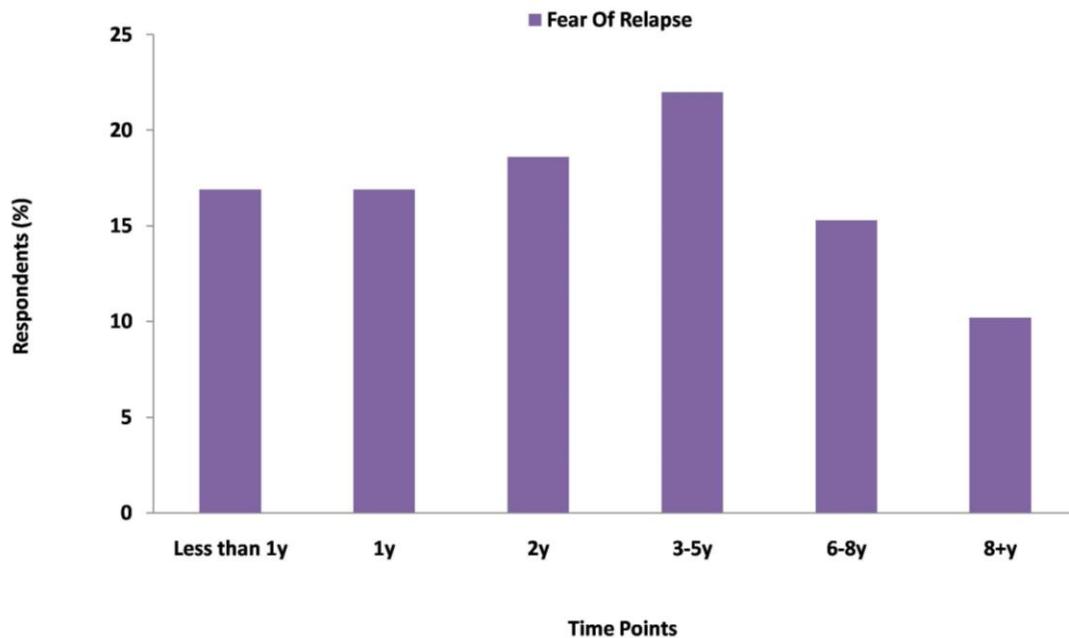
The 2016 Global Patient Survey indicated that psychosocial conditions have continued to negatively impact patients, with the fear of relapse having the most profound effect occurring most particularly after treatment (87% of those who reported fear of relapse reported it as occurring after treatment). We will further investigate ‘fear of relapse’ to ensure that patients are getting enough proactive psychosocial support during and after treatment.

#### Key Findings:

*Fear of relapse was experienced by respondents during treatment with levels rising significantly after treatment. Respondents reports of fear of relapse peaked around 2-5 years after treatment, and it was reported by some respondents to continue for 8+ years after treatment. Fear of relapse was associated with feelings of anxiety, depression and isolation. However, these feelings were rarely discussed with the doctor. Among respondents with fear of relapse, most felt they had adequate or somewhat adequate information. Both during and after treatment, respondents experiencing fear of relapse commonly reported doctors and websites as their primary sources of information.*

Fear of relapse was a major issue for respondents as it was present during and after treatment, showing a remarkable increase from 38% during treatment to 60% after treatment. Fear of relapse lasted for various lengths of time (Table 24) (Figure 4).

Of those who experienced fear of relapse, 39% discussed and somewhat discussed (17%) this fear with their doctor. Only, 32% felt this helped and 31% felt it helped somewhat. However, 24% did not feel it helped alleviate the fear.



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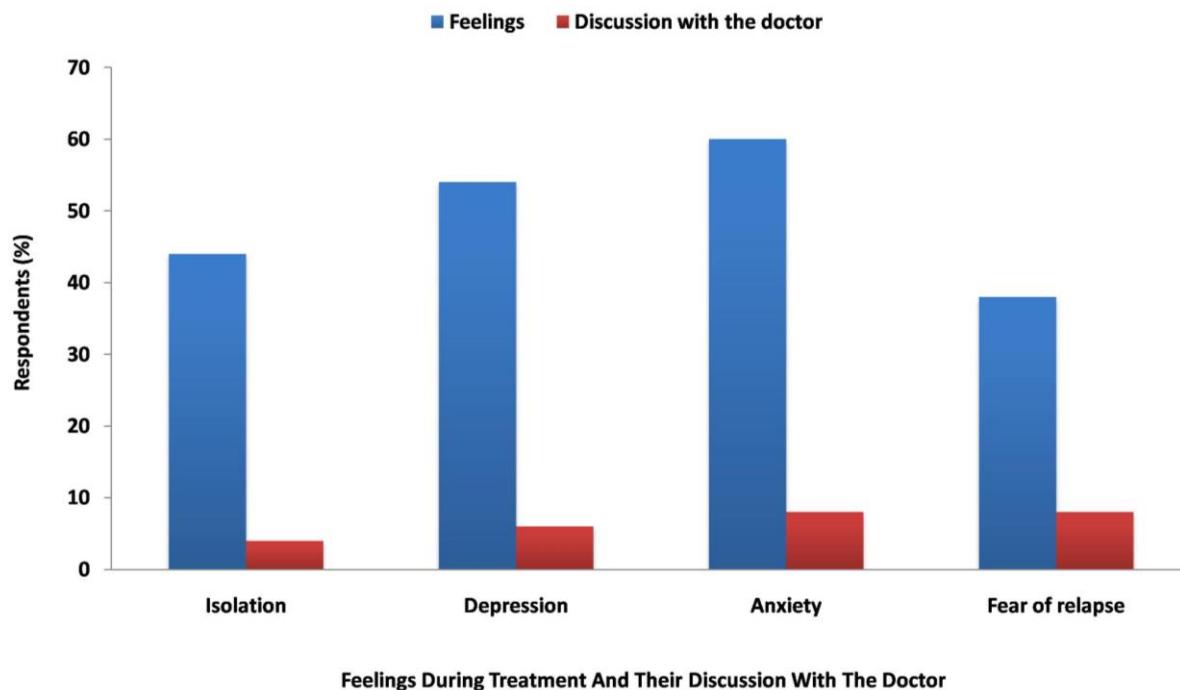
**Figure 4.** How long fear of relapse lasted amongst respondents.

In some cases, fear of relapse was accompanied with feelings of isolation, depression and anxiety either during treatment or after treatment (Tables 15 and 16) (Figures 5 and 6). Beside each feeling, respondents were asked to indicate if they had discussed it with their doctor. Respondents did not discuss their feelings of isolation, depression and anxiety as often as they felt them. Interestingly, even though most feelings were reported less frequently, they were still reported after the end of treatment.

**Table 15.** Feelings of isolation, depression and anxiety during treatment amongst respondents who experienced fear of relapse and their discussion with the doctor.

Feelings During Treatment	(%)	I Have Discussed It with My Doctor (%)
Isolation	44	4
Depression	54	6
Anxiety	60	8
Fear of relapse	38	8

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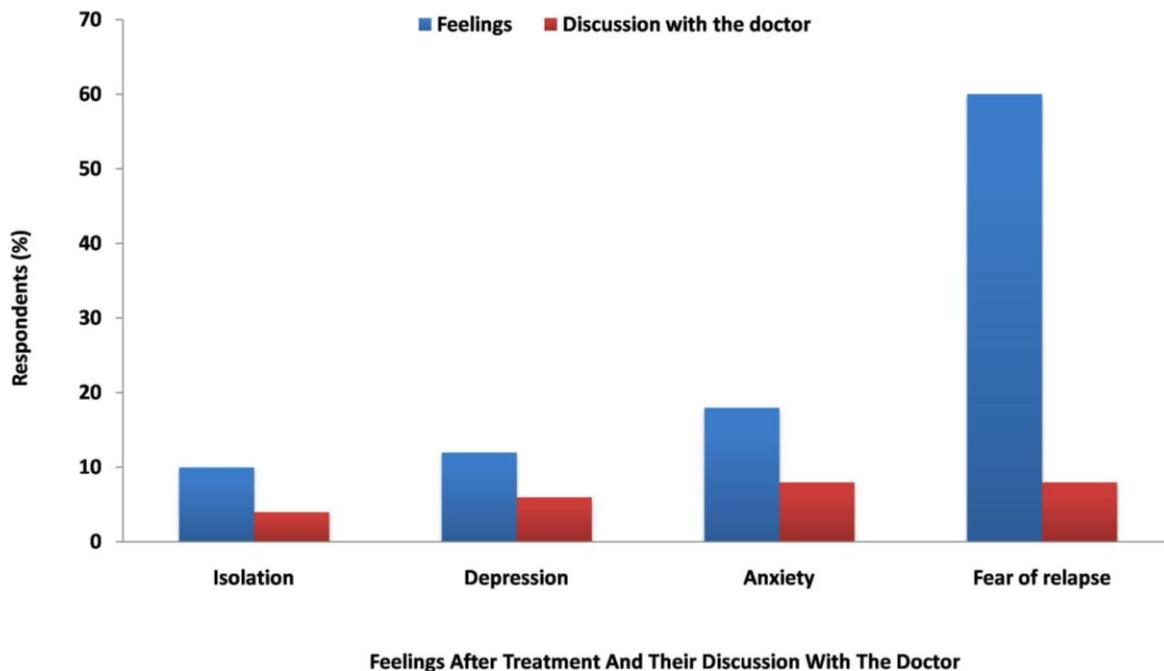
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**Figure 5.** Feelings of isolation, depression and anxiety during treatment amongst respondents who experienced fear of relapse and their discussion with the doctor.

**Table 16.** Feelings of isolation, depression and anxiety after treatment amongst respondents who experienced fear of relapse and their discussion with the doctor.

Feelings After Treatment	(%)	I Have Discussed It with My Doctor (%)
Isolation	10	4
Depression	12	6
Anxiety	18	8
Fear of relapse	60	8

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**Figure 6.** Feelings of isolation, depression and anxiety after treatment amongst respondents who experienced fear of relapse and their discussion with the doctor.

Among those with fear of relapse, 60% had adequate information, 25% had somewhat adequate and 15% had inadequate information.

Sources of information for those who experienced fear of relapse during treatment were doctors 84%, nurses 12%, websites 66%, online blogs 34%, family/friends 28% and patient organisations 10%. Those who experienced fear of relapse after treatment used sources as follows: doctors 83%, nurses 23%, websites 78%, online blogs 33%, family/friends 30%, and patient organisations 28%.

Moreover, for those who experienced fear of relapse, we tried to identify possible differences with regards to the use of sources depending on the level of information they felt they had. When directly examining the use of information sources by adequately informed respondents, it seems that respondents with fear of relapse rely more on doctors and websites both during and after treatment (90% and 72% vs. 89% and 82% respectively).

## IV) Fatigue

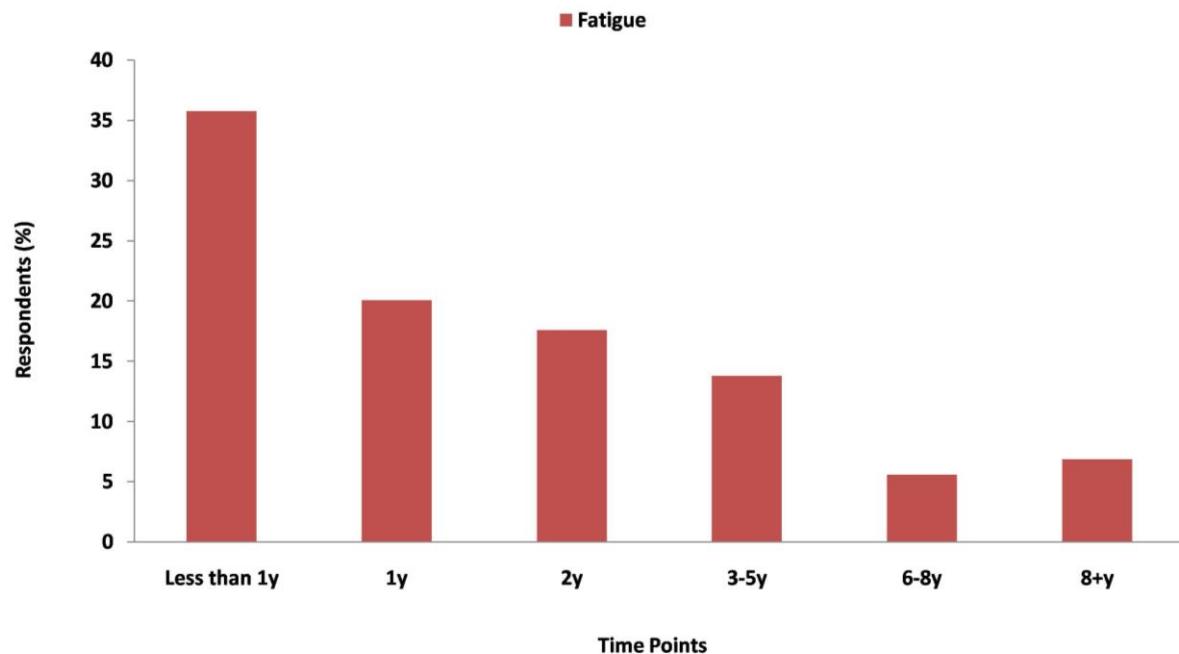
### LC Objectives:

The 2016 Global Patient Survey indicated that physical conditions continue to have a negative impact on patients, with fatigue still the pre-eminent condition reported in most countries. Despite its prominence, fatigue remains largely undiscussed across the healthcare community. We would like to further investigate a variety of fatigue-related issues and demographics and determine how often patients are communicating these issues to their healthcare providers.

### Key Findings:

*Fatigue was the most frequent physical condition experienced by respondents. Respondent's reports of fatigue peaked immediately following treatment, but some also reported it at 8+ years after treatment. Fatigue affected respondents' independence but more so their lifestyle, with general activity suffering a large impact. Interestingly, respondents who reported fatigue showed a higher percentage of fear of relapse and experienced more changes in relationships with loved ones, friends or co-workers/social life after the end of treatment. In terms of psychosocial issues, due to fatigue, respondents experienced concerns about body image/physical appearance changes and stress related to financial issues during treatment. Fear of relapse and changes in relationships with loved ones, friends or co-workers/social life were the most frequently reported psychosocial issues after treatment.*

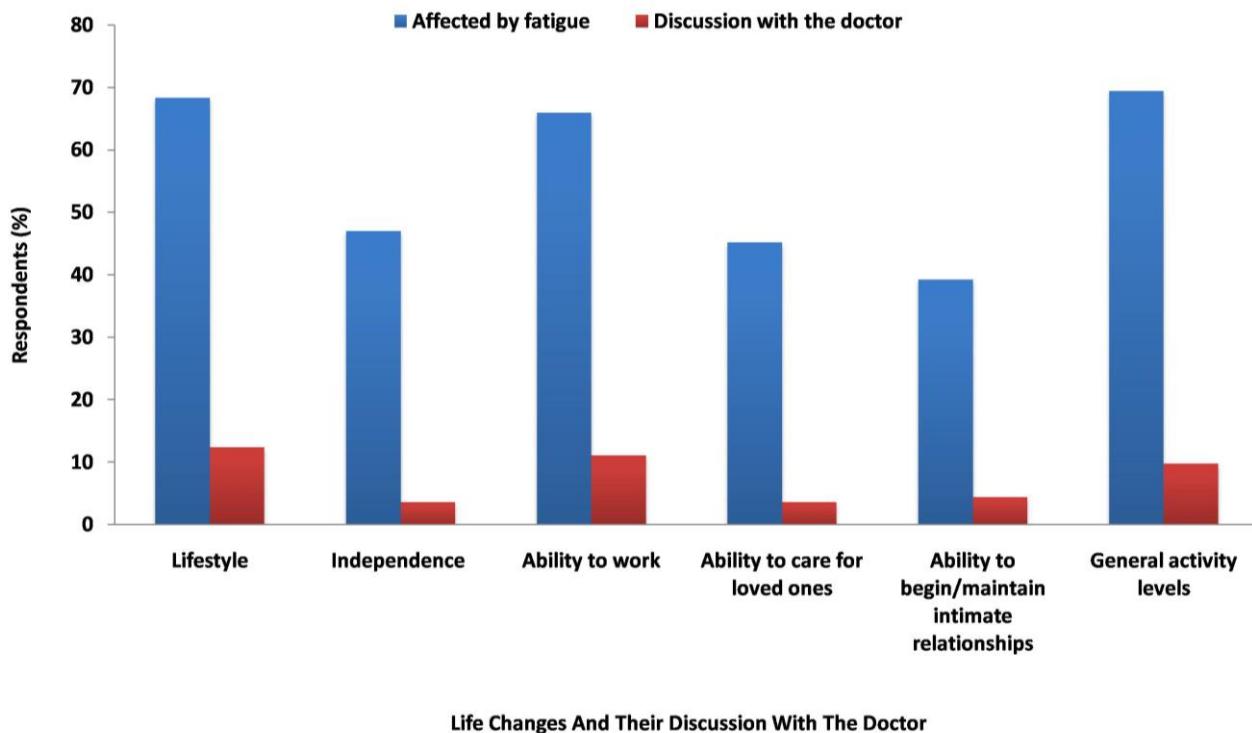
Fatigue was the most frequent physical condition affecting respondents' sense of wellbeing since diagnosis. It was reported by 83% of respondents and it lasted for various lengths of time (See Table 19) (Figure 7).



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**Figure 7.** How long fatigue lasted amongst respondents.

Those who experienced fatigue also reported that because of it, they have also experienced changes in several areas of life (Figure 8). Respondents reported that life has changed completely (42%) or moderately changed (68%), or that they sleep well but the fatigue does not go away (39%). Only the minority reported that fatigue is constant however it has not changed their daily activities (35%).



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**Figure 8.** Life changes brought on by fatigue and their discussion with the doctor.

Amongst respondents who reported fatigue, some also reported that their lifestyle was affected (68%) as was their independence (47%), and only in 30% of these cases did the doctor refer them for support.

Fatigue was associated with other issues as well (Table 17). Interestingly, respondents who reported fatigue showed a higher percentage of fear of relapse after the end of treatment (60%) than during treatment (38%). In addition, respondents who reported fatigue also experienced changes in relationships with loved ones, friends or co-workers/social life more frequently after treatment (36%) than during treatment (9%).

**Table 17.** Psychosocial Issues affecting wellbeing during and after treatment amongst respondents with fatigue.

Psychosocial Issues Affecting Wellbeing During and After Treatment Amongst Respondents with Fatigue	Treatment	
	During (%)	After (%)
Changes in relationships with loved ones, friends or co-workers/social life	9	36
Stress related to financial issues	42	34
Loss of self-esteem	17	8
Concerns about body image/physical appearance changes	44	21
Loss/reduction in employment	25	26
Isolation	34	12
Depression	37	19
Anxiety	39	24
Fear of relapse	38	60
Difficulty on the job or in school	17	17
Problems getting health or life insurance coverage	10	5
Difficulty working effectively through the healthcare system	12	10
None	12	15

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## V) Living with Side Effects

### LC Objectives:

It is important that LC continue its work investigating the issues around physical, medical, and psychosocial side effects. This includes exploring side effect management plans and further examination of longer-term medical issues reported by respondents. There appears to be a need for education and further examination of the relapsed stage (among all other stages) of the patient experience, as there seems to be an increased level of psychosocial issues in this group of patients. A discussion may need to be opened about what is an acceptable side effect, both short- and long-term. There may be an opportunity in this respect for LC to help make a difference at the clinical trials development stage.

### **Key Findings:**

*Overall, fatigue, hair loss and muscle weakness were the most frequently reported physical conditions. The most commonly reported medical issues during treatment were stomach-related issues and tingling. Tingling, heart-related issues, and issues with other organs were the most frequent medical issues reported after treatment. Changes in relationships with loved ones, friends or co-workers/social life was the most commonly reported psychosocial issue during treatment, while fear of relapse was very common after treatment. Respondents reports of fear of relapse peaked around 2-5 years after treatment, but some also reported it at 8+ years after treatment. In their totality, medical issues, physical conditions and psychosocial issues experienced were diverse and lasted for various lengths of time after treatment. Because of their lymphoma, most respondents in Slovakia had experienced changes in their lifestyle and about half had experienced changes in their independence. Respondents communicated medical issues to the doctor more frequently than they did emotional issues. Respondents raised the topic of treatment side effects in conversation with their doctor, and they often found ways to be supported.*

Looking at the entire sample, there is a range of physical conditions affecting the wellbeing of respondents. A significant percentage of respondents are facing fatigue (83%), hair loss (58%) and muscle weakness (49%) (Table 18). Respondents have reported these physical conditions to last for various lengths of time.

**Table 18.** Physical conditions affecting wellbeing since diagnosis.

Physical Conditions	Percentage of Respondents (%)
Fatigue	83
Hair loss	58
Muscle weakness	49
Changes in taste and smell	44
Nausea and vomiting	40
Changes in sleep patterns	39
Night sweats	39
Weight loss	34
Weight change	33
Bowel changes	32
Loss of appetite	30
Itching	24
Shortness of breath	23
Skin reactions	21
Change in sexual function	21
Problems fighting infections	17
Swelling of arms and legs	16
Trouble concentrating	16
Cramps	15
Fluid retention	14
Mucositis/mouth ulcers	13
Memory loss	10
Burning	8
Loss of fertility	7
Incontinence	7
Viral reactivations	5
Problems concentrating	5
I had no changes in my physical condition whatsoever	2

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**Table 19.** How long did these physical conditions affecting wellbeing last?

Physical Conditions	Time Points					
	Less than 1y (%)	1y (%)	2y (%)	3-5y (%)	6-8y (%)	8+y (%)
Fatigue	36	20	18	13	6	7
Hair loss	72	18	2	5	1	2
Muscle weakness	45	22	12	12	4	5
Trouble concentrating	62	11	10	9	5	3
Changes in sleep patterns	54	16	14	9	2	5
Changes in taste and smell	69	15	6	6	2	2
Bowel changes	66	17	5	5	2	5
Aching joints	50	12	12	13	7	6
Nausea and vomiting	84	7	5	3	-	1
Problems fighting infections	48	13	18	12	3	6
Memory loss	72	12	10	4	2	-
Skin reactions	63	18	5	3	6	5
Mucositis/mouth ulcers	75	10	7	2	2	4
Loss of appetite	79	10	6	3	1	1
Change in sexual function	54	11	12	12	3	8
Weight loss	65	20	8	5	1	1
Fluid retention	62	12	18	6	2	-
Weight change	49	26	5	11	4	5
Loss of fertility	63	12	2	5	2	16
Swelling of arms and legs	56	20	10	8	-	6
Itching	63	15	8	6	4	4
Burning	81	13	-	3	-	3
Incontinence	79	7	3	7	1	3
Cramps	68	5	5	9	6	7
Shortness of breath	60	9	14	7	3	7
Viral reactivations	61	15	12	6	3	3
Night sweats	60	22	10	5	-	3
Problems concentrating	64	15	15	4	2	-

\* Relative frequencies are displayed, and the percentages were calculated per issue (rows), and then compared within different time points (columns) to show the length of time each issue impacts patients reporting this specific concern. Each row totals 100%. Refer to Table 18 to see overall issue prevalence.

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Focusing on different lymphoma subtypes, it was evident that different physical conditions were more prominent in different lymphomas (Table 20). Subtype analysis was restricted only to lymphomas with more than 10 answers in this question to reach significant conclusions. For all respondents, the most prominent physical condition was fatigue, except for respondents with a DLBCL (not told the specific subtype, GCB and ABC

subtype) diagnosis; for these respondents, the most frequently reported issue was hair loss (81%) followed by fatigue (79%) (Table 20).

**Table 20.** Physical conditions amongst respondents with different lymphomas.

Physical Conditions	Lymphoma subtypes				
	CLL/SLL (%)	DLBCL (%)	Follicular (%)	Other indolent lymphomas (%)	Hodgkin (%)
Fatigue	80	79	84	92	84
Hair loss	44	81	37	31	70
Muscle weakness	48	58	42	54	52
Trouble concentrating	32	7	21	31	12
Changes in sleep patterns	36	48	42	39	42
Changes in taste and smell	40	54	16	39	50
Bowel changes	20	41	53	8	34
Aching joints	28	36	21	23	37
Nausea and vomiting	36	48	42	23	48
Problems fighting infections	28	31	21	-	13
Memory loss	20	10	11	-	7
Skin reactions	16	7	37	15	23
Mucositis/mouth ulcers	4	21	16	-	16
Loss of appetite	32	25	37	23	30
Change in sexual function	24	21	32	-	27
Weight loss	48	35	42	23	30
Fluid retention	12	25	11	8	14
Weight change	32	31	21	15	31
Loss of fertility	12	14	5	-	5
Swelling of arms and legs	20	11	16	23	16
Itching	24	18	32	-	27
Burning	-	4	11	8	11
Incontinence	12	7	11	8	4
Cramps	4	7	16	15	21
Shortness of breath	36	17	-	39	23
Viral reactivations	16	7	-	8	1
Night sweats	60	35	32	15	35
Problems concentrating	8	3	-	-	7
I had no changes in my physical condition whatsoever	8	-	5	-	1
Other	-	-	-	-	5

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Many of the medical issues that respondents had to cope with during their treatment were less reported after the end of treatment, whereas some others remained on the same levels. Stomach-related issues (40%) and tingling (30%) were commonly reported during treatment. Tingling (35%), heart-related issues (27%) and issues with other organs (27%) were commonly reported after treatment (Tables 21 and 22).

**Table 21.** Medical issues amongst respondents during and after treatment.

Medical Issues	Treatment	
	During (%)	After (%)
Heart-related issues	20	27
Stomach-related issues	40	21
Issues with other organs	24	27
Diarrhea	27	10
Numbness	23	8
Neutropenia	28	13
Osteoporosis	11	16
Any other blood condition	14	12
Secondary cancer	3	2
Diabetes	5	6
Tingling	30	35
Eyesight issues	22	22
Enlarged lymph nodes	17	13
Pain	29	19
Headaches	29	25
Bleeding	9	5
Thrombosis	5	4
I do not have any other medical issues	13	22

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**Table 22.** How long medical issues lasted after treatment.

Medical Issues	Time Points					
	Less than 1y (%)	1y (%)	2y (%)	3-5y (%)	6-8y (%)	8+y (%)
Heart-related issues	30	15	13	15	5	22
Stomach-related issues	37	20	19	7	4	13
Issues with other organs	34	3	16	13	9	25
Diarrhea	61	11	7	7	-	14
Numbness	35	22	30	9	4	-
Neutropenia	68	-	18	5	-	9
Osteoporosis	24	-	28	7	20	21
Any other blood condition	61	11	17	11	0	0
Secondary cancer	55	18	9	-	18	0
Diabetes	39	15	-	8	23	15
Tingling	34	24	16	13	5	8
Eyesight issues	31	26	11	9	6	17
Enlarged lymph nodes	33	27	10	20	3	7
Pain	33	21	15	21	7	3
Headaches	35	24	12	9	6	14
Bleeding	67	17	16	-	-	-
Thrombosis	64	9	-	18	-	9

\*Relative frequencies are displayed, and the percentages were calculated per issue (rows), and then compared within different time points (columns) to show the length of time each issue impacts patients reporting this specific concern. Each row totals 100%. Refer to Table 21 to see overall issue prevalence.

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Respondent's wellbeing was affected not only by physical and medical conditions, but also by psychosocial issues in different degrees and for various lengths of time (Tables 23 and 24).

Specifically, these issues seemed to differ in the respondents' experience during and after treatment (Table 23). Changes in relationships with loved ones, friends or co-workers/social life was most commonly reported during treatment (37%), while fear of relapse was common after treatment (30%). Moreover, respondents' report of fear of relapse peaked between 2 and 5 years after treatment, but some also reported it even 8+ years after treatment.

**Table 23.** Psychosocial issues affecting respondents' wellbeing during and after treatment.

Psychosocial Issues Affecting Wellbeing	Treatment	
	During (%)	After (%)
Changes in relationships with loved ones, friends or co-workers/social life	37	18
Stress related to financial issues	27	18
Loss of self-esteem	12	5
Concerns about body image/physical appearance changes	30	11
Loss/reduction in employment	17	14
Isolation	23	5
Depression	26	9
Anxiety	28	11
Fear of relapse	24	30
Difficulty on the job or in school	11	8
Problems getting health or life insurance coverage	7	3
Difficulty working effectively through the healthcare system	8	5
None	5	5
Other	37	18

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**Table 24.** How long psychosocial issues affecting wellbeing lasted.

Psychosocial Issues Affecting Wellbeing	Time Points					
	Less than 1y (%)	1y (%)	2y (%)	3-5y (%)	6-8y (%)	8+y (%)
Changes in relationships with loved ones, friends or co-workers/social life	38	15	19	18	3	7
Stress related to financial issues	32	23	20	8	5	12
Loss of self-esteem	58	19	7	3	3	10
Concerns about body image/physical appearance changes	48	24	10	6	4	8
Loss/reduction in employment	28	15	23	5	6	23
Isolation	38	25	19	3	2	13
Depression	39	11	25	14	2	9
Anxiety	33	20	20	7	2	18
Fear of relapse	17	17	19	22	15	10
Difficulty on the job or in school	40	20	16	-	8	16
Problems getting health or life insurance coverage	57	29	7	7	-	-
Difficulty working effectively through the	46	25	25	4	-	-

## healthcare system

\*Relative frequencies are displayed, and the percentages were calculated per issue (rows), and then compared within different time points (columns) to show the length of time each issue impacts patients reporting this specific concern. Each row totals 100%. Refer to Table 23 to see overall issue prevalence.

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Interestingly, respondents did not communicate the issues that they experience very frequently with their doctor (Table 25).

**Table 25.** Psychosocial issues affecting respondents' wellbeing and their communication with the doctor.

Psychosocial Issues Affecting Wellbeing	Respondents Who Have Discussed with Their Doctor (%)
Changes in relationships with loved ones, friends or co-workers/social life	6
Stress related to financial issues	2
Loss of self-esteem	1
Concerns about body image/physical appearance changes	1
Loss/reduction in employment	4
Isolation	3
Depression	2
Anxiety	3
Fear of relapse	8
Problems getting health or life insurance coverage	2
Difficulty working effectively through the healthcare system	-
None	2

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As a result of their lymphoma, 74% of the respondents in Slovakia had experienced changes in their lifestyle and 50% had experienced changes in their independence.

Respondents communicated medical issues to the doctor in 83% of cases and emotional issues in only 35% of cases.

Respondents indicated that the doctor was able to help with the medical issues in 63% of cases and to somewhat help in 30% of cases. As far as emotional issues are concerned; the doctor was only able to help in 46% of cases and to somewhat help in 26% of cases.

Turning to side effects, 69% of respondents communicated questions about side effects to their doctor, and 69% indicated that the doctor was able to answer these questions. In 67% of cases, respondents indicated that the doctor was able to help them cope with the side effects (Table 26).

**Table 26.** Communication with the doctor about side effects.

Communication of Side Effects	Respondents' Responses		
	Yes (%)	Somewhat (%)	No (%)
Did you bring forward questions about side effects?	69	15	12
Was the doctor able to answer your questions?	69	22	3
Was the doctor able to help you cope with side effects by providing medication or other support?	67	23	4

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Of those who after their initial visit to the doctor understood the potential side effects of treatment options, 72% brought forward questions about side effects to their doctor. 60% received answers from their doctor, and 66% received help coping with side effects by through the provision of medication or other support (Table 27).

**Table 27.** Respondents who communicated with the doctor about treatment side effects and who after their initial visit to the doctor understood the potential side effects of treatment options.

Communication of Side Effects	Respondents' Responses		
	Yes (%)	Somewhat (%)	No (%)
Did you bring forward questions about side effects?	72	9	13
Was the doctor able to answer your questions?	60	27	7
Was the doctor able to help you cope with side effects by providing medication or other support?	66	17	7

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## VI) Barriers & Impediments

### LC Objectives:

The 2016 Global Patient Survey examined barriers to care by gender and country. It was found that females had been experiencing more barriers to treatment in terms of their caregiver role and personal support, while males had been significantly more affected by medical issues such as access to treatments and specialty physicians. In the 2018 Global Patient Survey, we aim to examine the availability and efficacy of services by country and by area (rural/urban) and determine if and how this might affect the patient experience.

### Key Findings:

*Respondents from Slovakia commonly reported that financials constituted a barrier to treatment, followed by access to treatment centre/prohibitive travel. There were barriers found to be associated with respondent's area of residence. For example, for respondents living in a suburban area, personal support was identified more frequently as a barrier compared to respondents living in rural or urban areas. According to respondents,*

*complementary therapist and dietician/nutritionist services were not available in Slovakia. When respondents were asked to rate service types that they had already used, they specified that spiritual support services were the services that they found to be most helpful. Respondents who never or sometimes had good conversation with their doctors identified access to the most up to date treatment, specialty physician available locally and not being able to give up caregiver role while in treatment more than respondents who had good conversations with their doctors most days.*

The barriers respondents have identified in receiving their lymphoma treatment were:

- Financial (25%)
- Access to treatment centre/prohibitive travel (21%)
- None (21%)
- Wait time to treatment was longer than necessary (16%)
- Access to the most up to date treatment (8%)
- Specialty physician available locally (6%)
- Could not give up caregiver role (child, parent, disabled person) while in treatment (6%)
- Personal support (1%)

We asked participants to rate on a scale of 1-5 (5 being the highest) how helpful different services they may have used were, and to indicate if those services were not available in their country. Spiritual support services were rated to be the most helpful (23%). The highest rates of missing services in Slovakia were identified in complementary therapists (13%) (Table 28).

**Table 28.** Respondent's evaluation (1 lowest, 5 highest) of different services in Slovakia.

Types of Services	Evaluation of Services							
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	Not available in my country (%)	N/A (%)
Social worker	20	4	14	9	4	28	7	14
Patient organisation/ support group	14	6	15	8	19	23	9	6
Dietician/nutritionist	15	9	8	7	3	34	10	14
Counsellor/psychologist	13	7	10	11	13	30	4	12
Spiritual support	19	7	6	5	23	29	3	8
Physical therapy	15	7	10	9	12	27	9	11
Pain management	10	6	11	15	21	27	4	6
Complementary therapist	18	6	3	3	8	38	13	11

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For those who used the services mentioned above, the information for those services was provided by

- A doctor in 40% of cases;
- A nurse in 16% of cases;
- Patient organisation/support group in 15% of cases;
- Another patient in 14% of cases;
- A family member in 10% of cases;
- Online research in 8% of cases;
- A friend in 8% of cases and;
- Respondents were not provided with service information in 14% of cases.

In comparing the entire sample with only those that selected adequate information level, the efficacy rating of services did not change. The highest rates were also identified in spiritual support services (27%) (Table 29).

**Table 29.** Evaluation of different services in Slovakia by respondents with perceived adequate information.

Types of Services	Evaluation of Services							
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	Not available in my country (%)	N/A (%)
Social worker	20	2	17	8	5	29	5	14
Patient organisation/ Support group	16	4	15	9	16	26	6	8
Dietician/nutritionist	20	8	5	8	2	37	7	13
Counsellor/psychologist	17	8	11	9	12	30	3	10
Spiritual support	15	7	5	2	27	34	2	8
Physical therapy	21	7	7	7	11	30	5	12
Pain management	10	2	13	17	22	30	3	3
Complementary therapist	20	8	4	2	6	40	8	12

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For respondents living in a suburban area, personal support was identified more frequently as a barrier compared to respondents living in a rural or urban area (Table 30).

**Table 30.** Barriers to treatment based on area of residence.

Types of Barriers to Treatment	Area of Residence		
	Rural (%)	Urban (%)	Suburban (%)
Financial	40	34	38
Access to treatment centre/prohibitive travel	35	29	25
Access to the most up to date treatment	11	12	13
Wait time was longer than necessary	31	19	19
Personal support	2	-	13
Specialty physician available locally	11	7	13
Could not give up caregiver role (child, parent, disabled person) while in treatment	11	8	6
None	20	36	19

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Respondents who never or sometimes had good conversation with their doctors identified access to the most up to date treatment, specialty physician available locally and not being able to give up caregiver role while in treatment more than respondents who had good conversations with their doctors most days (Table 31).

**Table 31.** Barriers to treatment based on the quality of their communication with the doctor.

Good Conversation With Their Doctor	Barriers to Treatment						
	Financial	Access to treatment centre/prohibitive travel	Access to the most up to date treatment	Wait time was longer than necessary	Specialty physician available locally	Could not give up caregiver role while in treatment	None
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
most days	38	24	5	25	-	8	8
sometimes	32	32	13	19	3	3	19
never	50	67	50	50	17	33	17

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## APPENDIX 1

**Step 1.** The excel files were processed so that completed patients and caregivers were merged with the incomplete patients and caregivers. This included removal of the 'I don't know' columns from certain questions from the caregivers' version of the survey.

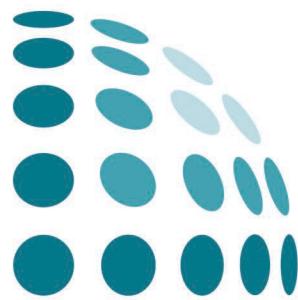
**Step 2.** The merged excel file was then exported into an SPSS file. This new SPSS file was then processed i.e. 'values' were put in, namely the coding of all variables, using the standard SPSS file you sent us as a guide. Open text variables were removed, as they make no sense in SPSS.

**Step 3.** Random checks were performed, to ascertain that no error had occurred during Steps 1 & 2. For example, 15 individual participants were selected from the SPSS file, subsequently traced in the Excel files using their ID number. The data recorded in the Excel files for each of those participants was compared with their data in the SPSS file. No errors were found.

**Step 4.** According to the key target variables included in the analysis, we defined a separate new variable for each one of them, i.e. 'name of variable\_M'. The Total\_M variable is defined as the sum of the 'name of variable\_M' variables and represents the percentage of all missing responses in the key target variables. We selected to keep participants with values in the Total\_M variable with a maximum of 0.70. These participants are therefore those who have completed at least 30% of these target variables. If we considered participants with for example a maximum value of 0.3 we would end up with 4.201 participants (approximately the completed study cases). So, we did consider a threshold that within reason led to the final number of 6,631.

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