

# 2018

## Global Patient Survey on Lymphomas & CLL

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### COUNTRY REPORT



# COLOMBIA

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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 organizations' 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 current survey based on the 2016 survey questions, which were modified and expanded as needed. The resulting questions were firstly reviewed by the Lymphoma Coalition board of directors, and then sent out to the Lymphoma Coalition membership for review. Subsequently, they were reviewed by an external scientific research body the Institute of Applied Biosciences at CERTH, The Centre for Research and Technology Hellas (INAB | CERTH). Commentary and feedback from all parties on the English version was reviewed and appropriate revisions and edits were made. The finalised version of the survey contained 29 questions. It was translated in 19 languages by a third party translation firm. As a final step, translated surveys were sent to Lymphoma Coalition membership for an opportunity to correct language errors. When the procedure was completed, the survey was launched hosted on a third party portal. Two versions were available namely a patient and a caregiver version. 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 47).

## Goals for the 2018 Global Patient Survey

The goal of the 2018 Global Patient Survey is 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 Colombia. With this information, LC and Fundación Colombiana de Leucemia y Linfoma, the lymphoma patient support group in Colombia, can be better equipped to serve the needs of their lymphoma community.

## OVERVIEW

*One hundred and eleven (111) respondents from Colombia took part in the 2018 LC survey. Most respondents in Colombia were aware of their subtype at the time of the survey. Many respondents found active surveillance difficult to understand following their initial diagnosis meeting. 43% of the respondents in Colombia wanted additional information and searched for information (56%) and support (55%) mostly immediately after their diagnosis. The primary sources of information for respondents in Colombia 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, muscle weakness and hair loss were the most frequently reported physical conditions. The most commonly reported medical conditions were pain and stomach-related issues during treatment, and stomach-related issues, tingling and diarrhea were the most frequent medical conditions after treatment. Changes in relationships with loved ones, friends or co-workers/social life and fear of relapse were the most commonly reported psychosocial issues both during and after treatment. In their totality, medical issues, physical conditions and psychosocial issues experienced were diverse and lasted for various lengths of time after treatment.*

*As a result of their lymphoma, the majority of respondents in Colombia had experienced changes in their lifestyle and independence. Respondents' reports of fear of relapse peaked during the first year after treatment, while some respondents reported that it continued for up to 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 during the first year after treatment. However, respondents reported fatigue even at 8+ years after treatment. Fatigue affected respondents' independence but more so their lifestyle, with general activity suffering the largest impact.*

*Respondents in Colombia reported that wait time to treatment constituted a barrier to treatment, followed by financials. There were barriers found to be associated with respondents' area of residence. For example, respondents living in rural areas identified barriers to treatment more frequently compared to respondents in urban areas-- except for specialty physician available locally (reported only by respondents in urban areas). Interestingly, 30% of respondents living in urban areas did not identify any barrier to treatment, a sharp contrast to those in rural areas, of whom 0% reported having no barriers to treatment.*

*Respondents' interest in services included treatment information and complementary nutrition/ fitness information. When respondents were asked to rate service types that they had already used, they specified that patient organisations and counsellor/psychologists were the services that they found to be most helpful.*

## SURVEY RESULTS

### I) Demographics

A total of 111 individuals from Colombia answered this year's Global Patient Survey.

Of these, 88 (79%) were patients diagnosed with a lymphoma and 23 (21%) were caregivers or family members answering on behalf of a patient. From this point forward, both groups will be considered as one and will be referred to as 'respondents'.

#### **Respondents' Demographic Profile**

102 (92%) of respondents said they had never participated in the Global Patient Survey, while of the 9 (8%) who said they had, some had participated more than one time so direct correlations could not be made for trending analysis.

53% were males, 47% were females.

62% of the respondents were older than 40 years old.

More specifically:

- 18-29 (19%)
- 30-39 (19%)
- 40-59 (32%)
- 60-69 (21%)
- 70+ (9%)

Regarding the area of residence:

- 92% lived in an urban area
- 1% lived in a suburban area
- 7% lived in a rural area

Responses varied with regards to the level of school completed/highest degree; however, most of the respondents had received pre-secondary, secondary school or attended college without receiving a degree. In more detail respondents had completed/acquired:

- No schooling completed: 5%
- Pre-secondary school: 26%
- Some secondary school, no diploma: 8%
- Secondary school diploma or equivalent: 15%
- Some college/university, no diploma/degree: 6%
- College/University diploma/degree: 14%



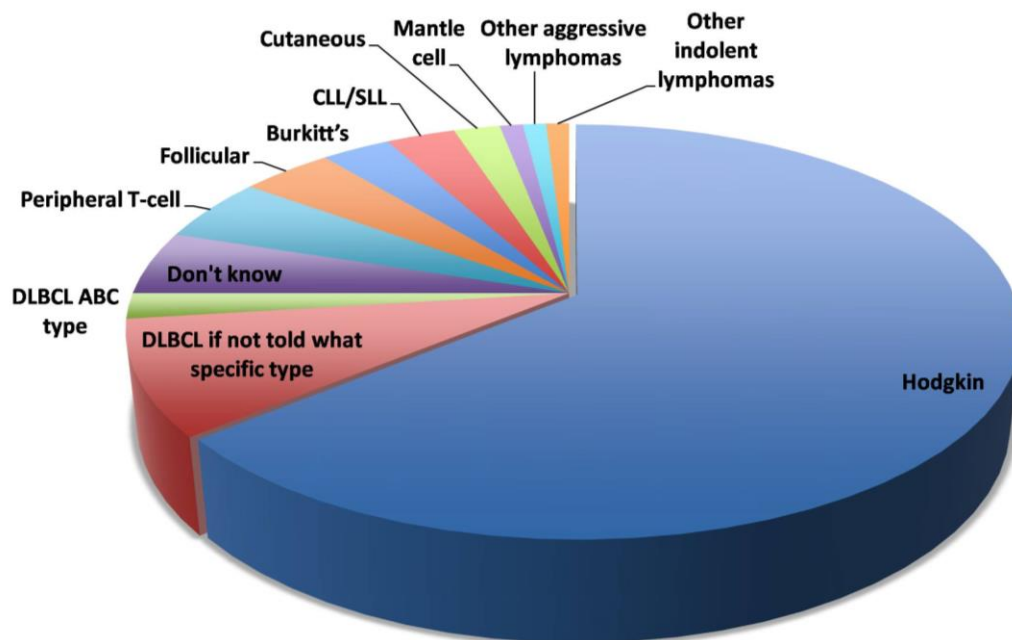
- Trade/technical/vocational training: 11%
- Doctorate degree: 1%
- Professional degree: 14%

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

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

<b>Lymphoma Subtype</b>	<b>% of Lymphoma Respondents</b>
Hodgkin	64
DLBCL if not told what specific type	9
DLBCL ABC type	2
DLBCL GCB type	-
Don't know	5
Peripheral T-cell	5
Follicular	4
Burkitt's	3
CLL/SLL	3
Cutaneous	2
Mantle cell	1
Other aggressive lymphomas	1
Other indolent lymphomas	1

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

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 Activated B-cell (ABC) DLBCL subtype. 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 Activated B-cell (ABC) subtype as one group (DLBCL).

Respondents reported their year of diagnosis as:

- Prior to 1995: 1%
- 2000-2005: 7%
- 2006-2010: 6%
- 2011-2016: 51%
- 2017: 32%
- Don't know: 3%

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

- 3% were newly diagnosed
- 44% had been diagnosed and were in treatment
- 7% were in remission and have been treatment free for 2 years or less
- 4% were in remission and have been treatment free for 2 to 5 years
- 6% were in remission and have been treatment free for more than 5 years
- 4% had relapsed for the first time and were in treatment
- 3% had relapsed more than 2 times and were in remission
- 6% had relapsed more than 2 times and were in treatment
- 23% 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 Colombia were aware of their subtype at the time of the survey. However, 11% found active surveillance difficult to understand following their initial diagnosis meeting. 43% of respondents in Colombia wanted additional information and searched for information (56%) and support (55%) mostly immediately after their diagnosis. The primary sources of information for respondents in Colombia were doctors and websites. Respondents who considered themselves to be adequately informed wanted to overcome the disease and felt mentally and physically strong and capable. Respondents who were somewhat adequately informed also wanted to overcome the disease but felt less mentally and physically strong and capable. Interestingly, inadequately informed respondents wanted to overcome the disease, but never felt mentally or physically strong and capable. Moreover, 'most days', adequately informed respondents felt confident they could determine if they needed medical care or could handle a health problem on their own, as well as determine the trustworthiness of information about their health condition and treatment choices. Most days, somewhat adequately informed and inadequately informed respondents felt less confident in the aforementioned areas. Most respondents in Colombia raised questions about side effects during discussions with their doctor and felt that it helped. Respondents' interest in services included treatment information and complementary nutrition/ fitness information.*

Most of the respondents (78%) were made aware of their lymphoma subtype during their initial diagnosis, whereas 14% were not informed and 8% 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 Colombia had the most difficulty understanding concerned active surveillance (11%) followed by characteristics of their particular subtype (9%) (responses 1+2).

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

Issues Around Diagnosis and Care	Respondents' Level of Understanding						N/A (%)
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	
Diagnosis	3	5	15	26	51	-	-
Characteristics of the particular subtype	6	3	19	26	45	1	-
Different medical treatment options	4	3	8	32	53	-	-
Initial treatment if started right away	2	5	7	26	60	-	-
Potential side effects of treatment options	3	3	7	29	58	-	-
Side effect management	4	4	7	30	55	-	-
Process and stages of care	1	4	9	28	58	-	-
Active surveillance ('watch and wait'), if applicable	3	8	8	21	47	5	8

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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:

- 43% received enough information
- 43% would like to receive additional information
- 3% felt overwhelmed and did not want more information as it was too much to take in at the time and,
- 11% did not want additional information.

Respondents were most active in seeking information immediately upon diagnosis (56%). The same was true for support (55%). Interestingly, 35% of respondents reported that they never sought support and 33% that they never sought information (Table 3).

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

Time Points	Information	Support
	(%) of Respondents	(%) of Respondents
Immediately upon diagnosis	56	55
1-3 months	8	7
3-6 months	2	1
6 months-year	1	1
1 year-onwards	-	1
Never	33	35

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

- 49% felt like they had the level/type of information they needed
- 27% felt they had the support they needed
- 10% did not want to know/were not interested
- 6% were fearful of what they might find out

- 4% asked someone (friend, spouse, caregiver etc.) to seek information for them
- 3% did not want support, wanted to fight this thing on their own
- 1% tried at first but did not understand the information online

When asked what level of information they felt they had overall, 83% felt they had received adequate information, 16% somewhat adequate information and only 1% (single respondent) 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	39	53	5	3
Out of control	5	51	44	-
Wanted to get into bed and hide	6	64	30	-
Wanted to overcome this disease	88	11	1	-
Overall fearful	26	53	21	-
Fearful for the future	24	55	21	-
At a loss	20	60	20	-
Confident	43	52	5	-
Felt mentally strong and capable	66	33	1	-
Felt physically strong and capable	63	35	2	-
Had good conversations with my doctor on my care and treatment plan	47	29	18	6
I was confident could determine if I needed to get medical care or if I could handle a health problem myself	53	46	1	-
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	56	44	-	-

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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	20	67	13	-
Out of control	15	54	31	-
Wanted to get into bed and hide	20	33	47	-
Wanted to overcome this disease	94	6	-	-

Overall fearful	39	50	11	-
Fearful for the future	38	50	12	-
At a loss	41	41	18	-
Confident	38	31	31	-
Felt mentally strong and capable	50	44	6	-
Felt physically strong and capable	33	67	-	-
Had good conversations with my doctor on my care and treatment plan	-	100	-	-
I was confident I could determine if I needed to get medical care or if I could handle a health problem myself	47	41	6	6
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	12	65	16	7

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

Feelings Experienced with an Inadequate Information Level	Associated Frequency of Feelings (%)			
	Most days*	Sometimes*	Never*	N/A
In control	-	-	100	-
Out of control	100	-	-	-
Wanted to get into bed and hide	100	-	-	-
Wanted to overcome this disease	100	-	-	-
Overall fearful	100	-	-	-
Fearful for the future	100	-	-	-
At a loss	100	-	-	-
Confident	-	-	100	-
Felt mentally strong and capable	-	-	100	-
Felt physically strong and capable	-	-	100	-
Had good conversations with my doctor on my care and treatment plan	-	100	-	-
I was confident I could determine if I needed to get medical care or if I could handle a health problem myself	-	100	-	-
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	-	100	-	-

\* Please note that the numbers in this table are 100% because they refer to one respondent.

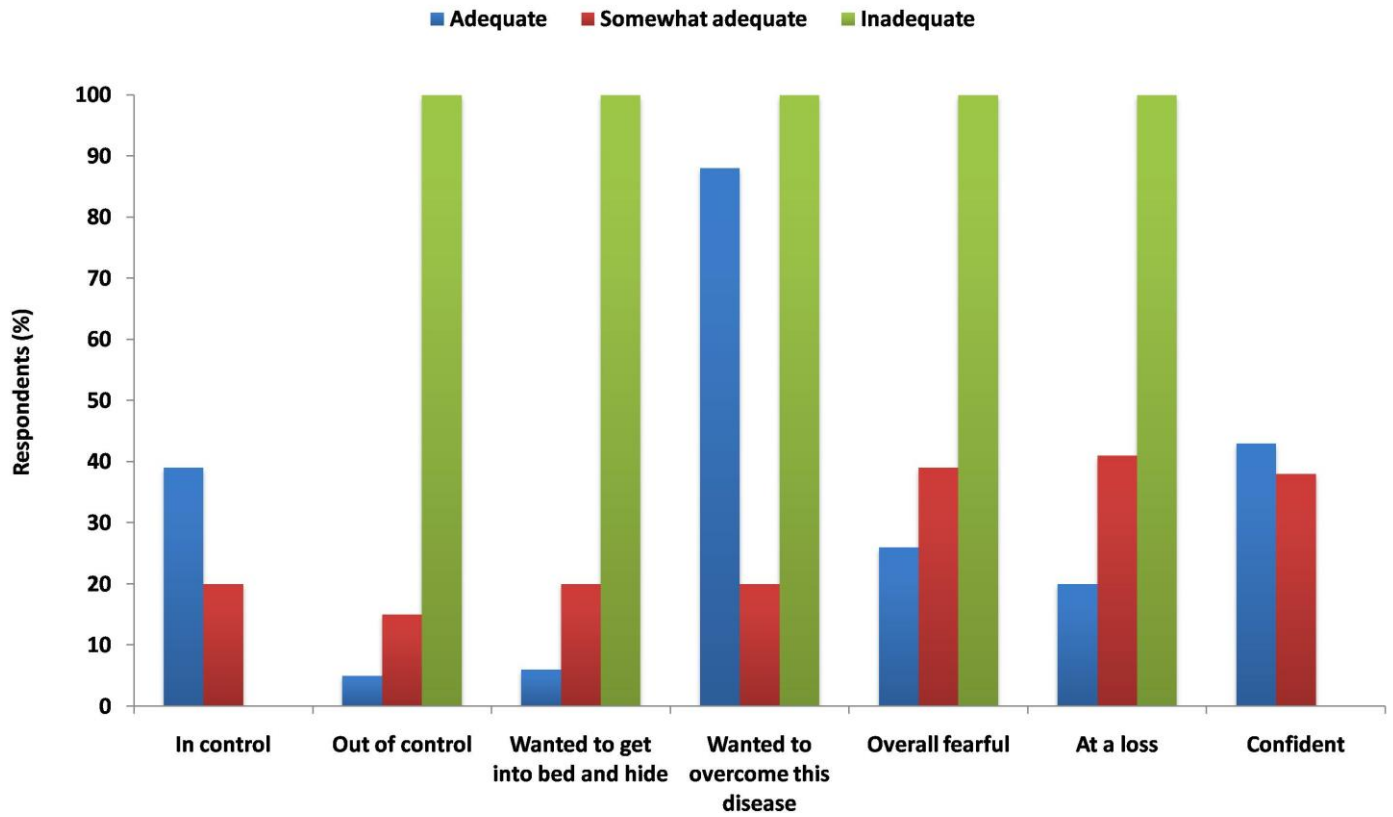
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In analysing what respondents felt 'most days' according to their perceived information level, respondents who considered themselves to be adequately informed wanted to overcome the disease (88%) and felt mentally (66%) and physically (63%) strong and capable. Respondents who were somewhat adequately informed wanted to overcome the disease (94%) but felt less mentally strong and capable (50%), as well as less physically strong and capable (33%). There was only one respondent in the inadequately informed category therefore the percentages indicating their responses are 100%. The respondent with an inadequate information level wanted to overcome the disease (100%) but never felt mentally strong and capable (100%) or physically strong and capable (100%).

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 (53%), as well as determine the trustworthiness of information about their health condition and treatment choices (56%). Somewhat adequately informed respondents felt less confident in the aforementioned areas (47% and 12% respectively). The respondent that indicated an inadequate information level only sometimes felt confident in these areas (100% and 100% respectively). Additionally, the respondent that indicated an inadequate information level never felt confident generally (100%).

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

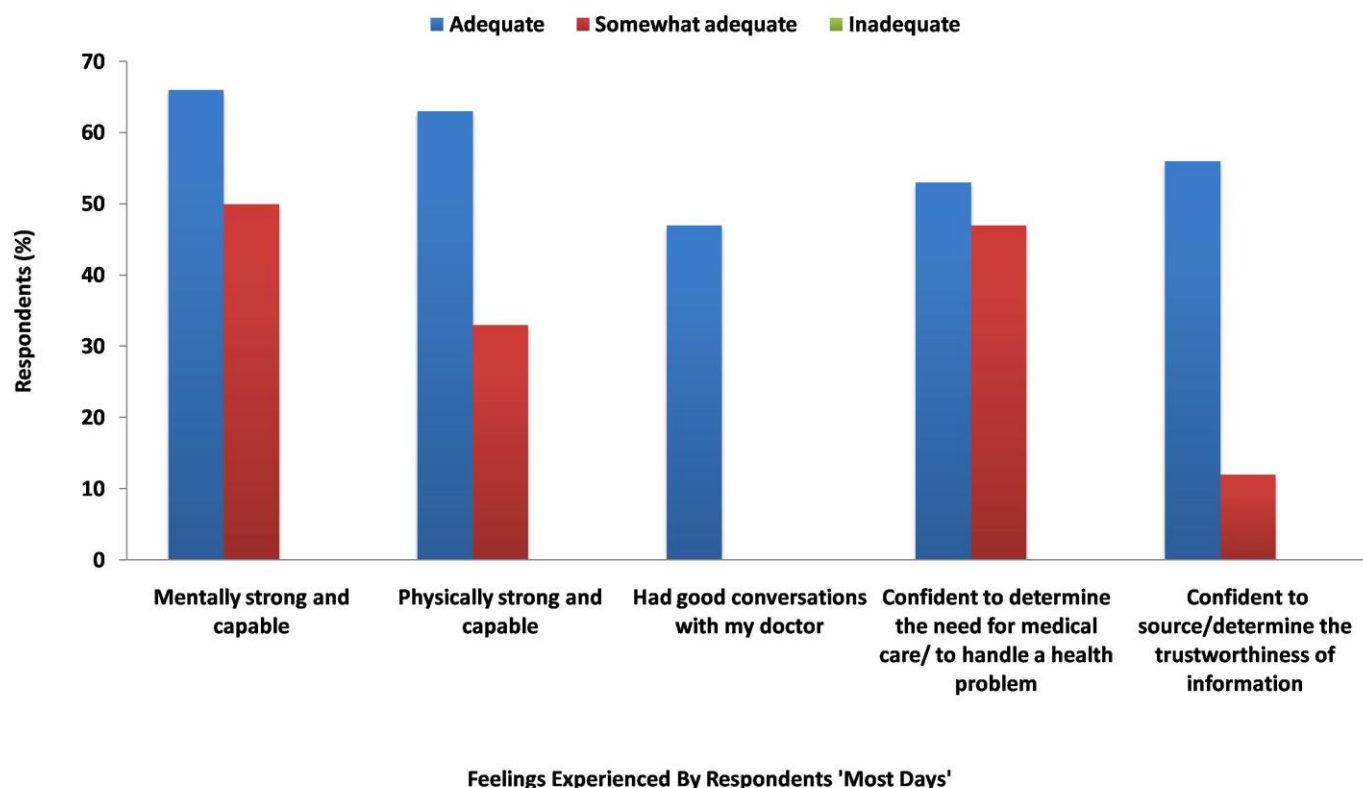




Feelings Experienced By Respondents 'Most Days'

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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'.

*\*Note: Bars for inadequate are missing as there is only one respondent who did not indicate feeling these feelings most days.*

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

- Doctor 88%
- Websites 56%
- Nurse 45%
- Online blogs/social media 39%
- Patients organisations 33%
- Family/friends 28%
- Other 4%

Table 7 describes different elements of the respondents' communication with the doctor, and the impact that this communication had on the issues 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?	93	7	-	-
Was the doctor able to help?	89	9	2	-
Have you communicated any of your emotional issues to the doctor?	82	7	11	-
Was the doctor able to help?	80	9	8	3
Did you bring forward questions about side effects?	89	7	4	-
Was the doctor able to answer your questions?	90	7	3	-
Was the doctor able to help you cope with your side effects by providing medication or other support?	89	10	1	-
Did you seek clarification on things you did not understand?	91	7	2	-
Was the doctor able to answer your questions?	90	8	2	-
Did you discuss your fear of relapse with your doctor	84	6	9	1
Do you feel that it helped to alleviate the fear?	79	11	6	4
Did the doctor or nurse refer you to further support that you were able to use?	80	7	12	1
Did you feel confident/comfortable voicing your concerns to your doctor?	89	6	5	-
If you experienced fatigue issues, did the doctor or nurse refer you to further support or information that you were able to use?	82	7	9	2

Did you feel you had the right to take the doctor's time to discuss any of the above during your visits?	88	7	5	-
Did the doctor encourage discussion with you on any of the above?	90	4	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.

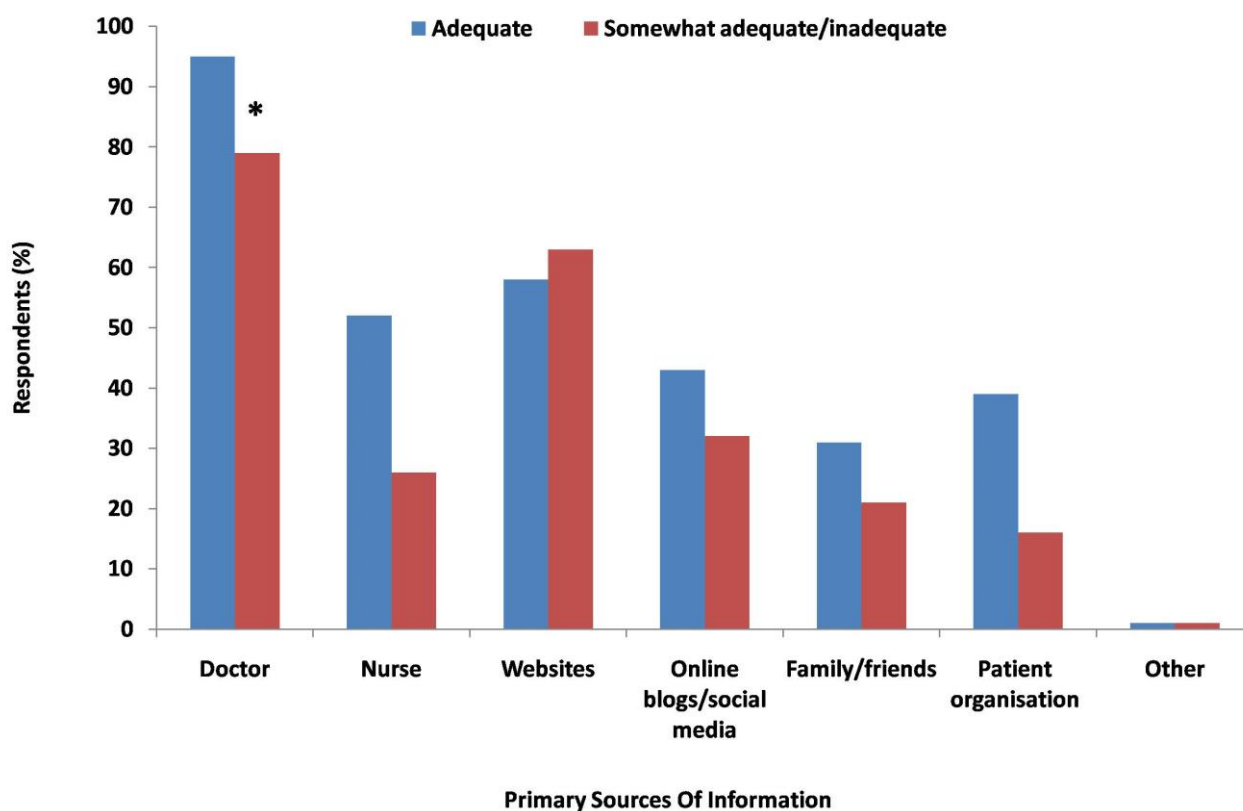
**Table 8.** Respondents' understanding after the initial visit with the doctor based on their perceived level of information.

Topics Around Diagnosis and Care	Adequate Information (%)	Somewhat adequate/ Inadequate Information* (%)
Diagnosis	82	53
Characteristics of the particular subtype	80	28
Different medical treatment options	88	72
Initial treatment if started right away	90	63
Potential side effects of treatment options	91	67
Side effect management	91	58
Process and stages of care	90	68
Active surveillance ('watch and wait'), if applicable	91	55

\* 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 inadequate (somewhat adequate/ inadequate combined for analysis) information. Those with a perceived adequate information level more frequently reported doctors to be 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	50	50	-
Urban	85	14	1
Suburban	100*	-	-

\* Please note that the number in the suburban category is 100% because it refers to one respondent.

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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 (95%) compared to those with somewhat adequate/inadequate information (74%).

The impact of the level of information on confidence was higher in respondents who felt they had adequate information. Of these, 43% felt confident most days versus 38% of those who received somewhat adequate/inadequate information.

97% of respondents with adequate information felt they had the right to take the doctor's time to discuss their concerns, as opposed to 47% 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 financials, access to the most up to date treatment and specialty physician available locally more frequently than those with adequate information.

Interestingly, experiencing no barriers in receiving lymphoma treatment was more frequently reported (31%) by respondents with adequate information than by somewhat/inadequately informed. None of the respondents identified 'could not give up caregiver role while in treatment' as a barrier (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	20	36
Access to treatment centre/prohibitive travel	20	13
Access to the most up to date treatment	1	7
Wait time was longer than necessary	65	67
Personal support	-	6
Specialty physician available locally	8	13
Could not give up caregiver role (child, parent, disabled person) while in treatment	-	-
None	31	13

\* 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 and complementary nutrition/fitness information (97% each). It is noteworthy that respondents seem to be interested in all the services listed. (Table 11).

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

<b>Service Type</b>	<b>Interest of Total Respondent Population (%)</b>
Treatment information	97
Complementary nutrition/fitness information	97
Information on patient organisation services	95
Patient organisation support	95
Professional emotional support	94
Credible website links	93
Live education sessions	93
Financial support	93
Fatigue support	93
In person support groups	92
Professional physical support	92
Hard copy materials	91
Support in navigating the insurance system	91
Clinical trial options	88
Phone-line support	88
Downloadable materials	88
Online chats	87

When compared to the total respondent population, those who felt they had received adequate information seemed to express interest in services in a very similar order (Table 12).

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

<b>Service Type</b>	<b>Interest of Adequate Information Respondents (%)</b>
Treatment information	97
Complementary nutrition/fitness information	97
Professional physical support	95
Professional emotional support	94
Information on patient organisation services	94
Patient organisation support	94
Financial support	93
Fatigue support	92
Support in navigating the insurance system	92
Live education sessions	92
Credible website links	92
Hard copy materials	92
Clinical trial options	91

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In person support groups	91
Phone-line support	91
Downloadable materials	89
Online chats	87

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; this included only DLBCL and Hodgkin lymphoma.

Respondents with a DLBCL diagnosis showed the greatest interest in treatment information, complementary nutrition/fitness information, information on patient organisation services and patient organisation support (all at 100%).

Respondents with a Hodgkin diagnosis were mostly interested in professional physical support (97%), followed by professional emotional support, treatment information and complementary nutrition/fitness information (96% each) (Table 13).

**Table 13.** Interest in different services by respondents with DLBCL and Hodgkin Lymphoma diagnosis

Service Type	DLBCL (%)	Hodgkin (%)
Professional physical support	83	97
Professional emotional support	92	96
Information on patient organisation services	100	94
Credible website links	92	94
Patient organisation support	100	94
Phone-line support	75	6
In person support groups	75	94
Online chats	64	90
Live education sessions	92	94
Hard copy materials	83	92
Downloadable materials	80	91
Financial support	83	92
Clinical trial options	83	90
Treatment information	100	96
Complementary nutrition/fitness information	100	96
Support in navigating the insurance system	83	93
Fatigue support	83	94

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In considering different stages of the patient experience, respondents who had finished treatment and were in maintenance therapy were 100% 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*	100	-	-	-
Diagnosed and currently in treatment	89	9	2	-
Diagnosed and have been told that treatment is not yet needed	-	-	-	-
In remission and treatment free for 2 years or less*	100	-	-	-
In remission and treatment free for 2 to 5 years*	75	-	25	-
In remission and treatment free for more than 5 years*	80	20	-	-
Have relapsed for the first time and currently in treatment*	100	-	-	-
Have relapsed more than two times and in remission*	67	33	-	-
Have relapsed more than two times and currently in treatment*	50	-	50	-
Have finished treatment and currently in maintenance therapy	100	-	-	-
Have transformed	-	-	-	-

\*These percentages were not used for comparison due to the small number of individual respondents per category (fewer than 10).

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### III) Fear of Relapse

#### LC Objectives:

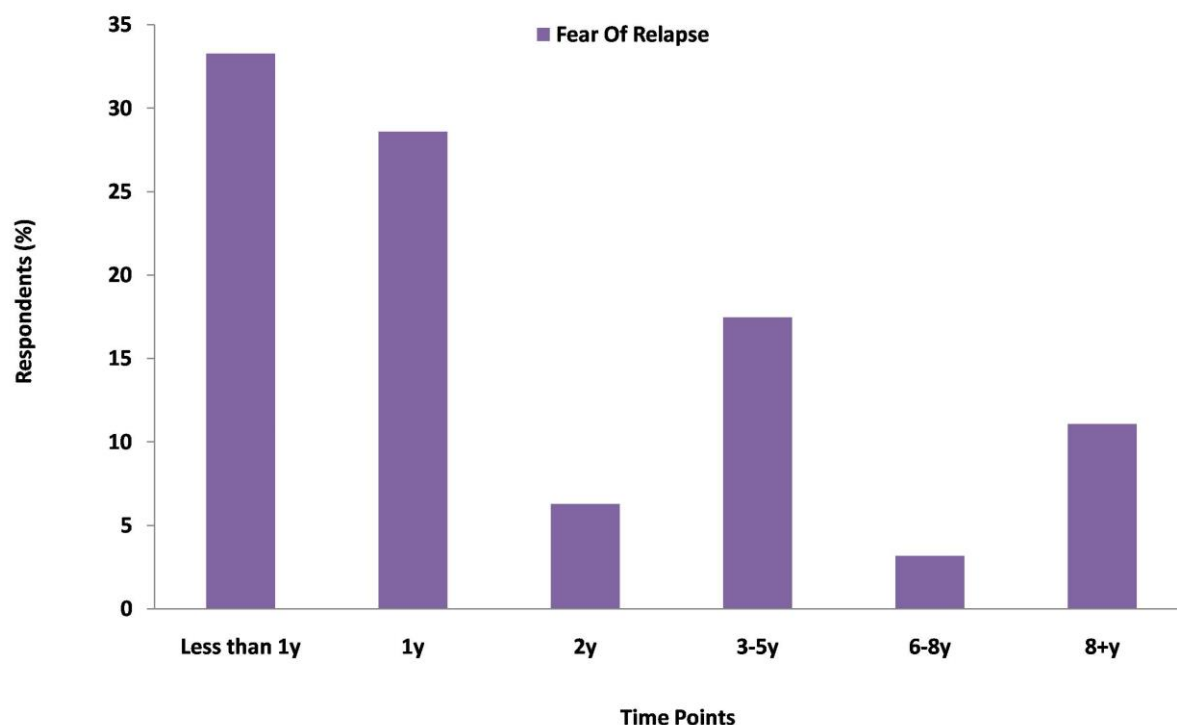
The 2016 Global Patient Survey indicated that psychosocial conditions have continued to negatively impact patients, with the fear of relapse having the most profound effect occurring most particularly after treatment (87% of those who reported fear of relapse reported it as occurring after treatment). 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 decreasing somewhat after treatment. Respondents' reports of fear of relapse peaked during the first year after treatment, and some respondents reported fear of relapse at 8+ years. Fear of relapse was associated with feelings of anxiety, depression and isolation. However, these feelings were very rarely discussed with the doctor. Among respondents with fear of relapse, most felt they had somewhat adequate information. Both during and after treatment, respondents experiencing fear of relapse commonly reported doctors and websites as their primary sources of information, followed by patient organisations.*

Fear of relapse was a major issue for respondents as it was present both during and after treatment. It showed a decrease from 78% during treatment to 61% after treatment. Fear of relapse lasted for various lengths of time (See Table 24) (Figure 4).

Of those who experienced fear of relapse, 84% discussed and 6% somewhat discussed this fear with their doctor. 79% felt this helped and 11% felt it somewhat helped. Only 6% did not feel it helped alleviate the fear.



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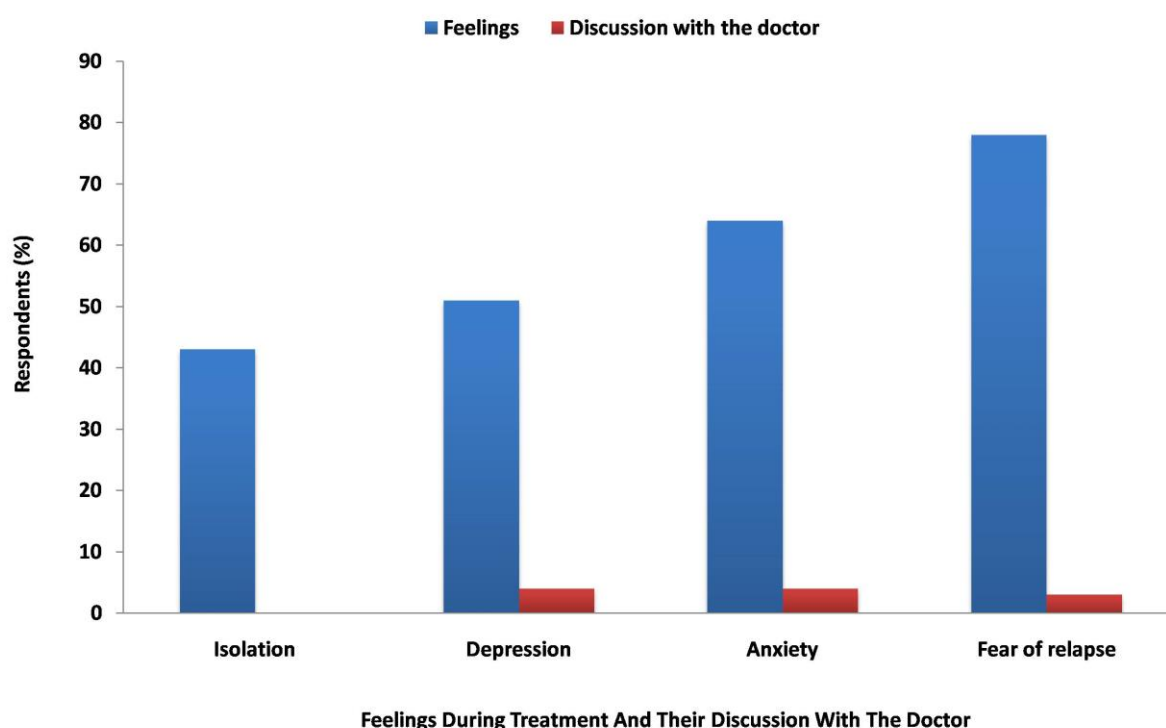
**Figure 4.** How long fear of relapse lasted amongst respondents.

In some cases, fear of relapse was accompanied by 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	43	-
Depression	51	4
Anxiety	64	4
Fear of relapse	78	3

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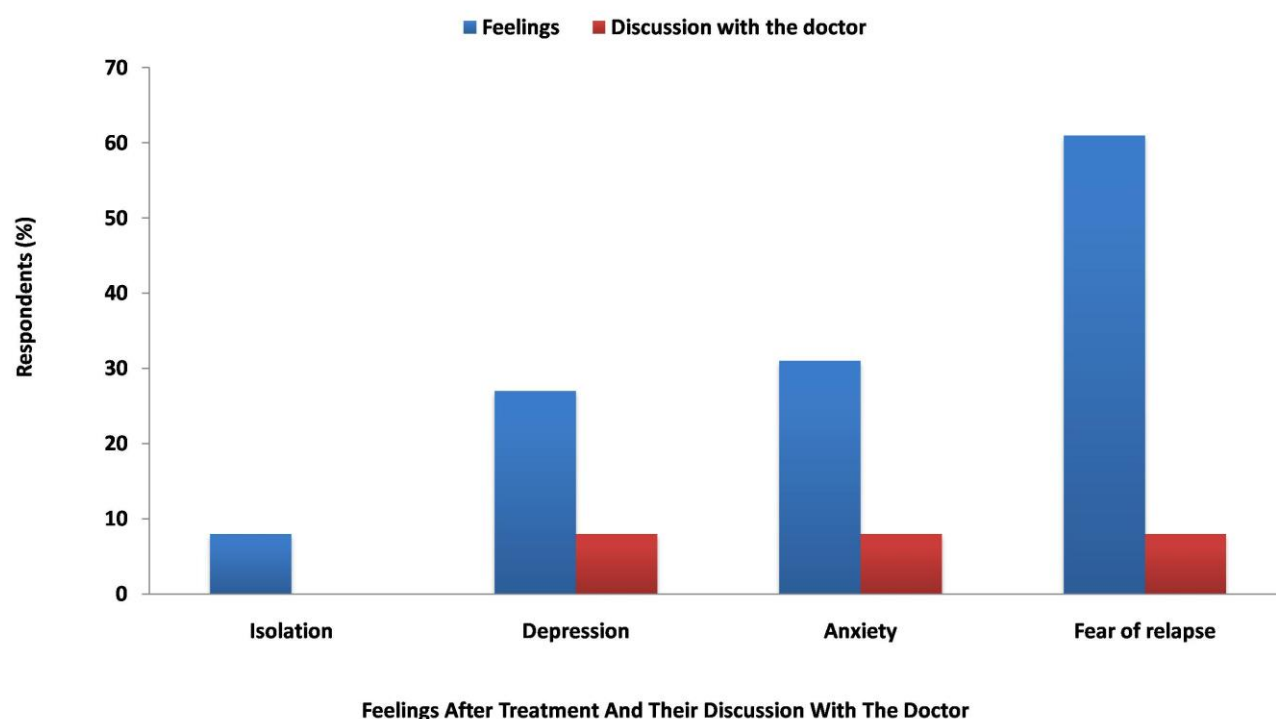
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**Figure 5.** Feelings of isolation, depression and anxiety during treatment amongst respondents who experienced fear of relapse, and their discussion with the doctor.

**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	8	-
Depression	27	8
Anxiety	31	8
Fear of relapse	61	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, 84% felt that had adequate information and 16% felt they had somewhat adequate information.

Sources of information for those who experienced fear of relapse during treatment were as follows: doctors 87%, nurses 48%, websites 60%, online blogs 39%, family/friends 29% and patient organisations 34%. Those who experience fear of relapse after treatment used sources as follows: doctors 81%, nurses 58%, websites 73%, online blogs 54%, family/friends 39%, and patient organisations 46%.

Moreover, for those who experienced fear of relapse, we tried to identify possible differences with regards to the information sources they used 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, nurses, online blogs, and patient organisations both during and after treatment.

## IV) Fatigue

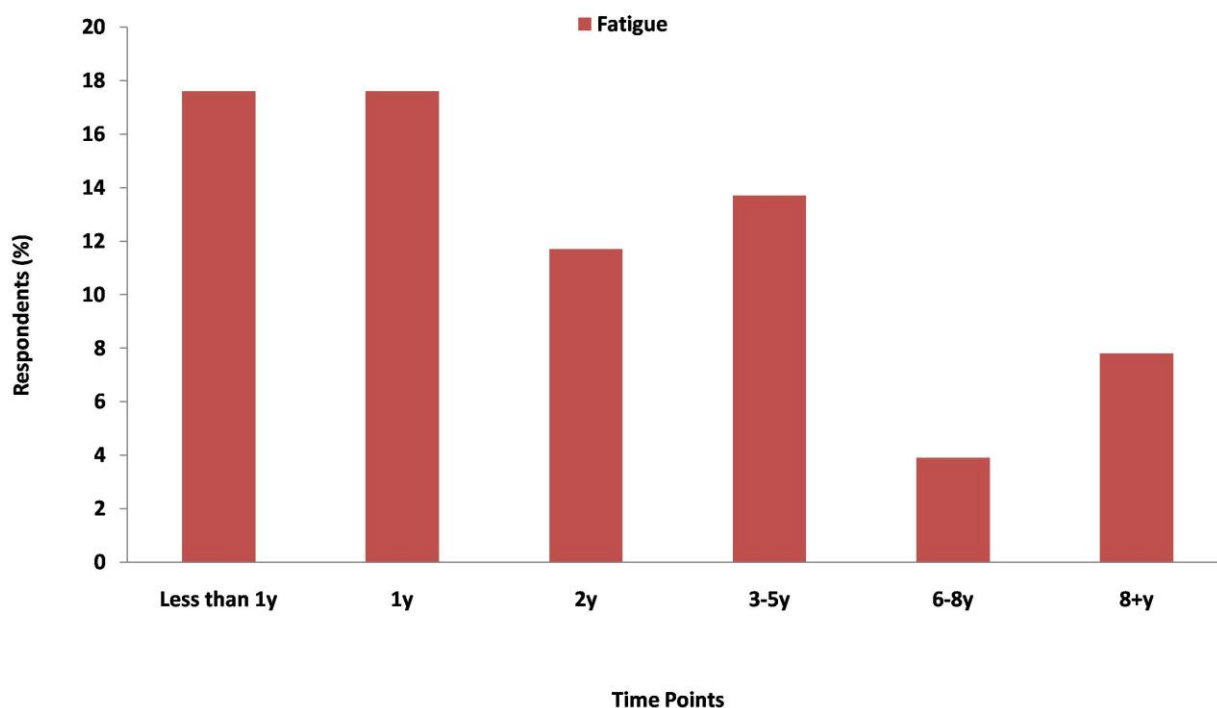
### LC Objectives:

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 one of the most frequent physical conditions experienced by respondents. Respondents' reports of fatigue peaked immediately following treatment and during the first year after treatment. Some respondents reported fatigue even at 8+ years after treatment. Fatigue affected respondents' independence but more so their lifestyle, with general activity suffering the greatest impact. Interestingly, respondents who reported fatigue also showed a high percentage of fear of relapse after the end of treatment. Psychosocial issues resulting from fatigue were reported both during and after treatment.*

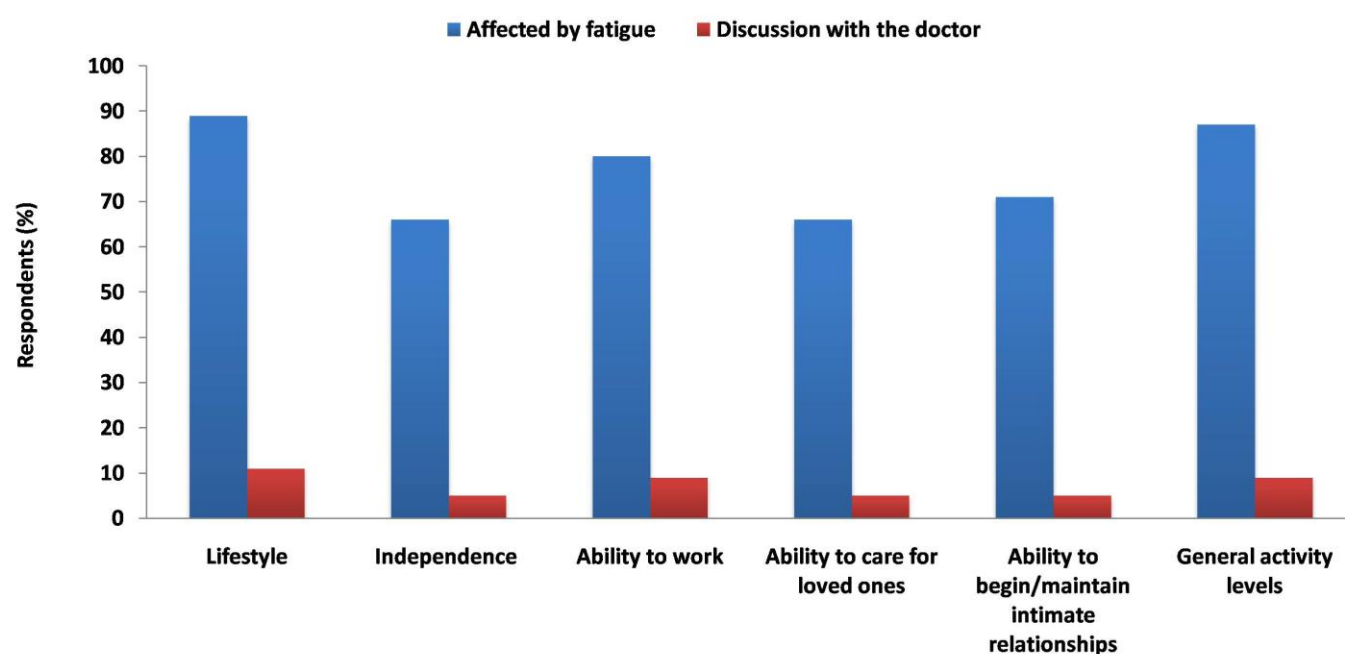
Fatigue was one of the physical conditions affecting respondents' sense of wellbeing since diagnosis. It was reported by 46% of respondents and it lasted for various lengths of time (Table 19) (Figure 7).



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

Those who experienced fatigue also reported that as a result of it, they have also experienced changes in several areas of life (Figure 8). Respondents mentioned that life has changed (46%) or moderately changed (56%), or that they sleep well but the fatigue does not go away (57%). Though many respondents indicated experiencing life changes because of fatigue, more than half of the respondents reported that fatigue is constant however it had not changed their daily activities (55%).



Life Changes And Their Discussion With The Doctor

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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 (89%) as was their independence (66%), and in 80% of these cases the doctor referred them for support. Only a small percentage of respondents discussed their life changes with their doctor.

Fatigue was associated with other issues as well (Table 17). Interestingly, respondents who reported fatigue showed a higher percentage of fear of relapse during treatment (68%) than after treatment (38%).



**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	64	32
Stress related to financial issues	36	14
Loss of self-esteem	14	6
Concerns about body image/physical appearance changes	54	14
Loss/reduction in employment	42	14
Isolation	36	6
Depression	44	12
Anxiety	54	12
Fear of relapse	68	38
Difficulty on the job or in school	38	8
Problems getting health or life insurance coverage	14	8
Difficulty working effectively through the healthcare system	26	6
None	-	-

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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, muscle weakness and hair loss were the most frequently reported physical conditions by respondents. The most commonly reported medical conditions during treatment were pain and stomach-related issues. Stomach-related issues, tingling and diarrhea were the most frequent medical issues reported after treatment. Both during and after treatment, changes in relationships with loved ones, friends or co-workers/social life and fear of relapse were the most commonly reported psychosocial issues. Respondents' reports of fear of relapse peaked during the first year after treatment, and it was reported by some respondents at 8+ years. 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 Colombia have experienced changes in their lifestyle and 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 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 patients are facing muscle weakness (70%) and hair loss (65%) (Table 18). Respondents have reported these physical conditions to last for various lengths of time (Table 19).

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

Physical Conditions	Percentage of Respondents (%)
Muscle weakness	70
Hair loss	65
Nausea and vomiting	61
Weight loss	56
Loss of appetite	52
Fatigue	46
Night sweats	44
Changes in taste and smell	35
Changes in sleep patterns	28
Cramps	23
Swelling of arms and legs	14
Trouble concentrating	14
Bowel changes	12
Mucositis/mouth ulcers	12
Weight change	11
Problems concentrating	10
I had no changes in my physical condition whatsoever	10
Memory loss	8
Problems fighting infections	7
Itching	6
Shortness of breath	6
Skin reactions	5
Change in sexual function	5
Fluid retention	4
Burning	4
Incontinence	4
Loss of fertility	2
Viral reactivations	2

**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	45	17	12	14	4	8
Hair loss	40	19	15	18	4	4
Muscle weakness	31	24	18	15	6	6
Trouble concentrating	42	29	4	13	4	8
Changes in sleep patterns	44	15	6	20	6	9
Changes in taste and smell	43	16	6	19	8	8
Bowel changes	65	7	-	7	-	21
Aching joints	34	21	24	9	3	9
Nausea and vomiting	38	16	16	15	9	6
Problems fighting infections	44	14	14	14	-	14
Memory loss	62	13	-	13	6	6
Skin reactions	58	17	-	-	8	17
Mucositis/mouth ulcers	56	13	13	6	6	6
Loss of appetite	34	28	7	18	5	8
Change in sexual function	54	13	13	13	-	7
Weight loss	43	24	14	9	5	5
Fluid retention	42	33	8	-	-	17
Weight change	49	19	9	9	9	5
Loss of fertility	56	11	11	11	-	11
Swelling of arms and legs	47	12	6	12	6	17
Itching	87	-	-	-	-	13
Burning	83	-	-	-	-	17
Incontinence	72	14	-	-	-	14
Cramps	50	17	17	11	-	5
Shortness of breath	83	17	-	-	-	-
Viral reactivations	66	17	-	17	-	-
Night sweats	47	22	6	17	3	5
Problems concentrating	50	20	10	10	-	10

\* 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 respondents with a DLBCL diagnosis the most prominent physical conditions were fatigue, muscle weakness and weight loss (58% each). For respondents with a Hodgkin diagnosis the most frequently reported condition was muscle weakness (67%) followed by hair loss (66%).

**Table 20.** Physical conditions amongst respondents with different lymphoma diagnosis.

Physical Conditions	Lymphoma Subtypes	
	DLBCL (%)	Hodgkin (%)
Fatigue	58	36
Hair loss	50	66
Muscle weakness	58	67
Trouble concentrating	42	6
Changes in sleep patterns	42	20
Changes in taste and smell	42	29
Bowel changes	42	6
Aching joints	50	21
Nausea and vomiting	50	64
Problems fighting infections	17	-
Memory loss	25	6
Skin reactions	-	3
Mucositis/mouth ulcers	33	3
Loss of appetite	50	57
Change in sexual function	8	-
Weight loss	58	60
Fluid retention	8	1
Weight change	17	6
Loss of fertility	8	-
Swelling of arms and legs	33	7
Itching	-	4
Burning	-	3
Incontinence	-	3
Cramps	42	20
Shortness of breath	25	-
Viral reactivations	8	-
Night sweats	50	39
Problems concentrating	25	7
I had no changes in my physical condition whatsoever	17	10
Other	-	-

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Many of the medical issues that respondents experienced during their treatment were less reported after the end of treatment; however, some issues showed an increase after treatment. Pain and stomach-related issues

were commonly reported during treatment (49% and 44% respectively). Stomach-related issues (37%), tingling (37%) and diarrhea (33%) were commonly reported after treatment (Table 21).

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

Medical Issues	Treatment	
	During (%)	After (%)
Heart-related issues	21	-
Stomach-related issues	44	37
Issues with other organs	21	7
Diarrhea	40	33
Numbness	10	11
Neutropenia	31	7
Osteoporosis	7	7
Any other blood condition	7	7
Secondary cancer	3	4
Diabetes	3	4
Tingling	29	37
Eyesight issues	29	26
Enlarged lymph nodes	16	4
Pain	49	4
Headaches	34	30
Bleeding	10	-
Thrombosis	5	-
I do not have any other medical issues	5	11

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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	31	15	15	23	8	8
Stomach-related issues	29	18	11	18	6	18
Issues with other organs	-	40	20	20	20	-
Diarrhea	33	33	8	13	-	13
Numbness	37	13	13	24	-	13
Neutropenia	39	31	15	15	-	-
Osteoporosis	17	33	33	17	-	-
Any other blood condition	33	-	-	67	-	-

Secondary cancer	33	33	34	-	-	-
Diabetes	-	-	22	11	-	67
Tingling	25	34	8	25	-	8
Eyesight issues	15	23	15	32	15	-
Enlarged lymph nodes	50	17	-	-	16	17
Pain	32	37	6	10	10	5
Headaches	41	29	6	6	6	12
Bleeding	33	34	33	-	-	-
Thrombosis	50	-	50	-	-	-

\*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 (See Table 23 and 24).

Specifically, these issues seemed to have an impact on the respondents' experience both during and after treatment (Table 23). Changes in relationships with loved ones, friends or co-workers/social life (84%) and fear of relapse (78%) were most commonly reported during treatment. These issues were the most frequently reported after treatment as well (67% and 61% respectively). Moreover, respondents' reports of fear of relapse peaked during the first year after treatment, but it was reported by some at 8+ years after treatment (11%).

**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	84	67
Stress related to financial issues	23	23
Loss of self-esteem	19	14
Concerns about body image/physical appearance changes	71	28
Loss/reduction in employment	33	21
Isolation	41	7
Depression	44	19
Anxiety	58	21
Fear of relapse	78	61
Difficulty on the job or in school	36	12
Problems getting health or life insurance coverage	12	9
Difficulty working effectively through the healthcare system	15	7
None	-	-
Other	-	-

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**Table 24.** How long psychosocial issues affecting well-being lasted after treatment.

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	25	34	11	17	4	9
Stress related to financial issues	19	48	-	11	7	15
Loss of self-esteem	14	52	10	10	-	14
Concerns about body image/physical appearance changes	23	37	11	16	3	10
Loss/reduction in employment	12	52	-	16	4	16
Isolation	19	50	6	12	-	13
Depression	21	46	10	18	-	5
Anxiety	28	36	6	19	2	9
Fear of relapse	33	29	6	18	3	11
Difficulty on the job or in school	19	41	7	18	-	15
Problems getting health or life insurance coverage	13	-	47	20	-	20
Difficulty working effectively through the healthcare system	13	47	7	20	7	6

\*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	3
Stress related to financial issues	3
Loss of self-esteem	2
Concerns about body image/physical appearance changes	4
Loss/reduction in employment	2
Isolation	2



Depression	4
Anxiety	3
Fear of relapse	3
Problems getting health or life insurance coverage	1
Difficulty working effectively through the healthcare system	1
None	1
	-

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As a result of their lymphoma, 92% of respondents had experienced changes in their lifestyle and 82% had experienced changes in their independence.

Respondents communicated medical issues to the doctor in 93% of cases and emotional issues in 82% of cases.

Respondents indicated that the doctor was able to help with the medical issues in 89% of cases, and to somewhat help in 9% of cases. As far as emotional issues are concerned; the doctor was able to help in 80% of cases and to somewhat help in 9% of cases.

89% of respondents communicated questions about side effects to their doctor, and 90% indicated that the doctor was able to answer these questions. In 89% 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?	89	7	4
Was the doctor able to answer?	90	7	3
Was the doctor able to help you cope with side effects by providing medication or other support?	89	10	1

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Of those who after their initial visit to the doctor, understood the potential side effects of treatment options, 67% brought forward questions about side effects to their doctor, 67% received answers from the doctor, and the majority (83%) received help coping with side effects 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?	67	-	33
Was the doctor able to answer your question?	67	-	33
Was the doctor able to help you cope with side effects by providing medication or other support?	83	-	17

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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 in Colombia reported that wait time to treatment constituted a barrier to treatment, followed by financials. There were barriers found to be associated with respondents' area of residence. For example, financials and wait time to treatment were the most frequently reported barrier for respondents who resided in a rural area compared to urban areas. When respondents were asked to rate service types that they had already used, they specified that patient organisations and counsellor/psychologists were the services they found to be most helpful. Respondents who had good conversations with their doctors most days or sometimes reported experiencing no barriers to treatment more frequently compared to those who reported that they never had good conversations.*

The barriers respondents identified in receiving their lymphoma treatment were:

- Wait time to treatment was longer than necessary (52%)
- None (23%)
- Financial (18%)
- Access to treatment centre/prohibitive travel (15%)
- Specialty physician available locally (7%)
- Access to the most up to date treatment (2%)
- 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. Patient organisation/support groups were rated to be the most helpful (45%) followed by counsellor/psychologist (39%) services (Table 28).

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

Types of Services	Evaluation of Services							
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	Not available in my country (%)	N/A (%)
Social worker	4	1	8	9	24	5	3	46
Patient organisation/ support group	2	-	10	23	45	7	2	11
Dietician/nutritionist	3	-	5	26	35	1	1	29
Counsellor/psychologist	4	1	4	27	39	-	2	23
Spiritual support	4	1	4	28	28	2	1	32
Physical therapy	5	2	6	19	18	3	3	44
Pain management	3	-	-	16	38	2	2	39
Complementary therapist	9	-	-	9	9	9	5	59

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

- A doctor in 31% of cases;
- A nurse in 22% of cases;
- Patient organisation/support group in 19% of cases;
- Online research in 6% of cases;
- Another patient in 6% of cases;
- Respondent were not provided with service information in 6% of cases;
- A friend in 5% of cases;
- A family member in 5% of cases.

In comparing the entire sample with only those that selected adequate information level, the highest rates were identified in patient organisation/support group services (Table 29).

**Table 29.** Evaluation of different services (1 lowest, 5 highest) in Colombia 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	2	2	6	11	24	2	2	51
Patient organisation/ support group	-	-	10	25	47	5	1	12
Dietician/nutritionist	2	-	3	25	38	-	2	30
Counsellor/psychologist	3	1	3	25	42	-	1	25
Spiritual support	3	1	3	32	27	-	1	33
Physical therapy	2	2	6	18	20	-	2	50
Pain management	-	-	-	15	39	-	2	44
Complementary therapist	-	-	-	13	13	-	7	67

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Respondents living in rural areas often identified barriers to treatment more frequently compared to respondents in urban areas (except for specialty physician available locally and access to the most up to date treatment, which were identified as a barrier only by respondents in urban areas). However, wait time to treatment was identified as a barrier more frequently by urban residents. Interestingly, 30% of the respondents living in urban areas did not identify any barrier to treatment: a sharp contrast to those in rural areas of whom 0% reported having no barriers to treatment (Table 30).

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

Types of Barriers to Treatment	Area of Residence		
	Rural (%)	Urban (%)	Suburban* (%)
Financial	60	23	-
Access to treatment centre/prohibitive travel	40	18	-
Access to the most up to date treatment	-	3	-
Wait time was longer than necessary	60	66	-
Personal support	20	-	-
Specialty physician available locally	-	10	-
Could not give up caregiver role (child, parent, disabled person) while in treatment	-	-	-
None	-	30	-

\*Please note that only 1% of the sample resided in a suburban area and this particular question received no answers.

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Respondents who never had good conversations with their doctor identified access to treatment center/prohibitive travel as a barrier more frequently than those who had good conversations most days or sometimes. In addition, respondents who had good conversations with their doctor most days or sometimes reported

encountering no barriers to treatment in 33% and 26% respectively. None of those who reported never having good conversations with their doctors reported experiencing no barriers to treatment. (0%) (Table 31)

**Table 31.** Barriers to treatment based on the quality of respondent communication with the 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	23	13	3	58	-	13	33
Sometimes	26	17	3	72	3	3	26
Never	-	50	-	50	-	-	-

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## APPENDIX 1

**Step 1.** The excel files were processed so that completed patients' and caregivers' responses were merged with the incomplete patients' and caregivers' responses. 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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