

# 2018

## Global Patient Survey on Lymphomas & CLL

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### GLOBAL REPORT



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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), Thessaloniki, Greece, performed the analysis and wrote the report.

Overall, 6631 participants took part from all over the world, demonstrating a marked increase from 4129 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 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 18 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 from their understanding of the patient experience.

### 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.

For the global report: 1) respondents' responses at a global level both for individual questions (i.e. q 2, q 3, q 4, etc.) as well as different combinations of questions (i.e. barriers to treatment according to area of residence) were analysed 2) cross country comparisons were performed to identify patterns and trends, and to highlight outliers.

Different countries' results are expressed in percentages thus enabling a straightforward comparison. Please note that balancing for the number of respondents from China, who represented nearly one third of the total respondent population, was decided against. Selecting a random sample of the population from China for analysis would not only lead to underrepresentation of respondents from China, but would also compromise cross-tabulation and comparisons across individual countries.

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 52).

## 2018 Global Patient Survey Goal

The goal for the 2018 Global Patient Survey is to gather information that will assist LC and its members to expand their understanding of 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 globally.

## OVERVIEW

*Six thousand, six hundred and thirty-one (6631) respondents globally took part in the 2018 LC survey. Most respondents were aware of their subtype at the time of the survey. However, when examining responses by-country, it was evident that respondents in most countries had the most difficulty (35%) understanding the characteristics of their particular subtype following their initial diagnosis meeting. Outliers in this trend existed in China, the United States(US), the United Kingdom(UK), and Japan. In these countries, respondents reported experiencing the most difficulty understanding the different medical treatment options, while Japan and the US also reported difficulty understanding side effect management.*

*64% of respondents wanted additional information and searched for information and support mostly immediately after their diagnosis. The primary sources of information for respondents globally were doctors and websites; except for respondents in Bulgaria, who mostly reported using websites and online blogs. Having a perceived adequate level of information was generally associated with positive feelings rather than negative. For example, respondents with adequate information felt more confident in determining the trustworthiness of information about their health condition and treatment choices and felt like they had the right to take the doctor's time to discuss their concerns.*

*Overall, fatigue and hair loss were the most frequently reported physical conditions. Fatigue was consistently one of the most frequently reported physical conditions across all countries. The most commonly reported medical issues were headaches and heart-related issues during treatment, and secondary cancer after treatment. Changes in relationships with loved ones, friends or co-workers/social life and anxiety were the most commonly reported psychosocial issues during treatment. Fear of relapse and changes in relationships with loved ones were very common after treatment. In their totality, medical issues, physical conditions and psychosocial issues were diverse and lasted for various lengths of time after treatment.*

*Because of their lymphoma, many respondents had experienced changes in their lifestyle and their independence; in all countries, the impact of the lymphoma diagnosis was greater on respondents' lifestyle than on their independence. Respondents reported experiencing fear of relapse both during and after treatment. Reported levels of fear of relapse peaked immediately after treatment and 3-5 years after treatment. Fear of relapse was associated with feelings of anxiety, depression and isolation, which were not frequently discussed with the doctor; this was a common finding in all countries. Respondents' reports of fatigue peaked immediately following treatment, and some even reported fatigue 8+ years after treatment.*

*In most countries, respondents' interest in services mainly included treatment information, credible website links, complementary nutrition/fitness information and downloadable materials. Some countries also reported interest in*

*patient organisation support, and financial support was rated as a top three service interest only by respondents in China.*

*When respondents were asked to rate service types that they had already used, they specified that patient organisation/support groups were the services that they found to be most helpful. This was true for most countries except for Argentina and Slovakia, where respondents indicated spiritual support services to be the most helpful. Counsellor/psychologist services were also rated highly in Italy. The support services most frequently reported to be unavailable globally were complementary therapists and social workers. Unavailable services were generally reported in low frequencies, except for in Argentina, where respondents often indicated that complementary therapist services were unavailable (26%), and Bulgaria where 31% of respondents indicated that social worker services were unavailable.*

*In terms of barriers to treatment, financials were the most frequently reported barrier by respondents in all countries except for respondents in Colombia, Argentina and Italy who mostly reported wait time to treatment (longer than necessary), and respondents in France who reported access to treatment centre/prohibitive travel. Respondents in the UK equally reported financials and access to the most up to date treatment as their top barriers. When examining respondent-reported barriers across different countries, there were barriers found to be associated with respondents' area of residence (rural, urban suburban). For example, in Italy, respondents living in urban areas identified wait time to treatment more frequently as a barrier compared to respondents living in suburban and rural areas. In Japan, respondents living in rural areas identified the availability of the appropriate specialty physician locally and wait time to treatment more often than respondents living in urban and suburban areas.*



## SURVEY RESULTS

*Please note: Comparisons across countries included countries with more than 100 respondents. Not all respondents replied to all questions, therefore the %s presented herein do not always refer to the total number of respondents that participated in the survey, but to the total number of respondents for each question. In some answers, the highest frequency reported may seem low (i.e. less than 50%) especially in questions with multiple possible answers. This is due to the distribution of the responses over a number of options.*

### I) Demographics

A total of 6631 individuals answered this year's Global Patient Survey.

Of these, 4744 (72%) were patients diagnosed with a lymphoma and 1887 (28%) were caregivers or family members answering on behalf of the patient. From this point forward, both groups will be considered as one and will be referred to as 'respondents'.

#### Respondents Demographic Profile

5973 (91%) respondents indicated that they had never participated in the Global Patient Survey, while of the 622 (9%) who said they had, some had participated in more than one year so direct correlations could not be made for trending analysis. Thirty-six respondents did not answer this question; therefore, percentages are based on the total number of replies to this question (6595).

48% were male, and 52% were female.

In most countries, the number of female and male respondents was relatively equal, with a few exceptions. Specifically, males were slightly overrepresented in China (55%) and females were overrepresented in Australia (67%), Argentina (74%), the UK (63%), Slovakia (63%), and New Zealand (58%).

71% of respondents were older than 40 years of age.

More specifically:

- 18-29 (12%)
- 30-39 (17%)
- 40-59 (35%)
- 60-69 (24%)
- 70+ (12%)

In all countries, at least half of the respondent population was older than 40 years; except for in Bulgaria, where 63% of respondents were younger than 40 years of age.

Regarding the area of residence:

- 52% lived in an urban area
- 25% lived in a suburban area
- 23% lived in a rural area

In most countries, the highest percentage of respondents lived in urban areas ranging from 45% in France and Japan, to 90% in Bulgaria. However, this was not the case for respondents in Australia, the UK, the US and New Zealand, where the highest percentage was noted for those who lived in suburban areas. In the Netherlands, 35% of respondents lived in urban areas and 35% in rural areas.

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

- No schooling completed: 2%
- Pre-secondary school: 2%
- Some secondary school, no diploma: 8%
- Secondary school diploma or equivalent: 21%
- Some college/university, no diploma/degree: 11%
- College/University diploma/degree: 33%
- Trade/technical/vocational training: 5%
- Master’s degree: 11%
- Doctorate degree: 3%
- Professional degree: 4%

Italy had the highest reported rate of pre-secondary education (41%) followed by Colombia (26%). New Zealand, the Netherlands, Australia, China, Bulgaria, Canada, Japan, the US and the UK had the highest rates of respondents who had completed college or university diploma/degree (ranging from 34% to 50%).

France was an exception in that the sample had an equal number of respondents who had completed secondary education and college or university.

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

**Table 1.** Distribution of lymphoma respondents globally.

<b>Lymphoma Subtype</b>	<b>% of Lymphoma Respondents</b>
Hodgkin	18
Follicular	14
DLBCL if not told what specific type	12
DLBCL GCB type	4
DLBCL ABC type	6
Waldenstrom’s Macroglobulinemia	12
CLL/SLL	9
Mantle cell	5
Cutaneous	3
Extranodal killer T-Cell	3
MALT/MZ	3
Peripheral T-Cell	2

Other indolent lymphomas	2
Other aggressive lymphomas	2
Don't know	2
Anaplastic large cell	2
Burkitt's	1

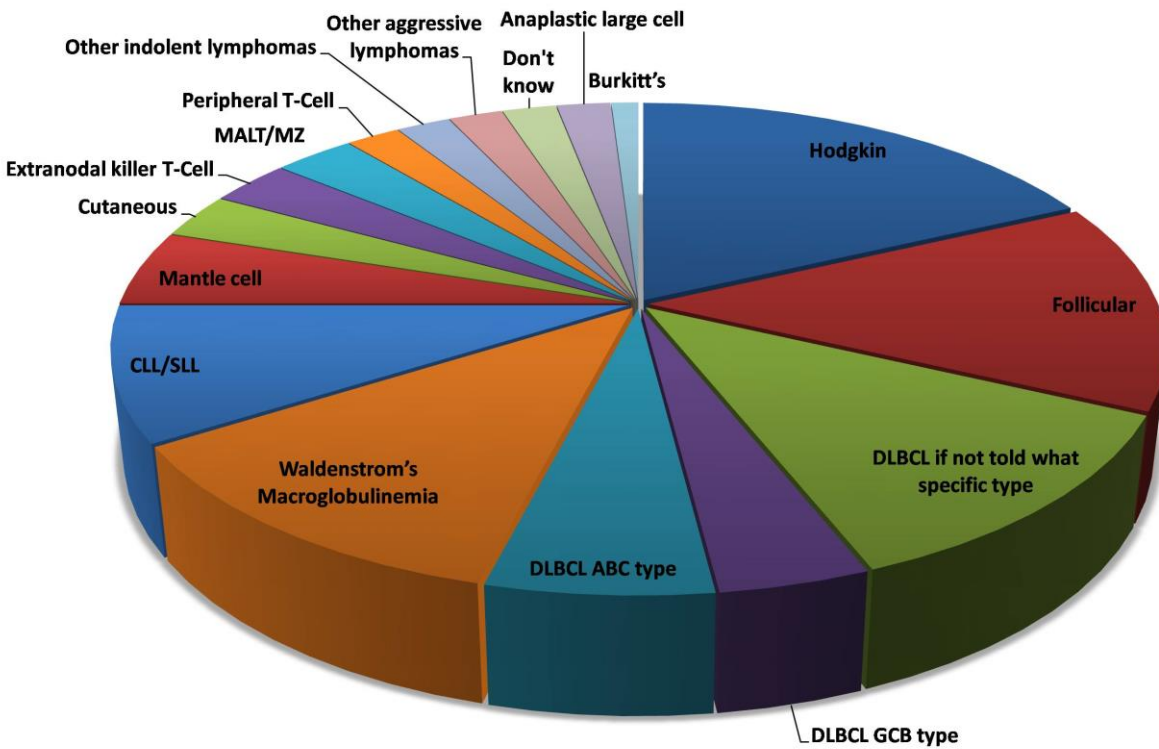
Abbreviations: CLL, Chronic Lymphocytic Leukaemia; SLL, Small Lymphocytic Lymphoma; DLBCL, Diffuse Large B-cell Lymphoma; GCB, Germinal Centre B-cell; ABC, Activated B-cell; MALT; Mucosa Associated Lymphoid Tissue, MZ; Marginal Zone.

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Hodgkin lymphoma was the most frequently reported subtype by respondents in most countries such as Colombia, Bulgaria, Argentina, the US, Slovakia, China and Italy, ranging from 14% of the sample in China to 64% of the sample in Colombia.

In contrast, in Canada and the UK, the most frequently reported subtype was Waldenstrom's Macroglobulinemia, while in Australia, France, Japan and New Zealand the most frequently reported subtype was follicular lymphoma. In the Netherlands, most respondents were diagnosed with follicular lymphoma or Diffuse Large B-cell lymphoma (DLBCL).

Please note that distribution of lymphoma respondents is based on respondent participation and not on the rates of the lymphoma diagnosis by country, thus the distribution of some lymphoma subtypes is different than what is normally reported.



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**Figure 1.** Distribution of lymphoma respondents globally.

Abbreviations: CLL, Chronic Lymphocytic Leukaemia; SLL, Small Lymphocytic Lymphoma; DLBCL, Diffuse Large B-cell Lymphoma; GCB, Germinal Centre B-cell; ABC, Activated B-cell, MALT; Mucosa Associated Lymphoid Tissue, MZ; Marginal Zone.

Respondents reported their year of diagnosis as:

- Prior to 1995: 1%
- 1996-2002: 4%
- 2003-2009: 11%
- 2010-2016: 52%
- 2017: 32%

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

- 2% were newly diagnosed

- 26% had been diagnosed and were in treatment
- 9% had been diagnosed and have been told treatment is not yet needed
- 17% were in remission and have been treatment free for 2 years or less
- 11% were in remission and have been treatment free for 2 to 5 years
- 9% were in remission and have been treatment free for more than 5 years
- 6% had relapsed for the first time and were in treatment
- 2% had relapsed more than 2 times and were in remission
- 5% had relapsed more than 2 times and were in treatment
- 12% had finished treatment and were in maintenance therapy
- 1% had transformed

In Colombia, China, Canada, Bulgaria, the Netherlands, Slovakia and the US, most respondents had been diagnosed and were in treatment at the time of the survey (ranging from 19% of the sample in Canada to as high as 44% of the sample in Colombia). In Italy, France, Australia, the UK and Argentina, most respondents were in remission and had been treatment free for various lengths of time.

## II) Patient Information, Guidance and Support

### LC Objectives:

The 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 LC’s 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. This report further explores this idea.

### Key Findings:

*Most respondents globally were aware of their subtype at the time of the survey. However, when examining respondents’ responses by-country, it was evident that respondents in the majority of countries had the greatest difficulty (35%) understanding the characteristics of their particular subtype following their initial diagnosis meeting. Some outliers did exist.*

*64% of respondents wanted additional information and searched for information and support mostly immediately after their diagnosis. In all countries, the primary sources of information for respondents were doctors and websites; except for respondents in Bulgaria, who reported acquiring information most often through websites and online blogs.*

*Respondents who considered themselves to be adequately informed wanted to overcome the disease, felt in control and had good conversations with their doctors ‘most days’. Respondents who were somewhat adequately or*

*inadequately informed also wanted to overcome the disease but felt in control and had good conversations with their doctors less frequently. Respondents with an adequate level of information were confident they could judge the trustworthiness of information and determine if medical care was needed or if they could handle a health problem on their own. Somewhat adequately and inadequately informed respondents felt less confident in these same two areas.*

*In comparing respondents' reported level of confidence with regards to the perceived level of information across different countries, all adequately informed respondents reported a higher level of confidence 'most days' (ranging from 26% in Japan to 81% in Italy) compared to respondents with somewhat adequate or inadequate information. Likewise, 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 raised questions about side effects during discussions with their doctor and felt that it helped. In the majority of countries, respondents' interest in services mainly included treatment information, credible website links, complementary nutrition/fitness information and downloadable materials.*

Most respondents (64%) were made aware of their lymphoma subtype during their initial diagnosis, whereas 25% were not informed and 11 % were not sure.

Participants were asked 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 treatment 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, more than 20% of respondents globally had difficulty understanding each of the different issues surrounding diagnosis and care after the initial visit to the doctor (responses 1+2). What respondents globally had the most difficulty understanding concerned the characteristics of their particular subtype (35%) (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						N/A (%)
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	
Diagnosis	14	12	22	20	24	6	2
Characteristics of the particular subtype	19	16	21	17	16	10	1
Different medical treatment options	19	14	20	18	19	9	1
Initial treatment if started right away	15	10	16	16	26	6	11
Potential side effects of treatment options	15	14	20	18	21	6	6
Side effect management	17	15	21	17	16	8	6
Process and stages of care	14	14	23	20	20	6	3
Active surveillance ('watch and wait'), if applicable	13	10	16	15	21	9	16

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When examining responses by-country (Table 3) it was evident that respondents in most countries had the greatest difficulty understanding the characteristics of their particular subtype; however, some outliers did exist. For example, respondents in China reported having the most difficulty understanding the different medical treatment options (41%). Respondents in Colombia identified active surveillance ('watch and wait') as the most difficult issue to understand (11%). Respondents in the US reported equal difficulty in understanding side effect management and the different medical treatment options (35% each). Respondents in the UK reported equal difficulty in understanding the characteristics of their particular subtype and the different medical treatment options (40% each), and respondents in Japan reported equal difficulty in understanding the different medical treatment options and side effect management (30% each).

**Table 3.** Topics surrounding diagnosis and care that respondents had difficulty understanding (levels 1+2) after their initial visit to the doctor in different countries.

Issues Around Diagnosis and Care	Respondents' Difficulty in Understanding (%)														
	North America		South America		Europe						Asia Pacific				Global
	US	CA	CO	AR	IT	FR	UK	BG	SK	NL	JP	AU	NZ	CN	Global
Diagnosis	28	27	8	8	11	16	22	25	16	14	21	22	21	36	26
Characteristics of the particular subtype	33	<b>42</b>	9	<b>28</b>	<b>36</b>	<b>36</b>	<b>40</b>	<b>44</b>	<b>23</b>	<b>31</b>	18	<b>39</b>	<b>30</b>	38	<b>35</b>
Different medical treatment options	<b>35</b>	33	7	10	20	18	<b>40</b>	40	21	21	<b>30</b>	26	25	<b>41</b>	33
Initial treatment if started right away	20	18	7	14	12	12	15	25	17	10	20	18	10	39	25
Potential side effects of treatment options	34	29	6	12	20	21	26	34	21	18	23	22	22	34	29
Side effect management	<b>35</b>	32	8	15	22	28	27	42	21	24	<b>30</b>	29	24	38	32
Process and stages of care	32	28	5	15	21	16	26	30	18	20	23	24	22	34	28
Active surveillance ('watch and wait'), if applicable	18	18	<b>11</b>	14	21	17	14	28	16	13	7	14	11	32	23

Abbreviations: US, United States; CA, Canada; CO, Colombia; AR, Argentina; IT, Italy; FR, France; UK, United Kingdom; BG, Bulgaria; SK, Slovakia; NL, The Netherlands; JP, Japan; AU, Australia; NZ, New Zealand; CN, China.

Comments: (i) Countries selected for comparisons are countries with more than 100 respondents in the LC 2018 survey.

(ii) Bold fonts are used to indicate the topic that received the most responses in the 1+2 levels of understanding in each country.

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

- 64% would like to receive additional information
- 23% were satisfied with the information they had received
- 9% felt overwhelmed and did not want more information as it was too much to take in at the time and,
- 4% did not want additional information.

The need for additional information was evident in respondents' reports from all countries, ranging from 37% of the sample in New Zealand to 82% of the sample in China.

Respondents were most active in seeking information immediately upon diagnosis (62%) and 1-3 months after diagnosis (20%). Similarly, they were most active in seeking support immediately upon diagnosis (45%) and 1-3 months after the diagnosis (21%) (Table 4).

**Table 4.** Respondents' information and support seeking at different time points.

<b>Time Points</b>	<b>Information (%) of Respondents</b>	<b>Support (%) of Respondents</b>
Immediately upon diagnosis	62	45
1-3 months	20	21
3-6 months	6	8
6 months-year	4	6
1 year-onwards	5	9
Never	3	11

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Interestingly respondents did not seek support as often as they sought information. More specifically, in most countries, respondents' reports of 'never' seeking information did not exceed 10%, except for respondents in Colombia who reported never seeking information in 33% of cases and respondents in Slovakia who reported never seeking information in 11% of cases. The highest percentage of respondents who reported 'never' seeking support was also identified in Colombia (35% of cases).

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

- 26% felt they had the support they needed
- 22% felt like they had the level/type of information they needed
- 15% felt like it would not make a difference
- 11% did not want support, wanted to fight this thing on their own
- 9% were fearful of what they might find out
- 7% did not want to know/were not interested
- 7% asked someone (friend, spouse, caregiver, etc.) to seek information for them
- 3% tried at first but did not understand the information online



When asked what level of information they felt they had overall, 34% of respondents globally felt they had received adequate information and 45% somewhat adequate information. Notably, 21% of respondents felt that they had received inadequate information.

Respondents in Italy, France, Bulgaria, Japan and China mostly felt they had received somewhat adequate information whereas respondents in all other countries mostly felt they had received adequate information. In Canada, the number of respondents who reported feeling adequately informed and somewhat adequately informed was approximately the same (Table 5). The highest percentages of inadequately informed respondents were identified in China (38%) and Bulgaria (30%). The lowest percentages of inadequately informed respondents were identified in Colombia (1%), Argentina (4%) and Italy (3%).

**Table 5.** Respondents’ perceived level of information in different countries.

Perceived Level of Information	Associated Frequency (%)														
	North America		South America		Europe						Asia Pacific			Global	
	US	CA	CO	AR	IT	FR	UK	BG	SK	NL	JP	AU	NZ	CN	Global
Adequate	<b>51</b>	<b>45</b>	<b>83</b>	<b>66</b>	44	39	<b>51</b>	21	<b>62</b>	<b>58</b>	30	<b>55</b>	<b>60</b>	12	34
Somewhat adequate	39	44	16	30	<b>53</b>	<b>49</b>	36	<b>49</b>	28	36	<b>51</b>	36	33	<b>50</b>	<b>45</b>
Inadequate	10	11	1	4	3	12	13	30	10	6	19	9	7	38	21

Abbreviations: US, United States; CA, Canada; CO, Colombia; AR, Argentina; IT, Italy; FR, France; UK, United Kingdom; BG, Bulgaria; SK, Slovakia; NL, The Netherlands; JP, Japan; AU, Australia; NZ, New Zealand; CN, China.

Comments: (i) Countries selected for comparisons are countries with more than 100 respondents in the LC 2018 survey.

(ii) Bold fonts are used to highlight the most reported information level for each country.

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Respondents’ associated feelings according to their perceived level of information, adequate, somewhat adequate and inadequate respectively, can be seen in Tables 6, 7, 8 below.

**Table 6.** 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	25	2	2
Out of control	7	47	38	8
Wanted to get into bed and hide	8	33	53	6
Wanted to overcome this disease	84	11	2	3
Overall fearful	16	61	20	3
Fearful for the future	19	60	17	4
At a loss	12	41	41	6

Confident	56	35	7	2
Felt mentally strong and capable	66	28	4	2
Felt physically strong and capable	49	42	7	2
Had good conversations with my doctor on my care and treatment plan	69	26	3	2
I was confident I could determine if I needed to get medical care or if I could handle a health problem myself	59	29	7	5
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	69	25	3	3

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**Table 7.** 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	41	49	6	4
Out of control	8	54	25	13
Wanted to get into bed and hide	11	38	37	14
Wanted to overcome this disease	73	20	4	3
Overall fearful	22	59	13	6
Fearful for the future	26	58	11	5
At a loss	17	53	23	7
Confident	39	45	12	4
Felt mentally strong and capable	48	41	8	3
Felt physically strong and capable	33	50	12	5
Had good conversations with my doctor on my care and treatment plan	37	50	9	4
I was confident I could determine if I needed to get medical care or if I could handle a health problem myself	35	45	13	7
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	39	48	7	6

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**Table 8.** 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	33	39	23	5
Out of control	14	46	22	17
Wanted to get into bed and hide	15	39	29	17
Wanted to overcome this disease	64	19	12	5
Overall fearful	32	44	17	7
Fearful for the future	34	44	15	7
At a loss	28	46	18	8
Confident	32	44	17	7
Felt mentally strong and capable	36	44	14	6
Felt physically strong and capable	25	46	18	11
Had good conversations with my doctor on my care and treatment plan	20	46	23	11
I was confident I could determine if I needed to get medical care or if I could handle a health problem myself	22	41	23	14
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	26	45	19	10

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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 (84%), felt in control (71%) and had good conversations with their doctors (69%). Respondents who were somewhat adequately informed also wanted to overcome the disease (73%) but felt in control in only 41% of cases and had good conversations with their doctors in only 37% of cases. Similarly, inadequately informed respondents also wanted to overcome the disease (64%) but felt in control in only 33% of cases and had good conversations with their doctors in only 20% of cases.

Additionally, adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own (59%), as well as determine the trustworthiness of information about their health condition and treatment choices (69%). Somewhat adequately informed respondents felt less confident in these same two areas (35% and 39%, respectively), and so did inadequately informed respondents (22% and 26%, respectively).

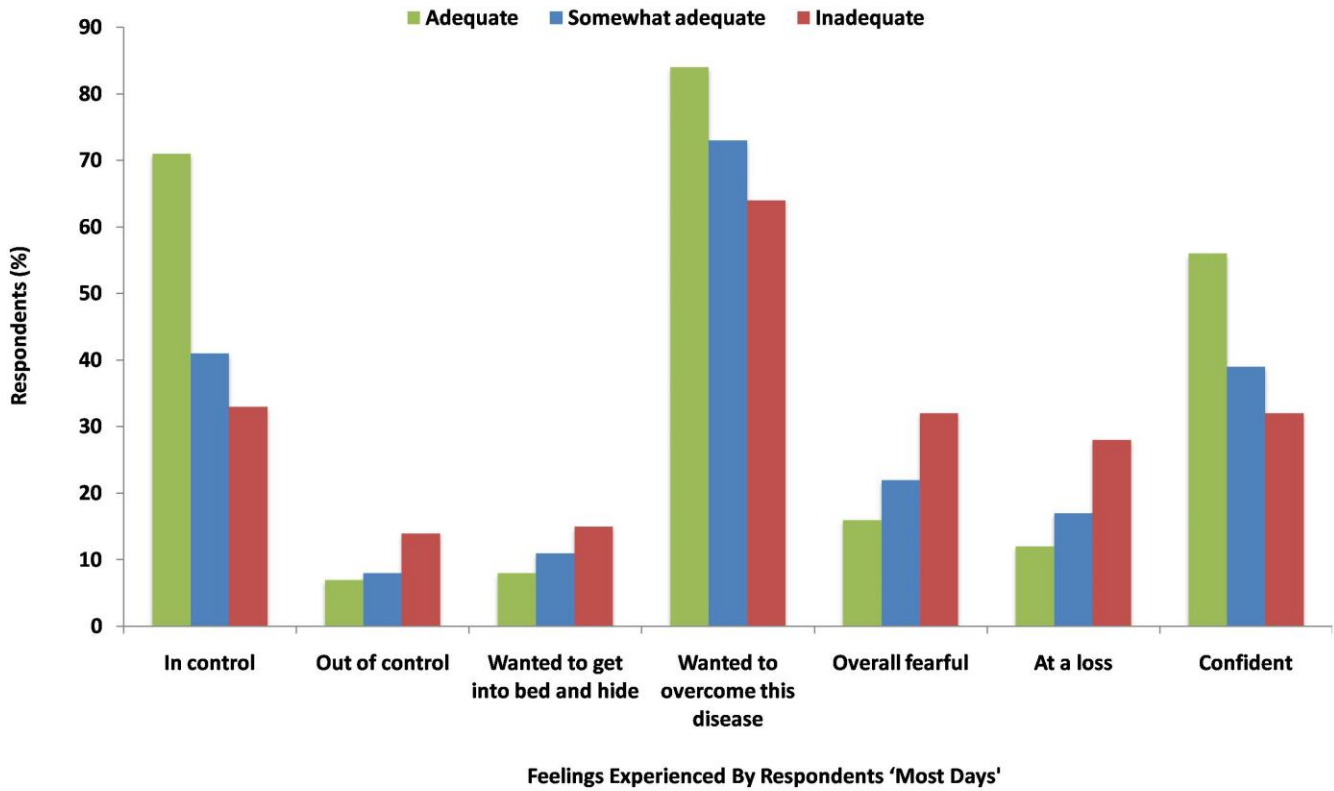
The impact of the perceived level of information on respondent reported confidence was higher in respondents who felt they had adequate information. Of these, 56% felt confident ‘most days’ versus 39% of those who felt they had received somewhat adequate information or 32% of those with inadequate information. In comparing the respondents’ reported level of confidence with regards to the perceived level of information across different

countries, all adequately informed respondents reported a higher level of confidence 'most days' than respondents with a somewhat adequate or inadequate level of information. The reported level of confidence amongst respondents with an adequate level of information ranged from 26% in Japan to 81% in Italy.

Based on the aforementioned results and the differences identified amongst respondents who were adequately informed and those who were somewhat or inadequately informed, some feelings (i.e. wanting to overcome the disease) seem to be related to the diagnosis of a lymphoma itself rather than the respondents' perceived level of information, whereas some others (i.e. level of confidence) seem to be related to the level of information. Communication with the doctor was found to vary with regards to the perceived level of information. Other feelings that varied with perceived level of information were overall fearfulness and feeling at a loss, which were more prevalent in inadequately informed respondents compared to somewhat and adequately informed respondents. Finally, the perceived level of information seemed to affect respondents' feelings of mental and physical strength; namely, adequately informed respondents felt stronger (both mentally and physically) compared to somewhat and inadequately informed respondents.

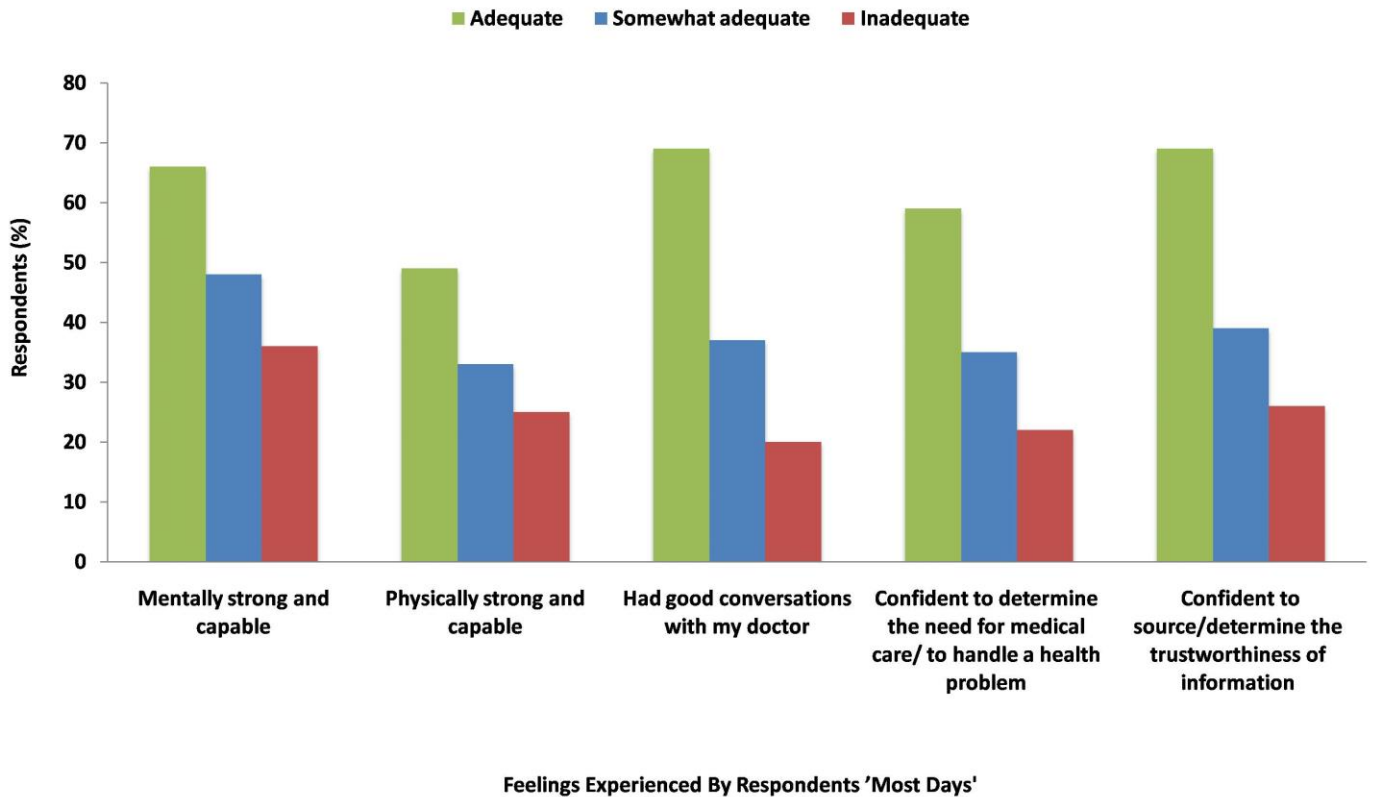
It is noteworthy that adequately informed respondents reported experiencing low levels of negative feelings 'most days', in contrast to inadequately informed respondents who reported experiencing lower levels of positive feelings 'most days'.

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.



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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 68%
- Websites 61%
- Patient organisations 42%
- Online blogs/social media 26%
- Nurse 22%
- Family/friends 18%
- Other 5%

Doctors and websites were the primary sources of information for respondents in all countries except for respondents in Bulgaria, who mostly reported using websites and online blogs.

Table 9 describes respondents' communication with the doctor, and the impact that this communication may have had on the different issues that the respondents faced.

**Table 9.** 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?	75	19	5	1
Was the doctor able to help?	44	39	12	5
Have you communicated any of your emotional issues to the doctor?	34	21	37	8
Was the doctor able to help?	30	27	22	21
Did you bring forward questions about side effects?	76	11	8	5
Was the doctor able to answer your questions?	61	26	7	6
Was the doctor able to help you cope with your side effects by providing medication or other support?	58	23	9	10
Did you seek clarification on things you did not understand?	73	15	7	5
Was the doctor able to answer your questions?	61	26	7	6
Did you discuss your fear of relapse with your doctor?	45	15	29	11
Do you feel that it helped to alleviate the fear?	29	29	20	22
Did the doctor or nurse refer you to further support that you were able to use?	37	16	37	10
Did you feel confident/comfortable voicing your concerns to your doctor?	52	24	18	6
If you experienced fatigue issues, did the doctor or nurse refer you to further support or information that you were able to use?	33	18	37	12
Did you feel you had the right to take the doctor's time to discuss any of the above during your visits?	65	19	12	4
Did the doctor encourage discussion with you on any of the above?	45	24	26	5

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No statistically significant differences could be identified at a global level between respondents communicating their medical/physical and respondents communicating their emotional issues to their doctor across different countries.

Specifically, when examining the demographic characteristics of respondents who indicated ‘yes’ to the question ‘Have you communicated any of your physical and/or medical issues to the doctor?’ at a global level, it was found that 52% lived in urban areas, 27% in suburban areas and 21% in rural areas. Furthermore, 75% were older than 40 years old and 25% were diagnosed and at the time of the survey and were undergoing treatment.

Specifically, when examining the demographic characteristics of respondents who indicated ‘yes’ to the question ‘Have you communicated any of your emotional issues to the doctor?’ at a global level, it was found that 54% of the respondents lived in urban areas, 22% in rural and 24% in suburban areas. Furthermore, 75% of the respondents were older than 40 years old and 23% were diagnosed and at the time of the survey were undergoing treatment.

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 all the following issues (Table 10) after the initial visit to the doctor.

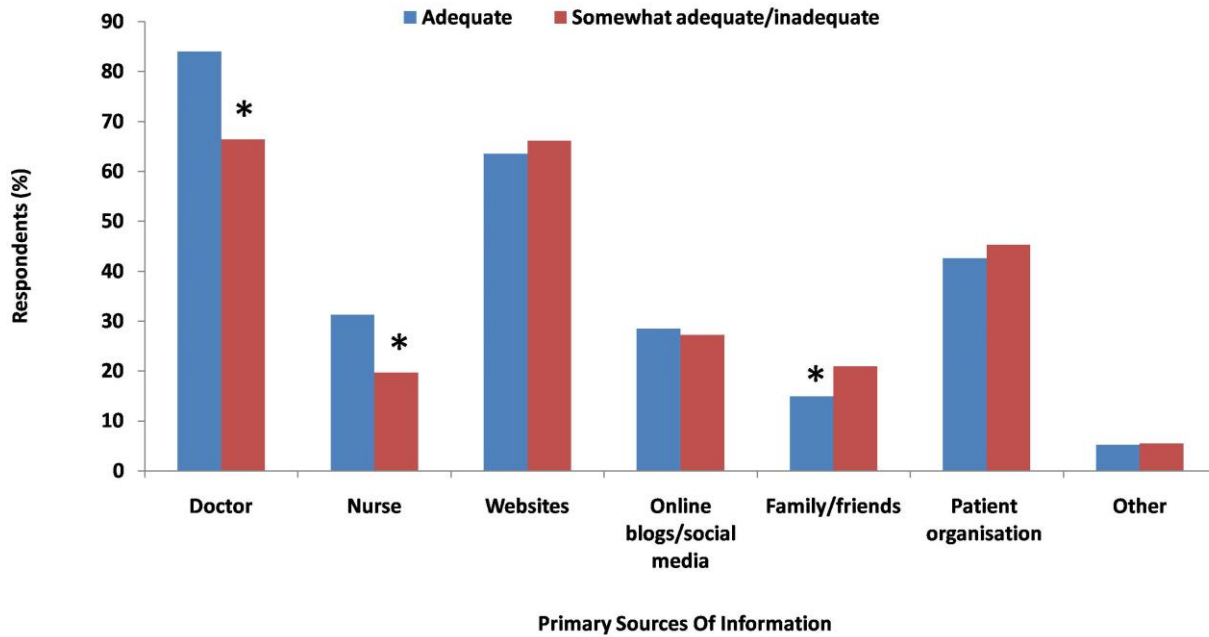
**Table 10.** Respondents’ understanding after the initial visit with the doctor based on their perceived level of information.

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

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

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) information. Those with a perceived adequate information level more frequently reported doctors and nurses as their main information source, and less frequently reported family/friends.





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

Interestingly, in all countries, no associations could be inferred between perceived level of information and area of residence (Table 11); except for in China, where respondents living in urban areas mostly reported having a somewhat adequate level of information.

**Table 11.** Respondents’ perceived level of information based on the area of residence.

Area of Residence	Respondents’ Level of Information		
	Adequate (%)	Somewhat Adequate (%)	Inadequate (%)
Rural	42	44	14
Urban	44	44	12
Suburban	47	44	9

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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 (82%) compared to those with somewhat adequate/inadequate information (67%). Moreover, respondents with adequate information felt more confident voicing their concerns to their doctors (73%) compared to respondents with somewhat adequate/ inadequate information (40%).

76% of respondents with adequate information felt they had the right to take the doctor’s time to discuss their concerns as opposed to 58% 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 to treatment more frequently than those who felt they had received adequate information. Some notable differences include: respondents with a somewhat adequate/inadequate information level reported financials as a barrier to treatment in 55% of cases whereas respondents with an adequate information level reported it in only 25% of cases. In addition, respondents with a somewhat adequate/inadequate level of information reported access to the most up to date treatment in 31% of cases in contrast to only 9% of the respondents with an adequate information level (Table 12).

Interestingly, experiencing no barriers in receiving lymphoma treatment was the option most reported by respondents with a perceived adequate level of information (54%) compared to only 22% of respondents with a somewhat adequate/inadequate level of information.

**Table 12.** 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	25	55
Access to treatment centre/prohibitive travel	13	22
	1	3
Access to the most up to date treatment	9	31
Wait time was longer than necessary	14	27
Personal support	1	2
Specialty physician available locally	9	20
Could not give up caregiver role (child, parent, disabled person) while in treatment	7	18
None	54	22

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

When asked about patient services, respondents showed the greatest interest in treatment information (92%) and reported less interest in phone-line support (46%) (Table 13).

**Table 13.** Respondents' interest in different services.

<b>Service Type</b>	<b>Interest of Total Respondent Population (%)</b>
Treatment information	92
Credible website links	91
Complementary nutrition/fitness information	84
Downloadable materials	83
Patient organisation support	83
Clinical trial options	82
Information on patient organisation services	82
Fatigue support	75
Hard copy materials	75
Financial support	72
Support in navigating the insurance system	69
Live education sessions	67
Professional emotional support	62
Online chats	61
Professional physical support	60
In person support groups	60
Phone-line support	46

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Interest in patient services was also analysed by country, and the top three interests were recorded (Table 14). In most countries, respondents' interest in services mainly included treatment information, credible website links, complementary nutrition/fitness information and downloadable materials. Patient organisation support services were also reported in some countries, whereas financial support was rated amongst the top three services of interest only by respondents in China (Table 14).

**Table 14.** Respondents’ top three interests in services in different countries.

Service Type	Top Interests of Respondent Population (By Country) (%)														
	North America		South America		Europe						Asia Pacific				Global
	US	CA	CO	AR	IT	FR	UK	BG	SK	NL	JP	AU	NZ	CN	Global
Treatment information	88	91	97	99	95	90	90	97	76	94	57	87	85	98	92
Credible website links	91	92			88		92		72	94	65	87	84	95	91
Complementary nutrition/fitness information			97	97	89	88		99	72				80	94	84
Downloadable materials	84	85				80	84	96	71	88	59	89			
Patient organisation support			95	96						86					
Financial support														95	

Abbreviations: US, United States; CA, Canada; CO, Colombia; AR, Argentina; IT, Italy; FR, France; UK, United Kingdom; BG, Bulgaria; SK, Slovakia; NL, The Netherlands; JP, Japan; AU, Australia; NZ, New Zealand; CN, China.

Comment: Countries selected for comparisons are countries with more than 100 respondents in the LC 2018 survey.

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When compared to the total respondent population, those who felt they had adequate information also showed the greatest interest in treatment information (87%) and reported less interest in phone-line support (39%).

Respondents globally were generally quite confident voicing their concerns to their doctor regardless of their stage in their patient experience (more than 45% in all stages). However, respondents who were in remission and treatment free for 2 to 5 years, or for more than 5 years, were the most confident voicing their concerns to their doctor (Table 15).

**Table 15.** Confidence in voicing concerns to the doctor at different stages of the lymphoma experience.

Stages	Responses			
	Yes (%)	Somewhat (%)	No (%)	N/A (%)
Newly diagnosed	46	21	25	8
Diagnosed and currently in treatment	52	23	20	5
Diagnosed and have been told that treatment is not yet needed	48	23	14	15
In remission and treatment free for 2 years or less	50	27	20	3
In remission and treatment free for 2 to 5 years	60	24	13	3

In remission and treatment free for more than 5 years	59	23	14	4
Have relapsed for the first time and currently in treatment	48	24	22	6
Have relapsed more than two times and in remission	55	27	14	4
Have relapsed more than two times and currently in treatment	53	26	15	6
Have finished treatment and currently in maintenance therapy	53	25	17	5
Have transformed	46	33	9	12

### 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 and 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:

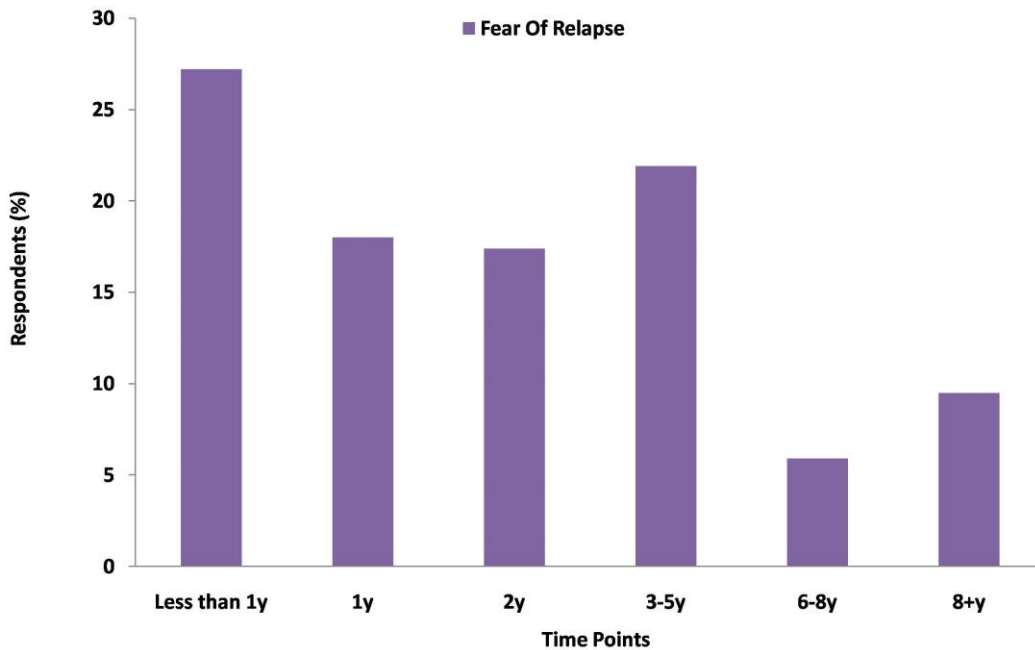
*Fear of relapse was experienced by respondents during treatment with levels rising significantly after treatment. This was consistent in all countries except for Colombia, where fear of relapse was reported less frequently after treatment than during treatment. Respondents’ reports of fear of relapse peaked immediately after treatment and 3-5 years after treatment, but it was also reported by some respondents at 8+ years after treatment. Fear of relapse was associated with feelings of anxiety, depression and isolation. However, these feelings were not frequently discussed with the doctor, and this was a common finding in all countries. Among respondents who reported fear of relapse, most felt they had somewhat adequate or inadequate information. This was a general observation for most countries except for Colombia, Australia, Italy, New Zealand, Slovakia and Argentina, where most respondents with fear of relapse reported having adequate information rather than somewhat adequate/inadequate information. In the UK, of those respondents reporting fear of relapse, 44% had adequate information and 41% 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.*

Fear of relapse was a major issue for respondents as it was reported both during and after treatment, showing a remarkable increase from 43% during treatment to 72% after treatment. This was a general observation in all countries; except for Colombia, where fear of relapse was reported less frequently after treatment than during treatment. Fear of relapse lasted for various lengths of time (See Table 23) (Figure 4).

Overall, the reported levels of fear of relapse after treatment in different countries were always high, ranging from 35% of the sample in China to 85% of the sample in Argentina.

Of those who experienced fear of relapse, 45% discussed and 15% somewhat discussed this fear with their doctor. Only 29% felt this helped and 29% felt it somewhat helped. However, 20% did not feel it helped alleviate the fear.

These results are quite representative of the responses received by-country with the exception of Colombia. In Colombia, of those who experienced fear of relapse, 84% discussed and 6% somewhat discussed this fear with their doctor. 79% felt this helped alleviate the fear and 11% felt it somewhat helped. Only 6% did not feel it helped alleviate the fear. Overall, percentages ranged from 32% of respondents in Bulgaria indicating 'yes' to the question 'Did you discuss your fear of relapse with your doctor?' to 84% in Colombia.



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

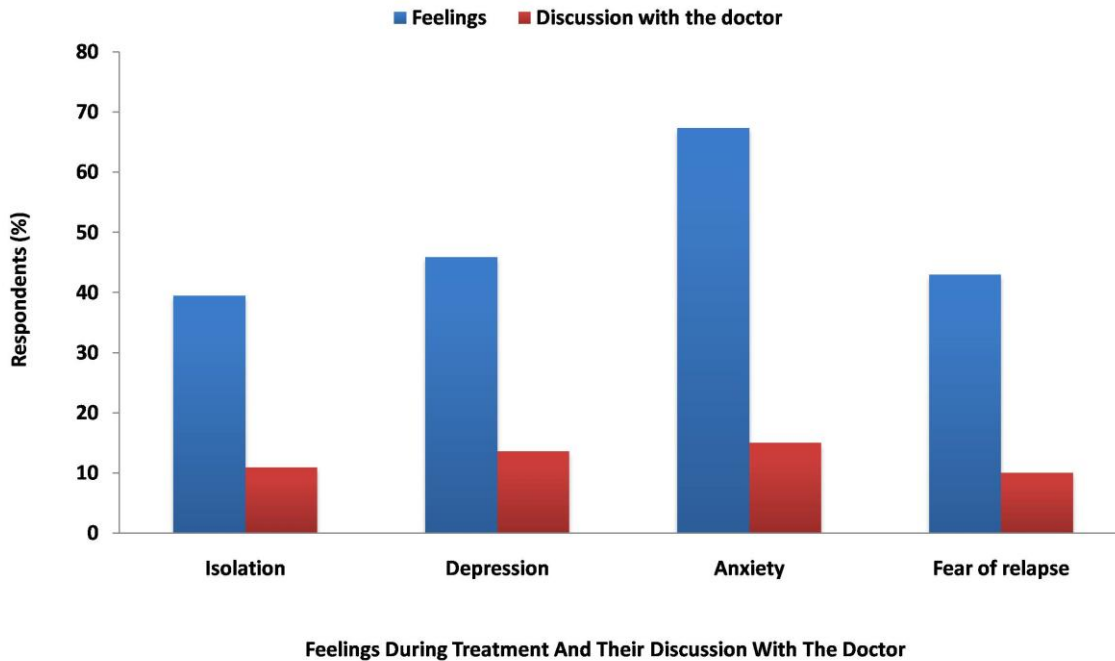
In some cases, fear of relapse was accompanied with feelings of isolation, depression and anxiety either during or after treatment (Tables 16 and 17) (Figures 5 and 6). Beside each feeling, respondents were asked to indicate if they

had discussed their feelings with their doctor. Respondents did not discuss their feelings of isolation, depression and anxiety as often as they felt them. This was a general observation in all countries. Interestingly, even though most feelings were reported less frequently after treatment, more than 20% of respondents globally continued reporting them after the end of treatment.

**Table 16.** 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	40	11
Depression	46	14
Anxiety	67	15
Fear of relapse	43	10

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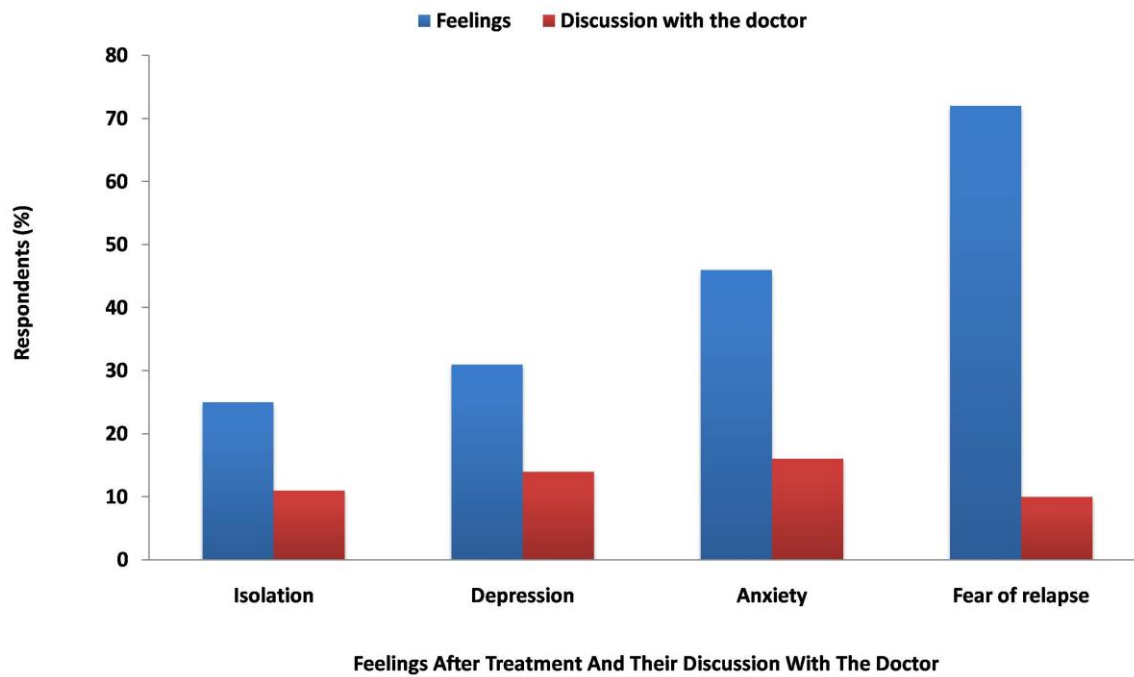
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**Figure 5.** Feelings of isolation, depression and anxiety during treatment amongst respondents who experienced fear of relapse, and their discussion with the doctor.

**Table 17.** 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	25	11
Depression	31	14
Anxiety	46	16
Fear of relapse	72	10

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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 globally, 30% had adequate information, 47% had somewhat adequate and 23% had inadequate information. In most countries, respondents with fear of relapse reported mostly having somewhat adequate information followed by adequate and inadequate information. However, in Colombia, Australia, Italy, New



Zealand, Slovakia and Argentina, most respondents with fear of relapse reported having adequate information rather than somewhat adequate/inadequate information. In the UK, among those with fear of relapse, 44% had adequate information and 41% had somewhat adequate information.

Sources of information for those who experienced fear of relapse during treatment were as follows: doctors 71%, nurses 28%, websites 71%, online blogs 34%, family/friends 21% and patient organisations 45%. Those who experienced fear of relapse after treatment used sources as follows: doctors 73%, nurses 27%, websites 69%, online blogs 31%, family/friends 19%, and patient organisations 48%.

For those who experienced fear of relapse, an attempt was made 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 and websites both during and after treatment.

## IV) Fatigue

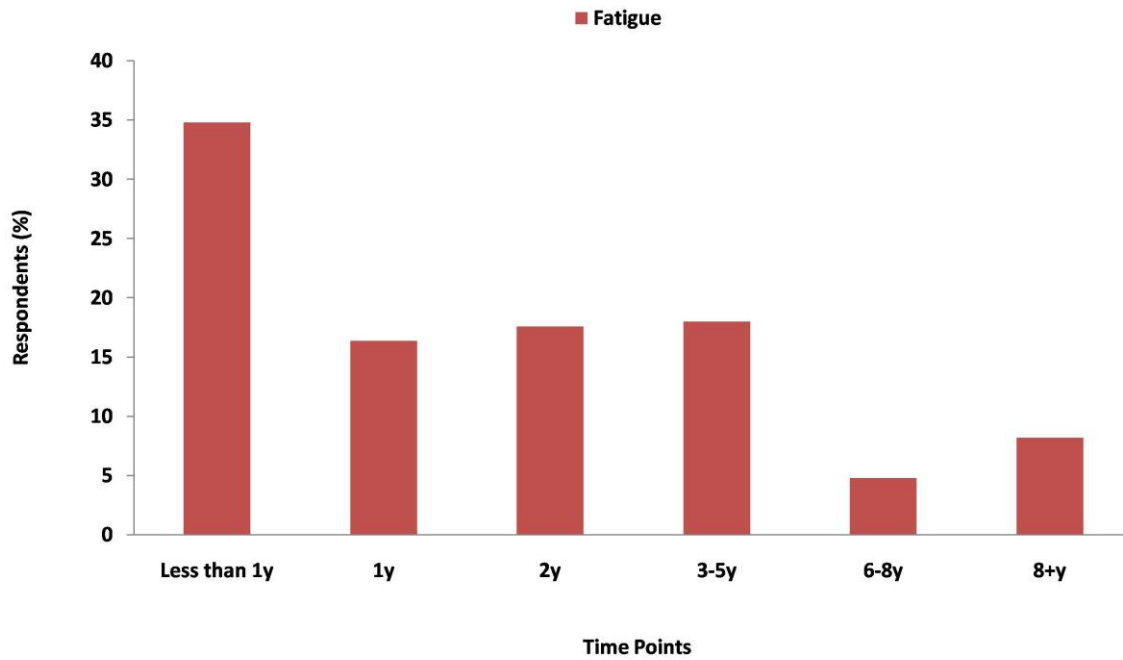
### LC Objectives:

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 under discussed across the healthcare community. We would like to further examine 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 amongst the most frequent of the physical conditions reported by respondents globally. Respondents' reports of fatigue peaked immediately following treatment, but some respondents reported experiencing fatigue for 8+ years after treatment. Fatigue affected respondents' independence but more so their lifestyle, with general activity suffering a large impact in all countries. Respondents who reported fatigue showed a higher percentage of fear of relapse after the end of treatment. This was a common finding in all countries except for Colombia. In terms of psychosocial issues due to fatigue, respondents mostly reported changes in relationships with loved ones during treatment and fear of relapse after treatment.*

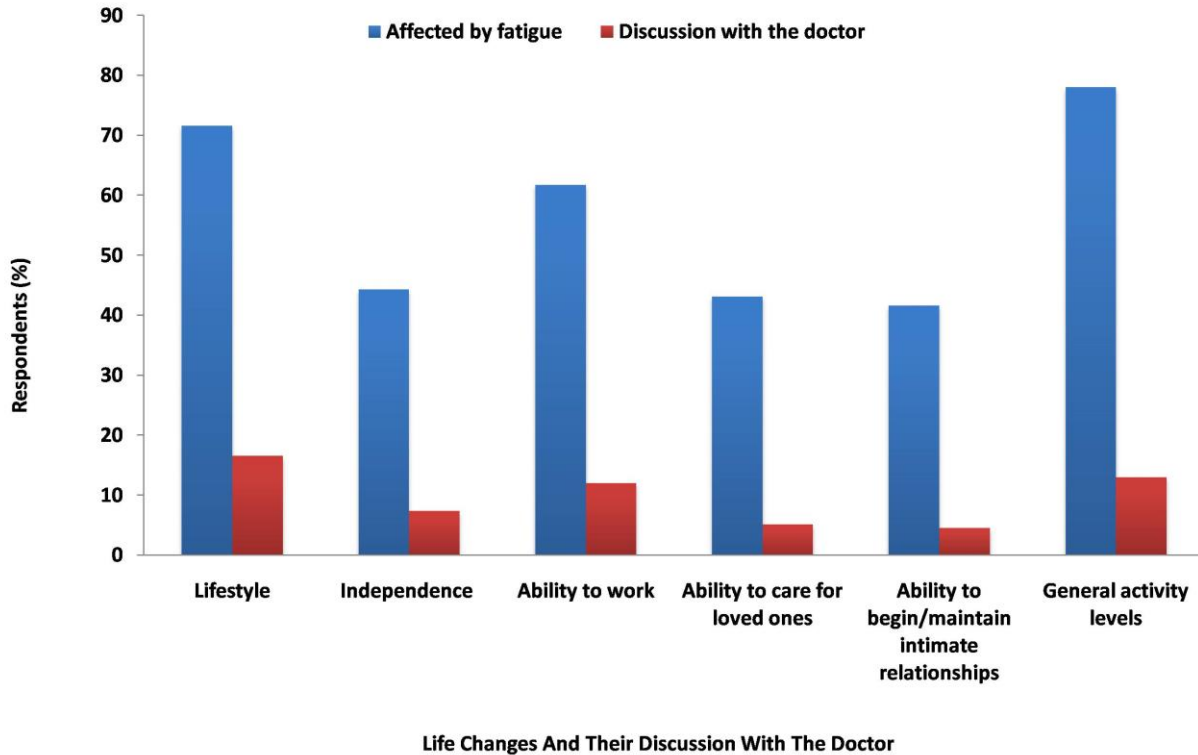
Fatigue was one of the most frequent physical conditions affecting respondents' sense of wellbeing since diagnosis. It was reported by 72% of respondents and lasted for various lengths of time (Table 19) (Figure 7).



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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 experienced changes in several areas of life (Figure 8). Respondents reported that life has changed (38%) or moderately changed (70%), or that they sleep well but the fatigue does not go away (55%).



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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 (72%) as was their independence (44%). Respondents' lifestyle was reported to be affected by fatigue more than their independence in all countries. In only 33% of cases did their doctor or nurse refer them for fatigue support, which was a lesser percentage than those who reported that they had not been referred for support (37%)

Fatigue was associated with psychosocial issues as well (Table 18). Specifically, due to fatigue, respondents reported experiencing mostly changes in relationships with loved ones, friends or co-workers/social life (35%) during treatment, and fear of relapse (37%) after treatment.

Respondents who reported fatigue reported experiencing a higher percentage of fear of relapse after the end of treatment (37%) than during treatment (25%). This was a common finding in all countries except for Colombia. Respondents from Colombia reported experiencing a higher percentage of fear of relapse during treatment than after treatment.

**Table 18.** 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	35	24
Stress related to financial issues	28	20
Loss of self-esteem	21	14
Concerns about body image/physical appearance changes	26	18
Loss/reduction in employment	20	18
Isolation	18	12
Depression	20	15
Anxiety	30	21
Fear of relapse	25	37
Difficulty on the job or in school	15	15
Problems getting health or life insurance coverage	10	14
Difficulty working effectively through the healthcare system	14	11
None	3	3

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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 and hair loss were the most frequently reported physical conditions. Fatigue was among the most frequently reported physical conditions by respondents in all countries. Many of the medical issues that respondents had to cope with during treatment were less frequently reported after the end of treatment. However, some others, like osteoporosis (26% after treatment vs 8% during treatment) and secondary cancer (72% after treatment vs 43% during treatment) were more prominent after treatment. Headaches and heart-related issues (59% each) were commonly reported during treatment, and secondary cancer was commonly reported after treatment (72%). Changes in relationships with loved ones, friends or co-workers/social life (59%) and anxiety (50%) were the most commonly reported psychosocial issues during treatment. Fear of relapse (72%) and changes in relationships with loved ones (45%) were very common after treatment. Moreover, respondents' reports of fear of relapse peaked immediately after treatment and 3-5 years after treatment, but some also reported it at 8+ years after treatment. In their totality, medical issues, physical conditions and psychosocial issues reported were diverse and lasted for various lengths of time. Respondents in all countries 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 reported feeling supported (58%).

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 (72%) and hair loss (48%) (Table 19). Respondents have reported these physical conditions to last for various lengths of time. Interestingly, at least some percentage of respondents reporting each condition indicated that it lasted for 8+ years after treatment.

**Table 19.** Physical conditions affecting wellbeing since diagnosis.

Physical Conditions	Percentage of Respondents (%)
Fatigue	72
Hair loss	48
Muscle weakness	41
Changes in sleep patterns	41
Problems fighting infections	38
Nausea and vomiting	35
Changes in taste and smell	33
Night sweats	32
Bowel changes	30
Loss of appetite	30
Trouble concentrating	28
Memory loss	27
Mucositis/mouth ulcers	24
Weight loss	24
Skin reactions	23
Itching	23

Weight change	22
Shortness of breath	21
Change in sexual function	20
Problems concentrating	20
Cramps	13
Swelling of arms and legs	12
Fluid retention	10
Burning	8
Loss of fertility	6
Viral reactivations	6
I had no changes in my physical condition whatsoever	5
Incontinence	4

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In all countries, fatigue was among the most frequently reported physical conditions. Other frequently reported physical conditions were hair loss, muscle weakness, changes in sleep patterns and trouble concentrating. Interestingly, there were no significant differences across countries or across respondents with different lymphoma subtypes (both within and across countries). For example, in Canada, fatigue (78%) was the most frequently reported physical condition, even when analysed by subtype: for example, Waldenstrom’s Macroglobulinemia 77%, follicular 71%, SLL/CLL 71%. A similar pattern was observed in the UK where fatigue was the most reported physical condition (88%). The same was true for respondents with Waldenstrom’s Macroglobulinemia who reported fatigue at 86%, respondents with SLL/CLL (81%), respondents with follicular lymphoma (83%), and respondents with Hodgkin lymphoma (94%).

**Table 20.** 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	35	16	18	18	5	8
Hair loss	73	13	6	4	2	2
Muscle weakness	48	17	14	13	3	5
Trouble concentrating	45	17	15	14	4	5
Changes in sleep patterns	44	15	14	16	4	7
Changes in taste and smell	66	13	9	7	2	3
Bowel changes	59	14	10	10	2	5
Aching joints	49	13	15	14	3	6
Nausea and vomiting	78	9	6	4	2	1
Problems fighting infections	43	15	16	15	3	8
Memory loss	45	14	16	16	4	5
Skin reactions	52	14	11	13	4	6
Mucositis/mouth ulcers	75	11	6	5	1	2

Loss of appetite	71	13	8	6	1	1
Change in sexual function	45	12	15	16	5	7
Weight loss	63	18	10	6	1	2
Fluid retention	68	11	9	7	3	2
Weight change	50	17	14	12	3	4
Loss of fertility	60	9	8	10	4	9
Swelling of arms and legs	67	11	8	8	3	3
Itching	51	14	13	12	4	6
Burning	70	9	7	8	2	4
Incontinence	74	8	6	6	3	3
Cramps	57	10	11	12	4	6
Shortness of breath	52	14	12	13	4	5
Viral reactivations	65	12	8	9	3	3
Night sweats	53	16	12	11	3	5
Problems concentrating	42	16	16	15	5	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 19 to see overall issue prevalence.

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Many of the medical issues that respondents reported during treatment were less reported after the end of treatment, whereas some others like osteoporosis and secondary cancer, were reported more frequently after treatment. Headaches and heart-related issues (59% each) were commonly reported during treatment, and secondary cancer (72%) after treatment. (Table 21).

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

Medical Issues	Treatment	
	During (%)	After (%)
Heart-related issues	59	45
Stomach-related issues	48	38
Issues with other organs	34	26
Diarrhea	44	33
Numbness	32	34
Neutropenia	29	21
Osteoporosis	8	26
Any other blood condition	50	38
Secondary cancer	43	72
Diabetes	24	28
Tingling	17	27
Eyesight issues	24	22
Enlarged lymph nodes	6	8

Pain	2	3
Headaches	59	45
Bleeding	48	38
Thrombosis	34	26
I do not have any other medical issues	44	33

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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	51	14	11	13	4	7
Stomach-related issues	47	15	13	14	4	7
Issues with other organs	50	13	12	13	5	7
Diarrhea	60	12	10	9	3	6
Numbness	43	15	14	15	4	9
Neutropenia	60	15	11	9	2	3
Osteoporosis	40	13	16	12	7	12
Any other blood condition	53	12	11	13	3	8
Secondary cancer	51	13	10	10	6	10
Diabetes	48	10	6	13	7	16
Tingling	41	15	13	16	6	9
Enlarged lymph nodes	36	17	17	17	5	8
Pain	49	15	14	13	4	5
Headaches	45	15	15	12	5	8
Bleeding	45	14	14	12	5	10
Thrombosis	61	10	10	10	4	5

\*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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Respondents' 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). Interestingly, even though less frequently, all psychosocial conditions were still reported (to some degree) 8+ years after the end of treatment.

Changes in relationships with loved ones, friends or co-workers/social life (59%) and anxiety (50%) were most commonly reported during treatment, whereas fear of relapse (72%) was very common after treatment. Most psychosocial issues were reported less frequently after treatment, however some others like depression, fear of relapse and problems getting health or life insurance coverage were reported more frequently after treatment. Furthermore, respondents' reports of fear of relapse peaked immediately after treatment and 3 and 5 years after treatment, but some also reported it at 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	59	45
Stress related to financial issues	48	38
Loss of self-esteem	34	26
Concerns about body image/physical appearance changes	44	33
Loss/reduction in employment	35	34
Isolation	29	21
Depression	8	27
Anxiety	50	38
Fear of relapse	43	72
Difficulty on the job or in school	24	28
Problems getting health or life insurance coverage	17	27
Difficulty working effectively through the healthcare system	24	22
None	6	8
Other	2	3

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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	39	18	17	16	4	6
Stress related to financial issues	32	20	18	18	5	7
Loss of self-esteem	39	17	18	16	4	6
Concerns about body image/physical appearance changes	37	20	18	16	3	6
Loss/reduction in employment	33	19	18	17	5	8
Isolation	40	20	16	14	4	6
Depression	36	20	16	17	4	7
Anxiety	34	18	17	18	5	8
Fear of relapse	27	18	17	22	6	10
Difficulty on the job or in school	34	21	17	17	5	6
Problems getting health or life insurance coverage	36	18	14	17	5	10
Difficulty working effectively through the healthcare system	60	13	10	8	2	7

\*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 (%)
Anxiety	7
Depression	4
Isolation	5
Changes in relationships with loved ones, friends or co-workers/social life	7
Concerns about body image/physical appearance changes	7
Fear of relapse	6
Problems getting health or life insurance coverage	7
Loss of self-esteem	8
Loss/reduction in employment	10
Stress related to financial issues	6
Difficulty working effectively through the healthcare system	4
None	5

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As a result of their lymphoma, 78% of respondents had experienced changes in their lifestyle and 50% had experienced changes in their independence. As a general observation, the impact of the lymphoma diagnosis was greater on respondents’ lifestyle than on their independence in all countries.

Respondents communicated medical issues to the doctor in 75% of cases and emotional issues in only 34% of cases. Interestingly, in all countries, medical issues were communicated more frequently than emotional issues.

Respondents indicated that the doctor was able to help with medical issues in only 44% of cases, whereas they were not helped or helped somewhat in 51% of cases. As far as emotional issues are concerned, the doctor was able to help in only 30% of cases, whereas they were not helped or helped somewhat in 49% of cases.

76% of respondents communicated questions about side effects to their doctor, and 61% indicated that the doctor was able to answer their questions. In 58% of cases, respondents indicated that the doctor was able to help them cope with the side effects (Table 26).

Communication of side effects was a major issue across different countries. Interestingly, even though most of the respondents brought forward questions about side effects (ranging from 65% in Argentina to 89% in Colombia) their reports of feeling supported varied across different countries ranging from 35% in Bulgaria to 89% in Colombia.

**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?	76	11	8
Was the doctor able to answer your questions?	61	26	7
Was the doctor able to help you cope with side effects by providing medication or other support?	58	23	9

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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. Respondents reported that they received answers from the doctor in 48% of cases, and received help coping with side effects through the provision of medication or other support in 47% of cases (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	13	10
Was the doctor able to answer?	48	33	11
Was the doctor able to help you cope with side effects by providing medication or other support?	47	30	13

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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:

*Globally, respondents commonly reported that financials constituted a barrier to treatment. This was consistent across all countries except for in Colombia, Argentina and Italy where wait time to treatment was most common, and in France, where access to treatment centre/prohibitive travel was highest. Further, in the UK, respondents reported financials and access to the most up to date treatment on the same level. When examining respondents' reports across different countries, there were barriers found to be associated with respondents' area of residence. Respondents living in suburban areas did not recognise any barrier in 49% of cases, as opposed to respondents living in rural (26%) and urban areas (29%). Support services most frequently reported to be unavailable globally were complementary therapist services. Respondents' reports of unavailable services were generally low except in Argentina, where respondents indicated that complementary therapist services were unavailable in 26% of cases, and in Bulgaria, where respondents indicated that social worker services were unavailable in 31% of cases. When respondents were asked to rate service types that they had already used, they specified that patient organisation/support groups were the services that they found to be most helpful. Patient organisation/support groups were rated as the most helpful services in the majority of countries except for Argentina and Slovakia, where respondents indicated that spiritual support services were the most helpful. Counsellor/psychologists were also highly rated in Italy. Respondents who 'most days' had good conversations with their doctors reported experiencing fewer barriers to treatment than did those who reported sometimes or never having good conversations.*

Overall, the barriers that respondents have identified in receiving their lymphoma treatment were:

- Financial (26%)
- None (20%)
- Access to the most up to date treatment (13%)
- Wait time to treatment was longer than necessary (13%)
- Access to treatment centre/prohibitive travel (11%)
- Specialty physician available locally (9%)
- Could not give up caregiver role (child, parent, disabled person) while in treatment (8%)
- Language (1%)
- Personal support (1%)

Interestingly, 20% of respondents did not identify any barrier in receiving their lymphoma treatment.

Financials was the most frequently reported barrier by respondents in all countries; except for respondents in Colombia, Argentina and Italy who mostly reported wait time to treatment (longer than necessary), and respondents in France who reported access to treatment centre/prohibitive travel (Table 28). Respondents in the UK equally reported financials and access to the most up to date treatment as their top barriers. The highest rate of ‘no barriers’ was observed in the Netherlands (67%), and the lowest rate of ‘no barriers’ was observed in China (6%).

**Table 28.** Barriers to treatment identified by respondents in different countries.

Barriers to Treatment	Associated Frequency (%)														
	North America		South America		Europe						Asia Pacific				Global
	US	CA	CO	AR	IT	FR	UK	BG	SK	NL	JP	AU	NZ	CN	Global
Financial	16	13	18	11	4	11	11	22	25	13	28	19	18	82	26
Access to the most up to date treatment	8	11	2	7	4	3	11	18	8	6	12	9	11	40	13
Wait time to treatment was longer than necessary	5	7	52	13	9	7	8	17	16	6	21	6	4	36	13
Access to treatment centre/prohibitive travel	11	7	15	5	6	12	6	10	21	7	19	10	6	21	11
Specialty physician available locally	14	7	7	6	6	6	8	9	6	5	4	5	9	22	9
Could not give up caregiver role (child, parent, disabled person) while in treatment	3	4	-	4	2	5	1	6	6	6	7	5	2	28	8
Language	1	1	-	-	-	-	1	2	-	-	1	1	-	3	1
Personal support	1	2	1	1	1	1	1	1	1	1	1	1	2	1	1
None	36	35	23	36	37	25	31	15	21	67	15	40	34	6	20

Abbreviations: US, United States; CA, Canada; CO, Colombia; AR, Argentina; IT, Italy; FR, France; UK, United Kingdom; BG, Bulgaria; SK, Slovakia; NL, The Netherlands; JP, Japan; AU, Australia; NZ, New Zealand; CN, China.

Comments: (i) Countries selected for comparisons are countries with more than 100 respondents in the LC 2018 survey.

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South American countries commonly reported wait time to treatment (longer than necessary) as a barrier to treatment, whereas North American countries, half of the European countries (of the ones considered) and the Asia Pacific countries mostly report financial issues as a significant barrier.

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 services are not available in their country. Patient organisation/support groups were rated to be the most helpful (34%). The highest rates of 'not available' services globally were identified in complementary therapists and social worker services, but this was fairly low at only 5% (Table 29).

**Table 29.** Respondent's evaluation (1 lowest, 5 highest) of different services globally.

Types of Services	Evaluation of Services							
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Don't know (%)	Not available in my country (%)	N/A (%)
Social worker	16	6	9	6	10	10	5	38
Patient organisation/ support group	8	6	14	16	34	6	3	13
Dietician/nutritionist	15	8	10	8	12	10	4	33
Counsellor/psychologist	14	6	8	8	17	10	4	33
Spiritual support	12	5	8	8	21	8	3	35
Physical therapy	13	6	9	8	11	12	3	38
Pain management	13	5	9	7	12	11	3	40
Complementary therapist	14	4	6	5	9	14	5	43

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

- A doctor in 30% of cases;
- Patient organisation/support group in 26% of cases;
- Online research in 20% of cases;
- A nurse in 18% of cases;
- A family member in 12% of cases;
- Another patient in 9% of cases;
- A friend in 8% of cases;
- Respondent was not provided with service information in 6% of cases.

Patient organisation/support groups were rated as the most helpful services in most countries except for Argentina and Slovakia, where respondents indicated spiritual support services to be the most helpful. Counsellor/psychologists were also highly rated in Italy (Table 30).

**Table 30.** Evaluation of different services by respondents in different countries.

Service Type	Evaluation of Services (%)														
	North America		South America		Europe						Asia Pacific				Global
	US	CA	CO	AR	IT	FR	UK	BG	SK	NL	JP	AU	NZ	CN	Global
Social worker	8	13	24	7	8	15	-	3	4	3	6	14	9	13	10
Patient organisation/ support group	<b>40</b>	<b>36</b>	<b>47</b>	<b>34</b>	<b>23</b>	<b>34</b>	<b>45</b>	<b>35</b>	19	<b>33</b>	<b>37</b>	<b>29</b>	<b>40</b>	<b>33</b>	<b>38</b>
Dietician/ nutritionist	6	14	38	23	15	15	8	12	3	12	3	6	12	14	15
Counsellor/ psychologist	8	14	42	36	<b>23</b>	28	14	12	13	16	6	20	20	14	20
Spiritual support	18	8	27	<b>52</b>	9	14	14	31	<b>23</b>	7	6	12	13	29	19
Physical therapy	7	6	20	22	5	6	7	4	12	21	3	8	11	14	12
Pain management	5	10	39	12	9	15	8	8	21	3	3	10	15	16	13
Complementary therapist	3	9	13	17	2	22	11	7	8	3	3	6	9	12	9

Abbreviations: US, United States; CA, Canada; CO, Colombia; AR, Argentina; IT, Italy; FR, France; UK, United Kingdom; BG, Bulgaria; SK, Slovakia; NL, The Netherlands; JP, Japan; AU, Australia; NZ, New Zealand; CN, China.

Comments: (i) Countries selected for comparisons are countries with more than 100 respondents in the LC 2018 survey.  
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When examining the three different regions (Americas, Europe and Asia Pacific), it is evident that there are certain patterns within and across countries. For example, respondents from South American countries have rated all services used very highly. Respondents from Japan gave the lowest evaluation rating of services (except for patient organisations / support group) not only within Asia Pacific, but also when compared to Europe and the Americas.

In comparing the entire sample with only those that reported an adequate information level, the highest rates were also identified in patient organisation/support group services (38%) (Table 31).

**Table 31.** Evaluation of different services (1 lowest, 5 highest) by respondents globally 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	9	4	5	7	10	7	4	54
Patient organisation/ support group	5	4	11	16	38	5	2	19
Dietician/nutritionist	9	5	8	11	15	7	3	42
Counsellor/psychologist	8	4	7	9	20	6	3	43
Spiritual support	7	3	6	9	19	7	2	47
Physical therapy	7	4	7	8	12	8	3	51
Pain management	6	3	6	8	13	8	3	53
Complementary therapist	8	2	3	6	9	9	5	58

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Respondents' reports of unavailable services were generally low except for Argentina, where respondents reported that complementary therapist services were unavailable in 26% of cases, and Bulgaria, where respondents reported that social worker services were unavailable in 31% of cases (Table 32).

**Table 32.** Reported frequency of services not available in different countries.

Service Type	Reported Frequency of Not Available Services (%)														
	North America		South America		Europe						Asia Pacific				Global
	US	CA	CO	AR	IT	FR	UK	BG	SK	NL	JP	AU	NZ	CN	Global
Social worker	1	1	2	21	13	1	4	31	7	4	6	2	1	5	4
Patient organisation/ support group	1	1	1	15	13	2	2	5	9	2	-	1	-	2	2
Dietician/ nutritionist	1	1	2	17	9	2	5	21	10	5	6	1	1	4	3
Counsellor/ psychologist	2	-	1	-	8	1	5	18	4	3	6	2	2	5	3
Spiritual support	1	-	1	15	7	2	5	10	3	4	13	2	1	3	2
Physical therapy	1	1	2	20	7	2	5	13	9	3	10	1	2	3	3



Pain management	1	1	2	24	9	1	2	12	4	3	10	2	-	3	3
Complementary therapist	2	2	7	26	15	1	4	19	13	3	10	5	6	5	5

Abbreviations: US, United States; CA, Canada; CO, Colombia; AR, Argentina; IT, Italy; FR, France; UK, United Kingdom; BG, Bulgaria; SK, Slovakia; NL, The Netherlands; JP, Japan; AU, Australia; NZ, New Zealand; CN, China.

Comments: (i) Countries selected for comparisons are countries with more than 100 respondents in the LC 2018 survey.

(ii) Bold fonts are used to highlight the most reported answer for each country.

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When examining the three different regions (Americas, Europe and Asia Pacific) it is evident that the availability of services is not uniform within each area. Argentina seems to be underprivileged in terms of service availability compared to Colombia and North American countries. The same can be observed in Bulgaria in Europe, and Japan in Asia Pacific.

For all respondents, financial issues were identified as the most frequent barrier. When examining barriers by area, respondents living in suburban areas did not recognize any barrier in 49% of cases as opposed to respondents living in rural (26%) and urban areas (29%) (Table 33).

When examining respondents' reports across different countries, there were barriers found to be associated with respondents' area of residence. For example, in Bulgaria, financials were the most frequently reported barrier to treatment for respondents living in rural and urban areas, whereas access to the most up to date treatment and wait time to treatment (longer than necessary) were identified as barriers mostly for respondents residing in suburban areas.

In the US, respondents living in rural areas identified access to treatment centre/prohibitive travel, availability of the appropriate specialty physician locally and access to the most up to date treatment more frequently than respondents living in urban and suburban areas.

In Colombia, 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 only by respondents in urban areas). However, wait time to treatment was identified more frequently by urban residents.

In Canada, for respondents living in rural areas, financials were the most frequently reported barrier. All other barriers were also more frequently reported by rural respondents compared to respondents living in urban and suburban areas.

Interestingly, in France and the UK, no statistically significant differences could be identified with regards to the barriers to treatment and the area of residence. In China, for respondents living in rural areas, financials were identified as a barrier to treatment more frequently compared to respondents living in urban and suburban areas. In Italy, respondents living in urban areas identified wait time to treatment (longer than necessary) more frequently compared to respondents living in suburban and rural areas. Respondents in Japan living in rural areas identified the availability of the appropriate specialty physician locally and wait time to treatment more often than respondents living in urban and suburban areas. In New Zealand, respondents living in rural areas identified financials, personal support and specialty physician available locally more frequently compared to respondents living in urban or

suburban areas. For respondents living in suburban areas in Slovakia, personal support was identified more frequently as a barrier compared to respondents living in rural or urban areas. Lastly, in the Netherlands, for respondents living in urban and suburban areas, financials were the most frequently reported barrier to treatment compared to respondents living in rural areas. Access to the most up to date treatment and wait time to treatment were identified as barriers mostly by respondents living in rural areas.

**Table 33.** Barriers to treatment based on area of residence.

Types of Barriers to Treatment	Area of Residence		
	Rural (%)	Urban (%)	Suburban (%)
Financial	51	48	32
Access to treatment centre/prohibitive travel	23	19	13
Language	2	2	1
Access to the most up to date treatment	21	26	17
Wait time was longer than necessary	24	27	14
Personal support	2	1	2
Specialty physician available locally	18	16	14
Could not give up caregiver role (child, parent, disabled person) while in treatment	14	16	9
None	26	29	49

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In addition, respondents globally who ‘most days’ had good communication with their doctor identified all barriers (except for language) less frequently than those who sometimes or never had good conversations with their doctors (Tables 34a and b). This was consistent across all countries.

The level of the respondents’ communication with the doctor affected their perception of the different barriers. For example, in Colombia, 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 Japan, respondents who never or sometimes had good conversation with their doctors identified wait time longer than necessary more than respondents who had good conversations with their doctors most days. In Slovakia, 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 34a.** Barriers to treatment based on the quality of respondent communication with the doctor.

<b>Good Conversation with Doctor</b>	<b>Barriers to Treatment</b>				
	<b>Financial (%)</b>	<b>Access to treatment centre/prohibitive travel (%)</b>	<b>Language (%)</b>	<b>Access to the most up to date treatment (%)</b>	<b>Wait time was longer than necessary (%)</b>
Most days	33	12	1	14	15
Sometimes	47	24	2	28	27
Never	58	25	3	36	31

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**Table 34b.** Barriers to treatment based on the quality of respondent communication with the doctor.

<b>Good Conversation With Doctor</b>	<b>Barriers to Treatment</b>			
	<b>Personal support (%)</b>	<b>Specialty physician available locally (%)</b>	<b>Could not give up caregiver role while in treatment (%)</b>	<b>None (%)</b>
Most days	-	11	10	47
Sometimes	2	18	14	28
Never	3	28	19	16

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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 submitted by LC to reference 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, (INAB | CERTH), 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. Participants with values in the Total\_M variable with a maximum of 0.70 were selected to keep. These participants are therefore those who have completed at least 30% of these target variables. If participants were considered with, for example, a maximum value of 0.3 we would end up with 4201 participants (approximately the completed study cases). So, a threshold was considered that within reason led to the final number of 6631.

**Step 5.** Comparisons across countries included countries with more than 100 respondents. Not all respondents replied to all questions therefore the % presented herein does not respond to the total number of respondents that participated in the survey but to the total number of respondents for each question. In some answers the highest frequency reported/presented may seem low (i.e less than 50%) especially in questions with multiple possible answers i.e. lymphoma subtypes; this is due to the distribution of the responses to more than one options.

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