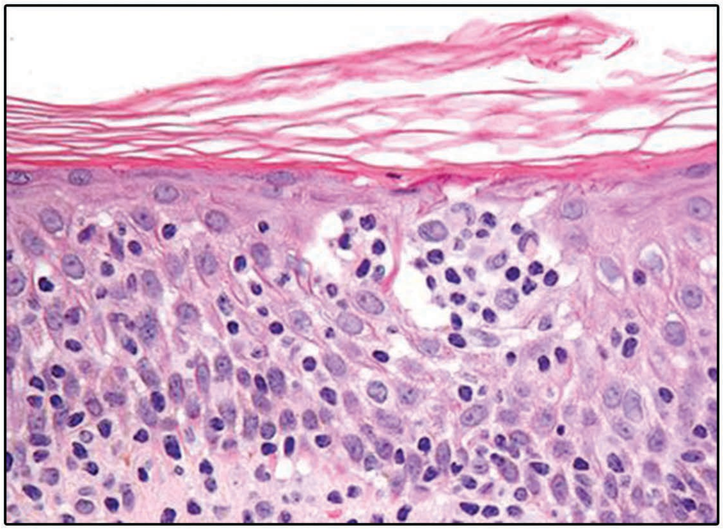
2018
Global Patient Survey on Lymphomas & CLL

SUBTYPE REPORT



CUTANEOUS LYMPHOMA

LYMPHOMA COALITION
Worldwide Network of
Lymphoma Patient Groups

Table of Contents

Table of Contents **2**

List of Figures 3

List of Tables 3

INTRODUCTION **5**

METHODOLOGY **5**

Survey Development and Launch 5

Survey Analysis 5

Goals for the 2018 Global Patient Survey 6

OVERVIEW **7**

SURVEY RESULTS **8**

I) Demographics 8

  Respondents' Demographic Profile 8

II) Patient Information, Guidance and Support 12

  Key Findings 12

III) Fear of Relapse 24

  Key Findings 24

IV) Fatigue 28

  Key Findings 28

V) Living with Side Effects 31

  Key Findings 31

VI) Barriers & Impediments **38**

  Key Findings 38

APPENDIX 1 .... **41**

List of Figures

Figure 1. Distribution of cutaneous lymphoma respondents in different countries 10
Figure 2a. Feelings experienced by cutaneous lymphoma respondents with different perceived information levels 'most days' 17
Figure 2b. Feelings experienced by cutaneous lymphoma respondents with different perceived information levels 'most days' 18
Figure 3. Primary sources of information by cutaneous lymphoma respondents' perceived level of information 21
Figure 4. How long fear of relapse lasted amongst cutaneous lymphoma respondents 25
Figure 5. Feelings of isolation, depression and anxiety during treatment amongst cutaneous lymphoma respondents who experienced fear of relapse, and their discussion with the doctor 26
Figure 6. Feelings of isolation, depression and anxiety after treatment amongst cutaneous lymphoma respondents who experienced fear of relapse, and who had a discussion with their doctor 27
Figure 7. How long fatigue lasted amongst cutaneous lymphoma respondents 29
Figure 8. Life changes brought on by fatigue and their discussion with the doctor 30

List of Tables

Table 1. Distribution of cutaneous lymphoma respondents in different countries........ 9
Table 2. Cutaneous lymphoma respondents' understanding (1 lowest, 5 highest) after the initial visit to the doctor 13
Table 3. Cutaneous lymphoma respondents' information and support seeking at different time points 13
Table 4. Feelings experienced by cutaneous lymphoma respondents with an adequate information level 14
Table 5. Feelings experienced by cutaneous lymphoma respondents with a somewhat adequate information level 15
Table 6. Feelings experienced by cutaneous lymphoma respondents with an inadequate information level 15
Table 7. Communication of topics concerning the patient experience with the doctor 19
Table 8. Cutaneous lymphoma respondents' understanding after the initial visit with the doctor based on their perceived level of information 20
Table 9. Cutaneous lymphoma respondents' perceived level of information based on the area of residence 21
Table 10. Barriers in receiving treatment based on cutaneous lymphoma respondents' perceived level of information 22
Table 11. Cutaneous lymphoma respondents' interest in different services 23
Table 12. Interest in different services by cutaneous lymphoma respondents with perceived adequate information 23
Table 13. Feelings of isolation, depression and anxiety during treatment amongst cutaneous lymphoma respondents who reported fear of relapse and who had a discussion with their doctor 25
Table 14. Feelings of isolation, depression and anxiety after treatment amongst cutaneous lymphoma respondents who experienced fear of relapse and who had a discussion with their doctor 26
Table 15. Psychosocial issues affecting wellbeing during and after treatment amongst cutaneous lymphoma respondents with fatigue 31
Table 16. Physical conditions affecting wellbeing since diagnosis 32
Table 17. How long did these physical conditions affecting wellbeing last? 33
Table 18. Medical issues amongst cutaneous lymphoma respondents during and after treatment 34
Table 19. How long medical issues lasted after treatment........ 34

Table 20. Psychosocial issues affecting cutaneous lymphoma respondents' wellbeing during and after treatment. 35
Table 21. How long psychosocial issues affecting wellbeing lasted........ 36

Table 22. Psychosocial issues affecting cutaneous lymphoma respondents' wellbeing and their communication with the doctor 36
Table 23. Communication with the doctor about side effects 37
Table 24. Cutaneous lymphoma 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 37
Table 25. Cutaneous lymphoma respondent's evaluation (1 lowest, 5 highest) of different services 39
Table 26. Barriers to treatment based on area of residence 40
Table 27. Barriers to treatment based on the quality of respondent communication with the doctor 40

INTRODUCTION

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

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

This report presents an overview of the responses cutaneous lymphoma respondents have provided in the 2018 Global Patient Survey. Overall, 203 cutaneous lymphoma patients and caregivers from all over the world took part in the LC survey.

METHODOLOGY

Survey Development and Launch

Lymphoma Coalition developed the 2018 survey based on the 2016 survey findings and questions, which were modified and expanded as needed. The resulting questions were first reviewed by the LC internal committee, and then sent out to the LC membership for review. The questions were subsequently reviewed by the Institute of Applied Biosciences at CERTH, (INAB | CERTH), which is an external scientific research body. Commentary and feedback from all parties on the English version was analysed, and appropriate revisions and edits were made. The finalised version of the survey contained 29 questions. It was translated into 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 on behalf of a patient.

Survey Analysis

In order to perform the analysis, the surveys completed by patients and those completed by caregivers were merged. For example, responses to question 1 completed by patients (Q1 P) and responses to question 1 completed by caregivers (Q1 C) were considered together and analysed as a single group of respondents (Q1 P + Q1 C= Q1 total). The same method was followed for all remaining survey questions. 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 42).

For this report, the responses of 203 cutaneous lymphoma respondents were filtered from the whole dataset of 6631 survey participants and analyzed both for individual questions (i.e. q 2, q 3, q 4, etc.) as well as different combinations of questions (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.

Goals for the 2018 Global Patient Survey

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

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

More specifically, the 2018 Global Patient Survey wanted 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 cutaneous lymphoma population. With this information, LC, the Cutaneous Lymphoma Foundation, and other LC members with a partial focus on this lymphoma subtype can be better equipped to serve the needs of the cutaneous lymphoma community.

OVERVIEW

Two hundred and three (203) cutaneous lymphoma respondents took part in the 2018 LC survey. Most respondents were made aware of their subtype during their initial diagnosis meeting with the doctor. However, many found the characteristics of their particular subtype, the processes and stages of care and side effect management difficult to understand. 65% of cutaneous respondents wanted additional information and searched for information and support mostly immediately after their diagnosis. The primary sources of information for cutaneous respondents were websites and doctors. If a respondent felt they had adequate information overall, it positively influenced such feelings as confidence in determining the trustworthiness of information about their health condition and treatment choices. It also positively impacted respondent's communication with the doctor; for example, feeling like they had the right to take the doctor's time to discuss their concerns.

In their totality, medical issues, physical conditions and psychosocial issues experienced were diverse and lasted for various lengths of time after treatment. Overall, fatigue and skin reactions were the most frequently reported physical conditions by cutaneous respondents. Cutaneous respondents' reports of fatigue peaked immediately following treatment as well as 3-5 years following treatment, but some respondents reported experiencing fatigue for 8+ years. Fatigue affected respondents' independence but more so their lifestyle, with general activity suffering the largest impact. The most commonly reported medical issues were pain and eyesight issues during treatment, and eyesight issues and numbness after treatment. Concerns about body image/ physical appearance changes and depression were the most commonly reported psychosocial issues during treatment, while fear of relapse was very common after treatment. Respondents' reports of fear of relapse peaked around 3-5 years after treatment, and it was reported by some respondents to continue for 8+ years after treatment. Fear of relapse was associated with feelings of anxiety, depression and isolation, which were not often discussed with the doctor.

As a result of their lymphoma, the majority of cutaneous respondents had experienced changes in their lifestyle and one third had experienced changes in their independence. The most reported barrier to treatment for cutaneous respondents was financial concerns. Barriers were also found to be associated with respondents' area of residence. For example, for respondents living in rural areas, certain barriers were identified more frequently compared to respondents living in urban and suburban areas, such as: financials, access to treatment centre/prohibitive travel and access to the most up to date treatment. Respondents' interest in services included: credible websites, patient organisation support, and complementary nutrition /fitness information. When respondents were asked to rate service types that they had already used, they specified that patient organisations/support groups and spiritual support were the services that they found to be most helpful.

SURVEY RESULTS

I) Demographics

A total of 203 respondents identified being diagnosed with cutaneous lymphoma. Of these, 173(85%) were patients and 30 (15%) were respondents answering on behalf of a patient. From this point forward, both groups will be considered as one and will be referred to as 'respondents'.

Respondents' Demographic Profile

188 (93%) of the respondents said they had never participated in the Global Patient Survey before, while of the 13 (7%) who said they had, some had participated in more than one year so direct correlations could not be made for trending analysis. Two respondents did not answer this question.

42% were male, and 58% were female.

86% of respondents were over 40 years old.

More specifically:
- 18-29 (4%)
- 30-39 (10%)
- 40-59 (33%)
- 60-69 (33%)
- 70+ (20%)

Regarding the area of residence:

- 26% lived in an urban area
- 46% lived in a suburban area
- 28% lived in a rural area

Responses varied with regards to the level of school completed/highest degree; however, many respondents had received college/university degree or higher. In more detail, respondents had completed/acquired:

- Pre-secondary school: 1%
- Some secondary school/ no diploma: 3%
- Secondary school diploma or equivalent: 13%
- Some college/university, no diploma/degree: 14%
- College/University diploma/degree: 36%
- Trade/technical/vocational training: 5%

- Master's degree: 17%
- Doctorate: 3%
- Professional degree: 8%

Table 1. Distribution of cutaneous lymphoma respondents in different countries.

Countries	% of Cutaneous Lymphoma Respondents
United States	70%
France	7%
Canada	6%
China	5%
United Kingdom	3%
Australia	1%
Colombia	1%
Japan	1%
Italy	1%
Egypt	1%
Mexico	1%
Portugal	1%
Serbia	1%
Slovakia	1%

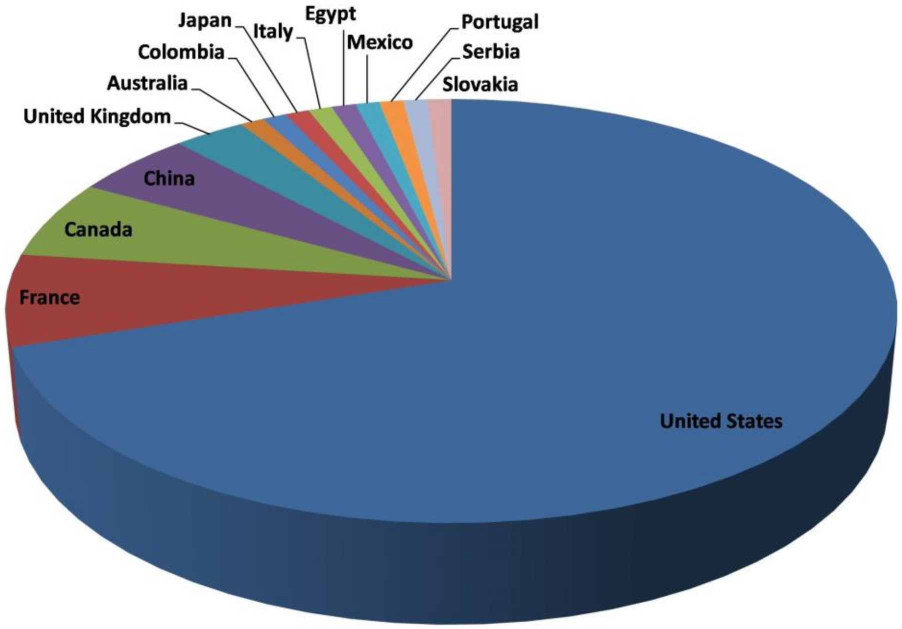


Figure 1. Distribution of cutaneous lymphoma respondents in different countries.

Respondents reported their year of diagnosis as:

- Prior to 1995: 3%
- 1996-2002: 5%
- 2003-2009: 17%
- 2010-2016: 50%
- 2017: 23%
- I don't know: 2%

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

- 4% were newly diagnosed
- 46% had been diagnosed and were in treatment
- 11% had been diagnosed and have been told treatment is not yet needed
- 8% were in remission and have been treatment free for 2 years or less

- 5% were in remission and have been treatment free for 2 to 5 years
- 4% were in remission and have been treatment free for more than 5 years
- 3% had relapsed for the first time and were in treatment
- 4% had relapsed more than 2 times and were in remission
- 7% had relapsed more than 2 times and were in treatment
- 7% had finished treatment and were in maintenance therapy
- 1% had transformed

II) Patient Information, Guidance and Support

LC Objectives:

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

Key Findings:

Most cutaneous respondents were made aware of their subtype at their initial diagnosis meeting with the doctor. However, many found the characteristics of their particular subtype, the processes and stages of care and side effect management difficult to understand. Approximately two thirds (65%) of cutaneous respondents wanted additional information and searched for information and support mostly immediately after their diagnosis. The primary sources of information for cutaneous respondents were websites and doctors. Respondents who considered themselves to be adequately informed wanted to overcome the disease and felt in control most days, they also had good conversations with their doctors. Respondents who were somewhat and inadequately informed wanted to overcome the disease but did not feel as in control and had good conversations with their doctors to a lesser extent. Adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own, they were also confident in their ability to determine the trustworthiness of information about their health condition and treatment choices. Somewhat adequately informed respondents felt less confident in the aforementioned areas, and so did inadequately informed respondents. Most respondents raised questions about side effects during discussions with their doctor and felt that it helped. Respondents' interest in patient services included credible websites, patient organisation support, and complementary nutrition /fitness information.

Most cutaneous respondents (74%) were made aware of their lymphoma subtype during their initial diagnosis, whereas 15% were not 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).

Respondents had the most difficulty understanding side effect management (41%), the process and stages of care and the characteristics of their particular subtype (38% each) (responses 1+2). Further, over 20% of respondents in each category surrounding diagnosis and care indicated some difficulty in understanding (responses rated 1+2).

Table 2. Cutaneous lymphoma respondents' understanding (1 lowest, 5 highest) after their initial visit to the doctor.

	Respondents' Level of Understanding						
Issues Around Diagnosis and Care	**1 (%)**	**2 (%)**	**3 (%)**	**4 (%)**	**5 (%)**	**Don't know (%)**	**N/A (%)**
Diagnosis	13	19	23	21	19	4	1
Characteristics of the particular subtype	20	18	24	18	15	5	-
Different medical treatment options	17	15	22	26	16	3	1
Initial treatment if started right away	12	10	20	24	24	4	6
Potential side effects of treatment options	20	17	18	18	17	5	5
Side effect management	25	16	20	15	14	6	4
Process and stages of care	20	18	20	20	13	6	3
Active surveillance ('watch and wait'), if applicable	16	9	17	11	15	7	25

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

- 65% would like to receive additional information
- 26% received enough information
- 5% 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.

Cutaneous lymphoma respondents were most active in seeking information immediately upon diagnosis (67%) and 1-3 months after diagnosis (13%). Similarly, they were most active in seeking support immediately upon diagnosis (36%) and 1-3 months after the diagnosis (23%) (Table 3).

Table 3. Cutaneous lymphoma respondents' information and support seeking at different time points.

Time Points	**Information (%) of Respondents**	**Support (%) of Respondents**
Immediately upon diagnosis	67	36
1-3 months	13	23
3-6 months	5	11
6 months-year	3	7
1 year-onwards	10	12
Never	2	11

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

- 38% felt it would not make a difference
- 31% felt they had the support they needed
- 23% felt like they had the level/type of information they needed
- 8% did not want support, wanted to fight this thing on their own

When asked what level of information they felt they had overall, 31% of cutaneous respondents felt they had received adequate information, 47% somewhat adequate information and 22% inadequate information. Respondents' associated feelings according to their perceived level of information, adequate, somewhat adequate and inadequate respectively, can be seen in Tables 4, 5 and 6 below.

Table 4. Feelings experienced by cutaneous lymphoma 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	74	20	3	3
Out of control	2	42	49	7
Wanted to get into bed and hide	4	33	56	7
Wanted to overcome this disease	75	15	2	8
Overall fearful	8	72	20	-
Fearful for the future	11	72	17	-
At a loss	7	30	61	2
Confident	51	40	7	2
Felt mentally strong and capable	65	33	-	2
Felt physically strong and capable	52	46	-	2
Had good conversations with my doctor on my care and treatment plan	76	19	3	2
I was confident could determine if I needed to get medical care or if I could handle a health problem myself	55	29	8	8
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	63	34	3	-

Table 5. Feelings experienced by cutaneous lymphoma 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	43	48	7	2
Out of control	5	52	39	4
Wanted to get into bed and hide	8	35	52	5
Wanted to overcome this disease	82	13	4	1
Overall fearful	21	57	18	4
Fearful for the future	26	59	14	1
At a loss	12	53	29	6
Confident	27	50	18	5
Felt mentally strong and capable	46	49	5	-
Felt physically strong and capable	41	53	5	1
Had good conversations with my doctor on my care and treatment plan	47	46	6	1
I was confident I could determine if I needed to get medical care or if I could handle a health problem myself	41	45	11	3
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	47	44	5	4

Table 6. Feelings experienced by cutaneous 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	31	51	18	-
Out of control	20	56	18	6
Wanted to get into bed and hide	23	43	28	6
Wanted to overcome this disease	67	28	3	2
Overall fearful	36	51	13	-
Fearful for the future	41	54	5	-
At a loss	31	47	16	6
Confident	11	51	35	3
Felt mentally strong and capable	21	58	18	3
Felt physically strong and capable	24	51	22	3
Had good conversations with my doctor on my care and treatment plan	16	71	13	-

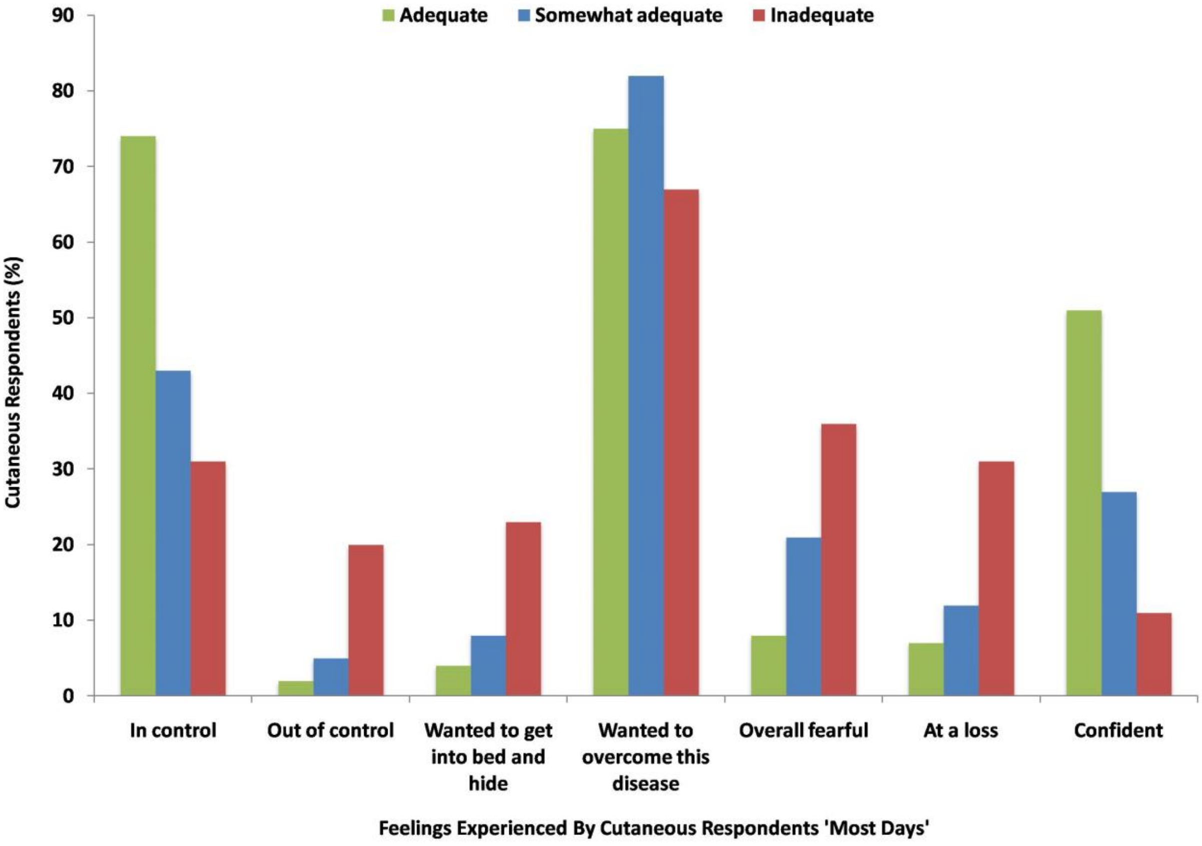
I was confident I could determine if I needed to get medical care or if I could handle a health problem myself	18	42	37	3
I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices	16	50	34	-

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 (75%), felt in control (74%) and had good conversations with their doctors (76%). Adequately informed respondents more often reported 'never' experiencing negative feelings and reported 'most days' experiencing the more positive feelings. For example, feeling 'out of control' was reported 'most days' in only 2% of cases and 'never' in 49% of cases. Similarly, wanting to get into bed and hide was reported 'most days' in 4% of cases and 'never' in 56% of cases. Adequately informed respondents reported feeling confident 'most days' in 51% of cases, and 'never' in only 7% of cases.

Respondents who were somewhat adequately informed wanted to overcome the disease (82%) but felt in control in only 43% of cases and had good conversations with their doctors in only 47% of cases. Inadequately informed respondents wanted to overcome the disease (67%) but felt in control only in 31% of cases and had good conversations with their doctors in only 16% of cases. They also felt fearful about the future (41%) and at a loss (31%). It is noteworthy that only 11% of inadequately informed respondents felt confident 'most days' while 35% 'never' felt confident.

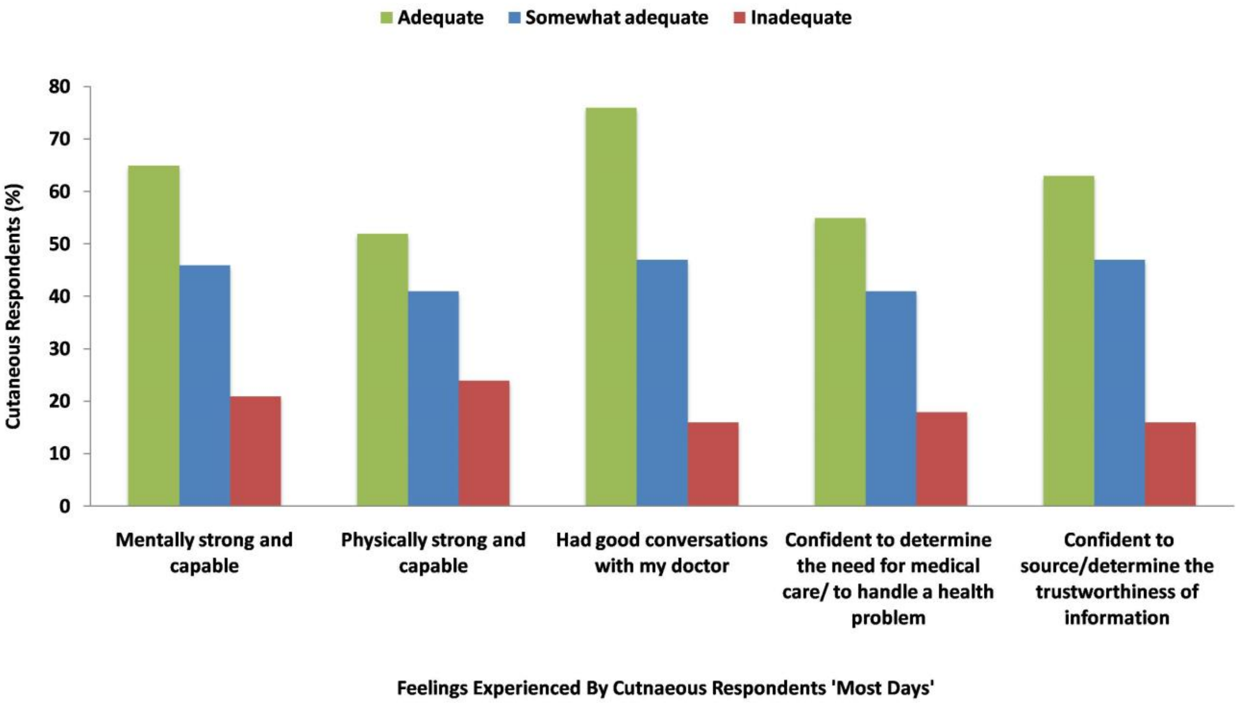
Furthermore, 'most days', adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own (55%), as well as determine the trustworthiness of information about their health condition and treatment choices (63%). Only 8% and 3% reported 'never' feeling confident in these areas respectively. Somewhat adequately informed respondents felt less confident ('most days') in these same two areas (41% and 47%, respectively), and it is noteworthy that inadequately informed respondents only felt confident ('most days') in these areas in 18% and 16% of cases respectively.

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.



Copyright © 2018 Lymphoma Coalition. All rights reserved.

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



Copyright © 2018 Lymphoma Coalition. All rights reserved.

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

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

- Websites 76%
- Doctor 72%
- Patients organisations 39%
- Online blogs/social media 32%
- Nurse 12%
- Family/friends 9%
- Other 5%

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

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

Communication with Doctor on Topics Concerning the Patient Experience	**Responses**			
	Yes (%)	**Somewhat (%)**	**No (%)**	**N/A (%)**
Have you communicated any of your physical and/or medical issues to the doctor?	63	26	8	3
Was the doctor able to help?	39	35	17	9
Have you communicated any of your emotional issues to the doctor?	32	19	40	9
Was the doctor able to help?	19	25	21	35
Did you bring forward questions about side effects?	73	11	9	7
Was the doctor able to answer your questions?	61	25	4	10
Was the doctor able to help you cope with your side effects by providing medication or other support?	48	19	13	20
Did you seek clarification on things you did not understand?	76	14	3	7
Was the doctor able to answer your questions?	58	31	5	6
Did you discuss your fear of relapse with your doctor?	43	15	25	17
Do you feel that it helped to alleviate the fear?	26	28	23	23
Did the doctor or nurse refer you to further support you were able to use?	30	16	40	14
Did you feel confident/comfortable voicing your concerns to your doctor?	63	23	11	3
If you experienced fatigue issues, did the doctor or nurse refer you to further support or information that you were able to use?	17	15	40	28
Did you feel you had the right to take the doctor's time to discuss any of the above during your visits?	66	23	7	4
Did the doctor encourage discussion with you on any of the above?	52	25	18	5

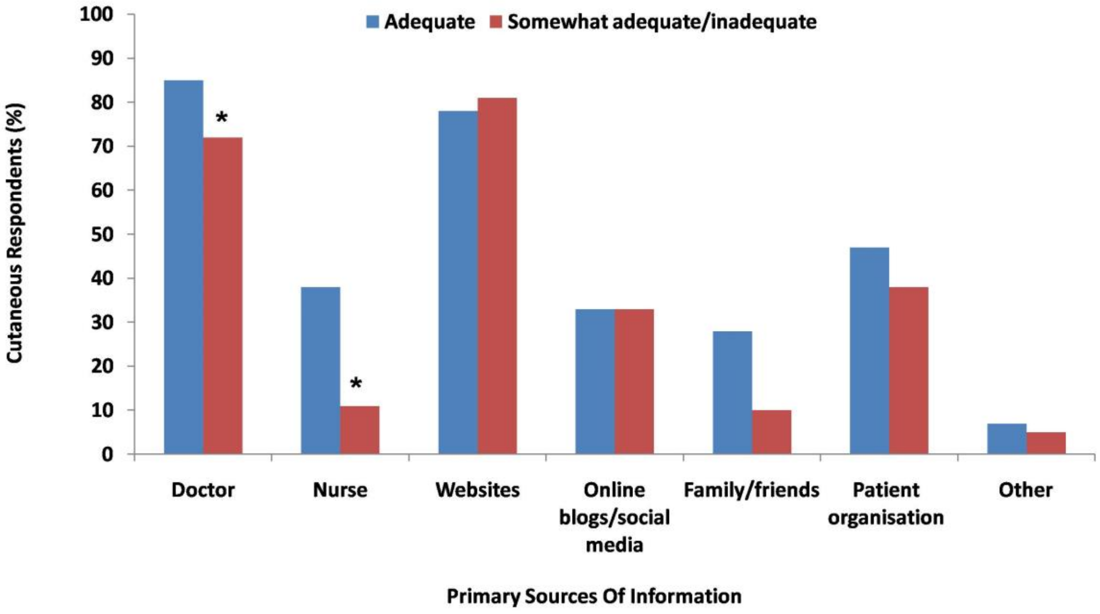
Cutaneous lymphoma respondents who felt, at the time of the survey, that they had adequate information also reported that they had a greater understanding of all of the following issues after the initial visit to the doctor, as reflected in Table 8.

Table 8. Cutaneous lymphoma 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	67	29
Characteristics of the particular subtype	66	22
Different medical treatment options	73	30
Initial treatment if started right away	82	38
Potential side effects of treatment options	56	30
Side effect management	52	23
Process and stages of care	67	22
Active surveillance ('watch and wait'), if applicable	68	31

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

Figure 3 points to where cutaneous lymphoma respondents were looking for information; those who felt they had received adequate information differed significantly from those who felt they had inadequate (somewhat adequate/ inadequate) information regarding their primary sources of information. Those with adequate information more frequently reported using doctors and nurses as their primary sources of information.



Copyright © 2018 Lymphoma Coalition. All rights reserved.

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

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

Table 9. Cutaneous lymphoma respondents' perceived level of information based on the area **of residence.**

Area of Residence	**Cutaneous Lymphoma Respondents' Level of Information**		
	Adequate (%)	**Somewhat Adequate (%)**	**Inadequate (%)**
Rural	21	31	30
Urban	33	25	22
Suburban	46	44	48

Copyright © 2018 Lymphoma Coalition. All rights reserved.

For this analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information. Cutaneous lymphoma respondents with adequate information sought clarification on things they did not understand more frequently (81%) compared to those with perceived somewhat adequate/inadequate information (73%). Moreover, respondents with adequate information felt more confident voicing their concerns to their doctors (83%) compared to respondents with somewhat adequate/inadequate information (53%).

Respondent-reported confidence was higher in those who felt they had adequate information. Of these, 51% felt confident most of the days versus 22% of those who felt they had received somewhat adequate /inadequate information. The majority (85%) of respondents with adequate information felt that they had the right to take the doctor's time to discuss their concerns as opposed to 57% of respondents with somewhat adequate/inadequate information.

When asked what barriers had been experienced in receiving lymphoma treatment, cutaneous lymphoma respondents who felt they had received somewhat adequate/inadequate information identified certain barriers more frequently compared to those who felt they had received adequate information. Specifically, these were: access to treatment centre/prohibitive travel, access to the most up to date treatment, personal support, specialty physician available and could not give up caregiver role.

Interestingly, experiencing no barriers in receiving lymphoma treatment was reported equally frequently by respondents with an adequate information level (27%) and respondents with a somewhat adequate/inadequate level of information (28%) (Table 10).

Table 10. Barriers in receiving treatment based on cutaneous lymphoma respondents' perceived level of information.

	Perceived Level of Information	
Barriers in Receiving Treatment	**Adequate Information (%)**	**Somewhat Adequate/Inadequate Information* (%)**
Financial	42	37
Access to treatment centre/prohibitive travel	32	37
Access to the most up to date treatment	12	29
Wait time was longer than necessary	20	18
Personal support	-	3
Specialty physician available locally	27	32
Could not give up caregiver role (child, parent, disabled person) while in treatment	2	9
None	27	28

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

When asked about patient services, cutaneous lymphoma respondents showed the greatest interest in credible website links (92%) and reported less interest in phone-line support (28%) (Table 11).

Table 11. Cutaneous lymphoma respondents' interest in different services.

Service Type	Interest of Total Cutaneous Respondent Population (%)
Credible website links	92
Patient organisation support	80
Complementary nutrition/fitness information	77
Information on patient organisation services	77
Clinical trial options	76
Treatment information	75
Hard copy materials	73
Support in navigating the insurance system	70
Downloadable materials	70
Live education sessions	69
Online chats	60
Financial support	61
Fatigue support	57
In person support groups	54
Professional emotional support	50
Professional physical support	39
Phone-line support	28

When compared to the total respondent population, those who felt they had adequate information expressed interest in services in a different order. However, their top interests remained the same, namely credible website links (93%) followed by patient organisation support and treatment information (78% each) (Table 12).

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

Service Type	Interest of Adequate Information Respondents (%)
Credible website links	93
Patient organisation support	78
Treatment information	78
Information on patient organisation services	76
Downloadable materials	75
Hard copy materials	68
Clinical trial options	67

Complementary nutrition/fitness information	63
Live education sessions	61
Financial support	57
Support in navigating the insurance system	51
Online chats	48
In person support groups	47
Fatigue support	41
Professional emotional support	32
Professional physical support	28
Phone-line support	20

III) Fear of Relapse

LC Objectives:

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

Key Findings:

Fear of relapse was experienced by cutaneous lymphoma respondents during treatment with levels rising significantly after treatment. Respondents' reports of fear of relapse peaked around 2-5 years after treatment, and it was reported by some respondents to continue for 8+ years. Fear of relapse was associated with feelings of anxiety, depression and isolation. However, these feelings were not often discussed with the doctor. Among cutaneous lymphoma respondents that reported fear of relapse, two thirds felt they had somewhat adequate or inadequate information. Both during and after treatment, respondents with fear of relapse commonly reported doctors and websites as their primary sources of information followed by patient organisations. Interestingly, following treatment, respondents indicated using patient organisations more often.

Fear of relapse was experienced by cutaneous lymphoma respondents during treatment with levels rising significantly after treatment, showing an increase from 35% during treatment to 57% after treatment. Fear of relapse lasted for various lengths of time (Table 23) (Figure 4).

Of those who reported fear of relapse, 43% discussed and somewhat discussed (15%) this fear with their doctor. Only, 26% felt this helped and 28% felt it helped somewhat. However, 23% did not feel it helped alleviate the fear.

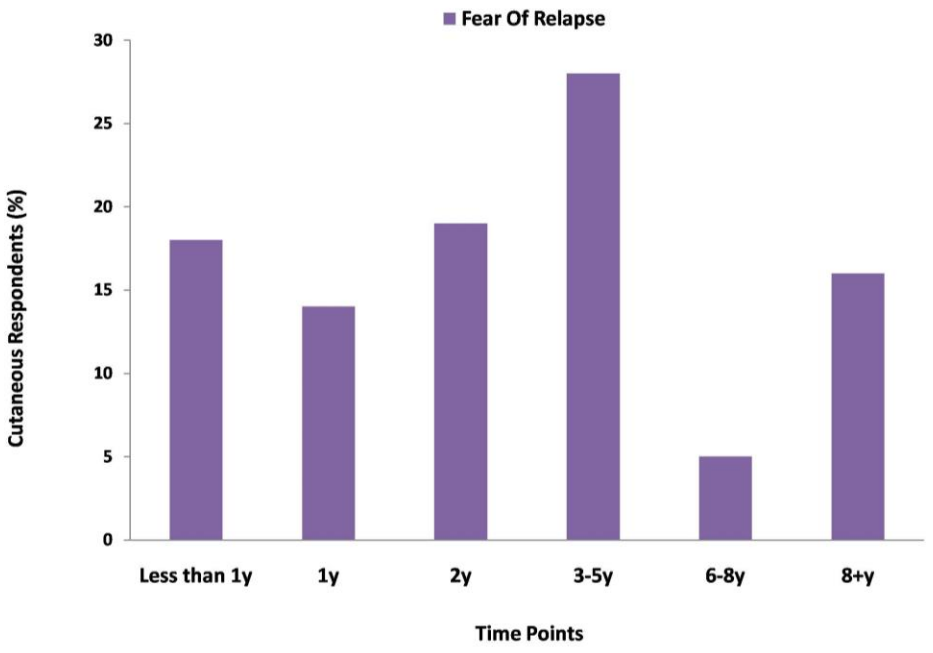


Figure 4. How long fear of relapse lasted amongst cutaneous lymphoma respondents.

In some cases, fear of relapse was accompanied with feelings of isolation, depression and anxiety either during treatment or after treatment (Tables 13 and 14) (Figures 5 and 6). Next to each feeling, respondents were asked to indicate if they had discussed it with their doctor. Respondents did not discuss their feelings of isolation, depression and anxiety as often as they felt them.

Table 13. Feelings of isolation, depression and anxiety during treatment amongst cutaneous lymphoma respondents who reported fear of relapse and who had a discussion with their doctor.

Feelings During Treatment	(%)	I Have Discussed It with My Doctor (%)
Isolation	55	5
Depression	67	10
Anxiety	70	13
Fear of relapse	35	7

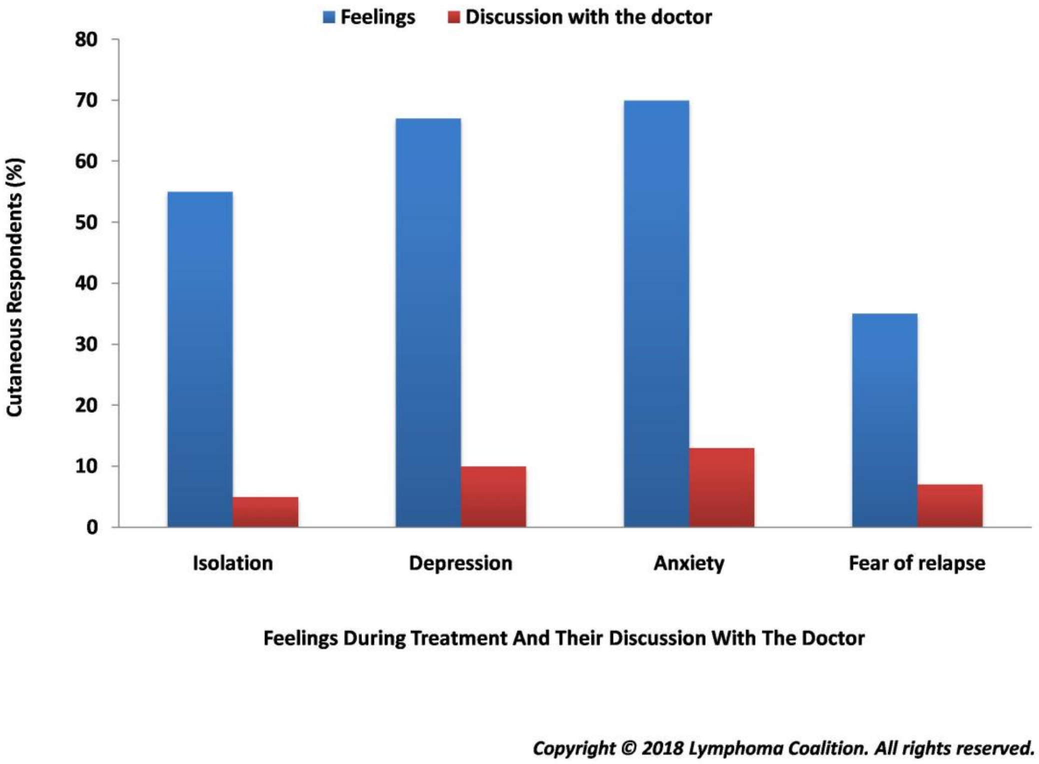


Figure 5. Feelings of isolation, depression and anxiety during treatment amongst cutaneous lymphoma respondents who experienced fear of relapse, and their discussion with the doctor.

Table 14. Feelings of isolation, depression and anxiety after treatment amongst cutaneous lymphoma respondents who experienced fear of relapse, and who had a discussion with their doctor.

Feelings After Treatment	(%)	I Have Discussed It with My Doctor (%)
Isolation	23	5
Depression	33	18
Anxiety	41	13
Fear of relapse	57	28

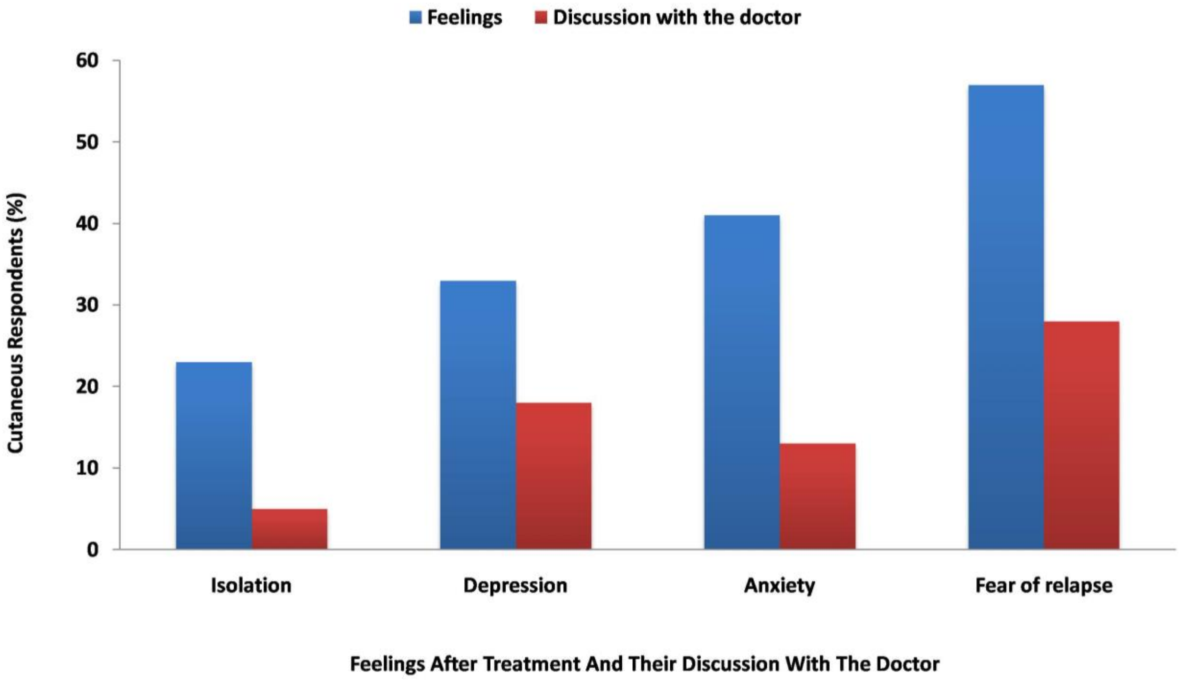


Figure 6. Feelings of isolation, depression and anxiety after treatment amongst cutaneous lymphoma respondents who reported fear of relapse, and who had a discussion with their doctor.

Among those who reported fear of relapse, 31% had adequate information, 47% had somewhat adequate and 21% had inadequate information.

Sources of information for those who reported fear of relapse during treatment were as follows:

- Doctors (62%)
- Nurses (10%)
- Websites (95%)
- Online blogs (50%)
- Patient organisations (50%)

For those who reported fear of relapse after treatment used sources as follows:

- Doctors (67%)
- Nurses (18%)
- Websites (90%)
- Online blogs (26%)
- Family/friends (5%)
- Patient organisations (56%)

IV) Fatigue

LC Objectives:

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

Key Findings:

Fatigue was the most frequent physical condition experienced by cutaneous respondents. Respondents' reports of fatigue peaked immediately following treatment as well as 3-5 years following treatment, but some respondents reported experiencing fatigue for 8+ years. Fatigue affected cutaneous respondents' independence but more so their lifestyle, with general activity suffering the largest impact. In terms of psychosocial issues, due to fatigue, cutaneous respondents mostly reported experiencing depression and concerns about body image/ physical appearance changes during treatment, and fear of relapse and concerns about body image/ physical appearance changes after treatment.

Fatigue was the most frequent physical condition affecting cutaneous lymphoma respondents' sense of wellbeing since diagnosis. It was reported by 65% of respondents and it lasted for various lengths of time (Table 16) (Figure 7).

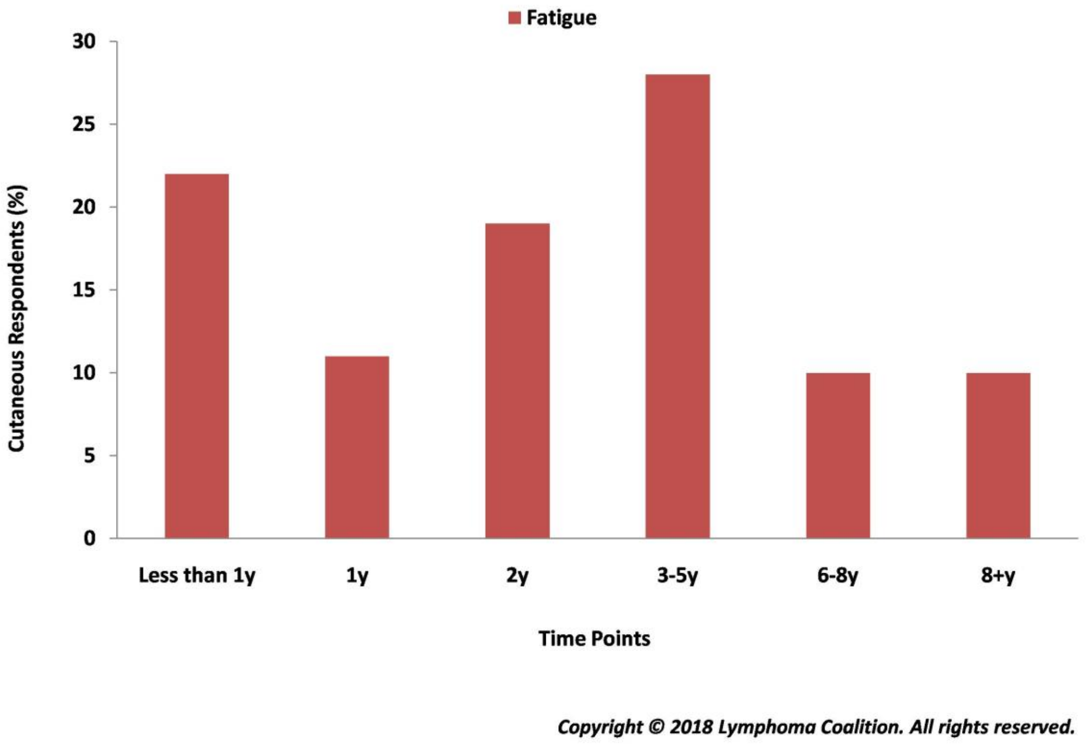


Figure 7. How long fatigue lasted amongst cutaneous lymphoma respondents.

Those who experienced fatigue also reported that as a result of it, they have also experienced changes in several areas of life (Figure 8). Respondents mentioned that life has changed completely (28%) or moderately (59%). Almost half of cutaneous lymphoma respondents reported that they sleep well but the fatigue does not go away (45%).

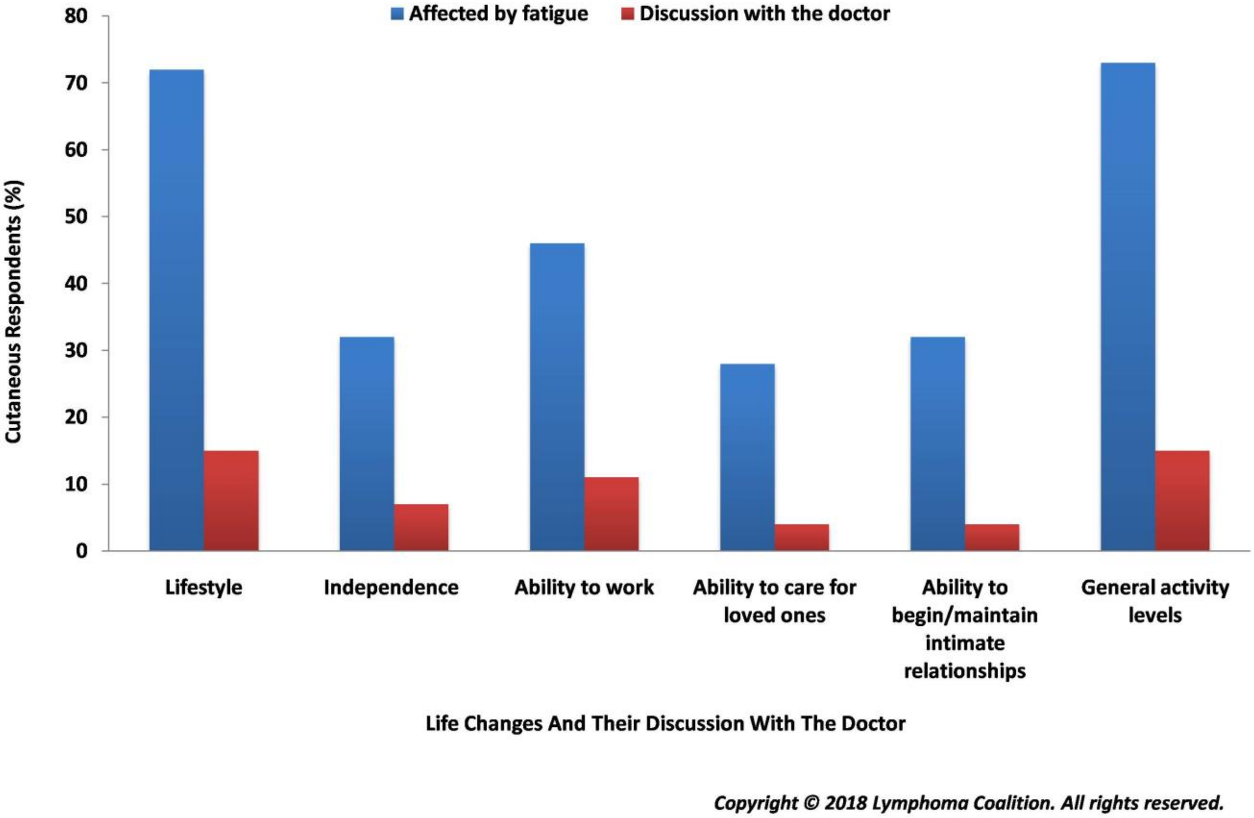


Figure 8. Life changes brought on by fatigue and their discussion with the doctor.

Of those cutaneous lymphoma respondents experiencing fatigue issues, only 17% reported that the doctor or nurse referred them to further support or information as opposed to 40% reporting that they were not referred. Amongst those cutaneous lymphoma respondents who reported fatigue, the majority reported that their lifestyle was affected (72%) as was their independence (32%).

Fatigue was associated with other issues as well (Table 16). It is noteworthy that all psychosocial issues were still being reported after treatment to varying degrees.

Table 15. Psychosocial issues affecting wellbeing during and after treatment amongst cutaneous lymphoma respondents with fatigue.

Psychosocial Issues Affecting Wellbeing During and After Treatment Amongst Cutaneous Respondents with Fatigue	**Treatment**	
	During (%)	**After (%)**
Changes in relationships with loved ones, friends or co-workers/social life	40	18
Stress related to financial issues	33	17
Loss of self-esteem	32	11
Concerns about body image/physical appearance changes	42	20
Loss/reduction in employment	20	12
Isolation	27	8
Depression	43	15
Anxiety	38	15
Fear of relapse	25	24
Difficulty on the job or in school	15	9
Problems getting health or life insurance coverage	13	11
Difficulty working effectively through the healthcare system	23	7
None	-	-

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 skin reactions were the most frequently reported physical conditions by cutaneous lymphoma respondents. The most commonly reported medical issues were pain and eyesight issues during *treatment and eyesight issues and numbness after treatment. Concerns about body image/ physical appearance changes and depression were the most commonly reported psychosocial issues during treatment, while fear of relapse was very common after treatment. In their totality, medical issues, physical conditions and psychosocial issues experienced were diverse and lasted for various lengths of time after treatment. As a result of their lymphoma, the majority of cutaneous lymphoma respondents had experienced changes in their lifestyle and one third had experienced changes in their independence. Cutaneous lymphoma respondents communicated medical issues to the doctor more frequently than they did emotional issues. Respondents raised the topic of treatment side effects in conversation with their doctor, and about half found ways to be supported.*

Looking at the entire sample, there is a range of physical conditions affecting the wellbeing of respondents. A significant percentage of cutaneous lymphoma respondents are facing fatigue (65%) and skin reactions (63%) (Table 16). Respondents have reported these physical conditions to last for various lengths of time (Table 17).

Table 16. Physical conditions affecting wellbeing since diagnosis.

Physical Conditions	**Percentage of Respondents (%)**
Fatigue	65
Skin reactions	63
Itching	60
Changes in sleep patterns	40
Trouble concentrating	33
Hair loss	31
Burning	27
Muscle weakness	25
Night sweats	24
Problems concentrating	23
Problems fighting infections	20
Memory loss	16
Change in sexual function	15
Bowel changes	15
Weight change	13
Changes in taste and smell	12
Weight loss	11
Swelling of arms and legs	11
Nausea and vomiting	10
Shortness of breath	10
Loss of appetite	9
Fluid retention	7
I had no changes in my physical condition whatsoever	6
Cramps	6
Mucositis/mouth ulcers	5
Incontinence	4

Viral reactivations	3
Loss of fertility	2

Table 17. 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	22	11	19	28	10	10
Hair loss	42	11	20	13	4	10
Muscle weakness	39	11	15	22	9	4
Trouble concentrating	29	21	23	20	5	2
Changes in sleep patterns	26	14	23	23	10	4
Changes in taste and smell	58	12	12	12	3	3
Bowel changes	58	8	11	11	8	4
Aching joints	25	10	25	21	15	4
Nausea and vomiting	73	-	19	8	-	-
Problems fighting infections	30	12	23	14	5	16
Memory loss	32	23	18	25	-	2
Skin reactions	13	11	8	24	15	29
Mucositis/mouth ulcers	64	8	4	20	4	-
Loss of appetite	70	13	7	7	3	-
Change in sexual function	39	15	9	21	9	7
Weight loss	51	31	9	9	-	-
Fluid retention	48	28	3	14	7	-
Weight change	40	17	14	20	9	-
Loss of fertility	63	-	19	-	6	12
Swelling of arms and legs	52	23	6	13	3	3
Itching	13	10	11	29	8	29
Burning	25	10	13	22	8	22
Incontinence	55	30	5	5	5	-
Cramps	74	11	-	11	4	-
Shortness of breath	43	13	17	10	10	7
Viral reactivations	68	14	5	-	5	8
Night sweats	47	16	13	11	5	8
Problems concentrating	26	24	26	19	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 16 to see overall issue prevalence.*

Many of the medical issues that cutaneous lymphoma respondents had to cope with during their treatment were less reported after the end of treatment, whereas some others remained on the same levels. The most commonly reported medical issues during treatment were pain (31%) and eyesight issues (29%) and after treatment eyesight issues (16%) and numbness (15%) were often reported (Table 18).

Table 18. Medical issues amongst respondents during and after treatment.

Medical Issues	**Treatment**	
	During (%)	**After (%)**
Heart-related issues	12	13
Stomach-related issues	22	9
Issues with other organs	15	11
Diarrhea	17	6
Numbness	9	15
Neutropenia	17	6
Osteoporosis	1	4
Any other blood condition	12	6
Secondary cancer	4	7
Diabetes	5	13
Tingling	21	11
Eyesight issues	29	16
Enlarged lymph nodes	19	6
Pain	31	11
Headaches	17	9
Bleeding	7	2
Thrombosis	1	2
I do not have any other medical issues	21	35

Table 19. 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	23	6	12	23	12	24
Stomach-related issues	24	24	12	29	11	-
Issues with other organs	23	31	23	-	8	15
Diarrhea	50	7	22	-	14	7
Numbness	25	19	6	38	6	6
Neutropenia	50	-	-	40	10	-
Osteoporosis	25	-	12	25	25	13
Any other blood condition	30	10	20	30	10	-
Secondary cancer	22	-	22	11	22	23

Diabetes	25	12	12	13	13	25
Tingling	11	17	17	44	6	5
Eyesight issues	25	10	20	25	15	5
Enlarged lymph nodes	27	13	13	27	7	13
Pain	10	19	19	28	19	5
Headaches	25	6	25	19	12	13
Bleeding	20	20	20	20	20	-
Thrombosis	33	-	-	33	34	-

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

Cutaneous lymphoma respondent’s wellbeing was affected not only by physical and medical conditions, but also by psychosocial issues in different degrees and for various lengths of time (Tables 20 and 21).

Specifically, these issues seemed to differ in the respondents’ experience during and after treatment (Table 20). Concerns about body image/ physical appearance changes were most commonly reported during treatment (60%), while fear of relapse was very common after treatment (57%). Though some exceptions did exist, it is noteworthy that many psychosocial issues were still experienced after treatment at approximately the same level.

Table 20. Psychosocial issues affecting cutaneous lymphoma 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	46	35
Stress related to financial issues	41	38
Loss of self-esteem	41	25
Concerns about body image/physical appearance changes	60	45
Loss/reduction in employment	25	26
Isolation	31	16
Depression	55	28
Anxiety	54	32
Fear of relapse	35	57
Difficulty on the job or in school	18	17
Problems getting health or life insurance coverage	17	26
Difficulty working effectively through the healthcare system	30	17
None	4	7
Other	1	1

Table 21. How long psychosocial issues affecting well being 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	25	16	18	25	6	10
Stress related to financial issues	19	21	8	30	9	13
Loss of self-esteem	19	21	21	24	5	10
Concerns about body image/physical appearance changes	9	18	21	27	11	14
Loss/reduction in employment	16	19	23	16	3	23
Isolation	25	12	19	25	13	6
Depression	27	17	19	25	6	6
Anxiety	21	22	12	28	5	12
Fear of relapse	18	14	19	28	5	16
Difficulty on the job or in school	12	28	28	28	4	-
Problems getting health or life insurance coverage	23	16	15	15	8	23
Difficulty working effectively through the healthcare system	18	18	28	18	9	9

**Relative frequencies are displayed, and the percentages were calculated per issue (rows), and then compared within different time points (columns) to show the length of time each issue impacts patients reporting this specific concern. Each row totals 100%. Refer to Table 20 to see overall issue prevalence.*

Interestingly, respondents did not communicate the issues they experienced very frequently with their doctor (Table 22).

Table 22. Psychosocial issues affecting cutaneous lymphoma respondents' wellbeing and their communication with the doctor.

Psychosocial Issues Affecting Wellbeing	**Respondents Who Discussed with Their Doctor**
	(%)
Changes in relationships with loved ones, friends or co-workers/social life	7
Stress related to financial issues	3
Loss of self-esteem	4
Concerns about body image/physical appearance changes	8
Loss/reduction in employment	3
Isolation	3
Depression	11

Anxiety	9
Fear of relapse	9
Difficulty on the job or at school	3
Problems getting health or life insurance coverage	2
Difficulty working effectively through the healthcare system	3

As a result of their lymphoma, 67% of respondents had experienced changes in their lifestyle and 31% had experienced changes in their independence.

Respondents communicated medical issues to the doctor in 63% of cases and emotional issues in only 32% of cases. Cutaneous lymphoma respondents indicated that the doctor was able to help with the medical issues in 39% of cases, and to somewhat help in 35% of cases. As far as emotional issues are concerned, the doctor was able to help in only 19% of cases and to somewhat help in 25% of cases.

Turning to side effects, 73% of cutaneous lymphoma respondents communicated questions about side effects to their doctor, and 61% indicated that the doctor was able to answer their questions. In 48% of cases, respondents indicated that the doctor was able to help them cope with the side effects (Table 23).

Table 23. Communication with the doctor about side effects.

Communication of Side Effects	**Respondents' Responses**		
	Yes (%)	**Somewhat (%)**	**No (%)**
Did you bring forward questions about side effects?	73	11	9
Was the doctor able to answer your questions?	61	25	4
Was the doctor able to help you cope with side effects by providing medication or other support?	48	19	13

Of those who after their initial visit to the doctor, understood the potential side effects of treatment options, 78% brought forward questions about side effects to their doctor. 49% received answers from the doctor, and 41% received help coping with side effects through the provision of medication or other support (Table 24).

Table 24. Cutaneous lymphoma 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?	78	9	9
Was the doctor able to answer your questions?	49	36	6
Was the doctor able to help you cope with side effects by providing medication or other support?	41	22	13

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:

Cutaneous lymphoma respondents commonly reported that financials constituted a barrier to treatment, followed by access to treatment centre/ prohibitive travel. There were barriers found to be associated with respondent's area of residence. For example, for respondents living in rural areas, certain barriers were identified more frequently compared to respondents living in urban and suburban areas. When cutaneous lymphoma respondents were asked to rate service types that they had already used, they specified that patient organisations/support groups and spiritual support were the services that they found to be most helpful. Cutaneous lymphoma respondents who had good conversations with their doctors most days reported experiencing fewer barriers to treatment than did those who reported having good conversations only sometimes or never.

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

- Financial (25%)
- Access to treatment centre/prohibitive travel (23%)
- Specialty physician available locally (20%)
- None (18%)
- Access to the most up to date treatment (15%)
- Wait time to treatment was longer than necessary (12%)
- Could not give up caregiver role (child, parent, disabled person) while in treatment (4%)
- Personal support (2%)
- Language (1%)

We asked participants to rate on a scale of 1-5 (5 being the highest) how helpful different services they may have used were, and to indicate if those services were not available in their country. Patient organisations/support groups were rated to be the most helpful service (32%), followed by spiritual support (12%) (Table 25).

Table 25. Cutaneous lymphoma respondent's evaluation (1 lowest, 5 highest) of different services.

Types of Services	**Evaluation of Services**							
	1 (%)	**2 (%)**	**3 (%)**	**4 (%)**	**5 (%)**	**Don't know (%)**	**Not available in my country (%)**	**N/A (%)**
Social worker	6	3	7	2	7	4	1	70
Patient organisation/ support group	4	7	11	17	32	3	1	25
Dietician/nutritionist	6	5	4	4	6	8	-	67
Counsellor/psychologist	7	4	3	10	7	6	-	63
Spiritual support	7	1	2	10	12	4	1	63
Physical therapy	6	2	6	3	6	7	-	70
Pain management	7	2	8	3	4	6	-	70
Complementary therapist	7	1	1	-	7	11	-	73

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

- A doctor in 27% of cases;
- Online research in 26% of cases;
- Patient organisation/support group in 19% of cases;
- A nurse in 13% of cases;
- A family member in 6% of cases;
- Another patient in 4% of cases and;
- A friend in 3% of cases.

Respondents were not provided with service information in 11% of cases.

For respondents living in rural areas, certain barriers were identified more frequently compared to respondents living in urban and suburban areas such as: financial issues, access to treatment centre/prohibitive travel, and access to the most up to date treatment. However, respondents living in suburban areas also identified certain barriers more often than other respondents such as: the availability of specialty physician locally and wait time to treatment longer than necessary. 27% of respondents living in all three areas (rural, urban and suburban) identified no barriers to lymphoma treatment (Table 26).

Table 26. Barriers to treatment based on area of residence.

Types of Barriers to Treatment	**Area of Residence**		
	Rural (%)	**Urban (%)**	**Suburban (%)**
Financial	46	41	32
Access to treatment centre/prohibitive travel	42	21	39
Language	-	3	-
Access to the most up to date treatment	30	24	20
Wait time was longer than necessary	12	16	24
Personal support	-	3	3
Specialty physician available locally	36	14	39
Could not give up caregiver role (child, parent, disabled person) while in treatment	6	5	8
None	27	27	27

Respondents who 'never' or 'sometimes' had good conversation with their doctors identified all listed barriers more frequently than respondents who had good conversations with their doctors 'most days', except for wait time longer than necessary. In addition, respondents who reported having good conversations with their doctors 'most days' did not identify barriers to treatment in 37% of cases compared to respondents who reported having good conversations with their doctors only 'sometimes' (22%) (Table 27).

Table 27. Barriers to treatment based on the quality of respondent communication with the doctor.

Good Conversation With Their Doctor	**Barriers to Treatment**						
	Financial (%)	**Access to treatment centre/ prohibitive travel (%)**	**Access to the most up to date treatment (%)**	**Wait time was longer than necessary (%)**	**Specialty physician available locally (%)**	**Could not give up caregiver role while in treatment (%)**	**None (%)**
Most days	27	27	12	12	24	3	37
Sometimes	46	44	29	27	38	9	22
Never	57	57	86	-	43	14	-

APPENDIX 1

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

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

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

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

LYMPHOMA COALITION

Worldwide Network of
Lymphoma Patient Groups

www.lymphomacoalition.org