About

Lymphoma Coalition

The Lymphoma Coalition (LC), a non-profit organisation, was formed in 2002 and incorporated in 2010 with the express purpose of facilitating lymphoma patient organisations around the world to form a community that could support one another's efforts in helping patients with lymphoma receive the best care and support. Lymphoma Coalition is committed to making sure that there is a level playing field of information globally for lymphoma patient organisations and patients, through education, information and advocacy activities. The need for a central hub of consistent as well as reliable current information was recognised as well as the need for lymphoma patient organisations to share resources, best practices, and policies and procedures. LC is made up of 75 patient organisations from 50 countries. The mission of the coalition is to be the global source for lymphoma facts and statistics; improve awareness and understanding of lymphomas; and build capacity for new and existing lymphoma groups.

Special Thanks
Special thanks to all patients and the LC member organisations who offered their insight and support as well as to the many other organisations, pharmaceutical companies, medical professionals, pharmacists and individuals who generously shared their knowledge, resources and understanding for this report. Thank you to those who provided an unrestricted grant to support this project: Celgene Corporation, Takeda, and Pfizer, Inc.

LeiP Team
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Disclaimer
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Warning
LC’s 2018 Report Card on Lymphomas should not be used for the purpose of self-diagnosis, self-treatment or as an alternative to medical care. If you have any concerns arising out of the information contained in this report, you should consult your own physician or medical advisor. If you suspect you have lymphoma, seek professional attention immediately.
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Message from the
Chair of the LC Medical Advisory Board

Laurie H. Sehn, MD, MPH
Chair, BC Cancer Lymphoma Tumour Group
Clinical Professor, University of British Columbia, Vancouver, Canada

I was pleased to support Lymphoma Coalition’s 2018 ASH abstract *Correlation of Lymphoma Patient Information Level with Healthcare Experience* which shows patients with adequate information report better management of their health and healthcare through improved understanding, confidence levels, and communication. Therefore, access to credible timely information is an important aspect to a successful patient experience.

In this Report Card, lymphoma patients indicate doctors are a top information source, but patients are not always getting satisfactory answers to the questions they ask. Doctors and other healthcare professionals cannot be expected to provide all the support that a patient requires. However, it is important that patients are directed to services that may help. This can include other resources that are hospital-based or community-based, as well as patient organisations.

Patient referrals are based on trust, respect and how an organisation operates which leads to a strong relationship between physicians and patient organisations. Lymphoma Coalition has developed the Standards of Excellence program for its member organisations, containing four templated modules which serve as guidelines for consistent high standards of operation that are rooted in high-quality patient-centric support. If you are hesitant to refer your patients to a local patient organisation for added support, I urge you to find out if they have completed the Standards of Excellence program as it may address any concerns you may have.

Let’s use all the avenues available to us to improve the overall patient experience.
This report highlights that patients want more information and support early in their disease experience. When I was diagnosed with cutaneous lymphoma in 1991, I did my best to educate myself on my disease and treatment options. At that time, it was hard to find information but now patients have more resources at their fingertips and are seeking knowledge through their doctors, the Internet, patient organisations, and other sources.

It is important to remember lymphoma is challenging on multiple levels. Patient organisations are not only a credible source of information but also connect patients with each other. These organisations provide support to help cope with emotional concerns and the barriers faced, through every stage of the patient experience. It’s critical that patients know they are not alone, especially when they are less likely to discuss the psychosocial aspects of their lymphoma with their doctors.

As a global lymphoma patient coalition, we call for patients to be referred to patient organisations, ideally when diagnosed. Care and support of an individual extends beyond the clinic and can last for many years post-treatment. Alongside healthcare professionals, patient organisations play an important role in helping ensure patients receive the right information and support they need to build their confidence, improve their overall experience and improve outcomes.
Message from the

Chief Executive Officer

Karen Van Rassel

The 2018 Report Card on Lymphomas reviews the overall patient experience, highlighting issues faced at different stages and key concerns overall.

Inadequate information, fear of relapse and fatigue consistently continue to be the leading issues reported by all patients.

Fatigue for example, is unique in that it is a symptom of lymphoma itself, as well as often being a side effect of treatment. Instead of fatigue levels improving as patients undergo treatment and recover, they may worsen. This highlights the importance of properly evaluating the patient perspective when investigating new therapies. For lymphoma patients, therapies may actually exacerbate the leading physical issue rather than controlling it. Fatigue is only one example of what can be learned by thoroughly examining the patient experience. What’s important is we all take these learnings and integrate them into future projects – whether they be research, clinical practice or support programs – so we can collectively improve the patient experience.

We ask that we all work to ensure that patients, upon diagnosis, are provided the proper pathway to credible information and support so they can go through their cancer experience with confidence.

Thank you for being part of the solution.

Many thanks to our financial supporters. It is through their support that we are able to undertake this important work that supports patients while, at the same time, identifies the gaps in patient care. As in previous years, heartfelt thanks to the editorial committee for reviewing this report as well as all the LC member organisations whose input has been most valuable. Thank you to the patients for responding to LC’s Global Patient Survey. Without your input we would not be able to understand the gaps in order to advocate on your behalf.
Overview

This report will highlight how different factors affect patients based on where they are in their patient experience. Despite the existence of well-defined care pathways and referral processes, patient’s experiences are rarely linear and always unique, which allows space for gaps in support. Through gaining a better understanding of the challenges and issues that patients face during each phase of their care, LC hopes to bring awareness to and aid in bridging these gaps. These challenges and issues take the form of physical and medical side effects, psychosocial issues, communication challenges with healthcare professionals (HCPs), information provision and barriers to timely and effective treatment.

The information in this report is largely based on the learnings from the 2018 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL (LC 2018 GPS) which had 6,631 respondents from all over the world. The patient experience was divided into and will be analysed according to the following six stages:

Table 1. Stage of patient experience as reported by respondents of LC 2018 GPS

<table>
<thead>
<tr>
<th>Stage of Patient Experience</th>
<th>Valid %</th>
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<tbody>
<tr>
<td>Newly Diagnosed</td>
<td>162</td>
</tr>
<tr>
<td>Watch and Wait</td>
<td>544</td>
</tr>
<tr>
<td>First Line Treatment</td>
<td>1661</td>
</tr>
<tr>
<td>Maintenance Therapy</td>
<td>729</td>
</tr>
<tr>
<td>Relapsed/Refractory/Transformed</td>
<td>864</td>
</tr>
<tr>
<td>Remission</td>
<td>2233</td>
</tr>
<tr>
<td>Totals</td>
<td>6193</td>
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n=438 patients did not indicate their stage so valid percent is used. "Valid percent" is the percent when missing data are excluded from the calculations.
Within each of these stages, key patient-reported issues have been evaluated and highlighted, including:

• Informational needs and understanding levels
• Physical conditions and medical issues (appendix B)
• Psychosocial issues (appendix B)
• Patient-doctor communication
• Barriers to treatment (appendix B)

Important to note is that this is not a temporal analysis; this report is not following the same group of individuals over time, rather has used stages of experience to categorise respondents and examine the keys issues within these categorised sample populations. A full methodology is available in Appendix A.

Objectives

• Identify issues that are consistent throughout the entire patient experience
• Identify key issues and challenges in each stage of the patient experience
• Determine areas where patients require additional information and support
Common Issues Throughout the Lymphoma Patient Experience

Patient-Doctor Communication

There is room for improvement in how patients and doctors are communicating with each other through every phase of the patient experience. The LC 2018 GPS showed that many patients will communicate their medical and/or physical issues to their doctor, right from the time they are diagnosed. Unfortunately, the same cannot be said for their emotional issues, even though patients indicate these concerns are affecting their quality of life.

When patients do communicate their issues, whether they be physical, medical or emotional, they are often not receiving satisfactory answers or support. It should be taken into consideration that patients who self-identify as being adequately informed report, amongst other things, the ability to know when to self-manage vs. when to seek HCP support for medical issues, have fewer negative psychosocial issues and experience fewer barriers to treatment. The combination of a reluctance to communicate emotional issues and a lack of support when the issue is actually communicated means a great deal more attention and support is required. It has been shown that patients who have usable and effective coping mechanisms to deal with stress have been shown to have lower levels of depression, anxiety, and symptoms related to the cancer and its treatment. To encourage communication, the emotional impact of a cancer diagnosis needs to be acknowledged at the outset, and the emotional cues from the patient must be recognised and responded to throughout their experience. The response of HCPs to a patient’s emotional cues has been proven to encourage patients to speak more freely about their feelings.

Patients perceive doctors are more helpful with medical and physical issues, but even in this area less than half of patients felt their problems were addressed well. The one area where most patients who had experienced treatment repeatedly reported asking questions, receiving good answers and being provided with medical interventions to help them cope with side effects. It seems this is a consistently comfortable area for discussion and action for both parties.

Patients should feel confident voicing all their concerns to their doctor and also letting their doctor know if they have not received a satisfactory answer or support.

Doctors and other HCPs cannot be expected to provide all the support that a patient requires. However, it is important that patients are directed to services that may help. This can include resources available in hospitals, other health services in the community, credible websites or other online resources, and local patient organisations.

**Fatigue**

Fatigue was by far the most commonly reported symptom for lymphoma patients overall, regardless of stage in their patient experience.
Since fatigue is a symptom of lymphoma itself, as well as a side effect of many of the therapies used to treat it, in many cases, the prevalence of fatigue increases instead of decreases through the patient experience. The highest reported prevalence of fatigue across all stage categories was reported in those who have relapsed or transformed lymphoma. When fatigue is looked at over time, some patients continue to report it 8+ years after treatment has been completed (figure 5).

This highlights the need for research into new therapies that do not include fatigue as a side effect, so treatments don’t exacerbate the leading symptom faced by lymphoma patients. What is also concerning is that most patients who experience fatigue are not being referred on to resources to help them cope, even though it is an acknowledged issue in the medical community and in treatment protocols.

Fatigue has a massive impact on many patient’s quality of life and health/wellbeing. The LC 2018 GPS showed that many of those who experienced fatigue also reported that as a result of it, they have experienced changes in their lifestyle, independence, ability to work, general activity levels, and ability to care for loved ones among other issues. It is important that more focus is placed on addressing this concern in research centres as well as in clinics.
Fear of Relapse

Across comorbidity studies, fear of relapse is consistently reported to be a predictor of overall quality of life, mental health-related quality of life, and physical health-related quality of life (QoL). The LC 2018 GPS provided evidence for the correlation of fear of relapse with isolation, depression, and anxiety. Studies also suggest that fear of relapse/recurrence is one of the most frequently cited unmet need among cancer survivors, which is corroborated in this group of patients. Those who experience fear of relapse must be identified, supported, and directed to appropriate resources.

Figure 7. Percentage of patients who report fear of relapse by patient experience stage

Surprisingly, fear of relapse is first reported as a significant concern by patients while they are still undergoing their initial treatment—speaking profoundly to the temporal reach of this fear. As expected, it is the maintenance therapy phase where fear of relapse begins to present as the largest psychosocial issue and patients in remission had the highest reported prevalence. When treatment ends, patients lose the support provided by regular contact with oncology staff, and so experiencing some emotional upheaval is common. As this is where fear of relapse is most expected and observed, it is critical for it to be recognised, openly discussed, and met with appropriate intervention and support.

Unfortunately, as shown in figure 8, only half of patients discuss their fear of relapse with their doctor, and even when they do, over 60% state their fear is not alleviated nor are they referred onto useful support.

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Conversations about fear of relapse must be initiated and encouraged in the clinic, and clear clinical pathways must be established to ensure that patients are receiving appropriate intervention and support for this issue, right from the beginning of their experience.
Key Issues and Challenges at Each Stage of the Patient Experience

Newly Diagnosed (No Treatment)

n=162 (2%)  
*For both medical and psychosocial issues, patients were asked to indicate the time points at which they experienced the issue in relation to treatment (before treatment, during, after). Since this section pertains only to newly diagnosed patients (who haven’t yet been treated), only the ‘before’ treatment numbers will be reported.

Patients who have been newly diagnosed with lymphoma are likely facing a multitude of concerns and uncertainties, especially as they pertain to their diagnosis and treatment. Yet, 1 in 5 newly diagnosed patients reported low levels of understanding of issues surrounding their diagnosis and care.

When first diagnosed, many patients are simply told they have Non-Hodgkin Lymphoma (NHL); but NHL isn’t a disease, it is a series of more than 80 subtypes. Each subtype requires different diagnostic evaluation and treatment approaches, yet over one third of patients continue to have trouble understanding the characteristics of their subtype.

Figure 9. Patient’s understanding (1 lowest, 5 highest) of their diagnosis after their initial visit to the doctor broken out by subtype (global data)

Patients with peripheral T cell and mantle cell lymphomas experienced the most difficulty (37% and 33% respectively) understanding their diagnosis. Those with the best understanding of their diagnoses were patients with Hodgkin or Burkitt lymphoma, where 1/3 of patients in each subtype rated their comprehension as high.
Patients with peripheral T cell and mantle cell lymphomas also experienced difficulty (47% and 40% respectively) understanding the characteristics of their subtype. Additionally, 40% of those with DLBCL, CLL/SLL, and anaplastic large cell lymphoma reported a low understanding of the characteristics of their subtype. Without this understanding, patients might not be aware of the appropriate treatment options for their specific subtype of lymphoma and may not be able to make an informed decision.

“Information gives a patient confidence, especially to the poor and uneducated. If you speak to them in a way they understand with terminology they will understand, they will have the confidence to ask more questions, seek more information, and then present this to the doctor.”

Vandana, India, diagnosed with Hodgkin lymphoma

Patients clearly indicated they would have liked to receive additional medical or associated support information at their initial diagnosis meeting with the doctor and most are seeking information immediately upon diagnosis or within the first three months of diagnosis.
Patients were asked to report what level of information they felt they had overall: adequate, somewhat adequate, or inadequate. Evidently, meeting the need for more information right from the beginning is critical as patients who reported an overall ‘adequate’ information level also reported a greater understanding of all issues surrounding diagnosis and care (figure 12) after their initial visit to the doctor. Having adequate information was also correlated with a number of positive feelings and outcomes throughout the patient experience\(^1\),\(^5\).

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

Information can come from multiple sources, including HCPs and patient organisations. Many patients will search for information about their cancer on the Internet. It is important they are directed to credible sources and know their subtype, so they use the correct search terms that apply to their own situation.

Physical, medical, and psychosocial concerns were apparent from the time of diagnosis. The top three physical conditions reported by those newly diagnosed were fatigue (55%), night sweats (28%) and changes in sleep patterns (26%), all traditional B symptoms common to lymphomas. It is unsurprising the top medical issue was enlarged lymph nodes (11%), another common lymphoma symptom.

The top three psychosocial issues reported were anxiety (12%), changes in relationships with loved ones/friends/social life (11%), and stress related to financial issues (10%). When examined individually, these may not look like high prevalence rates. However, it is important to remember almost 70% of patients are seeking support within the first three months of diagnosis, indicating their cancer diagnosis is affecting their quality of life and they need help coping.

The top three barriers to care were financial (30%), access to the most up to date treatment and wait time to treatment was longer than necessary (both 16%).

It is evident that in this stage of the experience, patients need much more information and support than is currently provided.

Watch and Wait (Active Surveillance)

n=544(9%)

*For both medical and psychosocial issues, patients were asked to indicate the time points at which they experienced the issue in relation to treatment (before treatment, during, after). Since this section pertains only to watch and wait patients, only the ‘before’ treatment numbers will be reported.

For patients who have been diagnosed with a lymphoma but who do not require immediate treatment, active surveillance (watch and wait) is difficult to understand as evidenced by the findings from the LC 2018 GPS. After their initial diagnosis meeting with the doctor, only 34% reported a very good understanding level of this treatment choice. Additionally, compared to the total patient population, watch and wait patients reported a lower understanding of the process and stages of their care (figure 13).

These patients do not thoroughly understand their initial treatment approach (active surveillance), nor what the plan is moving forward when their disease progresses. This lack of understanding is a likely contributor to the main psychosocial issue reported by this group, anxiety (experienced by 14% of watch and wait patients).

Although it may seem that because patients do not require immediate treatment they do not need support, findings from the LC 2018 GPS contradict this perception. Watchful waiting can elicit distress as it may seem a risky or passive approach to a very serious disease. It is likely that these patients require a great deal of reassurance that their symptoms are being actively monitored and that treatment will begin when necessary.
First Line Treatment *(Diagnosed and currently in treatment)*

\( n=1661 \ (26\%) \)

*For both medical and psychosocial issues, patients were asked to indicate the time points at which they experienced the issue in relation to treatment (before treatment, during, after). Since this section pertains only to patients diagnosed and currently in treatment, only the ‘during’ treatment numbers will be reported (before was used more for baseline reference).*

When specifically examining treatment options and their respective side effects, the majority of patients who were in first line treatment did not have a very good understanding (level 5) of any of these issues after their initial visit to the doctor as outlined in table 2 below.

"I hadn’t coped well with watch and wait. It seemed that my worry and stress about the situation helped to accelerate my lymphoma. I would check my lymph nodes daily. I felt like I had a time bomb inside me."

Shawn, Canada, diagnosed with stage III follicular lymphoma
It is concerning that within this specific group of patients, only 22% had a very good understanding (level 5) of potential side effects, and a mere 16% had a very good understanding (level 5) of side effect management. Understanding the side effects, and how to deal with them, is critically important to both their health and quality of life related outcomes.

It is in this patient group, perhaps unsurprisingly, that a large increase in the frequency of reported medical and psychosocial issues is observed, showing a nearly two-fold increase in reported prevalence in this group. The top three medical issues reported were neutropenia (21%), stomach-related issues (19%) and pain (15%) and the top three psychosocial issues reported were changes in relationships with loved ones/friends/social life (32%), stress related to financial issues (29%), and fear of relapse (28%). As a result of their lymphoma, 83% of patients had experienced changes in their lifestyle and 60% had experienced changes in their independence.

The physical conditions and medical issues are commonly reported treatment side effects. This obviously leads to the need for better treatment options with fewer side effects, and a discussion about what is an acceptable side effect both short and long-term.

When asked what barriers patients encountered in receiving their lymphoma treatment, the top barriers reported were finances (30%), wait time to treatment that was longer than necessary (16%) and access to the most up to date treatment (16%).

On this point, Lymphoma Coalition (LC) continues to track access to therapies within its member countries to provide a current and global view of the lymphoma treatment landscape.

For a complete list of treatments included in this report please see appendix C.

Figure 14 shows the diversity of access across the globe to novel therapies. Even though a treatment is listed on a reimbursed list, this does not always mean a patient will gain access due to other health system limitations like budgetary restrictions or specialised care is unavailable.

"Fear, uncertainty of living and other such apprehensions enveloped my mind. The news devastated me. I was left speechless, I did not know what to say, I did not know what to do."

Vandana, India, diagnosed with Hodgkin lymphoma

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Figure 14. Access to novel therapies by LC member country

*Only partial therapy access information found

As of July 2018
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Maintenance Therapy

n=729(12%)

“For both medical and psychosocial issues, patients were asked to indicate the time points at which they experienced the issue in relation to treatment (before treatment, during, after). Since this section pertains to patients who are continuing past their initial course of treatment and are in maintenance therapy, both the ‘during’ and ‘after’ treatment numbers will be reported.

Medical and physical side effects continue to be a burden during maintenance therapy. The top three physical conditions (fatigue 61%, hair loss 49% and muscle weakness 38%) reported prevalence was on par with those reported by patients undergoing their first line treatment. The top three psychosocial issues reported were:

**During treatment**
- changes in relationships with loved ones/friends/social life (35%)
- stress related to financial issues (27%)
- concerns about body image/physical appearance changes (24%)

**After treatment**
- fear of relapse (38%)
- changes in relationships with loved ones/friends/social life (24%)
- stress related to financial issues (22%)

Important to note here is that the top psychosocial issues are not seeing a large decrease in prevalence once treatment is completed; many of the psychosocial issues were reported on similar levels before and after treatment, and some see an increase in prevalence after treatment as patients adapt to life post-cancer (fear of relapse, loss/reduction in employment, problems getting health/life insurance, difficulty at job/school).

As shown by the above, more support is needed for this patient group as they cope with ongoing treatment. The LC 2018 GPS asked patients which services they would be interested in using; figure 15 below highlights the top patient service interests of those in maintenance therapy and provides many avenues for referrals.

**Figure 15. Maintenance therapy patients’ interest in different services**
Relapsed and Transformed

n=864 (14%)

*For both medical and psychosocial issues, patients were asked to indicate the time points at which they experienced the issue in relation to treatment (before treatment, during, after). Since this section pertains to patients who have relapsed or transformed, both the 'during' and 'after' treatment numbers will be reported (assuming that these patients have already completed some form of treatment and are currently now in treatment again/finished another treatment/in remission).

Unfortunately, patients may relapse, and/or their lymphoma can sometimes transform into another subtype requiring additional rounds of treatment and, as would be expected, this raises more questions and concerns needing attention.

The top three physical conditions reported were fatigue (73%), hair loss (46%) and problems fighting infection (45%). The prevalence of these top reported conditions are, for the most part, comparable percentages to what was seen in the first line treatment and maintenance therapy patient categories. More concerning is how long these physical conditions are affecting these patients (figure 16); except for hair loss, each of the top 5 physical conditions had a reported prevalence of 10% or higher in the 8+ years (following treatment completion) category. Fatigue was reported by 17% of those who experience it to last for 8+ years.

Figure 16. Physical conditions reported by relapsed/transformed patients across different time points
Again, though prevalence decreases after treatment, patients are still dealing with many of the same medical issues to some degree and for various lengths of time (figure 17). Except for neutropenia and eyesight issues, each of the top five medical issues during and after treatment (figure 17) had a reported prevalence at 8+ years which equalled or exceeded 10%.

Psychosocial issues are also of great concern within this patient group. Changes in relationships, anxiety, stress related to financial issues, and fear of relapse were among the top reported issues both during and after treatment. Again, the reported prevalence of these issues is not drastically decreasing after treatment is complete, and in some instances, prevalence actually increases. Except for concerns about body image, each of the top five psychosocial issues during and after treatment had a reported prevalence equal to or exceeding 11% in the 8+ years after treatment category. Fear of relapse had a reported prevalence of 18% in the 8+ years category.
Changes in relationships are a prominent issue that relapsed and transformed patients experience; many patients in this stage may feel as though people are tired and moving on, that people do not know how to support them any longer as the patients’ cancer persists, or that they are living in a different world than the one they previously shared. To this point, 84% of relapsed/transformed patients indicated that their lymphoma has affected their lifestyle, and 59% indicated that it has affected their independence.

Additionally, given that patients who have relapsed or transformed are likely undergoing numerous rounds of treatment, it is not surprising they are experiencing financial stress. This stress is not just related to therapy costs but may also be attributed to time off work (for both the patient and/or carer), travel costs, parking at hospitals/clinics, other hired assistance (day-cares, meal services, home nurse, etc.) and so on.

“Since I worked in a small office, I was afraid of losing my job if I couldn't work during treatment. For this reason, I wanted the oncologist to give me a therapy that allowed me to continue working.”

Rosmarie, Switzerland, diagnosed with follicular lymphoma and DLBCL
The main barriers to treatment experienced by relapsed/transformed patients are reflective of some of the psychosocial issues reported (i.e. stress related to finances) and include finances (32%), access to the most up to date treatment (19%) and wait time to treatment that was longer than necessary (17%).

Access to the most up to date treatment and wait time to treatment could relate to the fact that these patients have undergone multiple rounds of treatment, and/or different treatments, with limited or no success. In lymphoma, often times, the more therapies a patient undergoes, the harder they become to treat. Additionally, since this patient pool was global, access issues (approvals, reimbursement) arise depending on geography (refer to figure 14). As relapsed/transformed patients run out of traditional treatment options, they may need to be referred to a clinical trial to receive an experimental treatment. The increasing number of promising clinical trial options can provide hope to patients in this stage. It is important that doctors thoroughly discuss clinical trial options when appropriate, denoting the benefits, risks, side effects, etc.

Lymphoma Coalition continuously monitors and gathers data on lymphoma clinical trials occurring throughout the world. See figures 19 and 20 below which focus on clinical trials for relapsed patients by subtype and by country. Clinical trial data includes open phase 2 and 3 studies focused on standard and novel treatments in the relapsed setting. Sources for clinical trial data include ClinicalTrials.gov, EU Clinical Trials Register and the World Health Organisation. There are a lot of trials examining new therapies for relapsed lymphoma, but by far most of these trials are occurring in the USA. This of course impedes participation and access by patients globally.

Figure 19. Clinical trials (n=1) for relapsed patients by lymphoma subtype
Figure 20. Clinical trials (n=1) for relapsed patients by country

*No trials found

As of July 2018
Remission

n=2233 (37%)

*For both medical and psychosocial issues, patients were asked to indicate the time points at which they experienced the issue in relation to treatment (before treatment, during, after). Since this section pertains to patients in remission, both the ‘during’ and ‘after’ treatment numbers will be reported.

Being in remission does not, unfortunately, mean a cessation of side effects. They can continue to be an issue long after treatment is completed. Side effects can negatively impact a patients’ quality of life; **76% of patients in remission indicated that their lymphoma continues to affect their lifestyle, and 42% indicated that it continues to affect their independence.** Patients may have to develop a new ‘normal’ that incorporates the cancer experience into their lives.

“As I moved towards my ‘new normal’ I began to appreciate life on a new level. Though I lived with uncertainty, I was more aware and more determined to make the most of every moment. It was a challenging journey, which I packed with courage and faith as I got ready to move on. I can assure you, it did not come easily. Everyone told me to be positive, but no one told me that being positive included being grateful for what I already had rather than longing for what I did not; that being positive meant finding activities that matched my strengths and values.”

Vandana, India, diagnosed with Hodgkin lymphoma

Findings of the LC 2018 GPS showed that side effects do not always resolve once treatment has completed, and that patients continue to need support well into their remission. The top three physical conditions reported by patients in remission were fatigue (71%), hair loss (53%) and trouble concentrating (42%).

Medical issues continue to be reported after treatment, and each of the top five medical issues reported both during and after treatment are reported up to 8+ years following treatment completion (figure 21). If patients are not getting the support they need from their doctor in this area, they may have to seek additional support on their own, adding to the burden of coping with all the changes they will likely have experienced because of their cancer.
The top reported psychosocial issues in this patient group were observed in similar frequencies to those documented in active treatment, maintenance and relapsed/transformed groups. Additionally, psychosocial issues were reported in similar levels during and after treatment, signaling that they are continuing on after treatment ends. Again, like in previous stages, changes in relationships, anxiety, and fear of relapse were prominent themes. A top psychosocial issue unique to this stage that was highly reported both during and after treatment was concerns about body image/physical appearance changes (a very visible public sign that this person has cancer). The top five during and after psychosocial issues were all reported up to 8+ years after treatment completion (figure 22). Additionally, the majority of these issues were discussed with a doctor in less than 10% of cases.
In supporting these patients in their remission, both with physical/medical and emotional issues, who is expected to provide the support that patients require? Care needs to be more integrated so that patients are surrounded by a seamless system that ensures they know exactly where to go and can, as a result, focus on their health positively. Table 3 below provides an evaluation of services used by remission patients; the top-rated services (4+5) in terms of usefulness were patient organisation/support group services (50%), counselor/psychologists (28%), and spiritual support (28%). Additionally, figure 23 provides a list of services that patients in remission reported being interesting in using. Both of these provide many options for support referrals.

Table 3. Remission patient’s evaluation (1 lowest, 5 highest) of different support services

<table>
<thead>
<tr>
<th>Types of Services</th>
<th>Evaluation of Services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (%)</td>
</tr>
<tr>
<td>Social worker</td>
<td>15</td>
</tr>
<tr>
<td>Patient organisation/support group</td>
<td>7</td>
</tr>
<tr>
<td>Dietician/nutritionist</td>
<td>14</td>
</tr>
<tr>
<td>Counsellor/psychologist</td>
<td>12</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>12</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>11</td>
</tr>
<tr>
<td>Pain management</td>
<td>12</td>
</tr>
<tr>
<td>Complementary therapist</td>
<td>13</td>
</tr>
</tbody>
</table>

* teal highlight indicates top evaluated services (4+5 rating) red highlight indicates most poorly evaluated services (1+2 rating)

Figure 23. Remission patients’ interest in different services
Moving Forward

This Report Card on Lymphomas emphasises that patients in every stage of their experience need more information and support beyond what is currently being provided.

After the initial visit with the doctor, greater efforts are needed to ensure patients have a thorough understanding not only of their diagnosis but also their subtype’s characteristics, treatment options and potential side effects and how they will be managed. It is critical that this information be provided, both at initial diagnosis and throughout the patient’s experience, as the LC 2018 GPS indicated that having a perceived adequate information level was correlated with more self-reported positive healthcare experiences. Patients with adequate information reported bettered management of their health and healthcare through improved understanding, confidence levels, and communication\(^1\).

In each stage analysed, patients consistently reported doctors to be among their top three information sources (figure 24). Patients are going to their doctors for information; however, as results throughout this report highlighted, they are not always getting all the answers they require. Only 44% of lymphoma patients (globally, all stages) found their doctor’s responses to their questions about physical/medical issues helpful and less than one third (globally, all stages) found their doctor’s responses to their emotional concerns beneficial. If doctors are unable to provide adequate information, then patients need to be referred onto other resources such as the local patient organisation for support and information. As indicated in figure 24, they are going to websites for information, so let’s all ensure they are reading the most up-to-date and appropriate subtype information by making references to the best sites.

Figure 24. Top three information sources reported by patients in different stages
This stage by stage analysis also made apparent that patients experience many physical, medical and psychosocial issues in each step of their care. Some issues remain consistent themes across the patient experience.

1. **The most prominent physical condition, being the top reported in every stage, was fatigue.** Despite the massive impact of fatigue on health-related quality of life, a large percentage of patients who reported it were not referred onto further information or support by their doctor and/or nurse even though there are behaviour changes a patient can implement to help them cope. As well, research into new therapies that do not exacerbate a primary symptom of lymphoma is needed.

2. **The key psychosocial issue identified was fear of relapse.** As was previously mentioned, fear of cancer relapse is frequently cited as the greatest unmet need among cancer survivors. This was reflected in the LC 2018 GPS; fear of relapse was often underreported, and when reported to a doctor, many did not feel it helped alleviate the fear. Further, many patients who reported their fear of relapse were never referred onto further information or support by their doctor and/or nurse. Discussion of fear of relapse needs to be normalised for patients and referrals for extra support, such as cognitive behaviour therapy, made when warranted and to patient organisations who understand this issue so well. Refer to the Fear of Cancer Recurrence report, found on the LC website, for more information.

Moving forward, these key issues identified need to be made areas of focus for systematic change. **This analysis highlighted a major two-way communication issue between patients and their doctors.** In each stage, when asked specifically about the concerns they communicated to their doctor, it was evident that patients were much more likely to communicate their physical and/or medical issues than their emotional issues. When they do raise their emotional concerns, only the minority report that the doctor is able to help. The lack of emotional support patients received is concerning, so too is their reluctance to communicate these issues in the first place. Since evidence has been published linking the effective use of stress coping mechanisms with lower levels of depression, anxiety, and symptoms related to the cancer and its treatment, there are interventions that can be used to address patient concerns. As well, providing more information can help as the LC 2018 GPS showed that well-informed patients report lower levels of negative feelings and fewer barriers to care.

To encourage communication, the emotional impact of a cancer diagnosis needs to be acknowledged at the outset, and the emotional cues from the patient must be recognised and responded to throughout their experience.

Further, doctors cannot be expected to provide all the emotional support needed but they need to direct patients to where they can get information and support. This can include other resources that are hospital-based or community-based, as well as patient organisations.

Many resources are available to help a patient through each phase of their lymphoma experience. Care and support of a patient extends past the clinic and can last for many years post-treatment. **It is imperative everyone who is part of the lymphoma community – whether they be doctors, nurses, other HCPs, patient organisations - recognises the value each member brings and utilises the available resources to improve the overall patient experience.**
Appendix A

Methodology

To achieve these objectives, LC reviewed the data from the LC 2018 GPS. There were 6631 total survey respondents; however, 438 respondents did not indicate their stage, so they were eliminated from the data pool (n=6193). Data was then filtered by each stage, or stage grouping (i.e. relapsed/transformed, remission). Within each stage, data was pulled for reported physical conditions, medical issues (before, during, after treatment), psychosocial issues (before, during after treatment), communication with the doctor, information sources and understanding levels, and barriers to treatment. Some additional subtype analysis was conducted in certain areas. To calculate the prevalence of the physical, medical and psychosocial issues (at any given time point) n=x who reported the condition was divided by n=x in the stage (i.e. # of respondents who reported the issue/# of respondents in that stage). All statistical analyses were performed using Microsoft PowerBI and IBM SPSS v21.

Data from the LC 2018 GPS was supplemented with information from scientific peer-reviewed journals, clinical trial databases, drug regulatory/reimbursement websites, and qualitative patient interviews. LC interviewed Shawn, Vandana, and Rosmarie to gain a greater understanding of the issues patients have faced and continue to face as a result of their lymphoma.

Appendix B

List of Physical Conditions, Medical Issues, Psychosocial Issues and Barriers to Treatment Investigated in LC GPS 2018

For the purpose of the GPS, physical conditions include the following:

- Aching joints
- Bowel changes
- Burning
- Change in sexual function
- Changes in sleep patterns
- Changes in taste and smell
- Memory loss
- Mucositis/mouth ulcers
- Muscle weakness
- Nausea and vomiting
- Night sweats
- Problems concentrating
- Problems fighting infections
- Shortness of breath
- Skin reactions
- Swelling of arms and legs
- Trouble concentrating
- Viral reactivations
- Weight change
- Weight loss
- Cramps
- Fatigue
- Fluid retention
- Hair loss
- Incontinence
- Itching
- Loss of appetite
- Loss of fertility
Medical issues include the following:

- Any other blood condition
- Bleeding
- Diabetes
- Diarrhoea
- Enlarged lymph nodes
- Eyesight issues
- Headaches
- Heart-related issues
- Issues with other organs
- Neutropenia
- Numbness
- Osteoporosis
- Pain
- Secondary cancer
- Stomach-related issues
- Thrombosis
- Tingling

Psykosocial issues include the following:

- Anxiety
- Changes in relationships with loved ones, friends, or co-workers/social life
- Concerns about body image/physical appearance changes
- Depression
- Difficulty on the job or in school
- Difficulty working effectively through the healthcare system
- Fear of relapse
- Isolation
- Stress related to financial issues
- Loss/reduction in employment
- Loss of self-esteem
- Problems getting health or life insurance coverage

Barriers to treatment include the following:

- Access to the most up to date treatment
- Access to treatment centre/prohibitive travel
- Could not give up caregiver role
- Specialty physician available locally
- Wait time to treatment was longer than necessary
- Access to the most up to date treatment (child, parent, disabled person) while in treatment
- Financial
- Language
- Personal support
- Specialty physician available locally
- Wait time to treatment was longer than necessary

Appendix C

Novel Therapy List

Sources of therapy access related information includes regulatory and health medicine databases as well clinical treatment guidelines (ex. ESMO, NCCN).

For this report, 31 novel (approved post-rituximab) treatments were identified as actively used and are considered in the analysis (figure 14). Fully accessible are those therapies which are fully reimbursed through public healthcare or private insurance. Certain countries have special access programs which provide use to patients who meet selective criteria.

- Acalabrutinib
- BDR (Bortezomib, Dexamethosone, Rituximab)
- Belinostat
- Bendamustine
- Bendamustine-Ofatumumab
- Bendamustine-Rituximab
- Bortezomib
- Bortezomib-Rituximab
- Brentuximab Vedotin
- CAP-VcR
- CAR T Axicabtagene Ciloleucel
- CAR T Lisocabtagene Maraleucel
- CAR T Tisagenlecleucel
- Copanlisib
- IBR (Ibrutinib, Bendamustine, Rituximab)
- Ibrutinib
- Idelalisib
- Idelalisib-Ofatumumab
- Idelalisib-Rituximab
- Lenalidomide
- Lenalidomide-Rituximab
- Nivolumab
- Obinutuzumab Maintenance
- Obinutuzumab-Bendamustine
- Obinutuzumab-Chlorambucil
- Ofatumumab
- Ofatumumab-Chlorambucil
- Pembrolizumab
- Pixantrone
- Venetoclax
- Venetoclax-Rituximab
Appendix D

Overview of Top 3 Issues by Stage of Patient Experience (Physical, Medical, Psychosocial)

<table>
<thead>
<tr>
<th>Stage of Patient Experience</th>
<th>Top 3 Reported Physical Conditions</th>
<th>Top 3 Reported Medical Issues</th>
<th>Top 3 Reported Psychosocial Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newly Diagnosed</td>
<td>1. Fatigue (55%)</td>
<td>1. Enlarged lymph nodes (11%)</td>
<td>1. Anxiety (12%)</td>
</tr>
<tr>
<td></td>
<td>2. Night sweats (28%)</td>
<td>2. Diabetes (9%)</td>
<td>2. Changes in relationships (11%)</td>
</tr>
<tr>
<td></td>
<td>3. Change in sleep patterns (26%)</td>
<td>3. Eyesight issues (8%)</td>
<td>3. Stress related to finances (10%)</td>
</tr>
<tr>
<td>Watch &amp; Wait</td>
<td>1. Fatigue (52%)</td>
<td>1. Enlarged lymph nodes (13%)</td>
<td>1. Anxiety (14%)</td>
</tr>
<tr>
<td></td>
<td>2. Change in sleep patterns (28%)</td>
<td>2. Pain (5%)</td>
<td>2. Depression (10%)</td>
</tr>
<tr>
<td></td>
<td>3. Aching joints (22%)</td>
<td>3. Headaches (5%)</td>
<td>3. Changes in relationships (10%)</td>
</tr>
<tr>
<td>First Line Treatment</td>
<td>1. Fatigue (62%)</td>
<td>1. Neutropenia (21%)</td>
<td>1. Changes in relationships (32%)</td>
</tr>
<tr>
<td></td>
<td>2. Hair loss (43%)</td>
<td>2. Stomach-related issues (19%)</td>
<td>2. Stress related to finances (29%)</td>
</tr>
<tr>
<td></td>
<td>3. Change in sleep patterns (38%)</td>
<td>3. Pain (15%)</td>
<td>3. Fear of relapse (28%)</td>
</tr>
<tr>
<td>Maintenance Therapy</td>
<td>1. Fatigue (61%)</td>
<td>1. Neutropenia (29%)</td>
<td>1. Changes in relationships (35%)</td>
</tr>
<tr>
<td></td>
<td>2. Hair loss (49%)</td>
<td>2. Stomach-related issues (21%)</td>
<td>2. Stress related to finances (27%)</td>
</tr>
<tr>
<td></td>
<td>3. Muscle Weakness (38%)</td>
<td>3. Numbness (17%)</td>
<td>3. Anxiety &amp; concerns about body image (24%)</td>
</tr>
<tr>
<td>Relapsed/Transformed</td>
<td>1. Fatigue (73%)</td>
<td>1. Neutropenia (16%)</td>
<td>1. Changes in relationships (34%)</td>
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<tr>
<td></td>
<td>2. Hair loss (46%)</td>
<td>2. Eyesight issues (13%)</td>
<td>2. Anxiety (30%)</td>
</tr>
<tr>
<td></td>
<td>3. Problems fighting infection (45%)</td>
<td>3. Stomach-related issues (13%)</td>
<td>3. Stress related to finances (29%)</td>
</tr>
<tr>
<td>Remission</td>
<td>1. Fatigue (71%)</td>
<td>1. Neutropenia (16%)</td>
<td>1. Fear of relapse (40%)</td>
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<tr>
<td></td>
<td>2. Hair loss (53%)</td>
<td>2. Eyesight issues (13%)</td>
<td>2. Changes in relationships (25%)</td>
</tr>
<tr>
<td></td>
<td>3. Muscle weakness (42%)</td>
<td>3. Stomach-related issues (21%)</td>
<td>3. Stress related to finances (23%)</td>
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<tr>
<td></td>
<td></td>
<td>1. Numbness (14%)</td>
<td>1. Fear of relapse (45%)</td>
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<td></td>
<td>2. Tingling (14%)</td>
<td>2. Changes in relationships (27%)</td>
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<tr>
<td></td>
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<td>3. Eyesight issues (13%)</td>
<td>3. Anxiety (25%)</td>
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<tr>
<td></td>
<td></td>
<td>1. Changes in relationships (31%)</td>
<td>2. Anxiety (28%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Changes in relationships (31%)</td>
<td>3. Stress related to finances (23%)</td>
</tr>
</tbody>
</table>
This report is a valued product of the Lymphoma eInformation Project (LeIP)

Contact us if you are a patient organisation that focuses on lymphomas, including CLL, or if you are interested in starting a patient organisation.

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