It would be prudent for patient organisations and the healthcare community to work together to support the patient through their experience, both in the short and long term. Patient organisations have a key role to play in providing patients with a haven where their fears can be expressed long after they have seen their medical team.
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.

LC is made up of 66 patient organisations from 44 countries.

The need for a global coalition was recognised as a way to bring together members to share resources and best practices; collect global information and provide an online platform for information dissemination; and build a network of Lymphoma Opinion Leaders (LOLs). Working together, we can change the lymphoma landscape and achieve more for patients.

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, government agencies, pharmaceutical companies, medical professionals, pharmacists and individuals who generously shared their knowledge, resources and understanding for this report. Thank you to the editorial committee for making time to review the report: Dr. Laurie Sehn, Pru Etcheverry and Shawn Sajkowski. Thank you to those who provided an unrestricted grant to support this project: Celgene Corporation, The Takeda Oncology Company and Pfizer, Inc.

LeIP Team
Karen Van Rassel, Leonie Bedford, Shawn Sajkowski and Shafia Abdulhusein

Disclaimer
Lymphoma Coalition (LC) provides the 2016 LeIP Report Card on Lymphomas for general information related to topics relevant to lymphoma worldwide. While LC makes every effort to ensure accuracy, the information contained in the report is taken from various public and private sources. No responsibility can be assumed by LC for the accuracy or timeliness of this information.

Warning
LC’s 2016 LeIP 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 Chief
Executive Officer

Karen Van Rassel
CEO, Lymphoma Coalition

Great strides are being made in improving the understanding about lymphoma subtypes resulting in the development of more targeted therapies. However, what needs to change is how patients are informed about their subtype. Know Your Subtype, a worldwide campaign, supports this need for patients to not only know their subtype but also its cell of origin. In this report, we focus on ensuring information is reported by subtype to allow LC and its members to represent the unmet needs of patients at all levels as well as support patients when they reach out for help.

In this year’s report, using information from the 2016 Lymphoma Global Patient Survey, LC examined access to care for five subtypes; namely, chronic lymphocytic leukaemia, diffuse large B-cell lymphoma, follicular lymphoma, Hodgkin lymphoma and Waldenström’s macroglobulinaemia to determine if there are differences in the care each subtype receives based on the country of residence. While we have developed case studies by subtype, it is good to look at the whole picture to see how the rapidly changing understanding of the biology of the different subtypes is keeping up with access to therapies. As this report shows, when it comes to providing patients with treatment in a timely and cost-effective manner, it is not a level playing field.

Many thanks to our financial supporters. We could not undertake this important initiative without their recognition of the importance of this work that supports patients, helps in the development of research tools and determines gaps in patient care. Thanks also to the editorial committee for reviewing this report as well as all the patients and LC member organisations whose input has been most invaluable.
Message from
the Chair of the LC
Medical Advisory Board

Dr. Laurie H. Sehn, MD, MPH
Chair, BC Cancer Agency Lymphoma Tumour Group
Clinical Professor, University of British Columbia, Vancouver, Canada
Chair, LC Medical Advisory Board

The 2016 LeIP Report Card on Lymphomas highlights the ongoing need to track lymphoma universally according to individual histological subtypes. Non-Hodgkin lymphoma is a diverse collection of lymphoid cancers and information compiled as one disease does not provide sufficient detail to allow for proper trending and analysis.

The 2016 LeIP Report Card provides a detailed analysis for 12 of the 44 LC member countries (not all countries had public data). Results indicate that patient care varies widely by country and by lymphoma subtype, highlighting that there remains a large unmet need for patients to receive timely and cost-effective care.

The information reported in the 2016 Lymphoma Global Patient Survey (GPS) demonstrates that barriers to receiving treatment were more pronounced in some lymphoma subtypes compared with others, and were influenced by the respondents’ country of residence. The survey also examined the psychosocial barriers, as well as physical and medical issues encountered by patients. It is noteworthy that many of the concerns raised by respondents have persisted for many years, lasting more than eight years in some cases.

As a physician community, it is highly important to partner with patient organisations in order to provide support to the patient community. Patient and family support needs extend well beyond the physician’s office and patient support groups have established the required network and developed the capacity to address many of these needs. It is highly concerning that the GPS survey indicates that only 30% of respondents, regardless of their lymphoma subtype, feel that their doctor had been able to address both their physical and emotional issues. This raises the questions: where are the patients getting the support and information that they need and is it the right information?

As with previous report cards, the 2016 LeIP Report Card demonstrates that while much progress is being made in the understanding of the biology of the different lymphoma subtypes and that more targeted therapies are being developed, patients are still confronted by many barriers to timely and cost-effective treatment. Efforts to improve this for patients must continue and be front and centre of any patient care plan.
Message from
the Chair of the LC Board of Directors

Pru Etcheverry
CEO, Leukaemia & Blood Cancer New Zealand
Chair, LC Board of Directors

The Lymphoma Coalition (LC) continues to examine the numerous barriers patients encounter after diagnosis. Whether it is for treatment, or support for their medical, physical and psychosocial concerns, there can be many challenges that limit optimal care.

The work LC has undertaken to report by subtype is important for many reasons. Additionally, it is important that clinical trials ask and answer the right questions, support patients’ needs and that therapies can deliver durable benefits to patients with minimal adverse effects.

Findings from the 2016 Lymphoma Coalition Global Patient Survey (GPS) report that patients are living with long-term effects from their therapies both clinically and psychosocially for in excess of eight years. It is of concern that newer more targeted therapies still continue to deliver harmful adverse effects that can impact patients’ ability to remain on treatment.

It is encouraging to look at the whole picture to see how the changing understanding of the biology of lymphoma subtypes is being matched with new therapies. However, challenges remain with access to these therapies and the clinical trials that lead to their availability.

We know also from the 2016 Lymphoma GPS that 60% of patients turn to the internet for information. While the internet can be a great resource we want to ensure that patients can always access the right information. It is also critical that patients and families are able to access and receive appropriate support across all facets of their care.
Overview

Since 2012, the Lymphoma Coalition (LC) has provided an annual report that examines various aspects of the patient experience to determine whether patients receive care for their subtype of lymphoma in a timely and cost-effective manner.

The 2012 Lymphoma eInformation Project (LeIP) Report Card concluded that published information about the latest evidence-based standard of care, including diagnostics, lymphoma therapies and clinical trials, was difficult to access and either inadequate or inconsistent not only for lymphoma subtypes but also within LC member countries.

The 2013 LeIP Report Card pointed out that there were a myriad of barriers standing in the way of patients receiving care. For example, regulatory systems, i.e., drug regulatory approval and funding/reimbursement approval processes, were, in general, cumbersome and time-consuming. In addition, it was challenging to find information on what therapies had either regulatory or funding/reimbursement approval.

Again, in the 2014 LeIP Report Card, it was demonstrated through findings from the 2014 Lymphoma Global Patient Survey (GPS) that not only access to the most up-to-date therapies was a barrier for patients but that access to the appropriate specialty physician and treatment centre, as well as long wait times, were also barriers. Additionally, it was shown that not all clinical trials were available in all countries with some countries not having any available. 2014 also saw the start of LC tracking information by lymphoma subtype with the initial focus being on seven subtypes; namely, Burkitt’s lymphoma (BL), chronic lymphocytic leukaemia (CLL), diffuse large B-cell lymphoma (DLBCL), follicular lymphoma (FL), Hodgkin lymphoma (HL), mantle cell lymphoma (MCL) and peripheral T-cell lymphoma (PTCL).

The 2015 LeIP Report Card built on the reporting of information by subtype by focusing specifically on HL and MCL and the barriers patients with HL and MCL experienced not only in accessing treatment in a timely and cost-effective manner but also the psychosocial and physical challenges they encountered. What was demonstrated was that patients with HL and MCL continued to be confronted by many of the same challenges that prevent them from receiving optimal care. For example, patients with HL were confronted by long wait times while those with MCL faced some form of financial barrier. These findings and others demonstrated that greater efforts were needed in improving the patient experience and that not only did the patient’s cancer need to be treated but also the patient as a whole.
In 2016, LC began tracking clinical trial and therapy information for an additional eight subtypes; namely:

1. Adult T-cell leukaemia;
2. Anaplastic large cell lymphoma;
3. Cutaneous T-cell lymphoma;
4. Extranodal killer T-cell lymphoma;
5. Hairy cell leukaemia;
6. Marginal zone lymphoma/MALT;
7. Primary cutaneous anaplastic large cell lymphoma;
8. Waldenström’s macroglobulinaemia (WM).

Information on clinical trials and therapies by country and by subtype can be found in LC’s global database. Unfortunately, the barriers to receiving appropriate and timely care have not gone away, as will be demonstrated in the 2016 LeIP Report Card. Building on the findings from the 2016 Lymphoma GPS, LC undertook to investigate whether barriers to receiving treatment were more pronounced in some lymphoma subtypes compared with others based on the respondents’ country of residence. As well, LC examined the psychosocial barriers, physical and medical issues, the level of understanding of the different subtypes among respondents and the level of support provided by physicians.

5 Subtypes

For this report card, LC has focused on five subtypes in 12 member countries. These five subtypes were chosen because they had the highest number of respondents in the 2016 LC GPS (10% or higher) and, thus, ensured statistical significance.

The five subtypes are:

1. CLL
2. DLBCL
3. FL
4. HL
5. WM

12 Member Countries

The 12 member countries were chosen rather than all member countries to allow for the inclusion of information from the GPS to create a full situation analysis. For the other 32 member countries, there were insufficient data from the GPS to provide a situation analysis. Owing to insufficient responses, no findings on issues in Africa or the Middle East are included in this report.

For a listing of all LC members please visit the LC website.

The 12 LC member countries are, by region:
Objectives

The objectives of LC’s analysis were to:

1. Review clinical trials available for the five subtypes to determine how many were being undertaken in new therapy protocols, i.e., therapy protocols approved for a lymphoma subtype in the last five years;
2. Determine which of the new therapies listed by either the European Society of Medical Oncology (ESMO) or the National Cancer Comprehensive Network (NCCN) for the five different subtypes of lymphoma had funding/reimbursement approval in the 12 LC member countries;
3. Review barriers to treatment, psychosocial, physical and medical concerns, and the degree of support provided by doctors, by subtype and country.

To address the objectives of this review, LC:

- Analysed, by region, availability of clinical trials and therapies;
- Examined the barriers to treatment, psychosocial impacts, physical and medical effects, and support provided by doctors by subtype and country as reported in the 2016 Lymphoma GPS.

Methodology

To achieve its objectives, LC undertook a review of the availability of phase II and III clinical trials in 2016 for the five subtypes. This information was obtained from clinicaltrials.gov, the European Union Clinical Trials Register, the Australian Cancer Trials, the German Hodgkin Study Group and the World Health Organization websites. Compiled information can be found in LC’s global database by country and subtype.

To determine which therapies were available in the 12 LC member countries, LC obtained information from a quarterly review of member country regulatory and reimbursement websites, medical journals and general media press releases. LC also determined if the 12 countries had treatment guidelines developed by oncology, haematology and medical bodies. LC found that only Australia, Argentina, Canada and the USA had treatment guidelines. For Europe, LC referenced the ESMO guidelines. Information on therapy availability compiled by country and subtype can be found in LC’s global database.

In reviewing the patient experience, LC used information from the 2016 Lymphoma GPS in which 4,154 individuals from 72 countries, including 44 LC member countries, participated. Participation in the GPS by those living in Australia, Brazil and the USA was not as high as in 2014 because those member countries were undertaking their own surveys. Analysis is based on information provided by respondents from the 12 countries noted earlier. Based on subtype breakout, some subtypes have a greater representation than others. This accounts for why some issues are more notable in some subtypes in certain countries. For example, the majority of respondents from Argentina had HL; in the USA, a greater proportion of respondents had WM compared with the other subtypes.
Key Findings & Discussion
Clinical Trial Availability for Five Lymphoma Subtypes

In 2016, based on information LC gathered from its global database, there were 580 phase II/III clinical trials underway for the five subtypes LC reviewed for this report card. Table 1 shows the total number of clinical trials for each of the five subtypes, the number of subtype-specific clinical trials, i.e., those trials specific to that particular subtype, the number of clinical trials studying new therapies and the number of trials investigating therapies in combination with other established therapies.

Table 1. Subtype Clinical Trials

<table>
<thead>
<tr>
<th>Subtype</th>
<th>Total Clinical Trials for Subtype, n (%)</th>
<th>Subtype-Specific Clinical Trials, n (%)</th>
<th>New Therapy Clinical Trials, n (%)</th>
<th>Combination Therapy Trials, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLL</td>
<td>226 (31.7)</td>
<td>164 (72.6)</td>
<td>184 (81.4)</td>
<td>42 (18.6)</td>
</tr>
<tr>
<td>DLBCL</td>
<td>237 (33.2)</td>
<td>89 (37.6)</td>
<td>167 (70.5)</td>
<td>68 (28.7)</td>
</tr>
<tr>
<td>FL</td>
<td>226 (31.7)</td>
<td>51 (22.6)</td>
<td>169 (74.8)</td>
<td>49 (21.7)</td>
</tr>
<tr>
<td>HL</td>
<td>117 (16.4)</td>
<td>70 (59.8)</td>
<td>78 (66.7)</td>
<td>39 (33.3)</td>
</tr>
<tr>
<td>WM</td>
<td>66 (9.2)</td>
<td>4 (6.1)</td>
<td>47 (71.2)</td>
<td>19 (28.8)</td>
</tr>
</tbody>
</table>

† As of July 31, 2016
* A clinical trial may be undertaken in more than one subtype; therefore, the total percentage of clinical trials will not add up to 100%.

CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; n = number; WM = Waldenström’s macroglobulinaemia

Chronic Lymphocytic Leukaemia (CLL)

CLL had the highest number of clinical trials looking specifically at that subtype alone. Normally to study a subtype population, such as CLL, there are several subtypes involved requiring a subtype analysis to be performed. However, the CLL-specific trials are indicative of the insights into the biology of CLL that have occurred allowing for clinical trials to focus solely on this subtype. When looking at the number of clinical trials examining new therapies, the highest number is in CLL. Again, this is most likely a reflection of the major advances that have occurred in the understanding of CLL’s biology and immunology.

Follicular Lymphoma (FL)

In FL, while there were far fewer subtype-specific clinical trials, there were a considerable amount (n = 169) of clinical trials examining new therapies likely reflecting the research currently underway that has provided a better understanding of the biology of this subtype.

Diffuse Large B-cell Lymphoma (DLBCL)

In DLBCL, while there were 237 clinical trials underway of which 167 were specifically studying DLBCL, one of the challenges is to find therapies that specifically target the subsets of DLBCL. The most common subsets are germinal centre B-cell (GCB-type DLBCL) and activated B-cell (ABC-type DLBCL). ABC-type DLBCL has a more aggressive clinical course and the outcomes are not as significant as GCB type. Other subsets of DLBCL are double-hit lymphoma (DHL) and double expressor lymphoma. Patients with DHL tend to respond poorly to standard CHOP-R (cyclophosphamide, doxorubicin, vincristine, prednisone, rituximab) therapy; hence the need for a more targeted approach to treatment for this subtype of DLBCL as well as further molecular investigation.

For more information on:
- CLL, see the CLL subtype review on the LC website;
- DLBCL, see the DLBCL subtype review on the LC website;
- FL, see the FL subtype review on the LC website.
Hodgkin Lymphoma (HL)

For many years the standard of care for HL has been ABVD and BEACOPP with most patients achieving remission. However, greater emphasis is needed on the study of therapies for use in the first-line setting to avoid long-term survivorship issues such as cardiovascular disease and secondary cancers. As of July 2016, however, focus still appeared to be on the relapsed/refractory setting with 81 clinical trials compared with 33 in the first-line setting.

For more information on HL, see the HL subtype review on the LC website.

Waldenström’s Macroglobulinaemia (WM)

While there were few subtype-specific clinical trials for WM, likely reflecting the rarity of this blood cancer, it is important to note the very recent improvement in the understanding of the genomics of this subtype. As well, it is encouraging that there are therapeutic agents being studied in clinical trials such as ixazomib, a proteasome inhibitor, lenalidomide, an immunomodulatory agent and copanlisib, a phosphatidylinositol 3-kinase (PI3K) inhibitor.

For more information on WM, see the WM subtype review on the LC website.

Table 2 shows the number of clinical trials in the 12 LC countries for the five subtypes being examined in this report.

Very few subtype-specific clinical trials were available in Eastern Europe with Lithuania having the fewest. In Asia/Pacific, no HL clinical trials were available and in Latin America, neither any HL nor WM clinical trials were available. The implication of this is that patients, in those countries where few if any clinical trials are available, are likely not benefiting from newer therapy protocols under investigation and healthcare professionals (HCPs) are not getting exposure to new therapy protocols. As noted in the 2015 LeIP Report Card, LC would like to see clinical trials more widely available to better serve some of these woefully underserved regions.

Table 2. Subtype Clinical Trials Available in 12 Member Countries*

<table>
<thead>
<tr>
<th></th>
<th>CLL</th>
<th>DLBCL</th>
<th>FL</th>
<th>HL</th>
<th>WM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Clinical Trials for Subtype, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>226 (31.7)</td>
<td>237 (33.2)</td>
<td>226 (31.7)</td>
<td>117 (16.4)</td>
<td>66 (9.2)</td>
</tr>
<tr>
<td>Clinical Trials Available by Subtype in Each Country, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eastern Europe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lithuania</td>
<td>2 (0.9)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Serbia</td>
<td>1 (0.4)</td>
<td>2 (0.8)</td>
<td>1 (0.4)</td>
<td>1 (0.4)</td>
<td>0</td>
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<tr>
<td>Western Europe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>France</td>
<td>29 (12.8)</td>
<td>31 (13.1)</td>
<td>37 (16.4)</td>
<td>13 (11.1)</td>
<td>6 (9.1)</td>
</tr>
<tr>
<td>Italy</td>
<td>35 (15.5)</td>
<td>38 (16.0)</td>
<td>45 (19.9)</td>
<td>15 (12.8)</td>
<td>12 (18.2)</td>
</tr>
<tr>
<td>Spain</td>
<td>26 (11.5)</td>
<td>25 (10.5)</td>
<td>29 (12.8)</td>
<td>7 (6.0)</td>
<td>5 (7.6)</td>
</tr>
<tr>
<td>UK</td>
<td>32 (14.2)</td>
<td>23 (9.7)</td>
<td>31 (13.7)</td>
<td>8 (6.8)</td>
<td>5 (7.6)</td>
</tr>
<tr>
<td>Asia/Pacific</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Australia</td>
<td>22 (9.7)</td>
<td>27 (11.4)</td>
<td>30 (13.3)</td>
<td>4 (3.4)</td>
<td>9 (13.6)</td>
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<tr>
<td>Japan</td>
<td>1 (0.4)</td>
<td>7 (3.0)</td>
<td>13 (5.8)</td>
<td>2 (1.7)</td>
<td>1 (1.5)</td>
</tr>
<tr>
<td>New Zealand</td>
<td>11 (4.9)</td>
<td>5 (2.1)</td>
<td>8 (3.5)</td>
<td>0</td>
<td>4 (6.1)</td>
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<td>North America</td>
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<tr>
<td>Canada</td>
<td>26 (11.5)</td>
<td>25 (10.5)</td>
<td>26 (11.5)</td>
<td>10 (8.5)</td>
<td>6 (9.1)</td>
</tr>
<tr>
<td>USA</td>
<td>176 (77.9)</td>
<td>168 (70.9)</td>
<td>171 (75.7)</td>
<td>88 (75.2)</td>
<td>62 (93.9)</td>
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<td>Latin America</td>
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<tr>
<td>Argentina</td>
<td>7 (3.1)</td>
<td>4 (1.7)</td>
<td>4 (1.8)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*As of July 31, 2016

CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; n = number; UK = United Kingdom; USA = United States of America; WM = Waldenström’s macroglobulinaemia
Therapy Access to New Therapy Protocols for Five Lymphoma Subtypes

Based on information from two treatment sources – ESMO and NCCN – LC examined which of the new therapies noted in these listings could be accessed in the 12 LC member countries. For all the treatments recommended by ESMO and listed by NCCN, please see the subtype reviews on the LC website.

Chronic Lymphocytic Leukaemia (CLL)

While most patients with CLL may not need treatment at the time of diagnosis, most will require treatment at some point. In the last several years, major strides have been made in understanding the biology of CLL resulting in the development of many new targeted therapies with excellent response rates. Most of these therapies are oral, providing easier administration and convenience. Some of these therapies include novel CD20 monoclonal antibodies (ofatumumab and obinutuzumab), Bruton tyrosine kinase (BTK) inhibitors (ibrutinib), and PI3K inhibitors (idelalisib). Lenalidomide, an immunomodulatory drug, has also been studied in CLL. Table 3 shows the availability of these therapies in the 12 LC member countries.

As shown in Table 3, while many of the newer therapies had regulatory approval in one or more countries, very few had funding/reimbursement approval likely resulting in patients receiving older regimens that may not be as effective.

Although all therapies had regulatory approval in the USA, the level and type of insurance patients have will determine which, if any, of the new therapies a patient receives.

Table 3. CLL: Availability of New Therapies in 12 Member Countries*

<table>
<thead>
<tr>
<th>Country</th>
<th>Bendamustine ± rituximab</th>
<th>Ibrutinib</th>
<th>Ibrutinib ± rituximab</th>
<th>Idelalisib ± rituximab</th>
<th>Lenalidomide ± rituximab</th>
<th>Obinutuzumab</th>
<th>Obinutuzumab ± chlorambucil</th>
<th>Ofatumumab</th>
<th>Ofatumumab ± chlorambucil</th>
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<tr>
<td>Eastern Europe</td>
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*As of July 31, 2016
1Therapies in the USA are covered by private insurance. Level of coverage depends on individual plans. Usually requires co-payment from patient. 2Reimbursement information not available.
A = therapies have regulatory approval; R = therapies funded/reimbursed; UK = United Kingdom; USA = United States of America
**Diffuse Large B-cell Lymphoma (DLBCL)**

In DLBCL, the current standard of care should include rituximab as part of the treatment regimen. As shown in Table 4, this is not the case.

NCCN also lists anumber of newer regimes; namely, bendamustine ± rituximab, brentuximab vedotin and lenalidomide ± rituximab but they are only approved in the USA (see Table 4).

**Follicular Lymphoma (FL)**

FL is considered to be an indolent but incurable cancer marked by multiple relapses.

Over a lifetime, a patient with FL may require treatment with various protocols resulting in the patient having to manage many physical and medical issues including short-term and long-term adverse effects associated with these regimens.

Although many new therapies have been developed for FL, there is still no cure. Table 5 shows which of the new therapies recommended by either ESMO or listed by NCCN had funding/reimbursement approval in the 12 member countries.

With the exception of the USA, none of the 12 countries provided regulatory or funding/reimbursement approval for lenalidomide ± rituximab. In Eastern Europe, none of the new therapies were approved in Serbia. While bendamustine ± rituximab had regulatory approval in Lithuania, it did not have funding/reimbursement approval. As a result, patients in Eastern Europe likely have to rely on older regimens that may not be as effective as newer ones. In Latin America, Argentina did not have any of the new therapies approved. Again, forcing patients to receive older and likely less effective regimens.

<table>
<thead>
<tr>
<th>Country</th>
<th>Bendamustine ± rituximab A</th>
<th>Bendamustine ± rituximab R</th>
<th>Brentuximab vedotin A</th>
<th>Brentuximab vedotin R</th>
<th>Lenalidomide ± rituximab A</th>
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Hodgkin Lymphoma (HL)

While a number of new therapies are recommended for use in the relapsed/refractory setting for HL, brentuximab vedotin was the only one that had regulatory approval in 11 of the 12 countries. However, funding/reimbursement approval was available only in six countries (see Table 6). Consequently, greater efforts are needed to ensure brentuximab vedotin is made available so all patients with HL can benefit.

Table 6. HL: Availability of New Therapies in 12 Member Countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Bendamustine</th>
<th>Brentuximab vedotin</th>
<th>Everolimus</th>
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Waldenström’s Macroglobulinaemia (WM)

In WM, a number of new therapies are listed by ESMO and NCCN (see Table 7).

While there were a number of new therapies with regulatory approval for the treatment of WM, very few had funding/reimbursement approval. For example, ibrutinib, the only targeted therapy currently available for WM, had regulatory approval in seven of the 12 countries but was only funded/reimbursed in one. For more about WM, see the subtype review on the LC website.
### Table 7. WM: Availability of New Therapies in 12 Member Countries *

<table>
<thead>
<tr>
<th>Country</th>
<th>Alemtuzumab</th>
<th>Bendamustine ± rituximab</th>
<th>Bortezomib ± rituximab</th>
<th>Bortezomib, dexamethasone</th>
<th>Bortezomib, dexamethasone, rituximab</th>
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### Table 7. WM: Availability of New Therapies in 12 Member Countries * (continued)

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<thead>
<tr>
<th>Country</th>
<th>Cladribine ± rituximab</th>
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The Patient Experience

Every two years, LC engages with the global lymphoma community through a survey to help better understand the concerns and barriers to care confronting patients and caregivers. The results from this survey are then used to help guide LC’s patient activities and support. Findings from the 2016 Lymphoma GPS indicated that while 54% of respondents reported not having experienced any barriers to treatment, among the 46% who had, struggles with financial concerns and personal support were the biggest barriers.

To determine whether barriers to treatment and other aspects of the patient experience were more pronounced in some subtypes compared with others and if the respondent’s country had an effect on treatment, LC undertook a review of the following issues by subtype and country:

- Barriers to treatment;
- The impact of age on treatment;
- Psychosocial effects;
- Physical and medical adverse effects;
- Awareness and understanding about subtype;
- Level of support provided by respondent’s physician.

What LC found was that some subtypes in some countries fared much worse than others. For example, when looking at barriers to treatment to determine if they were more pronounced in some subtypes based on country of residence, it was found that respondents with HL living in Argentina (63%), Italy (44%) and Spain (41%) appeared to be most affected by barriers to treatment (see Figure 1). Other subtypes where barriers to treatment were of greater concern were FL: Japan (43%), Canada (30%) and Spain (29%) and DLBCL: Serbia (36%), Japan (30%) and Lithuania (20%).

The barriers to treatment of particular concern were:

- Access to up-to-date treatment
- Financial
- Lack of personal support
- Wait time to treatment

![Figure 1. Barriers to Treatment Based on Subtype and Country of Residence, %](image)

Source: 2016 LC Global Patient Survey. CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; UK = United Kingdom; USA = United States of America; WM = Waldenström’s macroglobulinaemia
Access to Up-to-Date Treatment

Access to up-to-date treatment was of particular concern for those respondents with HL which was highest in Argentina (86%) and Spain (50%), and for respondents with FL in Japan (63%). Figure 2 shows the level of concern among the different subtypes based on country of residence.

In Argentina, there are a number of possible explanations as to why access to up-to-date treatments might be an issue for patients with HL. Of the 25 therapies listed by either ESMO or NCCN, only 12 appeared to have regulatory approval in Argentina, three for use in first line and 11 for use in the relapsed/refractory setting. LC found no evidence that the following therapy protocols had regulatory approval: ABVD-R, C-MOPP, CHOP, CHOP-R, CVP-R, everolimus, lenalidomide, nivolumab and stem cell transplant. What is of even greater concern is that it is not clear what therapies for HL are funded/reimbursed. As illustrated in the 2013 LeIP Report Card on Lymphomas, most requests for funding/reimbursement in Argentina have to be negotiated on an individual basis with government to determine whether coverage will be provided. Another possible treatment option for patients is enrolment in a clinical trial. However, of the 117 clinical trials in HL, none were available in Argentina. Consequently, it is perhaps not surprising that access to up-to-date treatments is an issue for patients with HL living in Argentina.

In Japan, 63% of respondents who reported barriers with FL indicated that accessing up-to-date treatments was an issue. While 14 therapies had regulatory approval, of which 11 were used in first line and 13 in the relapsed/refractory setting, a number of therapies listed by either ESMO or NCCN were not approved; namely lenalidomide ± rituximab, idelalisib, radioimmunotherapy and RFND. However, those therapies that had regulatory approval were funded and reimbursed. The only treatment regimen not funded was fludarabine + rituximab. Availability of FL clinical trials was low in Japan: of the 226 clinical trials in FL, only 13 were available. Given the nature of FL – an indolent lymphoma that is incurable with multiple relapses – it likely means that patients in Japan are not receiving the best care possible which may be a cause for anxiety among this patient population.

(Subtype Review: Follicular Lymphoma)

Figure 2. Barrier: Lack of Access to Up-to-Date Treatment Based on Subtype, %

Source: 2016 LC Global Patient Survey. CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; UK = United Kingdom; USA = United States of America; WM = Waldenström’s macroglobulinaemia
In Spain, access to up-to-date treatment was reported as a concern for 50% of respondents with HL. Of the 25 therapies listed by either ESMO or NCCN, only 10 had regulatory approval: four in first line and eight in the relapsed/refractory setting. While many of these therapies had funding/reimbursement approval, brentuximab vedotin did not. Compounding this issue is that access to clinical trials was minimal as only seven of the 117 HL clinical trials were available in Spain.

### Financial Concerns

Financial issues were of concern for respondents who reported barriers with HL in Argentina (60%), Italy (52%) and Lithuania (40%); those with FL in Japan (45%), Spain (44%) and New Zealand (36%); those with DLBCL in Japan (33%), Serbia (32%) and France (21%). In the USA, patients with WM (33%) appeared to be more affected by financial issues compared with the other subtypes. Figure 3 shows the level of concern about financial issues based on the subtype and country of residence.

The countries where respondents reported a financial concern highlights how few of the therapies are funded/reimbursed resulting in patients not having access to the best possible care. Given the challenges with funding/reimbursement in Argentina, it is perhaps not surprising that patients with HL should also experience financial difficulties. In the USA, among those with WM who reported financial concerns, this is likely influenced by the type of insurance a patient has as it will determine what and how much treatment a patient will receive. Uncertainties over how patients will pay for their treatment are not helpful and do not contribute to a healthy patient experience.

### Lack of Personal Support

Lack of personal support was reported as a barrier for respondents with HL in Italy (47%) and Serbia (40%), for those with DLBCL (43%) in Japan and for those with FL in the UK (40%). However, this barrier was not specific to any particular age group. This concern among respondents was consistent with results from the 2014 GPS. Further investigation is required to go deeper into what impact this has on patients.

### Wait Time to Treatment

Wait time to treatment was a barrier for respondents with FL in Japan (69%), respondents with HL in Argentina (50%) and Italy (50%) and respondents with DLBCL in Serbia (49%). Again, respondents in Argentina, Japan and Spain not only had issues accessing up-to-date therapies, they reported also having to wait a long time to receive treatment.

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**Figure 3. Barrier: Financial Concerns by Subtype and Country, %**

![Graph showing financial concerns by subtype and country]

Source: 2016 LC Global Patient Survey. CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; UK = United Kingdom; USA = United States of America; WM = Waldenström’s macroglobulinaemia
Impact of Age on Barriers to Treatment

In eight of the 12 countries reviewed in the GPS, respondents with FL aged between 46 and 65 years were more affected by barriers to treatment compared with other subtypes, particularly in Japan (58%) (see Figure 4). Given the small sample size, it is not possible to break out the particular barriers experienced in this age group.

Psychosocial Impacts: Loss/Reduction in Employment

Exploration of psychosocial impacts was added to the 2016 survey as patient organisations have indicated they are of increasing importance. Respondents (22%) said they had been affected by loss of employment and 19% reported experiencing difficulties at their place of employment. Loss or reduction in employment was a bigger issue for some subtypes compared with others based on country of residence. This was particularly noticeable in those with HL in Argentina (50%) and Italy (47%) and those with FL in Japan (41%) (see Figure 5).

When looking at the impact of age on loss/reduction in employment, respondents with CLL, DLBCL and FL aged 46 to 65 years were more affected compared with the other age groups. Respondents with WM aged 65 years and older were more affected by loss/reduction in employment compared with the other subtypes (see Figure 6).

Loss/reduction in employment in those aged between 45 to 65 years likely contributes to financial concerns given that this is the age group that likely has other financial burdens in terms of looking after their own children or elderly parents.
Psychosocial Impacts: Fear of Relapse

Findings from the 2016 LC GPS showed that one of the common factors affecting patients’ sense of well-being was fear of relapse. This was the primary issue affecting 63% of respondents globally. When looking at fear of relapse by subtype, it was very evident how great a concern it was (see Figure 7).

Figure 7. Fear of Relapse among Subtypes, %

Fear of relapse was most notable in those respondents with DLBCL (58%), FL (57%) and HL (58%). A number of factors are responsible for this concern being so pronounced in these three subtypes and LC will explore this in the next survey. When looking at the lack of availability of treatment options for use in the relapsed/refractory setting alongside this concern, these patients not only need to discuss these issues but also need support from their healthcare professionals and local patient organisations. For example, brentuximab vedotin, a therapy listed by both ESMO and the NCCN for use in the relapsed/refractory setting, had regulatory approval in all 12 countries except New Zealand, but it was only funded/reimbursed in six countries. For more information on which therapies are funded/reimbursed, see Table 6 HL: Availability of New Therapies in 12 Member Countries as well as the subtype review on HL on the LC website.

Within DLBCL, the fear of relapse may be higher depending on the DLBCL subtype. Those with DLBCL-GCB will likely achieve remission with current treatment options; those with DLBCL-ABC will likely relapse and, currently, there are no treatment options that have been shown effective in this subtype. For these patients, support from patient groups, for example, is crucial. For more information on DLBCL, see the subtype review on the LC website.

Among those with FL, given that there is no cure and the likelihood of multiple relapses, it is no wonder patients dread the many rounds of different therapy protocols and all that they entail in terms of dealing with the adverse effects as well as medical issues. For more information on FL, see the subtype review on the LC website.

To get a sense of the concern about relapse, LC examined how these respondents felt both during and after treatment and for how long this concern lasted. During treatment, the fear of relapse was more prevalent in some subtypes compared with others. The fear of relapse was particularly noticeable in Argentina among respondents with HL (65%) (see Figure 8). Following treatment, fear of relapse remained high among those with HL in Argentina (58%) (see Figure 9). This is likely reflective of the challenges those with HL or any subtype of lymphoma face in Argentina. As well, it points to the fact that relapse is of great concern not only during treatment but also long after treatment is completed. Globally, while 25% indicated their fear of relapse lasted less than a year, for 11% of respondents it lasted eight years or more. This needs to be discussed with the doctor far more comprehensively and a support system put in place around patients. To date, however, it would appear that this topic is not discussed as frequently as it should be. Referring patients to the social services department or to patient organisations is one way to begin the support.
Going forward, it would be prudent for patient organisations and the healthcare community to work together to support the patient through their experience, both in the short and long term. Patient organisations have a key role to play in providing patients with a haven where their fears can be expressed long after they have seen their medical team.
Psychosocial Impacts: Concerns about Body Image

Body image is of great importance as it can be a physical outward sign of being unwell, knowledge that not all patients may wish to share.

Results from the 2016 Lymphoma GPS showed that concerns about body image affected 33% of all respondents. To determine if the year of diagnosis had an impact on concerns about body image, respondents were asked to indicate when they were diagnosed. Those with DLBCL and HL diagnosed between 2010 and 2016 were particularly concerned about body image compared with those diagnosed between 2003 and 2009.

It would appear that while there may be new therapy protocols available, they are not having a positive effect on the body image of patients (see Figure 10).

Concern about body image was considerably higher during treatment compared with before treatment for all subtypes except CLL.

While there was a decline reported following treatment, the decline was not as marked as expected (see Figure 11).

In some countries, concern about body image was higher than in others. Figure 12 shows the countries where concern was more noticeable.

Respondents living in the USA with CLL (47%) and WM (52%) had the highest level of concern about body image compared with the other subtypes. In Italy, respondents with HL (26%) had the highest level of concern about their body image.

Figure 10. Concerns about Body Image Based on Year of Diagnosis, %

Source: 2016 LC Global Patient Survey
CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; WM = Waldenström’s macroglobulinaemia

Figure 11. Concerns about Body Image Before, During and After Treatment, %

Source: 2016 LC Global Patient Survey
CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; WM = Waldenström’s macroglobulinaemia
Psychosocial Impacts: Problems Getting Life or Health Insurance

Findings from the GPS showed that obtaining life or health insurance was increasingly problematic compared with findings from the 2014 GPS. Having adequate life or health insurance may be a key factor in determining what treatment the patient will receive. LC examined whether some subtypes faced more challenges than others when seeking life or health insurance.

Prior to treatment, respondents did not appear to have difficulty obtaining life/health insurance. However, during treatment, some subtypes in some countries had more challenges compared with others. For example, 88% of respondents in Argentina with HL, 50% of respondents with DLBCL in Lithuania, and 44% of respondents with FL in Canada and 44% of respondents with FL in Japan had greater issues compared with other subtypes in those countries (see Figure 13). Following treatment, 88% of respondents with HL in Argentina, 67% of respondents with FL in Japan and 56% of respondents with HL in Spain had issues with obtaining life/health insurance (see Figure 14). Facing challenges in obtaining life/health insurance will only compound issues already confronting patients. Consequently, efforts need to be made to ensure patients have someone to talk to who can help them navigate their respective country’s healthcare system to obtain the best care both inside and outside the clinic.

Physical Adverse Effects

With the introduction of new therapies, the hope is that patients will not only achieve more enduring remissions but that they will also experience fewer adverse effects. To determine if newer therapies did result in any changes, respondents were asked to indicate when they were diagnosed. Although physical adverse effects appeared to be more prevalent between 2010 and 2016 compared with 2003 and 2009, the differences were not marked. When looking at the country of residence, some subtypes appeared to be more affected by physical adverse effects compared with others. This was particularly noticeable in respondents with HL in Argentina (56%), Italy (45%) and Spain (39%) and those with FL in Japan (44%) (see Figure 15).
Medical Concerns

In the 2016 Lymphoma GPS, respondents were asked if they had experienced any medical concerns as a result of their lymphoma or treatment. With the introduction of newer molecules, LC wanted to find out, in general, if medical issues by subtype were similar between 2003 and 2009 compared with 2010 and 2016 (see Figure 16). The biggest decline was seen in WM which went from 13% between 2003 and 2009 to 9% of respondents reporting medical issues between 2010 and 2016. HL had the biggest increase in medical concerns between 2010 and 2016 (23%) compared with 2003 and 2009 (19%).

When looking at the prevalence of medical concerns by subtype based on country of residence, a somewhat different picture emerged among respondents with WM in the USA as they reported facing a high degree of medical issues (42%). Respondents with HL in Argentina (49%) and Italy (41%), and those with FL in Japan (43%) also reported a high degree of medical issues (see Figure 17).

While it is encouraging that efforts are underway to develop new therapies that will provide a more targeted approach to treatment, what is of concern is that results from clinical trials still show that physical effects such as fatigue and physical weakness (asthenia) remain common adverse effects. Monitoring, education and follow up is critical especially with oral therapies.

New therapies, regardless of how effective they are, need to have fewer adverse effects so patients do not have the added burden of not only having to deal with these effects but also all the other factors such as psychosocial issues (e.g., fear of relapse) and barriers to treatment (e.g., financial concerns) that come with a diagnosis of lymphoma.
Support from Healthcare Professionals

In the 2016 Lymphoma GPS, only 30% of respondents indicated that their doctor had been able to help them with their physical and emotional issues. LC wanted to determine if the level of support received from doctors varied by subtype and country. Overwhelmingly, respondents, regardless of their subtype and country of residence, indicated that their doctor had only been able to help them somewhat or not at all (see Figure 18).

So where are patients getting their information from?

After doctors, online resources are the most frequently accessed sources of information (60%) followed by patient organisations (33%) (see Figure 19).

Given that 80% of respondents indicated that their doctor was their primary source of information but only 30% indicated that their doctor had been able to help means patients have to find information on their own.

While the internet is a wonderful resource, it is not possible to ensure that all information patients gather is relevant or even helpful, and this is of greater concern in light of the many subtypes of lymphoma. This situation presents an opportunity for patient organisations to play a greater role in reaching out to patients and the healthcare community to help patients get the information they need. Doctors cannot fulfil the role entirely on their own.
Awareness and Understanding about Subtype

Key to ensuring effective treatment and care is for patients to know their lymphoma subtype. Non-Hodgkin lymphoma (NHL) or indolent lymphoma are not descriptive, i.e., they do not describe the subtype. As reported, 60% of respondents used online resources to find information about their lymphoma. However, if patients were told they have NHL, they will not know what information to look for. Importantly, while 73% of respondents said they were told what their subtype was, only 57% indicated they had understood what they were told.

When looking at the GPS results to see if there was a difference in the understanding by subtype based on age, results showed that the lack of understanding about the different subtypes was fairly consistent among the different age groups at 30% or higher (see Figure 20). Lack of understanding was highest for DLBCL among those aged 30 to 45 years (49%) followed by 42% in those aged 45 to 65 years. Among those aged 18 to 29 years, the highest level of understanding appeared to be for FL as only 14% indicated lacking understanding. While lack of understanding about WM was high in those aged 46 to 65 years (40%), understanding among those aged 65 years and older was somewhat better as only 32% appeared to lack understanding.

In general, those diagnosed between 2010 and 2016 had a better understanding about the potential adverse effects associated with treatment options compared with those diagnosed between 1996 and 2009. The level of understanding of potential adverse effects was higher in all age groups than the lack of understanding (see Figure 21). Among respondents with CLL aged 46 to 65 years and those 65 years and older, the level of understanding and lack of understanding about the adverse effects associated with CLL therapy protocols was similar indicating that this group of patients may need additional support and information about the management of adverse effects. Among those aged 18 to 29 years with FL, the lack of understanding was considerably higher than the level of understanding about potential adverse effects.

Greater efforts are needed in helping patients know their subtype. LC’s Know Your Subtype campaign is an excellent way to help spread awareness that lymphoma comprises more than 60 subtypes that have unique characteristics requiring therapy to be tailored to the subtype. Patients need to be encouraged to ask their doctor what subtype they have and to realise that NHL itself does not provide them with helpful information.

When talking to HCPs about this topic, LC is often told that HCPs tell patients first they have NHL and then they may tell them what subtype they have. It is important to know that once a patient is told they have NHL and it is a cancer, their capacity to take in more information is limited. It is far better to tell them first what subtype they have and, if so desired, explain later that it is an NHL to ensure the intake of the most important information is not affected.
Figure 20. Patients Not Understanding Subtype by Age, %

<table>
<thead>
<tr>
<th>Age Group</th>
<th>CLL (36%)</th>
<th>DLBCL (49%)</th>
<th>FL (42%)</th>
<th>WM (36%)</th>
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<tbody>
<tr>
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<tr>
<td>30-45</td>
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<tr>
<td>46-65</td>
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</tr>
<tr>
<td>65+</td>
<td></td>
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</tbody>
</table>

Source: 2016 LC Global Patient Survey. CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; UK = United Kingdom; USA = United States of America; WM = Waldenström’s macroglobulinaemia

Figure 21. Lack of Understanding of Potential Adverse Effects by Age Group, %

<table>
<thead>
<tr>
<th>Age Group</th>
<th>CLL (79%)</th>
<th>DLBCL (80%)</th>
<th>FL (75%)</th>
<th>WM (78%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understood</td>
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<td></td>
<td></td>
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<tr>
<td>Did not understand</td>
<td></td>
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<tr>
<td>18-29</td>
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<td>65+</td>
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</tbody>
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Source: 2016 LC Global Patient Survey. CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; UK = United Kingdom; USA = United States of America; WM = Waldenström’s macroglobulinaemia
Moving Forward

The 2016 LeIP Report Card on Lymphomas shines a light on the many challenges that patients with CLL, DLBCL, FL, HL and WM face. While great advances are being made in the development of therapies that are more targeted and understanding about the biology of the different subtypes is improving, patients continue to be confronted by barriers to receiving effective treatment as well as long-lasting psychosocial, physical and medical concerns.

Barriers to treatment such as financial concerns and lack of personal support continue to plague patients. Psychosocial effects are of growing concern to patients with the fear of relapse being one of the common factors affecting all patients, regardless of subtype.

Although it is encouraging to see newer, more targeted therapies being developed, what is less encouraging is that they continue to be accompanied by significant adverse effects.

Findings from the 2016 GPS showed that many of the psychosocial effects last well past eight years. Consequently, greater efforts are needed to address the needs of patients so they receive effective support throughout their full treatment cycle ensuring they feel stronger and can focus on their health in a more positive way.

Patients continue to rely heavily on doctors for support yet they are not able to help all patients in a satisfactory manner resulting in patients having to rely on their own efforts to find information. Awareness and understanding about the different subtypes needs to improve. It is not enough to tell patients what their subtype is, they also have to understand what it means.

As a Coalition we call for:

1. The development of treatments that do not result in a high degree of adverse effects;
2. Better support systems for patients. We are asking the healthcare community to connect the patient to the local patient organisation(s);
3. Telling patients what subtype they have and then, if necessary, telling them it is a NHL.

In addition, LC will continue to:

1. Monitor and report on the funding/reimbursement and regulatory policy changes as they occur around the world;
2. Maintain the global resource on lymphoma facts and statistics on the LC website including updating information on therapies as they receive both regulatory and funding/reimbursement approval;
3. Continue to ensure that clinical trial information is readily available to the patient community. This will be accomplished by regularly updating the global database and ongoing reporting through the member newsletter.

The Know Your Subtype campaign is an important initiative and LC will continue to promote this. Patients need to know their subtype to ensure they receive the best possible treatment and support. HCPs and patient organisations can play a key role in this endeavour by ensuring subtypes are listed on their respective websites under the heading of “Lymphomas” rather than NHL and helping to spread the word about the Know Your Subtype campaign.

It is the intent of LC to ensure that we continue to provide current therapy protocols and clinical trial information in the LC Global Database so all LC members have timely access to good quality information to share with their patients. As a result, all patients will start from a level playing field of information.
Sources


Acronyms

A therapies have regulatory approval
ABC-type DLBCL activated B-cell type diffuse large B-cell lymphoma
ABVD±R adriamycin, bleomycin, vinblastine, dacarbazine with/without rituximab
BEACOPP bleomycin, etoposide, adriamycin, cyclophosphamide, vincristine, procarbazine, prednisone
BL Burkitt’s lymphoma
BR bendamustine with/without rituximab
BTK Bruton tyrosine kinase
C-MOPP cyclophosphamide, vincristine, procarbazine, prednisone
CHOP cyclophosphamide, vincristine, doxorubicin, prednisone
CHOP-R cyclophosphamide, vincristine, doxorubicin, prednisone, rituximab
CLL chronic lymphocytic leukaemia
CVP-R cyclophosphamide, vincristine, prednisone, rituximab
DLBCL diffuse large B-cell lymphoma
ESMO European Society of Medical Oncology
FL follicular lymphoma
GCB-type DLBCL germinal centre B-cell type diffuse large B-cell lymphoma
GPS Global Patient Survey
HL Hodgkin lymphoma
LC Lymphoma Coalition
LeIP Lymphoma eInformation Project
LR lenalidomide with/without rituximab
MCL mantle cell lymphoma
NCCN National Comprehensive Cancer Network
NHL non-Hodgkin lymphoma
PI3K phosphatidylinositol 3-kinase
PTCL peripheral T-cell lymphoma
R therapies funded/reimbursed
RFND rituximab, fludarabine, mitoxantrone, dexamethasone
SCT stem cell transplant
UK United Kingdom
USA United States of America
WM Waldenström’s macroglobulinaemia

1 The five subtypes reviewed in the 2016 LeIP Report card are: chronic lymphocytic leukaemia (CLL), diffuse large B-cell lymphoma (DLBCL), follicular lymphoma (FL), Hodgkin lymphoma (HL) and Waldenström’s macroglobulinaemia.  
2 The 12 LC member countries reviewed in the 2016 LeIP Report Card are Argentina, Australia, Canada, France, Italy, Japan, Lithuania, Serbia, Spain, New Zealand, United Kingdom and United States of America.
Working together, we can change the lymphoma landscape and achieve more for patients.

While great advances are being made in the development of therapies that are more targeted, and understanding about the biology of the different subtypes is improving, patients continue to be confronted by barriers to receiving effective treatment as well as long-lasting psychosocial, physical and medical concerns.

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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