LYMPHOMA COALITION

Worldwide Network of Lymphoma Patient Groups

LYMPHOMA CARE IN EUROPE

GAPS AND DISPARITIES IN PATIENT CARE

OCTOBER 2017

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Executive summary

Europeans need access to equal, adequate care. Care includes treatment, clinical trials, personal support and credible information.

Lymphoma is among the most active cancers for research as well as the introduction of new therapies, including novel targeted therapies, immunotherapies and a growing array of therapies used in combination. However, most are approved more rapidly in the United States of America (USA) than in Europe. Although the gap has narrowed since 2013, it still takes five to eight months longer, on average, to approve lymphoma therapies in Europe.

The introduction of approved lymphoma therapies at the national level in Europe varies widely in terms of health technology assessment and reimbursement. This leads to ongoing disparities in access to drugs by patients.

While the wide disparities are in novel therapies – particularly in Eastern Europe as well as in some Western European countries – it is concerning that differences were also found in availability of long-standing standard treatments. Shortages as well as the rationing of access to standard chemotherapies are common in some Eastern European countries. This can have serious implications for the care patients with lymphoma receive.

Information on available therapies for each lymphoma subtype is frequently scarce or not publicly accessible. This makes it very difficult for patients in Europe to know which treatment options are available for their specific subtype.

Not all therapies are available through mainstream health services. Some European countries operate special access schemes for novel therapies. These schemes – subject to frequent changes and inconsistencies – are no substitute for proper inclusion of effective therapies in national formularies. These factors contribute to making access more complex, place additional burden on healthcare professionals and create disparities among patients.

Clinical trials are critical for improving lymphoma treatment, but wide disparity in availability was found. While there are considerably more phase II and III lymphoma trials in the USA than in Europe – 479 versus 281 – the picture across Europe varies substantially, with Italy, Germany, France, the UK and Spain involved in approximately half of the total number of lymphoma trials. Moreover, rare lymphoma subtypes appear underserved by research compared with the most common forms of lymphomas.

Disparities in treatment among patients have a variety of reasons beyond difficulties with access to therapies or clinical trials. Although the wait time to treatment and financial concerns present particular challenges, the biggest barrier to adequate treatment in Europe for patients with lymphoma and their caregivers is the lack of personal support.

Doctor-patient communication is another key issue. Two in five people affected by lymphoma in Europe do not understand the nature of their particular lymphoma subtype and/or do not know how to manage side effects after their initial visit to the doctor. A majority of patients with lymphoma do not receive the expected support when contacting their physicians to discuss their emotional and physical concerns.

European healthcare systems typically do not consider patients' quality of life as much as they should. Many factors affect a patient's daily life and psychosocial well-being but fear of relapse and fatigue – which can be a lifelong condition for patients with lymphoma – dominate the concerns of patients.

European patients report strong interest in accessing information and support from a variety of sources. They are especially keen to be directed by their healthcare provider towards credible information on the internet as well as to lymphoma patient organisations. Findings from the 2016 Lymphoma Global Patient Survey showed that support from patient organisations appeared to meet the needs and expectations of a large majority of European patients.

73% of respondents had limited knowledge of lymphoma prior to diagnosis.

Introduction

Lymphoma, a group of cancers that arises in the lymphatic system, occurs when lymphocytes develop abnormally or fail to die when instructed.

There are more than 80 subtypes of lymphomas that have very different biology making this a complex group of cancers.

Despite being the most common haematological cancer – the most common cancer in adolescent and young adults as well as the fifth most common adult cancer in Europe – public awareness of lymphoma is low compared with that of leukaemia and solid tumours such as breast, lung and colon cancers.

The 2014 Lymphoma Global Patient Survey (GPS) found that 73% of respondents had limited knowledge of lymphoma prior to diagnosis.

The diversity of lymphomas has been uncovered only relatively recently due to advances in biological research, particularly genetic understanding. Some lymphomas are aggressive while others are indolent but have a higher relapse rate. Many different treatment strategies have emerged for the lymphoma subtypes, and continue to emerge, as much research is underway in what is one of the most active areas of oncology.

This complexity, however, poses several challenges:

- Lack of expert multidisciplinary teams to identify the lymphoma subtype results in delayed diagnosis as well as treatment.
- Global access to data on the incidence of the lymphoma subtype is minimal in many countries.
- Socioeconomic and geographical inequalities are undoubtedly factors in some people not being diagnosed, not receiving expert care and not being included in clinical trials.

Multidimensional care and wider support that address quality of life have not kept pace with medical advances. Support needs and quality-of-life outcomes are not often evaluated as part of clinical trials and standard treatments. This makes it difficult for patients to identify and access wider physical, medical and psychosocial care.

Patients with lymphoma deserve high-quality, patient-centred care and it is the aim of Lymphoma Coalition Europe (LCE) to highlight the knowledge, support and access gaps in the European region and Israel.

Objectives

Patients with lymphoma in Europe do not all receive the same high standard of treatment and care. LCE set out to examine the extent of the disparities from a multidimensional patient perspective.

Access to new treatments and to clinical trials in the fast-moving lymphoma field are obvious factors to examine, but patients are also disempowered through lack of information and support that can greatly affect their access to care and quality of life. Consequently, access to adequate care – including therapies, clinical trials, personal support and information – is the primary topic of our report.

Lymphoma subtypes are a particularly important focus. Treatments can vary greatly depending on subtype, and we must increasingly monitor how well patients – even those with rare lymphomas – are cared for along these different subtype courses.

Finally, this report draws together these findings and makes recommendations for policymakers, healthcare professionals and patient groups. Advocacy by cancer patient organisations such as LCE and its member organisations has led to far-reaching and sustainable changes in cancer care at national, European and global levels, but it must be based on high-quality evidence.

Methodology

This report uses several sources to generate data on access to lymphoma care in Europe and the patient experience.

Access to treatment and clinical trials

To identify the therapies available[a] in the 28 European countries[b] in which LCE has member organisations, online review of information from medicine agencies, government public health websites, haematology societies and lymphoma research groups was undertaken. In European countries where information was not publicly available national haematology experts, via member organisations, were consulted. It was especially difficult to obtain information in about a third of the countries examined. Latvia, Portugal, Poland and Ukraine were excluded from the analysis as accurate data on access to therapies for those countries were not available. All information presented on therapy access was obtained as of June 15, 2017.

Two classes of therapies were reviewed: novel therapies, i.e., therapies approved for use in treating lymphoma since the introduction of rituximab; and current therapies, i.e., therapies which do not contain novel drugs but are still widely used as standard treatments.

Because treatment and care vary greatly by lymphoma subtype, a comparison on treatment availability was made between the four most common subtypes in Europe: diffuse large B-cell lymphoma (DLBCL), follicular lymphoma (FL), chronic lymphocytic leukaemia (CLL) and Hodgkin lymphoma (HL). Waldenström's macroglobulinaemia (WM), a rare subtype, was also included to highlight challenges with an uncommon disease.

Finally, we identified the therapy-related clinical trials – phase II and III – in each country using these sources: ClinicalTrials.gov, the EU Clinical Trials Register and the World Health Organization (WHO) International Clinical Trials Registry Platform. Clinical trial data contained in the report were obtained up until June 15, 2017.

All the information on access to treatments and clinical trials is available in the Lymphoma Coalition Global Database.

Patient experience

European patient experience data were taken from the 2016 Lymphoma Global Patient Survey (GPS). This survey is conducted every two years to document and understand the lymphoma patient experience. The 2016 Lymphoma GPS received responses from 4,154 patients and caregivers from 72 countries. For this report 2,812 European respondents from 34 European countries were included.

The survey questions used for this report include these factors:

• Barriers to treatment • Treatment side effects • Psychosocial impacts • Patient information and support

[a]A therapy is deemed accessible when it has received marketing approval from the regulatory body (i.e., the European Medicines Agency) and is paid for through public healthcare.
[b]See http://www.lymphomacoalition.org/about-lce/member-organisations#c.

Lymphoma therapies in Europe

Lymphoma, which comprises more than 80 subtypes, has more standard and, in particular, more emerging, novel treatments than most other types of cancer. However, not all lymphoma therapies are available across Europe.

Medicines approval

The world's leading agencies that approve new medical agents for marketing authorisation are the European Medicines Agency (EMA) and the Food and Drug Administration (FDA) in the USA. The EMA is critical for patients with lymphoma in Europe because it approves all cancer therapies centrally in the European Economic Area (EEA).[c] Regulatory agencies in European countries outside the EU apply their own marketing authorisation procedures.

Since the approval of rituximab – the first monoclonal antibody for some lymphoma types – by the FDA in 1997 and the EMA in 1998,[1] there have been striking differences in the time taken to approve a range of lymphoma drugs by the EMA, with delays of several years for some.

Although the gap has narrowed since 2013 with efforts to harmonise the regulatory processes between both agencies,

it still takes, on average, five to eight months longer to approve lymphoma therapies in Europe.

The delay in approvals is partly because pharmaceutical companies usually apply for marketing authorisation in the USA first, which means European patients with lymphoma lag in accessing many treatments available to their American counterparts. The longer approval time by the EMA is also a result of its centralised process for the 28 member states of the European Union, which can result in "clock stops" for reviews. While the EMA evaluates the efficacy and safety of new drugs, it does not directly have the power of marketing approval and its recommendations are passed to the European Commission (EC) for final approval, which is another source of delay.[2]

In an important gain for European patients, the EMA has approved two rituximab biosimilars, Truxima and Rixathon, ahead of the FDA. But the biosimilar market for lymphoma is in its early stages; consequently, it is too soon to evaluate the benefit to the patient directly or the impact biosimilars will have on access to treatments in Europe.

Figure 1 shows the differences in approval times between the FDA and EMA.

[c]The EEA includes the 28 countries of the European Union, as well as Iceland, Liechtenstein and Norway.

Each European country makes its own decisions on price and reimbursement.

There are wide variations in how these very costly treatments reach patients.

Eastern Europe patients have access to less than half of the novel therapies.

Shortages and rationing of access to standard chemotherapies are common and can have serious implications.

Availability of therapies

Approval alone does not make treatment available. Each European country makes its own decisions on price and reimbursement, and there are wide variations in how and when these often very costly treatments reach patients.

Some countries experience many issues following approval by the EMA. Reimbursement procedures – including health technology assessments (HTAs) and price negotiations – can delay the introduction of therapies, while in some countries new drugs may not be considered for reimbursement at all.[3]

Disparities between Eastern and Western European countries

Overall, a larger number of therapies – novel therapies and standard therapies – are available in Western Europe than Eastern Europe.

In several Eastern Europe countries, the position is more acute for novel therapies as patients have access to less than half of the number that are currently available in Western Europe. With standard therapies, the situation is better for Eastern European patients as they officially have access to most of the standard therapies that are available in Western European countries (see Figure 2).

Growing challenges with access to current therapies

While all countries in Western Europe offer access to most current therapies – between 41 in Finland and 47 in Germany – Lithuania and Poland offer access to fewer than 35. However, there is not a consistent East-West divide as the Czech Republic, Slovenia and Turkey offer access to more than 40 standard therapies, the same as the lower tier of Western European countries (see Figure 3).

Among the standard therapies, it's worth noting that rituximab, which is now on the WHO's Model List of Essential Medicines, is not available to treat FL in the Russian Federation, and we found no evidence of rituximab maintenance availability for FL in Bulgaria, Poland and Slovenia. In Slovakia, it is only available through a special access scheme.

While officially available, shortages and rationing of access to standard chemotherapies are also common in some East European countries and can have serious implications for the care of patients with lymphoma.

"More and more chemotherapy drugs are no longer available on the Bulgarian market because of price disagreement between the National Health Insurance Fund and the pharmaceutical companies. For instance, several components of ABVD (adriamycin, bleomycin, vinblastine, dacarbazine) and BEACOPP (bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine, procarbazine, prednisone) combination therapies are missing, i.e., bleomycin, dacarbazine, etoposide and procarbazine, which makes the use of these standard therapies for HL practically impossible," states Pirinka Petrova, Chair of the Bulgarian Lymphoma Patients' Association.

Figure 1. Differences between FDA and EMA Approval (months)*

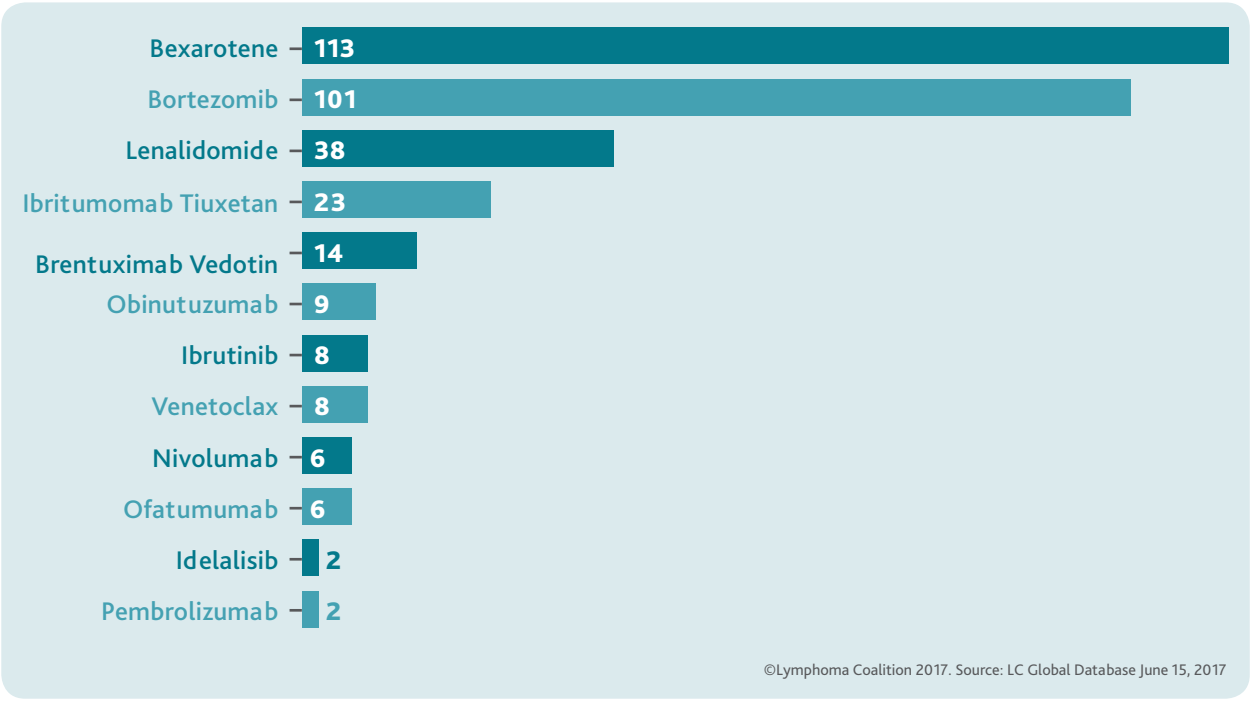
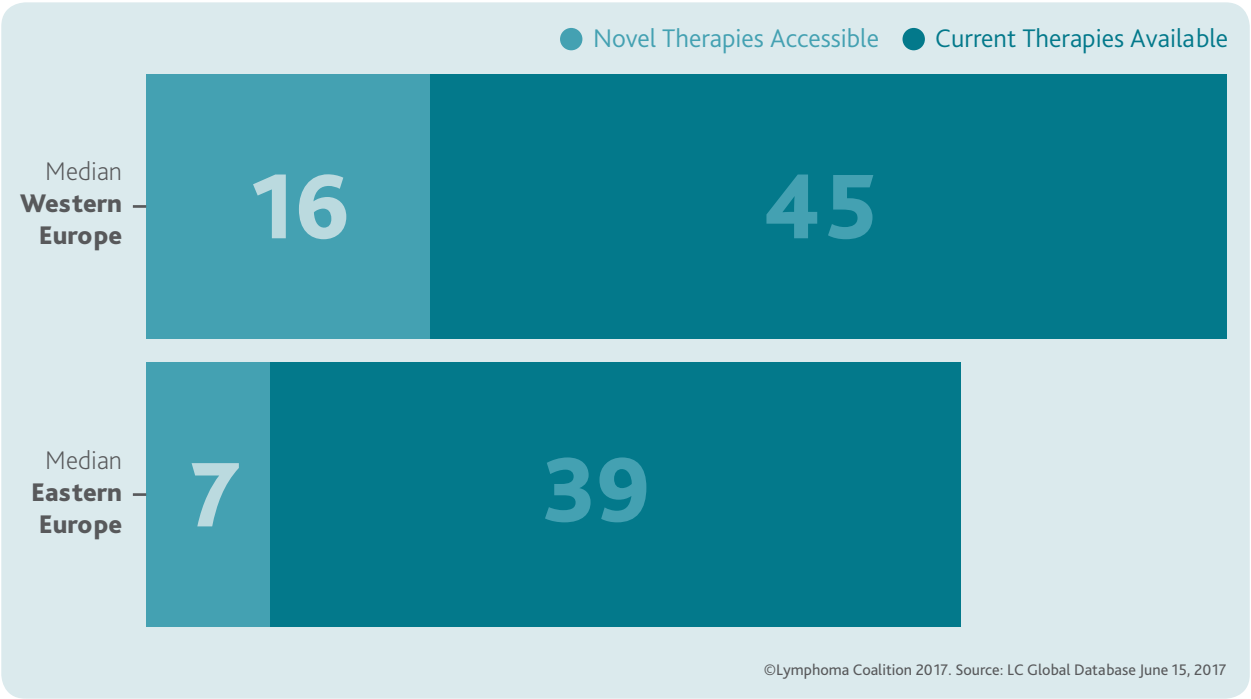


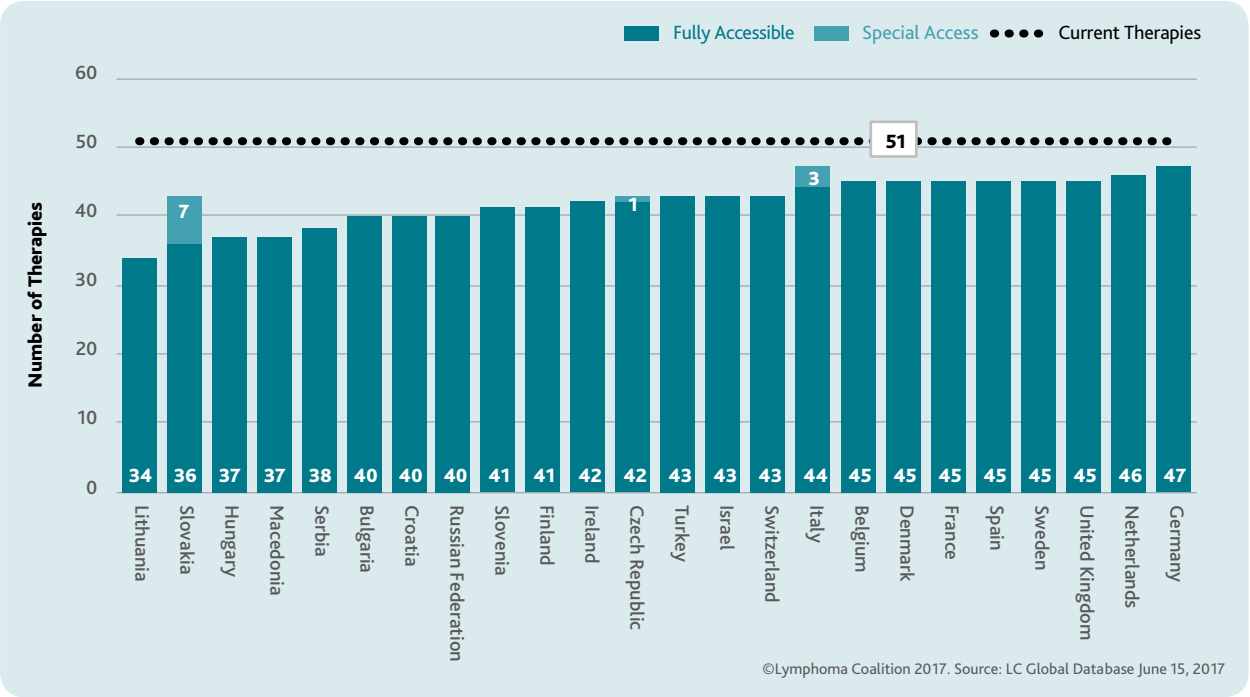
*Figure 1 only looks at regulatory approval (marketing authorisation). Therapies are those which received approval since the introduction of rituximab.

Figure 2. Median Number of Accessible Therapies in Eastern and Western Europe*



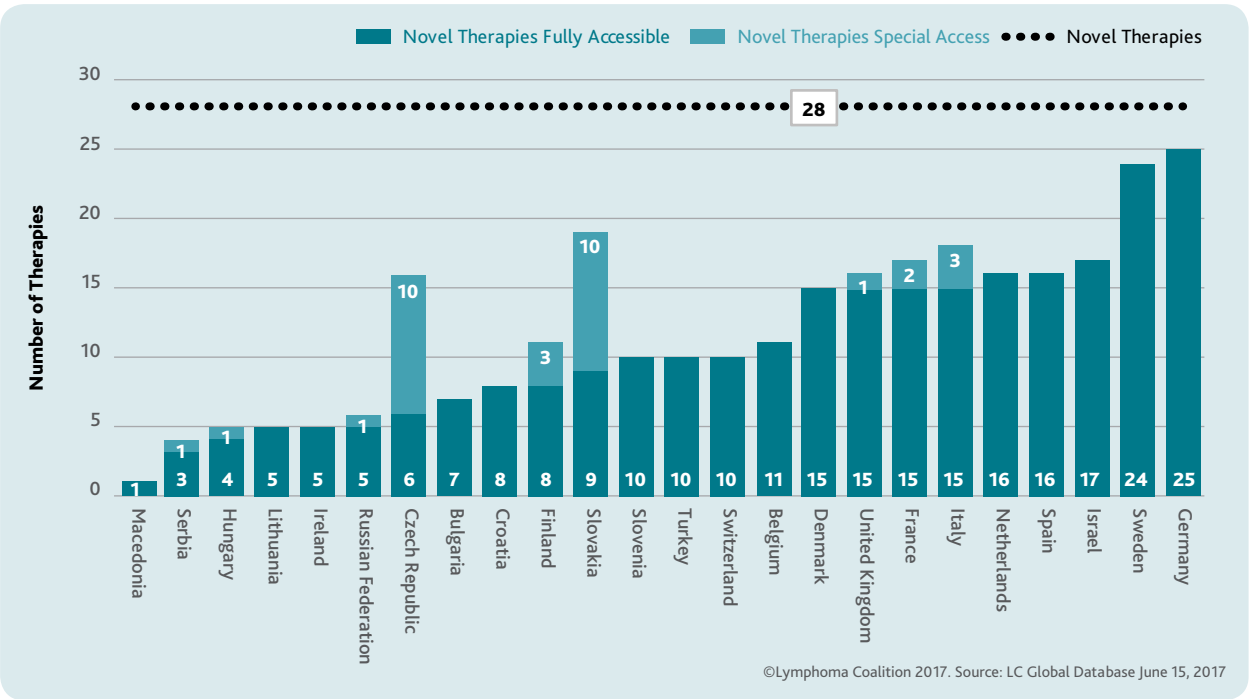
*The table only includes therapies available through publicly funded healthcare and does not include those available through special access schemes.

Figure 3. Availability of Standard Therapies in Europe*



*Includes therapies for all lymphoma subtypes. Information as of June 15, 2017.

Figure 4. Availability of Novel Therapies in Europe*



*Includes therapies for all lymphoma subtypes, not exclusive to the five mentioned in this report. Information as of June 15, 2017.

Access to novel therapies – the widest disparity

Countries in Eastern Europe are most likely to have limited access to new treatments. We found that some countries currently provide access to very few novel therapies: just one in Macedonia, for example, compared with 24 in Sweden and 25 in Germany. But again, as with standard therapies, by no means do all Western European countries provide access to as many novel lymphoma drugs. Notably, we found Ireland and Finland at the lower end (five and eight, respectively) (see Figure 4).

Looking at subtypes and novel therapy availability by country, we found a number of access gaps:

Hodgkin lymphoma (HL)

Access to nivolumab, an immunotherapy used to treat relapsed/refractory HL, is limited in many European countries, although it did receive European approval in November 2016. Nivolumab is not accessible through mainstream health services in any Eastern European country and in only five countries in Western Europe. While the comparator drug for nivolumab – brentuximab vedotin – is widely available, Spain, Macedonia, Russia and Slovakia report no availability.

Follicular lymphoma (FL)

Access to idelalisib, obinutuzumab maintenance and obinutuzumab-bendamustine – important options for patients whose disease has progressed following previous treatments – is heavily restricted in Eastern Europe; no countries except the Czech Republic have availability. These three drugs are also limited in Western Europe with only six countries offering obinutuzumab maintenance, seven obinutuzumab-bendamustine and nine idelalisib.

Diffuse large B-cell lymphoma (DLBCL)

Pixantrone is the only novel therapy with regulatory approval available for this subtype in Europe. Although pixantrone received regulatory approval from the EMA in 2012, it is not widely available throughout Europe.

Chronic lymphocytic leukaemia (CLL)

This subtype has the most options with novel therapies – some of them recently approved – but access to these drugs is limited. We found almost no country in Eastern Europe offering FCO (fludarabine, cyclophosphamide, ofatumumab), IBR (ibrutinib, bendamustine, rituximab), idelalisib-ofatumumab and venetoclax, and only a minority of countries in Western Europe. Access to other CLL drugs is generally wider in Western Europe, while only a few Eastern European countries offer bendamustine-ofatumumab, idelalisib-rituximab, ofatumumab and ofatumumab-chlorambucil.

Waldenström's macroglobulinaemia (WM)

While ibrutinib is the only novel therapy that has received EMA regulatory approval for WM, few European countries offer access to this therapy. It is mostly not available in Eastern Europe – except through special access schemes in the Czech Republic and Serbia – and we found evidence of funding in only seven Western European countries. Other therapies are being used off-label to treat this disease – mostly in Western Europe – but information is scarce. As a result, there is legal uncertainty and a lack of transparency about treatment options available to patients for this rare subtype.

For a complete listing of therapies by country available for each subtype, go to the Lymphoma Coalition Global Database.

Early and special access schemes allow patients with a clear unmet medical need access to drugs that have not yet been approved by the EMA or included on the national reimbursement list.

Special access schemes

Not all therapies are available through mainstream health services and a number of countries offer access to some lymphoma treatments – both novel and current therapies – through special access schemes as evidenced in Figures 3 and 4.

Early and special access schemes allow patients with a clear unmet medical need access to drugs that have not yet been approved by the EMA or have not yet been included on the national reimbursement list. These schemes, which are usually reserved for patients who have no other treatment options, help shorten the access time. However, they contribute to making standard access systems more complex and difficult to understand for patients. They may also create legal uncertainty as well as an additional administrative burden for the prescribing physician.

This is the case in Slovakia, as Miroslava Fövényes, chair of the local lymphoma patient organisation Lymfoma Slovensko, notes:

> “Our system of exceptions applies to all drugs which are not on the reimbursement list. If the drug is registered in the country but not on this list, the doctor has to ask for approval for each patient. There is no legal right for the patient and the decision is made by the insurance company. Our haemato-oncologists are also burdened with extra administrative work.”

Even early access schemes like the French Temporary Use Authorisation (ATU) system create paradoxical situations as illustrated by Guy Bouguet, President of the patient organisation France Lymphome Espoir:

> “The ATU system allows early access to drugs not yet covered by a marketing authorisation, but it does not cover the period between the European regulatory approval and the inscription of the drug on the French reimbursement list. As a result, patients who need treatment during this intermediary period – which can last for months – are not covered by any legal access scheme.”

Clinical trials in Europe

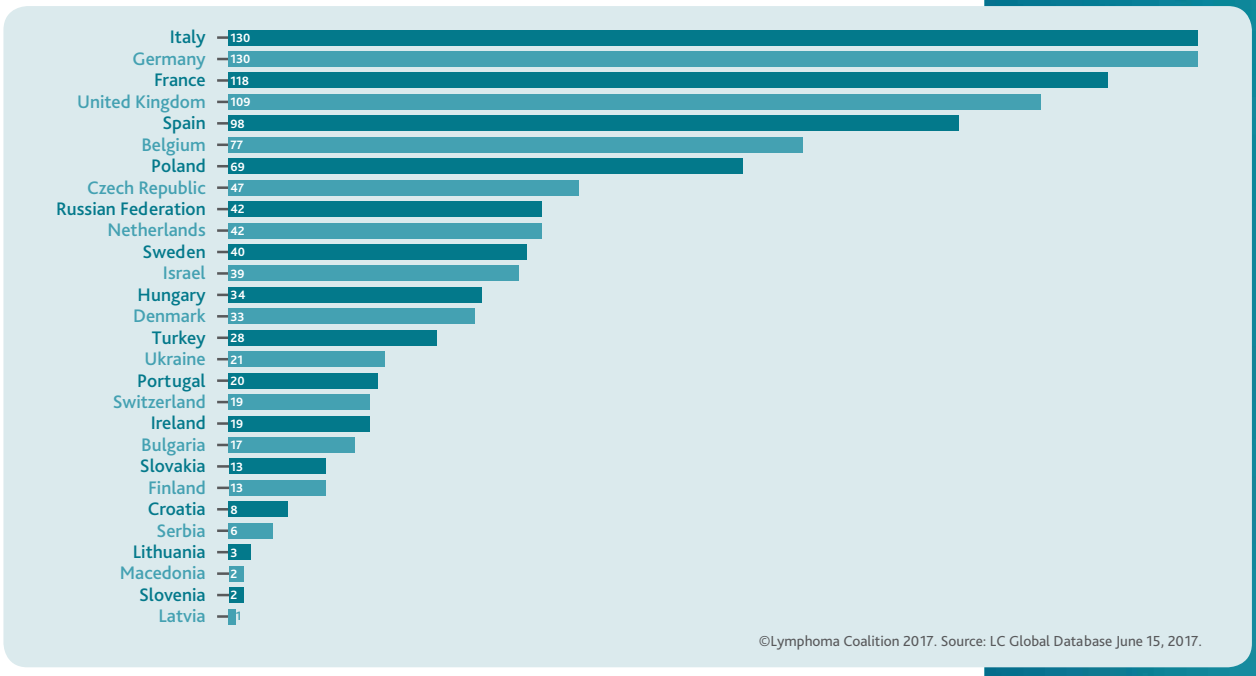
Clinical trials are crucial for the development of new therapies in lymphomas, especially for the subtypes with few or no effective treatment options. They also offer patients with lymphoma a way of gaining early access to new therapies. For some patients with lymphoma, participation in a clinical trial may be the only available treatment option.

More lymphoma trials are in the USA than in Europe – 479 versus 281

Geographical disparities in the availability of clinical trials

Considerably more lymphoma trials are in the USA than in Europe – 479 versus 281 – which is not surprising given that the USA hosts about half of the global clinical trial sites. However, the percentage of patients with cancer registered in trials is often higher in the major European countries.[d] The picture across Europe varies substantially with Western European countries running many more lymphoma trials than Eastern European countries (274 vs. 101). Italy, Germany, France, the UK and Spain have the highest number of lymphoma trials, about half of the total number in Europe (see Figure 5).

Figure 5. Number of Lymphoma Trials by Country in Europe



[d]The UK's National Cancer Research Institute reported in 2010 that fewer than one in 20 American patients with cancer participated in trials, compared with one in six in the UK (which was the highest in Europe). https://www.ncri.org.uk/wp-content/uploads/2013/09/NCRI-Press-Release-2010-7Nov.pdf

About 75% of all clinical trials are for 6 subtypes:

1. CLL
2. FL
3. DLBCL
4. MCL
5. MZL
6. HL

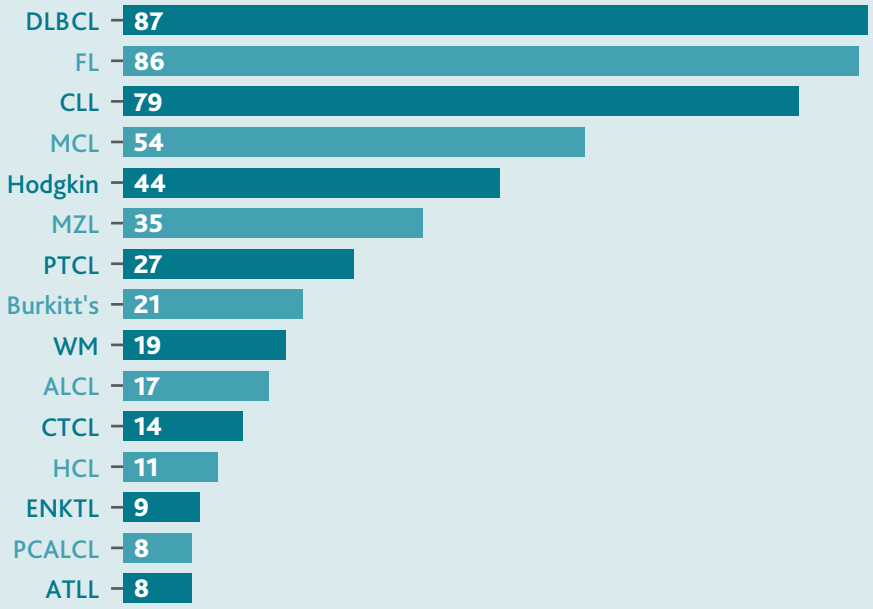
Fewer than 10 trials for:

- ATCL
- PCALCL
- ENKTL

Clinical trials by subtype: rare lymphomas underserved

Analysis of European clinical trials for 15 lymphoma subtypes reveals further variation (see Figure 6). About 75% of all clinical trials are carried out for six subtypes – CLL, FL, DLBCL, MCL, MZL and HL. Three – DLBCL, FL and CLL – account for nearly half of all clinical trials among these 15 subtypes. Fewer trials are active for the remainder, with particularly low numbers – fewer than 10 trials – for adult T-cell leukaemia/lymphoma (ATLL), primary cutaneous anaplastic large cell lymphoma (PCALCL) and extranodal NK/T-cell lymphoma (ENKTL). Other rare subtypes such as WM, anaplastic large cell lymphoma (ALCL), cutaneous T-cell lymphoma (CTCL) and hairy cell leukaemia (HCL) have fewer than 20 trials. These numbers highlight that rare subtypes are underserved by research compared with the most common forms of lymphoma.

Figure 6. Number of Clinical Trials by Lymphoma Subtype in Europe



©Lymphoma Coalition 2017. Source: LC Global Database June 15, 2017.

Patient experience

The 2016 Lymphoma GPS asked patients with lymphoma and their caregivers a range of questions about their experience with treatment, care and the effect on their physical, psychological and social well-being. The following analysis is based on the answers of European respondents.

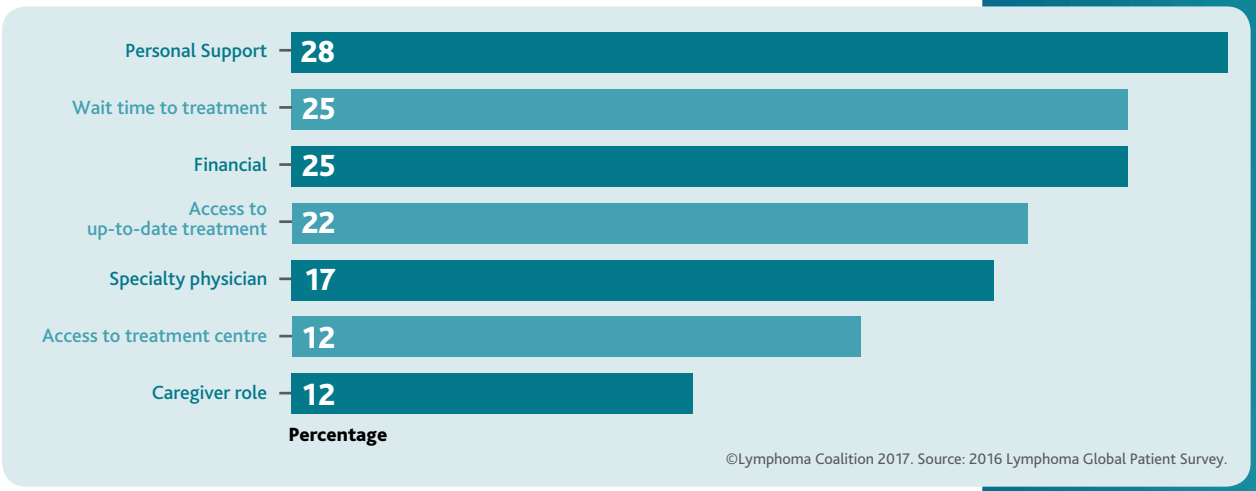
Barriers to care

Disparities in treatment among patients have a variety of reasons beyond difficulties in accessing treatments or clinical trials. We found that patients and caregivers considered the lack of personal support the biggest barrier to adequate treatment in Europe, suggesting that this important aspect of care may be overlooked in many European healthcare systems (see Figure 7). This can comprise a range of issues, including lack of support for physical and emotional needs, and lack of communication and information.

Wait time to treatment and financial concerns create particular challenges for patients with lymphoma. Regional disparities within countries can indeed make it difficult for patients with lymphoma to receive optimal care close to their home, which may entail lengthy and expensive travel to another hospital. Moreover, living with lymphoma and managing treatment and related fatigue can have an impact on the patient's ability to work.

Like many patients with cancer, access to specialty physicians and treatment centres is a concern. As well, in keeping with treatment variability across Europe, as we have reported, access to up-to-date treatments is a significant barrier.

Figure 7. Barriers to Up-to-Date Treatment in Europe*



*Approximately half of the respondents (n = 1,406) answered the GPS question on barriers to treatment.

Patients and caregivers considered the lack of personal support the biggest barrier to adequate treatment in Europe.

About 75% said they experienced fatigue

Fatigue is a long-term side effect which most have to live with for the rest of their lives

Over 50% reported hair loss

Quality of life

European healthcare systems typically do not take into account the patients' quality of life. While the main ambition for clinicians is to extend life, for patients with lymphoma, physical and psychosocial well-being are also considered.

Fatigue – a major issue

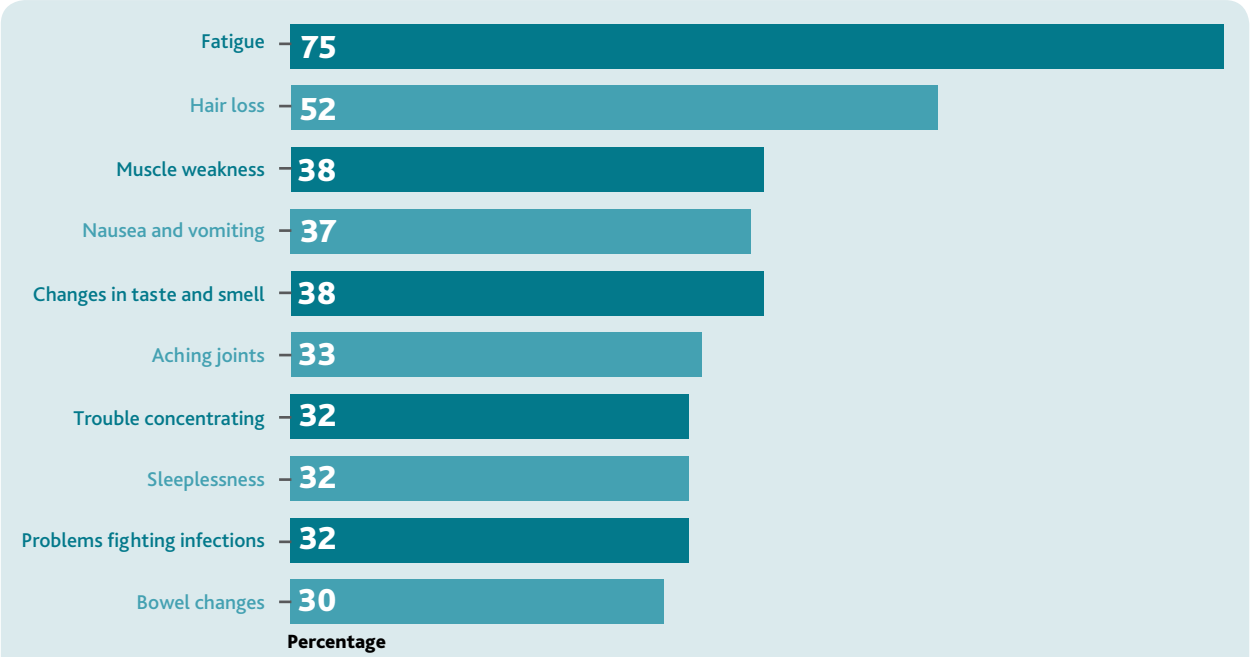
Many patients with lymphoma experience a variety of side effects as a result of the disease and its treatment but fatigue stands out as a major concern.

About 75% of European GPS respondents said they experienced fatigue and over half reported hair loss. Let's remember that hair loss is the outward evidence of cancer and until this occurs many people will not know a patient's situation. More than a third suggested problems related to eating, digesting food and, to a lesser extent, bowel problems. Muscle weakness and joint problems were reported by a third of respondents. Sleep and concentration issues featured for just under a third (see Figure 8).

Lymphoma-related fatigue is often long-lasting, and unlike other forms of fatigue, does not improve after periods of rest. There are several causes of fatigue including side effects from treatment and the stress and anxiety of living with a lymphoma diagnosis. Chronic fatigue is likely to have a negative impact on the physical, psychological and social aspects of quality of life.[4]

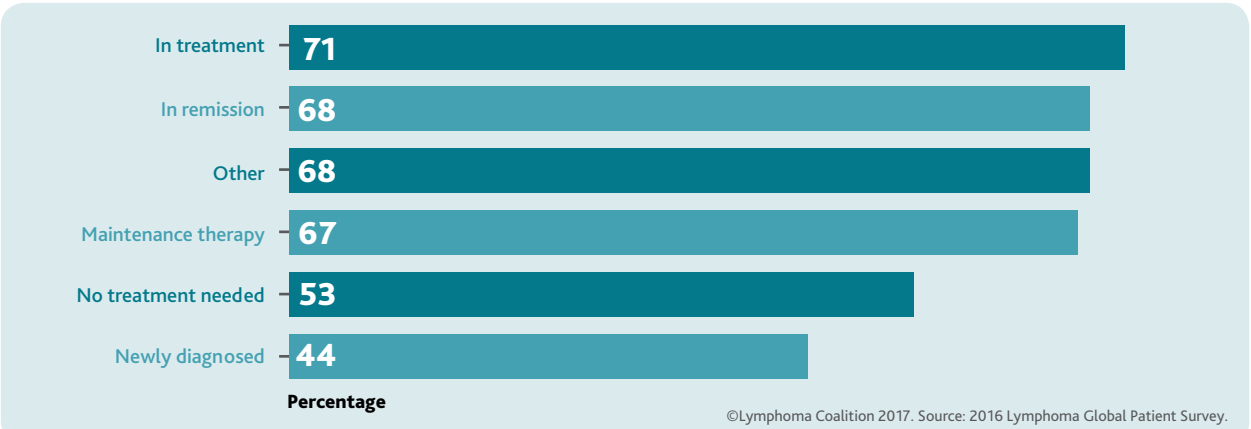
Fatigue is a long-term side effect which most patients have to live with for the rest of their lives as evidenced by the GPS. While the largest proportion of respondents reported fatigue while in treatment, it was only marginally higher than respondents in remission or on maintenance therapy (see Figure 9).

Figure 8. Physical Concerns of Patients with Lymphoma in Europe



©Lymphoma Coalition 2017. Source: 2016 Lymphoma Global Patient Survey.

Figure 9. Fatigue by Stage of Treatment in Europe



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Fear of relapse is the most important issue for patients

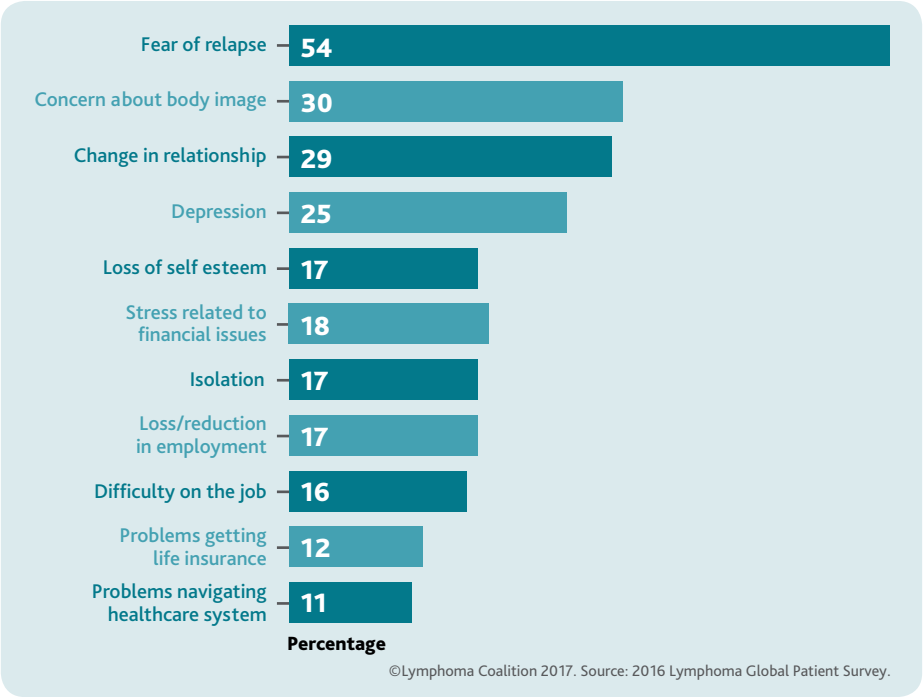
Well-being issues dominated by the fear of relapse

Many factors affect patients' daily life and psychosocial well-being but the fear of relapse is clearly the most important issue for patients.

More than half of the respondents reported fear of relapse as affecting their well-being. This may contribute to the reporting of depression that affected a quarter of respondents in Europe (see Figure 10). Other psychological issues such as loss of self-esteem and isolation were also reported. Concerns about changes to body image and relationships with loved ones were other important issues for about 30% of the respondents to the GPS.

Lymphoma diagnosis, treatment and long-term side effects also had an impact on the social and economic situation of respondents and their families. Stress related to financial issues, loss/reduction in employment and difficulties carrying out work all count among the factors that affected the well-being of respondents.

Figure 10. Factors Affecting the Well-being of Respondents with Lymphoma in Europe



©Lymphoma Coalition 2017. Source: 2016 Lymphoma Global Patient Survey.

Patient information and support

High-quality information and support are vital for patients to obtain the best care for their condition and the best treatment options. They help patients make shared decisions with their healthcare team, increase treatment compliance and reduce psychological stress. Patients with lymphoma often look for information and support – both inside and outside their healthcare team – to better understand their condition and help deal with their physical, emotional and social concerns. But the GPS revealed major shortcomings.

Communication between patients with lymphoma and healthcare teams

Given the number of lymphoma subtypes and the wide array of treatments, it is critical that patients with lymphoma understand the nature of their condition. But the GPS revealed that a large number of respondents – about 40% – reported that they left their doctor's office without understanding the characteristics of their subtype. This is a major shortcoming in doctor-patient communication that healthcare professionals must address.

Managing disease and treatment side effects are not always part of the conversation between patients and their physician either. According to the GPS, 39% of respondents did not know how to manage side effects after their initial visit to the doctor.

Further, when contacting their doctor to discuss a range of emotional and physical concerns, two-thirds reported that their physicians were not or were only a limited source of help (see Figure 11).

Figure 11. Proportion of Respondents Helped by their Physician

When patients with lymphoma were asked about getting help with their physical & emotional needs...

3 in 5
did not get all the support they needed from their doctor.

©Lymphoma Coalition 2017. Source: 2016 Lymphoma Global Patient Survey.

40% left their doctor's office without understanding their subtype

39% left their doctor's office without understanding how to manage side effects

2/3 are interested in being directed towards credible internet information

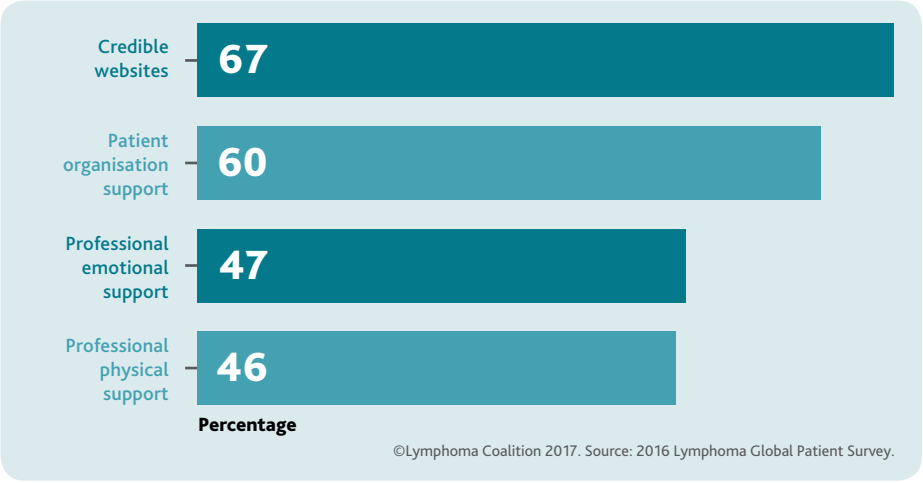
81% reported interest in gaining more treatment information

Other sources of information and support

Respondents reported a high interest in accessing information and support from a variety of sources. When asked in the GPS about being referred by their doctor or nurse to other sources of information and support, two-thirds of respondents indicated interest in being directed towards credible internet information on lymphoma and treatment options.

The GPS results also suggested a strong interest in being referred to lymphoma patient organisations for support and information (60%). Just under half indicated interest in a referral to either physical or emotional professional support (see Figure 12).

Figure 12. Degree of Interest in Receiving Referrals to Other Support in Europe



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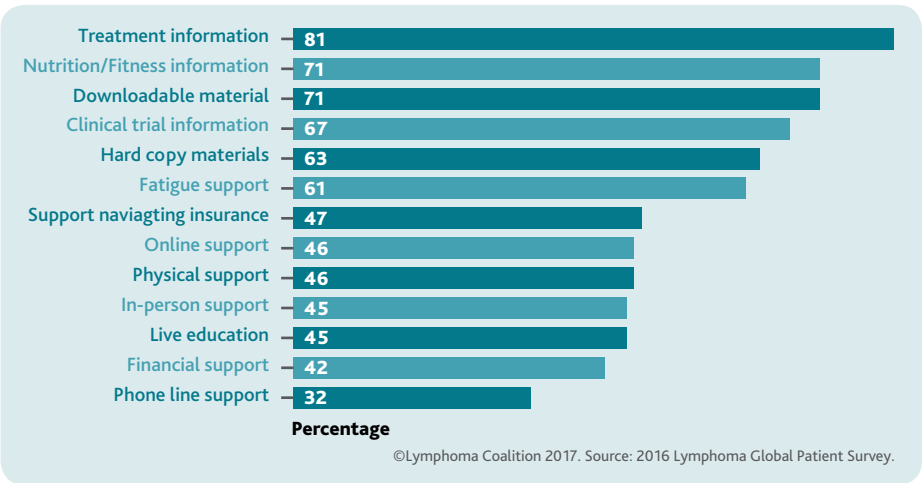
What support are patients looking for?

As for the kind of information and support patients expect, about 80% of the GPS respondents reported interest in gaining more treatment information. Most patients also wanted nutritional and fitness information, information on clinical trials and support to manage fatigue (see Figure 13).

Figure 13. Interest in Patient Organisation Services in Europe



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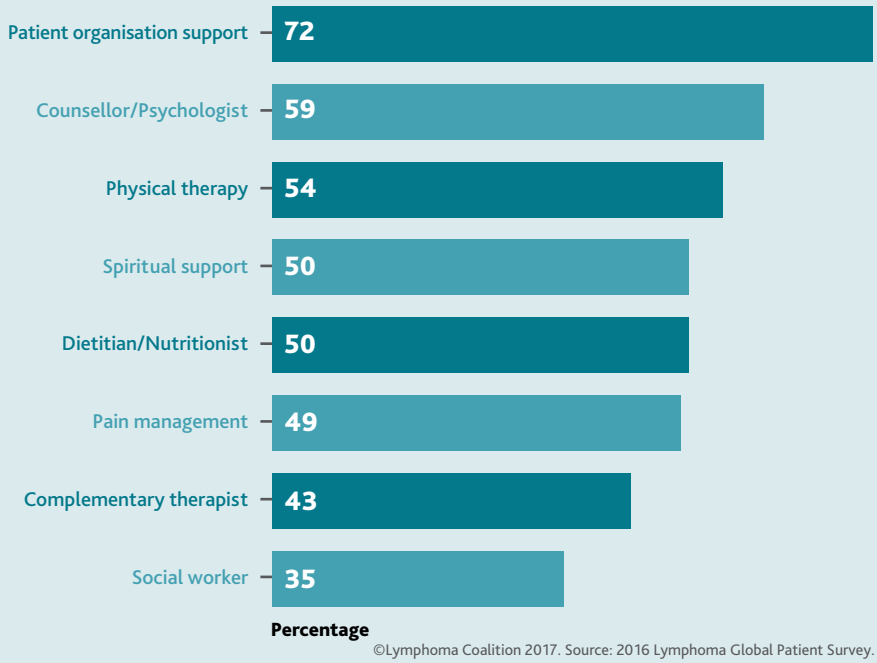
Usefulness of support services

The GPS respondents who had used support services identified patient organisations and related support groups as most helpful with 72% expressing a high degree of satisfaction. More than half of the respondents indicated they also benefited from support given by counsellors or psychologists and, to a lesser degree, physical therapists. A much smaller proportion of respondents gained useful support from complementary therapists or social workers.

Our data suggest that support from patient organisations meets patients' needs and is complementary to professional support (see Figure 14).

72% identified patient organisations and support groups as most helpful

Figure 14. Usefulness of Support Services in Europe



©Lymphoma Coalition 2017. Source: 2016 Lymphoma Global Patient Survey.

Recommendations

LCE invites the European lymphoma community, national regulators, HTA bodies, decision makers, healthcare providers, healthcare professionals, researchers and pharmaceutical companies to ensure that:

1. All patients with lymphoma in Europe have adequate and timely access to the care they need, without any discrimination, no matter where they live.[e]
2. Lymphoma patient organisations are systematically involved in the decisions about the availability of lymphoma care and treatments across Europe, with the aim of guaranteeing they include the perspective and experience of people affected by lymphoma.
3. Patients with lymphoma have access to accurate information on their specific subtype, their treatment options – including clinical trials – and are involved in the decision-making process when determining the course of their treatments.
4. People affected by lymphoma receive the physical and psychosocial support they need during and after the treatment period.
5. New clinical trial centres are identified in Europe, especially in Eastern European countries. All patients with lymphoma should have the option of participating in a clinical trial whenever it is the best treatment option for their condition.
6. The development and approval of new treatments for underserved lymphoma subtypes becomes a research and regulatory priority in Europe.
7. Healthcare professionals routinely refer patients with lymphoma to local patient organisations at the time of diagnosis.

[e]Lymphoma Coalition Patient Charter of Rights. http://www.lymphomacoalition.org/about-lc/international-lymphoma-patient-charter.

Acronyms

ABVD	adriamycin, bleomycin, vinblastine, dacarbazine
ALCL	anaplastic large cell lymphoma
ATLL	adult T-cell leukaemia/lymphoma
ATU	Temporary Use Authorisation
BEACOPP	bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine, procarbazine, prednisone
CLL	chronic lymphocytic leukaemia
CTCL	cutaneous T-cell lymphoma
DLBCL	diffuse large B-cell lymphoma
EC	European Commission
ENKTL	extranodal NK/T-cell lymphoma add in ENKTL
EEA	European Economic Area
EMA	European Medicines Agency
EU	European Union
FCO	fludarabine, cyclophosphamide, ofatumumab
FDA	Food and Drug Administration
FL	follicular lymphoma
GPS	global patient survey
HL	Hodgkin lymphoma
IBR	ibrutinib, bendamustine, rituximab
HTA	health technology assessment
LC	Lymphoma Coalition
LCE	Lymphoma Coalition Europe
MCL	mantle cell lymphoma
MZL	marginal zone lymphoma
NK	natural killer
PCALCL	primary cutaneous anaplastic large cell lymphoma
PCTL	peripheral T-cell lymphoma
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
WM	Waldenström's macroglobulinaemia

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LYMPHOMA COALITION

Worldwide Network of
Lymphoma Patient Groups

WWW.**LYMPHOMACOALITION**.ORG/EUROPE

Let's all ensure patients with lymphoma have access to accurate information on their specific subtype, their treatment options – including clinical trials – and are involved in the decision-making process when determining the course of their treatments.

know your subtype

Lyfe