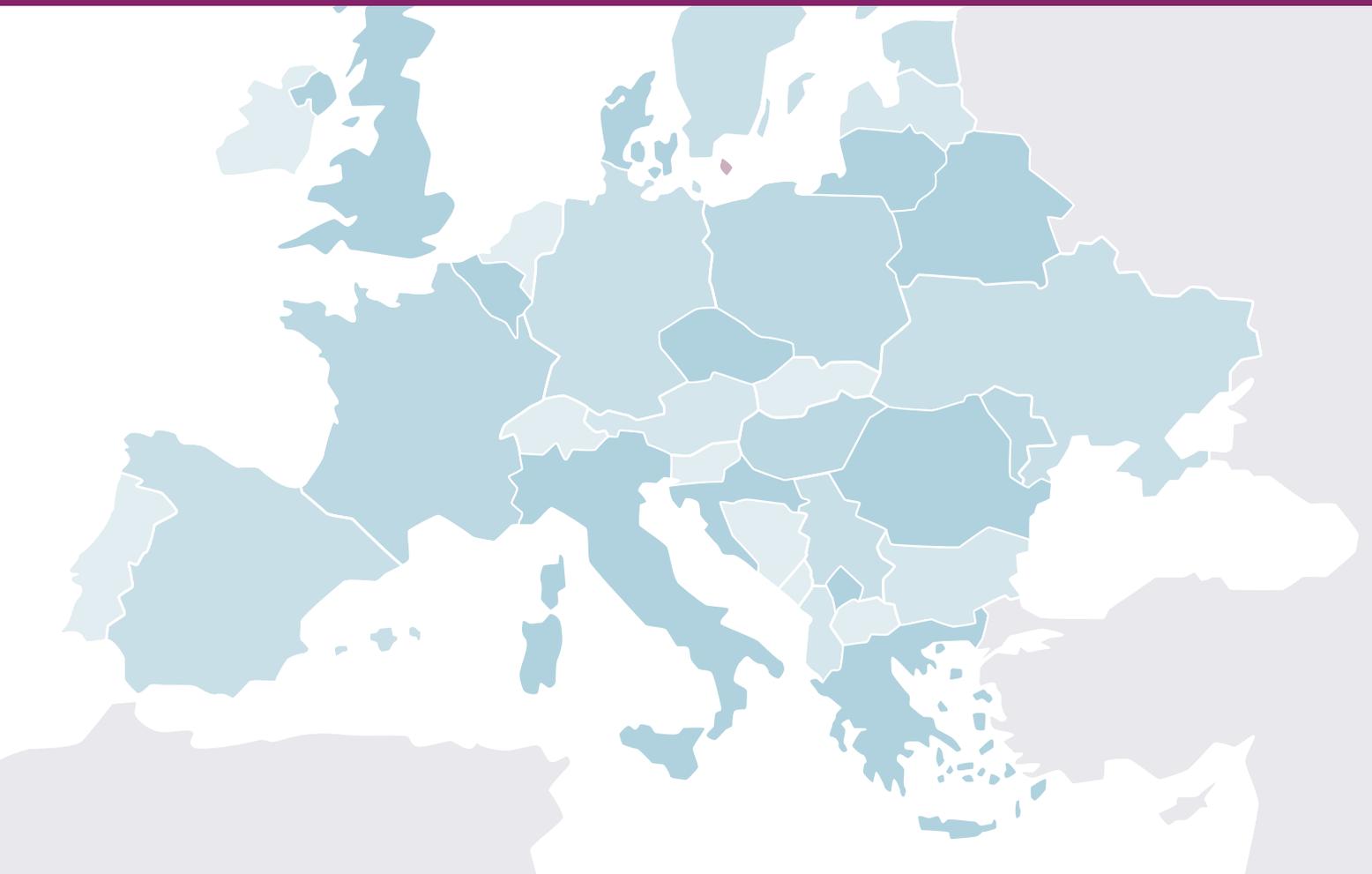


# LYMPHOMA CARE IN EUROPE

**REFLECTIONS ON PATIENT EXPERIENCE  
AND PRIORITIES FOR CARE**

**2022**





## Vision

Equity in lymphoma outcomes across borders.

## Mission

Enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

## ACKNOWLEDGMENTS

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Lymphoma Coalition Europe (LCE) would like to thank all those whose collaboration and support assisted in the development of this report, as well as companies that provided grants to make this report possible.

A special thank you to the patients and their caregivers who took the time to complete the 2020 Global Patient Survey on Lymphomas & CLL. We all learn so much from you.

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The objectives of the 2022 *Lymphoma Care in Europe* report are to:

1. Examine the burden of lymphoma (disease burden and economic impact) in Europe.
  2. Spotlight the experience of patients with lymphoma and why this experience matters for healthcare decision-making.
  3. Identify and make recommendations for future lymphoma advocacy initiatives in Europe.
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# Overview

Across the world, including Europe, the Covid-19 pandemic has greatly affected health budgeting and spending and how governments and health systems have deployed their health resources. The development of the crisis has seen the need for the rapid redeployment of resources across the health sector – building up testing and diagnostic capabilities, providing increased capacity for treatment of patients both in the hospital and community settings, and wide-reaching vaccination programmes. At the same time, many countries have seen significant reductions in non-COVID related services, such as primary healthcare consultations and elective surgeries. The health crisis has had markedly different outcomes across countries and across regions, reflecting the heterogeneous access to health services, differing vulnerability to diseases, and the diversity of socio-economic situations.

**However, the COVID 19 pandemic should not make us lose sight of the major impact of the ever-present burden of lymphoma, including chronic lymphocytic leukaemia (CLL), and the necessity to bring the needs of patients with lymphoma to the attention of policymakers.**

The 2019 *Lymphoma Care in Europe* report focused on exploring disparities in lymphoma care. This 2022 report builds on this theme by examining real-world information on the burden and economic impact of lymphoma in Europe and the experiences of patients with lymphoma. It is hoped this will serve as a guide for policy and decision-makers in planning and equitably allocating health resources to improve the health of patients with lymphoma.

## METHODOLOGY

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For this report, Lymphoma Coalition Europe (LCE) reviewed the burden of lymphoma in Europe, including Israel and Turkey\*, by examining the regional differences in incidence and mortality data in 2020 sourced from the Global Cancer Observatory and the European Cancer Information System (ECIS).<sup>3-4</sup> The data is based on national estimates of cancer incidence and mortality in 2020, from the major cancer sites in European countries.

LCE then looked at the economic burden of lymphomas across Europe by reviewing studies that have examined the direct and/or indirect costs of lymphomas, to help provide some insight into the cost of care and gaps in the health system where improvements can be made.

The experience of patients with lymphoma was examined by reviewing existing literature and the Lymphoma Coalition 2020 Global Patient Survey on Lymphomas & CLL (2020 GPS), in the following areas: experience and issues at diagnosis; information, guidance, and support; quality of life; and the impact of Covid-19 on their experience.

Further analyses were performed using health expenditure as a percentage of the Gross Domestic Product (GDP) based on the most recent data available in the World Health Organization Global Health Expenditure Database (GHED), and the 2020 GPS.<sup>34,52</sup> Countries **with below average health expenditure (BA-HE)** were compared with countries with above **average health expenditure (AA-HE)** to assess for any differences.

## HIGHLIGHTS

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### LCE determined that:

- Based on reviewed data, lymphomas still constitute a major cancer burden in Europe with 2 out of 5 patients developing lymphoma in their working years, which impacts workplace productivity.
- Lymphomas are costly diseases. This includes the direct costs of patient care and the indirect costs of care accrued by both patients and their caregivers, as well as lost productivity. Aggressive lymphomas are more costly than indolent lymphomas.
- The patient experience is an extremely valuable piece of evidence for decision-making in healthcare settings, contributing both to the clinical understanding of the disease and the real-world effect of lymphoma and its treatment on patients and caregivers.
- The pathway to diagnosis varies per individual patient, with some patients experiencing a long and stressful route to their diagnosis, suggesting inequalities in care.
- Patients with lymphoma continue to have their quality of life negatively impacted in physical, psychological, and social areas by their disease and side-effects of their treatment(s). It is important to remember and address the needs of patients groups whose illness may not be as visible (i.e., patients under active surveillance and those in remission).
- Improvement in patient support and patient-doctor communication is needed.
- Disparities continue to exist in how patients experience care in Europe. Patients in the BA-HE countries reported needing (but not receiving) more support financially and experiencing more barriers to their care than patients from AA-HE countries.

\*LCE has included Israel and Turkey in this report, even though there is a lack of consensus in how to list these two countries. For instance, the WHO includes Israel and Turkey as part of Europe while, the United Nations lists them as part of Western Asia.<sup>55-56</sup>

Lymphoma Coalition would like to eliminate the category of non-Hodgkin lymphoma (NHL) from the way lymphomas are listed, as it only brings an unneeded layer of complexity. The focus should be on individual lymphoma subtype identification and tracking.

# Introduction

## BRIEF BACKGROUND ON LYMPHOMAS

Lymphomas encompass a wide variety of distinct disease entities.<sup>1</sup> There are more than 80 different subtypes of lymphomas.<sup>2</sup> Depending on the subtype, the disease could be aggressive, progress rapidly, and be considered curable in certain instances, such as diffuse large B-cell lymphoma (DLBCL) and classical Hodgkin lymphoma (HL); others are indolent, generally advance more slowly, and are currently considered incurable, including follicular lymphoma (FL), marginal zone lymphoma (MZL) and chronic lymphocytic leukaemia (CLL); some may have both aggressive and indolent variants, like mantle cell lymphoma (MCL).

**A major challenge when examining aggregated lymphoma data (e.g., incidence and mortality data), is that the data is not commonly gathered by individual subtype.**

Except for Hodgkin lymphoma, other lymphoma data are usually gathered under a non-Hodgkin lymphoma (NHL) category, which is hugely limiting. The many subtypes lumped under NHL have different characteristics, treatments, survival rates and patient experiences. CLL data may be grouped with leukaemia data or NHL data.

Lymphoma Coalition would like to eliminate the term NHL from the way lymphomas are listed, as it only brings an unneeded layer of complexity. This report will include the term NHL only because this matches current data captures.

The Global Cancer Observatory ranked NHL as the 12<sup>th</sup> most frequent and Hodgkin lymphoma as the 25<sup>th</sup> most frequent cancer diagnosis in Europe in 2020.<sup>3</sup> Table 1 shows the incidence and mortality rate of lymphomas in Europe, including Israel and Turkey. There were 142,837 estimated new cases and about 53,637 deaths from all lymphoma subtypes (NHL + HL, excluding CLL) in Europe in 2020.<sup>3</sup> Northern and Western European regions reported the highest incidence and mortality rates of NHL while Eastern Europe had the least incidence rate of HL. The age standardized rate (ASR) for mortality from HL was similar across regions.

**NHL is more commonly diagnosed in older people, with the European Cancer Information System (ECIS) recording the highest incidence in patients aged 65-79 years.<sup>4</sup> Despite this, an estimated 40% of patients with NHL in Europe were diagnosed between 20 and 64 years, indicating that a substantial proportion of individuals develop lymphoma during their working years.<sup>4</sup> HL occurs more commonly in young adults, with 41% of cases diagnosed between the ages of 15-39 years.<sup>4</sup>**

**Table 1. Summary of the estimated incidence and mortality of non-Hodgkin and Hodgkin lymphoma in Europe in 2020**

Region/Country	Non-Hodgkin Lymphoma				Hodgkin Lymphoma			
	Incidence (Number of cases)	Incidence ASR* (Europe)	Mortality (Number of cases)	Mortality ASR* (Europe)	Incidence (Number of cases)	Incidence ASR* (Europe)	Mortality (Number of cases)	Mortality ASR* (Europe)
<b>Eastern Europe</b>	<b>26590</b>	<b>9.6</b>	<b>12669</b>	<b>4.8</b>	<b>6299</b>	<b>2.1</b>	<b>1724</b>	<b>0.6</b>
Belarus	766	8.7	451	5.4	224	2.4	61	0.6
Bulgaria	647	8.7	336	4.5	126	1.8	52	0.7
Czech Republic	1860	17.5	611	5.9	260	2.4	53	0.5
Hungary	1581	15.9	635	6.5	201	2.0	38	0.4
Moldova	313	8.7	176	5.3	55	1.4	26	0.7
Poland	4351	11.9	2437	6.9	598	1.6	193	0.5
Romania	1909	9.7	789	4.1	263	1.3	87	0.5
Russian Federation	11436	8.5	5336	4.2	3298	2.3	863	0.6
Slovakia	701	14.4	434	9.7	153	2.8	43	0.8
Ukraine	3026	7.0	1464	3.4	1121	2.5	308	0.7
<b>Northern Europe</b>	<b>24489</b>	<b>23.6</b>	<b>8308</b>	<b>8.0</b>	<b>3288</b>	<b>3.1</b>	<b>511</b>	<b>0.5</b>
Denmark	1458	25.1	340	5.9	155	2.7	31	0.5
Estonia	237	17.7	105	7.7	32	2.5	5	0.4
Finland	1342	22.3	487	8.0	166	3.0	35	0.6
Iceland	54	18.9	16	5.9	7	2.1	0	0.0
Ireland	905	23.9	343	9.8	138	3.2	29	0.8
Latvia	258	13.0	125	6.3	51	2.7	15	0.7
Lithuania	485	17.0	159	5.5	56	2.1	11	0.4
Norway	1053	21.2	312	6.5	158	2.9	19	0.4
Sweden	1819	17.7	777	7.4	212	2.1	33	0.3
United Kingdom	16806	25.6	5619	8.5	2313	3.5	333	0.5
<b>Southern Europe</b>	<b>28769</b>	<b>17.2</b>	<b>11284</b>	<b>6.5</b>	<b>4681</b>	<b>3.1</b>	<b>973</b>	<b>0.6</b>
Albania	54	2.1	30	1.2	50	1.7	17	0.6
Bosnia and Herzegovina	213	6.4	114	3.6	107	3.2	27	0.8
Croatia	577	13.2	321	7.3	97	2.3	17	0.4
Cyprus	182	18.5	83	9.3	42	3.4	3	0.3
Greece	1554	13.4	606	4.9	361	3.2	108	0.9
Italy	14032	20.3	5175	7.1	2120	3.4	416	0.6
Malta	96	21.4	31	7.0	12	2.6	1	0.2
Montenegro	95	17.0	32	6.0	22	3.5	6	1.0
North Macedonia	87	4.6	44	2.5	51	2.3	13	0.6
Portugal	2098	18.7	962	8.3	233	2.3	51	0.4
Serbia	938	10.9	518	6.2	239	2.7	84	1.0
Slovenia	617	28.1	305	14.0	47	2.3	8	0.4
Spain	8202	16.9	3054	6.2	1300	2.9	222	0.5
<b>Western Europe</b>	<b>43131</b>	<b>20.6</b>	<b>17423</b>	<b>8.0</b>	<b>5590</b>	<b>2.9</b>	<b>745</b>	<b>0.4</b>
Austria	1374	15.2	705	7.8	147	1.7	30	0.3
Belgium	2833	24.4	923	7.9	362	3.1	48	0.4
France	14446	21.0	5859	8.2	2044	3.1	257	0.4
Germany	18549	19.6	7798	7.8	2306	2.8	297	0.3
Luxembourg	103	19.3	30	6.1	15	2.5	0	0.0
Netherlands	4105	23.6	1462	8.5	461	2.7	81	0.5
Switzerland	1705	19.7	639	7.4	255	2.9	32	0.4
<b>EU-27</b>	<b>86321</b>	<b>19.3</b>	<b>34892</b>	<b>7.3</b>	<b>11958</b>	<b>2.7</b>	<b>2164</b>	<b>0.5</b>
<b>Europe**</b>	<b>122979</b>	<b>16.4</b>	<b>49684</b>	<b>6.7</b>	<b>19858</b>	<b>2.7</b>	<b>3953</b>	<b>0.5</b>
<b>Other**</b>		(World)		(World)		(World)		(World)
Israel	<b>1548</b>	<b>13.3</b>	<b>606</b>	<b>4.1</b>	<b>235</b>	<b>2.7</b>	<b>31</b>	<b>0.2</b>
Turkey	<b>6237</b>	<b>6.4</b>	<b>3067</b>	<b>3.0</b>	<b>1520</b>	<b>1.7</b>	<b>378</b>	<b>0.4</b>

Source: ECIS - European Cancer Information System from [ecis.jrc.ec.europa.eu](https://ecis.jrc.ec.europa.eu), accessed on 23/09/2021. © European Union, 2021.

\*ASR-Age standardized rate (ASR). \*\*Europe- Estimated incidence and mortality have been added for the following areas: Faeroe Islands and Isle of Man; Gibraltar, Holy See, and San Marino; Liechtenstein and Monaco. \*\*\*Source-The Global Cancer Observatory 2020.

[gco.iarc.fr/today/fact-sheets-cancers](https://gco.iarc.fr/today/fact-sheets-cancers) Last accessed 23<sup>rd</sup> Sept 2021.

## ECONOMIC BURDEN

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The resulting high consumption of care and the number of hospitalisations due to the increasing incidence of most lymphoma subtypes has led to significant lymphoma care cost and health spending.<sup>6-12</sup>

Policymakers are increasingly searching for real-world information on the economic impact of diseases on healthcare systems globally and how to best manage the disease from a healthcare resource perspective. Many countries have adopted health technology assessment (HTA) practices to measure the cost-effectiveness of new treatments and technologies in decision-making and health policy formulation.

In addition to the direct treatment and healthcare costs, there are other indirect costs (i.e., costs that are not directly related to patient care). As earlier stated, a significant proportion of individuals develop lymphoma in their working years. Consequently, lymphomas can have a substantial impact on workplace productivity by causing premature mortality of the workforce, absenteeism, short- and/or long-term disability and replacement of an absent worker (on average 90 days across all European countries) - all of which add to indirect costs.<sup>13-14</sup> A 2018 study from Spain estimated the 10-year cost of productivity losses due to premature mortality for HL to be €255 million and €1,107 million for NHL.<sup>11</sup> There are also other costs associated with supportive care including psychological support, physiotherapy, and palliative care.

Productivity losses of caregivers also contribute to indirect costs of lymphomas. Family members, in particular, have been shown to incur an economic burden (e.g., due to providing financial support), occupational burden (e.g., due to missed work), and psychosocial burden (e.g., due to anxiety or sadness), all of which add to the indirect costs.<sup>14</sup>

LCE reviewed existing literature to assess the economic burden of lymphomas (and other blood cancers) in Europe and Table 2 below shows the findings. Generally, lymphomas are among the more costly cancers.<sup>6-12</sup> A 2017 study from Norway estimated the average life-time cost per patient for NHL to be approximately €83,800, which was nearly double the average cost for all other cancers estimated at €46,000.<sup>8</sup>

**Costs varied based on the lymphoma subtype and the types of treatment given to the patient, with aggressive lymphomas (e.g., DLBCL) costing more than indolent lymphomas (e.g., FL).<sup>7</sup>**

Possible reasons for increased costs for aggressive lymphomas could be longer hospital stays (and related higher costs) and greater loss of productivity (patients with aggressive lymphomas tend to be more physically ill requiring absences from work and other activities).

Another study estimated the future costs for the management of lymphomas and other haematological cancers over the next 10 years to be between €28.5 billion and €32.8 billion for Europe, considering the emergence of expensive cell-based therapies such as chimeric antigen receptor T-cell (CAR-T) therapy.<sup>12</sup> The stage at which the diagnosis of an aggressive lymphoma is made is of great importance to the treatment intensity and thereby the cost of care. Programs and research directed at improving earlier lymphoma diagnoses in aggressive subtypes may reduce the lymphoma cost burden as early-stage disease can mean less intense treatment methods. This must be considered in resource allocation and management policies.<sup>11</sup>

It is important to consider that the economic information gathered for this report predates the Covid-19 pandemic, which has significantly changed most nations' healthcare spending priorities. Future studies on the economic burden of lymphomas may appear dramatically different than what is currently published. Another consideration is that these studies varied in their research gathering methods and economic measurements and may not necessarily be comparable. However, all the papers were able to calculate the economic impact of lymphoma (and other blood cancers in some cases) and present relevant findings.

**Table 2. Studies examining the cost of illness of lymphoma in Europe**

Study	Country	Study population	Key results
<b>Mounie et al (2019)</b>	France	224 lymphoma patients (with HL, FL and DLBCL) and 896 controls	<p>The mean additional monthly costs were</p> <ul style="list-style-type: none"> <li>• HL €5,188</li> <li>• FL €3,242</li> <li>• DLBCL €7,659</li> </ul> <p>Total mean monthly costs per patient</p> <ul style="list-style-type: none"> <li>• HL: €4,690 vs €212 control,</li> <li>• FL: €4,101 vs €281 control,</li> <li>• DLBCL: €7,745 vs €219 control.</li> </ul> <p>The top three most important cost drivers were</p> <ul style="list-style-type: none"> <li>• Inpatient stay</li> <li>• Outpatient medication and</li> <li>• Productivity loss</li> </ul>
	<a href="https://doi.org/10.1080/13696998.2019.1702990">DOI:10.1080/13696998.2019.1702990</a>		
<b>Bugge et al (2021)</b>	Norway	13 cancer types (including NHL) from the Norwegian patient registry N=560,265	<p>In general, cost per patient was highest during the first month after diagnosis and the last month before death.</p> <p>2017 Estimated lifetime direct medical costs in hospitals and cost by phase per patient (Undiscounted):</p> <p>Non-Hodgkin</p> <ul style="list-style-type: none"> <li>• Initial Phase €36,038</li> <li>• Continued Phase €26,290</li> <li>• Terminal Phase €21,534</li> <li>• Total €83,861.</li> </ul> <p>All Cancers (For comparison)</p> <ul style="list-style-type: none"> <li>• Initial Phase €22,018</li> <li>• Continued Phase €8,757</li> <li>• Terminal Phase €15,274</li> <li>• Total €46,049.</li> </ul>
	<a href="https://doi.org/10.1097/MD.00000000000026523">DOI:10.1097/MD.00000000000026523</a>		
<b>Wang et al (2018)</b>	United Kingdom	FL patients (N=740)	<p>Overall, the average cost per patient was around £18,705 [US\$23,390], excluding the impact of transformation to DLBCL.</p> <p>Costs for patients who received treatment with curative intent were higher (£24,872 [US\$31,102]) than for those who did not.</p> <p>The highest lifetime costs occurred among patients who received second-line treatment that included an SCT (stem cell transplant) (£60,261 [US\$75,356]), but this was accompanied by the longest survival (15.79 LYs).</p>
	<a href="https://doi.org/10.1016/j.jval.2018.03.007">DOI: 10.1016/j.jval.2018.03.007</a>		

Table continued on next page.

Study	Country	Study population	Key results
<b>Wang et al (2017)</b>	United Kingdom	DLBCL patients (n=271)	<p>Overall, the expected total medical costs were £22,122 for those treated with curative intent, and £2,930 for those managed palliatively.</p> <p>For curative chemotherapy, the predicted medical costs were:</p> <ul style="list-style-type: none"> <li>• First-line £14,966</li> <li>• Second-line £23,449</li> <li>• Third-line £7,376</li> </ul> <p>The estimated annual cost for treating DLBCL across the UK was around £88–92 million.</p> <p><i>As a sidenote: This estimation was done pre-CAR-T era. If CAR-T is considered, the cost analysis for DLBCL will increase.</i></p>
	<a href="https://doi.org/10.1007/s10198-016-0775-4">DOI:10.1007/s10198-016-0775-4</a>		
<b>Burns et al (2016)</b>	31 European countries including the 28 EU countries	Malignant blood disorders	<p>For all 31 countries, the estimated cost of malignant blood disorders in 2012 was €11.9 billion with inpatient care and drugs being the 2 highest cost categories (3.9 billion and 2.0 billion respectively).</p> <p>Malignant blood disorders contributed to 8% of the total cancer costs (€143 billion) in the 28 EU countries alone in 2012.</p> <p>In terms of healthcare costs, malignant blood disorders represented 12% of the €57 billion cancer healthcare costs second only to breast cancer (13%) and followed by colorectal and prostate cancers with 11% each.</p>
	<a href="https://doi.org/10.1016/S2352-3026(16)30062-X">DOI: 10.1016/S2352-3026(16)30062-X</a>		
<b>Darba et al (2018)</b>	Spain	HL and NHL deaths (n=26,660)	Productivity losses due to premature mortality in a ten-year period for HL was estimated to be €255 million and €1,107 million for NHL.
	<a href="https://doi.org/10.1080/14737167.2020.1769478">DOI: 10.1080/14737167.2020.1769478</a>		
<b>Heine et al (2021)</b>	EU-5 countries- France, Germany, Spain, Italy, and the United Kingdom	Estimation of the costs and budget impact of <b>CAR-T cell therapies</b> for current and future indications in haematological cancers from 2019-2029	<p>Cumulative expenditure estimates for existing and future indications from 2019 to 2029 were on average:</p> <ul style="list-style-type: none"> <li>• CAR T-cell therapy costs only €28.5 billion</li> <li>• CAR T-cell therapy costs including pre-and post-treatment €32.8 billion</li> <li>• Incremental CAR T-cell therapy costs €28.9 billion</li> </ul>
	<a href="https://doi.org/10.1097/HS9.0000000000000524">DOI: 10.1097/HS9.0000000000000524</a>		

## THE IMPORTANCE OF CAPTURING THE PATIENT EXPERIENCE

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The key objective of healthcare and health interventions is to improve the health of patients and populations and to do so in an equitable way. Good health is not just important in its own right, it also promotes personal, social, and economic well-being. Healthy residents create healthy communities and contribute towards a well-functioning, prosperous and more productive society.<sup>5</sup> Yet very few health systems assess the impact of interventions on health and well-being, from the perspective of the patients they serve.

Throughout the course of diagnosis, treatment, and follow-up care, living with lymphoma is a continuous experience for patients and their caregivers. Their experience with cancer, and lymphomas specifically, goes beyond the broad clinical classifications given to patients by their doctors (e.g., cancer in remission, cancer in active treatment, relapsed/refractory, **active monitoring\*** etc.) Patients must learn new skills, gather information, and understand options to adapt to their physical, emotional, and day-to-day changes.<sup>13</sup> A gap often exists between what patients and their families need and what healthcare providers think patients and their caregivers want. A relationship between the person with cancer and the clinicians who provide care should be based on reciprocity, actively listening, and sharing knowledge, considering preferences and the personal situation of the patient.

Patient experience is an important factor in healthcare decision-making and should be considered alongside other forms of evidence. **Patient experience, considered as evidence, contributes to understanding the nature of the condition, the effect of the treatment on the patient's health, and the effect of the treatment on patients' and carers' lives. It is important that patients also understand their role in contributing to the evidence analysed when making a healthcare decision.**<sup>14</sup>

## CANCER CARE DELIVERY SYSTEM

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Various personal factors impact a patient's lymphoma experience such as biological sex and age, income and work stability and place of residence. In a high-quality health system, patients are more likely to have the best possible experience when cancer care services are grounded in a patient-centred approach. However, performance metrics in assessing health outcomes tend to focus principally on clinical inputs and outputs (e.g., progression-free survival [PFS] and overall survival [OS]) but usually neglect things valued by patients such as their quality of life and their experience of care. Traditional outcome measures like survival-post-treatment will continue to remain useful but cannot capture subtle yet important factors such as patient's independence, sexual function, body image and time spent with loved ones.<sup>15</sup>

Insight into how patients experience treatment and care helps determine the best therapeutic approaches, techniques, and interventions.<sup>16-18</sup> Data that reveals the impact and value of health interventions on the patient's life should be routinely collected. For instance:

- What is the effect of delays in diagnosis on treatment effectiveness?
- How supported do patients feel and does patient support affect patient outcomes?
- Are treatment interventions making a difference in patient's lives and alleviating symptoms or are some treatments being given unnecessarily?

**\*Active monitoring (or active surveillance) refers to patients who do not yet need treatment for their lymphoma but whose disease is being actively monitored. It is also popularly referred to as 'Watch and Wait' but active monitoring better reflects the patient experience and is the more accurate terminology.**

These questions cannot be effectively answered without routinely collecting data on patient outcomes.

**When the discussion moves from 'what's the matter with you?' to 'what matters to you?' the focus of care is on the needs of the patient, which is a critical step in getting patients involved in decision-making in their healthcare.<sup>5</sup>**

Aggregated patient-reported outcomes can inform care decisions and help patients choose the right therapeutic option where various interventions (including 'active monitoring') are available.<sup>18</sup> For effective shared decision-making to happen, more focus needs to be placed on measuring and reporting patient metrics.

The most important goal of a high-quality cancer care delivery system is meeting the needs of patients and their families.<sup>19</sup> In addition to health outcomes, how patients are treated greatly matters. Pillars of a positive patient experience when patient-centeredness is the approach to care, include the following:<sup>20</sup>

- Patient being seen as an individual and not just a diagnosis
- Having healthcare providers who respond to the needs, preferences, and concerns of patients and their families
- Receiving credible, timely, tailored, and understandable information about their cancer and treatment options and having the opportunity to ask questions
- Being referred to care providers or peer/patient support groups for help with physical, emotional, or practical concerns, if needed, throughout the time the patient continues to be impacted by their lymphoma diagnosis

A positive care experience is also thought to be an important end in itself. All patients expect and deserve to be treated with compassion and dignity.

# The Patient Experience with Lymphoma

## BACKGROUND

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Findings from Lymphoma Coalition's 2020 Global Patient Survey on Lymphomas & CLL (2020 GPS) provide insights into the patient experience. The results are key in helping LC and its Member patient advocacy organisations ensure the patient perspective is central to planning, guides how healthcare systems deliver lymphoma care and direct the areas of focus for lymphoma research.

Of the 11,878 respondents from 90+ countries that participated in the survey (9,179 patients and 2,699 caregivers), **4,346 patients responded from 36 European countries, including Turkey.**

This section will focus on differences in patient experiences, based on countries' health spending/expenditure.

Expenditure on health includes medical services and goods, population health and prevention programmes, as well as administration of the health system. It combines both government spending and compulsory financing schemes, as well as voluntary health insurance and private funds such as households' out-of-pocket payments, and monies spent by both non-governmental organisations (NGOs) and private corporations. The level of health spending in a country and how it changes over time is dependent on a wide range of demographic, social and economic factors, as well as the financing arrangements and organisational structure of the health system itself. Given these factors, there are large variations in the level and growth of health spending across Europe.<sup>5</sup>

For this review, **health expenditure as a percentage of the Gross Domestic Product (GDP)** is used as an indicator of the resources available for healthcare. This reveals how much a country is willing to invest in its healthcare in relation to all other goods and services.<sup>5</sup> To a general extent, most countries that spend more on health have been associated with better health outcomes and better quality of care.<sup>5</sup>

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The 2020 Global Patient Survey on Lymphomas & CLL (GPS) included 4,346 patient responses from 36 European countries. LCE uses GPS data to advance the patients' voices in Europe and work towards ensuring equity in lymphoma outcomes.

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The 2019 data was the most recent data available provided by the World Health Organisation (WHO) Global Health Expenditure Database and it was used for this comparison.<sup>21</sup> On average, governments of European countries that had patient respondents to the 2020 GPS allocated 8.2% of GDP to health funding. Countries with **below average health expenditure (BA-HE) (number of patients=452)** were compared to countries with **above average health expenditure (AA-HE) (number of patients=3894)** (Table 3). While there is a significantly higher number of survey respondents in the AA-HE group, the number of respondents in the BA-HE is robust enough to allow for a useful comparison. Even though Euros are the main currency in most European countries, the analysis uses USD as that is the currency used in the aforementioned databases.

A limitation of the use of health expenditure as a percentage of GDP as an indicator is that in Ireland and Luxembourg, both in the BA-HE group, a significant proportion of GDP refers to profits exported and not available for national consumption. In spite of their relatively low health care spending in relation to GDP ratios (Ireland 7% and Luxembourg 5%), these two countries have a relatively high level of health expenditure per capita (Ireland \$6,010.00 USD and Luxembourg \$6,757.00 USD), compared to some other countries in the AA-HE group such as Serbia and Bosnia and Herzegovina that both spent 9% and 9% respectively of their GDP on health but had actual amounts per capita of \$1,686.00 USD and \$1,477.00 USD respectively (Table 3). The gross national income (GNI) may be a more meaningful measure than GDP in these specific examples, but for international comparability, GDP is a better measure (Table 3).<sup>5</sup>

**Table 3. Healthcare spending (2019) per GPD patient respondent countries (Europe)**

Countries	Number of patient respondents in the 2020 LC GPS	Health Expenditure/ spending as a % of GDP (2019)*	Current health expenditure per capita (USD), using purchasing power parities (PPP) (2019)
<b>Countries below average health expenditure % of GDP (BA-HE) N=452</b>			
Albania	1	**5	**\$697.00
Andorra	1	7	\$3,716.00
Bulgaria	82	7	\$1,798.00
Croatia	18	7	\$2,168.00
Cyprus	3	7	\$3,017.00
Czech Republic	8	8	\$3,377.00
Georgia	1	7	\$970.00
Greece	8	8	\$2,419.00
Hungary	3	6	\$2,156.00
Ireland	148	7	\$6,010.00
Lithuania	37	7	\$2,797.00
Luxembourg	3	5	\$6,757.00
Malta	1	8	\$4,040.00
Monaco	1	2	\$4,040.00
Poland	1	7	\$2,207.00
Romania	1	6	\$1,907.00
Slovakia	132	7	\$2,267.00
Turkey	3	4	\$1,187.00

Table continued on the next page.

Countries	Number of patient respondents in the 2020 LC GPS	Health Expenditure/ spending as a % of GDP (2019)*	Current health expenditure per capita (USD), using purchasing power parities (PPP) (2019)
<b>Countries above average health expenditure % of GDP (AA-HE)</b> N=3894			
<b>Austria</b>	7	10	\$6,134.00
<b>Belgium</b>	147	11	\$5,847.00
<b>Bosnia and Herzegovina</b>	4	9	\$1,477.00
<b>Denmark</b>	18	10	\$6,015.00
<b>Finland</b>	51	9	\$4,710.00
<b>France</b>	1577	11	\$5,493.00
<b>Germany</b>	44	11	\$6,739.00
<b>Iceland</b>	1	9	\$5,636.00
<b>Italy</b>	578	9	\$3,998.00
<b>Netherlands</b>	306	10	\$6,248.00
<b>Norway</b>	6	11	\$7,217.00
<b>Portugal</b>	22	10	\$3,518.00
<b>Serbia</b>	142	9	\$1,686.00
<b>Slovenia</b>	13	9	\$3,629.00
<b>Spain</b>	50	9	\$3,984.00
<b>Sweden</b>	186	11	\$6,223.00
<b>Switzerland</b>	63	11	\$8,532.00
<b>United Kingdom</b>	679	10	\$5,087.00
<b>Overall average</b>		<b>8.2</b>	

Source: World Health Organization Global Health Expenditure Database (<https://apps.who.int/nha/database/Select/Indicators/en>)<sup>21</sup>

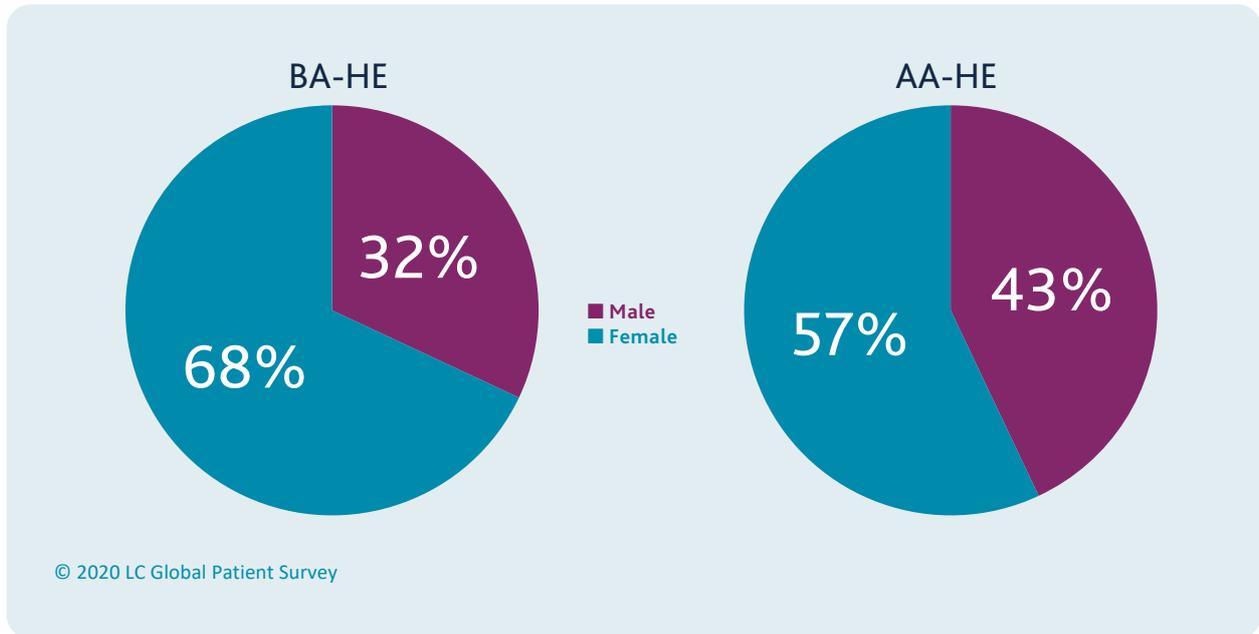
\*To the nearest whole number \*\*2019 data unavailable, 2018 data used

## Brief demographic description

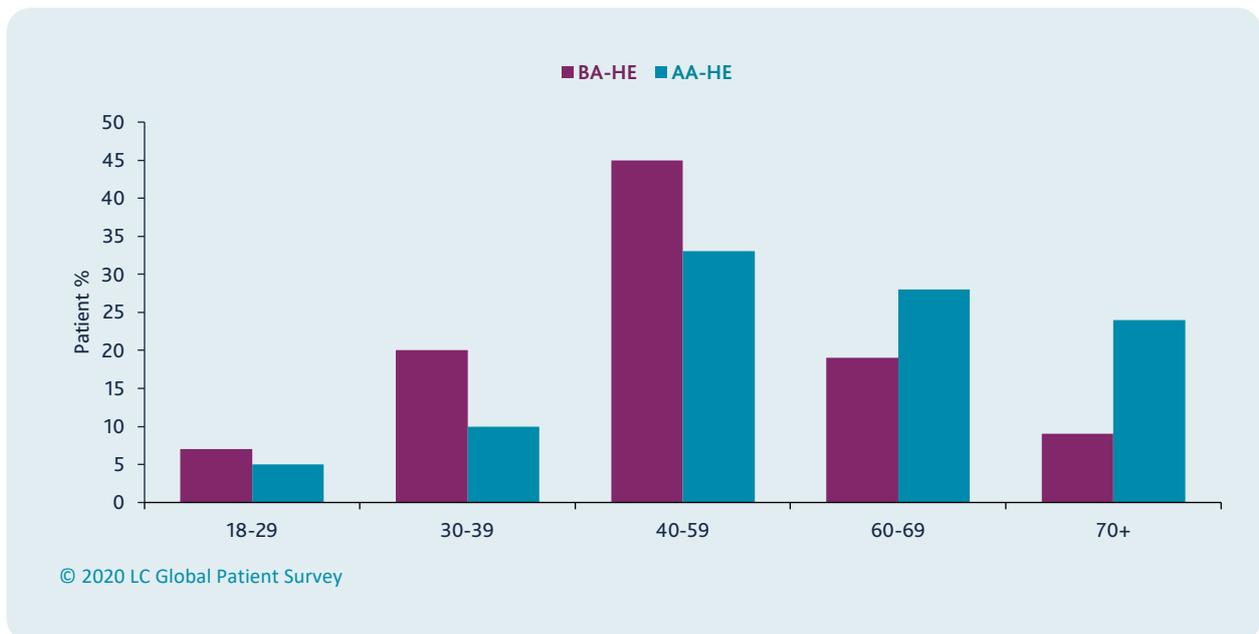
A higher proportion of the patients responding from the BA-HE countries were female (68%) compared to the AA-HE countries (57%). The BA-HE patients were also different from the AA-HE patients in age distribution. There were more patients in the younger age groups (18-59 years) in the BA-HE group while the AA-HE group had more patients in the 60 years and above age groups.

The top three subtypes of the patients responding to the survey were CLL, Hodgkin and DLBCL in BA-HE and CLL, Hodgkin and FL in AA-HE.

**Figure 1. Biological sex distribution by country grouping**



**Figure 2. Age distribution by country grouping**



**Table 4. Lymphoma subtype by country grouping**

BA-HE	No. of patients	%	AA-HE	No. of patients	%
Chronic Lymphocytic Leukaemia (CLL)/ Small Lymphocytic Lymphoma (SLL)	147	33%	Chronic Lymphocytic Leukaemia (CLL)/ Small Lymphocytic Lymphoma (SLL)	1015	26%
Hodgkin	136	30%	Hodgkin	643	17%
Diffuse Large B-Cell lymphoma (DLBCL)	72	16%	Follicular	607	16%
Follicular	27	6%	Diffuse Large B-Cell lymphoma (DLBCL)	476	12%
Don't know	18	4%	Waldenstrom's macroglobulinemia/ Lymphoplasmacytic lymphoma	391	10%
Other indolent lymphoma	14	3%	Other indolent lymphoma	153	4%
Other aggressive lymphoma	7	2%	Other aggressive lymphoma	118	3%
Waldenstrom's Macroglobulinemia/ Lymphoplasmacytic Lymphoma	7	2%	Mantle Cell	115	3%
Mantle Cell	4	1%	Don't know	88	2%
Anaplastic Large Cell	4	1%	Mucosa-Associated Lymphoid Tissue (MALT)/Marginal Zone	69	2%
Mycosis Fungoides	4	1%	Mycosis Fungoides	68	2%
Peripheral T-Cell	3	1%	Transformed (i.e., indolent (follicular) to aggressive DLBCL)	51	1%
Peripheral T-Cell Transformed (i.e. indolent (follicular) to aggressive (DLBCL)	3	1%	Peripheral T-Cell	23	1%
Mucosa-Associated Lymphoid Tissue (MALT)/Marginal Zone	2	0%	Cutaneous	22	1%
Burkitt's	1	0%	Burkitt's	21	1%
Cutaneous	1	0%	Anaplastic Large Cell	19	1%
Sézary Syndrome	2	0%	Sézary Syndrome	11	0%
Extranodal Killer T-Cell	0	0%	Extranodal Killer T-Cell	4	0%
<b>Total</b>	<b>452</b>	<b>100%</b>	<b>Total</b>	<b>3894</b>	<b>100%</b>

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## DIAGNOSIS

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Lymphomas often present a diagnostic challenge and there are no screening programs to help with prompt or early diagnosis. This challenge is further complicated by the fact that lymphomas are a mixed group of cancers that have a variety of clinical presentations ranging from an indolent course to an aggressive disease. Long time to diagnosis can result in increased patient anxiety and may impact the patient's survival and quality of life.<sup>22-23</sup>

Patients with lymphoma have diverse symptoms that often include painless enlarged lymph node swellings under the skin, infection, fatigue, lethargy, fever, night sweats, sweating, itching and breathlessness. Symptoms can affect patients' lives in many ways and patients may try practical or psychological ways to cope with the symptoms (e.g., taking a bath to relieve severe itching, napping or sleeping more when tired, or propping up with extra pillows to relieve breathlessness) before seeking healthcare.<sup>23-24</sup>

A qualitative study that examined patients' experiences before lymphoma and myeloma diagnosis described participants who had vague symptoms (such as fever or lethargy) or misattributed their symptoms to other illnesses experienced more diagnostic delays and had a chaotic diagnostic pathway including consulting various healthcare professionals, often many times, as symptoms persisted/progressed.<sup>25</sup> Another qualitative study from the UK showed that many of the patients that had a sudden illness or swellings described having anxiety, fear, and panic while those with long-term and vague symptoms generally felt unease about their health rather than experiencing anxiety or panic.<sup>26</sup>

Even after seeking help from their primary care physicians for their symptoms, some patients may experience a diagnostic delay if the doctor doesn't investigate further. For example, in the UK, many symptoms reported by patients are not included in the UK referral guidance, a document available to help General Practitioners (GPs) identify suspected lymphoma. Current guidance focuses on the most common signs such as swollen lymph nodes, weight loss and night sweats, but many patients experienced a wider range of symptoms. A patient may make repeated visits to the clinic for the same symptoms before the need for referral is eventually recognized.<sup>22,24</sup> This delay often results in patients feeling distressed, anxious, and frustrated. In some cases, patients or their relatives have to advocate for themselves to ensure that they get the necessary referral and investigations done.<sup>24,27</sup>

Survey respondents were asked how long it took from their first appointment with their GP to report their symptoms to getting a diagnosis of lymphoma or CLL. Less than half of patients from BA-HE countries (40%) received their diagnosis in less than 3 months compared to half of the respondents from the AA-HE countries (50%) (Figure 3).

**Over 10% of patients in both country groups (BA-HE- 14%; AA-HE-13%) reported it took more than 12 months after their first GP visit to get a diagnosis (Figure 3).**

**Figure 3. Time from first appointment with GP about symptoms to getting diagnosis of lymphoma or CLL**



As many as two in five cases of lymphoma are diagnosed through emergency presentation at the hospital and this is usually linked with advanced disease, more complications and poorer survival.<sup>28</sup>

To reduce the delay and difficulties associated with the diagnosis of lymphomas, a UK hospital established a nurse practitioner-led lymphoma rapid diagnosis clinic (LRDC). Analysis of results over a 30-month period found that patients with suspected lymphoma had a decreased time to diagnosis and initiation of treatment and a lower number of patients requiring multiple biopsies to obtain a definitive diagnosis, compared to two previous time periods at the same hospital before the clinic was instituted.<sup>29</sup>

Patient response to a diagnosis of lymphoma varies. Some feel disbelief initially and then shock as they come to terms with their diagnosis, while others feel relieved that their symptoms have been acknowledged, have been associated with an illness and treatment can commence.<sup>26</sup>

Communication with healthcare professionals is key at this point in time as patients will use this information to make sense of their unfolding situation. Many patients struggle with a lack of understanding as they may have never heard about lymphoma before. It may even be more confusing if a clear explanation is not given for certain patient care options, such as patients who have been diagnosed with an indolent lymphoma being told they have cancer but won't need or receive immediate treatment (i.e., placed in active monitoring). They should know this is a validated part of the patient care pathway. Patients need tailored information to deal with their diagnosis and care.

## QUALITY OF LIFE

Quality of life (QoL) is an individual's assessment of one's life at any time relative to one's previous state or prior experiences. Health-related QoL is multidimensional, relating to a state of daily physical, psychological, sexual, and social/family functioning.<sup>30</sup> **Haematological cancers have been found to have a negative impact on overall QoL and health-related QoL.**<sup>31</sup> A variety of factors have been shown to impact QoL of a patient living with lymphoma, such as the physical symptoms associated with the underlying lymphoma, the stage of the lymphoma, the type of treatments administered, the presence of comorbid conditions, and the emotional and social state of the patient.<sup>30, 32-34</sup>

When patients were asked to rate disease outcomes in order of importance to them, 'quality of life' ranked second to 'a cure' for patients in both country groups, showing how highly this is valued.

**Table 5. Disease outcomes ranked by patients per country group**

Patient ranking	Outcomes
<b>BA-HE</b>	
1 <sup>st</sup>	A cure
2 <sup>nd</sup>	Quality of life
3 <sup>rd</sup>	Fewer side effects to tolerate
4 <sup>th</sup>	Duration of treatment
5 <sup>th</sup>	Treatment at home versus treatment in the clinic
6 <sup>th</sup>	What's best for my caregiver
<b>AA-HE</b>	
1 <sup>st</sup>	A cure
2 <sup>nd</sup>	Quality of life
3 <sup>rd</sup>	Fewer side effects to tolerate
4 <sup>th</sup>	Duration of treatment
5 <sup>th</sup>	Treatment at home versus treatment in the clinic
6 <sup>th</sup>	What's best for my caregiver

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Some patients with lymphoma are more affected by physical symptoms than others, which impacts their well-being.<sup>4</sup>

The top five symptoms reported by patients in both country groups were examined (Table 6). Fatigue was the most prevalent symptom in both groups (69% prevalence each).

**Table 6. Top five patients' symptoms and their duration by country group**

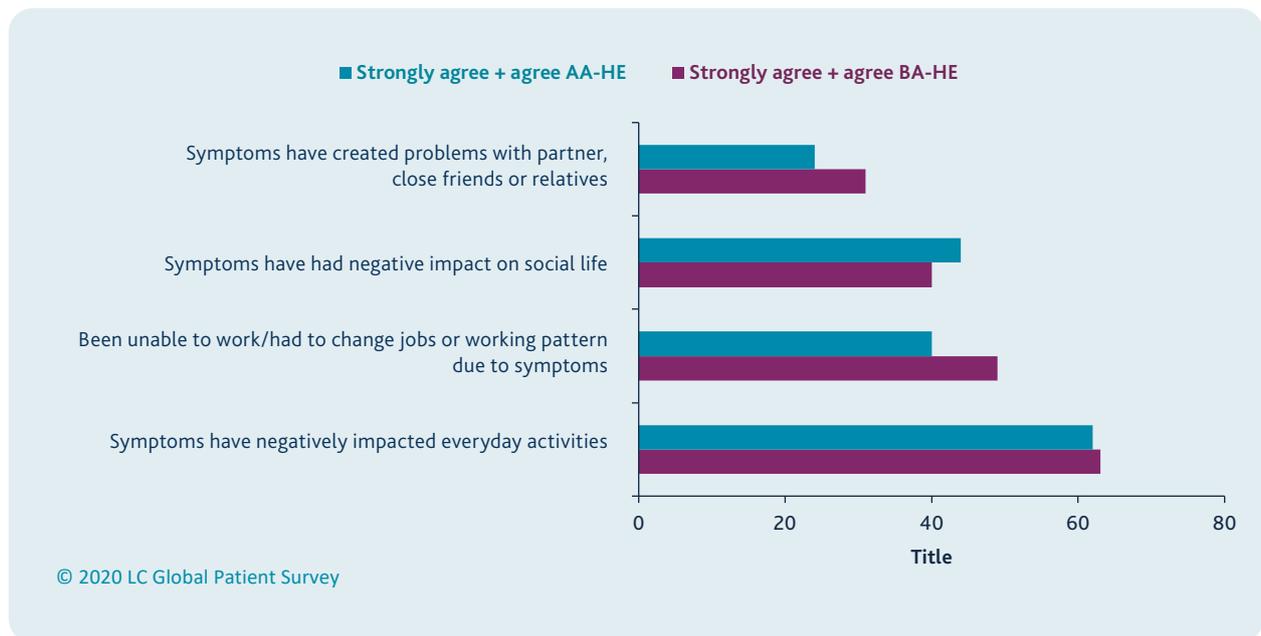
Symptom	Patient (%)	How long symptoms persisted for				
		< 1 yr. (%)	1-2 yrs. (%)	2-5 yrs. (%)	5-8 yrs. (%)	>8 yrs. (%)
<b>BA-HE</b>						
<b>Fatigue</b>	69%	29%	24%	22%	9%	15%
<b>B-symptoms</b>	36%	59%	19%	7%	4%	5%
<b>Frequent infections</b>	30%	26%	21%	29%	9%	14%
<b>Lymph node swelling</b>	29%	56%	13%	16%	5%	9%
<b>Shortness of breath</b>	29%	44%	21%	21%	6%	5%
<b>AA-HE</b>						
<b>Fatigue</b>	69%	23%	23%	26%	9%	13%
<b>Lymph node swelling</b>	36%	47%	19%	16%	4%	6%
<b>B-symptoms</b>	34%	50%	20%	14%	4%	5%
<b>Shortness of breath</b>	33%	36%	24%	22%	7%	7%
<b>Frequent Infections</b>	23%	18%	23%	28%	12%	16%

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For patients diagnosed in 2015 or prior, 39%- 43% reported experiencing repeated infections, skin rashes and fatigue for more than 5 years (43%, 39% and 43% respectively).

Patients reported that their symptoms negatively impact their everyday living compared to other people their age. Almost two-thirds of patients reported that symptoms negatively impacted their everyday activities (63%-BA-HE, 62%-AA-HE) (Figure 4). Almost half of the patients who reported symptoms in the BA-HE group (49%) reported that their symptoms affected their work (i.e., that they were unable to work or had changed jobs or working patterns) compared to 40% of AA-HE group (Figure 4). This would align with the BA-HE group being comprised of younger patients who would still be working while the AA-HE group is older and more likely to be retired. Patients also reported that the symptoms had a negative impact on their family and social lives (Figure 4).

**Figure 4. Patients who agreed + strongly agreed to statements about how their symptoms affected their quality of life.**



Treatment options for lymphoma may include chemo, immuno-, targeted or radiotherapy, stem cell transplantation (SCT), CAR T-cell therapy or a combination of these treatments. These treatments come with significant effects like fatigue, cytopenia, cognitive impairments, peripheral neuropathies, sexual difficulties, muscle wasting and pain. The side effects impact greatly on the patient's QoL, with some patients experiencing them for a long period of time even after their treatment has ended.<sup>35</sup>

Results from the 2020 GPS showed both groups had the same top-5 side effects (Table 7). Cancer-related fatigue was the most reported side effect impacting patients, with three-quarters of patients in both country groups affected (Table 7). Patients reported experiencing fatigue anywhere from less than one year to greater than eight years, showing the persistence of this issue.

Hair loss and nausea and vomiting were also top concerns for over half of respondents in both country groups. These are issues that usually resolve following completion of treatment and most said they were affected for less than a year to 1-2 years.

Numbness and tingling, and pain in joints and muscles are bothersome for patients long-term.

**Table 7. Most common side effects of treatments and their duration by country group**

Symptom	Patient (%)	How long symptoms persisted for				
		< 1 yr. (%)	1-2 yrs. (%)	2-5 yrs. (%)	5-8 yrs. (%)	>8 yrs. (%)
<b>BA-HE</b>						
Fatigue	75	28	22	20	7	23
Hair loss	64	61	27	7	1	1
Nausea and vomiting	54	77	13	5	2	1
Numbness and tingling	44	33	31	19	6	11
Pain in joints and muscle	45	43	17	20	12	7
<b>AA-HE</b>						
Fatigue	75	24	25	28	9	13
Hair loss	58	74	18	4	1	2
Nausea and vomiting	52	87	7	3	1	2
Numbness and tingling	45	29	25	25	8	10
Pain in joints and muscle	41	32	27	24	8	8

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Cancer-related fatigue is often described as paralyzing and can severely impact the lives of those affected. The areas and activities affected by fatigue in patients' lives were similar in both country groups. Half or more of the patients in both groups reported that fatigue affected their ability to carry out their general and physical activities and daily housework. Fatigue also affected mood and enjoyment of life.

**Table 8. Top 5 activities and areas of life affected by fatigue**

Area/activities affected by fatigue	BA-HE	AA-HE
General activities	61%	62%
Physical activities	58%	63%
General housework (daily chores)	50%	50%
Mood	46%	46%
Enjoyment of life	45%	42%

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When asked about what coping mechanism had helped them the most, half of the respondents in both country groups reported balancing their time schedules (i.e., planning, prioritising, or pacing their activities) as the most common coping mechanism (Figure 5). This was followed by exercise programs and mind-body interventions.

**Surprisingly, despite the effect that fatigue had on their lives, one-fifth of patients had no coping mechanism for dealing with fatigue. More needs to be done on all fronts of lymphoma care in Europe to alleviate the effects of fatigue.**

**Figure 5. Mechanisms patients use to cope with fatigue**



For more on fatigue, please read [LC's report on cancer-related fatigue](#).

**Completion of successful treatment that puts the lymphoma into remission does not necessarily translate to a better quality of life for patients with lymphoma if they are still dealing with symptoms and side effects, in some cases for up to eight or more years after treatment ends. It is key that patients receive support and ongoing management of these issues.**

Patients were asked if they experienced any barriers to receiving care. The highest proportion of patients in each group did not experience any barriers to their care (BA-HE-78% and AA-HE-89%) (Table 9).

**Table 9. Barriers to receiving treatment/care**

Barriers	BA-HE		AA-HE	
	n=1	%	n=1	%
Financial difficulties	17	7	34	1
Could not give up working/job	4	2	31	1
Time I would need to take out of day-to-day life	21	8	44	2
Access or transport to treatment centre	9	4	35	1
Language barriers	0	0	5	0
Access to most up-to-date treatment	15	6	54	2
Treatment waiting times	17	7	55	2
Other	6	2	121	5
None	192	78	2073	89

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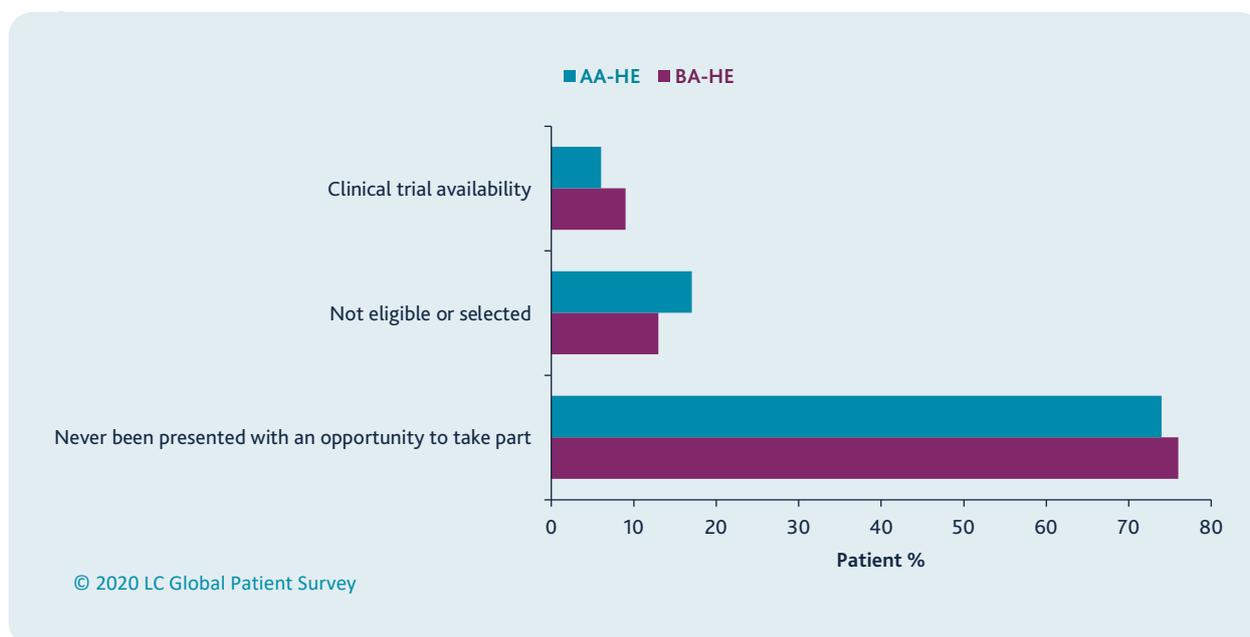
The top three reported barriers to care were time needed to take out of day-to-day living, treatment wait times, and financial barriers (8%, 7% and 7% respectively) for BA-HE countries, and treatment wait times, access to the most-up-to-date treatment, and time needed to take out of day-to-day living (2%, 2% and 2% respectively) for AA-HE countries.

When asked about prior or current participation in a clinical trial for their lymphoma or CLL, a similar proportion of patients in both country groups reported that they had participated in one (BA-HE-13%, AA-HE-16%).

The main barrier reported by about three-quarters of those who had never participated in a clinical trial in both country groups was that they had never been presented with an opportunity to take part in a clinical trial (Figure 6). Other barriers included not being eligible for the study and a lack of clinical trial availability.

More needs to be done to ensure that patients have access to quality care and opportunities to participate in clinical trials and that this access is given without undue financial and logistical stress for the patients and their families.

**Figure 6. Top 3 barriers to clinical trial participation by country groups**



Many patients with lymphoma also experience psychosocial issues. These include concerns such as fear, anxiety, and depression. They are often related to uncertainties about their cancer and its treatment, side effects of treatment and fear of unknown cancer outcomes. Fear of cancer recurrence (FCR) is a major issue that patients with cancer experience. It has been associated with worsened patient outcomes in areas such as general health status, cognitive, emotional, and social functioning.<sup>36</sup> Cancer patients should be given opportunities to express these feelings with their health professionals who can give them the help that they need to manage these issues.

At least one in four of all the patients in both country groups experienced a psychosocial issue in the last 12 months before the survey (Table 10). **Fear of cancer relapse was the most reported issue by patients from both country groups, followed by fear of lymphoma progression and anxiety.**

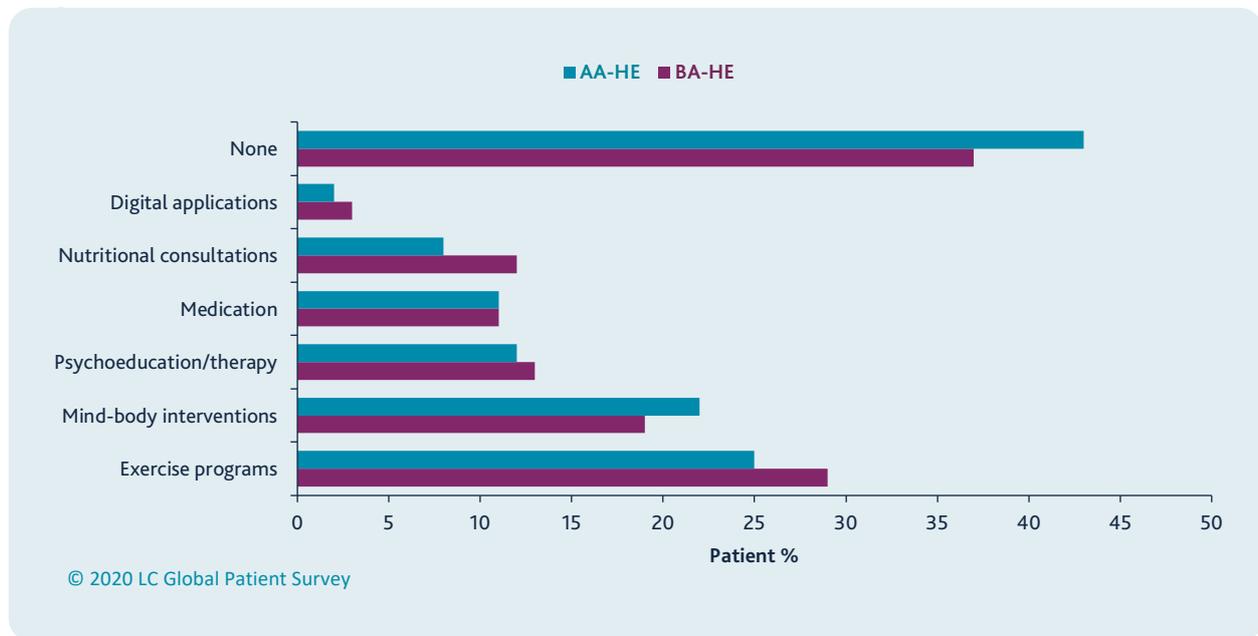
**Table 10. Top five psychosocial issues by country group**

Psychosocial issues experienced in the last 12 months	Patient (%)	
	BA-HE	AA-HE
<b>Fear of cancer relapse</b>	49%	51%
<b>Fear of lymphoma progression</b>	37%	35%
<b>Anxiety</b>	36%	28%
<b>Depression</b>	28%	26%
<b>Concerns about body image/physical appearance</b>	25%	25%

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When asked about mechanisms used to cope with the fear of relapse, unfortunately about 40% of all patients had none. For those who had coping mechanisms, exercise programs, mind-body interventions and psychoeducation/therapy were most frequently employed (Figure 7).

**Figure 7. Top mechanisms patients use to cope with fear of relapse**



Addressing the psychosocial impact of lymphomas must be a major focus of care and it is clear that there is a gap in helping patients deal with these issues.

It is important to remember not to neglect the psychosocial needs of patients that may not be undergoing active treatment or having frequent hospital visits, such as patients who are under active monitoring for their lymphoma and patients who have completed treatment and are in remission.<sup>36-39</sup> They are more acutely faced with worries about cancer recurrence or cancer progression. They may also not have the kind of social support that patients undergoing active treatment have because the impact of their cancer is not as visible to their loved ones, or their social circle believes the impact of lymphoma ceased when treatment ended.

## INFORMATION, GUIDANCE, AND SUPPORT

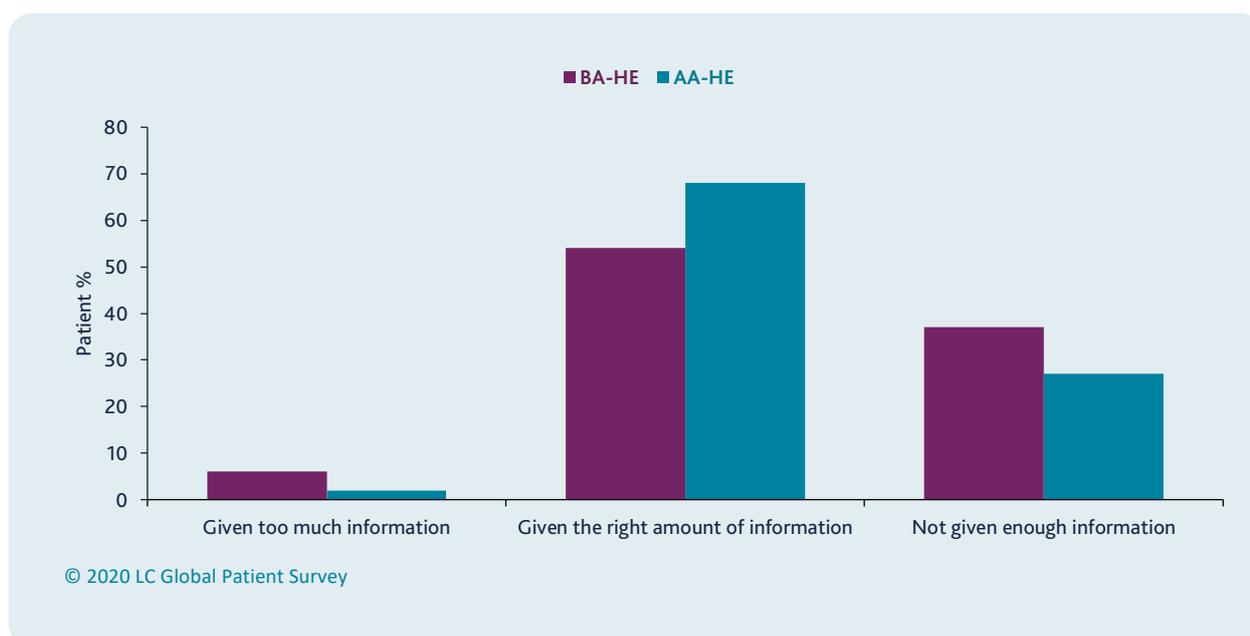
A patient-centred approach by doctors to communicating information has been shown to increase patient confidence and satisfaction with treatment decisions, enhance their trust in the healthcare team, increase treatment adherence, improve the health-related QoL and improve physical health.<sup>40-41</sup> For some lymphomas where there is no uniform standard of care and multiple treatment options exist with variable impact on the QoL, (e.g. chronic lymphocytic leukaemia (CLL)), the implementation of a more collaborative treatment decision-making process, known as shared decision-making (SDM) is essential in facilitating patient care.<sup>42</sup>

The LC GPSs have repeatedly shown that some patients with lymphoma still experience a gap in communication with their doctors as they ask for more information regarding their diagnosis, treatment options, side-effects, and participation in clinical trials. For those who felt they received adequate information, further analysis found them to have a greater understanding of topics around their diagnosis and care and they also felt more confident in the management of their condition.<sup>43</sup>

Over half of patients (57%) in both the BA-HE and AA-HE reported they had the greatest need for information within the first month of diagnosis.

However, when all the patients were asked how they felt about the amount of information given to them around the time they were first diagnosed, two-thirds of patients from AA-HE countries (68%) felt that they had been given the right amount of information compared to about half of patients from BA-HE countries (54%). On the other hand, more patients from the BA-HE countries (37%) compared to AA-HE patients (27%) felt they were not given enough information (Figure 8). More patients from BA-HE countries (6%) also reported feeling that they were given too much information compared to AA-HE patients (2%) though this number was small in both instances (Figure 8).

**Figure 8. Patients' experience with the amount of information given to them at diagnosis**



Almost two-thirds of patients from AA-HE countries (65%) were told their lymphoma subtype at diagnosis compared to half (49%) of BA-HE patients (Table 11).

More AA-HE patients (about half) also received and understood better the information given to them on their different medical options, the processes and stages of their care, and management of side effects of treatment (if they were treated) compared to BA-HE patients (about a third) (Table 11).

**Table 11. Information experiences at diagnosis**

Information experiences at diagnosis of lymphoma or CLL	BA-HE	AA-HE
Patients who were told their lymphoma subtype	49%	65%
Was information given on the different medical treatment options (including active surveillance) when patients were first diagnosed? Yes, and it was completely understood	34%	50%
Was information given on the processes and the stages of their care? Yes, and it was completely understood	36%	53%
Was information given on how to manage side effects of treatment (for those who started treatment)? Yes, and it was completely understood	33%	44%

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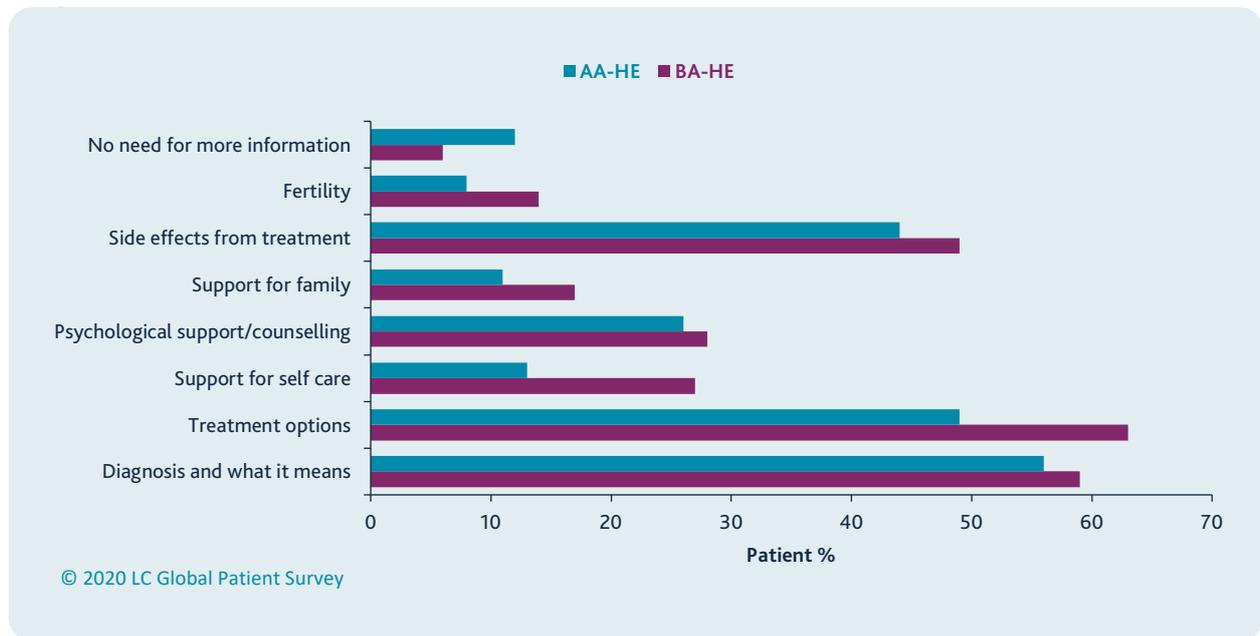
When asked about the areas where more information was required, generally patients from the BA-HE group reported needing more information in all the areas examined compared to patients from the AA-HE group (Figure 9).

The top three areas where more information was needed for both groups of patients were:

1. treatment options (63%- BA-HE; 49%-AA-HE)
2. diagnosis and what it means (59%- BA-HE; 56%-AA-HE); and
3. side effects of treatment (49%- BA-HE; 44%-AA-HE).

AA-HE patients were more likely to report not needing more information in any of the examined areas (12%) than BA-HE patients (6%) (Figure 9).

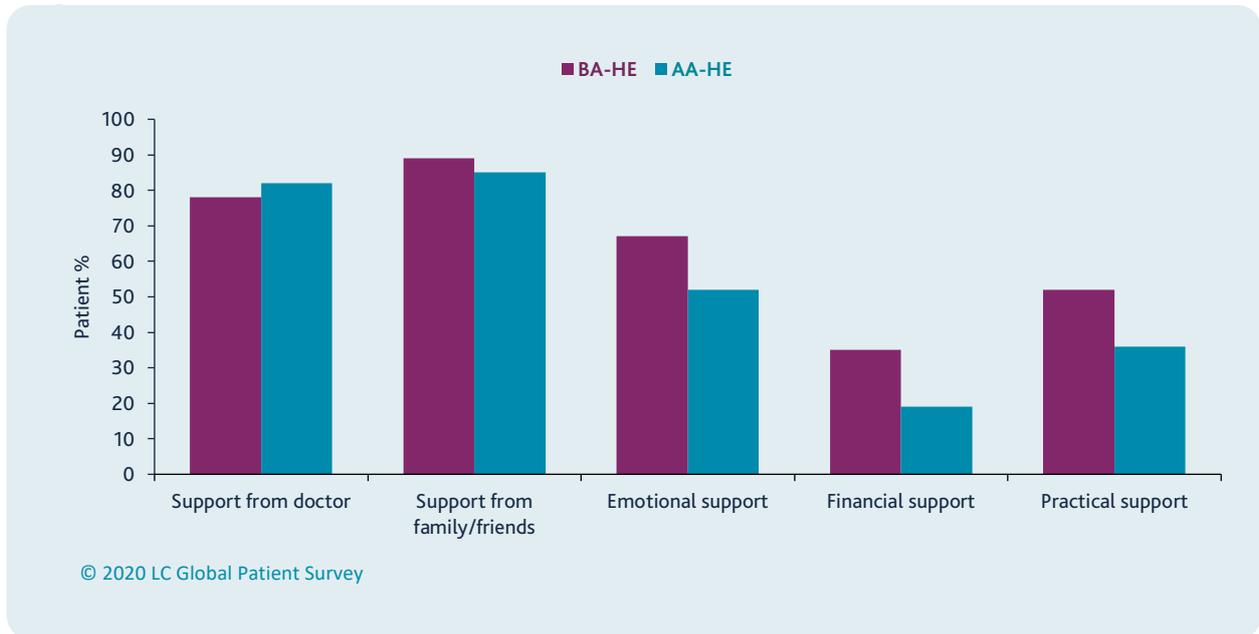
**Figure 9. Areas where patients needed more information**



In addition to information, patients need help and support to help them cope with the challenges they face during their care process. A study examining coping strategies used by patients with lymphoma showed many different strategies are employed. Some patients cope by viewing life through a different lens and working more towards creating short-term goals rather than long-term ones, while others awaken their interest in spiritual beliefs and praying. Some cope by putting up a front of cheerfulness so as not to show their family members their anxieties and fears about their disease, while others cope by trying to put the thoughts of their disease and treatment out of their minds.<sup>42</sup>

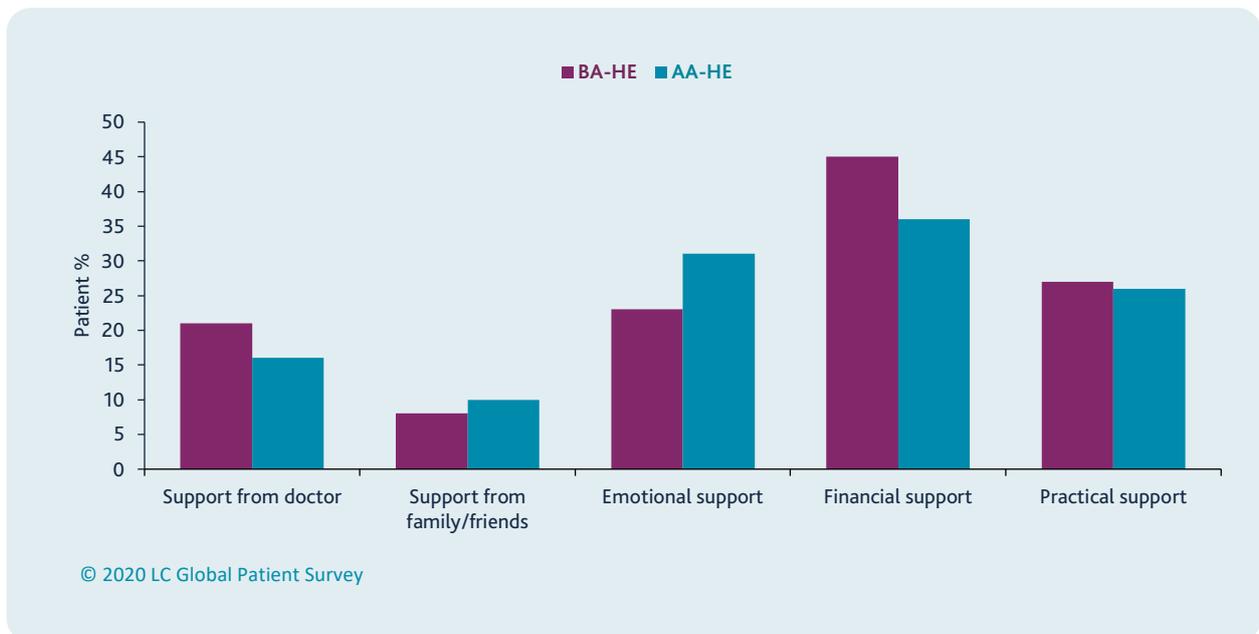
Support from family and friends was needed and received by patients in both BA-HE and AA-HE groups (89% and 85% respectively) and from their doctors (82% and 78% respectively) (Figure 10). Notably, a third of BA-HE patients (35%) needed and received financial support compared to a fifth of AA-HE patients (19%). BA-HE patients were also more in need of emotional and practical support compared to AA-HE patients.

**Figure 10. Patients who needed and received support from the listed areas**



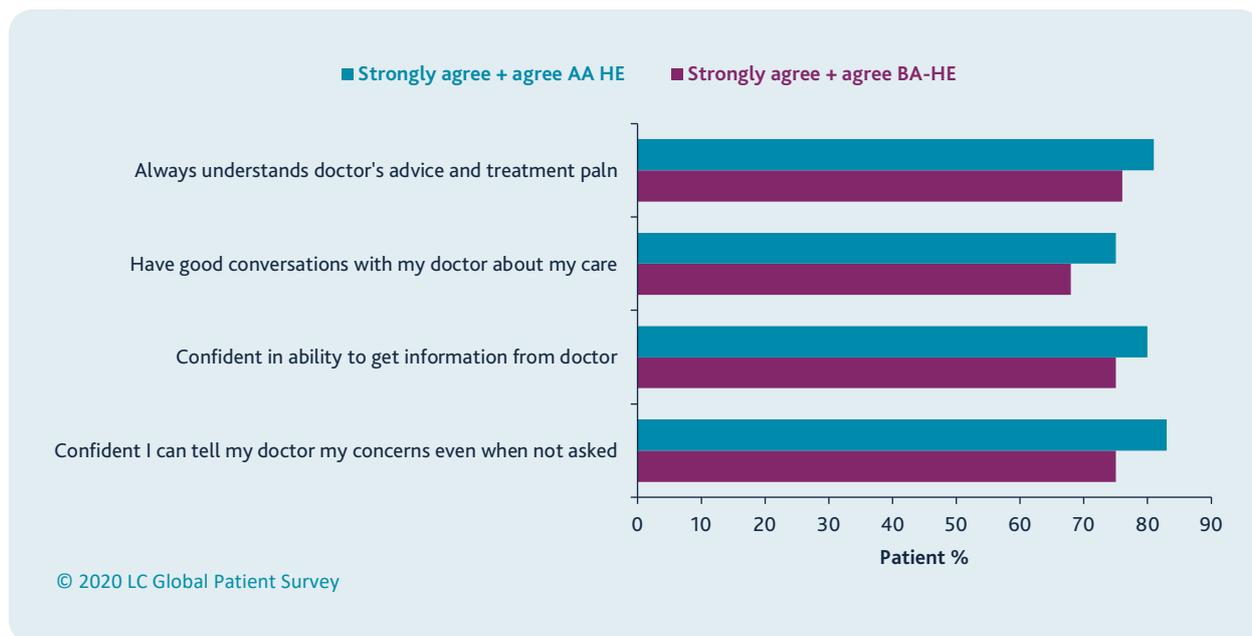
It is very important for patients to receive support for them to have a positive patient experience. **When examining unmet support needs of patients, financial (BA-45%, AA-HE-36%) and practical support (BA-27%, AA-HE-36%) were the two leading areas in both groups where patients needed support but did not receive it, followed by emotional support (BA-23%, AA-HE-31%) and support from the doctor (BA-21%, AA-HE-16%) (Figure 11).**

**Figure 11. Patients who needed support from the listed areas but did not receive it**



Good conversations between the patient and their doctor are crucial to a successful patient experience. About 70% of patients reported having good conversations with their doctors about their care while slightly more patients (75%- BA-HE and 80%- AA-HE) were confident in their abilities to get information from their doctors about their care (Figure 12). A similar proportion of patients felt confident telling their doctors their concerns, even if they were not asked. About 80% of patients in both country groups said they always understood their doctor's advice and treatment plan.

**Figure 12. Patients who agreed + strongly agreed to statements about patient-doctor communication**



Generally, a higher proportion of patients discussed their issues (side effects, fatigue, fear of relapse, depression, and/or anxiety) with their doctors in the AA-HE countries compared to BA-HE countries, while most patients in both groups felt that their doctor was only able to help them to some extent with their issues (Table 12). Almost all patients that had side effects from their treatments in AA-HE countries discussed them with their doctors (96%) but only 23% felt their doctor was definitely able to help them while 55% felt their doctor only helped to some extent. Similarly, 91% of BA-HE patients discussed their side effects and only 22% felt their doctor was definitely able to help them with their side effects while 58% felt their doctor only helped to some extent.

**A lower proportion of patients discussed their psychosocial issues (fear of relapse, anxiety, depression) with their doctors, and of those who did, 50% or more felt their doctor only helped to some extent with their fear of relapse or depression or anxiety in both country groups.**

Most patients in both country groups reported that their doctor only followed up to some extent on their fatigue, fear of relapse, depression, or anxiety.

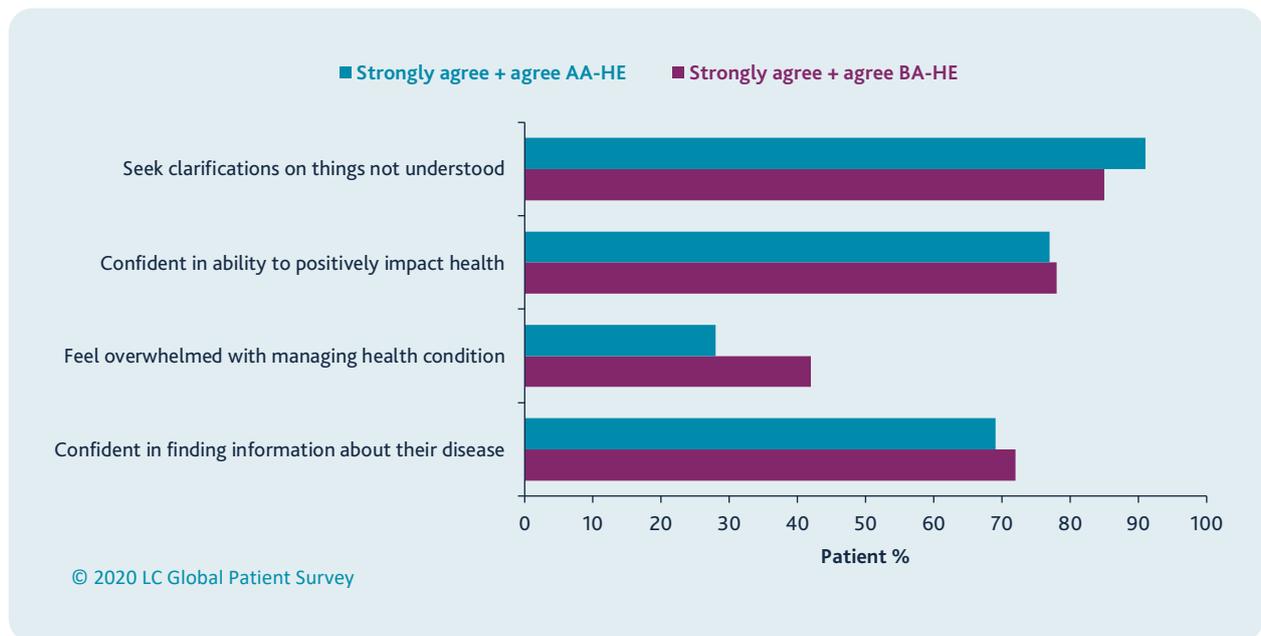
**Table 12. Communication about issues of concern during the patient experience**

Topic		BA-HE (%)	AA-HE (%)
<b>Discussed issues with the doctor</b>			
<b>Side effects</b>	Yes, discussed	91%	96%
	No, not discussed	6%	3%
<b>Fatigue</b>	Yes, discussed	60%	73%
	No, not discussed	36%	24%
<b>Fear of relapse</b>	Yes, discussed	44%	57%
	No, not discussed	55%	42%
<b>Depression</b>	Yes, discussed	31%	46%
	No, not discussed	66%	52%
<b>Anxiety</b>	Yes, discussed	37%	56%
	No, not discussed	59%	42%
<b>Doctor provided help</b>			
<b>Side effects</b>	Yes, definitely	22%	23%
	Yes, to some extent	58%	55%
	No	20%	21%
<b>Fear of relapse</b>	Yes, definitely	28%	31%
	Yes, to some extent	51%	50%
	No	20%	19%
<b>Anxiety</b>	Yes, definitely	21%	25%
	Yes, to some extent	63%	51%
	No	17%	25%
<b>Depression</b>	Yes, definitely	23%	25%
	Yes, to some extent	61%	52%
	No	13%	22%
<b>Doctor followed-up on issues</b>			
<b>Depression</b>	Yes, definitely	32%	27%
	Yes, to some extent	39%	49%
	No	19%	31%
<b>Fear of relapse</b>	Yes, definitely	26%	27%
	Yes, to some extent	38%	40%
	No	31%	30%
<b>Anxiety</b>	Yes, definitely	29%	25%
	Yes, to some extent	40%	40%
	No	23%	33%
<b>Fatigue</b>	Yes, definitely	27%	20%
	Yes, to some extent	41%	37%
	No	26%	4%

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Patients were asked how much they agreed with statements describing their ability to handle their disease (Figure 13). Patients from both country groups similarly agreed with all the statements in all but one of the categories examined. **More patients from the BA-HE group (42%) reported feeling overwhelmed with managing their health condition than patients from AA-HE countries (28%).**

**Figure 13. Patients who agreed + strongly agreed to statements about patient's ability to deal with their disease**



**Patients need to be supported throughout their care experience and referred to relevant resources by their healthcare providers when needed. This is required not only for physical or medical ailments, but doctors should also actively seek out and help with the psychosocial issues that patients may have too.**

Help and support from the healthcare workers is also crucial. Patients mention wanting to be treated as an individual rather than an object of clinical attention.<sup>44</sup> Nurses can play a key role in this regard by encouraging patients who are receiving treatment and giving them informational support. Referral by healthcare workers to patient support and advocacy groups that are dedicated to supporting patients have also been found to be very useful. When it comes to social relationships, the role that family and friends play in providing physical and emotional support is a major key to having good patient outcomes.<sup>45-46</sup>

**Healthcare providers need to continue to work with patients to explore and fulfil their information needs, coping strategies, and support requirements, and in conjunction with the patients and caregivers develop individualised care plans to empower patients to cope effectively during their patient experience.**

## IMPACT OF COVID-19 ON THE LYMPHOMA PATIENT EXPERIENCE

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The coronavirus disease 2019 (Covid-19) was first detected in December 2019 and declared a pandemic by the World Health Organisation (WHO) on 11 March 2020. This pandemic has exhausted the capacity of health systems and resources around the world and has had major consequences on non-Covid-19 medical care, including cancer care. **Research has shown that patients with hematologic malignancies experience more complications, morbidities, and higher mortality rates due to Covid-19 than the general population.**<sup>47-49</sup> In addition to the vulnerabilities that patients with lymphoma face in terms of contracting Covid-19, the pandemic has also impacted the management and care of their cancer.

Patients have experienced difficulties in accessing and completing necessary diagnostic and staging tests in a timely manner.<sup>50</sup> Reasons for this include laboratory activities being reorganized to facilitate the development and deployment of reliable tests for Covid-19, staff shortages and elective surgical procedures (including lymph node biopsies needed to confirm lymphoma diagnosis) which have been restricted to make room for urgent life-saving interventions. **In addition, the pandemic has resulted in the reluctance of some people to visit healthcare facilities, even when they are symptomatic.**<sup>51</sup> **This has implications for cancer diagnosis as patients cannot be diagnosed if they never see a doctor.**

When it comes to treatment decisions in patients with cancer, oncologists are having to revise their treatment protocols to minimize the number of inpatient visits required as well as to reduce the level of immunosuppression.<sup>52</sup> Some patients have had procedures such as stem cell transplants and CAR T-cell therapy therapy postponed due to the potential need for acute care with these treatments, something not easily provided as patients with Covid occupied intensive care units. These therapy changes could have a negative consequence on patients' clinical outcomes. Additionally, a lot more patients have experienced their medical appointments via telemedicine, where patients are able to speak with their doctors via video conferencing on computers or phones. This experience may have unintended negative consequences such as the inability of the doctor to pick up on physical signs of the disease and the body language of the patient that they would normally see in an in-person interaction, which may lead to the doctor missing out on important cues that could guide the patient's treatment.

There is also an increased risk of misunderstandings. The inability for caregivers to attend face-to-face appointments due to hospital restrictions has meant patients need to ask all necessary questions, take notes, etc. There is no one with them to provide general support. This can be especially difficult for someone newly diagnosed who is still struggling to grasp the terminology and understand their disease.

The impact of Covid-19 has been shown to increase the stress, anxiety, and depression of patients with cancer. This has been attributed to the added stressors of social distancing, home restrictions and isolation, job loss and constant exposure to stressful news, added to the ever-present uncertainties about diagnosis and treatment.

For more on the impact of Covid-19 on cancer care in general and in lymphomas in particular please read the [Lymphoma Coalition 2020 Report Card on Lymphomas](#).

World Lymphoma Awareness Day (WLAD), held every year on 15<sup>th</sup> September, is a day dedicated to raising awareness of lymphoma. WLAD 2021 focused on ending the unintended consequences the pandemic has put on the lymphoma community with the theme **"We Can't Wait"**:

- We can't wait to know and notice signs and symptoms of lymphoma.
- We can't wait to diagnose and treat lymphomas as we advocate for the safe resumption of standard clinical protocols and practices.
- We can't wait to support people living with lymphomas - we will always need the help of volunteers and supporters for the lymphoma community.

## LIMITATIONS OF THE SURVEY

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It is important to remember that some of the differences in patient reporting noticed between the BA-HE and AA-HE country groups could be due to the differing demographic make-up of the groups and as such should be interpreted with that in mind. For example, the differences in information experiences and support needs could also reflect the age difference between the two country groups. Prior analysis of the GPS has shown that patients in the younger age groups report needing more information and support than the patients in the older age groups.<sup>53-54</sup>

Secondly, the results of the survey are only reflective of patients with lymphoma who responded to our survey and will be biased towards their experiences. There may be other experiences outside the reported ones that were never captured for the European region.

Research highlighting patient experience is a growing and necessary field to help advance the understanding of lymphomas and inform medical product development. LCE will continue to use available data from the GPS to advance the patients' voices in Europe and work towards ensuring equity in lymphoma outcomes.

# Conclusion and Recommendations

<p><b>1</b></p>	<p>The burden of lymphoma is high in terms of incidence mortality and cost.</p>
<p>1.1</p>	<p><b>How LCE can help:</b> Support patient organisations in collecting evidence on the total amount of lymphoma burden in their respective countries and develop cost analyses to inform recommendations.</p>
<p> </p>	<p><b>High-Level Plan:</b> Over the next two years, work with patient organisations to help identify evidence-based information that will inform policy development and address gaps or inequities in the allocation of budgetary and/or health resources.</p>
<p>1.2</p>	<p><b>How LCE can help:</b> Provide guidance to policymakers and health planners who manage cancer registries to help change practice and invest in new ways of collecting data by lymphoma subtype.</p>
<p></p>	<p><b>High-Level Plan:</b> Develop strategies aimed toward encouraging registries to track lymphoma by subtype and advise on data collection standards and guidelines. (For example: data provided by ENCR affiliated cancer registries for publication on the European Cancer Information System that does not presently differentiate between the more than 80 different subtypes.)</p>
<p>1.3</p>	<p><b>How LCE can help:</b> Make available up-to-date lymphoma data and other relevant information in a centralized location.</p>
<p> </p>	<p><b>High-Level Plan:</b> Advocate for registries to fully integrate patient reported outcomes and clinical data, particularly for rare lymphomas. Concurrently, ensure LC provides updated and publicly accessible information on the LC Clinical Trials Database for phases II and III.</p>

Lymphoma Coalition has a 5-year strategic plan based on two pillars of activity:



**1. Advocacy**



**2. Information**

The following explains actions LCE will take to address the identified inequities, within these two defined work areas.

<p>2</p>	<p>Disparities exist in European patient experiences, with patients in countries with above average health expenditure generally reporting faster diagnoses, better communication with doctors and absence of barriers to care than patients in countries with lower-than- average health expenditure.</p>
<p>2.1</p>	<p><b>How LCE can help:</b> Work with National Societies and the European Lymphoma Institute (ELI) to promote strategies oriented to improving diagnosis and treatment decision-making.</p>
	<p><b>High-Level Plan:</b> Support the work of ELI in building recommendations for a well-functioning lymphoma clinic.</p>
<p>2.2</p>	<p><b>How LCE can help:</b> Connect the scientific or clinical community with the patient advocacy community to drive evidence-based information sharing and improve access to support and information.</p>
 	<p><b>High-Level Plan:</b> Work with the scientific, clinical, and patient organisations to update clinical practice guidelines, produced by EHA-ESMO, to reflect newly approved therapies and ensure the best standards of care for patients with lymphoma. Further, support the adoption of concrete and consensus-based recommendations developed by the Coalition For Reducing Bureaucracy In Clinical Trials across the European Union. Further, LCE can participate in workshops, contribute to scientific programmes, and/or disseminate information specific to clinical research to LC member organisations.</p>
<p>2.3</p>	<p><b>How LCE can help:</b> Work with patient organisations to ensure their digital platforms (website) and materials are up to date and medically vetted.</p>
	<p><b>High-Level Plan:</b> Consult with and/or advise patient organisations on best practices and governance strategies to help ensure their digital platforms (website) contain updated and evidence-based information, particularly with respect to novel therapies such as immunotherapies.</p>

<p>3</p>	<p>Analysis of the 2020 GPS on Lymphoma &amp; CLL showed that some issues transcend economic disparities and affect all patients. This includes:</p> <ul style="list-style-type: none"> <li>i. Late diagnosis was experienced by patients in both groups</li> <li>ii. Quality-of-life issues in both groups were similar, with fatigue, fear of cancer relapse and fear of cancer progression being the top physical and psychosocial issues for patients.</li> </ul>
<p>3.1</p>	<p><b>How LCE can help:</b> Raise awareness of lymphoma and CLL on World Lymphoma Awareness Day and throughout the year.</p>
<p> </p>	<p><b>High-Level Plan:</b> Increase awareness of across the lymphoma care and treatment pathways by developing and disseminating information.</p>
<p>3.2</p>	<p><b>How LCE can help:</b> Champion the recognition of fatigue as diminishing patients' quality of life and actively work to introduce active monitoring of fatigue in the lymphoma care pathway.</p>
<p> </p>	<p><b>High-Level Plan:</b> Leverage the GPS to increase awareness of fatigue as a symptom and side effect. Support the adoption of active monitoring as outlined in cancer-related fatigue clinical practice guidelines to improve quality of care and inform fatigue management plans. Relevant patient-centric information will be widely disseminated to member organisations.</p>
<p>3.3</p>	<p><b>How LCE can help:</b> Build an evidence-based framework of systemic patient-centric questions to guide physician-patient communication.</p>
<p></p>	<p><b>High-Level Plan:</b> Promote a patient-centric approach to physician-patient communication by developing questions that ensure patient concerns are addressed, to guide communication and support individual treatment plans. Thought will be given to health literacy issues when developing these tools.</p>
<p>3.4</p>	<p><b>How LCE can help:</b> Connect doctors and patients with local patient organisations to provide support with physical, emotional, and/or practical needs.</p>
<p></p>	<p><b>High-Level Plan:</b> Identify patient organisations that offer psychosocial or supportive services to patients with lymphoma, through stakeholder mapping, to support seamless integrated care.</p>

<p><b>4</b> Patient experience data is necessary to foster a patient-centred healthcare environment. All relevant evidence must be integrated to drive cost-effective health interventions, policy, and recommendations to achieve holistic care.</p>	
<p><b>4.1</b></p>	<p><b>How LCE can help:</b> Work for the inclusion of the patient perspective across the life cycle of medicine.</p>
	<p><b>High-Level Plan:</b> Equip member organisations with the knowledge and skills to act locally in support of the inclusion of patient perspectives. For example, offer e-learning opportunities (online seminars) to member organisations who wish to increase their knowledge or understanding of the best practices of regulatory agencies and HTA bodies in their respective region.</p>
<p><b>4.2</b></p>	<p><b>How LCE can help:</b> Connect and partner with clinicians and stakeholders to share evidence-based knowledge in support of multidisciplinary, continuous, and participative care.</p>
 	<p><b>High-Level Plan:</b> Highlight the key findings of the GPS and present at the LC Global Summit, external scientific programmes (such as EBMT, EHA, and others), and/or submit for publication in evidence-based journals.</p>
<p><b>4.3</b></p>	<p><b>How LCE can help:</b> Utilise Community Advisory Boards (CABs) to help build research that examines key areas of shared priorities, interests, and/or concerns.</p>
	<p><b>High-Level Plan:</b> Host stakeholder dialogues to generate insights, inform or define priorities, and propose strategies to support implementation within national health systems across a broad spectrum of topics including rare cancers. For example, inform ERN EuroBloodNet and the Rare Cancer ePAGs initiatives to improve patient health outcomes or the acceleration of the Rare Cancer Agenda 2030 and inclusion of rare lymphomas in Europe's Beating Cancer Plan implementation. As well, design and deliver enhanced training to CAB members to increase their engagement and support the expansion of the CAB model.</p>
<p><b>4.4</b></p>	<p><b>How LCE can help:</b> Support the adjustment and validation of tools for collecting quality of life and Patient-Reported Outcomes (PRO) and/or other patient-centric measurements.</p>
 	<p><b>High-Level Plan:</b> Inform the validation and integration of PROs to help standardize symptom assessment processes and support the use of aggregated data to drive system-wide improvements in the quality of care</p>
<p><b>4.5</b></p>	<p><b>How LCE can help:</b> Anchor health literacy as a key factor of health promotion and quality of life.</p>
	<p><b>High-Level Plan:</b> Address health literacy as a barrier to access and an influential factor in determining patient outcomes and quality of life with key stakeholders to help inform position statements, policy development, or shared strategic actions.</p>

<p>5</p>	<p>Covid-19 pandemic has redefined the way medical care (and cancer care in particular) is given. It has also affected the functioning of some patient organisations by putting a strain on their finances, staff availability and overall sustainability. Patient organisations should continue to work with the rest of the lymphoma community to highlight and work towards resolving the issues that patients, their caregivers, and the organisations themselves face in relation to their care during this pandemic.</p>
<p>5.1</p>	<p><b>How LCE can help:</b> Coordinate efforts to strengthen patient organisational management and governance structure to help increase effectiveness, performance, and impact.</p>
<p> </p>	<p><b>High-Level Plan:</b> Support patient organisations in achieving good governance practices by providing information and opportunities for e-learning.</p>
<p>5.2</p>	<p><b>How LCE can help:</b> Use the GPS to collect data on issues, including how Covid-19 affects the healthcare of patients with lymphoma.</p>
<p> </p>	<p><b>High-Level Plan:</b> Analyse data and disseminate information on key or emerging issues. For example, use data to prepare position statements, inform policy discussions, promote engagement and sharing of perspectives, identify new opportunities to accelerate shared priorities, or promote awareness between patient organisations, policymakers, and others.</p>

## How can you help?

Improving care for those affected by lymphoma requires the cooperation and effort of many stakeholders.

If you have ideas on what else can be done or would like to see how you can get involved in Lymphoma Coalition's plans, please email [info@lymphomacoalition.org](mailto:info@lymphomacoalition.org).

If you represent a patient advocacy organisation and would like to be a Member of Lymphoma Coalition, you can find more information at [lymphomacoalition.org/membership](https://lymphomacoalition.org/membership).



# References

1. Jaffe E, Swerdlow S, Vardiman J. Haematopoietic and lymphoid malignancies. In Stewart B and Wild C (eds). World Cancer Report 2014. Lyon, France: International Agency for Research on Cancer, World Health Organization, 2014;482-494.
2. Know your subtype. Lymphoma Coalition (2018) [https://lymphomacoalition.org/home/know\\_your\\_subtype](https://lymphomacoalition.org/home/know_your_subtype).
3. The Global Cancer Observatory 2020. <https://gco.iarc.fr/today/fact-sheets-cancers>. Last accessed September 23, 2021.
4. Estimates of cancer incidence and mortality in 2020, for all countries. European Cancer Information System [Website](#). Last accessed September 22, 2021.
5. OECD (2019). "Measuring what matters for people-centred health systems", in *Health at a Glance 2019: OECD Indicators*, OECD Publishing, Paris, <https://doi.org/10.1787/4bbba455-en>.
6. Burns R, Leal J, Sullivan R, Luengo- Fernandez R (2016). Economic burden of malignant blood disorders across Europe: a population-based cost analysis. *The Lancet Haematology* 3 (8), 3362-e370. [https://doi.org/10.1016/S2352-3026\(16\)30062-X](https://doi.org/10.1016/S2352-3026(16)30062-X).
7. Mounié M, Costa N., Conte C. et al. (2020) Real-world costs of illness of Hodgkin and the main B-Cell Non-Hodgkin lymphomas in France, *Journal of Medical Economics*, 23:3, 235-242. doi:10.1080/13696998.2019.1702990.
8. Bugge C; Brustugun O; Sæther E; Kristiansen I. Phase- and gender-specific, lifetime, and future costs of cancer, *Medicine: July 02, 2021 - Volume 100 - Issue 26 - p e26523* doi:10.1097/MD.00000000000026523.
9. Wang H, Roman E, Crouch S, Aas E, Burton C, Patmore R and Smith A. A Generic Model for Follicular Lymphoma: Predicting Cost, Life Expectancy, and Quality-Adjusted-Life-Year Using UK Population-Based Observational Data, *Value in Health*, Volume 21, Issue 10, 2018, Pages 1176- 1185, ISSN 1098-3015, <https://doi.org/10.1016/j.jval.2018.03.007>.
10. Wang H, Smith A, Aas E et al. Treatment cost and life expectancy of diffuse large B-cell lymphoma (DLBCL): a discrete event simulation model on a UK population-based observational cohort. *Eur J Health Econ* **18**, 255–267 (2017). <https://doi.org/10.1007/s10198-016-0775-4>.
11. Darbà J and Marsà A (2021) Burden of Hodgkin and non-Hodgkin lymphoma in Spain over a 10-year period: productivity losses due to premature mortality, *Expert Review of Pharmacoeconomics & Outcomes Research*, 21:1, 87-92, doi:10.1080/14737167.2020.1769478.

12. Heine R, Thielen FW, Koopmanschap M et al. Health Economic Aspects of Chimeric Antigen Receptor T-cell Therapies for Hematological Cancers: Present and Future. *Hemasphere*. 2021;5(2): e524. Published 2021 Jan 28. doi:10.1097/HS9.0000000000000524.
13. Fitch MI, Porter HB, Page BD Supportive care framework: a foundation for person-centered care.
14. Rand L, Dunn M, Slade I et al. Understanding and using patient experience as evidence in healthcare priority setting. *Cost Eff Resource Allocation* (2019) 17:20 <https://doi.org/10.1186/s12962-019-0188-1>.
15. Abahussin, A. et al. (2018), "PROMs for Pain in Adult Cancer Patients: A Systematic Review of Measurement Properties", *Pain Practice*, Vol. 19/1, pp. 93-117. <http://dx.doi.org/10.1111/papr.12711>.
16. Donovan, J. et al. (2016), "Patient-Reported Outcomes after Monitoring, Surgery, or Radiotherapy for Prostate Cancer", *New England Journal of Medicine*, , Vol. 375/15, pp. 1425-1437. <http://dx.doi.org/10.1056/nejmoa1606221>.
17. Hamdy, F. et al. (2016), "10-Year Outcomes after Monitoring, Surgery, or Radiotherapy for Localized Prostate Cancer", *New England Journal of Medicine*, , Vol. 375/15, pp. 1415-1424. <http://dx.doi.org/10.1056/nejmoa1606220>.
18. Veroff D, Marr A, Wennberg DE. Enhanced support for shared decision-making reduced costs of care for patients with preference-sensitive conditions. *Health Aff (Millwood)*. 2013 Feb;32(2):285-93. doi:10.1377/hlthaff.2011.0941. PMID: 23381521.
19. Arora NK. Can You Hear Me Now? Importance of Assessing Patients' Cancer Care Experiences. *Journal of Oncology Practice* 13, no. 8 (August 01, 2017) 515-518. doi:10.1200/JOP.2017.025130. Epub 2017 Jul 24. PMID: 28737962.
20. Living with cancer: A report on the patient experience. Canadian Partnership Against Cancer. Toronto (ON): Canadian Partnership Against Cancer; 2018 Jan. <https://s22457.pcdn.co/wp-content/uploads/2019/01/Living-with-cancer-report-patient-experience-EN.pdf>. Last accessed September 7, 2021.
21. World Health Organization Global Health Expenditure database (<apps.who.int/nha/database>). <https://apps.who.int/nha/database/ViewData/Indicators/en> Last accessed, March 11, 2022.
22. Neal RD, Tharmanathan P, France B, et al. Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? systematic review. *Br J Cancer* 2015;112: S92-107. 10.1038/bjc.2015.48.
23. Howell D, Hart R, Smith A, Macleod U, Patmore R, Roman E. 'Unpacking' pathways to lymphoma and myeloma diagnosis: Do experiences align with the Model of Pathways to Treatment? Findings from a UK qualitative study with patients and relatives. *BMJ Open*. 2020;10(2): e034244. Published 2020 Feb 12. doi:10.1136/bmjopen-2019-034244.
24. Wall C, Glenn S and Pole H (2011) Experiences prior to diagnosis of non-Hodgkin lymphoma: a phenomenological study. *Journal of Advanced Nursing*, 67(11), 2363-2372. doi:10.1111/j.1365-2648.2011.05657.x.
25. Obtel M, Berraho M, Abda N, et al. Factors Associated with Delayed Diagnosis of Lymphomas: Experience with Patients from Hematology Centers in Morocco. *Asian Pac J Cancer Prev*. 2017;18(6):1603-1610. Published 2017 Jun 25. doi:10.22034/APJCP.2017.18.6.1603.
26. Chircop D, Scerri J (2017): Being diagnosed with cancer: The experience of patients with non-Hodgkin's lymphoma. *Journal of Clinical Nursing*, 26(23-24),4899-4904. doi:10.1111/jocn.13967.

27. Howell DA, Smith AG, Jack A, et al. Time-to-diagnosis and symptoms of myeloma, lymphomas and leukaemias: a report from the haematological malignancy research network. *BMC Blood Disord* 2013; 13:9 10.1186/2052-1839-13-9.
28. Kane E, Howell D, Smith A, et al. Emergency admission and survival from aggressive non-Hodgkin lymphoma: a report from the UK's population-based haematological malignancy research network. *Eur J Cancer* 2017; 78:53–60. 10.1016/j.ejca.2017.03.013.
29. Nixon S, Bezverbnaya K, Maganti M et al. Evaluation of lymphadenopathy and suspected lymphoma in a lymphoma rapid diagnosis clinic. *JCO Oncology Practice* 16, no 1 (January 01, 2020) e-29-e36 doi:10.1200/JOP.19.00202.
30. Ferrell BR, Hassey Dow K, Grant M. Measurement of the quality of life in cancer survivors. *Qual Life Res.* 1995; **4**:523–531.
31. Allart-Vorelli P, Porro B, Baguet F, Michel A and Cousson-Gélie F. Haematological cancer and quality of life: a systematic literature review.
32. Heinonen H, Volin L, Uutela A, Zevon M, Barrick C, Ruutu T. Quality of life and factors related to perceived satisfaction with quality of life after allogeneic bone marrow transplantation. *Ann Hematol.* 2001; **80**:137–143. [[PubMed](#)] [[Google Scholar](#)]
33. Allart P, Souberyran P. & Cousson-Gélie F. (2012). Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of literature.
34. Ng D, Leong Y, and Gan G (2016). Quality of life among lymphoma survivors in developing countries. *Supportive care in cancer*, 24 (12), 5015-5023. doi:10.1007/s00520-016-3364-2
35. Lymphoma Coalition Global Patient Survey on Lymphomas and CLL 2020 <https://lymphomacoalition.org/wp-content/uploads/LC-2020-GPS-Global-Report-Final.pdf>.
36. Kim S, Kang D, Kim I et al. (2019) Impact of fear of cancer recurrence on survival among lymphoma patients. *Psycho-oncology* doi:10.1002/pon.5265.
37. Trevino k, Martin P, Chen Z, Leonard J (2021) Worsening quality of life of Indolent Non-Hodgkin Lymphoma and Chronis Lymphocytic Leukaemia patients in Active surveillance: A 12-month longitudinal study. *Clinical lymphoma Myeloma and Leukaemia*.
38. Franco K, Shuk E, Philip E, et al. Communication between oncologists and lymphoma survivors during follow-up consultations: A qualitative analysis. *J Psychosoc Oncol.* 2017;35(5):513-530. doi:10.1080/07347332.2017.1313352.
39. Trachtenberg E, Gurin R, Mashiach T, Tadmor T, et al (2019). Recognizing sever fatigue and decline in quality of life in Hodgkin lymphoma survivors. *Leukaemia & Lymphoma*, 1-6. doi:10.1080/10428194.2019.1641803.
40. Epstein E, Street R Jr. Patient centered communication in cancer care: Promoting healing and reducing suffering. NCI, 2007.
41. Gilligan T, Coyle N, Frankel R et al Patient-Clinician communication: American Society of Clinical Oncology Consensus guideline. *J.Clin Oncol.* 36 (2017) 3618-3622.
42. LeBlanc TW, Baile WF, Eggy S et al. Review of the patient-centered communication landscape in multiple myeloma and other hematologic malignancies.
43. Dren. N, Warwick, L., Van Rassel, K., Moysiadis, T., Karamanidou, C., Xochelli, A. (2018). Correlation of lymphoma patient information level with healthcare experience. *Blood*, 132(supplement 1): 4782. <https://doi.org/10.1182/blood-2018-99-115392>.
44. Chircop, D, Scerri J (2017) Coping with non-Hodgkin's lymphoma: a qualitative study of patient perceptions and supportive care needs whilst undergoing chemotherapy. *Supportive care in Cancer*, 25 (8), 2429-2435. doi:10.1007/s00520-017-3649-0.

45. Hung CT, Chen YJ, Chan JC, Fang YY, Li IF, Shih HH, Ku HY, Chiu WT, Lee YH. Psychological distress, social support, self-management ability and utilization of social resources for female patients with cancer in Oncology Outpatient Settings in Taiwan. *Support Care Cancer*. 2020 Jul;28(7):3323-3330. doi:10.1007/s00520-019-05143-y. Epub 2019 Nov 22. PMID: 31758322.
46. Korotkin BD, Hoerger M, Voorhees S, Allen CO, Robinson WR, Duberstein PR. Social support in cancer: How do patients want us to help? *J Psychosoc Oncol*. 2019 Nov-Dec;37(6):699-712. doi:10.1080/07347332.2019.1580331. Epub 2019 Apr 1. PMID: 30929593.
47. Wood WA, Neuberg DS, Thompson JC et al. Outcomes of patients with hematologic malignancies and COVID-19: a report from the ASH Research Collaborative Data Hub. *Blood Adv*. 2020 Dec 8;4(23):5966-5975. doi:10.1182/bloodadvances.2020003170. PMID: 33278301; PMCID: PMC7724912.
48. Shah V, Ko Ko T, Zuckerman M, et al. Poor outcome and prolonged persistence of SARS-CoV-2 RNA in COVID-19 patients with haematological malignancies; King's College Hospital experience. *Br J Haematol*. 2020;190(5): e279-e282. doi:10.1111/bjh.16935.
49. Martín-Moro F, Marquet J, Piris M, et al. Survival study of hospitalised patients with concurrent COVID-19 and haematological malignancies. *Br J Haematol*. 2020;190(1): e16-e20. doi:10.1111/bjh.16801.
50. Isidori A, de Leval L, Gergis U, Musto P, Porcu P. Management of patients with hematologic malignancies during the COVID-19 pandemic: Practical considerations and lessons to be learned. *Front Oncol*. 2020; 10:1439. Published 2020 Aug 14. doi:10.3389/fonc.2020.01439.
51. Helsper CW, Campbell C, Emery J, et al. Cancer has not gone away: A primary care perspective to support a balanced approach for timely cancer diagnosis during COVID-19. *Eur J Cancer Care (Engl)*. 2020;29(5): e13290. doi:10.1111/ecc.13290.
52. Rosenbaum L. The untold toll- The pandemic's effects on patients without Covid-19. *N Engl J Med*. 2020; 382:2368-2371. Published 2020 Jun 11. doi:10.1056/NEJMms2009984.
53. Cordoba, R., Bolanos N., Warwick L. & Dren, N. (2020). Age-related lymphoma patient experience: Results from the Lymphoma Coalition 2018 Global Patient Survey. *Journal of Clinical Oncology*, 38 (Suppl; abstr e20071). doi:10.1200/JCO.2020.38.15\_suppl.e20071.
54. Bamigbola O. and Warwick L. (2021) Age-Related Differences in the Informational Experiences and Needs of Patients with Lymphoma: Results from the 2020 Lymphoma Coalition Global Patient Survey 2021. <https://ash.confex.com/ash/2021/webprogram/Paper148525.html>.
55. United Nations Statistical Division: Methodology- Standard country or area codes for statistical use (M49) UN. <https://unstats.un.org/unsd/methodology/m49>. Last accessed October 29, 2021.
56. World Health Organization. Regional Office for Europe. <https://www.euro.who.int/en/countries/>. Last accessed October 29, 2021



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