2014 LeIP REPORT CARD ON LYMPHOMAS

LYMPHOMA COALITION

Worldwide Network of Lymphoma Patient Groups

Lymphoma eInformation Project (LeIP)

While it's encouraging that new molecules and combination therapies are being developed and approved at the regulatory level, it is not very encouraging that so few are actually accessible to the patient.

ABOUT LYMPHOMA COALITION

The Lymphoma Coalition (LC), a worldwide network of lymphoma patient groups, was formed in 2002 and incorporated in 2010 with the express purpose of facilitating lymphoma patient organisations around the world to form a community that could support one another's efforts in helping patients with lymphoma receive the care and support needed. LC is a not-for-profit organisation with 60 member organisations from 43 countries.

The need for a global coalition was recognised as a way of helping lymphoma organisations share resources and best practices. In addition, LC recognised the need for a central hub of up-to-date, evidence-based information about lymphoma and its management.

SPECIAL THANKS to all patients and the LC member organisations who offered their insight and support as well as to the many other organisations, government agencies, pharmaceutical companies, pharmacists and individuals who generously shared their knowledge, resources and understanding for this report.

Thank you to the editorial committee for making time to review the report: Dr. Laurie Sehn, Guy Bouguet, Pru Etcheverry, Brian Tomlinson and Anna Williamson.

Thank you to Celgene Corporation and Millennium: The Takeda Oncology Company for supporting LeIP over the past three years. Your funding is critical to this project as LC builds the lymphoma story. Thank you also to Pfizer Inc. and F. Hoffmann-La Roche for your 2014 financial support and to the Gilead team for your information support. The support from each of you demonstrates your commitment to patient care.

LeIP TEAM: Karen Van Rassel, Leonie Bedford, Sarah Malleau and Shawn Sajkowski

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MESSAGE FROM THE EXECUTIVE DIRECTOR

Karen Van Rassel
Executive Director
Lymphoma Coalition

Over the last three years, the Lymphoma Coalition (LC) has been gathering data and statistics to help tell the lymphoma story. In 2012, global and local information was gathered on standards of care, clinical trials, treatment availability and demographics. In 2013 LC built on this information by examining the regulatory and funding/reimbursement processes and procedures to see if therapies were reaching patients in a timely and cost-effective manner. As the 2013 LeIP Report Card on Lymphomas highlighted, patients faced many barriers. In 2014, LC has undertaken a review of what therapies patients actually have access to and how many of those therapies are new molecules, in combination or available through clinical trials. As will be seen in this report card, the findings suggest clearly that access is not equitable between or within regions worldwide and it is discouraging to know that it is not getting better.

LC is fortunate in the ongoing partnership with the INTERLYMPH Consortium. Through this partnership, LC is kept up-to-date on the latest research results on risk factors and causes of lymphomas. Having this information is very beneficial as it helps substantiate LC's information dissemination. Please refer to the update report provided by INTERLYMPH on page 18.

Information in the 2014 LeIP Report Card on Lymphomas was gathered by LC's researcher Shawn Sajkowski, BBA, and written by LC's healthcare writer Leonie Bedford, BAA, Journalism. Thank you for the tireless work and energy you put into LeIP.

We need to continue our efforts to ensure all patients with lymphomas receive the best care no matter where they live.

MESSAGE FROM THE CHAIR OF THE LC MEDICAL ADVISORY BOARD

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

The 2014 LeIP Report Card on Lymphomas provided by the Lymphoma Coalition represents a sobering document. While advances in lymphoma care continue at a rapid pace, the high cost of many of the newer therapies has led to a worldwide disparity with respect to access. Improved biologic insight has led to the development of a large number of targeted agents that aim to exploit key molecular pathways that are unique to individual lymphoma subtypes. In many instances, these novel agents exhibit improved efficacy while limiting toxicity as normal cells are spared. As a result, therapeutic options have increased and outcomes have improved. While the duration of time from initial drug development to US Food and Drug Administration approval appears to be decreasing, regulatory approval within individual countries and the subsequent delay in funding approval represents an ongoing barrier to access.

The LeIP Report Card on Lymphomas serves to highlight not only restricted access to newer therapies but also to lymphoma specialists and clinical trials. Access to clinical trials is an issue of high priority. In light of the large number of drugs that remain in development, and the many unanswered questions regarding optimal usage of recently approved agents, expansion of clinical trials to underserved areas would be highly valuable. In addition to expediting progress, wider availability of clinical trials would provide crucial access to novel agents and valuable physician experience in many countries where the introduction of these drugs remains delayed. The information provided by the LeIP Report Card on Lymphomas should provide patients and healthcare providers with a barometer of access and may serve as a valuable tool for ongoing advocacy.

MESSAGE FROM THE CHAIR OF THE LC BOARD OF DIRECTORS

Anna Williamson
Head, Research and Advocacy
Leukaemia Foundation of Australia
Chair, LC Board of Directors

As Chair of the Board of the Lymphoma Coalition (LC), I'm very pleased with the progress LC has made in gathering relevant information to strengthen and support the lymphoma story. This has been a three-year undertaking that started in 2012 when we gathered information on lymphoma demographics, clinical trials, standard of care and therapies for five lymphoma subtypes. Building on this information, the 2013 LeIP Report Card on Lymphomas examined the approval processes for new therapies at the government level before they become accessible to patients. LC found that there are a myriad of barriers preventing therapies from reaching patients in a timely and affordable manner.

This year's report card takes a closer look at therapy availability and accessibility. The findings are not encouraging for most member countries. LC found that of the 119 therapies that have received regulatory approval, only four countries among the 43 member countries provide funding/reimbursement approval for 50% or more of these therapies. Without funding or reimbursement, therapies are too expensive for most people. The report has not attempted to include therapies available through special access schemes, hospital-specific drug schemes or other local schemes with restricted access.

LC will continue its efforts in highlighting discrepancies in care so we can work toward finding ways to make therapies and access to the best care more accessible to patients with lymphomas.

OVERVIEW

Over the last three years, the Lymphoma Coalition (LC) has endeavoured to build the lymphoma story in order to present the facts on access to care for patients with lymphomas. Given the extensive amount of information compiled, an online global database search function was created to make it easier for members to access this information on the LC website. Through this database, members can access information on global therapies, clinical trials and demographics by LC member country and subtype.

The goal of this review was to evaluate access to care among LC member countries around therapies, clinical trials and diagnostics. This report highlights which therapies are available to patients through government reimbursement and co-pay methods, including newer molecules and combinations with regulatory approval. This report also includes a brief overview of each country's funding/reimbursement body.

The review includes an examination of the access to clinical trials by member country as this is another way in which patients can access new therapies. What LC found, though, was that availability of clinical trials is not the same in all member countries with some member countries not having any clinical trials available. In spite of the crucial role clinical trials play in the development of new therapies, it is LC's understanding that enrolment in clinical trials continues to decline. In the 2014 LC Lymphoma Global Patient Survey, only 19% of the nearly 3,500 respondents had been approached to participate in a clinical trial compared with 25% in the 2012 global survey.

LC also attempted to determine if patients have access to essential diagnostics within LC member countries. While there are numerous diagnostic guidelines available, it was not possible for LC to determine what guidelines are followed by each LC member country. LC will continue to undertake efforts to find this information.

Like 2013, LC's findings are not very encouraging and demonstrate that access to care is very sporadic. For example, of the 119 therapies that have received regulatory approval in one or more of the LC member countries, for the seven lymphoma subtypes LC has been tracking, only four member countries have granted funding/reimbursement approval for 50% or more. While it's encouraging that new molecules and combinations are being developed and approved at the regulatory level, it is not encouraging that so few of them are actually accessible to patients.

Note: Only countries that are members of LC are included in this analysis. For a listing of all members please visit the LC website.

OBJECTIVES

The objectives of LC's analysis were to:

- Highlight the disparities among countries in terms of accessing therapies as well as clinical trials;
- Determine the degree of accessibility to newer therapies in each country;
- Highlight the importance of early and appropriate diagnosis.

To address the objectives of this review, this report card focuses on four issues:

1. Funding and reimbursement processes by country;
2. Access to therapies by country;
3. Access to phase II and III clinical trials by country;
4. Access to diagnostics.

For this research initiative, LC has been tracking the number of clinical trials and therapies for seven subtypes; namely:

- Burkitt's lymphoma (BL);
- Chronic lymphocytic leukaemia (CLL);
- Diffuse large B-cell lymphoma (DLBCL);
- Follicular lymphoma (FL);
- Hodgkin lymphoma (HL);
- Mantle cell lymphoma (MCL);
- Peripheral T-cell lymphoma (PTCL).

METHODOLOGY

To achieve its goal, LC undertook a review of the regulatory-approved/registered therapies for the seven lymphoma subtypes it has been tracking. This entailed examining what therapies have regulatory approval in each LC member country and, of those therapies, which ones have funding/reimbursement approval. In addition, LC reviewed, by country, the number of clinical trials available. LC attempted to determine to what degree patients have access to the most up-to-date diagnostics in each country for each subtype and found that this information is not readily available. Consequently, LC will continue its research in this area through 2015.

To uncover the information needed the following methodology was used:

- Review of each country's funding/reimbursement process to determine if there is a formal process in place. This was accomplished through review of country websites, member country feedback, industry input and consultations with healthcare providers.
- Review of all regulatory and funded/reimbursed therapy websites, databases and relevant government sites and publications in each country to determine what therapies are actually available to patients. Consultations with member countries and industry were also undertaken.
- An examination of all phase II and III clinical trials by country, population and subtype. This entailed:
  - Reviewing all clinical trial websites listed in the *Clinical Trials Website Resources* chart found on the LC website. Any clinical trial listed on one of these websites that could be tracked and identified on www.clinicaltrials.gov was not counted twice.
  - Subscribing to clinical trial websites and journals and RSS feeds to ensure receipt of updates;
  - Searching for active lymphoma trials via global websites;
  - Reviewing each clinical trial to ensure it was a phase II or III non-observational trial.
- Interviewed healthcare professionals and industry, as well as researched, via government and medical association websites, what diagnostics are available in each country, including haematology-specific diagnostics.

Please note, data on CLL were extrapolated from the GLOBOCAN 2012 data and are a conservative estimate based on 30% of all leukaemia incidence.

DEFINITIONS

Regulatory Approval/Registration

Before a therapy can be sold/proposed to a patient, its efficacy, tolerability and safety have to be assessed by the country's respective regulatory body to ensure that it not only provides benefit but that it can be safely used in humans. Each country has its own process for undertaking this review.

Therapy Funding/Reimbursement Approval

Once a therapy has received regulatory approval, the usual next step is to determine if it will be funded, reimbursed or insured, i.e., who will reimburse or partially reimburse patients who have been prescribed the therapy or what government body will fund a therapy. The types of funders that help with funding are government agencies, insurance companies (private payers) and, at times, the drug industry.

KEY FINDINGS & DISCUSSION

The challenge still exists for patients around the world to equitably receive access to the most up-to-date care. The following are the key findings that illustrate these challenges that confront patients.

1. Funding and Reimbursement Processes

Once a therapy has received regulatory approval, it then has to be determined how or if it will be funded, insured or reimbursed in each country. For information on the length of time reimbursement decisions take, see the 2013 LeIP Report on Card on Lymphomas found on the LC website.

Some form of funding or reimbursement is provided at the government level with most member countries having a formal process in place. Within many of these processes, the performance of a health technology assessment (HTA) is a requirement. The HTA examines the safety, clinical efficacy and effectiveness, as well as the cost and cost-effectiveness of a new therapy to determine how it compares with available therapy alternatives. For more information on HTAs, go to www.htai.org. This information is then used to determine whether or not to fund/reimburse the therapy. Table 1 shows funding/reimbursement bodies by country. The table also notes which countries have an HTA as part of the decision process.

TABLE 1. LC MEMBER COUNTRY FUNDING/REIMBURSEMENT BODIES

LC Member Country	Funding/Reimbursement Body	Undertake an HTA: Yes/No
Europe		
Belgium	Drug Reimbursement Committee (CRM/CTG)	Yes
Bulgaria	National Council on Pricing and Reimbursement	Yes
Croatia	Croatian Health Insurance Fund (HZZO)	Yes
Czech Republic	State Institute for Drug Control (SUKL)	Yes
Denmark	Danish Health and Medicines Authority (DMHA)	Yes
England, N. Ireland	National Institute for Health and Clinical Excellence (NICE)	Yes
France	Transparency Commission	Yes
Germany	Institute for Quality and Efficiency in Health Care (IQWiG)	Yes
Hungary	National Health Insurance Fund Administration (OEP)	Yes
Ireland	National Centre for Pharmacoeconomics (NCPE)	Yes
Italy	Italian Medicines Agency (AIFA) • Funding/reimbursement decision made at national level but implementation is at regional level which can cause delays in new therapies being added to regional formularies	Yes
Latvia	National Health Service (NVD)	Yes
Lithuania	Ministry of Health	Information not available
Macedonia	Ministry of Health	Information not available
Netherlands	Health Care Insurance Board (CVZ)	Yes
Poland	Ministry of Health (MZ)	Yes
Portugal	National Authority of Medicines and Health Products (INFARMED)	No
Russian Federation	Ministry of Health and Social Development	No
Scotland	Scottish Medicines Consortium (SMC)	Yes
Serbia	Serbian Health Insurance Office (RZZO)	Information not available
Slovakia	Categorisation Committee	Yes
Slovenia	Drug Reimbursement Committee	Yes
Spain	Interministerial Commission for Pharmaceutical Prices (CIPM) • Funding/reimbursement decision made at national level but each state then makes own funding/reimbursement decision	Yes
Sweden	Pharmaceutical Benefits Board (TLV)	Yes
Switzerland	Federal Drug Commission (FDC)	Yes
Turkey	Social Security Institution (SGK)	Yes
Ukraine	No funding/reimbursement system in place	No
Wales	All Wales Medicines Strategy Group (AWMSG)	Yes
Asia/Pacific		
Australia	Pharmaceutical Benefits Advisory Committee (PBAC)	Yes
China	Ministry of Labour and Social Security (MLSS)	Information not available
India	Ministry of Health and Family Welfare (MHFW)	Information not available
Japan	Ministry of Health, Labour and Welfare	No
New Zealand	Pharmaceutical Management Agency (PHARMAC)	Yes
Singapore	Drug Advisory Committee (DAC)	Yes
North America		
Canada	pan-Canadian Oncology Drug Review (pCODR) • Funding/reimbursement decision made at national level but each province and territory then makes own funding/reimbursement decision	Yes
USA	US reimbursement system is fragmented with many different payers • Centers for Medicare & Medicaid Services (CMS) makes funding decision for Medicare (for those aged 65 years and older) • Each state must have a single agency that administers Medicaid (for individuals or families with low income or certain disabilities); subject to oversight by the CMS • Private insurance companies for those not covered by Medicare or Medicaid	Information not available or unclear
Latin America		
Argentina	Drug coverage is provided through public health insurance, social insurance (mandatory for employers and employees) or private insurance (voluntary)	No
Barbados	Funding/reimbursement process unclear	No
Brazil	National Commission for Incorporation of Technologies (CONITEC)	Yes
Colombia	Ministry of Health	No*
Mexico	Consejo de Salubridad General (CSG)	Information not available
Uruguay	Ministry of Health	Information not available
Venezuela	Venezuela Institute of Social Insurance (IVSS)	Information not available
Africa and Middle East		
Israel	Pharmaepidemiologics and Drug Economics Department	Yes
Algeria	Information unavailable	Information not available
South Africa	National Essential Medicines Committee (NEMC)	Yes

HTA = health technology assessment

* Colombia does not undertake its own HTA but bases its funding/reimbursement decisions on data from decisions made by the National Institute for Health and Clinical Excellence for England and Northern Ireland.

Ukraine is the only country that does not appear to have a funding/reimbursement system in place while the process followed in Barbados is unclear. Of the 43 LC member countries, six do not undertake an HTA as part of their decision process; namely Argentina, Barbados, Japan, Portugal, the Russian Federation and Ukraine. HTAs can be a time-consuming and expensive component of the approval process but it is encouraging that there is a growing movement to involve patients and patient advocacy groups in this process. The patient perspective helps decision-makers understand the unmet needs of the patients as well as better understand how well the new therapy manages disease symptoms and improves quality of life.

To determine which countries list, via a government website, therapies that are funded/reimbursed proved to be very challenging. For those that do have a website that lists the therapies, a number are out of date; namely China, India, Italy and Mexico. While Portugal has a website listing, no cancer therapies are listed. Turkey appears to have a website listing of funded/reimbursed therapies but it is only accessible to those living in Turkey. Uruguay has a website listing but only therapies for CLL are recorded. It would appear from LC's review that a number of countries do not have a website listing of funded/reimbursed therapies; namely Argentina, Barbados, Brazil, Germany, Ireland, Macedonia and Venezuela.

The section on Access to Therapies will provide further insights into the number of therapies available in each LC member country including the number of therapies funded/reimbursed.

2. Access to Therapies

Therapies with Regulatory Approval

While many therapies for lymphomas have received regulatory approval in one or more countries, when it comes to funding/reimbursement, access continues to be an issue as many of the therapies that have regulatory approval do not have funding/reimbursement approval. Of the 119 approved therapies for the seven subtypes that LC has been tracking, the USA has the most approved at 96 (80.6%). While the EU countries and Switzerland each have 68 (57.1%), 28 fewer than the USA. The countries with the fewest therapies with approval are Barbados (seven therapies), Macedonia (eight therapies) and Venezuela (six therapies).

An interesting finding is that rituximab (MabThera/Rituxan), which can be considered one of the standards of therapy regimens, appears not to have regulatory approval in all LC member countries. Based on LC's research, rituximab (MabThera/Rituxan) is a component of 40 therapy regimens.

Table 2 shows, by country, the number and percentage of the 119 therapies that have received regulatory approval, the number of therapies that are funded/reimbursed and the mortality numbers.

The following therapies are approved in all LC member countries:

- CHOP;
- CVP;
- Cyclophosphamide;
- Methotrexate;
- Radiation;
- Stem cell transplant.

For information on what therapies are part of CHOP and CVP, see the acronyms listed on page 19.

Newer Therapies and Combinations

All the newer molecules and therapy combinations noted in Table 3, with the exception of pixantrone (Pixuvri), have regulatory approval in the USA. Table 3 shows which member countries have granted regulatory as well as funding/reimbursement approval of these newer therapies.

TABLE 2. ACCESS TO THERAPIES (AS OF SEPTEMBER 2014)

LC Member Country	Therapies with Regulatory Approval, No. (%)	Therapies with Funding/ Reimbursement Approval, No. (%)	Population*	Deaths from Lymphomas per 100,000, 2012†	Five-year Change (2008-2012) in Death, %§
Europe					
Belgium	68 (57.1)	48 (70.5)	10,438,353	8.7	8.0
Bulgaria	68 (57.1)	10 (14.7)	7,037,935	6.5	21.9
Croatia	68 (57.1)	37 (54.4)	4,480,043	7.5	2.0
Czech Republic	68 (57.1)	40 (60.6)	10,177,300	6.3	-4.3
Denmark	68 (57.1)	39 (58.8)	5,543,453	7.4	-3.6
France	68 (57.1)	46 (67.6)	64,612,939	8.3	3.9
Germany	68 (57.1)	50 (73.5)	81,305,856	8.3	1.5
Hungary	68 (57.1)	23 (33.8)	9,958,453	6.4	-12.0
Ireland	68 (57.1)	44 (64.7)	4,722,028	6.6	0.5
Italy	68 (57.1)	48 (70.5)	61,261,254	9.7	-9.5
Latvia	68 (57.1)	18 (26.4)	2,191,580	7.6	12.7
Lithuania	68 (57.1)	13 (19.1)	3,525,761	5.9	-3.0
Macedonia	8 (6.7)	1 (12.5)‡	2,082,370	3.3	N/A
Netherlands	68 (57.1)	49 (72.0)	16,730,632	7.4	-6.3
Poland	68 (57.1)	43 (63.2)	38,415,284	5.4	-0.7
Portugal	68 (57.1)	N/A‡	10,799,270	7.8	N/A
Russian Federation	39 (32.7)	39 (100.0)	142,517,670	4.5	7.1
Serbia	42 (35.2)	41 (97.6)	7,276,604	8.6	21.3
Slovakia	68 (57.1)	30 (44.1)	5,483,088	5.4	0.2
Slovenia	68 (57.1)	43 (63.2)	1,996,617	9.5	25.6
Spain	68 (57.1)	65 (95.5)	47,042,984	6.4	-11.6
Sweden	68 (57.1)	50 (73.5)	9,103,788	7.8	-8.3
Switzerland	68 (57.1)	48 (70.5)	7,925,517	7.5	-14.0
Turkey	44 (36.9)	N/A‡	79,749,461	5.3	31.4
Ukraine	15 (12.6)	N/A‡	44,854,065	4.3	7.0
UK			63,047,162	8.4	-6.2
-England/ Northern Ireland	68 (57.1)	65 (95.5)		Information on the number of deaths only available for the UK as a whole rather than for each country with the UK. However, each country in the UK makes its own funding/ reimbursement decision.	
-Scotland	68 (57.1)	54 (79.4)			
-Wales	68 (57.1)	53 (77.9)			
Asia/Pacific					
Australia	54 (45.3)	44 (81.4)	22,015,576	7.9	-9.7
China	40 (33.6)	9 (22.5)	1,343,239,923	2.5	19.8
India	43 (36.1)	13 (30.2)	1,205,073,612	2.0	-0.3
Japan	48 (40.3)	44 (91.6)	127,368,088	9.6	18.9
New Zealand	44 (36.9)	44 (100.0)	4,327,944	8.3	-3.8
Singapore	65 (54.6)	4 (6.1)	5,353,494	4.4	3.5
Latin America					
Argentina	46 (38.6)	N/A‡	42,192,494	4.4	-5.2
Barbados	7 (5.8)	N/A‡	287,733	3.6	14.7
Brazil	40 (33.6)	N/A‡	199,321,413	3.2	14.8
Colombia	45 (37.8)	25 (55.5)	45,239,079	3.6	20.8
Mexico	39 (32.7)	39 (100.0)	114,975,406	3.2	0.2
Uruguay	30 (25.2)	28 (93.3)	3,316,328	8.4	-4.6
Venezuela	6 (5.0)	N/A‡	28,047,938	3.3	3.6
Middle East and Africa					
Israel	40 (33.6)	35 (87.5)	7,707,042	7.7	5.5
Algeria	43 (36.1)	43 (100.0)	30,087,812	4.5	N/A
South Africa	42 (35.2)	6 (14.2)	48,601,098	3.7	-18.8
North America					
Canada	69 (57.9)	63 (91.3)	34,300,083	9.4	-8.7
USA	96 (80.6)	Medicare, Medicaid, Private Insurance	313,847,465	8.4	5.4

*As of March 2014
†Death rate for CLL was estimated to be 29%; this is based on CLL data from Cancer.net
‡Incomplete or no information available on what therapies are funded/reimbursed for these LC member countries
§The five-year change in deaths from lymphomas is calculated based on population changes between 2008 and 2012
CLL = chronic lymphocytic leukaemia; N/A = information not available; UK = United Kingdom; USA = United States of America

TABLE 3. LC MEMBER COUNTRIES WITH REGULATORY AND FUNDING/REIMBURSEMENT APPROVAL OF NEW THERAPIES (AS OF SEPTEMBER 2014)

			Bendamustine (Treanda)		**Bendamustine plus rituximab** (Treanda, MabThera/ Rituxan)		**Brentuximab vedotin** (Adcetris)		**Ibrutinib** (Imbruvica)		**Idelalisib** (Imbruvica)		**Idelalisib plus rituximab** (Zydelig, MabThera/ Rituxan)	
Country			Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*
Algeria			✓	✓										
Argentina			✓											
Australia			✓		✓		✓							
Canada			✓	✓	✓	✓	✓	✓						
China														
Colombia			✓											
LC EU MEMBER COUNTRIES	Belgium		✓	✓	✓	✓	✓		✓		✓			
	Bulgaria		✓	✓	✓	✓	✓		✓		✓			
	Croatia		✓		✓		✓		✓		✓			
	Czech Republic		✓	✓	✓		✓		✓		✓			
	Denmark		✓		✓		✓		✓		✓			
	France		✓	✓	✓		✓	✓	✓		✓			
	Germany		✓	✓	✓		✓	✓	✓		✓			
	Hungary		✓		✓		✓		✓		✓			
	Ireland		✓		✓	✓	✓		✓		✓			
	Italy		✓		✓	✓	✓		✓		✓			
	Latvia		✓		✓		✓		✓		✓			
	Lithuania		✓		✓		✓		✓		✓			
	Netherlands		✓		✓		✓	✓	✓		✓			
	Poland		✓	✓	✓		✓		✓		✓			
	Portugal		✓		✓		✓		✓		✓			
	Slovakia		✓	✓	✓		✓		✓		✓			
	Slovenia		✓		✓		✓	✓	✓		✓			
	Spain		✓	✓	✓	✓	✓	✓	✓		✓			
	Sweden		✓	✓	✓		✓	✓	✓		✓			
	UK†	England N. Ireland	✓	✓	✓	✓	✓	✓	✓		✓			
		Scotland	✓	✓	✓		✓		✓		✓			
		Wales	✓	✓	✓		✓		✓		✓			
India			✓											
Israel							✓							
Japan			✓	✓			✓	✓						
New Zealand			✓											
Serbia				✓										
Singapore			✓		✓		✓							
South Africa			✓											
Switzerland			✓	✓	✓	✓	✓	✓						
Turkey			✓											
Uruguay			✓	✓	✓	✓								
USA			✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Lenalidomide (Revlimid)		**Lenalidomide plus rituximab** (Revlimid, MabThera/Rituxan)		**Obinutuzumab** (Gazyva)		**Ofatumumab** (Arzerra)		**Pixantrone** (Pixuvri)		**Pralatrexate** (Folotyn)		**Romidepsin** (Istodax)	
Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*	Regulatory Approved	Funded/ Reimbursed*
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* In the USA, with the exception of pixantrone (Pixuvri), all newer therapies may be available through a patient's insurance plan. The degree of coverage, however, will depend on the type of insurance plan the patient has.
† Each country within the UK makes its own funding/reimbursement decision
EU = European Union; UK = United Kingdom; USA = United States of America

With the exception of bendamustine (Treanda) which is approved in most countries (n = 36), most of the newer therapies and combinations are not widely available with three of the newer therapies/combinations only available in the USA.

Therapies with Funding/Reimbursement Approval

Not one of the 119 therapies that have received regulatory approval are funded/reimbursed in all LC member countries. Therapies that are funded/reimbursed in 30 or more countries are CHOP, CHOP-R, CHOEP, CODOX-M, CVP, cyclophosphamide, EPOCH, methotrexate and rituximab (MabThera/Rituxan).

While all EU LC member countries have the same number of therapies with regulatory approval (n = 68), the same approach does not apply when it comes to funding/reimbursement as each country makes its own decision. Hence, the large disparity among the EU members as to the number of therapies actually available to the patient. Table 2 notes the number of funded/reimbursed therapies in each EU member country.

When looking at Table 2, the number of therapies that received funding/reimbursement approval might appear to be encouraging. For example, in Spain 98.4% of the therapies with regulatory approval have funding/reimbursement approval. However, given that only 68 of the 119 therapies have regulatory approval, this number is not so encouraging. LC has been unable to find or access a funding/reimbursement therapies listing for Argentina, Barbados, Brazil, Macedonia, Turkey and Ukraine.

Impact of Therapy Availability on Mortality

Although there is not a direct correlation between mortality and availability, the trend was worth reviewing. Between 2008 and 2012, 18 countries showed a decline in the number of deaths from lymphomas. Table 2 shows the number of deaths as well number of therapies available.

The countries with the largest increase in deaths from lymphomas between 2008 and 2012 were Bulgaria (21.9%), China (19.8%), Colombia (20.8%), Japan (18.9%), Serbia (21.3%), Slovenia (25.6%) and Turkey (31.4%). For some of these countries the lack of funded/reimbursed therapies, including newer therapies and combinations, may be a factor. For example, in Bulgaria only 10 of the 68 therapies approved by the EMA are funded/reimbursed; in China, only nine of the 41 therapies with regulatory approval are funded/reimbursed but, in Slovenia, where more therapies are funded/reimbursed (43 of the 68), the reasons for the increase are unclear.

From a global perspective, results of the 2014 LC Lymphoma Global Patient Survey may provide some insight into issues patients face when it comes to accessing care. Of the nearly 3,500 respondents, 60% indicated they had faced barriers to treatment. Among those aged 46 to 65 years, barriers included:

- **Lack of access to the most up-to-date therapies (49%);**
- Lack of a locally available specialty physician (45%);
- Inability to give up their caregiver role (45%);
- Lack of access to a treatment centre/prohibitive travel (44%);
- Lack of personal support (44%);
- Financial concerns (43%);
- Long wait times to treatment (40%).

In spite of 96 of the 119 therapies having regulatory approval in the USA, there was a 5.4% increase in the number of deaths from lymphomas between 2008 and 2012. Of the 902 USA respondents, 60% had faced barriers with 18% noting financial issues as being the main barrier. Among those aged 46 to 65 years, 52% indicated that financial issues were a major barrier but **long wait times to treatment, lack of access to a treatment centre, no local access to a specialty physician and lack of access to the latest therapies were bigger barriers.**

While all the mortality factors are not clearly known or understood, greater efforts are needed to ensure that access to therapies is improved substantially.

3. Access to Clinical Trials

Clinical trials are another way in which patients can access therapies. However, as shown in the LC 2014 Special Report on Clinical Trials found on the LC website, there is a wide disparity among member countries in clinical trial availability.

LC's search for clinical trial websites identified five clinical trial registries that LC suggests provide the most thorough information on phase II and III clinical trials; namely:

- Australia Cancer Trials (one trial);
- Clinicaltrials.gov (541 trials);
- European Union Clinical Trials Register (four trials);
- German Hodgkin Study Group (one trial);
- World Health Organisation (two trials).

There may well be other national institutions that run clinical trials, e.g., research institutions and hospitals, but LC is not adequately resourced to review each one.

LC found a total of 549 phase II and III clinical trials for the seven subtypes LC has been tracking. Of the 549 trials, 144 are available in two or more countries. Table 4 shows how many of the 549 trials are available in each country as well as each country's GDP, population and incidence of lymphomas.

As shown in Table 4, the majority of phase II and III active clinical trials in lymphomas and CLL are available in the USA.

TABLE 4. GDP, POPULATION, INCIDENCE AND CLINICAL TRIALS AVAILABLE

Country	GDP Per Capita, US$*	Population*	Incidence of Lymphomas†	Total Phase II and III Clinical Trials‡	% of Total Clinical Trials‡
Europe					
Switzerland	54,600	7,925,517	2,059	12	2.2%
Netherlands	42,300	16,730,632	4,193	29	5.3%
Ireland	41,700	4,722,028	1,011	16	2.9%
Sweden	41,700	9,103,788	2,120	36	6.6%
Germany	39,100	81,305,856	19,925	85	15.5%
Belgium	38,100	10,438,353	2,815	55	10.0%
Denmark	37,700	5,543,453	1,334	22	4.0%
UK	36,700	63,047,162	15,935	76	13.8%
France	35,500	64,612,939	16,023	88	16.0%
Spain	30,400	47,042,984	8,837	76	13.8%
Italy	30,100	61,261,254	16,643	86	15.7%
Slovenia	28,600	1,996,617	402	1	0.2%
Czech Republic	27,200	10,177,300	1,832	42	7.7%
Slovakia	24,300	5,483,088	894	11	2.0%
Portugal	23,000	10,799,270	2,466	15	2.7%
Poland	21,000	38,415,284	4,373	56	10.2%
Lithuania	20,100	3,525,761	548	2	0.4%
Hungary	19,800	9,958,453	1,474	28	5.1%
Croatia	18,100	4,480,043	841	4	0.7%
Latvia	18,100	2,191,580	307	2	0.4%
Russian Federation	17,700	142,517,670	14,158	39	7.1%
Turkey	15,000	79,749,461	7,856	20	3.6%
Bulgaria	14,200	7,037,935	882	9	1.6%
Macedonia	10,700	2,082,370	154	2	0.4%
Serbia	10,500	7,276,604	1,458	4	0.7%
Ukraine	7,600	44,854,065	4,229	18	3.3%
Asia/Pacific					
Singapore	60,900	5,353,494	734	10	1.8%
Australia	42,400	22,015,576	6,197	57	10.4%
Japan	36,200	127,368,088	25,094	17	3.1%
New Zealand	28,800	4,327,944	1,120	16	2.9%
China	9,100	1,343,239,923	33,263	22	4.0%
India	3,900	1,205,073,612	23,769	13	2.4%
Latin America					
Barbados	25,500	287,733	22	0	0.0%
Argentina	18,200	42,192,494	4,360	19	3.5%
Uruguay	15,800	3,316,328	566	1	0.2%
Mexico	15,300	114,975,406	8,073	15	2.7%
Venezuela	13,200	28,047,938	1,793	1	0.2%
Brazil	12,000	199,321,413	13,828	28	5.1%
Colombia	10,700	45,239,079	4,377	13	2.4%
Middle East and Africa					
Israel	32,200	7,707,042	2,181	35	6.4%
South Africa	11,300	48,601,098	3,148	11	2.0%
Algeria	7,300	30,087,812	2,599	0	0.0%
North America					
USA	49,800	313,847,465	83,564	406	74.0%
Canada	41,500	34,300,083	9,835	71	12.9%

*As of March 2014
†Data on CLL were extrapolated from the GLOBOCAN 2012 data and are an estimated calculation based on 30% of all leukaemia incidence
‡As of September 2014
GDP = gross domestic product; UK = United Kingdom; USA = United States of America

Clinical trials are an indicator of best practice healthcare but require significant resources and expertise that not every country has available. Patients and healthcare professionals in these countries are clearly disadvantaged by the absence of clinical trials.

Table 5 shows the number of phase II and III trials available by subtype.

TABLE 5. CLINICAL TRIALS BY SUBTYPE (AS OF SEPTEMBER 2014)

Subtype	Phase II Clinical Trials	% of Total Phase II Clinical Trials	Phase III Clinical Trials	% of Total Phase III Clinical Trials	Total Phase II and III Clinical Trials	% of Total Clinical Trials*
BL	70	12.8	2	0.4	72	13.1
CLL	160	29.1	37	6.7	191	35.9
DLBCL	152	27.7	17	3.1	169	30.8
FL	157	28.6	34	6.2	191	34.8
HL	89	16.2	10	1.8	99	18.0
MCL	148	27.0	15	2.7	163	29.7
PTCL	76	13.8	12	2.2	88	16.0

* Note that a clinical trial may be undertaken in more than one subtype; therefore, the total percentage of clinical trials will not add up to 100%.
BL = Burkitt's lymphoma; CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; MCL = mantle cell lymphoma; PTCL = peripheral T-cell lymphoma

While the USA has the most clinical trials by subtype, some LC member countries do not have any. Table 6 shows which countries do not have any lymphoma subtype trials.

TABLE 6. COUNTRIES WITH NO LYMPHOMA SUBTYPE CLINICAL TRIALS (AS OF SEPTEMBER 2014)

Subtype	Country with No Clinical Trials
BL	Algeria, Barbados, Bulgaria, Colombia, Croatia, Ireland, Latvia, Lithuania, Macedonia, Serbia, Slovenia, South Africa, Uruguay, Venezuela
CLL	Algeria, Barbados, Venezuela
DLBCL	Algeria, Barbados, Bulgaria, Latvia, Lithuania, Macedonia, Slovenia, Uruguay
FL	Algeria, Barbados, Lithuania, Slovenia, Uruguay
HL	Algeria, Argentina, Barbados, Colombia, Croatia, India, Ireland, Latvia, Lithuania, Macedonia, Mexico, Portugal, Slovakia, Slovenia, Sweden, Ukraine, Uruguay, Venezuela
MCL	Algeria, Barbados, Bulgaria, Croatia, Latvia, Lithuania, Macedonia, Serbia, Slovenia, Uruguay, Venezuela
PTCL	Algeria, Barbados, Bulgaria, Colombia, Latvia, Lithuania, Macedonia, Serbia, Slovenia, Uruguay, Venezuela

BL = Burkitt's lymphoma; CLL = chronic lymphocytic leukaemia; DLBCL = diffuse large B-cell lymphoma; FL = follicular lymphoma; HL = Hodgkin lymphoma; MCL = mantle cell lymphoma; PTCL = peripheral T-cell lymphoma

Among the 43 LC member countries, 18 do not have any HL trials available. CLL clinical trials would appear to be more widely available with only three countries not having any CLL trials.

Although clinical trials are becoming more global in nature, access to clinical trials is sporadic in spite of the fact that many patients are eager to participate. This is supported by results from the 2014 LC Global Patient Survey showing only 9% of respondents indicating they were unlikely to participate in a clinical trial if asked.

4. Access to Diagnostics

While access to clinical trials and therapies is important, access to diagnostics to ensure receipt of the most appropriate therapy is also key. The results of the 2014 Lymphoma Global Patient Survey showed that only 16% of respondents were correctly diagnosed with lymphoma based on their symptoms at their initial presentation. Results also showed that compared with results from the 2012 Lymphoma Global Patient Survey, respondents were diagnosed later and less accurately in 2014. Only 33% of respondents indicated they were accurately diagnosed based on their initial symptoms within the first four weeks.

LC endeavoured to determine if there were standard diagnostic guidelines in each member country for the seven subtypes LC has been tracking. At this point in LC's review, however, it is not clear what guidelines each country is following; the search for this information will continue in 2015.

LC did find four international organisations that listed comprehensive guidelines. These organisations are:

- British Columbia Cancer Agency (BCCA) (bccancer.bc.ca/HPI/CancerManagementGuidelines/Lymphoma)
- European Society of Medical Oncology (ESMO) (esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines)
- Haemato-oncology Task Force of the British Committee for Standards in Haematology (BCSH) (bcshguidelines.com/4_HAEMATOLOGY_GUIDELINES)
- National Comprehensive Cancer Network (NCCN) (nccn.org)

The results of the 2014 LC Lymphoma Global Patient Survey indicated the important role diagnostics play at time of presentation. The survey findings revealed that while Japan's healthcare practitioners had the greatest awareness and understanding (31%), UK was poorest at 8% as highlighted in Table 7. The degree of misdiagnosis may be the result of the low level of awareness and understanding about lymphomas among healthcare practitioners.

TABLE 7. LYMPHOMA AWARENESS AMONG HEALTHCARE PRACTITIONERS

Region	North America		South America			Pacific			Europe			Global
Country	USA	Canada	Brazil	Argentina	Colombia	New Zealand	Australia	Japan	Italy	France	UK	
% diagnosed for lymphoma with initial symptoms	14%	16%	25%	23%	14%	14%	14%	31%	11%	15%	8%	16%
% accurately diagnosed within the first 4 weeks	34%	28%	36%	34%	15%	36%	40%	37%	51%	37%	25%	33%
% to whom medication was wrongly prescribed upon misdiagnosis	50%	30%	55%	38%	40%	28%	31%	34%	54%	45%	40%	42%

Legend

Plus or minus 5% above the global average

Plus or minus 5% below the global average

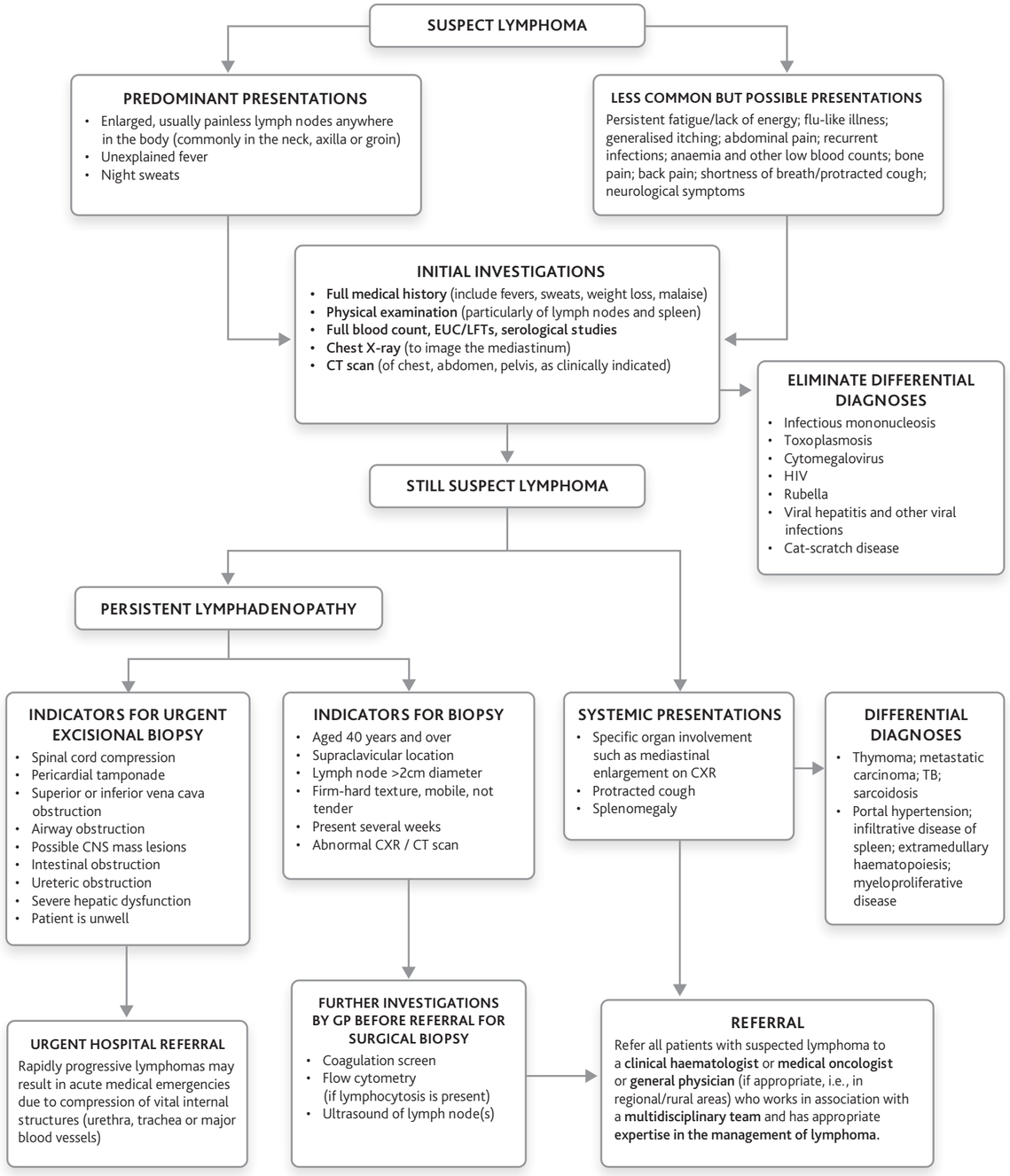
UK = United Kingdom; USA = United States of America

It is key that greater efforts be made to ensure lymphomas are accurately diagnosed at the initial presentation. As stated by Dr. Laurie Sehn: "It's critical that people become more aware of what lymphoma is and how it's characterised because we don't know how to prevent this type of cancer, the best we can do is try to get patients diagnosed early. Our best defence against lymphoma is to detect it early in the disease course." Dr. Sehn is Chair, BC Cancer Agency Lymphoma Tumour Group, Clinical Associate Professor, University of British Columbia, Canada and Chair of the Medical Advisory Board for LC.

As a starting point, the diagnostic algorithm developed by the Leukaemia Foundation of Australia provides an excellent overview of the steps to take to accurately diagnose lymphomas (see Figure 1).

FIGURE 1. DIAGNOSING LYMPHOMAS

GENERAL PRACTIONER DIAGNOSIS ALGORITHM



Footnote – Not all the factors listed above need to be present before further investigation or referral.

MOVING FORWARD

This report has shown that patients face a daunting battle when it comes to obtaining the care they need. From a global perspective, access to care is sporadic. As results of the 2014 LC Lymphoma Global Patient Survey showed it's not only access to the most up-to-date therapies that is a barrier, it is also access to the appropriate specialty physician and treatment centre, and long wait times. Access to clinical trials is also an impediment as not all trials are available in all countries and some countries do not have access to any. Of those that are available, many healthcare professionals are not informing patients about them. Findings from the Global Patient Survey shed light on what some of the barriers are to enrolment in clinical trials. Among the barriers identified were patients not being asked if they wished to participate in a trial. Since 2008, fewer respondents (19% versus 25% in 2008) had been asked if they wished to participate in a clinical trial. Of the 74% who had not been approached about participating in a clinical trial, 27% said they would have likely participated in one, 55% said they would have needed more information and only 9% said it was unlikely they would have participated.

LC will monitor and update members on the progress of a therapy once the results of the trial have been released so we can be proactive in our actions.

Today, it is understood that NHL is made up of 60 subtypes and should be recognized as such. LC is working towards breaking out NHL global data into subtypes by contacting each country's respective local registry to ensure that each subtype is tracked for trends and receives the attention and results it requires.

As a Coalition we call for:

- Greater efforts to be made in making more clinical trials available in LC member countries especially in those countries where few or none are currently available;
- The increasing involvement and more effective engagement of patients and patient groups in the funding/reimbursement decision-making process;
- The increasing involvement of patients and patient groups at the planning stage of clinical trial development;
- Concerted efforts to have more of the newer therapies available by improving regulatory approval and reimbursement rates in many countries. Alternate mechanisms like shared risk or managed entry schemes as well as designated funds for cancer drugs may need to be considered and funded to improve drug access.

In addition, LC will continue to:

- Monitor and report on the funding/reimbursement and regulatory policy changes as they occur around the world;
- Maintain the global resource on lymphoma facts and statistics including updating information on therapies as they receive both regulatory and funding/reimbursement approval;
- Continue to ensure that clinical trial information is readily available to the patient community. This will be accomplished by regularly updating the global database on the LC website;
- Create a toolkit to help healthcare professionals facilitate connections between newly diagnosed patients and patient groups for support and lymphoma education;
- Work closely with drug developers to ensure that as the development and use of oral therapies becomes more prevalent for the treatment of lymphomas, patient needs are taken into account, e.g., provide patient education to deal with compliance issues, use of blister packs, etc.

It is the intent of LC to ensure that all members have up-to-date therapy and clinical trial information as well as current information on diagnostic procesess and procedures so all members will have timely access to good quality information to share with their patients.

LATEST FINDINGS FROM THE INTERLYMPH CONSORTIUM 2014

ENVIRONMENTAL & GENETIC RISK FACTORS OF LYMPHOMA

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What is InterLymph?

The International Lymphoma Epidemiology Consortium (InterLymph) is an open scientific forum for epidemiologic research in malignant lymphoma. Established in 2001, the Consortium is an international collaboration of scientists who undertake research projects that pool data across studies to better understand lymphoma risk factors. Although the main emphasis of the collaboration is epidemiology, InterLymph has expanded to include geneticists, pathologists, immunologists, clinicians and other scientists and now includes more than 100 members. InterLymph consists of four working groups (immunology and infection, lifestyle and environment, pathology and survival, genetics), and has evolved to include multiple large scale projects that operate across working groups. In 2014, several large pooling projects have been successfully finalised (see epi.grants.cancer.gov/InterLymph/).

What are the goals of InterLymph?

The overarching goal of InterLymph is to identify patterns of commonality and heterogeneity in the aetiology of lymphoma subtypes which may assist in illustrating mechanisms of the development of lymphoma. This knowledge has implications for understanding biology, aetiology, prevention and control of these malignancies. The Consortium aims to achieve this by addressing research questions that are difficult to answer in individual studies, by sharing data and biological samples. The Consortium has established a central data coordinating centre that is a repository of pooled, harmonised data from all recently completed international case-control studies of lymphoma. In recent years, the collaboration has also expanded to several international cohort studies.

Latest findings from InterLymph

In the largest pooling project of environmental aetiology so far conducted in the history of InterLymph (the InterLymph Non-Hodgkin Lymphoma subtypes project), medical history, lifestyle, family history and occupational risk factors were investigated for risk of 11 non-Hodgkin lymphoma (NHL) subtypes (Journal of the National Cancer Institute Monograph August 2014). In addition, aetiologic heterogeneity among subtypes was assessed using novel statistical methods. The analysis involved 17,471 lymphoma patients and 23,096 controls recruited in 20 case-control studies in North America, Europe and Australia. Risks differed significantly among NHL subtypes for medical history factors, alcohol consumption, cigarette smoking and certain occupations, whereas generally similar risks were observed for family history of lymphoma, recreational sun exposure, hay fever, allergy and socioeconomic status. Overall, the greatest difference in risk factors occurred between T-cell and B-cell lymphomas, but there were also substantial differences among B-cell lymphomas.

Several large-scale investigations of genetic risk factors for lymphoma subtypes were also published in 2014. A pooled genome-wide association study (GWAS) was conducted for diffuse large B-cell lymphoma which included 5,216 cases and 12,223 controls of European ancestry (Cerhan et al., Nature Genetics 2014). Five independent risk SNPs in four loci were identified (in or nearby the genes *EXOC2*, *HLA-B*, *NCOA1* and *PVT1*). The results point towards genetic pathways involved in immune recognition and immune function in the pathogenesis of diffuse large B-cell lymphoma. In another pooled study of genetic variation in risk of follicular lymphoma (FL) (4,523 cases and 13,344 controls), a strong association with variation in the human leukocyte antigen (HLA) region was confirmed. In addition, for the first time, risk loci were also identified outside of the HLA region, near or in the genes *CXCR5*, *ETS1*, *LPP*, *BCL2* and *PVT1*. These findings implicate a role for genetic regions involved in lymphocyte biology and survival in FL risk. A third study investigated genetic variation in risk of Hodgkin lymphoma (HL) (Cozen et al., Nature Communications, 2014). Here, a novel variant was identified at 19p13.3 located in intron 2 of *TCF3* (also known as *E2A*), a regulator of B- and T-cell lineage commitment known to be involved in HL pathogenesis. These findings will help to elucidate mechanisms of development of lymphoma subtypes and to understand patterns of gene-environment interaction.

SOURCES

In the development of the 2014 LeIP Report Card on Lymphomas, the following information sources were consulted:

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International Society for Pharmacoeconomics and Outcomes Research

Kantar Health 2012

Member countries

Pharmaceutical companies

The World Bank

World Health Organisation

Country-Specific Information

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Medicines Australia, 2012

Belgium
KCE Reports

Bulgaria
Pharmdedict

Canada
pan-Canadian Oncology Drug Review

Czech Republic
State Institute for Drug Control

Denmark
Danish Health and Medicines Authority

Ireland
National Centre for Pharmacoeconomics

Italy
Italian Medicines Agency

Japan
Pacific Bridge Medical

Lithuania
Ministry of Health

Macedonia
Bureau for Medicinal Products

Netherlands
Netherlands Reimbursement Information

New Zealand
PHARMAC

Portugal
ClinicoEconomics and Outcomes Research

Slovakia
Journal of Health Policy and Outcomes Research

Slovenia
Ministry of Health

UK
All Wales Medicines Strategy Group

National Institute for Health and Clinical Excellence (England/Northern Ireland)

Scottish Medicines Consortium

Uruguay
Ministry of Health

Access to Therapies

Algeria
ANDS

Department of Health

Argentina
National Administration of Drugs, Food and Medical Technology

Australia
Australian Register of Therapeutic Goods

Australian Therapeutic Goods Administration

Department of Health

National Health and Medical Research Council (Australia)

Cancer Institute NSW

Cancer Institute NSW

Barbados
Ministry of Health Barbados

Belgium
Belgian Haematological Society

National Institute for Sickness and Invalidity Insurance

Brazil
Agência Nacional de Vigilância Sanitária

Bulgaria
National Health Insurance Fund

Canada
Cancer Drug Access

Drug Coverage.ca

Health Canada

Alberta Health Services

British Columbia Cancer Agency

Cancer Care Ontario

London Health Sciences Centre

Cancer Care Nova Scotia

Health PEI

Government of Saskatchewan

Saskatchewan Cancer Agency

China
China Food and Drug Administration

Ministry of Health

Colombia
INVIMA

Ministry of Health and Social Protection

Croatia
Croatian Health Insurance Fund

Czech Republic
State Institute for Drug Control

Denmark
Danish Health and Medicines Authority

Europe
European Medicines Agency

European Society for Medical Oncology

INFOLinks

France
Ministry of Health and Social Affairs

Germany
PharmNet.Bund

German Institute of Medical Documentation and Information

Hungary
National Health Insurance Fund Administration

India
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National List of Essential Medicines of India 2011

Ireland
Irish Medicines Board

Haematology Ireland

Israel
Ministry of Health

Italy
Italian Medicines Agency

Japan
Ministry of Health, Labour and Welfare

Pharmaceuticals and Medical Devices Agency

Latvia
National Health Service

Lithuania
Ministry of Health of the Republic of Lithuania

Mexico
Comisión Federal para la Protección contra Riesgos Sanitarios

Ministry of Health

Netherlands
Medicines Evaluation Board (Netherlands)

Netherland Healthcare Authority

New Zealand
New Zealand Medicines and Medical Devices Safety Authority

New Zealand Universal List of Medicines

Portugal
Ministry of Health

Serbia
Medicines and Medical Devices Agency of Serbia

Republic Fund of Health Insurance

Singapore
Health Sciences Authority

Singapore Society of Oncology

Slovakia
Ministry of Health Slovakia

Slovenia
Health Insurance Institute Slovenia

South Africa
Department of Health

South African Medicine Price Registry

Spain
Agencia Espanola de Medicamentos y Productos Sanitarios

Sweden
FASS

Switzerland
Federal Office of Public Health

Swissmedic

Turkey
ilacabak

Social Insurance

Ukraine
Ministry of Health

United Kingdom
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National Health Service

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Scottish Medicines Consortium

United States of America
Food and Drug Administration

National Comprehensive Cancer Network

Uruguay
Ministry of Public Health

National Resources Fund

Access to Clinical Trials
General Sources

Center Watch

Clinical Trials Search

ClinicalTrials.gov

Controlled Trials

European Organisation for Research & Treatment of Cancer

International Federation of Pharmaceutical Manufacturers & Associations

World Health Organisation

Country-Specific Information

Australia
Australian Cancer Trials

Australian New Zealand Clinical Trials Registry

Cancer Australia

Cancer Trials Australia

Therapeutic Goods Administration

Belgium
Belgian Society of Medical Oncology

Canada
Canadian Cancer Trials

NCIC Clinical Trials Group

Ontario Institute of Cancer Research

Czech Republic
State Institute for Drug Control

Denmark
Danish Health and Medicines Authority

European Union
European Medicines Agency

Germany
University Cancer Center Hamburg

India
Clinical Trials Registry – India

Ireland
Irish Pharmaceutical Healthcare Association

Italy
Instituto Oncologico Romagnolo

Japan
JAPIC Clinical Trials Information

National Institute of Public Health

Latvia
State Agency of Medicines of Latvia

Netherlands
Integraal Kankercentrum Nederland

Netherlands Trial Register

New Zealand
Australian New Zealand Clinical Trials Registry

Medsafe

Singapore
Haematology Oncology Research Group

South Africa
South African National Clinical Trial Register

Spain
Spanish Medicines Agency

Sweden
Karolinska Clinical Trials Registry

Switzerland
Swiss Clinical Trial Organisation

Swissmedic

United Kingdom
Cancer Research UK

Leeds Teaching Haematology Hospital Clinical Trials

Medicines and Healthcare products Regulatory Agency

National Health Service

National Institute for Health Research (NCRN)

National Institute for Health Research-People in Research

United States of America
Clinical Connection

Coalition of Cancer Cooperative Groups

Cutaneous Lymphoma Foundation

Food and Drug Administration

National Cancer Institute

Access to Diagnostics

Australia
National Health and Medical Research Council

Canada
British Columbia Cancer Agency

Europe
European Society of Medical Oncology

Germany
German Hodgkin Study Group

United Kingdom
Haemato-oncology Task Force of the British Committee for Standards in Haematology

United States of America
National Comprehensive Cancer Network

ACRONYMS

BCCA	British Columbia Cancer Agency
BL	Burkitt's lymphoma
BCSH	British Committee for Standards in Haematology
CHOEP	cyclophosphamide, vincristine, doxorubicin, etoposide, prednisone
CHOP	cyclophosphamide, vincristine, doxorubicin, prednisone
CHOP-R	cyclophosphamide, vincristine, doxorubicin, prednisone, rituximab
CLL	Chronic lymphocytic leukaemia
CODOX-M	cyclophosphamide, vincristine, doxorubicin, methotrexate
CVP	cyclophosphamide, vincristine, prednisone
DLBCL	Diffuse large B-cell lymphoma
EMA	European Medicines Agency
ESMO	European Society of Medical Oncology
EPOCH	etoposide, prednisone, vincristine, cyclophosphamide, doxorubicin
EU	European Union
GDP	gross domestic product
FL	Follicular lymphoma
HL	Hodgkin lymphoma
LC	Lymphoma Coalition
LeIP	Lymphoma eInformation Project
MCL	Mantle cell lymphoma
NCCN	National Comprehensive Cancer Network
NHL	Non-Hodgkin lymphoma
PTCL	Peripheral T-cell lymphoma
USA	United States of America

www.lymphomacoalition.org

For current lymphoma statistics,
visit the Global Database Search on the LC website.

LYMPHOMA
COALITION
Worldwide Network of
Lymphoma Patient Groups

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

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