

# LYMPHOMA COALITION

Worldwide Network of  
Lymphoma Patient Groups



# Lymphoma Coalition



- Since 2002
- 63 member organisations -44 countries
- Global Board of Directors
- Global Medical Advisory Board + access to 58 around the world
- Patient leaders in blood cancers
- Share best practice and resources
- Think Global – Act Local
- Gather and disseminate information on all lymphomas including CLL
- 600,000++ database

[www.lymphomacoalition.org](http://www.lymphomacoalition.org)

# LC Mission

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- To be the global source for lymphoma facts & statistics
- To improve awareness and understanding of lymphomas and
- To build capacity for new & existing lymphoma groups.

# How Do We Achieve Our Mission?



## Gather and Disseminate Credible Current Lymphoma and CLL Information

- Gather
  - Current information for global database on all lymphoma & CLL clinical trials, therapies, demographics by subtype and country (see search function on LC homepage)
  - Global Patient Survey – every two years
  - Building the Lymphoma Resource Library and Best Practice information in members only section of website
- Disseminate – potential of over 600,000 email addresses
  - Website, social media – links to member organisations
  - Global database search function – links to member organisations
  - LeIP Report Card on Lymphomas
  - Global Patient Survey reports – the patient journey
  - Monthly members newsletter and Quarterly newsletter to friends of lymphoma

Strength in understanding the global landscape so all members have a level playing from which to support the patient



## Karen's Highlights

### Patient Awareness of Lymphoma

Global patient survey respondents in the USA, Canada and Australia had the highest awareness about lymphoma prior to diagnosis, while six of the 11 countries surveyed had an awareness significantly below the global average.

#### Patient Awareness of Lymphoma Prior to Diagnosis



USA - 38% Canada - 35% Australia - 34% Italy - 27%  
 Brazil - 24% UK - 22% Argentina - 18% New Zealand - 17%  
 Japan - 15% France - 15% Colombia - 6%

Global Patient Survey 2014 (3,500 respondents)

Ensure members of your community know the signs and symptoms of lymphoma.

## What's In This Issue

### Research News

*Lymphoma in Colombia*  
*Novel Tumour Markers for CTCL*  
*Outcomes of Early-Stage HL*  
*Pain Management Education*

### Best Practices

*"A Peek at Group Nexus Japan"*

### Event Reminders

**USA Today:**  
*The Future of Blood Cancer*

### Member Newsletters

### Education Sessions

March 2015

LYMPHOMA IN COLOMBIA	NOVEL TUMOUR MARKERS FOR CTCL	OUTCOMES OF EARLY-STAGE HL	PAIN MANAGEMENT EDUCATION
A study was undertaken to determine the general features of lymphoma in Colombia. Patients (n = 819) with newly diagnosed lymphoma were included in the study.	Findings from a study have identified IL-13 and its receptors as novel tumour markers for cutaneous T-cell lymphoma (CTCL) that could serve as potential treatment targets.	An analysis of the National Cancer Data Base in the USA was undertaken to determine what factors affect treatment selection and survival outcomes in patients with early-stage HL.	The knowledge of cancer pain management among oncologists (n = 570), specialists in palliative medicine (n = 280) and specialists in pain medicine (n = 266) in the USA was evaluated.
<a href="#">Read more here.</a>	<a href="#">Read more here.</a>	<a href="#">Read more here.</a>	<a href="#">Read more here.</a>

# Point to Member Organisations at Every Opportunity - USA Today Advertising in Hematology Special Insert

## Is lymphoma on your radar?

**63%** of lymphoma patients did not know what lymphoma was until they were diagnosed.  
(Global Patient Survey 2014)

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**Know the signs and symptoms.**  
[lymphomacoalition.org/symptoms](http://lymphomacoalition.org/symptoms)

Lymphoma Coalition is a worldwide membership of 61 lymphoma patient organizations from 44 countries.  
We support our members *globally* so they can support patients *locally*.

Connect with your local member organization in the United States

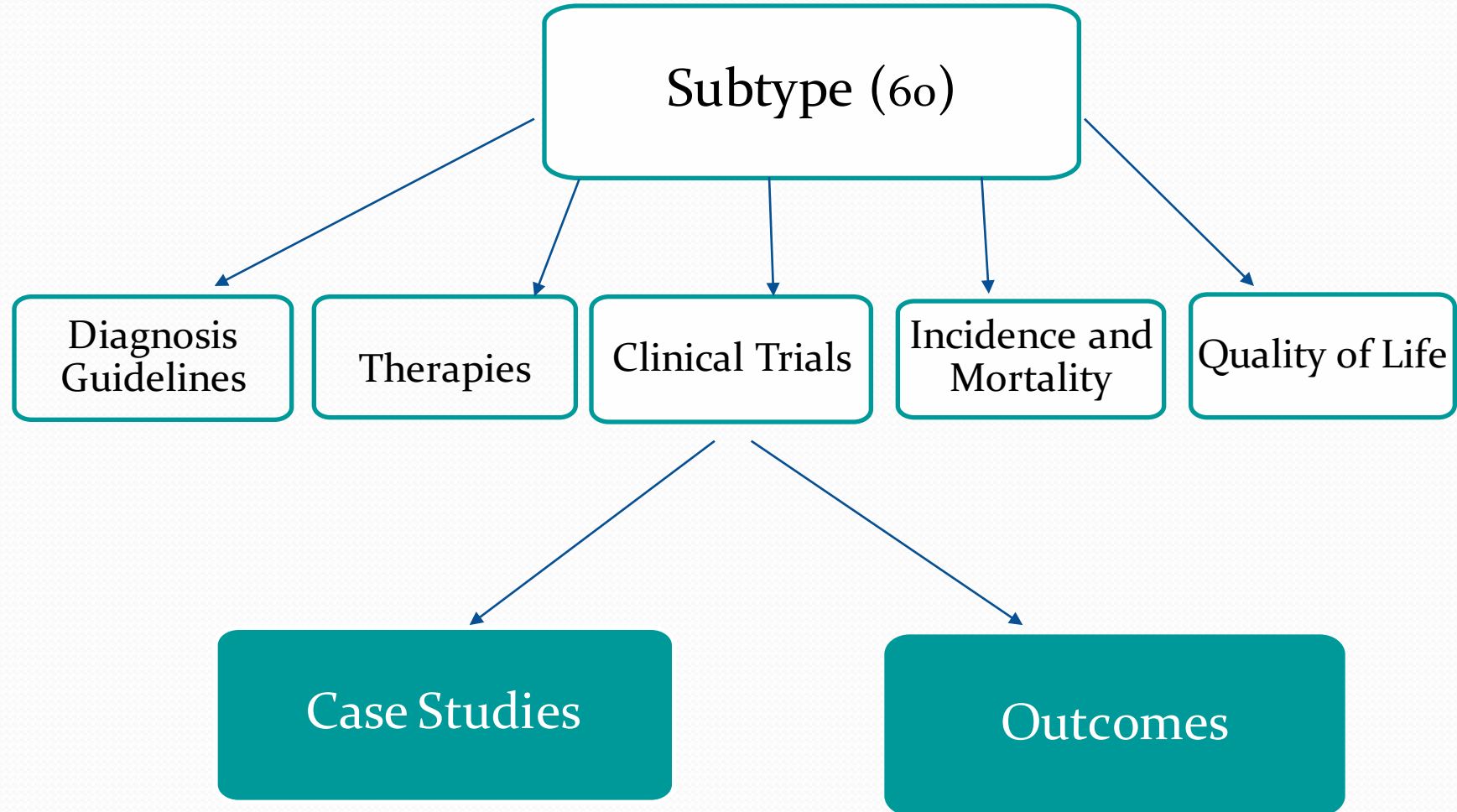




# How Do We Achieve Our Mission?

- Coalition of members – share best practice, build the lymphoma story, that result in case studies and reviews of subtype outcomes
  - Build capacity by assisting all members to understand access to care options – treatment option, biology updates, ct's, quality of life issues for patients by country/subtype
    - Builds the strength of the local organisation
    - Builds the strength of the coalition body
  - Share resources - GP Algorithm/GP accreditation programs, subtype literature, sustainability
  - World Lymphoma Awareness Day
- Advocacy – to date – reactive, based on an invite by the local or regional groups
  - Advocate for patients in areas that a patient group does not exist

# ALGORITHM OF CARE







# Subtype Story

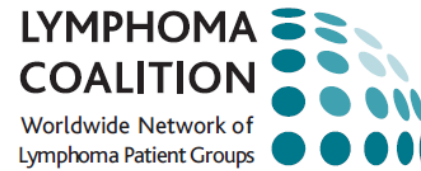
- Non hodgkin lymphomas are lumped under one category - NHL
  - Opportunity to work together to change NHL as a disease and have W.H.O. collect data by subtype as well as include CLL under the NHL category
  - In the meantime - gathering information from 365 registries (websites provided by Globocan) to determine if we can break out mortality and incidence by subtype not just by NHL

Assist in the subtype story and outcome analysis – ensure that the subtype is showing positive outcomes for patients



# What Do We Do With the Information

# 2014 LeIP REPORT CARD ON LYMPHOMAS



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.*

# Issue Awareness

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## Initial Diagnosis

**How long did it take patients with lymphoma to visit their doctor after first experiencing symptoms?**

(Global Patient Survey 2014)

**58%**



**Within 6 Months**

**18%**



**6-12 Months**

**8%**



**1-2 Years**

**5%**



**3-5 Years**

**4%**



**5+ Years**



# Issue Awareness

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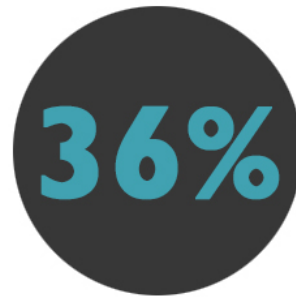


## Lymphoma Patient Diagnosis

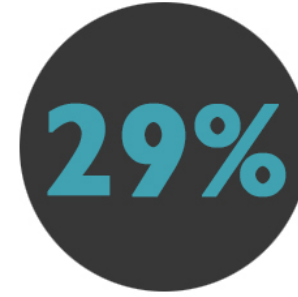
(2014 Global Patient Survey)



Were accurately diagnosed  
for their initial symptoms  
within the first four weeks.



Were accurately diagnosed  
based on initial symptoms  
within the first four months.



Were accurately diagnosed  
based on initial symptoms  
after the first four months.

Only **35%** were diagnosed properly the first time.

# Issue Awareness - Diagnosis

- Japan's healthcare practitioners were 'best in class' for their awareness and understanding of lymphoma
- Healthcare practitioners in Canada, Australia, New Zealand and Japan were least responsible for wrongly prescribing medication upon misdiagnosis while there are opportunities for improvement in Brazil, Italy and the U.S.
- Patients were diagnosed earliest in Italy and Australia.

Region	NORTH AMERICA		SOUTH AMERICA			PACIFIC			EUROPE			GLOBAL
Country	United States	Canada	Brazil	Argentina	Colombia	New Zealand	Australia	Japan	Italy	France	United Kingdom	
% 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												
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 15px; background-color: #90EE90; border: 1px solid black; margin-right: 5px;"></div> <span>Plus or minus 5% above the global average</span> </div>												
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 15px; background-color: #FF0000; border: 1px solid black; margin-right: 5px;"></div> <span>Plus or minus 5% below the global average</span> </div>												

# Best Practice Sharing

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## Diagnosis

- General Practitioner (GP) Diagnosis Algorithm – developed by a member LFA and their Scientific Board - translated into 8 languages among LC members.
- GP online accreditation program through Lymphoma Association UK; Leukaemia and Blood Cancer NZ has a program as well
- Working with the healthcare professionals to educate the GP's in their communities – Lymphoma Hub

LC facilitates best practice.

# Regulatory Approval

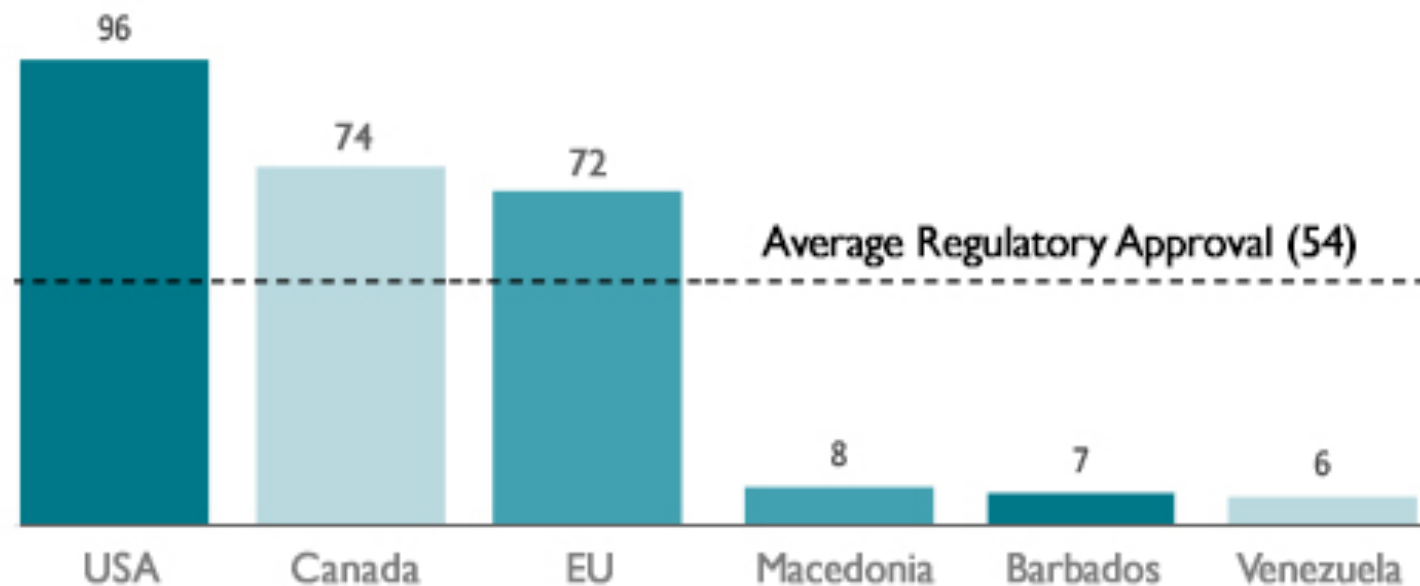
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## Regulatory Approval Comparison by Country

Out of 119 therapies, USA, Canada, and the EU have the highest approval numbers with Barbados, Venezuela and Macedonia having the lowest approval numbers.





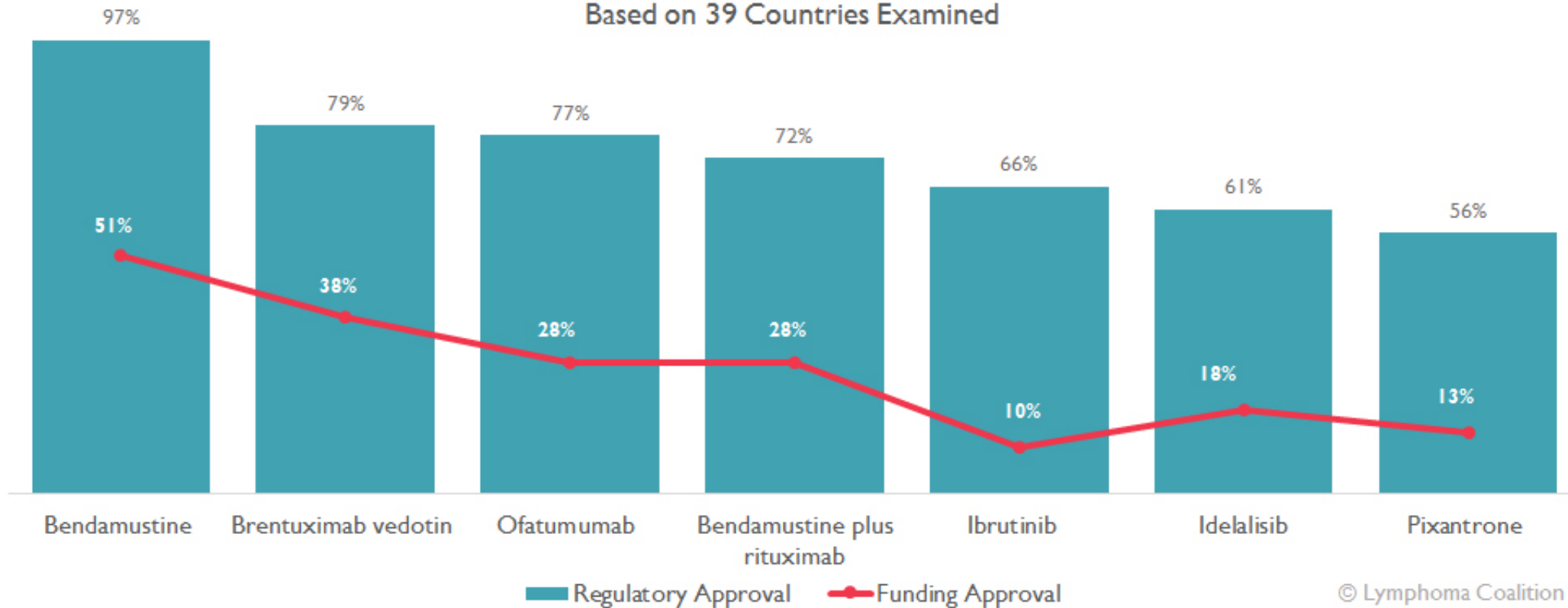
# Therapy Availability

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Approvals for New Therapies and Combinations  
Based on 39 Countries Examined



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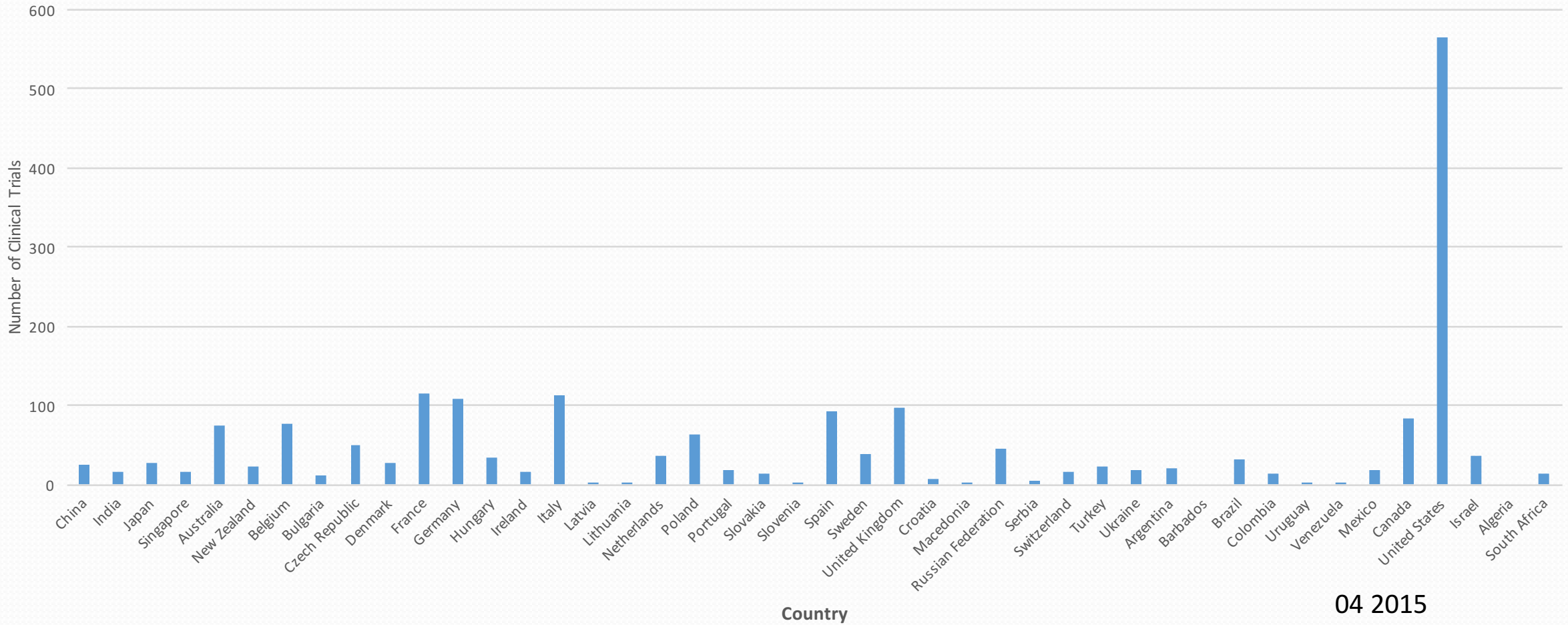


# Inequalities in Access to Care

- Of the 3500 respondents from the global patient survey, 60% indicated they faced barriers to treatment
  - Long wait times to treatment
  - Lack of access to treatment centre
  - No local specialty physician
  - Access to latest treatments
- Broken out by country to serve the members with local advocacy initiatives



# Clinical Trials Available by Country



04 2015

# Clinical Trial- Patient Survey



- At the time of diagnosis, 46% of respondents understood what a clinical trial (ct) was
- Despite these results, since 2012, significantly fewer respondents had been approached to participate in a ct, **74% had not.**
- Of the 19% who had been approached, as many as 71% had agreed to participate in one.
- **Similar to 2012 results, the 74% who had not been approached to participate in a ct:**
  - 27% said they would likely have participated in one,
  - 58% said they would have needed to have had more information, and
  - 9% said it was unlikely they would have participated.

# Clinical Trial Education

- What LC does with the information....
  - Tie into the LeIP Report Card
  - LC disseminates and educates member organisations on ct availability through the global data base, newsletters and websites
  - CT design – focus on side effects to provide a better quality of life long term – tie in the patient survey results – goal - partner in trial design
  - Educate healthcare professionals at every opportunity
  - Discuss what to do about engaging biosimilar enrolment
  - Mapping what therapies are not available against what is available through a ct as an option to care

# Quality of Life Issues

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## Physical & Emotional Impacts

- Since diagnosis, one third to one half of patients reported being affected mostly by:
  - Fatigue (50%) – Fatigue Consortium
  - Hair loss (34%)
  - Muscle weakness (31%) followed by:
    - Sleeplessness (28%)
    - Aching joints (26%)
    - Bowel changes (23%)
    - Nausea & vomiting (21%)
    - Changes in taste and smell (27%),
    - Trouble concentrating (24%)
    - Problems fighting infections (21%)
    - Changes in sexual function (18%)
- Newly diagnosed patients not connecting with patient groups early in their journey

# Patient Healthcare Communication

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- Only 52% of newly diagnosed patients reached out to their doctors for help compared to those who:
  - Were in remission (66%),
  - Were in other stages of diagnosis (66%),
  - Had relapsed (61%), and
  - Had been treatment free (64%).
- Only 35% of patients were provided with information about support services by healthcare professionals

# Patient Healthcare Communication

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65% of all respondents said they had communicated issues regarding the effects of lymphoma on the quality of their lives with their doctors, and of those:

- 38% said Yes their doctor had been able to help them
- 50% said Somewhat
- 9% said they had Not been able to help

If not talking to their healthcare professional then who are they talking to? Where are they getting their information?

- Online research 19%
- Friends, family members, and other patients 16%
- Patient support groups 10% and
- Patient organisations 6%



# Quality of Life Support

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PATIENT SUPPORT SERVICE	Most helpful	Aware but not using	Unaware
Social worker	20%	36%	31%
Referral to external support group	33%	34%	22%
Patient organisation	34%	28%	27%
Dietician/ nutritionist	26%	33%	26%
Counsellor/ psychologist	28%	38%	22%
Chaplain/ church group	23%	42%	20%
Physical therapy	16%	37%	31%
Pain management	18%	39%	27%
Complementary therapist	14%	33%	37%
LEGEND			
	The most helpful service, i.e. The highest proportion of respondents who found the service to be 'Very' or 'Somewhat' helpful.		
	The least used service, i.e. The highest proportion of respondents who were both unaware of the service and who were aware of the service but did not use it.		

# Case Studies

- Develop the full story from all pillars of the algorithm of care by country and subtype

2015:

- Building 2 subtype specific case studies for the LeIP Report Card on Lymphomas
- Discover cultural differences – build on support for these insights
- HTA groups are asking for case studies and member organisation opinions – case studies will be prepared and localized



# Working Together

- Create “How To” tools – world awareness, case studies, promotional material – what is a potential main message that can be used worldwide
- Connecting with the newly diagnosed patient

Strength in understanding the global landscape and developing a worldwide message

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