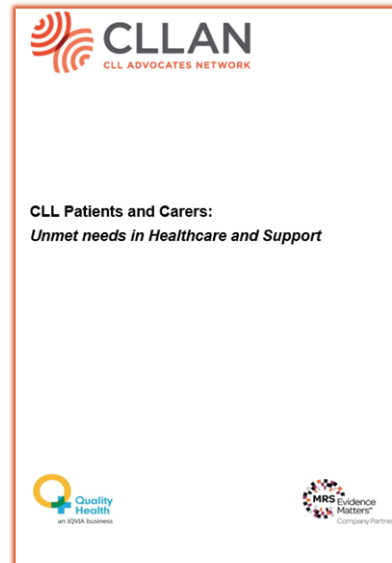


# CLLAN's Survey Comparison Report

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## CLL Patients and Carers: Unmet needs in Healthcare and Support



# Overview

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- CLLAN conducted and co-conducted global multiple stakeholder surveys
  - to understand current lived experience and needs of patients and carers and
  - map current gaps and opportunities to address equity, service and unmet need.
- A comparative analysis was undertaken from the findings of separate lived experience surveys conducted between 2021 and 2022 with CLL patients, their carers, and support organisations from across the globe:
  - [CLLAN 2021 Resource Mapping and Unmet Needs Survey vs.](#)
  - [CLL aspects 2021/22 patient experience survey and](#)
  - [CLL aspects 2022 carer experience survey](#)
- Abstract submitted to iwCLL 2023: “Global Perspectives through multi stakeholder mapping of lived experience with CLL – insights to improve equity, services, and unmet need”



March 30, 2023

CLLAN 2021 Survey  
Report and  
Recommendations now  
available!

# Methodology

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- Responses from:
  - 40 countries (across surveys).
  - 1202 patients, 137 carers
  - 57 support organisations
- Broad global reach, but most responses from the patient and carer surveys were from the UK and North America.
- Online surveys available in ten languages.
- Countries were segmented into low-and-middle-income countries (LMIC) and high-income countries (HIC) according to the OECD\* to understand and identify geographical impacts on lived experience.
- As sample populations within the surveys are distinct, the findings are drawn from comparison of overlapping and complementary areas across responses to all three surveys.

*\* Organisation for Economic Co-operation and Development*

Countries in Blue: **Low-and-middle-income countries (LMIC)**.

Countries in Green: **High income countries (HIC)**

Total Patients from **Low-and-middle-income countries (LMIC): 11**

Total Patients from **High income countries (HIC): 1118**

*(73 responses were missing information on country)*

Survey Global Reach:

**Figure 1** Patient and Carer Experience surveys: Responses by country

Country	No. of respondents (Patient)	Number of respondents (Carer)	Country	No. of respondents (Patient)	Number of respondents (Carer)
Argentina	3	0	Hungary	1	0
Armenia	0	0	India	1	0
Australia	21	1	Ireland	23	2
Barbados	0	0	Israel	34	4
Belgium	3	0	Macedonia	1	0
Bolivia	1	0	New Zealand	19	1
Canada	92	13	Norway	1	0
Costa Rica	2	0	Slovenia	1	0
Croatia	1	2	South Korea	16	1
Denmark	12	10	Spain	1	0
Ecuador	1	0	Sweden	0	1
Finland	2	1	Switzerland	1	1
France	6	3	Tanzania	1	0
Germany	5	2	The Netherlands	13	0
Greece	3	0	United Kingdom (UK)	762	81
Guatemala	1	0	United States of America (USA)	101	15

Total organisations **Low-and-middle-income countries (LMIC): 19**

Total organisations **High income countries (HIC): 38**

**Figure 2** CLL Patient Advocacy and Support survey: Responses by country

Country	No. of respondents (Organisations)	Country	No. of respondents (Organisations)
Argentina	1	Italy	1
Armenia	1	South Korea	1
Australia	1	Macedonia	2
Barbados	1	Mali	1
Belgium	1	Mexico	2
Bolivia	1	Morocco	1
Bulgaria	1	Nepal	1
Canada	3	New Zealand	2
Colombia	2	Portugal	1
Costa Rica	1	Russia	1
Croatia	1	Serbia	1
Czech Republic	1	Spain	1
Denmark	1	Sweden	1
Estonia	1	Switzerland	2
France	2	Tanzania	1
Germany	3	The Netherlands	1
Greece	1	Ukraine	1
India	2	United Kingdom (UK)	4
Ireland	2	United States of America (USA)	3
Israel	1	Venezuela	1

Figure 3: European reach of all three surveys (based on total response numbers)

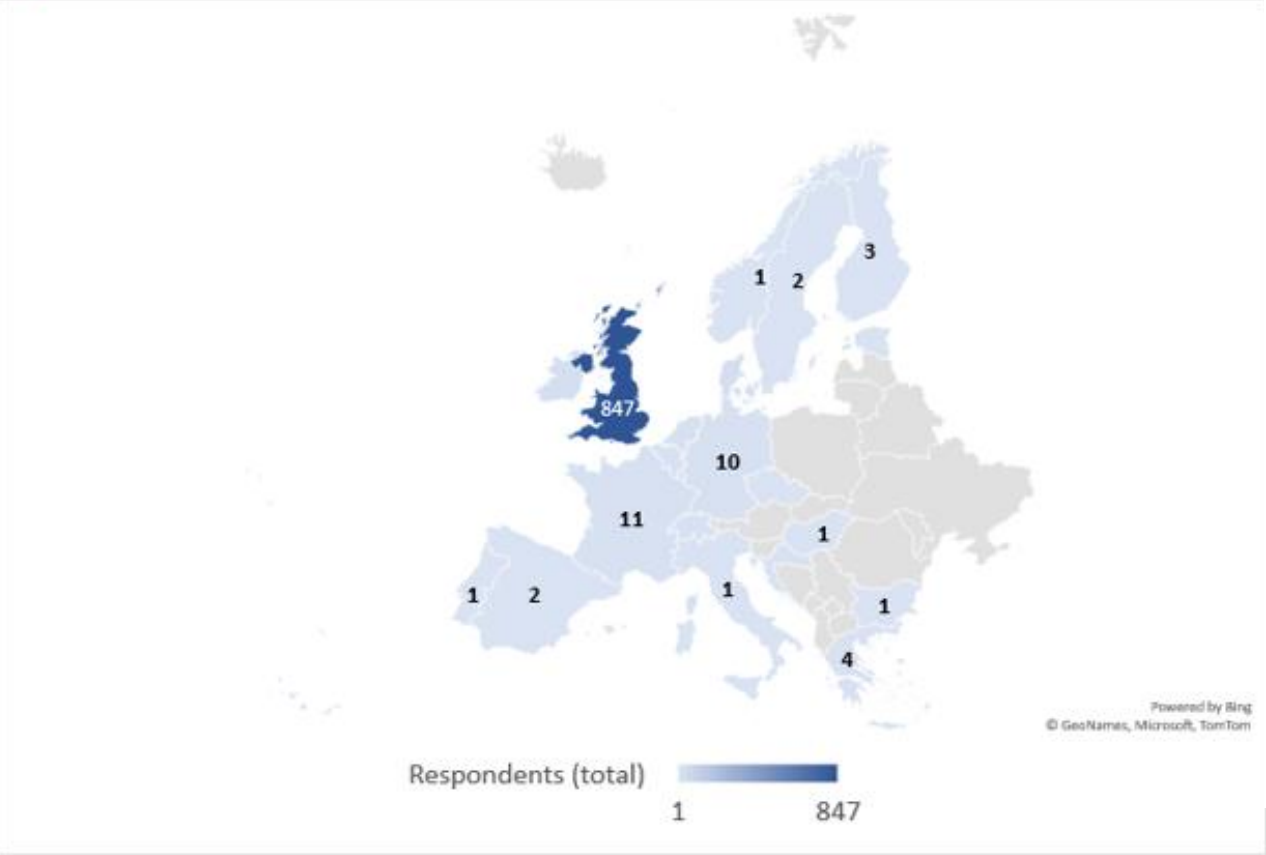
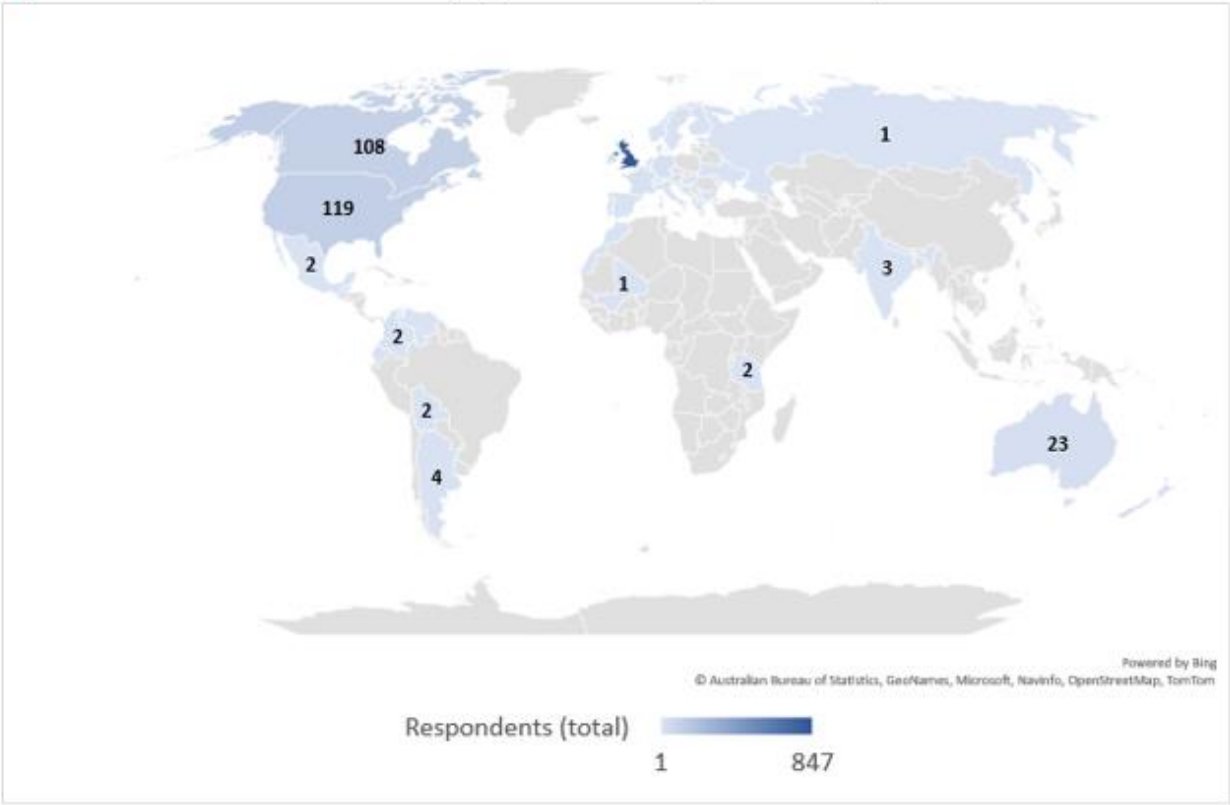


Figure 4: Global reach of all three surveys (based on total response numbers)



# Results

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Insights from the surveys and analysis have identified differing patient and disease profiles for CLL patients/carers between HIC and LMIC.

Key insights can be themed into four distinct areas:

1. Geographical differences for patient outcomes
2. Correlation of awareness of CLL and late diagnosis
3. Unmet need in information and support referrals
4. Availability of clinical trials and treatments

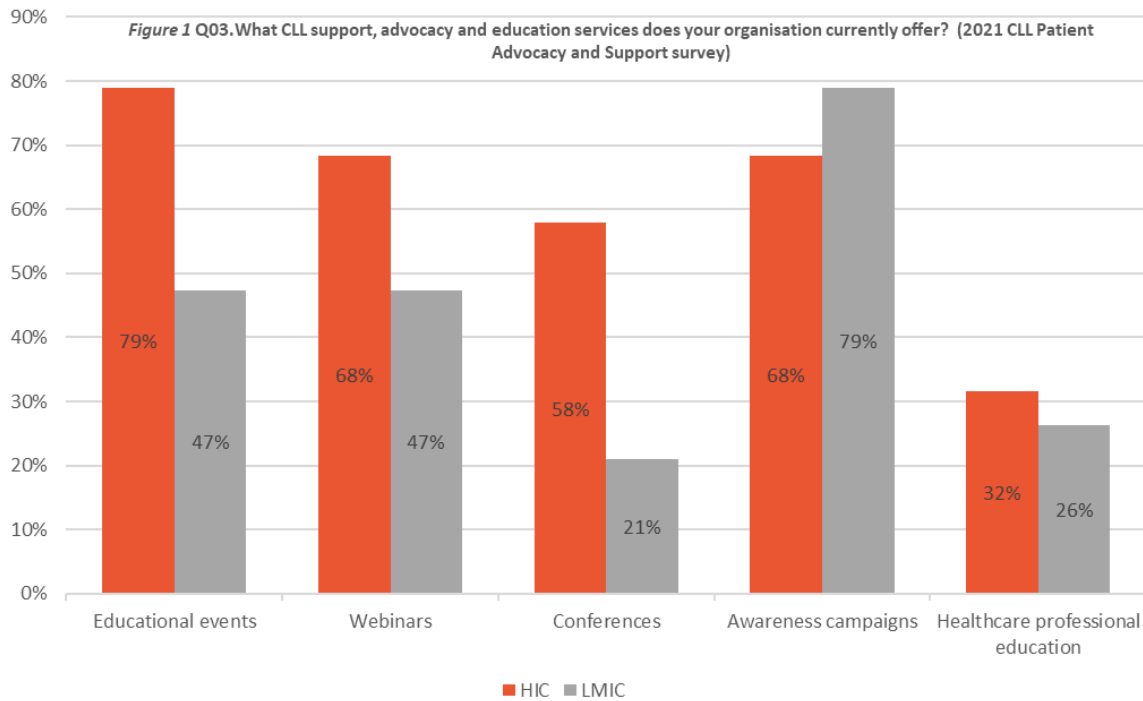
# 1. Geographical differences for patient outcomes

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- Responses from patients and support organisations suggest that there are **geographical disparities for patient outcomes and for support services**.
- Many countries **lack a dedicated community or patient groups** to support people as they navigate the treatment and holistic impacts of their diagnosis.
- **Unmet need** was higher in **LMIC** around their **CLL diagnosis, treatment and support** than those residing in HIC.
- Patient organisations in **HIC** are more likely to provide **wider services** such as education events and webinars than those from LMIC resulting in further gaps for those in LMIC.

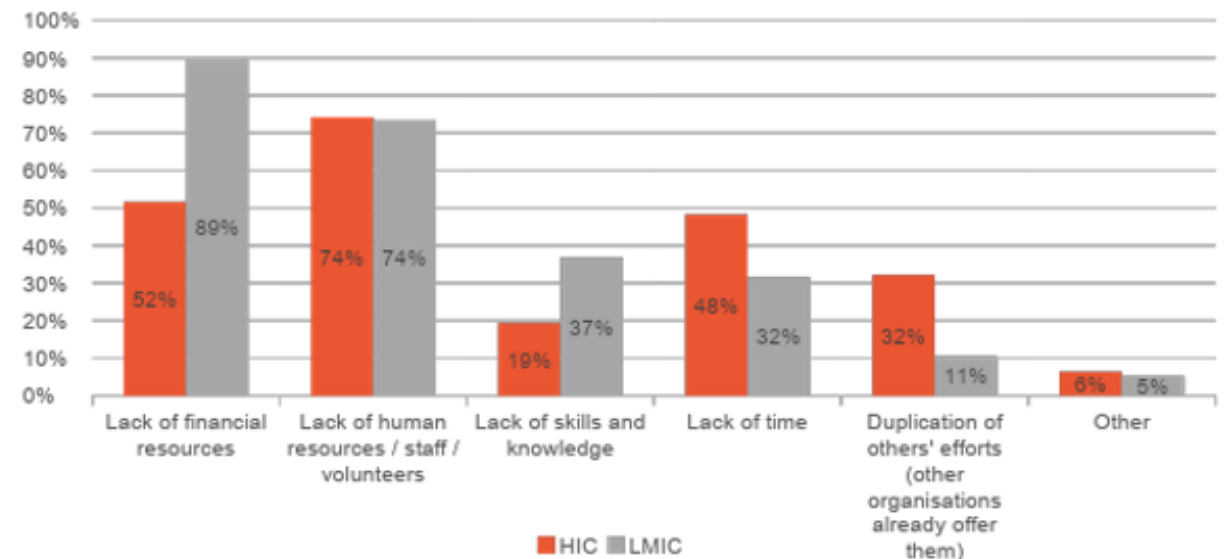
# 1. Geographical differences for patient outcomes

## Geographical comparison of services



## Geographical comparison of service delivery challenges

*Figure 33 Q11. What are the reasons you do not currently offer the CLL support, advocacy, and education services selected in the previous question? (CLL Patient Advocacy and Support survey)*





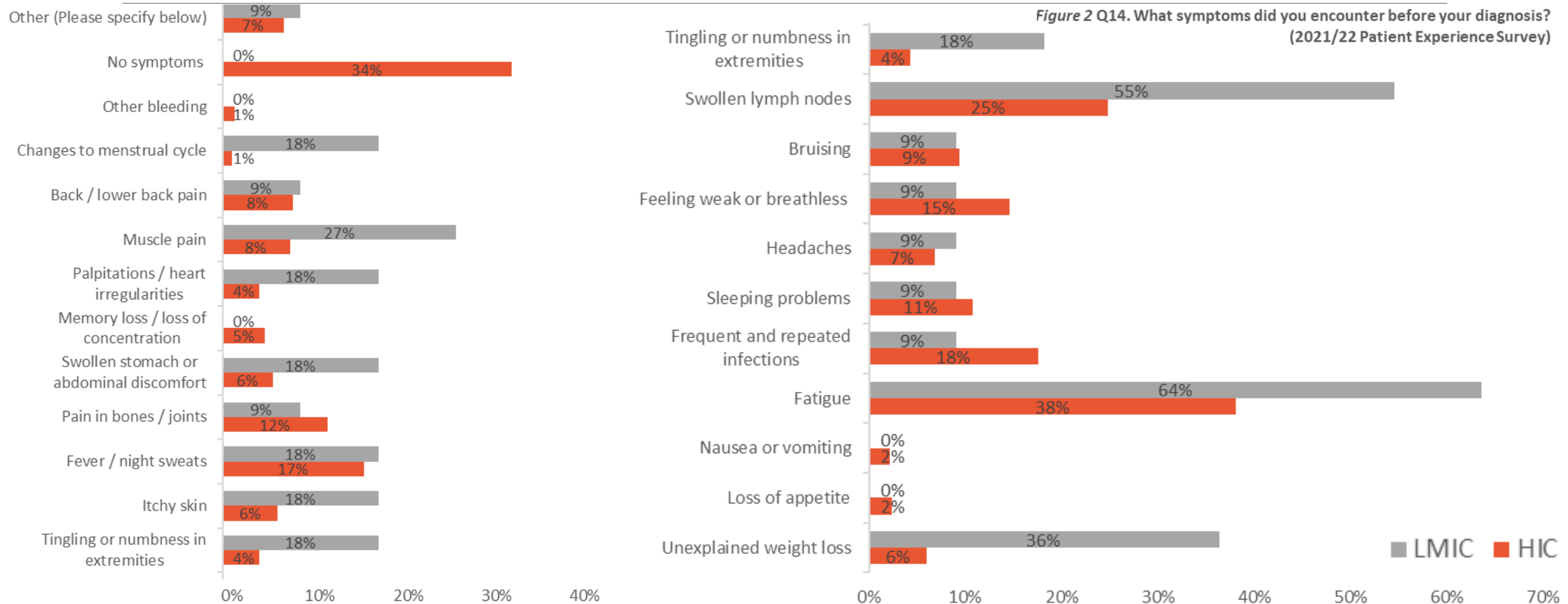
## 2. Correlation of awareness of CLL and late diagnosis

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- Reduced awareness about CLL correlates with late diagnosis in the survey responses from patients and support organisations.
- **34%** of respondents from **HIC** reported **no symptoms** and were diagnosed through routine tests.
- In contrast, respondents from **LMIC** **all reported some symptoms** prior to diagnosis.
- Patient organisations reported they were **less likely to be engaged in healthcare education** suggesting a possible **opportunity to improve knowledge share** between support organisations and healthcare professionals.

# 2. Correlation of awareness of CLL and late diagnosis

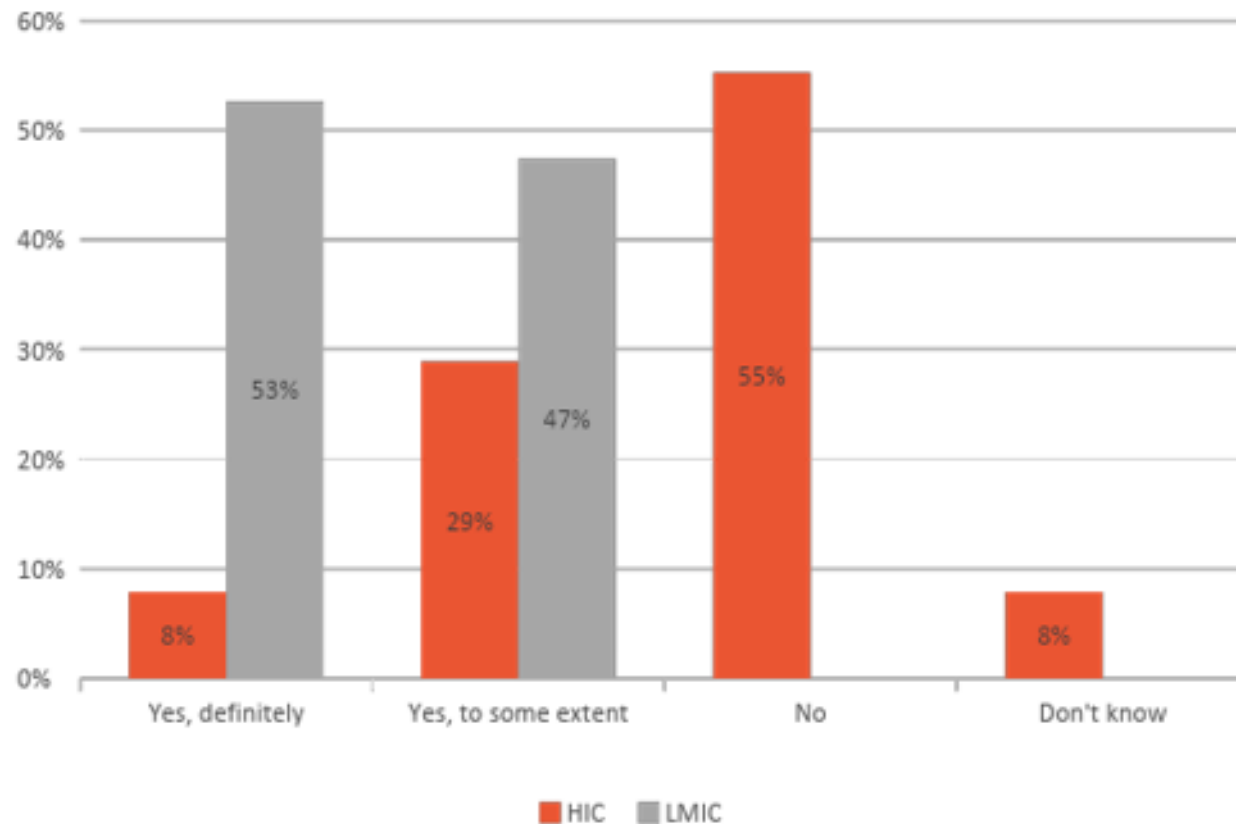
Geographical comparison of pre diagnosis symptom prevalence



## 2. Correlation of awareness of CLL and late diagnosis

Geographical Patient Organization perception of delayed diagnosis

**Figure 18** Q20. Is delayed / late diagnosis an issue for CLL patients in your country? (CLL Patient Advocacy and Support survey)



# 3. Unmet need in information and support referrals

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Respondents / the surveys reported:

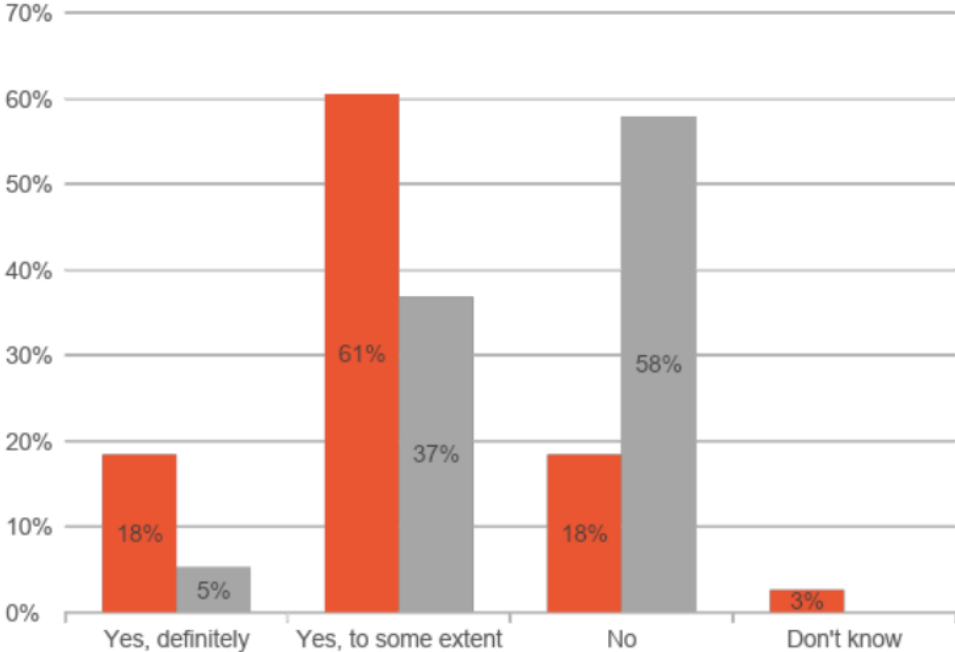
- **Unmet need around information and support** offered to patients across their CLL journey, in particular around **diagnosis** and **'Watch and Wait'**.
- **Reduced understanding of the diagnosis** (only 35% of patients from HIC and 27% of patients from LMIC reported full understanding),
- A **lack of sensitivity** around their diagnosis
- Advocating **greater involvement in their treatment decisions**.

# 3. Unmet need in information and support referrals

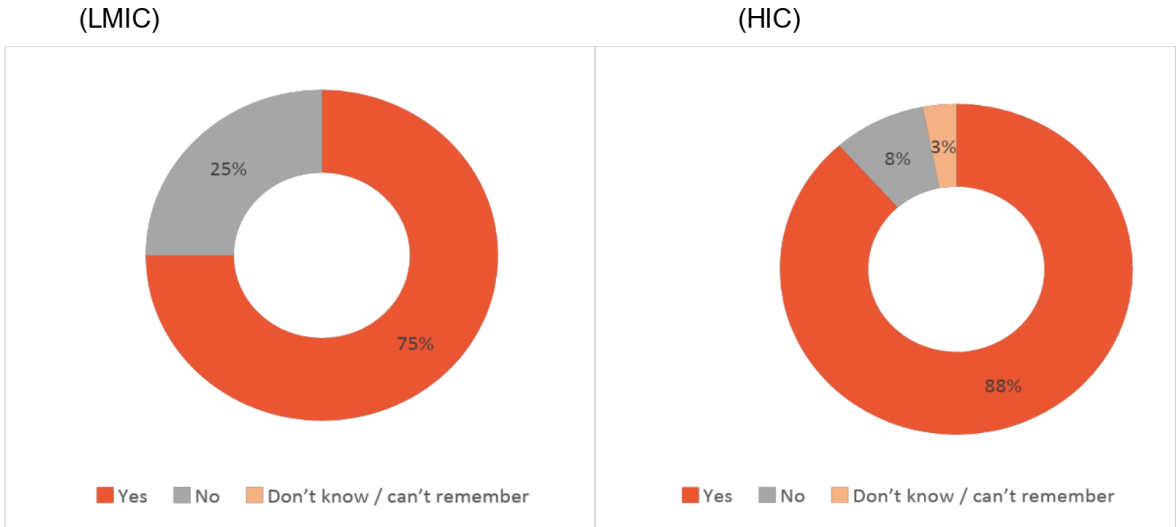
## Comparative access to support

## Comparative patient understanding of treatment path

**Figure 66** Q26. Are CLL patients in your country able to get support for mental health issues directly resulting from their CLL diagnosis / treatment through healthcare providers? (CLL Patient Advocacy and Support survey)



**Figure 35** When you were placed on 'watch and wait' for the FIRST time were you given an explanation why? (Patient Experience survey)



# 3. Unmet need in information and support referrals

## Comparison and mapping of information provision and patient understanding

Figure 26 Q31. Were you given written information about your leukemia at your diagnosis? (Patient survey)

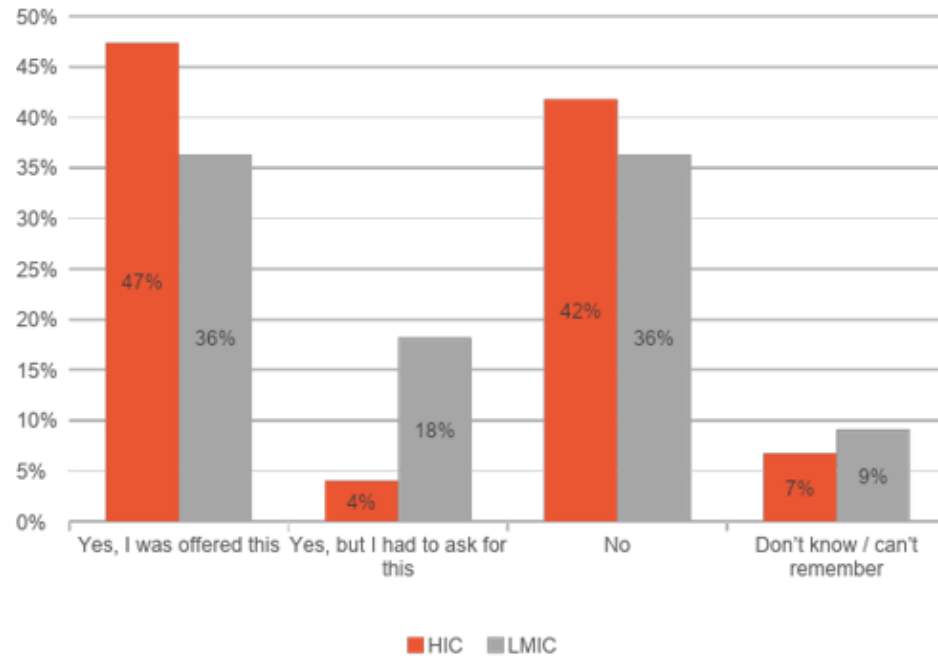
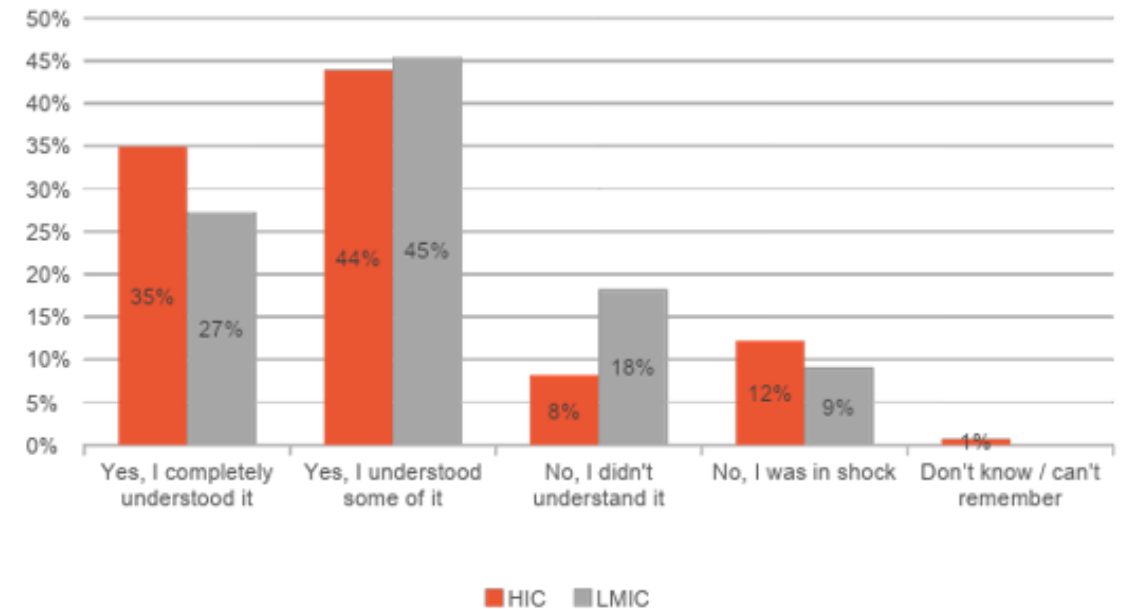


Figure 23 Q27. Did you understand the explanation about what was wrong with you? (Patient Experience Survey)



# 4. Availability of clinical trials and treatment

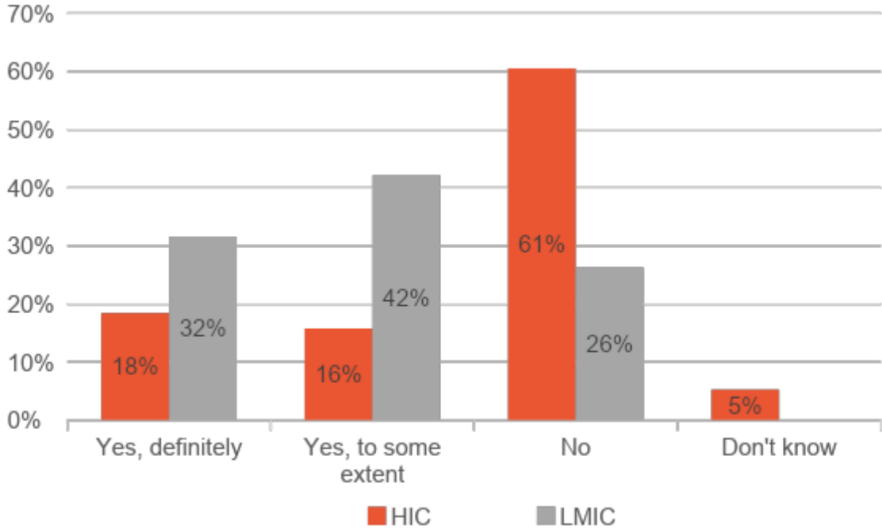
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- Patient organisations reported **perceived issues in access** to affordable **therapies** and **clinical trials**.
- While these are global issues, results demonstrate that it's **more pronounced in LMIC**. 84% of organisations from LMIC responded patients weren't able to access clinical trials, opposed to 26% from those countries classed as HIC.
- Although 54% of CLL patient respondents stated that they were **completely involved in their treatment decisions**, this was **only 30% in LMIC**.
- **Almost all** patient respondents reported being on at some time a **'Watch and Wait'** monitoring plan.
- The majority also reported they had treatment since diagnosis so **access to best practice therapies is vital**.

# 4. Availability of clinical trials and treatment

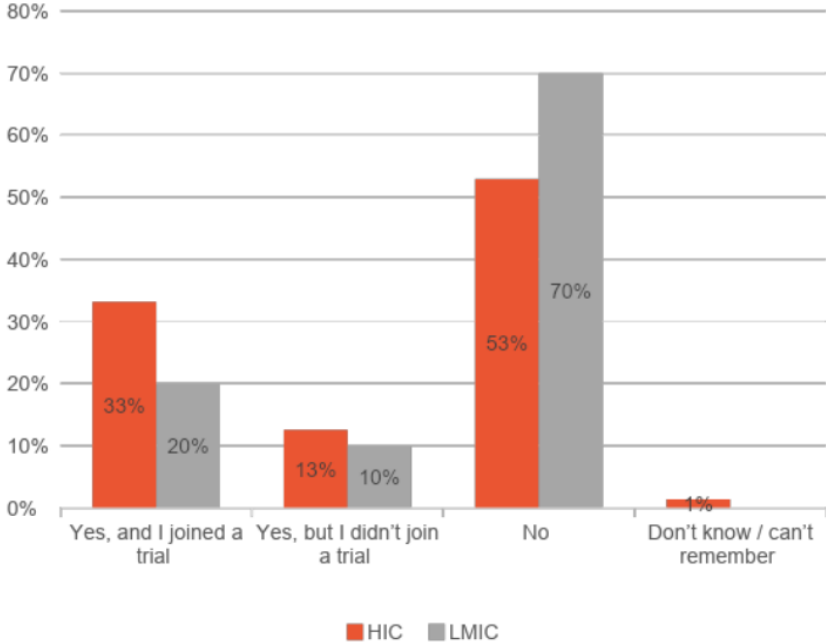
## Comparative of treatment affordability

Figure 48 Q18. Is being able to afford treatment and care an issue for CLL patients in your country? (CLL Patient Advocacy and Support survey)



## Comparative of trial discussions

Figure 56 Q86. Were you given the option of participating in a clinical trial? (Patient Experience Survey)

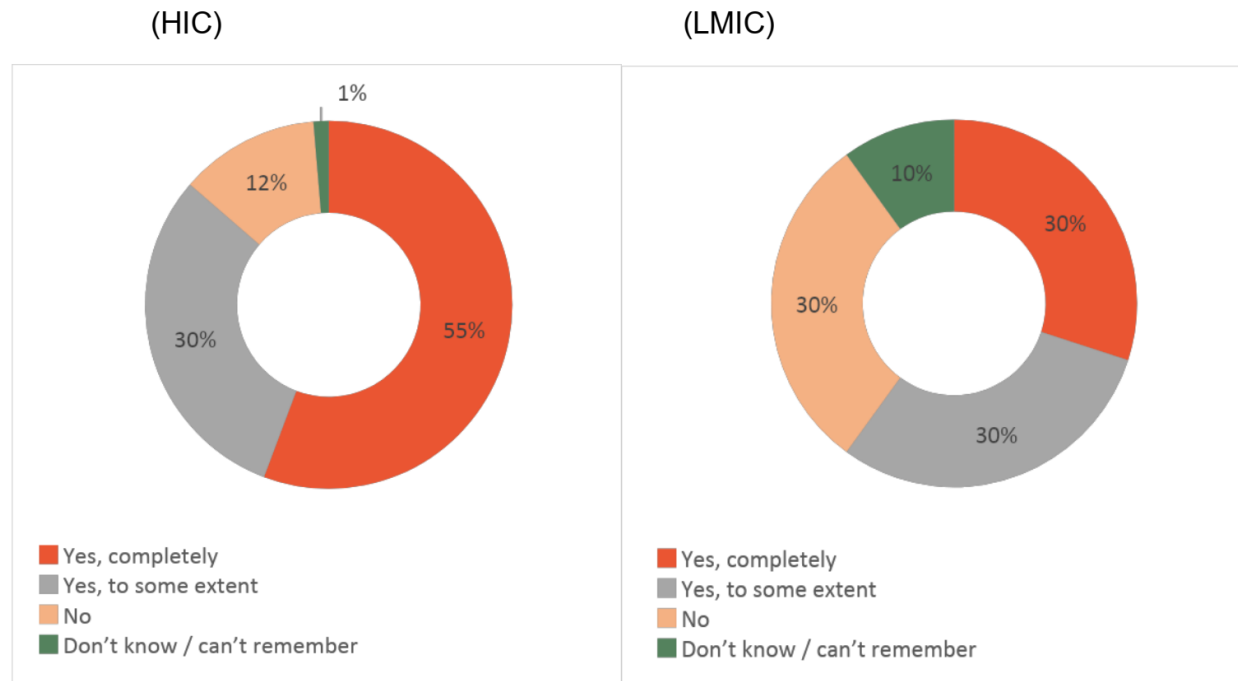




# 4. Availability of clinical trials and treatment

## Comparison of patient participation in treatment decisions

**Figure 51** Q64. Were you involved as much as you wanted to be in decisions about your treatment?  
(Patient Experience Survey)



# Conclusion

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- Overall, patients and carers would like to have **more choice in their treatment decisions, increased access to clinical trials and better information and support across the whole of their patient journey.**
- Understanding the unique unmet needs and gaps in provision, will help the wider healthcare and support providers to **strategically target the development of current services** most beneficial to patients and carers.
- **Support particularly targeted at the different patient profiles in different countries** will also help to reduce the current disparity across the whole landscape of CLL.
- There is **opportunity globally to improve collaboration and connection between patient organisations and treating teams** to address the gaps in need and support the whole life experience of CLL.