GLOBAL PERSPECTIVES THROUGH MULTI STAKEHOLDER MAPPING OF LIVED EXPERIENCE WITH CLL - INSIGHTS TO IMPROVE EQUITY, SERVICES, AND UNMET NEED

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INTRODUCTION

Many countries exist without dedicated community or patient groups to support people as they navigate the treatment and holistic impacts of their diagnosis. The CLL Advocates Network, a global network of patient advocacy organisations, 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.

METHODOLOGY

A comparative analysis was undertaken from the findings of three separate lived experience surveys conducted between 2021 and 2022 with CLL patients, their carers, and support organisations from across the globe. The first of these surveys was the CLL Patient Advocacy and Support Survey (CLL-PAGS) conducted by CLLAN in 2021. This was followed by the Global Leukemia Patient Experience Survey (GPES) conducted in 2021/22 in collaboration with Acute Leukemia Advocates Network (ALAN) and CML Advocates Network (CMLAN). The third survey that the analysis is based on was the Global Leukemia Carer Experience Survey (GCES) conducted in 2022. Similar to the GPES, this also was a collaboration between CLLAN, ALAN and CMLAN. CLL-specific data were extracted from the latter two surveys. Across the surveys, respondents represented people and organisations from 40 countries. Responses were obtained from 1202 patients, 137 carers and 57 support organisations. Although there was broad global reach, most responses from the patient and carer surveys were from the UK and North America. The surveys were completed online and available in ten languages.

Countries were segmented into low-and-middle-income countries (LMIC) and high-income countries (HIC) according to the Organisation for Economic Co-operation and Development (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.

RESULTS

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:

Geographical differences for patient outcomes

Responses from patients and support organisations suggest that there are geographical disparities for patient outcomes and for support services. Unmet need was higher in LMIC around their CLL diagnosis, treatment and support than those residing in HIC. Patient organisations in HIC are also more likely to provide wider services such as education events and webinars than those from LMIC resulting in further gaps for those in LMIC.

Correlation of awareness of CLL and late diagnosis

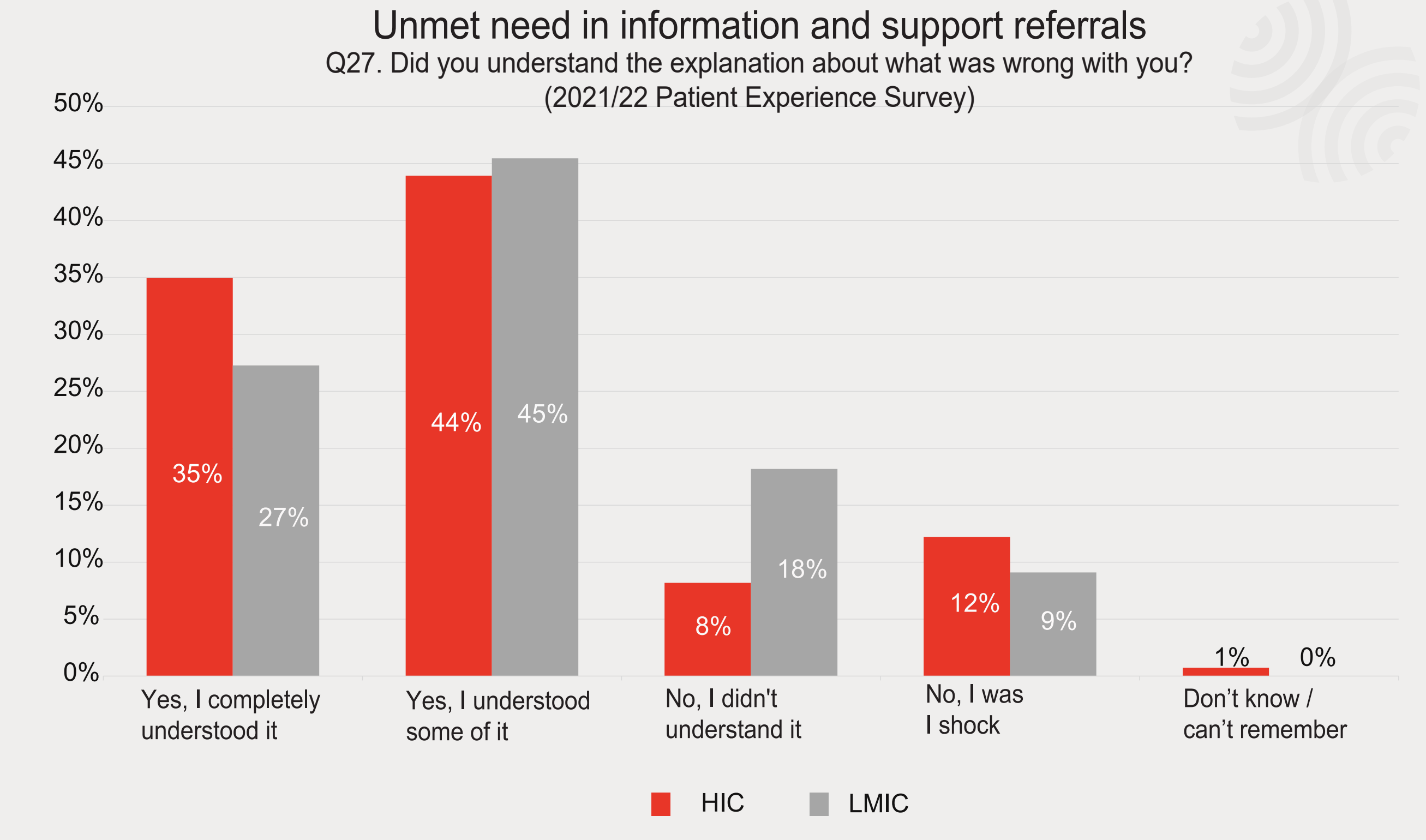
Reduced awareness about CLL correlates with late diagnosis in the survey responses from patients and support organisations. 34% of respondents from HIC reported no symptoms and were diagnosed through routine tests. In contrast, respondents from LMIC all reported some symptoms prior to diagnosis. Patient 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.

Unmet need in information and support referrals

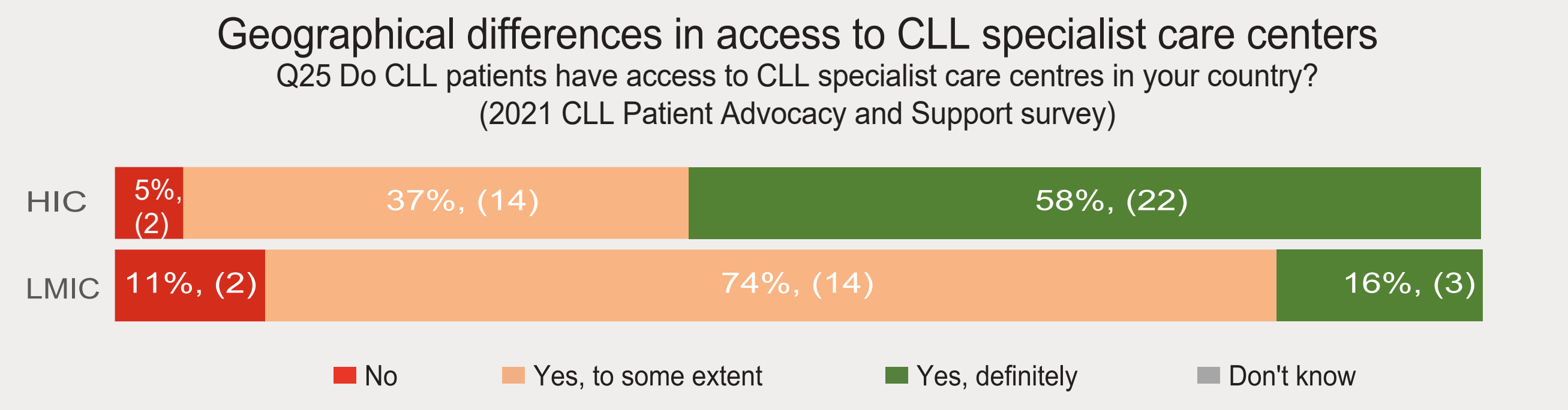
Respondents reported unmet need around information and support offered to patients across their CLL journey, in particular around diagnosis and 'Watch and Wait'. The surveys reported reduced understanding of the diagnosis (only 35% of patients from HIC and 27% of patients from LMIC reported full understanding), a lack of sensitivity around their diagnosis and advocating greater involvement in their treatment decisions.

Availability of clinical trials and treatments

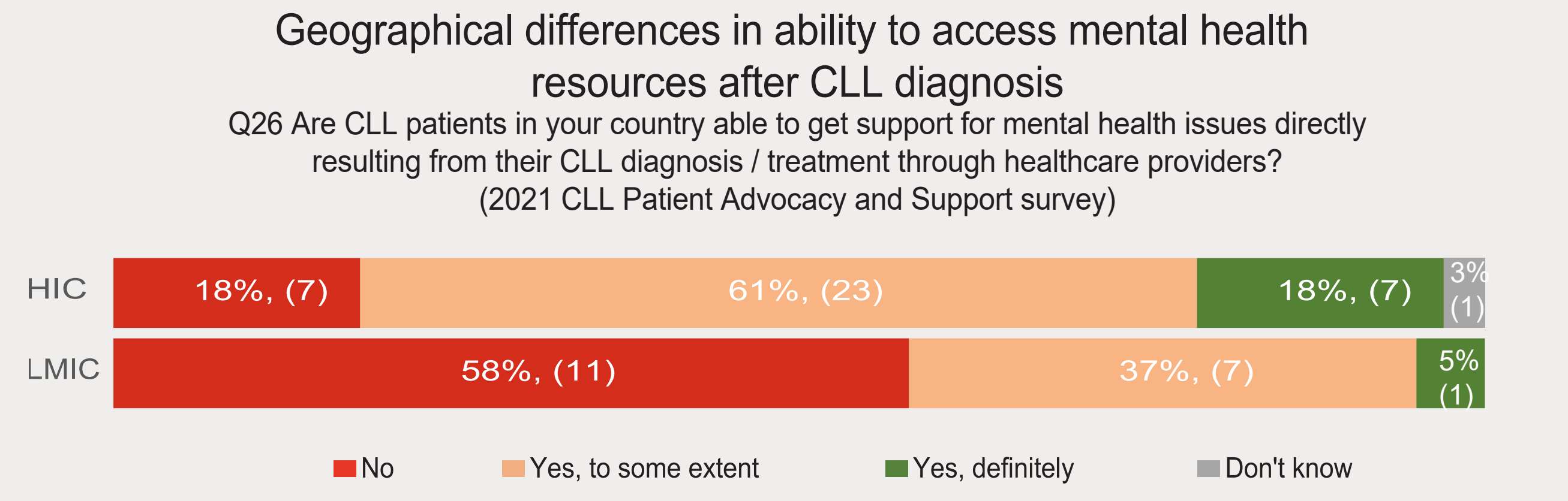
Patient organisations reported perceived issues in access to affordable therapies and clinical trials. While these are global issues, results demonstrate that it's more pronounced in LMIC. 84% of organisations from LMIC responded patients weren't able to access clinical trials, opposed to 26% from those 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.



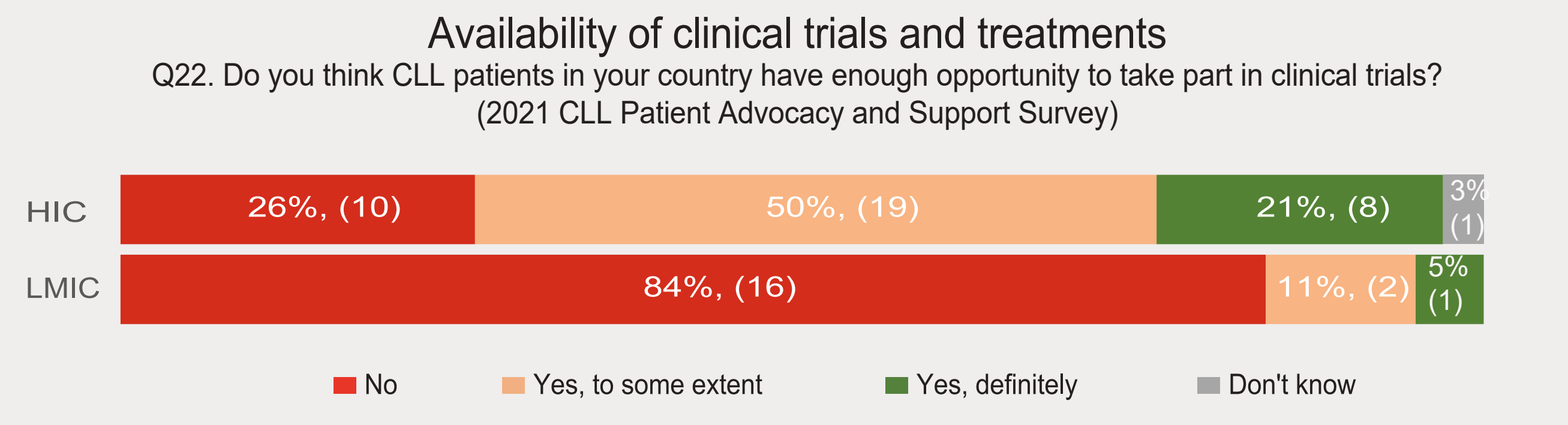
Unmet need in information and support referrals
Q27. Did you understand the explanation about what was wrong with you?
(2021/22 Patient Experience Survey)



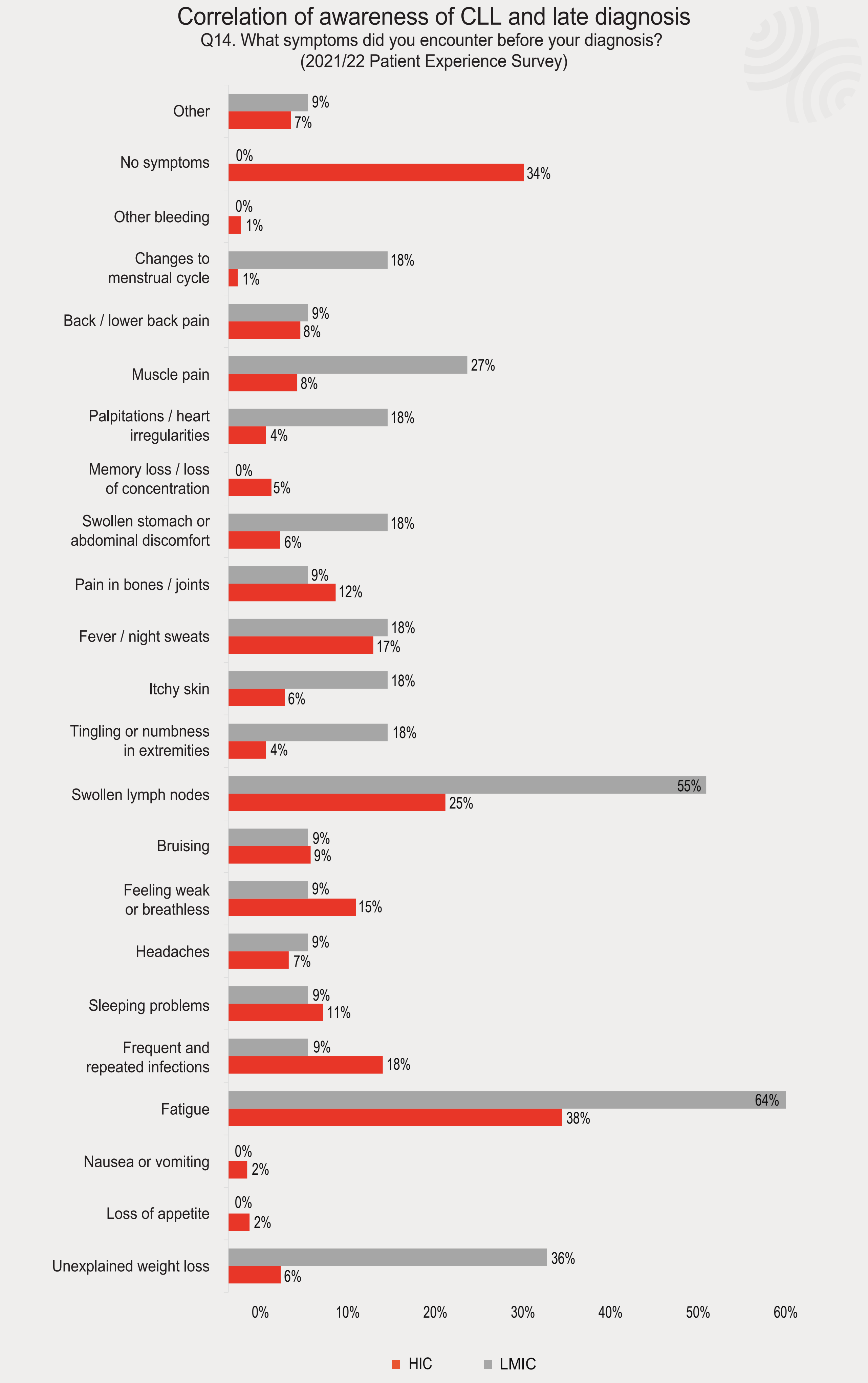
Geographical differences in access to CLL specialist care centers
Q25 Do CLL patients have access to CLL specialist care centres in your country?
(2021 CLL Patient Advocacy and Support survey)



Geographical differences in ability to access mental health resources after CLL diagnosis
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?
(2021 CLL Patient Advocacy and Support survey)



Availability of clinical trials and treatments
Q22. Do you think CLL patients in your country have enough opportunity to take part in clinical trials?
(2021 CLL Patient Advocacy and Support Survey)



Correlation of awareness of CLL and late diagnosis
Q14. What symptoms did you encounter before your diagnosis?
(2021/22 Patient Experience Survey)

CONCLUSIONS

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 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. Through this collaboration there is also opportunity to ensure equity of information and support globally.

CONTACT INFORMATION

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