



CLL Patients and Carers:
Unmet needs in Healthcare and Support
--- Comparison Survey ---

Table of Contents

1. Executive Summary	4
2. Background and Objectives	6
2.1. Background	6
2.2. Objective of this report	6
2.3. Methodology	7
2.4. Identification of questionnaire respondents	7
2.5. Questionnaire design, development, and fieldwork	7
2.6. Scoring methodology	7
2.7. Limitations	8
3. Responses	8
3.1. Response rates	8
3.2. Analysis	12
3.3. Date of Diagnosis	12
3.4. Age of respondents	13
3.5. Gender	15
3.6. Life circumstances of patients and carers	17
3.7. Summary	19
4. Before Diagnosis	20
4.1. Awareness and diagnosis of CLL and CLL education	20
4.2. Summary	26
5. Diagnosis	26
5.1. Understanding their diagnosis	26
5.2. Written information about their diagnosis	28
5.3. Support	31
5.4. Summary	34
6. 'Watch and Wait'	35
6.1. Numbers of patients on 'Watch and Wait'	35
6.2. Written information about 'Watch and Wait'	37
6.3. Support for those on 'Watch and Wait'	38
6.4. Summary	40
7. Treatment	40
7.1. Starting treatment	40
7.2. Treatment choice	43
7.3. Types of therapy	46
7.4. Summary	48

7.5. Clinical trials	48
7.6. Information and support	50
7.7. Summary	53
8. Emotional impact	54
8.1. Mental wellbeing post diagnosis	54
8.2. Support and information	55
8.3. Treatment by Healthcare professionals	57
8.4. Summary	57
9. Information and support	57
9.1. Online support and resources	57
9.2. Additional support and resources	59
10. Summary and recommended actions	60
10.1. Overall Summary	60
10.2. Recommended Actions	61

1. Executive Summary

Background, Aims and Methodology

Chronic lymphocytic leukemia (CLL) is the most common leukemia in the Western world, but despite this many countries do not have a community or patient groups dedicated to specifically supporting CLL patients. The CLL Advocates Network (CLLAN), a patient-led non-profit foundation for self-sustained patient advocacy initiatives, aims to improve CLL patient outcomes and enhance CLL patient care across the globe.

As part of this mission, CLLAN was interested in exploring the experience and needs of patients and carers and if and how those needs are currently being met. This report aims to provide a comparison analysis of the findings from three separate recent surveys conducted in 2021 and 2022 with CLL patients, their carers and support organisations from across the globe about their experiences. Alongside other literature and information, the findings here have supported CLLAN to create a strategic plan of priority activities to tackle the identified unmet needs and gaps in service provision.

In total, the surveys reached people and organisations across 40 countries using questionnaires available in ten languages. Responses were obtained from a total of 1202 patients, 137 carers and 57 support organisations. Although there was a broad global reach, most responses from the patient and carer surveys were from the UK and North America.

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's (OECD) [DAC list of ODA recipients](#).

All surveys that this report relates to were conducted during the worldwide COVID-19 pandemic. That said, the responses given by respondents – and therefore the findings here – have been influenced by the effects of the pandemic. This should be considered when making strategic decisions based on this report.

Key Findings

Geographical differences for patient outcomes

Although the numbers of patient respondents from LMIC were relatively small, the responses from patients and from support organisations suggest that there are geographical disparities for patient outcomes and for support services between HIC and LMIC. Patients from countries defined as LMIC have more challenges around their CLL diagnosis, treatment and support than those from HIC. Support services across the globe universally provide support for blood cancer patients, although those based in HIC are more likely to provide information and support specifically for patients with CLL. These organisations are also more likely to be involved in wider services such as education events and webinars than those from LMIC.

Current lack of awareness of CLL and issues of late diagnosis

The lack of awareness about CLL can be seen through issues around late diagnosis, suggested by the responses from patients and support organisations and the importance that support organisations place on raising awareness as part of their activities. Around 1/3 of patient respondents reported having no symptoms and were diagnosed through routine tests whilst the majority report a variety of symptoms prior to diagnosis; these symptoms were more pronounced in those responding from LMIC. Organisations across the globe were less likely to be engaged in healthcare education events suggesting a possible disconnect between support organisations and healthcare professionals.

Lack of information and support referrals for patients and carers

There is a distinct lack of information and support offered to patients across their CLL journey, in particular around diagnosis and 'Watch and Wait'. Diagnosis of CLL and the subsequent journey with the condition causes anxiety and concern for the majority of patients and their carers. They also report a lack of understanding of the diagnosis (only 1/3 fully understand this), a lack of sensitivity around their diagnosis

and would like to be more involved in their treatment decisions. This, and the lack of referral to support organisations offered through interactions with healthcare professionals, again suggests a potential disconnect between healthcare professionals and their awareness of unmet needs for patients and carers and the role support organisations can play to address these needs.

Concerns around the availability of clinical trials and treatments

The responses from the network organisations suggests an issue around access to affordable therapies and access to clinical trials and although there are issues worldwide this is more pronounced in LMIC. Although almost all of the patient respondents had been put on a 'Watch and Wait' monitoring plan, the majority had started treatment at some point since diagnosis so their access to appropriate therapies is vital. Over half of patients weren't able to access clinical trials and over half reported that they didn't have a choice around their treatments either.

Key Actions

CLLAN should encourage and promote collaborative working between organisations within the network to share resources and best practice along with the need to engage with local healthcare provision to improve outcomes for patients and reduce the current gaps and unmet needs.

ACTION: Raise CLL awareness through education and awareness campaigns provided to the general public and to healthcare professionals in particular to help increase knowledge of the condition. Shared resources between CLLAN organisations could improve this globally.

ACTION: Work collaboratively with healthcare professionals to increase their knowledge of local and wider support organisations and promote the use of information and other support resources as well as the benefits of referral for support for patients.

ACTION: Advocates and organisations should work with CLLAN and local healthcare providers and researchers to initiate clinical trials at locations where there are currently none or very few.

ACTION: Work collaboratively with healthcare professionals and organisations to raise awareness of treatment access disparities and explore alternative ways for patients, particularly those in LMIC, to access appropriate treatments and care.

ACTION: Share resources globally and work to promote the needs of patients for information and support particularly at the points of diagnosis, treatment and at 'Watch and Wait'.

2. Background and Objectives

2.1. Background

Leukemia is a cancer which starts in blood-forming tissue, usually the bone marrow. It leads to the over-production of abnormal white blood cells, the part of the immune system which defends the body against infection. In most cases of leukemia, there is no obvious cause.

There are a number of different types of leukemia. Chronic lymphocytic leukemia (CLL) is the most common leukemia in the Western world, with approximately 4 to 5 people in every 100,000 affected. Although common, it is currently poorly understood. Chronic leukemias, such as CLL, tend to progress slowly and although it is not usually possible to cure chronic leukemia with standard treatments, it can be treated and managed as a long-term condition. Despite being the most common leukemia, many countries do not have a community or patient groups dedicated to specifically supporting CLL patients.

A global network is indispensable to share knowledge, experience and best practices across countries, advocate for equitable standards of care and treatment standards and to help improve patients' understanding of clinical trials and the drug development process. The CLL Advocates Network (CLLAN) was founded in 2014 and is hosted under the umbrella of the Leukemia Patient Advocates Foundation (LePAF), a patient-led non-profit foundation for self-sustained patient advocacy initiatives¹. CLLAN serves patient organisations and key patient thought leaders around the world. As a global network CLLAN's mission is to improve CLL patient outcomes and enhance CLL patient care.

In 2021, CLLAN commissioned Quality Health (now part of IQVIA), to deliver a global survey of organisations that support CLL patients with a view to understanding what support provision looks like in different parts of the world and the support services available to patients and to better understand the key priorities of support groups ("Global CLL resource mapping & unmet needs survey"). Alongside that survey, the recent global surveys that explored the experience of both leukemia patients ("Global Leukemia Patient Experience Survey") and their carers ("Global Leukemia Carer Experience Survey") have provided a wealth of knowledge around what it's like living with this disease.

2.2. Objective of this report

CLLAN is interested in exploring the experience and needs of patients and carers and if and how those needs are currently being met.

This report provides a comparison analysis of the 2021 Global CLL resource mapping & unmet needs survey (hereinafter referred to as CLL Patient Advocacy and Support survey), the 2021/22 Leukemia Patient Experience survey and the 2022 Leukemia Carer Experience survey. For the latter two surveys, this report concentrates on data relating to CLL patients only (a subset of the wider data across different leukemia types). By doing this, the aim is to provide CLLAN and therefore advocacy groups and the wider CLL community with an understanding of the journey of those with CLL and uncover the needs of patients and their carers alongside where there are gaps in service provision. CLLAN will then create a strategic plan of priority activities to tackle the identified unmet needs.

¹ <http://www.lepaf.org/>

2.3. Methodology

Surveys

Leukemia Patient Experience survey (2021/22) and Leukemia Carer Experience survey (2022): The surveys were a collaboration between Acute Leukemia Advocates Network (ALAN), CML Advocates Network (CMLAN) and CLLAN (all three referred to throughout this report as “the networks”) with IQVIA.

In the case of the “Leukemia Patient Experience Survey” data was collected through a questionnaire completed by leukemia patients diagnosed with CLL, on their experience, from symptoms prior to diagnosis through the entirety of their CLL journey. For the “Leukemia Carer Experience Survey” another separate questionnaire was completed by carers of individuals with CLL on their experiences.

CLL Patient Advocacy and Support survey: This survey was conducted by CLLAN in 2021. A final questionnaire was completed by organisations that support people with CLL. This explored the services provided by these organisations for patients and the wider CLL/leukemia community and their views on healthcare for patients in their respective countries.

Comparison report

A review was completed from the results of the three different surveys. This identified areas of comparison that matched the objectives of this report. The results of the particular areas from the three surveys were then described, analysed and interpreted to meet the aims of the report and provide potential recommended actions. As there were no directly comparable questions between all three questionnaires and the sample populations were distinct, the findings and recommendations are drawn from a comparison of overlapping and complementary areas across the responses to all three surveys.

2.4. Identification of questionnaire respondents

Organisations that completed CLLAN’s CLL Patient Advocacy and Support survey were targeted through CLLAN’s global membership. In addition, a scoping exercise was carried out to identify additional organisations that support CLL patients, but who were not members. Organisations identified through this exercise were also invited to respond. The survey was completed exclusively online. The questionnaire was made available in seven languages: Arabic, English, European Portuguese, French, Russian, Simplified Chinese and Spanish.

The Leukemia Patient Experience and Leukemia Carer Experience surveys were also global pieces of research and were completed exclusively online. Respondents were recruited through the networks, via methods such as email, online forums, newsletter and social media to maximise potential participation. These questionnaires were made available in ten languages in total: Chinese (Simplified), English, French, German, Hebrew, Italian, Korean, Portuguese (Brazilian), Russian and Spanish.

2.5. Questionnaire design, development, and fieldwork

CLLAN’s CLL Patient Advocacy and Support questionnaire was developed and designed in 2021, following detailed discussion between the CLLAN steering committee and IQVIA. The fieldwork was conducted for 12 weeks, closing in August 2021.

The Leukemia Patient and Carer Experience questionnaires were developed through a literature review, patient advisory session and advice from an expert panel. The patient questionnaire was finalized in August 2021. Following translation and set-up of the questionnaire, the survey went live in September 2021 and closed at the end of November 2021. The carer survey was conducted between June and October 2022.

2.6. Scoring methodology

For all questions (with the exception of those asked in the form of “tick all that apply”) the percentage responses are calculated after excluding those respondents that did not answer that particular question.

The base size for questions that have been asked in the form of “tick all that apply” is determined by the number of respondents eligible to respond. As such, the missing count for a “tick all that apply” response option represents any eligible respondents who have chosen not to select that particular option or have missed the question for some other reason.

All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

On some questions, scores have been recalculated to exclude non-specific responses, (such as don't know/can't remember) or responses indicating that the question was not applicable to the participant's circumstances. On occasions, where pertinent, this has been referred to within the narrative.

2.7. Limitations

All of the surveys included in this comparison provided a global reach throughout many different countries. In order to provide the most useful analysis of the data it was agreed to break the data down into HIC and LMIC where possible (see figure 1 and 2 below). LMIC include those classified as

- Least developed countries or
- Low-income countries or
- Lower middle-income countries and territories or
- Upper middle-income countries and territories

by the Organisation for Economic Co-operation and Development's (OECD) [DAC list of ODA recipients](#). This had already been the agreed data breakdown for the CLL Patient Advocacy and Support questionnaire and made this more comparable with the previous report. For the carer survey, the small number of responses meant that this would not be possible and therefore the global results of this survey were compared with the results from the other two.

The relatively small response numbers and the different methodologies utilised for these surveys mean that each area (and each question asked in the surveys) cannot be compared absolutely and it is difficult to draw firm generalisable conclusions. In order to make comparisons, some assumptions were made between questions and the comparison is identified and drawn out within the report here. However, taking all this into account, this report does provide a unique opportunity to view the experience of CLL from a number of different angles.

Lastly, the projects recruited respondents through the networks and other online engagement forums. Although this is a convenient and appropriate sampling strategy, inevitably only those already engaged and/or seeking support are likely to respond. This should be borne in mind when drawing conclusions and producing actions directly as a result of the findings here.

3. Responses

3.1. Response rates

57 support organisations responded to the CLL Patient Advocacy and Support survey, covering 40 countries.

The Patient Experience survey received 1202 responses from those identifying that they have CLL across 30 countries. For the Carer Experience survey, 137 responses were provided from 14 countries.

See Figures 1 and 2 below.

The global reach of the three surveys has been depicted across a global map and a more detailed European map (figures 3 and 4).

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

Figure 1

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)

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 2

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

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

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

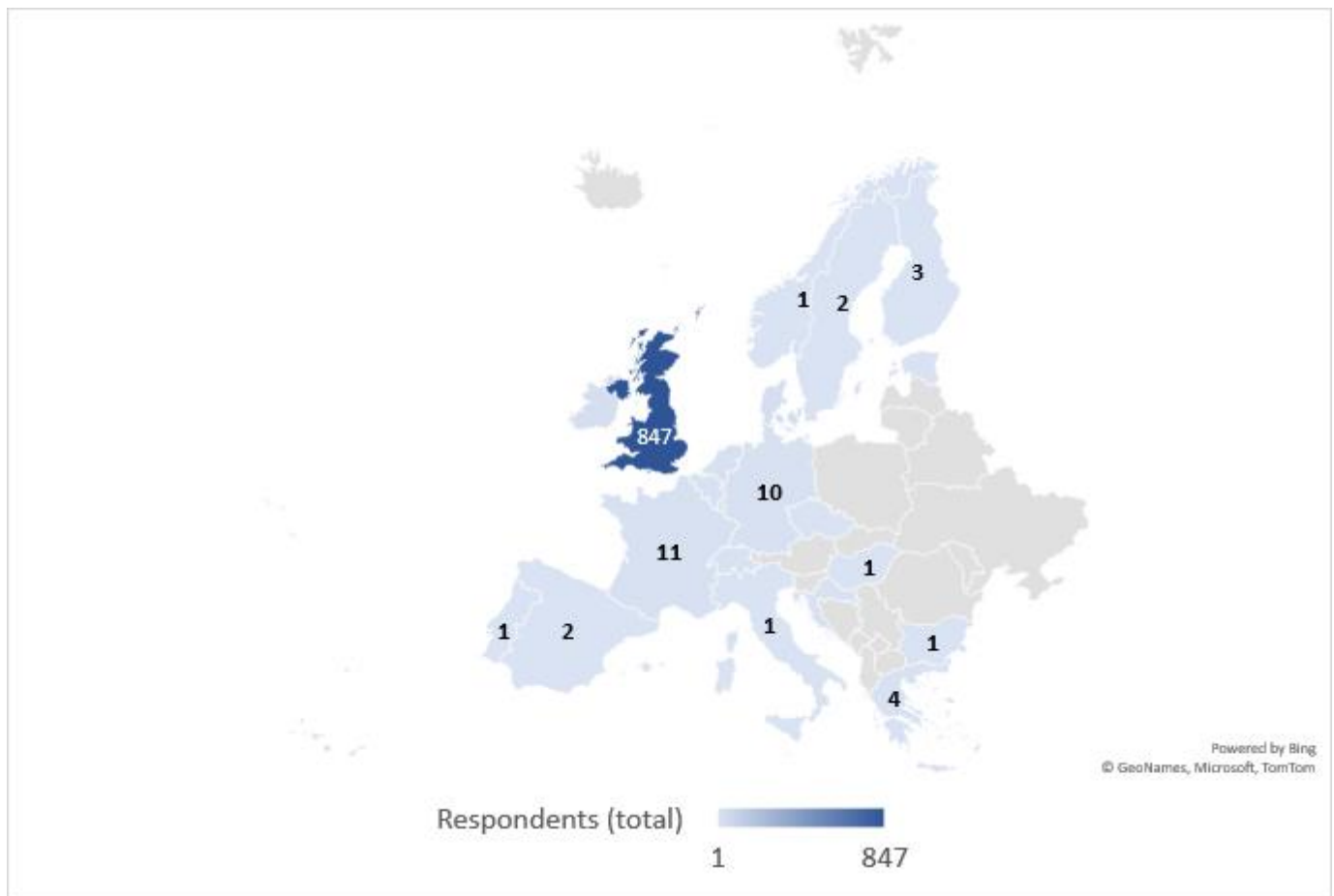
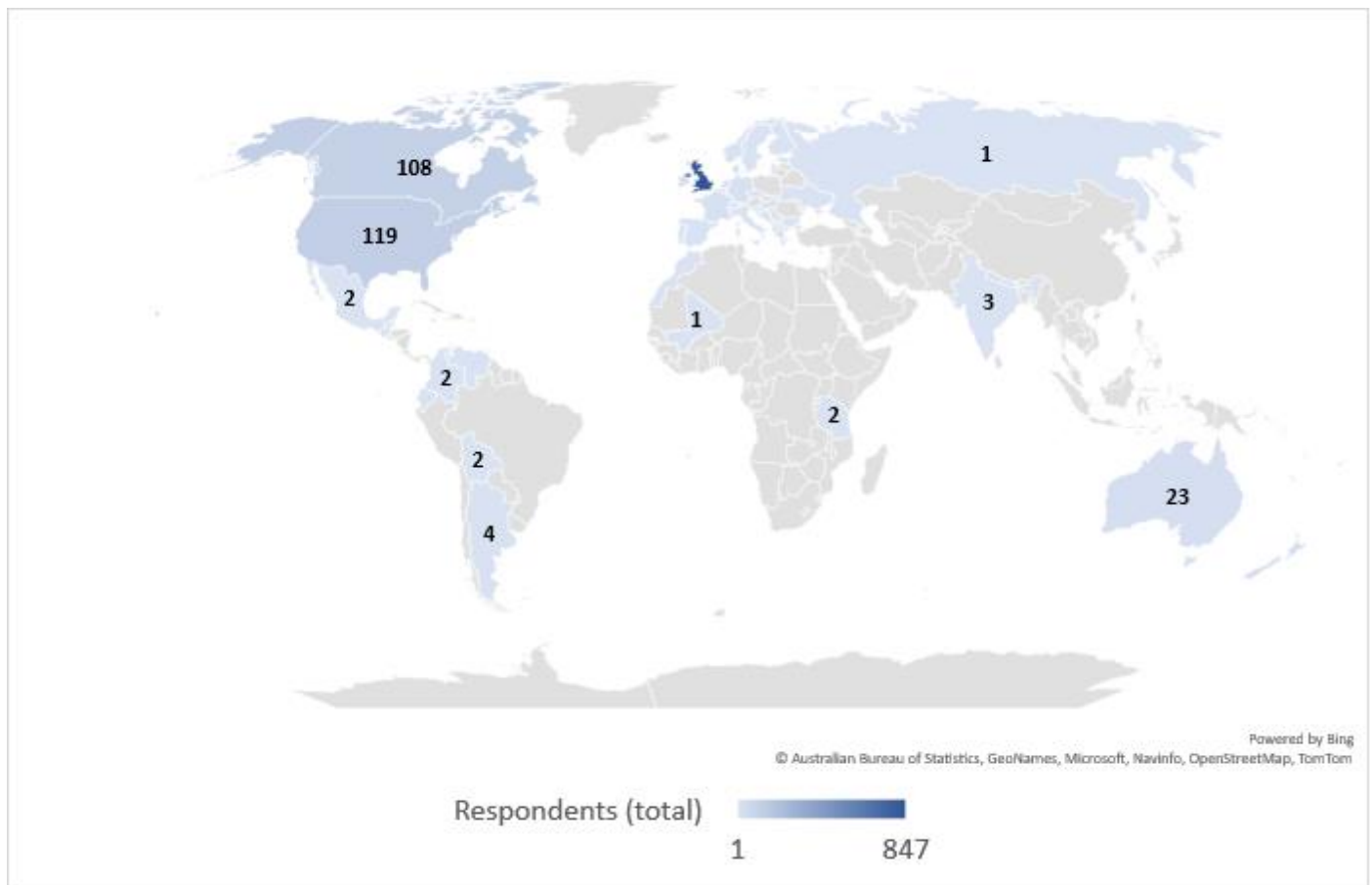


Figure 4: Global reach of all three surveys (based on total response numbers)



3.2. Analysis

The relatively low response rate from the carer survey means that we are unable to use data more detailed geographically than the global level.

For both the patient survey and the CLL Patient Advocacy and Support survey, for the purposes of this report as already noted, the data was aggregated into countries classed as HIC and LMIC (see figures 1 and 2). This provides the ability to make comparisons between these groups as well as across the survey findings more generally.

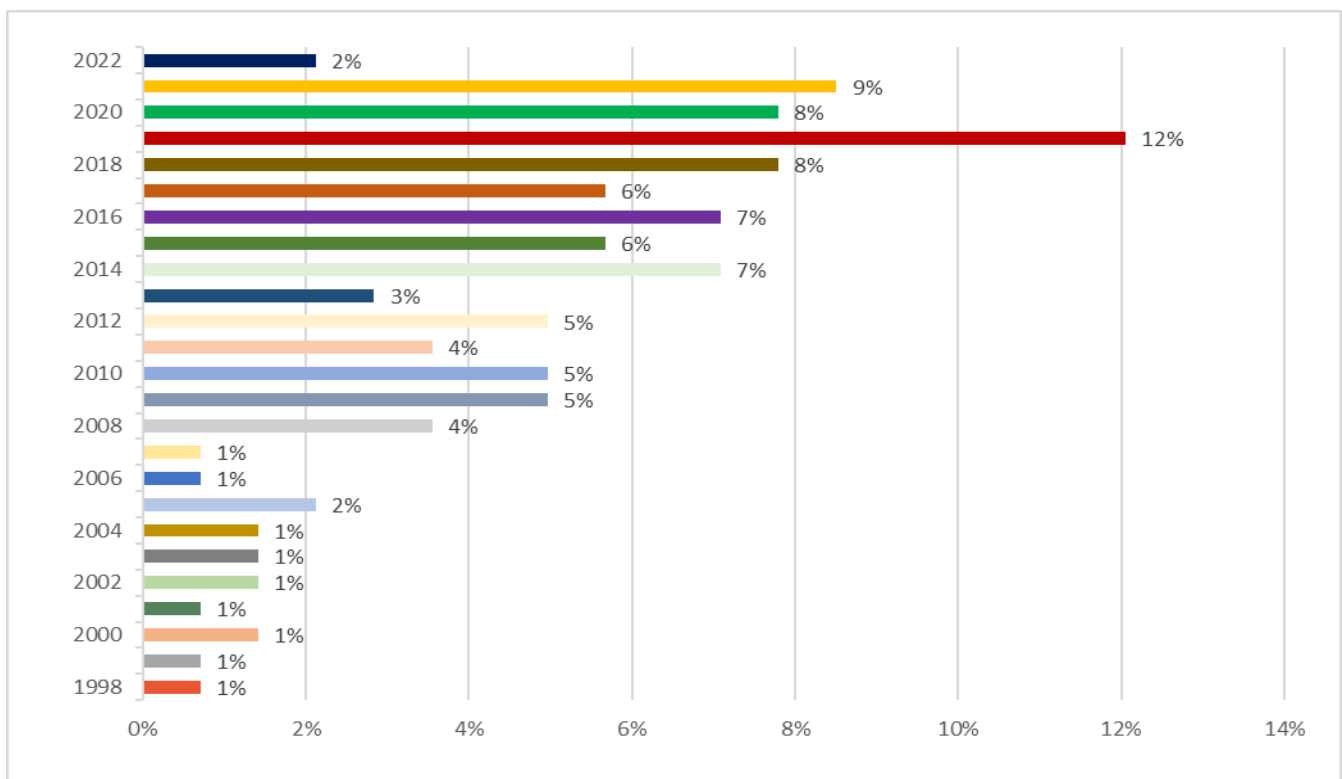
As can be seen from the response data, the vast majority of patients responded from HIC. 63% of respondents were from the UK and a further 8% from the USA (total of 75% from these two areas alone). Although not broken down as HIC and LMIC, the respondents to the carers survey are again mostly from the UK and the USA (60% and 11%). Although it is invaluable to be able to compare geographically, and the information from this survey does suggest that there are geographic differences, the skew of the location of the respondents needs to be borne in mind.

The CLL Patient Advocacy and Support survey respondents were split with around 2/3 of organisations that respondents being from HIC and the further 1/3 from countries classed as LMIC.

When reporting the findings here, responses are reported both in terms of the worldwide response rate and responses broken down to HIC and LMIC as detailed above. The charts within this report include the responses broken down geographically rather than the worldwide data and due to the number differential between the respondents from HIC and LMIC, the worldwide total is not an aggregation of the percentages for the two.

3.3. Date of Diagnosis

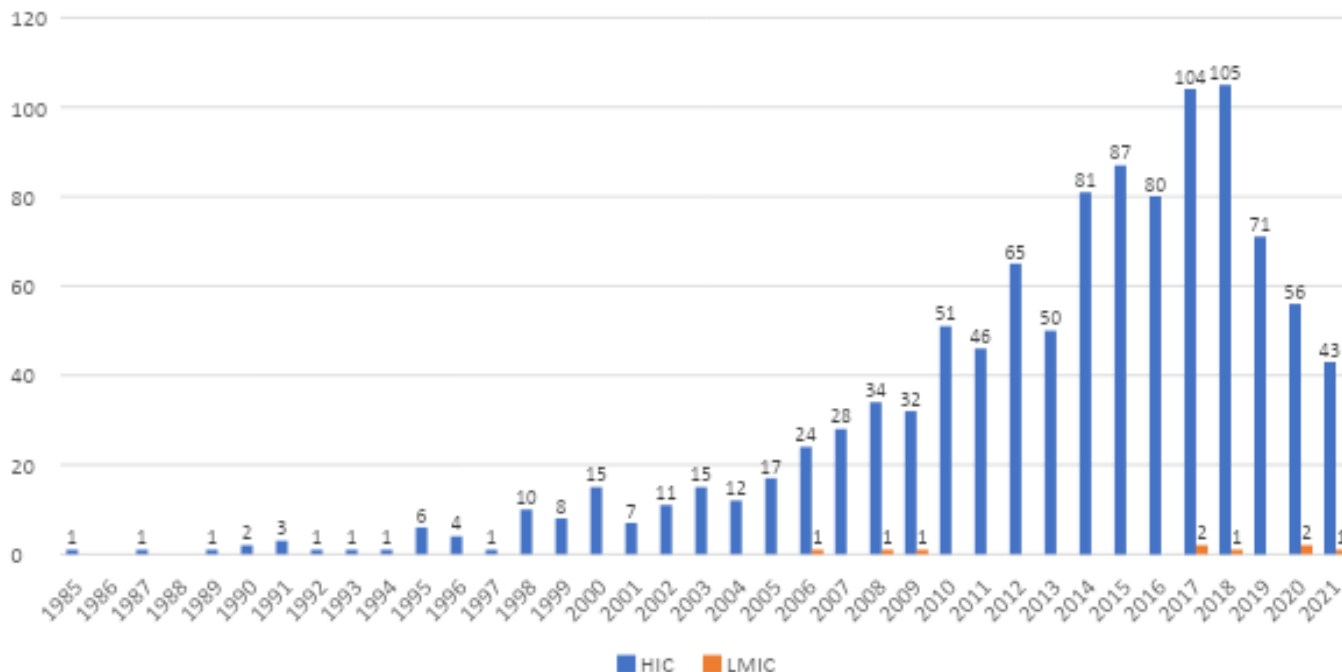
Figure 5 Q77. What year was the patient diagnosed? (Carer Experience Survey)



As part of the carer's questionnaire, respondents were asked about the year that patients were diagnosed. 73% of patients had been diagnosed in the last 10 years, with 39% being diagnosed within the last five years. There are, however, patients that had been diagnosed as far back as 1998.

From the patient survey, of those that reported their date of diagnosis, the earliest diagnosis was in 2006 (and this was for a respondent from LMIC) although most respondents were diagnosed from 2017 onwards (this was only 9 responses but 82% of respondents). Of those that reported their date of diagnosis from HIC (total of 1074 respondents, 96%), 58% were diagnosed in 2014 or more recently with 27% diagnosed 20 years ago or longer.

Figure 6 What year were you diagnosed? (Patient Experience Survey, numbers of those diagnosed)



(Total of 1083 respondents)

This is broadly in keeping with previous surveys and the wider literature that suggests patients with CLL live with this condition for many years. The higher percentage of more recent diagnoses seen here will likely be from a combination of the later age at which this disease tends to develop, the survival rate and engagement with the networks through which recruitment was conducted for this survey.

3.4. Age of respondents

Figure 7 Q76. What is the age of the patient? (Patient Experience Survey)

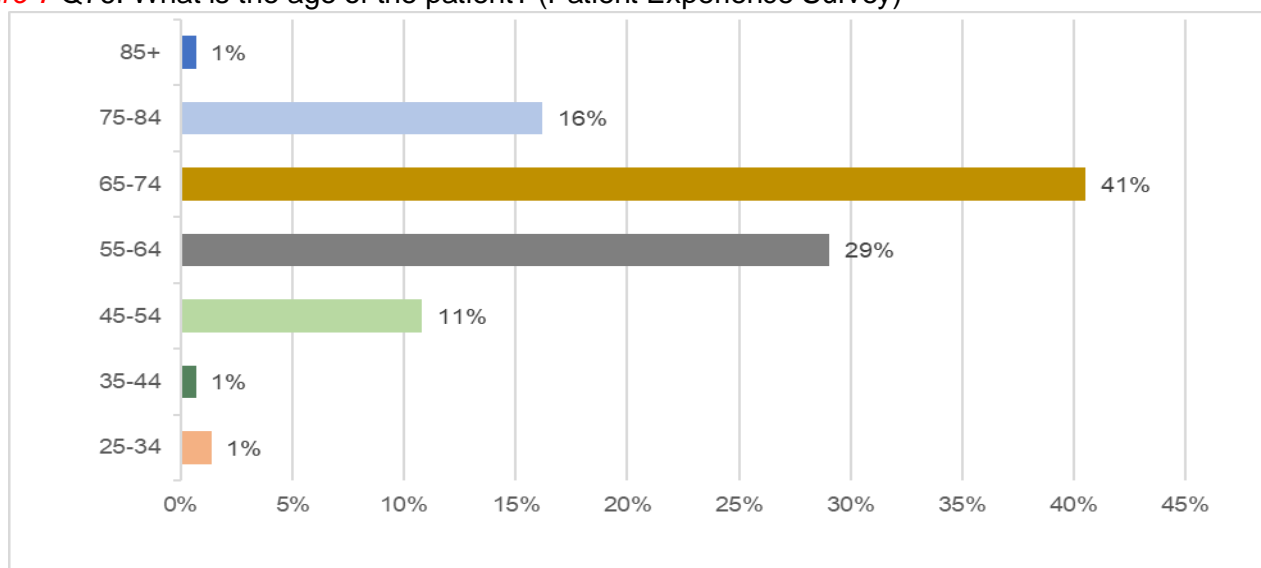
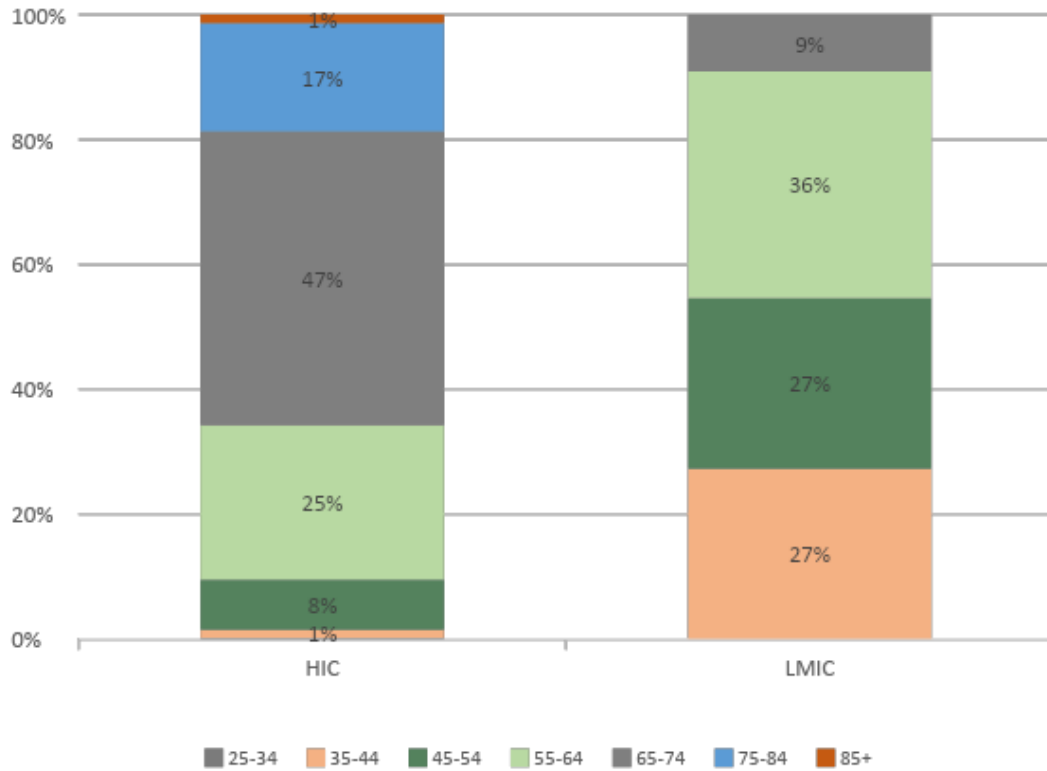


Figure 8 Q193. Age band (Carer Experience Survey)



The age of patients, derived here from both the patient and carer surveys, demonstrates the similarity with previous studies showing that CLL tends to be seen predominantly in older people.

Only a small number of patients from both the patient and carer surveys were aged 35-44 years (total of 19 participants out of 1202). The patient survey identified 3 patients (2%) under the age of 35 and the carer survey identified 2 patients (1%) as under 35 years of age.

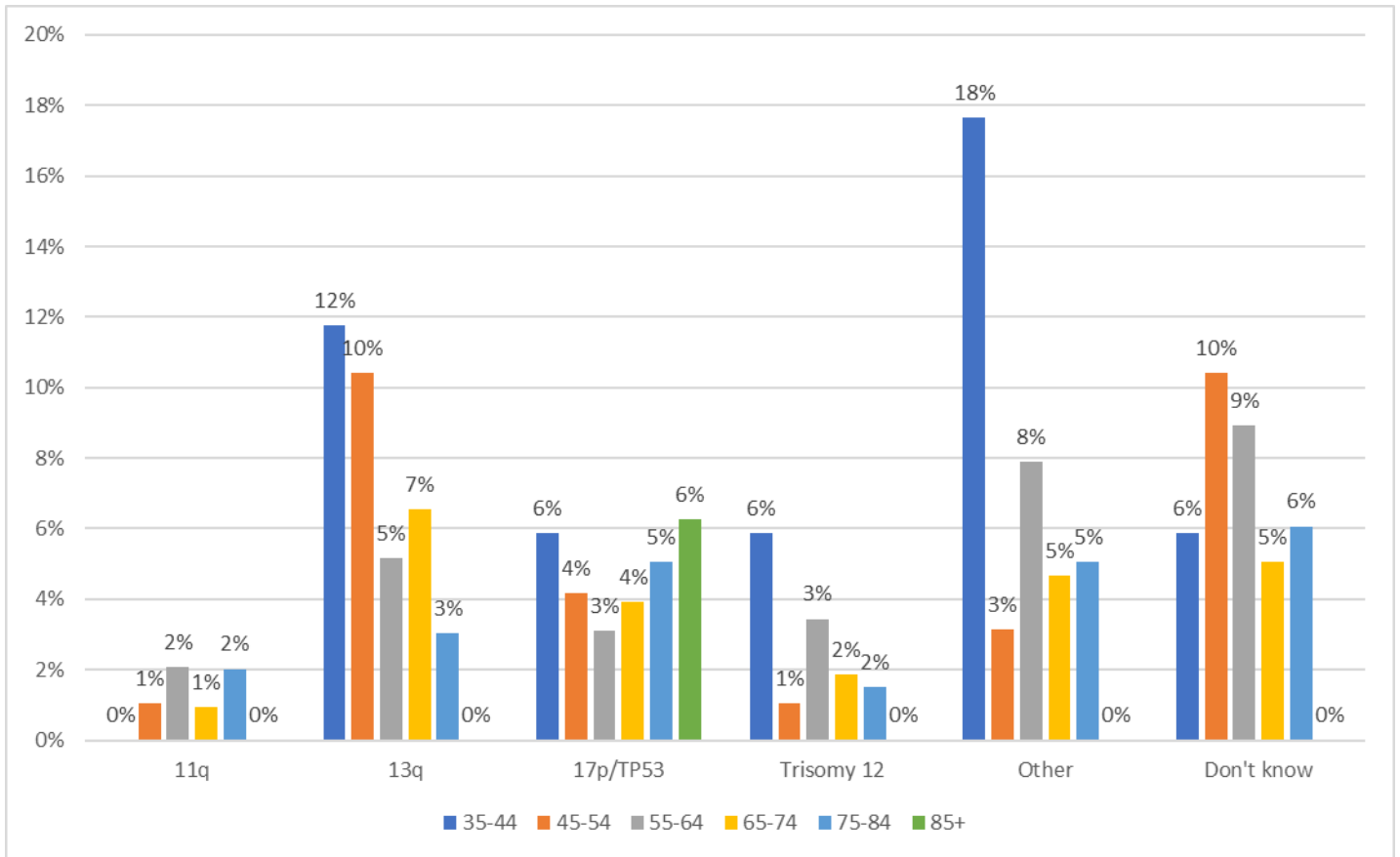
There was also a higher proportion of younger people seen in the respondents to the patient survey from the LMIC (90% of respondents were aged 35-64 years) whereas 65% of respondents from HIC were aged over 65 years.

There were no responses from anyone over the age of 74 from LMIC. Although this may be a comment on the age of those that have engaged with the survey, when we bear in mind the younger age of diagnosis and the higher proportion of symptoms in LMIC that may be seen as this comparison report progresses, there is the possibility that the lives of CLL patients in LMIC is shorter.

The subtype of CLL was also compared with age. Only 19% of the total number of respondents reported that they were aware of their subtype and of those that did report this, most were either 13q or 17p/TP53 subtypes (see figure 9 below).

Taken all together this suggests that younger people may be being diagnosed with the disease in LMIC and may well have different needs, prognosis and a different experience of CLL. This will feature again at further points within this report.

Figure 9 Age and subtype of CLL comparison



3.5. Gender

Figure 10 What is your gender (Carer Experience Survey)

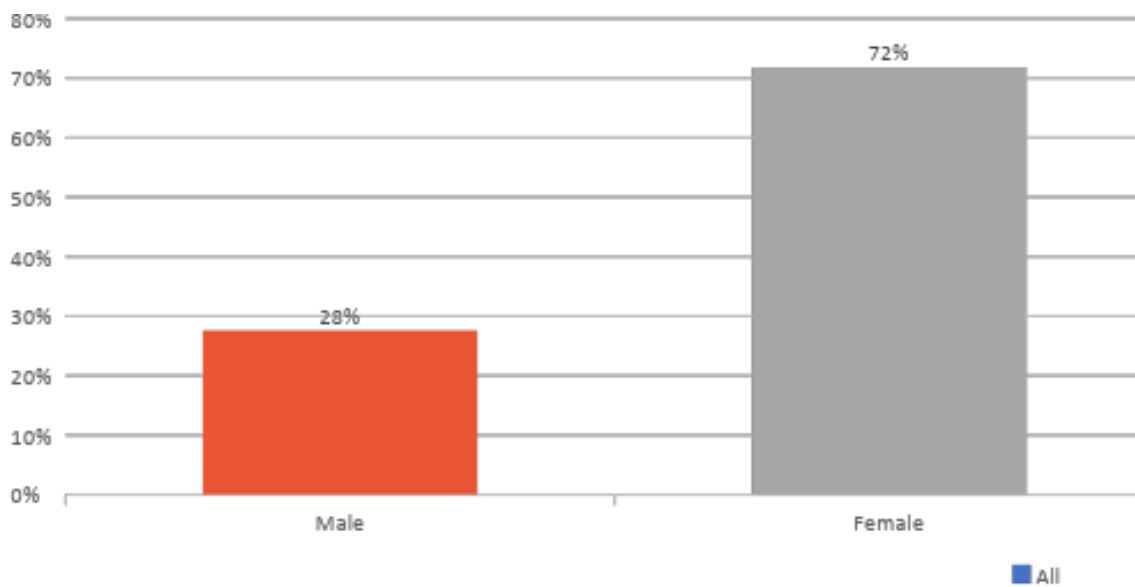
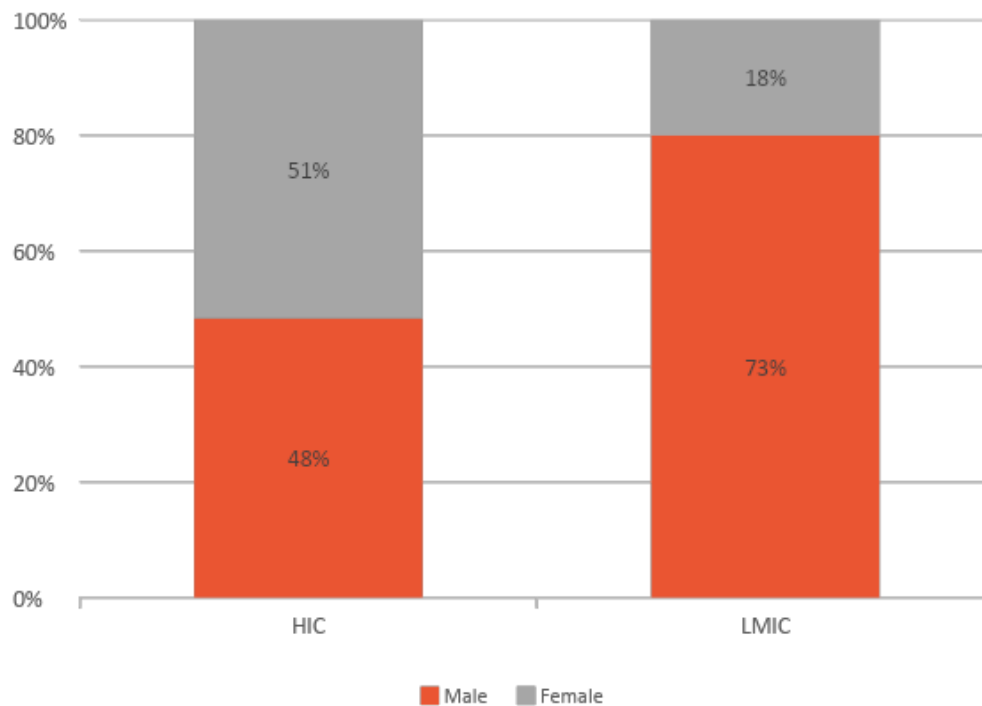


Figure 11 Q194. What is your gender? (Patient Experience Survey)



(The remaining 9% for LMIC preferred not to reveal their gender)

Across the HIC there was an even split for the gender of patients whereas 73% of the respondents in the LMIC were male (see figure 11). The gender of the carers that completed the survey was, in the main, female (72%). Previous literature would suggest that more men than women are diagnosed with CLL and most carers (85%) are the partner of the patient.

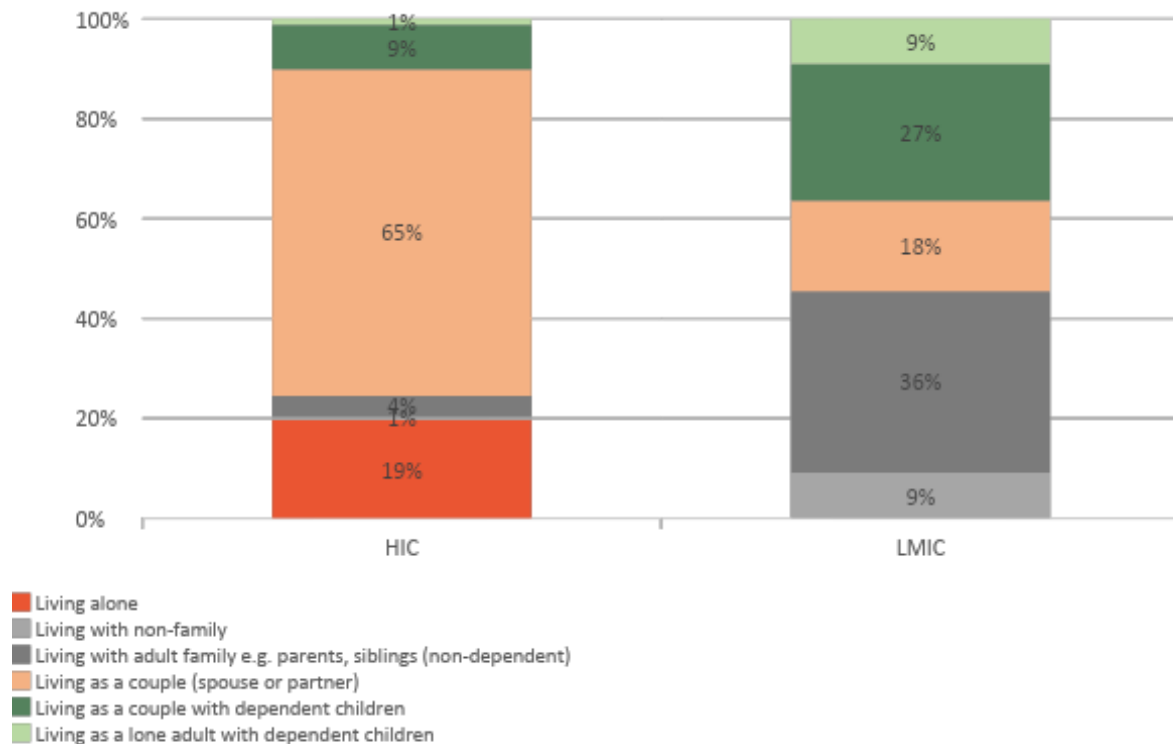
The response here from HIC for the gender of the patient may therefore be slightly out of kilter with previous research. However, this could potentially be explained by the fact that the participants were mostly recruited through support networks, with women often more likely to access support than men.

The results of the 2018 Leukemia Patient Experience Survey (an earlier survey than the one included in this comparison) showed a higher percentage of men responded than women but this was less pronounced when recruited through the support networks which would tend to confirm the suggested explanation above. It may therefore be beneficial to provide targeted encouragement for men to access support for CLL.

3.6. Life circumstances of patients and carers

Living Situation

Figure 12 Q196. What best describes your living situation? (Patient Experience Survey)



Although the responses here mirror previous literature, there are marked differences between the respondents from HIC and LMIC.

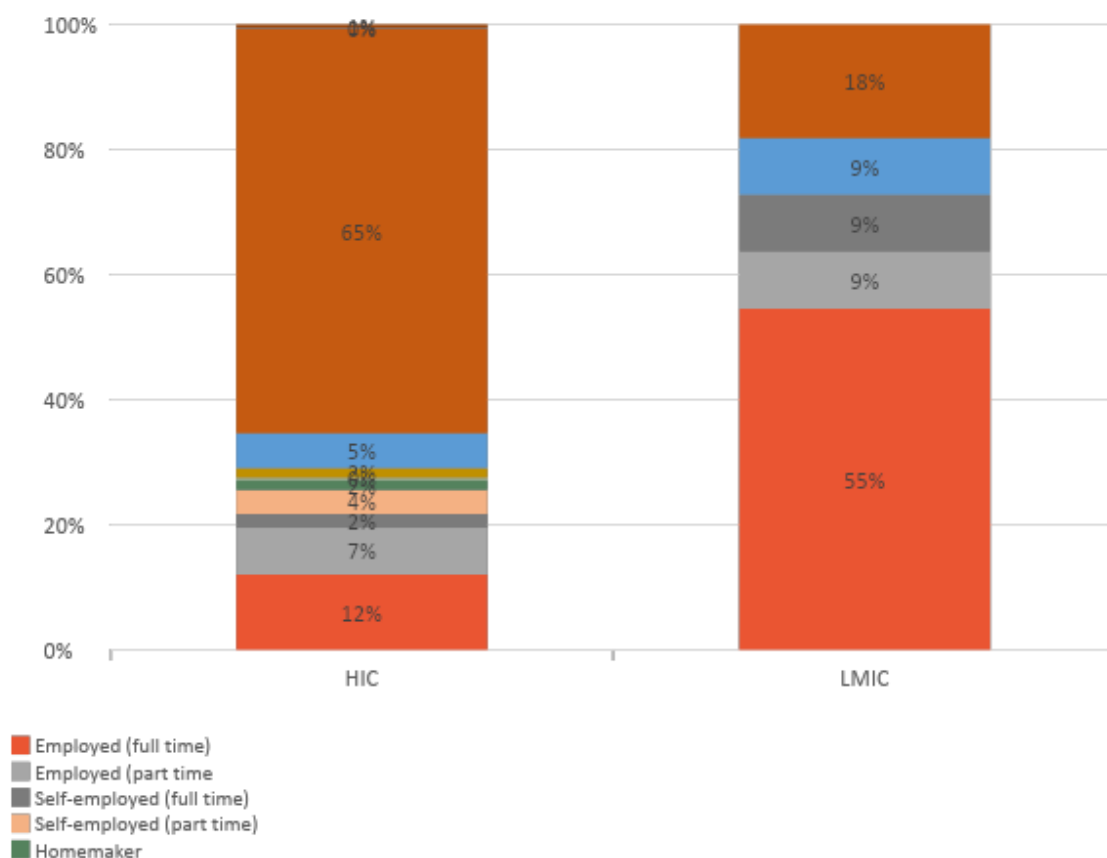
For both, the largest number of respondents were those living as a couple or as a couple with dependent children (74% HIC, 45% LMIC). However, 36% of those from LMIC reported that they were living with adult family and a further 27% with dependent children. This is likely reflective of the younger age of patients seen within this group compared with those from HIC. We also need to consider the cultural differences here where in some countries across the globe it is common for a number of generations to reside together. 19% of those from HIC reported living alone, whilst no one reported this from LMIC. This may be as a result of the cultural differences remarked on above, but it does mean that these patients are more likely to be isolated and have different, additional support needs, particularly as their CLL progresses.

From the carer survey, 96% of those that responded reported living with the person that they cared for, 85% of whom were their spouse/partner. Of the remainder, only 1% was a parent and 7% were the son/daughter of the person with CLL.

Overwhelmingly this survey has shown that carers for people with CLL are family members, most frequently their spouse or partner. Caring responsibilities often fall to family members who, as the disease progresses, may need additional help and support with the care that they are providing but also for their own needs. This is common and can be seen in many chronic conditions. Having additional caring responsibilities such as dependent children alongside caring for someone with CLL could take an added toll for those carers and the patients themselves.

Employment

Figure 13 Q197. What best describes your employment status? (Patient Experience Survey)



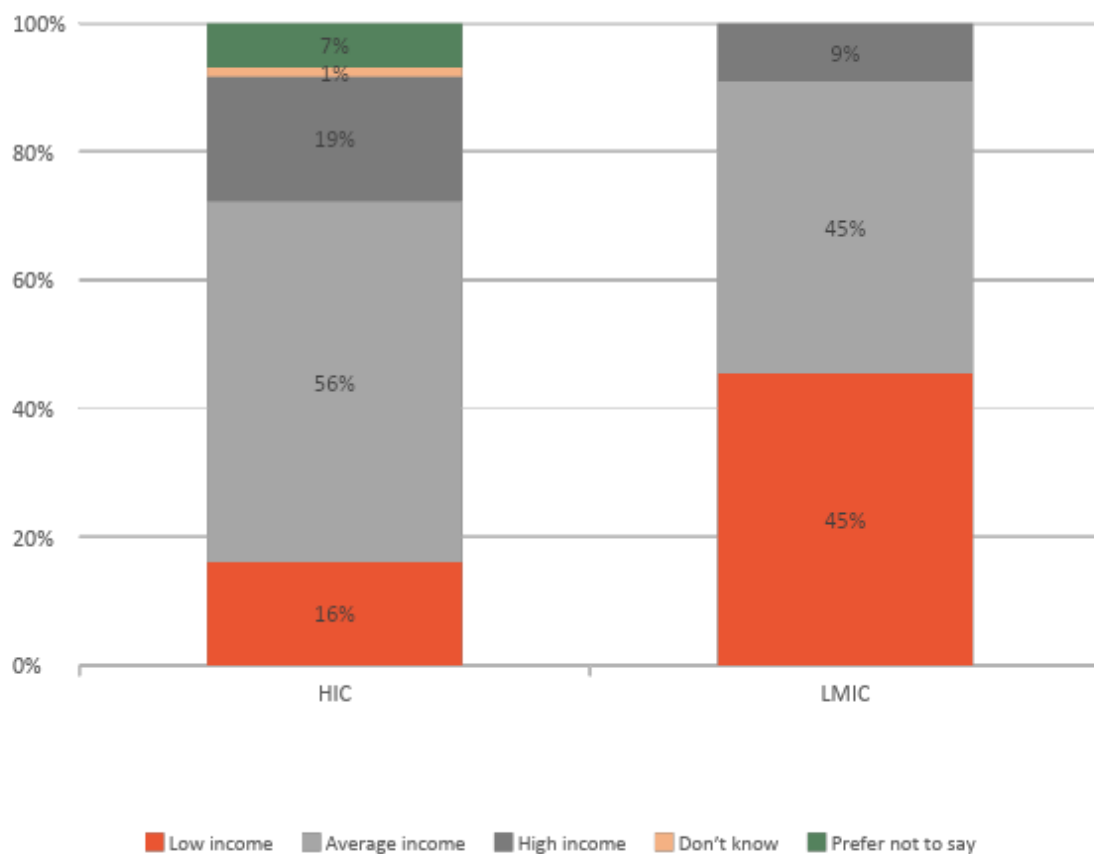
Again, there is a marked difference between the current employment status of patients: in HIC 65% are retired with only 5% unable to work, whereas almost 2/3 of respondents from LMIC are in work either full (55%) or part (9%) time.

Of those surveyed from LMIC, 9% reported being unable to work. Considering the age and living situation of the respondents, it is likely that this is linked and again will impact on their prognosis and potentially on the life course of their CLL.

For carers, 44% reported that they were retired although a further 43% were either in full time (25%) or part time (8%) work or were self-employed (10%). This suggests that carers are managing their care responsibilities around a number of other requirements such as work and other family life. It is assumed that access to help and support for their role and managing a number of priorities would be beneficial.

Income

Figure 14 Q198. For your country how would you describe your annual household income? (Patient Experience Survey)



As expected, when considering the responses from the questions considered so far, there is a marked difference here between the income of those from HIC and LMIC.

Those from LMIC we may expect to have a lower income as a result of the general economic conditions however this may be exacerbated by the age of diagnosis, symptoms and living conditions that have already been discussed.

45% of those from LMIC reported being of low income, with the majority of the remainder reporting being of average income. In contrast only 16% of those from HIC categorised themselves as being of low income with 56% being of average income and a further 19% identifying themselves as of high income. From the carers survey, the majority of respondents are of average income (51%) with a further 18% of low income.

Both CLL patients and their carers living in LMIC would seem to be at a disadvantage in relation to their life circumstances and may require additional help and support.

3.7. Summary

From the findings from this section, it is clear that the responses from these surveys are broadly in line with previous surveys and the wider literature.

There are however some marked differences between the responses of those from HIC and those who reside in LMIC. In particular, those from LMIC tend to be younger and in a more precarious living and economic situation than those from HIC. While the LMIC population were markedly younger than the HIC respondents, based on these findings, the needs of people with CLL and their carers from LMIC may differ to those from HIC and this needs to be borne in mind when providing healthcare and services to these populations.

4. Before Diagnosis

The route to diagnosis for CLL patients and their carers may be complex. Respondents from the patient and carer surveys were asked questions around their symptoms and healthcare contacts prior to diagnosis. Advocacy and support organisations were asked about what information/education they provide for healthcare professionals and the wider population and about late diagnosis.

4.1. Awareness and diagnosis of CLL and CLL education

Symptoms and Diagnosis

34% of respondents from HIC didn't have any symptoms prior to diagnosis. However, this was not the case for those from LMIC where **all** respondents had some symptoms prior to being diagnosed with CLL. The below chart demonstrates the difference in symptoms between those experienced by patients in HIC and those in LMIC (figure 15). The most common symptom experienced prior to diagnosis was fatigue (38% in HIC, 64% in LMIC) followed by swollen lymph nodes (25% in HIC, 55% in LMIC).

54% of patients from HIC and 73% of patients from LMIC didn't speak to their GP/family doctor about their symptoms. Of those that did speak to their family doctor, 36% of patients in HIC and 33% of those in LMIC were diagnosed after one visit, with another 33% in LMIC diagnosed within three visits and the other 33% within five or more visits (see figure 17). It took longer to diagnose in LMIC with only 9% being diagnosed within 2 weeks of first seeing their healthcare professional compared with 24% in HIC.

When looking at age, there seems to be no significant correlation between age and symptom profile.

Raising awareness of symptoms and the disease, particularly in LMIC may help encourage people with symptoms to access their healthcare services at an earlier point and may also help them to access support services. This may also increase the number of routine healthcare checks that are conducted amongst a targeted age group and therefore also help to reduce the time taken to diagnose patients, increase those diagnosed with no symptoms and encourage those without symptoms to access services.

Figure 15 Q14. What symptoms did you encounter before your diagnosis? (Patient Experience Survey)

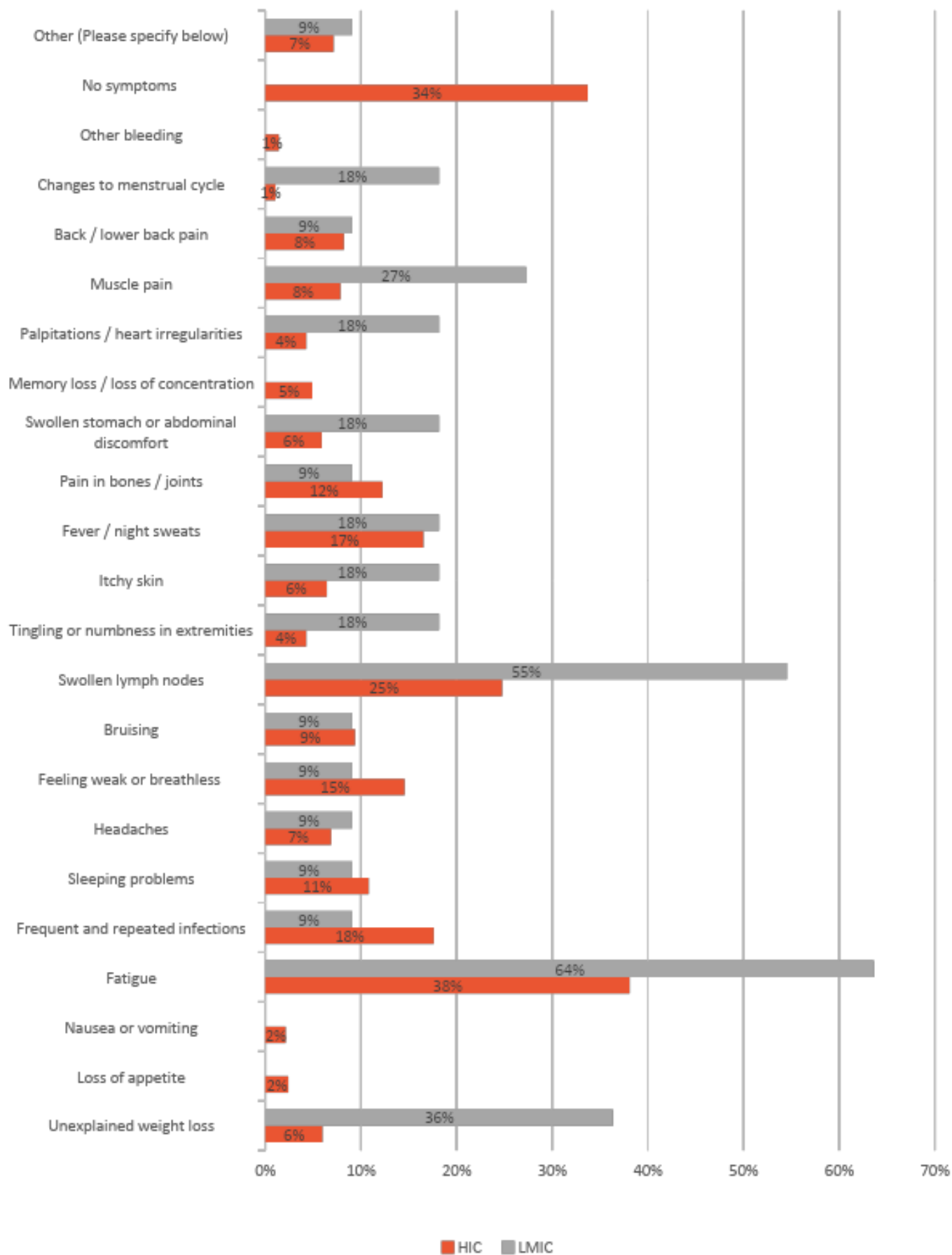


Figure 16 Q18. Did you speak to your GP / family doctor about the symptoms caused by leukemia before you were diagnosed? (Patient Experience Survey)

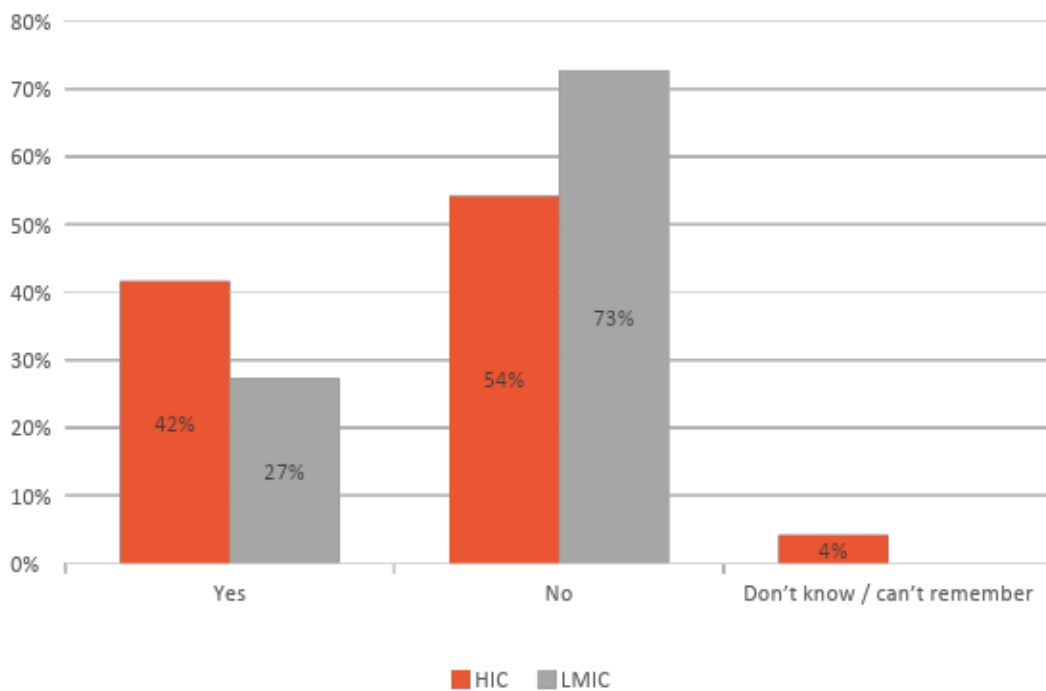
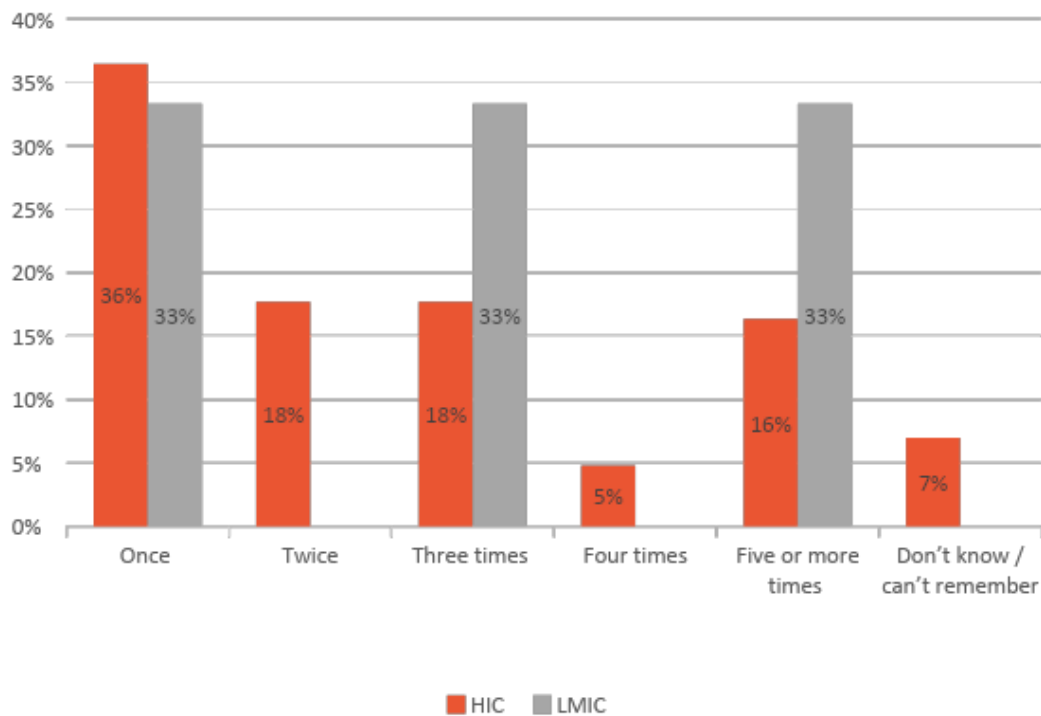


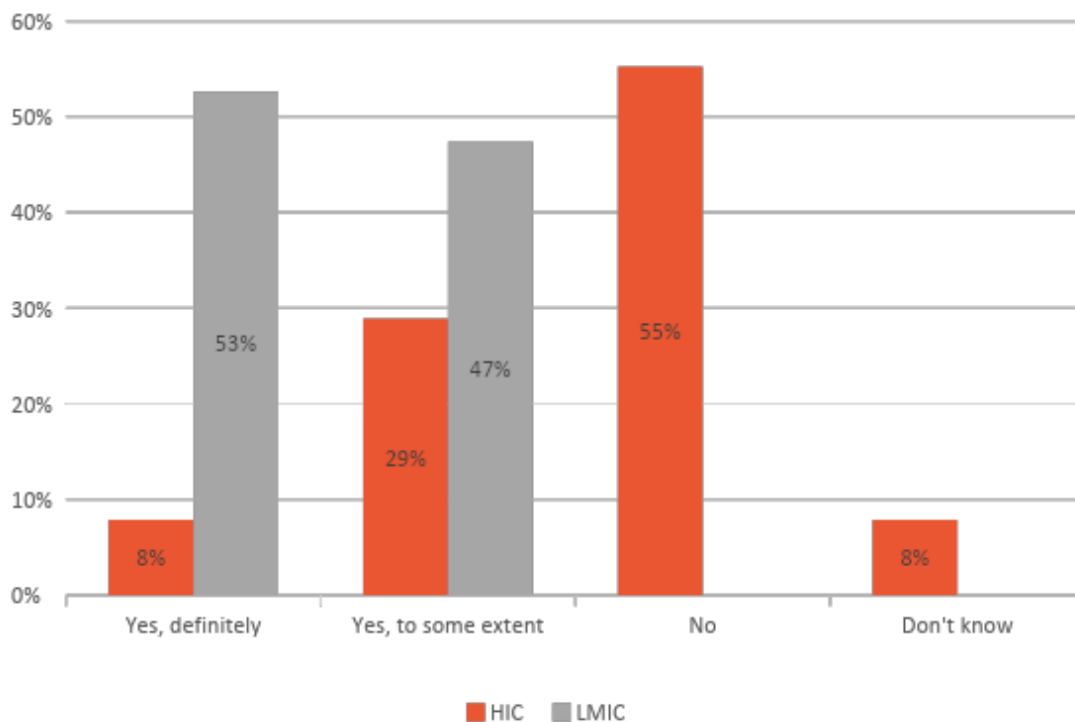
Figure 17 Q19. How many times did you see your GP / family doctor about your leukemia symptoms before you were diagnosed? (Patient Experience Survey)



As CLL is a disease that develops slowly, with people across the globe often diagnosed without symptoms and through routine tests, the findings here would seem to suggest that diagnosis is later in LMIC where patients have many more symptoms and less access to primary healthcare than those in HIC.

This is echoed by support organisations where the majority of organisations worldwide that responded to the survey felt that late diagnosis was definitely or at least to some extent an issue in their country. This was 100% for LMIC compared to 37% for HIC (see figure 18 below).

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



Awareness of CLL & CLL education

46% of the total number of organisations worldwide that responded to the support and advocacy survey felt that primary healthcare providers aren't well informed about CLL. This percentage was higher in LMIC (68%) and lower in HIC (34%).

There is a wide range of information aimed specifically at healthcare providers provided by network organisations (see figure 19 and figure 20). Website pages and printed materials are the most common ways that information is provided, however this is still relatively low particularly in LMIC where only 16% of organisations produce these, compared to 29% (website pages) and 24% (printed materials) in HIC.

Organisations seem less likely to be involved in education events targeted specifically at healthcare providers (32% in HIC and 26% in LMIC) than in more general educational activities (79% in HIC and 47% in LMIC offering general educational events and 68% in HIC and 47% in LMIC offering webinars), see figure 21. 32% of organisations in LMIC compared to only 16% in HIC do currently not offer but would like to offer specific HCP education activities (see figure 22). This may be reflective of the perceived greater lack of knowledge of healthcare professionals in these countries. Similarly, of the organisations currently not offering these services, 11% of organisations in HIC and 32% in LMIC would like to offer general educational events and 11% of organisations in HIC and 16% in LMIC would like to offer webinars (see figure 22). The most common reasons for not being able to provide these activities worldwide were lack of human resources (74%) and funding (66%).

Figure 19 Q04d. What written information has your organisation developed for.... **Healthcare professionals** (CLL Patient Advocacy and Support survey)

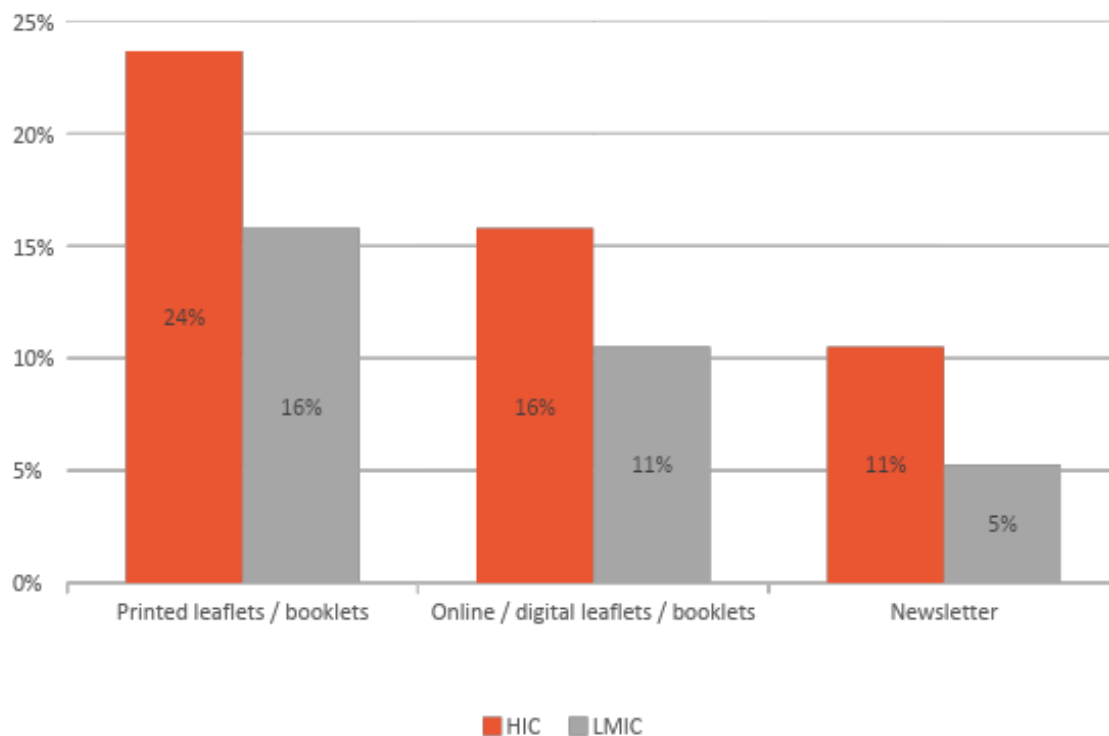
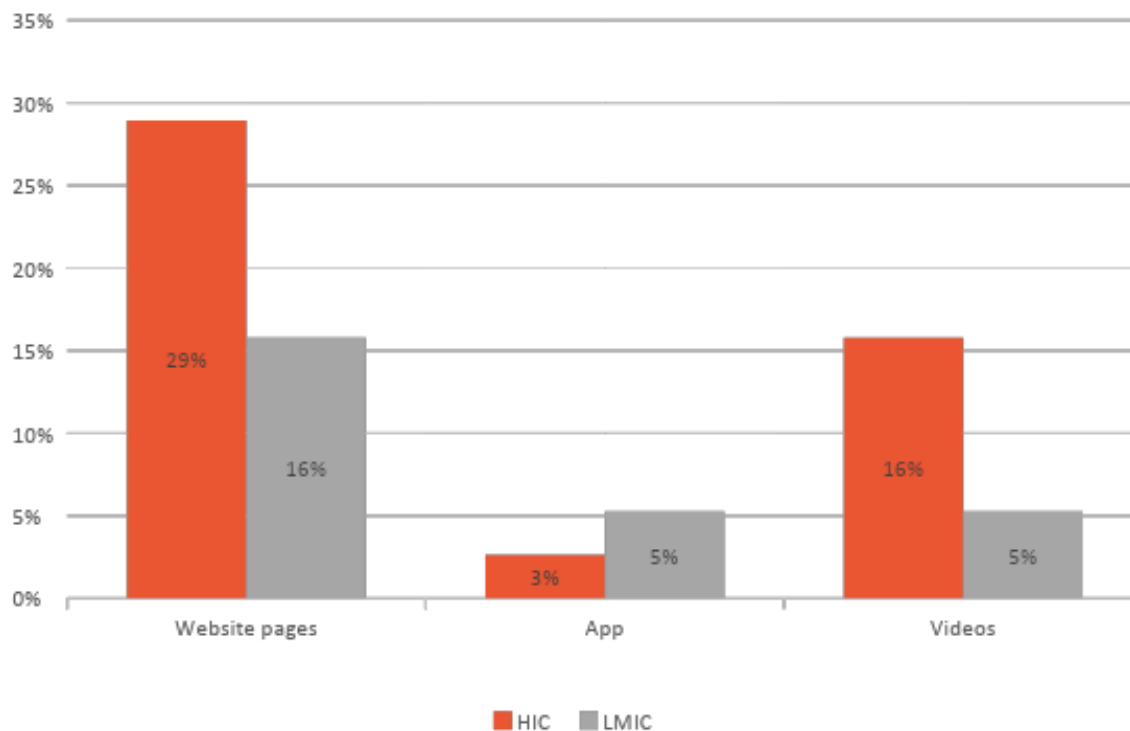


Figure 20 Q05d. What other information has your organisation developed for.... **Healthcare professionals** (CLL Patient Advocacy and Support survey)



When it comes to raising awareness and education around CLL, 68% of organisations from HIC and 79% of organisations from LMIC stated that they carry out awareness campaigns around CLL (see figure 21), with a further 11% of organisations from HIC and 26% of organisations from LMIC stating that they would like to do this in addition to the current services they provide (see figure 22). This demonstrates how important organisations feel that these services are that they provide in the area of CLL.

Increased engagement and a collaborative approach between healthcare professionals and support organisations could help improve information and support currently provided for and accessed by patients and carers. This would bridge some of the gaps and needs identified through the surveys here.

Figure 21 Q03. What CLL support, advocacy and education services does your organisation currently offer? (CLL Patient Advocacy and Support survey)

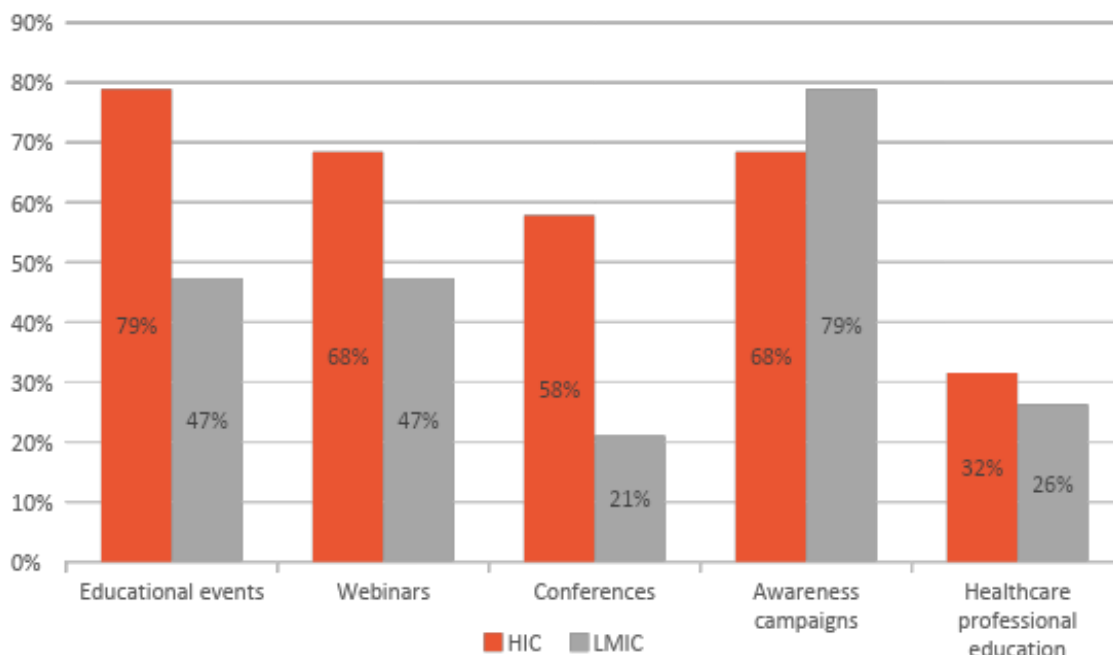
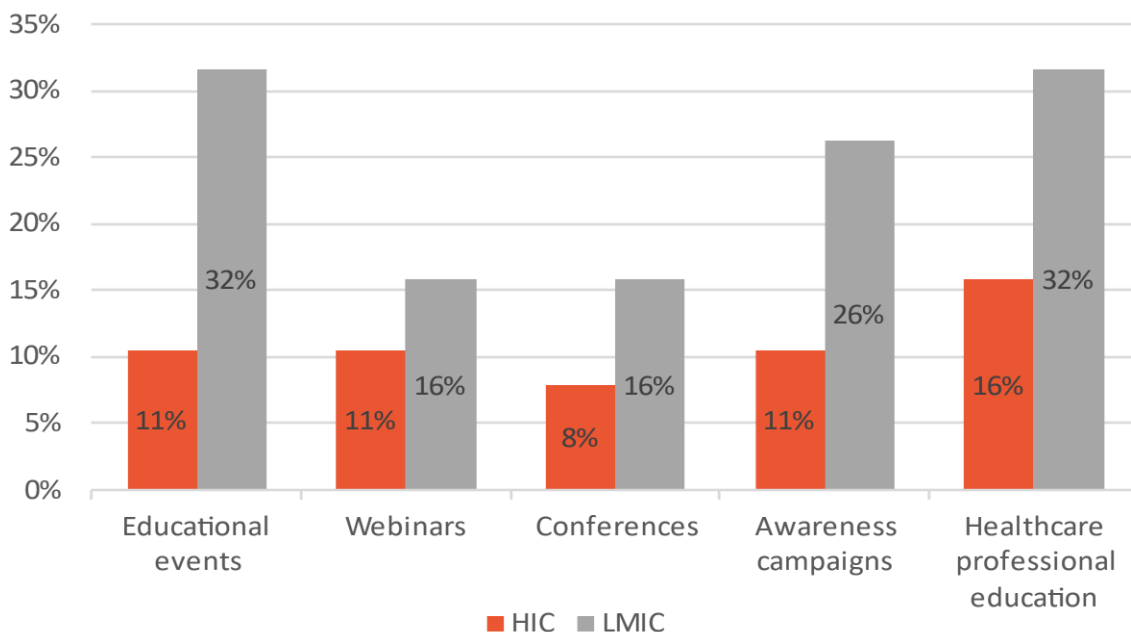


Figure 22 Q10. What CLL support, advocacy, and education services do you NOT currently offer but would like to? (CLL Patient Advocacy and Support survey)



In addition, from the patient and carers surveys, the vast majority of patients and their families were unaware that the symptoms that they had could have been a form of leukemia (93% of patients and 86% of carers). This does suggest that generally there is a lack of awareness of CLL and leukemia more widely from the general public and from those working in primary healthcare.

4.2. Summary

This section has demonstrated that there is a differing picture across the globe around the awareness of CLL and when it is diagnosed.

Patients from LMIC are more likely to display symptoms prior to diagnosis and there is a general lack of awareness around leukemia and how the disease presents. It is not clear whether this is a more generalised issue across these countries but is certainly suggestive for CLL through the findings here. We should also be mindful of the high proportion of patients across the globe diagnosed with CLL but without displaying any symptoms and the apparent lower incidence of this that may be suggested here across LMIC.

Advocacy and support organisations have identified this lack of awareness of leukemia as an issue and awareness campaigns are seen as important for organisations to conduct regardless of where they are situated across the globe.

This lack of awareness is also apparent in primary healthcare, although again this seems to be more apparent in LMIC than HIC. The responses to this survey identify that advocacy and support organisations have less involvement in healthcare education but would like to and are concerned about late diagnosis for their patients.

All of these findings here suggest that there is an issue around late diagnosis that might be exacerbated in LMIC. To improve the situation with regard to diagnosis for patients, particularly in LMIC, further education and awareness events and resources for healthcare providers in particular would seem to be beneficial. It is also vital that support organisations and advocates engage with local healthcare providers in a collaborative approach to improving patient outcomes.

5. Diagnosis

5.1. Understanding their diagnosis

79% of HIC respondents and 72% of LMIC respondents with CLL that responded to this survey understood at least some of the explanation of their diagnosis, with 35% of those from HIC and 27% of those from LMIC fully understanding it (see figure 23). 12% of patients from HIC and 9% of patients from LMIC reported they were in shock. Slightly fewer carers globally (70%) reported that they understood the diagnosis completely or at least partially, but more carers globally stated that they were in shock at the time (19%, figure 24).

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

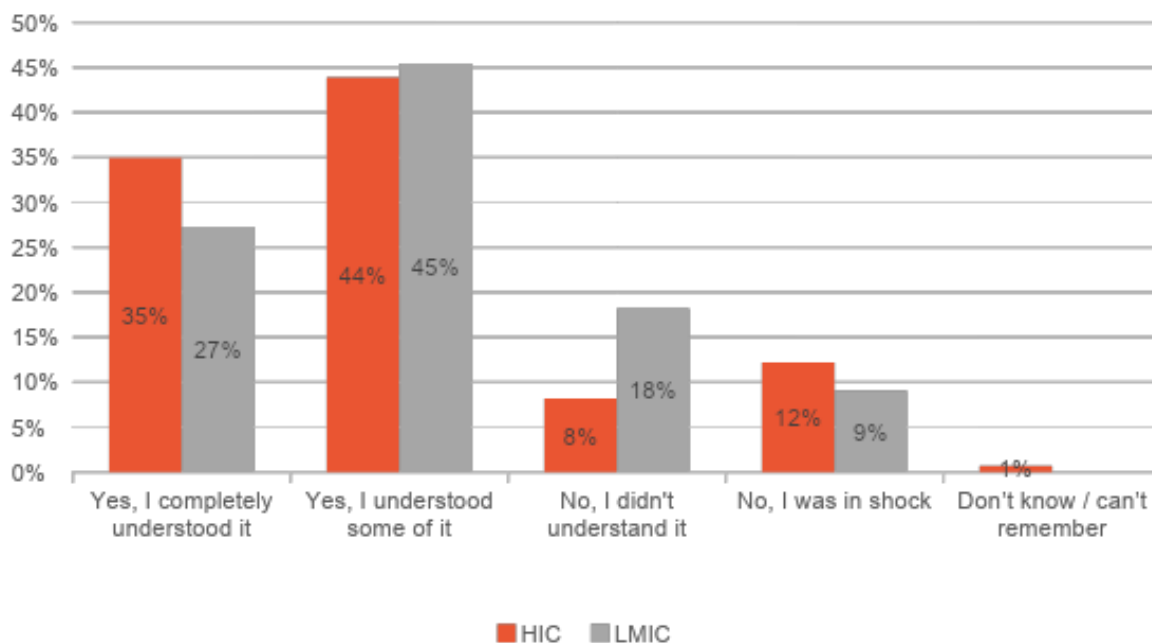
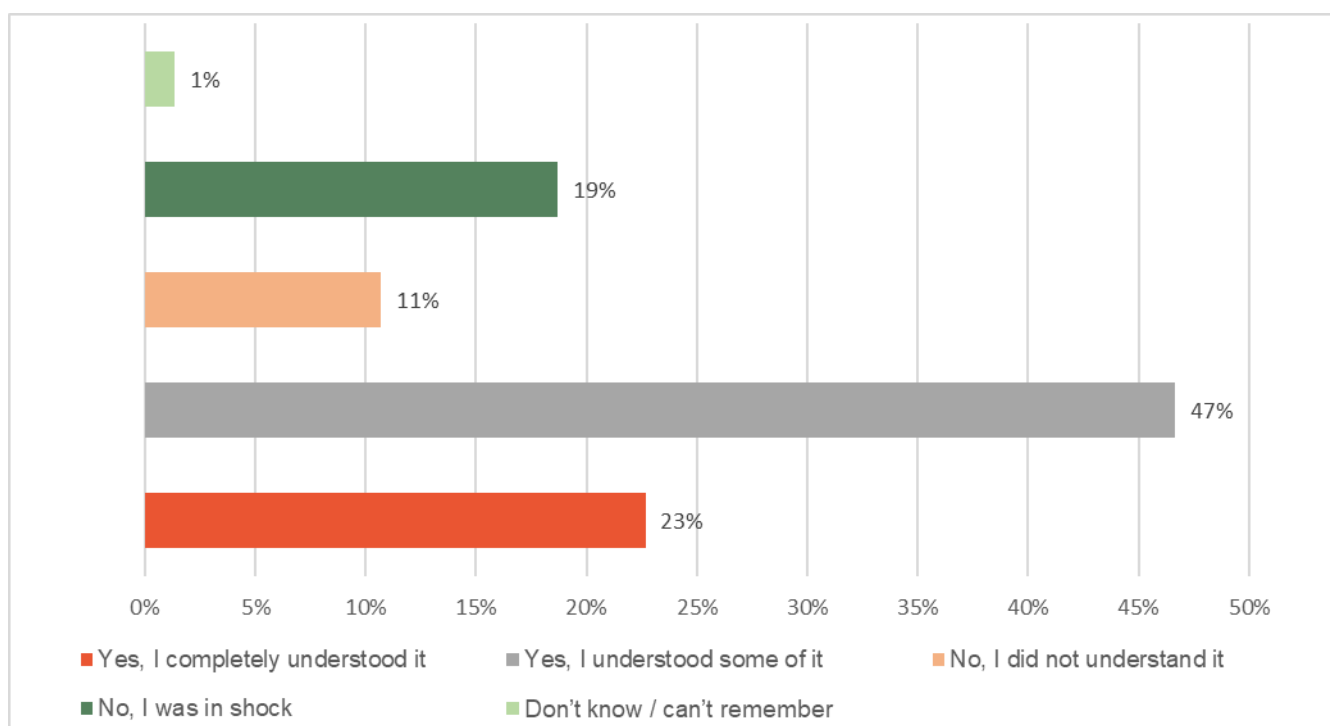


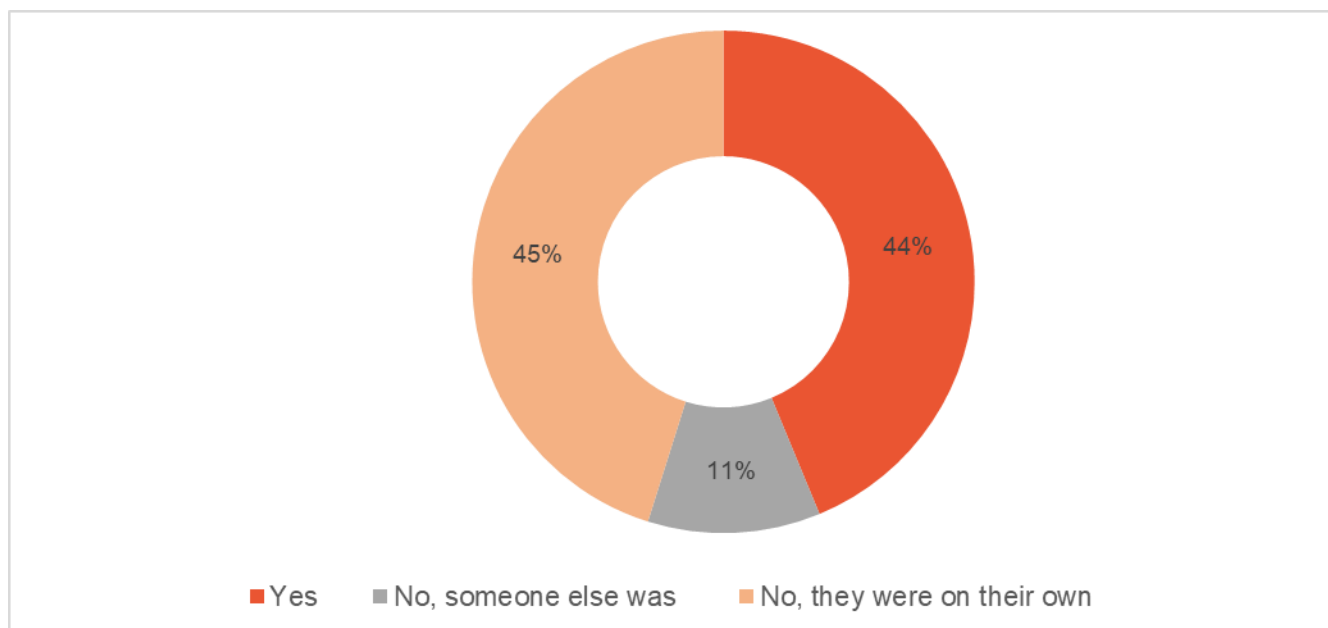
Figure 24 Q14. Did YOU understand the explanation of what was wrong with the patient? (Carer Experience survey)



55% of patients felt that the way that they were told that they had CLL had been handled sensitively, with just over 40% feeling that it should have been done at least a little more sensitively.

45% of carers stated that the person was on their own when they were told that they had CLL (figure 25). This is understandable as often diagnosis is made either from routine tests or with the absence of severe symptoms that would suggest cancer.

Figure 25 Q10. When the patient was told they had leukemia, were you with them? (Carer Experience Survey)



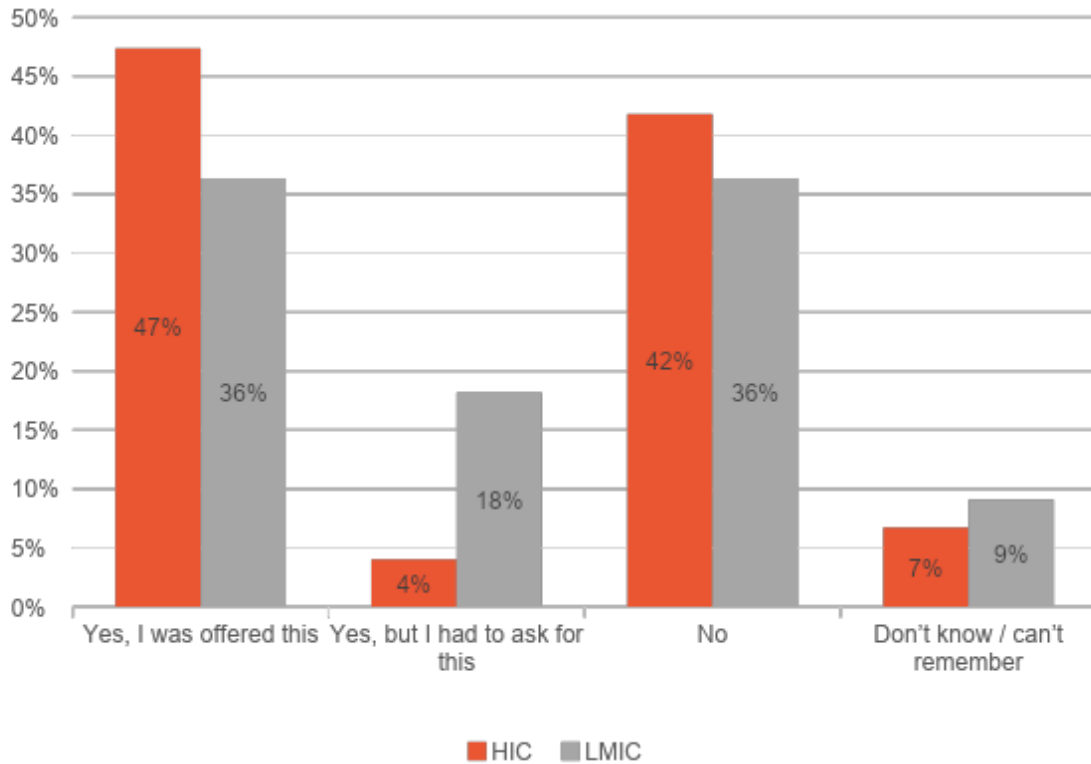
We have seen from the previous section that there is a general lack of awareness globally and within the healthcare community around CLL. The majority of patients and carers had some lack of understanding and knowledge around CLL at the time of diagnosis and many patients were alone when given their diagnosis and felt that it could have been handled better by their healthcare professional. Awareness raising and collaboration between healthcare providers and support organisations in particular could help to improve knowledge around CLL.

Time, and the assessment of the understanding of patients, from those giving the diagnosis and additional resources for the patient and their carer would help to improve their experiences at this pivotal point in their journey. Referral to appropriate support agencies and the provision of relevant information would also be extremely beneficial to patients and their families.

5.2. Written information about their diagnosis

47% of those diagnosed with CLL were offered written information regarding their diagnosis; over 70% of those who did not have written information stated that they would have liked it. This differed between those from HIC and those from LMIC (see figure 26). Interestingly here, fewer patients from HIC were offered written information (51% of patients from HIC compared to 54% of patients in LMIC), but 18% of those that were provided information in LMIC had to specifically request this vs. only 4% in HIC. Almost half of patients in LMIC (49%) and 45% of patients in HIC were not given any information or don't remember receiving any (see figure 26). In relation to their understanding, over 90% understood the written information that they had been provided.

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



With the findings here suggesting that a diagnosis of leukemia is likely to be a shock and that many people are diagnosed whilst alone, written information or resources that patients could return to when they wish to would be an important part of the process of diagnosis. Ensuring that healthcare providers diagnosing patients have written (and/or online) resources to provide to patients would be of huge benefit.

Turning our attention to the information provided through support organisations, organisations surveyed in HIC offer a vast range of written information for those diagnosed specifically with CLL. Written information in these countries is provided as printed, online/digital information and as newsletters. Other information comes in the form of website pages and videos. The majority of organisations provide information that encompasses CLL specifically for patients. Collaborative engagement between healthcare providers and support organisations could help to reduce the deficit here.

As shown in figures 26 and 27, the provision of written materials and other information aimed specifically at CLL patients is significantly lower in LMIC. This can be seen across materials and is another deficit clearly revealed by the surveys. If we compare this with wider blood cancer information, 63% of organisations provide written/printed information and 32% provide online information. This illustrates that there is support and information in LMIC but that this is not specific to CLL. Supporting organisations in these countries to develop or access resources for CLL patients specifically may enhance the support and information that these patients receive as the needs of CLL patients will be different to patients with other blood cancers.

Figure 27 Q04a. What written information has your organisation developed for.... CLL patients only (CLL Patient Advocacy and Support survey)

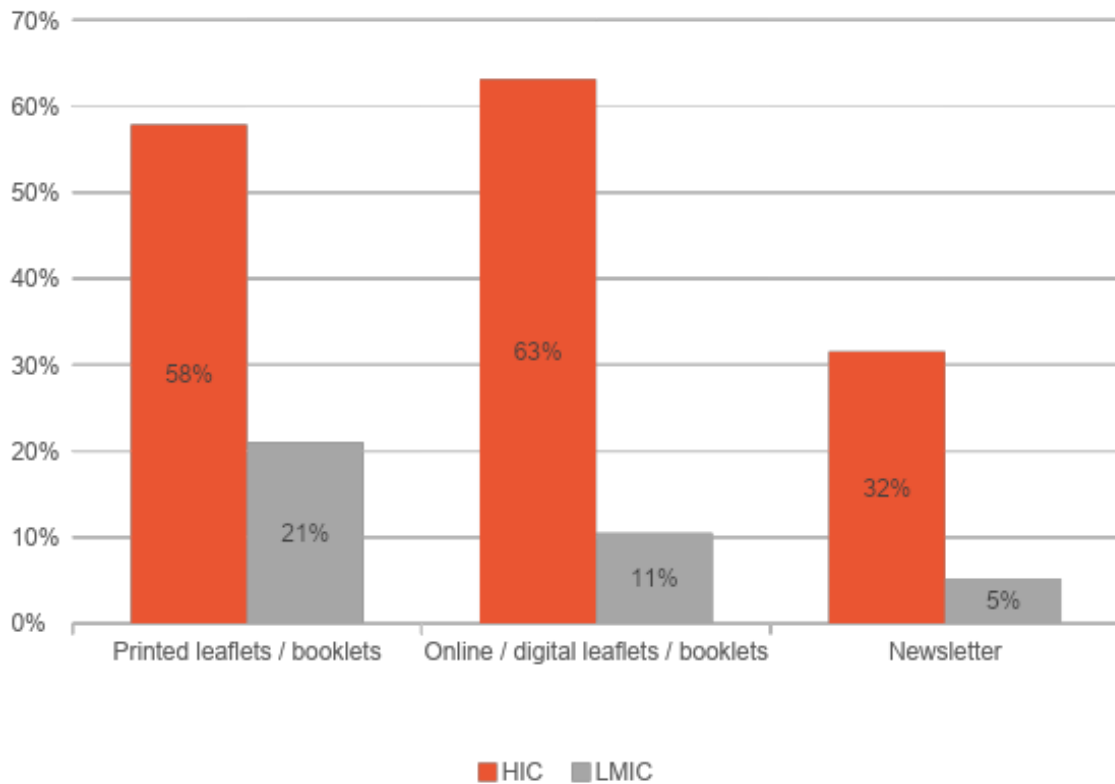
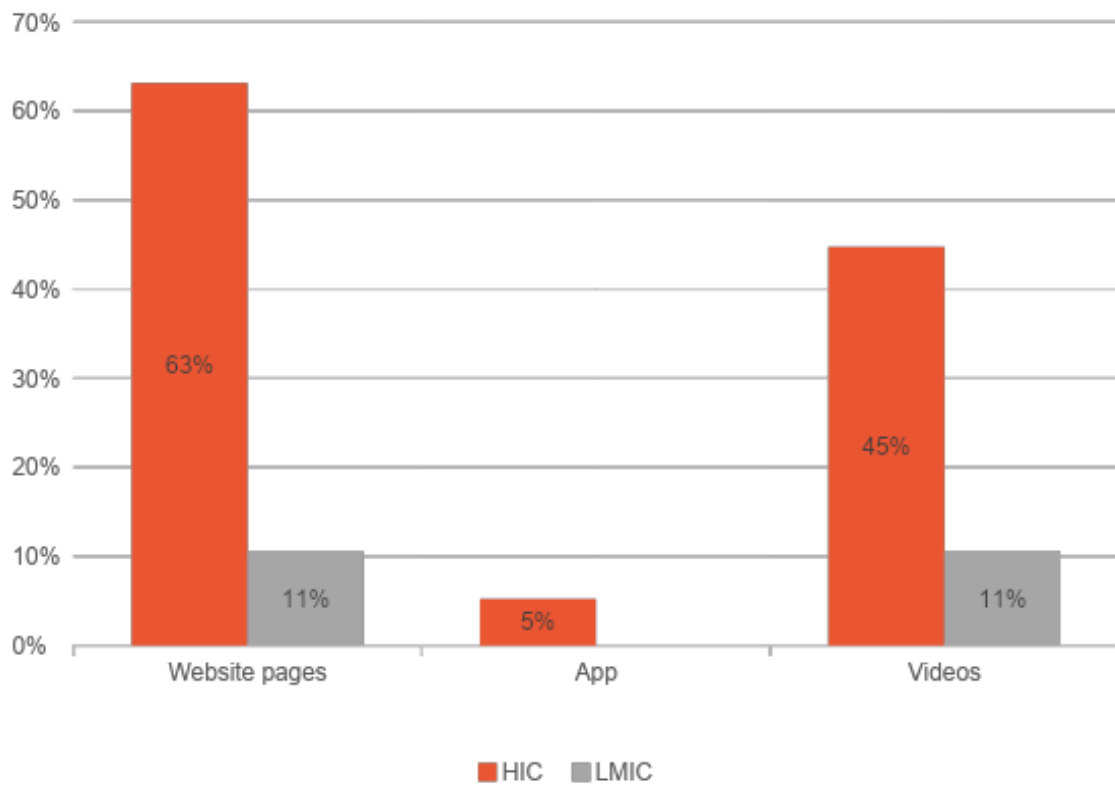


Figure 28 Q05a. What other information has your organisation developed for.... CLL patients only (CLL Patient Advocacy and Support survey)



All of the above would seem to highlight that more could be done to direct patients and carers to written (either printed or online) information and that more could be done to educate healthcare practitioners on managing the diagnosis process with patients. Appropriate counselling, information and support at this point could help to allay concerns and fears and educate patients and their carers on both the condition and the journey to come.

5.3. Support

Only 36% of those diagnosed with CLL in HIC compared to 55% of those in LMIC were directed or offered support for any concerns or worries that they had around their diagnosis (see figure 29). For those that were offered support, in the case of HIC this was mostly in the form of written information (72%) with only half of patients reporting that they had been directed to support groups. The numbers for LMIC look quite different with only 17% having received support in the form of written information. The rate of referrals to support groups or charities was, however, similar to HIC (see figure 30). Interestingly, we can see those patients in LMIC were most likely to be offered psychological support compared to only 7% in HIC (figure 30).

Figure 29 Q34. At diagnosis were you offered or directed to any support to help with concerns and worries about your leukemia? (Patient Experience Survey)

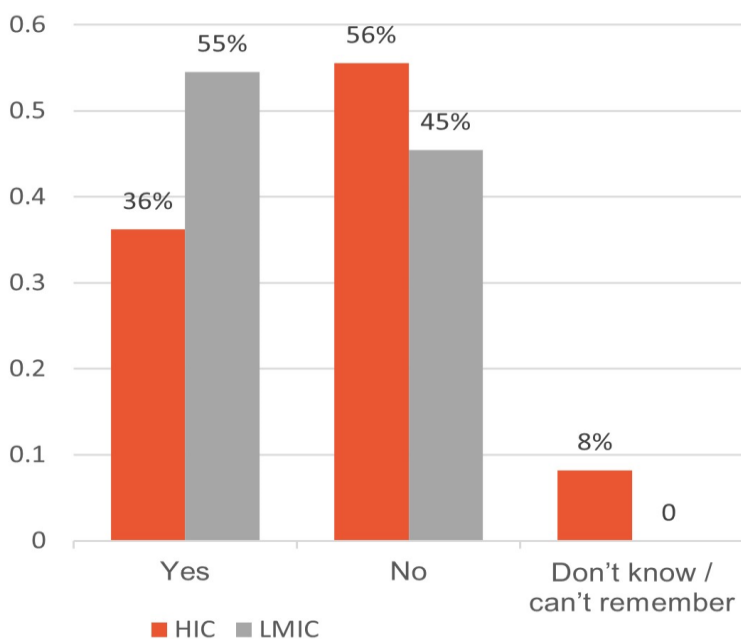
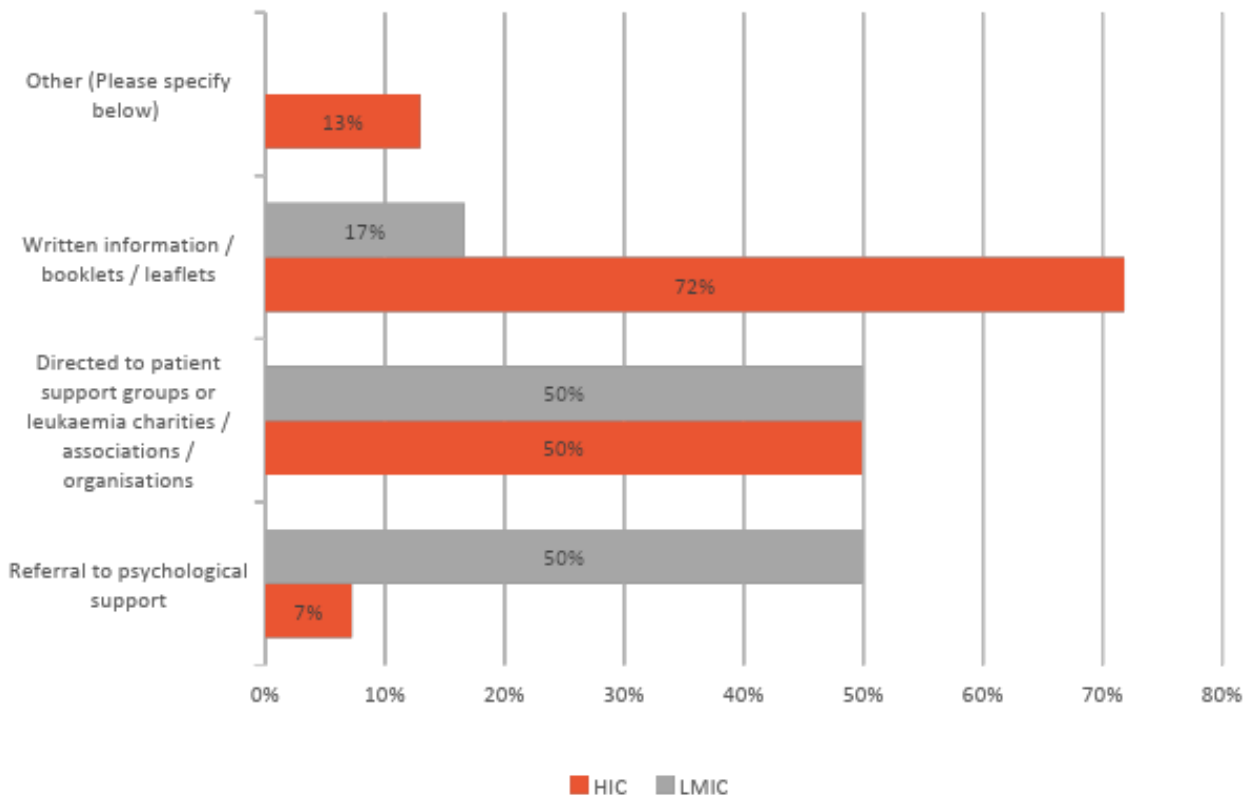


Figure 30 Q35. At diagnosis what support were you offered or directed to? (Patient Experience survey)



What CLL support, advocacy and education services provided by advocacy organisations is concerned, the responses indicate that support for patients is a paramount activity and there is a myriad of support opportunities currently offered (see figure 31). In most cases, figures are lower in LMIC compared to HIC, with patient meetings and telephone support / support helplines being the only two exceptions (84% of organisations in LMIC and 74% of those in HIC provide patient meetings and 79% of organisations in LMIC and 63% of those in HIC provide telephone support / support helplines).

When we consider the whole number of respondents here, only 18% of the total CLL patient population had been directed to support groups. Of those that weren't offered support, 72% would have liked this. It is important to highlight here that this question only addressed support for those with worries or concerns about their CLL rather than support more generally around their CLL and therefore the actual number of those that would like to access information and support may be higher.

Figure 31 Q03. What CLL support, advocacy and education services does your organisation currently offer? (CLL Patient Advocacy and Support survey)

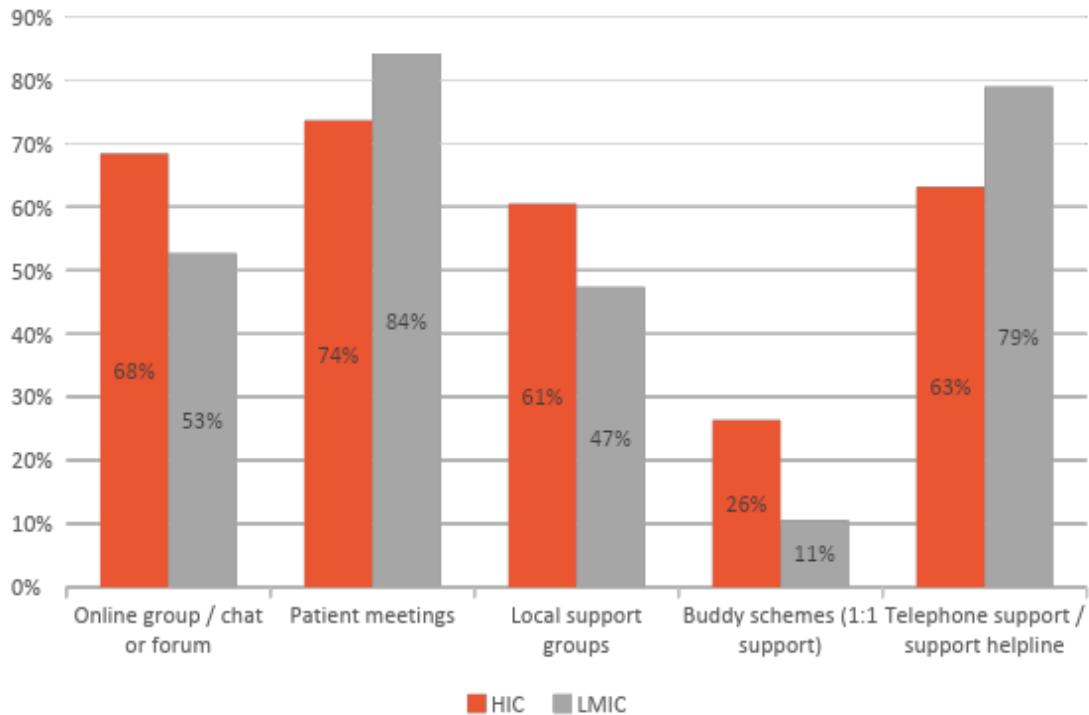


Figure 32 Q10. What CLL support, advocacy, and education services do you NOT currently offer but would like to? (CLL Patient Advocacy and Support survey)

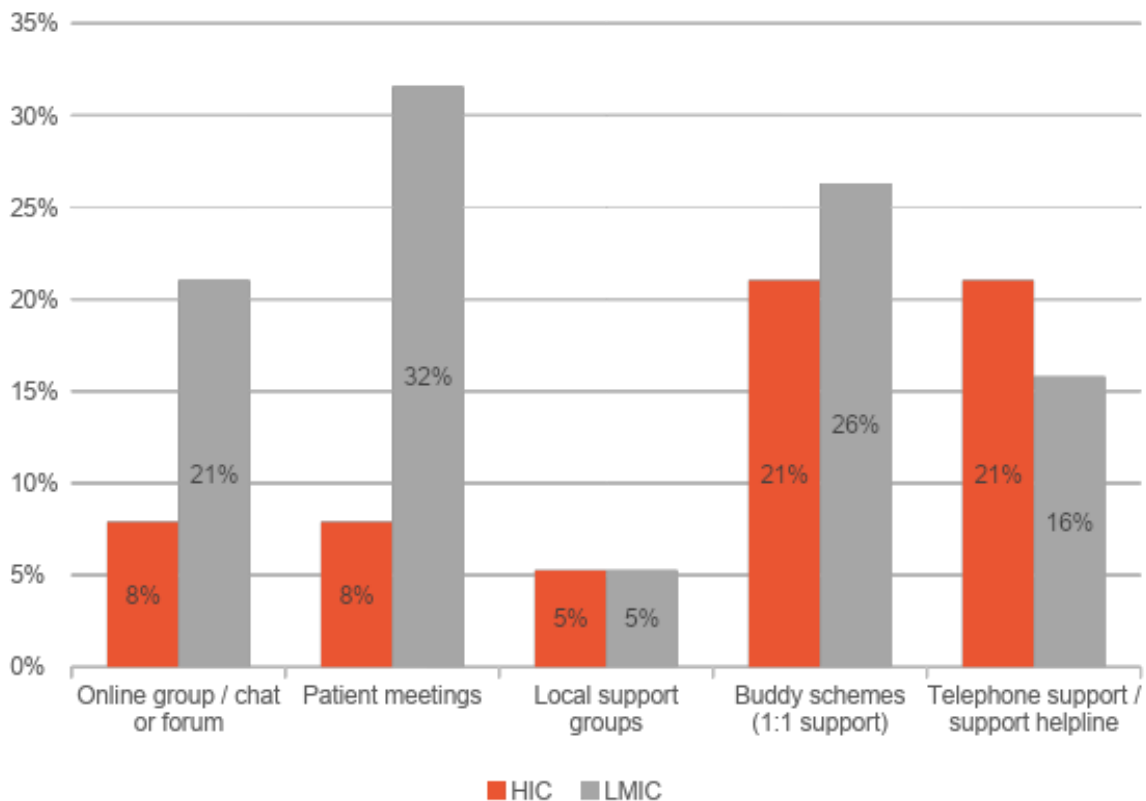


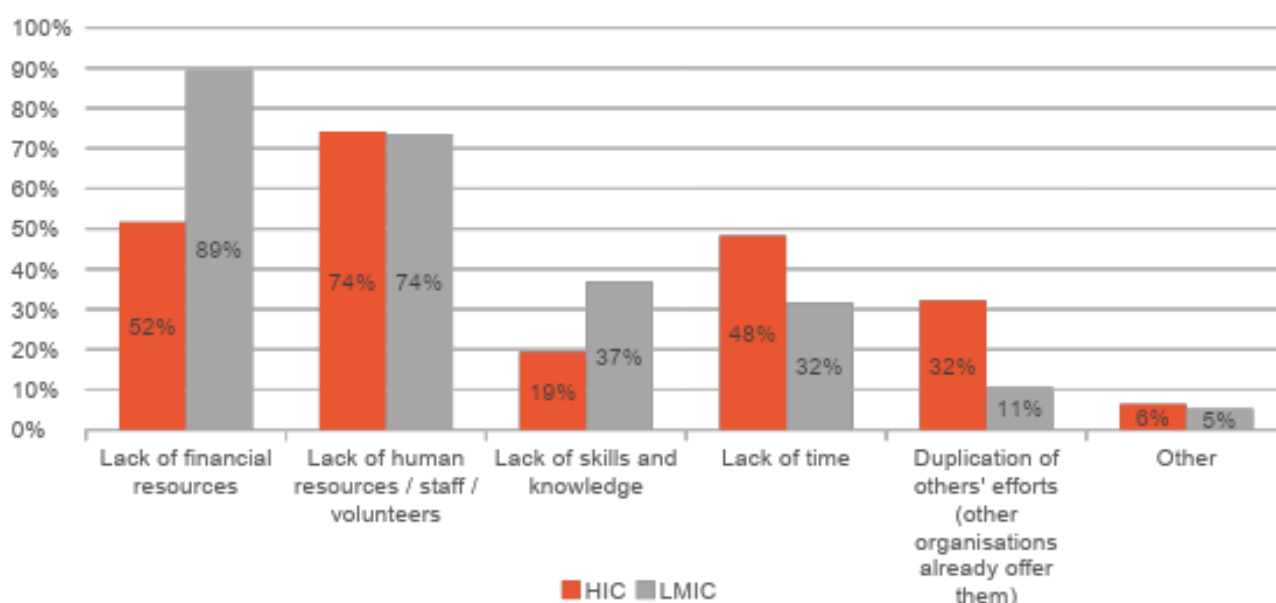
Figure 32 above shows the patient-related services these organisations don't currently provide but would like to offer. For organisations from HIC, buddy schemes and telephone support / support helpline rank highest, for LMIC patient meetings, buddy schemes and online groups/chats or forums are the top three highest ranking services for patients these organisations would like to provide. This demonstrates the

demand for patient-oriented support services across the globe. Many of these are already widely available and provided by organisations.

All of the above would seem to suggest that there is a lack of knowledge and referral for support for people diagnosed with CLL, although the demand for and presence of these services is clearly illustrated.

Collaborations between those organisations that provide support for patients and their carers and the local healthcare providers could prove hugely beneficial to improving this aspect of care for patients and their families. Identifying areas where support organisations are lacking and/or underdeveloped and providing support to develop these and improve their capacity could also be of tremendous benefit to patients and carers.

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)



Lastly, in figure 33 the reasons behind lack of provision for services are articulated by the organisations. Unsurprisingly lack of appropriate finance (52% for HIC and 89% for LMIC) and lack of human resources (74% for both HIC and LMIC) are the two main reasons. Lack of skills or knowledge was also identified by 37% of those from LMIC (vs. 19% for HIC), whereas in HIC 48% cited a lack of time (vs. 32% for LMIC) and 32% cited duplication of the work other organisations are doing.

Providing support to these organisations in terms of assistance accessing funds and providing access to shared resources, such as best practice from other global organisations in providing additional services will help to enhance the support offered across the globe.

More importantly, most organisations across the globe offer patient specific and other services for patients, carers and the wider CLL community. Encouraging and enabling collaboration between organisations and healthcare providers could all help to improve the situation for patients and carers by increasing awareness of available local and/or online support services and the benefits of engagement and support.

5.4. Summary

This section suggests that there is a deficit in the information and support provided to patients and their carers at the point of diagnosis. Healthcare providers need to ensure that the news of a diagnosis is conveyed in a sensitive and informative manner and that patients and carers have access to resources that they can return to that will help them to digest and understand the information that they need.

The survey findings here from both patients and support organisations highlights the importance that information and support can have for people with CLL, not just in relation to their concerns about their diagnosis but in more general terms around seeking information and being able to engage with other CLL patients.

It is important to note the differences in support delivery between HIC and LMIC. Quite understandably more weight appears to be given to support groups, patient meetings and telephone support and less to written information in LMIC. We do not have any evidence here, but it is worth considering whether levels of illiteracy (perceived or actual) are also a barrier to patients gaining information in a written format in LMIC.

Organisations should be encouraged and supported to engage with healthcare providers, both locally and more widely, to promote their services and the benefits that these can have to patients. Organisations should also be supported to overcome the barriers to service provision that they have encountered.

6. 'Watch and Wait'

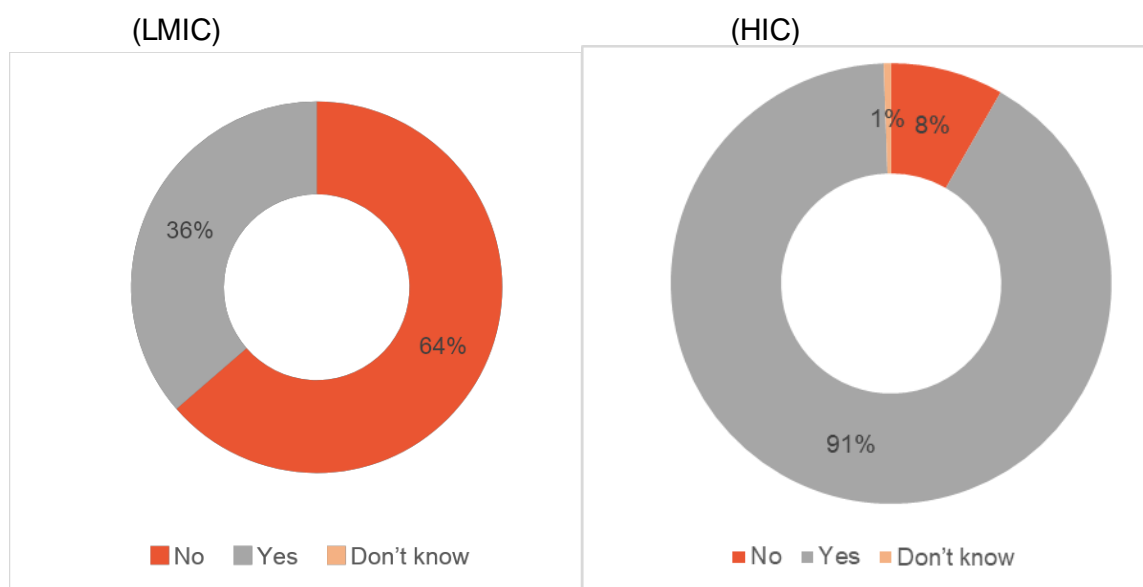
Using 'Watch and Wait' (also called 'active monitoring' or 'active surveillance') is a common tool for healthcare providers as part of a management plan for patients diagnosed with CLL. 'Watch and Wait' involves closely monitoring a patient's condition and disease progression without giving any treatment until symptoms appear or change, amongst other criteria.

6.1. Numbers of patients on 'Watch and Wait'

90% of those diagnosed with CLL stated that they had been placed on a 'Watch and Wait' monitoring plan, with 87% of carers also responding the same.

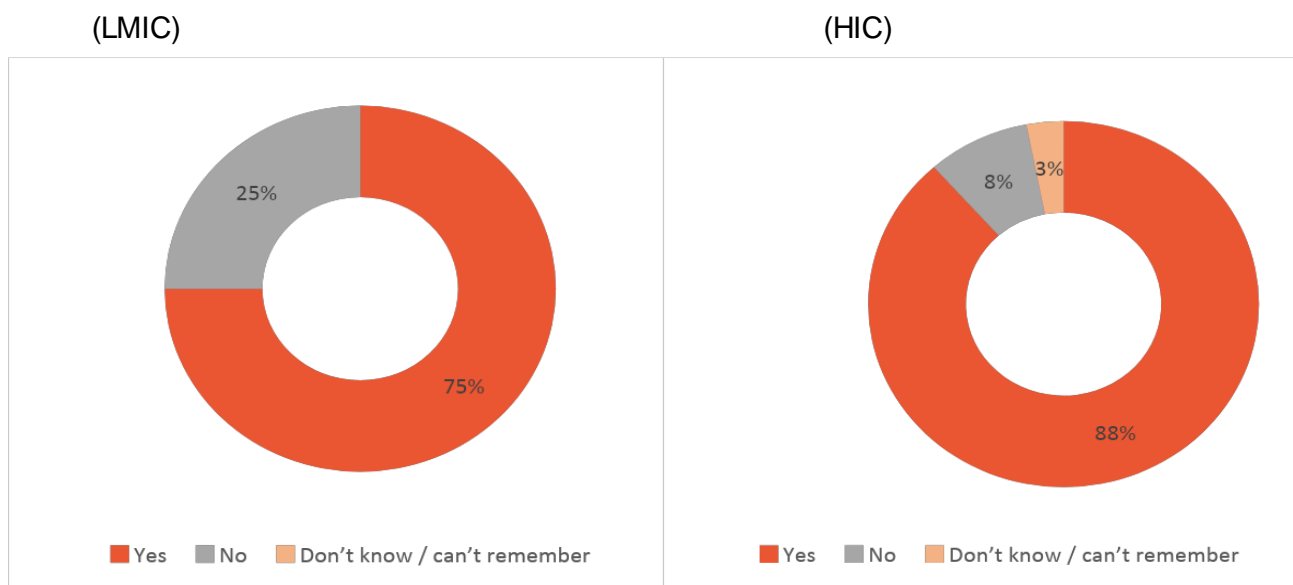
Interestingly, this seems to be much lower in LMIC at 36% (see figure 34). This could suggest that, as these patients seem to be diagnosed later and with more symptoms, they are more likely to require treatment or potentially that healthcare providers are less inclined to monitor patients, preferring treatment provision. It needs to be borne in mind that this survey has very low response numbers from LMIC and the recruitment was through the network of support organisations. If patients on 'Watch and Wait' are not accessing information and support, then they may have not been able to access this survey.

Figure 34 Q37. Have you ever been placed on a 'Watch and Wait' monitoring plan?
(Patient Experience survey)



The majority of those on 'Watch and Wait' were given an explanation, although this is lower for LMIC (75%) compared to HIC (88%).

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



The majority of respondents across the globe had at least some concerns about being on 'Watch and Wait' with 75% of carers also having at least some concerns here (see figure 37). Patients' concerns were much higher in HIC than LMIC (79% in HIC vs. only 25% in LMIC, see figure 36 below). This is understandable, many patients may feel anxious to be told that they have a blood cancer and yet not receive any treatment. A thorough explanation, information resources and referral for ongoing support may well be beneficial at this point whatever stage of the disease the patient (and their carer) is at.

Figure 36 Q44. How did you feel when you were put on 'Watch and Wait' for the FIRST time? (Patient Experience survey)

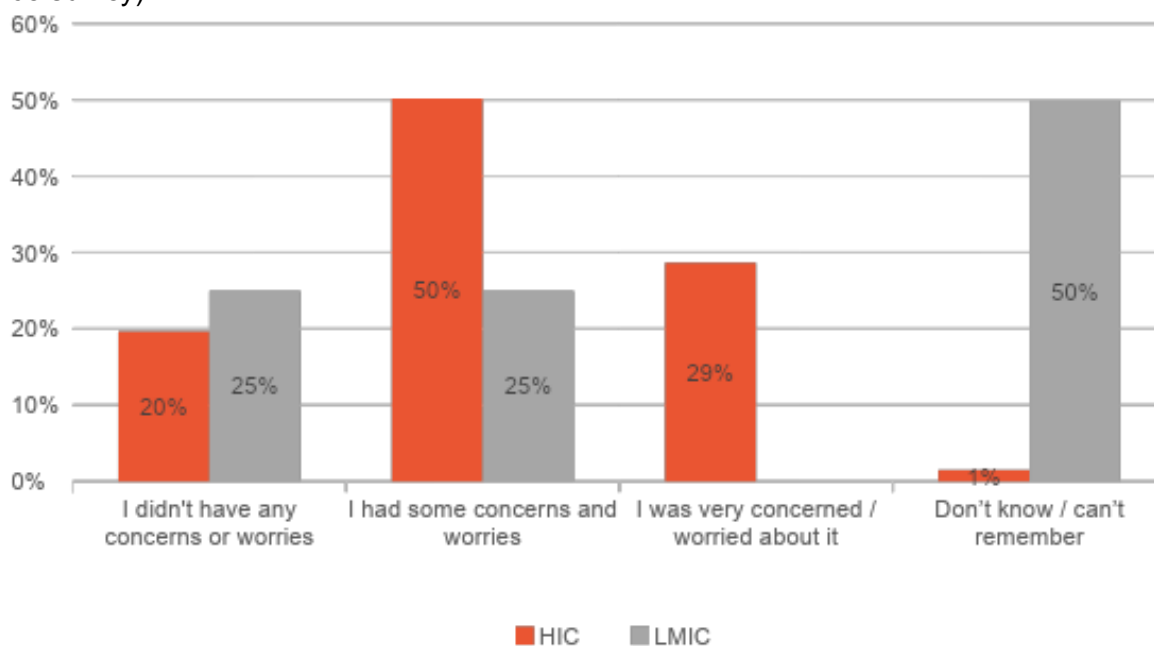
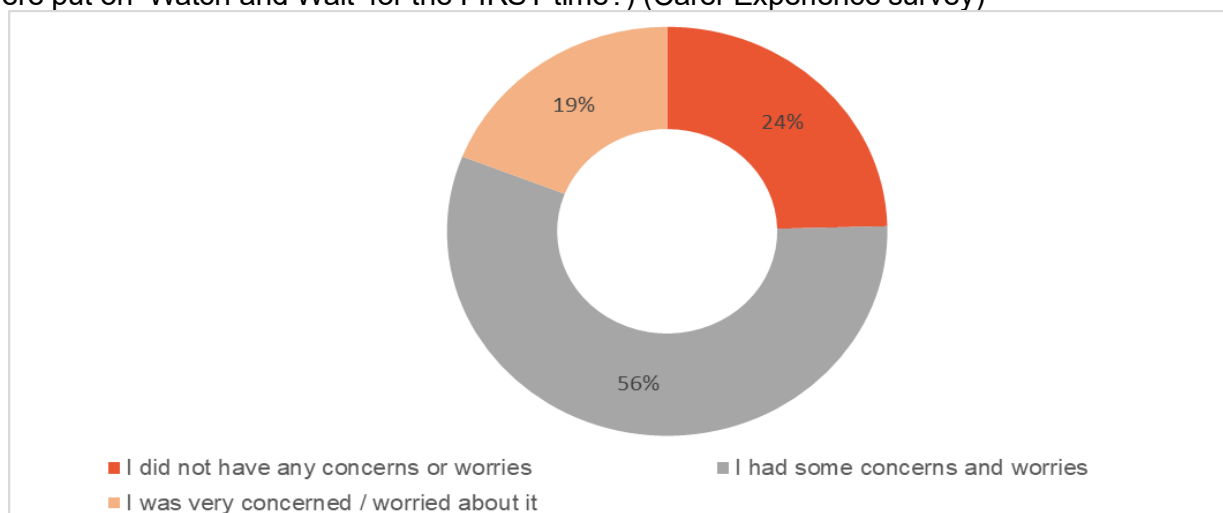


Figure 37 Q21. How did YOU feel about the patient being put on 'Watch and Wait'? (How did you feel when you were put on 'Watch and Wait' for the FIRST time?) (Carer Experience survey)



Half (50%) of those from LMIC could not remember how they felt about 'Watch and Wait' and none suggested that they were very concerned. This may be because those from LMIC here were put on treatment at the time of diagnosis or a short while after; all of them had been or were currently on an active treatment plan rather than 'Watch and Wait'.

It's clear from these results and the wider literature around CLL that 'Watch and Wait' is a well utilised tool for the management of CLL patients. The majority of patients are on or have been on 'Watch and Wait' monitoring and the majority of patients and their carers had at least some concerns about this. More needs to be done here to inform and support those on 'Watch and Wait' about their plan and their prognosis.

The involvement of well-informed advocacy and support organisations could make a real difference at this stage for patients and the wider CLL community.

6.2. Written information about 'Watch and Wait'

52% of CLL patient respondents from HIC stated that they weren't given written information about their 'Watch and Wait' plan (see figure 38). This rose to 75% in LMIC. Only 33% of carers were provided with written information.

Figure 38 Q41. When you were FIRST told you had been put on a 'Watch and Wait' plan were you given written information about this? (Patient Experience survey)

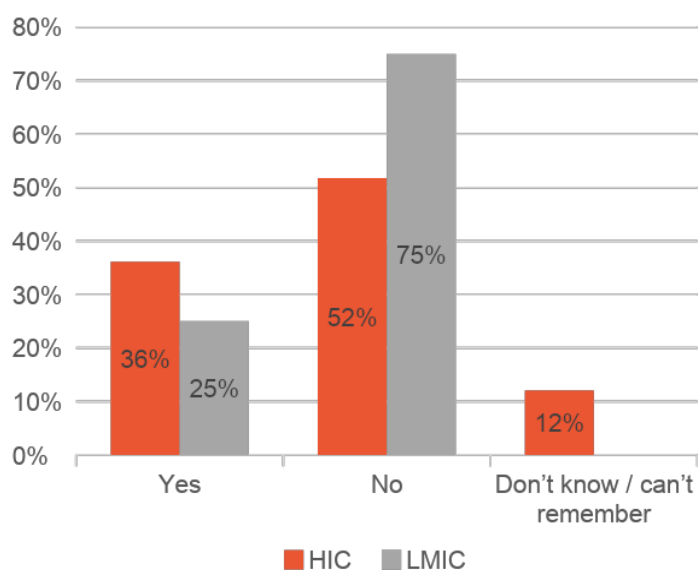
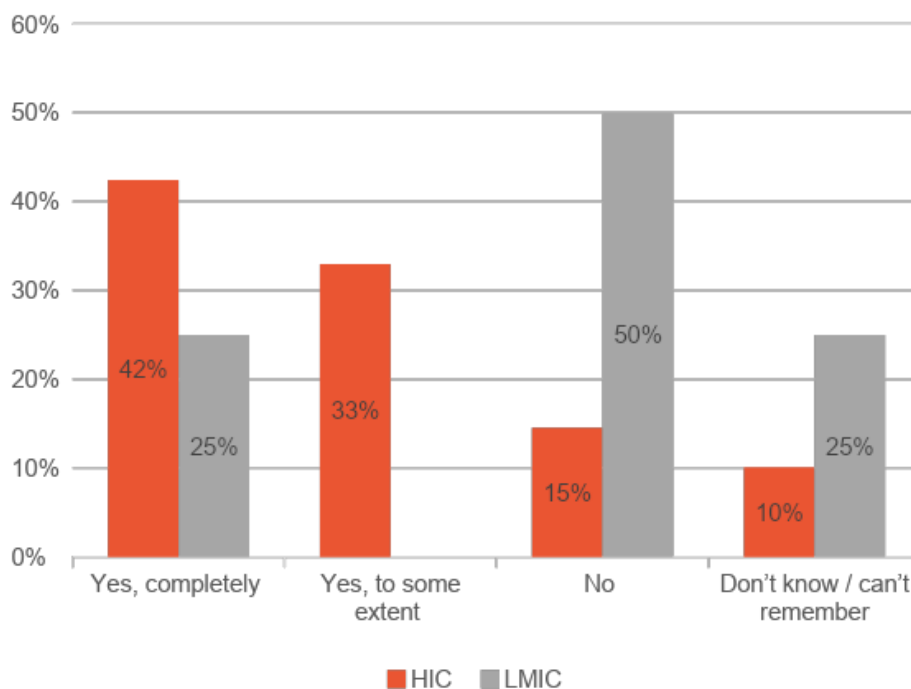


Figure 39 Q42. Did you understand the written information you had been given about your ‘Watch and Wait’ plan? (Patient Experience survey)



75% of patients from HIC and only 25% indicated that they had either completely understood or at least understood to some extent the information that they received (see figure 39), and of those that didn't receive any, 64% would have liked to.

Although ‘Watch and Wait’ from this survey seems to be less well utilised, these patients report that they were also less likely to understand this type of monitoring. Patients would seem to benefit from more information and reassurance around their monitoring plan. Support organisations should collaborate with healthcare providers to ensure that patients have information, preferably in a format that they can return to (for example written leaflets or website pages) that ensures that they understand why they are on ‘Watch and Wait’ and what will happen.

6.3. Support for those on ‘Watch and Wait’

Only 30% of patients worldwide on a ‘Watch and Wait’ plan were offered/directed to support, figures 40 and 41 below showing the breakdowns by HIC and LMIC. Of those that were, none of the respondents in the LMIC were offered anything other than psychological support whereas just over 60% of HIC country CLL patients were offered written and support group support (see figure 42). Of the total population here, 17% of all respondents replied that they had been offered support for ‘Watch and Wait’. Again, similarly to the findings around diagnosis this is a small minority.

Figure 40 Q45. Are you offered or directed to any support to help with any concerns and worries about being on 'Watch and Wait'? (**HIC**, Patient Experience Survey)

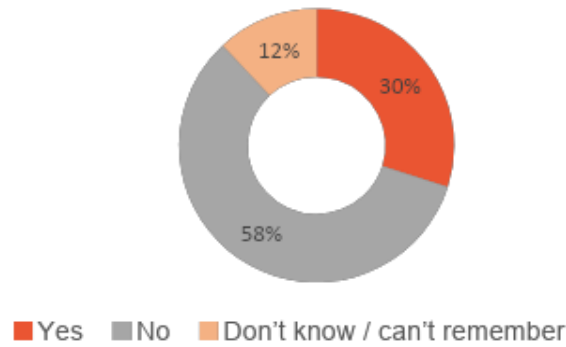


Figure 41 Q45. Are you offered or directed to any support to help with any concerns and worries about being on 'Watch and Wait'? (**LMIC**, Patient Experience Survey)

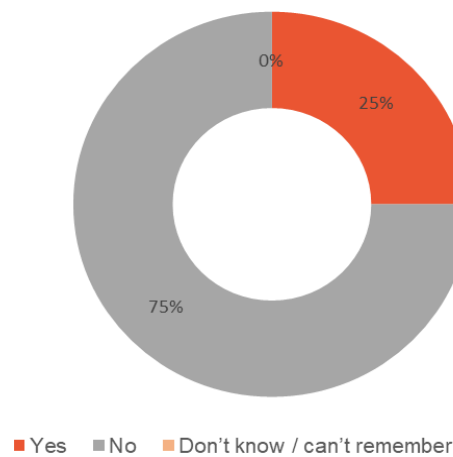
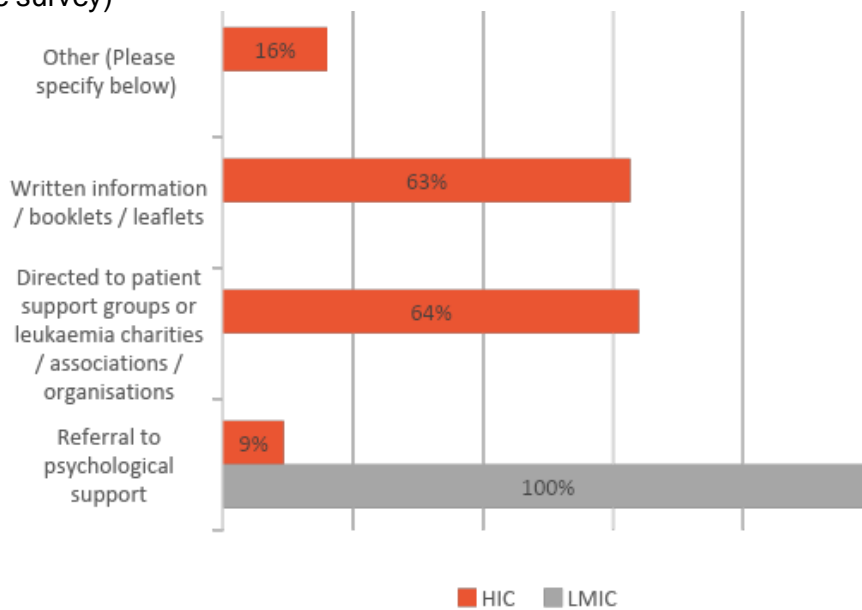


Figure 42 Q46. While on 'Watch and Wait' what support are you offered or directed to? (Patient Experience survey)



Lastly in this section, for the majority that weren't offered information and support, around half (49%) reported that they would have liked to. The results here suggest that information and support is vital at both diagnosis and at the point of 'Watch and Wait'.

6.4. Summary

This survey reflects other findings about the prevalent use of 'Watch and Wait' as a management tool for CLL. What is clear here is that patients need information and reassurance about this method of managing their leukemia; however, the provision of written information and referral to support is not well utilised.

We know that support organisations, from the previous section, provide a myriad of resources around information and support and therefore they should be encouraged to collaborate with healthcare providers, both locally and further afield, to ensure that patients can access them. The benefits of access to information and support for patients should also be more widely promoted.

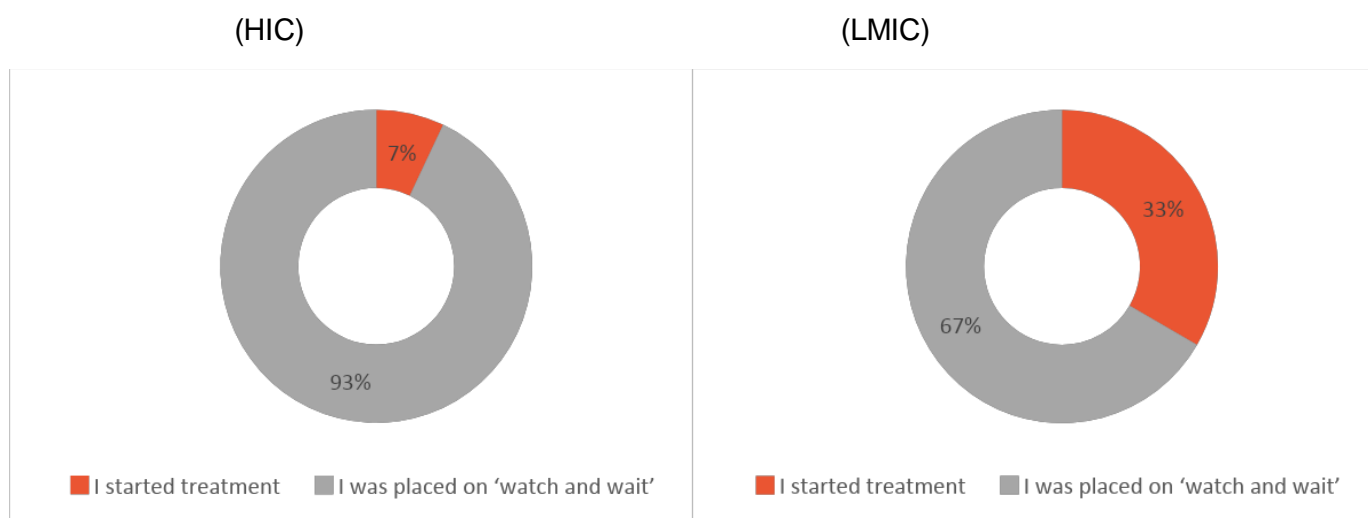
7. Treatment

Treatment for CLL can be complex, with many different approaches and types of treatment available to patients across the globe.

7.1. Starting treatment

Only 7% of those with CLL worldwide had started treatment immediately after diagnosis, with 50% that responded to this question on the survey stating that they had never had treatment. There were significant differences between those from HIC and those from LMIC.

Figure 43 Q57. When you were diagnosed, were you told that you would start treatment or were you told you would be put on a 'Watch and Wait' monitoring plan? (Patient Experience Survey)



A quarter of those that responded started treatment within the first month after diagnosis. There was a significant difference here between LMIC and HIC. All of those that responded from LMIC had started treatment within two years whereas 42% of those from HIC did not start treatment for 2 years or more (see figure 44 below). This clearly illustrates the difference here from the respondents to this survey. Those that responded from LMIC were more likely to have symptoms and to have taken longer to diagnose, it is not clear if this is more reflective of the wider picture across LMIC due to the small sample size for this survey. However, for those that have responded here it is obvious that they have started treatment at an earlier point than those in HIC.

Figure 44 Q61. How long after being told your diagnosis was it before you started treatment for your specific leukemia? (Patient Experience Survey)

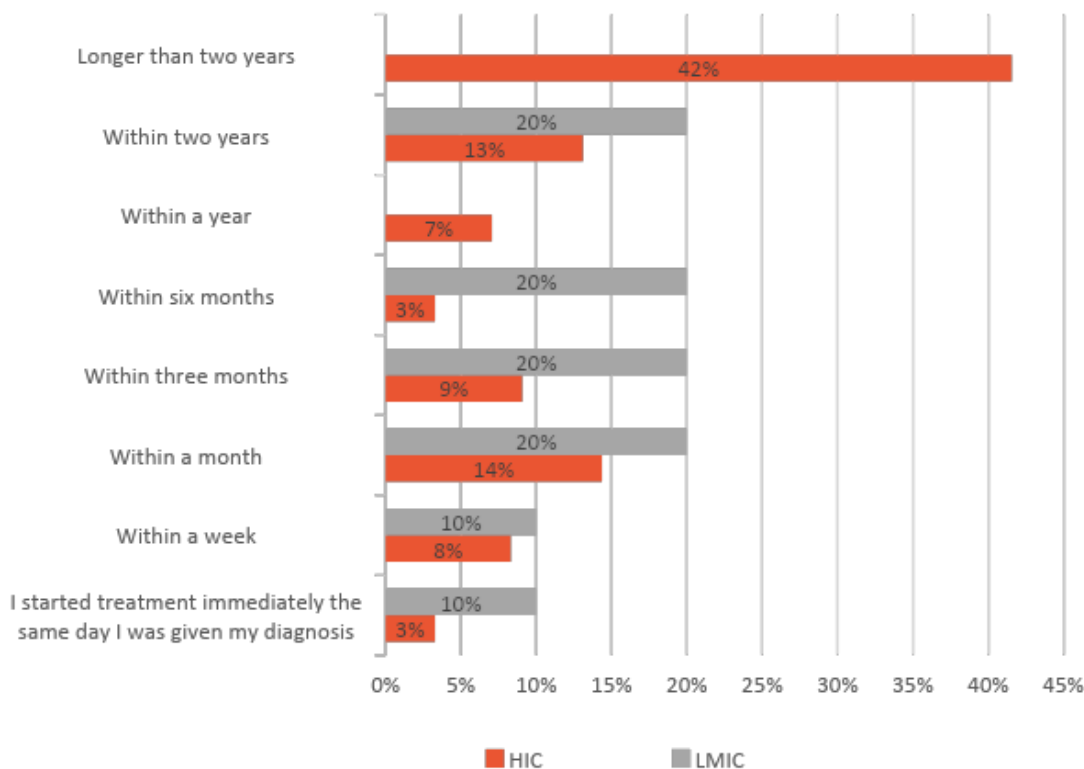
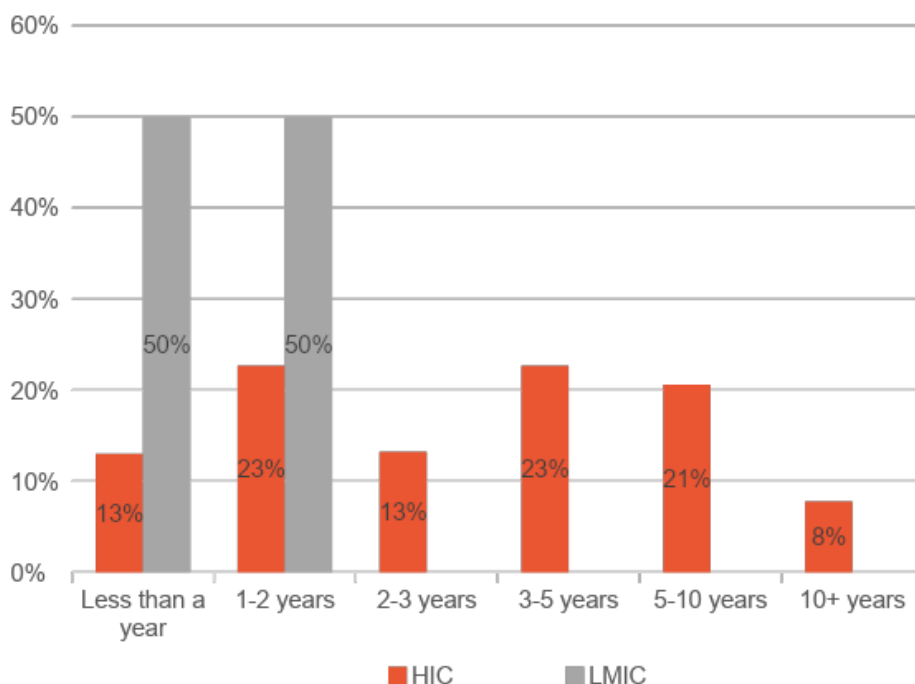


Figure 45 Q58. How long were you on 'Watch and Wait' before starting treatment? (Patient survey)



Essentially here the responses suggest that a 'Watch and wait' strategy is more commonly used in HIC, however as noted in the limitations to this report, this survey only included very low numbers of respondents from LMIC and no firm conclusions can be drawn. Asymptomatic patients are likely to be found across the globe, however what could be relevant here is that there may be less emphasis placed on patients without symptoms in different countries. Asymptomatic patients and those on 'Watch and wait' may be less likely to be accessing support in LMIC and therefore may not have responded to this survey.

Engagement between support organisations and healthcare providers to improve access to information and support for all patients is a paramount action across the globe.

Lastly in this section, although globally, according to the network organisations, 60% definitely had access to specialist doctors and 44% access to specialist centres. This is much lower in LMIC where it was only 32% that definitely had access to specialist doctors and 16% to specialist centres (see figure 46 and 47 below). This may help to understand the later diagnosis in these countries and therefore the differential treatment suggested from the responses here.

Figure 46 Q24. Do CLL patients have access to specialist doctors in your country? (CLL Patient Advocacy and Support survey)

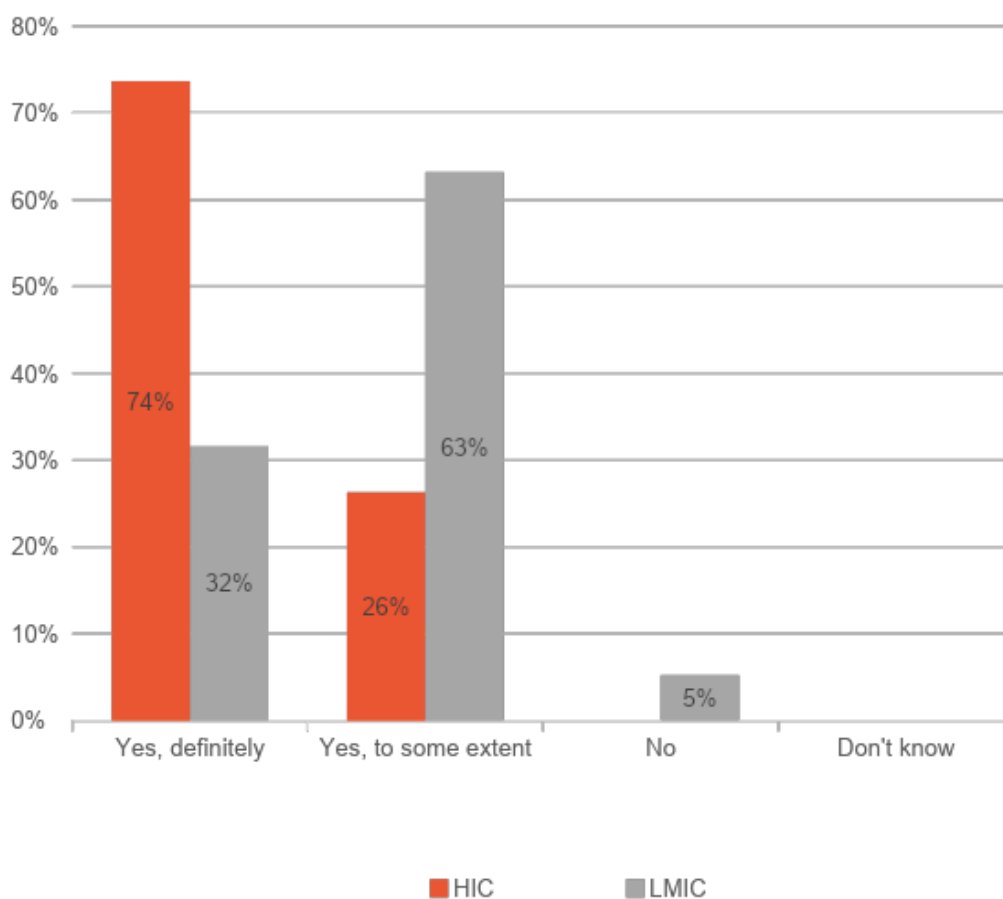
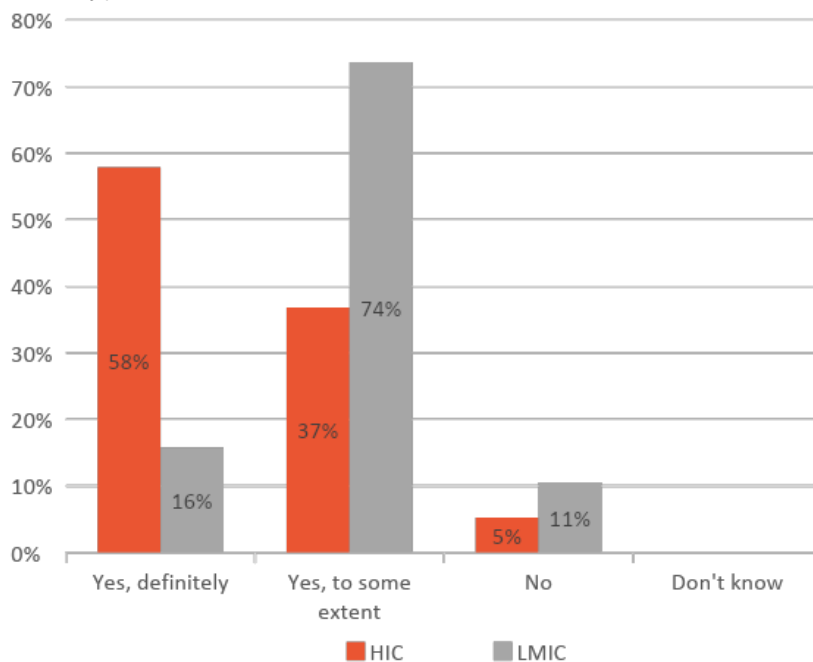


Figure 47 Q25. Do CLL patients have access to CLL specialist care centres in your country? (CLL Patient Advocacy and Support survey)



This may provide some explanation around the difference in the diagnosis and management of CLL patients.

7.2. Treatment choice

Across the world, 47% of the network organisations stated that they thought that there were enough approved therapies in their country. Again, here there is a significant difference between HIC and LMIC where 32% felt that there were enough approved therapies compared to 55% for LMIC (see figure 49). The organisations in LMIC also felt that for the most part (74%) the affordability of treatment and care was an issue to at least some extent, compared to 34% of HIC respondents (see figure 48). Although there is a clear geographical difference here, support organisations are clearly highlighting a global issue around access to improved therapies and affordable treatments.

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)

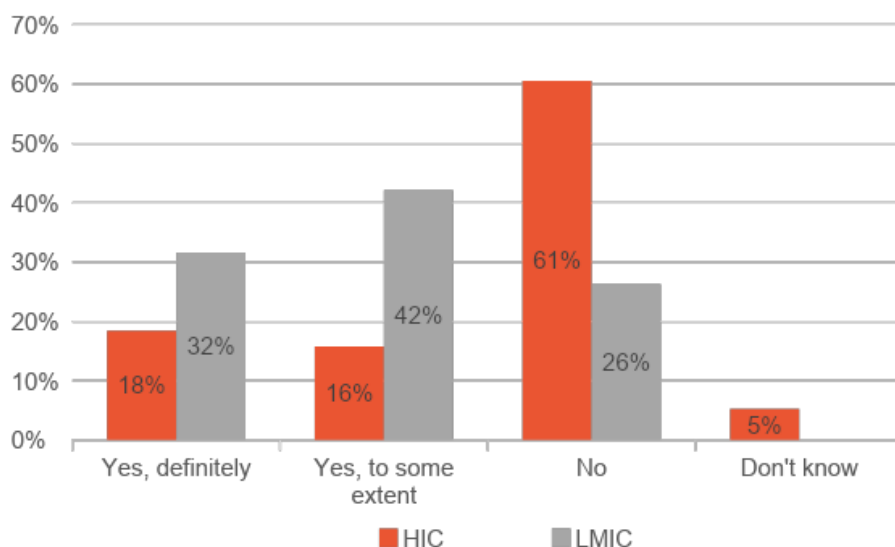
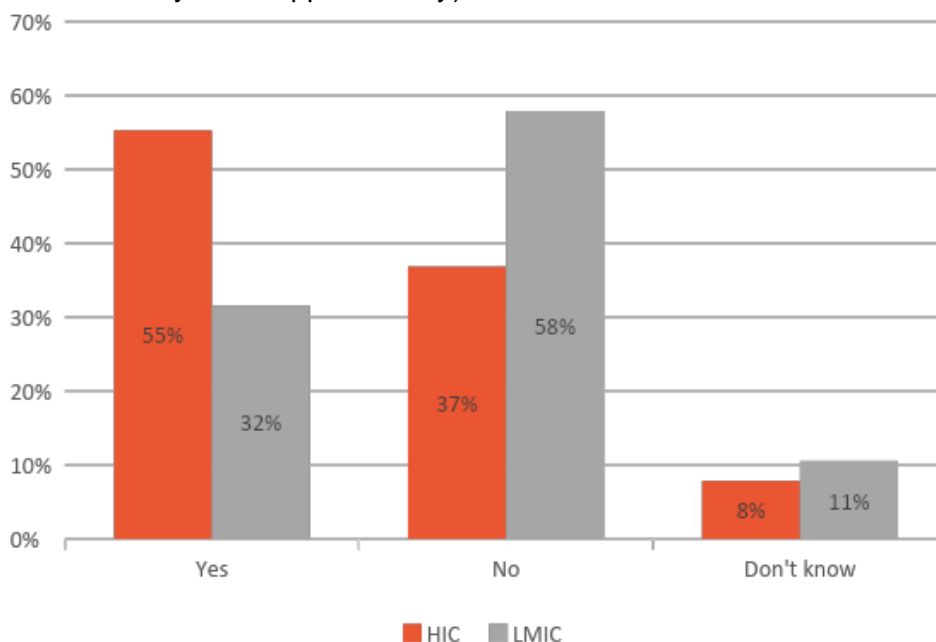
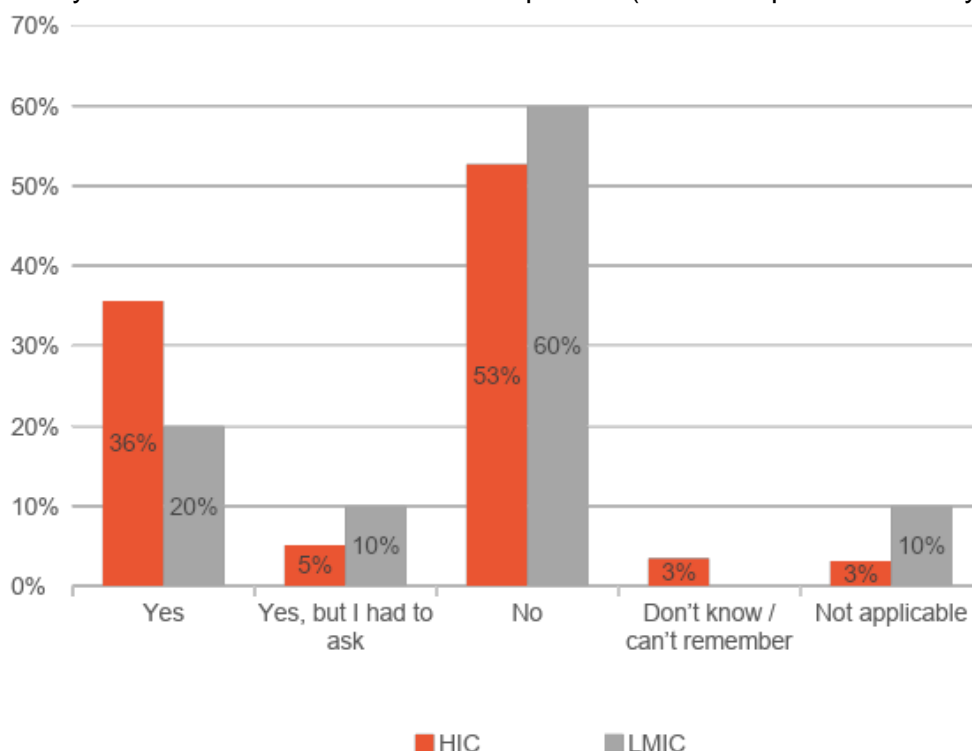


Figure 49 Q23. Do you think there are enough approved therapies available for CLL patients in your country? (CLL Patient Advocacy and Support survey)



For those that did start treatment, 52% globally noted that they didn't have a choice of treatment options. This was slightly higher for LMIC (60%).

Figure 50 Q62. Were you offered a choice of treatment options? (Patient Experience survey)



Although 54% of CLL patient respondents stated that they were completely involved in their decisions, this is less so in LMIC where only 30% felt that they were completely involved in treatment decisions. When carers were asked this question, 62% felt that the patient was involved in their treatment decisions which is slightly higher than the patients.

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

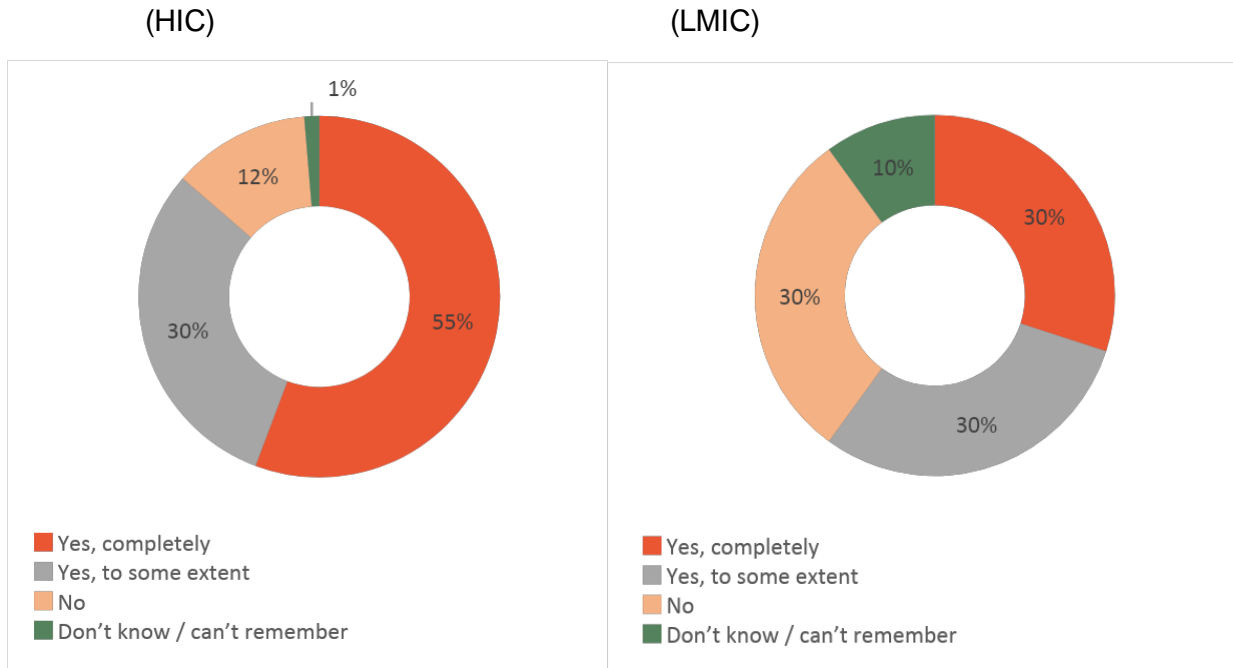
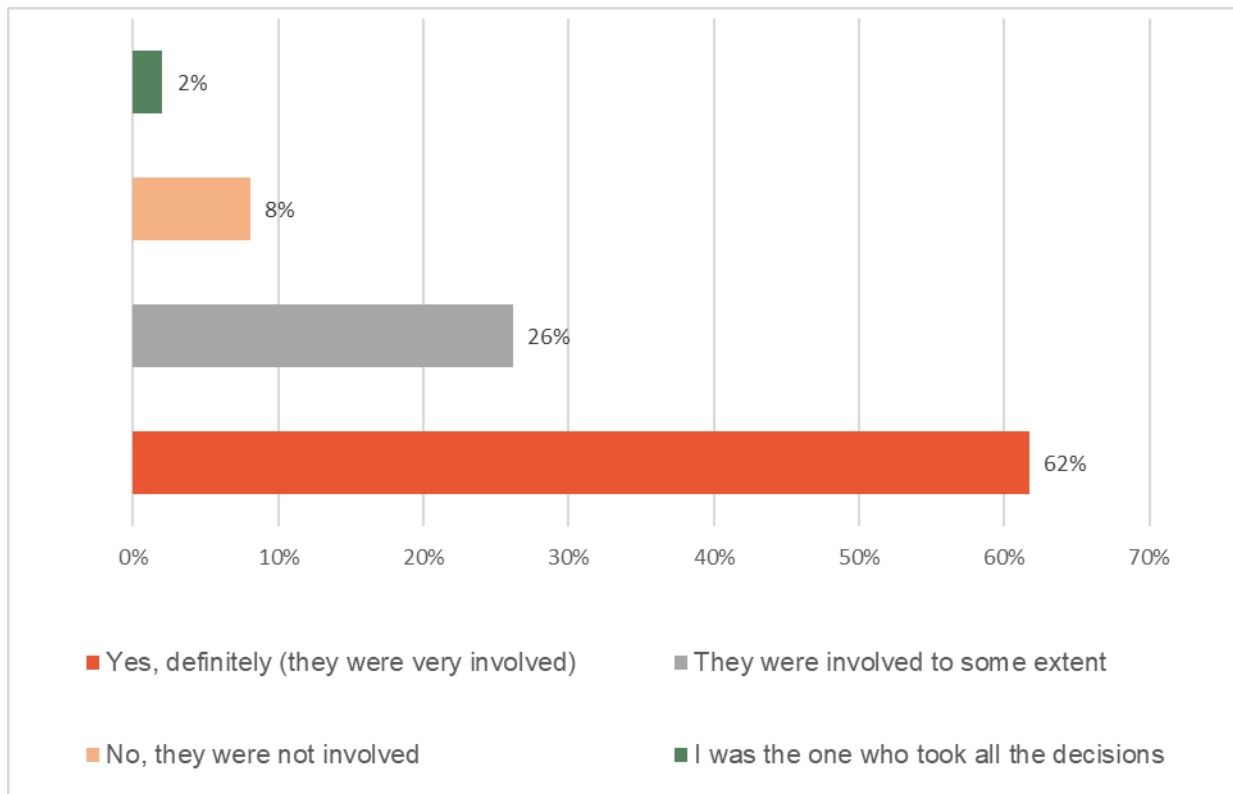


Figure 52 Q17. Do you think the patient was involved as much as they should have been in decisions about their treatment and care? (Carer Experience Survey)



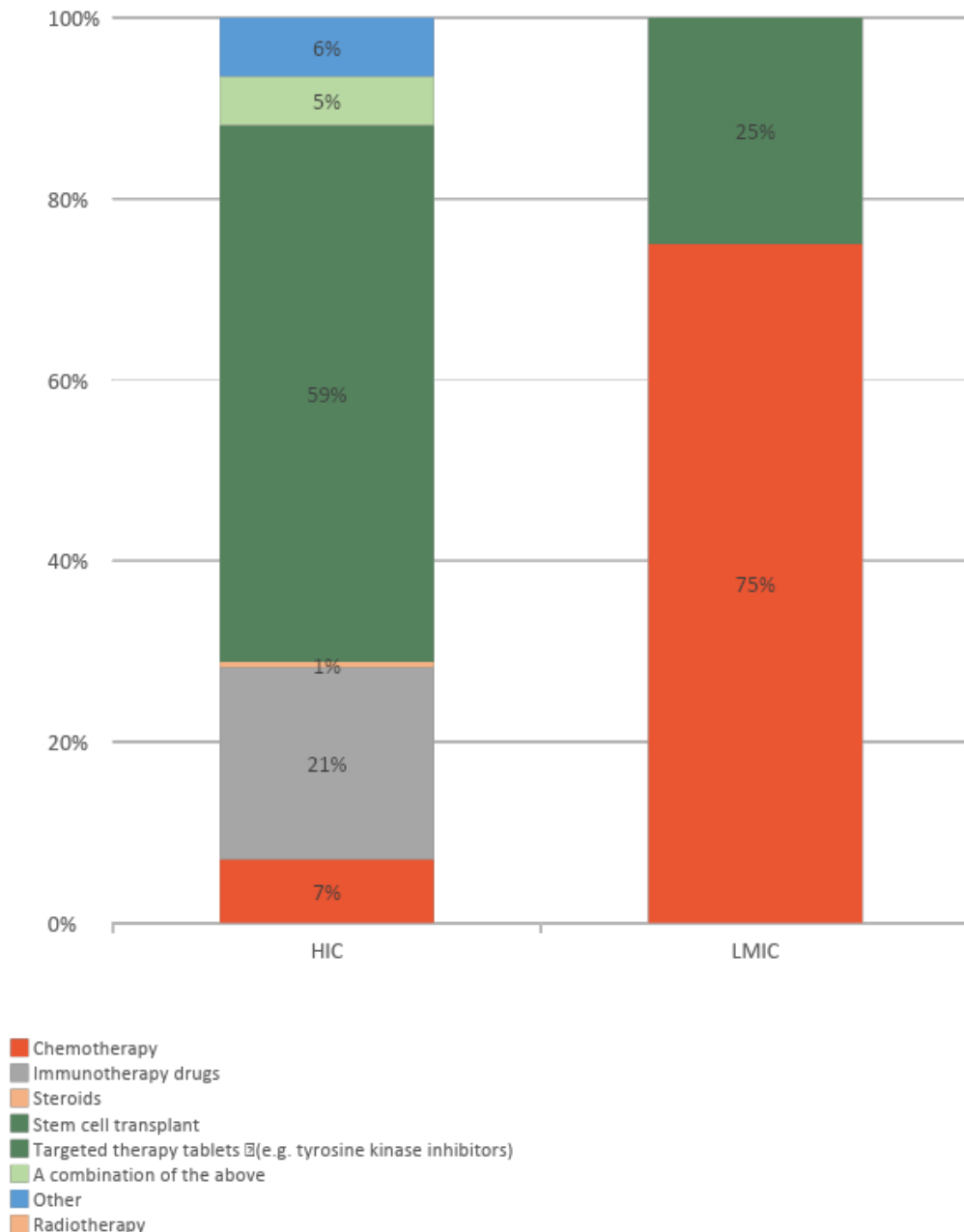
The lack of specialist doctors, centres and affordability and availability of treatments would appear to impact here for all patients but most specifically those from LMIC. The impact can be seen in the treatments available and the choice and decisions that patients have in their treatments.

7.3. Types of therapy

The CLL treatment landscape seems to have changed quite quickly over recent years through the use of clinical trials². There are changes to the types of treatment used over the course of current and most recent treatments, evidencing the landscape change in treatment type.

Currently 75% of those on treatment from LMIC are on chemotherapy, whereas for those who aren't currently on treatment the most common recent treatment was immunotherapy. For HIC, the majority currently on therapy are on targeted therapy tablets (59%) followed by immunotherapy (21%). Chemotherapy makes up a larger proportion amongst those not currently receiving treatment.

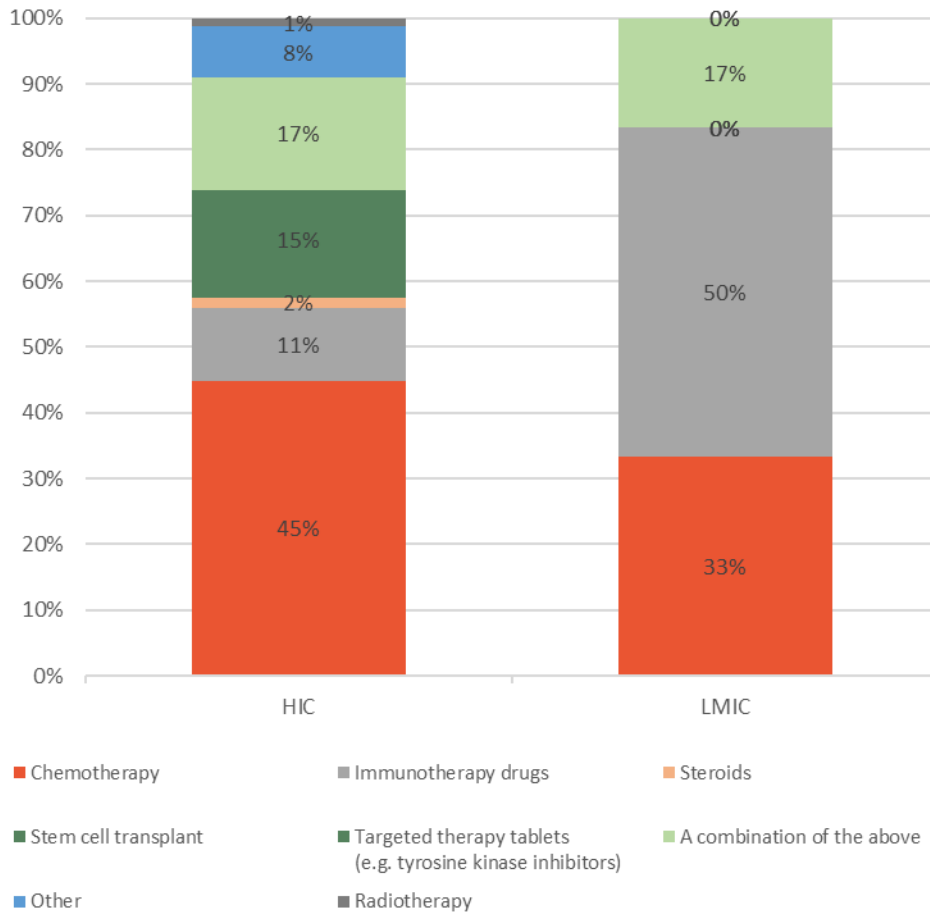
Figure 53 Q66. What is your current treatment? (Patient Experience Survey)



² [CLL Information - CLL Advocates Network](#)

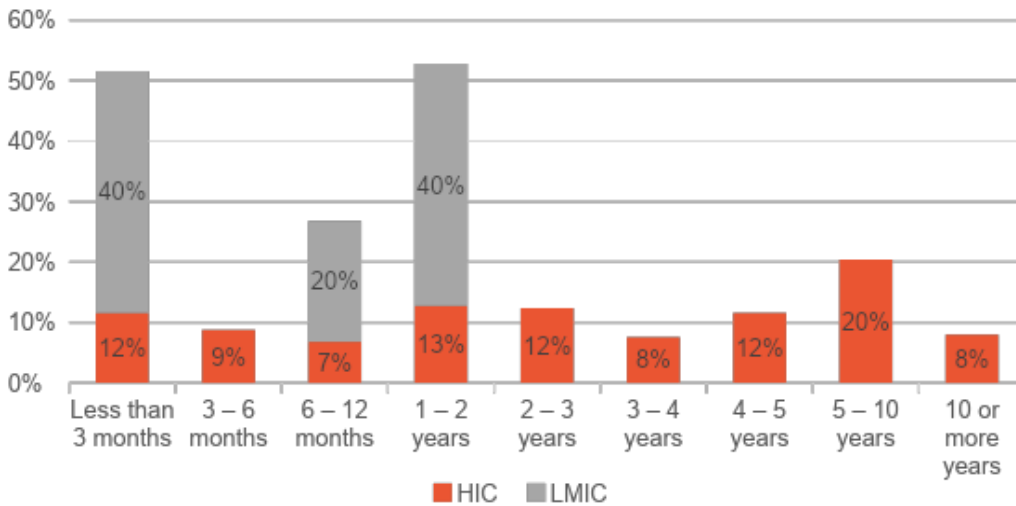
When looking at the most recent treatment for those not currently receiving treatment, for HIC chemotherapy (45%) was most commonly used followed by a combination of treatments (see figure 54 below).

Figure 54 Q67. What was your last / most recent treatment? (Patient Experience Survey)



28% from HIC had their last treatment over 5 years ago. This may explain the change in treatment options/utilisations here. With LMIC, all respondents had treatment in the last 2 years (see figure 55 below).

Figure 55 Q68. How long was your last / most recent treatment? (Patient Experience Survey)



This again illustrates here the potential difference in management of patients and the difference in treatment types and utilisation across the globe with affordability and lack of specialist clinical input a potential factor. Again, this has to be treated with caution due to the numbers of respondents and the recruitment method and so cannot be provided as a definitive conclusion, but coupled with the responses from the support organisations there is a clear issue.

7.4. Summary

This section has demonstrated the complex global picture around the management of CLL, bringing into focus the geographical differences in patient involvement and treatment options.

Patients and carers across the globe would like more involvement and choice in the types of treatment that they/the patient receive/receives.

Network organisations should raise awareness of the disparity around access to treatment, treatment choice and work collaboratively to reduce the deficit.

7.5. Clinical trials

Clinical trials are considered an important aspect of the treatment landscape for CLL. When looking at the data on clinical trials gathered through the CLL Patient Advocacy and Support survey, globally 46% of network organisations felt that people didn't have the opportunity to take part in a clinical trial. This differs significantly with 84% of organisations from LMIC responding in this way as opposed to 26% from those classed as HIC. Only 18% of organisations currently provide a clinical trials directory whereas 42% would like to provide this. The data from the Patient Experience Survey show the following: 54% of people with CLL said that they weren't given the opportunity to take part in a trial and again this is much higher (70%) in LMIC than HIC (53%), see figure 56.

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

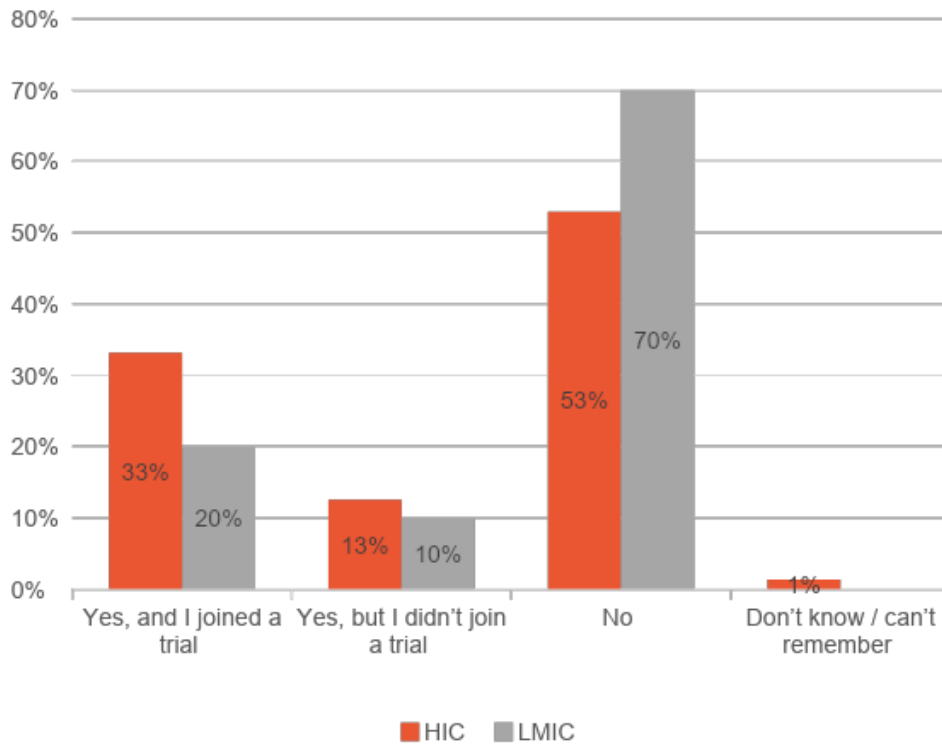
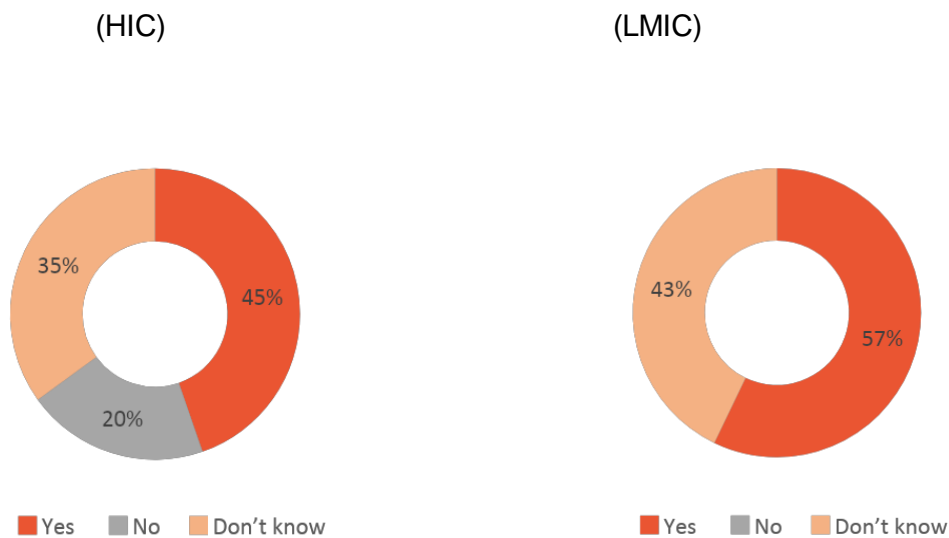
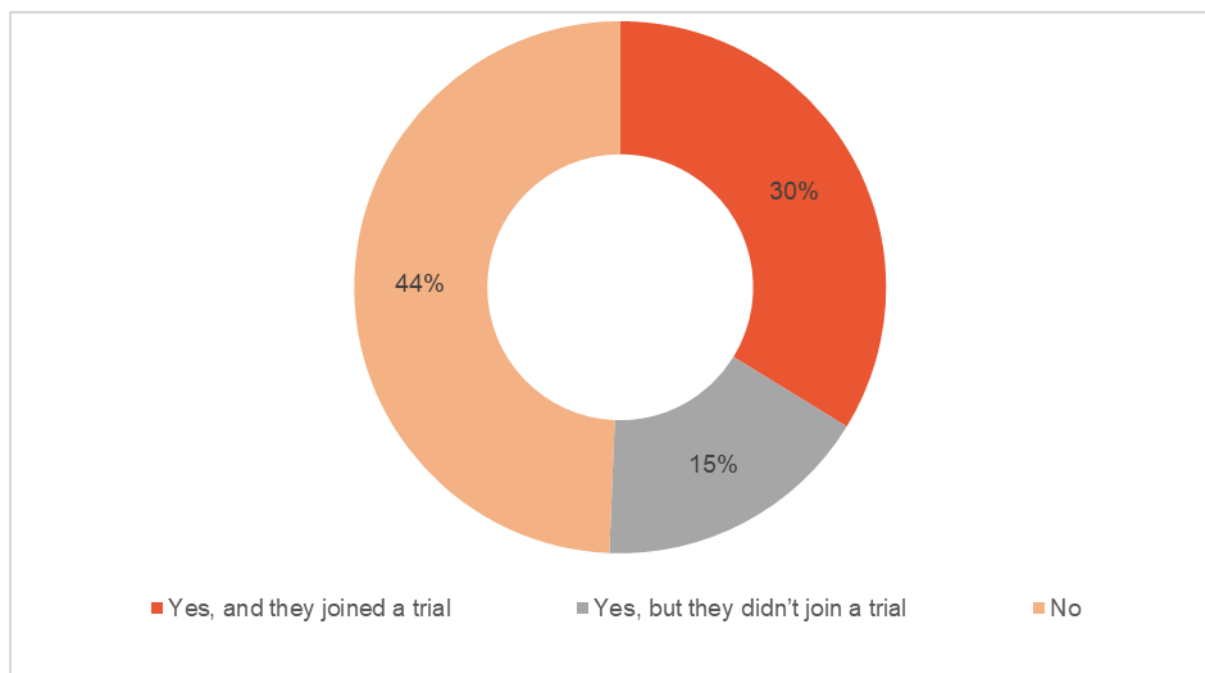


Figure 57 Q87. Would you have liked to have been given the option of participating in a clinical trial? (Patient Experience Survey)



With regard to carers, 44% of those that responded worldwide stated that the person that they cared for wasn't given the option to take part in a trial and a further 45% stated they would have liked to have been offered this (see figure 58).

Figure 58 Q33. Was the patient / you given the option of participating in a clinical trial? (Carer Experience Survey)



Of those that did take part 86% found this a positive experience with no one reporting this as negative. The availability and utilisation of clinical trials, when considering the results here, differs geographically with those in LMIC provided less opportunities (see figure 57) but it also seems to be lower than expected across the globe. Around half of the respondents to all three surveys felt that patients are not given enough opportunities to attend clinical trials and the highly popular suggestion to produce and disseminate a clinical trials directory would also suggest that knowledge around clinical trials is not as developed as it could be. This may also help to highlight a disparity in specific research within certain populations across the globe, particularly focused on LMIC.

This clearly defined issue has been exacerbated by the global effects of the COVID-19 pandemic within which these surveys were conducted and any actions to improve the situation should include continuity plans to combat future similar global (or more local) incidents.

Participating in a clinical trial isn't appropriate for everyone diagnosed with CLL however these responses and the wider literature around CLL would seem to suggest that education for patients and healthcare professionals around clinical trials would be beneficial. Engagement to promote their use and advocacy in local areas where there are clear deficits to initiate trials will also be of benefit.

7.6. Information and support

Although 3/4 of patients globally stated that they had been given information about their most recent/current treatment, this was only 50% in LMIC. This information on the whole was well understood across those in HIC (71%), less so by patients in LMIC (40%).

Figure 59 Q69. Were you given written information about your most recent / current treatment plan? (Patient Experience Survey)

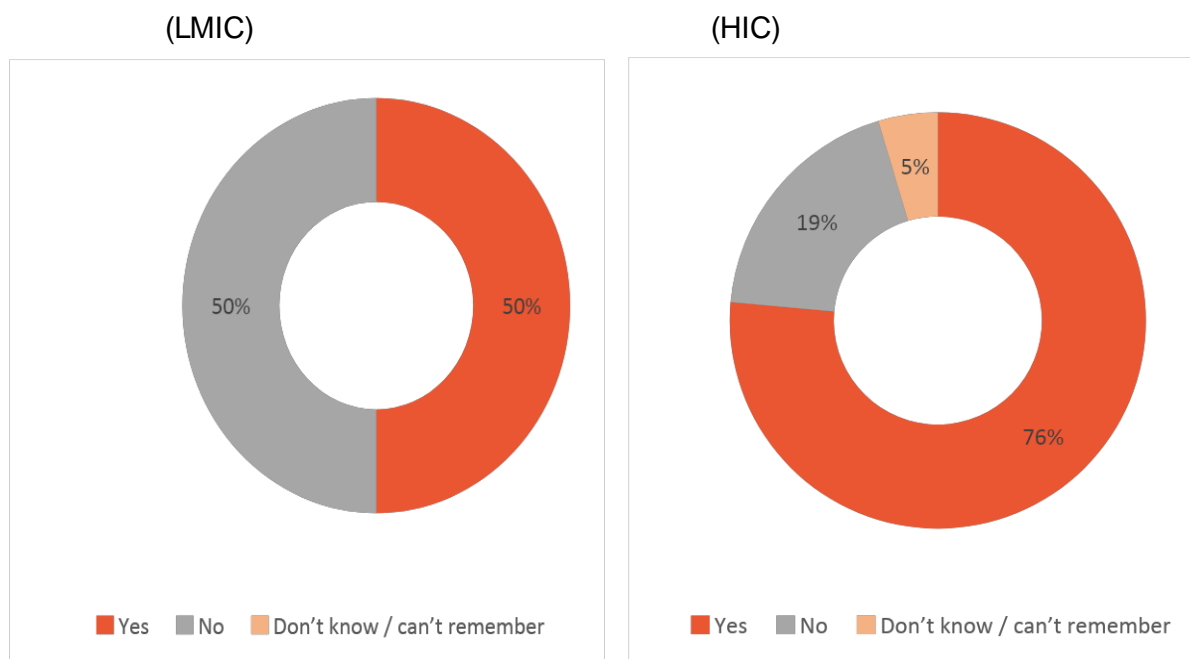
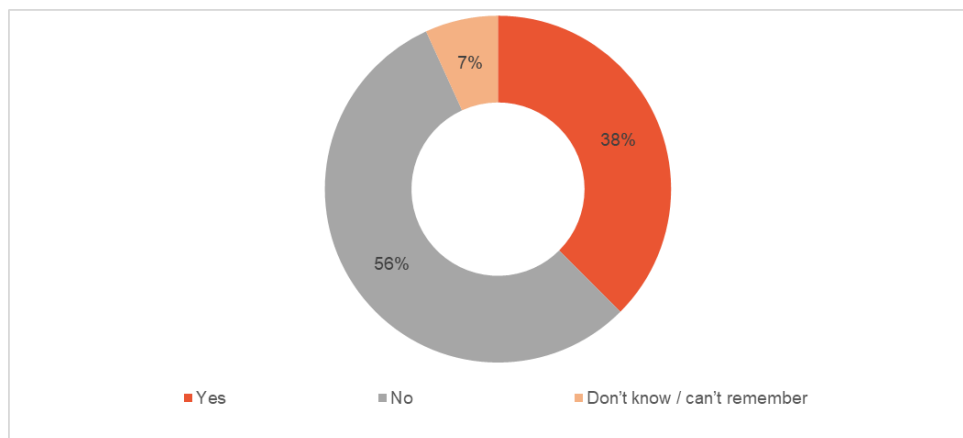
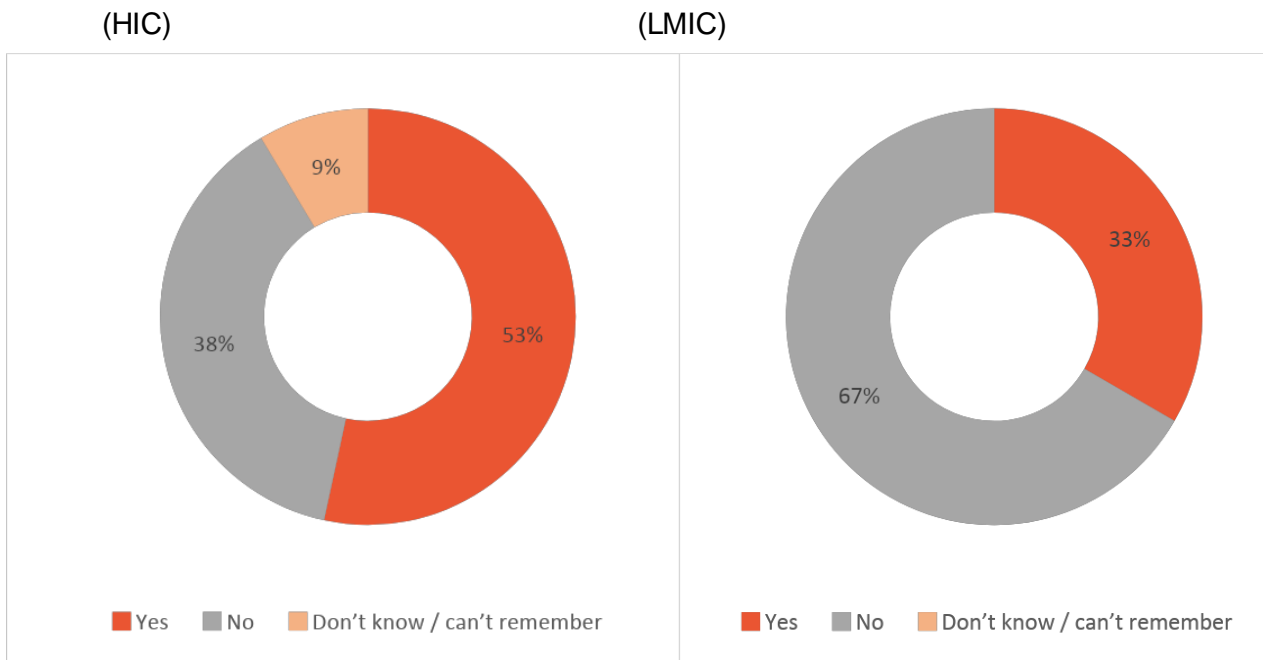


Figure 60 Q28. Were YOU given or directed to written information about the patient's / your most recent / current treatment plan? (Carer Experience Survey)



Similarly, to the other areas that this report has already covered, only 52% of those that responded worldwide stated that they had been offered or directed to support for any concerns that they had around their treatment. This was again lower in LMIC at only 33% (see figure 61 below).

Figure 61 Q72. Were you offered or directed to any support to help with any concerns and worries whilst being on your most recent / current treatment plan? (Patient survey)



Written information was the most common support offered with those from LMIC again most likely to be offered psychological support than those from HIC. Less than half (44%) were offered or directed towards support groups or organisations. Some patients can be on treatments for lengthy periods of time and therefore information and support are vital to help them to navigate the different types of treatment and associated side effects.

Figure 62 Q73. While on your most recent / current treatment plan what support were you offered or directed to? (Patient survey)

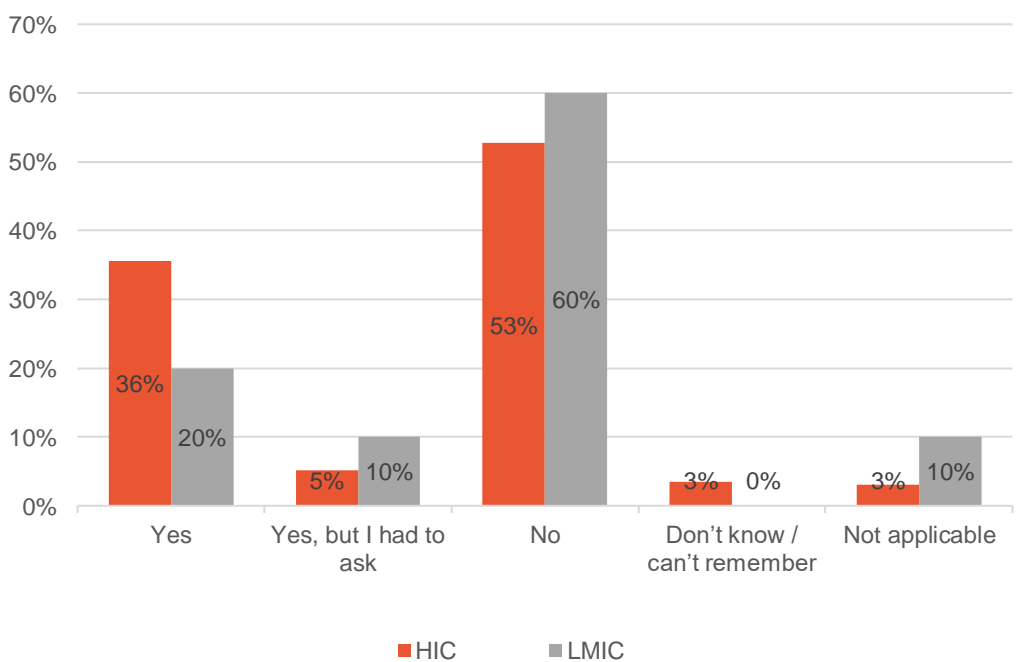
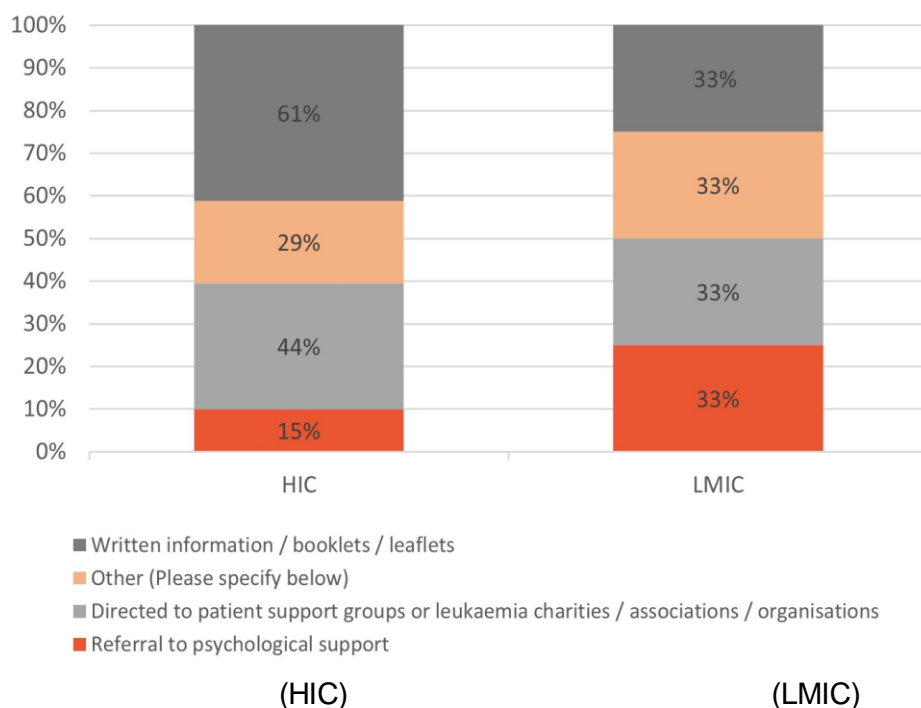


Figure 63 Q75. While on your most recent / current treatment plan what support were you offered or directed to? (Please tick all that apply) (Patient survey)



As you would expect more people report being given information at this stage, about their treatment, than at other points in their journey. This information will be important for patients and their carers about what the expectations and potential outcomes of their treatments are but also about potential side effects and how to manage these. A higher percentage of those in HIC were provided with information than those in LMIC. This is of concern, particularly in light of the fact that all patients surveyed from LMIC had been placed on a treatment regime as opposed to on active monitoring.

A higher number of patients also report being offered support at this point. More people from LMIC report that they would have liked to have received support if they had not been offered it (83%).

Where organisations providing support are concerned, we know that the vast majority of them provide written and digital information alongside patient specific support such as patient meetings, telephone support and online forums. In line with other sections of this report, information and support for patients and their carers is an important aspect of the patient journey empowering them to feel informed and confident about the trajectory of their disease.

7.7. Summary

This section again emphasises the difference in provision between HIC and LMIC.

There is a global concern around the availability, information, and utilisation of clinical trials particularly in LMIC where access appears to be lower than in other areas of the world. The use of a clinical trials directory is seen as an important tool to improve the current position, and this should be prioritised particularly in areas of greater deprivation and need.

Although information and support around treatments would seem to be more widely accessed than at other points in a patient and carers journey, the provision is still relatively low and again this is lowest in LMIC. Support organisations should work collaboratively with health care providers to ensure that patients are well informed and supported about the treatments that they are receiving.

8. Emotional impact

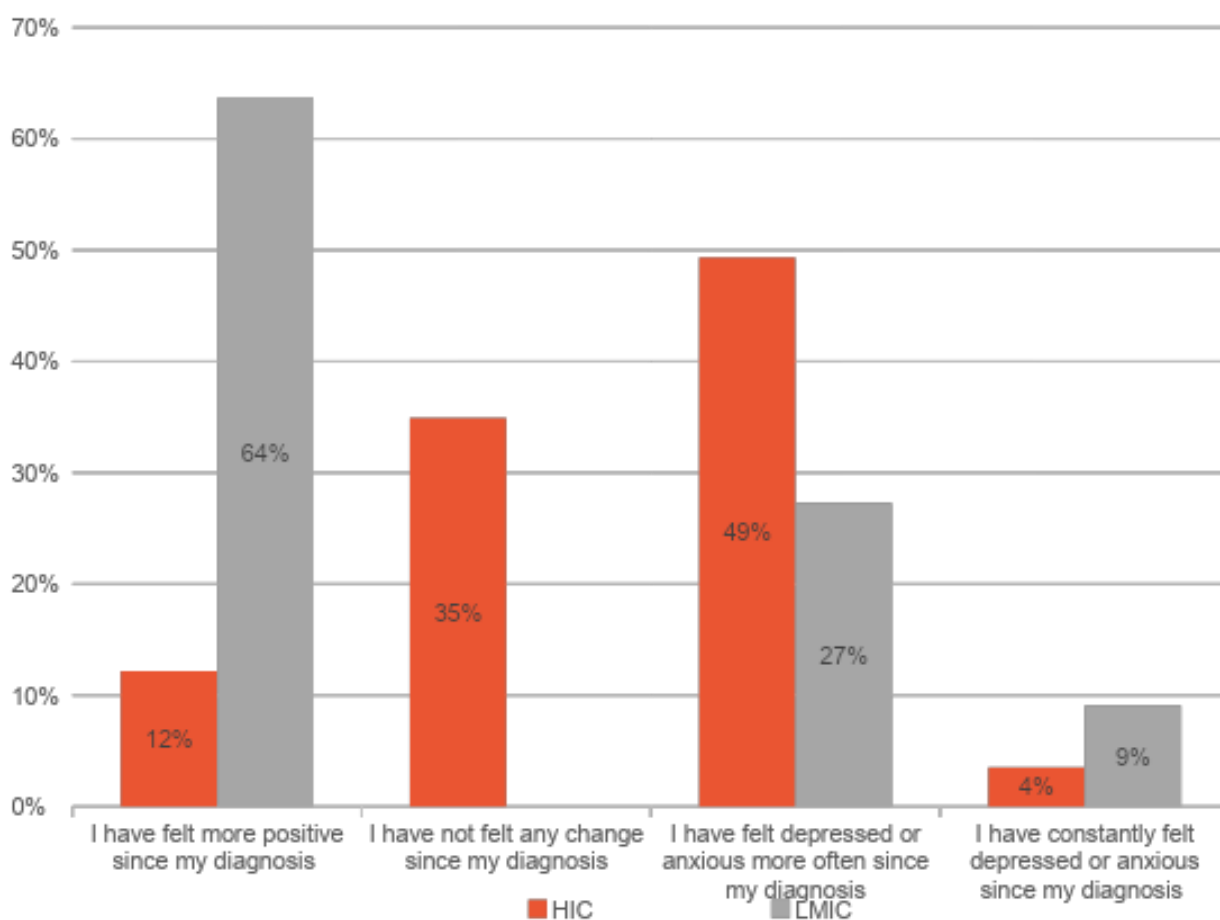
CLL, as a chronic condition that changes and progresses over the life course, will inevitably impact on the emotional wellbeing of both patients and their carers.

8.1. Mental wellbeing post diagnosis

64% of people with CLL from LMIC felt more positive since their diagnosis whereas only 12% felt this from HIC (see figure 64). This could be linked to the fact that people from LMIC are more likely to have been experiencing symptoms before their diagnosis, with the diagnosis at least providing them with an explanation for their symptoms.

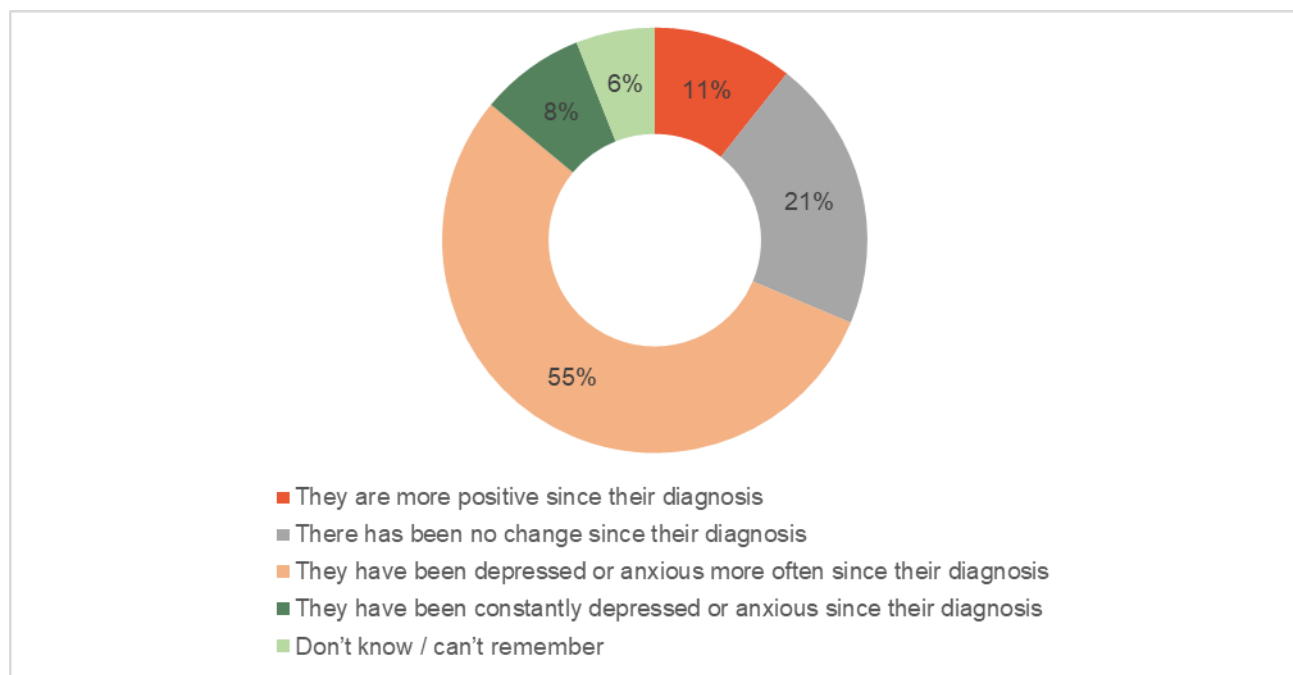
For respondents from HIC, almost half (49%) felt more depressed or anxious since diagnosis compared to 27% from LMIC.

Figure 64 Q138. Overall, how has your emotional well-being changed since your diagnosis? (Patient Experience Survey)



Only 11% of carers worldwide noted that the patient that they care for has been more positive since diagnosis whilst 63% stated that they had been more or constantly depressed/anxious (see figure 65). Around half 46% noted that their own wellbeing had been negatively affected (with a score of 7 or more out of 10) since diagnosis.

Figure 65 Q48. Overall, how do YOU think the emotional well-being of the PATIENT has changed as a result of their leukemia diagnosis? (Carer Experience Survey)



This presents a mixed picture around the emotional impact of CLL on patients and their carers. 64% of LMIC patients felt more positive after receiving a diagnosis and understanding their condition, an understanding of what was wrong with them could be beneficial to their mental state, particularly as they were more likely to have been experiencing symptoms at the point they were diagnosed and more likely to start treatment earlier.

The low level of positivity reported at diagnosis by those from HIC could be linked to the fact that they had no symptoms and were diagnosed through routine tests or had minor symptoms that they had not considered to be a form of cancer. This would link with the finding that the majority of people were not expecting a leukemia diagnosis. This could also be linked to the finding that the majority of patients spend long amounts of time on 'Watch and Wait' monitoring and the anxiety already reported surrounding this.

Although it may be a relief to have a diagnosis, anxiety around the progression of the disease and the impact on their daily life could be detrimental to their mental health and that of their carer. The high level of decline in mental health from the majority of patients and the impact on carers could also be linked to the amount of time that they have lived with the condition.

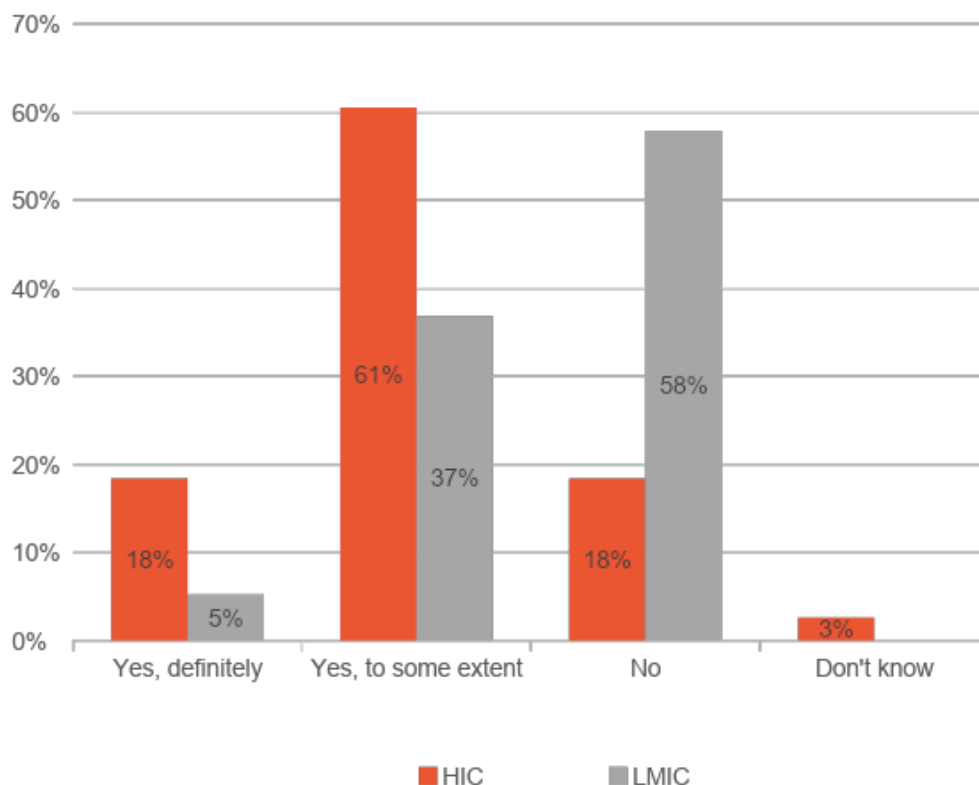
Lastly, those offered help and support at the point of diagnosis were less likely to feel more anxious and depressed (43% felt more depressed as opposed to 52% of those not offered support). They were also more likely to feel more positive (17% as opposed to 10%).

Information and support for their CLL across their life course and more specifically in relation to their mental health could help to alleviate these issues.

8.2. Support and information

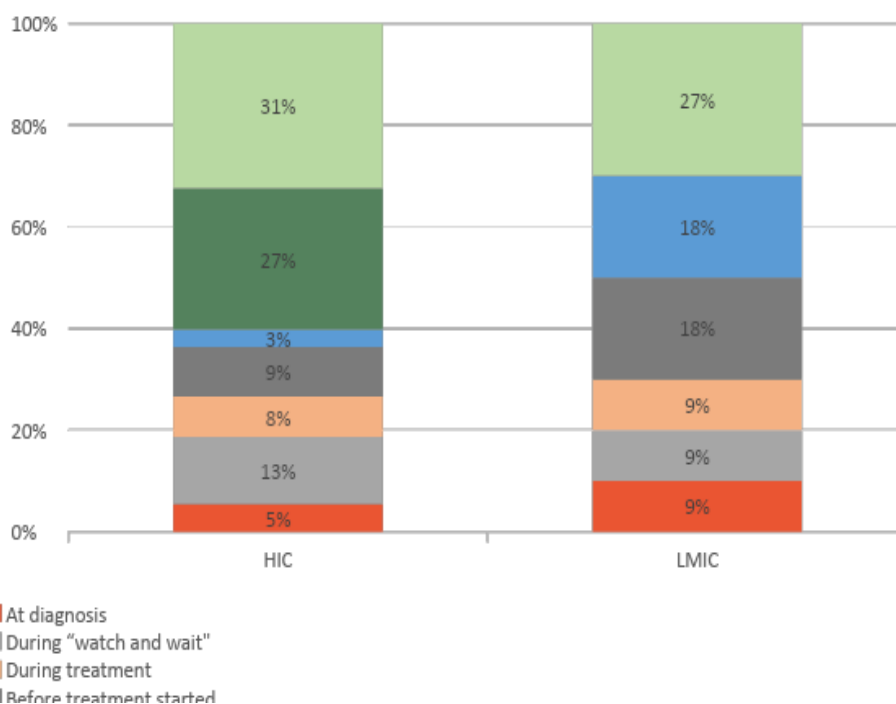
The patient and carer survey results would seem to suggest that mental wellbeing is of concern for people with CLL. 67% of the advocacy and support organisations surveyed globally report that patients can access healthcare support for their mental health needs as a result of their CLL. Again, there are clear differences here with only 42% in LMIC feeling that there is support versus 79% in HIC (see figure 66).

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)



When asked about information on mental wellbeing, 31% in HIC and 27% in LMIC felt that this was not applicable to them. In keeping with other findings from this report, patients from LMIC were most likely to be given information just before treatment started, and in HIC this was most likely during 'Watch and Wait'. 27% in HIC reported that they hadn't been given information at any stage of their patient journey (see figure 67).

Figure 67 Q159. Please select when you were given or directed to information during your treatment journey. Mental wellbeing (Patient Experience Survey)



8.3. Treatment by Healthcare professionals

Both carers and those living with CLL were asked about how well they felt that the emotional impact had been managed by healthcare practitioners. They were asked to rate their care from 0-10 (with 0 being very dissatisfied through to 10 and very satisfied). For patients, 48% of respondents rated the management of the emotional impact as 7 or above. However, those from LMIC were less satisfied overall. From the carers that responded here, 34% rated the management of emotional impact as 4/5/6 out of 10 and a further 38% rating it 8/9/10.

8.4. Summary

Clearly this section identifies that emotional wellbeing is important to both patients and their carers. 2/3 of advocacy and support organisations felt that patients were able to access the appropriate care that they needed and care from their healthcare professionals was generally felt to be well managed. Information and support that includes help around emotional wellbeing when diagnosed, particularly where there was no prior warning or symptoms and as the disease progresses could help to alleviate potential trigger points around mental distress.

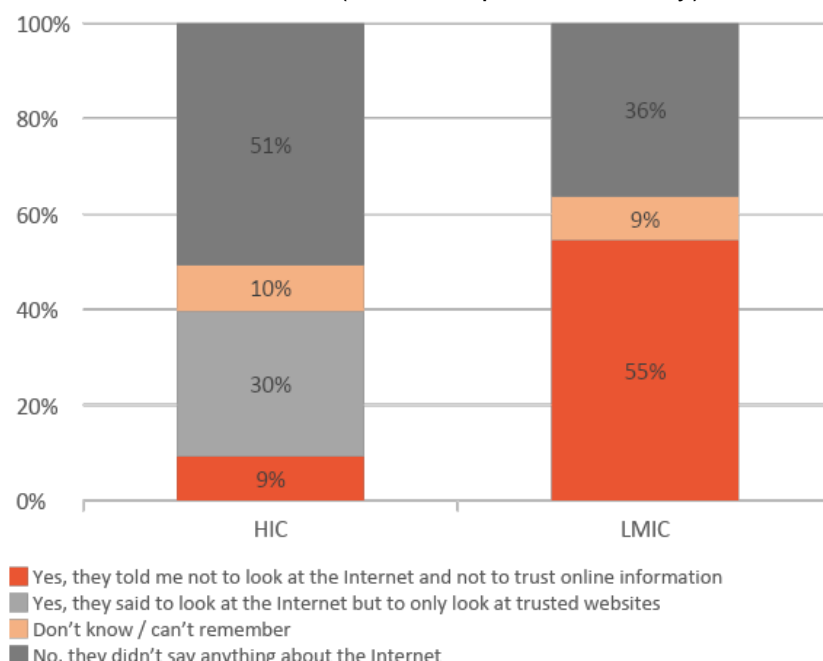
9. Information and support

Information and support have been discussed throughout this report at the appropriate points in the patients CLL journey. This section specifically includes online and other additional sources of support for patients and their carers.

9.1. Online support and resources

Respondents to the patient survey were asked to comment about whether any healthcare professionals had referenced online resources to them. 51% of respondents from HIC and 36% of respondents from LMIC stated that this had not been raised by their healthcare practitioners, although 30% of healthcare professionals in HIC had told them to only look at trusted websites. 55% of respondents from LMIC stated that they had been told not to trust information found online (see figure 68).

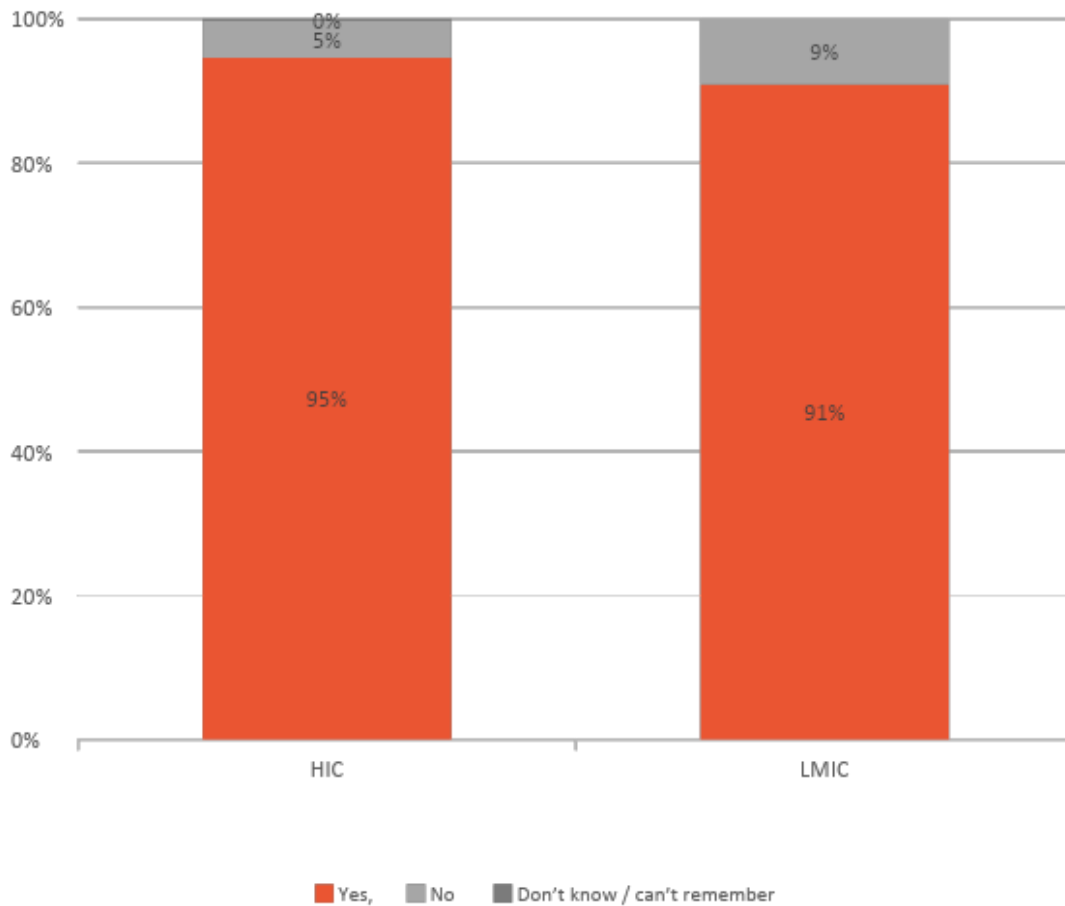
Figure 68 Q164. At any point in your diagnosis or treatment journey has a healthcare professional made reference to online information or the internet? (Patient Experience Survey)



This is worrying as patients in LMIC are less likely to be provided or access sources of information and support. As there are many reliable digital resources, including those developed by healthcare and support organisations specifically aimed at leukemia as we have seen throughout this report this finding is perhaps a little surprising. The promotion of some of these resources globally to organisations and healthcare providers could help to alleviate concerns around internet information.

In reality, over 90% of respondents in both LMIC and HIC had utilised the internet to find information on their disease and/or their treatments (see figure 69) so it seems to be a well-used and important resource that could be maximised to enhance the information and support that is available for patients and carers.

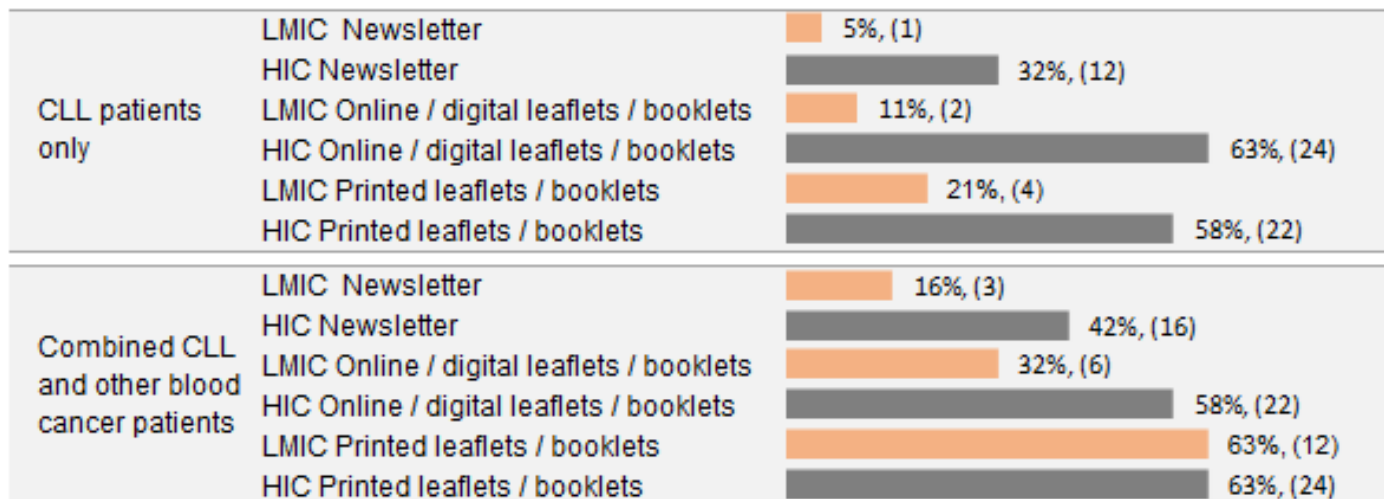
Figure 69 Q165. Have you ever used the internet to find information regarding your leukemia and / or treatment? (Patient Experience Survey)



For those that had accessed online information, information from support groups was rated most highly with 86% rating this as good or very good. Almost half (46%) answered not applicable to online information provided by their healthcare team suggesting here that this was not a resource popular with healthcare staff and would underline the finding referenced above.

Online support, in the form of information resources or online groups, is provided by advocacy and support organisations across the world and engagement from patients would suggest that these are a popular form of information and support (see figure 70).

Figure 70 What written information has your organisation developed for patients? (CLL Patient Advocacy and Support survey)



Further development of these, particularly those that could be shared more globally, could make a real difference to patients.

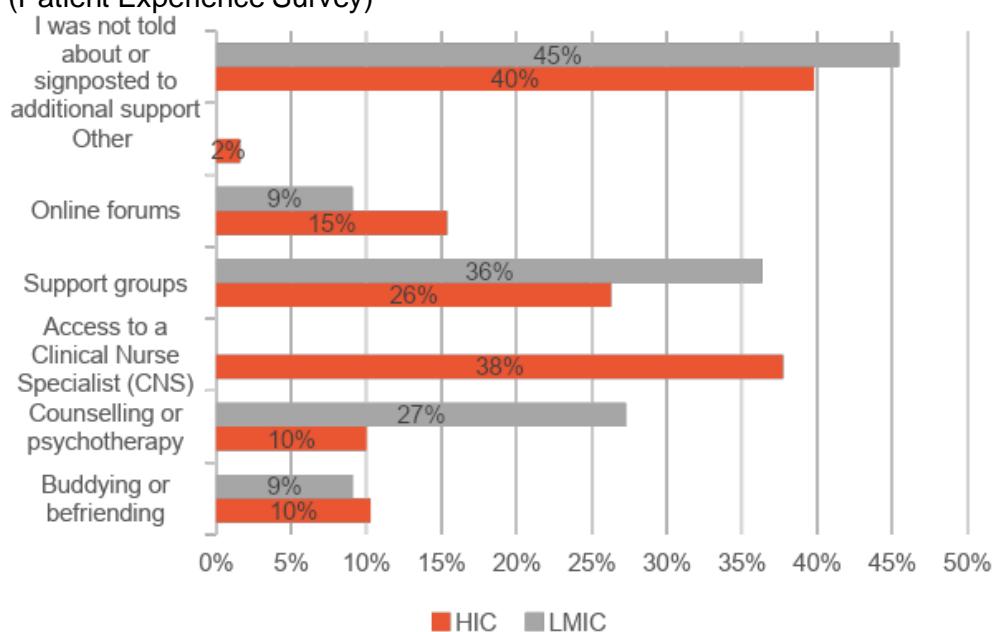
9.2. Additional support and resources

Additional support

With regard to additional support for patients, 40% of people with CLL from HIC and 45% of people with CLL from LMIC noted that they were not told or signposted to any additional support (see figure 71).

26% of people with CLL from HIC and 36% of people with CLL from LMIC were signposted to support groups. For those in HIC, 38% had been signposted to a specialist nurse, a service that – as per the survey responses – was not available in LMIC. 27% of those from LMIC were signposted to counselling or psychotherapy with a much lower figure of 10% for HIC.

Figure 71 Q170. Were you told about, or signposted to additional support in any of the following areas? (Patient Experience Survey)



Almost all (95%) that accessed additional support stated that it had helped them at least to some extent. The information from patients and carers, the fact that they report that they would like to be provided with information and support and the fact that it is rated highly by those that are able to access it all suggest that

more information and support should be provided to patients and carers to access if they wish to. It is not clear from these surveys whether healthcare providers are not aware of organisations or for example if referral mechanisms are not routinely practised as part of healthcare appointments. The provision of additional information and support would allow patients and their carers to feel empowered, more engaged, and less anxious about CLL and the progression of the disease.

10. Summary and recommended actions

10.1. Overall Summary

This comparison suggests a differing patient and disease profile for CLL patients/carers between HIC and LMIC. The services offered by organisations also differ and would tend to support the information from patients even though the numbers from countries classed as LMIC is very low. By highlighting these unmet needs and gaps in provision, this will help CLLAN (and the wider healthcare and support providers) to strategically target the development of aspects of current services that are most beneficial to patients and their carers.

Patients/carers in LMIC are more likely to:

- be younger
- have caring responsibilities for dependents
- be working full time
- have symptoms when diagnosed

than those living in HIC. This clearly impacts on patient outcomes and the burden on their carers. Patients in LMIC that responded to this survey were also less likely to be placed on 'Watch and Wait', access different treatments and are less likely to be able to participate in clinical trials.

Support organisations in LMIC overwhelmingly provide patient-oriented services but are less likely to be working on education and policy activities. By bolstering patient-oriented services in areas where this may be lacking and by working with organisations and healthcare providers collaboratively to develop education and policy activities will help to reduce the current disparity in provision.

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. Patients that are provided access to information on the whole do find this understandable and beneficial, however more should be done to improve information that they can access. In particular patients and carers report utilising the internet to identify information and support around CLL, although particularly in LMIC they are often discouraged from doing so. They found this very useful and in particular rated websites that had been recommended by support organisations more highly than those from other sources.

Patients are more likely to be provided with information than referred to or provided resources around support services that they can access. Patients that weren't provided with information about this would have liked it and those that did access these found this of benefit. The vast majority of support and advocacy organisations across the world that were surveyed identified that they provided patient specific support services and the few that didn't highlight that they would like to do so. They also identified that they felt that these services were provided at a high level. Organisations in LMIC were less likely to provide CLL specific resources, information and support than those in HIC. Information and support is vital to help patients and carers navigate a CLL diagnosis and the progression of the disease.

Developing, publishing and sharing information and support resources specifically aimed at CLL patients more widely and working in collaboration with healthcare providers will enhance the information and support that patients and carers can access and by making these available more openly across the world will reduce the current geographical deficit. This is important at key points for patients such as diagnosis, 'Watch and Wait', treatment and as the disease progresses and they reach the end of their lives.

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.

10.2. Recommended Actions

To best support patients and carers, CLLAN should consider the actions recommended below. These link with the recommended actions in the CLLAN Patient Advocacy and Support survey Report: “Resource Mapping and Unmet Needs Survey: Service Provision and Impact of COVID-19.” The most important factor in managing the current gaps in service and unmet needs is to promote and foster engagement between network organisations and local healthcare providers, researchers and pharmaceutical companies.

Diagnosis

There is a different patient and carer profile that can be seen across the globe. This could impact, particularly in LMIC, on the ability of patients and carers to cope mentally, physically, financially and with their other work and caring responsibilities. Patients in HIC were more likely to live alone, impacting on their ability to cope particularly as the condition progresses.

ACTION: Raise CLL awareness through education and awareness campaigns provided to the general public and to healthcare professionals in particular to help increase knowledge of the condition. Shared resources between CLLAN organisations could improve this globally.

ACTION: Organisations in LMIC are less likely to be involved in education and policy, provide support to enable these organisations to expand their remit through pooling resources or providing best practice support from more developed network organisations.

ACTION: Use the global resource directory to support organisations to share best practice and encourage collaborations between organisations and engagement with local healthcare professionals.

ACTION: Work collaboratively with healthcare professionals to increase their knowledge of local and wider support organisations and promote the use of information and other support resources as well as the benefits of referral for support for patients.

ACTION: Develop resources that support patients (and their carers) that are specific to issues within geographic locations for example those diagnosed younger or those that reside alone and therefore may need additional financial and physical support.

ACTION: Raise awareness and engage and empower primary care practitioners with education campaigns and shared resources to help to reduce late diagnosis where possible.

ACTION: Continue to produce global, targeted public awareness campaigns around CLL and its signs & symptoms.

Treatment

Treatments differ across the world and there is a lack of consistent access to treatments including clinical trials. Although information and support seem to be more accessible at the point of treatment, this still seems to be inconsistent, and more could be done to support patients at this point. ‘Watch and wait’ is a well-used tool for the management of CLL patients, particularly in HIC but many patients and carers would benefit from more information and support at this point of their experience.

ACTION: Work with healthcare professionals and organisations to access mapping of the current clinical trial and treatment landscape, and local clinical trials directories. Ensure that this is shared and promoted in LMIC and through advocacy to promote equitable access for all patients worldwide.

ACTION: There are clearly barriers to the access of clinical trials, knowledge of clinical trials and engagement with advocacy and support organisations around clinical trials. Highlight this issue and identify avenues such as national and international platforms where these barriers could be explored.

ACTION: Local organisations and advocates should engage local clinical trial stakeholders, researchers and healthcare professionals to take steps to encourage the initiation of trials in areas where these are lacking or where there are diverse needs.

ACTION: CLLAN should use an international platform to encourage collaboration between support, healthcare, research and pharmaceutical companies to increase access and use of treatments and promote further funding opportunities for organisations.

ACTION: Disseminate learning from conferences, research and other education opportunities to wider organisations, providing a central knowledge pool that organisations and healthcare professionals can access. This could be done through the use of the current newsletter, conference summaries, the promotion of webinars etc.

ACTION: Work collaboratively with healthcare professionals and organisations to raise awareness of treatment access disparities and explore alternative ways for patients, particularly those in LMIC, to access appropriate treatments and care.

ACTION: Share resources globally and work to promote the needs of patients for information and support at the point of treatment and at 'Watch and Wait'.

ACTION: Engage collaboratively with healthcare providers to enhance those that are offered information and support at the point of 'Watch and Wait' to help patients and carers manage this aspect of their care and how their disease may progress.

Mental Health

Mental wellbeing with chronic conditions, particularly where the condition progresses and changes as time goes on is likely to deteriorate and the findings here suggest that mental wellbeing is a real concern around those diagnosed with CLL. Mental health support would be beneficial both at diagnosis, particularly for patients from HIC where diagnosis is often unexpected and for everyone as the disease progresses. The ongoing challenge that CLL can create for patients and their carers is likely exacerbated by a lack of comprehensive information and support across the life course of the disease.

ACTION: Coordinate and advertise shared and local resources that patients and organisations can access around mental health support for patients, but also around specific CLL support for patients and carers.

ACTION: Promote the use of patient meetings, peer support and other support schemes both online and in person where patients can gain vital support.

ACTION: Engage with healthcare professionals to promote the need for enhanced wellbeing and mental health support for patients with CLL, at all points in their life course but particularly at 'Watch and Wait' and at monitoring appointments where the patients have lived with CLL for a long time.

Online and digital resources

The widespread use of technology and the way that people utilise the internet and other digital media mean that this is a vital resource for support organisations and healthcare providers. The development of websites, apps and other resources that can be accessed through technology is important for patients & carers.

ACTION: Support organisations and healthcare providers to utilise digital media, explore existing apps and share resources and access to these with organisations across the globe where possible.

ACTION: Work collaboratively to roll out the use of apps across organisations globally.

ACTION: Where possible encourage and promote the use of verified digital resources to patients and carers.