



**CLL patients and carers:
*Unmet Needs in Healthcare and Support***

--- Comparison Survey ---

EXECUTIVE SUMMARY

Background

[CLL Advocates Network \(CLLAN\)](#), a patient-led non-profit foundation for self-sustained patient advocacy initiatives, aims to improve CLL patient outcomes and enhance care for persons with CLL across the globe. As part of this mission, CLLAN are interested to explore the experience and needs of patients and carers and if and how those needs are currently being met.

This document is the short version ('Executive Summary') of the full report which aims to provide a comparison analysis of the findings from three separate recent surveys, conducted in 2021 and 2022 of individuals with CLL and their carers about their experiences, and with patient organisations from across the globe about CLL resources provided and unmet needs.

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. These surveys were conducted during the worldwide COVID-19 pandemic so the responses given by respondents, and therefore the findings here will have been influenced by the effects of the pandemic. The Global CLL resource mapping & unmet needs survey was conducted in 2021, with fieldwork closing in August 2021.

This Executive Summary provides a snapshot of the comparison analysis of the 2021 Global CLL resource mapping and unmet needs survey, the 2021/22 Leukemia Patient Experience survey, and the 2022 Leukemia Carer Experience survey. For the latter two surveys, the full report concentrates on data relating to CLL patients only (a subset of the wider data across different leukemia types).

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: 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.

57 support organisations responded to the CLL Patient Advocacy and Support survey ('Global CLL resource mapping & unmet needs survey'), covering 40 countries. The Leukemia Patient Experience Survey received 1202 responses from those identifying that they have CLL across 30 countries. For the Leukemia Carer Experience Survey, 137 responses were provided from 14 countries.

For both the Leukemia Patient Experience Survey and the CLL Patient Advocacy and Support survey, 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](#). As can be seen from the response data, the vast majority of patients responding to the Leukemia Patient Experience Survey were from HICs. 63% of respondents were from the UK and a further 8% from the USA (total of 75% from these two areas alone). The respondents to the Leukemia Carer Experience Survey are again mostly from the UK and the USA (60% and 11%). The CLL Patient Advocacy and Support survey respondents were split with around 2/3 of organisations being from HIC and the further 1/3 from countries classed as LMIC.

Comparison of reports

A review was completed of the results of the three different surveys; this identified areas of comparison that matched the objectives of this report. The results of the areas from the three surveys were then described, analysed and interpreted to meet the aims of the report and provide potential recommended actions.

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 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.

Overall summary

This comparison suggests a differing patient and disease profile for persons with CLL/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.

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.

The majority of support and advocacy organisations across the world that were surveyed identified that they provided patient specific support services, and 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.

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.

Recommended Actions

The recommended actions 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.

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.

Mental health

The findings 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.

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. Although not subject of this research, there may be marked differences in the access to technology and digital resources between HIC and LMIC.