Resource Mapping and Unmet Needs Survey: *Service Provision and Impact of COVID-19*

EXECUTIVE SUMMARY

In 2021, CLL Advocates Network (CLLAN) commissioned Quality Health (now part of IQVIA), to deliver a global survey of organisations that support individuals with chronic lymphocytic leukemia (CLL). CLLAN has used the findings to formulate a strategic plan to help inform CLL Advocates Network prioritise activities to tackle identified unmet needs. This survey was originally conducted in 2021, with fieldwork closing in August of that year.

The main objective was to analyse the services and support offered to patients worldwide by CLL organisations and to explore services offered by both organisations that were members of CLLAN (Member Organisation = MO) as well as those that currently weren't (Non-Member Organisation = NMO). The survey and the report focus on three main areas:

- Provision of support services for persons with CLL
- Access to CLL healthcare prior to the COVID-19 pandemic
- Impact of COVID-19 on access to support and delivery of CLL treatment and care

Respondents were targeted through CLLAN's membership. In addition, a scoping exercise was carried out to identify additional organisations that support individuals with CLL, but who were not members. The final number of responses was 57, covering 40 countries. From most countries (70%) there was a response from 1 organisation only. 54% of the organisations taking part in this survey were members of CLLAN, with the remaining 46% being non-members.

Overall, this survey has demonstrated the high level of interest and engagement in networked activities for both current members of CLLAN and non-member organisations. It has also highlighted the breadth of services that organisations are offering to patients and the promotion and education around CLL more widely.

Through this survey, gaps in service provision have been identified, and it has been described how this differs across organisations and between different countries.

Countries were segmented into low-and-middle-income countries (LMIC) and high-income countries (HIC). 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 (OECD). There is a deficit in services particularly for patients in low-and-middle-income countries (LMIC) versus high-income countries (HIC). Through insights obtained from the responses to this survey, CLLAN has already built the first global directory of CLL support resources in a shared central database open to the international CLL community.

The report contains certain key recommendations that encompass the need for CLLAN and its member organisations to continue to work in collaboration with healthcare, research, and policy makers across the globe to improve the outcomes for all persons with CLL regardless of their location and socioeconomic status.

It is also clear from these findings that the COVID-19 pandemic has been a real challenge and that organisations, patients and healthcare providers have worked hard to minimise its impact.

Data from the survey can help inform recommendations from behavioural practices, priority service provision needs, and good practice employed by respondents with service provision to enable best support of needs of individuals with CLL who are all immunocompromised. Thus, the COVID-19 pandemic poses ongoing challenges to those with CLL and their carers – a need that CLLAN can and should respond to.

Provision of support services for CLL by organisations

The services provided by most organisations to individuals with CLL are

- patient meetings,
- awareness campaigns,
- support helpline, and
- educational events.

However, provision was not uniform with NMOs and organisations in LMICs being less likely to provide most services but most notably non-patient specific services, such as those aimed at education and policy making. Of the services that organisations would like to provide but that are not yet offered, 42% chose “clinical trials directory”. Initial steps to build or adapt such a directory have been taken by CLLAN.

When asked why the services they would like to offer were not provided to those with CLL, both MOs and NMOs reported that lack of human resources/staff/volunteers, financial resources and time were the main reasons. In LMICs, it was not only the lack of financial resources available to organisations for providing services and support that is noticeable, but also the lack of skills and knowledge available.

A larger proportion of MOs have developed written information for all the different groups. Printed materials targeting patients were more likely to be provided than digitally hosted materials. Across the majority of categories, organisations in HIC tended to have the higher uptake of digital media which may well reflect access to technology and online resources.

Across the globe there were clearly a wide range of CLL-specific, innovative support services being developed and utilised by organisations and the wider research and healthcare communities. Improved collaboration and communication between all those involved in CLL will improve outcomes for all patients regardless of their geographical location. CLLAN can help support, promote, and facilitate these.

When asked what their organisations did well,

- Advocacy,
- Communication,
- Education, and
- Support for patients, families, or carers

were the themes that were reported most frequently. Organisations in LMICs were more likely to be involved in patient specific support than wider services.

The three key reasons that helped organisations to do well were (i) grants/ donations/sponsorships from pharmaceutical and non-pharmaceutical partners, (ii) volunteers, and (iii) learning and insight from conferences. Access to financial support, funding, and the financial sustainability of organisations seems to remain a key challenge.

The top resources organisations reported they would be likely to use are best practice sharing, regular updates via newsletter *"CLL Matters"* and regular updates via social media. The differences between HICs and LMICs were pronounced. Although best practice sharing was the most popular idea, there would be a high demand in LMICs for all resources if they were available.

Access to CLL healthcare prior to the COVID-19 pandemic

Even before the pandemic, there were widespread differences for those with CLL to access treatments and care in their countries, with LMICs clearly facing more challenges. Prohibitive treatment costs not covered by national healthcare systems, unaffordable medical insurance, travelling costs to and from treatment centres were the main issues reported by the participants. Another problem patients faced in LMICs was the lack of access to CLL specialists and centres of excellence.

46% of all organisations reported that their patients could not access clinical trials. The discrepancy between HICs and LMICs is wide with 84% of organisations in LMICs confirming their patients could not access clinical trials versus 26% of organisations in HICs. Another problem was the lack of access to new therapies. This rises to 58% of organisations in LMICs. One of the reasons reported was the length of time it takes to approve new drugs by their national healthcare systems, with the cost of the CLL drugs being the main reason for delays or for not being approved at all. These findings hint to a strong need for policy advocacy, especially in LMICs.

58% of organisations stated that individuals with CLL experienced delays in being diagnosed with the condition to at least some extent. In LMICs all the organisations reported that persons with CLL experience delays or delays to some extent in receiving a CLL diagnosis. One of the reasons was the reported lack of knowledge primary care providers have of CLL. 46% of the organisations reported that General Practitioners, generally the first point of contact for a patient, were not knowledgeable or well informed about CLL and the symptoms associated with it.

32% of the organisations worldwide reported a lack of support for those with CLL who experienced mental health issues because of their diagnosis or treatment. This was more pronounced in LMICs where 58% stated that individuals with CLL receive no support to help with their mental health.

Impact of the COVID-19 pandemic

The research clearly illustrates the significant impact that the COVID-19 pandemic had on the delivery of CLL healthcare, support services and funding for blood cancer (and other cancer) organisations globally.

We need to acknowledge that organisations have worked hard to meet the challenges presented through the pandemic, evolving services in different and innovative ways. This survey has revealed the need for broader collaboration to address the ongoing needs in terms of safety measures to help immunocompromised patients to navigate the pandemic and more widely potential future similar events. Since this survey was conducted, collaborative initiatives such as the International COVID-19 Blood Cancer Coalition (ICBCC, led by CLLAN) have emerged and are being carried forward and adjusted to fit the current landscape. The COVID-19 pandemic is not over for immunocompromised persons such as those with CLL.

LMICs reported those that have CLL had a more challenging time with more treatment delayed (58% vs 38% in HIC), in person appointments cancelled by healthcare providers (68% vs 58% in HIC) and fewer remote appointments (44% vs 74% in HIC). It’s important to note that the cancellations derived from both patients and providers, with 67% of organisations stating that patients had postponed or cancelled their routine appointments This highlights the current and ongoing concern that immunocompromised individuals such as those with CLL had about their safety across the pandemic and beyond.

64% of organisations reported that those with CLL had remote routine appointments. This was more likely to happen in organisations from HICs although interestingly 23% of NMO's didn't know if this was happening or not. There was a significant drop off in recruitment into clinical trials. 24% of organisations reported that recruitment into CLL trials had stopped, however more pronounced was that 63% did not know what the status was and again this was more pronounced across LMICs (82%).

53% of organisations had to stop or reduce some of the support / services they provide to individuals with CLL because of the COVID-19 pandemic. Most organisations stated that they stopped face-to-face / in person events and converted to virtual support. Organisations spoke about holding patient meetings, support groups, conferences and events virtually, they also organised webinars and communicated with patients through social media. Lockdown restrictions were the highest reason reported as a barrier to service provision, followed by reduced income and lack of volunteers across the board.

39% of organisations reported that persons with CLL already engaged with them made more contact during the COVID-19 pandemic. However, this was reported most within MOs and organisations in HICs.

There was also a significant impact on access to funding, with 67% of respondents reporting a negative impact; LMICs have faced the biggest shortfall (81%). The two main areas of downturn were a reduction in grants, sponsorship, and funding from 'major donors' and the cancellation of large fundraising events. A slightly higher proportion of NMOs and organisations in LMICs said they had found new ways to source income, the majority doing this by 'going virtual' and either having new fundraising events online or moving existing ones to a virtual platform. There was also a theme of encouraging fundraising on a smaller/local scale. This demonstrates how quickly and effectively some organisations have adapted to the change in circumstances, but also highlights the need for capacity building and eventual central intervention from CLLAN in ascertaining funding streams.

Key learnings and next steps

The findings have highlighted both the depth and breadth of support services across the globe, alongside deficits in the current picture and in particular the geographical disparity in both healthcare, support services and also in relation to the response to the pandemic.

From the interim findings, CLLAN has already started to act to improve the outcomes for patients across the globe and it is hoped that this more detailed report will aid in shaping the CLL landscape for patients and their carers. As with many aspects of healthcare, a collaborative approach that encompasses the perspective of patients and carers alongside the work of researchers, support organisations, healthcare providers, pharmaceutical companies and wider policy makers will be the most progressive route to make lasting changes.

There are many benefits to being part of CLLAN and opportunities for membership should be discussed with non-member organisations identified through this research that have indicated their interest.

Funding and staffing have been highlighted by organisations as being key barriers to the development of their services. CLLAN should consider prioritising some of the actions in these areas such as support for organisations in identifying and compiling successful funding bids and utilising well developed, established member organisations to help to upskill others.

The COVID-19 pandemic is an ongoing concern for those with CLL and their carers, and the potential for new pandemics or other similar disruptions is an important consideration. CLLAN should also prioritise supporting organisations to produce continuity or succession plans to minimise the detrimental effects on patients and promote more remote access to services that will be of wider benefit than just those affected by the pandemic.

Comparing the findings from this research with ongoing and planned activities and work streams of CLLAN three areas stand out where additional strategic work and decisions are needed:

1. There was a marked difference in the preparedness, capacities and capabilities of organisations operating in HICs and LMICs, which requires continued and dedicated attention and specific considerations from CLLAN.
2. Stronger policy advocacy with clear focus on access to knowledge, diagnostics, treatment, and clinical trials.
3. The mapping and systematic development of funding streams and opportunities so that available funding is distributed more equally and equitably across patient groups globally.