



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



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1. Executive Summary

1.1. Background and Key Objectives

Background

The CLL Advocates Network (CLLAN) serves patient organisations and key patient thought leaders around the world. As a global network CLLAN's mission is to improve chronic lymphocytic leukemia (CLL) patient outcomes and enhance CLL patient care for all.

In 2021, CLLAN commissioned Quality Health (now part of IQVIA), to deliver a global survey of organisations that support CLL patients. CLLAN has used the findings to formulate a strategic plan to help CLLAN prioritise activities to address identified unmet needs.

Objectives

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 as well as non-members.

Objectives fall into three main topical areas:

Provision of Support Services for CLL

- Explore the services delivered by organisations worldwide to CLL patients and the challenges organisations experience in delivering these services.
- Investigate the forms of communication used between organisations and CLL patients, suggest efficient ways for organisations to increase CLL awareness.
- Look at the services that organisations deliver successfully and consider best practice.
- Explore what specific resources organisations would use if CLLAN provided them.

Access to CLL Healthcare prior to the COVID-19 Pandemic

- Investigate how accessible new therapies and clinical trials are to CLL patients.
- Explore the access to treatment and care CLL patients had before the COVID-19 pandemic and the challenges that they have faced as a result of the pandemic.
- Raise awareness of the condition among the public, healthcare professionals and promote CLL research as much as possible.

Impact of COVID-19 on Access to support and Delivery of CLL Treatment and Care

- Look into the impact COVID-19 had on organisations' abilities to deliver their services to CLL patients and how the support provision changed.
- Investigate how the level of patients' engagement with the organisations changed during the COVID-19 pandemic.

1.2. Methodology

Respondents were targeted through CLLAN's membership. In addition, a scoping exercise was carried out to identify additional organisations that support CLL patients. All non-members identified were offered the opportunity to respond to the survey.

Survey Design and Fieldwork

The questionnaire was designed and developed in seven different languages. The fieldwork ran for 12 weeks closing in August 2021.

Organisations that responded were given the opportunity to provide information in their own words alongside the multiple-choice questions; this included for example providing information about what they thought that they were doing well and what they thought the main challenges for their organisation were.

The final number of responses was 57, covering 40 countries. From most countries (70%) we had a response from 1 organisation only.

Just over half of the organisations (54%) taking part in this survey were members of CLLAN (MOs), with the remaining 46% being non-members (NMOs).

Analysis

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](#). 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 have already built the first [global directory of CLL support resources](#) in a shared central database open to the international CLL community.

1.3. Key findings and recommended actions for each area

1.3.1. Overall Summary

This provides a summary of each section of the survey and recommended actions.

Overall, this survey has demonstrated the high level of interest and engagement in networked activities for both current members of CLLAN (MOs) and non-member organisations (NMOs). 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, we have identified gaps in service provision and how this differs across organisations and between different countries across the globe. There is clearly, from the responses provided to this survey, a deficit in services particularly for patients in LMIC.

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 following recommendations 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 CLL patients regardless of their location and life situation.

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. The information gained by this survey was at a fixed point during the pandemic's early progress, with the fieldwork completed in August 2021. This data can help inform recommendations from behavioural practises, prioritise service provision needs and share good practice employed by respondents to enable best support of the needs of CLL patients globally (who are predominantly immune compromised). This can then aid planning for any future pandemics and the ongoing needs of the community in the current COVID-19 pandemic which is still restrictive for CLL patients, their families and consequently support providers.

1.3.2. Provision of services for CLL by organisations

Support services

The services provided by most organisations to CLL patients are patient meetings, followed by awareness campaigns, support helpline and educational events. However, provision was not uniform with NMOs and organisations in LMIC 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, over 2/5 chose "clinical trials directory".

Not surprisingly, NMOs and organisations in LMIC have more services that they would like to deliver compared to MOs and in HIC.

When asked why the services they would like to offer were not provided to CLL patients, both MOs and NMOs reported that lack of human resources/staff/volunteers, financial resources and time were the main reasons.

In LMIC it is 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. In these countries, services were more likely to be patient specific support such as patient meetings rather than the wider education and policy related services.

ACTION: NMOs and those in LMIC are less likely to be involved in education and policy, provide support to enable these organisations to expand their remit.

ACTION: Raise CLL awareness through education and training provided to organisations to help increase knowledge of the condition. This would improve the skills and knowledge of volunteers and the support that can be offered.

ACTION: Refine and define CLLAN membership and its benefits and then offer and support membership to CLLAN for NMOs identified through this research.

ACTION: Work with healthcare professionals and organisations to provide an up-to-date resource as part of the CLLAN website that includes all known clinical trials directories, particularly ensure that this is shared and promoted in LMIC.

ACTION: Use the global resource directory to support organisations to share best practice and encourage collaborations.

ACTION: Organisations should be supported to offer services in a variety of ways including digital, through printed materials and through face-to-face interactions.

Information developed by the organisations

The organisations reported on the forms of communication used to disseminate information across different segments of the population.

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

Organisations still have a clear ongoing need to provide CLL material and resources to patients, with the use of apps, videos and newsletters being the most mentioned tools.

Across the globe there are 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 to support, promote and facilitate these.

ACTION: Continue dissemination of written materials to support key topics using the most appropriate media based on the need, age and location of the audience.

ACTION: Collaborate with healthcare providers and organisations to develop best practice for organisations and upskill staff around information for patients.

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 with healthcare professionals to increase the knowledge of local and wider support organisations and promote the referral of patients and use of information and resources.

ACTION: Work collaboratively to encourage the development and evaluation of appropriate apps across organisations globally. This could include current apps and research and development of new ones.

Organisations' views on their own service provision

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. LMIC were less likely to highlight communication and education as part of their response. This can be linked to the finding that organisations in LMIC are more likely to be involved in patient specific support than wider services.

The three key reasons that helped organisations to do well were grants/donations/sponsorships from pharmaceutical and non-pharmaceutical partners, volunteers, learning and insight from conferences.

While the top response was financial assistance from pharmaceutical partners, the results also highlight the importance of volunteers and learning from conferences. There are also some interesting differences between MO and NMOs, with NMOs reporting less input from pharmaceutical partners and more from non-pharmaceutical financial support.

ACTION: Support NMOs and organisations within LMIC (in particular) to access funding opportunities and engage with potential sponsors and sponsorship/funding routes. This could include working with organisations across the network who could provide guidance on how they have accessed and identified funding opportunities and helping organisations collaborate with healthcare providers to generate opportunities.

ACTION: Develop and share resources/training to support staff in organisations to successfully tender for funding and to engage potential local funding opportunities themselves.

ACTION: CLLAN could use an international platform to encourage collaboration between support, healthcare, research and pharmaceutical companies to promote further funding opportunities.

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.

Support from CLLAN

Organisations were asked how likely they would be to use specific resources if CLLAN provided them.

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 MOs and NMOs were not as pronounced as between organisations in HIC and LMIC.

Although best practice sharing was the most popular idea, there would be a high demand in LMIC for all resources if they were available. This is not surprising considering the findings across this survey that LMIC are less able to provide comprehensive and specific support around CLL.

Of the organisations who replied about what topics they would like to see CLLAN cover, medical updates on CLL, CLL research and patient support were the ones mostly mentioned.

ACTION: CLLAN to coordinate and share resources through the directory to help and support member organisations to develop and maintain best practice and promote collaboration.

ACTION: CLLAN to continue producing a regular newsletter shared digitally, through social media and on paper where appropriate to increase the skills and knowledge within organisations and across healthcare professionals.

ACTION: CLLAN to promote access to conferences and cutting-edge research and clinical practice more widely through, for example, the use of online technology rather than the requirement for in person attendance at conferences and producing conference summaries for dissemination.

ACTION: CLLAN to use the findings here and collaboration with more established and developed organisations to provide a 'toolkit' for new and less developed organisations to help them to grow their organisations and the services that they can provide to patients.

ACTION: Although digital resources and support - particularly in light of the pandemic and the current global widespread use of technology - are important, resources should be accessible in a number of appropriate formats including printed materials and face-to-face interactions.

1.3.3. Access to CLL Healthcare prior to the COVID-19 Pandemic

Access to treatment and care

Even before the pandemic, there were widespread differences for CLL patients to access treatments and care in their countries, with LMIC clearly facing more challenges.

More than half of the organisations reported that one of the issues CLL patients face is the cost associated with treatments and care, and this was higher among NMOs and in LMIC. Prohibitive treatments costs not covered by national healthcare systems, unaffordable medical insurances, travelling costs to and from treatments centres were the main issues reported by the participants.

Another problem patients face in LMIC is the lack of access to CLL specialists and centres of excellence. This problem is especially noticeable in remote areas where less than 1/3 of organisations confirmed their patients have access to CLL specialists and only 3 organisations reported their patients having access to specialist care centres.

ACTION: Highlight through global education, advocacy and policy work the difficulties faced by patients identified in this research, such as travel costs, at a government/policy level and work to reduce these.

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.

Access to new therapies and clinical trials

Nearly half of all organisations reported that their patients could not access clinical trials. The discrepancy between HIC and LMIC is wide with 84% of organisations in LMIC confirming their patients are deprived of this opportunity versus just over 1/4 of organisations in HIC.

Another issue, that more than 2/5 of organisations reported, is the lack of access to new therapies. This rises to nearly 3/5 of organisations in LMIC. 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.

ACTION: There are clearly barriers to the access to 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: Raise awareness of clinical trials through the use of a shared clinical trials resource (as previously mentioned) but also through advocacy to promote equitable access for all patients worldwide.

ACTION: Genetic and subtype variation of CLL affects treatment and care for patients. Research into this is vital. Identify avenues through which research is being conducted, highlight gaps and disseminate research findings through shared resources, newsletters etc.

ACTION: Engage with the research community, healthcare providers and other stakeholders to develop clinical trials in locations where there is a current deficit.

Diagnosis

With regard to diagnosis, 58% of organisations stated that CLL patients experienced delays in being diagnosed with the condition, to at least some extent. The picture is worse in LMIC where all the organisations reported that CLL patients experience delays or delays to some extent in receiving a CLL diagnosis.

One of the reasons for this delay is the reported lack of knowledge primary care providers have of CLL. Nearly half of the organisations (46%) reported that General Practitioners, generally the first point of contact for a patient, are not knowledgeable or well informed on CLL and the symptoms associated with it.

In LMIC only 1/10 of primary care providers were able to recognise the symptoms of CLL.

ACTION: Continue to raise awareness of CLL and of the associated symptoms through media exposure.

ACTION: Raise awareness and empower primary care practitioners with education campaigns and shared resources to help to reduce late diagnosis where possible and to support and effectively manage CLL patients as their CLL progresses. Explore more innovative opportunities, such as the use of digital technology, to support primary care practitioners here.

Mental Health support

32% of organisations worldwide reported a lack of support for CLL patients who experienced mental health issues as a result of their diagnosis or treatment. Not surprisingly, this was more pronounced in LMIC where 58% stated that CLL patients receive no support to help with their mental health.

ACTION: Coordinate and advertise shared and local resources that patients and organisations can access around mental health support for patients.

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: Promote the need for mental health support for CLL through education and awareness work with primary care practitioners and the referral and signposting to appropriate support organisations.

ACTION: CLLAN to coordinate, through the development of shared resources and training, support to upskill organisations and their staff around supporting CLL patients/carers and their mental health. This may include for example supporting wider access to already published online tools and resources and enabling shared learning between member organisations.

1.3.4. Impact of 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.

This survey report is retrospective, capturing a specific point in time when COVID-19 was having the biggest impact on CLL patients, the healthcare profession and support services. 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. There remains an ongoing need for work such as that of the ICBCC to collaborate, raise awareness and take appropriate actions for communities still heavily impacted by COVID-19.

Clinical care

There were widespread disruptions to CLL clinical care with appointment delays and cancellations made, by both patients and healthcare providers. LMIC reported their CLL patients have 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 across both HIC and LMIC stating that patients had postponed or cancelled their routine appointments. This would seem to highlight the current and ongoing concern that immunocompromised CLL patients have had about their safety across the pandemic and beyond.

Organisations and practitioners adapted through the provision of more online services and the use of remote routine appointments and consultations. Just under 2/3 of organisations reported that their CLL patients were having remote routine appointments as reported above. This was more likely to happen in organisations from HIC countries although interestingly nearly 1/4 (23%) of NMO's didn't know if this was the happening or not.

There were some areas where adaptation was not feasible or was not prioritised. For example, 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 LMIC (82%).

ACTION: CLL patients are still impacted by the pandemic and continued restrictions, either as a result of those imposed through their healthcare needs and/or self-imposed so that they feel safer. CLLAN could help provide and promote resources to help organisations to better support patients through online technologies and other innovative service provision methods.

ACTION: CLLAN should work with healthcare providers across the globe to raise awareness and promote the use of online technologies where preferable to keep CLL patients feeling safe whilst still accessing necessary care. This type of technology can also help patients to maintain their access to healthcare and support where there are other concerns for them such as their location, mobility and capacity.

ACTION: Work collaboratively with other appropriate organisations to map the current clinical trials landscape to help inform the clinical trials resources as discussed, and to highlight gaps.

ACTION: Alongside promoting equitable access to clinical trials for all CLL patients worldwide as noted in the action section around new therapies, CLLAN should support efforts to minimise disruption to clinical trials such as that caused by the COVID-19 pandemic.

Patient support

Just over half of organisations had to stop or reduce some of the support / services they provide to CLL patients because of the COVID-19 pandemic (53%). The vast majority of 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. Organisations in HIC gave more examples of the ways they adapted, compared to those in LMIC.

Lockdown restrictions were the highest reason reported as a barrier to service provision, followed by reduced income and lack of volunteers across the board. In relation to the impact of lockdowns, a slightly higher proportion of MOs and organisations in HIC cited this as the dominant factor in their reduction of support, while in LMIC lack of income and volunteers was more important.

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

32% said that more CLL patients contacted them for the first time during the COVID-19 pandemic. The highest percentage of organisations who felt fewer patients were contacting them for the first time was within LMIC.

ACTION: Use the directory to share best practice via pooled resources between organisations that can be regularly updated around ways in which organisations have engaged with patients.

ACTION: Use business planning techniques to create a template to ensure that organisations can plan for continuity of services where there are risks such as the COVID-19 pandemic. This could be a shared resource that organisations can adapt as appropriate.

Funding

There was also a significant impact on access to funding, with 67% of respondents reporting a negative impact. LMIC have faced the biggest shortfall (81%).

The two main areas of downturn were a reduction in grants, sponsorship, funding from 'major donors' and the cancellation of large fundraising events. Interestingly and perhaps paradoxically, a slightly higher proportion of NMOs and organisations in LMIC 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 adapted to the change in circumstances. Shared knowledge, resources and ideas from this experience would benefit other network organisations.

ACTION: Support the development of an ongoing, updated list of funding avenues that local organisations can access and update and support the development of an income toolkit to help organisations to enhance how they access and tender for funding opportunities. More developed, larger organisations may be able to support others in this capacity.

ACTION: Use the existing national and international platforms that CLLAN is already involved with such as conferences etc to engage with potential funders and raise the importance of funding for CLL support.

ACTION: Include a section on funding and continued funding opportunities in the continuity template discussed above that can be explored, completed and updated locally by each organisation.

2. Background and Objectives

2.1. Background

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 initiatives. CLLAN serves patient organisations and key patient thought leaders around the world. As a global network CLLAN's mission is to improve chronic lymphocytic leukemia (CLL) patient outcomes and enhance CLL patient care for all.

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, to better understand the key priorities of support groups, and to understand the impact that the COVID-19 pandemic has had on these organisations and their ability to continue with service provision through what has been an incredibly challenging period. CLLAN has used the findings to formulate a strategic plan to help CLL Advocates Network prioritise activities to address identified unmet needs.

2.2. Objectives

The main objective was to analyse the services and support offered to patients worldwide by CLL organisations. We wanted to consider organisations that are both members (MOs) and non-members (NMOs) of CLLAN, located both in high income (HIC) and low-and-middle income countries (LMIC) and to consider the impact that the COVID-19 pandemic has had on these organisations and the patients that they support.

Furthermore, the survey has the objective to collect data about patient experience in order to:

Provision of Support Services for CLL

- Explore the services delivered by organisations worldwide to CLL patients and the challenges organisations experience in delivering these services.
- Investigate the forms of communication used between organisations and CLL patients, suggest efficient ways for organisations to increase CLL awareness.
- Look at the services that organisations deliver successfully and consider best practice.
- Explore what specific resources organisations would use if CLLAN provided them.

Access to CLL Healthcare prior to the COVID-19 Pandemic

- Investigate how accessible new therapies and clinical trials are to CLL patients.
- Explore the access to treatment and care CLL patients had before the COVID-19 pandemic and the challenges that they have faced as a result of the pandemic.
- Raise awareness of the condition among the public, healthcare professionals and promote CLL research as much as possible.

Impact of COVID-19 on Access and Delivery of CLL Treatment and Care

- Look into the impact COVID-19 had on organisations' abilities to deliver their services to CLL patients and how the support provision changed.
- Investigate how the level of patients' engagement with the organisations changed during the COVID-19 pandemic.

3. Methodology

3.1. Identification of Non-member organisations

Respondents were targeted through CLLAN's membership. In addition, a scoping exercise was carried out to identify additional organisations that support CLL patients. This included organisations that provide support to CLL patients as part of a broader remit of patient support. These non-member organisations were subsequently offered the opportunity to be included in the survey.

3.2. Questionnaire design and development

The questionnaire was developed and designed in early 2021, following detailed discussion between the CLLAN steering committee and IQVIA. Questions were developed around the key themes of:

- Support services that organisations provide in relation to CLL
- Resources that organisations would like CLLAN to provide
- Delivery of CLL healthcare prior to COVID
- Impact of COVID-19 on the delivery of CLL healthcare
- Impact of COVID-19 on the services organisations provide in relation to CLL
- Organisation details

3.3. Survey fieldwork

The questionnaire was hosted via IQVIA's online platform and made available in seven languages: Arabic, English, European Portuguese, French, Russian, Simplified Chinese and Spanish.

The questionnaire was agreed upon in April 2021. Following translation and set-up of the questionnaire, the survey went live on 6th May. Fieldwork closed on 2nd August 2021 (12 weeks later).

3.4. 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 which 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.

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.

4. Responses

The final number of responses was 57, covering 40 countries. From most countries (70%) we had a response from 1 organisation.

As it was of interest to consider and compare the services and support offered across the globe, the responses were broken down into those from low-and-middle-income countries (LMIC) and those from high-income countries (HIC). See table below, figure 1. 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](#).

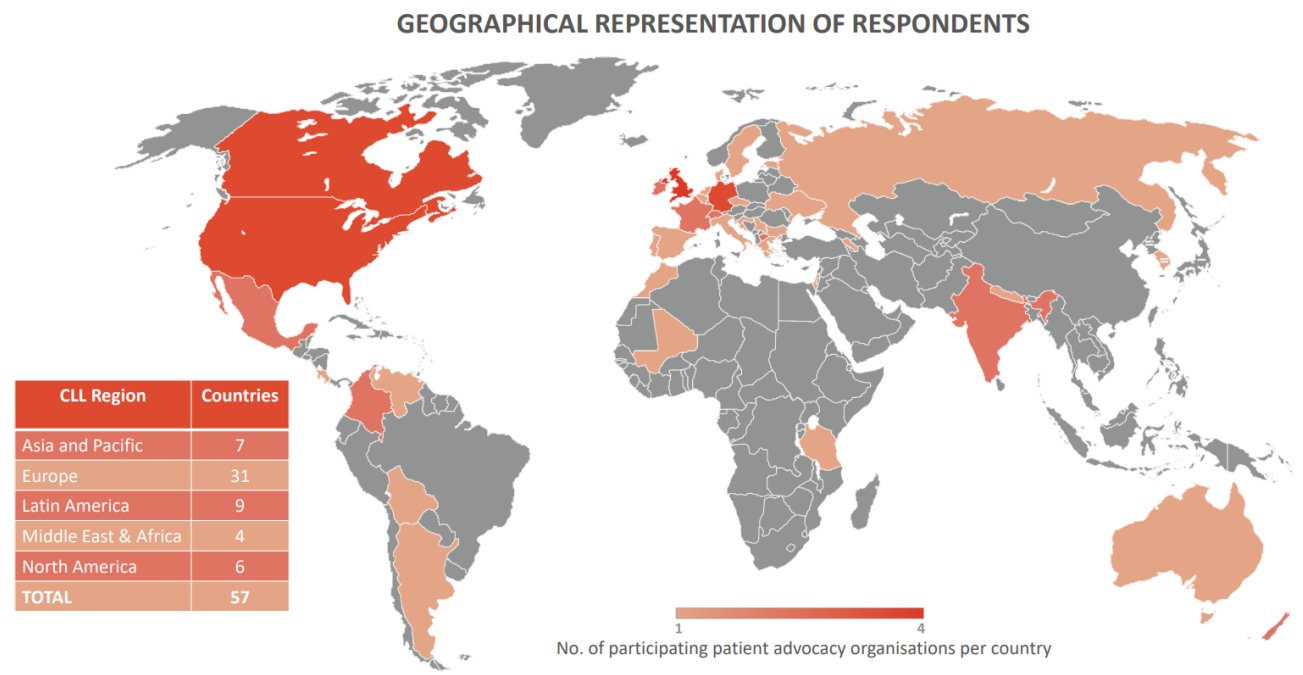
Responses were further broken down by member and non-member organisations.

There is a deficit in services particularly for patients in LMIC versus 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.

Global reach (figure 1)

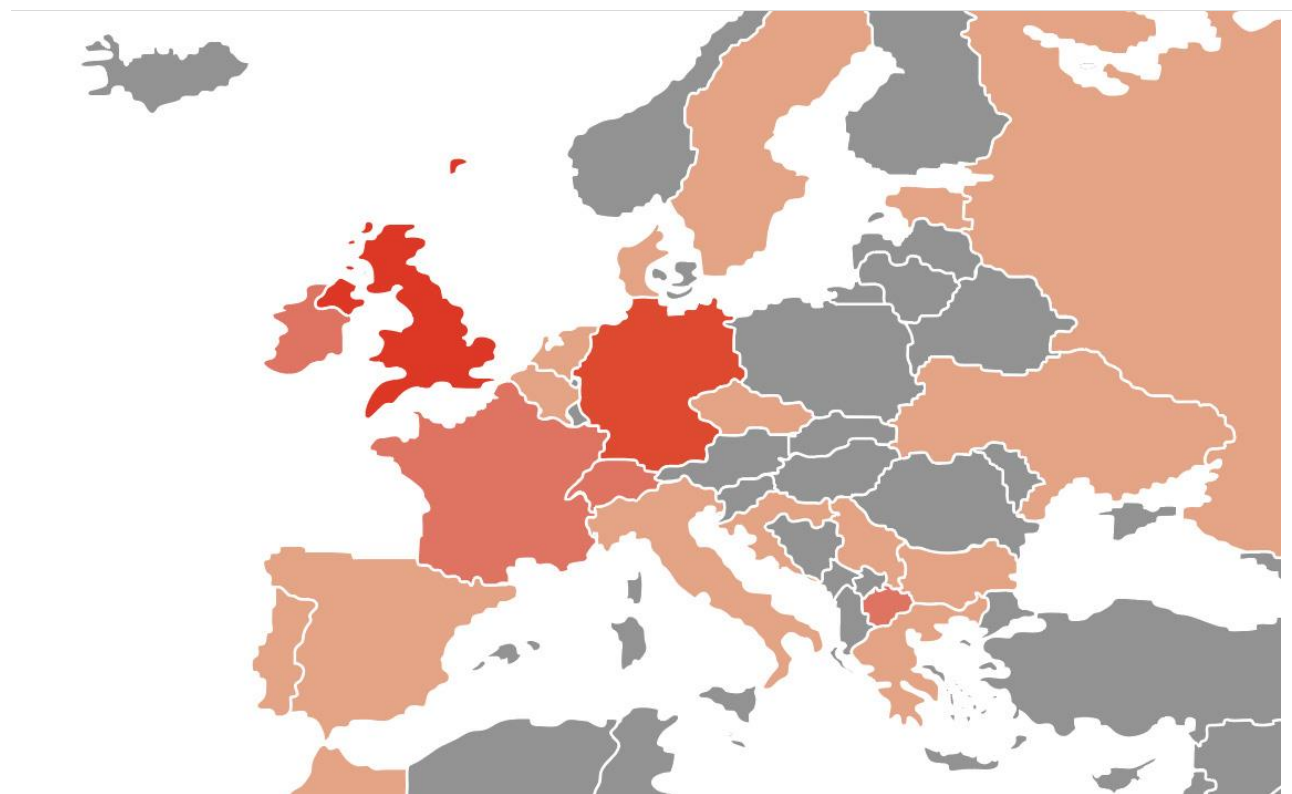
Country	No. of respondents	Country	No. of respondents
Argentina	1	Italy	1
Armenia	1	Korea	1
Australia	1	Macedonia	2
Barbados	1	Mali	1
Belgium	1	Mexico	2
Bolivia	1	Morocco	1
Bulgaria	1	Nepal	1
Canada	3	New Zealand	2
Colombia	2	Portugal	1
Costa Rica	1	Russia	1
Croatia	1	Serbia	1
Czech Republic	1	Spain	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

Global responses by country



Based on 57 responses

European responses by country



Based on 29 responses, see figure 1 for detail, as above the darker red colour equates to a higher number of responses

4.1. CLLAN membership

54% of the organisations taking part in this survey were members of CLLAN (MOs), with the remaining 46% being non-members (NMOs). Having a similar number of MOs and NMOs participating in the survey allows the opportunity to compare findings more accurately. Throughout the rest of the report we shall refer to these organisations as NMOs and MOs.

Figure 2



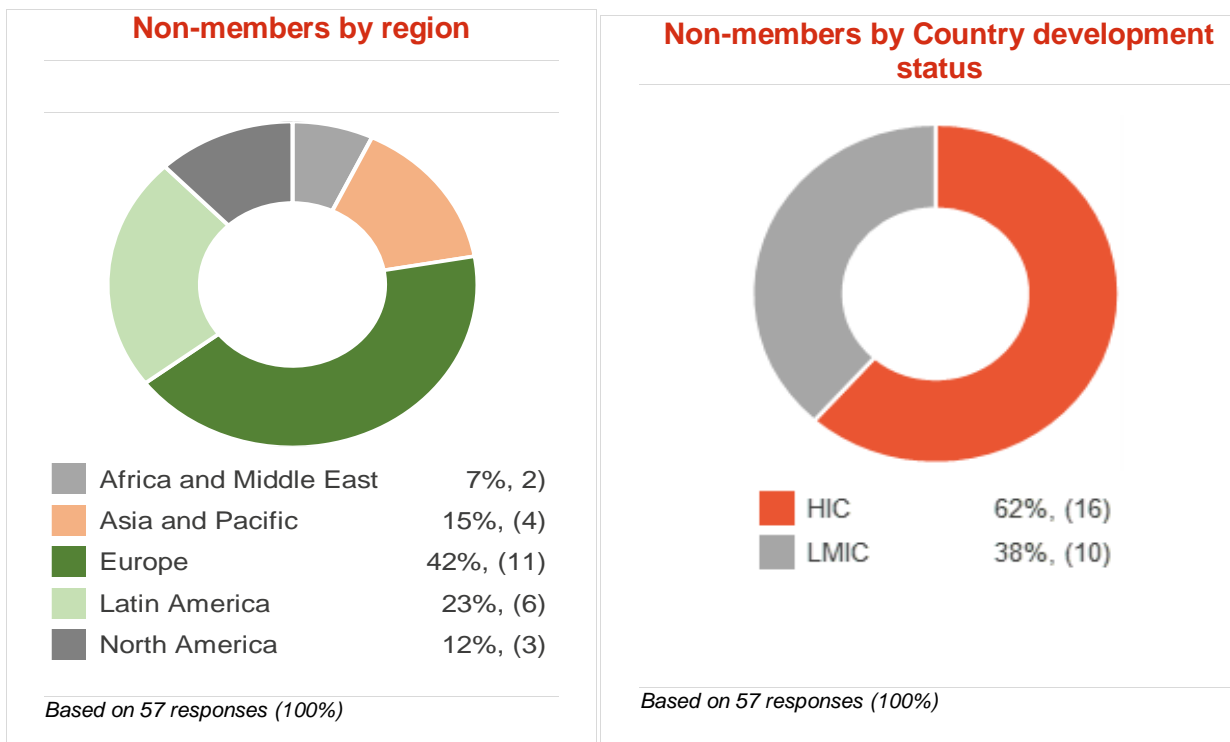
4.2. Identifying new CLL organisations

As previously noted, a scoping exercise was carried out to find organisations that provide CLL support but were not members of CLLAN. Through this research 118 groups were identified and invited to complete the survey, with 26 organisations taking up the opportunity to take part, giving a response rate of 22%.

Key features of NMOs:

- They are predominantly non-CLL-specific blood cancer support organisations (65%).
- 46% have 1-10 active volunteers.
 - 23% have between 11 and 50 and 19% have more than 100.
- 38% have no paid staff.
 - 35% have 10 or fewer paid members of paid staff and 27% have more than 10, including 3 that have more than 100.
- They are likely to be led by either patients / carers (28%), or a combination of patients / carers and healthcare professionals (32%).
- 62% were from HIC with 42% based in Europe.
- 88% were interested in becoming members of CLLAN.

Figure 3



4.3. Members

There were 36 full / associate members of CLLAN at the time of the survey. All members were invited to participate with 31 organisations that completed the survey, giving a response rate of 86% indicating a high level of engagement with both CLLAN and the objectives of the survey.

Figure 4

Member organisation	Country	Member organisation	Country
AGALEMO	Costa Rica	Flute of Light	Israel
AILPAZIENTI	Italy	Hellenic Group of Patients with CLL	Greece
ALMA	Argentina	HEMA Association	Macedonia
Armenian Hematology Association	Armenia	HULL	Croatia
Association des Malades Atteints de Leucémies AMAL	Morocco	Korea Blood Disease & Cancer Association	Korea
Blood Cancer Society	Nepal	Leukaemia Care	UK
Bloodcancerförbundet	Sweden	Leukämiehilfe RHEIN-MAIN	Germany
Bulgarian Lymphoma Association	Bulgaria	Leukemia & Lymphoma Society, LLS	USA
CFP «DROP OF BLOOD»	Ukraine	LYLE	Denmark
CLL Advocates NZ	New Zealand	Lymphoma Action	UK
CLL Canada	Canada	Lymphoma Canada	Canada
CLL Ireland	Ireland	LYPA	Serbia
CLL Society	USA	SILLC	France
CLL SUPPORT	UK	Stichting Hematon	The Netherlands
Deutsche Leukämie- & Lymphom-Hilfe e.V. - DLH	Germany	V Care Foundation	India
Diagnóza leukemie	Czech Republic		

There was a difference noted in set up, support and leadership between NMOs and MOs. MOs were more likely to represent a larger population of patients than NMOs, with 65% MOs representing over 100 patients whereas only 24% of NMOs represented over 100 patients. Half of NMOs represented 50 patients or fewer.

This correlated with LMIC where again around half (53%) represented fewer than 50 patients. This would suggest that there are more NMOs in LMIC and organisations are able to support fewer patients in these countries, although there may be fewer CLL patients in these countries and this therefore cannot be discounted.

Interestingly, NMOs and MOs surveyed reported similar numbers of both active volunteers and paid staff members, although a higher percentage of MOs (52%) reported having no paid staff at all than in the NMOs (38%).

The benefits of membership to CLLAN should be promoted to all NMOs identified through this research.

5. Provision of Support Services for CLL

This section of the survey focused on collecting information on what services the responding organisations provide and who these are directed towards. Respondents were also asked what they believe are their organisational strengths and what contributes to this, along with gaps in and barriers to service provision.

5.1. CLL support, advocacy, and education services that organisations currently offer

Respondents were asked to indicate what CLL support, advocacy, and education services their organisation currently offers.

Overall, the most frequently provided services are patient meetings, awareness campaigns and educational events. The less frequently provided services (excluding “other”) are clinical trials directories, petitions, and welfare / financial support.

Of the 8 organisations that selected “other”, 3 specified what these services were: accommodation, research funding, clinical trial support, centre oncology nurse navigation program, and transportation to hospital during COVID-19.

Figure 5

03. What CLL support, advocacy and education services does your organisation currently offer? (Please tick all that apply)	All	
	n	%
Patient meetings	44	77%
Awareness campaigns	41	72%
Educational events	39	68%
Telephone support / support helpline	39	68%
CLL news and conference coverage	37	65%
Online group / chat or forum	36	63%
Webinars	35	61%
Local support groups	32	56%
Input in writing and / or in person to government and regulatory organisations	27	47%
Publications and presentations at relevant blood cancer meetings	27	47%
Conferences	26	46%

Surveys of the community served	26	46%
Advisory statements and position papers	25	44%
Personal advocacy	19	33%
Healthcare professional education	17	30%
Directory of local / national support groups	16	28%
Fundraising resources	13	23%
Health Technology Assessment (HTA)	12	21%
Buddy schemes (1:1 support)	12	21%
Welfare / financial support	12	21%
Petitions	11	19%
Clinical trials directory	10	18%
Other	8	14%

It is important to note that provision of these services is not uniform across all organisations. In order to try and understand this more we carried out further analysis to see if there were any patterns in service provision relating to their CLLAN membership or country of origin.

On average, NMOs were less likely to provide services than MOs. The biggest differences in service provision were:

- CLL news and conference coverage (81% MO / 46% NMO)
- Conferences (61% MO / 27% NMO)
- Input in writing and / or in person to government and regulatory organisations (61% MO / 31% NMO)

It is also worth noting that a very small number of NMOs (2) reported taking part in Health Technology Appraisals (HTA).

In general, NMOs' services tend to be more oriented towards patients themselves rather than the wider knowledge and education aspects of service provision. 77% of NMOs provide patient meetings with the same percentage working on awareness campaigns. The next most common service provided was helpline/telephone support (69%).

As we have already seen, NMOs tend to represent fewer numbers of patients and have fewer volunteers than MOs, suggesting that there is perhaps less infrastructure in NMOs. The lack of membership within their organisation and therefore potentially the lack of involvement in a network could also help to explain why these organisations concentrate on more patient specific services than the wider support and education services.

Overall, and similar to the picture referred to in the previous section, a higher proportion of organisations in HIC provide services. However, a higher percentage of organisations in LMIC say they provide CLL Patient meetings, Awareness campaigns and Telephone support / support helplines, Personal advocacy and Petitions.

The biggest difference in service provision were:

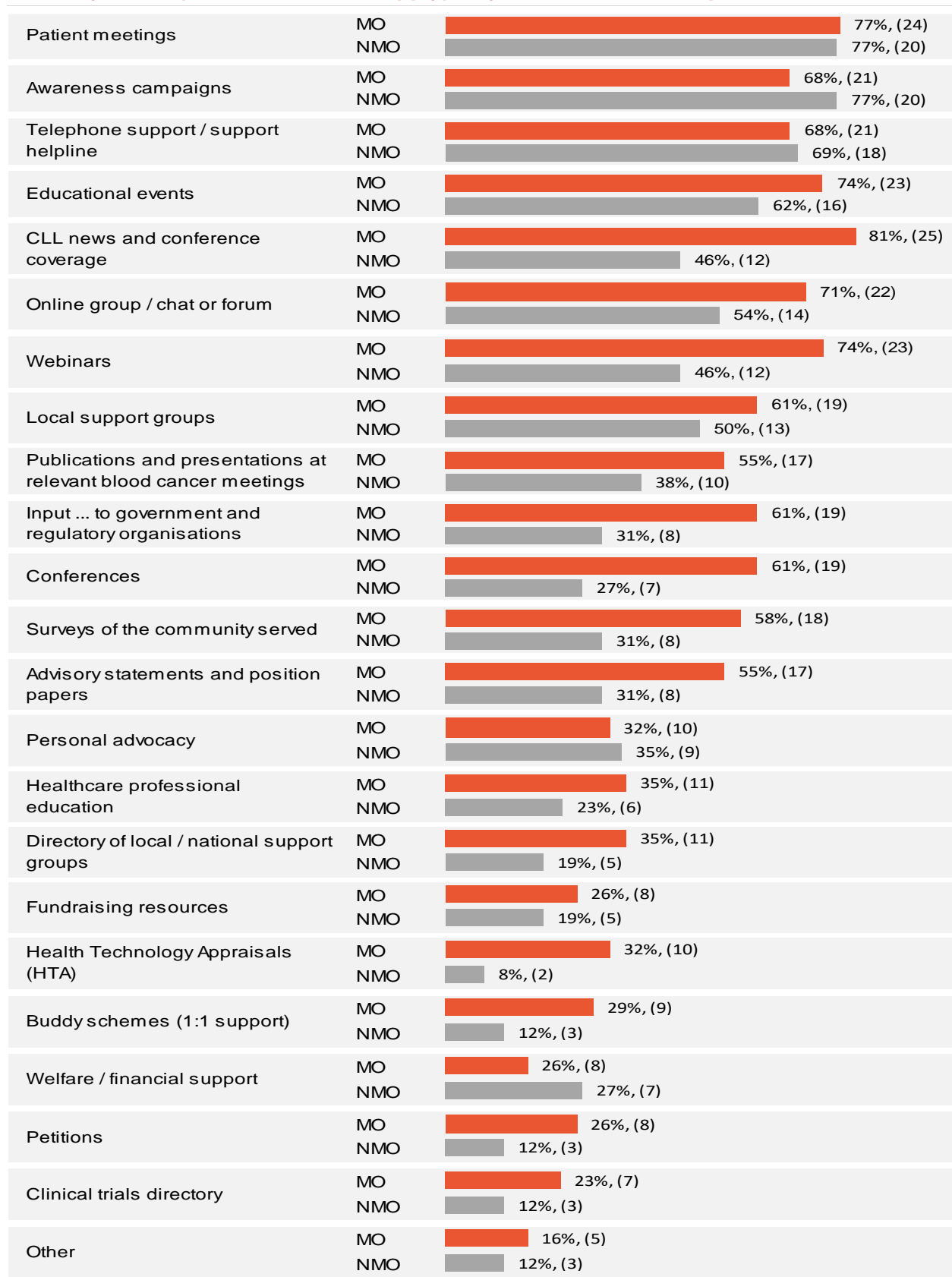
- CLL news and conference coverage (79% HIC / 37% LMIC)
- Conferences (58% HIC/ 21% LMIC)
- Advisory statements and position papers (55% HIC / 21% LMIC)

The charts on the following pages illustrate the breakdown of service provision by organisation membership status, country development status and global region. Again here, organisations based in LMIC have

services that are more likely to be patient oriented in a similar way to NMOs above. Those in HIC are more likely to provide services that include wider education, research and policy development.

Figure 6

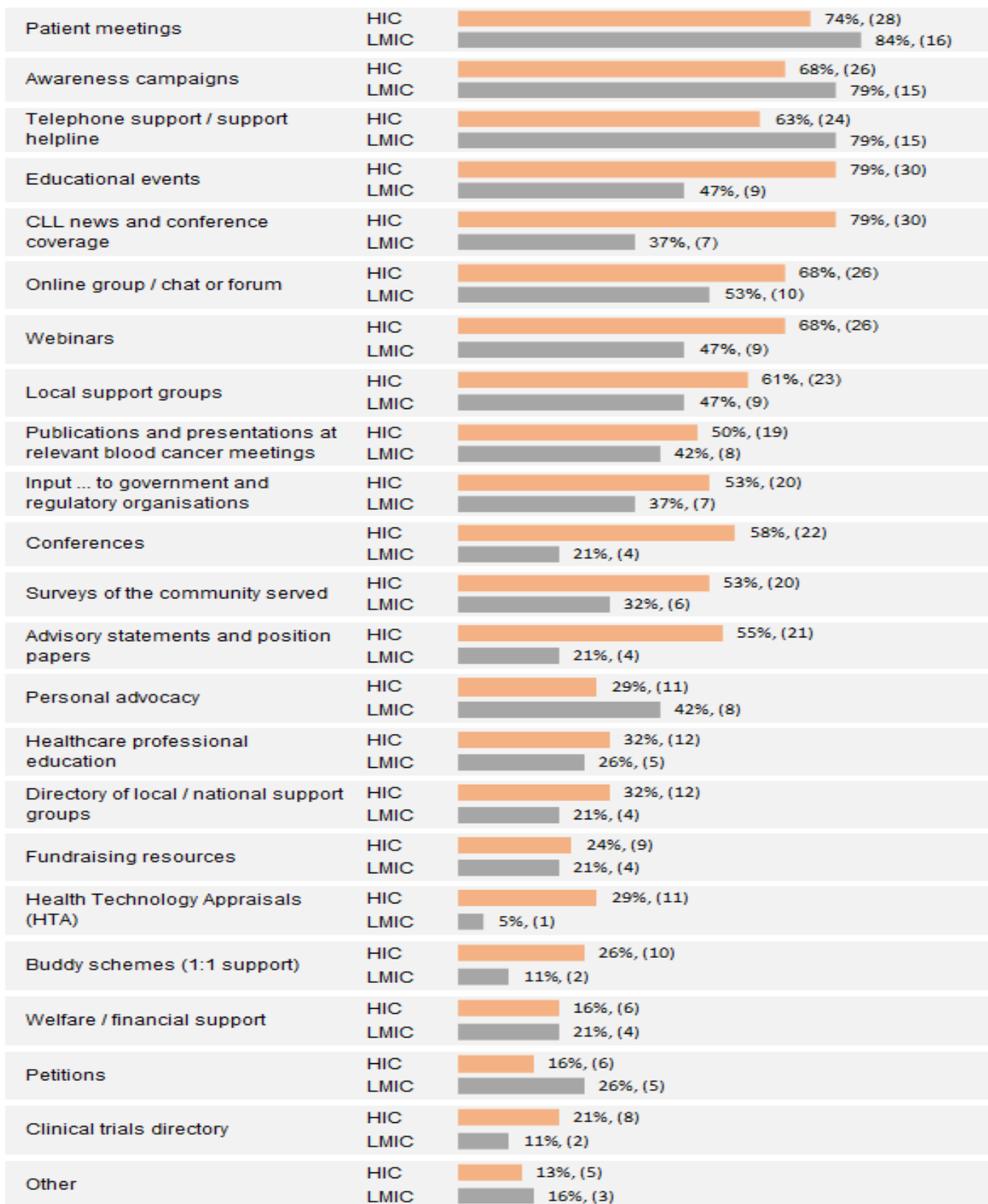
Q3. What CLL support, advocacy and education services does your organisation currently offer? (Please tick all that apply) – by CLLAN membership status



Based on 57 responses (100%)

Figure 7

Q3. What CLL support, advocacy and education services does your organisation currently offer? (Please tick all that apply) – by country development status



Based on 57 responses (100%)

5.2. CLL support, advocacy, and education services that organisations would like to offer

Respondents were asked to indicate what services they do not currently offer but would like to. Responses to the answer options within this question are lower here than in the previous section, based on the responses below this may indicate that patient specific elements of service provision are more of a priority for organisations.

By far the most popular service that organisations would like to offer is a clinical trials directory, with 42% of respondents selecting this option. Clinical trials are a key part of the developing treatment landscape, so this is perhaps unsurprising.

Figure 8

10. What CLL support, advocacy, and education services do you NOT currently offer but would like to? (Please tick all that apply)	All	
	n	%
Clinical trials directory	24	42%
Health Technology Assessments (HTAs)	16	28%
Publications and presentations at relevant blood cancer meetings	16	28%
Welfare / financial support	15	26%
Fundraising resources	14	25%
CLL news and conference coverage	13	23%
Buddy schemes (1:1 support)	13	23%
Healthcare professional education	12	21%
Telephone support / support helpline	11	19%
Advisory statements and position papers	10	18%
Educational events	10	18%
Patient meetings	9	16%
Directory of local / national support groups	9	16%
Awareness campaigns	9	16%
Webinars	7	12%
Online group / chat or forum	7	12%
Surveys of the community served	7	12%
Conferences	6	11%
Input in writing and / or in person to government and regulatory organisations	6	11%
Personal advocacy	6	11%
Petitions	5	9%
Local support groups	3	5%
Other	0	0%

A larger proportion of NMOs have services they want to deliver compared to MOs. In particular there is greater desire within NMOs to provide (see figure 9):

- Advisory statements and position papers (35% NMO / 3% MO)
- Conferences (23% NMO / 0% MO)
- Publications and presentations at relevant blood cancer meetings (38% NMO / 19% MO)

However, a Clinical trials directory and Health Technology Appraisals (HTAs) are in demand by both NMOs and MOs.

As we have seen in the previous section, NMOs tend to provide fewer services than MOs. This would also suggest that some NMOs would like to widen their services outside of the patient specific support that they currently offer. Support for these organisations to do so would be beneficial to the patients that they represent and the wider CLL community.

Organisations in LMIC are also more likely to have services they want to provide when compared to those within HIC. The biggest differences are (see figure10):

- CLL news and conference coverage (53% LMIC / 8% HIC)
- Patient meetings (32% LMIC / 8% HIC)
- Publications and presentations at relevant blood cancer meetings (42% LMIC / 21% HIC)
- Educational events (32% LMIC / 11% HIC)

No organisations in LMIC reported that they wished to input into government and regulatory organisations.

We also gave organisations the option to select 'None of the above'. Of the 7 organisations that selected this option, 5 were MOs and 2 were NMOs. No organisations within LMIC chose this option again highlighting the greater requirement for service development in these countries.

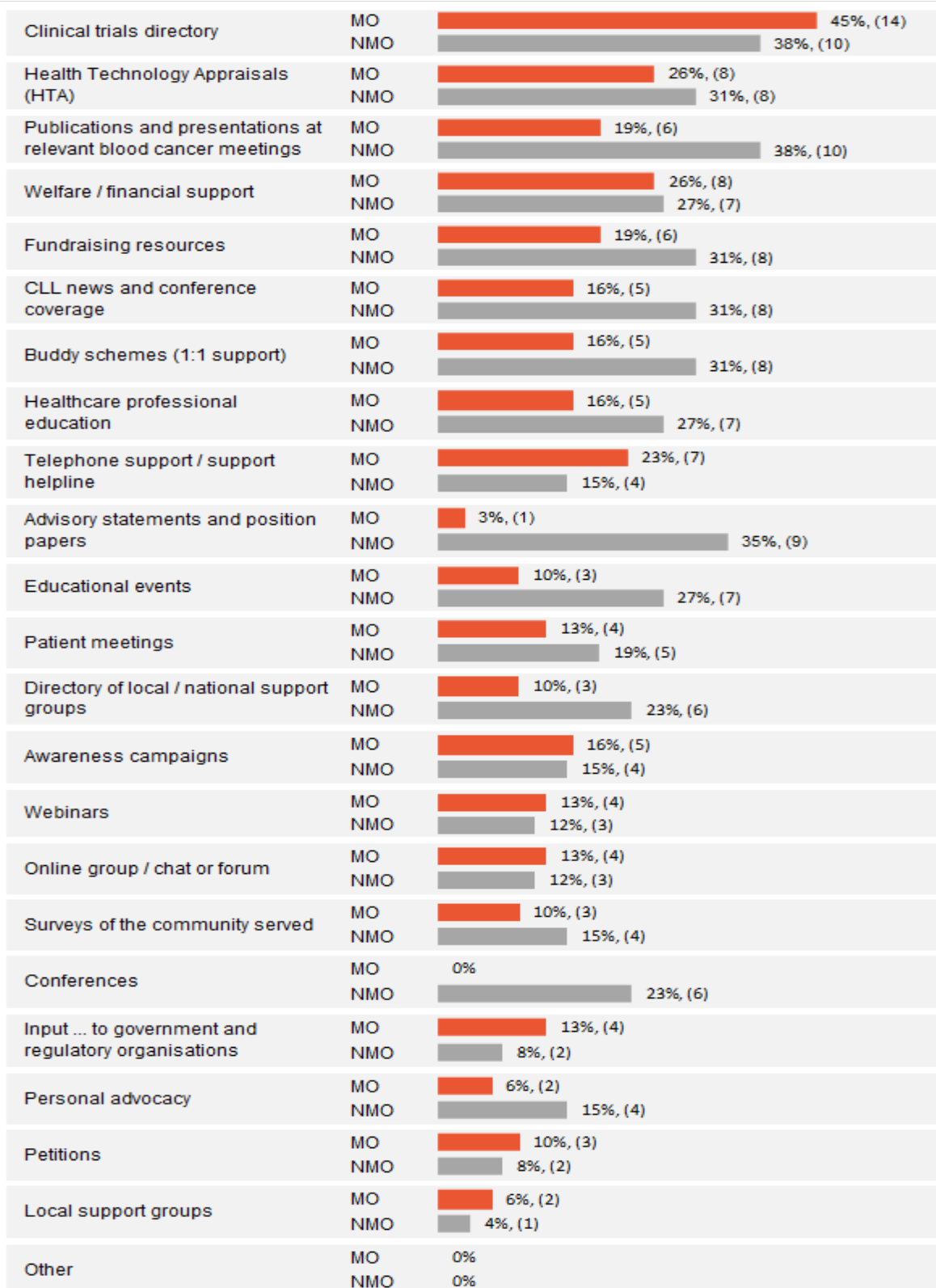
Of note, 77% of organisations provide patient meetings (see figure 5), and of those that don't the vast majority would like to. There is an almost identical picture for telephone support where 68% provide this already, and the majority of those that don't, would like to. Although similar, there is slightly less interest in online support with 63% providing this and a further 12% that would like to. This highlights the need for organisations to provide patient specific support, information and advice and that in person support is a priority over services that incorporate technology. Additional support to provide these services, access to best practice and sharing of resources could assist these organisations to enhance the support that they provide to patients and their input into the wider CLL support and advocacy landscape.

Overall, this research suggests that NMOs and organisations based in LMIC are more likely to offer patient specific support services but would also like to widen their participation into more education and policy work. Providing additional support to these organisations to branch out in this way will impact positively on the services provided and awareness of CLL, particularly in countries that have a greater economic challenge.

The charts on the following pages illustrate the breakdown of service provision by organisation membership and country income status.

Figure 9

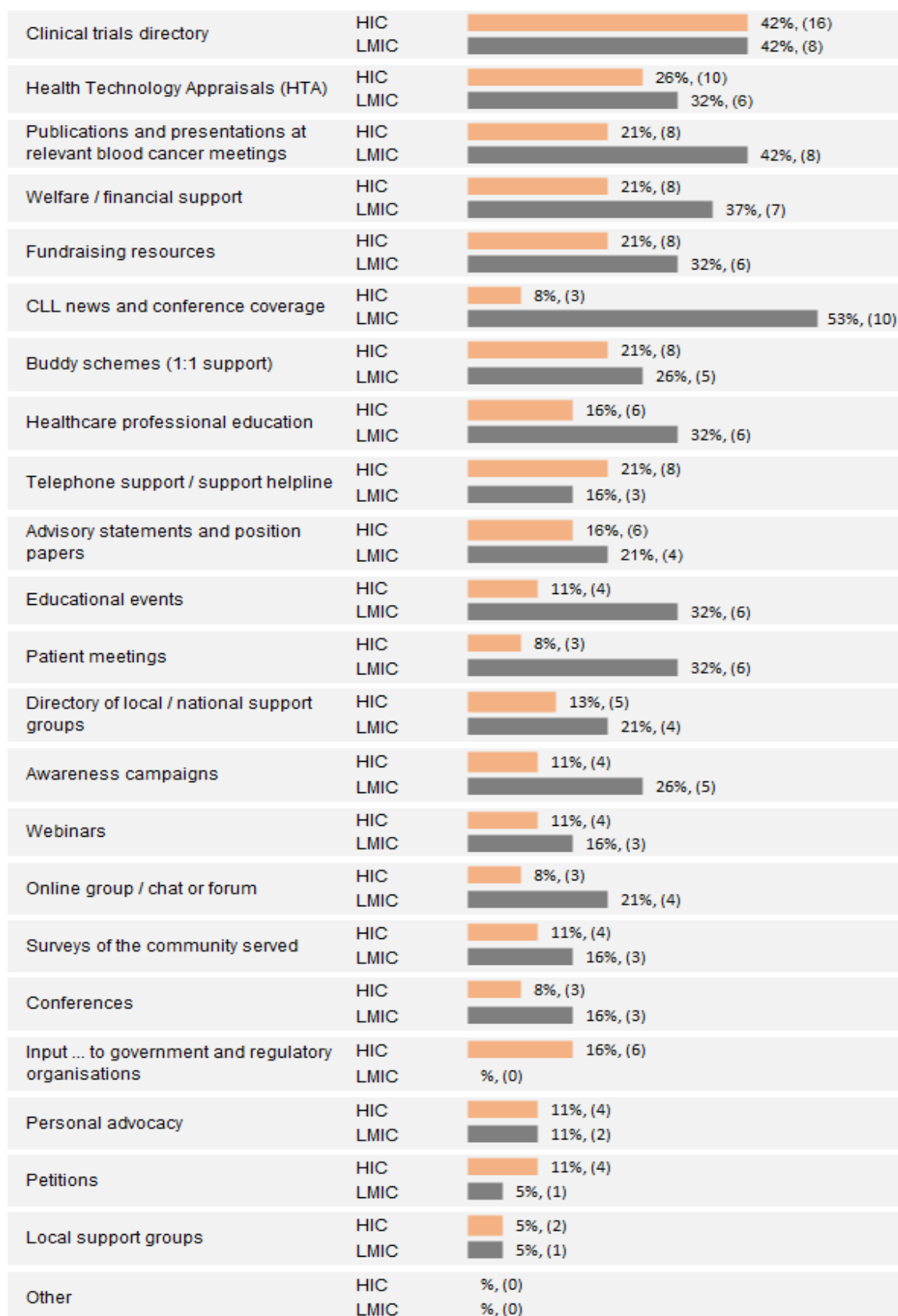
10. What CLL support, advocacy, and education services do you NOT currently offer but would like to? (Please tick all that apply) – by CLLAN membership status



Based on 57 responses (100%)

Figure 10

10. What CLL support, advocacy, and education services do you NOT currently offer but would like to? (Please tick all that apply) – by country development status



Based on 57 responses (100%)

5.3. Reasons for lack of provision

Organisations were asked to select the reasons that they do not offer the services reported in the previous section.

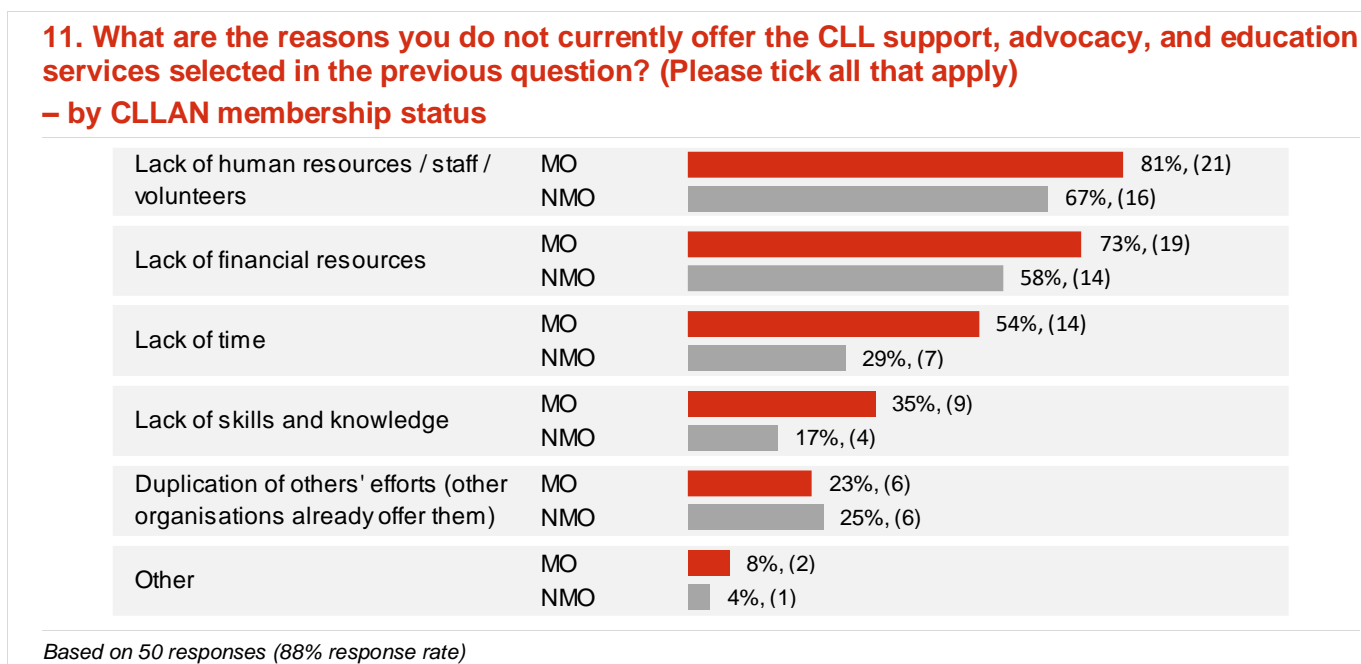
Lack of human resources was the overall key driver across all organisations, however for organisations in LMIC this was less of an issue than lack of financial resources.

Figure 11

11. What are the reasons you do not currently offer the CLL support, advocacy, and education services selected in the previous question? (Please tick all that apply)	All	
	n	%
Lack of human resources / staff / volunteers	37	74%
Lack of financial resources	33	66%
Lack of time	21	42%
Lack of skills and knowledge	13	26%
Duplication of others' efforts (other organisations already offer them)	12	24%
Other	3	6%

Interestingly, more MOs reported multiple reasons for not providing services than NMOs (see figure 12 below).

Figure 12

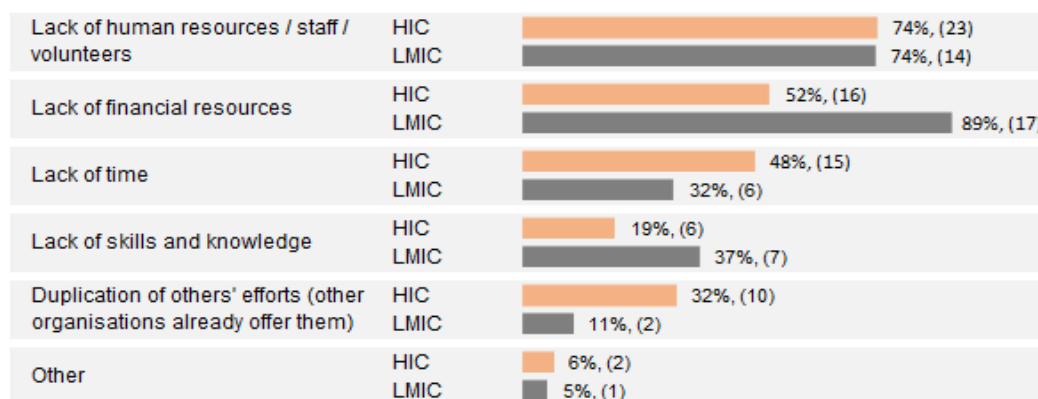


As well as the lack of financial resources, there is a big difference in skills and knowledge to provide services between organisations in HIC (19%) and LMIC (37%).

It also appears that 32% of organisations in HIC do not feel the need to provide certain services because they are offered/available elsewhere.

Figure 13

**11. What are the reasons you do not currently offer the CLL support, advocacy, and education services selected in the previous question? (Please tick all that apply)
– by country development status**



Based on 50 responses (88%)

Providing shared resources and publishing best practice may support organisations with providing services that they currently are unable to by freeing up time, being cost effective, improving knowledge, and reducing duplication.

5.4. Written materials

Organisations were then asked specifically what written information they have developed in the form of printed media or digital media to:

- CLL patients only
- Combined CLL and other blood cancer patients
- Carers (unpaid)
- Healthcare professionals (including paid carers)
- Patient Advocates
- Media
- General public
- Other

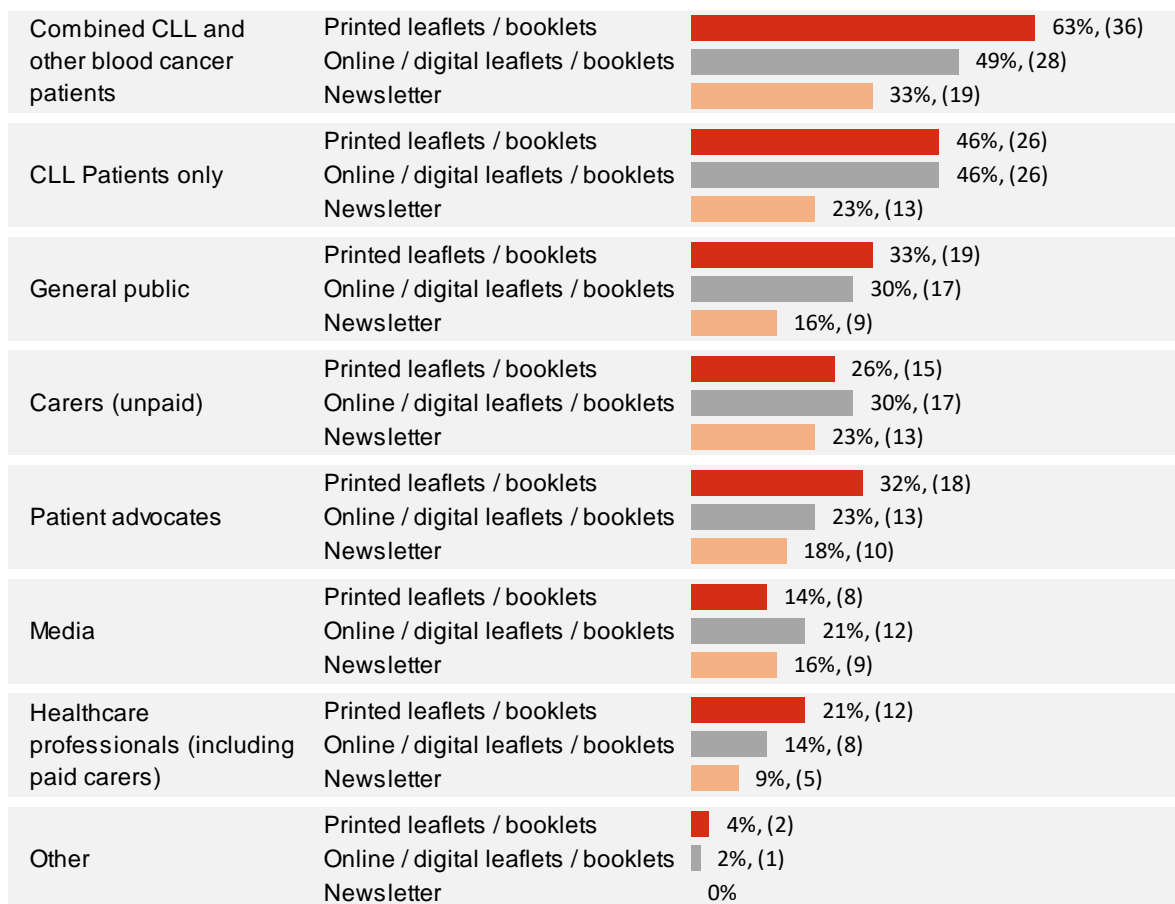
Unsurprisingly, written information targeting patients themselves had the most responses with 63% providing this. More organisations produce this information for the wider blood cancer patient population than for CLL patients specifically (where this was 46%, see chart below figure 14).

The next highest groups are unpaid Carers and the General public, closely followed by Patient Advocates. Healthcare professionals and the Media are less well served in this regard.

As a whole printed materials are provided slightly more than digitally hosted materials.

Figure 14

04. What written information has your organisation developed for:



Based on 57 responses (100%)

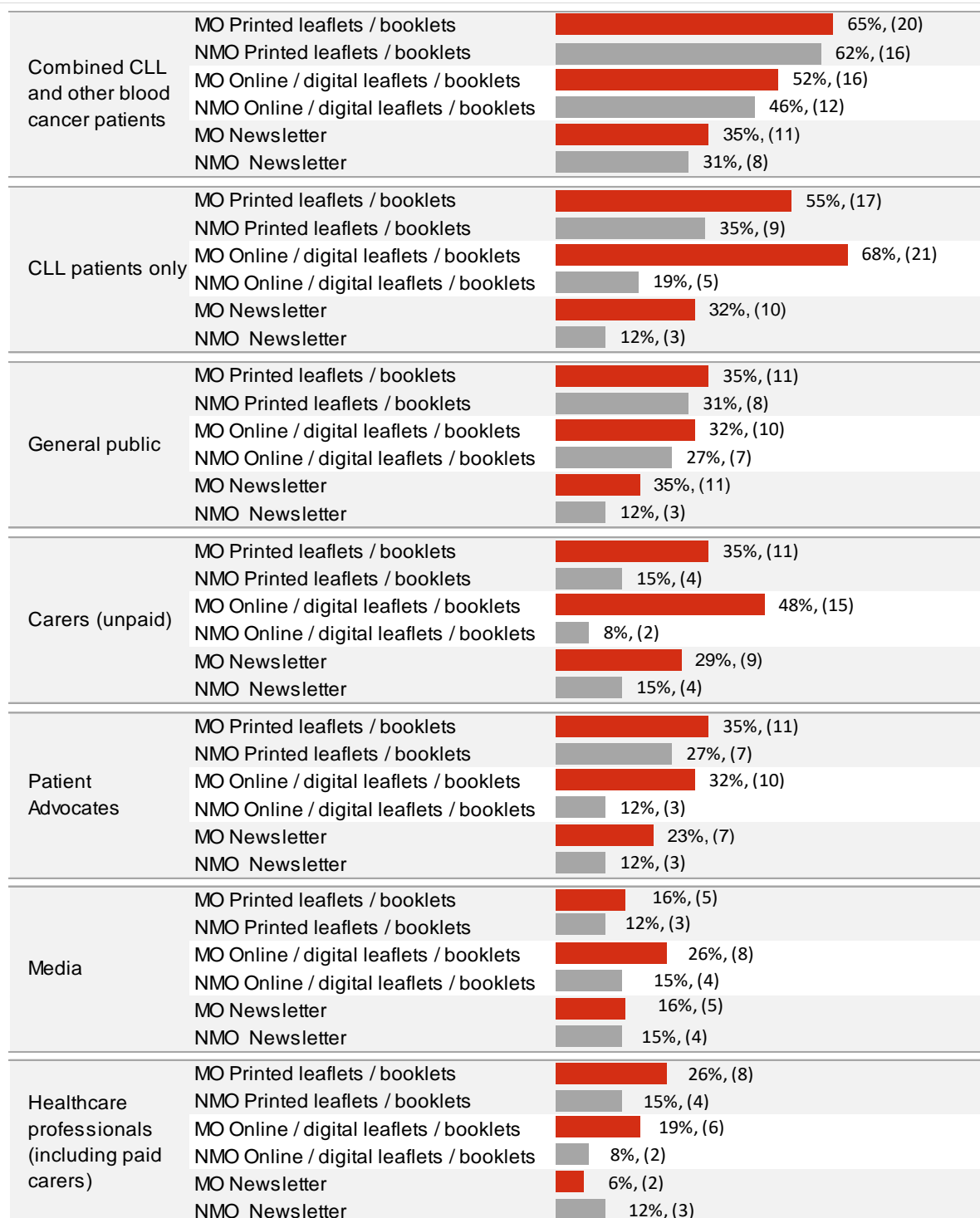
A slightly higher proportion of MOs have developed written information across all the different groups, see figure 15 below. Compared to NMOs, they were significantly more likely to have developed printed leaflets and booklets specifically for CLL patients (65% vs 62%), unpaid carers (35% vs 15%) and patient advocates (35% vs 27%).

A higher percentage of MOs provide digital information for CLL specific patients, unpaid carers and the media than they do printed materials.

MOs are more likely to provide information for CLL patients specifically than NMOs. Part of the benefit of membership for these organisations and the patients that they support may be access to shared resources around CLL specifically.

Figure 15

04. What written information has your organisation developed for: - by CLLAN membership



Based on 57 responses (100%)

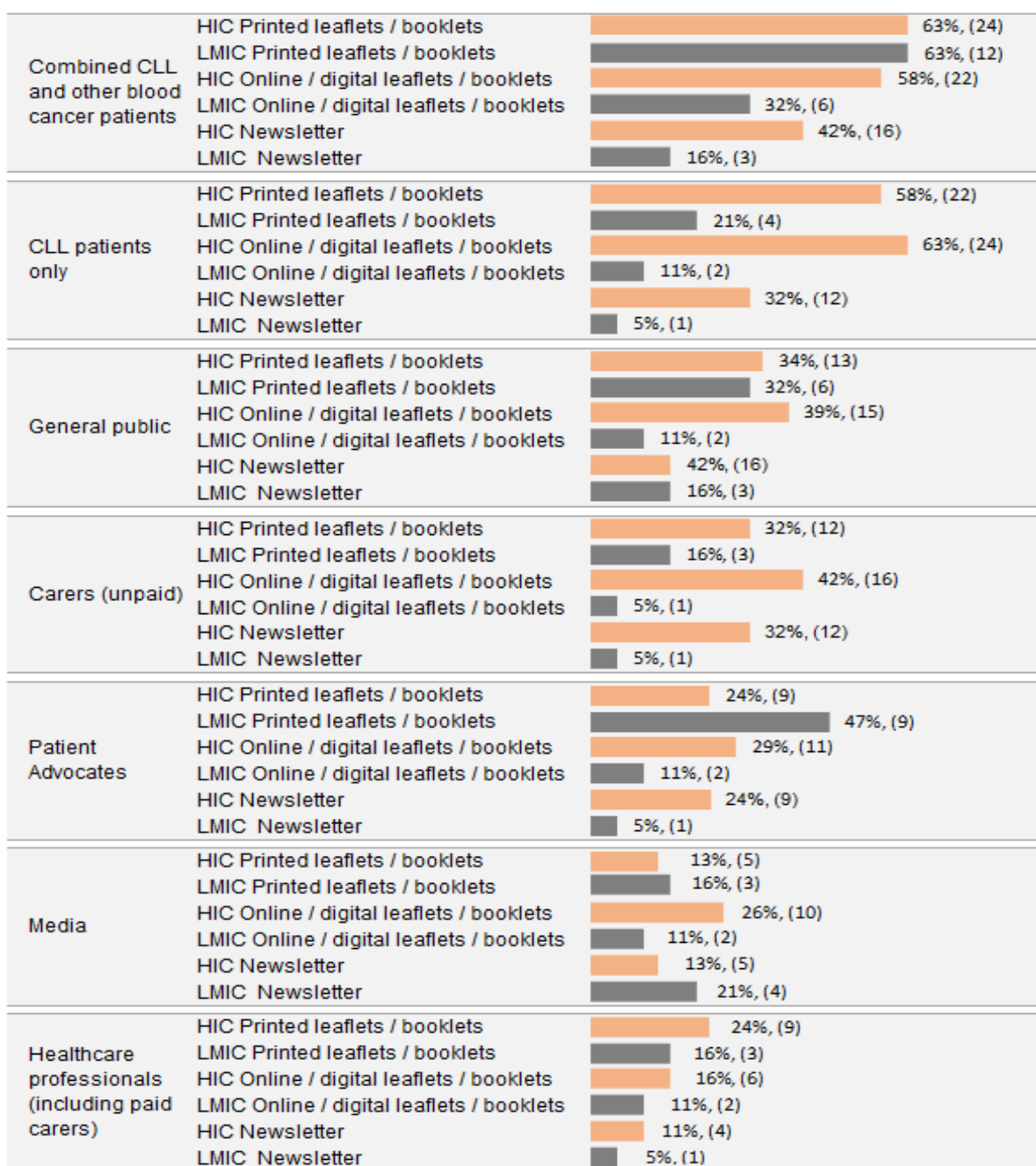
There are large differences in the percentage of organisations who provide this information depending on if they are within a HIC or not.

There is the opportunity to support organisations in LMIC with specific CLL patient and unpaid carer information. Interestingly 47% of organisations in LMIC reported having provided printed leaflets / booklets for patient advocates (47%) whilst this is more likely to be online in HIC (29%).

Overall, LMIC were much less likely to produce online/digital material than printed. This is an area where best practice and resources could be effectively shared globally to support organisations and patients.

Figure 16

**04. What written information has your organisation developed for:
– by country development status**



Based on 57 responses (100%)

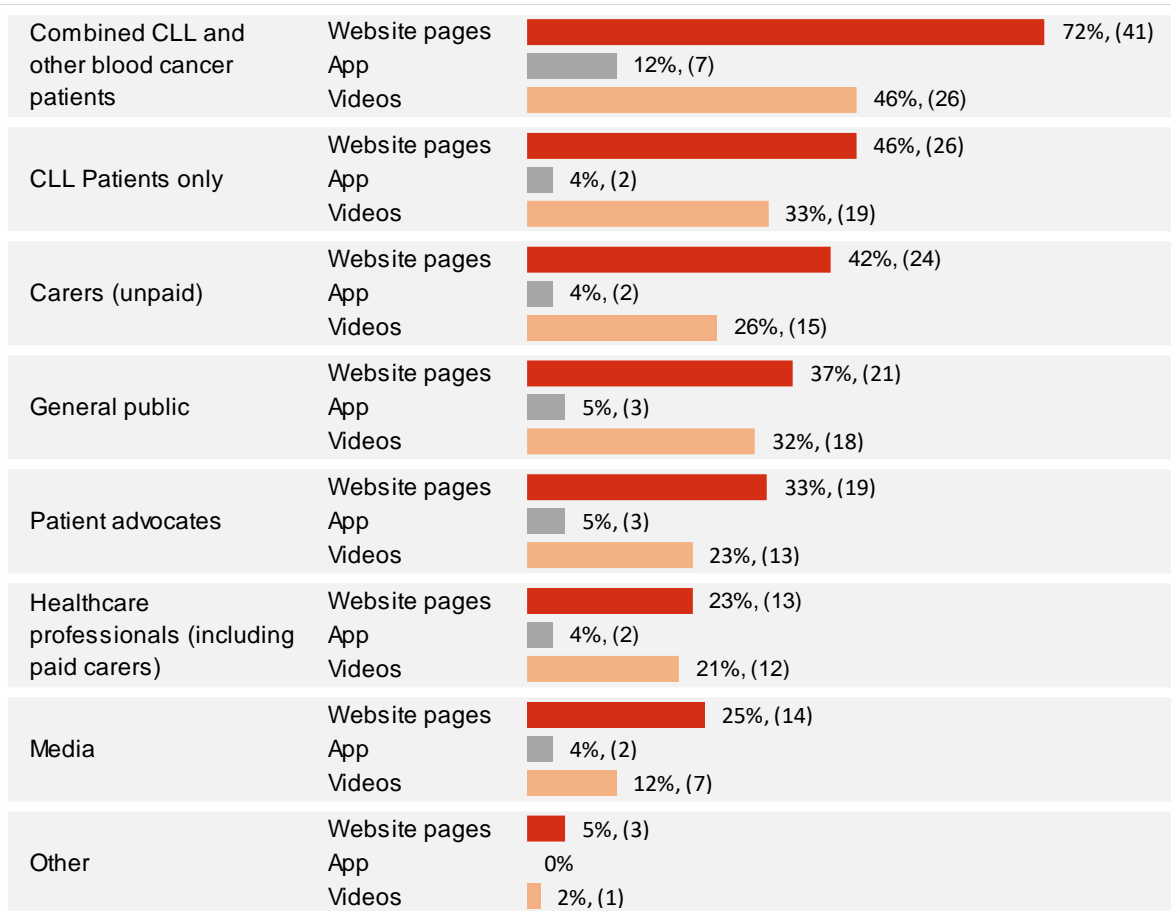
Organisations were asked if they have developed other information resources in the form of website pages, apps, or videos. Website information targeting patients had the most responses and these mostly related to wider blood cancer patients (72%) rather than CLL specifically (46%). As with written information, the next highest groups served are unpaid Carers and the General public.

Videos are also being implemented frequently across the different categories, see the chart below (figure 17).

The use of apps, however, is very low compared to other digital/online resources, see the chart below (figure 17). With the widespread global use of smart technology this again is an area where best practice and resources could be shared and improve services for the CLL community.

Figure 17

05. What written information has your organisation developed for:

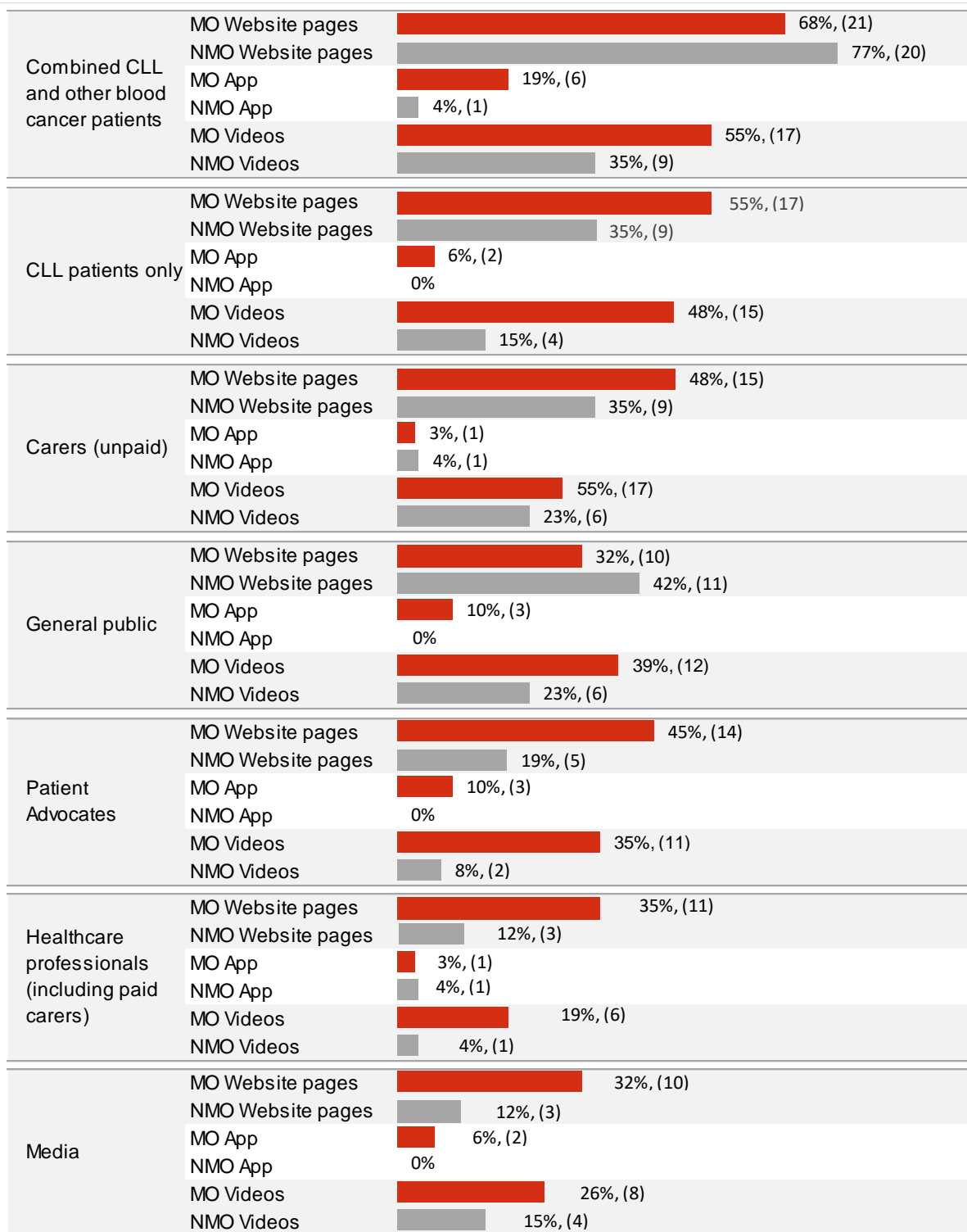


Based on 57 responses (100%)

Across the majority of categories, MOs have the higher utilisation of digital media although 77% of NMOs have website pages which is slightly higher than MOs (68%).

Figure 18

05. What other information has your organisation developed for: - by CLLAN membership



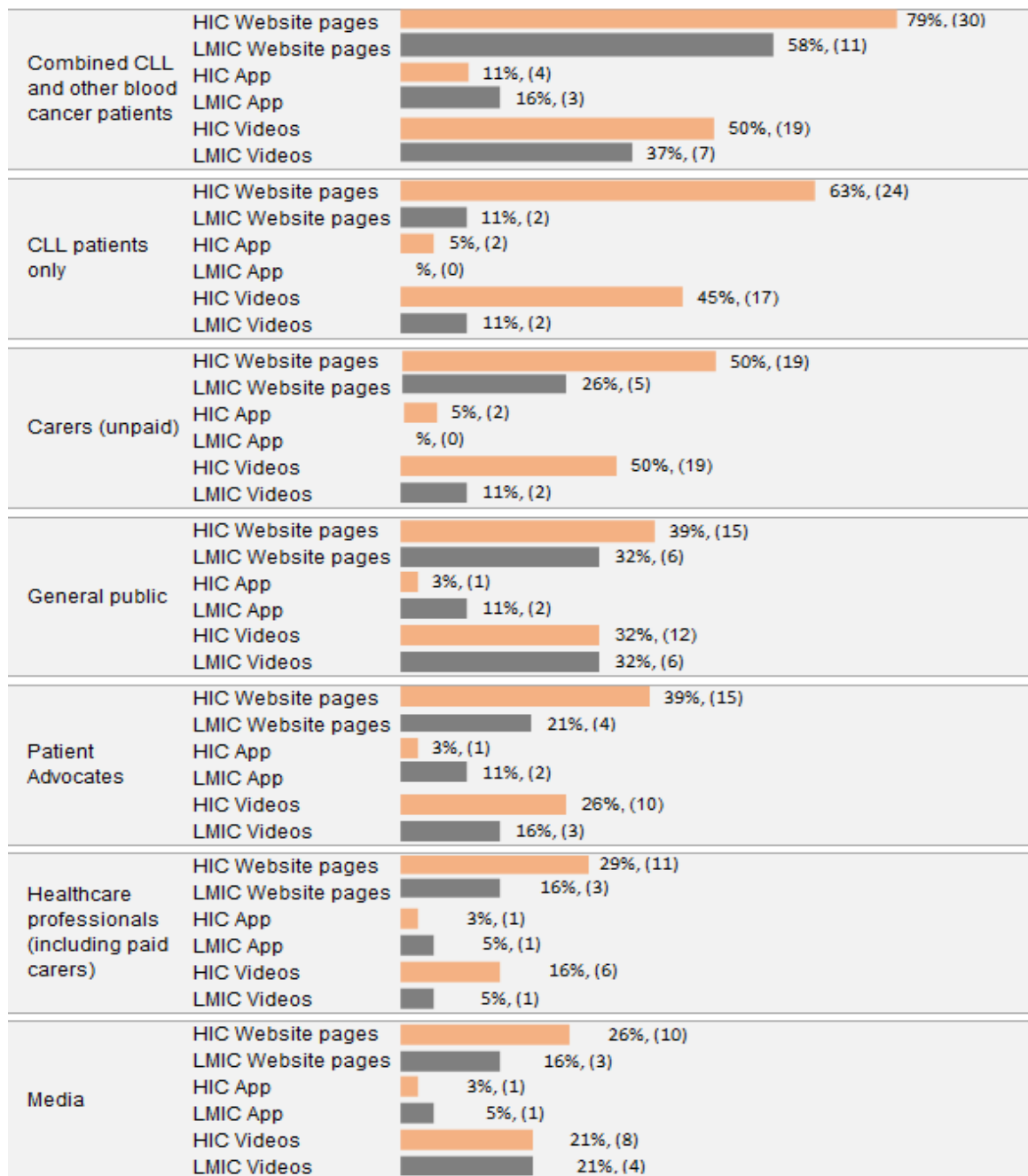
Based on 57 responses (100%)

Across the majority of categories, organisations in HIC tend to have the higher uptake of digital media. This is most noticeable in the CLL patient category.

The organisations in LMIC that are producing apps are MOs.

Figure 19

**05. What other information has your organisation developed for:
- by country development status**



Based on 57 responses (100%)

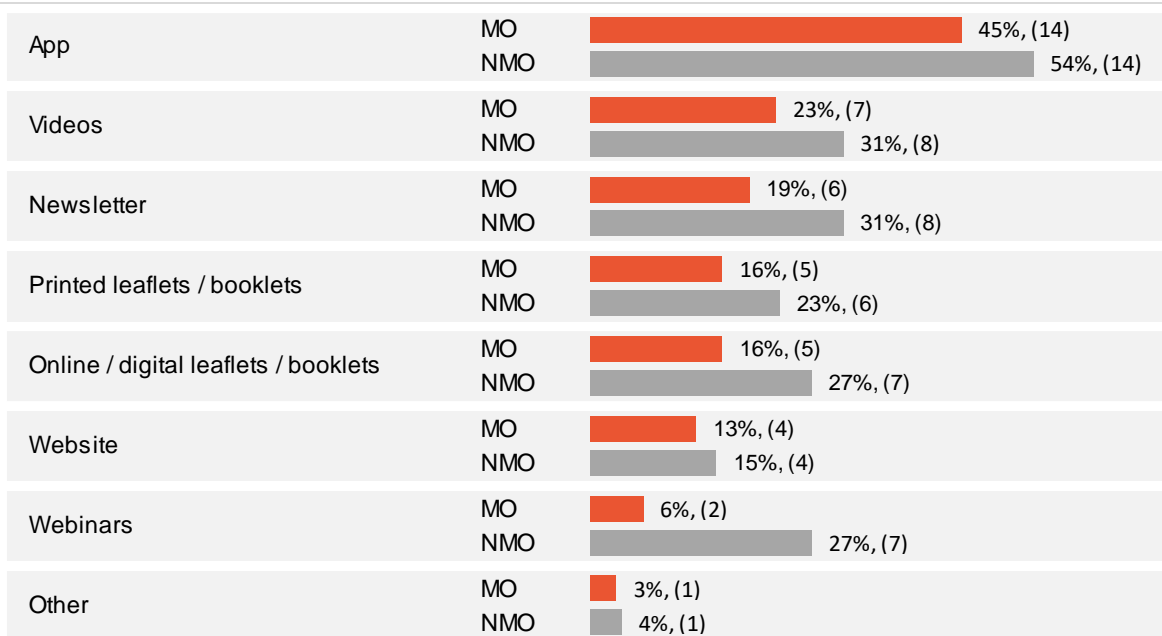
The top three materials and resources organisations do not currently provide to patients but want to are Apps, Videos, and Newsletters. 49% of organisations are wanting to offer apps.

Figure 20

12. What CLL materials and resources do you NOT currently offer to your patients but would like to? (Please tick all that apply)	All	
	n	%
App	28	49%
Videos	15	26%
Newsletter	14	25%
Online / digital leaflets / booklets	12	21%
Printed leaflets / booklets	11	19%
None of the above	11	19%
Webinars	9	16%
Website	8	14%
Other	2	4%

Figure 21

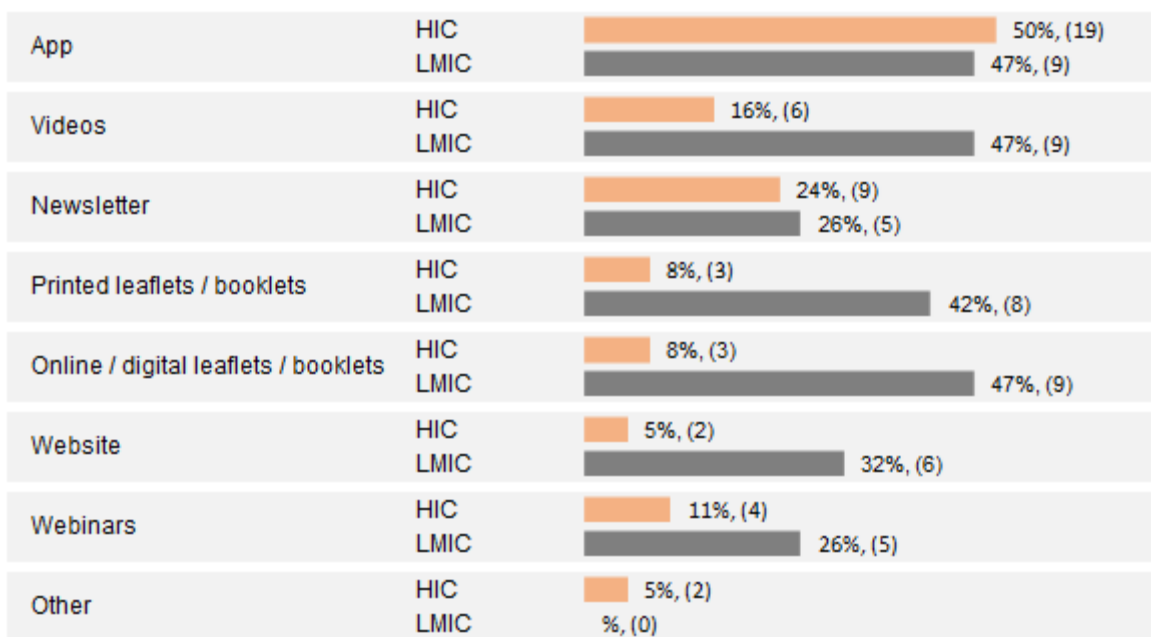
12. What CLL materials and resources do you NOT currently offer to your patients but would like to? (Please tick all that apply) – by CLLAN membership



Based on 57 responses (100%)

Figure 22

12. What CLL materials and resources do you NOT currently offer to your patients but would like to? (Please tick all that apply) – by country development status



Based on 57 responses (100%)

Around half of those that responded would like to provide the opportunity to use an app to patients, with the same number from LMIC wishing to utilise videos.

With the current more widespread availability of technology apps and other digital/online media could be a cost-effective way to share resources, best practice and information between organisations and patients across the globe.

The differences between types of CLL and the ever-changing care and treatment landscape, mean that these resources could have the potential for patients, organisations and healthcare providers to be kept up to date quickly and efficiently.

5.5. Organisations' views on their service provision

Respondents were asked what they thought their organisation did particularly well. This required a free text response and 48 out of 57 (84%) organisations chose to respond and explain this in their own words.

An analysis was carried out to identify common themes in what organisations feel is done well and uncover if there are any patterns in the responses provided.

The comments were organised into four main themes and then subthemes within these:

A. Advocacy

- General advocacy (i.e. no further detail beyond saying 'advocacy')
- Access to treatment
- Fundraising
- Policy contribution
- Research

B. Communication

- Circulating information
- Networking
- Website

C. Education

- General education (generalised comments around 'education')
- Awareness
- Conferences
- Disease information
- Education for healthcare professionals
- Webinars

D. Support

- General support (i.e. no further detail beyond saying 'support')
- Advice from healthcare professionals
- Emotional support
- Financial support
- Helpline
- Peer support

In addition, it was noted if organisations specifically stated if their provisions were for patients and/or family and carers.

Organisations in LMIC had more codes attributed to them, regardless of if they were a member or not.

A. Advocacy

Access to treatment

10 MO's spoke about access to treatment, compared to 3 NMOs. MOs specifically cited HTA (Health Technology Assessment) submissions in their comments, although others also spoke about "lobbying" and advocating for access to innovative drugs.

"Interest policy advocacy work for patient influence in HTA, clinical trials etc." – MO HIC

"HTA activity." – MO HIC

"...presenting the patient voice in the HTA process; we provide submissions into this process for 100% of all new indications entering [country removed]" – MO HIC

"We campaign for access to effective treatments. We work with the [name of regulatory body removed] and other organisations to ensure patients can access the best possible treatment for them and when they can't we advocate on their behalf." – MO HIC

"We also have an incredible group of oncology nurse navigators that provide individual clinical trial searches" – MO HIC

"Navigating CLL patients for a second opinion over treatment strategy to leading CLL experts." – MO HIC

"...lobbying for access of novel therapies" – MO LMIC

"Advocacy for the rights of patients with CLL to therapy with innovative drugs" – MO LMIC

"We provide support for access to treatment" – NMO LMIC

Fundraising

5 organisations spoke about their fundraising efforts (MO=3 / NMO=2).

“We support the thousands of fundraisers and volunteers who make our work possible.” – MO HIC

“Fundraising and spreading awareness on blood cancers.” – NMO HIC

“...fundraising for patients.” – NMO LMIC

Policy contribution

4 MOs commented on work they do, related to policy contribution (2 each HIC/LMIC), however there were 3 NMOs in LMIC that made reference to this subtheme.

“We raise awareness and make sure that lymphoma/CLL is not forgotten by government and policymakers.” – MO HIC

“Interest policy advocacy work for patient influence in HTA, clinical trials etc.” – MO HIC

“Work in a network at a national and international level for political advocacy initiatives.” – MO LMIC

“Incidence in public policies” – NMO LMIC

“...our actions have led the constitutional court to issue a ruling regarding quality of medicines in our country.” – NMO LMIC

Research

Research was almost entirely cited by organisations in HIC (6 MOs/ 5 NMOs). The type of research spoken about varied, from patient experience to clinical.

Connecting patients with researchers – MO HIC

We conduct research to improve patient experience. We listen to patients and using the evidence we gather improve our services and focus our campaigning. – MO HIC

We carry out surveys – MO HIC

Some focus groups and events – MO HIC

Analysis of data from the global patient survey. – NMO HIC

Participating in surveys for pharmaceutical companies to improve the care of CLL patients. – NMO HIC

Funds blood cancer research in [country removed] – NMO HIC

Supporting research with grants – NMO HIC

B. Communication

Circulating information

This subtheme covered the sharing of information in a broad over-arching capacity, rather than the more specific resources covered in the ‘Education’ theme.

“Reporting on local and international haematology (CLL-specific) events.” – MO HIC

“Transferring topics discussed within CLLAN events into the [country removed] patient community.” – MO HIC

“Provide information in writing and during patient meetings (national and regional).” – MO HIC

“We also provide exceptional patient resources which are disseminated to patients across all hospitals and cancer centres.” – MO HIC

“...translated important materials.” – MO LMIC

“We are excellent story tellers, news-gatherers and media savvy reporters, with a long history of relationships globally with specialists, researchers and patient advocates” – NMO HIC

“We have different channels of communication towards [name of organisation removed], website, social networks, telephone numbers, email.” – NMO LMIC

Networking

10 organisations made comments around networking (5 MOs / 5 NMOs), either specifically, or in terms of relationships, and collaboration. Organisations spoke about networking with other groups and with healthcare professionals.

“Relationship with hematologists. International presence.” – MO HIC

“...our social media has a strong following and support from other leading local cancer charities.” – MO HIC

“...collaborate with other local and international organisations” – MO HIC

“Getting and communicating updated information through networking and magazines.” – MO HIC

“Work in a network at a national and international level for political advocacy initiatives.” – MO LMIC

“...interacting with medical staff and other health care personnel.” – NMO HIC

“Networking.” – NMO HIC

“We are excellent story tellers, news-gatherers and media savvy reporters, with a long history of relationships globally with specialists, researchers and patient advocates” – NMO HIC

“...meetings with institutions.” – NMO LMIC

“...regional cooperation.” – NMO LMIC

Website

4 organisations mentioned their website.

“We update our patient information materials on the webpage frequently and the information is thorough.” – NMO HIC

C. Education

General education

18 organisations made generalised comments about the education services they provide (9 MOs / 9 NMOs). More organisations in HIC made comments than those in LMIC.

“Patients education.” – MO HIC

“It is solely focused on CLL/SLL, run by people with CLL/SLL and content approved by the [name of organisation removed], so people who use feel we have empathy with condition and advice is accurate as approved by the HCP CLL Community.” – MO HIC

“Patients education and empowerment.” – MO HIC

“Education.” – MO LMIC

“Educating all blood cancer patients.” – NMO HIC

“Education material in multiple formats; podcasts, quick reads in plain language, animated videos,

webcasts, personal stories, practical information, etc.” – NMO HIC

“Educational activities.” – NMO HIC

“We carry out education through social networks for empowerment, management and self-care during this time of pandemic, when everything returns to normal after the pandemic we will resume face-to-face educational tours in the different cities of the country “ – NMO LMIC

“Educational material such as primers, brochures, videos” – NMO LMIC

Awareness

Comments around the awareness of blood cancer/CLL were mainly made by MOs (8 MOs / 3 NMOs). Most organisations cited the awareness they create, although there were some that described how they accomplish it.

“We help people to understand what leukemia is and that it can affect anyone at any age.” – MO HIC

“We are good at highlighting the unmet needs of our patient community and their families.” – MO HIC

“Our organisation is doing well in creating awareness among the patients, their relatives and caregivers.” – MO LMIC

“In the pandemic, since more than a year we have been doing many Facebook live sessions on various topics for creating awareness of cancer” - MO LMIC

“Raising awareness.” – MO LMIC

“...spreading awareness on blood cancers.” – NMO HIC

“Use social media to raise awareness of all types of blood cancer.” – NMO HIC

“Raising awareness.” – NMO LMIC

Conferences

4 organisations told us about the conferences they run.

“Organising patient conferences for CLL patients accompanied by caregivers, with lectures.” – MO HIC

“[Conference name removed] conferences for patients.” – MO HIC

“Educational events such as symposiums, congresses, conferences.” – NMO LMIC

“Conferences.” – NMO LMIC

Disease information

One of the most spoken about topics was disease information (9 MOs / 7 NMOs)

“[Organisation name removed] has many ways to provide disease information and support, allowing patients and caregivers to choose which approach they are most comfortable with.” – MO HIC

“We are dedicated to ensuring that anyone affected by blood cancer receives the right information, advice and support.” – MO HIC

“Various type of education program for CLL patients.” – MO HIC

“Booklet on CLL” – MO HIC

“...we empower people with accredited information” – MO HIC

“contact with patients and caregivers, brochures/leaflets for blood cancers” – MO LMIC

“that they know the treatments and suitable medical attention.” – MO LMIC

“...providing CLL patients and their carers with up-to-date, credible and compassionate information that supports through the entire cancer journey including survivorship.” – NMO HIC

“Providing information by sending brochures for free.” – NMO HIC

“Support for the Patient and their environment, on education regarding Lymphomas, symptoms, treatments, nutrition.” – NMO LMIC

Education for healthcare professionals

2 MOs in HIC spoke about the information they provide for healthcare professionals.

“We support doctors and nurses so that they can provide the best care possible to people with lymphoma/CLL.” – MO HIC

“We save lives through earlier diagnosis. We raise awareness of the signs and symptoms of leukemia and work with healthcare professionals such as GPs, dentists and pharmacists to help them spot leukemia.... We support healthcare professionals to help their patients. We empower GPs and other healthcare professionals to spot leukemia through awareness events and online learning. We provide nurses with tailored conferences, online learning and bursaries to enhance their knowledge of leukemia and patient care.” – MO HIC

Webinars

5 organisations spoke about the webinars they carry out (2 MOs / 3 NMOs)

“Educational webinars.” – MO HIC

“Webinars.” – MO LMIC

“Providing information by organising webinars and symposia.” – NMO HIC

D. Support

Advice from healthcare professionals

4 organisations from HIC (3 MOs / 1 NMO) provide support in the form of advice from healthcare professionals

“We also have an information resource centre where masters level clinicians provide education, disease and treatment information, connection to possible resources and support.” – MO HIC

“Patient information meetings with hematologists” – MO HIC

“...we empower people with accredited information, support from clinical nurse specialists.” – MO HIC

“meetings of patients ..., with the psychologist, with hematology staff” – NMO HIC

Emotional support

8 organisations told us about the emotional support they provide (3 MOs / 5 NMOs).

“...psycho-social support.” – MO HIC

“Psychological aid.” – MO HIC

“...emotional support.” – NMO HIC

“Guiding patients through their journey and give mental support.” – NMO HIC

“...counselling.” – NMO LMIC

“Our association helps new patients a lot to support the disease psychologically.” – NMO LMIC

Financial support

Only 3 organisations specifically spoke about financial support (1 MO / 2 NMO).

“Our financial assistance programs are incredibly valuable to CLL and blood cancer patients.” – MO HIC

“...financial support.” – NMO HIC

“financially helps patients in need as far as possible.” – NMO LMIC

Helpline

2 organisations in HIC provide helplines.

“Running a non-stop telephone helpline to provide information and peer-to-peer support.” – MO HIC

“...telephone support.” – NMO HIC

Peer support

9 organisations commented on the provision of peer support (4 MOs / 5 NMOs), all but 2 were in HIC. Organisations spoke about connecting patients through hosting forums, patient support groups.

“Patient forum” – MO HIC

“peer-to-peer support.” – MO HIC

“Patient support groups.” – MO HIC

“The union of patients.” – MO LMIC

“online meetings of patients (among peers, with other patients who have already undergone their treatment/disease...)” – NMO HIC

“Facebook group for support.” – NMO HIC

“Patient Support Groups.” – NMO LMIC

5.6. Factors supporting service provision

We asked respondents to select the key factors that help them to excel in what they do particularly well (as described in their own words in the previous question).

While the top response was financial assistance from pharmaceutical partners (65%), the results also highlight the importance of volunteers and learning from conferences, with both of these being just under 2/3.

This relates back to the reasons that organisations cited for not being able to provide services being finance and human resources.

Figure 23

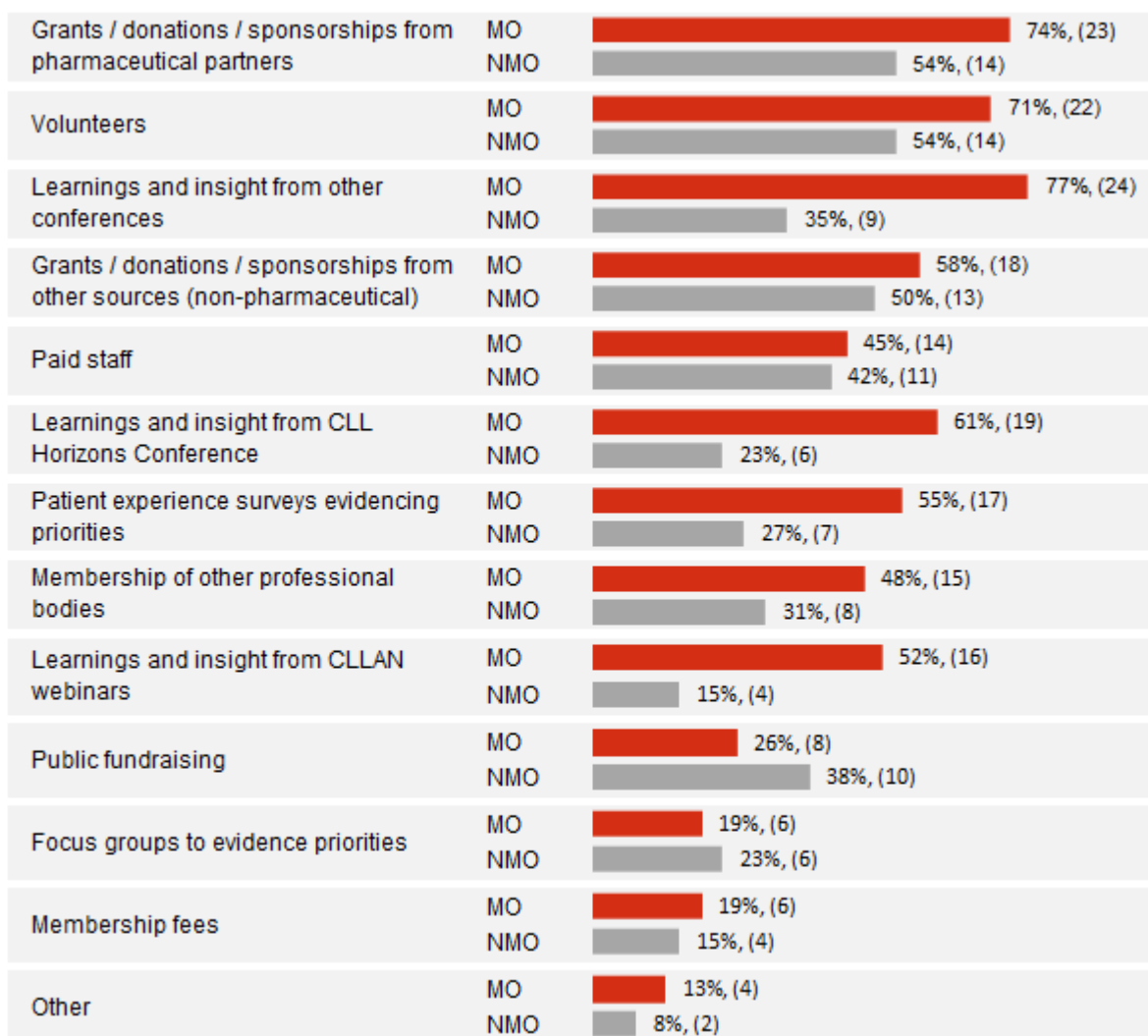
Thinking about your answer to question 8, what are the key factors that help you to do this? (Please tick all that apply)	All	
	n	%
Grants / donations / sponsorships from pharmaceutical partners	37	65%
Volunteers	36	63%
Learnings and insight from other conferences	33	58%
Grants / donations / sponsorships from other sources (non-pharmaceutical)	31	54%
Paid staff	25	44%
Learnings and insight from CLL Horizons Conference	25	44%
Patient experience surveys evidencing priorities	24	42%
Membership of other professional bodies	23	40%
Learnings and insight from CLLAN webinars	20	35%
Public fundraising	18	32%
Focus groups to evidence priorities	12	21%
Membership fees	10	18%
Other	6	11%

There are also some interesting differences between MO and NMOs, with NMOs reporting less input from pharmaceutical partners and more from public fundraising.

The following chart illustrates this (figure 24):

Figure 24

9. Thinking about your answer to question 8, what are the key factors that help you to do this? (Please tick all that apply) – by CLLAN membership status



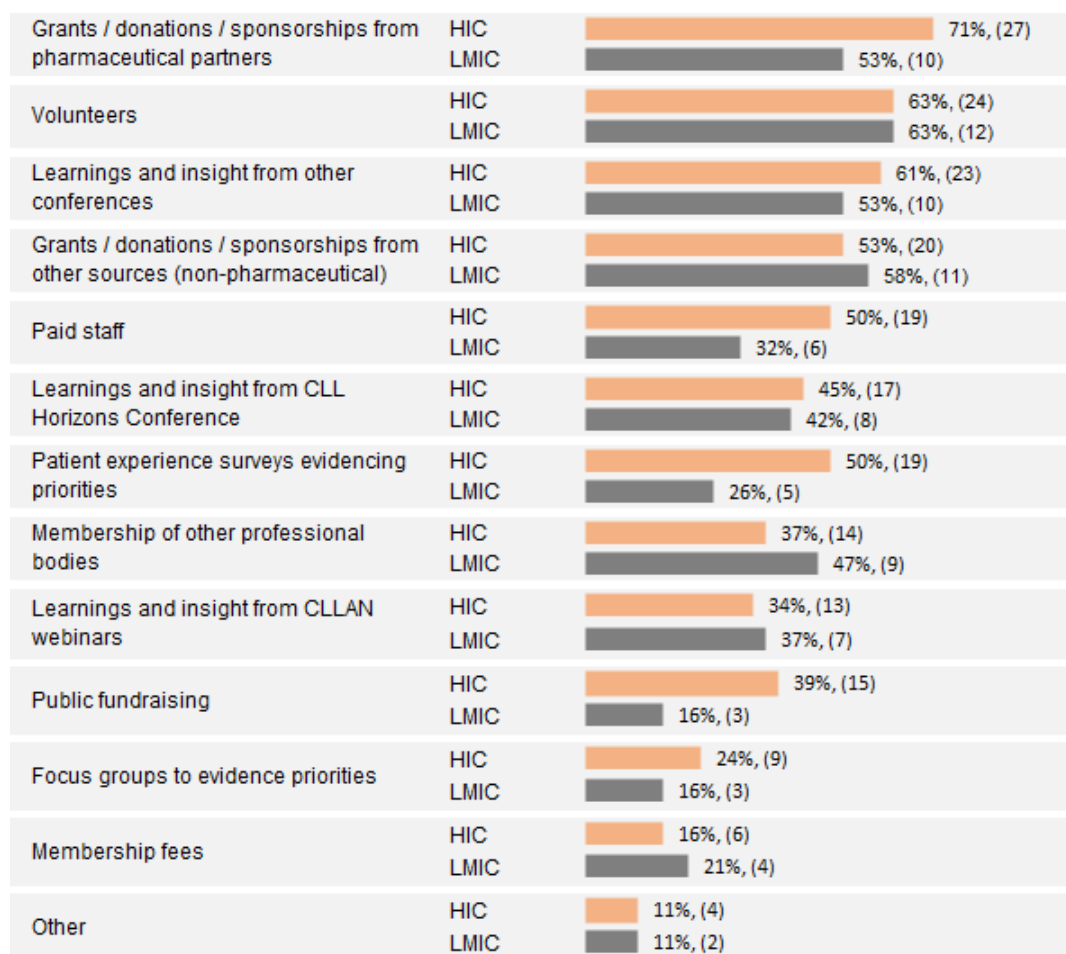
Based on 57 responses (100%)

The responses here would tend to suggest that MOs have the potential to access additional funding opportunities and information from a wider range of sources such as surveys and conferences. This highlights the benefits of membership for organisations and could help to improve the access and reach that NMOs have with patients and the wider community.

A larger percentage of organisations in LMIC cited non-pharmaceutical financial support and their membership of other professional bodies, however less emphasis was placed on public fundraising.

Figure 25

9. Thinking about your answer to question 8, what are the key factors that help you to do this? (Please tick all that apply) – by country development status



Based on 57 responses (100%)

5.7. Section summary

NMOs and organisations based in LMIC are more likely to offer patient specific services exclusively such as patient meetings rather than wider education or policy-based work. Of those NMOs and organisations from LMIC that don't provide some of the patient related services they all suggested that they would like to.

Advocacy, education, communication and support are what organisations themselves feel that they do well although education and communication was more likely to be cited in HIC.

MOs and organisations in HIC are more likely to gain pharmaceutical or other more structured sponsorship than NMOs/LMIC.

Printed information is the most common support information produced by organisations however MOs and organisations based in HIC are much more likely to provide digital/online information than NMOs and organisations from LMIC. Half of all organisations would like to provide an app as part of their support provision. Information produced by MOs is also more likely to target CLL patients and their carers specifically than NMOs.

Lack of human resources and lack of finance are the main reasons across the board as to why organisations are unable to offer the services that they would like to with finance issues seen as the greatest barrier in LMIC.

Support to identify and access funding opportunities will help organisations, particularly those in LMIC, to maximise their services and sharing of best practice and resources between organisations may support organisations with their human resource issues. Support for NMOs to take up membership may help them to provide more specific CLL information and support by being able to access and share resources. Being able to work collaboratively and learn from other organisations is a key way that organisations across the globe can develop. The opportunity to develop shared learning and shared resources to improve access to funding, including for example, support to develop successful bids could be a key benefit for organisations.

6. Support from CLLAN

Organisations were asked how likely they thought they would use specific resources if CLLAN provided them.

6.1. Services and resources through CLLAN

The table below illustrates the percentage of those who said they would be likely/very likely to use them. Between 2 and 4 organisations didn't respond to each question.

Figure 26

How likely are you to use the following CLLAN resources? ¹	All	
	n	%
Best practice sharing	49	89%
Regular updates via newsletter "CLL Matters"	45	83%
Regular updates via social media	40	73%
Virtual conferences for capacity building, digital learning and networking	40	73%
Face to face capacity building events / learning events such as conferences	40	73%
Training / courses, e.g. online learning modules	40	71%
Regular updates via the website	35	66%
Webinars for capacity building and digital learning	34	62%

The differences between MO and NMO's answers are not as pronounced as between organisations in HIC and LMIC.

A higher percentage of organisations in LMIC said they would be likely/very likely to use all the resources listed.

Best practice sharing was the resource organisations said they would be most likely to use. In order to meet this CLLAN needs to collate examples from organisations to define what best practice looks like.

^{1,2} Best practice sharing - 55 responses; Regular newsletter updates - 54 responses; Regular social media updates - 55 responses; Virtual conferences - 55 responses; Face to face events - 55 responses; Training / courses - 56 responses; Regular website updates - 53 responses and Webinars - 55 responses.

Figure 27

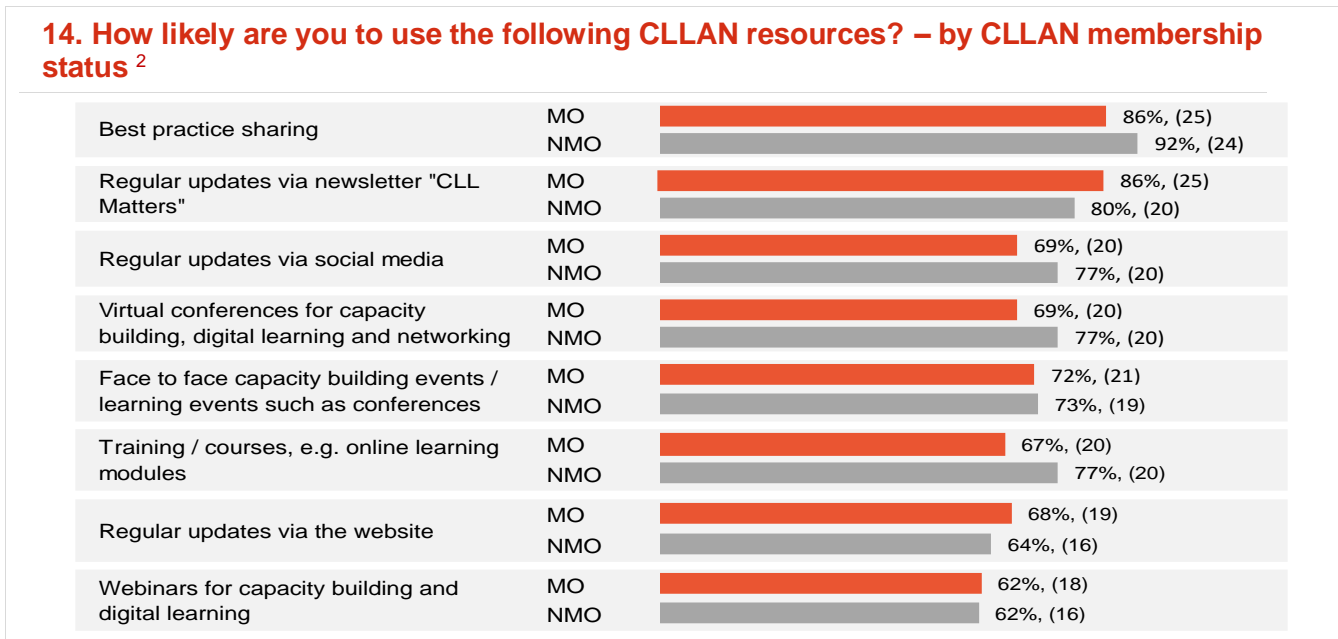
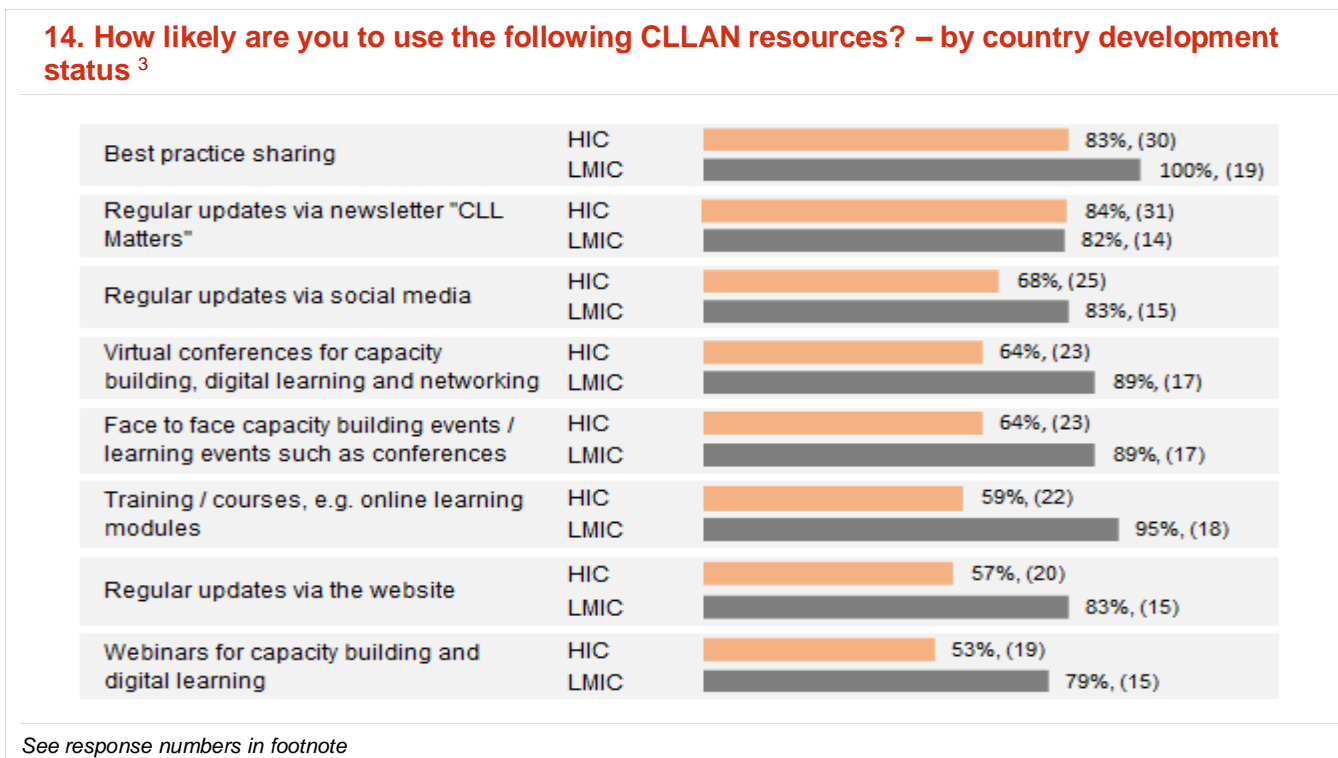


Figure 28



Across the board, the responses to these questions were positive from around 2/3 or more of the respondents showing that organisations are engaged with CLLAN and the work that the network is involved in. It is quite clear that the sharing of best practice and resources is a high priority for organisations, particularly in ways that they can be regularly updated such as by the use of social media and newsletters.

³ Best practice sharing - 55 responses; Regular newsletter updates - 54 responses; Regular social media updates - 55 responses; Virtual conferences - 55 responses; Face to face events - 55 responses; Training / courses - 56 responses; Regular website updates - 53 responses and Webinars - 55 responses.

6.2. Themes for CLLAN to support on

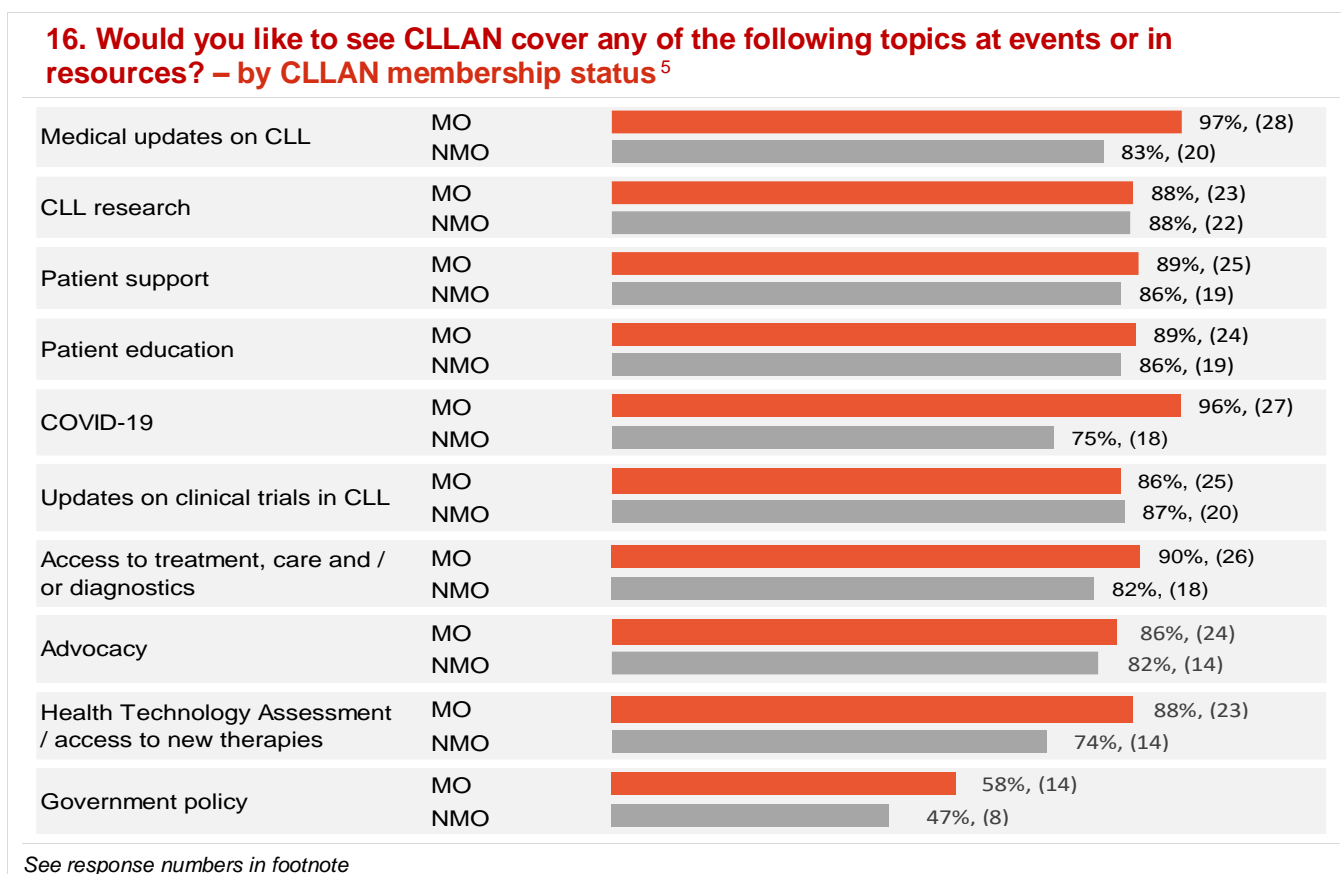
Organisations were asked if they would like to see CLLAN cover specific topics at events or in resources.

The table below (figure 29) illustrates the percentage of those who said 'Yes', they would like to see the topic covered by CLLAN. A high proportion of organisations who answered the questions indicated an interest in all the topics listed, with the exception of Government policy.

Figure 29

16. Would you like to see CLLAN cover any of the following topics at events or in resources? ⁴	All	
	n	%
Medical updates on CLL	48	91%
CLL research	45	88%
Patient support	44	88%
Patient education	43	88%
COVID-19	45	87%
Updates on clinical trials in CLL	44	86%
Access to treatment, care and / or diagnostics	38	84%
Advocacy	22	84%
Health Technology Assessment / access to new therapies	37	82%
Government policy	22	54%

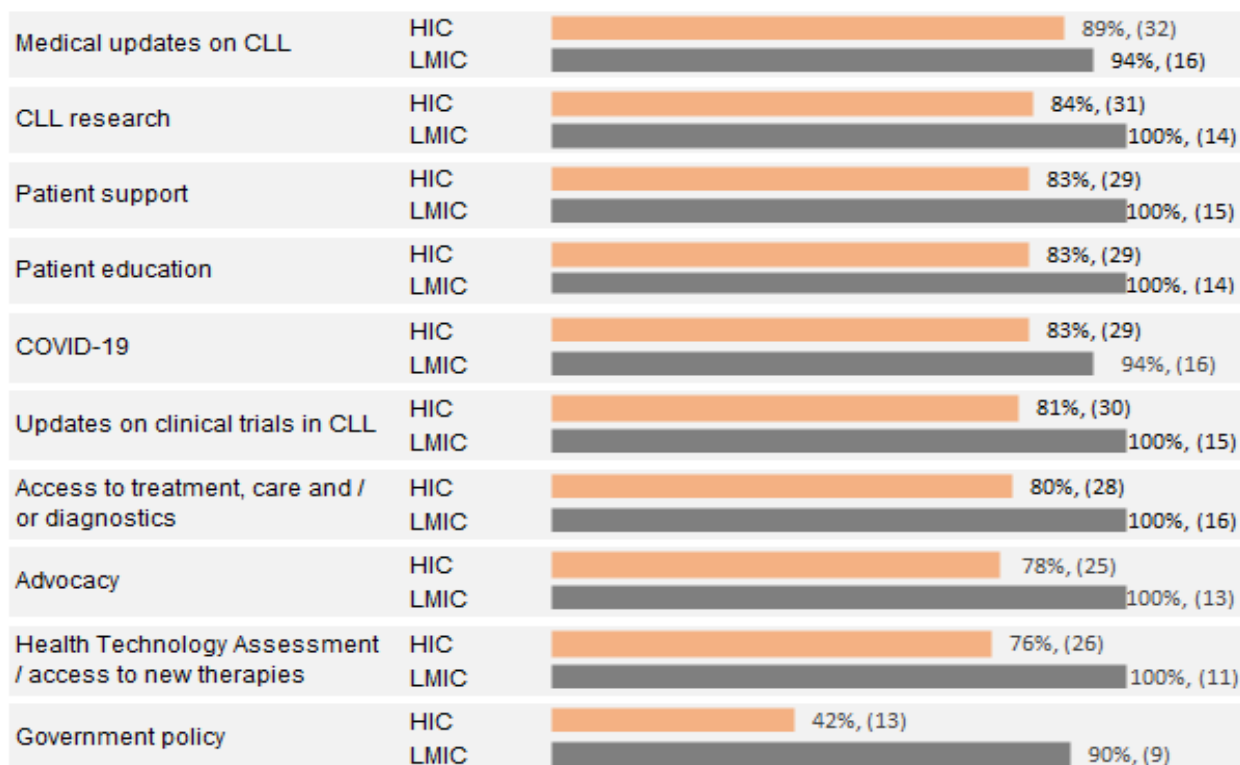
Figure 30



^{4,5} Medical updates on CLL - 53 responses; CLL research - 51 responses; Patient support - 50 responses; Patient education - 49 responses; COVID-19 - 52 responses; Updates on clinical trials in CLL - 52 responses; Access to treatment, care and / or diagnostics - 51 responses; Advocacy - 45 responses; Health Technology - 45 responses; Assessment / access to new therapies - 51 responses and Government policy - 41 responses

Figure 31

16. Would you like to see CLLAN cover any of the following topics at events or in resources? – by country development status⁶



See response numbers in footnote

6.3. Section summary

The provision of resources by CLLAN for use by organisations was positively received across the board. Regular updates and the sharing of best practice are the resources that would be most likely to be used by organisations.

Organisations from LMIC were more likely to use all resources produced on all the topics suggested than those from HIC. This echoes other findings that organisations from LMIC are the most in need of support to upskill themselves and maximise the services that they are able to provide.

The most popular topics for resources are:

- Updates on research
- Treatment
- Clinical trials
- Support for patients

This provides a good indication for CLLAN for the resources that organisations would like to access and how best to support member organisations.

⁶ Medical updates on CLL - 53 responses; CLL research - 51 responses; Patient support - 50 responses; Patient education - 49 responses; COVID-19 - 52 responses; Updates on clinical trials in CLL - 52 responses; Access to treatment, care and / or diagnostics - 51 responses; Advocacy - 45 responses; Health Technology - 45 responses; Assessment / access to new therapies - 51 responses and Government policy - 41 responses

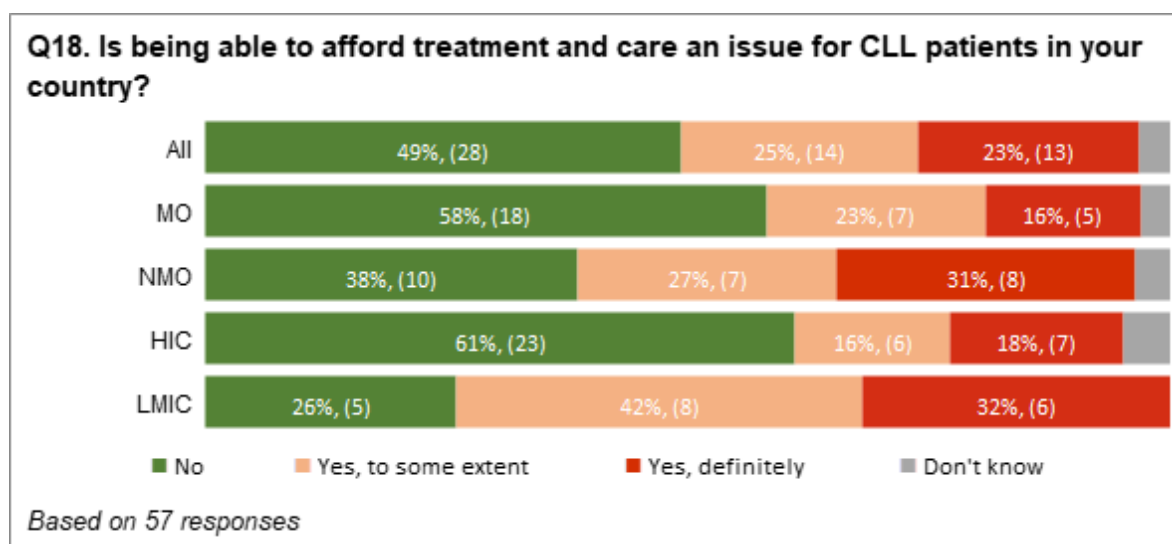
7. Access to CLL Healthcare prior to the COVID-19 Pandemic

This section of the survey focused on the healthcare situation of CLL patients worldwide before the impact of the COVID-19 pandemic. Organisations were asked to express their views on access to healthcare for CLL patients before the pandemic.

48% of all organisations reported that it was an issue for CLL patients to be able to afford treatment and care in their own country (23% reporting this was definitely an issue, 25% to some extent).

However, only 26% of patients in LMIC had access to affordable care and treatment versus 61% in HIC. There are also some interesting differences between MO and NMOs, with NMOs reporting CLL patients having more difficulty in accessing affordable treatment and care. Again, this could relate to higher economic deprivation in LMIC. The following chart illustrates this (figure 32).

Figure 32



7.1. Organisations' views on treatment and care issues

The organisations were asked to tell in their own words why affording treatment and care was an issue for CLL patients in their country; 25 organisations responded (11 MOs and 14 NMOs) with 12 organisations in HIC and 13 in LMIC.

Three main areas where negative impact was reported were cost of treatments, access to specialist centres and availability of new treatments.

Cost of treatments

“Since average age of diagnosis is 70 years old, many of the CLL patients are on [name of insurer removed]. There is a significant cost to patients. While co-pay programs help many, some exceed the income limits and although higher income cost would be prohibitive, patient assistance programs are not able to help [name of insurer removed] recipients.” – NMO HIC

“Cost of new treatments is huge, especially if one does not have insurance; we do not have a robust national healthcare insurance program.” – MO LMIC

“Due to the deplorable economic situation in the country and the lack of access to an efficient health system. The high costs of medicines, complementary studies and medical consultations.” – NMO LMIC

“Because the medication for the treatment of CLL and other kind of blood cancers are very expensive. That is why the rural patients can't afford the treatment for CLL and other kind of blood cancers.” – MO LMIC

Access to treatment centres and specialists

“Access to latest treatments for many segments of our population is not good; country size makes access to centres of excellence, trial sites and specialists more difficult for CLL patients in remote areas especially.” – MO LMIC

“Care is offered in tertiary health care facilities where you find specialists. CLL specialists are very few so in most parts of the country they are not available. It takes time to make a correct diagnosis of CLL in the rural areas and when the diagnosis is eventually suspected, patients have to travel to towns with the tertiary hospitals so they can access diagnosis and care. Even in the towns, the care they provide is not what you read in CLL updates, but rather what is available which doesn't always work for all patients”. – NMO LMIC

“Travelling costs to and from treatment may be an issue.” – NMO HIC

Availability of new treatments

“We feel that innovative therapies take time to be incorporated into the clinical practice.” – MO HIC

“Not on the reimbursement list yet due to limited health budget”. – MO LMIC

“Access to new drugs, especially in combination is definitely a big issue.” – MO HIC

“Treatments for LLC patients are very expensive and social security does not acquire them for the same reason”. – NMO LMIC

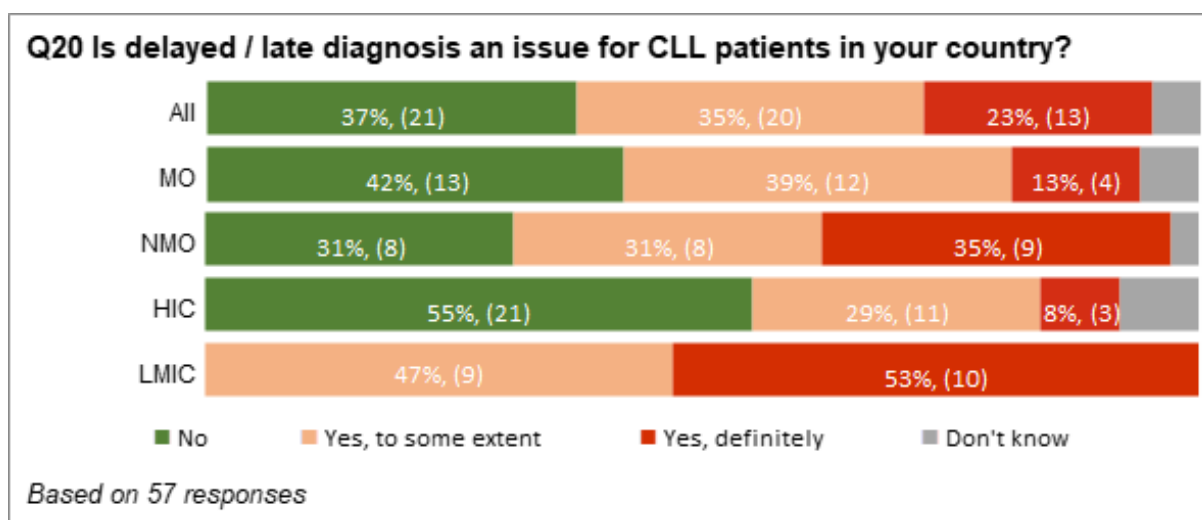
“Lack of access to innovative drugs for the treatment of CLL.” – MO LMIC

“Our drug approval system is one of the slowest in Europe and the cost of drugs is a reason they are not approved.” – MO HIC

7.2. CLL late diagnosis and GP's knowledge of CLL

58% of all organisations stated that their CLL patients had experienced delays or delays to some extent in receiving a diagnosis. The differences between MOs and NMOs answers are not as pronounced as between organisations in HIC and LMIC. All respondents from LMIC felt that there was a delay in diagnosis, with 53% of organisations reporting that delayed diagnosis was definitely an issue with an additional 47% reporting patients faced delays to some extent. In stark contrast, only 37% of organisations in HIC felt that there was a delay to diagnosis for patients.

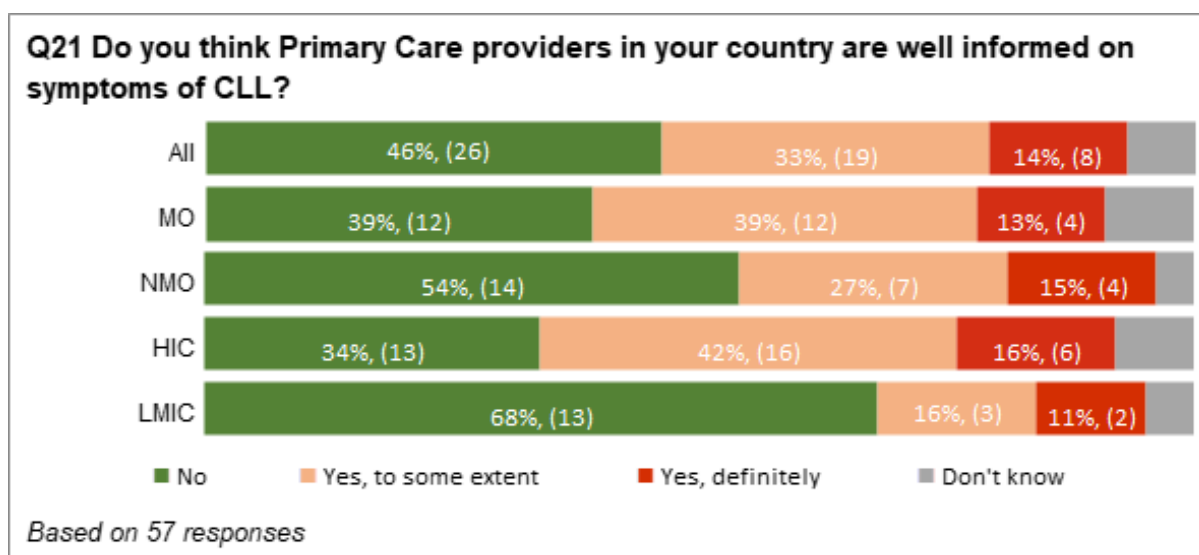
Figure 33



(100% response rate)

46% reported that in their country, family doctors/general practitioners were not well informed on the symptoms of CLL. The percentages were higher for NMOs (54%) and organisations in LMIC (68%).

Figure 34



(100% response rate)

Clearly, organisations feel that there is both a lack of knowledge around CLL within primary care and that there is a delay to diagnosis for patients. This is much more pronounced in LMIC. Tackling awareness and education within primary care settings, particularly in LMIC and cultivating closer links between organisations and primary care will help to reduce this deficit and improve the experience of patients.

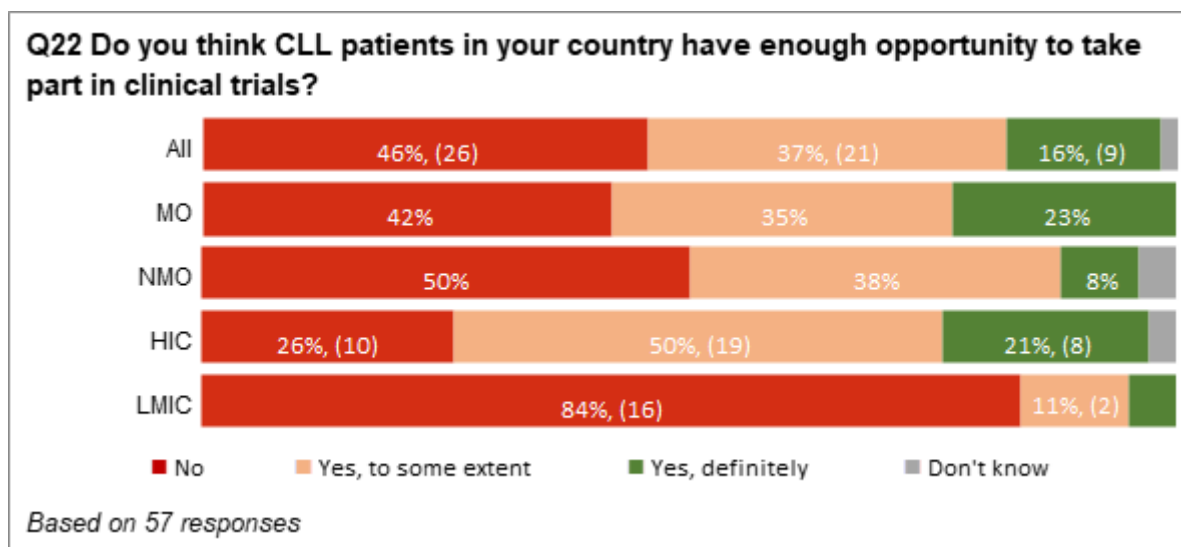
7.3. Access to clinical trials and new therapies

46% of organisations reported that their CLL patients do not have enough opportunities to take part in clinical trials for new CLL treatments. The discrepancy between HIC and LMIC is very pronounced with 84% of organisations in LMIC reporting a lack of clinical trial opportunities versus only 26% of organisations in HIC.

With clinical trials being a significant part of the development of treatments for CLL, this finding is concerning. The production of a clinical trials directory as previously established may help to provide a platform for patients to access clinical trials. However, the opportunities may be lower in LMIC.

Providing organisations with local information about what is currently available as well as knowledge of potential treatments being trialled more widely will empower organisations to advocate for their patients and the CLL community to access more advanced treatments.

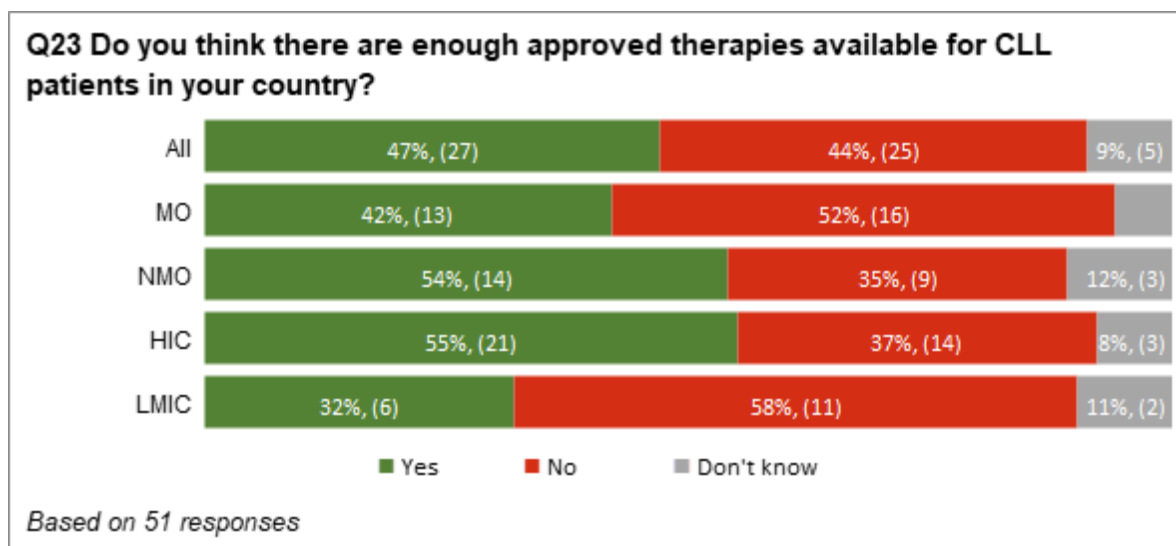
Figure 35



(100% response rate)

47% of all organisations agree that there are enough approved therapies available for CLL patients in their own country. However, in LMIC (58%) and among MOs (52%) over half of the organisations reported a lack of approved therapies available. This continues the picture that patients in LMIC do not have an equitable service to those in HIC and organisations should be empowered to look to address these issues.

Figure 36

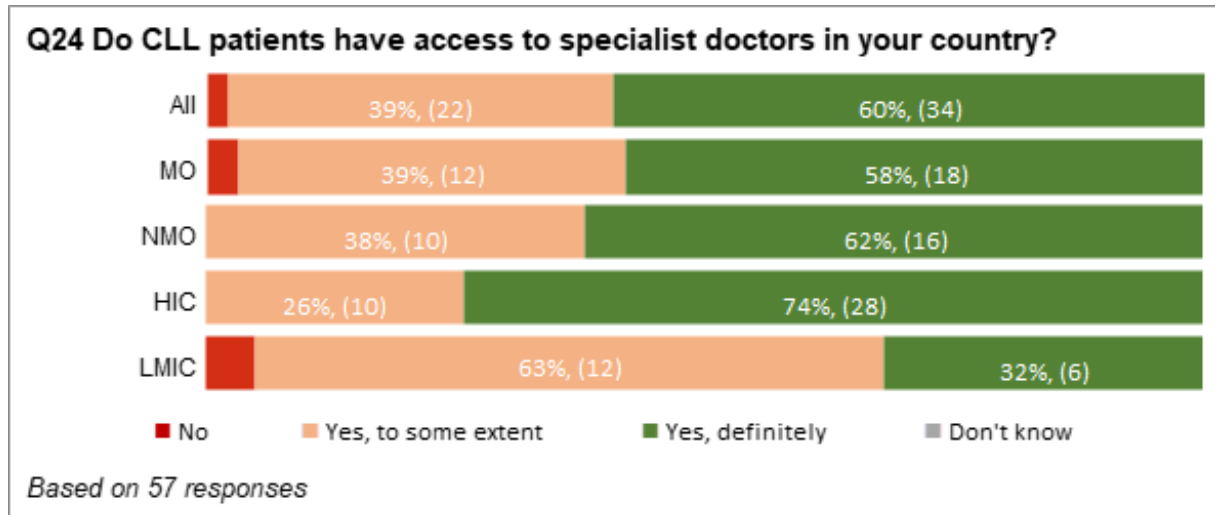


(89% response rate)

7.4. Access to CLL specialists and specialist centres

Almost all organisations reported that their CLL patients have access or access to some extent to specialist doctors in their own country (99%). The difference between MOs and NMOs answers are not as pronounced as between organisations in HIC and LMIC. 32% of organisations in LMIC stated patients definitely have access to specialist doctors versus 74% in the HIC.

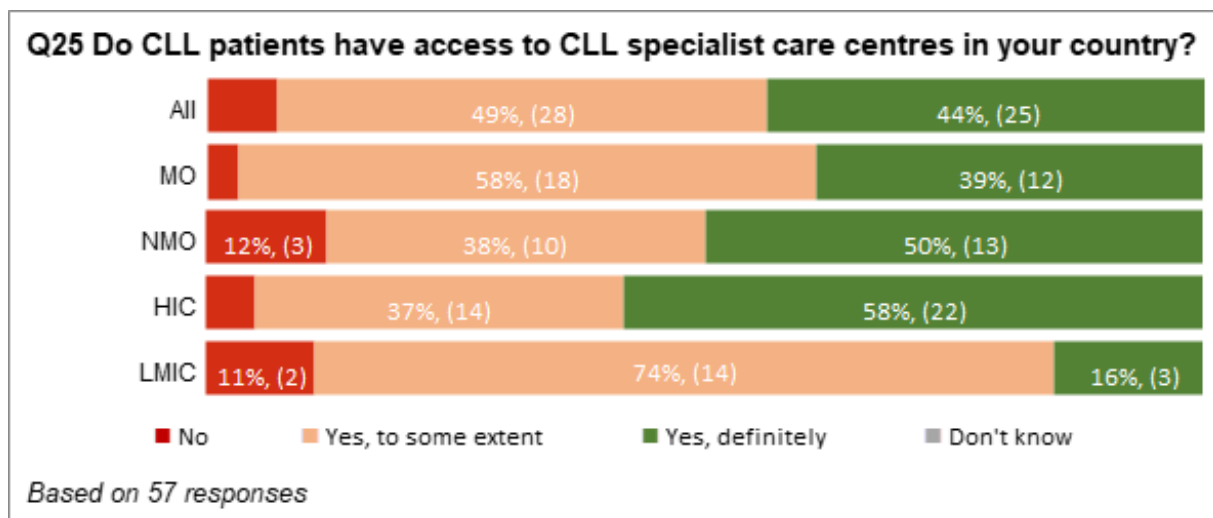
Figure 37



(100% response rate)

Overall, most organisations reported that their CLL patients definitely or to some extent have access to CLL specialist care centres. However, in LMIC only 16% have access to CLL specialist centres. More concerning is the fact that 12% of NMOs and 11% of LMIC organisations report that their patients do not have access to CLL specialist centres.

Figure 38



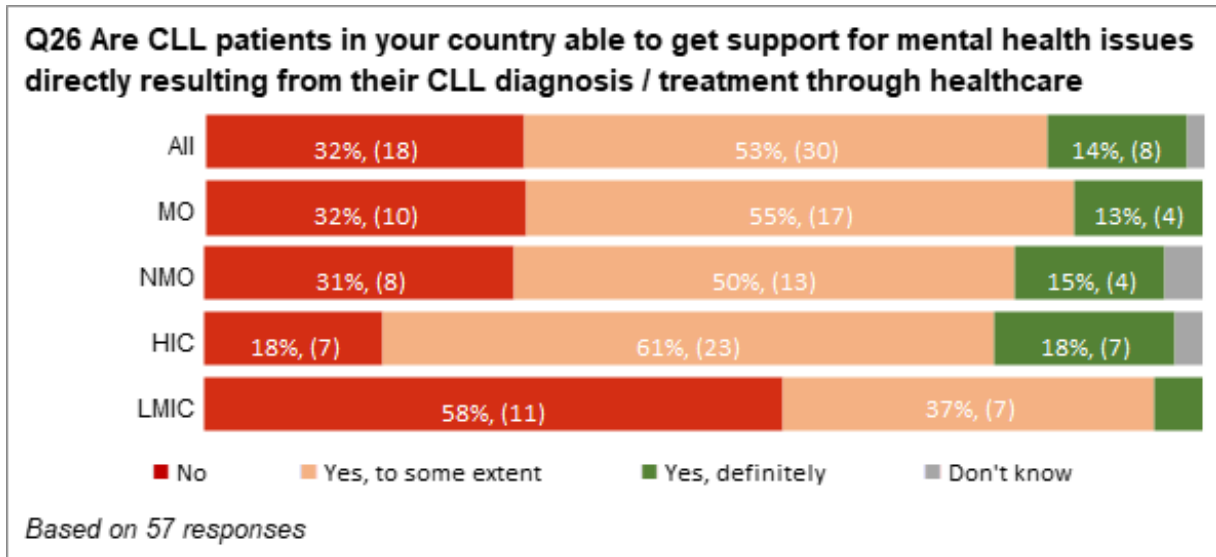
(100% response rate)

The contrast between LMIC and HIC here across each aspect is of concern. This would suggest that there is a discrepancy in outcomes between patients diagnosed with CLL in LMIC and HIC, an important consideration when looking at the global picture for CLL.

7.5. Patients' mental support

Only a small portion of all organisations (14%) reported that their CLL patients who experienced mental health issues as results of their CLL diagnosis/treatment definitely received support through their healthcare system. A further 53% felt that patients received support to some extent. However, 58% of organisations in LMIC reported a lack of mental health support for patients.

Figure 39



(100% response rate)

7.6. Section summary

Overall, in this section we can see that the survey paints the picture that patients in LMIC are less likely to:

- Have access to affordable therapies
- Access to mental health support
- Access to specialist doctors and specialist centres
- Access to approved therapies
- Access to clinical trials

We have also seen that LMIC seem to have fewer support services for patients and CLL support organisations are less likely to be involved in wider education, knowledge, and policy work than their counterparts in HIC.

As such, this would all suggest that there are currently fewer positive outcomes for patients in these countries than for those living in HIC.

To reduce the current geographical disparity here for patients and their carers, CLLAN and support organisations should work collaboratively with policy makers, healthcare providers and pharmaceutical companies. This will enable patients to have better access to the most appropriate treatments, clinical trials and the breadth of support that they need to effectively manage this progressive condition.

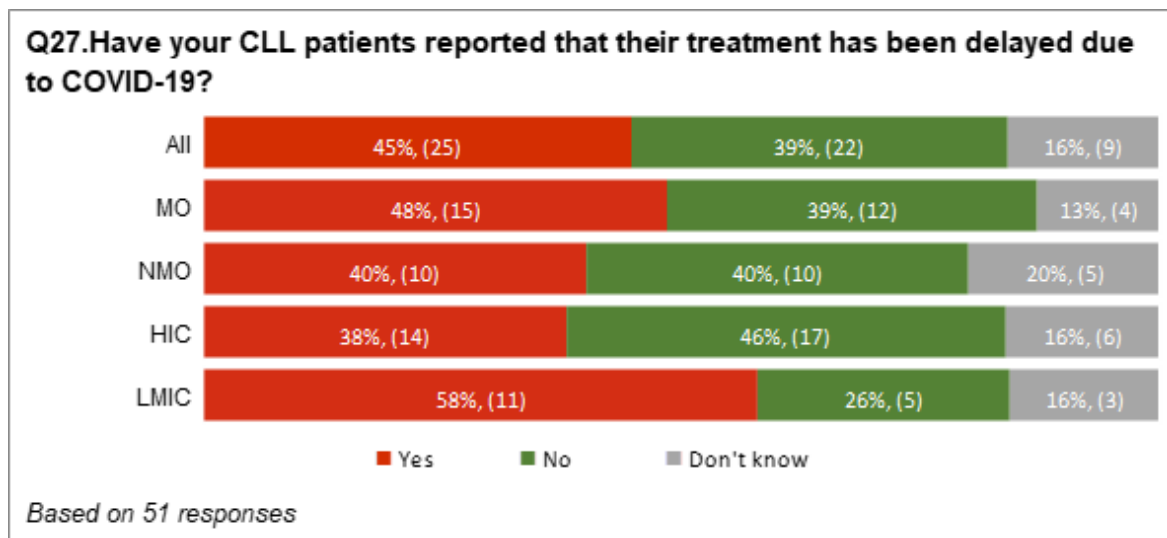
8. Impact of COVID-19 on Access and Delivery of CLL Treatment and Care

This section of the survey focused on the impact that the COVID-19 pandemic had on patients and CLL organisations. Organisations were asked to tell us about their views on how the CLL patients they support were impacted by COVID-19.

8.1. Access to care

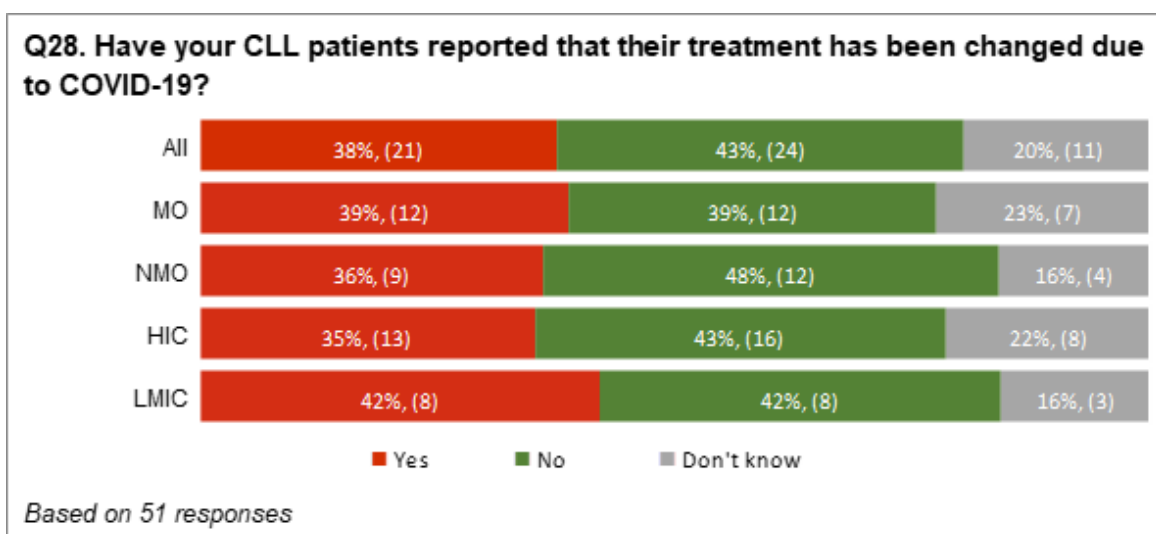
45% of organisations said that their CLL patients reported that their treatment had been delayed due to COVID-19, with the highest proportion being within those in LMIC (58%).

Figure 40



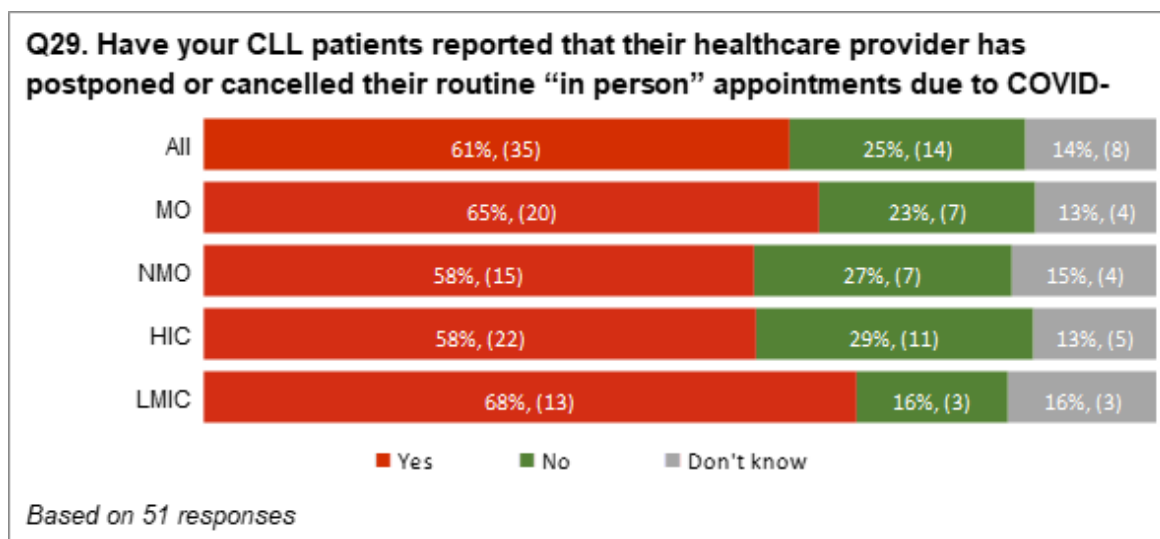
38% said that their CLL patients reported that their treatment had been changed, again with the highest proportion being within those in LMIC (42%).

Figure 41



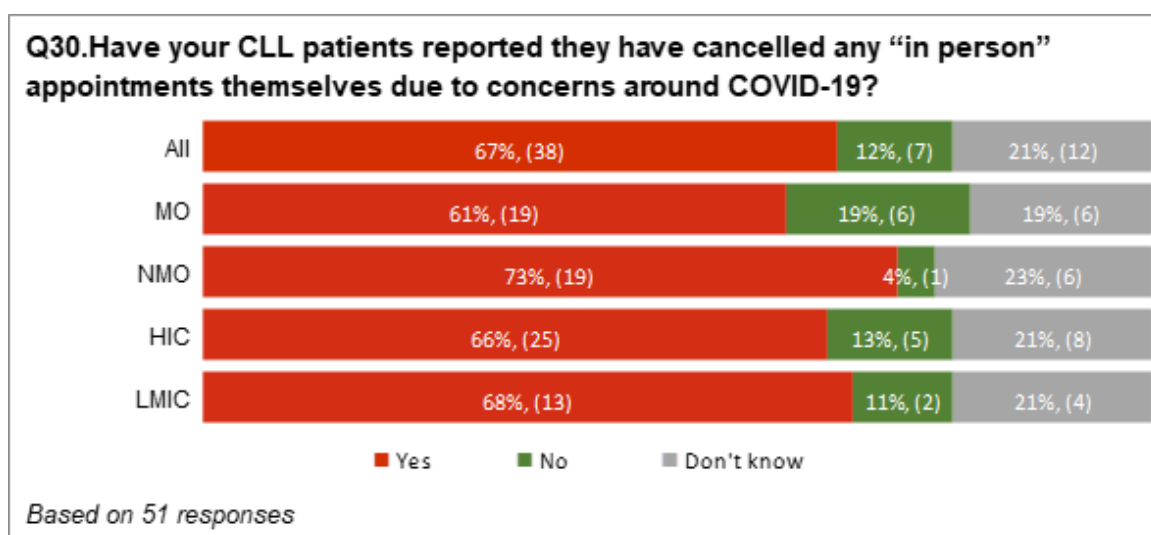
61% of organisations reported that their CLL patients' healthcare provider had postponed or cancelled routine in person appointments. This was higher (68%) for organisations in LMIC.

Figure 42



67% of organisations reported that their CLL patients had postponed or cancelled routine in person appointments. This was quite similar for organisations in HIC and LMIC. With 73%, NMOs have the highest proportion of organisations saying that this was the case.

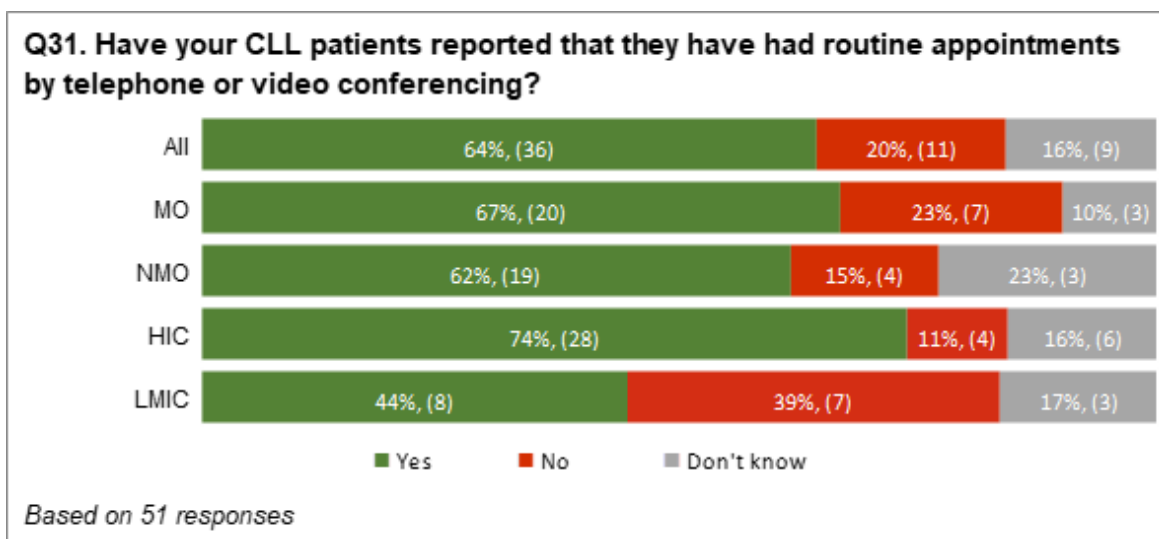
Figure 43



64% of organisations reported that their CLL patients were having remote routine appointments. There was a pronounced difference between organisations in HIC and LMIC, with 74% from HIC reporting that this was the case as opposed to 44% from LMIC.

In addition, nearly 1/4 of NMOs didn't know if this was happening or not.

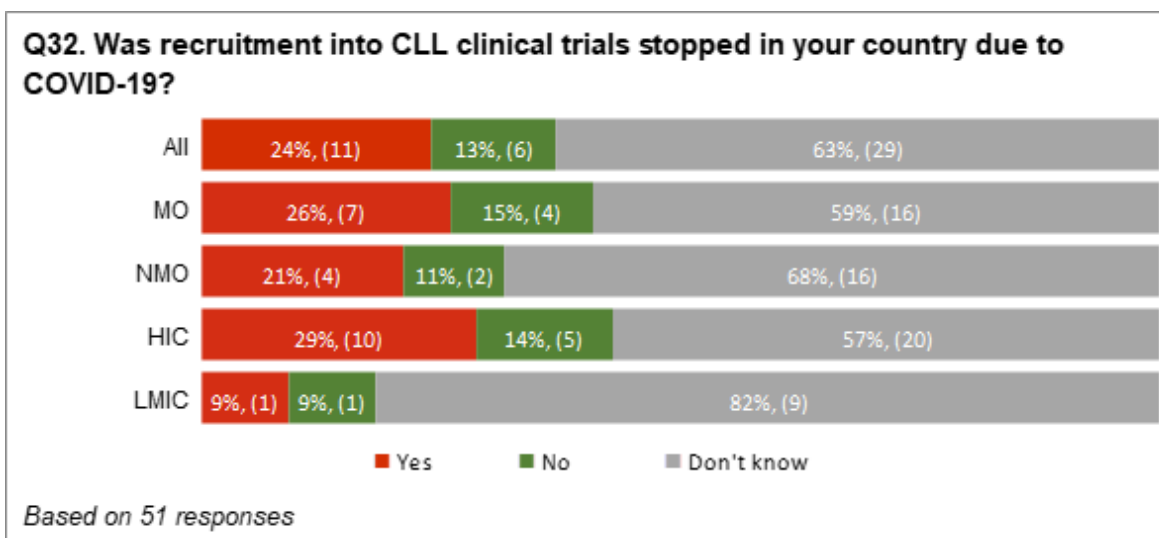
Figure 44



8.2. Clinical Trials

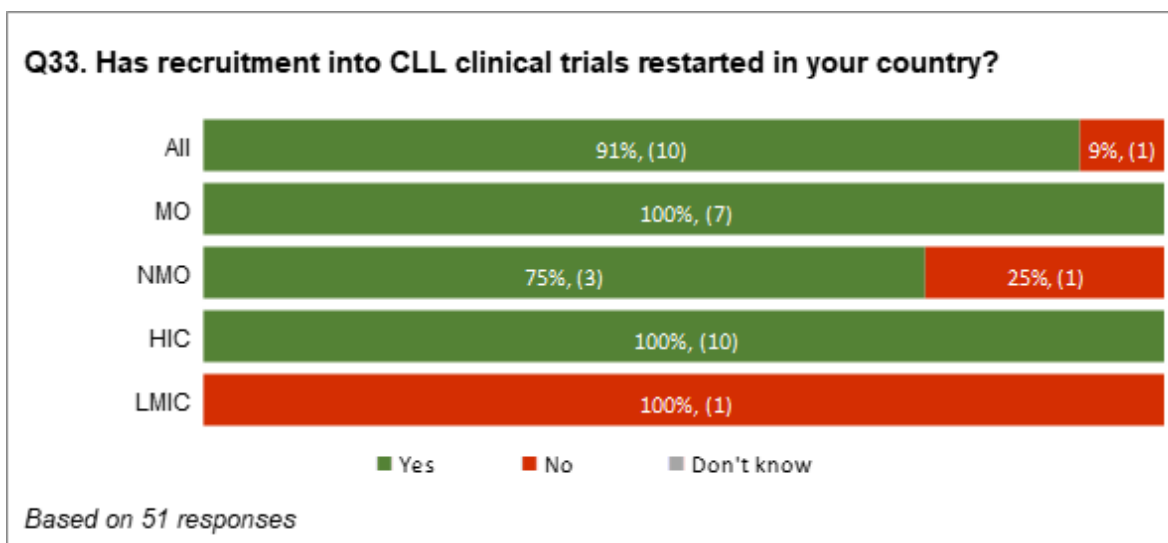
Where applicable, nearly 24% of organisations reported that recruitment into CLL trials had stopped, however more pronounced was that just 63 % did not know what the status was. This would seem to suggest that the landscape during COVID-19 is unclear.

Figure 45



Of the 11 organisations who said recruitment into trials stopped during the pandemic, 10 reported that it has since restarted, however all of these were in HIC. 42% of organisations in LMIC stated that clinical trial recruitment was not applicable and 82% were not aware whether clinical trial recruitment had stopped or not. This links to the much lower number of opportunities to participate in clinical trials reported in LMIC (only 16%).

Figure 46



8.3. Section summary

Yet again in this section there was an identifiable difference between organisations in HIC and those in LMIC. Challenges to healthcare provision for patients during COVID-19 were more pronounced in LMIC than HIC.

A high proportion of patients themselves were changing their 'in person' appointments suggesting that patients were very concerned about the impact that COVID-19 might have on them. The use of remote technology for appointments was much more likely to be used in HIC and therefore potentially caused less disruption to treatment in these countries.

Clinical trials were disrupted during COVID-19 however the extent and impact of this is unclear from this survey as many organisations were unaware of the current situation.

Sharing resources across the globe and supporting organisations to adapt their services using technology and other more innovative methods will help patients to access services in a way that makes them feel safe. This includes the need to promote and encourage the use of clinical trials across the globe and to increase the knowledge and education of patients and healthcare practitioners in current clinical trials.

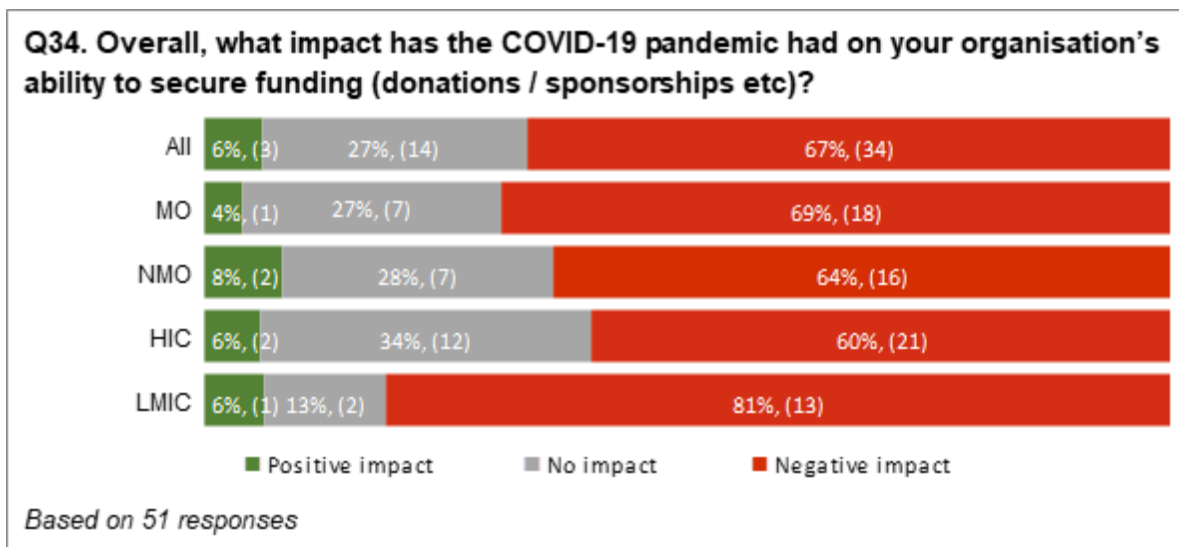
9. Impact of COVID-19 on delivery of CLL Support Services

The timing of the survey allowed a unique opportunity to understand the impact COVID-19 had on the organisations’ abilities to deliver their services to CLL patients. Respondents were asked what changed during the global pandemic, what challenges they have faced and if they have been able to adapt as a consequence.

9.1. Impact on securing funding

Organisations were asked what overall impact the COVID-19 pandemic had on their ability to secure funding. Of those respondents who felt they could answer, 67% said that the impact was negative. LMIC had the largest proportion of organisations reporting a negative impact (81%). When considering the more in-depth responses from organisations detailed on the following page the only real positive change was an uplift in some funding from pharmaceutical companies to organisations in HIC.

Figure 47



We asked organisations to tell us in their own words what impact COVID-19 has had on their ability to secure funding. Only 33 of the organisations responded (17 MOs and 16 NMOs), with 20 organisations in HIC and 13 in LMIC. Two main areas where negative impact was reported were a reduction in grants, sponsorship and funding from ‘major donors’ and the cancellation of large fundraising events.

Major donors

“The pharma did not fund anything because of the pandemic.” – MO HIC

“Major donors have begun to allocate money to a greater extent to overcome COVID-1.” – MO LMIC

“...conservatism in major donor philanthropy.” – NMO HIC

“Sponsorships have decreased a lot and they want projects for another type of blood cancer.” – NMO LMIC

Large fundraising events

“We have been unable to have funding events.” – MO HIC

“Cancelling of large-scale fundraising events.” – NMO HIC

“It has not been possible to carry out events from which we normally obtain funds to be able to continue working.” – NMO HIC

Reluctance to donate/volunteer

Organisations also felt that individuals were less likely to donate/volunteer due to personal hardships.

“People were less willing to donate during times of financial instability.” – MO HIC

“Less financial support and limited voluntary work.” – NMO LMIC

“With the Covid the population has suffered financially and all people of good will have preferred to keep what little they have.” – NMO LMIC

Increased fund from pharmaceutical companies

There were a small number of organisations (3) who spoke about a positive impact on funding due to COVID-19 which was credited to increased funding from pharmaceutical companies. All of these were in HIC.

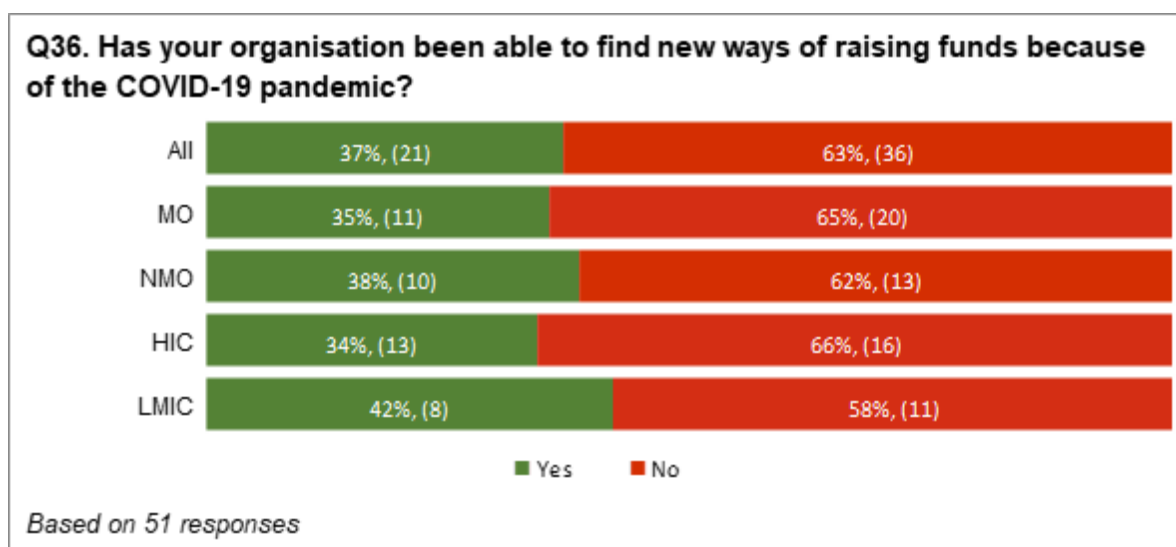
“More grants and funding from Pharma; we doubled our income.” – MO HIC

“Pharma's have increased funding.” – MO HIC

“More money from pharmaceutical companies.” – NMO HIC

Encouragingly, 37% of organisations reported that they had been able to find new ways of raising funds due to COVID-19. A slightly higher proportion of NMOs (38%) and organisations in LMIC (42%) said that they had been able to access new ways of funding.

Figure 48



21 organisations told us in their own words how they had found new ways of fundraising. 11 MOs and 10 NMOs with 13 organisations in HIC and 8 in LMIC.

The majority of organisations spoke about raising funds 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. 4 respondents spoke about getting funding or grants.

Virtual fundraising

“Adapted some regular events to make online/COVID-19 safe.” – MO HIC

“Digital fundraising activities, events and initiatives.” – MO HIC

“Virtual events.” – MO HIC

“Online collection platform. We had made an agreement prior to the pandemic with an E-commerce company, the advent of covid and the restrictions generated that all the collection of individual donors was through this means.” – MO HIC

“Reaching out using social media and lots of phone calls.” – NMO HIC

“We ran a number of virtual challenges to encourage supporters to fundraise.” – NMO HIC

“...online events...” – NMO HIC

“Doing small FR events.” – MO LMIC

“Ask personal donors” – MO LMIC

Grants or funding

“Applied for some emergency funding. Appeals.” – MO HIC

“Training in regulations on public resources to bid for projects sponsored by public institutions.” – MO LMIC

“We were able to access other sources of funding, e.g. government grants.” – NMO HIC

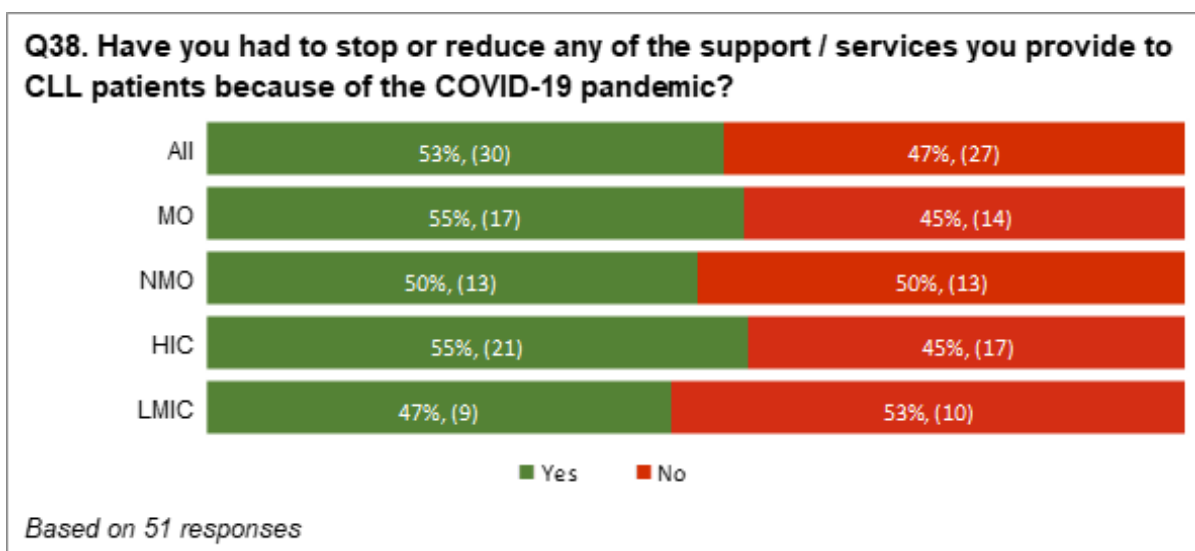
“Government special fund.” – NMO LMIC

9.2. Change to support provision

53% of organisations had to stop or reduce some of the support / services they provide to CLL patients because of the COVID-19 pandemic.

Interestingly a slightly higher proportion of MOs and organisations in HIC said this was the case and this may be because they provide a wider range of services around education, research and policy. This may also have been impacted by more stringent and widespread restrictions during the height of the pandemic (figure 49).

Figure 49



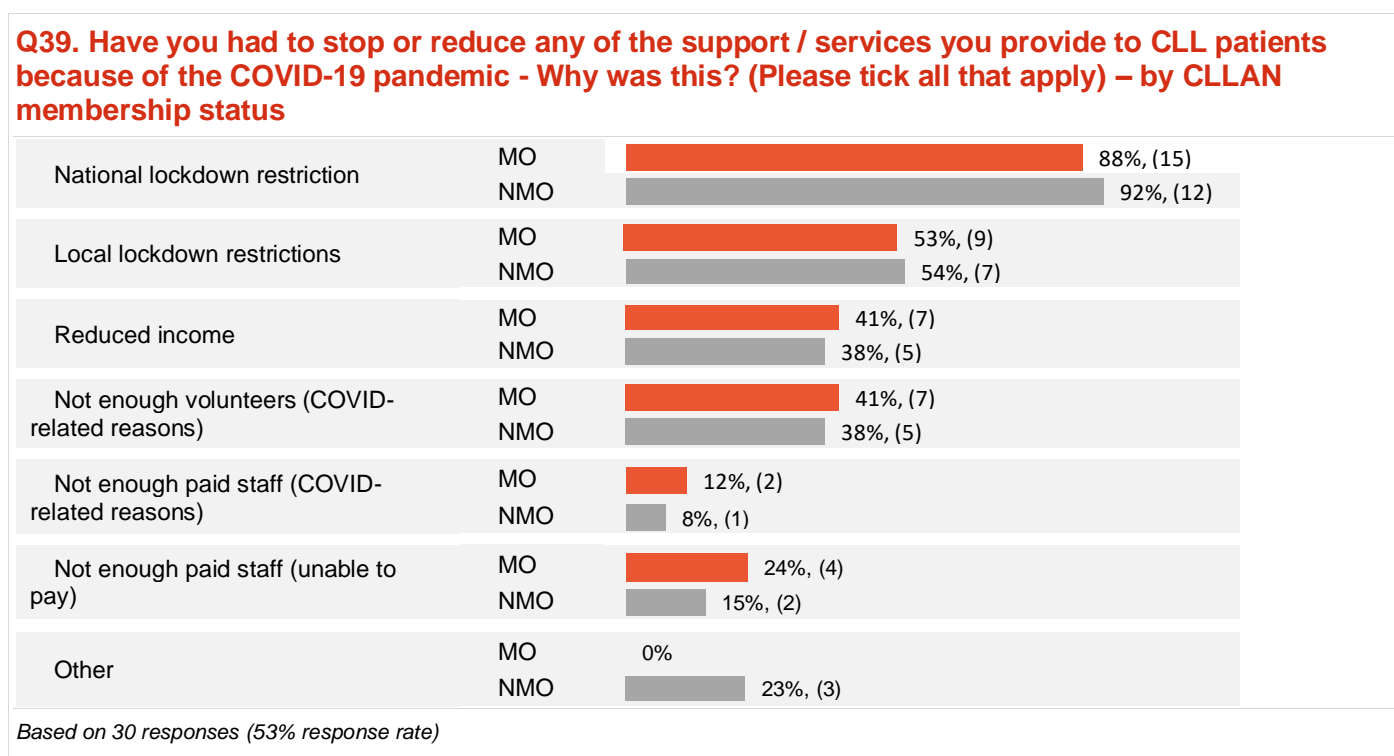
We asked the organisations who said they had stopped or reduced services to give the reasons for this. Lockdown restrictions were by far the highest reported reason, followed by reduced income and lack of volunteers. See the table below (figure 50).

Figure 50

Q39. Have you had to stop or reduce any of the support / services you provide to CLL patients because of the COVID-19 pandemic - Why was this? (Please tick all that apply)	All	
	n	%
National lockdown restriction	27	90%
Local lockdown restrictions	16	53%
Reduced income	12	40%
Not enough volunteers (due to shielding or other COVID-related reasons)	12	40%
Not enough paid staff (unable to pay)	6	20%
Not enough paid staff (due to shielding or other COVID-related reasons)	3	10%
Not enough paid staff (unable to pay)	6	20%
Other	3	10%

Looking at MOs and NMOs, there was little difference in the reasons for organisations stopping or reducing services (figure 51).

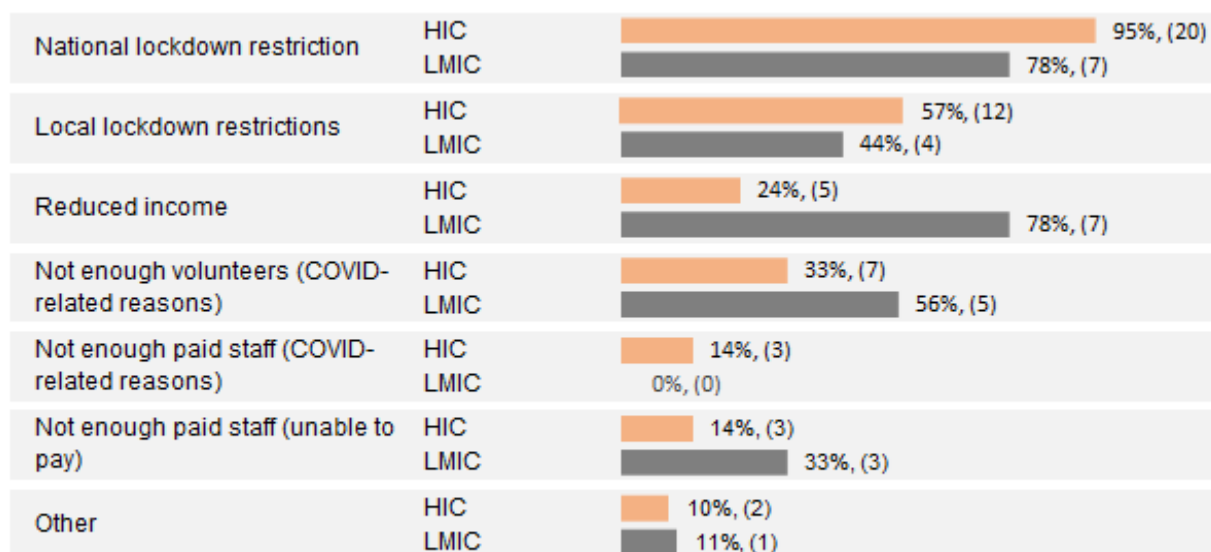
Figure 51



There were some slightly more pronounced differences between the reasons given by organisations in HIC and LMIC. Lockdown restrictions were reported more as a reason in HIC than in LMIC while reduced income and lack of volunteers were more frequently reported in LMIC (see figure 53 below). In this way we can see that the pandemic has had a wider impact on those in LMIC here.

Figure 52

Q39. Have you had to stop or reduce any of the support / services you provide to CLL patients because of the COVID-19 pandemic - Why was this? (Please tick all that apply) – by country development status

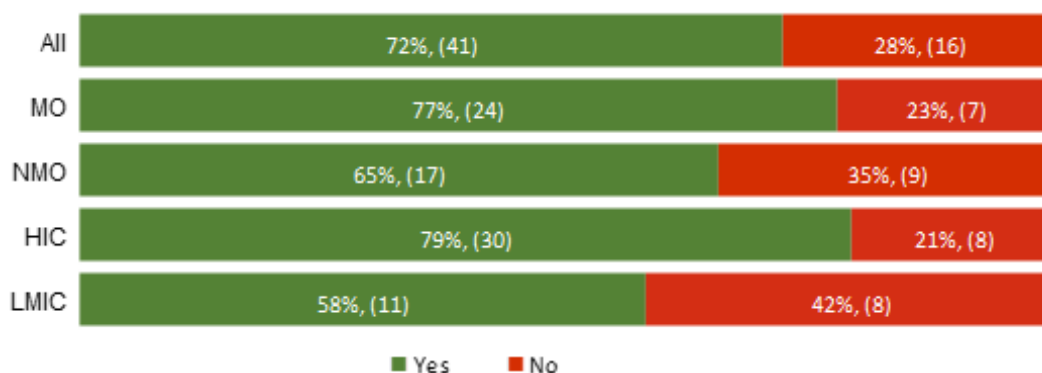


Based on 57 responses

72% of organisations reported having to adapt some of the support / services they provide to CLL patients because of the COVID-19 pandemic. Again, there was a higher proportion of MOs and organisations in HIC who said they had to adapt.

Figure 53

Q40. Have you had to adapt any of the support / services you provide to CLL patients because of the COVID-19 pandemic?



Based on 51 responses

A total of 41 organisations told us in their own words how they adapted their service provision including 24 MOs and 17 NMOs with 30 organisations in HIC and 11 in LMIC. The vast majority of organisations spoke about stopping face-to-face / in person events and going virtual.

Adaptation to virtual

Organisations spoke about holding patient meetings, support groups, conferences and events virtually. They also organised webinars and communicated with patients through social media.

Organisations in HIC gave many multiple and more examples of the ways they adapted, compared to those in LMIC.

“We moved from face to face to virtual meetings.” – MO HIC

“Virtual meetings and support groups.” – MO HIC

“We also added new services such as a national closed Facebook group, podcasts, webinars, etc.” – MO HIC

“...private FB chat to connect with patients.” – MO HIC

“Webinars replace face-to-face meetings” – MO HIC

“Had to stop all in-person activities/events/services. Converted all in-person activities into digital/virtual services, e.g. support group meetings became online meetings.” – MO HIC

“Online events.” – MO LMIC

“...now they are in the form of online webinars.” – MO LMIC

“No live events possible. Changed physical support group meetings to virtual meetings. Changed physical patient symposium to virtual symposium.” – NMO HIC

“We stopped doing in-person events and produced them as live streamed or recorded events,” – NMO HIC

“...increase of Facebook closed group engagement.” – NMO HIC

“...online support groups” – NMO HIC

“support groups, etc, almost everything is now virtual” – NMO LMIC

Telephone

Some organisations used telephone to provide support and communication.

“The support was provided mainly by telephone helpline and social media.” – MO HIC

“No group meetings, just individual phone calls.” – NMO HIC

“Through telephone consultation etc.” – NMO HIC

“working more by phone or email” – NMO LMIC

WhatsApp

There were organisations in LMIC that utilised WhatsApp as a method of communication and delivering services.

“Support by phone/WhatsApp” – MO LMIC

“We changed face-to-face conferences for 10-minute audio conferences through WhatsApp so that patients and caregivers can listen to them at any time of the day” – NMO LMIC

“WhatsApp” – NMO LMIC

Data collection and COVID specific information

2 MOs in HIC carried out data collection through surveys and focus groups to understand changing needs. In addition, organisations in HIC created/shared information on COVID-19.

“Greater engagement through digital focus groups and surveys to fast adapt to changing needs of those affected by the pandemic. Collaboration with other CLL support charities and the CLL clinical community to

react to the changing needs identified by surveys and focus group to shape guidelines, services, care and support.” – MO HIC

“We carried out surveys” – MO HIC

“We have invested resources to develop information resources on COVID-19” – NMO HIC

“Main topic was COVID vaccination, so we have regularly published updates from video conferences of the Patient Advisory Board with the Health Minister and leaflets released by Health Ministry. This activity was well taken by the haematology patient community in general, clinicians and pharma partners.” – MO HIC

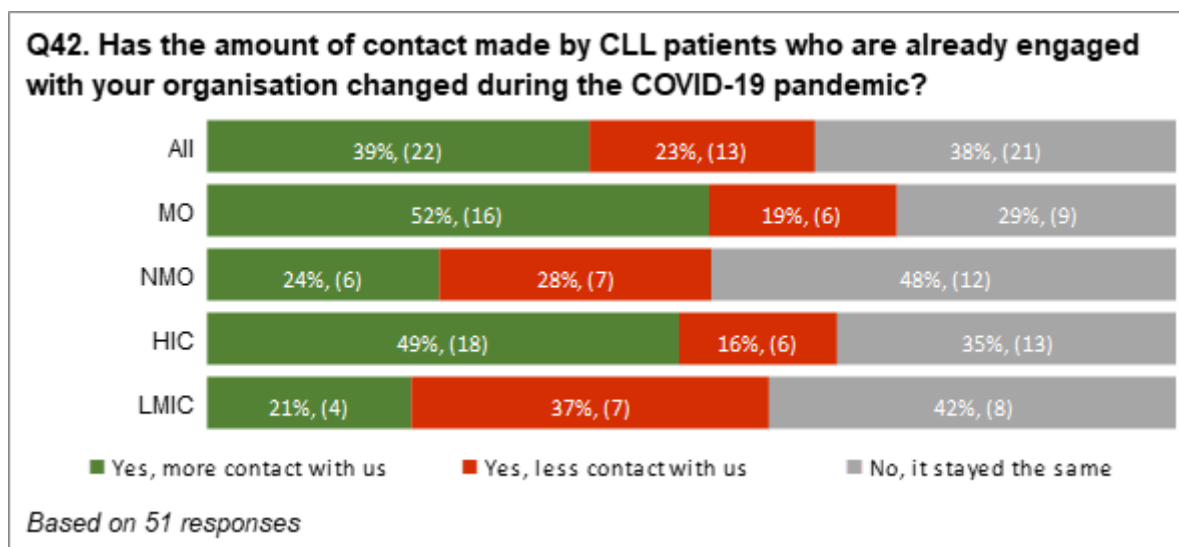
The adaptations mostly related to moving away from in person services to those run through differing types of technology. Services also adapted to provide information that was COVID-19 specific, something that will have been of great help to patients who have clearly found the pandemic of concern.

9.3. Change to level of patient engagement

39% of organisations reported that the CLL patients who were already engaged with them made more contact during the COVID-19 pandemic.

However, this was reported most within MOs and organisations in HIC.

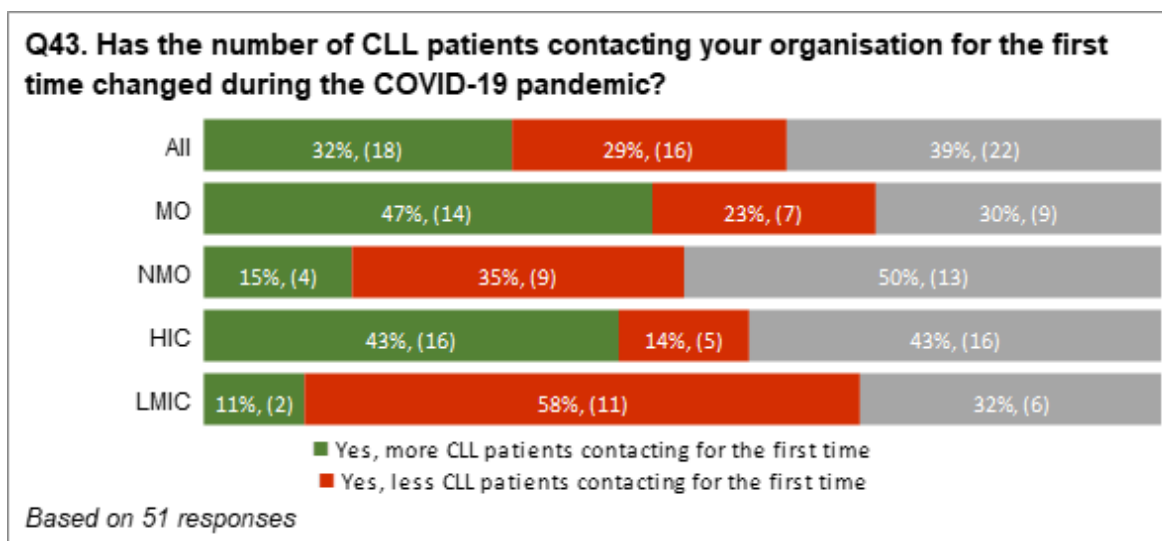
Figure 54



32% of organisations said that more CLL patients contacted them for the first time during the COVID-19 pandemic. NMOs were more likely to say they didn't know.

The highest percentage of organisations who felt fewer patients were contacting them for the first time was within LMIC. There are a number of factors that could have influenced this finding here. These countries were hardest hit with funding and other deficits and may have less access to additional technologies to provide the change to online and other innovative services as quickly as those in HIC.

Figure 55



9.4. Provision of COVID-19 specific support

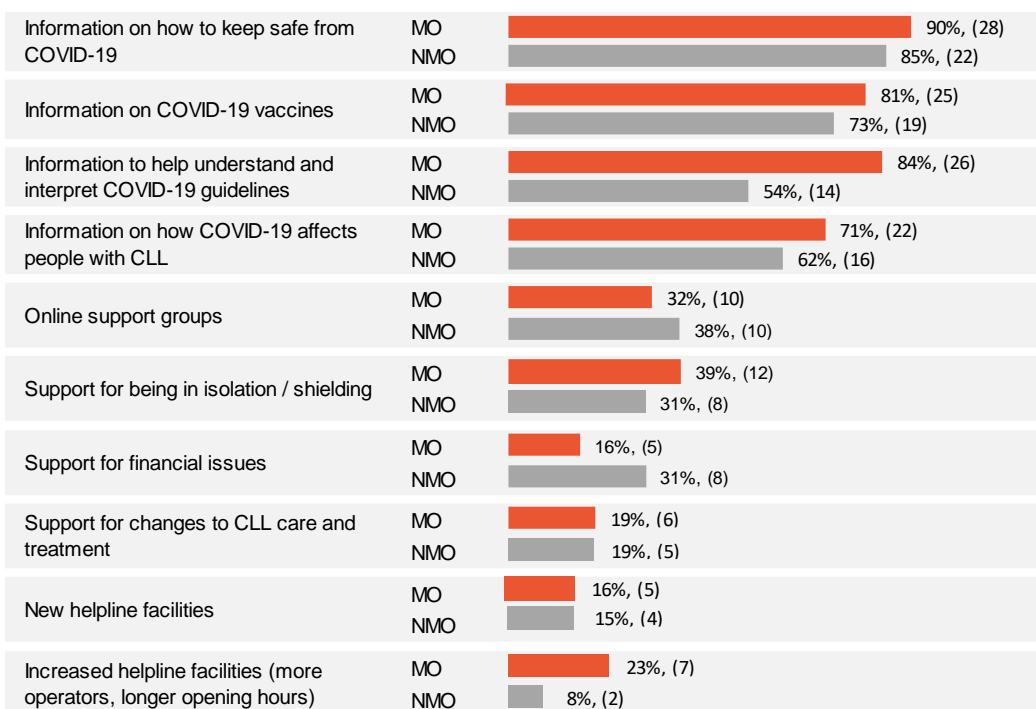
Most organisations had provided some type of support and other services specifically due to COVID-19. Information provision around COVID-19 was reported more frequently than delivery of support services.

Figure 56

What support or services have you provided to CLL patients specifically due to COVID-19? (Please tick all that apply)	All	
	n	%
Information on how to keep safe from COVID-19	50	88%
Information on COVID-19 vaccines	44	77%
Information to help understand and interpret COVID-19 guidelines	40	70%
Information on how COVID-19 affects people with CLL	38	67%
Online support groups	20	35%
Support for being in isolation / shielding	20	35%
Support for financial issues	13	23%
Support for changes to CLL care and treatment	11	19%
New helpline facilities	9	16%
Increased helpline facilities (more operators, longer opening hours)	9	16%

Figure 57

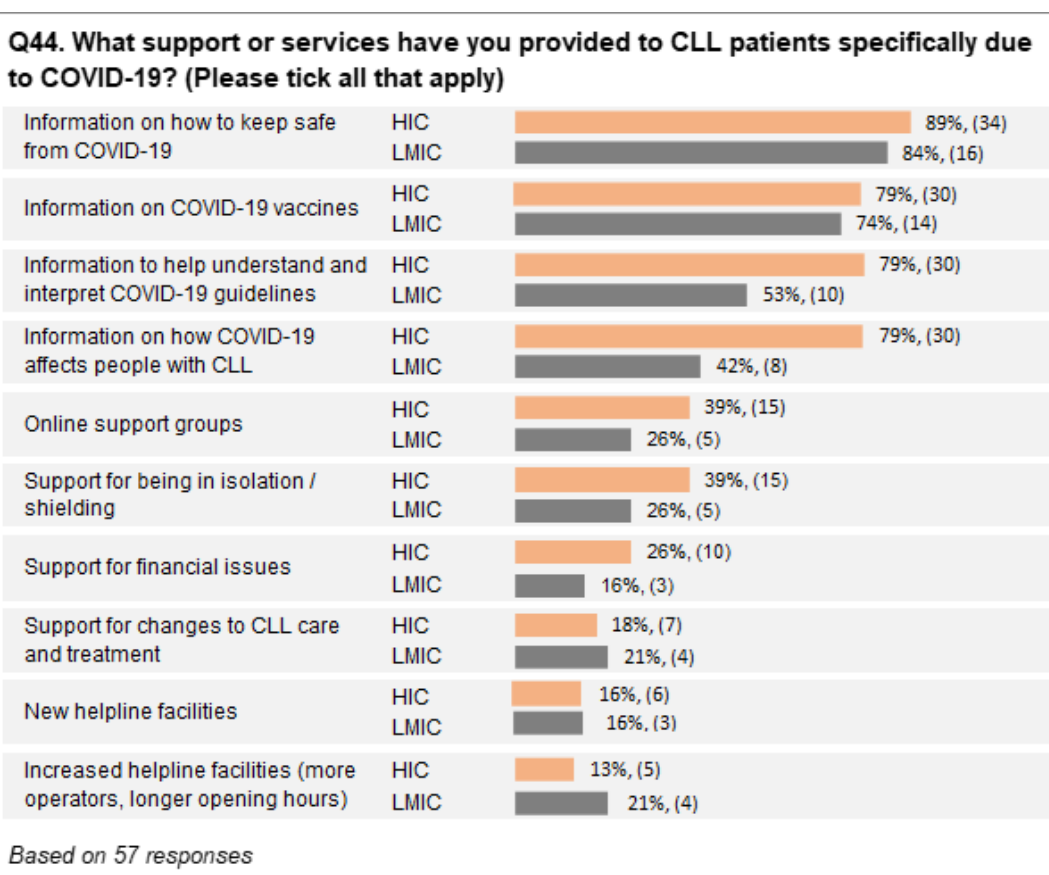
Q44. What support or services have you provided to CLL patients specifically due to COVID-19? (Please tick all that apply)



Based on 57 responses

A higher percentage of organisations in HIC provided support or services due to COVID-19 across the majority of categories.

Figure 58



Based on 57 responses

9.5. Section summary

Funding for organisations across the board was hampered during the pandemic although this was more pronounced for those in LMIC.

Lockdown restrictions were the biggest reason for the reduction in support services during the pandemic, particularly with regard to national restrictions, although income was a real issue in LMIC.

Most organisations had to adapt their services, in the main utilising online technology and social media to help them to continue providing support. Again, this was less utilised in LMIC.

The pandemic altered engagement with organisations for both current and new patients. This was more likely to have increased for organisations in HIC than those in LMIC. This may be due to HIC more able to utilise online and social media technologies to engage than those in LMIC.

10. Key learnings and next steps

This provides an overall brief summary of the key learnings from this survey, alongside the next steps that CLLAN should consider. The main recommended actions as well as a detailed summary of the findings from this survey are included in the executive summary at the start of this report.

It is encouraging to see the positive engagement from both member and non-member organisations with this survey. 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.

This survey was originally conducted in 2021, with fieldwork closing in August of that year. 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.

In taking the next steps, it would be beneficial for CLLAN to use this report alongside other relevant research and literature to identify a strategic plan that will encompass the actions that have been recommended.

Next steps

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 CLL patients 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 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.

Lastly, CLLAN and IQVIA would like to thank those that took the time and effort to participate in this research.