CLL Advocacy Survey 2024

Results Report

January 2025

Picker

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Contents

Background

The CLL Advocates Network (CLLAN) serves patient organisations and patient thought leaders around the world. CLLAN's mission is to improve chronic lymphocytic leukemia (CLL) patient outcomes as a global network of CLL patient advocates. The CLLAN has a global reach of 52 member organisations across 43 countries. The network is indispensable to:

- Sharing knowledge, experiences, and best practice across countries
- Advocating for equitable standards of care and treatment
- Helping to improve patients' understanding of clinical trials and the drug development process

In 2021, CLLAN launched a CLL Advocacy Survey to highlight the unmet needs, key issues and collective experience of CLL patient advocacy groups and CLL support service providers globally. The 2021 CLL Advocacy Survey findings were instrumental in developing the CLLAN Resource Hub, a global directory of CLL support resources launched in June 2022. The findings shaped the priorities and session content for the CLL Horizons 2021 conference, where they were presented alongside practical recommendations and calls to action. CLLAN commissioned Picker to deliver their 2024 CLL Advocacy Survey of CLL patient advocacy groups and CLL support service providers.

The survey sought to identify changes in the CLL support service provision landscape since the COVID-19 pandemic and highlight areas where organisations might further support CLL patients and caregivers in their service and resource provision. The findings will inform resource mapping activities and provide evidence for future strategic projects. Moreover, data collected from the CLL Advocacy Survey informs CLLAN's overarching objective of enhancing CLL patient care and improving patient outcomes.

Executive summary

The purpose of the 2024 CLL Advocacy Survey was to highlight the unmet needs, key issues and collective experience of CLL patient advocacy groups and support CLL service providers globally. The survey was hosted online and 145 organisations from 70 countries were invited to participate via emails to representatives. The survey was available to complete for a period of 6 weeks from 23rd September to 31st October 2024. The survey received 55 responses from 42 countries.

CLLAN services and resources

Overall, there is a high level of engagement with the resources provided by CLLAN, with 89% (n=41) of organisations using at least one resource. Organisations were most likely to use the CLLAN website (65%, n=30) and the World CLL Day campaign materials provided by CLLAN (57%, n=26). All organisations who used CLLAN resources found them helpful to at least some extent.

When looking to the future, organisations were most likely to report they are likely or very likely to use regular updates via the "CLL Matters" newsletter (89%, n=39), CLLAN World CLL Day campaign materials (83%, n=29), regular updates via CLLAN social media (78%, n=33), and regular updates via the CLLAN website (76%, n=32). Organisations in LMIC were more likely to report intent to utilise the CLLAN resources in future, than HIC organisations.

When developing new resources and events, organisations would like CLLAN to prioritise medical updates on CLL (47%, n=22), patient education (38%, n=18), advocacy (36%, n=17), access to treatment, care and/or diagnostics (34%, n=16) and patient support (32%, n=15).

Access to CLL healthcare

It is well known that access to timely services and receiving clear information are central to high quality care. Importantly, 75% (n=33) of organisations agreed CLL patients have access to specialist doctors in their local country. Despite this, half (50%, n=23) agreed delayed / late diagnosis is an issue for CLL patients.

44% (n=19) of organisations disagreed that CLL patients have enough opportunity to take part in clinical trials, and 43% (n=19) disagreed that CLL patients are able to get support for emotional and psychological issues directly resulting from their CLL diagnosis / treatment through healthcare providers.

Access to CLL healthcare varied when comparing organisations in HIC and LMIC. For example, 83% (n=15) of LMIC organisations reported that delayed / late diagnosis is an issue for CLL patients, compared to 26% (n=7) of HIC organisations.

Current organisational services and resources

When responding to current service offerings, organisations were most likely to offer information-based services to patients and caregivers, such as educational events (Patients: 84%, n=41; Caregivers: 80%, n=32). Support based services for patients and caregivers, such as local support groups, were less common (Patients: 45%, n=22; Caregivers: 40%, n=16).

When asked about their organisational priorities, respondents were most likely to report their organisation primarily focuses on advocacy (59%, n=23), support for patients, families or carers (55%, n=23) and education (54%, n=20).

Volunteers were identified as the leading contributor to organisational success (51%, n=24). This was followed by networking / collaboration with other patient advocacy groups / organisations (47%, n=22) and grants / donations / sponsorships from pharmaceutical partners (40%, n=19).

Barriers to delivery of services and resources

Organisations identified key barriers to offering services (e.g., educational events, awareness campaigns etc) and resources (e.g., printed leaflets, websites etc). Insufficient financial resources (82%, n=37 for services; 80%, n=36 for resources) and a shortage of human resources, including staff and volunteers (76%, n=34 for services; 80%, n=36 for resources) were cited.

Experience of barriers to service delivery were notably different between organisations based in HIC and those based in LMIC. 100% (n=18) of LMIC organisations cited insufficient financial resources as a barrier to service delivery, compared to 69% (n=18) of HIC organisations.

Changing landscape of service provision since COVID-19

Since Covid-19, organisations were most likely to report an increase in the frequency at which they offer personal advocacy (59%, n=13), online group / chat or forum (59%, n=13) and healthcare professional education (59%, n=10).

Organisations were most likely to report an increase in the demand at which they currently offer personal advocacy (68%, n=15), welfare / financial support (67%, n=6) and online group / chat or forum (64%, n=14).

For 40% (n=17) of organisations, immune-related challenges have not impacted their ability to secure funding. However, as a result of immune related challenges, many organisations reported patients being more cautious about entering public spaces or events and the resulting impact on their emotional wellbeing. To address immune-related challenges, organisations are commonly investing in online information and communication methods.

Recommendations

The data collected has provided important information to help highlight the unmet needs, key issues and collective experience of CLL patient advocacy groups and support CLL service providers globally. The following recommendations have been created to inform where

CLLAN and the wider CLL advocacy network should focus efforts, to further support CLL patients and caregivers in their service and resource provision.

CLLAN services and resources

Although the website is the most commonly accessed CLLAN resource, the resource hub and advocacy toolkit available on the website are not as widely used by organisations. With advocacy reported as a key organisational priority, further promotion of these resources may be beneficial to the patient organisations. Further to the awareness campaign, support on utilising these resources may be beneficial to support understanding and how to use them effectively. Additionally, it may be useful to gather further information from organisations on any barriers they have experienced which may be preventing them from accessing these resources.

When developing new resources and events, CLLAN should prioritise medical updates on CLL, patient education, advocacy, access to treatment, care and/or diagnostics and patient support.

Access to CLL healthcare

There is evident inequity in access to CLL healthcare, identified by organisations based in HIC and LMIC. CLLAN must work with partner organisations to address these inequities, such as working with pharmaceutical companies to promote CLL clinical trials in LMIC, understand and address the infrastructure limitations in LMIC, and working with clinicians to improve diagnostic pathways for CLL patients.

Current organisational services and resources

Whilst organisations cite support of patients, families or carers as one of the top organisational priorities, this is not reflected in the services offered. Support such as telephone support and buddy systems are not as widely offered when compared to information-based services. CLLAN could support with networking opportunities for organisations to share best practice for delivering more support-based services.

Additionally, CLLAN assisting patient organisations with campaigns to attract more volunteers, identified as the leading contributor to organisational success, will subsequently enable organisations to deliver a wider range of services and sustainability.

Barriers in delivery of services and resources

Organisations cited insufficient financial resources and a shortage of human resources, including staff and volunteers as barriers to offering the services and resources they would like to offer. This was especially pertinent for organisations based in LMIC who also reported skill set as a barrier to deliver services. Further promotion of existing materials, such as the advocacy toolkit and resource hub may address some of the challenges organisations are experiencing. Additionally, CLLAN should work with organisations to address inequity in resources and services across countries, for example, supporting organisations based in LMIC to develop skill sets with support on how to apply for funding grants.

Changing landscape of service provision since Covid-19

CLLAN should develop guidance and best practice for delivering online services to support organisations with the increase in demand. This can include, for example, how to successfully run online groups, chats or forums. Moreover, online services do not adequately replace face to face services. However, as detailed by organisations, CLL patients experience difficultly socialising or attending events due to their immunity status, leading to heightened anxiety and poor mental wellbeing. CLLAN should develop guidance and best practice for how organisations can deliver in person services for patients with weakened immune systems. By doing so, CLL patients can be confident that they are entering a space where precautions have been taken to protect their health.

Methodology

Questionnaire development

The CLLAN 2021 CLL Advocacy Survey underwent extensive review by CLLAN and Picker to address new organisational aims and objectives. The questionnaire requested information about each organisation (e.g., location, number of patients represented, number of staff etc) to inform and update the CLLAN database of members and non-members. The final questionnaire covered the following areas:

- About the organisation
- CLLAN services and resources
- Access to CLL Healthcare
- Current organisational services and resources
- Barriers to delivery of services and resources
- Changing landscape of service provision since Covid-19

The English questions were translated into six languages by an approved language translation service using native speakers to translate and proofread. Native-speaking CLLAN members reviewed the final translations. The survey was available online in the following languages:

- Arabic
- Chinese
- English
- French
- Portuguese
- Russian
- Spanish

A copy of the questionnaire can be found in Appendix 2.

Sampling method

CLLAN provided a contact list to Picker with 204 unique email addresses for representatives of 152 organisations that support CLL patients. The contact list contained contact information for membership organisations, and non-member organisations who provide support to CLL patients as part of a broader remit of patient support.

Of the 204 emails, 14 ‘bounced’ or failed to send. Therefore, the final sample consisted of 190 unique email addresses for representatives of 145 organisations from 70 countries. Of the 190 representatives, 70 were from member organisations, and 120 were from non-member organisations.

Survey Fieldwork

The survey was hosted on the third-party online survey portal Qualtrics for a period of 6 weeks from 23rd September to 31st October 2024. Unique survey links were sent via e-mail, with a reminder sent to non-responders every Monday throughout the fieldwork period.

Data cleaning and validation

The data cleaning process included the following steps:

1. Partially completed surveys were removed from the dataset if respondents had not completed at least one question from Q4 onwards (inclusive).

2. Duplicate responses from the same organisation were excluded from the final data. Where duplicate responses were identified, the response with the fewest survey questions completed was removed.

In total, 13 responses were removed from the dataset.

The 2024 CLL Advocacy Survey achieved 55 responses, representing a 38% response rate of organisations invited to participate in the survey (Table 1).

Table 1. Final response rates for the 2024 CLL Advocacy Survey

	Sample size	Number of responses	Response rate
Member Organisations	51	38	75%
Non-member Organisations	94	17	18%
Overall	**145**	**55**	**38%**

Suppression

There is an agreed upon reporting threshold of 5 responses to protect the confidentiality of individual survey responses. This means where fewer than 5 respondents have answered a particular question, the results are suppressed. This threshold applies at an individual question level and across all results breakdowns.

Data presentation

We use ‘positive scores’ as a summary measure for the results of this survey. Positive scores show the percentage of respondents who gave a favourable response to applicable questions (Figure 1 and Figure 2). The scores remove any ‘don’t know’ answers prior to

calculating percentages. Not all questions can have a positive score; exceptions include demographic information such as length of service. Higher scores indicate more positive results.

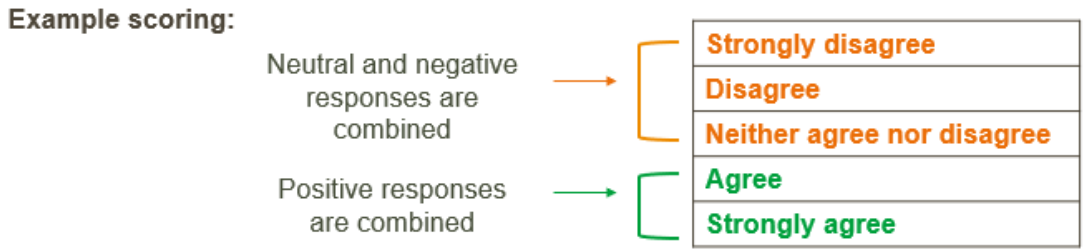
A plus sign '+' after the question number denotes where any positive scores have been reported.

Figure 1. Example of creating a positive score.

Q28 - When considering the country your organisation is based in, do you agree with the following statements? There are enough approved therapies available for CLL patients.		
Strongly agree…	3	7%
Agree…	11	26%
Neither agree nor disagree	6	14%
Disagree	13	30%
Strongly disagree	5	12%
Don't know	5	12%
Total…	*43*	*100%*

Q28+ - When considering the country your organisation is based in, do you agree with the following statements? There are enough approved therapies available for CLL patients.		
Strongly agree / agree…	**14**	**37%**
Neither agree nor disagree…	6	16%
Strongly disagree / disagree	18	47%
Total…	38	*100%*

Figure 2. Example image of creating a positive score.



Throughout this report, percentages have been rounded to 0 decimal places. This means that sometimes, the total for a single-response question can be just below or above 100%.

Where data is reported for a response option as 0%, this means the percentage had been rounded down to 0%, not that it had zero respondents.

The number of respondents to each question or response is indicated as n=(x), where x equals the number of respondents. Due to question routing within the survey, and because responding to all questions was not mandatory, the number of respondents to each question varies throughout the results.

Where response numbers are low, caution should be taken when interpreting the results. Conclusions cannot be drawn solely from the feedback gathered from the 2024 CLL Advocacy Survey, and these results should be triangulated with other sources of data to inform resource mapping and provide evidence for future projects.

Please note data collected from some questions related to organisational information have not been included in this report.

Respondent profile

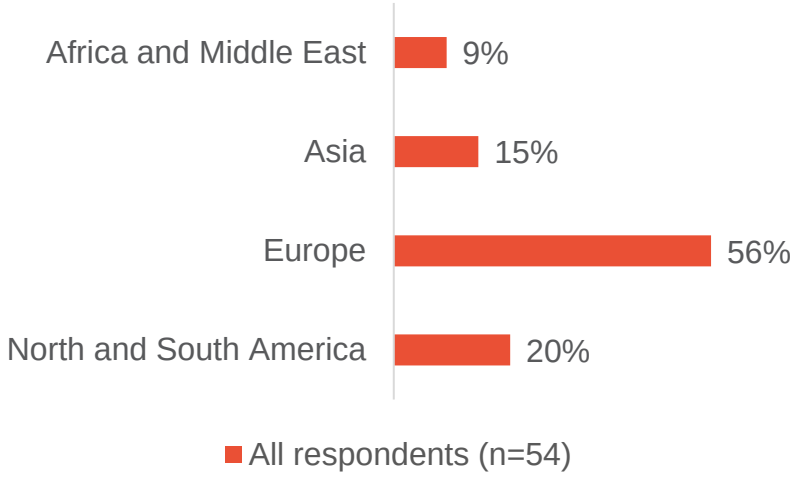
The 2024 CLL advocacy survey received 55 responses from 42 countries, as detailed in Table 2. A list of organisations who responded to the survey can be found in Appendix 3.

Table 2. Q2 Where is your organisation based?

Country	Count (n=)	Country	Count (n=)
Argentina	1	Latvia	1
Armenia	1	Mali	1
Belgium	1	Mexico	1
Bolivia	1	Morocco	1
Brazil	1	Nepal	1
Bulgaria	1	Netherlands	1
Canada	2	North Macedonia	1
China	2	Poland	1
Costa Rica	1	Republic of Korea	1
Croatia	1	Romania	1
Czechia (Czech Republic)	1	Serbia	1
Denmark	1	Slovenia	1
Estonia	1	Spain	1
France	2	Switzerland	2
Germany	2	Türkiye	1
Greece	2	Ukraine	1
Guatemala	1	United Kingdom	4
India	2	United Republic of Tanzania	1
Ireland	1	United States of America	3
Israel	1	Yemen	1
Italy	2	Prefer not to say	1

Figure 3 shows the regional distribution of responses, with the highest proportion of organisations located in Europe (56%, n=30). One-fifth (20%, n=11) of organisations were based in North or South America, followed by 15% (n=8) in Asia, and 9% (n=5) in Africa and the Middle East.

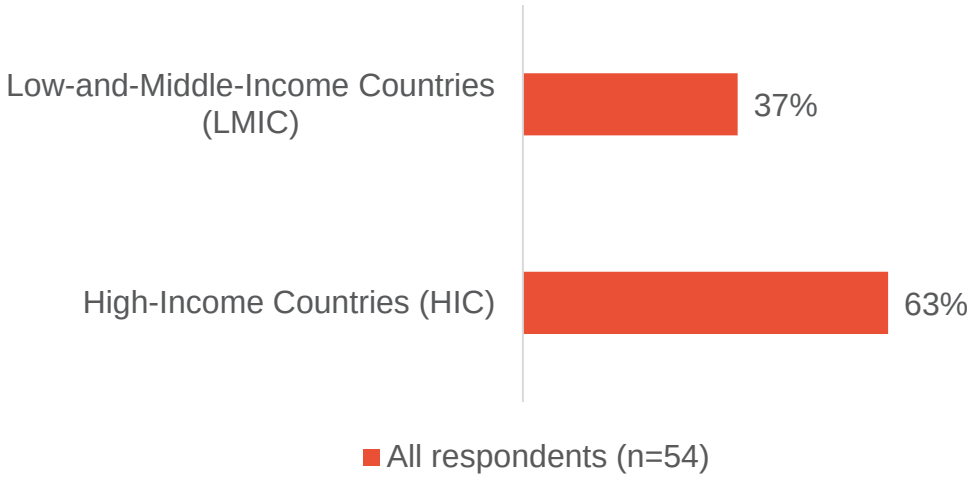
Figure 3. Q2 Where is your organisation based? By regional groups.



Organisations were categorised into low and middle-income countries (LMIC) or high-income countries (HIC) based on their location to identify variance in organisational experience. The categorisation was based upon the World bank definitions and current classification list from 2023 which can be accessed on the World Bank website.

Almost two-thirds (63%, n=34) of organisations were classified as being in a high-income country, while 37% (n=20) were classified as being in a low or middle-income country (Figure 4).

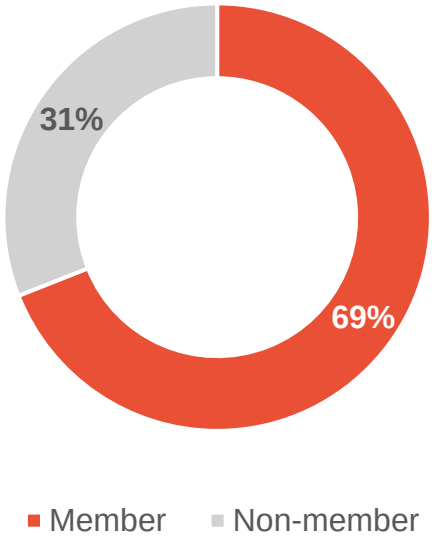
Figure 4. Q2 Where is your organisation based? By LMIC vs. HIC



Membership status

Of the 55 survey responses, 69% (n=38) were received from member organisations, while 31% (n=17) were from non-member organisations (Figure 5).

Figure 5. Membership status.



The largest proportion of both member and non-member organisations who responded to the survey were from Europe (55%, n=21, and 56%, n=9 respectively) (Table 3).

Table 3. Membership status by regional group

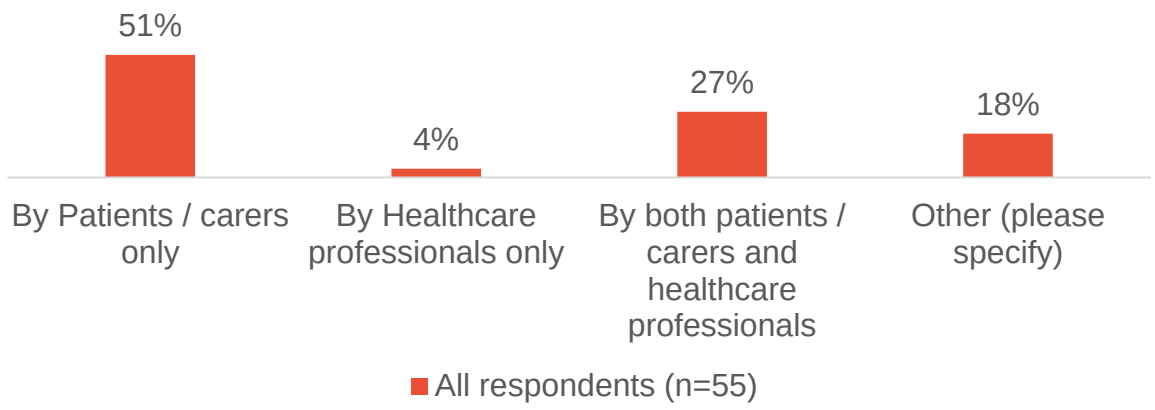
	Member		Non-Member	
Region	**Number (n=)**	**Percentage (%)**	**Number (n=)**	**Percentage (%)**
Africa and the Middle East	3	8%	2	13%
Asia and Pacific	5	13%	3	19%
Europe	21	55%	9	56%
North and South America	9	24%	2	13%
Total Responses	**38**	**100%**	**16**	**100%**

Organisation information and structure

Half (51%, n=28) of the organisations surveyed reported being led by patients and caregivers only, 27% (n=15) were led by patients, caregivers and healthcare professionals, and 4% (n=2) were led by healthcare professionals only (Figure 6).

Of the 18% (n=10) of organisations who selected ‘Other (please specify)’ there was a variety of leadership structures which included being led by patient advocates and a board of trustees.

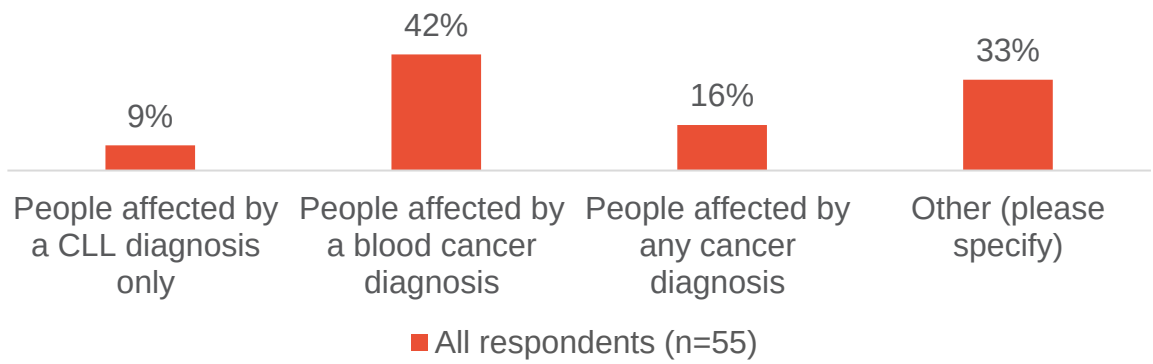
Figure 6. Q4 How is your organisation led?



Organisations were most likely to provide support to those affected by a blood cancer diagnosis (42%, n=23). 16% (n=9) provide support to individuals affected by any cancer diagnosis and 9% (n=5) provide support to those affected by a CLL diagnosis only (Figure 7).

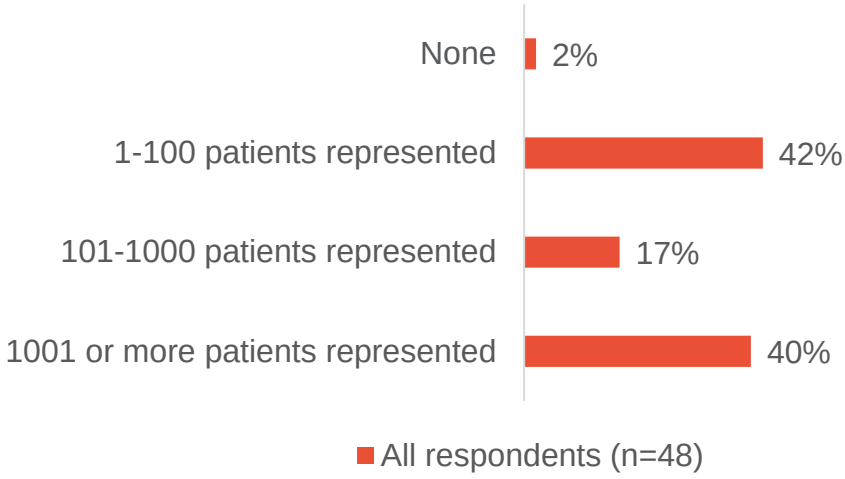
Of the 33% (n=18) of organisations who selected ‘Other (please specify)’ there was a range of combinations of patient groups that they support. Notably, many indicated a focus on supporting individuals with conditions such as lymphoma, leukemia, or myelodysplastic syndromes (MDS).

Figure 7. Q5 Who does your organisation provide support and services to?



The largest proportion of organisations represent 1-100 patients (42%, n=20), while 17% (n=8) represent between 101 and 1000 patients. 40% (n=19) represent more than 1,000 patients (Figure 8).

Figure 8. Q6+ How many CLL patients does your organisation represent?



Please note that respondents answering 'Don't know' have been excluded.

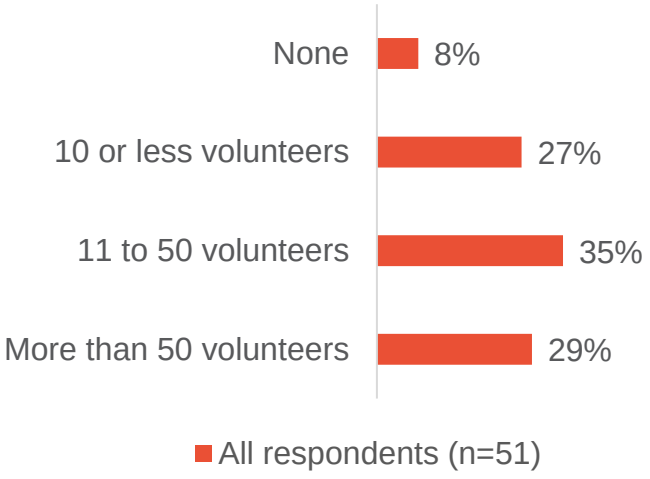
Nearly 1 in 3 (29%, n=15) organisations reported having no paid staff. 35% (n=18) reported having less than 5 paid staff, while 35% (n=18) reported 5 or more paid staff (Figure 9).

Figure 9. Q7+ How many paid staff members does your organisation have?

Please note that respondents answering 'Don't know' have been excluded.

A small proportion of organisations reported they did not have any volunteers (8%, n=4), 27% (n=14) had 10 or less volunteers, 35% (n=18) had 11-50 volunteers and 29% (n=15) had more than 50 volunteers (Figure 10).

Figure 10. Q8+ How many active volunteers does your organisation have?



Please note that respondents answering 'Don't know' have been excluded.

Survey results

CLLAN services and resources

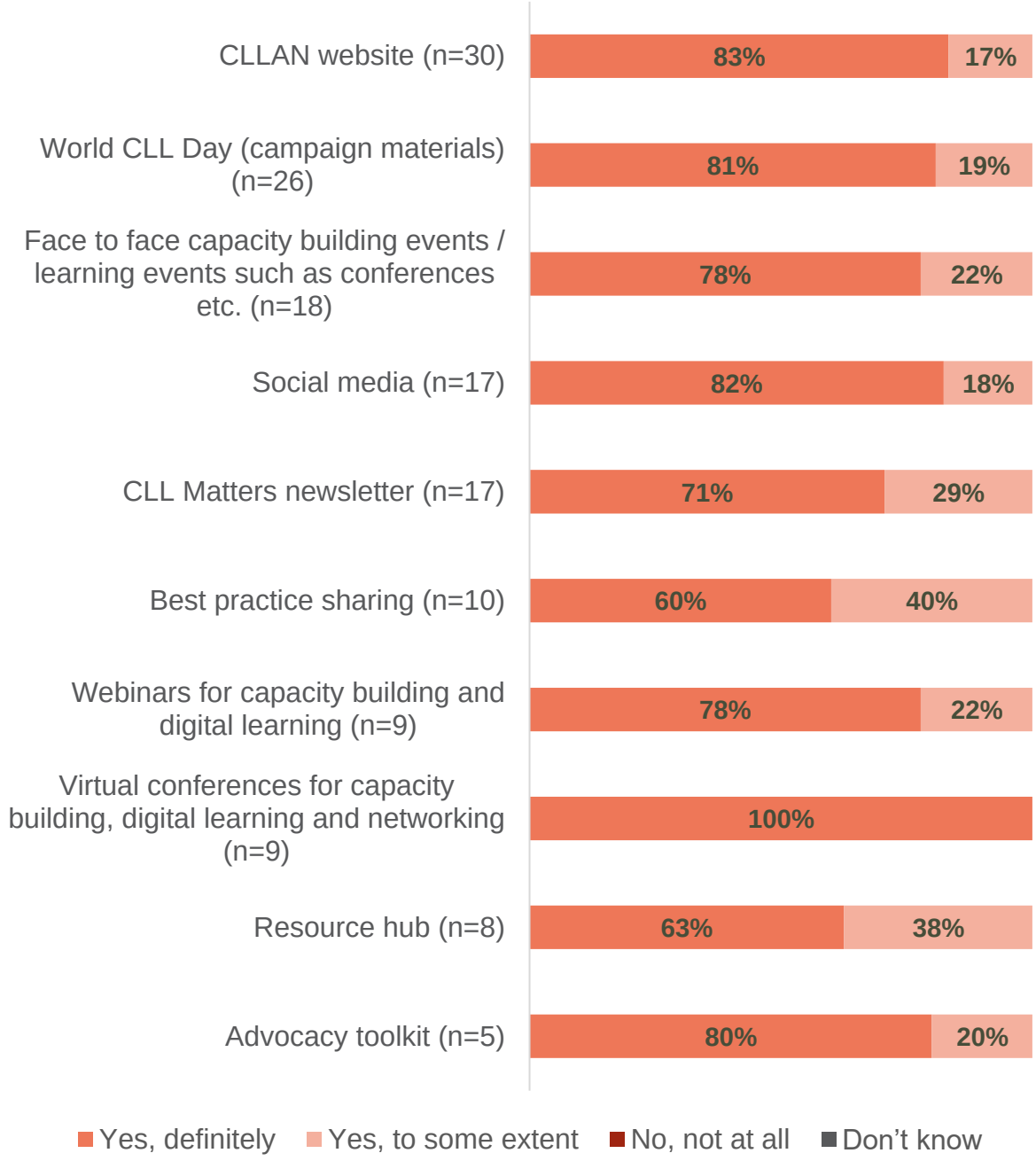
Figure 11 displays the proportion of organisations who use each CLLAN resource. 89% (n=41) of organisations reported they use at least one resource provided by CLLAN:

- The CLLAN website was the most widely used resource (65%, n=30)
- Over half of organisations (57%, n=26) used the World CLL Day campaign materials provided by CLLAN
- Nearly 40% (39%, n=18) of organisations access CLLAN face to face events for capacity building and learning, such as conferences
- More than one third of organisations (37%) use CLLAN social media (n=17) and the CLL Matters newsletter (n=17)
- Only 17% (n=8) used the CLLAN Resource Hub

Figure 11. Q24 Do you currently use any of the following CLLAN resources? Please select all that apply.

Those who accessed CLLAN resources were asked how useful they found each resource. Overall, organisations found the CLLAN resources useful, with 100% of organisations (base ranging from n=5 to n=30) finding each resource useful to at least some extent – see Figure 12.

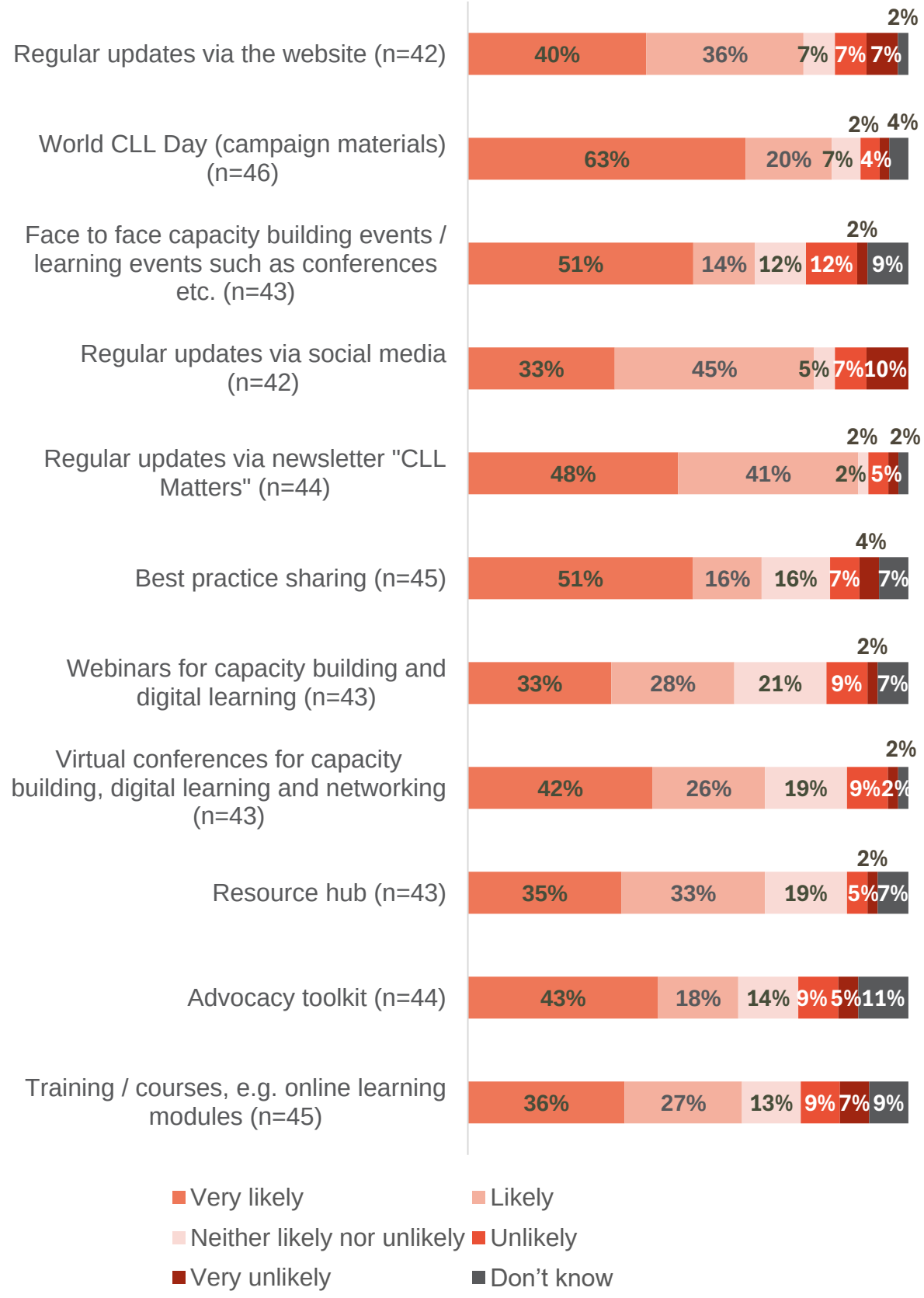
Figure 12. Q25 Do you find the following CLLAN resources useful?



Please note that the response option 'Training / courses, e.g. online learning modules' has been removed from this analysis due to suppression.

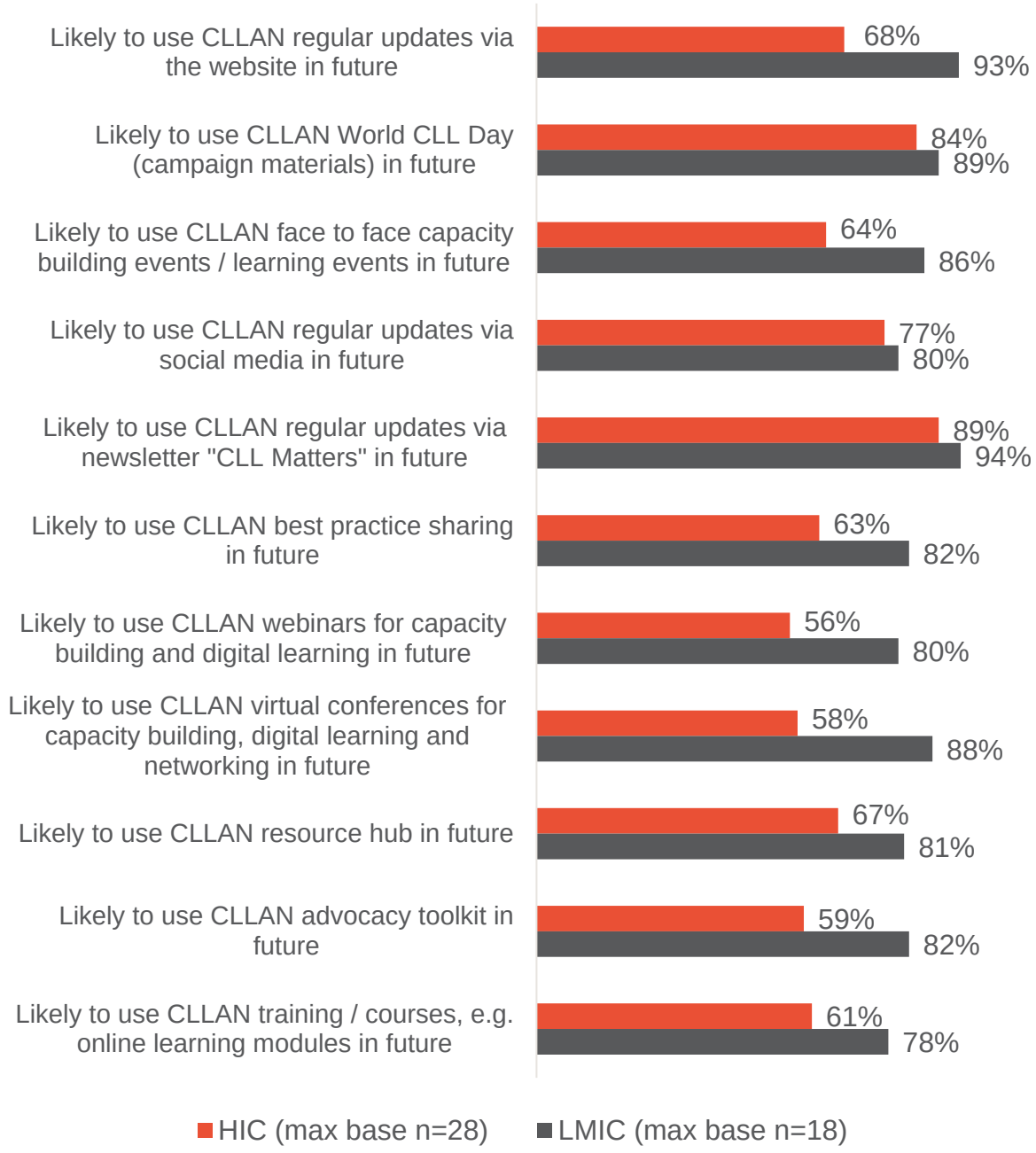
When looking to the future, organisations were most likely to report they are likely or very likely to use regular updates via the "CLL Matters" newsletter (89%, n=39), followed by using CLLAN World CLL Day campaign materials (83%, n=29), regular updates via CLLAN social media (78%, n=33), and regular updates via the CLLAN website (76%, n=32) (Figure 13).

Figure 13. Q26 How likely are you to use the following CLLAN resources in the future?



Organisations from LMIC are more likely to use CLLAN resources in the future, than organisations from HIC (Figure 14). For example, 88% (n=14) of LMIC organisations would use CLLAN virtual conferences in future, compared to 58% (n=15) of HIC organisations.

Figure 14. Q26+ How likely are you to use the following CLLAN resources in the future? HIC vs LMIC.



When asked to select the top three topics CLLAN should prioritise when developing resources and events, organisations were most likely to select:

- Medical updates on CLL (47%, n=22)
- Patient education (38%, n=18)
- Advocacy (36%, n=17)
- Access to treatment, care and/or diagnostics (34%, n=16)
- Patient support (32%, n=15)

Development of resources and events related to capacity building (11%, n=5), immune-related challenges (11%, n=5), directory of clinical trials (11%, n=5), government policy (11%, n=5) and Covid-19 (0%, n=0) were of least priority to organisations (Figure 15).

Figure 15. Q27 Which of the following topics would you like CLLAN to prioritise in resources and events? Please select up to 3.

Access to CLL healthcare

Access to timely services and receiving high quality information are central to high quality care. Organisations were asked to what extent they agreed or disagreed with statements relating to CLL patients accessing treatment in the country they are based (Figure 16).

Organisations were most likely to *agree* that in their country:

- CLL patients have access to specialist doctors (75%, n=33)
- CLL patients have access to CLL specialist care centres (58%, n=25)
- Delayed / late diagnosis is an issue for CLL patients (50%, n=23)

Organisations were most likely to *disagree* that in their country:

- CLL patients have enough opportunity to take part in clinical trials (44%, n=19)
- CLL patients struggle to afford treatment and care for CLL (44%, n=19)
- CLL patients are able to get support for emotional and psychological issues directly resulting from their CLL diagnosis / treatment through healthcare providers (43%, n=19)

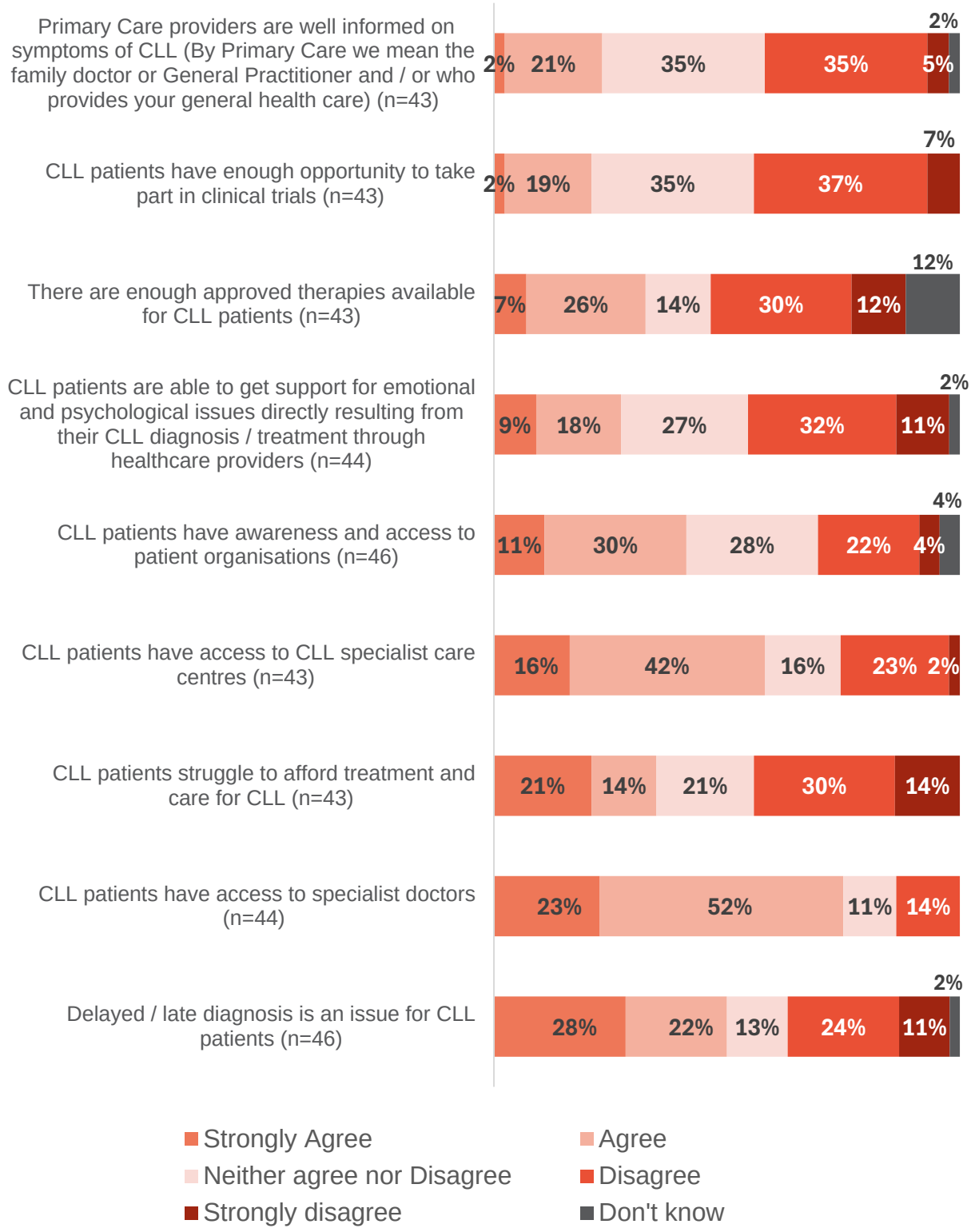
Organisations who agreed that CLL patients struggle to afford treatment and care for CLL were asked why affording treatment is a challenge. Organisations highlighted the high cost of treatment, and the difficulty of accessing care without insurance. They emphasised the financial burden of managing a chronic, lifelong condition, including costs of travel to appointments:

"The financial impact of a CLL diagnosis goes beyond the cost of initial treatment."

"Cost of travel for monitoring and specialist appointments (especially for those in rural areas)"

"Because in the private sector it is excessively expensive and not everyone has access to social security or private insurance."

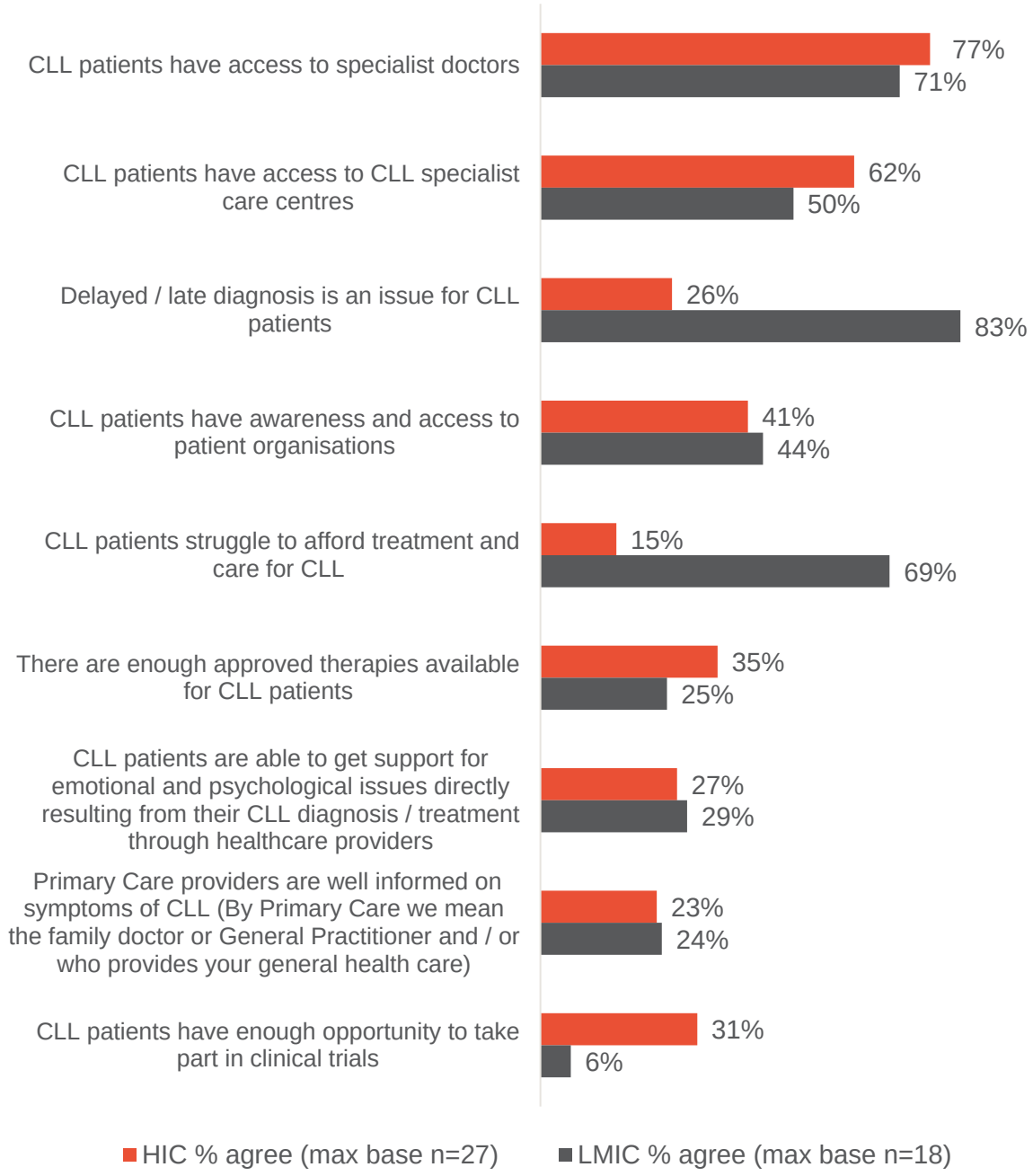
Figure 16. Q28 When considering the country your organisation is based in, do you agree with the following statements?



When comparing access to CLL healthcare across HIC and LMIC organisations, there are some notable differences (Figure 17):

- 83% (n=15) of LMIC organisations agreed delayed / late diagnosis is an issue for CLL patients, compared to 26% (n=7) of HIC organisations
- 69% (n=11) of LMIC organisations agreed CLL patients struggle to afford treatment and care for CLL, compared to 15% (n=4) of HIC organisations
- 6% (n=1) of LMIC organisations agreed CLL patients have enough opportunity to take part in clinical trials, compared to 31% (n=8) of HIC organisations

Figure 17. Q28 When considering the country your organisation is based in, do you agree with the following statements? HIC vs LMIC.



Current organisational services and resources

Organisations were asked about the current services and resources they provide to patients and caregivers.

Services offered to patients and caregivers

Information based services were the most widely offered to patients and caregivers:

- Educational events (Patients: 84%, n=41; Caregivers: 80%, n=32)
- Awareness campaigns (Patients: 78%, n=38; Caregivers: 75%, n=30)
- CLL news and conference coverage (Patients: 76%, n=37; Caregivers: 70%, n=28)
- Webinars (Patients: 71%, n=35; Caregivers: 68%, n=27)

Support based services for patients and caregivers were less common, with the following proportion of organisations offering:

- Telephone support/ telephone helpline (Patients: 65%, n=32; Caregivers: 58%, n=23)
- Online group/ chat or forum (Patients: 61%, n=30; Caregivers: 63%, n=25)
- Support meetings (Patients: 53%, n=26; Caregivers: 55%, n=22)
- Buddy schemes (1:1 support) (Patients: 51%, n=25; Caregivers: 43%, n=17)
- Local support groups (Patients: 45%, n=22; Caregivers: 40%, n=16)
- Directory of local/ national support groups (Patients: 24%, n=12; Caregivers: 23%, n=9)

Resources offered to patients and caregivers

The top 3 resources organisations offer to both patients and caregivers were:

- Printed leaflets / booklets (Patients: 86%, n=42; Caregivers: 79%, n=31)
- Website (Patients: 86%, n=42; Caregivers: 79%, n=31)
- Videos (Patients: 76%, n=37; Caregivers: 74%, n=29)

See Figure 18, Figure 19, Figure 20 and Figure 21 for full breakdown of results.

Figure 18. Q17 What CLL support, advocacy and education services does your organisation currently offer - for patients? Please select all that apply.

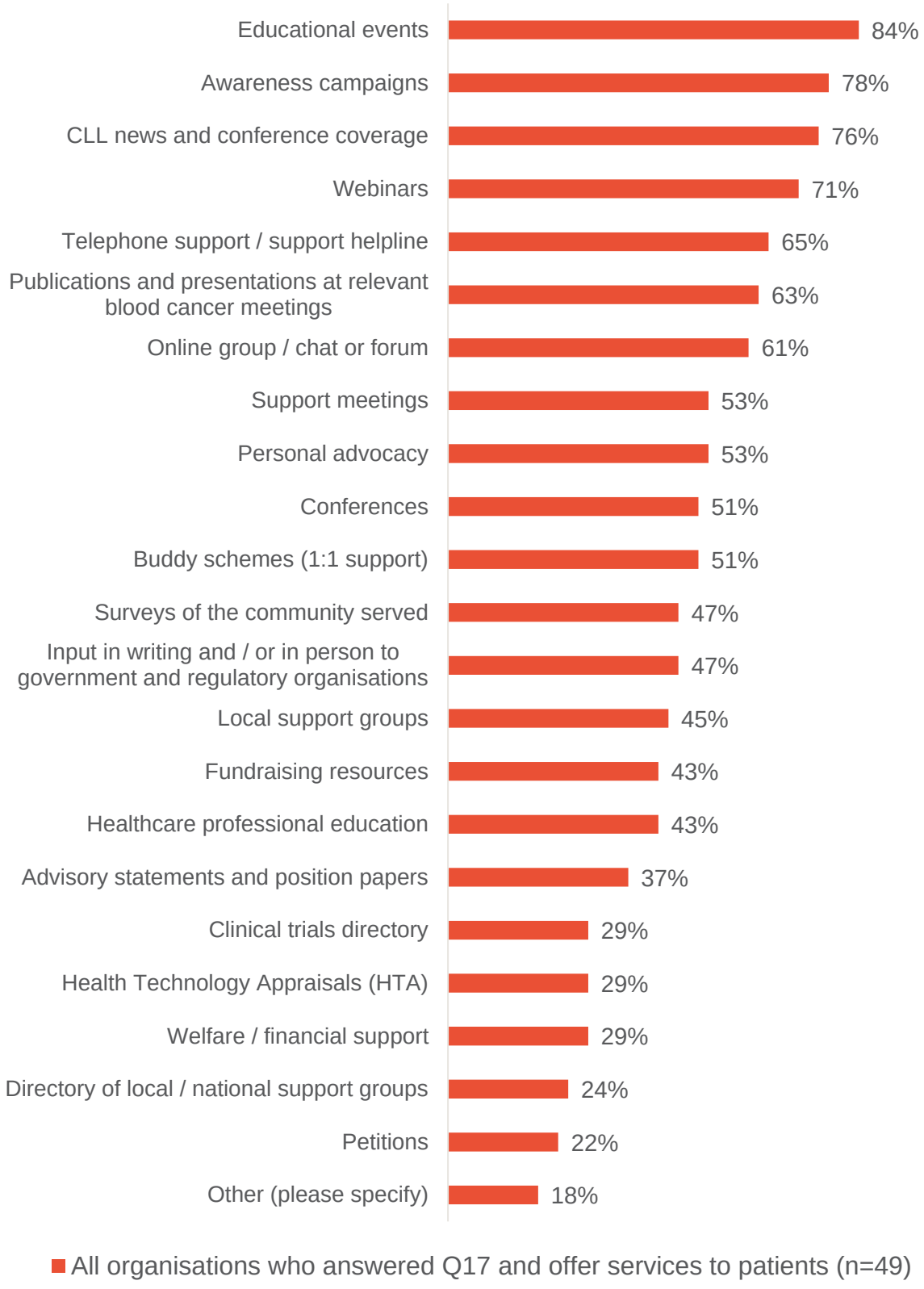


Figure 19. Q17 What CLL support, advocacy and education services does your organisation currently offer - for carers? Please select all that apply.

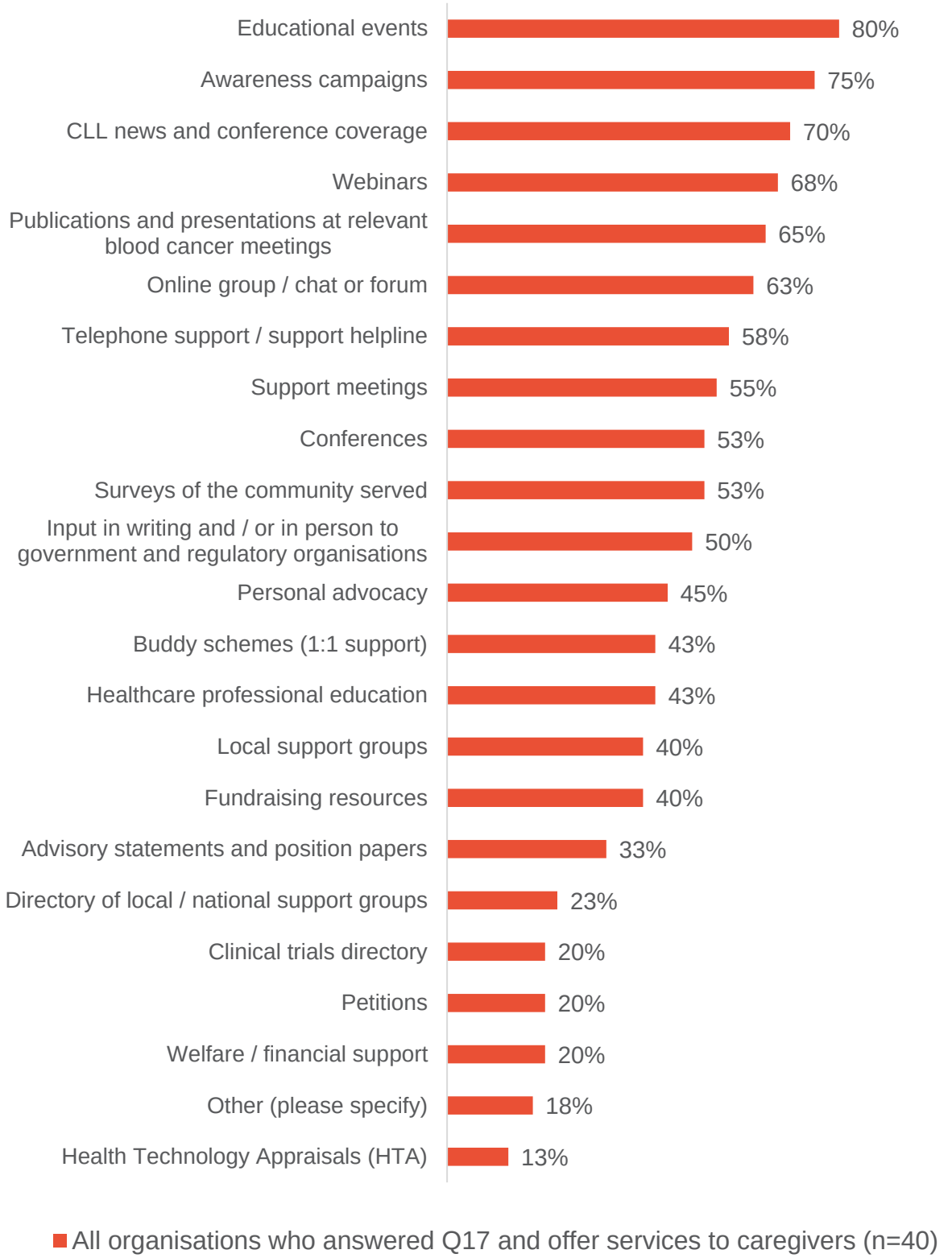


Figure 20. Q18 Does your organisation offer any of the following resources - for patients? Please select all that apply.

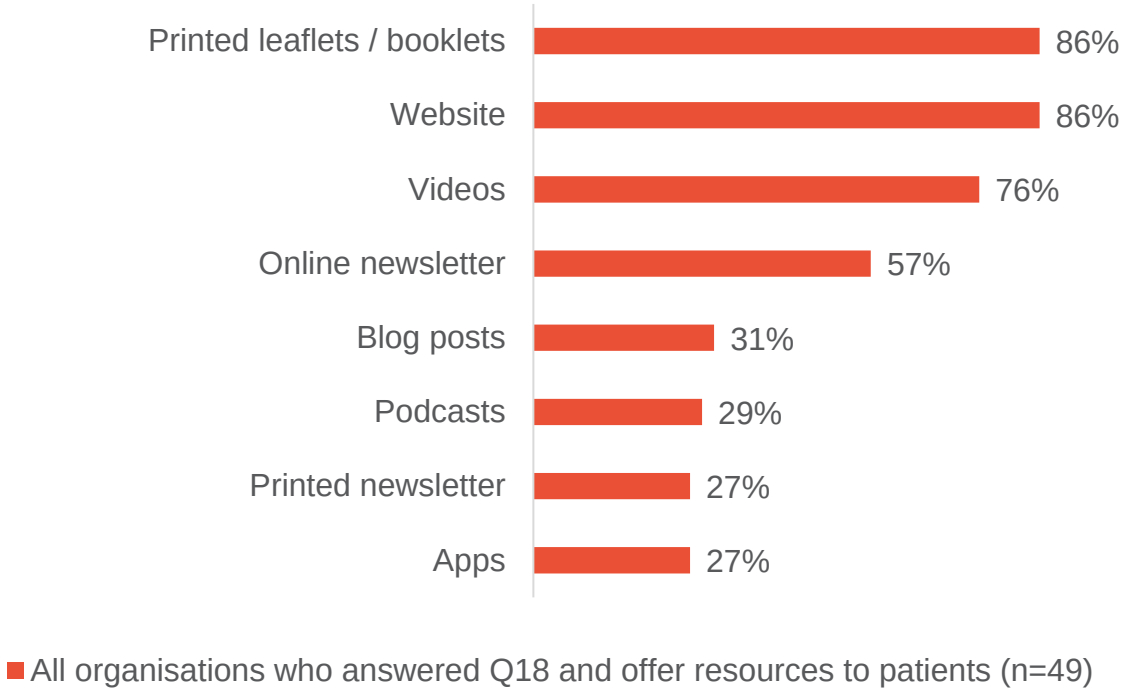
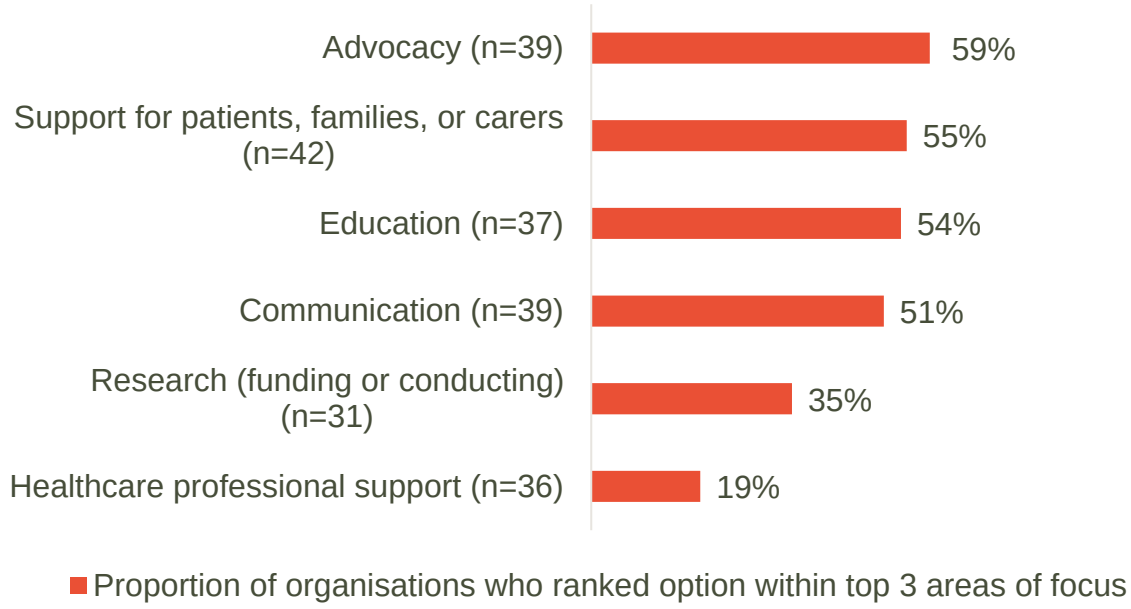


Figure 21. Q18 Does your organisation offer any of the following resources - for caregivers? Please select all that apply.

Organisational priorities and areas of success

Organisations were asked to rank several areas of focus, where being ranked as 1 was the highest focus of the organisation. As shown in Figure 22, organisations were most likely to primarily focus on advocacy (59%, n=23), followed by support for patients, families or carers (55%, n=23), education (54%, n=20) and communication (51%, n=20).

Figure 22. Q19 Which of the following does your organisation primarily focus on? Please rank all that apply where 1 is the highest focus.



Respondents were then asked what they felt their organisation did well. Several organisations highlighted CLL information and education provision:

"Information, support and representing the interest of those with CLL/SLL"

"Gives patients and their loved one's information about the disease, what to expect, possibilities and how to deal with the situation."

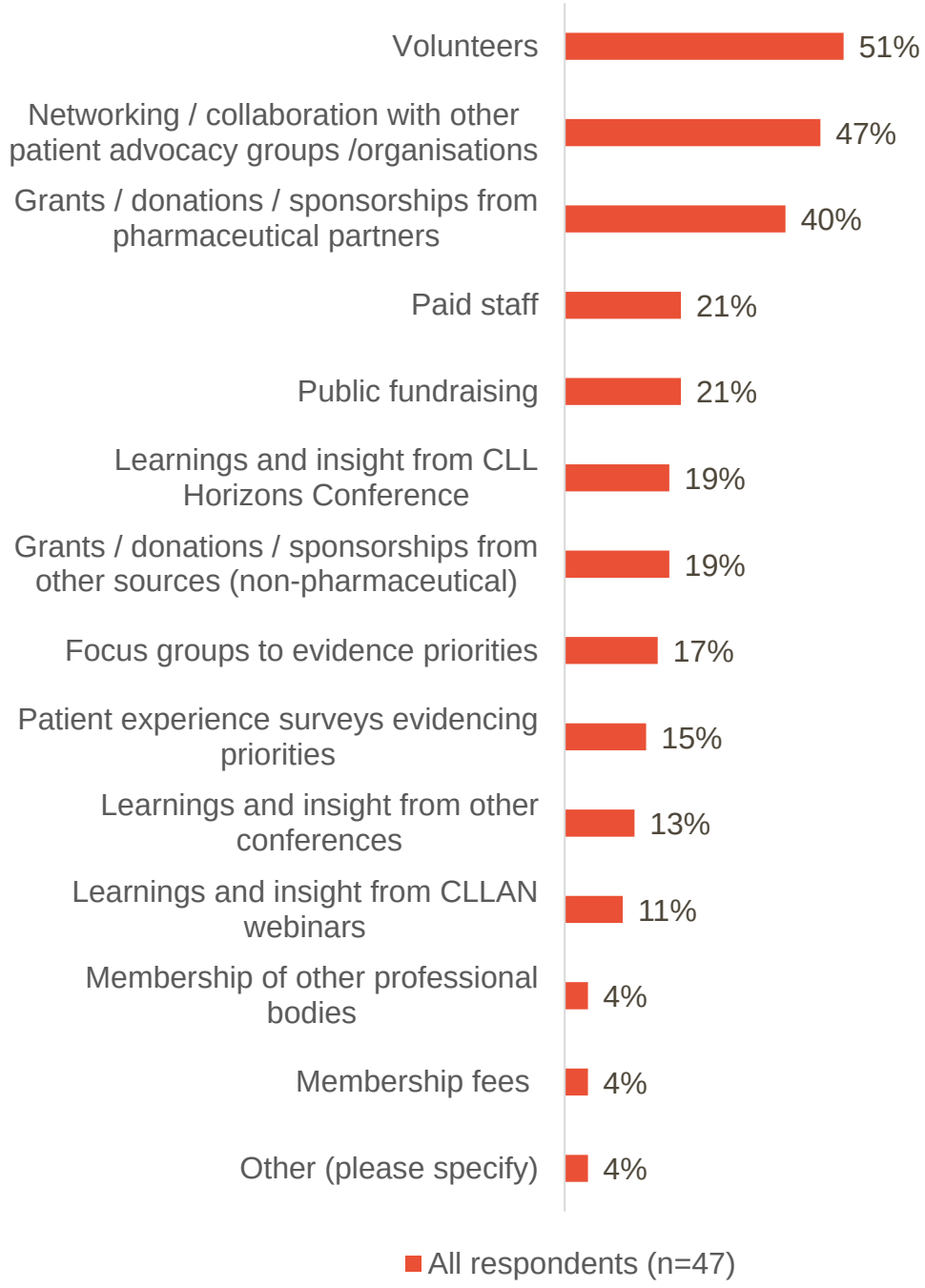
"We conduct more than 100 educational programs a year for haematology and oncology patients."

"Giving information about CLL and updates on treatments and bringing CLL patients together."

"Our organization specializes in online patient education and patient advocacy."

Volunteers were identified as the leading contributor to organisational success (51%, n=24). This was followed by networking / collaboration with other patient advocacy groups / organisations (47%, n=22) and grants / donations / sponsorships from pharmaceutical partners (40%, n=19) (Figure 23).

Figure 23. Q21 What are the key factors contributing to your organisation's success? Please select up to three options.



Barriers to delivery of services and resources

Organisations were asked if they would like to offer any of the services and resources they do not currently provide to patients and / or caregivers.

Services that organisations would like offer to patients and caregivers

Organisations would most like to offer the following services to **patients**:

- CLL news and conference coverages (100%, n=9)
- Awareness campaigns (80%, n=8)
- Publications and presentations at relevant blood cancer meetings (75%, n=9)
- Fundraising resources (74%, n=17)

Organisations would most like to offer the following services to **caregivers**:

- CLL news and conference coverages (100%, n=16)
- Webinars (82%, n=14)
- Education events (82%, n=9)
- Support meetings (80%, n=16)

Resources that organisations would like to offer to patients and caregivers

The top 3 resources organisations would like to offer to both patients and caregivers were:

- Website (Patients: 88%, n=7; Caregivers: 87%, n=13)
- Videos (Patients: 83%, n=10; Caregivers: 80%, n=12)
- Printed leaflets / booklets (Patients: 67%, n=4; Caregivers: 85%, n=11)

See Figure 24, Figure 25, Figure 26 and Figure 27 for full details of results.

Figure 24. Q30 Of the services you do not currently offer for patients, would you like to offer any of these to patients?

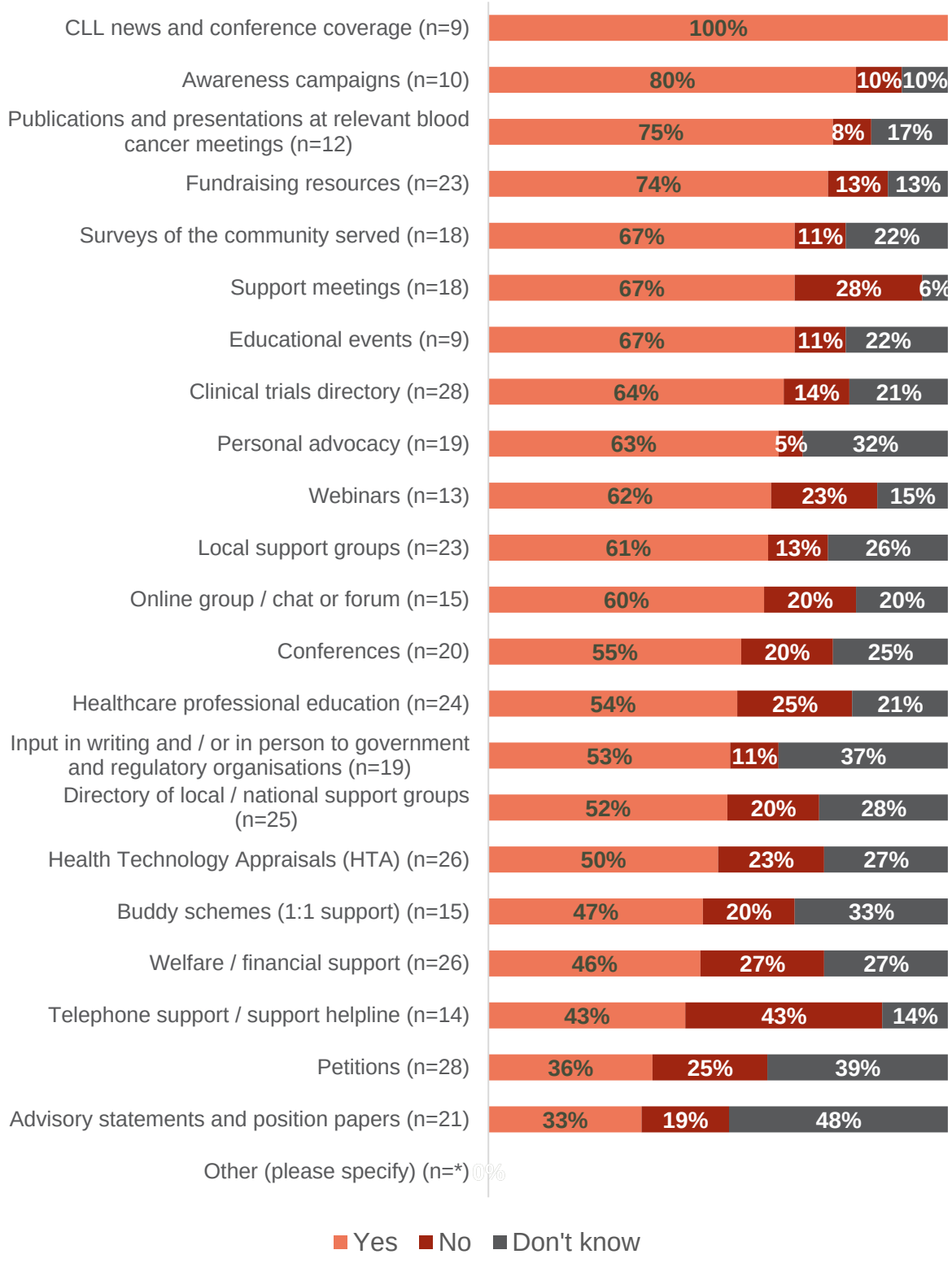


Figure 25. Q31 Of the services you do not currently offer for carers, would you like to offer any of these to carers?

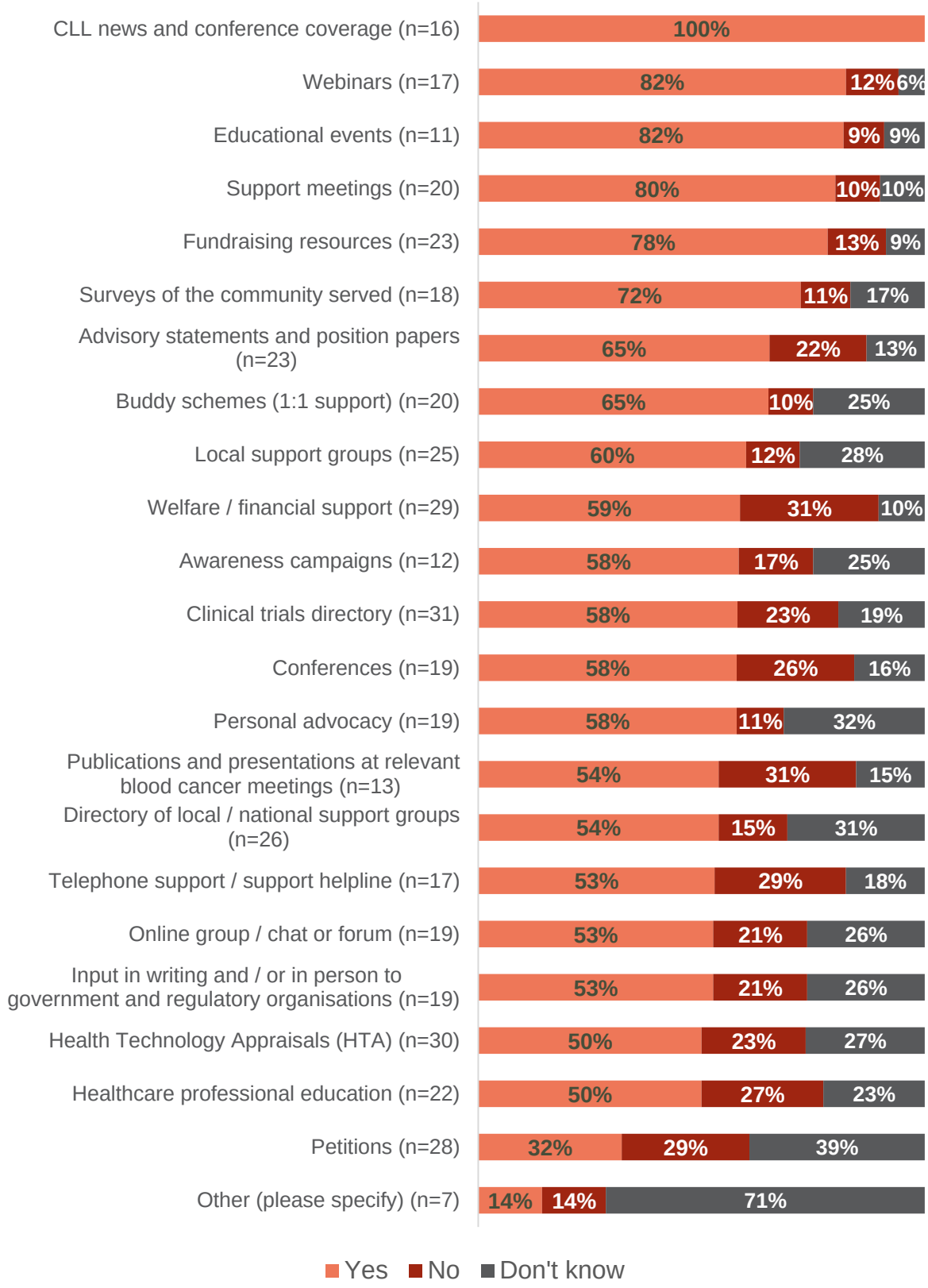


Figure 26. Q33 Of the resources you do not currently offer for patients, would you like to offer any of these to patients?

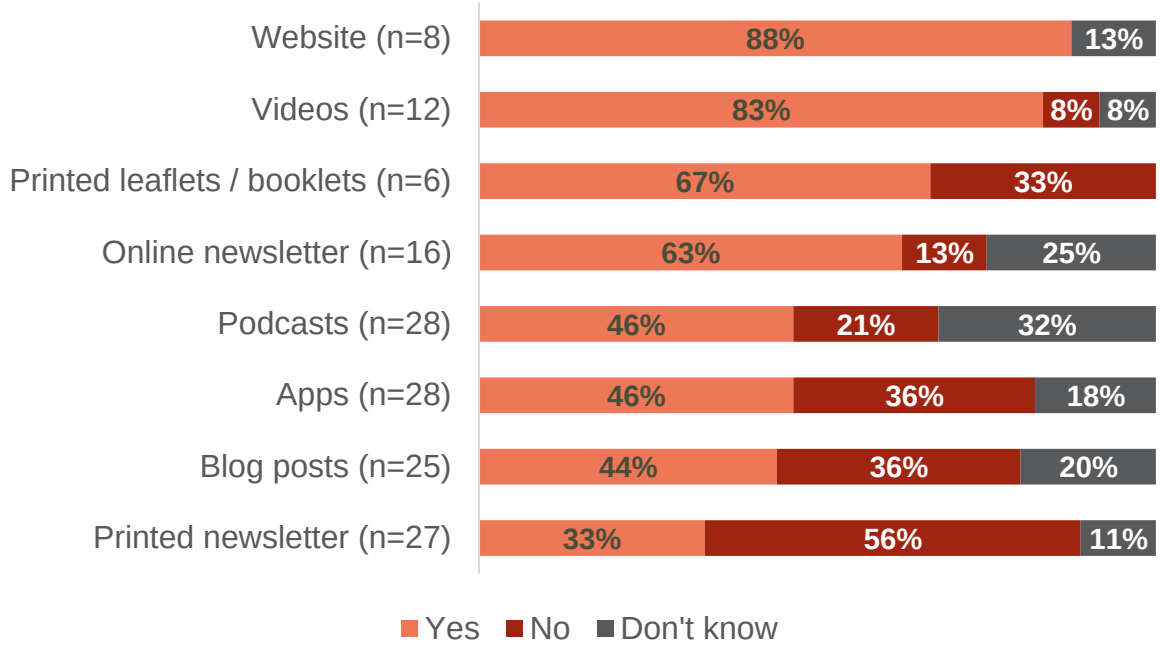
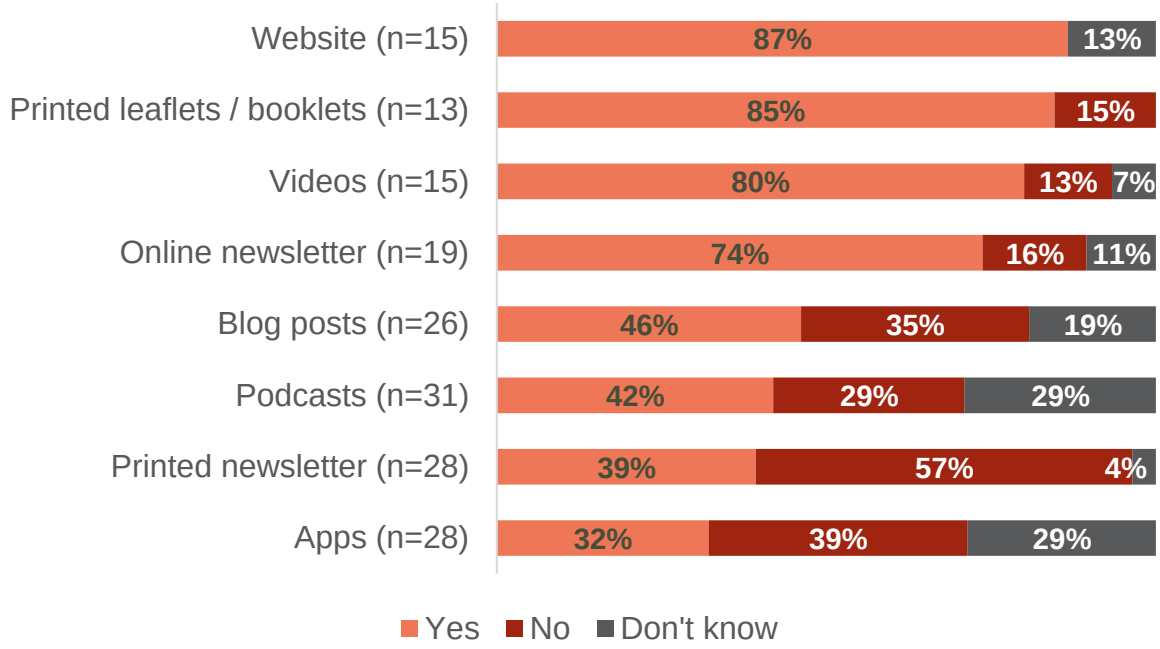
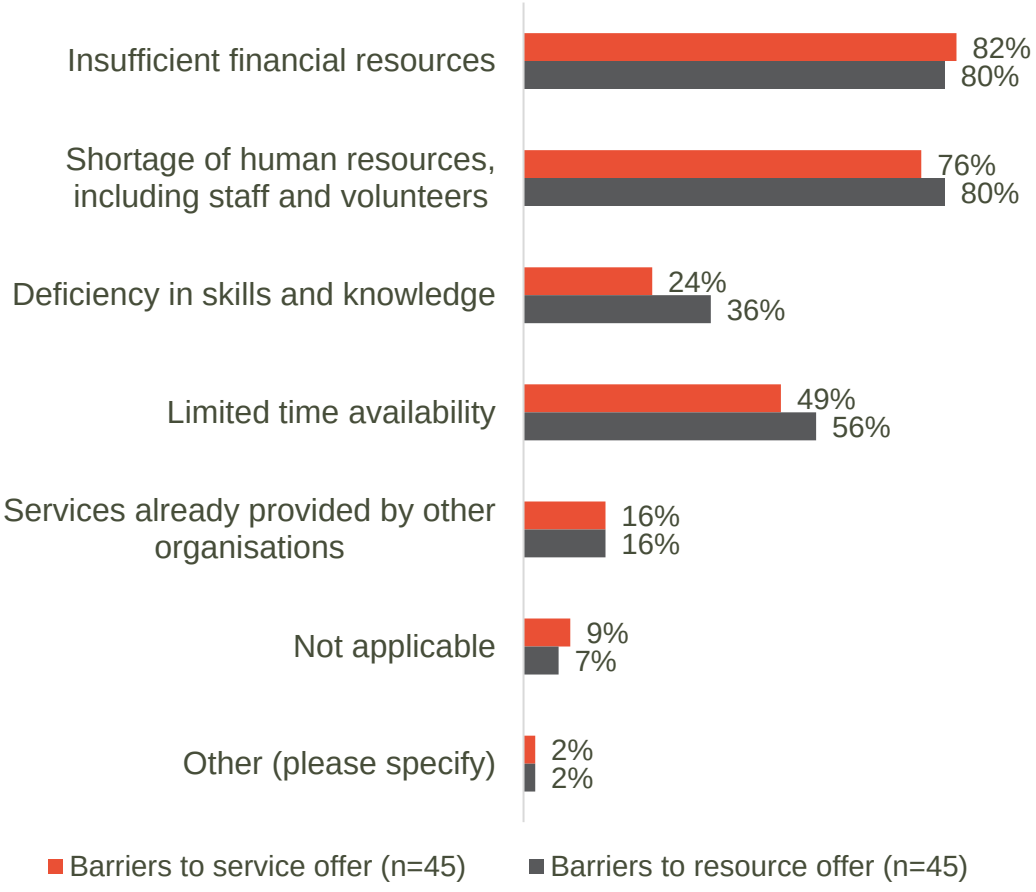


Figure 27. Q34 Of the resources you do not currently offer for carers, would you like to offer any of these to carers?



Organisations were asked if they experience any barriers that stops them from offering the services and resources they would like to offer. As shown in Figure 28, organisations cited insufficient financial resources (82%, n=37 for services; 80%, n=36 for resources) and a shortage of human resources, including staff and volunteers (76%, n=34 for services; 80%, n=36 for resources) as barriers to offering the services and resources they would like to offer.

Figure 28. Q32 Thinking about the services you would like to offer, what are the current barriers to offering these? Please select all that apply. & Q35 Thinking about type(s) of CLL resources you would like to offer, what are the current barriers to offering these? Please select all that apply.



Respondents were asked more detail about the biggest challenges their organisation currently faces. Several organisations cited a lack of financial and human resources:

"Insufficient human resources and finances."

"Sustainable funding to continue the valuable work we are doing."

"Human resource challenges. Availability of volunteers with correct skillsets."

Experience of barriers to service delivery were notably different between organisations based in HIC and those based in LMIC (Figure 29, Figure 30).

Barriers to service delivery

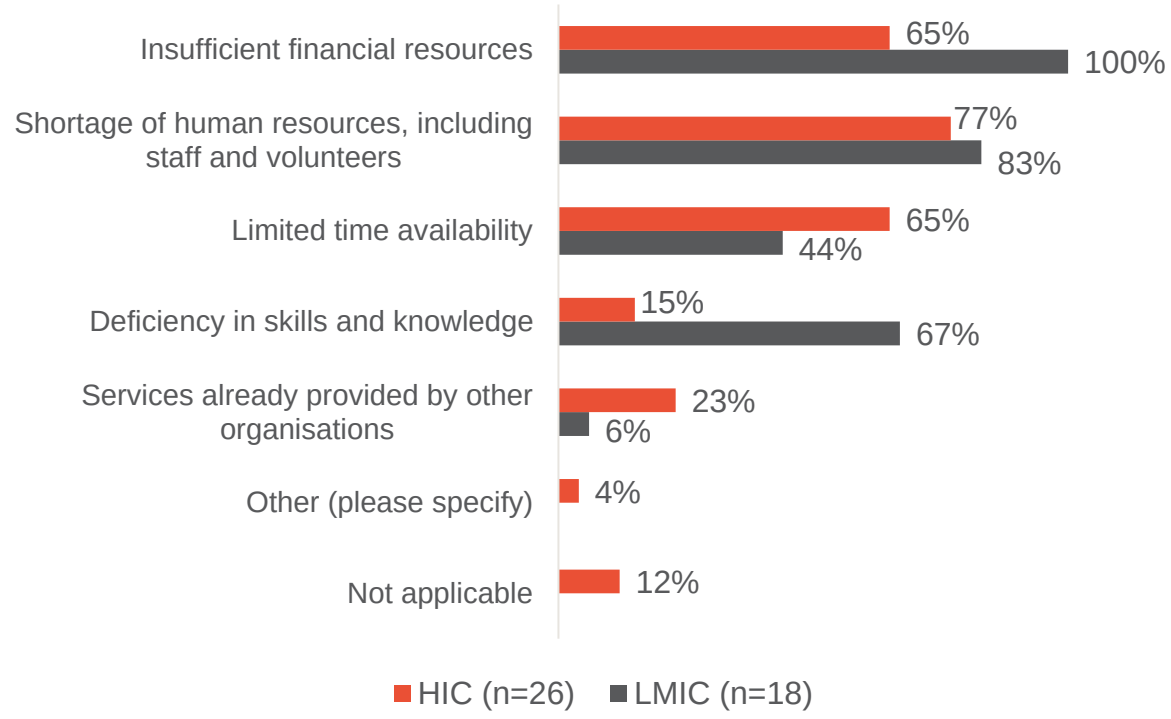
- 100% (n=18) of LMIC organisations cited insufficient financial resources as a barrier, compared to 69% (n=18) of HIC organisations
- 83% (n=15) of LMIC organisations cited a shortage of human resources, including staff and volunteers as a barrier, compared to 69% (n=18) of HIC organisations
- 44% (n=8) of LMIC organisations cited limited time availability as a barrier, compared to 54% (n=14) of HIC organisations
- 39% (n=7) of LMIC organisations cited a deficiency in skills and knowledge as a barrier, compared to 15% (n=4) of HIC organisations

Barriers to resource delivery

- 100% (n=18) of LMIC organisations cited insufficient financial resources as a barrier, compared to 65% (n=17) of HIC organisations
- 67% (n=12) of LMIC organisations cited a deficiency in skills and knowledge as a barrier, compared to 15% (n=4) of HIC organisations
- 44% (n=8) of LMIC organisations cited limited time availability as a barrier, compared to 65% (n=17) of HIC organisations

Figure 29. Q32 Thinking about type(s) of CLL services you would like to offer, what are the current barriers to offering these? Please select all that apply. HIC vs LMIC

Figure 30. Q35 Thinking about type(s) of CLL resources you would like to offer, what are the current barriers to offering these? Please select all that apply. HIC vs LMIC



Changing landscape of service provision since Covid-19

Endemic COVID-19 refers to the stage where the virus becomes a constant presence in the population but at relatively stable and manageable levels. While COVID-19 has become a less significant issue for most people, some groups like certain blood cancer patients remain at elevated risk with profound effects on their lives.

Organisations were asked how the frequency and demand of the services they provide has changed since Covid-19 (Figure 31; Figure 32).

Since Covid-19, organisations were most likely to report an *increase* in the frequency at which they currently offer the following services:

- Personal advocacy (59%, n=13)
- Online group / chat or forum (59%, n=13)
- Healthcare professional education (59%, n=10)

Since Covid-19, organisations were most likely to report an *increase* in the demand at which they currently offer the following services:

- Personal advocacy (68%, n=15)
- Welfare / financial support (67%, n=6)
- Online group / chat or forum (64%, n=14)

Figure 31. Q37 Since Covid-19, how has the frequency changed at which you currently offer the following services?

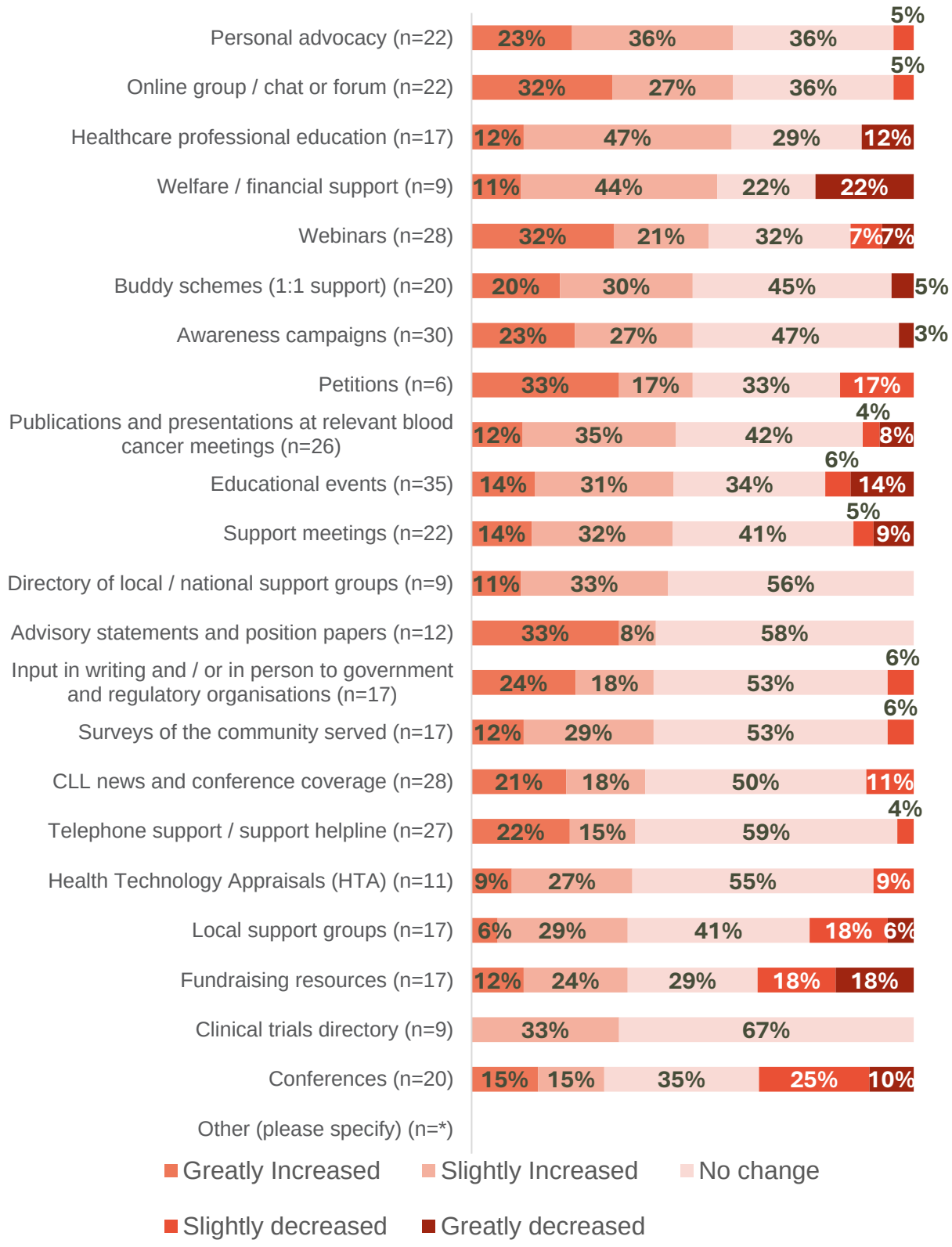
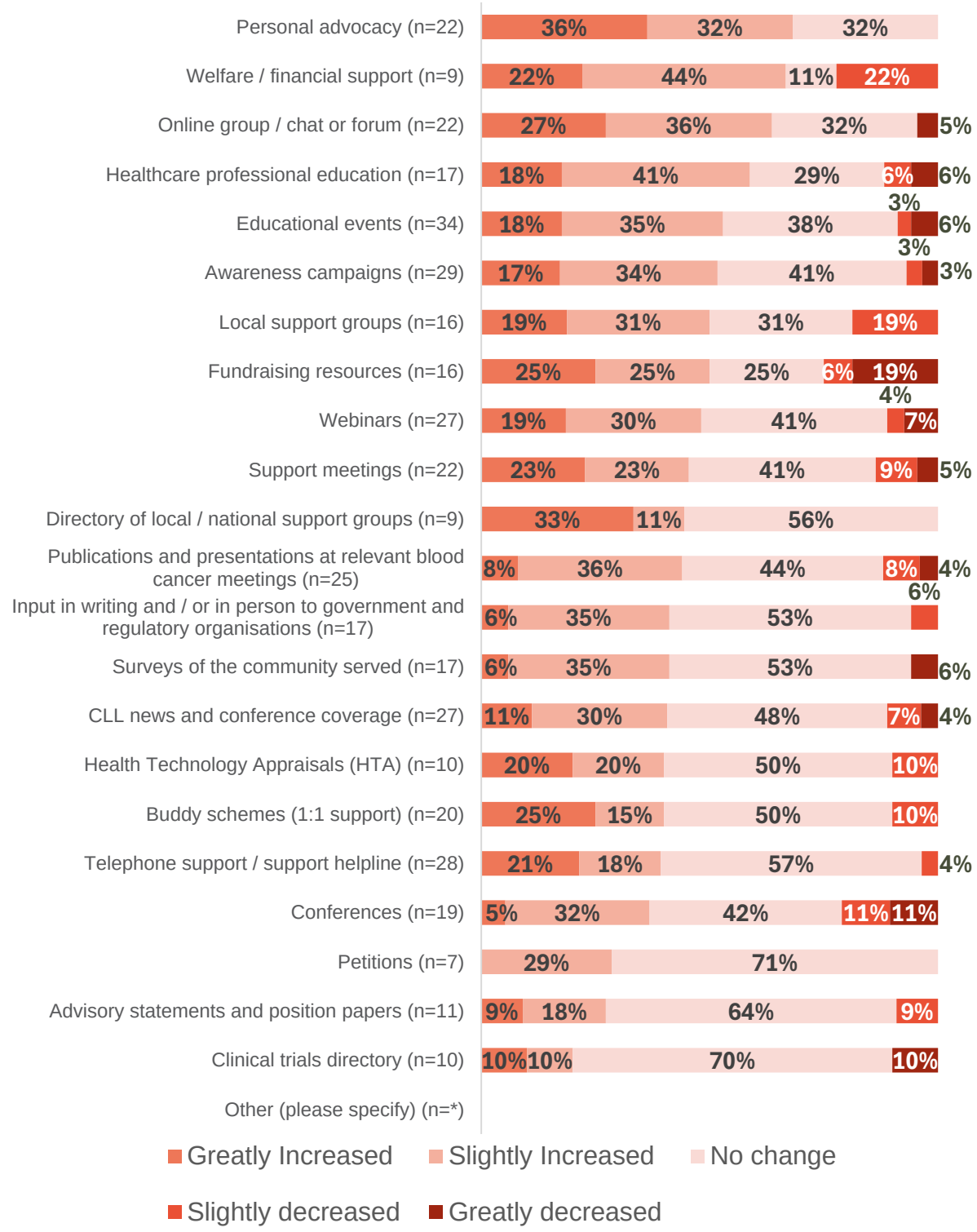


Figure 32. Q38 Since Covid-19, how has demand changed for your services?



Organisations were asked how immune-related challenges have impacted patient behaviour. Many organisations reported patients being more cautious about entering public spaces or events and the emotional impact this can have:

"Some of the patients tell us that they have difficulty socialising or attending events due to their weakened immune system."

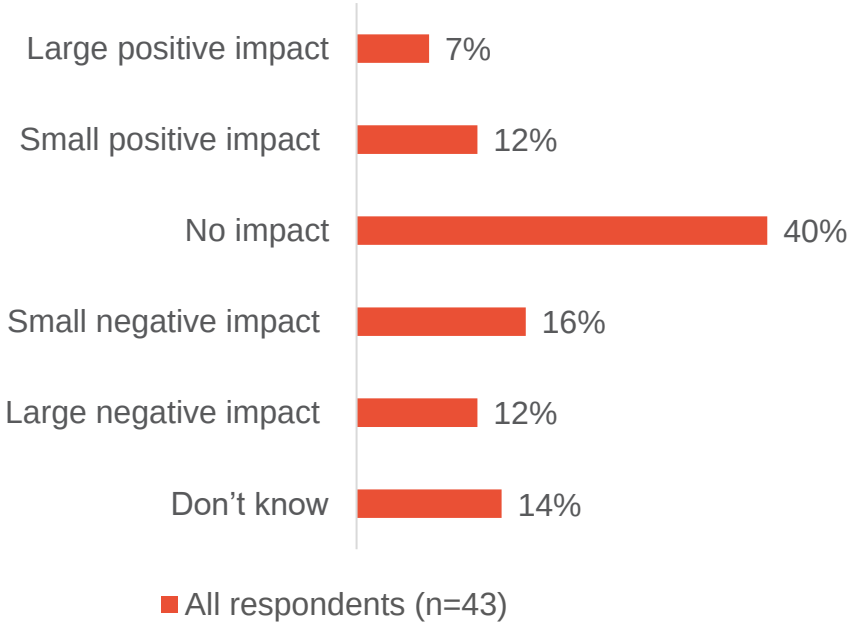
"They tend to go out less to protect themselves from other infections."

"The emotional anxiety caused by immune issues is quite prominent."

"Isolation - Patients limit social interactions and public exposure which can affect their mental health (loneliness, depression, anxiety)."

For 40% (n=17) of organisations, immune-related challenges have not impacted their ability to secure funding. 19% (n=8) report that these challenges have had a positive impact on their ability to secure funding, while 28% (n=12) report they have had a negative impact (Figure 33).

Figure 33. Q40 What impact do immune-related challenges have on your organisation's ability to secure funding (donations / sponsorships etc)?



Organisations were asked how immune-related challenges have impacted them. Many organisations reported experiencing an increase in demand for online services, compared to in-person services:

“We take great care when we hold face to face meetings.”

“No in person meetings.”

“Webinars are now a normal part of our work.”

“Pivoted to virtual services.”

Organisations were asked to describe any actions their organisation has taken or plans to take to address immune-related challenges (e.g., actions around information/knowledge sharing). Investment into online information and communication methods was a common action taken by organisations:

“We have expanded our media and online communication official channels”

“Publication of useful information on our Facebook resources.”

“Information sharing via L&L info days, webinars, on social media, in other media sources...”

“More virtual events”

“Increased online patient education meetings on related topics”

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