Global Patient and Carer Experience Survey

2021-2022

September 2023

ALAN Acute Leukemia Advocates Network

CML ADVOCATES NETWORK

CLLAN CLL ADVOCATES NETWORK

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1. Executive summary

In 2021, the Acute Leukemia Advocates Network (ALAN), the CML Advocates Network (CMLAN) and the CLL Advocates Network (CLLAN) (all three referred to throughout this report as “the Networks”) with the support of IQVIA as external provider, carried out a global leukemia patient experience survey. In parallel, the views of carers were collected in a global leukemia carer experience survey. The results of both surveys are shared in this report.

The Networks are global and self-sustained umbrella organisations of national patient groups. The Networks operate independently under the umbrella of their legal host, the Leukemia Patient Advocates Foundation (LePAF, www.lepaf.org) based in Switzerland.

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

There are a number of different types of leukemia, but the four most common are:

Acute myeloid leukemia (AML) – Rapidly developing, affects myeloid cells (granulocytes).

Chronic myeloid leukemia (CML) – Slowly developing, affects myeloid cells (granulocytes).

Acute lymphoblastic leukemia (ALL) – Rapidly developing, affects lymphocytes.

Chronic lymphocytic leukemia (CLL) – Slowly developing, affects lymphocytes.

Acute leukaemia progress rapidly unless effectively treated, but they can sometimes be cured with standard treatments, such as bone marrow transplants. Chronic leukaemia often progress slowly, and although it is not usually possible to cure them with standard treatments they can be treated and managed as a long-term condition.

1.1. Key findings

- A total of 2,646 patients responded to the patient experience survey. The responses were spread as follows: CLL 45% (n=1,202), CML 34% (n=896), AML 12% (n=312), ALL 4% (n=104), Other 5% (n=132).
- A total of 571 carers responded to the carer experience survey. The spread of caring responsibilities by leukemia type was as follows: CLL 26% (n=150), CML 33% (n=183), AML 19% (n=110), ALL 18% (n=100), Other 5% (n=28).

1.1.1. Respondent demographics

Type of leukemia from Patient Survey

- The majority of respondents (79%, n=2,098) were living with a chronic leukemia. Of those living with chronic leukemia, the majority (57% n=1,202) had CLL.
- Sixteen percent (n=416) of respondents to the patient survey were living with an acute leukemia. The majority of these (75%, n=312) had AML.

Gender

- Overall, there were more female than male patients who responded to the patient survey: (ALL 56%, n=56, AML 64%, n=194, CML 61%, n=526, and CLL 51%, n=593).
- The majority of carers, who responded to the survey, were females (72%, n=405).

Age

- Patients were asked their year of birth. They were then placed in the following age (years) brackets: <16, 16-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+.
- The age bracket with the highest proportion of patients was the 65-74 years bracket (31%, n=786). However, this is skewed by the older age profile of CLL respondents (45%, n=1,202), who were the biggest respondent group. ALL in particular has a much younger age profile, which aligns with previous knowledge of ALL patient characteristics.
- From the carer survey, there were significant differences in the split of ages reported, but these were in line with other demographics such as the profile of the carer as detailed below.

Living arrangements

- More than half (52% [n=1,352]) of the patients live with their spouse/partner and 17% (n=444) also have dependent children. This was higher for people living with CML, where 29% (n=253) had children living with them.
- In line with the findings reported around age, 31% (n=31) of ALL patients (as opposed to 15%, n=46 of AML patients) lived with their parents or other adult family members.
- Ninety-percent (n=515) of carers were related to the patient as parent, partner, or child.

Employment and Education

- Forty-three percent 43% (n=1,102) of patients who responded to the survey were retired, although again this is skewed by the substantial proportion of patients living with CLL who were more likely to be older and not in work.

- Sixty percent (n=1,538) of respondents were in, or looking for work, prior to their diagnosis; this was slightly different between the different types of leukemia: ALL 60% (n=,60), AML 70% (n=215), CML 66% (n=577), and CLL 52% (n=605).
- The largest proportion of carers (35%, n=199) were still in employment. However, 23% of carers were retired (n=131).
- Fifty-two percent (n=1,356) of all patients had university level qualifications.

Income

- Fifty-four percent (n=1,398) of patients had what they would describe as 'average income', 23% (n=588) low income and 16% (n=408) of high income.

Symptoms prior to diagnosis

- Prior to diagnosis, fatigue was the most commonly experienced symptom (51%, n=1,353).
- Pre-diagnosis, the most commonly reported other early symptoms across all types of leukemia feeling weak or breathless (28%, n=740) and fever (28%, n=743).
- Although there was significant overlap, there were also differences in symptoms experienced by those with different leukemia types due to the nature of the disease. For example, those with AML reported fatigue and feeling breathless as main symptoms, whilst those with CML reported unexplained weight loss.
- The vast majority of patients (91%, n=2,116) and carers (86%, n=490) were unaware that their symptoms pre-diagnosis could be associated with leukemia.

1.1.2. Diagnosis

- As had been identified through previous research[1], challenges around diagnosis remain. Leukemia patients were most likely to be diagnosed via a test for something other than leukemia (51%, n=1,342).
- As expected, diagnosis was often a shock for the vast majority of respondents, 91%(n=2,116) did not know their symptoms could be related to a leukemia diagnosis.
- Carers have similar views: just 7% (n=38) of carers thought the patient's symptoms may have been leukemia.
- The majority of patients (78% [n=2,048]) did, however, know that leukemia was a form of blood cancer.

1.1.3. Information and support at diagnosis

- The lack of information provision remains an issue. Less than half of the patients (48%, n=1,255) stated that they had been given or directed to written information about their leukemia at diagnosis.
- Among those not offered written information at diagnosis, the majority reported that they would have appreciated this (68%, n=346).
- Fifty-one percent (n=1,337) of the patients were not offered or referred to any support services to help with concerns and worries about their leukemia at diagnosis.

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6893268/

- When provided, the most common support (64%, n=682) referred newly diagnosed patients to 'additional written material', booklets, or leaflets. As the second most common source of support, patients were directed to patient advocacy and support groups (50%, n=539).
- Fifty-four percent (n=1,413) of patients had someone with them when they were diagnosed. This matches almost exactly to the results of the carer survey. Fifty-four percent of carers (n=287) reported that they accompanied the person they cared for at their diagnosis.
- The manner in which the patient was informed they had leukemia could be improved. Thirty-eight percent of patients (n=982) and 30% (n=88) of carers felt the diagnosis could have been handled more sensitively.
- Twelve percent (n=313) of patients reported that healthcare professionals told them not to look at the internet for information on their leukemia. A further 29% (n=744) of patients reported they were told to look only at trusted websites. Forty-eight percent (n=1,227) of patients reported that their healthcare professionals did not mention the internet at all.
- Ninety-two percent (n=2,362) of patients and 83% (n=464) of carers reported that they had used the Internet to search for further information about leukemia.
- Of those who were directed to further support, the majority of patients (59%, n=1,222) did access this support.
- Of those who accessed the support, the vast majority of patients (94%, n=1,188) found it helpful, at least to some extent.

1.1.4. Watch and Wait[2]

- Ninety percent of CLL patients (n=1,080) reported being placed on ‘Watch and Wait’ at some point.
- Those that were on ‘Watch and Wait’ reported that they were given an explanation (88%, n=1,110), and that they could understand it completely (57%, n=655), while 39% (n=451) said they understood the explanation only partially.
- There was a lack in the provision of written information. While only 35% (n=443) of patients were given written information on ‘Watch and Wait’, 4% (n=274) of patients reported they would have liked this information but were not given it.
- Of those who were placed on ‘Watch and Wait,’ 78% (n=982) had worries and fears about it, 58% (n=719) reported not being offered or directed to support to help them with their worries and fears.
- Forty percent (n=220) of patients were moved from ‘Watch and Wait’ to active treatment within two years. This was most commonly reported due to disease progression (79%, n=439).
- Eighty-six percent (n=167) of carers understood why the patient was put on ‘Watch and Wait’ but only 33% (n=65) of carers reported being given written information about ‘Watch and Wait’. The majority of carers (77%, n=151) had worries and fears about this.

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

1.1.5. Treatment

- Fifty-seven percent (n=1,037) of patients reported being given active treatment within a week of diagnosis. This obviously varied highly amongst the different leukemia subtypes: ALL 93% (n=93), AML 87% (n=264), CML 66% (n=575), CLL 12% (n=52), Other 54% (n=53).
- Forty-three percent (n=882) of patients and 74% (n=364) of carers reported researching the internet around different treatment options. This was lower for those with acute rather than chronic leukemia. 62% (n=1,268) of patients were given written information on their treatment while 51% (n=250) of carers did not receive any information.
- Sixty-two percent (n=1,271) of patients were not offered a choice of treatments.
- However, 44% (n=915) of patients felt that they were involved completely in decisions around their treatment and care. The results were similar in the carers survey where (48%, n=273) reported being involved in decisions.
- For those concerned, 36% (n=479) of patients reported missing a dose of their medication. The most common reason was that the patient forgot to take their medication.
- Sixty-six percent (n=1,346) of patients reported taking an oral drug to treat their leukemia.
- Sixty-one percent (n=1,221) of patients reported that their symptoms have improved with their current treatment.
- Fatigue was the most common side effect with 53% of patients (n=1,103) experiencing this. Overall, 45% (n=854) of patients reported that side effects had a small impact on their lives, while 48% (n=238) of carers reported that side effects had a large impact on the life of the patient they were caring for.
- Twenty-seven percent (n=517) of patients and 20% (n=101) of carers were satisfied with the way the side effects were managed by their healthcare professionals.
- Sixty-percent (n=1,225) of patients reported that they were not offered a clinical trial, but 43% (n=523) would have liked to have been offered this opportunity.
- Chemotherapy was significantly more common amongst both acute leukemia types.
- Fourteen percent (n=287) of acute patients had a stem cell transplant as part of their leukemia treatment.
- Oral treatments were relatively common for those with chronic leukemia; and these were also the most popular administration route requested for new treatments.
- When asking opinions on potential new treatments, 53% (n=1,333) of patients and 34% (n=193) of carers responded positively if a treatment plan contained a treatment-free period or included stopping treatment altogether.
- Of those with childbearing potential, only 23% (n=590) of patients were informed about the impact treatment could have on their fertility.

1.1.6. Ongoing monitoring

- Forty-six percent (n=133) of patients are moderately or extremely worried about the potential for relapse. Carers were reportedly more worried than patients. 75% (n=372) of carers reported being moderately or extremely worried about relapse.
- Overall, 94% (n=2,458) of patients were undergoing regular testing / monitoring: CML 97%, (n=855), CLL 94%, (n=1,123), ALL 88%, (n=90), and AML 88%, (n=271).

- Patients and carers reported positively around ongoing tests, but experienced anxiety around waiting for results. Twenty-one percent (n=110) of carers reported being extremely worried while waiting for the results; for patients, 30% (n=649) reported that they rated their anxiety as 8 out of 10 or above.
- Sixty-five percent of patients (n=2,217) stated that the results of these tests were always explained to them, even though sometimes they had to ask. Those with acute leukemia were more likely to report the results of tests always being explained (AML 74%, n=200, ALL 70%, n=63, CML 64%, n=551, and CLL 63%, n=703).
- Patients reported positively on being able to access test results themselves. Overall, 75% of patients (n=1,835) reported that they were able to access their own results.

1.1.7. Living with leukemia

- Leukemia can have a profound impact on those diagnosed with the disease and clearly also has an impact on those who care for them. It is therefore important to identify and understand this impact to be able to provide appropriate healthcare and comprehensive support.
- Quality of Life (QoL) can be severely affected whilst living with leukemia. Most commonly patients reported difficulty with self-care and leaving their house.
- Carers were overall more likely to report more severe QoL issues for the patients than the patients themselves. Sixty-four percent (n=1,649) of all leukemia patients felt that they did not have any difficulties with their relationships, and 39% (n=977) felt that they had no issues with their sex life.
- Emotional wellbeing is affected when living with leukemia. Isolation in particular can negatively affect mental health. In total, 39% (n=1,007) of respondents have felt isolated since their diagnosis. Patients with acute leukemia were much more likely to report feeling isolated (ALL 57%, AML 51%).
- Forty-eight percent (n=1,231) of patients reported that they have felt anxious and depressed more often since their diagnosis and 49% (n=276) of carers reported that the patient, they were caring for, was more often depressed and anxious.
- The views of carers differed from patients around emotional wellbeing; 20% (n=115) felt that the patient with leukemia was actually more positive since their diagnosis. However, 58% (n=328) of carers felt that the patient had been depressed or anxious (9% of which felt that they were constantly depressed or anxious).
- Noteworthy, leukemia patients rated positively the way healthcare professionals managed the emotional impact of leukemia, with most rating their care as 7 out of 10 or above. The results for carers were similar.

1.1.8. Impact on carers

- Quality of life is important for both patients and carers. Carers and patients inevitably felt that leukemia had a significant impact on their quality of life. This was rated as less severe for those caring for someone with chronic leukemia compared to acute leukemia.
- Majority of carers (64% [n=365]) reported that caring for someone with leukemia had a negative impact on their wellbeing.
- Forty-nine percent (n=275) reported an overall negative impact of leukemia on their finances due to increased costs and / or reduced income.

1.1.9. Impact of COVID-19

The survey was carried out whilst the COVID-19 pandemic was still ongoing and inevitably the pandemic had an impact on the care and experience of patients and their carers.

- Patients reported some gaps in the information provided from government, healthcare professionals and support organisations during the COVID-19 pandemic.
- Encouragingly, very few patients reported that their treatment was changed; just 9% (n=242) reported a change in their treatment. However, a much higher proportion reported appointments being postponed or cancelled (47%, n=1,192).
- Half (50% [n=1,265] of the patients reported that treatment and care remained the same during the COVID-19 pandemic.
- Thirty-seven percent of patients (n=886) reported that cancelled appointments were not reinstated. The rest were replaced through video or phone consultations. However, most patients reported they remained satisfied with their care (38%, n=587).
- Vaccinations and safety were important to patients and carers, with 91% (n=2,330) of patients stating that they had had both vaccine doses. A similar number of carers reported receiving both doses of the COVID-19 vaccine (93%, n=524).
- Patients and carers recognise that these were unprecedented times and healthcare and support organisations had to make fundamental changes to ensure patient treatment, care, and welfare.

1.2. Recommendations

The survey objectives were to aid patient advocates and advocacy groups to inform and influence stakeholder communities, industry, and policymakers, through the collection of patient and carer experiences and quality of life data throughout the leukemia patient pathway.

The most important factor in managing the identified unmet needs from the survey is to promote and foster engagement between network organisations and local healthcare providers, researchers, and pharmaceutical companies. Provision of information and support appears to be a particular issue across all stages of leukemia and this engagement should provide a holistic, integrated approach that encompasses high-quality healthcare with improved access to information and support.

The recommendations provided below and co-authored with support from the Networks are intended to be top-level strategic actions. It is suggested that more detailed plans are created at a local level.

Pre-diagnosis

There remain clear challenges around the recognition and diagnosis of leukemia. This includes both the general public and primary healthcare providers.

- Continue to raise awareness campaigns aimed at both the general public and primary healthcare providers. Ensure communications are targeted in order to maximise impact.
- Primary care has a vital role in supporting patient autonomy to enable people living with leukemia to manage their own health and wellness. Late diagnosis often leads to poorer outcomes. Introduce capacity-building and education programmes for primary healthcare providers. This should include engagement with all primary care settings such as GPs, Opticians, Dentists etc, and work with local community and patient groups.
- Enhance information provision and support services with a particular focus on diagnosis, prognosis, and the impact of living with leukemia.

Diagnosis

- A diagnosis of acute leukemia will clearly have a different intervention than for a diagnosis of chronic leukemia. Support services need to be segmented accordingly.
- A diagnosis of leukemia can often impact financial wellness, particularly those from lower income backgrounds. Additional information and support services specifically focused on financial wellness should be implemented particularly at diagnosis. This is a challenging area and appropriate support is still needed by those who had financial problems before diagnosis, and those who have financial issues caused only by their leukemia diagnosis. Support services provided directly by patient groups are proven to be effective (e.g. Macmillan in the UK)[3].

[3] https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/money-finance-and-insurance

‘Watch and Wait’

- ‘Watch and Wait’ is a common management tool for chronic leukemia (particularly in the US and the UK). There continues to be a significant lack of understanding of what it means to be on ‘Watch and Wait.’
- Patients can feel like their care team is not doing enough to treat their condition. This directly impacts mental wellbeing. Providing information and support particularly at diagnosis is needed.
- Nurse-led initiatives should be encouraged. Access to Clinical Nurse Specialists (CNSs) can often be restricted to those in active treatment; access to a CNS for those on ‘Watch and Wait’ should be considered.

Treatment

- There is a lack of information at the start of leukemia treatment and care, most notably on side effects. A holistic approach involving the clinical community and patient organisations will aid improvements. Patient organisations can support empowerment of patients to understand what information they need.
- Involvement in treatment decisions and choices for patients and carers needs to be improved. Advocacy Networks should continue to highlight and promote the benefits and importance of empowering patients and carers.

Clinical Trials

- The findings of this survey shown a lack of involvement in clinical trials, with many patients unaware of available trials; coupled with a lack of trials in lower income countries. With the ever-changing treatment landscape, the ability to be involved in trials is important. Development of an international database of available clinical trials in leukemia should be prioritised.
- The Networks should continue to work collaboratively with the healthcare community, researchers, and pharmaceutical companies to promote appropriate trials, and support the involvement of patients and carers.

Living with leukemia

- Leukemia has an obvious negative impact on patients, carers, and their wider families. It is important that healthcare is delivered holistically at every point in the patient journey/pathway, and considers wider quality of life issues when looking at treatment, management, and ongoing care.
- Emotional and mental health can be more negatively affected than physical well-being, and experiences differ between different groups. Support needs to be improved, tailored and targeted.
- Isolation and mental health are affected by a leukemia diagnosis and treatment. It is further affected longer-term while patients live with the disease. Support for this should be promoted, particularly at these points for patients and their carers.
- Leukemia can negatively impact a person's work and financial situation; especially during treatment. It varies by subtype and by demographics. Consider a flexible support program to alleviate these issues and improve patient and carer well-being.

COVID-19

- This survey was conducted at a time when COVID-19 measures were in place. As a result, many systems and processes have changed.
- COVID-19 had a significant impact on healthcare; in particular for those that are immunocompromised such as leukemia patients. Broader collaboration regarding safety measures has proven effective such as the International COVID-19 Blood Cancer Coalition (ICBCC, led by CLLAN).
- These collaborative efforts like those led by the ICBCC are crucial to raising awareness, coordinating interventions, and taking appropriate actions.
- Continuity plans should be developed collaboratively with healthcare providers to minimise any impact on patients and carers.
- Support for patients should be planned and delivered from central government and healthcare systems, it is not the responsibility of patient groups, or the Networks, to drive this support.
- Steps should be taken to improve access to healthcare and provide support to patients who are still experiencing the effects of COVID-19. An important aspect of this is the exploration of alternative technologies and idea generation for novel ways to increase service provision.

2. Background and methodology

2.1. Background and objectives

This report covers two surveys delivered in 2021-2022. The first was aimed at patients and covered typical patient experience measures to explore the patient journey, and quality of life issues. The second survey was aimed at those who were caring for someone with a diagnosis of leukemia, and aimed to capture the carer voice alongside those of patients.

These two surveys were a collaboration between Acute Leukemia Advocates Network (ALAN), CML Advocates Network (CMLAN) and CLL Advocates Network (CLLAN).

The aim was to create further evidence about patient experience and QoL at different points in the patient's journey with leukemia, and in addition to gain evidence about the impact from the perspective of carers of those with leukemia. By understanding what information, care and support are available to patients and caregivers, the Networks can identify priority topics and assess areas for change, enabling evidence-based advocacy.

2.2. Design and development of the questionnaires

Two online questionnaires were used to collect data:

1. A patient questionnaire designed for use by patients with leukemia.
2. Carer questionnaire designed for individuals who are responsible for providing care to a person who has been diagnosed with leukemia or who lives with them.

Development of the patient questionnaire

The patient questionnaire was developed based on existing patient pathway experience questionnaires used in the ALAN 2019 Quality of Life (QoL) global survey, alongside other previous and related questionnaires. Furthermore, the Networks decided to include a number of questions regarding the COVID-19 pandemic.

The questionnaire consisted of 200 questions (with some sub-questions) including haematological malignancy-patient-reported outcome (HM-PRO), a validated QoL assessment tool applied to those with haematological malignancies.

The measure is a validated questionnaire and is a composite measure of two parts, combining the impact of disease and treatment on the QoL of a patient (Part A), and the resulting signs and symptoms (Part B). For this survey, we only collected information to measure Part A.

The final patient questionnaire covered the following areas:

- Disease profile
- Before diagnosis
- Receiving diagnosis
- Watch and Wait (CLL only)
- Treatment
- Transplants
- Relapse
- Testing and Monitoring
- Quality of Life (QoL)
- Emotional impact
- Work and education
- Financial impact
- Information and support
- Impact of COVID-19
- Views on new treatments
- Patient demographics

Testing of the patient questionnaire

Once the question set was agreed, the questionnaire was tested by nine volunteers.

- 1 ALL patient
- 2 AML patients
- 4 CLL patients
- 2 CML patients

The testing process consisted of volunteers completing the questionnaire followed by a telephone interview, to discuss their thoughts on all aspects of the questionnaire design. This exercise contributed towards refining the questionnaire into a finished version.

Following the testing and subsequent changes, the final questionnaire was reviewed by the Networks and signed off in August 2021.

2.3. Development of the carer questionnaire

The carer questionnaire was developed following the patient questionnaire structure to allow comparability. The questions predominantly focussed on the carer's experiences of the same areas and covered their own experience and their perceptions of the experience of the patient that they care for. It also included HM-PRO.

The final carer questionnaire covered the following areas:

- Patient´s disease
- Caring role
- Receiving diagnosis
- Treatment and care
- Relapse
- Testing and Monitoring
- Quality of Life (QoL)
- Emotional impact
- Work and education
- Financial impact
- Information and support
- Impact of COVID-19
- Views on new treatments
- Patient profile
- Carer demographics

The questionnaire was reviewed by three carers and advocates from the Networks.

2.4. Timescales and Fieldwork

The patient questionnaire was agreed upon in August 2021. Following the translation and set-up of the questionnaire, the survey went live in September 2021. Fieldwork was completed in January 2022.

The carer questionnaire was confirmed in May 2022. Following the translation and set-up of the questionnaire, the survey went live in May/June 2022. The fieldwork closed on 19 October 2022.

2.5. Methodology

The surveys were a global piece of research and, as such, were completed exclusively online.

Respondents were recruited through the Networks, via email, online forums, social media, newsletters and through active contact to network members.

The questionnaires were made available in 10 languages: Chinese (Simplified), English, French, German, Hebrew, Italian, Korean, Portuguese (Brazilian), Russian, and Spanish. There was an additional translation into Arabic for the carer questionnaire.

Patients completed the sections relevant to their type of leukemia. Data on relevant patients' characteristics, such as gender, age, and country of residence, were collected in the demographic section.

Patients and carers completed different but linked surveys.

The surveys were designed to focus on the patient's or carer's perspective. The aim was to ask questions that allowed understanding and insight into what the patient and the carer had experienced, rather than from a clinical perspective. It did not seek to replicate the formal collection of scientific data such as patient preferences.

2.6. Understanding the results

For all questions (with the exception of those asked in the form of "tick all that apply") the percentage responses were 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" was 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 chose 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 rounding.

On some questions, scores have been recalculated to exclude non-specific responses (such as do not know/can't remember/other), or responses indicating that the question was not applicable to the participant's circumstances.

There were some limitations to these surveys. Firstly, although the surveys had a global reach, the majority of the responses were from Europe (74%) with 54% being from the UK. Response rates from some countries were so low that the results could not be reported separately from the aggregated global data. This made it difficult to fully understand differences across regions and countries across the globe. Therefore, responses are reported for all respondents rather than being analysed geographically.

Recruitment was completed through the Networks. Although this was an appropriate and convenient method of global recruitment, particularly during the COVID-19 pandemic restrictions, it is restrictive around those who could be recruited, and may not reflect the perspectives and perceptions of the broader leukemia patient and carer community. To broaden the population, that provides responses for future surveys, it would be beneficial to consider alternative sampling methods such as partnering with healthcare organisations and utilising online recruitment techniques.

This report incorporates responses from both patient and carer surveys. The respondents to these surveys were not recruited together, and the carers and patients were therefore, not linked or related meaning that the responses cannot be directly compared. Instead, the responses were discussed together to allow inferences to be drawn. This will provide a unique opportunity to view leukemia from the experience of both patients and carers.

Lastly, although the survey has a global reach, only a relatively small number of responses were collected from those with acute leukemia (416) and their carers (210). Although we would expect lower numbers of responses from those with acute disease, it is difficult to draw generalisable conclusions from the given responses. This should be taken into account when interpreting the findings. The figures for those with chronic leukemia were higher (2,098 patients and 333 carers), the latter still being too small to be truly representative.

Where possible and appropriate, the responses have been compared with previous similar surveys to provide additional context for the findings.

3. Results of the questionnaire

3.1. Patient and Carer Responses

Overall, 2,646 patients and 571 carers from a total of eighty-seven countries responded to the survey.

Country	Patients	Carers	Total	Country	Patients	Carers	Total
Afghanistan	1		1	Nepal	13	5	18
Argentina	33	11	44	Netherlands	18	3	21
Australia	70	6	76	New Zealand	46	2	48
Austria	4		4	Nigeria	31	1	32
Bangladesh	1		1	Norway	1	1	2
Belgium	7	1	8	Palestine	1		1
Bolivia	20		20	Panama	4		4
Brazil	12		12	Paraguay	1		1
Bulgaria	1	1	2	Peru	1	1	2
Cambodia	1		1	Philippines	30	1	31
Canada	110	15	125	Poland	4	1	5
Chile	11	10	21	Portugal	2	4	6
China		1	1	Romania	1		1
Colombia	18	1	19	Russia	13		13
Costa Rica	10	6	16	Saudi Arabia		1	1
Croatia	10	12	22	Senegal	1		1
Czech Republic	1		1	Slovenia	4		4
Denmark	42	31	73	South Africa	4		4
Dominican Republic	3		3	South Korea	48	3	51
Ecuador	11	1	12	Spain	14	5	19
Egypt		2	2	Sudan		4	4
Estonia	4		4	Sweden		10	10
Finland	7	1	8	Switzerland	4	1	5
France	57	97	154	Taiwan		3	3
Georgia	2		2	Tanzania	1		1
Germany	52	23	75	Thailand	6		6
Ghana	8		8	Trinidad and Tobago		2	2
Greece	9		9	Tunisia	1		1
Guatemala	20	34	54	Turkey	1		1
Honduras	7		7	Ukraine	60		60
Hungary	1		1	United Arab Emirates (UAE)	2		2
India	9	4	13	United Kingdom (UK)	1314	151	1465
Indonesia	13		13	United States of America (USA)	147	39	186
Iraq		2	2	Uruguay	1		1
Ireland	26	4	30	Venezuela	5		5
Israel	71	29	100	Vietnam	1	1	2
Italy	1		1	Zimbabwe		2	2
Kazakhstan	14		14				

Country	Patients	Carers	Total	Country	Patients	Carers	Total
Kenya	15		15				
Kosovo		1	1				
Kyrgyzstan	3		3				
Lebanon	1		1				
Libya	1		1				
North Macedonia	1		1				
Madagascar		1	1				
Malaysia	13	1	14				
Mauritius	1	1	2				
Mexico	7	2	9				
Morocco	5	6	11	Missing	151	26	177
Namibia	1		1	Total	2646	571	3217

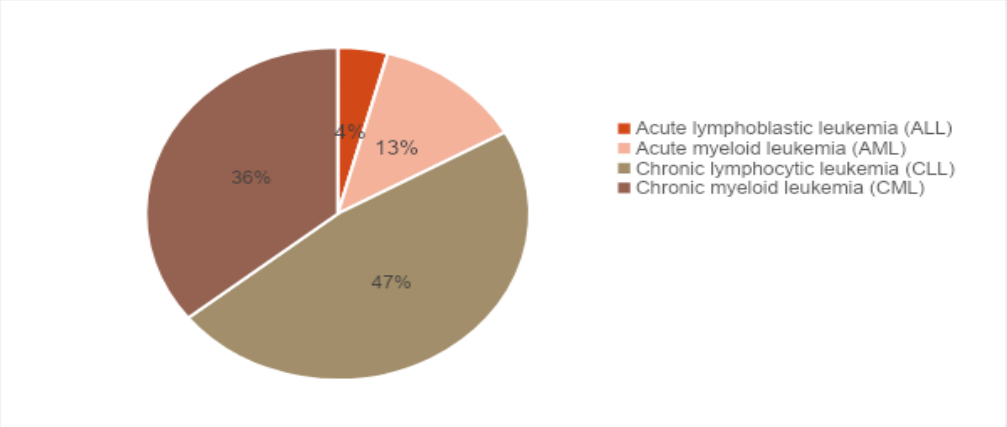
4. Respondent characteristics

4.1. Leukemia diagnosis

Of the 2,646 respondents in the patients' experience survey, 47% (n =1,202) had CLL, 36% (n=896) reported having CML, 13% (n= 312) reported having AML, and 4% (n = 104) had ALL. (Figure 1)

From the carers' survey, there were 571 respondents: 32% (n=183) with CML, 26% (n=150) with CLL, 19% (n =110) with AML, and 18% (n=100) cared for someone with ALL.

Figure 1: Q1 What is your confirmed diagnosis? (Patients)

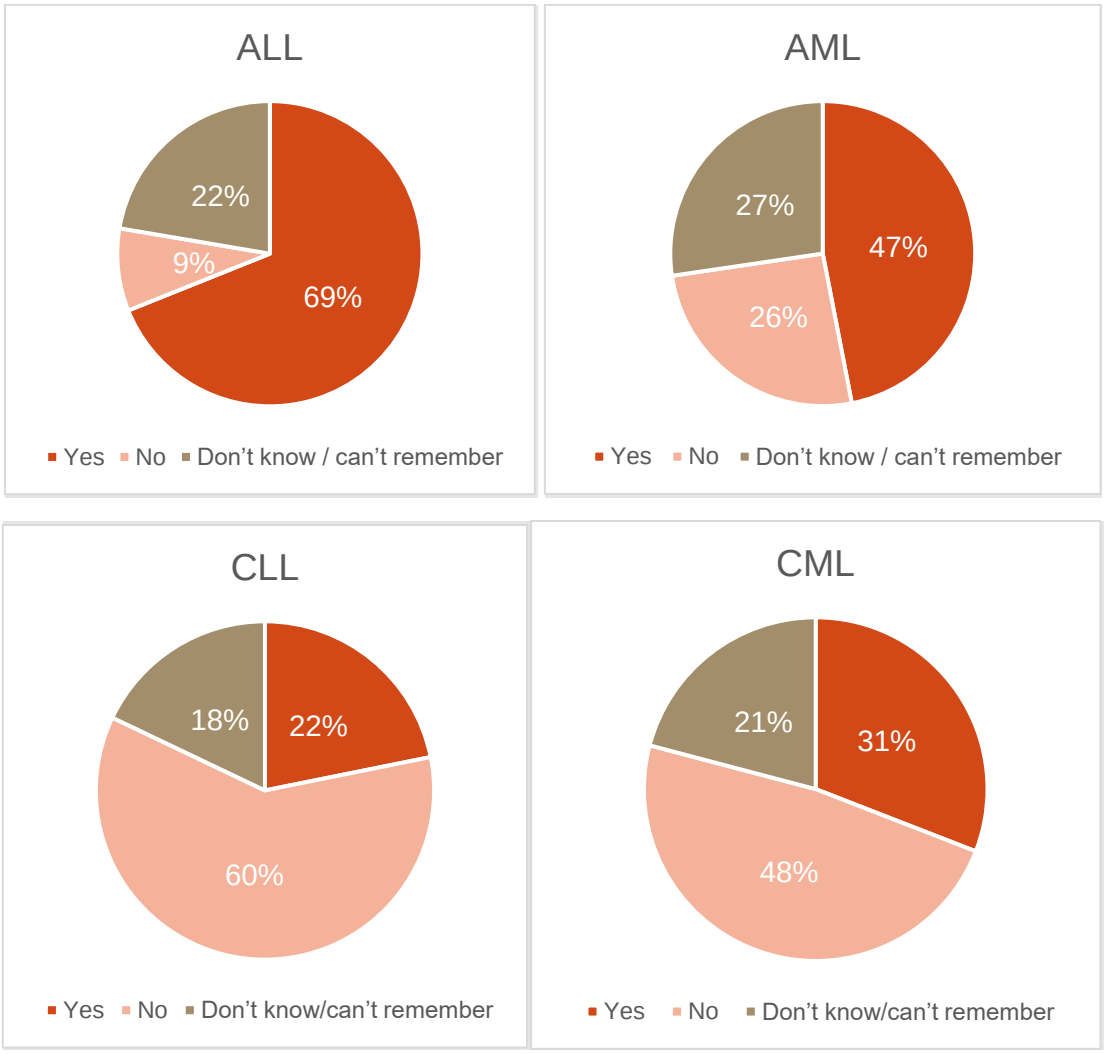


In total, 69% (n=71) of patients with ALL and 47% (n=146) of patients with AML had been informed of their subtype. Of those AML patients that had been informed, 29% (n=43) reported that they had the FLT3 mutation. (Figure 2)

Twenty-two percent (n=262) of those with CLL had been informed of their subtype with 23% (n=71) stating that they had the chromosomal alteration referred to as Del(13q).

Thirty-one percent (n=275) of those with CML had been told their subtype with 10% (n=28) reported that they had the T315i mutation.

Figure 2: Q: Have you been informed of your sub-type? (Patients)



4.2. Gender

Patients

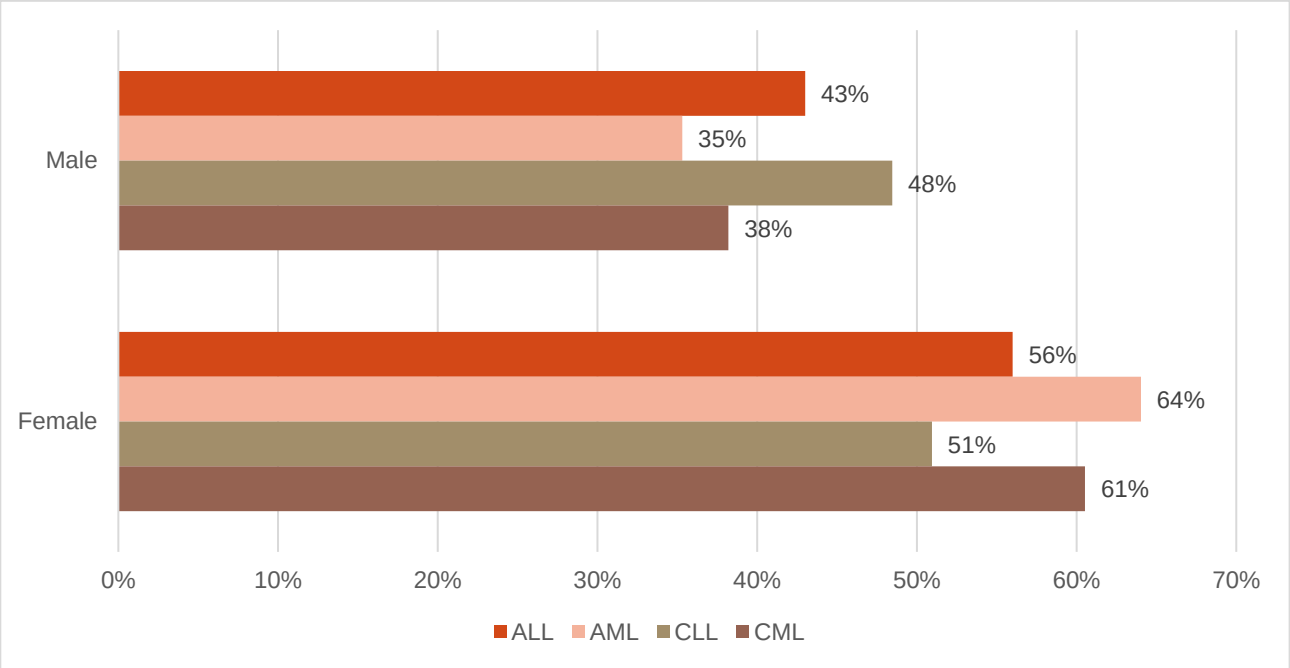
For both ALL and AML there were more females than males, who responded to the survey: 56% (n=56) of ALL respondents and 64% (n=194) of AML respondents were female. (Figure 3)

There were also more female respondents with chronic leukemia than males: 61% (n=526) of those with CML and 51% (n=593) with CLL. [4] (Figure 3)

This may suggest that there is a lack of representation in the results for male patients. In previous studies, it has been shown that male patients are more likely to be diagnosed with leukemia than female patients, and existing evidence indicates that female respondents are generally more likely to respond to patient surveys.

4 In order to determine if there are clear gender differences in patient experience, additional qualitative research should be conducted at a later time

Figure 3: Q194 What is your gender? (Patients)

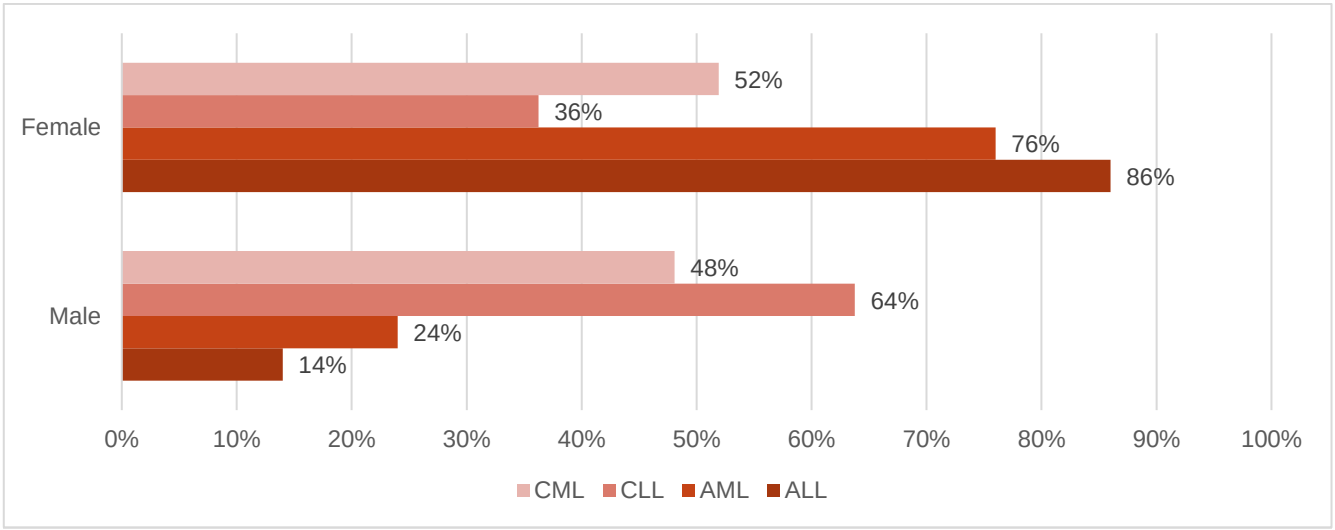


Carers

Carers of those living with leukemia were mostly females (72%, n=405). (Figure 4)

When carers were asked to report the gender of the patient, there were slightly more males than females (Males 54%, n=307, Females 45%, n=258) (Figure 4). There may be a number of factors that influence this finding including that more males are diagnosed than females, for example women may be more likely to access support, and children, diagnosed with leukaemia, may be more likely to have their mother or another female family member as a carer.

Figure 4: Q80C. What is your gender (Carers)



4.4. Age

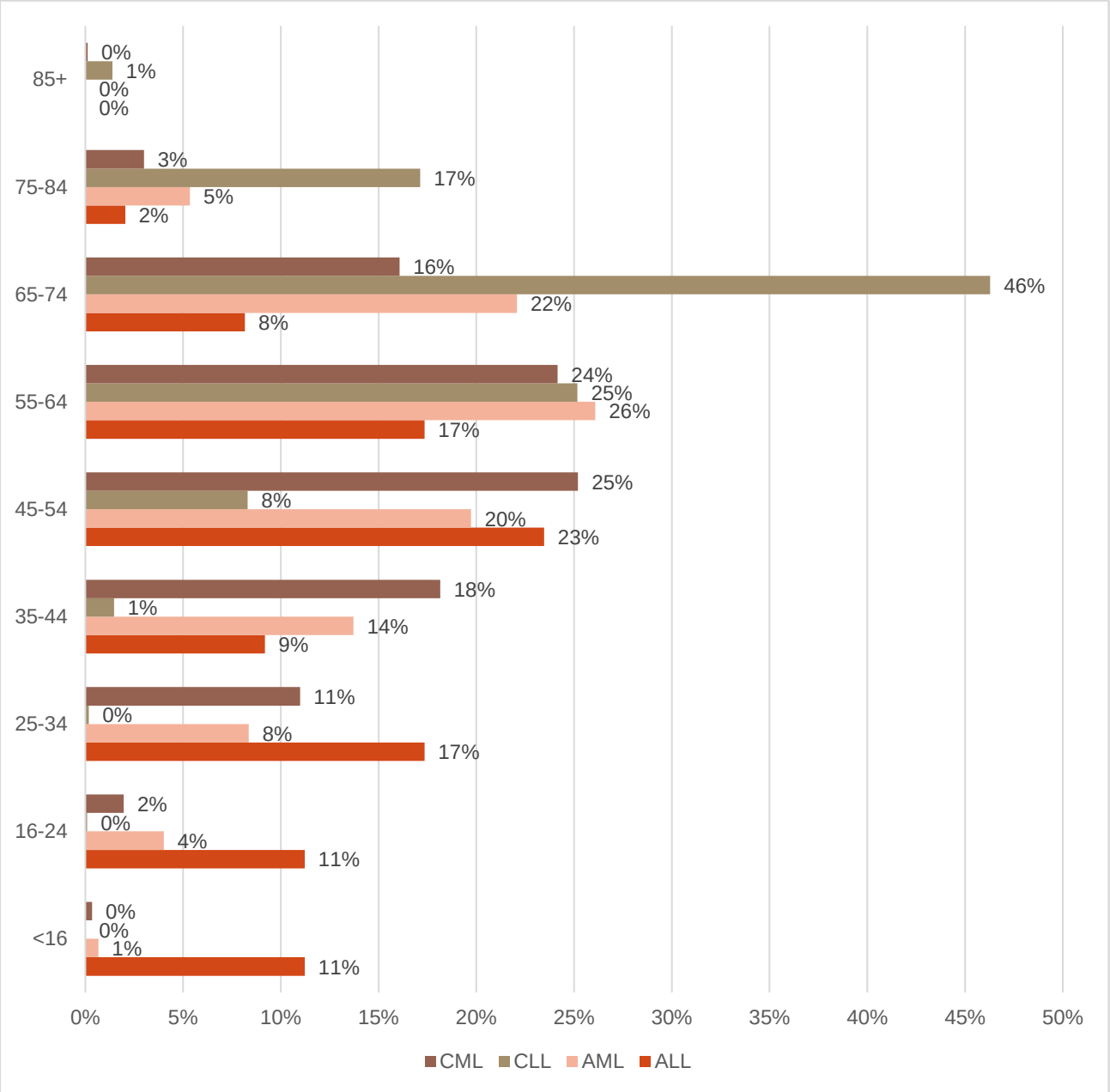
Patients

Only 3% (n=60) of patients were aged under 24 years. Those diagnosed with ALL were most likely to be within this younger age group. In contrast, 73% (n=219) of AML respondents were aged 45 years or older.

Although this could appear to differ from current literature known about the age of patients diagnosed with ALL, the majority are still younger, and the recruitment process here is the likely reason for this difference.

In line with previous literature and other iterations of this survey, CLL patients were mainly older; 90% (n=1,040) were aged 55 years and older. In contrast, those with CML reported a broader spread of ages with 56% (n=487) younger than 54 years of age. This is slightly lower than expected from existing literature; although it can develop in younger people. The incidence would be expected to be much higher in the older age categories.

Figure 5: Q193 Age band (Patients)

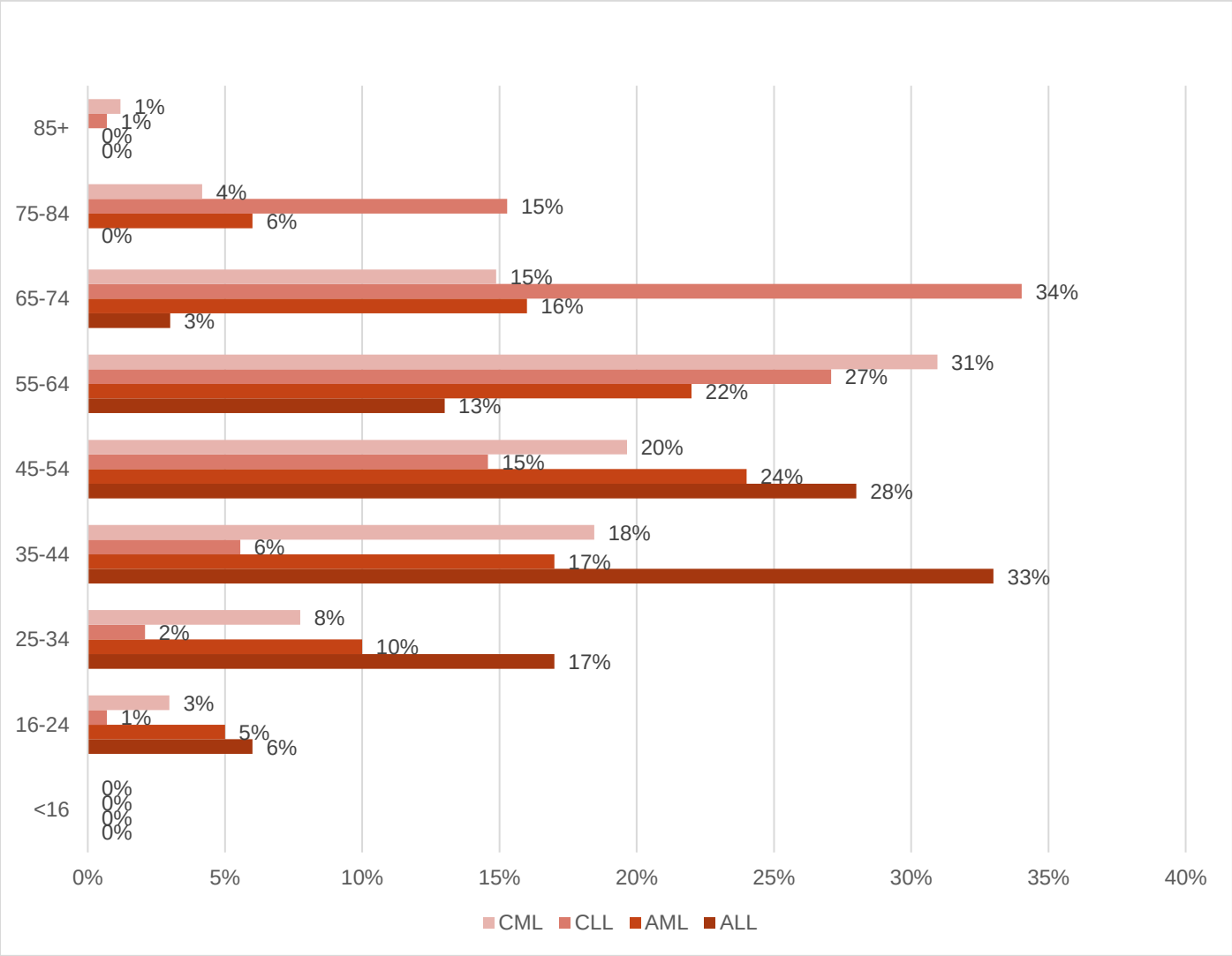


Carers

From the carer survey, there is a significant difference in the ages reported for patients. For the carers themselves, there is a broad split in ages, although those caring for someone with CLL were generally older than those caring for patients with other leukemia types. Whilst 84% (n=75) of ALL carers were aged 54 years and under, this was 56% (n=58) for AML carers and 49% (n=82) for CML. Only 24% (n=33) of those caring for people with CLL were aged under 55 years. (Figure 6)

This is broadly in line with the reported incidence of different leukemia types.

Figure 6: Q78C Age band (Carers)

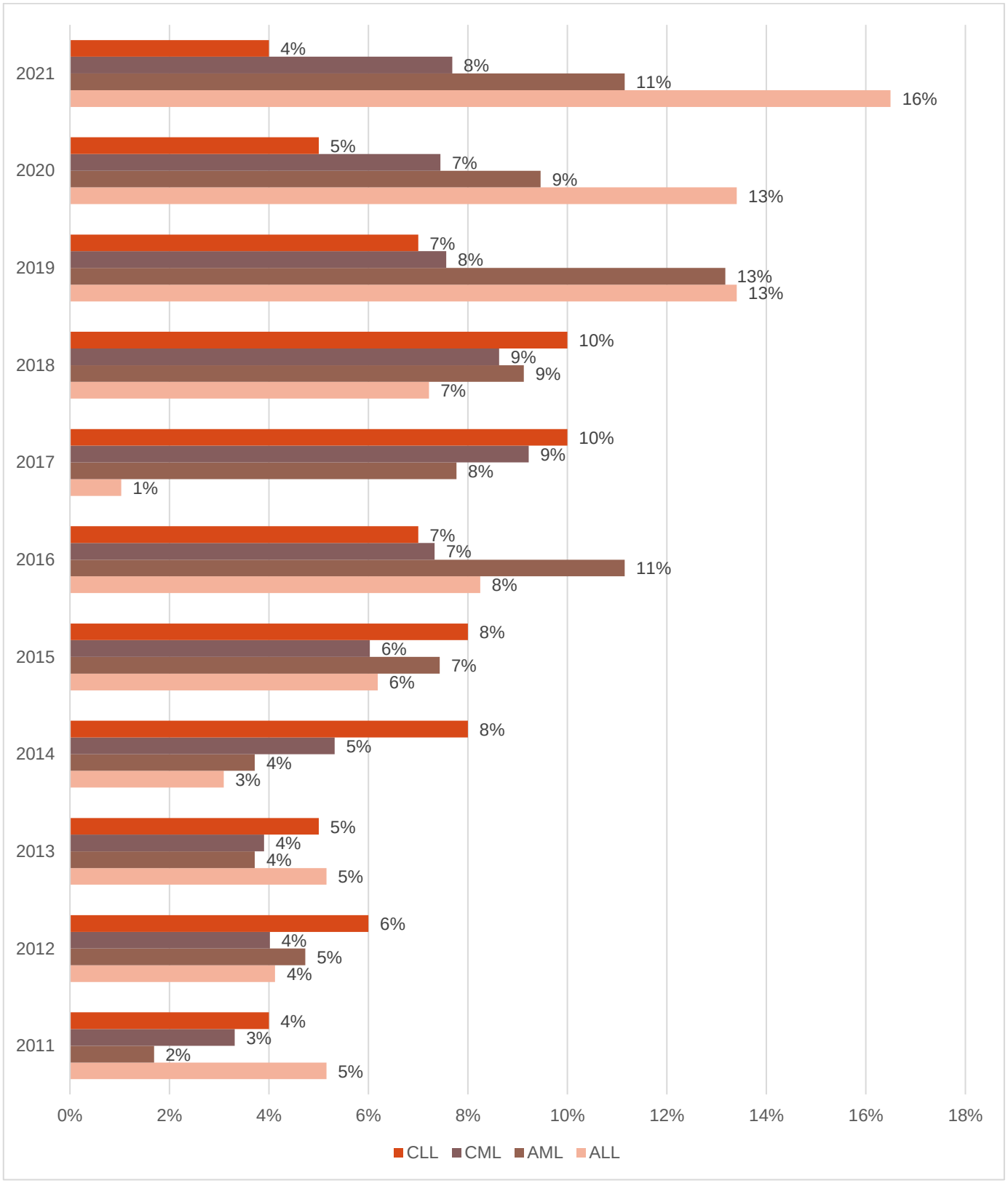


4.5. Date of Diagnosis

Fifty percent of those with ALL and AML (n=208) were diagnosed between 2017; and the survey being conducted, with a further 31% of those with ALL (n=32) and 33% (n=69) with AML diagnosed since 2011 (see Figure 7).

Those with a chronic leukemia can live with the disease for many years. Five percent of those with CLL (n=60) had been diagnosed 20 years prior to the survey or more although, 70% (n=841) of respondents had been diagnosed within the last 10 years prior to the survey. Again, this supports the findings from the 2018 Leukemia Care survey, where 50% of CLL (n=1,101) respondents were diagnosed in 2020 or earlier. For those with CML, 70% (n=627) of patients had been diagnosed in the last 10 years prior to the survey, with 41% (n=367) diagnosed in the last 5 years prior to the survey.

Figure 7: Date of Diagnosis (Patients)



4.6. Living situation and relationship

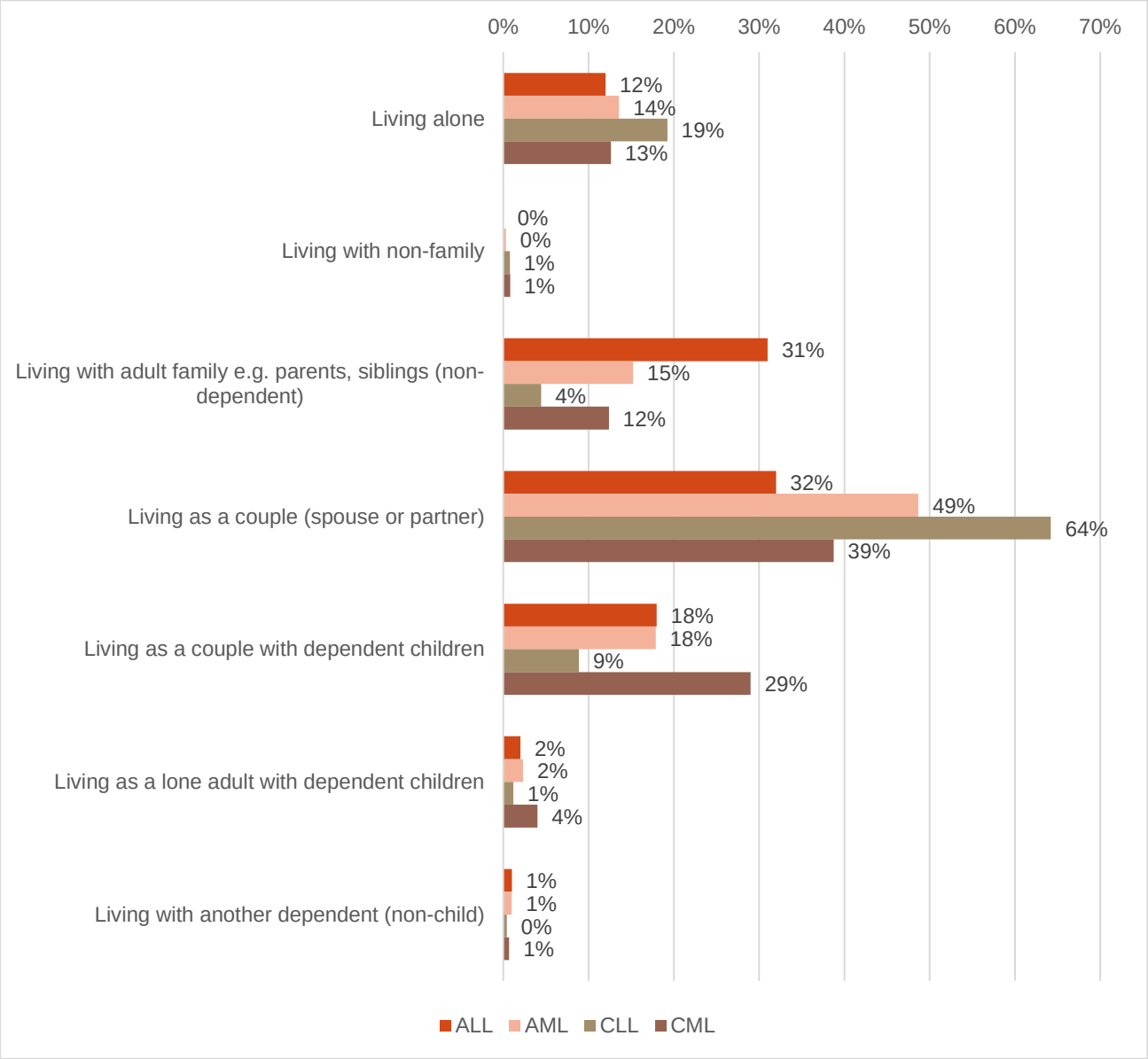
Patients

From the patients' questionnaire responses, 49% of AML (n=147) and 32% of ALL (n=32) patients reported that they were living with their spouse/partner with a further 18% (n=18), who also had dependent children living with them. In line with the findings reported around age, 31% of ALL (n=31) patients (as opposed to 15%, n=46 of AML) were living with their parents or other adult family members. (Figure 8)

Moreover, 73% (n=858) of respondents with CLL reported that they were living as a couple, with 9% (n=54) of those having dependent children. However, 19% (n=226) of those with CLL were living alone. Respondents with CML: 68% (n=591) were living as a couple, with 29% (n=253) of them having dependent children, 13% (n=110) reported that they lived alone and 12% (n=108) lived with adult family members. (Figure 8)

This correlates with the age demographic, with a larger proportion of those with CLL living alone and a higher proportion of the other subtypes living with an adult family. (Figure 8)

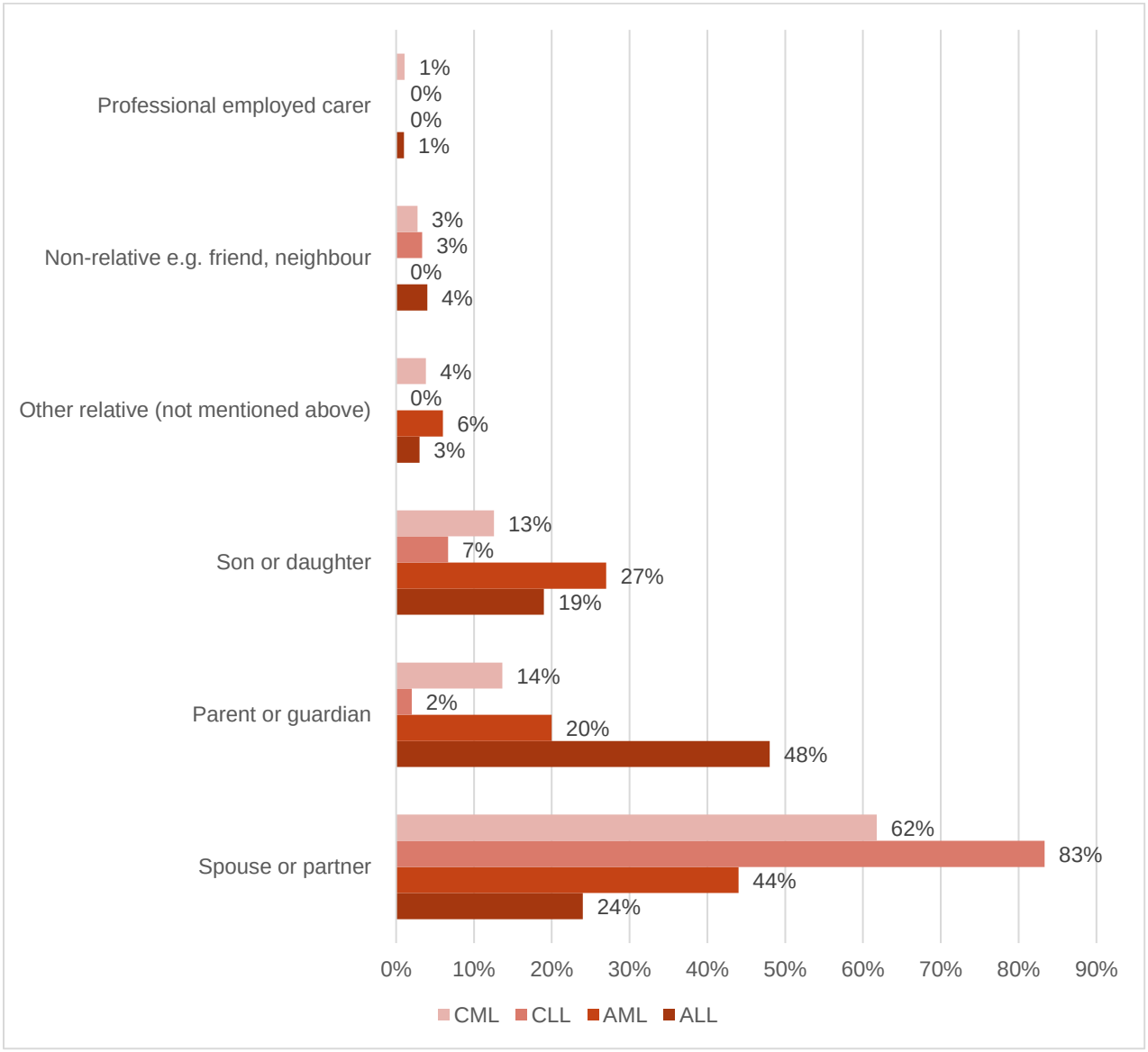
Figure 8: Q196 What best describes your living situation? (Patients)



Carers

Majority (90% [n=590]) of all carers reported that they were related to the patient as a spouse, parent, or child (see Figure 9). This differed slightly across leukemia types and could be related to age as previously reported. Forty-four percent of AML (n=48) carers reported being the spouse or partner, whereas this was only 24% for ALL (n=24). Meanwhile, 48% of ALL (n=48) carers stated that they were the parent or guardian of the patient. Eighty-three percent of those caring for a CLL (n=125) patient and 62% (n=113) of those caring for a CML patient reported that they were the spouse of the patient. A further 14% (n=25) of those with CML were the parent of the patient and 13% (n=23) were their children.

Figure 9: Q2C What is your relationship to the patient (Carers)



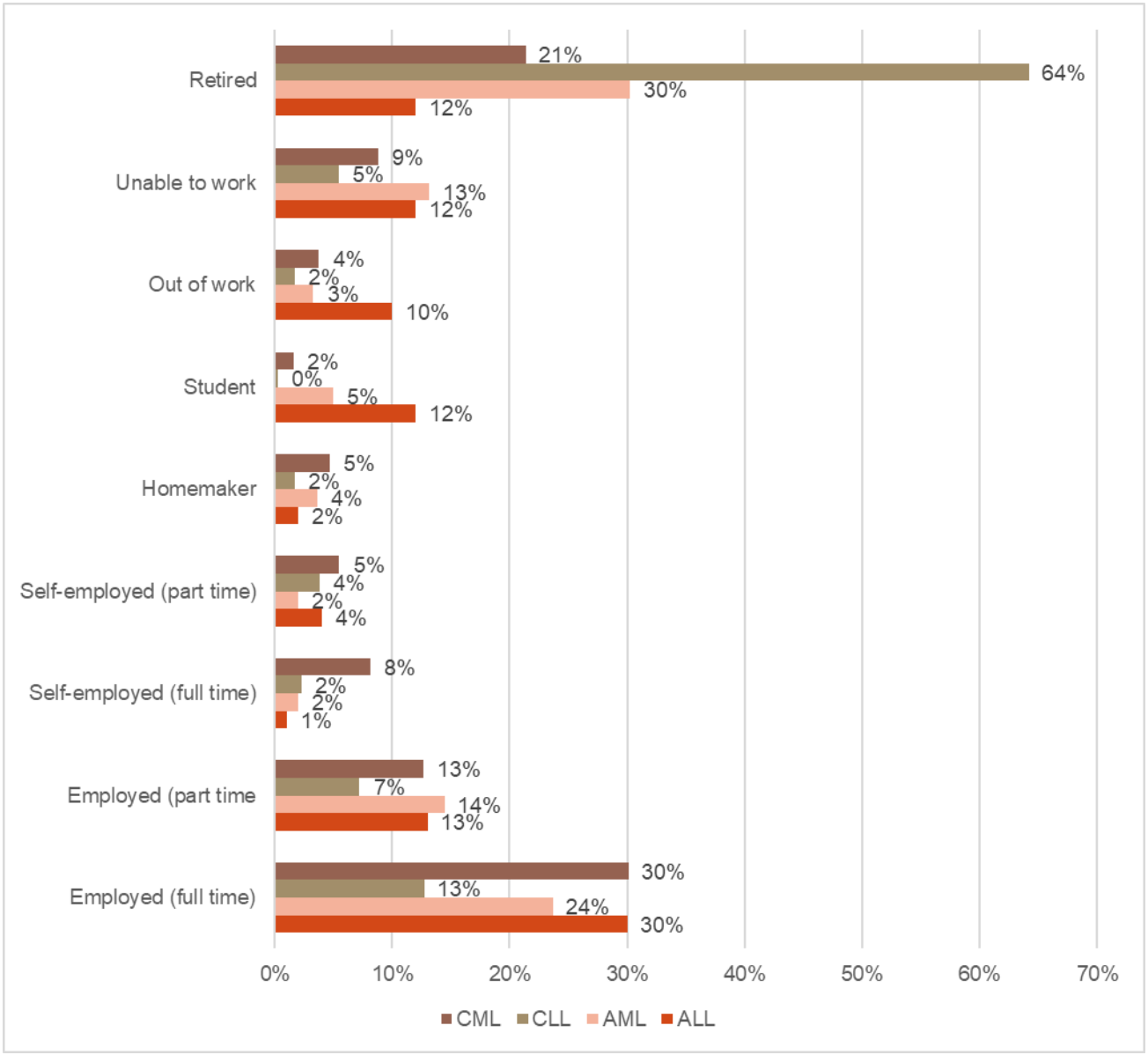
4.7. Employment

Patients

The number of patients with acute leukemia who were in full-time or part-time work, was reported as lower than that of carers (ALL 43%, n=43,and AML 38%, n=116). Also, 30% (n=110) of AML patients reported that they had retired and 13% (n=40) of patients stated that they were unable to work.

For those with chronic leukemia, 66% (n=577) of those with CML and 52% (n=605) of those with CLL had been in work when they had been diagnosed. This contrasts with those with acute leukemia, where a much higher proportion reported continuing to work as usual (CLL 45%, n=274 CML 40%, n=234). Although, CML had the lowest proportion of patients who had to stop working (27%, n=158) followed by CLL at 31% (n=190), 25% of those with CML (n=143) and 20% with CLL (n=123) reported that they had to reduce their working hours, see Figure 10.

Figure 10: Q197 What best describes your employment status? (Patients)

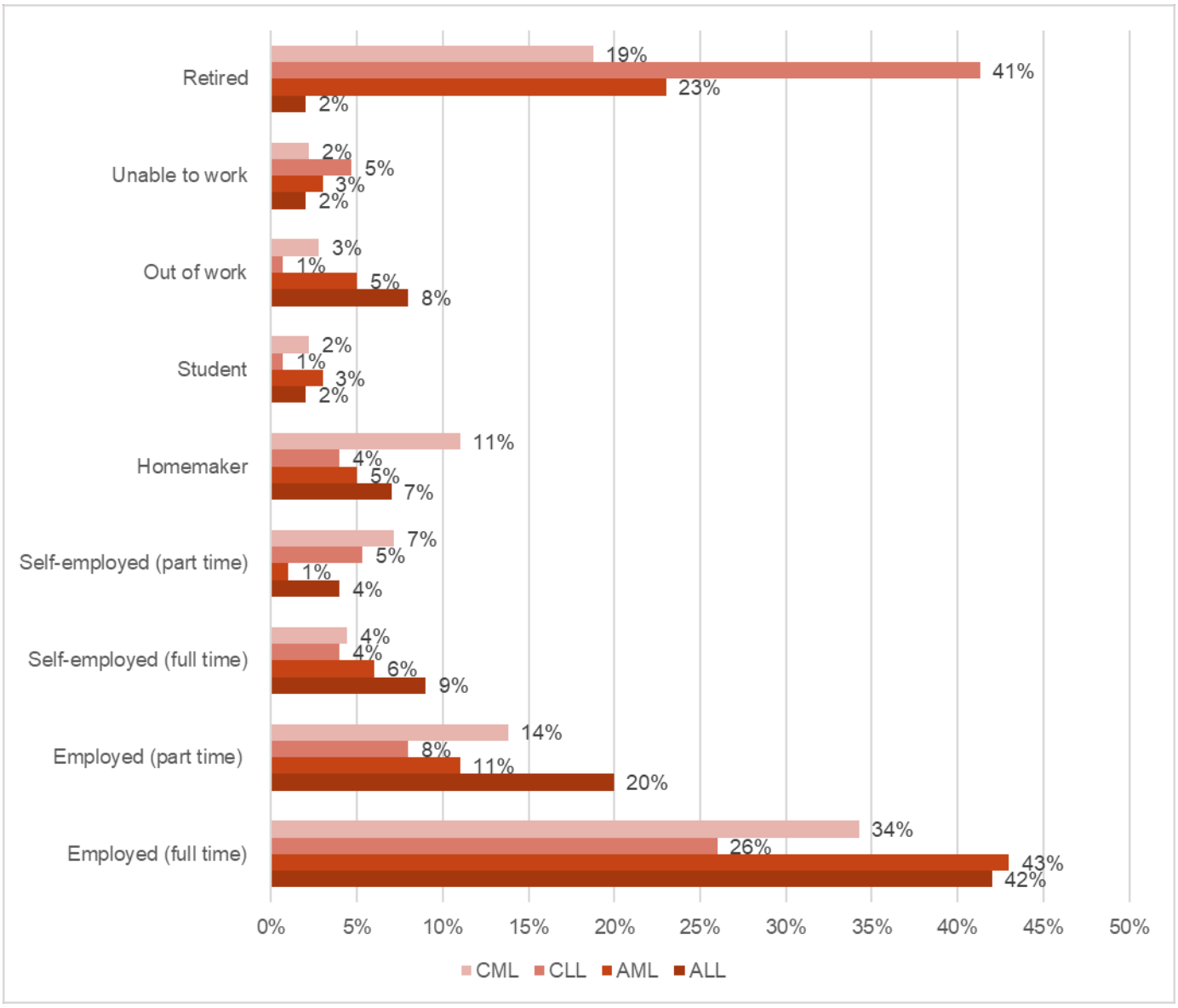


Carers

As 42% (88) of carers of those with acute leukemia were employed full-time, a further 15% (n=31%) were employed part-time. Similarly, 34% of CLL (n=51) carers and 48% of CML (n=87) carers were employed either full or part time. There was a significant difference between those that were retired and caring for someone with CLL (41%, n=62) and those with CML (19%, n=34). (Figure 11)

Again, this would appear to correlate with the age profile here.

Figure 11: Q81C. What best describes your employment status? (Carers)



4.8. Finance

Those with CLL reported the least issues financially out of all of the leukemia types with only 25% (n=296) stating that there was an overall negative impact on their finances. This was highest for those with ALL (64%, n=63). When looking at the impact on their finances in wider terms, those with CML had the highest impact in terms of increased costs (CML 34%, n=150 compared with CLL 13%, n=39, AML 29%, n=47, and ALL 19%, n=19) whilst those with acute leukemia reported a higher reduction in income of 40% or higher (ALL 47%, n=28 and AML 49%, n=83). (Figure 12)

The findings from the carer survey were broadly in line with 44% (n=237) reporting no financial impact, and 49% (n=265) reporting a negative financial impact. More carers of those with acute leukemia reported some form of impact on their finances as a result of the cancer.

Slightly more CML carers reported a higher level of impact of 40% or higher, compared with 26% (n=36) for those with ALL/AML. Only 10% (n=5) of those with CLL reported that the impact was high. Around half of respondents for each leukemia type reported that they either did not know or it was not applicable to them. This would tend to suggest that higher costs are more of an issue for carers. (Figure 13)

Figure 12: Q57C. Overall, have YOU experienced a financial impact as a result of the patient's leukemia diagnosis (positive or negative)? (Carers)

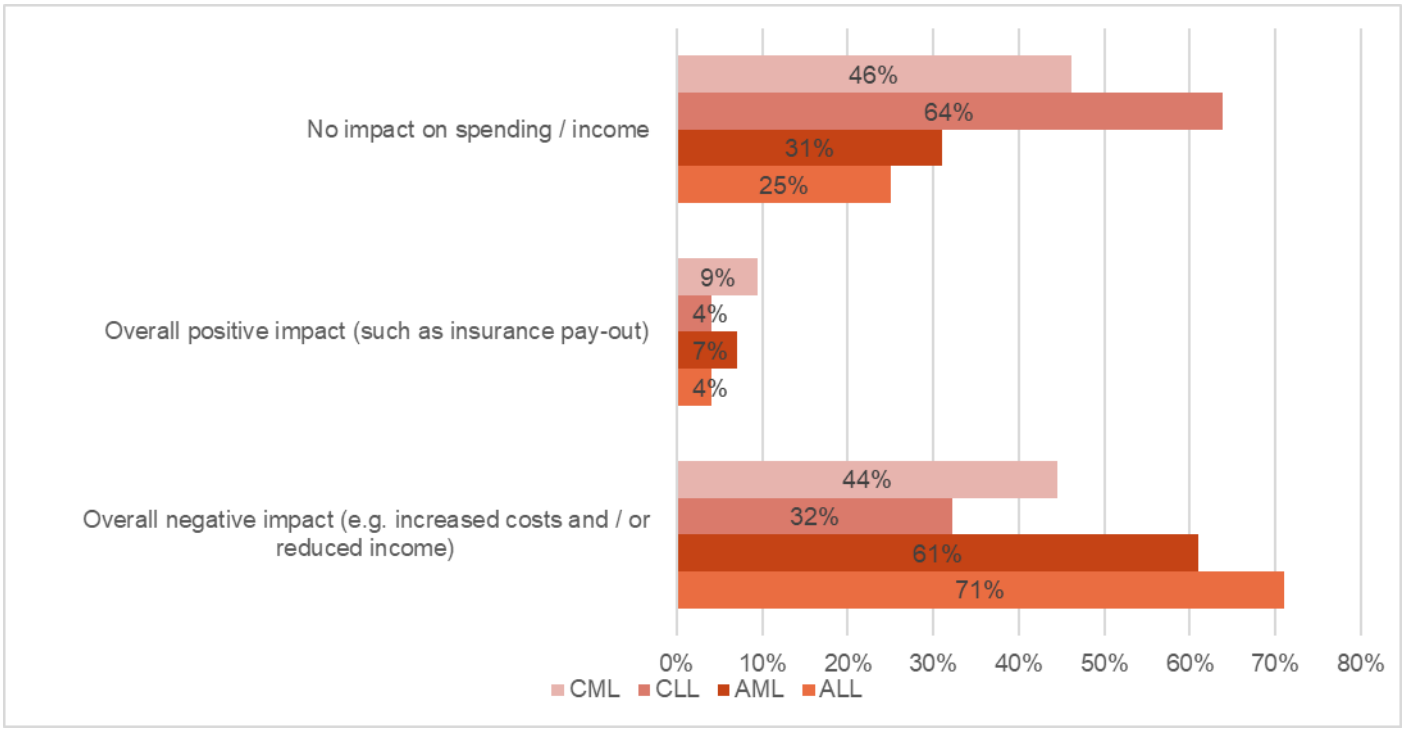
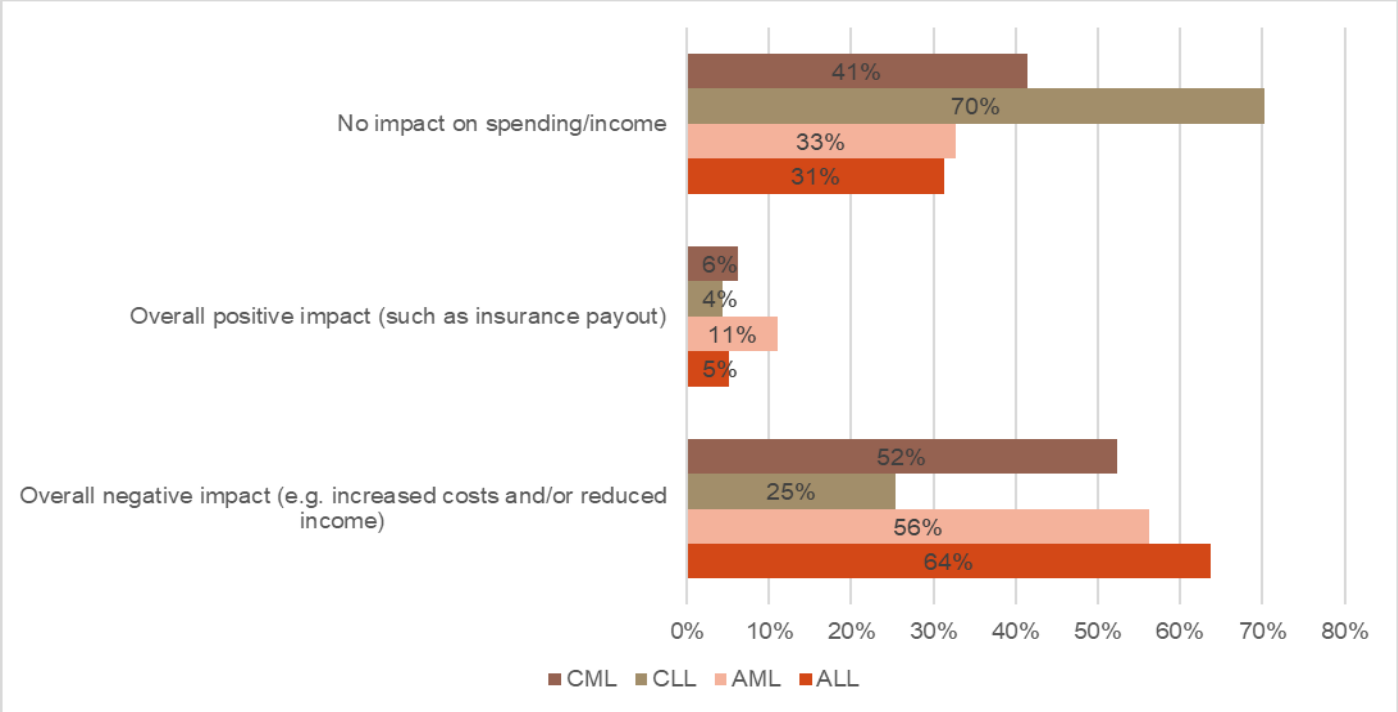


Figure 13: Q150. Overall, since your diagnosis, have you experienced a financial impact as a result of having leukemia (positive or negative)? (Patients)



This would tend to suggest that the older age of those that responded to the survey lowers the likelihood of financial issues.

4.9. Income

Income was reported broadly similarly across all leukemia types for patients (see Figure 14). While 54% (n=1,398) of all respondents reported that they had an average income, 23% (n=588) reported that they were of low income, and only 16% (n=408) noting that they were of high income.

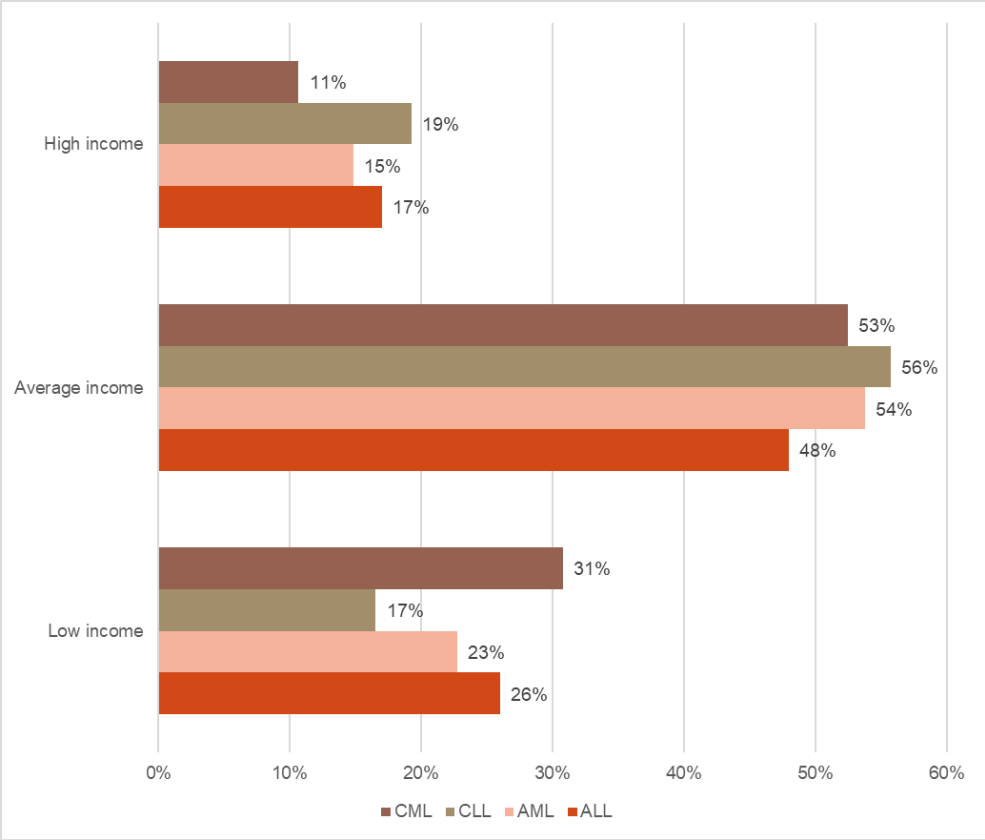
Overall, 60% (n=1,538) of respondents were in work prior to their diagnosis, this was slightly different between the different types of leukemia: ALL (60%, n=60), AML (70%, n=215), CML (66%, n=577) and CLL (52%, n=605).

As we have seen previously, those with CLL were, in the main, older, and a large proportion were retired or able to retire. However, those with ALL were younger and often not at the age where they would be working. This makes a big impact on patients' employment status , but also links to the impact on their carer and wider family.

With regards to carers, for those with ALL, CML and AML, they tend to be caring for younger patients and have more issues around being able to continue working (either as a patient or carer).

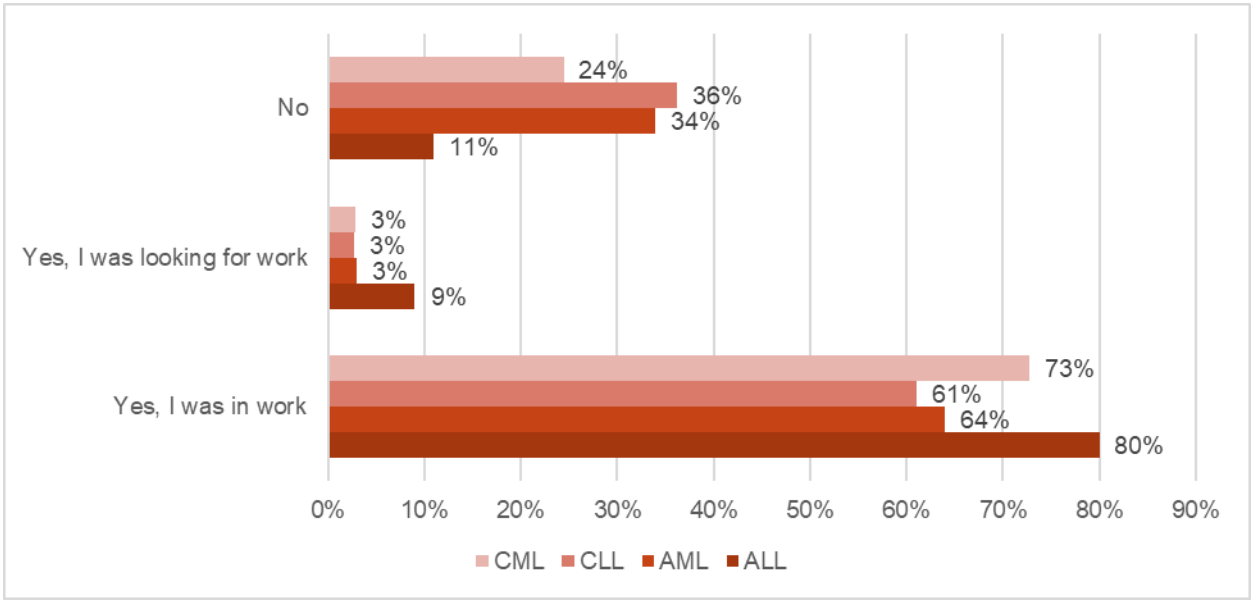
The majority of carers stated that they were in work or looking for work at the time of diagnosis. In line with the comment and findings noted above, 73% (n=392) of ALL carers were in work at the time of diagnosis with this lower for those with AML (64%) and CLL (61%), see Figure 15.

Figure 14: Q198. For your country how would you describe your annual household income? (Patients)



Being able to work impacts on their ability to manage financially but also their ability to care for the patient. Information and support around finance and work is important at diagnosis and treatment in particular as these are the points where patients often find working difficult even if it is for a short time.

Figure 15: Q51C. Were YOU in, or looking for, work before the patient was diagnosed with leukemia? (Carers)



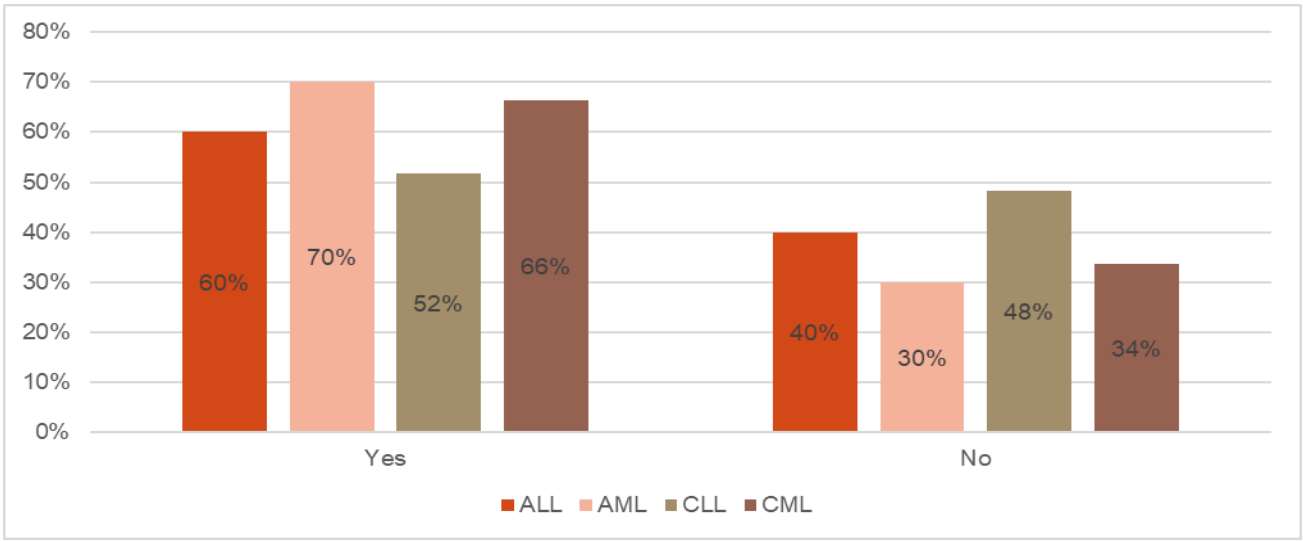
Patients

Of those that were working or looking for work the impact on acute patients in particular was profound. Majority (75% [n=45]) of those with ALL and 78% with AML (n=167) had to stop working and a further 7% (n=12) had to stop looking for work with the remaining respondents noting that they had to alter their working hours. Only 6% (n=16) were able to continue work as usual. In contrast, those with s chronic leukemia were much less likely to need to stop work or looking for work (32%, n=199 with CLL and 31%, n=31 with CML). (Figure 16)

When looking at these results in more detail, only 22% (n=12) of those with ALL and 35% (n=112) of those with CML had to stop work permanently. Almost half of those with AML (45%, n=90) and CLL (48%, n=153) however had to stop work permanently. So, the majority of those with AML in particular were profoundly impacted with regard to their work (over 75%) and that this was permanent (45%).

There was a high percentage of respondents for CLL and CML patients that reported that they did not know (27%, n=86 CLL and 22%, n=70 CML) whether this was permanent or temporary and this may reflect on the chronic and progressive nature of the chronic conditions. Again, here information and support to be able to deal with the changing nature of the chronic disease would be beneficial.

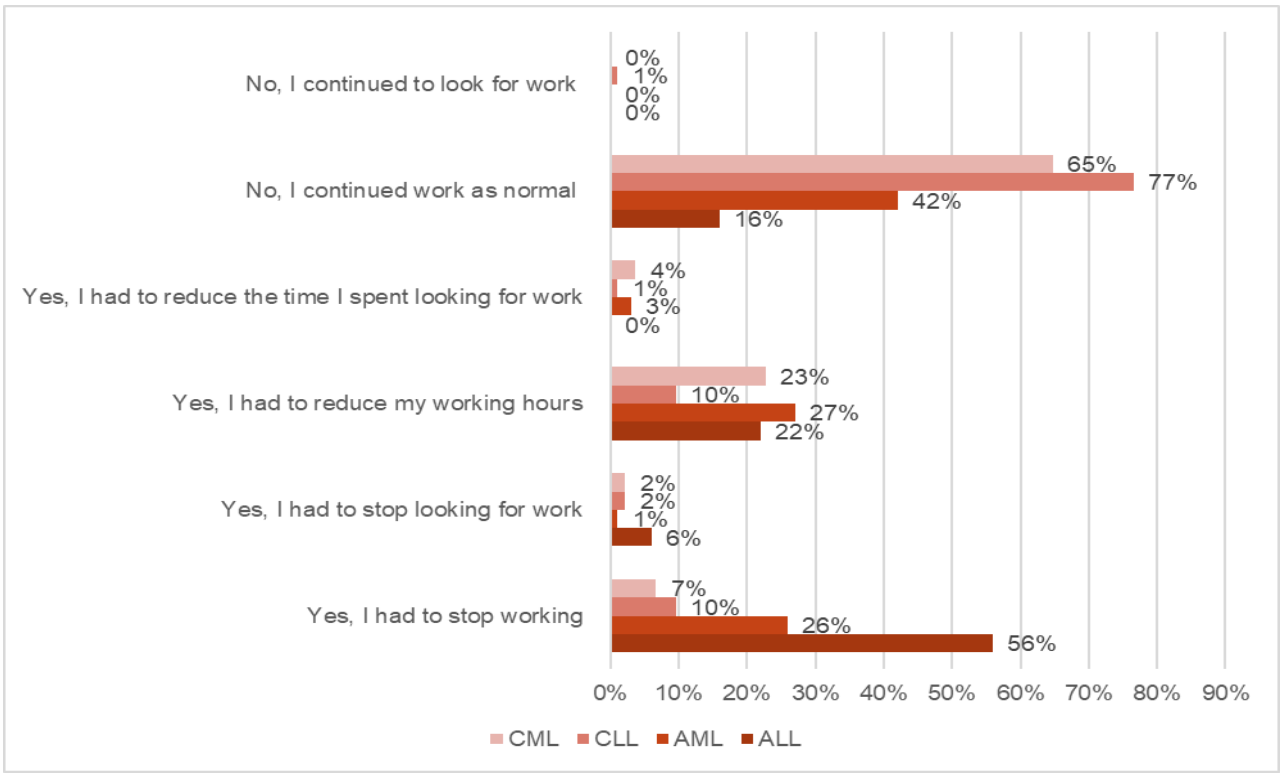
Figure 16: Q144. Were you in, or looking for work before your leukemia diagnosis? (Patients)



Carers

From the carers' perspective, there were significant differences between the leukemia types. 56% (n=49) of those caring for someone with ALL had to stop working, whilst this was only 26% (n=19) for those caring for someone with AML, 10% (n=9) CLL and 7% (n=9) CML. Although more ALL carers had to stop work, a lower percentage (14%, n=10) of those had to stop permanently. This was much higher however for those that had to stop work as they were caring for someone with CLL (43%, n=10). Those with CML would appear to be less burdensome on carers than other leukemia types. (Figure 17)

Figure 17: Q52C. Has caring / supporting the patient affected YOUR ability to work? (At any point since you were diagnosed with leukemia, has your ability to work, or to look for work been affected? (Carers)



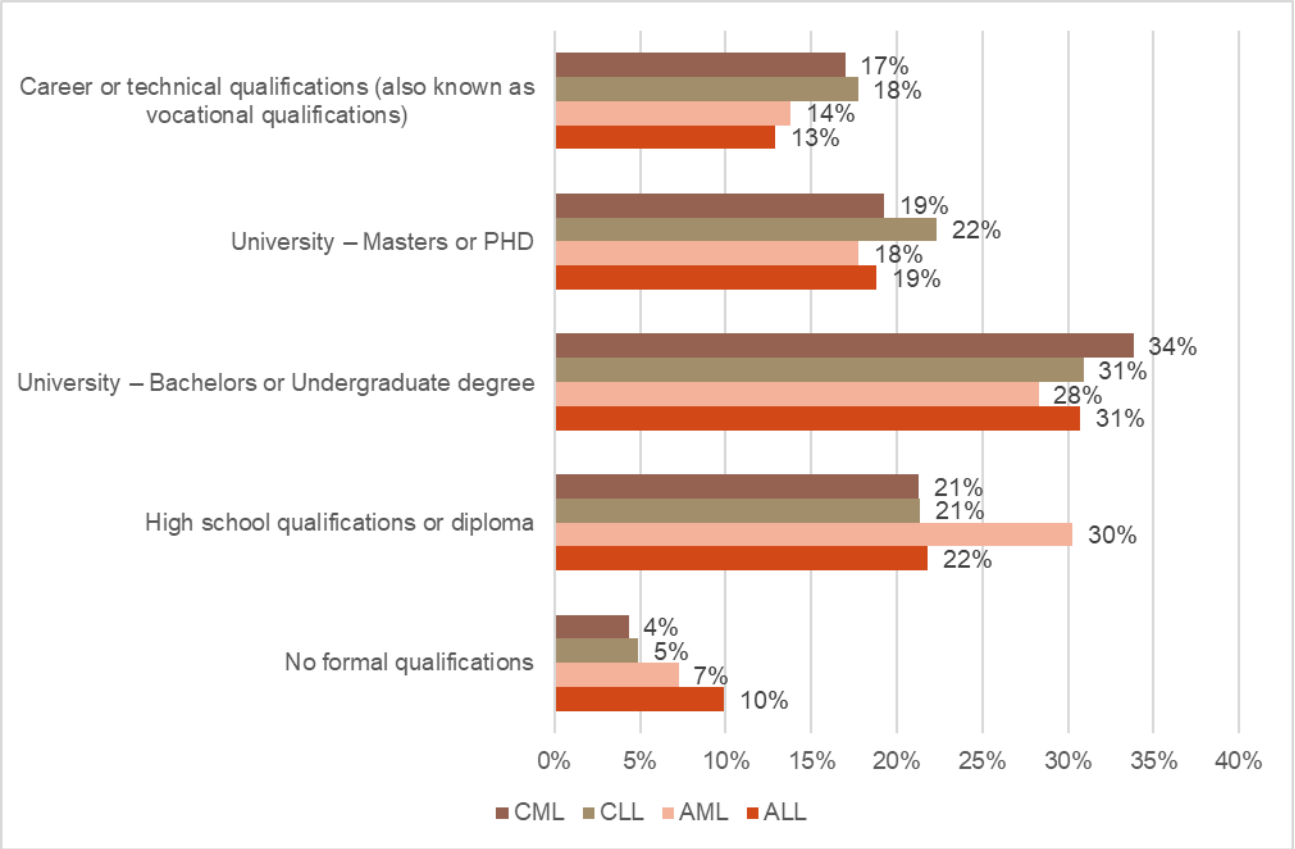
This demonstrates that acute leukemia can have a significant impact on daily and family life, particularly whilst undergoing treatment which can be for lengthy time periods.

4.10. Education

In the patient survey around half of all respondents had a university qualification.

The majority of patients reported that they were not in education at the time that they responded to the survey, although this was higher for those with ALL (26%, n=26) in particular. Of those that were in education, the impact on them is similar here to that reported by those in work. A much lower proportion of those with chronic disease had to halt their education. This demonstrates a similar picture to work, acute leukemia is more impactful on patients in the shorter term. (Figure 18)

Figure 18: Q199. What is your highest level of qualification? (Patients)



5. Before diagnosis

This section of the questionnaire aimed to explore the circumstances through which respondents were diagnosed and the understanding of leukemia within the primary healthcare community.

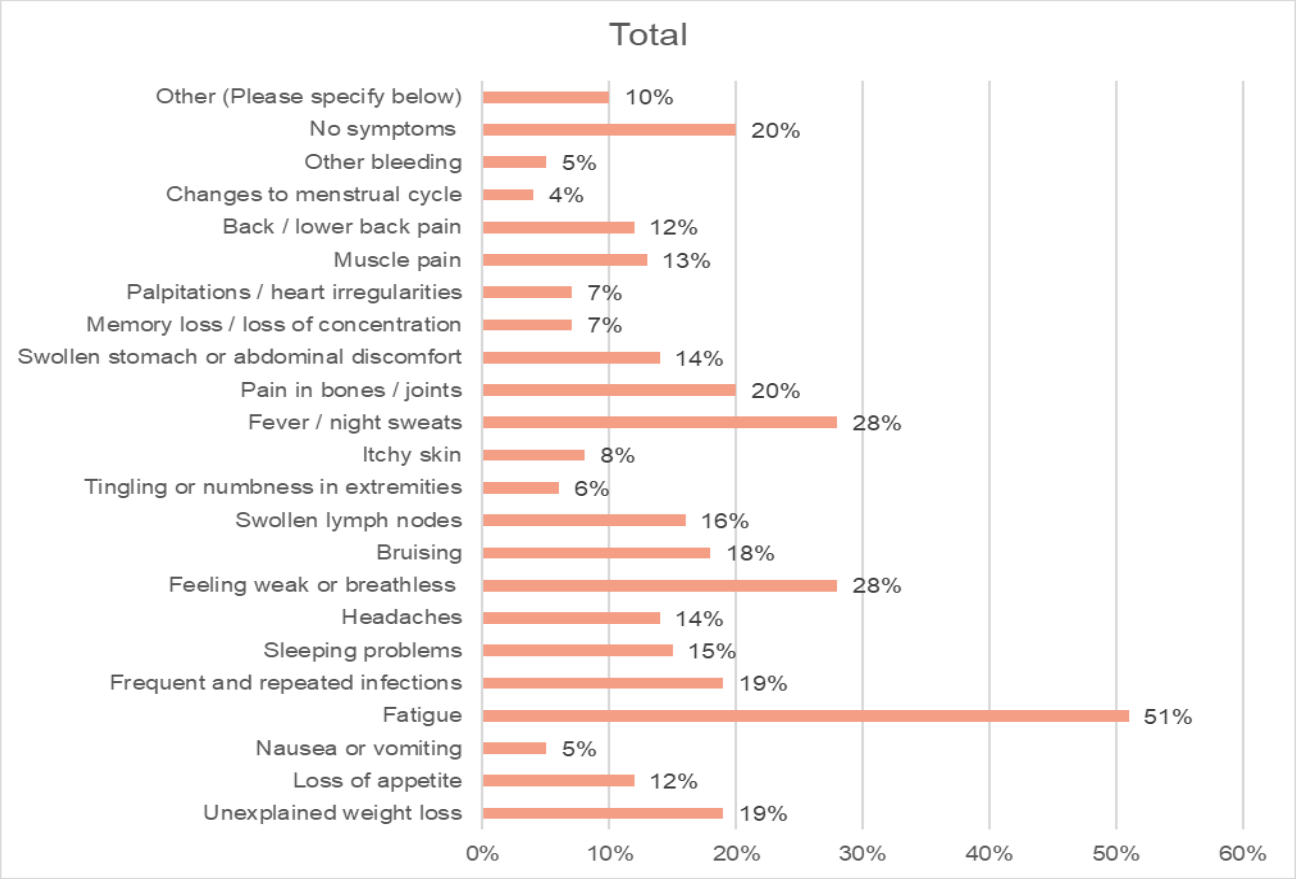
5.1. Symptoms before diagnosis

A wide range of symptoms were experienced by people prior to their diagnosis of leukemia (see Figure 19).

Overwhelmingly, for all leukemia patients, fatigue was the most common symptom experienced before diagnosis (see Figure 20). Overall, 75% (n=463) AML, 62% (n=64) ALL, 58% (n=518) CML and 39% (n=463) CLL respondents reported experiencing this. This was followed by feeling weak or breathless for acute patients 57% (n=179) AML and 42% (n=44) ALL. This was followed by bruising (34%, n=107) for those with AML and pain in the bones (34%, n=35) for those with ALL.

For those with chronic leukemia, a third of those with CLL (33%, n=396) did not have any symptoms prior to diagnosis with this much lower in all of the other three leukemia types. Other than fatigue, swollen lymph nodes was the next most common symptom (26%, n=307) for those with CLL. In contrast, 39% (n=353) of those with CML reported fever/night sweats which was more in line with the responses for acute leukemia and those with CML were also much more likely to report unexplained weight loss (38%, n=337) than other leukemia patients.

Figure 19: Symptoms experienced prior to diagnosis- All Leukemia types together (Patients)

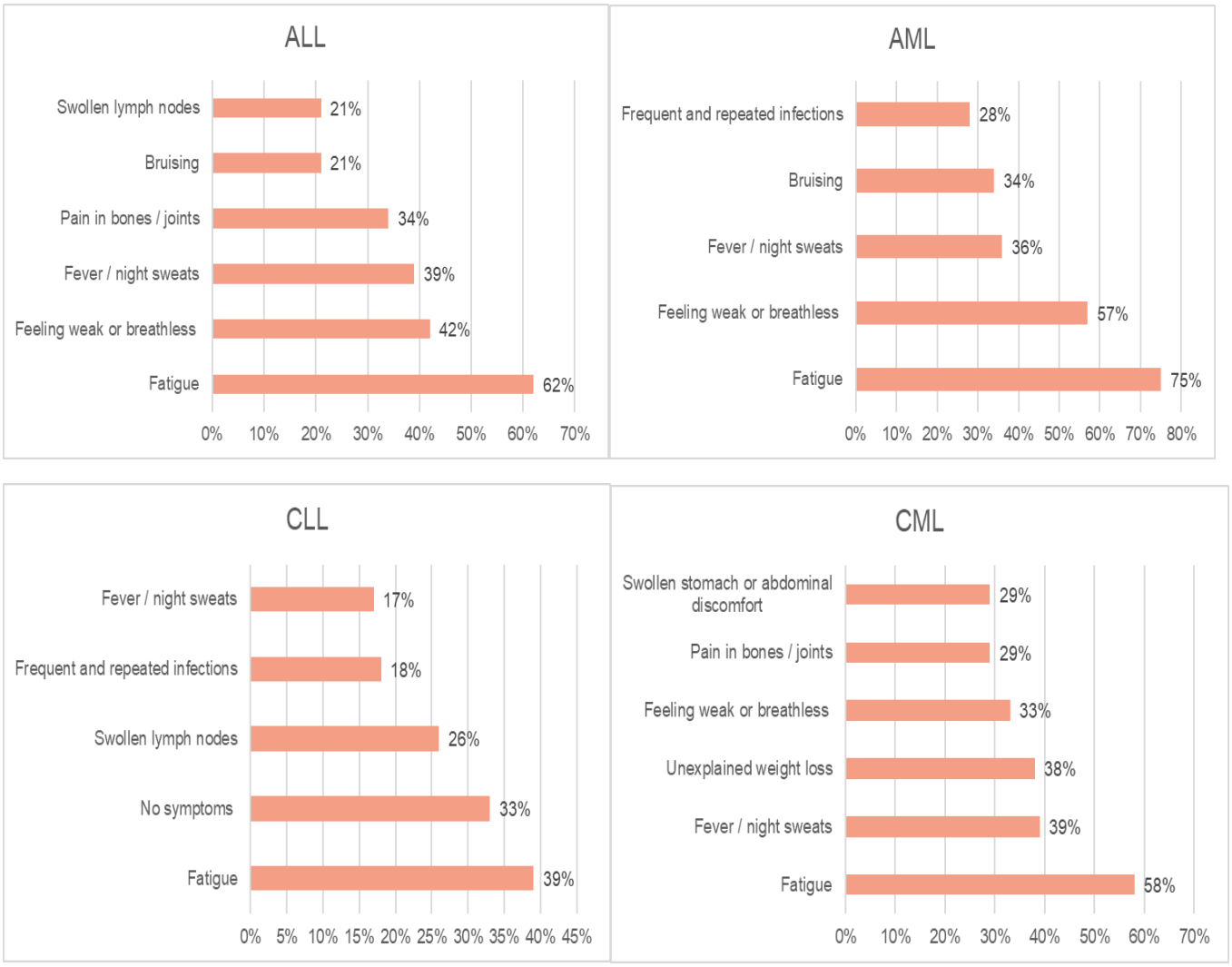


These results are similar to those seen in previous surveys such as the Leukaemia Care survey of 2018 (although this was only conducted with people within the UK) where fatigue was again the most common symptom that respondents reported experiencing prior to any diagnosis.

Only 1% (n=1) of ALL and 6% (n=19) of AML patients reported not experiencing any symptoms prior to diagnosis, however in contrast 11% (n=102) of those with CML and 33% (n=396) of those with CLL reported that they had not experienced any symptoms.

These findings echo previous literature around symptoms experienced by patients prior to their diagnosis.

Figure 20: Most reported symptoms by patients prior to diagnosis for each leukemia type (Patients)



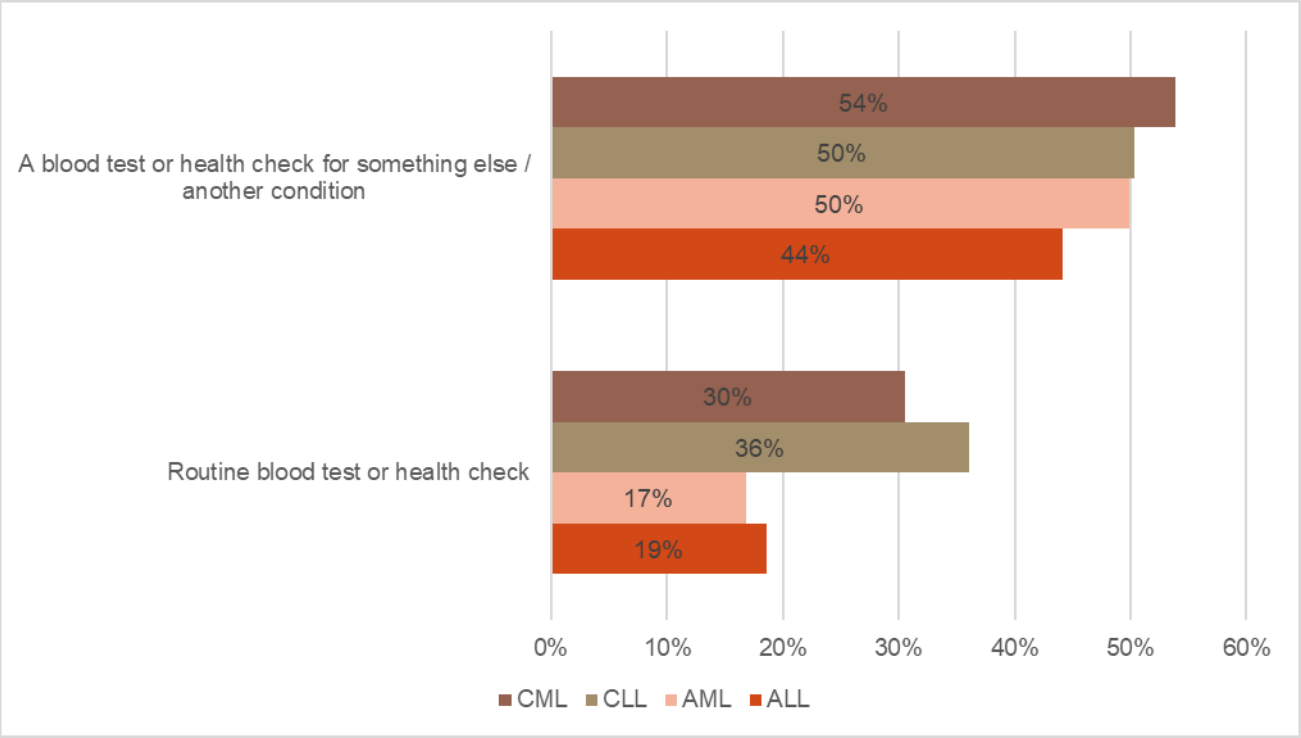
5.2. Route to diagnosis

5.2.1. Diagnostic tests and time to diagnosis

Fifty-one percent (n=1342) of respondents reported that they were diagnosed through tests for something other than their leukemia (see Figure 21). Patients with CLL were most likely to be diagnosed through routine health check or tests (36%, n=431).

Those with chronic leukemia were much more likely than those with acute leukemia to be diagnosed either through a routine test or a test for another health condition.

Figure 21: Q13. Was your leukemia detected as a result of the following? (Patients)



5.2.2. Primary healthcare professionals' understanding of blood cancers

It was reported that 25% (n=579) of patients visited their GP within a month of experiencing symptoms. However, there were significant differences between leukemia types. Those with acute disease were more likely to see their GP within a shorter period (ALL 51%, n=52, AML 45%, n=136). In contrast, only 22% (n=200) of those with CLL and 19% (n=160) of those with CML attended within a month.

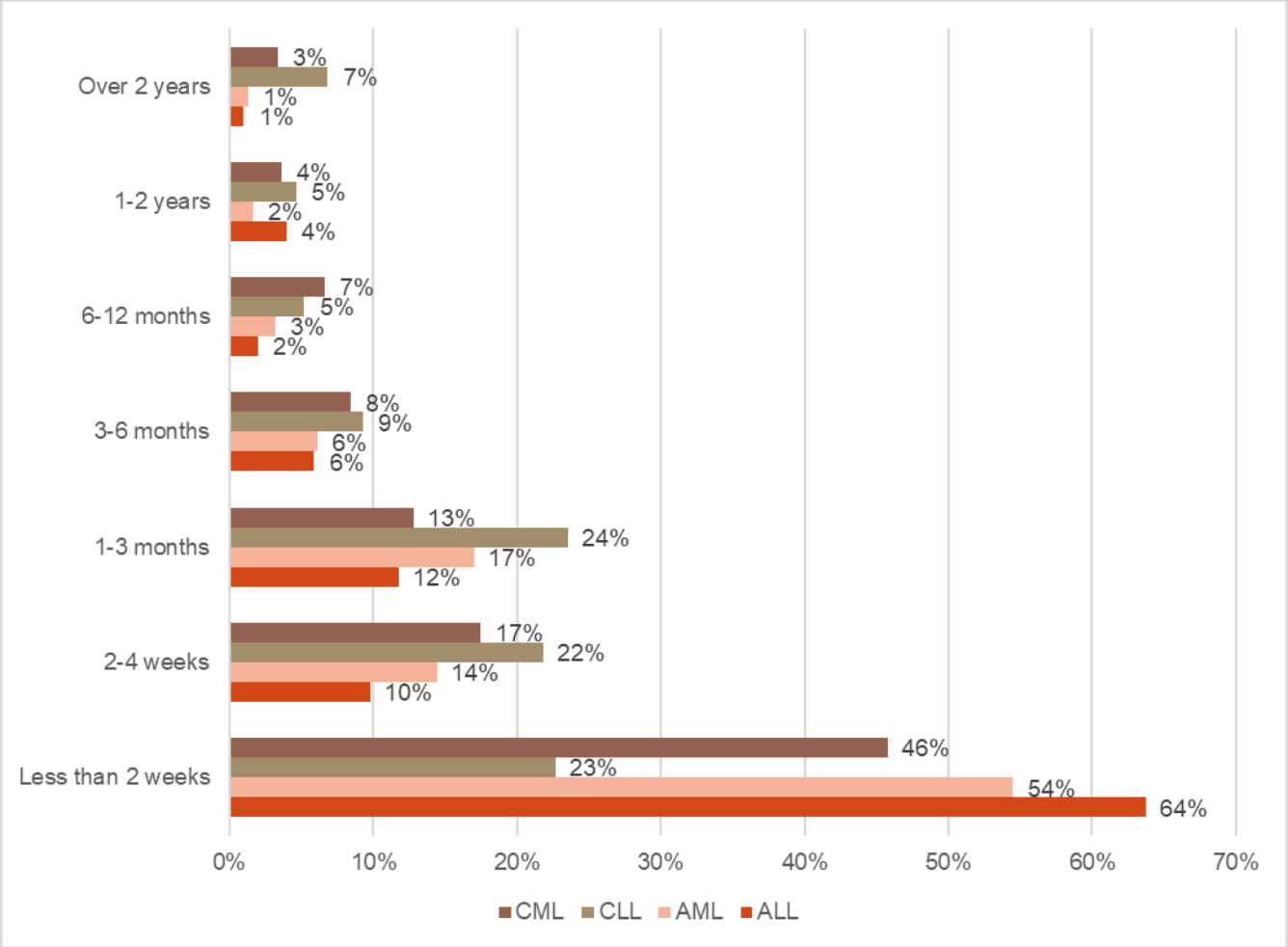
Over 90% of acute leukemia respondents saw their GP within 6 months of starting to experience symptoms. This was much lower for those with chronic disease. The responses here are similar to the Leukemia Care survey in 2018, although less respondents across all leukemia types than 2018 saw a healthcare professional at an early point after experiencing symptoms, particularly for those with chronic disease.

At first glance this may seem concerning, however the impact of the COVID-19 pandemic may have affected the results with people more reluctant or unable to attend their GP unless their condition was more urgent. It should also be noted that symptoms of leukemia are often vague and nonspecific which may discourage people from visiting their GP.

Of those that visited their GP, just under half (43%, n=80) of those with acute disease responded that they were diagnosed on their first visit as opposed to around 1/3 of those with chronic disease (CLL 37%, n=147, and CML 35%, n=111). However, 71% of all respondents were diagnosed within 3 visits (ALL 76%, n=37, AML 69%, n=94, CLL 72%, n=286, and CML 72%, n=228).

In terms of time taken to get a diagnosis, two thirds (64%, n=65) of those with ALL and 54% (n=170) of those with AML were diagnosed within 2 weeks of seeing their GP with over 80% of respondents diagnosed within 3 months. The picture is a little different for those with chronic leukemia. Only 23% (n=266) of those with CLL were diagnosed within 2 weeks, rising to 69% (n=798) within 3 months, just under half (46%, n=409) of those with CML were diagnosed within two weeks and 76% (n=679) within 3 months. (Figure 22)

Figure 22: Q20. How long was it from the time you first saw a healthcare professional until you were diagnosed with your condition? (Patients)



5.3. Summary

In line with prior surveys and published literature, fatigue was the most common symptom experienced prior to diagnosis. Almost all respondents reported experiencing symptoms, regardless of how their diagnosis came about, apart from those with CLL where a higher proportion do not experience any symptoms and most experience fewer symptoms than other types of leukemia.

There is still, however, a potential lack of awareness across the primary healthcare community and the general public more widely. Almost all respondents reported symptoms, but around half were diagnosed as a result of tests that were either routine or in relation to another condition rather than for leukemia and only a minority suspected that their health issues could be blood cancer.

As early diagnosis is important to manage the disease promptly and effectively, awareness raising across primary healthcare and the general public more generally could help to further improve the route of diagnosis.

6. Diagnosis

This section of the questionnaire explored the respondents' experiences of diagnosis, how well they understood their diagnosis, and the information and support that they received at the time.

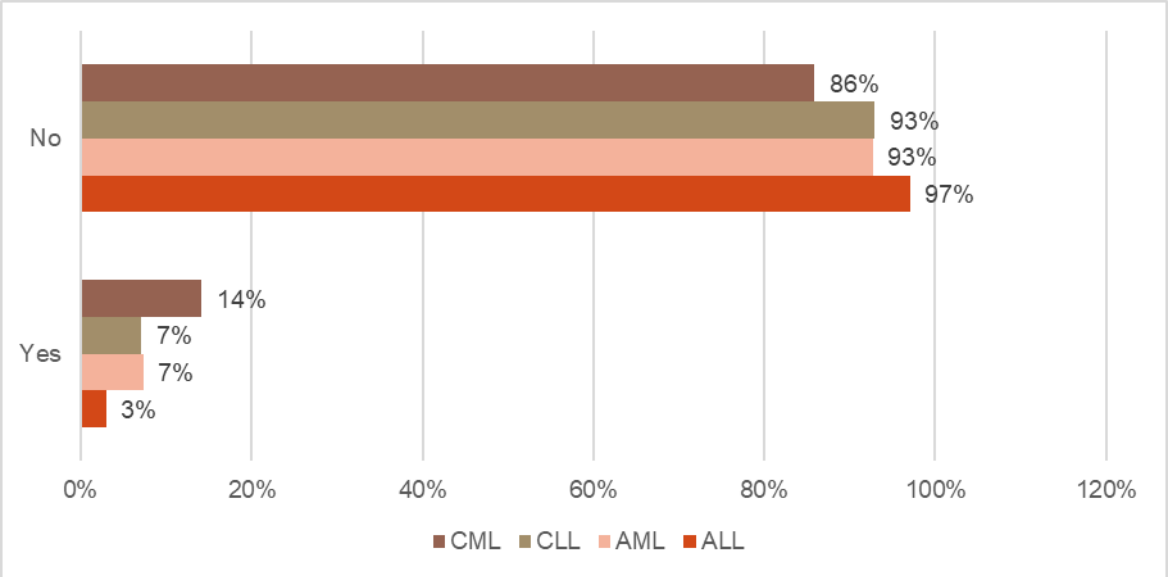
6.1. Understanding the explanation of what was wrong

Patients

The vast majority of respondents (85%, n = 2224) were not aware, prior to diagnosis, that their symptoms could be as a result of leukemia. As a result, diagnosis was likely to be a shock. (Figure 23)

There were some differences between leukemia types. Those with CML were more likely to report that they thought their symptoms may be leukemia (14%, n=122). Those with ALL were least likely (3%, n=3).

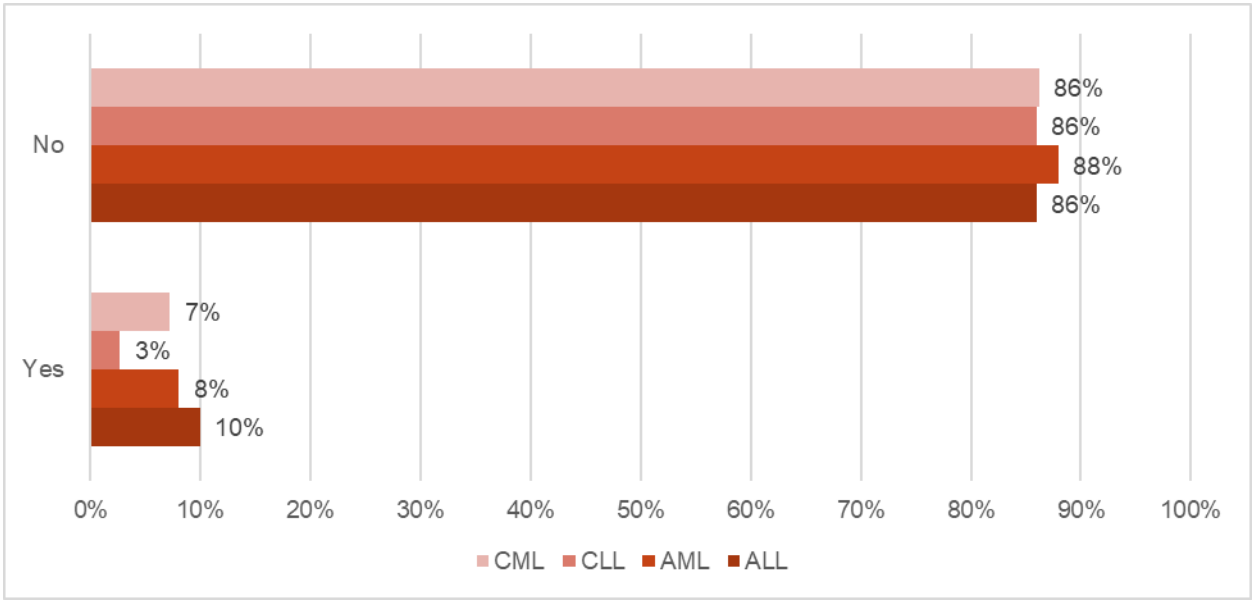
Figure 23: Did you know that the health problems you were experiencing could be symptoms of leukemia?(Patients)



Carers

Similarly, 86% (n=490) of all respondents from the carers survey were not aware that the patients' symptoms may have been leukemia. (Figure 24)

Figure 24: Q 8C. Before the diagnosis were you aware that the health problems the patient was experiencing could have been the symptoms of leukemia? (Carers)



As presented in Figure 25, 81% (n=2,116) of patients that responded to the survey understood their diagnosis, at least to some extent. However, just 39% (n=1,027) fully understood it (see figure 27). This did vary across leukemia type. Those given a diagnosis of ALL were most likely to report completely understanding it (45%, n=46).

If they did not understand the diagnosis most patients stated that this was because they were in shock (12%, n=316) rather than that they simply did not understand it (7%, n=177). All others understood or completely understood the explanation received at diagnosis. (Figure 26)

Figure 25: Q26 When you were given your diagnosis of leukaemia, were you aware it was a form of cancer? (Patients)

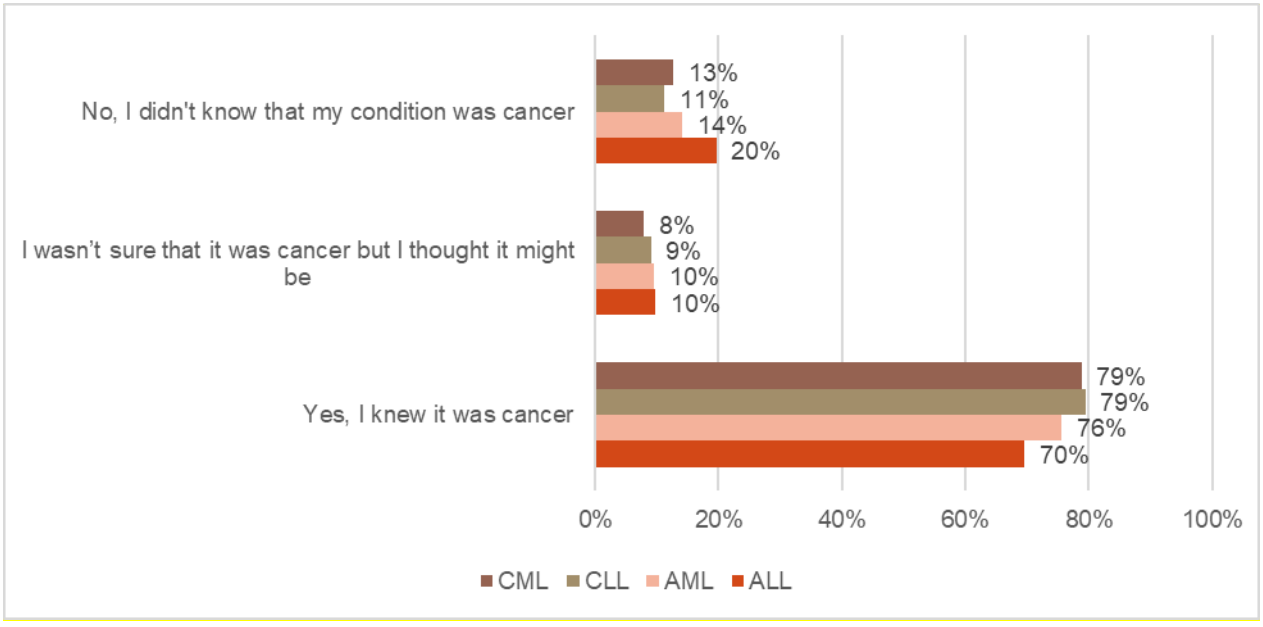
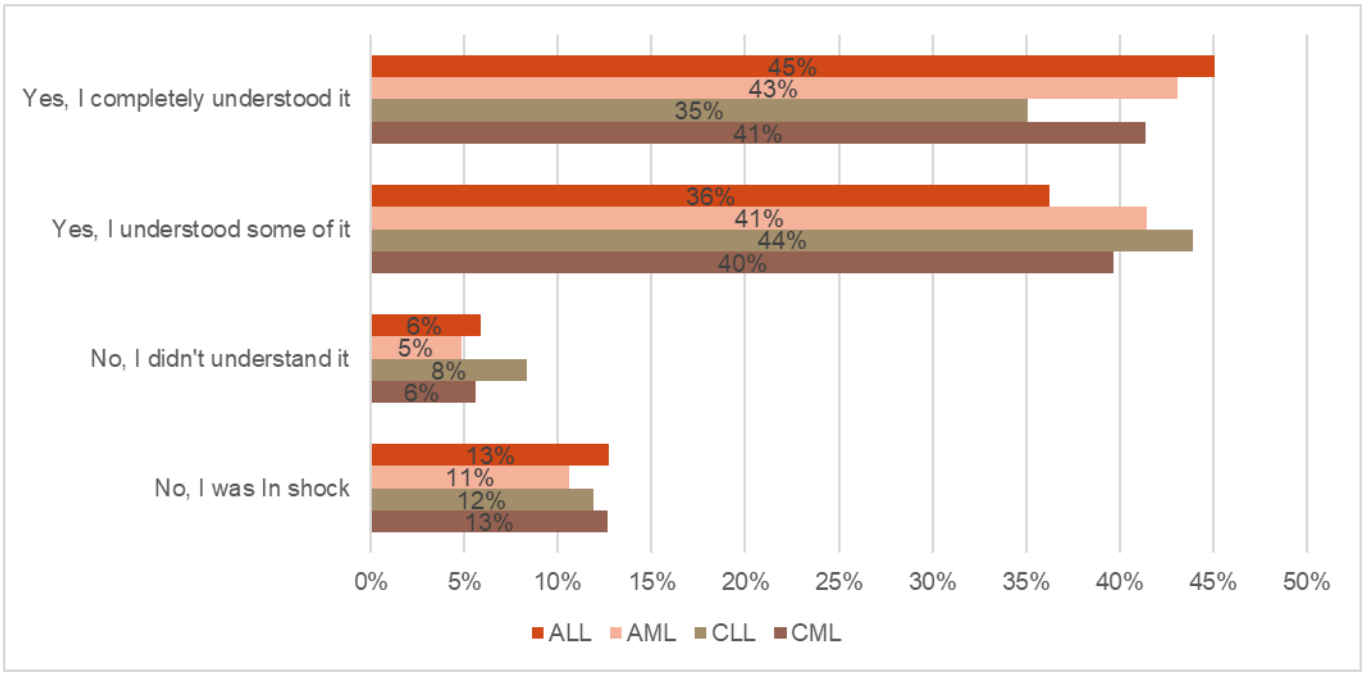


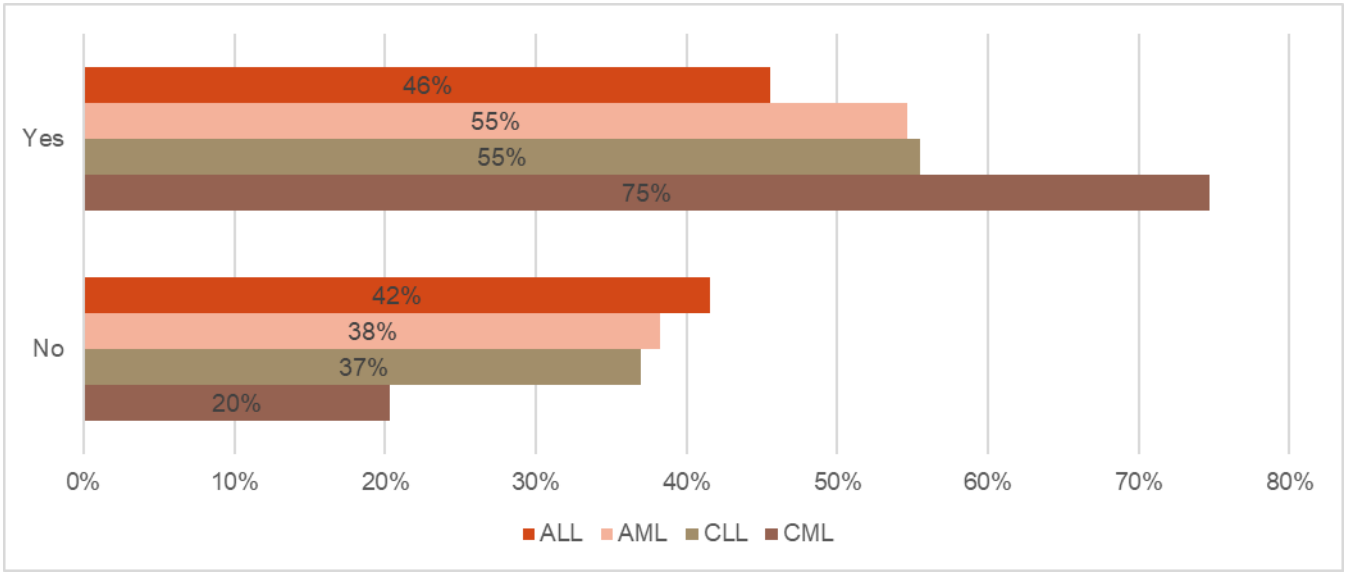
Figure 26: Q27. Did you understand the explanation about what was wrong with you? (Patients)



The responses for the carers survey are almost identical to these.

As presented in Figure 27, 62% (n=1,636) of patients were told their prognosis. This did vary by leukemia type. Patients living with CML were most likely to be told their prognosis (75%, n=666), those with ALL least likely (46%, n=46).

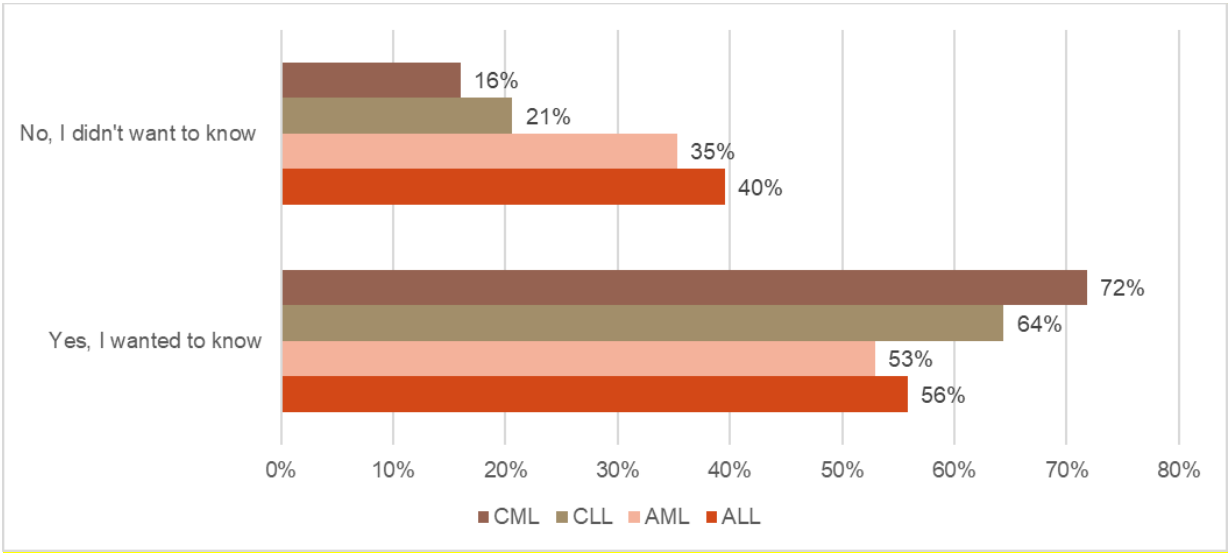
Figure 27: Q28. When you were given your diagnosis of leukemia, did the person who told you speak about your prognosis (likely survival chances)? (Patients)



The responses from the carer survey were again similar here, although, interestingly slightly more carers reported that they wanted to know the prognosis than the patients that responded here.

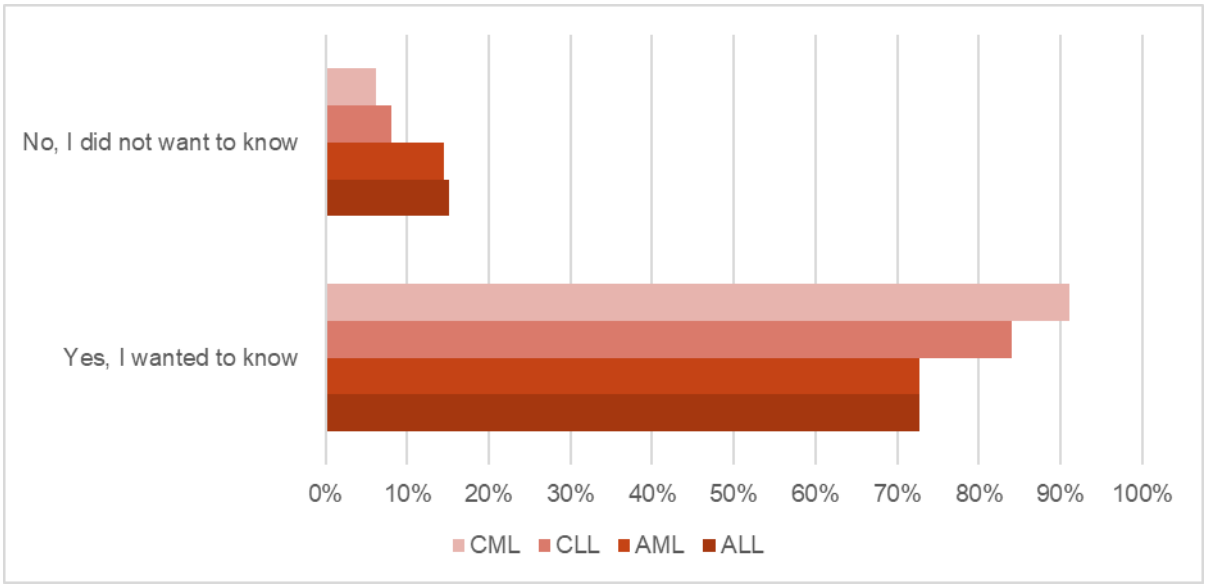
Patients

Figure 28: Did you want to know your prognosis? (Patients)



Carers

Figure 29: Did you want to know the patient's prognosis (likely survival chances)?

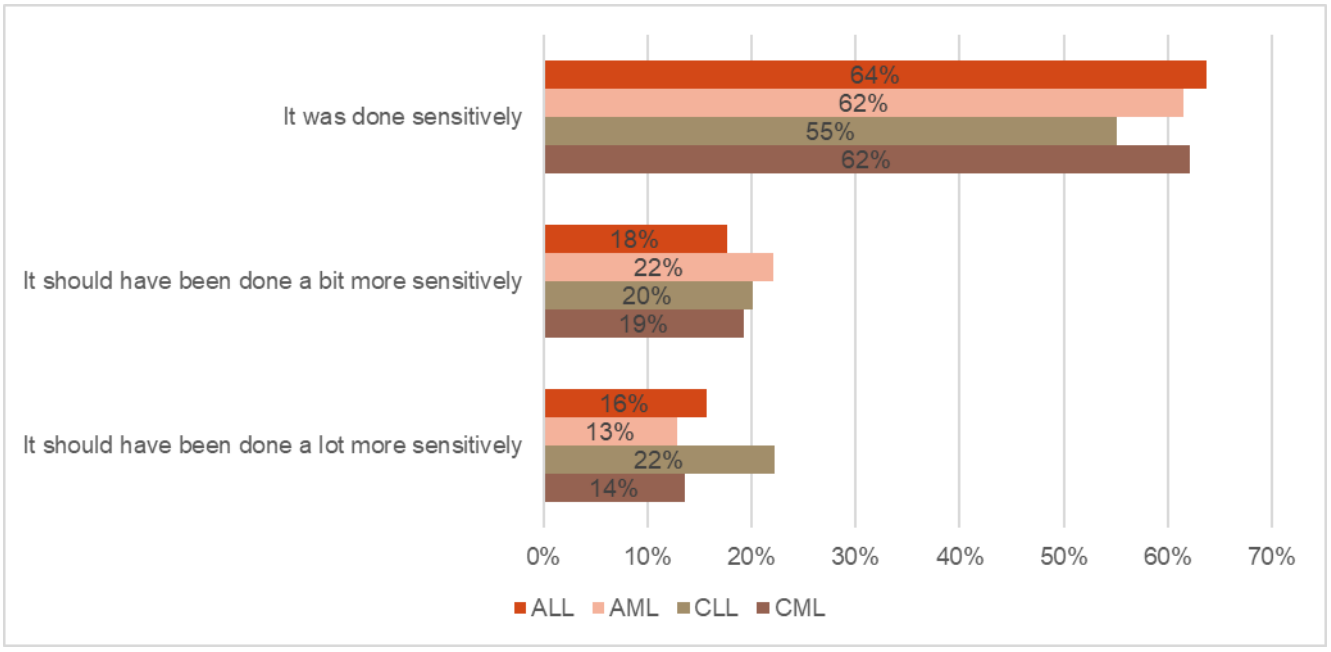


Although it is frightening to be diagnosed with leukemia, an understanding of the prognosis of the disease, disease progression and chances of survival can help people to understand the disease more comprehensively and make plans for their future. This should be part of a sensitive explanation of the disease at diagnosis.

Patients

From those that responded to the patient survey, 59% (n=1,548) felt that the diagnosis had been made sensitively. This was similar across all leukemia types. (Figure 30)

Figure 30: Q30. How do you feel about the way you were told you had leukemia? (Patients)



Almost all (89%, n=2,350) of diagnoses took place face to face with only around 10% (n=282) taking place by other means, most commonly over the phone.

Carers

From the carers survey, the vast majority of patients were told that they had leukemia by their healthcare professional, with the rest being told by either the carer or another member of the family. It was more common for the carer to inform the patient in those with ALL and this is in all likelihood related to the younger age of the patients. (Figure 32)

Figure 31: Q11. How do YOU feel about the way the patient was told they had leukaemia? (How do you feel about the way you were told you had leukaemia?) (Carers)

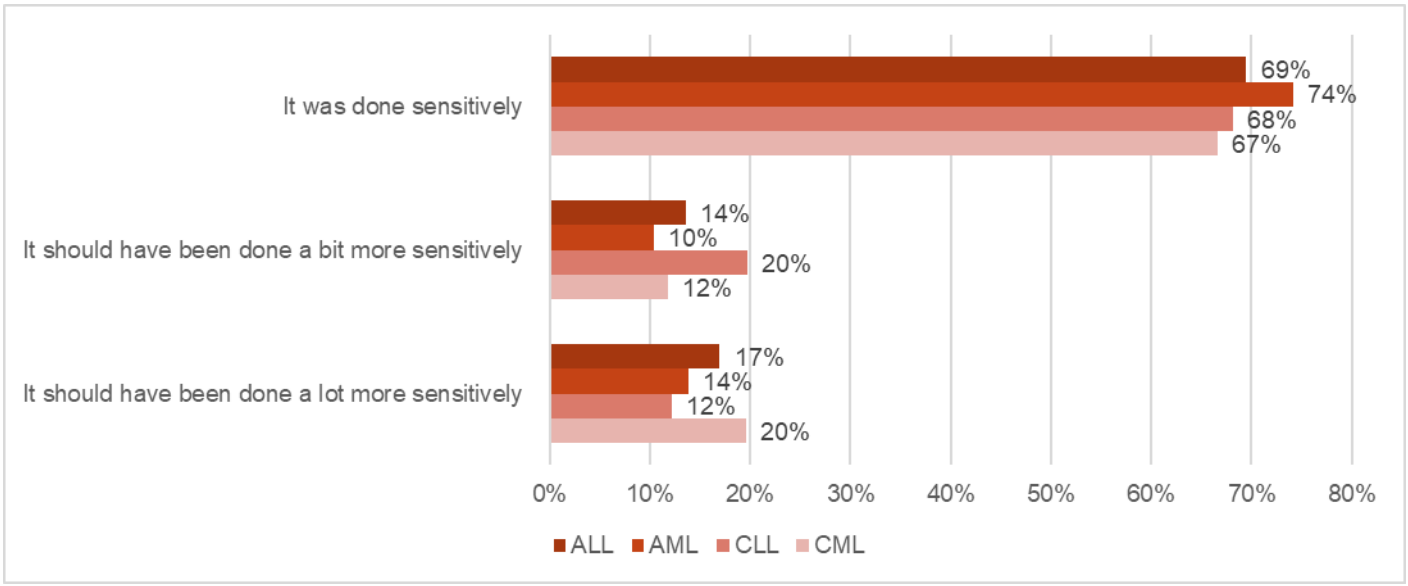


Figure 32: Q9C. Who told the patient they had leukemia? (Carers)

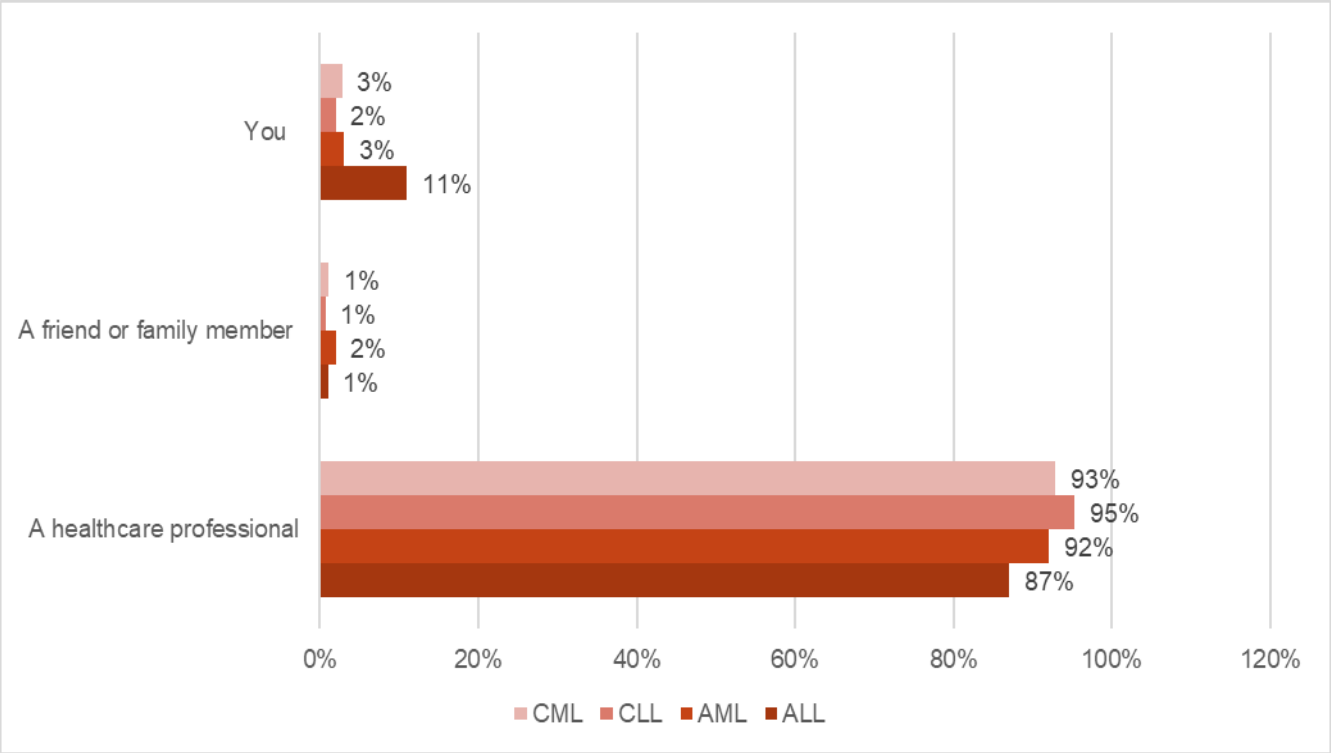
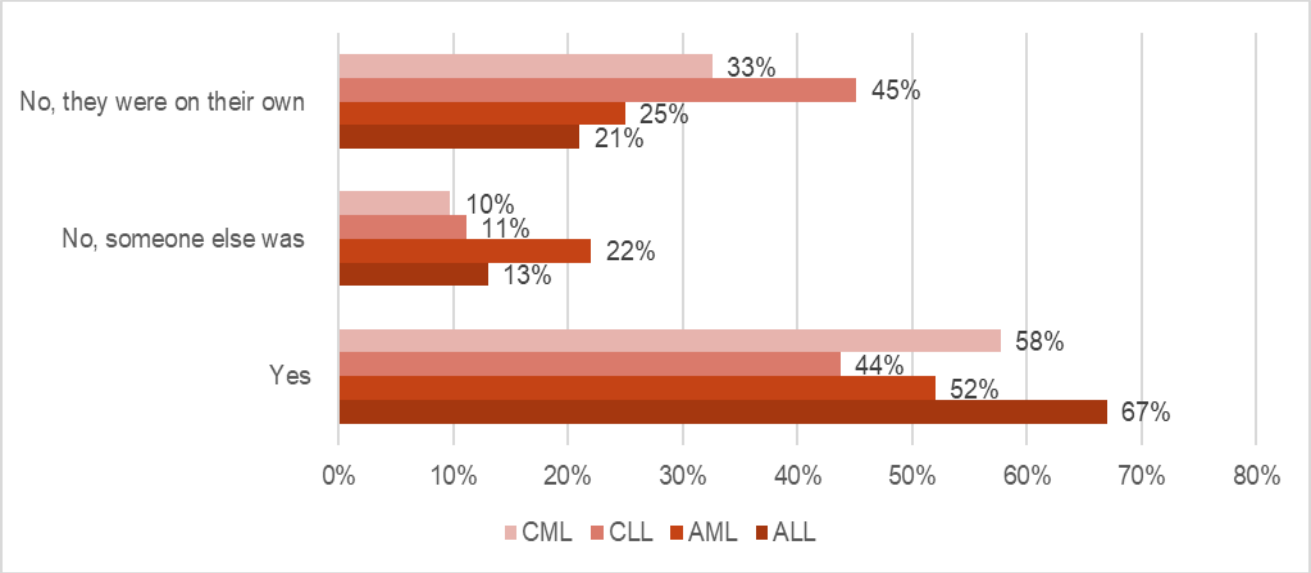


Figure 33: Q10 when the patient was told they had leukaemia, were you with them (Carers)



7. Treatment and care

In this section of the questionnaire, respondents were asked about the treatment and care that the patients received. This included their treatments, the impact of those treatments along with their experience around clinical trials, and their experiences of 'Watch and Wait' monitoring.

7.1. ‘Watch and Wait’

‘Watch and Wait’ is a commonly used management tool for CLL and isn’t applicable to other leukemia types. In this survey a number of patients and carers with other leukemia types responded to this question and so their responses have been disregarded here.

Patients

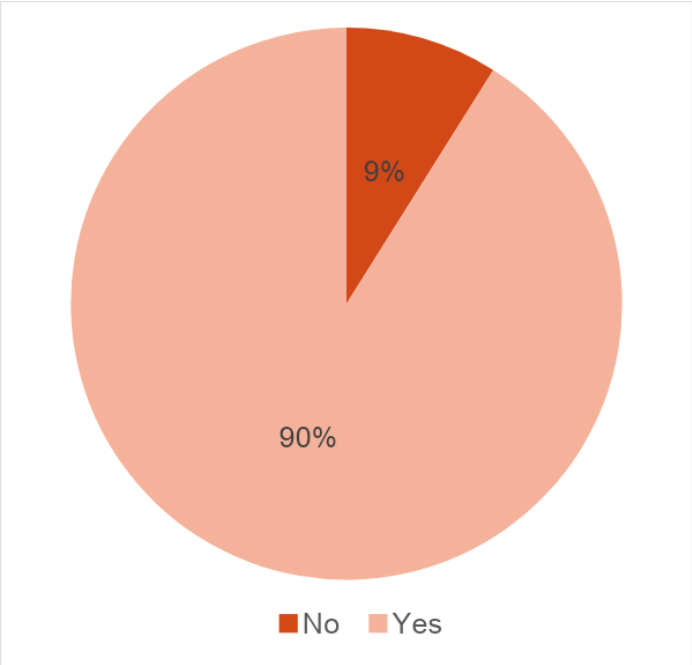
Only 9% (n=106) of those with CLL ***had not*** been on ‘Watch and Wait’ (see Figure 34) with 50% (n=528) of those that responded had never received treatment since their diagnosis.

For those that were on ‘Watch and Wait,’ over 80% (n=955) were given an explanation of this and the majority (95%, n=949) understood this explanation at least to some extent. Even though the majority understood the reasons they had been placed on ‘Watch and Wait,’ 78% (n=840) had at least some concerns about being on ‘Watch and Wait’ with 28% (n=299) of those very concerned or worried. (Figure 36)

Carers

Similarly, to the results from the patient survey, 85% (n=127) of those caring for someone with CLL stated that they ***had*** been on ‘Watch and Wait’. Although, 84% (n=107) understood the reasons for this, however, only 40% (51) reported that they fully understood the reasons for this.

Figure 34: Q37. Have you ever been placed on ‘Watch and Wait’ monitoring? (Patients)



The results here are in keeping with the current literature confirming ‘Watch and Wait’ monitoring as a common management tool for CLL.

Figure 35: Q56. What best describes your current 'watch and wait' situation? (Patients)

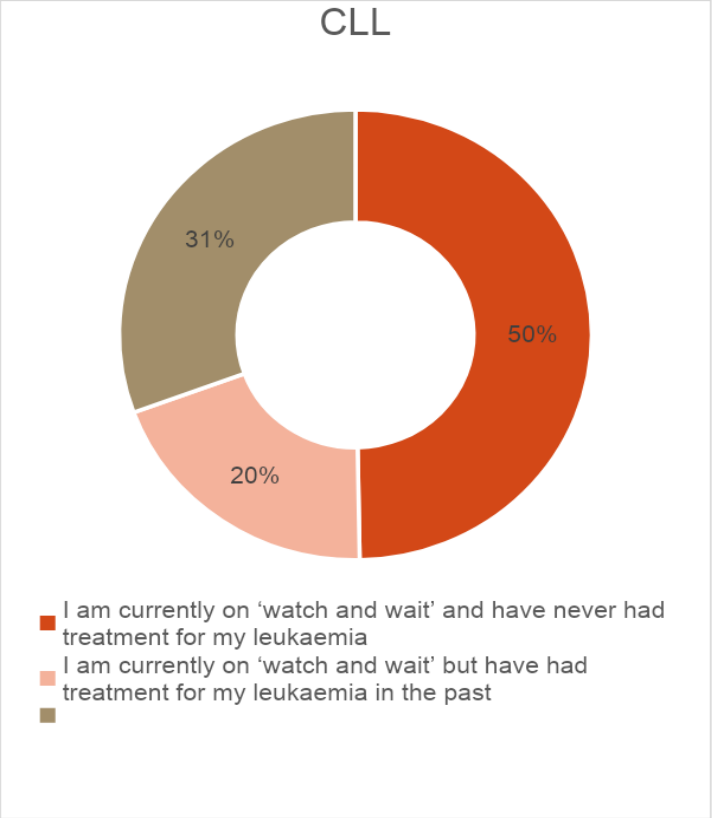
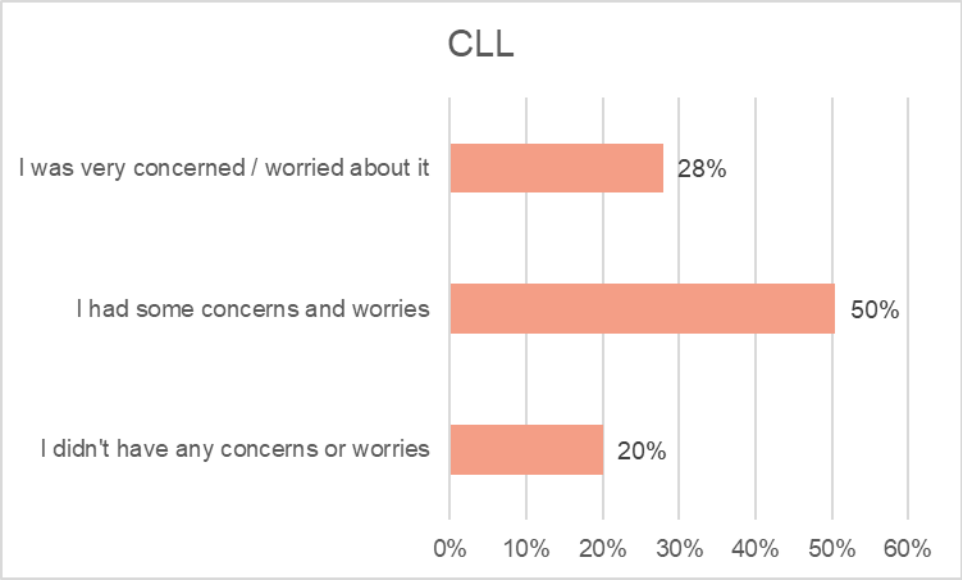


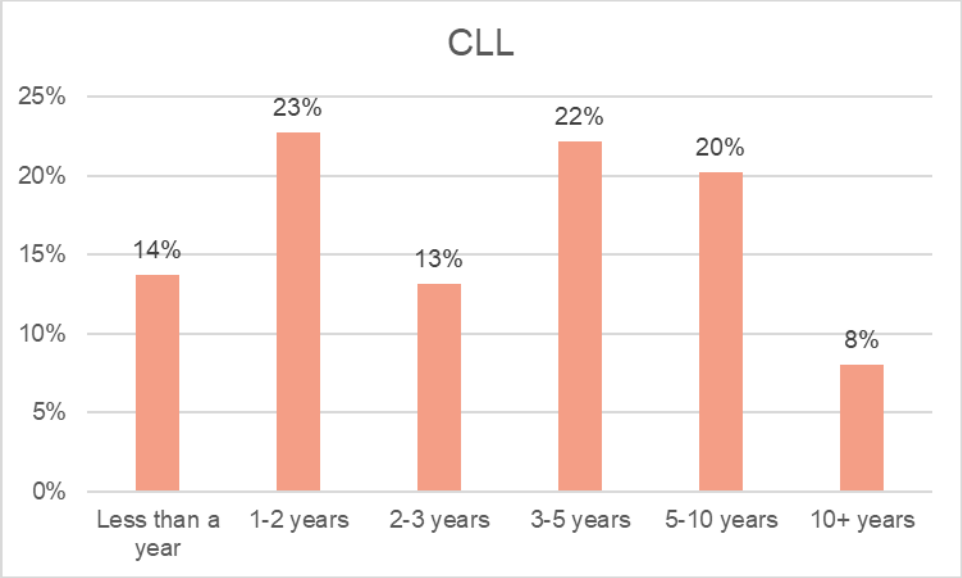
Figure 36: Q44. How did you feel when you were put on 'watch and wait' for the FIRST time? (Patients)



7.1.1. Length of time on ‘watch and wait’

For those placed on a ‘Watch and Wait’ monitoring plan, the majority of those with CLL were on ‘Watch and Wait’ for longer than a year (86%, n=440).

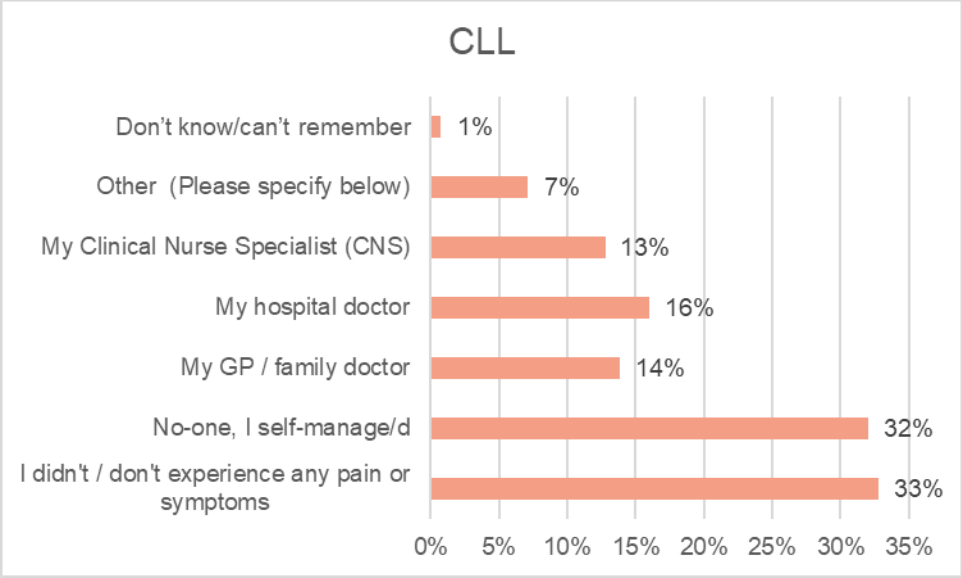
Figure 37: Q58. How long were you on ‘watch and wait’ before starting treatment? (Patients)



7.1.2. Symptoms whilst on ‘Watch and Wait’

Whilst, 32% (n=346) of those with CLL managed the symptoms on their own, a much lower proportion (16%, n=173) were aided by a hospital doctor.

Figure 38: Q54. While on ‘watch and wait,’ who helps you with pain or symptoms related to your diagnosis? (Patients)



7.1.3. Summary

'Watch and Wait,' in line with prior surveys and relevant research literature, is a common management tool for those with CLL and these patients typically spend much longer on 'Watch and Wait' before moving onto treatment.

There is a lack of complete understanding about 'Watch and Wait,' with a minority being offered written information and/or support to help them understand and manage any concerns that they may have.

Support organisations and healthcare providers should work collaboratively to improve access to information and support for patients and carers.

7.2. Starting Treatment

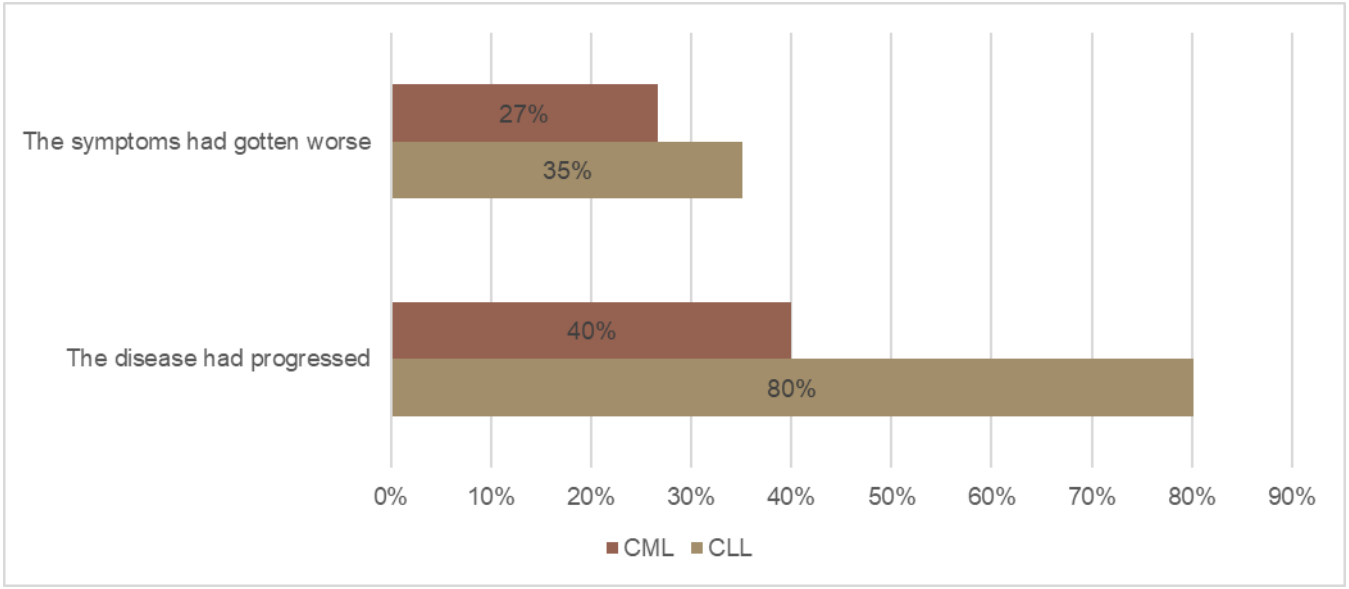
Respondents were asked questions around their current and most recent treatment. They were also asked about their experiences around the types and impact of the treatment that they have received alongside any side effects that they have encountered.

Patients

The majority of patients start treatment for acute leukemia and CML shortly after they are diagnosed with most of the remainder of patients starting treatment within a year.

For those with chronic leukemia, patients with CML, only 40% (n=6) started treatment due to the progression of their disease, 27%(n=4) reported that their symptoms had become more severe, and 27% (n=4) were unaware of the reason that they started treatment. In contrast, 80% of those with CLL started treatment due to disease progression (n=408).

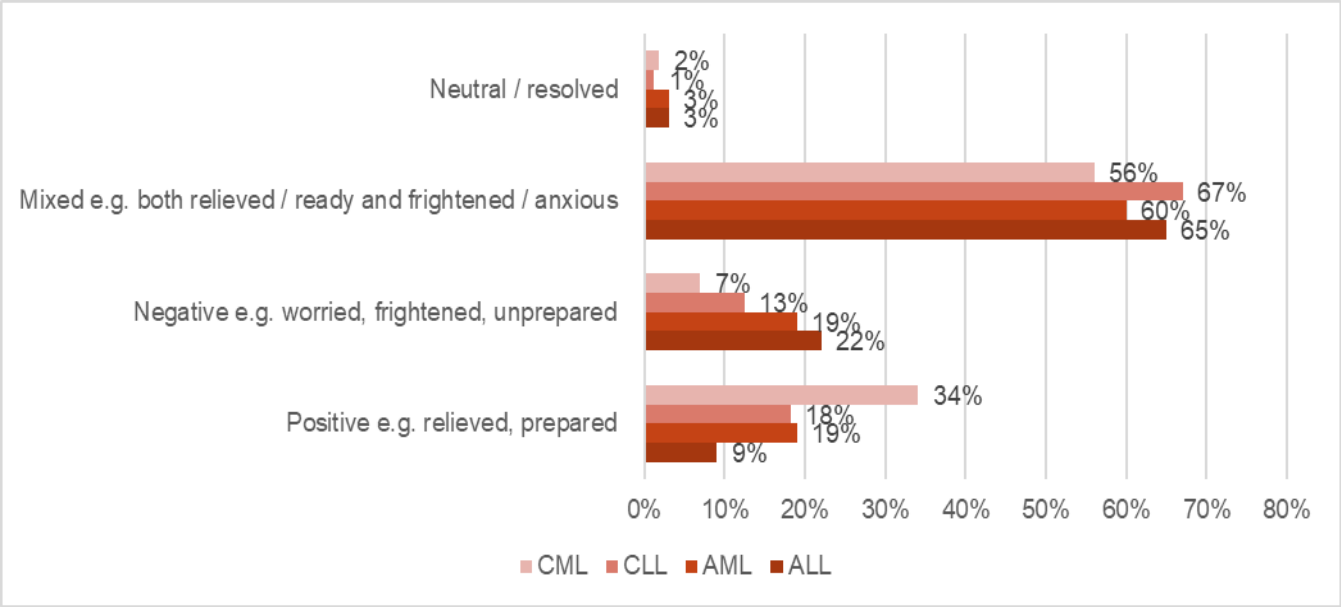
Figure 39: Q59. Why did you eventually start treatment? (Patients)



Carers

Carers were asked to consider how they felt about the patient starting treatment. Overall, 61% (n=285) of all carers of those with all types of leukemia felt mixed emotions, both relieved and anxious although, this was slightly lower for those caring for someone with CML (56%, n=97) (see Figure 40). Further, 20% (n=42) of those caring for someone with acute leukemia felt negatively about it. A much lower proportion for CML (7%, n=12) felt negatively and a much higher proportion felt positive about treatment being started (34%, n=59).

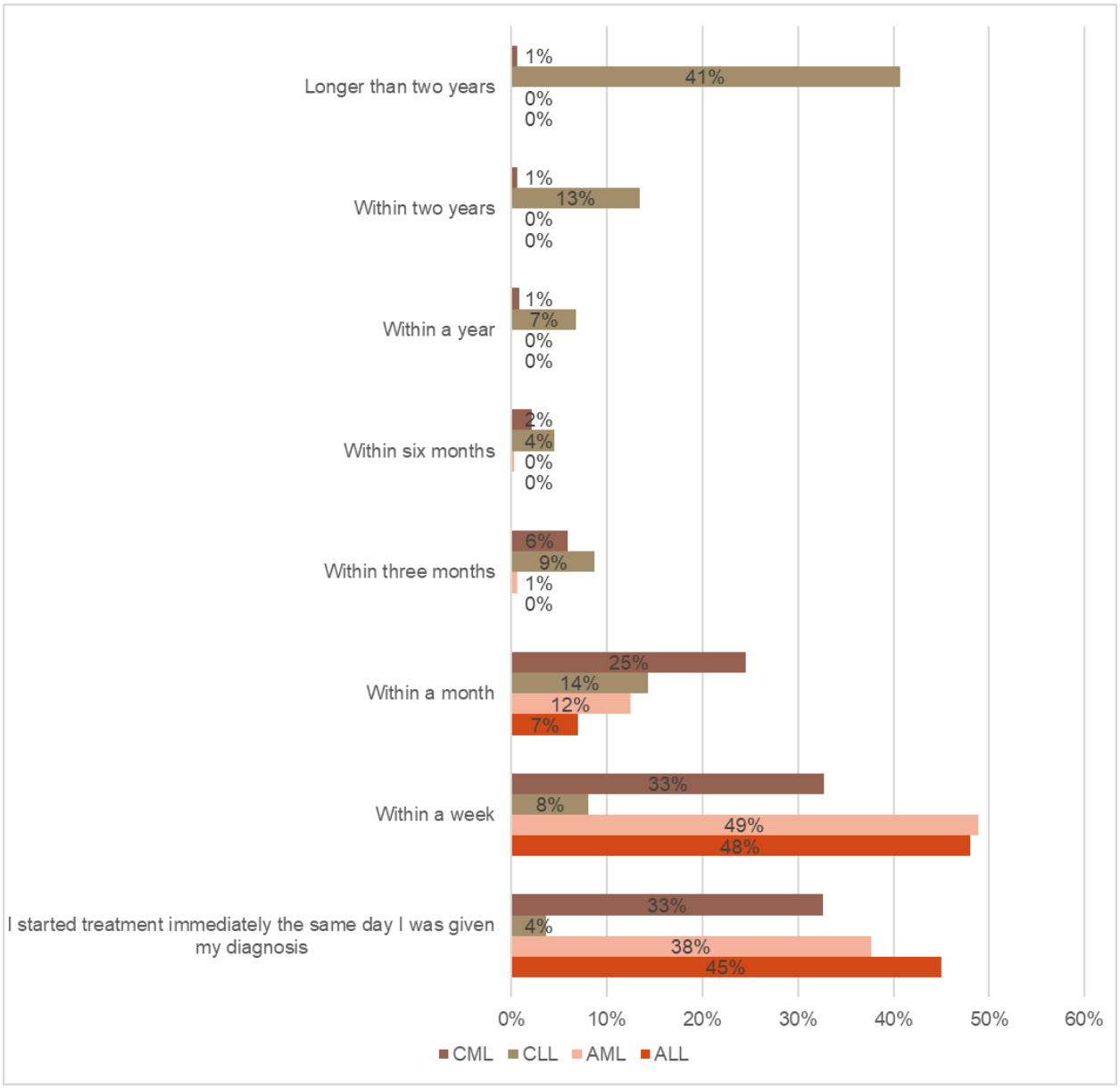
Figure 40: Q 26. How did YOU feel when they started treatment? (Carers)



Of those that started treatment, 45% (n=45) of those with ALL, 38% (n=115) of those with AML and 33% (n=287) with CML started on the same day as their diagnosis. A further 49% (n=197) for both acute types started treatment within a week and 100% of those with acute leukemia and 91% of those with CML started within a month of diagnosis.

In contrast, only 26% (n=116) of those with CLL reported starting treatment within a month of diagnosis with only 4% (n=16) starting when diagnosed. This is broadly in line with the Leukemia Care survey from 2018, although there were only 21% of those with CLL reported waiting two years or more, here it was 41% (n=182). (Figure 41)

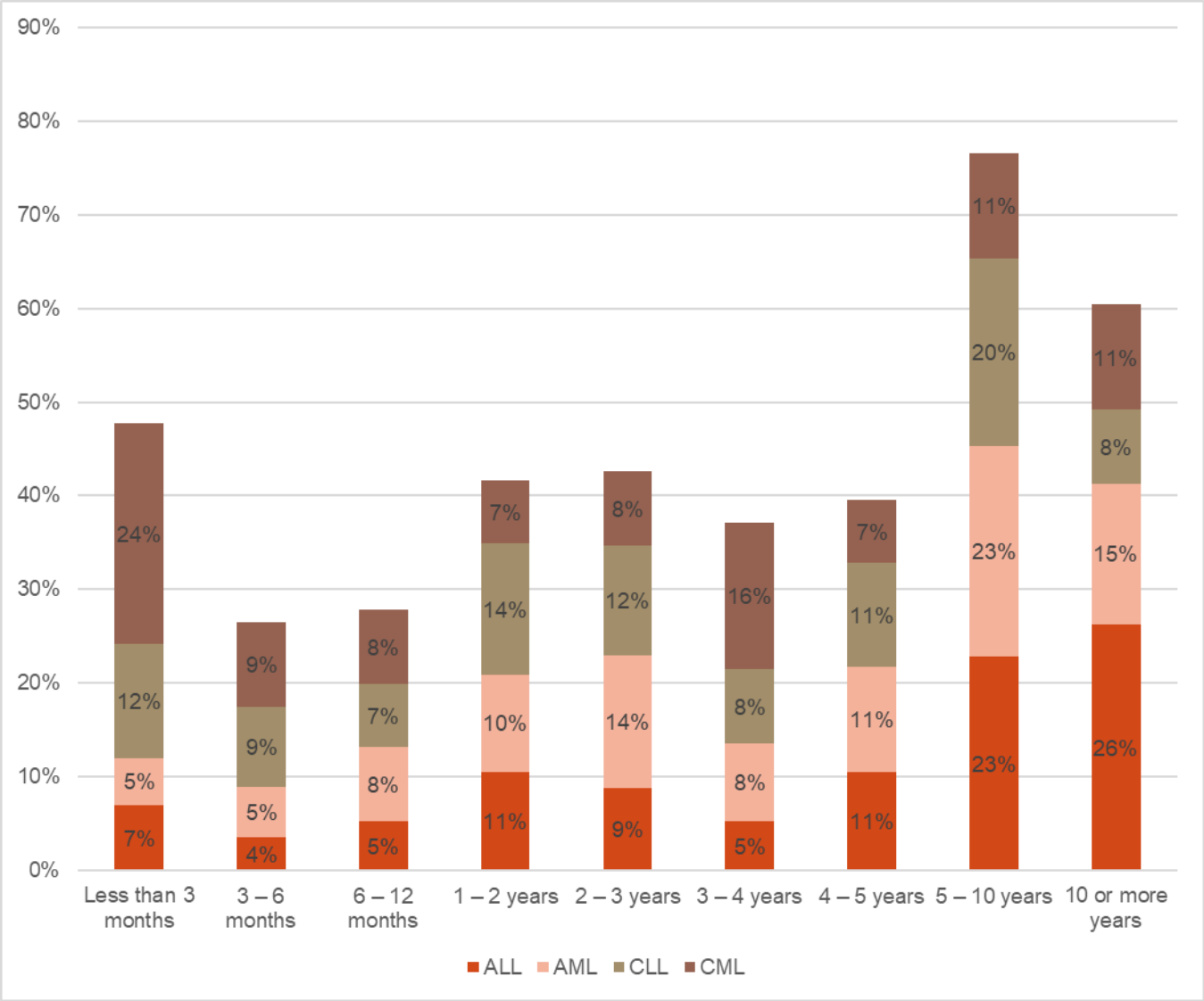
Figure 41: At what point after diagnosis did you start treatment? (Patients)



For those not currently on treatment, the highest number of respondents indicated that their last treatment was more than 5 years ago (ALL 49%, n= 28 and AML 38%, n=90). Patients with CML, 24% (n=21) stated that their last treatment was less than 3 months ago, only 22% (n=20) were last treated more than 5 years ago. (42)

There is a real mix of timepoints at which those with CLL reported that they started treatment. This may be expected as this is a chronic progressive disease with differences across subtypes and the changes in the disease across the lifespan can lead to uncertainties and challenges for this group of patients that are very different to other blood cancer disease types.

Figure 42: Q68 How long ago was your most recent treatment? (Patients)



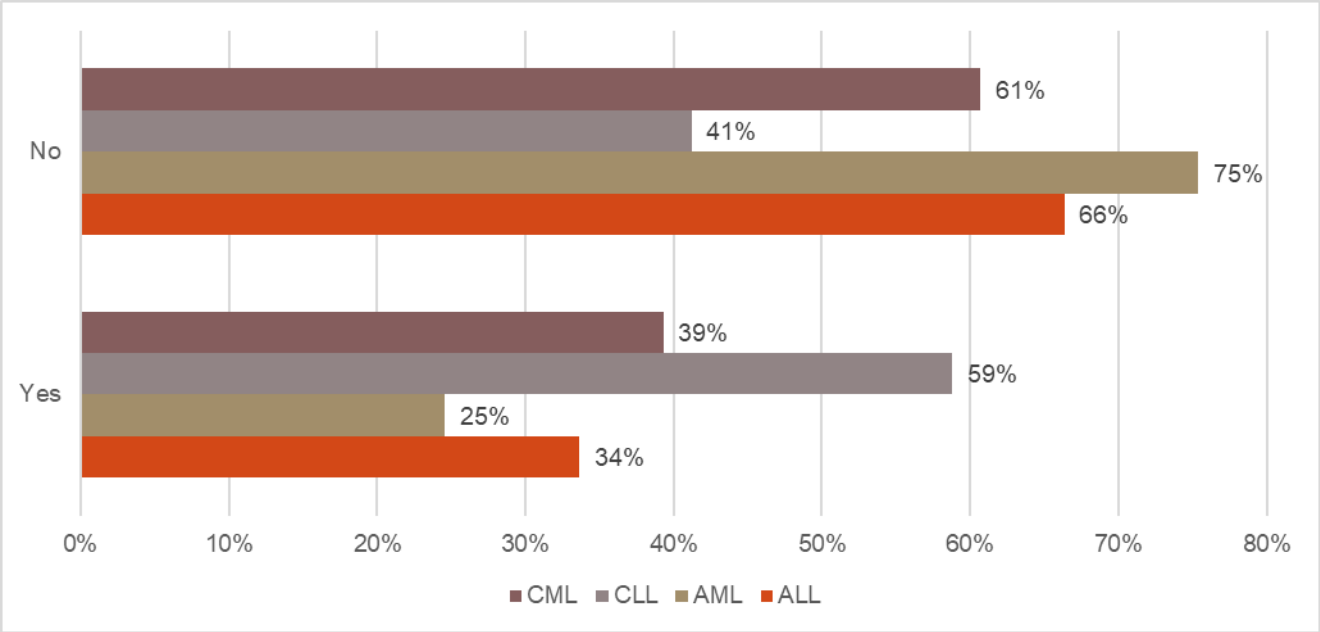
7.3. Treatment options

Patients

In all 30% (n=89) of patients with acute leukemia researched treatment options themselves. When looking in more detail at the different types, 34% (n=34) of ALL and 25% (n=75) of AML respondents conducted their own research (see Figure 43). This would suggest that most people with acute leukemia do not have time to educate themselves on potential treatments, relying on their healthcare professionals to advise them accordingly.

In contrast, 39% (n=345) of those with CML and 59% (n=388) of those with CLL conducted their own research. The age, demographic and chronic aspect of the disease may have impacted these findings along with the chronic nature of the disease allowing patients a longer time to conduct research.

Figure 43: Q63. Did you undertake any research into different treatment options? (Patients)

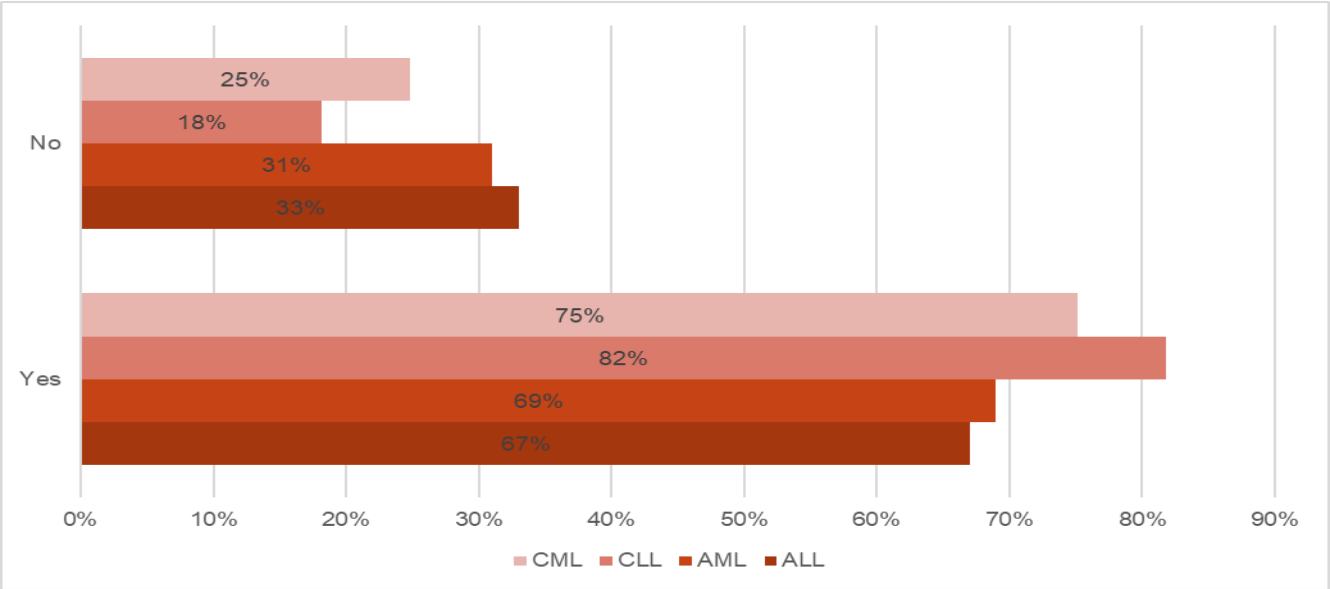


Carers

From the carers survey, interestingly, the findings are different with 73% (342) stating that they had used the internet to obtain further information about treatment options. Again, this was higher in carers caring for someone with a chronic disease; CLL 82% (n=72) and CML 75% (n=130). (Figure 44)

Firstly, the questions were worded slightly differently which may help to explain the discrepancy between patient and carer responses, however, the age and position differential between the patients and carers may also have affected the responses.

Figure 44: Q27C. Have YOU ever used the Internet to find further information relating to different treatment options? (Carers)

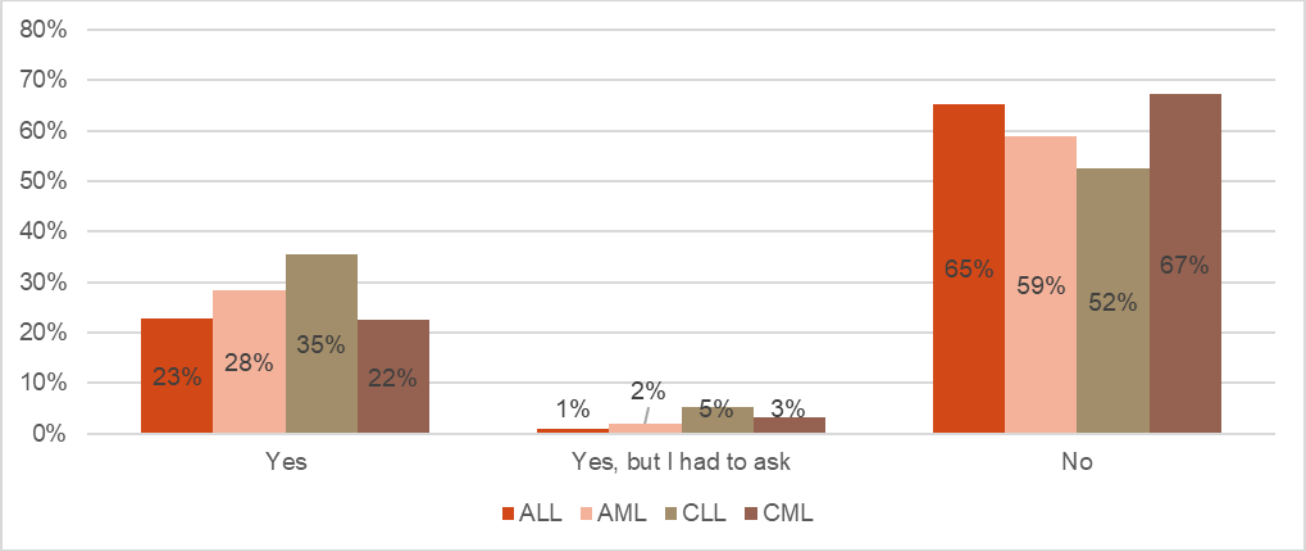


7.4. Treatment Involvement and choice

Patients

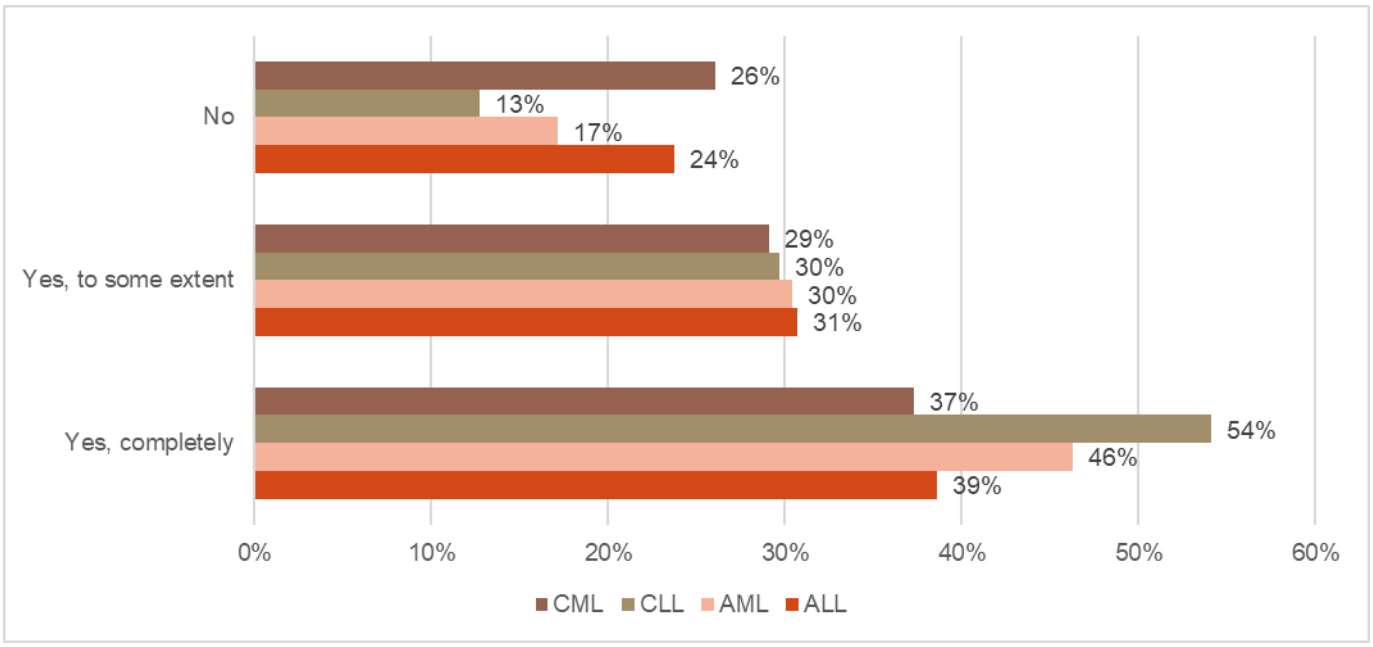
Around a quarter of respondents (ALL 23%, n=23, AML 28%, n=87,, CML 22%, n=197) reported that they had been offered a choice of treatments with a further 3% (n=71) stating that they were only offered this after asking for it. This was slightly higher for those with CLL (35%, n=235 and 5%, n=35). The majority of respondents were not offered a choice (see Figure 45).

Figure 45: Q62. Were you offered a choice of treatment options? (Patients)



Most patients , when asked, felt that they were involved in the decisions about their care at least to some extent (ALL 70%, n=70, AML 76%, n=237, CLL 84%, n=559, and CML 66%, n=584, see Figure 46).

Figure 46: Q64. Were you involved as much as you wanted to be in decisions about your treatment? (Patients)



Carers

When asked whether they thought that the patient was involved as much as they should have been in their treatment and care, around half (49%, n=103) of carers of those with acute leukemia felt that they definitely had been, with a further 38% (n=80) feeling that they were to some extent. More than half (57% [n=63]) of the AML carers felt that this was the case compared to only 40% (n=40) of those caring for someone with ALL. Majority (78% [n=164])) of the carers also felt that they themselves were involved in the decisions, at least to some extent (see Figure 48).

A higher proportion of carers for those with chronic disease felt that the patients were ***definitely*** involved (62%, n=92 CLL and 71%, n=128 CML), whilst 72% (n=108) of CLL carers and 82% (n=149) of CML felt that they themselves were involved.

Figure 47: Q17C. Do you think the patient was involved as much as they should have been in decisions about their treatment and care (Carers)

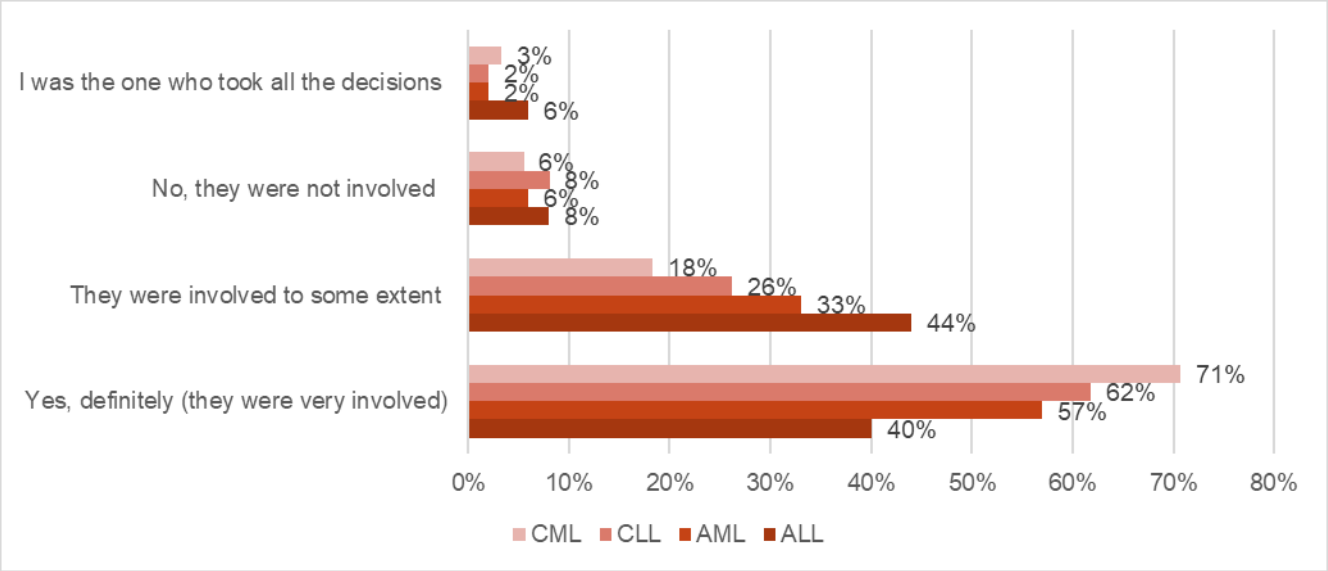
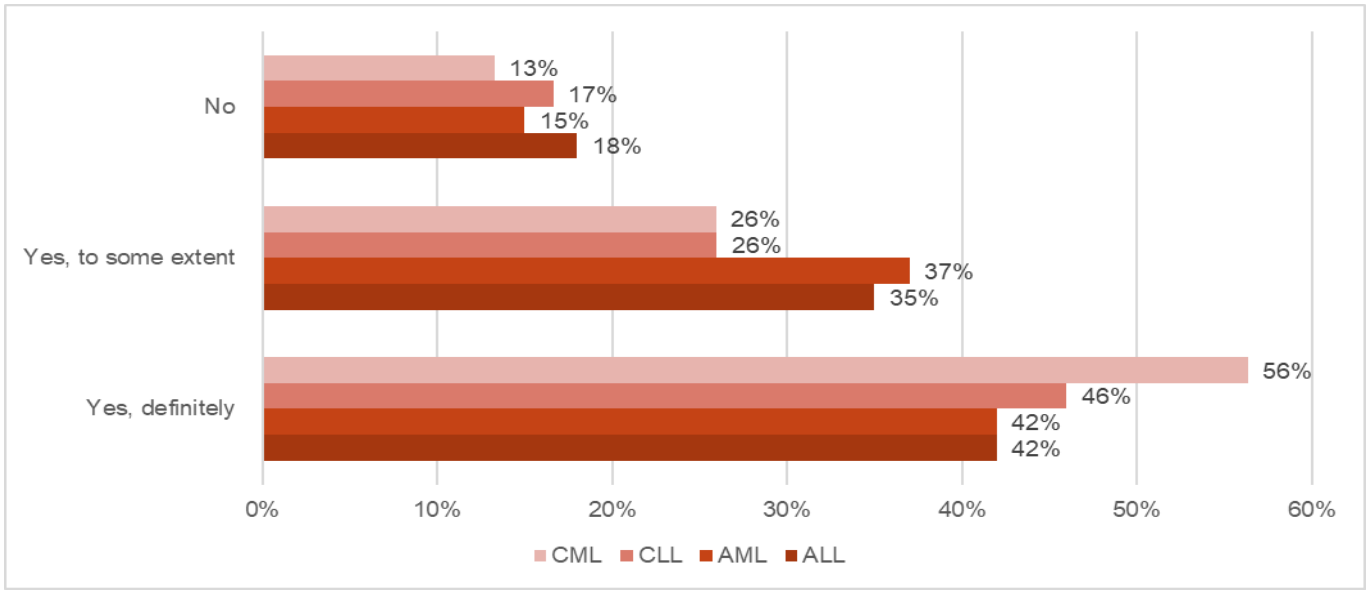


Figure 48:18C. Do you think that YOU were involved as much as you should have been in decisions about the patient's treatment and care? (Carers)



7.5. Treatment methods

Effective treatments differ for patients depending on a number of factors for example leukemia type, individual patient circumstances, and when the patient received their last treatment.

Patients were asked to report on their current and most recent treatments ensuring that this survey would encompass everyone who had received treatment at some point since diagnosis even if they were not on treatment at the point that the survey was conducted.

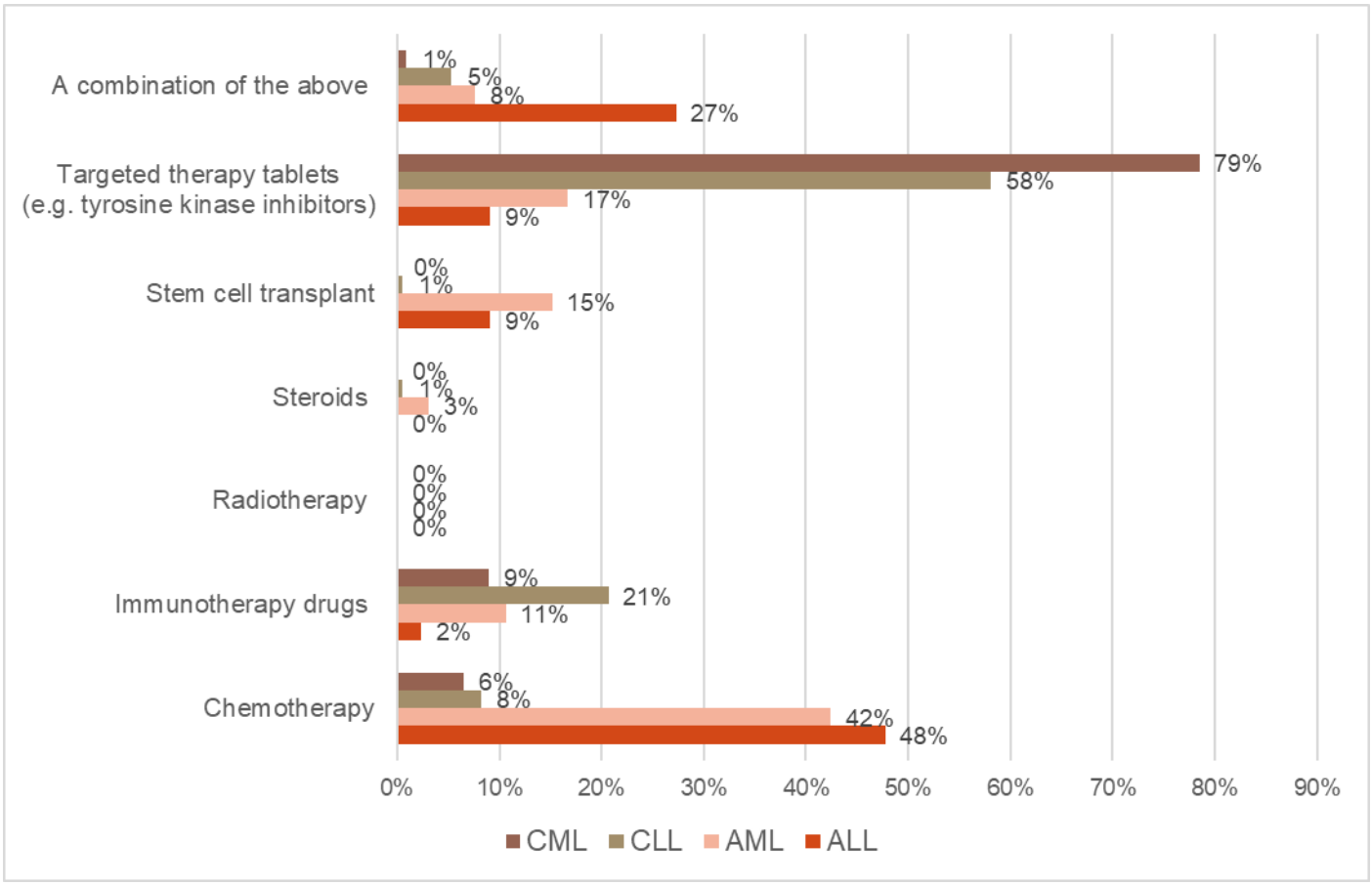
Current Treatment

For patients ***currently*** on treatment, the most common treatment for both ALL and AML patients was chemotherapy (45%, n=49). Twenty-seven percent (n=12) of ALL patients were on a combination of treatments, whereas only 8% (n=5) of AML patients received combination therapy. The next most common treatments for AML patients were targeted therapy tablets (17%, n=11 of respondents) and stem cell transplant (15%, n=10). No patients reported being on radiotherapy.

In comparison, the majority of chronic patients were on a targeted oral treatment (CLL 58%, n=219 and CML 79%, n=618 CML), with 21% (n=78) of those with CLL on immunotherapy. (Figure 49)

This demonstrates the difference in treatment between the acute and chronic types of the disease.

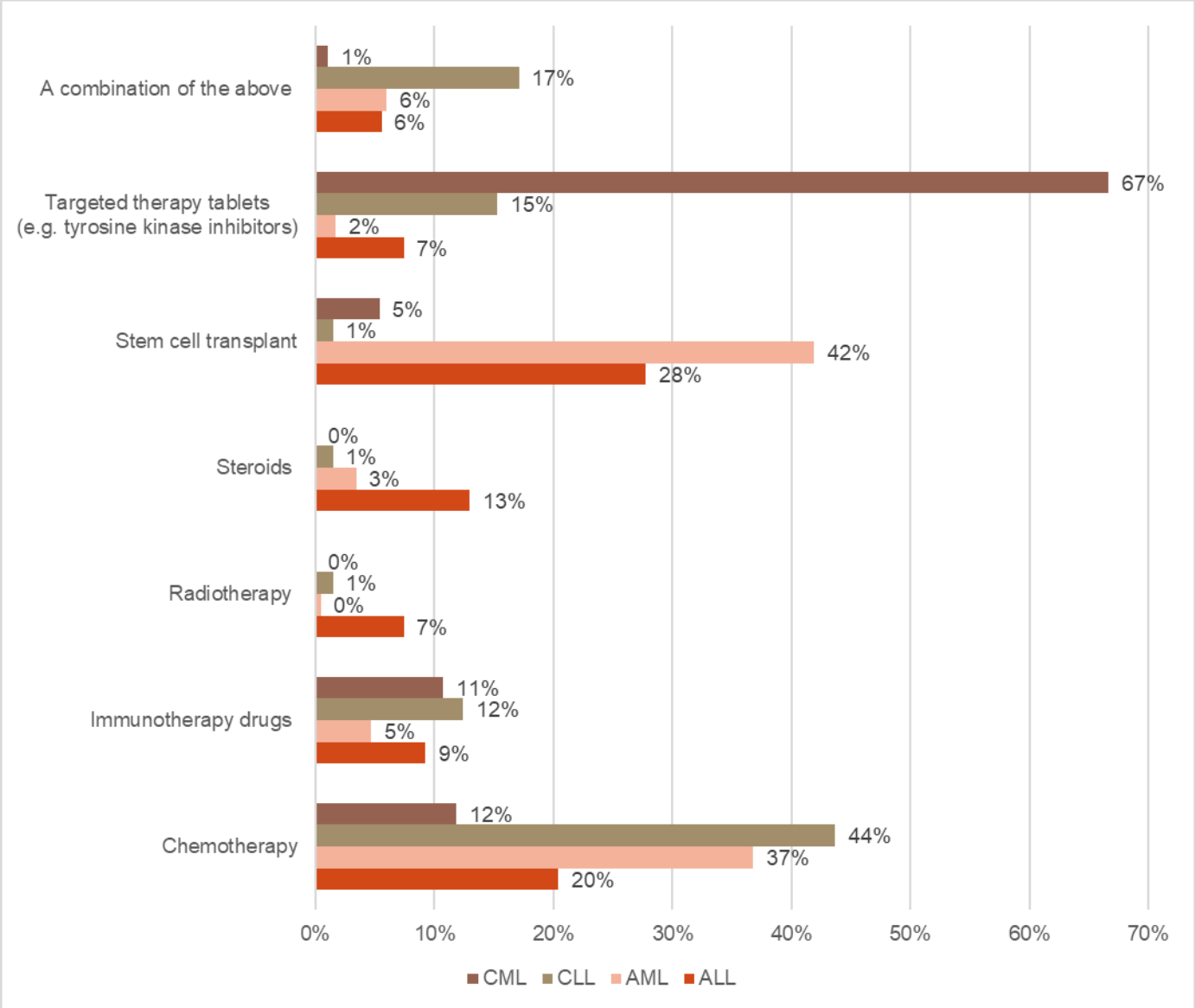
Figure 49: Q66. What is your current treatment? (Patients)



Recent Treatment

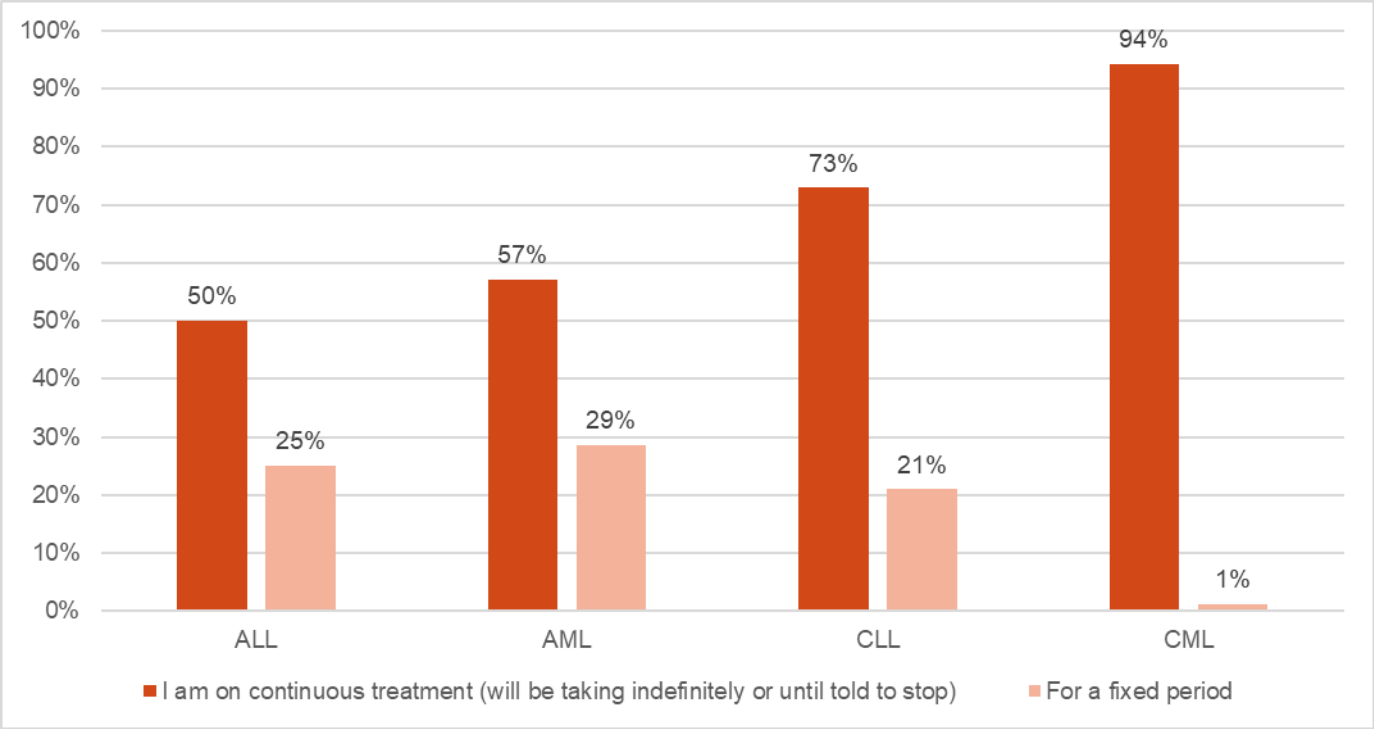
The most common ***recent treatment*** that patients reported being on was stem cell transplant (SCT) for both ALL (28%, n=15) and AML (42%, n=98), followed by chemotherapy (20%, n=11 ALL and 37%, n=86 AML).The SCT was used rarely for those with a chronic leukemia (CLL 1%, n=4 and CML 5%, n=5). These patients were more likely to report chemotherapy (CLL 44%, n=120) and targeted therapy as their most recent treatment types. (Figure 50)

Figure 50: Q67 What was your recent treatment? (Patients)



Oral administration was used by about a quarter of acute patients as their most recent treatment (ALL 27% , n=27 and AML 21%, n=64) although, this was much higher for those with chronic disease (CML 97%, n=848 and CLL 57%, n=371). Of those taking oral treatments, just over half of acute patients were on the treatment indefinitely, whilst it was higher for chronic patients:73% (n=261) of those with CLL and 94% (n=780) of those with CML (see Figure 51). There may be a geographical element to this result as the majority of respondents were from the UK, and this is a treatment that is prevalent in the UK, therefore, any conclusions drawn from this should be done so with caution.

Figure 51: Q77. How long will you be taking your oral treatment for? (Patients)



The proportion of those who had missed a dose of their treatment differed across the leukemia types. Those with CLL and CML were more likely to report that they had missed a dose (CLL 32%, n=115 and CML 40%, n=337). Of those that have missed a dose, around half did so because they had forgotten, or the reminder failed. A third of ALL (33%, n= 2) patients reported that their doctor had told them that they could miss a dose.

7.6. Clinical trials

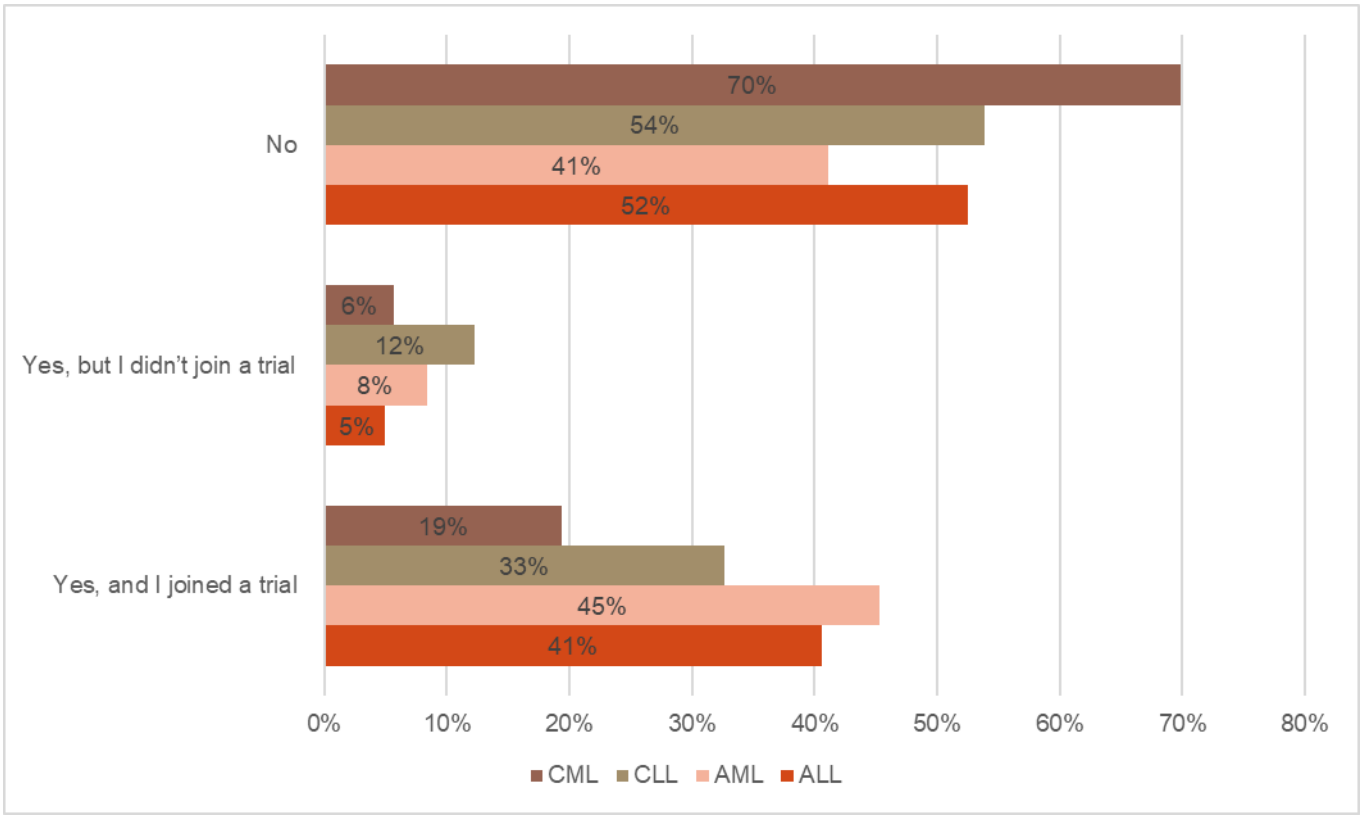
Patients

The treatment landscape for leukemia treatments is constantly evolving. For some patients, the best way to access treatment may be participation in a clinical trial.

Around a third (36%, n=750) of those that responded were given the option of participating in a clinical trial, with 45%, n=181 of acute leukemia patients that had actually joined a trial and a third (33%, n=215) of those with CLL. This was slightly higher for those with AML (45%, n=140) than ALL (41%, n=41). Only a quarter (25%, n=219) of those with CML were given the opportunity to participate in a trial, with 19% (n=169) actually taking up the opportunity. (Figure 52)

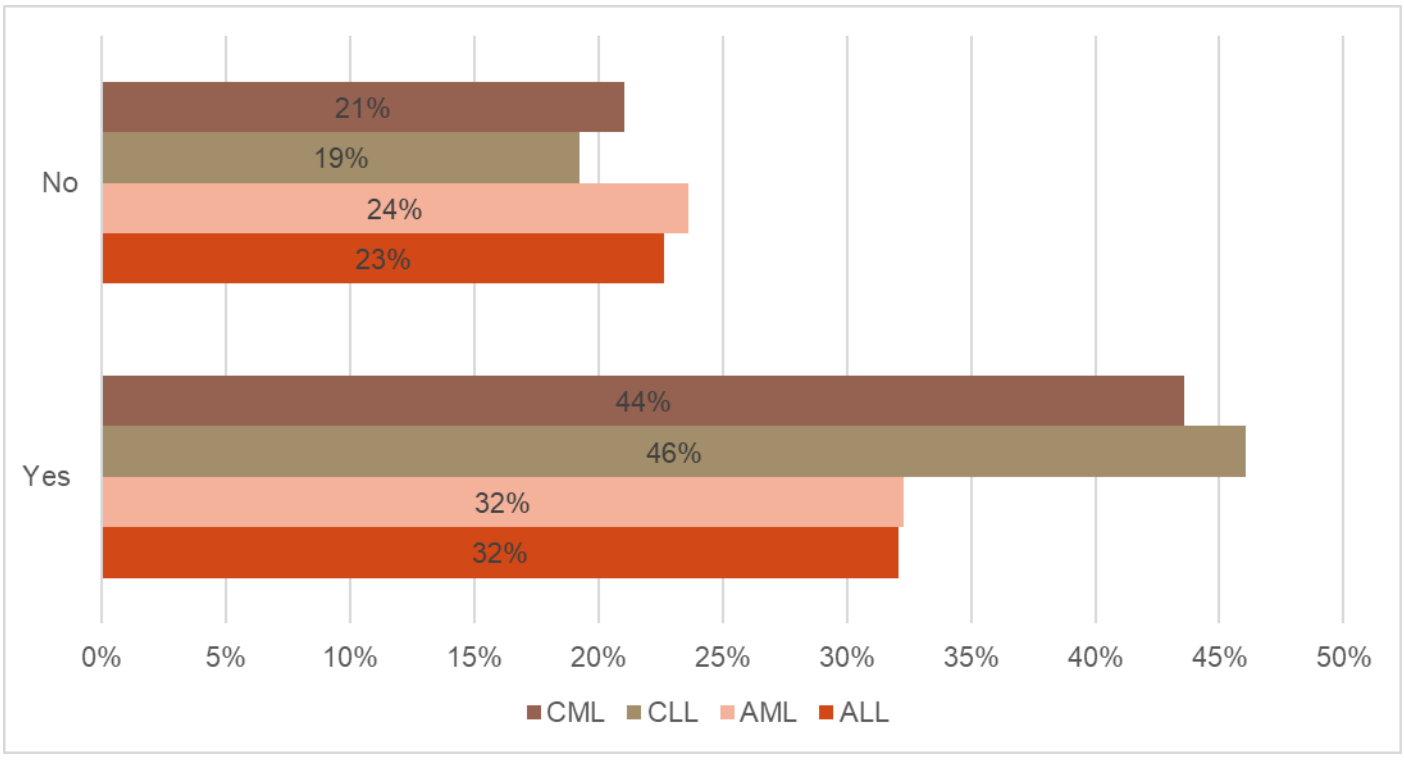
While 32% (n=180) of those with acute leukemia were not offered the opportunity and would have liked to have been alongside, 45% (n=80)stated that they did not know. For those with chronic disease, 45% (n=428) would have liked the opportunity and 35% (n=338) did not know. (Figure 53)

Figure 52: Q86. Were you given the option of participating in a clinical trial? (Patients)



(the missing % relates to the option don't know/can't remember)

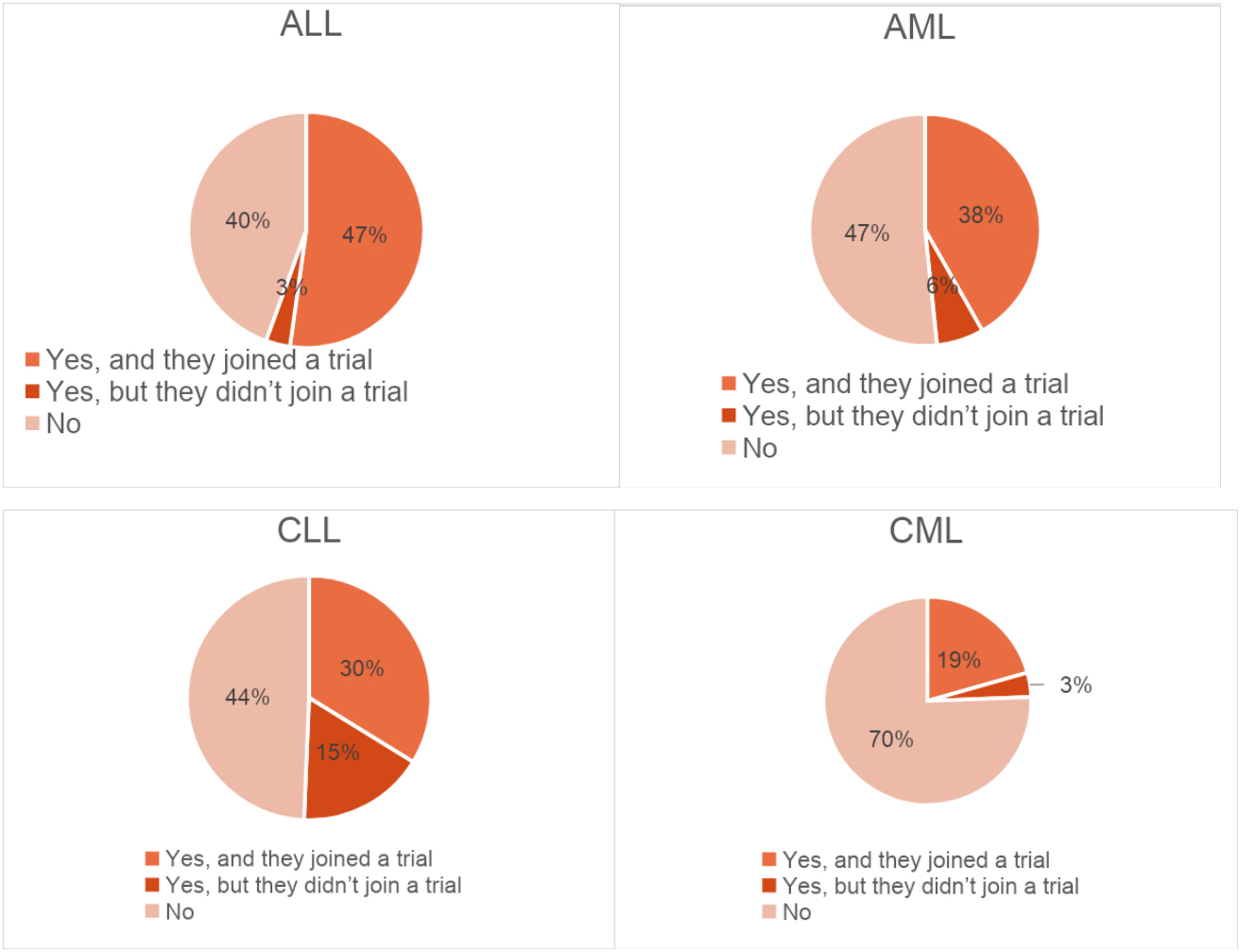
Figure 53: Q87. Would you have liked to have been given the option of participating in a clinical trial? (Patients)



Carers

From the carers survey, 37% (n=175) stated that the patient had been given the opportunity to participate and 70% (n=124) of those that did participate felt positive about the experience. (Figure 54)

Figure 54: Q33C. Was the patient / you given the option of participating in a clinical trial? (Carers)



With the clear importance of the impact of clinical trials on the treatment landscape, and the noted change in treatments that have been seen through the responses to this questionnaire, the findings around clinical trials is perhaps surprising here.

Further information should be made available for healthcare professionals and patients around clinical trials and their importance. The engagement between patients, healthcare providers, and support organisations may assist with this aspect of treatment and care.

7.7. Stem cell transplant

A stem cell transplant (SCT) can allow doctors to use higher doses of chemotherapy, sometimes along with radiation therapy, to treat leukemia. After these treatments, the patient receives a transplant of blood-forming stem cells to restore the bone marrow.[5]

Of those that responded to this survey, 47% (n=47) of ALL and 58% (n=180) of AML patients responded that they had received an SCT with most of these being allogenic (stem cells received from a donor). Only 2%

[5] Stem Cell Transplant for Chronic Lymphocytic Leukemia (cancer.org)

(n=15) of CLL and 3% (n=24) of CML had received an SCT. The majority of these (ALL 74%, n=35 and AML 86%, n=154) were at least a year ago, with just over 40% (n=134) being at least 5 years ago. (Figure 55)

The response rate from those currently undergoing SCT to this survey is lower than expected. This may be due to the significant impact on patients undergoing SCT since these patients may not have been able to complete the survey.

Figure 55: Q88. Have you ever had a stem cell transplant as part of your treatment for leukemia?

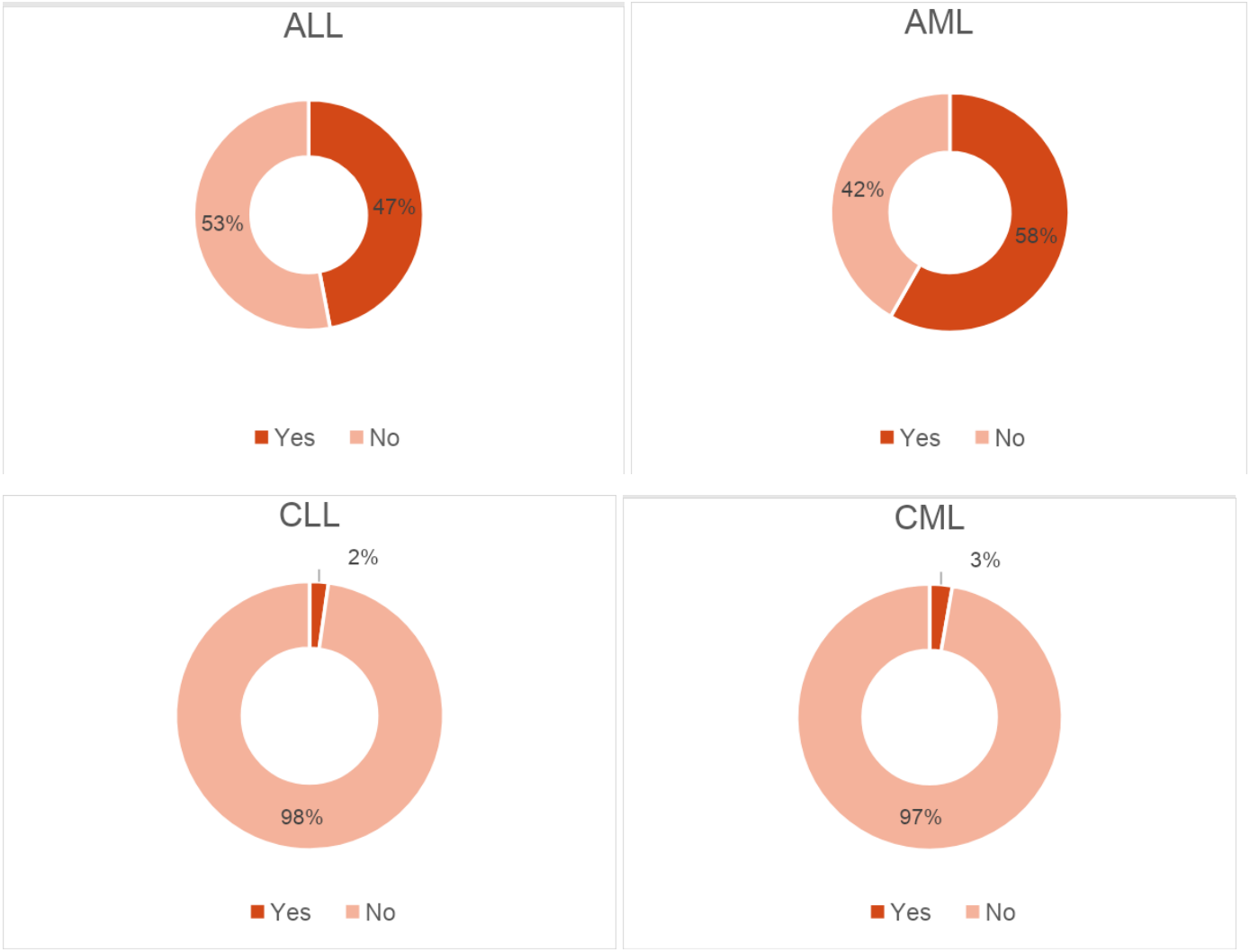
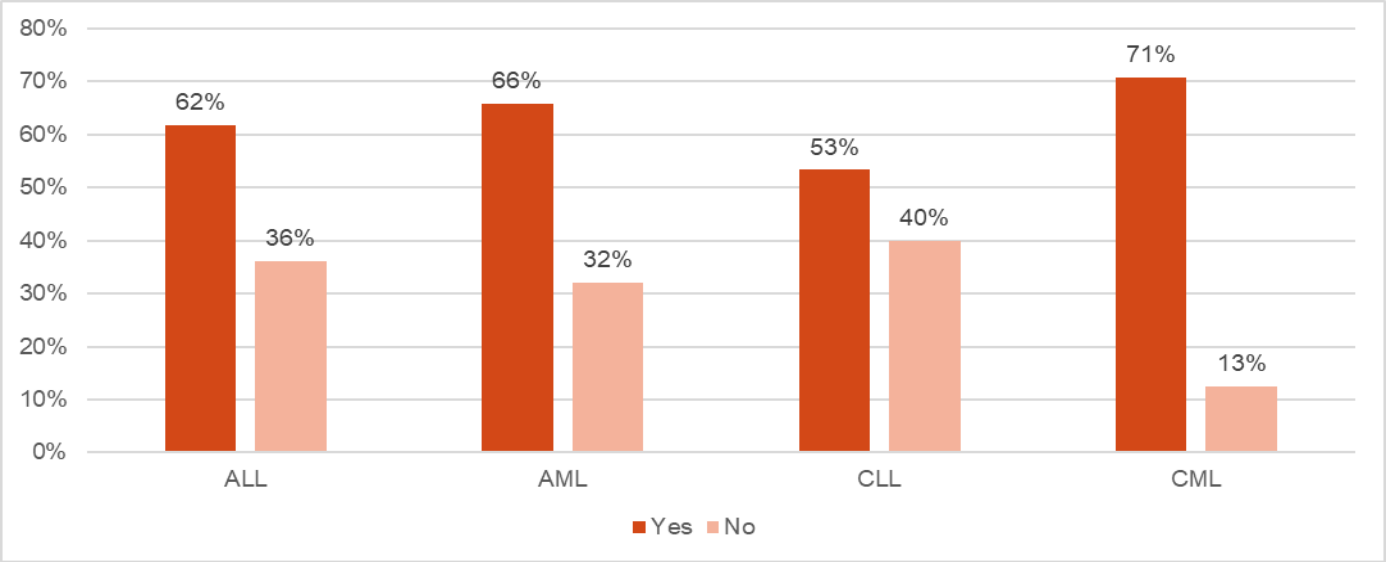


Figure 56: Q92. Did you develop complications following your stem cell transplant? (Patients)



Of those that received an SCT, around 2/3 had complications as a result. The most common complications were caused by either acute or chronic graft vs host disease. Graft vs host disease refers to the transplanted stem cells from the donor reacting against the cells of the host (patient who has had the transplant).

While 62% (n=252) of acute patients felt that they would consider it a positive step to undergo treatment that would enable them to have an SCT, this was much lower for those with a chronic disease (CLL 35%, n=399 CLL, and CML 30%, n=261).

7.8. Relapse

One percent (n=60) had had a relapse after SCT, although this was much higher for those with a chronic disease.

Of these, 83% (n=147) of those with AML had had to change their treatment plan once with 55% (n=5) of ALL patients having to change their plan either once (22%, n=2) or twice (33%, n=3). See Figure 57.

Figure 57: Q102. How concerned are you that your leukaemia will reoccur/that you will relapse? (Patients)

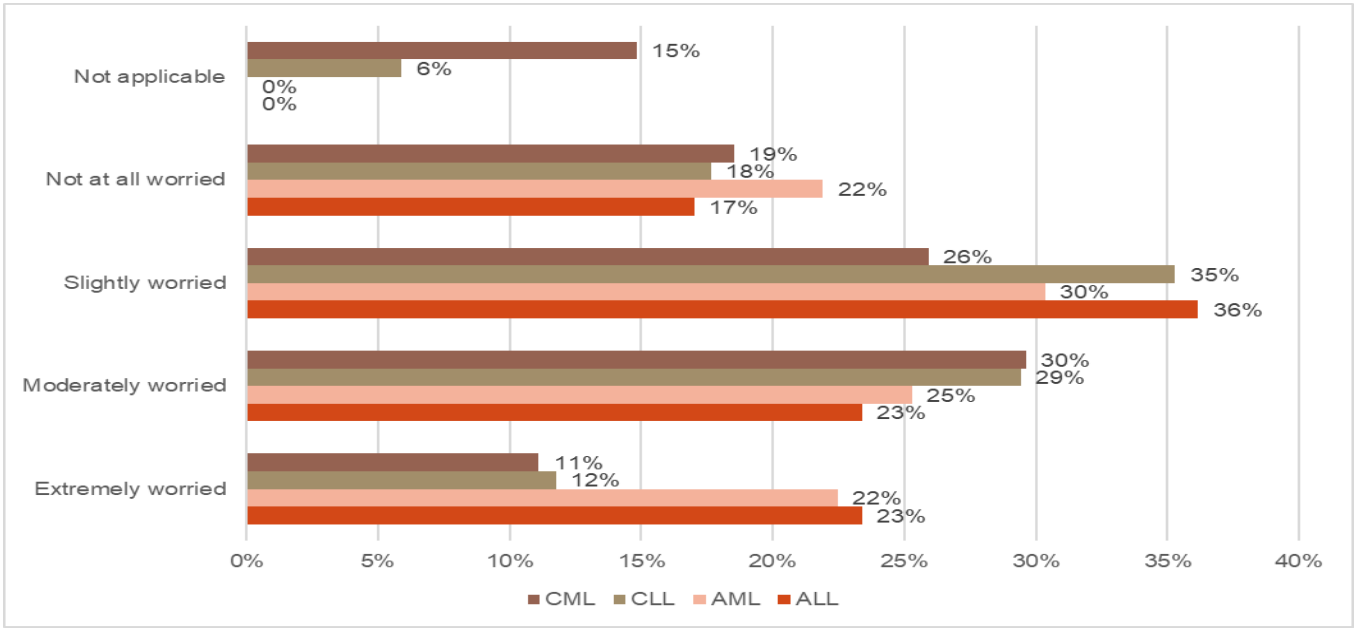
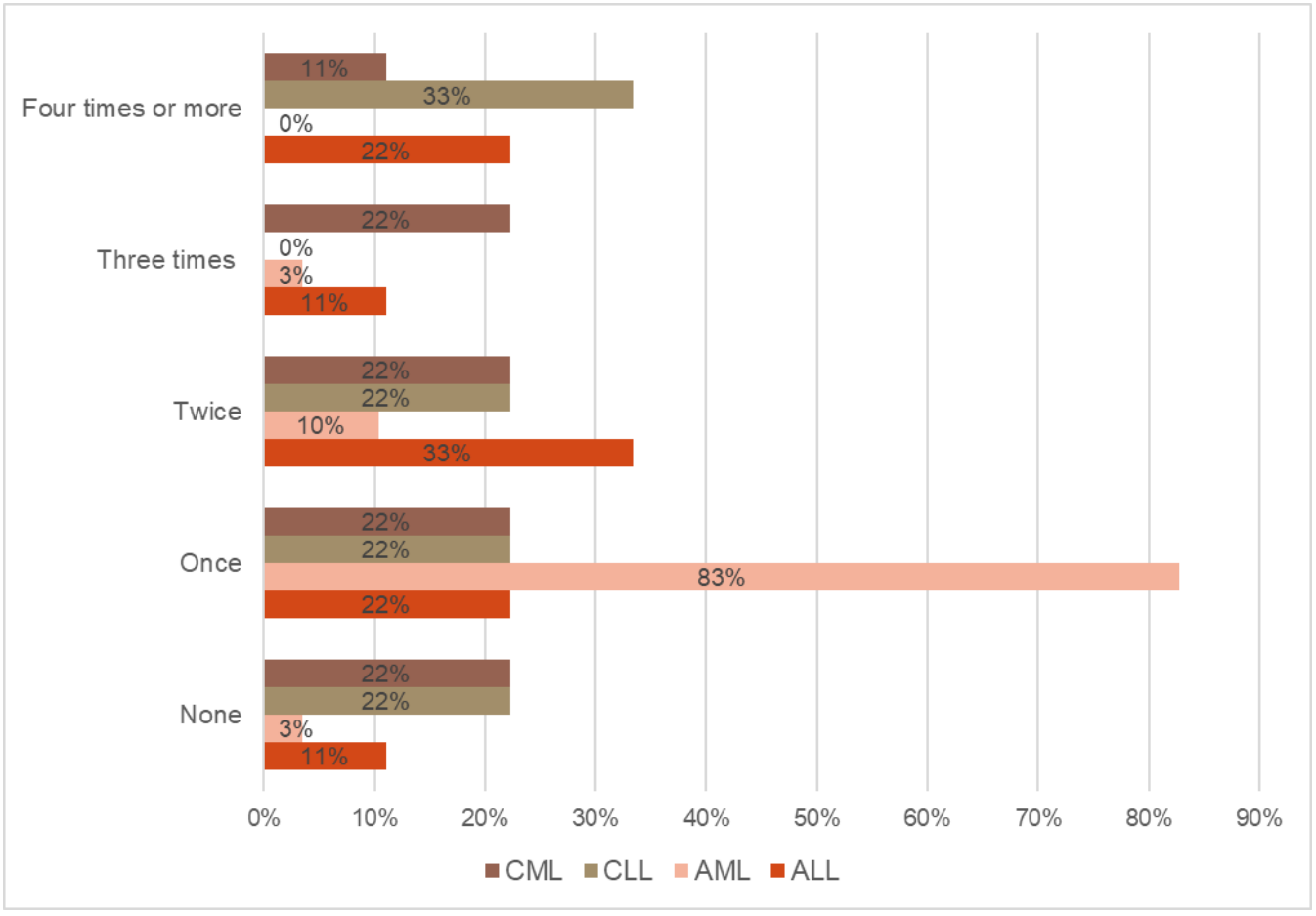
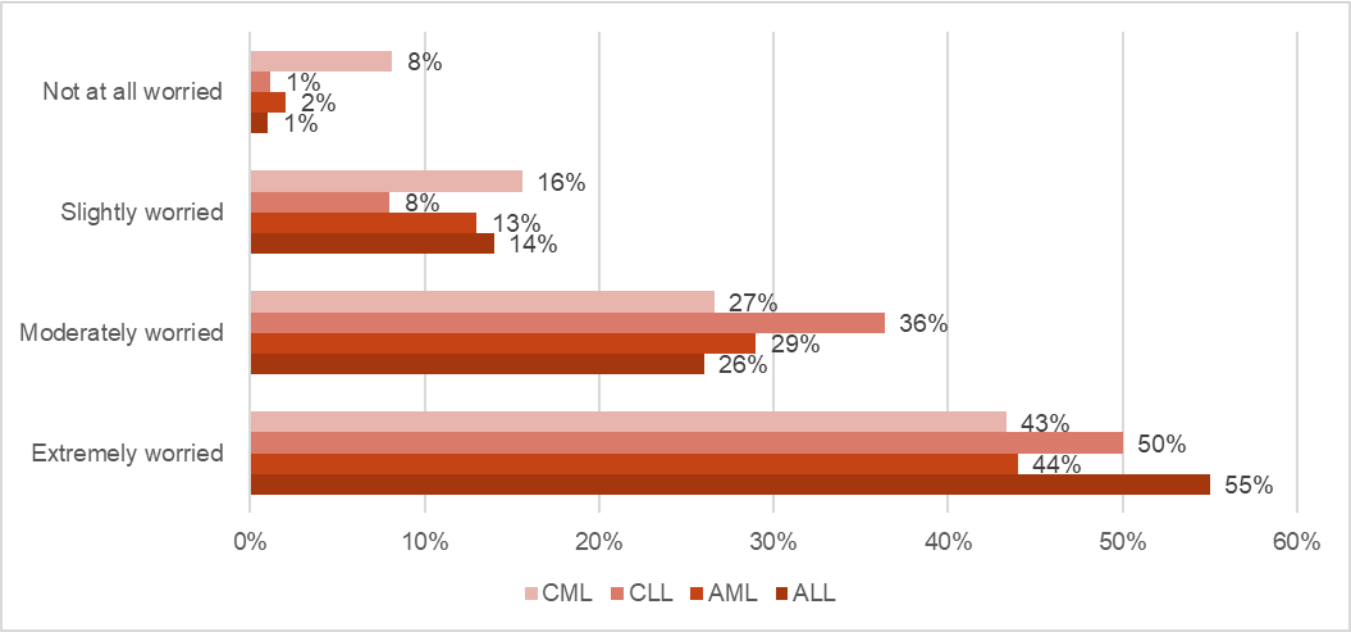


Figure 58: Q104. How many times have you had to change your treatment or treatment plan as a result of a relapse? (Patients)



From the carers survey, 76% (n=355) of carers stated that they were at least moderately worried that the patient would relapse, whereas only 46% (n=133) of patients felt the same way (see Figure 57).

Figure 59: Q37C. How concerned are YOU that the patient's / your leukemia will reoccur / that they will relapse? (Carers)



7.9. Fertility

It was much more likely that those with acute disease would have their treating doctor discuss their fertility with them (see Figure 60 and Figure 61). Those with acute disease are diagnosed at a much younger age and more likely to undergo more radical treatment regimens that will impact on their fertility. Almost half of those with CML (48%, n=165) and 74% of those with CLL (n=300) stated that a discussion about fertility was not necessary for them.

Figure 60: Q153. Did someone speak to you about the impact treatment could have on your fertility? (Patients)

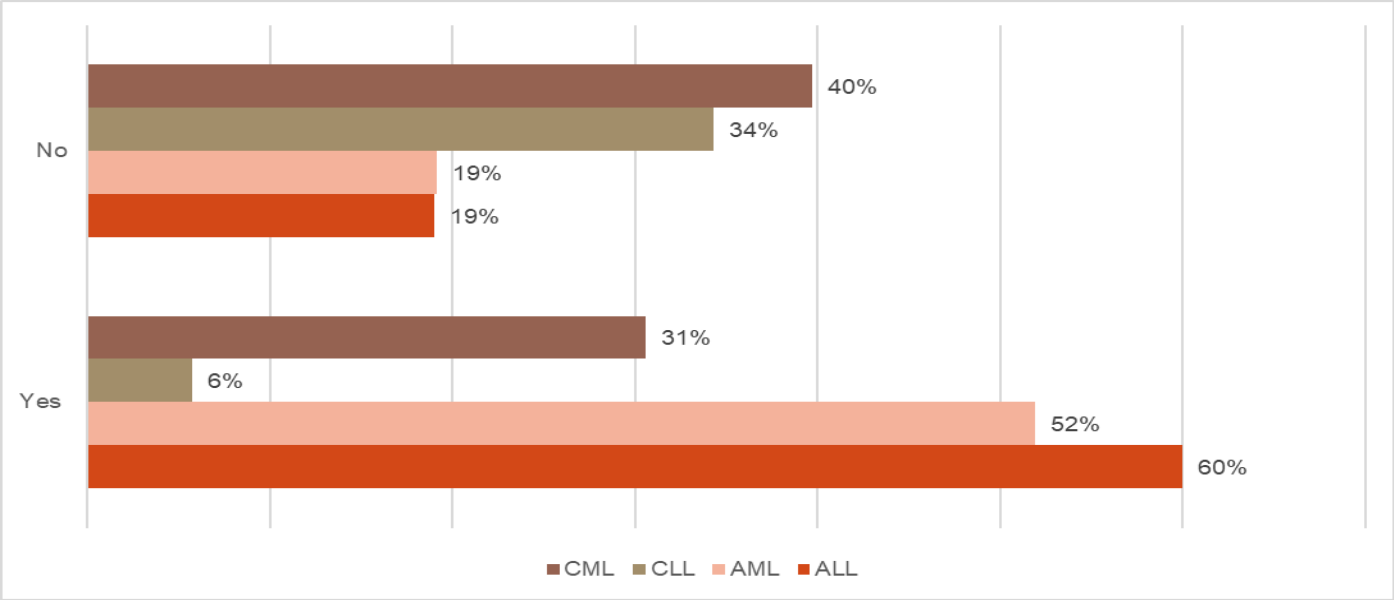
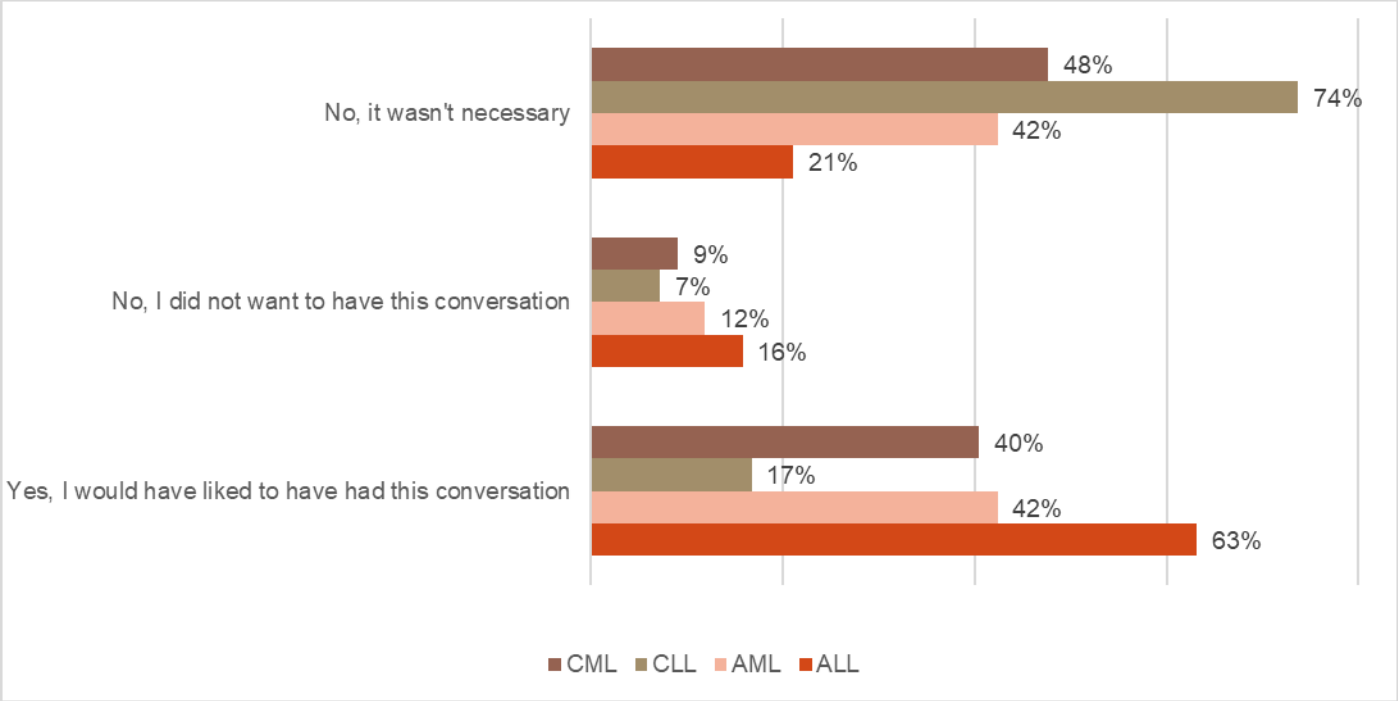


Figure 61: Q154. Would you have liked someone to have spoken to you about the impact treatment could have on your fertility? (Patients)



8. Preferences for new treatments

From the response to the question here, oral treatments would seem to be the preference (86%, n=2,274) with this being stable as the treatment of choice across all leukemia types (see Figure 62). This is much higher, however, for those with chronic disease (CLL 89%, n=1,070 and CML 91%, n=814) and lower for those with AML (65%, n=204). Interestingly and maybe surprisingly, a third of acute respondents (AML 34% , n=106 and ALL 33%L, n= 34) would prefer intravenous IV as their method of choice.

The question of potentially having a treatment free period or stopping treatment was asked from patients.

While 32% (n=126) of acute patients would be in favour of this, however 46% (n=177) did not know if they would consider it a positive. This may be because they would need to understand the implications before being able to adequately answer the question. In contrast, 52% (n=603) of CLL and 65% (n=556) of CML patients would consider this as a positive. (Figure 63)

Figure 62: Q189. If you were given the choice, which treatment methods would you prefer? (Patients)

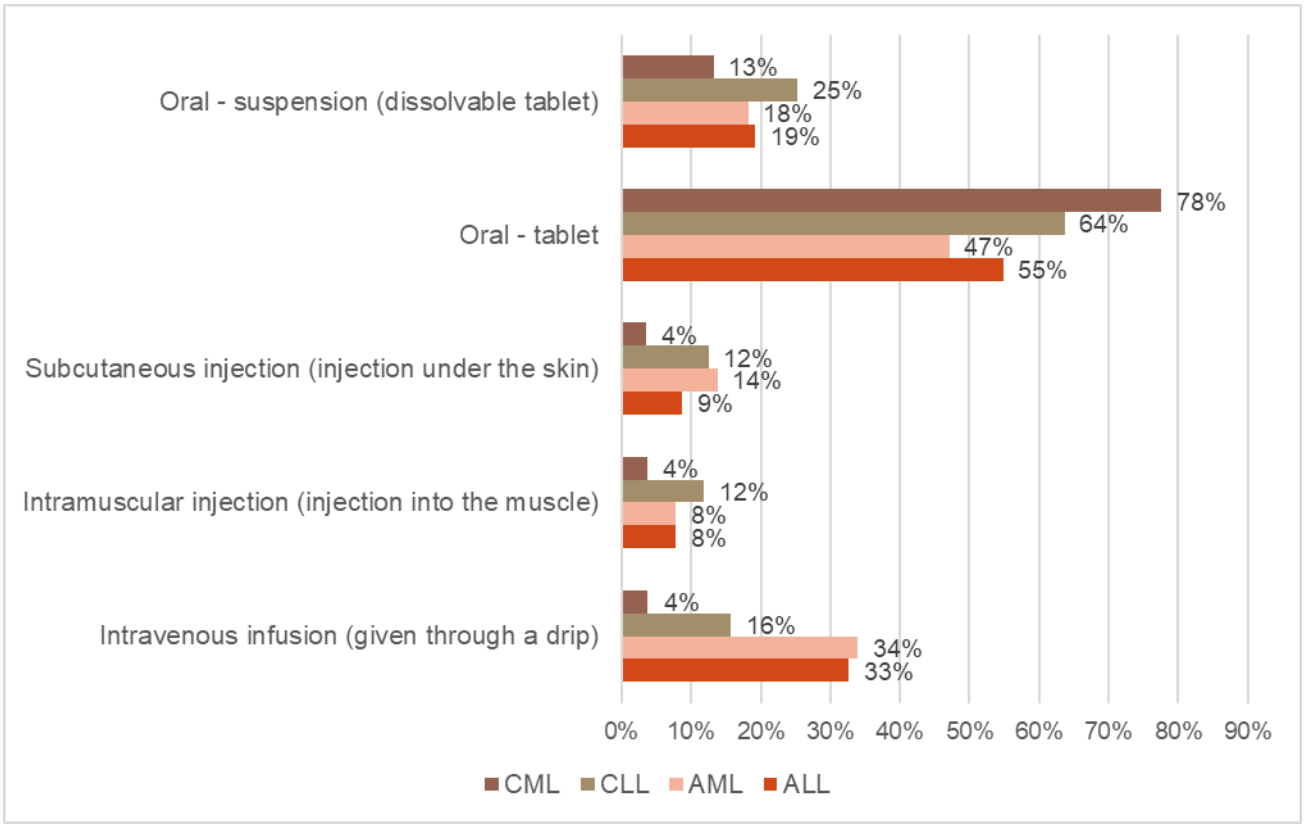
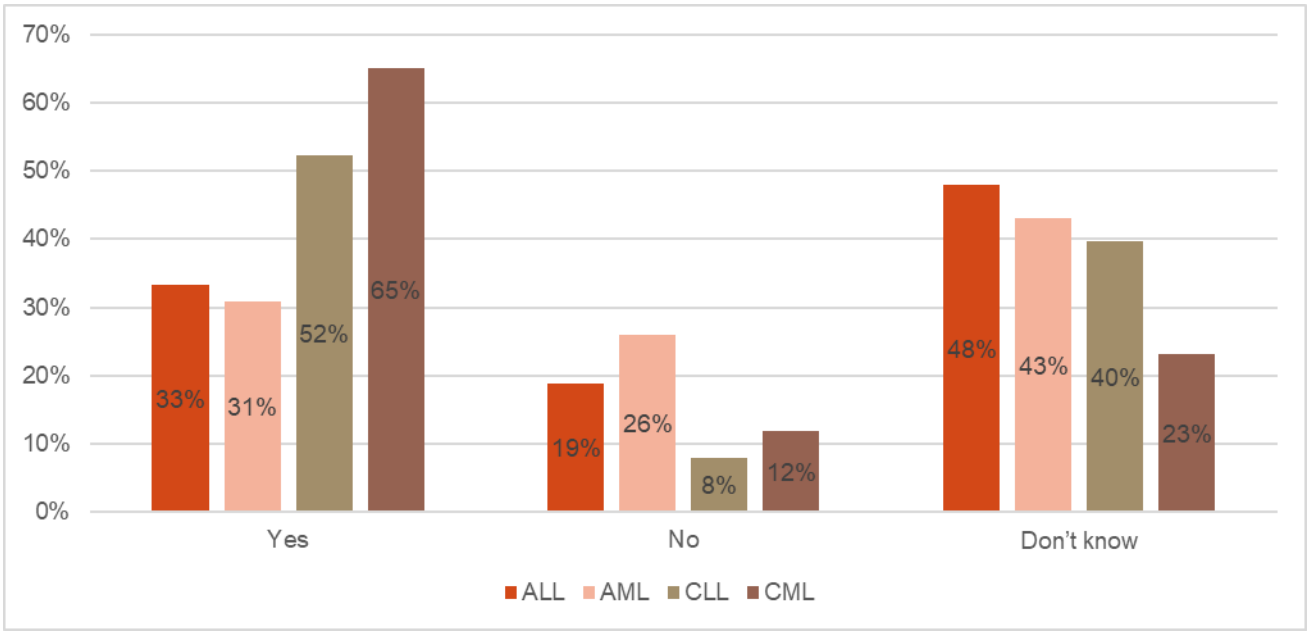


Figure 63: Q188. Would you consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether? (Patients)

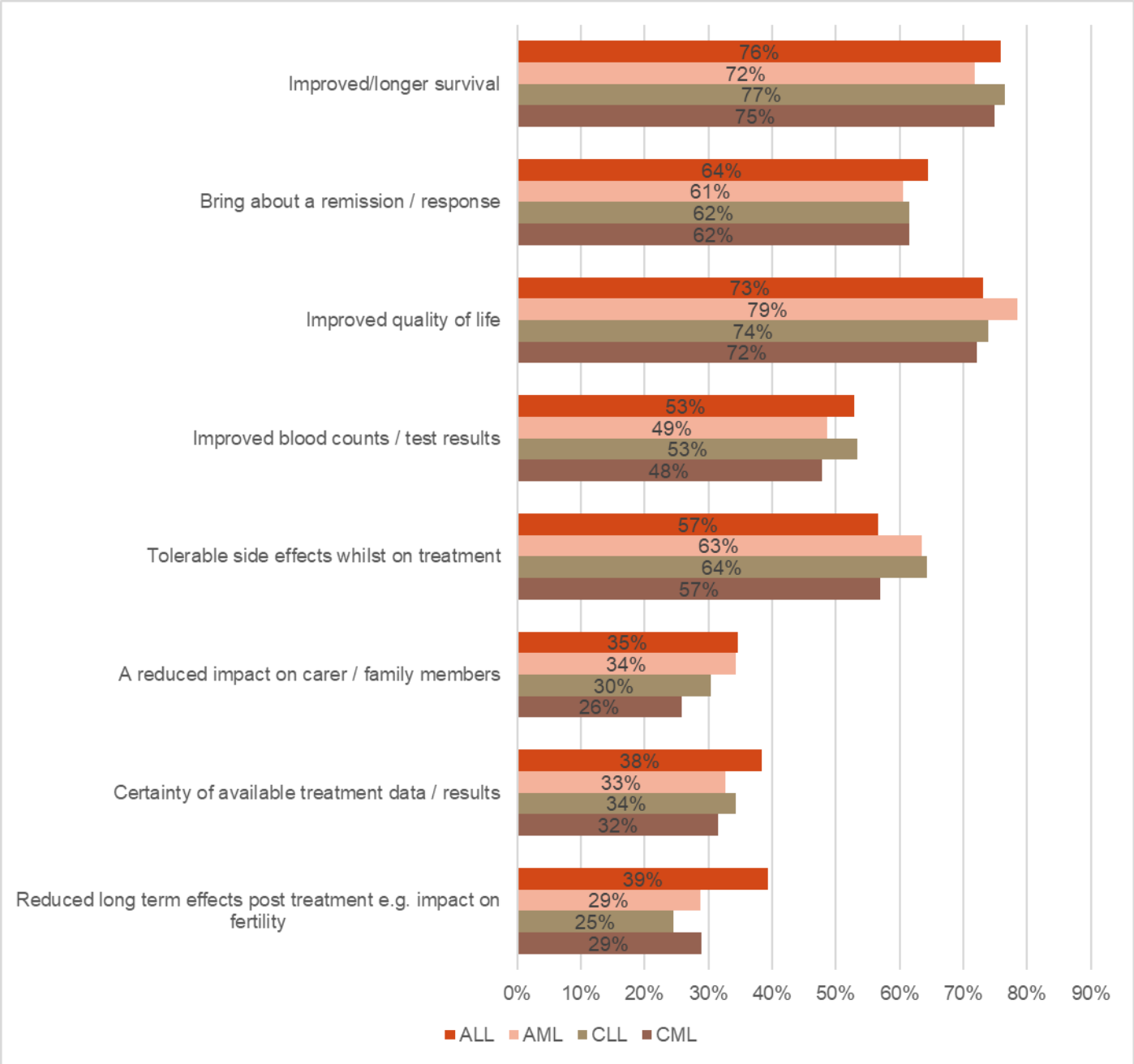


When asked about the key features that the respondents would like to see in a new treatment, 5 of the features suggested had 50% or more of patients feeling that they were important (see Figure 64).

An improvement in their length and quality of life were, perhaps unsurprisingly, seen as the most important features by the respondents (around 75% across all leukemia types). This was followed by a treatment having tolerable side effects and the treatment bringing about remission.

Just over half of patients would be willing to experience additional side effects, if it meant that their treatment was more effective (ALL 57%, n=55, AML 59%, n=179, and CLL 53%, n=608). However, only 30% (n=259) of those with CML would accept this. A large proportion of respondents stated that they did not know (around 30% for all leukemia types, slightly higher at 38%, n=440 for those with CLL).

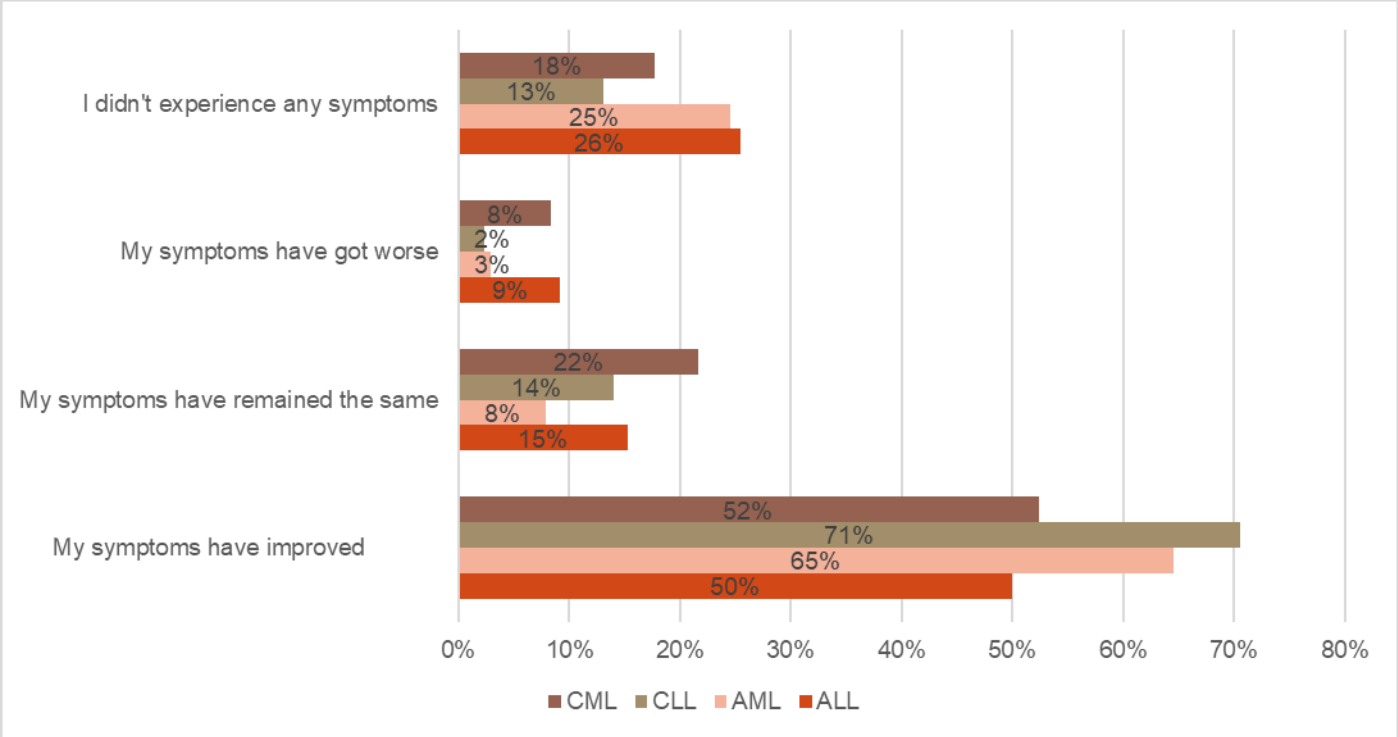
Figure 64: Q191. What do you consider to be important features of a new treatment? (Patients)



8.1. Impact of treatment on symptoms

When asked about the impact on their symptoms, 65%, n=197 of AML, 50%, n=49 of ALL and 52%, n=453 of CML patients felt that their symptoms had improved. This was slightly higher with those with CLL (71%, n=453). Only 3% (n= 9) AML and 9% (n=9) ALL patients felt that their symptoms had worsened. This was similar to the chronic patients, where 2% (n=15) CLL and 8% (n=72) CML patients felt that they had worsened. The findings here are similar to Leukaemia Care survey of 2018 (UK-specific survey), where 78% felt their symptoms had improved and only 2% felt they had worsened. (Figure 65)

Figure 65: Q81. What impact has your most recent or current treatment had on the symptoms that you were experiencing? (Patients)



8.2. Treatment side effects

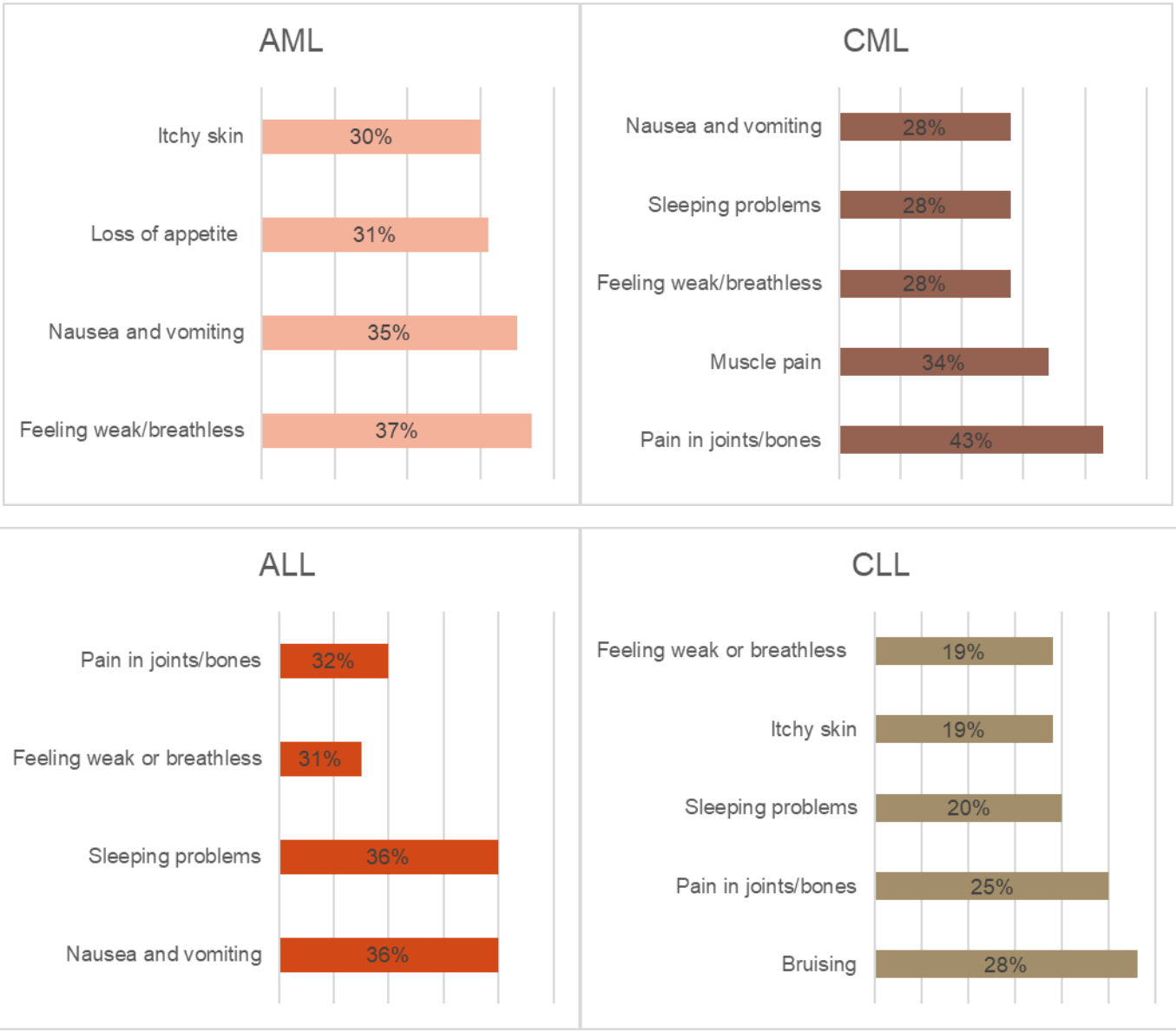
All treatments have the potential for side effects, and it is important to monitor the effects of the treatments, both in terms of efficacy and additional impact on patients through any side effects experienced.

Patients

Fatigue was the most common side effect noted by respondents (50% for all respondents; ALL 57%, n=59, AML 60%, n=186, CLL 44%, n=296, and CML 55%, n=484). The next most common side effects can be seen in the graphs in

Figure 66.

Figure 66: Q82 What side effects have you encountered as a result of your most recent or current treatment? (Patients)



In the Leukemia Care survey of 2018, fatigue was the most prevalent symptom , although then 57% reported this.

Figure 67: Q82. What side effects have you encountered as a result of your most recent or current treatment? (Patients)

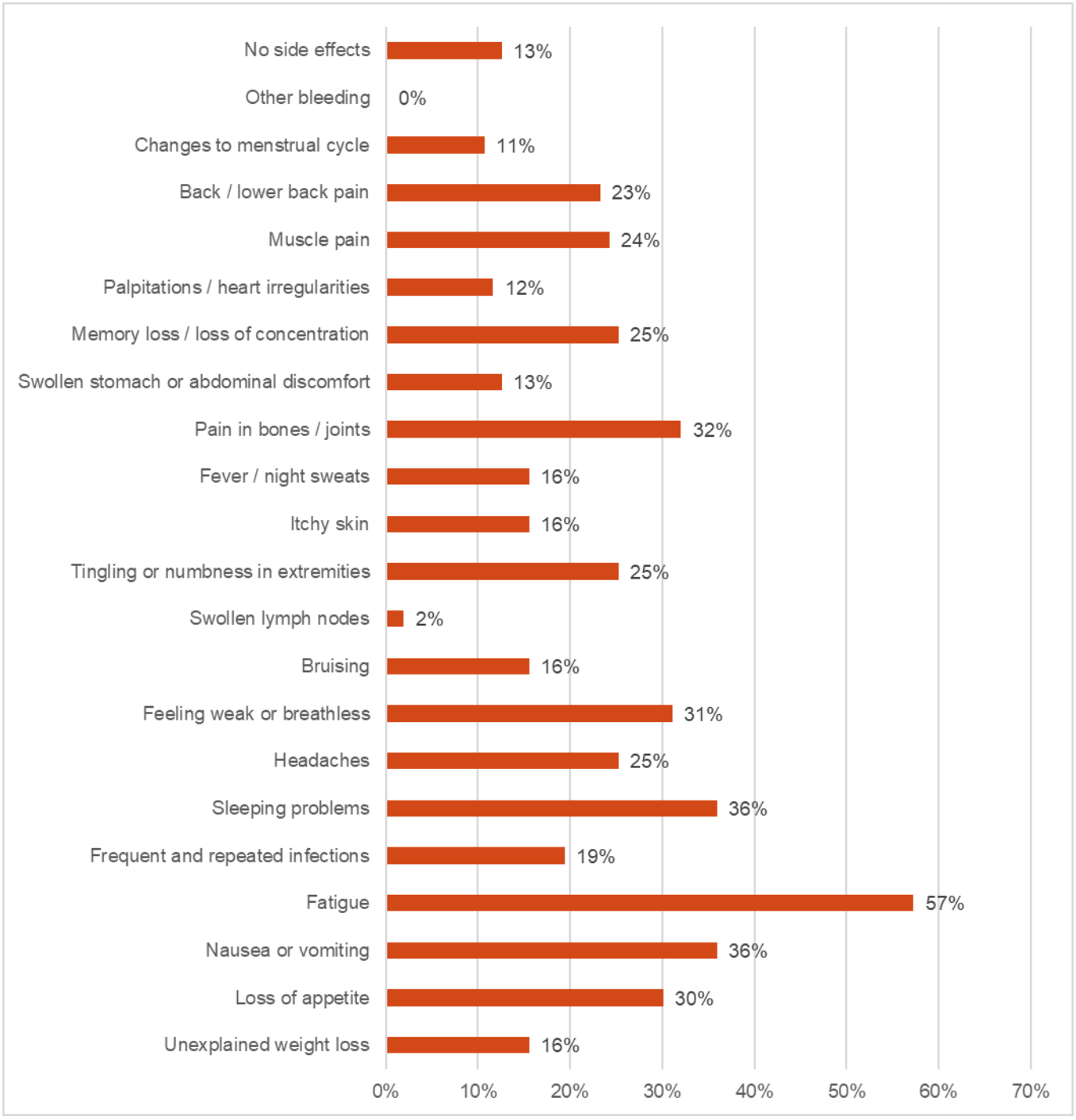
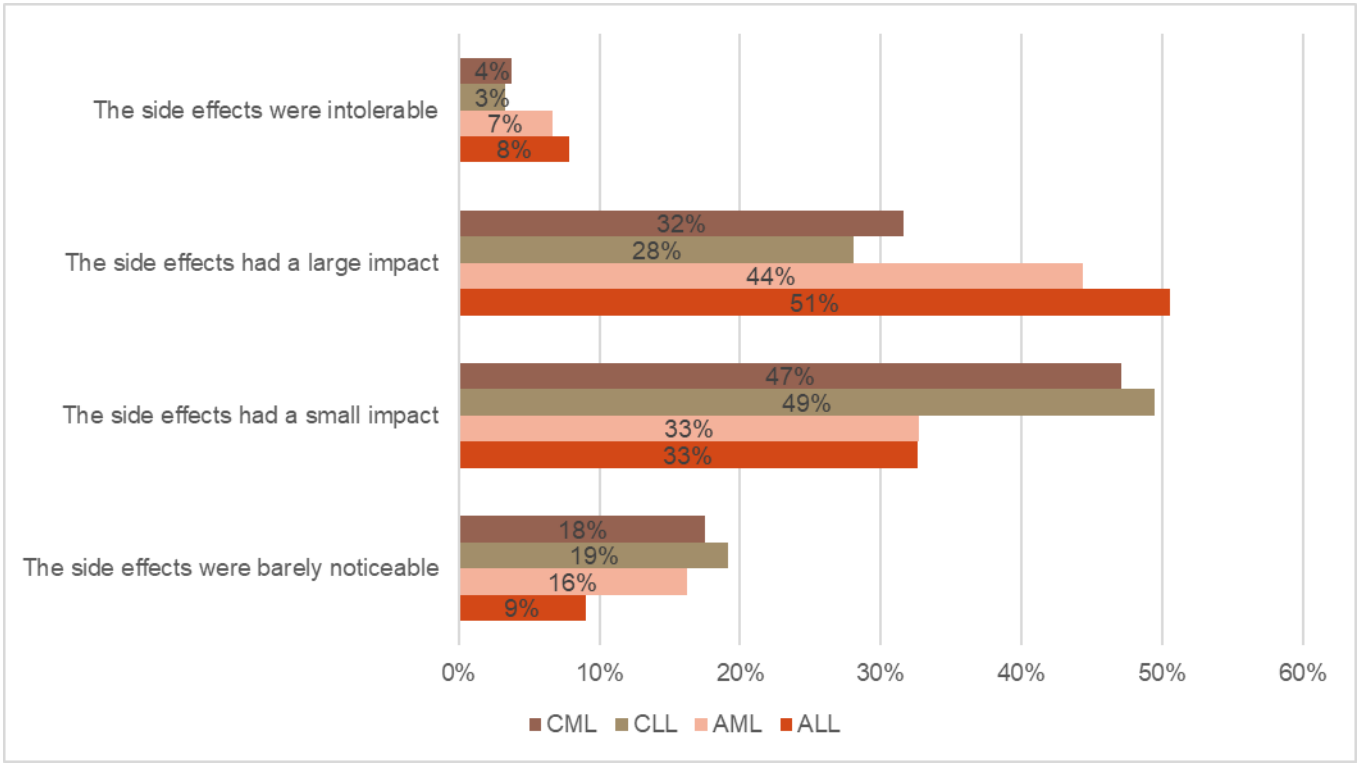


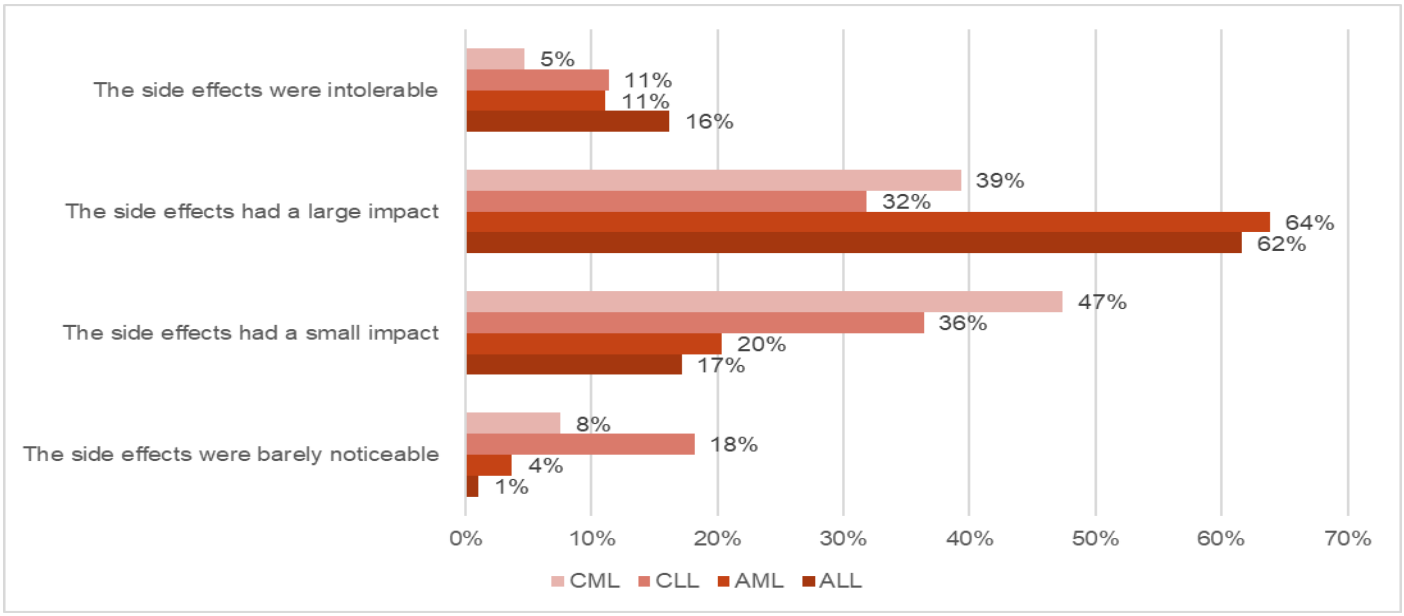
Figure 68: Q84. Overall, how would you rate the impact of the side effects of your most recent or current treatment? (Patients)



Carers

Overall, 63% (n=130) of carers noted that side effects had a large impact on acute patients with 14% (n=28) stating that these were intolerable. This was very different for those with chronic disease. Only 18% (n=16) of those with CLL reported that the side effects of treatment were barely noticeable, while 32% (n=28) with CLL and 39% (n=68) with CML stating that the side effects on them had a large impact. (Figure 69)

Figure 69: Q31. Thinking about their most recent or current treatment - overall, how would YOU rate any negative impact of the side effects on the patient? (Carers)



8.3. Management of Side Effects

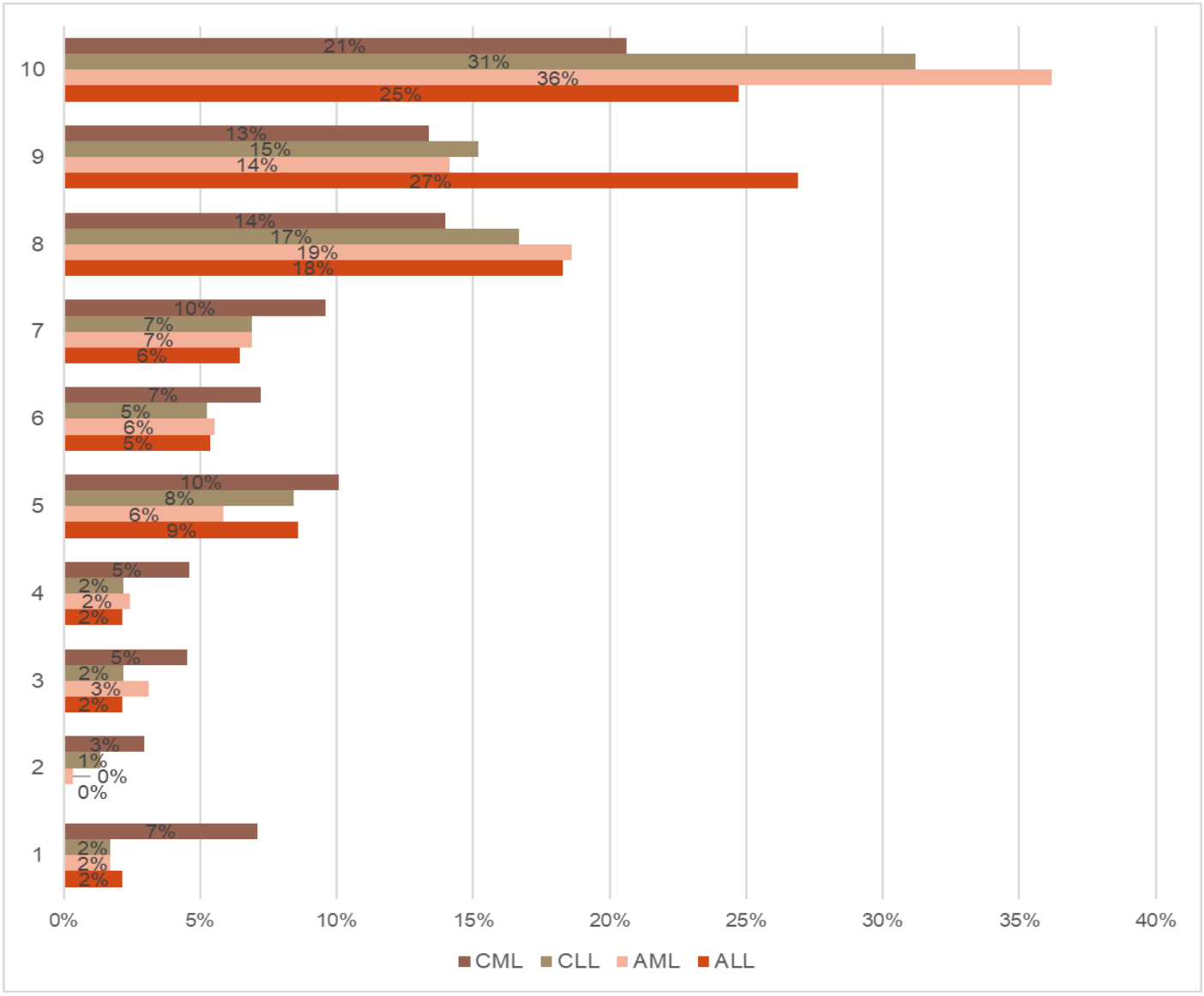
Patients and carers were asked to rate the way that their side effects had been managed by their healthcare professionals, on a scale of 1 (very dissatisfied) to 10 (very satisfied) (see Figure 70).

Overall, patients felt that their side effects had been managed well: 66% (n=1,262) patients rating their care as 7/10 or higher with only 21% (n=412) rating it 5/10 or below. This was very similar across both acute leukemia types, although these are slightly lower for CLL and CML.

The results from the carers survey were similar with 60% (n=278) rating the management of the patients' side effects as 7/10 or better, again these were slightly lower for those caring for someone with CML (53%, n=92).

This, on the whole, is a very positive finding with respect to treatment side effects and how they are managed by healthcare professionals. However, side effects and disease symptoms are difficult for patients of both acute and chronic leukemia.

Figure 70: Q85. Overall, how would you rate the way the physical side effects of your most recent or current leukemia treatment have been managed by your healthcare professionals? (Scale 1, very dissatisfied – 10, very satisfied)



8.4. Summary

All of the responses here suggest that enhanced collaboration between healthcare providers, researchers, and those involved in supporting patients would lead to better outcomes for patients and the wider blood cancer community across the globe.

A minority of patients research their diagnosis and treatments themselves, and only a quarter are offered a choice of treatments. Less than half of both patients and carers felt that patients were completely involved in decisions around their treatment and care.

Different treatment types are reported as being most common in ALL and AML and these have changed over time. Intravenous medication (as an inpatient) was the most common treatment routes with SCT being the most common current treatment, although chemotherapy was the most common recent treatment. Oral treatments are relatively common; however these are also the most popular route requested for new treatments.

Patients and carers wanted to see improved length and QoL from new treatments. With the QoL being seen as important from this, treatment and care that focuses on both managing and curing their leukemia as well as managing their symptoms and side effects is paramount. Interestingly, only about half noted that their symptoms improved through treatment, however side effects were experienced by most patients and overlapped with symptoms.

More can be done around clinical trials as only around half were offered a trial, but of interest a significant number did not know whether they would want to take up a trial. This suggests the need to improve awareness and information around trials.

Information and support were offered to more patients at this stage, but there were still significant gaps suggesting additional scope for improvement.

All of this would suggest that improved collaboration between researchers, healthcare providers, and support organisations would improve the treatment landscape for patients.

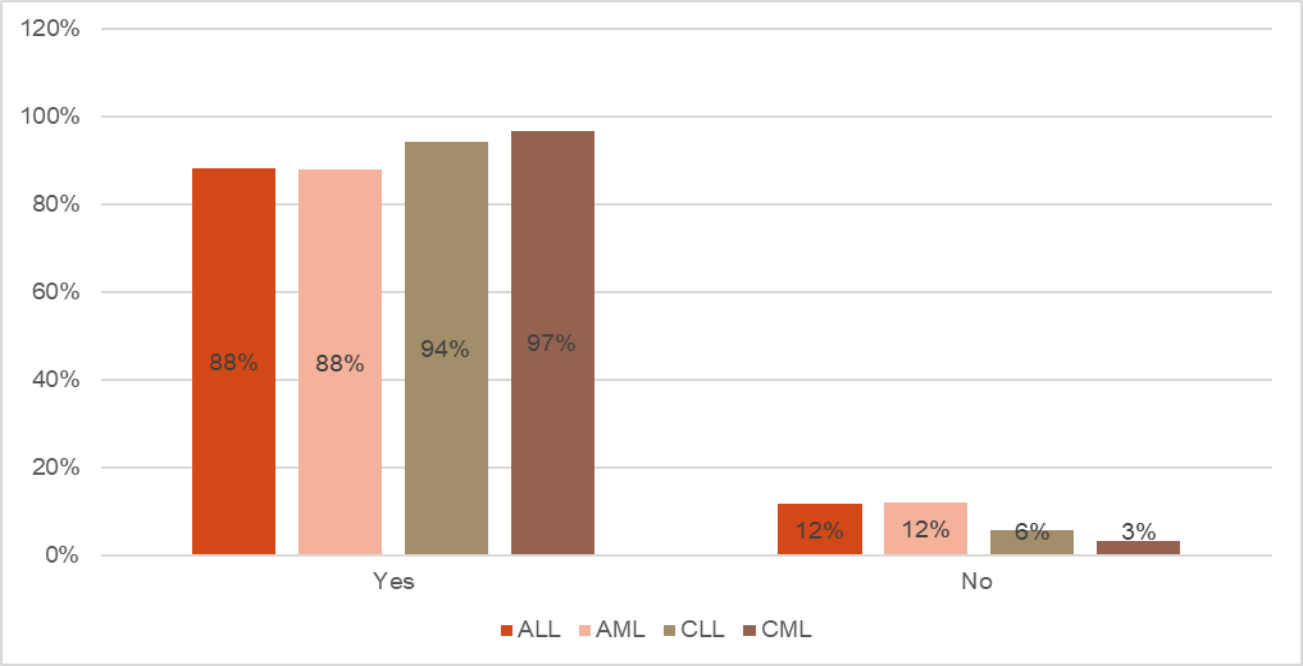
9. Ongoing monitoring

This section of the questionnaire focused on the tests and regular monitoring that patients received.

Acute respondents (88% [n=361]) stated that they were currently undergoing regular testing/monitoring for their leukemia with this slightly higher for those with a chronic form (94%, n=1,123 CLL and 97%, n=855 CML).

A similar number reported this through the carer survey, with over 90% of those with ALL, CLL and CML undergoing regular testing. This was slightly lower for those with AML (79%, n=85).

Figure 71: Q105. Are you currently undergoing regular testing or monitoring for your leukemia?



Patients

Seventy-three percent (n=263) of those with acute leukemia and 63% (n=1,254) of those with chronic leukemia stated that the results of these tests were always explained to them with a further 25% (n=622) noted that these were only sometimes explained.

Interestingly, only around half of respondents stated that they did not have to ask for the test results to be explained to them (ALL 54%, n=45, AML 51%, n=134, CLL 52%, n=510, and CML 48%, n=374). When they did receive an explanation, 67% (n=231) of all acute respondents stated that they understood this, however the percentage was slightly lower for CLL (54%, n=529) and CML (62%, n=484).

Eighty-three percent (n=5) of ALL and CML (n=62) respondents and 72% (n=102) with CLL stated that they would have liked an explanation if one was not provided as opposed to only 58% (n=7) of those with AML.

Figure 72: Q107. Are the results of your test/s explained to you? (Patients)

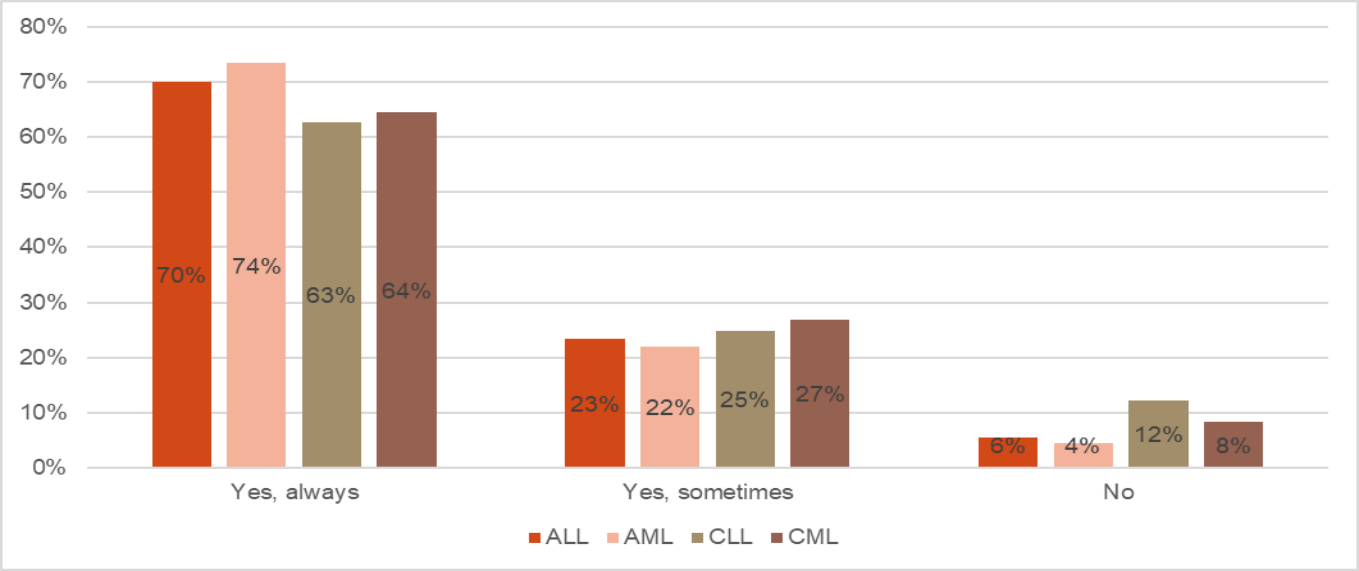
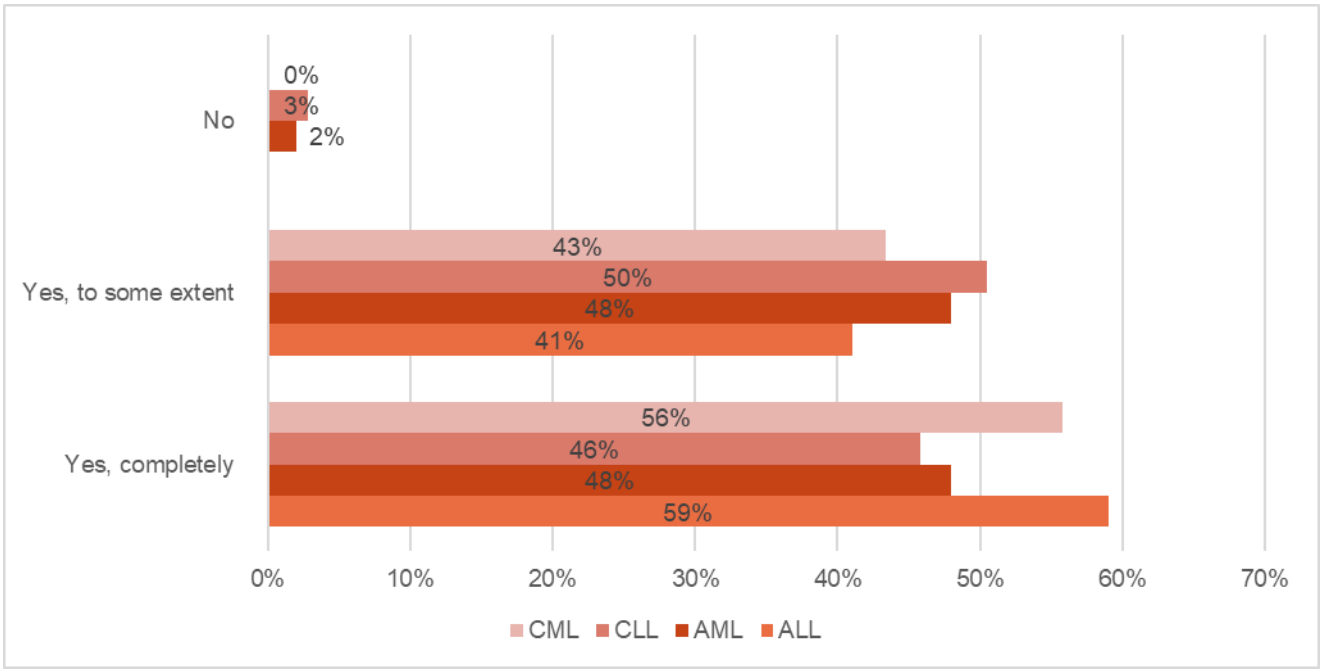


Figure 73: Q42. Do you understand the explanation you are given? (Patients)



Carers

Overall, 74% (n=370) of those that responded to the carers survey noted that the test results were explained to them, at least at some time. However, the majority stated that they had to ask for this to be done at least sometimes (62%, n=229). When given an explanation almost all understood this at least to some extent (98%, n=360).

Figure 74: Q40C. Are the results of the patient's / your test's explained to you by a healthcare professional? (Carers)

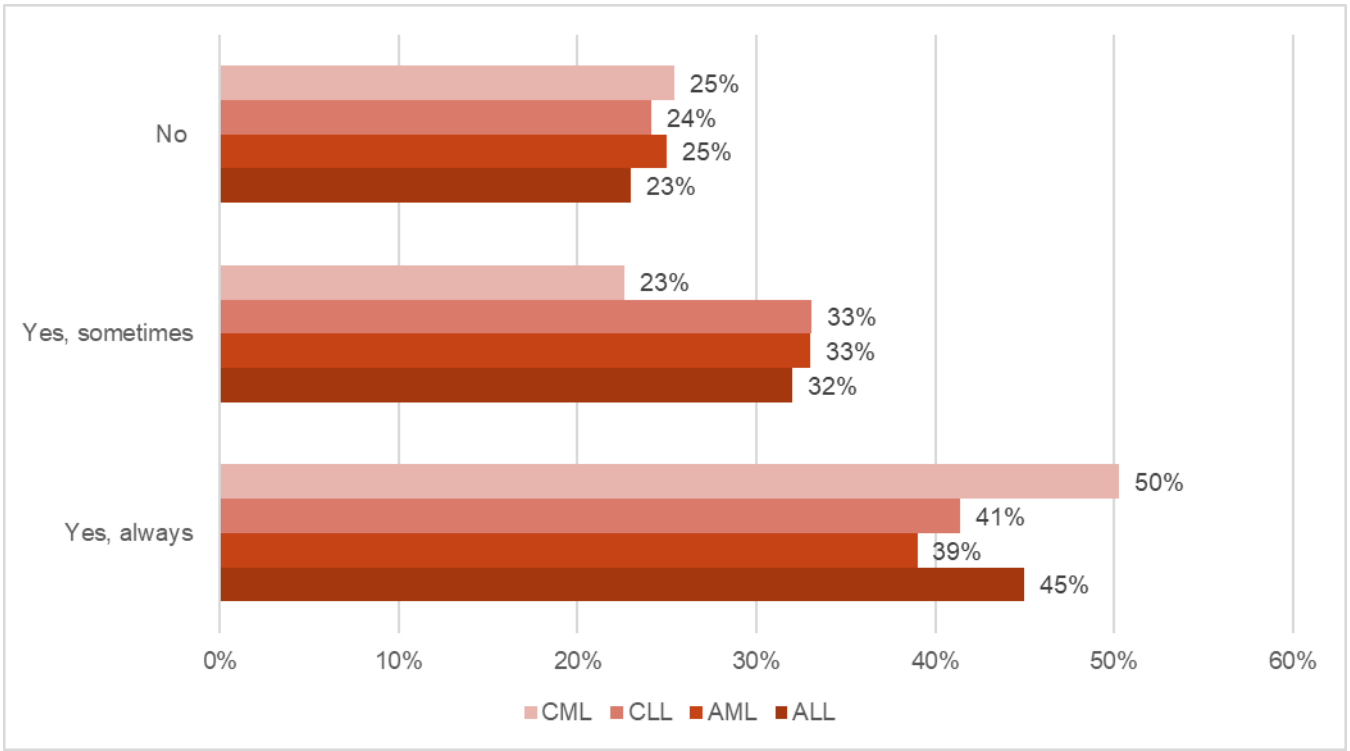
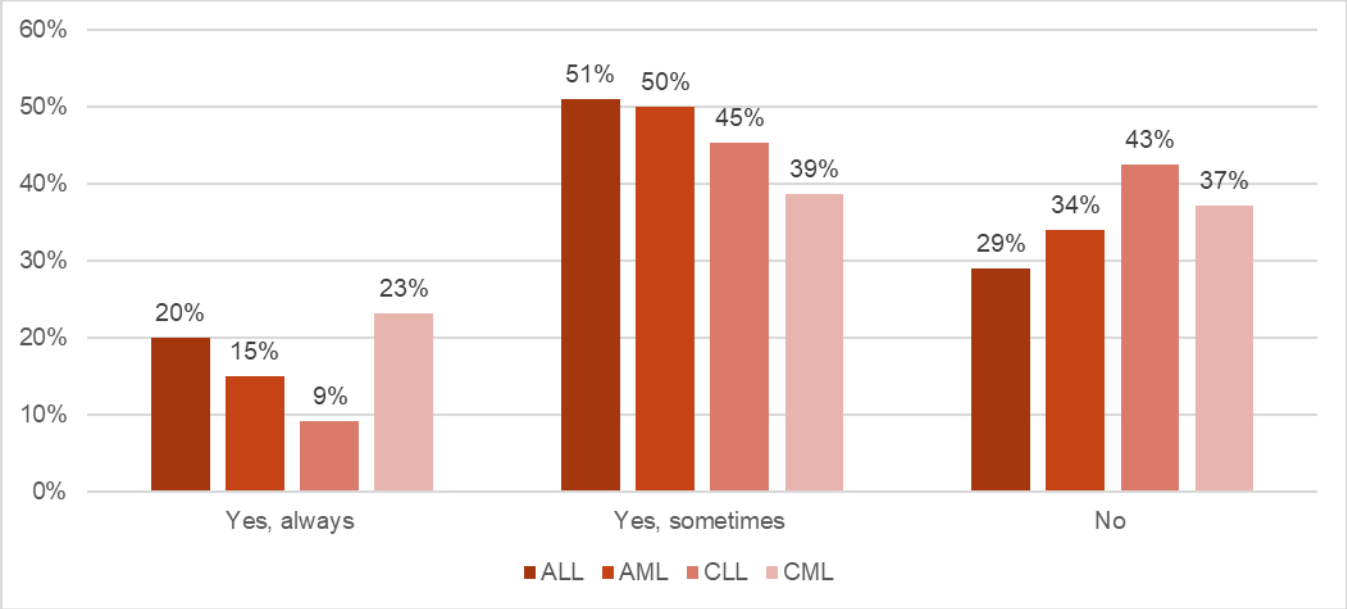


Figure 75: Q41C: Do you have to ask for the results to be explained? (Carers)



Slightly more ALL respondents (77%, n=69) and those with CLL (75%, n=846) and CML (78%, n=662) than AML respondents (66%, n=179) reported that they were able to access their own results.

Lastly in this section, when asked about how anxious they were whilst waiting for their results, the responses were mixed. Respondents were asked to rate how worried they were on a scale between 0 and 10, where 0 represented not being at all worried/anxious and 10 extremely worried/anxious. Half of ALL patients (50%, n=44) rated their anxiety as 7 or above out of 10, with 45% of those with AML (n= 110) and CML (n=331) rating this the same. This was slightly less for those with CLL (37%, n=379). The responses here would suggest that there is a high level of anxiety in this patient population.

Carers were more likely to report feeling anxious while waiting for test results than patients themselves. The results between ALL and AML for carers were not significantly different. The carers of those with chronic leukemia reported slightly lower levels of anxiety.

Figure 76: Q106. How worried / anxious do you feel when waiting for the results of your regular testing/monitoring? (Patients) 0 is not at all worried / anxious and 10 is extremely worried / anxious

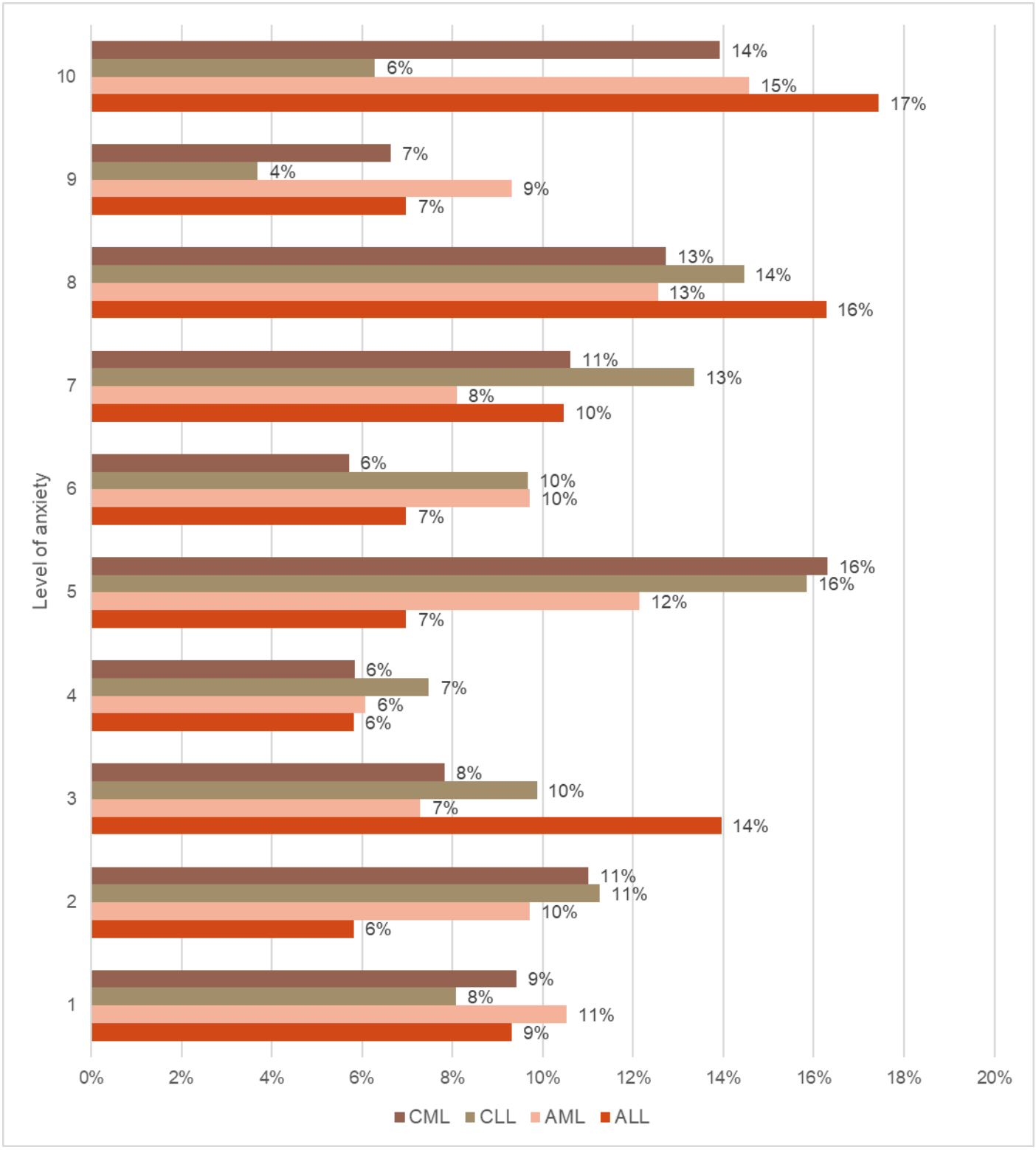
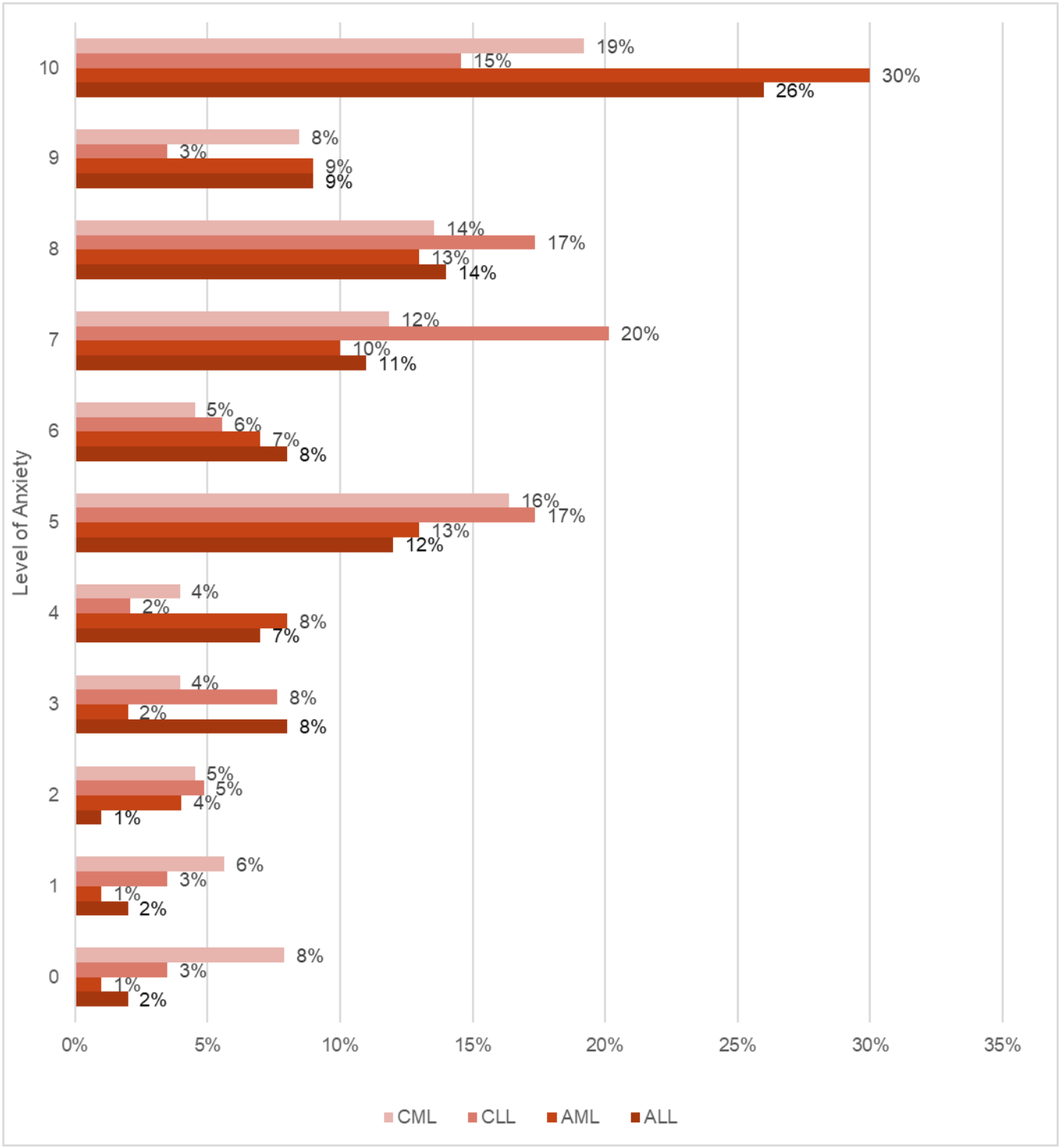


Figure 77: Q39C. How worried / anxious do YOU feel when waiting for the results of (their) regular testing / monitoring? 0 is not at all worried / anxious and 10 is extremely worried / anxious (Carers)



It is important for patients to be kept fully informed of the current situation with their leukemia, particularly as this can be a life-threatening illness and a progressive disease with a changing symptom profile. Ongoing and regular testing with the results fully explained to each patient is a good way to keep patients involved and up to date with their disease progress, and will be likely to improve their mental as well as physical health.

10. Living with Leukemia

Leukemia can have a profound impact on those diagnosed with the disease and their carers. It is important in particular to identify and understand this impact to be able to provide appropriate healthcare and comprehensive support. This section of the questionnaire asked respondents about their day-to-day life living with leukemia from physical and emotional wellbeing to the impact on their work, education, and relationships.

10.1. Quality of Life

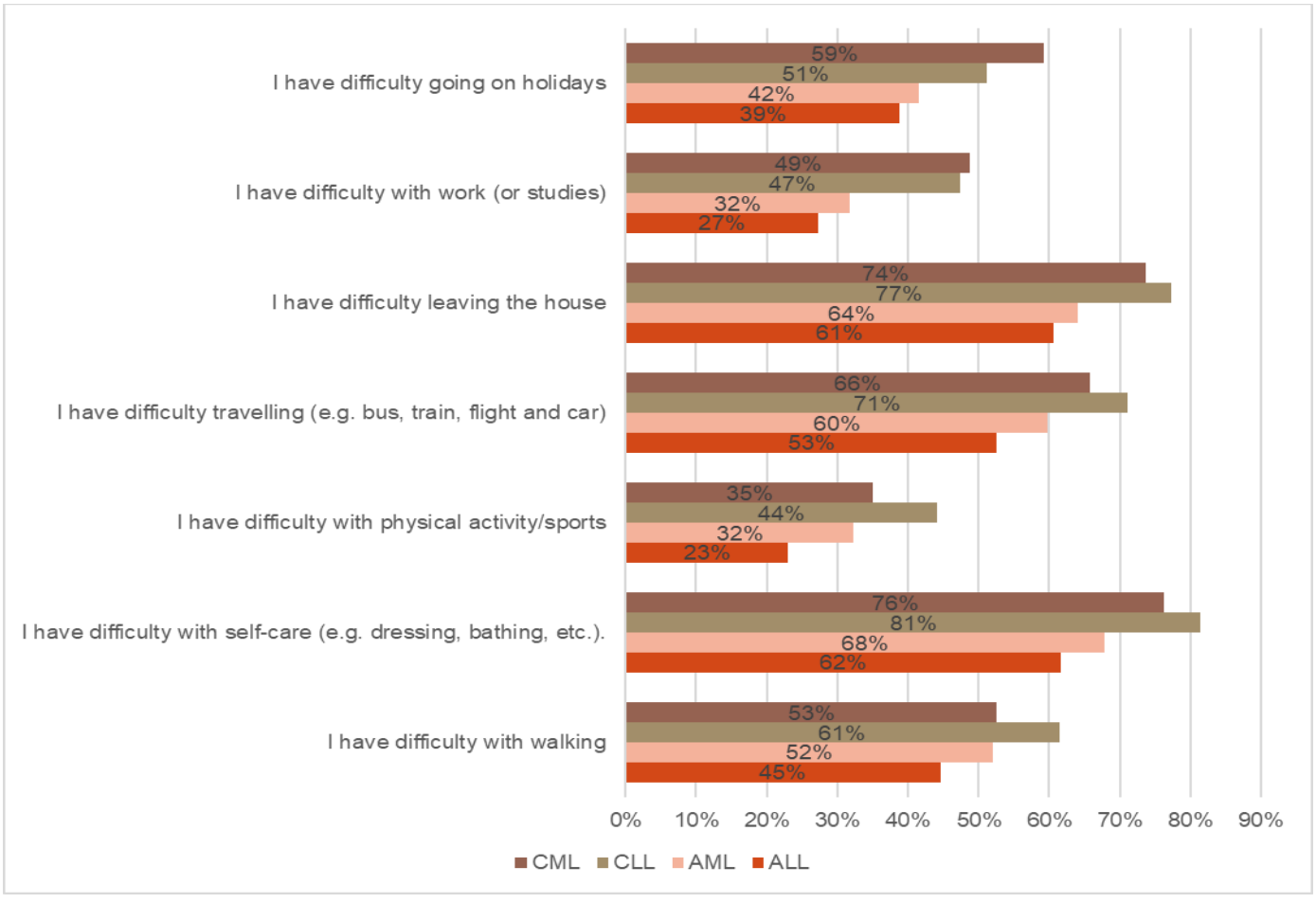
10.1.1. Physical Wellbeing

Patients

The responses relating to the physical impacts on respondents present a mixed picture, although the results are broadly similar for the acute types of leukemia (ALL and AML). Most respondents with acute leukemia had little difficulty physically (see Figure 78 and Figure 79) with self-care (66%, n=269) or leaving the house (63%, n=254), with around half stating that they had no trouble at all with walking (50%, n=196) or travelling (58%, n=236).

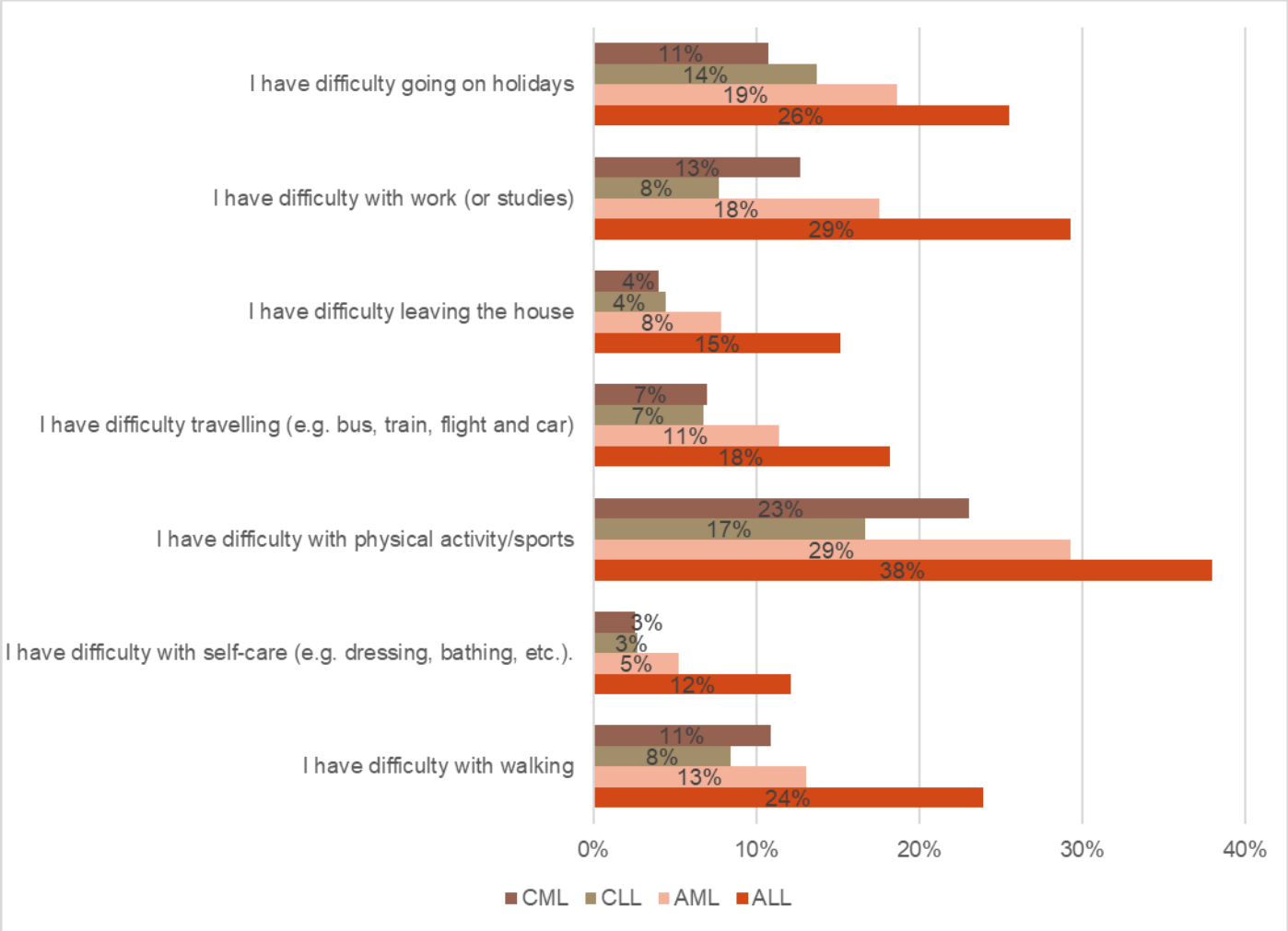
For most of those that reported significant difficulty with physical aspects of their life, this was most notable in relation to physical activity and sports (31%, n=128), although this was higher for those with ALL (38%, n=38) than AML (29%, n=90). Twenty-one percent stated that they had a lot of difficulty working and again this was different between ALL (29%, n=29) and AML (18%, n=54). Of note, 29% (n=90) of those with AML and 14% (n=14) of those with ALL reported that difficulty working was not applicable to them.

Figure 78: Q114-120 Level of difficulty with Physical Behaviour - "Not at all" (Patients)



For those with chronic leukemia, across the board there is less impact on patients reported than for those with acute disease and CML patients report higher incidence of difficulty than those with CLL. Most significant difficulty is again reported with physical activity and sports, CLL (17%, n=193) and CML (23%, n=198), however 13% (n=109) of those with CML reported significant difficulty working. In line with previous information about those with CLL, 33% (n=381) reported that difficulty with work was not applicable to them.

Figure 79: Q114-120. Level of difficulty with Physical Behaviour - "A lot"



Younger people with ALL reported a higher level of difficulty than those that were older. For those with AML, lower numbers than ALL reported difficulties, and age does not seem to be a factor here. In general, younger people diagnosed with CLL reported greater difficulties than those that were older. In contrast, physical difficulty generally increases with age for those with CML (see Figure 80).

Figure 80: Q114-193 Level of difficulty with Physical Behaviour (Walking) vs. Age (A lot)

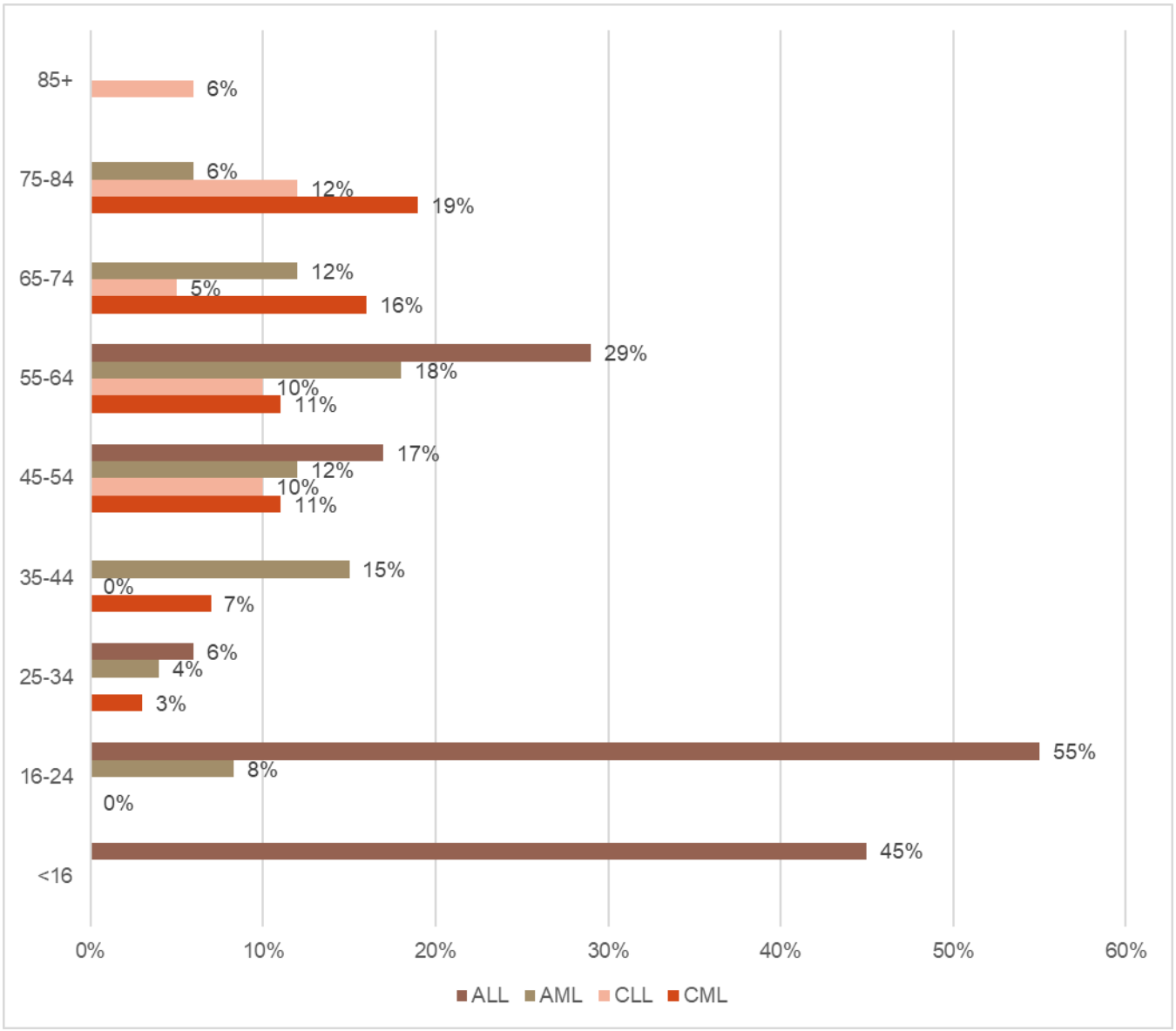
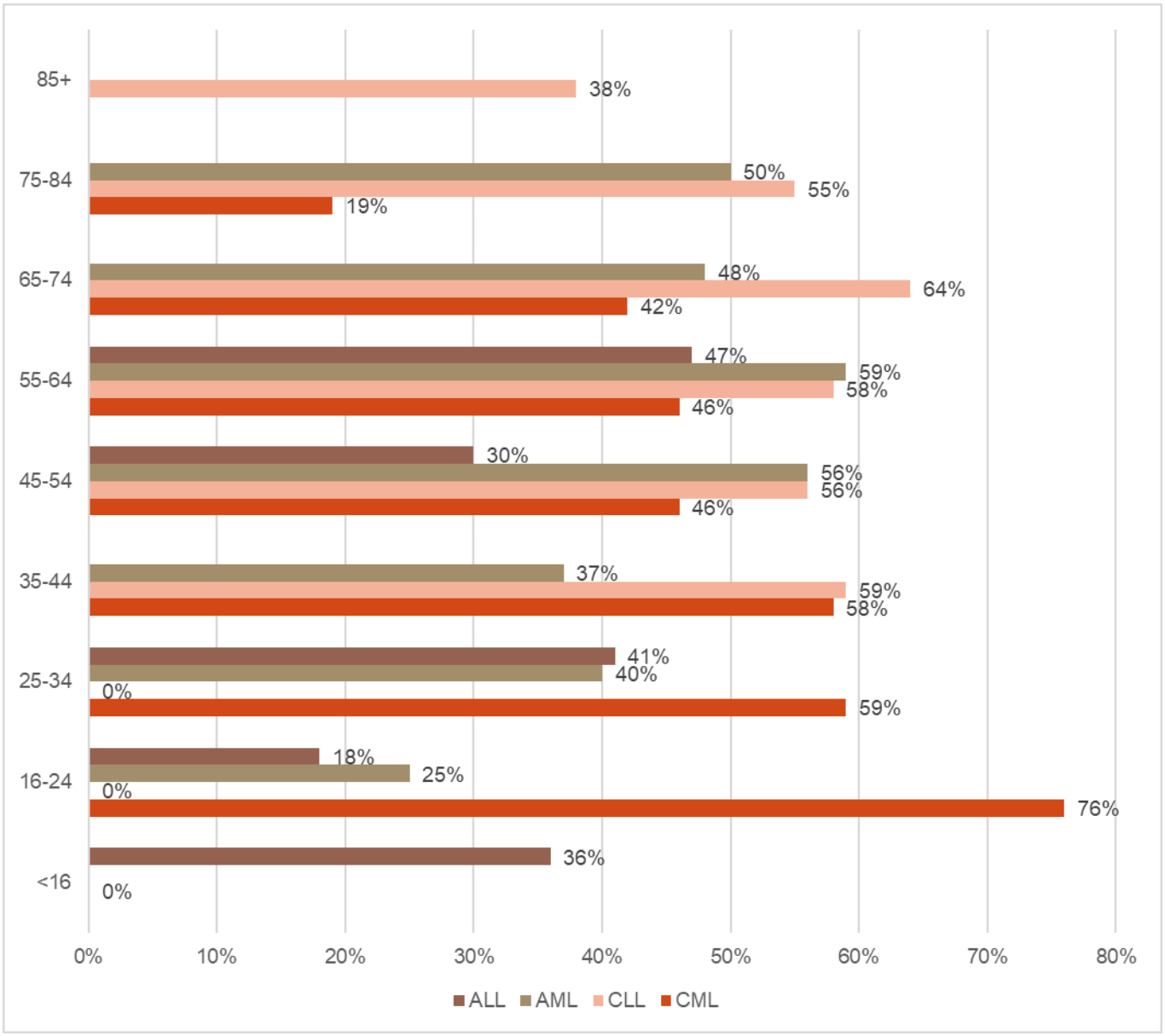


Figure 81: Q114-193 Level of difficulty with Physical Behaviour (Walking) vs. Age (Not at all)



Fewer people with lower income have no difficulties than those with average or high income other than those with ALL where it is similar across the different income types.

Figure 82: Q114-198 Level of difficulty with Physical Behaviour (Walking) vs. Income (A lot)

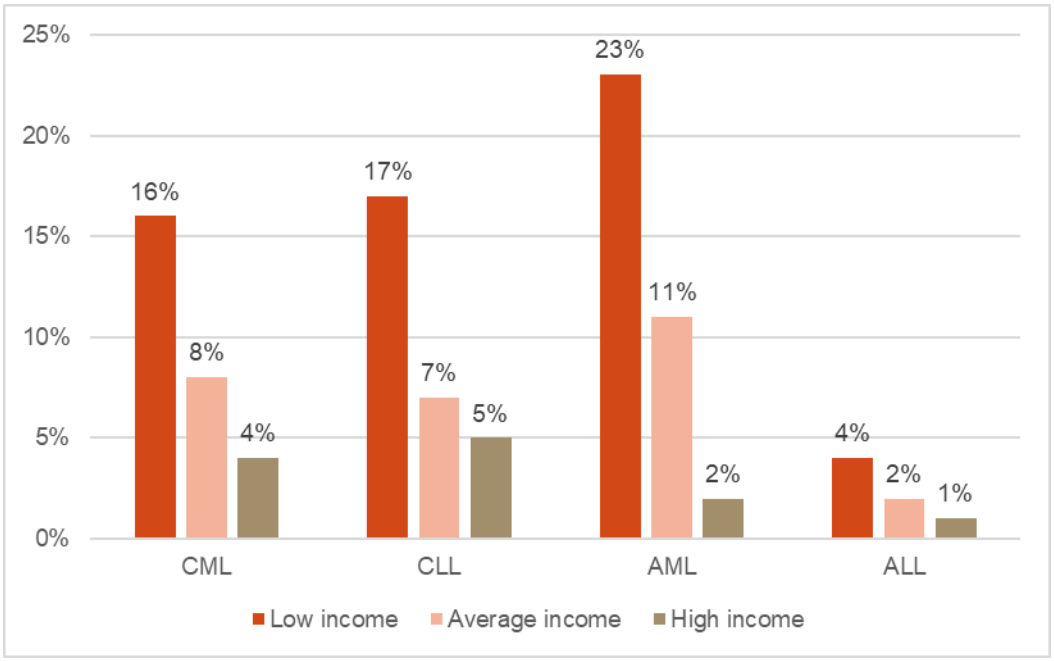
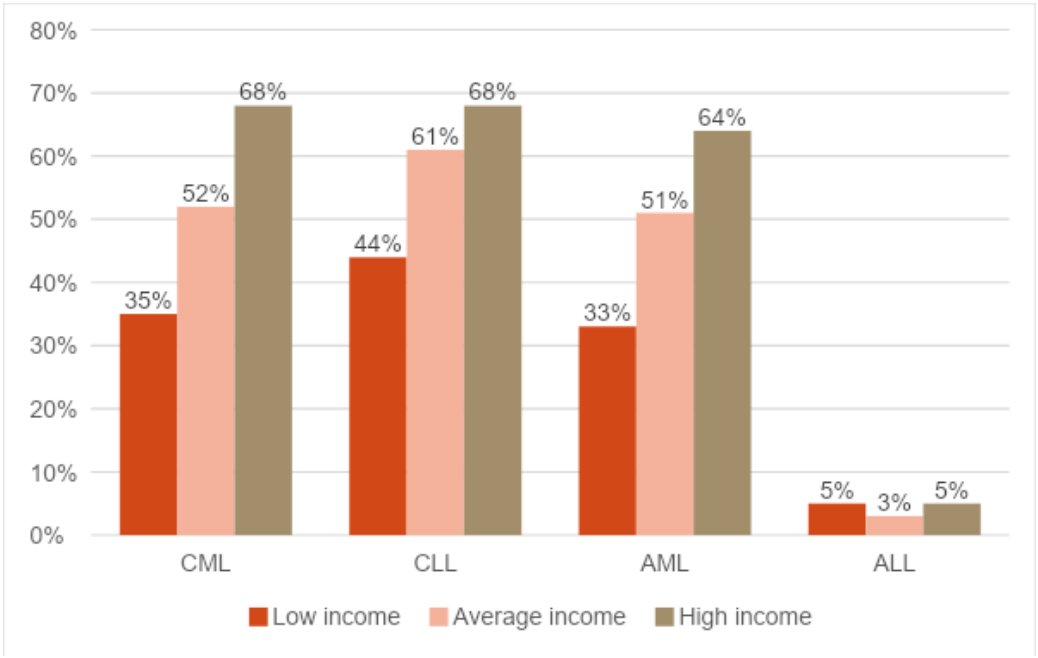


Figure 83: Q114-198 Level of difficulty with Physical Behaviour (Walking) vs. Income (Not at all)



Carers

Those that responded to the carers survey were asked the same questions regarding their perception of the impact on the patient that they were caring for. Across the board, carers of those with acute leukemia rated the level of physical difficulty, experienced by the patient, as higher than the patients themselves. This is more of a mixed picture for those caring for patients with chronic leukemia when compared with the responses of the patients, but they are very similar.

In line with the patients' survey, the biggest difficulty reported is physical activity/sports. Half (50%, n=106) of those with acute leukemia and a quarter (25%, n=85) of those with chronic leukemia stated that the patient had a lot of difficulty, and a further 37% (n=122) stated that they had at least some difficulties (although this was 41%, n=75 for those with CML).

For those with acute disease, difficulties with work (43%, n=91) were the biggest issue followed by going on holidays (39%, n=82). The least amount of difficulty reported was with self-care, where only 16% (n=34) of carers for those with acute disease and 3% (n=43) of carers for those with chronic leukemia felt that the patient had a lot of difficulties. Lastly, 9% (n=9) of carers for ALL and 7% (n=12) CML noted that difficulty at work was not applicable to the patient that they cared for, whereas this was 25% for those caring for someone with AML (n=28) and CLL (n=36).

Figure 84: Q44C- a-g. The following statements describe the patient's / my Physical behaviour-"Not at all" (carers)

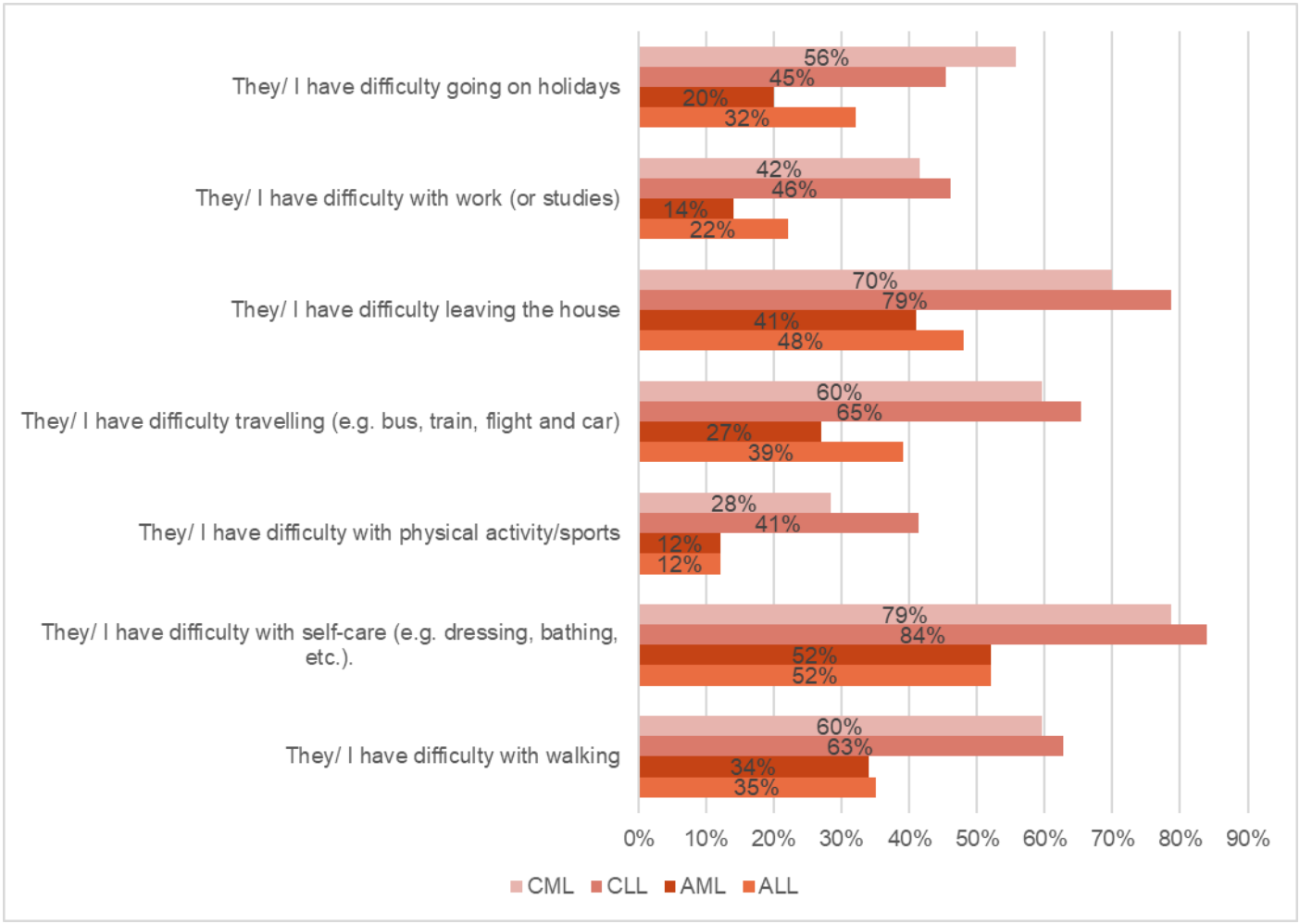
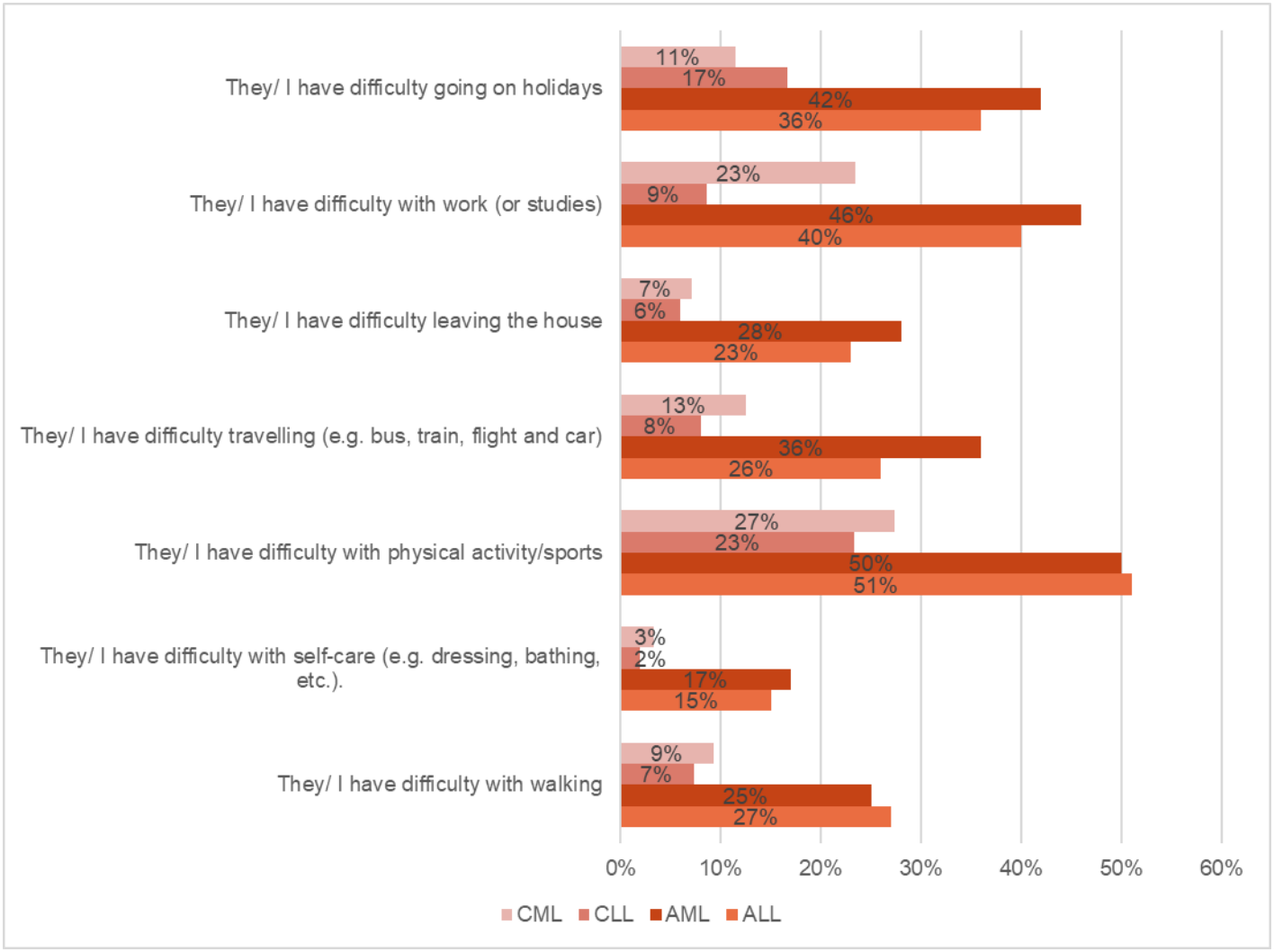


Figure 85: Q44C- a-g. The following statements describe the patient's / my Physical behaviour- "A lot" (Carers)



10.1.2. Social wellbeing

There were significant differences between leukemia types with regard to the social wellbeing for patients.

Patients

Overall, 64% (n=1622) of patients felt that they did not have any difficulties with their relationships with 39% (n=977) felt that they had no issues with their sex life.

Twenty-eight percent of ALL patients (n=28) felt that sex life difficulties were not applicable to them, compared to 19% with AML (n=56). In patient with chronic leukaemia, 69% (n=797) of those with CLL and 64% (n=546) of those with CML had no difficulty with their relationships. Although, 40% (n=464) of those with CLL, and 43% (n=365) with CML reported no difficulty with their sex lives, a significant proportion noted that this was not applicable to them (CLL 28%, n=326 and CML 16%, n=133).

More ALL patients felt that they had a lot of difficulties with their social wellbeing than those with AML (see Figure 87). For those with chronic leukemia, patients reported less difficulty than those with acute disease. More than half of those with CLL) and CML reported no difficulty with socialising (CLL 51%, n=573 and CML 58%, n=466, respectively).

Age

Younger respondents living with ALL were more likely to have issues around their ability to socialise. Those aged 16-24 years were more likely to report issues with their relationships. There was little difference for those with AML across the different age groups.

Young patients with CLL, that were diagnosed, reported higher issues with their social wellbeing (see Figure 87). For those with CML, the younger patients reported significant issues with their socialising.

Income

Those who reported they had a low income were less likely to report having no difficulties than those with a higher income. This was less pronounced for those with ALL.

Figure 86: Q 121-123 Level of difficulty with social wellbeing - "Not at all" (Patients)

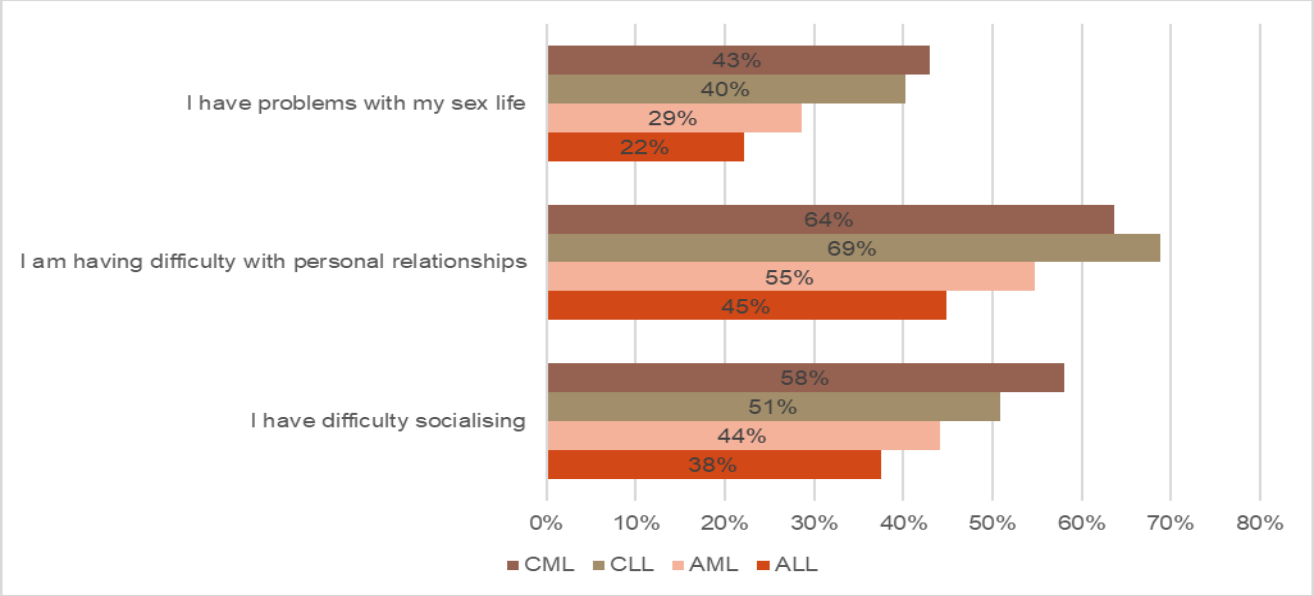
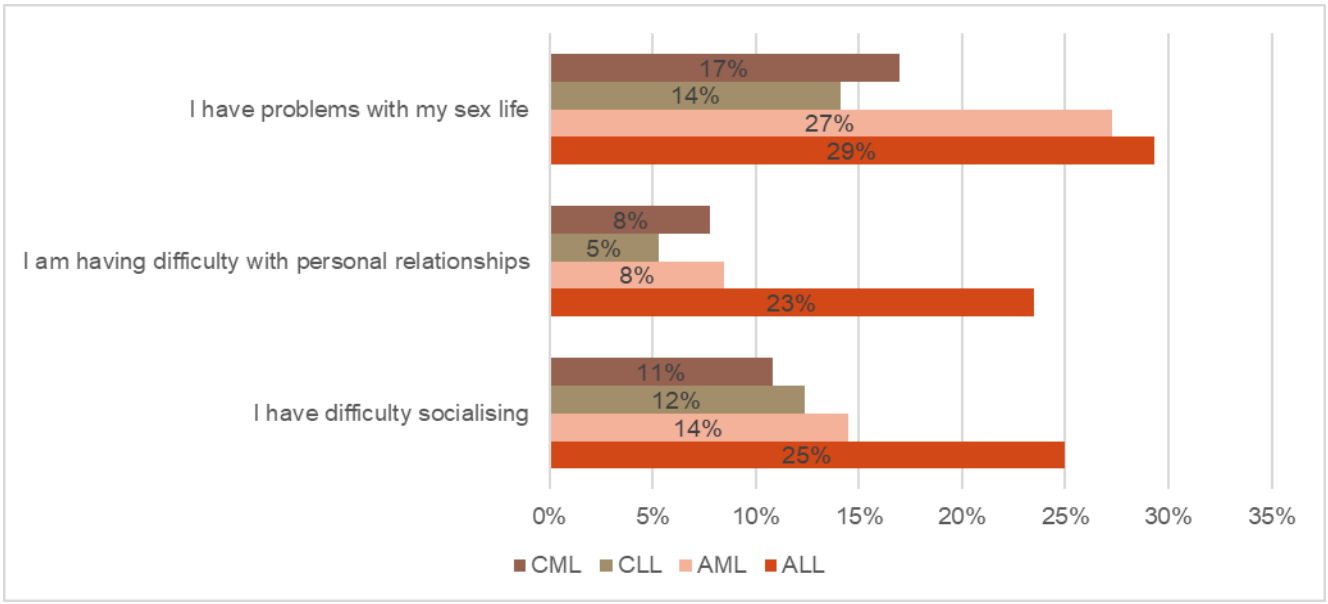


Figure 87: Q 121-123 Level of difficulty with social wellbeing - "A lot" (Patients)



Carers

In contrast to their perception around physical difficulties, carers perceived patients' difficulties with their social wellbeing similar to the patients themselves. Twenty-nine percent (n=168) felt that the patient had little difficulty with both relationships and socialising. This was lower for those caring for someone with chronic leukemia.

Figure 88: Q 45C, a-b- Level of difficulty with social wellbeing - "Not at all" (Carers)

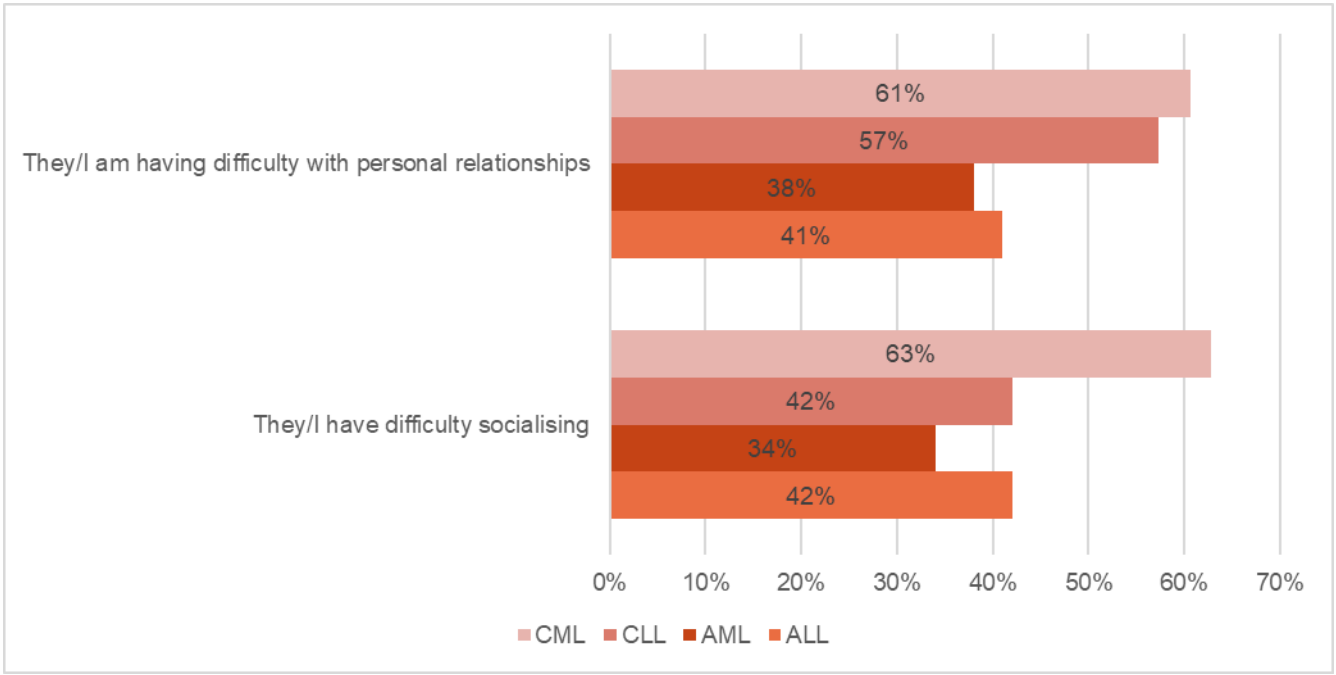
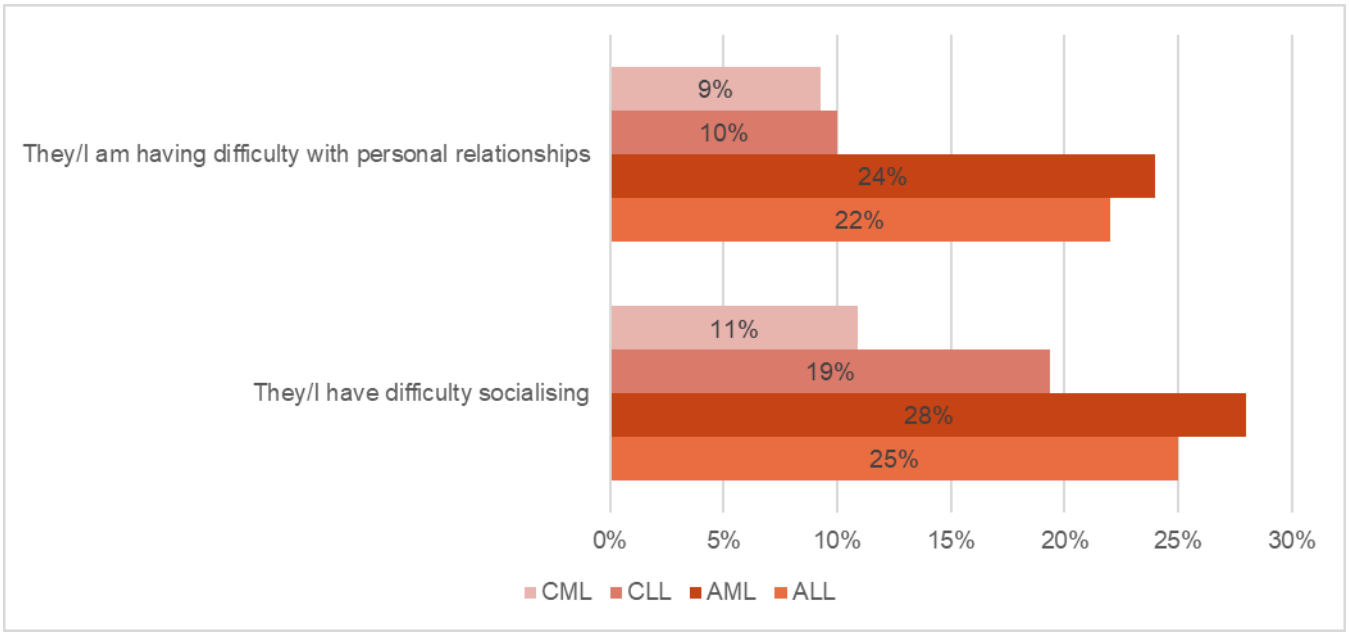


Figure 89: Q 45C, a-b- Level of difficulty with social wellbeing - "A lot"



The results here suggest that patients have more issues with their social wellbeing than their physical wellbeing.

10.1.3. Emotional wellbeing

Patients

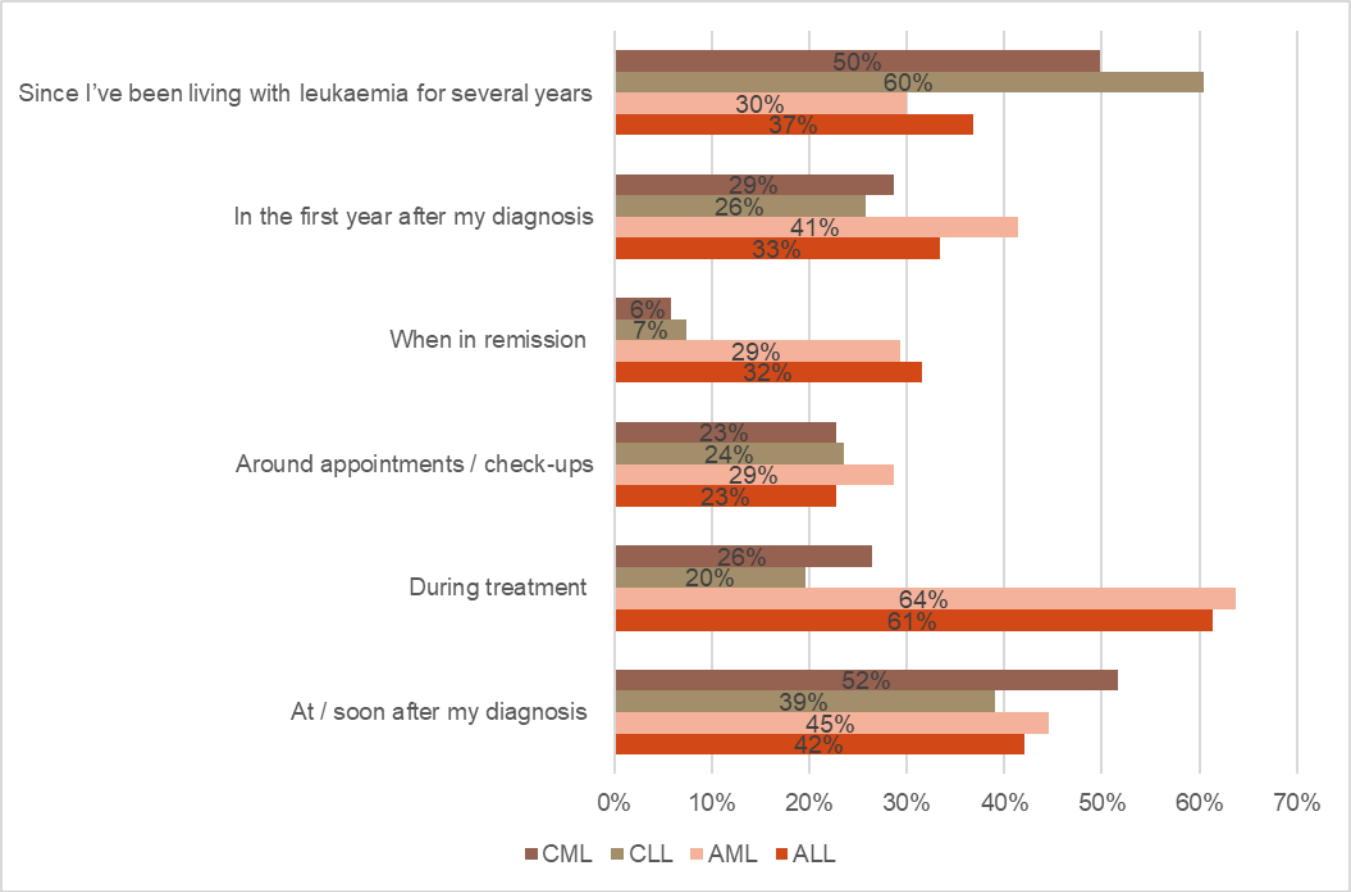
While 53% (n=215) of acute leukemia respondents reported feeling isolated since their diagnosis, this was slightly more for ALL patients (57%, n=57).

Moreover, it was lower (36%, n=731) for those with chronic leukemia (see Figure 90). Isolation was most prevalent for both ALL and AML patients at the point of treatment (63%, n=135), followed by at diagnosis (44%, n=94). For those with CLL, isolation was mostly reported as a result of living with the disease for a number of years (60%, n=246) followed by at diagnosis (39%, n=159), whereas for those with CML, this was highest at diagnosis (52%, n=168) and then as a result of living with the disease for some time (50%, n=162).

Although isolation does not appear to be a universal difficulty for leukemia patients, it is understandable that a significant number feel isolated at the beginning of their journey with the disease. Additional support, resources, and signposting at diagnosis, and then at the point when treatment is initiated could help to minimise isolation and reduce negative impact on mental wellbeing.

For those with chronic leukemia, it is also important to discuss their mental wellbeing as their disease progresses, and during monitoring, when they have lived with the condition for some time.

Figure 90: Q142. When have you felt isolated? (Patients)



Carers

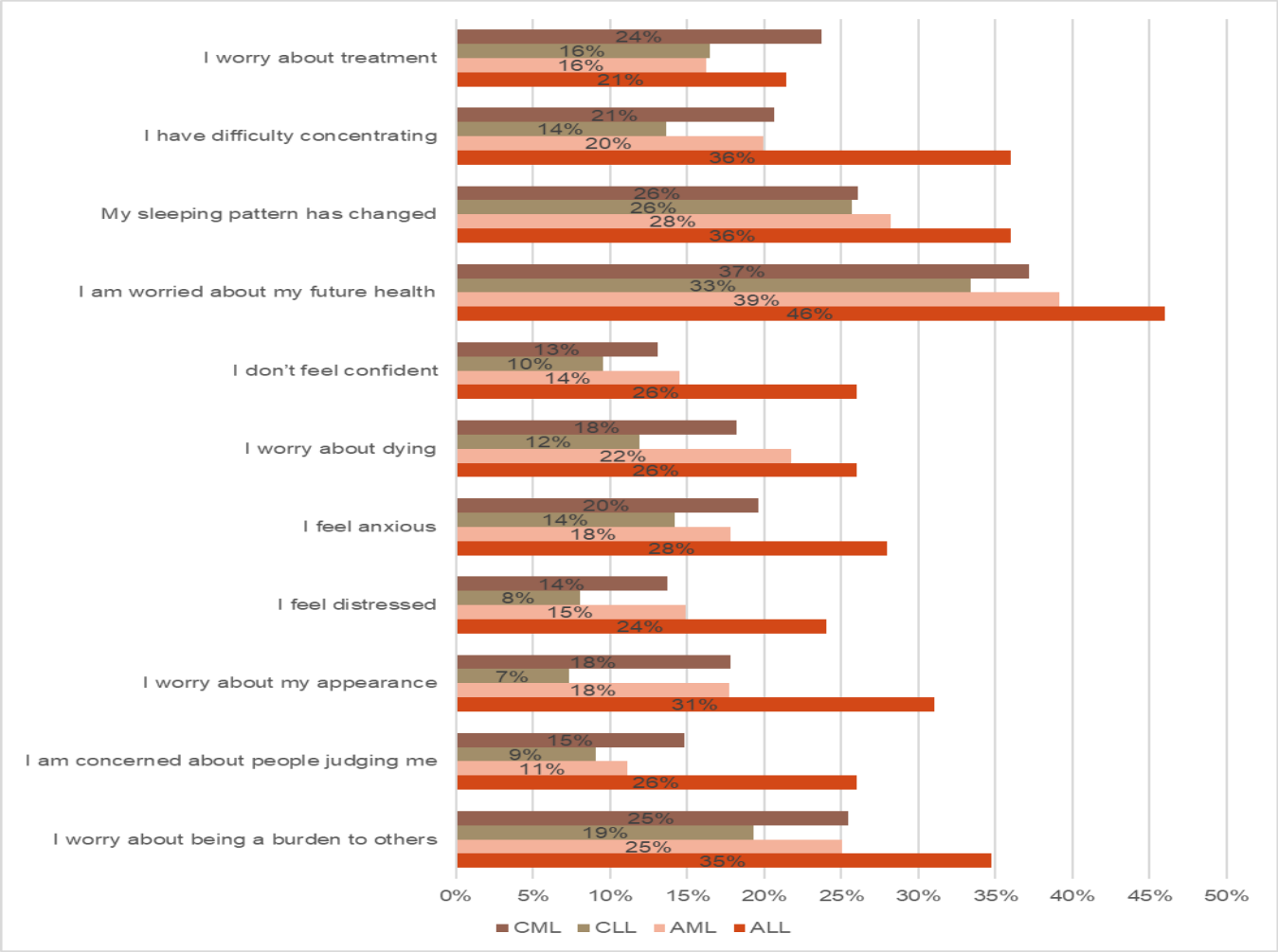
Carers were asked to comment on whether they thought that the overall emotional wellbeing of the patient had changed as a result of their diagnosis. Only 21% (n=43) felt that the patient with acute leukemia was actually more positive since their diagnosis, however, 48% (n=160) felt that the patient had been depressed or anxious. The results for chronic leukemia are broadly similar to acute leukemia, although there is a noticeable difference between sub-types. Only 11% (n=16) of those with CLL felt more positive compared to 29% (n=53) with CML.

Patients

Patients were also asked how they felt their emotional wellbeing had been since their diagnosis. In line with the carers survey responses, 24% (n=97) of acute leukemia patients felt that they had been more positive since their diagnosis, with 54% (n=218) feeling that they were depressed/anxious or constantly depressed/anxious. However, conversely to the carers survey, ALL patients reported higher levels of negative emotional wellbeing than those with AML. The responses for those with chronic disease were also in line with that of the carers.

To gain information about their wider emotional wellbeing the respondents were asked a number of questions around their ability to concentrate, sleep, and their anxiety and worries about their leukemia. The majority of respondents (ALL 86%, n= 86, CLL 86%, n=1,000, CML 83%, n=711, and AML 83%, n=253) worry about their future health, at least to some extent.

Figure 91: Q124-134-Level of Emotional difficulty "A lot" (Patients)



Anxiety affects patients across the board. 66% (n=66) of ALL, 62% (n=187) of AML, 65% (n=747) of CLL, and 64% (n=542) of CML patients reported that they felt anxious either "a little" or "a lot". Universally, ALL patients were more likely to report that their emotional difficulty was affected "a lot" than those with AML, and on the whole more of those with CML reported issues than those with CLL.

Although, respondents reported a high level of anxiety and worry about their future, a slightly lower proportion of respondents worried about dying (16%, n=410); these findings are similar across all leukemia types.

Sleeping is clearly affected. Those with ALL were most likely to report issues with sleeping, 36% (n=36) reported their sleeping pattern had changed a lot).

When looking at any differences through age, those aged 16-35 years with ALL were more likely to experience higher levels of emotional issues; in particular, they were more likely to report feeling like a burden and felt that people were judging them. Younger people were more worried about treatment than those that were older.

Consistently across patients with AML, those reporting lower income are more impacted with their emotional wellbeing. For those with ALL, there was little difference as a result of age. When looking at the responses from CML and CLL, emotional difficulties were higher for those with lower income.

Carers

The highest proportion of emotional impact reported by carers was that the patient worried about their future health.

For carers of a patient with acute disease, 48% (n= 101) reported that they worried “a lot”, followed by an additional 30% (n=62) who worried about their future health “a little”.

The results were broadly similar for carers of a patient with chronic disease: 43% (n= 79) reported that they worried “a lot”, followed by an additional 43% (n=78) who worried about their future health “a little”.

These results are in line with the responses from patients.

Carers also reported that the patient experienced anxiety as a result of their diagnosis: 31% (n=166) of carers reported that the patient was anxious “a lot”. This differed by leukemia type. Carers of those patients with acute leukemia were more likely to say the patient experienced anxiety “a lot” (39% acute vs 26% chronic.)

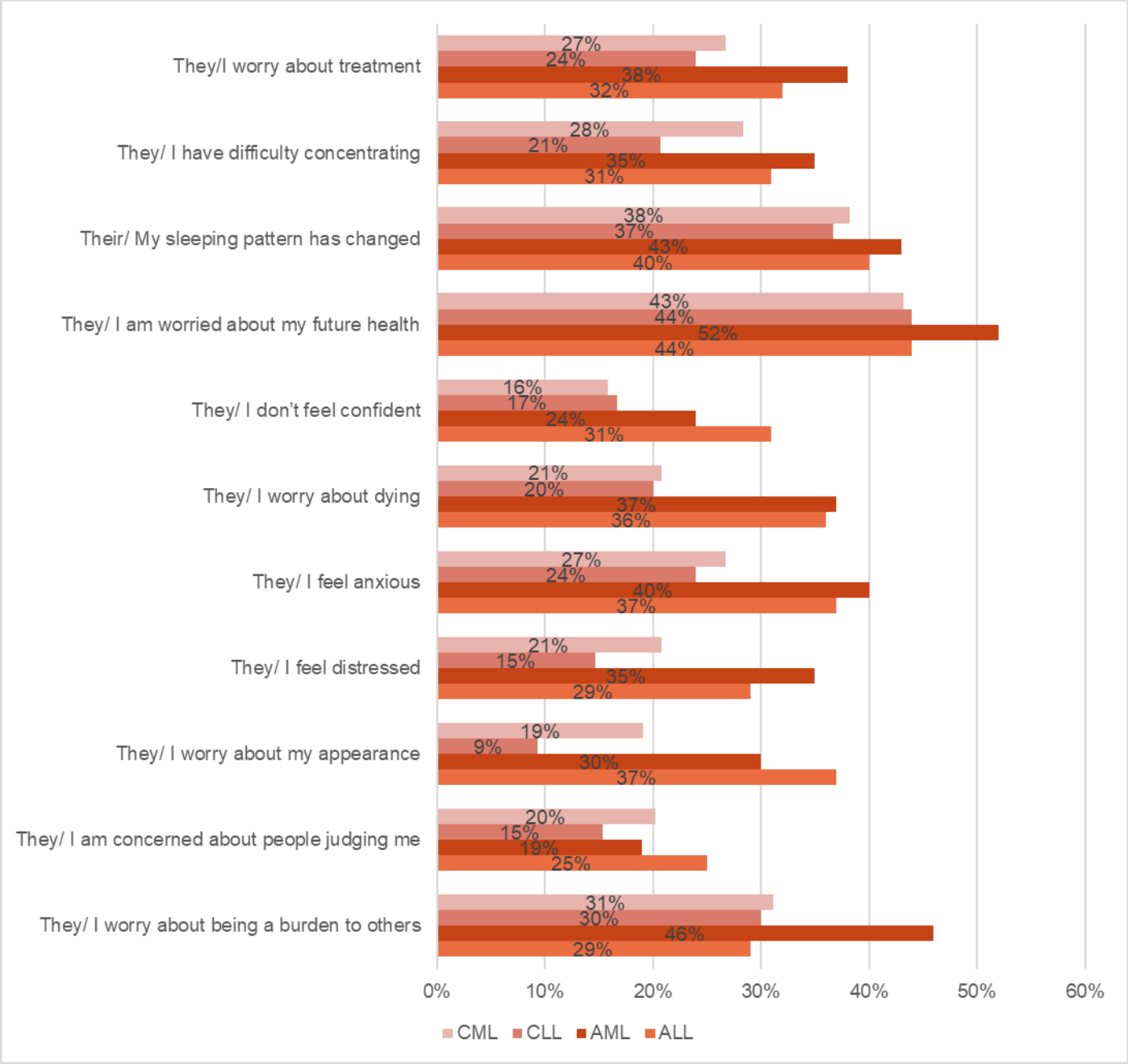
In line with the responses from the patient survey, a lower proportion felt that the patient worried “a lot” about dying (37% acute and 20% chronic). Most carers of patients, living with acute leukemia, felt that the patient they cared for had difficulty concentrating. However, this was a little lower for those caring for someone with a chronic condition.

A significantly higher proportion of those with AML felt that they were a burden on others (46%, n=51) compared to ALL (29%, n=29). For those with a chronic form of leukemia, the carers consistently rated emotional wellbeing more negatively than patients.

The results suggest that there is a need for effective information and support at diagnosis, before treatment, and at regular monitoring or testing.

The results also show that carers would benefit from additional information and support around treatment and ways in which they can improve their emotional wellbeing.

Figure 92: Q. 46C-a-k the following statements describe the patient's / my Emotional behaviour: "A lot" (Carers)



10.1.4. Eating and drinking

Majority of (63% [n=1,489]) of respondents felt that they had no trouble with their appetite, with only 8% (n=179) stating that they had a lot of difficulty. Patients living with CLL were most likely to report issues with appetite.

Conversely, just 45% (n=247) of carers reported that the patients, they were caring for had no trouble with appetite, and 21% (n=114) reported the patient had a lot of difficulty. Carers of those with acute disease were much more likely to report difficulty.

Across both the patient and carer surveys, there were more issues noted with eating than drinking. There are pronounced issues reported by ALL patients with their eating (69% (n=69), reported their eating habits had changed) than those with AML (52% (n=157) reported changes to their eating habits).

Carers of AML patients were most likely to report that the patient had changed their drinking habits (68%, n=75), only 50% (n=50) of ALL carers felt the same.

The responses for those with CML are very similar to those with AML, however the responses were less pronounced in those with CLL. Moreover, 70% (n= 761) of those with CLL had no issues with their appetite.

The remaining results were broadly similar.

Figure 93: Q 47C a-c - The following statements describe the patient's / my Eating and Drinking "A lot" (Carers)

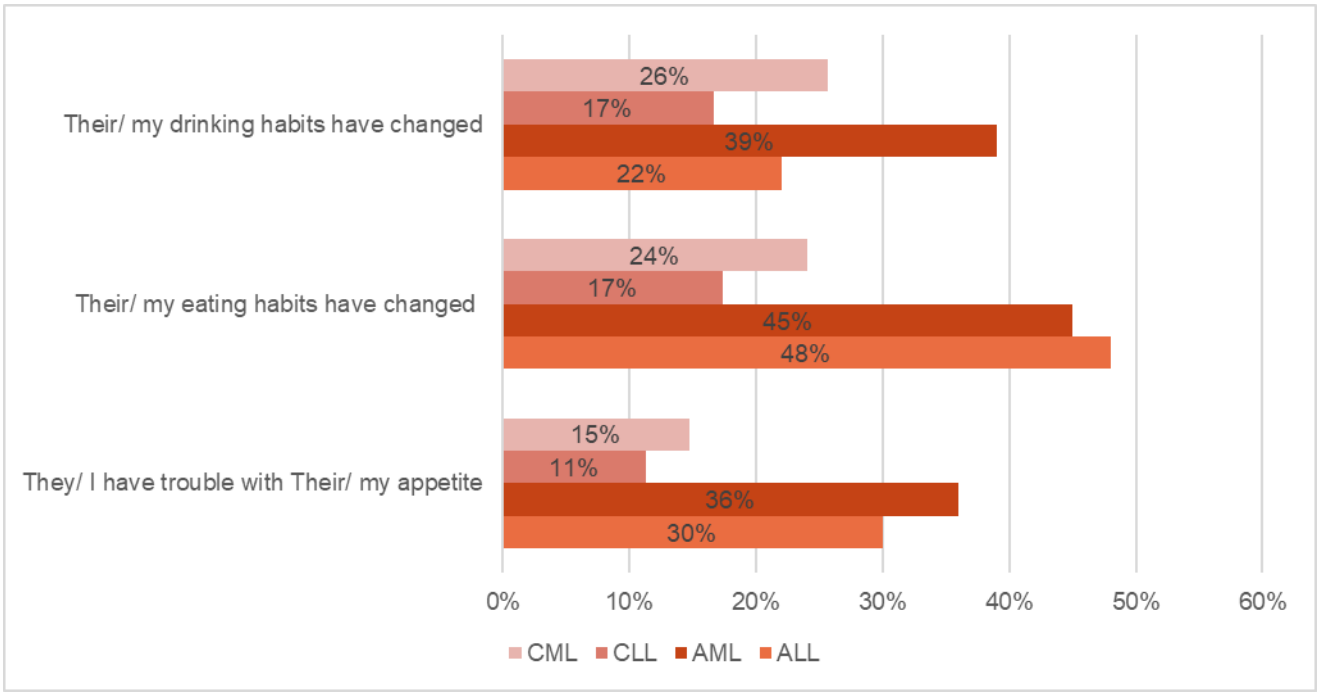
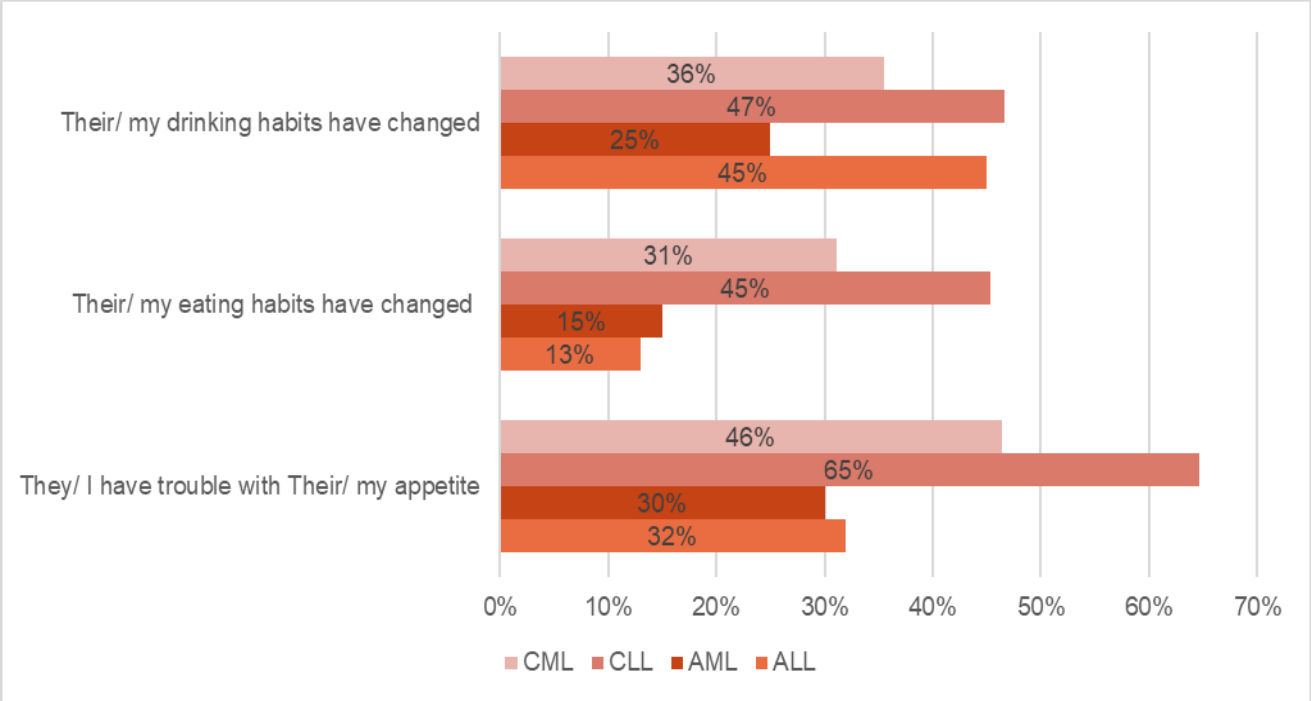


Figure 94: Q 47C a-c - The following statements describe the patient's / my Eating and Drinking "Not at all" (Carers)



10.1.5. Negative impact of leukemia on wellbeing of carers

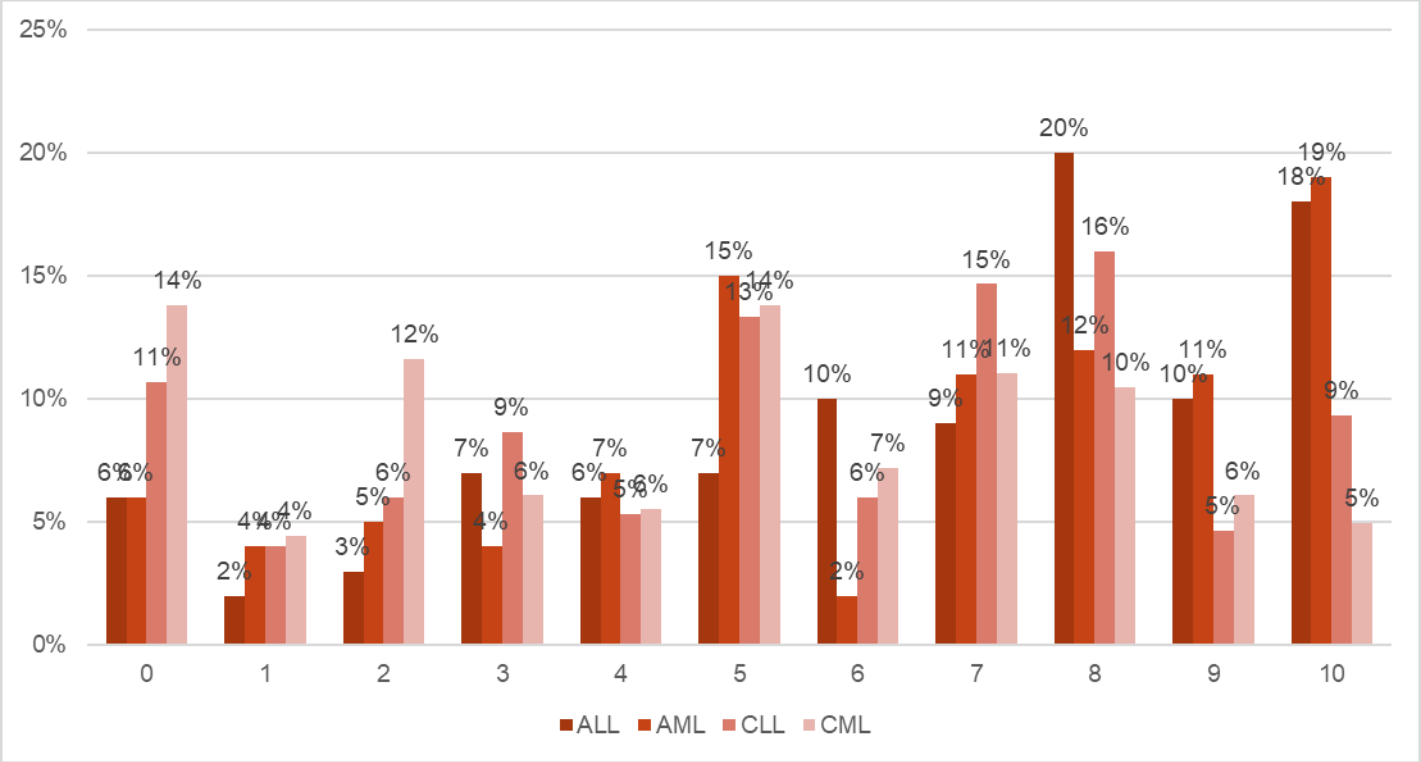
Carers were asked how much leukemia had impacted on their own wellbeing on a scale of 0 to 10 (0 being no negative impact, and 10 being severe impact). Just over half of carers of patients with both types of acute cancer rated the impact as 7/10 or above, meaning that they felt that leukemia had a significant impact on their life.

Fewer carers of patients with chronic leukemia rated that the impact was as severe on their lives (45%, n=67 CLL and 33%, n=59 CML).

Patients were asked to rate the wellbeing impact on their carers. The findings were similar to the carer survey. Fifty-two percent (n=51) of ALL patients and 42% (n=129) of those with AML rated the impact as 7/10 or higher.

The findings again clearly demonstrate that acute disease affects wellbeing more severely than chronic disease. Patients with chronic leukemia rated that the impact on their carer and other family was lower than those with acute disease.

Figure 95: Q50C.Overall, how would you rate the way (caring for someone with) leukemia has negatively impacted on your wellbeing and life? 0 is no negative impact and 10 is large negative impact.



Although responses were collated from patients and carers across all four of the main leukemia types, the carers and patients were not related (i.e., carer x did not care for patient y), and therefore direct comparisons between the results of these two surveys cannot be made.

10.2. Management of emotional impact by HCPs

Patients were asked to rate how the emotional impact of their blood cancer and any treatment was managed by their healthcare professionals. They were asked to rate on a scale of 0 to 10 (where 0 is very dissatisfied, and 10 is very satisfied).

Sixty-two percent (n=189) of patients with AML felt that the emotional impact of their cancer had been managed effectively, rating healthcare professionals as 7 out of 10 or higher. This was lower for those with other leukemia types, where only 49% (n=49) of ALL, 50% (n=578) of CLL patients, and 53% (n=461) of those with CML rated their care as 7/10 or above. This might suggest that more needs to be done to support the emotional impact of a leukemia diagnosis, particularly for those with chronic illness.

Fifty-six percent (n=117) of carers, who were caring for a patient with acute leukemia, felt that the patients' emotional impact had been managed effectively by HCPs by rating them at 7/10 or above.

Fifty-one percent (n=169) of carers, who were caring for a patient with chronic leukemia, felt that the patients' emotional impact had been managed effectively by HCPs by rating them at 7/10 or above.

Figure 96: Q 143. Overall, how would you rate the way the emotional impact of your blood cancer and any treatment has been managed by your healthcare professionals? (Patients) 0 is very dissatisfied and 10 is very satisfied

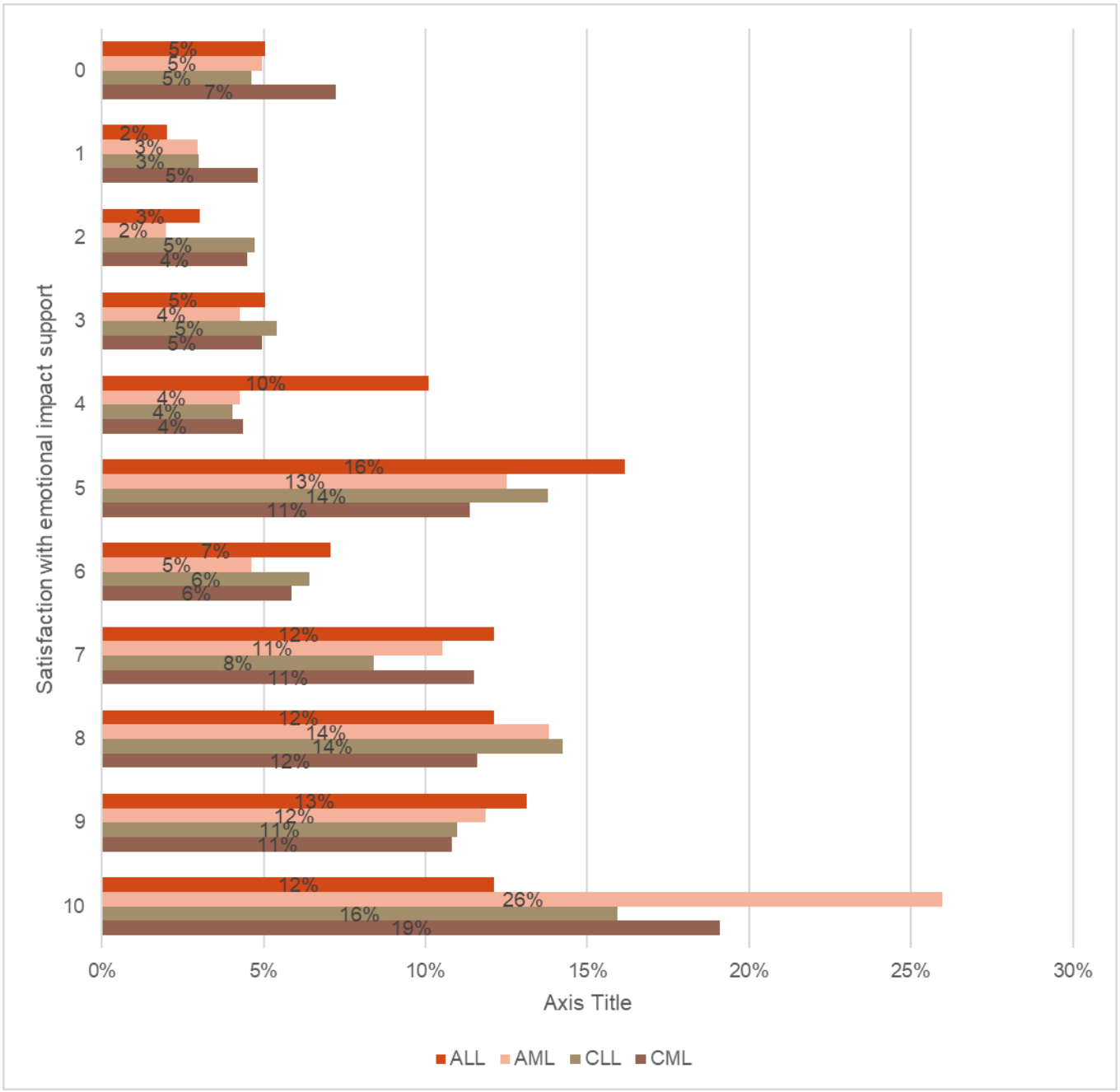
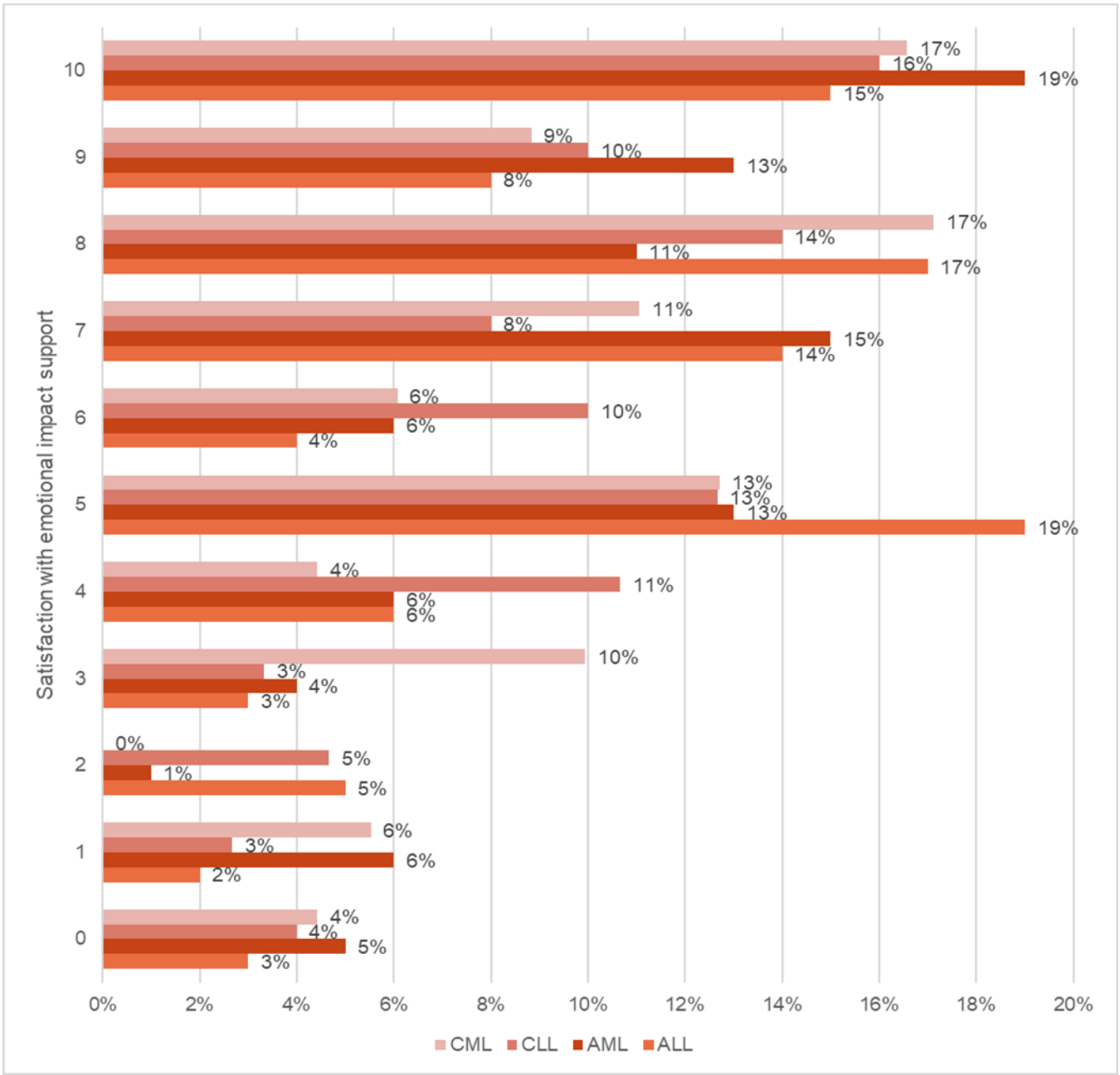


Figure 97: Q49C. Overall, how would you rate the way the emotional impact of the patient's / your leukemia and any treatment has been managed by their healthcare professionals? 0 is very dissatisfied and 10 is very satisfied (Carers)



10.3. Summary

Although responses were collated from patients and carers across all four of the main leukemia types, the carers and patients were not related (carer x did not care for patient y), and therefore direct comparisons between the results of these two surveys cannot be made.

'Quality of life' (QoL) is important for patients and carers of those with leukemia; patients outlined the need for treatments to greatly improve their QoL.

In general, carers reported that leukemia had a greater impact on the lives of patients than the patients themselves. From the patients' perspective, there was a higher impact on their social and emotional

wellbeing, than their physical wellbeing, with most patients having the biggest physical difficulty with sports or other similar physical activities. Acute leukemia patients universally reported a more severe impact on their wellbeing than those with chronic leukemia.

Both age and income appear to have some impact on wellbeing. Younger patients with ALL reported a more severe impact on wellbeing. However, with other leukemia types, difficulties generally increase with older age. Those who reported a low income, in general, reported a more severe negative impact on their wellbeing than those reported from a higher income.

Leukemia, whether acute or chronic, can have a significant impact on QoL, and the results show this can differ with a variety of factors. Personalised information and support tailored to each individual patient, alongside quality, joined-up, healthcare, is vital to help minimise the impact on patients, their carers, and wider family.

11. Information and Support for people with blood cancers

Accessible, personalised, and easy to understand information and support is key to effectively support patients living with a diagnosis of leukemia.

In this section of the questionnaire, respondents were asked about their experiences with information and support throughout their journey.

From the responses provided as part of this survey, it would seem that information is provided to most people, diagnosed with leukemia, that wished to access it at some point across their disease journey, however the point at which they are provided with this differs across leukemia types.

11.1. Information and support at diagnosis

11.1.1. Information

Receiving a diagnosis of a blood cancer can be overwhelming[6]. It would be helpful for patients and carers to be provided with information and other resources that they can return to after the initial shock of a diagnosis.

Patients

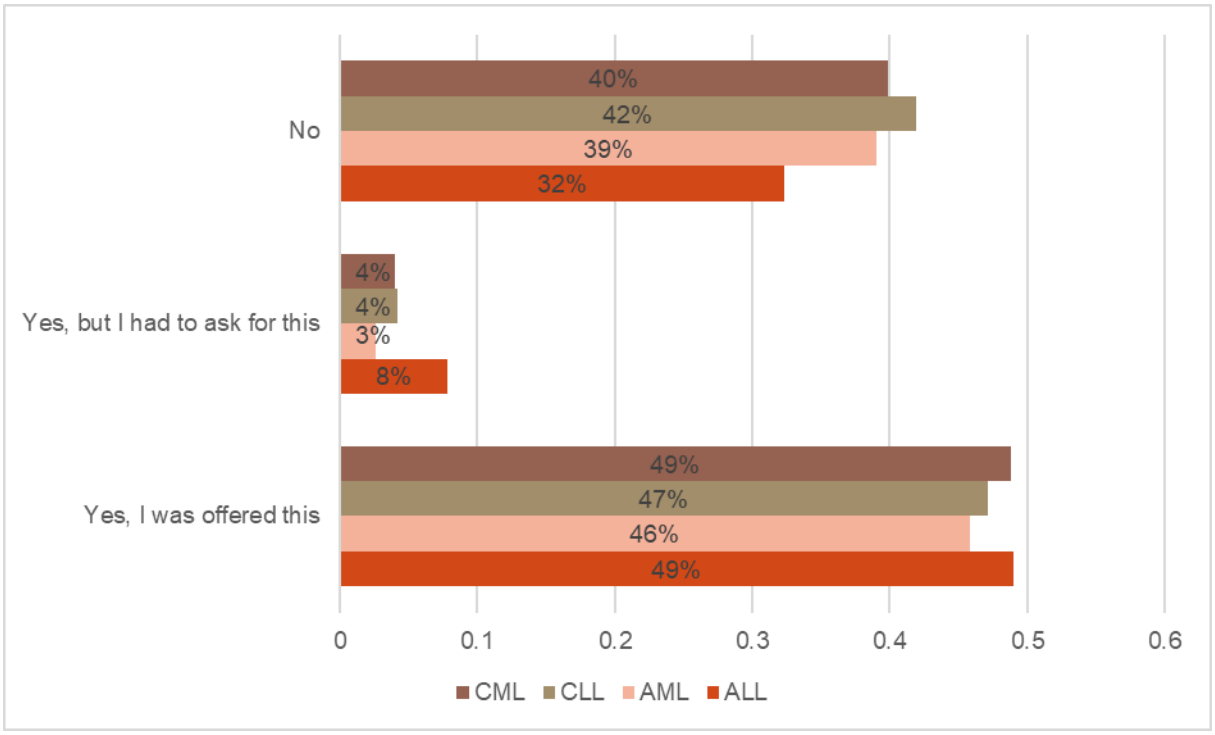
While 48% (n=1,255) of respondents stated that they had been given written information about their leukemia, just 4% (n=105) received this information when they asked for it. Patients living with ALL were most likely to have to request written information.

The results show that over half of patients are not being routinely offered written information at diagnosis. This is consistent across all leukemia types and suggests a significant gap in provision. Sixty-eight percent (n=346) of patients would have liked to have been offered written information.

The results also suggest that the quality of written information being offered to patients could be improved. Only 43% (n=584) of patients fully understood the written information they were given. This varies by leukemia type (CLL 48% (n=72), CML 42% (n=200), AML 41% (n=254), and ALL 38% (n=22).

[6] I've just been told I have blood cancer | Blood Cancer UK

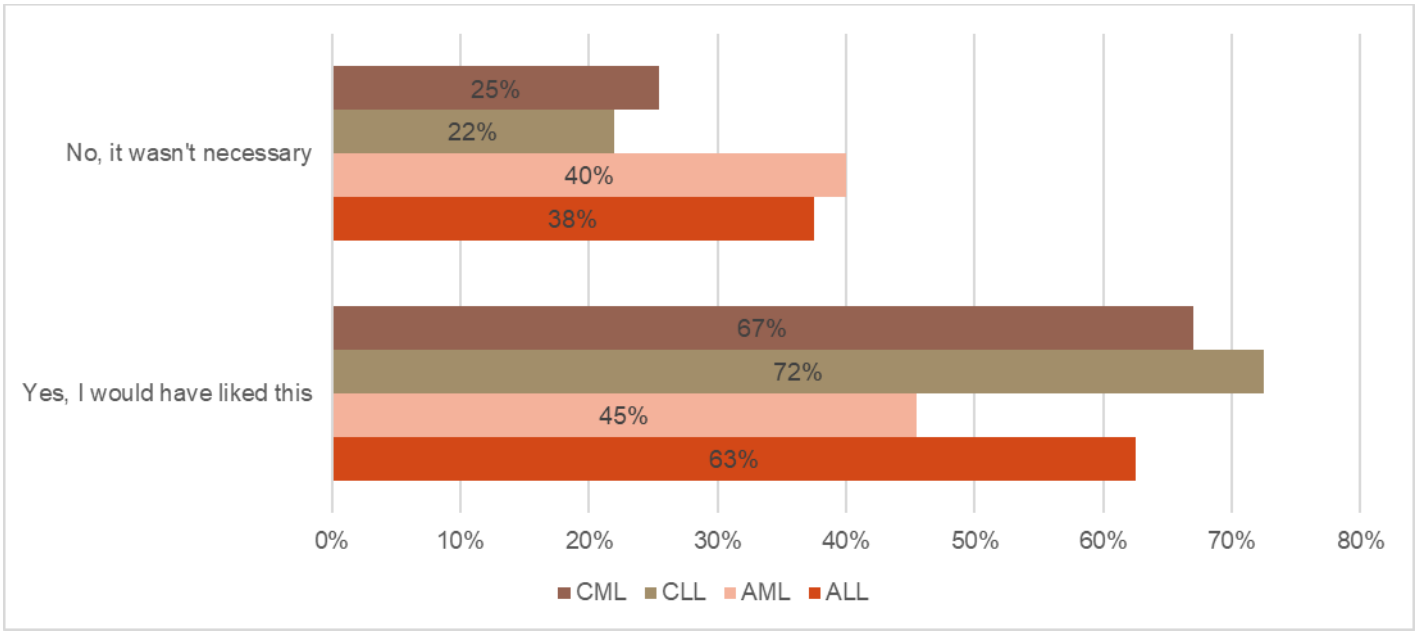
Figure 98: Q31. Were you given written information about your leukemia at your diagnosis? (Patients)



Of those that were not provided any written information, 72% (n=221) CLL, 67% (n=71) CML patients and 63% (n=5) of ALL reported that they would have liked this. This was much lower for those with AML patients (45%, n=25).

Effective information at the point of diagnosis can support patients as they navigate their journey with the disease. The results suggest more can be done to ensure patients are provided, or signposted to, sources of information.

Figure 99: Q33. Would you have liked to have been given written information about your leukemia at diagnosis? (Patients)



(the missing % relates to the option don't know/can't remember)

11.1.2. Support

Patients

Of those that responded about support that they were offered, there are clear differences between the different leukemia types. While 60% (n=61) of those with ALL reported that they were offered support, this was much lower for the other leukemia types (AML 44%, n=135, CML, 43%, n=380, CLL, 37%, n=435). (see Figure 100). Of those that were not offered or directed to support, the majority of patients would have liked this (74%, n=984).

Patients with CML were most likely to be directed to support organisations (56%, n=212). Those with ALL were more likely to be referred for psychological support (43%, n=26) than any of the other leukemia types.

Figure 100: Q34. At diagnosis were you offered or directed to any support to help with concerns and worries about your leukemia? (Patients)

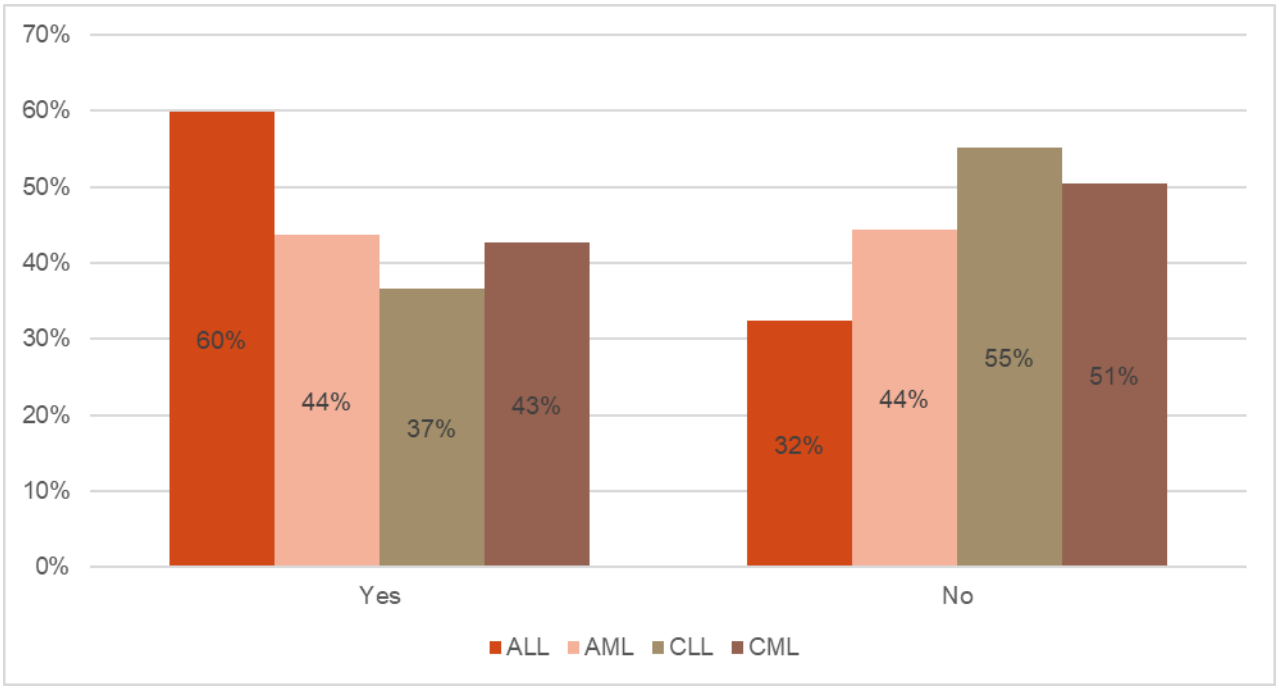
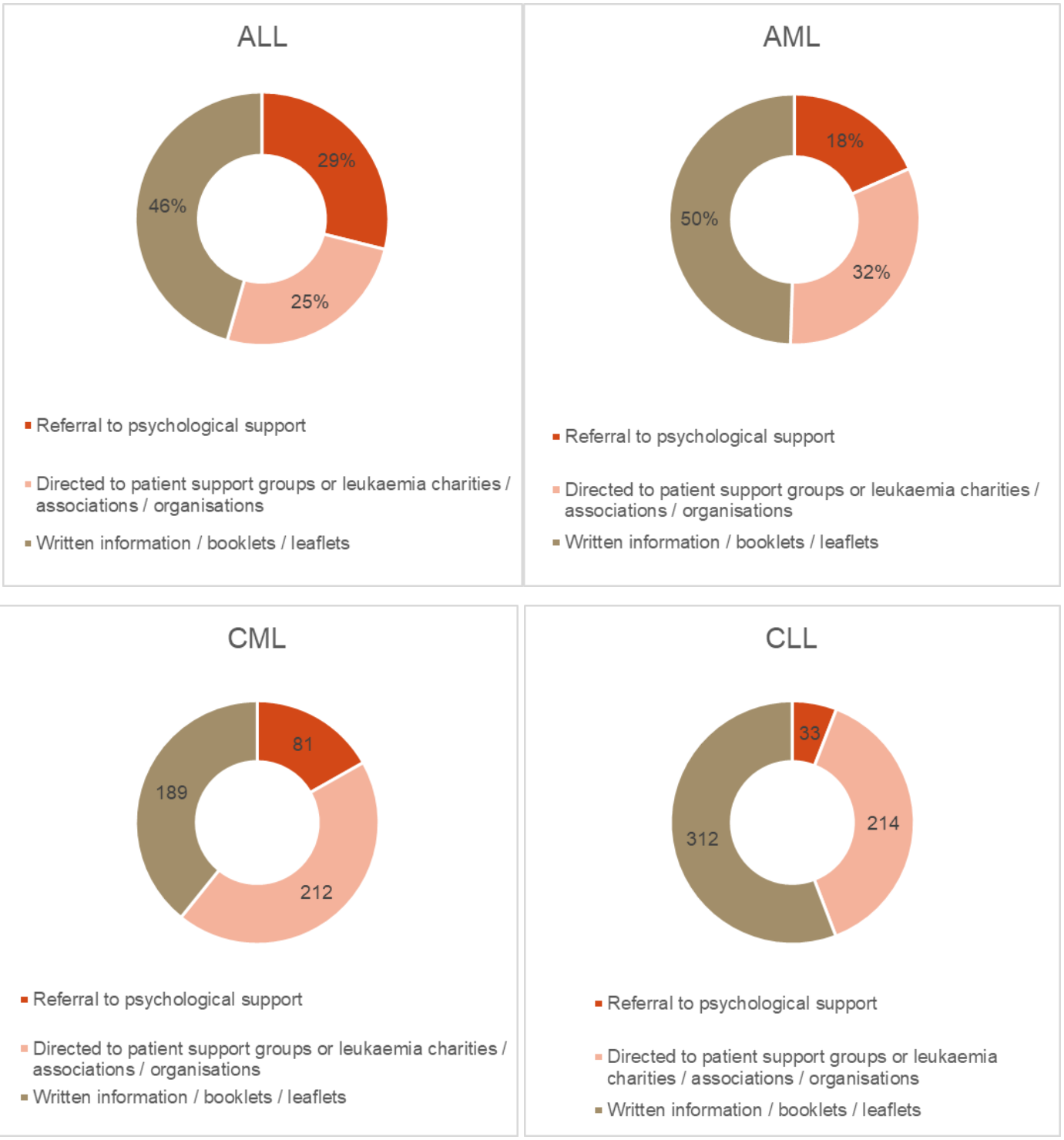


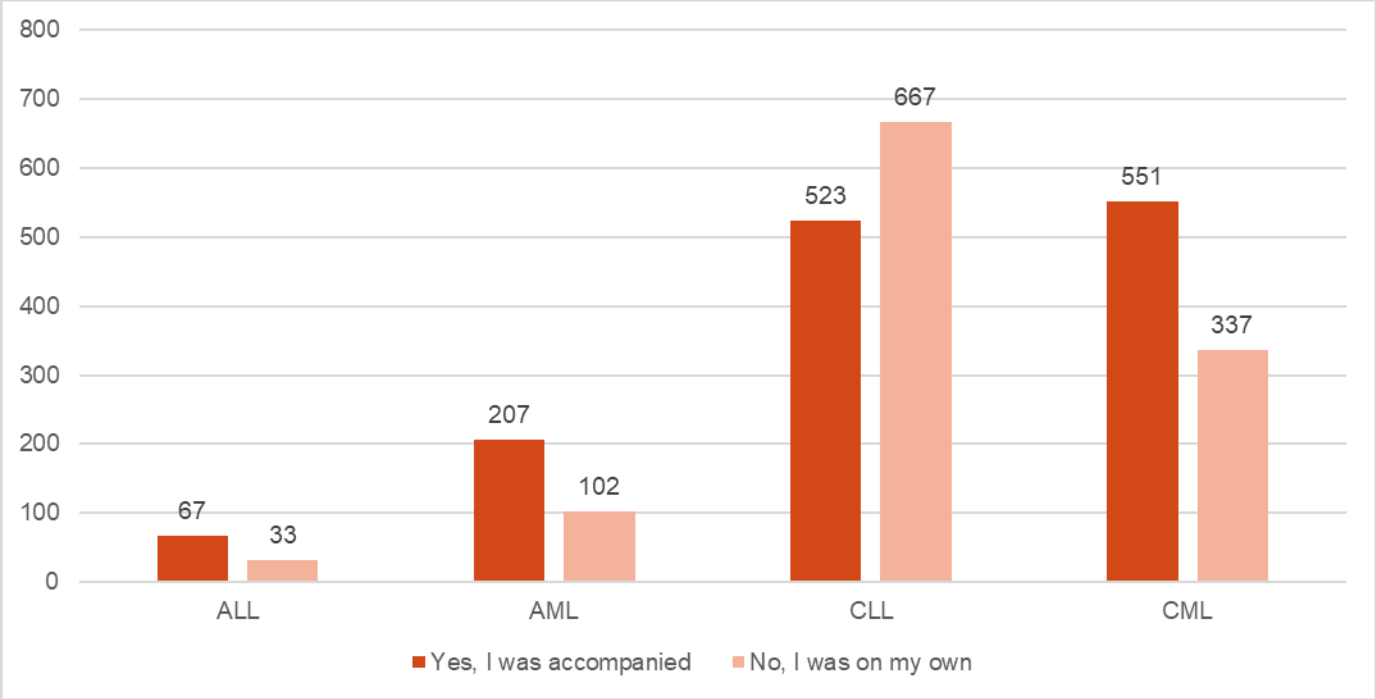
Figure 101: Q35. At diagnosis what support were you offered or directed to? (Patients)



Most respondents report that they would want information and support for their leukemia (74%, n=984). There were similar findings in the previous survey which suggests that the provision of, and referral to, support at this point for leukemia patients is still lacking.

Fifty-four percent (n= 1,413) of all respondents to the patient survey stated that they had someone with them, although this was much lower for those with CLL (44%, n=523). This is understandable as those with CLL are more likely to be older and diagnosed as the result of more routine tests than other leukemia types.

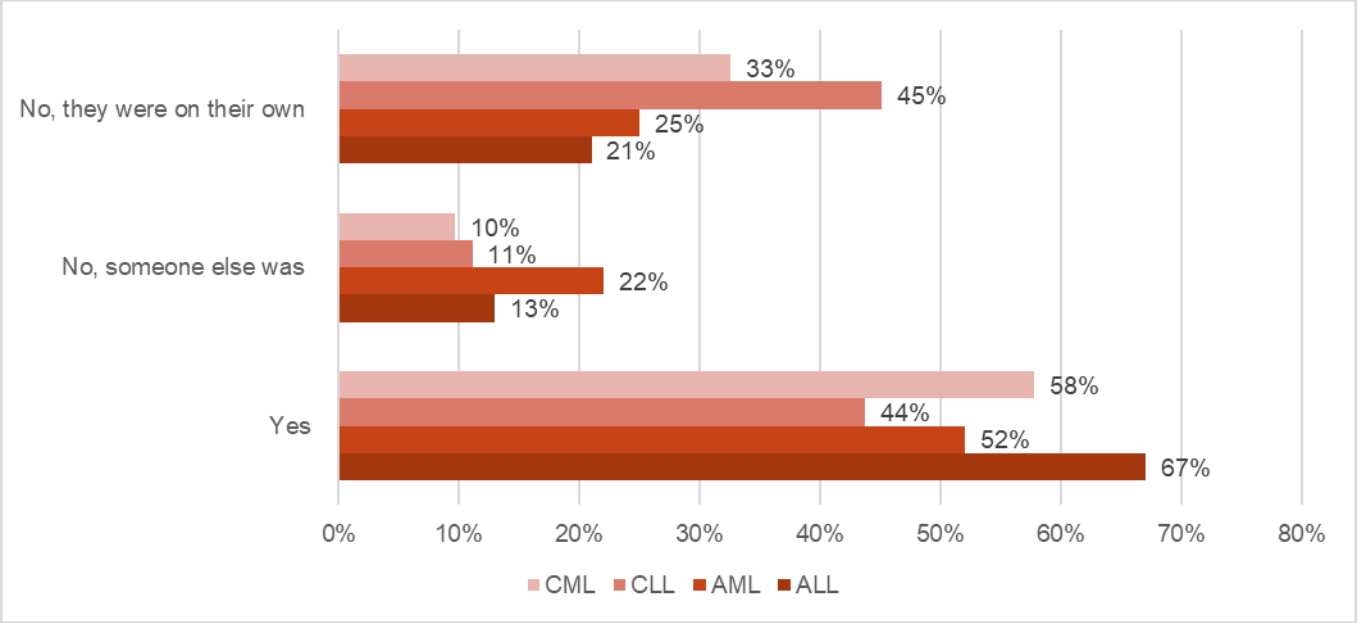
Figure 102: Q25. When you were given your diagnosis, was someone you know with you? (Patients)



Carers

The findings within the carer survey were similar (54%, n=276 of all carers said they accompanied the patient at diagnosis). This did vary by leukemia type, where those with ALL were most likely to accompany the patient (67%, n=58). CLL patients were least likely to have a carer with them at diagnosis (44%, n=63). The differences may be due to the demographic of those diagnosed with ALL vs CLL, and varying age groups of these two leukemia types.

Figure 103: Q10C. When the patient was told they had leukemia, were you with them? (carer)



11.1.3. Summary

The findings continue to suggest that patients and their carers would benefit from improvements to information provision, particularly at diagnosis. We know that effective information provision can help patients navigate their treatment journey and can help lessen the negative impact of a diagnosis.

Just 39% (n=1,027) of respondents fully understood their diagnosis. Also, 62% (n=1,636) were told about their prognosis, suggesting there are still some improvements to be made.

Lastly, information and support are not well understood by patients or well utilised by healthcare professionals. Any improvements to existing information and closer collaboration between healthcare providers and support organisations can only be beneficial for patients and their carers.

11.2. Information and support on 'Watch and Wait'

Patients

When it comes to being given written information about their 'Watch and Wait' monitoring, only a minority received any written information (CLL 36%, n=389). The majority of patients who were given information understood it at least to some extent (96%, n=1106) and of those that were not given this, most would have liked to have received it.

As 31% (n=384) of patients were also offered or directed to support, the majority were directed to sources of written information, or to patient support groups / leukemia charities.

Figure 104: Q41. When you were FIRST told you had been put on a 'watch and wait' plan were you given written information about this? (Patients)

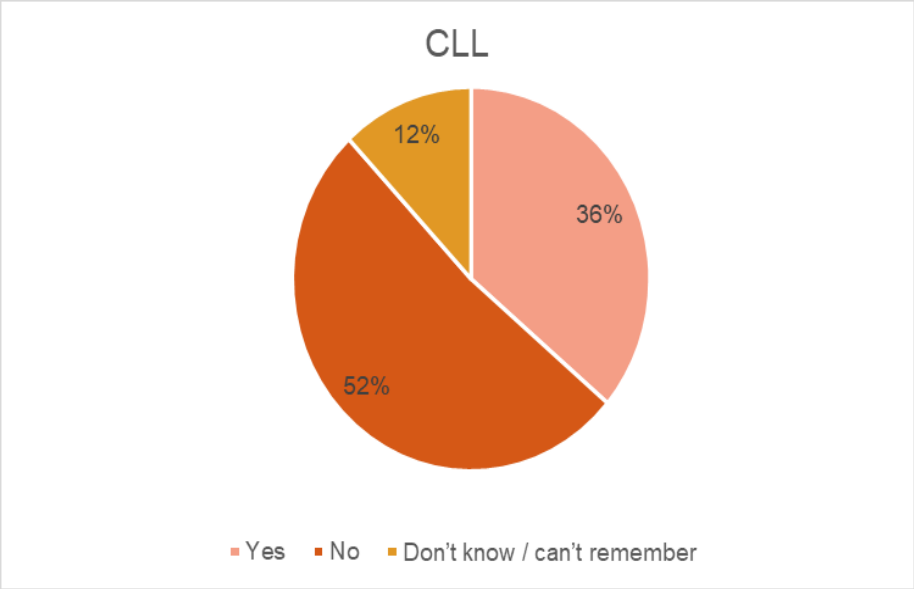
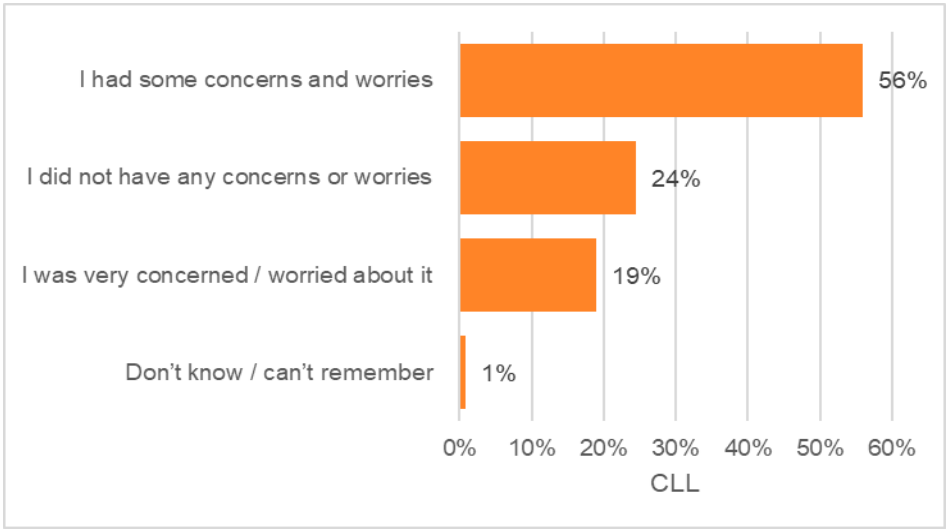


Figure 105: Q21C. How did YOU feel about the patient being put on 'watch and wait'? (How did you feel when you were put on 'watch and wait' for the FIRST time?). (carers)

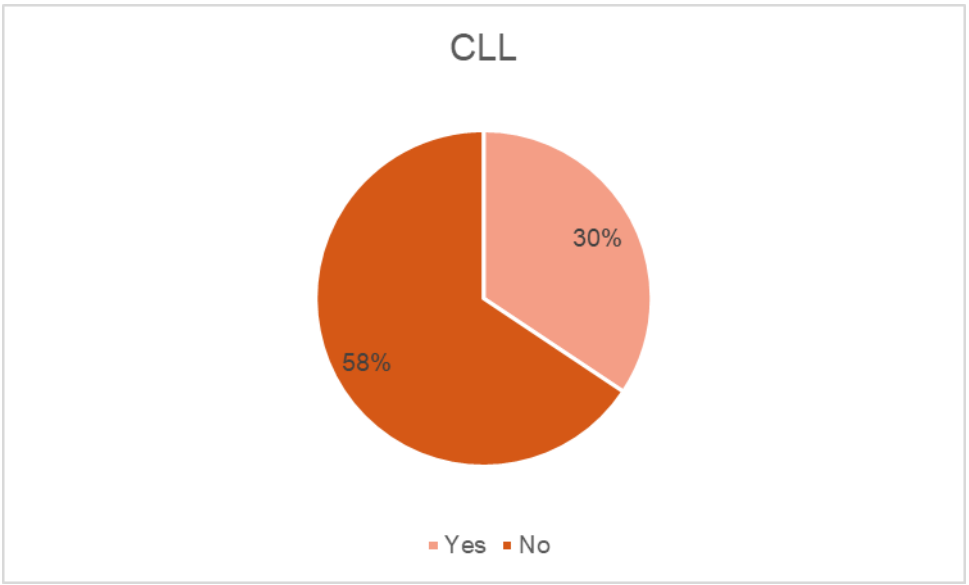


Carers

With 34% (n=63) of carers, for patients with leukemia, reported being given written information about 'Watch and Wait' and this being slightly higher in those with ALL (43%, n=3). Carers report positively on this information, where they are being given it: 100% (n=63) reported that they understood this information, at least to some extent.

Where 'Watch and Wait' is used, it is vital to provide in-depth information for patients and their carers to help them understand the implications of 'Watch and Wait' and to help alleviate concerns.

Figure 106: Q45. Were you offered or directed to any support to help with any concerns and worries about being on 'watch and wait'? (Patients)



11.3. Information and support when on treatment

In many instances, patients living with leukemia may be on treatments for extended time periods, and may undergo changes to their treatment regimen. The results of the survey demonstrate that living with leukemia, and undergoing treatment for extensive periods of time, can significantly affect the patient, especially in terms of physical and emotional wellbeing.

Coping with diagnosis and ongoing treatment also has a demonstrable impact on work and relationships.

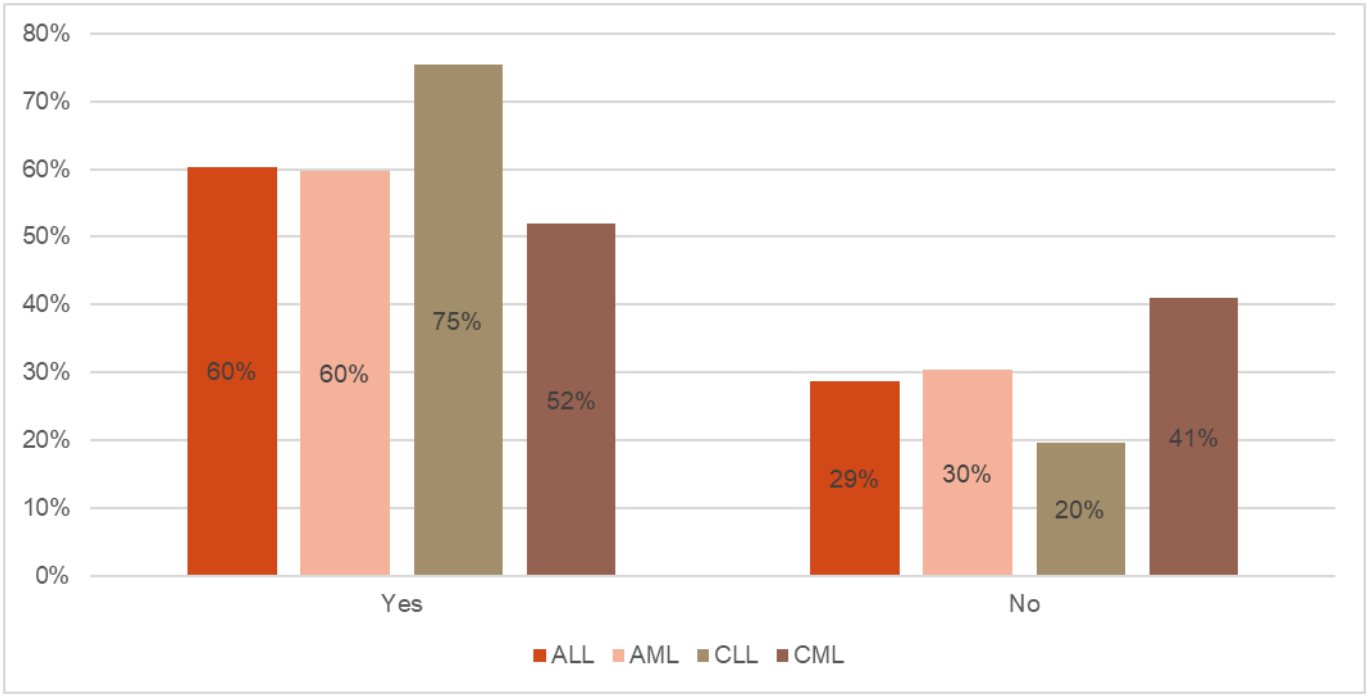
Effective information and support concerning leukemia treatment and care is crucial in helping patients and their carers better manage their disease, and its effects on their daily life.

Patients

Overall, 62% (n=1,268) of patients reported that they were given written information about their current/most recent treatment plan (see Figure 107). Patients living with a diagnosis of CLL were most likely to be given written information about their treatment plan (75%, n=498). Patients living with a diagnosis of CML were least likely to be offered written information about their treatment plan (52%, n=454).

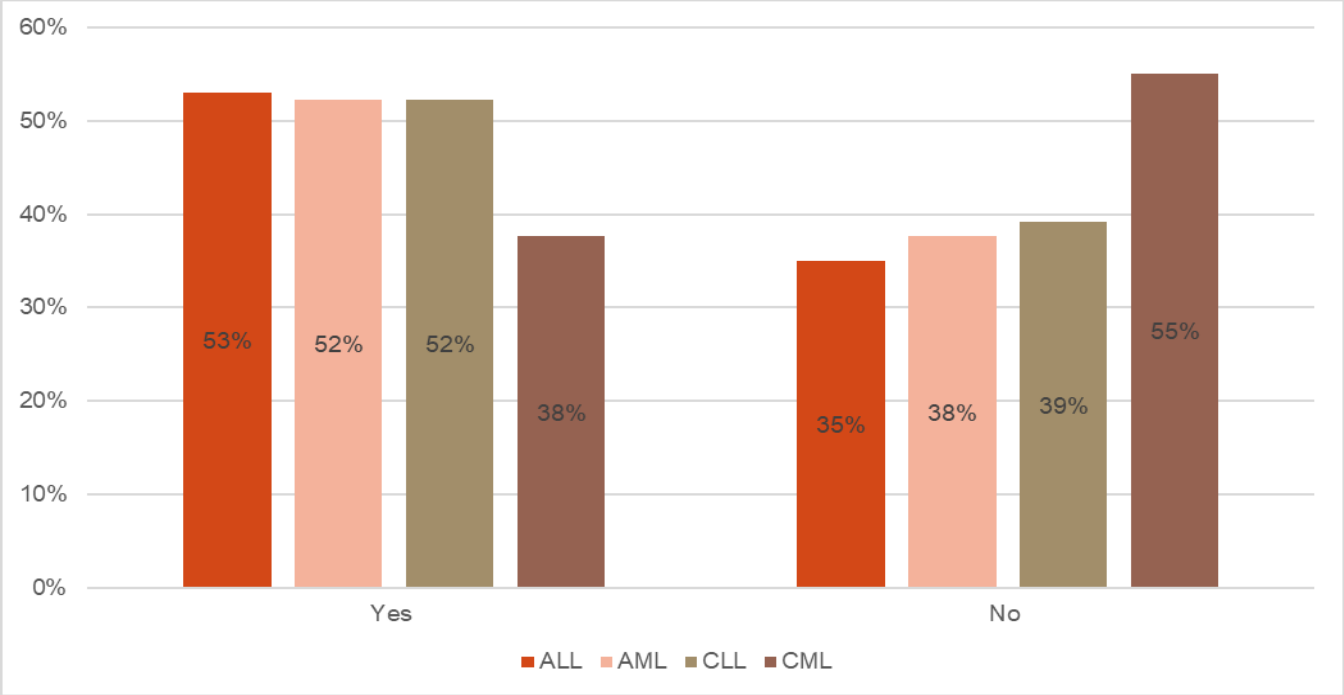
Of those patients who were not offered written information about their treatment plan, patients with CML were most likely to report that they would have liked to have been offered written information (63%, n=224). Patients with AML were least likely to report they would have liked written information (56%, n=51).

Figure 107: Q69. Were you given written information about your most recent / current treatment plan? (Patients)



Patients (46% [n=942]) were offered or were directed to support for help with any concerns around their treatment. There were some differences amongst the different leukemia subtypes. Patients with ALL were most likely to be directed to additional support (53%, n=53), while those with CML were least likely (38%, n=329).Of those patients that were not offered this support, 57% (n=524) reported that they would have liked to have been offered this. Patients with ALL were most likely to report wanting this support (74%, n=26). Those with CLL were least likely (42%, n=107).

Figure 108: Q72. Were you offered or directed to any support to help with any concerns and worries whilst being on your most recent / current treatment plan? (Patients)

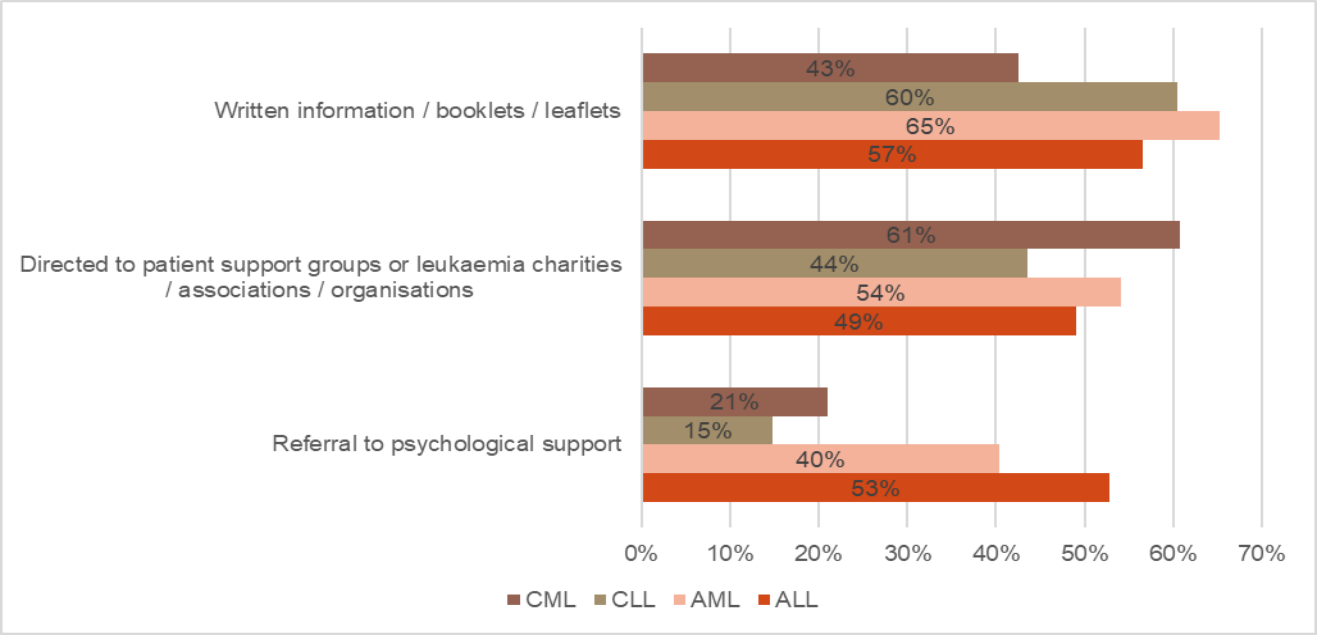


Most commonly patients are directed to sources of written information (54%, n=513) or directed to patient support groups (53%, n=199).

Patients living with a diagnosis of ALL were most likely to be offered psychological support (53%, n=28) compared to those with CLL, who were least likely being offered this (15%, n=51).

Majority of ALL patients (74% [n=26]) were not offered support, although they would have liked it. This was much lower for patients with CLL (42%, n=107).

Figure 109: Q73. While on your most recent / current treatment plan what support were you offered or directed to?



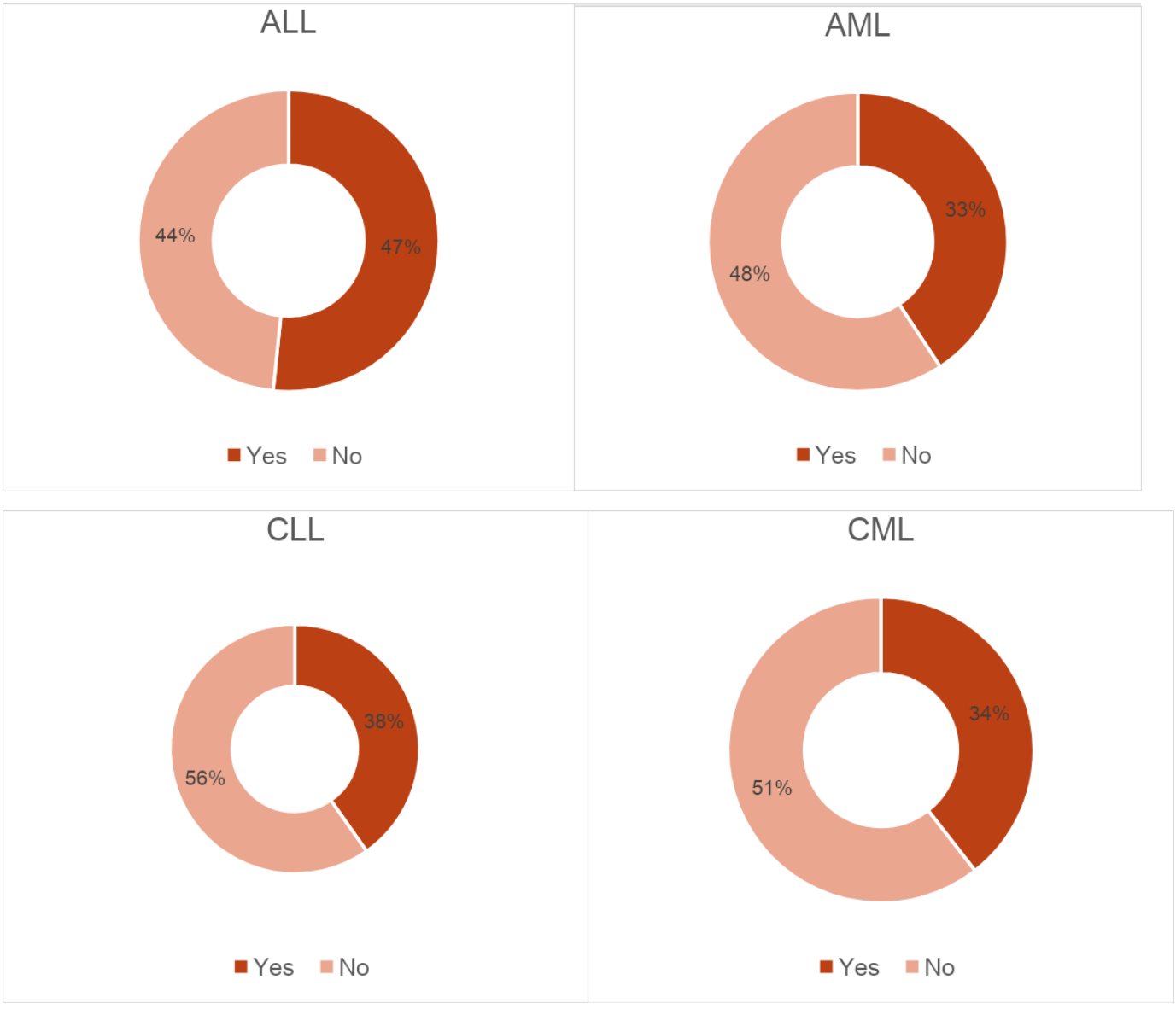
Carers

Just 37% (n=174) of carers reported that they were provided with information about the patients' treatment. This did vary amongst the leukemia subtypes. Carers of patients with a diagnosis of ALL were most likely to report receiving written information (47%, n=47).

In all, 49% (n=145) of carers, who did not receive any information, reported that they would have liked this. There were no noticeable differences across the leukemia types.

Of those carers that were provided written information, it was well understood. Fifty-two percent (n=90) understood this information completely with a further 45% (n=79) understanding it to at least some extent.

Figure 110: Q28C. Were YOU given or directed to written information about the patient's / your most recent / current treatment plan? (carer)



Patients

Of the different types of information on offer, patients were most likely to be offered information on side effects of their leukemia treatment. However, this particular information was least likely to be offered to patients with CLL; this is perhaps understandable as fewer of these patients access treatment.

Twenty-three percent (n=601) of respondents did not have information on end-of-life care and 42% (n=1,124) of patients felt information on end-of-life care was not applicable to them. Patients with CLL were most likely to report never receiving any information on end-of-life care (33%, n=392).

Of the information that was provided, this was most often provided after or during treatment at each point that patients were asked about (see Figure 111).

Carers

There were similar findings in the carer survey. Most carers noted that they had received information about side effects. Only 14% (n=79) of carers reported that they had not received this information. Carers of patients with CLL were least likely to have been given this information which is in line with the patient survey.

Sixty-six percent (n=360) of carers stated that they have either never received information about end-of-life care or felt that this was not applicable to them.

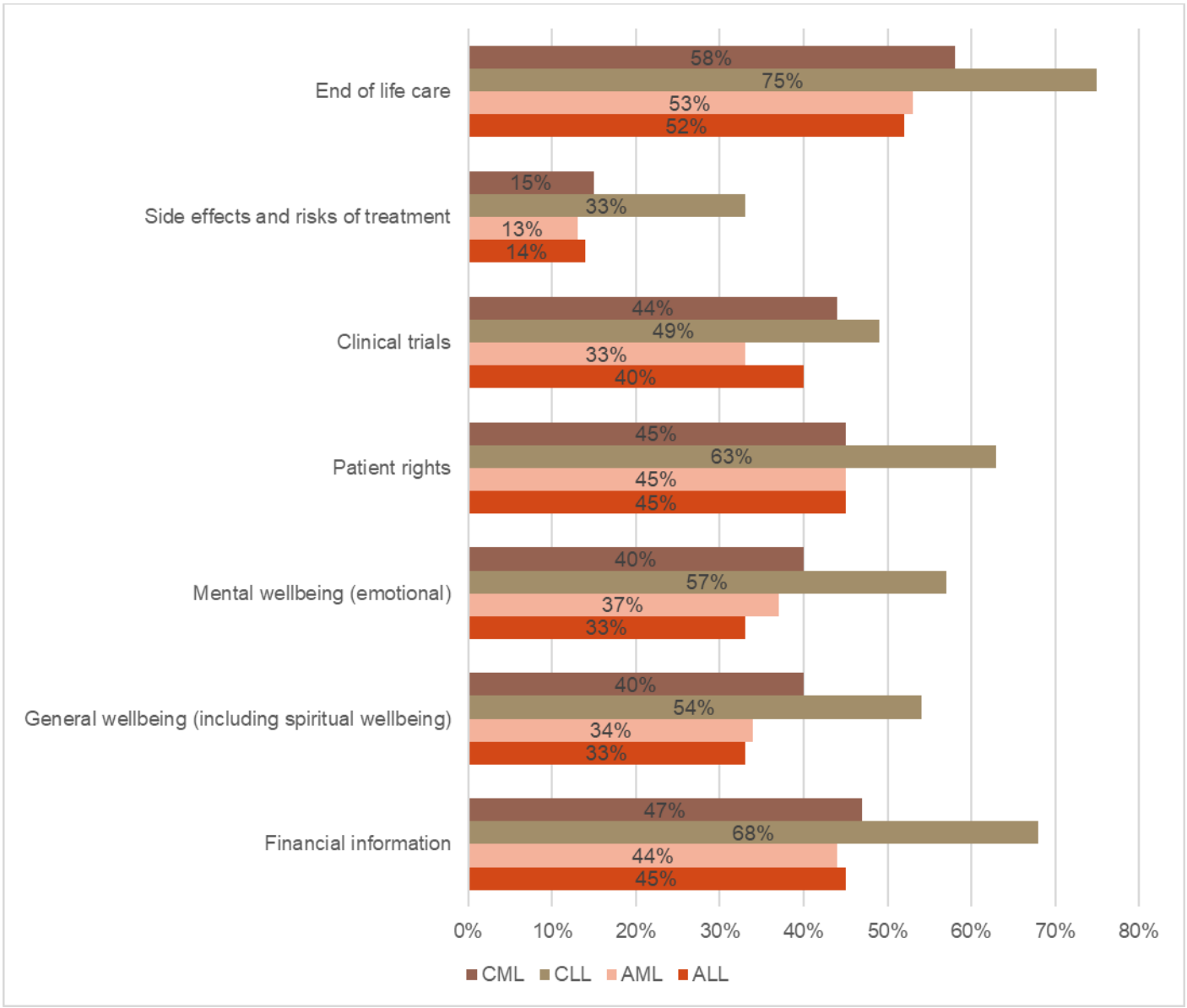
Figure 111: Information given or directed to patients throughout their blood cancer journey

In contrast to the patient survey, most carers reported receiving adequate information at diagnosis, with an exception for patients with CLL.

A slightly higher proportion of ALL carers reported receiving information for each aspect than AML and CML carers.

Although, most patients and carers reported having some form of information provided at some point in the patient's pathway, it is clear from this data that gaps remain. In particular, those with CLL seem to be less likely to be provided with any information from the viewpoint of both patients and carers.

Figure 112: Information given or directed to during your treatment journey: Never and Not Applicable (Patients)

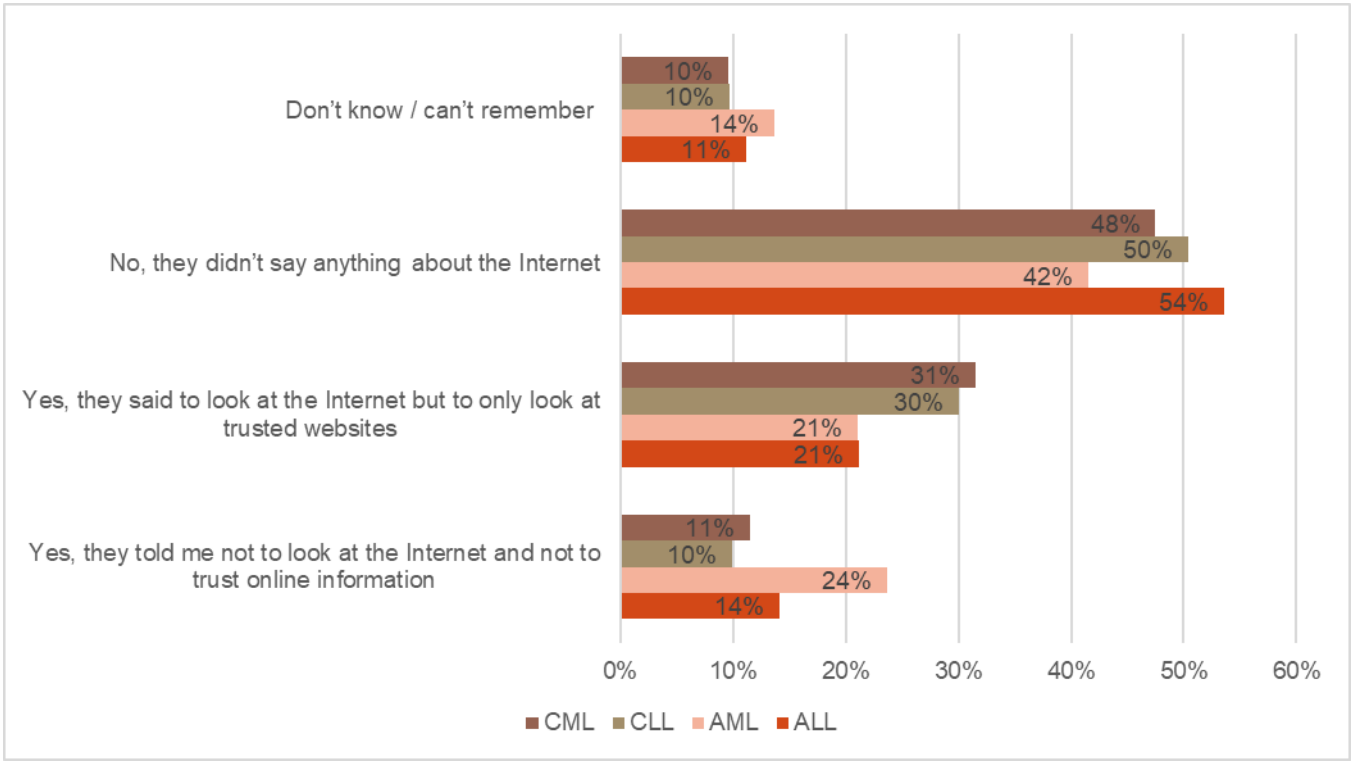


11.4. Information from the Internet

Forty-eight percent (n=1227) of patients stated that their healthcare professionals did not say anything about the internet. There were some differences between leukemia subtypes: 14% (n=14) of ALL, 24% (n=73) of AML, 10% (n=114) of CML, and 11% (n=99) of CLL patients were told not to look at the internet. The findings were similar in the carers survey.

However, the vast majority of patients (92%, n=2362) stated that they had used the internet to research their leukemia and appropriate treatments. This was slightly higher for those with chronic disease (94% CML, n=810 and 94% CLL, n=1,098) than those with acute leukemia (AML 82%, n=252 and ALL 89%, n=89).

Figure 113: Q164. At any point in your diagnosis or treatment journey has a healthcare professional made reference to online information or the Internet? (Patients)

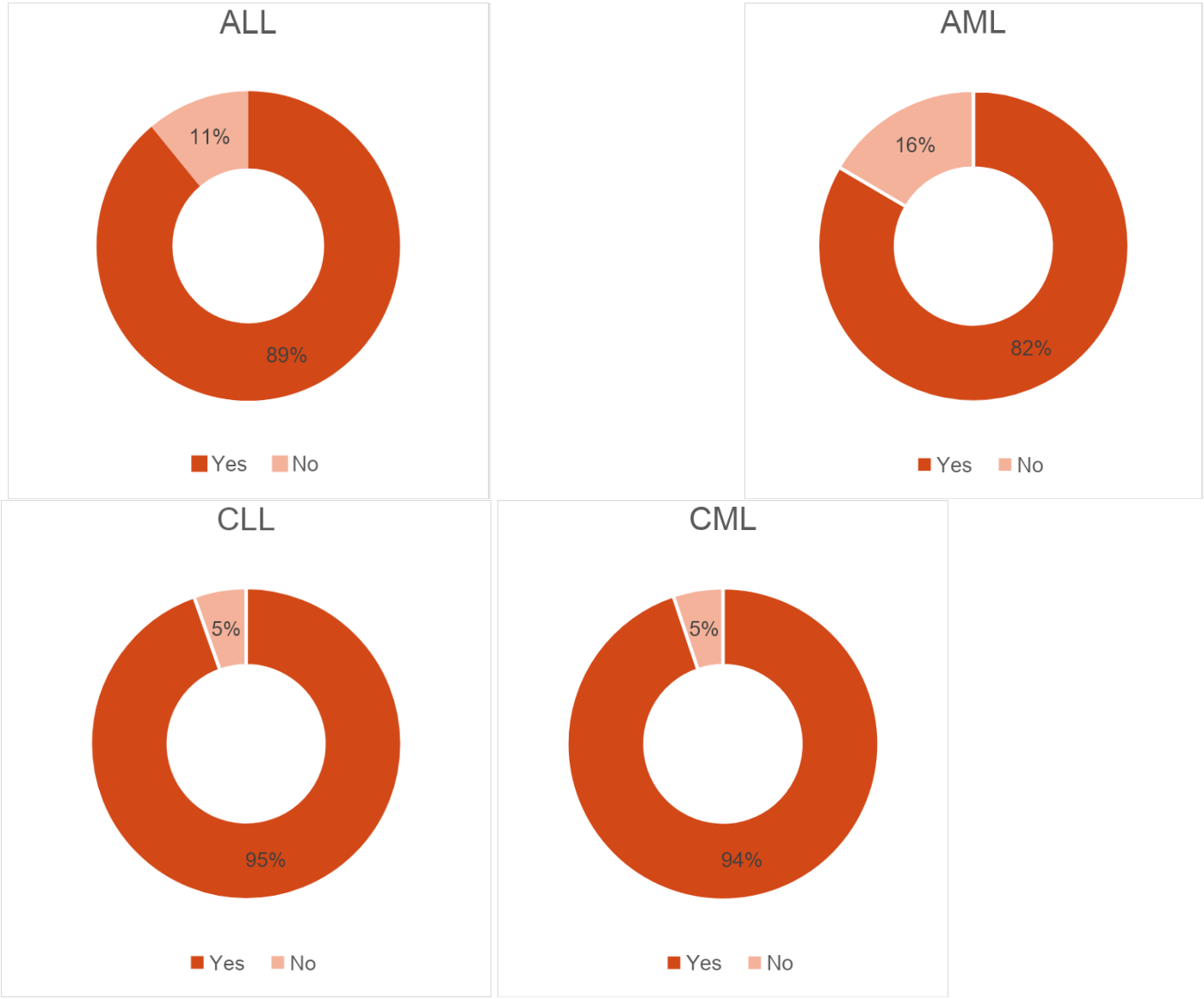


Nearly half of the patients (51% [n=1246]) did not respond to the question about websites recommended by their healthcare team, whereas 86% (n=2178) responded about websites recommended by support organisations.

Patients were positive about websites recommended by support organisations with most patients rating them as either good or very good (78%, n=1981). Patients living with CLL were most likely to be positive about websites recommended by support groups (86%, n=1,002 rated them as good or very good).

From the carers survey, more carers for those with ALL (67%, n=48) and CML (71%, n=89) received information from their healthcare professional than those with AML (53%, n=50) and CLL (60%, n=56). Carers responded similarly to patients: most people rated the information from support organisations as good or very good compared to information they were able to get from anywhere else.

Figure 114: Q165. Have you ever used the Internet to find information regarding your leukemia and/ or treatment?



The data from the survey continue to demonstrate that people living with leukemia feel that they need further information about their illness and treatments than is provided by their healthcare team. In addition, information provided online needs to be accessible and helpful to maximise benefit to leukemia patients and their carers. Using a collaborative approach between healthcare professionals and support groups to collate and share appropriate and relevant resources with patients and carers, it will help to maximise the information and support available for those with leukemia, their carers, and wider family.

11.5. Additional areas/types of support

Thirty-seven percent (n=977) of patients were not told about or signposted to additional support (38% of ALL, n= 39, 39% of CLL, n=464 and 40% of CML, n=360). Patients living with CML were least likely to be signposted to additional support (40%, n=360), compared to patients living with AML, who were most likely (75%, n=234).

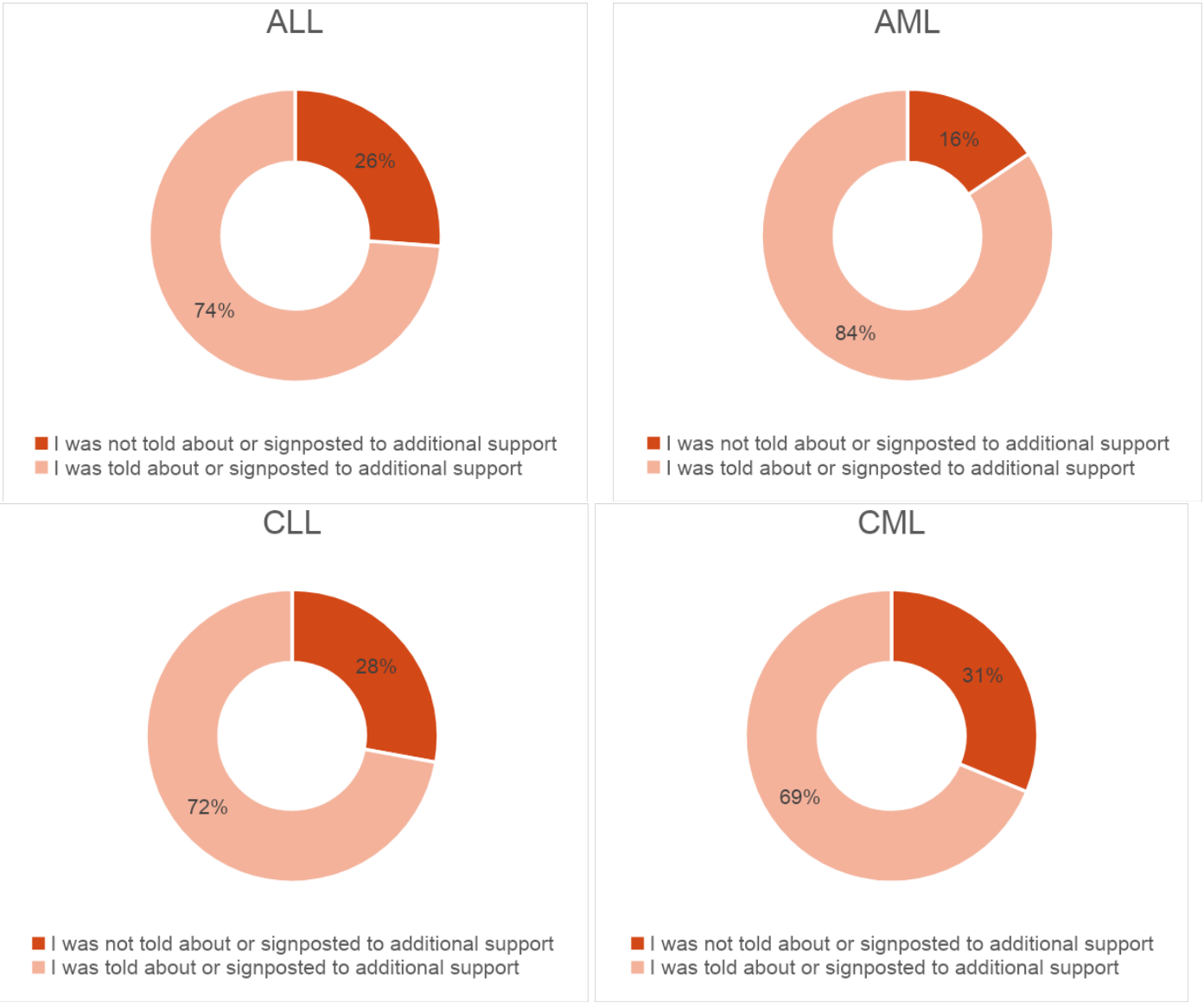
As 26% (n=27) of ALL, 37% (n=445) of CLL, 39% (n=123) of AML, were directed to support from a CNS (Clinical Nurse Specialist, a nurse acting as the main point of contact for patients and their care), this was much lower (17%, n=153) for those with CML.

The highest proportion of CML patients were referred to support groups than any other type of support.

Those with acute leukemia were most likely to be referred for psychotherapy/counselling (29%, n=30 ALL and 31%, n=97 AML). For those with chronic disease this was much lower: 10% (n=119) for CLL and 13% (n=120) for CML. This is perhaps surprising considering chronic leukemia is a lifelong condition. Additional support for people with chronic disease could help them to navigate the different aspects of their journey.

The responses here suggest that the provision of access to additional support is lacking across all leukemia types.

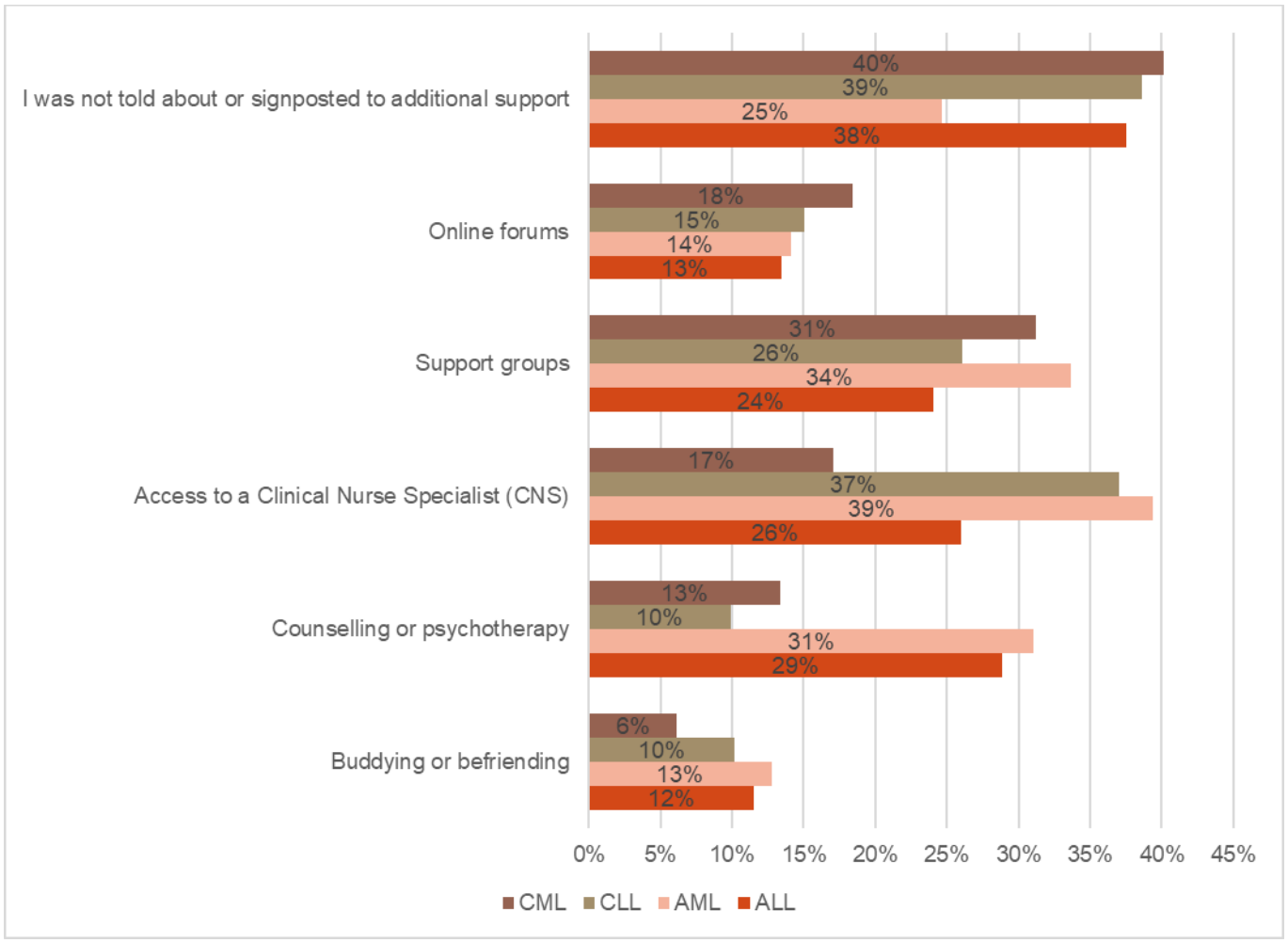
Figure 115: Q114. Were you told about, or signposted to additional support in any of the following areas?



Overall, 59% (n=1,222) accessed the support that they were offered and this was similar across all leukemia types.

Of those that did access additional support, it is universally well received. Majority of respondents (94% [n=1,188]) reported that the additional support helped them, at least to some extent.

Figure 116: Q170. Were you told about, or signposted to additional support in any of the following areas?



11.6. Summary

Encouragingly, most patients responded that they had received information at some point in their journey. This was most often during or after treatment, although carers reported this was most likely received at an earlier stage. It was likely to be either at diagnosis, or before treatment was provided.

Of all the different types of information provided, information on side effects of treatment was the most likely to be provided to patients.

However, overall, there remain gaps in information provision, and wider support, to both patients and carers. This is apparent across the entire patient journey, from diagnosis onwards.

Patients and carers have different needs and concerns at different points, and this should be addressed as part of healthcare monitoring. Healthcare providers and support organisations should work collaboratively to improve the situation for patients, ensuring care is tailored for each individual and their circumstances.

12. Impact of the COVID-19 pandemic

The COVID-19 pandemic has had a profound and lasting impact on healthcare provision across the world. As part of this survey, we wanted to explore the impact on leukemia patients and their carers, during the pandemic and any long-lasting effects that they experienced.

Figure 117: Q174. Overall, did you receive enough guidance from your country's government / leaders to protect yourself from COVID-19 infection? (Patient)

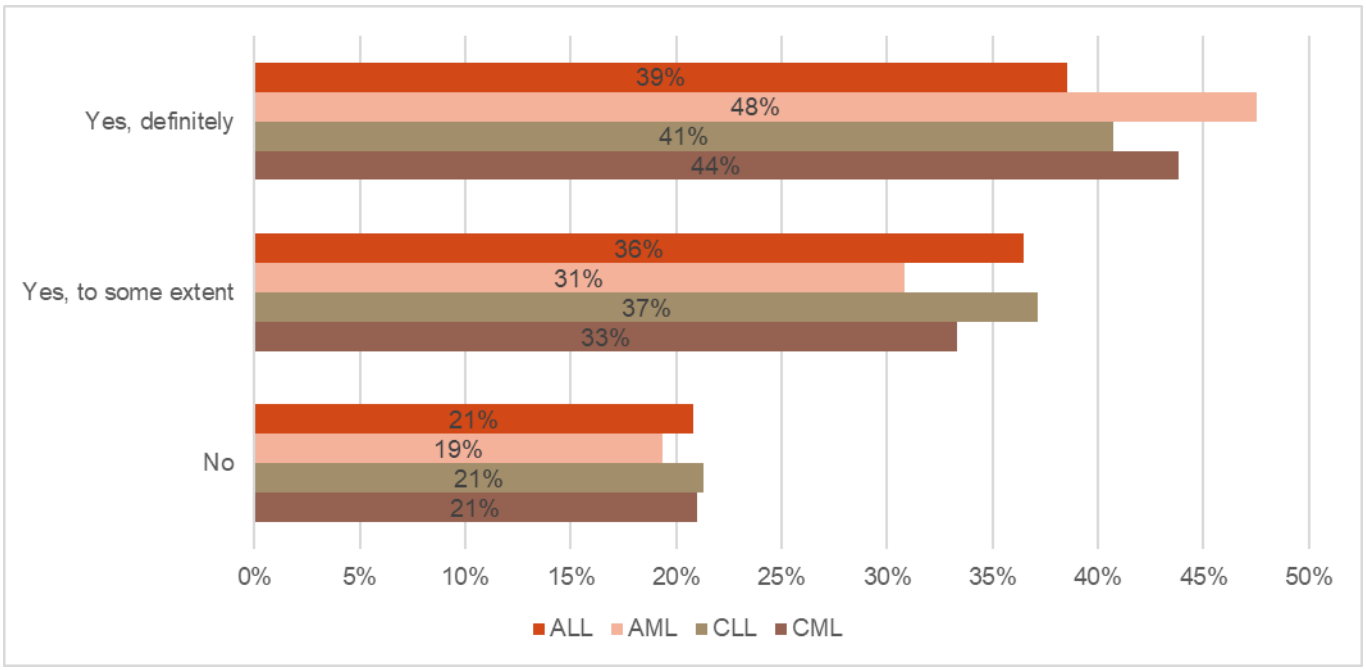
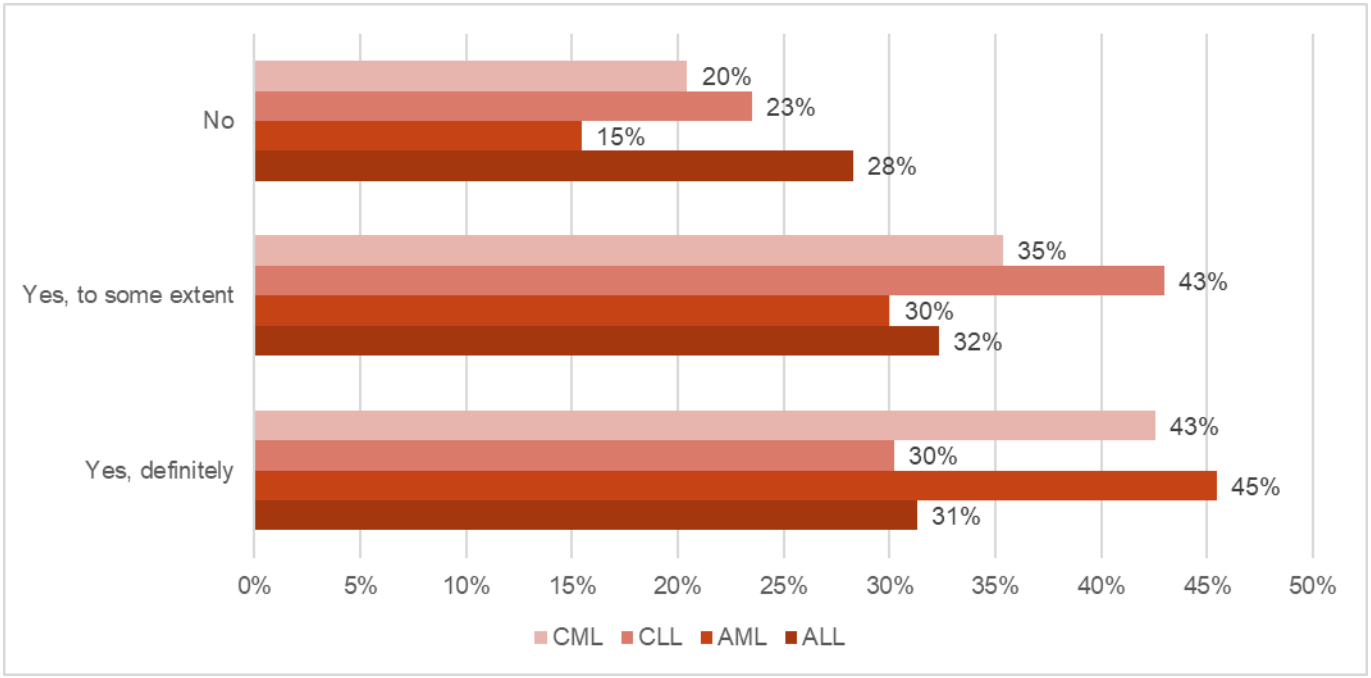


Figure 118: Q. 64C Overall, did YOU receive enough guidance from your country's government / leaders to protect yourself from COVID-19 infection? (Carers)



Over three quarters of patients (78%, n=1986) surveyed across the world felt that, at least to some extent, they had had enough guidance from their government to protect themselves against infection from COVID-19 (see Figure 117and Figure 118).

Patients living with ALL were least likely to report they had definitely received this guidance. This was broadly in line with the carers survey, where 73% (n=413) felt that they had enough guidance.

Carers were also asked about guidance that they received from doctors and support organisations and 68% (n=388) of carers felt that they had received enough guidance from doctors, whereas only 56% (n=318) felt that they had had enough guidance from their support organisations.

Figure 119: Q65C. Overall, did YOU receive enough guidance from your doctor/s on how to protect yourself from COVID-19 infection? (carers)

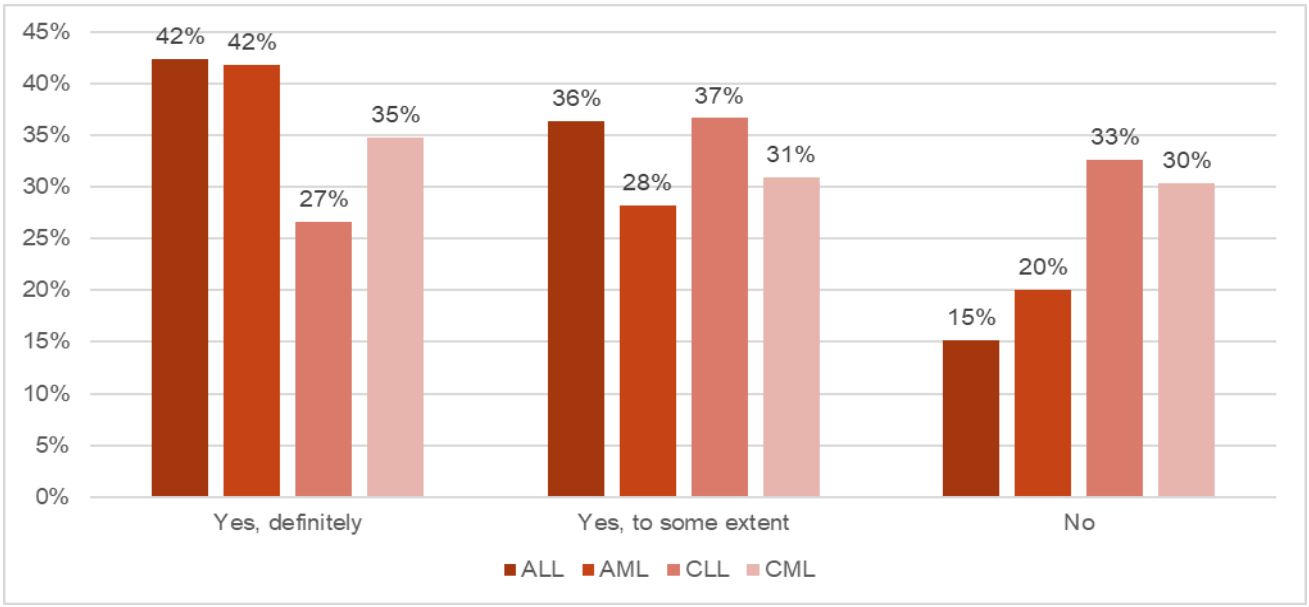
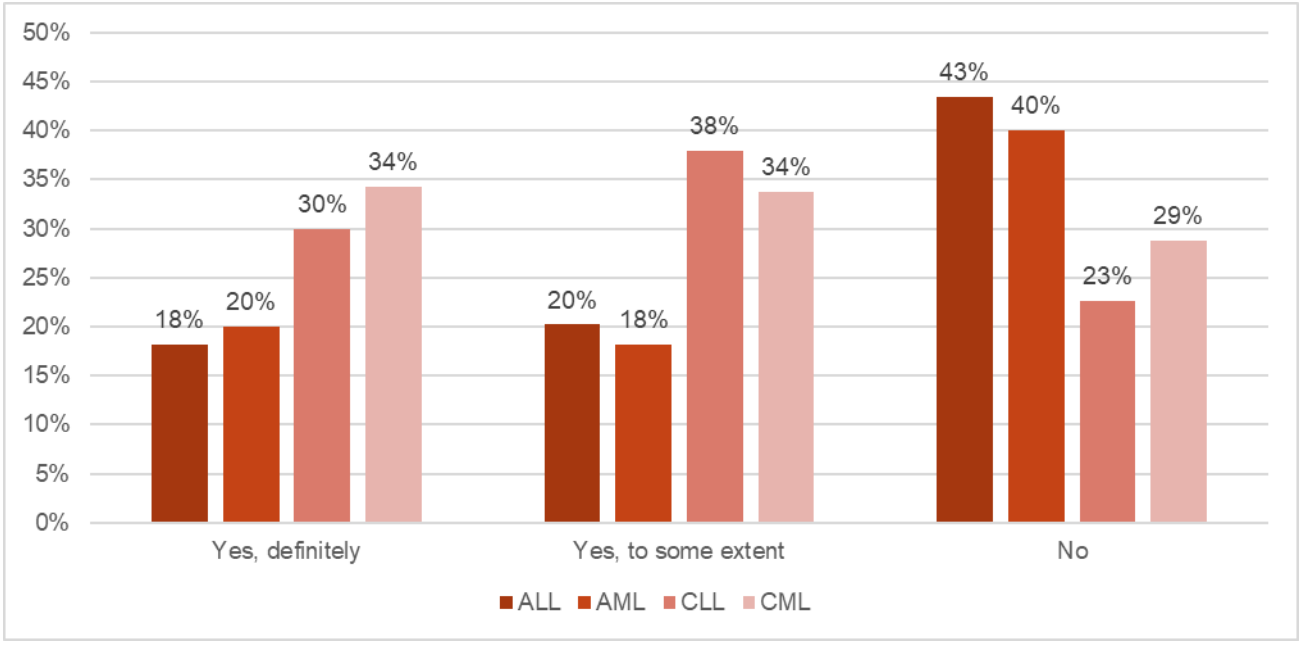


Figure 120: Q. 66C. Overall, did YOU receive enough guidance from patient organisations on how to protect yourself from COVID-19 infection? (Carers)



12.1. Shielding

When asked about ‘shielding’ (defined in the questionnaire as ‘protecting yourself by staying at home and having little or no in person contact with people outside your household’), the vast majority of respondents across the world had shielded during the pandemic, and this was broadly the same across leukemia types.

Although overall the proportion was the same, slightly more CLL reported that they were still shielding at the time of the survey than the other leukemia types (see Figure 108).

Responses from carers were all broadly in line with the responses from patients, which were expected.

Figure 121: Q175. Did you shield during the pandemic? (Patient)

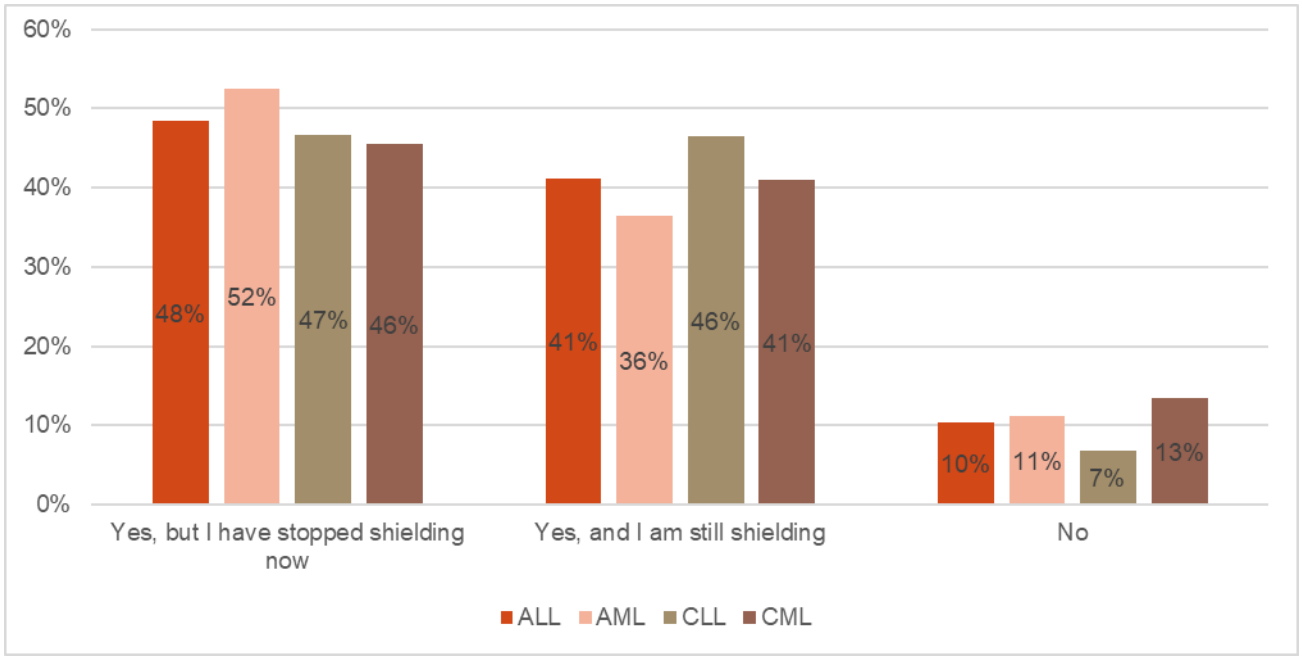
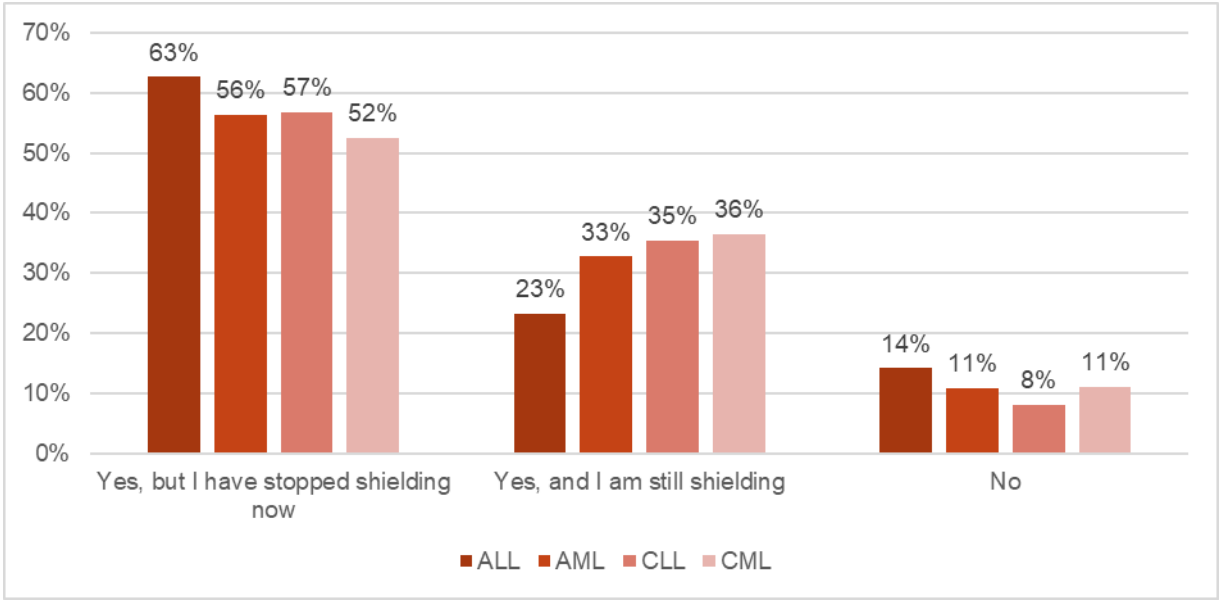


Figure 122: Q67C. Did you shield during the pandemic? (Carer)



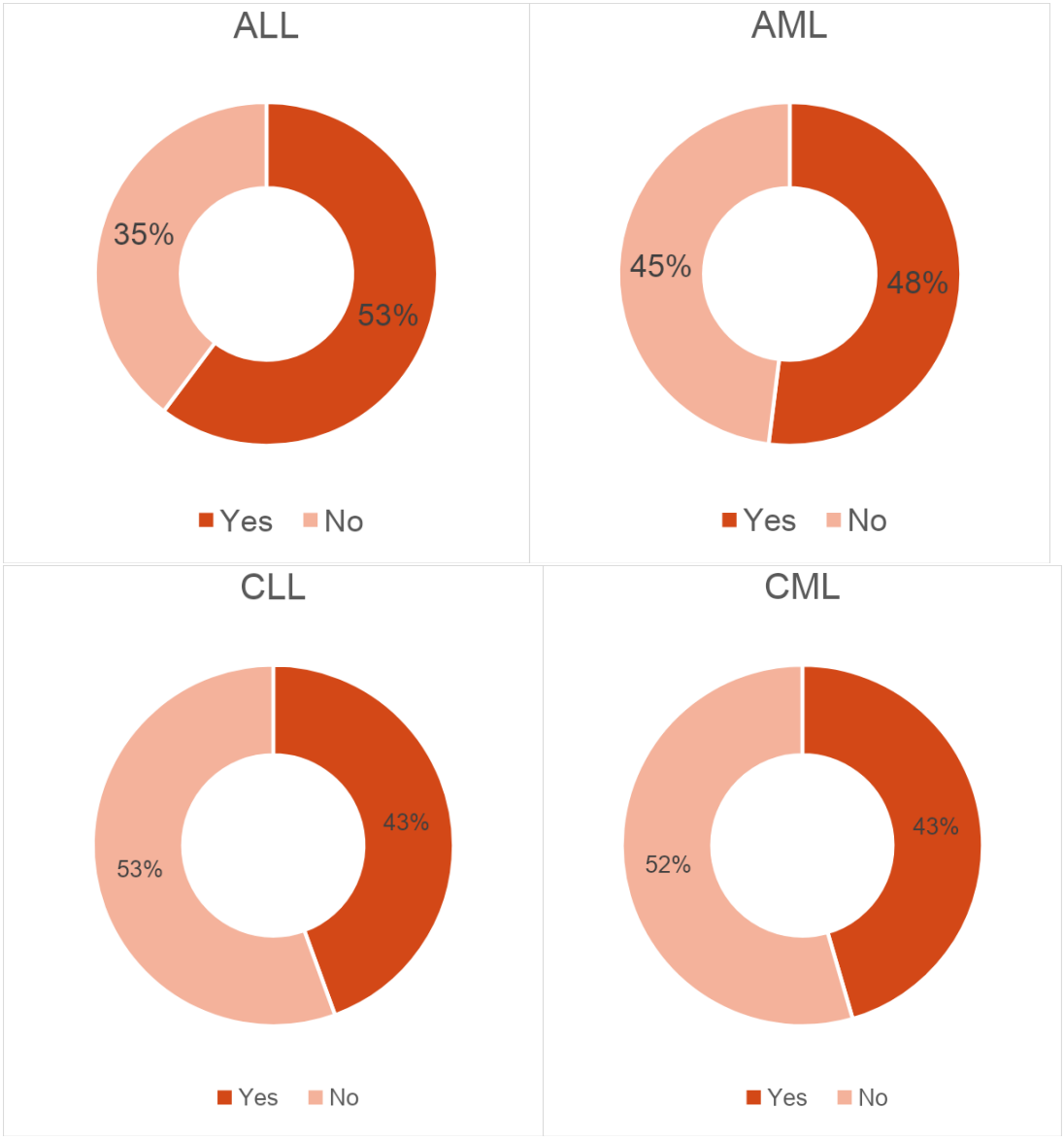
12.2. Healthcare appointments and treatment

Whilst the COVID-19 pandemic was a challenging time for everyone, it was particularly difficult for those with ongoing and serious health conditions. This is especially the case for those that have conditions such as those with leukemia.

Information, guidance, and support, from the government and healthcare providers was important to help patients to navigate the difficulties and dangers of the pandemic.

Only 44% (n=1,111) of patients who responded to this survey reported being in touch with their healthcare teams during the pandemic. This was highest for those with ALL (53%, n=50) and lowest for those with CLL (43%, n=495) and CML (43%, n=374).

Figure 123: Q176. Did your healthcare team communicate with you about how your care and treatment for leukemia may be affected by COVID-19? (Patients)

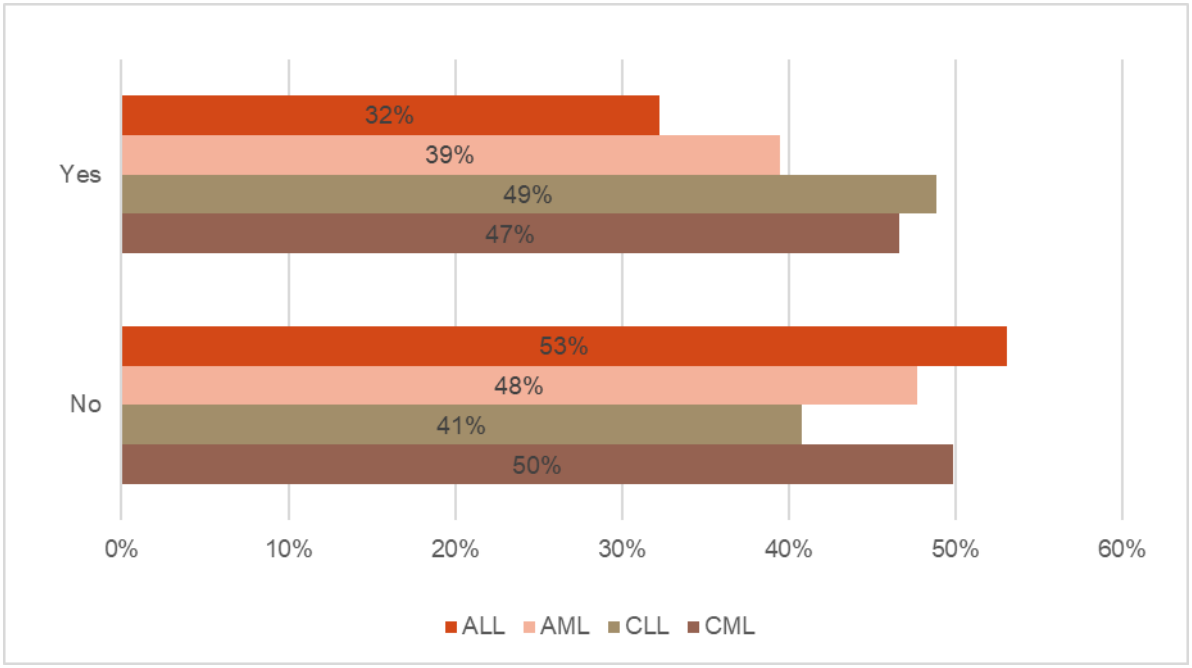


Due to the restrictions on ‘in person’ appointments during the pandemic, patients were often unable to be seen face to face. There was a move to using digital appointments – such as connecting with a healthcare professional via an online teleconference service, such as MS Teams or Zoom.

We asked patients about changes to their treatment due to COVID-19. Twenty-one percent (n=549) said that this question was not applicable to them. Just 9% (n=242) reported that they had their treatment changed. CML patients were most likely to report a treatment change due to COVID-19 (12%, n=100), AML patients were least likely to report a change in treatment due to COVID-19 (7%, n=21).

We then asked patients whether any of their inpatient appointments were cancelled due to COVID-19. Consequently, 47% (n=1,192) reported that they had inpatient appointments cancelled due to the pandemic. CLL patients were most likely to report having an appointment postponed or cancelled (49%, n=571), ALL least likely (32%, n=31).

Figure 124: Q179. Has your healthcare team postponed or cancelled any of your “in person” appointments due to COVID-19? (Patients)



Of the patients that stated they had utilised remote appointments, 60% (n=926) reported being satisfied or very satisfied with these. Patients living with AML were most satisfied with their remote appointments (68%, n=116 reported they were satisfied or very satisfied). Patients living with CLL were least satisfied with their remote appointments (59%, n=461 reported being satisfied or very satisfied).

Patients were then asked about their opinion on their care and treatment during COVID-19 compared to their “normal” care and treatment. Half of the respondents (n=1,265) felt that their care was the same. This was a little better for those with chronic disease, where 53% (n=457) of those with CML and 52% (n=602) with CLL felt their care was the same. Those living with acute disease were less positive. Carers responses were broadly the same.

As many patients were still shielding at the time of this survey and the threat to the immune system from COVID-19 was still ongoing, it would be worth exploring relevant and appropriate use of technology to improve and develop healthcare for leukemia patients across the globe - especially with a view to potentially new pandemics.

Figure 125: Q180. Did your healthcare team replace any of your "in person" appointments with remote video or phone appointments? (patients)

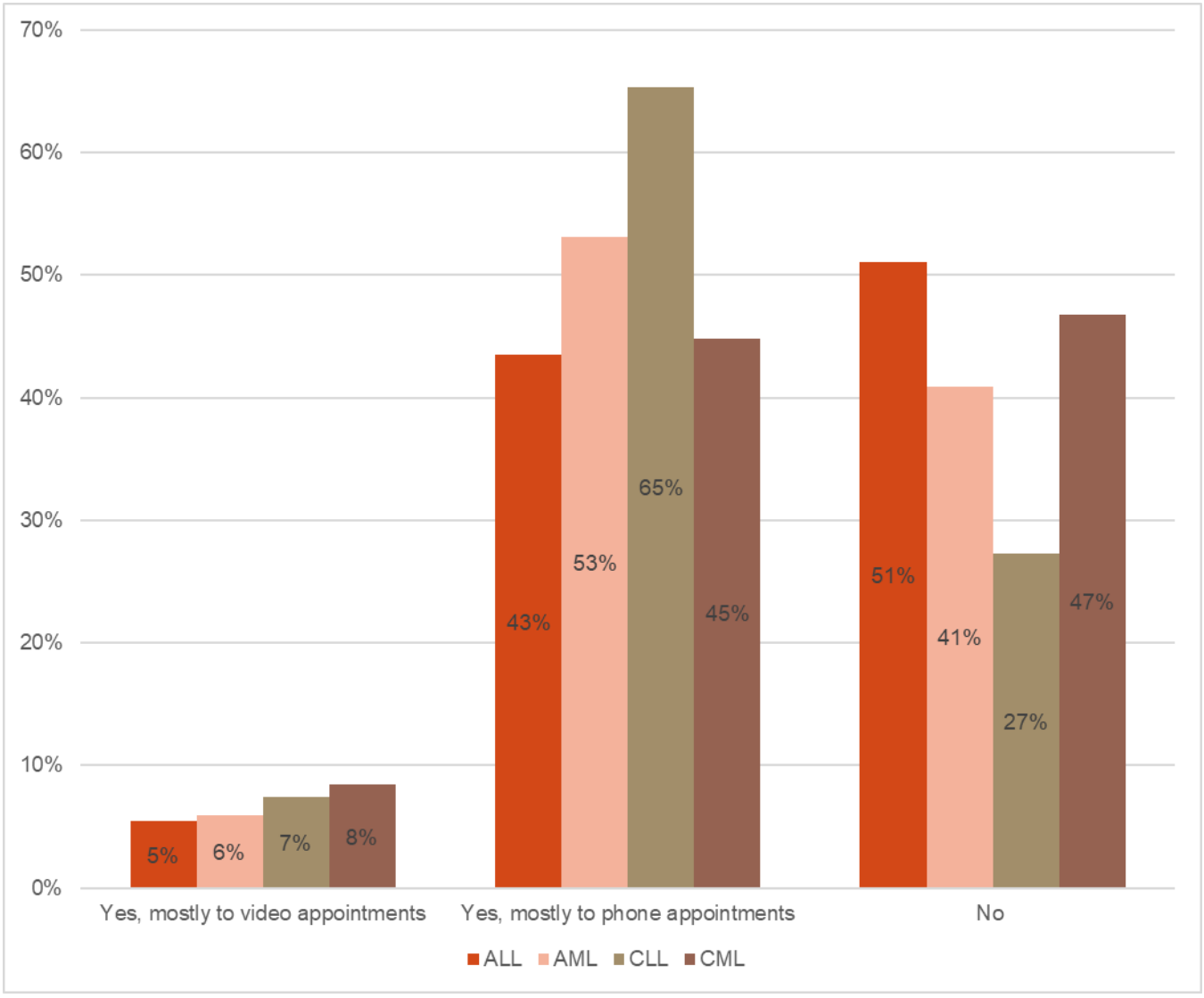
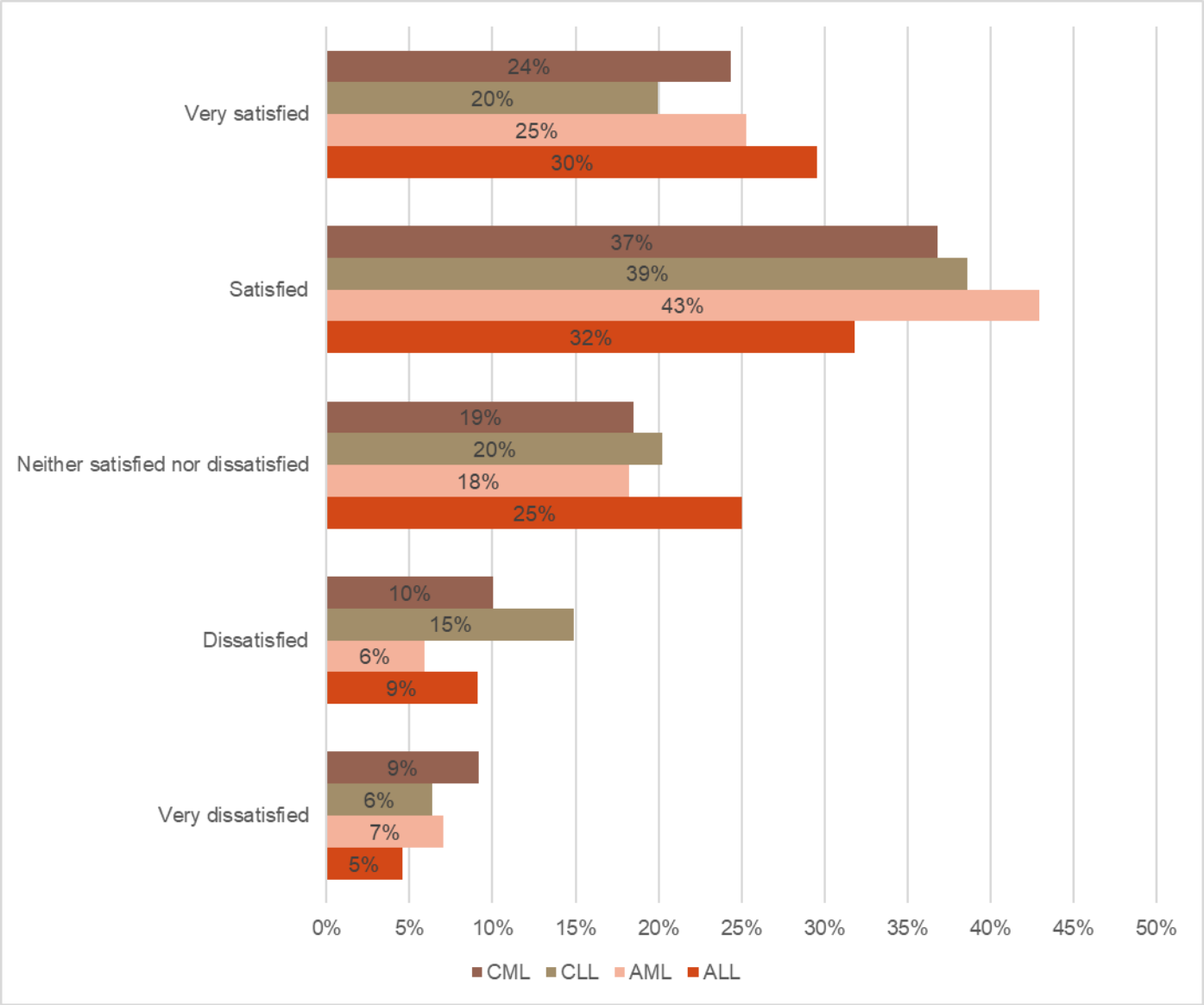


Figure 126: Q181. How satisfied were you with your remote appointments?



The majority of patients (88%, n=2058) did not cancel appointments themselves due to COVID-19. Those with CML (20%, n=167) were the most likely to cancel, and those with AML (8%, n=21) and CLL (8%, n=84) were least likely.

The majority of people that responded to this survey had not had COVID-19 (over 85%, n=2173). In contrast, 48% (n=270) reported having had a previous COVID-19 infection.

The majority of patients reported that they would continue to utilise safety measures against COVID-19 after they had been vaccinated. The most noted methods were handwashing and mask wearing. Most patients also noted that they would continue social distancing and avoid crowded places, while those with CML reported lower likelihoods of using protective measures (see figure 130).

Although fewer carers than patients reported that they would continue with safety measures overall, 81% (n=461) stated that they would continue with handwashing and 68% (n=390) would avoid crowded places (see Figure 129).

Figure 127: Q184. Have you had COVID-19?

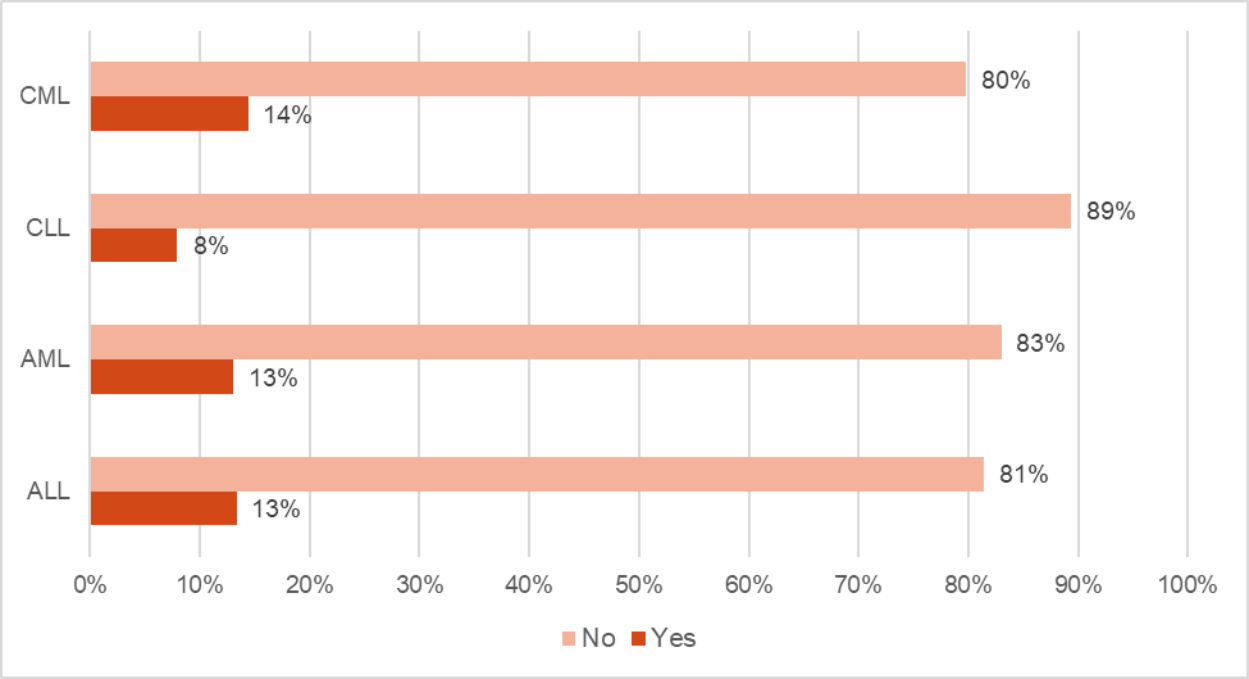


Figure 128: Q186. What safety measures will you continue after vaccination to protect yourself from COVID-19 infection? Please tick all that apply

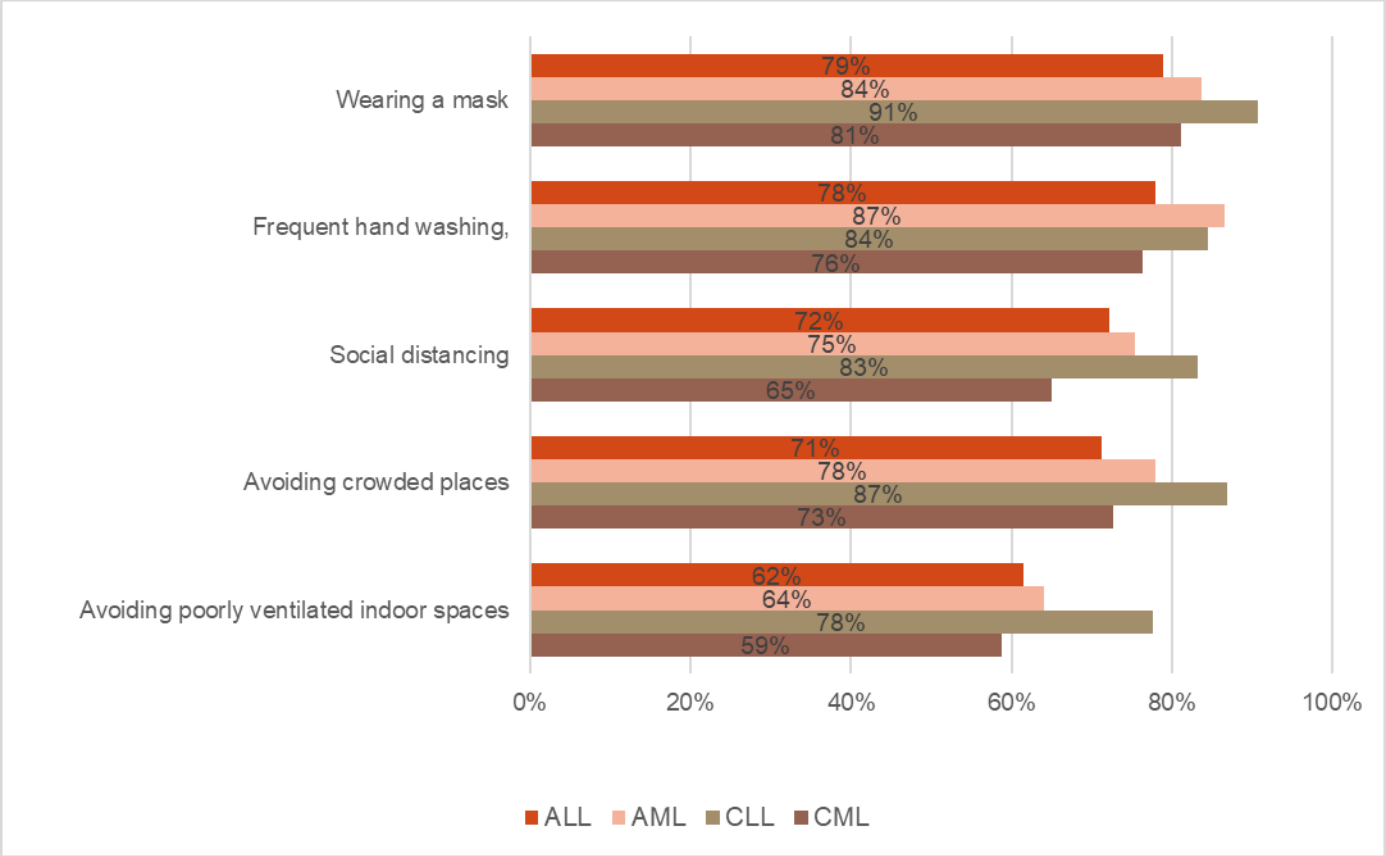
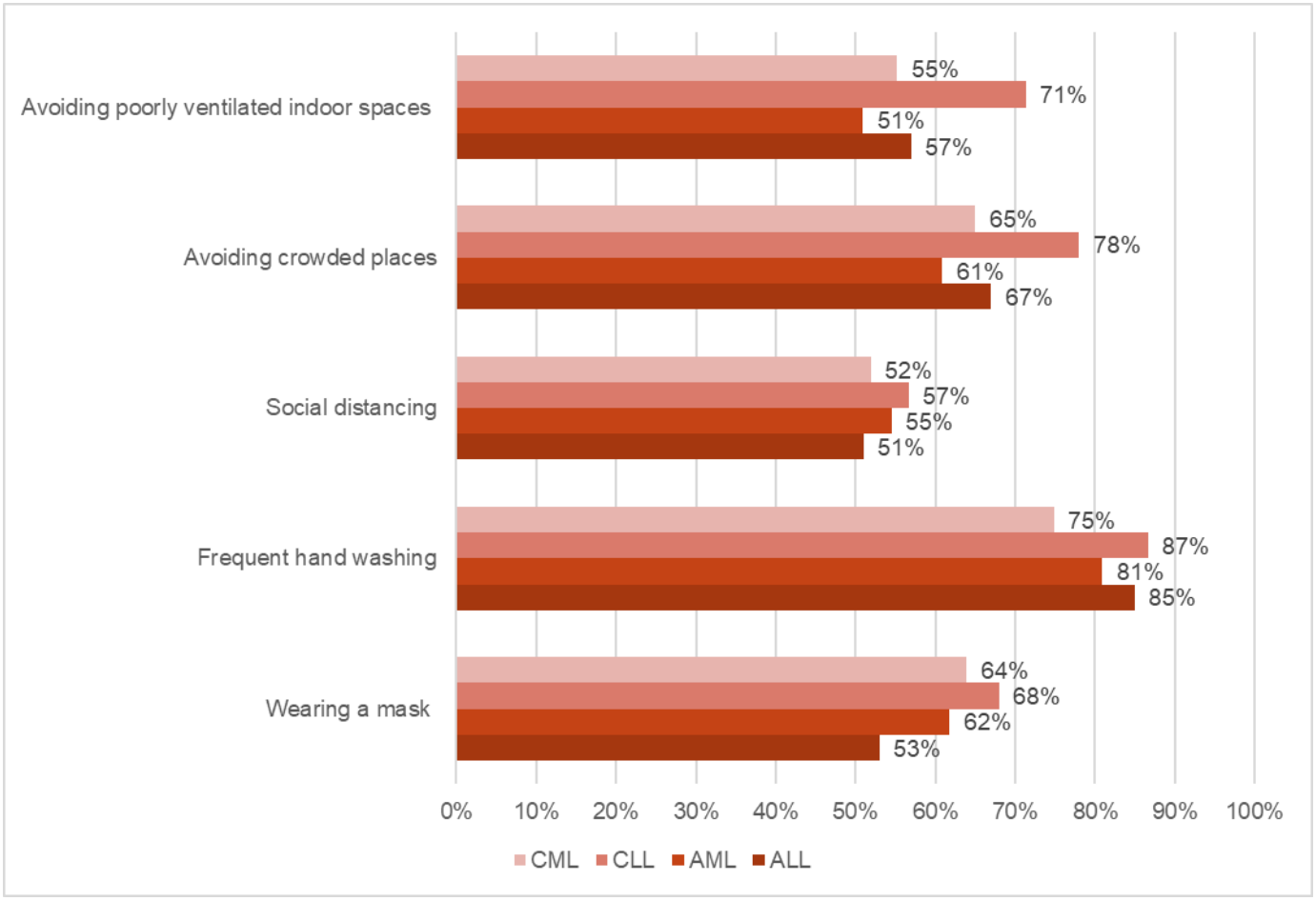


Figure 129: Q 71C. What safety measures will YOU continue after vaccination to protect yourself from COVID-19 infection?



12.3. Summary

Respondents reported positively on communication from government, healthcare professionals, and support organisations around the pandemic. However, gaps still remain as 21% (n=535) reported that they were not given enough information from government. There was little difference across leukemia types.

Just 10% (n=254) of patients reported that their treatment was delayed due to COVID-19, which is encouraging.

However, 47% (n=1,192) had their in-person appointments cancelled or postponed due to COVID-19 and 37% (n=886) of these were not reinstated, while the rest were replaced through video or phone consultations.

These were unprecedented times; healthcare and support organisations had to make fundamental changes to ensure patient treatment, care, and welfare.

The lessons learned during the global COVID-19 pandemic should be considered and utilised to - at the very least - provide contingency plans to minimise disruption for any future events. Lessons should also be used to ensure ongoing, improved, cohesive and collaborative care, and support for immunocompromised patients and their carers.

13. Summary and recommended actions

Actions:

Pre-diagnosis

There remain clear challenges around the recognition and diagnosis of leukemia. This includes both the general public and primary healthcare providers.

- Continue to raise awareness campaigns aimed at both the general public and primary healthcare providers. Ensure communications are targeted in order to maximise impact.
- Primary care has a vital role in supporting patient autonomy to enable people living with leukemia to manage their own health and wellness. Late diagnosis often leads to poorer outcomes. Introduce capacity-building and education programmes for primary healthcare providers. This should include engagement with all primary care settings such as GPs, Opticians, Dentists etc, and work with local community and patient groups.
- Enhance information provision and support services with a particular focus on diagnosis, prognosis, and the impact of living with leukemia.

Diagnosis

- A diagnosis of acute leukemia will clearly have a different intervention than for a diagnosis of chronic leukemia. Support services need to be segmented accordingly.
- A diagnosis of leukemia can often impact financial wellness, particularly those from lower income backgrounds. Additional information and support services, specifically focused on financial wellness, should be implemented particularly at diagnosis. This is a challenging area and appropriate support is still needed by those who had financial problems before diagnosis, and those who have financial issues caused only by their leukemia diagnosis. Support services provided directly by patient groups are proven to be effective (e.g. Macmillan in the UK)[7].

'Watch and Wait'

- 'Watch and Wait' is a common management tool for chronic leukemia (particularly in the US and the UK). There continues to be a significant lack of understanding of what it means to be on 'Watch and Wait.'
- Patients can feel like their care team is not doing enough to treat their condition. This directly impacts mental wellbeing. Providing information and support, particularly at diagnosis, is needed.
- Nurse-led initiatives should be encouraged. Access to Clinical Nurse Specialists (CNSs) can often be restricted to those in active treatment; access to a CNS for those on 'Watch and Wait' should be considered.

Treatment

- There is a lack of information at the start of leukemia treatment and care, most notably on side effects. A holistic approach involving the clinical community and patient organisations will aid improvements. Patient organisations can support empowerment of patients to understand what information they need.

[7] https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/money-finance-and-insurance

- Involvement in treatment decisions and choices for patients and carers needs to be improved. Advocacy Networks should continue to highlight and promote the benefits and importance of empowering patients and carers.

Clinical Trials

- The findings of this survey shown a lack of involvement in clinical trials, with many patients unaware of available trials; coupled with a lack of trials in lower income countries. With the ever-changing treatment landscape, the ability to be involved in trials is important. Development of an international database of available clinical trials in leukemia should be prioritised.
- The Networks should continue to work collaboratively with the healthcare community, researchers, and pharmaceutical companies to promote appropriate trials and support the involvement of patients and carers.

Living with leukemia

- Leukemia has an obvious negative impact on patients, carers, and their wider families. It is important that healthcare is delivered holistically at every point in the patient journey/pathway, and considers wider quality of life issues when looking at treatment, management, and ongoing care.
- Emotional and mental health can be more negatively affected than physical well-being, and experiences differ between different groups. Support needs to be improved, tailored, and targeted.
- Isolation and mental health are affected by a leukemia diagnosis and treatment. It is further affected longer-term while patients live with the disease. Support for this should be promoted, particularly at these points for patients and their carers.
- Leukemia can negatively impact a person's work and financial situation; especially during treatment. It varies by subtype and by demographics. Consider a flexible support program to alleviate these issues and improve patient and carer well-being.

COVID-19

- This survey was conducted at a time when COVID-19 measures were in place. As a result, many systems and processes have changed.
- COVID-19 had a significant impact on healthcare; in particular for those that are immunocompromised such as leukemia patients. Broader collaboration regarding safety measures has proven effective such as the International COVID-19 Blood Cancer Coalition (ICBCC, led by CLLAN).
- These collaborative efforts like those led by the ICBCC are crucial to raising awareness, coordinating interventions, and taking appropriate actions.
- Continuity plans should be developed collaboratively with healthcare providers to minimise any impact on patients and carers.
- Support for patients should be planned and delivered from central government and healthcare systems, it is not the responsibility of patient groups, or the Networks, to drive this support.
- Steps should be taken to improve access to healthcare and provide support to patients who are still experiencing the effects of COVID-19. An important aspect of this is the exploration of alternative technologies and idea generation for novel ways to increase service provision.