Global Leukemia Experience Survey 2023 Report

July 2024

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Picker

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- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

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Foreword

In 2023, ALAN, CMLAN and CLLAN with the support of Picker as their chosen external provider, carried out a global leukemia patient and carer experience survey. The results of both surveys are shared in this report.

The ALAN, CMLAN and CLLAN are global and self-sustained umbrella organizations of national patient groups and 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 leukemia progress rapidly unless effectively treated, but they can sometimes be cured with standard treatments, such as bone marrow transplants. Chronic leukemia 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.

The Acute Leukemia Advocates Network (ALAN) is an independent global network of patient organizations, dedicated to changing outcomes of patients with acute leukemias by strengthening patient advocacy in that area. They aim to maximize the capacity of members within the network to allow them to deliver tailored services to acute leukemia patients and carers on the national level.

The CLL Advocates Network (CLLAN) was founded in 2014 by representatives from Canada, Czech Republic, France, Ireland, Italy, Portugal, UK and the United States. It is hosted under the umbrella of the Leukemia Patient Advocates Foundation (LePAF), a patient-led non-profit foundation based in Switzerland acting as a legal platform for self-sustained patient advocacy initiatives. The CLL Advocates Network is governed by a Steering Committee consisting of 9 members, of whom 6 are patients and 1 is a carer.

The CML Advocates Network (CMLAN) is an international organization that connects 131 patient organizations, across the globe in 96 countries. Initially founded by four CML patient leaders from Germany, Israel, the Czech Republic and the UK, it is led by a Steering Committee comprised of nine patient advocates representing all six world regions. Patients run CMLAN independently and it is hosted by the patient-run Leukemia Patient Advocates Foundation.

Executive summary

The 2023 global leukemia experience survey achieved 2,260 patient responses, and 694 carer responses from 69 countries. The survey was published online in 13 languages and promoted and distributed by ALAN, CLLAN and CMLAN via email, online forums, social media, newsletters and through active contact to network members. The survey was directed to patients and carers aged 18 and above, directly or indirectly, affected by a diagnosis of leukemia.

The purpose was to provide understanding and insight into the experiences of the patient and the carer, rather than from a clinical perspective. It did not seek to replicate the formal collection of scientific data such as patient preferences. Patients, carers and advocates from ALAN, CLLAN and CMLAN reviewed both the patient and carer questionnaires during development and provided their feedback for improvements.

Diagnosis

Awareness of symptoms of leukemia was incredibly low. The majority of patients (90%, n=1,648) who experienced symptoms prior to their diagnosis did not know these could be symptoms of leukemia. The majority of carers (85%, n=416) too, were not aware that the health problems the patient was experiencing could have been symptoms of leukemia. On the contrary, awareness that leukemia is a form of cancer was much higher; 90% (n=2,000) of patients were aware that this was a form of cancer when they received their diagnosis of leukemia.

Overall, 62% of patients (n=1,133) waited 3 months or less from the time they first experienced symptoms before speaking to a healthcare professional (HCP). Patients with chronic leukemia reported a less positive experience of diagnosis than patients with acute leukemia, and length of time before diagnosis varied considerably. Patients with CLL (27%, n=155) and CML (24%, n=131) seemed to wait more than 6 months before speaking to a HCP, than patients with ALL (2%, n=4 or AML (4%, n=14).

Patients with chronic leukemia waited longer for their diagnosis. 67% (n=555) of patients with CLL, and 74% (n=476) with CML were diagnosed within 3 months of first seeing a HCP, compared to 88% (n=236) of patients with ALL and 89% (n=301) with AML who were diagnosed within 3 months of first seeing a HCP. 25% (n=142) of patients with CLL, and 24% (n=128) of patients with CML had to visit a HCP four or more times before they were diagnosed, compared to 11% (n=35) for AML patients and 18% (n=48) for ALL patients.

Less than half of patients (48%, n=1,059) reported that their diagnosis was completely explained to them in a way they could understand. Comparably, 53% (n=257) of carers who were told about the patient's leukemia diagnosis by a HCP reported that their diagnosis was completely explained to them in a way they could understand.

Watch and Wait (CLL only)

Watch and wait’ or ‘active monitoring’ involves close monitoring of a CLL patient’s condition, without giving treatment until symptoms appear or change. ‘Watch and wait’ or ‘active monitoring’ may be used to monitor asymptomatic, symptomatic or progressive CLL.

84% (n=701) of CLL patients who responded to the survey, and 83% (n=76) of carers for CLL patients said they had been placed on a 'watch and wait' or 'active monitoring' monitoring plan.

59% (n=407) of CLL patients completely understood the explanation they received about why they were placed on ‘watch and wait’ or ‘active monitoring’ for the first time. Comparably, 60% (n=45) of carers for CLL patients completely understood the reasons why the patient had been placed on 'watch and wait' or 'active monitoring' for the first time.

Less than half of CLL patients (47%, n=313) said they were definitely involved as much as they wanted to be in decisions about being put on 'watch and wait' or 'active monitoring'. This may be linked to experience of worry and concern at this stage, with 25% (n=172) of patients reporting they were very concerned and worried about being put on 'watch and wait' or 'active monitoring', while 49% (n=339) had some concerns and worries.

When asked if they were confident about recognizing the signs and symptoms of CLL progression, 45% (n=309) of patients were very confident, 46% (n=320) were somewhat confident and 9% (n=60) were not confident.

Treatment

Patients reported involvement in treatment decision-making varied considerably across several measures. Patients were most likely to report they were definitely involved as much as they wanted to be in decisions about their treatment if they had CLL (52%, n=228), were older patients aged 66-75 (54%, n=156) or 76 and over (54%, n=64), had a postgraduate university degree (Masters, PhD or MD) (53%, n=178) and lived in a high-income household (55%, n=112). Patients were least likely to report they were definitely involved as much as they wanted to be in decisions about their treatment if they had ALL (36% (n=89), were younger patients aged 18-25 (36%, n=43), lived in China (37%, n=121) or Brazil (47%, n=94), and lived in a low-income household (39%, n=162).

The majority of patients (89%, n=1,523) who had received treatment reported experiencing side effects from their most recent or current treatment. Carers reported a higher instance (98%, n=586) of patients experiencing side effects from their most recent or current treatment. Only 43% (n=721) of patients were given completely clear information about any side effects from their most recent or current treatment.

77% of patients (n=1,076) reported their symptoms had improved as a result of their current or most recent treatment.

42% (n=672) of patients reported that they experienced a barrier that affected their treatment choices. The most common barrier experienced was the cost of treatment, which was cited by 1 in 5 patients (20%, n=320). Patients with acute leukemia were more likely to report they had experienced a barrier (68% for ALL, n=147; 48% for AML, n=136) than patients with chronic leukemia (38% for CML, n=228; 27% for CLL, n=113).

Testing and Monitoring

The majority of patients (94%, n=1,964) and carers (90%, n=589) reported they were/ the patient was currently undergoing regular testing or monitoring for their leukemia. Carers (92%, n=530) appeared to be more worried or anxious when waiting for results of the patients regular testing, than patients were (77%, n=1,507).

Positively, 93% (n=1,737) of patients reported they were able to access their test results, or copies of their test results if they wanted to. 62% of patients (n=1,201) and 52% (n=298) of carers reported the results of their tests were completely explained to them in a way they could understand. However, 18% of patients (n=352) and 19% of carers (n=102) said they always have to ask for the results to be explained.

Interestingly, carers who look after someone with CLL (73%, n=63), were more likely to report they knew the patient's immunity status, than patients themselves (53%, n=416). 46% of both patients (n=190) and carers (n=29) reported they received completely clear information about what steps they/ the patient can take to stay healthy and avoid infections. 39% (n=307) of patients with CLL, and 27% (n=22) of carers for those with CLL reported they received complete information about the protocols for CLL immunizations / vaccinations, including which they should receive and which they should avoid.

Information and support

82% (n=1,649) of patients were given or directed to information or support during their treatment journey. The most common resources patients were given or directed to were side effects and risks of treatment (39% n=793), written information / booklets / leaflets (36%, n=729), leukemia charities / associations / organizations (30%, n=607), mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy (29%, n=590), and patient support groups (29%, n=580).

Patients reported that the following types of information and support helped them feel better or more positive: buddying or befriending (79%, n=166), online forums (78%, n=275), patient support groups (76%, n=410) and leukemia charities / associations / organizations (76%, n=431).

The majority of patients (91%, n=1,839) and carers (90%, n=542) conducted their own research into varying stages of the patient journey. Patients and carers researched the same top three topics: diagnosis (75% of patients, n=1,516; 74% of carers, n=450), treatments available (70% of patients, n=1,419; 73% of carers, n=439) and side effects (68% of patients, n=1,380; 70% of carers, n=421).

Quality of Life

One third of patients (34%, n=679) reported their disease and treatment had a moderate to severe impact on their quality of life. Interestingly, carers reported disease and treatment had a greater impact on patient's quality of life (45%, n=263), than patients did.

Patients with acute leukemia (57% for ALL, n=124; 45% for AML, n=126) reported a greater impact on their quality of life than patients with chronic leukemia (23% for CLL, n=178; 32% for CML, n=195). This trend was also evident in the carer data, with 52% (n=87) for ALL, 52% (n=75) for AML, compared to 29% (n=29) for CLL and 38% (n=45) for CML reporting a moderate to severe impact.

Patients were most likely to indicate they experienced a moderate to severe impact on their quality of life if they were aged 18-25 (56%, n=57), female (37%, n=412), and lived in a low-income household (53%, n=224).

One in ten patients (10%, n=195) and 16% (n=90) of carers reported the symptoms and/ or side effects they or the patient experienced had a moderate to severe impact on their/ the patient's quality of life.

69% (n=375) of carers have experienced a moderate to extremely large effect on their quality of life as a result of the person they care for having leukemia. Carers were most likely to experience a moderate to extremely large effect on their quality of life if they cared for someone with acute leukemia (89% for ALL, n=137; 76% for AML, n=103), were younger (79% for carers aged 26-35, n=77) and female (75%, n=279), and if the patient was younger (79% for carers looking after someone aged 36-45, n=46) and male (72%, n=207).

52% (n=595) of patients have had to stop working either temporarily or permanently since they were diagnosed with leukemia. 21% (n=246) have had to reduce their working hours, and 27% (n=306) have continued to work as normal. Patients with acute leukemia (79% for ALL, n=136; 76% for AML, n=162) were more than twice as likely to have to stop working either temporarily or permanently since they were diagnosed with leukemia, than patients with chronic leukemia (35% for CLL, n=99; 37% for CML, n=148).

50% (n=938) of patients have experienced an overall negative financial impact since their diagnosis. Patients with acute leukemia (82% for ALL, n=169; 74% for AML, n=194) were far more likely to experience an overall negative financial impact since their diagnosis, than patients with chronic leukemia (30% for CLL, n=225; 49% for CML, n=279).

Views on new potential treatments

When asked about their preferred treatment method, 73% (n=1415) chose oral treatment methods, such as pills, tablets and liquid solutions, 19% (n=363) chose intravenous infusions given through a drip and 12% (n=228) chose injections, either through the muscle or under the skin. 52% (n=1004) of patients reported they would be willing to experience additional side effects for a more effective treatment

Both patients and carers prioritized the same important features of a new treatment, including improved / longer survival (75% of patients, n=1439; 78% of carers, n=421), improved quality of life (75% of patients, n=1436; 79% of carers, n=424), and to bring about a remission / response (62% of patients, n=1186; 69% of carers, n=372).

Recommendations

The data collected has provided important information to help understand the key issues, experiences, and unmet needs for leukemia patients and carers. The following recommendations have been created to inform where advocacy groups efforts should be focused, and to drive improvements in care quality and experience for leukemia patients and carers.

Increase awareness of symptoms

Low awareness of symptoms of leukemia is concerning, as this lack of awareness will delay patients visiting a HCP and consequently delay diagnosis and treatment. Positively, however, the majority of patients were aware that leukemia is a form of cancer when they received their diagnosis. The same advocacy efforts that were implemented to enhance knowledge of leukemia as a form of cancer can be used to increase awareness of symptoms of leukemia. #BeLeukemiaAware and World Leukemia Day are ideal existing campaigns to increase awareness within the public.

Information and explanations

There is abundant evidence that patients and carers are not receiving adequate levels of information and explanations at key points in the patient’s journey. This includes, but is not limited to, during diagnosis, information on subtype or mutation, treatment options, clinical trials, fertility, emotional wellbeing, results of tests, clear information about side effects of treatment and immunizations/ vaccines. HCPs must improve how they communicate with patients and carers, ensuring they receive vital information at key stages and are offered the opportunity to ask questions and receive answers to these questions at each stage to aid understanding. Signposting patients and carers to patient organization groups for further support and information should consistently be part of the consultation process.

Involvement in decision-making

People have a right to be involved in and to make decisions about their health and care. HCPs must work with patients and their carers, in partnership, to involve them in decision-making throughout their journey. As part of this process, HCPs must ensure patients are well informed and that their personal preferences are respected.

Directing patients to information and support resources

The resources that patients rated as most helpful were not the most commonly cited resources patients were directed to. HCPs and advocacy groups should work towards greater facilitation and access to buddying or befriending, online forums, patient support groups and leukemia charities / associations / organizations as patients were most likely to report these resources as helpful.

Address variance in experience

Throughout the findings in this report, there are clear variances in experience by leukemia type, age, gender, country, annual household income and level of education. While some variance by leukemia type can be expected due to the nature and progression of disease, there are several areas where work to address this variance is much needed, particularly in relation to impact on quality of life. Patients with ALL, AML, who were younger, female and live in a low-income household reported far greater impact to their quality of life than other groups. Enhanced care and support for these groups should be enforced to mitigate this impact.

Background and methodology

Background

This report details the findings from the 2023 Global Leukemia Experience Survey. The survey was a collaboration between Acute Leukemia Advocates Network (ALAN), CML Advocates Network (CMLAN) and CLL Advocates Network (CLLAN).

The questionnaire asked about experience of diagnosis, care and treatment for leukemia, information and support, quality of life and views on potential new treatments. Its purpose was to provide information to help understand the key issues, experiences, and unmet needs for leukemia patients and carers. This data is used to drive improvements in care quality and experience for leukemia patients and carers, and to inform where advocacy groups efforts should be focused.

Two question sets were designed, one for patients, and one for carers. The survey was open to anyone aged 18 and above, directly or indirectly affected by a diagnosis of leukemia, whether this was somebody who had received a diagnosis, or who is or has been a carer to someone with a diagnosis.

Questionnaire development

Both the 2021 patient survey and 2022 carer survey underwent extensive review by ALAN, CLLAN, CMLAN and Picker. The 2021 patient survey was reduced from 200 to 100 questions. The 2022 carer survey was reduced from 83 to 47 questions. Several changes were made to existing question wording and format to simplify language, streamline completion and improve data quality. Due to these extensive changes, historical comparison with the 2021 and 2022 results was limited and consequently not included in this report.

The aim of the questionnaires was to ask questions that allowed understanding and insight into the experiences of the patient and the carer, rather than from a clinical perspective. It did not seek to replicate the formal collection of scientific data such as patient preferences. Patients, carers and advocates from ALAN, CLLAN and CMLAN reviewed both the patient and carer questionnaires during development and provided their feedback for improvements.

Before starting the survey, respondents were informed of the purpose of the program; that completing the survey was voluntary and any feedback would be kept confidential; and how the results would be used.

To enhance analysis, demographic questions were included that asked about subtype, age, gender, country of residence, household composition, employment status, and level of qualification. Carer respondents were asked demographic questions for themselves and for the patient.

Two licensed Patient Reported Outcome Measure (PROM) tools were included in the survey. These were the HM-PRO[1] and FROM-16[2]. The HM-PRO is designed to measure patient quality of life and symptoms and was asked of both patients and carers on patients' behalf. The FROM-16 is designed to measure impact on the quality of life of an adult family member or partner resulting from having a person (of any age) in a family with any disease or condition, across all of medicine and was asked only of carers.

The English (UK) questions were translated into 13 languages by an approved language translation service using native speakers to translate and proofread. The final translations were reviewed by native ALAN, CLLAN or CMLAN members. The survey was available in the following languages:

- Brazilian Portuguese
- Chinese (Simplified)
- Czech
- Danish
- Dutch
- English (UK)
- English (US)
- French
- German
- Hebrew
- Italian
- Korean
- Russian
- Spanish

The final questionnaires were signed off Friday 7 July 2023. The questionnaires covered the following areas:

- Demographics
- Care and support (carer only)
- Diagnosis
- Watch and Wait (CLL only)
- Treatment
- Testing and Monitoring
- Information and support
- Quality of Life
- Views on new potential treatments

During fieldwork, some amendments were made to the live survey. Amendments were made to the Hebrew translation during fieldwork, shortly after the survey was launched. Amendments were made to Q1 and C1 which asked about leukemia subtype shortly after the survey was launched. The question was updated to send respondents with Hodgkin

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[1] https://hmpro.co.uk

[2] https://www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires/family-reported-outcome-measure

Lymphoma, Non-Hodgkin Lymphoma, Myeloma, Myelodysplastic syndromes (MDS), Myelofibrosis, Essential thrombocythemia, Polycythemia vera, and Waldenström's macroglobulinemia to the end of the survey i.e., not collect feedback from this group.

A copy of the Global Leukemia Experience Survey 2023 can be found in Appendix 2.

Survey fieldwork

The survey was hosted on the third-party online survey portal Qualtrics. Respondents were recruited through ALAN, CLLAN and CMLAN, via email, online forums, social media, newsletters and through active contact to network members. The survey was administered through an open link, distributed by ALAN, CLLAN and CMLAN global affiliates to patients and carers aged 18 and above, directly or indirectly, affected by a diagnosis of leukemia as a cross-sectional study. Respondents completed the sections relevant to their type of leukemia.

As patient and carer respondents were recruited together, some patients and carers are related or connected where they have completed both surveys in the same response. In these instances, the responses to these surveys can be directly compared.

The survey was available online between 19 August 2023 and 5 January 2024. It was promoted at regular intervals by ALAN, CLLAN and CMLAN and their members and partners.

Limitations

Limitations of the survey include the recruitment of respondents. Recruitment through the three networks was the most appropriate and convenient method of recruitment. It is, however, restricted to people who engage with the networks and in the advocacy space. Therefore, variations in findings across countries may reflect bias in how respondents were accrued.

Due to the nature of acute leukemia and its rapid disease progression, recruiting individuals with acute leukemia is more difficult, and they have a lower response rate to this survey compared to individuals with chronic leukemia.

The survey utilized an online survey methodology and individuals who did not have access to the internet were not able to respond to the survey.

Consequently, data collected from the surveys may not be reflective of perspectives and perceptions of the broader leukemia patient and carer community.

Analysis and reporting

Standard validation practices have been used in the survey tool and on the data collected, in this and associated reports to improve representativeness. Practices are outlined below:

Questionnaire routing

To improve respondent experience, routed questions were used in the survey tool to ensure respondents were only shown questions that were relevant to them. For example: Q58: “Have you ever had a stem cell transplant as part of your treatment for leukemia?”. Only respondents who answered “Yes” to this question, were directed to Q59: “How long ago did you have your most recent stem cell transplant?”. Consequently, some questions were only asked of a subset of respondents.

Please note Q81 in the patient questionnaire ‘Did the information and support you accessed make you feel more confident to be involved in decisions about your care and treatment?’ has not been included in this report due to incorrect routing applied in the survey.

Data cleaning and validation

When the survey closed, the raw data were analyzed and feedback that did not meet the inclusion criteria was removed. Criteria for inclusion was:

- At least 6 completed questions in the patient survey, excluding demographic questions i.e., 6 completed questions from Q9 (start of Diagnosis section).
- At least 3 completed questions in the carer survey, excluding demographic questions. i.e., 3 completed questions from C11 (start of Care and support section).

511 responses were removed from the patient dataset, and 325 responses were removed from the carer dataset as they did not meet the inclusion criteria.

Derived questions

Some questions were not applicable to all respondents but were not preceded by a filter/routing question. These questions have response options such as “I did not need any information” or “Don’t know / can’t remember”. Overall percentages were calculated after removing these non-applicable respondents (Figure 1). This ensures that the reported data remains focused on those respondents to whom the question applied or who could recall the details. These questions are indicated with a [Derived] label in the figure and table captions, along with a note of how many responses have been removed.

Figure 1. Derived question example

Q16 Have you been informed of your leukemia subtype or specific mutation?

Yes	1,447	66%
No	508	23%
Don't know / can't remember	224	10%
Total	*2,179*	*100%*

Q16 Have you been informed of your leukemia subtype or specific mutation? [Derived]

Yes	1,447	74%
No	508	26%
Total	*1,955*	*100%*

Subgroup analysis

To examine and identify variance in experience, data have been considered as a whole and in a series of cross-tabulations to investigate patterns in care experiences by:

- Leukemia type
- Country (with more than 100 responses)
- Age
- Gender
- Level of education
- Average household income
- Current or most recent treatment method

Please note, for any sub-group analysis, data are not reported on any groups with fewer than 30 respondents. This is to protect respondent confidentiality and because data can be misleading and unrepresentative from low numbers of respondents. It is important to note that statistical testing has not been conducted to understand whether differences in responses between sub-groups are statistically significant or not.

Data presentation

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

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

Throughout this report the number of respondents to each question is indicated as n=(x), where x equals the number of respondents. Because responding to all questions was not mandatory, the number of respondents to each question varies throughout the results.

To help easily identify when a chart is displaying patient data or carer data, we have included [Patient] or [Carer] labels in the figure or table headers, and highlighted the text red for patients, and blue for carers.

Patient demographics

Leukemia type of patient profile was:

12% had ALL (n=271)

15% had AML (n=341)

1% had APML/ APL (n=29)

37% had CLL (n=846)

29% had CML (n=660)

5% had another type of leukemia (n=110)

<1% didn't know / couldn't remember (n=3)

(Q1 What is your confirmed diagnosis?)

We received **2,260** patient responses from **64 countries**.

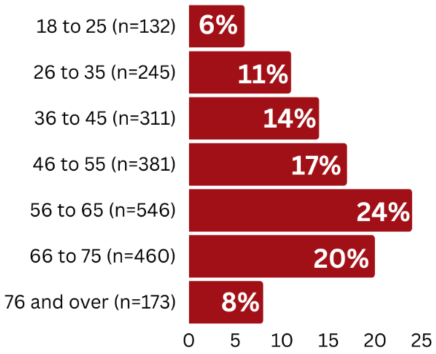
(Q4 In which country do you live?)

55% were female (n=1,251)
36% were male (n=816)

3% preferred to self-describe (n=64)
6% preferred not to say (n=129)

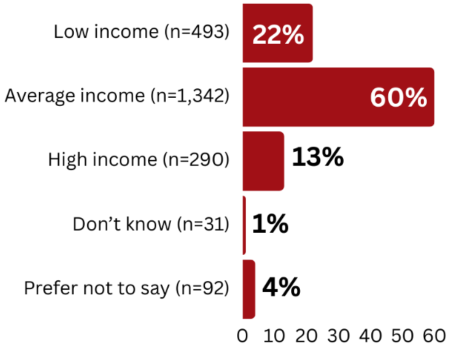
(Q3 What is your gender?)

Patient respondents were most likely to be aged 56 to 65:



(Q2 What year were you born?)

More than half of patients described their annual household income as average:



(Q7 For your country, how would you describe your annual household income?)

Level of education of the patient profile was:

5% no formal qualifications (n=110)

26% high school qualifications or diploma (n=577)

55% university degree (n=1,213)

10% career or technical qualifications (n=219)

4% preferred not to say (n=79)

(Q8 What is your highest level of qualification?)

Full details of patient demographics can be found in Appendix 3.

Carer demographics

Leukemia type of patient profile they were caring for:

29% had ALL (n=203)

26% had AML (n=178)

2% has APML/ APL (n=11)

16% had CLL (n=112)

20% had CML (n=140)

6% had another type of leukemia (n=45)

1% didn't know / couldn't remember (n=5)

(C1 What is the patient's confirmed diagnosis?)

We received **694** carer responses from **46 countries**.

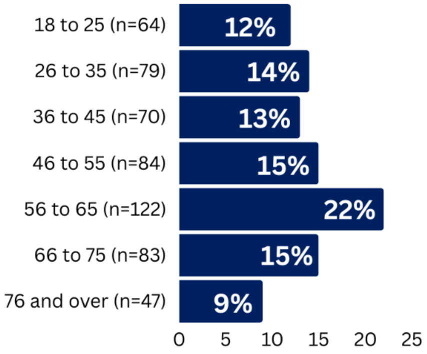
(C7 In which country do you live?)

70% of carers were female (n=485)
23% of carers were male (n=162)

3% preferred to self-describe (n=21)
4% preferred not to say (n=26)

(C6 What is your gender?)

Carers were most likely to care for someone aged 56 to 65:



(C2 What year was the patient born?)

Carers were most likely to care for their spouse or partner:

41% spouse and partner (n=288)

30% parent or guardian (n=206)

20% son or daughter (n=141)

4% other relative (n=26)

5% other relationship (n=33)

(C11 What is your relationship to the patient?)

81%

of carers lived

with the

patient (n=542)

(C12 Do you live with the patient?)

Carers were most likely to provide the following care and support activities:

86% provide emotional support (n=597)

75% accompany the patient on trips or appointments (n=515)

73% help with household tasks e.g. cooking, cleaning, other household chores (n=504)

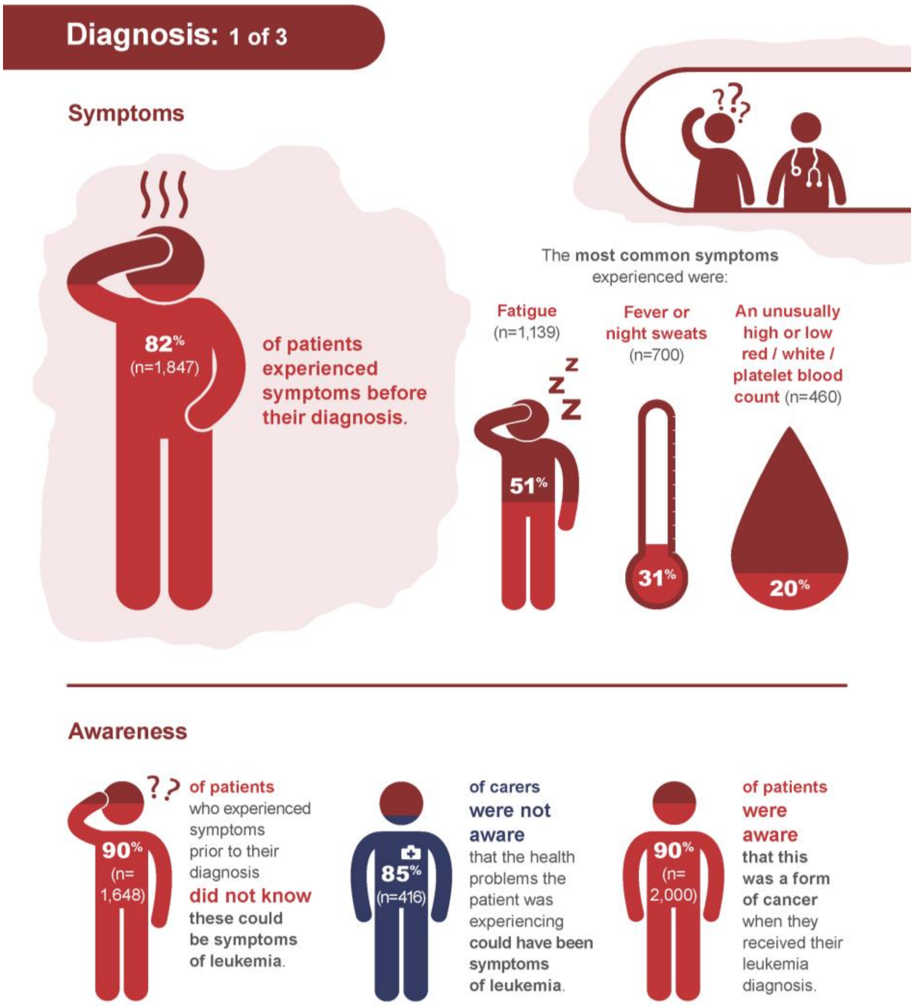
(C13 As a result of their leukemia diagnosis, which of the following care and support activities do you provide? Please select all that apply.)

Full details of carer demographics can be found in Appendix 3.

Global Leukemia Experience Survey 2023

Diagnosis

Diagnosis



Diagnosis: 1 of 3

Symptoms

82% (n=1,847) **of patients experienced symptoms before their diagnosis.**

The **most common symptoms** experienced were:

Fatigue (n=1,139) **51%**

Fever or night sweats (n=700) **31%**

An unusually high or low red / white / platelet blood count (n=460) **20%**

Awareness

90% (n=1,648) **of patients** who experienced symptoms prior to their diagnosis **did not know these could be symptoms of leukemia**.

85% (n=416) **of carers were not aware** that the health problems the patient was experiencing **could have been symptoms of leukemia**.

90% (n=2,000) **of patients were aware that this was a form of cancer** when they received their leukemia diagnosis.

Diagnosis: 2 of 3

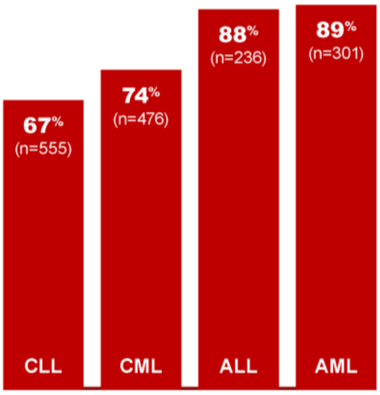
Length of time before diagnosis

32% (n=593)
of patients waited
<1 month
from the time they
first experienced
symptoms to speak to
a healthcare professional.

Patients with
CLL 27% (n=155) and **CML 24%** (n=131)
were far more likely
to wait >6 months
before speaking to a healthcare professional,
than patients with
ALL 2% (n=4) or **AML 4%** (n=14).

75%
(n=1,671)

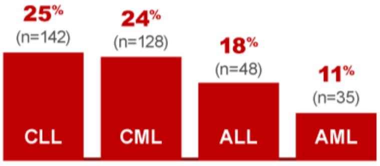
of patients received their diagnosis **within 3 months** of first visiting a healthcare professional.



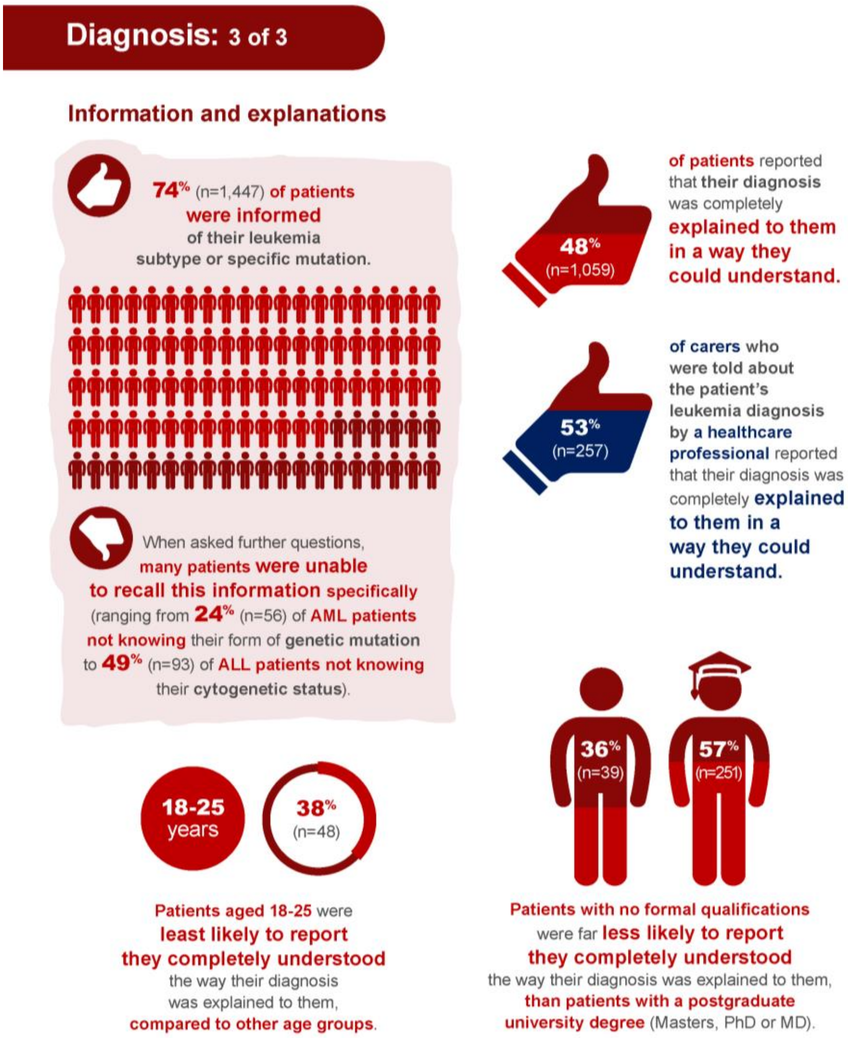
Patients with acute leukemia were more likely to be diagnosed **within 3 months** of first seeing a healthcare professional, **than patients with chronic leukemia**.

of patients visited a healthcare professional about their symptoms just **1 time** before they were diagnosed.

1/5 saw a healthcare professional **4 or more times** before they were diagnosed.



of patients had to visit a healthcare professional **4 or more times** before they were diagnosed.



Diagnosis: 3 of 3

Information and explanations

74% (n=1,447) **of patients were informed** of their leukemia **subtype or specific mutation.**

When asked further questions, **many patients were unable to recall this information specifically** (ranging from **24%** (n=56) of **AML patients not knowing** their form of **genetic mutation** to **49%** (n=93) of **ALL patients not knowing** their **cytogenetic status**).

48% (n=1,059) **of patients** reported that **their diagnosis** was completely **explained to them in a way they could understand.**

53% (n=257) **of carers** who **were told about the patient's leukemia diagnosis by a healthcare professional** reported that their diagnosis was completely **explained to them in a way they could understand.**

18-25 years

38% (n=48)

Patients aged 18-25 were **least likely to report they completely understood** the way their diagnosis was explained to them, **compared to other age groups.**

36% (n=39)

57% (n=251)

Patients with no formal qualifications were far **less likely to report they completely understood** the way their diagnosis was explained to them, **than patients with a postgraduate university degree** (Masters, PhD or MD).

Year of diagnosis

In both patient and carer responses, those with acute leukemia (ALL 68%, n=181; AML 63%, n=208; Carer ALL 72%, n=147; Carer AML 80%, n=142) were diagnosed more recently, since 2020 than respondents which chronic leukemia (CLL 30%, n=246; CML 37%, n=241; Carer CLL 34%, n=38; Carer CML 43%, n=60) (Figure 2; Figure 3)

Figure 2. [Patient] Q9 What year were you diagnosed? Please enter in the format YYYY e.g., 2010

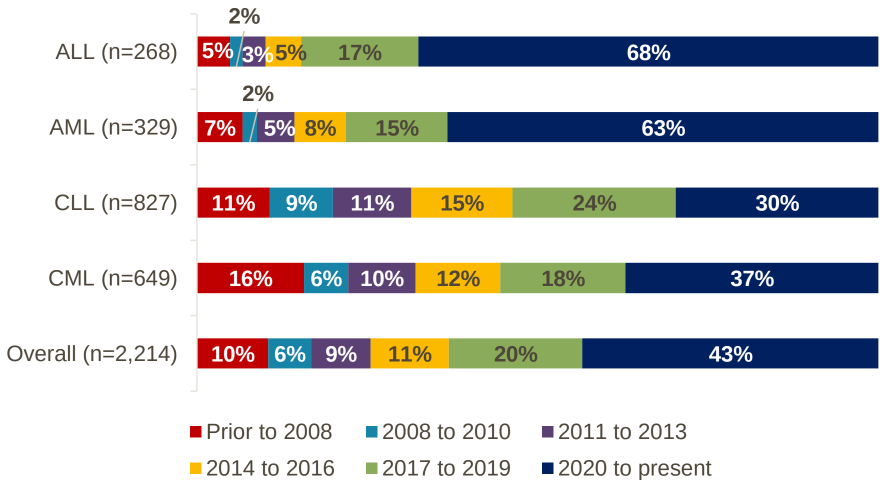
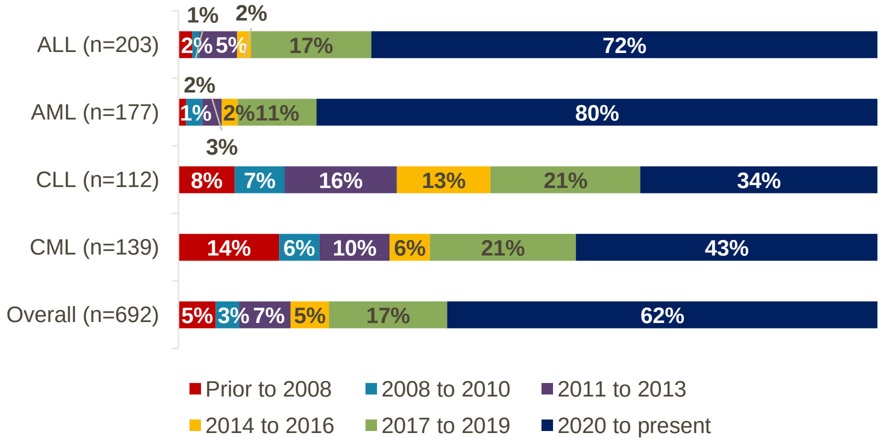


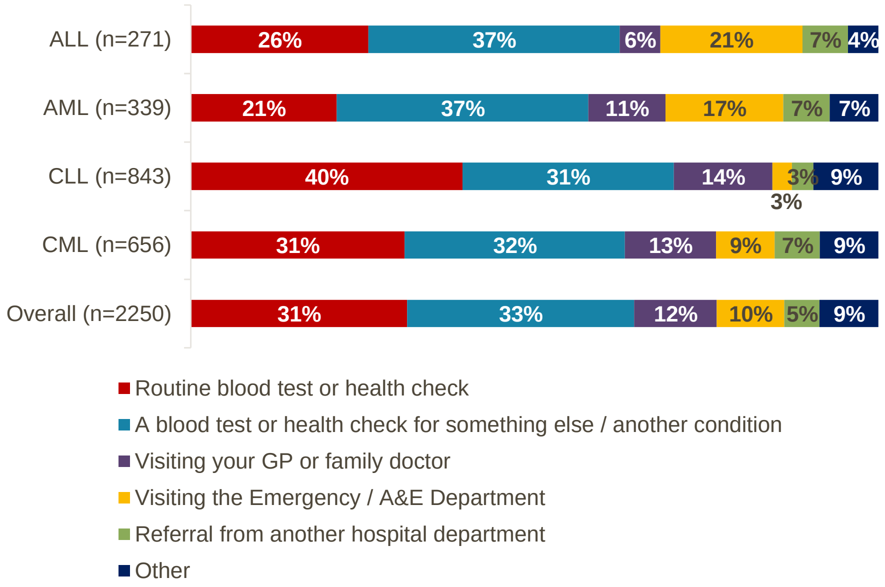
Figure 3. [Carer] C4 What year was the patient diagnosed? Please enter in the format YYYY e.g., 2010



Diagnostic tests

The most common way leukemia was detected was via a blood test or health check for something else / another condition (33%, n=742), followed by a routine blood test or health check (31%, n=708) (Figure 4).

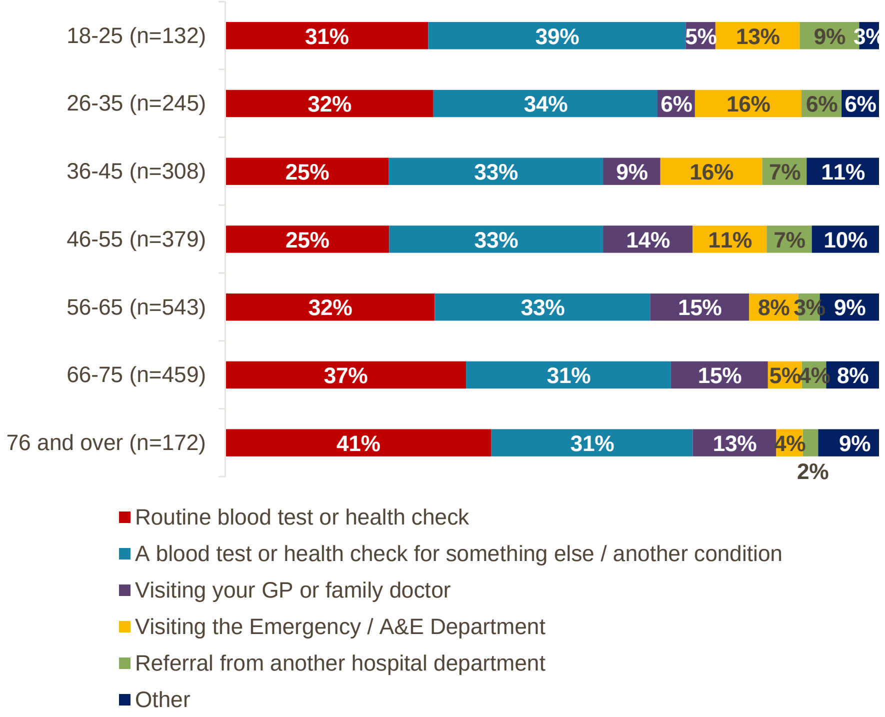
Figure 4. [Patient] Q10 - Was your leukemia detected as a result of one of the following? Please select one answer.



Analysis by age finds (Figure 5):

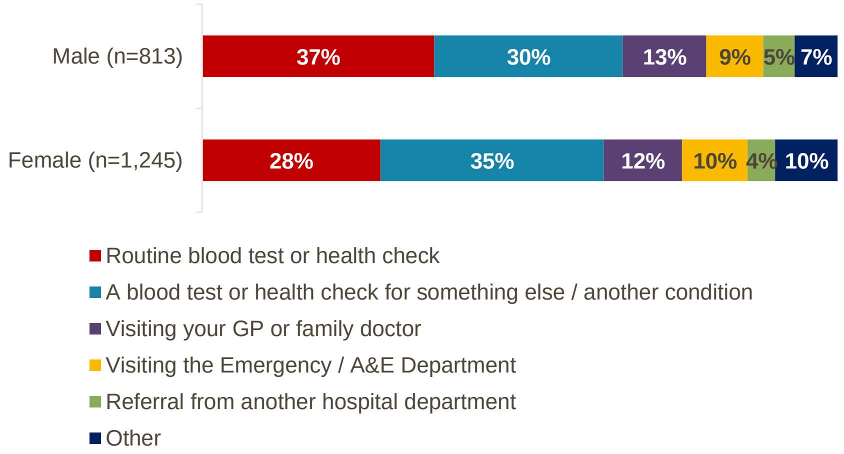
- Diagnosis via a routine blood test or health check was more common for older patients aged 66-75 (37%, n=169) and 76 and over (41%, n=70) than younger age groups.
- Diagnosis via visiting a GP or family doctor was more common for patients aged 46 and over, particularly those aged 56-65 (15%, n=82) and 66-75 (15%, n=68).
- Diagnosis via visiting the emergency / A&E department was more common for younger aged groups, particularly those aged 26-35 (16%, n=40) and 36-45 (16%, n=48).

Figure 5. [Patient] Q10 - Was your leukemia detected as a result of one of the following? Please select one answer. by age



As shown in Figure 6, a routine blood test or health was the most common way male patients (37%, n=297) were diagnosed, while a blood test or health check for something else / another condition was the most common way female patients (35%, n=438) were diagnosed.

Figure 6. [Patient] Q10 - Was your leukemia detected as a result of one of the following? Please select one answer. by gender



Symptoms

Overall, 82% (n=1,847) of patients experienced symptoms before their diagnosis. The most common symptoms experienced were fatigue (51%, n=1,139), fever or night sweats (31%, n=700) and an unusually high or low red / white / platelet blood count (20%, n=460).

Patients with acute leukemia reported a higher instance of experiencing symptoms prior to diagnosis (ALL 98%, n=265; AML 94%, n=319) than respondents which chronic leukemia (CLL 69%, n=582; CML 84%, n=551).

Full breakdown of symptoms experienced by leukemia type is displayed in Table 1.

Table 1. [Patient] Q11 What symptoms did you encounter before your diagnosis? Please select all that apply. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**2,252**	271	341	841	658
Fatigue	**51%**	54%	59%	40%	58%
Fever / night sweats	**31%**	45%	35%	19%	39%
Unusually high or low red / white / platelet blood count	**20%**	27%	26%	15%	20%
Pain in bones / joints	**18%**	31%	13%	12%	22%
Unexplained weight loss	**16%**	15%	12%	7%	32%
Swollen lymph nodes	**16%**	21%	9%	27%	5%
Shortness of breath	**16%**	21%	26%	9%	17%
Bruising	**14%**	18%	23%	8%	13%
Loss of appetite	**13%**	26%	14%	3%	19%
Frequent and repeated infections	**13%**	8%	16%	13%	13%
Sleeping problems	**13%**	16%	11%	9%	16%
Headaches	**12%**	17%	12%	6%	17%
Swollen stomach or abdominal discomfort	**11%**	9%	6%	6%	22%
Muscle pain	**11%**	11%	8%	8%	16%
Back pain	**10%**	13%	9%	7%	12%
Other symptoms	**10%**	7%	15%	6%	10%
Bleeding	**8%**	12%	19%	2%	6%
Nausea or vomiting	**6%**	13%	10%	2%	8%
Itchy skin	**6%**	4%	5%	7%	7%
Palpitations / heart irregularities	**6%**	10%	9%	3%	5%
Memory loss / loss of concentration	**5%**	6%	4%	4%	7%
Tingling or numbness in extremities	**5%**	3%	2%	6%	5%
High blood pressure (Hypertension)	**5%**	2%	1%	8%	4%
Changes to menstrual cycle	**4%**	6%	6%	1%	5%
Broken blood vessel in eye (Subconjunctival hemorrhage)	**2%**	1%	3%	1%	2%
No symptoms	**18%**	2%	6%	31%	16%

Awareness of symptoms of leukemia

The majority of patients (90%, n=1,648) who experienced symptoms prior to their diagnosis did not know that the health problems they were experiencing could be symptoms of leukemia (Figure 7).

Carers (15%, n=74) were more likely to report that before the diagnosis, they were aware that the health problems the patient experienced could be symptoms of leukemia (Figure 8), than patients reported (10%, n=177).

Figure 7. [Patient] Q12 Did you know that the health problems you were experiencing could be symptoms of leukemia?

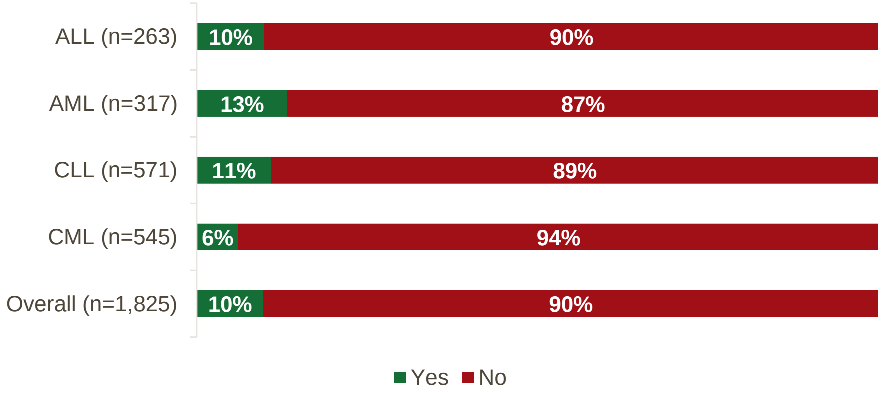
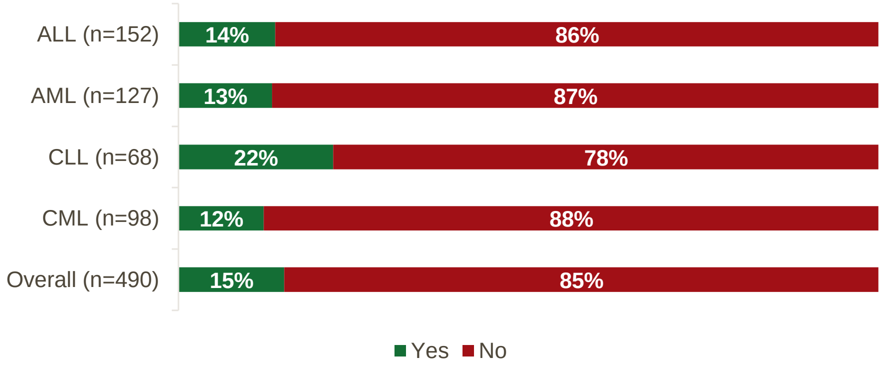


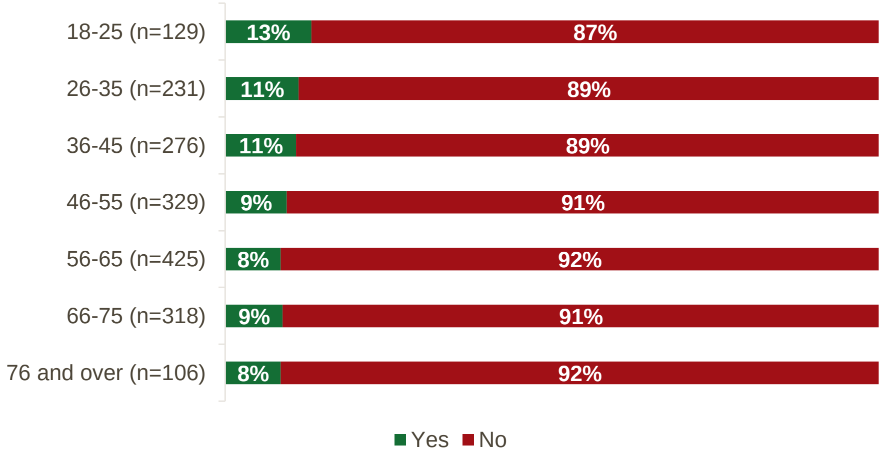
Figure 8. [Carer] C15 Before the diagnosis were you aware that the health problems the patient was experiencing could have been the symptoms of leukemia? [Derived]



Please note carers who answered ‘they did not have symptoms’ (n=101) or ‘I was not aware of their symptoms before diagnosis’ (n=85) were removed from analysis of C15.

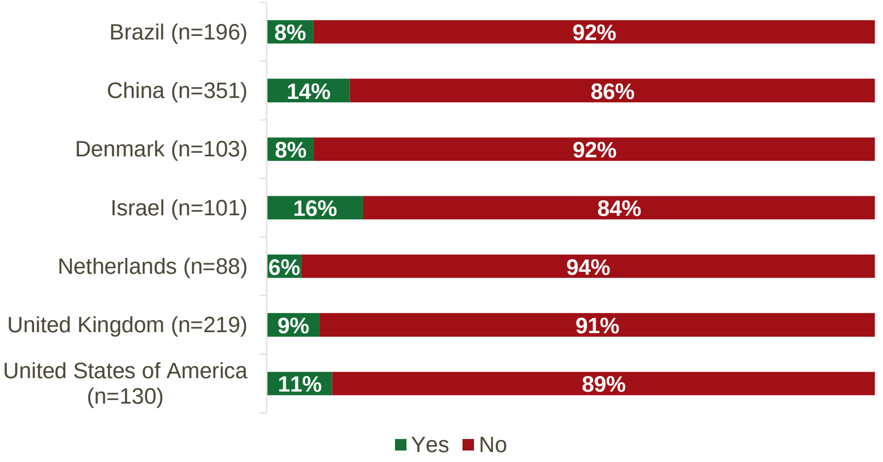
Analysis by age finds that while awareness that health problems the patient was experiencing could be symptoms of leukemia was low across all age groups, knowledge of leukemia symptoms was slightly higher among younger age groups – see Figure 9.

Figure 9. [Patient] Q12 Did you know that the health problems you were experiencing could be symptoms of leukemia? by age



Awareness that the health problems they were experiencing could be symptoms of leukemia was highest in Israel (16%, n=16), and lowest in the Netherlands (6%, n=5) (Figure 10).

Figure 10. [Patient] Q12 Did you know that the health problems you were experiencing could be symptoms of leukemia? by country

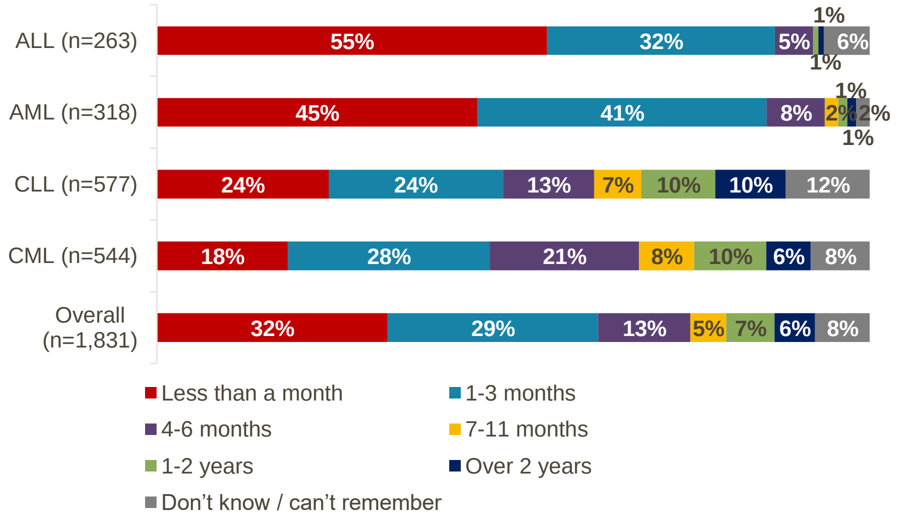


Length of time before diagnosis

Overall, one third of patients who experienced symptoms (32%, n=593) waited less than one month from the time they first experienced symptoms before speaking to a healthcare professional (Figure 11).

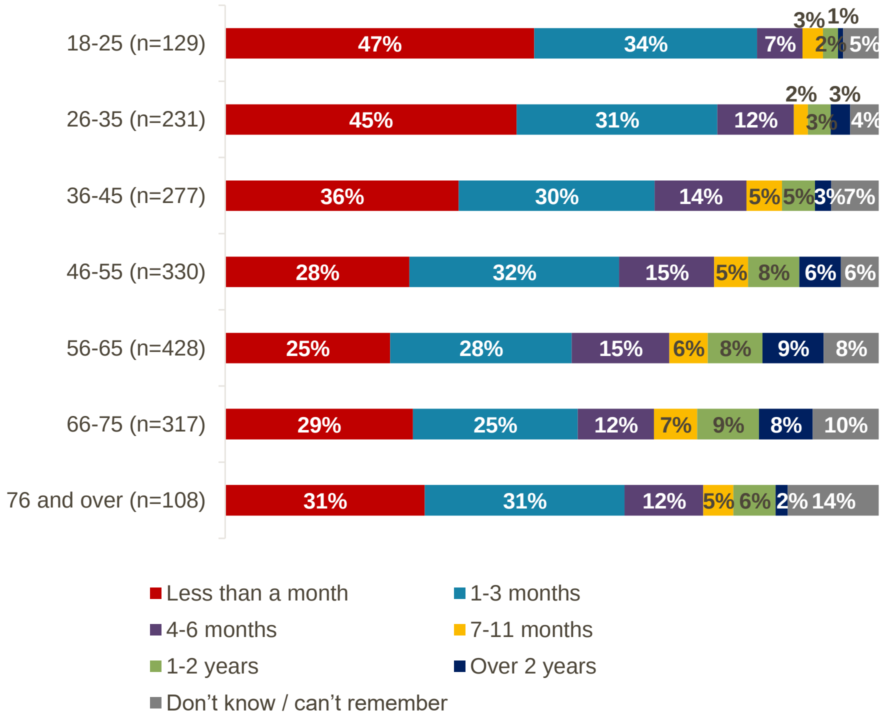
Patients with CLL (27%, n=155) and CML (24%, n=131) were far more likely to wait more than 6 months before speaking to a healthcare professional, than patients with ALL (2%, n=4 or AML (4%, n=14).

Figure 11. [Patient] Q13 How long was it from the time you first experienced symptoms until you first spoke to a healthcare professional about them? By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc.



Younger age groups 18-25 (47%, n=61) and 26-35 (45%, n=103) were most likely to speak to a healthcare professional quickly, waiting less than one month from when they first experienced symptoms (Figure 12).

Figure 12. [Patient] Q13 How long was it from the time you first experienced symptoms until you first spoke to a healthcare professional about them? By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc. by age



Analysis by country reveals patients in China (82%, n=290) were most likely to see a healthcare professional quickly, within 3 months.

Conversely, 1 in 5 patients in Israel (20%, n=20) and the Netherlands (22%, n=19) waited 12 months or more from the time they first experienced symptoms before seeing a healthcare professional.

See Figure 13 for breakdown by country.

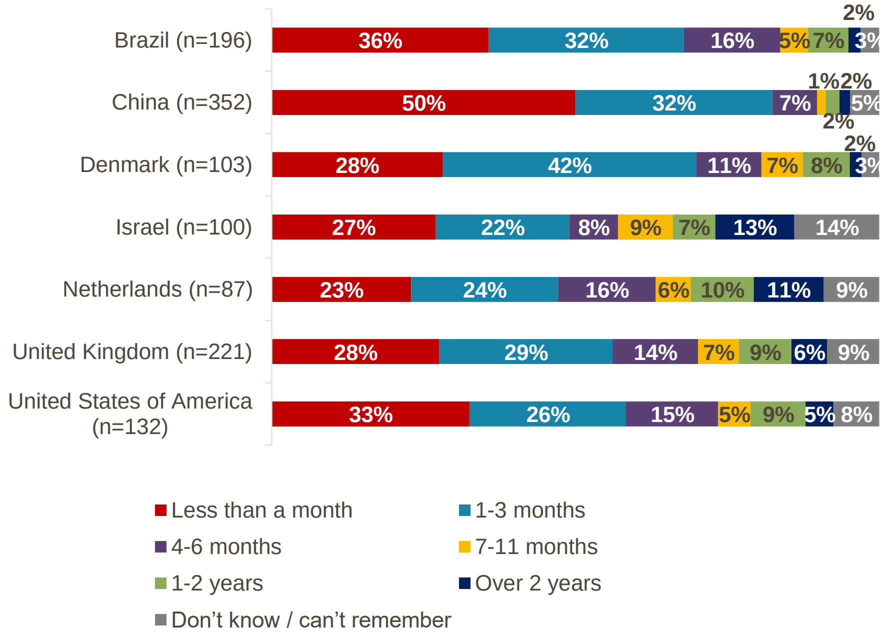
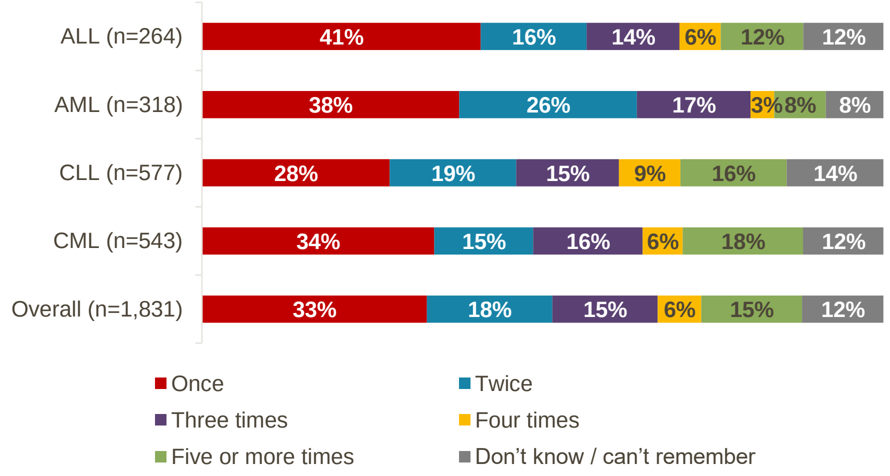


Figure 13. [Patient] Q13 How long was it from the time you first experienced symptoms until you first spoke to a healthcare professional about them? By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc. by country

One third of patients who experienced symptoms (33%, n=604) visited a healthcare professional about their symptoms just once before they were diagnosed. One fifth (21%, n=388) saw a healthcare professional four or more times before they were diagnosed (Figure 14).

25% (n=142) of patients with CLL, and 24% (n=128) of patients with CML had to visit a healthcare professional four or more times before they were diagnosed. This is compared to 11% (n=35) for AML patients and 18% (n=48) for ALL patients.

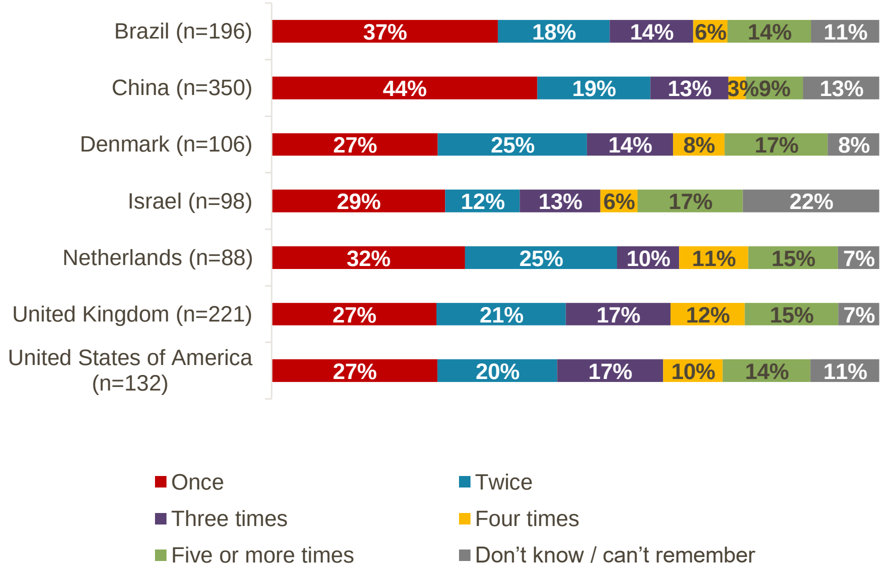
Figure 14. [Patient] Q14 How many times did you see a healthcare professional about your symptoms before you were diagnosed? By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc.



Patients in China (44%, n=153) and Brazil (37%, n=73) were most likely to say they visited a healthcare professional about their symptoms just once before they were diagnosed (Figure 15).

More than 1 in 5 patients in Denmark (25%, n=27), Israel (23%, n=23), the Netherlands (26%, n=23), the UK (28%, n=61) and the USA (24%, n=32) had to see a healthcare professional four or more times before they were diagnosed. This is compared to 19% (n=38) in Brazil, and just 12% (n=43) in China.

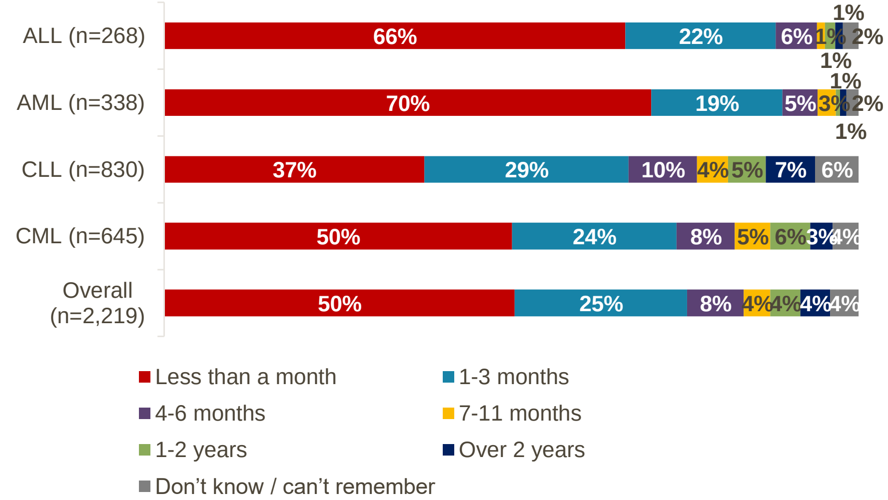
Figure 15. [Patient] Q14 How many times did you see a healthcare professional about your symptoms before you were diagnosed? By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc. by country



From the time they first saw a healthcare professional, three quarters of patients (75%, n=1,671) received their diagnosis within 3 months (Figure 16).

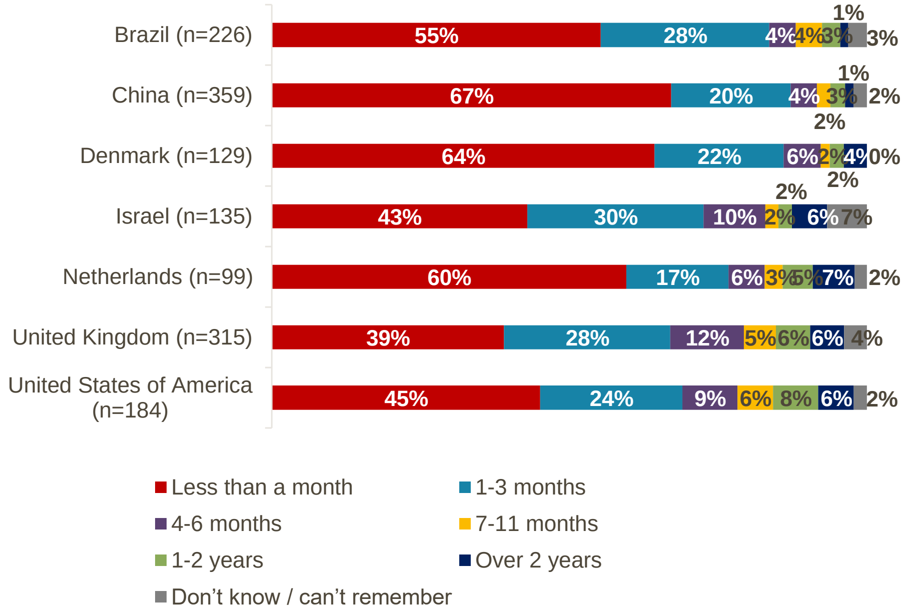
Patients with chronic leukemia waited longer for their diagnosis. 67% (n=555) of patients with CLL, and 74% (n=476) with CML were diagnosed within 3 months of first seeing a healthcare professional. This is compared to 88% (n=236) of patients with ALL and 89% (n=301) with AML who were diagnosed within 3 months of first seeing a healthcare professional.

Figure 16. [Patient] Q15 How long was it from the time you first saw a healthcare professional until you were diagnosed with your condition? By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc.



Patients in China (87%, n=313), Denmark (86%, n=111), and Brazil (84%, n=189) were most likely to report they received their diagnosis within 3 months of first seeing a healthcare professional. Patients in the UK (67%, n=211) and the USA (69%, n=127) were least likely to receive their diagnosis within 3 months (Figure 17).

Figure 17. [Patient] Q15 How long was it from the time you first saw a healthcare professional until you were diagnosed with your condition? By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc. by country

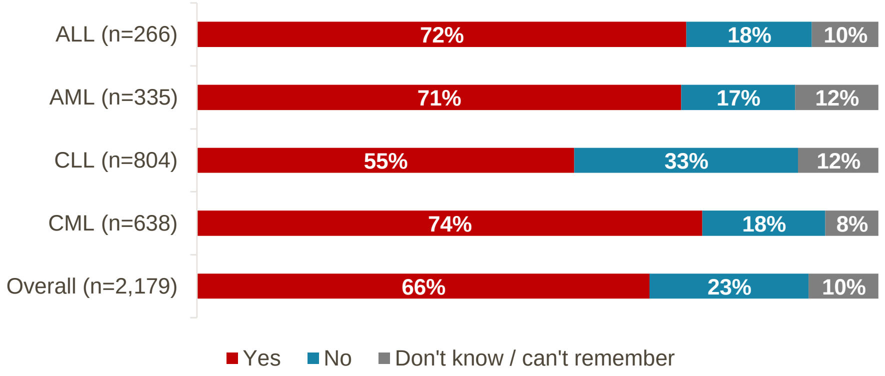


Information on leukemia subtype or specific mutation

All patients were asked if they had been informed of their leukemia subtype or specific mutation. Those who had received this information, and indicated they had ALL, AML, CLL or CML were then asked follow-up questions about their subtype or specific mutation.

As shown in Figure 18, 66% of patients (n=1,447) were informed of their leukemia subtype or specific mutation. CLL patients (55%, n=445) were least likely to report they had received this information.

Figure 18. [Patient] Q16 Have you been informed of your leukemia subtype or specific mutation? [Derived]



Despite indicating they had been informed of their leukemia subtype or specific mutation, when asked about their specific mutation, status or subtype, many patients reported that they did not know:

- 24% (n=56) of AML patients did not know their form of genetic mutation (Figure 19).
- 49% (n=93) of ALL patients did not know their cytogenetic status (Figure 20).
- 46% (n=199) of CLL patients did not know their CLL subtype (Figure 21).
- 45% (n=195) of CLL patients did not know if their immunoglobulin heavy chain mutation status (Figure 22).
- 46% (n=212) of CML patients did not know if they had the T315I mutation (Figure 23).

CML awareness of knowing which phase of CML patients were in was much higher, with just 4% (n=20) reporting they did not know (Figure 24).

Figure 19. [Patient] Q17 What form of genetic mutation do you have? (AML only)

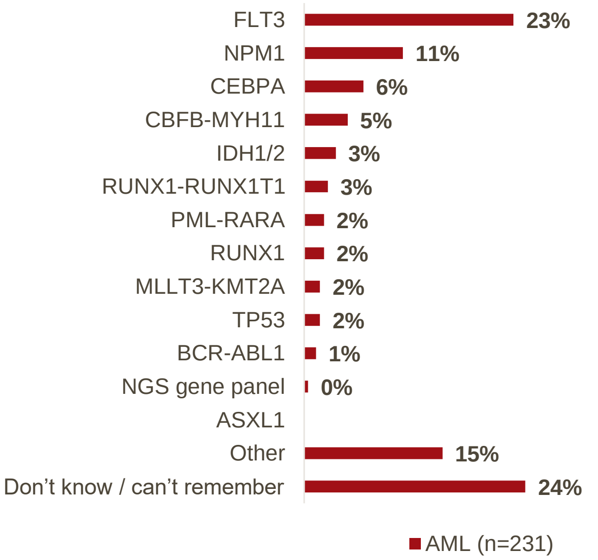


Figure 20. [Patient] Q18 What is your cytogenetic status? (ALL only)

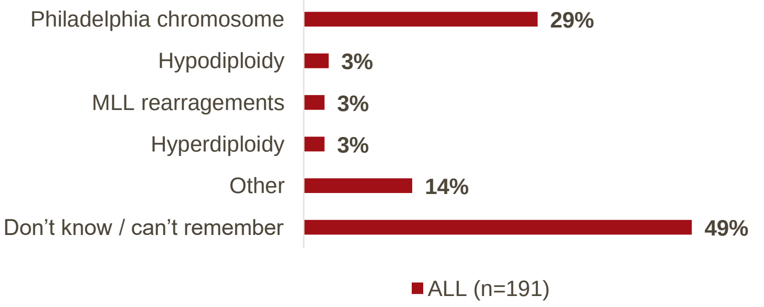


Figure 21. [Patient] Q19 What is your CLL subtype? (CLL only)

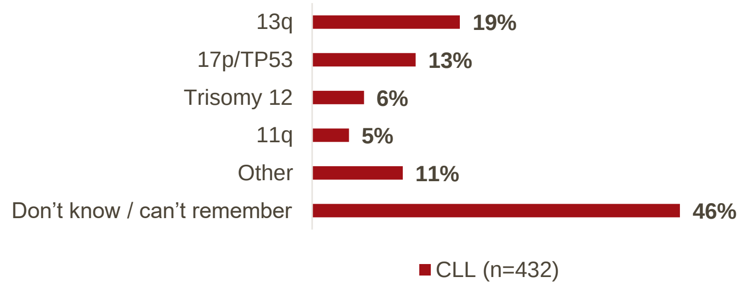


Figure 22. [Patient] Q20 What is your immunoglobulin heavy chain (IGHV) mutation status? (CLL only)

Figure 23. [Patient] Q21 Have you got the T315I mutation? (CML only)

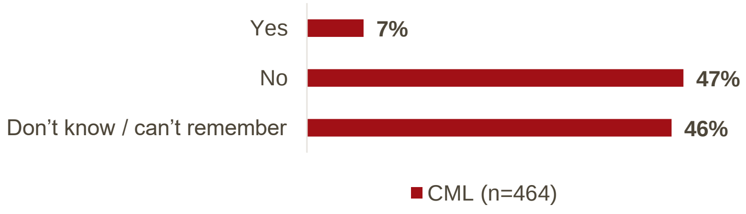
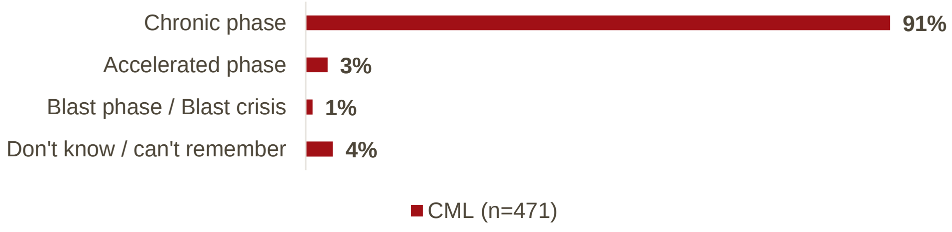


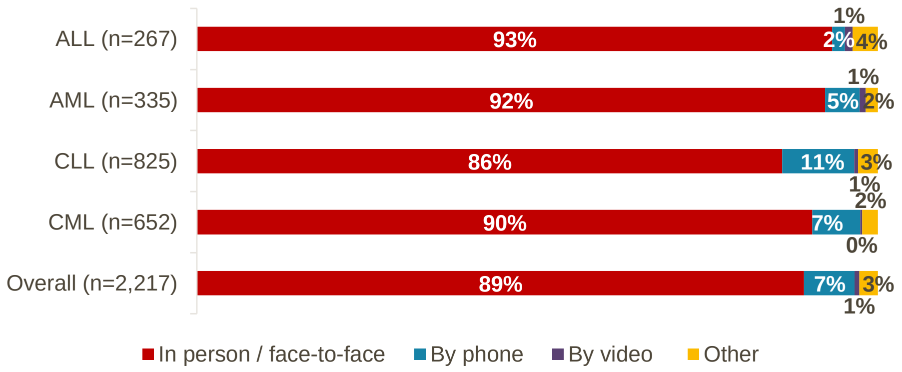
Figure 24. [Patient] Q22 Do you know which phase of CML you are in? (CML only)



Diagnostic consultation

The majority of patients had their diagnosis consultation in person / face to face (89%, n=1,976) (Figure 25).

Figure 25. [Patient] Q23 How did your diagnosis consultation take place?



When they were told they had leukemia, patients were most likely to be accompanied by their spouse or partner (41%, n=920) or a parent or guardian (15%, n=328). 37% (n=817) of patients reported they were on their own when they received this news (Table 2).

Patients with chronic leukemia were far more likely than the overall average to report they were on their own when they received this news (53%, n=436 for CLL, and 35%, n=230 for CML).

Table 2. [Patient] Q24 When you were told you had leukemia, who was with you? Please select all that apply. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**2,224**	269	337	829	650
My spouse or partner	**41%**	38%	49%	40%	42%
My parent(s) or guardian(s)	**15%**	49%	25%	0%	13%
My son or daughter	**6%**	5%	12%	4%	6%
Another relative (not mentioned above)	**6%**	7%	8%	3%	7%
Non-relative e.g. friend, colleague	**3%**	2%	1%	2%	4%
No one, I was on my own	**37%**	13%	20%	53%	35%
Don’t know / can’t remember	**0%**	-	-	0%	0%

As age increases, the proportion of patients who receive their leukemia diagnosis alone increases. Half of patients aged 66-75 (50%, n=227) and 76 and over (51%, n=86) were alone when they told they had leukemia, compared to 11% (n=15) of 18–25-year-olds (Table 3).

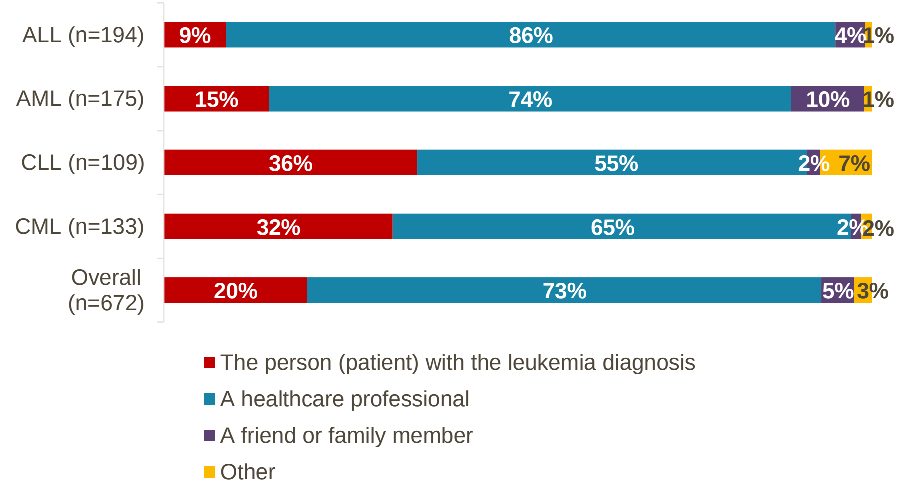
Table 3. [Patient] Q24 When you were told you had leukemia, who was with you? Please select all that apply. by age [Multiple choice]

	18-25	26-35	36-45	46-55	56-65	66-75	76+
Base (n=)	131	241	305	378	538	451	168
My spouse or partner	5%	41%	45%	46%	46%	41%	41%
My parent(s) or guardian(s)	81%	45%	20%	8%	1%	0%	0%
My son or daughter	0%	1%	1%	8%	10%	9%	4%
Another relative (not mentioned above)	8%	6%	10%	8%	6%	2%	3%
Non-relative e.g. friend, colleague	1%	3%	3%	4%	2%	2%	1%
No one, I was on my own	11%	18%	30%	35%	42%	50%	51%
Don't know / can't remember	0%	0%	0%	0%	0%	1%	1%

Carers involvement in the diagnostic consultation

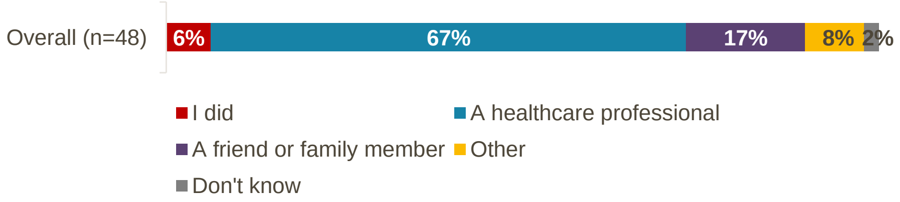
In the carer survey, respondents were asked how they learned about the patient's diagnosis. Overall, 20% (n=136) were told by the patient, 73%, (n=488) were told by a healthcare professional, 5% (n=31) by a friend or family member, and 3% (n=17) from another source (Figure 26).

Figure 26. [Carer] C16 Who told YOU about the patient's leukemia diagnosis?



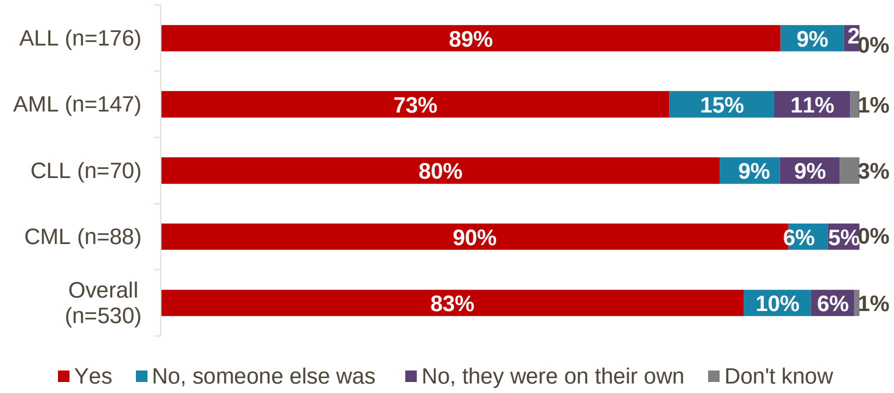
Carers who were told about the patient’s leukemia diagnosis by a friend or family member, or another source, were then asked who told the patient they had leukemia. Carers were most likely to say the patient was told by a healthcare professional (67%, n=32) (Figure 27).

Figure 27. [Carer] C18 Who told the patient they had leukemia?



Carers who indicated the patient was told about their diagnosis from a healthcare professional, a friend of family member, or another source were then asked if they were with the patient when they received their diagnosis. The majority of carers (83%, n=442) reported they were with the patient (Figure 28).

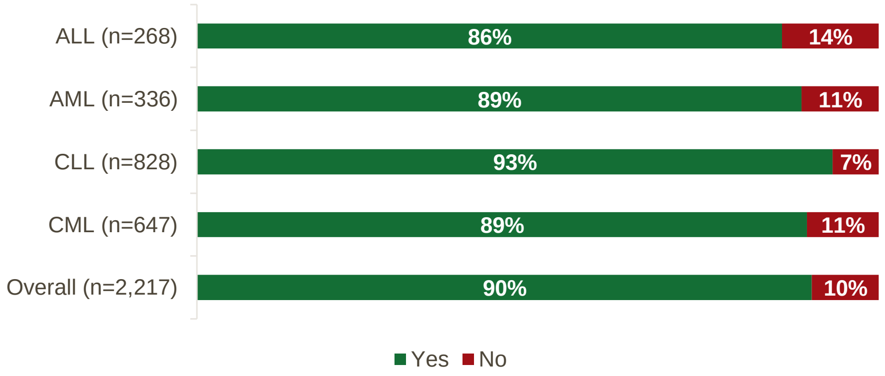
Figure 28. [Carer] C19 When the patient was told they had leukemia, were you with them?



Awareness leukemia was a form of cancer

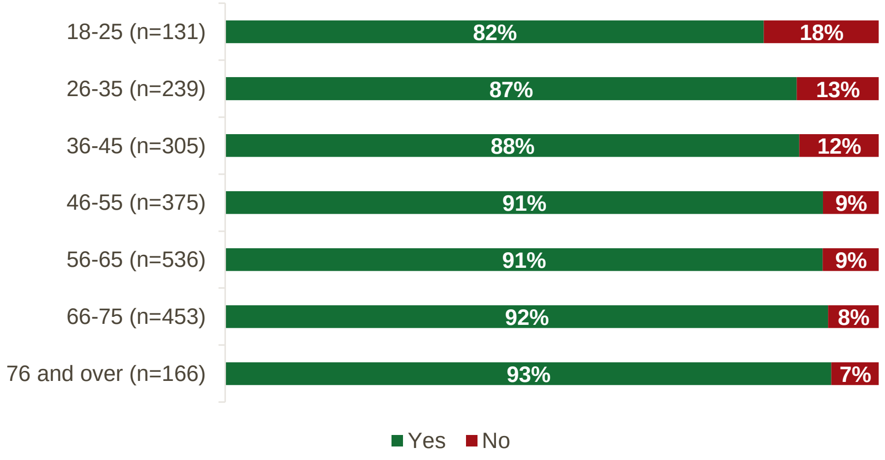
When they received their leukemia diagnosis, the majority of patients (90%, n=2,000) were aware that this was a form of cancer. As displayed in Figure 29, there was marginal variance by leukemia type.

Figure 29. [Patient] Q25 When you were given your diagnosis of leukemia, were you aware it was a form of cancer?



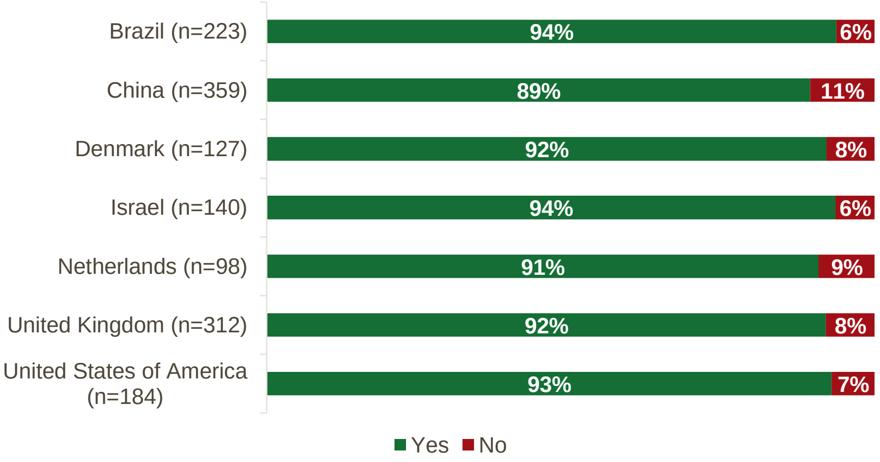
When they received their leukemia diagnosis, 93% (n=154) of patients aged 76 and over were aware that this was a form of cancer. This is compared to 82% (n=108) of patients aged 18-25 (Figure 30).

Figure 30. [Patient] Q25 When you were given your diagnosis of leukemia, were you aware it was a form of cancer? by age



Awareness at diagnosis that leukemia was a form of cancer was considerably high across all countries, but lowest in China (89%, n=321) (Figure 31).

Figure 31. [Patient] Q25 When you were given your diagnosis of leukemia, were you aware it was a form of cancer? by country

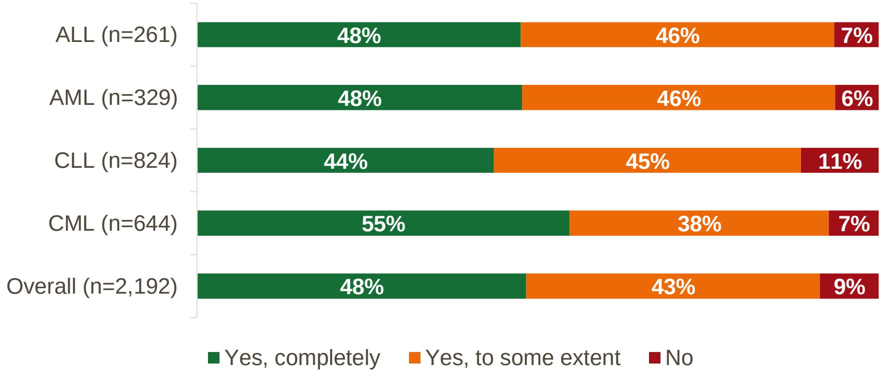


Information and explanations during diagnostic conversation

Just under half of patients (48%, n=1,059) reported that their diagnosis was completely explained to them in a way they could understand. 43% (n=944) said it was explained to some extent, while 9% (n=189) said their diagnosis was not explained to them in a way they could understand (Figure 32).

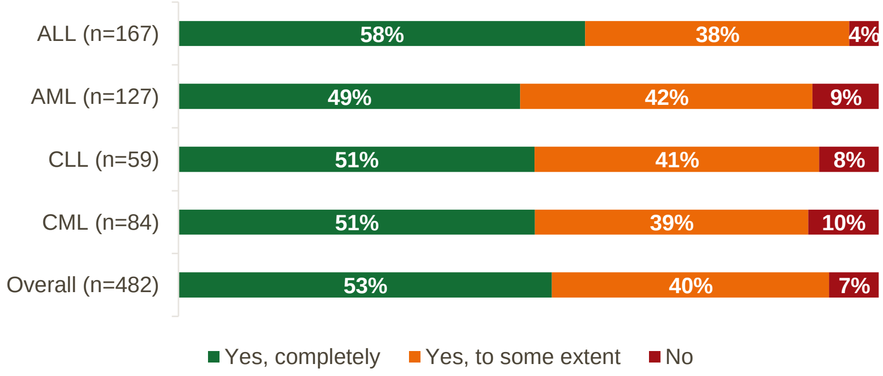
Carers who said they were told about the patient's leukemia diagnosis by a healthcare professional were asked if the diagnosis was explained to them in a way they could understand. Carers reported a slightly more positive experience than patients, with 53% (n=257) reporting the diagnosis was explained completely (Figure 33).

Figure 32. [Patient] Q26 Was your diagnosis explained to you in a way you could understand? [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=26) were removed from analysis for Q26.

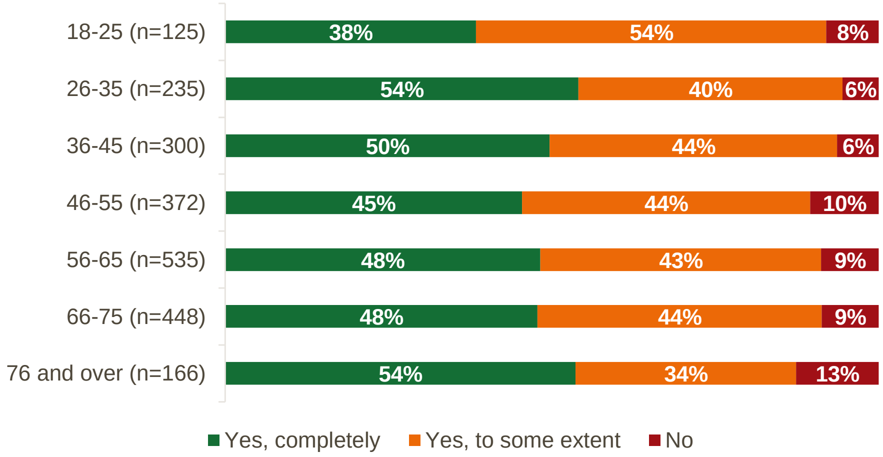
Figure 33. [Carer] C17 Was the diagnosis explained to you in a way you could understand? [Derived]



Please note carers who answered ‘don't know / can't remember’ (n=1) were removed from analysis for C17.

Patients aged 18-25 (38%, n=48) were least likely to report they completely understood the way their diagnosis was explained to them, compared to other age groups (Figure 34).

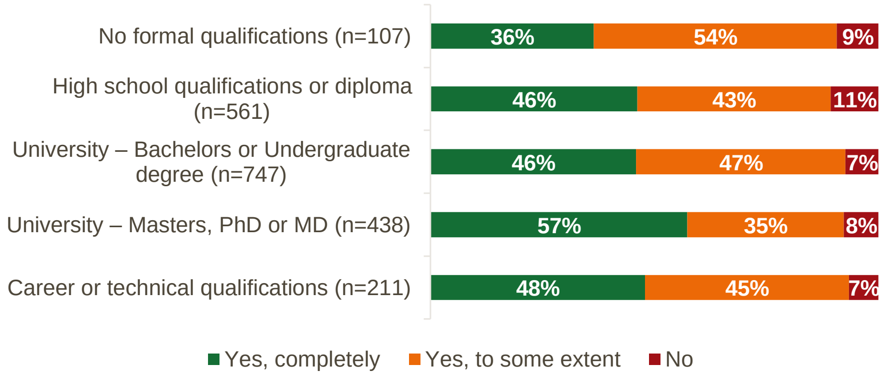
Figure 34. [Patient] Q26 Was your diagnosis explained to you in a way you could understand? by age [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=26) were removed from analysis for Q26.

Patients with no formal qualifications (36%, n=39) were far less likely to report they completely understood the way their diagnosis was explained to them, than patients with a postgraduate university degree (Masters, PhD or MD) (57%, n=251) (Figure 35).

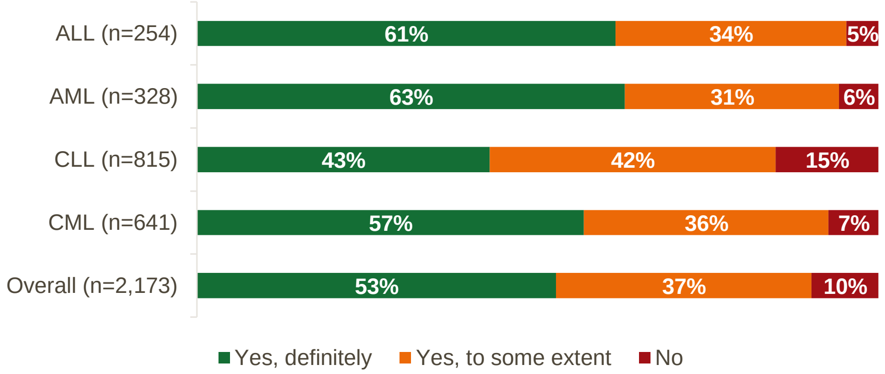
Figure 35. [Patient] Q26 Was your diagnosis explained to you in a way you could understand? By level of education [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=26) were removed from analysis for Q26.

When asked if they were given clear information about their diagnosis, 53% (n=1,145) of patients said yes, definitely, 37% (n=814) said yes, to some extent, and 10% (n=214) said no. Patients with CLL (43%, n=350) were least likely to say they definitely received clear information about their diagnosis (Figure 36).

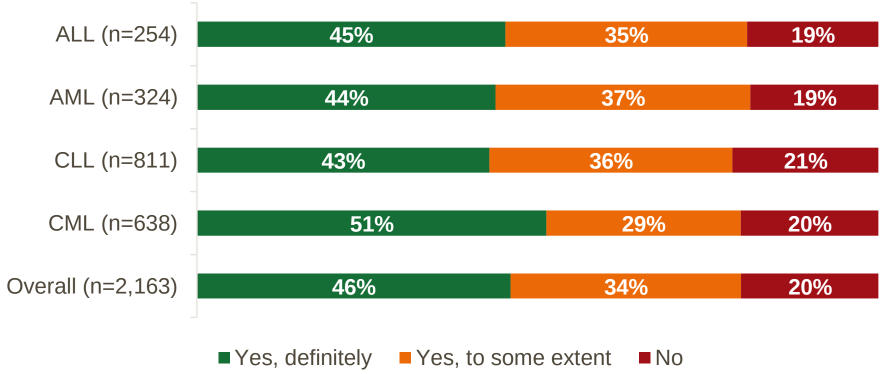
Figure 36. [Patient] Q27 Were you given clear information about your diagnosis? [Derived]



Please note patients who answered 'don't know / can't remember' (n=21) were removed from analysis for Q27.

Just less than half of patients (46%, n=995) said they were definitely told about their leukemia in a sensitive way. This was most likely to be the experience of patients with CML (51%, n=327) (Figure 37).

Figure 37. [Patient] Q28 Were you told about your leukemia in a sensitive way? [Derived]

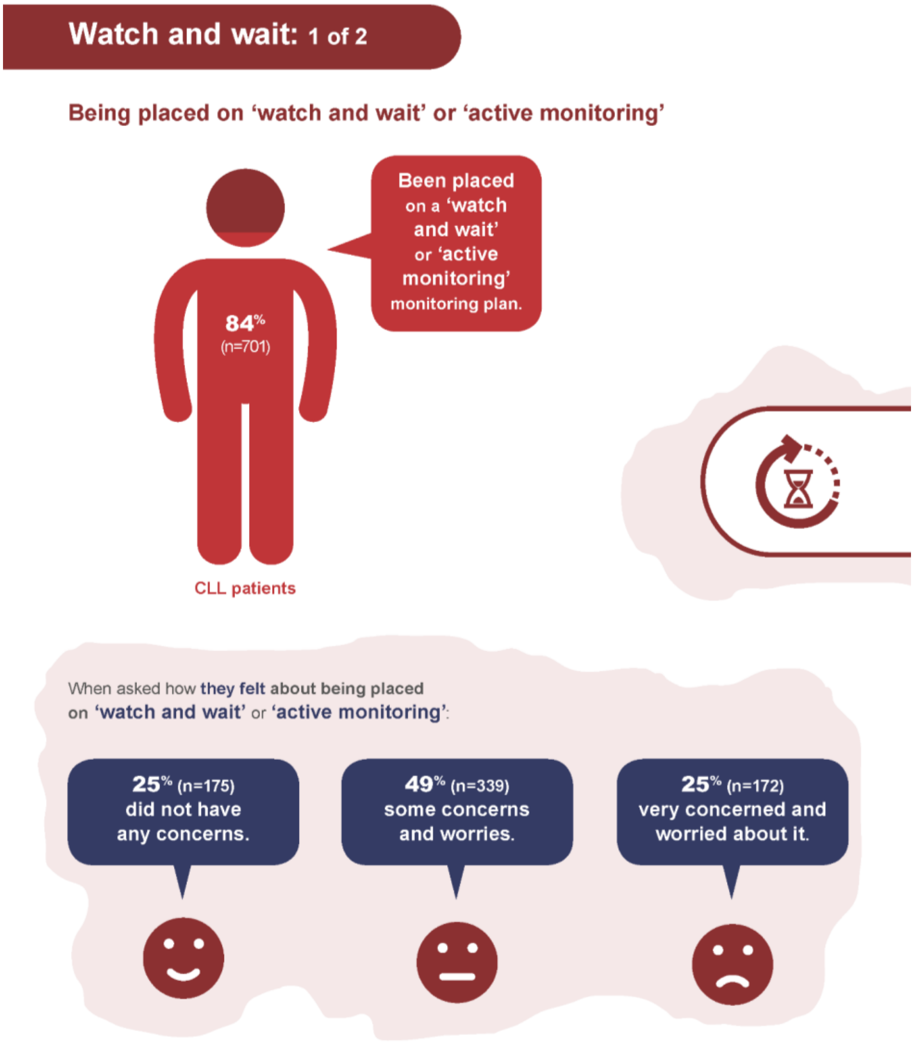


Please note patients who answered 'don't know / can't remember' (n=44) were removed from analysis for Q28.

Global Leukemia Experience Survey 2023

Watch & Wait

Watch and wait



Watch and wait: 1 of 2

Being placed on 'watch and wait' or 'active monitoring'

84% (n=701)

Been placed on a 'watch and wait' or 'active monitoring' monitoring plan.

CLL patients

When asked how **they felt** about being placed on **'watch and wait'** or **'active monitoring'**:

25% (n=175) did not have any concerns.

49% (n=339) some concerns and worries.

25% (n=172) very concerned and worried about it.

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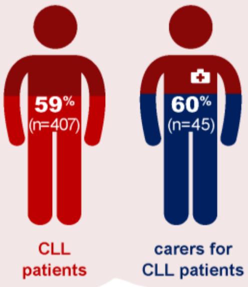
Watch and wait: 2 of 2

Information and explanations

Completely understand the explanation received about why we were placed on 'watch and wait' or 'active monitoring' **for the 1st time.**



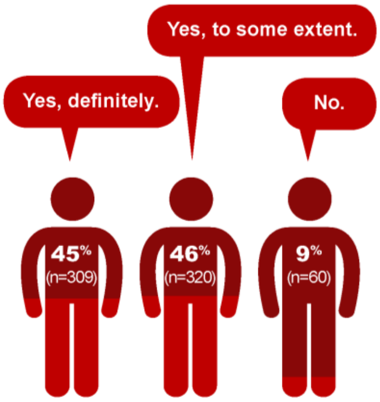
Completely understand the reasons why the patient has been placed on 'watch and wait' or 'active monitoring' **for the 1st time.**

Involvement in decision-making

less than 1/2 of CLL patients (47% n=313) **said they were definitely involved as much as they wanted to be in decisions** about being put on 'watch and wait' or 'active monitoring'.

Recognizing CLL progression

When asked if they were **confident about recognizing the signs and symptoms of CLL progression**:

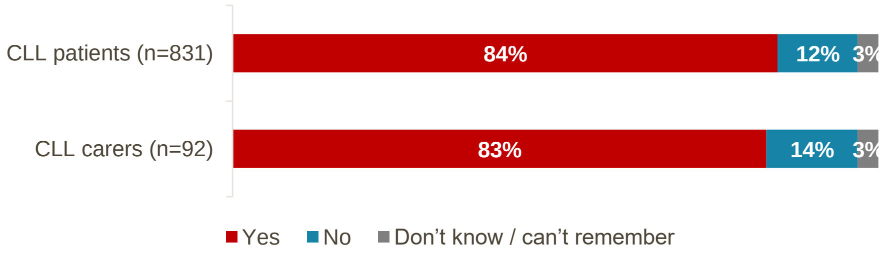


Being placed on 'watch and wait' or 'active monitoring'

‘Watch and wait’ or ‘active monitoring’ involves close monitoring of a CLL patient’s condition, without giving treatment until symptoms appear or change. ‘Watch and wait’ or ‘active monitoring’ may be used to monitor asymptomatic, symptomatic or progressive CLL.[3] Consequently, only CLL respondents were asked the following questions about ‘watch and wait’ or ‘active monitoring’.

84% (n=701) CLL patients had been placed on a 'watch and wait' or 'active monitoring' monitoring plan. 83% (n=76) of carers for CLL patients said they had been placed on a 'watch and wait' or 'active monitoring' monitoring plan (Figure 38).

Figure 38. [Patients] Q29 Have you ever been placed on a 'watch and wait' or 'active monitoring' monitoring plan? & [Carer] C20 Has the patient ever been placed on a 'watch and wait' or 'active monitoring' plan?



When asked how they felt about being placed on ‘watch and wait’ or ‘active monitoring’, 25% (n=175) said they did not have any concerns, 49% (n=339) had some concerns and worries, while 25% (n=172) were very concerned and worried about it (Figure 39).

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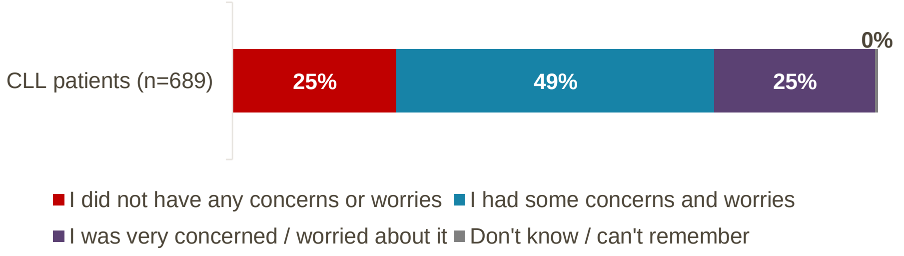
[3] CLL information: Understanding CLL, CLL Advocates Network, https://www.clladvocates.net/cll-information/ [accessed: 04/04/2024].

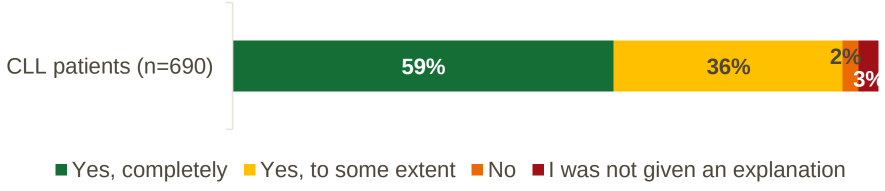
Figure 39. [Patient] Q34 How did you feel about being put on 'watch and wait' or 'active monitoring'? If you have been on 'watch and wait' or 'active monitoring' more than once, please think back to the first time.



Explanations and involvement in decision-making

59% (n=407) of CLL patients completely understood the explanation they received about why they were placed on ‘watch and wait’ or ‘active monitoring’ for the first time. This is compared to 36% (n=245) who said it was explained to some extent, 2% (n=17) who said it was not explained in a way that was understood, and 3% (n=21) who were not given an explanation (Figure 40).

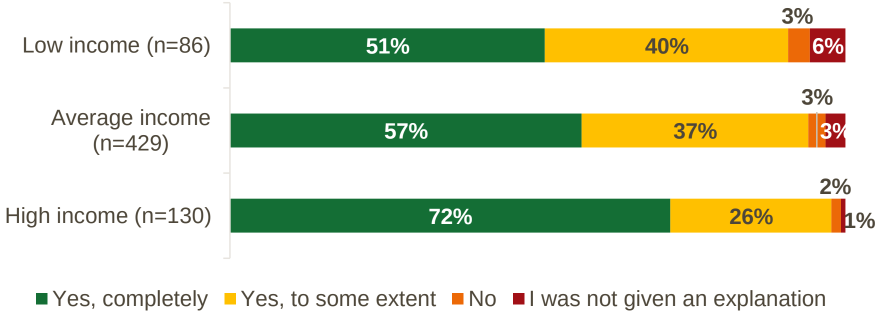
Figure 40. [Patient] Q30 When you were placed on 'watch and wait' or 'active monitoring' for the FIRST time, was it explained to you in a way you could understand? [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=7) were removed from analysis for Q30.

Analysis by annual household income finds that CLL patients who live in a high-income household reported a more positive experience of receiving an explanation about being placed on ‘watch and wait’ or ‘active monitoring’. 72% (n=93) of those in a high-income household said they received a complete explanation that they could understand. This is compared to 51% (n=44) of those in a low-income household, and 57% (n=245) who live in an average income household (Figure 41).

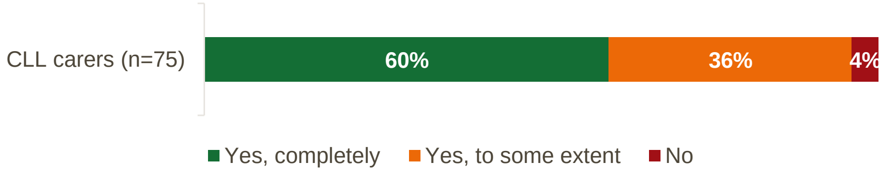
Figure 41. [Patient] Q30 When you were placed on 'watch and wait' or 'active monitoring' for the FIRST time, was it explained to you in a way you could understand? By annual household income [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=7) were removed from analysis for Q30.

Carers were asked if they understood the reasons why the patient had been placed on 'watch and wait' or 'active monitoring' the first time. As displayed in Figure 42, 60% (n=45) completely understood, 36% (n=27) understood to some extent, and 4% (n=3) did not understand.

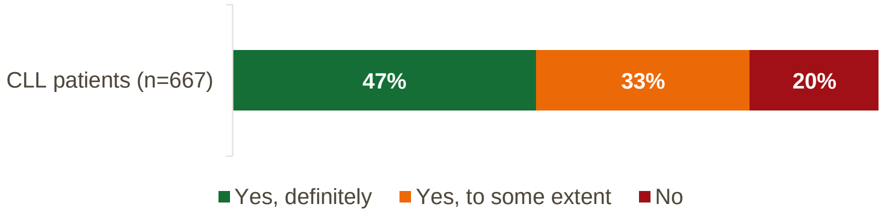
Figure 42. [Carer] C21 When they were placed on 'watch and wait' or 'active monitoring' for the FIRST TIME did YOU understand the reasons why? [Derived]



Please note carers who answered ‘don't know / can't remember’ (n=1) were removed from analysis for C21.

Less than half of CLL patients (47%, n=313) said they were definitely involved as much as they wanted to be in decisions about being put on 'watch and wait' or 'active monitoring' (Figure 43).

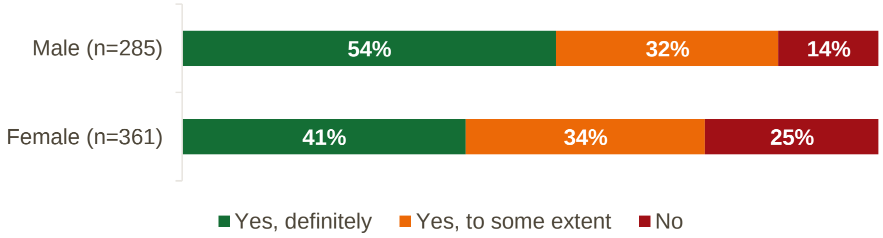
Figure 43. [Patient] Q35 Were you involved as much as you wanted to be in decisions about being put on 'watch and wait' or 'active monitoring'? [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=22) were removed from analysis for Q35.

Analysis by gender, shown in Figure 44, shows male patients (54%, n=153) were far more likely to say they were definitely involved as much as they wanted to be in decisions about being put on 'watch and wait' or 'active monitoring', than female patients (41%, n=147).

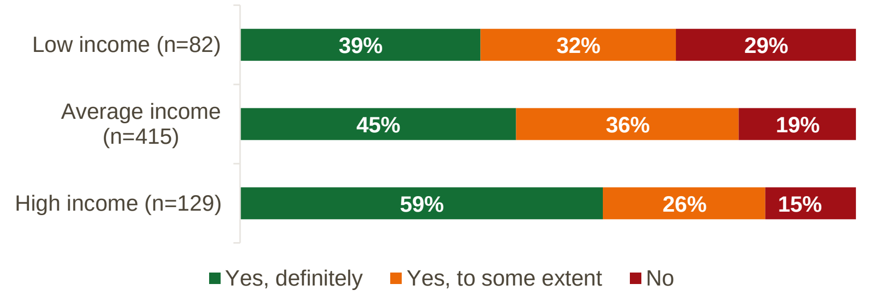
Figure 44. [Patient] Q35 Were you involved as much as you wanted to be in decisions about being put on 'watch and wait' or 'active monitoring'? by gender [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=22) were removed from analysis for Q35.

CLL patients who lived in a high-income household (59%, n=76) were far more likely to say they were definitely involved as much as they wanted to be in decisions about being put on 'watch and wait' or 'active monitoring', than patients who lived in a low-income (39%, n=32) or average income (45%, n=186) household (Figure 45).

Figure 45. [Patient] Q35 Were you involved as much as you wanted to be in decisions about being put on 'watch and wait' or 'active monitoring'? by annual household income [Derived]

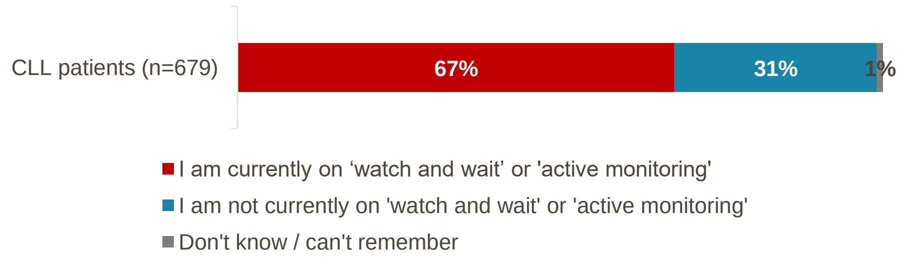


Please note patients who answered ‘don't know / can't remember’ (n=22) were removed from analysis for Q35.

Current monitoring situation

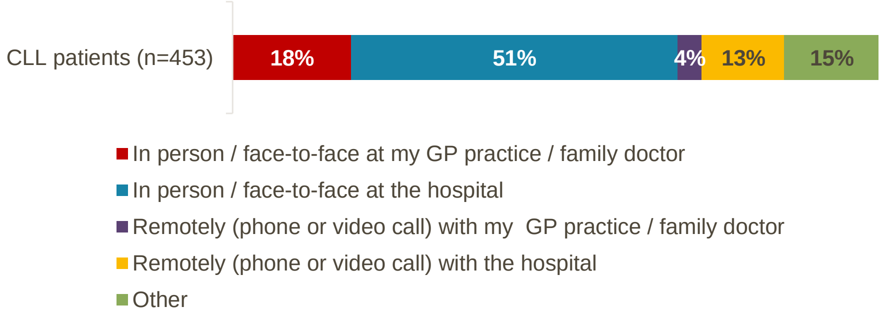
CLL patients who indicated they have been placed on ‘watch and wait’ or 'active monitoring' were asked about their current monitoring situation. Two thirds (67%, n=457) indicated they are currently on ‘watch and wait’ or 'active monitoring', 31% (n=212) are not currently on 'watch and wait' or 'active monitoring', and 1% (n=10) did not know (Figure 46).

Figure 46. [Patient] Q31 What best describes your current 'watch and wait' or 'active monitoring' situation?



The most common way monitoring visits take place is in person / face-to-face, with 51% (n=229) taking place at the hospital, and 18% (n=83) taking place at the patients GP or family doctor practice (Figure 47).

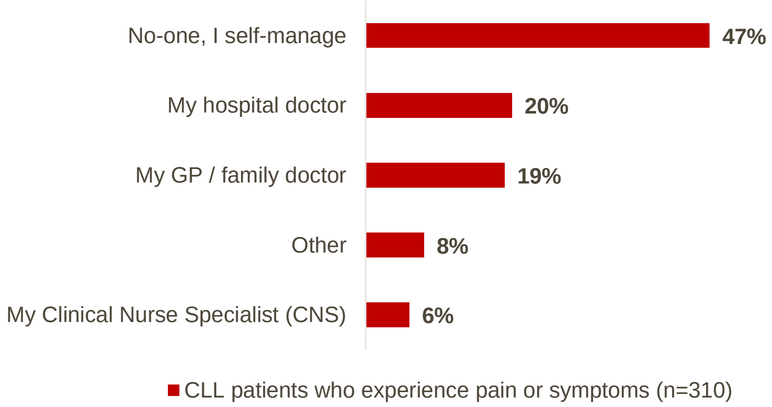
Figure 47. [Patient] Q32 What is the main way your monitoring visits take place? A monitoring visit is a regular check up with a member of your medical team to check if your leukemia needs treatment.



CLL patients who are currently on 'watch and wait' or 'active monitoring' were asked who helps them with pain or symptoms. 38% (n=173) reported that they do not experience any pain or symptoms.

Where pain or symptoms were present, 47% (n=145) self-manage, 20% (n=62) receive help from their hospital doctor, and 19% (n=59) receive help from their GP or family doctor (Figure 48).

Figure 48. [Patient] Q33 While on 'watch and wait' or 'active monitoring', who helps you with pain or symptoms related to your diagnosis? Please select all that apply. [Multiple choice]

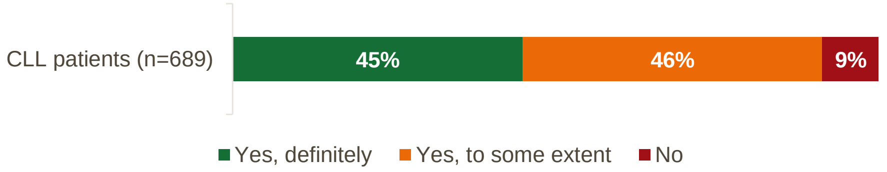


Please note the response option 'my Clinical Nurse Specialist (CNS)' was shown only to patients in the United Kingdom.

Recognizing CLL progression

CLL patients who had been placed on 'watch and wait' or 'active monitoring' were asked if they were confident about recognizing the signs and symptoms of CLL progression. 45% (n=309) answered yes, definitely, 46% (n=320) answered yes, to some extent, and 9% (n=60) answered no (Figure 49).

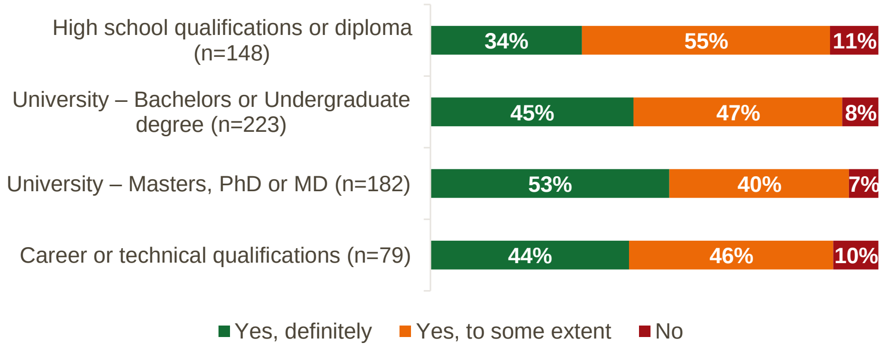
Figure 49. [Patient] Q36 Are you confident you can recognize the signs and symptoms of CLL progression?



As displayed in Figure 50, as level of education increases, the proportion of CLL patients who indicated they are definitely confident they can recognize the signs and symptoms of CLL progression increases:

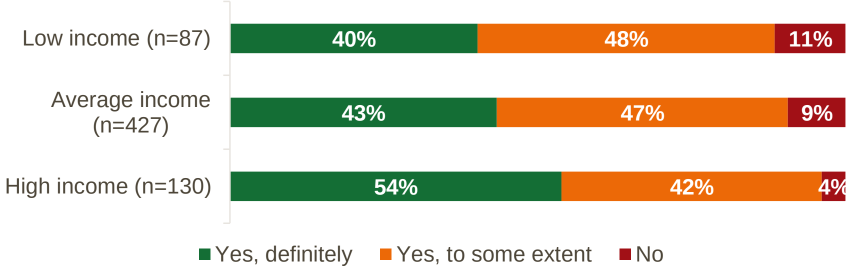
- 34% (n=50) with high school qualifications or a diploma said they were confident;
- 44% (n=35) with career or technical qualifications;
- 45% (n=101) with an undergraduate university degree (Bachelors) and;
- 53% (n=97) with a postgraduate degree (Masters, PhD or MD).

Figure 50. [Patient] Q36 Are you confident you can recognize the signs and symptoms of CLL progression? by level of education



In a similar trend as with level of education, as annual household income increases, the proportion of CLL patients who indicated they are definitely confident they can recognize the signs and symptoms of CLL progression increases (Figure 51). The proportion of confident CLL patients rises from 40% (n=35) for low-income households and 43% (n=185) in average income households to 54% (n=70) for high-income households.

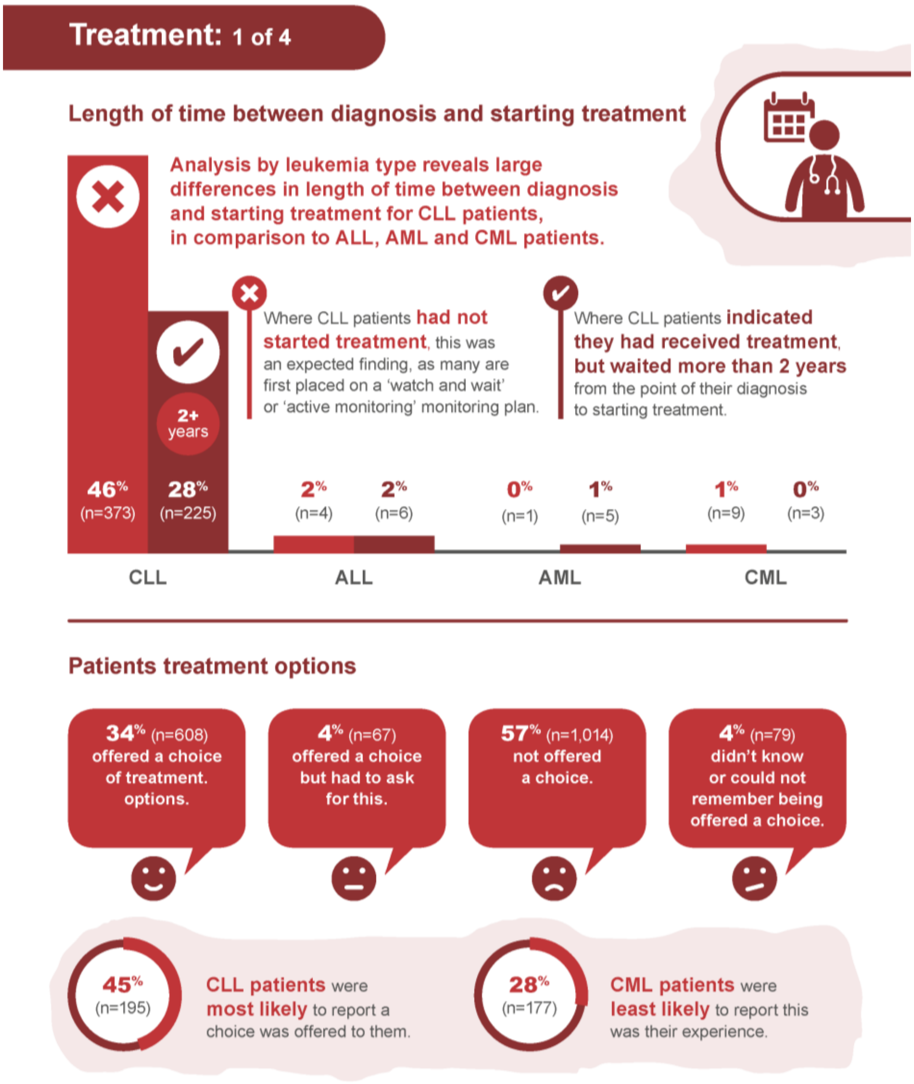
Figure 51. [Patient] Q36 Are you confident you can recognize the signs and symptoms of CLL progression? by annual household income



Global Leukemia Experience Survey 2023

Treatment

Treatment



Treatment: 1 of 4

Length of time between diagnosis and starting treatment

Analysis by leukemia type reveals large differences in length of time between diagnosis and starting treatment for CLL patients, in comparison to ALL, AML and CML patients.

Where CLL patients **had not started treatment**, this was an expected finding, as many are first placed on a 'watch and wait' or 'active monitoring' monitoring plan.

Where CLL patients **indicated they had received treatment, but waited more than 2 years** from the point of their diagnosis to starting treatment.

Patients treatment options

34% (n=608) **offered a choice of treatment. options.**

4% (n=67) **offered a choice but had to ask for this.**

57% (n=1,014) **not offered a choice.**

4% (n=79) **didn't know or could not remember being offered a choice.**

45% (n=195) **CLL patients** were **most likely** to report a choice was offered to them.

28% (n=177) **CML patients** were **least likely** to report this was their experience.

Treatment: 2 of 4

Involvement in decision-making

Patients who were **most likely** or **least likely** to report they were definitely **involved as much as they wanted to be in decisions about their treatment if they:**

Most likely

- **52%** (n=228) Had CLL.
- **54%** (n=156) Older patients aged 66-75. (66-75 years)
- **54%** (n=64) Older patients aged 76+. (76+ years)
- **53%** (n=178) Had a postgraduate university degree (Masters, PhD or MD).
- **55%** (n=112) Lived in a high-income household.

Least likely

- **36%** (n=89) Had ALL.
- **36%** (n=43) Younger patients aged 18-25. (18-25 years)
- **37%** (n=121) Lived in China.
- **47%** (n=94) Lived in Brazil.
- **39%** (n=162) Lived in a low-income household.

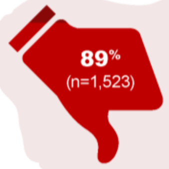
Treatment and side effects

67% (n=1,168) were currently receiving treatment for their leukemia.

26% (n=446) of patients had missed a dose of their treatment in the last year.

Treatment: 3 of 4

Treatment and side effects



The majority of patients who had received treatment **reported experiencing side effects** from their most recent or current treatment.

Carers reported a higher instance of patients **experiencing side effects** from their most recent or current treatment.

The most common side-effects experienced were:

Fatigue (n=893)

Pain in bones / joints (n=541)

Nausea or vomiting (n=470)

Sleeping problems (n=440)

Muscle pain (n=426)

The most common side effects cited by carers differed to those reported by patients:

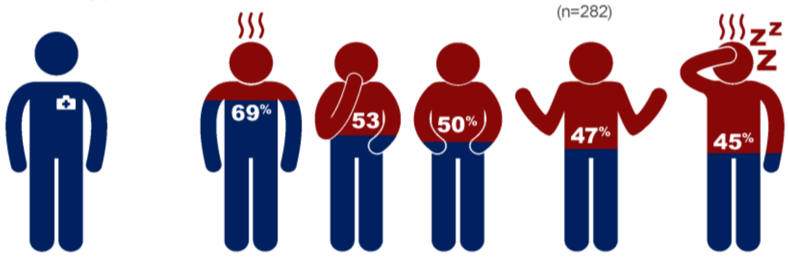
Fatigue (n=413)

Nausea or vomiting (n=314)

Loss of appetite (n=297)

Unusually high or low red / white / platelet blood count (n=282)

Fever / night sweats (n=267)



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Treatment: 4 of 4

Treatment and side effects

77% (n=1,076) of patients reported their symptoms had improved as a result of their current or most recent treatment.

16% (n=220) of patients reported their symptoms remained the same.

7% (n=99) of patients reported their symptoms have gotten worse.

43% (n=721) of patients were given completely **clear information** about any side effects from their most recent or current treatment.

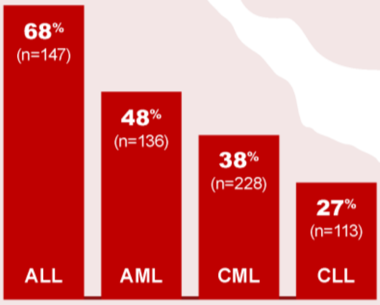
53% (n=225) **CLL patients were most likely** to report they received completely **clear information.**

Barriers to treatment

42% (n=672) of patients reported that they **experienced a barrier that affected their treatment choices.**

The most **common barrier** experienced was the **cost of treatment, 20%** (n=320), **which was cited by 1 in 5 patients.**

Analysis by leukemia type finds:



of patients experienced a barrier that affected their treatment choices.

Length of time between diagnosis and starting treatment

As shown in Table 4, analysis by leukemia type reveals large differences in length of time between diagnosis and starting treatment for CLL patients, in comparison to ALL, AML and CML patients.

- 46% (n=373) of CLL patients had not started treatment. This is compared to 2% (n=4) of ALL, 0% (n=1) of AML and 1% (n=9) of CML patients.
- Where CLL patients indicated they had received treatment, 28% (n=225) waited more than 2 years from the point of their diagnosis to starting treatment. This is compared to 2% (n=6) of ALL, 1% (n=5) of AML and 0% (n=3) of CML patients.

Table 4. [Patient] Q37 How long was it between your diagnosis and starting treatment for your specific leukemia e.g. CML, CLL, AML, ALL? By treatment we mean chemotherapy, immunotherapy, radiotherapy, steroids, stem cell transplants or targeted therapy you have had to treat your leukemia. Please don't include any other treatment you may have received for your symptoms.

	Overall	ALL	AML	CLL	CML
Base (n=)	**2,205**	265	335	818	649
The same day I was given my diagnosis	**13%**	19%	22%	1%	20%
Within 1 week	**26%**	47%	53%	2%	33%
Within 1 month	**18%**	20%	16%	5%	34%
Within 3 months	**5%**	2%	2%	4%	8%
Within 6 months	**2%**	3%	1%	2%	2%
Within 1 year	**3%**	3%	1%	5%	1%
Within 2 years	**3%**	2%	1%	7%	1%
More than 2 years	**11%**	2%	1%	28%	0%
I have not had treatment	**19%**	2%	0%	46%	1%

The proportion of patients who haven't had treatment was greater for older age groups than younger. 17% (n=63) of patients aged 46-55, 24% (n=127) aged 56-65, 34% (n=152) aged 66-75 and 27% (n=45) aged 76 and over reported they had not had treatment. This is compared to just 1% (n=1) of patients aged 18-25, 3% (n=6) aged 26-35 and 5% (n=14) aged 36-45 (Table 5).

Similarly, where patients indicated they had received treatment, older patients were far more likely to wait longer between diagnosis and starting treatment. 22% (n=97) of patients aged 66-75 and 22% (n=37) aged 76 and over reported waiting 2 years from their diagnosis to starting treatment. This is compared to 1% (n=3) of patients aged 26-35 and 2% (n=6) aged 36 to 45.

Table 5. [Patient] Q37 How long was it between your diagnosis and starting treatment for your specific leukemia e.g. CML, CLL, AML, ALL? By treatment we mean chemotherapy, immunotherapy, radiotherapy, steroids, stem cell transplants or targeted therapy you have had to treat your leukemia. Please don't include any other treatment you may have received for your symptoms by age

	18-25	26-35	36-45	46-55	56-65	66-75	76+
Base (n=)	131	236	303	372	535	450	166
The same day I was given my diagnosis	15%	21%	20%	16%	12%	6%	5%
Within 1 week	50%	42%	42%	30%	19%	10%	12%
Within 1 month	22%	22%	21%	17%	19%	13%	14%
Within 3 months	3%	3%	6%	5%	4%	6%	2%
Within 6 months	2%	4%	1%	2%	2%	2%	4%
Within 1 year	3%	3%	1%	2%	3%	4%	5%
Within 2 years	2%	1%	2%	2%	4%	4%	8%
More than 2 years	3%	1%	2%	8%	13%	22%	22%
I have not had treatment	1%	3%	5%	17%	24%	34%	27%

Analysis by country reveals patients in the United Kingdom (44%, n=134) were most likely to report they had not had treatment. Patients in China (2%, n=8) were least likely to report they had not had treatment (Table 6).

Where patients indicated they had received treatment:

- Denmark (21%, n=27) had the highest proportion of patients starting treatment on the same day they received their diagnosis.
- Patients in China (81%, n=290) and Brazil (79%, n=175) were most likely to start treatment quickly, within 1 month or less from the point of receiving their diagnosis. Patients in the United Kingdom (16%, n=50) were least likely to report they started treatment quickly, within 1 month or less.
- Patients in the United Kingdom (22%, n=68) were most likely to wait more than 2 years between receiving their diagnosis and starting treatment. The United Kingdom had a high proportion of patient’s with CLL in their response profile, and it is expected that patient’s with CLL would be placed on a ‘watch and wait’ or ‘active monitoring’ plan until they require treatment.

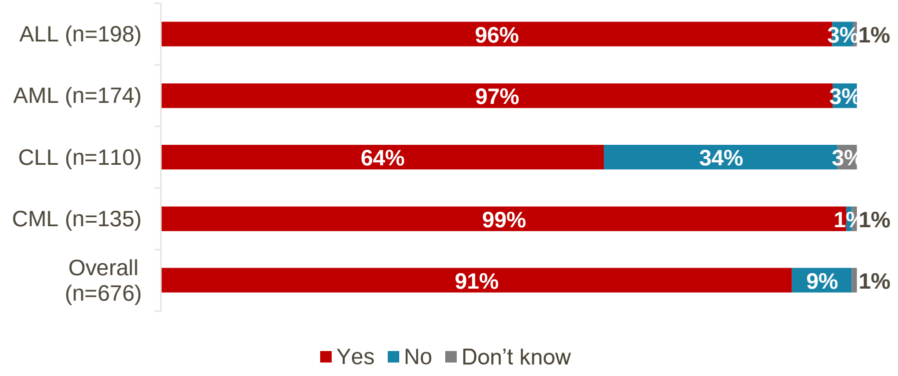
Table 6. [Patient] Q37 How long was it between your diagnosis and starting treatment for your specific leukemia e.g. CML, CLL, AML, ALL? By treatment we mean chemotherapy, immunotherapy, radiotherapy, steroids, stem cell transplants or targeted therapy you have had to treat your leukemia. Please don't include any other treatment you may have received for your symptoms by country

	Brazil	China	Denmark	Israel	Netherlands	United Kingdom	United States of America
Base (n=)	222	357	126	142	97	308	183
The same day I was given my diagnosis	16%	12%	21%	11%	18%	4%	3%
Within 1 week	36%	48%	26%	22%	21%	5%	14%
Within 1 month	27%	21%	12%	18%	10%	7%	22%
Within 3 months	7%	3%	1%	4%	4%	4%	7%
Within 6 months	3%	2%	2%	0%	2%	1%	2%
Within 1 year	1%	4%	3%	5%	3%	5%	4%
Within 2 years	0%	4%	3%	0%	4%	9%	4%
More than 2 years	2%	4%	14%	18%	13%	22%	12%
I have not had treatment	8%	2%	17%	23%	25%	44%	31%

Carers awareness of patients treatment

Carers were asked if the patient they care for had treatment for their leukemia. Overall, 91% (n=613) reported they had had treatment, 9% (n=58) reported they had not, and 1% (n=5) did not know (Figure 52).

Figure 52. [Carer] C22 Has the patient had treatment for their leukemia?



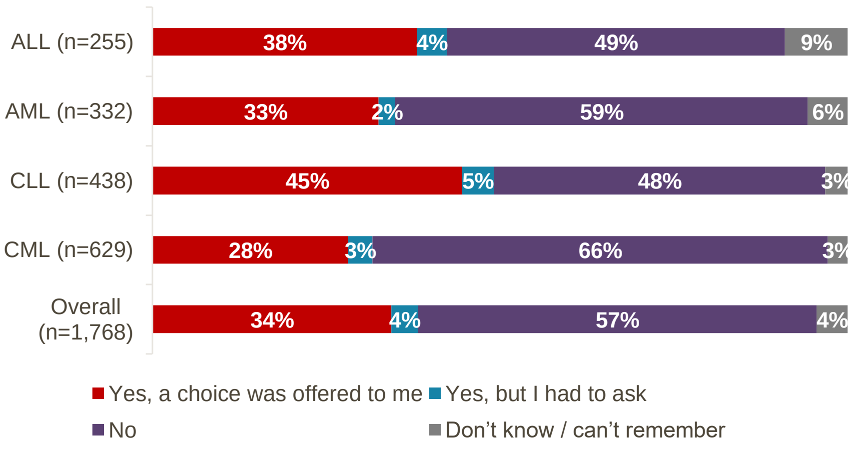
Treatment options

One third of patients (34%, n=608) were offered a choice of treatment options, 4% (n=67) were offered a choice but had to ask for this, 57% (n=1,014) were not offered a choice, and 4% (n=79) didn't know or could not remember if they had been offered a choice (Figure 53).

CLL patients (45%, n=195) were most likely to report a choice was offered to them, while CML patients (28%, n=177) were least likely to report this was their experience.

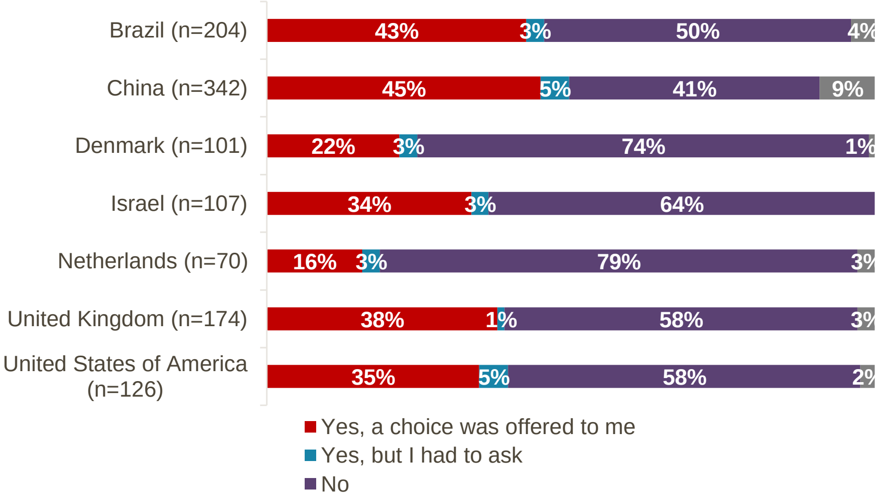
Patients with acute leukemia (9%, n=23 for ALL; 6%, n=19 for AML) were more likely to report they didn't know or couldn't remember being offered a choice than patients with chronic leukemia (3%, n=14 for CLL; 3%, n=18 for CML). This finding is not unexpected, as patients with acute leukemia are much more likely to require urgent treatment.

Figure 53. [Patient] Q38 Were you offered a choice of treatment options?



Analysis by country reveals patients in China (45%, n=154), followed by Brazil (43%, n=87) were most likely to report a choice of treatment options was offered to them. Patients in the Netherlands (79%, n=55) and Denmark (74%, n=75) were most likely to report they were not offered a choice of treatment options (Figure 54).

Figure 54. [Patient] Q38 Were you offered a choice of treatment options? by country

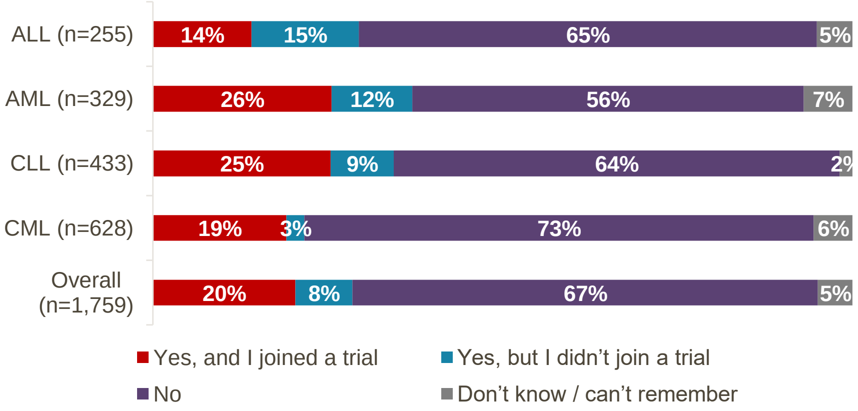


Participating in a clinical trial

Overall, 29% (n=502) of patients were offered the option of participating in a clinical trial. 20% (n=358) of patients joined a trial, while 8% (n=144) did not join a trial (Figure 55).

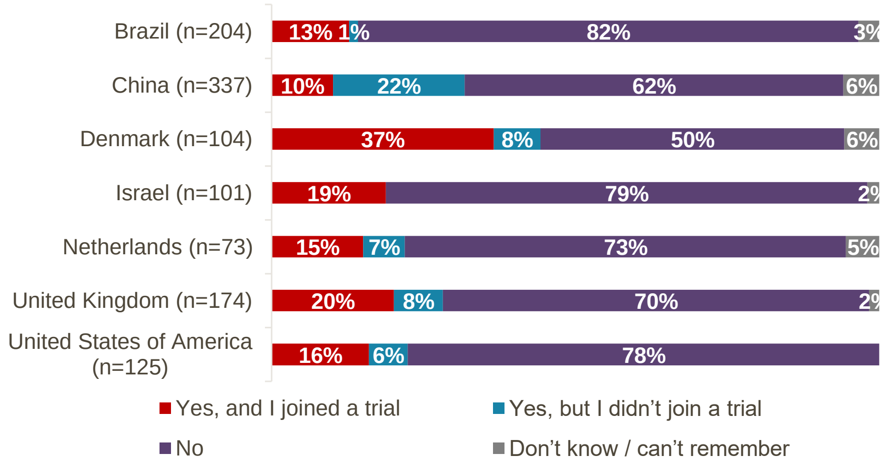
AML (26%, n=84) and CLL (25%, n=110) patients were most likely to report they joined a clinical trial.

Figure 55. [Patient] Q39 Were you given the option of participating in a clinical trial?



Patients in Denmark (37%, n=38) were most likely to report they joined a clinical trial. Brazil (82%, n=168) had the highest proportion of patients reporting they were not given the option of participating in a clinical trial (Figure 56).

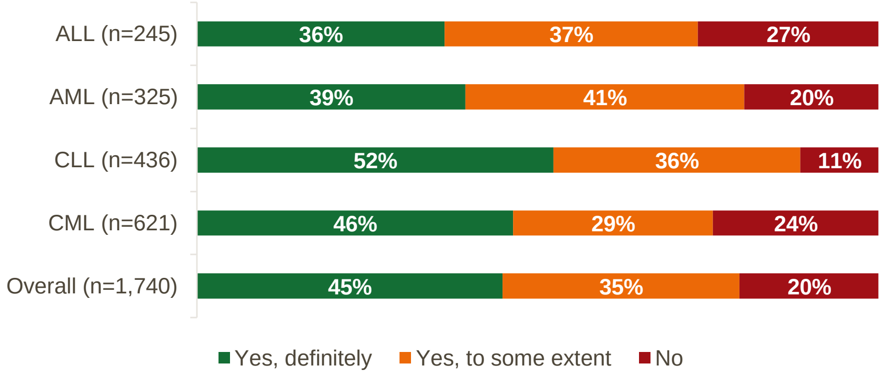
Figure 56. [Patient] Q39 Were you given the option of participating in a clinical trial? by country



Involvement in decision-making

Half of CLL patients (52%, n=228) reported they were definitely involved as much as they wanted to be in decisions about their treatment. This is compared to 46% (n=288) of patients with CML, 39% (n=128) with AML and 36% (n=89) with ALL (Figure 57).

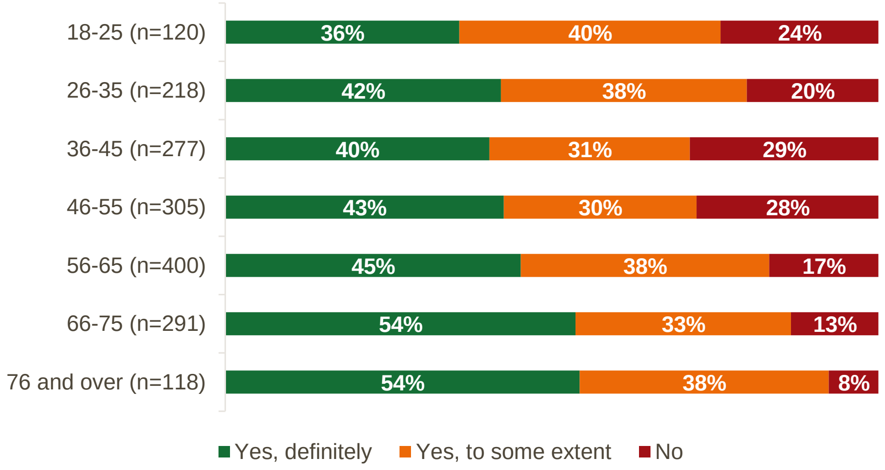
Figure 57. [Patient] Q40 Were you involved as much as you wanted to be in decisions about your treatment? [Derived]



Please note patients who answered 'don't know / can't remember' (n=35) were removed from analysis for Q40.

As displayed in Figure 58, older patients aged 66-75 (54%, n=156) and 76 and over (54%, n=64) were much more likely to report they were definitely involved as much as they wanted to be in decisions about their treatment, than younger patients.

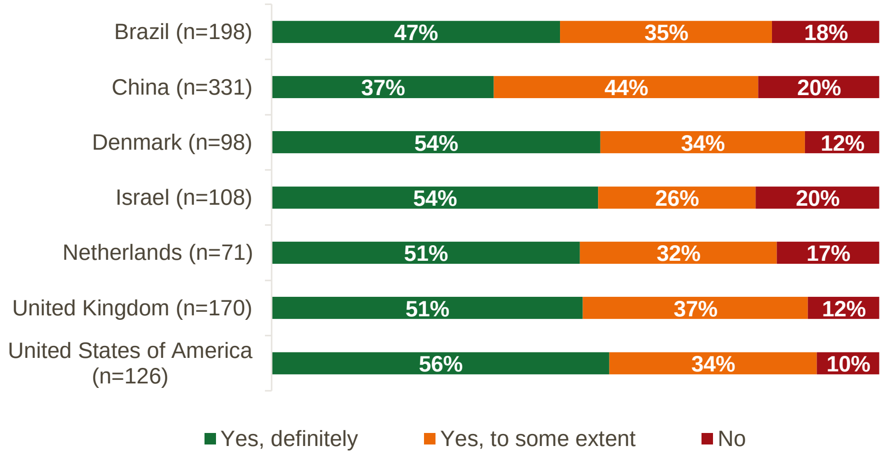
Figure 58. [Patient] Q40 Were you involved as much as you wanted to be in decisions about your treatment? by age [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=35) were removed from analysis for Q40.

Patients in China (37%, n=121) and Brazil (47%, n=94) were least likely to report they were definitely involved as much as they wanted to be in decisions about their treatment (Figure 59).

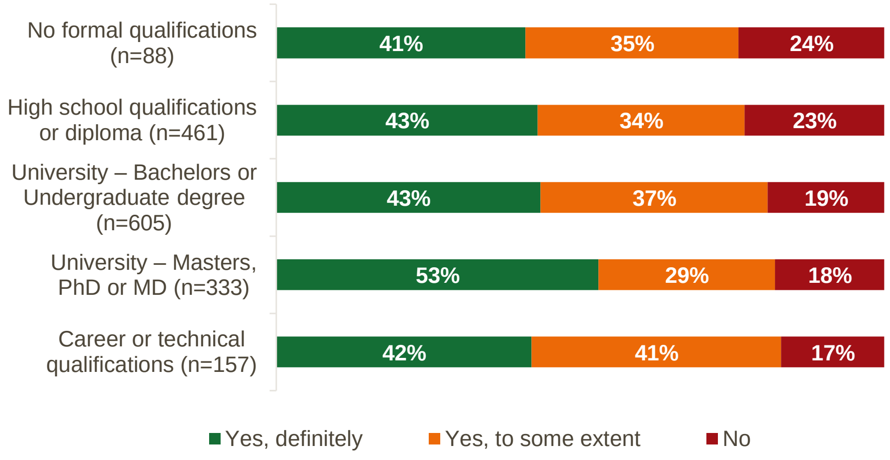
Figure 59. [Patient] Q40 Were you involved as much as you wanted to be in decisions about your treatment? by country [Derived]



Please note patients who answered 'don't know / can't remember' (n=35) were removed from analysis for Q40.

As shown in Figure 60, patients with a postgraduate university degree (Masters, PhD or MD) (53%, n=178) were the most likely to report they were definitely involved as much as they wanted to be in decisions about their treatment.

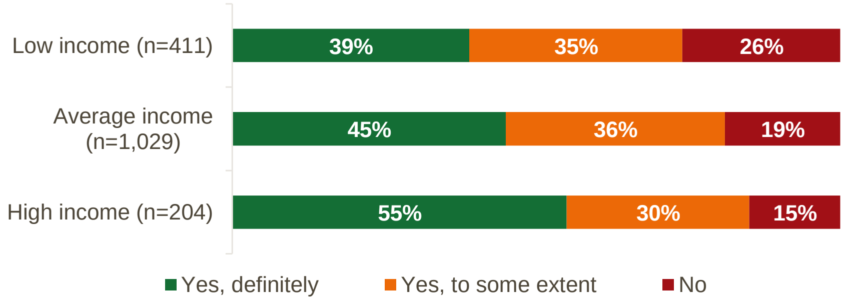
Figure 60. [Patient] Q40 Were you involved as much as you wanted to be in decisions about your treatment? by level of education [Derived]



Please note patients who answered 'don't know / can't remember' (n=35) were removed from analysis for Q40.

As annual household income increases, the proportion of patients who reported they were definitely involved as much as they wanted to be in decisions about their treatment increases. 39% (n=162) of patients living in a low-income household were definitely involved as much as they wanted to be in decisions about their treatment. This is compared to 45% (n=460) of patients in an average income household, and 55% (n=112) in a high-income household (Figure 61).

Figure 61. [Patient] Q40 Were you involved as much as you wanted to be in decisions about your treatment? by annual household income [Derived]



Overall, 24% (n=425) of patients reported making decisions about their treatment alone. Where patients received support to make these decisions, this was most likely to be from their:

- Spouse or partner (43%, n=754)
- Parent(s) or guardian(s) (19%, n=331)
- Son or daughter (11%, n=187)

Patients with chronic leukemia (29%, n=128 for CLL; 29%, n=180 for CML) were more likely to report they made decisions about their treatment alone, than patients with acute leukemia (17%, n=42 for ALL; 16%, n=51 for AML) (Table 7).

Table 7. [Patient] Q41 Who or what else helped you make decisions about your treatment? Please select all that apply. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**1,755**	253	328	437	622
My spouse or partner	**43%**	38%	49%	46%	39%
My parent(s) or guardian(s)	**19%**	48%	33%	1%	12%
My son or daughter	**11%**	8%	15%	12%	8%
Another relative (not mentioned above)	**7%**	13%	9%	5%	5%
Non-relative e.g. friend, colleague	**3%**	3%	5%	3%	2%
My family doctor	**6%**	2%	4%	5%	10%
A patient organization or support group	**6%**	7%	2%	8%	8%
Online resources	**8%**	6%	5%	12%	8%
It was my decision alone	**24%**	17%	16%	29%	29%
My personal financial situation	**2%**	5%	2%	2%	2%
Other	**9%**	3%	6%	13%	10%

As age increases, the proportion of patients who made decisions about their treatment alone increases, from 6% (n=8) of patients aged 18-25 to 31% (n=90) of patients aged 66-75 and 30% (n=35) of those aged 76 and over (Table 8).

Table 8. [Patient] Q41 Who or what else helped you make decisions about your treatment? Please select all that apply. by age [Multiple choice]

Base (n=)	18-25 126	26-35 222	36-45 277	46-55 304	56-65 402	66-75 294	76+ 118
My spouse or partner	9%	43%	48%	45%	46%	44%	54%
My parent(s) or guardian(s)	82%	46%	26%	11%	2%	0%	-
My son or daughter	1%	0%	4%	13%	18%	18%	9%
Another relative (not mentioned above)	10%	9%	12%	8%	6%	3%	-
Non-relative e.g. friend, colleague	3%	2%	4%	5%	3%	3%	2%
My family doctor	2%	6%	8%	6%	5%	9%	4%
A patient organization or support group	6%	8%	6%	7%	4%	6%	8%
Online resources	6%	8%	5%	8%	8%	10%	10%
It was my decision alone	6%	17%	21%	26%	29%	31%	30%
My personal financial situation	5%	5%	3%	2%	1%	3%	0%
Other	5%	4%	8%	12%	12%	10%	8%

Overall, support with decisions about treatment was very similar for males and females, with the exception of receiving support from children. 12% (n=117) of females reporting receiving help from their son or daughter to make decisions about their treatment, compared to 7% (n=44) of males (Table 9).

Table 9. [Patient] Q41 Who or what else helped you make decisions about your treatment? Please select all that apply. by gender [Multiple choice]

	Male	Female
Base (n=)	624	960
My spouse or partner	47%	42%
My parent(s) or guardian(s)	17%	18%
My son or daughter	7%	12%
Another relative (not mentioned above)	6%	8%
Non-relative e.g. friend, colleague	3%	3%
My family doctor	6%	6%
A patient organization or support group	6%	7%
Online resources	9%	8%
It was my decision alone	25%	24%
My personal financial situation	2%	2%
Other	7%	11%

Patients reporting that they made decisions about their treatment alone was most prevalent in the United Kingdom (36%, n=63) and least prevalent in China (10%, n=34). See Table 10 for breakdown of support by country.

Table 10. [Patient] Q41 Who or what else helped you make decisions about your treatment? Please select all that apply. by country [Multiple choice]

	Brazil	China	Denmark	Israel	Netherlands	United Kingdom	United States of America
Base (n=)	201	340	101	108	72	173	126
My spouse or partner	39%	43%	58%	40%	65%	43%	56%
My parent(s) or guardian(s)	24%	46%	7%	10%	7%	2%	6%
My son or daughter	6%	15%	5%	18%	18%	6%	13%
Another relative (not mentioned above)	8%	10%	12%	10%	8%	5%	5%
Non-relative e.g. friend, colleague	1%	3%	5%	4%	10%	2%	4%
My family doctor	16%	2%	1%	9%	0%	1%	10%
A patient organization or support group	1%	6%	1%	12%	7%	7%	9%
Online resources	4%	6%	6%	7%	6%	10%	17%
It was my decision alone	22%	10%	22%	19%	19%	36%	24%
My personal financial situation	2%	6%	0%	0%	1%	1%	4%
Other	8%	2%	8%	15%	7%	12%	10%

As annual household income increases, the proportion of patients who made decisions about their treatment alone decreases. 27% (n=112) of those in a low-income household made decisions about their treatment alone, compared to 24% (n=249) of those in an average household, and 22% (n=44) for those in a high-income household (Table 11).

Table 11. [Patient] Q41 Who or what else helped you make decisions about your treatment? Please select all that apply. by annual household income [Multiple choice]

Base (n=)	Low income 419	Average income 1,034	High income 201
My spouse or partner	32%	44%	60%
My parent(s) or guardian(s)	23%	18%	10%
My son or daughter	12%	10%	10%
Another relative (not mentioned above)	8%	7%	5%
Non-relative e.g. friend, colleague	2%	3%	7%
My family doctor	5%	7%	6%
A patient organization or support group	6%	6%	9%
Online resources	6%	8%	10%
It was my decision alone	27%	24%	22%
My personal financial situation	3%	3%	0%
Other	8%	10%	8%

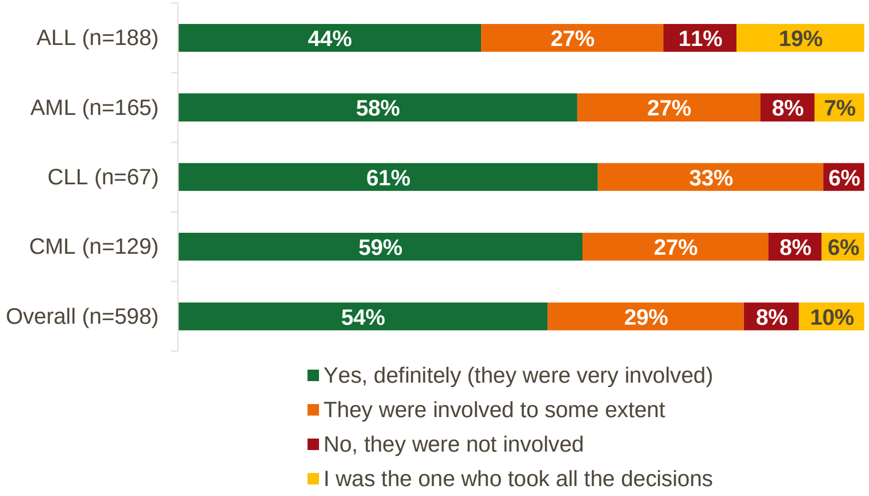
Patients with a postgraduate university degree (30%, n=98) were most likely to report they made decisions about their treatment alone, while patients with no formal qualifications were least likely to make decisions about treatment alone (12%, n=11) (Table 12).

Table 12. [Patient] Q41 Who or what else helped you make decisions about your treatment? Please select all that apply. by level of education [Multiple choice]

Base (n=)	No formal qualifications 91	High school qualifications or diploma 466	University – Bachelors or Undergraduate degree 605	University – Masters, PhD or MD 331	Career or technical qualifications 157
My spouse or partner	47%	38%	46%	45%	48%
My parent(s) or guardian(s)	11%	18%	25%	13%	10%
My son or daughter	29%	12%	8%	7%	11%
Another relative (not mentioned above)	8%	7%	8%	6%	7%
Non-relative e.g. friend, colleague	4%	2%	4%	5%	2%
My family doctor	3%	5%	8%	5%	5%
A patient organization or support group	3%	6%	8%	8%	4%
Online resources	2%	5%	8%	15%	8%
It was my decision alone	12%	24%	22%	30%	28%
My personal financial situation	2%	3%	3%	1%	3%
Other	7%	11%	8%	10%	9%

Overall, 54% (n=322) of carers thought that the patient was involved as much as they should have been in decisions about their treatment and care. Carers for ALL patients (19%, n=35) were most likely to report they were the one who took all the decisions about the patient's treatment and care (Figure 62).

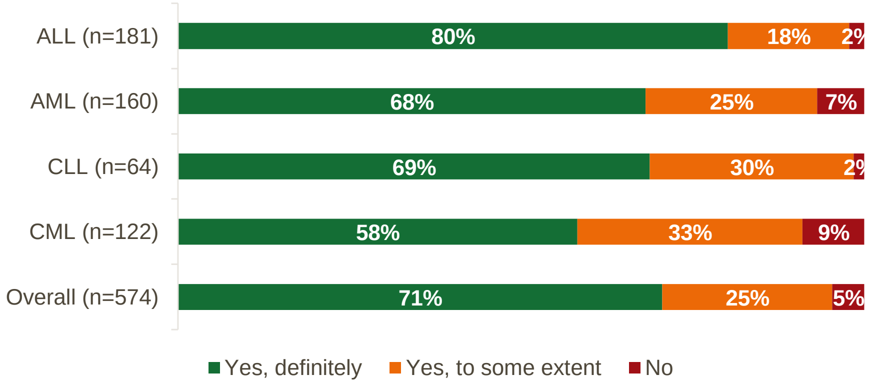
Figure 62. [Carer] C23 Do you think the patient was involved as much as they should have been in decisions about their treatment and care? [Derived]



Please note carers who answered ‘don't know / can't remember’ (n=4) were removed from analysis for C23.

Overall, 71% (n=405) of carers thought they were definitely involved as much as they should have been in decisions about the patient's treatment and care. This was most likely the case for carers for ALL patients (80%, n=145) (Figure 63).

Figure 63. [Carer] C24 Do you think that YOU were involved as much as you should have been in decisions about the patient's treatment and care? [Derived]



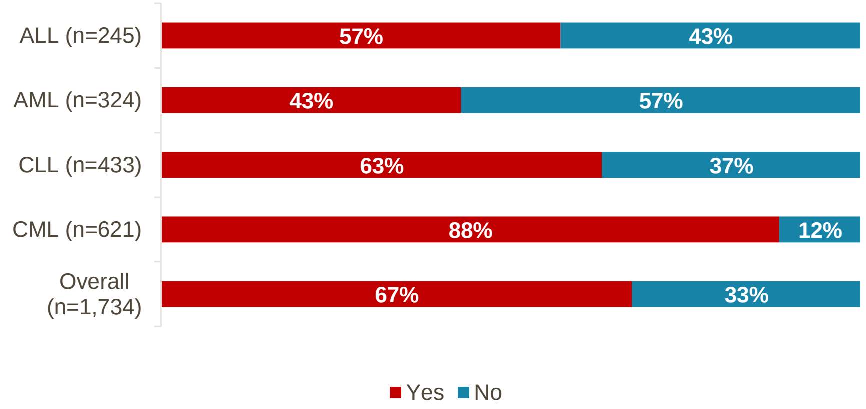
Please note carers who answered ‘don't know / can't remember’ (n=8) or ‘not applicable’ (n=14) were removed from analysis for C24.

Current / most recent treatment

Overall, two thirds of patients (67%, n=1,168) were currently receiving treatment for their leukemia, and one third of patients (33%, n=566) were not (Figure 64).

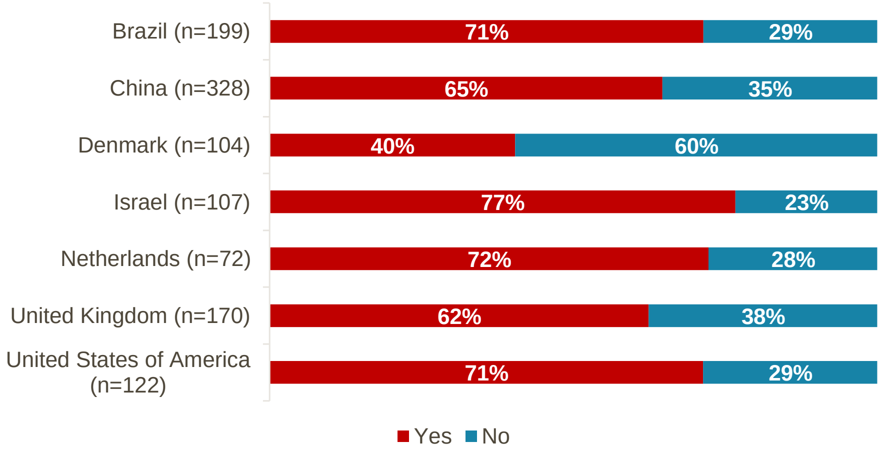
CML patients (88%, n=549) had the highest proportion of patients in active treatment, while AML (43%, n=139) had the lowest.

Figure 64. [Patient] Q42 Are you currently receiving treatment for your leukemia? By this we mean the disease itself, not treatment for any side effects or resulting conditions.



Israel (77%, n=82) had the highest proportion of patients in active treatment, while Denmark (40%, n=42) had the lowest (Figure 65).

Figure 65. [Patient] Q42 Are you currently receiving treatment for your leukemia? By this we mean the disease itself, not treatment for any side effects or resulting conditions. by country



Patients who reported they were currently receiving treatment were asked about their current treatment method(s). Patients were most likely to be receiving targeted therapy (e.g. tyrosine kinase inhibitors) (54%, n=625), followed by chemotherapy (24%, n=271) (Table 13).

Table 13. [Patient] Q43 What is your current treatment? Please select all that apply. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**1,148**	138	138	268	538
Chemotherapy	**24%**	56%	50%	14%	10%
Immunotherapy	**8%**	16%	4%	19%	2%
Radiotherapy	**1%**	6%	1%	-	-
Steroids	**1%**	6%	1%	-	0%
Stem cell transplant	**12%**	44%	45%	1%	0%
Targeted therapy (e.g. tyrosine kinase inhibitors)	**54%**	20%	15%	57%	76%
Other	**15%**	5%	12%	22%	15%

Analysis of current treatment method(s) by age (Table 14) reveals variance across age groups, particularly for younger age groups:

- Younger patients aged 18-25 (47%, n=34) and 26-35 (38%, n=55) were most likely to currently be receiving chemotherapy.
- Younger patients aged 18-25 (40%, n=29) and 26-35 (25%, n=37) were most likely to be receiving treatment for a stem cell transplant.
- Younger patients aged 18-25 (26%, n=19) were least likely to currently be receiving targeted therapy, compared to other age groups.

Table 14. [Patient] Q43 What is your current treatment? Please select all that apply. by age [Multiple choice]

	18-25	26-35	36-45	46-55	56-65	66-75	76+
Base (n=)	73	146	190	193	263	196	78
Chemotherapy	47%	38%	26%	19%	17%	19%	10%
Immunotherapy	11%	7%	6%	5%	9%	12%	13%
Radiotherapy	3%	4%	1%	-	-	1%	-
Steroids	4%	2%	1%	1%	1%	1%	-
Stem cell transplant	40%	25%	17%	8%	5%	3%	-
Targeted therapy (e.g. tyrosine kinase inhibitors)	26%	43%	54%	61%	64%	56%	58%
Other	4%	11%	13%	16%	13%	22%	32%

Analysis of current treatment method(s) by country reveals variance across countries, particularly for chemotherapy and targeted therapy. 46% (n=96) of patients in China, and 37% (n=52) in Brazil were receiving chemotherapy, compared to just 2% (n=2) in Israel. The proportion of patients in the United States of America on targeted therapy (73%, n=63) was more than twice the proportion seen in China (27%, n=57) (Table 15).

Table 15. [Patient] Q43 What is your current treatment? Please select all that apply. by country [Multiple choice]

	Brazil	China	Denmark	Israel	Netherlands	United Kingdom	United States of America
Base (n=)	142	210	41	81	52	106	86
Chemotherapy	37%	46%	12%	2%	17%	20%	12%
Immunotherapy	8%	8%	15%	6%	10%	10%	10%
Radiotherapy	1%	3%	-	-	2%	-	-
Steroids	**-**	0%	-	1%	-	-	3%
Stem cell transplant	8%	44%	7%	1%	2%	1%	6%
Targeted therapy (e.g. tyrosine kinase inhibitors)	49%	27%	46%	49%	62%	64%	73%
Other	11%	5%	27%	47%	23%	16%	12%

Patients who reported they were <u>not</u> currently receiving treatment, were asked about their more recent treatment method(s). Patients were most likely to most recently receive chemotherapy (41%, n=227), followed by a stem cell transplant (37%, n=204) (Table 16).

Table 16. [Patient] Q44 What was your most recent treatment? Please select all that apply. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**551**	102	183	156	69
Chemotherapy	**41%**	33%	49%	50%	9%
Immunotherapy	**15%**	7%	6%	38%	1%
Radiotherapy	**3%**	6%	4%	1%	3%
Steroids	**5%**	6%	10%	2%	-
Stem cell transplant	**37%**	68%	58%	-	19%
Targeted therapy (e.g. tyrosine kinase inhibitors)	**18%**	4%	3%	28%	70%
Other	**9%**	6%	7%	13%	9%

Analysis of most recent treatment method(s) by age (Table 17) reveals variance across age groups:

- Chemotherapy was least common for patients aged 18-25 (28%, n=13).
- Immunotherapy and targeted therapy were most likely to be received by older age groups aged 56 and over.
- 85% (n=39) of patients aged 18-25 said they most recently received a stem cell transplant. This is compared to just 9% (n=8) of patients aged 66-75.

Table 17. [Patient] Q44 What was your most recent treatment? Please select all that apply. by age [Multiple choice]

	18-25	26-35	36-45	46-55	56-65	66-75	76+
Base (n=)	46	71	78	100	132	86	35
Chemotherapy	28%	44%	49%	39%	39%	42%	49%
Immunotherapy	2%	4%	4%	14%	25%	24%	20%
Radiotherapy	2%	4%	5%	5%	3%	1%	0%
Steroids	2%	3%	6%	8%	6%	2%	6%
Stem cell transplant	85%	46%	46%	48%	25%	9%	11%
Targeted therapy (e.g. tyrosine kinase inhibitors)	-	7%	12%	16%	27%	30%	26%
Other	9%	8%	6%	8%	10%	16%	6%

Most recent treatment varied by country of residence, particularly for Chemotherapy, Immunotherapy, Stem cell transplant and Targeted therapy (e.g. tyrosine kinase inhibitors). Please see Table 18 for details but please note small base sizes for this analysis.

Table 18. [Patient] Q44 What was your most recent treatment? Please select all that apply. by country [Multiple choice]

Base (n=)	Brazil 57	China 111	Denmark 59	United Kingdom 63	United States of America 34
Chemotherapy	61%	23%	41%	59%	26%
Immunotherapy	4%	7%	29%	24%	21%
Radiotherapy	2%	0%	8%	3%	0%
Steroids	2%	2%	3%	8%	3%
Stem cell transplant	47%	68%	44%	10%	21%
Targeted therapy (e.g. tyrosine kinase inhibitors)	5%	5%	19%	25%	41%
Other	4%	10%	3%	6%	12%

All patients who reported they had had treatment were asked how long ago their most recent treatment was. Just over half (55%, n=925) of patients said their most recent treatment was less than 3 months (Table 19).

Table 19. [Patient] Q45 How long ago was your most recent treatment?

Base (n=)	**Overall** **1,687**	ALL 248	AML 331	CLL 409	CML 585
Less than 3 months ago	**55%**	48%	41%	51%	70%
3 – 6 months ago	**6%**	10%	7%	4%	4%
7 – 11 months ago	**6%**	7%	8%	6%	3%
1 – 2 years ago	**11%**	13%	11%	14%	6%
3 – 4 years ago	**8%**	8%	12%	9%	4%
5 or more years ago	**13%**	13%	19%	14%	10%
Don’t know / can’t remember	**2%**	1%	2%	2%	3%

Treatment administration

The most common administration method of most recent treatment was an oral drug (pill / tablet / liquid solution) (73%, n=1,266), followed by an intravenous (IV) drug given as a hospital inpatient (22%, n=379) and an intravenous (IV) drug given as a hospital outpatient (14%, n=244) (Table 20).

Patients with acute leukemia (48%, n=119 for ALL; 53%, n=172 for AML) were far more likely to receive their most recent treatment by an intravenous (IV) drug given as a hospital inpatient than patients with chronic leukemia (10%, n=44 for CLL; 1%, n=9 for CML).

The vast majority of CML patients (96%, n=597) received their most recent treatment via an oral drug, compared to just 37% (n=122) of AML patients.

Table 20. [Patient] Q46 How is / was your most recent / current treatment administered? Please select all that apply. [Multiple choice]

Base (n=)	**Overall** **1,743**	ALL 248	AML 326	CLL 433	CML 623
An oral drug (pill / tablet / liquid solution)	**73%**	52%	37%	82%	96%
An intravenous (IV) drug given as a hospital inpatient	**22%**	48%	53%	10%	1%
An intravenous (IV) drug given as a hospital outpatient	**14%**	13%	12%	31%	2%
Other	**5%**	6%	9%	4%	2%
Don’t know / can’t remember	**2%**	3%	3%	0%	1%

Analysis of most treatment administration method(s) by age (Table 21) reveals variance across age groups:

- As age increases, the proportion of patients receiving treatment using oral drugs (pill / tablet / liquid solution) increases, from 49% (n=61) of 18–25-year-olds, to 83% (n=97) of patients aged 76 and over.
- Younger patients were more likely to be treated with an intravenous (IV) drug given as a **hospital inpatient** than older patients - 52% (n=65) of 18–25-year-olds compared to 9% (n=10) of patients aged 76 and over.
- Older patients were more likely to be treated with an intravenous drug given as a **hospital outpatient** – 22% (n=62) of 66-75 year olds, compared to 6% (n=8) of 18–25-year-olds.

Table 21. [Patient] Q46 How is / was your most recent / current treatment administered? Please select all that apply. by age [Multiple choice]

Base (n=)	18-25 124	26-35 221	36-45 279	46-55 300	56-65 403	66-75 287	76+ 117
An oral drug (pill / tablet / liquid solution)	49%	67%	69%	74%	78%	80%	83%
An intravenous (IV) drug given as a hospital inpatient	52%	35%	24%	20%	16%	10%	9%
An intravenous (IV) drug given as a hospital outpatient	6%	9%	9%	10%	19%	22%	21%
Other	5%	4%	6%	5%	5%	6%	6%
Don't know / can't remember	4%	2%	3%	2%	0%	1%	1%

As shown in Table 22, treatment administration via oral drugs (pill / tablet / liquid solution) was the most common method across each country. Variance can be seen for:

- **An intravenous (IV) drug given as a hospital inpatient**: 50% (n=167) of patients in China received treatment via an IV drug as a hospital inpatient, compared to just 3% (n=2) in the Netherlands.
- **An intravenous (IV) drug given as a hospital outpatient**: 30% (n=51) of patients in the United Kingdom received treatment via an IV drug as a hospital outpatient, compared to just 5% in China (n=16) and Israel (n=5).

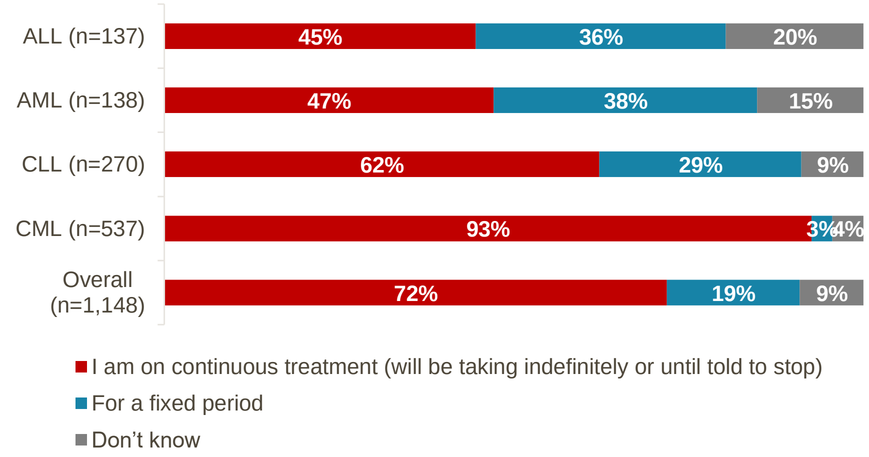
Table 22. [Patient] Q46 How is / was your most recent / current treatment administered? Please select all that apply. by country [Multiple choice]

Base (n=)	Brazil 202	China 333	Denmark 102	Israel 107	Netherlands 73	United Kingdom 171	United States of America 124
An oral drug (pill / tablet / liquid solution)	73%	52%	60%	84%	78%	82%	81%
An intravenous (IV) drug given as a hospital inpatient	24%	50%	18%	12%	3%	13%	9%
An intravenous (IV) drug given as a hospital outpatient	19%	5%	27%	5%	23%	30%	19%
Other	4%	5%	7%	8%	7%	4%	2%
Don't know / can't remember	1%	2%	5%	-	-	1%	1%

Patients who indicated they were in active treatment were asked how long their treatment will last. Overall, 72% (n=825) of patients are on continuous treatment (will be taking indefinitely or until told to stop), 19% (n=218) are on treatment for a fixed period, and 9% (n=105) did not know how long they will be taking their treatment (Figure 66).

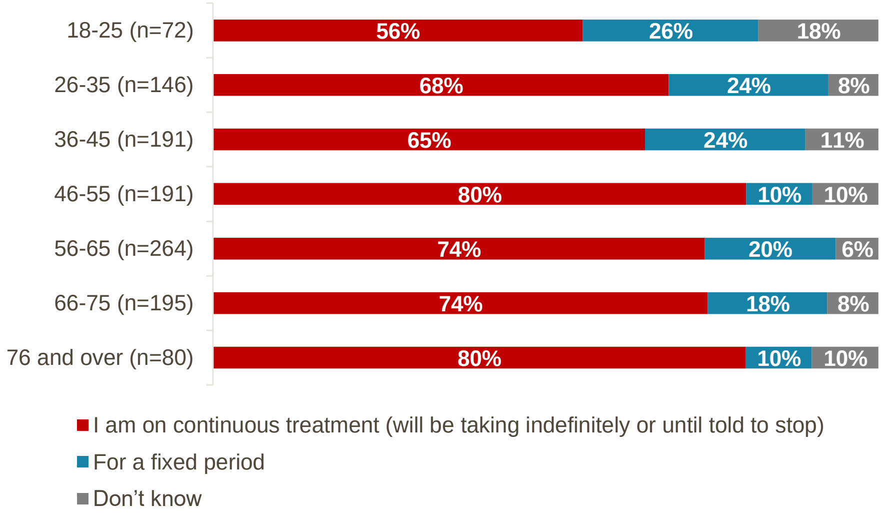
The vast majority of CML patients (93%, n=497) reported being on continuous treatment, compared to 62% (n=168) for CLL, 47% (n=65) for AML and 45% (n=61) for ALL.

Figure 66. [Patient] Q47 For how long will you be taking your treatment?



Younger patients aged 18-25 were least likely to report they were on continuous treatment (56%, n=40), and most likely to report they did not know how long they will be taking their treatment in comparison to other age groups (Figure 67).

Figure 67. [Patient] Q47 For how long will you be taking your treatment? by age

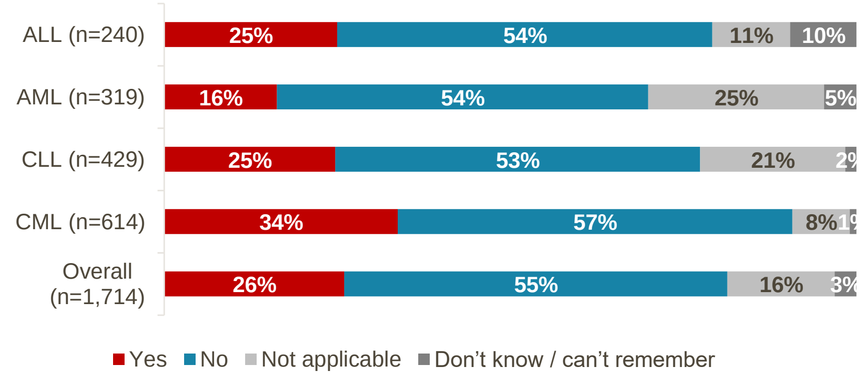


Treatment adherence

Patients who indicated they received their most recent treatment via an oral drug (pill / tablet / liquid solution), or an intravenous (IV) drug given as a hospital inpatient or hospital outpatient were asked if they have missed a dose of their treatment in the last year. Overall, one quarter of patients (26%, n=446) had missed a dose, 55% (n=948) hadn’t missed a dose, 16% (n=266) said this was not applicable to them, and 3% (n=54) didn’t know or could not remember (Figure 68).

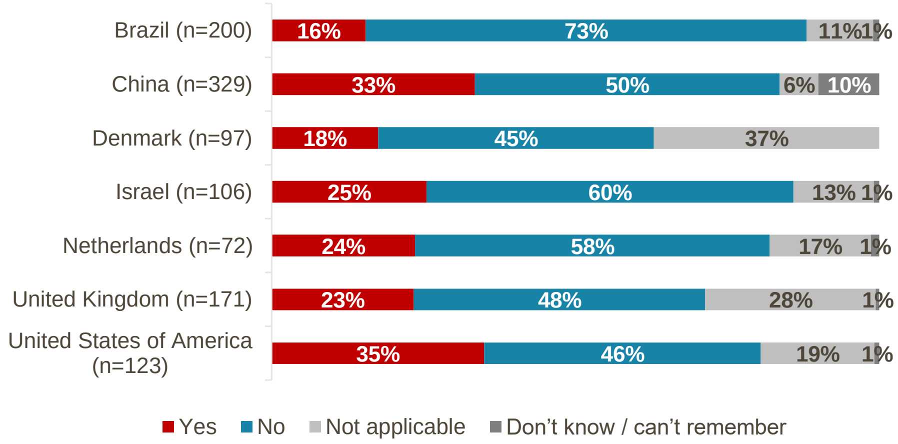
AML patients (16%, n=52) were least likely to report they had missed a dose of their treatment in the last year, while CML patients (34%, n=207) were most likely to report they had missed a dose. CML patients would mainly be treated via oral drugs, and AML patients would mainly be treated by chemotherapy, so this variance in treatment adherence is expected due to varying treatment methods.

Figure 68. [Patient] Q48 Have you missed a dose in the last year?



Analysis by country finds patients in Brazil (16%, n=31) and Denmark (18%, n=17) were least likely to report they had missed a dose of their treatment in the last year, while patients in China (33%, n=110) and the United States of America (35%, n=43) were most likely to report they had missed a dose. More than one third of patients in Denmark (37%, n=36) reported that this was not applicable to them (Figure 69).

Figure 69. [Patient] Q48 Have you missed a dose in the last year? by country



Patients who reported they had missed a dose of their treatment in the last year were asked why they had missed a dose. The most common reason cited was that patients forgot to take their medication, or their reminder to take their medication failed (49%, n=214) (Table 23).

A review of the 'other' reasons provided by patients found many patients missed a dose due to experiencing other health conditions e.g., they had COVID, they were told to stop medication before surgery.

Table 23. [Patient] Q49 For what reason did you miss the dose? Please select all that apply. [Multiple choice]

Base (n=)	**Overall** **441**	ALL 58	AML 51	CLL 105	CML 206
I forgot / reminder failed	**49%**	72%	75%	32%	42%
Other	**15%**	2%	4%	40%	10%
To reduce my side effects	**14%**	10%	8%	18%	17%
I ran out of medication	**13%**	9%	16%	7%	17%
I was not feeling well	**12%**	14%	14%	10%	13%
My routine was interrupted	**12%**	5%	4%	10%	17%
My doctor told me I could / should	**9%**	-	8%	13%	9%
It interfered with my plans e.g. socializing, working, travelling	**4%**	-	2%	1%	8%
I was feeling down / depressed	**4%**	3%	4%	1%	4%
I was feeling better	**2%**	3%	10%	-	2%
I couldn't afford my medication / I wanted to save money	**2%**	2%	6%	1%	2%
My dosing schedule is / was too complicated	**2%**	5%	4%	-	1%
I couldn't swallow the tablets	**1%**	7%	2%	-	-
Don't know / can't remember	**0%**	-	-	-	1%

Analysis by age reveals variances across age groups. For example, 85% (n=28) of 18–25-year-olds missed a dose of their medication because they forgot/ their reminder failed compared to 37% (n=26) of 66–75-year-olds. See Table 24 for details by age group but please note small base sizes for this analysis.

Table 24. [Patient] Q49 For what reason did you miss the dose? Please select all that apply. by age [Multiple choice]

Base (n=)	18-25 33	26-35 53	36-45 80	46-55 74	56-65 101	66-75 71
I forgot / reminder failed	85%	66%	54%	41%	40%	37%
Other	3%	2%	6%	14%	23%	31%
To reduce my side effects	6%	11%	13%	12%	7%	31%
I ran out of medication	9%	25%	13%	19%	10%	8%
I was not feeling well	12%	15%	13%	11%	13%	13%
My routine was interrupted	6%	9%	11%	15%	15%	13%
My doctor told me I could / should	-	4%	6%	12%	11%	11%
It interfered with my plans e.g. socializing, working, travelling	3%	8%	4%	5%	5%	3%
I was feeling down / depressed	6%	6%	8%	1%	2%	3%
I was feeling better	6%	9%	5%	-	-	-
I couldn’t afford my medication / I wanted to save money	3%	4%	1%	1%	4%	1%
My dosing schedule is / was too complicated	3%	6%	4%	-	-	-
I couldn’t swallow the tablets	9%	2%	1%	-	-	-
Don’t know / can’t remember	-	-	-	1%	1%	-

Overall, reasons for missing a dose of medication are relatively similar between male and female patients (Table 25). Some variances include:

- Females (17%, n=42) were more likely to miss a dose to reduce their side effects than males (11%, n=16).
- Males (19%, n=27) were more likely to report they missed a dose because they ran out of medication than females (9%, n=23).
- Females (15%, n=38) were more likely to miss a dose because they were not feeling well than males (6%, n=9).
- Females (11%, n=28) were more likely to report they missed a dose because their doctor told me I could / should than males (6%, n=9).

Table 25. [Patient] Q49 For what reason did you miss the dose? Please select all that apply. by gender [Multiple choice]

Base (n=)	Male 142	Female 250
I forgot / reminder failed	49%	45%
Other	16%	17%
To reduce my side effects	11%	17%
I ran out of medication	19%	9%
I was not feeling well	6%	15%
My routine was interrupted	13%	13%
My doctor told me I could / should	6%	11%
It interfered with my plans e.g. socializing, working, travelling	2%	6%
I was feeling down / depressed	4%	4%
I was feeling better	3%	2%
I couldn’t afford my medication / I wanted to save money	1%	2%
My dosing schedule is / was too complicated	-	2%
I couldn’t swallow the tablets	1%	1%
Don’t know / can’t remember	1%	-

Reasons for missing a dose of medication varied by country as shown in Table 26:

- The main reason for missing a dose in Brazil was running out of medication (42%, n=13).
- The main reason for missing a dose in China (79%, n=85) and the USA (33%, n=14) was forgetting or a reminder failing.
- The main reason for missing a dose in the U.K. was ‘other’ reasons not listed (35%, n=14).

Table 26. [Patient] Q49 For what reason did you miss the dose? Please select all that apply. by country [Multiple choice]

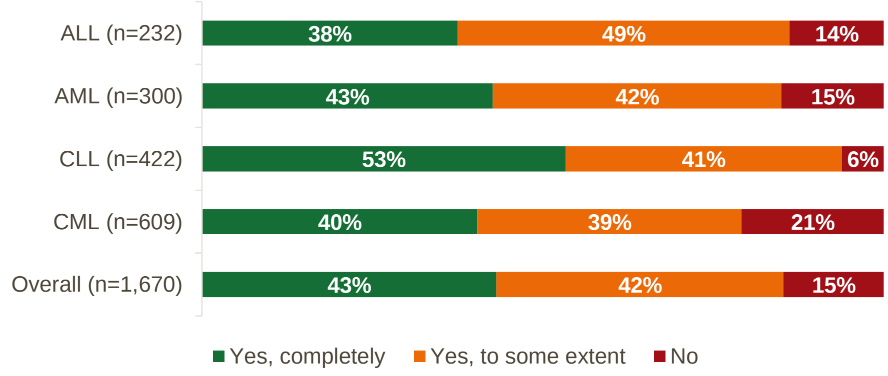
Base (n=)	Brazil 31	China 107	United Kingdom 40	United States of America 42
I forgot / reminder failed	19%	79%	30%	33%
Other	6%	2%	35%	29%
To reduce my side effects	23%	7%	18%	26%
I ran out of medication	42%	12%	3%	5%
I was not feeling well	13%	14%	15%	21%
My routine was interrupted	6%	5%	15%	17%
My doctor told me I could / should	-	1%	20%	12%
It interfered with my plans e.g. socializing, working, travelling	6%	1%	-	2%
I was feeling down / depressed	6%	5%	5%	5%
I was feeling better	6%	7%	-	-
I couldn't afford my medication / I wanted to save money	3%	4%	-	-
My dosing schedule is / was too complicated	-	4%	-	-
I couldn't swallow the tablets	-	5%	-	-
Don't know / can't remember	-	-	-	-

Information on side effects

Overall, 43% (n=721) of patients were given completely clear information about any side effects from their most recent or current treatment. 42% (n=704) received partial information, and 15% (n=245) did not receive clear information about any side effects (Figure 70).

CLL patients (53%, n=225) were most likely to report they received completely clear information about any side effects from their most recent or current treatment, in comparison to other subgroups.

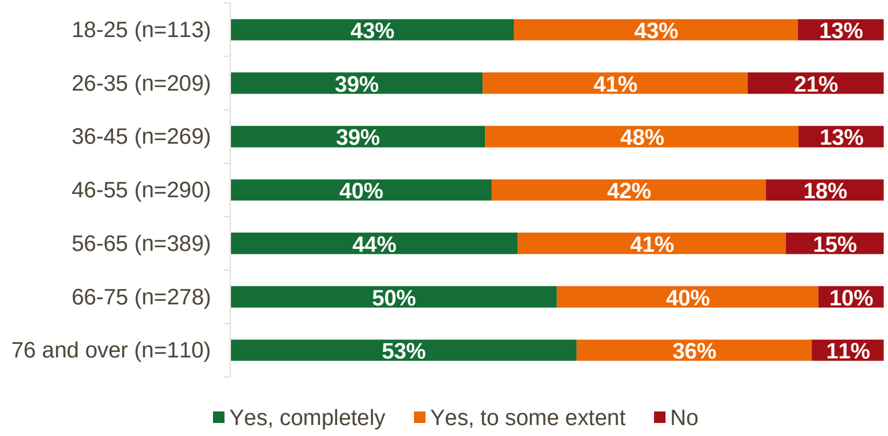
Figure 70. [Patient] Q50 Were you given clear information about any side effects from your most recent or current treatment? [Derived]



Please note patients who answered ‘I did not need any information’ (n=44) or ‘don’t know / can’t remember’ (n=26) were removed from analysis for Q50.

Older patients aged 66-75 (50%, n=139) and 76 and over (53%, n=58) were more likely to report they were given completely clear information about any side effects from their most recent or current treatment than younger age groups – see Figure 71.

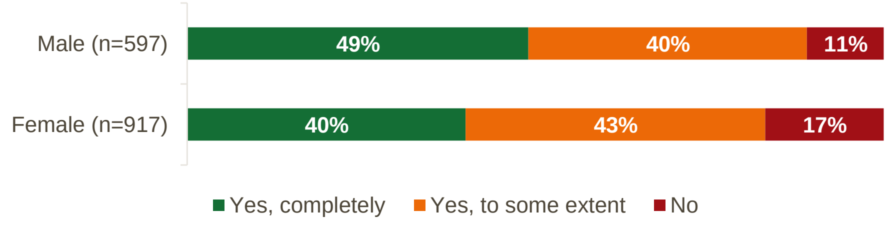
Figure 71. [Patient] Q50 Were you given clear information about any side effects from your most recent or current treatment? by age [Derived]



Please note patients who answered ‘I did not need any information’ (n=44) or ‘don’t know / can’t remember’ (n=26) were removed from analysis for Q50.

Males (49%, n=294) were more likely to report they were given completely clear information about any side effects from their most recent or current treatment than females (40%, n=369) (Figure 72).

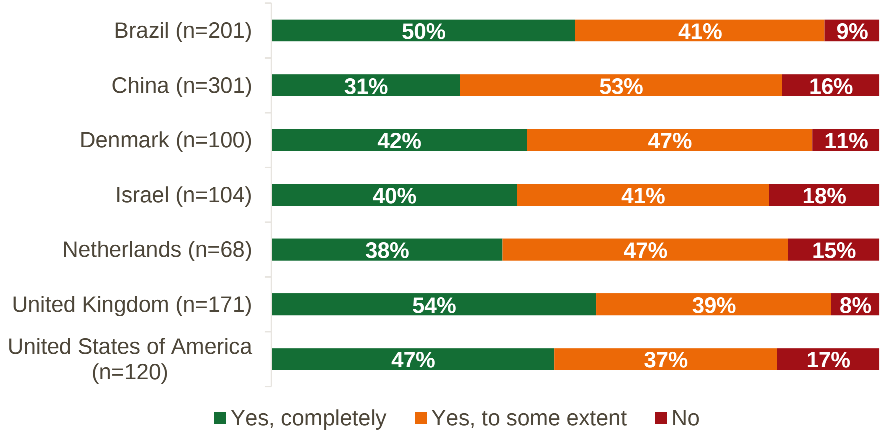
Figure 72. [Patient] Q50 Were you given clear information about any side effects from your most recent or current treatment? by gender [Derived]



Please note patients who answered 'I did not need any information' (n=44) or 'don't know / can't remember' (n=26) were removed from analysis for Q50.

The proportion of patients who received completely clear information about side effects from their most recent or current treatment was much higher in the U.K. (54%, n=92) than in China (31%, n=92) (Figure 58).

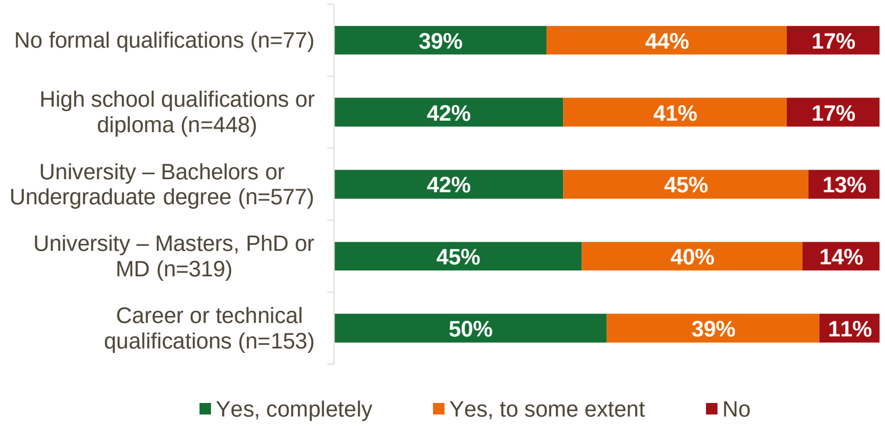
Figure 73. [Patient] Q50 Were you given clear information about any side effects from your most recent or current treatment? by country [Derived]



Please note patients who answered 'I did not need any information' (n=44) or 'don't know / can't remember' (n=26) were removed from analysis for Q50.

Patients with no formal qualifications (39%, n=30) were least likely to report that they were given completely clear information about side effects from their most recent or current treatment. See Figure 74.

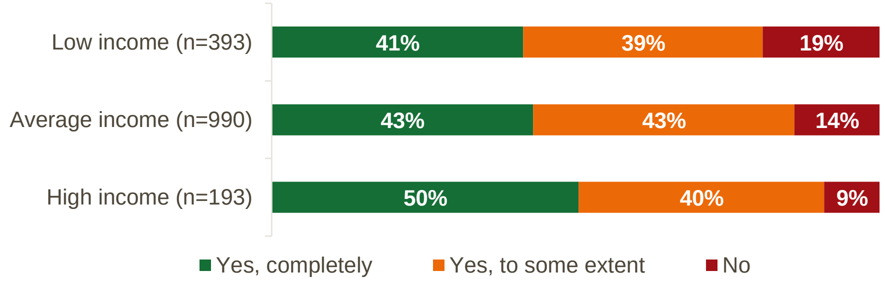
Figure 74. [Patient] Q50 Were you given clear information about any side effects from your most recent or current treatment? by level of education [Derived]



Please note patients who answered ‘I did not need any information’ (n=44) or ‘don’t know / can’t remember’ (n=26) were removed from analysis for Q50.

Patients who live in a high-income household (50%, n=97) were more likely to report they were given completely clear information about side effects from their most recent or current treatment than patients who live in an average income household (43%, n=427) or low-income household (41%, n=163) (Figure 75).

Figure 75. [Patient] Q50 Were you given clear information about any side effects from your most recent or current treatment? by annual household income [Derived]



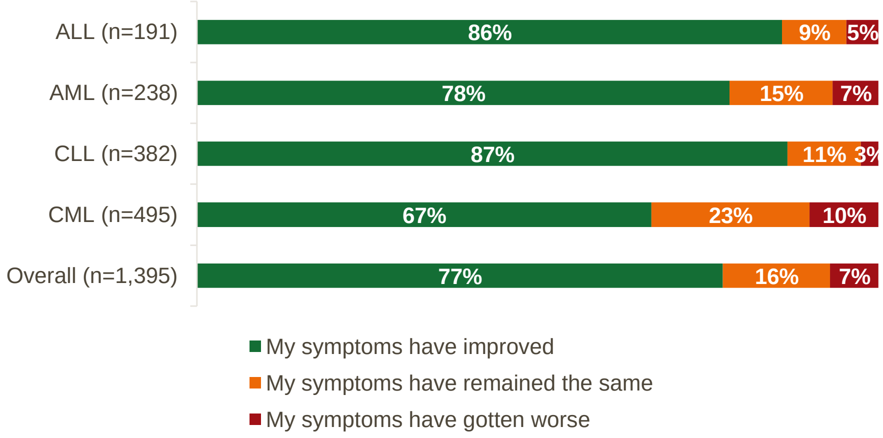
Please note patients who answered ‘I did not need any information’ (n=44) or ‘don’t know / can’t remember’ (n=26) were removed from analysis for Q50.

Impact of treatment on symptoms

When asked what impact their most recent or current treatment has had on the symptoms they were experiencing, 77% (n=1,076) of patients reported their symptoms had improved. 16% (n=220) reported their symptoms remained the same, while 7% (n=99) reported their symptoms have gotten worse (Figure 76).

CLL patients (87%, n=331) were most likely to report their symptoms have improved, while CML patients (67%, n=330) were least likely to report they have experienced an improvement in their symptoms.

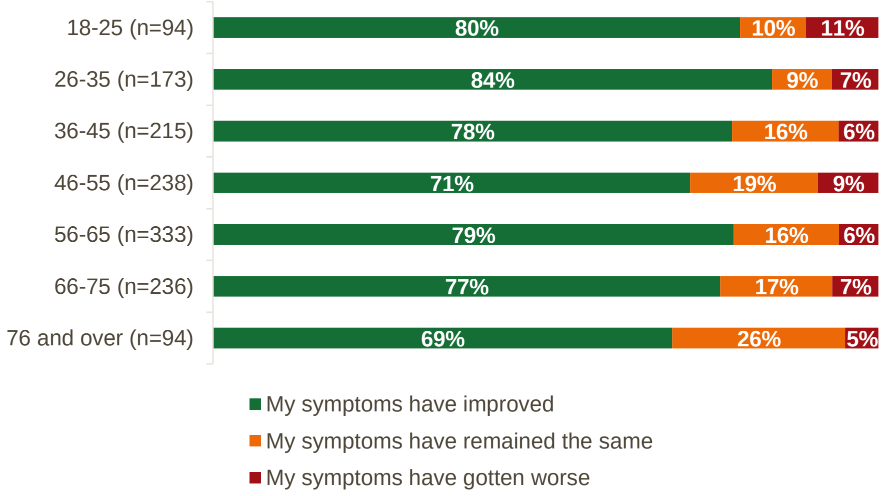
Figure 76. [Patient] Q51 What impact has your most recent or current treatment had on the symptoms that you were experiencing? [Derived]



Please note patients who answered ‘not applicable - I didn't have any symptoms’ (n=255) or ‘don’t know / can’t remember’ (n=77) were removed from analysis for Q51.

While the proportion of patients who reported their symptoms have improved as a result of their current or most recent treatment is high across all age groups, patients aged 76 and over (69%, n=65) were least likely to report they have experienced an improvement in their symptoms (Figure 77).

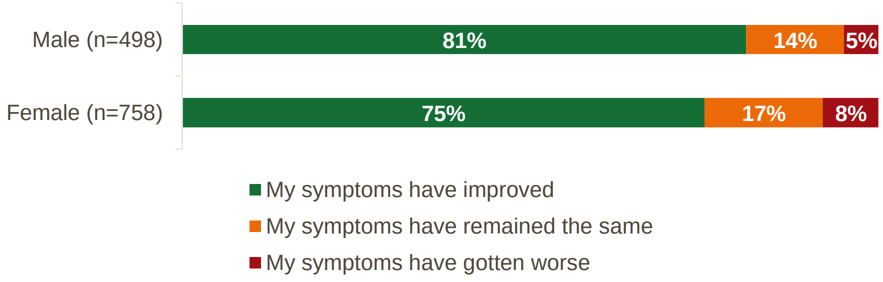
Figure 77. [Patient] Q51 What impact has your most recent or current treatment had on the symptoms that you were experiencing? by age [Derived]



Please note patients who answered 'not applicable - I didn't have any symptoms' (n=255) or 'don't know / can't remember' (n=77) were removed from analysis for Q51.

81% (n=401) of males reported their symptoms have improved as a result of their most recent or current treatment, compared to 75% (n=566) of females (Figure 78).

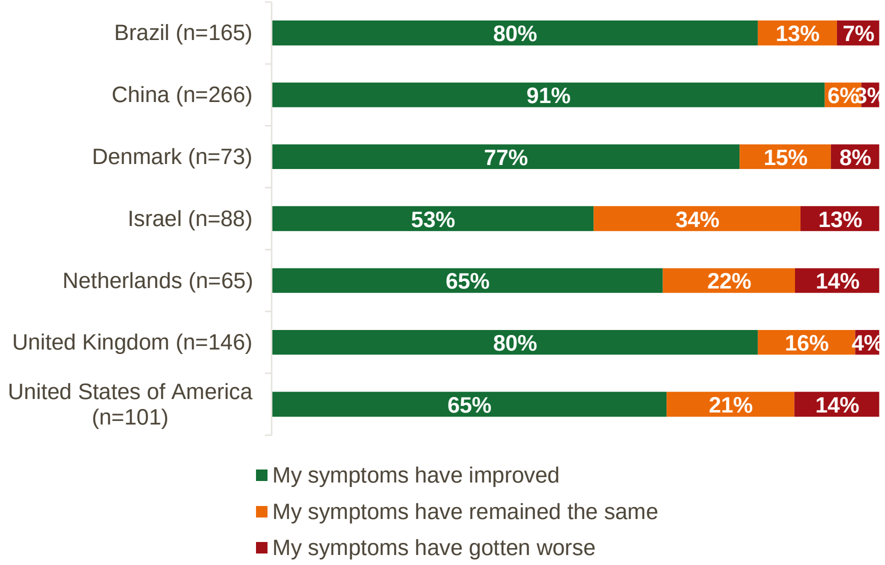
Figure 78. [Patient] Q51 What impact has your most recent or current treatment had on the symptoms that you were experiencing? by gender [Derived]



Please note patients who answered 'not applicable - I didn't have any symptoms' (n=255) or 'don't know / can't remember' (n=77) were removed from analysis for Q51.

Analysis by country reveals large variances of treatment impact on symptoms. The vast majority of patients in China (91%, n=241) reported that their symptoms have improved as a result of their most recent or current treatment. This is compared to just 53% (n=47) of patients in Israel who reported an improvement in their symptoms (Figure 79).

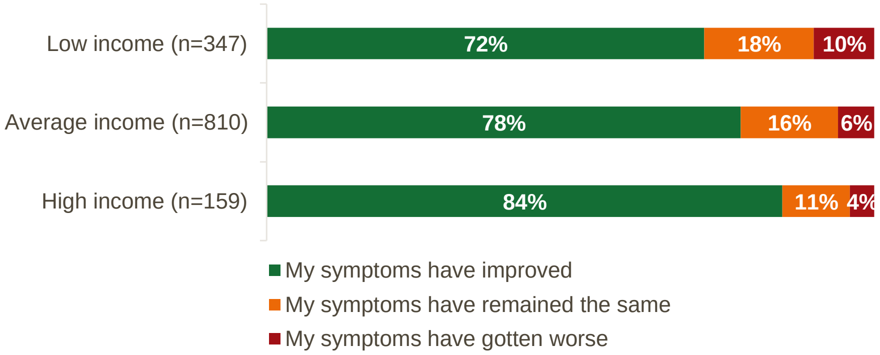
Figure 79. [Patient] Q51 What impact has your most recent or current treatment had on the symptoms that you were experiencing? by country [Derived]



Please note patients who answered ‘not applicable - I didn't have any symptoms’ (n=255) or ‘don’t know / can’t remember’ (n=77) were removed from analysis for Q51.

As annual household income increases, the proportion of patients who reported their symptoms have improved as a result of their most recent or current treatment increases. 72% (n=249) of patients who live in a low-income household said their symptoms improved, compared to 78% (n=635) of those living in an average-income household, and 84% (n=134) living in a high-income household (Figure 80).

Figure 80, [Patient] Q51 What impact has your most recent or current treatment had on the symptoms that you were experiencing? by annual household income [Derived]



Please note patients who answered ‘not applicable - I didn't have any symptoms’ (n=255) or ‘don’t know / can’t remember’ (n=77) were removed from analysis for Q51.

Side effects of treatment

The majority of patients (89%, n=1,523) who had received treatment reported experiencing side effects from their most recent or current treatment (Table 27). The most common side-effects experienced were:

- Fatigue (52%, n=893)
- Pain in bones/ joints (32%, n=541)
- Nausea or vomiting (27%, n=470)
- Sleeping problems (26%, n=440)
- Muscle pain (25%, n=426)

Carers reported a higher instance (98%, n=586) of patients experiencing side effects from their most recent or current treatment (Table 28). The most common side effects cited by carers differed to those reported by patients:

- Fatigue (69%, n=413)
- Nausea or vomiting (53%, n=314)
- Loss of appetite (50%, n=297)
- Unusually high or low red / white / platelet blood count (47%, n=282)
- Fever / night sweats (45%, n=267)

The proportion of patients experiencing side effects from their current or most recent treatment was high for all leukemia types:

- **CML:** 92% of patients (n=566); 99% of carers (n=130)
- **AML:** 91% of patients (n=290); 98% of carers (n=159)
- **ALL:** 88% of patients (n=211); 98% of carers (n=183)
- **CLL:** 84% of patients (n=360); 97% of carers (n=66)

Please see Table 27 and Table 28 for breakdown by leukemia type.

Table 27. [Patient] Q52 What side effects have you encountered as a result of your most recent or current treatment? Please select all that apply. [Multiple choice]

Base (n=)	**Overall** **1,717**	ALL 239	AML 320	CLL 431	CML 618
Fatigue	**52%**	35%	45%	51%	63%
Pain in bones / joints	**32%**	19%	22%	23%	47%
Nausea or vomiting	**27%**	33%	37%	17%	27%
Sleeping problems	**26%**	26%	29%	18%	29%
Muscle pain	**25%**	15%	16%	17%	39%
Memory loss / loss of concentration	**21%**	18%	23%	16%	26%
Itchy skin	**20%**	11%	20%	18%	25%
Loss of appetite	**19%**	32%	33%	10%	12%
Headaches	**18%**	11%	17%	10%	23%
Unusually high or low red / white / platelet blood count	**17%**	22%	22%	20%	10%
Tingling or numbness in extremities	**16%**	13%	12%	14%	22%
Shortness of breath	**16%**	9%	16%	14%	21%
Swollen stomach or abdominal discomfort	**16%**	13%	15%	11%	21%
Fever / night sweats	**16%**	16%	24%	10%	16%
Back pain	**15%**	8%	11%	10%	22%
Other	**14%**	8%	8%	14%	18%
Bruising	**13%**	6%	9%	24%	11%
Frequent and repeated infections	**13%**	9%	16%	15%	11%
Palpitations / heart irregularities	**12%**	9%	10%	10%	14%
High blood pressure (Hypertension)	**8%**	7%	8%	9%	9%
Changes to menstrual cycle	**8%**	13%	13%	1%	8%
Unexplained weight loss	**8%**	9%	12%	6%	6%
Broken blood vessel in eye (Subconjunctival hemorrhage)	**7%**	2%	5%	4%	12%
Bleeding	**6%**	5%	9%	10%	4%
Swollen lymph nodes	**3%**	2%	2%	5%	4%
No side effects	**11%**	12%	9%	16%	8%

Table 28. [Carer] C25 What side effects have you witnessed the patient experience as a result of their most recent or current treatment? Please select all that apply. [Multiple choice]

Base (n=)	**Overall** **598**	ALL 187	AML 162	CLL 68	CML 131
Fatigue	**69%**	65%	69%	76%	73%
Nausea or vomiting	**53%**	67%	60%	24%	40%
Loss of appetite	**50%**	63%	62%	28%	26%
Unusually high or low red / white / platelet blood count	**47%**	58%	52%	37%	27%
Fever / night sweats	**45%**	51%	51%	32%	32%
Pain in bones / joints	**41%**	42%	32%	29%	55%
Sleeping problems	**39%**	40%	42%	31%	34%
Muscle pain	**36%**	35%	29%	21%	53%
Frequent and repeated infections	**32%**	37%	38%	28%	16%
Headaches	**31%**	29%	32%	25%	37%
Itchy skin	**30%**	28%	31%	24%	34%
Swollen stomach or abdominal discomfort	**28%**	28%	23%	19%	34%
Memory loss / loss of concentration	**28%**	19%	28%	32%	31%
Shortness of breath	**27%**	25%	31%	28%	21%
Back pain	**24%**	20%	24%	22%	31%
Unexplained weight loss	**24%**	24%	27%	21%	21%
Bruising	**22%**	22%	26%	34%	17%
Bleeding	**19%**	22%	24%	16%	10%
Palpitations / heart irregularities	**19%**	17%	17%	19%	21%
Tingling or numbness in extremities	**18%**	14%	16%	18%	24%
High blood pressure (Hypertension)	**14%**	11%	15%	10%	20%
Swollen lymph nodes	**13%**	14%	10%	24%	12%
Broken blood vessel in eye (Subconjunctival hemorrhage)	**10%**	5%	12%	13%	15%
Changes to menstrual cycle	**9%**	11%	12%	3%	8%
Other	**9%**	10%	7%	10%	10%
No side effects	**2%**	2%	2%	3%	1%

Overall, the majority of all age groups experienced side-effects from their most recent or current treatment, though patients aged 76 and over (19%, n=22) were least likely to experience side-effects.

Some variances in experience of side-effects include fevers and night sweats, and nausea or vomiting being more common in younger patients, while bruising was more common for older patients. See Table 29 for full details.

Female patients (90%, n=843) were slightly more likely than male patients (86%, n=526) to experience side-effects from their most recent or current treatment (Table 30). Some notable differences in experience can be seen for side effects, which females were much more likely to experience:

- Pain in bones / joints (Females 37%, n=343; Males 24%, n=147)
- Nausea or vomiting (Females 33%, n=308; Males 20%, n=123)
- Changes to menstrual cycle (Females 13%, n=120; Males 0%, n=1)[4]
- Headaches (Females 23%, n=212; Males 11%, n=68)
- Sleeping problems (Females 29%, n=275; Males 19%, n=118)
- Memory loss / loss of concentration (Females 26%, n=244; Males 16%, n=96)

There was a marginal difference in the proportion of carers reporting that the male (99%, n=310) or female (97%, n=228) patients they care for experienced side-effects from their most recent or current treatment. Some notable gender differences reported by carers included:

- Changes to menstrual cycle (Females 22%, n=51; Males, n=0)
- Nausea or vomiting (Females 59%, n=139; Males 47%, n=149)
- Headaches (Females 38%, n=89; Males 26%, n=83)

Please see Table 31 for breakdown by carer reported side-effects by patient gender.

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[4] The male patient who selected menstrual cycle changes may have selected this option in error, or they may potentially have transitioned from female to male and experienced this side effect prior to their transition.

Table 29. [Patient] Q52 What side effects have you encountered as a result of your most recent or current treatment? Please select all that apply. by age [Multiple choice]

	18-25	26-35	36-45	46-55	56-65	66-75	76+
Base (n=)	117	215	277	296	397	288	116
Fatigue	38%	35%	55%	56%	60%	56%	48%
Pain in bones / joints	15%	25%	41%	37%	36%	25%	23%
Nausea or vomiting	44%	35%	32%	31%	23%	19%	8%
Sleeping problems	26%	26%	29%	26%	28%	24%	13%
Muscle pain	13%	18%	31%	28%	29%	24%	16%
Memory loss / loss of concentration	18%	16%	26%	25%	29%	14%	9%
Itchy skin	9%	15%	23%	23%	22%	21%	21%
Loss of appetite	38%	24%	17%	20%	17%	13%	9%
Headaches	17%	18%	23%	22%	18%	11%	4%
Unusually high or low red / white / platelet blood count	29%	20%	14%	12%	16%	19%	20%
Tingling or numbness in extremities	7%	9%	16%	24%	19%	16%	16%
Shortness of breath	12%	13%	11%	19%	20%	18%	17%
Swollen stomach or abdominal discomfort	17%	13%	17%	20%	16%	12%	14%
Fever / night sweats	27%	23%	16%	17%	14%	11%	9%
Back pain	7%	13%	16%	18%	16%	13%	10%
Other	6%	14%	13%	13%	15%	16%	15%
Bruising	6%	4%	8%	17%	16%	19%	21%
Frequent and repeated infections	12%	11%	14%	13%	13%	15%	8%
Palpitations / heart irregularities	15%	9%	8%	15%	13%	12%	9%
High blood pressure (Hypertension)	6%	4%	6%	8%	11%	11%	8%
Changes to menstrual cycle	17%	15%	18%	8%	2%	0%	1%
Unexplained weight loss	10%	7%	8%	9%	7%	5%	7%
Broken blood vessel in eye (Subconjunctival hemorrhage)	3%	3%	5%	7%	9%	9%	8%
Bleeding	9%	8%	4%	6%	6%	7%	7%
Swollen lymph nodes	1%	3%	1%	3%	5%	4%	4%
No side effects	9%	14%	9%	12%	9%	11%	19%

Table 30. [Patient] Q52 What side effects have you encountered as a result of your most recent or current treatment? Please select all that apply. by gender [Multiple choice]

Base (n=)	Male 613	Female 937
Fatigue	49%	56%
Pain in bones / joints	24%	37%
Nausea or vomiting	20%	33%
Sleeping problems	19%	29%
Muscle pain	20%	29%
Memory loss / loss of concentration	16%	26%
Itchy skin	17%	22%
Loss of appetite	17%	19%
Headaches	11%	23%
Unusually high or low red / white / platelet blood count	16%	18%
Tingling or numbness in extremities	13%	19%
Shortness of breath	14%	19%
Swollen stomach or abdominal discomfort	11%	19%
Fever / night sweats	11%	19%
Back pain	10%	18%
Other	13%	14%
Bruising	12%	15%
Frequent and repeated infections	10%	14%
Palpitations / heart irregularities	7%	14%
High blood pressure (Hypertension)	10%	7%
Changes to menstrual cycle	0%	13%
Unexplained weight loss	8%	7%
Broken blood vessel in eye (Subconjunctival hemorrhage)	5%	8%
Bleeding	8%	5%
Swollen lymph nodes	3%	4%
No side effects	14%	10%

Table 31. [Carer] C25 What side effects have you witnessed the patient experience as a result of their most recent or current treatment? Please select all that apply. by patient gender [Multiple choice]

Base (n=)	Male 314	Female 234
Fatigue	68%	75%
Nausea or vomiting	47%	59%
Loss of appetite	48%	52%
Unusually high or low red / white / platelet blood count	49%	45%
Fever / night sweats	43%	48%
Pain in bones / joints	43%	41%
Sleeping problems	37%	40%
Muscle pain	40%	33%
Frequent and repeated infections	32%	32%
Headaches	26%	38%
Itchy skin	32%	28%
Swollen stomach or abdominal discomfort	30%	25%
Memory loss / loss of concentration	28%	29%
Shortness of breath	27%	30%
Back pain	26%	24%
Unexplained weight loss	27%	20%
Bruising	25%	20%
Bleeding	21%	15%
Palpitations / heart irregularities	20%	15%
Tingling or numbness in extremities	20%	17%
High blood pressure (Hypertension)	16%	11%
Swollen lymph nodes	17%	9%
Broken blood vessel in eye (Subconjunctival hemorrhage)	11%	9%
Changes to menstrual cycle	-	22%
Other	11%	6%
No side effects	1%	3%

Frequency and severity of side effects of treatment

Both patients and carers were asked about how frequently they / the patient experienced the side-effects from their most recent or current treatment.

As shown in Figure 81, patients were most likely to report they always experienced:

- Changes to menstrual cycle (54%, n=72)
- High blood pressure (Hypertension) (40%, n=57)
- Unusually high or low red / white / platelet blood count (39%, n=109)

Carers were most likely to report the patient always experienced (Figure 82):

- Changes to menstrual cycle (46%, n=23)
- Another side effect not listed (37%, n=13)
- Unusually high or low red / white / platelet blood count (27%, n=74)

Patients were then asked how severe the side effects from their most recent or current treatment were (Figure 83). The side effects patients were most likely to report they experienced severely were:

- Changes to menstrual cycle (43%, n=57)
- Another side effect not listed (35%, n=59)
- Unusually high or low red / white / platelet blood count (31%, n=84)

Please see frequency tables in Appendix 4, Appendix 5 and Appendix 6 for full details on frequency and severity of side-effects by leukemia type.

Figure 81. [Patient] Q53 How often do / did you experience the side effects of your most recent or current treatment?

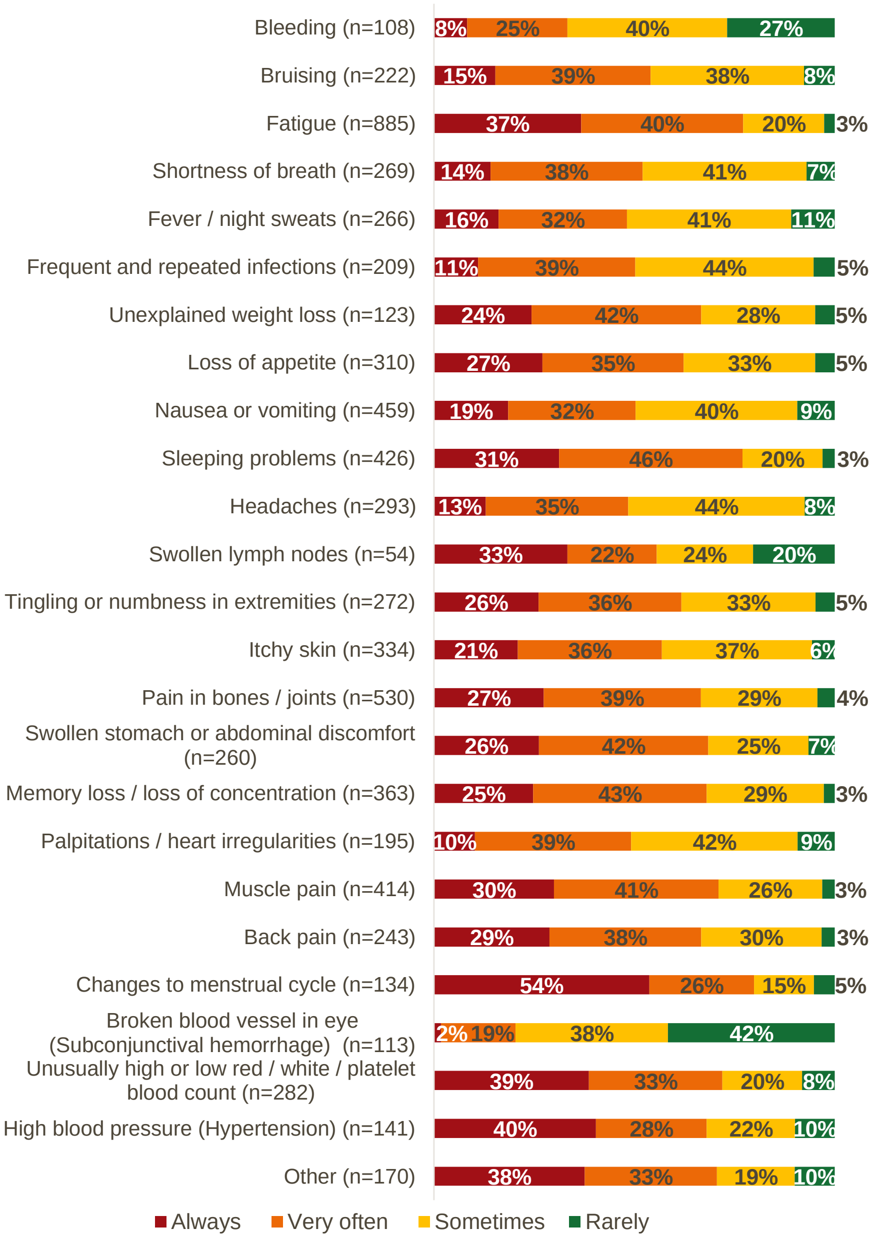


Figure 82. [Carer] C26 How often do / did they experience the side effects of their most recent or current treatment?

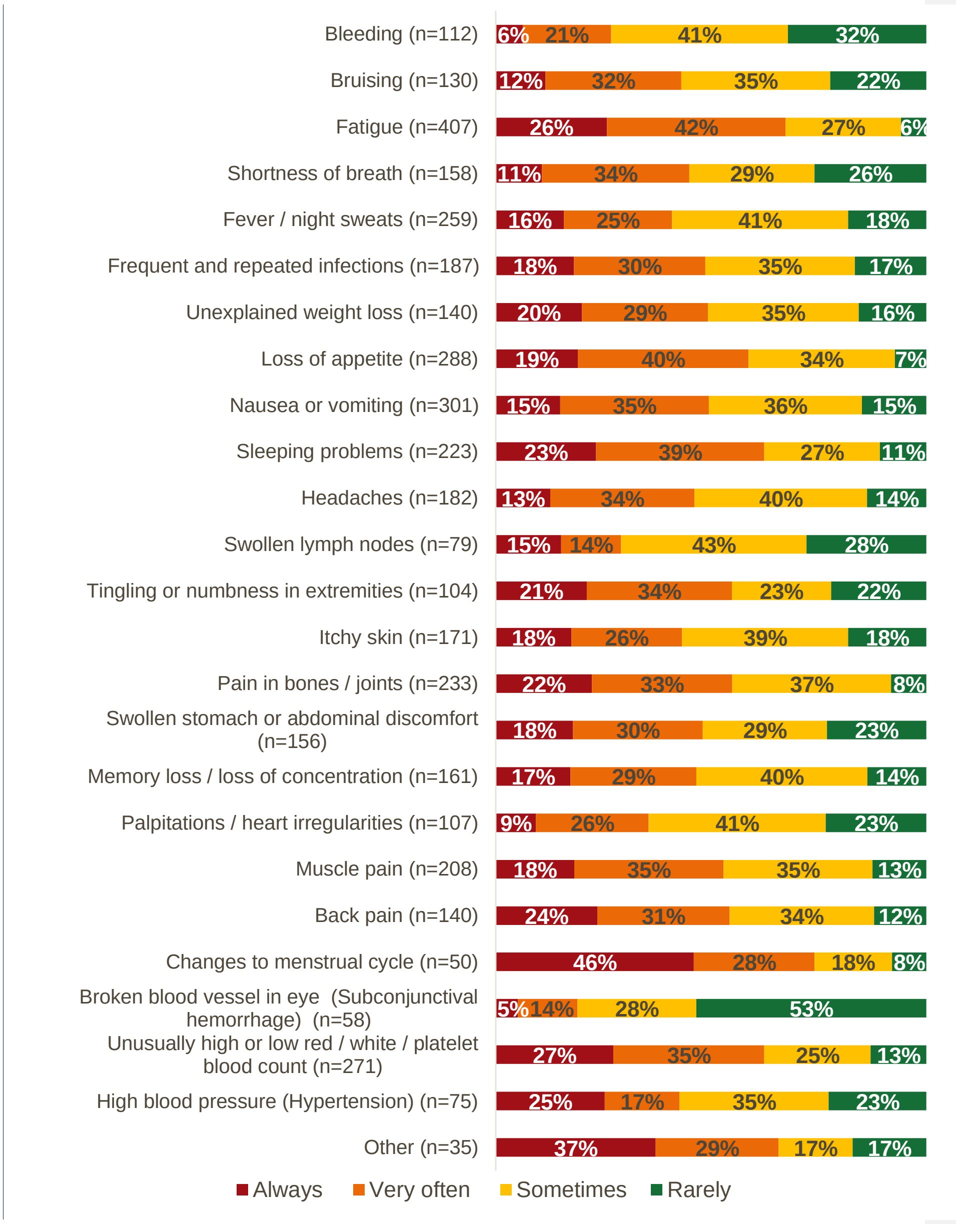
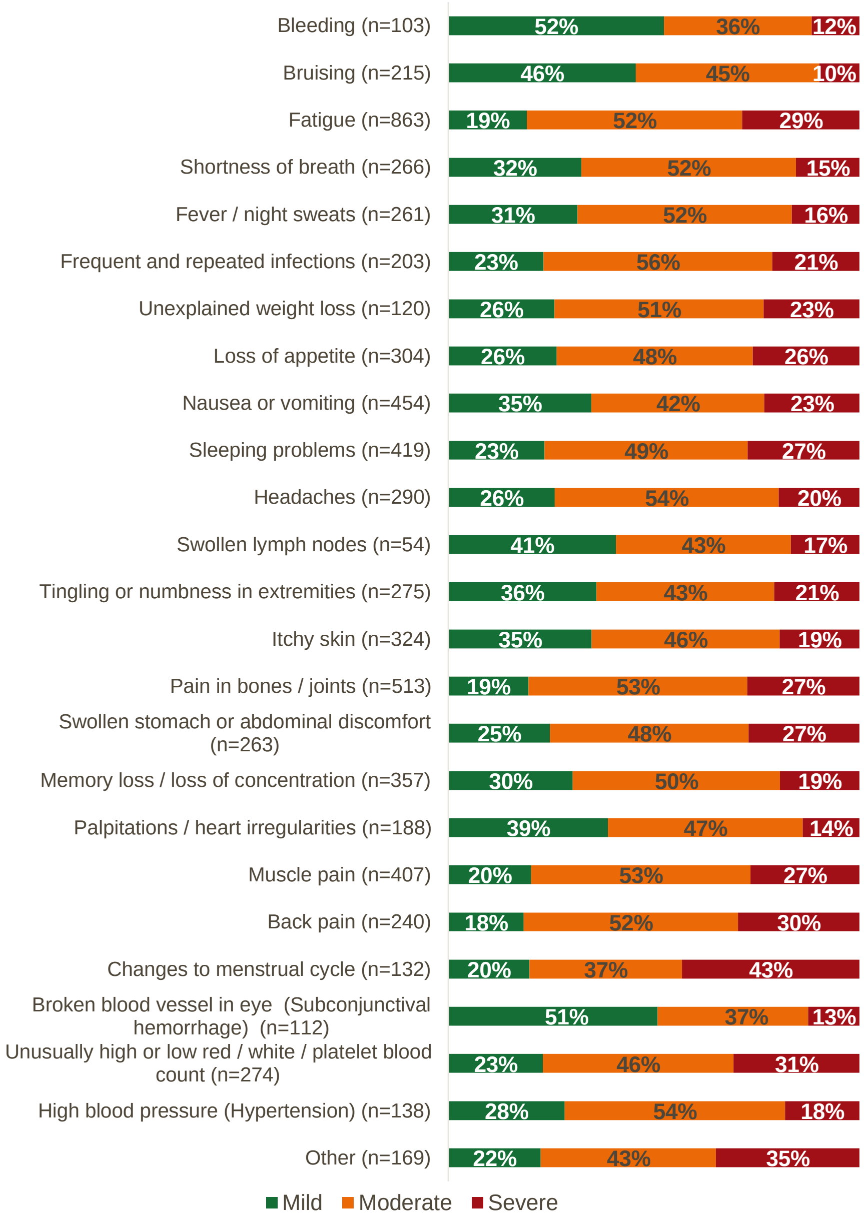


Figure 83. [Patient] Q54 How severe are / were the side effects of your most recent or current treatment?



Management of side effects by healthcare professionals

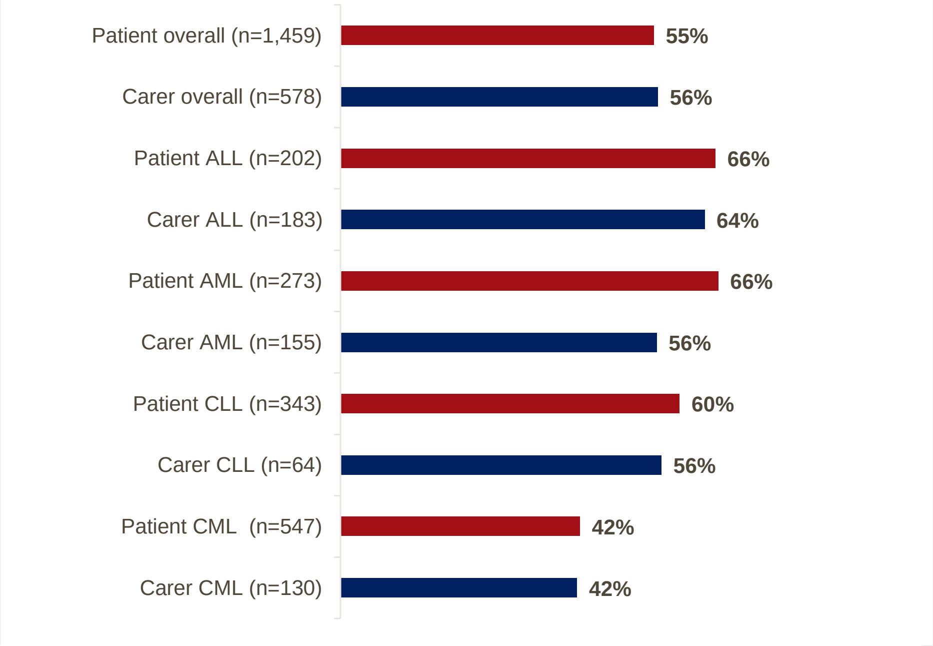
Both patients and carers were asked how they would rate how healthcare professionals managed the physical side effects of their/ the patients most recent or current leukemia treatment. Figure 84 displays the proportion of respondents who were very satisfied with how physical side effects were managed, rating this measure as 8 or more out of 10.

Overall, 55% (n=802) of patients, and 56% (n=322) of carers rated the way physical side effects were managed by healthcare professionals as 8 or more out of 10.

CML respondents, for both patients (42%, n=230) and carers (42%, n=54) were least likely to report they were very satisfied with how their physical side effects were managed by healthcare professionals.

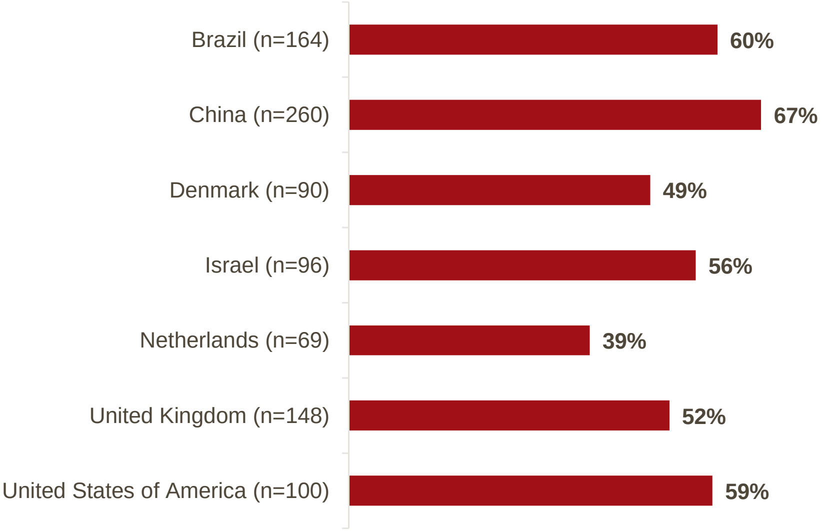
The biggest variance in satisfaction can be seen for AML. 66% (n=181) of AML patients were very satisfied with how their physical side effects were managed by healthcare professionals, compared to 56% (n=86) of AML carers.

Figure 84. [Patient] Q55 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? 0 is very dissatisfied and 10 is very satisfied. & [Carer] C27 Overall, how would YOU rate the way the physical side effects of the leukemia treatment have been managed by the patient's healthcare professionals? 0 is very dissatisfied and 10 is very satisfied. [Rated 8 or more out of 10]



Satisfaction with how physical side effects were managed by healthcare professionals varied by country. 39% (n=27) of patients in the Netherlands rated the way their side effects were managed as 8 or more out of 10, compared to 67% (n=174) in China (Figure 85).

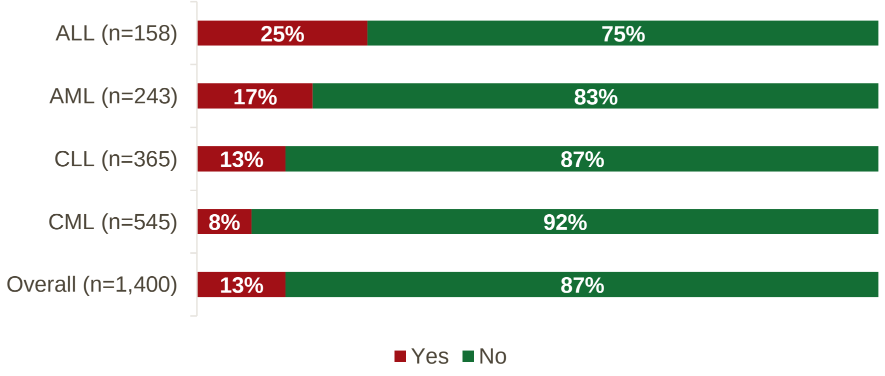
Figure 85. [Patient] Q55 Overall, how would you rate the way the physical side effects of your most recent or current leukemia treatment have been managed by your healthcare professionals? 0 is very dissatisfied and 10 is very satisfied. by country



Impact of COVID-19 on treatment

Overall, 13% (n=179) of patients had treatment delayed due to COVID-19. ALL patients (25%, n=39) were most likely to be experience a delay (Figure 86).

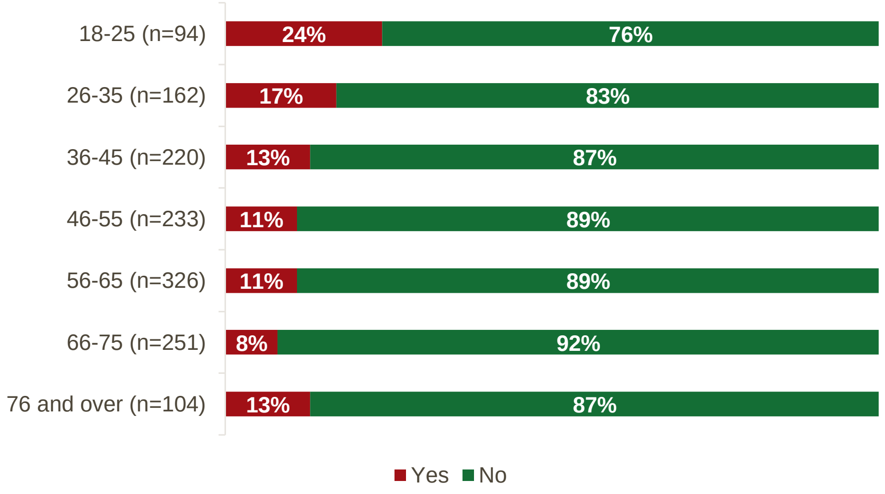
Figure 86. [Patient] Q56 Did you have any treatment for your leukemia delayed due to COVID-19? [Derived]



Please note patients who answered ‘don’t know / can’t remember’ (n=93) or ‘not applicable’ (n=212) were removed from analysis for Q56.

1 in 4 patients aged 18-25 (24%, n=23) had treatment delayed due to COVID-19. This is compared to 8% (n=20) for patients aged 66-75 (Figure 87).

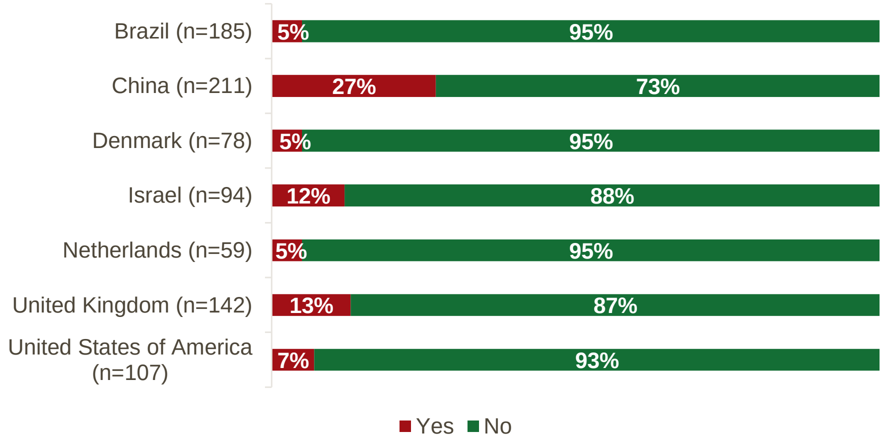
Figure 87. [Patient] Q56 Did you have any treatment for your leukemia delayed due to COVID-19? by age [Derived]



Please note patients who answered ‘don’t know / can’t remember’ (n=93) or ‘not applicable’ (n=212) were removed from analysis for Q56.

Patients in China (27%, n=58) were almost six times as likely to experience a delay in treatment due to COVID-19 than patients in Brazil (5%, n=9), Denmark (5%, n=4) or the Netherlands (5%, n=3) (Figure 88).

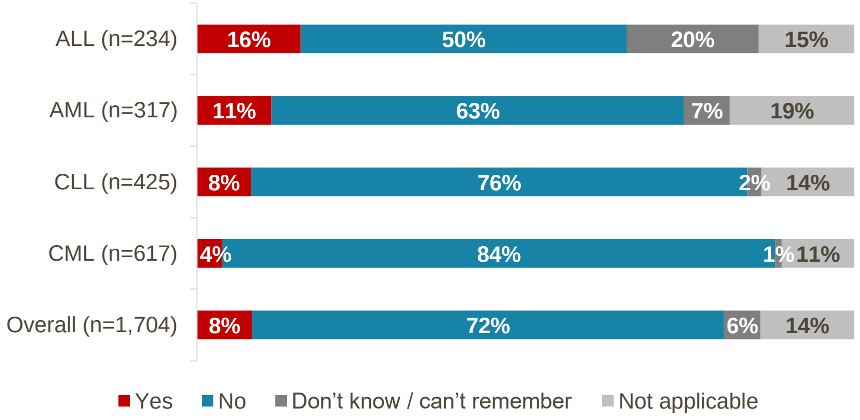
Figure 88. [Patient] Q56 Did you have any treatment for your leukemia delayed due to COVID-19? by country [Derived]



Please note patients who answered 'don't know / can't remember' (n=93) or 'not applicable' (n=212) were removed from analysis for Q56.

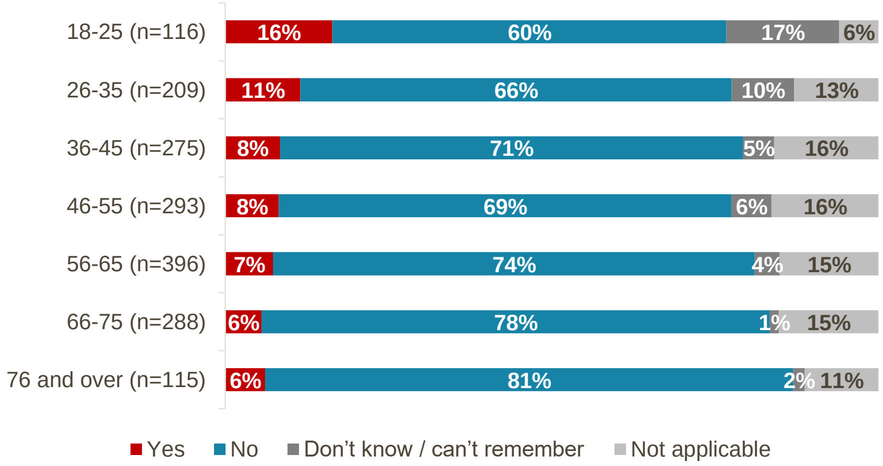
Overall, 8% (n=143) of patients' treatment changed due to COVID-19. This was more likely for patients with acute leukemia (16%, n=37 for ALL; 11%, n=36 for AML) than for patients with chronic leukemia (8%, n=35 for CLL; 4%, n=24 for CML) (Figure 89).

Figure 89. [Patient] Q57 Did your leukemia treatment change due to COVID-19?



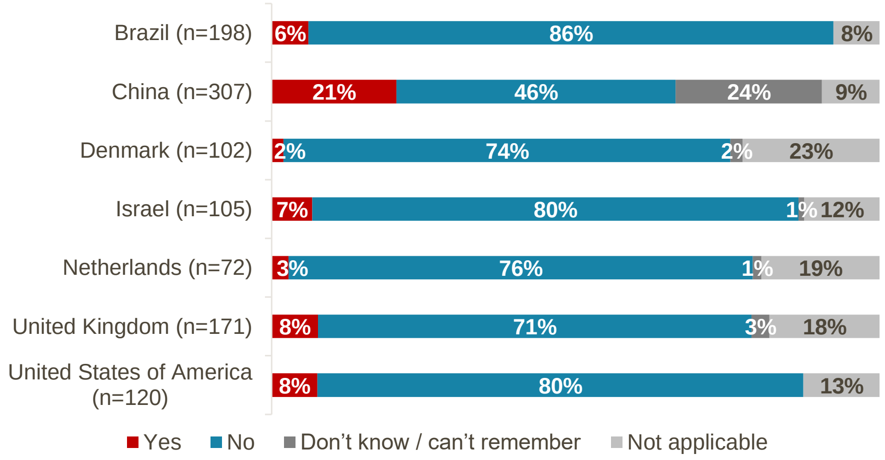
Patients aged 18-25 (16%, n=19) were most likely to report that their treatment changed due to COVID-19 (Figure 90).

Figure 90. [Patient] Q57 Did your leukemia treatment change due to COVID-19? by age



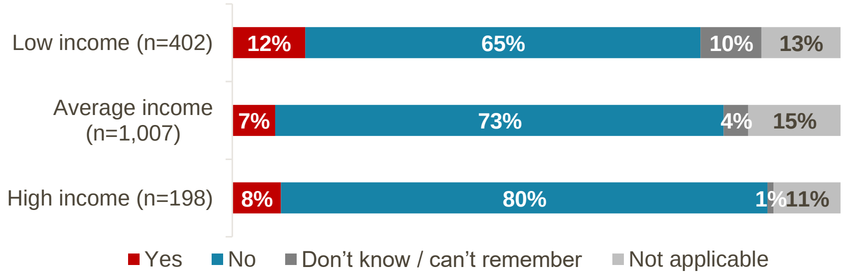
One fifth of patients in China (21%, n=63) reported that their treatment changed due to COVID-19. This is in comparison to just 2% (n=2) of patients in Denmark (Figure 91).

Figure 91. [Patient] Q57 Did your leukemia treatment change due to COVID-19? by country



Patients in a low-income household (12%, n=47) were most likely to report that their treatment changed due to COVID-19 (Figure 92Figure 90).

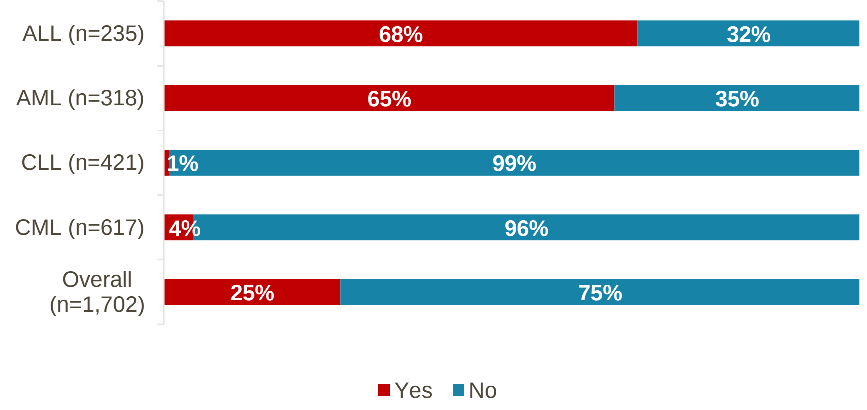
Figure 92. [Patient] Q57 Did your leukemia treatment change due to COVID-19? by annual household income



Stem cell transplants

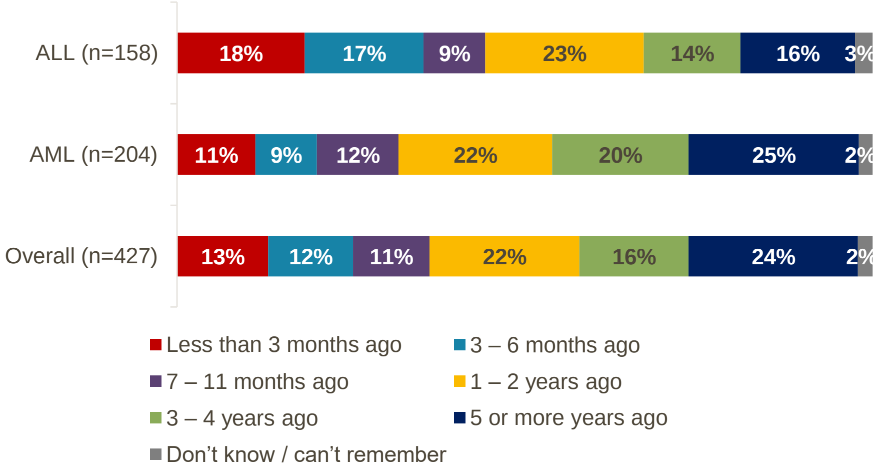
68% (n=160) of patients with ALL, and 65% (n=206) with AML have had a stem cell transplant as part of their treatment for leukemia. This is compared to just 1% (n=3) for CLL and 4% (n=26) for CML (Figure 93).

Figure 93. [Patient] Q58 Have you ever had a stem cell transplant as part of your treatment for leukemia?



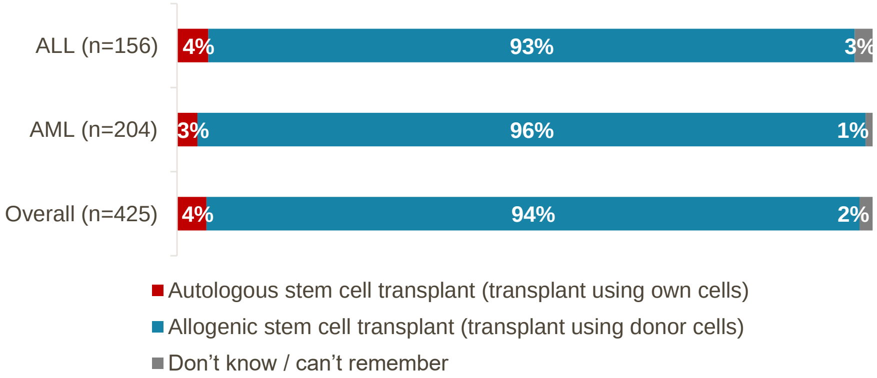
Overall, 36% (n=155) of patients had their most recent stem cell transplant less than 1 year ago, 37% (n=159) between 1 year and 4 years ago, and 24% (n=104) 5 or more years ago (Figure 94).

Figure 94. [Patient] Q59 How long ago did you have your most recent stem cell transplant?



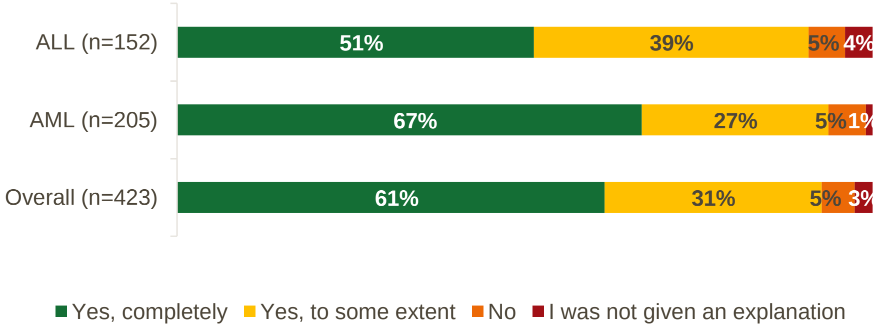
94% (n=399) of patients had an allogenic stem cell transplant (transplant using donor cells), while 4% (n=18) had an autologous stem cell transplant (transplant using own cells) (Figure 95).

Figure 95. [Patient] Q60 What was your most recent stem cell transplant?



AML patients (67%, n=137) were far more likely to report they completely understood the explanation they received about the possibility of complications, than patients with ALL (51%, n=78) (Figure 96).

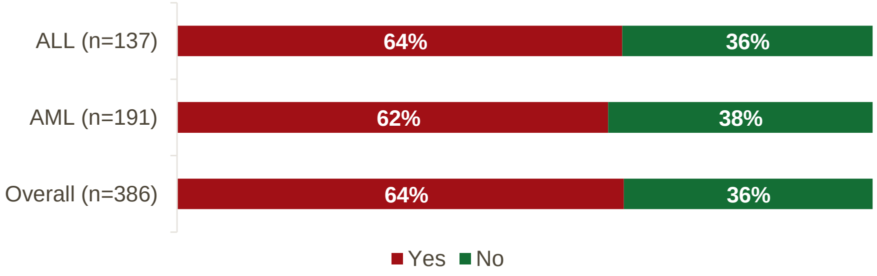
Figure 96. [Patient] Q61 Before your stem cell transplant, did you receive an explanation about the possibility of complications in a way you could understand? [Derived]



Please note patients who answered ‘don’t know / can’t remember’ (n=5) were removed from analysis for Q61.

Almost two thirds of patients (64%, n=248) developed complications following their stem cell transplant (Figure 97).

Figure 97. [Patient] Q62 Did you develop complications following your stem cell transplant? [Derived]



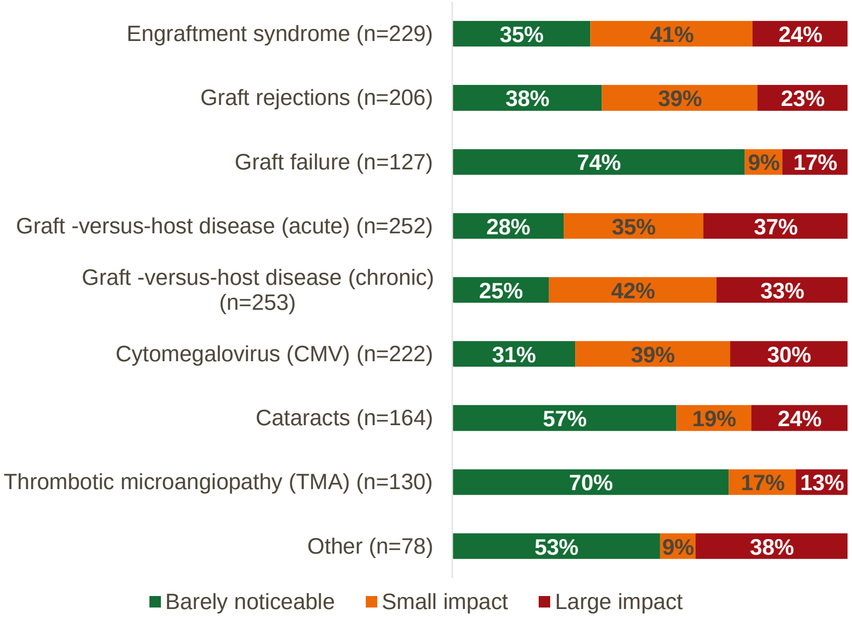
Please note patients who answered ‘don’t know / can’t remember’ (n=29) were removed from analysis for Q62.

Patients were asked to rate the negative impact of side effects post stem cell treatment (Figure 98). Patients were most likely to rate the following side effects as having a large negative impact:

- Another side effect not listed (38%, n=30)
- Graft -versus-host disease (acute) (37%, n=92)
- Graft -versus-host disease (chronic) (33%, n=84)

Please see Appendix 7 for breakdown by leukemia type.

Figure 98. [Patient] Q63 If you experience/d the following side effects post treatment, overall, how would you rate their negative impact? [Derived]

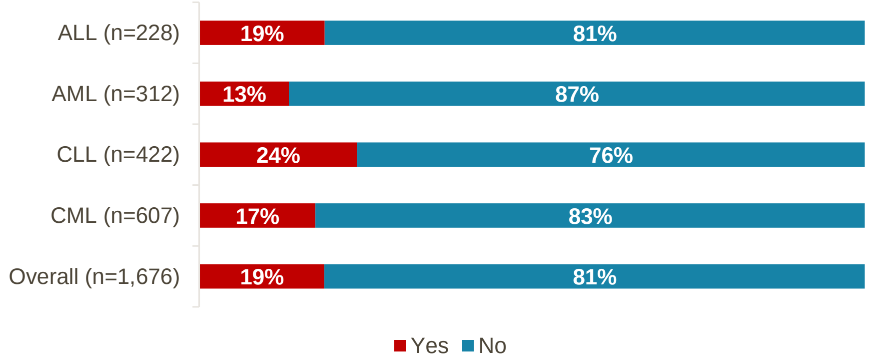


Please note patients who answered ‘not applicable’ at Engraftment syndrome (n=109), Graft rejections (n=131), Graft failure (n=178), Graft -versus-host disease (acute) (n=89), Graft -versus-host disease (chronic) (n=93), Cytomegalovirus (CMV) (n=109), Cataracts (n=151), Thrombotic microangiopathy (TMA) (n=178) and Other (n=94) were removed from analysis at Q63.

Relapse

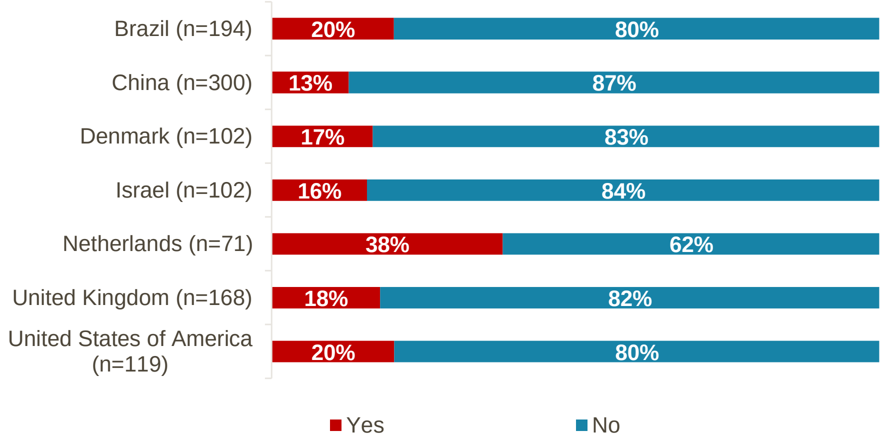
Overall, one fifth of patients (19%, n=315) reported they have had a relapse. CLL patients (24%, n=100) were most likely to experience a relapse, followed by ALL (19%, n=43), CML (17%, n=106) and AML patients (13%, n=42) (Figure 99).

Figure 99. [Patient] Q64 Have you had a relapse?



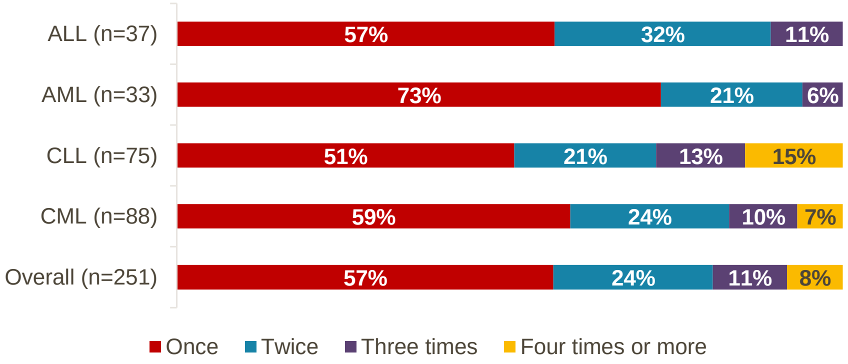
Analysis by country finds patients in the Netherlands (38%, n=27) were most likely to report they had had a relapse, while patients in China (13%, n=38) were least likely (Figure 100).

Figure 100. [Patient] Q64 Have you had a relapse? by country



CLL patients (49%, n=37) were most likely to report they have had to change their treatment or treatment plan as a result of a relapse more than once. This was followed by ALL (43%, n=16), CML (41%, n=36) and AML (27%, n=9) (Figure 101).

Figure 101. [Patient] Q65 How many times have you had to change your treatment or treatment plan as a result of a relapse?



Barriers to treatment

Overall, 42% (n=672) of patients reported that they experienced a barrier that affected their treatment choices. The most common barrier experienced was the cost of treatment, which was cited by 1 in 5 patients (20%, n=320) (Table 32).

Analysis by leukemia type finds:

- 68% (n=147) of ALL patients experienced a barrier that affected their treatment choices.
- 48% (n=136) of AML patients were faced with a barrier.
- 38% (n=228) of CML patients encountered a barrier.
- 27% (n=113) of CLL patients experienced a barrier.

Table 32. [Patient] Q66 Which barriers (if any) have you experienced that affected your treatment choices? Please select all that apply. [Multiple choice]

Base (n=)	**Overall** **1,618**	ALL 215	AML 286	CLL 417	CML 593
Cost of treatment	**20%**	46%	28%	9%	14%
Other barrier	**7%**	6%	5%	6%	9%
Lack of access to treatment center / prohibitive travel	**7%**	14%	8%	5%	5%
Wait time to treatment was an issue for me	**7%**	16%	8%	4%	4%
Lack of access to the most up-to-date treatment or equipment	**6%**	9%	6%	7%	5%
Fear of discrimination if my employer / friends / family knew about my disease	**6%**	8%	7%	2%	8%
No specialty doctor locally	**6%**	13%	6%	5%	4%
Lack of personal support	**5%**	4%	3%	3%	9%
Difficulty managing my carer / caregiver role (child, parent, disabled person) while in treatment	**4%**	8%	5%	0%	5%
No available treatment for my specific leukemia type	**2%**	3%	3%	1%	3%
Language / inability to understand the treatment	**1%**	1%	1%	0%	2%
I experienced no barriers	**58%**	32%	52%	73%	62%

Analysis by age reveals that as age increases, the proportion of patients who reported they experienced a barrier that affected their treatment choices decreases (Table 33). 75% (n=82) of 18–25-year-olds reported that they encountered a barrier, compared to 20% (n=22) of those aged 76 and over.

Table 33. [Patient] Q66 Which barriers (if any) have you experienced that affected your treatment choices? Please select all that apply. by age [Multiple choice]

Base (n=)	18-25 110	26-35 194	36-45 253	46-55 280	56-65 380	66-75 277	76+ 112
Cost of treatment	55%	39%	23%	14%	11%	13%	4%
Other barrier	1%	6%	8%	7%	8%	9%	7%
Lack of access to treatment center / prohibitive travel	18%	14%	6%	5%	4%	5%	1%
Wait time to treatment was an issue for me	17%	8%	8%	6%	5%	4%	3%
Lack of access to the most up-to-date treatment or equipment	14%	10%	2%	5%	8%	4%	4%
Fear of discrimination if my employer / friends / family knew about my disease	19%	10%	8%	8%	3%	2%	2%
No specialty doctor locally	14%	10%	4%	5%	4%	5%	4%
Lack of personal support	7%	7%	7%	7%	5%	4%	1%
Difficulty managing my carer / caregiver role (child, parent, disabled person) while in treatment	11%	4%	6%	7%	3%	1%	0%
No available treatment for my specific leukemia type	3%	4%	4%	3%	1%	1%	2%
Language / inability to understand the treatment	3%	1%	1%	2%	1%	1%	1%
I experienced no barriers	25%	38%	54%	60%	68%	69%	80%

Patients in China (81%, n=237) were most likely to report that they experienced a barrier that affected their treatment choices. Patients in Denmark (20%, n=19) and the United Kingdom (20%, n=34) were least likely to report they experienced a barrier (Table 34).

Cost of treatment was most prohibitive in China, with 65% (n=189) of patients reporting this was a barrier to their treatment choices.

Table 34. [Patient] Q66 Which barriers (if any) have you experienced that affected your treatment choices? Please select all that apply. by country [Multiple choice]

Base (n=)	Brazil 185	China 292	Denmark 93	Israel 99	Netherlands 67	United Kingdom 169	United States of America 118
Cost of treatment	12%	65%	6%	2%	1%	2%	19%
Other barrier	9%	4%	8%	12%	12%	7%	8%
Lack of access to treatment center / prohibitive travel	2%	17%	1%	4%	3%	2%	10%
Wait time to treatment was an issue for me	6%	16%	5%	3%	1%	4%	3%
Lack of access to the most up-to-date treatment or equipment	5%	14%	3%	-	4%	5%	6%
Fear of discrimination if my employer / friends / family knew about my disease	5%	11%	1%	5%	3%	2%	3%
No specialty doctor locally	2%	12%	-	2%	6%	4%	11%
Lack of personal support	4%	3%	3%	5%	7%	7%	11%
Difficulty managing my carer / caregiver role (child, parent, disabled person) while in treatment	3%	5%	1%	1%	6%	2%	4%
No available treatment for my specific leukemia type	2%	5%	-	-	4%	-	2%
Language / inability to understand the treatment	2%	1%	-	1%	-	2%	2%
I experienced no barriers	67%	19%	80%	71%	70%	80%	59%

As annual household income increases, the proportion of patients who reported experiencing a barrier that affected their treatment choices decreases. 62% (n=236) of patients living in a low-income household experienced a barrier, compared to 37% (n=350) of those living in an average income household, and 25% (n=48) of those living in a high-income household (Table 35).

Patients in a low-income household (34%, n=131) were more than 4 times as likely to cite cost of treatment as a barrier than patients in a high-income household (7%, n=13).

Table 35. [Patient] Q66 Which barriers (if any) have you experienced that affected your treatment choices? Please select all that apply. by annual household income [Multiple choice]

Base (n=)	Low income 380	Average income 956	High income 190
Cost of treatment	34%	17%	7%
Other barrier	7%	7%	9%
Lack of access to treatment center / prohibitive travel	10%	6%	4%
Wait time to treatment was an issue for me	8%	6%	4%
Lack of access to the most up-to-date treatment or equipment	8%	6%	4%
Fear of discrimination if my employer / friends / family knew about my disease	11%	5%	3%
No specialty doctor locally	7%	5%	5%
Lack of personal support	12%	4%	3%
Difficulty managing my carer / caregiver role (child, parent, disabled person) while in treatment	7%	3%	1%
No available treatment for my specific leukemia type	4%	2%	1%
Language / inability to understand the treatment	3%	1%	1%
I experienced no barriers	38%	63%	75%

Patients with career or technical qualifications (24%, n=36) were least likely to report they experienced a barrier to their treatment choices, while patients with no formal qualifications (55%, n=41) were most likely to experience a barrier. See Table 36 for analysis by level of education.

Table 36. [Patient] Q66 Which barriers (if any) have you experienced that affected your treatment choices? Please select all that apply. by level of education [Multiple choice]

Base (n=)	No formal qualifications 75	High school qualifications or diploma 433	University – Bachelors or Undergraduate degree 552	University – Masters, PhD or MD 314	Career or technical qualifications 148
Cost of treatment	35%	21%	24%	11%	9%
Other barrier	7%	6%	8%	11%	5%
Lack of access to treatment center / prohibitive travel	9%	7%	7%	5%	6%
Wait time to treatment was an issue for me	9%	8%	7%	4%	3%
Lack of access to the most up-to-date treatment or equipment	5%	7%	8%	5%	4%
Fear of discrimination if my employer / friends / family knew about my disease	3%	6%	8%	4%	3%
No specialty doctor locally	7%	6%	6%	6%	3%
Lack of personal support	5%	8%	4%	4%	5%
Difficulty managing my carer / caregiver role (child, parent, disabled person) while in treatment	1%	5%	5%	3%	3%
No available treatment for my specific leukemia type	4%	3%	2%	1%	1%
Language / inability to understand the treatment	4%	1%	1%	1%	1%
I experienced no barriers	45%	57%	53%	67%	76%

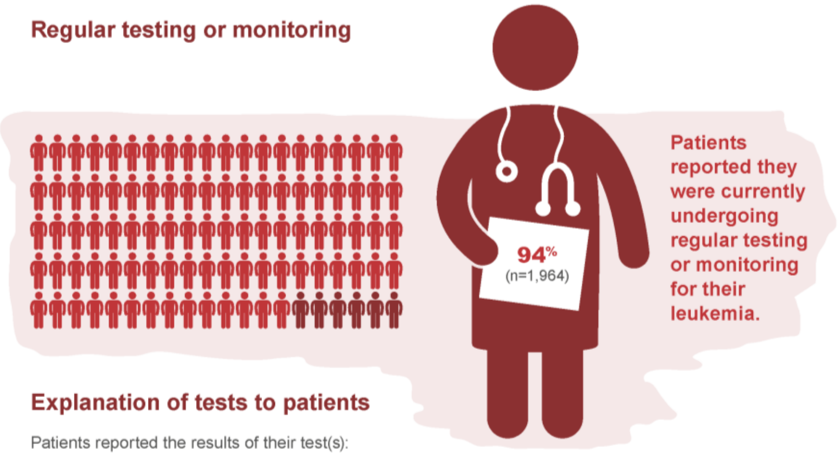
Global Leukemia Experience Survey 2023

Testing and monitoring

Testing and monitoring

Testing and monitoring: 1 of 3

Regular testing or monitoring



Patients reported they were currently undergoing regular testing or monitoring for their leukemia.

Explanation of tests to patients

Patients reported the results of their test(s):

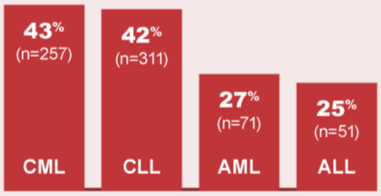
62% (n=1,201) **completely explained in a way they could understand.**

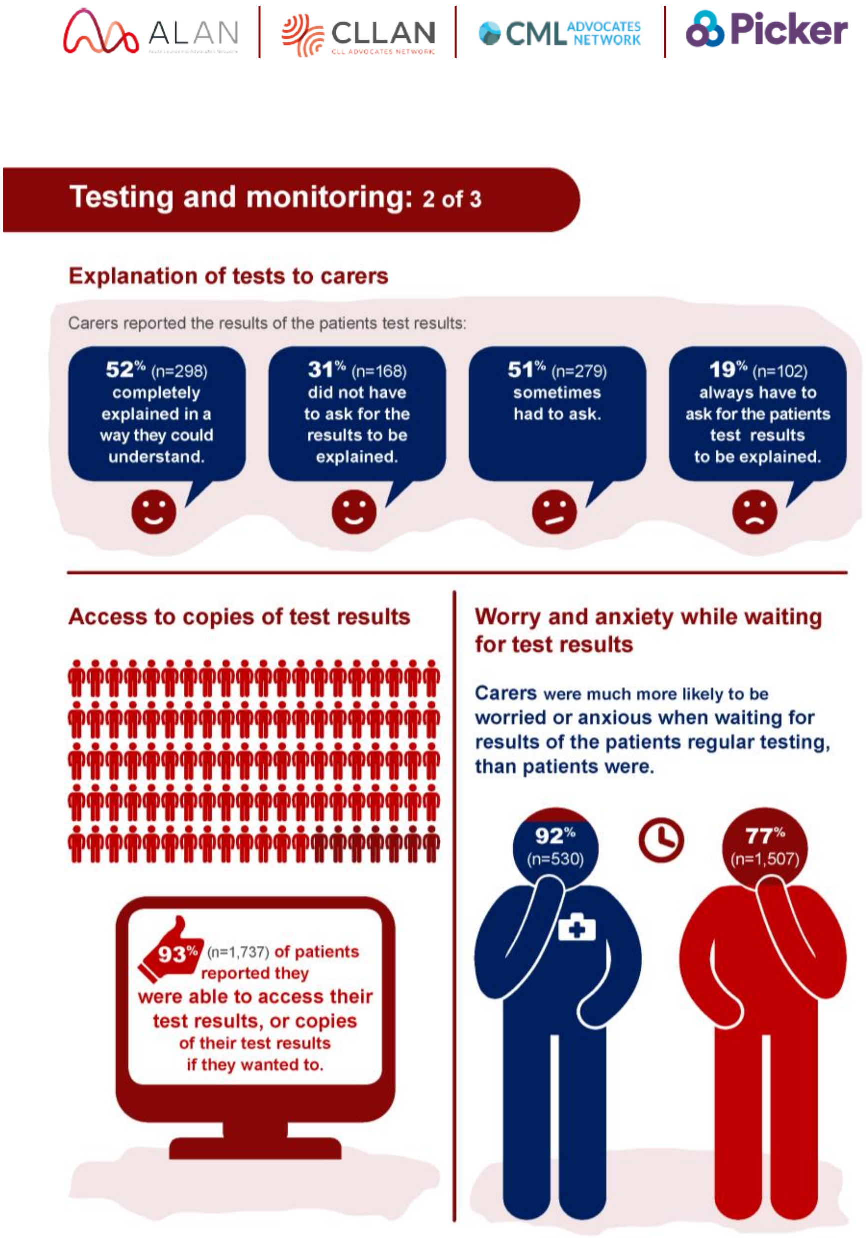
38% (n=734) **are always explained, without first having to ask.**

43% (n=830) **sometimes have to ask for results to be explained.**

18% (n=352) **always have to ask for the results to be explained.**

Patients with chronic leukemia were more likely to report test results, **as always explained to them without first having to ask,** than patients with acute leukemia.





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Testing and monitoring: 2 of 3

Explanation of tests to carers

Carers reported the results of the patients test results:

- **52%** (n=298) completely explained in a way they could understand.
- **31%** (n=168) did not have to ask for the results to be explained.
- **51%** (n=279) sometimes had to ask.
- **19%** (n=102) always have to ask for the patients test results to be explained.

Access to copies of test results

93% (n=1,737) of patients reported they were able to access their test results, or copies of their test results if they wanted to.

Worry and anxiety while waiting for test results

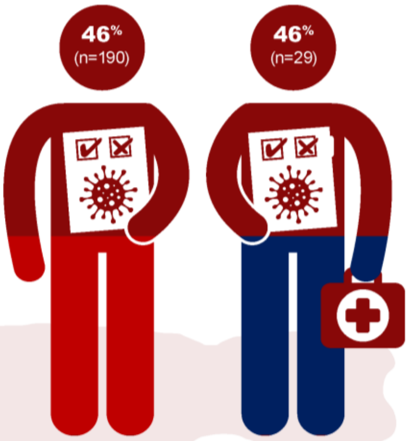
Carers were much more likely to be worried or anxious when waiting for results of the patients regular testing, than patients were.

Testing and monitoring: 3 of 3

Immunity status and avoiding infection for CLL patients

53% (n=416)
of CLL patients knew their immunity status.

73% (n=63)
of carers for CLL patients knew the patient's immunity status.



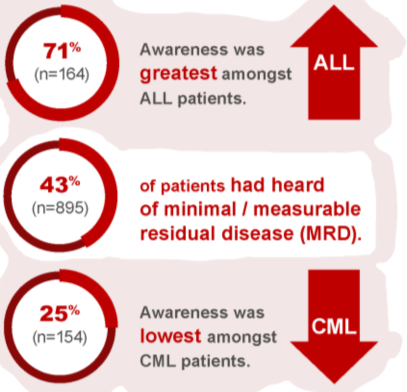
Less than half of both patients and carers reported that they **received completely clear information** about what steps they / the patient can take **to stay healthy and avoid infections.**

39% (n=307) **of patients with CLL**

27% (n=22) **of carers for those with CLL**

had reported they **received complete information** from a health professional **about the protocols for CLL immunizations / vaccinations, including which they should receive and which they should avoid.**

Awareness of minimal / measurable residual disease (MRD)



Awareness was **greatest** amongst ALL patients.

of patients had heard of minimal / measurable residual disease (MRD).

Awareness was **lowest** amongst CML patients.

Regular testing or monitoring

Overall, 94% (n=1,964) of patients, and 90% (n=589) of carers reported they were/ the patient was currently undergoing regular testing or monitoring for their leukemia (Figure 102; Figure 103).

Figure 102. [Patient] Q67 Are you currently undergoing regular testing or monitoring for your leukemia?

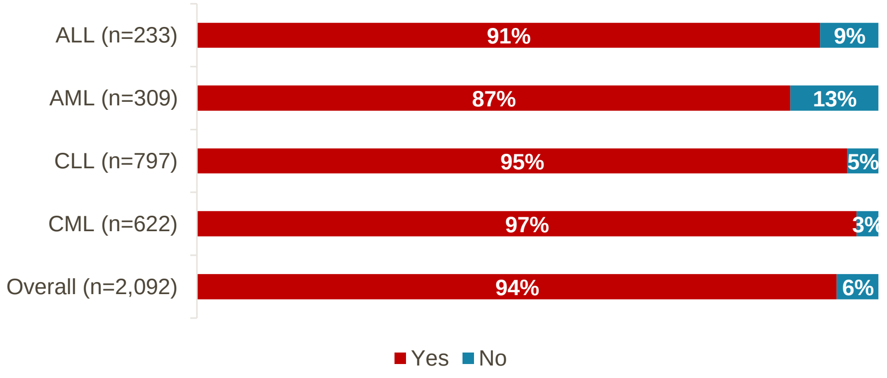
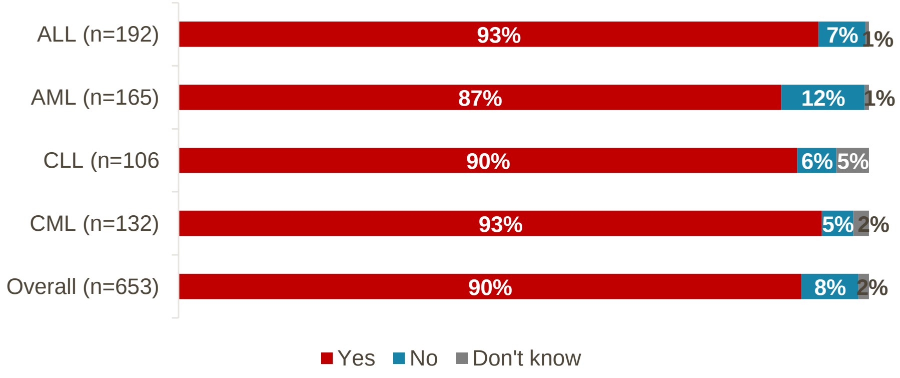


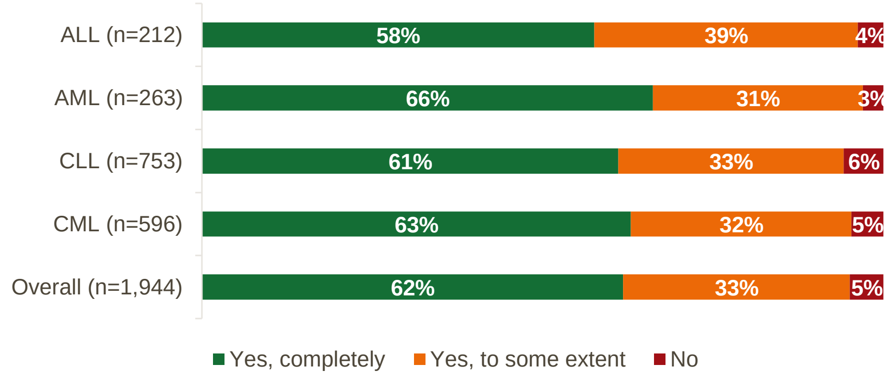
Figure 103. [Carer] C28 Is the patient currently undergoing regular testing or monitoring for their leukemia?



Explanation of tests to patients

Overall, two thirds of patients (62%, n=1,201) reported the results of their test(s) were completely explained to them in a way they could understand. Patients with AML (66%, n=174) were most likely to report they received a complete explanation (Figure 104).

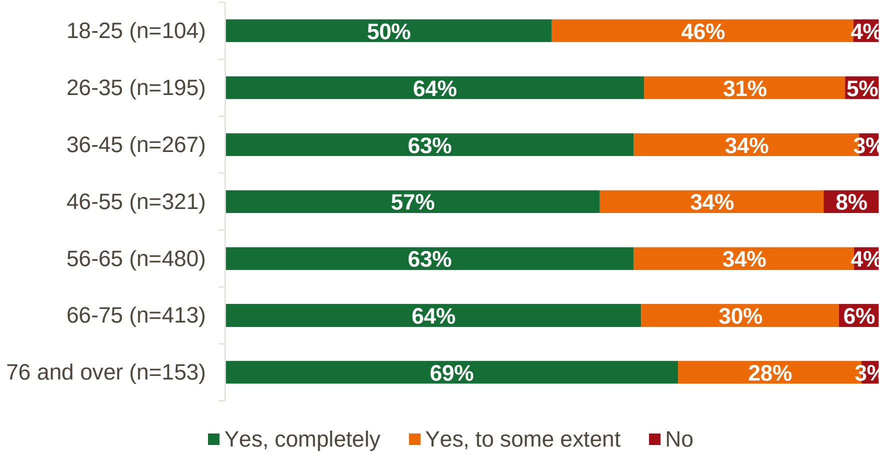
Figure 104. [Patient] Q68 Are the results of your test(s) explained to you in a way you can understand? [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=7) were removed from analysis for Q68.

Patients aged 18-25 (50%, n=52) were least likely to report they completely understood the explanation of test results, compared to other age groups (Figure 105).

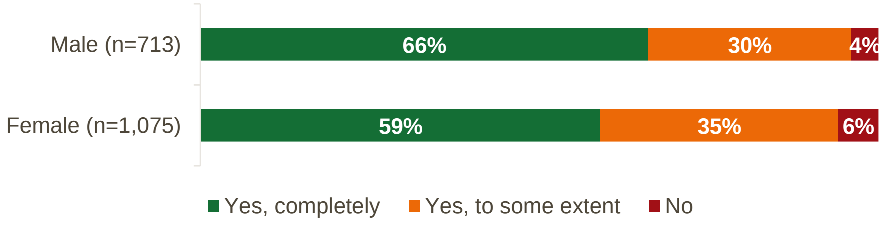
Figure 105. [Patient] Q68 Are the results of your test(s) explained to you in a way you can understand? by age [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=7) were removed from analysis for Q68.

Analysis by gender finds male respondents (66%, n=473) were more likely to report they completely understood the explanation of test results, than female respondents (59%, n=634) (Figure 106).

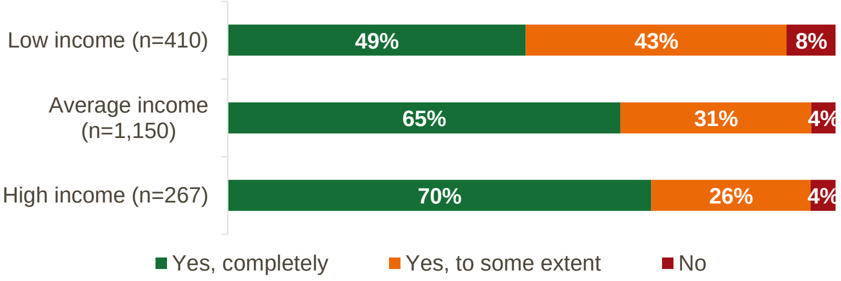
Figure 106. [Patient] Q68 Are the results of your test(s) explained to you in a way you can understand? by gender [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=7) were removed from analysis for Q68.

As displayed in Figure 107, as annual household income increases, the proportion of patients who reported they completely understood the explanation of test results increases. 49% (n=201) of patients living in a low-income household completely understood the explanation they received, compared to 70% (n=186) of patients living in a high-income household.

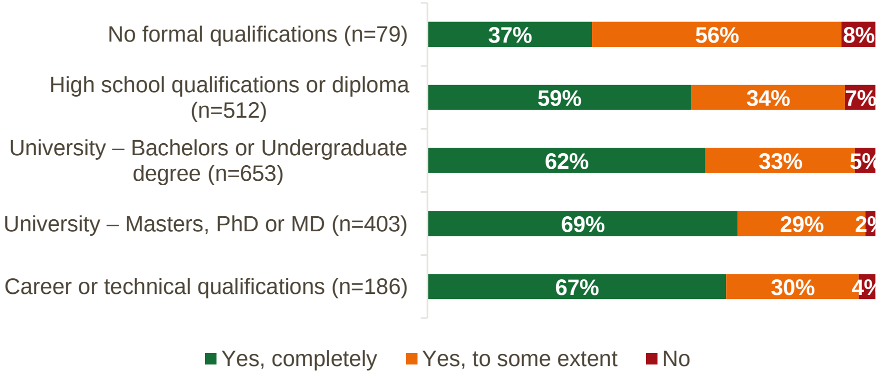
Figure 107. [Patient] Q68 Are the results of your test(s) explained to you in a way you can understand? by annual household income [Derived]



Please note patients who answered 'don't know / can't remember' (n=7) were removed from analysis for Q68.

Patients with a postgraduate university degree (Masters, PhD or MD) (69%, n=279) were almost twice as likely to report they completely understood the explanation of test results, than patients with no formal qualifications (37%, n=29) (Figure 108).

Figure 108. [Patient] Q68 Are the results of your test(s) explained to you in a way you can understand? by level of education [Derived]

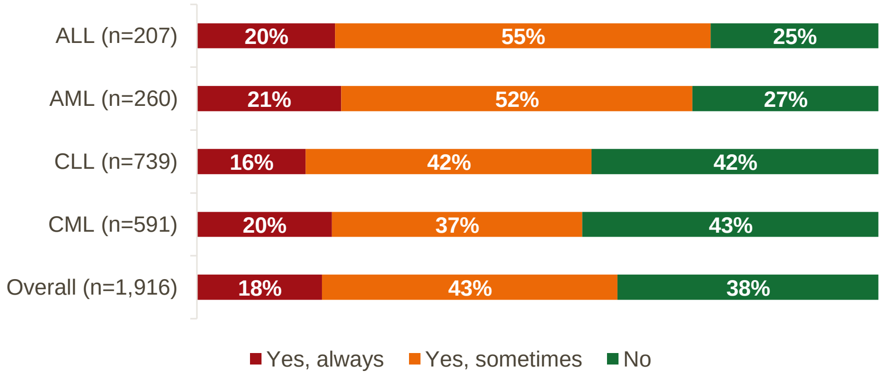


Please note patients who answered 'don't know / can't remember' (n=7) were removed from analysis for Q68.

Just 38% (n=734) of patients reported that test results are always explained to them without first having to ask. 43% (n=830) said they sometimes have to ask for their results to be explained, while 18% (n=352) said they always have to ask for the results to be explained.

Patients with chronic leukemia (42%, n=311 for CLL; 43%, n=257 for CML) were more likely to report test results are always explained to them without first having to ask, than patients with acute leukemia (25%, n=51 for ALL; 27%, n=71 for AML) (Figure 109).

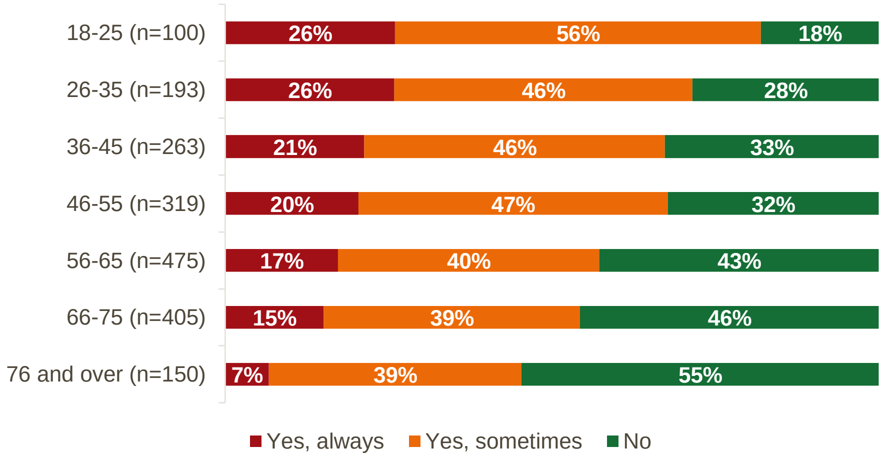
Figure 109. [Patient] Q69 Do you have to ask for the results to be explained? [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=10) were removed from analysis for Q69.

Younger patients aged 18-25 (26%, n=26) and 26-35 (26%, n=50) were almost four times as likely to report they always have to ask for their test results to be explained, than patients aged 76 and over (7%, n=10) (Figure 110).

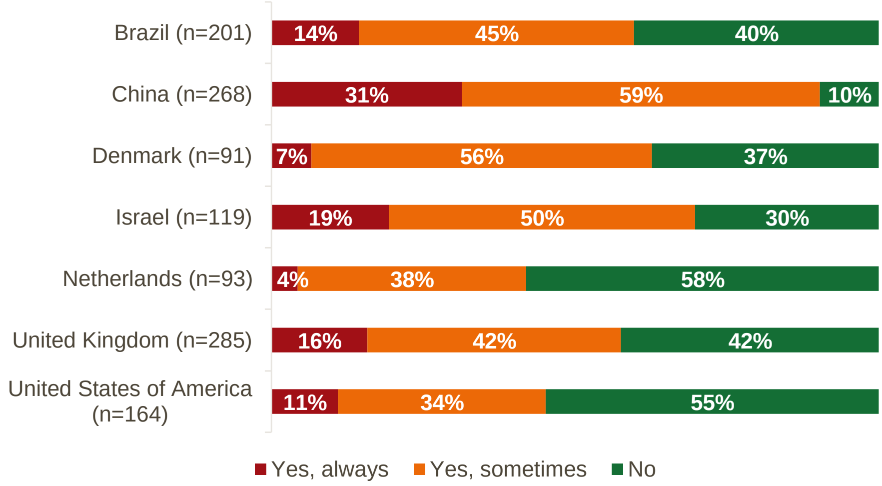
Figure 110. [Patient] Q69 Do you have to ask for the results to be explained? by age [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=10) were removed from analysis for Q69.

7The proportion of patients who reported they always have to ask for their test results to be explained varied widely by country (Figure 111). 31% (n=84) of patients in China reported they always have to ask for an explanation, compared to just 4% (n=4) in the Netherlands.

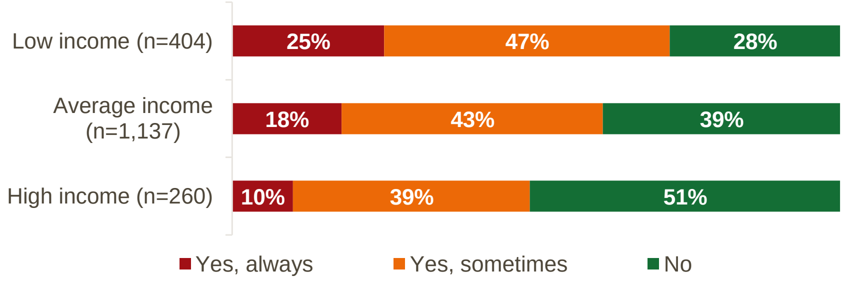
Figure 111. [Patient] Q69 Do you have to ask for the results to be explained? by country [Derived]



Please note patients who answered 'don't know / can't remember' (n=10) were removed from analysis for Q69.

Patients living in low-income households (25%, n=101) were more than twice as likely to report they always have to ask for their test results to be explained than patients in a high-income household (10%, n=27) (Figure 112).

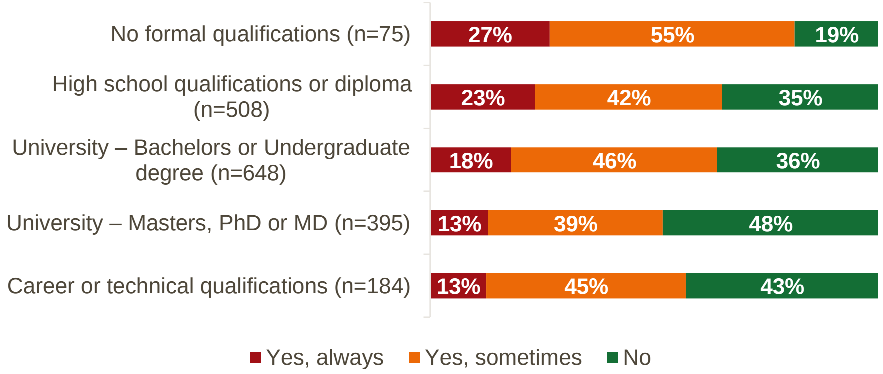
Figure 112. [Patient] Q69 Do you have to ask for the results to be explained? by annual household income [Derived]



Please note patients who answered 'don't know / can't remember' (n=10) were removed from analysis for Q69.

Patients with no formal qualifications (27%, n=20) were more than twice as likely to report they always have to ask for their test results to be explained than patients than patients with a postgraduate university degree (Masters, PhD or MD) (13%, n=51) or those with career or technical qualifications (13%, n=23) (Figure 113).

Figure 113. [Patient] Q69 Do you have to ask for the results to be explained? by level of education [Derived]



Please note patients who answered 'don't know / can't remember' (n=10) were removed from analysis for Q69.

Explanation of tests to carers

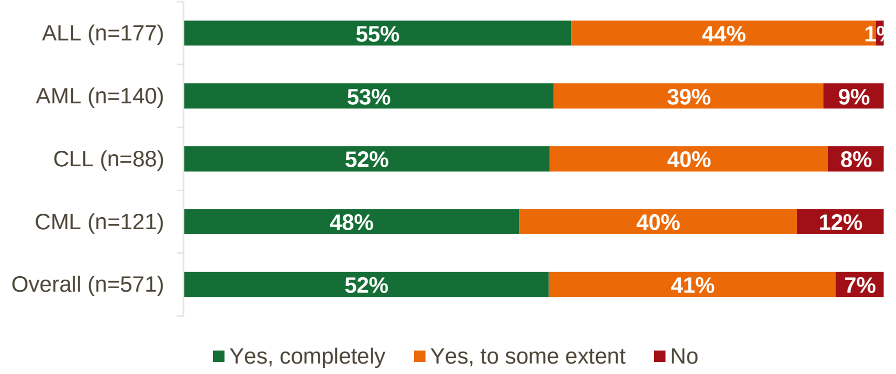
Carers were asked about their experience of receiving explanations of the patients test results. Overall, 52% (n=298) reported the results of the patients test results were completely explained to them in a way they could understand (Figure 114).

When asked if the carer themselves had to ask for the results to be explained, 31% (n=168) said they did not have to ask, 51% (n=279) said they sometimes had to ask and 19% (n=102) reported that they always have to ask for the patients test results to be explained to them.

A distinction between the patient and carer data can be seen for leukemia type (Figure 109; Figure 115). Similar proportions of patients and carers reported never having to ask for test results to be explained, with the exception of CML:

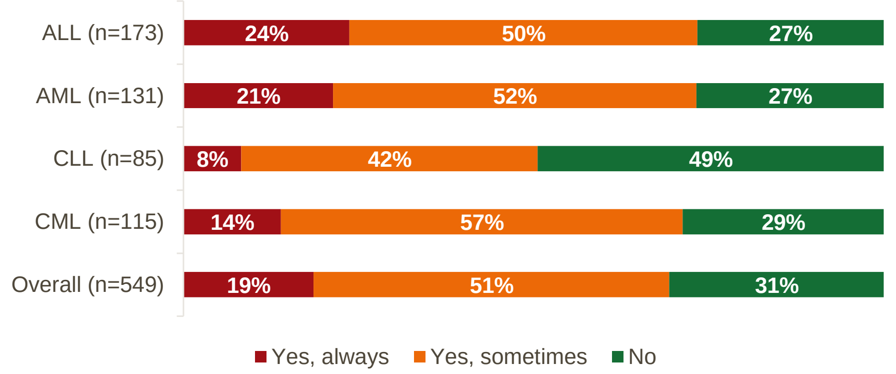
- **ALL**: 25% of patients (n=51); 27% of carers (n=46)
- **AML**: 27% of patients (n=71); 27% of carers (n=35)
- **CLL**: 42% of patients (n=311); 49% of carers (n=42)
- **CML**: 43% of patients (n=257); 29% of carers (n=33)

Figure 114. [Carer] C29 Are the results of test(s) explained to YOU in a way you can understand? [Derived]



Please note carers who answered ‘don't know / can't remember’ (n=4) or ‘not applicable’ (n=9) were removed from analysis for C29.

Figure 115. [Carer] C30 Do YOU have to ask for the results to be explained? [Derived]

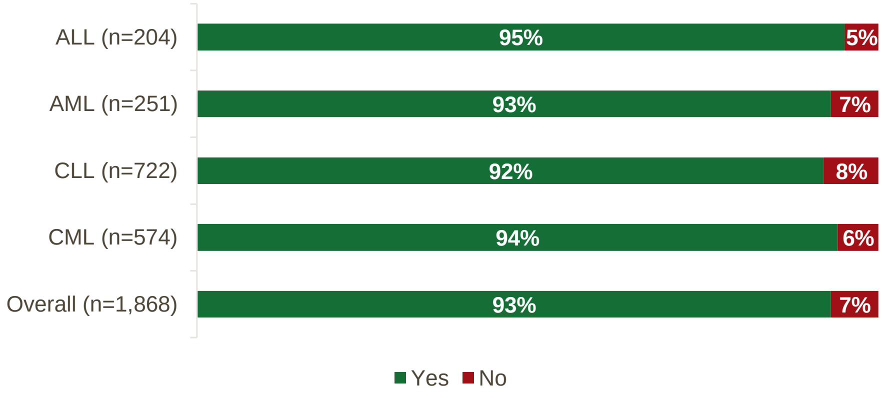


Please note carers who answered ‘don't know / can't remember’ (n=8) or ‘not applicable’ (n=24) were removed from analysis for C30.

Access to copies of test results

Overall, 93% (n=1,737) of patients reported they were able to access their test results, or copies of their test results if they wanted to (Figure 116).

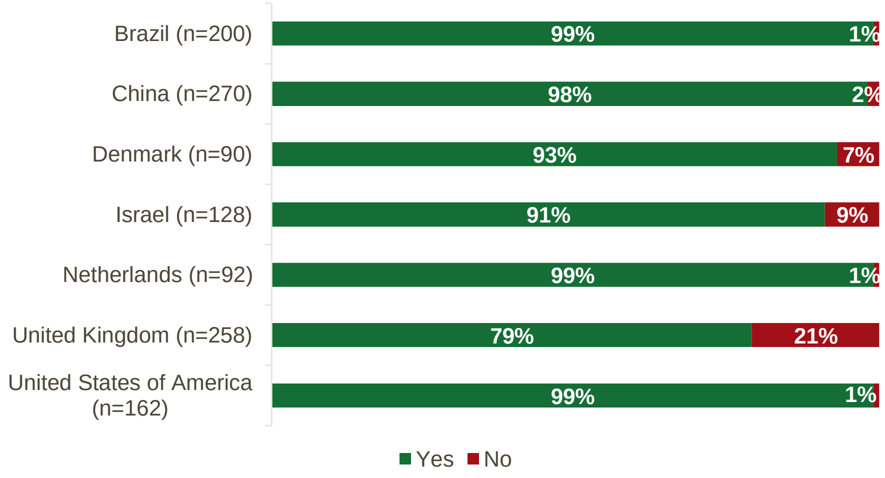
Figure 116. [Patient] Q70 Are you able to access your test results, or copies of your test results, if you want to? [Derived]



Please note patients who answered 'don't know / can't remember' (n=81) were removed from analysis for Q70.

Patients in the United Kingdom (79%, n=204) were far less likely to report they were able to access their test results, or copies of their test results if they wanted to, compared to other countries (Figure 117).

Figure 117. [Patient] Q70 Are you able to access your test results, or copies of your test results, if you want to? by country [Derived]



Please note patients who answered 'don't know / can't remember' (n=81) were removed from analysis for Q70.

Worry and anxiety while waiting for test results

Figure 118 displays the proportion of patients and carers who rated how worried or anxious they feel while waiting for test results as 3 or more out of 10 (mild to extreme worry or anxiety).

Overall, carers (92%, n=530) were much more likely to be worried or anxious when waiting for results of the patients regular testing, than patients were (77%, n=1,507).

Both patients with acute leukemia, and carers for patients with acute leukemia, reported a higher instance of worry and anxiety (3 or more out of 10) while waiting for test results than those with chronic leukemia or looking after someone with chronic leukemia:

- **ALL:** 88% of patients (n=185); 97% of carers (n=171)
- **AML:** 85% of patients (n=227); 96% of carers (n=138)
- **CLL:** 73% of patients (n=551); 83% of carers (n=76)
- **CML:** 74% of patients (n=442); 82% of carers (n=98)

Figure 118. [Patient] Q71 How worried / anxious do you feel when waiting for the results of your regular testing / monitoring? 0 is not at all worried/ anxious and 10 is extremely worried/ anxious & [Carer] C31 How worried / anxious do YOU feel when waiting for the results of the patient's regular testing / monitoring? 0 is not at all worried / anxious and 10 is extremely worried / anxious. [Rated 3 or more out of 10]

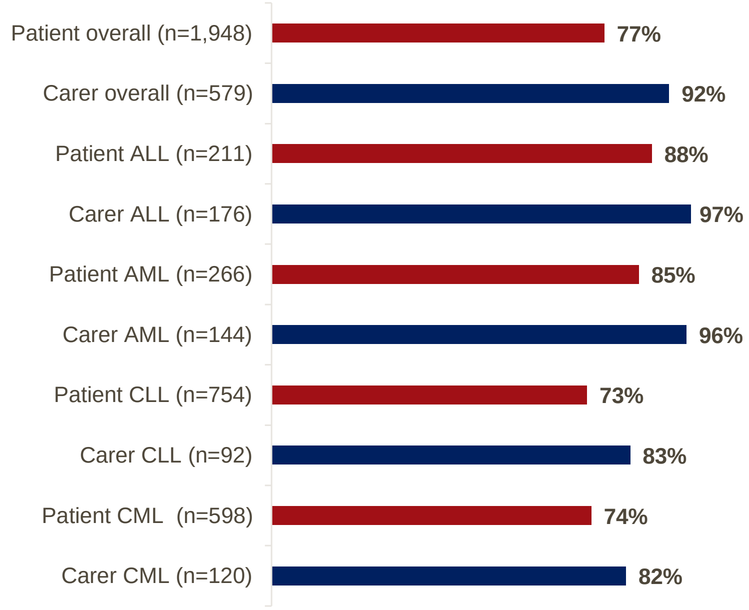
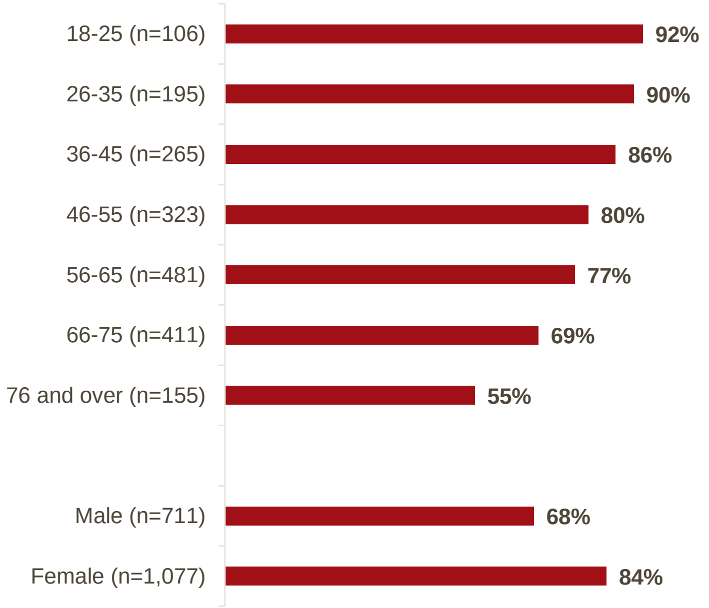


Figure 119 displays the proportion of patients who rated how worried or anxious they feel while waiting for test results as 3 or more out of 10 (mild to extreme worry or anxiety) by age and gender.

Younger patients were far more likely to experience worry or anxiety when waiting for results of the patients regular testing, than older patients. 92% (n=97) of 18- to 25-year-olds felt mild to extreme worry or anxiety while waiting for results, compared to 55% (n=85) of patients aged 76 and over.

Female patients (84%, n=904) were far more likely to experience worry or anxiety when waiting for results of the patients regular testing, than male patients (68%, n=483).

Figure 119. [Patient] Q71 How worried / anxious do you feel when waiting for the results of your regular testing / monitoring? 0 is not at all worried/ anxious and 10 is extremely worried/ anxious by age and gender [Rated 3 or more out of 10]

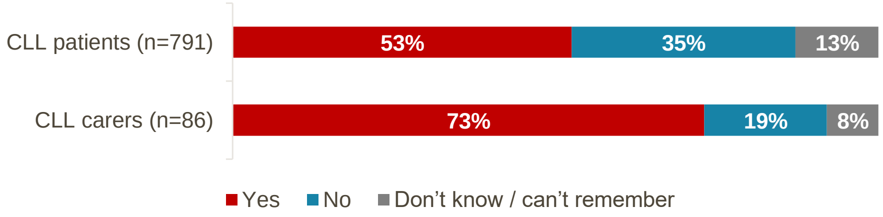


Immunity status and avoiding infection for CLL patients

Patients with CLL, and carers for patients with CLL, were asked about patient immunity status, and information they have received from healthcare professionals about how to stay healthy and avoid infection.

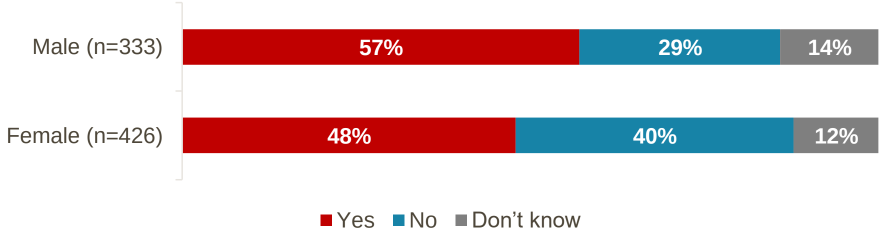
As shown in Figure 120, 53% (n=416) of CLL patients knew their immunity status, while 73% (n=63) of carers for CLL patients knew the patient's immunity status.

Figure 120. [Patient] Q72 Do you know your immunity status? Your immunity and immunity status are connected to your immune system, which is the body's center for fighting infection and disease. Your immunity is your body's overall ability to fight these infections and diseases. & [Carer] C32 Do you know the patient's immunity status? Immunity and immunity status are connected to the immune system, which is the body's center for fighting infection and disease. The patient's immunity is their body's overall ability to fight these infections and diseases.



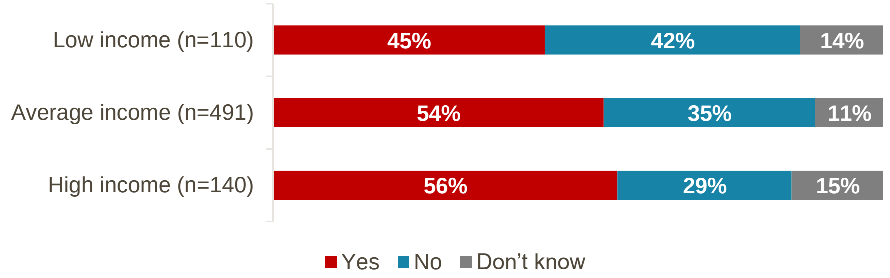
Male patients (57%, n=190) were more likely to know their immunity status than female patients (48%, n=204) (Figure 121).

Figure 121. [Patient] Q72 Do you know your immunity status? Your immunity and immunity status are connected to your immune system, which is the body's center for fighting infection and disease. Your immunity is your body's overall ability to fight these infections and diseases. by gender



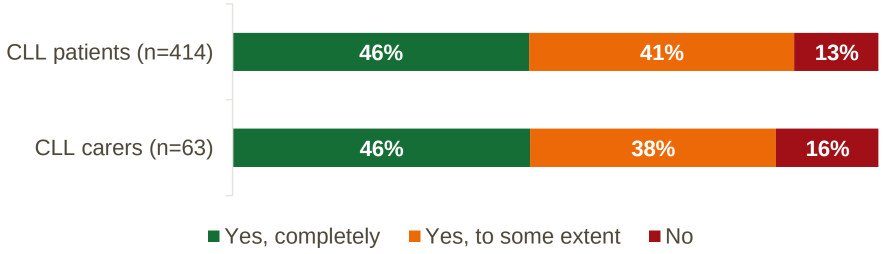
Patients living in a low-income household (45%, n=49) were less likely to know their immunity status than patients living in an average income household (54%, n=266) or high-income household (56%, n=79) (Figure 122).

Figure 122. [Patient] Q72 Do you know your immunity status? Your immunity and immunity status are connected to your immune system, which is the body's center for fighting infection and disease. Your immunity is your body's overall ability to fight these infections and diseases. by annual household income



Patients and carers who were aware of immunity status, were then asked if they were given clear information about what steps they/ the patient can take to stay healthy and avoid infections. 46% of both patients (n=190) and carers (n=29) reported they received completely clear information about what steps they/ the patient can take to stay healthy and avoid infections (Figure 123).

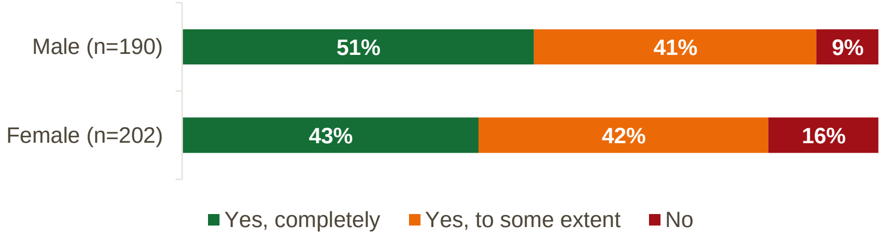
Figure 123. [Patient] Q73 Were you given clear information about what steps you can take to stay healthy and avoid infections? & [Carer] C33 Were YOU given clear information about what steps the patient can take to stay healthy and avoid infections? [Derived]



Please note patients who answered 'don't know / can't remember' (n=2) were removed from analysis for Q73.

Male patients (51%, n=96) were more likely to receive completely clear information about what steps they can take to stay healthy and avoid infections, than female patients (43%, n=86) (Figure 124).

Figure 124. [Patient] Q73 Were you given clear information about what steps you can take to stay healthy and avoid infections? by gender [Derived]

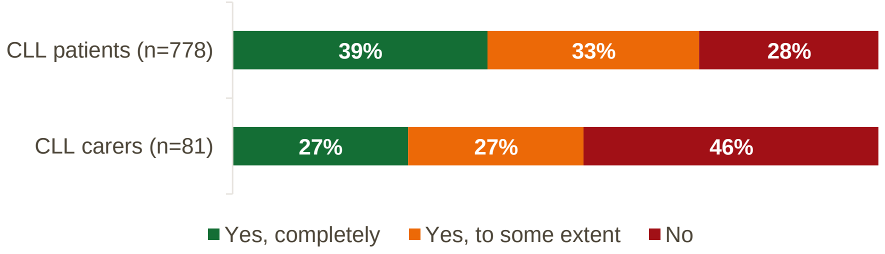


Please note patients who answered ‘don't know / can't remember’ (n=2) were removed from analysis for Q73.

39% (n=307) of patients with CLL reported they received complete information from a health professional about the protocols for CLL immunizations / vaccinations, including which they should receive and which they should avoid. This is compared to 33% (n=255) who received partial information, and 28% (n=216) who did not receive this information from a health professional (Figure 125).

In comparison, 27% (n=22) of CLL carers received complete information from a health professional about the protocols for CLL immunizations / vaccinations, including which the patient should receive and which they should avoid, 27% (n=22) received partial information, and 46% (n=37) did not receive this information.

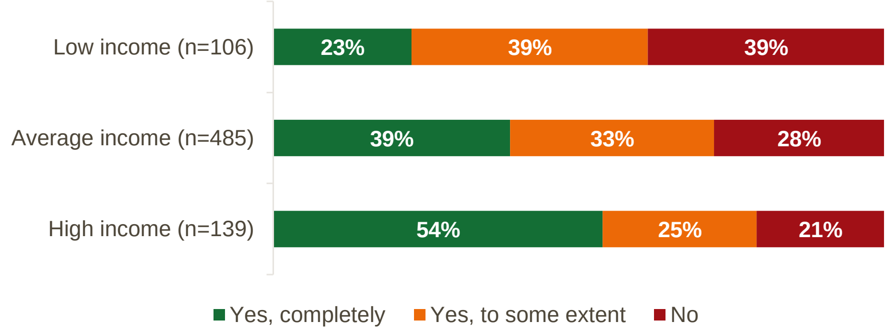
Figure 125. [Patient] Q74 Has a health professional spoken to you about the protocols for CLL immunizations / vaccinations, including which you should receive and which you should avoid? & [Carer] C34 Has a health professional spoken to YOU about the protocols for CLL immunizations / vaccinations, including which the patient should receive and which they should avoid? [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=11) were removed from analysis for Q74 and carers who answered ‘don't know / can't remember’ (n=3) or ‘not applicable (n=1) were removed from analysis for C34.

Patients living in a high-income household (54%, n=75) were more than twice as likely to report they received completely clear information about what steps they can take to stay healthy and avoid infections, than patients living in a low-income household (23%, n=24) (Figure 126).

Figure 126. [Patient] Q74 Has a health professional spoken to you about the protocols for CLL immunizations / vaccinations, including which you should receive and which you should avoid? by annual household income

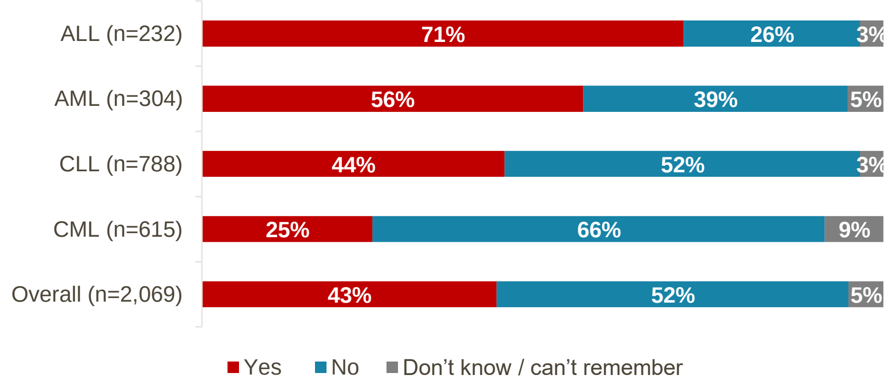


Please note patients who answered ‘don't know / can't remember’ (n=11) were removed from analysis for Q74

Awareness of minimal / measurable residual disease (MRD)

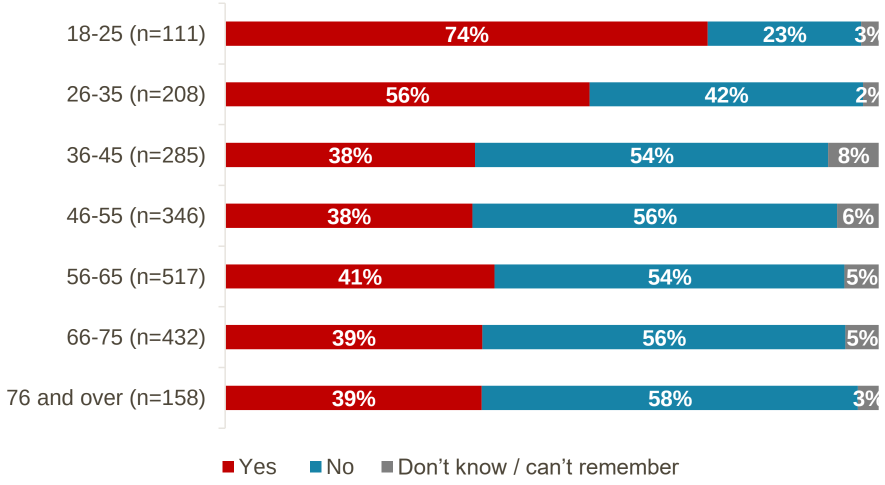
Overall, 43% (n=895) of patients had heard of minimal / measurable residual disease (MRD). Awareness was greatest amongst ALL patients (71%, n=164) and lowest amongst CML patients (25%, n=154) (Figure 127).

Figure 127. [Patient] Q75 Have you heard of minimal / measurable residual disease? (MRD)



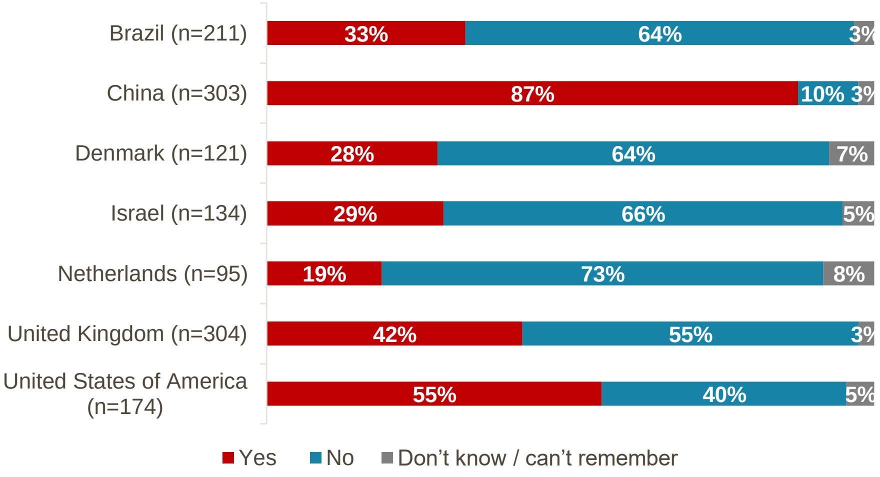
Patients aged 18-25 (74%, n=82) and 26-35 (56%, n=116) were far more likely to be aware of minimal / measurable residual disease, compared to older age groups (Figure 128).

Figure 128. [Patient] Q75 Have you heard of minimal / measurable residual disease? (MRD) by age



Awareness of minimal / measurable residual disease varied widely by country (Figure 129). Patients in China (87%, n=265) were most likely to have heard of minimal / measurable residual disease, while patients in the Netherlands (19%, n=18) were least likely.

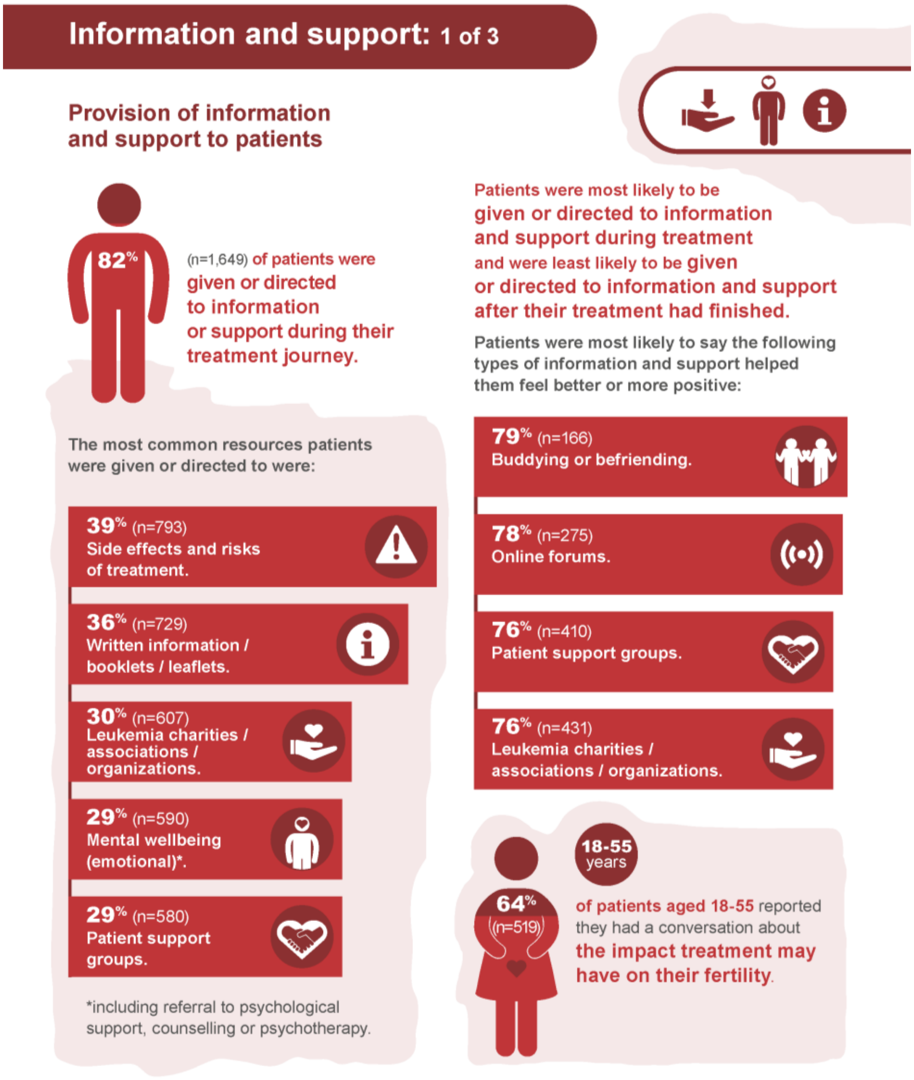
Figure 129. [Patient] Q75 Have you heard of minimal / measurable residual disease? (MRD) by country



Global Leukemia Experience Survey 2023

Information and support

Information and support



Information and support: 1 of 3

Provision of information and support to patients

82% (n=1,649) of patients were given or directed to information or support during their treatment journey.

The most common resources patients were given or directed to were:

39% (n=793) Side effects and risks of treatment.

36% (n=729) Written information / booklets / leaflets.

30% (n=607) Leukemia charities / associations / organizations.

29% (n=590) Mental wellbeing (emotional)*.

29% (n=580) Patient support groups.

*including referral to psychological support, counselling or psychotherapy.

Patients were most likely to be given or directed to information and support during treatment and were least likely to be given or directed to information and support after their treatment had finished.

Patients were most likely to say the following types of information and support helped them feel better or more positive:

79% (n=166) Buddying or befriending.

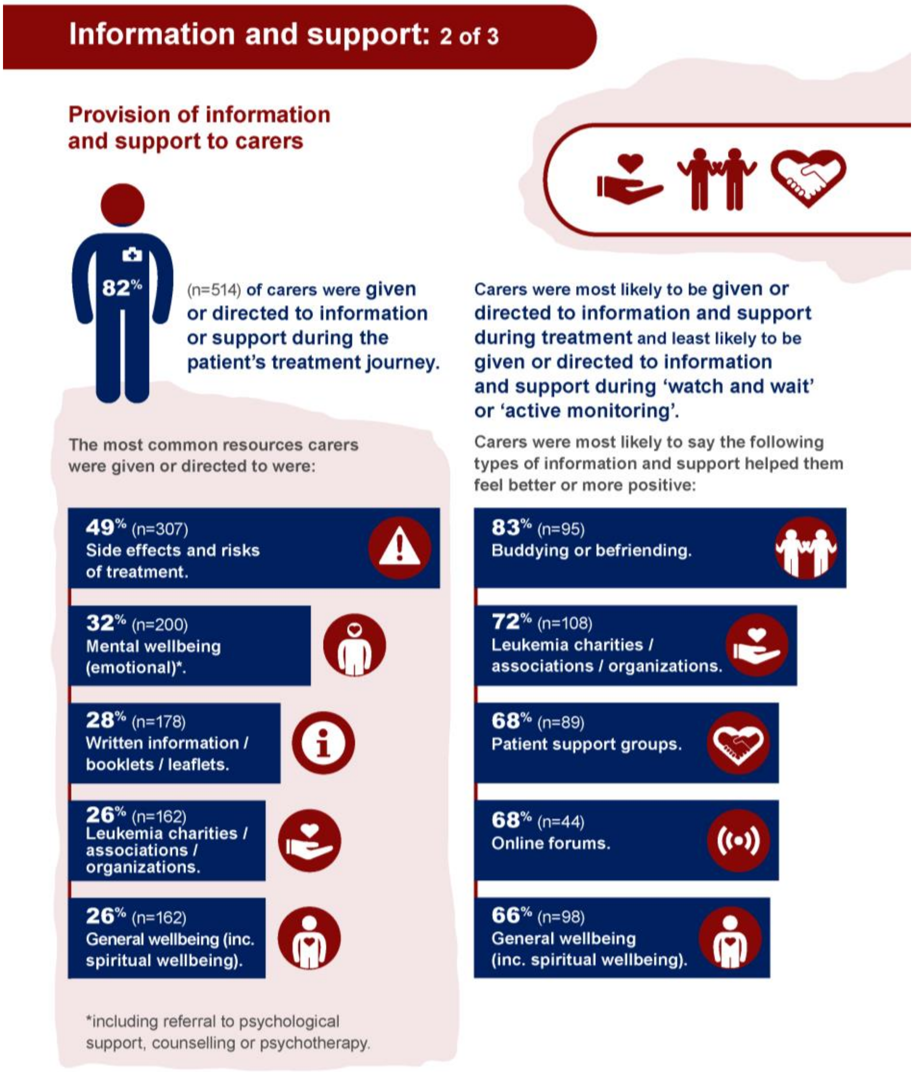
78% (n=275) Online forums.

76% (n=410) Patient support groups.

76% (n=431) Leukemia charities / associations / organizations.

18-55 years

64% (n=519) of patients aged 18-55 reported they had a conversation about the impact treatment may have on their fertility.



Information and support: 2 of 3

Provision of information and support to carers

82% (n=514) of carers were **given or directed to information or support during the patient's treatment journey.**

The most common resources carers were given or directed to were:

- **49%** (n=307) Side effects and risks of treatment.
- **32%** (n=200) Mental wellbeing (emotional)*.
- **28%** (n=178) Written information / booklets / leaflets.
- **26%** (n=162) Leukemia charities / associations / organizations.
- **26%** (n=162) General wellbeing (inc. spiritual wellbeing).

*including referral to psychological support, counselling or psychotherapy.

Carers were most likely to be **given or directed to information and support during treatment** and least likely to be **given or directed to information and support during 'watch and wait' or 'active monitoring'.**

Carers were most likely to say the following types of information and support helped them feel better or more positive:

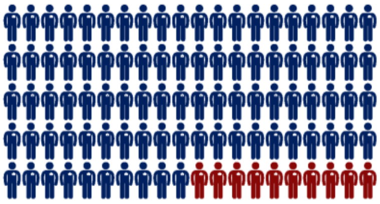
- **83%** (n=95) Buddying or befriending.
- **72%** (n=108) Leukemia charities / associations / organizations.
- **68%** (n=89) Patient support groups.
- **68%** (n=44) Online forums.
- **66%** (n=98) General wellbeing (inc. spiritual wellbeing).

Information and support: 3 of 3

Conducting own research

The majority of patients 91% (n=1,839) **conducted their own research into varying stages of their treatment journey.**

90% of carers (n=542) **reported that they conducted their own research into varying stages of the patient's treatment journey.**



Patients were most likely to research:

75% (n=1,516) **Diagnosis.**

70% (n=1,419) **Treatments available.**

68% (n=1,380) **Side effects.**

Carers were most likely to research:
(the same three topics as patients)

74% (n=450) **Diagnosis.**

73% (n=439) **Treatments available.**

70% (n=421) **Side effects.**

Provision of information and support to patients

82% (n=1,649) of patients were given or directed to information or support during their treatment journey (Table 37). The most common resources patients were given or directed to were:

- Side effects and risks of treatment (39% n=793)
- Written information / booklets / leaflets (36%, n=729)
- Leukemia charities / associations / organizations (30%, n=607)
- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy (29%, n=590)
- Patient support groups (29%, n=580)

AML patients (91%, n=261) were most likely to be given or directed to resources, followed by ALL (89%, n=201), CML (83%, n=502) and CLL (76%, n=588) patients. The greatest variances of information provision by leukemia type can be seen for:

- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy: 47% for AML (n=134), compared to 18% for CLL (n=139).
- Written information / booklets / leaflets: 44% for CLL (n=336), compared to 18% for ALL (n=40).
- Side effects and risks of treatment: 55% for AML (n=157) compared to 31% for CLL (n=239).
- Buddying or befriending: 29% for ALL (n=65), compared to just 6% for CLL (n=46) and 7% for CML (n=43).

Table 37. [Patient] Q78 Please select what information and support you were given or directed to during your treatment journey. Please select all that apply [Multiple choice]

Base (n=)	**Overall** **2,014**	ALL 225	AML 288	CLL 770	CML 605
Side effects and risks of treatment	**39%**	52%	55%	31%	39%
Written information / booklets / leaflets	**36%**	18%	37%	44%	36%
Leukemia charities / associations / organizations	**30%**	26%	33%	34%	27%
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	**29%**	42%	47%	18%	28%
Patient support groups	**29%**	24%	25%	29%	34%
General wellbeing (including spiritual wellbeing)	**19%**	28%	29%	14%	18%
Online forums	**19%**	14%	11%	21%	21%
Clinical trials	**19%**	15%	23%	19%	19%
Patient rights	**17%**	26%	25%	12%	17%
Buddying or befriending	**11%**	29%	17%	6%	7%
Access to a Clinical Nurse Specialist (CNS)	**9%**	-	2%	19%	3%
Financial information	**8%**	10%	17%	7%	6%
End of life care	**2%**	2%	2%	2%	2%
I was not given or directed to information or support	**18%**	11%	9%	24%	17%

Please note the response option 'access to a Clinical Nurse Specialist (CNS)' was shown only to patients in the United Kingdom.

Patients aged 18-25 (91%, n=98) were most likely to report they were given or directed to information and support during their treatment journey, while patients aged 56-65 (81%, n=410) and 76 and over (84%, n=131) were least likely (Table 38). The greatest variances of information provision by age group can be seen for:

- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy: 44% for 18-25 (n=48), compared to just 6% for 76 and over (n=10).
- Written information / booklets / leaflets: 49% for 76 and over (n=76), compared to 16% for 18-25 (n=17).
- Buddying or befriending: 33% for 18-25 (n=36), compared to just 2% for 76 and over (n=3).

Table 38. [Patient] Q78 Please select what information and support you were given or directed to during your treatment journey. Please select all that apply. by age [Multiple choice]

	18-25	26-35	36-45	46-55	56-65	66-75	76+
Base (n=)	108	200	275	332	504	427	156
Side effects and risks of treatment	48%	52%	45%	35%	38%	36%	33%
Written information / booklets / leaflets	16%	21%	23%	35%	43%	46%	49%
Leukemia charities / associations / organizations	34%	25%	25%	27%	34%	31%	36%
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	44%	42%	40%	34%	30%	16%	6%
Patient support groups	34%	31%	21%	29%	32%	27%	31%
General wellbeing (including spiritual wellbeing)	27%	27%	26%	22%	18%	13%	9%
Online forums	24%	12%	15%	19%	20%	20%	24%
Clinical trials	12%	16%	19%	21%	18%	20%	18%
Patient rights	24%	25%	24%	14%	16%	13%	12%
Buddying or befriending	33%	21%	17%	9%	7%	5%	2%
Access to a Clinical Nurse Specialist (CNS)	-	1%	1%	7%	12%	14%	19%
Financial information	7%	11%	9%	8%	9%	7%	6%
End of life care	2%	2%	3%	2%	2%	3%	2%
I was not given or directed to information or support	9%	13%	16%	21%	19%	23%	16%

Please note the response option ‘access to a Clinical Nurse Specialist (CNS)’ was shown only to patients in the United Kingdom.

Analysis by gender finds male patients (85%, n=626) were more likely to be given or directed to information and support during their treatment journey, than female patients (80%, n=890) (Table 39). The greatest variances of information provision by gender can be seen for:

- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy: 33% of female patients (n=366), compared to 26% for male patients (n=188).
- Side effects and risks of treatment: 43% of male patients (n=314), compared to 38% for female patients (n=420).
- Patient support groups: 32% of male patients (n=232), compared to 27% for female patients (n=300).
- Clinical trials: 22% of male patients (n=163), compared to 17% for female patients (n=186).

Table 39. [Patient] Q78 Please select what information and support you were given or directed to during your treatment journey. Please select all that apply. by gender [Multiple choice]

	Male	Female
Base (n=)	736	1,111
Side effects and risks of treatment	43%	38%
Written information / booklets / leaflets	39%	37%
Leukemia charities / associations / organizations	32%	30%
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	26%	33%
Patient support groups	32%	27%
General wellbeing (including spiritual wellbeing)	22%	18%
Online forums	21%	17%
Clinical trials	22%	17%
Patient rights	18%	16%
Buddying or befriending	9%	12%
Access to a Clinical Nurse Specialist (CNS)	11%	8%
Financial information	7%	10%
End of life care	2%	2%
I was not given or directed to information or support	15%	20%

Please note the response option ‘access to a Clinical Nurse Specialist (CNS)’ was shown only to patients in the United Kingdom.

Being given or directed to information or support during the patients treatment journey was more likely in China (87%, n=252) and the United Kingdom (87%, n=260) than in the Netherlands (74%, n=70) (Figure 40). The greatest variances of information provision by country can be seen for:

- Written information / booklets / leaflets: 59% in the United Kingdom (n=178), compared to 11% in Brazil (n=22) and 12% in China (n=35).
- Leukemia charities / associations / organizations: 50% in the United Kingdom (n=150), compared to 12% in the Netherlands (n=11).
- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy: 55% in Brazil (n=112), compared to 19% in the United Kingdom (n=58).

Table 40. [Patient] Q78 Please select what information and support you were given or directed to during your treatment journey. Please select all that apply. by country [Multiple choice]

	Brazil	China	Denmark	Israel	Netherlands	United Kingdom	United States of America
Base (n=)	204	289	116	128	94	300	172
Side effects and risks of treatment	44%	44%	44%	27%	31%	32%	46%
Written information / booklets / leaflets	11%	12%	47%	26%	35%	59%	51%
Leukemia charities / associations / organizations	20%	26%	22%	24%	12%	50%	35%
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	55%	30%	28%	26%	28%	19%	23%
Patient support groups	15%	31%	21%	33%	33%	30%	31%
General wellbeing (including spiritual wellbeing)	32%	27%	16%	7%	7%	12%	17%
Online forums	8%	15%	10%	17%	28%	22%	27%
Clinical trials	13%	13%	16%	10%	24%	19%	17%
Patient rights	28%	21%	16%	27%	1%	4%	31%
Buddying or befriending	28%	26%	3%	7%	0%	4%	2%
Access to a Clinical Nurse Specialist (CNS)	-	-	-	-	-	59%	-
Financial information	7%	7%	7%	5%	0%	6%	23%
End of life care	2%	1%	1%	0%	0%	1%	3%
I was not given or directed to information or support	21%	13%	25%	23%	26%	13%	20%

Please note the response option ‘access to a Clinical Nurse Specialist (CNS)’ was shown only to patients in the United Kingdom.

Patients who were given or directed to information or support during their treatment journey were asked when they received this. As shown in Figure 130 and Figure 131, provision of information varied widely throughout the treatment journey:

- Patients were most likely to be given or directed to information and support during treatment, with 9 of the 13 types of information or support most likely to be received during this stage of the treatment journey.
- At diagnosis, it was most likely for patients to receive information and support relating to access to a Clinical Nurse Specialist (CNS) (UK patients only) (44%, n=72), patient rights (44%, n=134) and written information / booklets / leaflets (51%, n=315).
- Importantly, information provision about side effects and risks of treatment was most likely to be received after diagnosis, but before treatment started (50%, n=368).
- Patients were least likely to be given or directed to information and support after their treatment had finished. Just 4% (n=6) of patients who were directed to financial information were provided this after their treatment had finished.
- Information provision for 'watch and wait' or 'active monitoring' was limited (CLL patients only). Just 9% (n=50) of patients who were directed to mental wellbeing support received this during 'watch and wait' or 'active monitoring'.

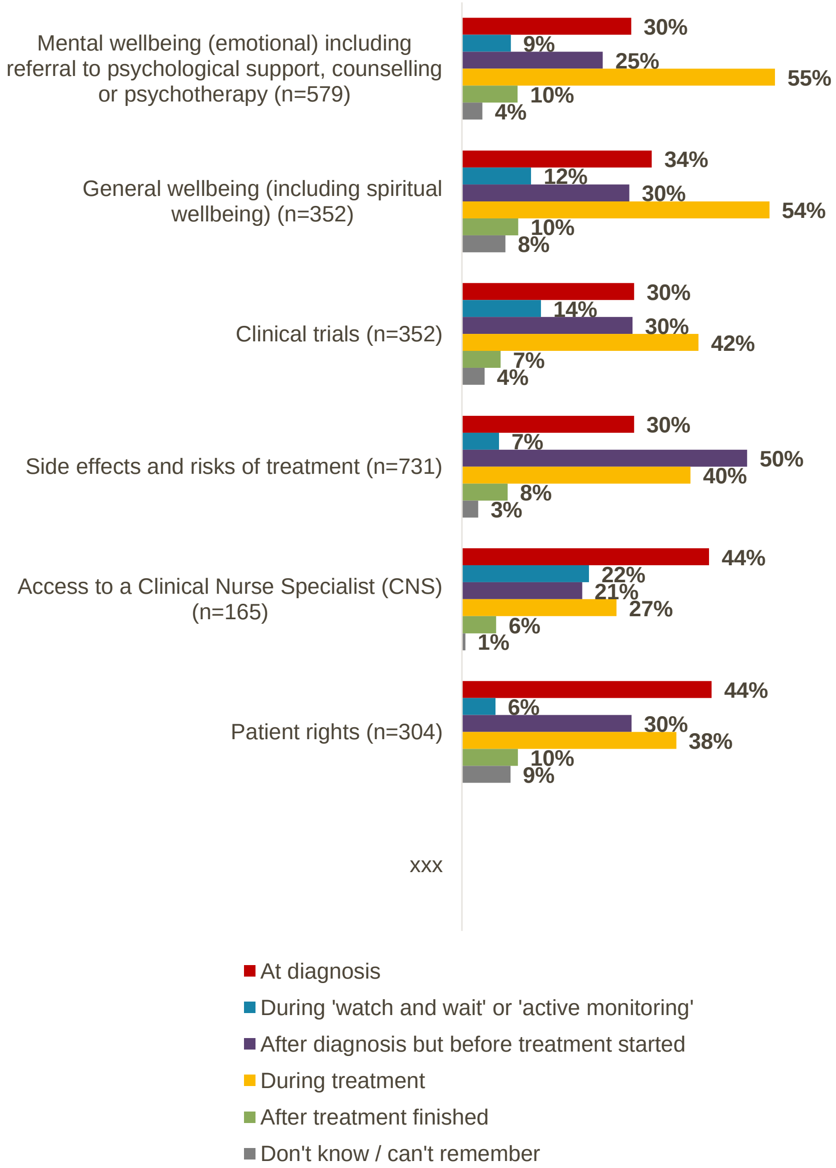
Patients who were given or directed to information or support during their treatment journey were then asked if they had accessed this information or support, and whether doing so helped them. Positively, the majority of patients (more than 50%) who accessed each type of support said it helped them feel better or more positive (Please note the response option ‘during ‘watch and wait’ or ‘active monitoring’ was shown only to patients with CLL.
Figure 132; Figure 133). Patients were most likely to say the following types of information and support helped them feel better or more positive:

- Buddying or befriending (79%, n=166)
- Online forums (78%, n=275)
- Patient support groups (76%, n=410)
- Leukemia charities / associations / organizations (76%, n=431)

Information and support related to side effects and risks of treatment (32%, n=237) had the highest proportion of patients who said they accessed this, but it did not help them feel any better or more positive. Patients were least likely to access end of life care support (23%, n=9).

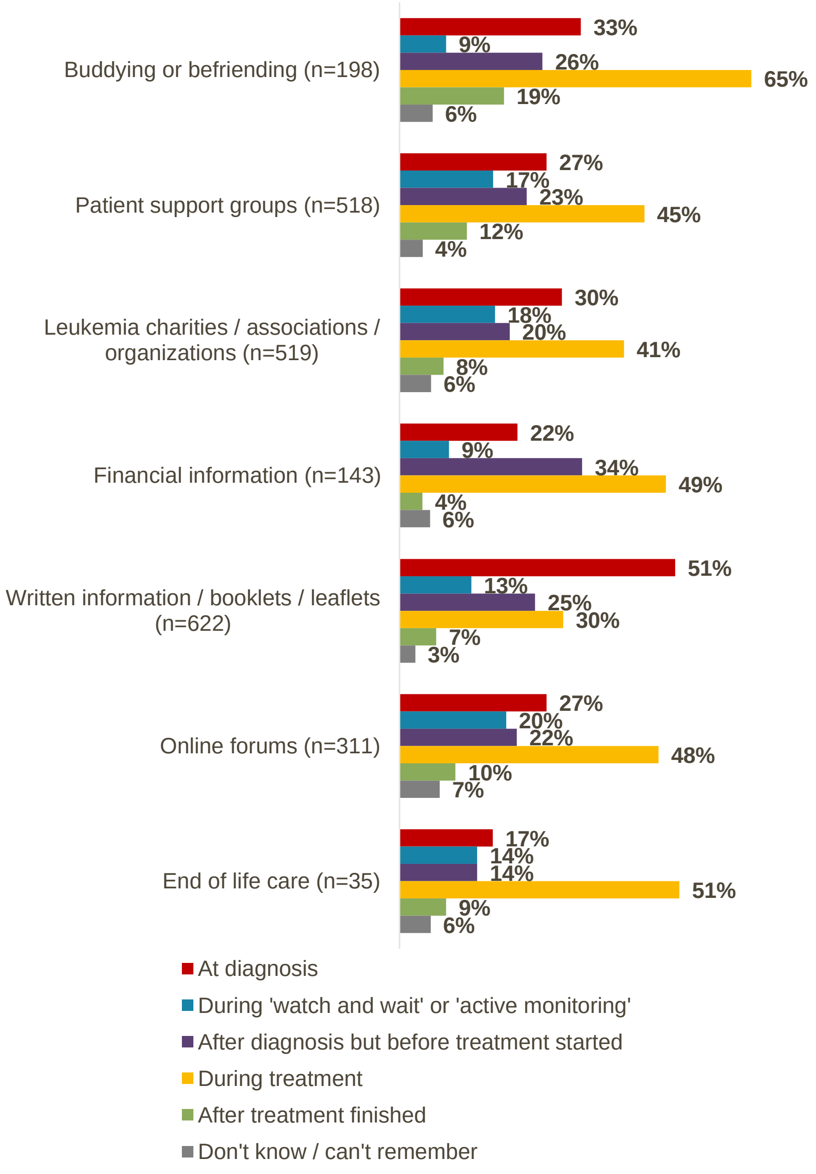
See Appendix 8 and Appendix 9 for breakdown by leukemia type.

Figure 130. [Patient] Q79 When in your treatment journey were you given or directed to the information and support? [Multiple choice] – Part A



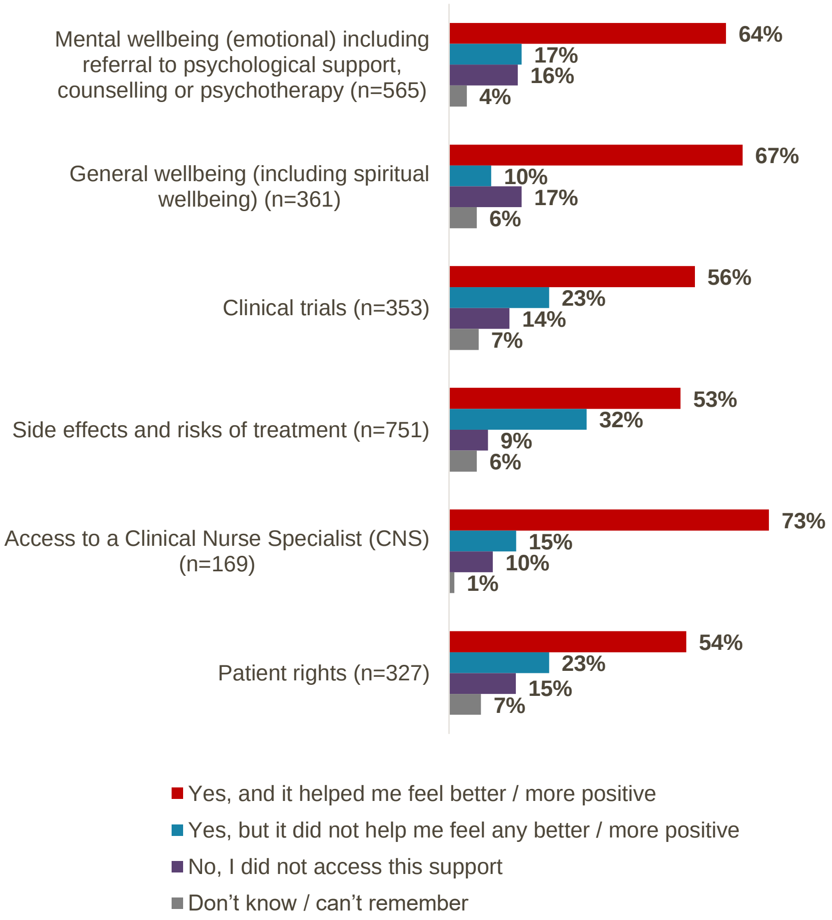
Please note the response option 'during 'watch and wait' or 'active monitoring' was shown only to patients with CLL and 'access to a clinical nurse specialist (CNS) was shown only to UK patients.

Figure 131. [Patient] Q79 When in your treatment journey were you given or directed to the information and support? [Multiple choice] – Part B



Please note the response option ‘during ‘watch and wait’ or ‘active monitoring’ was shown only to patients with CLL.

Figure 132. [Patient] Q80 Did you access this support and did it help you? - Part A



Please note the response option 'access to a clinical nurse specialist (CNS) was shown only to UK patients.

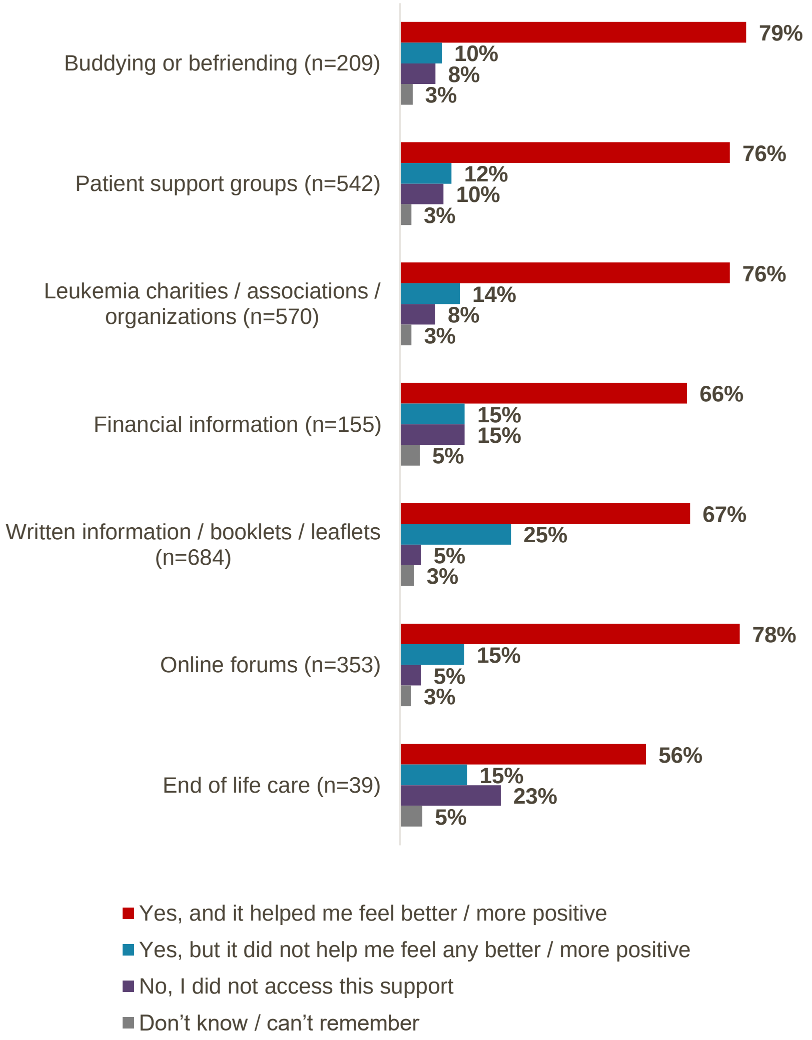


Figure 133. [Patient] Q80 Did you access this support and did it help you? - Part B

Provision of information and support to carers

82% (n=514) of carers were given or directed to information or support during the patient's treatment journey (Table 41). This is the same proportion as reported by patients (82%, n=1,649). The most common resources carers were given or directed to were:

- Side effects and risks of treatment (49%, n=307)
- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy (32%, n=200)
- Written information / booklets / leaflets (28%, n=178)
- Leukemia charities / associations / organizations (26%, n=162)
- General wellbeing (including spiritual wellbeing) (26%, n=162)

In a similar trend as was reported by patients, carers for those with acute leukemia were more likely to be given or directed to resources (91% for ALL, n=169; 86% for AML, n=138) than those caring for patients with chronic leukemia (67% for CLL, n=66; 72% for CML, n=92).

Table 41. [Carer] C35 Please select what information and support you were given or directed to during the patient's treatment journey. Please select all that apply. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**627**	185	160	98	128
Side effects and risks of treatment	**49%**	58%	53%	33%	44%
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	**32%**	39%	36%	22%	20%
Written information / booklets / leaflets	**28%**	26%	28%	37%	27%
General wellbeing (including spiritual wellbeing)	**26%**	32%	27%	18%	20%
Leukemia charities / associations / organizations	**26%**	28%	29%	23%	23%
Patient support groups	**23%**	23%	22%	22%	23%
Clinical trials	**22%**	24%	24%	21%	16%
Patient rights	**21%**	25%	23%	10%	16%
Buddying or befriending	**20%**	34%	16%	4%	12%
Financial information	**14%**	22%	14%	7%	7%
Online forums	**11%**	9%	10%	15%	14%
End of life care	**5%**	4%	7%	5%	3%
Access to a Clinical Nurse Specialist (CNS)	**3%**	1%	1%	11%	0%
I was not given or directed to information or support	**18%**	9%	14%	33%	28%

Please note the response option ‘access to a Clinical Nurse Specialist (CNS)’ was shown only to patients in the United Kingdom.

Carers who were given or directed to information or support during the patient's treatment journey were asked when they received this. As shown in Figure 134 and Figure 135:

- Carers were most likely to be given or directed to information and support during treatment. Almost all types of information or support that were listed were most likely to be received during this stage of the treatment journey. The one exception being end of life care information, which was jointly received during treatment (39%, n=12) and after treatment finished (39%, n=12).
- Carers were least likely to be given or directed to information and support during 'watch and wait' or 'active monitoring' (CLL patients only). All reported types of information or support were least likely to be received during this stage of the treatment journey. Specifically, 0 carers reported they were given or directed to information or support related to buddying or befriending during 'watch and wait' or 'active monitoring'.

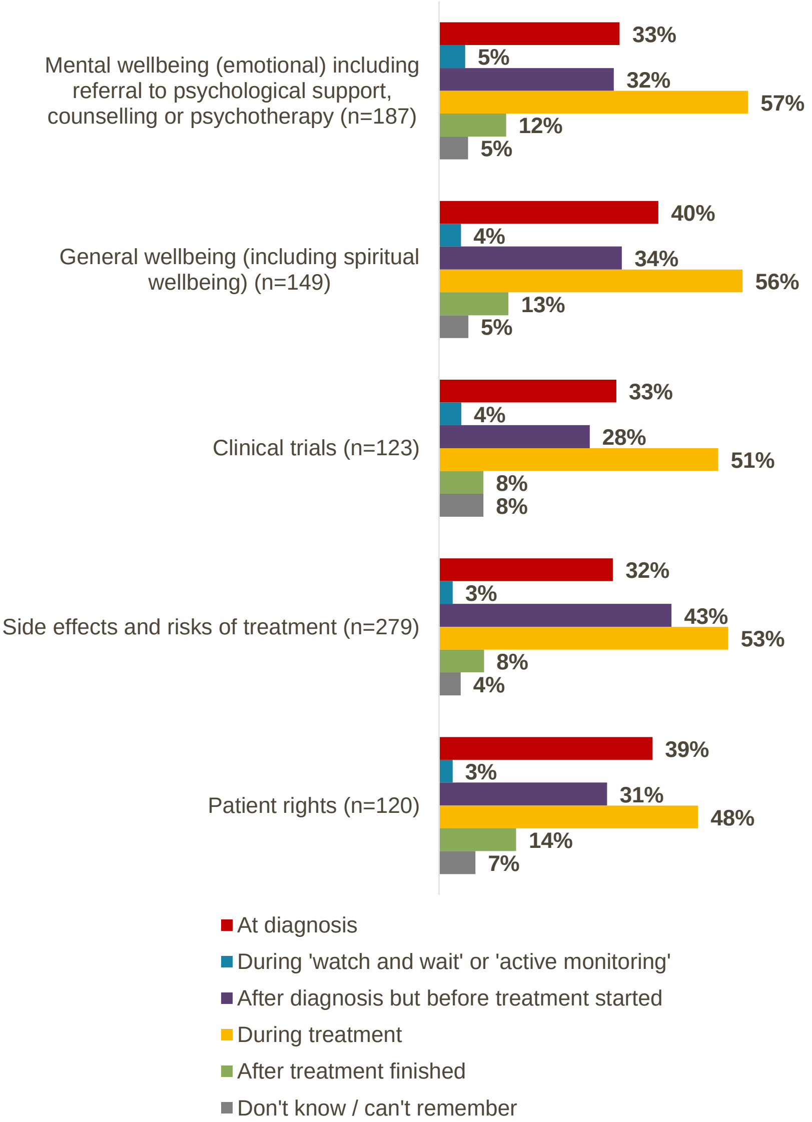
Carers who were given or directed to information or support during the patient's treatment journey were then asked if they had accessed this information or support, and whether doing so helped them (Figure 136; Figure 137). Carers were most likely to say the following types of information and support helped them feel better or more positive:

- Buddying or befriending (83%, n=95).
- Leukemia charities / associations / organizations (72%, n=108).
- Patient support groups (68%, n=89).
- Online forums (68%, n=44).
- General wellbeing (including spiritual wellbeing) (66%, n=98).

In a similar trend as reported by patients, information and support related to side effects and risks of treatment (43%, n=124) had the highest proportion of carers who said they accessed this, but it did not help them feel any better or more positive. Carers were least likely to access end of life care support (28%, n=9).

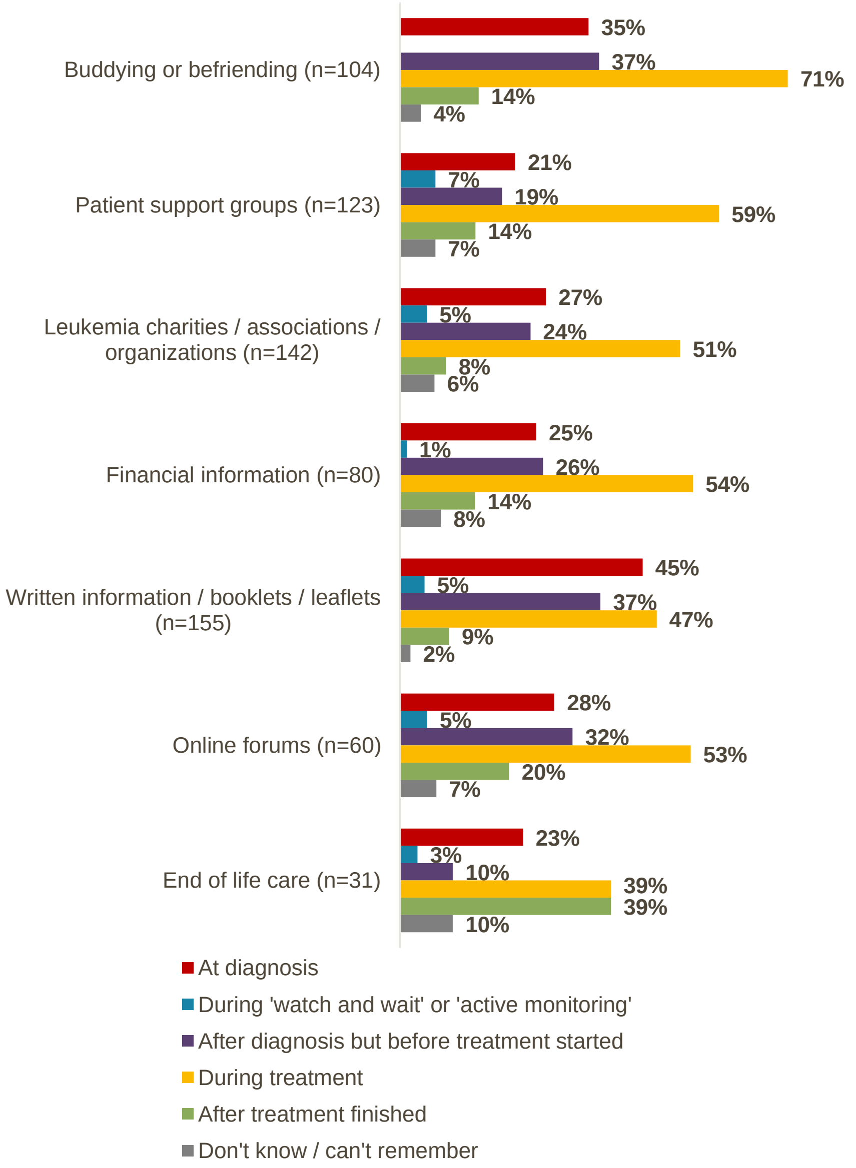
See Appendix 10 and Appendix 11 for breakdown by leukemia type.

Figure 134. [Carer] C36 When in the patient's treatment journey were you given or directed to the information and support? [Multiple choice] – Part A



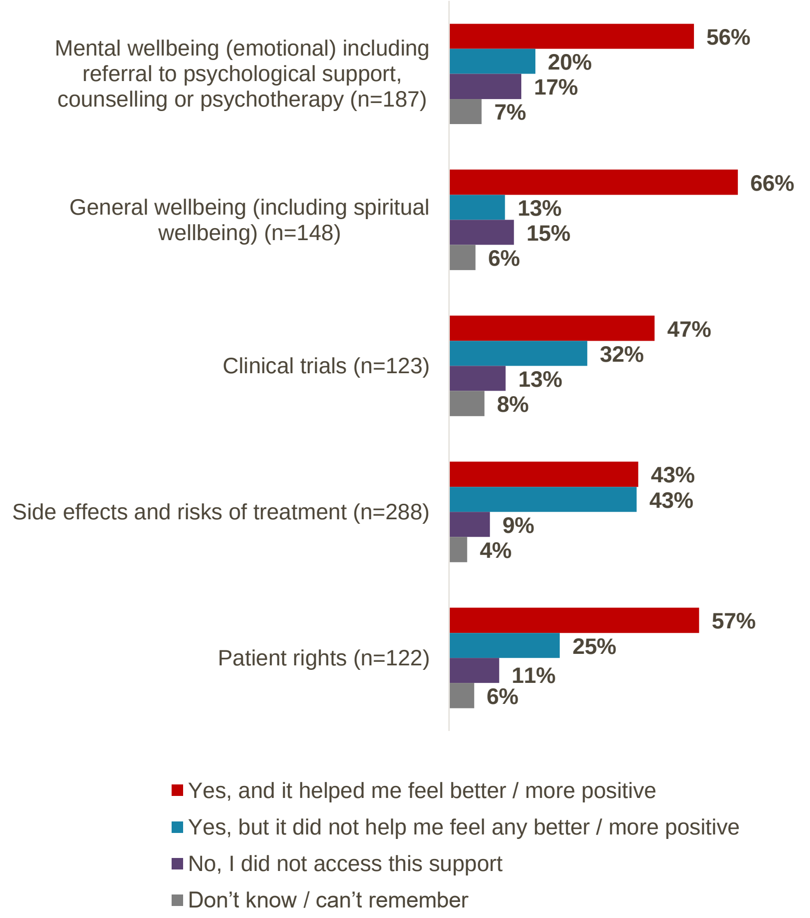
Please note the response option ‘during ‘watch and wait’ or ‘active monitoring’ was shown only to CLL carers and ‘access to a clinical nurse specialist (CNS) was shown only to UK carers. Please note less than 30 carers selected ‘access to a Clinical Nurse Specialist (CNS)’ which falls below the reporting threshold. Consequently, this response option has not been reported in the analysis of C36.

Figure 135. [Carer] C36 When in the patient's treatment journey were you given or directed to the information and support? [Multiple choice] - Part B



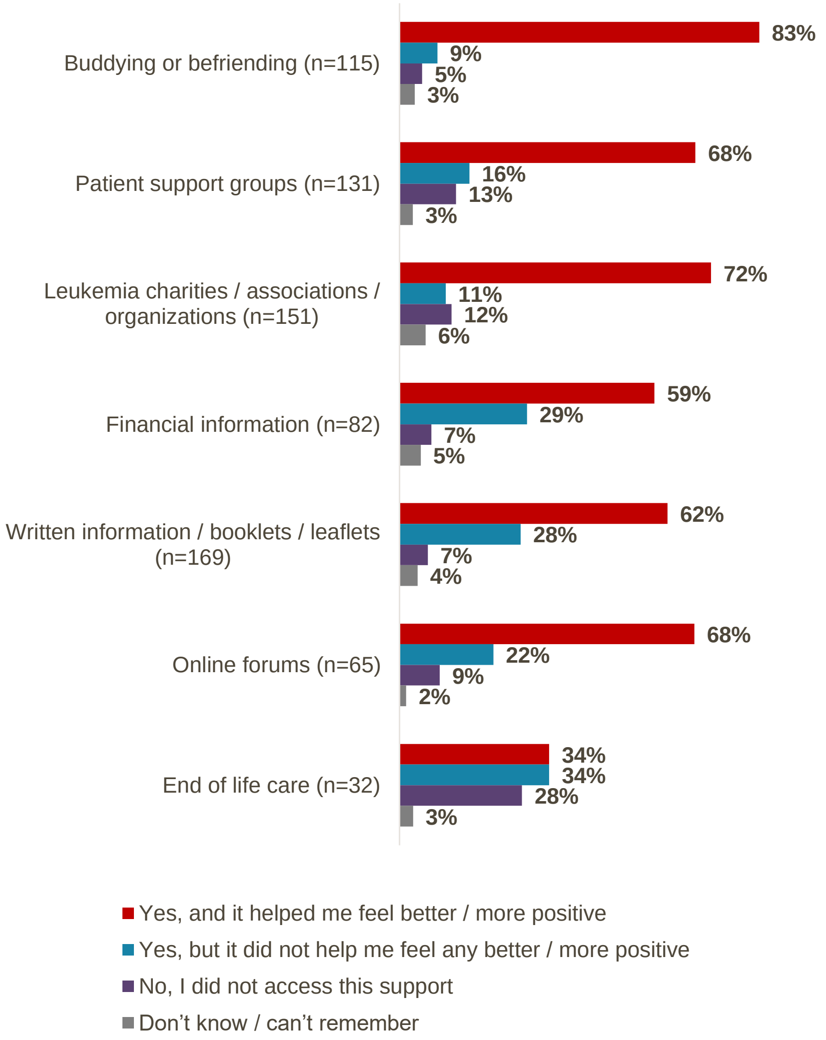
Please note the response option ‘during ‘watch and wait’ or ‘active monitoring’ was shown only to CLL carers.

Figure 136. [Carer] C37 Did you access this support and did it help you? – Part A



Please note the response option ‘access to a clinical nurse specialist (CNS) was shown only to UK carers. Please note less than 30 carers selected ‘access to a Clinical Nurse Specialist (CNS)’ which falls below the reporting threshold. Consequently, this response option has not been reported in the analysis of C37.

Figure 137. [Carer] C37 Did you access this support and did it help you? - Part B



Conducting own research

The majority of patients (91%, n=1,839) conducted their own research into varying stages of their treatment journey. Patients were most likely to research diagnosis (75%, n=1,516), treatments available (70%, n=1,419) and side effects (68%, n=1,380) (Table 42).

Patients with chronic leukemia (92% for CLL, n=713; 93% for CML, n=562) were slightly more likely to report they conducted their own research than patients with acute leukemia (88% for ALL, n=199; 87% for AML, n=250).

Table 42. [Patient] Q82 Did you conduct any of your own research into any of the following? Please select all that apply. This can include internet searches, reading research articles, listening to podcasts and videos etc. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**2,025**	225	288	776	607
Diagnosis	**75%**	66%	65%	80%	77%
Treatments available	**70%**	64%	58%	74%	75%
Clinical trials	**36%**	25%	22%	42%	41%
Testing and monitoring (incl. results)	**53%**	56%	47%	56%	51%
Side effects	**68%**	64%	59%	64%	79%
Other	**7%**	2%	5%	8%	8%
No, I did not conduct my own research	**9%**	12%	13%	8%	7%

While the proportion of patients who conducted their own research was high in all countries, it was lowest in Israel (81%, n=108) (Table 43). Research of each aspect varied by country, for example, researching clinical trials was twice as likely in the United States of America (47%, n=82) than in China (21%, n=60).

Table 43. [Patient] Q82 Did you conduct any of your own research into any of the following? Please select all that apply. This can include internet searches, reading research articles, listening to podcasts and videos etc. by country [Multiple choice]

Base (n=)	Brazil 208	China 289	Denmark 115	Israel 133	Netherlands 95	United Kingdom 299	United States of America 173
Diagnosis	85%	63%	84%	56%	84%	81%	84%
Treatments available	75%	67%	53%	62%	72%	76%	82%
Clinical trials	45%	21%	25%	17%	42%	42%	47%
Testing and monitoring (incl. results)	56%	65%	36%	29%	54%	56%	75%
Side effects	76%	55%	70%	60%	72%	66%	79%
Other	4%	1%	5%	4%	11%	9%	14%
No, I did not conduct my own research	5%	11%	9%	19%	6%	6%	6%

90% of carers (n=542) reported that they conducted their own research into varying stages of the patient’s treatment journey. Carers were most likely to research the same three topics as patients: diagnosis (74%, n=450), treatments available (73%, n=439) and side effects (70%, n=421) (Table 44).

Table 44. [Carer] C38 Did you conduct any of your own research into any of the following? Please select all that apply. This can include internet searches, reading research articles, listening to podcasts and videos etc. [Multiple choice]

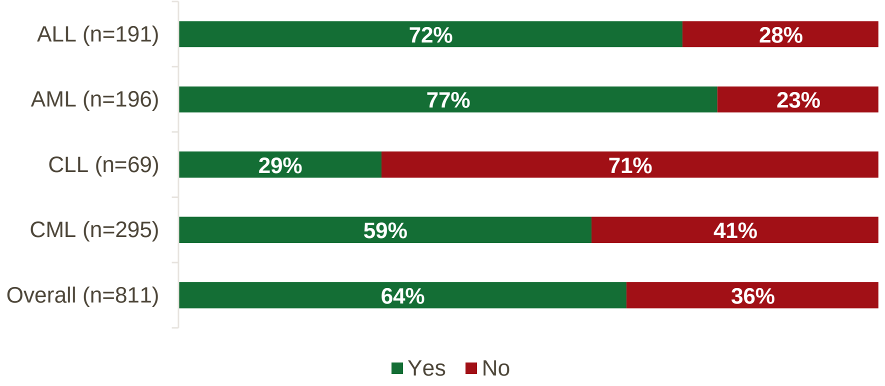
Base (n=)	**Overall** **605**	ALL 174	AML 153	CLL 100	CML 124
Diagnosis	**74%**	80%	73%	71%	72%
Treatments available	**73%**	75%	72%	65%	76%
Clinical trials	**43%**	50%	41%	41%	40%
Testing and monitoring (incl. results)	**55%**	64%	48%	54%	54%
Side effects	**70%**	80%	63%	56%	76%
Other (please specify)	**7%**	5%	3%	11%	11%
No, I did not conduct my own research	**10%**	5%	14%	14%	10%

Information about impact on fertility

Patients aged 18 to 55 were asked if someone spoke to them about the impact treatment could have on their fertility. Overall, 64% (n=519) of patients reported they had a conversation about the impact treatment may have on their fertility, while 36% (n=292) did not (Figure 138).

Patients with acute leukemia (72% for ALL, n=138; 77% for AML, n=150) were much more likely to report someone spoke to them about the impact treatment could have on their fertility, than patients with chronic leukemia (29% for CLL, n=20; 59% for CML, n=174).

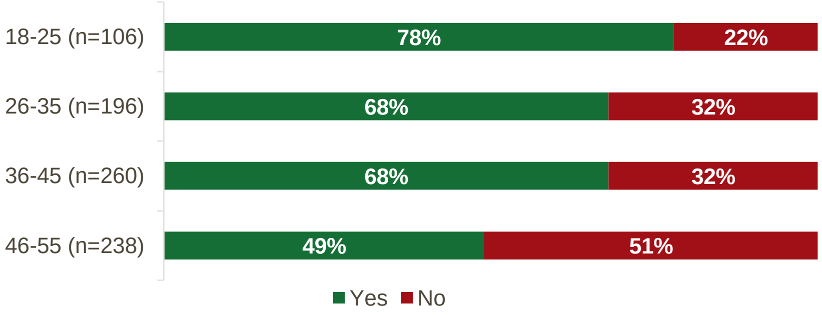
Figure 138. [Patient] Q76 Did someone speak to you about the impact treatment could have on your fertility? [Derived]



Please note patients who answered 'don't know / can't remember' (n=37) or 'not applicable' (n=108) were removed from analysis for Q76

Analysis by age finds patients aged 18-25 (78%, n=83) were more likely to report someone spoke to them about the impact treatment could have on their fertility, compared to other age groups (Figure 139).

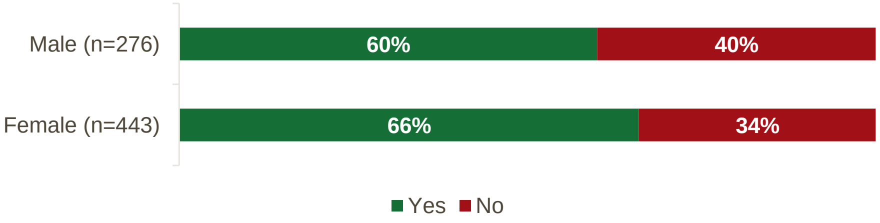
Figure 139. [Patient] Q76 Did someone speak to you about the impact treatment could have on your fertility? by age [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=37) or ‘not applicable’ (n=108) were removed from analysis for Q76

Female patients (66%, n=294) were more likely to report someone spoke to them about the impact treatment could have on their fertility, than male patients (60%, n=165) (Figure 140).

Figure 140. [Patient] Q76 Did someone speak to you about the impact treatment could have on your fertility? by gender [Derived]



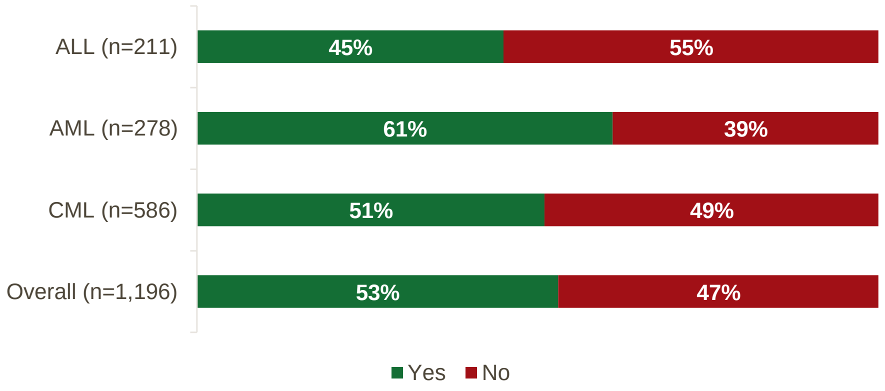
Please note patients who answered ‘don't know / can't remember’ (n=37) or ‘not applicable’ (n=108) were removed from analysis for Q76

Immunizations / vaccinations

Patients with ALL, AML, and CML were asked if a health professional had spoken to them about immunizations or vaccinations, including which they should receive and which they should avoid. Overall, 53% (n=630) of patients reported they had a conversation with a health professional about immunizations or vaccinations (Figure 141). CLL patients were asked about immunizations or vaccinations in the testing and monitoring section, and 39% (n=307) of patients with CLL reported they received complete information from a health professional about the protocols for CLL immunizations / vaccinations, including which they should receive and which they should avoid (Figure 125) .

Patients with AML (61%, n=169) were most likely to report they had a conversation with a health professional about immunizations or vaccinations, followed by patients with CML (51%, n=296) and ALL (45%, n=96).

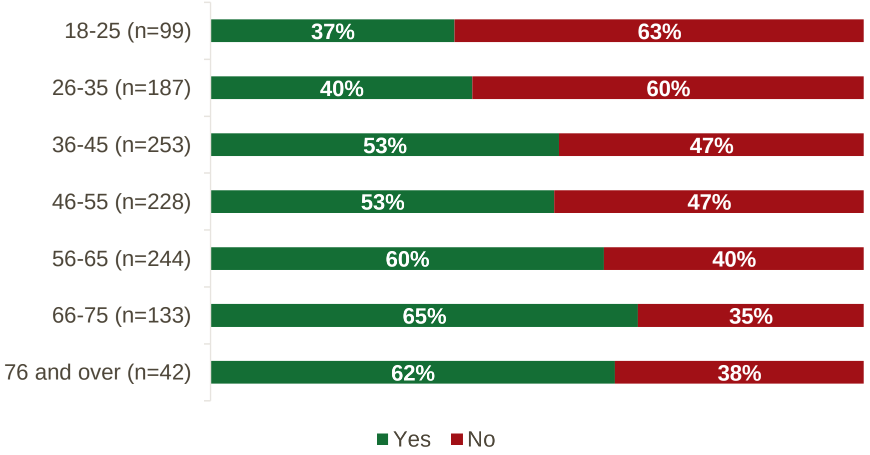
Figure 141. [Patient] Q77 Has a health professional spoken to you about immunizations / vaccinations, including which you should receive and which you should avoid? [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=76) were removed from analysis for Q77

Patients aged 18-25 (37%, n=37) and 26-35 (40%, n=75) were far less likely to report they had a conversation with a health professional about immunizations or vaccinations, compared to older age groups (Figure 142).

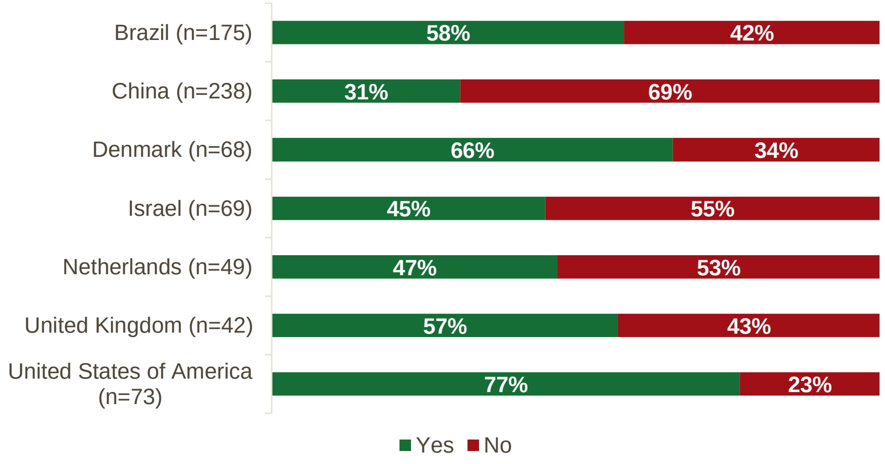
Figure 142. Q77 Has a health professional spoken to you about immunizations / vaccinations, including which you should receive and which you should avoid? by age [Derived]



Please note patients who answered ‘don't know / can't remember’ (n=76) were removed from analysis for Q77

As displayed in Figure 143, experience of having had a conversation with a health professional about immunizations or vaccinations varies widely by country. Patients living in the United States of America (77%, n=56) were more than twice as likely to have had a conversation with a health professional about immunizations or vaccinations than patients living in China (31%, n=73).

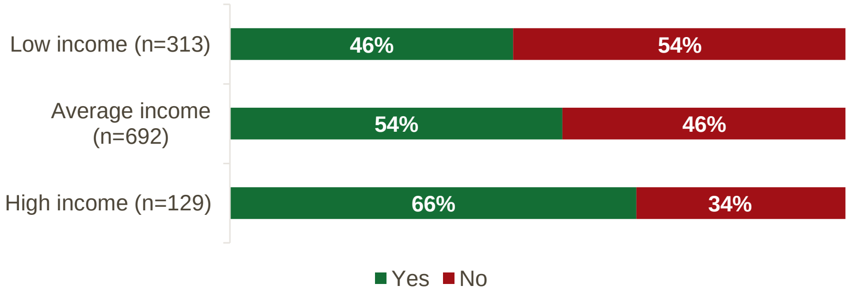
Figure 143. Q77 Has a health professional spoken to you about immunizations / vaccinations, including which you should receive and which you should avoid? by country [Derived]



Please note patients who answered 'don't know / can't remember' (n=76) were removed from analysis for Q77

Two thirds of patients (66%, n=85) living in a high-income household to have had a conversation with a health professional about immunizations or vaccinations. This is compared to 54% (n=377) of patients living in an average income household, and 46% (n=145) of patients living in a low-income household (Figure 144).

Figure 144. Q77 Has a health professional spoken to you about immunizations / vaccinations, including which you should receive and which you should avoid? by annual household income [Derived]



Please note patients who answered 'don't know / can't remember' (n=76) were removed from analysis for Q77

Global Leukemia Experience Survey 2023

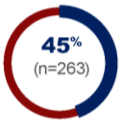
Quality of Life

Quality of life

Quality of life: 1 of 4

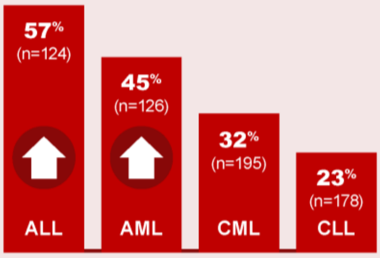
Impact of disease and treatment on the quality of life of a patient

1/3 of patients reported their disease and treatment had a moderate to severe impact on their quality of life.

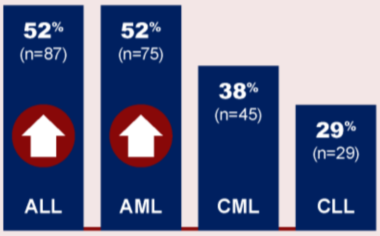


Interestingly, carers reported a greater impact on patient's quality of life than patients did.

Patients with acute leukemia reported a greater impact on their quality of life than patients with chronic leukemia.



This trend was also evident in the carer data reporting a moderate to severe impact.



Patients that were most likely to indicate they experienced a moderate to severe impact on their quality of life if they were:

- **18-25 years** **56%** (n=57) Younger patients aged 18-25.
- **37%** (n=412) Female.
- **53%** (n=224) Lived in a low-income household.

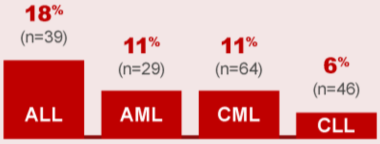
Quality of life: 2 of 4

Signs and symptoms

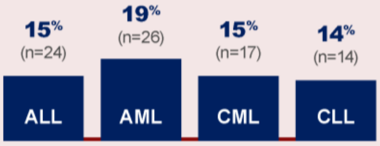
1/10 of patients reported the symptoms and / or side effects they experienced had a moderate to severe impact on their quality of life.

of carers who reported that the person they care for had been moderately to severely impacted by symptoms and / or side effects.

Patients reported their **disease symptoms or treatment side effects had a moderate to severe impact** on their quality of life.

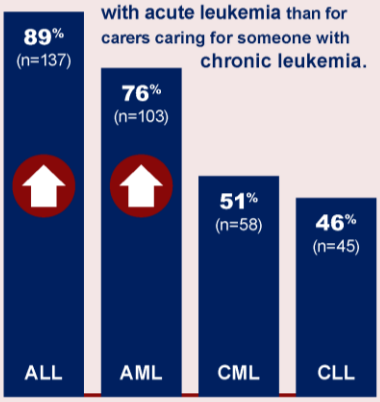


Carer response **differed to patient reported impact:**



Impact on quality of life in family members / carers

Impact on carers quality of life was greater for carers caring for someone **with acute leukemia** than for carers caring for someone with **chronic leukemia.**

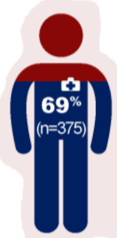


Carers were most likely to experience a moderate to extremely large effect on their quality of life if they were:

- 26-35 years — **79%** (n=77) **Younger carers aged 26-35.**
- ♀ — **75%** (n=279) **Female carers.**
- 36-45 years — **79%** (n=46) **Patient was younger.** (For carers looking after someone aged 36-45).
- ♂ — **72%** (n=207) **Patient is male.**

Quality of life: 3 of 4

Impact on quality of life in family members / carers



of carers have experienced **a moderate to extremely large effect on their quality of life** as a result of the person they care for having leukemia.

Quality of life

Patients with ALL, who were younger, and female consistently reported the greatest impact on their sense of emotional wellbeing since their diagnosis.

Patients reporting they always, very often, or sometimes experience general anxiety since their diagnosis:

- ALL patient — **80%** (n=168) **ALL patients.**
- 26-35 years — **79%** (n=148) **Patients aged 26-35.**
- ♀ — **71%** (n=752) **Female patients.**

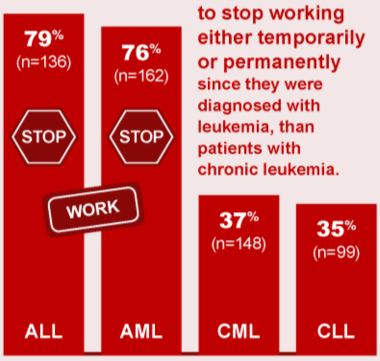
Impact on work

52% (n=595) of patients **have had to stop working** either temporarily or permanently since they were diagnosed with leukemia.

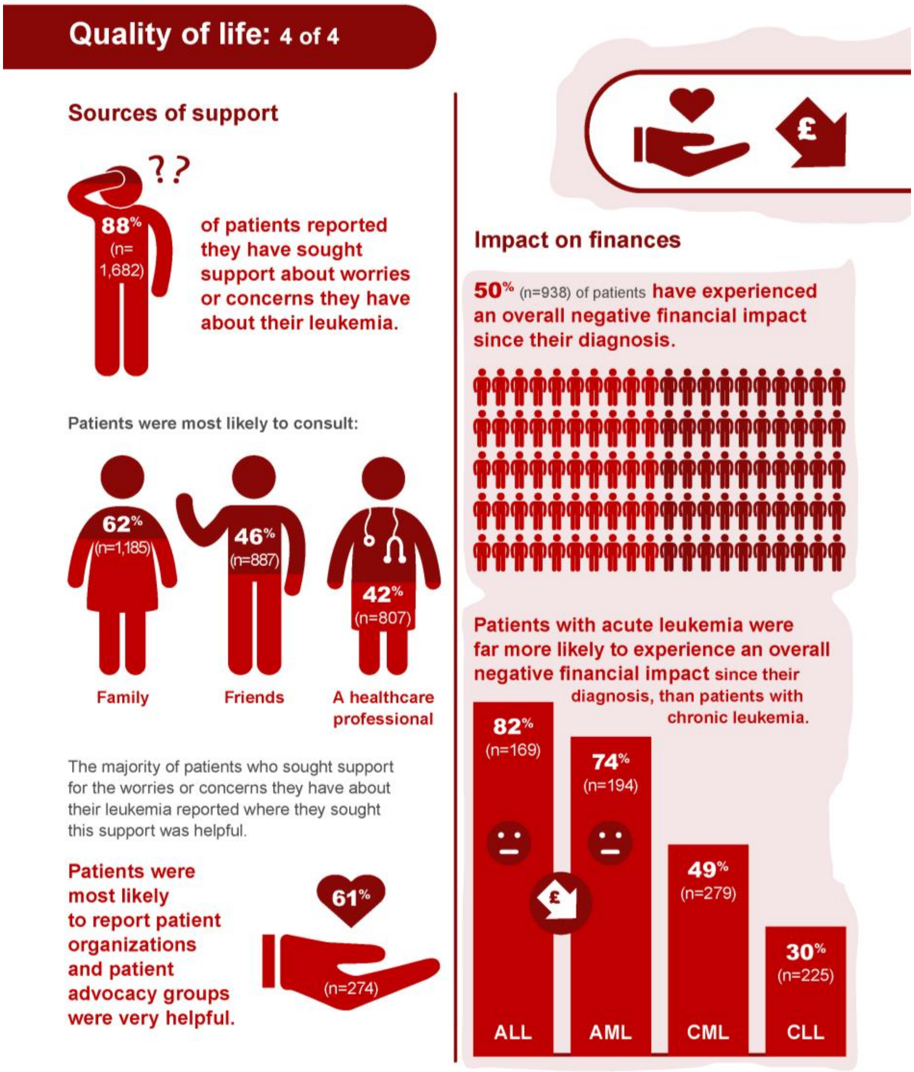
21% (n=246) have had to **reduce** their working hours.

27% (n=306) **continued** to work as normal.

Patients with acute leukemia were more than twice as likely to have to stop working either temporarily or permanently since they were diagnosed with leukemia, than patients with chronic leukemia.



Male patients were more likely to continue to work as normal since their diagnosis, than female patients.



Quality of life: 4 of 4

Sources of support

88% (n=1,682) of patients reported they have sought support about worries or concerns they have about their leukemia.

Patients were most likely to consult:

- Family: **62%** (n=1,185)
- Friends: **46%** (n=887)
- A healthcare professional: **42%** (n=807)

The majority of patients who sought support for the worries or concerns they have about their leukemia reported where they sought this support was helpful.

Patients were most likely to report patient organizations and patient advocacy groups were very helpful. **61%** (n=274)

Impact on finances

50% (n=938) of patients **have experienced an overall negative financial impact since their diagnosis.**

Patients with acute leukemia were far more likely to experience an overall negative financial impact since their **diagnosis, than patients with chronic leukemia.**

- ALL: **82%** (n=169)
- AML: **74%** (n=194)
- CML: **49%** (n=279)
- CLL: **30%** (n=225)

HM-PRO

The Hematological Malignancy Patient-Reported Outcome Measure (HM-PRO)[5] is a validated questionnaire. It is a composite measure combining impact of disease and treatment on the quality of life of a patient, Part A, and the resulting signs and symptoms, Part B.

HM-PRO is the only generic hematological malignancy specific patient-reported outcome measure covering quality of life and symptoms. It has been developed directly from the experience of patients, for patients.

The HM-PRO has 24 items in Part A and 18 items in Part B. The score range for Part A is 0-48 and for Part B is 0-36. The higher the total score, the greater the effect on a patient's quality of life.

The HM-PRO was included in both the patient and carer surveys. Carers were asked to complete the HM-PRO to show what they thought about the patient experience.

HM-PRO Part A - Impact of disease and treatment on the quality of life of a patient

Overall, one third of patients (34%, n=679) reported their disease and treatment had a moderate to severe impact on their quality of life (scoring 19 or above out of 48). Interestingly, carers reported a greater impact on patient's quality of life (45%, n=263) than patients did.

Patients with acute leukemia (57% for ALL, n=124; 45% for AML, n=126) reported a greater impact on their quality of life than patients with chronic leukemia (23% for CLL, n=178; 32% for CML, n=195). This trend was also evident in the carer data, with 52% (n=87) for ALL, 52% (n=75) for AML, compared to 29% (n=29) for CLL and 38% (n=45) for CML reporting a moderate to severe impact (Figure 145; Figure 146).

As age increases, the proportion of patients reporting a moderate to severe impact on their quality of life decreases. 56% (n=57) of patients aged 18-25 reported a moderate to severe impact, compared to 12% (n=19) of patients aged 76 and older. Interestingly, this trend was not evident in carer data. 46% (n=25) of carers caring for a patient aged 18-25 reported a moderate to severe impact, a similar proportion as for those caring for someone 76 and older (47%, n=18) (Figure 147; Figure 148).

Female patients (37%, n=412) were more likely to report a moderate to severe impact on their quality of life, than male patients (27%, n=198). Interestingly, within the carer reported data, the scores for male and female patients were almost identical (Figure 149; Figure 150).

Reported impact of disease and treatment on quality of life varied by country. 54% (n=149) of patients in China reported a moderate to severe impact, compared to 23% (n=69) in the United Kingdom, and 24% (n=24) in the Netherlands (Figure 151).

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[5] HM-PRO, https://hmpro.co.uk/ [accessed: 16 May 2024]

More than half of patients living in a low-income household (53%, n=224) reported a moderate to severe impact on their quality of life. This proportion is much higher than reported for patients living in an average income household (30%, n=357) or high-income household (21%, n=57) (Figure 152).

Figure 145. [Patient] HM-PRO PART A

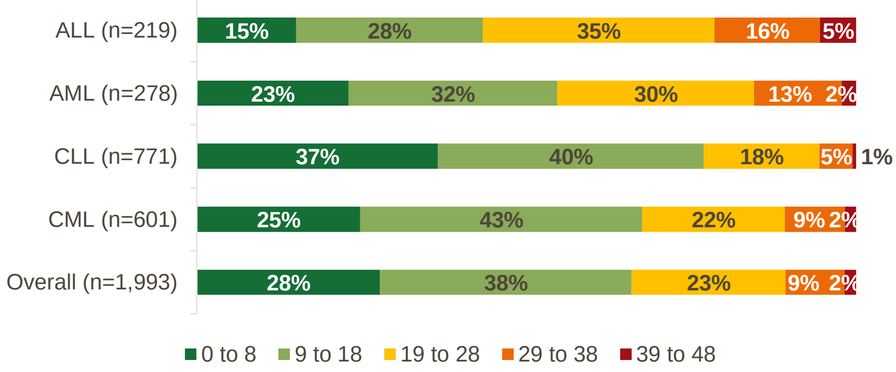


Figure 146. Figure 146. [Carer] HM-PRO PART A

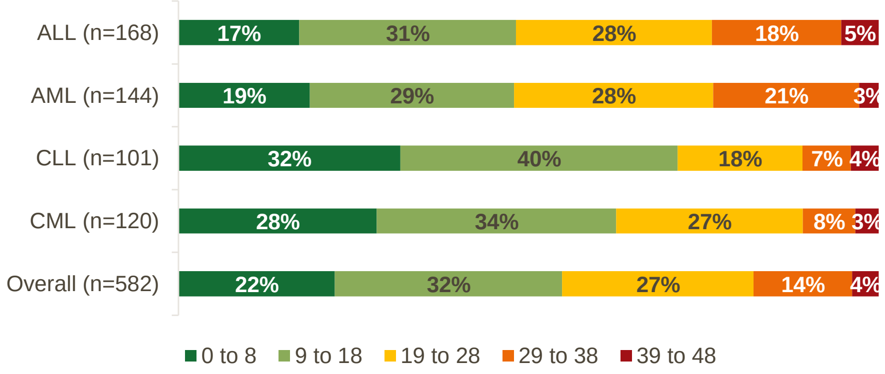


Figure 147. [Patient] HM-PRO PART A by age

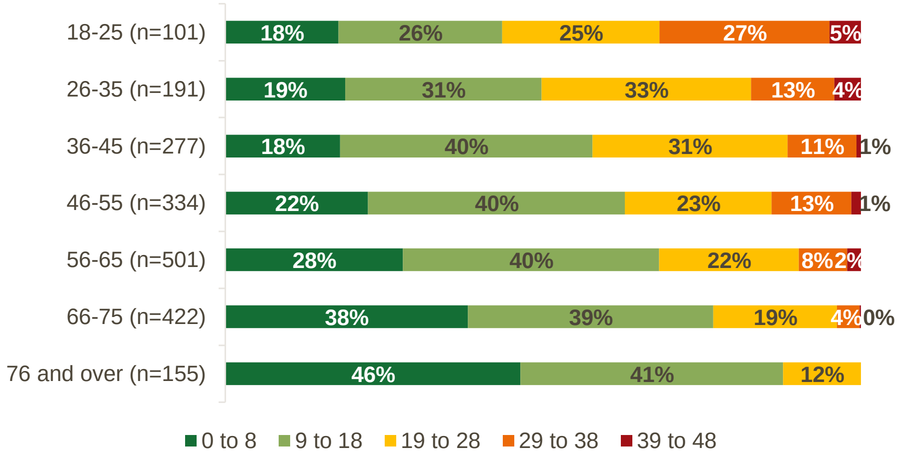


Figure 148. [Carer] HM-PRO PART A by patient age

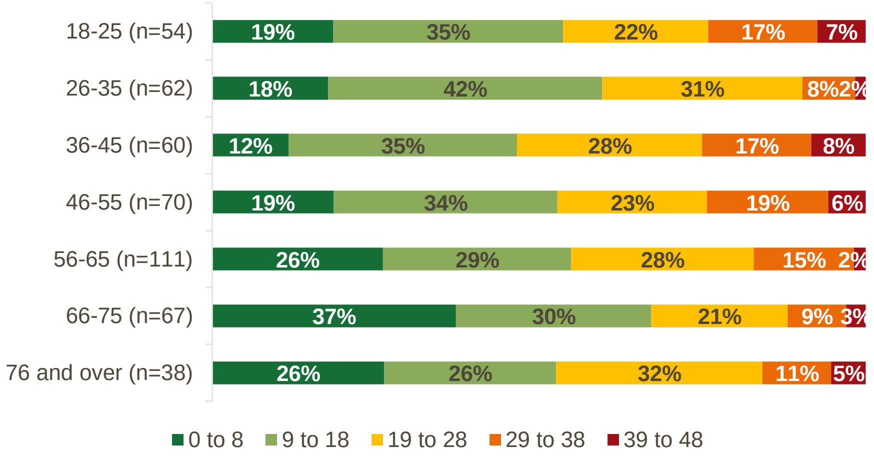


Figure 149. [Patient] HM-PRO PART A by gender

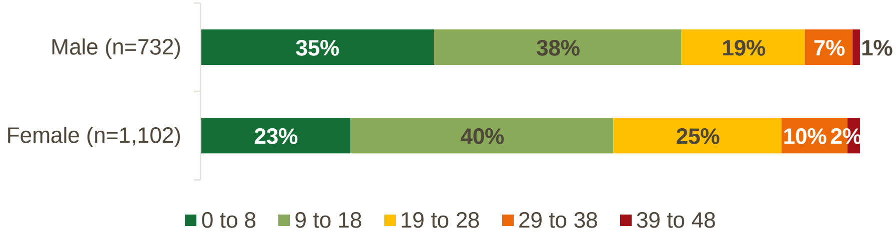


Figure 150. [Carer] HM-PRO PART A by patient gender

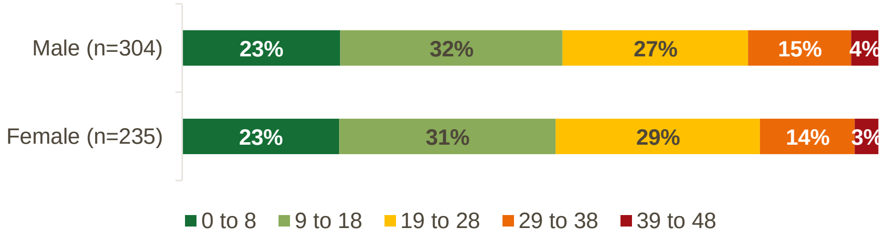


Figure 151. [Patient] HM-PRO PART A by country

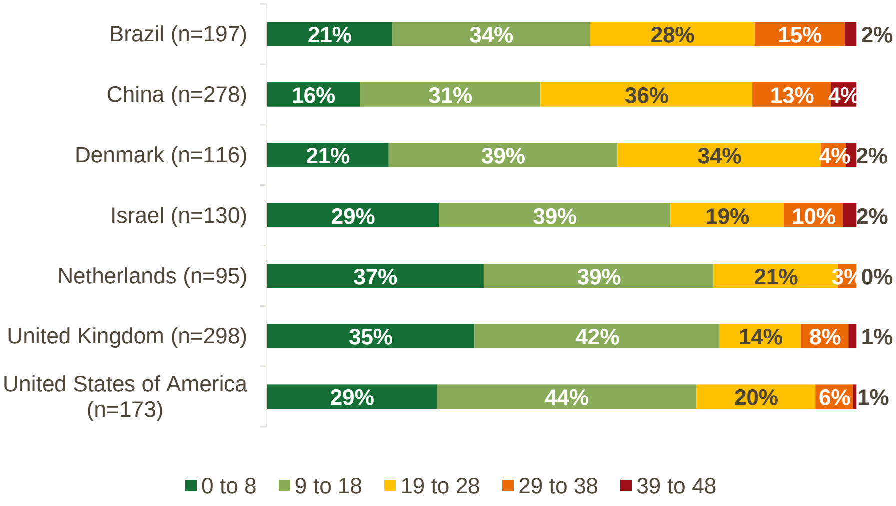
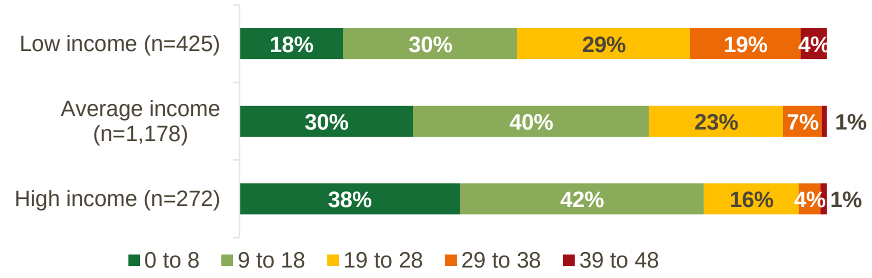


Figure 152. [Patient] HM-PRO PART A by annual household income



HM-PRO Part B – Signs and symptoms

The HM-PRO Part B asked patients about disease symptoms or treatment side effects experienced within the last 3 days of the point of responding to the survey. Overall, one in ten patients (10%, n=195) reported the symptoms and/ or side effects they experienced had a moderate to severe impact on their quality of life (scoring 16 or above out of 36). This is lower than the 16% (n=90) of carers who reported that the person they care for had been moderately to severely impacted by symptoms and/ or side effects.

18% (n=39) of ALL patients reported a moderate to severe impact. This is compared to 11% (n=29) of AML patients, 11% (n=64) of CML patients and 6% (n=46) of CLL patients. Carer response differed, with 19% (n=26) for AML, 15% (n=24) for ALL, 15% (n=17) for CML and 14% (n=14) for CLL reporting a moderate to severe impact (Figure 153; Figure 154).

Unlike HM-PRO Part A, age appears to be less of a factor when considering the impact of symptoms and side effects on quality of life. Patients aged 76 and over (4%, n=6) were least likely to report a moderate to severe impact on their quality of life, compared to other age groups. Carers reported a greater impact of symptoms and side effects on patient's quality of life than patients reported for all age groups except 46-55. Carers for patients aged 36-45 (22%, n=13) were more than twice as likely to report a moderate to severe impact on the patients quality of life, than patient's aged 36-45 reported (9%, n=25) (Figure 155; Figure 156).

Female patients (11%, n=123) reported a slightly greater impact to their quality of life than male patients (7%, n=49). This trend also emerged in the carer responses, where 19% (n=42) reported a moderate to severe impact for female patients, compared to 14% (n=40) for male patients (Figure 157; Figure 158).

Reported impact of symptoms and side effects was low across all countries. Patients in China (15%, n=41) and Israel (15%, n=19) did report a greater impact on their quality of life than patients in the United States of America (6%, n=11) (Figure 159).

19% (n=80) of patients living in a low-income household reported a moderate to severe impact of symptoms and side effects on their quality of life. This is greater than reported by patients living in an average income household (7%, n=82) or high-income household (7%, n=18) (Figure 160).

Figure 153. [Patient] HM-PRO PART B

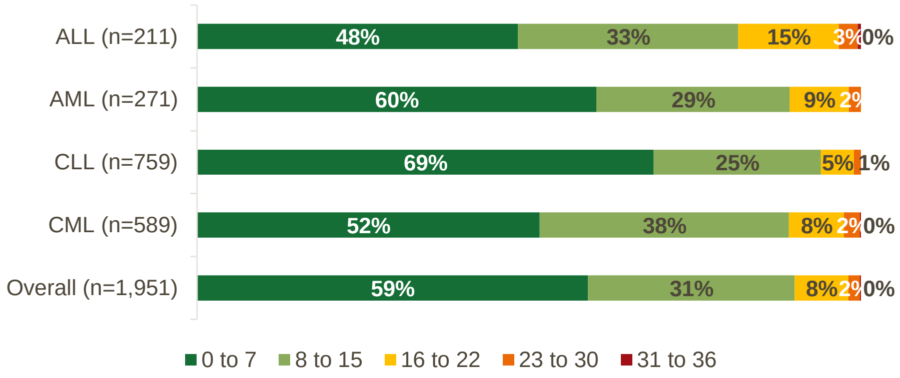


Figure 154. Figure 146. [Carer] HM-PRO PART B

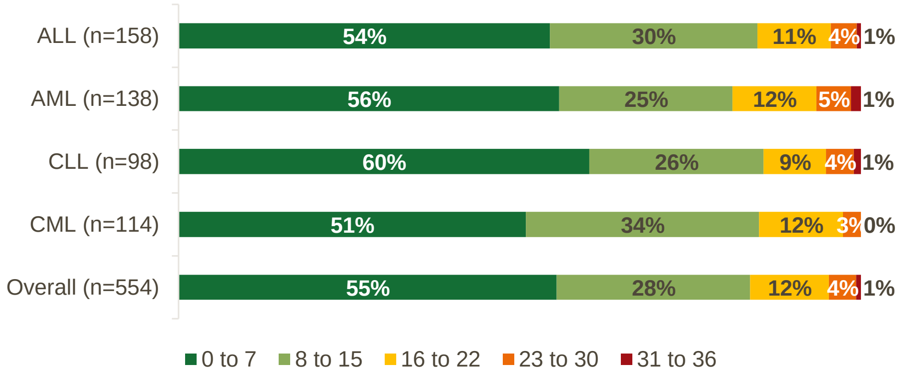


Figure 155. [Patient] HM-PRO PART B by age

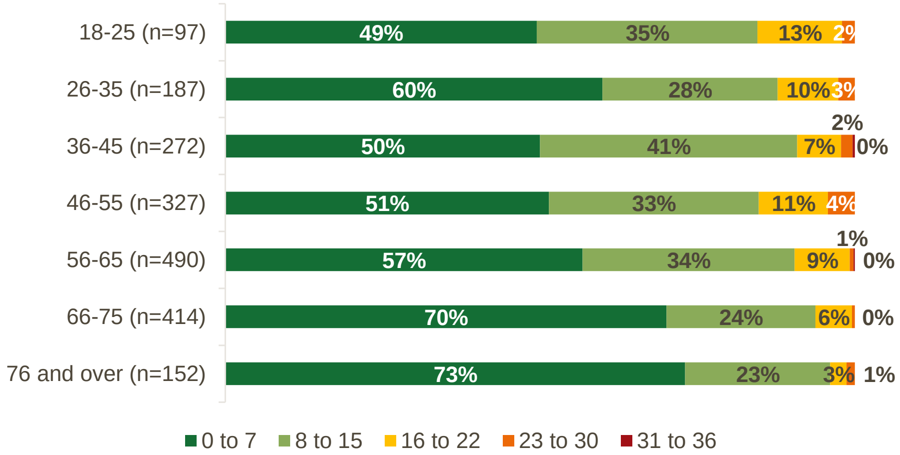


Figure 156. [Carer] HM-PRO PART B by patient age

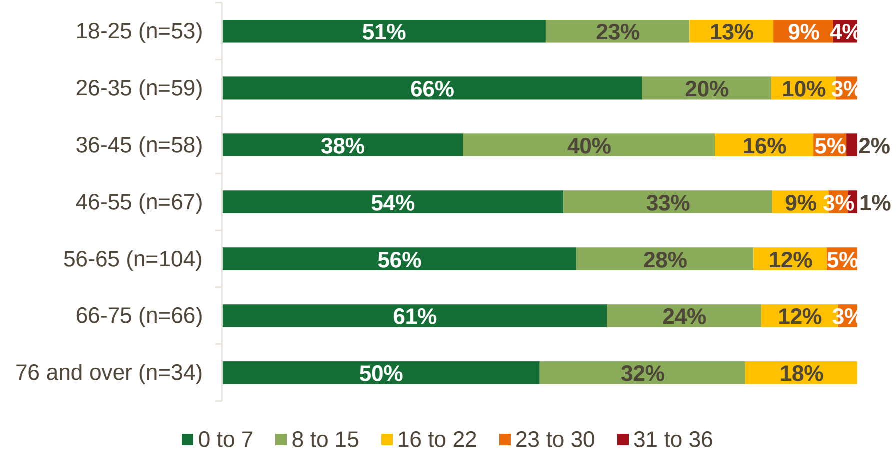


Figure 157. [Patient] HM-PRO PART B by gender

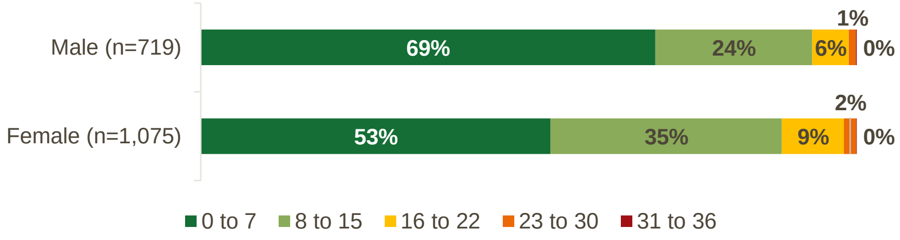


Figure 158. [Carer] HM-PRO PART B by patient gender

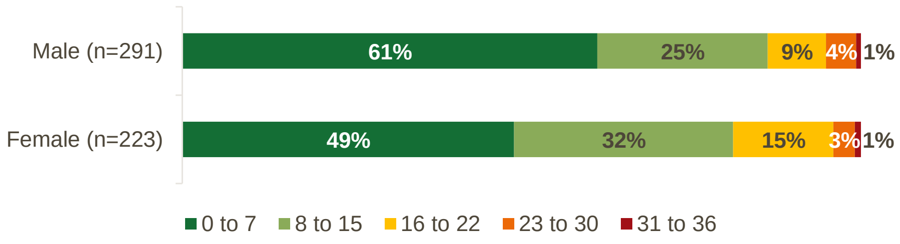


Figure 159. [Patient] HM-PRO PART B by country

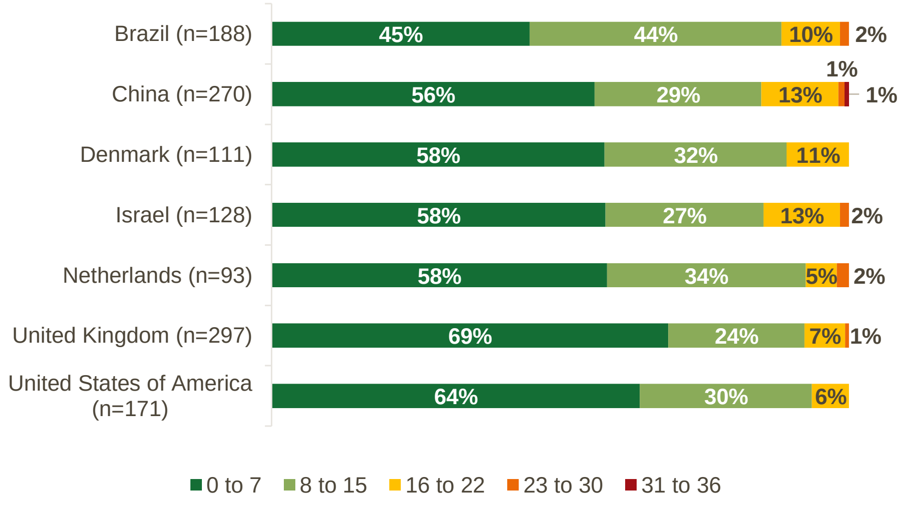
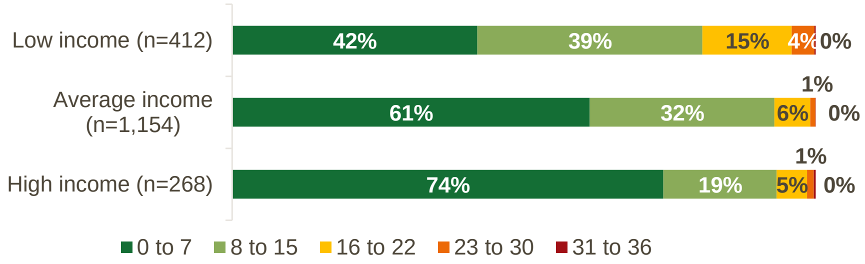


Figure 160. [Patient] HM-PRO PART B by annual household income



FROM-16 – Impact on quality of life in family members / carers

The Family Reported Outcome Measure (FROM-16)[6] is a questionnaire that measures the impact on the quality of life of an adult family member or partner resulting from having a person (of any age) in a family with any disease or condition, across all of medicine.

FROM-16 has 16 questions. The total score range (FROM-16-total) is 0-32. The higher the total score, the greater the effect on the family member's quality of life.

As shown in Figure 161, overall, 69% (n=375) of carers reported they have experienced a moderate to extremely large effect on their quality of life as a result of the person they care for having leukemia.

Reported impact on quality of life was greater for carers caring for someone with acute leukemia (89% for ALL, n=137; 76% for AML, n=103) than for carers caring for someone with chronic leukemia (46% for CLL, n=45; 51% for CML, n=58).

Carers were more likely to experience a moderate to extremely large effect on their quality of life if they were younger and female. 79% (n=77) of carers aged 26-35, and 78% (n=122) aged 36-45 experienced a moderate to extremely large effect on their quality of life, compared to 51% (n=26) of carers aged 66-75. 75% (n=279) of female carers reported a moderate to extremely large effect on their quality of life, compared to 55% (n=77) of male carers (Figure 162; Figure 163).

Carers were more likely to experience a moderate to extremely large effect on their quality of life if the patient was younger and male. 79% (n=46) of carers looking after a patient aged 36-45, and 78% (n=40) of those caring for someone aged 18-25 experienced a moderate to extremely large effect on their quality of life. This is compared to 48% (n=31) of carers caring for someone 66-75. 72% (n=207) of carers looking after male patients experienced a moderate to extremely large effect on their quality of life, compared to 63% (n=139) of carers looking after a female patient (Figure 164; Figure 165).

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[6] FROM-16, https://www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires/family-reported-outcome-measure [accessed: 16 May 2024]

Figure 161. [Carer] FROM-16

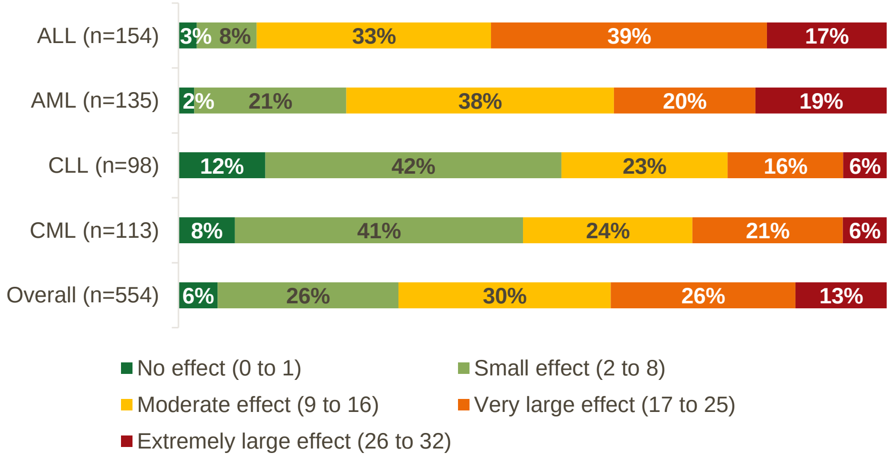


Figure 162. [Carer] FROM-16 by carer age

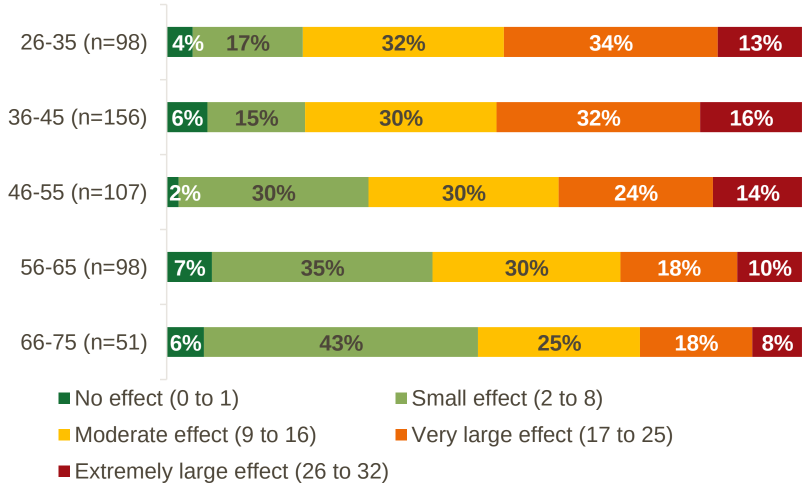


Figure 163. [Carer] FROM-16 by carer gender

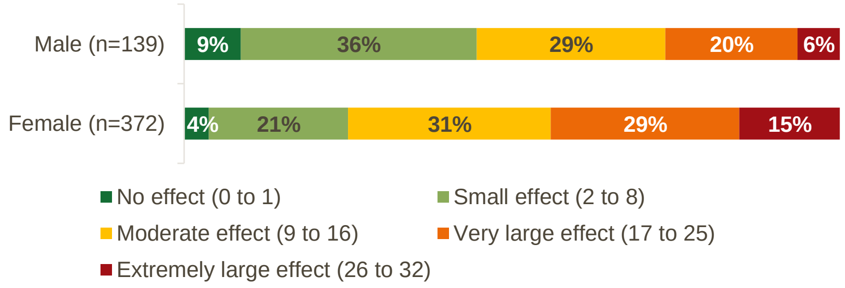


Figure 164. [Carer] FROM-16 by patient age

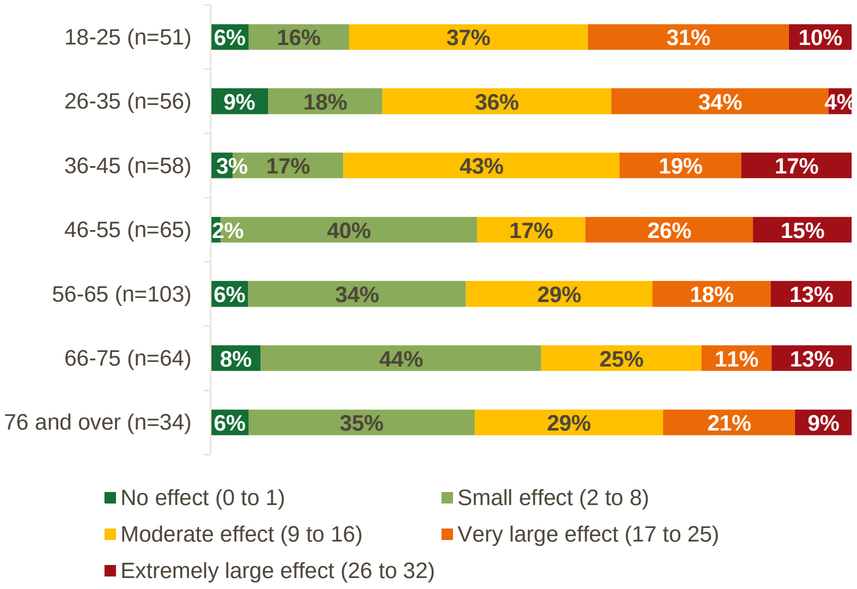
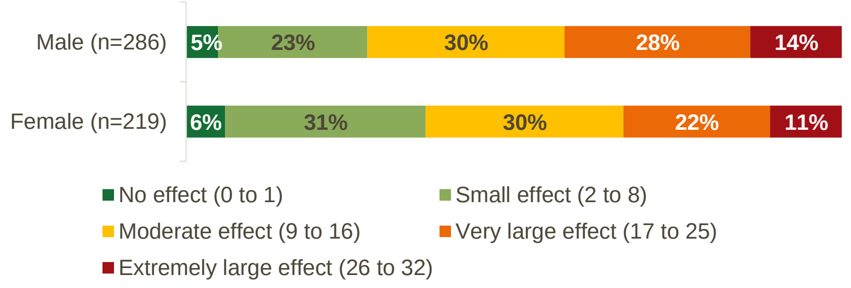


Figure 165. [Carer] FROM-16 by patient gender



General anxiety

Overall, two thirds of patients (66%, n=1,273) reported always, very often, or sometimes experiencing general anxiety since their diagnosis. Patients with ALL (80%, n=168) were most likely to experience general anxiety, while patients with CLL (59%, n=440) were least likely (Figure 166).

Younger patients were more likely to experience general anxiety since their diagnosis, compared to older patients. 79% (n=148) of 26–35-year-olds reported they have experienced general anxiety, compared to 45% (n=68) of patients aged 76 and over (Figure 167).

Female patients (71%, n=752) were more likely to report they have experienced general anxiety since diagnosis, than male patients (59%, n=421) (Figure 168).

Figure 166. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – General anxiety

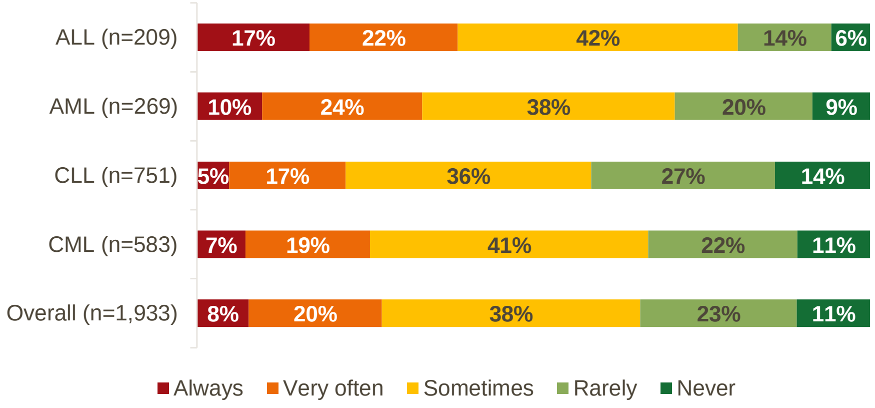


Figure 167. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – General anxiety by age

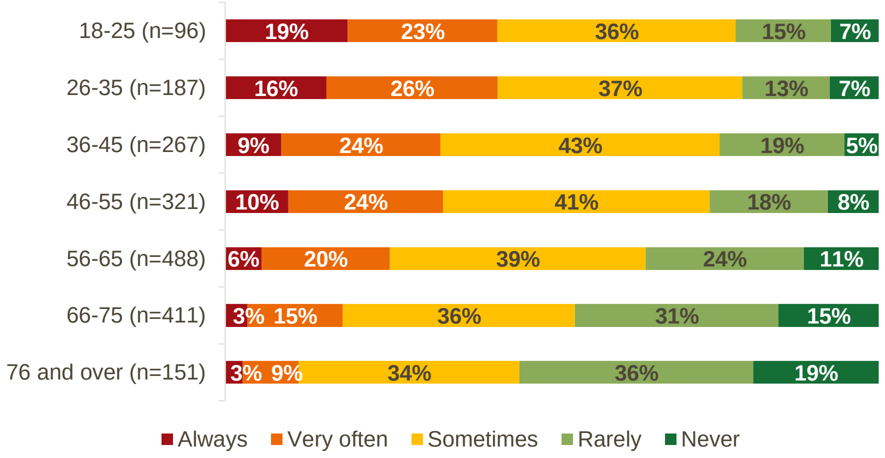
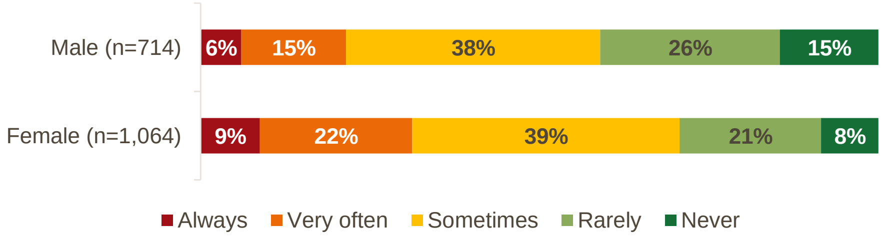


Figure 168. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – General anxiety by gender



Disease-related anxiety

70% (n=1,353) of patients reported always, very often, or sometimes experiencing disease-related anxiety since their diagnosis. Patients with ALL (82%, n=171) were most likely to experience disease-related anxiety, while patients with CLL (65%, n=488) were least likely (Figure 169).

Disease-related anxiety was of least concern to patients aged 76 and over (49%, n=74), compared to other age groups (Figure 170).

Female patients (76%, n=808) were more likely to report they have experienced disease-related anxiety since diagnosis, than male patients (63%, n=448) (Figure 171).

Figure 169. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Disease-related anxiety

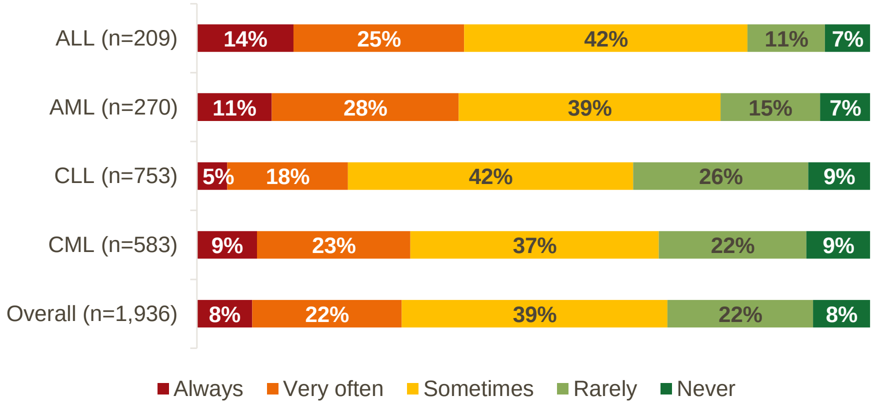


Figure 170. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Disease-related anxiety by age

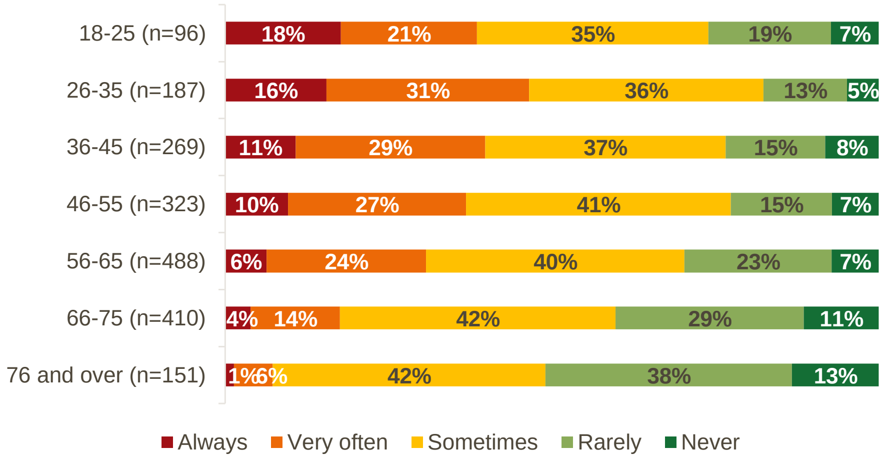
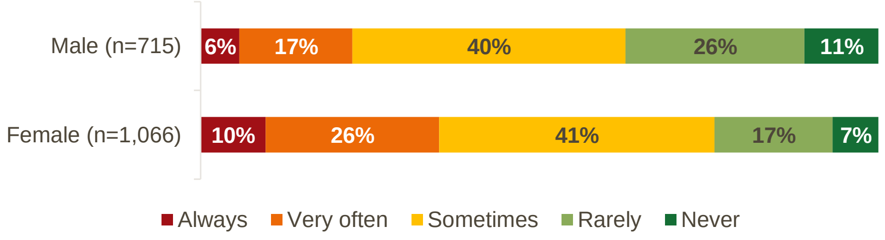


Figure 171. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Disease-related anxiety by gender



Fear of dying

51% (n=990) of patients reported always, very often, or sometimes experiencing fear of dying since their diagnosis. Patients with ALL (63%, n=131) and AML (62%, n=167) were most likely to experience fear of dying, while patients with CLL (43%, n=325) were least likely (Figure 172).

Younger patients were more likely to experience fear of dying since their diagnosis, compared to older patients. 68% (n=127) of 26–35-year-olds reported they have experienced fear of dying, compared to 30% (n=45) of patients aged 76 and over (Figure 173).

Female patients (56%, n=592) were more likely to report they have experienced fear of dying since diagnosis, than male patients (43%, n=308) (Figure 174).

Figure 172. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying

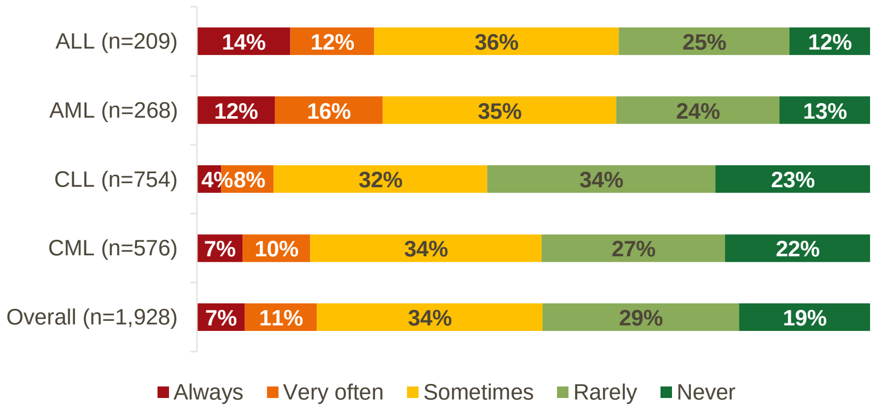


Figure 173. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying by age

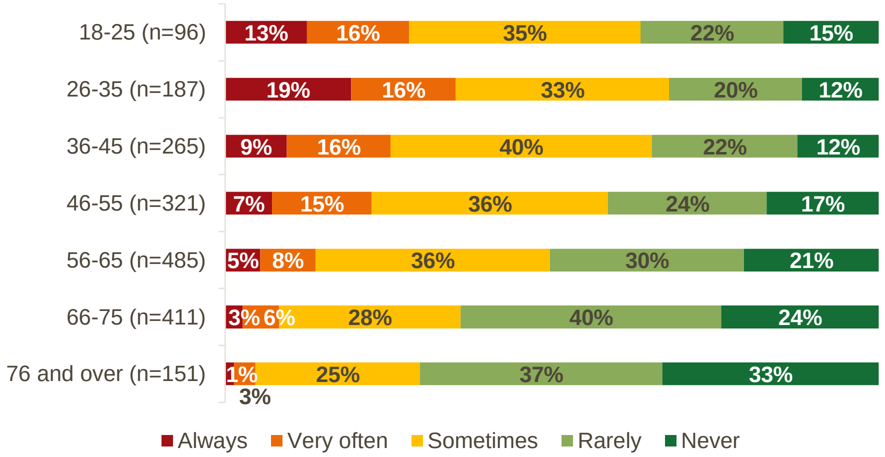
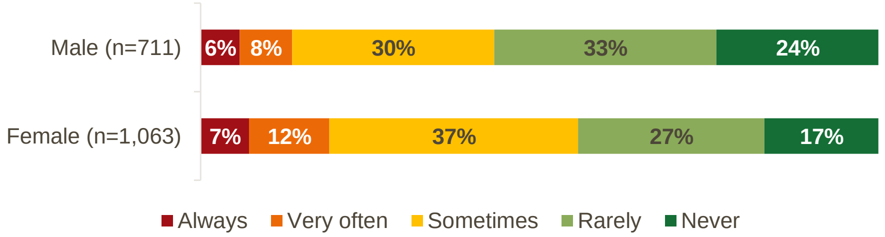


Figure 174. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying by gender



Fear of the cancer coming back (recurrence / relapse)

66% (n=1,270) of patients reported always, very often, or sometimes experiencing fear of the cancer coming back, also known as recurrence or relapse, since their diagnosis. Patients with ALL (79%, n=165) and AML (79%, n=213) were most likely to experience fear of recurrence, while patients with CLL (58%, n=431) were least likely (Figure 175).

Younger patients were more likely to experience fear of recurrence since their diagnosis, compared to older patients. 83% (n=154) of 26–35-year-olds reported they have experienced fear of recurrence, compared to 50% (n=75) of patients aged 76 and over (Figure 176).

Female patients (71%, n=750) were more likely to report they have experienced fear of recurrence since diagnosis, than male patients (59%, n=422) (Figure 177).

Figure 175. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of cancer coming back (recurrence)

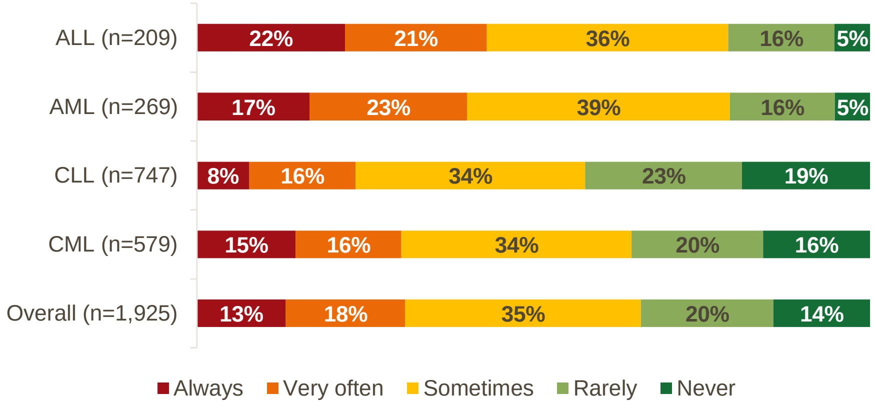


Figure 176. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of cancer coming back (recurrence) by age

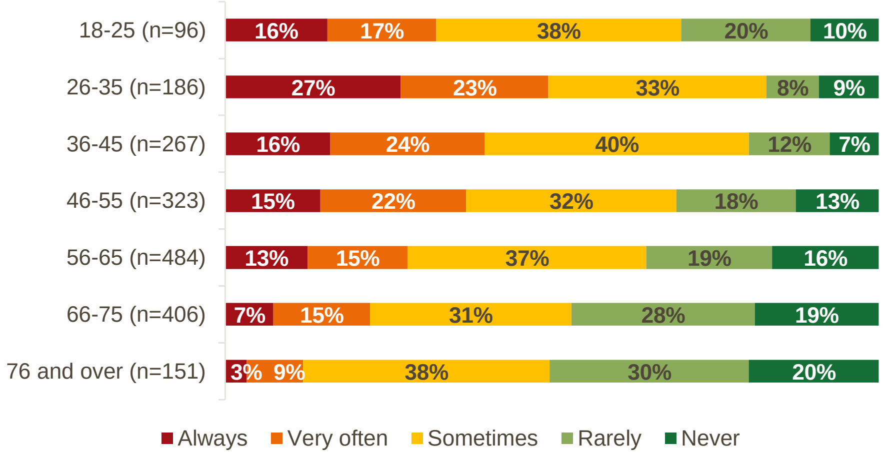
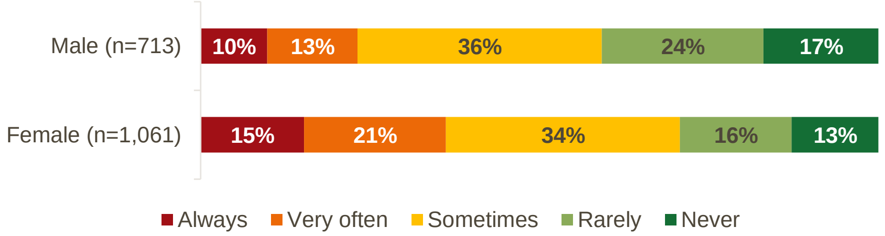


Figure 177. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of cancer coming back (recurrence) by gender



Depression

45% (n=874) of patients reported always, very often, or sometimes experiencing depression since their diagnosis. Patients with ALL (55%, n=115) were most likely to depression, while patients with CLL (40%, n=304) were least likely (Figure 178).

Younger patients were more likely to experience depression since their diagnosis, compared to older patients. 55% (n=103) of 26–35-year-olds reported they have experienced depression, compared to 31% (n=47) of patients aged 76 and over (Figure 179).

Female patients (50%, n=534) were more likely to report they have experienced depression since diagnosis, than male patients (38%, n=273) (Figure 180).

Figure 178. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Depression

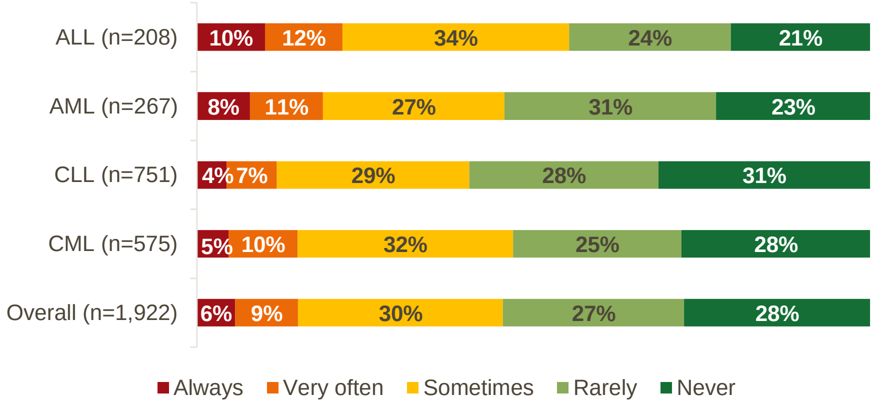


Figure 179. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Depression by age

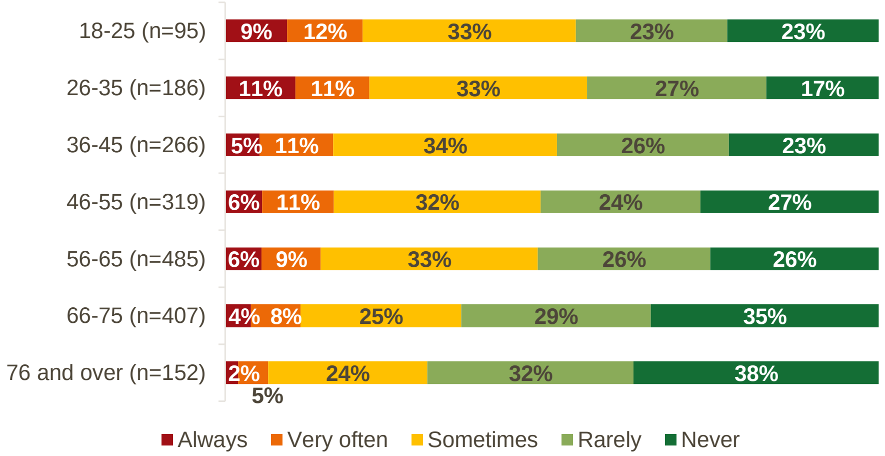
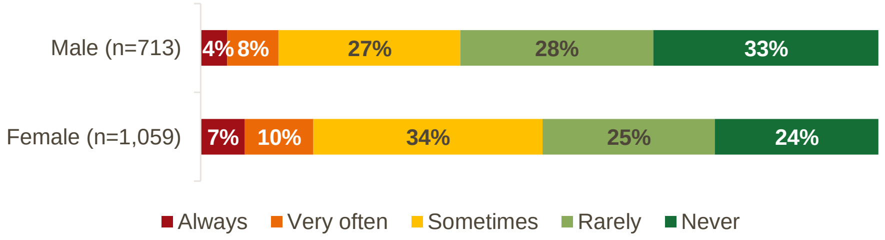


Figure 180. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Depression by gender



Isolation

41% (n=782) of patients reported always, very often, or sometimes experiencing isolation since their diagnosis. Patients with ALL (54%, n=111) were most likely to experience isolation, while patients with CLL (35%, n=266) were least likely (Figure 181).

Younger patients were more likely to experience isolation since their diagnosis, compared to older patients. 57% (n=54) of 18–25-year-olds reported they have experienced isolation, compared to 22% (n=33) of patients aged 76 and over (Figure 182).

Female patients (47%, n=493) were more likely to report they have experienced isolation since diagnosis, than male patients (32%, n=227) (Figure 183).

Figure 181. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Isolation

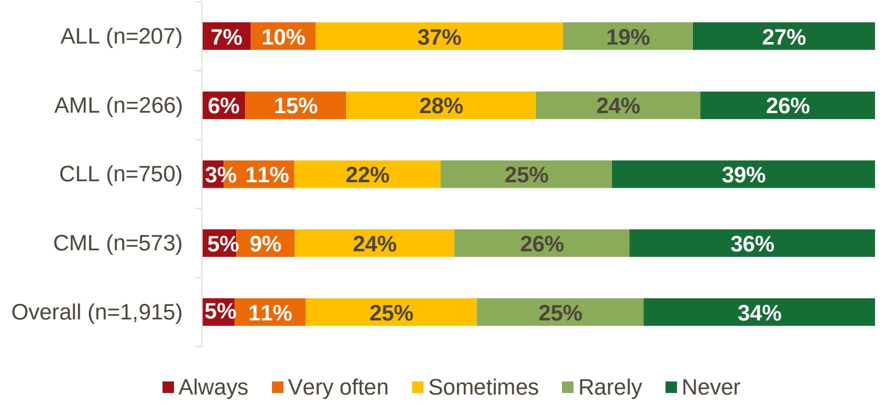


Figure 182. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Isolation by age

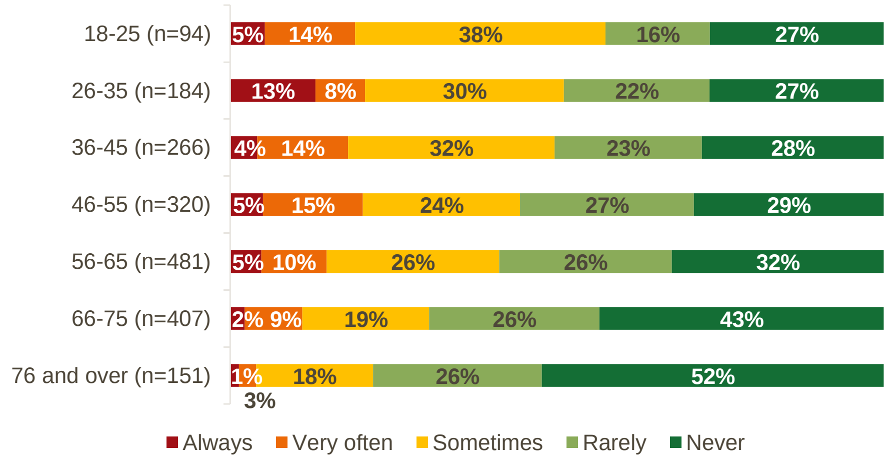
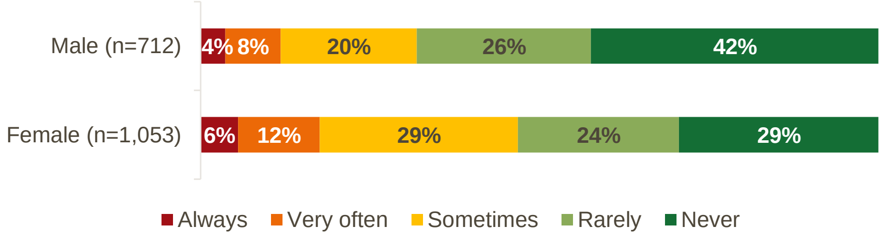


Figure 183. [Patient] Q88 How often have the following impacted your sense of emotional well-being since your diagnosis? – Isolation by gender

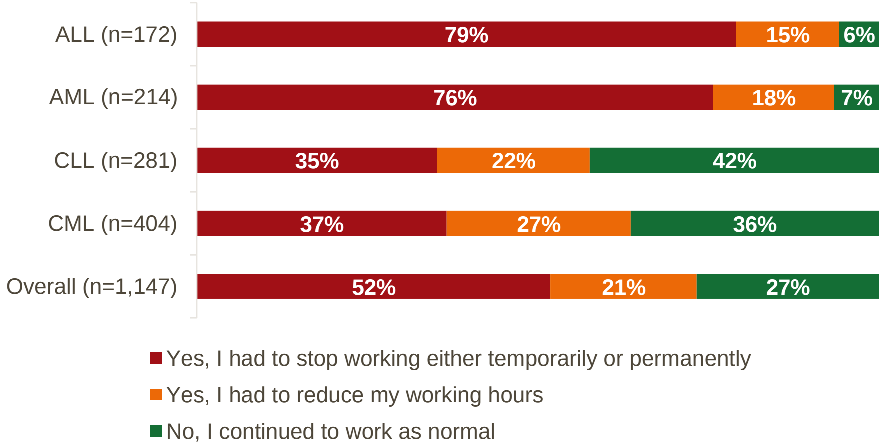


Impact on work and study

Overall, 52% (n=595) of patients have had to stop working either temporarily or permanently since they were diagnosed with leukemia. 21% (n=246) have had to reduce their working hours, and 27% (n=306) have continued to work as normal (Figure 184).

Patients with acute leukemia (79% for ALL, n=136; 76% for AML, n=162) were more than twice as likely to have to stop working either temporarily or permanently since they were diagnosed with leukemia, than patients with chronic leukemia (35% for CLL, n=99; 37% for CML, n=148).

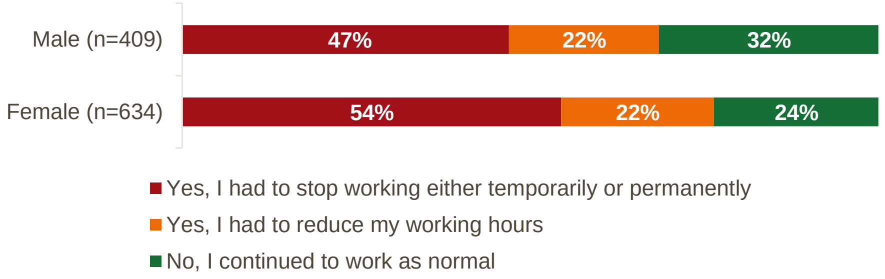
Figure 184. [Patient] Q89 At any point since you were diagnosed with leukemia, has your ability to work been affected? [Derived]



Please note patients who answered 'not applicable' (n=127) were removed from analysis for Q89

Male patients (32%, n=129) were more likely to continue to work as normal since their diagnosis, than female patients (24%, n=150) (Figure 185).

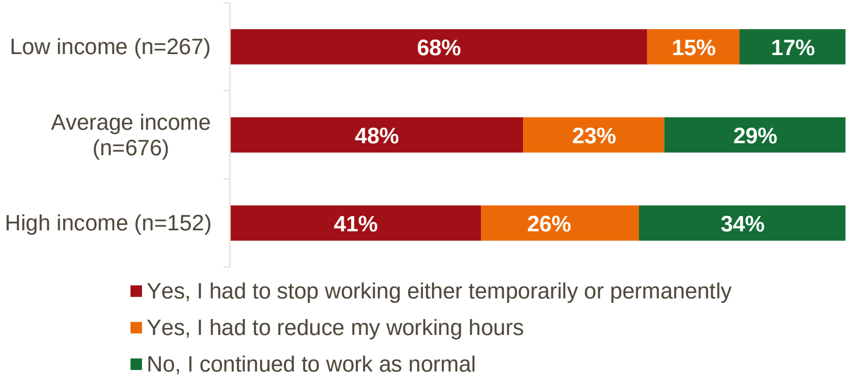
Figure 185. [Patient] Q89 At any point since you were diagnosed with leukemia, has your ability to work been affected? by gender [Derived]



Please note patients who answered 'not applicable' (n=127) were removed from analysis for Q89

Patients who lived in a low-income household (68%, n=181) were far more likely to report they had to stop working either temporarily or permanently since they were diagnosed with leukemia, than patients living in an average-income household (48%, n=322) and high-income household (41%, n=62) (Figure 186).

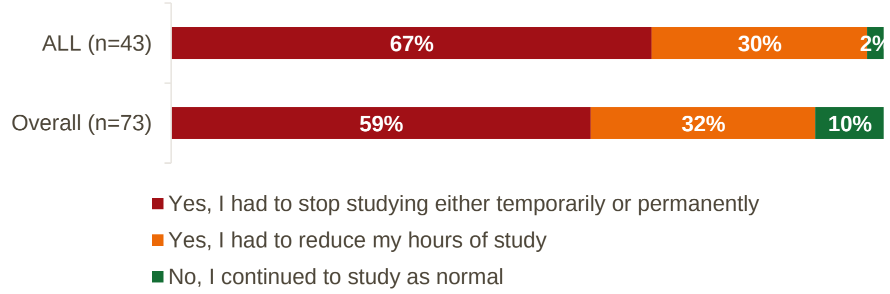
Figure 186. [Patient] Q89 At any point since you were diagnosed with leukemia, has your ability to work been affected? by annual household income [Derived]



Please note patients who answered 'not applicable' (n=127) were removed from analysis for Q89

Of the small proportion of patient respondents who were students, 59% (n=43) had to stop studying either temporarily or permanently, 32% (n=23) had to reduce their hours of study, and 10% (n=7) have continued to study as normal (Figure 187).

Figure 187. [Patient] Q90 At any point since you were diagnosed with leukemia, has your ability to study been affected?



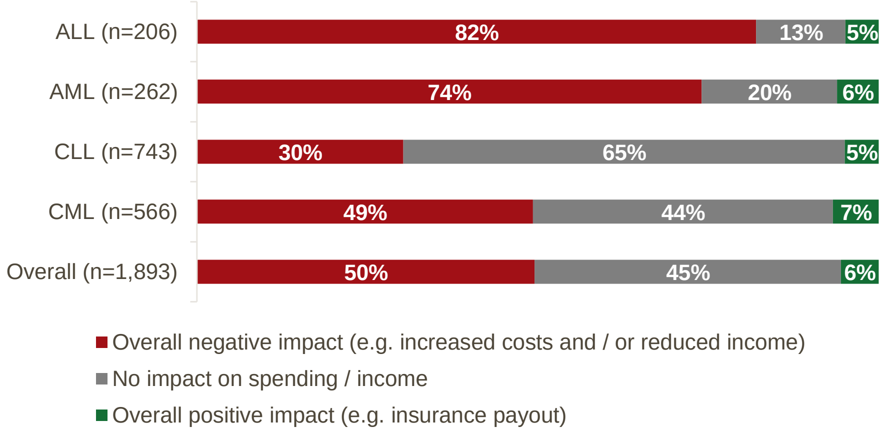
Please note patients who answered ‘not applicable’ (n=3) were removed from analysis for Q90

Impact on finances

50% (n=938) of patients have experienced an overall negative financial impact since their diagnosis. 45% (n=850) have had no impact on their spending or income since their diagnosis, while 6% (n=105) have experienced and overall positive impact (Figure 188).

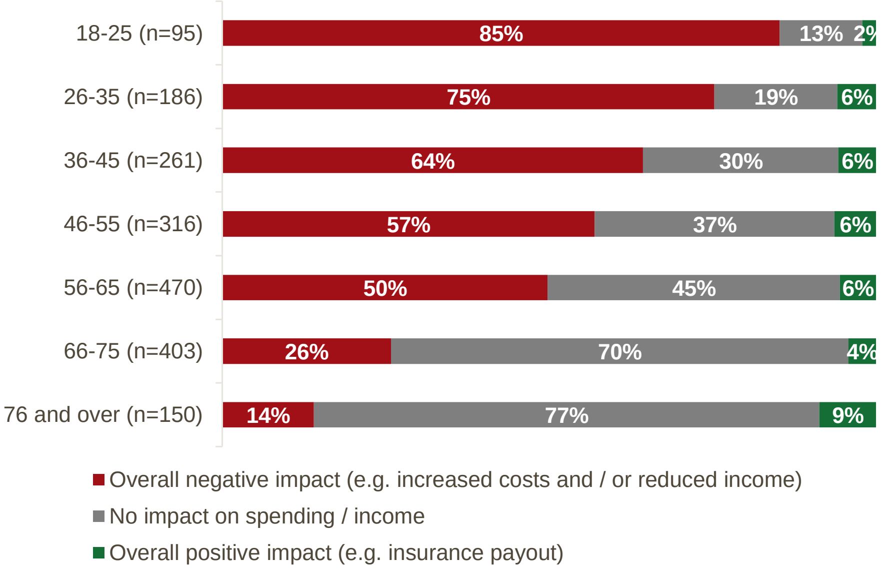
Patients with acute leukemia (82% for ALL, n=169; 74% for AML, n=194) were far more likely to experience an overall negative financial impact since their diagnosis, than patients with chronic leukemia (30% for CLL, n=225; 49% for CML, n=279).

Figure 188. [Patient] Q91 Overall, since your diagnosis, have you experienced a financial impact as a result of having leukemia (positive or negative)?



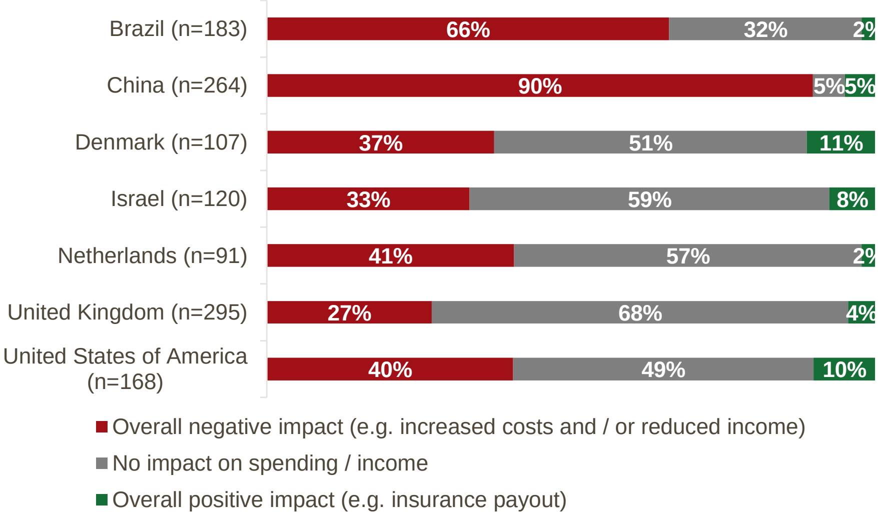
Younger patients were far more likely than older patients to experience an overall negative financial impact since their diagnosis. 85% (n=81) of patients aged 18-25 reported they have experienced an overall negative financial impact since their diagnosis, compared to just 14% (n=21) of patients aged 76 and over (Figure 189).

Figure 189. [Patient] Q91 Overall, since your diagnosis, have you experienced a financial impact as a result of having leukemia (positive or negative)? by age



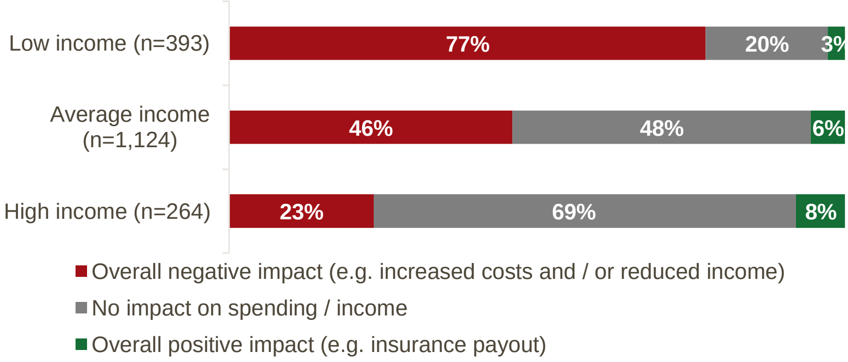
Analysis by country finds variance in financial impact following leukemia diagnosis. As shown in Figure 190, patients in China (90%, n=237) and Brazil (66%, n=121) were far more likely to report they have experienced an overall negative financial impact since their diagnosis, compared to other countries.

Figure 190. [Patient] Q91 Overall, since your diagnosis, have you experienced a financial impact as a result of having leukemia (positive or negative)? by country



Patients living in a low-income household (77%, n=304) were three times as likely to report they have experienced an overall negative financial impact since their diagnosis, than patient’s living in a high-income household (23%, n=62) (Figure 191).

Figure 191. [Patient] Q91 Overall, since your diagnosis, have you experienced a financial impact as a result of having leukemia (positive or negative)? by annual household income



Sources of support

88% (n=1,682) of patients reported they have sought support about worries or concerns they have about their leukemia. Patients were most likely to consult:

- Family (62%, n=1,185)
- Friends (46%, n=887)
- A healthcare professional (42%, n=807)

Table 45. [Patient] Q92 Have you ever talked to any of the following about any worries or concerns about your leukemia? Please select all that apply. [Multiple choice]

	Overall	ALL	AML	CLL	CML
Base (n=)	**1,921**	206	269	750	578
Family	**62%**	68%	66%	55%	65%
Friends	**46%**	46%	49%	42%	49%
Healthcare professional	**42%**	33%	42%	42%	44%
Patient organizations / patient advocacy groups	**23%**	17%	19%	23%	29%
Psychologist	**20%**	19%	25%	14%	25%
Counsellor	**7%**	4%	7%	8%	7%
Other	**2%**	0%	1%	3%	3%
None of the above	**12%**	10%	9%	18%	9%

Analysis by age finds patients aged 66-75 (80%, n=327) and 76 and over (81%, n=121) were least likely to report they have sought support for the worries or concerns they have about their leukemia, compared to other age groups (Table 46).

Table 46. [Patient] Q92 Have you ever talked to any of the following about any worries or concerns about your leukemia? Please select all that apply. by age [Multiple choice]

	18-25	26-35	36-45	46-55	56-65	66-75	76+
Base (n=)	95	186	268	318	485	408	149
Family	63%	65%	67%	64%	63%	54%	58%
Friends	58%	48%	51%	50%	47%	40%	35%
Healthcare professional	18%	39%	44%	45%	45%	42%	42%
Patient organizations / patient advocacy groups	21%	18%	23%	22%	27%	23%	23%
Psychologist	15%	22%	30%	29%	22%	11%	5%
Counsellor	3%	4%	8%	9%	9%	8%	3%
Other	-	1%	2%	3%	3%	4%	-
None of the above	11%	10%	6%	9%	12%	20%	19%

Overall, a similar proportion of male (86%, n=608) and female (88%, n=935) patients reported seeking help for their worries or concerns about their leukemia (Table 47). There were variances in where they sought this support:

- 64% (n=678) of female patients spoke to family about their worries and concerns, compared to 57% (n=405) of male patients.
- 52% (n=553) of female patients spoke to friends about their worries and concerns, compared to 38% (n=267) of male patients.
- 25% (n=269) of female patients spoke to a psychologist about their worries and concerns, compared to 15% (n=106) of male patients.

Table 47. [Patient] Q92 Have you ever talked to any of the following about any worries or concerns about your leukemia? Please select all that apply. by gender [Multiple choice]

Base (n=)	Male 706	Female 1,061
Family	57%	64%
Friends	38%	52%
Healthcare professional	45%	42%
Patient organizations / patient advocacy groups	25%	23%
Psychologist	15%	25%
Counsellor	6%	9%
Other	2%	2%
None of the above	14%	12%

Analysis by country finds variance in the proportion of patients who sought support for the worries or concerns they have about their leukemia, and large variances in where they sought this support from. See Table 48 for full details.

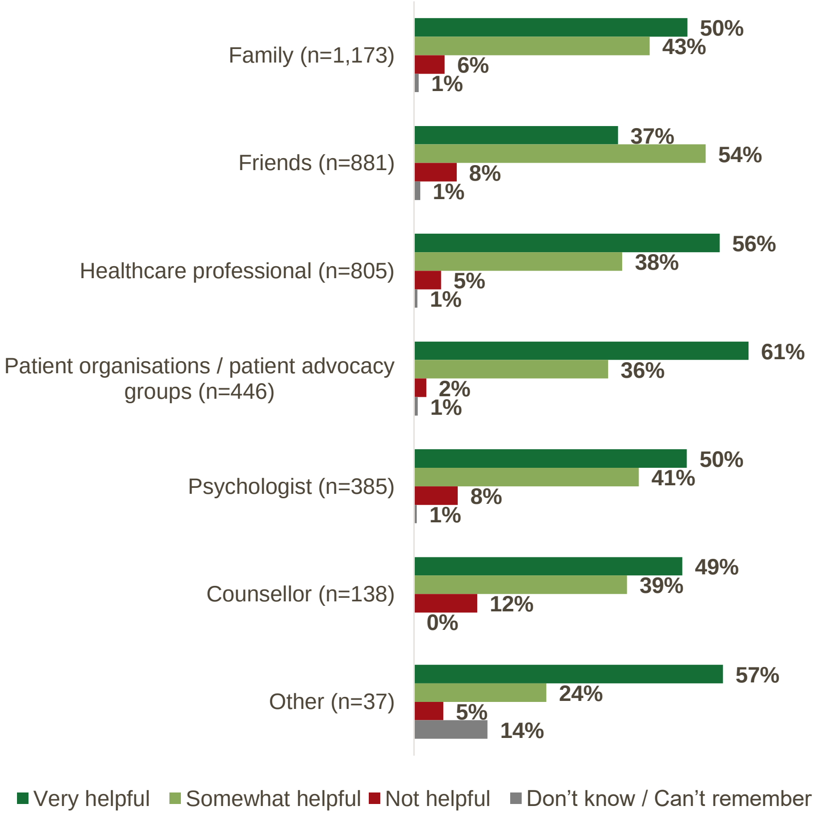
Table 48. [Patient] Q92 Have you ever talked to any of the following about any worries or concerns about your leukemia? Please select all that apply. by country [Multiple choice]

Base (n=)	Brazil 185	China 263	Denmark 110	Israel 125	Netherlands 90	United Kingdom 296	United States of America 169
Family	68%	68%	65%	58%	72%	50%	63%
Friends	45%	47%	50%	36%	64%	39%	51%
Healthcare professional	48%	27%	47%	23%	39%	36%	61%
Patient organizations / patient advocacy groups	13%	19%	30%	10%	23%	24%	31%
Psychologist	41%	5%	35%	30%	30%	6%	16%
Counsellor	5%	1%	8%	3%	10%	13%	15%
Other	2%	1%	3%	3%	1%	3%	4%
None of the above	6%	10%	14%	18%	9%	22%	10%

The majority of patients who sought support for the worries or concerns they have about their leukemia reported where they sought this support was helpful. Patients were most likely to report patient organizations and patient advocacy groups (61%, n=274) were very helpful (Figure 192).

See Appendix 12 for breakdown by leukemia type.

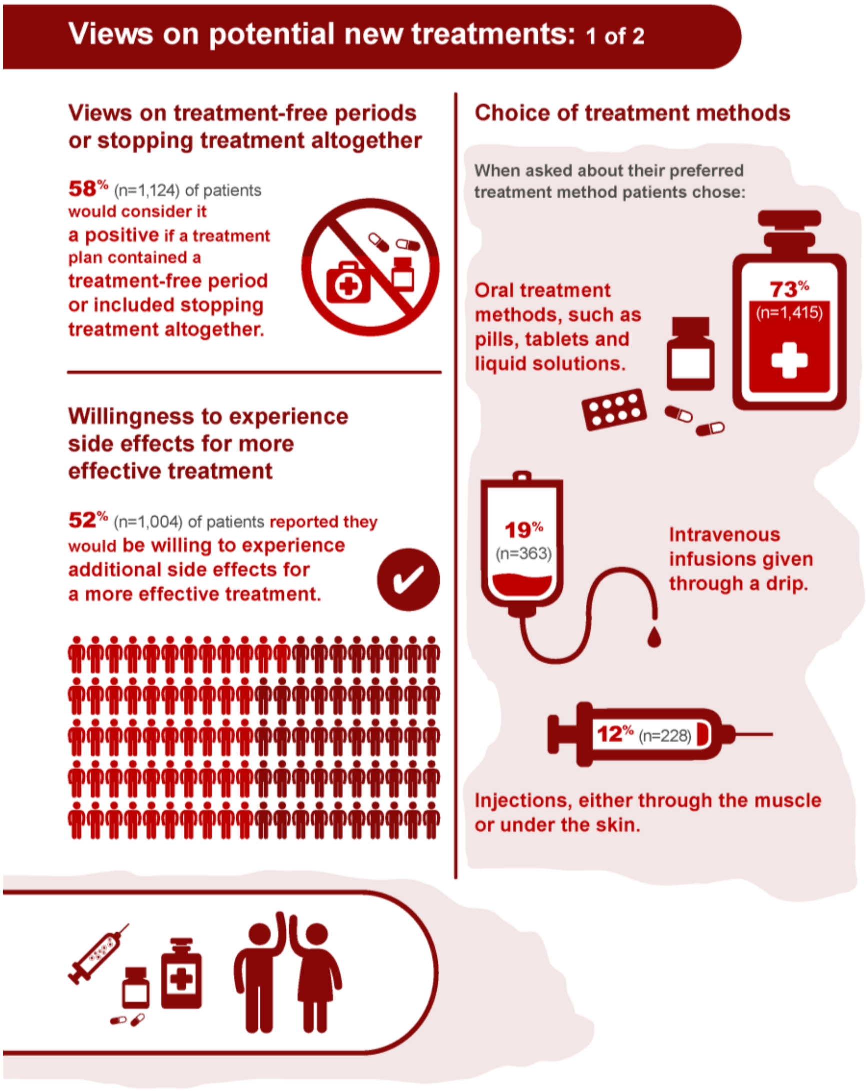
Figure 192. [Patient] Q93 How helpful were they?



Global Leukemia Experience Survey 2023

Views on Potential New Treatments

Views on potential new treatments



Views on potential new treatments: 1 of 2

Views on treatment-free periods or stopping treatment altogether

58% (n=1,124) of patients **would consider it a positive** if a treatment plan contained a **treatment-free period or included stopping treatment altogether.**

Willingness to experience side effects for more effective treatment

52% (n=1,004) of patients reported they would **be willing to experience additional side effects for a more effective treatment.**

Choice of treatment methods

When asked about their preferred treatment method patients chose:

73% (n=1,415)

Oral treatment methods, such as pills, tablets and liquid solutions.

19% (n=363)

Intravenous infusions given through a drip.

12% (n=228)

Injections, either through the muscle or under the skin.

Views on potential new treatments: 2 of 2

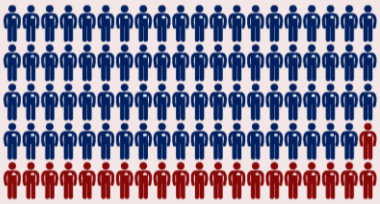
Important features of a new treatment

Both patients and carers prioritized the following important features of a new treatment:

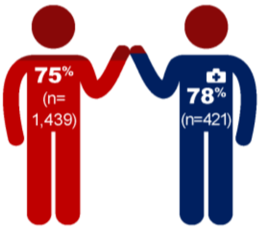
Improved quality of life

75% (n=1,436) **of patients.**

79% (n=424) **of carers.**



Improved / longer survival

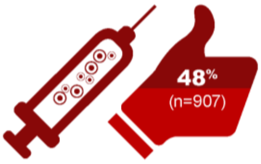


Bring about a remission / response

62% (n=1,186)
of patients.

69% (n=372)
of carers.

Undergoing treatment to subsequently enable a stem cell transplant

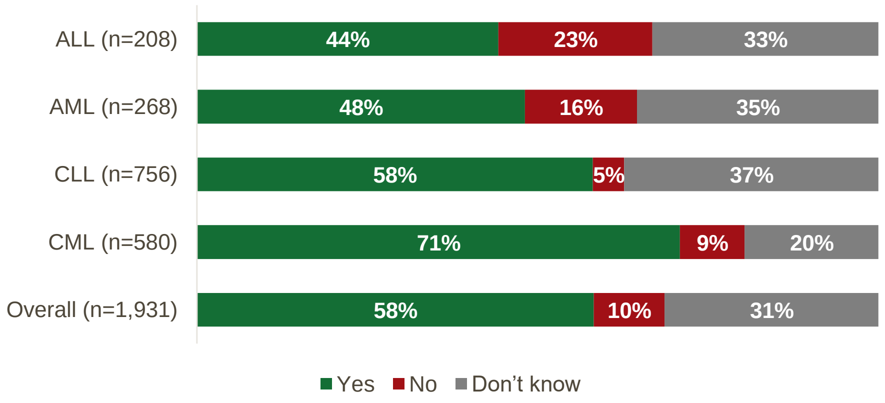


of patients would consider it **positive** if undergoing a treatment would subsequently **enable them to have a stem cell transplant.**

Views on treatment-free periods or stopping treatment altogether

Overall, 58% (n=1,124) of patients would consider it a positive if a treatment plan contained a treatment-free period or included stopping treatment altogether. Patients with CML (71%, n=411) were most likely to report they would consider a treatment-free period or stopping treatment altogether as part of their treatment plan a positive. This is compared to 44% (n=92) of patients with ALL, 48% (n=129) with AML, and 58% (n=439) with CLL (Figure 193).

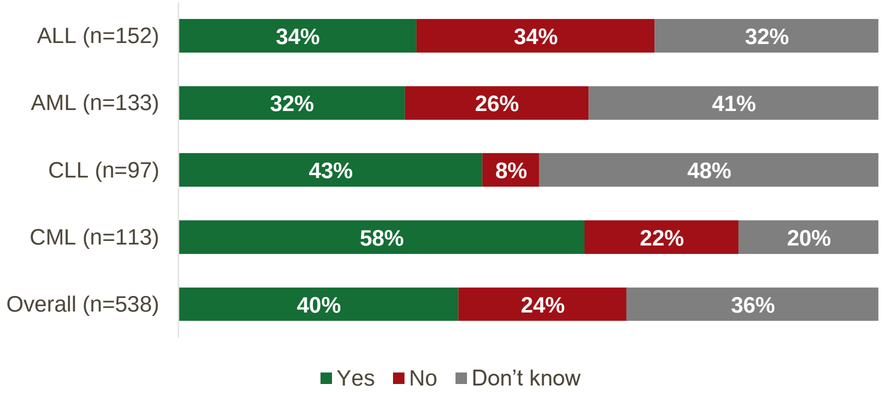
Figure 193. [Patient] Q94 Would you consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether?



The views of carers differed from patient views at an overall level (Figure 194). 40% (n=215) of carers viewed a treatment-free period or stopping treatment altogether as part of the patient's treatment plan as a positive, compared to 58% (n=1,124) of patients. Carers (24%, n=129) were more than twice as likely as patients (10%, n=201) to disagree this would be considered a positive.

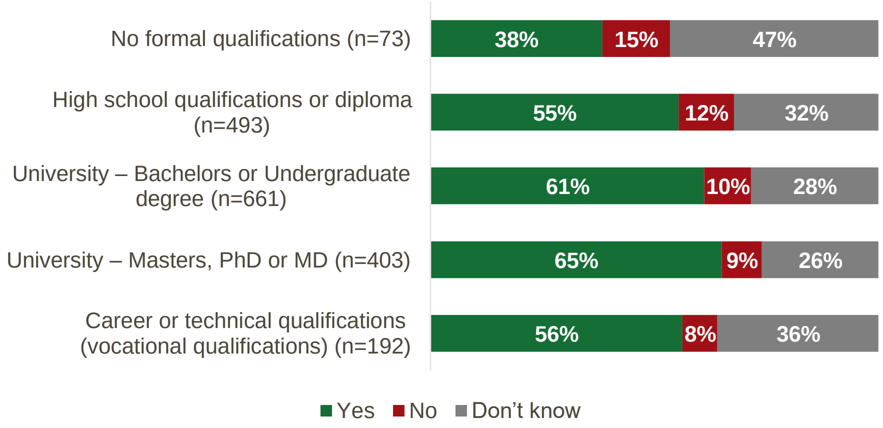
Similarities emerge when considering leukemia type. CML carer respondents (58%, n=65) were the most likely to report they would consider a treatment-free period or stopping treatment altogether as part of their treatment plan a positive, as were the CML patient respondents (71%, n=411).

Figure 194. [Carer] C46 Would YOU consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether? By treatment-free we mean that the patient and their doctor agree that they stop taking their medication



The proportion of patients who stated that they did not know if they would consider a treatment-free period or stopping treatment altogether as part of their treatment plan to be positive varied by level of education. As shown in Figure 195, as level of education increases from no formal qualifications to postgraduate degree level, the proportion of patients who did not know decreases from 47% (n=34) to 26% (n=105).

Figure 195. [Patient] Q94 Would you consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether? by level of education

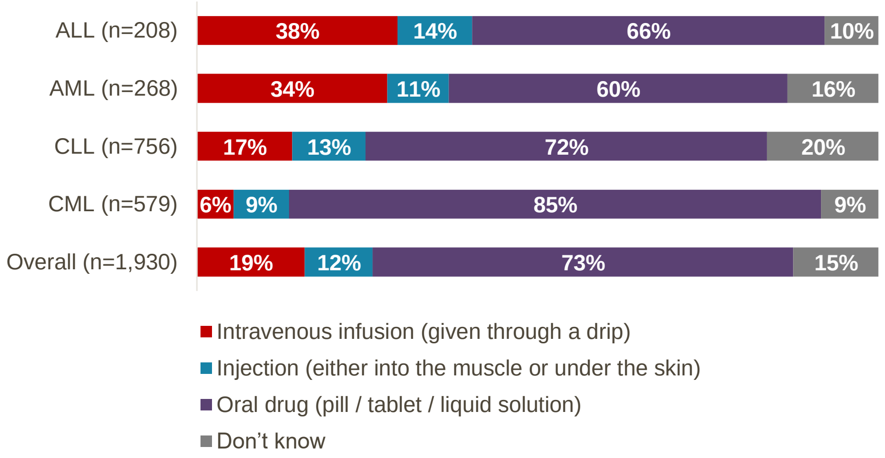


Choice of treatment methods

If given a choice, oral treatment methods, such as pills, tablets and liquid solutions (73%, n=1,415) were the most popular treatment method chosen by patients (Figure 196). 19% (n=363) would choose intravenous infusions given through a drip, and 12% (n=228) would choose injections, either through the muscle or under the skin.

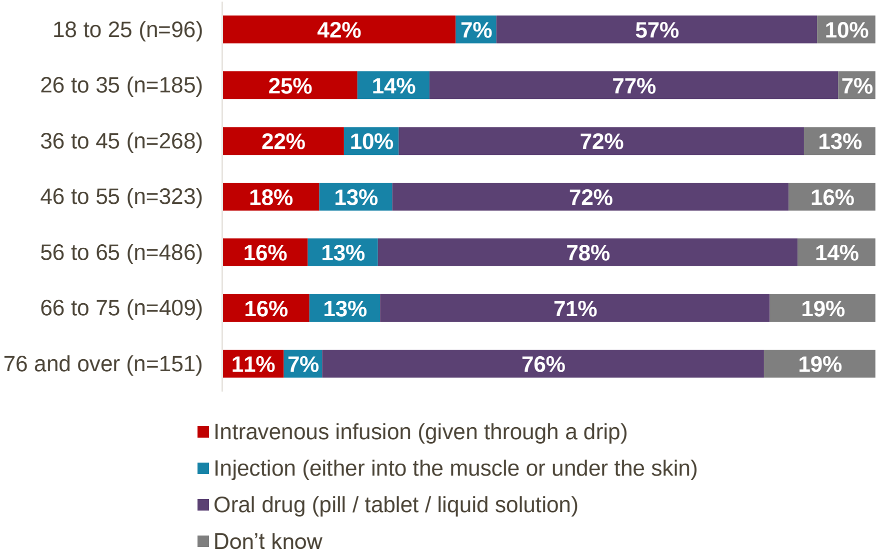
Intravenous infusions given through a drip were more likely to be a preferred treatment choice for patients with ALL (38%, n=78) and AML (34%, n=90) than for those with CLL (17%, n=130) or CML (6%, n=34).

Figure 196. [Patient] Q95 If you were given the choice, which treatment methods would you prefer? [Multiple choice]



Younger patients aged 18 to 25 were least likely to prefer oral treatment methods (57%, n=55) and most likely to prefer intravenous infusions given through a drip (42%, n=40). Older patients aged 66 to 75 (19%, n=79) and 76 and over (19%, n=29) were most likely to not know what their preferred treatment method would be. See Figure 197 for full breakdown.

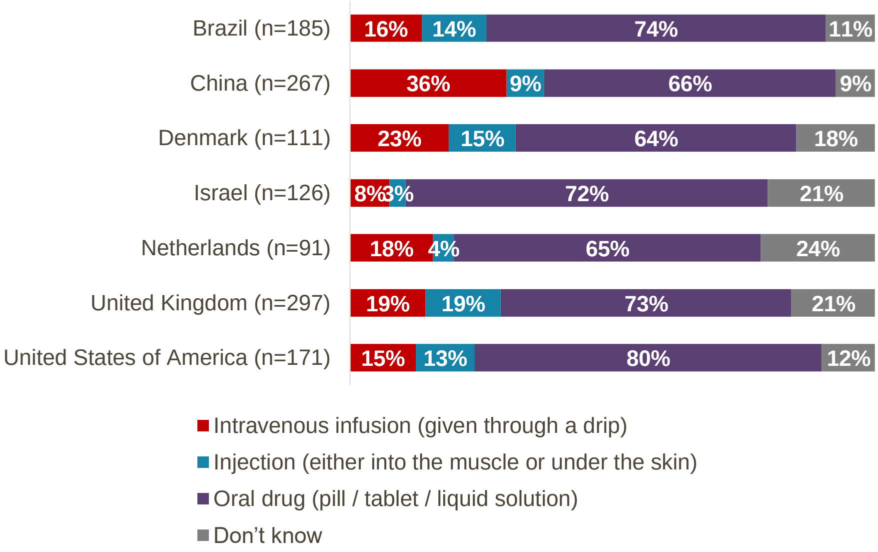
Figure 197. [Patient] Q95 If you were given the choice, which treatment methods would you prefer? [Multiple choice] by age



Preferred treatment method varied by country. As shown in Figure 198:

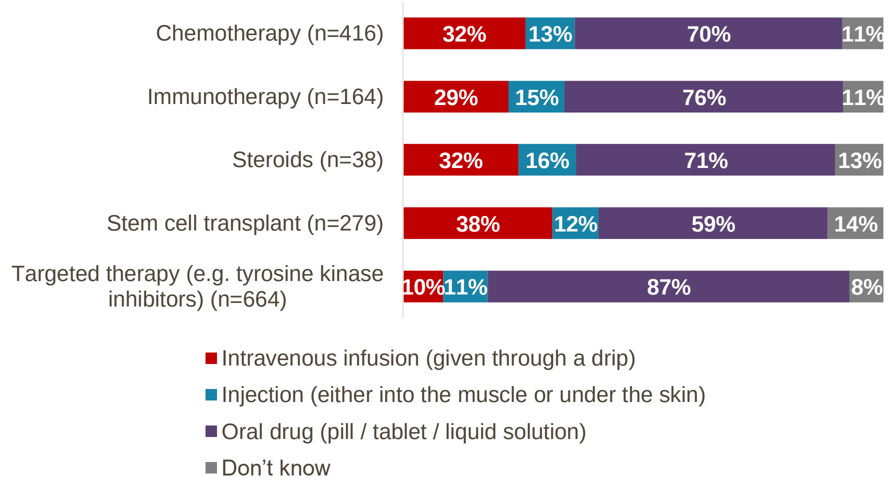
- Intravenous infusions given through a drip were most popular in China (36%, n=95) and least popular in Israel (8%, n=10).
- Injections, either through the muscle or under the skin, were most likely to be chosen by UK patients (19%, n=56), and least likely to be chosen by Israel patients (3%, n=4).
- Oral treatment methods, such as pills, tablets and liquid solutions were US patients (80%, n=137) preferred choice of treatment. Denmark (64%, n=71) had the lowest proportion of patients who selected oral treatment methods as their preferred choice.
- The proportion of patients who reported not knowing their preferred treatment method was highest in the Netherlands (24%, n=22) and lowest in China (9%, n=24).

Figure 198. [Patient] Q95 If you were given the choice, which treatment methods would you prefer? [Multiple choice] by country



Analysis by current or most recent treatment reveals some variance in preferred treatment methods (Figure 199). Patients who currently or most recently received targeted therapy were most likely to prefer oral treatment methods (87%, n=578) and least likely to prefer intravenous infusions given through a drip (10%, n=64).

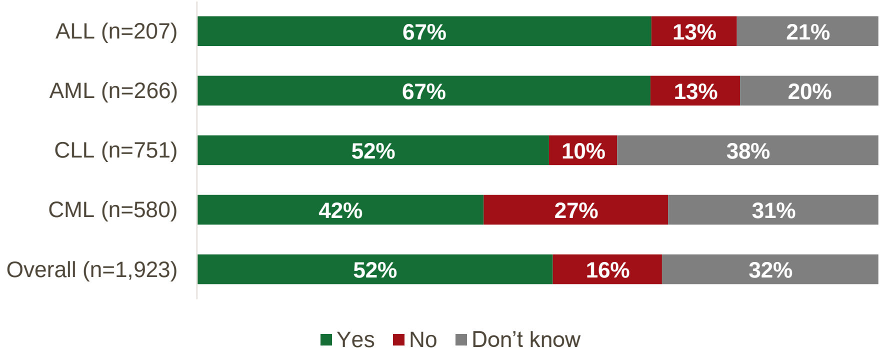
Figure 199. [Patient] Q95 If you were given the choice, which treatment methods would you prefer? [Multiple choice] by current or most recent treatment method



Willingness to experience additional side effects for more effective treatment

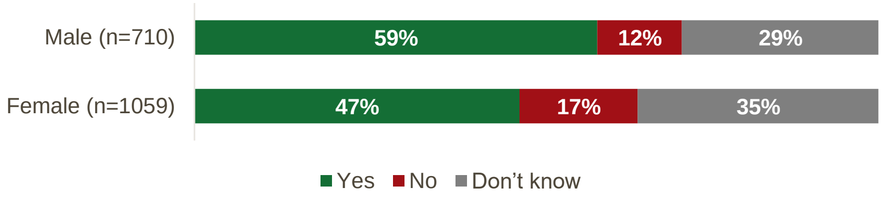
Globally, 52% (n=1,004) of patients reported they would be willing to experience additional side effects for a more effective treatment. Willingness to experience additional side effects for a more effective treatment was higher for patients with ALL (67%, n=138) and AML (67%, n=177), than with CLL (38%, n=288) or CML (42%, n=244) (Figure 200).

Figure 200. [Patient] Q96 Would you be willing to experience additional side effects for a more effective treatment?



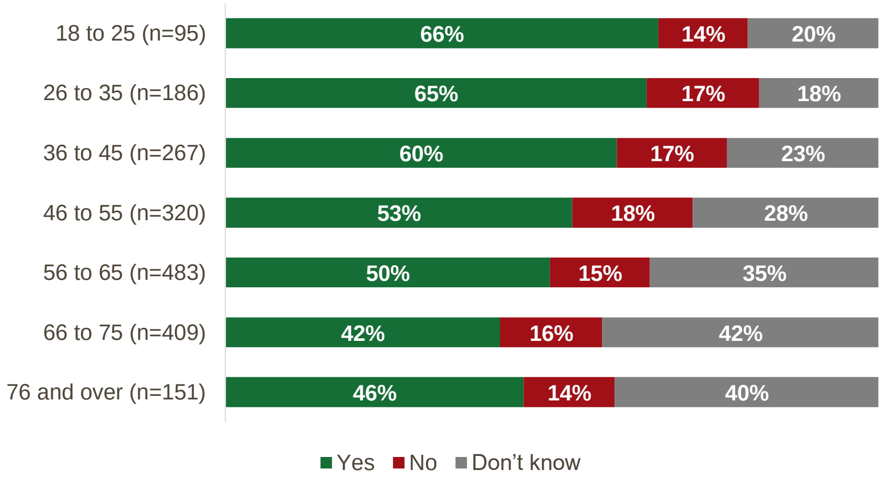
Male patients (59%, n=418) were more likely than female patients (47%, n=503) to be willing to experience additional side effects for a more effective treatment. Female patients (35%, n=373) were more likely to be uncertain than males (29%, n=204) (Figure 201).

Figure 201. [Patient] Q96 Would you be willing to experience additional side effects for a more effective treatment? by gender



Younger patients aged 18 to 25 (66%, n=63) and 26 to 35 (65%, n=120) would be more willing to experience additional side effects for a more effective treatment than older patients aged 66 to 75 (42%, n=172) and 76 and over (46%, n=69) (Figure 202).

Figure 202. [Patient] Q96 Would you be willing to experience additional side effects for a more effective treatment? by age



When asked to what extent and how often they would be willing to experience side effects:

- AML had the highest proportion of patients willing to experience severe side effects (12%, n=31) and highest proportion willing to experience side effects frequently (17%, n=44).
- In contrast, CML had the highest proportion of patients only willing to experience mild side effects (51%, n=291) and the highest proportion willing to experience side effects rarely (26%, n=150).

See Figure 203 and Figure 204 for full breakdown by leukemia type.

Figure 203. [Patient] Q97 To what extent would you be willing to experience side effects for a more effective treatment?

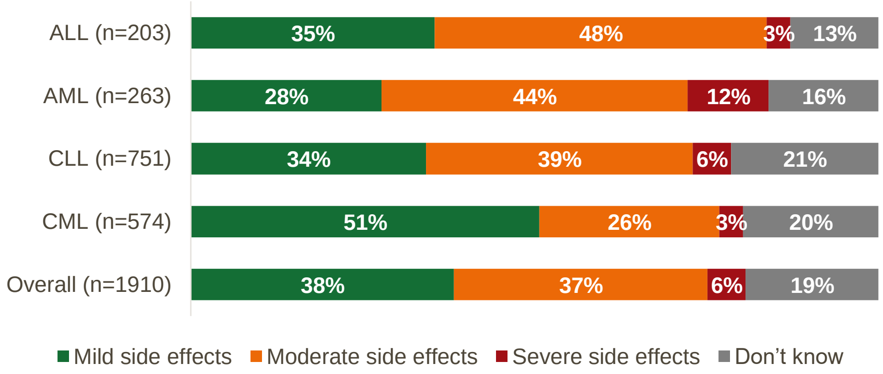
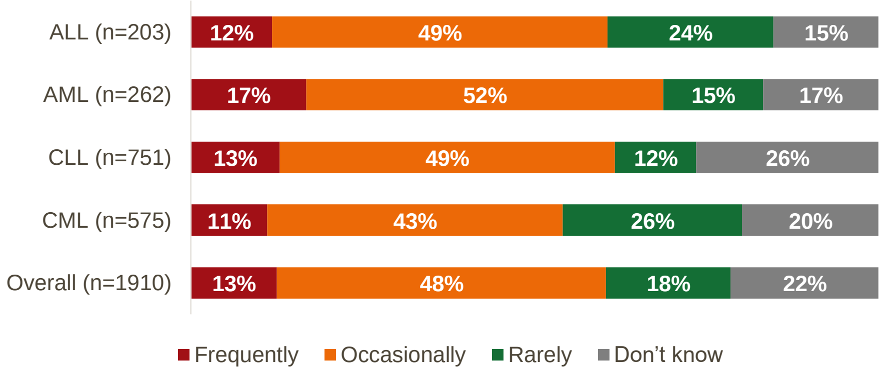


Figure 204. [Patient] Q98 How often would you be willing to experience the side effects for a more effective treatment?



Important features of a new treatment

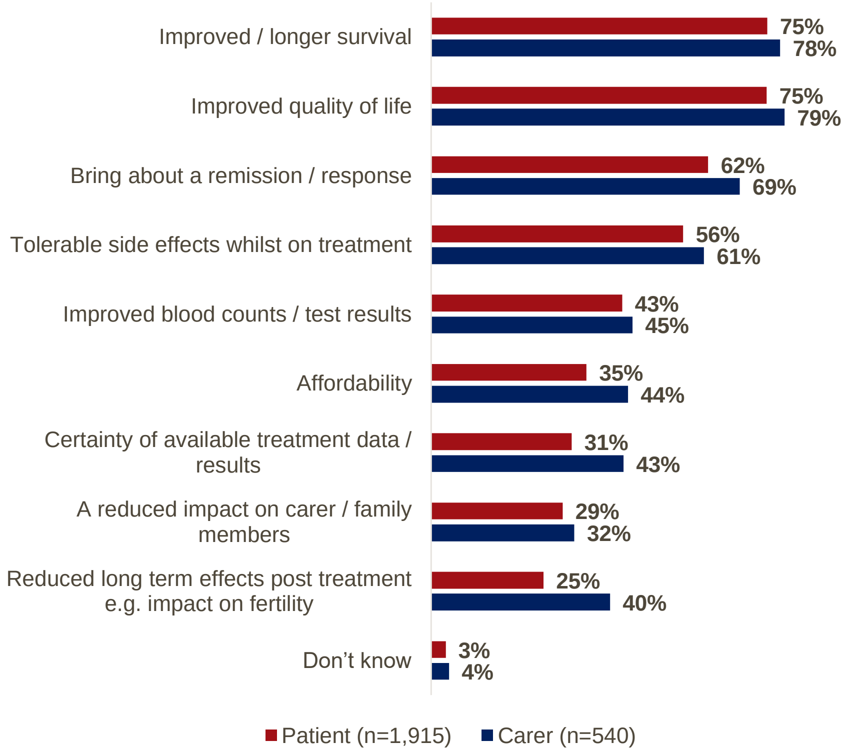
Both patients and carers were asked what they would consider to be important features of a new treatment. Overall, carers were more likely than patients to choose each feature provided. As can be seen in Figure 205, both cohorts of respondents prioritized:

- Improved / longer survival (75% of patients, n=1439; 78% of carers, n=421).
- Improved quality of life (75% of patients, n=1436; 79% of carers, n=424).
- Bring about a remission / response (62% of patients, n=1186; 69% of carers, n=372).

The biggest variances between the two groups were:

- 40% (n=216) of carers selected reduced long term effects post treatment e.g. impact on fertility, compared to 25% (n=481) of patients.
- 43% (n=234) of carers selected certainty of available treatment data / results, compared to 31% (n=602) of patients.
- 44% (n=235) of carers selected affordability, compared to 35% (n=665) of patients.

Figure 205. [Patient] Q99 What do you consider to be important features of a new treatment? [multiple choice] & [Carer] C47 What do YOU consider to be important features of a new treatment? [multiple choice]



The largest variances of important features of a new treatment by leukemia type are:

- 53% (n=397) of CLL patients considered improved blood counts / test results to be an important feature of a new treatment, compared to 27% of ALL (n=56) and AML (n=72) patients.
- 42% (n=87) of ALL patients considered reduced long term effects post treatment e.g. impact on fertility to be an important feature of a new treatment, compared to 16% (n=116) of CLL patients.

See Table 49 for full details.

Table 49.[Patient] Q99 What do you consider to be important features of a new treatment? [multiple choice]

Base (n=)	**Overall** **1915**	ALL 207	AML 265	CLL 748	CML 576
Improved / longer survival	**75%**	82%	79%	80%	66%
Bring about a remission / response	**62%**	59%	59%	64%	62%
Improved quality of life	**75%**	75%	74%	76%	74%
Improved blood counts / test results	**43%**	27%	27%	53%	41%
Tolerable side effects whilst on treatment	**56%**	51%	46%	60%	60%
A reduced impact on carer / family members	**29%**	31%	35%	31%	24%
Certainty of available treatment data / results	**31%**	35%	26%	37%	26%
Reduced long term effects post treatment e.g. impact on fertility	**25%**	42%	33%	16%	28%
Affordability	**35%**	54%	43%	29%	31%
Don't know	**3%**	4%	5%	2%	4%

Figures highlighted in red in table indicate most important feature of a new treatment for each leukemia type.

The largest variances of important features of a new treatment by leukemia type for carers are:

- 56% (n=86) of ALL carers considered reduced long term effects post treatment e.g. impact on fertility to be an important feature of a new treatment, compared to 31% (n=41) of AML carers and 31% (n=30) CLL carers.
- 54% (n=52) of CLL carers considered improved blood counts / test results to be an important feature of a new treatment, compared to 39% (n=52) of AML carers.
- 87% (n=116) of AML carers considered improved / longer survival to be an important feature of a new treatment, compared to 73% (n=82) of CML carers.

See Table 50 for full details.

Table 50. [Carer] C47 What do YOU consider to be important features of a new treatment? Please select all that apply. [Multiple choice]

Base (n=)	**Overall** **540**	ALL 153	AML 134	CLL 97	CML 113
Improved / longer survival	**78%**	78%	87%	77%	73%
Bring about a remission / response	**69%**	74%	72%	62%	65%
Improved quality of life	**79%**	83%	77%	75%	78%
Improved blood counts / test results	**45%**	44%	39%	54%	44%
Tolerable side effects whilst on treatment	**61%**	65%	57%	58%	64%
A reduced impact on carer / family members	**32%**	35%	30%	33%	30%
Certainty of available treatment data / results	**43%**	49%	37%	44%	44%
Reduced long-term effects post treatment e.g. impact on fertility	**40%**	56%	31%	31%	39%
Affordability	**44%**	48%	44%	36%	42%
Don’t know	**4%**	1%	1%	10%	3%

As shown in Table 51, age impacts how patients perceive important features of a new treatment. The largest variances were:

- Affordability was more of a priority for respondents aged 18 to 25 (62%, n=59) than those aged 76 and over (21%, n=32).
- 46% (n=44) of patients aged 18 to 25 chose reduced long term effects post treatment e.g. impact on fertility as an important feature. This is of least concern to patients aged 76 and over (8%, n=12).
- 53% (n=215) of patients aged 66 to 75 said improved blood counts / test results were important to them. This is comparable to 23% (n=22) of 18- to 25-year-olds.
- Tolerable side effects whilst on treatment was of more importance to those aged 56 to 65 (62%, n=300) and 66 to 75 (62%, n=250) than those aged 18 to 25 (39%, n=37).
- 42% (n=40) of patients aged 18 to 25 said a reduced impact on carer / family members was an important feature. This is compared to 21% (n=32) of those aged 76 and over.

Table 51. [Patient] Q99 What do you consider to be important features of a new treatment? [multiple choice] by age

	18 to 25	26 to 35	36 to 45	46 to 55	56 to 65	66 to 75	76 and over
Base (n=)	95	184	267	320	482	405	150
Improved / longer survival	**75%**	**75%**	**72%**	**79%**	78%	**74%**	65%
Bring about a remission / response	68%	65%	57%	62%	64%	63%	55%
Improved quality of life	73%	73%	70%	78%	**79%**	**74%**	71%
Improved blood counts / test results	23%	28%	36%	39%	48%	53%	48%
Tolerable side effects whilst on treatment	39%	48%	52%	56%	62%	62%	54%
A reduced impact on carer / family members	42%	22%	29%	28%	32%	30%	21%
Certainty of available treatment data / results	28%	28%	27%	30%	35%	34%	30%
Reduced long term effects post treatment e.g. impact on fertility	46%	43%	35%	27%	20%	17%	8%
Affordability	62%	47%	37%	34%	33%	29%	21%
Don't know	5%	2%	4%	1%	4%	4%	3%

Figures highlighted in red in table indicate most important feature of a new treatment for each age group.

Variances found in attributed importance to features of a new treatment by country are (Table 52):

- 68% of patients in China (n=181) and the USA (n=115) said affordability was an important feature to them. This is comparable to just 5% (n=5) of patients in Denmark and 6% (n=8) in Israel.
- 77% (n=130) of USA patients selected to bring about a remission / response as an important feature. This is compared to 33% (n=37) in Denmark.
- 61% (n=178) of patients in the UK selected improved blood counts / test results. This was of least concern to those in China (19%, n=50).

Table 52. [Patient] Q99 What do you consider to be important features of a new treatment? [multiple choice] by country

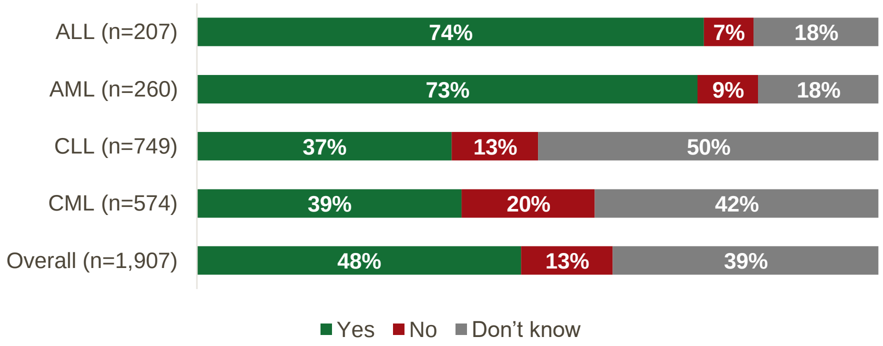
	Brazil	China	Denmark	Israel	Netherlands	United Kingdom	United States of America
Base (n=)	183	265	111	124	90	294	168
Improved / longer survival	61%	**88%**	80%	55%	61%	**82%**	**80%**
Bring about a remission / response	**73%**	57%	33%	46%	50%	66%	77%
Improved quality of life	71%	74%	**81%**	**77%**	**76%**	78%	79%
Improved blood counts / test results	46%	19%	34%	40%	30%	61%	52%
Tolerable side effects whilst on treatment	50%	42%	52%	49%	60%	65%	72%
A reduced impact on carer / family members	26%	33%	14%	19%	26%	34%	40%
Certainty of available treatment data / results	29%	31%	20%	24%	23%	37%	41%
Reduced long term effects post treatment e.g. impact on fertility	21%	37%	10%	20%	10%	17%	26%
Affordability	45%	68%	5%	6%	12%	13%	68%
Don’t know	2%	5%	4%	5%	3%	3%	2%

Figures highlighted in red in table indicate most important feature of a new treatment for each country.

Undergoing treatment to subsequently enable a stem cell transplant

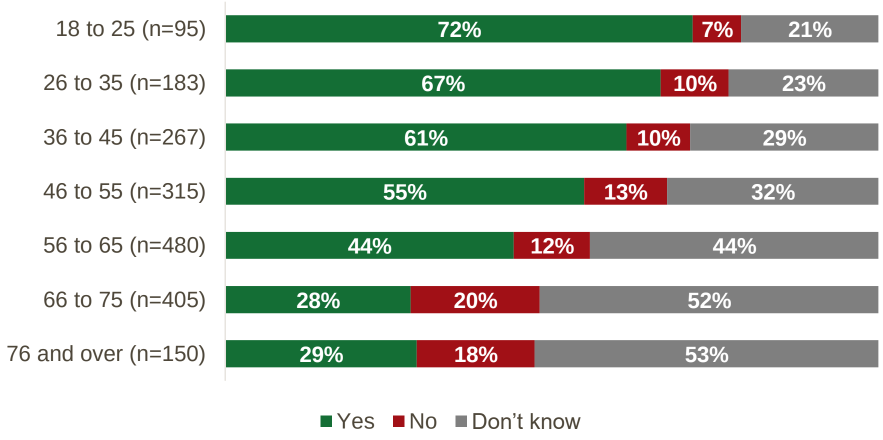
Patients with an acute diagnosis were far more likely to consider it positive if undergoing a treatment would subsequently enable them to have a stem cell transplant. As shown in Figure 206, 74% (n=154) of patients with ALL and 73% (n=191) with AML would consider this a positive outcome, compared to just 37% (n=280) of patients with CLL and 39% (n=223) with CML.

Figure 206. [Patient] Q100 Would you consider it positive if undergoing a treatment would subsequently enable you to have a stem cell transplant?



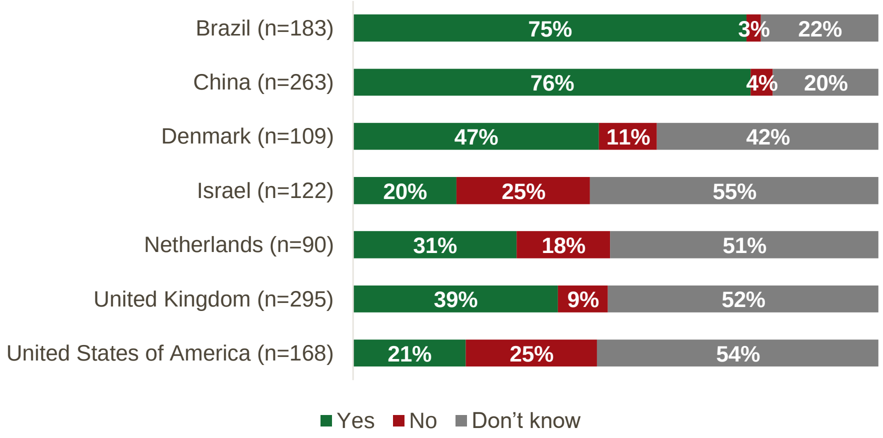
As age increases, patients perceiving undergoing a treatment to subsequently enable a stem cell transplant as a positive outcome decreases (Figure 207). 72% (n=68) of 18- to 25-year-olds would consider undergoing treatment that subsequently enables a stem cell transplant positive, compared to just 28% (n=115) of those aged 66 to 75 and 29% (n=44) aged 76 and over.

Figure 207. [Patient] Q100 Would you consider it positive if undergoing a treatment would subsequently enable you to have a stem cell transplant? by age



Perceiving undergoing a treatment to subsequently enable a stem cell transplant as a positive outcome varies widely by country of residence. Patients in China (76%, n=199) and Brazil (75%, n=137) were more than three times as likely to consider this a positive, than patients in Israel (20%, n=24) or the USA (21%, n=36) (Figure 208).

Figure 208. [Patient] Q100 Would you consider it positive if undergoing a treatment would subsequently enable you to have a stem cell transplant? by country



Conclusions

This report presents the data from the 2023 global leukemia experience survey, where 2,260 patients, and 694 carers from 69 countries shared their experience. The data collected has provided important information to help understand the key issues, experiences, and unmet needs for leukemia patients and carers. The following recommendations have been created to inform where advocacy groups efforts should be focused, and to drive improvements in care quality and experience for leukemia patients and carers.

Increase awareness of symptoms: Low awareness of symptoms of leukemia is concerning, as this lack of awareness will delay patients visiting a healthcare professional and consequently delay diagnosis and treatment. Positively, however, the majority of patients were aware that leukemia is a form of cancer when they received their diagnosis. The same advocacy efforts that were implemented to enhance knowledge of leukemia as a form of cancer can be used to increase awareness of symptoms of leukemia. #BeLeukemiaAware and World Leukemia Day are ideal existing campaigns to increase awareness within the public.

Information and explanations: There is abundant evidence that patients and carers are not receiving adequate levels of information and explanations at key points in the patient's journey. This includes, but is not limited to, during diagnosis, information on subtype or mutation, when being placed on 'watch and wait' or 'active monitoring', recognizing the signs and symptoms of CLL progression, results of test(s), clear information about side effects of treatment, information on CLL immunity status, immunizations/ vaccines and what steps CLL patients should take to avoid infection. Healthcare professionals must improve how they communicate with patients and carers, ensuring they receive vital information at key stages and are offered the opportunity to ask questions and receive answers to these questions at each stage to aid understanding. Signposting patients and carers to patient organizations groups for further support and information should become part of the consultation process.

Involvement in decision-making: People have a right to be involved in and to make decisions about their health and care. Healthcare professionals must work with patients and their carers in partnership to involve them in decision-making throughout their journey. As part of this process, healthcare professionals must ensure patients are well informed and that their personal preferences are respected.

Directing patients to information and support resources: The resources that patients rated as most helpful were not the most commonly cited resources patients were directed to. Healthcare professionals and advocacy groups should work towards greater facilitation and access to buddying or befriending, online forums, patient support groups and leukemia charities / associations / organizations as patients were most likely to report these resources as most helpful.

Address variance in experience: Throughout the findings in this report, there are clear variances in experience by leukemia type, age, gender, country, annual household income and level of education. While some variance by leukemia type can be expected due to the nature and progression of disease, there are several areas where work to address this variance is much needed, particularly in relation to impact on quality of life. Patients with ALL, AML, who were younger, female and live in a low-income household reported far greater impact to their quality of life than other groups. Enhanced care and support for these groups should be enforced to mitigate this impact.

Appendix 1 – List of figures and tables

List of figures

List of tables

Appendix 2 - Copy of the Global Leukemia Experience Survey 2023

Q1 What is your confirmed diagnosis?

○ Acute lymphoblastic leukemia (ALL)

○ Acute myeloid leukemia (AML)

○ Chronic lymphocytic leukemia (CLL)

○ Chronic myeloid leukemia (CML)

○ Hairy cell leukemia (HCL)

○ Chronic myelomonocytic leukemia (CMML)

○ Acute promyelocytic leukemia (APML / APL)

○ Other leukemia

○ Hodgkin Lymphoma

○ Non-Hodgkin Lymphoma

○ Myeloma

○ Myelodysplastic syndromes (MDS)

○ Myelofibrosis

○ Essential thrombocythaemia

○ Polycythaemia vera

○ Waldenström's macroglobulinaemia

○ Other (please specify) ____

○ Don't know / can't remember

Q2 What year were you born? Please enter in the format YYYY e.g., 1982

____

Q3 What is your gender?

○ Male

○ Female

○ Prefer to self-describe (please specify)
____

○ Prefer not to say

Q4 In which country do you live?

[List of countries]

Q5 What best describes your living situation?

○ Living alone

○ Living with adult family e.g. parents, siblings, children (non-dependent)

○ Living as a couple (spouse or partner)

○ Living as a couple with dependent children

○ Living as a lone adult with dependent children

○ Living with another dependent (non-child)

○ Living with non-family e.g. friends, house mates

○ Prefer not to say

○ Other (please specify) ____

Q6 What best describes your employment status? Please select one answer.

○ Full time employment

○ Part time employment

○ Self employment

○ Stay at home parent

○ Student

○ Retired

○ Unemployed and seeking work

○ Unemployed and unable to work for health reasons (NOT seeking work)

○ Unemployed and unable to work for non-health related reasons (NOT seeking work)

○ Full time carer (unable to work as caring for family member or friend due to illness)

○ Prefer not to say

○ Other (Please specify) ____

Q7 For your country, how would you describe your annual household income?

○ Low income

○ Average income

○ High income

○ Don’t know

○ Prefer not to say

Q8 What is your highest level of qualification?

○ No formal qualifications

○ High school qualifications or diploma

○ University – Bachelors or Undergraduate degree

○ University – Masters, PhD or MD

○ Career or technical qualifications (also known as vocational qualifications)

○ Prefer not to say

DIAGNOSIS

Q9 What year were you diagnosed? Please enter in the format YYYY e.g., 2010

____

Q10 Was your leukemia detected as a result one of the following? Please select one answer.

○ Routine blood test or health check

○ A blood test or health check for something else / another condition

○ Visiting your GP or family doctor

○ Visiting the Emergency / A&E Department

○ Referral from another hospital department

○ Other (please specify) ____

Q11 What symptoms did you encounter before your diagnosis? Please select all that apply.

☐ Bleeding
☐ Bruising
☐ Fatigue
☐ Shortness of breath
☐ Fever / night sweats
☐ Frequent and repeated infections
☐ Unexplained weight loss
☐ Loss of appetite
☐ Nausea or vomiting
☐ Sleeping problems
☐ Headaches
☐ Swollen lymph nodes
☐ Tingling or numbness in extremities
☐ Itchy skin
☐ Pain in bones / joints
☐ Swollen stomach or abdominal discomfort
☐ Memory loss / loss of concentration
☐ Palpitations / heart irregularities
☐ Muscle pain
☐ Back pain
☐ Changes to menstrual cycle

☐ Broken blood vessel in eye (Subconjunctival hemorrhage)

☐ Unusually high or low red / white / platelet blood count

☐ High blood pressure (Hypertension)

☐ No symptoms

☐ Other (Please specify) ____

Q12 Did you know that the health problems you were experiencing could be symptoms of leukemia?

○ Yes

○ No

Q13 How long was it from the time you first experienced symptoms until you first spoke to a healthcare professional about them?

By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc.

○ Less than a month

○ 1-3 months

○ 4-6 months

○ 7-11 months

○ 1-2 years

○ Over 2 years

○ Don’t know / can’t remember

Q14 How many times did you see a healthcare professional about your symptoms before you were diagnosed?

By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc.

○ Once

○ Twice

○ Three times

○ Four times

○ Five or more times

○ Don’t know / can’t remember

Q15 How long was it from the time you first saw a healthcare professional until you were diagnosed with your condition?

By this we mean any medical professional you saw, this could be a GP / family doctor, hospital doctor, etc.

○ Less than a month

○ 1-3 months

○ 4-6 months

○ 7-11 months

○ 1-2 years

○ Over 2 years

○ Don’t know / can’t remember

Q16 Have you been informed of your leukemia subtype or specific mutation?

○ Yes

○ No

○ Don't know / can't remember

Q17 What form of genetic mutation do you have?

○ PML-RARA

○ RUNX1-RUNX1T1

○ CBFB-MYH11

○ MLLT3-KMT2A

○ BCR-ABL1

○ NPM1

○ CEBPA

○ FLT3

○ IDH1/2

○ RUNX1

○ ASXL1

○ TP53

○ NGS gene panel

○ Other (please specify) ____

○ Don’t know / can’t remember

Q18 What is your cytogenetic status?

○ Philadelphia chromosome

○ Hypodiploidy

○ MLL rearragements

○ Hyperdiploidy

○ Other (please specify) ____

○ Don’t know / can’t remember

Q19 What is your CLL subtype?

○ 11q

○ 13q

○ 17p/TP53

○ Trisomy 12

○ Other (please specify) ____

○ Don’t know / can’t remember

Q20 What is your immunoglobulin heavy chain (IGHV) mutation status?

○ Mutated

○ Unmutated

○ Don’t know / can’t remember

Q21 Have you got the T315I mutation?

○ Yes

○ No

○ Don’t know / can’t remember

Q22 Do you know which phase of CML you are in?

○ Chronic phase

○ Accelerated phase

○ Blast phase / Blast crisis

○ Don't know / can't remember

Q23 How did your diagnosis consultation take place?

○ In person / face-to-face

○ By phone

○ By video

○ Other (Please specify) ____

Q24 When you were told you had leukemia, who was with you? Please select all that apply.

☐ My spouse or partner

☐ My parent(s) or guardian(s)

☐ My son or daughter

☐ Another relative (not mentioned above)

☐ Non-relative e.g. friend, colleague

☐ No one, I was on my own

☐ Don’t know / can’t remember

Q25 When you were given your diagnosis of leukemia, were you aware it was a form of cancer?

○ Yes

○ No

Q26 Was your diagnosis explained to you in a way you could understand?

○ Yes, completely
○ Yes, to some extent
○ No
○ Don’t know / can’t remember

Q27 Were you given clear information about your diagnosis?

○ Yes, definitely
○ Yes, to some extent
○ No
○ Don’t know / can’t remember

Q28 Were you told about your leukemia in a sensitive way?

○ Yes, definitely
○ Yes, to some extent
○ No
○ Don’t know / can’t remember

'Watch and Wait' or 'Active Monitoring'

Q29 Have you ever been placed on a 'watch and wait' or 'active monitoring' monitoring plan?

○ Yes
○ No
○ Don’t know

Q30 When you were placed on 'watch and wait' or 'active monitoring' for the FIRST time, was it explained to you in a way you could understand?

○ Yes, completely

○ Yes, to some extent

○ No

○ I was not given an explanation

○ Don’t know / can’t remember

Q31 What best describes your current 'watch and wait' or 'active monitoring' situation?

○ I am currently on ‘watch and wait’ or 'active monitoring'

○ I am not currently on 'watch and wait' or 'active monitoring'

○ Don't know / can't remember

Q32 What is the main way your monitoring visits take place?

A monitoring visit is a regular check up with a member of your medical team to check if your leukemia needs treatment.

○ In person / face-to-face at my GP practice / family doctor

○ In person / face-to-face at the hospital

○ Remotely (phone or video call) with my GP practice / family doctor

○ Remotely (phone or video call) with the hospital

○ Other (Please specify) ____

Q33 While on 'watch and wait' or 'active monitoring', who helps you with pain or symptoms related to your diagnosis? Please select all that apply.

☐ I don't experience any pain or symptoms

☐ No-one, I self-manage

☐ My GP / family doctor

☐ My hospital doctor

☐ My Clinical Nurse Specialist (CNS)

☐ Other (Please specify) ____

☐ Don't know / can't remember

Q34 How did you feel about being put on 'watch and wait' or 'active monitoring'? If you have been on 'watch and wait' or 'active monitoring' more than once, please think back to the first time.

○ I did not have any concerns or worries

○ I had some concerns and worries

○ I was very concerned / worried about it

○ Don't know / can't remember

Q35 Were you involved as much as you wanted to be in decisions about being put on 'watch and wait' or 'active monitoring'?

○ Yes, definitely

○ Yes, to some extent

○ No

○ Don't know / can't remember

Q36 Are you confident you can recognise the signs and symptoms of CLL progression?

○ Yes, definitely

○ Yes, to some extent

○ No

TREATMENT

Q37 How long was it between your diagnosis and starting treatment for your specific leukemia e.g. CML, CLL, AML, ALL?

By treatment we mean chemotherapy, immunotherapy, radiotherapy, steroids, stem cell transplants or targeted therapy you have had to treat your leukemia. Please don't include any other treatment you may have received for your symptoms.

○ The same day I was given my diagnosis

○ Within 1 week

○ Within 1 month

○ Within 3 months

○ Within 6 months

○ Within 1 year

○ Within 2 years

○ More than 2 years

○ I have not had treatment

Q38 Were you offered a choice of treatment options?

○ Yes, a choice was offered to me

○ Yes, but I had to ask

○ No

○ Don’t know / can’t remember

Q39 Were you given the option of participating in a clinical trial?

○ Yes, and I joined a trial

○ Yes, but I didn’t join a trial

○ No

○ Don’t know / can’t remember

Q40 Were you involved as much as you wanted to be in decisions about your treatment?

○ Yes, definitely

○ Yes, to some extent

○ No

○ Don’t know / can’t remember

Q41 Who or what else helped you make decisions about your treatment? Please select all that apply.

☐ My spouse or partner

☐ My parent(s) or guardian(s)

☐ My son or daughter

☐ Another relative (not mentioned above)

☐ Non-relative e.g. friend, colleague

☐ My family doctor

☐ A patient organisation or support group

☐ Online resources

☐ It was my decision alone

☐ My personal financial situation

☐ Other (Please specify) ____

Q42 Are you currently receiving treatment for your leukemia? By this we mean the disease itself, not treatment for any side effects or resulting conditions.

○ Yes

○ No

Q43 What is your current treatment? Please select all that apply.

☐ Chemotherapy

☐ Immunotherapy

☐ Radiotherapy

☐ Steroids

☐ Stem cell transplant

☐ Targeted therapy (e.g. tyrosine kinase inhibitors)

☐ Other (Please specify) ____

Q44 What was your most recent treatment? Please select all that apply.

☐ Chemotherapy

☐ Immunotherapy

☐ Radiotherapy

☐ Steroids

☐ Stem cell transplant

☐ Targeted therapy (e.g. tyrosine kinase inhibitors)

☐ Other (Please specify) ____

Q45 How long ago was your most recent treatment?

○ Less than 3 months ago
○ 3 – 6 months ago
○ 7 – 11 months ago
○ 1 – 2 years ago
○ 3 – 4 years ago
○ 5 or more years ago
○ Don't know / can't remember

Q46 How is / was your most recent / current treatment administered? Please select all that apply.

☐ An oral drug (pill / tablet / liquid solution)
☐ An intravenous (IV) drug given as an hospital inpatient
☐ An intravenous (IV) drug given as an hospital outpatient
☐ Other (Please specify) ____
☐ Don't know / can't remember

Q47 For how long will you be taking your treatment?

○ I am on continuous treatment (will be taking indefinitely or until told to stop)
○ For a fixed period
○ Don't know

Q48 Have you missed a dose in the last year?

○ Yes
○ No
○ Not applicable
○ Don't know / can't remember

Q49 For what reason did you miss the dose? Please select all that apply.

☐ To reduce my side effects

☐ I was not feeling well

☐ I was feeling down / depressed

☐ It interfered with my plans e.g. socialising, working, travelling

☐ My doctor told me I could / should

☐ I forgot / reminder failed

☐ My routine was interrupted

☐ I ran out of medication

☐ My dosing schedule is / was too complicated

☐ I couldn’t swallow the tablets

☐ I was feeling better

☐ I couldn’t afford my medication / I wanted to save money

☐ Other (Please specify) ____

☐ Don’t know / can’t remember

Q50 Were you given clear information about any side effects from your **most recent or current treatment**?

○ Yes, completely

○ Yes, to some extent

○ No

○ I did not need any information

○ Don’t know / can’t remember

Q51 What impact has your **most recent or current treatment** had on the symptoms that you were experiencing?

○ My symptoms have improved

○ My symptoms have remained the same

○ My symptoms have gotten worse

○ Not applicable - I didn't have any symptoms

○ Don’t know / can’t remember

Q52 What side effects have you encountered as a result of your **most recent or current treatment**? Please select all that apply.

☐ Bleeding
☐ Bruising
☐ Fatigue
☐ Shortness of breath
☐ Fever / night sweats
☐ Frequent and repeated infections
☐ Unexplained weight loss
☐ Loss of appetite
☐ Nausea or vomiting
☐ Sleeping problems
☐ Headaches
☐ Swollen lymph nodes
☐ Tingling or numbness in extremities
☐ Itchy skin
☐ Pain in bones / joints
☐ Swollen stomach or abdominal discomfort
☐ Memory loss / loss of concentration
☐ Palpitations / heart irregularities
☐ Muscle pain
☐ Back pain

☐ Changes to menstrual cycle

☐ Broken blood vessel in eye (Subconjunctival hemorrhage)

☐ Unusually high or low red / white / platelet blood count

☐ High blood pressure (Hypertension)

☐ No side effects

☐ Other (Please specify) ____

Q53 How often do / did you experience the side effects of your most recent or current treatment?	Always	Very often	Sometimes	Rarely
Bleeding	○	○	○	○
Bruising	○	○	○	○
Fatigue	○	○	○	○
Shortness of breath	○	○	○	○
Fever / night sweats	○	○	○	○
Frequent and repeated infections	○	○	○	○
Unexplained weight loss	○	○	○	○
Loss of appetite	○	○	○	○
Nausea or vomiting	○	○	○	○
Sleeping problems	○	○	○	○
Headaches	○	○	○	○
Swollen lymph nodes	○	○	○	○
Tingling or numbness in extremities	○	○	○	○
Itchy skin	○	○	○	○
Pain in bones / joints	○	○	○	○
Swollen stomach or abdominal discomfort	○	○	○	○
Memory loss / loss of concentration	○	○	○	○
Palpitations / heart irregularities	○	○	○	○
Muscle pain	○	○	○	○

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Back pain	○	○	○	○
Changes to menstrual cycle	○	○	○	○
Broken blood vessel in eye (Subconjunctival hemorrhage)	○	○	○	○
Unusually high or low red / white / platelet blood count	○	○	○	○
High blood pressure (Hypertension)	○	○	○	○
Other (Please specify)	○	○	○	○

Q54 How severe are / were the side effects of your most recent or current treatment?	Mild	Moderate	Severe
Bleeding	○	○	○
Bruising	○	○	○
Fatigue	○	○	○
Shortness of breath	○	○	○
Fever / night sweats	○	○	○
Frequent and repeated infections	○	○	○
Unexplained weight loss	○	○	○
Loss of appetite	○	○	○
Nausea or vomiting	○	○	○
Sleeping problems	○	○	○
Headaches	○	○	○
Swollen lymph nodes	○	○	○
Tingling or numbness in extremities	○	○	○
Itchy skin	○	○	○
Pain in bones / joints	○	○	○
Swollen stomach or abdominal discomfort	○	○	○

Memory loss / loss of concentration	○	○	○
Palpitations / heart irregularities	○	○	○
Muscle pain	○	○	○
Back pain	○	○	○
Changes to menstrual cycle	○	○	○
Broken blood vessel in eye (Subconjunctival hemorrhage)	○	○	○
Unusually high or low red / white / platelet blood count	○	○	○
High blood pressure (Hypertension)	○	○	○
Other (Please specify)	○	○	○

Q55 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? 0 is very dissatisfied and 10 is very satisfied.

○ 0
○ 1
○ 2
○ 3
○ 4
○ 5
○ 6
○ 7
○ 8
○ 9
○ 10

Q56 Did you have any treatment for your leukemia delayed due to COVID-19?

○ Yes
○ No
○ Don’t know / can’t remember
○ Not applicable

Q57 Did your leukemia treatment change due to COVID-19?

○ Yes
○ No
○ Don’t know / can’t remember
○ Not applicable

Q58 Have you ever had a stem cell transplant as part of your treatment for leukemia?

○ Yes

○ No

Q59 How long ago did you have your most recent stem cell transplant?

○ Less than 3 months ago

○ 3 – 6 months ago

○ 7 – 11 months ago

○ 1 – 2 years ago

○ 3 – 4 years ago

○ 5 or more years ago

○ Don’t know / can’t remember

Q60 What was your most recent stem cell transplant?

○ Autologous stem cell transplant (transplant using own cells)

○ Allogenic stem cell transplant (transplant using donor cells)

○ Don’t know / can’t remember

Q61 Before your stem cell transplant, did you receive an explanation about the possibility of complications in a way you could understand?

○ Yes, completely

○ Yes, to some extent

○ No

○ I was not given an explanation

○ Don’t know / can’t remember

Q62 Did you develop complications following your stem cell transplant?

○ Yes

○ No

○ Don’t know / can’t remember

Q63 If you experience/d the following side effects post treatment, **overall** how would you rate their negative impact?	Barely noticeable	Small impact	Large impact	Not applicable
Engraftment syndrome	○	○	○	○
Graft rejections	○	○	○	○
Graft failure	○	○	○	○
Graft -versus-host disease (acute)	○	○	○	○
Graft -versus-host disease (chronic)	○	○	○	○
Cytomegalovirus (CMV)	○	○	○	○
Cataracts	○	○	○	○
Thrombotic microangiopathy (TMA)	○	○	○	○
Other (Please specify)	○	○	○	○

Q64 Have you had a relapse?

○ Yes

○ No

Q65 How many times have you had to change your treatment or treatment plan as a result of a relapse?

○ None

○ Once

○ Twice

○ Three times

○ Four times or more

Q66 Which barriers (if any) have you experienced that affected your treatment choices? Please select all that apply.

☐ Cost of treatment

☐ Lack of access to treatment centre / prohibitive travel

☐ Language / inability to understand the treatment

☐ Lack of access to the most up-to-date treatment or equipment

☐ Wait time to treatment was an issue for me

☐ Lack of personal support

☐ No speciality doctor locally

☐ Difficulty managing my carer / caregiver role (child, parent, disabled person) while in treatment

☐ Fear of discrimination if my employer / friends / family knew about my disease

☐ No available treatment for my specific leukemia type

☐ I experienced no barriers

☐ Other barrier not mentioned above (please specify)

____

TESTING AND MONITORING

Q67 Are you currently undergoing regular testing or monitoring for your leukemia?

○ Yes

○ No

Q68 Are the results of your test(s) explained to you in a way you can understand?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don't know / can't remember

Q69 Do you have to ask for the results to be explained?

○ Yes, always

○ Yes, sometimes

○ No

○ Don't know / can't remember

Q70 Are you able to access your test results, or copies of your test results, if you want to?

○ Yes

○ No

○ Don't know

Q71 How worried / anxious do you feel when waiting for the results of your regular testing / monitoring? 0 is not at all worried/ anxious and 10 is extremely worried/ anxious.

○ 0

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10

Q72 Do you know your immunity status?

Your immunity and immunity status are connected to your immune system, which is the body's centre for fighting infection and disease. Your immunity is your body's overall ability to fight these infections and diseases.

○ Yes

○ No

○ Don’t know

Q73 Were you given clear information about what steps you can take to stay healthy and avoid infections?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don't know / can't remember

Q74 Has a health professional spoken to you about the protocols for CLL immunisations / vaccinations, including which you should receive and which you should avoid?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don't know / can't remember

Q75 Have you heard of minimal / measurable residual disease? (MRD)

○ Yes

○ No

○ Don't know / can't remember

INFORMATION AND SUPPORT

Q76 Did someone speak to you about the impact treatment could have on your fertility?

○ Yes

○ No

○ Don't know / can't remember

○ Not applicable

Q77 Has a health professional spoken to you about immunisations / vaccinations, including which you should receive and which you should avoid?

○ Yes

○ No

○ Don’t know / can’t remember

Q78 Please select what information and support you were given or directed to during your treatment journey. Please select all that apply

☐ Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy

☐ General wellbeing (including spiritual wellbeing)

☐ Clinical trials

☐ Side effects and risks of treatment

☐ Access to a Clinical Nurse Specialist (CNS)

☐ Patient rights

☐ Buddying or befriending

☐ Patient support groups

☐ Leukemia charities / associations / organisations

☐ Financial information

☐ Written information / booklets / leaflets

☐ Online forums

☐ End of life care

☐ I was not given or directed to information or support

Q79 When in your treatment journey were you given or directed to the information and support?	At diagnosis	During 'watch and wait' or 'active monitoring'	After diagnosis but before treatment started	During treatment	After treatment finished	Don't know / can't remember
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	☐	☐	☐	☐	☐	☐
General wellbeing (including spiritual wellbeing)	☐	☐	☐	☐	☐	☐
Clinical trials	☐	☐	☐	☐	☐	☐
Side effects and risks of treatment	☐	☐	☐	☐	☐	☐
Access to a Clinical Nurse Specialist (CNS)	☐	☐	☐	☐	☐	☐
Patient rights	☐	☐	☐	☐	☐	☐
Buddying or befriending	☐	☐	☐	☐	☐	☐
Patient support groups	☐	☐	☐	☐	☐	☐
Leukemia charities / associations / organisations	☐	☐	☐	☐	☐	☐

Financial information	☐	☐	☐	☐	☐	☐
Written information / booklets / leaflets	☐	☐	☐	☐	☐	☐
Online forums	☐	☐	☐	☐	☐	☐
End of life care	☐	☐	☐	☐	☐	☐

Q80 Did you access this support and did it help you?	Yes, and it helped me feel better / more positive	Yes, but it did not help me feel any better / more positive	No, I did not access this support	Don't know / can't remember
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	○	○	○	○
General wellbeing (including spiritual wellbeing)	○	○	○	○
Clinical trials	○	○	○	○
Side effects and risks of treatment	○	○	○	○
Access to a Clinical Nurse Specialist (CNS)	○	○	○	○
Patient rights	○	○	○	○
Buddying or befriending	○	○	○	○
Patient support groups	○	○	○	○
Leukemia charities / associations / organisations	○	○	○	○
Financial information	○	○	○	○
Written information / booklets / leaflets	○	○	○	○
Online forums	○	○	○	○
End of life care	○	○	○	○

Q81 Did the information and support you accessed make you feel more confident to be involved in decisions about your care and treatment?

○ Yes, definitely

○ Yes, to some extent

○ No

○ Don’t know / can’t remember

Q82 Did you conduct any of your own research into any of the following? Please select all that apply.

This can include internet searches, reading research articles, listening to podcasts and videos etc.

☐ Diagnosis

☐ Treatments available

☐ Clinical trials

☐ Testing and monitoring (incl. results)

☐ Side effects

☐ Other (please specify) ____

☐ No, I did not conduct my own research

QUALITY OF LIFE

The following questions seek your views about how your disease condition and / or treatment is affecting your daily life. All statements must be answered.

If the area is not a problem for you in any way, please select the 'not at all' option.

If the area is affected by your hematological condition, please choose the extent to which it is affected by selecting either the 'a little' or 'a lot' option.

If any of the statements do not apply to you, please select the 'not applicable' option.

There is no 'right' or 'wrong' answer. If you are unsure about how to answer a question, please give the best answer you can.

Q83 The following statements describe your physical behaviour	Not at all	A little	A lot	Not applicable
I have difficulty with walking	○	○	○	○
I have difficulty with self-care (e.g. dressing, bathing, etc.).	○	○	○	○
I have difficulty with physical activity / sports	○	○	○	○
I have difficulty travelling (e.g. bus, train, flight and car)	○	○	○	○
I have difficulty leaving the house	○	○	○	○
I have difficulty with work (or studies)	○	○	○	○
I have difficulty going on holidays	○	○	○	○

Q84 The following statements describe your social wellbeing	Not at all	A little	A lot	Not applicable
I have difficulty socialising	○	○	○	○
I am having difficulty with personal relationships	○	○	○	○
I have problems with my sex life	○	○	○	○

Q85 The following statements describe your emotional behaviour	Not at all	A little	A lot	Not applicable
I worry about being a burden to others	○	○	○	○
I am concerned about people judging me	○	○	○	○
I worry about my appearance	○	○	○	○
I feel distressed	○	○	○	○
I feel anxious	○	○	○	○
I worry about dying	○	○	○	○
I don’t feel confident	○	○	○	○
I am worried about my future health	○	○	○	○
My sleeping pattern has changed	○	○	○	○
I have difficulty concentrating	○	○	○	○
I worry about treatment	○	○	○	○

Q86 The following statements describe your eating and drinking

	Not at all	A little	A lot	Not applicable
I have trouble with my appetite	○	○	○	○
My eating habits have changed	○	○	○	○
My drinking habits have changed	○	○	○	○

Q87 The following statements describe disease symptoms or treatment side effects. Please select the box which best describes the symptoms you have been experiencing over the past **three days**. If you do not experience a symptom listed below, please select the 'not at all' option. If the symptom is affecting you, please choose the severity of the symptom by selecting either the 'mild' or 'severe' option.

	Not at all	Mild	Severe
I have / had fever	○	○	○
I have stomach ache	○	○	○
I have problems with my energy level	○	○	○
I have hair loss	○	○	○
I feel tired	○	○	○
I have back pain	○	○	○
I have problems with my sense of taste	○	○	○
I have difficulty breathing	○	○	○
I have skin problems (e.g. itching, bruises, rashes, etc.)	○	○	○
I have headaches	○	○	○
I have constipation	○	○	○
I have lumps	○	○	○
I have body pain	○	○	○
I have infections (e.g. chest, lung, urinary, etc.)	○	○	○

I have night sweats	○	○	○
I have diarrhoea	○	○	○
I have nausea	○	○	○
I have / had chest pain	○	○	○

Q88 How often have the following impacted your sense of emotional well-being since your diagnosis?	Always	Very often	Sometimes	Rarely	Never
General anxiety	○	○	○	○	○
Disease-related anxiety	○	○	○	○	○
Fear of dying	○	○	○	○	○
Fear of the cancer/growth coming back (recurrence)	○	○	○	○	○
Depression	○	○	○	○	○
Isolation	○	○	○	○	○

Q89 At any point since you were diagnosed with leukemia, has your ability to work been affected?

○ Yes, I had to stop working either temporarily or permanently

○ Yes, I had to reduce my working hours

○ No, I continued to work as normal

○ Not applicable

Q90 At any point since you were diagnosed with leukemia, has your ability to study been affected?

○ Yes, I had to stop studying either temporarily or permanently

○ Yes, I had to reduce my hours of study

○ No, I continued to study as normal

○ Not applicable

Q91 Overall, since your diagnosis, have you experienced a financial impact as a result of having leukemia (positive or negative)?

○ Overall negative impact (e.g. increased costs and / or reduced income)

○ No impact on spending / income

○ Overall positive impact (e.g. insurance payout)

Q92 Have you ever talked to any of the following about any worries or concerns about your leukemia? Please select all that apply.

☐ Healthcare professional
☐ Patient organisations / patient advocacy groups
☐ Psychologist
☐ Counsellor
☐ Family
☐ Friends
☐ Other (please specify) ____
☐ None of the above

Q93 How helpful were they?	Very helpful	Somewhat helpful	Not helpful	Don’t know / Can’t remember
Healthcare professional	○	○	○	○
Patient organisations / patient advocacy groups	○	○	○	○
Psychologist	○	○	○	○
Counsellor	○	○	○	○
Family	○	○	○	○
Friends	○	○	○	○
Other (please specify)	○	○	○	○

YOUR VIEWS ON POTENTIAL NEW TREATMENTS

Q94 Would you consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether?

○ Yes

○ No

○ Don't know

Q95 If you were given the choice, which treatment methods would you prefer? Please select all that apply.

☐ Intravenous infusion (given through a drip)

☐ Injection (either into the muscle or under the skin)

☐ Oral drug (pill / tablet / liquid solution)

☐ Don't know

Q96 Would you be willing to experience additional side effects for a more effective treatment?

○ Yes

○ No

○ Don't know

Q97 To what extent would you be willing to experience side effects for a more effective treatment?

○ Mild side effects

○ Moderate side effects

○ Severe side effects

○ Don't know

Q98 How often would you be willing to experience the side effects for a more effective treatment?

○ Frequently

○ Occasionally

○ Rarely

○ Don’t know

Q99 What do you consider to be important features of a new treatment? Please select all that apply.

☐ Improved / longer survival

☐ Bring about a remission / response

☐ Improved quality of life

☐ Improved blood counts / test results

☐ Tolerable side effects whilst on treatment

☐ A reduced impact on carer / family members

☐ Certainty of available treatment data / results

☐ Reduced long term effects post treatment e.g. impact on fertility

☐ Affordability

☐ Don’t know

Q100 Would you consider it positive if undergoing a treatment would subsequently enable you to have a stem cell transplant?

○ Yes

○ No

○ Don’t know

CARER SURVEY

ABOUT THE PATIENT

C1 What is the patient’s confirmed diagnosis?

○ Acute lymphoblastic leukemia (ALL)

○ Acute myeloid leukemia (AML)

○ Chronic lymphocytic leukemia (CLL)

○ Chronic myeloid leukemia (CML)

○ Hairy cell leukemia (HCL)

○ Chronic myelomonocytic leukemia (CMML)

○ Acute promyelocytic leukemia (APML / APL)

○ Other leukemia

○ Hodgkin Lymphoma

○ Non-Hodgkin Lymphoma

○ Myeloma

○ Myelodysplastic syndromes (MDS)

○ Myelofibrosis

○ Essential thrombocythaemia

○ Polycythaemia vera

○ Waldenström's macroglobulinaemia

○ Other (please specify) ____

○ Don't know / can't remember

C2 What year was the patient born? Please enter in the format YYYY e.g., 1982

____

C3 What is the gender of the patient?

○ Male

○ Female

○ Prefer to self-describe (please specify)

____

○ Prefer not to say

C4 What year was the patient diagnosed? Please enter in the format YYYY e.g., 2010

____

ABOUT YOU

C5 What year were you born? Please enter in the format YYYY e.g., 1982

____

C6 What is your gender?

○ Male

○ Female

○ Prefer to self-describe (please specify)

____

○ Prefer not to say

C7 In which country do you live?

[List of countries]

C8 What best describes your employment status? Please select one answer.

○ Full time employment

○ Part time employment

○ Self employment

○ Stay at home parent

○ Student

○ Retired

○ Unemployed and seeking work

○ Unemployed and unable to work for health reasons (NOT seeking work)

○ Unemployed and unable to work for non-health related reasons (NOT seeking work)

○ Full time carer (unable to work as caring for family member or friend due to illness)

○ Prefer not to say

○ Other (Please specify) ____

C9 For your country, how would you describe your annual household income?

○ Low income

○ Average income

○ High income

○ Don’t know

○ Prefer not to say

C10 What is your highest level of qualification?

○ No formal qualifications

○ High school qualifications or diploma

○ University – Bachelors or Undergraduate degree

○ University – Masters, PhD or MD

○ Career or technical qualifications (also known as vocational qualifications)

○ Prefer not to say

CARE AND SUPPORT

C11 What is your relationship to the patient?

○ Spouse or partner

○ Parent or guardian

○ Son or daughter

○ Other relative (not mentioned above)

○ Non-relative e.g. friend, neighbour

○ Professional employed carer

○ Other (please specify) ____

C12 Do you live with the patient?

○ Yes

○ No

C13 As a result of their leukemia diagnosis, which of the following care and support activities do you provide? Please select all that apply.

☐ Emotional support

☐ Communication e.g. Interaction with health and social care professionals and / or helping with phone calls / write letters / emails

☐ Household tasks e.g. cooking, cleaning, other household chores

☐ Personal care e.g. wash, dress, use the toilet, feed

☐ Collect prescriptions

☐ Providing transport / travel

☐ Accompanying on trips or appointments

☐ Giving medication

☐ Looking after children

☐ Manage finances

☐ Shopping

☐ Other support (please specify) ____

C14 On average how many hours do you spend providing care and support to the patient?

○ Less than 1 hour
○ 1-4 hours a week
○ 5-9 hours a week
○ 10-19 hours a week
○ 20-35 hours a week
○ 36-49 hours a week
○ 50+ hours a week
○ Don't know

DIAGNOSIS

C15 Before the diagnosis were you aware that the health problems the patient was experiencing could have been the symptoms of leukemia?

○ Yes
○ No
○ They did not have symptoms
○ I was not aware of their symptoms before diagnosis

C16 Who told **YOU** about the patient's leukemia diagnosis?

○ The person (patient) with the leukemia diagnosis
○ A healthcare professional
○ A friend or family member
○ Other (please specify) ____

C17 Was the diagnosis explained to you in a way you could understand?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don’t know / can’t remember

C18 Who told the patient they had leukemia?

○ I did

○ A healthcare professional

○ A friend or family member

○ Other (please specify) ____

○ Don't know

C19 When the patient was told they had leukemia, were you with them?

○ Yes

○ No, someone else was

○ No, they were on their own

○ Don't know

'Watch and Wait' or 'Active Monitoring'

C20 Has the patient ever been placed on a 'watch and wait' or 'active monitoring' plan?

○ Yes

○ No

○ Don’t know / can’t remember

C21 When they were placed on 'watch and wait' or 'active monitoring' for the **FIRST TIME** did **YOU** understand the reasons why?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don’t know / can’t remember

TREATMENT

C22 Has the patient had treatment for their leukemia?

○ Yes

○ No

○ Don’t know

C23 Do you think the patient was involved as much as they should have been in decisions about their treatment and care?

○ Yes, definitely (they were very involved)

○ They were involved to some extent

○ No, they were not involved

○ I was the one who took all the decisions

○ Don’t know / can’t remember

C24 Do you think that **YOU** were involved as much as you should have been in decisions about the patient's treatment and care?

○ Yes, definitely

○ Yes, to some extent

○ No

○ Don't know / can't remember

○ Not applicable

C25 What side effects have you witnessed the patient experience as a result of their **most recent or current treatment**? Please select all that apply.

☐ Bleeding

☐ Bruising

☐ Fatigue

☐ Shortness of breath

☐ Fever / night sweats

☐ Frequent and repeated infections

☐ Unexplained weight loss

☐ Loss of appetite

☐ Nausea or vomiting

☐ Sleeping problems

☐ Headaches

☐ Swollen lymph nodes

☐ Tingling or numbness in extremities

☐ Itchy skin

☐ Pain in bones / joints

☐ Swollen stomach or abdominal discomfort

☐ Memory loss / loss of concentration

☐ Palpitations / heart irregularities

☐ Muscle pain

☐ Back pain

☐ Changes to menstrual cycle

☐ Broken blood vessel in eye (Subconjunctival hemorrhage)

☐ Unusually high or low red / white / platelet blood count

☐ High blood pressure (Hypertension)

☐ No side effects

☐ Other (Please specify) ____

C26 How often do / did they experience the side effects of their most recent or current treatment?	Always	Very often	Sometimes	Rarely
Bleeding	○	○	○	○
Bruising	○	○	○	○
Fatigue	○	○	○	○
Shortness of breath	○	○	○	○
Fever / night sweats	○	○	○	○
Frequent and repeated infections	○	○	○	○
Unexplained weight loss	○	○	○	○
Loss of appetite	○	○	○	○
Nausea or vomiting	○	○	○	○
Sleeping problems	○	○	○	○
Headaches	○	○	○	○
Swollen lymph nodes	○	○	○	○
Tingling or numbness in extremities	○	○	○	○
Itchy skin	○	○	○	○

Pain in bones / joints	○	○	○	○
Swollen stomach or abdominal discomfort	○	○	○	○
Memory loss / loss of concentration	○	○	○	○
Palpitations / heart irregularities	○	○	○	○
Muscle pain	○	○	○	○
Back pain	○	○	○	○
Changes to menstrual cycle	○	○	○	○
Broken blood vessel in eye (Subconjunctival hemorrhage)	○	○	○	○
Unusually high or low red / white / platelet blood count	○	○	○	○
High blood pressure (Hypertension)	○	○	○	○
Other (Please specify)	○	○	○	○

C27 Overall, how would **YOU** rate the way the physical side effects of the leukemia treatment have been managed by the patient's healthcare professionals? 0 is very dissatisfied and 10 is very satisfied.

○ 0

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10

TESTING AND MONITORING

C28 Is the patient currently undergoing regular testing or monitoring for their leukemia?

○ Yes

○ No

○ Don't know

C29 Are the results of test(s) explained to **YOU** in a way you can understand?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don’t know / can’t remember

○ Not applicable

C30 Do **YOU** have to ask for the results to be explained?

○ Yes, always

○ Yes, sometimes

○ No

○ Don’t know / can’t remember

○ Not applicable

C31 How worried / anxious do **YOU** feel when waiting for the results of the patient's regular testing / monitoring? 0 is not at all worried / anxious and 10 is extremely worried / anxious

○ 0

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10

C32 Do you know the patient's immunity status?

Immunity and immunity status are connected to the immune system, which is the body's centre for fighting infection and disease. The patient's immunity is their body's overall ability to fight these infections and diseases.

○ Yes

○ No

○ Don’t know

C33 Were **YOU** given clear information about what steps the patient can take to stay healthy and avoid infections?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don’t know / can’t remember

○ Not applicable

C34 Has a health professional spoken to **YOU** about the protocols for CLL immunisations / vaccinations, including which the patient should receive and which they should avoid?

○ Yes, completely

○ Yes, to some extent

○ No

○ Don’t know / can’t remember

○ Not applicable

INFORMATION AND SUPPORT

C35 Please select what information and support you were given or directed to during the patient's treatment journey. Please select all that apply.

☐ Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy

☐ General wellbeing (including spiritual wellbeing)

☐ Clinical trials

☐ Side effects and risks of treatment

☐ Access to a Clinical Nurse Specialist (CNS)

☐ Patient rights

☐ Buddying or befriending

☐ Patient support groups

☐ Leukemia charities / associations / organisations

☐ Financial information

☐ Written information / booklets / leaflets

☐ Online forums

☐ End of life care

☐ I was not given or directed to information or support

C36 When in the patient's treatment journey were you given or directed to the information and support?	At diagnosis	During 'watch and wait' or 'active monitoring'	After diagnosis but before treatment started	During treatment	After treatment finished	Don't know / can't remember
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	☐	☐	☐	☐	☐	☐
General wellbeing (including spiritual wellbeing)	☐	☐	☐	☐	☐	☐
Clinical trials	☐	☐	☐	☐	☐	☐
Side effects and risks of treatment	☐	☐	☐	☐	☐	☐
Access to a Clinical Nurse Specialist (CNS)	☐	☐	☐	☐	☐	☐
Patient rights	☐	☐	☐	☐	☐	☐
Buddying or befriending	☐	☐	☐	☐	☐	☐
Patient support groups	☐	☐	☐	☐	☐	☐
Leukemia charities / associations / organisations	☐	☐	☐	☐	☐	☐

Financial information	☐	☐	☐	☐	☐	☐
Written information / booklets / leaflets	☐	☐	☐	☐	☐	☐
Online forums	☐	☐	☐	☐	☐	☐
End of life care	☐	☐	☐	☐	☐	☐

C37 Did you access this support and did it help you?	Yes, and it helped me feel better / more positive	Yes, but it did not help me feel any better / positive	No, I did not access this support	Don't know / can't remember
Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy	○	○	○	○
General wellbeing (including spiritual wellbeing)	○	○	○	○
Clinical trials	○	○	○	○
Side effects and risks of treatment	○	○	○	○
Access to a Clinical Nurse Specialist (CNS)	○	○	○	○
Patient rights	○	○	○	○
Buddying or befriending	○	○	○	○
Patient support groups	○	○	○	○
Leukemia charities / associations / organisations	○	○	○	○
Financial information	○	○	○	○
Written information / booklets / leaflets	○	○	○	○
Online forums	○	○	○	○
End of life care	○	○	○	○

C38 Did you conduct any of your own research into any of the following? Please select all that apply.

This can include internet searches, reading research articles, listening to podcasts and videos etc.

☐ Diagnosis
☐ Treatments available
☐ Clinical trials
☐ Testing and monitoring (incl. results)
☐ Side effects
☐ Other (please specify) ____
☐ No, I did not conduct my own research

THE PATIENT'S QUALITY OF LIFE

The following questions seek the patient's views about how their disease condition and / or treatment is affecting their daily life. While the statements refer to 'I', we are asking you to complete the questions based on what you know and believe the patient's experience to be. All statements must be answered.

If the area is not a problem for the patient in any way, please select the 'not at all' option.

If the area is affected by the patient's hematological condition, please choose the extent to which it is affected by selecting either the 'a little' or 'a lot' option.

If any of the statements do not apply to the patient, please select the 'not applicable' option.

There is no 'right' or 'wrong' answer. If you are unsure about how to answer a question, please give the best answer you can.

C39 The following statements describe your physical behaviour	Not at all	A little	A lot	Not applicable
I have difficulty with walking	○	○	○	○
I have difficulty with self-care (e.g. dressing, bathing, etc.)	○	○	○	○
I have difficulty with physical activity / sports	○	○	○	○
I have difficulty travelling (e.g. bus, train, flight and car)	○	○	○	○
I have difficulty leaving the house	○	○	○	○
I have difficulty with work (or studies)	○	○	○	○
I have difficulty going on holidays	○	○	○	○

C40 The following statements describe your social well-being	Not at all	A little	A lot	Not applicable
I have difficulty socialising	○	○	○	○
I am having difficulty with personal relationships	○	○	○	○
I have problems with my sex life	○	○	○	○

C41 The following statements describe your emotional behaviour	Not at all	A little	A lot	Not applicable
I worry about being a burden to others	○	○	○	○
I am concerned about people judging me	○	○	○	○
I worry about my appearance	○	○	○	○
I feel distressed	○	○	○	○
I feel anxious	○	○	○	○
I worry about dying	○	○	○	○
I don't feel confident	○	○	○	○
I am worried about my future health	○	○	○	○
My sleeping pattern has changed	○	○	○	○
I have difficulty concentrating	○	○	○	○
I worry about treatment	○	○	○	○

C42 The following statements describe your eating and drinking	Not at all	A little	A lot	Not applicable
I have trouble with my appetite	○	○	○	○
My eating habits have changed	○	○	○	○
My drinking habits have changed	○	○	○	○

C43 The following statements describe disease symptoms or treatment side effects. Please select the box which best describes the symptoms the patient has been experiencing over the past **three days**. If they do not experience a symptom listed below, please select the 'not at all' option. If the symptom is affecting them, please choose the severity of the symptom by selecting either the 'mild' or 'severe' option.

	Not at all	Mild	Severe
I have / had fever	○	○	○
I have stomach ache	○	○	○
I have problems with my energy level	○	○	○
I have hair loss	○	○	○
I feel tired	○	○	○
I have back pain	○	○	○
I have problems with my sense of taste	○	○	○
I have difficulty breathing	○	○	○
I have skin problems (e.g. itching, bruises, rashes, etc.)	○	○	○

I have headaches	○	○	○
I have constipation	○	○	○
I have lumps	○	○	○
I have body pain	○	○	○
I have infections (e.g. chest, lung, urinary, etc.)	○	○	○
I have night sweats	○	○	○
I have diarrhoea	○	○	○
I have nausea	○	○	○
I have / had chest pain	○	○	○

YOUR QUALITY OF LIFE

The following questions are about how your life is being affected by the patient's condition at the moment.

The following questions are standardised questions and while they may reference family member's condition, please do still respond to the survey if the person you are caring for is not a family member.

If the area is not a problem for you in any way, please select the 'not at all' option.

If the area is affected by the patient's condition, please choose the extent to which it is affected by selecting either the 'a little' or 'a lot' option.

C44 Because of my family member’s condition…	Not at all	A little	A lot
I feel worried	○	○	○
I feel angry	○	○	○
I feel sad	○	○	○
I feel frustrated	○	○	○
It is difficult to find someone to talk to about my thoughts	○	○	○
Caring for my family member is difficult	○	○	○

C45 Because of my family member's condition…	Not at all	A little	A lot
It is hard to find time for myself	○	○	○
My every day travel is affected	○	○	○
My eating habits are affected	○	○	○
My family activities are affected	○	○	○
I experience problems with going on holiday	○	○	○
My sex life is affected	○	○	○
My work or study is affected	○	○	○
My relationships with other family members are affected	○	○	○
My family expenses are increased	○	○	○
My sleep is affected	○	○	○

YOUR VIEWS ON POTENTIAL NEW TREATMENTS

C46 Would **YOU** consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether? By treatment-free we mean that the patient and their doctor agree that they stop taking their medication.

○ Yes

○ No

○ Don’t know

C47 What do **YOU** consider to be important features of a new treatment? Please select all that apply.

☐ Improved / longer survival

☐ Bring about a remission / response

☐ Improved quality of life

☐ Improved blood counts / test results

☐ Tolerable side effects whilst on treatment

☐ A reduced impact on carer / family members

☐ Certainty of available treatment data / results

☐ Reduced long-term effects post treatment e.g. impact on fertility

☐ Affordability

☐ Don’t know

Appendix 3 – Patient and carer demographics

About you
Q1 What is your confirmed diagnosis?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Acute lymphoblastic leukemia (ALL)	271	12%	271	100%	0	0%	0	0%	0	0%
Acute myeloid leukemia (AML)	341	15%	0	0%	341	100%	0	0%	0	0%
Chronic lymphocytic leukemia (CLL)	846	37%	0	0%	0	0%	846	100%	0	0%
Chronic myeloid leukemia (CML)	660	29%	0	0%	0	0%	0	0%	660	100%
Hairy cell leukemia (HCL)	6	0%	0	0%	0	0%	0	0%	0	0%
Chronic myelomonocytic leukemia (CMML)	17	1%	0	0%	0	0%	0	0%	0	0%
Acute promyelocytic leukemia (APML / APL)	29	1%	0	0%	0	0%	0	0%	0	0%
Other leukemia	21	1%	0	0%	0	0%	0	0%	0	0%
Other (please specify)	66	3%	0	0%	0	0%	0	0%	0	0%
Don't know / can't remember	3	0%	0	0%	0	0%	0	0%	0	0%
Total Responses	2260	100%	271	100%	341	100%	846	100%	660	100%

About you

patient_age_grouped Patient age grouped

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
18 to 25	132	6%	73	28%	34	10%	0	0%	15	2%
26 to 35	245	11%	87	33%	58	17%	3	0%	77	12%
36 to 45	311	14%	51	19%	80	24%	24	3%	133	20%
46 to 55	381	17%	25	10%	71	21%	110	13%	149	23%
56 to 65	546	24%	19	7%	64	19%	270	32%	160	24%
66 to 75	460	20%	7	3%	24	7%	316	37%	89	13%
76 and over	173	8%	0	0%	7	2%	123	15%	37	6%
Total Responses	2248	100%	262	100%	338	100%	846	100%	660	100%

About you

Q3 What is your gender?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Male	816	36%	95	35%	100	29%	357	42%	226	34%
Female	1251	55%	135	50%	201	59%	454	54%	378	57%
Prefer to self-describe (please specify)	64	3%	4	1%	10	3%	15	2%	26	4%
Prefer not to say	129	6%	37	14%	30	9%	20	2%	30	5%
Total Responses	2260	100%	271	100%	341	100%	846	100%	660	100%

About you

Q4 In which country do you live? To quickly find your country in the list below, please click on the box and start to type in the country.

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Afghanistan	1	0%	0	0%	0	0%	0	0%	0	0%
Albania	0	0%	0	0%	0	0%	0	0%	0	0%
Algeria	0	0%	0	0%	0	0%	0	0%	0	0%
Andorra	1	0%	0	0%	0	0%	0	0%	1	0%
Angola	1	0%	0	0%	0	0%	0	0%	0	0%
Antigua and Barbuda	0	0%	0	0%	0	0%	0	0%	0	0%
Argentina	1	0%	0	0%	0	0%	0	0%	1	0%
Armenia	0	0%	0	0%	0	0%	0	0%	0	0%
Australia	51	2%	3	1%	4	1%	12	1%	26	4%
Austria	2	0%	0	0%	1	0%	0	0%	1	0%
Azerbaijan	0	0%	0	0%	0	0%	0	0%	0	0%
Bahamas	0	0%	0	0%	0	0%	0	0%	0	0%
Bahrain	0	0%	0	0%	0	0%	0	0%	0	0%
Bangladesh	0	0%	0	0%	0	0%	0	0%	0	0%
Barbados	0	0%	0	0%	0	0%	0	0%	0	0%
Belarus	0	0%	0	0%	0	0%	0	0%	0	0%
Belgium	10	0%	0	0%	1	0%	6	1%	3	0%
Belize	0	0%	0	0%	0	0%	0	0%	0	0%
Benin	0	0%	0	0%	0	0%	0	0%	0	0%
Bhutan	0	0%	0	0%	0	0%	0	0%	0	0%
Bolivia	1	0%	0	0%	0	0%	0	0%	1	0%
Bosnia and Herzegovina	0	0%	0	0%	0	0%	0	0%	0	0%

Botswana	0	0%	0	0%	0	0%	0	0%	0	0%
Brazil	226	10%	41	15%	37	11%	32	4%	89	14%
Brunei	0	0%	0	0%	0	0%	0	0%	0	0%
Bulgaria	2	0%	0	0%	0	0%	0	0%	2	0%
Burkina Faso	0	0%	0	0%	0	0%	0	0%	0	0%
Burundi	0	0%	0	0%	0	0%	0	0%	0	0%
Cote d'Ivoire	0	0%	0	0%	0	0%	0	0%	0	0%
Cabo Verde	0	0%	0	0%	0	0%	0	0%	0	0%
Cambodia	0	0%	0	0%	0	0%	0	0%	0	0%
Cameroon	3	0%	0	0%	0	0%	0	0%	3	0%
Canada	92	4%	1	0%	2	1%	69	8%	18	3%
Central African Republic	0	0%	0	0%	0	0%	0	0%	0	0%
Chad	0	0%	0	0%	0	0%	0	0%	0	0%
Chile	20	1%	0	0%	1	0%	2	0%	14	2%
China	366	16%	166	62%	131	39%	29	3%	8	1%
Colombia	2	0%	0	0%	1	0%	0	0%	1	0%
Comoros	0	0%	0	0%	0	0%	0	0%	0	0%
Costa Rica	4	0%	0	0%	0	0%	0	0%	4	1%
Croatia	1	0%	0	0%	0	0%	0	0%	1	0%
Cuba	0	0%	0	0%	0	0%	0	0%	0	0%
Cyprus	0	0%	0	0%	0	0%	0	0%	0	0%
Czechia (Czech Republic)	84	4%	2	1%	10	3%	24	3%	47	7%
Democratic Republic of the Congo	0	0%	0	0%	0	0%	0	0%	0	0%
Denmark	130	6%	4	1%	28	8%	52	6%	38	6%
Djibouti	0	0%	0	0%	0	0%	0	0%	0	0%
Dominica	0	0%	0	0%	0	0%	0	0%	0	0%
Dominican Republic	0	0%	0	0%	0	0%	0	0%	0	0%
Ecuador	2	0%	0	0%	0	0%	0	0%	2	0%
Egypt	0	0%	0	0%	0	0%	0	0%	0	0%
El Salvador	1	0%	0	0%	0	0%	0	0%	1	0%

Equatorial Guinea	0	0%	0	0%	0	0%	0	0%	0	0%
Eritrea	0	0%	0	0%	0	0%	0	0%	0	0%
Estonia	1	0%	0	0%	0	0%	0	0%	1	0%
Eswatini	0	0%	0	0%	0	0%	0	0%	0	0%
Ethiopia	0	0%	0	0%	0	0%	0	0%	0	0%
Fiji	0	0%	0	0%	0	0%	0	0%	0	0%
Finland	15	1%	0	0%	2	1%	5	1%	8	1%
France	53	2%	12	4%	25	7%	3	0%	9	1%
Gabon	0	0%	0	0%	0	0%	0	0%	0	0%
Gambia	0	0%	0	0%	0	0%	0	0%	0	0%
Georgia	0	0%	0	0%	0	0%	0	0%	0	0%
Germany	45	2%	0	0%	3	1%	10	1%	32	5%
Ghana	0	0%	0	0%	0	0%	0	0%	0	0%
Greece	9	0%	0	0%	0	0%	7	1%	2	0%
Grenada	0	0%	0	0%	0	0%	0	0%	0	0%
Guatemala	22	1%	0	0%	0	0%	0	0%	20	3%
Guinea	0	0%	0	0%	0	0%	0	0%	0	0%
Guinea-Bissau	0	0%	0	0%	0	0%	0	0%	0	0%
Guyana	0	0%	0	0%	0	0%	0	0%	0	0%
Haiti	0	0%	0	0%	0	0%	0	0%	0	0%
Honduras	0	0%	0	0%	0	0%	0	0%	0	0%
Hong Kong (S.A.R.)	0	0%	0	0%	0	0%	0	0%	0	0%
Hungary	0	0%	0	0%	0	0%	0	0%	0	0%
Iceland	1	0%	0	0%	0	0%	0	0%	1	0%
India	5	0%	0	0%	1	0%	1	0%	3	0%
Indonesia	3	0%	0	0%	0	0%	0	0%	3	0%
Iran	0	0%	0	0%	0	0%	0	0%	0	0%
Iraq	1	0%	0	0%	0	0%	0	0%	1	0%
Ireland	31	1%	0	0%	2	1%	27	3%	1	0%
Israel	146	6%	3	1%	15	4%	68	8%	55	8%

Italy	41	2%	0	0%	0	0%	35	4%	1	0%
Jamaica	0	0%	0	0%	0	0%	0	0%	0	0%
Japan	4	0%	0	0%	1	0%	0	0%	3	0%
Jordan	0	0%	0	0%	0	0%	0	0%	0	0%
Kazakhstan	0	0%	0	0%	0	0%	0	0%	0	0%
Kenya	47	2%	0	0%	1	0%	1	0%	43	7%
Kiribati	0	0%	0	0%	0	0%	0	0%	0	0%
Kuwait	0	0%	0	0%	0	0%	0	0%	0	0%
Kyrgyzstan	0	0%	0	0%	0	0%	0	0%	0	0%
Laos	0	0%	0	0%	0	0%	0	0%	0	0%
Latvia	0	0%	0	0%	0	0%	0	0%	0	0%
Lebanon	0	0%	0	0%	0	0%	0	0%	0	0%
Lesotho	0	0%	0	0%	0	0%	0	0%	0	0%
Liberia	0	0%	0	0%	0	0%	0	0%	0	0%
Libya	0	0%	0	0%	0	0%	0	0%	0	0%
Liechtenstein	0	0%	0	0%	0	0%	0	0%	0	0%
Lithuania	0	0%	0	0%	0	0%	0	0%	0	0%
Luxembourg	1	0%	1	0%	0	0%	0	0%	0	0%
Madagascar	0	0%	0	0%	0	0%	0	0%	0	0%
Malawi	0	0%	0	0%	0	0%	0	0%	0	0%
Malaysia	3	0%	0	0%	0	0%	0	0%	3	0%
Maldives	0	0%	0	0%	0	0%	0	0%	0	0%
Mali	0	0%	0	0%	0	0%	0	0%	0	0%
Malta	0	0%	0	0%	0	0%	0	0%	0	0%
Marshall Islands	0	0%	0	0%	0	0%	0	0%	0	0%
Mauritania	0	0%	0	0%	0	0%	0	0%	0	0%
Mauritius	0	0%	0	0%	0	0%	0	0%	0	0%
Mexico	1	0%	0	0%	0	0%	0	0%	0	0%
Micronesia	0	0%	0	0%	0	0%	0	0%	0	0%
Moldova	0	0%	0	0%	0	0%	0	0%	0	0%

Monaco	2	0%	0	0%	0	0%	2	0%	0	0%
Mongolia	0	0%	0	0%	0	0%	0	0%	0	0%
Montenegro	0	0%	0	0%	0	0%	0	0%	0	0%
Morocco	0	0%	0	0%	0	0%	0	0%	0	0%
Mozambique	0	0%	0	0%	0	0%	0	0%	0	0%
Myanmar	0	0%	0	0%	0	0%	0	0%	0	0%
Namibia	0	0%	0	0%	0	0%	0	0%	0	0%
Nauru	0	0%	0	0%	0	0%	0	0%	0	0%
Nepal	4	0%	0	0%	0	0%	0	0%	4	1%
Netherlands	101	4%	0	0%	1	0%	50	6%	43	7%
New Zealand	31	1%	1	0%	3	1%	18	2%	8	1%
Nicaragua	0	0%	0	0%	0	0%	0	0%	0	0%
Niger	0	0%	0	0%	0	0%	0	0%	0	0%
Nigeria	4	0%	0	0%	0	0%	0	0%	4	1%
North Macedonia	0	0%	0	0%	0	0%	0	0%	0	0%
Norway	26	1%	6	2%	7	2%	5	1%	7	1%
Oman	0	0%	0	0%	0	0%	0	0%	0	0%
Pakistan	1	0%	0	0%	1	0%	0	0%	0	0%
Palau	0	0%	0	0%	0	0%	0	0%	0	0%
Panama	0	0%	0	0%	0	0%	0	0%	0	0%
Papua New Guinea	0	0%	0	0%	0	0%	0	0%	0	0%
Paraguay	0	0%	0	0%	0	0%	0	0%	0	0%
Peru	1	0%	0	0%	0	0%	1	0%	0	0%
Philippines	0	0%	0	0%	0	0%	0	0%	0	0%
Poland	2	0%	0	0%	0	0%	0	0%	2	0%
Portugal	4	0%	1	0%	1	0%	1	0%	1	0%
Qatar	0	0%	0	0%	0	0%	0	0%	0	0%
Republic of Congo (Congo-Brazzaville)	0	0%	0	0%	0	0%	0	0%	0	0%
Republic of Korea	50	2%	16	6%	21	6%	2	0%	11	2%

Romania	0	0%	0	0%	0	0%	0	0%	0	0%
Russia	1	0%	0	0%	0	0%	0	0%	1	0%
Rwanda	1	0%	0	0%	0	0%	0	0%	1	0%
Saint Kitts and Nevis	0	0%	0	0%	0	0%	0	0%	0	0%
Saint Lucia	0	0%	0	0%	0	0%	0	0%	0	0%
Saint Vincent and the Grenadines	0	0%	0	0%	0	0%	0	0%	0	0%
Samoa	0	0%	0	0%	0	0%	0	0%	0	0%
San Marino	0	0%	0	0%	0	0%	0	0%	0	0%
Sao Tome and Principe	0	0%	0	0%	0	0%	0	0%	0	0%
Saudi Arabia	0	0%	0	0%	0	0%	0	0%	0	0%
Senegal	2	0%	0	0%	0	0%	0	0%	2	0%
Serbia	0	0%	0	0%	0	0%	0	0%	0	0%
Seychelles	0	0%	0	0%	0	0%	0	0%	0	0%
Sierra Leone	0	0%	0	0%	0	0%	0	0%	0	0%
Singapore	0	0%	0	0%	0	0%	0	0%	0	0%
Slovakia	2	0%	0	0%	0	0%	0	0%	2	0%
Slovenia	0	0%	0	0%	0	0%	0	0%	0	0%
Solomon Islands	0	0%	0	0%	0	0%	0	0%	0	0%
Somalia	0	0%	0	0%	0	0%	0	0%	0	0%
South Africa	4	0%	1	0%	0	0%	1	0%	1	0%
South Sudan	0	0%	0	0%	0	0%	0	0%	0	0%
Spain	42	2%	1	0%	8	2%	3	0%	21	3%
Sri Lanka	0	0%	0	0%	0	0%	0	0%	0	0%
State of Palestine	0	0%	0	0%	0	0%	0	0%	0	0%
Sudan	0	0%	0	0%	0	0%	0	0%	0	0%
Suriname	0	0%	0	0%	0	0%	0	0%	0	0%
Sweden	2	0%	0	0%	1	0%	1	0%	0	0%
Switzerland	4	0%	0	0%	1	0%	0	0%	3	0%
Syria	0	0%	0	0%	0	0%	0	0%	0	0%
Tajikistan	0	0%	0	0%	0	0%	0	0%	0	0%

Tanzania	16	1%	0	0%	0	0%	1	0%	15	2%
Thailand	14	1%	0	0%	4	1%	0	0%	9	1%
Timor-Leste	0	0%	0	0%	0	0%	0	0%	0	0%
Togo	0	0%	0	0%	0	0%	0	0%	0	0%
Tonga	0	0%	0	0%	0	0%	0	0%	0	0%
Trinidad and Tobago	0	0%	0	0%	0	0%	0	0%	0	0%
Tunisia	0	0%	0	0%	0	0%	0	0%	0	0%
Turkey	3	0%	1	0%	1	0%	0	0%	1	0%
Turkmenistan	0	0%	0	0%	0	0%	0	0%	0	0%
Tuvalu	0	0%	0	0%	0	0%	0	0%	0	0%
Uganda	0	0%	0	0%	0	0%	0	0%	0	0%
Ukraine	0	0%	0	0%	0	0%	0	0%	0	0%
United Arab Emirates	0	0%	0	0%	0	0%	0	0%	0	0%
United Kingdom	317	14%	1	0%	10	3%	272	32%	24	4%
United States of America	186	8%	7	3%	13	4%	105	12%	50	8%
Uruguay	0	0%	0	0%	0	0%	0	0%	0	0%
Uzbekistan	0	0%	0	0%	0	0%	0	0%	0	0%
Vanuatu	0	0%	0	0%	0	0%	0	0%	0	0%
Venezuela	1	0%	0	0%	0	0%	0	0%	1	0%
Vietnam	0	0%	0	0%	0	0%	0	0%	0	0%
Yemen	0	0%	0	0%	0	0%	0	0%	0	0%
Zambia	0	0%	0	0%	0	0%	0	0%	0	0%
Zimbabwe	0	0%	0	0%	0	0%	0	0%	0	0%
Total Responses	2251	100%	268	100%	338	100%	845	100%	658	100%

Q5 What best describes your living situation?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Living alone	294	13%	16	6%	30	9%	143	17%	89	14%
Living with adult family e.g. parents, siblings, children (non-dependent)	383	17%	115	43%	97	29%	47	6%	94	14%
Living as a couple (spouse or partner)	1015	45%	67	25%	118	35%	521	62%	254	39%
Living as a couple with dependent children	420	19%	59	22%	73	21%	89	11%	173	26%
Living as a lone adult with dependent children	48	2%	6	2%	8	2%	11	1%	19	3%
Living with another dependent (non-child)	11	0%	0	0%	2	1%	3	0%	4	1%
Living with non-family e.g. friends, house mates	13	1%	2	1%	0	0%	3	0%	7	1%
Prefer not to say	35	2%	5	2%	9	3%	9	1%	8	1%
Other (please specify)	34	2%	0	0%	3	1%	19	2%	9	1%
Total Responses	2253	100%	270	100%	340	100%	845	100%	657	100%

About you

Q6 What best describes your employment status? Please select one answer.

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Full time employment	601	27%	77	29%	118	35%	155	19%	216	34%
Part time employment	187	8%	11	4%	28	8%	66	8%	71	11%
Self employment	126	6%	10	4%	16	5%	34	4%	56	9%
Stay at home parent	64	3%	12	5%	19	6%	12	1%	13	2%
Student	91	4%	52	20%	21	6%	2	0%	11	2%
Retired	743	34%	17	6%	56	17%	476	58%	160	25%
Unemployed and seeking work	51	2%	7	3%	10	3%	5	1%	28	4%
Unemployed and unable to work for health reasons (NOT seeking work)	211	10%	57	22%	46	14%	44	5%	48	7%
Unemployed and unable to work for non-health related reasons (NOT seeking work)	20	1%	6	2%	4	1%	1	0%	4	1%
Full time carer (unable to work as caring for family member or friend due to illness)	7	0%	2	1%	1	0%	0	0%	2	0%
Prefer not to say	35	2%	6	2%	8	2%	10	1%	9	1%
Other (Please specify)	71	3%	6	2%	12	4%	17	2%	25	4%
Total Responses	2207	100%	263	100%	339	100%	822	100%	643	100%

About you
Q7 For your country, how would you describe your annual household income?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Low income	493	22%	89	33%	75	22%	119	14%	168	26%
Average income	1342	60%	157	58%	210	62%	528	63%	373	57%
High income	290	13%	12	4%	31	9%	145	17%	83	13%
Don’t know	31	1%	4	1%	5	1%	7	1%	12	2%
Prefer not to say	92	4%	9	3%	19	6%	41	5%	20	3%
Total Responses	2248	100%	271	100%	340	100%	840	100%	656	100%

About you
Q8 What is your highest level of qualification?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
No formal qualifications	110	5%	20	7%	21	6%	37	5%	21	3%
High school qualifications or diploma	577	26%	90	33%	73	22%	187	23%	187	29%
University – Bachelors or Undergraduate degree	769	35%	102	38%	140	42%	272	33%	205	32%
University – Masters, PhD or MD	444	20%	27	10%	60	18%	203	25%	130	21%
Career or technical qualifications (also known as vocational qualifications)	219	10%	15	6%	24	7%	99	12%	72	11%
Prefer not to say	79	4%	16	6%	17	5%	21	3%	19	3%
Total Responses	2198	100%	270	100%	335	100%	819	100%	634	100%

About the patient

C1 What is the patient’s confirmed diagnosis?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Acute lymphoblastic leukemia (ALL)	203	29%	203	100%	0	0%	0	0%	0	0%
Acute myeloid leukemia (AML)	178	26%	0	0%	178	100%	0	0%	0	0%
Chronic lymphocytic leukemia (CLL)	112	16%	0	0%	0	0%	112	100%	0	0%
Chronic myeloid leukemia (CML)	140	20%	0	0%	0	0%	0	0%	140	100%
Hairy cell leukemia (HCL)	1	0%	0	0%	0	0%	0	0%	0	0%
Chronic myelomonocytic leukemia (CMML)	3	0%	0	0%	0	0%	0	0%	0	0%
Acute promyelocytic leukemia (APML / APL)	11	2%	0	0%	0	0%	0	0%	0	0%
Other leukemia	8	1%	0	0%	0	0%	0	0%	0	0%
Other (please specify)	33	5%	0	0%	0	0%	0	0%	0	0%
Don't know / can't remember	5	1%	0	0%	0	0%	0	0%	0	0%
Total Responses	694	100%	203	100%	178	100%	112	100%	140	100%

About the patient
patient_age_grouped_c Patient age grouped

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
18 to 25	64	12%	32	32%	15	9%	2	2%	14	11%
26 to 35	79	14%	31	31%	18	11%	2	2%	17	13%
36 to 45	70	13%	20	20%	19	12%	5	5%	19	15%
46 to 55	84	15%	12	12%	32	20%	9	8%	23	18%
56 to 65	122	22%	4	4%	37	23%	40	36%	29	23%
66 to 75	83	15%	1	1%	28	18%	30	27%	14	11%
76 and over	47	9%	1	1%	9	6%	22	20%	10	8%
Total Responses	549	100%	101	100%	158	100%	110	100%	126	100%

About the patient
C3 What is the gender of the patient?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Male	363	52%	104	51%	77	43%	68	61%	78	56%
Female	274	39%	78	38%	86	48%	41	37%	51	36%
Prefer to self-describe (please specify)	19	3%	5	2%	5	3%	2	2%	6	4%
Prefer not to say	38	5%	16	8%	10	6%	1	1%	5	4%
Total Responses	694	100%	203	100%	178	100%	112	100%	140	100%

About the patient

year_of_diagnosis_c Year of diagnosis grouped

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Prior to 2008	37	5%	4	2%	2	1%	9	8%	20	14%
2008 to 2010	23	3%	2	1%	4	2%	8	7%	8	6%
2011 to 2013	51	7%	11	5%	5	3%	18	16%	14	10%
2014 to 2016	38	5%	4	2%	4	2%	15	13%	8	6%
2017 to 2019	117	17%	35	17%	20	11%	24	21%	29	21%
2020 to present	426	62%	147	72%	142	80%	38	34%	60	43%
Total Responses	692	100%	203	100%	177	100%	112	100%	139	100%

About the carer

carer_age_grouped Carer age group

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
18 to 25	15	2%	3	1%	7	4%	2	2%	3	2%
26 to 35	131	19%	53	26%	40	22%	6	5%	20	14%
36 to 45	203	29%	83	41%	52	29%	16	14%	31	22%
46 to 55	140	20%	50	25%	36	20%	9	8%	35	25%
56 to 65	115	17%	9	4%	28	16%	34	31%	32	23%
66 to 75	65	9%	3	1%	10	6%	33	30%	14	10%
76 and over	21	3%	0	0%	5	3%	11	10%	4	3%
Total Responses	690	100%	201	100%	178	100%	111	100%	139	100%

About the carer
C6 What is your gender?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Male	162	23%	33	16%	45	25%	29	26%	43	31%
Female	485	70%	158	78%	120	67%	78	70%	87	62%
Prefer to self-describe (please specify)	21	3%	4	2%	6	3%	3	3%	5	4%
Prefer not to say	26	4%	8	4%	7	4%	2	2%	5	4%
Total Responses	694	100%	203	100%	178	100%	112	100%	140	100%

About the carer
C7 In which country do you live? To quickly find your country in the list below, please click on the box and start to type in the country.

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
All other countries	0	0%	0	0%	0	0%	0	0%	0	0%
Afghanistan	0	0%	0	0%	0	0%	0	0%	0	0%
Albania	0	0%	0	0%	0	0%	0	0%	0	0%
Algeria	0	0%	0	0%	0	0%	0	0%	0	0%
Andorra	0	0%	0	0%	0	0%	0	0%	0	0%
Angola	0	0%	0	0%	0	0%	0	0%	0	0%
Antigua and Barbuda	0	0%	0	0%	0	0%	0	0%	0	0%
Argentina	0	0%	0	0%	0	0%	0	0%	0	0%
Armenia	0	0%	0	0%	0	0%	0	0%	0	0%

Australia	19	3%	5	2%	6	3%	2	2%	3	2%
Austria	0	0%	0	0%	0	0%	0	0%	0	0%
Azerbaijan	0	0%	0	0%	0	0%	0	0%	0	0%
Bahamas	0	0%	0	0%	0	0%	0	0%	0	0%
Bahrain	1	0%	1	0%	0	0%	0	0%	0	0%
Bangladesh	0	0%	0	0%	0	0%	0	0%	0	0%
Barbados	0	0%	0	0%	0	0%	0	0%	0	0%
Belarus	0	0%	0	0%	0	0%	0	0%	0	0%
Belgium	3	0%	1	0%	0	0%	0	0%	2	1%
Belize	0	0%	0	0%	0	0%	0	0%	0	0%
Benin	0	0%	0	0%	0	0%	0	0%	0	0%
Bhutan	0	0%	0	0%	0	0%	0	0%	0	0%
Bolivia	0	0%	0	0%	0	0%	0	0%	0	0%
Bosnia and Herzegovina	0	0%	0	0%	0	0%	0	0%	0	0%
Botswana	0	0%	0	0%	0	0%	0	0%	0	0%
Brazil	143	21%	68	34%	29	16%	7	6%	25	18%
Brunei	0	0%	0	0%	0	0%	0	0%	0	0%
Bulgaria	0	0%	0	0%	0	0%	0	0%	0	0%
Burkina Faso	0	0%	0	0%	0	0%	0	0%	0	0%
Burundi	0	0%	0	0%	0	0%	0	0%	0	0%
Cote d'Ivoire	0	0%	0	0%	0	0%	0	0%	0	0%
Cabo Verde	0	0%	0	0%	0	0%	0	0%	0	0%
Cambodia	0	0%	0	0%	0	0%	0	0%	0	0%
Cameroon	0	0%	0	0%	0	0%	0	0%	0	0%
Canada	24	3%	2	1%	0	0%	19	17%	3	2%
Central African Republic	0	0%	0	0%	0	0%	0	0%	0	0%
Chad	0	0%	0	0%	0	0%	0	0%	0	0%
Chile	5	1%	1	0%	2	1%	0	0%	2	1%
China	126	18%	56	28%	45	26%	7	6%	2	1%
Colombia	0	0%	0	0%	0	0%	0	0%	0	0%

Comoros	0	0%	0	0%	0	0%	0	0%	0	0%
Costa Rica	4	1%	0	0%	0	0%	0	0%	4	3%
Croatia	0	0%	0	0%	0	0%	0	0%	0	0%
Cuba	0	0%	0	0%	0	0%	0	0%	0	0%
Cyprus	0	0%	0	0%	0	0%	0	0%	0	0%
Czechia (Czech Republic)	14	2%	2	1%	3	2%	5	4%	3	2%
Democratic Republic of the Congo	0	0%	0	0%	0	0%	0	0%	0	0%
Denmark	32	5%	7	3%	12	7%	3	3%	8	6%
Djibouti	0	0%	0	0%	0	0%	0	0%	0	0%
Dominica	0	0%	0	0%	0	0%	0	0%	0	0%
Dominican Republic	1	0%	0	0%	0	0%	1	1%	0	0%
Ecuador	0	0%	0	0%	0	0%	0	0%	0	0%
Egypt	0	0%	0	0%	0	0%	0	0%	0	0%
El Salvador	0	0%	0	0%	0	0%	0	0%	0	0%
Equatorial Guinea	0	0%	0	0%	0	0%	0	0%	0	0%
Eritrea	0	0%	0	0%	0	0%	0	0%	0	0%
Estonia	0	0%	0	0%	0	0%	0	0%	0	0%
Eswatini	0	0%	0	0%	0	0%	0	0%	0	0%
Ethiopia	0	0%	0	0%	0	0%	0	0%	0	0%
Fiji	0	0%	0	0%	0	0%	0	0%	0	0%
Finland	1	0%	0	0%	0	0%	0	0%	1	1%
France	52	8%	20	10%	20	11%	1	1%	4	3%
Gabon	0	0%	0	0%	0	0%	0	0%	0	0%
Gambia	0	0%	0	0%	0	0%	0	0%	0	0%
Georgia	0	0%	0	0%	0	0%	0	0%	0	0%
Germany	7	1%	1	0%	0	0%	0	0%	6	4%
Ghana	0	0%	0	0%	0	0%	0	0%	0	0%
Greece	3	0%	0	0%	0	0%	2	2%	1	1%
Grenada	0	0%	0	0%	0	0%	0	0%	0	0%
Guatemala	10	1%	1	0%	0	0%	0	0%	9	6%

Guinea	0	0%	0	0%	0	0%	0	0%	0	0%
Guinea-Bissau	0	0%	0	0%	0	0%	0	0%	0	0%
Guyana	0	0%	0	0%	0	0%	0	0%	0	0%
Haiti	0	0%	0	0%	0	0%	0	0%	0	0%
Honduras	0	0%	0	0%	0	0%	0	0%	0	0%
Hong Kong (S.A.R.)	0	0%	0	0%	0	0%	0	0%	0	0%
Hungary	0	0%	0	0%	0	0%	0	0%	0	0%
Iceland	0	0%	0	0%	0	0%	0	0%	0	0%
India	1	0%	0	0%	1	1%	0	0%	0	0%
Indonesia	1	0%	0	0%	0	0%	0	0%	1	1%
Iran	0	0%	0	0%	0	0%	0	0%	0	0%
Iraq	0	0%	0	0%	0	0%	0	0%	0	0%
Ireland	1	0%	0	0%	0	0%	1	1%	0	0%
Israel	15	2%	2	1%	2	1%	5	4%	5	4%
Italy	7	1%	1	0%	0	0%	3	3%	0	0%
Jamaica	0	0%	0	0%	0	0%	0	0%	0	0%
Japan	1	0%	0	0%	0	0%	0	0%	1	1%
Jordan	0	0%	0	0%	0	0%	0	0%	0	0%
Kazakhstan	0	0%	0	0%	0	0%	0	0%	0	0%
Kenya	14	2%	0	0%	0	0%	0	0%	11	8%
Kiribati	0	0%	0	0%	0	0%	0	0%	0	0%
Kuwait	0	0%	0	0%	0	0%	0	0%	0	0%
Kyrgyzstan	0	0%	0	0%	0	0%	0	0%	0	0%
Laos	0	0%	0	0%	0	0%	0	0%	0	0%
Latvia	0	0%	0	0%	0	0%	0	0%	0	0%
Lebanon	0	0%	0	0%	0	0%	0	0%	0	0%
Lesotho	0	0%	0	0%	0	0%	0	0%	0	0%
Liberia	0	0%	0	0%	0	0%	0	0%	0	0%
Libya	0	0%	0	0%	0	0%	0	0%	0	0%
Liechtenstein	0	0%	0	0%	0	0%	0	0%	0	0%

Lithuania	0	0%	0	0%	0	0%	0	0%	0	0%
Luxembourg	0	0%	0	0%	0	0%	0	0%	0	0%
Madagascar	0	0%	0	0%	0	0%	0	0%	0	0%
Malawi	0	0%	0	0%	0	0%	0	0%	0	0%
Malaysia	0	0%	0	0%	0	0%	0	0%	0	0%
Maldives	0	0%	0	0%	0	0%	0	0%	0	0%
Mali	0	0%	0	0%	0	0%	0	0%	0	0%
Malta	0	0%	0	0%	0	0%	0	0%	0	0%
Marshall Islands	0	0%	0	0%	0	0%	0	0%	0	0%
Mauritania	0	0%	0	0%	0	0%	0	0%	0	0%
Mauritius	1	0%	1	0%	0	0%	0	0%	0	0%
Mexico	1	0%	0	0%	0	0%	0	0%	0	0%
Micronesia	0	0%	0	0%	0	0%	0	0%	0	0%
Moldova	0	0%	0	0%	0	0%	0	0%	0	0%
Monaco	0	0%	0	0%	0	0%	0	0%	0	0%
Mongolia	0	0%	0	0%	0	0%	0	0%	0	0%
Montenegro	0	0%	0	0%	0	0%	0	0%	0	0%
Morocco	0	0%	0	0%	0	0%	0	0%	0	0%
Mozambique	0	0%	0	0%	0	0%	0	0%	0	0%
Myanmar	0	0%	0	0%	0	0%	0	0%	0	0%
Namibia	0	0%	0	0%	0	0%	0	0%	0	0%
Nauru	0	0%	0	0%	0	0%	0	0%	0	0%
Nepal	3	0%	0	0%	0	0%	0	0%	3	2%
Netherlands	18	3%	0	0%	0	0%	8	7%	8	6%
New Zealand	5	1%	0	0%	1	1%	3	3%	1	1%
Nicaragua	0	0%	0	0%	0	0%	0	0%	0	0%
Niger	0	0%	0	0%	0	0%	0	0%	0	0%
Nigeria	2	0%	0	0%	0	0%	1	1%	1	1%
North Macedonia	0	0%	0	0%	0	0%	0	0%	0	0%
Norway	3	0%	2	1%	1	1%	0	0%	0	0%

Oman	0	0%	0	0%	0	0%	0	0%	0	0%
Pakistan	1	0%	0	0%	1	1%	0	0%	0	0%
Palau	0	0%	0	0%	0	0%	0	0%	0	0%
Panama	1	0%	1	0%	0	0%	0	0%	0	0%
Papua New Guinea	0	0%	0	0%	0	0%	0	0%	0	0%
Paraguay	0	0%	0	0%	0	0%	0	0%	0	0%
Peru	1	0%	0	0%	0	0%	0	0%	1	1%
Philippines	1	0%	0	0%	0	0%	0	0%	1	1%
Poland	3	0%	0	0%	0	0%	0	0%	3	2%
Portugal	2	0%	2	1%	0	0%	0	0%	0	0%
Qatar	0	0%	0	0%	0	0%	0	0%	0	0%
Republic of Congo (Congo-Brazzaville)	0	0%	0	0%	0	0%	0	0%	0	0%
Republic of Korea	61	9%	19	9%	32	18%	4	4%	6	4%
Romania	0	0%	0	0%	0	0%	0	0%	0	0%
Russia	0	0%	0	0%	0	0%	0	0%	0	0%
Rwanda	1	0%	1	0%	0	0%	0	0%	0	0%
Saint Kitts and Nevis	0	0%	0	0%	0	0%	0	0%	0	0%
Saint Lucia	0	0%	0	0%	0	0%	0	0%	0	0%
Saint Vincent and the Grenadines	0	0%	0	0%	0	0%	0	0%	0	0%
Samoa	0	0%	0	0%	0	0%	0	0%	0	0%
San Marino	0	0%	0	0%	0	0%	0	0%	0	0%
Sao Tome and Principe	0	0%	0	0%	0	0%	0	0%	0	0%
Saudi Arabia	0	0%	0	0%	0	0%	0	0%	0	0%
Senegal	0	0%	0	0%	0	0%	0	0%	0	0%
Serbia	0	0%	0	0%	0	0%	0	0%	0	0%
Seychelles	0	0%	0	0%	0	0%	0	0%	0	0%
Sierra Leone	0	0%	0	0%	0	0%	0	0%	0	0%
Singapore	0	0%	0	0%	0	0%	0	0%	0	0%
Slovakia	1	0%	0	0%	0	0%	0	0%	1	1%

Slovenia	0	0%	0	0%	0	0%	0	0%	0	0%
Solomon Islands	0	0%	0	0%	0	0%	0	0%	0	0%
Somalia	0	0%	0	0%	0	0%	0	0%	0	0%
South Africa	2	0%	1	0%	0	0%	1	1%	0	0%
South Sudan	0	0%	0	0%	0	0%	0	0%	0	0%
Spain	19	3%	3	1%	4	2%	2	2%	7	5%
Sri Lanka	0	0%	0	0%	0	0%	0	0%	0	0%
State of Palestine	0	0%	0	0%	0	0%	0	0%	0	0%
Sudan	0	0%	0	0%	0	0%	0	0%	0	0%
Suriname	0	0%	0	0%	0	0%	0	0%	0	0%
Sweden	0	0%	0	0%	0	0%	0	0%	0	0%
Switzerland	1	0%	1	0%	0	0%	0	0%	0	0%
Syria	0	0%	0	0%	0	0%	0	0%	0	0%
Tajikistan	0	0%	0	0%	0	0%	0	0%	0	0%
Tanzania	4	1%	0	0%	0	0%	0	0%	4	3%
Thailand	5	1%	0	0%	1	1%	0	0%	3	2%
Timor-Leste	0	0%	0	0%	0	0%	0	0%	0	0%
Togo	0	0%	0	0%	0	0%	0	0%	0	0%
Tonga	0	0%	0	0%	0	0%	0	0%	0	0%
Trinidad and Tobago	0	0%	0	0%	0	0%	0	0%	0	0%
Tunisia	0	0%	0	0%	0	0%	0	0%	0	0%
Turkey	0	0%	0	0%	0	0%	0	0%	0	0%
Turkmenistan	0	0%	0	0%	0	0%	0	0%	0	0%
Tuvalu	0	0%	0	0%	0	0%	0	0%	0	0%
Uganda	0	0%	0	0%	0	0%	0	0%	0	0%
Ukraine	0	0%	0	0%	0	0%	0	0%	0	0%
United Arab Emirates	0	0%	0	0%	0	0%	0	0%	0	0%
United Kingdom	43	6%	2	1%	11	6%	26	23%	1	1%
United States of America	26	4%	0	0%	5	3%	11	10%	9	6%
Uruguay	0	0%	0	0%	0	0%	0	0%	0	0%

Uzbekistan	0	0%	0	0%	0	0%	0	0%	0	0%
Vanuatu	0	0%	0	0%	0	0%	0	0%	0	0%
Venezuela	0	0%	0	0%	0	0%	0	0%	0	0%
Vietnam	0	0%	0	0%	0	0%	0	0%	0	0%
Yemen	0	0%	0	0%	0	0%	0	0%	0	0%
Zambia	0	0%	0	0%	0	0%	0	0%	0	0%
Zimbabwe	0	0%	0	0%	0	0%	0	0%	0	0%
Total Responses	690	100%	201	100%	176	100%	112	100%	140	100%

About the carer

C8 What best describes your employment status? Please select one answer.

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Full time employment	271	39%	81	40%	79	44%	29	26%	56	40%
Part time employment	65	9%	16	8%	11	6%	18	16%	19	14%
Self employment	49	7%	13	6%	11	6%	3	3%	16	12%
Stay at home parent	59	9%	32	16%	12	7%	2	2%	8	6%
Student	7	1%	1	0%	2	1%	2	2%	2	1%
Retired	107	15%	7	3%	22	12%	47	42%	24	17%
Unemployed and seeking work	22	3%	9	4%	8	4%	0	0%	3	2%
Unemployed and unable to work for health reasons (NOT seeking work)	8	1%	1	0%	1	1%	1	1%	4	3%
Unemployed and unable to work for non-health related reasons (NOT seeking work)	4	1%	3	1%	1	1%	0	0%	0	0%
Full time carer (unable to work as caring for family member or friend due to illness)	62	9%	32	16%	18	10%	3	3%	1	1%
Prefer not to say	19	3%	2	1%	7	4%	4	4%	5	4%
Other (Please specify)	20	3%	6	3%	6	3%	3	3%	1	1%
Total Responses	693	100%	203	100%	178	100%	112	100%	139	100%

About the carer

C9 For your country, how would you describe your annual household income?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Low income	145	21%	51	25%	34	19%	15	14%	32	23%
Average income	439	64%	136	67%	120	68%	62	56%	83	59%
High income	67	10%	7	3%	13	7%	22	20%	19	14%
Don’t know	8	1%	4	2%	3	2%	0	0%	1	1%
Prefer not to say	32	5%	4	2%	7	4%	12	11%	5	4%
Total Responses	691	100%	202	100%	177	100%	111	100%	140	100%

About the carer

C10 What is your highest level of qualification?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
No formal qualifications	32	5%	12	6%	11	6%	3	3%	4	3%
High school qualifications or diploma	169	26%	59	31%	45	26%	19	19%	34	26%
University – Bachelors or Undergraduate degree	274	42%	76	40%	75	43%	47	46%	51	39%
University – Masters, PhD or MD	93	14%	19	10%	25	14%	16	16%	24	18%
Career or technical qualifications (also known as vocational qualifications)	57	9%	17	9%	13	7%	9	9%	11	8%
Prefer not to say	29	4%	5	3%	6	3%	8	8%	6	5%
Total Responses	654	100%	188	100%	175	100%	102	100%	130	100%

Care and support

C11 What is your relationship to the patient?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Spouse or partner	288	41%	40	20%	59	33%	83	74%	77	55%
Parent or guardian	206	30%	104	51%	47	26%	9	8%	30	21%
Son or daughter	141	20%	44	22%	57	32%	12	11%	18	13%
Other relative (not mentioned above)	26	4%	9	4%	11	6%	1	1%	3	2%
Non-relative e.g. friend, neighbor	7	1%	0	0%	0	0%	0	0%	3	2%
Professional employed carer	5	1%	2	1%	1	1%	1	1%	1	1%
Other (please specify)	21	3%	4	2%	3	2%	6	5%	8	6%
Total Responses	694	100%	203	100%	178	100%	112	100%	140	100%

Care and support

C12 Do you live with the patient?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Yes	542	81%	178	92%	115	67%	87	81%	117	85%
No	126	19%	15	8%	57	33%	20	19%	20	15%
Total Responses	668	100%	193	100%	172	100%	107	100%	137	100%

Care and support

C13 As a result of their leukemia diagnosis, which of the following care and support activities do you provide? Please select all that apply.

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Emotional support	597	86%	180	89%	156	88%	94	85%	115	83%
Communication e.g. Interaction with health and social care professionals and / or helping with phone calls / write letters / emails	407	59%	138	68%	97	54%	55	50%	80	58%
Household tasks e.g. cooking, cleaning, other household chores	504	73%	169	83%	123	69%	76	68%	90	65%
Personal care e.g. wash, dress, use the toilet, feed	296	43%	151	74%	71	40%	15	14%	27	20%
Collect prescriptions	360	52%	136	67%	95	53%	41	37%	52	38%
Providing transport / travel	373	54%	131	65%	108	61%	44	40%	56	41%
Accompanying on trips or appointments	515	75%	173	85%	136	76%	72	65%	89	64%
Giving medication	305	44%	141	69%	71	40%	24	22%	35	25%
Looking after children	174	25%	101	50%	30	17%	9	8%	18	13%
Manage finances	251	36%	102	50%	58	33%	25	23%	38	28%
Shopping	371	54%	133	66%	90	51%	59	53%	53	38%
Other support (please specify)	33	5%	6	3%	4	2%	12	11%	4	3%
Total Responses	691	100%	203	100%	178	100%	111	100%	138	100%

Care and support

C14 On average how many hours do you spend providing care and support to the patient?

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Less than 1 hour	46	7%	4	2%	7	4%	17	15%	16	12%
1-4 hours a week	72	11%	5	3%	19	11%	20	18%	26	19%
5-9 hours a week	78	11%	13	7%	20	11%	17	15%	21	15%
10-19 hours a week	63	9%	12	6%	21	12%	13	12%	12	9%
20-35 hours a week	58	9%	19	10%	20	11%	7	6%	7	5%
36-49 hours a week	33	5%	8	4%	11	6%	0	0%	6	4%
50+ hours a week	227	33%	112	57%	58	33%	12	11%	25	18%
Don't know	104	15%	24	12%	20	11%	25	23%	23	17%
Total Responses	681	100%	197	100%	176	100%	111	100%	136	100%

Appendix 4 – Frequency tables for [Patient] Q53 How often do / did you experience the side effects of your most recent or current treatment?

Treatment

Q53_1 How often do / did you experience the side effects of your most recent or current treatment? - Bleeding

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	9	8%	*	*	*	*	3	7%	*	*
Very often	27	25%	*	*	*	*	11	26%	*	*
Sometimes	43	40%	*	*	*	*	20	48%	*	*
Rarely	29	27%	*	*	*	*	8	19%	*	*
Total Responses	108	100%	*	*	*	*	42	100%	*	*

Treatment

Q53_2 How often do / did you experience the side effects of your most recent or current treatment? - Bruising

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	34	15%	*	*	*	*	19	19%	7	11%
Very often	86	39%	*	*	*	*	40	39%	22	34%
Sometimes	85	38%	*	*	*	*	38	37%	28	43%
Rarely	17	8%	*	*	*	*	5	5%	8	12%
Total Responses	222	100%	*	*	*	*	102	100%	65	100%

Treatment

Q53_3 How often do / did you experience the side effects of your most recent or current treatment? - Fatigue

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	325	37%	28	33%	55	39%	74	34%	154	40%
Very often	358	40%	36	43%	58	41%	85	39%	155	40%
Sometimes	179	20%	16	19%	24	17%	50	23%	72	19%
Rarely	23	3%	4	5%	5	4%	8	4%	5	1%
Total Responses	885	100%	84	100%	142	100%	217	100%	386	100%

Treatment

Q53_4 How often do / did you experience the side effects of your most recent or current treatment? - Shortness of breath

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	38	14%	*	*	7	15%	9	16%	15	12%
Very often	102	38%	*	*	19	40%	23	41%	46	37%
Sometimes	110	41%	*	*	16	34%	23	41%	56	45%
Rarely	19	7%	*	*	5	11%	1	2%	7	6%
Total Responses	269	100%	*	*	47	100%	56	100%	124	100%

Treatment

Q53_5 How often do / did you experience the side effects of your most recent or current treatment? - Fever / night sweats

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	43	16%	7	18%	11	14%	7	18%	15	16%
Very often	85	32%	8	21%	26	34%	15	38%	31	33%
Sometimes	109	41%	18	47%	30	39%	14	35%	37	39%
Rarely	29	11%	5	13%	9	12%	4	10%	11	12%
Total Responses	266	100%	38	100%	76	100%	40	100%	94	100%

Treatment

Q53_6 How often do / did you experience the side effects of your most recent or current treatment? - Frequent and repeated infections

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Always	23	11%	*	*	11	23%	5	8%	2	3%
Very often	82	39%	*	*	12	25%	28	44%	29	45%
Sometimes	93	44%	*	*	19	40%	28	44%	31	48%
Rarely	11	5%	*	*	6	13%	2	3%	3	5%
Total Responses	209	100%	*	*	48	100%	63	100%	65	100%

Treatment

Q53_7 How often do / did you experience the side effects of your most recent or current treatment? - Unexplained weight loss

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Always	30	24%	*	*	9	24%	*	*	8	23%
Very often	52	42%	*	*	17	45%	*	*	14	40%
Sometimes	35	28%	*	*	10	26%	*	*	11	31%
Rarely	6	5%	*	*	2	5%	*	*	2	6%
Total Responses	123	100%	*	*	38	100%	*	*	35	100%

Treatment

Q53_8 How often do / did you experience the side effects of your most recent or current treatment? - Loss of appetite

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	84	27%	23	30%	27	27%	11	29%	18	25%
Very often	109	35%	25	32%	36	36%	13	34%	27	37%
Sometimes	102	33%	25	32%	32	32%	12	32%	25	34%
Rarely	15	5%	4	5%	6	6%	2	5%	3	4%
Total Responses	310	100%	77	100%	101	100%	38	100%	73	100%

Treatment

Q53_9 How often do / did you experience the side effects of your most recent or current treatment? - Nausea or vomiting

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	85	19%	17	21%	33	28%	6	9%	23	14%
Very often	146	32%	24	30%	34	29%	28	40%	49	30%
Sometimes	185	40%	30	38%	34	29%	31	44%	78	48%
Rarely	43	9%	9	11%	15	13%	5	7%	11	7%
Total Responses	459	100%	80	100%	116	100%	70	100%	161	100%

Treatment

Q53_10 How often do / did you experience the side effects of your most recent or current treatment? - Sleeping problems

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	133	31%	16	25%	29	32%	26	35%	57	33%
Very often	195	46%	20	32%	42	47%	33	45%	85	49%
Sometimes	85	20%	20	32%	18	20%	14	19%	27	16%
Rarely	13	3%	7	11%	1	1%	1	1%	3	2%
Total Responses	426	100%	63	100%	90	100%	74	100%	172	100%

Treatment

Q53_11 How often do / did you experience the side effects of your most recent or current treatment? – Headaches

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	38	13%	*	*	5	9%	3	7%	20	14%
Very often	104	35%	*	*	19	35%	18	44%	51	36%
Sometimes	129	44%	*	*	23	43%	16	39%	62	44%
Rarely	22	8%	*	*	7	13%	4	10%	8	6%
Total Responses	293	100%	*	*	54	100%	41	100%	141	100%

Treatment

Q53_12 How often do / did you experience the side effects of your most recent or current treatment? - Swollen lymph nodes

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	18	33%	*	*	*	*	*	*	*	*
Very often	12	22%	*	*	*	*	*	*	*	*
Sometimes	13	24%	*	*	*	*	*	*	*	*
Rarely	11	20%	*	*	*	*	*	*	*	*
Total Responses	54	100%	*	*	*	*	*	*	*	*

Treatment

Q53_13 How often do / did you experience the side effects of your most recent or current treatment? - Tingling or numbness in extremities

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	71	26%	*	*	13	36%	16	28%	25	19%
Very often	97	36%	*	*	8	22%	19	33%	57	42%
Sometimes	91	33%	*	*	14	39%	16	28%	49	36%
Rarely	13	5%	*	*	1	3%	6	11%	4	3%
Total Responses	272	100%	*	*	36	100%	57	100%	135	100%

Treatment

Q53_14 How often do / did you experience the side effects of your most recent or current treatment? - Itchy skin

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	70	21%	*	*	9	15%	18	25%	32	21%
Very often	120	36%	*	*	24	39%	24	34%	56	36%
Sometimes	125	37%	*	*	26	42%	25	35%	59	38%
Rarely	19	6%	*	*	3	5%	4	6%	9	6%
Total Responses	334	100%	*	*	62	100%	71	100%	156	100%

Treatment

Q53_15 How often do / did you experience the side effects of your most recent or current treatment? - Pain in bones / joints

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	145	27%	11	24%	23	33%	25	26%	74	26%
Very often	208	39%	15	33%	19	28%	45	47%	116	40%
Sometimes	154	29%	16	35%	23	33%	22	23%	87	30%
Rarely	23	4%	4	9%	4	6%	4	4%	10	3%
Total Responses	530	100%	46	100%	69	100%	96	100%	287	100%

Treatment

Q53_16 How often do / did you experience the side effects of your most recent or current treatment? - Swollen stomach or abdominal discomfort

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	68	26%	*	*	13	31%	9	21%	35	27%
Very often	110	42%	*	*	14	33%	17	40%	60	47%
Sometimes	65	25%	*	*	11	26%	13	31%	27	21%
Rarely	17	7%	*	*	4	10%	3	7%	6	5%
Total Responses	260	100%	*	*	42	100%	42	100%	128	100%

Treatment

Q53_17 How often do / did you experience the side effects of your most recent or current treatment? - Memory loss / loss of concentration

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	90	25%	15	35%	23	32%	12	18%	37	24%
Very often	157	43%	19	44%	33	46%	30	45%	62	40%
Sometimes	106	29%	7	16%	15	21%	24	36%	52	33%
Rarely	10	3%	2	5%	1	1%	1	1%	5	3%
Total Responses	363	100%	43	100%	72	100%	67	100%	156	100%

Treatment

Q53_18 How often do / did you experience the side effects of your most recent or current treatment? - Palpitations / heart irregularities

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	20	10%	*	*	4	13%	5	12%	8	9%
Very often	76	39%	*	*	13	43%	15	37%	35	40%
Sometimes	81	42%	*	*	11	37%	16	39%	35	40%
Rarely	18	9%	*	*	2	7%	5	12%	10	11%
Total Responses	195	100%	*	*	30	100%	41	100%	88	100%

Treatment

Q53_19 How often do / did you experience the side effects of your most recent or current treatment? - Muscle pain

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	124	30%	7	19%	17	35%	17	25%	74	31%
Very often	170	41%	16	43%	17	35%	29	43%	99	41%
Sometimes	107	26%	13	35%	12	25%	19	28%	58	24%
Rarely	13	3%	1	3%	2	4%	2	3%	8	3%
Total Responses	414	100%	37	100%	48	100%	67	100%	239	100%

Treatment

Q53_20 How often do / did you experience the side effects of your most recent or current treatment? - Back pain

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	70	29%	*	*	9	26%	14	35%	36	27%
Very often	92	38%	*	*	14	41%	14	35%	53	39%
Sometimes	73	30%	*	*	10	29%	9	23%	42	31%
Rarely	8	3%	*	*	1	3%	3	8%	4	3%
Total Responses	243	100%	*	*	34	100%	40	100%	135	100%

Treatment

Q53_21 How often do / did you experience the side effects of your most recent or current treatment? - Changes to menstrual cycle

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	72	54%	16	53%	24	59%	*	*	21	43%
Very often	35	26%	6	20%	9	22%	*	*	17	35%
Sometimes	20	15%	7	23%	4	10%	*	*	9	18%
Rarely	7	5%	1	3%	4	10%	*	*	2	4%
Total Responses	134	100%	30	100%	41	100%	*	*	49	100%

Treatment

Q53_22 How often do / did you experience the side effects of your most recent or current treatment? - Broken blood vessel in eye (Subconjunctival hemorrhage)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	2	2%	*	*	*	*	*	*	0	0%
Very often	21	19%	*	*	*	*	*	*	16	22%
Sometimes	43	38%	*	*	*	*	*	*	26	36%
Rarely	47	42%	*	*	*	*	*	*	30	42%
Total Responses	113	100%	*	*	*	*	*	*	72	100%

Treatment

Q53_23 How often do / did you experience the side effects of your most recent or current treatment? - Unusually high or low red / white / platelet blood count

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	109	39%	19	36%	28	41%	32	40%	19	32%
Very often	94	33%	22	42%	25	37%	23	29%	20	33%
Sometimes	56	20%	9	17%	10	15%	17	21%	16	27%
Rarely	23	8%	3	6%	5	7%	8	10%	5	8%
Total Responses	282	100%	53	100%	68	100%	80	100%	60	100%

Treatment

Q53_24 How often do / did you experience the side effects of your most recent or current treatment? - High blood pressure (Hypertension)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	57	40%	*	*	*	*	10	29%	29	50%
Very often	39	28%	*	*	*	*	15	43%	17	29%
Sometimes	31	22%	*	*	*	*	5	14%	10	17%
Rarely	14	10%	*	*	*	*	5	14%	2	3%
Total Responses	141	100%	*	*	*	*	35	100%	58	100%

Treatment

Q53_26 How often do / did you experience the side effects of your most recent or current treatment? - Other (Please specify)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	64	38%	*	*	*	*	10	23%	42	48%
Very often	56	33%	*	*	*	*	23	53%	23	26%
Sometimes	33	19%	*	*	*	*	5	12%	20	23%
Rarely	17	10%	*	*	*	*	5	12%	3	3%
Total Responses	170	100%	*	*	*	*	43	100%	88	100%

Appendix 5 – Frequency tables for [Carer] C26 How often do / did they experience the side effects of their most recent or current treatment?

Treatment

C26_1 How often do / did they experience the side effects of their most recent or current treatment? - Bleeding

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	7	6%	2	5%	4	11%	*	*	*	*
Very often	23	21%	10	25%	5	13%	*	*	*	*
Sometimes	46	41%	19	48%	14	37%	*	*	*	*
Rarely	36	32%	9	23%	15	39%	*	*	*	*
Total Responses	112	100%	40	100%	38	100%	*	*	*	*

Treatment

C26_2 How often do / did they experience the side effects of their most recent or current treatment? - Bruising

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	15	12%	5	13%	3	8%	*	*	*	*
Very often	41	32%	10	25%	17	43%	*	*	*	*
Sometimes	45	35%	13	33%	10	25%	*	*	*	*
Rarely	29	22%	12	30%	10	25%	*	*	*	*
Total Responses	130	100%	40	100%	40	100%	*	*	*	*

Treatment

C26_3 How often do / did they experience the side effects of their most recent or current treatment? - Fatigue

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	105	26%	17	14%	36	33%	14	28%	26	28%
Very often	169	42%	48	40%	48	44%	18	36%	38	40%
Sometimes	109	27%	42	35%	21	19%	14	28%	28	30%
Rarely	24	6%	13	11%	5	5%	4	8%	2	2%
Total Responses	407	100%	120	100%	110	100%	50	100%	94	100%

Treatment

C26_4 How often do / did they experience the side effects of their most recent or current treatment? - Shortness of breath

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	17	11%	4	9%	3	6%	*	*	*	*
Very often	54	34%	14	31%	17	34%	*	*	*	*
Sometimes	46	29%	14	31%	18	36%	*	*	*	*
Rarely	41	26%	13	29%	12	24%	*	*	*	*
Total Responses	158	100%	45	100%	50	100%	*	*	*	*

Treatment

C26_5 How often do / did they experience the side effects of their most recent or current treatment? - Fever / night sweats

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	41	16%	9	10%	15	19%	*	*	6	15%
Very often	65	25%	21	22%	21	26%	*	*	12	30%
Sometimes	106	41%	49	52%	31	38%	*	*	12	30%
Rarely	47	18%	15	16%	14	17%	*	*	10	25%
Total Responses	259	100%	94	100%	81	100%	*	*	40	100%

Treatment

C26_6 How often do / did they experience the side effects of their most recent or current treatment? - Frequent and repeated infections

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	34	18%	10	15%	11	19%	*	*	*	*
Very often	57	30%	21	31%	22	37%	*	*	*	*
Sometimes	65	35%	26	39%	15	25%	*	*	*	*
Rarely	31	17%	10	15%	11	19%	*	*	*	*
Total Responses	187	100%	67	100%	59	100%	*	*	*	*

Treatment

C26_7 How often do / did they experience the side effects of their most recent or current treatment? - Unexplained weight loss

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	28	20%	6	14%	13	30%	*	*	*	*
Very often	41	29%	17	39%	12	27%	*	*	*	*
Sometimes	49	35%	16	36%	12	27%	*	*	*	*
Rarely	22	16%	5	11%	7	16%	*	*	*	*
Total Responses	140	100%	44	100%	44	100%	*	*	*	*

Treatment

C26_8 How often do / did they experience the side effects of their most recent or current treatment? - Loss of appetite

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	55	19%	15	13%	28	29%	*	*	1	3%
Very often	114	40%	51	45%	35	36%	*	*	13	38%
Sometimes	98	34%	36	32%	31	32%	*	*	17	50%
Rarely	21	7%	11	10%	4	4%	*	*	3	9%
Total Responses	288	100%	113	100%	98	100%	*	*	34	100%

Treatment

C26_9 How often do / did they experience the side effects of their most recent or current treatment? - Nausea or vomiting

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	45	15%	13	11%	17	18%	*	*	7	13%
Very often	104	35%	43	36%	34	35%	*	*	18	35%
Sometimes	107	36%	49	41%	28	29%	*	*	19	37%
Rarely	45	15%	14	12%	17	18%	*	*	8	15%
Total Responses	301	100%	119	100%	96	100%	*	*	52	100%

Treatment

C26_10 How often do / did they experience the side effects of their most recent or current treatment? - Sleeping problems

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	52	23%	10	14%	19	29%	*	*	9	21%
Very often	87	39%	30	42%	25	38%	*	*	18	42%
Sometimes	60	27%	23	32%	15	23%	*	*	11	26%
Rarely	24	11%	8	11%	7	11%	*	*	5	12%
Total Responses	223	100%	71	100%	66	100%	*	*	43	100%

Treatment

C26_11 How often do / did they experience the side effects of their most recent or current treatment? - Headaches

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	23	13%	4	7%	5	10%	*	*	7	15%
Very often	61	34%	22	41%	11	22%	*	*	20	43%
Sometimes	73	40%	23	43%	25	49%	*	*	15	32%
Rarely	25	14%	5	9%	10	20%	*	*	5	11%
Total Responses	182	100%	54	100%	51	100%	*	*	47	100%

Treatment

C26_12 How often do / did they experience the side effects of their most recent or current treatment? - Swollen lymph nodes

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	12	15%	*	*	*	*	*	*	*	*
Very often	11	14%	*	*	*	*	*	*	*	*
Sometimes	34	43%	*	*	*	*	*	*	*	*
Rarely	22	28%	*	*	*	*	*	*	*	*
Total Responses	79	100%	*	*	*	*	*	*	*	*

Treatment

C26_13 How often do / did they experience the side effects of their most recent or current treatment? - Tingling or numbness in extremities

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	22	21%	*	*	*	*	*	*	6	19%
Very often	35	34%	*	*	*	*	*	*	10	31%
Sometimes	24	23%	*	*	*	*	*	*	8	25%
Rarely	23	22%	*	*	*	*	*	*	8	25%
Total Responses	104	100%	*	*	*	*	*	*	32	100%

Treatment

C26_14 How often do / did they experience the side effects of their most recent or current treatment? - Itchy skin

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	30	18%	6	12%	9	18%	*	*	6	14%
Very often	44	26%	6	12%	18	36%	*	*	14	32%
Sometimes	66	39%	25	51%	15	30%	*	*	16	36%
Rarely	31	18%	12	24%	8	16%	*	*	8	18%
Total Responses	171	100%	49	100%	50	100%	*	*	44	100%

Treatment

C26_15 How often do / did they experience the side effects of their most recent or current treatment? - Pain in bones / joints

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	52	22%	13	18%	12	24%	*	*	17	24%
Very often	76	33%	24	32%	15	30%	*	*	25	35%
Sometimes	86	37%	31	42%	16	32%	*	*	26	37%
Rarely	19	8%	6	8%	7	14%	*	*	3	4%
Total Responses	233	100%	74	100%	50	100%	*	*	71	100%

Treatment

C26_16 How often do / did they experience the side effects of their most recent or current treatment? - Swollen stomach or abdominal discomfort

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	28	18%	8	17%	6	17%	*	*	9	21%
Very often	47	30%	11	23%	10	28%	*	*	12	28%
Sometimes	45	29%	15	32%	10	28%	*	*	14	33%
Rarely	36	23%	13	28%	10	28%	*	*	8	19%
Total Responses	156	100%	47	100%	36	100%	*	*	43	100%

Treatment

C26_17 How often do / did they experience the side effects of their most recent or current treatment? - Memory loss / loss of concentration

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Always	28	17%	7	19%	4	9%	*	*	14	34%
Very often	47	29%	10	28%	13	30%	*	*	7	17%
Sometimes	64	40%	15	42%	20	45%	*	*	14	34%
Rarely	22	14%	4	11%	7	16%	*	*	6	15%
Total Responses	161	100%	36	100%	44	100%	*	*	41	100%

Treatment

C26_18 How often do / did they experience the side effects of their most recent or current treatment? - Palpitations / heart irregularities

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Always	10	9%	4	13%	*	*	*	*	*	*
Very often	28	26%	6	19%	*	*	*	*	*	*
Sometimes	44	41%	14	45%	*	*	*	*	*	*
Rarely	25	23%	7	23%	*	*	*	*	*	*
Total Responses	107	100%	31	100%	*	*	*	*	*	*

Treatment

C26_19 How often do / did they experience the side effects of their most recent or current treatment? - Muscle pain

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	38	18%	8	13%	8	17%	*	*	15	22%
Very often	72	35%	29	47%	14	30%	*	*	23	34%
Sometimes	72	35%	18	29%	15	32%	*	*	25	37%
Rarely	26	13%	7	11%	10	21%	*	*	5	7%
Total Responses	208	100%	62	100%	47	100%	*	*	68	100%

Treatment

C26_20 How often do / did they experience the side effects of their most recent or current treatment? - Back pain

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	33	24%	8	22%	7	19%	*	*	9	23%
Very often	43	31%	12	33%	12	32%	*	*	14	35%
Sometimes	47	34%	15	42%	9	24%	*	*	13	33%
Rarely	17	12%	1	3%	9	24%	*	*	4	10%
Total Responses	140	100%	36	100%	37	100%	*	*	40	100%

Treatment

C26_21 How often do / did they experience the side effects of their most recent or current treatment? - Changes to menstrual cycle

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	23	46%	*	*	*	*	*	*	*	*
Very often	14	28%	*	*	*	*	*	*	*	*
Sometimes	9	18%	*	*	*	*	*	*	*	*
Rarely	4	8%	*	*	*	*	*	*	*	*
Total Responses	50	100%	*	*	*	*	*	*	*	*

Treatment

C26_22 How often do / did they experience the side effects of their most recent or current treatment? - Broken blood vessel in eye (Subconjunctival hemorrhage)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	3	5%	*	*	*	*	*	*	*	*
Very often	8	14%	*	*	*	*	*	*	*	*
Sometimes	16	28%	*	*	*	*	*	*	*	*
Rarely	31	53%	*	*	*	*	*	*	*	*
Total Responses	58	100%	*	*	*	*	*	*	*	*

Treatment

C26_23 How often do / did they experience the side effects of their most recent or current treatment? - Unusually high or low red / white / platelet blood count

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Always	74	27%	27	26%	26	32%	*	*	4	12%
Very often	95	35%	44	42%	25	31%	*	*	11	33%
Sometimes	67	25%	25	24%	20	25%	*	*	12	36%
Rarely	35	13%	8	8%	10	12%	*	*	6	18%
Total Responses	271	100%	104	100%	81	100%	*	*	33	100%

Treatment

C26_24 How often do / did they experience the side effects of their most recent or current treatment? - High blood pressure (Hypertension)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Always	19	25%	*	*	*	*	*	*	*	*
Very often	13	17%	*	*	*	*	*	*	*	*
Sometimes	26	35%	*	*	*	*	*	*	*	*
Rarely	17	23%	*	*	*	*	*	*	*	*
Total Responses	75	100%	*	*	*	*	*	*	*	*

Treatment

C26_26 How often do / did they experience the side effects of their most recent or current treatment? - Other (Please specify)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Always	13	37%	*	*	*	*	*	*	*	*
Very often	10	29%	*	*	*	*	*	*	*	*
Sometimes	6	17%	*	*	*	*	*	*	*	*
Rarely	6	17%	*	*	*	*	*	*	*	*
Total Responses	35	100%	*	*	*	*	*	*	*	*

Appendix 6 – Frequency tables for [Patient] Q54 How severe are / were the side effects of your most recent or current treatment?

Treatment
Q54_1 How severe are / were the side effects of your most recent or current treatment? - Bleeding

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	54	52%	*	*	*	*	23	55%	*	*
Moderate	37	36%	*	*	*	*	16	38%	*	*
Severe	12	12%	*	*	*	*	3	7%	*	*
Total Responses	103	100%	*	*	*	*	42	100%	*	*

Treatment
Q54_2 How severe are / were the side effects of your most recent or current treatment? - Bruising

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	98	46%	*	*	*	*	43	43%	31	52%
Moderate	96	45%	*	*	*	*	47	47%	23	38%
Severe	21	10%	*	*	*	*	9	9%	6	10%
Total Responses	215	100%	*	*	*	*	99	100%	60	100%

Treatment

Q54_3 How severe are / were the side effects of your most recent or current treatment? - Fatigue

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Mild	165	19%	21	26%	22	16%	51	24%	62	16%
Moderate	452	52%	46	56%	70	50%	104	49%	200	53%
Severe	246	29%	15	18%	47	34%	56	27%	114	30%
Total Responses	863	100%	82	100%	139	100%	211	100%	376	100%

Treatment

Q54_4 How severe are / were the side effects of your most recent or current treatment? - Shortness of breath

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Mild	86	32%	*	*	17	35%	16	29%	40	33%
Moderate	139	52%	*	*	21	44%	33	60%	65	53%
Severe	41	15%	*	*	10	21%	6	11%	17	14%
Total Responses	266	100%	*	*	48	100%	55	100%	122	100%

Treatment

Q54_5 How severe are / were the side effects of your most recent or current treatment? - Fever / night sweats

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	82	31%	11	31%	22	30%	8	21%	36	38%
Moderate	136	52%	17	47%	39	53%	21	54%	49	52%
Severe	43	16%	8	22%	13	18%	10	26%	10	11%
Total Responses	261	100%	36	100%	74	100%	39	100%	95	100%

Treatment

Q54_6 How severe are / were the side effects of your most recent or current treatment? - Frequent and repeated infections

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	47	23%	*	*	10	21%	15	25%	16	25%
Moderate	113	56%	*	*	27	57%	31	53%	41	64%
Severe	43	21%	*	*	10	21%	13	22%	7	11%
Total Responses	203	100%	*	*	47	100%	59	100%	64	100%

Treatment

Q54_7 How severe are / were the side effects of your most recent or current treatment? - Unexplained weight loss

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	31	26%	*	*	8	24%	*	*	7	21%
Moderate	61	51%	*	*	14	41%	*	*	22	65%
Severe	28	23%	*	*	12	35%	*	*	5	15%
Total Responses	120	100%	*	*	34	100%	*	*	34	100%

Treatment

Q54_8 How severe are / were the side effects of your most recent or current treatment? - Loss of appetite

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	80	26%	21	28%	28	28%	10	26%	16	22%
Moderate	145	48%	36	49%	43	43%	16	42%	39	53%
Severe	79	26%	17	23%	28	28%	12	32%	18	25%
Total Responses	304	100%	74	100%	99	100%	38	100%	73	100%

Treatment
Q54_9 How severe are / were the side effects of your most recent or current treatment? - Nausea or vomiting

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	158	35%	23	29%	35	31%	26	39%	61	38%
Moderate	191	42%	36	46%	35	31%	26	39%	77	48%
Severe	105	23%	19	24%	43	38%	15	22%	24	15%
Total Responses	454	100%	78	100%	113	100%	67	100%	162	100%

Treatment
Q54_10 How severe are / were the side effects of your most recent or current treatment? - Sleeping problems

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	98	23%	27	44%	22	25%	14	19%	28	17%
Moderate	207	49%	25	40%	46	52%	36	50%	85	50%
Severe	114	27%	10	16%	20	23%	22	31%	56	33%
Total Responses	419	100%	62	100%	88	100%	72	100%	169	100%

Treatment

Q54_11 How severe are / were the side effects of your most recent or current treatment? - Headaches

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	75	26%	*	*	18	35%	14	33%	25	18%
Moderate	158	54%	*	*	23	44%	22	51%	85	61%
Severe	57	20%	*	*	11	21%	7	16%	29	21%
Total Responses	290	100%	*	*	52	100%	43	100%	139	100%

Treatment

Q54_12 How severe are / were the side effects of your most recent or current treatment? - Swollen lymph nodes

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	22	41%	*	*	*	*	*	*	*	*
Moderate	23	43%	*	*	*	*	*	*	*	*
Severe	9	17%	*	*	*	*	*	*	*	*
Total Responses	54	100%	*	*	*	*	*	*	*	*

Treatment

Q54_13 How severe are / were the side effects of your most recent or current treatment? - Tingling or numbness in extremities

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	99	36%	9	30%	11	31%	21	36%	56	42%
Moderate	119	43%	11	37%	18	50%	26	45%	54	40%
Severe	57	21%	10	33%	7	19%	11	19%	24	18%
Total Responses	275	100%	30	100%	36	100%	58	100%	134	100%

Treatment

Q54_14 How severe are / were the side effects of your most recent or current treatment? - Itchy skin

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	113	35%	*	*	19	32%	22	31%	57	38%
Moderate	148	46%	*	*	36	60%	32	46%	58	39%
Severe	63	19%	*	*	5	8%	16	23%	34	23%
Total Responses	324	100%	*	*	60	100%	70	100%	149	100%

Treatment

Q54_15 How severe are / were the side effects of your most recent or current treatment? - Pain in bones / joints

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	100	19%	12	27%	23	35%	10	11%	50	18%
Moderate	273	53%	23	51%	28	42%	60	64%	146	53%
Severe	140	27%	10	22%	15	23%	24	26%	81	29%
Total Responses	513	100%	45	100%	66	100%	94	100%	277	100%

Treatment

Q54_16 How severe are / were the side effects of your most recent or current treatment? - Swollen stomach or abdominal discomfort

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	65	25%	*	*	13	30%	9	21%	28	22%
Moderate	127	48%	*	*	19	43%	24	56%	63	49%
Severe	71	27%	*	*	12	27%	10	23%	37	29%
Total Responses	263	100%	*	*	44	100%	43	100%	128	100%

Treatment

Q54_17 How severe are / were the side effects of your most recent or current treatment? - Memory loss / loss of concentration

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	108	30%	10	24%	21	30%	21	32%	45	29%
Moderate	180	50%	25	60%	31	44%	33	51%	79	51%
Severe	69	19%	7	17%	18	26%	11	17%	31	20%
Total Responses	357	100%	42	100%	70	100%	65	100%	155	100%

Treatment

Q54_18 How severe are / were the side effects of your most recent or current treatment? - Palpitations / heart irregularities

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	73	39%	*	*	*	*	13	33%	33	38%
Moderate	89	47%	*	*	*	*	16	41%	45	52%
Severe	26	14%	*	*	*	*	10	26%	9	10%
Total Responses	188	100%	*	*	*	*	39	100%	87	100%

Treatment

Q54_19 How severe are / were the side effects of your most recent or current treatment? - Muscle pain

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	82	20%	16	46%	11	24%	13	19%	39	17%
Moderate	217	53%	14	40%	25	54%	40	59%	126	54%
Severe	108	27%	5	14%	10	22%	15	22%	70	30%
Total Responses	407	100%	35	100%	46	100%	68	100%	235	100%

Treatment

Q54_20 How severe are / were the side effects of your most recent or current treatment? - Back pain

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	44	18%	*	*	9	26%	7	18%	24	18%
Moderate	125	52%	*	*	19	56%	20	53%	68	51%
Severe	71	30%	*	*	6	18%	11	29%	42	31%
Total Responses	240	100%	*	*	34	100%	38	100%	134	100%

Treatment

Q54_21 How severe are / were the side effects of your most recent or current treatment? - Changes to menstrual cycle

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	26	20%	*	*	10	25%	*	*	8	16%
Moderate	49	37%	*	*	13	33%	*	*	23	47%
Severe	57	43%	*	*	17	43%	*	*	18	37%
Total Responses	132	100%	*	*	40	100%	*	*	49	100%

Treatment

Q54_22 How severe are / were the side effects of your most recent or current treatment? - Broken blood vessel in eye (Subconjunctival hemorrhage)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	57	51%	*	*	*	*	*	*	35	49%
Moderate	41	37%	*	*	*	*	*	*	26	36%
Severe	14	13%	*	*	*	*	*	*	11	15%
Total Responses	112	100%	*	*	*	*	*	*	72	100%

Treatment

Q54_23 How severe are / were the side effects of your most recent or current treatment? - Unusually high or low red / white / platelet blood count

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	63	23%	11	21%	15	23%	22	28%	14	24%
Moderate	127	46%	28	53%	27	42%	36	46%	28	48%
Severe	84	31%	14	26%	22	34%	21	27%	16	28%
Total Responses	274	100%	53	100%	64	100%	79	100%	58	100%

Treatment

Q54_24 How severe are / were the side effects of your most recent or current treatment? - High blood pressure (Hypertension)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	39	28%	*	*	*	*	7	19%	12	21%
Moderate	74	54%	*	*	*	*	26	72%	29	52%
Severe	25	18%	*	*	*	*	3	8%	15	27%
Total Responses	138	100%	*	*	*	*	36	100%	56	100%

Treatment

Q54_26 How severe are / were the side effects of your most recent or current treatment? - Other (Please specify)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Mild	38	22%	*	*	*	*	10	26%	14	16%
Moderate	72	43%	*	*	*	*	21	54%	37	41%
Severe	59	35%	*	*	*	*	8	21%	39	43%
Total Responses	169	100%	*	*	*	*	39	100%	90	100%

Appendix 7 – Frequency tables for [Patient] Q63 If you experience/d the following side effects post treatment, overall, how would you rate their negative impact? [Derived]

Treatment

Q63_1 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Engraftment syndrome

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	80	35%	35	41%	39	36%	*	*	*	*
Small impact	94	41%	33	38%	43	40%	*	*	*	*
Large impact	55	24%	18	21%	26	24%	*	*	*	*
Total Responses	229	100%	86	100%	108	100%	*	*	*	*

Treatment

Q63_2 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Graft rejections

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	78	38%	34	37%	39	44%	*	*	*	*
Small impact	81	39%	34	37%	37	42%	*	*	*	*
Large impact	47	23%	25	27%	13	15%	*	*	*	*
Total Responses	206	100%	93	100%	89	100%	*	*	*	*

Treatment

Q63_3 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Graft failure

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	94	74%	43	72%	42	78%	*	*	*	*
Small impact	12	9%	7	12%	5	9%	*	*	*	*
Large impact	21	17%	10	17%	7	13%	*	*	*	*
Total Responses	127	100%	60	100%	54	100%	*	*	*	*

Treatment

Q63_4 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Graft -versus-host disease (acute)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	71	28%	29	29%	34	29%	*	*	*	*
Small impact	89	35%	31	31%	44	37%	*	*	*	*
Large impact	92	37%	41	41%	41	34%	*	*	*	*
Total Responses	252	100%	101	100%	119	100%	*	*	*	*

Treatment

Q63_5 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Graft -versus-host disease (chronic)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	62	25%	23	24%	32	26%	*	*	*	*
Small impact	107	42%	37	39%	54	44%	*	*	*	*
Large impact	84	33%	35	37%	37	30%	*	*	*	*
Total Responses	253	100%	95	100%	123	100%	*	*	*	*

Treatment

Q63_6 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Cytomegalovirus (CMV)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	69	31%	22	21%	35	40%	*	*	*	*
Small impact	87	39%	46	44%	34	39%	*	*	*	*
Large impact	66	30%	37	35%	18	21%	*	*	*	*
Total Responses	222	100%	105	100%	87	100%	*	*	*	*

Treatment

Q63_7 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Cataracts

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	93	57%	40	58%	43	61%	*	*	*	*
Small impact	31	19%	14	20%	13	18%	*	*	*	*
Large impact	40	24%	15	22%	15	21%	*	*	*	*
Total Responses	164	100%	69	100%	71	100%	*	*	*	*

Treatment

Q63_8 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Thrombotic microangiopathy (TMA)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	91	70%	40	65%	41	84%	*	*	*	*
Small impact	22	17%	12	19%	4	8%	*	*	*	*
Large impact	17	13%	10	16%	4	8%	*	*	*	*
Total Responses	130	100%	62	100%	49	100%	*	*	*	*

Treatment

Q63_9 If you experience/d the following side effects post treatment, overall how would you rate their negative impact? - Other (Please specify)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Barely noticeable	41	53%	*	*	19	46%	*	*	*	*
Small impact	7	9%	*	*	5	12%	*	*	*	*
Large impact	30	38%	*	*	17	41%	*	*	*	*
Total Responses	78	100%	*	*	41	100%	*	*	*	*

Appendix 8 – Frequency tables for [Patient] Q79 When in your treatment journey were you given or directed to the information and support?

Information and support

Q79_1 When in your treatment journey were you given or directed to the information and support? - Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	173	30%	30	32%	33	25%	40	29%	57	34%
During 'watch and wait' or 'active monitoring'	50	9%	0	0%	0	0%	50	37%	0	0%
After diagnosis but before treatment started	144	25%	28	30%	31	24%	27	20%	41	24%
During treatment	320	55%	59	63%	82	63%	37	27%	111	66%
After treatment finished	57	10%	14	15%	26	20%	7	5%	5	3%
Don't know / can't remember	21	4%	6	6%	8	6%	4	3%	3	2%
Total Responses	579	100%	94	100%	130	100%	136	100%	168	100%

Information and support

Q79_2 When in your treatment journey were you given or directed to the information and support? - General wellbeing (including spiritual wellbeing)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	118	34%	20	34%	18	24%	35	37%	38	38%
During 'watch and wait' or 'active monitoring'	43	12%	0	0%	0	0%	43	46%	0	0%
After diagnosis but before treatment started	104	30%	24	41%	23	30%	21	22%	31	31%
During treatment	191	54%	39	66%	49	64%	27	29%	64	64%
After treatment finished	35	10%	12	20%	16	21%	4	4%	1	1%
Don't know / can't remember	27	8%	7	12%	7	9%	8	9%	3	3%
Total Responses	352	100%	59	100%	76	100%	94	100%	100	100%

Information and support

Q79_3 When in your treatment journey were you given or directed to the information and support? - Clinical trials

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	107	30%	6	18%	24	39%	29	22%	45	39%
During 'watch and wait' or 'active monitoring'	49	14%	0	0%	0	0%	49	37%	0	0%
After diagnosis but before treatment started	106	30%	7	21%	21	34%	51	38%	25	22%
During treatment	147	42%	21	64%	31	50%	24	18%	67	58%
After treatment finished	24	7%	5	15%	7	11%	7	5%	4	3%
Don't know / can't remember	14	4%	1	3%	4	6%	6	5%	3	3%
Total Responses	352	100%	33	100%	62	100%	133	100%	115	100%

Information and support

Q79_4 When in your treatment journey were you given or directed to the information and support? - Side effects and risks of treatment

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	222	30%	38	34%	44	29%	39	18%	90	42%
During 'watch and wait' or 'active monitoring'	48	7%	0	0%	0	0%	48	22%	0	0%
After diagnosis but before treatment started	368	50%	65	59%	82	54%	118	54%	81	38%
During treatment	295	40%	55	50%	69	46%	67	31%	87	41%
After treatment finished	59	8%	19	17%	22	15%	6	3%	5	2%
Don't know / can't remember	21	3%	4	4%	7	5%	3	1%	5	2%
Total Responses	731	100%	111	100%	151	100%	217	100%	212	100%

Information and support

Q79_5 When in your treatment journey were you given or directed to the information and support? - Access to a Clinical Nurse Specialist (CNS)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	72	44%	*	*	*	*	61	45%	*	*
During 'watch and wait' or 'active monitoring'	37	22%	*	*	*	*	37	27%	*	*
After diagnosis but before treatment started	35	21%	*	*	*	*	25	18%	*	*
During treatment	45	27%	*	*	*	*	37	27%	*	*
After treatment finished	10	6%	*	*	*	*	9	7%	*	*
Don't know / can't remember	1	1%	*	*	*	*	0	0%	*	*
Total Responses	165	100%	*	*	*	*	137	100%	*	*

Information and support

Q79_6 When in your treatment journey were you given or directed to the information and support? - Patient rights

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	134	44%	24	44%	28	43%	27	36%	47	51%
During 'watch and wait' or 'active monitoring'	18	6%	0	0%	0	0%	18	24%	0	0%
After diagnosis but before treatment started	91	30%	21	39%	24	37%	21	28%	22	24%
During treatment	115	38%	27	50%	27	42%	15	20%	40	43%
After treatment finished	30	10%	12	22%	9	14%	2	3%	4	4%
Don't know / can't remember	26	9%	3	6%	8	12%	8	11%	5	5%
Total Responses	304	100%	54	100%	65	100%	76	100%	93	100%

Information and support

Q79_7 When in your treatment journey were you given or directed to the information and support? - Buddying or befriending

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	66	33%	19	31%	12	29%	12	32%	16	40%
During 'watch and wait' or 'active monitoring'	17	9%	0	0%	0	0%	17	45%	0	0%
After diagnosis but before treatment started	52	26%	16	26%	12	29%	7	18%	13	33%
During treatment	128	65%	43	69%	31	74%	13	34%	32	80%
After treatment finished	38	19%	17	27%	16	38%	2	5%	1	3%
Don't know / can't remember	12	6%	7	11%	1	2%	3	8%	1	3%
Total Responses	198	100%	62	100%	42	100%	38	100%	40	100%

Information and support
Q79_8 When in your treatment journey were you given or directed to the information and support? - Patient support groups

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	140	27%	13	24%	12	17%	67	34%	43	24%
During 'watch and wait' or 'active monitoring'	89	17%	0	0%	0	0%	89	45%	0	0%
After diagnosis but before treatment started	121	23%	21	39%	16	23%	33	17%	45	26%
During treatment	233	45%	35	65%	47	67%	33	17%	106	60%
After treatment finished	64	12%	16	30%	22	31%	11	6%	7	4%
Don't know / can't remember	22	4%	5	9%	4	6%	8	4%	5	3%
Total Responses	518	100%	54	100%	70	100%	196	100%	176	100%

Information and support
Q79_9 When in your treatment journey were you given or directed to the information and support? - Leukemia charities / associations / organizations

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	155	30%	10	19%	11	13%	90	40%	36	27%
During 'watch and wait' or 'active monitoring'	91	18%	0	0%	0	0%	91	41%	0	0%
After diagnosis but before treatment started	105	20%	13	25%	20	24%	32	14%	36	27%
During treatment	214	41%	37	70%	52	63%	32	14%	78	58%
After treatment finished	42	8%	13	25%	15	18%	6	3%	5	4%
Don't know / can't remember	30	6%	3	6%	6	7%	16	7%	3	2%
Total Responses	519	100%	53	100%	82	100%	223	100%	135	100%

Information and support

Q79_10 When in your treatment journey were you given or directed to the information and support? - Financial information

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	31	22%	*	*	6	15%	6	14%	10	33%
During 'watch and wait' or 'active monitoring'	13	9%	*	*	0	0%	13	30%	0	0%
After diagnosis but before treatment started	48	34%	*	*	12	29%	16	36%	11	37%
During treatment	70	49%	*	*	26	63%	18	41%	10	33%
After treatment finished	6	4%	*	*	3	7%	0	0%	0	0%
Don't know / can't remember	8	6%	*	*	4	10%	2	5%	2	7%
Total Responses	143	100%	*	*	41	100%	44	100%	30	100%

Information and support

Q79_11 When in your treatment journey were you given or directed to the information and support? - Written information / booklets / leaflets

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	315	51%	12	34%	36	38%	173	61%	84	45%
During 'watch and wait' or 'active monitoring'	82	13%	0	0%	0	0%	82	29%	0	0%
After diagnosis but before treatment started	155	25%	12	34%	41	43%	43	15%	51	28%
During treatment	187	30%	24	69%	49	52%	32	11%	72	39%
After treatment finished	42	7%	8	23%	16	17%	8	3%	7	4%
Don't know / can't remember	18	3%	1	3%	1	1%	10	4%	5	3%
Total Responses	622	100%	35	100%	95	100%	283	100%	185	100%

Information and support

Q79_12 When in your treatment journey were you given or directed to the information and support? - Online forums

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	84	27%	9	29%	3	10%	44	35%	22	21%
During 'watch and wait' or 'active monitoring'	61	20%	0	0%	0	0%	61	48%	0	0%
After diagnosis but before treatment started	67	22%	12	39%	9	29%	22	17%	19	18%
During treatment	148	48%	21	68%	22	71%	23	18%	72	70%
After treatment finished	32	10%	14	45%	6	19%	5	4%	4	4%
Don't know / can't remember	23	7%	1	3%	4	13%	8	6%	8	8%
Total Responses	311	100%	31	100%	31	100%	126	100%	103	100%

Information and support

Q79_13 When in your treatment journey were you given or directed to the information and support? - End of life care

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	6	17%	*	*	*	*	*	*	*	*
During 'watch and wait' or 'active monitoring'	5	14%	*	*	*	*	*	*	*	*
After diagnosis but before treatment started	5	14%	*	*	*	*	*	*	*	*
During treatment	18	51%	*	*	*	*	*	*	*	*
After treatment finished	3	9%	*	*	*	*	*	*	*	*
Don't know / can't remember	2	6%	*	*	*	*	*	*	*	*
Total Responses	35	100%	*	*	*	*	*	*	*	*

Appendix 9 – Frequency tables for [Patient] Q80 Did you access this support and did it help you?

Information and support
Q80_1 Did you access this support and did it help you? - Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	359	64%	58	64%	83	65%	73	55%	110	68%
Yes, but it did not help me feel any better / more positive	94	17%	20	22%	25	20%	16	12%	26	16%
No, I did not access this support	89	16%	9	10%	10	8%	42	32%	20	12%
Don't know / can't remember	23	4%	3	3%	10	8%	2	2%	6	4%
Total Responses	565	100%	90	100%	128	100%	133	100%	162	100%

Information and support

Q80_2 Did you access this support and did it help you? - General wellbeing (including spiritual wellbeing)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	243	67%	40	69%	55	73%	45	45%	84	82%
Yes, but it did not help me feel any better / more positive	35	10%	8	14%	10	13%	10	10%	5	5%
No, I did not access this support	60	17%	4	7%	5	7%	39	39%	9	9%
Don’t know / can’t remember	23	6%	6	10%	5	7%	6	6%	4	4%
Total Responses	361	100%	58	100%	75	100%	100	100%	102	100%

Information and support

Q80_3 Did you access this support and did it help you? - Clinical trials

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	199	56%	19	61%	25	42%	89	64%	60	53%
Yes, but it did not help me feel any better / more positive	81	23%	8	26%	20	34%	21	15%	31	27%
No, I did not access this support	49	14%	1	3%	10	17%	24	17%	12	11%
Don’t know / can’t remember	24	7%	3	10%	4	7%	4	3%	11	10%
Total Responses	353	100%	31	100%	59	100%	138	100%	114	100%

Information and support

Q80_4 Did you access this support and did it help you? - Side effects and risks of treatment

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	399	53%	48	43%	75	51%	133	58%	117	53%
Yes, but it did not help me feel any better / more positive	237	32%	48	43%	51	35%	56	25%	68	31%
No, I did not access this support	67	9%	9	8%	8	5%	28	12%	20	9%
Don’t know / can’t remember	48	6%	6	5%	12	8%	11	5%	17	8%
Total Responses	751	100%	111	100%	146	100%	228	100%	222	100%

Information and support

Q80_5 Did you access this support and did it help you? - Access to a Clinical Nurse Specialist (CNS)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	124	73%	*	*	*	*	105	75%	*	*
Yes, but it did not help me feel any better / more positive	26	15%	*	*	*	*	18	13%	*	*
No, I did not access this support	17	10%	*	*	*	*	15	11%	*	*
Don’t know / can’t remember	2	1%	*	*	*	*	2	1%	*	*
Total Responses	169	100%	*	*	*	*	140	100%	*	*

Information and support

Q80_6 Did you access this support and did it help you? - Patient rights

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	178	54%	33	61%	40	60%	40	45%	52	54%
Yes, but it did not help me feel any better / more positive	75	23%	13	24%	18	27%	18	20%	21	22%
No, I did not access this support	50	15%	5	9%	3	4%	22	25%	17	18%
Don’t know / can’t remember	24	7%	3	6%	6	9%	8	9%	7	7%
Total Responses	327	100%	54	100%	67	100%	88	100%	97	100%

Information and support

Q80_7 Did you access this support and did it help you? - Buddying or befriending

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	166	79%	46	74%	38	83%	29	67%	37	90%
Yes, but it did not help me feel any better / more positive	20	10%	10	16%	3	7%	3	7%	3	7%
No, I did not access this support	17	8%	3	5%	3	7%	10	23%	1	2%
Don’t know / can’t remember	6	3%	3	5%	2	4%	1	2%	0	0%
Total Responses	209	100%	62	100%	46	100%	43	100%	41	100%

Information and support

Q80_8 Did you access this support and did it help you? - Patient support groups

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	410	76%	33	62%	52	78%	155	74%	155	81%
Yes, but it did not help me feel any better / more positive	64	12%	11	21%	4	6%	22	11%	24	13%
No, I did not access this support	54	10%	6	11%	8	12%	26	12%	10	5%
Don’t know / can’t remember	14	3%	3	6%	3	4%	6	3%	2	1%
Total Responses	542	100%	53	100%	67	100%	209	100%	191	100%

Information and support

Q80_9 Did you access this support and did it help you? - Leukemia charities / associations / organizations

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	431	76%	37	67%	63	71%	187	75%	125	83%
Yes, but it did not help me feel any better / more positive	78	14%	15	27%	12	13%	35	14%	11	7%
No, I did not access this support	46	8%	2	4%	10	11%	20	8%	12	8%
Don’t know / can’t remember	15	3%	1	2%	4	4%	7	3%	2	1%
Total Responses	570	100%	55	100%	89	100%	249	100%	150	100%

Information and support

Q80_10 Did you access this support and did it help you? - Financial information

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	102	66%	*	*	33	72%	31	63%	22	67%
Yes, but it did not help me feel any better / more positive	23	15%	*	*	5	11%	6	12%	5	15%
No, I did not access this support	23	15%	*	*	3	7%	10	20%	6	18%
Don’t know / can’t remember	7	5%	*	*	5	11%	2	4%	0	0%
Total Responses	155	100%	*	*	46	100%	49	100%	33	100%

Information and support

Q80_11 Did you access this support and did it help you? - Written information / booklets / leaflets

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	455	67%	22	58%	52	53%	228	71%	136	67%
Yes, but it did not help me feel any better / more positive	174	25%	13	34%	34	35%	69	22%	49	24%
No, I did not access this support	33	5%	2	5%	6	6%	13	4%	11	5%
Don’t know / can’t remember	22	3%	1	3%	6	6%	9	3%	6	3%
Total Responses	684	100%	38	100%	98	100%	319	100%	202	100%

Information and support

Q80_12 Did you access this support and did it help you? - Online forums

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	275	78%	23	74%	18	60%	127	83%	89	75%
Yes, but it did not help me feel any better / more positive	52	15%	5	16%	7	23%	19	12%	18	15%
No, I did not access this support	17	5%	3	10%	4	13%	5	3%	5	4%
Don't know / can't remember	9	3%	0	0%	1	3%	2	1%	6	5%
Total Responses	353	100%	31	100%	30	100%	153	100%	118	100%

Information and support

Q80_13 Did you access this support and did it help you? - End of life care

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	22	56%	*	*	*	*	*	*	*	*
Yes, but it did not help me feel any better / more positive	6	15%	*	*	*	*	*	*	*	*
No, I did not access this support	9	23%	*	*	*	*	*	*	*	*
Don't know / can't remember	2	5%	*	*	*	*	*	*	*	*
Total Responses	39	100%	*	*	*	*	*	*	*	*

Appendix 10 – Frequency tables for [Carer] C36 When in the patient's treatment journey were you given or directed to the information and support?

Information and support

C36_1 When in the patient's treatment journey were you given or directed to the information and support? - Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	62	33%	26	39%	17	31%	*	*	*	*
During 'watch and wait' or 'active monitoring'	9	5%	0	0%	0	0%	*	*	*	*
After diagnosis but before treatment started	60	32%	26	39%	14	26%	*	*	*	*
During treatment	106	57%	46	69%	29	54%	*	*	*	*
After treatment finished	23	12%	13	19%	7	13%	*	*	*	*
Don't know / can't remember	10	5%	2	3%	2	4%	*	*	*	*
Total Responses	187	100%	67	100%	54	100%	*	*	*	*

Information and support

C36_2 When in the patient's treatment journey were you given or directed to the information and support? - General wellbeing (including spiritual wellbeing)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	60	40%	26	47%	14	35%	*	*	*	*
During 'watch and wait' or 'active monitoring'	6	4%	0	0%	0	0%	*	*	*	*
After diagnosis but before treatment started	50	34%	21	38%	10	25%	*	*	*	*
During treatment	83	56%	32	58%	23	58%	*	*	*	*
After treatment finished	19	13%	11	20%	4	10%	*	*	*	*
Don't know / can't remember	8	5%	4	7%	2	5%	*	*	*	*
Total Responses	149	100%	55	100%	40	100%	*	*	*	*

Information and support

C36_3 When in the patient's treatment journey were you given or directed to the information and support? - Clinical trials

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	40	33%	13	31%	10	28%	*	*	*	*
During 'watch and wait' or 'active monitoring'	5	4%	0	0%	0	0%	*	*	*	*
After diagnosis but before treatment started	34	28%	11	26%	8	22%	*	*	*	*
During treatment	63	51%	29	69%	16	44%	*	*	*	*
After treatment finished	10	8%	4	10%	4	11%	*	*	*	*
Don't know / can't remember	10	8%	3	7%	4	11%	*	*	*	*
Total Responses	123	100%	42	100%	36	100%	*	*	*	*

Information and support

C36_4 When in the patient's treatment journey were you given or directed to the information and support? - Side effects and risks of treatment

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	89	32%	37	38%	19	25%	*	*	15	28%
During 'watch and wait' or 'active monitoring'	7	3%	0	0%	0	0%	*	*	0	0%
After diagnosis but before treatment started	119	43%	47	48%	36	47%	*	*	18	34%
During treatment	148	53%	58	59%	36	47%	*	*	31	58%
After treatment finished	23	8%	10	10%	6	8%	*	*	2	4%
Don't know / can't remember	11	4%	2	2%	3	4%	*	*	6	11%
Total Responses	279	100%	98	100%	76	100%	*	*	53	100%

Information and support

C36_5 When in the patient's treatment journey were you given or directed to the information and support? - Access to a Clinical Nurse Specialist (CNS)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
At diagnosis	*	*	*	*	*	*	*	*	*	*
During 'watch and wait' or 'active monitoring'	*	*	*	*	*	*	*	*	*	*
After diagnosis but before treatment started	*	*	*	*	*	*	*	*	*	*
During treatment	*	*	*	*	*	*	*	*	*	*
After treatment finished	*	*	*	*	*	*	*	*	*	*
Don't know / can't remember	*	*	*	*	*	*	*	*	*	*
Total Responses	*	*	*	*	*	*	*	*	*	*

Information and support

C36_6 When in the patient's treatment journey were you given or directed to the information and support? - Patient rights

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	47	39%	17	40%	13	39%	*	*	*	*
During 'watch and wait' or 'active monitoring'	3	3%	0	0%	0	0%	*	*	*	*
After diagnosis but before treatment started	37	31%	16	38%	11	33%	*	*	*	*
During treatment	57	48%	23	55%	12	36%	*	*	*	*
After treatment finished	17	14%	8	19%	4	12%	*	*	*	*
Don't know / can't remember	8	7%	2	5%	3	9%	*	*	*	*
Total Responses	120	100%	42	100%	33	100%	*	*	*	*

Information and support

C36_7 When in the patient's treatment journey were you given or directed to the information and support? - Buddying or befriending

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	36	35%	16	31%	*	*	*	*	*	*
During 'watch and wait' or 'active monitoring'	0	0%	0	0%	*	*	*	*	*	*
After diagnosis but before treatment started	38	37%	22	43%	*	*	*	*	*	*
During treatment	74	71%	44	86%	*	*	*	*	*	*
After treatment finished	15	14%	7	14%	*	*	*	*	*	*
Don't know / can't remember	4	4%	0	0%	*	*	*	*	*	*
Total Responses	104	100%	51	100%	*	*	*	*	*	*

Information and support

C36_8 When in the patient's treatment journey were you given or directed to the information and support? - Patient support groups

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	26	21%	8	21%	*	*	*	*	*	*
During 'watch and wait' or 'active monitoring'	8	7%	0	0%	*	*	*	*	*	*
After diagnosis but before treatment started	23	19%	11	28%	*	*	*	*	*	*
During treatment	72	59%	30	77%	*	*	*	*	*	*
After treatment finished	17	14%	8	21%	*	*	*	*	*	*
Don't know / can't remember	8	7%	1	3%	*	*	*	*	*	*
Total Responses	123	100%	39	100%	*	*	*	*	*	*

Information and support

C36_9 When in the patient's treatment journey were you given or directed to the information and support? - Leukemia charities / associations / organizations

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	38	27%	13	28%	10	24%	*	*	*	*
During 'watch and wait' or 'active monitoring'	7	5%	0	0%	0	0%	*	*	*	*
After diagnosis but before treatment started	34	24%	14	30%	9	22%	*	*	*	*
During treatment	73	51%	30	65%	18	44%	*	*	*	*
After treatment finished	12	8%	5	11%	5	12%	*	*	*	*
Don't know / can't remember	9	6%	3	7%	4	10%	*	*	*	*
Total Responses	142	100%	46	100%	41	100%	*	*	*	*

Information and support

C36_10 When in the patient's treatment journey were you given or directed to the information and support? - Financial information

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	20	25%	9	24%	*	*	*	*	*	*
During 'watch and wait' or 'active monitoring'	1	1%	0	0%	*	*	*	*	*	*
After diagnosis but before treatment started	21	26%	11	30%	*	*	*	*	*	*
During treatment	43	54%	23	62%	*	*	*	*	*	*
After treatment finished	11	14%	3	8%	*	*	*	*	*	*
Don't know / can't remember	6	8%	2	5%	*	*	*	*	*	*
Total Responses	80	100%	37	100%	*	*	*	*	*	*

Information and support

C36_11 When in the patient's treatment journey were you given or directed to the information and support? - Written information / booklets / leaflets

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	69	45%	18	41%	21	50%	15	50%	*	*
During 'watch and wait' or 'active monitoring'	7	5%	0	0%	0	0%	7	23%	*	*
After diagnosis but before treatment started	57	37%	21	48%	17	40%	4	13%	*	*
During treatment	73	47%	26	59%	18	43%	6	20%	*	*
After treatment finished	14	9%	8	18%	4	10%	1	3%	*	*
Don't know / can't remember	3	2%	1	2%	0	0%	0	0%	*	*
Total Responses	155	100%	44	100%	42	100%	30	100%	*	*

Information and support

C36_12 When in the patient's treatment journey were you given or directed to the information and support? - Online forums

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	17	28%	*	*	*	*	*	*	*	*
During 'watch and wait' or 'active monitoring'	3	5%	*	*	*	*	*	*	*	*
After diagnosis but before treatment started	19	32%	*	*	*	*	*	*	*	*
During treatment	32	53%	*	*	*	*	*	*	*	*
After treatment finished	12	20%	*	*	*	*	*	*	*	*
Don't know / can't remember	4	7%	*	*	*	*	*	*	*	*
Total Responses	60	100%	*	*	*	*	*	*	*	*

Information and support

C36_13 When in the patient's treatment journey were you given or directed to the information and support? - End of life care

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
At diagnosis	7	23%	*	*	*	*	*	*	*	*
During 'watch and wait' or 'active monitoring'	1	3%	*	*	*	*	*	*	*	*
After diagnosis but before treatment started	3	10%	*	*	*	*	*	*	*	*
During treatment	12	39%	*	*	*	*	*	*	*	*
After treatment finished	12	39%	*	*	*	*	*	*	*	*
Don't know / can't remember	3	10%	*	*	*	*	*	*	*	*
Total Responses	31	100%	*	*	*	*	*	*	*	*

Appendix 11 – Frequency tables for [Carer] C37 Did you access this support and did it help you?

Information and support

C37_1 Did you access this support and did it help you? - Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	105	56%	44	66%	27	50%	*	*	*	*
Yes, but it did not help me feel any better / positive	37	20%	13	19%	14	26%	*	*	*	*
No, I did not access this support	31	17%	5	7%	8	15%	*	*	*	*
Don't know / can't remember	14	7%	5	7%	5	9%	*	*	*	*
Total Responses	187	100%	67	100%	54	100%	*	*	*	*

Information and support

C37_2 Did you access this support and did it help you? - General wellbeing (including spiritual wellbeing)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	98	66%	39	72%	20	51%	*	*	*	*
Yes, but it did not help me feel any better / positive	19	13%	8	15%	6	15%	*	*	*	*
No, I did not access this support	22	15%	5	9%	7	18%	*	*	*	*
Don’t know / can’t remember	9	6%	2	4%	6	15%	*	*	*	*
Total Responses	148	100%	54	100%	39	100%	*	*	*	*

Information and support

C37_3 Did you access this support and did it help you? - Clinical trials

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	58	47%	21	51%	14	41%	*	*	*	*
Yes, but it did not help me feel any better / positive	39	32%	14	34%	10	29%	*	*	*	*
No, I did not access this support	16	13%	3	7%	6	18%	*	*	*	*
Don’t know / can’t remember	10	8%	3	7%	4	12%	*	*	*	*
Total Responses	123	100%	41	100%	34	100%	*	*	*	*

Information and support

C37_4 Did you access this support and did it help you? - Side effects and risks of treatment

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	125	43%	44	44%	25	32%	21	70%	26	48%
Yes, but it did not help me feel any better / positive	124	43%	47	47%	43	54%	5	17%	19	35%
No, I did not access this support	27	9%	7	7%	7	9%	3	10%	7	13%
Don’t know / can’t remember	12	4%	2	2%	4	5%	1	3%	2	4%
Total Responses	288	100%	100	100%	79	100%	30	100%	54	100%

Information and support

C37_5 Did you access this support and did it help you? - Access to a Clinical Nurse Specialist (CNS)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	*	*	*	*	*	*	*	*	*	*
Yes, but it did not help me feel any better / positive	*	*	*	*	*	*	*	*	*	*
No, I did not access this support	*	*	*	*	*	*	*	*	*	*
Don’t know / can’t remember	*	*	*	*	*	*	*	*	*	*
Total Responses	*	*	*	*	*	*	*	*	*	*

Information and support

C37_6 Did you access this support and did it help you? - Patient rights

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Yes, and it helped me feel better / more positive	70	57%	27	66%	16	48%	*	*	*	*
Yes, but it did not help me feel any better / positive	31	25%	10	24%	10	30%	*	*	*	*
No, I did not access this support	14	11%	2	5%	4	12%	*	*	*	*
Don’t know / can’t remember	7	6%	2	5%	3	9%	*	*	*	*
Total Responses	122	100%	41	100%	33	100%	*	*	*	*

Information and support

C37_7 Did you access this support and did it help you? - Buddying or befriending

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Yes, and it helped me feel better / more positive	95	83%	53	90%	*	*	*	*	*	*
Yes, but it did not help me feel any better / positive	10	9%	4	7%	*	*	*	*	*	*
No, I did not access this support	6	5%	0	0%	*	*	*	*	*	*
Don’t know / can’t remember	4	3%	2	3%	*	*	*	*	*	*
Total Responses	115	100%	59	100%	*	*	*	*	*	*

Information and support

C37_8 Did you access this support and did it help you? - Patient support groups

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Yes, and it helped me feel better / more positive	89	68%	29	74%	*	*	*	*	*	*
Yes, but it did not help me feel any better / positive	21	16%	7	18%	*	*	*	*	*	*
No, I did not access this support	17	13%	3	8%	*	*	*	*	*	*
Don’t know / can’t remember	4	3%	0	0%	*	*	*	*	*	*
Total Responses	131	100%	39	100%	*	*	*	*	*	*

Information and support

C37_9 Did you access this support and did it help you? - Leukemia charities / associations / organizations

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Yes, and it helped me feel better / more positive	108	72%	33	69%	29	67%	*	*	*	*
Yes, but it did not help me feel any better / positive	16	11%	6	13%	4	9%	*	*	*	*
No, I did not access this support	18	12%	4	8%	6	14%	*	*	*	*
Don’t know / can’t remember	9	6%	5	10%	4	9%	*	*	*	*
Total Responses	151	100%	48	100%	43	100%	*	*	*	*

Information and support

C37_10 Did you access this support and did it help you? - Financial information

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	48	59%	21	55%	*	*	*	*	*	*
Yes, but it did not help me feel any better / positive	24	29%	13	34%	*	*	*	*	*	*
No, I did not access this support	6	7%	2	5%	*	*	*	*	*	*
Don’t know / can’t remember	4	5%	2	5%	*	*	*	*	*	*
Total Responses	82	100%	38	100%	*	*	*	*	*	*

Information and support

C37_11 Did you access this support and did it help you? - Written information / booklets / leaflets

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	104	62%	29	64%	24	55%	20	59%	22	67%
Yes, but it did not help me feel any better / positive	47	28%	12	27%	14	32%	9	26%	9	27%
No, I did not access this support	11	7%	2	4%	3	7%	4	12%	2	6%
Don’t know / can’t remember	7	4%	2	4%	3	7%	1	3%	0	0%
Total Responses	169	100%	45	100%	44	100%	34	100%	33	100%

Information and support

C37_12 Did you access this support and did it help you? - Online forums

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	44	68%	*	*	*	*	*	*	*	*
Yes, but it did not help me feel any better / positive	14	22%	*	*	*	*	*	*	*	*
No, I did not access this support	6	9%	*	*	*	*	*	*	*	*
Don’t know / can’t remember	1	2%	*	*	*	*	*	*	*	*
Total Responses	65	100%	*	*	*	*	*	*	*	*

Information and support

C37_13 Did you access this support and did it help you? - End of life care

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Yes, and it helped me feel better / more positive	11	34%	*	*	*	*	*	*	*	*
Yes, but it did not help me feel any better / positive	11	34%	*	*	*	*	*	*	*	*
No, I did not access this support	9	28%	*	*	*	*	*	*	*	*
Don’t know / can’t remember	1	3%	*	*	*	*	*	*	*	*
Total Responses	32	100%	*	*	*	*	*	*	*	*

Appendix 12 – Frequency tables for [Patient] Q93 How helpful were they?

Quality of life
Q93_1 How helpful were they? - Healthcare professional

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Very helpful	452	56%	37	54%	75	66%	180	57%	133	53%
Somewhat helpful	308	38%	28	41%	32	28%	117	37%	104	41%
Not helpful	40	5%	3	4%	6	5%	16	5%	14	6%
Don’t know / Can’t remember	5	1%	0	0%	0	0%	3	1%	0	0%
Total Responses	805	100%	68	100%	113	100%	316	100%	251	100%

Quality of life
Q93_2 How helpful were they? - Patient organizations / patient advocacy groups

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Very helpful	274	61%	18	50%	29	60%	118	67%	99	60%
Somewhat helpful	159	36%	16	44%	19	40%	54	31%	59	36%
Not helpful	10	2%	1	3%	0	0%	3	2%	4	2%
Don’t know / Can’t remember	3	1%	1	3%	0	0%	0	0%	2	1%
Total Responses	446	100%	36	100%	48	100%	175	100%	164	100%

Quality of life
Q93_3 How helpful were they? - Psychologist

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Very helpful	193	50%	14	35%	39	58%	55	52%	73	52%
Somewhat helpful	159	41%	21	53%	18	27%	44	42%	58	41%
Not helpful	31	8%	5	13%	10	15%	6	6%	8	6%
Don’t know / Can’t remember	2	1%	0	0%	0	0%	1	1%	1	1%
Total Responses	385	100%	40	100%	67	100%	106	100%	140	100%

Quality of life
Q93_4 How helpful were they? - Counsellor

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Very helpful	68	49%	*	*	*	*	31	50%	21	54%
Somewhat helpful	54	39%	*	*	*	*	20	32%	17	44%
Not helpful	16	12%	*	*	*	*	11	18%	1	3%
Don’t know / Can’t remember	0	0%	*	*	*	*	0	0%	0	0%
Total Responses	138	100%	*	*	*	*	62	100%	39	100%

Quality of life
Q93_5 How helpful were they? - Family

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Very helpful	589	50%	76	54%	110	63%	173	42%	184	50%
Somewhat helpful	508	43%	60	43%	58	33%	207	50%	157	42%
Not helpful	66	6%	3	2%	6	3%	26	6%	26	7%
Don’t know / Can’t remember	10	1%	1	1%	1	1%	4	1%	3	1%
Total Responses	1173	100%	140	100%	175	100%	410	100%	370	100%

Quality of life
Q93_6 How helpful were they? - Friends

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Very helpful	330	37%	32	34%	63	48%	100	32%	112	40%
Somewhat helpful	472	54%	55	59%	60	46%	185	59%	146	52%
Not helpful	69	8%	7	7%	7	5%	27	9%	21	7%
Don’t know / Can’t remember	10	1%	0	0%	1	1%	4	1%	4	1%
Total Responses	881	100%	94	100%	131	100%	316	100%	283	100%

Quality of life

Q93_7 How helpful were they? - Other (please specify)

	Overall		Acute lymphoblastic leukemia (ALL)		Acute myeloid leukemia (AML)		Chronic lymphocytic leukemia (CLL)		Chronic myeloid leukemia (CML)	
Option	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Very helpful	21	57%	*	*	*	*	*	*	*	*
Somewhat helpful	9	24%	*	*	*	*	*	*	*	*
Not helpful	2	5%	*	*	*	*	*	*	*	*
Don’t know / Can’t remember	5	14%	*	*	*	*	*	*	*	*
Total Responses	37	100%	*	*	*	*	*	*	*	*

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