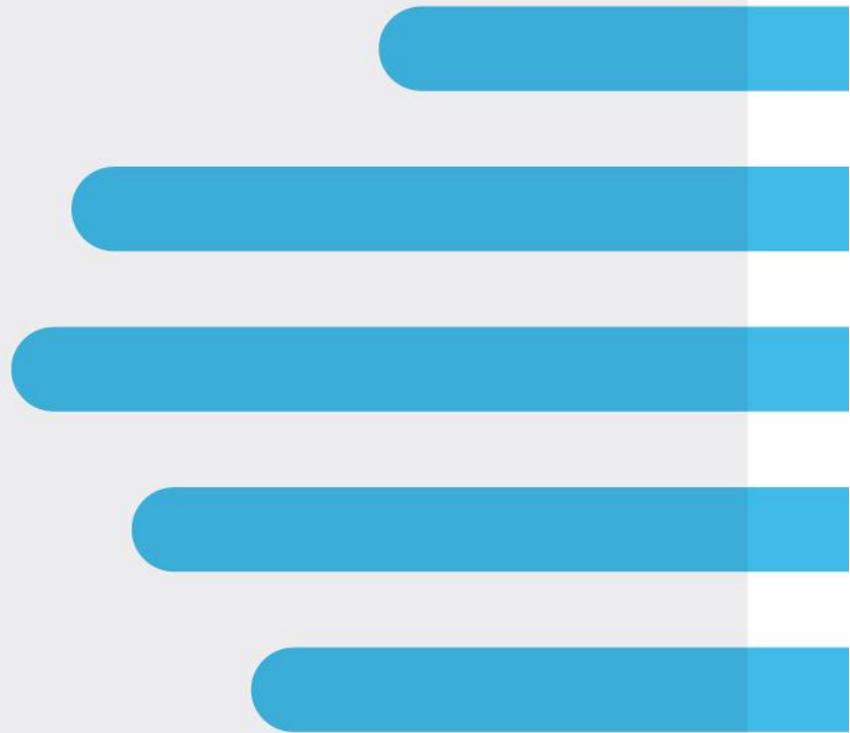


# Global Patient and Carer Experience Survey *Executive Summary*

2021-2022

September 2023



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## Executive summary

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

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

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

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

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

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

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

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

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

## 1.1 Key findings

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

## 1.2 Respondent demographics

### Type of leukemia from Patient Survey

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

### Gender

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

### Age

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

### Living arrangements

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

### Employment and Education

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

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

## Income

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

## Symptoms prior to diagnosis

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

### 1.3 Diagnosis

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

### 1.4 Information and support at diagnosis

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

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6893268/>

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

### 1.5 Watch and Wait<sup>2</sup>

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

### 1.6 Treatment

- Fifty-seven percent (n=1,037) of patients reported being given active treatment within a week of diagnosis. This obviously varied highly amongst the different leukemia subtypes: ALL 93% (n=93), AML 87% (n=264), CML 66% (n=575), CLL 12% (n=52), Other 54% (n=53).

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

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

## 1.7 Ongoing monitoring

- Forty-six percent (n=133) of patients are moderately or extremely worried about the potential for relapse. Carers were reportedly more worried than patients. 75% (n=372) of carers reported being moderately or extremely worried about relapse.
- Overall, 94% (n=2,458) of patients were undergoing regular testing / monitoring: CML 97%, (n=855), CLL 94%, (n=1,123), ALL 88%, (n=90), and AML 88%, (n=271).
- Patients and carers reported positively around ongoing tests, but experienced anxiety around waiting for results. Twenty-one percent (n=110) of carers reported being extremely worried while waiting for the results; for patients, 30% (n=649) reported that they rated their anxiety as 8 out of 10 or above.

- Sixty-five percent of patients (n=2,217) stated that the results of these tests were always explained to them, even though sometimes they had to ask. Those with acute leukemia were more likely to report the results of tests always being explained (AML 74%, n=200, ALL 70%, n=63, CML 64%, n=551, and CLL 63%, n=703).
- Patients reported positively on being able to access test results themselves. Overall, 75% of patients (n=1,835) reported that they were able to access their own results.

## 1.8 Living with leukemia

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

## 1.9 Impact on carers

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

## 1.10 Impact of COVID-19

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

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

### 1.11 Recommendations

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

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

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

#### Pre-diagnosis

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

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

#### Diagnosis

- A diagnosis of acute leukemia will clearly have a different intervention than for a diagnosis of chronic leukemia. Support services need to be segmented accordingly.

- A diagnosis of leukemia can often impact financial wellness, particularly those from lower income backgrounds. Additional information and support services specifically focused on financial wellness should be implemented particularly at diagnosis. This is a challenging area and appropriate support is still needed by those who had financial problems before diagnosis, and those who have financial issues caused only by their leukemia diagnosis. Support services provided directly by patient groups are proven to be effective (e.g. Macmillan in the UK)<sup>3</sup>.

### **‘Watch and Wait’**

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

### **Treatment**

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

### **Clinical Trials**

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

### **Living with leukemia**

- Leukemia has an obvious negative impact on patients, carers, and their wider families. It is important that healthcare is delivered holistically at every point in the patient journey/pathway, and considers wider quality of life issues when looking at treatment, management, and ongoing care.
- Emotional and mental health can be more negatively affected than physical well-being, and experiences differ between different groups. Support needs to be improved, tailored and targeted.

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<sup>3</sup> <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/money-finance-and-insurance>

- Isolation and mental health are affected by a leukemia diagnosis and treatment. It is further affected longer-term while patients live with the disease. Support for this should be promoted, particularly at these points for patients and their carers.
- Leukemia can negatively impact a person's work and financial situation; especially during treatment. It varies by subtype and by demographics. Consider a flexible support program to alleviate these issues and improve patient and carer well-being.

## **COVID-19**

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