Leukaemia Care
YOUR Blood Cancer Charity

Standards of Care: Addressing Disparities in Holistic Care for Leukaemia Patients

Executive Summary

Leukaemia patients across the UK continue to face disparities in access to holistic support, despite national improvements in cancer care provision. While clinical outcomes are critical, patients repeatedly tell us that their wider needs - emotional, psychological, practical, and financial - are often unmet or offered only at isolated points in their care journey.

Building on our previous campaigns (#MyCNSMatters and #WatchWaitWorry) and the findings from our 2024 focus groups, this report sets out a new **Standards of Care** framework for leukaemia patients. These standards provide a clear and consistent benchmark for the level of care that all patients should expect to receive, regardless of their leukaemia type, treatment status, or where they are in their cancer journey.

Why this work was needed:

- National survey data (CPES) shows that while many patients are given information about support at diagnosis, fewer receive ongoing support for mental health, long-term side effects, or financial challenges.
- International survey data highlights inequalities between different leukaemia types, with some groups - particularly CLL patients - less likely to access key support services such as a Clinical Nurse Specialist (CNS).
- Patients told us their needs fluctuate over time, and support must be flexible and accessible at multiple points, not just at diagnosis or treatment initiation.

Our approach:

We undertook a three-stage process to co-develop and validate the Standards of Care:

1. **Literature review** – Identified effective interventions such as health education, care planning, and empathetic nursing.
2. **Working group consultation** – Patients, CNSs, nursing professionals, and specialist healthcare groups refined draft statements based on lived experience and clinical expertise.
3. **Consensus meetings** – Brought together clinicians, patients, healthcare bodies, and cancer alliances to agree on final statements. Consensus was achieved when ≥75% of attendees supported a statement.

Key outcomes:

- **19 Standards of Care** were agreed, with all statements achieving consensus (lowest agreement 88%; several achieving 100%).
- Core themes include:
  - Every patient should have a named specialist haematology nurse as their key worker.
  - Support must address emotional, psychological, financial, and practical needs as much as physical health.
  - Patients should be provided with clear, accessible, and high-quality information at diagnosis and throughout their care.
  - Services should ensure proactive, ongoing contact, not only reactive or one-off support.
  - Hospitals and commissioners should work collaboratively with third-sector organisations to deliver holistic support.

Looking ahead:

The Standards of Care are intended to provide a unifying framework for healthcare providers, commissioners, and policymakers. They give patients a clear sense of what they should expect and provide professionals with a consensus-backed benchmark for delivering consistent, holistic, and equitable care.

Our next step is to publish and promote these standards widely across the cancer community, encouraging adoption into practice and ensuring that all adult leukaemia patients, regardless of diagnosis or treatment pathway, receive the support they need.

Introduction

Building on Previous Campaigns

Our Standards of Care project builds on two recent campaigns:

- **#MyCNSMatters** – called for every patient to have access to a Clinical Nurse Specialist (CNS) from diagnosis throughout their cancer journey.
- **#WatchWaitWorry** – focused on improving support for patients with CLL on active monitoring, including CNS access from diagnosis, not only at the point of treatment.

Both campaigns were aimed at addressing the inequalities in access to CNSs for leukaemia patients compared to patients from other tumour types.

Having access to a CNS has been shown to significantly improve patients experience of care. However, workforce pressures have meant that other members of patients' care team are taking on more responsibility, some associated with that of a CNS. Therefore, we wanted to broaden our focus away from solely advocating for more CNSs and actively explore how we could help improve adult leukaemia patients' experience of care.

Disparities in Care

Surveys of leukaemia patients have shown throughout the years that patients don't feel as supported as they would like following a diagnosis of cancer. The latest Cancer Patient Experience Survey (CPES) in England reported that 92.3% of cancer patients said that staff provided them with relevant information on available support after diagnosis [1]. Although this is positive, delving further into the point at which patients get support or the type of support they are offered begins to show some gaps or differences in care:

- 77.5% of patients said they definitely got the right support for their overall health and wellbeing from hospital staff
- 71.9% of patients were offered information about how to get financial help or benefits
- After treatment, only 33.5% of patients definitely could get enough emotional support at home from community or voluntary services
- 64.9% of patients were given enough information about the possibility and signs of cancer coming back or spreading
- 70.9% of patients were always offered practical advice on dealing with any immediate side effects from treatment
- 55.6% of patients were definitely able to discuss options for managing the impact of any long-term side effects

Wider emotional, psychological and practical challenges after a cancer diagnosis are less likely to be addressed by hospital teams than medical issues, according to the data above. CPES results in all UK nations do not show any major differences in experience and holistic support between all cancer patients and leukaemia patients as a whole. Yet the CPES data cannot be further broken down to look at individual leukaemia types. Therefore, we cannot see whether patients are experiencing different things based on their specific diagnosis. Additionally, CPES does not include patients not treated in the last 18 months, such as those discharged recently or those on active monitoring. Therefore, Leukaemia Care has been involved in surveys to explore the patient experience in more detail. We have reported the results of these surveys over the years, but here we refer to the most recent iteration available at the time of writing.

In 2021, the Acute Leukaemia Advocates Network, Chronic Myeloid Leukaemia Advocates Network and Chronic Lymphocytic Leukaemia Advocates Network jointly conducted a survey [2] that included patients with any of the 4 main types of leukaemia. This enabled us to explore how each patient group experienced support, comparing between them and to what we see in CPES overall.

Of the UK patients that responded about support that they were offered, there are clear differences between the different leukaemia types. While 60% of those with ALL reported that they were offered support, this was much lower for the other leukaemia types (AML 44%, CML 43%, CLL 37%). Three quarters of people who were not offered support would have liked the option to seek further help.

We begin to see variations between patients by diagnosis too. Patients with CML were most likely to be directed to support organisations (56%). Those with ALL were more likely to be referred for psychological support (43%) than any of the other leukaemia types. Previous work by Leukaemia Care, using previous iterations of the same survey, has highlighted that CLL patients were less likely to get access to various forms of support than other leukaemia types, particularly missing out on access to a CNS. The international survey from 2021 did not allow us to explore this again, but we have no evidence that this has changed based on anecdotal evidence from CLL patients.

Variations in access to support could be for many reasons. The commonplace public view of cancer as something that is treated and then the patient is cured or dies, does not apply to all leukaemia types. Both chronic and acute leukaemia patients show a need for ongoing support that is not clear if the simplistic view of a cancer patient journey prevails. We highlighted one example of how this manifests into poor experience in our #WatchWaitWorry campaign [3]. Active monitoring patients are shown to have emotional support needs on par with other leukaemia patients but are the least likely to access certain types of support.

Leukaemia Care believes everyone should have access to the care they need and leukaemia changes lives, even when it is easily treatable. Therefore, we are undertaking this work to understand why variation exists by leukaemia type and set out a standard that applies to all leukaemia patients to dispel any myths about their needs.

Recent work that has led to the development of the Standards of Care

In 2024, we held focus groups to better understand the existing gaps in care provision and the what the key areas of focus should be in taking steps to reducing such inequalities:

- One with leukaemia patients from throughout the UK
- One with Clinical Nurse specialists from throughout the UK

The results were analysed to identify themes in:

- Barriers to patient access
- Barriers to CNSs delivering good care
- What was considered to be good care for leukaemia more generally

From this research, we concluded with the main themes, i.e. the key principles of 'good' care for leukaemia patients:

1. Access to support is independent of cancer type or treatment status.
2. The key worker or point of contact is accessible, not just known to the person.
3. Consistency - clearer definition of care teams' individual roles and duties, a supportive non-medical and administrative team, and clear access/entry and exit routes into the service.
4. Trust – in both medical and nonmedical staff to support patients' holistic needs.
5. Better recognition and value of the skills of the CNS.
6. The people with direct patient contact and/or triaging have appropriate condition specific knowledge.
7. Maximise team working, internally to the NHS and externally.
8. Managing expectations and patient empowerment are key to cost effective delivery of support.

It was agreed that a set of standards or framework was needed to in order to reduce inequalities in access to good care. These 8 'principles of care' were then used as a foundation in the drafting of the final 'Standards of Care' statements outlined later in this report.

For more information on this stage of our research, please see our previous report which concluded that there was a need for a framework in order to reduce inequalities in holistic care provision [3].

Our Research

Methodology

Building on our previous report [4], we carried out a three-stage research process:

1. **Literature review** of existing nursing and healthcare interventions.
2. **Working groups** with patients and professionals to co-develop draft statements.
3. **Consensus meetings** to refine and finalise the Standards of Care.

Literature Review

We searched medical journals via Google Scholar using terms such as blood cancer, leukaemia, nurse interventions, holistic care interventions, and non-clinical care.

Findings

Effective interventions included:

- Psychological support
- Health education
- Self-management programmes
- Care planning interventions
- Empathetic forms of nursing

The strongest evidence showed that **patient involvement in care planning, health education, and empathetic nursing** reduce stress and anxiety and improve patients' understanding of treatment.

However, most interventions were delivered at **specific timepoints** (e.g., diagnosis or start of treatment), rather than **throughout the cancer journey**.

This echoes what patients told us in our 2024 focus groups [4]: support needs fluctuate, and access to care should not be limited to a single point in the pathway. Patients described changing support networks, financial situations, and mental health over time, with gaps appearing when support was unavailable later in their journey.

Conclusion: The literature review highlighted the limited evidence on nursing interventions and support throughout a patient's cancer journey. Therefore, any Standards of Care must reflect the need for support to be offered **at multiple points throughout the cancer journey**, not only at specific points such as at diagnosis or treatment initiation.

We concluded that a consensus process was needed in order to gather expertise in the absence of evidence focused on consistent interventions. This was needed to find the balance between what was possible to achieve from a professional standpoint, and what would be useful to patients who receive care.

Working Groups

Using the literature review and the eight 'principles of good care' from our 2024 report, we drafted initial statements outlining the basic care leukaemia patients should receive. These were then refined through 3 working groups:

- **Clinical Nurse Specialists (CNSs) and other nursing professionals**
- **Patients**, evenly split between those with acute and chronic leukaemias
- **UK Oncology Nursing Society's Haemato-oncology Members Interest Group**

We also consulted with:

- The British Society of Haematology
- The UK Acute Oncology Society

Each group met at least **three times**, reviewing and amending the draft statements collaboratively. This process resulted in **19 agreed-upon draft statements**.

Consensus Meetings

In May and June of 2025, we held consensus meetings to discuss, amend, and subsequently vote upon the drafted statements. The aim of these two meetings was to ensure that the final document had agreement from representatives from across the healthcare community, including those responsible for delivering care and those receiving it.

Participants included:

- Clinicians
- Patients
- Cancer Alliances
- Patient organisations
- National healthcare bodies

The Process:

- Each statement was presented, discussed, and amended in real time.
- Participants then voted. A combined 75% voting either ‘Strongly Agree’ or ‘Agree’ was needed for consensus on a statement to be achieved.

Outcome:

All statements achieved consensus, forming the basis of the final Standards of Care document.

Findings of Consensus Meetings

Overall Consensus

- All 19 statements reached consensus (defined as ≥75% of attendees selecting Strongly Agree or Agree).
- The lowest agreement was **88%**, while several statements achieved **100% agreement**.

Participants were shown each statement, given time for discussion, and invited to suggest amendments. After discussion, agreed changes were made before voting. The options available were:

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Neither Agree nor Disagree
- Don't Know

Areas of Strong Agreement

Several statements received overwhelming consensus. For example:

> "All patients with leukaemia, MPNs, and MDS should have a named specialist haematology nurse as their key worker."
>
> **100% Overall Agreement (75% Strongly Agree, 25% Agree).**

Discussion emphasised the vital role of key workers with tumour-specific knowledge in providing the appropriate care and information to patients. This aligns with national cancer strategies, such as Northern Ireland's 2022–32 Cancer Strategy [5], which states that all patients should have access to a Clinical Nurse Specialist throughout their care pathway.

> "Patients with leukaemia, MPNs, and MDS on a self-management pathway must have clear pathways to access specialist support, and must include proactive check-ins with patients."
>
> **100% Overall Agreement (75% Agree, 25% Strongly Agree).**

Areas of Lower Agreement

The statement with the lowest agreement was:

> "Significant changes in care and support should be proactively and promptly communicated with the patient."
>
> **88% Overall Agreement (6% Disagree, 6% Neither Agree nor Disagree).**

Discussion centred on whether all changes, including minor administrative updates, needed to be communicated. The group agreed to specify "significant changes," meaning those directly affecting continuity of care (e.g., a change in key worker or treatment plan). Patients reiterated the points made by healthcare professionals, expressing that they want information and changes to their care that will be directly felt by them to be explained.

Amendments to Statements

In one case, a statement was amended and split into two separate ones after initial confusion:

Original statement (did not reach consensus):

> "All patients with leukaemia should be offered written information about their condition, at diagnosis and throughout their cancer journey, from an organisation which meets an approved quality standard (such as the Patient Information Forum (PIF) Tick)."
>
> **66% Agreement (53% Strongly Agree, 13% Agree; 13% Disagree; 20% Neither).**

Participants were unclear whether this wording excluded other quality-approved sources. After clarification, the statement was split into two, with both statements achieving overwhelming consensus:

> "All patients with leukaemia, MPNs, and MDS should be offered written information about their condition, at diagnosis and throughout their cancer journey, so they can refer back to it as needed."
>
> **100% Agreement (63% Strongly Agree & 37% Agree).**

> "Written information provided should meet an approved quality standard (such as the Patient Information Forum (PIF) Tick)."
>
> **89% Agreement (44.5% Strongly Agree. 44.5% Agree, 11% Neither Agree nor Disagree)**

Next Steps/Going Forward

These Standards of Care are intended to provide a unifying framework for healthcare providers, commissioners, and policymakers. They give patients a clear sense of what they should expect and provide professionals with a consensus-backed benchmark for delivering consistent, holistic, and equitable care.

Our next step is to publish and promote these standards widely across the cancer community, encouraging adoption into practice and ensuring that all leukaemia patients, regardless of diagnosis or treatment pathway, receive the support they need.

We are already in discussions with cancer alliances and hospitals regarding the implementation of the standards. The standards will be updated as we work with healthcare professionals to ensure that the statements continue to reflect the care that is essential to improving patients' non-clinical care.

If you are interested to learn more or would like to work with us to implement these standards of care in your area, then please get in touch at: campaigns@leukaemiacare.org.uk

References

[1] National Cancer Patient Experience Survey 2024. Available: https://www.ncpes.co.uk/latest-national-results/

[2] Global Leukaemia Experience Survey. Available: https://www.clladvocates.net/wp-content/uploads/2023/09/Global-Leukemia-Experience-Survey_FullReport.pdf

[3] Left to Watch Wait Worry Campaign Report 2023. Available: https://www.leukaemiacare.org.uk/our-campaigns/watch-wait-worry/

[4] My CNS Matters: Addressing Disparities in Holistic Care for Leukaemia Patients Report 2024. Available: https://www.leukaemiacare.org.uk/our-campaigns/mycnsmatters/

[5] Northern Ireland Cancer Plan 2022 to 2032. Available: https://www.healthni.gov.uk/sites/default/files/publications/health/doh-cancer-strategymarch-2022.pdf

Appendix

Agreed Standards of Care

The statements below are the 19 statements that were agreed upon through our consensus meeting process.

Overview statements:

Practical, emotional, financial and other holistic care needs are as important to the wellbeing of leukaemia patients as physical health interventions.

52% Strongly Agree, 43% Agree, 5% Don't Know.

There is a need for a framework or document that sets out the care that all patients should receive.

42% Strongly Agree, 53% Agree, 5% Strongly Disagree.

Communication & Information:

All patients with leukaemia, MPNs, and MDS should be offered written information about their condition, at diagnosis and throughout their cancer journey, so they can refer back to it as needed.

63% Strongly Agree & 37% Agree.

Written information provided should meet an approved quality standard (such as the Patient Information Forum (PIF) Tick).

44.5% Strongly Agree. 44.5% Agree, 11% Neither Agree nor Disagree.

Any information shared with patients, their family, friends and/or carers must be tailored to and accessible to the recipient, e.g. sensitive to their emotional state and provided in a format of their choosing, where possible.

18% Strongly Agree, 76% Agree, 6% Disagree.

Patients should be able to access their test results if they request them in a timely fashion, offered support and for the results to be explained to them in a way that is accessible to the patient.

44% Strongly Agree, 56% Agree.

Significant changes in care and support should be proactively and promptly communicated with the patient.

25% Strongly Agree, 63% Agree, 6 % Disagree, 6% Neither Agree nor Disagree.

Support:

All patients with leukaemia should be given opportunities to discuss their future hopes and wishes with a trained professional, and have the principles of shared decision making adhered to at all times.

39% Strongly Agree, 61% Agree.

There must be a clear process in place to refer patients to holistic support as soon as a need is identified.

42% Strongly Agree, 58% Agree.

All patients with leukaemia, MPNs, and MDS should have a named specialist haematology nurse as their key worker.

75% Strongly Agree, 25% Agree.

All patients with leukaemia, MPNs, and MDS should be able to access their assigned key worker in a variety of ways that is accessible to them.

50% Strongly Agree, 44% Agree, 6% Don't Know.

Patients with leukaemia, MPNs, and MDS should be informed, in writing and orally, who to contact and how if they have any questions or issues.

67% Strongly Agree, 33% Agree.

Patients should be regularly and proactively reminded of and directed to organisations such as Leukaemia Care that can offer them information, advice, and support. This should be done from diagnosis.

50% Strongly Agree, 50% Agree.

All patients should have their psychological needs assessed, ongoing from the point of diagnosis and regardless of their leukaemia type, and offered a referral to further for an appropriate level of psychological support.

31% Strongly Agree, 63% Agree, 6% Neither Agree nor Disagree.

Support services offered by local services should be co-designed with those affected by leukaemia, MPNs, and MDS.

33% Strongly Agree, 60% Agree, 7% Neither Agree nor Disagree.

Patients with leukaemia, MPNs, and MDS on a self-management pathway must have clear pathways to access specialist support, and must include proactive check ins with patients.

25% Strongly Agree, 75% Agree.

The Clinic or Hospital Setup:

The hospital team should include patient navigators, support workers, social workers and/or other staff who are specifically available in person to discuss a patient's holistic needs.

44% Strongly Agree, 56% Agree.

Hospitals, commissioners and/or trusts should collaborate with third sector organisations such as Leukaemia Care for advice, support and innovation in the services they provide for those affected by leukaemia, MPNs, and MDS.

56% Strongly Agree, 44% Agree.

Hospitals or clinics should measure whether the patients' goals for their care have been met using an effective patient reported outcome measure (PROM), rather than outputs or activities alone.

25% Strongly Agree, 75% Agree.

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To find out more or to get involved with the work we do,
email campagins@leukaemiacare.org.uk or go to leukaemiacare.org.uk