

Advocating for better lymphoma diagnosis, treatment and care

Our policy priorities for 2026-2029





The need for change

Being diagnosed with cancer is a life-changing event, affecting every aspect of a person's life. Every year, more than 18,000 people in the UK are told they have lymphoma - it is the most common blood cancer¹.

Lymphoma Action is the UK's leading charity dedicated to lymphoma, providing trusted information and support since 1986. Our work is grounded in what our community of people affected by lymphoma tell us matters most. Although advances in the treatment of lymphoma are being made, there are still key challenges to address.

We have identified that urgent improvements are needed across diagnosis, treatment and care and this document sets out our commitment to making these changes happen. By championing better outcomes, we can make sure that everyone gets the care they need.

Facts about lymphoma

-  Lymphoma is the most common blood cancer in the UK¹
-  More than 50 people diagnosed with lymphoma every day¹
-  The most common cancer in young people aged 15-24²
-  Over 60 different subtypes of lymphoma³

Key challenges: Diagnosis

Diagnosis is frequently delayed. Symptoms are often vague, especially if there is no obvious lump, leading to repeated GP visits and confusion with other conditions.

More than a quarter of people wait over 6 months after first noticing symptoms before seeking medical help⁴.

Over a fifth wait a further 6 months or more for a diagnosis, even after seeking help⁴.

Over 40% of lymphoma patients are diagnosed at later stages (stage 3 or 4).⁵

About 1 in 5 Hodgkin lymphoma patients⁵ and more than 1 in 4 non-Hodgkin lymphoma patients⁶ are diagnosed through emergency routes, which is higher than for many other cancers.

“ *Lymphoma is probably a form of cancer that you haven't heard of - not many people have heard of it.*

Jacqueline

“ *That was the scariest part, I think, because it was the A&E doctor that discovered it. So he couldn't give me any answers.*

Mollie



Mollie, diagnosed with diffuse large B-cell lymphoma (DLBCL) in 2023

Key challenges: Access to treatment and care

Currently, there is no screening for lymphoma.

Some patients do not have a clear understanding of the type and stage of their cancer⁴.

Not everyone has timely access to a full range of newer, more effective treatments with fewer side effects.

People are not always involved in decisions about their own treatment⁴.

Not everyone has the support of a specialist nurse.

There is unequal access to care and clinical trials across the UK, with ethnic minority groups and other underserved communities facing greater obstacles.

“ *The relentless nature of chemotherapy is really tough.*
Sandra

Key challenges: Living with and beyond lymphoma

Some people must live with lymphoma as a long-term condition, knowing they have cancer but are not being medically treated for it (active monitoring). This can lead to confusion and uncertainty, feeling unsupported and distrust of the healthcare system.

There is a lack of sufficient screening and monitoring of the development of second cancers and other health related issues following treatment for lymphoma.

The huge emotional and physical impact on patients and their carers is often not adequately addressed⁴.

“ *When you're on active monitoring, there is a cloud of uncertainty which hangs over everything you do.*
Jeff



Jeff, diagnosed with follicular lymphoma in 2012

Progress and opportunities

Despite the challenges, treatment options for many types of lymphoma have improved dramatically over the last ten years. More people are being treated successfully and surviving lymphoma, with particularly good outcomes for young people.

The NHS has ambitious plans for cancer services, including more use of technology and community healthcare, but the system is under immense strain, making achieving these a daunting task.

“ *The major developments in the treatment of lymphoma over the last 5 years have been with immunotherapy and in particular in CAR-T cell therapy and bispecific antibody treatment.*

However, the expansion of treatment options has led to significant challenges for an already strained UK haematology infrastructure. As more trials are conducted and the application of these approaches grows, these challenges will continue.

Also, these drugs are very expensive and the current way of assessing cost-effectiveness needs to be reviewed, particularly if those with some of the rarer subtypes of lymphoma are to benefit.

Professor Graham Collins
Consultant Haematologist and Lymphoma Lead, Oxford
University Hospitals NHS Foundation Trust
Member of the Lymphoma Action Medical Advisory Panel



Together with our community, we are committed to working with the Government and all decision-makers to make change happen.



Our vision for change

For 40 years we have supported the lymphoma community. We're pushing harder than ever to make sure everyone with lymphoma gets the care they need.

Here we set out clearly the **four policy priorities** that will drive our public affairs and advocacy work over the next three years and beyond.

1

We will work to improve diagnosis and reduce emergency presentations

- We will campaign so that more people know how to spot lymphoma symptoms and advocate for themselves within the healthcare system. This is especially important for those patients who make several return GP visits without a diagnosis.
- We will review primary care pathways to understand how we can better support pharmacists, GPs and other healthcare professionals to recognise and diagnose lymphoma earlier. We will work to promote timely and well-managed referrals to secondary care, reducing emergency presentations.

“Ensuring a quick referral and subsequent diagnosis of lymphoma is important, not only to allow treatment to start more quickly, but also to reduce the time of uncertainty which can cause so much stress for patients.”

Lymphoma Action has been working with NHS England to produce a Best Practice Timed Pathway to identify the essential components and timepoints from referral and diagnosis and when they should be achieved.

Dr Wendy Osborne
Consultant Haematologist,
Chair of the Best Practice Timed Pathway Task & Finish Group
Member of the Lymphoma Action Medical Advisory Panel

2

We will advocate for better treatment and care

- We will support improvements in the lymphoma pathway from referral and diagnosis of lymphoma, through to treatment.
 - We will work to improve access to new medicines, including through clinical trials, and will ensure that patients and their needs are central to the assessment of new therapies.
 - We will promote improved data capture and reporting to improve patient care and reduce variation across the UK.
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“ *The national NHL Audit is studying the treatment and outcomes of all NHL patients diagnosed in England and Wales on an ongoing basis. Our aim is to identify inequalities and target areas for improvement.*

As well as clinical and statistical expertise we have the input of patients, members of the public and appropriate charities to make sure that all the relevant voices are heard.

In order to publish meaningful results, it is important that the data collected nationally is accurate and complete and to achieve this we are supporting all NHS Trusts to initiate a quality improvement project.

David Cutter

Clinical Lead (Oncology), NATCAN National Non-Hodgkin Lymphoma Audit

3

We will empower our community to be partners in their own care

- We will promote opportunities for patients to directly participate in conversations with decision-makers.
 - We will advocate for the patient voice to be central to research projects from initial design stages through to completion.
 - We will empower patients to better discuss their lymphoma diagnosis and treatment with their healthcare team.
 - We will work to promote the automatic signposting by healthcare professionals to patient charities such as Lymphoma Action.
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“ *By advocating on behalf of patients, empowering them, and signposting them to the appropriate support, Lymphoma Action enables patients to take an active role in their own health and medical care.*

Ann, member of the Lymphoma Action Insights Panel

“ *The projects I have worked on with Lymphoma Action make a real impact – helping health professionals, patients and carers drive for quality care and treatment.*

Frank, patient representative

“ *I've joined the UK Blood Cancer Biobank Oversight group as the Lymphoma Action patient representative. This is great because I've got experience of cell banking through my professional work. I enjoy it and hopefully I'll be able to contribute and help the project and Lymphoma Action.*

Neil, patient representative

4

We will ask decision makers to focus on long-term quality of life

- We will work with other charities to push the government for systemic change which improves long-term outcomes for people affected by lymphoma.
 - We will work to increase awareness and support of projects which will improve research into late effects, including second cancers.
 - We will push to ensure a proper focus on long-term quality of life and psychosocial support, based on the results of our national patient survey.
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“ *Lymphoma Action is proud to be working with the SEARCH team (Screening for Early detection of second lung cancer After Radiotherapy and Chemotherapy for Hodgkin lymphoma) helping to improve the long-term quality of life for those in remission. We are committed to shaping a future where life beyond lymphoma is defined by health and peace of mind, not just survival. Supporting this research is one of the ways we are making sure our community has the proactive care they deserve.*

Anna Grint
Public and Patient Affairs Advisor
Lymphoma Action

Commitment and hope

People affected by lymphoma want to know that organisations like Lymphoma Action are taking every opportunity to fight their corner on the important decisions that affect them. This is why we are committed to advocating on their behalf.

We have ambitious plans to address the challenges our community faces, support developments that will improve diagnosis, treatment and care in the NHS and push for better, kinder and more effective therapies.

For forty years, we have been making sure that no one has to face lymphoma alone. By working together with patients, healthcare professionals, and decision makers, we believe we can build a better future for everyone affected by lymphoma.

“ There are lots of opportunities to improve how people with lymphoma are diagnosed, treated and cared for. Our role is to represent our lymphoma community to the best of our abilities so that no opportunity is missed and so that every donation that we receive from our community is translated into better outcomes for everyone affected by lymphoma.

Ropinder Gill
CEO, Lymphoma Action



References:

¹Haematological Malignancy Research Network, 2025. Incidence: Total incidence. Includes chronic lymphocytic leukaemia (CLL). Available at: <https://hmrn.org/statistics/incidence>

²National Disease Registration Service, 2021. Children, teenagers and young adults UK cancer statistics report 2021. Available at: <https://digital.nhs.uk/ndrs/data/data-outputs/cancer-publications-and-tools/ctya-uk-cancer-statistics-report-2021>

³Alaggio R, et al. The 5th edition of the World Health Organization classification of haematolymphoid tumours: lymphoid neoplasms. *Leukaemia*, 2022. 36: 1720–1748. Available at: <https://www.nature.com/articles/s41375-022-01620-2>

⁴Lymphoma Coalition, 2024. 2024 Global Patient Survey on Lymphomas and CLL. United Kingdom of Great Britain and Northern Ireland Report. Available at: <https://lymphoma-action.org.uk/sites/default/files/media/documents/2025-02/Patient%20survey%20lymphomas%20%26amp%3B%20CLL%20UK%20report.pdf>

⁵National Disease Registration Service, 2025. Incidence by Stage - Rapid Cancer Registration Data (RCRD). Available at: https://crukancerintelligence.shinyapps.io/EarlyDiagnosis/_w_de0f8f316007415d9439882bb57b80bc/?Tab=incByStageRCRD via Cancer Research UK Early Cancer Diagnosis Data Hub.

⁶National Cancer Audit Collaborating Centre, Royal College of Surgeons of England, 2024. National Non-Hodgkin Lymphoma Audit State of the Nation Public and Patient Report 2024. Available at: <https://www.natcan.org.uk/wp-content/uploads/2025/09/NNHLA-SoTN-2024.pdf>

Lymphoma Action is the UK's leading charity dedicated to supporting people affected by lymphoma, the most common blood cancer. We've been providing trusted information and support since 1986.

We are here for everyone affected by lymphoma and provide expert information, dedicated support and a community that understands – right from day one. We also support healthcare professionals and advocate for better treatment and care.

Together, we can make sure no one faces lymphoma alone.

If you're affected by lymphoma, we are here for you:



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Live Chat via our website
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