NNHLA
National Non-Hodgkin Lymphoma Audit

NATCAN
National Cancer Audit Collaborating Centre

National Non-Hodgkin Lymphoma Audit State of the Nation Patient and Public Report 2025

An audit of care received by people diagnosed with non-Hodgkin lymphoma from 1 January 2022 and 31 December 2022 in England and 1 January 2023 and 31 December 2023 in Wales

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The Royal College of Surgeons of England is an independent professional body committed to enabling surgeons to achieve and maintain the highest standards of surgical practice and patient care. As part of this it supports audit and the evaluation of clinical effectiveness for surgery. Registered Charity no: 212808.

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The British Society for Haematology (BSH) is the professional body for haematologists. It is one of the key partners of the Audit. Registered Charity no. 1005735

The Royal College of Radiologists is the professional body for clinical radiologists and clinical oncologists. It is one of the key partners of the Audit. Registered Charity no: 211540

This work uses data that has been provided by patients and collected by the NHS as part of their care and support. For patients diagnosed in England, the data is collated, maintained and quality assured by the National Disease Registration Service (NDRS), which is part of NHS England. Access to the data was facilitated by the NHS England Data Access Request Service.

NHS Wales is implementing a new cancer informatics system. As a result, the quality and completeness of data from Wales is likely to have been impacted due to implementation of this new system across multiple NHS organisations (Health Boards), which has resulted in data being supplied by both old and new systems. Additionally, and reflecting the uncertainty of data quality, the data submitted to the audit may not have undergone routine clinical validation prior to submission to the Wales Cancer Network (WCN), Public Health Wales.

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Contents

1. Introduction

1.1 What is the National Non-Hodgkin Lymphoma Audit?

The National Non-Hodgkin Lymphoma Audit (NNHLA) forms part of the National Cancer Audit Collaborating Centre (NATCAN) within the Clinical Effectiveness Unit at the Royal College of Surgeons of England. The audit uses national data to understand how National Health Service (NHS) care is delivered to people with non-Hodgkin lymphoma (NHL) (a type of blood cancer) in England and Wales. It aims to drive improvements in diagnosis, treatment, and outcomes for people with NHL.

The NNHLA measures the quality of care and outcomes across eleven performance indicators, set out in its Quality Improvement Plan. This plan was developed by reviewing medical guidelines and literature, working together with guiding bodies, patient bodies and charities.

1.2 What is this report about?

The NNHLA State of the Nation report 2025 shares important feedback on how care is being delivered and the outcomes for people with NHL in England (for the year 2022) and Wales (for the year 2023), building on last year's report. Future reports will cover additional findings from the audit as more data becomes available.

The results from this report are used to create 5 key recommendations that are fed back to all the relevant organisations from Government to cancer alliances, to hospitals/trusts and health boards, to suggest areas for improvement across both England and Wales.

This document aims to complement the NNHLA State of the Nation report 2025 which contains detailed data aimed at healthcare professionals. This report will explain the key points of the report in clear, easy-to-understand language for people with NHL, and the wider public.

1.3 How else does the audit feed back results?

An interactive dashboard of results is updated every 3 months to help individual hospitals monitor their performance and guide local improvement. This can be accessed on our website.

1.4 Who is included in the audit?

All people over the age of 18 with a diagnosis of NHL, diagnosed or treated in an NHS hospital in England (2022) and Wales (2023) are included.

The NHL subtypes reported in the State of the Nation include:

— Mature B-cell lymphomas

- Large B-cell lymphoma
- Burkitt lymphoma
- Mantle cell lymphoma
- Marginal zone lymphoma

— Follicular lymphoma

— Chronic Lymphocytic Leukaemia

— Mature Tand NK-cell lymphomas

— Cutaneous T-cell lymphomas

— Peripheral T-cell lymphomas

— NHL, not otherwise specified (NOS/Other (includes the more rare or mixed sub-types))

2.1 Snapshot of the Patient and Public Summary Report

What is this report about?

This report complements the second State of the Nation Report, presenting its key findings in clear, simple language for people with non-Hodgkin lymphoma (NHL), and the public. While the full State of the Nation report is aimed at healthcare professionals and contains detailed data, this report focuses on what these results mean for your care; what's working well, where improvements are needed, and how the results will be used to improve care.

What have we found?

- **More than a quarter of people with NHL are diagnosed in an emergency setting**, such as in A&E.
- Hospitals need to **improve their recording of specialist nurse support** to make sure people with NHL have access to the support they need.
- Hospitals also need to improve their **recording and timeliness of discussions** (multi-disciplinary) about the care of those with NHL to make sure treatments decisions are made in a timely manner.
- **Some people are waiting longer than recommended to start treatment**:
    - Only around **half** start anti-cancer treatment (systemic therapy) within the 62-day National Health Service (NHS) target.
    - Only about **a third** who need radiotherapy after systemic therapy start it within 8 weeks.
- **Very few people with NHL are receiving care as part of a clinical trial**.
- There are **differences in care delivery between hospitals and different areas**.
- **Survival rates vary** depending on the type of NHL and how fast it grows.
- Many hospitals are **not recording all the important information** needed. This makes it harder to see what's working and what needs to change.

What is being done to improve things?

The audit has made the following recommendations to the relevant organisations (cancer alliances, health boards and trusts/hospitals) to take steps to improve care:

1. Reducing emergency diagnoses: Organisations need to review pathways for referral and diagnosis to make them quicker and smoother, to reduce the number of emergency diagnoses.

2. Faster Treatment by reviewing causes of delays in starting treatment at hospitals:

- Making sure people with high-grade NHL **start systemic anti-cancer therapy within 62 days** of being referred.
- Reducing delays in starting **radiotherapy** after systemic anti-cancer therapy, when it is needed.

3. Improve Access to Clinical Trials:

- Understanding why some people are **not enrolled in trials** and helping to improve access to trials.

4. Better Data:

- Hospitals are being asked to **improve their records**, especially around diagnosis, treatment, and support.
- A new **national Quality Improvement (QI) intervention** is being launched by the audit team later this year; to help trusts and hospitals improve the quality of their data.

In addition to a yearly update on their performance, hospitals also get an update on certain areas of performance including how complete their data is on a three-monthly basis, on publicly available interactive dashboards.

Every person's experience with non-Hodgkin lymphoma is unique. This report is for information only, and if you have questions, you should ask your care team to tell you how your hospital is involved in the audit and what these results mean for your care.

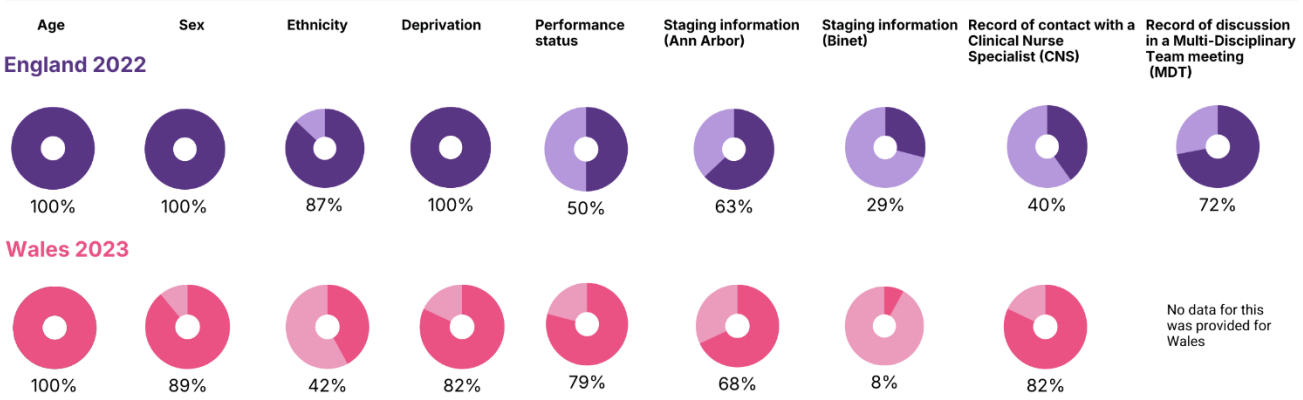
2.2 Infographic

NNHLA
National Non-Hodgkin Lymphoma Audit

Patient and Public Report 2025

Summary of results for people diagnosed with Non-Hodgkin Lymphoma (NHL) in England (2022) and Wales (2023).

DATA COMPLETENESS: How complete is the data we have?



DIAGNOSIS AND STAGING

How many people were diagnosed with NHL?

England (2022): 15,433

Wales (2023): 729

69 years — Average age at diagnosis in England & Wales

Grade of lymphoma at diagnosis?

Around 50% newly diagnosed in England (2022) and Wales (2023) were **high-grade cases.** — 50%

Emergency presentations in England (2022)* — 28%

*Percentage of people with a new diagnosis of NHL who initially present as an emergency or attend the emergency department up to 28 days prior to being diagnosed.
Development work underway for Welsh data.

What percentage were discussed in a specialist MDT meeting within 4 weeks of diagnosis?*

No data provided for Wales
*where recorded

60%

What percentage were seen by a Clinical Nurse Specialist?*

83% England (2022)
96% Wales (2023)
*where recorded

TREATMENT

How quickly does systemic anti-cancer therapy (SACT) start?

Percentage of people diagnosed with high-grade lymphoma, who receive SACT within 62 days of being referred:

England 2022 — 55%

Wales 2023 — 48%

How quickly is radiotherapy given (if required) after systemic anti-cancer therapy (SACT)?

Percentage of people diagnosed with high-grade lymphoma who received radiotherapy within 8 weeks of completing their first SACT treatment (first-line):

England 2022 — 33%

End date for chemotherapy was not provided for Wales so this could not be measured.

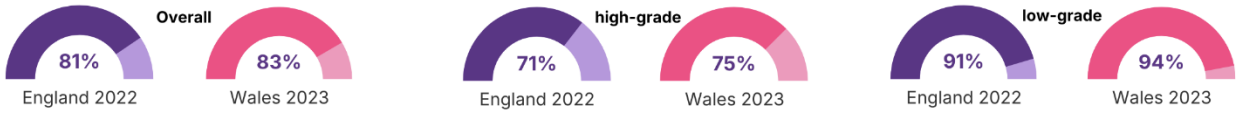
Trial Participation?

Percentage of people with NHL with a record of care within a clinical trial setting in **England 2022***
*Note 47% data missing (England) and no data on trial participation for Wales was available

2%

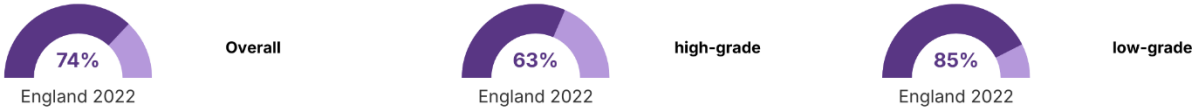
SURVIVAL: What are the survival outcomes for people diagnosed with NHL?

One-year survival outcomes



Two-year survival outcomes*

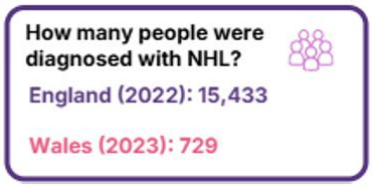
*Not available for Wales due to insufficient follow-up period



Click the icon while pressing the control button for more information!

3. Diagnosis

3.1 Who is diagnosed with non-Hodgkin lymphoma (NHL)?



The audit identified that NHL was diagnosed in 15,433 people in England in 2022 and around 729 people in Wales in 2023. The average age of people diagnosed with NHL was 69 and just over half (53.3-57.5%) were male.

Most people diagnosed were White British (>90%) and were more likely to be from a less deprived background than the general population. People diagnosed with NHL tended to be fit and independent, and around 75% of people had no more than one medical condition (where recorded).

What stage do people with non-Hodgkin lymphoma present at?

Staging (Ann Arbor or Binet) is used to describe how far through the body the cancer has spread (i.e how advanced the disease is). Prognostic indices use this information and other factors to predict the outcome of an individual's cancer.

One area of concern is the lack of some key data, especially about the stage of the disease at diagnosis. Missing information has been presented in ranges below to show how much is missing (across England in 2022, and Wales in 2023).

Where staging information is available, around 50% of people with NHL present with advanced stage (4) disease as per the Ann Arbor Classification staging system in England (53%) and Wales (47%).

People diagnosed with Chronic Lymphocytic Leukaemia were more likely to present with early-stage disease, with around 75% presenting with stage A disease.

Key message: Improved recording of staging information should be prioritised to better understand the extent of disease in those newly diagnosed with NHL. This will allow better understanding of the treatment decisions, ensuring people are receiving the right care. It will also allow better comparison of outcomes like survival for similar groups of people with NHL, between different hospitals.
This has been highlighted to healthcare professionals as a vital area for improvement.

3.2 How many people diagnosed with NHL present as an emergency prior to diagnosis?

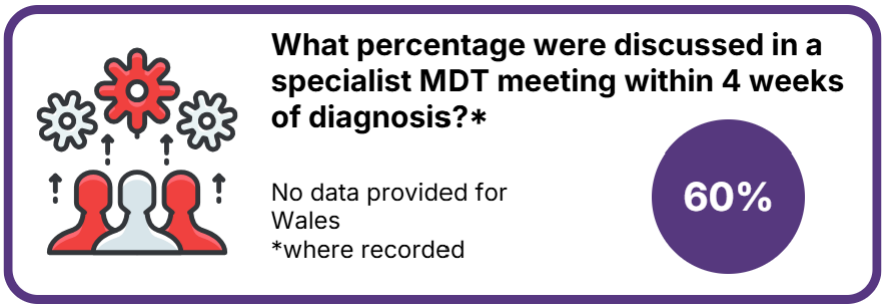
In 2022, more than one in four people with newly diagnosed NHL in England presented in the emergency setting, with little variation between hospitals.

An emergency diagnosis was more common in people over 80 and those from minority ethnic backgrounds. It was also more common in people with faster-growing (more aggressive) types of NHL, such as Burkitt lymphoma, Large B-cell lymphoma, and Peripheral T-cell lymphoma.

A similar pattern was seen in 2021, showing this is an ongoing problem. It may also help explain why some people with NHL are diagnosed at a later stage of the disease.

Key message: NHS providers should prioritise review of the referral pathways in the community setting (primary care) and hospital setting (secondary care) for those newly diagnosed with NHL to reduce the rate of emergency presentations.

3.3 What happens after diagnosis?

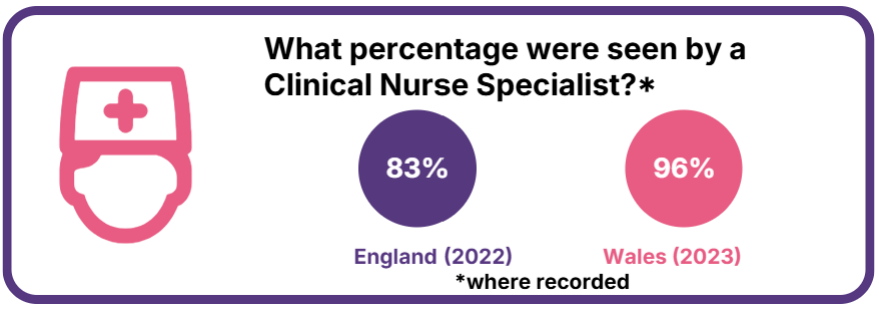


After someone is diagnosed with NHL, it is important for their tests and results to be discussed in a meeting of specialists. This is called a multi-disciplinary team (MDT) meeting, and it helps make sure each person gets a personalised, tailored treatment plan.

In 2022, 60% of people with NHL in England were discussed at an MDT within 4 weeks of diagnosis. This was higher for people with more aggressive (high-grade) lymphoma, but the percentage varied between NHS trusts.

Compared to 2020–2021, this is a reduction in the proportion of people discussed in 4 weeks. This may be due to resource pressures and reduced capacity after COVID-19. (No MDT data is available yet for Wales.)

It is also important that when newly diagnosed and undergoing treatment or monitoring, people with NHL are supported through their journey by a clinical nurse specialist.



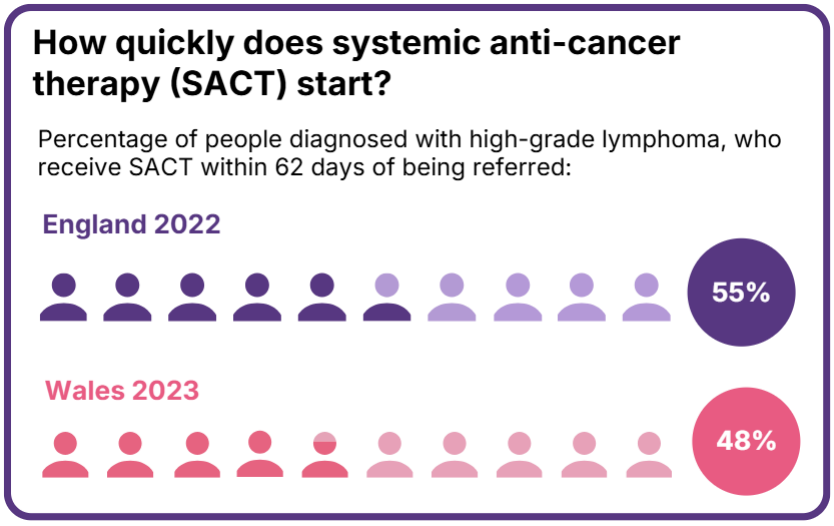
In England, 83% of people with NHL were seen by a CNS, compared to 96% in Wales (where this was recorded). These numbers were higher for people with high-grade lymphoma. However, CNS information was recorded for only 40% of people in England, compared to 82% in Wales. Overall, the proportion of people with NHL in England and Wales who had contact with their CNS has stayed about the same as last year.

Key message: NHS hospitals in England must ensure that those newly diagnosed with NHL are discussed in an MDT in a timely manner, particularly if high-grade. Protocols should be put in place with trained professionals monitoring the quality and record-keeping of these discussions.
It is also important to ensure that there is a proper record of CNS involvement to ensure each person with NHL is receiving the appropriate support.

4 Treatment

4.1 What treatment starts first?

NHS guidelines say that treatment should begin within 62 days of the first referral. This treatment is usually called systemic anti-cancer therapy (or simply systemic therapy, SACT), which includes medicines like chemotherapy, immunotherapy, and targeted therapy. For most people with high-grade NHL, these are the main and most effective first treatments.



There are a range of different systemic treatment options that can be given for those diagnosed with high-grade NHL, and these can vary depending by subtype.

In England in 2022, many different first treatments were recorded but almost all people with NHL received one that was the acceptable first choice treatment for them:

- **Diffuse Large B-cell lymphoma* (*DLBCL, not otherwise specified):** There were almost 60 different first treatments recorded, but almost everyone (around 98%) received a treatment that is considered the acceptable standard treatment.
- **Burkitt lymphoma:** There were almost 20 different first treatments recorded, and most people (about 91%) received one of the acceptable standard treatments.
- **Peripheral T-cell lymphoma* (*PTCL, not otherwise specified):** There were almost 20 different first treatments recorded, and nearly everyone (around 98%) got one of the acceptable standard treatments.

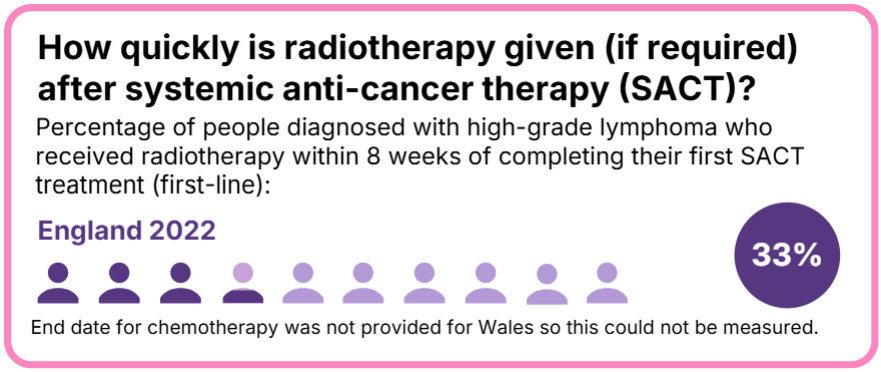
A small number of people in each NHL subtype above were recorded as not receiving the standard “acceptable” treatment. Instead, they were given a “suboptimal” treatment plan. In many cases, this was still the right choice for that individual, for example, if their overall health meant they could not cope with the more intensive standard

treatments. These treatments are grouped separately because they may not work as well or are thought to be less effective than the standard options.

Key message: Approximately one in two people with high-grade NHL in England and Wales, start systemic therapy within 62 days of referral.
Almost all individuals with high-grade NHL received an acceptable initial treatment.

4.2 What about radiotherapy?

Radiotherapy is often given after systemic therapy to add to or strengthen the effect of systemic therapy for people with high-grade NHL. If the medical team recommend this, it should start within 8 weeks of completing systemic therapy based on the consensus from our Clinical Reference Group.



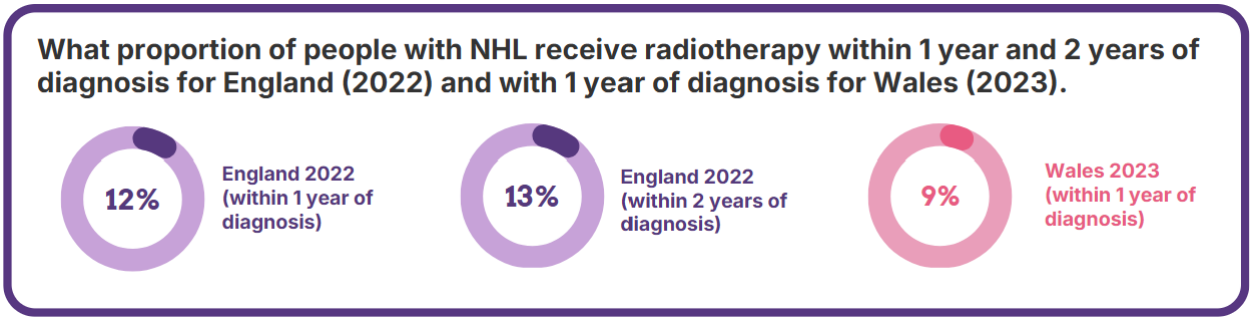
33% of people in England who received radiotherapy, began treatment within 8 weeks of completing systemic therapy. This percentage varied between NHS trusts. No results can be provided for Wales as we do not have detailed enough information about systemic therapy given in Wales.

When comparing this year's report (England 2022) to last year's report (England 2021), we can see there is a drop in the percentage of people receiving radiotherapy in a timely manner. This requires further assessment and review by NHS providers.

Radiotherapy can also be given by itself with the intent of cure or for symptom management (palliative) for a range of NHL subtypes.

The most common subtypes receiving radiotherapy were large B-cell lymphoma, follicular lymphoma, marginal zone lymphoma and cutaneous T-cell lymphoma in both England, with a similar pattern seen in Wales. Compared to results from last year's report, there has been no major change in which subtypes receive radiotherapy, but the rates differ between hospitals.

In Wales, the recorded numbers are lower, which may partly be due to gaps in how radiotherapy is recorded in the database rather than fewer people receiving it.



Key message: About one in three people with high-grade lymphoma who should have radiotherapy after systemic therapy, receive it within 8 weeks. The numbers vary between different NHS trusts.
This year's report shows that fewer people are getting radiotherapy on time compared to last year. NHS hospitals are encouraged to review their local practice to understand why and to make improvements.

4.3 What about clinical trial participation?

In England, about 2% of people with non-Hodgkin lymphoma (NHL) received care through a clinical trial in 2022 (where records were available). However, for about half of cases, this information was missing or not recorded.

People with high-grade NHL were slightly more likely to take part in a trial than those with low-grade NHL.

The most common subtype to receive care through a clinical trial was large B-cell lymphoma (LBCL). The least common subtypes were Burkitt lymphoma and cutaneous T-cell lymphoma.

Overall, the percentage of people with NHL in trials went up from 1.6% in 2021 to 2% in 2022, possibly showing a return to more normal research activity after the COVID-19 pandemic.

Key message: 2.0% all individuals diagnosed with NHL in England in 2022 were recorded as having received care as part of a clinical trial.

5 Outcomes

5.1 What are the outcomes for people with non-Hodgkin lymphoma?

It is key for people with NHL to understand the likely outcomes of their treatment, particularly survival. This information is not only useful for people undergoing treatment but is also used to guide treatment decisions. Survival estimates are given below for all people with NHL and then divided by those with high-grade and low-grade cases.

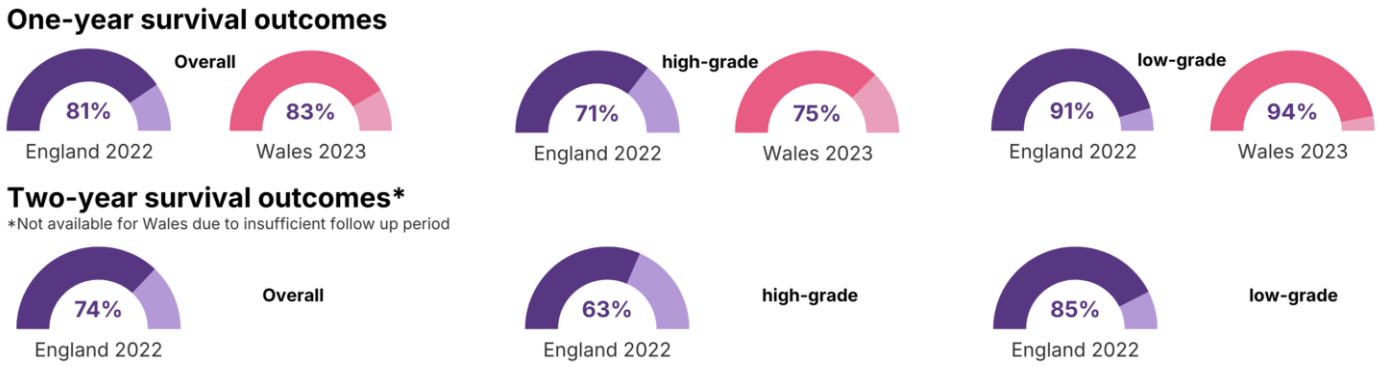
For people diagnosed with non-Hodgkin lymphoma (NHL) in England in 2022, both 1-year and 2-year survival figures are now available.

For those diagnosed in Wales in 2023, only 1-year survival figures are currently available. This is because there hasn't yet been enough time to follow up outcomes beyond the first year.

Overall, 1-year survival for all NHL cases was slightly higher in Wales compared to England.

It is important to remember that the survival outcomes shown below are averages or estimates. They don't predict exactly what will happen for any one person. Everyone is different, and factors like general health, the type of NHL, and response to treatment can all affect survival.

If you would like to know more about what these figures mean for you personally, please speak with your healthcare professional.



Key message: Overall 1-year survival for all NHL cases was approximately 80% in England and Wales; around 70% for high-grade cases and 90% for low-grade cases.
Overall 2-year survival was around 70% for all NHL cases in England; reducing to around 60% for high-grade cases and around 85% for low-grade cases in England.

6 Summary

6.1 What are the key findings from this audit?

This is the second State of the Nation report outlining delivery of care for people with NHL in England and Wales at both a national and local level. The key findings and areas for further focus are:

- **Improving the completeness of data collected**
- **Reducing delays in diagnosis, multi-disciplinary discussions and treatment delivery**
- **Improving access to and enrolment into clinical trials (as well as record-keeping).**

Care for people with NHL can vary between hospitals. A key priority is improving the completeness and accuracy of data collected and recorded. More complete and accurate data will help provide a clearer understanding of current care and guide how things can be improved. In Wales, work is already underway to improve the databases and systems used to collect information.

The performance in several of the indicators compared to last year's state of the nation report, highlights the urgent need focussed improvement at NHS hospitals. Trends over time can be seen in Table 15 in the following link: Supplementary Tables. This includes changes from 2020 to 2022 in England and 2022 to 2023 in Wales.

Of particular concern is the difference in 1-year and 2-year survival outcomes between hospitals. This suggests that not all people with NHL receive the same level of care and therefore should be a priority for further review to understand why this is the case.

One of the main potential reasons may be delays in starting systemic therapy, especially for those with high-grade lymphoma. Delays in discussions in a multi-disciplinary setting may delay treatment decisions, and delays in starting radiotherapy after systemic therapy may also be contributory factors. Starting treatment as quickly as is safely possible is important to improve outcomes for people with NHL.

A high number of people are also diagnosed with NHL in an emergency setting. There are many reasons that could be contributing to this, which will remain a focus for further work within the audit. This highlights the need for NHS

providers to review their referral pathways both in the community and hospital setting, to facilitate earlier diagnoses.

The audit will continue working on developing results for the other performance indicators and analysing up-to-date data over the coming years. It will publish these findings to provide the most current overview of care.

The audit has also developed interactive, publicly available dashboards that provide updates to the data every 3 months. There is a six-month delay from when data is collected from NHS hospitals and when it is available on the dashboards. The dashboards will allow hospitals to check their performance and progress more regularly.

The NNHLA is working to launch an upcoming national quality improvement initiative later this year. The aim of this is to work with NHS hospitals in England to improve the quality of data collected. This will provide the audit and NHS hospitals a better understanding of current non-Hodgkin lymphoma care, so that they can monitor their performance and identify areas for further improvement.

7 Key Recommendations

The key messages outlined throughout this document will be shared as part of our State of the Nation report with health care professionals; to draw these issues to their attention. These key messages have helped shape five key recommendations that will be shared in our national report.

The following 5 key recommendations have been fed back to healthcare professionals at a national and local level alongside an Action Plan Template to help guide improvement initiatives.

Recommendations made to Healthcare professionals:	Why is it important?
1. Reduce the current rate of emergency presentations of NHL by reviewing diagnostic pathways into and within secondary care to improve timely investigation and examine variation in rates of emergency presentation by geographies and population groups to identify potential causes of this.	- Reducing emergency admissions, which often happen when the cancer is more advanced, can ensure people with NHL are diagnosed earlier. - Earlier diagnosis usually results in better outcomes for those with NHL. - Improving referral pathways for those with a new diagnosis of NHL, may also improve the patient experience.
2. Local review at NHS trust/health board level is needed to identify diagnostic and treatment pathway delays and reduce inter-provider variation in people with high-grade NHL starting SACT within 62 days of referral. This may include examination of delays along the pathway, chemotherapy unit capacity and staffing, and mode of delivery of SACT, in order to understand system-level delays.	- Starting treatment quickly is crucial for the best possible results. - Delays may allow the cancer to grow and become harder to treat. - By starting treatment in a timely manner, doctors can help prevent complications and improve the chances of successful treatment.
3. Identify patient and hospital factors contributing to delays in starting radiotherapy after last administered dose of SACT and explore strategies to reduce inter-provider variation across NHS trusts and health boards. **This may include ensuring specialist representation at MDT meetings, in line with the national requirement for individual scheduled treatment planning MDT meetings to be quorate on 95% or more occasions, earlier identification of appropriate candidates for radiotherapy through an MDT setting with mandated clinical oncology attendance and earlier referral and review by clinical oncology teams to discuss radiotherapy suitability prior to completion of systemic treatment. It may also include review of radiotherapy unit capacity and staffing.**	- Giving radiotherapy after systemic therapy can improve treatment results for people with NHL. To get the best benefit, radiotherapy should be started within 8 weeks after finishing systemic therapy *(as per CRG consensus).*
4. Identify reasons why individuals with non-Hodgkin lymphoma are not enrolled in clinical trials to ensure equitable access to research opportunities, while also strengthening clinical record-keeping practices to	- Improving the number of people taking part or having access to a clinical trial means more people with NHL have access to the latest research as well as new and potentially better treatments.

support identification and reduction of participation disparities.	- Improving record-keeping helps us better identify those who may be missing out, so action can be taken to ensure equal access to research opportunities.
5. Ensure there is a designated coordinator or clinician to improve the completeness and quality of data items recorded in the national cancer datasets at each NHS trust/health board (with particular focus on staging in England and Wales and treatment delivery in Wales). **This will allow better risk adjustment of outcome variables including survival outcomes for people with non-Hodgkin lymphoma and effectively inform outlier identification.** **The launch of the Audit's national quality improvement intervention in October 2025 will further support this effort. NHS trusts/health boards are encouraged to participate in the initiative to enhance data quality.**	- Incomplete data makes it difficult to understand treatment outcomes. - Cancer staging information is essential for grouping people with NHL, ensuring they receive the right care, and predicting their outcomes. - By improving data collection, we can enhance our understanding of current care and find better ways to deliver cancer treatment. - Our outlier process depends on accurate, high-quality data. It helps the audit identify NHS hospitals that are performing poorly, so they can be urgently supported to review and improve their practice. It also highlights trusts that are performing well, so they can share their best practice.

8 Further information/ support

Guidelines:

British Society of Haematology: https://b-s-h.org.uk/guidelines/about-our-guidelines
National Institute for Clinical Excellence: https://www.nice.org.uk/guidance/ng47
NHS Long Term Plan: https://www.longtermplan.nhs.uk/

Charities:

Lymphoma Action: https://lymphoma-action.org.uk
Blood Cancer UK: https://bloodcancer.org.uk/
Cancer Research UK: https://www.cancerresearchuk.org/about-cancer/non-hodgkin-lymphoma
Macmillan: https://www.macmillan.org.uk/cancer-information-and-support/lymphoma/non-hodgkin

NNHLA

Website: https://www.natcan.org.uk/audits/non-hodgkin-lymphoma/
State of the Nation Report: https://www.natcan.org.uk/wp-content/uploads/2025/09/NNHLA-SoTN-2025.pdf
Quarterly report dashboard: rcs-ceu.shinyapps.io/NNHLA/
Quality Improvement plan: https://www.natcan.org.uk/reports/nnhla-quality-improvement-plan-2024/
Patient forum and Blog: https://www.natcan.org.uk/news/the-power-of-data-how-using-statisticalanalysis-will-generate-insights-and-identify-best-practice-for-the-quality-of-care-of-people-with-adiagnosis-of-non-hodgkin-lymphoma/

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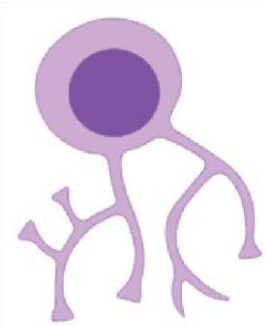
9 Appendix Information

Information Point 1:

What is NHL?



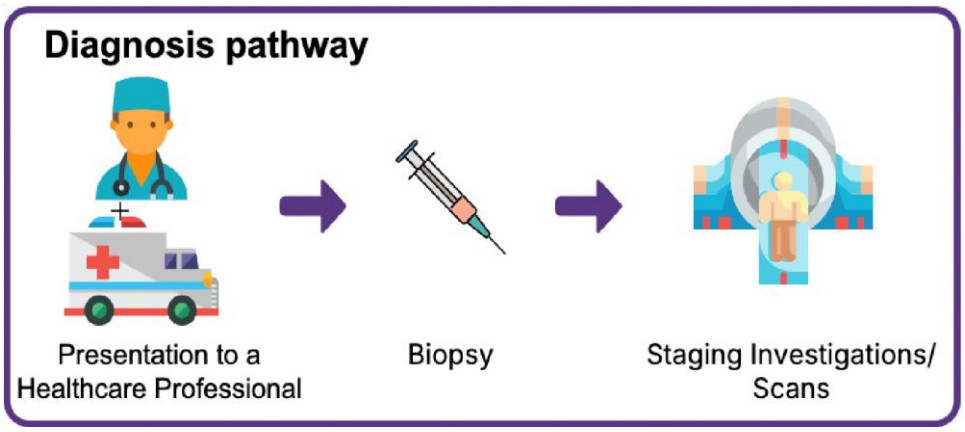
Non-Hodgkin lymphoma (NHL) is a type of blood cancer that affects white blood cells called lymphocytes. They can be found in the lymphatic system which is the body's own plumbing network that helps fight off infections and filter out abnormal cells to keep the body safe. This is part of the immune system. However, in NHL, the white blood cells divide continuously and in an abnormal way so do not develop or behave in the way they should. This leaves the body vulnerable to infections and other illnesses.

NHL is a complex cancer with almost 200 different subtypes. A simpler way we can group them is either by:

1) The type of cell: T-cell or B-cell; or
2) The grade, which is an indicator of how aggressive the cells are: high-grade or low-grade. This helps us predict how the NHL will behave, the types of treatment to offer and the likely outcome.

Information Point 2:

How do we diagnose NHL?



People with NHL are diagnosed after seeing their GP with certain symptoms or after abnormalities are picked up on a blood test. The most common symptom is a lump. The individual is then referred to the speciality where the lump is located, for example a neck lump is referred to an ear, nose and throat specialist. Alternatively, if the individual has noticed symptoms such as weight loss or night sweats (which are often referred to as B symptoms), blood tests may be carried out first and the individual may be directly referred to a haematology specialist. In some cases, they can become unwell very quickly so are first seen in the emergency department.

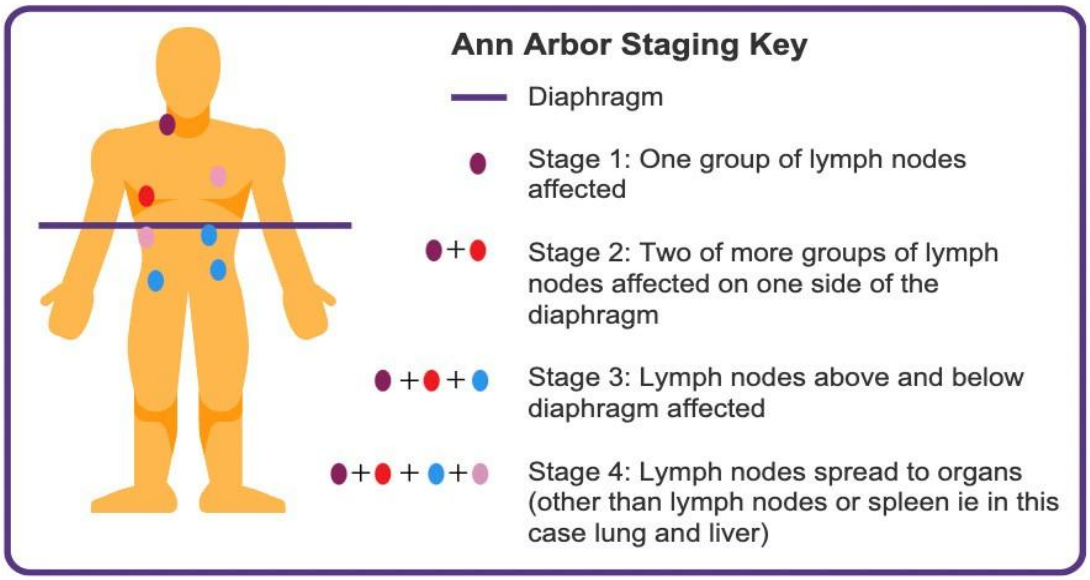
These cases are often more advanced.

A diagnosis is made after taking a sample of a concerning lymph gland or removing the lymph gland completely, otherwise known as a biopsy. This is then sent to be looked at by a pathologist under a microscope to determine if it is a cancer and if so, further specialised tests can be carried out on the sample to give us more information about the cancer. This information can then help doctors decide the best treatment for the individual.

Once a diagnosis of cancer has been confirmed, scans called staging scans (often PET/CT) are organised to assess if other parts of the body are involved. In the case of follicular lymphoma, a sample from the bone marrow is also often arranged. If the bone marrow is not involved this implies an earlier stage of disease so more conservative approaches to treatment can be adopted.

Information Point 3:

What are the stages of NHL?



The "stages" of NHL describe the extent of the body involved by NHL. This helps doctors (along with other tests and factors) decide the best course of treatment and predict the outcome of these treatments.
Most sub-types of NHL are described using the Ann Arbor Classification system, which uses Roman numerals from I to IV (1-4) . This considers the number and location of lymph glands involved in relation to the diaphragm (a muscle that divides the chest and abdomen). Stage 1 and 2 describe a limited or earlier stage of disease, and stage 3 and 4 cases are more advanced. Sometimes letters are also used after the numbers to help provide more information (A, B, X).
The Binet Classification system is used to described staging for chronic lymphocytic leukaemia cases only. These cases are grouped into A, B and C based on information from blood tests and the number of lymph nodes that are enlarged, with C being the most advanced stage.
Prognostic indices are a scoring system. There is IPI (International Prognostic Index) which is used for most sub-types of NHL and FLIPI (follicular lymphoma IPI) for follicular lymphoma. These are calculated by combining information about the stage of cancer, blood tests and patient characteristics to help predict outcomes like survival.

Information Point 4:

Who is involved in my care?

There are a team of specialists who deliver care for people with NHL.
When someone is diagnosed with NHL, they are discussed in a haematology or lymphoma specialist multi-disciplinary team setting (MDT) with all the specialists present to determine the best management plan for each individual. This team consists of:

- NHL clinical nurse specialists (CNS)
- Haematology specialist doctors
- Oncology specialist doctors
- Pathology specialist doctors
- Radiology specialist doctors and
- Multi-disciplinary team co-ordinators.

Information Point 5:

What are the treatment options?

The treatment options vary on a case-by-case basis but the options for treatment are as follows:

- **Active monitoring** (often called "watch and wait" approach) (often seen in early stage/ low-grade follicular lymphoma).
- **Systemic Anti-Cancer Therapy (SACT) or systemic therapy** – this is an umbrella term for medication often given through a drip or as a tablet form which travels around the body. This damages cancer cells and stops them from growing. This can include medications like chemotherapy, immunotherapy and targeted therapy. SACT can be given by itself, with CAR-T treatment or with radiotherapy. It can also be given with curative or palliative intent.
- **Radiotherapy** – this is high dose X-ray treatment delivered to areas of concern in the body. The aim of radiotherapy is to damage cancer cells in a targeted way and stop them from growing. This can be given alone, following completion of systemic therapy (to enhance its effect) or as a bridge to further treatment. Radiotherapy can be given with curative or palliative intent.
- **Other treatment options** include stem cell transplants/CAR-T and clinical trials.

10 Glossary

Ann Arbor Staging System – This refers to the way healthcare professionals classify the different stages of lymphoma and gives an indication of how much the cancer has spread.

Audit – This involves a thorough assessment and review of medical records or practice to check guidelines are being followed to the best care to people with NHL.

Average – This can be either the mean (calculated by adding up all the numbers and dividing it by the number of items) or the median (calculated by listing all items in ascending number order and taking the middle number).

B-cell lymphoma – This is sub-type of non-Hodgkin lymphoma that originates from a white blood cell (lymphocyte) called a B-cell. Examples include diffuse large B-cell lymphoma and follicular lymphoma.

Binet Classification System – This refers to the way healthcare professionals classify the different stages for chronic lymphocytic leukaemia and indicates how advanced the cancer is.

Biopsy – This is test where a small piece of tissue is taken from the body and examined under the microscope; this helps doctors diagnose different diseases.

Cancer – This is a disease where cells grow rapidly and abnormally forming tumours or disrupting the normal function of parts of the body.

CAR-T - CAR-T treatment stands for Chimeric Antigen Receptor T-cell therapy which is cutting-edge cancer treatment that uses your own immune cells (T-cells) that are modified in a lab and re-inserted into your body to help detect and kill cancer cells.

Chemotherapy – This is a drug treatment that can be administered as a tablet, bolus or infusion with the aim of killing cancer cells.

Clinical Nurse Specialist – This is an advanced registered nurse who provides specialist care, advice and information to people with NHL. They also provide support with coordination of their care and emotional support with certain medical conditions.

Clinical Reference Group – This is consortium of key stakeholders and clinical experts who meet to provide expert clinical and professional opinions on a range of clinical issues based on current evidence and best practice.

Curative intent – This refers to treatment given with the aim of curing or eliminating the cancer.

Data completeness – This is the extent to which all the expected data items are present and available (i.e. no information missing).

First-line systemic anti-cancer therapy – This is the first or initial treatment given to someone diagnosed with NHL after their diagnosis. It is usually given as part of a standard treatment approach that is selected based on efficacy, suitability for the person receiving treatment and after consideration of the risks and benefits.

Grade – Non-Hodgkin lymphomas can be grouped as "low-grade" or "high-grade". This is a measure of how quickly they grow and can indicate how aggressive the type of lymphoma is. This is an important factor when clinicians are considering treatment options.

Health board - This is an organisation responsible for planning and delivering healthcare services in a specific area, overseeing hospitals, clinics and other facilities to ensure appropriate medical care is being provided (main terminology used in Wales).

Integrated care boards – This is an organisation within the NHS that plans health services for their local population. They manage the budget and work with local providers including the hospitals, and GP practices in this area to formulate a 5-year strategy to improve health and social care services.

Lymph node/gland – This refers to glands that make up the lymphatic system.

Lymphatic system – This refers to a network of tissues (including lymph nodes), vessels and organs that make up an important part of the immune system, fighting infections and helping the body filter harmful waste or toxins.

Multi-disciplinary Team (meeting) – This is a meeting that occurs on a weekly or monthly basis between health care professionals from different specialities, to discuss decisions regarding the treatment of people with NHL (or other medical conditions) on an individualised basis.

NATCAN – This is the National Cancer Audit Collaborating Centre that brings together multiple national cancer audits in one place, sharing best practice and clinical excellence.

National Data Resource (NDR) - The National Data Resource (NDR) is a national data platform that will join up both health and social care data services in Wales.

NHS – This is the National Health Service that was set up in 1948 to provide everyone in the UK with free healthcare based on their medical needs.

NHS Trust – This is an organisational unit within the NHS which provides care to a specific geographical area or a for a specialised service (main terminology used in England).

NICE – This is the National Institute for Health and Care Excellence, sponsored by the Department of Health and Social Care, to provide guidance to health and care practitioners.

Palliative intent – This refers to treatment given with the aim of slowing down the progression of cancer, or controlling the cancer for a period of time. It can also be given to provide relief of symptoms and therefore improve quality of life. This treatment is not given with the aim of curing the cancer.

Performance Indicator – This is a measure of outcome or performance that can be quantified over a specified time frame against a set of targets or objectives.

Performance Status – This is a measure of a patient's level of functioning (0 – fully active , 1 – restricted in strenuous physical activity but ambulatory , 2 – ambulatory and managing selfcare but unable to carry out work activities, 3 – limited selfcare (needing assistance, confined to chair/bed for >50% waking hours, 4 – completely dependent for selfcare and confined to bed/chair, 5 – deceased).

PET/CT scan – This is a type of scan that is used to detect cancer and help with staging cancers to determine extent of disease. It is also helpful at assessing response to treatment.

Prognostic index– this is a tool used by clinicians to predict the outcome (prognosis) of people with cancer. In non-Hodgkin lymphoma, the two indices are the IPI (international prognostic index) or FLIPI (follicular lymphoma prognostic index). These combine factors like age, fitness, stage, extent of disease on imaging and blood test results to provide a score.

Quarterly Reporting – This is a summary report of findings from the audit that is published every 3 months.

Radiotherapy – This is a form of treatment where radiation (usually high dose X-rays) is given to danage and kill cancer cells.

Stem cell transplant - A medical procedure where healthy stem cells are given to replace damaged/ diseased cells. This can be used to treat certain cancers or blood disorders by helping your body produce new, healthy blood cells.

Stage – This is the classification or way of describing the size or extent of cancer when it is first diagnosed. This can help clinicians determine the best course of treatment and prognosis of the cancer. In non-Hodgkin lymphoma there are two classification systems used.

Systemic anti-cancer therapy or systemic therapy– This is the treatment of cancer with drugs including chemotherapy and immunotherapy; the aim of this treatment is to destroy or damage cancer cells. It can be given in a tablet, drip or injection form.

T-cell lymphoma – This is a rare sub-type of non-Hodgkin lymphoma that originates from a white blood cell (lymphocyte) called a T-cell. An example includes cutaneous T-cell lymphoma.

Trial – This is a type of research comparing either existing treatments or new treatments (either with other new treatments or existing treatments) to evaluate their effects. The overall aim is to improve future options for treatments for those affected by a medical illness (in this case NHL).

Variation – This encompasses the difference in healthcare process or outcomes compared to evidence-based guidelines.

Watch and wait approach – This refers to a strategy where healthcare professionals opt to monitor a condition closely rather than commencing treatment immediately, especially when the disease is slow growing, indolent or not causing symptoms.