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 2024

An audit of care received by people diagnosed with non-Hodgkin lymphoma in England (2020-2021) and Wales (2022)

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HQIP
Healthcare Quality Improvement Partnership

The National Cancer Audit Collaborating Centre NATCAN is commissioned by the Healthcare QualityImprovement Partnership HQIP as part of the National Clinical Audit and Patient Outcomes Programme NCAPOP. NATCAN delivers national cancer audits in non-Hodgkin lymphoma, bowel, breast (primary and metastatic), oesophago-gastric, ovarian, kidney, lung, pancreatic and prostate cancers. HQIP is led by a consortium of the Academy of Medical Royal Colleges and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme NCAPOP, comprising around 40 projects covering care provided to people with a wide range of medical, surgical, and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies. https://www.hqip.org.uk/nationalprogrammes

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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

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

NDRS
NATIONAL DISEASE REGISTRATION SERVICE

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.

GIG CYMRU NHS WALES
Rhwydwaith Canser Cymru
Wales Cancer Network

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.

Contents

Introduction

What is the National Non-Hodgkin Lymphoma Audit?

The National Non-Hodgkin Lymphoma Audit (NNHLA) is a new audit run by 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) 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.

What is this report about?

The first NNHLA State of the Nation report (2024) shares important feedback on how care is being delivered and the outcomes for people with NHL in England (for the years 2020 and 2021) and Wales (for the year 2022). This is the first of what will be a series of yearly reports. Future reports will cover additional findings from the audit as more data becomes available.

This document aims to explain the key points of the report in simple, easy-to-understand language for patients and the public.

How else does the audit feed back results?

An interactive dashboard of results is updated every 3 months to help individual trusts and health boards with their local improvement initiatives. This can be accessed on our website.

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 and Wales are included. It is important to note that this data was collected during the COVID-19 pandemic so the numbers presented may be slightly different to what would be expected.

The three most common sub-types reported in the State of the Nation report were:

- Large B cell lymphoma (including diffuse large B-cell lymphoma (DLBCL))
- Chronic lymphocytic leukaemia
- Follicular lymphoma.

The other types of NHL included in the NNHLA are:

- Mature B-cell lymphomas
    - Burkitt lymphoma
    - Mantle cell lymphoma
    - Marginal zone lymphoma
- Mature T- and 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))

Diagnosis

Who is diagnosed with non-Hodgkin lymphoma?

Diagnoses per year

England (2020-2021)
~14,100-15,000

Wales (2022)
~600 diagnosed in 2022

69 years Average age at diagnosis

80% were fit and well (Performance Status 0-1)*

75% had one or fewer other medical conditions*

*approximate values

NHL was diagnosed in around 14100-15000 people in England and around 600 people in Wales each year. The average age of people diagnosed with NHL was 69 and 60% of people 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 three-quarters of people had no more than one other medical condition.

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 (how advanced the disease is). Prognostic indices use this information and other patient 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 unavailable (across England in 2020 and 2021, and Wales in 2022).

~24-40% of cases with missing Ann Arbor staging information

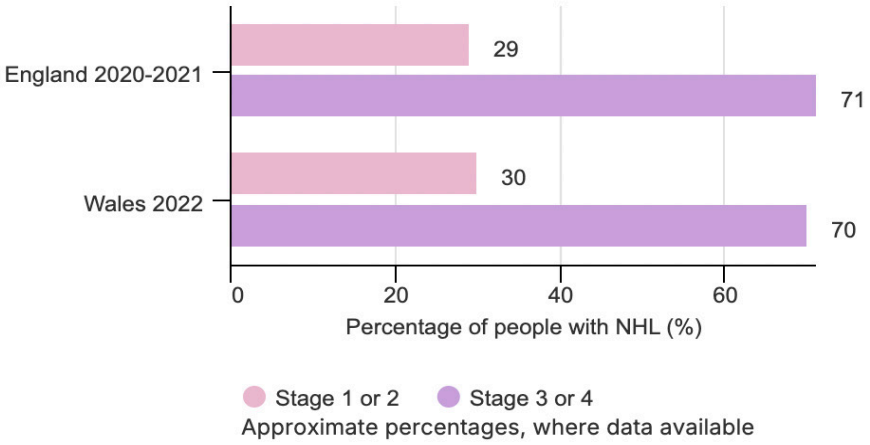
~68-90% of cases with missing Binet staging information

~89-91% of cases with a missing prognostic index score

Around 70% of people with NHL present with advanced stage (3 or 4) disease as per the Ann Arbor Classification staging system.

In contrast, for people with chronic lymphocytic leukaemia (CLL), around 60-80% present at an earlier stage; this may be because this sub-type tends to be slower growing and less aggressive, rather than due to faster referral and diagnosis.

Stage at presentation (Ann Arbor)



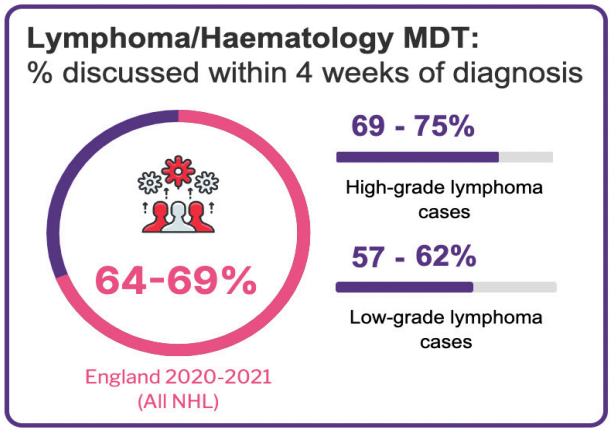
Key message: People with NHL were more likely to present at an advanced stage. Missing staging and prognostic index information is an issue. This has been highlighted to healthcare professionals as an area for improvement.

Treatment

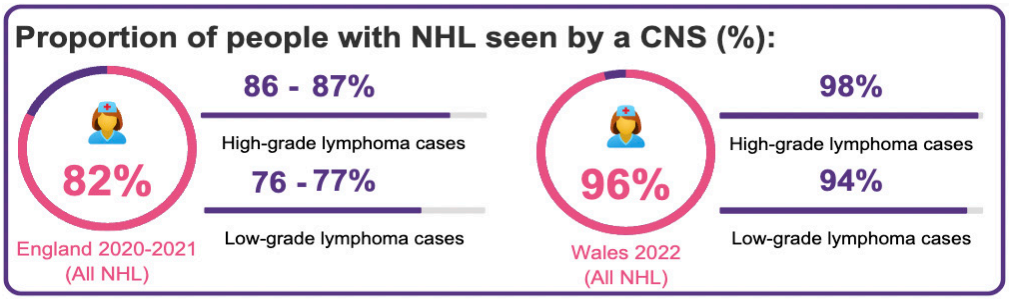
What happens after diagnosis?

60-70% of all people with NHL were discussed at a specialist multi-disciplinary meeting (MDT) within 4 weeks of diagnosis in England in 2020 and 2021. This percentage was higher for people with high-grade lymphoma, and varied across NHS trusts.

(No data about MDT discussions is currently available for people diagnosed in Wales.)



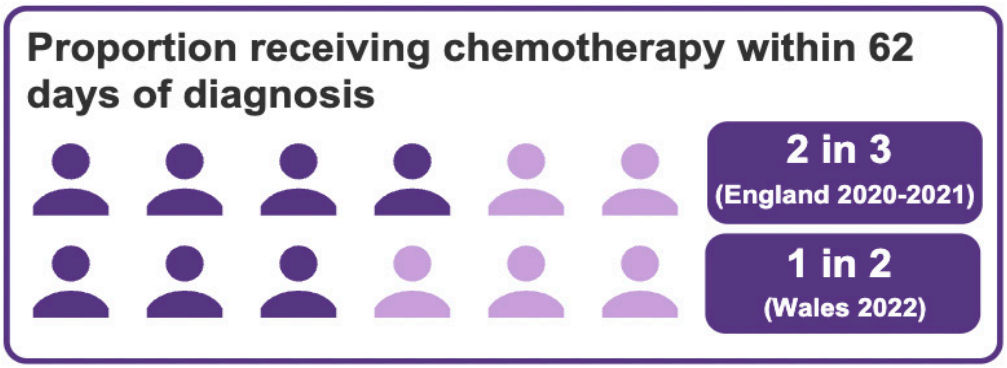
82% of people with NHL were seen by their Clinical Nurse Specialist (CNS) in England compared to 96% in Wales, where this information was recorded. These percentages were higher in people with high-grade lymphoma. CNS information was only recorded for 36-38% of people in England compared to 69% in Wales.



Key message: There is poor record keeping of MDT discussions and CNS involvement. Only 2/3 to 3/4 of high-grade cases are discussed in an MDT within 4 weeks; this is lower for low-grade cases. Where records are available, there are lower rates of CNS involvement in England compared to Wales.

How quickly should I expect to start treatment?

NHS guidelines advise that treatment should start within 62 days of initial referral. Chemotherapy is generally the first and most effective treatment option for most people with high-grade NHL..



Key message: Less than 2/3 of people with high-grade NHL in England, and about 1/2 of people with high-grade NHL in Wales, start chemotherapy within 62 days of referral.

What about radiotherapy?

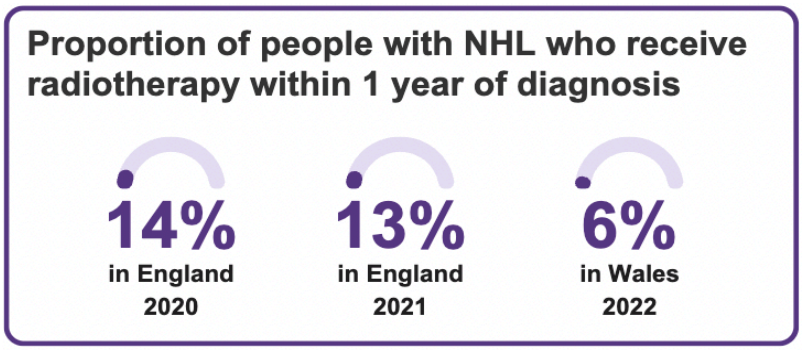
Radiotherapy is often given after chemotherapy to add to or strengthen the effect of chemotherapy for people with high-grade NHL. If the medical team recommend this, it should start within 8 weeks of completing chemotherapy based on the consensus from our Clinical Reference Group.

Around 43-44% of people in England who received radiotherapy, began treatment within 8 weeks of completing chemotherapy. This percentage varied between NHS trusts. No results can be provided for Wales as we do not have detailed enough information about chemotherapy given in Wales.

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

The three most common sub-types receiving radiotherapy within 1 year of diagnosis include: diffuse large B-cell lymphoma, cutaneous T-cell lymphoma and marginal zone lymphoma.

The diagram below shows the rates of radiotherapy use within 1 year of diagnosis in England and Wales with variation between hospitals for different sub-types. There is also concern about poor recording of radiotherapy delivery in the Welsh databases (which may explain the low proportion in Wales).

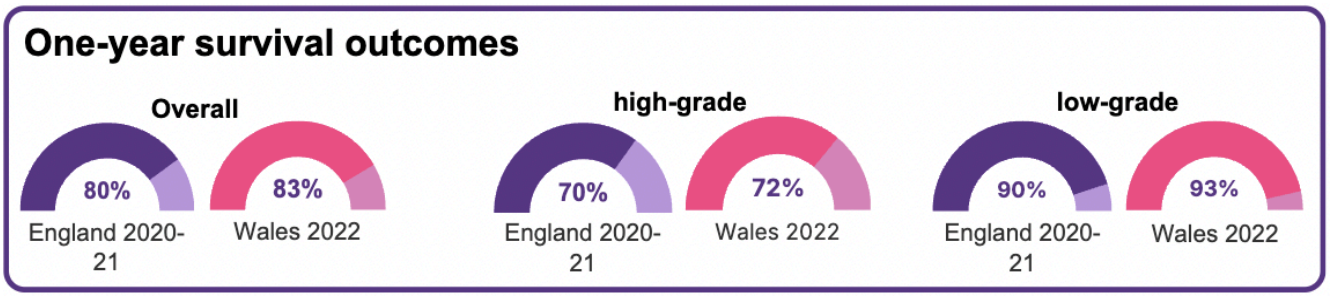


Key messages: 1) Less than 44% of people with high-grade NHL start their radiotherapy within 8 weeks of finishing chemotherapy.
2) In line with the Digital Strategy for Wales, improvements are underway to improve the record-keeping of radiotherapy use in Wales.
3) Further data will need to be collected and analysed to understand the use of radiotherapy in people with NHL in England and Wales, and explore varying practice across trusts and hospitals.

Outcomes

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. Stage of disease, the treatment received and other factors like medical history and fitness, will also affect their survival.



Key message: Across all sub-types the average one year survival was around 80%. This increased to 90% in low-grade cases compared to 70% in high-grade cases.

Summary

What are the key findings from this audit?

This is the first 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:

Care for people with NHL can vary between hospitals. A key priority is improving the completeness and accuracy of data collection to gain a clearer understanding of the current situation. This will help guide recommendations on how to improve care. In Wales, work is already underway to enhance databases and systems, which will provide vital information.

Improvements are needed to ensure timely discussions in MDTs and starting of treatment as early as possible.

There also needs to be a better understanding of the use of radiotherapy and the reasons for delays in starting this treatment. Addressing these delays will help improve radiotherapy delivery.

The NNHLA 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, helping guide improvements in NHL treatment.

Key Recommendations

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.

1

Recommendation 1: Identify and address factors delaying people with NHL being discussed at a haematology or lymphoma MDT including referral pathways, staging investigations and record-keeping.

Why is it important?
Reducing delays in specialist discussions allows doctors to make faster decisions about treatment, which can lead to better outcomes for people with NHL.

2

Recommendation 2: Identify pathway factors contributing to delays in people with high-grade NHL starting chemotherapy within 62 days of referral to develop strategies for process improvement.

Why is it important?
Starting treatment quickly is crucial for the best possible results. Delays may allow the cancer to grow and become harder to treat. By starting chemotherapy in a timely manner, doctors can help prevent complications and improve the chances of successful treatment.

3

Recommendation 3: Identify patient and hospital factors contributing to delays in radiotherapy delivery since final dose of chemotherapy

Why is it important?
Giving radiotherapy after chemotherapy can improve treatment results for people with NHL. To get the best benefit, radiotherapy should be started within 8 weeks after finishing chemotherapy *(as per CRG consensus).*

4

Recommendation 4: Ensure adequate resource allocation for data provision. Integrated care boards should support hospitals/trusts/ health boards in England and Wales with coding, data entry, and quality assurance to improve quality and completeness of data submitted. Data items of focus include:
- Cancer staging (Ann Arbor and Binet)
- Prognostic indices for NHL

Why is it important?
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.

5

Recommendation 5: Deliver more comprehensive cancer data in Wlaes, with particular focus on:
- Chemotherapy regimens and delivery
- Radiotherapy regimes and delivery
This is in the process of being developed with the introduction of National Data Resource, part of the newly established Digital Health and Care Wales as part of the Digital Strategy for Wales.

Why is it important?
Accurate data on cancer treatment delivery will help guide improvement of services and care for people in Wales.

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/reports/nnhla-state-of-the-nation-report-2024/
Quarterly report dashboard: https://www.natcan.org.uk/reports/nnhla-quarterly-report-january-2021-to-december-2023-published-july-2024/
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-statistical-analysis-will-generate-insights-and-identify-best-practice-for-the-quality-of-care-of-people-with-a-diagnosis-of-non-hodgkin-lymphoma/

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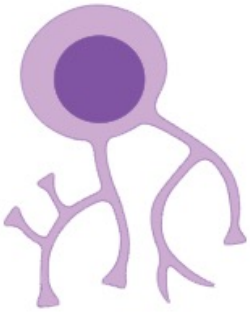
Appendix Information

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:

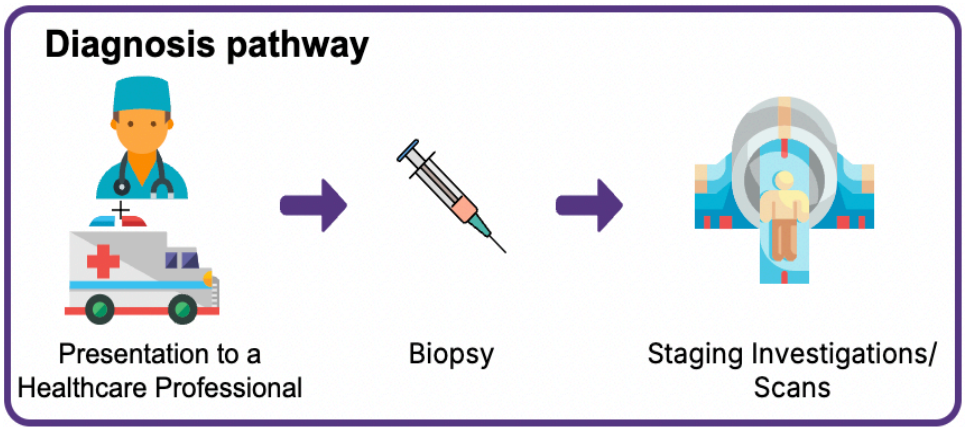
1) The type of cell: T-cell or B-cell OR
2) The grade, which is an indicator of how aggressive the cells are: high-grade or low-grade.

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.

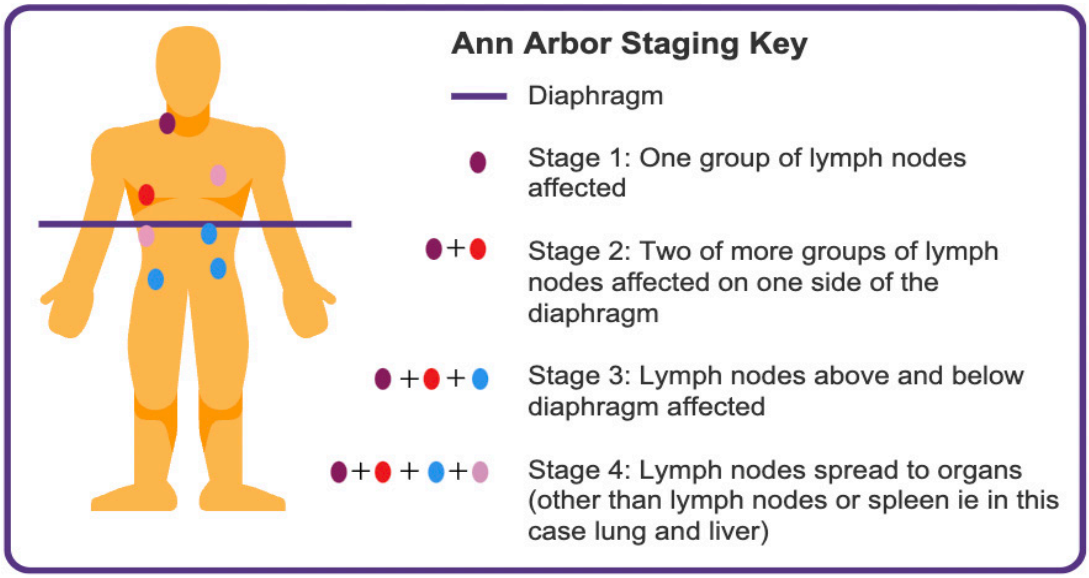


A diagnosis is made after taking a sample of a concerning lymph gland or removing the lymph gland completely, otherwise known as a biopsy. This is then sent to be looked at by a pathologist under a microscope to determine if it is a cancer and if so, further specialised tests can be carried out on the 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 takes into account 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).

- **Chemotherapy** – this is often given through a drip or as a tablet which travels around the body. This damages cancer cells and stops them from growing. Chemotherapy can be given by itself, with CAR-T treatment or with radiotherapy. Chemotherapy can 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 chemotherapy (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, newer immunotherapy approaches and clinical trials.

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).

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 – This is the treatment of cancer with drugs including chemotherapy and immunotherapy; the aim of this treatment is to destroy or damage cancer cells.

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.

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.