

## Glossary

**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.

**Cancer Registration Gold Dataset** – This is a comprehensive, validated dataset containing detailed records of cancer diagnoses in England. It is compiled from a combination of national cancer registries and linked with other healthcare datasets, such as hospital records to carry out analyses for the audit.

**Charlson comorbidity index** – This is a system used to categorise and quantify a range of concurrent medical conditions for a patient. Each medical condition is weighted. This score can be used to predict mortality and survival rates for patients.

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

**Clinical Nurse Specialist** – This is an advanced registered nurse who provides specialist care, advice and information to patients. 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.

**Clinical Trial** – This is a type of research that investigates new interventions or treatments and their effects on health outcomes.

**Consolidative Radiotherapy** – This is treatment given after the cancer has disappeared following initial treatment. It is given with the intent of killing any remaining cancer cells left behind to improve outcomes. In the case of NHL, radiotherapy can be used with this intent after initial (or first line).

**Contextualising Measure** – This is an indicator collected alongside the stated outputs of the audit that helps provide a background to the patient population or system factors that may affect the outcomes of the audit. It does not directly assess the quality of care delivered (like the current performance indicators) but allows for better understanding of the results presented and can help to provide a narrative on influencing factors.

**COSD (Cancer Outcomes and Services Dataset)** – This is a dataset that includes all patients diagnosed with or receiving cancer treatment by the NHS. Data is collated via the NDRS. This allows for a robust data collection to support national cancer registration and analysis at a local, regional and international level.

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

**Data quality** – This is a measure of a dataset’s accuracy, completeness, reliability and validity.

**First-line treatment** – This is the initial treatment given after diagnosis, which usually is chemotherapy based for those diagnosed with NHL. This is usually based on medical guidelines or local guidelines and can sometimes be called the primary treatment or therapy.

**Grade (high/low)** – 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.

**Hospital Episode Statistics (HES)** – This is a dataset that contains details of all admissions, outpatient appointments, and emergency attendances across NHS hospitals in England.

**ICD-10** – This is the 10<sup>th</sup> revision of the international classification of diseases and related health problems, which classifies medical conditions as per the World Health Organisation.

**IMD Quintiles (Index of multiple deprivation)** – This is a classification system that divides areas into five unique quintiles (or groups) based on relative disadvantage. Quintile 1 is the most deprived area, whilst Quintile 5 is the least deprived area.

**Incidence** – This is the rate of new cases or events over a specific period of time for a specified population

**Multi-disciplinary Team (meeting)** – This is a meeting that occurs on a weekly or monthly basis between health care professions from different specialities, to discuss decisions regarding the treatment of patients on an individualised basis.

**MYC testing** – This is the testing of a proto-oncogene commonly expressed in B-cell lymphomas. It is important to test for myc as it can guide on treatment decisions and outcomes (prognosis) for patients.

**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.

**NDRS** – This is the National Disease Registration Service that manages 2 services, one of which is the National Cancer Registration and Analysis Service (NCRAS). This data resource collects, and quality assures data on every patient diagnosed with cancer.

**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 with 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.

**Outlier Process** – This is the process by NATCAN where the performance of individual providers is assessed for an indicator (in this case, survival outcomes). If the performance of a provider is found to fall outside the expected range for selected performance indicators (either positive or negative) during the analysis for the State of the Nation report, it is flagged and there is a process of steps the audit must follow in line with our Outlier Policy (available on our website).

**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 – full active, 1 – restricted in strenuous physical activity but ambulatory, 2 – ambulatory and managing selfcare but unable 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).

**Primary care** – This encompasses health care provided in the community (for example General Practitioners) and often is the first point or initial contact for advice or treatment.

**Prognostic index**– this is a tool developed by clinicians to predict the outcome (prognosis) of patients 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.

- IPI (Internation Prognostic Index) is used to predict the outcomes or prognosis of those with aggressive NHL sub-types like DLBCL. It factors in components like age, extent of disease (Ann Arbor stage and extent of extranodal involvement), fitness (performance status) and blood tests (lactate dehydrogenase levels)
- FLIPI1 (Follicular Lymphoma International Prognostic Index) is used to predict outcomes for those with follicular lymphoma. It factors in components like age, extent of disease (Ann Arbor stage and number of nodal sites involved) as well as blood tests (haemoglobin and lactate dehydrogenase levels).
- FLIPI2 – this is an updated version of FLIPI1 developed following the introduction of rituximab (a type of anti-cancer treatment). It takes into account factors including age, the size of nodes involved, involvement of the bone marrow and blood tests ( $\beta$ 2-microglobulin and haemoglobin levels).

**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 kill cancer cells.

**Rapid Cancer Registration Dataset (RCRD)** -This is a dataset that provides a provisional version of the standard cancer registration data in England. It allows for earlier access to cancer diagnosis information and access to preliminary data as full cancer registry data can take longer to collate.

**Relapse** – [In the context of non-Hodgkin lymphoma] This a deterioration or recurrence of a patient’s cancer after a period of improvement

**Secondary care** – This is the care provided when your primary care provider (for example GP) refers you to a specialist with more specific expertise pertaining to the health issue you are facing.

**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 (Ann Arbor and Binet – see methodology supplement for more detail).

**Systemic anti-cancer therapy (SACT)** – This is the treatment of cancer with drugs including chemotherapy and immunotherapy; the aim of this treatment is 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.

**Tertiary Referral/Centres** - This is a speciality hospital dedicated to a particular sub-speciality like cancer. Patients are often referred here from secondary care.

**Toxicity** – This is the extent to which something (in this case, treatment) is harmful and includes reference to side effects.

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

**Wales Cancer network** – This is part of the NHS Executive for Wales working to improve outcome and care for people with cancer in Wales.

**Welsh Health Board** – This is an organisational unit in Wales that provides and plans delivery of care for a specific geographical area or for a specialised service.