

Understanding lymphoma: the importance of patient data

Introduction – what is a cancer registry and why is it important?

Cancer registries collect detailed, personalised information and data about cancer patients' diagnosis, treatment and status. The information and data helps the NHS track how many people have cancer, the types of cancer they have and how they are treated. This drives better understanding and improvements in cancer management, so leading to better outcomes and survival rates for cancer patients. Thus, this 'real-world' observational data is incredibly important in planning cancer care.¹

Typically, data is collected directly from hospital and laboratory systems and held centrally by different cancer registries. In England, there are eight regional cancer registries which pool the cancer data from the hospital registries in their area. All the registries are part of the National Cancer Registration and Analysis Service (NCRAS) which is responsible for cancer registration in England. As part of its role, it produces and maintains the National Cancer Data Repository (NCDR), comprising the data collected by the eight individual cancer registries. While the registries work to a common set of policies, there have been variations between registries in recording of data.

Scotland, Wales and Northern Ireland each have their own cancer registries. This briefing refers specifically to the English cancer registry, with some discussion of practices in the devolved nations.

Furthermore, the classification of cancers can change over time with clinicians, diagnostic laboratories and registries adopting new forms of classification at different points in time. This is particularly so in the field of blood cancers, where there is significant complexity and a large number of subtypes, each with their own diagnostic challenges, prognoses and treatment options.

Current Issues with lymphoma data collection

As noted above, blood cancers, including lymphomas, are a very diverse range of diseases. With more than 60 subtypes, patients with lymphoma will differ in presentation, diagnosis, treatment and outcomes. For example, some lymphomas are high-grade and can be treated with curative intent, whilst there are a group of incurable but comparably indolent subtypes such as follicular lymphoma and marginal zone lymphoma where the initial treatment option may be a period of 'active-monitoring/watch and wait'. When treatment becomes necessary, it will then be with a view to managing the disease and the inevitable remissions and relapses that will occur, often over many, many years.

The NCDR Blood Cancers Data Quality Report from 2010 (NCDR BCDQR),² which assessed the data quality and completeness of cancer registry data, showed a large variability in the distribution of recorded treatment. This could indicate substantial under-recording of cancer registration, staging and treatment in some registries in England. The National Cancer Intelligence Network (NCIN) used to be responsible for collection and analysis of national cancer patient data to drive improvements in care. Recently, it merged with the National Cancer Registry Service to form NCRAS, which is part of Public Health England. NCRAS now covers the whole patient pathway of data, with the hope that having one unified body will improve the quality of data collected. In 2015, they released the Equality Metrics report, which shows that the proportion of cancers with a recorded stage is increasing, with particular improvements since 2012 for non-Hodgkin lymphoma (NHL) (when less than 40% of cases had a recorded stage at diagnosis). In 2013, just over 70% of registered NHL cases in England had a recorded stage. Despite this being a positive step, the figure remains much lower than for other cancers including breast, lung, colon and malignant melanoma, which were well above 80%.³

The former National Cancer Action Team (NCAT), which has since been absorbed into NHS England, was tasked with supporting the NHS in delivery of world-class cancer services. In its report *Additional Best*

Practice Commissioning Guidance for Developing Haematology Diagnostic Services,⁴ NCAT concluded that national datasets for haematological cancers, specifically lymphoma, were particularly poor. The report suggests that data currently being produced is effectively ‘meaningless’ and therefore not cost-effective. NCAT suggest that this comes down to the lack of a standardised approach to diagnostic processes and data recording practices. Many laboratories and clinical databases will have different methods of data capture, meaning compiled national data will be grouped together for overall ‘haematological malignancies’, rather than broken down into subtypes. Given the diversity of lymphoma, such grouping reduces the value of the data considerably (see NCAT report, pages 16 and 17). At present, there is no incidence, mortality or survival statistics available for the different subtypes, and stages, of lymphoma, with the sole exception of Hodgkin lymphoma (HL), despite NHL being far more common than HL.

In 2003, the National Institute for Health and Care Excellence (NICE), in its *Haematological cancers: improving outcomes* guidance, recommended that *all* haematological malignancies are diagnosed through a specialist integrated haematological malignancy diagnostic service (SIHMDS). In 2016, in an updated version of this guidance, NICE reiterated this recommendation, adding a number of new points, including that SIHMDS report diagnoses subtype by the current World Health Organisation classification.⁵ In its associated *Resource Impact Report*,⁶ NICE states that its recommendations had still not being fully implemented despite additional guidance from the Department of Health in 2012. Last year (2015), all hospital and trust haematological cancer services were peer reviewed and it was found that some institutions were not compliant. One hospital stated:

‘The diagnostic services do not fully participate in the specialist integrated haematological malignancy diagnostic service (SIHMDS) resulting in a lack of an integrated report for this group of patients which may impact on patient care as essential diagnostic information may be overlooked.’

Without consistent and reliable data, further opportunities to improve the diagnosis, treatment and aftercare for lymphoma patients will be missed. To achieve collection of accurate and complete data, the individual laboratories and registries should implement protocols and procedures that encourage consistent, standardised practice.

The HMRN – a model for consistent and standardised cancer data registration

The Haematological Malignancy Research Network (HMRN) was established in 2004 with the mandate of providing UK specific ‘real-world’ observational data, to be used to inform clinical practice and research. It was formed in the regions of Yorkshire and the Humber & Yorkshire Coast because the population of nearly four million has a socio-demographic composition (age, gender, deprivation) that mirrors the UK as a whole. Funds have been ploughed into this, and have set an example of what is achievable with current scientific advances.⁷

Within the HMRN, 14 hospitals are organised into five multi-disciplinary teams (MDTs) where clinical practice adheres to national guidelines. Clinical specialists, working in line with the World Health Organisation (WHO) classifications, record each diagnosis at the Haematological Malignancy Diagnostics Service (HMDS), a centralised service under one roof for the whole network. This means that patient subtype data is recorded by a specialist pathologist, which is key to maintaining accuracy.

Once a diagnosis is made, data from the whole patient journey is recorded. This includes full details of treatments, responses and outcomes, which are all collected to clinical trials standards. HMRN are also able to link their patient data to the Medical Research Information Service (MRIS) to flag for subsequent cancer registrations or death and also access and link to nationwide HES (Hospital Episode Statistics) data.

As a result of the HMRN’s work, we now have accurate diagnostic and treatment data on people who have been affected by lymphoma within a specific area of England, and which is broken down into subtypes. This data can highlight areas of concern and of good practice. For example, we can see that while 5-year

survival for all haematological malignancies is at 69%, this masks the very low survival rates faced by those diagnosed with mantle cell lymphoma – a high grade form of NHL – with only 39% surviving five years.⁸ We simply would not have had evidence of this reliability and quality had HMRN not collected accurate, subtype specific data.

Information like this can be invaluable in providing an evidence base for future research, while the pooling of specialist knowledge in such a network is a fantastic way to promote best practice amongst clinical specialists. Therefore, we would strongly recommend that cancer registries apply the HMRN registration model across the country in order to improve the accuracy and completeness of data.

Proposal to launch a national lymphoma audit: the case for change

The National Clinical Audit and Patient Outcomes Programme (NCAPOP) runs audits commissioned and managed on behalf of NHS England by the Healthcare Quality Improvement Partnership (HQIP). These audits collect and analyse data supplied by a local clinician to provide a national picture of care standards for a specific condition. There are more than 30 national audits currently running. For cancers, audits have been run, or are currently taking place, for bowel, prostate, oesophago-gastric and head and neck cancers. There have also been four breast cancer audits.

As the UK's fifth most common cancer, it seems unjust that there has not yet been a lymphoma audit. When taking into account the cost of lymphoma, this point is simply reinforced. Leukaemia Care's *Blood Cancers: improving outcomes and efficiency* report⁹ estimates that in 2007/08 the cost to the NHS for blood cancers, including lymphomas, was £550million. Including lost productivity the figures increase to £1,730,000,000. In the same report, the estimated non-NHS cost of HL and NHL, is £600 million. Wang et al, more recently in the *European Journal of Health Economics* puts the estimated treatment cost of diffuse large B-cell lymphoma at £90million.¹⁰ Given these figures, should we not know much more about this disease?

By way of example, the National Lung Cancer Audit (NLCA) was created to improve the outcomes of lung cancer patients. It was evident in the late 1990s that outcomes varied greatly across the UK, and were lagging behind those of other western countries. It was unclear to what extent variation in outcomes across the UK could be attributed to differences in care, highlighting the need to establish the NLCA.

UK cancer registries had been collecting data on lung cancer since the 1970s. However, much like the current state of affairs for lymphoma data, the data for lung cancer had limited value as it missed key factors such as treatment option and stage of disease.¹¹

Alongside the registries, the Department of Health did capture some elements of the data in HES data. They were not, however, reliably collecting clinical data at the level of detail required for clinically relevant national comparison.

By measuring key indicators of the quality of care such as waiting times, treatment options and the proportion of patients discussed at MDTs, the audit has successfully transformed lung cancer care in the UK. Since its launch, clinical practice has significantly improved; average rates of active treatment, surgery, histological diagnosis and access to a lung cancer nurse specialist have all improved. The audit has played an important role in supporting clinical research, with 13 clinical research projects underway in 2013 that were making use of NLCA data to better understand where lung cancer care improvements can be made.¹² NICE has used the audit considerably in updating lung cancer guidelines. This is a strong demonstration of the value of this dataset to improving lung cancer outcomes in the UK.

Much can be learned from the NLCA and other audits in developing a successful national lymphoma audit. The NLCA struggled for credibility in the early years due to poor data completeness, an issue which was reversed as hospital trust uptake grew. This stresses the importance of persevering, with a long-term view in both planning and funding. Also, whilst detail is the key component missing in current lymphoma data,

those involved in developing the NLCA have cautioned against compiling a ‘very detailed dataset capturing all the minutiae of the patient journey’, emphasising the need to strike a balance between completeness and comprehensiveness of data collected.

Our recommendations for a national lymphoma audit

The key issue preventing the accurate collection and analysis of national lymphoma data is the actual process of recording that data within individual laboratories and hospitals, something that is exacerbated by the complexity of a lymphoma itself. Analysis carried out by NCRAS/PHE and published in May 2016 shows the scale of the problem for lymphoma (see NCRAS data briefing, *Completeness of the national Systemic Anti-Cancer Therapy data set compared with the Cancer Waiting Times data set*).

Completeness of data

Individual chemotherapy treatment for cancer patients is recorded in both the Cancer Waiting Times (CWT) data collected by hospitals and the Systemic Anti-Cancer Therapy (SACT) data that they also collect. By comparing the two datasets, NCRAS could see which data were missed from the SACT data. NCRAS found that in 2014, of those cancer patients in the CWT data who were recorded as having chemotherapy, 88% were also recorded in the SACT data. So, 12% or 13,000 patients were missing.¹³ The percentage varied across different forms of cancer, but a significant proportion of the missing patients related to lymphoma.

In summary, 14% of lymphoma patients were missing, representing about 1,600 patients or 12% of the 13,000 total. Two other significant areas of missing data were for leukaemia and myeloma, further acknowledging the particular challenges in blood cancer.

This all highlights the difficulty of collecting “complete” data, which has to be the first step in collecting “accurate” data.

A national lymphoma audit could focus on the completeness of lymphoma data by analysing the pathways for data collection. Feedback from clinicians, along with analysis and understanding from NCRAS’s Site Specific Clinical Reference Group for Haematology, suggests that clinical validation of lymphoma data is the key issue in collecting complete and accurate data. There are many ways in which hospital cancer registries and cancer managers collect the data, ranging from handwritten notes to digital systems that capture information live at Multidisciplinary Team (MDT) meetings. When data is put into the registration system, practice also varies as to whether this is with or without clinical input, oversight, expertise. And, again, before the data is submitted to NCRAS, practices vary as to whether the collected data is subject to clinical review and validation.

These variations lead directly to poor national data. Thus, **our first recommendation is:**

A national lymphoma audit should review hospital cancer registration for lymphoma with a view to ensuring diagnosis and treatment data is collected live at the MDT and then reviewed for accuracy by a clinician with expertise in haematology before it is submitted to NCRAS.

Subtype data

Given the complexity of lymphoma and its high number of subtypes, it is vitally important that the diagnosis and treatment data is collected accurately by subtype. Only in this way will we be able to get a clear national picture for lymphoma and then also be able to identify any local or regional variations in clinical practice. It is widely acknowledged by clinicians and data analysts that different recording systems and nomenclature operate across the country.

Our second recommendation is:

A national lymphoma audit should review the range of subtype classifications used within hospital cancer registries with a view to standardising the recording of lymphoma diagnosis and treatment by subtype.

With a consistent recording system in place, there are a whole host of data opportunities that could be seized. However, learning from other audits that have been carried out, focusing on key data requirements would have the greatest impact.

As such, **our third recommendation is:**

A national lymphoma audit should ensure that all hospitals collect and submit accurate data on one-year and five-year lymphoma survival by subtype.

Conclusion

Both the HMRN and NLCA provide a strong argument for, as well as a means of, achieving collection of accurate and complete data in lymphoma. The HMRN provides a framework of protocols and procedures that should be seen as the gold standard and rolled out across the UK. The NLCA has been a remarkable achievement, providing a model for how a national lymphoma audit with a mandate of improving patient outcomes could be successfully implemented. The introduction of a national lymphoma audit gives the NHS the opportunity to significantly raise the standards of the data available on lymphoma patient outcomes, treatment and care. We have made three important recommendations for a national lymphoma audit covering lymphoma registration, classification and survival rates. If introduced into lymphoma data collection, these recommendations will ensure a national lymphoma audit is provided with standardised, complete and accurate data, taking into account the diversity of lymphoma with its many subtypes, each with their own diagnostic challenges, prognoses and treatment options.

Without consistent and reliable data, further opportunities to improve the diagnosis, treatment and aftercare for lymphoma will be missed.

References:

- ¹ Isabel dos Santos Silva (1999). *Cancer Epidemiology: Principles and Methods*. World Health Organisation. International Agency for Research of Cancer
- ² Public Health England. National Cancer Intelligence Network (2010). *Blood Cancers Data Quality Report*. National Cancer Data Repository (NCDR)
- ³ NCIN (2015). *Cancer and equality groups: key metrics*. [online] Available at: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/equality. (Accessed January 2016)
- ⁴ The National Cancer Action Team and the Royal College of Pathologists (2012). *Additional Best Practice Commissioning Guidance for Developing Haematology Diagnostic Services*.
- ⁵ Nice.org.uk. (2016). [online] Available at: <https://www.nice.org.uk/guidance/dg21/resources/resource-impact-report-2312936173> [Accessed August 2016].
- ⁶ Nice.org.uk. (2016). *Haematological cancers: improving outcomes | recommendations | Guidance and guidelines | NICE*. [online] Available at: <https://www.nice.org.uk/guidance/NG47/chapter/Recommendations#integrated-diagnostic-reporting> [Accessed August 2016].
- ⁷ Smith A, Crouch S, Lax S, et al. Lymphoma incidence, survival and prevalence 2004–2014: subtype analyses from the UK's Haematological Malignancy Research Network. *British Journal of Cancer*. 2015;112(9):1575-1584. doi:10.1038/bjc.2015.94.
- ⁸ Haematological Malignancy Research Network Survival Dataset. [online] Available at: <https://www.hmrn.org/statistics/survival> (Accessed July 2016).
- ⁹ Leukaemia Care, (2011). *Blood Cancers: Improving outcomes and efficiency*. [online] Available at: <http://www.leukaemiacare.org.uk/resources/blood-cancers-improving-outcomes-and-efficiency> [Accessed August 2016].
- ¹⁰ Wang, H., Smith, A., Aas, E., Roman, E., Crouch, S., Burton, C. and Patmore, R. (2016). Treatment cost and life expectancy of diffuse large B-cell lymphoma (DLBCL): a discrete event simulation model on a UK population-based observational cohort. *The European Journal of Health Economics*.
- ¹¹ P Beckett, I Woolhouse, R Stanley and MD Peake (2012). *Exploring variations in lung cancer care across the UK – the 'story so far' for the National Lung Cancer Audit*.
- ¹² Royal College of Physicians. National Lung Cancer Audit annual report 2015.
- ¹³ National Cancer Intelligence Network. Systemic Anti-Cancer Therapy Chemotherapy Dataset. 12 Month Regimen Benchmark Report. [online] Available at: <http://www.chemodataset.nhs.uk/reports/> (Accessed August 2016).