

Introduction

As the most common haematological cancer, almost 15,000 people in the UK are diagnosed with lymphoma every year, with around 125,000 people currently living with or beyond the disease. While being more common in those of an older age, it also happens to be the most common cancer in teenagers and young adults under thirty. Lymphoma comprises two main categories: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL); and within these two categories are more than 60 sub-types. Patient experience will vary according to the diagnosis of either HL or NHL and then within NHL the subtype, as well as whether the cancer is low-grade or high-grade (i.e. indolent or aggressive). Furthermore, outcomes also vary according to NHL subtype, patient age and route of diagnosis.

About the Lymphoma Association

The Lymphoma Association (www.lymphomas.org.uk) is a national charity, established in 1986, which provides high quality information, advice and support to people affected by lymphoma (lymphatic cancer). We also provide education, training and support to healthcare practitioners who work with lymphoma patients. In addition, we engage in policy and lobbying work at government level and within the National Health Service, with the aim of improving the patient journey and experience of people affected by lymphoma. We are the only UK charity which specialises in providing support and information on lymphomas.

Any questions or comments regarding this response should be made to:

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What progress has been made in implementing the Cancer Strategy? Is progress happening at a pace which will enable successful delivery of the Strategy against the timescales set out in the Taskforce's report?

While it is encouraging that the Strategy does give acknowledgement to rare and less common cancers and the differing approaches these may require, we believe this acknowledgement needs to be taken further. The Strategy, and the corresponding implementation plan, focuses on improving outcomes for the most common cancers at the expense of rare and less common cancers, even though the latter group accounts for almost half of all cancer diagnoses, and more pertinently over half of all cancer deaths. Within that rare and less common cancer grouping, there is a major group of cancers in the form of haematological cancers (including lymphoma, which is the most common form of blood-related cancer) which needs separate strategic attention, as the key issues around prevention, diagnosis, treatment and survivorship/palliative care are completely different. In this way much more progress could be made to draw attention to reviewing the strategies, policies and practice that would have the most impact on patients living with, or beyond, a rare/less common cancer, such as lymphoma.

The Strategy rightly identified the need for a new, long-term replacement for the Cancer Drugs Fund to ensure that patients have greater access to new and innovative treatments, with the new model due to launch on 1 July 2016. While this is progress towards implementing (hopefully) a more sustainable operating system, we are concerned that the new model may continue to disadvantage patients with a rare or less common cancer by not allowing flexibility in the evidence used to assess drug treatments. With rare and less common cancers, low patient numbers can mean drug manufacturers can find it difficult to move into the more advanced stages of clinical trials required for approval under the current system. Further progress in this area will ensure that lymphoma patients (and all those with a rare and less common cancer) are able to access new and innovative treatments.

What needs to be in place to ensure successful delivery of the Cancer Strategy? Are these structures and systems being established effectively and/or at the necessary pace - particularly when it comes to rarer cancers?

Acknowledgment of less common and rare cancers

The biggest barrier to improving cancer services is the lack of awareness of rare and less common cancers, including lymphoma, which leads to them being accorded lower priority within NHS and government policy, even though they account for nearly half of diagnosed cases and over half of cancer-related deaths.

Haematological cancers, particularly lymphoma, have characteristics that make them different and which warrant a change of approach within mainstream cancer policy and healthcare practice. Furthermore, mainstream public health messages around cancer don't always chime with lymphoma. For example:

For most cases of lymphoma, there is no known cause. Therefore, positive health promotion messages will have little impact.

For many indolent or low grade forms of lymphoma, the initial treatment will be "no treatment", in the form of 'watch and wait'. This runs counter to mainstream cancer messaging which concentrates on spotting and understanding the signs and symptoms of cancer, leading to earlier diagnosis and speedy treatment, with, in many cases, a direct link to vastly improved outcomes. This is not the case for many forms of lymphoma. The implementation of the Strategy should acknowledge this difference in the promotion of better awareness and understanding of the disease, as well as initiatives to enable people living with a lymphoma diagnosis (but no treatment) to access counselling and psychological support.

Further to this point, while the majority of cancers, particularly solid tumour ones, will be treated with curative intent, many forms of lymphoma are not curable, but they are eminently manageable as long-term diseases. As such, many people will live with lymphoma for a long time, with a number of relapses. This presents a range of

additional issues for lymphoma patients and their families, including those around psychological support and a different approach to survivorship support. In order to 'transform our approach to living with and beyond cancer', the Strategy, therefore, needs to address the system of support available to lymphoma (and other haematological cancer) patients.

Cancer alliances:

We are concerned that there remains an unacceptable variation in the delivery of cancer services including diagnosis, treatment and post-treatment care for lymphoma patients across England. The Taskforce has acknowledged that whilst the NHS can boast of some cancer centres that provide world-class care, this level of quality is not uniform and consistent across the UK. Remedying this variation is, therefore, a top priority. The establishment of Cancer Alliances at sub-regional level so that variation can be easily determined, and indeed eradicated, between CCGs should be prioritised, with the hope that this transparency and accountability will make it easier to remedy the difference in care.

Specialised integrated haematological malignancy diagnostic services (SIHMDS):

Lymphoma is a hard disease to diagnose accurately, but it is crucial to do so, given the many different subtypes and corresponding different treatment options and pathways. Failure to diagnose both the lymphoma and its subtype can lead to inappropriate and sometimes unnecessary treatment. Furthermore, even when a proper referral has been made to the hospital for detailed diagnostic services, there are varying approaches to diagnosis within UK hospitals. Due to its complexity, lymphoma diagnosis will involve a number of diagnostic techniques, often requiring different processing. It's common for samples to be sent to different laboratories with each laboratory issuing a separate report. In order for a definitive and accurate diagnosis to be made, all results should be brought together by a SIHMDS. However, according to a survey carried out the National Cancer Intelligence Network (as it then was) in 2015, only half of haematology/lymphoma MDTs had access to a SIHMDS despite a NICE recommendation on this, dating back to 2003 (NICE Improving Outcomes Guidance on Haematological Cancers). The need for SIHMDS had been recognised due to consistent evidence of a significant level of inaccuracy of diagnosis, e.g.

- All Wales Lymphoma Pathology Review (1998-2000) – major diagnosis discordance in 20% of the 275 cases reviewed.
- Regional centre review, Lancashire (1995) – 36% had major discrepancies.
- North-east England audit – 26% diagnostic discrepancy rate that would have changed management.
- Scottish and Newcastle group – 28% had revised histological subtype and a resulting change in management in 10% of cases.

The 2003 Guidance has been updated and reissued in 2016, with the SIHMDS recommendation remaining substantively the same. Ahead of the 2016 update, NICE had drawn attention to the matter again in 2012, when it presented guidance highlighting more recent data from a 2011 study (I Proctor, C McNamara, et al, JCO April 10, 2011, vol 29 no.11 1431-1435), which can be summarised as follows:

- Looked at 1,949 patient samples in North Central London Lymphoma Network between 2003 and 2008:
 - Overall discordance rate of 27.3%.
 - Among the 10 most commonly referred lymphoid malignancies, discordance rate varied between 3.6% and 34.1%.
 - Of the 512 discordant diagnoses, possible to assess 350 patients re whether central review would have changed management:
 - In 39 patients (11%) – significant change to clinical management, with 19 of these patients (5.4%) misdiagnosed with either reactive or malignant conditions.
 - In 136 patients (39%), only minimal changes would have been made.
 - In 175 patients (50%) primary diagnosis provided insufficient or outdated information and would have resulted in either delayed or potentially inappropriate treatment.
- During the 6-year study, discordance rate improved, decreasing from 32% to 13%.

If we are to improve diagnosis rates, and contribute to better survival rates for lymphoma patients, and indeed other haematological cancer patients, as a result of appropriate treatment plans, the commitment to expanding access to SIHMDS needs to be a top priority.

A sustainable model for the Cancer Drugs Fund

As written in the strategy implementation plan, we must ‘ensure access to the best treatments possible’ and ‘ensure that patients are able to appropriately access new cancer drugs’. Ultimately, we believe the successor to the CDF should be rooted in the real world for real people, with patients at the very centre of its thinking and operation and we need to recognise the importance of patient voice in the appraisal process, such that their needs can not only be heard but met. For rarer cancers, like many lymphoma subtypes, we must strive to provide access to the most innovative treatments, seeing them as a stepping stone to improved overall care.

Recovery package

People with rarer cancers are more likely to encounter proper patient experience and feel more isolated than those with common cancers. Furthermore, due to the complexity and uniqueness of rarer cancers, patients find it more difficult to access support. Therefore, a key priority is to fully implement the Recovery Package, and for the NHS to call upon and use the voluntary sector to fill some of these gaps in support provision.

What are the key challenges in implementing the Cancer Strategy, and how well are these being addressed?

We believe that this strategy can only be deemed a success if, by 2020, there is a clear and proven improvement in outcomes for patients, including those living with or beyond a rare or less common cancer. For this to happen, a number of key challenges need to be addressed, including:

- An improvement in the amount and quality of registration data available and a consistent approach to how data is collected by cancer registries. There has been increasing recognition of the data needs about patients with rare and less common cancers. There are a range of challenges for this patient group, including the most appropriate coding and effectiveness of the current data being collected. Haematological cancers, including lymphomas, are a very diverse range of diseases that differ in presentation, diagnosis, treatment and outcomes. Without consistent and reliable data, the diagnosis and treatment will not improve and will remain inconsistent across England (and the UK). To achieve collection of accurate and complete data, the Strategy should implement a system to ensure registries employ protocols and procedures that encourage consistent, standardised practice.
- In particular for lymphomas (and other haematological cancers), there needs to be a step-change in data collection and management, so that there is reliable and accurate data on treatment and survival data by subtype. Currently the data collected nationally for lymphoma has lower levels of completeness compared to most other forms of cancers, although there have been some significant improvements in recent years. In addition, it appears to be difficult to provide national data by subtype – given the wide variety of subtypes and related outcomes, it's not that helpful to have national data reported simply by lymphoma as a whole category (or just by Hodgkin and Non-Hodgkin Lymphoma). One of the main problems is that many individual cancer registries submit data to Public Health England's National Cancer Registration and Analysis Service which has not been clinically checked and validated. This results in either inaccurate and/or incomplete data, meaning that proper analysis and understanding of lymphoma clinical practice cannot be undertaken. To remedy this we believe there needs to be a national lymphoma audit to better understand the issues around the collection and verification of cancer registries' data on lymphoma.
- The implementation of the Strategy relies on an empowered, informed and supported workforce. For example, we know there is a need to provide further support and training to GPs in identifying the complexities of lymphoma. We also know from various surveys, including the National Cancer Patient Experience Survey, that care is improved when patients have access to a Clinical Nurse Specialist. This is particularly the case for rare and less common cancer patients as their information needs and preferences may differ to patients with more common cancers.

Lymphoma Association

Written submission to APPGC call for evidence on progress of England Cancer Strategy |

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- A significant challenge lies in integrating aspects of the Strategy with social care policies and service delivery. A sizeable number of lymphoma patients will live with their lymphoma for a number of years and may very well outlive their cancer and die of another cause. The challenge in creating a system that supports people to live with a cancer diagnosis is of utmost priority.

What should the priorities be for the Cancer Transformation Board and the National Cancer Advisory Group in the next 12 months with regards to delivering the Cancer Strategy?

- Reviewing the diagnosis pathway for lymphoma and haematological cancers, given the disproportionate level of diagnoses via emergency presentation. Approximately 280,000 patients with a rare or less common cancer were diagnosed in A&E between 2006 and 2013, compared with 207,000 common cancers. More than 56,000 of these rare/less common cancer diagnoses were haematological cancers. A key priority of the implementation plan is ensuring that Recommendation 25 – that a significant event audit should become routine if patients are diagnosed in A&E - is implemented and strengthened, by the requirement that discussion between primary and secondary care services takes place and leads to recorded actions to improve practice.
- Improved processes to gather accurate, comprehensive data about rare and less common cancers, particularly for lymphoma and other haematological cancers.
- The formation of Cancer Alliances to reduce regional variation.
- The rollout of a new CDF system ensuring that it is, and remains, a fit-for-purpose system for accessing new and innovative treatments for rare and less common cancers like lymphoma.
- Launch pilots of MDTs.
- Incorporating the patient perspective throughout implementation.

Has sufficient funding been allocated and made available for delivery of the Strategy?

Without more detail and information, we are unable to answer this question.

What mechanisms are in place to involve patients in the delivery of the Strategy, and how effective have these been during the first year?

It is encouraging that there is patient representation on the independent advisory board and that a number of charities that represent charities are also involved. It is of our view that it is too early to tell how effective this has been during the first year. Their involvement, however, should be maintained, and where necessary increased, throughout implementation of the Strategy.

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