

NHS Strategy Review

Lymphoma Action response

Introduction to Lymphoma Action

Lymphoma Action is the UK's only charity dedicated to lymphoma. We've been providing in-depth, expert information for over 30 years, helping thousands of people affected by lymphoma, the fifth most common cancer. Our work drives improvements in the diagnosis, treatment and aftercare of lymphoma.

We welcome this opportunity to contribute to NHS England's 10-year-plan for the NHS with respect to cancer care provision. We have formulated the below responses with input from our patient advisory panel on what matters to them and where they feel there could be improvements in cancer care.

We also support submissions from the Blood Cancer Alliance.

Responses to NHS England questions about cancer care

What are your top three priorities for improving cancer outcomes over the next five and ten years?

1. Improve the technology appraisal process so that the NHS can be at the forefront of driving forward improvements in treatment for all types of cancer. The current system does not take sufficient account of the difficulties in conducting large clinical trials in rare cancers, or the lack of comparators when there is no standard treatment.
2. Ensure recovery starts at diagnosis, by embedding psychological and holistic support throughout the cancer pathway, with particular consideration for the challenges some lymphoma patients face associated with living with an often incurable cancer or an active monitoring ('watch and wait') strategy.
3. Improve data collection and reporting to ensure that people with rare cancers, such as many types of lymphoma, are represented and considered by policy-makers. Focus on the 'big 4' could impact on the speed of advances in other, rarer, cancers, where data is lacking. It is important to recognise that there are many different types of blood cancer, and to acknowledge that sometimes these need to be considered as a group, where there are similar challenges, but that the rarity of the individual types of blood cancer can be a stumbling block in driving forward progress.

What more can be done to ensure that:

More cancers are prevented?

Unlike some other types of cancer, most cases of lymphoma have no known cause. There are risk factors for some types of lymphoma, but lifestyle factors are not strongly associated with development of lymphoma.

Our patient advisory panel still recognise the importance of lifestyle factors in the development of many types of cancer, and urged that the NHS continue their work on raising awareness of healthy living.

More cancers are diagnosed early and quickly?

Improvements in cancer diagnosis rely on:

- **Education** – Lymphoma can have vague symptoms that can be difficult for GPs to recognise, particularly in older people and those with other co-morbidities. Both the public and GPs and other primary care health professionals would benefit from further education about symptoms to look out for. Too many people with lymphoma are currently diagnosed in A&E, after multiple visits to their GP.
- **Resources to take pressure off GPs** – Walk-in/mobile centres for discussing cancer worries, similar to mobile breast screening units, could take the pressure off GPs and allow the public rapid access to expert advice when they need it. Cancer-specific phone/digital contacts that could make prompt appointments for people with cancer worries could be an alternative. Specialist diagnostic centres could also improve consistency and take pressure off other services.
- **Screening** – there are already screening programmes for some cancers. Second cancers are a risk following some types of treatment for lymphoma and it is important that patients and primary care clinicians are counselled about the risks and what to look out for, in order to ensure a prompt diagnosis. The screening measures that are being piloted and implemented for certain populations, for example BARD (Breast screening After Radiation Dataset), should continue to be developed and rolled out to help keep at-risk patients vigilant and improve early diagnosis and outcomes.
- **Expert histopathology services** to ensure patients are diagnosed accurately. Lymphoma has many different subtypes, and can be very difficult to diagnose. Accurate diagnosis is key to exploring the most appropriate treatment options, but many people with lymphoma report that there was uncertainty over their diagnoses.

People have a good quality of life after cancer?

Specialised and tailored support should be consistently available to all cancer patients across the UK. At present, there are many good programmes but they have patchy coverage, meaning that not all patients can access the support they need. People with lymphoma have specific needs, particularly those with low-grade lymphomas that are incurable but might be managed over many years. People on active monitoring in particular can feel very isolated with their disease. The charity sector, including organisations like Lymphoma Action, offers many support activities to benefit patients and there should be more integration of these throughout the NHS.

More joined-up thinking could help to deliver consistency. Communication between different services is key to reducing frustration for patients.

Psychological support from diagnosis through treatment and beyond is crucial in helping people manage the emotional impact of a life-changing condition.

For lymphomas that are now managed very effectively, it is important that there is forward-thinking in terms of treatment choice. The long-term and late effects of lymphoma treatment can be very damaging, and it is important to identify patients who could have a good outcome with reduced toxicity. Research into treatments for people with Hodgkin lymphoma is driving forward progress, and this should be continued and extended to other types of lymphoma where possible. Similarly, there is an urgent need to establish defined ways to identify patients for more aggressive therapies up-front, in order to give them the best chance of a good outcome. Haematology is leading the way in precision medicine, to identify which treatments would be most beneficial for which patients.

People with cancer have a good quality of care?

- **Co-ordination of care and communication** – Lymphoma patients often see a variety of healthcare professionals at local and regional hospitals, and in different departments, such as haematology and oncology, as well as their primary care clinicians. Effective communication between everyone involved in a patient’s care, including access to results and letters, would improve care. Clinical nurse specialists are a very effective link between patients and their other clinicians and support services, and their support is invaluable. All lymphoma patients should have a clinical nurse specialist to help co-ordinate their care.
- **Effective, personalised treatment across the UK** – as the range of new treatments for lymphoma grows, it is becoming increasingly clear that there is a need to personalise treatment for each patient, to ensure they are getting the safest and most effective treatment. This relies on new advances being available in a timely manner and communicated effectively to healthcare professionals so that they are fully appraised of the available options. Commissioning differences between Scotland and the rest of the UK can be a source of great frustration and more should be done to make sure treatments are consistently available across the UK. For personalised medicine to be effective, services such as genetic testing for mutations must be offered routinely and across the UK.
- **Efficient and comfortable consultations and treatments** – outpatients might have to wait a long time for an appointment, or sit having treatment for long periods. Waiting rooms and day units can be quite bleak places, and increasing comfort could ease the process and help patients who are struggling with symptoms and side effects.
- **Access to psychological and holistic support services** – appropriate and timely support services can be just as important as clinical care in helping patients manage their illness and feel supported.
- **Extend the concept of holistic needs assessments and recovery packages.** As well as improvements in treatments allowing more people to survive cancer, there is an increasing population of people living with cancer. Lymphoma is not the only type of cancer that has people live with for many years, thanks to advances in treatment allowing people with incurable cancers to manage their disease on treatment over prolonged periods. Even in people who have been ‘cured’ of cancer, there can be an ongoing legacy of long-term and late effects, both physical and emotional. There is an increasing need for recovery and personalised support to begin at diagnosis and support patients’ holistic needs throughout their cancer treatment and recovery.

Programmes such as Lymphoma Action's 'Live your Life' help people to live with and beyond cancer.

How can we recruit, train and retain the workforce to deliver the changes we need and the priorities you have shared?

Clinical nurse specialists are the cornerstone of managing care for lymphoma patients, and offer a vital connection between other services. The NHS should ensure that recruitment for these roles and retention of specialist staff are a priority for cancer care. Clinical nurse specialists should be supported with regular training and development to enable them to be at the forefront of patient care. Clinical nurse specialists should have adequate resources to prevent them becoming over-stretched and unable to deliver the continuity of care that is so important to patients.

People will only be attracted to health service careers if there is adequate resourcing, and ongoing training and development opportunities to retain specialist staff.

Histopathologists must be expertly trained to identify subtypes of lymphoma accurately. If local centres do not have this expertise, they must forward samples to specialist services.

There should be greater integration between the NHS and the expert information and support offered by the charity sector, such as Lymphoma Action's 'Live your Life' programme. These programmes should be integrated throughout the UK, to allow everyone with cancer to access the support they need.

How can we address variation and inequality to ensure everyone has access to cancer diagnostic services, treatment and care?

Reducing fragmentation in care and commissioning across the UK is vital in delivering consistency.

- **Clear, joined-up care pathways** for all types of treatment and care should be created to deliver consistency of services for patients across the UK.
- **Reduce variation in support services.** The NHS should work with support services, including charity offerings, such as the expert information and support offered by Lymphoma Action, to ensure all patients have access to reliable information and continuous support.
- **National standards** for care should be monitored to ensure consistent care across the UK. Good practice should be shared with under-performing areas.
- **Centres of excellence** for cancer care should have good connections with local surgeries and hospitals to enable expertise to be shared.
- **Access to the best treatments** – commissioning should be consistent across the UK and the specific needs of people with lymphoma and other blood cancers should be addressed. New drugs are transforming outcomes in these types of cancer and commissioners should be mindful of the particular circumstances of people with lymphoma who are more reliant on new drugs to drive forward progress in treatment than those with other types of cancer who can be treated with other methods, such as surgery or radiotherapy. The rarity of some diseases should be better considered in health technology assessments, as it is not always possible to

conduct large clinical trials or have adequate comparators for new treatments in these circumstances. More consideration should be given to real-world data and it is very important that the timeframes for collecting adequate data through the Cancer Drugs Fund are appropriate for rare cancers.