

# All Party Parliamentary Group on Blood Cancer Inquiry into Blood Cancer Care in the NHS Call for Written Evidence

## Lymphoma Association | June 2016

---

### 1.1 What improvements can we make to ensure we diagnose blood cancer early?

Every 28 minutes someone is diagnosed with lymphoma. It is the fifth most common cancer in the UK and the most common form of blood cancer. Around 19,000 diagnoses are made each year in the UK, including chronic lymphocytic leukaemia, which despite its name is now clinically recognised as a form of lymphoma. It is also the most common cancer in teenagers and young adults.

Despite these statistics, there are still too many people being diagnosed too late.

***N.B. As the UK's only charity solely focussed on providing specialist information and support to people affected by lymphoma, for the purpose of this submission we have concentrated on lymphoma, not blood cancer as a whole.***

While we know that lymphoma is a complex cancer and can be incredibly difficult to diagnose, much could be done to encourage earlier diagnosis such as:

- ensuring there is greater awareness of the signs and symptoms among the general public
- equipping GPs so they are better able to recognise lymphoma-related symptoms
- ensuring haematological cancer services across the UK have access to a Specialised Integrated Haematological Malignancy Diagnostic Service (SIHMDS).

NHS England has used its Be Clear on Cancer campaigns to raise awareness among the public of other less well-known cancers, which has proved to be successful. We would strongly urge NHS England to develop such a campaign for lymphoma, or at the very least blood cancer. This may very well encourage a number of people to visit their GP about symptoms they may be experiencing but attributing to other conditions such as the menopause or flu.

We also know, however, that there is a need to provide further support and training to GPs in identifying lymphoma. In 2016, we surveyed 3,380 lymphoma patients about their experiences of diagnosis, treatment and aftercare. Only 51% of those respondents said their GP had a complete understanding of lymphoma. We believe the government and NHS should commit to researching and developing a diagnostic tool that is compatible with primary care IT systems and that will enable a range of symptoms to be flagged as a possible cancer.

Finally, a lymphoma diagnosis involves a number of diagnostic techniques and its currently common practice for samples to be sent to different laboratories with each laboratory issuing a separate report. Ensuring access to a SIHMDS would ensure accurate, definitive diagnoses to be made more efficiently.

## **1.2 What types of blood cancers are most challenging to diagnose early and why?**

Lymphoma is a complex disease with two main categories: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL), the latter of which also has a great number of subtypes with varying treatment options and pathways. For some forms of lymphoma, particularly high-grade or aggressive ones, early detection can help improve the chance of survival and patient experience. For low-grade or 'chronic' lymphomas, early detection may not make a difference.

Failure to diagnose both the lymphoma and its subtype can lead to inappropriate and sometimes unnecessary treatment. Even when timely and proper referral has been made to hospital for more detailed diagnostic services, the situation remains complex and uncertain for many lymphoma patients, due to the varying approaches to diagnosis within the UK's hospitals.

These varying qualities can make lymphoma an incredibly challenging cancer to diagnose.

## **1.3 How can we improve awareness of the signs and symptoms of blood cancer?**

As the UK's only charity supporting people affected by lymphoma, we play a fundamental role in improving awareness of the signs and symptoms of lymphoma through our annual Lymphatic Cancer Awareness Week campaign, our on-going press and media work and supporting our volunteers and beneficiaries to fundraise and promote our messages within their own networks. Other blood cancer charities and organisations do similar work to improve awareness of their individual blood cancers (or blood cancer taken together) and of course, this should continue.

However, lymphoma concerns a part of the body that few people know or understand – the lymphatic system. Therefore, we feel that NHS England should develop a Be Clear on Cancer campaign to raise awareness among the public. Many people who go on to be diagnosed with lymphoma experienced symptoms that they could easily attributed to other conditions e.g. the menopause, stress, the flu, a cough that won't shift. A Be Clear on Campaign can highlight the main signs and symptoms of lymphoma and encourage people to think differently about their symptoms, especially when taken all together, and visit their GP with a more specific description of the symptoms they are experiencing.

## **1.4 What support do patients need at diagnosis?**

Given the complexity of lymphoma, patients need to be provided with relevant information and support from the moment they are diagnosed. The majority of cancers, particularly solid tumour ones, are treated with curative intent and mainstream cancer messaging tends to reflect this experience. However, for some forms of lymphoma, particularly indolent or low grade forms, the initial treatment will be "no treatment", in the form of 'watch and wait', whereby people with a diagnosis but no troublesome symptoms will see their specialist for regular check-ups and only begin treatment if problematic symptoms develop. Essentially, this sort of 'chronic' cancer will be manageable as a long-term disease. As such, many people will live with

lymphoma for a long time, with a number of relapses. It may well be that they outlive their cancer, but die from some other cause.

This presents a whole range of additional issues for lymphoma patients and their families, including those around psychological support for coping with a long-term incurable cancer and a different approach to survivorship support. Being diagnosed with cancer is difficult enough, but then to be told no treatment is required, and may not be for some time, can cause distress and anxiety. As a result, counselling and psychological support for those with a diagnosis should be offered and available in their area.

### **1.5 Are there any improvements needed at this stage, and what are they?**

A significant proportion of lymphomas are only detected through emergency presentations at hospital A&E departments (which in some cases will have been direct referral of a patient by their GP to A&E). This partly reflects the fact that lymphoma is hard to diagnose, and high-grade lymphomas in particular can be very aggressive and develop quickly.

Without an increased focus on reliable primary care diagnostic tools and greater awareness and education, it is unlikely that we will be able to reduce the number of lymphoma cases identified during A&E presentation. We wholeheartedly support the proposals in the Cancer Taskforce's proposed Cancer Strategy for England (*Achieving World Class Outcomes for Cancer 2015 to 2020*) that call for an audit in the future of all cancer cases detected in A&E departments. We would go further, however, and call for evidenced and documented follow up between A&E departments and local GP networks on the learnings from such audits, given the high numbers of lymphoma cases detected in this way.

### **1.6 What can be done to improve awareness of blood cancer among the general public, decision makers and healthcare professionals?**

As mentioned above, awareness of blood cancers can be improved among the public through blood cancer-specific Government awareness campaigns and individual organisations' press, media and campaigning activity.

In terms of decision makers, we believe that because of the issues faced by lymphoma and other blood cancer patients, there needs to be a distinct strand of cancer policy that distinguishes haematological cancers from solid tumour types and accords them the same focus and attention. To make more decision makers aware of the issues faced by blood cancer patients and their families, voluntary sector organisations should draw upon their position as experts in their fields and engage with policy makers, especially in terms of ensuring the Government's cancer strategy better reflects/addresses the needs of rare and less common cancer patients, including blood cancers.

## **2.1 What areas of patient care are the most successful at meeting patients' needs?**

We hear first-hand from our supporters that access to, and the support of, a clinical nurse specialist is invaluable.

## **2.2 Which areas of patient care are the least successful at meeting patients' needs?**

As the UK's only charity focussing exclusively on supporting people affected by lymphatic cancer, we hear first-hand that many patients feel neglected once their treatment is over and find it hard to move on emotionally, especially if they are suffering with the lasting effects of treatment. At this stage, many people will contact us. Concerns about relapse or contracting a secondary cancer can be overwhelming.

Additionally, the number of people living with a lymphoma on a 'watch and wait' basis is rising. For these people, living with a long-term, indolent cancer can cause distress and create a need for psychological support. It is hard to get on with your life, when you know that you have cancer and will need chemotherapy at some point in the future – but not know when.

We also know from our work with health professionals that the need for additional support during and after treatment is widely acknowledged among clinical nurse specialists and other professionals working with lymphoma patients and that they would welcome the ability to offer additional forms of support.

## **2.3 In what way can the blood cancer patient experience differ from that of solid-tumour cancers?**

For most cases of lymphoma, there is no known cause. It is a great 'unknown' and 'unknowable' disease. Therefore, mainstream public health messages around cancer do not always chime with lymphoma and positive health promotion messages e.g. stop smoking, exercise etc. will have little impact.

For some forms of lymphoma, particularly indolent or low grade forms, the initial treatment will be "no treatment", in the form of 'watch and wait', whereby people with a diagnosis but no troublesome symptoms will see their specialist for regular check-ups and only begin treatment if problematic symptoms develop. 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.

Furthermore, while the majority of cancers, particularly solid tumour ones, will be treated with curative intent, many forms of lymphoma are not curable but are eminently manageable as long-term diseases. As such, many people will live with lymphoma for a long time, with a number of relapses. It may well be that they outlive their cancer, but die from some other cause. This presents a whole range of additional issues for lymphoma patients and their families, including those around psychological support for coping with a long-term incurable cancer and a different approach to survivorship support.

In contrast, some forms of lymphoma are aggressive and, if not treated quickly and effectively, will become terminal. Yet, at the same time, many of these aggressive forms are the ones that can be treated most successfully and have the potential to be cured. All this adds further to the complexity of lymphoma and highlights how the blood cancer patient experience can differ from that of solid tumours.

#### **2.4 What kind of support or intervention would bring about the most significant improvement in patient experience, and how could these be achieved?**

The availability of high quality and appropriate forms of support such as counselling, psychotherapy, peer-to-peer support and buddying schemes. This can be achieved by NHS England working more closely and collaboratively with the voluntary sector.

#### **3.1 What is your experience of the Cancer Recovery Package?**

N/A

#### **3.2 Does the current Cancer Recovery Package meet the needs of blood cancer patients?**

Although the *Living with and Beyond Cancer* programme has a psychological support element, we know that people affected by lymphoma and other haematological cancers (especially ones that behave in a similar way to chronic diseases) feel that their experience is different from other cancers and consequently want lymphoma-specific support.

In response, we have launched our own programme. The *Live your life – living with and beyond lymphoma* is a support programme of online, print, audio-visual and educational resources, that have been designed to help people affected by lymphoma when they might feel isolated, neglected and finding it hard to move on with their lives. This is just one example of many where the voluntary sector can offer services beyond what statutory services alone can achieve. Furthermore, it demonstrates why we want to see a commitment from the NHS to working more closely, collaboratively and supportively with the wider voluntary sector, in order to improve overall outcomes for people affected by lymphoma.

#### **3.3 What can be improved?**

While this philosophy of collaborative working is recognised by NHS England in its Five Year Forward View report, which recognises that the voluntary sector is often 'better able to reach underserved groups', more needs to be done to ensure that:

- stronger, local partnerships between the NHS and the voluntary sector are established
- there is local uptake of voluntary sector services to prevent patients falling through the gaps that currently exist in service provision
- this philosophy is rolled out across the UK in order to put an end to the NHS postcode lottery.

### **3.4 What should best practice care and support look like for people living with and beyond blood cancer?**

People living with and beyond lymphoma should follow a **supported** pathway of diagnosis, treatment (where applicable) and aftercare that enables them to live the lives they want and need; to have a good quality of life, have fulfilled relationships and be able to go back to work. Investment in these areas will almost certainly have an impact on reducing financial costs to the state, NHS and individuals affected and importantly improving quality of life for individuals living with and beyond lymphoma.

### **3.5 Which areas of care for those living with and beyond blood cancer are in most need of improvement?**

Emotional/psychological support. Because of the diverse, chronic nature of some forms of non-Hodgkin lymphoma, which can lead to greater anxiety and uncertainty, patients need to be able to access tailored information and support to cope with the varying nature of the disease. Moreover, people who have low-grade non-Hodgkin lymphoma may not be in treatment immediately but many are still unable to continue employment following diagnosis, need to miss days of work or require support from a caregiver. This can compound the need for emotional support.

Our *Understanding lymphoma* survey revealed that additional support is not being offered enough to people with lymphoma during and after treatment. 62% of respondents had not been offered additional support, with 17% offered access to counselling or psychotherapy, despite the widely acknowledged high levels of need. The survey also found that when people were provided with additional support, 85% of them found it made them feel better and more positive.

The NHS is under considerable pressure and we know from our service users that lymphoma patients' support needs are not always met by NHS services. To ease the burden, those charged with commissioning services should realise the value in voluntary sector service provision.

### **4.1 Are blood cancer patients able to access the treatments they need?**

In our recent *Understanding lymphoma as a cancer* survey, we asked lymphoma patients about their access to treatment and the length of time it took from being diagnosed to having treatment. The responses indicated that for the most part, lymphoma patients are accessing treatment appropriately. The vast majority (71%), started treatment within a month – in fact sooner for many and nearly half the respondents (45%) were treated within two weeks. These are likely to be patients with aggressive or fast-growing disease, or advanced stage lymphoma, or indolent forms with troublesome symptoms. Those that were treated from three months onwards were mainly accounted for by people who placed on a “watch and wait” regime.

However it should also be noted that the new treatments being developed for lymphomas (and other blood cancers) are typically innovative, less understood, used in smaller populations, less likely to be approved

by NICE for use within the NHS and often much more expensive. The previous Cancer Drugs Funds was rightly remodelled because it ultimately became a not-fit-for-purpose system, especially for rare and less common cancers. At the time of writing, the new managed-access Cancer Drugs Fund has launched but at such an early stage, it is still not clear whether treatments for lymphoma (and other blood cancers) will fare any better under the new system.

#### **4.2 Are their experiences similar or different to other clinical areas in accessing treatments?**

There are undoubtedly improvements required across all clinical areas in ensuring access to treatments. However, in order to bring to market a diverse range of effective and innovative treatments for blood cancers, there has to be flexibility when it comes to collecting evidence about the efficacy and cost-effectiveness of new drugs. Without it, it means there will continue to be less treatment options available for blood cancer patients than those available for most common types of cancers.

#### **4.3 What are the major challenges facing blood cancer research, and how these can be overcome?**

Our *Understanding lymphoma as a cancer* survey clearly revealed the limited opportunities that people with lymphoma have for entering a clinical trial, despite lymphoma being one of the clinical research areas where trial recruitment is below expected levels. It is well known that recruitment to lymphoma trials and other haematological malignancies is at lower levels than other disease areas. 77% of respondents reported not being given the opportunity to join a trial, and within these responses, there was significant regional variation. However, overall, when people were offered the opportunity to enter a trial, two-thirds of those people succeeded in joining a trial. There is a major missed opportunity here for more people with lymphoma to access new and innovative therapies, treatments and regimes that would not otherwise be available on the NHS. Similarly, failure to recruit more people on to trials hinders progress and advances in clinical and observational research.

All lymphoma treatment centres should ensure patients are made aware of clinical trials and the opportunity they may afford. Treating hospitals should put in place an action plan with targets to evidence that information on trials is being provided to patients, and to record the numbers that do and do not enter a trial, and the reasons. This would help to increase opportunities for lymphoma patients to take part in clinical trials and aid the development of more innovative treatments.

Furthermore, to help overcome such challenges, the voluntary sector is again stepping in to fill gaps. In 2016, we launched our Lymphoma TrialsLink service ([www.lymphomas.org.uk/lymphoma-trialslink](http://www.lymphomas.org.uk/lymphoma-trialslink)). A key resource for patients and clinicians alike in finding out which trials are running in which areas for which treatments or regimes, similar initiatives could be developed for other forms of blood cancer.

### **5.1 Does the commissioning of NHS services work for blood cancer patients?**

The current commissioning of NHS services for cancer patients is disproportionately focused on solid tumour cancers and therefore, is not always the most appropriate for blood cancer patients (and other rare and less common cancer patients).

### **5.2 Are there significant areas where commissioning is working well/poorly?**

As described in previous questions, we know that the commissioning of appropriate support services for lymphoma patients is not working well.

### **5.3 Are there any improvements needed in the commissioning of services, and what are they?**

NHS England commissioning managers should draw upon the experiences of their colleagues in social care and local government, who, through the contracting of services from charities and third sector organisations, have been able to ensure specific services are delivered to those in need.

Because of its expertise and close connection to patients and their families, the voluntary sector is in a valuable position to help ease burdens within the NHS. Because we know the NHS does not always meet the needs of lymphoma patients, especially with regard to living with and beyond a lymphoma diagnosis, we have developed our own well-being programme (as mentioned in question 3.2), to fill that gap in service provision. Many other voluntary sector organisations are developing similar initiatives. We, therefore, believe improvements could be made to ensure the NHS works more closely, collaboratively and supportively with the voluntary sector in order to deliver more and better support service.

### **5.4 What should the focus of Cancer Alliances and Vanguard be to improve patient outcomes and experience in blood cancer?**

Learning from, and learning about, specific cancer patient populations and their needs so that the most appropriate forms of treatment and support packages are available, and offered, to lymphoma (and other blood cancer) patients.

**-End-**