



Understanding lymphoma as a cancer

**Patients' experiences of lymphoma
diagnosis, treatment and aftercare**

**Lymphoma Association
survey 2016**



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1. Executive summary

Every 28 minutes someone in the UK is diagnosed with lymphoma. Lymphoma is currently the fifth most common cancer diagnosed by clinicians in the UK (after breast, lung, colon and prostate cancers). It is the most common haematological cancer.

Lymphoma can occur at any age. Although it increases in incidence with age, it is also the most common cancer affecting teenagers and young adults, and those under the age of 30.

While lymphoma shares some similarities and characteristics with other types of cancer, there are important aspects where it differs that give a distinct slant to the Lymphoma Association's work in supporting people with a diagnosis. We highlight these in more detail in the introduction to the report, but key among those differences are the clinical complexity of the disease, the range of over 60 subtypes and the fact that many forms of lymphoma are indolent or chronic and so while not curable can be managed and treated over a long period of time. Furthermore, the causes of lymphoma are unknown. This makes a dramatic difference to the issues of prevention, diagnosis, treatment, aftercare and follow-up/survivorship. We argue that these fundamental differences should result in cancer policy and practice that is different to the mainstream approach taken within the UK by the departments of health in the four nations of the UK and the respective NHS in each of those countries. The mainstream approach of the National Cancer Strategy for England typifies this, side-lining as it does the different issues with lymphoma and other haematological cancers. Unfortunately, the strategy appears to focus heavily on improving outcomes for the most common cancers at the expense of rare and less common cancers (including lymphomas), even though the latter group accounts for almost half of all cancer diagnoses, and more than half of all cancer deaths.

With this in mind, the Lymphoma Association commissioned Quality Health to undertake a survey of individuals who had, or were undergoing, treatment for lymphoma. The survey aimed to gain valuable data on the impact of lymphoma on quality of life, patients' experiences of their diagnosis and treatment journey, and their access to information, support and aftercare.

A follow-up survey to the National Cancer Patient Experience Survey in England was sent to 4,243 people who had been treated for lymphoma and who had previously consented to further contact. There were 3,380 responses, equating to a response rate of 80%, the highest ever recorded for this type of survey run by Quality Health.

The main profile of the respondents was as follows:

- Just over a half of the respondents (51%) were diagnosed between one and three years ago.
- Over half of the respondents (56%) were aged between 55 and 74; 25% were aged between 75 and 84; and 17% were aged over 65; just 8% were aged 45 to 54; and 7% were under the age of 44.
- 54% of respondents were male, 46% were female.

The results from the survey have provided a powerful dataset which covers a wide range of themes. This data has highlighted particular areas for further policy and campaigning work to improve the lives of those affected by a lymphoma diagnosis and subsequent treatment. These areas are set out below.

Routes to diagnosis

The survey findings challenge some of the available national data on individuals' route to diagnosis. While the National Cancer Intelligence Network's *Routes to Diagnosis* data for in England during 2006 to 2013 records that 26% of non-Hodgkin lymphoma and 17% of Hodgkin

lymphoma cases are diagnosed in an emergency setting, our data suggests that the overall figure for all lymphoma cases is more like 18% (which includes the 7% of respondents who the GP sent directly to hospital). While it was reassuring that two-thirds (66%) of respondents reported being referred appropriately via the “two-week-wait” scheme or by non-urgent referral to a specialist, it was more of a concern that 17% were initially treated for another condition by their GP.

- **Recommendation 1:** Further work should be undertaken to improve awareness and understanding of lymphoma within general practice.
- **Recommendation 2:** There should be a review of national lymphoma data collection and ideally a national audit, as this is one of many areas where NHS statistics for lymphoma do not match either the lived or clinical experience.

GPs, primary care and time to diagnosis

While 19% of respondents said that their GP didn't seem to know about lymphoma, we were pleased that 81% reported that their GP had a complete or partial understanding of lymphoma. As a cancer support charity report we receive a lot of feedback from people with lymphoma who complain about their GPs' involvement in their diagnosis, so it is reassuring to hear of a positive experience for the vast majority. While there are still great improvements that can be made in GP awareness and understanding of lymphoma, the generalist nature of primary care, the relative scarcity of lymphoma and the uncertainty of the presenting symptoms are very real challenges and barriers.

GPs and primary care services play an important role throughout a lymphoma patient's experience, and not just at the point of early identification of lymphoma. For many people with lymphoma, especially those living with chronic or indolent forms, post-treatment follow-up and aftercare at a primary care level is very important. So, again, while it was positive to hear that the vast majority of people thought their GP had a good or some understanding of lymphoma, it was much more of a concern to hear that 23% said their general practice was of no help or support during and after treatment, with a further 9% saying that more help could have been provided. In terms of the practical support that was offered, the limited responses we received were that 5% said a support plan had been discussed and agreed with them, 3% said the signs and symptoms of recurrence or relapse had been discussed, 3% had been directed to other sources of information and support, and 1% had been provided with access to a “living well” or survivorship programme.

- **Recommendation 3:** General practices should work more with specialist lymphoma organisations to understand better the nature of living with lymphoma and develop practical and meaningful support plans for people going through and recovering from treatment, including providing accurate and up-to-date signposting services.

Stronger awareness and understanding of lymphoma

Despite being the UK's fifth most common cancer, lymphoma is neither well-known nor easily understood and some of the survey's responses confirm this, with just over a third (34%) of people diagnosed saying they had not heard of lymphoma previously. Similarly, awareness of lymphoma as a form of cancer was limited. In a similar vein, the survey found a clear need to improve the understanding of the lymphoma information that is provided to patients. While 60% said that the information they received from the likes of their treating hospital, Macmillan and the Lymphoma Association (the three most common sources of information by far) was easy-to-understand, most of the other respondents (37%) only understood some of the information, and 3% did not understand most of it. Furthermore, the biggest barrier to improving cancer services is the lack of awareness of rare and less common cancers such as 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.

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- **Recommendation 4:** Consideration should be given to initiatives to improve health education around lymphoma among both adults and children/young people. Featuring lymphoma in a future Public Health/NHS *Be Clear on Cancer* campaign could have a massive impact on improved awareness and understanding.
 - **Recommendation 5:** Information providers, whether hospitals, charities (including the Lymphoma Association) and other organisations need to reconsider their approach to accessible and understandable information in order to ensure their written materials meet the needs of even more people.

Know your subtype

The survey provided revealing information about how little people are told about their lymphoma subtype, despite it being an important factor in helping them understand their diagnosis, treatment and prognosis, not to mention in finding the best information and support. We were shocked to discover that 14% of people were told simply they had lymphoma and only 13% were told their non-Hodgkin lymphoma subtype.

- **Recommendation 6:** All clinicians should inform patients of their lymphoma subtype and refer them to appropriate, specialised forms of support relevant to their subtype.

Information provision

As noted above, the three most common sources of information provided to respondents by healthcare professionals by far were from the hospital's own resources (61%), Macmillan (45%) or the Lymphoma Association (25%). Obviously, we were disappointed that more of our specialised lymphoma information and materials wasn't distributed directly to people with lymphoma, especially given that all hospitals that treat lymphoma either request or receive our resources. More importantly however, the responses show that there must be a lot of duplication in the information that is provided and the resources that go into producing it. Surely, it would save important NHS resources if information development and provision were subcontracted to specialist providers in the voluntary sector, such as the Lymphoma Association or Macmillan.

In a similar vein, not enough people were told about how to find further information or support – 20% said they were told nothing about other sources of information. In a separate question, 75% said they were told nothing about using the internet and only 16% were advised to use trusted websites. Despite this, nearly half (46%) of respondents used the internet to find further information. Of these people, 25% said they found the Lymphoma Association's website the most useful, with 23% and 20% saying the same for Macmillan and Cancer Research UK's websites, respectively.

- **Recommendation 7:** NHS information providers should work more closely with the voluntary sector to ensure the provision of accurate, timely and specialised written, audio-visual and digital resources to people affected by lymphoma.

“Watch and wait”

The survey also confirmed what we knew already about the significant proportion of people that start their treatment journey on “watch and wait” or “active monitoring”, due to the indolent, slow-growing nature of their lymphoma. In our sample, 20% of people said that after diagnosis, they were placed on “watch and wait”, with the vast majority (91%) saying they understood the reasons for this. Although there was a reassuring level of understanding about “watch and wait”, over half (53%) either had some concerns and worries (45%) or were very worried (8%). Despite these worries and concerns, 41% reported that they weren't given any written information on “watch and wait”.

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- **Recommendation 8:** All lymphoma patients who are placed on a “watch and wait” regime should be provided with clear and easily understandable written information on what that means and the implications for their future treatment plan and health outcomes. For instance, the Lymphoma Association provides a wealth of information on “watch and wait” – see www.lymphomas.org.uk/about-lymphoma/treatment-lymphoma/watch-and-wait-lymphoma.

Additional sources of support

Perhaps one of the most concerning findings in the survey was the lack of further support provided to people with lymphoma during and after treatment. Nearly two-thirds (62%) of people were not offered additional support, with only 17% offered access to counselling or psychotherapy, despite the widely acknowledged high levels of need. Just as concerning was the apparent age discrimination operating within the system, with nearly half (47%) of 25 to 34-year-olds being offered additional support compared to an overall average of 17%, and older patients being less likely to be offered extra help. For instance, 68% of 75 to 84-year-olds weren't offered such support and nor were 78% of those aged 85 or over. To rub salt into the wounds, the survey found that when people were provided with additional support, it was overwhelmingly beneficial, with 85% of respondents saying that it made them feel better and more positive.

- **Recommendation 9:** The NHS should work with the voluntary sector to understand better the positive impact of additional support services and to commission lymphoma-specific programmes of support.

Clinical trials

Our 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. Over three-quarters of respondents said they were not 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 which 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. There are a number of possible explanations for the shortcomings the survey responses have identified.

- **Recommendation 10:** All lymphoma treatments 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. The Lymphoma Association's Lymphoma TrialsLink service (www.lymphomas.org.uk/lymphoma-trialslink), launched in 2016, is a key resource for patients and clinicians alike in finding out which trials are running in which areas for which treatments or regimes.

2. Background and methodology

2.1 Background

Lymphoma is the fifth most common cancer in the UK, with more than 15,000 people diagnosed every year, and rising to 19,000 a year when diagnoses of chronic lymphocytic leukaemia (CLL) are included (which is a form of lymphoma, despite its name). While the majority of people diagnosed with lymphoma will be over the age of 55, lymphoma is also the most prevalent cancer among teenagers and young adults aged under 30. Approximately 125,000 people are living with lymphoma and CLL in the UK.

While lymphoma shares some similarities with other types of cancer, there are important aspects where it differs and that give a distinct slant to the Lymphoma Association's work in supporting people affected by a diagnosis.

For most cases of lymphoma, there is no known cause. Therefore, positive health promotion messages will have little impact. In this sense, it's a great "unknown" and "unknowable" disease.

Lymphoma concerns a part of the body that few people know or understand – the lymphatic system. As such it can affect any part of the body. This makes it even harder to cope with and explain to other people. 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.

Many forms of lymphoma are chronic cancers – while the majority of other 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. 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 and difficulty in understanding lymphoma as a disease and cancer.

While "solid tumour" cancers will have a range of treatment options including surgery, radiotherapy and chemotherapy, surgery isn't an option for treating lymphoma and the key backbone of treatment regimes is chemotherapy, and sometimes radiotherapy.

Age is an important factor in cancer diagnosis, treatment and survival generally. It is particularly important in lymphoma because of the two peaks of incidence – one in younger people under the age of 30 and the other in older people, particularly over the age of 55.

Because of these fundamental differences, the Lymphoma Association believes that lymphoma and other haematological cancers need a distinct strand of cancer policy given the issues that distinguish them from the approach taken for more common cancers and/or "solid tumour" cancers. Put plainly, the mainstream approach of prevention, early detection/diagnosis, speedy treatment and aftercare/survivorship issues, does not work for lymphoma and for many other haematological cancers, for the reasons identified above. To reflect this, there should be a shift in cancer policy and practice in the UK by the departments of health in the four nations of the UK and the respective NHS in each of those countries. The mainstream approach of the National Cancer

Strategy for England typifies this, side-lining as it does the different issues with lymphoma and other haematological cancers. Unfortunately, the strategy appears to focus heavily on improving outcomes for the most common cancers or “solid tumour” cancers at the expense of rare and less common cancers (including lymphomas), even though the latter group accounts for almost half of all cancer diagnoses, and more than half of all cancer deaths. Within that rare and less common cancer grouping, lymphomas and haematological cancers are a significant proportion of the overall total with a strong need for separate policy and practice attention.

2.2 Objectives

The Lymphoma Association interacts with thousands of individuals each year through our information and support services, both online and offline. Our work can be broadly grouped as follows:

- Information and publishing – we provide a range of high quality, award-winning, information leaflets and publications (including audio-visual resources), which we distribute via our website and in hard-copy formats to hospitals and cancer information centres.
- Lymphoma TrialsLink – an online clinical trials database and information service (see www.lymphomas.org.uk/lymphoma-trialslink)
- Helpline – open five days a week, throughout the year, we deal with more than 6,000 enquiries per year, providing in many cases much-needed emotional support for those affected by lymphoma.
- Support groups – we operate a network of circa 45 volunteer-run local support groups across the UK, offering information, support and local communities for people living with lymphoma.
- Buddy scheme – we have a team of over 150 trained buddies whom we link with people who need additional support or who want to speak with someone who has shared similar experiences.
- Psychological support services – we appointed our first clinical psychologist role in November 2016.
- Events – we run national and regional events for people affected by lymphoma, including carers, friends and relatives.
- Healthcare education and training – we run training events and conferences for, and provide information to, healthcare practitioners working in the field of lymphoma, including GPs, nurses, specialist trainees and consultants.
- Website – our website offers a range of information and support, including hosting a number of online forums for people affected by lymphoma to share experiences and seek mutual support.

Anecdotally, we are aware that there are a range of issues that accompany a lymphoma diagnosis including the psychological impacts of lymphoma diagnoses and treatments on individuals. As with other cancers, we believe the impact is greatly underestimated by the state and healthcare profession. We wanted to collect data through a standardised and rigorous survey methodology to better understand and ascertain the impacts of a lymphoma diagnosis and subsequent treatment on patients across the country.

We had a number of key objectives with this project:

- To ascertain the impact on individuals diagnosed and treated for lymphoma.
- To identify gaps in provision of quality care for these patients.
- To use the results to seek improvement in the care and support offered to individuals affected by impacts of lymphoma treatment.
- To use the results to influence health policymakers to ensure individuals are offered better choices and care.
- To produce the biggest survey and data set on the impact of lymphoma.

2.3 Questionnaire design and development

The questionnaire was designed and developed towards the end of 2015 and early 2016. This involved a detailed process of drafting, reviewing, testing and revising the questions. Quality Health worked closely with the Lymphoma Association on designing and agreeing the final question set.

As a part of the process, cognitive testing was carried out with 16 volunteers who have lymphoma; we are very grateful for their time and input into the process. The volunteers completed the draft questionnaire and were then invited to share their answers to the questions, and to comment on the wording, the response options, any omissions; and any comments on the layout and length of the survey. In total, 16 people were interviewed about the design of the questionnaire.

2.3.1 Sampling and National Cancer Patient Experience Survey data

The respondents all came from the data gathered as part of the National Cancer Patient Experience Survey (CPES) 2015. Every respondent to that survey has the option of agreeing to receive further questionnaires about their health. It is only these people who are approached with any follow-up survey.

When follow-on surveys have been sent to CPES respondents, ICD10 codes are used to identify the cohort of patients required. We therefore extracted a sample that included all people with lymphoma by using the following ICD10 codes.

ICD-10 Four Character Sub-Category Code	Tumour Grouping	ICD-10	Description
C810	Haematological	C81	Nodular lymphocyte predominant Hodgkin lymphoma
C811	Haematological	C81	Nodular sclerosis (classical) Hodgkin lymphoma
C812	Haematological	C81	Mixed cellularity (classical) Hodgkin lymphoma
C813	Haematological	C81	Lymphocyte depleted (classical) Hodgkin lymphoma
C814	Haematological	C81	Lymphocyte-rich (classical) Hodgkin lymphoma
C817	Haematological	C81	Other (classical)

			Hodgkin lymphoma
C819	Haematological	C81	Hodgkin lymphoma, unspecified
C820	Haematological	C82	Follicular lymphoma grade I
C821	Haematological	C82	Follicular lymphoma grade II
C822	Haematological	C82	Follicular lymphoma grade III, unspecified
C823	Haematological	C82	Follicular lymphoma grade IIIa
C824	Haematological	C82	Follicular lymphoma grade IIIb
C825	Haematological	C82	Diffuse follicle centre lymphoma
C826	Haematological	C82	Cutaneous follicle centre lymphoma
C827	Haematological	C82	Other types of follicular lymphoma
C829	Haematological	C82	Follicular lymphoma, unspecified
C830	Haematological	C83	Small cell B-cell lymphoma
C831	Haematological	C83	Mantle cell lymphoma
C833	Haematological	C83	Diffuse large B-cell lymphoma
C835	Haematological	C83	Lymphoblastic (diffuse) lymphoma
C837	Haematological	C83	Burkitt lymphoma
C838	Haematological	C83	Other non-follicular lymphoma
C839	Haematological	C83	Non-follicular (diffuse) lymphoma, unspecified
C851	Haematological	C85	B-cell lymphoma, unspecified
C852	Haematological	C85	Mediastinal (thymic) large B-cell lymphoma
C857	Haematological	C85	Other specified types of non-Hodgkin lymphoma
C859	Haematological	C85	Non-Hodgkin lymphoma, unspecified

The total sample size was 4,243. This represented every patient from CPES15 who had reported having any type of lymphoma, and who had given consent to further contact and/or receiving a follow-up survey.

2.4 Timescales and fieldwork

The fieldwork was undertaken between 25 April (initial send out date) and 15 July 2016 (the closing date). The send out of surveys and subsequent promotion followed this pattern:

- Initial send out, with covering letter, and language line leaflet, paper copy of the questionnaire and reply paid envelope – respondents could opt to complete the questionnaire online.
- First reminder, including letter and language line leaflet.
- Final reminder, including a further copy of the paper questionnaire, with a reply paid envelope.

2.5 Response rate

The final response rate was 80%, which was a total of 3,380 responses from 4,243 sent out.

This is the highest response rate ever recorded for this type of survey run by Quality Health.

3. Results of the questionnaires

3.1 Respondent characteristics

3.1.1 Age

Just 6% of respondents were aged between 25 and 44; 27% of respondents were aged between 45 and 64; 66% were aged over 65. Just 1% of respondents were aged 16-24. The chart (Fig.1) below shows the age breakdown in more detail.

For the purposes of this report, respondents' age bands were merged as follows, to ensure that numbers were sufficient to draw meaningful conclusions: (25-34 and 35-44; 45-54 and 55-64; 65 and above).

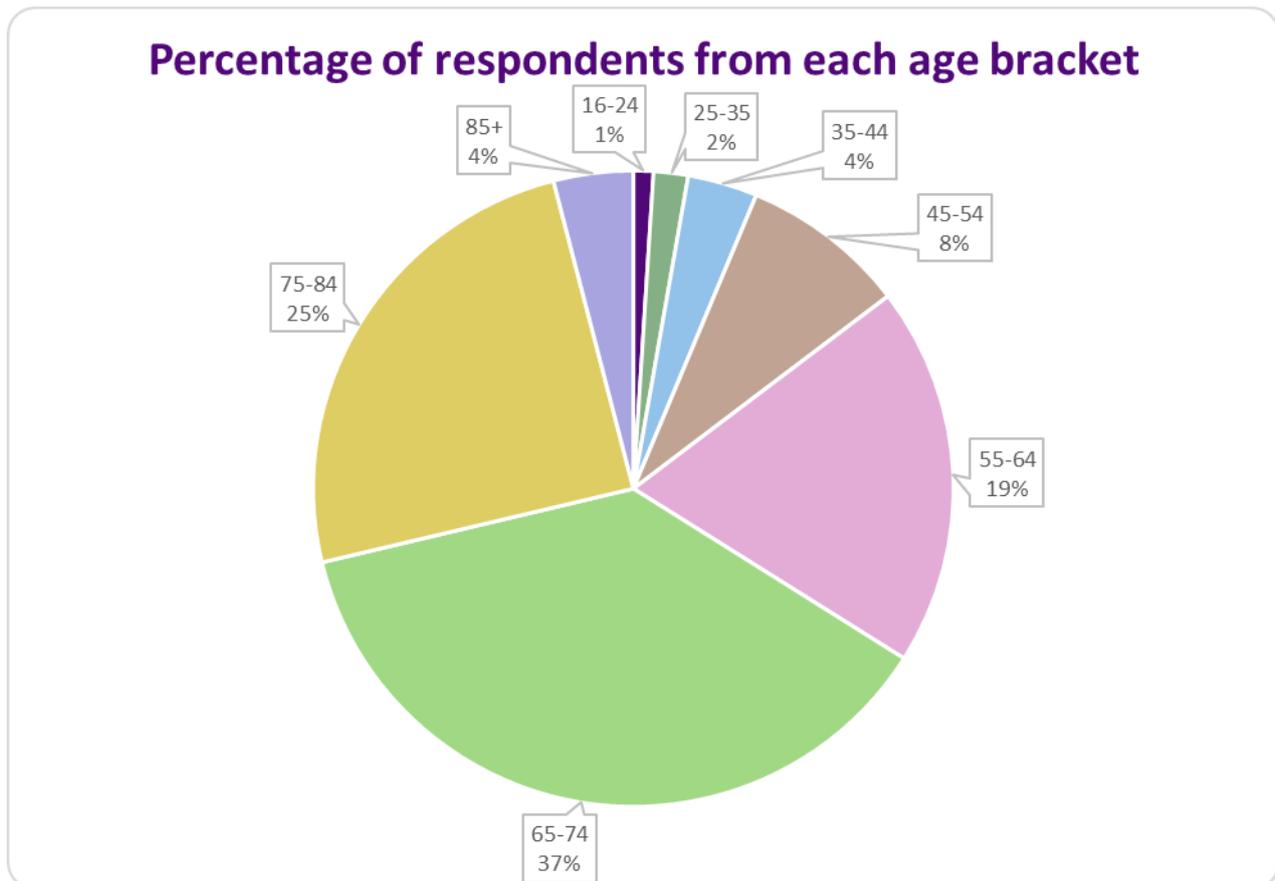


Fig 1. Respondent age groups

3.1.2 Ethnicity

93% of respondents identified as being white British; 4% white 'other', 1% as Indian and 1% as 'other Asian background'.

3.1.3 Gender

54% of respondents to the survey were male. 46% of respondents were female.

3.1.4 Time since starting treatment for lymphoma

Most respondents (51%) had started treatment for lymphoma between one and three years ago. 27% had started treatment within the last year, 9% between three and five years ago, and 13% had started treatment more than five years ago.

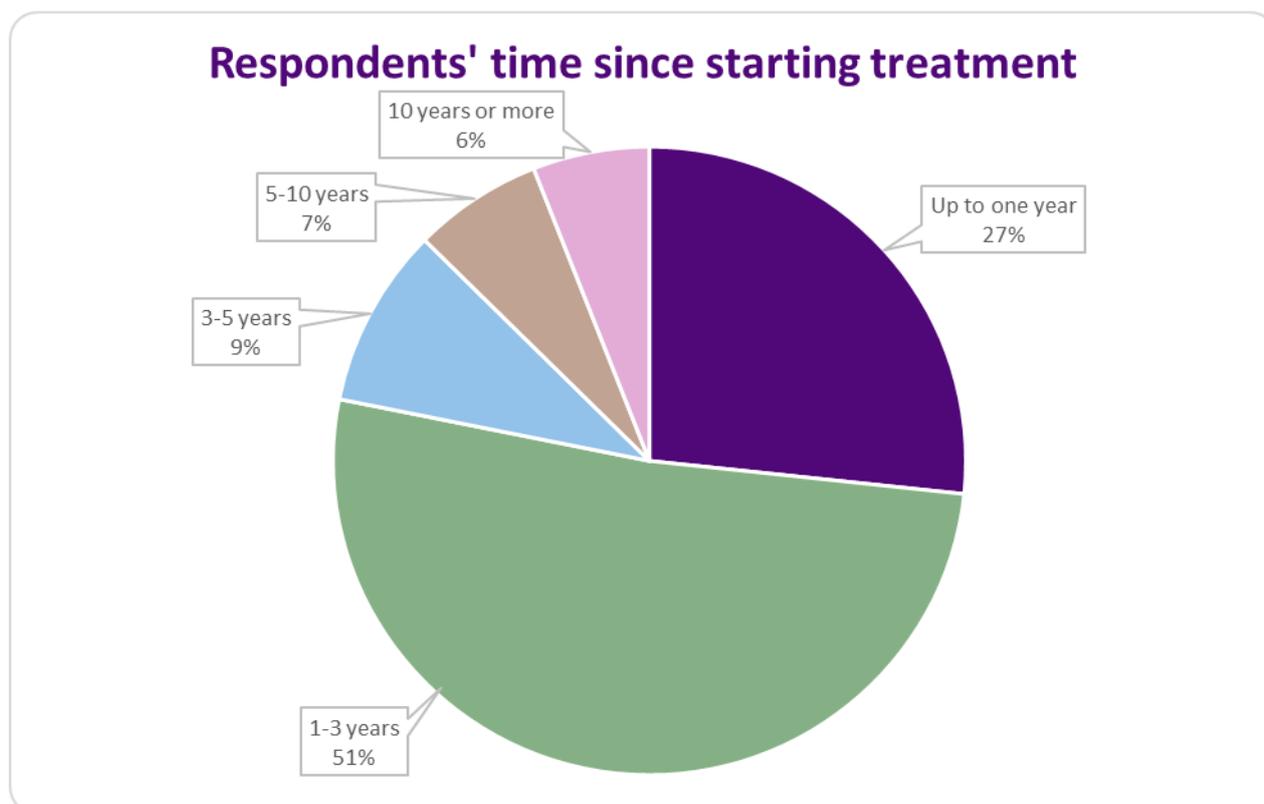


Fig 2. Respondents' time since starting treatment

3.2 Before diagnosis

The following questions looked at respondents' experience before their diagnosis, including whether they thought their GP had a good understanding of lymphoma; their route to being diagnosed; whether they knew what the signs and symptoms of lymphoma were; and, whether they knew that lymphoma was a form of cancer.

3.2.1 GPs' understanding of lymphoma

The following chart (Fig.3) shows the percentage of respondents who felt their GP had a good understanding of lymphoma. 51% of respondents felt their GP had a complete understanding of lymphoma with 19% of respondents feeling their GP did not know about lymphoma at all. While understandable to some extent given the generalist nature of primary care and the relative scarcity of lymphoma, this highlights the difficulties for patients and GPs in identifying the signs and symptoms of lymphoma. Improved understanding and awareness can play an important role in improved diagnosis and better patient experience. That is why the Lymphoma Association developed an e-learning module for lymphoma, in partnership with the Royal College of GPs, as a way of supporting ongoing learning and continuing professional development in primary care. For more information on the module, see www.lymphomas.org.uk/supporting-health-professionals/gp-online-training-course. Figure 3, over the page, illustrates this.

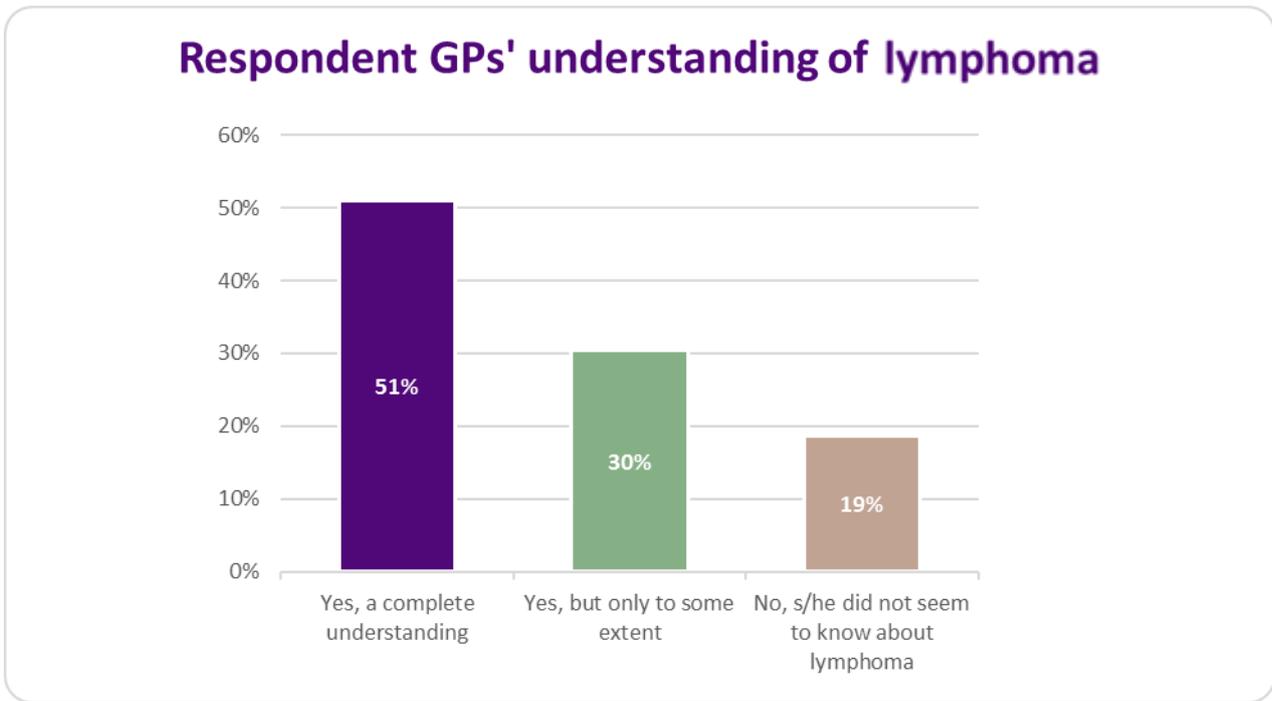


Fig 3. GPs' knowledge of lymphoma

When analysed by age range, it was clear that younger people were less likely to feel their GP has a complete understanding of lymphoma than older people, e.g., only 25% in the 16 to 24 age bracket compared to 55% in the 65 to 74 bracket.

“Because my lymphoma was so rare, my GP had no knowledge of this illness.”

“I believe I was fortunate to have a GP that recognised that I was in need of a specialist referral even though my symptoms did not indicate non-Hodgkin's lymphoma at the time.”

When analysed by lymphoma subtype (using the ICD10 codes referred to on pages 12 and 13), it was clear that those with non-Hodgkin subtypes believed that their GP had a better understanding of lymphoma than those diagnosed with Hodgkin lymphoma. For those who reported their GP had a complete understanding of lymphoma, the response rate was 42% for Hodgkin lymphoma, compared to 52% for follicular lymphoma and similar rates for other subtypes (and an overall average of 51% as shown in the above chart).

3.2.2 Route to diagnosis

We then asked respondents to explain their initial route to being diagnosed with lymphoma. The chart below breaks down the way in which respondents answered this question. Well over a third (38%) were diagnosed via a GP referral under the “two-week-wait” scheme. 28% were referred to the hospital outside of this scheme; 7% were sent to hospital the same day as seeing their GP and 17% reported being initially treated for another condition.

These figures highlight the patchiness and inconsistency in patients’ routes to diagnosis. While it is reassuring to see that two-thirds of patients (66%) are appropriately referred via the “two-week-wait” scheme or by non-urgent referral to a specialist, it is a concern that close to a third (28%) were either treated for another condition by the GP (17%) or only had their lymphoma initially identified in an accident and emergency unit (11%).

It is interesting to speculate what may be behind this range of responses. Certainly the difficulty in diagnosing a less common form of cancer with no or limited symptoms which may also be vague or mirror other conditions is likely to be one factor. Similarly, lack of awareness among both patients and GPs of lymphoma is likely to be another, despite it being the fifth most common cancer in the UK.

It is also interesting to note how the survey results differ from the available national data on routes to diagnosis for lymphoma and other haematological cancers. According to the *Routes to Diagnosis* data and reports produced by the National Cancer Intelligence Network (now part of the National Cancer Registration and Analysis Service) for England during the period 2006 to 2013, 26% of non-Hodgkin lymphoma cases are diagnosed as emergency presentations and 17% of Hodgkin lymphoma cases. Our surveys suggests a figure of 11% of all lymphoma cases, although if we include the 7% of cases in the survey where the GP sent the respondent directly to hospital, then the total is more like 18%. It’s worth noting that the NCIN figures themselves also include cases where GPs had referred cases directly to accident and emergency services. Furthermore, it is widely acknowledged that national data for lymphoma, although improving, has issues around completeness and accuracy.

Either way, if the survey results are a true reflection of routes to diagnosis for lymphoma, then they paint a better picture than the national data, although they still allow for great improvement.

When we analysed the survey data against whether people had either Hodgkin and non-Hodgkin lymphoma we found no significant difference in their route to diagnosis, which again conflicts with some of the national data that suggests those with Hodgkin lymphoma can have an easier route to diagnosis, with fewer emergency presentations.

However, when looked at from an age perspective, younger people were more likely to be referred under the “two-week-wait” scheme (47% of 16 to 24 year olds compared to 38% overall). This suggests that, irrespective of younger people’s confidence levels in GPs’ understanding of lymphoma (see responses to earlier questions), the response within primary care was to take their signs and symptoms more seriously.

Figure 4, over the page, illustrates the route to diagnosis.

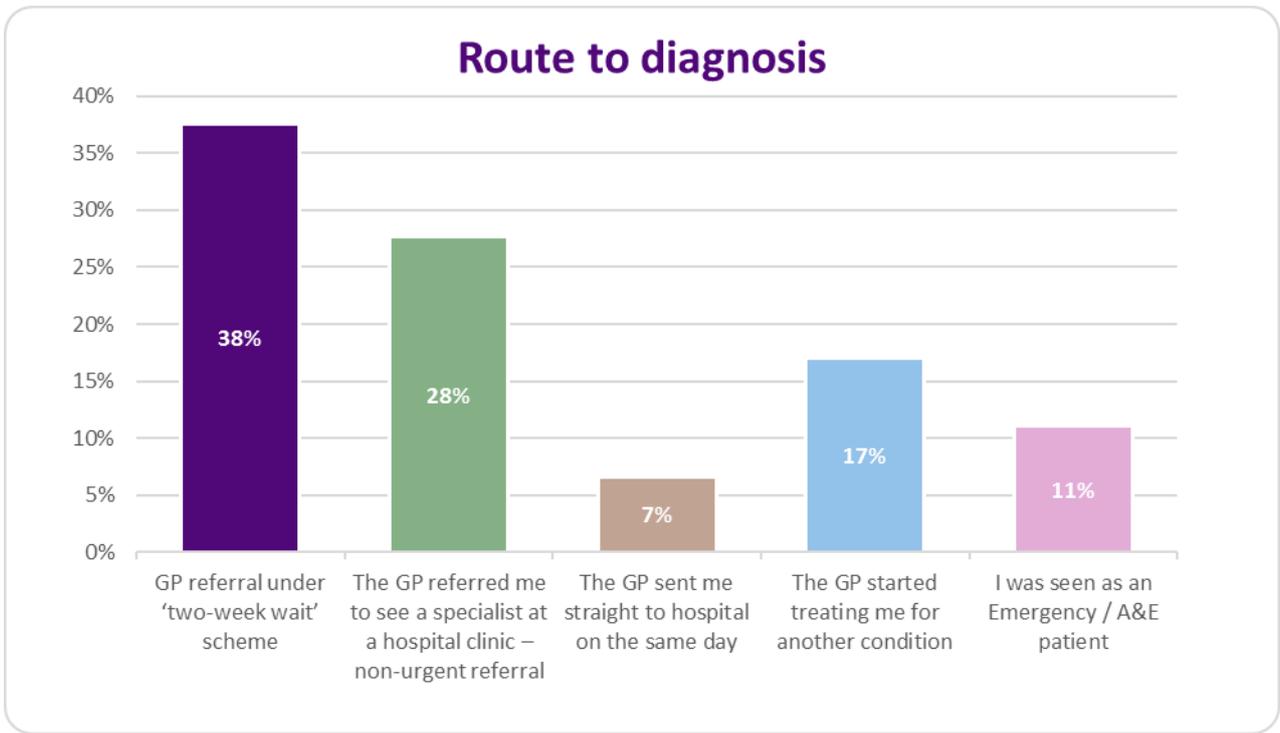


Fig 4. Route to diagnosis

3.2.3 Time from thinking something might be wrong to seeing a hospital doctor

We asked respondents how long it has been from when they first thought something might be wrong with them until they saw a hospital doctor. Almost three-quarters (73%) were seen in under three months. Given the high numbers of people that the Lymphoma Association hears from where there are complaints about the length of time the route to a diagnosis can take, the figure of 73% being seen by a hospital doctor within three months was reassuring, especially when we realise the question focuses on the respondent's perception of when something might be wrong with their health and not necessarily their first GP appointment. However, it remains a concern that for 10% of people it took seven months or more to see a hospital doctor, including a number of years for a small minority. It would be interesting to understand more about what these cases involved.

When we looked at the data by subtype, it was interesting to see that Hodgkin lymphoma patients were less likely to see a hospital doctor within three months (62%) compared to non-Hodgkin lymphoma patients (ranging from 72% to 75%, depending upon subtype). It's difficult to understand fully the explanation for this, but there may be less of inclination to suspect or refer for cancer in the Hodgkin group of patients, which (as in our survey) will tend to reflect a younger age range.

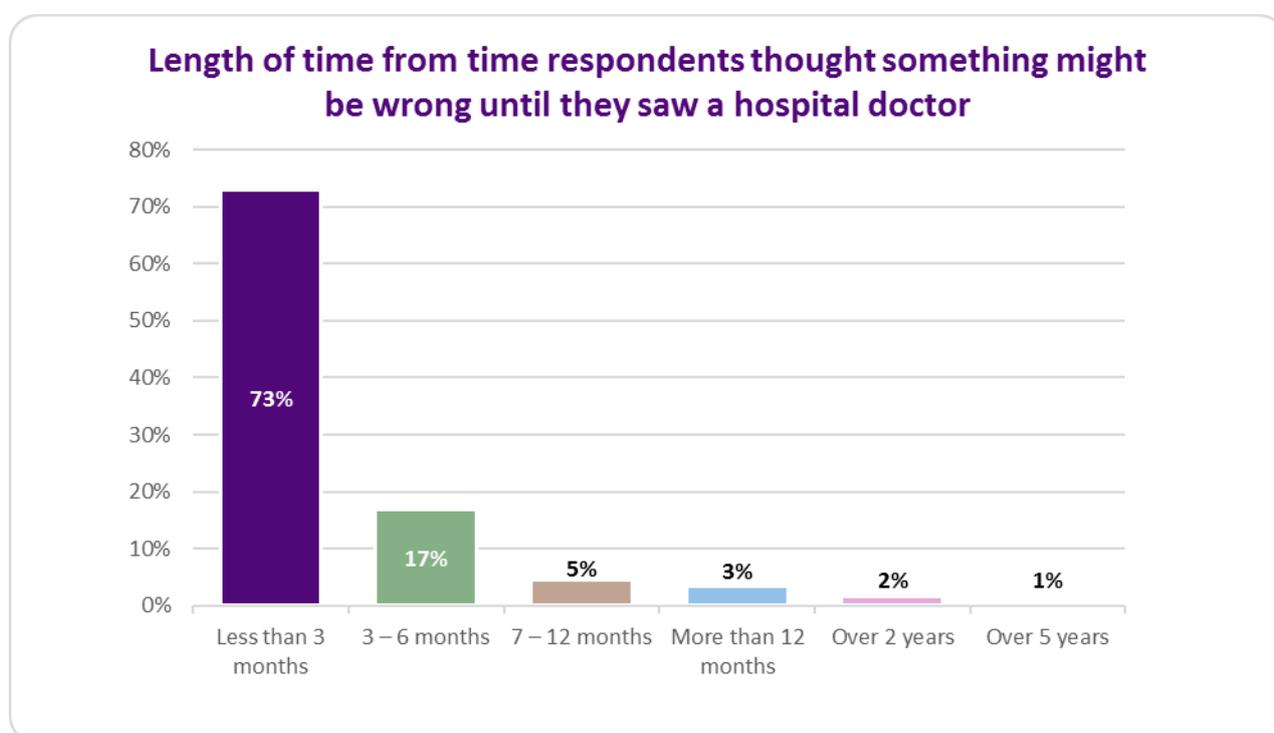


Fig 5. Length of time from time respondents thought something might be wrong until they saw a hospital doctor

“It took over a year from first symptoms to get a diagnosis and I saw many different types of consultant prior to diagnosis. I have a very rare form and many took no notice. Since then I have been looked after superbly both by doctors, nurses and all staff.”

3.2.4 Respondents' expectations of what was wrong

We also asked respondents if they suspected that they might have cancer before they were diagnosed. Just 7% of respondents fully expected it to be cancer, 27% had some suspicions that they may have cancer. However, two-thirds (66%) of respondents did not think they had cancer at all before they were diagnosed with lymphoma.

3.2.5 Respondents who had heard of lymphoma

Finally, we asked respondents if they had heard of lymphoma before they were diagnosed. 19% of respondents had heard of lymphoma and knew what type of cancer it was. Almost half (48%) had heard of lymphoma but didn't know specifics about the type of cancer. Just over a third of respondents (34%) had not heard of lymphoma at all. The responses to the question highlight the lower levels of awareness of lymphoma compared to more common forms of cancer. Further analysis of those who had some awareness of lymphoma is needed to understand the depth of that understanding.

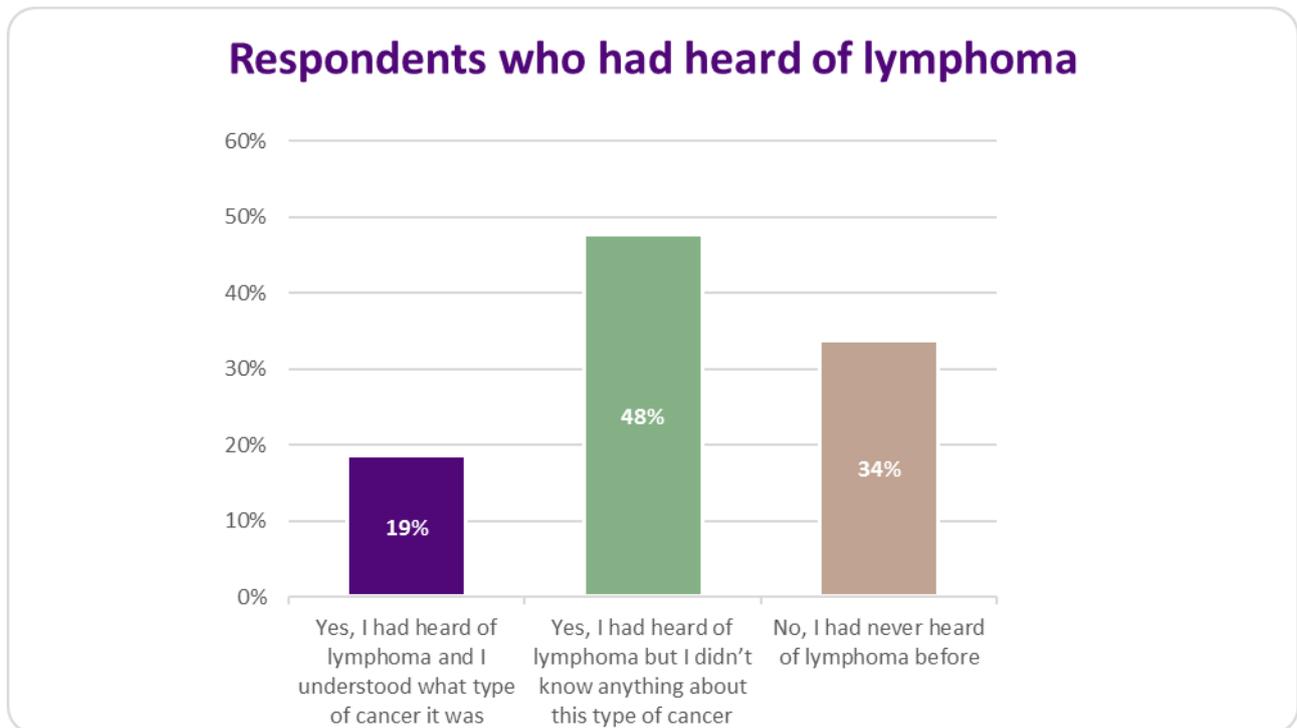


Fig 6. Respondents who had heard of lymphoma

The responses are perhaps unsurprising given that lymphoma, despite being the UK's fifth most common cancer, is neither well-known nor easily understood. While the Lymphoma Association does a lot of work to raise awareness of lymphoma and its signs and symptoms, we believe that as an important cancer grouping it would massively benefit from a Government-backed awareness campaign such as NHS England's Be Clear on Cancer campaign.

This campaign has proved successful for other forms of cancer, mainly the more common ones. This type of awareness-raising could very well help increase understanding among the general public as well as encourage some people to visit their GP about symptoms they may be experiencing but that they might be attributing to other conditions such as the menopause or flu.

3.3 Finding out what was wrong with you

This section of the questionnaire asked respondents about what happened to them during the course of their diagnosis. For example, it asked them questions on information they were given; whether they were told they could bring someone with them; and, how they were told.

3.3.1 Respondents who were told about their particular type of cancer

11% of respondents were told they had Hodgkin lymphoma, 59% were told they had non-Hodgkin lymphoma.

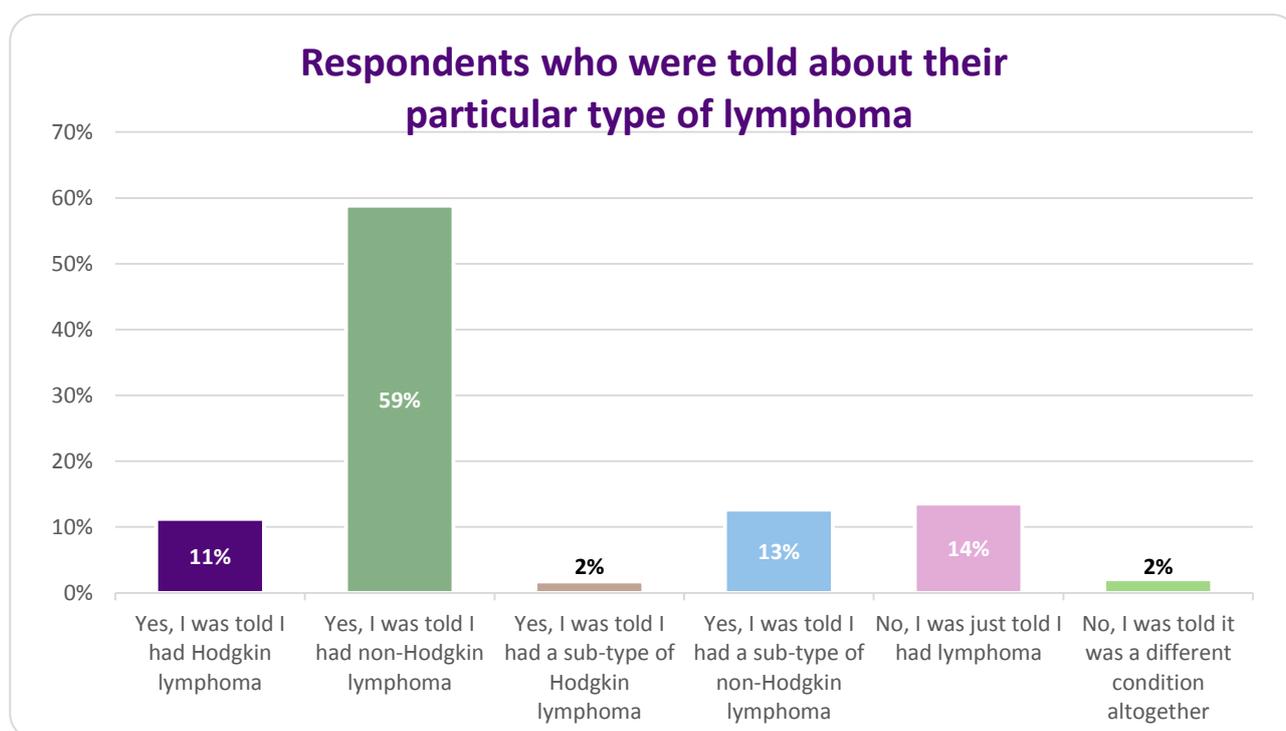


Fig 7. Respondents who were told about their particular type of lymphoma

With over 60 different forms of lymphoma, we know how important it is for people to understand which subtype they have, both in terms of their diagnosis, treatment and prognosis, but also for accessing the right information and support. Not only is it important to know the general lymphoma category, either Hodgkin or non-Hodgkin, it is also vital that people understand their subtype. This is especially important for non-Hodgkin lymphoma where there are many, many different subtypes, both aggressive and indolent, with varying presentations, treatment plans and prognoses.

Within the responses, it was shocking to see that 14% of people were told simply that they had lymphoma, with presumably no more specific information, along with a minority (2%) who were presumably misdiagnosed. Similarly, only 13% of respondents reported that they were told their subtype of non-Hodgkin lymphoma – less than one-quarter of those were diagnosed with non-Hodgkin lymphoma.

For Hodgkin lymphoma, it was the same story with less than one-fifth of those told they had Hodgkin lymphoma then being told their particular subtype. However, this may be more understandable, given the preponderance of classical Hodgkin lymphoma (albeit with its own subtypes) diagnoses in the overall Hodgkin category.

Overall there may be several explanations from the straightforward to the more complex. On one level, clinicians may simply not be telling people their subtype because they don't believe it's

important or that it's of limited value or relevance, or that it over-complicates matters in what is a complex disease and at a difficult time. Conversely, patients may have been told and may not have heard, remembered or taken in the information at the point of diagnosis. Indeed, 3% of responses said that they "don't know/can't remember".

Furthermore, when we analysed this data by ICD10 code (thus providing more detail on lymphoma subtype), the results revealed that some respondents indicated they received a diagnosis that was at odds with the ICD10 code recorded for them. For example:

- 5% of people recorded as having follicular lymphoma, a subtype of NHL, responded that they were told they had Hodgkin lymphoma
- 4% of people recorded as having diffuse large B-cell lymphoma, a subtype of NHL, responded that they were told they had Hodgkin lymphoma
- 6% of people recorded as having Hodgkin lymphoma responded that they were told they had non-Hodgkin lymphoma.

These conflicting results could indicate that certain responses misinterpreted the survey question, or made an error in completing the survey, or misunderstood their diagnosis, or that they were, in fact, misdiagnosed.

While we can only report the survey results, the proportion of respondents answering in this way is significant enough to suggest not just errors in completing the survey, but a degree of misdiagnosis. This strengthens our calls for a better understanding of lymphoma subtype and improvements to diagnosis and diagnostic procedures.

In particular, the variation in responses taps into issues of specialised integrated diagnostic services (and the ability of doctors and hospitals to access such reports) in making an accurate diagnosis by subtype. Similarly, the issues around national data collection by lymphoma subtype are well-known and this too may play a role. Diagnostics and data are complex issues and beyond the remit of this report, however, for further information and a general overview, see the Lymphoma Association's briefing *Understanding lymphoma: the importance of patient data* (September 2016; available at www.lymphomas.org.uk/about-us/campaigning/campaigning-for-you/briefings-and-consultations).

During our 2016 Lymphatic Cancer Awareness Week, we campaigned on the importance of knowing your subtype and developed a simple but effective tool to help clinicians and patients record information on lymphoma subtype – our "What's My Type" card on which an individual subtype can be recorded for ease of reference.

"I do not know what my prognosis is. I have a disease which I understand is incurable. When I ask, I am told people with your illness can live a good time."

"Months later I still don't know if I have Hodgkin's or non-Hodgkin's! I feel that families should be offered instant support ASAP as it's more traumatic for them. I feel that they get pushed to one side a little."

3.3.2 Respondents' understanding that lymphoma is a type of cancer

Two-thirds of respondents (66%) were aware that lymphoma was a type of cancer when they were first given their diagnosis; 18% weren't sure that lymphoma was cancer but they thought it might be; 16% did not know that lymphoma was a type of cancer at all.

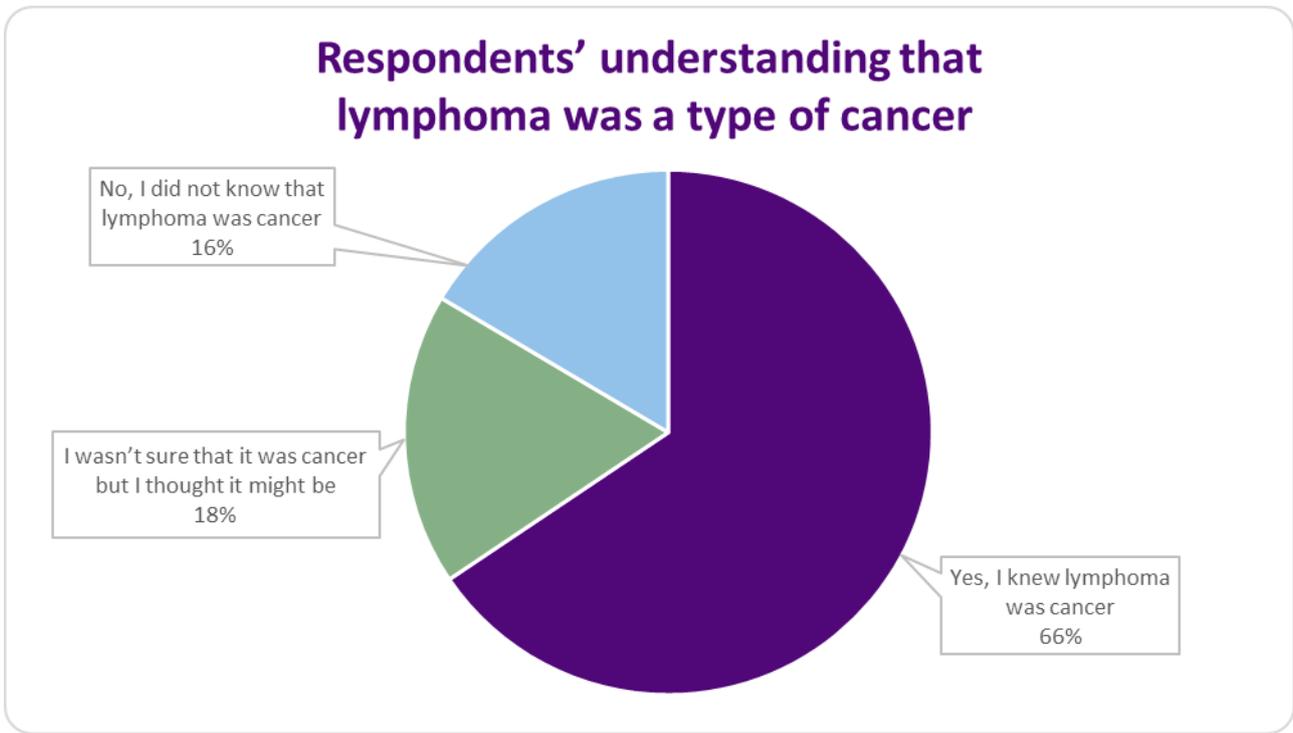


Fig 8. Respondents' understanding that lymphoma was a type of cancer

Although on the face of it the responses to this question show a relatively high awareness of lymphoma as a cancer, there is some conflict or tension with the answers to an earlier question highlighted in section 3.2.5. In that question, 34% said they hadn't heard of lymphoma at all. In the question here, there is a suggestion here that about 84% of people were aware of lymphoma. This may be down to poor framing of the survey questions or the structure of the survey. However, if there is some confusion around understanding lymphoma, this may further highlight the limited awareness of this form of cancer.

3.3.3 Understanding the explanation of what was wrong

When asked if they understood the explanation they were given of what lymphoma is, more than a half of respondents (54%) said they completely understood the explanation. 4% did not understand the explanation, with the remaining understanding some of the explanation given.

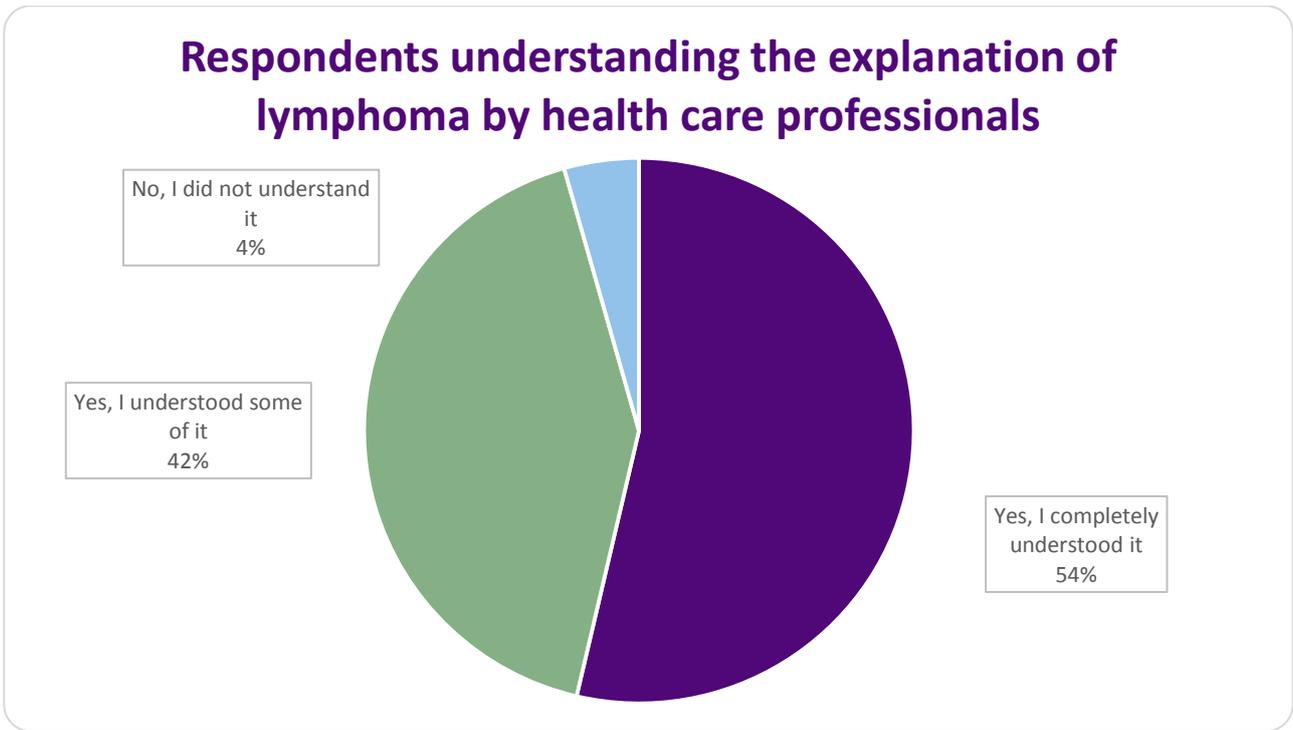


Fig 9. Respondents' understanding the explanation of lymphoma by healthcare professionals

This chimes with the CPES 2015 survey in which only 59% of haematology patients said they completely understood the explanation of what was wrong with them, compared to 73% of all cancer patients. It is clear that for lymphoma, and blood cancers in general, the need for additional information, advice and support is significant in order for patients to understand their individual diagnosis.

3.3.4 Accompanying person at diagnosis

We asked who accompanied the respondent to their diagnosis meeting. More than a half (55%) of respondents attended their diagnosis meeting with their spouse or partner, 27% were on their own, which is a worryingly high level. Given the impact of a cancer diagnosis, particularly a hard-to-understand, relatively unknown one, then the importance of being accompanied cannot be underestimated. Looked at from an age perspective, worryingly, the survey responses showed that the chances of someone being unaccompanied at the time of diagnosis increased as they got older. This highlights the need for further support for older people, who may be more vulnerable than younger age groups.

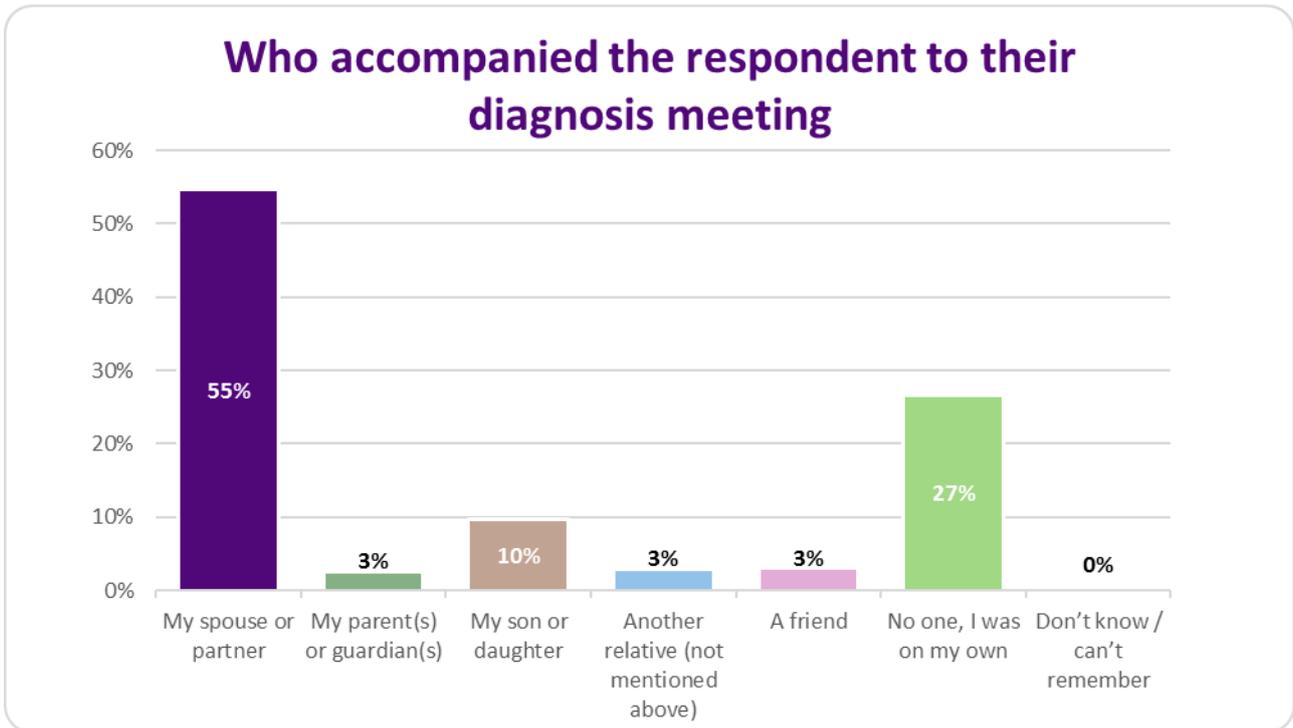


Fig 10. Who accompanied the respondent to their diagnosis meeting?

3.3.5 Types of written information given

We then asked respondents whether they were given written information and, if so, what this information was. The following chart shows the range of different information which was offered. 9% of respondents were not offered or did not need any written information.

While a good range of information is available, with information from the diagnosing hospital, Macmillan and the Lymphoma Association being the three most common sources by far, it is surely worth asking whether the right information is being provided to patients and supporters at the right time. Similarly, what are the levels of duplication between what the hospital is offering, the more generalist information provided by Macmillan and the specialist information provided by the Lymphoma Association? Could valuable NHS resources be saved by building stronger relationships with professional information and support providers such as the Lymphoma Association? While we distribute our information to all the hospitals treating lymphoma in the UK, it was disappointing to learn that only 25% of people received it at the point of diagnosis in the hospital.

When analysed by subtype, it was clear that respondents with Hodgkin lymphoma were more likely to be given information from the Lymphoma Association (35% against an average of 25%) and Macmillan (53% against an average of 45%) than people with other forms of lymphoma. The hospital's own information tended to be uniformly distributed across all subtypes. This suggests that, for whatever reason, the generally younger Hodgkin lymphoma patients are targeted differently to older, non-Hodgkin lymphoma patients, as far as their information needs are concerned.

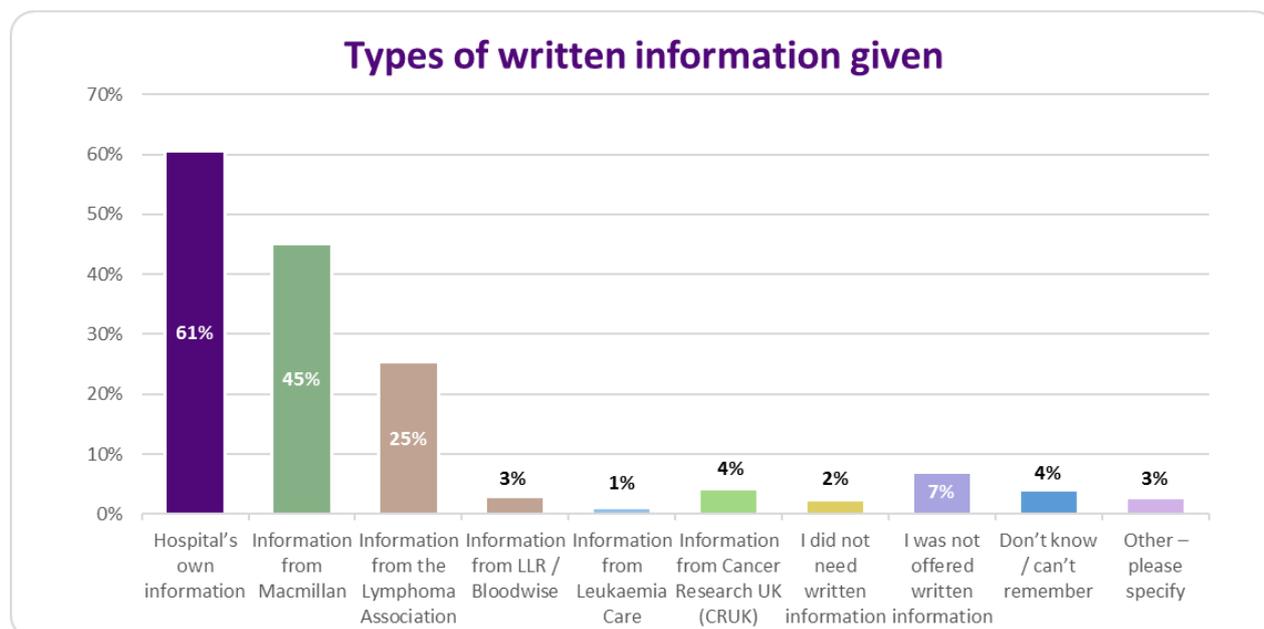


Fig 11. Types of written information given

3.3.6 Understanding the information given

Nearly two-thirds of respondents said that they were given written information that they could completely understand, however, well over one-third (40%) were not able to understand either some or most of it.

When analysed by lymphoma subtype, it was clear that those with Hodgkin lymphoma said they had a better understanding of the information they received than those with non-Hodgkin lymphoma (68% versus an overall average of 60% found the information easy-to-understand). As we know from the earlier responses in the survey that those with Hodgkin lymphoma had a higher chance of receiving more information from other sources, including the Lymphoma Association and Macmillan, it may be that more information aids understanding, or that the additional information was easier to understand, or both.

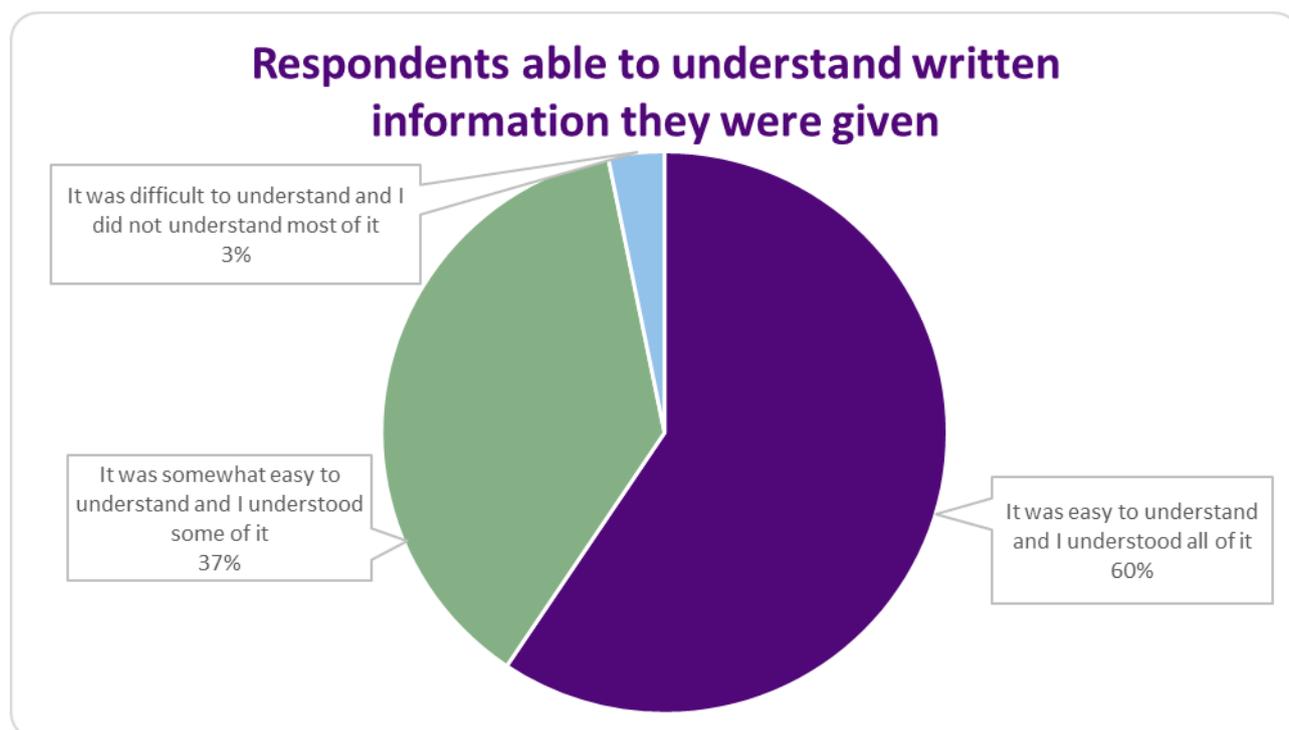


Fig 12. Respondents able to understand written information they were given

It is reassuring that the majority of patients who receive written information found it easy-to-understand. However, the number of people not able to understand some, or all of it, is still far too high and suggests that further work needs to be done to ensure organisations are producing accessible, high-quality information. This is something on which the Lymphoma Association is actively working on, with our information increasingly available in different formats and media, and written with different levels of understanding in mind (e.g., see our *All About Lymphoma (EasyRead version)* (first published 2015)).

“The main thing I found difficult was accessing more detailed information on: - My cancer, my drugs, treatment regime, everything is at very high level and that is understood and expected to support a wide audience. However, often it is good to be able to investigate more on the history, experience and wider medical knowledge of a disease; its causes, occurrence and treatment options. It would be nice to provide access or sign posts to this level of information.”

3.3.7 Other sources of information

Respondents were asked if they were told about additional sources of information. There was a range of responses, but being told to contact the hospital (40% of respondents) was the most common response. However, one in five (20%) were not told how to find additional information. 14% of respondents were told to contact the Lymphoma Association. 28% were told to contact Macmillan.

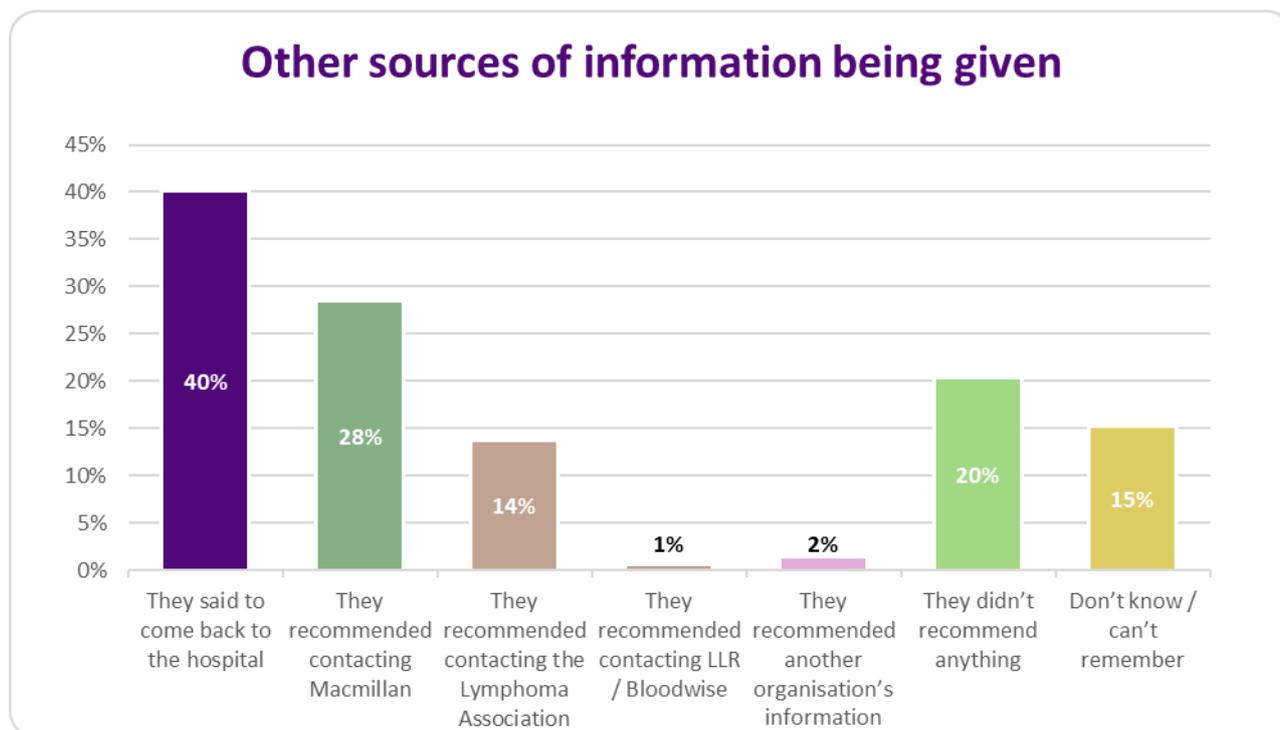


Fig 13. Other sources of information being given

Given the high proportion of people not fully understanding lymphoma in general or the explanation provided to them about their diagnosis, we would like to see haematology services within hospitals provide or direct patients to access a specialist information and support service, such as that provided by the Lymphoma Association, to help people understand and cope with their diagnosis. This could involve being linked with a trained buddy or befriender or advocate, who could help explain lymphoma in terms that patients can understand, and at a time when they are better able to absorb the information (e.g., in a non-hospital setting).

"I think counselling should be offered as soon possible after diagnosis. There should generally be more psychological support, before, during and after treatment. I was given many booklets from the hospital. When you are in shock the last thing you can do is think practically and fill out forms. There needs to be more attention paid to each individual who is going through this awful trauma. I felt I needed the most support after I had finished treatment. This is when you are left to fend for yourself and you try to process what's happened to you. More emotional support please NHS!"

3.3.8 Using the internet to find further information

Under half of respondents (46%) used the internet to find further information about their diagnosis. Yet, only 16% of respondents were told to only look at trusted websites for online information, with three-quarters of people (75%) saying that their healthcare professions said nothing about using the internet. This is disappointing. Of course, in general terms, information on the internet has to be treated with caution, and healthcare professionals may well have justifiable concerns about what people might find and read, and how this might lead to further anxiety and misunderstanding. However, the internet is also an invaluable resource of high quality, accessible, reliable information and support. Rather than ignoring the reality of modern life, would it not be better for hospitals to make clear recommendations about trusted websites and information sources, which can lead to a much more positive patient experience for people with lymphoma.

When looked at by subtype, it was clear that stronger recommendations to look at trusted websites were made to respondents with Hodgkin lymphoma compared to those with non-Hodgkin lymphoma (25% versus 15% for subtypes such as follicular and diffuse large B-cell).

When respondents were then asked if they went on to use the internet to find further information, just under half (46%) said that they did, but there was a marked difference between those with Hodgkin lymphoma and those with non-Hodgkin lymphoma. For the former group, 61% reported using the internet, but for other subtypes, the rates were much lower, eg, 47% for follicular lymphoma respondents and 42% for subtypes such as diffuse large B-cell, mantle cell and Burkitt's. While it may be tempting to ascribe this to an age-related reason, given the younger demographic of those with Hodgkin lymphoma, we know that the internet and digital information sources are used strongly across most, if not all, age groups. It's unlikely that the large differences are solely due to age, but may also be influenced by the recommendations of healthcare professionals. If we assume that some people don't use or won't benefit from information on the internet, then some of those people will live up to those assumptions or prejudices.

For those who did use the internet to search for further information, 25% said that they found the Lymphoma Association's the most useful, with 23% and 20% saying the same for Macmillan's and Cancer Research UK's websites, respectively. 16% said the NHS's was the most useful. The full range of responses is provided in Figure 14 over the page. The responses to this question provide further evidence – were it needed – for people affected by lymphoma to be actively directed towards the resources of the Lymphoma Association, Macmillan and Cancer Research UK, both online and offline. When looked at by subtype, we were interested to learn that those with Hodgkin lymphoma and follicular lymphoma found the Lymphoma Association's website much more useful than those people with other subtypes. This was also reflected in respondents' usage of Macmillan's website.

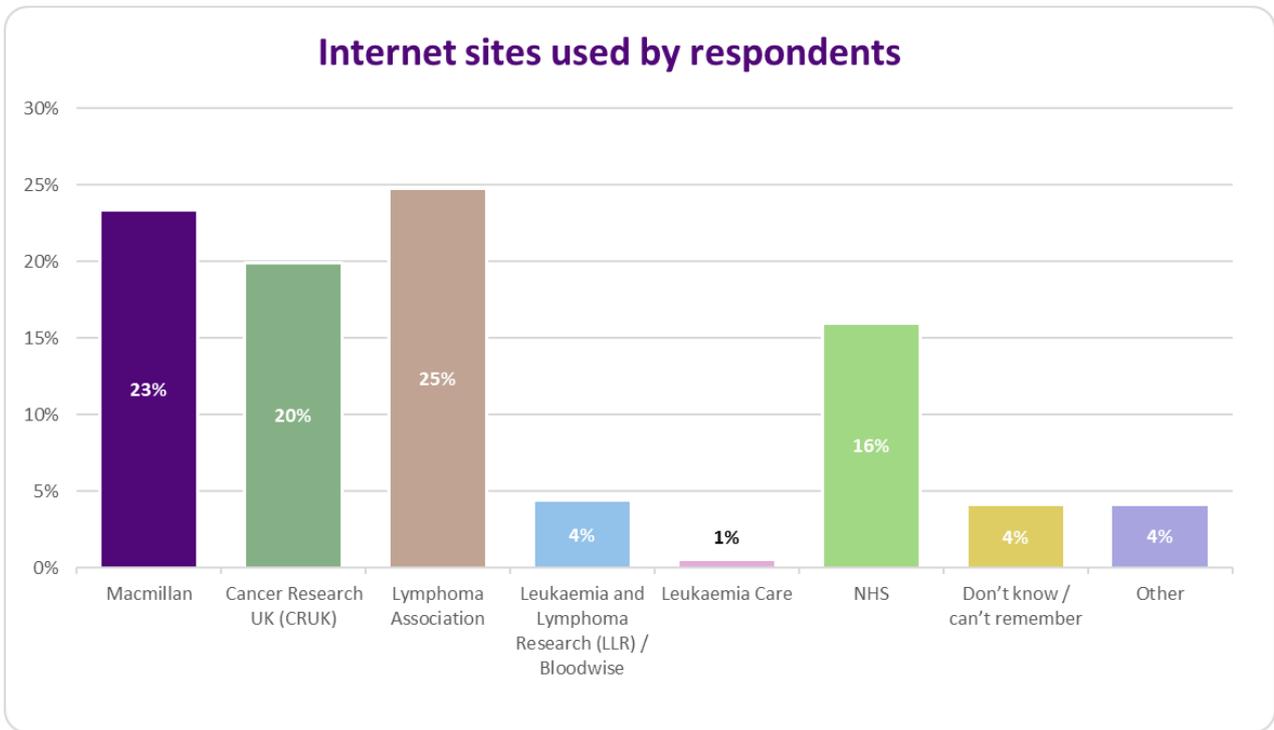


Fig 14. Most useful internet sites

3.4 Treatment and care

In this section we asked respondents about their treatment and care, including: the contact they had with a clinical nurse specialist/key worker; whether they felt involved in decisions about their treatment and care; and what their overall experience of treatment and care was.

3.4.1 Treatment v “watch and wait”

One key area – among many – where lymphoma differs from the mainstream approach to cancer diagnosis is the fact that for indolent (or low grade, slow-growing) subtypes, such as follicular, marginal zone, Waldenström’s Macroglobulinaemia and chronic lymphocytic leukaemia, the initial treatment might be no treatment in the form of “watch and wait” or “active monitoring”. Colloquially known as “watch and worry” by many people with lymphoma, this can be an incredibly difficult phase, as it makes it hard to carry on with “life as normal”. In our survey, we asked whether respondents were told they would start treatment immediately or be put on a “watch and wait” scheme. The vast majority of respondents (80%) were told they would start treatment immediately, with one-fifth (20%) being told they would be put on a “watch and wait” scheme.

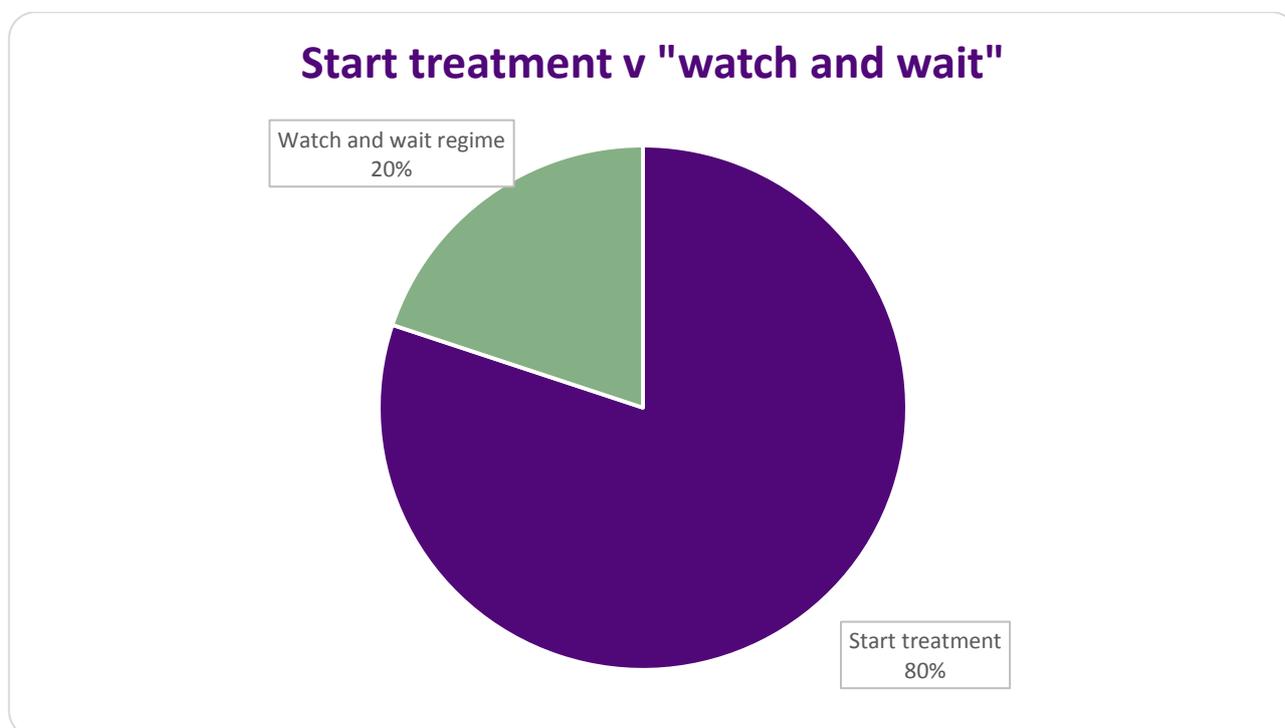


Fig 15. Start treatment v “watch and wait”

3.4.2 “Watch and wait”

Of those who were placed on “watch and wait”, the vast majority (91%) understood the reasons for this. Just 9% of those placed on ‘watch and wait’ did not understand the reasons. Although a positive response, we were surprised that the number of people not understanding the reasons was so low, as we are contacted a lot as a charity about concerns over (including the reasons for) “watch and wait”.

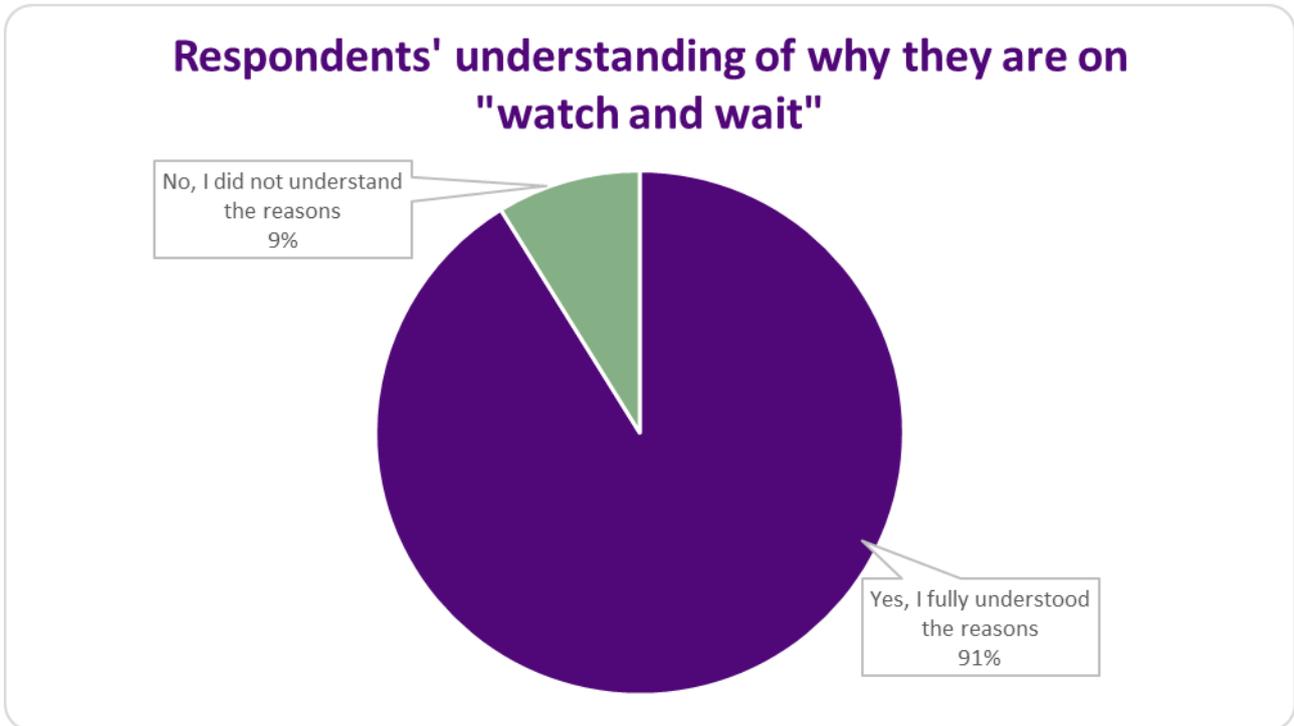


Fig 16. Respondents' understanding of why they are on “watch and wait”

“When I was diagnosed we had a lot of information. Now with the wait and see it would be handy to talk to people in the same position. As to what to expect and how other people cope with their situations. Like a group.”

“Is ‘watch and wait’ ‘treatment’, not sure really.”

3.4.3 Concerns around “watch and wait”

47% of respondents did not have any concerns or worries about being placed on “watch and wait”. However, the majority (53%) had at least some worries, with some being very concerned.

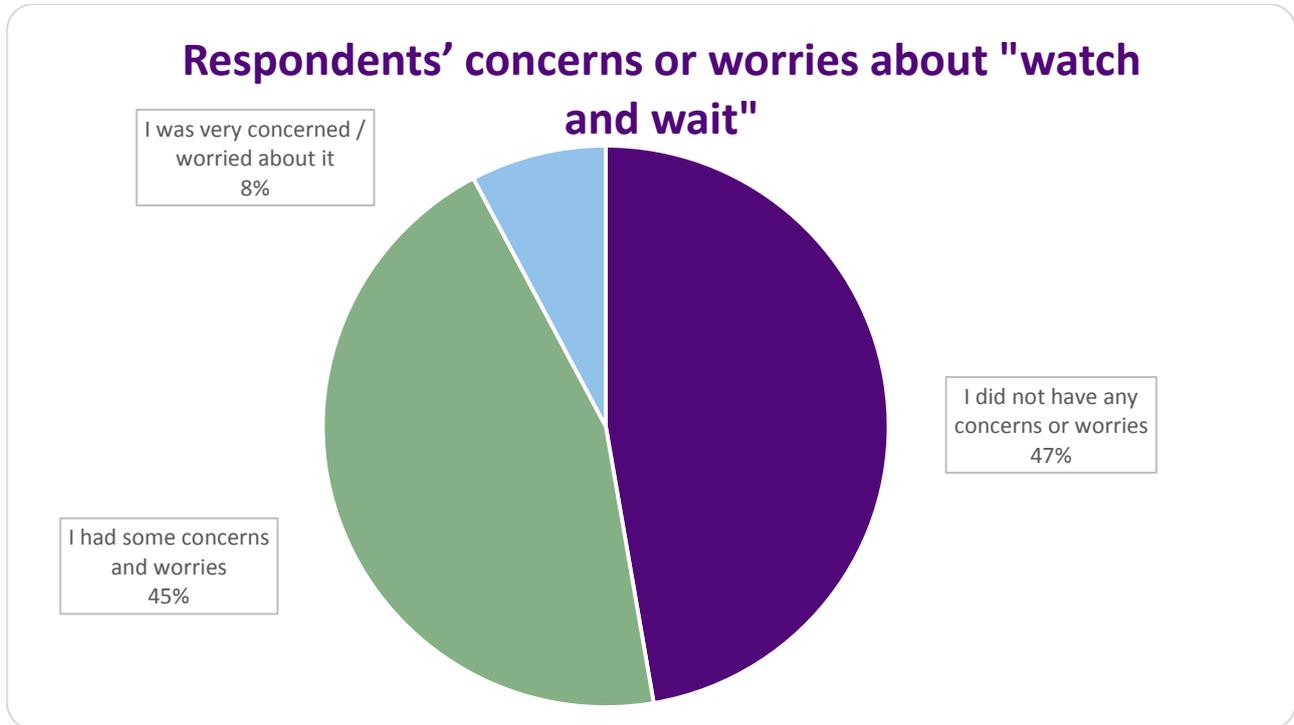


Fig 17. Respondents' concerns or worries about “watch and wait”

We hear first-hand from patients living with lymphoma on a “watch and wait” basis. For many of these people living with a long-term, indolent cancer can cause distress and create a need for psychological support. It’s hard to get on with your life, when you know you have cancer and need chemotherapy at some point in the future – but not know when.

“When I was told that I would be put on watch and wait I was very worried because I thought the earlier you found the cancer the better chance you had of survival.”

3.4.4 Written information on “watch and wait”

54% of respondents were given written information about “watch and wait” that was easy-to-understand. 41% were not given written information at all.

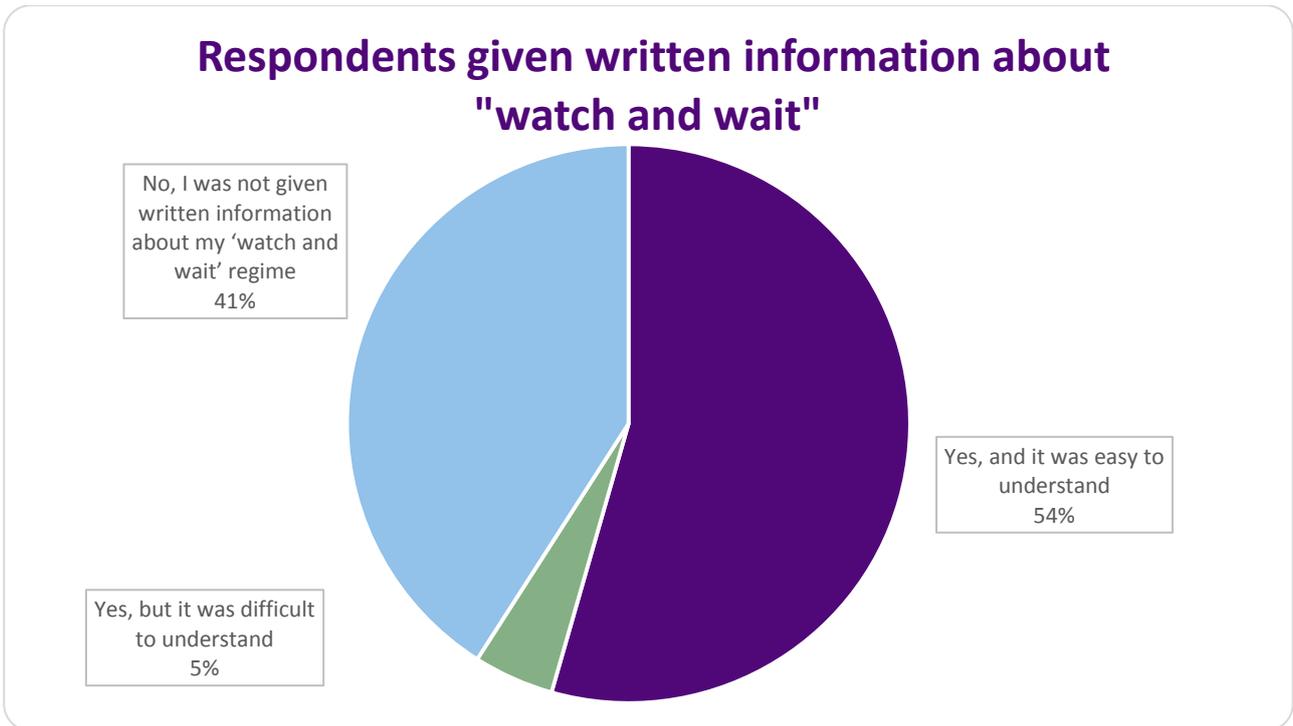


Fig 18. Respondents given written information about “watch and wait”

This echoes the points made above that the indolent, chronic nature of some forms of non-Hodgkin lymphoma can lead to greater anxiety and uncertainty among patients who then need to be able to access tailored information to cope with their disease. It was disappointing that so many people were not given information on “watch and wait”, given that the majority of people had some concerns or were very concerned (see previous section).

3.4.4 Length of time from diagnosis to start of treatment

We then asked respondents how long it was from their diagnosis to them starting treatment. Almost a quarter (24%) started treatment within a week – with 5% starting it the same day they received their diagnosis.

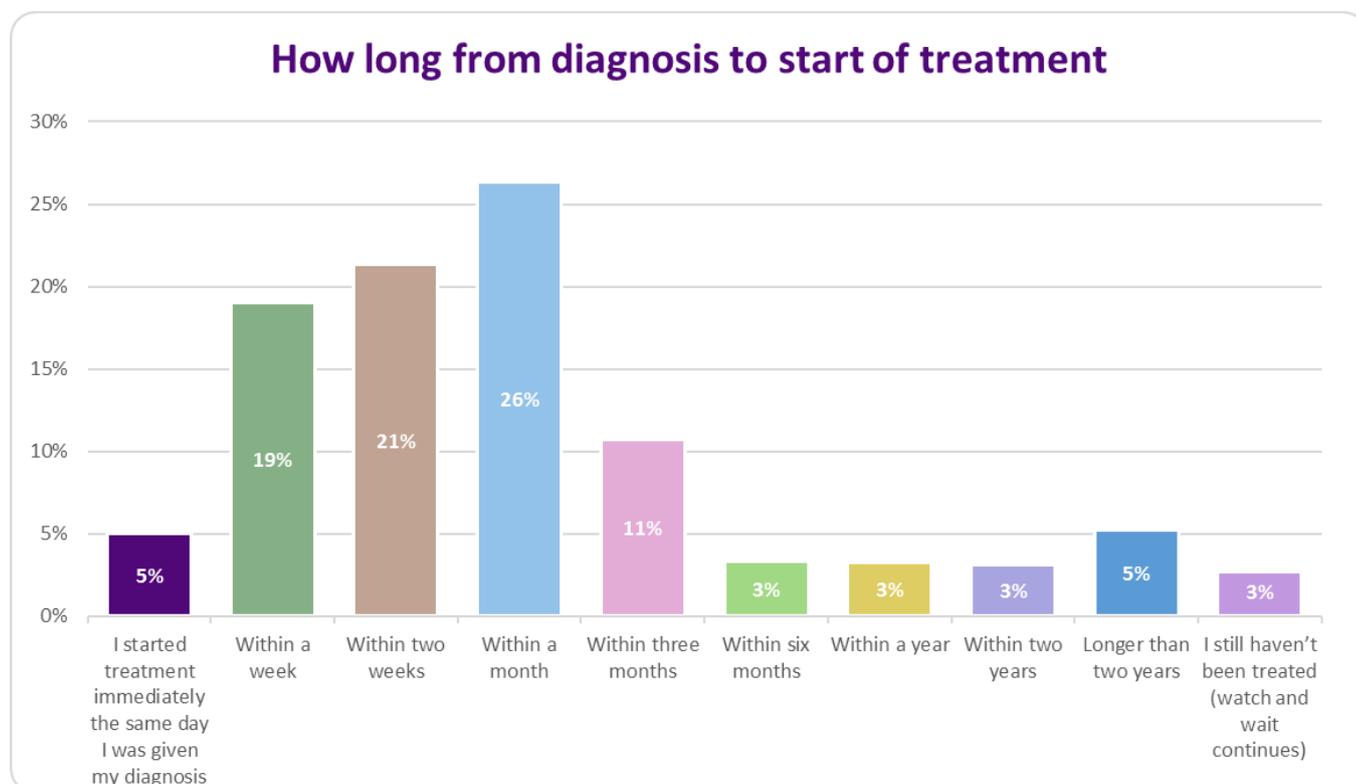


Fig 19. How long from diagnosis to start of treatment

These figures clearly illustrate the varying nature of different forms of lymphoma. For the vast majority (71%), treatment will start within a month – in fact sooner for many; nearly half the respondents (45%) were being 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. The “long tail” of responses who were treated from three months onwards in Figure 19 is accounted for by the 20% who were placed on a “watch and wait” regime, although there is likely to be a small group of patients – perhaps close to 10% or so who were first treated somewhere between one and three months after diagnosis. It’s not clear why this group of patients were not treated sooner, and it may indicate some delay or difficulty in those people accessing treatment services, either due to process delay within the NHS or possibly co-morbidities affecting treatment decisions.

When analysed by lymphoma subtype, it was clear to see that Hodgkin lymphoma patients were treated much more quickly than other subtypes, with virtually all (99%) of the respondents with Hodgkin lymphoma starting treatment within three months. For the other ICD10 categories, the corresponding figures were as follows:

- C82 (follicular lymphoma) 74%
- C83 (small cell B-cell, mantle cell, diffuse large B-cell, lymphoblastic (diffuse) and Burkitt lymphomas) 88%
- C85 (B-cell lymphoma unspecified, mediastinal (thymic) large B-cell lymphoma, other specified types of non-Hodgkin lymphoma and non-Hodgkin lymphoma unspecified) 79%

Given the nature of most forms of Hodgkin lymphoma you would expect treatment to start quickly, which would not be the case for indolent or low grade forms of non-Hodgkin lymphoma.

3.4.5 Clinical trials

Only a quarter of respondents (23%) were given the option of participating in a clinical trial, which is disappointing given the wide range of lymphoma clinical trials that are taking place in the UK, and which potentially offer access to new and innovative treatments or regimes that are not otherwise available on the NHS in the UK. Furthermore, it is well-known that recruitment to lymphoma trials and other haematological malignancies is at lower levels than other disease areas. Of those who were offered the opportunity to join a trial, two-thirds (66%) went on to join a trial, demonstrating just how important it is for clinicians to discuss the subject of clinical trials with their patients.

From an age perspective, perhaps not unsurprisingly younger people in the 16 to 24 years old age range had a better chance of being offered a trial (32%). More surprisingly, however, only 14% of people in the 35 to 44 age bracket were offered a trial. When analysed by lymphoma subtype, no great difference was seen.

Overall, 77% of respondents were not given the option of participating in a trial.

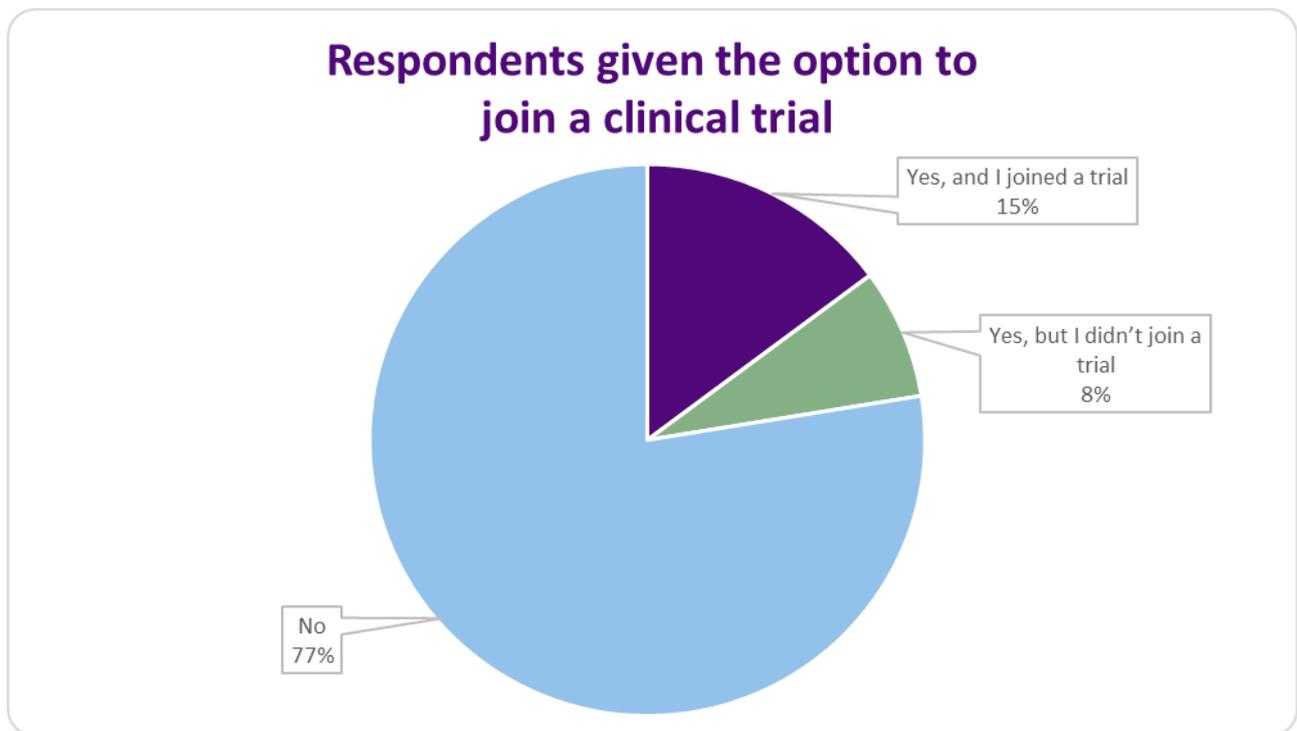


Fig 20. Clinical trials

From the geographical analysis (by Strategic Clinical Network) of the data, it was clear to see that some areas performed much better than others. For instance, East Midlands, London and the South West had higher levels of responses than average, with 26% or 27% of patients being offered access to a trial, and with Wessex achieving more than one-third (35%). At the other end of the scale, Cheshire and Mersey (16%), Greater Manchester, Lancashire & South Cumbria (16%), Northern (14%), West Midlands (15%) all offered lower access than the norm. The reasons for this disparity are not immediately clear, but the differences deserve further scrutiny.

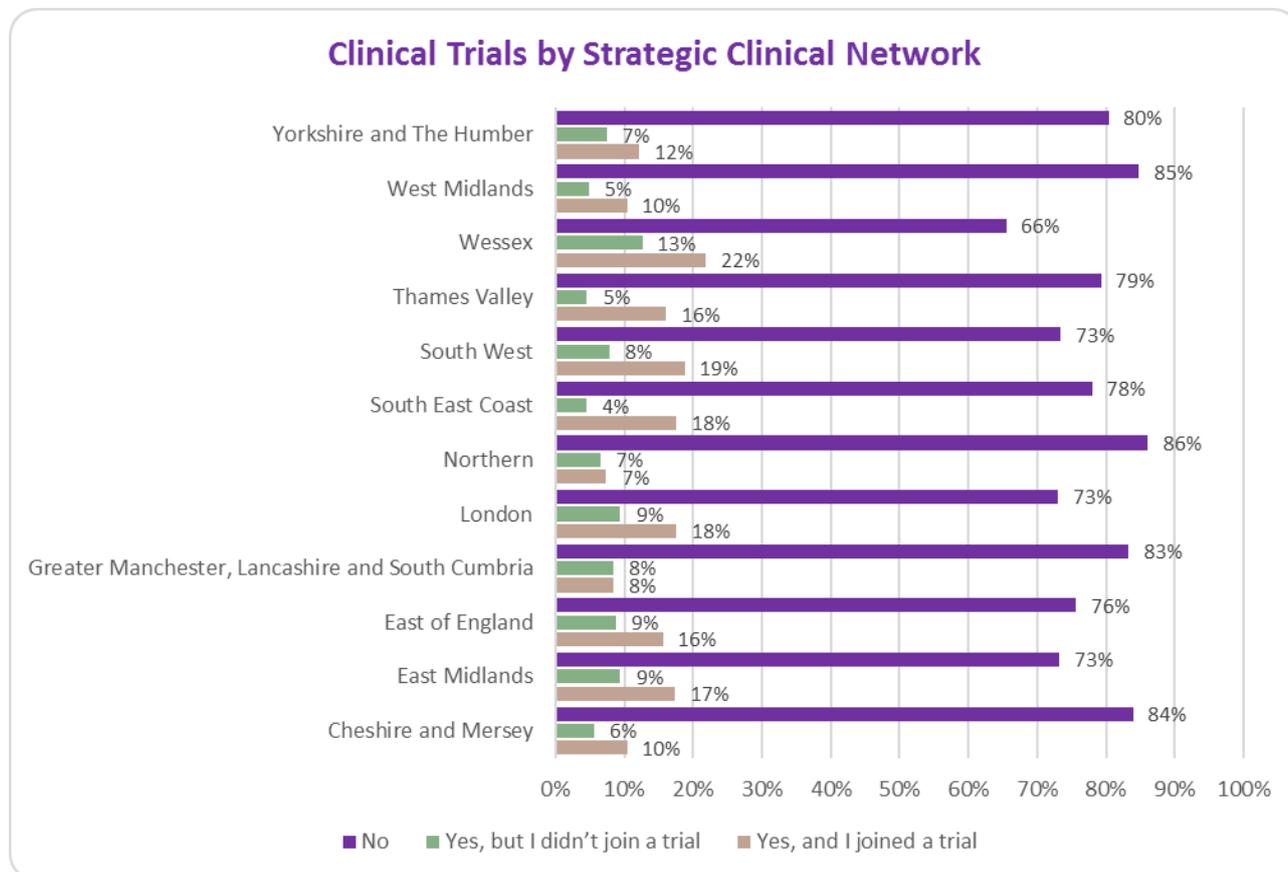


Fig 21. Clinical trial by Strategic Clinical Network

There is a need to do much better in promoting increased access to clinical trials. After all, trials are a fundamental part of the process for developing new drugs and treatments, and testing new regimes, so that the best treatments and therapies can be made available to all patients. We also know that there is no formal or coordinated approach to recruit patients to lymphoma trials and, as mentioned above, there is an acknowledged shortage of trial participants. Furthermore, in the past there has not been a dedicated resource that provides clear, accessible plain English information to patients and potential trial participants about lymphoma trials. Because of this, in September 2016 the Lymphoma Association launched [Lymphoma TrialsLink](http://www.lymphomas.org.uk), an online tool providing easy-to-understand, up-to-date information about clinical trials into treatments for lymphoma, searchable by subtype or location, and other filters. Visit the Lymphoma Association website (www.lymphomas.org.uk) for more information and for access to Lymphoma TrialsLink.

For those who chose not to join a trial having been offered the opportunity, a range of reasons were offered. A minority of respondents (ranging from 4% to 14%) cited reasons such as:

- They didn't have time to take part.
- The trial was too invasive.
- It did not fit with my day-to-day activities.

- Concerned about being given a placebo.
- Worried about side effects.
- The location of the trial was too far away.

The only other reason given by 19% of respondents was that they were rejected for the trial.

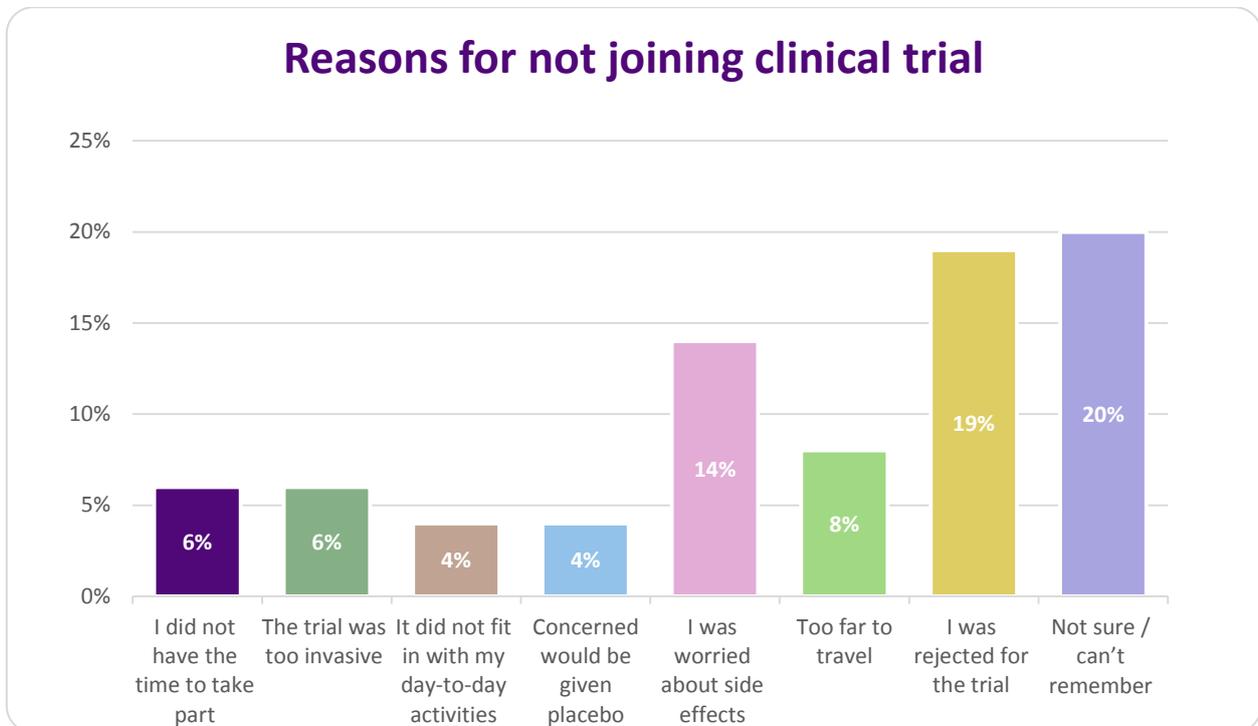


Fig 22. Reasons for not joining clinical trial

“I have a rare type of non-Hodgkin lymphoma (Waldenström’s Macroglobulinemia - WM). My consultant happened to be an expert on WM, and she put me on a clinical trial. Both the clinical and chemotherapy staff were wonderful, and the outcome has been very successful.”

“I would have liked to have been asked to go on clinical trials.”

“I would like to see more clinical trials and would hope that we could catch other countries up with the treatment we receive.”

3.5 Support for people with lymphoma

This section asked respondents about support for people with lymphoma, including: what support they had received and when; whether the support they received helped them; and how they rated the support they received.

3.5.1 Information on support for people with lymphoma

We asked respondents when they had been given information about support for people with lymphoma. Just under half (48%) received information at the point of diagnosis, but the evidence shows that information provision starts to wane as treatment progresses: 37% of people were given information during treatment. Just 1% said they were not given any information until after treatment.

When asked about whether they had been told about support that was available, over a third of the respondents said they had been told about their hospital's own services (36%) and about Macmillan (39%), while only 14% were told about the Lymphoma Association. The full range of responses is given in the table below.

When we analysed this data by lymphoma subtype, it was clear that respondents with Hodgkin lymphoma (who were generally younger) tended to be told much more about other support being available (whether the hospital's own support services or those of another provider).

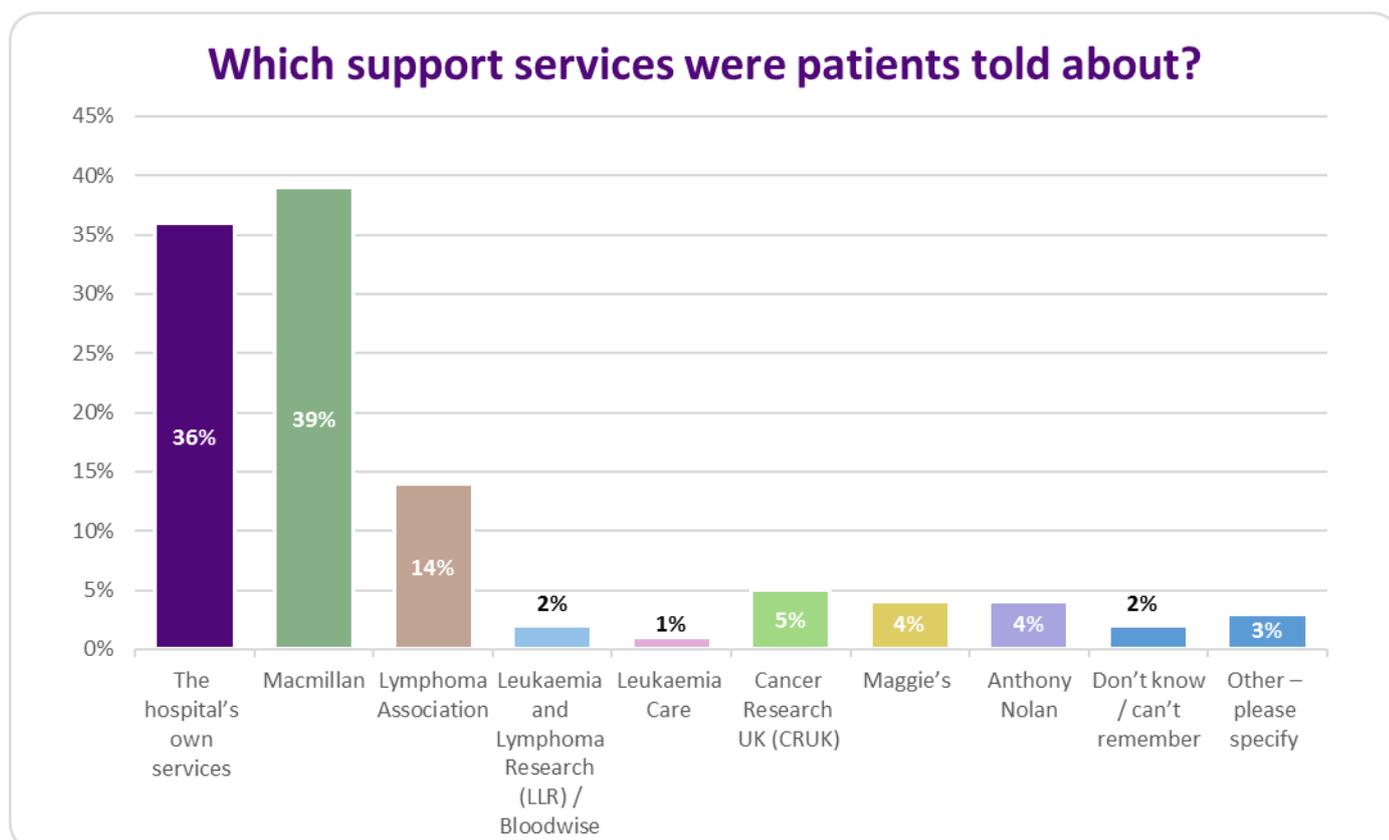


Fig 23. Which support services were patients told about?

3.5.2 Quality of information given about support services

We asked respondents to rate the quality of the information they were given about available support services. The vast majority (85%) rated the quality of that information as excellent or very good.

This clearly demonstrates that where patients are being given information on available support, then it is seen as of a good quality which better supports the patient through their journey.

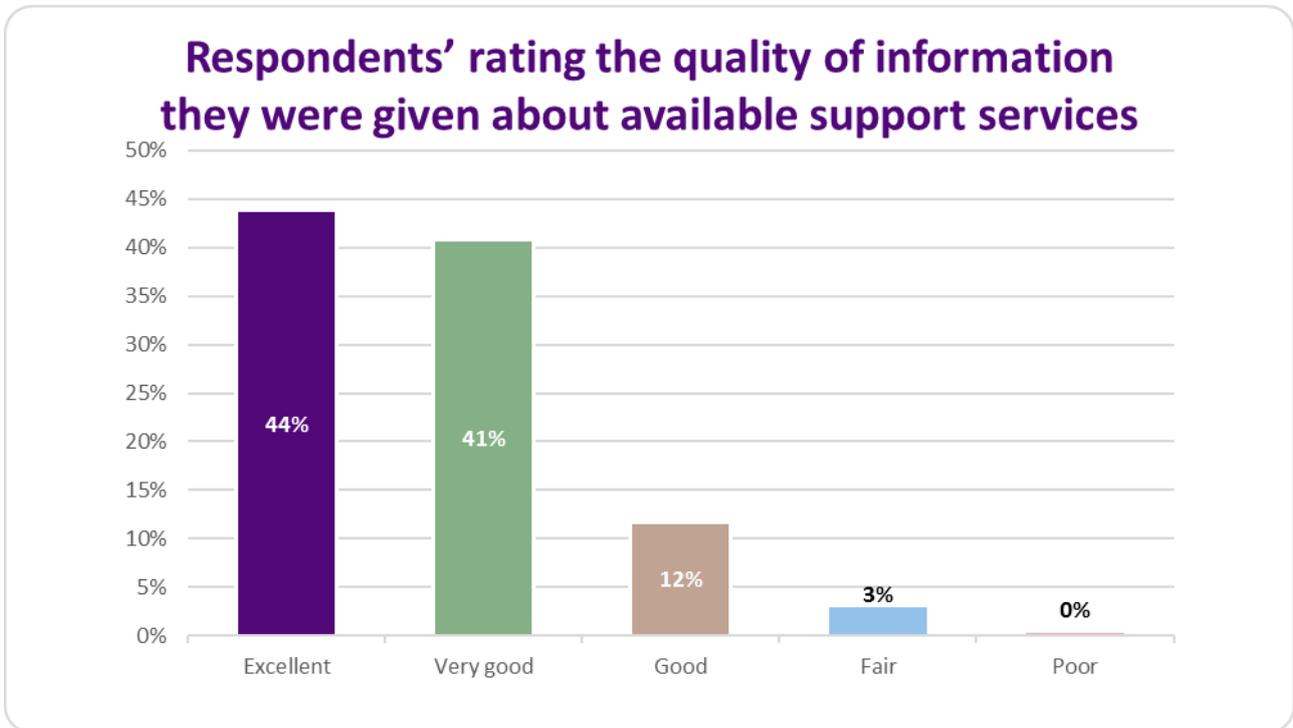


Fig 24. Respondents' rating of the quality of information they were given about available support services

3.5.3 Information on self-help groups for people with lymphoma

The majority of respondents (79%) were given information about self-help groups for people with lymphoma. However, more than a fifth (21%) did not get this information and would have liked to receive it. The Lymphoma Association, as well as other charities and patient organisations, provide these sorts of services, so it's disappointing that so many people aren't given the opportunity to access peer support. Figure 25 illustrates this.

Information on self-help groups for patients with lymphoma

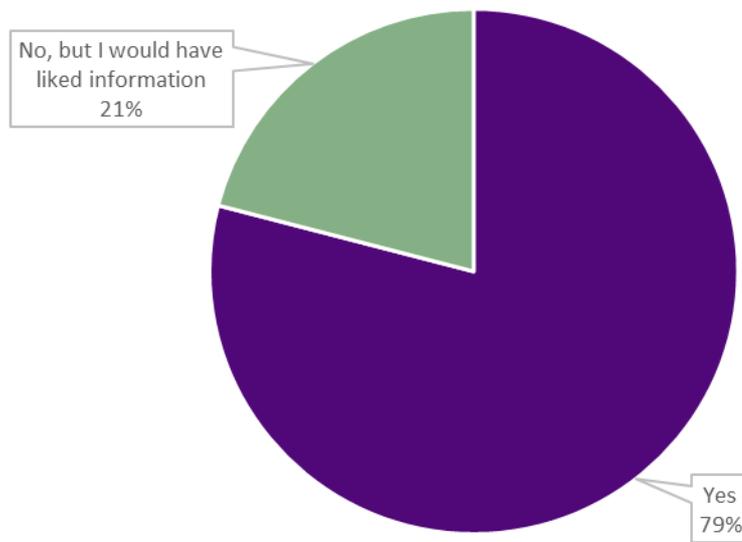


Fig 25. Information on self-help groups for patients with lymphoma

“Overall the consultations and treatment have been excellent, although there is always too little time in the consultation. The experience before and after diagnosis was harrowing and too little emphasis is placed on the psychological impact of cancer. I sought out most of the information myself during watch and wait, although the Lymphoma Association website and meetings have been very helpful.”

“I would have liked to have had a local group to join, just to talk about lymphoma experiences, treatment, feelings, effects on my own and family members’ attitude etc. etc. I never felt ill enough for groups on offer locally (I was lucky, as I felt mostly well throughout treatment). I was referred for counselling at one stage, during treatment, as I felt very down and tearful. The counsellor offered meditation and although I did try a session, decided it was not for me. There was no follow up appointment.”

3.5.4 Additional sources of support

We asked whether respondents had been made aware about sources of additional support such as counselling/psychotherapy. The graph below (Fig. 26) shows the different additional support that they were offered. Almost two-thirds of respondents (62%) were not offered any form of additional support, which is incredibly disappointing given the range of support that is available from other organisations, including the Lymphoma Association.

When analysed from an age perspective however, it was clear to see that younger patients were more likely to be offered additional support such as counselling or psychotherapy. Nearly half (47%) of 25 to 34-year-olds were offered such support compared to an overall average of 17% - a marked difference. Older patients were less likely to be offered any form of additional support, with 68% of 75 to 84-year-olds and 78% of those aged over 85 not being offered any additional support. It's hard to see what could justify this unacceptable discrimination towards older people.

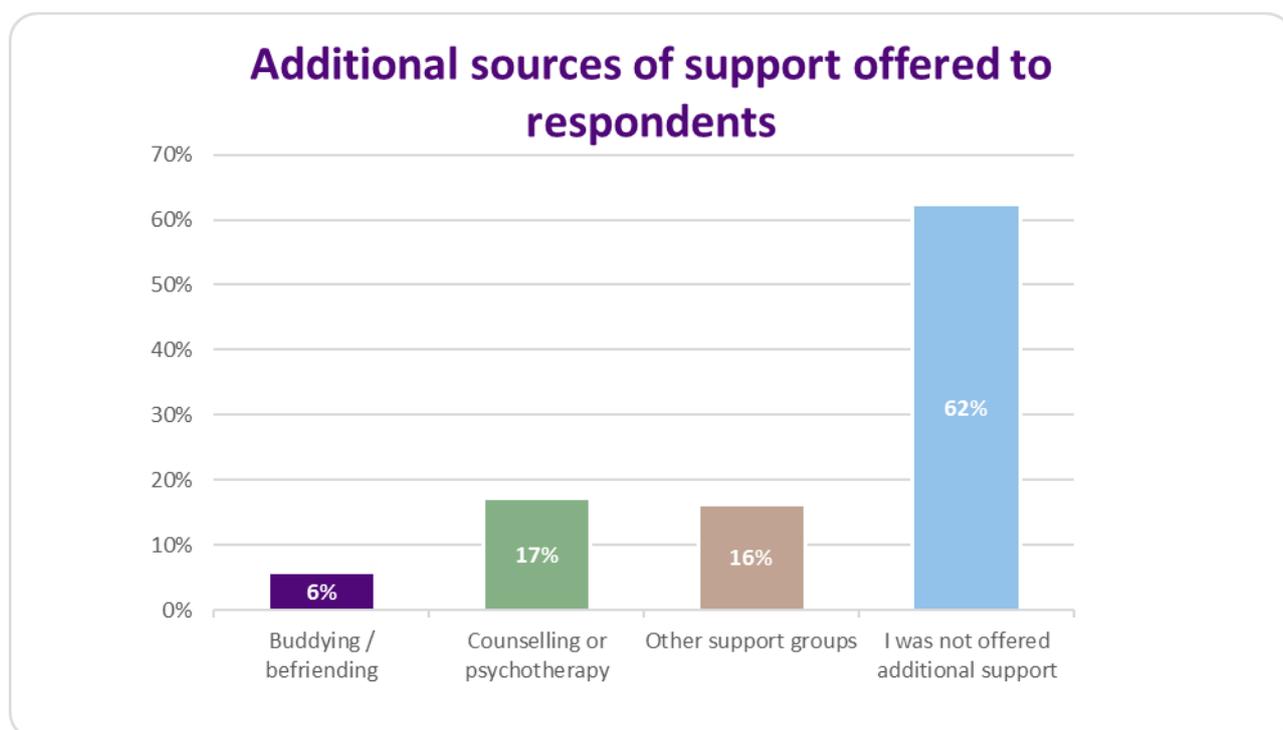


Fig 26. Additional sources of support offered to respondents

As highlighted throughout this report, a lymphoma diagnosis can bring about a significant need for additional, sometimes long-term, support. It is, therefore, disappointing to learn from these figures that patients are not being offered the services they may very well need either at the point of diagnosis or further along their lymphoma 'journey'.

In our *Lymphoma – what's that?* report, published in January 2016, we called on the Government to commit to ensuring the NHS works more closely, collaboratively and supportively with the voluntary sector in order to deliver more and better support services for those affected by lymphoma.

We know that the NHS is under considerable pressure and we know from our service users that their needs are not always met by NHS services. Our *Live your life – living with and beyond lymphoma* programme, a support programme of online, print, audio-visual and educational resources, has 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 above and beyond statutory services alone.

“It's not at the time that I needed or wanted emotional support. A year later and I'm now feeling nervous and anxious about the whole cancer and treatment.”

“Whilst the care and support from the hospital was excellent during diagnosis and treatment, once the treatment was completed I felt almost abandoned. I believed the aftercare, particularly from an emotional perspective could be improved.”

“I sailed through the cancer treatment but it is now that I am in remission and on maintenance treatment that I feel low and insecure.”

“I wish I had been told more about how chemotherapy would affect me, so I would understand why I felt so differently. Psychologically, my mind has been all over the place.”

3.5.5 Did the provision of additional support help?

We then asked whether they had received this support and whether it had helped them. The chart (Fig. 27) shows how respondents answered this question. The majority of respondents (60%) did not access this support at all, but for those who did, 85% said that it helped them feel better/more positive.

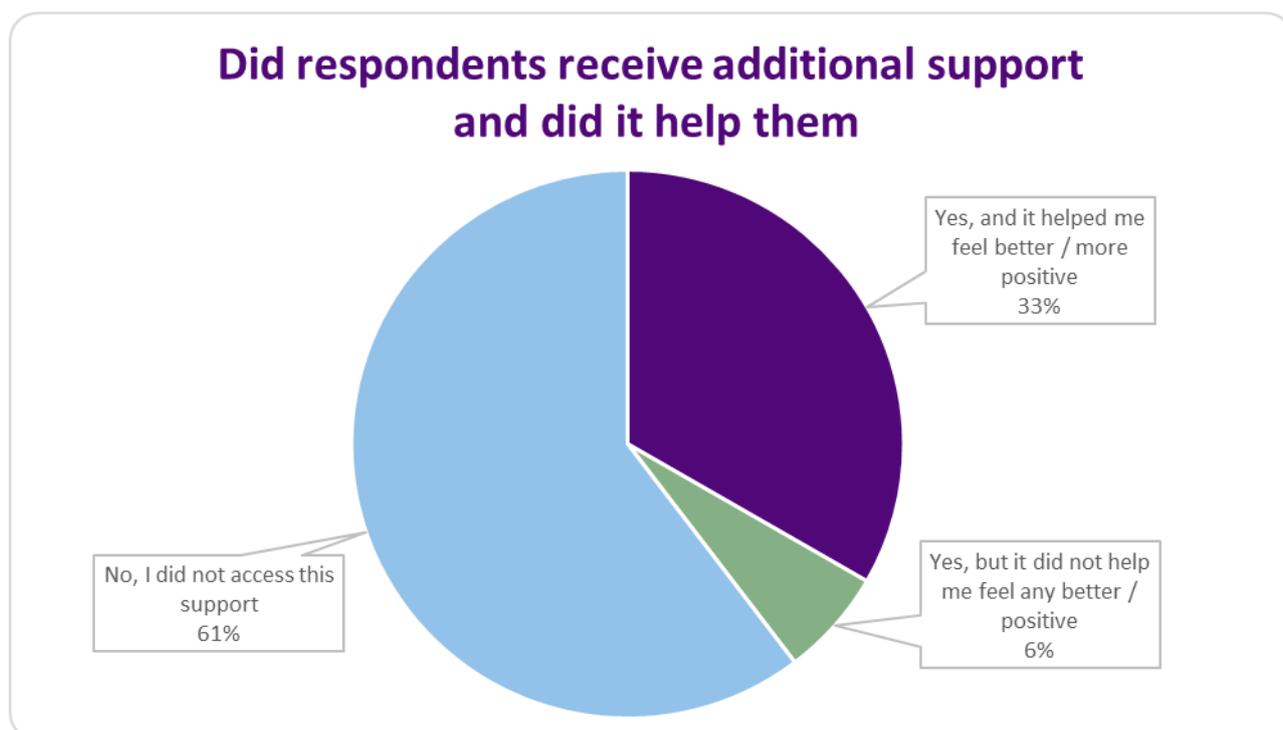


Fig 27. Did respondents receive additional support and did it help them?

“I fully recommend anyone with any form of cancer to join a support group as I thought it really helped me get through my treatment.”

“When I was given my diagnosis, I was given a big bag of literature all about my condition. Side-effects of treatments etc. which was much too much to take in at the time, for I felt in shock about what was happening to me. I was given a Macmillan nurse specialist who came to see me and we talked. My anxiety level went down and I felt more in control. I am very thankful for all the help I have had this time.”

3.5.6 Information and support affecting treatment choices

We asked if the provision of information and support had affected the patient’s treatment choices. The vast majority (89%) said that it had not affected their treatment choices at all. This is perhaps not surprising given that for many types of lymphoma, there are clear clinical protocols and standards of care, including for different lines of treatment, following relapse or disease progression.

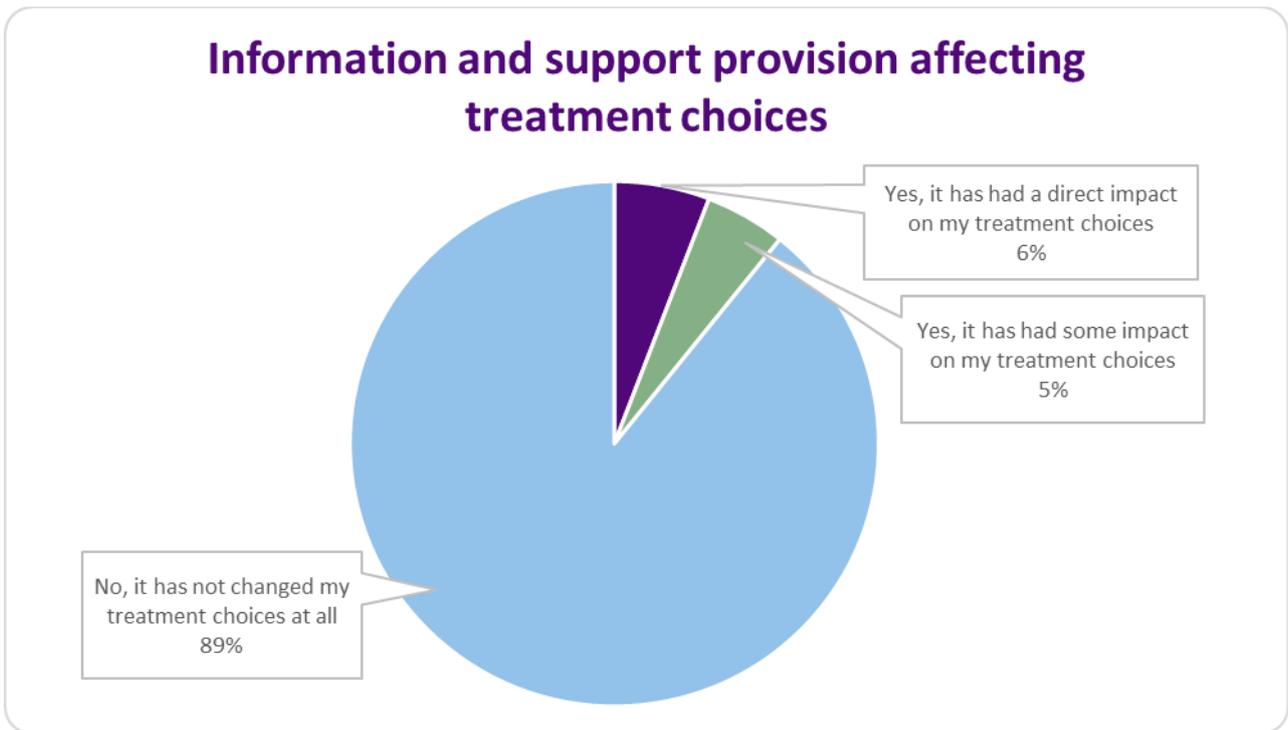


Fig 28. Information provision affecting treatment choices

3.5.7 Respondents reporting information affected their treatment choices

Of the small number of respondents who reported that information provision had affected their treatment choices, over a third (38%) said that as a result of the provision of information they chose a specific form of treatment, with over a fifth (22%) saying that they asked to be treated sooner. The chart below (Fig. 29) breaks this down in more detail.

Those who ticked 'other' in response to this question, generally listed the following reasons:

- Patient chose specific form of treatment recommended by their consultant (most popular response)
- Patient felt there was no choice but to accept treatment offered
- Patient chose to have holistic treatment in addition to medical treatment
- Patient ticked this option incorrectly as they felt the provision of treatment did not affect their treatment choices.

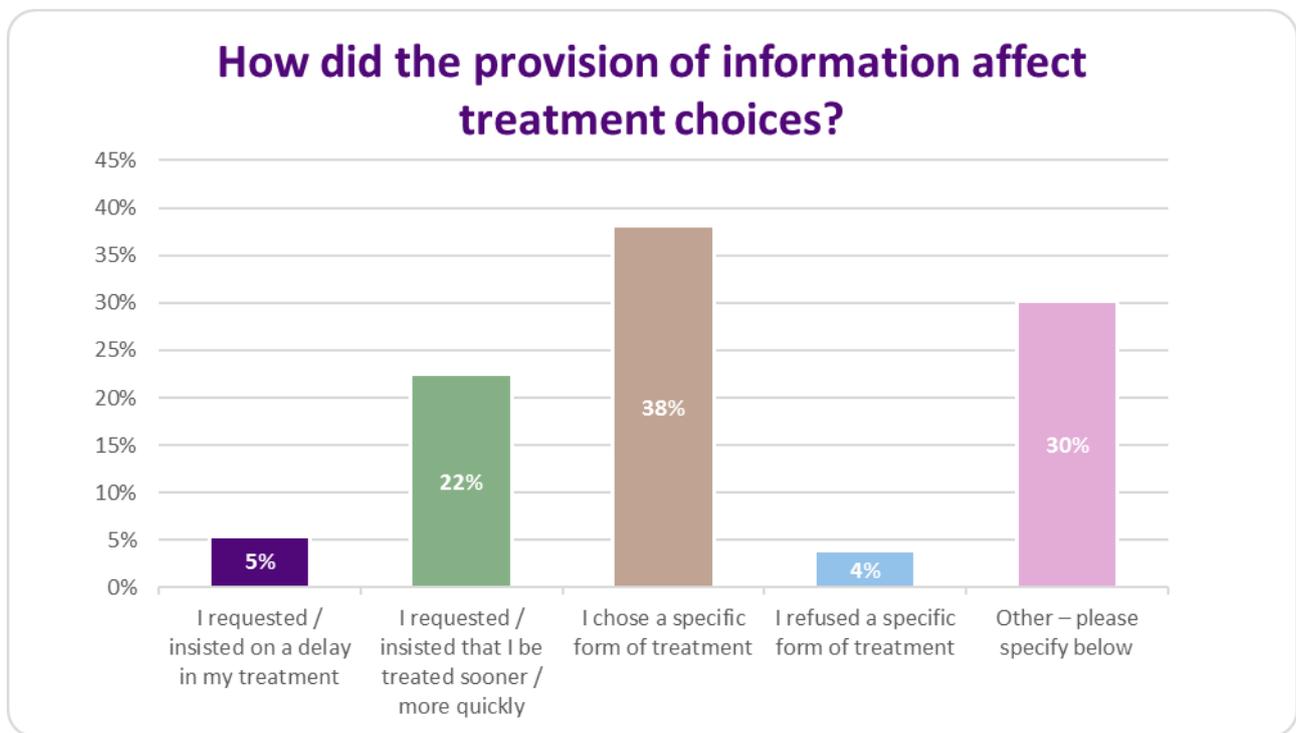


Fig 29. How did the provision of information affect treatment choices?

3.6 Care from general practitioners

This section looked at the care provided to lymphoma patients from their general practitioner (GP).

3.6.1 Were GPs given enough information from hospital

We asked whether respondents thought their GP was given enough information about their condition and treatment they had received at the hospital. Almost all respondents (94%) said that their GP was given enough information. This is a very positive message about the connections and communications between secondary/tertiary care and primary care services.

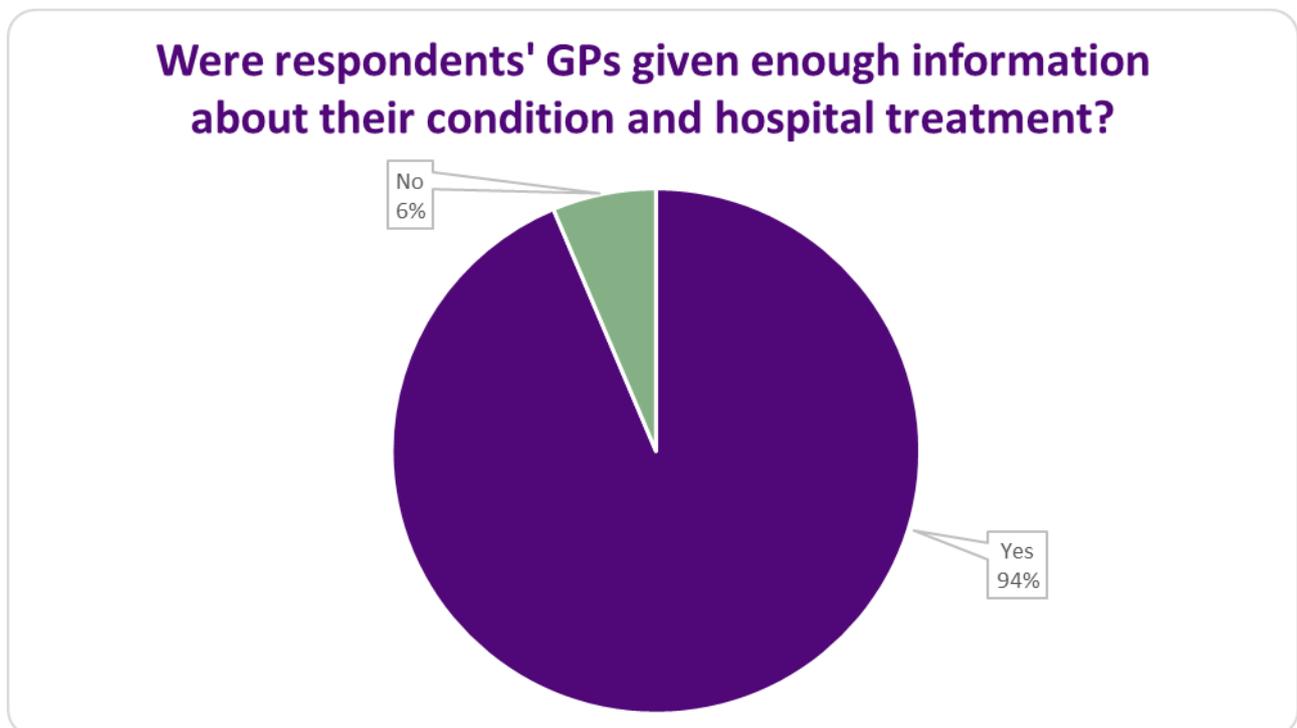


Fig 30. Information given to GP from hospital

“Although my GP care has been virtually non-existent, I am not critical at all, as my hospital care has provided me with everything I have needed, and has been outstanding. Provision of patient information has improved during my treatment, and my responses now if a new patient would be very different from my original responses in this survey.”

3.6.2 GPs' understanding of lymphoma

We also asked respondents if they thought their GP had a good understanding of lymphoma. The vast majority (93%) of respondents said that their GP had a complete understanding or some level of understanding. Just 7% said that their GP did not have any knowledge of lymphoma. Again this is reassuring set of responses, as it would be unrealistic to expect all or a majority of GPs to have a complete understanding of lymphoma, given its prevalence and the range of other conditions and issues with which they have to deal.

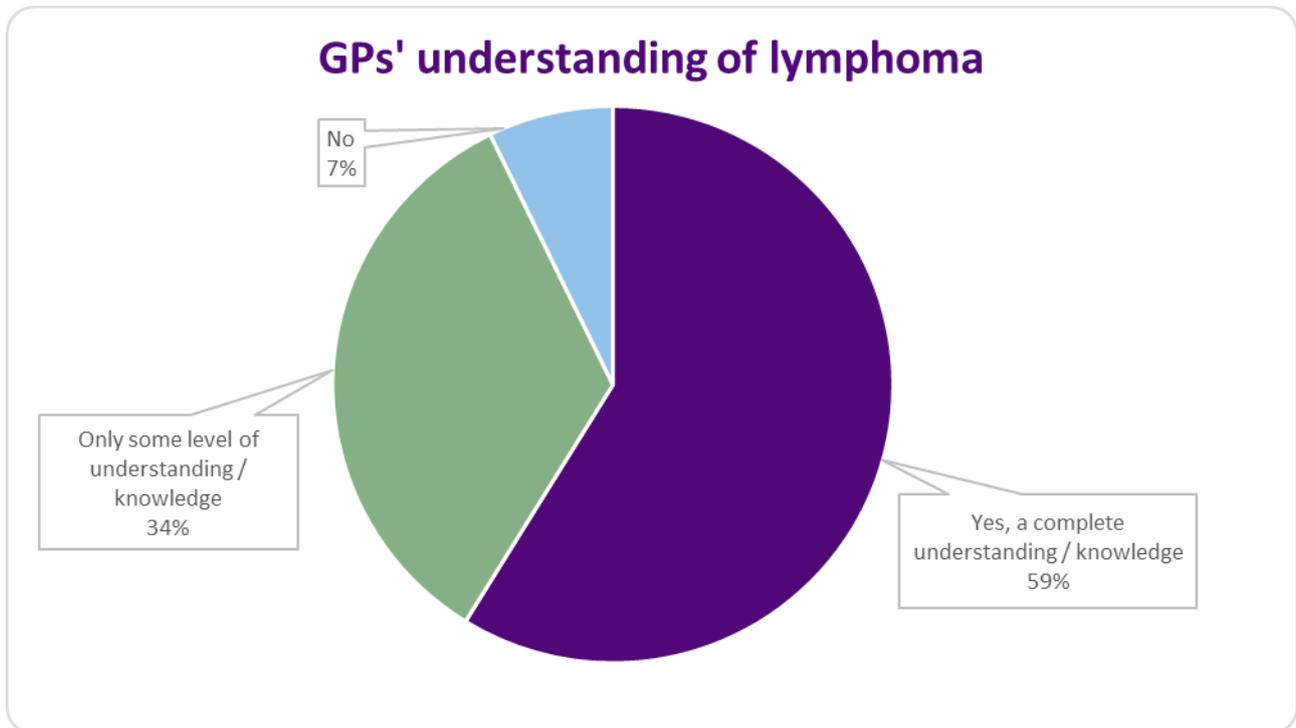


Fig 31. GPs' understanding of lymphoma

"I feel the care I have received has been excellent. I have Waldenström's Macroglobulinemia which is very rare and more closely related to multiple myeloma than lymphoma. I was impressed that my GP recognised I was very ill, despite symptoms being so vague including bone pain and tiredness."

3.6.3 GPs and nurses at local surgery as sources of support

Just over two-thirds of respondents (68%) reported that the GPs and nurses at their local surgery did everything they could to support them- at least to some extent. However, almost a quarter (23%) said that their GP practice was of no support whatsoever. When we probed further about the lack of support or what more could have been done, over a fifth (22%) said there had been no discussion at the GP practice about their lymphoma diagnosis and treatment. Given the aftercare and long-term support needs of people living with lymphoma, it's clear that more needs to be done to improve the post-treatment phase.

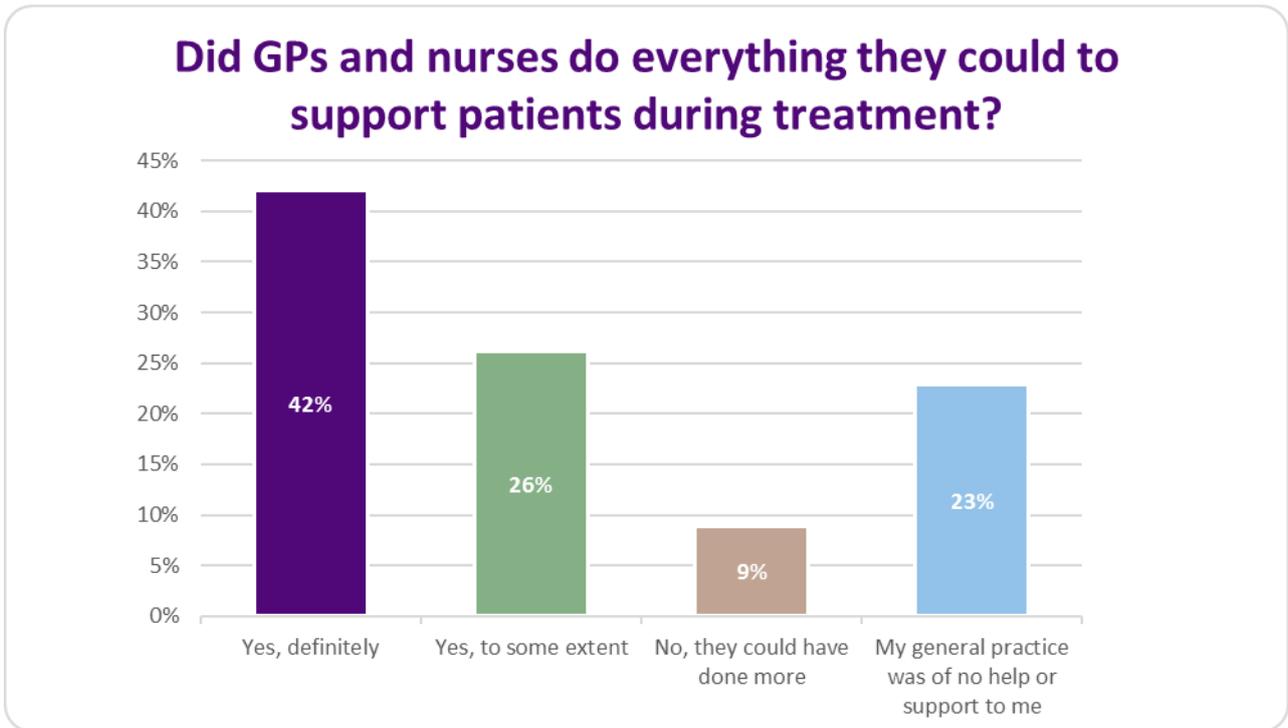


Fig 32. GPs' and nurses' level of support to patients

3.6.4 Nature of support from GPs

Where support from GPs and primary care was given, we then asked about the nature of that support. The majority (59%) reported that their GP had access to their medical records and so understood what treatment they had received. Beyond that however, the practical support offered was minimal, and there is an opportunity here for a more joined-up approach between hospital services, primary care and the charity sector around long-term support. The chart below (Fig. 33) breaks this down in more detail.

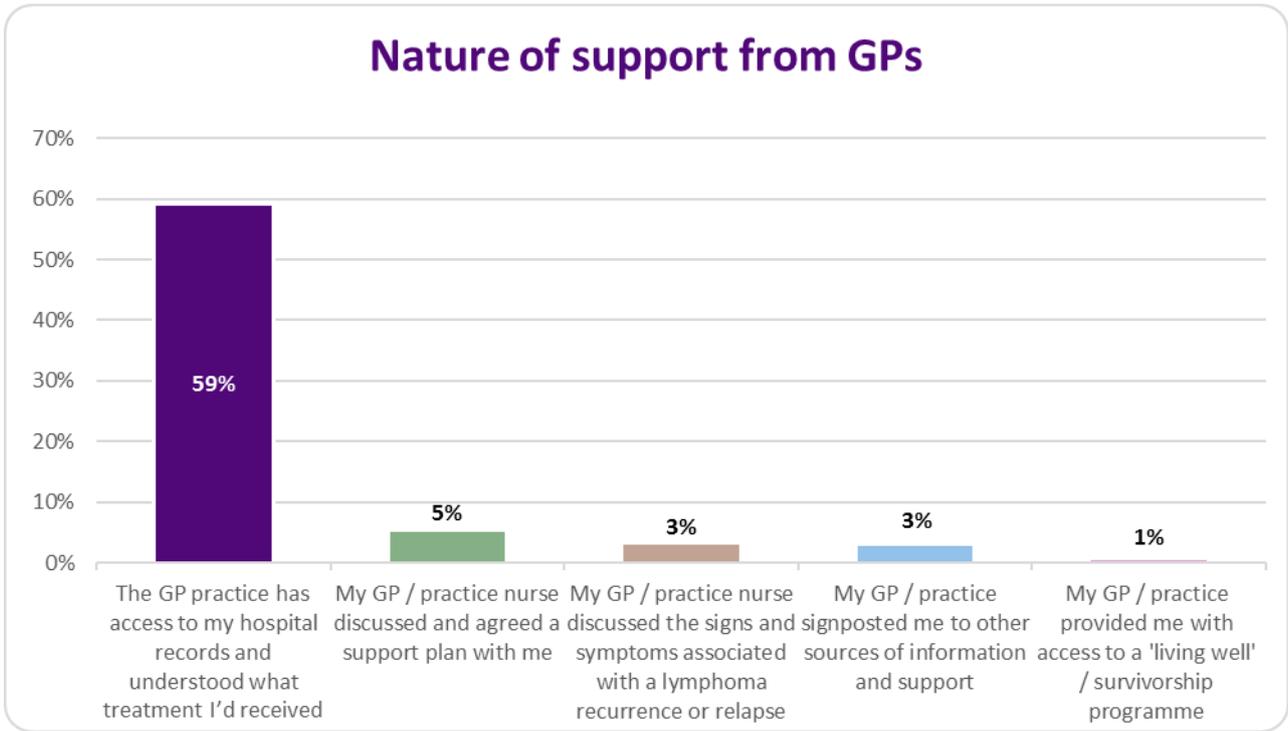


Fig 33. Nature of support from GPs

3.7 After treatment

3.7.1 Length of remission time

In the final section of the questionnaire, we asked respondents what the length of remission time was from their first treatment. The majority (84%) reported anything up to three years. The chart below (Fig. 34) breaks this down in more detail.

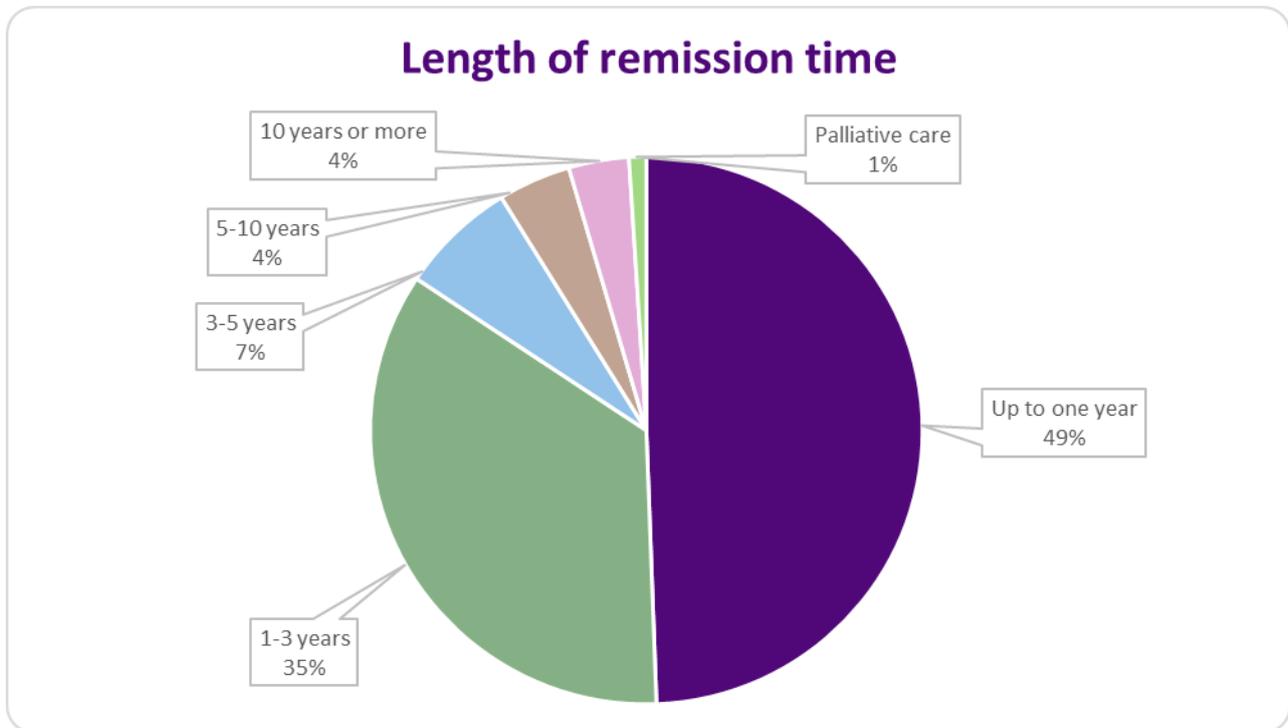


Fig 34. Length of remission time

“The longer you survive; the less people seem to know how to treat you. The after effects of chemo treatment is not told to you, what could happen to your heart, lungs etc. I feel that not enough is known about how to treat people who stay alive more than five years.”

3.7.2 Respondents who had experienced a relapse

78% of respondents said that they had not had a relapse, just over a fifth (22%) said that they had.

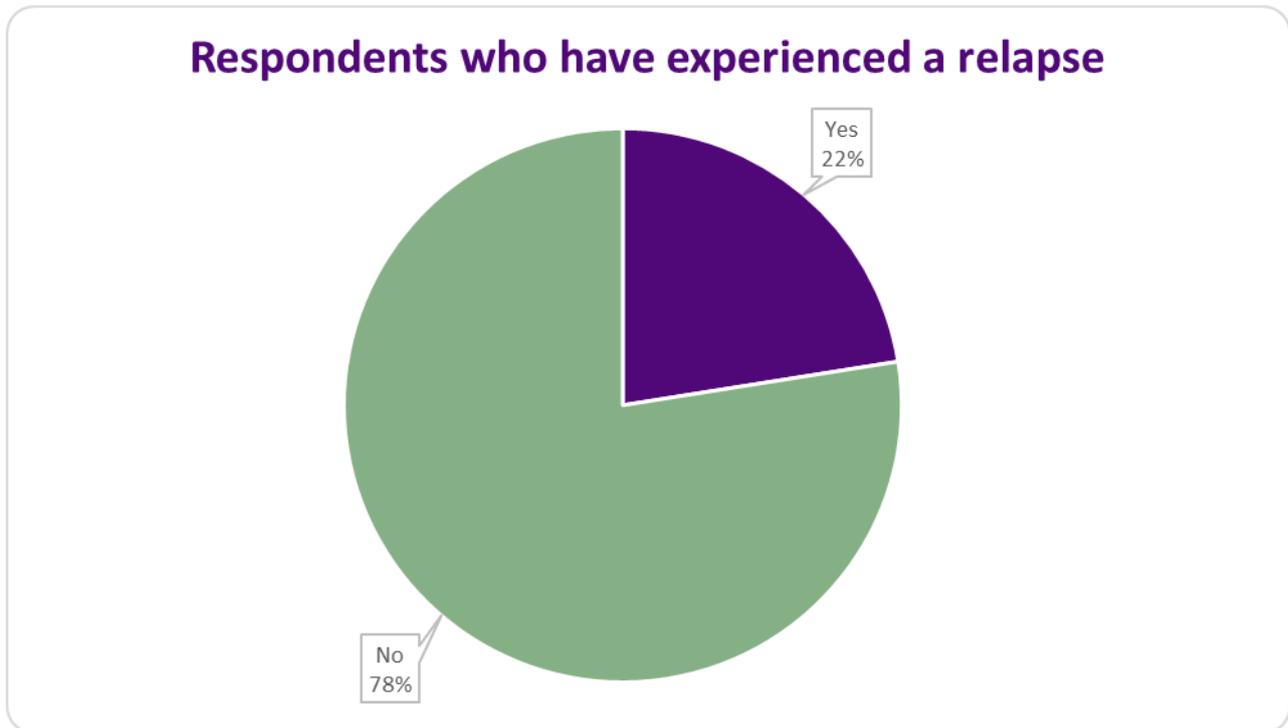


Fig 35. Respondents who have experienced a relapse

3.7.3 Number of relapses

Of those respondents who had experienced a relapse, almost two-thirds (64%) had only had one relapse. 18% had experienced two relapses. 10% of respondents had experienced four or more relapses.

These responses, taken with the answers in the previous two sections, illustrate some of the complexities and differences with lymphoma, especially the relapsing and remitting nature of many of the subtypes, including those with chronic and incurable forms. Such a profile has significant implications for aftercare and survivorship services.

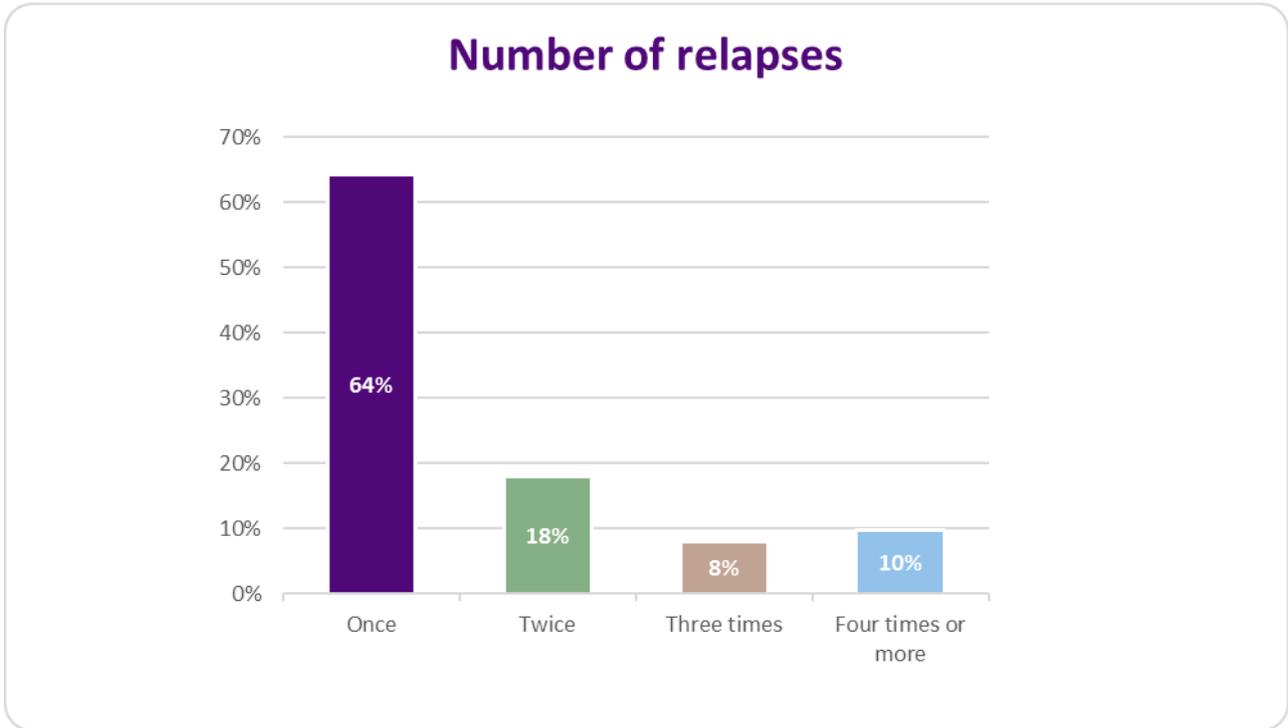


Fig 36. Number of relapses

3.7.4 Transplants

Finally, we looked at transplants – specifically which transplant a respondent had received (if at all) for their treatment for lymphoma. Just 7% had received a transplant with the majority (93%) reporting that they had not received a transplant as part of their treatment. The chart below (Fig. 37) breaks this down.

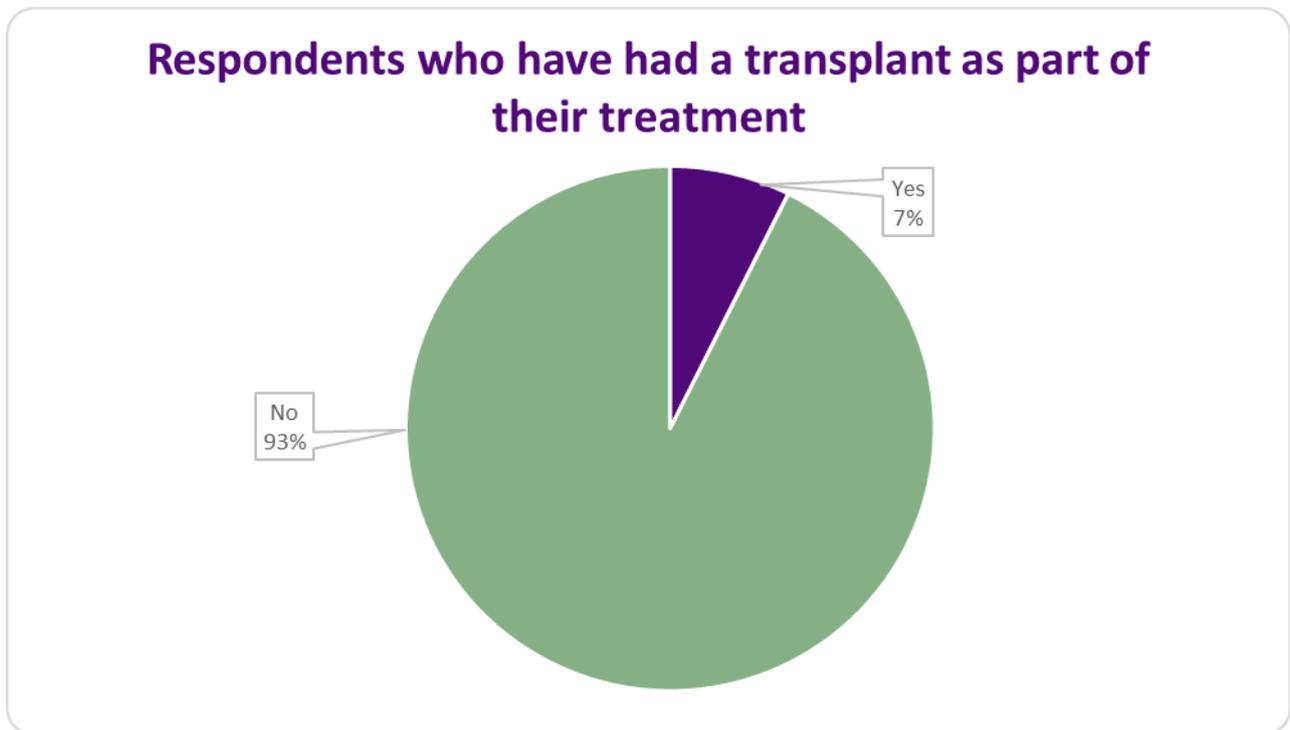


Fig 37. Respondents who have had a transplant as part of their treatment

3.7.5 Type of transplant

Finally, we asked those respondents who had received a transplant as part of their treatment, which transplant this was. The majority (79%) had received an autologous stem cell transplant (which uses the person's own stem cells). The chart below (Fig. 38) illustrates.

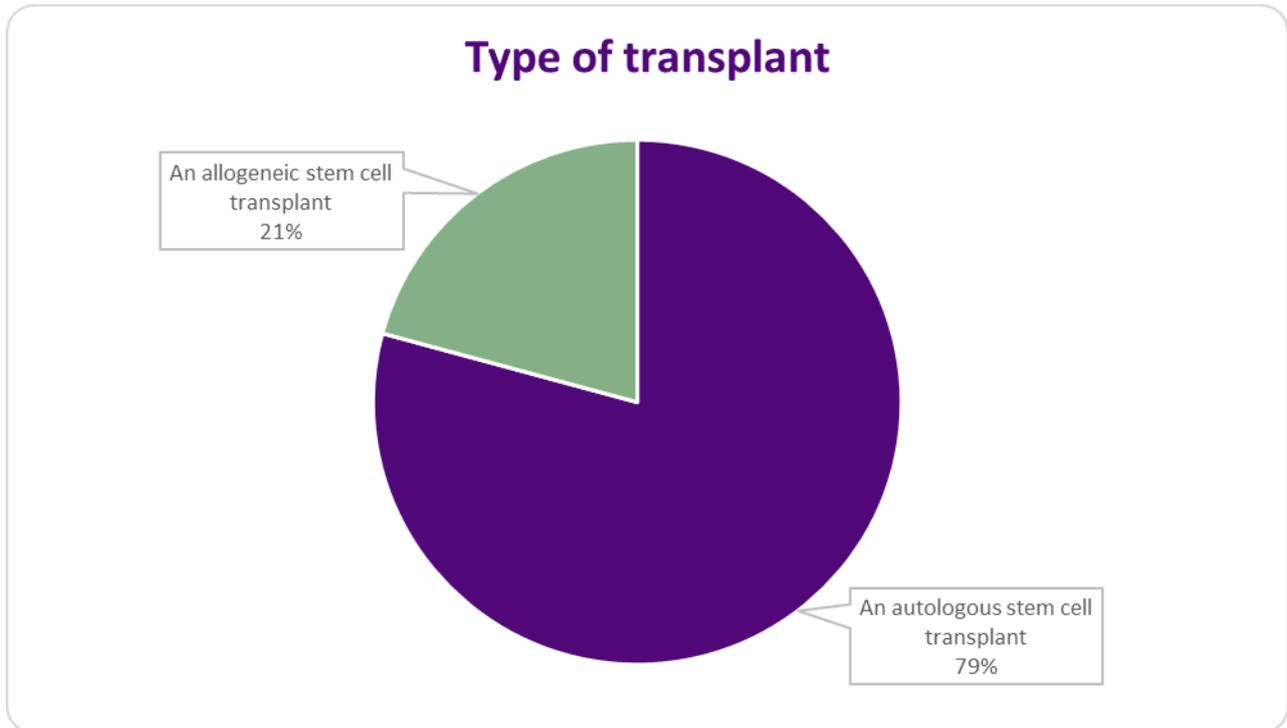


Fig 38. Type of transplant

4. Data breakdown analysis

As part of the data analysis, we also broke down the data, according to a number of key variables, to identify areas where individuals may be in particular need of additional services and support*. The areas in which we have provided further analysis:

- Age
- Ethnicity
- Gender
- Strategic Clinical Networks
- Route to diagnosis

*Please note we have only reported those figures where we have had enough significant data to draw meaningful conclusions.

4.1 Age breakdown

The breakdown we carried out on the data looked at how individuals answered according to which age group they belonged to.

Age group	Number of individuals
16-24	34
25-34	59
35-44	119
45-54	283
55-64	653
65-74	1,261
75-84	835
85+	136

There were some differences between the responses from different age groups, and there were some questions which showed a noticeable lack of difference between age groups. Some of the key differences are summarised below:

Those responding to the survey:

- Younger people were less likely to feel their GP had a complete understanding of lymphoma than older people (16-24 – 25%, 65-74 – 55%, 51% overall).
- Younger people were more likely to be referred under the ‘two week wait’ scheme (16-24 – 47%, 38% overall).
- Unsurprisingly, younger people are more likely to wait before first seeking help. 50% of 16-24 year olds sought help in less than three months when they thought something might be wrong compared to an average of 73% across the age brackets. The older respondents seek help more quickly.
- In terms of expectations that an individual had cancer before a diagnosis, responses were reasonably spread across the spectrum. Younger people were less likely to expect a cancer diagnosis, but the difference was not huge.
- Respondents’ understanding of what lymphoma is before diagnosis increases as they get older. Just 3% of 16-24 year olds had heard of lymphoma before they were diagnosed (25-

34 – 19%, 35-44 – 13%, 45-54 – 19%, 55-64 – 20%, 65-74 – 20%, 75-84 – 16%, 85+ - - 16%). The average across the age brackets was 19%.

- Cancer type. The responses confirmed broadly what we would expect regarding the age distribution of lymphoma between Hodgkin and non-Hodgkin lymphoma. Younger individuals are far more likely to be diagnosed with Hodgkin lymphoma than non-Hodgkin lymphoma. Hodgkin lymphoma diagnoses (16-24 – 82%, 25-34 – 73%, 35-44 - 30%, 45-54 – 18%, 55-64 – 8%, 65-74 – 7%, 75-84 – 8%, 85+ - 6%). Conversely, non-Hodgkin lymphoma is diagnosed more frequently in the older age brackets (65% of 65-74 year olds, compared to just 9% of 16-24 year olds).
- In terms of prognosis, perhaps unsurprisingly younger patients were given better outcomes (97% of 16-24 year olds were told their chances were good compared to an average of 73%). Older patients aged 85+ had the highest frequency of being told their chances were not good.
- Younger people were more likely to be accompanied at the time of their diagnosis. As you move up through the age brackets, there are increased numbers of patients attending on their own.
- Younger patients were more likely to be given written information from the Lymphoma Association and Cancer Research UK than older patients. Half of 16-24 year olds were given information from Lymphoma Association compared to just 17% of those aged 85+.
- Older patients were more likely to be told not to look at information online than younger patients. Perhaps unsurprisingly, younger patients were far more likely to look up information online than older patients (80% of 25-34 year olds compared to 25% of 75-84 year olds and 19% of patients aged 85+).
- Younger patients were far more likely to start treatment straight away rather than be put on a “watch and wait” regime. This is likely to be related to the fact that younger people will be more likely to be diagnosed with Hodgkin lymphoma (see above), which will usually require immediate treatment. 100% of patients aged 16-24 started treatment immediately and 98% of those aged 25-34 were also treated immediately. 65-74 year olds were most likely to have treatment delayed and be placed on “watch and wait” (22% put on watch and wait compared to an average of 20%).
- Those aged 85+ were least likely to be given written information about “watch and wait” (60% not given written information compared to an average of 41%).
- The youngest age category (16-24) were more likely to join a clinical trial (24% of respondents compared to an average of 15%).
- Younger patients were more likely to be offered additional support such as counselling or psychotherapy. 47% of 25-34 year olds were offered this support compared to an average of 17%. Older patients were less likely to be offered any form of additional support (68% of 75-84 year olds and 78% of those aged 85+ were not offered any additional support).
- Older patients, however, were more likely to access this support.
- The provision of information and support was less likely to affect the treatment choices of older patients than younger patients. 26% of 16-24 year olds and 14% of 25-34 year olds said that it had some impact compared to just 11% of 75-84 year olds and 9% of those aged 85+. Younger patients were more likely to choose a specific form of treatment as a result of the provision of information than older patients.

-
- Older patients are generally more satisfied with their GPs than younger patients. Those who thought their GP had a complete understanding of their cancer (16-24 – 34%, 25-34 – 51%, 35-44 - 42%, 45-54 – 53%, 55-64 – 53%, 65-74 – 61%, 75-84 – 65%, 85+ - 71%).

4.2 Ethnicity

NOTE: The numbers of those identifying themselves as BME within the survey respondents is very low (just 7% of survey respondents). The conclusions drawn from this breakdown of the data, therefore, should be used with extreme caution without further empirical investigation.

For the purposes of breaking down the data, we have grouped respondents who identified themselves as ‘white’ in one group, and all those who identified themselves as black and minority ethnic (BME) in another group.

Before diagnosis

- BME respondents are less likely to feel their GP has a good understanding of lymphoma at the point of diagnosis (White – 51% say their GP had a complete understanding, BME – 35%).
- The route to diagnosis is very similar across ethnicities, however those patients from BME communities are less likely to be referred under the “two-week-wait” scheme (White – 38%, BME – 30%).
- In terms of how long had elapsed between thinking something might be wrong and seeing a hospital doctor – those from BME communities generally waited longer (just 61% of BME patients were seen in under 3 months, compared to 73% of white respondents).
- Those from BME communities are less likely to expect they have cancer before they are diagnosed. Those who didn’t think they had cancer at all (White – 65%, BME – 79%).
- Looking at those who understood what lymphoma was, at least to some extent, those from BME communities are less likely to know what lymphoma is before diagnosis (BME – 37%, White – 68%).

Diagnosis

- Those from BME communities are more likely to be given information from Macmillan at diagnosis and less likely to be given information from the Lymphoma Association, though the difference is negligible.
- Those from BME communities are more likely to struggle to understand the information they are given.
- The hospital is more likely to recommend a patient contact the hospital for further information if they are from a BME community (BME – 51%, White – 40%).
- Those from BME communities were more likely to start treatment straight away – and therefore less likely to be placed on “watch and wait” compared to White patients. (BME – 90% started treatment straight away, White – 80%).

Treatment and care

- Those from BME communities are more likely to be given written information about “watch and wait” (BME – 88% given information which was easy-to-understand, White – 54%).

-
- Patients from BME communities are more likely to start treatment sooner. 30% of BME patients started within a week, compared to 24% of White patients.

Support for people with lymphoma

- BME patients are more likely to be offered counselling and psychotherapy than White patients (BME – 29%, White – 17%).
- BME patients are more likely to access additional sources of support and to find it helpful (49% of BME patients said that additional support helped them feel more positive, compared to 33% of White patients).
- The provision of information is more likely to affect the treatment choices of BME patients. 26% of BME patients said that the provision of information had at least some impact on their treatment choices compared to just 10% of White patients.
- As a result of the provision of information, BME patients are more likely to insist on being treated sooner (BME – 40% insisted on being treated sooner, White – 21%).

Care from GPs

- White patients are more likely to report that their GP was given enough information from the hospital about their treatment for lymphoma (White – 94%, BME – 82%).

After treatment

- BME patients are represented at a higher level than White patients in reporting remission time of up to one year (BME – 60%, White – 49%).
- BME patients were more likely to receive a transplant as part of their treatment for lymphatic cancer (BME – 13%, White – 7%).
- BME patients are represented at a higher level than White patients in the 16-24 age category (BME – 5%, White – 1%).

4.3 Gender

Before diagnosis

- Female patients are more likely to wait longer before being seen by a hospital doctor after thinking something was wrong (75% of men are seen in less than three months compared to 70% of women).
- Female patients are more likely to have heard of lymphoma before diagnosis (Female – 22%, Male – 15%).

Diagnosis

- Contrary to national incidence and prevalence data, the survey included a slightly higher proportion of females being diagnosed with non-Hodgkin lymphoma (Female – 62%, Male – 56%).
- Female patients are more likely to know that lymphoma is a type of cancer (Female – 70%, Male – 62%).
- When attending their diagnosis meeting, female patients are less likely than male patients to bring a partner or spouse with them and more likely to bring a son or daughter. 48% of female patients brought their partner compared to 61% of male patients.

Treatment and care

- Female patients are generally more worried about being placed on “watch and wait” than male patients. In terms of being very worried about “watch and wait”, 11% of female patients reported being very worried compared to 5% of male patients.
- In terms of clinical trials, female patients are more likely to be worried about side effects than male patients. (Female – 21%, Male – 15%).
- Female patients are less likely to be given information on self-help groups for people with lymphoma than male patients (Female - 73%, Male – 84%).

Support for people with lymphoma

- Male patients are more likely to be offered information produced by Macmillan than female patients (Male – 43%, Female – 34%).
- Female patients are more likely to access additional support such as counselling and to find it helpful than male patients (Female – 41%, Male 26%). There is no difference between genders in terms of being offered this kind of support.
- Female patients are less likely to choose a specific form of treatment as a result of the provision of information and support than male patients (Female – 34%, Male – 42%).

Care from GPs

- Male patients are more likely to feel that their GP has a complete understanding of lymphoma. 61% of male patients said that they thought their GP had a complete understanding of their lymphoma compared to 56% of female patients.

After treatment

- All scores within this section are very similar and show little difference between genders to draw any meaningful conclusions.

4.4 Strategic clinical networks (SCN)

Before diagnosis

- All the scores within this section are very similar and show very little difference between strategic clinical networks.

Diagnosis

- Those patients most likely to be given produced by the Lymphoma Association were from Thames Valley SCN (41% of patients compared to an average of 25%).
- The SCN most likely to treat patients straight away is Cheshire and Mersey (86% of patients started treatment immediately compared to an average of 80%).
- West Midlands SCN is most likely to place patients on “watch and wait” (25% of patients compared to an average of 20%).

Treatment and care

- There is a noticeable difference between SCNs around how well “watch and wait” is being explained to patients. From Greater Manchester, Lancashire and South Cumbria SCN (100% of those placed on “watch and wait” fully understood the reasons), down to Thames Valley SCN where just 63% of patients understood the reasons. Other high performing SCNs in this area are: East Midlands (98% of patients), East of England (93% of patients), South West (96% of patients) – all compared to an average of 90%.
- There is a correlation between those SCNs who score well above and patients feeling less worried about being on “watch and wait”. Those who score poorly on explaining this to patients, perhaps unsurprisingly score poorly on concerns around “watch and wait”.
- There is again a noticeable difference around information being given about watch and wait. The number of patients reporting getting information on “watch and wait” that was easy-to-understand varies hugely (just 27% in Cheshire and Mersey, 38% in South East Coast, up to 67% in South West SCN). Numbers are low here so fluctuations are expected.
- Wessex SCN was most likely to offer patients the option of participating in a clinical trial and for the patient to take part (22% of patients compared to an average of 15%).

Support for people with lymphoma

- Patients from Thames Valley SCN are most likely to be told about the support offered by the Lymphoma Association (37% of patients compared to an average of 19%).
- Patients from London SCN were most likely to be offered counselling or psychotherapy (22% of patients compared to an average of 17%).

Care from GPs

- GPs from Northern SCN, South West SCN and Wessex SCN are reported to have a complete understanding of lymphoma at a higher rate than other SCNs (65%, 66% and 64% respectively, compared to an average of 59%).
- GPs from Northern SCN and Wessex SCN are reported to have helped their patients as far as was possible at a higher rate than other SCNs (50% and 52% respectively, compared to an average of 42%).

After treatment

- Patients from East Midlands SCN, South East Coast SCN and West Midlands SCN are less likely to have experienced a relapse than patients from other SCNs. The difference is small.
- Patients from Greater Manchester SCN are more likely to have experienced four or more relapses than patients from other SCNs (17% compared to an average of 10%).

4.5 Route to diagnosis

Before diagnosis

- Patients who were referred to hospital as an urgent referral are more likely to report that their GP has a good understanding of lymphoma before diagnosis (65% compared to an average of 51%).

Diagnosis

- Patients who were referred as a non-urgent referral are less likely to completely understand what they are being told during diagnosis (50% of patients compared to an average of 54%).
- Patients who were urgently referred were more likely to be told their chances were good (78% of patients compared to an average of 73%).
- Those who were referred non-urgently were more likely to have treatment delayed and be placed on “watch and wait” than patients who were referred urgently (28% of non-urgently referred patients were placed on “watch and wait” compared to an average of 20%).

Treatment and care

- Patients who were referred urgently were more likely to fully understand the reasons behind being placed on “watch and wait” than others (96% fully understood the reasons compared to an average of 90%).
- Patients who were referred to hospital the same day – and then placed on “watch and wait” – were more likely to be worried about this than others (55% had some concern and worries compared to an average of 45%).
- Those patients who were urgently referred were more likely to be given written information about “watch and wait” that was easy-to-understand (65% compared to an average of 51%).

Support for people with lymphoma

- Patients who were urgently referred or seen as an A&E patient are more likely to rate the quality of the information they are given as excellent (50% and 51% respectively, compared to an average of 44%).
- Of those patients who said their treatment choices were affected by the provision of information, those most likely to be affected were patients who were urgently referred by their GP (47% chose a specific form of treatment, compared to an average of 38%).
- The remaining areas in this section either have very similar scores or the numbers involved are too low to draw any other meaningful conclusions.

Care from GPs

- Those patients who were urgently referred by their GP are more likely to highly rate the quality of the care they receive from their GP. 70% of those patients who were urgently referred by their GP said that their GP had a complete understanding of lymphoma (compared to an average of just 59%).
- Those whose GP urgently referred them or who sent them to hospital the same day were more likely to report that their GP had access to their hospital records and understood what treatment they had received (both 69% of patients, compared to an average of 59%).

After treatment

- All areas in this section either have very similar scores or the numbers involved are too low to draw any other meaningful conclusions.

4.6 Other breakdowns

Quality Health also carried out breakdown analysis under the following areas:

- Support providers
- Watch and wait
- Told lymphoma type
- Used internet to find information
- Information about support services

These breakdowns generally did not provide enough variance to effectively analyse, or the numbers involved were too low. However, there were the following exceptions:

- Patients who were given information from the Lymphoma Association are most likely to know that lymphoma was a type of cancer (72%, compared to an average of 66%).
- The information most likely to be rated as easy-to-understand was produced by Cancer Research UK (70% of respondents rated it as easy-to-understand, Lymphoma Association – 66%, Macmillan 63%, average of 59%), although as can be seen from the responses, this information was only distributed at low levels.
- Patients who were given information from the Lymphoma Association are most likely to fully understand the reasons for being placed on “watch and wait” (97%, compared to an average of 91%).
- Those with Hodgkin lymphoma are more likely to be told that their chances were good than those with non-Hodgkin lymphoma (82% compared to 75%).
- Those with Hodgkin lymphoma are more likely to use the internet to find further information (53% of patients compared to 42% of those with non-Hodgkin lymphoma).
- Patients with non-Hodgkin lymphoma were more likely to be placed on “watch and wait” (20% compared to 7%).
- Patients with Hodgkin lymphoma were more likely to access counselling and psychotherapy than those with non-Hodgkin lymphoma (25% vs 16%).

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- Patients with Hodgkin lymphoma were more likely to have had a transplant as part of their treatment (13% vs 6%), and this was more likely to be an allogeneic stem cell transplant than those with non-Hodgkin lymphoma.
 - Patients who used the internet to look up further information about their lymphoma are more likely to have concerns, specifically around “watch and wait” (39% of those patients who used the internet did not have any worries about “watch and wait”, compared to 57% of those who did).
 - Patients who used the Internet to look up further information about their lymphoma are less likely to rate positively the information they were given in hospital (40% of patients who used the internet rated the information they were given as excellent, compared to 47% who did not).
 - Patients who used the Internet to look up further information about their lymphoma are less likely to report their GP as having a complete understanding of their lymphoma (51% of patients who used the internet said that their GP had a complete understanding of their lymphoma, compared to 65% who did not).

All breakdowns have been provided in full as part of this report and further analysis and conclusions could be carried out.

5. Comments and analysis

This section of the report presents a thematic analysis of Lymphoma Association's free text comments received from lymphoma patients who returned a questionnaire.

At the end of the survey, respondents were invited to record any further comments that they wished to make. This report presents a thematic analysis of those comments.

5.1 Thematic analysis

In order for Lymphoma Association to understand and identify the main issues contained within the comments, Quality Health carried out a systematic analysis of the comments by theme.

There were 1,701 comments received in total. Due to the high number of comments received, a thematic analysis has been carried out on a random selection of 20% of the comments (a total of 340). All the other comments have been provided as a separate PDF to the Lymphoma Association.

Every comment has been typed up by Quality Health staff, and "sanitised" (removing any patient identifiable data, and removing any staff names or details). Lymphoma Association has also been given a 'raw data' file containing all of these comments.

During this process, Quality Health categorised the comments in two ways:

- By the nature of the comment, i.e., whether it is positive, negative, mixed or neutral.
- By the theme which it addresses. The themes arising from the comments are listed below in order of the highest number of comments, to lowest:
 - Treatment and care (including NHS)
 - Diagnosis
 - About GPs
 - Cancer nurses / Macmillan / CNS
 - Feeling fully informed about care and treatment / lack of information
 - Support groups
 - Side effects
 - Coping / depression
 - Relapse / worry about recurrence
 - About the survey
 - "Watch and wait"
 - Medication
 - Clinical trials
 - Travel related to lymphoma treatment
 - Lymphoma Association

Within each of these categories, Quality Health has identified comments as positive, negative, mixed and neutral.

A summary of the overall responses is provided in the next section of this report. The more detailed section that follows reports on each theme individually and provides examples of actual comments against each.

5.2 Summary results

The themes covered by the comments are shown below and the numbers of comments recorded in that theme. Some comments relate to more than one theme, and so these have been recorded more than once. Therefore, the numbers of comments below will add up to more than 340.

In the 340 comments analysed, there were:

- 191 positive comments.
- 59 negative comments.
- 64 neutral comments.
- 26 mixed comments.

NOTE: the conclusions below have been drawn by looking at the proportion of comments within each category rather than by total comments received. For example, if 10 out of 10 comments within a particular section are positive that will be rated as having a higher proportion of positive comments than a section with 100 out of 500 positive comments.

The themes with the highest proportion of positive comments were:

- Cancer nurses / CNS
- Lymphoma Association

The themes with the highest number of negative comments were:

- Side effects
- About the survey
- GPs

The themes which attracted no positive comments, with all, or most comments being negative were:

- Side effects
- Coping / depression
- About the survey

The table on the following page breaks down each comment by theme and then by positive, negative, neutral or mixed. Some comments are categorised more than once.

Theme	Total number of comments	Positive	Negative	Neutral	Mixed
Treatment and care (including NHS)	257	170	29	35	23
Diagnosis	88	23	30	25	10
About GPs	88	31	26	18	13
Cancer nurses / Macmillan / CNS	29	27	0	2	0
Feeling fully informed about care and treatment / lack of information	29	16	9	1	3
Support groups	24	9	7	8	0
Side effects	20	3	14	1	2
Coping / depression	17	3	9	5	0
Relapse / worry about recurrence	11	4	2	5	0
About the survey	9	0	6	3	0
Watch and Wait	7	3	1	3	0
Medication	6	1	3	2	0
Clinical trials	3	2	0	1	0
Travel related to lymphoma treatment	3	1	2	0	0
Lymphoma Association	2	2	0	0	0
TOTAL	593	295	138	109	51

5.3 Results by theme

There were a high number of comments received and therefore a large number of categories. The results by theme section below explores the top 5 categories.

5.3.1 Treatment and care

There were 257 comments on treatment and care. This included details on their treatment which they were undergoing, or consequences of treatment that they were experiencing.

170 were positive, 29 were negative, 35 were neutral, 23 were mixed.

Some examples of positive comments included:

“Couldn't have received better treatment from my GP hospital doctor and nurses.”

“Totally satisfied with the treatment; I am now living on borrowed time. At all times I have instant contact with a specialist nurse and the consultant. After some phone calls they referred me to my GP for instant investigation.”

“Between my retired GP and the treatment I have received at four different hospitals; the service has been excellent in all areas with the associated problems I have encountered related to the main condition.”

The negative comments included:

“Prior to diagnosis, for six months, visited my GP multiple times, had several telephone appointments, all to say I had severe abdominal pain at night, had lost two stones in weight and previously had cancer. All they could say was 'bloods good, you are stressed because of ill relative'.”

“Very poor treatment for my lymphedema.”

“Since having chemotherapy I am having problems; I am informed that my nerves have been damaged. It appears permanently. I am having 6 monthly infusions.”

5.3.2 Diagnosis

There were 88 comments relating to diagnosis or the route to being diagnosed with lymphoma.

23 were positive, 39 were negative, 25 were neutral, 10 were mixed.

Positive comments included:

“All staff kind and considerate to my needs. Diagnosis to treatment was fast and good.”

“The best part was the confidence that the doctors and nurses gave, that you would get better. This meant that, from day one, I felt I was going to get well. Also, by starting the treatment on the same day I was diagnosed, I felt that no time was wasted but straight into treatment. Also the doctors and nurses have answered all of my questions straight away or found the answers and let me know this meant not worrying needlessly.”

Negative comments included:

“This survey has been difficult to fill in as I was wrongly diagnosed. Only after my first chemotherapy session was I diagnosed properly. It was a good job, I was on the trial, so some questions are answered when I thought I had my wrongly diagnosed illness.”

“Straight after an investigation I was told I had cancer. The doctor just told us this and then said we would have a further appointment. The initial shock was very hard to deal with.”

“Still in shock! It took over 8 months for a full diagnosis to be given to me, and being a NHS [job title removed] makes it even harder!”

5.3.3 About GPs

There were also 88 comments relating to GPs. 16 people commented specifically on whether they felt fully informed about their care and treatment and on the provision of information. 15 of these comments were negative and one was neutral.

31 were positive, 26 were negative, 18 were neutral, 13 were mixed.

Negative comments tended to focus on GPs mis-diagnosing the patient or not being fully informed about treatment that had taken place. Unsurprisingly, positive comments included GPs providing a swift diagnosis or referring patients urgently to hospital.

Positive comments included:

“Couldn’t have received better treatment from my GP, hospital doctor and nurses.”

“Treatment at hospital, consultant and nurses excellent. Only complaint at onset after five blood tests was told ok and then called back and told by a locum I had blood cancer and when asked what were chances, replied don’t know. Rectified by my own GP who rang two hours later and got me into hospital straight away.”

“The care and treatment at my GP and Musgrove was nothing short of excellent.”

Some examples of the negative comments are:

“Nothing is really explained; you have to think up the questions. GPs are either clueless or do not have the time. My consultant was very caring, nice and helpful - I was lucky. When she went on maternity leave, the doctor who was put in her place were less than supportive, either “I don’t know” or “go to your GP”. I have felt worse since having my treatment the during the constant worry and anxiety as well and extreme tiredness, despite blood test being ok.”

“This survey does not reflect the time it took to actually see a lymphoma consultant and to get a diagnosis. For over one year I visited my GP many times complaining I was unwell, during that time I was sent to see a hospital chest clinic doctor who said that I had some bronchitis. I later saw a hospital GP who could not find a problem, but suggested perhaps I should have an endoscopy following the endoscopy in May 2015 I was immediately admitted to hospital. I spent over 3 weeks as an inpatient having tests, scans and 3 more endoscopies. When they said I had gastric lymphoma I refused to go home until an appointment was made for me to see a consultant at the cancer hospital. Talking to other patients whilst undergoing chemotherapy at least two others commented it had taken over a year to be diagnosed.”

5.4.4 Cancer nurses/Macmillan nurses/CNSs

29 people commented on the role of the cancer nurse – also referred to as a Macmillan nurse or Clinical Nurse Specialist (CNS).

Almost all comments were positive suggesting this is a hugely important role for those being treated for lymphatic cancer. Of 29 comments analysed, there were 27 positive comments and 2 neutral comments. There were no negative comments.

A selection of positive comments includes:

“All professionals have been amazing to me. The nurses that did my bloods counts every month have now become friends of mine. Force centre were also amazing receiving messages through my treatment and given complete support, advice whenever I ring or visit. Force centre citizen advice bureau service was over and above supportive, assisting myself to have PIP payments and a blue badge provided, which has improved my life dealing with cancer and looking forward in a positive way.”

“Support of cancer nurse specialist is indispensable. High level of compassion and care from nurses, but lack of empathy from some doctors and consultants.”

“Overall a very positive experience at a very distressing, scary and busy time. Great care shown by the vast majority of NHS staff. Very good support available afterwards in the form of clinical psychology and nurses who were an open ear for me. Thanks to all involved. Long live the NHS!”

“Oncology nurses at Lancaster are excellent. Always caring and very professional.”

“Nurses at the chemotherapy ward are without fail brilliant. The atmosphere is really good despite the treatment people are receiving. They are very positive and caring, a credit to the NHS. Thank You.”

5.4.5 Information/feeling informed

There were also 29 comments around information provision or patients feeling informed about their lymphoma.

Of these comments, 16 were positive, 9 were negative, 1 was neutral and 3 were mixed.

Some examples of the positive comments are:

“The care and attention given to me by the doctors and nursing staff at the hospital was excellent. I had a 24-hour phone number to a dedicated nurse that I could use at any time if I needed advice or assurance on my condition. Twice I was admitted to A&E and my care was excellent.”

“Overall, I have had excellent treatment from both doctors and nurses, nothing is a trouble to them with both information and care.”

“On the whole I received very good treatment and when I asked questions I was always given help or pointed in the right direction.”

Negative comments included:

“The bone marrow treatment I had was on a used dirty bed, complained to consultant who I feel didn't believe me. Since moving to Churchill Hospital I have had excellent treatment.”

The present consultant I am with now told me I had a cancer - no one ever mentioned it before."

"Oncologist was brilliant, very thorough and understanding. My relative tried to contact Macmillan for some help and advice when I first got home, but they were no helpful at all. I found more information from Macmillan on a course after chemotherapy, which would have been useful earlier. It is good to chat to other patients and compare notes and symptoms."

"Very satisfied with my treatment at hospital. But not much information on what to expect in the future."

6. Conclusions and recommendations

6.1 Conclusions

We believe this work will result in the largest patient experience dataset worldwide on the consequences and effects of lymphoma treatments. The high response rate, coupled with the results show why it was so important to have commissioned this project:

First phase data has shown higher than anticipated numbers of individuals reporting consequences from their lymphoma treatment. The results highlight that many individuals struggle post treatment and have identified that they need more support, information and improved signposting.

It is worrying that patients are not disclosing long term consequences of their treatment and 'putting up with it', thus living in isolation, often even unable to leave their homes. It is also essential the right questions are asked in primary and secondary care settings whilst the data confirms anecdotal worries we had that the emotional wellbeing needs of these individuals are not being met

Investment is needed in training, care and referral to enable individuals to have the services and care that will enable them to start living 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.

6.2 Recommendations

From analysis of the data in the survey, we have identified the following 10 key recommendations.

6.2.1 Routes to diagnosis

The survey findings challenge some of the available national data on individuals' route to diagnosis. While the National Cancer Intelligence Network's *Routes to Diagnosis* data for in England during 2006 to 2013 records that 26% of non-Hodgkin lymphoma and 17% of Hodgkin lymphoma cases are diagnosed in an emergency setting, our data suggests that the overall figure for all lymphoma cases is more like 18% (which includes the 7% of respondents who the GP sent directly to hospital). While it was reassuring that two-thirds (66%) of respondents reported being referred appropriately via the "two-week-wait" scheme or by non-urgent referral to a specialist, it was more of a concern that 17% were initially treated for another condition by their GP.

- **Recommendation 1:** Further work should be undertaken to improve awareness and understanding of lymphoma within general practice.
- **Recommendation 2:** There should be a review of national lymphoma data collection and ideally a national audit as this is one of many areas where NHS statistics for lymphoma do not match either the lived or clinical experience.

6.2.2 GPs, primary care and time to diagnosis

While 19% of respondents said that their GP didn't seem to know about lymphoma, we were pleased that 81% reported that their GP had a complete or partial understanding of lymphoma. As a cancer support charity report we receive a lot of feedback from people with lymphoma who complain about their GPs' involvement in their diagnosis, so it is reassuring to hear of a positive experience for the vast majority. While there are still great improvements that can be made in GP awareness and understanding of lymphoma, the generalist nature of primary care, the relative scarcity of lymphoma and the uncertainty of the presenting symptoms are very real challenges and barriers.

GPs and primary care services play an important role throughout a lymphoma patient's experience, and not just at the point of early identification of lymphoma. For many people with lymphoma, especially those living with chronic or indolent forms, post-treatment follow-up and aftercare at a primary care level is very important. So, again, while it was positive to hear that the vast majority of people thought their GP had a good or some understanding of lymphoma, it was much more of a concern to hear that 23% said their general practice was of no help or support during and after treatment, with a further 9% saying that more help could have been provided. In terms of the practical support that was offered, the limited responses we received were that 5% said a support plan had been discussed and agreed with them, 3% said the signs and symptoms of recurrence or relapse had been discussed, 3% had been directed to other sources of information and support, and 1% had been provided with access to a "living well" or survivorship programme.

- **Recommendation 3:** General practices should work more with specialist lymphoma organisations to understand better the nature of living with lymphoma and develop practical and meaningful support plans for people going through and recovering from treatment, including providing accurate and up-to-date signposting services.

6.2.3 Stronger awareness and understanding of lymphoma

Despite being the UK's fifth most common cancer, lymphoma is neither well-known nor easily understood and some of the survey's responses confirm this, with just over a third (34%) of people diagnosed saying they had not heard of lymphoma previously. Similarly, awareness of lymphoma as a form of cancer was limited. In a similar vein, the survey found a clear need to improve the understanding of the lymphoma information that is provided to patients. While 60% said that the information they received from the likes of their treating hospital, Macmillan and the Lymphoma Association (the three most common sources of information by far) was easy-to-understand, most of the other respondents (37%) only understood some of the information, and 3% did not understand most of it. Furthermore, the biggest barrier to improving cancer services is the lack of awareness of rare and less common cancers such as 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.

- **Recommendation 4:** Consideration should be given to initiatives to improve health education around lymphoma among both adults and children/young people. Featuring lymphoma in a future Public Health/NHS *Be Clear on Cancer* campaign could have a massive impact on improved awareness and understanding.
- **Recommendation 5:** Information providers, whether hospitals, charities (including the Lymphoma Association) and other organisations need to reconsider their approach to accessible and understandable information in order to ensure their written materials meet the needs of even more people.

6.2.4 Know your subtype

The survey provided revealing information about how little people are told about their lymphoma subtype, despite it being an important factor in helping them understand their diagnosis, treatment and prognosis, not to mention in finding the best information and support. We were shocked to discover that 14% of people were told simply they had lymphoma and only 13% were told their non-Hodgkin lymphoma subtype.

- **Recommendation 6:** All clinicians should inform patients of their lymphoma subtype and refer them to appropriate, specialised forms of support relevant to their subtype.

6.2.5 Information provision

As noted above, the three most common sources of information provided to respondents by healthcare professionals by far were from the hospital's own resources (61%), Macmillan (45%) or the Lymphoma Association (25%). Obviously, we were disappointed that more of our specialised lymphoma information and materials wasn't distributed directly to people with lymphoma, especially given that all hospitals that treat lymphoma either request or receive our resources. More importantly however, the responses show that there must be a lot of duplication in the information that is provided and the resources that go into producing it. Surely, it would save important NHS resources if information development and provision were subcontracted to specialist providers in the voluntary sector, such as the Lymphoma Association or Macmillan.

In a similar vein, not enough people were told about how to find further information or support – 20% said they were told nothing about other sources of information. In a separate question, 75% said they were told nothing about using the internet and only 16% were advised to use trusted websites. Despite this, nearly half (46%) of respondents used the internet to find further information. Of these people, 25% said they found the Lymphoma Association's website the most useful, with 23% and 20% saying the same for Macmillan and Cancer Research UK's websites, respectively.

- **Recommendation 7:** NHS information providers should work more closely with the voluntary sector to ensure the provision of accurate, timely and specialised written, audio-visual and digital resources to people affected by lymphoma.

6.2.6 “Watch and wait”

The survey also confirmed what we knew already about the significant proportion of people that start their treatment journey on “watch and wait” or “active monitoring”, due to the indolent, slow-growing nature of their lymphoma. In our sample, 20% of people said that after diagnosis, they were placed on “watch and wait”, with the vast majority (91%) saying they understood the reasons for this. Although there was a reassuring level of understanding about “watch and wait”, over half (53%) either had some concerns and worries (45%) or were very worried (8%). Despite these worries and concerns, 41% reported that they weren't given any written information on “watch and wait”.

- **Recommendation 8:** All lymphoma patients who are placed on a “watch and wait” regime should be provided with clear and easily understandable written information on what that means and the implications for their future treatment plan and health outcomes. For instance, the Lymphoma Association provides a wealth of information on “watch and wait” – see www.lymphomas.org.uk/about-lymphoma/treatment-lymphoma/watch-and-wait-lymphoma.

6.2.7 Additional sources of support

Perhaps one of the most concerning findings in the survey was the lack of further support provided to people with lymphoma during and after treatment. Nearly two-thirds (62%) of people were not offered additional support, with only 17% offered access to counselling or psychotherapy, despite the widely acknowledged high levels of need. Just as concerning was the apparent age discrimination operating within the system, with nearly half (47%) of 25 to 34-year-olds being offered additional support compared to an overall average of 17%, and older patients being less likely to be offered extra help. For instance, 68% of 75 to 84-year-olds weren't offered such support and nor were 78% of those aged 85 or over. To rub salt into the wounds, the survey found that when people were provided with additional support, it was overwhelmingly beneficial, with 85% of respondents saying that it made them feel better and more positive.

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- **Recommendation 9:** The NHS should work with the voluntary sector to understand better the positive impact of additional support services and to commission lymphoma-specific programmes of support.

6.2.8 Clinical trials

Our 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. Over three-quarters of respondents said they were not 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 which 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. There are a number of possible explanations for the shortcomings the survey responses have identified.

- **Recommendation 10:** All lymphoma treatments 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. The Lymphoma Association's Lymphoma TrialsLink service (www.lymphomas.org.uk/lymphoma-trialslink), launched in 2016, is a key resource for patients and clinicians alike in finding out which trials are running in which areas for which treatments or regimes.

7. Next steps

This project has been an incredibly useful piece of work and we hope the data, its analysis and our interpretation of it will help add to the "pool of understanding" for lymphoma. More than that, we hope the recommendations we have identified will lead to improved practices for diagnosing, treating and supporting people affected by lymphoma, which in turn will make a dramatic impact on outcomes and improved patient experience.

The survey and its findings have also identified important priorities and actions for the Lymphoma Association itself, in relation to its work both with its immediate beneficiaries (i.e., those personally affected by lymphoma) and with the healthcare practitioners it also helps and supports.