

National Institute for Health and Care Excellence

NICE guideline NG52

# Non-Hodgkin's lymphoma: diagnosis and management

## Appendix H: Findings of patient experience survey

Final version, July 2016



*This guideline was developed by the National Guideline Alliance, hosted by the Royal College of Obstetricians and Gynaecologists*

### Disclaimer

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**The specific information and support needs of people with non-Hodgkin's lymphoma and their carer(s) at the time of diagnosis and treatment planning, as well as during and after treatment.**

**What are the information and support needs of patients with a diagnosis of non-Hodgkin's Lymphoma and their carers?**

## **Report on the findings from the secondary analysis of the 2014 Cancer Patient experience Survey of patients with diagnosis of Non-Hodgkin's Lymphoma**

### **Summary of findings:**

- Whilst similar to all cancer patient reports from the survey, there are potential areas where patient needs may warrant further attention around diagnosis , particularly to ensure patients fully understand their test results, have their diagnosis explained fully and are given the opportunity/choice to have a friend/relative present.
- Approximately 70% of patients with NHL reported that their views were taken account and that they were involved in decisions regarding their treatment and care; similar to all cancer patients. However, the findings suggest an unmet need around information given on longer-term side effects for patients with NHL.
- Ensuring easy access to a CNS for all patients is warranted given the high endorsement that CNS's listened to, and provided understandable answers to their patients' questions all or most of the time.
- There may be unmet needs in informing patients of and allowing access to participation in clinical trials.
- Patients should be assessed on their individual needs to receive information/advice on work/education and choice given to participate in support groups.
- Attention to ensuring easy to understand written information both before and after procedures is relevant and an important area to address.
- Approximately 80% of patients expressed satisfaction with their hospital doctors; an unmet need for patients with NHL may be ensuring their carer/relative/friend has sufficient opportunity to ask questions.

## Non-Hodgkin's lymphoma: diagnosis and management

- Over 75% of patients with NHL felt positively about the way they were treated by doctors and nurses. Ensuring patients are given opportunity to discuss worries and fears when required by the individual patient warrants further consideration.
- Whilst the majority of patients with NHL were given information on what to do and whom to contact, a potential unmet need is the information provided to relatives/friends on how to care for him/her at home.
- The majority of patients with NHL reported positive endorsement of their care given to control side-effects but further attention may be needed to ensure patients have access and opportunity to receive emotional support.

**The results from the CPES survey state that for NHL patients: [the (%) bracket reports figures for all cancer patients]:**

### **Information and support needs around diagnosis**

- 78% had their diagnosis explained fully (84%).
- 84 % said that their tests and investigations had been fully explained by a member of staff (87%).
- 63% received written information about investigations that was easy to understand (87%) .
- 73% received a completely understandable explanation of their tests results (78%).
- 73% were given the opportunity to bring a friend/relative with them (75%).
- 80% were informed of their diagnosis in a sensitive manner (84%).
- 59% completely understood the explanation of what was wrong with them (73%).
- 70% were given written information (72%).

### **Treatment decision making**

- 72% were not given a choice of treatments as only one was available (59%).
- 74% were definitely informed of treatment side-effects in a way that was understandable (75%).
- 82% received written information that was easy to understand (82%).
- 48% were told about side-effects which could affect them in the longer-term (55%).
- 70% were definitely involved in decisions about their care (72%).
- 86% were given the name of a clinical nurse specialist (CNS) in charge of their care (89%).
- 68% found it easy to contact their CNS (73%).
- 92% said their CNS definitely listened to them (91%).
- 92% said their CNS gave him/her understandable answers all or most of the time (91%).

### **Support for patients**

- 64% said they were given information by hospital staff about support or self-help groups (83%).

## Non-Hodgkin's lymphoma: diagnosis and management

- Q26
- Of those who said it was necessary, 54% of patients with NHL received information about financial help or benefits (54%).
- 81% (who said it was necessary) received information about free prescriptions (78%).
- 88% had seen information about cancer research (86%).
- 24% were informed by staff about taking part in clinical trials (31%); of these, 59% were enrolled in a trial (63%).

### Operations

- 26% of patients with NHL reported they had had an operation in the past 12 months (55%)
- 
- 79% were informed of what would happen (88%)
- 54% received written information that was easy to understand ; (76%).
- 68% received information that was easy to understand after their operation (78%) .

### Hospital Doctors

- 56% reported an overnight stay in the last 12 months (66%).
- 80% received answers to their questions from doctors that were easy to understand most or all of the time (83%).
- 85% had confidence and trust in all of their doctors (85%).
- 83% said doctors did not talk in front of them, as if they were not there, all of the time (84%).
- 62% said their relative/carer/friend was given enough opportunity to ask questions (67%).

### Ward Nurses

- 74% received answers to their questions from ward nurses which were easy to understand (76%).
- 76% had confidence and trust in all of their ward nurses (71%).
- 86% said ward nurses did not talk in front of them, as if they were not there all of the time (85%).
- 60% said there were always enough nurses on duty (60%).
- 88% said they never thought their doctors or nurses were deliberately withholding information (88%).
- 76% said they were never given different information from different doctors or nurses (79%).
- 85% were always given privacy when discussing their condition or treatment (85%).
- 94% were always given privacy during examinations or procedures (95%).
- 60% were given opportunity to discuss their worries/fears with staff when they wanted to (65%).
- 86% had everything done to control their pain by hospital staff (86%).
- 86% were always treated with dignity and respect (84%).

**Information about leaving hospital and support.**

- 75% were given clear written information on what and what not to do on leaving hospital (85%).
- 95% were told who to contact if worried after leaving hospital (94%).
- 53% said their relative/friend was given all the information needed to care for them at home (60%).

**Day/Outpatient care**

- 74% had everything done to help control the side effects of chemotherapy (81%).
- 79% had everything done to control their pain (82%).
- 70% were definitely given emotional support (70%).
- 97% had attended an appointment in the last 12 months (94%).
- 95% said their doctors had access to the relevant notes and records (96%).

## **Introduction:**

The clinical evidence review conducted to address the review question above assessed 31 eligible studies. The majority (n=26) were cross-sectional studies with two key limitations identified: 1) The studies only provided a snapshot of time with high potential for recall bias in retrospective studies and; 2) most studies cannot infer causality i.e. factors such as sexual health problems may be associated with age or other factors and not their diagnosis of Non-Hodgkin's Lymphoma (NHL) or treatments associated. Studies were heterogeneous in sample size, response rates, measures used and statistical analysis; thus limiting any formal (qualitative or quantitative) synthesis of results.

Key outcomes reported were:

- Patient satisfaction/experience
- Psycho-social impact
- Health-related quality of life
- Informed decision making
- Treatment decision making
- Patient reported outcomes

The findings from the evidence review reported support and information needs across several domains. It was agreed with the Guideline Committee to explore the use of information from the English NHS Cancer Patient Experience Survey to provide additional information to the Guideline Committee on the support and information needs of adults with NHL, to inform the recommendations for this topic.

The focus of this report is to provide supplementary evidence [in addition to the review of the clinical evidence] to the Guideline Committee members on the information and support needs of people with NHL. The analysis undertaken focuses on the needs of NHL patients in the survey relevant to the secondary care setting e.g. diagnosis, during treatment, after treatment, at point of consideration of palliative care, commensurate with the PICO.

The results are presented in order of each question that was asked in the survey. Where data is not shown e.g. because the question was not relevant to the needs of NHL patients in the secondary care setting or where numbers were too low to report any findings, this has been made explicit in the report.

### **Objectives:**

The objective was to present the experiences of patients with NHL, and where data allowed, NHL sub-types, as reported in the 2014 Cancer Patient Experience Survey; with focus on information and support needs for patients (and carers).

## **Methods:**

### ***Cancer Patient Experience Survey***

The Cancer Patient Experience Survey (CPES)<sup>1</sup> is conducted by Quality Health to provide a snapshot of cancer patient experience in English NHS Trusts, with 153 Trusts included representing all Trusts that treat adult patients with cancer. The last survey available was undertaken in 2014. The survey was administered to all patients who had been treated as inpatients or day cases between 1<sup>st</sup> September and 30<sup>th</sup> September

The survey was a questionnaire administered by post with two follow up reminders. It was intended to be self-completed by the patient. The survey achieved a response rate of 64%. It comprised of 63 questions split into 16 categories. It allowed specific tumour types to be extracted based on ICD-10 criteria. Permission was given to the NCC-C to have the full dataset to extract the information related to people with NHL.

### **Sample**

In the 2014 survey, 2530 patients with an ICD-10 code related to NHL were available for extraction. This comprised of 698 patients with FL, 1370 patients with DLBCL with other sub-types (Burkett's, MALT, Mantle Cell and Peripheral T Cell lymphomas).

### **Analysis**

A secondary cross-sectional analysis of the 2014 findings was undertaken to present the findings of the CPES relevant to patients with NHL. The analysis would be basic descriptive data, with results presented in a similar format to the main survey report (e.g. bar charts with narrative commentary). The analysis undertaken reported findings for all NHL patients, with separate analysis of the main sub-types ( FL , DLBCL, and other NHL)...

The dataset was checked for any anomalies and re-categorised into each of questionnaire response scale format to allow easier interpretation.. Analysis was undertaken on all available data, with no manipulation or imputing of missing variables..

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<sup>1</sup> A copy of the survey is available at <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-materials>

Non-Hodgkin's lymphoma: diagnosis and management

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Results

Demographic and clinical characteristics

Age of patients with NHL

	All NHL		FL		DLBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
<b>16 - 25</b>	9	0.4%	0	0.0%	7	0.5%	2	0.4%
<b>26 - 35</b>	31	1.2%	2	0.3%	27	2.0%	2	0.4%
<b>36 - 50</b>	181	7.2%	68	9.7%	93	6.8%	20	4.3%
<b>51 - 65</b>	699	27.6%	207	29.7%	355	25.9%	137	29.7%
<b>66 - 75</b>	924	36.5%	255	36.5%	496	36.2%	173	37.4%
<b>76+</b>	686	27.1%	166	23.8%	392	28.6%	128	27.7%
<b>Gender of patients with NHL</b>								
	All NHL		FL		DLBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
<b>Female</b>	1097	43.4%	357	51.1%	595	43.4%	145	31.4%
<b>Male</b>	1433	56.6%	341	48.9%	775	56.6%	317	68.6%

Employment status of NHL patients

	All NHL		FL		DLBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
<b>Full time employment</b>	444	18.4%	133	19.9%	238	18.2%	73	16.6%
<b>Part time employment</b>	160	6.6%	58	8.7%	79	6.0%	23	5.2%
<b>Homemaker</b>	47	1.9%	11	1.6%	31	2.4%	5	1.1%



Non-Hodgkin's lymphoma: diagnosis and management

<b>Student (in education)</b>	9	0.4%	4	0.6%	4	0.3%	1	0.2%
<b>Retired</b>	1586	65.6%	406	60.8%	871	66.5%	309	70.1%
<b>Unemployed - and seeking work</b>	10	0.4%	3	0.4%	6	0.5%	1	0.2%
<b>Unemployed - unable to work for health reasons</b>	112	4.6%	41	6.1%	52	4.0%	19	4.3%
<b>Other</b>	51	2.1%	12	1.8%	29	2.2%	10	2.3%

**Length of time treated for NHL**

	All NHL		FL		DLBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
<b>Less than 1 year</b>	1506	61.4%	277	41.2%	1011	75.8%	218	49.0%
<b>1 to 5 years</b>	759	31.0%	330	49.1%	250	18.7%	179	40.2%
<b>More than 5 years</b>	181	7.4%	62	9.2%	72	5.4%	47	10.6%
<b>Don't now / can't remember</b>	5	0.2%	3	0.4%	1	0.1%	1	0.2%

**Cancer status for NHL patients**

	All NHL		FL		DLBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
<b>Yes, this is the first time I have been treated for cancer</b>	1854	75.8%	519	77.1%	1011	76.1%	324	73.0%
<b>No, I have been treated for the same type of cancer before but it has now come back</b>	355	14.5%	104	15.5%	170	12.8%	81	18.2%
<b>No, I have been treated for a different type of cancer before</b>	236	9.7%	50	7.4%	147	11.1%	39	8.8%

**Treatment response of NHL patients**

	All NHL		FL		DLBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
Treatment has not yet started for this cancer	13	0.5%	9	1.4%	2	0.2%	2	0.5%
I am in the course of treatment and I can't tell yet how my cancer has responded	778	32.6%	245	37.7%	390	29.9%	143	32.9%
The treatment has been effective and I have no signs or symptoms of cancer	988	41.4%	202	31.1%	624	47.8%	162	37.3%
I have finished the course of treatment but my cancer is still present	198	8.3%	84	12.9%	77	5.9%	37	8.5%
My cancer is being treated again because it has not responded fully to treatment	104	4.4%	29	4.5%	41	3.1%	34	7.8%
I am not in active treatment but I am on "Watch and Wait"	303	12.7%	79	12.2%	170	13.0%	54	12.4%
My cancer has not been treated at all	5	0.2%	2	0.3%	1	0.1%	2	0.5%

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**Age of patients with NHL**

	N	Mean	Std. Deviation
All NHL	2530	67.82	11.92
FL	698	66.98	11.49
DLBCL	1370	67.94	12.40
NHL Other	462	68.70	11.01

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Non-Hodgkin's lymphoma: diagnosis and management

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1 **1. Seeing your GP**

2 **Q1. Before you were told you needed to go to hospital about cancer, how many times did you**  
3 **see your GP (family doctor) about the health problems caused by cancer?**

4 As this question concerned support and information needs in primary care, no analysis was  
5 undertaken.

6 **Q2. How do you feel about the length of time you had to wait before your first appointment**  
7 **with a hospital doctor?**

8 As this question concerned support and information needs in primary care, no analysis was  
9 undertaken.

10 **Q3. How long was it from the time you first thought something might be wrong with you until**  
11 **you first saw a hospital doctor?**

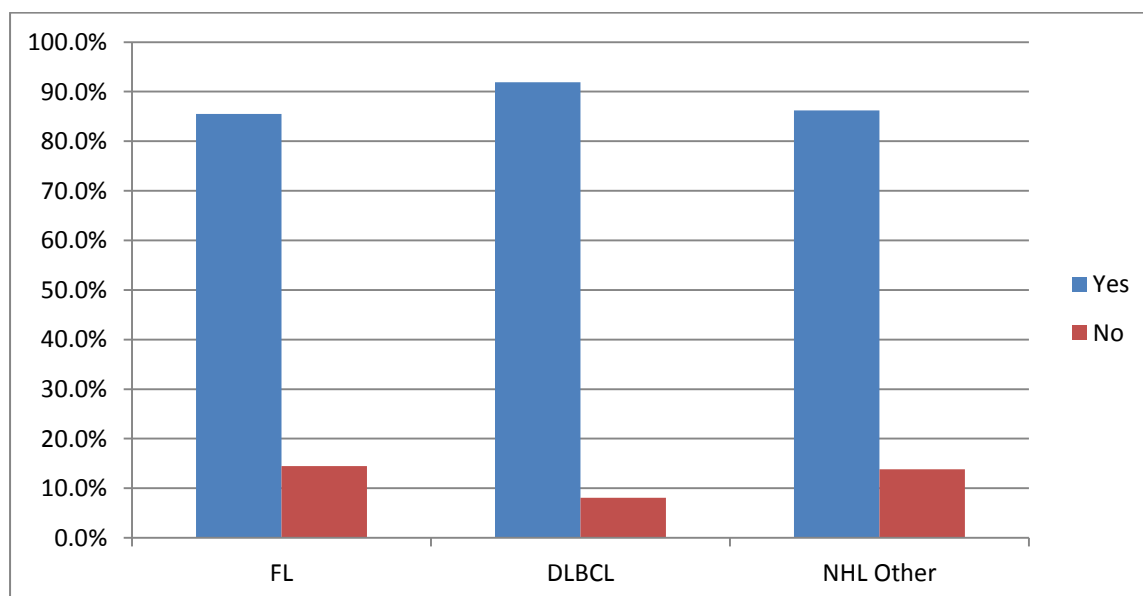
12 As this question concerned support and information needs in primary care, no analysis was  
13 undertaken.

14 **Q4. Did your health get worse, get better or stay the same while you were waiting for your**  
15 **first appointment with a hospital doctor?**

16 As this question concerned support and information needs in primary care, no analysis was  
17 undertaken.

18 **2. Information and support needs around diagnosis**  
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20 **Q5. Diagnostic tests in the last 12 months**

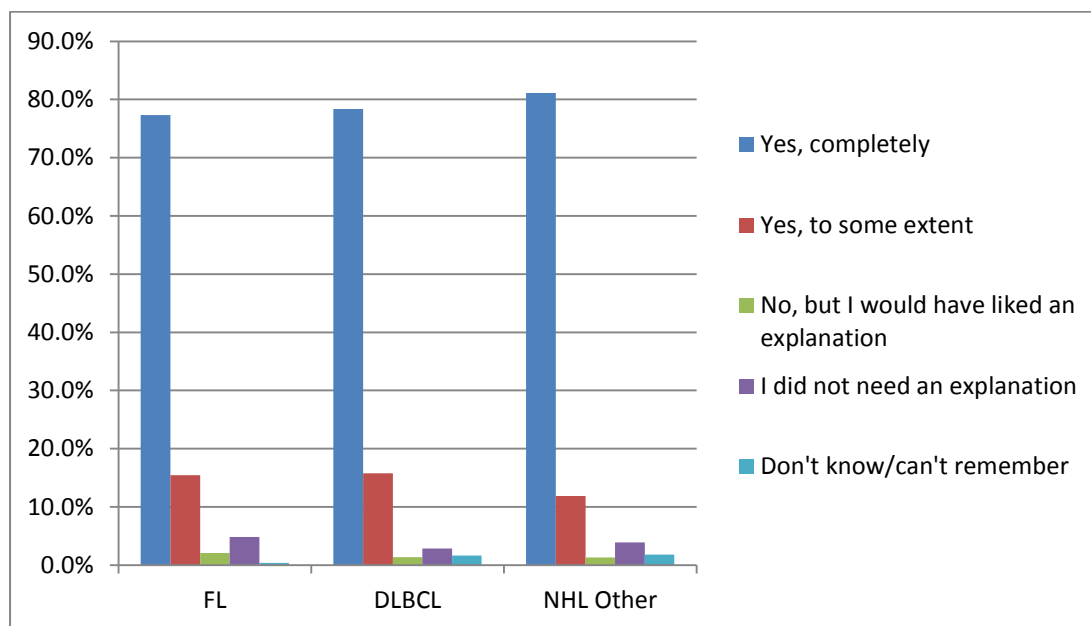


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1 In patients with NHL , 89% stated they had a diagnostic test in the last 12 months (86% vs. 92% vs.  
 2 86%; FL vs. DLBCL vs. other NHL) which was commensurate with the overall CPES survey, where 89%  
 3 of all cancer patients surveyed said they had had a diagnostic test.

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12 **Q6. Beforehand, did a member of staff explain the purpose of the test(s)?**

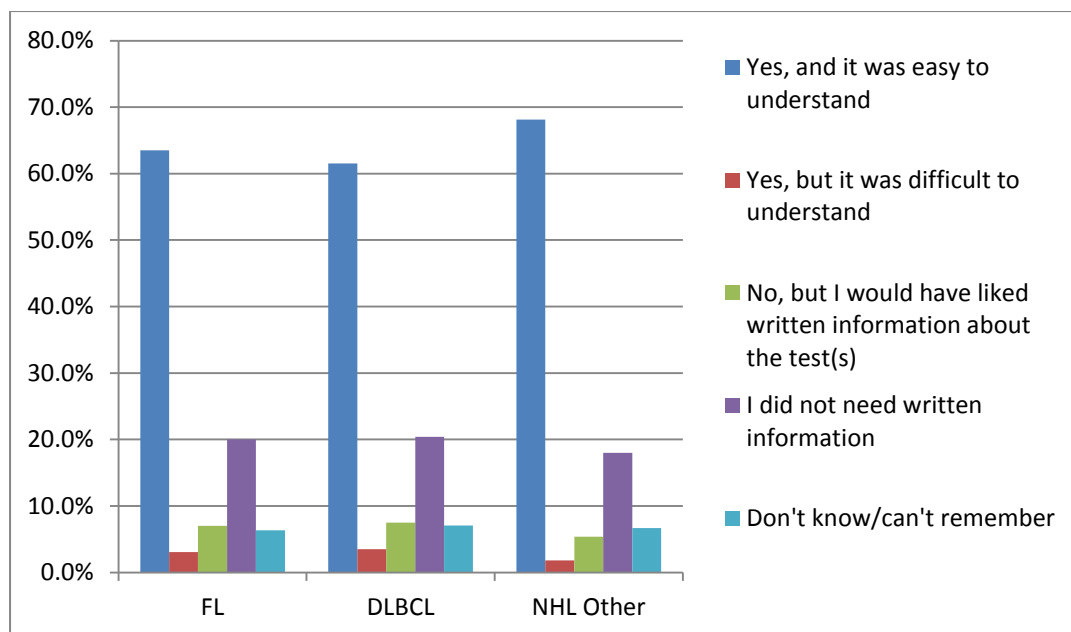


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In the patients with NHL, there was reasonable consistency in reporting with 77% vs. 78% vs. 81% (FL vs. DLBCL vs. other NHL) stating that staff had explained fully; with overall, 78% of NHL patients stated they had received a full explanation. This was slightly lower than the overall CPES survey; 84% of patients said that staff explained fully; but the 2 % of patients reporting they had not received an explanation was similar in patients with NHL and overall CPES patients ).

21 **Q7. Beforehand, did a member of staff explain what would be done during the test(s)?**

## Non-Hodgkin's lymphoma: diagnosis and management



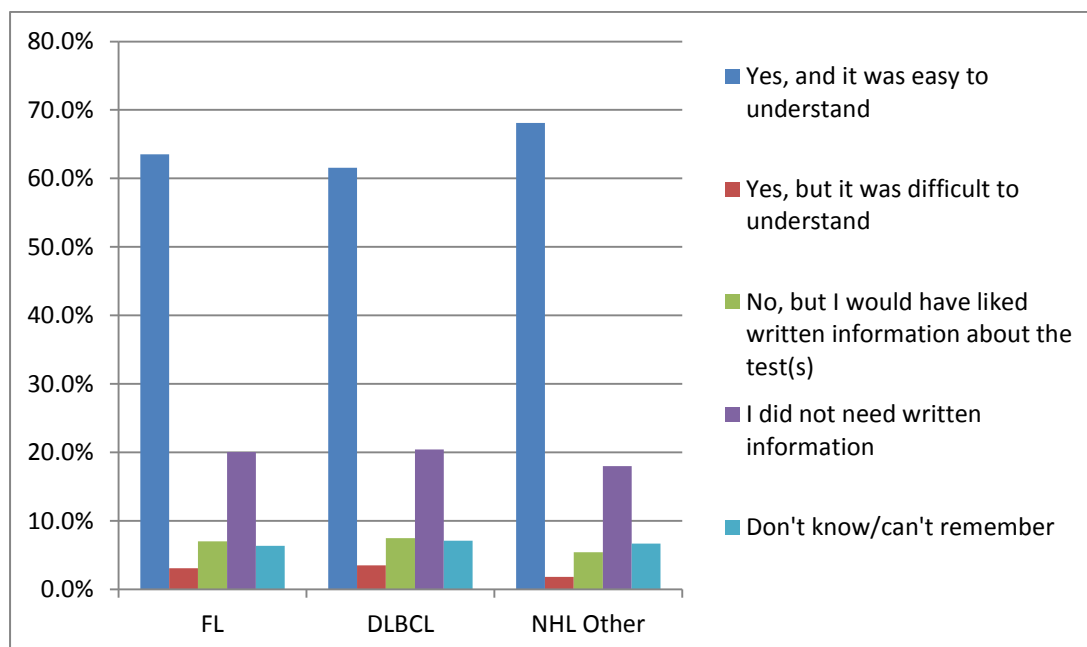
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3 There were consistent reports across patients with NHL. Overall, 84% of patients stated they had  
 4 been given a full explanation of the procedure with 82% vs. 85% vs. 87% (FL vs. DLBCL vs. other NHL)  
 5 reporting a complete explanation; this was slightly lower than in the overall CPES survey (87%).  
 6 Answers were the same from patients with NHL and overall CPES patients with 12% stating they  
 7 had received some explanation (and 1% reporting they had no explanation, respectively).

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### 9 Q8. Beforehand, were you given written information about your tests?



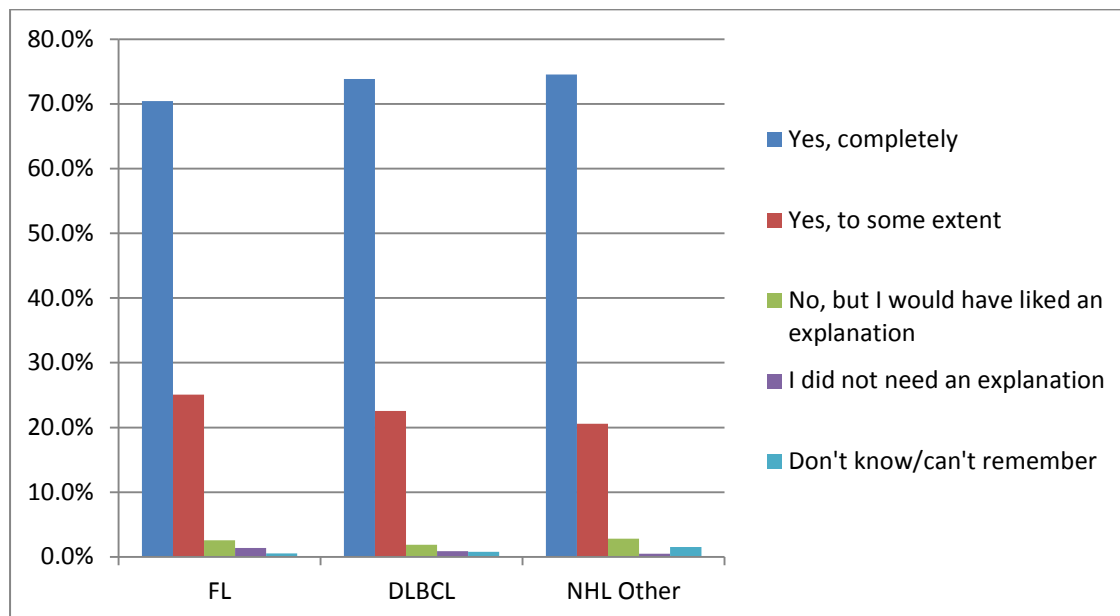
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11 Overall, patients with NHL did not state they had been given easy to understand information as  
 12 often with 63% reporting they had done so compared to 87% of patients in the CPES survey. There  
 13 were similar responses in FL and DLBCL patients (64% vs. 62%) respectively although other NHL  
 14 patients reported slightly higher satisfaction (68%). However, patients with NHL stated slightly less  
 15 frequently that they had received information that was difficult to understand (3% vs. 4%; NHL vs.

1 all CPES) or that they had been given no information (7% vs. 9%; NHL vs. all CPES). Twenty per cent  
 2 of patients with NHL stated they didn't need written information.

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4 **Q9. Were the results of the test(s) explained in a way you could understand?**



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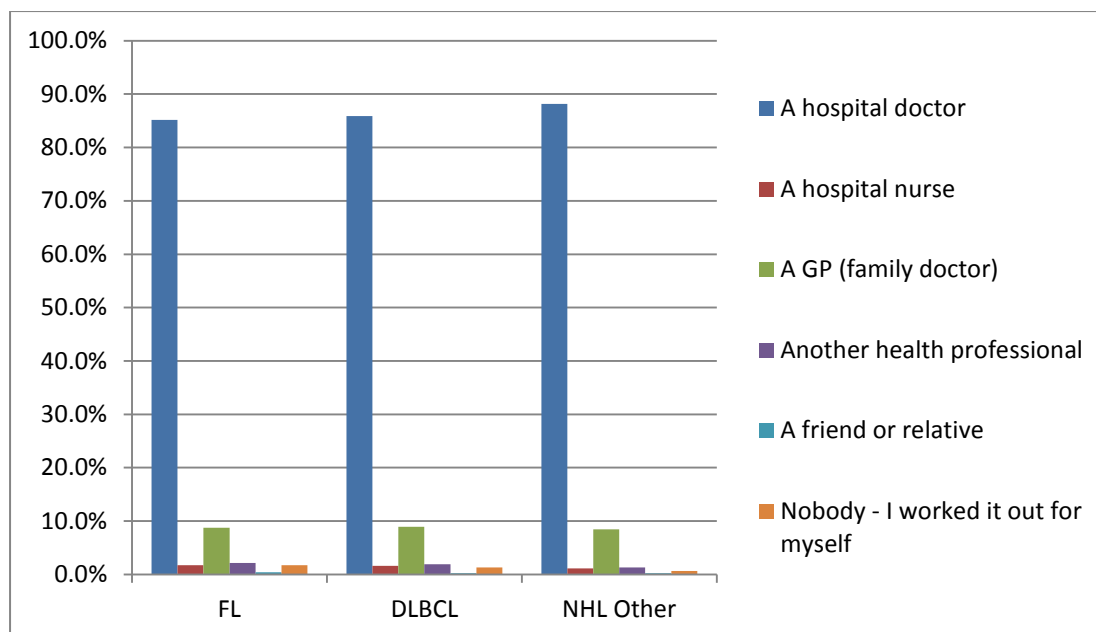
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7 Overall, 73% of patients with NHL reported that they had received a completely understandable  
 8 explanation of their test results compared to 78% of patients in the overall CPES survey with 70% vs.  
 9 74% vs. 75% (FL vs. DLBCL vs. other NHL) reporting they had fully understood. 23% of patients with  
 10 NHL reported that they had understood to some extent (compared to 19% of all CPES survey  
 11 patients) with similar results across patients with NHL compared to all CPES patients who reported  
 12 they had not received an explanation (2%)

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14 **10. Who first told you that you had cancer?**

## Non-Hodgkin's lymphoma: diagnosis and management

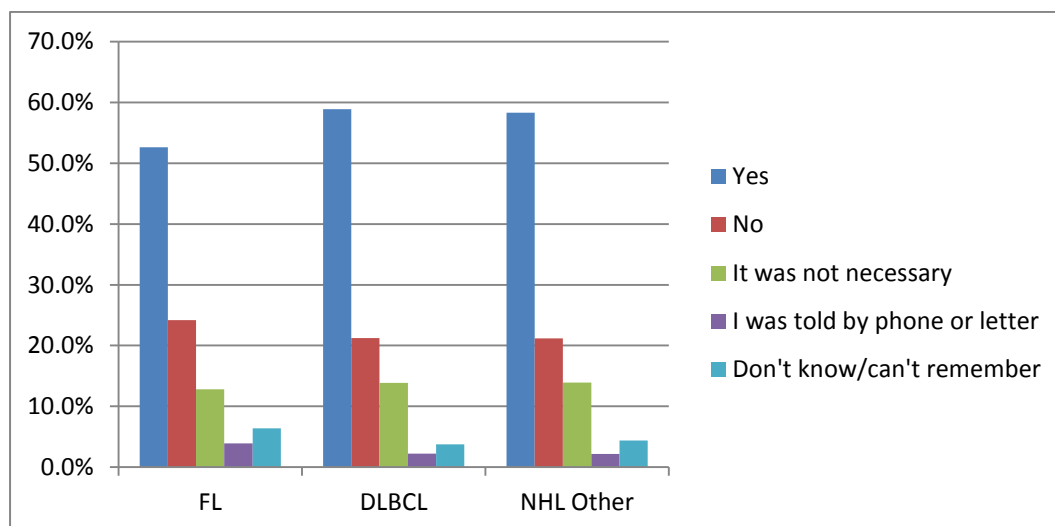


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2 A hospital doctor told 86% of patients with NHL their diagnosis compared to 82% in the overall CPES  
 3 survey. 12% of patients were told by another health care professional (nurse, GP or other)  
 4 compared to 16% of all CPES patients. Similar reports from patients with NHL compared to CPES  
 5 patients were given where a friend/relative had told them or they had figured out their diagnosis for  
 6 themselves (2%). Similar reports were seen from patients with different sub-types of NHL.

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8 **Q11. When you first were told you had cancer, had you been told you could bring a family**  
 9 **member or friend with you?**



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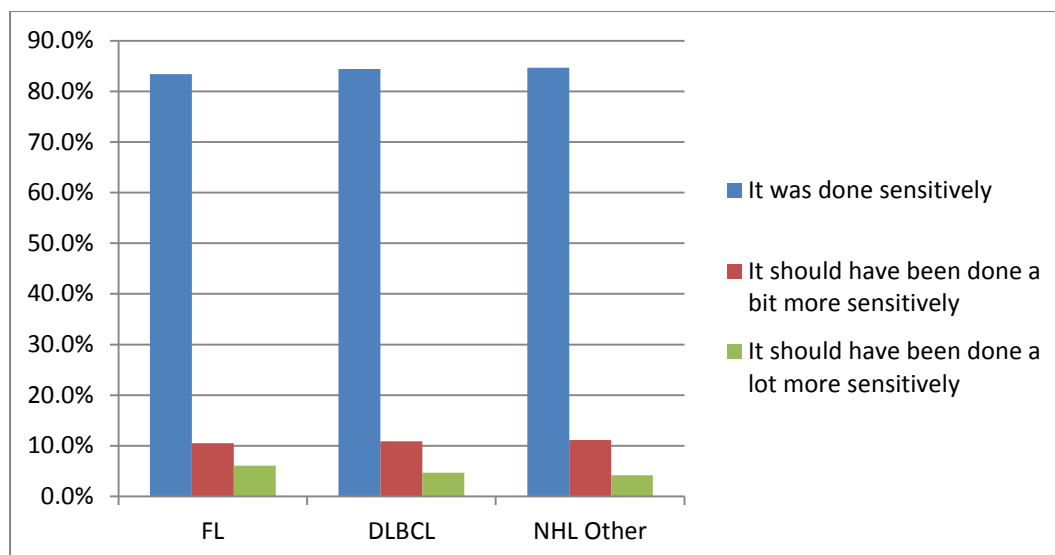
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12 Across all patients with NHL, 73% stated they were told they could bring a friend/relative which is  
 13 similar to the results across all CPES survey patients (75%). However, there is a notable difference in  
 14 FL patients who reported that only 53% were told they could bring someone, compared to 59% and  
 15 58% of DLBCL and other NHL patients respectively. Across all NHL patients, approximately 13%  
 16 stated that they felt bringing a friend/relative to receive their diagnosis was not necessary.

17 **Q12. How do you feel about the way you were told you had cancer?**



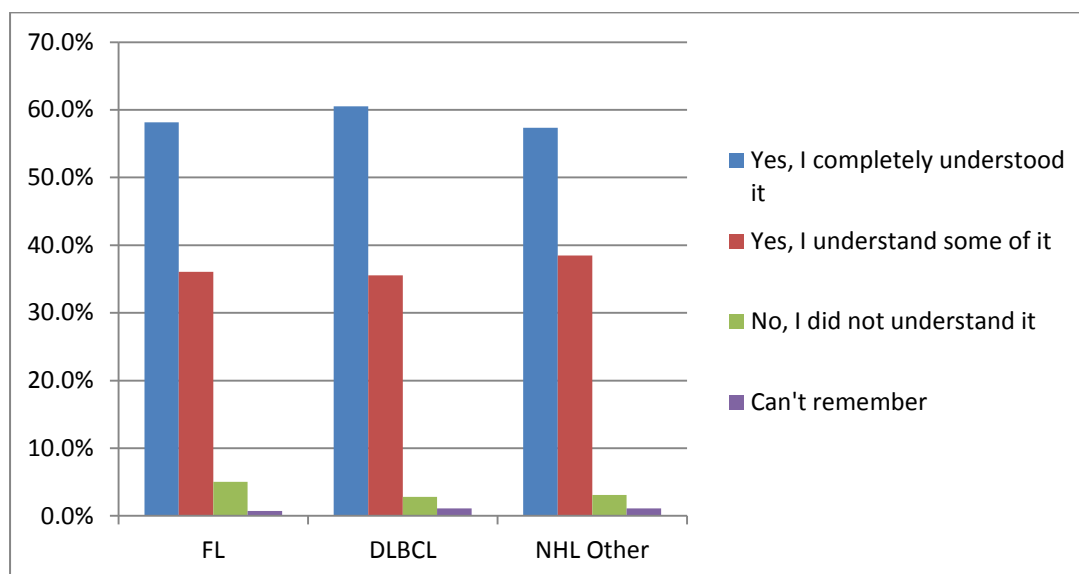
## Non-Hodgkin's lymphoma: diagnosis and management



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3 In the patients with NHL, 84% of patients stated that they had been told they had cancer in a  
4 sensitive manner and this is consistent with the report of all CPES patients (84%). Reports were  
5 consistent across the different sub groups of NHL patients, with 11% and 5% of patients with NHL  
6 reporting it could have been done a bit more or a lot more sensitively; compared to 11% and 5% of  
7 all CPES patients, respectively.

### 8 Q13. Did you understand the explanation of what was wrong with you?



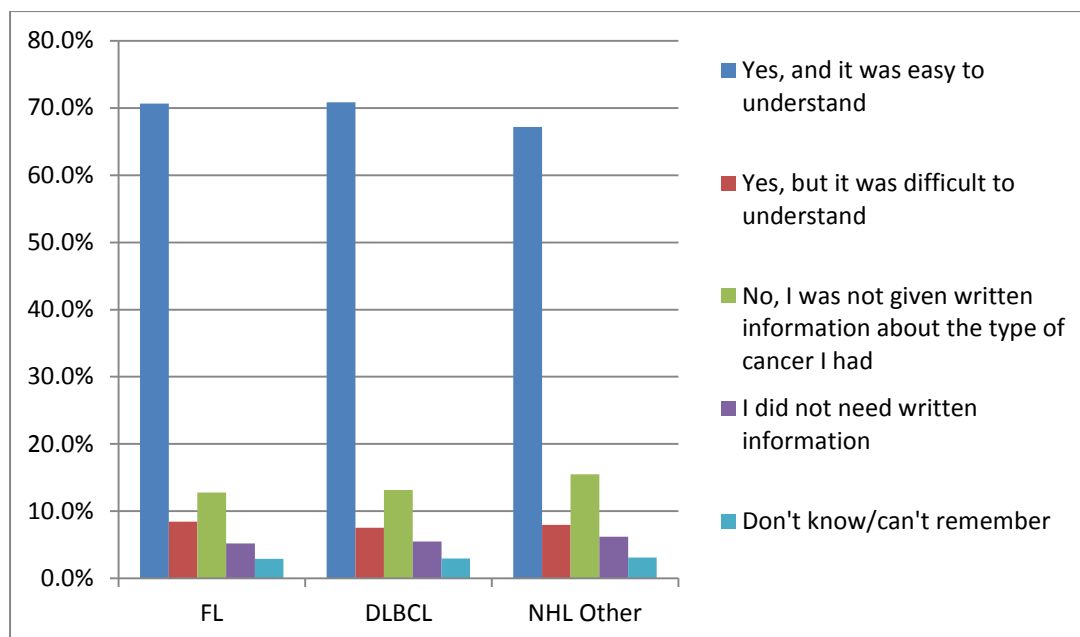
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10 Across all patients with NHL, 59% stated they had completely understood the explanation of what  
11 was wrong with them compared to 73% of all CPES patients. This was consistent when NHL sub-  
12 types were examined. Overall, 36% of NHL patients stated they understood some of the explanation  
13 with 4% stating they did not understand; compared to 25% and 2% of all CPES patients.

14

### 15 Q14. When you were told you had cancer, were you given written information about the type of 16 cancer you had?

## Non-Hodgkin's lymphoma: diagnosis and management



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3 Overall, 70% of patients with NHL said they had been given information that was easy to understand  
 4 compared to 72% of patients in the overall CPES survey. However, 14% of patients with NHL stated  
 5 they had not received information compared to 20% of patients in the overall CPES survey. Results  
 6 were similar for patients with all sub-types of NHL.

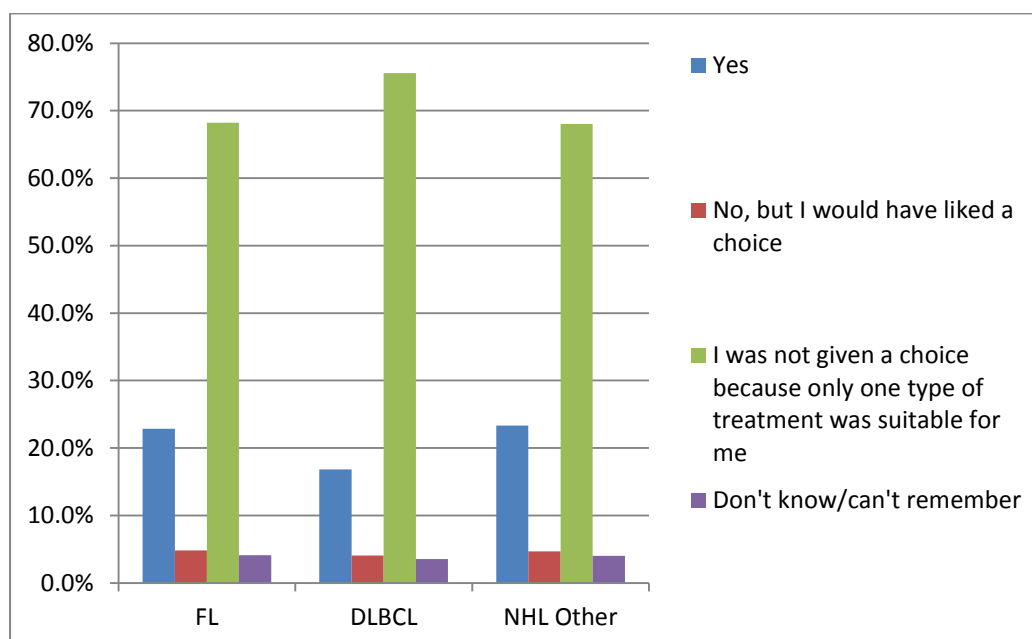
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### 1. Treatment decision making

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10 **Q15. Before your cancer treatment started, were you given a choice of different types of**  
 11 **treatment?**

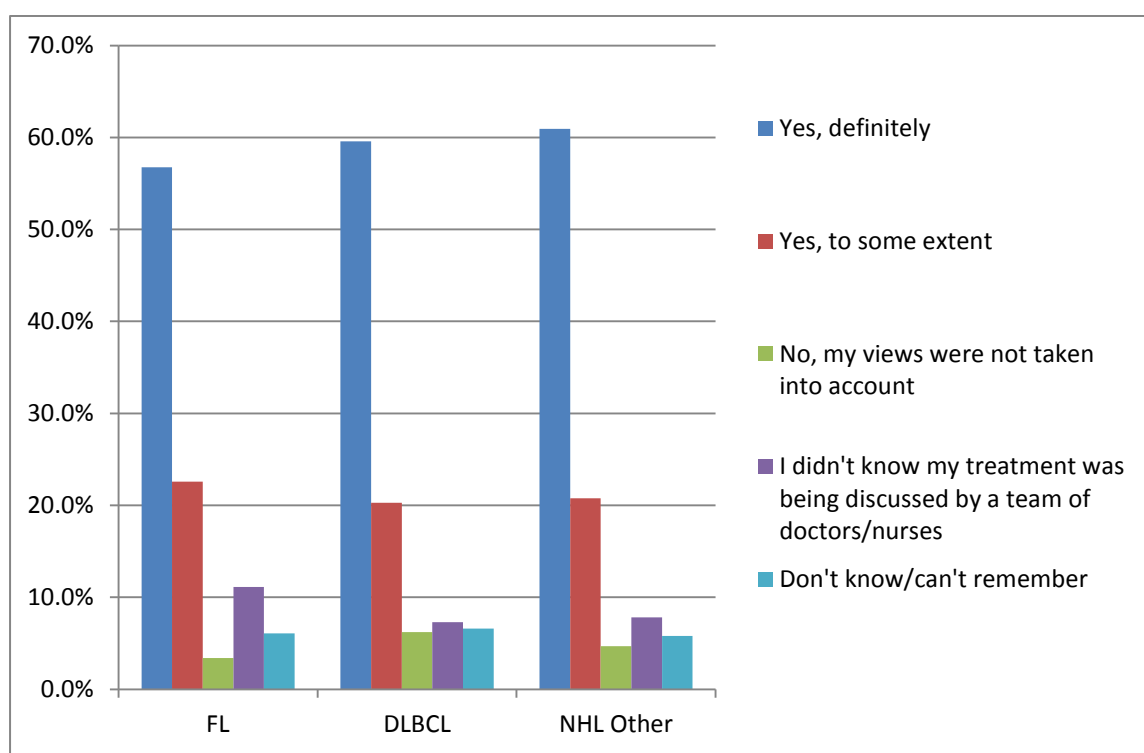


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Overall, 72% of patients with NHL stated they were not given a choice of treatment because only one treatment type was suitable, compared to 59% of all CPES survey patients. There were some differences between sub-types (68% vs. 76% vs. 68%; FL vs. DLBCL vs. other NHL). Of the remaining patients, overall only 4% of patients with NHL stated they were not given a choice but would have liked one compared to 14% of all CPES patients.

**16. Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?**



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Overall, 8% of patients with NHL did not know their treatment was being discussed by their team and 6% could not recall, compared to 7% and 5% of patients in the overall CPES survey.

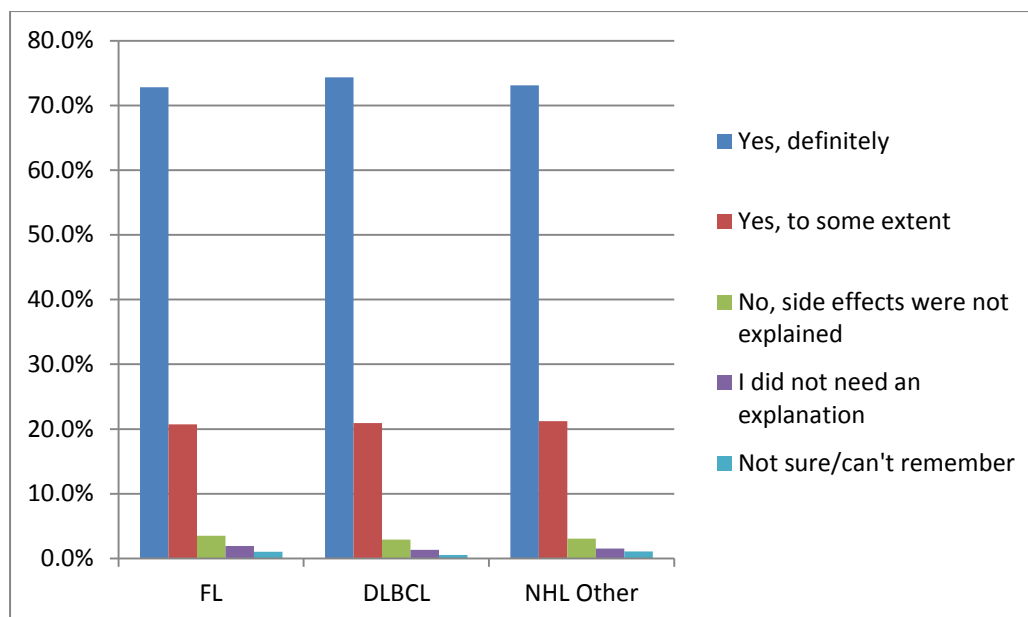
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. Of those who did know, 59% of patients with NHL compared to 71% of all CPES survey patients said their views were definitely taking into account; . When results were compared across all categories of responses, results were similar for patients with all sub-types of NHL.

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**19 Q17. Were the possible side-effects of treatment(s) explained in a way you could understand?**

## Non-Hodgkin's lymphoma: diagnosis and management

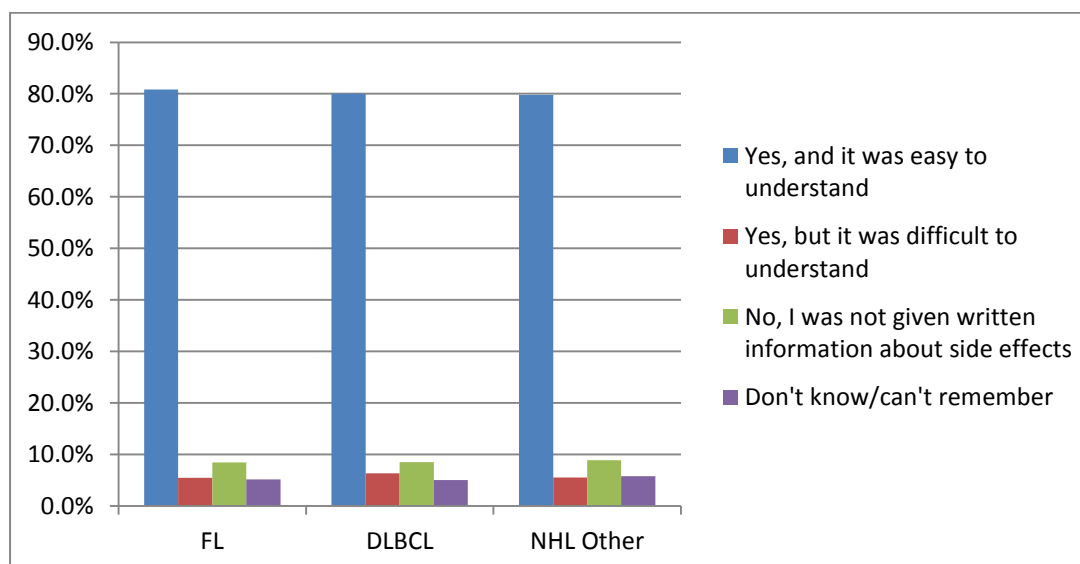


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3 Across all patients with NHL, 74% stated they had definitely been told about the possibility of side  
4 effects, with 21% stating they had been told to some extent. In the overall CPES survey, 75% of  
5 patients said they had definitely had an explanation of possible side-effects with a further 21% and  
6 4% saying the explanation was understandable to a certain extent or not at all, respectively. These  
7 responses appeared to be consistent for patients with all different sub-types of NHL.

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9 **Q18. Before you started your treatment, were you given written information about the side-**  
10 **effects of treatment(s)?**

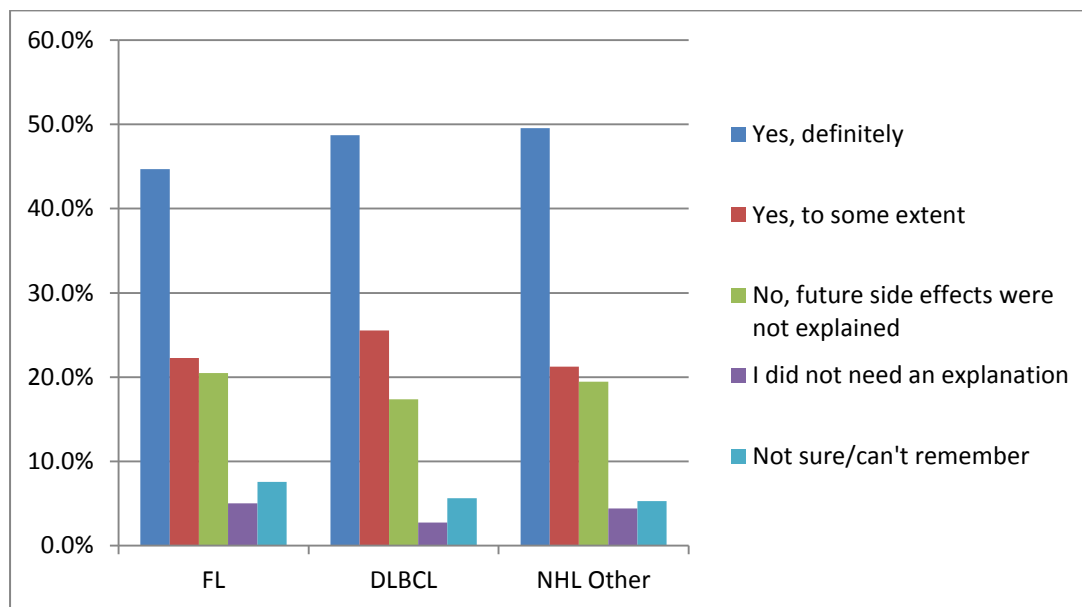


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12 **Eighty per cent of patients with NHL said they had been given easy to understand information.**  
13 **Eighty two per cent of patients in the CPES survey said they had received written information.**  
14 Results were similar when compared across the different sub-types of NHL patients.

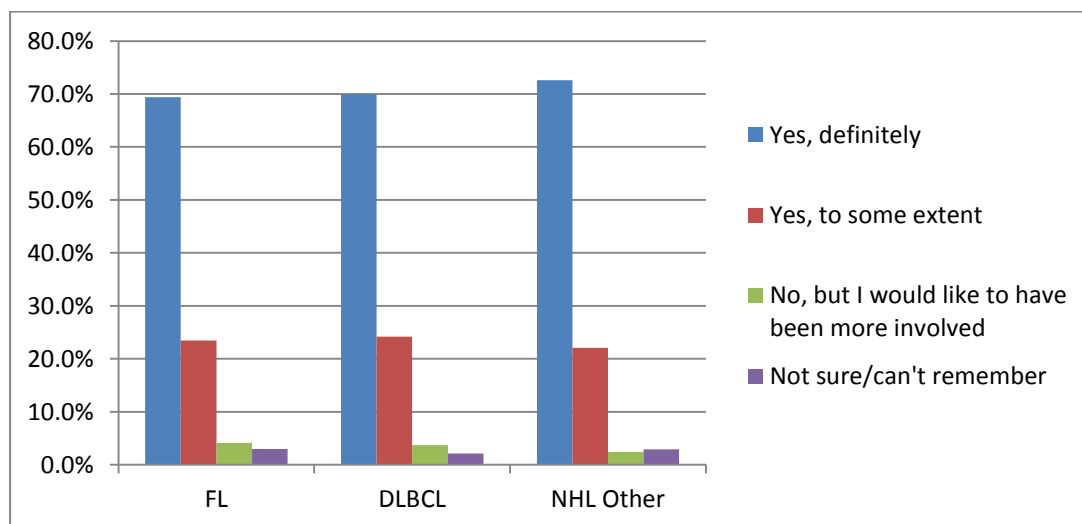
15

1 **Q19. Before you started your treatment, were you also told about any side effects of the**  
 2 **treatment that could affect you in the future rather than straight away?**



3  
 4 Overall, 48% of patients with NHL stated they were definitely told about longer-term side effects  
 5 which was lower than patients in the overall CPES survey (55%). Forty five per cent of patients with  
 6 FL said they were told compared to 49% and 50% of DLBCL and other NHL patients respectively.  
 7 Overall, 19% of patients said nothing had been explained and 4% said they did not need an  
 8 explanation compared to 18% and 6% of all CPES patients surveyed.

9  
 10  
 11 **Q20. Were you involved as much as you wanted to be in decisions about your care and treatment?**

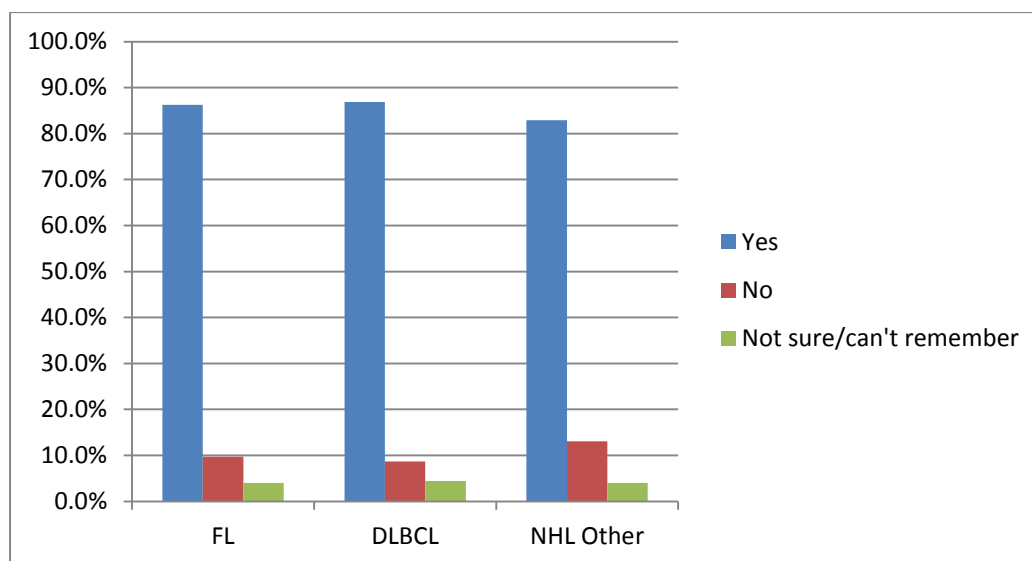


12  
 13  
 14 Seventy per cent of patients with NHL reported that they had definitely been involved in decisions,  
 15 which was similar to the 72% of patients in the overall CPES survey who said they had definitely been  
 16 involved. Results were consistent across the different sub-types of NHL.

17

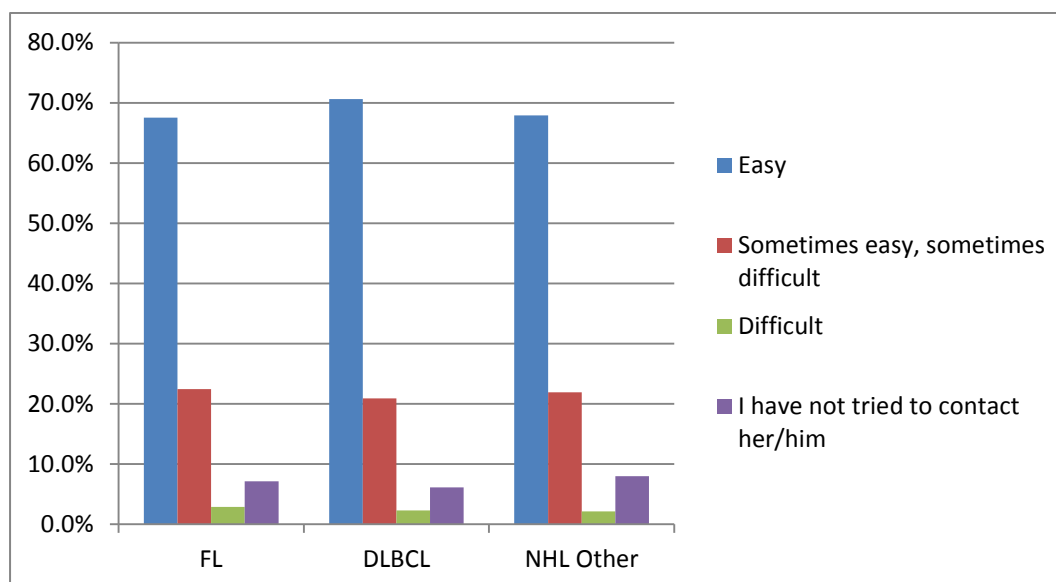
## 2. Clinical nurse specialist (CNS) support

### 21. Were you given the name of a CNS who would be in charge of your care?



Eighty-six per cent of patients with NHL stated they had definitely been given a name with 10% saying they had not. This was slightly lower in the other NHL sub-type (83%) compared to patients with FL and DLBCL (87% said they had definitely been given a name in both groups), but generally results were comparable with the overall CPES survey population (89% vs. 11%; yes vs. no.).

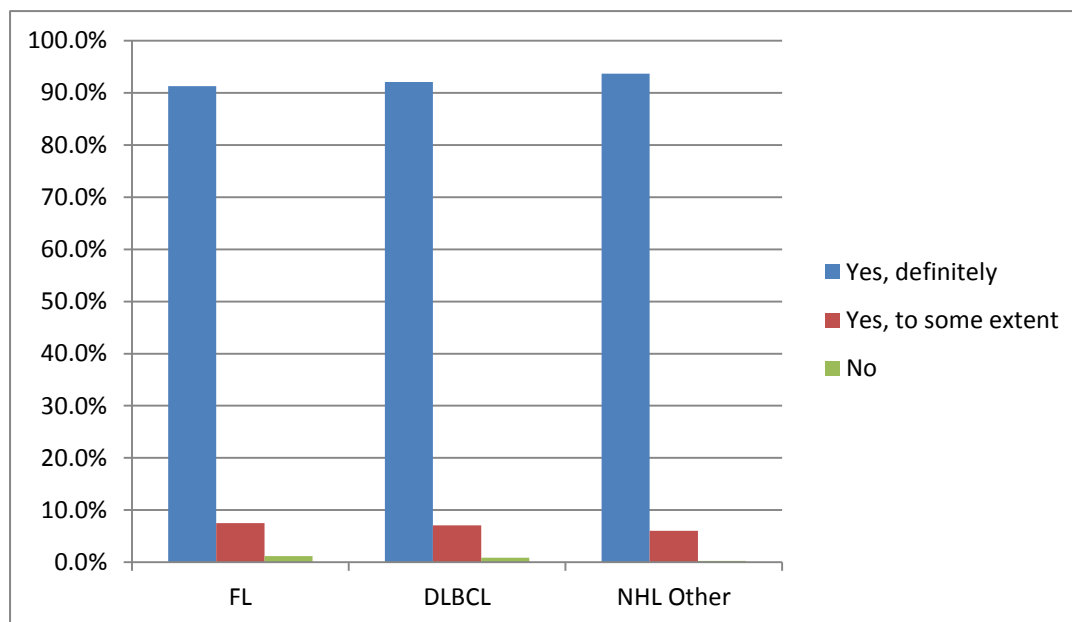
### 22. How easy is it for you to contact your CNS?



Overall, 70% of patients said they had found it easy to contact their CNS, with 22% saying it was sometimes easy, sometimes difficult, 2% stating difficulties and 7% saying they had not tried to contact their CNS. Results were similar across different groups of NHL patients but reporting of easy contact was slightly lower compared to patients who had tried to contact in the overall CPES survey, where 73% said they had found it easy.

1

2 **23. The last time you spoke to your CNS, did he/she listen to you?**



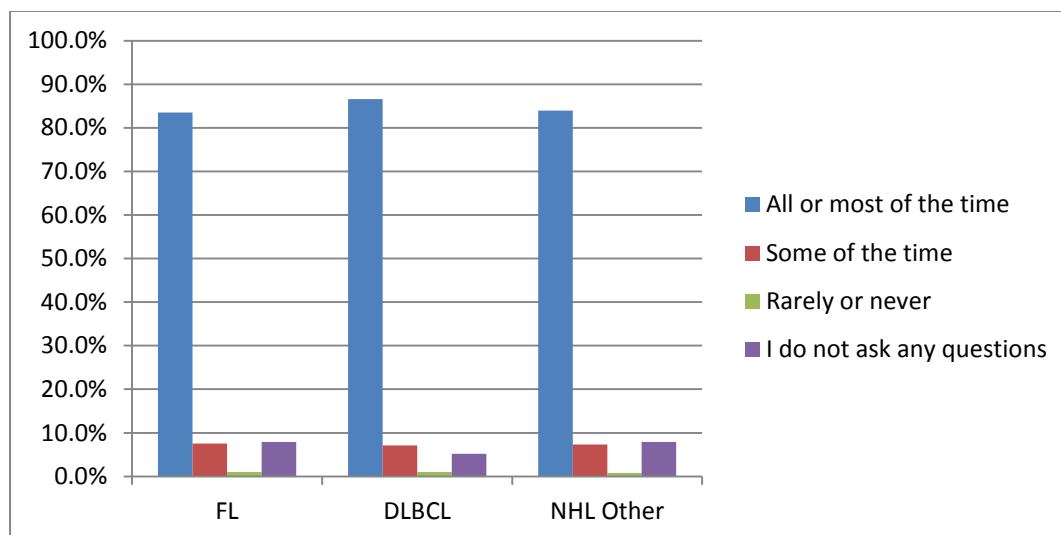
3

4 Ninety two per cent of patients with NHL said that their CNS definitely listened to them,  
 5 commensurate with 91% of all CPES patients. Results were similar across all sub-types of NHL.

6

7

8 **Q24. When you have some important questions to ask your CNS how often did you get answers  
 9 you could understand?**



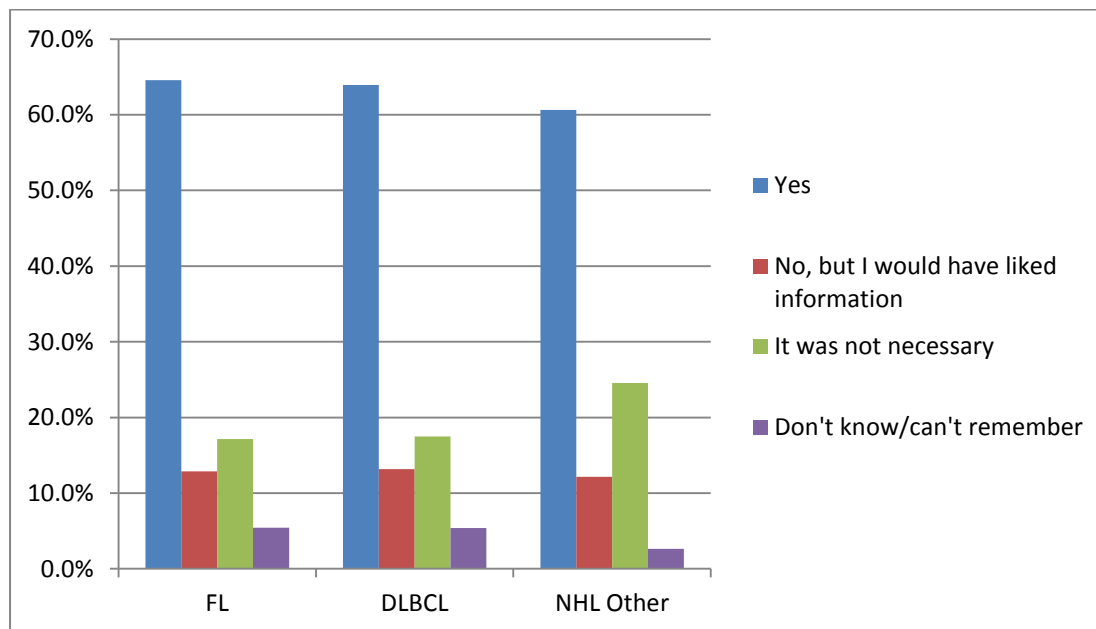
10

11 Overall, 92% of patients with NHL reported they definitely got answers they could understand,  
 12 similar to the overall CPES survey were 91% said they had received understandable answers all or  
 13 most of the time. These responses were consistent across the different sub-types of NHL.

14

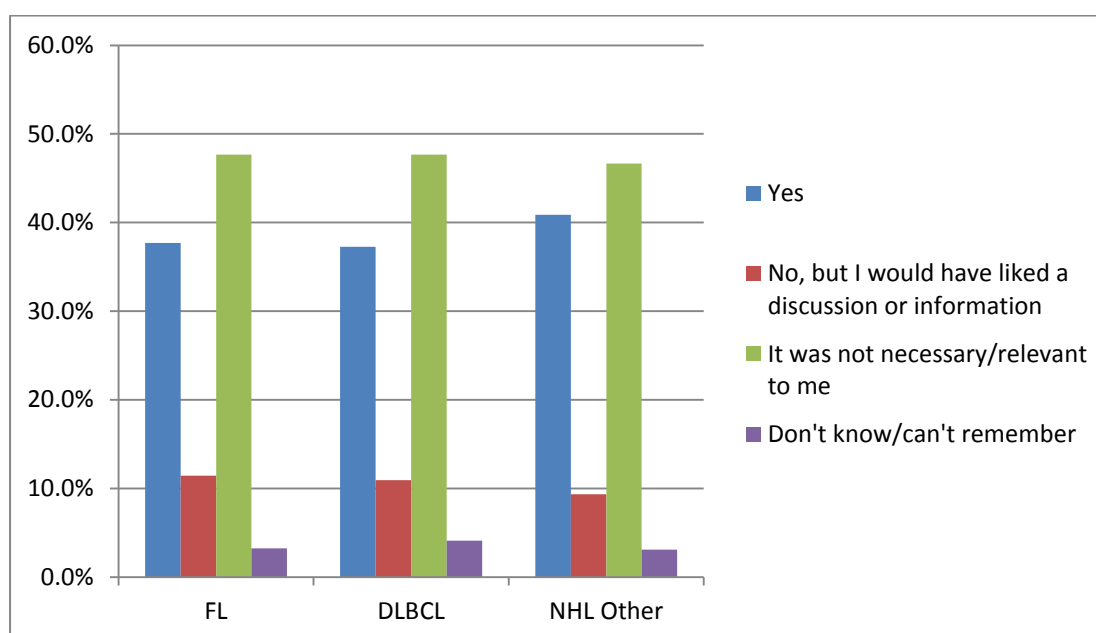
### 3. Support for patients

**Q25. Did hospital staff give you information about support or self-help groups for people with cancer?**



Overall 64% of patients with NHL were given information with 13% stating they would have liked information and 18.7% saying it was not necessary. These results were similar across FL and DLBCL patients but slightly different in other NHL sub-types where 61% of patients stated they were given information and 25% of patients reported that this was not necessary. This is somewhat different to the overall CPES survey where 83% of patients stated they were given information and 17% said they did not get any information but would have liked some.

**Q26. Did hospital staff discuss with you or give you information about the impact cancer could have on your work life or education?**



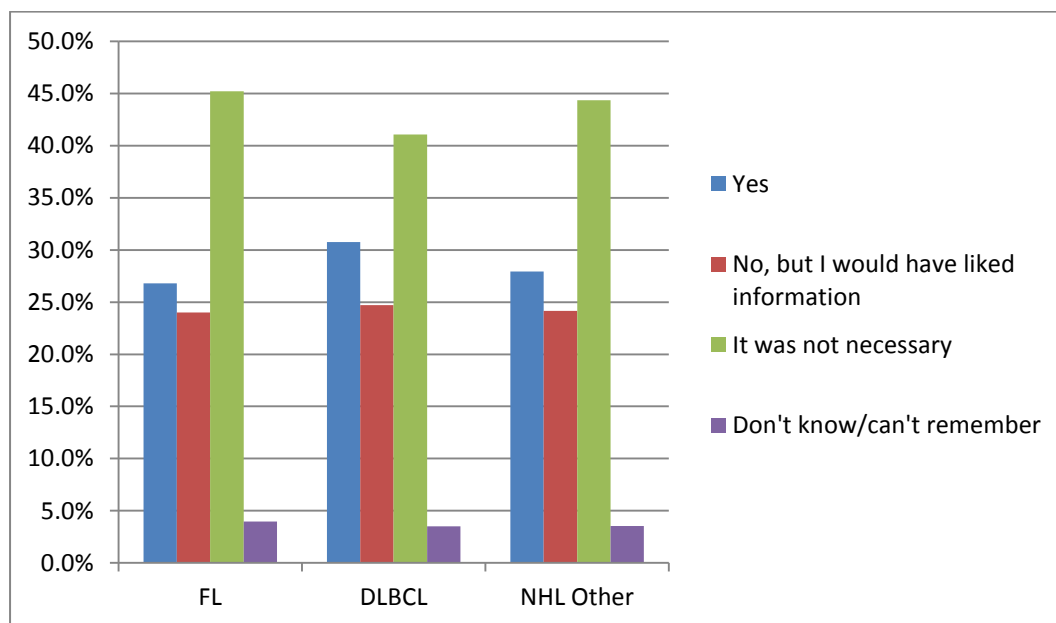


1 As with the overall CPES survey patients where 48% of respondents stated this was not necessary or  
 2 relevant to them, 48% of all patients with NHL also said this information was not necessary. Overall,  
 3 72% of patients said they had been given the opportunity which is similar to overall CPES patients  
 4 (75%)

5  
 6 In patients with NHL who said this question was relevant to them, there were small differences in  
 7 responses across different sub-types of NHL with regard to whether this information was necessary  
 8 or relevant to him/her and if so the % of responses who reported they had received information.

9  
 10

11 **Q27. Did hospital staff give you information about how to get financial help or any benefits that**  
 12 **you might be entitled to?**



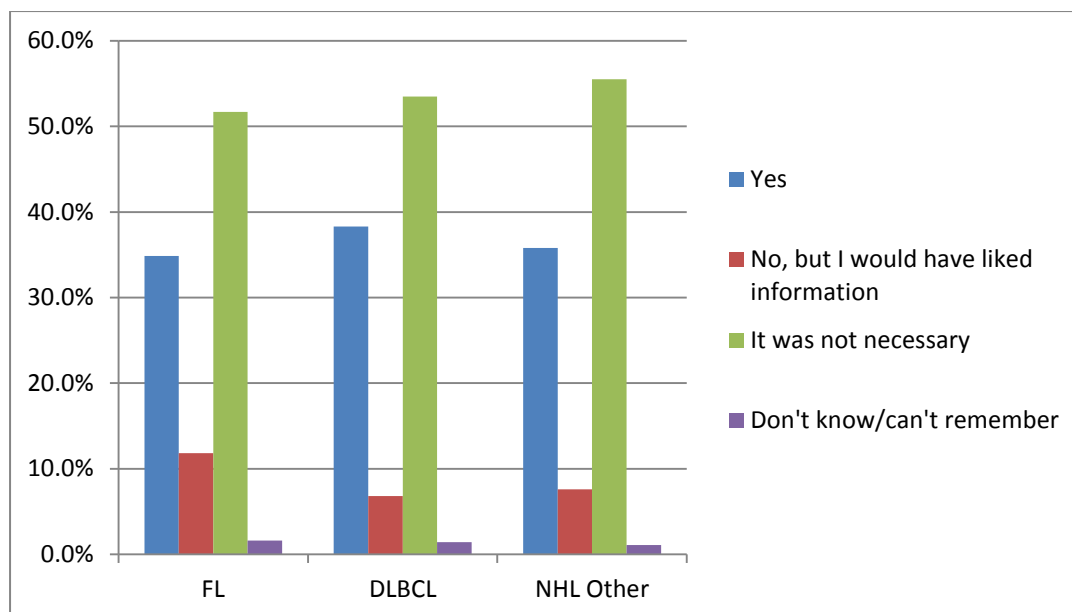
13

14 In patients with NHL who said this was necessary, 54% had been given information which was  
 15 exactly the same as reported by patients in the overall CPES survey (54%). / . These results appeared  
 16 similar when different NHL sub-types were examined with regard to whether this was necessary and  
 17 the % of patients who reported they had been given this information .

18

19 **Q28. Did hospital staff tell you that you could get free prescriptions?**

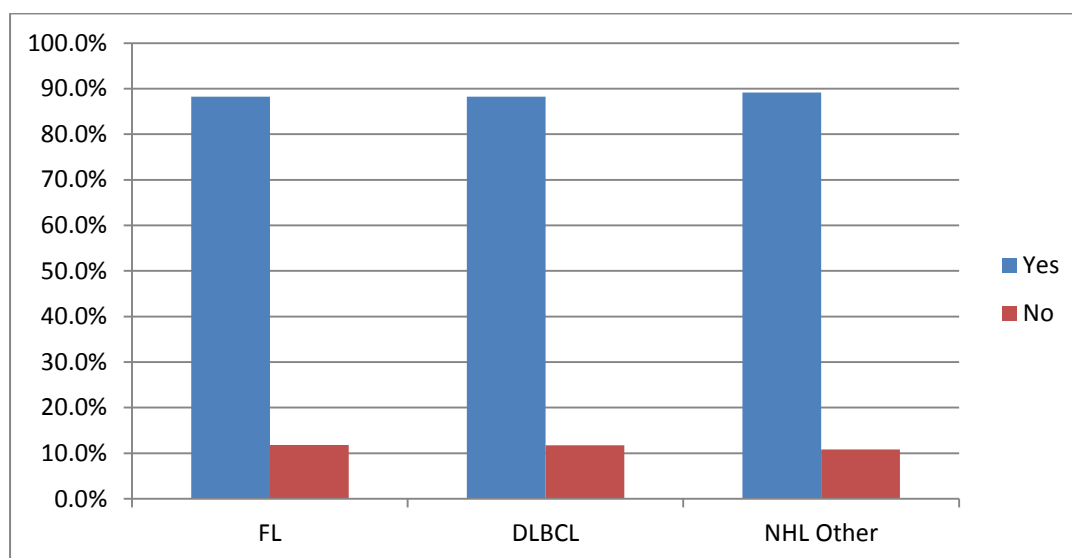
## Non-Hodgkin's lymphoma: diagnosis and management



1

2 Overall, 81% of patients with NHL who said it was necessary, reported they had been given  
 3 information similar to 78% reported in the overall CPES survey. These responses were similar across  
 4 patients with different sub-types of NHL with regard to whether this was necessary and if so, the %  
 5 of patients who reported they had received the information.

6 **Q29. Have you seen information (such as leaflets, posters) about cancer research in your hospital?**



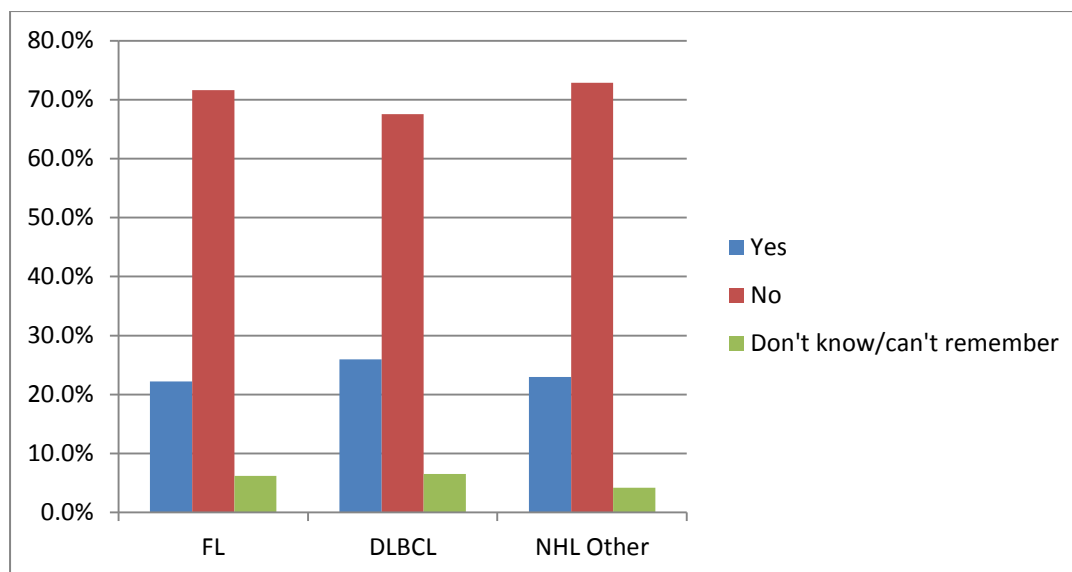
7

8

9 Eighty-eight per cent of patients with NHL reported that they had seen information which was  
 10 similar across the different sub-types of NHL and similar to the 86% of patients in the overall CPES  
 11 survey.

12 **Q30. Since your diagnosis has anyone discussed with you whether you would like to take part in  
 13 cancer research?**

## Non-Hodgkin's lymphoma: diagnosis and management

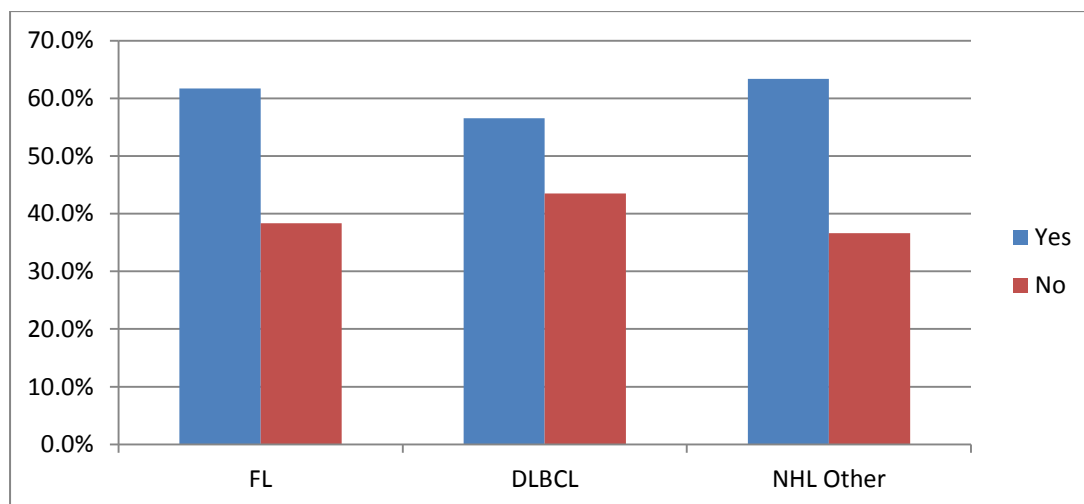


1

2 Only 24% of patients with NHL stated that someone had discussed taking part in cancer trials and  
 3 this was similar across the different sub-types of NHL patients. This was lower than the overall CPES  
 4 survey results where 31% of patients said that taking part in research had been discussed.

5

6 **Q31. If yes, did you then go on to take part in cancer research?**



7

8 Fifty-nine per cent of patients with NHL who had been invited to do so reported that they had taken  
 9 part in research compared to 63% of patients in the overall CPES survey. Responses were similar  
 10 across different sub-types of NHL patients.

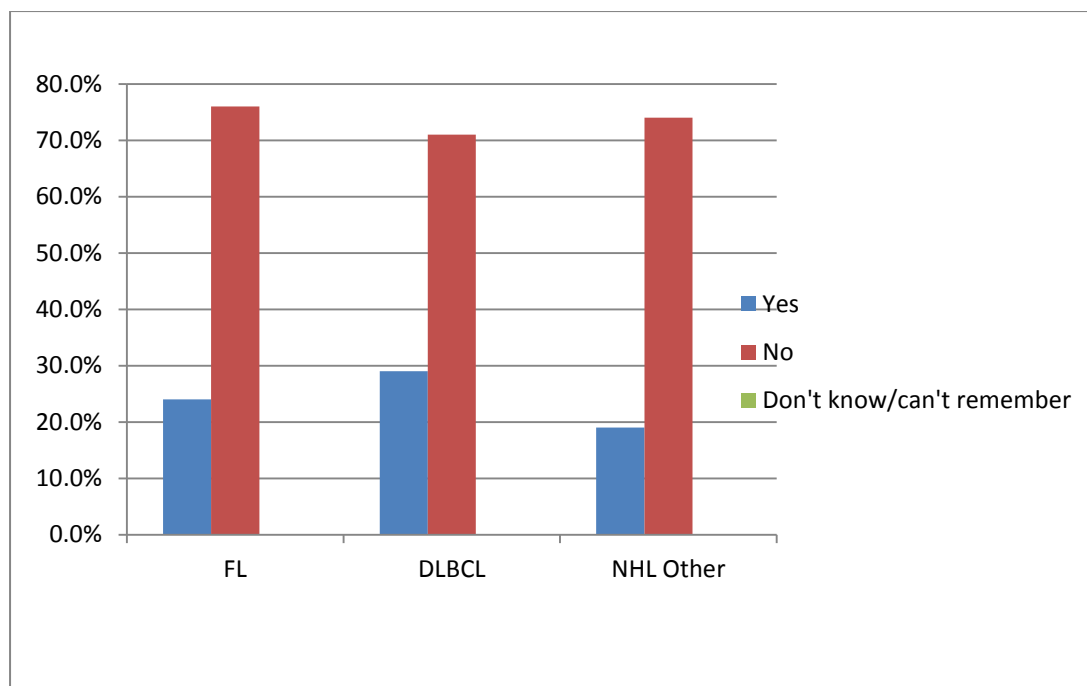
11

## 12 Operations

13

14 **Q32. During the last 12 months, have you had an operation (such as a removal of a tumour of**  
 15 **lump)**

## Non-Hodgkin's lymphoma: diagnosis and management

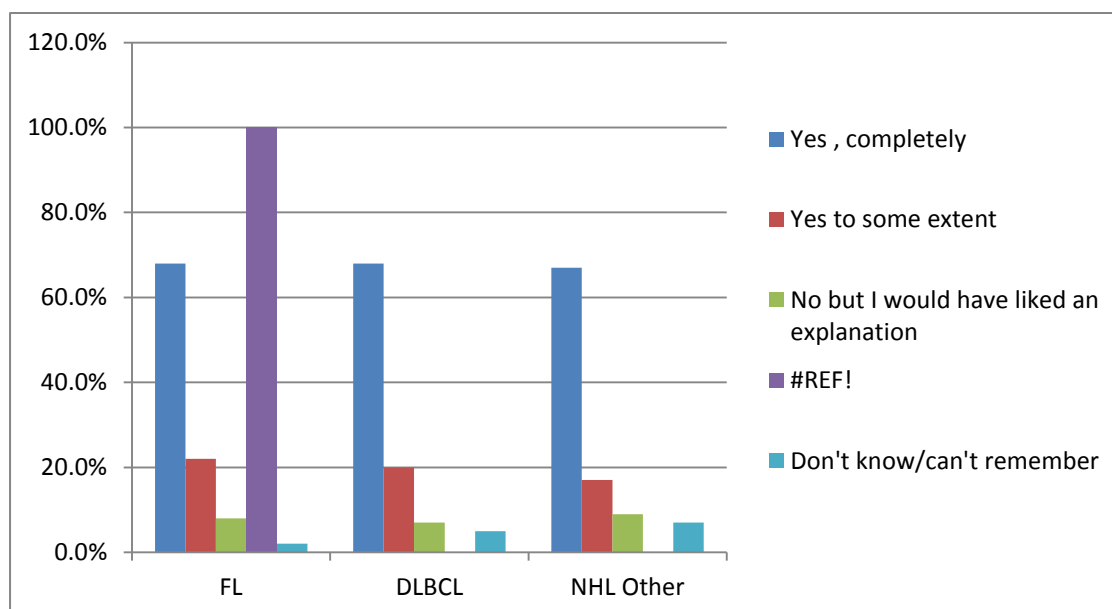


1

2

3 There were different responses shown across the different sub-types of patients with NHL with 24%,  
 4 29% and 19% of patients with FL, DLBCL and other NHL sub-types, respectively reporting they had  
 5 received an operation in the last 12 months. Overall, 26% of patients with NHL reported they had  
 6 had an operation compared to 55% of all CPES patients.

7 **Q33. Before you had your operation, did a member of staff report what would be done?**



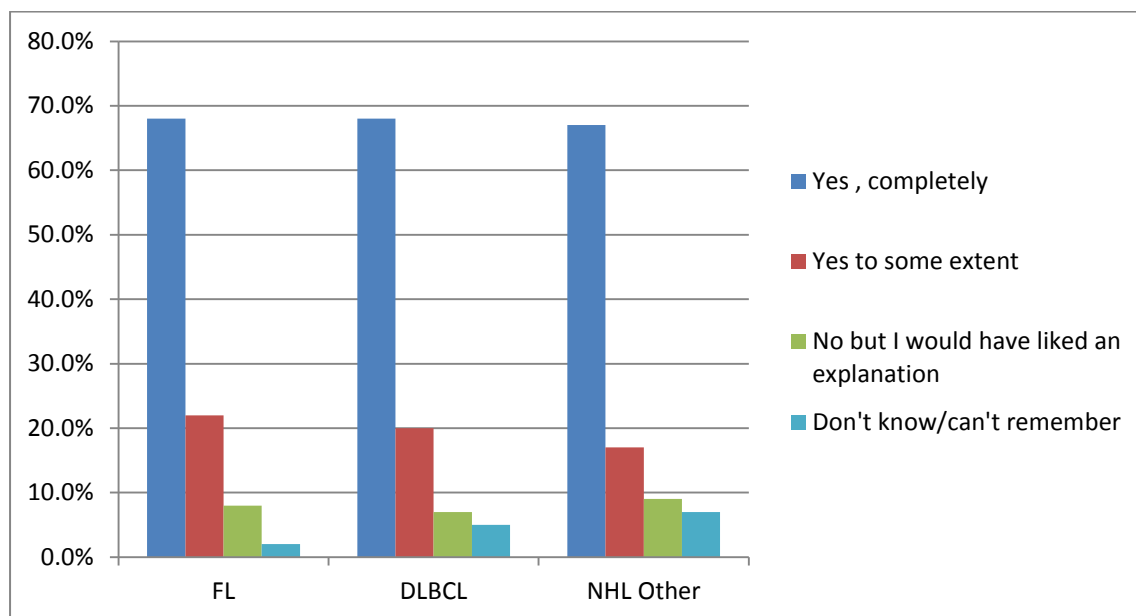
8

9 Overall, 79% of patients with NHL who had reported they had received an operation in the past 12  
 10 months stated that they had been told by a member of staff what would be done in comparison to  
 11 88% in the overall CPES. These results were similar across the different sub-types of NHL patients.

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**Q34. Before your operation, did you receive written information?**



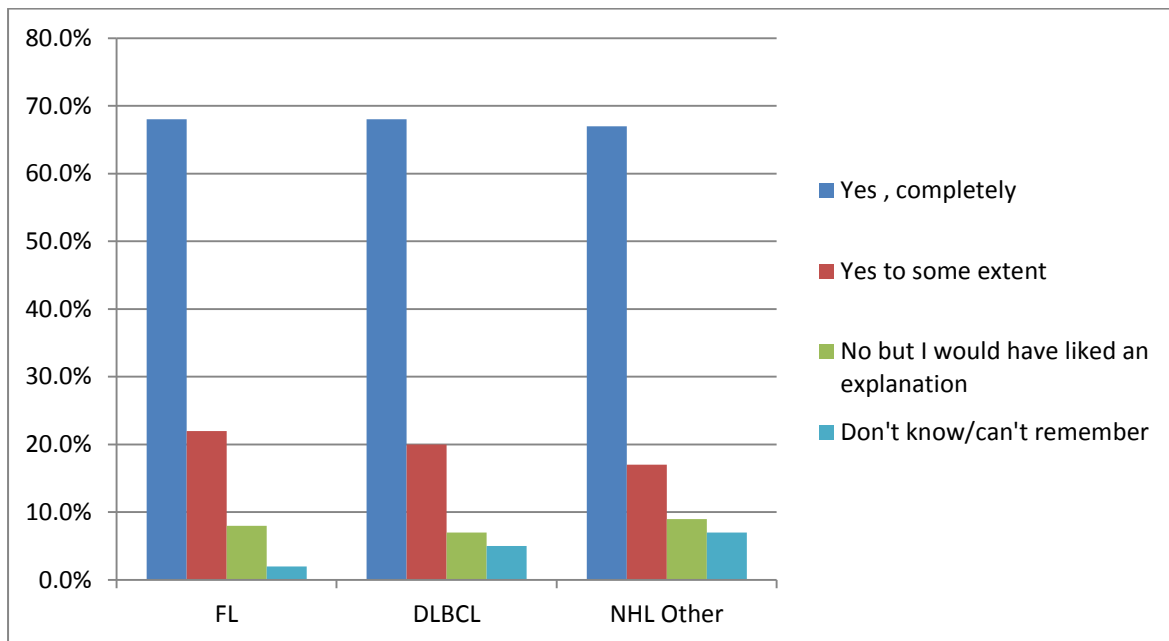
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Overall, 54% of all patients with NHL who had received an operation, stated they had been given written information which was easy to understand with 31% stating they were not given any information. This was particularly low in patients with other NHL diagnoses with only 45% stating they had been given information which was easy to understand. For the CPES survey, 76% of patients said they had been given easy to understand written information.

**Q35. After the operation did a member of staff explain in a way you could understand?**

## Non-Hodgkin's lymphoma: diagnosis and management

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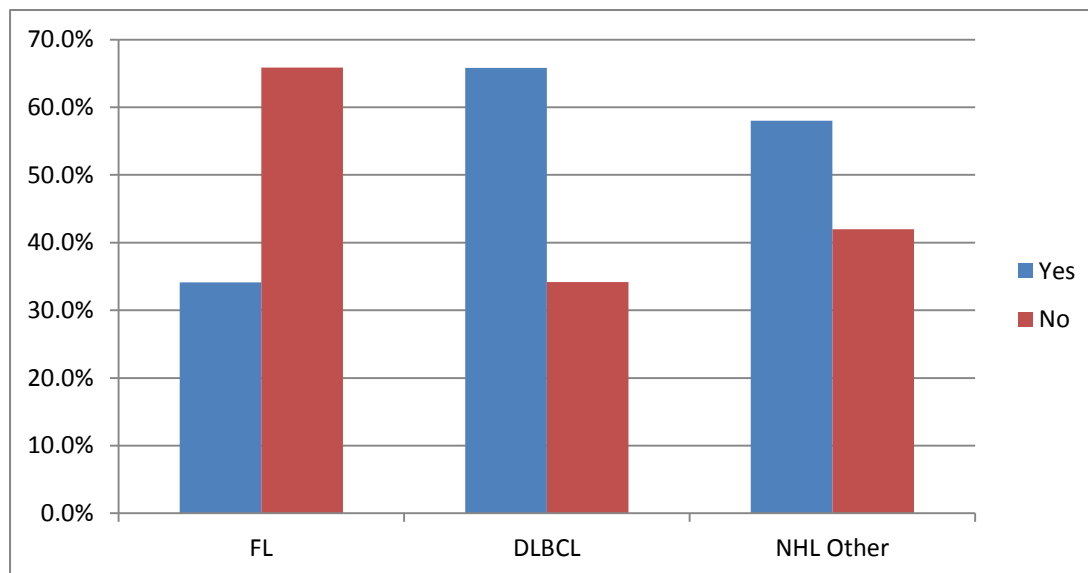
2

3 Overall, 68% of patients with NHL said they had received information that they completely  
4 understood from a member of staff, with similar results reported across the different sub-types of  
5 NHL patients. Overall, 78% of CPES patients reported they had received a completely  
6 understandable explanation.

7

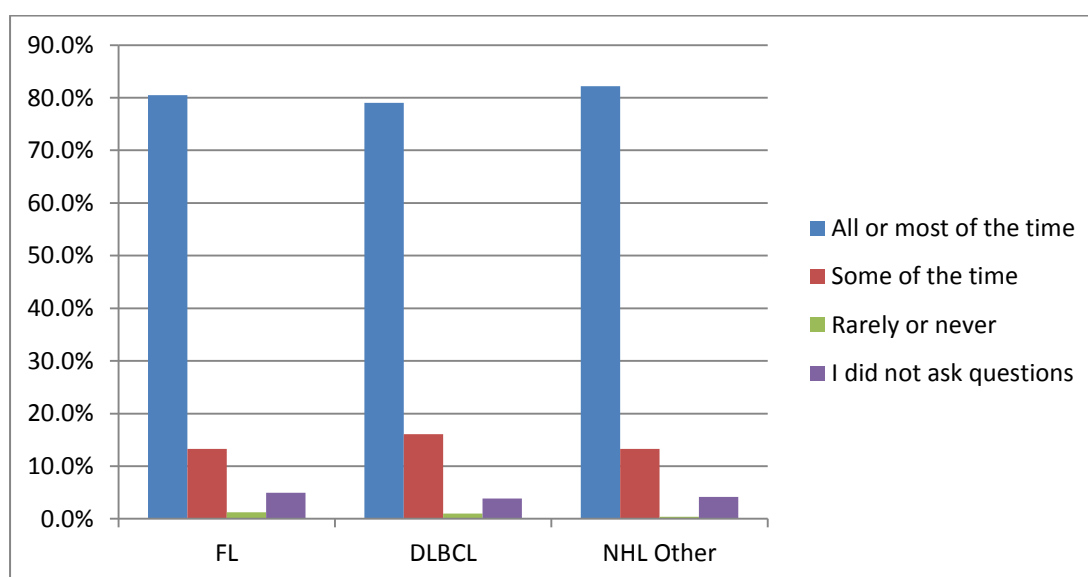
**4. Hospital doctors**

**Q36. During the last 12 months have you had an operation or stayed overnight for cancer care at one of the hospitals [named in covering letter]?**



Overall, 56% of patients with NHL stated they had stayed in hospital overnight which was lower than the overall CPES survey which reported 66% of patients who had said they had had an overnight stay. There were considerable differences across patients with different sub-types of NHL with 34% vs. 66% vs. 58% of FL vs. DLBCL vs. other NHL sub-types reporting an overnight stay, respectively.

**Q37. When you had important questions to ask a doctor, how often did you get an answer you could understand?**



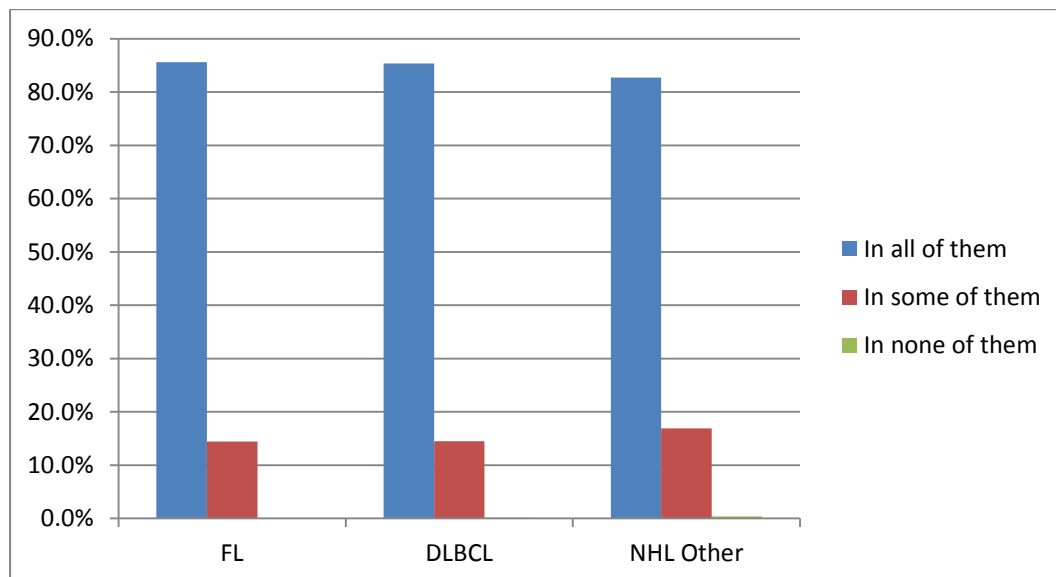
Eighty per cent of patients with NHL reported they were given an answer they understood most or all of the time; compared to 83% of patients in the overall survey. Fifteen per cent reported they

## Non-Hodgkin's lymphoma: diagnosis and management

1 had answers which they understood some of the time and 0.9% reported they rarely or never got  
 2 answers compared to 16% and 2% respectively in the overall CPES survey. Responses were similar  
 3 across the different sub-types of NHL patients.

4

5 **Q38. Did you have confidence and trust in the doctors treating you?**

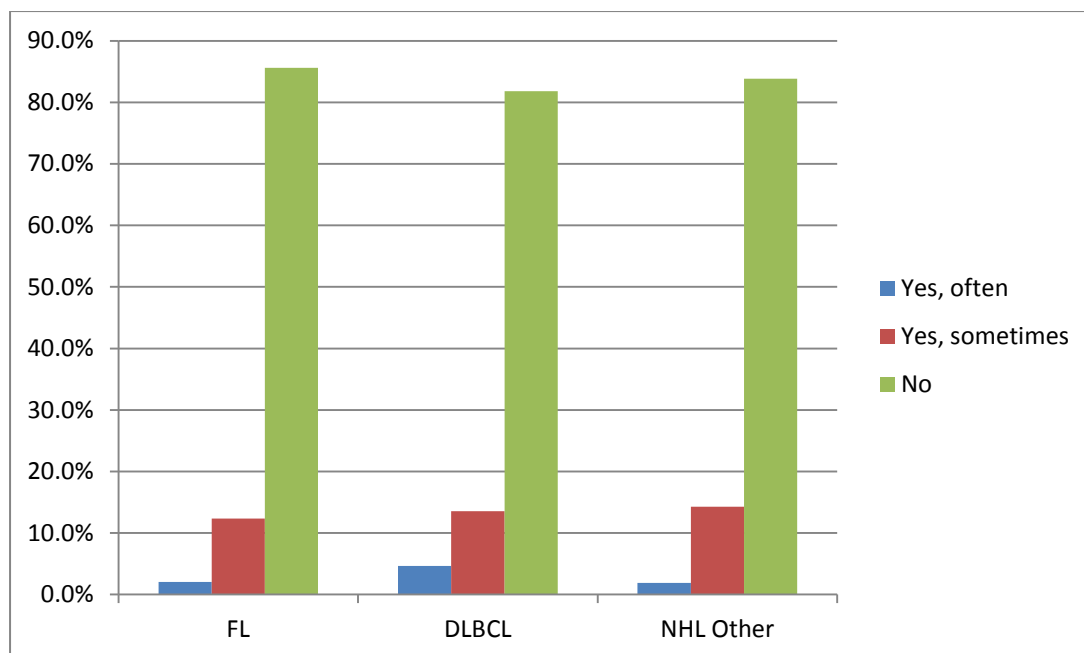


6

7 In patients with NHL, 85% said they had confidence and trust in their doctors which was exactly the  
 8 same as the overall CPES survey response of 85%, with 15% of both patients with NHL and overall  
 9 CPES patients saying they had confidence and trust in some of them. The results were similar across  
 10 the different sub-types of NHL patients.

11

12 **Q39. Did doctors talk in front of you as if you weren't there?**

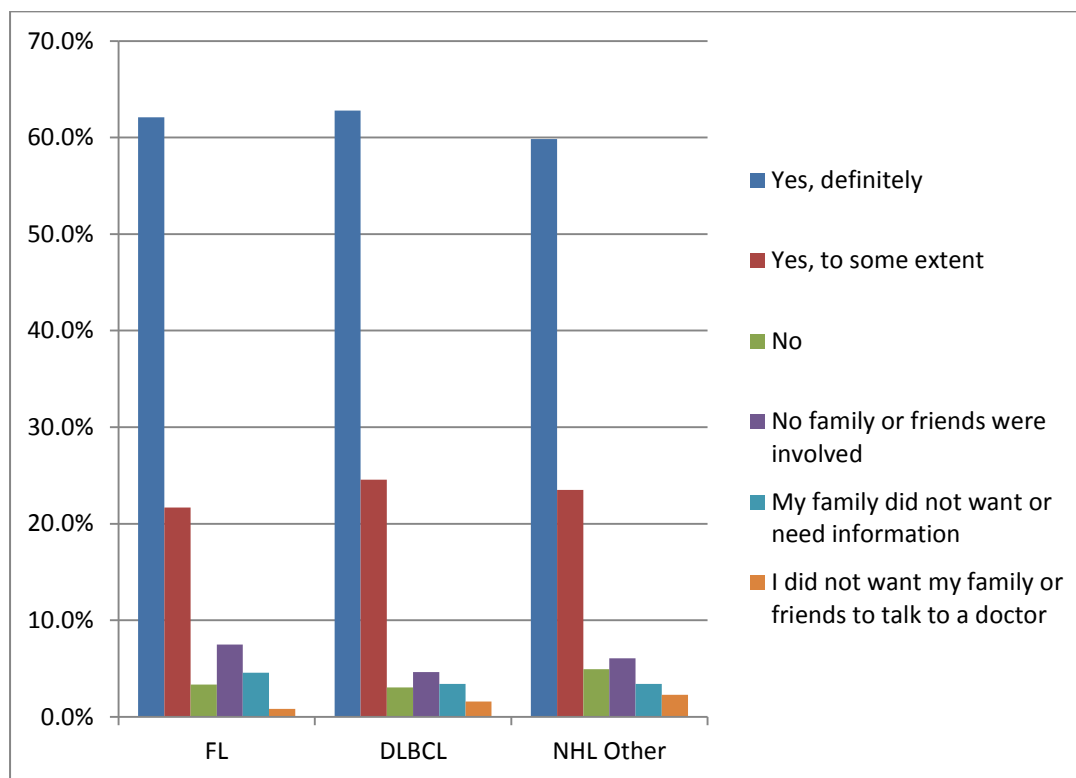


13



1 Overall, 83% of patients with NHL reported that doctors did not talk in front of them with 14%  
 2 saying sometimes and 4% said this often occurred. These results were similar to patients in the  
 3 overall CPES survey (84%). There were similar responses across the different sub-types of NHL  
 4 patients.

5 **Q40. If your family or someone else close to you wanted to talk to a doctor, did they have enough**  
 6 **opportunity to do so?**



7  
 8 Overall, 62% of patients with NHL said that this opportunity was definitely offered, with 23.8%  
 9 stating it was offered to some extent and 4% of patients saying this was not offered, with similar  
 10 responses from patients across the different sub-types of NHL. Of all CPES patients, 67% said that  
 11 they definitely had opportunity, 26% to some extent and 6% said they did not.

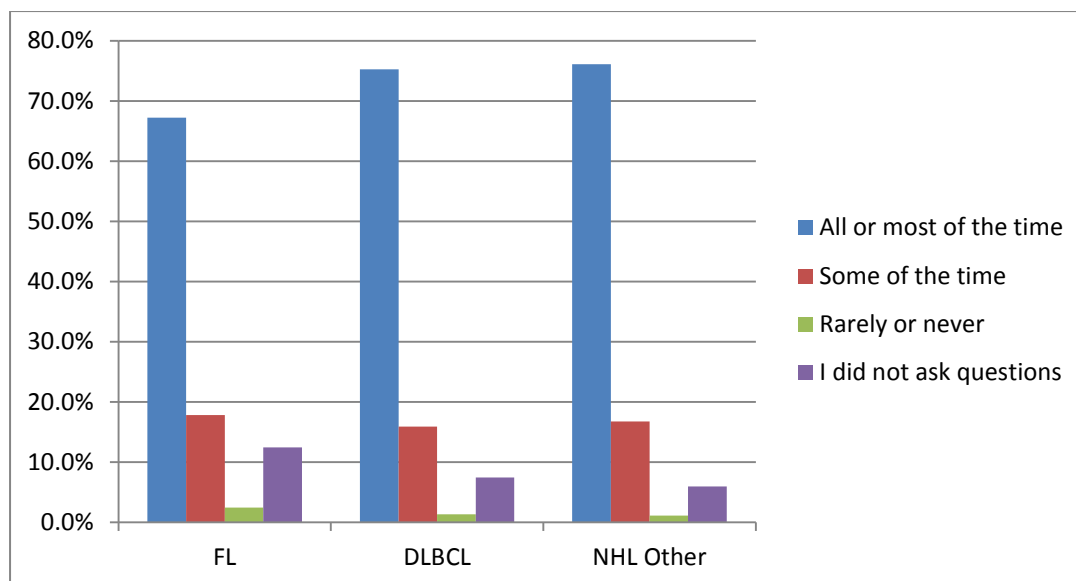
12

## 13 5. Ward nurses

14

15 **Q41. When you had important questions to ask a ward nurse, how often did you get answers you**  
 16 **could understand?**

## Non-Hodgkin's lymphoma: diagnosis and management

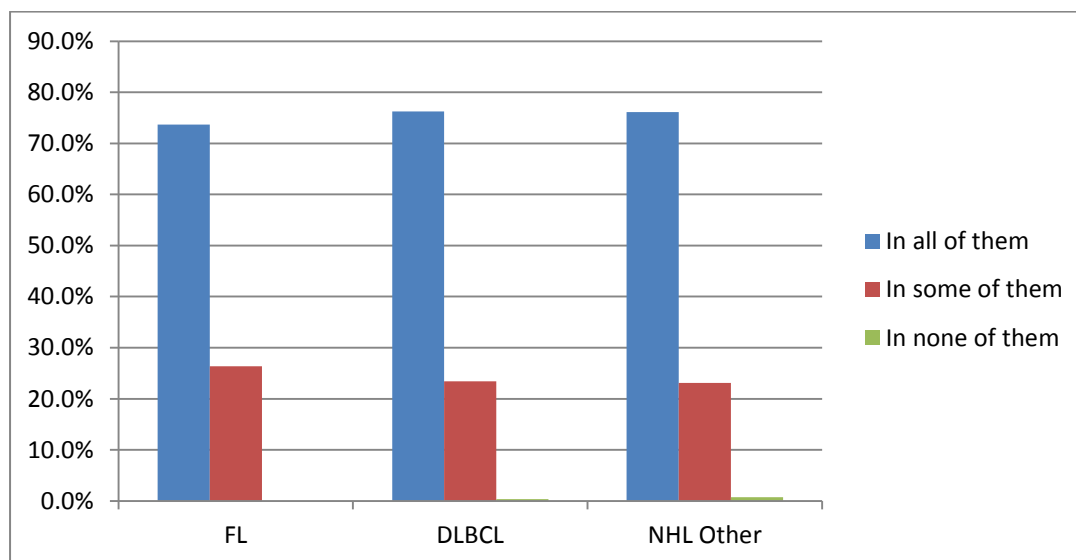


1

2 Seventy four per cent of patients with NHL said that nurses gave them answers they could  
 3 understand most or all of the time, similar to the overall CPES survey, where 76% of patients said  
 4 nurses gave them answers they could understand most or all of the time. There were some small  
 5 differences between NHL sub-types, with 67% of FL patients stating they had received answers that  
 6 they could understand most or all of the time, compared to 75% of patients with DLBCL and other  
 7 NHL sub-types.

8

### 9 **Q42. Did you have confidence and trust in the ward nurses treating you?**



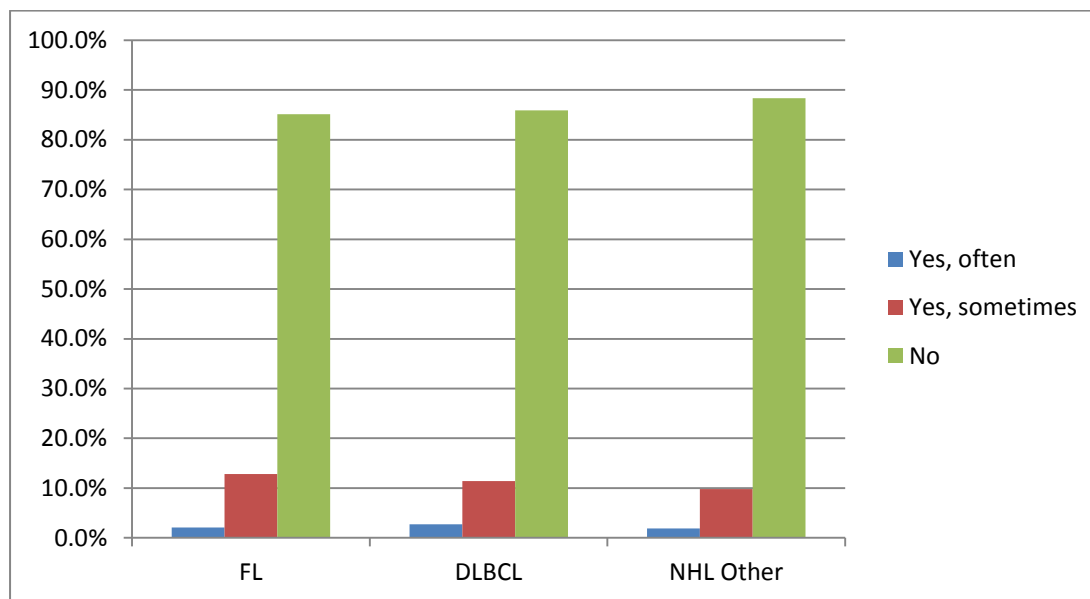
10

11 Seventy six per cent of patients with NHL said they had confidence and trust in all the nurses and  
 12 this was similar across patients of all sub-types of NHL. This was slightly higher than the overall CPES  
 13 survey, where 71% of patients said they had confidence and trust. Only 0.4% of patients with NHL  
 14 said they had no trust or confidence compared to 1% of all CPES patients.

15

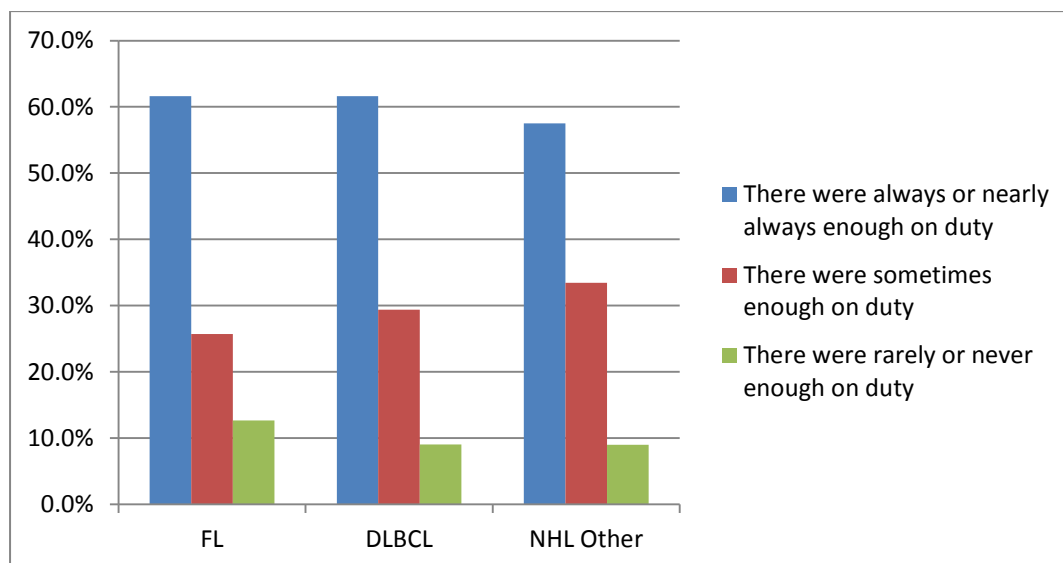
16

1 **Q43. Did ward nurses talk in front of you as if you were not there?**



2  
3 Just over 86% of patients with NHL said that nurses did not talk in front of them, similar to 85% of  
4 patients in the general CPES survey. Results appear similar for patients with different sub-types of  
5 NHL.

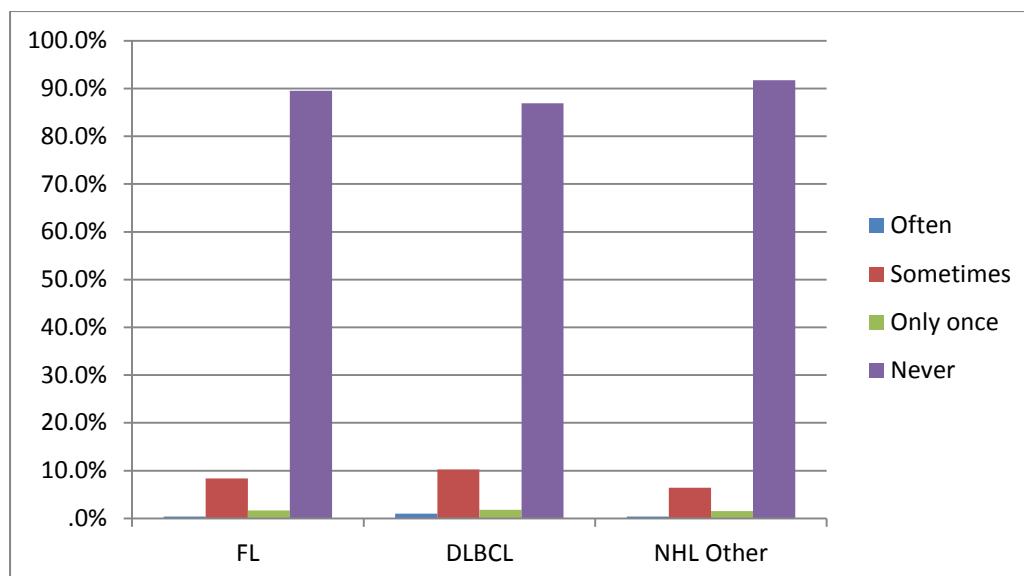
6 **Q44. In your opinion, were there enough nurses on duty to care for you in hospital?**



7  
8 Sixty per cent of patients with NHL said there were always or nearly always enough nurses on duty.  
9 Thirty per cent % said this was the case sometimes and 10% reported there were rarely enough  
10 nurses on duty, which was similar to the responses in the overall CPES survey, with 62% reporting  
11 there were always or nearly always enough nurses on duty. These results were reasonably  
12 consistent across the different sub-types of NHL patients.

13 **Q45. While you were in hospital did you ever think that the doctors or nurses were deliberately**  
14 **not telling you certain things that you wanted to know?**

## Non-Hodgkin's lymphoma: diagnosis and management

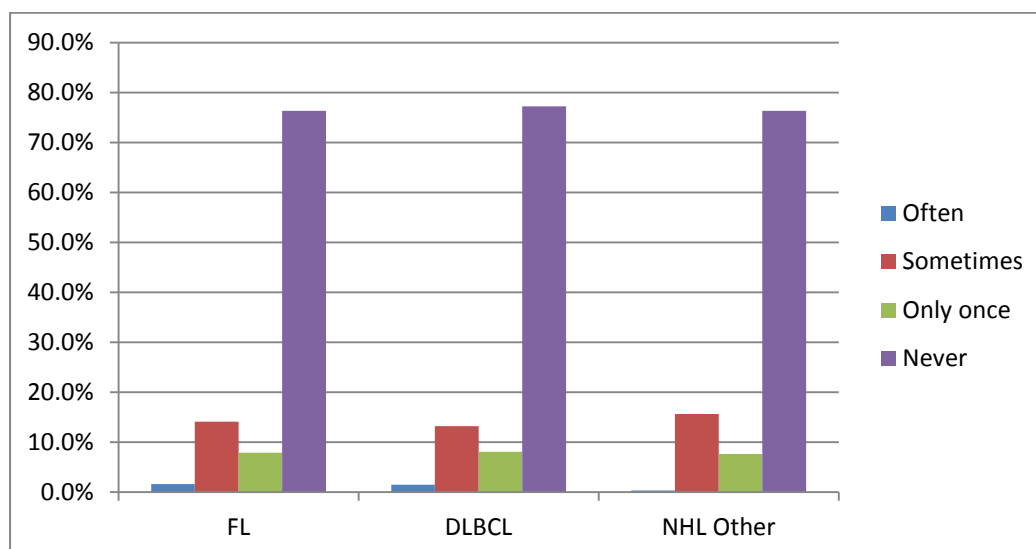


1

2 Eighty eight per cent of patients with NHL said they never thought that they were deliberately being  
 3 withheld information, commensurate with overall CPES survey which also reported that 88% of  
 4 patients stated they never thought that doctors or nurses were deliberately not telling them certain  
 5 things. There were similar responses across the different sub-types of NHL patients.

6

7 **Q46. While you were in hospital, did it ever happen that one doctor or nurse said one thing about**  
 8 **your condition or treatment and another said something different?**



9

10 Overall, 76% of patients with NHL said they had never had one doctor or nurse say something about  
 11 their condition or treatment and another say something different. In the overall CPES survey, 79% of  
 12 patients said this was never the case. There were similar responses across the different sub-types of  
 13 NHL patients.

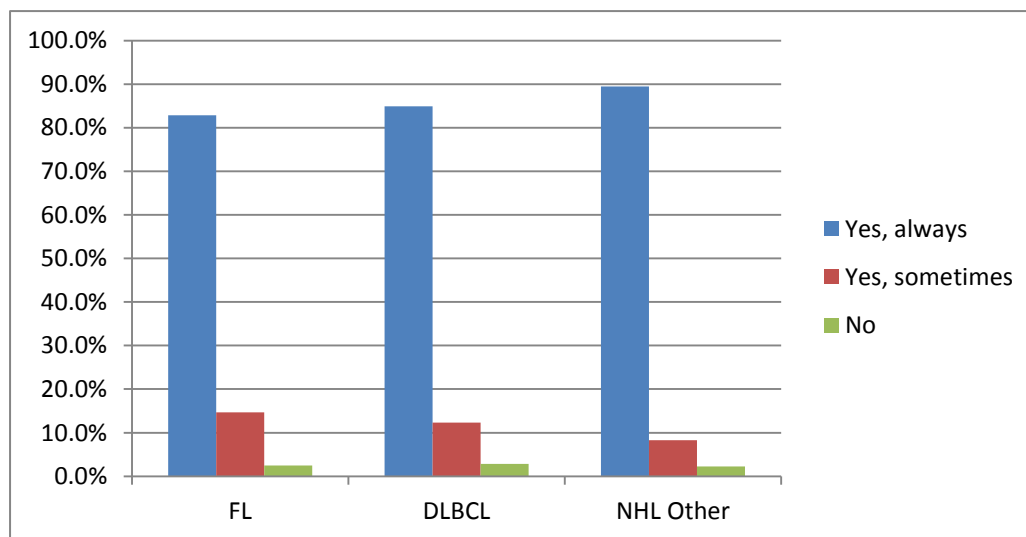
14

15 **Q47. Preferred name**

16 This question was not analysed because it did not relate to information or support needs.

1

2 **Q48. Were you given enough privacy when discussing your condition or treatment?**

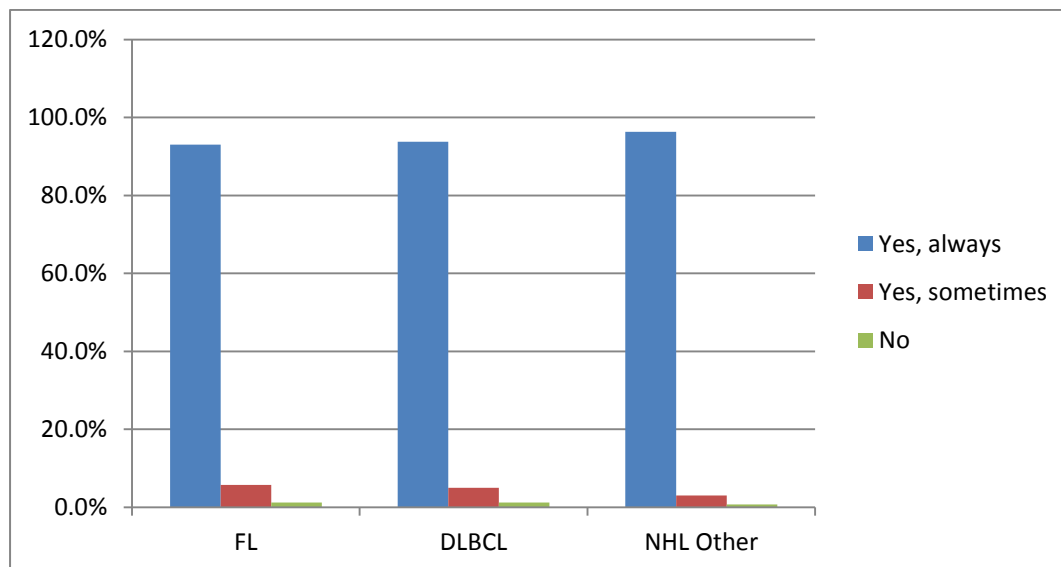


3

4 Overall, 85% of patients with NHL said they were always given privacy which was the same as 85% of  
 5 patients who reported this in the overall CPES survey. Results were slightly higher in patients  
 6 with other sub-types of NHL compared to DLBCL and FL patients (90% vs.85%. vs. 83%,  
 7 respectively).

8

9 **Q49. Were you given enough privacy when being examined or treated?**

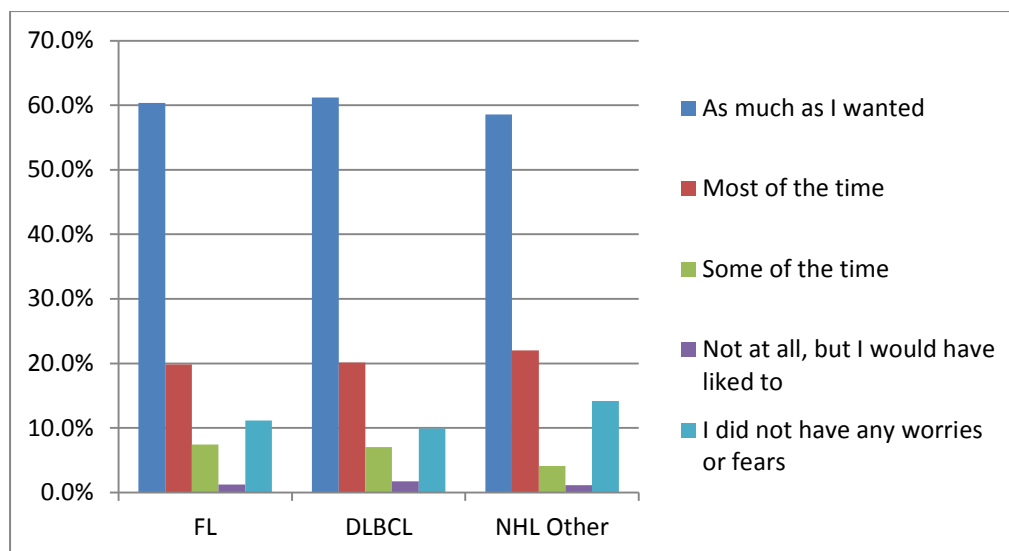


10

11 Ninety four per cent of patients with NHL said they were always given privacy, similar to the 95% of  
 12 patients in the overall CPES survey. Responses were similar across the different sub-types of NHL  
 13 patients.

14 **Q50. Were you able to discuss any worries or fears with staff during your hospital visit?**

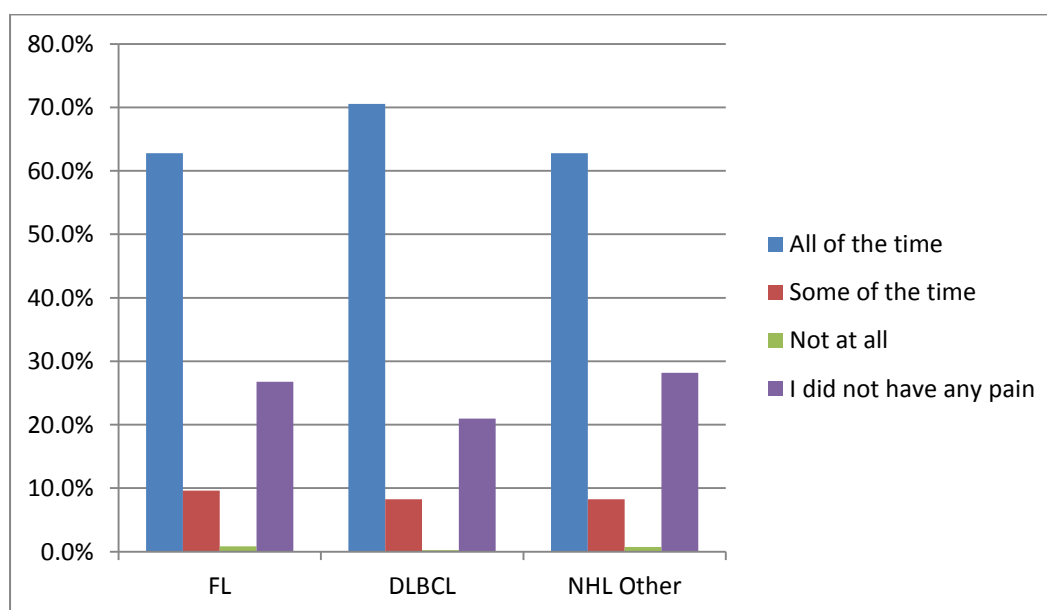
## Non-Hodgkin's lymphoma: diagnosis and management



1

2 Overall, 60% of patients with NHL said they were able to discuss as much as they wanted, slightly  
 3 lower than, 65% of patients in the overall CPES survey who said they had been able to discuss their  
 4 worries and fears as much as they wanted with staff. There were similar responses across the  
 5 different sub-types of NHL patients.

6 **Q51. Do you think the hospital staff did everything they could to help control your pain?**



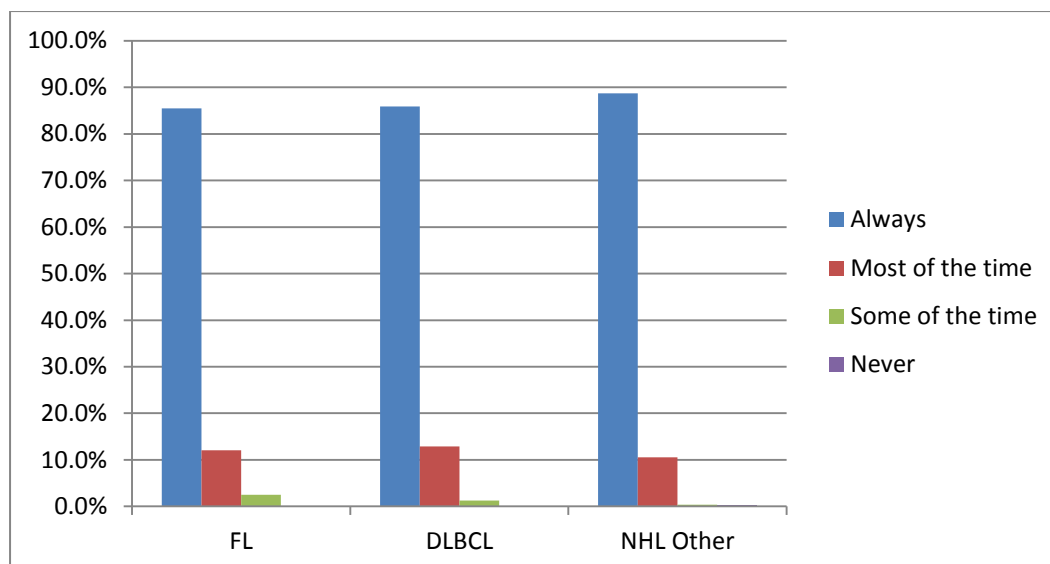
7

8 Overall, 86% of patients with NHL said that staff had done everything they could all or some of the  
 9 time; commensurate with the 86% of patients who had reported this in the overall CPES survey.  
 10 There was slight variation between patients with different sub-types of NHL, with 62%, 71% and  
 11 62% of patients with FL, DLBCL and other NHL reporting that staff had done all they could all of the  
 12 time.

13

14 **Q52. Were you treated with respect and dignity by the doctors and nurses and other hospital**  
 15 **staff?**

## Non-Hodgkin's lymphoma: diagnosis and management



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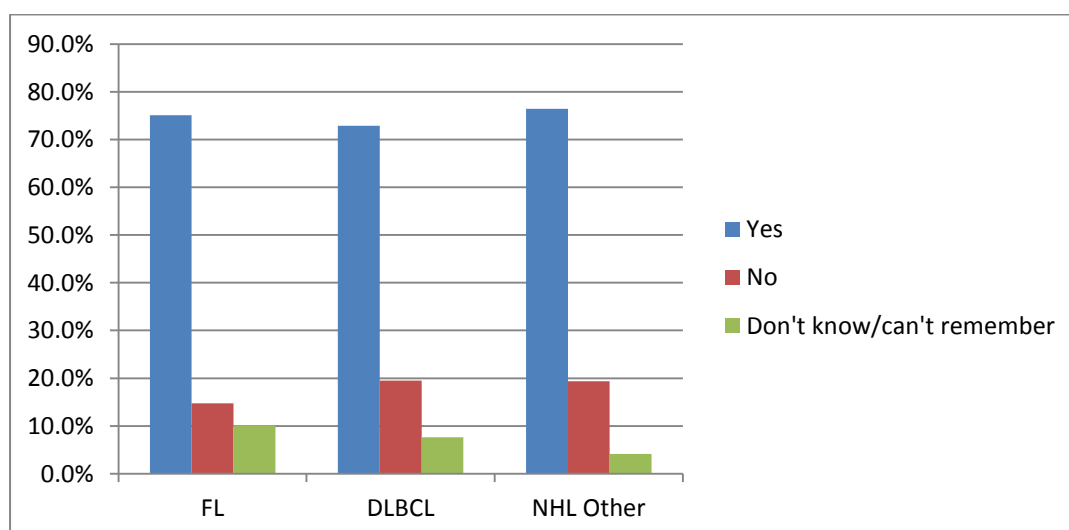
2 Overall, 86% of patients with NHL stated they were always treated with dignity and respect, and this  
 3 was similar to the 84% of all CPES patients who reported this. Responses were similar across all sub-  
 4 types of NHL patients.

5

## 6 7. Information about leaving and home support

7

8 **Q53. Where you give clear written information about what you should or should not do after**  
 9 **leaving hospital?**

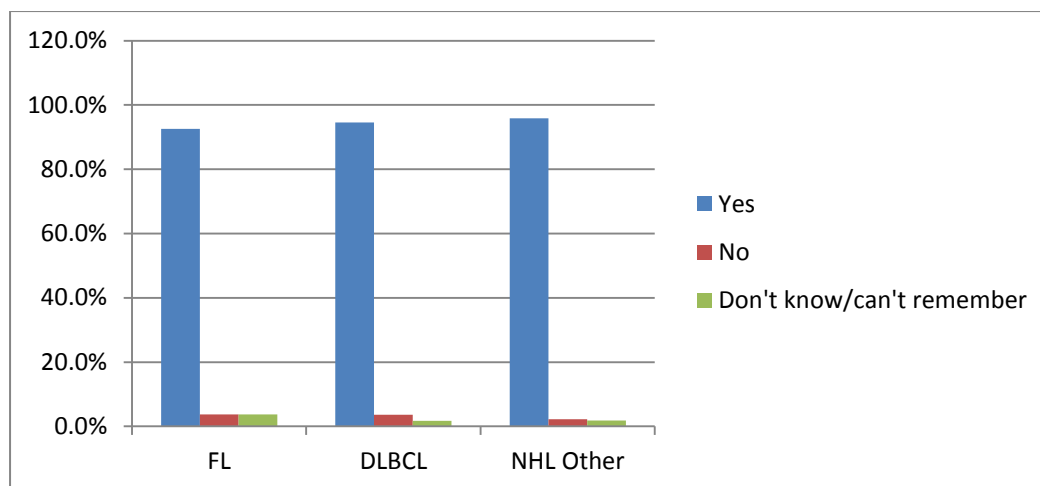


10

11 Seventy five per cent of patients with NHL reported that they were always given clear information,  
 12 with 19% of patients reporting this was the case most of the time and 7% stating they were not  
 13 given information. These responses were similar across all sub-types of NHL patients. This was lower  
 14 than the overall CPES survey where 85% of patients said they were given clear information.

15 **Q54. Did hospital staff tell you who to contact if you were worried about our condition or**  
 16 **treatment after you left hospital?**

## Non-Hodgkin's lymphoma: diagnosis and management

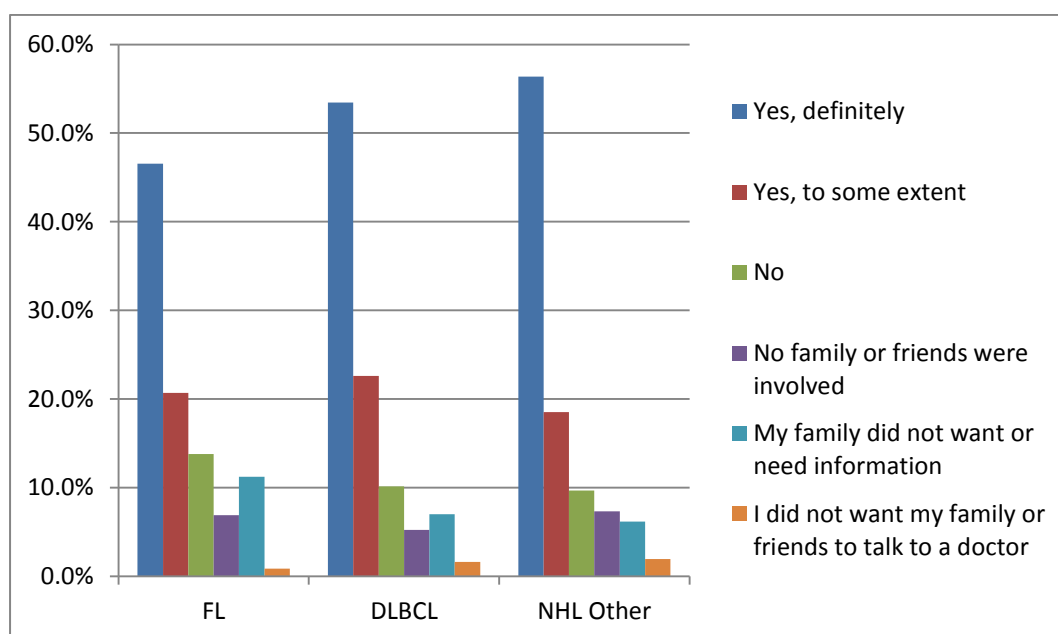


1

2 Overall 95% of patients with NHL said they were told who to contact similar to the overall CPES  
 3 survey where 94% of patients said they had been given contact information. The responses were  
 4 consistent across all of sub-types of NHL patients.

5

6 **55. Did the doctors or nurses give your family or someone close to you all the information they**  
 7 **needed to help care for you at home?**



8

9 Overall, 53% of patients with NHL said their family were given all the information needed; with 22%  
 10 stating they were to some extent and 11% said they were not given information. There were some  
 11 differences between patients with different NHL sub-types with 47% of FL patients reporting their  
 12 family had been given all the information needed compared to 53% and 56% of DLBCL and other  
 13 NHL patients, respectively. These responses were lower compared to the overall CPES survey, where  
 14 60% said their family were given all the information needed; 24% said to some extent and 16% said  
 15 their family did not get all the information needed.

16

17 **56. Help from community health and social services**



1 This question was not analysed because social services are outside the scope of the guideline.

2

3 **8.Day/outpatient care**

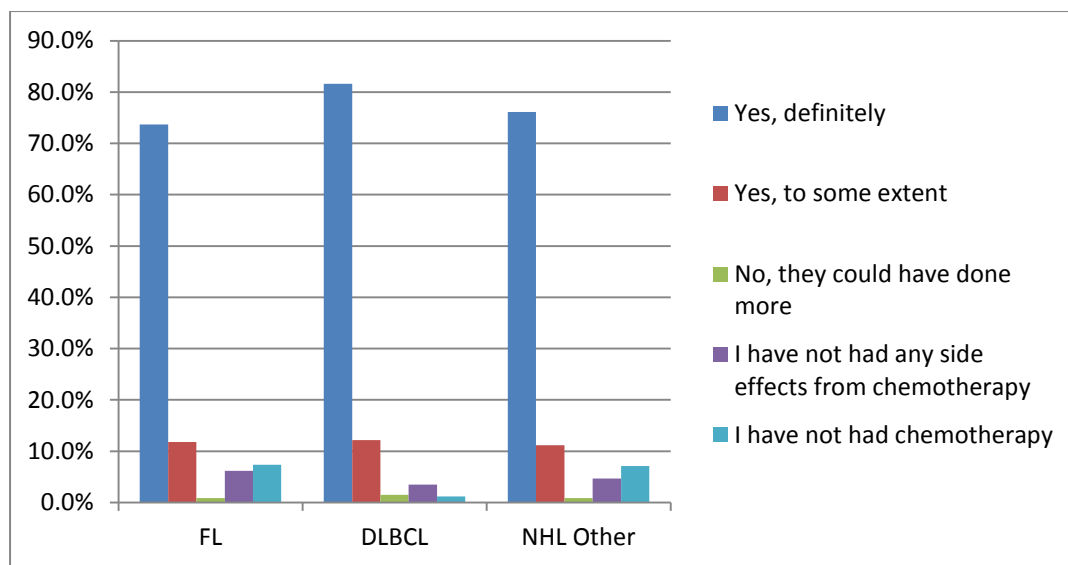
4

5 **Q57. Did hospital staff do everything possible to control the side effects of radiotherapy?**

6 The number of respondents within the NHL cohort was too low to analyse.

7

8 **Q58. Did hospital staff do everything possible to control the side effects of chemotherapy?**



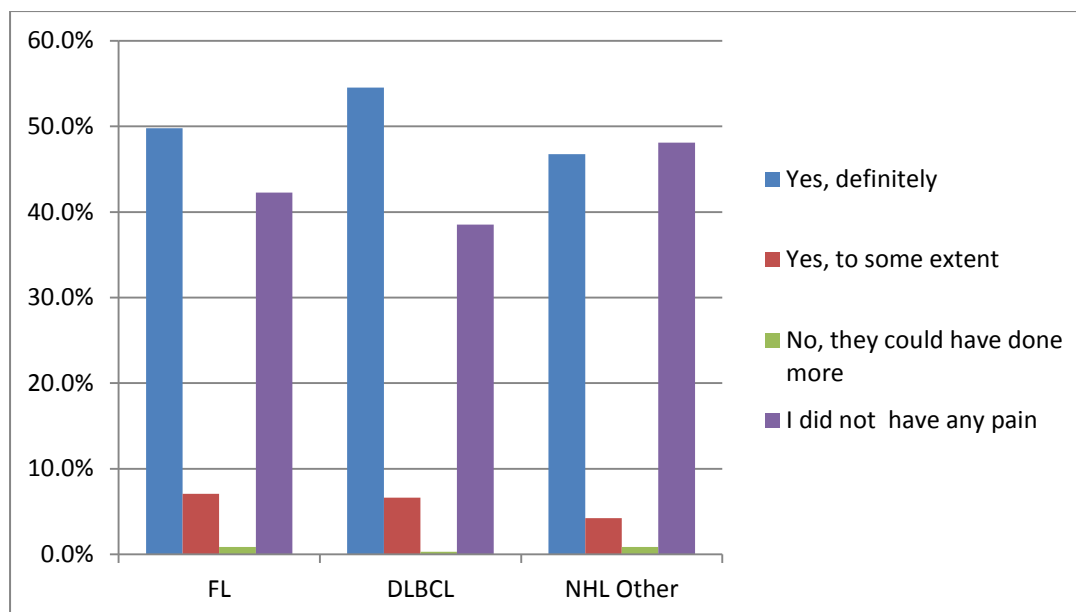
9

10 Seventy four per cent of patients with FL said hospital staff had done everything to control their  
 11 side effects, compared with 81% of those with DLBCL and 76% of patients with other sub-types of  
 12 NHL. The overall response for patients with NHL was 74% reported that staff had definitely done  
 13 everything they could have done compared to 81% of patients in the overall CPES survey..

14

15 **Q59. While you were being treated as an outpatient or day case, did hospital staff do everything**  
 16 **they could to help control your pain?**

## Non-Hodgkin's lymphoma: diagnosis and management

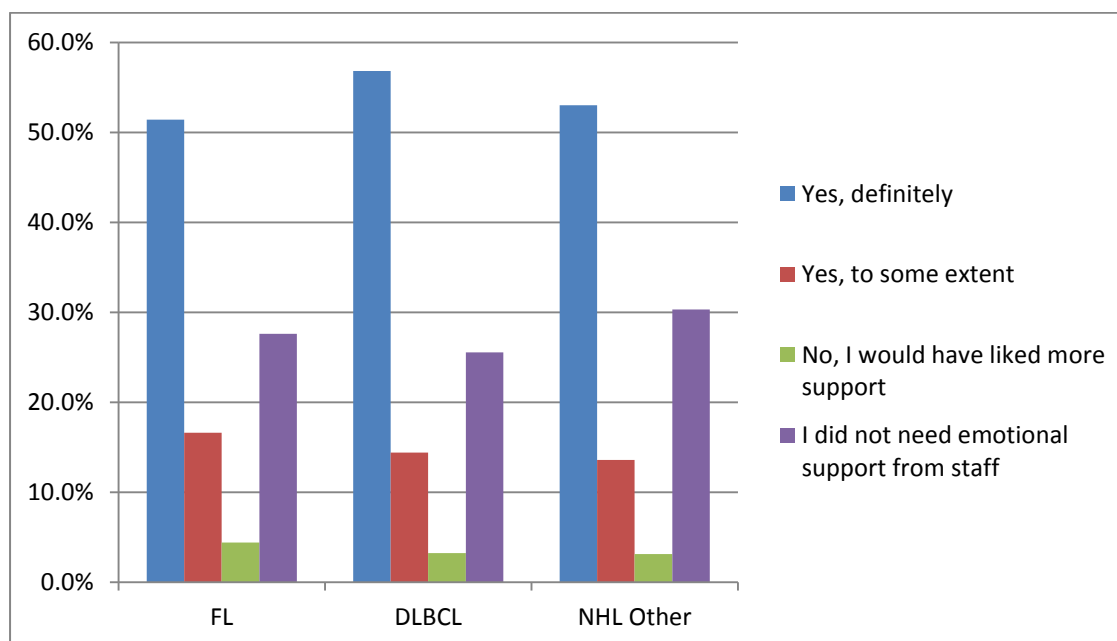


1

2 Overall, 79% of patients with NHL who reported that they had pain, said everything was done to  
 3 help, similar to 82% of patients in the overall CPES survey. There were slight differences across  
 4 patients with different sub-types of NHL with 50%, 54% and 47% of patients with FL, DLBCL and  
 5 other NHL sub-types reporting that everything was being done when they were in pain.

6

7 **60. While you were being treated as an outpatient or day case, were you given enough emotional**  
 8 **support from hospital staff?**

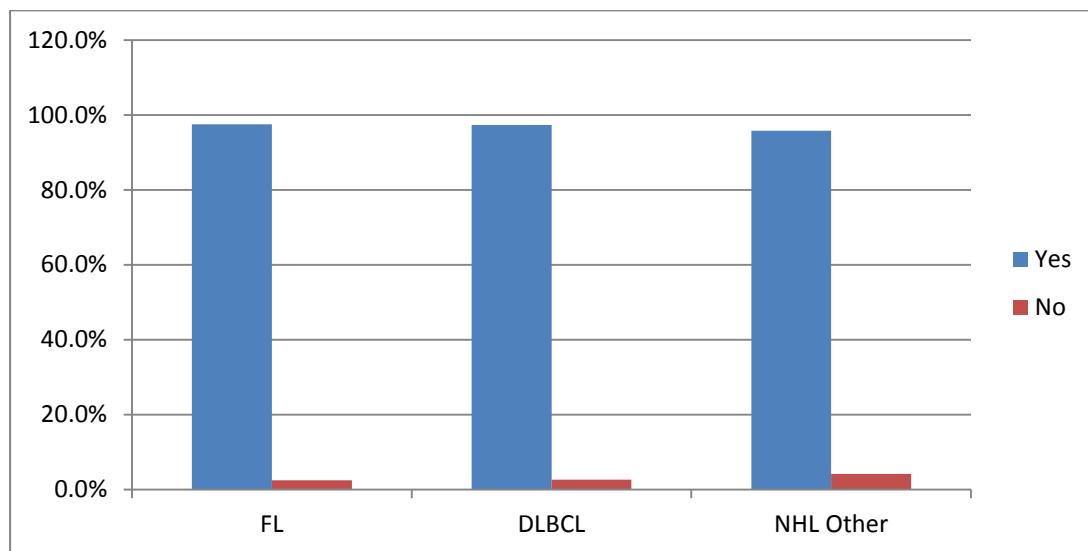


9

10 In patients with NHL, 70% reported that they were definitely given emotional support which is the  
 11 same report from the overall CPES survey (70%). Responses were similar for patients across the  
 12 different sub-types of NHL.

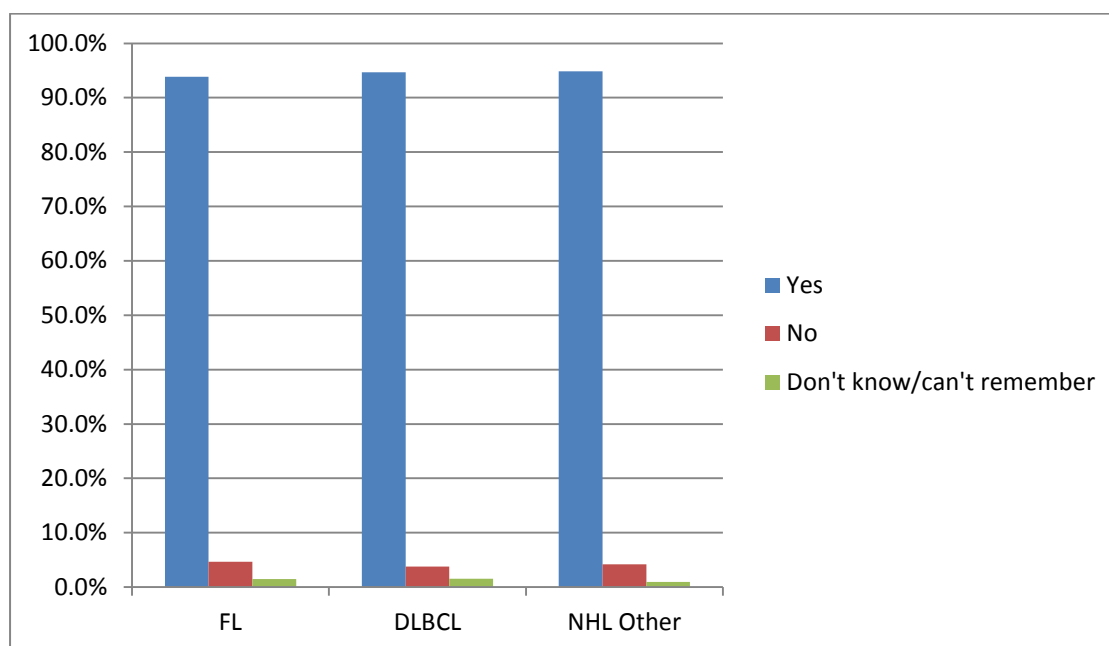
13

1 **61. In the last 12 months have you had an outpatients appointment with a cancer doctor at one of**  
 2 **the hospitals named in the covering letter?**



3 Overall,  
 4 97% of patients with NHL reported that they had attended an outpatient appointment, similar to  
 5 94% in the overall CPES. Responses were similar for patients across all different sub-types of NHL.

6  
 7 **62. The last time you had an appointment with a cancer doctor, did they have the right documents**  
 8 **such as medical notes?**



9  
 10 Overall, 95% of patients with NHL said that their doctor had the right documents, similar to the  
 11 overall CPES report (96%). There were consistent responses from patients across the different sub-  
 12 types of NHL.

13  
 14 **5.14. Care from General Practices**

## Non-Hodgkin's lymphoma: diagnosis and management

1 This question was not analysed because it was an overall rating of satisfaction of care and did not  
2 relate to information or support needs.

3

### 4 **5.15. Overall NHS Care.**

5 This question was not analysed because it was an overall rating of satisfaction of care and did not  
6 relate to information or support needs.

7