Non Hodgkin's Lymphoma: diagnosis and management

Appendix H: Findings of patient experience survey

Developed for NICE by the National Collaborating Centre for Cancer

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 2014 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 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 patient's 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 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.

- Over 75% of patients with NHL stated positively on the way they were treated by doctors and nurses. Ensuring patients are given opportunity to discuss worries and fear when wanted 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/friend 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.

- There are no obvious differences between sub-types, length of treatment, treatment pathway (e.g. in active treatment or follow up).

The results from the CPES survey state that for NHL patients: [the (%) bracket is 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 987%).
- 63% received written information about investigations that was easy to understand (87%) .
- 73% received a completely understandable explanation of their tests results (80%).
- 73% were given the opportunity to bring a friend/relative with them; with 52% of patients with FL given this opportunity .
- 80% were informed of their diagnosis in a sensitive manner.
- 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; with some small differences between sub- types of NHL diagnoses (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 (72%).
- 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%) ; but 19% said this wasn't necessary.
- 81% (who said it was necessary) received information about free prescriptions (78%).
- 88% had seen information about cancer research (86%).
- 25% were informed by staff about taking part in clinical trials (31%); of these, 59% were enrolled in a trial (63%).

Operations

- Of the 25% of patients who reported having an operation (including biopsy); 79% were informed of what would happen and 54% received written information that was easy to understand ; this was lower in patients with FL with 45% reporting that they had (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 doctors 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%).
- 77% 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 (66%).
- 86% had everything done to control their pain by hospital staff (85%).
- 86% were always treated with dignity and respect (86%).

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 him/her at home (60%).

Day/Outpatient care

- 78% had everything done to help control the side effects of chemotherapy (81%)
- 79% had everything done to control his/her pain (82%).
- 70% were definitely given emotional support.
- 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) 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 in several domains. . Subgroup analysis of patients with NHL included in the English NHS Cancer Patient Experience Survey was done to provide additional evidence about the information needs in this group.

Objectives:

The primary objective was to present the experiences of patients with NHL, and where data allowed, sub-type, as reported in the 2014 Cancer Patient Experience Survey; with focus on information and support needs for patients (and carers). A secondary objective was to present experiences by treatment status (e.g. watch and wait, in active treatment or follow up) or age bands; subject to data availability.

Methods:

Cancer Patient Experience Survey

The Cancer Patient Experience Survey (CPES)[1] 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 is 2014. The survey is administered to all patients who had been treated as inpatients or day cases between 1st September and 30th September.

The survey is a questionnaire administered by post with two follow up reminders. It is intended to be self-completed by the patient. The survey achieved a response rate of 64%. It comprises of 63 questions split into 16 categories. It allows 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.

---

[1] 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

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 DCBL with other sub-types (Burkitts, 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 descriptives, with results presented similar to the main survey report (e.g. bar charts with narrative commentary). The primary analysis would be to report findings for all NHL patients, with separate analysis of main sub-groups (FL , DCBL, other NHL). Secondary analysis would consider findings in relation to different treatment status and age, should data have allowed. Due to time constraints, this secondary analysis may form the basis of a separate paper to be written by members of the NCC-C and GDG.

The dataset was checked for any anomalies and re-categorised into questionnaire response scale format to allow easier interpretation. This was undertaken by a research assistant at the Swansea Centre for Health Economics and checked by DF. A complete case analysis was undertaken, with no manipulation/imputing of missing variables. It was anticipated that further analysis could be undertaken to explore associations/differences in findings. This would be additional work beyond the current report. The focus was on reporting needs of patients relevant to the secondary care setting e.g. diagnosis, during treatment, after treatment, at point of consideration of palliative care, commensurate with the PICO.

Results

Demographic and clinical characteristics

1. Age of patients with NHL

	All NHL		Follicular Lymphoma		DCBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
16 - 25	9	.4%	0	0.0%	7	.5%	2	.4%
26 - 35	31	1.2%	2	.3%	27	2.0%	2	.4%
36 - 50	181	7.2%	68	9.7%	93	6.8%	20	4.3%
51 - 65	699	27.6%	207	29.7%	355	25.9%	137	29.7%
66 - 75	924	36.5%	255	36.5%	496	36.2%	173	37.4%
76+	686	27.1%	166	23.8%	392	28.6%	128	27.7%
Gender of patients with NHL i.								
	All NHL		**Follicular Lymphoma**		**DCBCL**		**NHL Other**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Female	1097	43.4%	357	51.1%	595	43.4%	145	31.4%
Male	1433	56.6%	341	48.9%	775	56.6%	317	68.6%

Employment status of NHL patients

	All NHL		Follicular Lymphoma		DCBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
Full time employment	444	18.4%	133	19.9%	238	18.2%	73	16.6%
Part time employment	160	6.6%	58	8.7%	79	6.0%	23	5.2%
Homemaker	47	1.9%	11	1.6%	31	2.4%	5	1.1%
Student (in education)	9	.4%	4	.6%	4	.3%	1	.2%

Retired	1586	65.6%	406	60.8%	871	66.5%	309	70.1%
Unemployed - and seeking work	10	.4%	3	.4%	6	.5%	1	.2%
Unemployed - unable to work for health reasons	112	4.6%	41	6.1%	52	4.0%	19	4.3%
Other	51	2.1%	12	1.8%	29	2.2%	10	2.3%

Length of time treated for NHL

	All NHL		**Follicular Lymphoma**		**DCBCL**		**NHL Other**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Less than 1 year	1506	61.4%	277	41.2%	1011	75.8%	218	49.0%
1 to 5 years	759	31.0%	330	49.1%	250	18.7%	179	40.2%
More than 5 years	181	7.4%	62	9.2%	72	5.4%	47	10.6%
Don’t now / can’t remember	5	.2%	3	.4%	1	.1%	1	.2%

Cancer status for NHL patients

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

Treatment response of NHL patients

	All NHL		Follicular Lymphoma		DCBCL		NHL Other	
	No.	%	No.	%	No.	%	No.	%
Treatment has not yet started for this cancer	13	.5%	9	1.4%	2	.2%	2	.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	.2%	2	.3%	1	.1%	2	.5%

1

Age of patients with NHL

	N	Mean	Std. Deviation
All NHL	2530	67.82	11.917
Follicular Lymphoma	698	66.98	11.493
DCBCL	1370	67.94	12.396
NHL Other	462	68.70	11.010

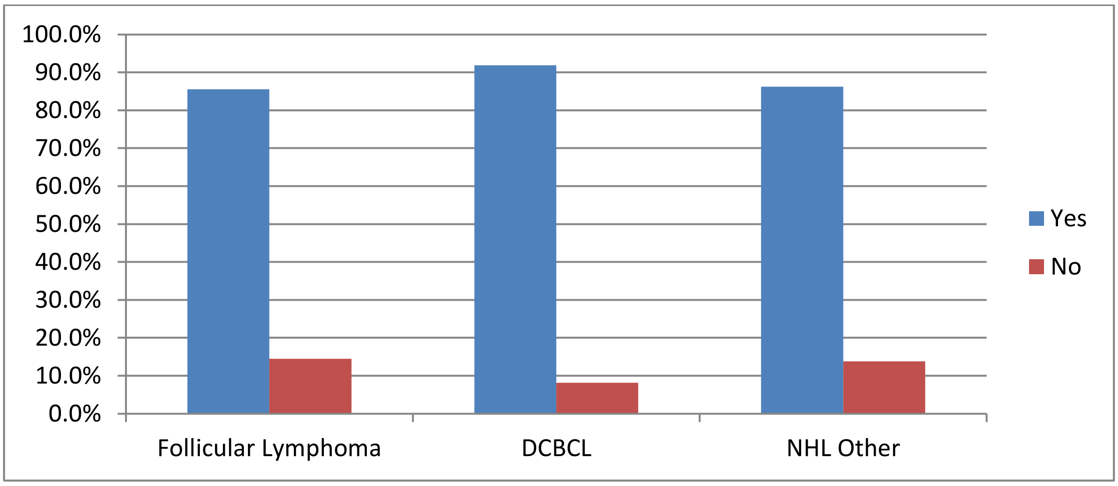
2

3

4

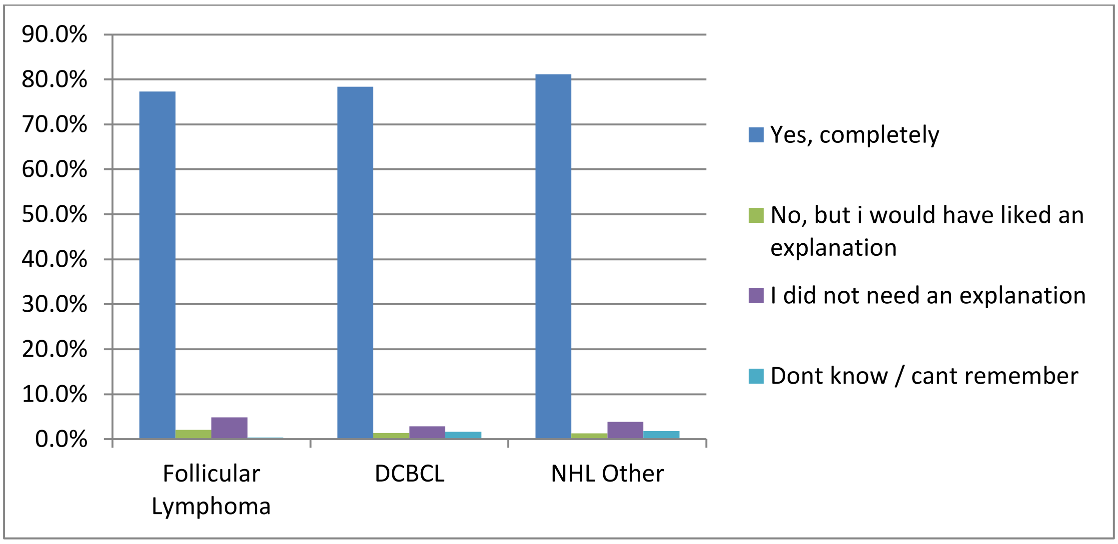
1. Information and support needs around diagnosis

Q5. Diagnostic tests in the last 12 months



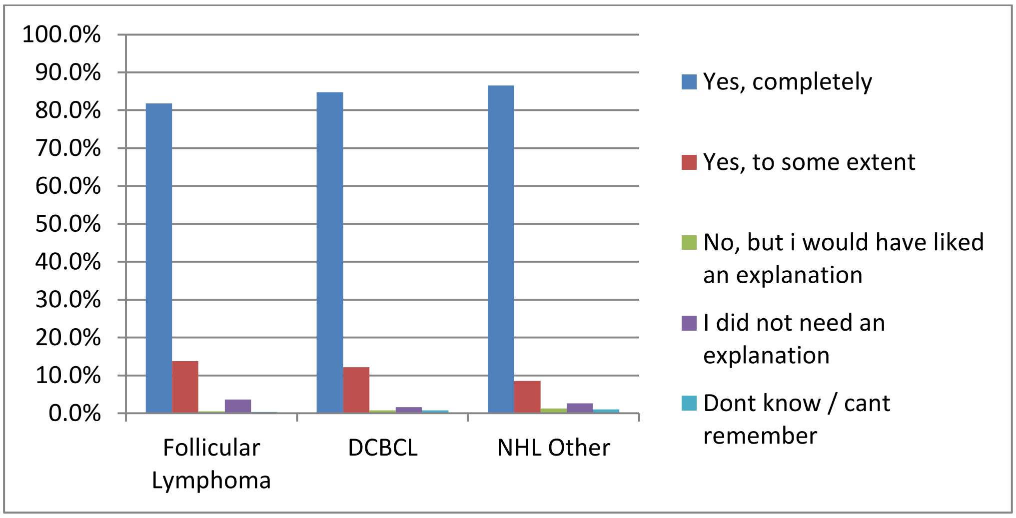
In the NHL patients, 89.1% stated they had a diagnostic test in the last 12 months (85.5% vs. 91.9% vs. 86.2%; FL vs. DCBL vs. other NHL) which is commensurate with the overall CPES survey, where 89% of patients said they had had a diagnostic test.

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



In the NHL patients, there was reasonable consistency in reporting with 77.3% vs. 78.4% vs. 81.1% (FL vs. DCBL vs. other NHL) stating that staff had explained fully; with overall, 78.6% of NHL patients stated they had a full explanation. This is slightly lower than the overall CPES survey, 84% of patients said that staff explained fully; but the % of patients reporting they had not received an explanation slightly lower when compared to all CPES patients (1.5% vs. 2%; NHL vs. all CPES).

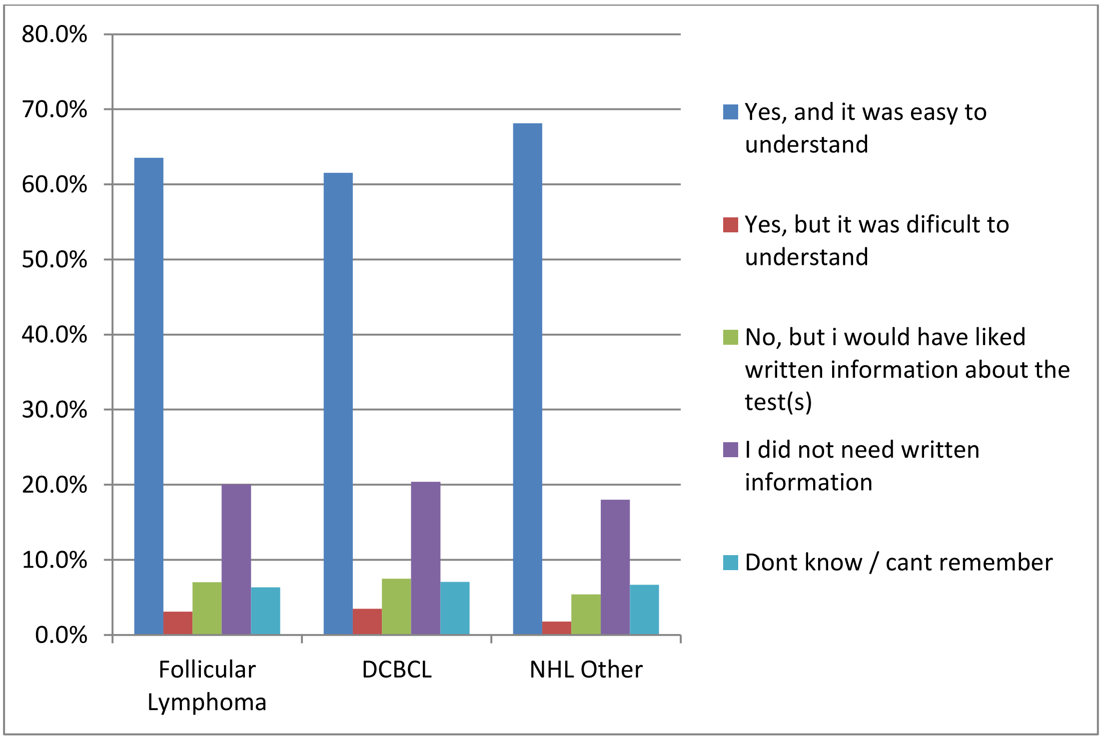
Q7. Beforehand, did a member of staff explain what would be done during the test(s)?



There were consistent reports across NHL patients. Overall, 84% of patients stated they had been given a full explanation of the procedure with 81.8% vs.84.8% vs.86.6% (FL vs. DCBL vs. other NHL) reporting a complete explanation; although overall this is slightly lower than the overall CPES survey (87%). There was similar reports from patients that had stated they had received some explanation (11.9% vs. 12%; all NHL vs. all CPES) and no explanation (0.8% vs. 1%; NHL vs. all CPES) respectively.

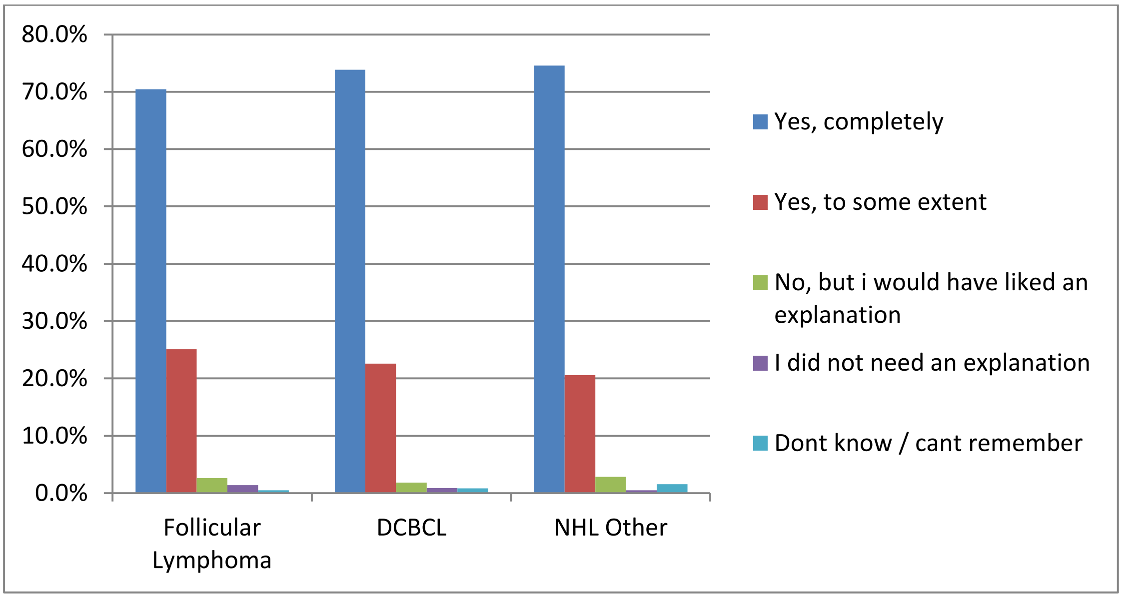
In the overall CPES survey, 87% of patients stated that staff explained completely with 12% and 1% saying they had some explanation or no explanation but wished to have more, respectively.

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



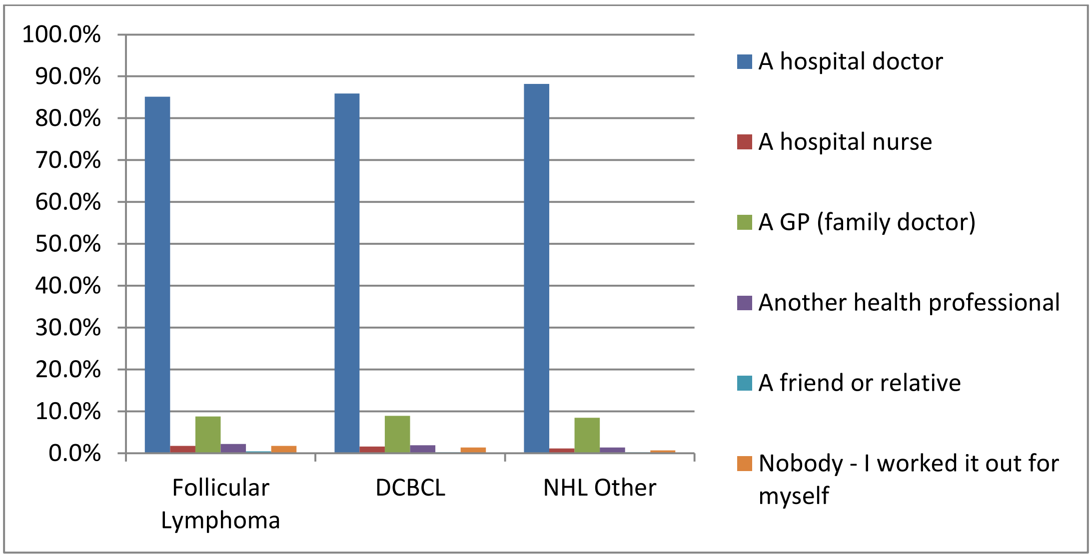
Overall, NHL patients did not state they had been given easy to understand information with 63.2% reporting they had done so compared to 87% of patients in the CPES survey. There were consistent reports in FL and DCBL (63.5% vs. 61.6%) respectively although other NHL patients reported slightly higher satisfaction (68.1%). However, NHL patients less frequently reported information that was difficult to understand (3.1% vs. 4%; NHL vs. all CPES) and no information given (7% vs. 9%; NHL vs.all CPES). This may be explained in part with approximately 1/5th of patients (19.9%) stating they didn't need written information.

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



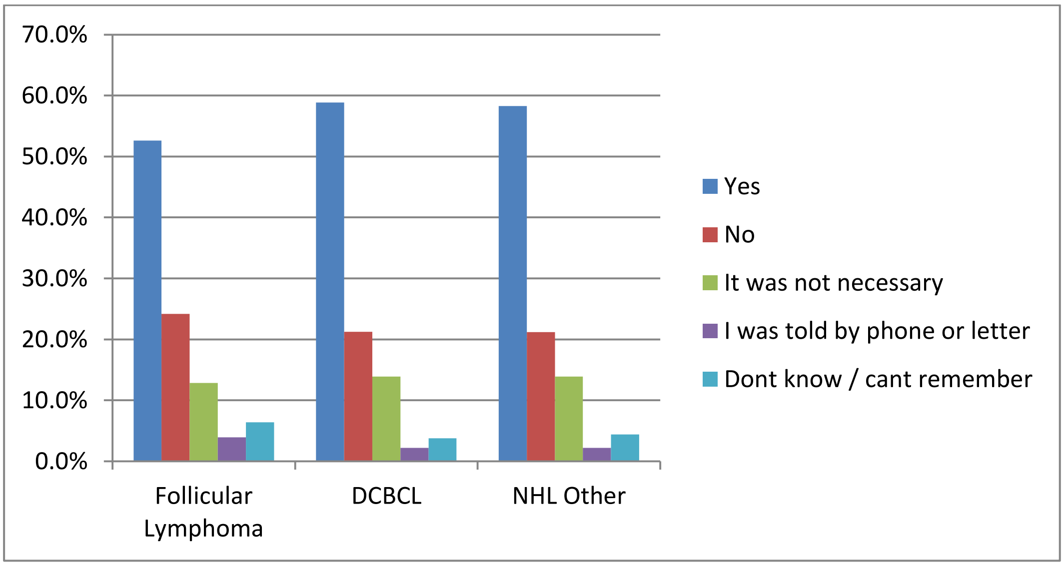
Overall, 73.1% of NHL patients reported that they had received a completely understandable explanation of their test results compared to 78% of patients in the overall CPES survey with 70.4% vs. 73.9% vs. 74.6% (FL vs. DCBL vs. other NHL) reporting they had fully understood. 22.9% of NHL patients reported that they had understood to some extent (compared to 19% of all CPES survey patients) with similar results across NHL and sub-types compared to all CPES patients who reported they had not received an explanation (2.2% vs. 2% respectively).

Q10. Who first told you that you had cancer?



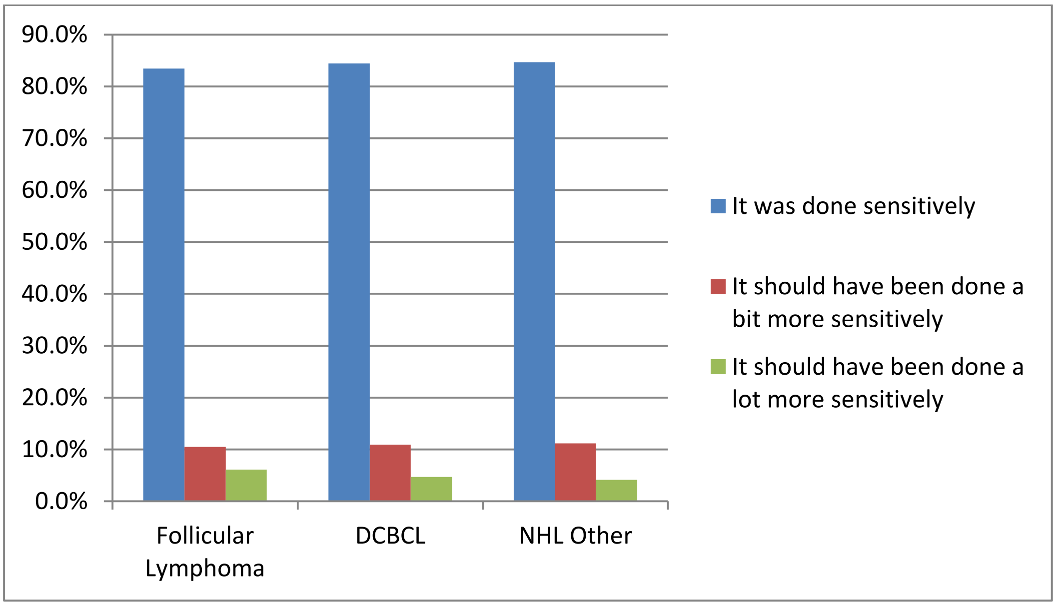
A hospital doctor told 86.1% of NHL patients their diagnosis compared to 82% in the overall CPES survey. 12.3% of patients were told by another health care professional (nurse, GP or other) compared to 16% of all CPES patients. Similar reports from NHL patients compared to CPES patients were given where a friend/relative had told them or they had figured out their diagnosis for themselves (1.6% vs. 2%; NHL vs. all CPES patients). Similar reports were seen across NHL sub-types.

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



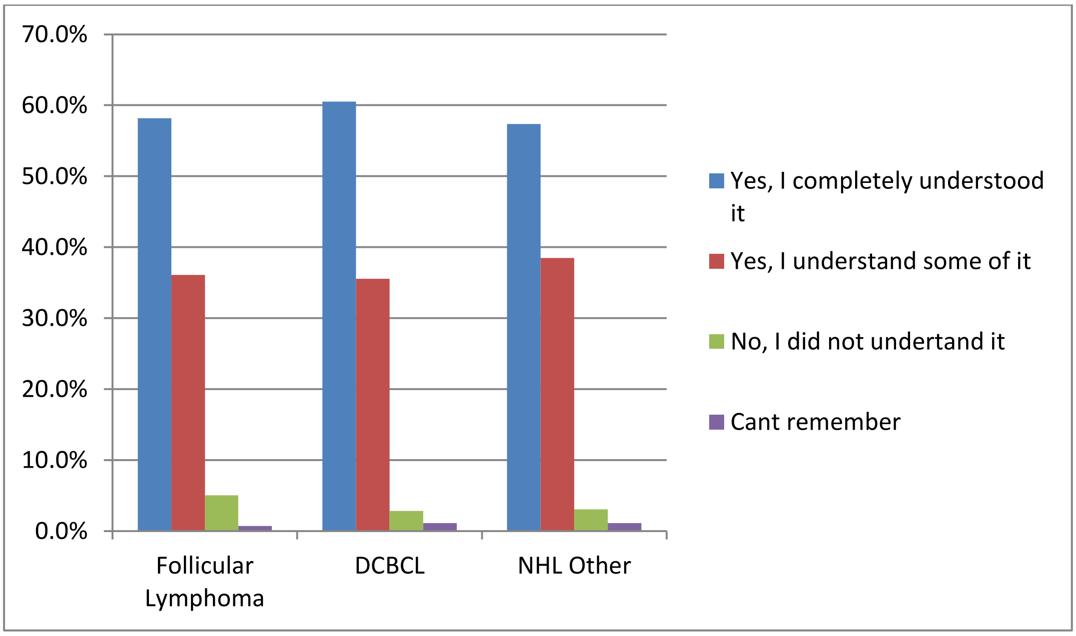
Across all NHL patients, 73.1% stated they were told they could bring a friend/relative which is similar to the results across all CPES survey patients (75%). However, there is notable difference in FL patients who reported that only 52.6% were told they could bring someone. Across all NHL patients, approximately 13% stated this was not necessary. The somewhat contradictory results within groups compared to overall NHL patients may be partly explained by % of patients stating they could not recall.

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



In the NHL patients, 84.2% of patients stated that they had been told they had cancer in a sensitive manner and this is consistent with the report of all CPES patients (84%). Reports are consistent across NHL sub-types, with 10.8% and 5% of NHL patients reporting it could have been done a bit more or a lot more sensitively; compared to 11% and 5% of all CPES patients, respectively.

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



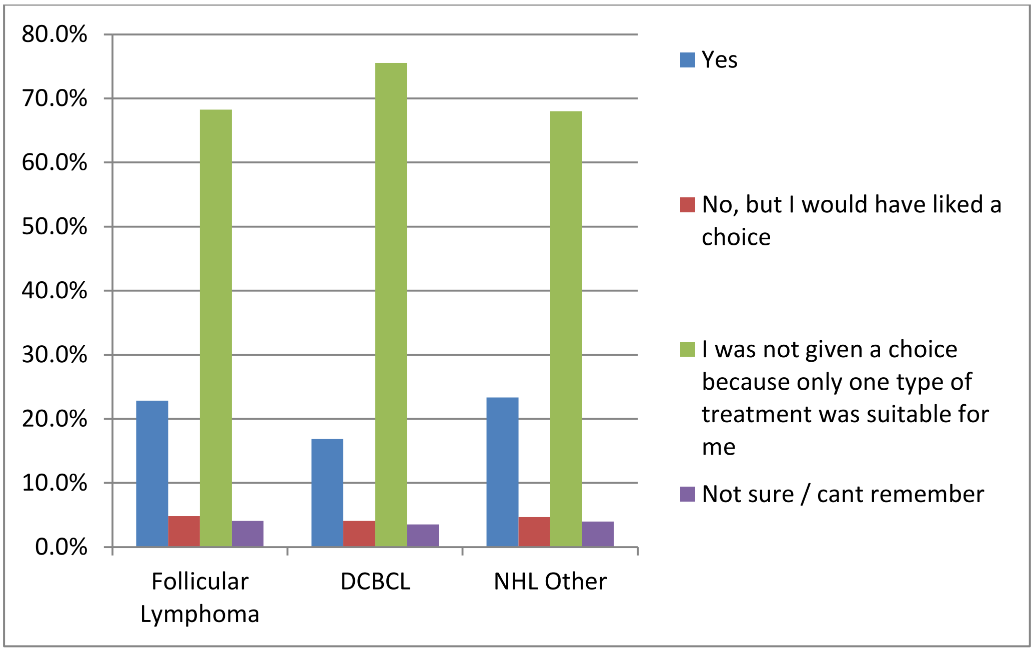
Across all NHL patients, 59.2% stated they completely understood the explanation of what was wrong with them compared to 73% of all CPES patients. This was consistent when NHL sub-types were examined. Overall, 36.2% of NHL patients stated they understood some of the explanation with 3.5% stating they did not understand ; compared to 25% and 2% of all CPES patients.

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

Overall, 70.1% of NHL patients said they had been given information that was easy to understand compared to 72% of patients in the overall CPES survey. However, 13.5% of patients stated they had not received information compared to 20% of patients in the overall CPES survey.

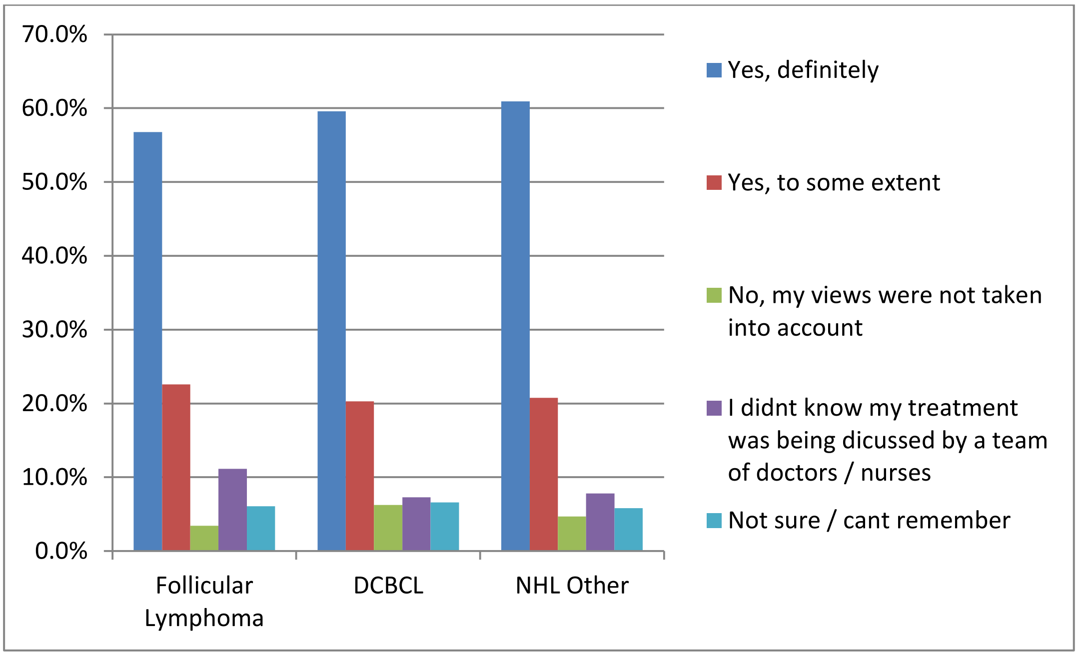
2. Treatment decision making

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



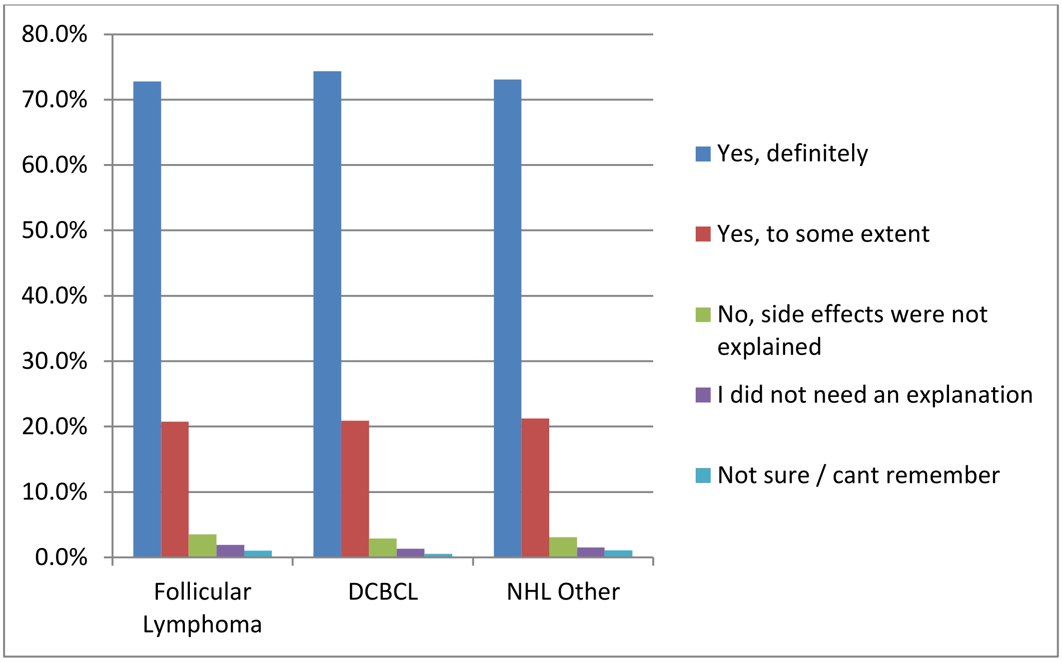
Overall, 72.2% of NHL patients stated they were not given a choice of treatment because only one treatment type was suitable, compared to 59% of all CPES survey patients. There were some differences between sub-groups (68.2% vs. 75.6% vs. 68%; FL vs. DCBL vs. other NHL). Of those remaining patients, overall only 4.4% of NHL patients stated they were not given a choice but would have liked one compared to 14% of all CPES patients.

Q16. 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?



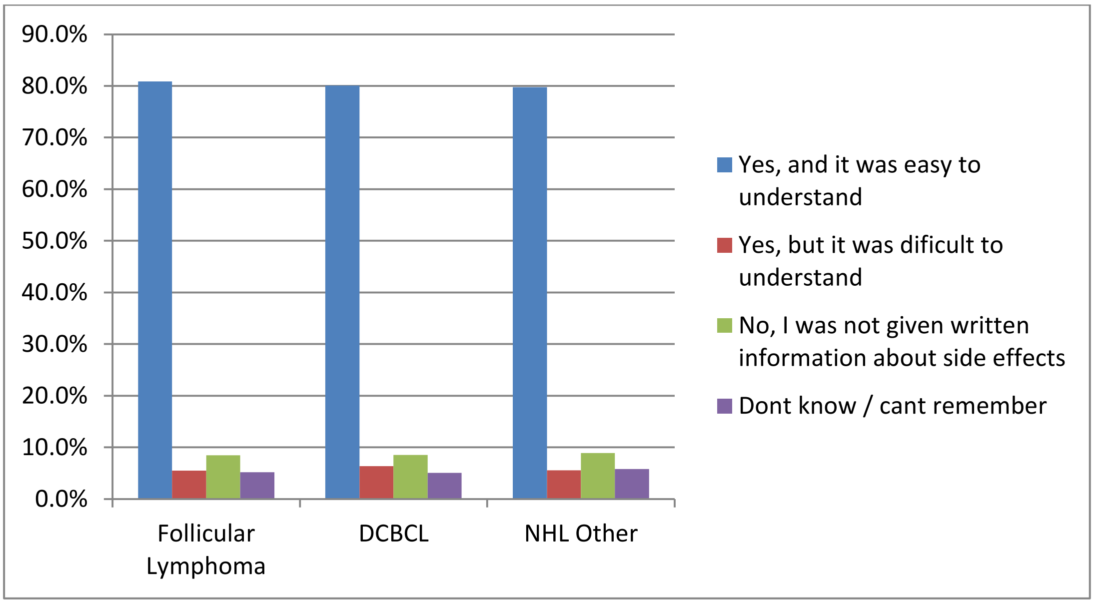
Seven per-cent of patients in the overall CPES survey didn't not know their treatment was being discussed by a team and 5% could not recall. Of those who did know, 71% said their views were definitely taking into account; 23% to some extent and 6% said their views were not included.

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



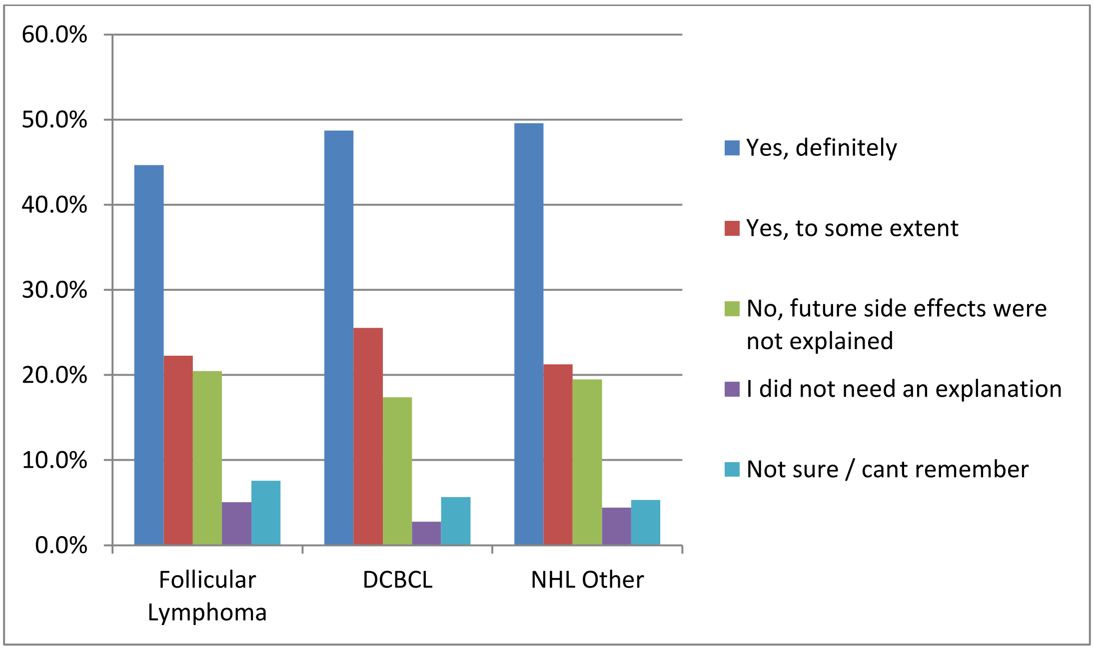
Across all NHL patients, 73.7% stated they had definitely been told about the possibility of side effects, with 21% stating they had been told to some extent. In the overall CPES survey, 75% said they were definitely explained with a further 21% and 4% saying the explanation was understandable to a certain extent or not at all, respectively.

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



Eighty per cent of patients with NHL said they had been given easy to understand information. Eighty two per-cent of patients in the CPES survey said they had received written information; 5% said they found it difficult and 12% said they were not given written information.

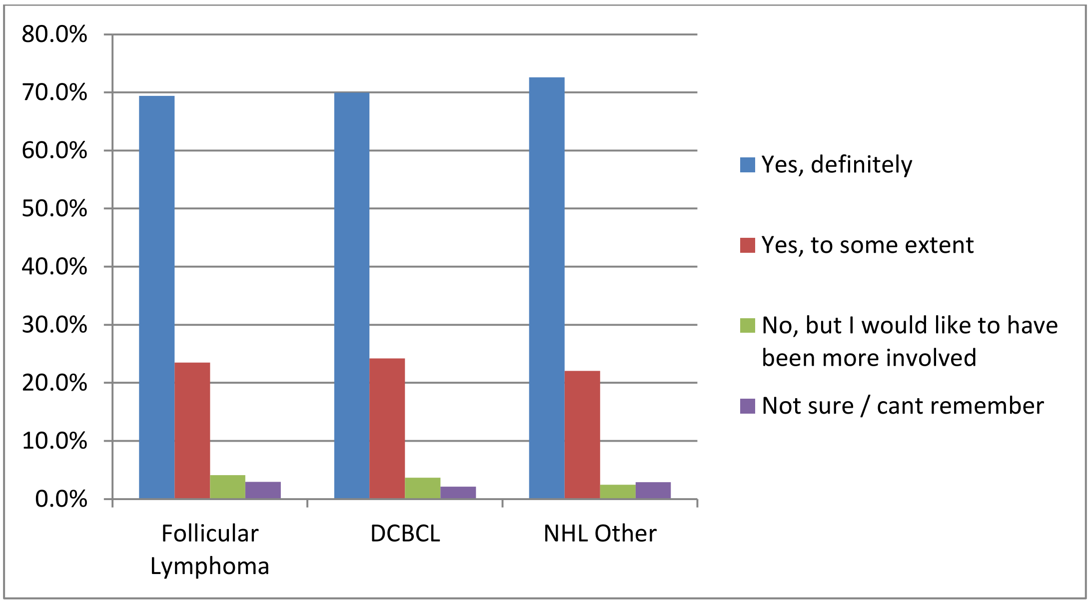
Q19. Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away?



Overall, 47.8% of NHL patients stated they were definitely told about longer-term side effects which is lower than patients in the overall CPES survey (55%). 44.7% of FL patients said they were told compared to 48.7% and 49.6% of DCBL and other NHL patients respectively. Overall, 18.6% of patients said nothing had been explained and 3.7% said they did not need an explanation compared to 18% and 6% of all CPES patients.

.

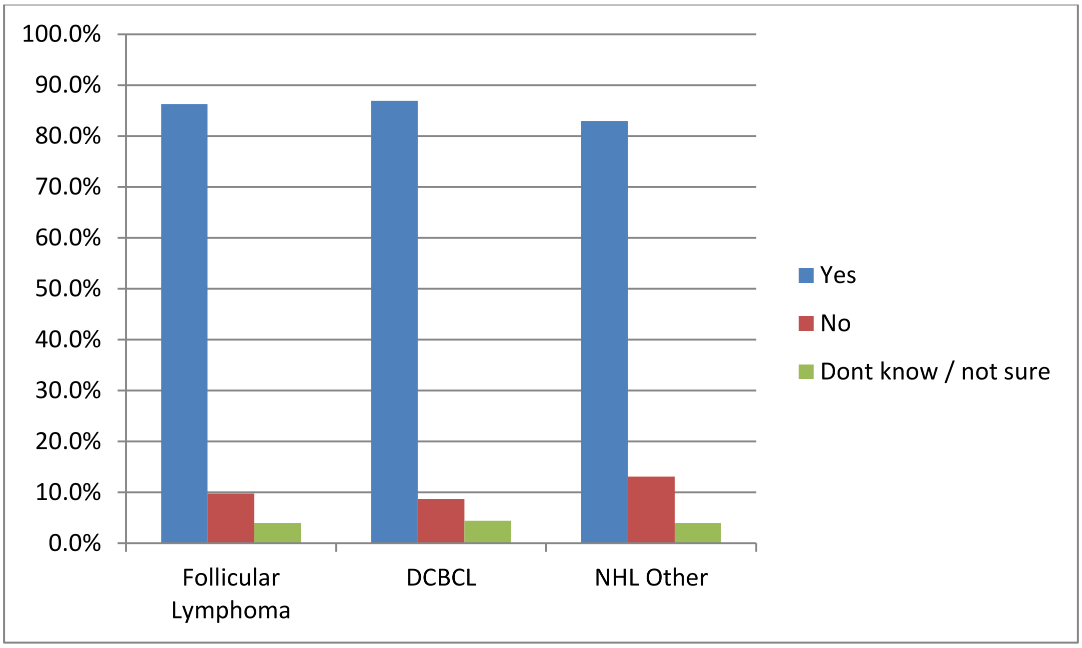
Q20. Were you involved as much as you wanted to be in decisions about your care and treatment?



Seventy per-cent of NHL patients reported that they had definitely been involved in decisions, similar to 72% of patients in the overall survey. Results were consistent across sub-groups.

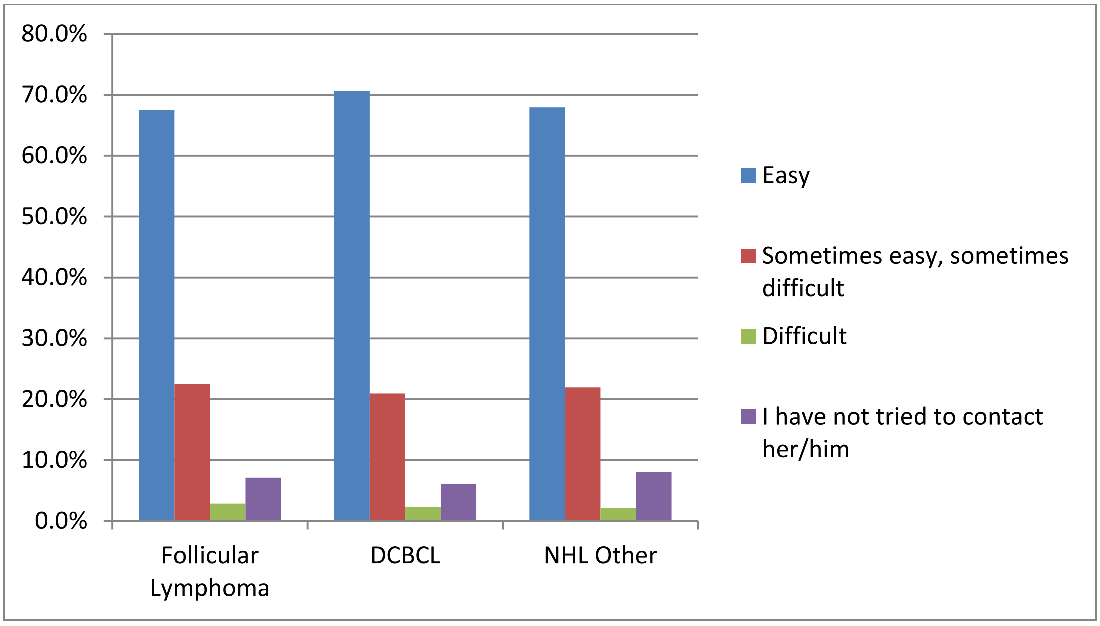
3. Clinical nurse specialist (CNS) support

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



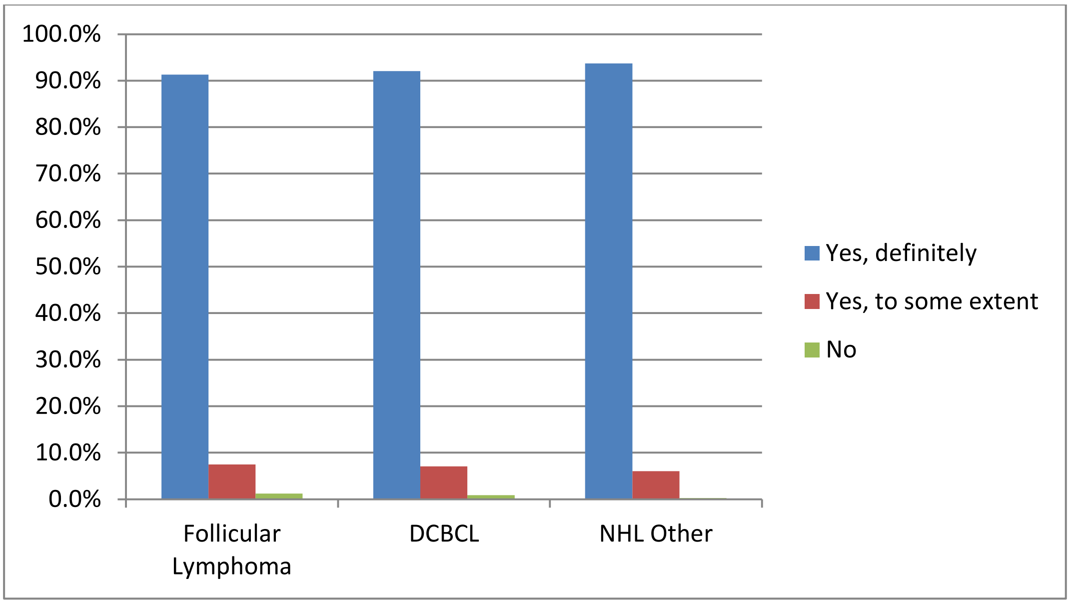
Eight-six per-cent of NHL patients stated they had definitely been given a name with 9.8% saying they had not. This was slightly lower in the other NHL sub-group (82.9%), but generally results are comparable with the overall CPES survey population (89% vs. 11%; yes vs. no.).

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



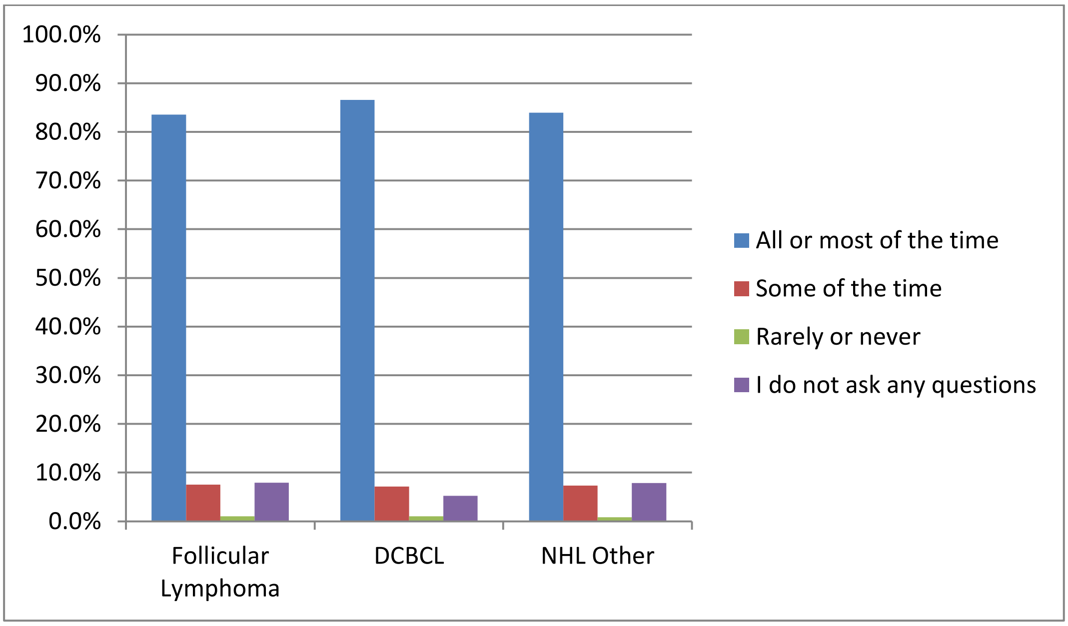
Overall, 69.7% of patients said they had found it easy to contact their CNS, with 21.5% saying it was sometimes easy, sometimes difficult, 2.4% stating difficulties and 6.8% saying they had not tried to contact him/her. Results were similar across NHL groups but reporting of ease was slightly lower compared to patients who had tried to contact in the overall CPES survey where 73% said they found it easy.

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



Ninety two per-cent of NHL patients said that he/she definitely listened, commensurate with 91% of all CPES patients.

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



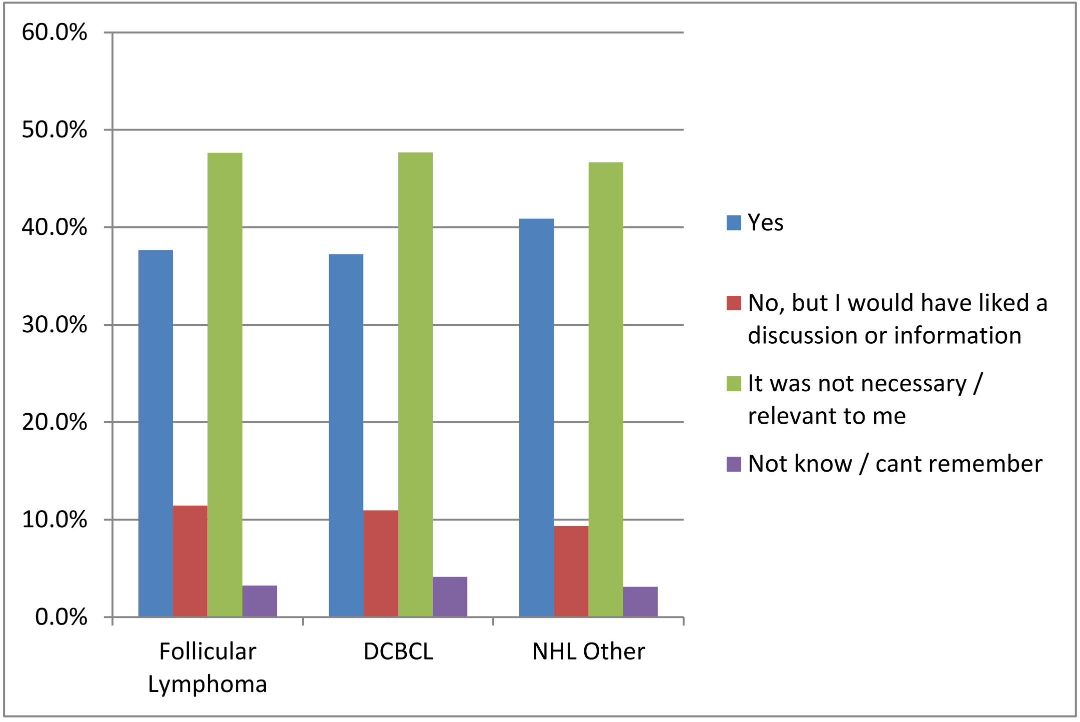
Overall, 92.1% of NHL patients reported they definitely got answers to understand, similar to the overall CPES survey were 91% said they got understandable answers all or most of the time.

4. Support for patients

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

Overall 63.5% of patients were given information with 12.9% stating they would have liked information and 18.7% saying it was not necessary. This is somewhat different to the overall CPES survey where 83% of patients stated they were given information.

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



As with the overall CPES survey patients, 48% of all NHL patients said this information was not necessary.

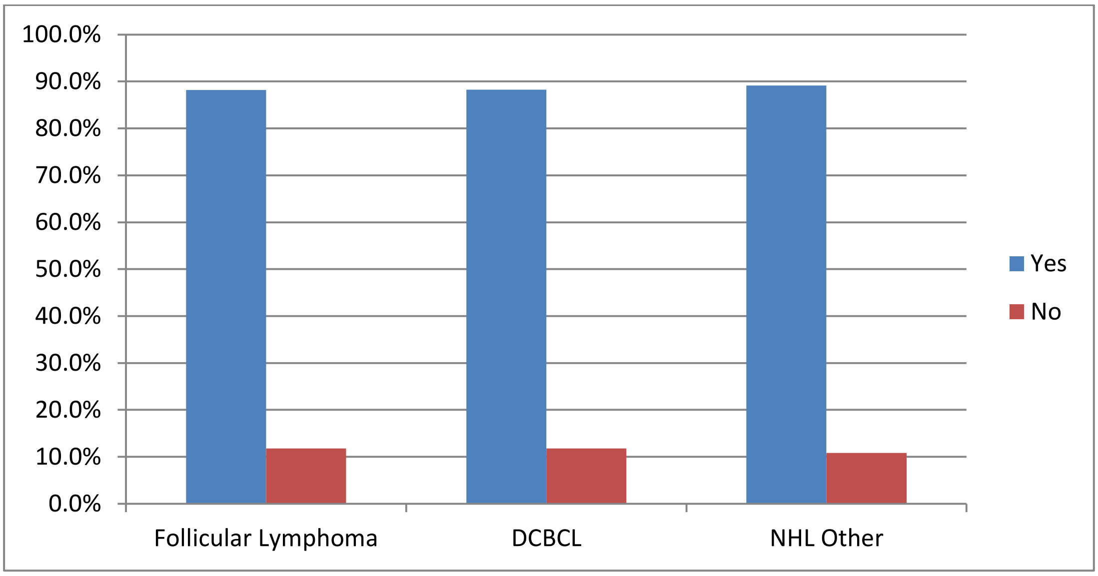
Q27. Did hospital staff give you information about how to get financial help or any benefits that you might be entitled to?

In NHL patients (who said this was necessary) 54% they had been given information; commensurate to the overall CPES survey.

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

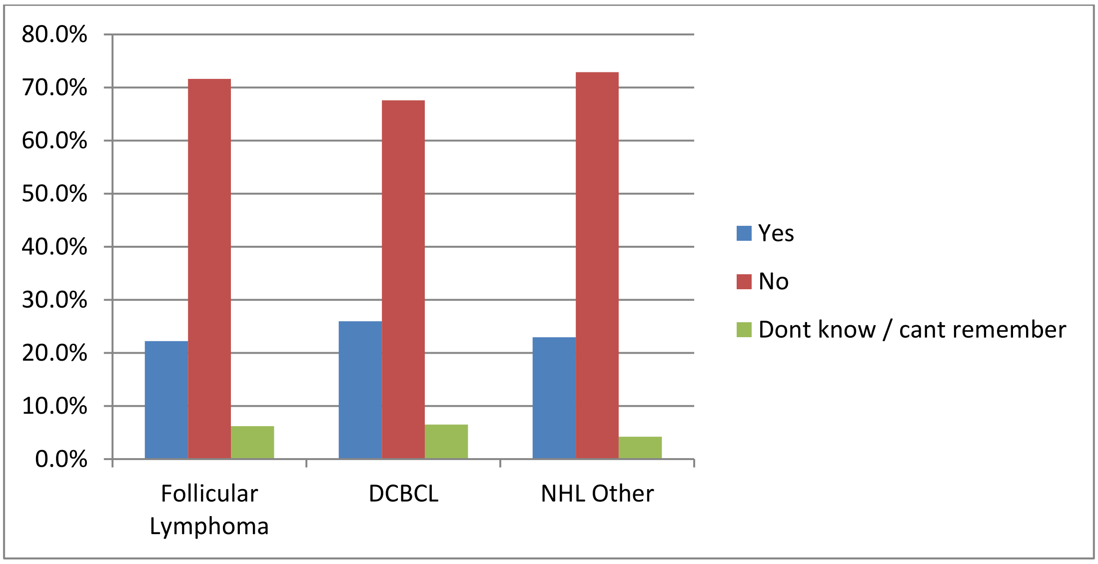
Overall 81% of NHL patients (who said it was necessary)reported they had been given information similar to 78% reported in the overall CPES survey.

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



Eighty-eight per-cent of NHL patients reported they had seen information which was similar across NHL sub-types and similar to the 86% of patient who reported they had seen information in the overall CPES survey.

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



Only 24.4% of patients stated that someone had discussed taking part in cancer trials and this was similar across the NHL sub-types. This is lower than the over CPES survey, where 31% of patients said that taking part in research had been discussed.

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

Fifty-nine per-cent of NHL patients took part in research compared to 63% in the overall CPES survey.

Operations

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

Twenty five per-cent of NHL patients reported they had received an operation, compared to 55% of all CPES patients

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

Overall 78.6% of patients who stated they had an operation said in comparison to 88% in the overall CPES.

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

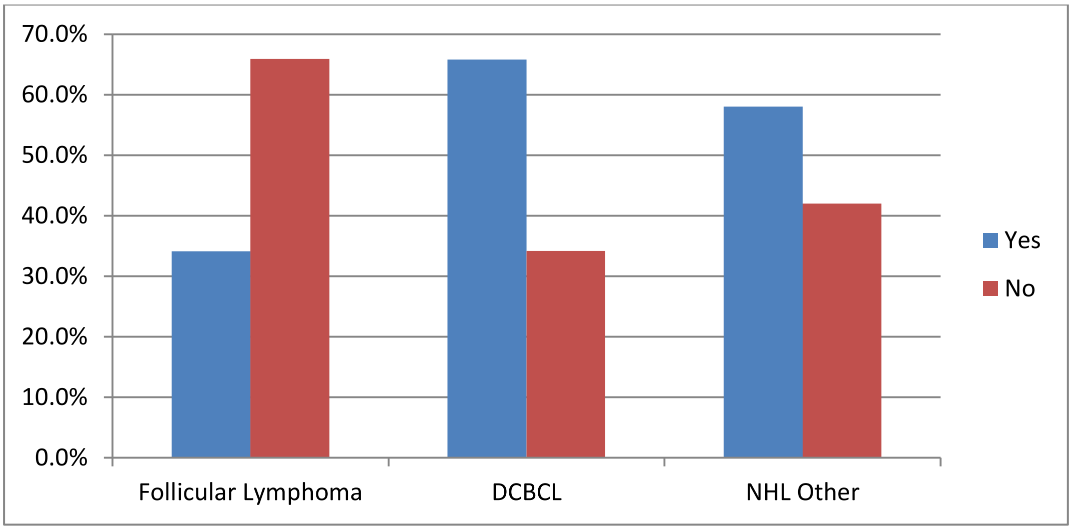
Overall 53.9% of all NHL patients stated they had been given written information which was easy to understand with 31% stating they were not given any information. This was particularly low in other NHL patients with 45.3% stating they had been given information which was easy to understand. For the CPES survey , 68% 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?

Overall, 67.8% of patients said they had received information that they completely understood from a member of staff, with similar results across NHL sub-types. Overall, 78% of CPES patients reported they had received a completely understandable explanation.

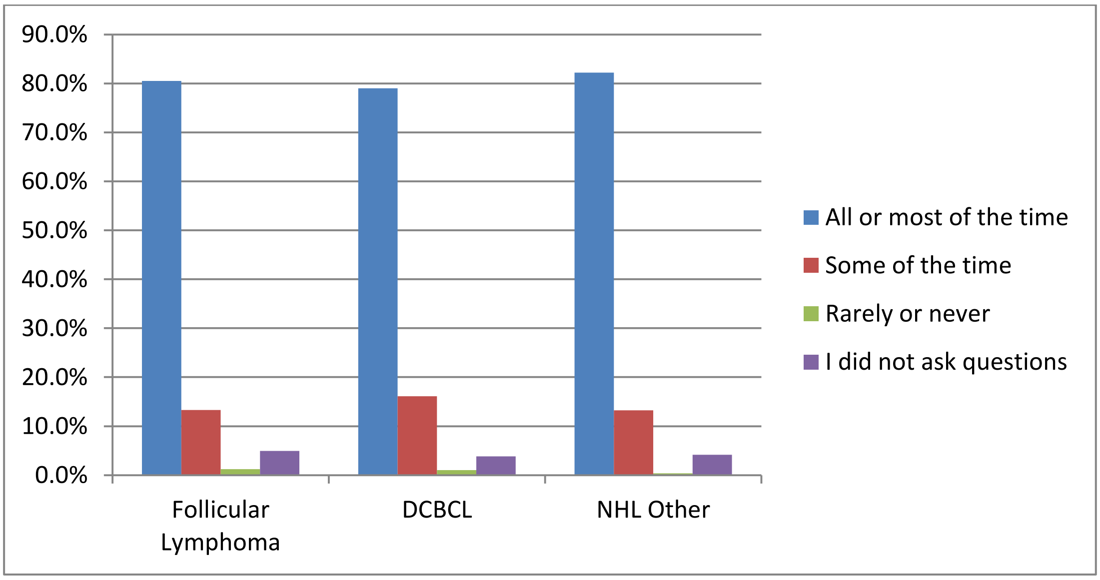
5. Hospital doctors

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]?



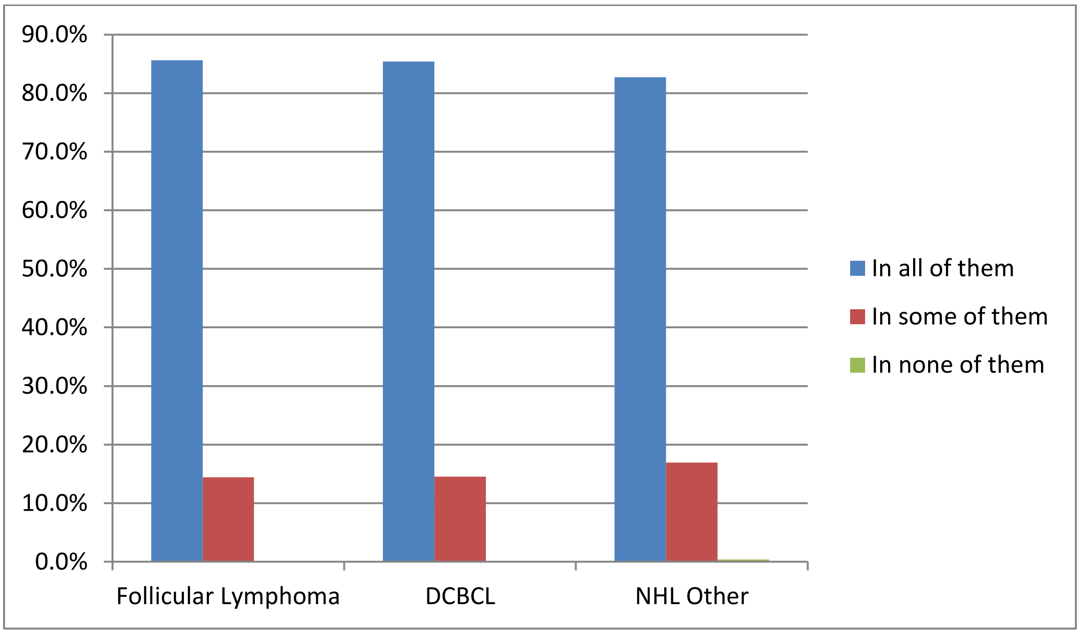
Overall, 55.6% of NHL patients stated they had stayed overnight; lower than the overall CPES survey which reported 66% of patients had said they had had an overnight stay.

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



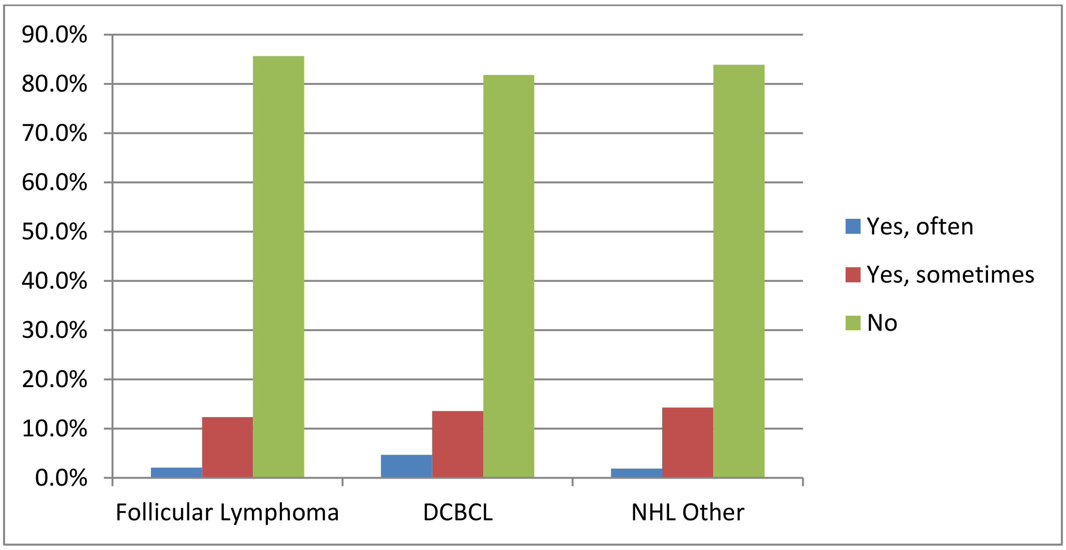
Eighty per cent of patients reported they were given an answer they understood most or all of the time; compared to 83% of patients in the overall survey. 15% reported they had answers which they understood some of the time and 0.9% reported they rarely or never got answers compared to 16% and 2% respectively in the overall CPES survey.

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



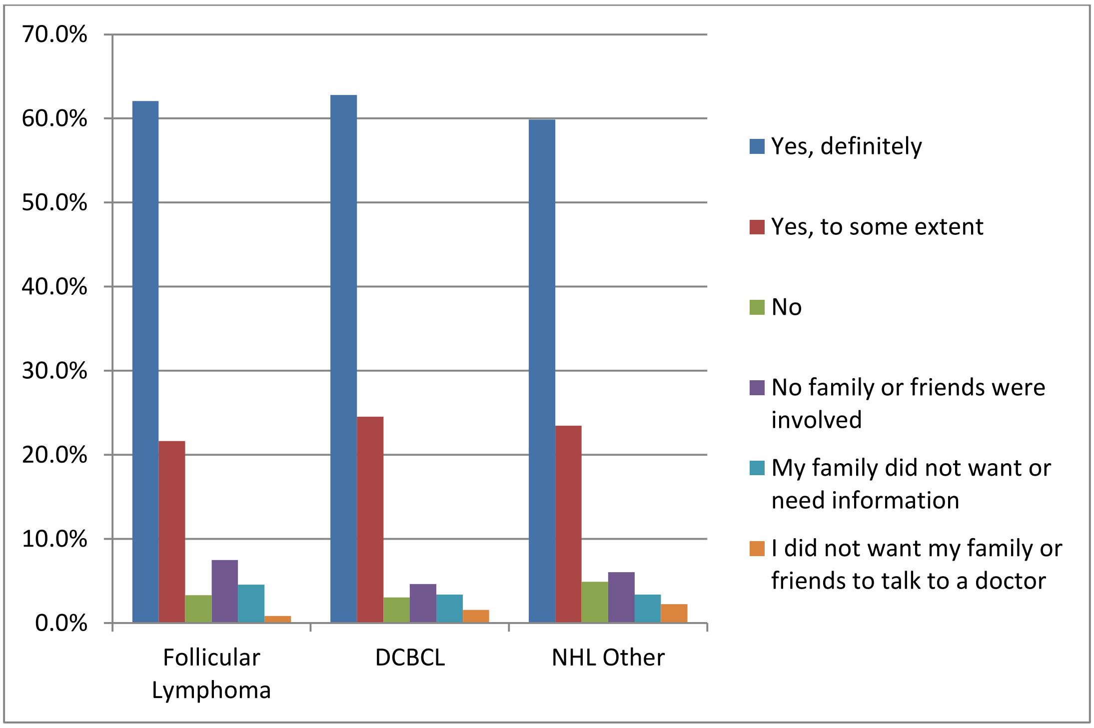
In both NHL patients and overall CPES survey patients, 85% said they had confidence and trust in their doctors; with 15% saying they had confidence and trust in some of them.

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



Overall, 82.8% of NHL patients reported that doctors did not talk in front of them with 13.5% saying sometimes and 3.7% said this often occurred, similar to overall CPES survey.

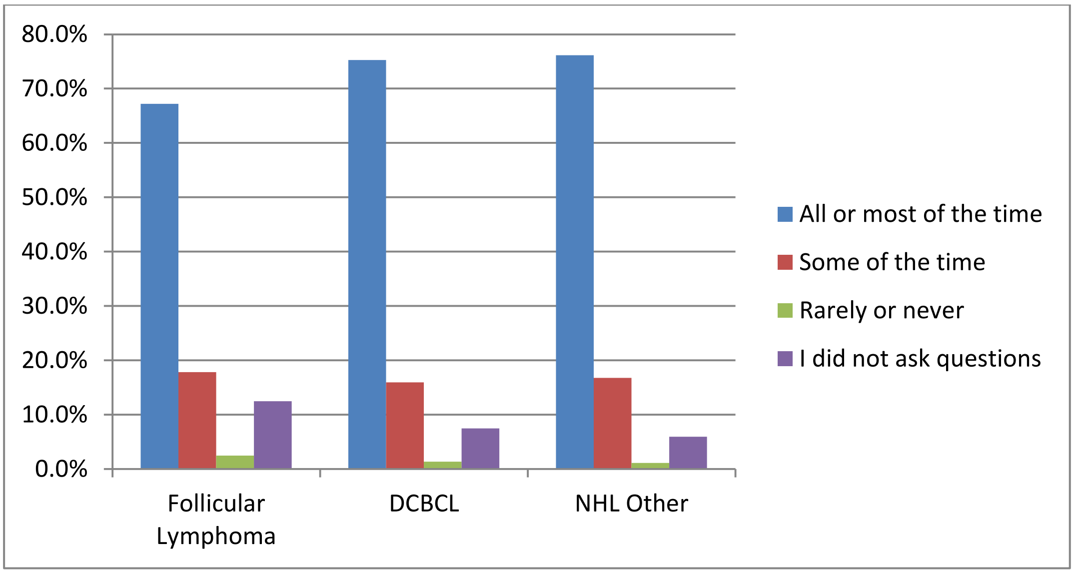
Q40. If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?



Overall, 62.1% of patients said that this was definitely offered, with 23.8% stating it was offered to some extent and 3.5% of patients saying this was not offered. Across all CPES patients, 67% said that they definitely had opportunity and 26% to some extent. 6% said they did not.

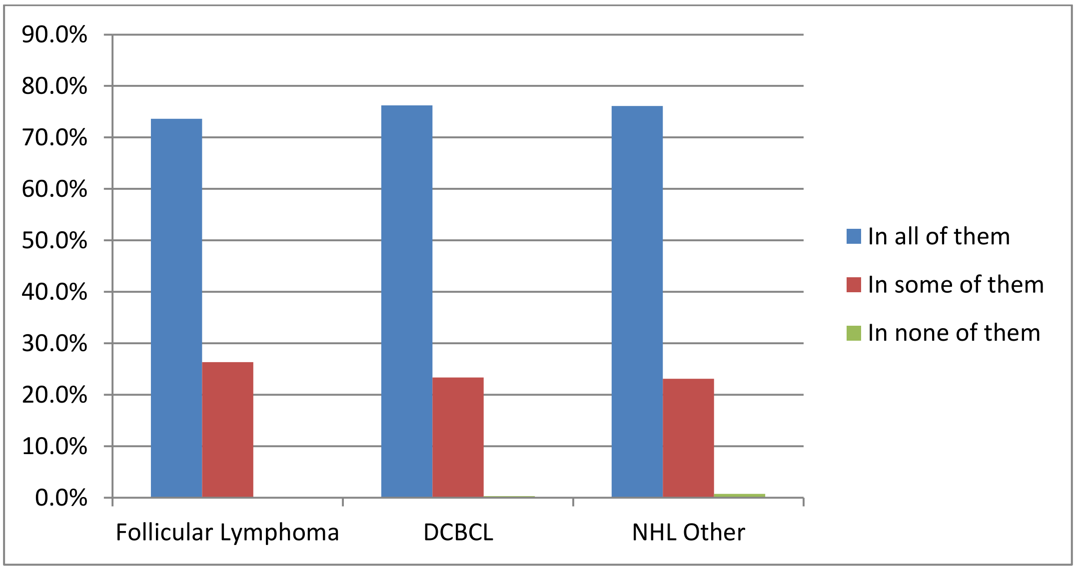
6. Ward nurses

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



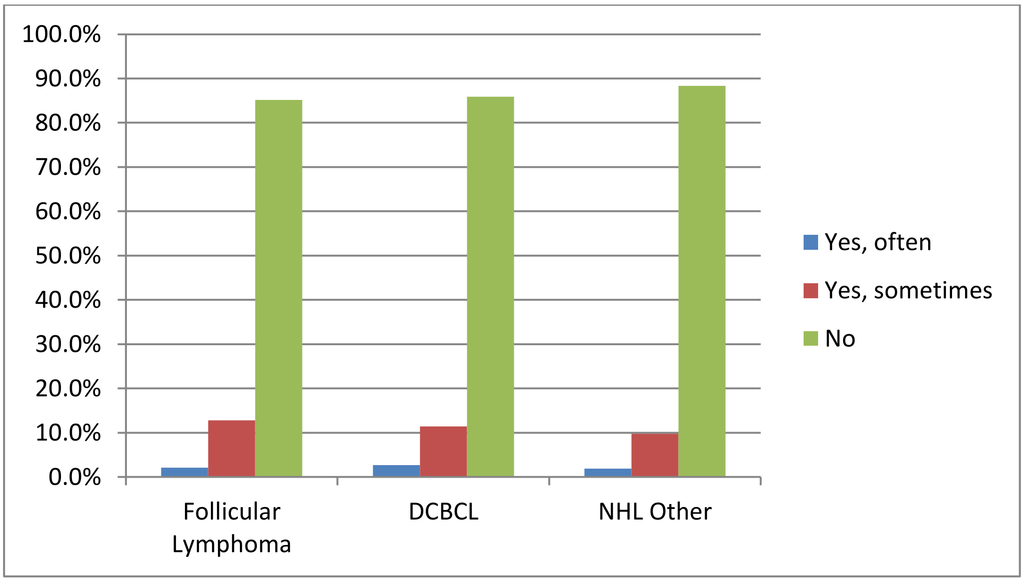
Seventy four per-cent of NHL patients said that nurses gave them answers they could understand most or all of the time, similar to the overall CPES survey, where 76% of patients said nurses gave them answers they could understand most or all of the time.

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



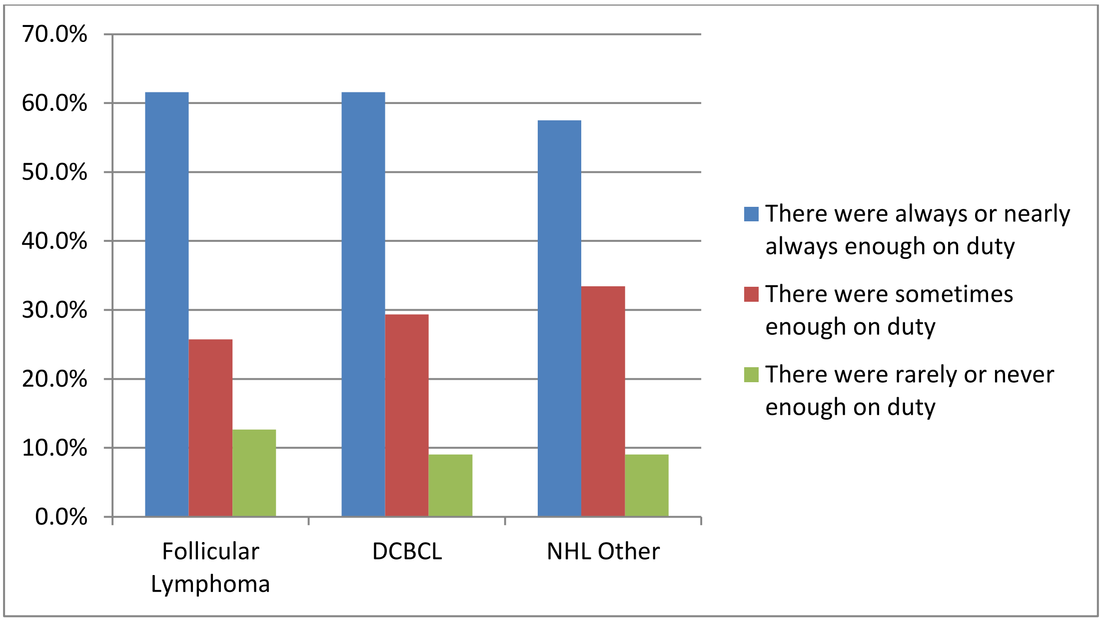
Seventy six per-cent of NHL patients said they had confidence and trust in all the nurses and this was similar across NHL sub-types. This was slightly higher than the overall CPES survey, where 71% of patients said they had confidence and trust. Only 0.4% of patients said they had no trust or confidence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

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



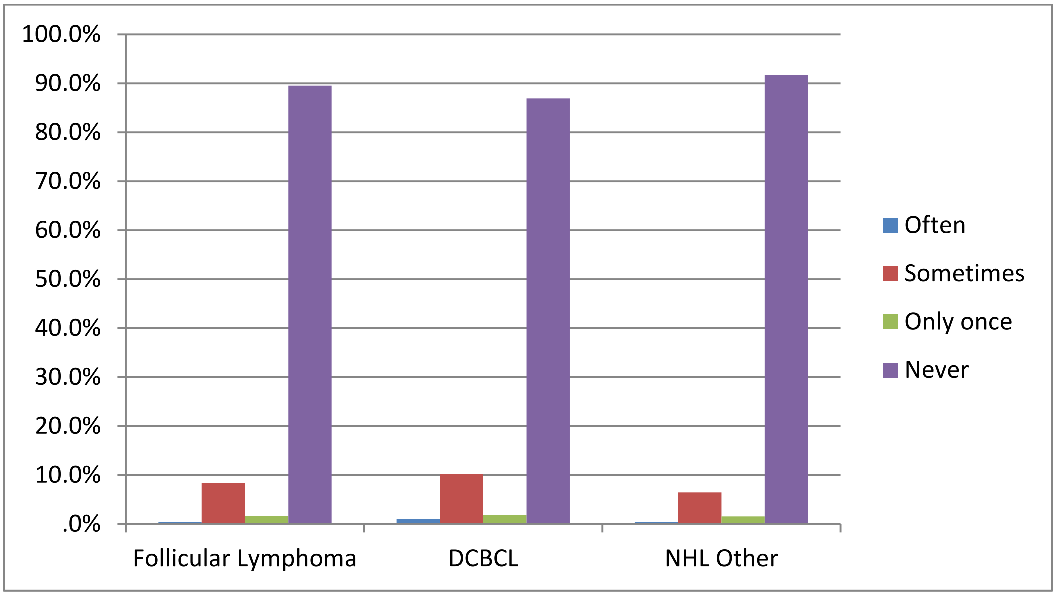
Just over 86% of NHL patients said nurses did not talk in front of them, similar to 85% of patients across the CPES survey. In the overall CPES survey, 85% of patients said nurses did not talk in front of them.

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



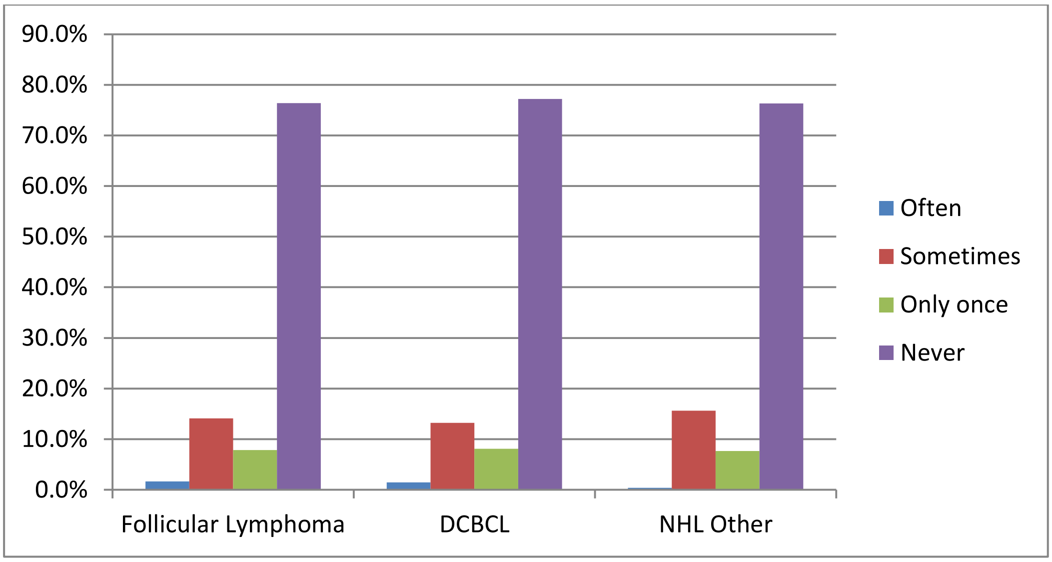
Sixty per cent of NHL patients said there were always or nearly always enough nurses on duty. 29.5% said this was the case sometimes and 9.7% reported there were rarely enough nurses on duty. These were similar results to the overall CPES survey.

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



Eighty eight per-cent of NHL patients said they never thought this, commensurate with overall CPES survey.

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

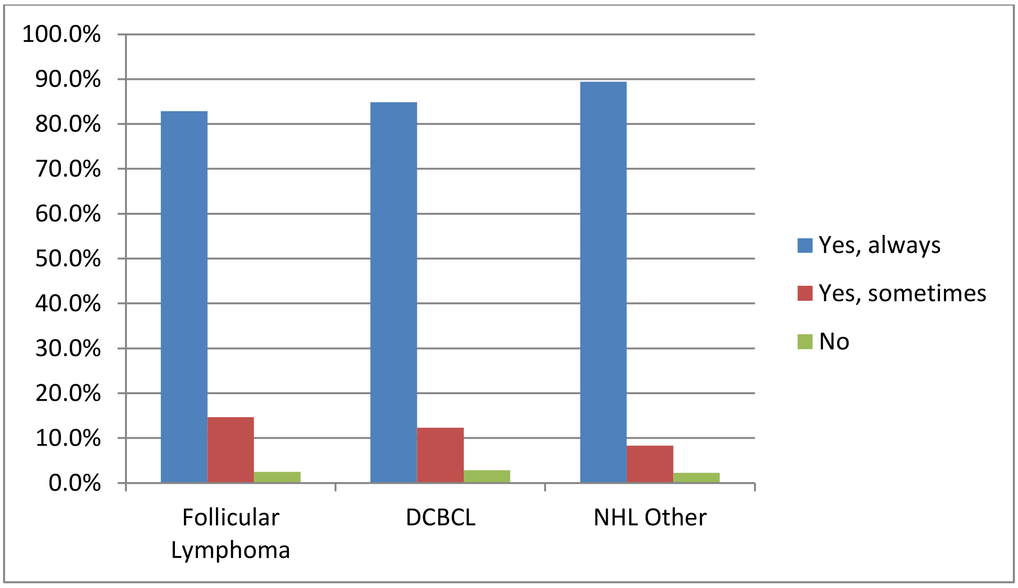


In the overall CPES survey, 79% of patients said this was never the case; 7% said this happened once with 12% saying it happened sometimes and 2% happened often.

Q47. Preferred name

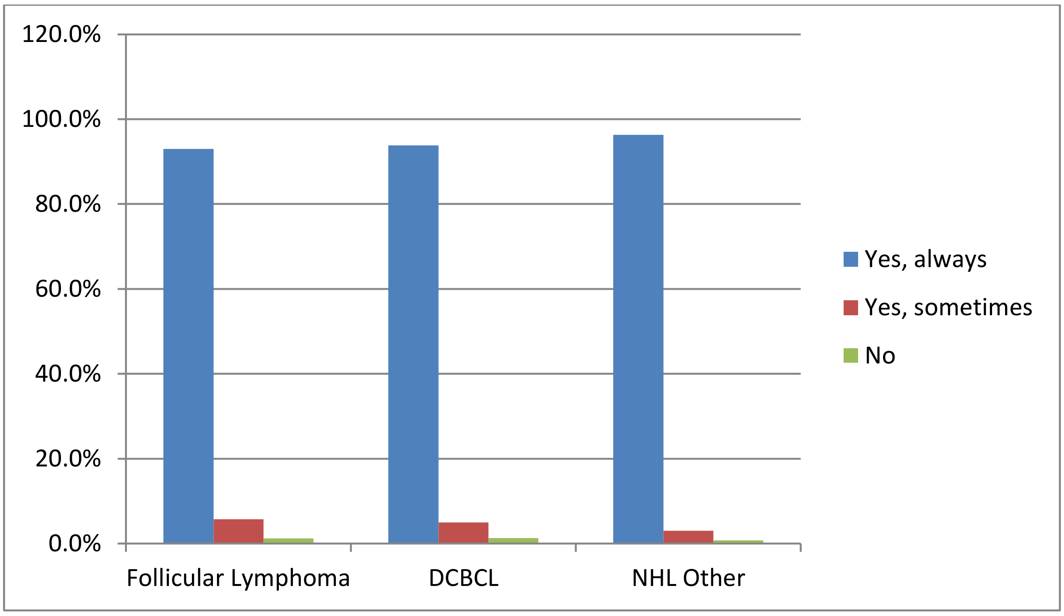
This question was not analysed because it did not relate to information or support needs.

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



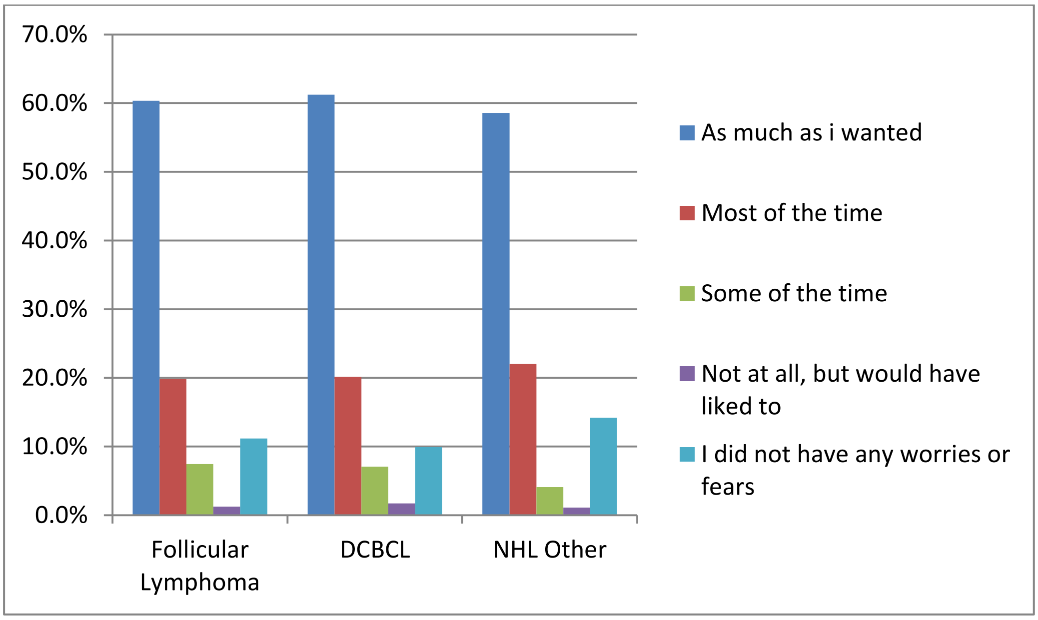
Overall, 85.4% of NHL patients said they were always given privacy similar to the 85% of patients reporting this in the overall CPES survey.

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



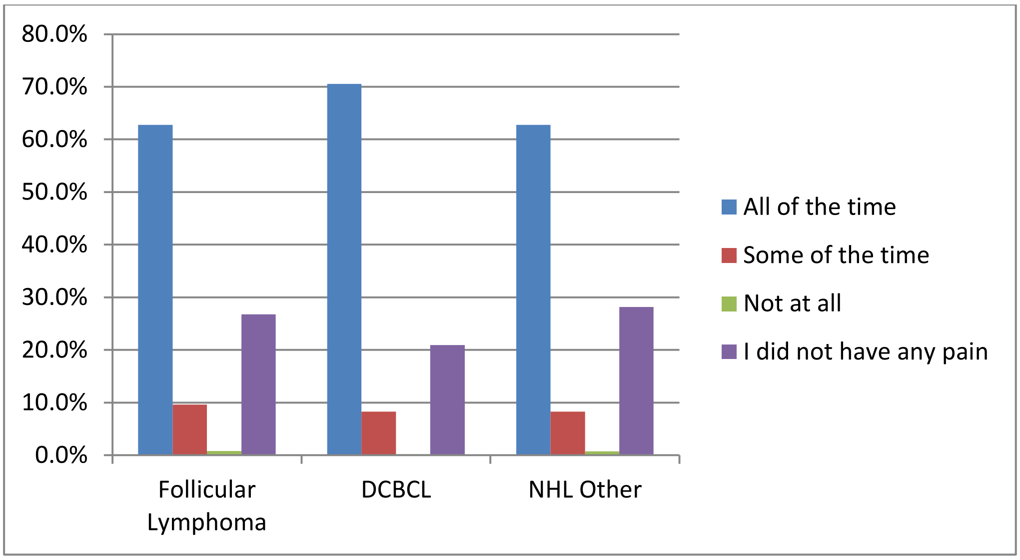
Ninety four per-cent of NHL patients said they were always given privacy, similar to the 95% of patients in the overall CPES survey.

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



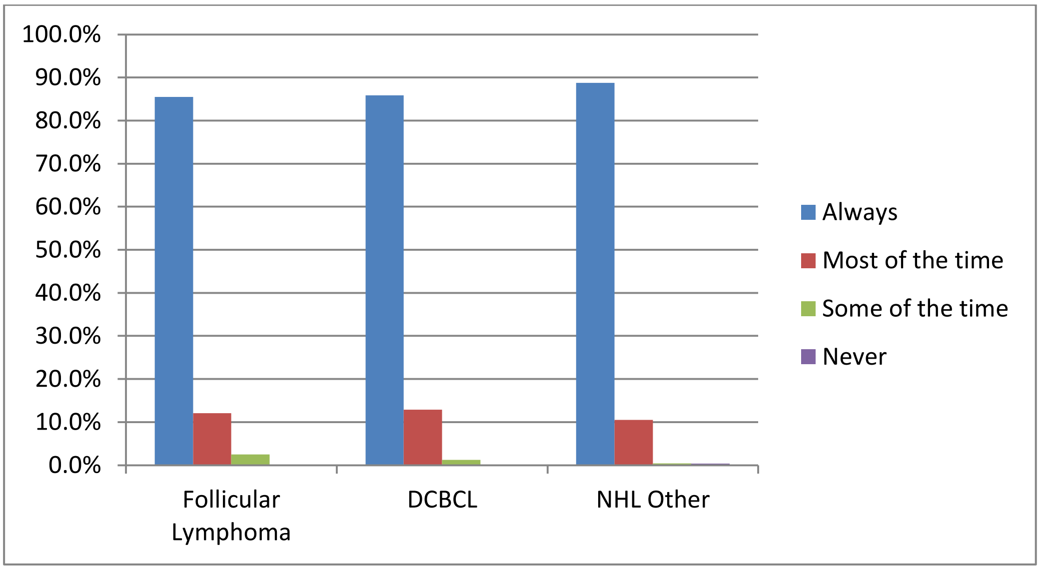
Overall 60% of patients said they were able to discuss as much as they wanted, slightly lower than, 66% said they were able to discuss their worries and fears as much as they wanted with staff.

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



Overall, 86.4% of NHL patients said that staff had done everything they could; commensurate with the 85% of patients reporting this in the overall CPES survey.

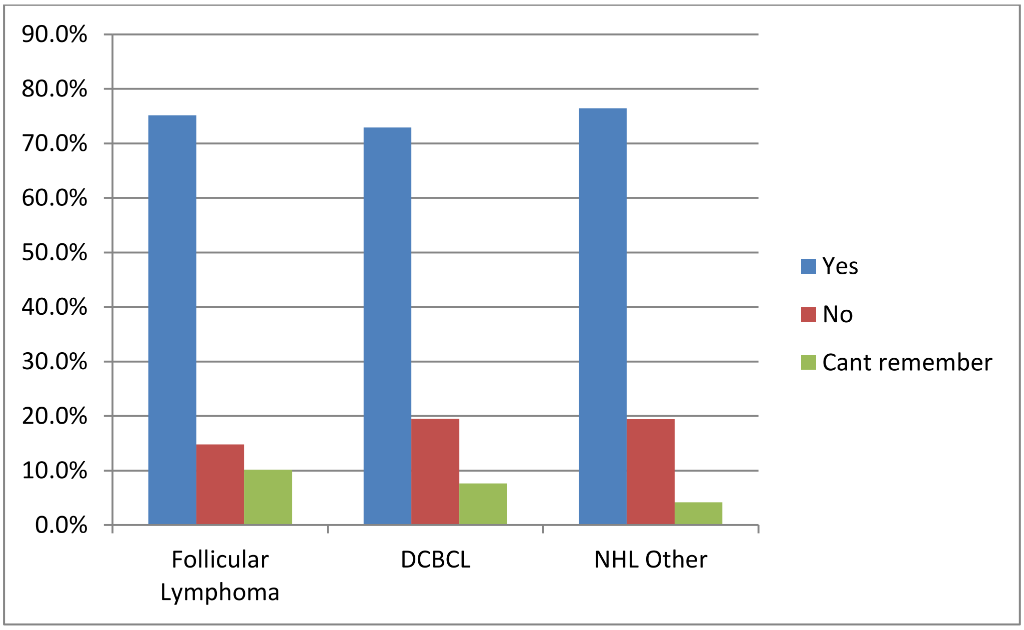
Q52. Were you treated with respect and dignity by the doctors and nurses and other hospital staff?



Overall, 86.4% of patients stated they were always treated with dignity and respect, similar to the 86% of all CPES patients reporting this.

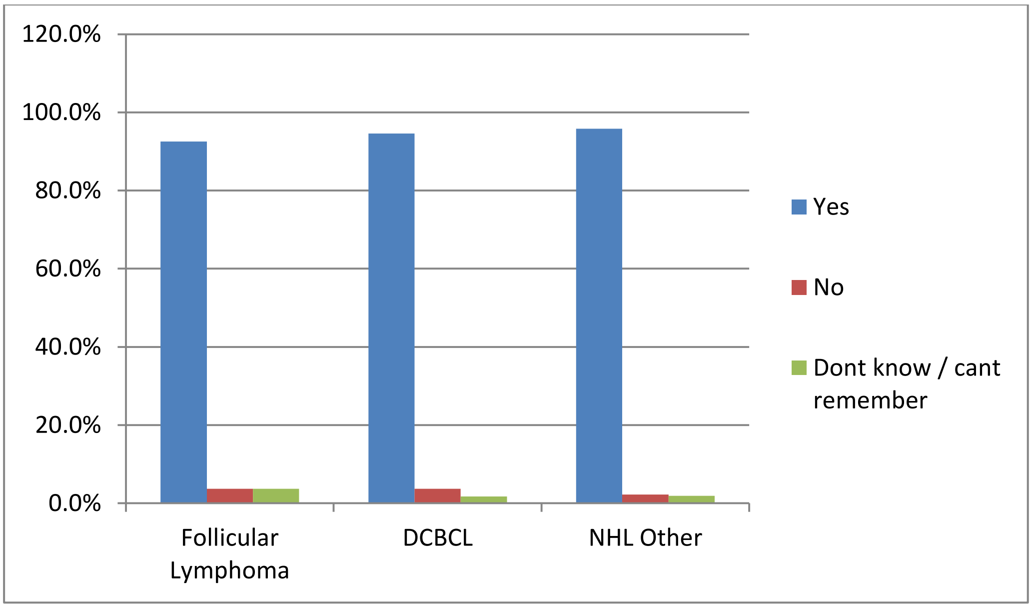
7. Information about leaving and home support

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



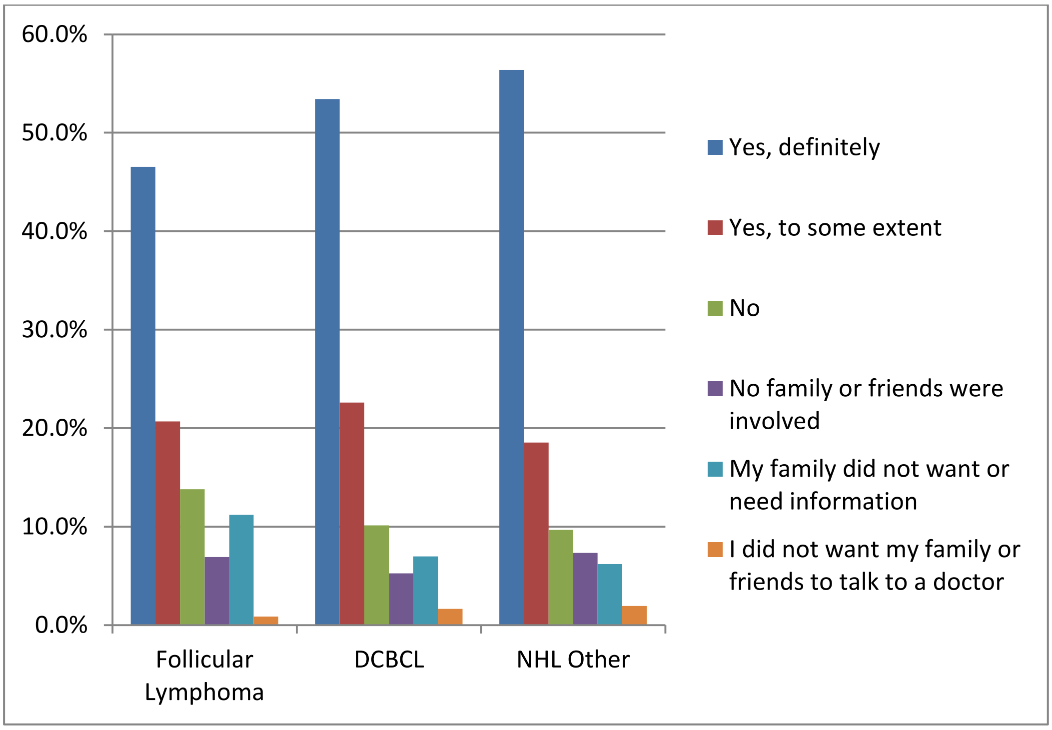
Seventy five per-cent of patients said they were always given clear information, with 18.7% saying this was the case most of the time and 7.4% stating they were not given information. This is lower than the overall CPES survey where 85% of patients said they were given clear information.

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



Overall 94.5% of NHL patients said they were told who to contact similar to the overall CPES survey where 94% of patients said they were told who to contact.

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



Overall, 52.8% of patients said their family were given all the information needed; with 21.5% stating they were to some extent and 10.7% said they were not given information. In the overall CPES survey, 60% said their family were given all the information needed; 24% said to some extent and 16% said their family did not get all the information needed.

56. Help from community health and social services

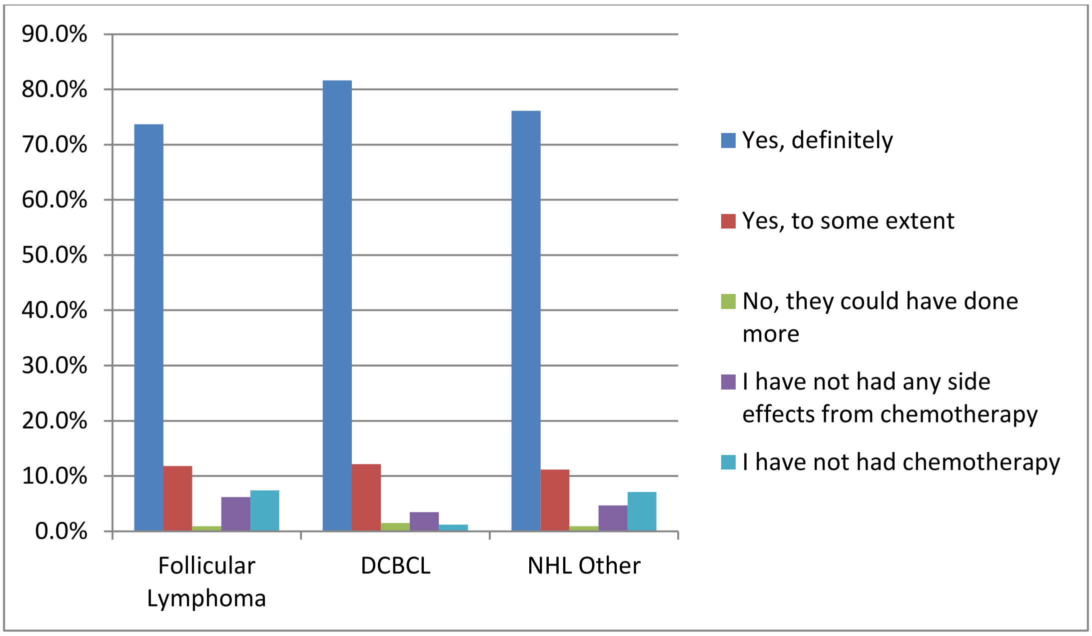
This question was not analysed because social services are outside the scope of the guideline.

8.Day/outpatient care

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

The number of respondents was too low to analyse

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



74% of patients with follicular lymphoma said hospital staff had done everything to control their side effects, this compared with 81% for those with DLBCL and 76% for those with other NHL subtypes.

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

Overall, 79% of patients said everything was done to help, similar to 82% of patients in the overall CPES survey.

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

In the overall NHL and CPES survey, 70% said they were definitely given some emotional support.

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

Overall, 97% of NHL patients reported that they had attended an appointment, similar to 94% in the overall CPES.

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

Overall, 4.5% of NHL patient said their doctor had the right documents, similar to the overall CPES report (96%).

5.14. Care from General Practices

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

5.15. Overall NHS Care.

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