

Chemotherapy Patient Experience Survey 2013

National Report



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Chemotherapy Patient Experience Survey 2013

National Report

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Prepared by Quality Health

Contents

1. Introduction.....	4
2. Executive Summary	5
3. Response rates & helpline calls	9
Response rates	10
Helpline calls	10
4. Patient demographics	11
5. Section by section	13
Before the chemotherapy	14
Having chemotherapy.....	25
Serious side effects	32
When chemotherapy finished and overall rating	35
6. Demographic analyses.....	39
7. Data processing and analysis	41
8. Survey results.....	42

1. Introduction

This is the first national patient experience survey to be conducted covering chemotherapy patients and we in NHS England are grateful for all the people involved in the production of this survey, especially the patients who have given valuable feedback on the service they experienced.

As with any first survey in such a multifaceted issue as chemotherapy, we are learning as to which questions most help us to clearly identify the lessons that will result in the improvement of the service. We are also aware of the timing of the survey as many of the question reflected events and discussions which may have happened a considerable time before the completion of the survey.

There is much to commend about the feedback on the chemotherapy services that are being delivered today in England as assessed by the patients that use them. The standard is high in terms of the information given about chemotherapy and its side-effects, the treatment plan, the telephone support service that is available for patients and carers and the high percentage of patients being offered the option of participating in a clinical trial. A 91% rating of the chemotherapy service as excellent or very good is a tribute to all the staff involved in the delivery of chemotherapy, especially at a time when chemotherapy activity and thus the pressures on the service continue to increase.

However, there are significant concerns about some of the results of the survey. Many patients did not report exploration of their practical, emotional, psychological, spiritual and financial concerns before chemotherapy started. About 10% of patients missed scheduled chemotherapy because of staff shortages. Only 75% regarded the treating nurse as being fully knowledgeable about the side-effects of the treatment received. An additional concern is that there appears to be a difference between the care accompanying intravenous versus oral chemotherapy in that patients receiving intravenous treatment were more likely to be offered a written treatment plan and information, a discussion as to side-effects and information concerning the telephone information service.

The first national patient experience survey on chemotherapy has thus taught us much as to what we do well and the features of the service which we need to improve. Each chemotherapy team needs to critically examine all the findings in this report to learn all the lessons which will result in each chemotherapy patient and their carers being treated as individuals with unique needs at a very difficult period in their lives. NHS England's Chemotherapy Clinical Reference Group will also be stimulated by this survey to revise or produce suitable guidance to commissioners which will also help keep the patients and their cares at the centre of all our endeavours.

Professor Peter Clark

Chair, NHS England Chemotherapy Clinical Reference Group

2. Executive Summary

The Chemotherapy Patient Experience Survey was undertaken by Quality Health for the Department of Health and the National Cancer Action Team between February and June 2013 in order to obtain information about the specific treatment and information given to chemotherapy patients, supplementing that contained in the national Cancer Patient Experience Survey. NHS England took responsibility for the survey and for publication of the results in April 2013.

The chemotherapy survey was designed in conjunction with the clinical advisory group on chemotherapy and implemented in 141 NHS Trusts in England undertaking chemotherapy work. It is the first time that a national survey of chemotherapy patients has been undertaken.

35,000 patients who had received chemotherapy treatment were included in the initial samples taken from Trust records. The response rate of 65% confirms that cancer patients will reply to questionnaires about their care and treatment in large numbers. The high response and substantial sample size produces a confidence interval of +/- 0.6% at 95% at all respondents level.

The findings of the Chemotherapy Survey are broadly positive. Of the 56 scored questions in the survey, 30 received ratings of 80% or over as follows:

Q02	Plenty of time to ask questions before signing the consent form	91%
Q05	Told very clearly why chemotherapy was needed	90%
Q08	Told about risks or side effects there might be with chemotherapy	81%
Q10	Told very clearly about treatment plan	85%
Q11	Told could bring someone to appointments	92%
Q12	Able to talk to staff completely about worries	84%
Q14	Given written information about chemotherapy and side effects	95%
Q15a	Written information said what to do if had temperature or fever	97%
Q15b	Written information said what to do if had persistent vomiting	95%
Q15c	Written information said what to do if had persistent diarrhoea	94%
Q16	Told about importance of sharing information with family	85%
Q17	Given contact number if had questions about care	98%

Q18	Given card with 24 hour helpline in case worried or unwell	95%
Q21	Told what tests were for	96%
Q25a	Given written information about missed dose oral chemotherapy	83%
Q25b	Given written information about how to handle oral chemotherapy	86%
Q28	Chemo appointment never changed because of staff shortages	91%
Q29	Never missed chemo because pre-meds or chemo not ready	91%
Q30	Waiting area before chemotherapy comfortable	95%
Q31	Enough seats for patients in waiting area	92%
Q32	Somewhere to get refreshments near waiting area	96%
Q33	Staff available to answer questions in waiting area	95%
Q34	Nurse asked about any side effects patient experiencing	91%
Q35	Given very clear explanation of why treatment changed	84%
Q37	Felt comfortable speaking to staff with other patients in room	93%
Q39	Staff available to help all or most of the time during chemo	86%
Q40	Given very clear explanation of how to take drugs being taken home	93%
Q42	Was not sick after last treatment	83%
Q46	Told what to do if noticed new symptoms or had worries	82%
Q52	Overall rating of care excellent or very good	91%

There are, however, a number of issues on which patients rated the chemotherapy service that they received in a less positive fashion; on 26 questions, a score of less than 80% was achieved, including 21 where the score achieved was less than 70% as follows:

Q03	Offered a written record of discussion about treatment	66%
Q04	Spoken to about taking part in clinical trials	42%
Q06	Given choice about where to have chemotherapy	26%
Q07	Told why did not get choice about where to have chemo	25%
Q13a	Given opportunity to talk to someone about emotional concerns	62%
Q13b	Given opportunity to talk to someone about practical concerns	65%

Q13c	Given opportunity to talk to someone about financial concerns	44%
Q13d	Given opportunity to talk to someone about psychological concerns	48%
Q13e	Given opportunity to talk to someone about spiritual concerns	32%
Q22	Waited up to 1 hour for blood test results on same day	45%
Q41	Did not feel sick after last treatment	51%
Q43	Did not have any problems with mouth or throat after last treatment	58%
Q47	Told completely about long term side effects	45%
Q48	Told how long it might take to recover	65%
Q49a	After treatment finished, given opportunity to talk to someone about emotional concerns	44%
Q49b	After treatment finished, given opportunity to talk to someone about practical concerns	44%
Q49c	After treatment finished, given opportunity to talk to someone about financial concerns	32%
Q49d	After treatment finished, given opportunity to talk to someone about psychological concerns	37%
Q49e	After treatment finished, given opportunity to talk to someone about spiritual concerns	26%
Q50	Offered a care plan to specifically help with concerns	63%
Q51	Offered written information about the treatment received	41%

It is clear from the data that some of the most positive responses relate to the giving of information on why the patient needed chemotherapy (score 90%); being told clearly about their chemotherapy treatment plan (85%); being given a contact number to ring if they had any questions about their care (98%); being given a card which set out a 24 hour helpline number if they felt worried or unwell; and being told what tests undertaken before chemotherapy started were for.

In contrast, some of the least positive scores in the survey were achieved in respect of patients being given the opportunity to talk to someone about financial, psychological or spiritual concerns that they may have had, both before and especially after treatment; waiting times for blood tests on the same day as a chemotherapy session, where many patients waited longer than an hour; feeling nauseous after their last treatment (only 51% did not feel sick); being told about any long term effects of chemotherapy (45% told); and being offered written information about the treatment they had (41% offered such information).

Conclusions

The Chemotherapy survey shows that patients are in general very satisfied with the quality of treatment they are receiving. However, some patient groups are less positive, namely, patients who received intravenous chemotherapy were more likely to report nausea and vomiting than patients who received oral chemotherapy, but were more likely to receive written information, care plans and contact cards. Patients using oral chemotherapy were more likely to give positive scores than others.

There are some regional differences in the scores give by patients, with the East Midlands being the least positive region as a whole. The prominence of London as a poorly performing area, found in the national cancer patient experience survey (CPES), is not repeated.

Some differences in scores between groups of respondents, based on demographic and other factors which appear in the CPES results, are also present in the chemotherapy survey results. Men are more positive than women; respondents who describe themselves as non-heterosexuals are also largely more positive than heterosexuals; and patients in the least deprived areas are less positive than those in the more deprived ones.

Some patterns of scores are different, however, from the CPES. London does not feature as the poorest performing area; there are hardly any differences between White patients and patients from ethnic minority groups; and on balance non heterosexuals are more positive, whereas in the CPES they are not.

Despite the scores being substantially positive, there are many areas on which to focus quality improvement, for example improving the coverage of treatment plans, and mitigating the side effects of chemotherapy for some patients.

Detailed analyses of the chemotherapy patient experience survey responses are set out in section 6 of this report.

3. Response rates & helpline calls

A total of 28,166 patients who had received chemotherapy treatment between February and June 2013 were included in the sample for the survey.

During the survey process Quality Health undertook Demographics Batch Service (DBS) checks on patient records on 3 occasions to remove deceased patients from the samples: before the first send out, before the first reminders were sent and before the second reminders were sent.

This procedure, undertaken centrally at Quality Health has the positive effect of substantially reducing the numbers of deceased patients who are sent questionnaires. A central procedure enables tighter control on the existence and timing of DBS checks to be effected, with the positive consequence that the number of deceased patients reported through the helpline has dropped significantly.

Cancer patients often make a number of visits to a hospital or hospitals for a variety of treatments or consultations in a short period of time. To ensure that patients were not sent more than one questionnaire, checks were undertaken on all Trust samples for the survey to ensure that patients appeared on the list only once. Further checks were made between Trusts to ensure that patients did not appear on the lists of more than one Trust. If patients were found on Trust lists more than once then their most recent treatment was taken as the episode to use in respect of the survey sample. This brought the initial national sample of 35,000 down to the 28,166 who were sent questionnaires.

3,636 patients were also removed from the samples after send out arising from calls to the helpline, postal communications that were received during the fieldwork and DBS checking. These included additional deceased patients, those who had moved and could not be traced and other ineligible patients.

Response rates

The response rate to the Chemotherapy Patient Experience Survey in 2012 was 65% (16,002 completed questionnaires from a final sample of 24,530). This corresponds favourably with the response rate to the national Cancer Patient Experience Survey (64%) in 2013. Taken together, these response rates indicate strong willingness by many cancer patients to comment on the care and treatment received, their health status, and symptoms they experienced.

Response rates to the survey varied by Trust, ranging from 91% to 21%, with half of the Trusts with lower response rates being in London. However, response rates in many Trusts were higher than in the national Inpatient Survey, where questionnaires are sent to patients discharged from all specialties.

Helpline calls

Quality Health provides a dedicated survey helpline staffed by trained in-house operators. 1,461 calls were received during the fieldwork. Calls to the helpline fell into the following categories:

- Patients calling for general advice about completing the questionnaire
- Patients calling to say they were too ill or did not want to participate
- Relatives calling to report deceased patients
- Patients reported as having moved
- Patients calling for help with translation facilities

As soon as calls were received, the nature of the call and any required action was logged on the database to ensure that, in particular, patients who were deceased or did not want any further communication did not receive survey reminders. Patients who raised queries about their health status were offered information about the Macmillan Cancer Support website and helpline or referred to their originating Trust if this was appropriate.

4. Patient demographics

The survey questionnaire included a number of questions asking for demographic information about the patient. The tables below show the percentage and number of respondents by gender, age, ethnicity, sexual orientation and long term condition.

Gender of respondents	Number of respondents	Percentage
Male	6168	40.1%
Female	9219	59.9%

Table 1 Respondents by gender

Age of respondents	Number of respondents	Percentage
16-25 years of age	73	0.5%
26-35 years of age	278	1.8%
36-50 years of age	2023	13.4%
51-65 years of age	5410	35.8%
66-75 years of age	4817	31.9%
76+ years of age	2519	16.7%

Table 2 Respondents by age group

Ethnicity of respondents	Number of respondents	Percentage
White (British, Irish or other white)	14,798	94.9%
Asian or Asian British	340	2.2%
Black or Black British	275	1.8%
Mixed background	92	0.4%
Other	86	0.6%

Table 3 Respondents by ethnicity

Sexual orientation of respondents *	Number of respondents	Percentage
Heterosexual	14097	94.1%
Bisexual	27	0.2%
Gay or lesbian	130	0.9%
Other sexuality	43	0.3%

Table 4 Respondents by sexuality

* 4.5% of patients said they preferred not to answer this question, and a further 6% of all respondents to the survey did not answer the question at all.

Respondents with long term conditions *	Number of respondents	Percentage
Deafness or severe hearing impairment	1103	6.9%
Blindness or partially sighted	267	1.7%
A longstanding physical condition	1849	11.6%
A learning disability	80	0.5%
A mental health condition	336	2.1%
A long standing illness	1846	11.5%

Table 5 Respondents with long term conditions

* 63% of patients said they did not have a long-standing condition other than cancer. The table shows the percentage and numbers of patients saying they had one or more of each of the long-standing conditions specified.

5. Section by section

This section of the report describes the results for each part of the questionnaire in the order in which it was read by the patient. The survey order was designed to reflect the patient's journey through their chemotherapy treatment, starting before the treatment and ending with their overall ratings of their care.

The results from each question in the survey are described in the following sections. The number of the question in the questionnaire is shown, and the text of the question is displayed. The full survey results are set out in Appendix A.

Key scores in the section have been calculated after removing any patients who said that the question did not apply to them, who ticked 'don't know / can't remember' or who did not answer at all. On some questions the 'don't know / can't remember' responses have been reported in the text as this response is given by large numbers of patients and is therefore a major response category even though it has been removed from the key score calculation.

Where the key score has been constructed from more than one response option to a particular question (e.g. excellent and very good), then the response options that make up that key score are described.

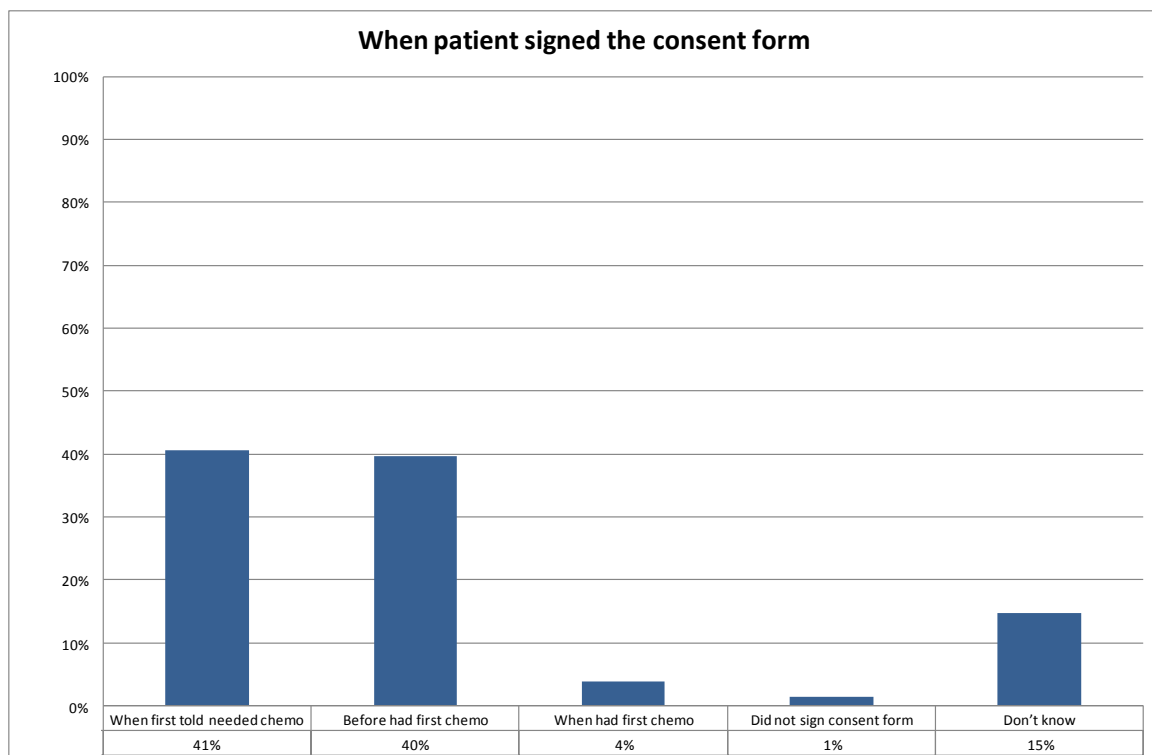
Before the chemotherapy

The questions in this section of the survey were designed to ascertain patient awareness and involvement of the consent process, choices and information before treatment started.

1. Signing the consent form

When did you sign the consent form for your chemotherapy?

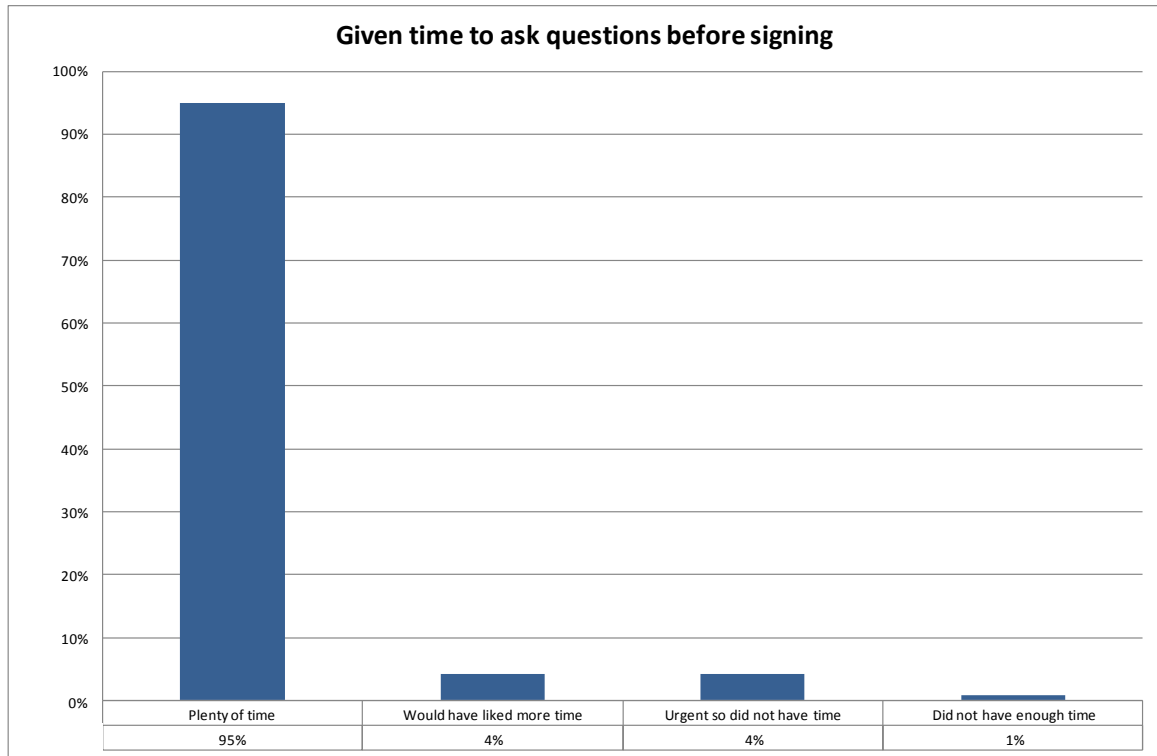
41% of patients said they signed the consent form when they were first told they needed chemotherapy; 40% signed it before they had their first treatment and 4% signed it on the day of their first treatment; 15% did not know or could not remember. 1% said they did not sign a consent form.



2. Time to ask questions

Do you think you were given enough time to ask questions between being told you needed chemotherapy and signing the consent form?

95% of patients said they were given plenty of time; 4% would have liked more time and 1% said no, they did not have enough time. 4% said their case was urgent so they did not have time.



3. Written record

Were you offered a written record or summary of the discussion about your treatment?

66% of patients who could remember said they were given the opportunity to ask questions; 34% said they were not given the opportunity. 22% did not know or could not remember.

4. Clinical trials

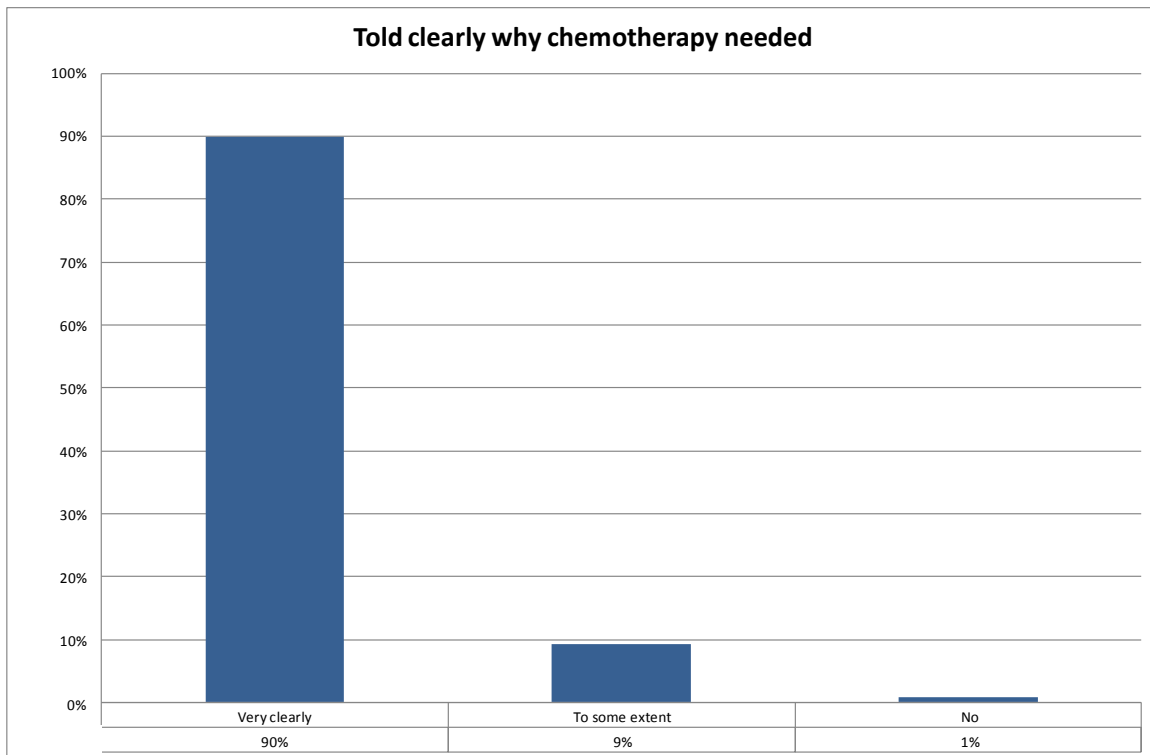
Before you started your treatment, did anyone talk to you about whether you would like to take part in clinical trials?

42% of patients said they were talked to about clinical trials; 58% were not talked to. 10% did not know or could not remember.

5. Told why chemotherapy needed

Were you told clearly why you needed chemotherapy?

90% of patients said they were told very clearly why they needed chemotherapy; 9% said they were told to some extent and 1% were not told.



6. Choice of where to have treatment

Were you given a choice about where you would have your chemotherapy?

26% of patients said they were given a choice about where to have their chemotherapy; 74% said they were not given a choice.

7. Told why no choice given

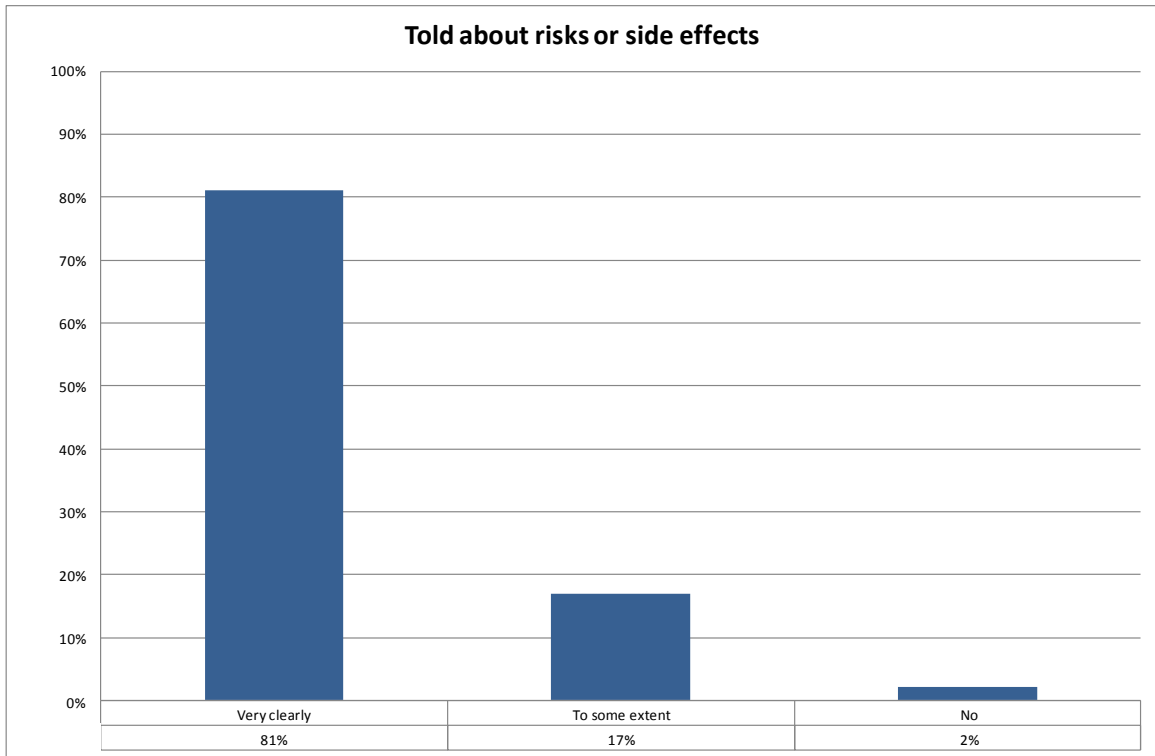
If you were not given a choice, were you told why not?

25% of patients not given a choice said they were told why they could not have a choice; 75% were not told.

8. Told about risks

Were you told about any risks or side effects that there might be with the chemotherapy that you would be having?

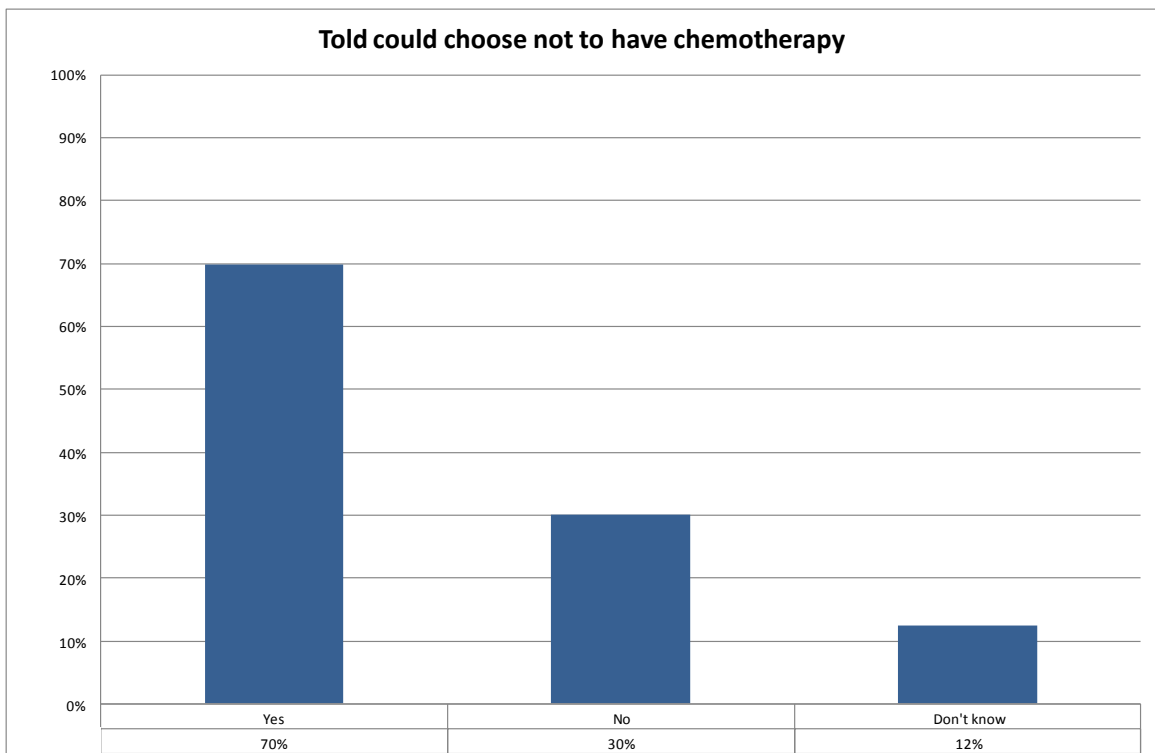
81% of patients said they were told very clearly about risks or side effects with the chemotherapy; 17% were told to some extent and 2% said they were not told.



9. Choosing not to have chemotherapy

Were you told you could choose not to have chemotherapy if you did not want it?

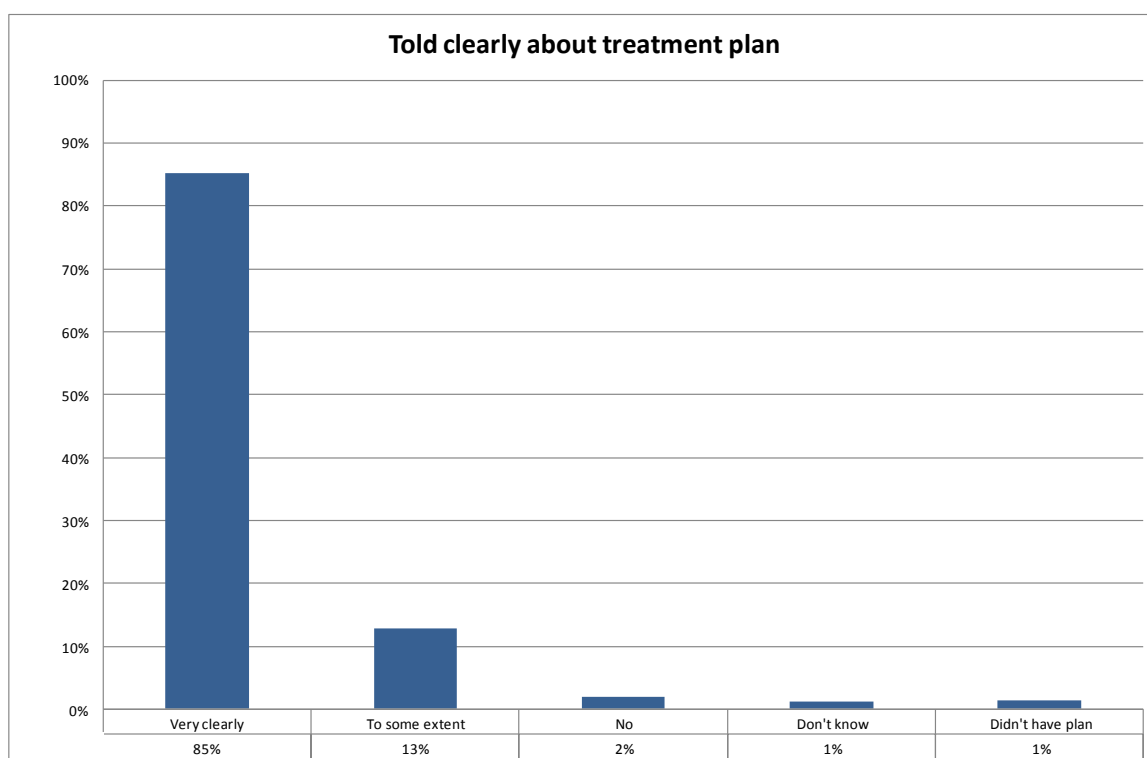
70% of patients said they were told they could choose not to have chemotherapy; 30% said they were not told they had this choice. 12% did not know or could not remember.



10. Treatment plans

Patients should have a chemotherapy 'treatment plan' which should include information about the number of cycles, how often the chemotherapy would be, how long the treatment plan would last etc. Were you told clearly about your treatment plan?

85% of patients said they were told very clearly about their treatment plan; 13% were told to some extent and 2% said they were not told. 1% said they did not have a treatment plan.



11. Bring someone

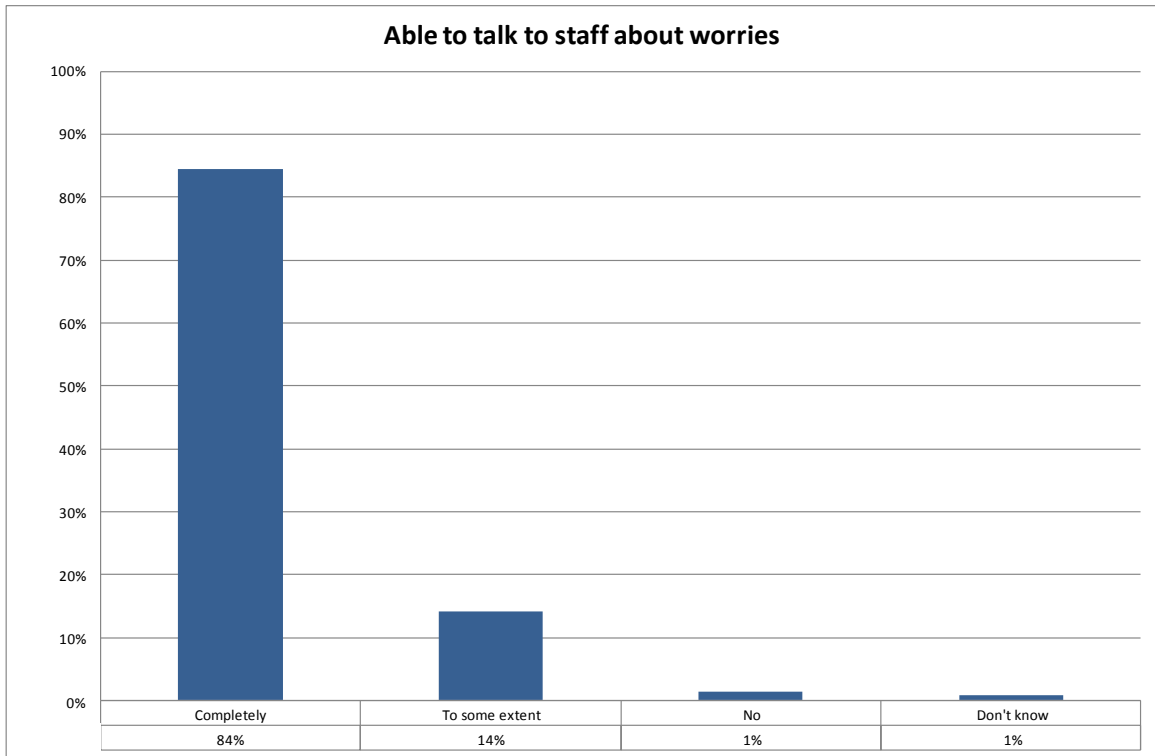
Were you told you could bring someone with you to your appointments if you wanted to?

92% of patients said they were told they could bring someone with them; 8% were not told.

12. Worries about chemotherapy

If you had any worries about the chemotherapy, were you able to talk about these with the staff?

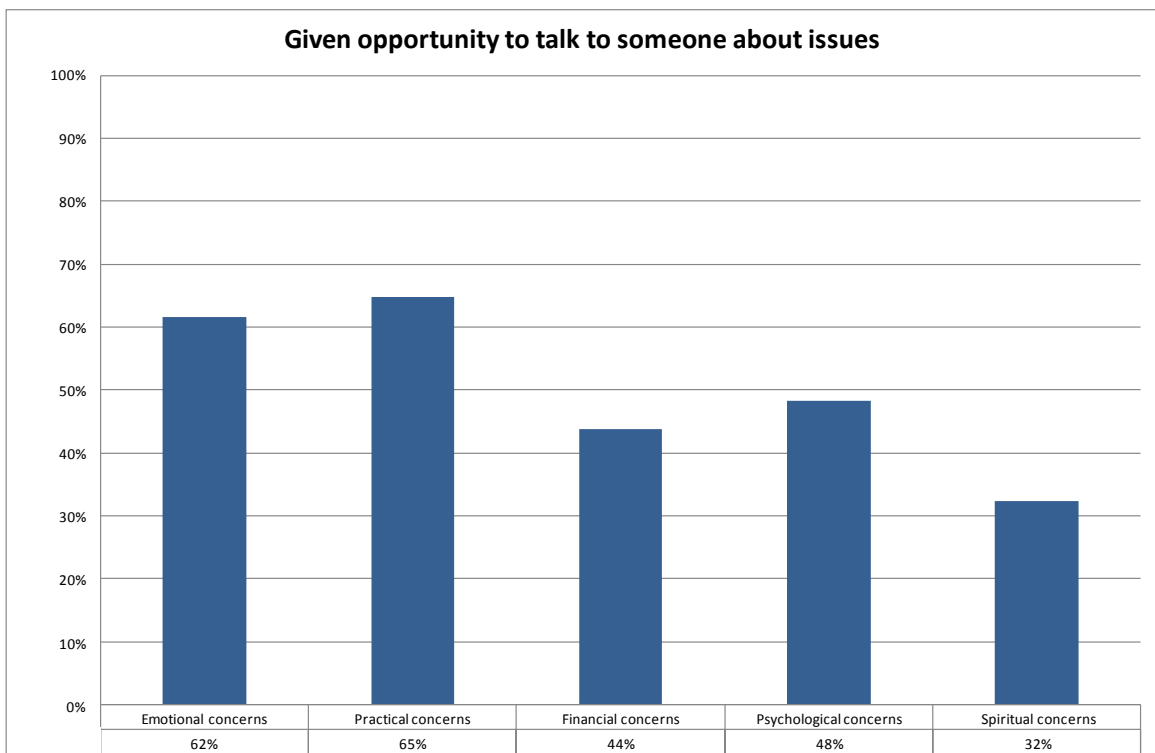
84% of patients said they were able to talk about their worries with the staff completely; 14% were to some extent and 1% said they were not able to talk about them to staff.



13. Issues to talk to someone about

Before your treatment began, were you given the opportunity to talk to someone about any of the following issues?

The chart shows the proportions of patients who said they were given the opportunity to talk to someone about the issues listed.



14. Written information about side effects

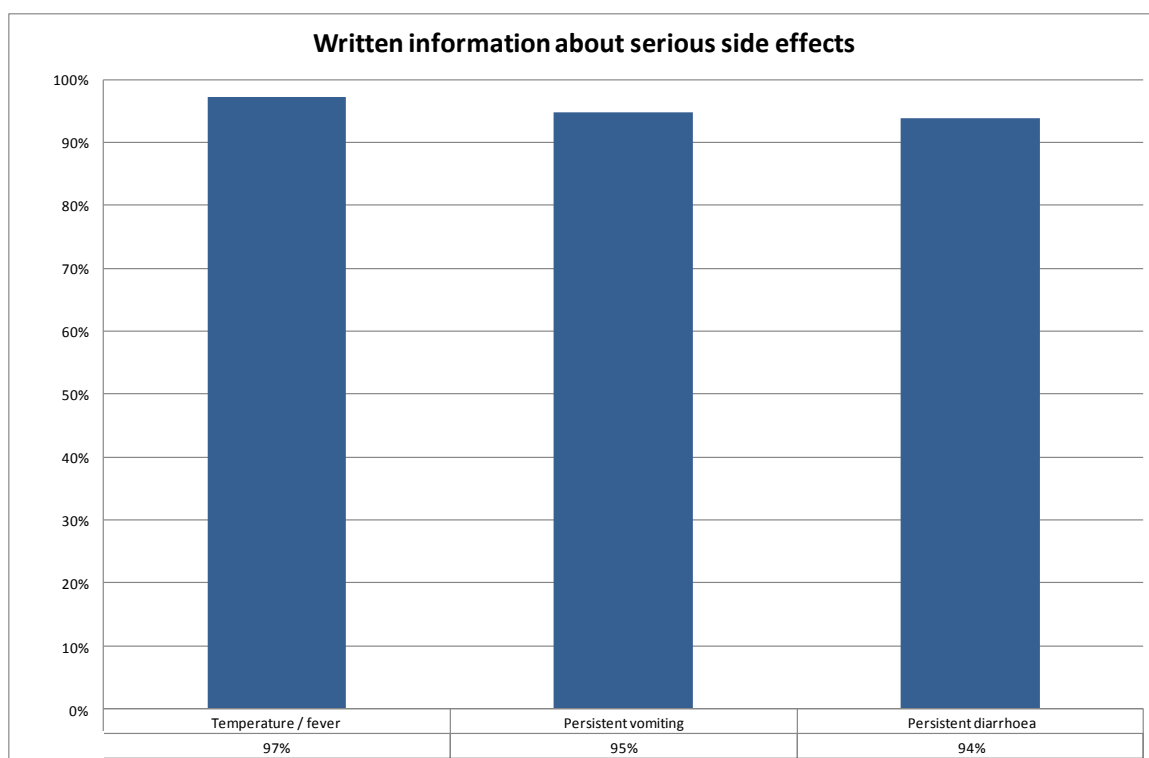
Were you given written information about the chemotherapy and its side effects?

95% of patients said they were given written information about the chemotherapy and its side effects; 5% were not given such information.

15. Serious side effects

If you were given written information, did it tell you what to do if you had any of the following serious side effects:

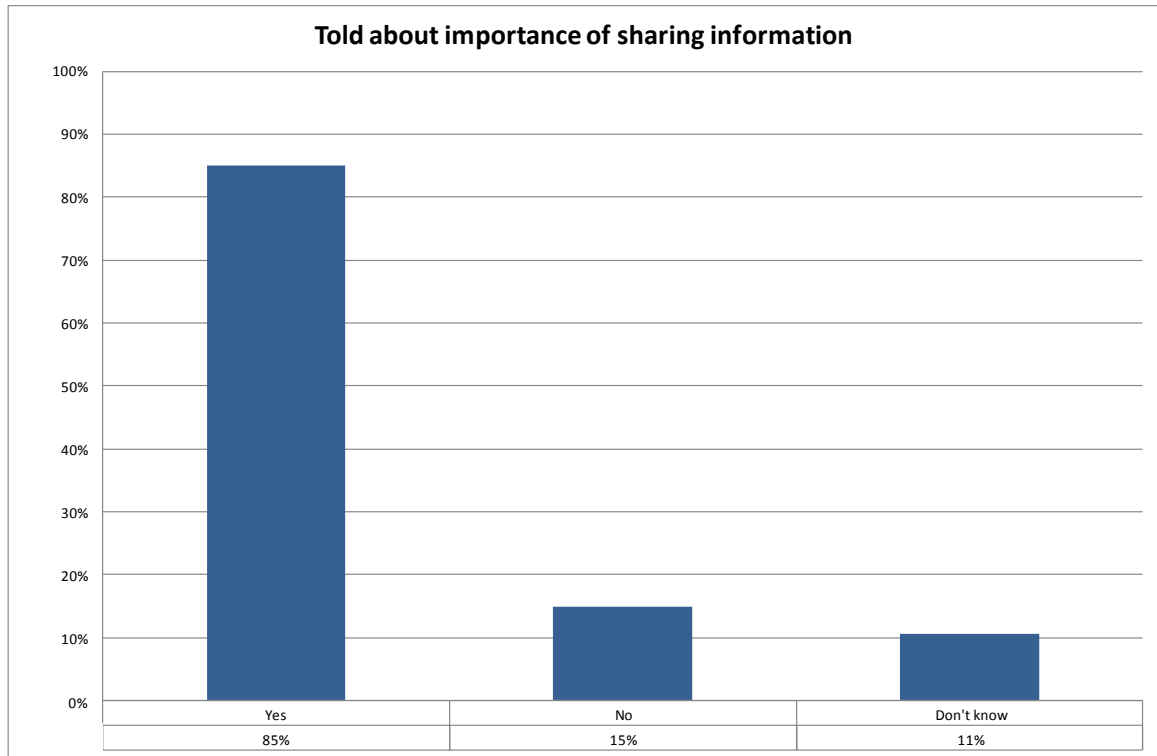
The chart shows the proportions of patients who said they were given written information about the serious side effects listed.



16. Sharing information

Were you told about the importance of sharing this information with your family / next of kin / carers?

85% of patients said they were told about sharing information with their family; 15% said they were not told this. 11% said they did not know or could not remember.



17. Contact number

Were you given a contact number to ring if you had any questions about your care?

98% of patients said they were given a contact number in case they had any questions about their care; 2% said they were not given a number.

18. Given a card

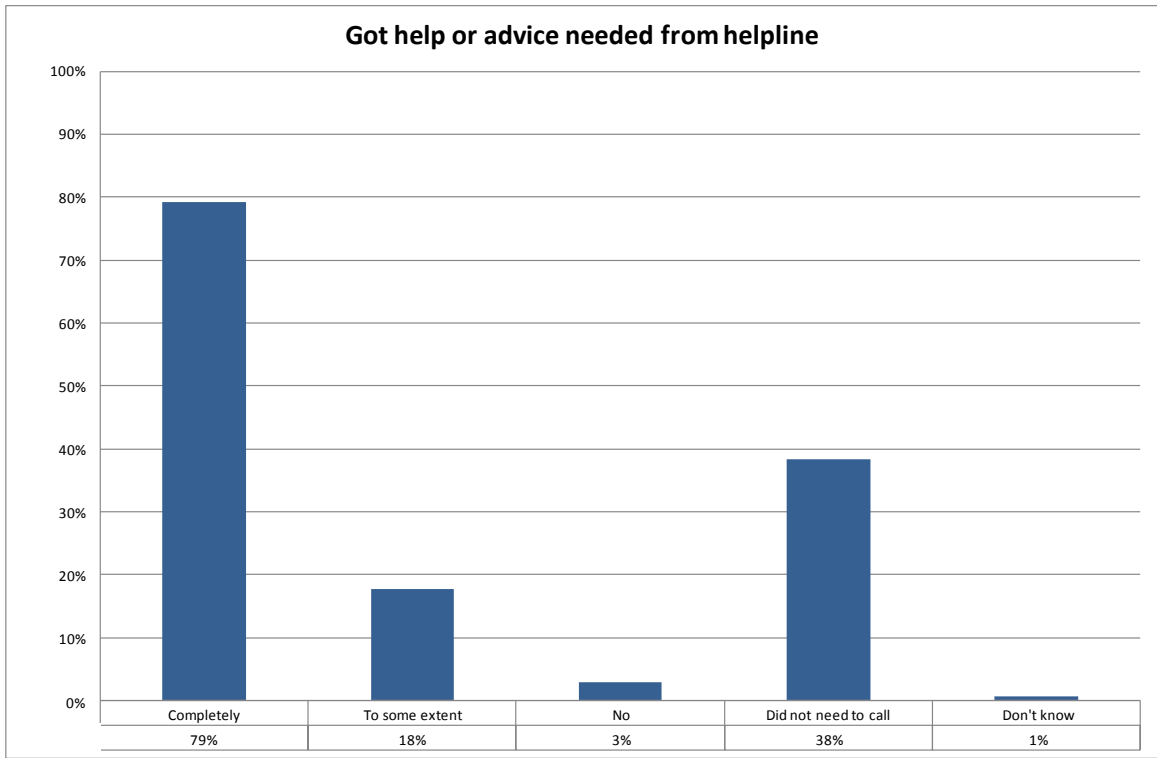
Were you given a card which included a 24 hour helpline number to call if you felt worried or unwell at any time during your chemotherapy?

95% of patients said they were given a card with a 24 hour helpline number in case they felt worried or unwell; 5% said they were not given a card.

19. Calling the helpline

If you or a relative called the 24 hour helpline, did you get the help or advice you needed?

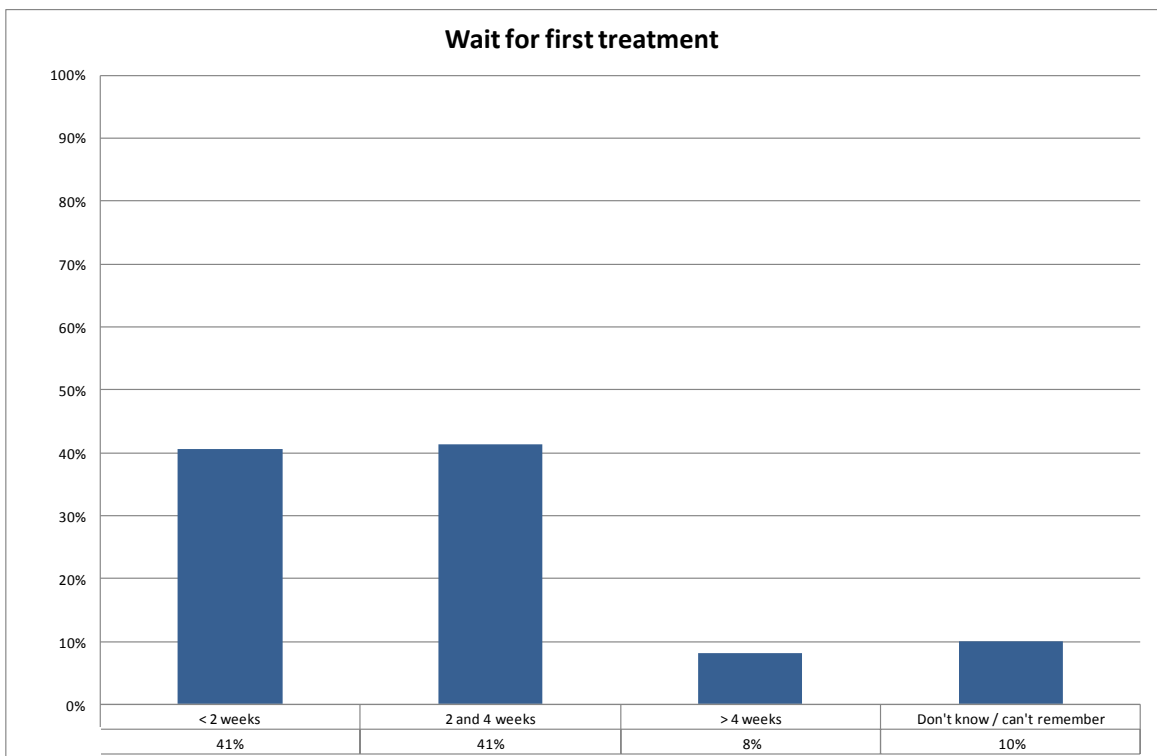
Of those patients that called the helpline, 79% said they completely got the help or advice needed; 18% said they did to some extent and 3% said they did not get such help or advice. 38% said they did not need to call the helpline.



20. Wait for first treatment

After you were told you were ready to start chemotherapy, how long did you have to wait for your first treatment?

The chart shows the time patients said they had to wait before their first treatment.



21. Tests

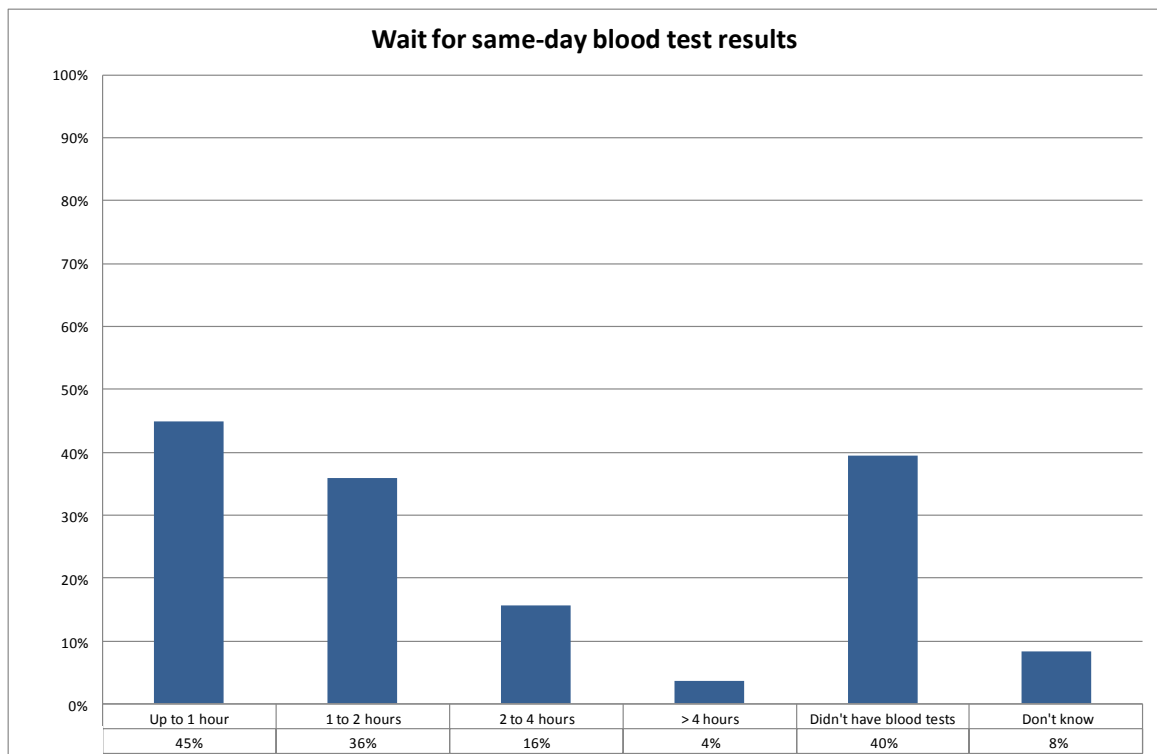
If you had tests before your chemotherapy, were you told what these tests were for?

Of those patients that said it was necessary, 96% said they were told what the tests were for; 4% said they were not told but would have liked to be told and 10% said they did not know or could not remember. 14% said they did not need such information.

22. Blood tests

If you had blood tests on the same day as your chemotherapy, how long did you have to wait for the results?

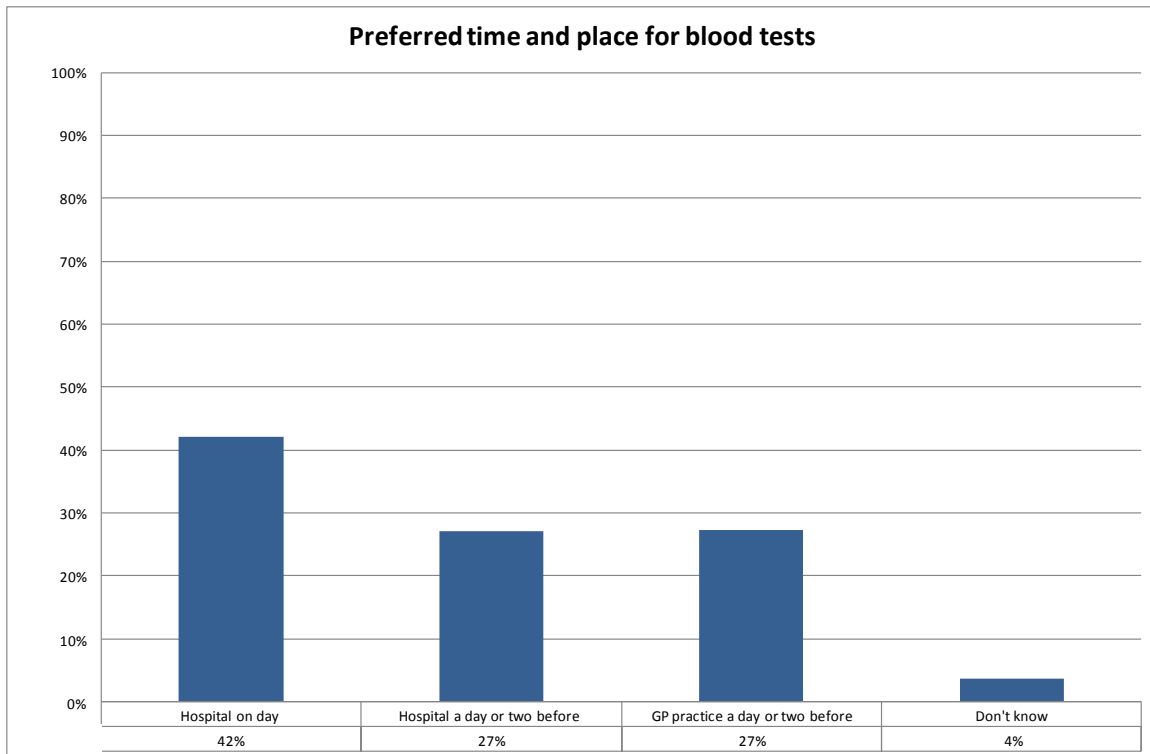
The chart shows the time patients said they had to wait for the results of blood tests. 40% did not have blood tests on the same day and 8% did not know or could not remember.



23. Preference for place to have blood tests

If you had the choice, where and when would you like to have your blood taken?

The chart shows the preferred place patients said they would like to have blood tests.



Having chemotherapy

The questions in this section of the survey were about the type of treatment patients had and the place they had it. Patients who said they had all or most of their treatment at home in response to question 26 were routed to question 41.

24. Oral treatment

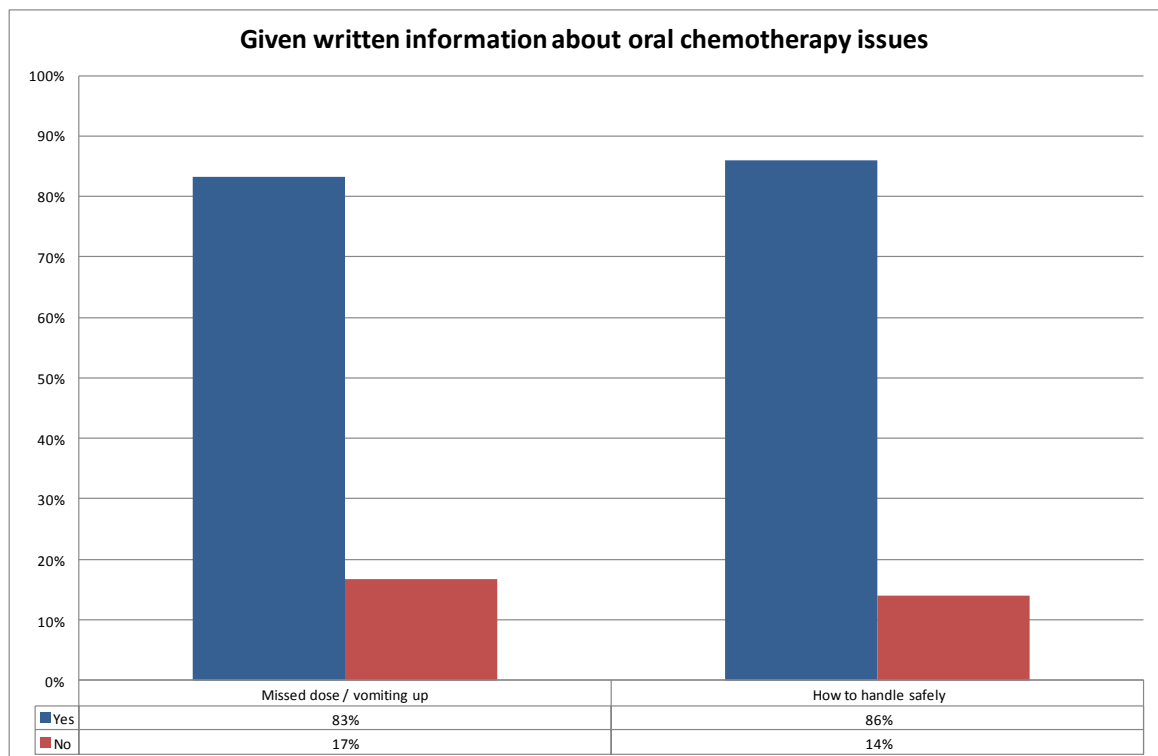
Did you have all or most of your chemotherapy as an oral treatment?

23% of patients said they did have their chemotherapy as an oral treatment; 77% did not.

25. Information about oral treatment

If you did have oral chemotherapy, were you given written information about the following:

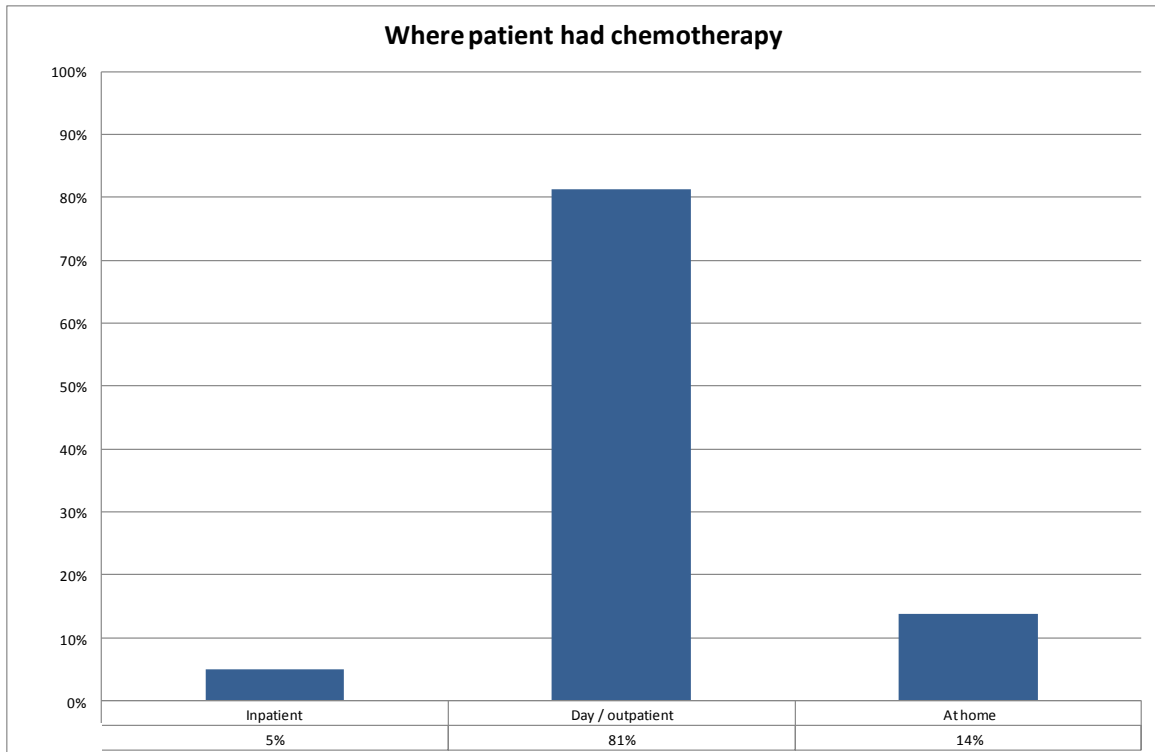
Of those patients having oral treatment, 83% said they were given written information about missed doses and vomiting it up and 86% how to handle the medication safely.



26. Place patient had chemotherapy

Where did you have your chemotherapy?

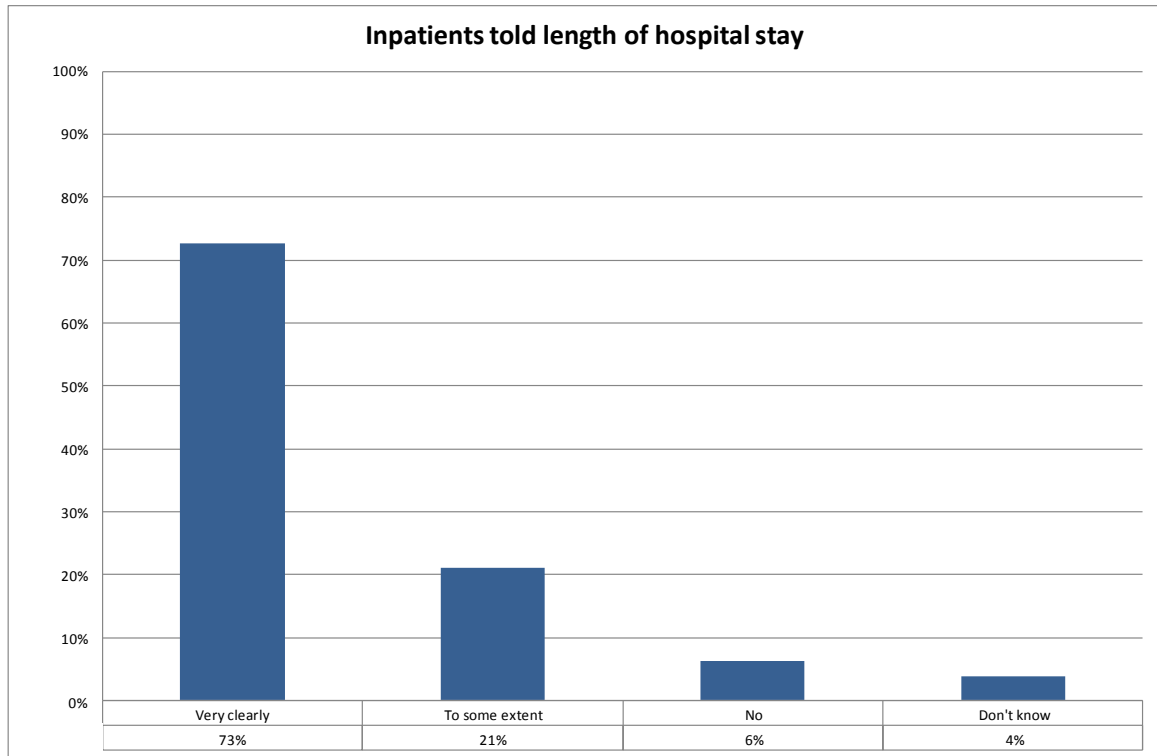
The chart shows the proportions of patients and the places they had chemotherapy.



27. Inpatient stays

If you were an inpatient, were you told how long you would be in hospital each time you went for your chemotherapy?

73% of patients who were inpatients said they were told how long the stay would be very clearly; 21% said they were to some extent and 6% said they were not.



28. Changes to appointments

Has your chemotherapy appointment ever been changed because of staff shortages?

91% of patients said their appointment had never been changed because of staff shortages; 8% said it had once or twice and 1% a lot of times.

29. Missed appointments

Have you ever had to miss your chemotherapy for other reasons such as your pre-meds or chemotherapy not being ready for you at the hospital?

91% of patients said their appointment had never been missed because of meds or chemotherapy not being ready; 9% said it had once or twice and less than 1% a lot of times.

30. Comfort of waiting area

While you were waiting to have your most recent chemotherapy, was the place where you had to wait comfortable?

95% of patients said the place they waited was comfortable; 5% said it was not comfortable.

31. Enough seats

While you were waiting to have your most recent chemotherapy, were there enough seats for patients?

92% of patients said there were enough seats in the place they waited; 8% said there were not enough seats.

32. Refreshments

While you were waiting to have your most recent chemotherapy, was there somewhere to get something to drink or eat nearby?

96% of patients said there was somewhere near the place they waited to get refreshments; 4% said there were not anywhere nearby.

33. Staff to answer questions

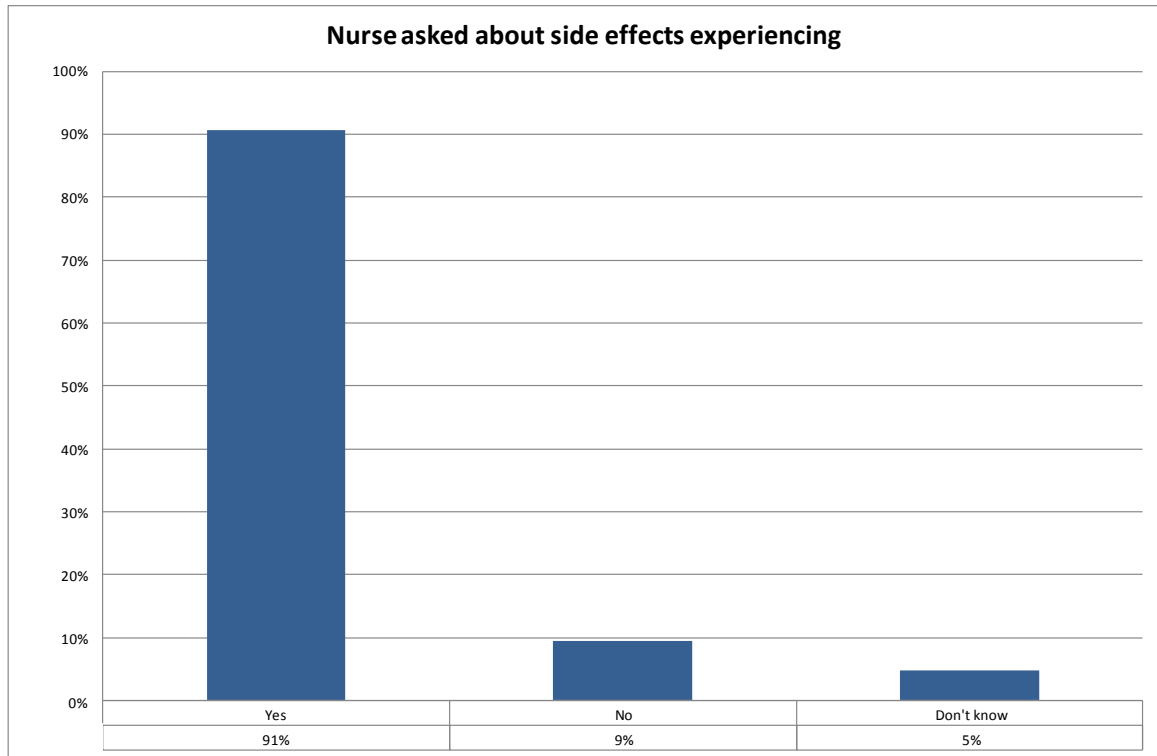
While you were waiting to have your most recent chemotherapy, were there staff available to answer any questions you had?

95% of patients said there were staff available to answer questions while they were waiting; 5% said there were not any staff available.

34. Side effects

Before your last treatment, did the nurse giving your chemotherapy ask about any side effects (e.g. sickness, problems with mouth or throat) that you might have been experiencing?

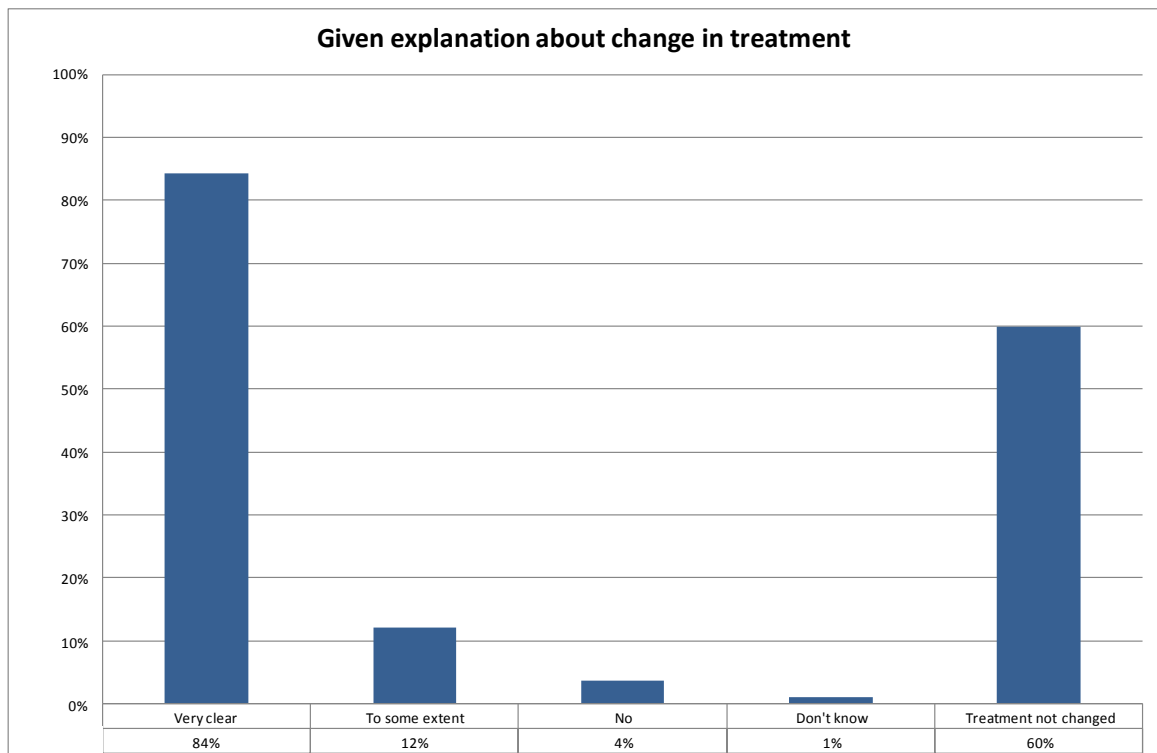
91% of patients said they were asked about any side effects they were experiencing; 9% said they were not asked.



35. Changes to treatment

If your treatment has been changed for any reason, were you given a clear explanation about why this was?

84% of patients whose treatment had been changed said they were given a very clear explanation about why this was; 12% said they were to some extent and 4% said they were not. 60% said their treatment had not been changed.



36. Type of room

When you had your most recent chemotherapy were you:

8% of patients said they were in a room on their own for their chemotherapy; 92% were in a room with other patients.

37. Privacy

If you were in a room with other patients did you feel comfortable speaking to staff about your treatment or other issues?

93% of patients who were in a room with other patients said they felt comfortable speaking to staff about their treatment; 7% were not comfortable speaking to staff.

38. Choice of type of room

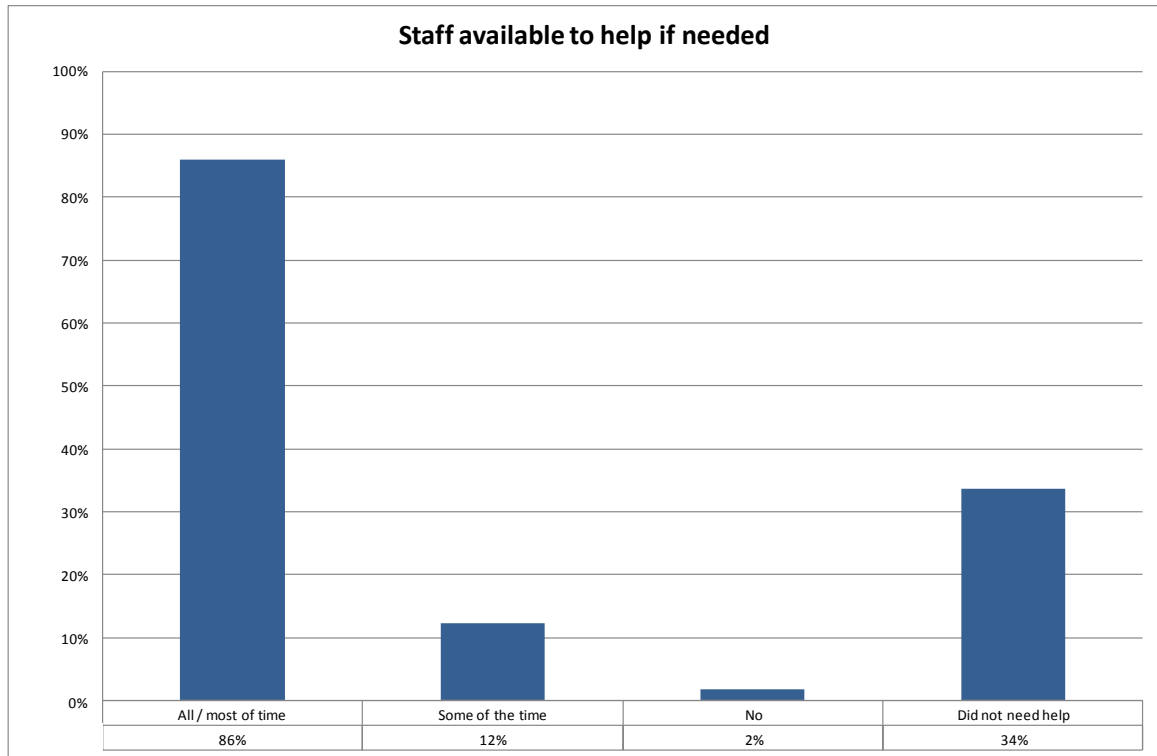
If you had the choice, would you prefer to have your chemotherapy:

22% of patients said they would prefer a room on their own for their chemotherapy; 78% would prefer a room with other patients.

39. Assistance from staff

If you needed help (e.g. getting a drink, taken to the toilet) while you were having your most recent chemotherapy, was there a member of staff there to help you?

86% of patients needing help said there was a member of staff available all or most of the time; 12% said there was only some of the time and 2% said there wasn't anyone to help. 34% said they did not need help from staff.



40. Drugs to take home

If you were given any drugs to take home with you, were you given a clear explanation about how to take them?

93% of patients said they were given a very clear explanation about how to take any drugs they were given to take home; 5% were to some extent and 1% were not given a clear explanation.

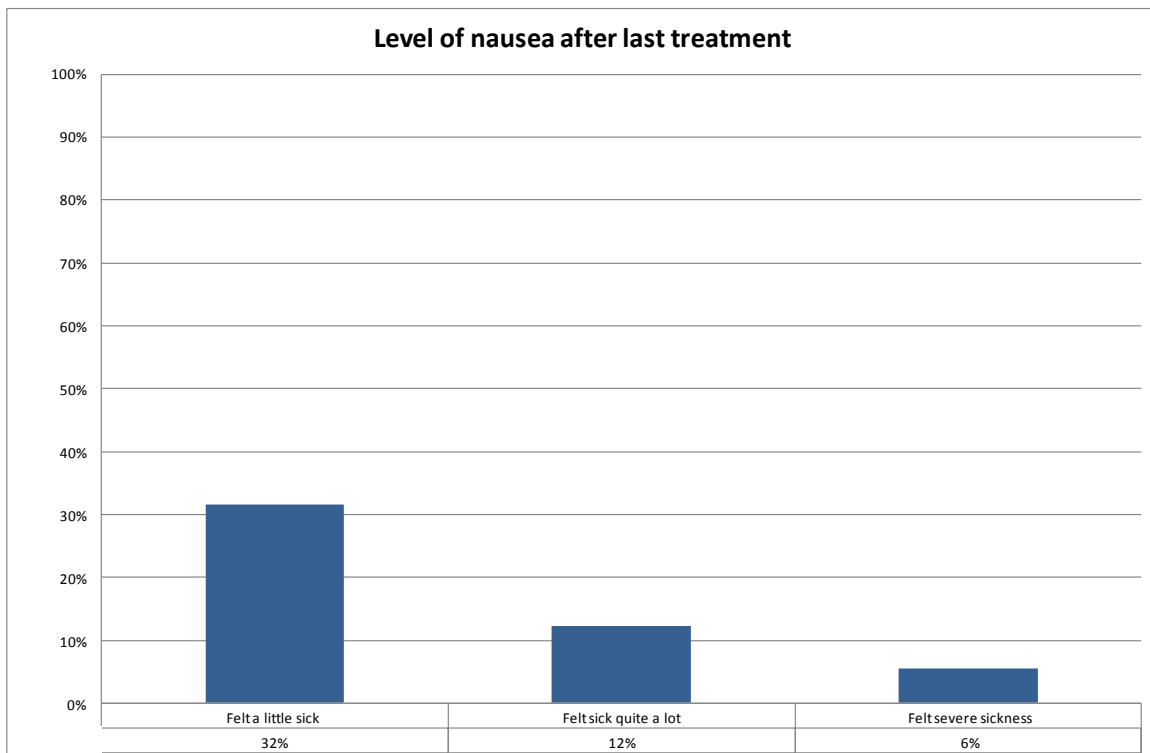
Serious side effects

The questions in this section of the survey are about any serious side effects patients might have experienced, staff knowledge of these side effects and advice to manage them.

41. Feeling sick

After your last treatment did you feel sick (nauseous)?

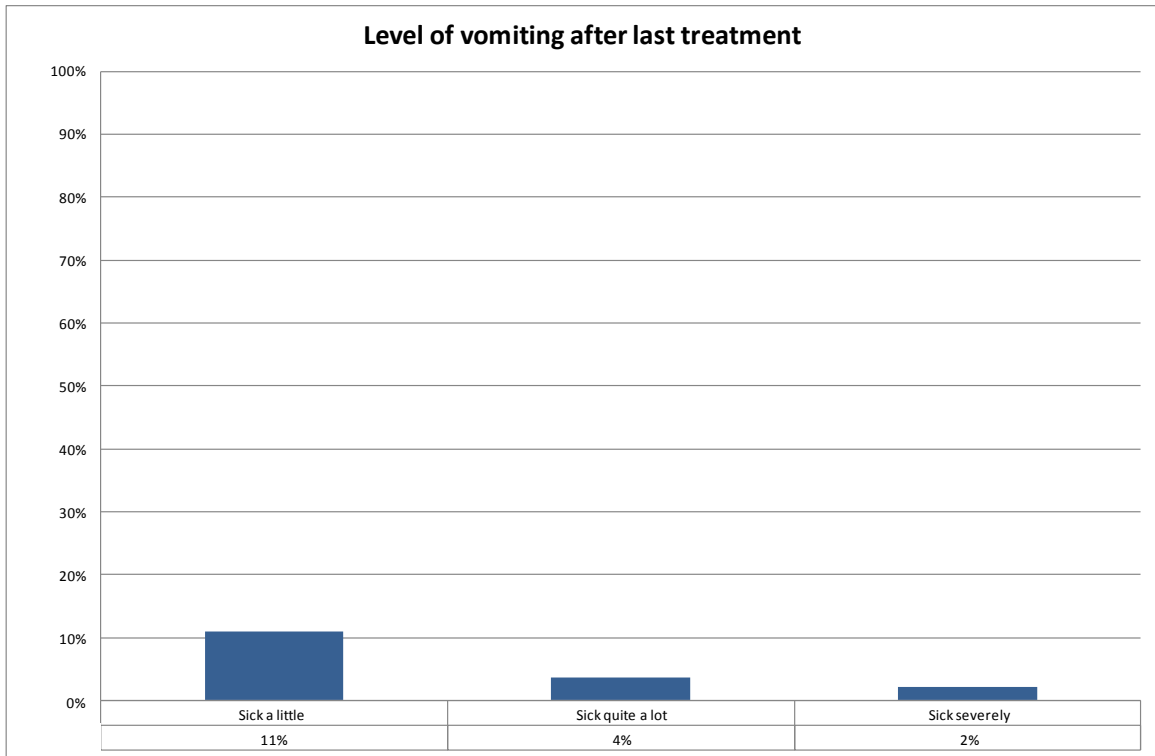
51% of patients said they did not feel sick. The chart shows the level of nausea experienced by those who did feel sick.



42. Being sick

After your last treatment were you sick (did you vomit)?

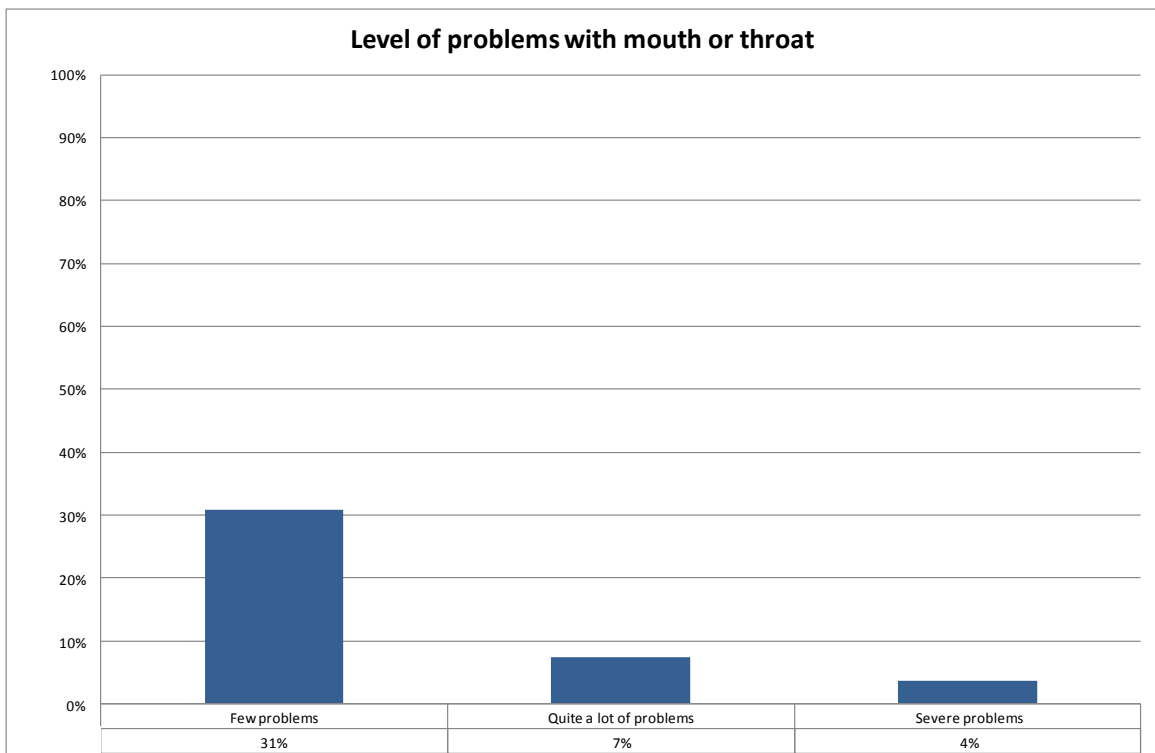
83% of patients said they did not vomit. The chart shows the level of vomiting experienced by those who were sick.



43. Problems with mouth or throat

After your last treatment did you have any problems with your mouth or throat?

58% of patients said they did not have any problems with their mouth or throat. The chart shows the level of problems experienced by those who did have them.



44. Staff knowledge of side effects

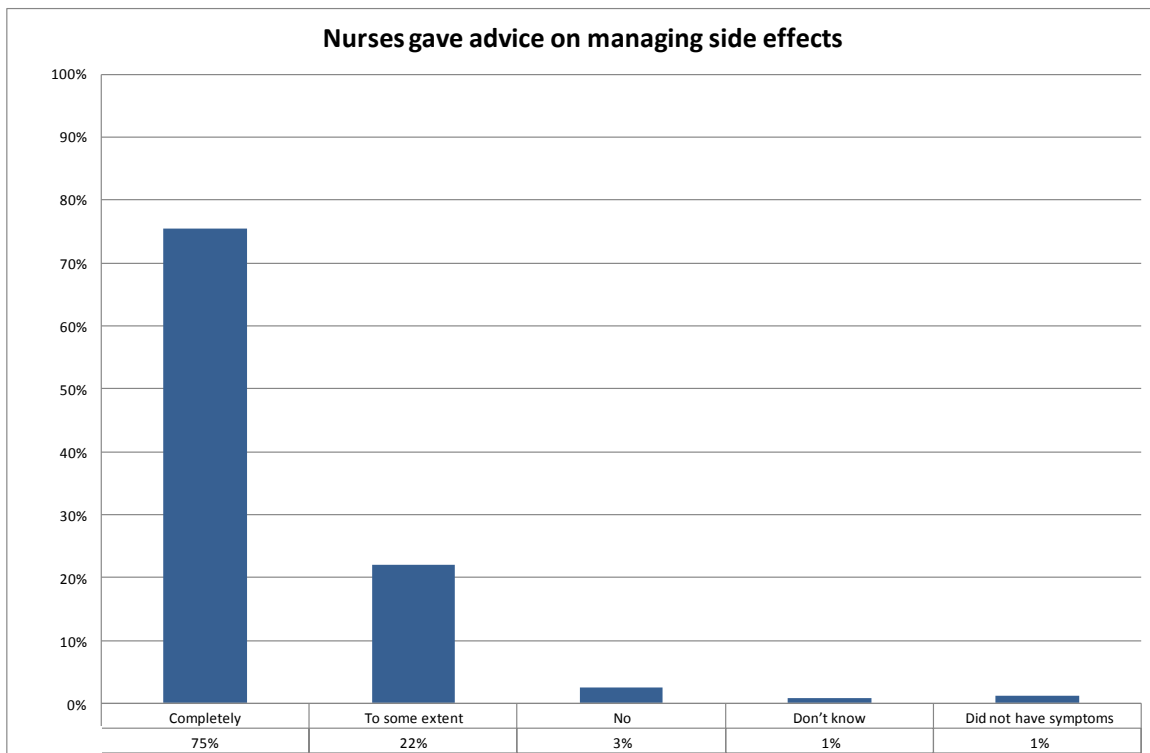
Did the nurses who gave you your chemotherapy know about the side effects you experienced after the treatment?

75% of patients experiencing side effects said the nurses giving their chemotherapy knew about these completely; 19% said they did to some extent and 6% said they did not know. 18% said they did not have any symptoms.

45. Advice on managing side effects

Did the nurses give you advice on how to manage these side effects?

75% of patients experiencing side effects said the nurses gave them advice on managing these completely; 22% said they did to some extent and 3% said they did not give such advice. 1% said they did not have any symptoms.



When chemotherapy finished and overall rating

The questions in this section of the survey were to ascertain patient views about the information they were given when their care finished and their overall rating of care. Patients who had not finished their treatment were just asked to respond to question 52.

46. New symptoms or worries

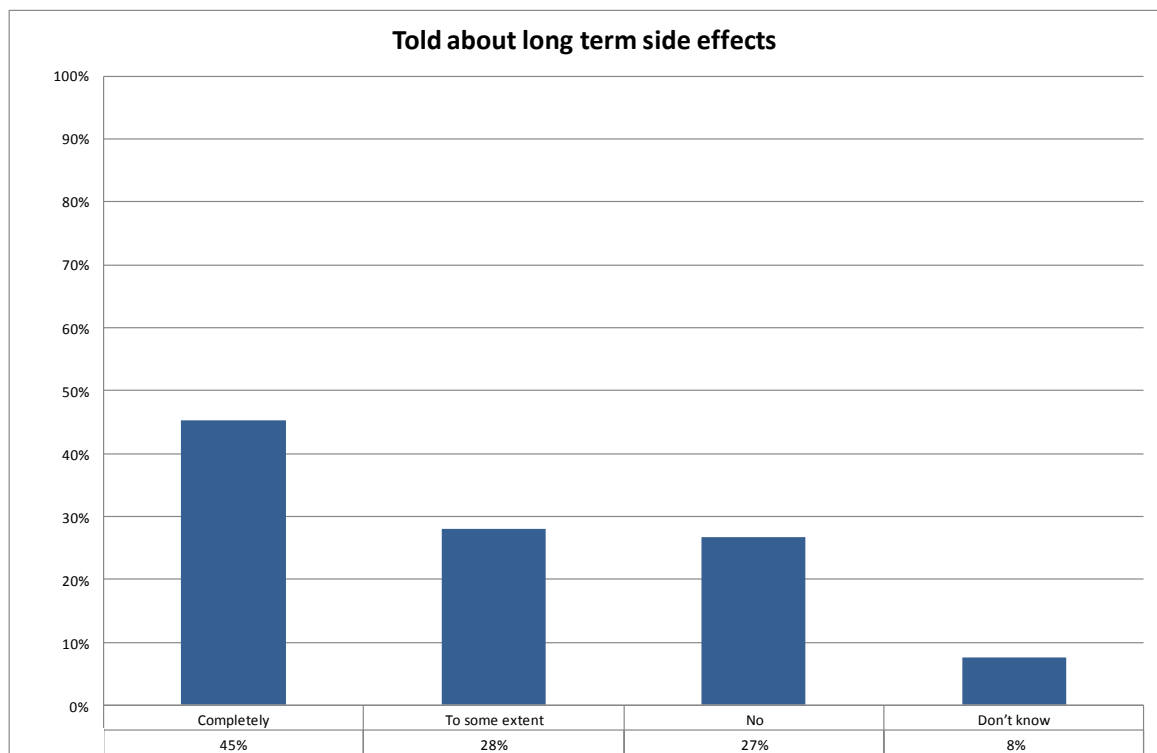
When your course of chemotherapy treatment finished, were you told what to do if you noticed any new symptoms or had any worries about your health?

82% of those patients whose treatment had finished said they were told what to do if they noticed any new symptoms or had any worries; 18% said they were not told. 7% did not know or could not remember.

47. Long term side effects

Were you told about any long term side effects of your chemotherapy treatment?

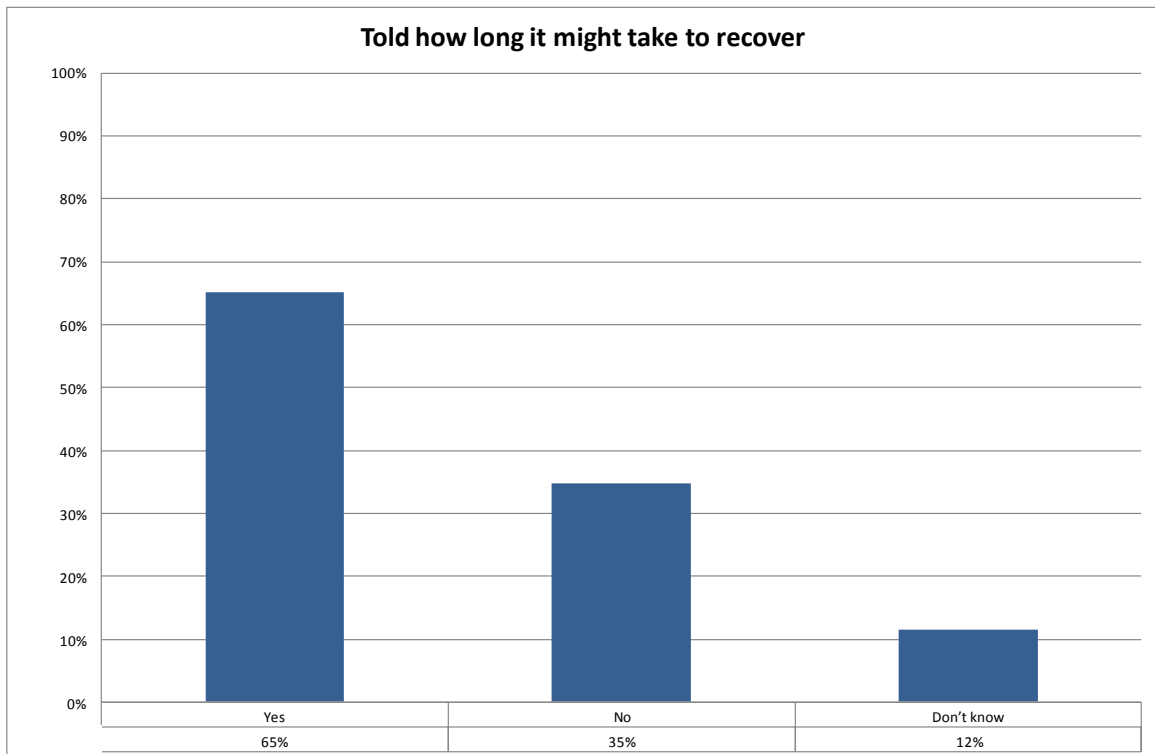
45% of those patients whose treatment had finished said they were told about long term side effects completely; 28% said they were told to some extent and 27% said they were not told. 8% did not know or could not remember.



48. Time to recover

Were you told how long it might take you to recover from the effects of the chemotherapy?

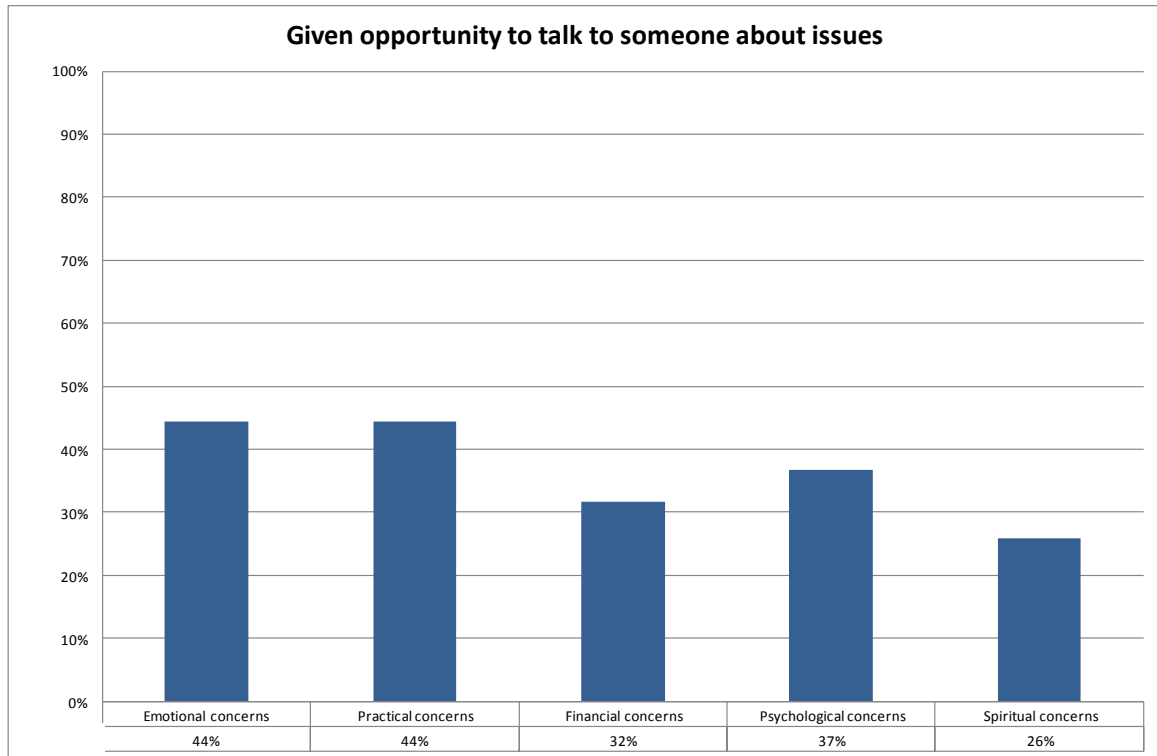
65% of those patients whose treatment had finished said they were told how long it might take to recover; 35% said they were not told. 12% did not know or could not remember.



49. Opportunity to talk

After your treatment finished, were you given the opportunity to talk to someone about any of the following issues?

The chart shows the proportions of those patients whose treatment had finished who said they were given the opportunity to talk about each of the issues listed.



50. Offered a care plan

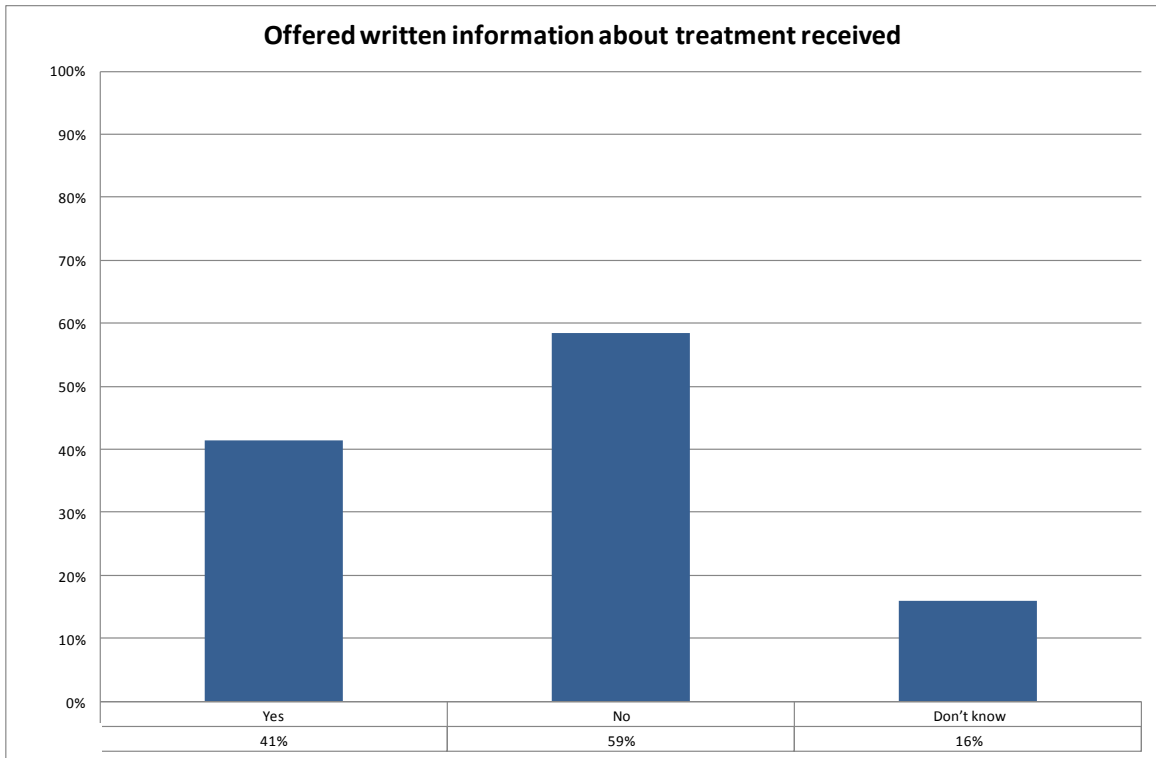
If you did have any of these concerns, were you offered a care plan to specifically help with these concerns?

63% of those patients whose treatment had finished said they were offered a care plan to help with concerns; 37% said they were not offered a plan. 24% did not know or could not remember.

51. Written information

At the end of your treatment, were you offered written information about the treatment you had?

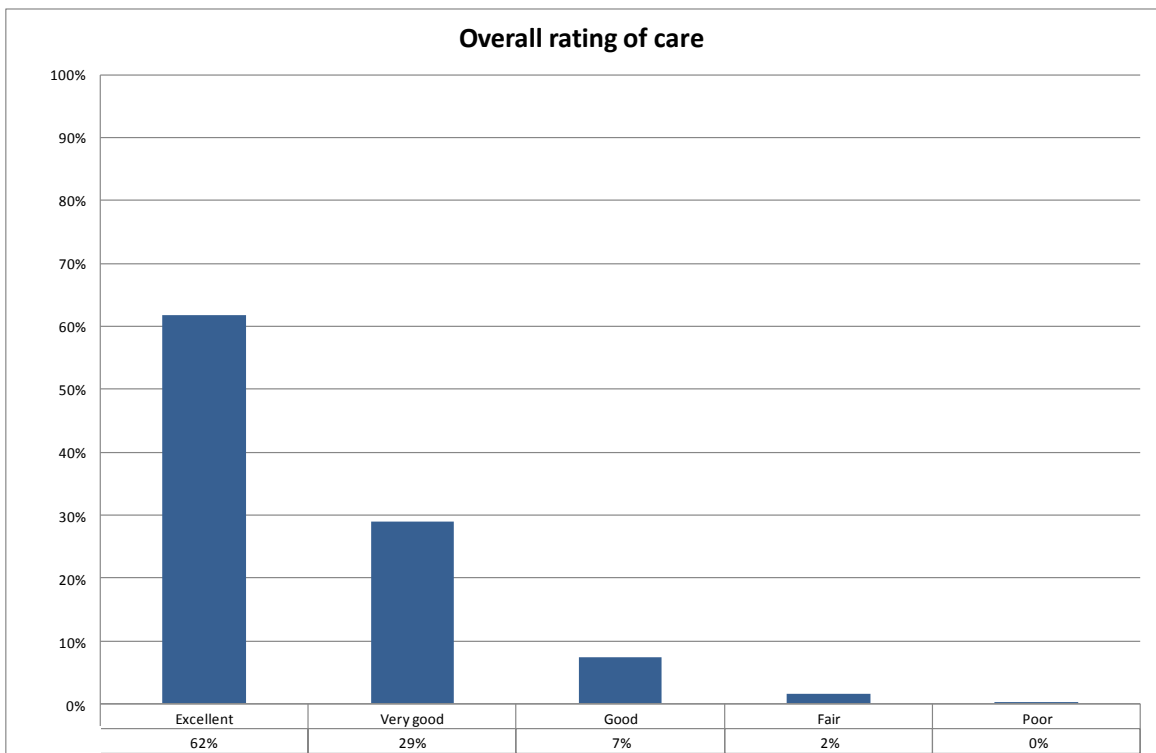
41% of those patients whose treatment had finished said they were offered written information about their treatment; 59% said they were not offered information. 16% did not know or could not remember.



52. Overall rating of care

Overall, how would you rate your care?

91% of patients rated their overall care as excellent or very good; (62% and 29% respectively); 7% as good; 2% as fair and less than 1% as poor.



6. Demographic analyses

Further analysis has been undertaken on the chemotherapy patient experience data to examine the differences that exist between different groups of patients who responded to the survey. As in the national CPES, there are numerous statistically significant differences between patient groups, summarised below:

Age

There are many statistically significant differences of view between patients in different age groups, on 20 scored questions in the survey. On most of these questions it is patients aged 76 and over who gave the lowest scores; but younger patients aged 16-35 had the lowest proportions saying that they did not feel sick, or actually vomited, after their last treatment. They were also the least likely to say that they did not have problems with their mouth or throat following treatment.

Ethnicity

The substantial differences in views about care and treatment between White patients and patients from some ethnic minority backgrounds in the national Cancer Patient Experience Survey are not replicated in the chemotherapy survey. Only on one scored question are there statistically significant differences between groups of patients, on the issue of choice of where to have their chemotherapy - where fewer White patients were given a choice of having their chemotherapy at hospital, at home, or at a primary or community location. It is clear, however, that the scores for some ethnic minority groups are lower than for White patients on many questions, but they do not reach statistical significance.

Sexual orientation

In terms of sexual orientation, there are 9 questions on which patients who describe themselves as non heterosexual (gay, lesbian, bisexual, other sexuality) differ in their views from those who say they are heterosexual. On most of the questions where there are statistically significant differences, non heterosexuals are more positive, with 5 of the 8 questions on which non heterosexuals score more positively being questions asking whether they were given the opportunity to talk to someone about emotional, practical, financial, or psychological concerns before or after their chemotherapy. Heterosexuals are more positive only on one question - more reported that they did not feel sick after their chemotherapy.

Regional variations

Analysis of the chemotherapy survey data by region (based on the former SHA geographical areas) shows that there are statistically significant regional differences, as there are in the national Cancer Patient Experience Survey. In the chemotherapy survey, there are 12 questions on which there are significant differences, with the East Midlands being the poorest performing region on 5 of the 12 questions. In contrast with the Cancer Patient Experience Survey data, where London is by far the worst performing region, on the chemotherapy survey London hospitals perform less well than hospitals in other regions on only 1 of the 12 items. The questions on which the East Midlands performs more poorly are almost all related to the questions on being able to discuss financial psychological or spiritual concerns with staff.

Deprivation

The chemotherapy survey data has been analysed using the Index of Multiple Deprivation, linked to the patient's postcode. As on the Cancer Patient Experience Survey we have used IMD quintiles to group the data; and analysis of these shows that there are 6 questions in the survey on which there are statistically significant differences between the least deprived quintile (quintile 1) and the most deprived quintile (quintile 5). On all questions where there are such differences between the least deprived and most deprived quintiles, patients in quintile 1 (the least deprived) gave the lowest scores.

Methods of administering chemotherapy

Analysis was undertaken examining differences of view between patients who had experienced different methods of administration of chemotherapy, especially looking at the two most frequent methods, intravenous and oral, where there were substantial numbers of responses in both categories. There are 21 questions in the survey on which there are statistically significant differences of view between patients in these categories; patients having intravenous chemotherapy were more likely to be offered a written record of the discussion about their chemotherapy, were more likely to be told about potential side effects and risks, to be told about their treatment plan, to be given written information on risks, serious side effects, and to be given a contact number to use and a contact card if they felt worried or unwell. Patients who received their chemotherapy orally were more likely to be given a choice in the first place about the location where they could have it (hospital, home, community location), and were more likely to say that they did not feel sick and did not vomit. The differences of view on whether the patient vomited are very substantial: 48% of patients having intravenous chemotherapy said they did not vomit, whereas 60% of those receiving oral chemotherapy said they did not. Patients using oral chemotherapy were also more likely to give positive scores on their overall care.

7. Data processing and analysis

All response data was verified and checked before submission for analysis.

On some questions patients were asked to skip forward if the main question was not relevant to them. For example, question 6 which asked patients if they were given a choice about where they had their chemotherapy. Where patients said 'no', they were then asked to go to question 8. In cases such as this special rules were applied to the data in question 7 to remove any responses where patients said 'no' to question 6 but went on to answer question 7.

Overall, there are 56 "indicator" or scored questions in the survey on which analysis has been undertaken. There are 12 questions in the questionnaire which are not scored. These questions are information or routing questions e.g. question 1 which asks when the patient signed the consent for chemotherapy.

For the 56 indicator questions key scores have been calculated after removing any patients who said that the question did not apply to them, who ticked 'don't know / can't remember' or who did not answer at all; these key scores are also used in the charts and tables.

No weighting or standardisation was applied to the data before analysis. The conventions used in this Report in respect of analysing and presenting data are as follows:

In each section of this Report, two kinds of statistical tests have been used to assess whether apparent differences in results have real significance. These are the T test, used to assess whether differences between one group and the total are of real standing. At whole survey level the confidence interval at 95% is +/- 0.6%.

The second statistical test used is chi squared, giving an analysis of whether the differences seen across for example all age groups (or other categories) are in fact significant taking them as a whole.

Where we are analysing the results by any particular group, we only report results that have been identified as significantly different from the results for all respondents.

8. Survey results

This section sets out the full results from the 2013 Chemotherapy Survey ordered in exactly the same way as in the survey questionnaire sent to patients.

The results are shown firstly in absolute numbers then as percentages.

The percentages are calculated after excluding those patients who did not answer that particular question and neutral responses e.g. 'don't know' or 'can't remember'. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total exactly 100% because of this rounding.

On some questions there are also some figures which are italicised. The percentages on these questions have been recalculated to exclude responses where the question was not applicable to the patient's circumstances. The italicised percentages will add up to 100%.

The 'Missing' figures show the number of patients who did not reply to a particular question. In some cases, the 'Missing' figure is quite high because it includes patients who did not answer that question or group of questions because it was not applicable to their circumstances (e.g. question 7).

There are a number of questions which are 'routed' (i.e. where patients are directed to a subsequent question depending on their answer to the lead question). Sometimes there are conflicts in the answers that patients give to these questions and the data is corrected to account for this. For example, if response option 1 in question 6 is ticked and the patient goes on to answer question 7, then any data between question 6 and question 8 (where the patient was directed) will be deleted as question 7 should not have been answered by the patient.

BEFORE YOUR CHEMOTHERAPY		Total	All
1.	When did you sign the consent form for your chemotherapy?		
	I signed the consent form when I was first told I needed chemotherapy	6308	41%
	I signed the consent form before I had my first chemotherapy treatment	6176	40%
	I signed the consent form when I had my first chemotherapy treatment	585	4%
	I did not sign a consent form	213	1%
	Don't know / can't remember	2285	15%
	Missing	435	
2.	Do you think you were given enough time to ask questions between being told you needed chemotherapy and signing the consent form?		
	<i>Yes plenty of time</i>	13235	95%
	<i>I would have liked more time</i>	576	4%
	My case was urgent so I did not have time	667	4%
	<i>No I did not have enough time</i>	123	1%
	Don't know / can't remember	1103	7%
	Missing	298	
3.	Were you offered a written record or summary of the discussion about your treatment?		
	Yes	8072	66%
	No	4189	34%
	Don't know / can't remember	3468	22%
	Missing	273	
4.	Before you started your treatment, did anyone talk to you about whether you would like to take part in clinical trials?		
	Yes	5985	42%
	No	8273	58%
	Don't know / can't remember	1537	10%
	Missing	207	
5.	Were you told clearly why you needed chemotherapy?		
	<i>Yes very clearly</i>	14218	90%
	<i>Yes to some extent</i>	1460	9%
	No	131	1%
	Don't know / can't remember	80	1%
	Missing	113	
6.	Were you given a choice about where you would have your chemotherapy? (e.g. hospital, home, GP surgery, community clinic)		
	Yes	3924	26%
	No	11193	74%
	Don't know / can't remember	576	4%
	Missing	309	

BEFORE YOUR CHEMOTHERAPY		Total	All
7.	If you were not given a choice were you told why not?		
	<i>Yes</i>	2570	25%
	<i>No</i>	7518	75%
	<i>Don't know / can't remember</i>	878	8%
	<i>Missing</i>	5036	
8.	Were you told about any risks or side effects that there might be with the chemotherapy that you would be having?		
	<i>Yes very clearly</i>	12722	81%
	<i>Yes to some extent</i>	2654	17%
	<i>No</i>	329	2%
	<i>Don't know / can't remember</i>	166	1%
	<i>Missing</i>	131	
9.	Were you told you could choose not to have chemotherapy if you did not want it?		
	<i>Yes</i>	9634	70%
	<i>No</i>	4153	30%
	<i>Don't know / can't remember</i>	1969	12%
	<i>Missing</i>	246	
10.	Patients should have a chemotherapy 'treatment plan' which should include information about the number of cycles, how often the chemotherapy would be, how long the treatment plan would last etc. Were you told clearly about your treatment plan?		
	<i>Yes very clearly</i>	13162	85%
	<i>Yes to some extent</i>	1995	13%
	<i>No</i>	291	2%
	<i>Don't know / can't remember</i>	181	1%
	<i>I didn't have a treatment plan</i>	219	1%
	<i>Missing</i>	154	
11.	Were you told you could bring someone with you to your appointments if you wanted to?		
	<i>Yes</i>	14014	92%
	<i>No</i>	1243	8%
	<i>Don't know / can't remember</i>	576	4%
	<i>Missing</i>	169	
12.	If you had any worries about the chemotherapy, were you able to talk about these with the staff?		
	<i>Yes completely</i>	13285	84%
	<i>Yes to some extent</i>	2211	14%
	<i>No</i>	231	1%
	<i>Don't know / can't remember</i>	123	1%
	<i>Missing</i>	152	

BEFORE YOUR CHEMOTHERAPY	Total	All
13. Before your treatment began, were you given the opportunity to talk to someone about any of the following issues:		
Emotional concerns		
Yes	8804	62%
No	5472	38%
Missing	1726	
Practical concerns		
Yes	8983	65%
No	4886	35%
Missing	2133	
Financial concerns		
Yes	5697	44%
No	7299	56%
Missing	3006	
Psychological concerns		
Yes	6260	48%
No	6713	52%
Missing	3029	
Spiritual concerns		
Yes	4009	32%
No	8372	68%
Missing	3621	
14. Were you given written information about the chemotherapy and its side effects?		
Yes	14531	95%
No	724	5%
Don't know / can't remember	545	3%
Missing	202	

BEFORE YOUR CHEMOTHERAPY		Total	All
15.	If you were given written information, did it tell you what to do if you had any of the following serious side effects:		
	Temperature / fever		
	Yes	13757	97%
	No	396	3%
	Missing	1849	
	Persistent vomiting		
	Yes	12830	95%
	No	705	5%
	Missing	2467	
	Persistent diarrhoea		
	Yes	12623	94%
	No	827	6%
	Missing	2552	
16.	Were you told about the importance of sharing this information with your family / next of kin / carers?		
	Yes	10534	85%
	No	1848	15%
	Don't know / can't remember	1476	11%
	Missing	2144	
17.	Were you given a contact number to ring if you had any questions about your care?		
	Yes	15355	98%
	No	288	2%
	Don't know / can't remember	222	1%
	Missing	137	
18.	Were you given a card which included a 24 hour helpline number to call if you felt worried or unwell at any time during your chemotherapy?		
	Yes	14623	95%
	No	803	5%
	Don't know / can't remember	424	3%
	Missing	152	
19.	If you or a relative called the 24 hour helpline, did you get the help or advice you needed?		
	Yes completely	6946	79%
	Yes to some extent	1554	18%
	No	259	3%
	I did not need to call the helpline	5513	38%
	Don't know / can't remember	88	1%
	Missing	1642	

BEFORE YOUR CHEMOTHERAPY		Total	All
20.	After you were told you were ready to start chemotherapy, how long did you have to wait for your first treatment?		
	Less than 2 weeks	6312	41%
	Between 2 and 4 weeks	6421	41%
	More than 4 weeks	1262	8%
	Don't know / can't remember	1550	10%
	Missing	457	
21.	If you had tests before your chemotherapy, were you told what these tests were for?		
	Yes	11187	96%
	<i>No but I would have like to be told</i>	508	4%
	It was not necessary	2227	14%
	Don't know / can't remember	1580	10%
	Missing	500	
22.	If you had blood tests on the same day as your chemotherapy, how long did you have to wait for the results?		
	<i>Up to 1 hour</i>	3535	45%
	<i>More than 1 hour but less than 2 hours</i>	2832	36%
	<i>More than 2 hours but less than 4 hours</i>	1231	16%
	<i>More than 4 hours</i>	287	4%
	I didn't have blood tests the same day	5982	40%
	Don't know / can't remember	1275	8%
	Missing	860	
23.	If you had the choice, where and when would you like to have your blood taken?		
	At the hospital on the day of treatment	6428	42%
	At the hospital a day or two before treatment	4129	27%
	At my GP practice a day or two before treatment	4151	27%
	Don't know / not sure	549	4%
	Missing	745	

HAVING YOUR CHEMOTHERAPY		Total	All
24.	Did you have all or most of your chemotherapy as an oral treatment?		
	Yes	3526	23%
	No	11765	77%
	Missing	711	
25.	If you did have oral chemotherapy, were you given written information about the following:		
	What to do if you missed a dose (including vomiting it up)		
	Yes	2669	83%
	No	539	17%
	Missing	12794	
	How to handle the oral chemotherapy safely		
	Yes	2592	86%
	No	420	14%
	Missing	12990	
26.	Where did you have your chemotherapy?		
	I had all or most of my chemotherapy as an inpatient in hospital (planned stay overnight)	779	5%
	I had all or most of my chemotherapy as a day or outpatient at the hospital	12519	81%
	I had all or most of my chemotherapy at home	2108	14%
	Missing	596	
27.	If you were an inpatient, were you told how long you would be in hospital each time you went for chemotherapy?		
	<i>Yes very clearly</i>	624	73%
	<i>Yes to some extent</i>	182	21%
	<i>No</i>	54	6%
	<i>Don't know / can't remember</i>	34	4%
	Missing	15108	
28.	Has your chemotherapy appointment ever been changed because of staff shortages?		
	<i>Yes a lot of times</i>	108	1%
	<i>Only once or twice</i>	1086	8%
	<i>No never</i>	12094	91%
	<i>Don't know / can't remember</i>	224	2%
	Missing	2490	
29.	Have you ever had to miss your chemotherapy for other reasons such as your pre-meds or chemotherapy not being ready for you at the hospital?		
	<i>Yes a lot of times</i>	62	0%
	<i>Only once or twice</i>	1196	9%
	<i>No never</i>	12121	91%
	<i>Don't know / can't remember</i>	112	1%
	Missing	2511	

HAVING YOUR CHEMOTHERAPY		Total	All
30.	While you were waiting to have your most recent chemotherapy, was the place where you had to wait comfortable?		
	Yes	12841	95%
	No	634	5%
	Don't know / can't remember	51	0%
	Missing	2476	
31.	While you were waiting to have your most recent chemotherapy, were there enough seats for patients?		
	Yes	12363	92%
	No	1034	8%
	Don't know / can't remember	113	1%
	Missing	2492	
32.	While you were waiting to have your most recent chemotherapy, was there somewhere to get something to drink or eat nearby?		
	Yes	12792	96%
	No	578	4%
	Don't know / can't remember	161	1%
	Missing	2471	
33.	While you were waiting to have your most recent chemotherapy, were there staff available to answer any questions you had?		
	Yes	12634	95%
	No	672	5%
	Don't know / can't remember	234	2%
	Missing	2462	
34.	Before your last treatment, did the nurse giving your chemotherapy ask about any side effects (e.g. sickness, problems with mouth or throat) that you might have been experiencing?		
	Yes	11639	91%
	No	1205	9%
	Don't know / can't remember	645	5%
	Missing	2513	
35.	If your treatment has been changed for any reason, were you given a clear explanation about why this was?		
	Yes very clear	4396	84%
	Yes to some extent	631	12%
	No	192	4%
	My treatment has not been changed	7977	60%
	Don't know / can't remember	137	1%
	Missing	2669	
36.	When you had your most recent chemotherapy were you:		
	In a room on your own	1108	8%
	In a room with other patients	12274	92%
	Missing	2620	

HAVING YOUR CHEMOTHERAPY		Total	All
37.	If you were in a room with other patients did you feel comfortable speaking to staff about your treatment or other issues?		
	Yes	11767	93%
	No	918	7%
	Missing	3317	
38.	If you had the choice, would you prefer to have your chemotherapy:		
	In a room on your own	2919	22%
	In a room with other patients	10171	78%
	Missing	2912	
39.	If you needed help (e.g. getting a drink, taken to the toilet) while you were having your most recent chemotherapy, was there a member of staff there to help you?		
	<i>Yes all or most of the time</i>	7571	86%
	<i>Yes but only some of the time</i>	1081	12%
	No	164	2%
	I did not need help from staff	4480	34%
	Missing	2706	
40.	If you were given any drugs to take home with you, were you given a clear explanation about how to take them?		
	<i>Yes very clear</i>	12151	93%
	<i>Yes to some extent</i>	687	5%
	No	174	1%
	Don't know / can't remember	126	1%
	Missing	2864	
41.	After your last treatment did you feel sick (nauseous)?		
	No I did not feel sick (nauseous)	7829	51%
	Yes I felt a little sick (nauseous)	4872	32%
	Yes I felt sick (nauseous) quite a lot	1909	12%
	Yes I felt severe sickness (nausea)	853	6%
	Missing	539	
42.	After your last treatment were you sick (did you vomit)?		
	No I was not sick (did not vomit)	12860	83%
	Yes I was sick (vomited) a little	1685	11%
	Yes I was sick (vomited) quite a lot	550	4%
	Yes I was sick (vomited) severely	326	2%
	Missing	581	
43.	After your last treatment did you have any problems with your mouth or throat?		
	No I did not have any problems with my mouth or throat	8965	58%
	Yes I did have a few problems with my mouth or throat	4760	31%
	Yes I did have quite a lot of problems with my mouth or throat	1151	7%
	Yes I did have severe problems with my mouth or throat	565	4%
	Missing	561	

HAVING YOUR CHEMOTHERAPY	Total	All
44. Did the nurses who gave you your chemotherapy know about the side effects you experienced after the treatment?		
<i>Yes completely</i>	8948	75%
<i>Yes to some extent</i>	2257	19%
<i>No</i>	655	6%
I did not have any symptoms	2763	18%
Don't know / not sure	466	3%
Missing	913	
45. Did the nurses give you advice on how to manage these side effects?		
<i>Yes completely</i>	8294	75%
<i>Yes to some extent</i>	2420	22%
<i>No</i>	275	3%
I did not have any symptoms	131	1%
Don't know / not sure	91	1%
Missing	4791	

WHEN CHEMOTHERAPY FINISHED		Total	All
46.	When your course of chemotherapy treatment finished, were you told what to do if you noticed any new symptoms or had any worries about your health?		
	<i>Yes</i>	9781	82%
	<i>No</i>	2083	18%
	Don't know / can't remember	879	7%
	Missing	3259	
47.	Were you told about any long-term side effects of your chemotherapy treatment?		
	<i>Yes completely</i>	5356	45%
	<i>Yes to some extent</i>	3309	28%
	<i>No</i>	3147	27%
	Don't know / can't remember	960	8%
	Missing	3230	
48.	Were you told how long it might take you to recover from the effects of the chemotherapy?		
	<i>Yes</i>	7353	65%
	<i>No</i>	3933	35%
	Don't know / can't remember	1478	12%
	Missing	3238	

WHEN CHEMOTHERAPY FINISHED	Total	All
49. After your treatment finished, were you given the opportunity to talk to someone about any of the following issues:		
Emotional concerns		
Yes	5084	44%
No	6360	56%
Missing	4558	
Practical concerns		
Yes	4968	44%
No	6212	56%
Missing	4822	
Financial concerns		
Yes	3351	32%
No	7244	68%
Missing	5407	
Psychological concerns		
Yes	3938	37%
No	6788	63%
Missing	5276	
Spiritual concerns		
Yes	2653	26%
No	7592	74%
Missing	5757	
50. If you did have any of these concerns, were you offered a care plan to specifically help with these concerns?		
Yes	2366	63%
No	1378	37%
Don't know / can't remember	1177	24%
Missing	11081	
51. At the end of your treatment, were you offered written information about the treatment you had?		
Yes	4359	41%
No	6152	59%
Don't know / can't remember	2001	16%
Missing	3490	

YOUR OVERALL NHS CARE	Total	All
52. Overall, how would you rate your care?		
Excellent	9616	62%
Very good	4523	29%
Good	1140	7%
Fair	253	2%
Poor	56	0%
Missing	414	

ABOUT YOU	Total	All
53. Age:		
16 - 25	73	0%
26 - 35	278	2%
36 - 50	2023	13%
51 - 65	5410	36%
66 - 75	4817	32%
76+	2519	17%
Missing	882	

54. Are you male or female?		
Male	6168	40%
Female	9219	60%
Missing	615	

55. Do you have any of the following longstanding conditions?		
Deafness or severe hearing impairment	1103	7%
Missing	14899	
Blindness or partially sighted	267	2%
Missing	15735	
A long-standing physical condition	1849	12%
Missing	14153	
A learning disability	80	0%
Missing	15922	
A mental health condition	336	2%
Missing	15666	
A long-standing illness such as HIV diabetes chronic heart disease or epilepsy	1846	12%
Missing	14156	
No I do not have a longstanding condition	10119	63%
Missing	5883	

ABOUT YOU	Total	All
56. Which of the following best describes your sexual orientation?		
Heterosexual / straight (opposite sex)	14097	94%
Bisexual (both sexes)	27	0%
Gay or Lesbian (same sex)	130	1%
Other	43	0%
Prefer not to answer	678	5%
Missing	1027	
57. To which of these ethnic groups would you say you belong?		
White British	14199	91%
White Irish	242	2%
Any other White background	357	2%
White and Black Caribbean	29	0%
White and Black African	8	0%
White and Asian	30	0%
Any other mixed background	25	0%
Indian	160	1%
Pakistani	71	0%
Bangladeshi	26	0%
Any other Asian background	83	1%
Caribbean	158	1%
African	106	1%
Any other Black background	11	0%
Chinese	52	0%
Any other ethnic group	34	0%
Missing	411	