National Cancer Patient Experience Survey Programme

2010 National Survey Report

December 2010

The National Cancer Patient Experience Survey Programme is
being undertaken by Quality Health on behalf of the Department of Health

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Description	This is the National Cancer Patient Experience Survey report for 2010. This report indicates direct feedback from 67,000 cancer patients who were admitted inpatients / day patients Jan - March 2010. The patients were drawn from samples provided by 158 Trusts. In addition to this national report, Local Trusts are being provided bespoke reports and some key data is being published on NHS Choices
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1. Foreword

This national report provides insights into the care experienced by cancer patients across England who were treated as day cases or inpatients during the first three months of 2010. 158 NHS Trusts providing cancer services identified patients and 67,713 patients chose to respond. The high response rate (67%) shows how willing patients are to report on their care and thereby help to improve future service quality.

This survey is almost certainly one of the largest to have been undertaken involving cancer patients anywhere in the world. The national report will be accompanied by individual Trust level reports which will also provide information at tumour group (or multidisciplinary team) level where there are sufficient numbers of cases to provide meaningful results.

The 2010 survey builds on a previous survey undertaken in 2000 involving over 65,000 cancer patients and a smaller survey undertaken in 2004 involving 4,300 patients. Importantly the 2010 survey is the first to involve patients with all types of cancer. It is also the first national survey in this country in which the word cancer has been explicitly used.

The results show that many patients report very positively on their care. On 33 of the 59 items for which assessments were made, positive responses were reported by at least 80% of patients. For example, 90% of patients had waited less than four weeks between referral and first hospital visit, 85% reported that staff had done everything they could to control pain, 84% had confidence and trust in all of their doctors and 82% said they were always treated with dignity and respect.

However, on 12 of the 59 items less than 70% of patients reported positively, showing the scope available for improvement. For example, only 50% of patients who said it was necessary had received information about financial help; only 61% reported that clinicians working in hospitals and the community worked well together; only 62% reported that there were enough nurses on duty when they were admitted to hospital and only 66% reported receiving written information about their cancer.

One of the most positive aspects of this survey relates to the care given by Clinical Nurse Specialists (CNSs). 84% of patients reported that they had been given the name of a Clinical Nurse Specialist. Of these over 90% reported that the Clinical Nurse Specialist had listened carefully and that they got understandable answers from the Clinical Nurse Specialist all or most of the time. Importantly, this survey shows the impact of having a Clinical Nurse Specialist on patients' experience of care. Patients with a Clinical Nurse Specialist reported much more favourably than those without on a range of items related to information, choice and care.

The survey reveals significant variations between patient groups. In general, the following groups report less favourably on their care:

- Younger (age 16-25 years) and older (age over 75 years) patients
- Those who were diagnosed more than a year ago
- Women
- Patients from black and minority ethnic groups
- Non-heterosexuals
- Those living in London
- Patients living in the most deprived areas
- Patients with some long term conditions other than cancer

Variations in experience of care by the NHS can be marked. Although for most items the 'middle 60%' (i.e. those Trusts between the 20th and 80th percentiles) are not widely separated, the differences between the best and the worst trusts can be very wide, exceeding 40 percentage points in some instances. For instance in one Trust only 13% of patients reported being given written information about their operation, while in another the figure was 91%. 'The proportion of patients reporting that the hospital and community worked well together varied from 38% to 78%. Responses to the item on whether there were enough nurses on duty varied from 30% to 89%.

Based on these findings, I would strongly urge clinicians, managers and commissioners to look carefully at their local reports to assess areas where change is urgently needed. At a national level we will wish to learn more about those services that are performing very highly.

On almost all items which are comparable between this survey and the general inpatient survey, the overall results for cancer patients are better than those for inpatients as a whole. However, the examples given above show there are no grounds for complacency. In addition there is a mixed picture for those tumour groups and items which can be compared between 2000 and 2010. On four items there have been statistically significant improvements. These include being treated with dignity and respect and being given information about discharge. However, on three items there has been a significant decline in scores. These include patients understanding the explanation of what was wrong with them and patients reporting that there were enough nurses on duty.

At a national level the results of this survey are being fed into the review of the Cancer Reform Strategy. The survey provides valuable data on information, choice and patients' experience of care, each of which is central to the future direction of NHS cancer care.

Professor Sir Mike Richards,
National Cancer Director

2. Introduction

The Cancer Reform Strategy (CRS) published in 2007 set out a commitment to establish a new NHS Cancer Patient Experience Survey programme. The 2010 National Cancer Patient Experience Survey was designed to monitor national progress on cancer care; and to provide information that could be used to drive local quality improvements; and to help gather vital information on the *Transforming Inpatient Care* Programme, the *National Cancer Survivorship* Initiative and the *National Cancer Equality* Initiatives.

A National Cancer Patients' Experience Advisory Group co-chaired by Professor Jessica Corner of Macmillan Cancer Support and Professor Sir Mike Richards, National Clinical Director for Cancer and End of Life Care, oversaw the principles and objectives of the survey and the questionnaire development.

Prior to this survey, national surveys of cancer patients' experience of NHS services also took place in 2000 and 2004. One of the aims of the 2010 survey was to assess whether there has been further improvement over the past 10 years and where efforts need to be focused over the coming years. Comparisons have been made in this report with the results from the 2000 baseline survey where these are possible.

Since the 2000 and 2004 national cancer surveys were undertaken, there have been a number of major policy initiatives and associated publication of Guidance by the National Institute for Health and Clinical Excellence (NICE). In particular, the publication of Improving Outcomes Guidance by NICE for particular groups of cancers has systematised information in respect of best practice treatment and support for patients; and has strengthened commitments to providing good information to patients, supporting access by patients to Clinical Nurse Specialists, and ensuring that tumour management is handled through a Multi Disciplinary Team (MDT). NICE has also published Guidance in respect of Supportive and Palliative Care which had the objective of improving information to patients and families; and work has been undertaken to support the creation of Information Prescriptions for patients by placing detailed patient friendly information about 25 cancer types on the NHS Choices website, ready for use by clinicians and patients.

The creation of Clinical Nurse Specialist posts, designed to support patients who have been diagnosed with cancer, has had a marked effect on patients' experiences of cancer care, as this report shows; Clinical Nurse Specialist posts have been designated following the publication and implementation of the NICE *Improving Outcomes Guidance*, and this development has been underpinned by the roll out of the Advanced Communications Programme for clinicians, which is designed to further improve the communication skills of cancer service staff.

This survey has therefore been undertaken after a period of significant activity designed to improve the support and information given to patients, and is consequently a yardstick against which to judge the effectiveness of improvements to cancer care.

3. Executive Summary

The results of the 2010 National Cancer Patient Experience Survey indicate that cancer inpatients are significantly more satisfied with their care and treatment than are hospital inpatients generally, and that on some issues significant progress has been made since the last comprehensive survey of patients was completed in 2000.

The 2010 National Cancer Patient Experience Survey is one of the first to use the word “cancer” explicitly in the questionnaire and covering documents to patients, bringing the advantage that we can be sure that the results of this survey are focused clearly on cancer services and not on patients’ other NHS experiences. In 2010 a wider group of cancer types was also surveyed than in previous national cancer surveys.

Response rates

The response rate (67%) compares very favourably with the response rate for the 2009 National Inpatient Survey[1] organised by the Care Quality Commission (52%). It is encouraging that a very high proportion of responders (83%) have indicated that they would be willing to participate further in surveys designed to understand their experiences of cancer services. The high response rate to the 2010 National Cancer Patient Experience Survey means that for most trusts there are sufficient numbers of responders to make robust comparisons among Trusts and in many instances among Cancer Groups within trusts.

Rarer Cancers

The 2010 National Cancer Patient Experience Survey is also the first to cover all cancer groups; previous cancer patient experience surveys have concentrated on some of the most common cancer groups. The responses to the 2010 survey indicate that there are important differences of perception by patients in different cancer groups in respect of the quality of treatment they have received. The findings of the 2010 survey indicate that patients in the some of the rarer cancer groups have less positive views of their treatment.

Positive Assessments

On many questions in the National Cancer Patient Experience Survey, patients’ overall responses were positive. 33 questions had positive scores of 80% or more[2] covering the following aspects of the service:

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[1] CQC, National Inpatient Survey Results, May 2010, www.cqc.org.uk/publications.cfm?fde_id=15551

[2] All percentages are based on scored questions which exclude all neutral responses e.g. ‘don’t know’, ‘can’t remember’ etc.

- 90% of patients reported that their first appointment with a hospital doctor was no more than 4 weeks after being told by their GP that they needed to go to hospital
- 81% of patients felt they were seen as soon as necessary by a hospital doctor
- 81% of patients said that staff gave them a complete explanation of the purpose of test(s)
- 84% of patients said that staff explained completely what would be done during test(s)
- 85% of patients were given easy to understand written information about test(s)
- 83% of patients felt they were told sensitively that they had cancer
- 83% of patients were given a choice of different types of cancer treatment before their treatment started
- 84% of patients were given the name of the Clinical Nurse Specialist in charge of their care
- 91% of patients said their Clinical Nurse Specialist definitely listened carefully to them the last time they spoke to them
- 91% of patients said they got understandable answers to important questions all or most of the time from their Clinical Nurse Specialist
- 95% of patients said that the last time they were seen or spoken to, the time spent with the Clinical Nurse Specialist was about right
- 89% of patients reported that their admission date for their operation was not changed to a later date by the hospital
- 85% of patients said staff gave a complete explanation of what would be done during their operation
- 81% of patients said they got understandable answers to important questions all or most of the time from doctors
- 84% of patients had confidence and trust in all of the doctors treating them
- 89% of patients thought doctors definitely knew enough about how to treat their cancer
- 83% of patients said doctors did not talk in front of them as if they were not there
- 83% of patients said ward nurses did not talk in front of them as if they were not there
- 87% of patients did not think doctors or nurses were deliberately not telling them certain things that they wanted to know
- 82% of patients said they were always given enough privacy when discussing condition or treatment
- 93% of patients said they were always given enough privacy when being examined or treated
- 85% of patients said hospital staff did everything to help control their pain all of the time
- 82% of patients were always treated with respect and dignity by the doctors, nurses and other hospital staff
- 82% of patients were given clear written information about what they should or should not do after leaving hospital
- 92% of patients said staff told them who to contact if they were worried about their condition or treatment after leaving hospital
- 82% of patients said staff definitely did everything possible to control the side effects of radiotherapy
- 85% of patients said staff definitely did everything possible to control the side effects of chemotherapy
- 83% of outpatients / day case patients said staff definitely did everything they could to help control their pain

- 94% of patients thought the cancer doctor who they saw during their outpatient appointment spent about the right amount of time with them
- 95% of patients said the cancer doctor they saw during their outpatient appointment had the right notes and other documentation with them
- 93% of patients said their GP was given enough information about their condition and hospital treatment
- 88% of patients felt they were given the right amount of information about their condition and treatment
- 80% of patients did not feel that they were treated as 'a set of cancer symptoms' rather than a whole person

It is also clear from a comparison of results between the National Inpatient Survey conducted on behalf of the CQC in acute hospitals in England in 2009, and the National Cancer Patient Experience Survey 2010, that cancer inpatients are more positive about their care and treatment on almost all the questions which are comparable between the two surveys.

Less Positive Assessments

The specific areas which scored 70% or lower[3] where patients are more critical of cancer services are:

- 66% of patients were given easy to understand written information about the type of cancer they had
- 50% of patients said hospital staff gave them information about how to get financial help or benefits
- 68% of patients said hospital staff told them that they could get free prescriptions
- 68% of patients were given easy to understand written information about their operation
- 66% of patients said their family or someone else close to them definitely had enough opportunity to talk to doctor if they wanted to
- 66% of patients had confidence and trust in all the ward nurses treating them
- 62% of patients felt there were always or nearly always enough nurses on duty to care for them
- 58% of patients said doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home
- 60% of patients were definitely given enough care and help from health or social services after leaving hospital
- 68% of patients said their appointment started within 30 minutes of their appointment time at their last outpatient appointment with a cancer doctor
- 69% of patients said GPs and nurses at their general practice did everything they could to support them while they were having cancer treatment
- 61% of patients said different people (e.g. GPs, hospital doctors / nurses, specialist and community nurses) treating and caring for them always worked well together to give them the best possible care

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[3] All percentages are based on scored questions which exclude all neutral responses e.g. ‘don’t know’, ‘can’t remember’ etc.

Length of time since diagnosis

Analysis of the 2010 National Cancer Patient Experience Survey allows an assessment of the different views of those patients who have been diagnosed with cancer in the last year and those who were diagnosed some time ago. On 25 separate items there are significant differences of view between patients diagnosed in the last year and those diagnosed earlier, with recently diagnosed patients always being the most positive group. These more positive assessments are on a wide range of issues, and there are no instances where service quality as seen by the patient is worse amongst newly diagnosed patients; patients who began treatment more than 5 years ago gave a less positive assessment of their treatment than patients who started treatment in the last year. It is the case that patients who have had to be readmitted for treatment because of a recurrence of cancer may be less positive about their treatment than others; but it is also the case that there are identifiable long term care and treatment changes (such as the availability of more Clinical Nurse Specialists) which will have had the effect of increasing the proportion of recent patients who are satisfied with their treatment.

Variations between Trusts

The 2010 survey shows substantial differences between trusts in patients' experiences of cancer care. For example, the proportion of patients saying that they had been given the name of a Clinical Nurse Specialist (CNS) ranged from 97% in the best performing Trust to 59% in the poorest performing Trust (excluding Trusts with low response numbers under 20).

Longitudinal comparisons

There are 10 questions which are comparable between the 2000 cancer survey and the 2010 National Cancer Patient Experience Survey. A comparison of these questions shows that there have been improvements on four issues, with the most substantial improvement being in respect of patients being given information when leaving hospital. However, there are significantly poorer scores on three issues. It is not possible to compare the 2010 survey with that conducted in 2004 because of sampling frame differences.

Most questions relating to nurses were not used in these comparisons even where they are similar because of wording changes to these questions in the 2010 survey which inserted the word 'ward' before nurse to differentiate ward nurses from Clinical Nurse Specialists and other specialist cancer nurses in patients' responses.

Clinical Nurse Specialists

The 2010 survey results demonstrate the positive impact of Clinical Nurse Specialists on patients' experiences. On every question, patients who had contact with a Clinical Nurse Specialist were more positive than those that did not; and the differences between these two groups were in most cases large. There is however, evidence that some older patients in some tumour groups, and some patients who started treatment over 5 years ago, have unequal access to the support of a Clinical Nurse Specialist. The impact of Clinical Nurse Specialists is profound and clearly very positive overall for the patient experience of cancer care.

Differences between tumour groups

In both 2000 and 2004 there was strong evidence that prostate cancer patients' had worse experiences than patients with other cancer types such as breast and lung. In contrast, the 2010 survey results show that, in general, the experience of patients with prostate cancer is largely in line with treatment in other tumour groups, although there are still some areas of concern, such as the provision of information on financial support. Indeed, on some issues (such as the provision of written information about the type of cancer, and on choice of treatment) patients in the prostate cancer group are more positive than patients in any other cancer group. This demonstrates significant progress in the treatment of prostate cancer patients.

There are significant differences among cancer groups in the quality of treatment. The cancer groups which are the most frequent poor performers are 'other cancers', sarcoma, brain / central nervous system, and urology[4].

Differences between ethnic groups

Cancer patients from ethnic minority groups are significantly less likely to be positive about some aspects of communication with them, and about the way they are treated as patients by the staff that they are in contact with, than are white patients. This key finding replicates the findings of surveys of NHS patients in other patient pathways.

Differences between age groups

Cancer patients in both the youngest and oldest age groups (16-25, and 76+ respectively) often have less positive views about their treatment than cancer patients in the middle age groups. There are 42 separate issues on which there are significant differences between age groups as a whole in this survey; and there are clear themes in relation to young patients, related specifically to ensuring that explanations of treatment, condition, tests etc. are given in a fashion which recognises the lack of hospital experience which many of this age group will have at the time they start treatment. As far as older people are concerned, there is strong evidence that fewer of them have easy access to Clinical Nurse Specialists and fewer of them receive information about financial help and benefits than is the case for other age groups.

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[4] The urological tumour group excluded prostate cancer, which was included as a separate tumour group for the purposes of the survey.

Differences relating to gender

On most issues, men are significantly more positive than are women, replicating the findings of other NHS patient surveys. There are 43 issues on which there are significant differences between the views of men and of women; men are more positive for example about staff, privacy and respect and dignity. Differences between the attitudes of men and women remain substantial even when we remove those cancer groups that are wholly or almost wholly single gender, with men remaining more positive than women when patients in the breast, prostate and gynaecological cancer groups are removed from the analysis.

Differences relating to sexual orientation

For the first time, a question was asked in the 2010 National Cancer Patient Experience Survey about patients' sexual orientation. Analysis based on responses to this question shows that there are 16 questions on which there are significant differences of opinion as between heterosexual patients and non-heterosexual patients, with 11 of these items relating to communication and (broadly) to the respect and dignity with which the patients was treated. In all cases non heterosexuals were less positive than heterosexuals.

Patients with long term conditions

Cancer patients were asked if they had other long term health conditions (LTCs); and on 48 questions there were statistically significant differences of opinion between those patients with a long term condition or conditions and those without one. In almost all cases the patients with long term conditions were less positive. When we look at individual long term conditions, it is clear that patients with mental health conditions and those with learning disabilities were very much less positive than cancer patients without long term conditions of any kind, and less positive than patients with other kinds of long term conditions.

The impact of deprivation

Our analysis of the findings using postcodes matched to the Index of Multiple Deprivation (IMD) indicates that there are no significant differences among the deprivation quintiles, but there are a large number of differences in scores between the least deprived decile and the most deprived decile. In the 37 cases where there was such a significant difference, 16 demonstrated that patients in the most deprived decile were more positive than those in decile 1 (least deprived). However, there were 21 items where patients in the most deprived decile were less positive, with many of these questions relating to information giving, getting understandable information from staff, and patients being treated in a respectful way. We have also analysed the postcodes of non-responders to the survey in respect of the IMD and this shows that patients in decile 1 (least deprived) had a response rate of 71%, compared to 51% in decile 10 (most deprived). Less response data is therefore available from the most deprived groups of patients.

Differences between London and non-London patients

> The differences that were revealed between London and Non-London Trusts in previous national cancer surveys are also evident in the results of the 2010 National Cancer Patient Experience Survey. Patients in London are significantly more critical of cancer services in respect of being told they could bring family with them to their appointment, getting understandable answers to important questions from ward nurses, contacting their Clinical Nurse Specialist, and in terms of the general organisation of NHS services, especially those “reaching” into the community and primary care.

The patient survey therefore gives clear indications to Trusts, Commissioners, and Cancer Networks, as to the focus of their quality improvement initiatives. The survey results also point to areas of policy which could be the subject of further intervention and monitoring.

Trust level reports will be published following this national report and key information from these reports will be available to the public via NHS Choices.

4. Response rate & helpline calls

A total of 109,477 patients who had received treatment for cancer during January to March 2010 were included in the sample for the Cancer Patient Experience Survey. These patients fell into 13 different cancer groups.

Response rate

During the survey process Demographics Batch Service (DBS) checks were undertaken on 3 occasions to remove deceased patients: before the first send out, before the first reminders were sent and before the second reminders were sent. Trusts also undertook their own internal checks for deceased patients. Patients were also removed arising from calls to the helpline and via postal communications that were received. These included additional deceased patients, those who had moved and could not be traced and other ineligible patients. This produced a final sample of 101,773.

The response rate to the Cancer Patient Experience Survey in 2010 was 67% (67,713 completed surveys) from the final sample of 101,773. This compared to response rates of 74% and 55% in 2000 and 2004 respectively.

The seeming differences in response rates are related to differences in methodology and practice in previous years. The total number of respondents was 65,337 in 2000 and 4,300 in 2004, when only a small proportion of Trusts (49) were surveyed. In 2004 only patients in the breast, lung, bowel, and prostate tumour groups were surveyed.

Response rates in 2010 varied by Trust, ranging from 77% to 39%. Many of the Trusts with lower response rates were in London. However, response rates in almost all Trusts were higher in the National Cancer Patient Experience Survey than in the National Inpatient Survey, where questionnaires are sent to patients discharged from all specialties. In some Trusts that drew most of their patients from heavily urbanised areas outside London, response rates were very high.

Helpline calls

Quality Health provides a dedicated survey helpline staffed by trained in-house operators. 4,505 calls were made to the helpline; these included calls which 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.

Future research

Patients were asked if a survey could be sent to them in the future to ask about their health and healthcare: 83% of respondents said yes, a further survey could be sent.

5. Patient demographics

The survey included all patients having treatment for cancer during January to March 2010 where this treatment was recorded by Trusts as falling within the first diagnosis field. Patients were placed into one of 13 cancer groups using their ICD10 code. The survey covered both inpatients and day case patients, with 40% being inpatients and 60% being day cases (49% general day cases and 11% frequent day cases).

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 hospital episode was taken as the episode to use in respect of the survey sample.

The 'big 4' cancers (breast, colorectal / lower gastrointestinal, lung and prostate) accounted for 50% of all respondents. Breast cancer accounted for a larger proportion of patients than did any other cancer group (21% of all respondents).

The table below shows the percentage and number of respondents by tumour group.

Tumour Group	**Number of respondents**	**Percentage**
Breast	14264	21%
Colorectal / lower gastrointestinal	10537	16%
Lung	3758	6%
Prostate	5270	8%
'Big 4' combined	**33829**	**50%**
Brain / central nervous system (CNS)	2382	4%
Gynaecological	3933	6%
Haematological	10113	15%
Head and neck	2856	4%
Sarcoma	713	1%
Skin	1322	2%
Upper gastrointestinal	3577	5%
Urological (excluding prostate)	8548	13%
Other cancers	440	1%

Table 1 Tumour group by response

The tables below show the percentage and number of respondents by gender, age, ethnicity, sexual orientation, long term condition and length of time since patients were first treated for this cancer.

Gender of respondents	Number of respondents	Percentage
Male	31694	47%
Female	36019	53%

Table 2 Respondents by gender

Age of respondents	Number of respondents	Percentage
16-25 years of age	442	1%
26-35 years of age	1100	2%
36-50 years of age	7313	11%
51-65 years of age	22957	34%
65-75 years of age	21141	31%
76+ years of age	14760	22%

Table 3 Respondents by age group

Ethnicity of respondents	Number of respondents	Percentage
White (British, Irish or other white)	61757	96%
Asian or Asian British	1007	1.6%
Black or Black British	879	1.4%
Mixed background	260	0.4%
Other	215	0.3%

Table 4 Respondents by ethnicity

Sexual orientation of respondents *	Number of respondents	Percentage
Heterosexual	58674	99%
Bisexual	130	0.2%
Gay or lesbian	362	0.6%
Other sexuality	308	0.5%

Table 5 Respondents by sexuality

* 5% of patients said they preferred not to answer this question, and a further 8% 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	6626	10%
Blindness or partially sighted	1684	2%
A longstanding physical condition	9168	14%
A learning disability	301	0.4%
A mental health condition	1184	2%
A long standing illness	8695	13%

Table 6 Respondents with long term conditions

* 59% of patients said they did not have a long-standing condition other than cancer. The table shows the percentage and number of patients saying they had one or more of each of the long-standing conditions specified.

Length of time since respondents were first treated for this cancer	**Number of respondents**	**Percentage**
Less than 1 year	41386	64%
1 to 5 years	16621	26%
More than 5 years	6129	10%

Table 7 Length of time since respondents first treated for this cancer

6. 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 cancer treatment, starting with referral and ending with care from the patient's General Practice and lastly their overall rating of NHS 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.

For each question 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.

The key score for each question is shown firstly as an overall percentage of all respondents to the survey; this same key score is then used to highlight variations between tumour groups. Where the key score has been constructed from more than one response option to a particular question (e.g. patient saw their GP once; patient saw their GP twice), then the response options that make up that key score are described.

The charts in this section show the key score for each of the cancer groups. The overall score for all respondents (the national average) is shown as a red line.

For each question, significance tests have been used to establish whether particular tumour groups have scores at variance from the "all cancers" group of respondents. Where reference is made in the text of the report to the views of respondents in particular tumour groups, in all cases the differences between the named tumour group and the "national average" is significant.

A small number of pertinent patient comments are displayed throughout this section. These comments have been taken from the 100,000+ separate comments written by patients in the comments section of the questionnaire.

Seeing your GP

The early diagnosis of cancers is seen in the Cancer Reform Strategy as a critical issue and the second Annual Report on the CRS states that "patients in this country are diagnosed later and with more advanced disease than elsewhere in Europe"[5]. The questions in this section of the survey were designed to identify the view of patients about seeing their GP prior to referral to hospital, the length of time that elapsed and changes to their health status during the important assessment and referral period.

1. Number of times seen by GP

Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?

Overall findings

Of those patients who saw their GP before going to hospital, 75% said that they saw their GP either once (54%) or twice (21%) before they were told they needed to go to hospital about the health problem caused by cancer.

16% saw their GP 3 or 4 times, and 9% saw their GP 5 or more times. 20% said they did not see their GP before going to hospital.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they saw their GP only once or twice before being referred on to a cancer specialist. Scores ranged from 92% (breast cancer) to 59% (other cancers).

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[5] Page 5 Cancer Reform Strategy Second Annual Report December 2009 Gateway Ref. 12927

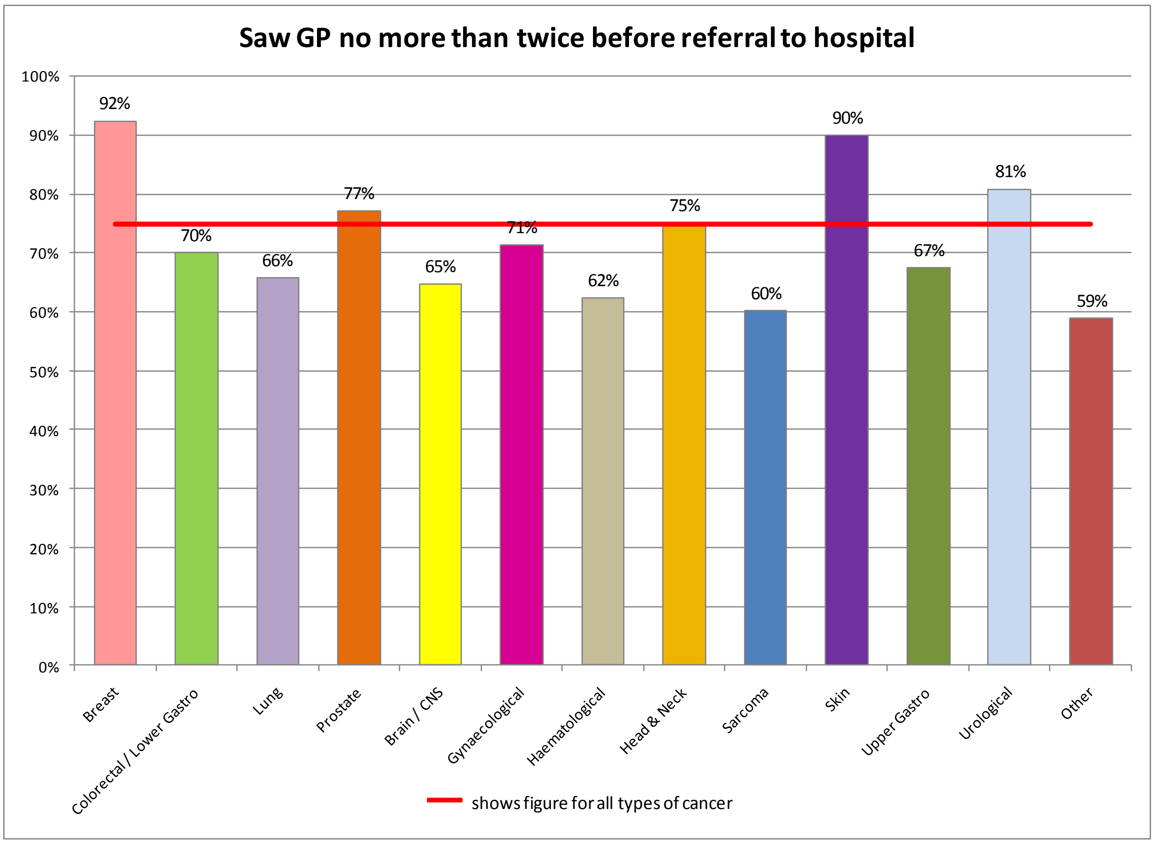

Chart 1 Saw GP no more than twice

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they saw their GP only once or twice before being referred on to a cancer specialist. Scores in Trusts ranged from 52% as the lowest score to 90% as the highest Trust score.

The 20th percentile threshold is 72%; the 80th percentile threshold is 79%.

2. Wait before first appointment with hospital doctor

After your GP first told you that you would need to see a hospital doctor, how long did you have to wait before your first appointment with a hospital doctor?

Overall Findings

90% of patients who said they had seen their GP said they waited no more than 4 weeks before their first appointment with a hospital doctor. Of this group, 10% were seen on the same or next day, 58% were seen within 2 to 14 days, and 23% were seen in 3 to 4 weeks.

9% of patients waited between 1 and 4 months and 1% said they waited more than 4 months to be seen.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they waited no more than 4 weeks for their first appointment. Scores ranged from 96% (breast cancer) to 80% (sarcoma).

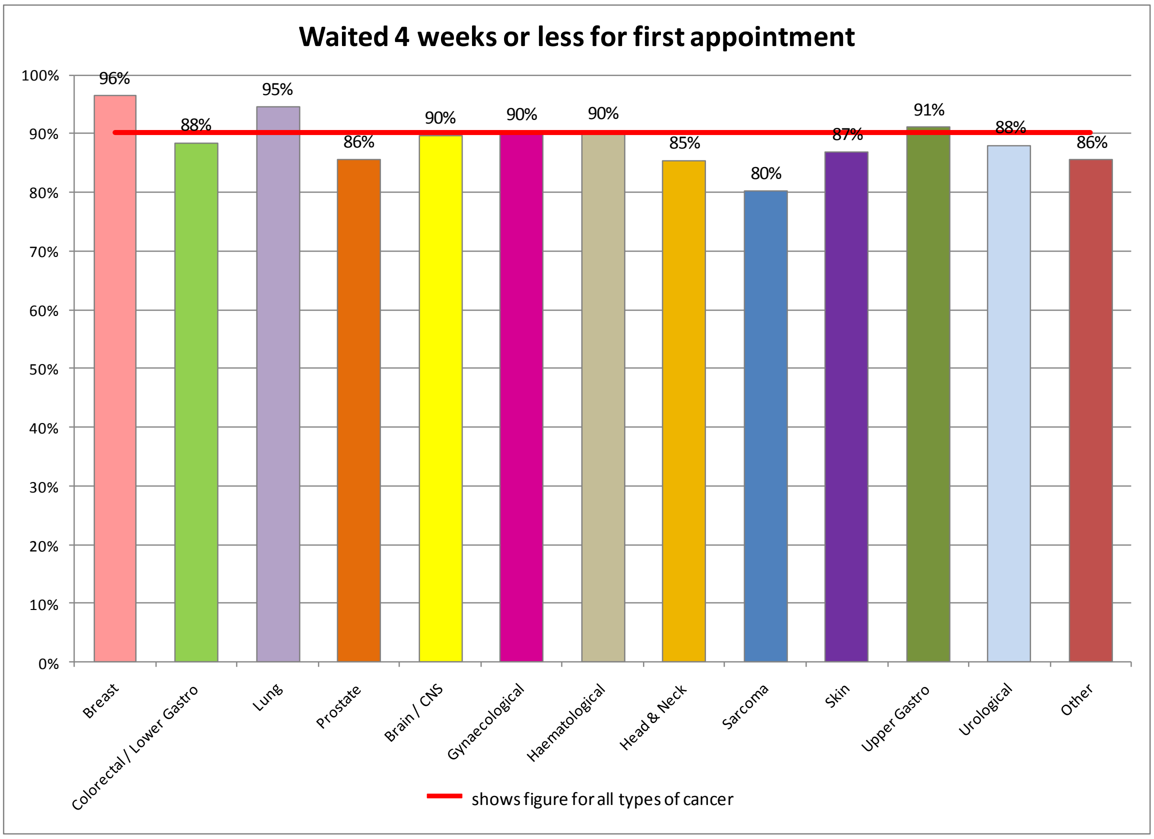

Chart 2 Waited 4 weeks or less for appointment

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they waited 4 weeks or less for their first appointment. Scores in Trusts ranged from 59% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 88%; the 80th percentile threshold is 93%.

3. First appointment as soon as was necessary

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

Overall Findings

81% of patients in all cancer groups said they felt that they were seen as soon as they thought was necessary: 12% felt they should have been seen a bit sooner and a further 7% felt they should have been seen a lot sooner.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were seen as soon as they thought necessary. Scores ranged from 84% (lung and prostate cancer groups) to 68% (sarcoma).

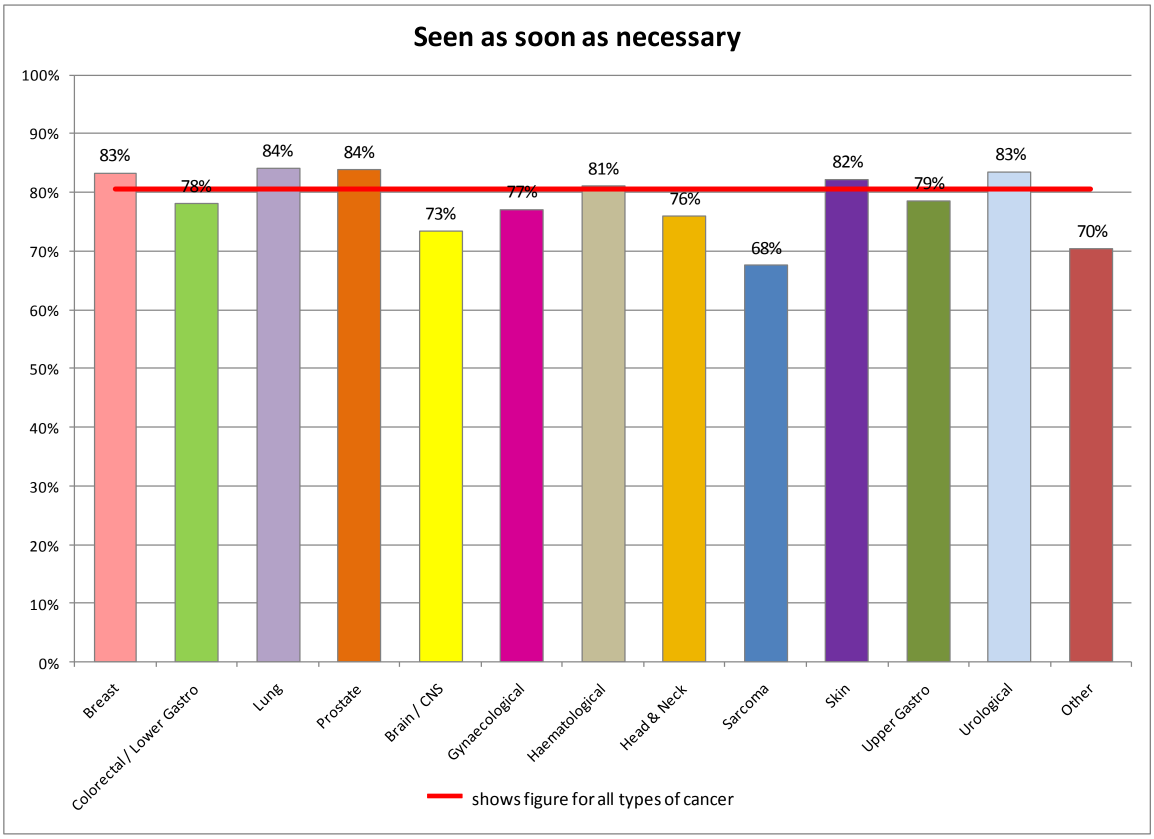

Chart 3 Seen as soon as necessary

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were seen as soon as necessary. Scores in Trusts ranged from 57% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 78%; the 80th percentile threshold is 85%.

4. Length of time before first seeing a hospital doctor

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

Overall Findings

77% of patients said that the gap between the time when they first thought something might be wrong and when they first saw a hospital doctor was less than 3 months. 14% said the gap was 3-6 months; 5% said 6-12 months and 4% said more than 12 months.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were seen by a hospital doctor within 3 months of thinking something might be wrong. Scores ranged from 87% (breast cancer) to 63% (sarcoma).

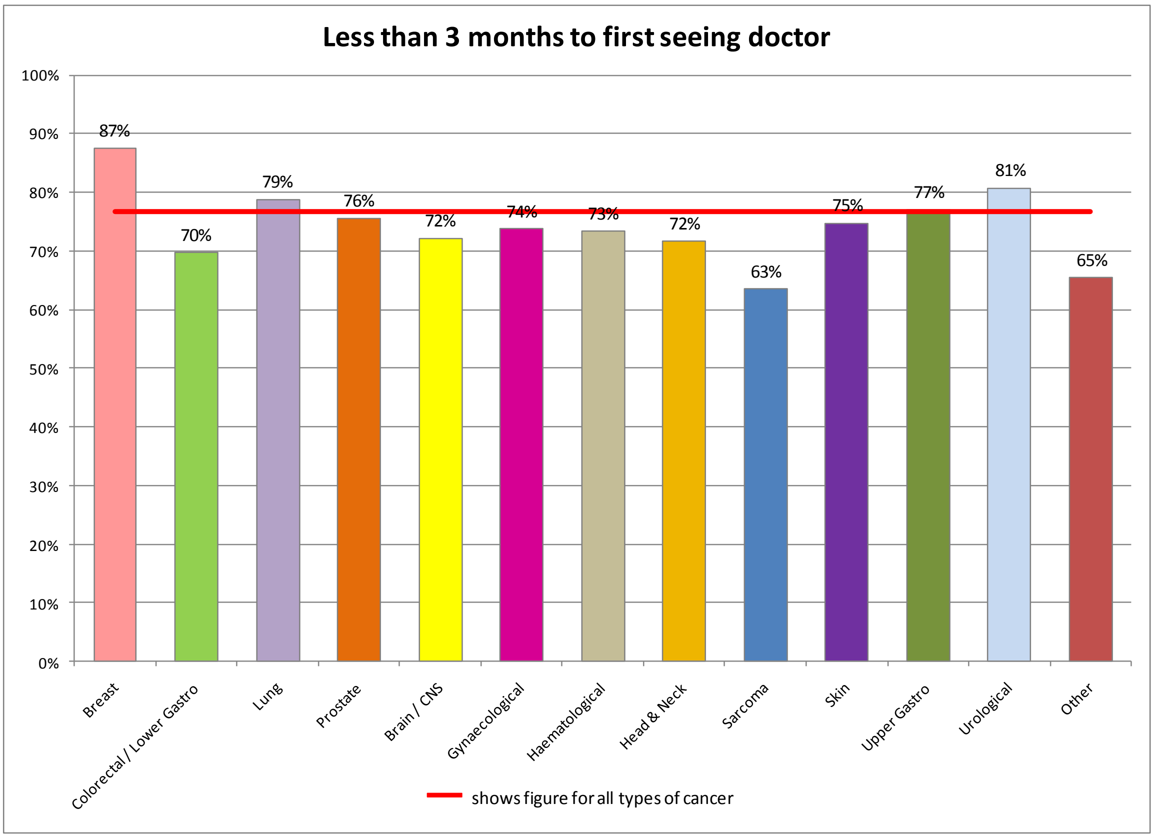

Chart 4 Less than 3 months to first seeing doctor

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were seen by a hospital doctor within 3 months of thinking something might be wrong. Scores in Trusts ranged from 52% as the lowest score to 86% as the highest Trust score.

The 20th percentile threshold is 74%; the 80th percentile threshold is 80%.

5. State of health whilst waiting for first appointment

Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?

Overall Findings

78% of patients in all cancer groups said that their health got better (1%) or stayed about the same (77%) during the time they were waiting for their first appointment with a hospital doctor; 22% said their health got worse.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying their health got better or stayed about the same. Scores ranged from 94% (skin cancer) to 61% (sarcoma).

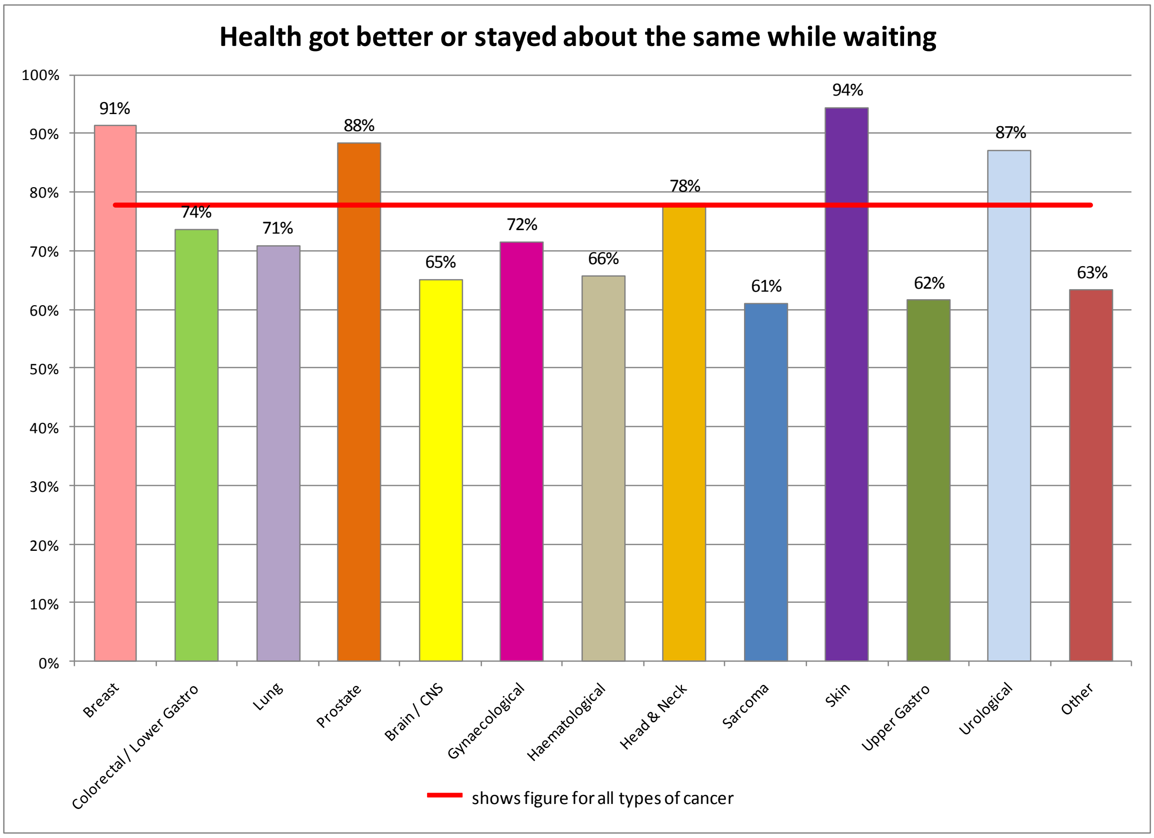

Chart 5 State of health while waiting

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying their health got better or stayed about the same. Scores in Trusts ranged from 45% as the lowest score to 92% as the highest Trust score.

The 20th percentile threshold is 74%; the 80th percentile threshold is 82%.

Patient views

Colorectal/Lower GI: "My diagnosis for bowel cancer was initiated through my participation in the bowel cancer screening programme in November 2009. I feel that the speed with which this whole process was completed must be something particularly good about NHS cancer care."

Breast: "My own GP made me feel that I was wasting her time and in her own words she only sent me for an appointment to put my mind at rest. Talking to other patients this seems to be a common experience. GPs need to send people to see cancer experts sooner if lives are to be saved."

Diagnostic Tests

This section describes the views of patients who had diagnostic tests about the explanations and information given about those tests and test results.

6. Patients having tests

In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?

Overall Findings

90% of patients overall said they had diagnostic tests for cancer such as an endoscopy, biopsy, mammogram or scan.

7. Explanations of the purpose of tests

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

Overall Findings

Of those patients who said they needed an explanation, 81% said staff explained the purpose of tests completely; a further 17% said the purpose was explained to some extent. 2% of patients said the purpose was not explained but that they would have liked an explanation.

Findings by Tumour Group

There was some variation in the proportion of patients receiving explanations of tests between cancer types, but statistical tests reveal that these differences are not as a whole significant.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying staff explained the purpose of tests completely. Scores in Trusts ranged from 58% as the lowest score to 93% as the highest Trust score.

The 20th percentile threshold is 78%; the 80th percentile threshold is 84%.

8. Explanations of what would be done during tests

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

Overall Findings

Of those patients who said they needed an explanation, 84% said staff explained what would be done during tests completely a further 14% said it was explained to some extent. 1% said it was not explained but that they would have liked an explanation.

Findings by Tumour Group

There was some variation in the proportion of patients receiving explanations of what would be done during such tests, but statistical tests reveal that these differences are not as a whole significant.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying staff explained what would be done during tests completely. Scores in Trusts ranged from 68% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 81%; the 80th percentile threshold is 87%.

9. Given written information about tests

Beforehand, were you given written information about your test(s)?

Overall Findings

Of those patients who said they needed written information about their tests, 85% said they were given written information that was easy to understand; 4% were given information but it was difficult to understand. 11% said they were not given written information but would have liked some.

Findings by Tumour Group

There was some variation in the proportion of patients being given written information about their tests as between cancer types, but statistical tests reveal that these differences are not as a whole significant.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were given written information that was easy to understand. Scores in Trusts ranged from 61% as the lowest score to 94% as the highest Trust score.

The 20th percentile threshold is 81%; the 80th percentile threshold is 88%.

10. Explanations of test results

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

Overall Findings

Of those patients who said they needed an explanation, 76% said they received a completely understandable explanation of their test results; a further 21% said the explanation was only understandable to some extent. 3% said the results were not explained but they would have liked an explanation.

Findings by Tumour Group

There was some variation in the number of patients saying they had a completely understandable explanation of their tests results. Scores ranged from 82% (skin cancer) to 66% (other cancers).

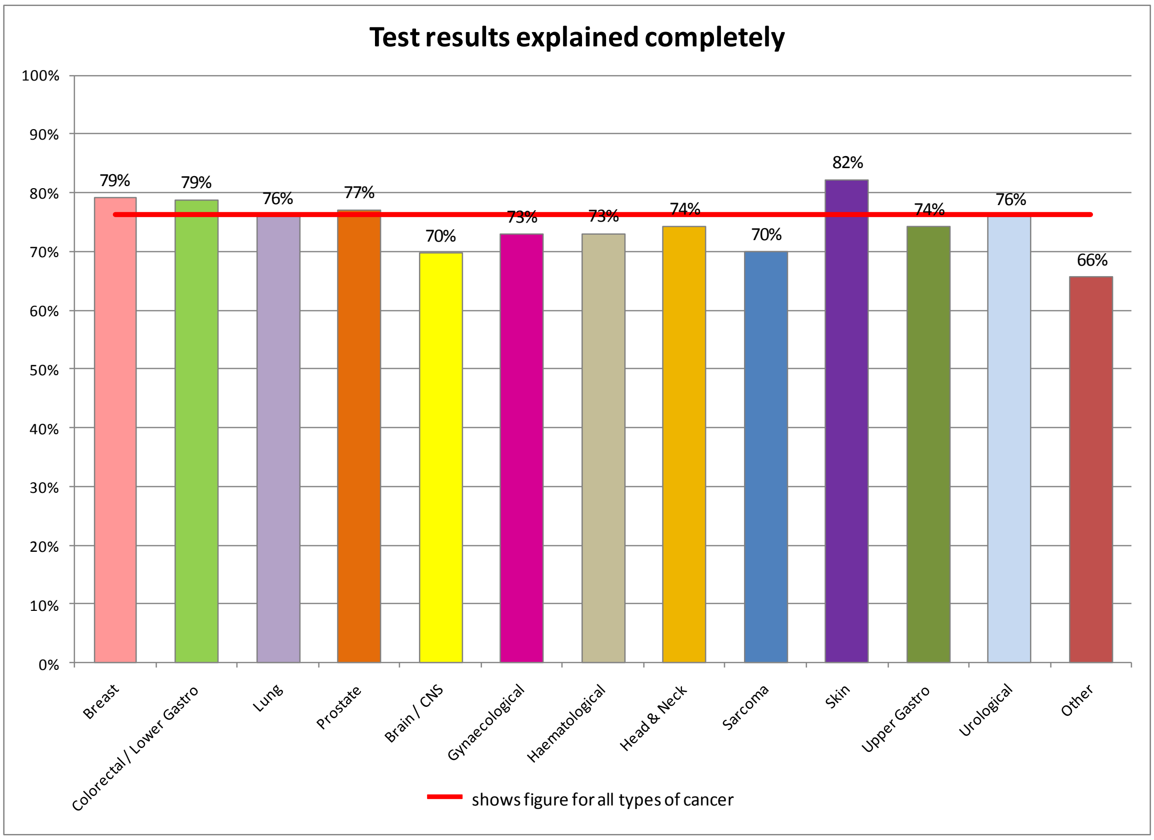

Chart 6 Test results explained

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had a completely understandable explanation of their test results. Scores in Trusts ranged from 65% as the lowest score to 94% as the highest Trust score.

The 20th percentile threshold is 73%; the 80th percentile threshold is 80%.

Patient views

Sarcoma: “It took nearly 12 months for my condition to be diagnosed - even though I was (frequently) presenting classic symptoms of my cancer - very long delays between medical tests and receiving results of the tests: doctors not listening to me during diagnostic stage. Long delay from diagnosis to the start of treatment.”

Finding out what was wrong

This section describes who first told the patient that they had cancer and what they felt about the way they were told and the information given to them.

11. Who first told the patient they had cancer

Who first told you that you had cancer?

Overall Findings

83% of patients said they were first told they had cancer by a hospital doctor; 5% said they were told by a nurse, 7% were told by their GP and 3% by another health professional. 2% said that a friend or relative told them or that they worked it out for themselves.

12. Having a family member or friend present

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

Overall Findings

Of those patients who felt it necessary, 71% overall said they were told they could bring a family member or friend with them; 29% were not told. 2% said they were told they had cancer by phone or letter.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were told they could bring a family member or friend with them. Scores ranged from 78% (breast cancer) to 60% (skin cancer).

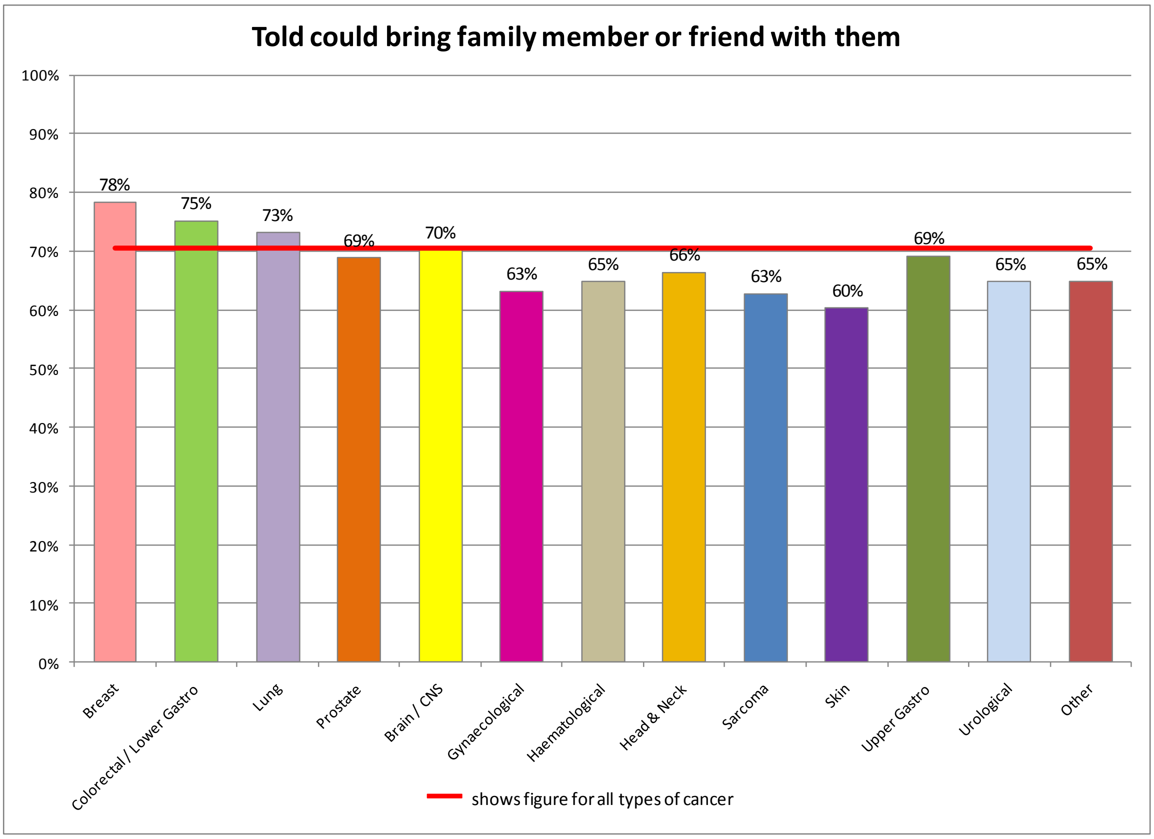

Chart 7 Told could bring family member

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were told they could bring a family member or friend with them. Scores in Trusts ranged from 47% as the lowest score to 86% as the highest Trust score.

The 20th percentile threshold is 65%; the 80th percentile threshold is 76%.

13. Patients feelings about the way they were told

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

Overall Findings

Overall, 83% of patients felt that the way they were told they had cancer was done sensitively; 12% felt it could have been done a bit more sensitively and a further 6% said it could have been done a lot more sensitively.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying the way they were told they had cancer was done sensitively. Scores ranged from 87% (breast cancer) to 76% (other cancers).

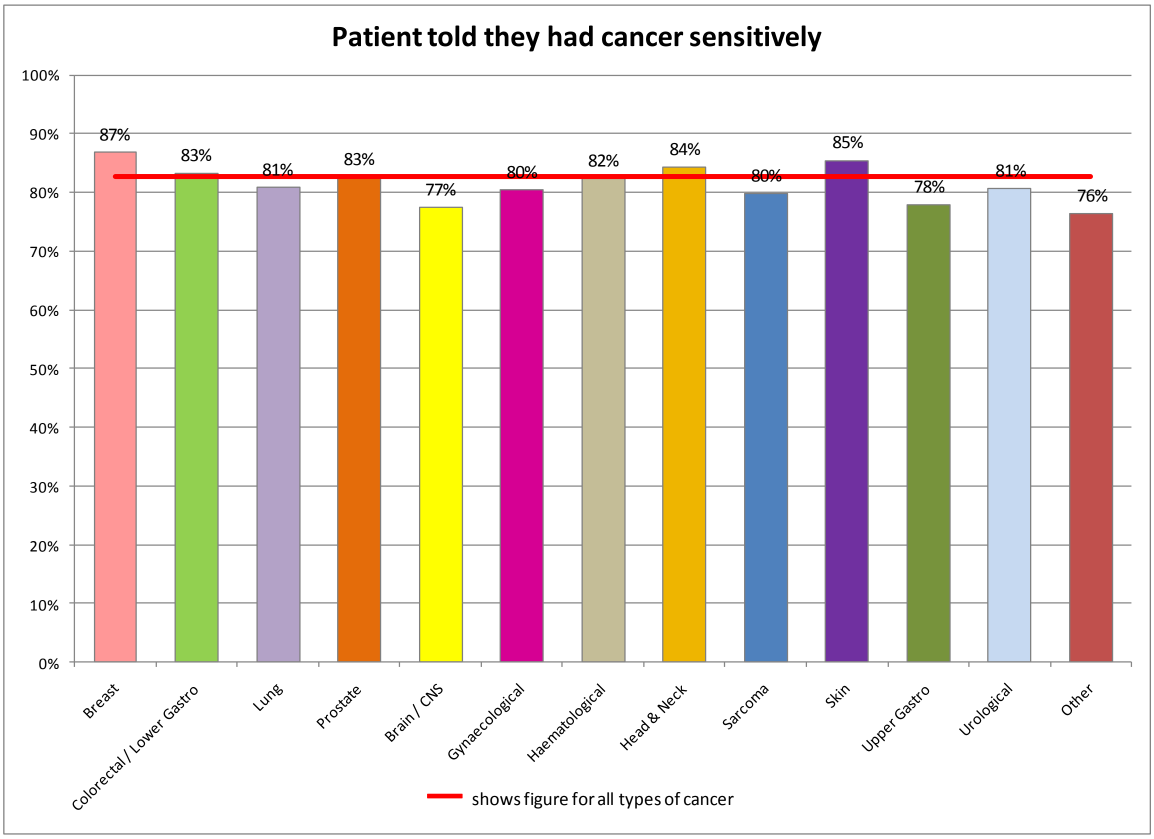

Chart 8 Patient told they had cancer sensitively

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying the way they were told they had cancer was done sensitively. Scores in Trusts ranged from 74% as the lowest score to 96% as the highest Trust score.

The 20th percentile threshold is 81%; the 80th percentile threshold is 86%.

14. Patients understanding explanations of what was wrong

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

Overall Findings

74% of patients said that they completely understood the explanation of what was wrong with them; 24% said that they understood some of it. 2% said that they did not understand the explanation they were given.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they completely understood the explanation that they received of what was wrong with them. Scores ranged from 79% (breast cancer) to 58% (haematological cancer).

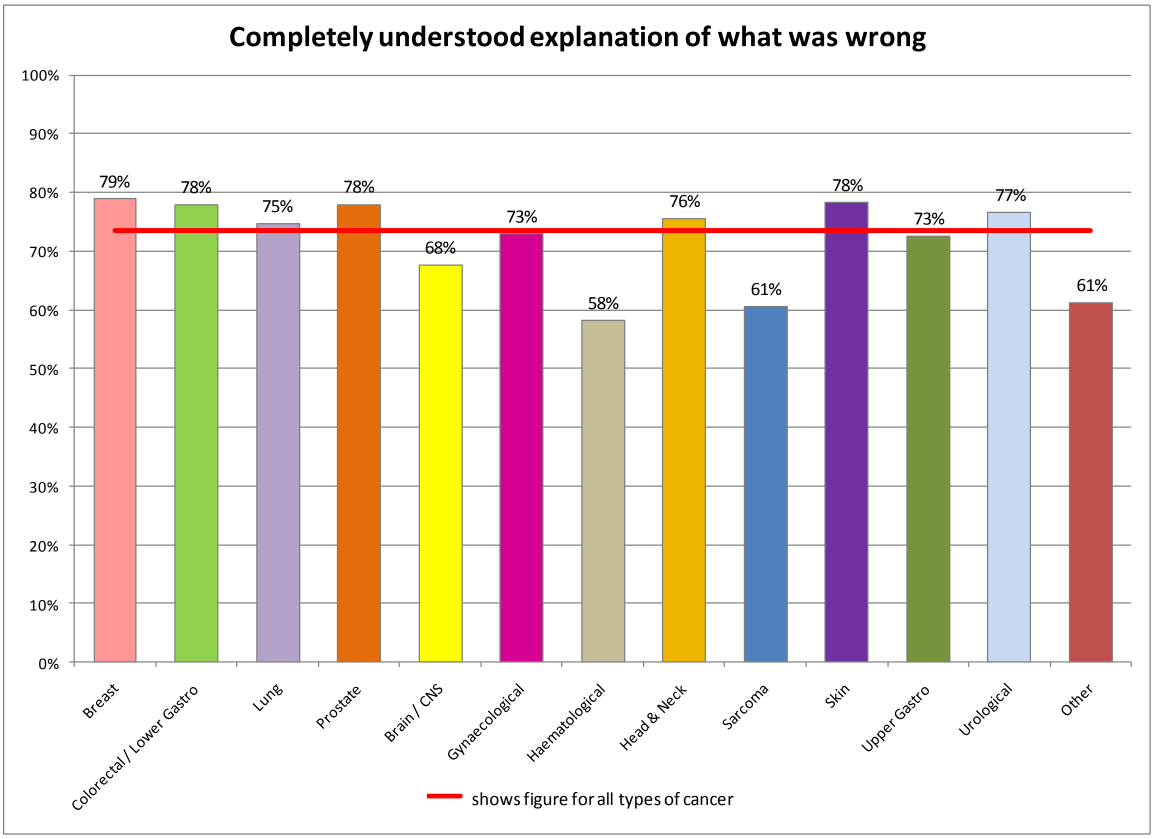

Chart 9 Completely understood what was wrong

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they completely understood the explanation that they received of what was wrong with them. Scores in Trusts ranged from 57% as the lowest score to 93% as the highest Trust score.

The 20th percentile threshold is 71%; the 80th percentile threshold is 77%.

15. Written information about the type of cancer

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

Overall Findings

Of those patients who said they needed it, 66% overall said they were given written information about the type of cancer that they had and that it was easy to understand; a further 7% were given written information but said it was difficult to understand. 27% were not given written information.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were given written information about the type of cancer that they had and that it was easy to understand. Scores ranged from 75% (prostate cancer) to 41% (other cancers).

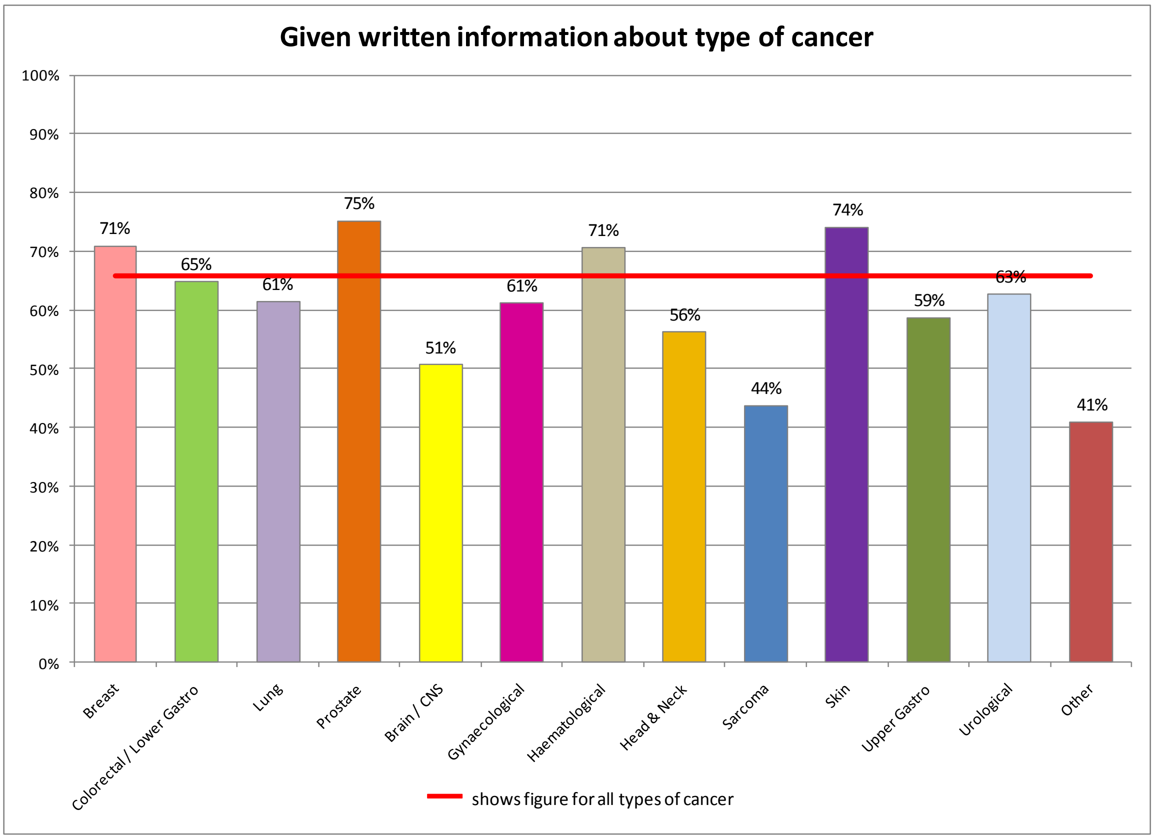

Chart 10 Given written information about type of cancer

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were given written information about the type of cancer that they had and that it was easy to understand. Scores in Trusts ranged from 25% as the lowest score to 82% as the highest Trust score.

The 20th percentile threshold is 62%; the 80th percentile threshold is 70%.

Patient views

Brain / central nervous system: "As mentioned before, my doctor was very kind in visiting me at home to break the bad news. He has told me I'm welcome to ring him at any time."

Skin: "The way I was told was appalling - a copy of the letter which had been sent to my GP. It then took 10 weeks before my op despite being told several times it would be 2-3 weeks. It took over 2 weeks to get my first appointment after receiving the diagnosis which I didn't fully understand. Getting info from the NHS is like getting blood out of a stone - the only helpful people were the cancer helpline at the hospital. I only found out about them because I looked in the phone book."

Deciding the best treatment

This section describes the patients' views about the choice and information they were given, and their involvement in decisions about treatment.

16. Choice about types of treatment

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

Overall Findings

62% of patients overall said only one type of treatment was suitable for them; of the remaining patients, 83% said they were given a choice of different types of treatment; 17% said they were not given a choice but would have liked one.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were given a choice of different types of treatment. Scores ranged from 89% (prostate cancer) to 71% (other cancers).

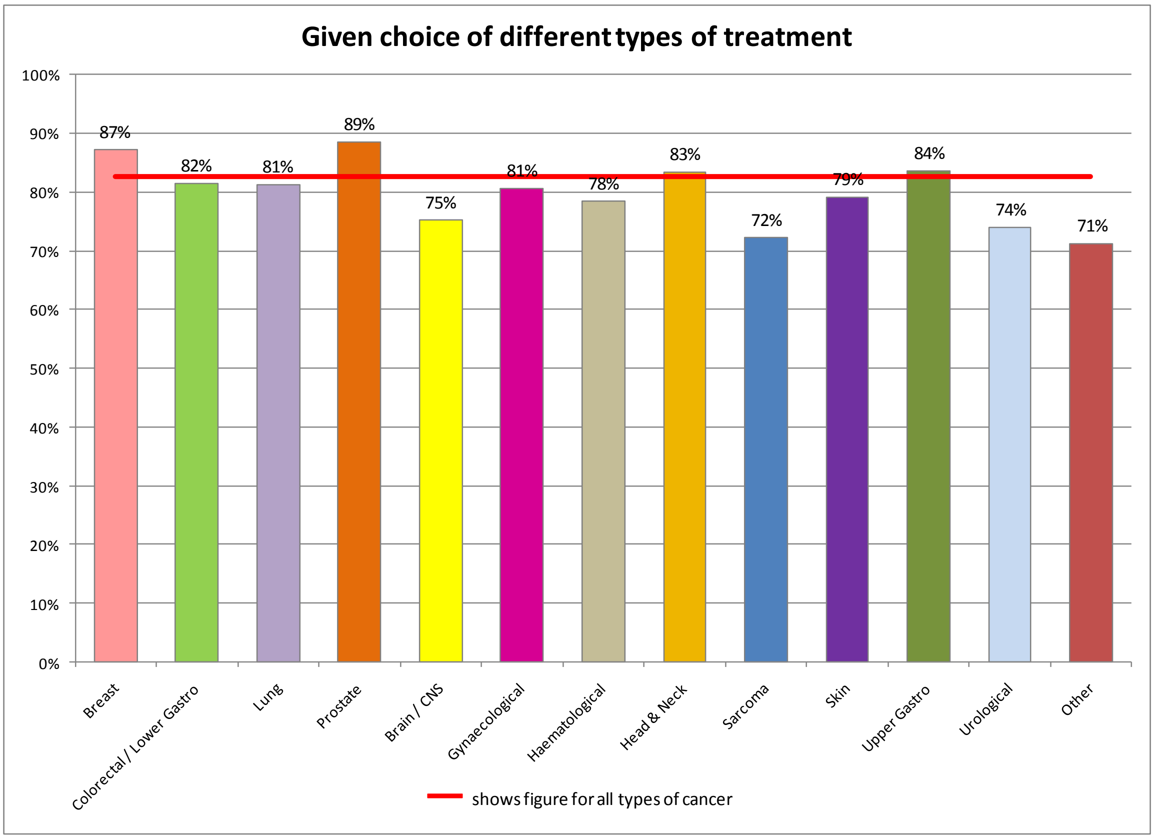

Chart 11 Given choice of treatment

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were given a choice of different types of treatment. Scores in Trusts ranged from 47% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 79%; the 80th percentile threshold is 86%.

17. Explanations about side effects of treatment

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

Overall Findings

Of those patients saying they needed an explanation, 72% said possible side effects of treatment were definitely explained to them in a way they could understand; a further 23% said the explanation was understandable to some extent. 5% said side effects were not explained to them.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying possible side effects of treatment were definitely explained to them. Scores ranged from 76% (colorectal / lower gastrointestinal cancer) to 67% (urological cancer).

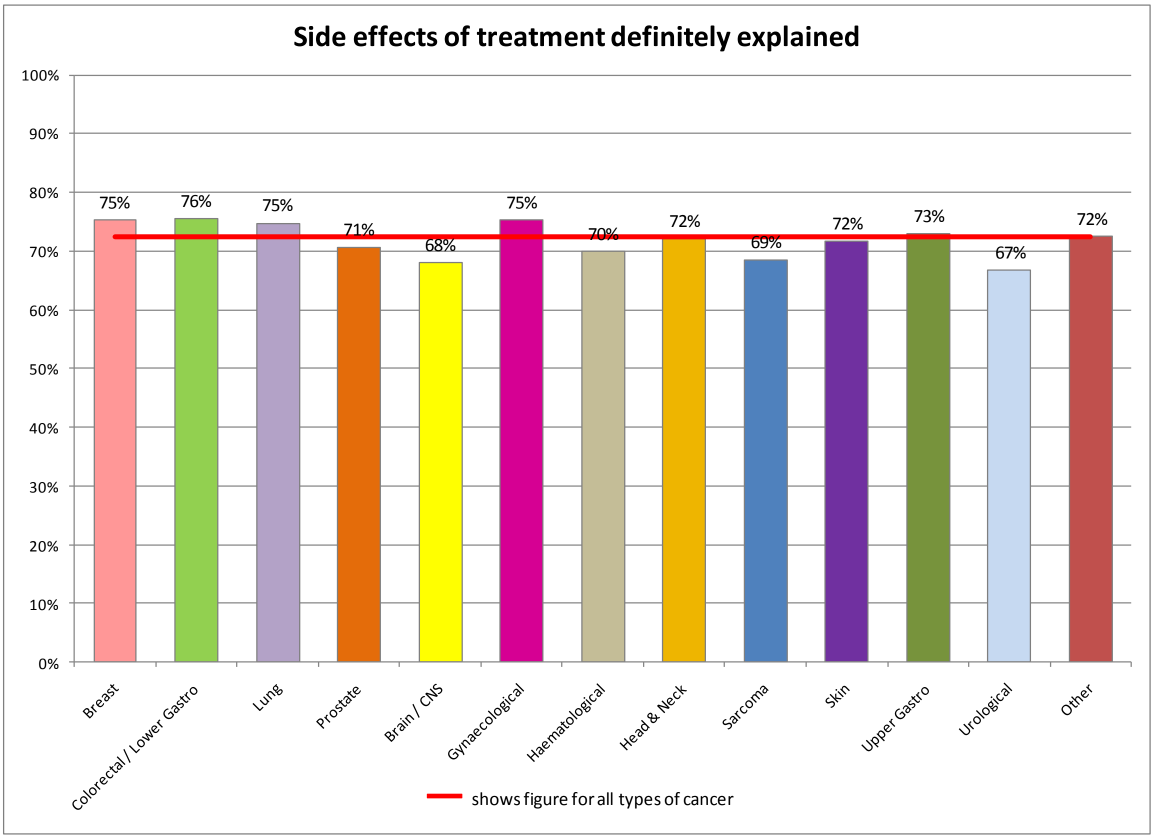

Chart 12 Side effects explained

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying possible side effects of treatment were definitely explained to them. Scores in Trusts ranged from 51% as the lowest score to 89% as the highest Trust score.

The 20th percentile threshold is 68%; the 80th percentile threshold is 75%.

18. Written information about side effects of treatment

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

Overall Findings

79% of patients said that they had received written information about the side effects of treatment and that it was easy to understand; a further 5% were given written information but it was difficult to understand. 16% of patients said they were not given written information about side effects.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they had received written information about the side effects of treatment. Scores ranged from 88% (breast cancer) to 60% (skin cancer).

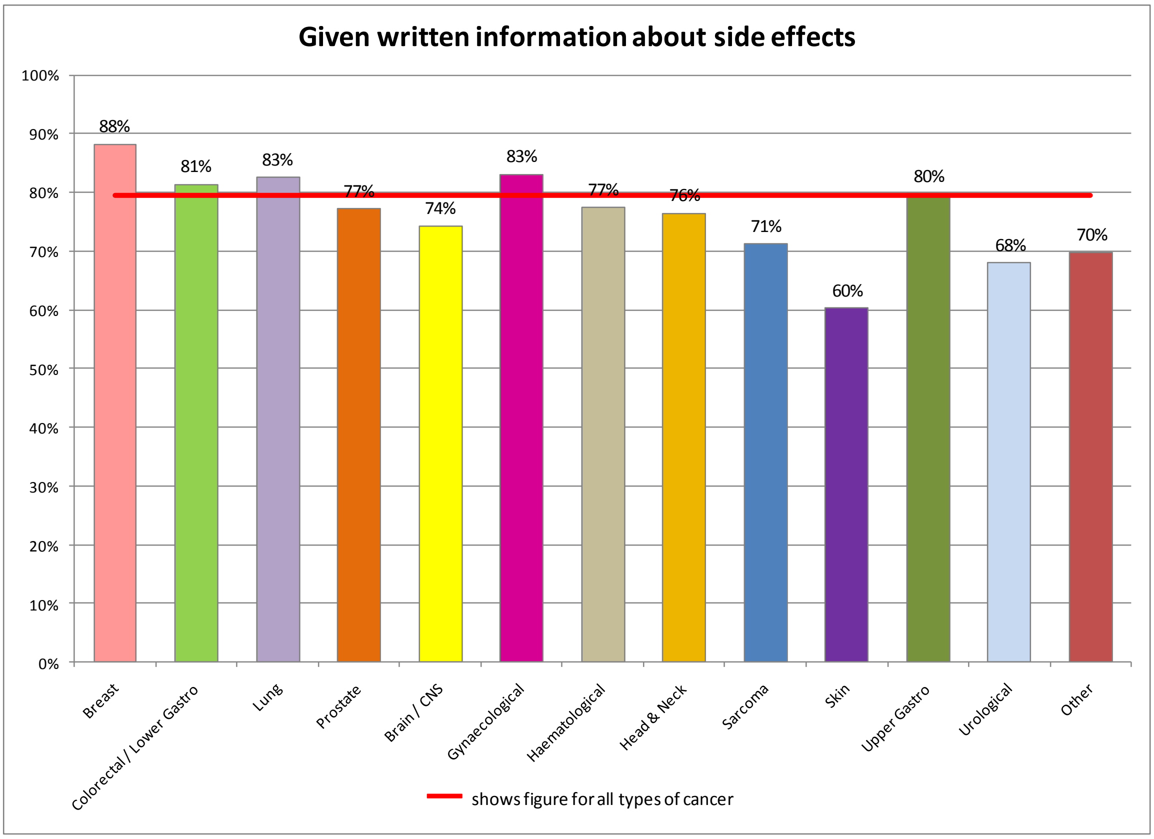

Chart 13 Given written information about side effects of treatment

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had received written information about the side effects of treatment. Scores in Trusts ranged from 29% as the lowest score to 90% as the highest Trust score.

The 20th percentile threshold is 74%; the 80th percentile threshold is 83%.

19. Patient involvement in decisions about treatment

Were you involved as much as you wanted to be in decisions about which treatment(s) you would have?

Overall Findings

Of those patients who thought that more than one type of treatment was suitable for them, 71% said that they were definitely involved as much as they wanted to be in decisions about their treatment; 22% said they were involved to some extent. 6% said they would have liked to have been more involved.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were definitely involved in decisions about treatment. Scores in Trusts ranged from 51% as the lowest score to 87% as the highest Trust score.

The 20th percentile threshold is 67%; the 80th percentile threshold is 75%.

Patient views

Colorectal/lower gastrointestinal: "I was involved in discussion about my treatment and its consequences from the very beginning. I was always treated as a person rather than just a patient with a collection of symptoms. The staff at the Centre where I received my chemotherapy treatment were, without exception, warm and sensitive in their treatment of me. They were proactive in dealing with any problems which arose."

Clinical nurse specialist

This section describes the patients' views about Clinical Nurse Specialists, their availability to patients, and information given by them.

20. Given the name of a Clinical Nurse Specialist

Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

Overall Findings

84% of patients overall said that they had been given the name of a Clinical Nurse Specialist; 16% were not given the name of a Clinical Nurse Specialist.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were given the name of a Clinical Nurse Specialist. Scores ranged from 93% (breast cancer) to 69% (urological cancer).

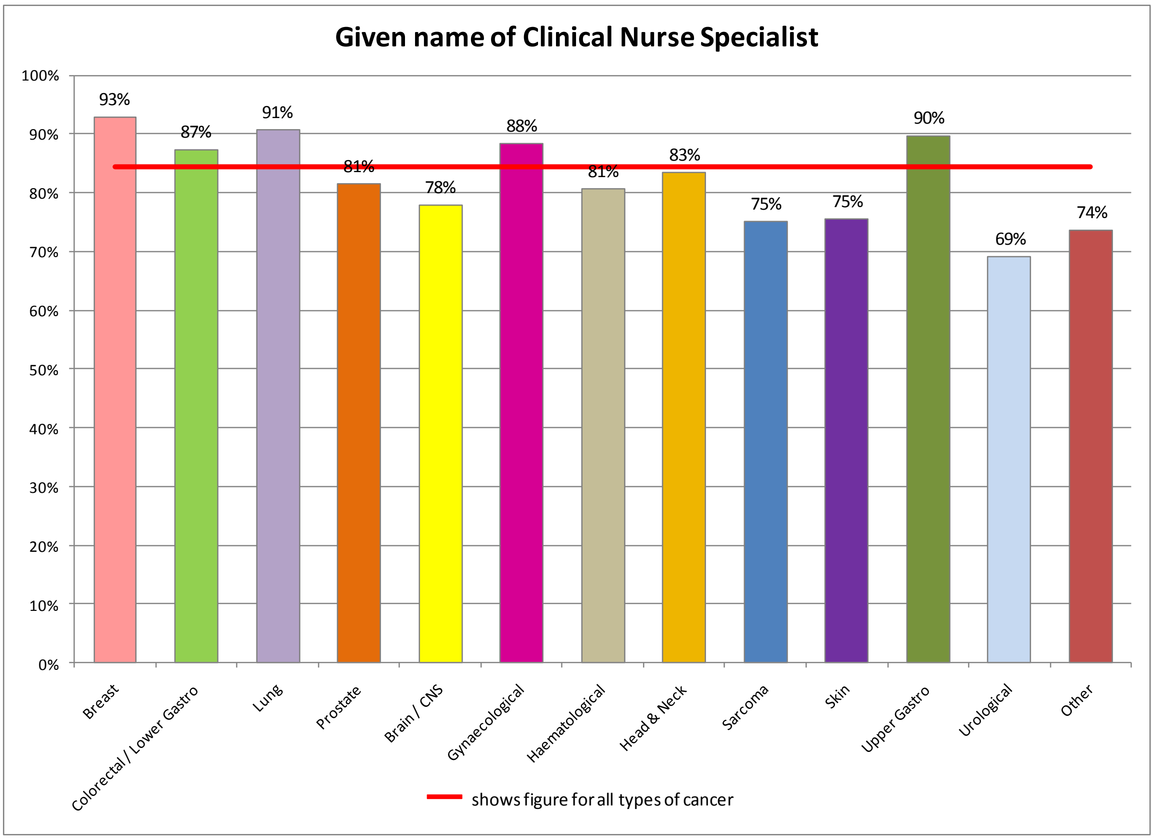

Chart 14 Given name of CNS

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were given the name of a Clinical Nurse Specialist. Scores in Trusts ranged from 59% as the lowest score to 97% as the highest Trust score.

The 20th percentile threshold is 81%; the 80th percentile threshold is 88%.

21. Ease of contacting the Clinical Nurse Specialist

How easy is it for you to contact your Clinical Nurse Specialist?

Overall Findings

Of those patients who had tried to contact their Clinical Nurse Specialist, 75% said that it was easy to contact them; 22% said it was sometimes easy, sometimes difficult; and 3% said it was difficult.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying it was easy to contact their Clinical Nurse Specialist. Scores in Trusts ranged from 57% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 70%; the 80th percentile threshold is 80%.

22. Clinical Nurse Specialist Listening carefully

The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?

Overall Findings

91% of patients overall said that the Clinical Nurse Specialist definitely listened carefully to them when they last spoke to them; 7% said they listened carefully to some extent. 1% said they did not listen carefully.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying the Clinical Nurse Specialist definitely listened carefully. Scores in Trusts ranged from 71% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 90%; the 80th percentile threshold is 94%.

23. Asking the Clinical Nurse Specialist important questions

When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

Overall Findings

Of those patients who said that they asked the Clinical Nurse Specialist questions, 91% said that they got understandable answers all or most of the time, 8% said they did so only some of the time and 1% said they rarely or never did.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they got understandable answers all or most of the time from the Clinical Nurse Specialist. Scores in Trusts ranged from 77% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 89%; the 80th percentile threshold is 93%.

24. Time spent with the Clinical Nurse Specialist

The last time you saw or spoke to your Clinical Nurse Specialist, do you feel that the time you spent with them was too long, too short or about right?

Overall Findings

95% of patients said that the last time they spoke to their Clinical Nurse Specialist the time spent with them was about right; 5% said the time spent was too short. A very small number of patients said the time spent was too long.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying the time spent with them by the Clinical Nurse Specialist was about right. Scores in Trusts ranged from 83% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 93%; the 80th percentile threshold is 97%.

Patient views

Lung: "I am more than satisfied with the care, and the Information Centre is brilliant. The nurses in day unit - brilliant. Everyone else - brilliant. I also like the garden and the general feeling of being treated as a person, with a life-style and a future I had two particular sessions with a specialist nurse that (how shall I say...) put my head together. Fantastic service."

Haematology: "Never been able to get any support from my cancer support worker at the hospital so easier access to this service would be an improvement. With my treatment being 'shared care' between dermatology, haematology, GP and radiotherapy has been quite confusing when chasing results and appointments."

Support for patients

This section describes the information given to patients about support groups, financial help and free prescriptions.

25. Information about support groups

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

Overall Findings

Of those patients who said it was necessary, 79% reported having been given information about support or self-help groups for people with cancer by hospital staff. 21% said they did not get any information but would have liked some.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they had been given information about support or self-help groups. Scores ranged from 86% (breast cancer) to 60% (urological cancer).

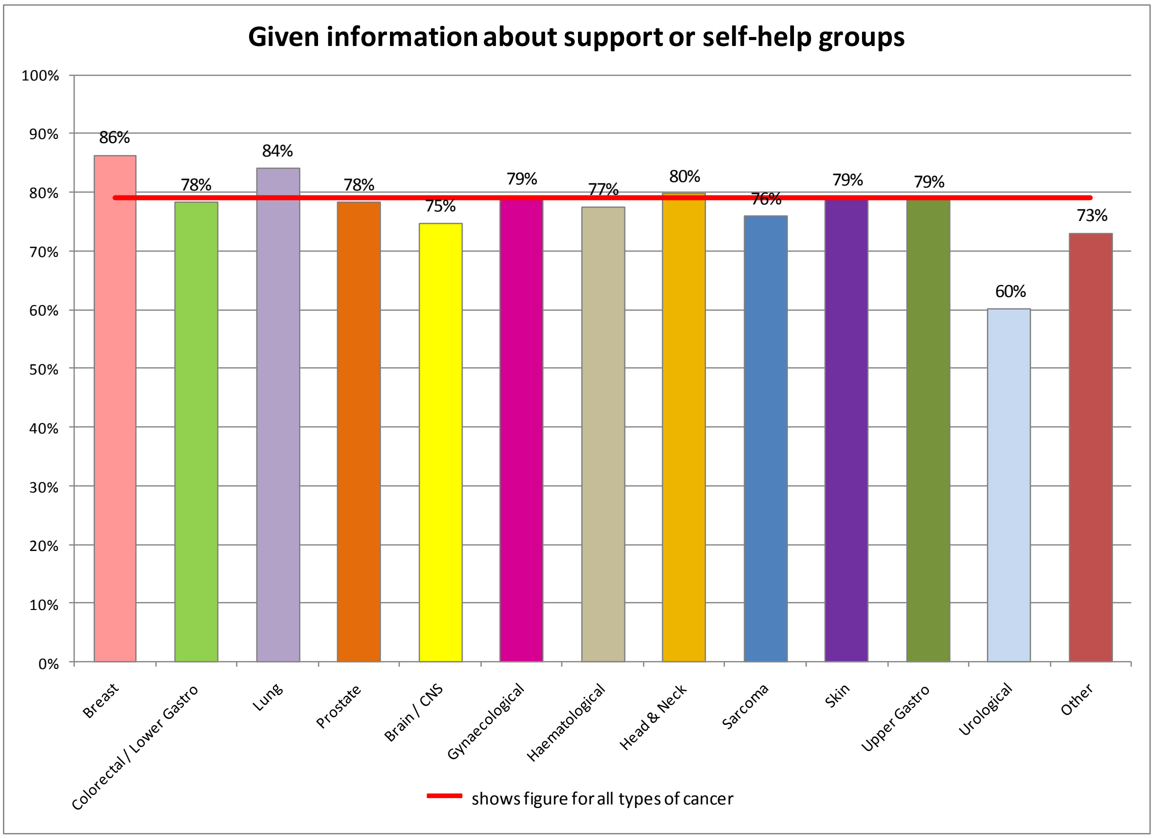

Chart 15 Given information about support groups

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had been given information about support or self-help groups. Scores in Trusts ranged from 54% as the lowest score to 94% as the highest Trust score.

The 20th percentile threshold is 74%; the 80th percentile threshold is 83%.

26. Information about financial help

Did hospital staff give you information about how to get financial help or benefits?

Overall Findings

Of those patients who said it was necessary, 50% said they had been given information about how to get financial help or benefits by hospital staff. 50% said they did not get any information but would have liked some.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they had been given information about how to get financial help or benefits. Scores ranged from 71% (lung cancer) to 26% (urological cancer).

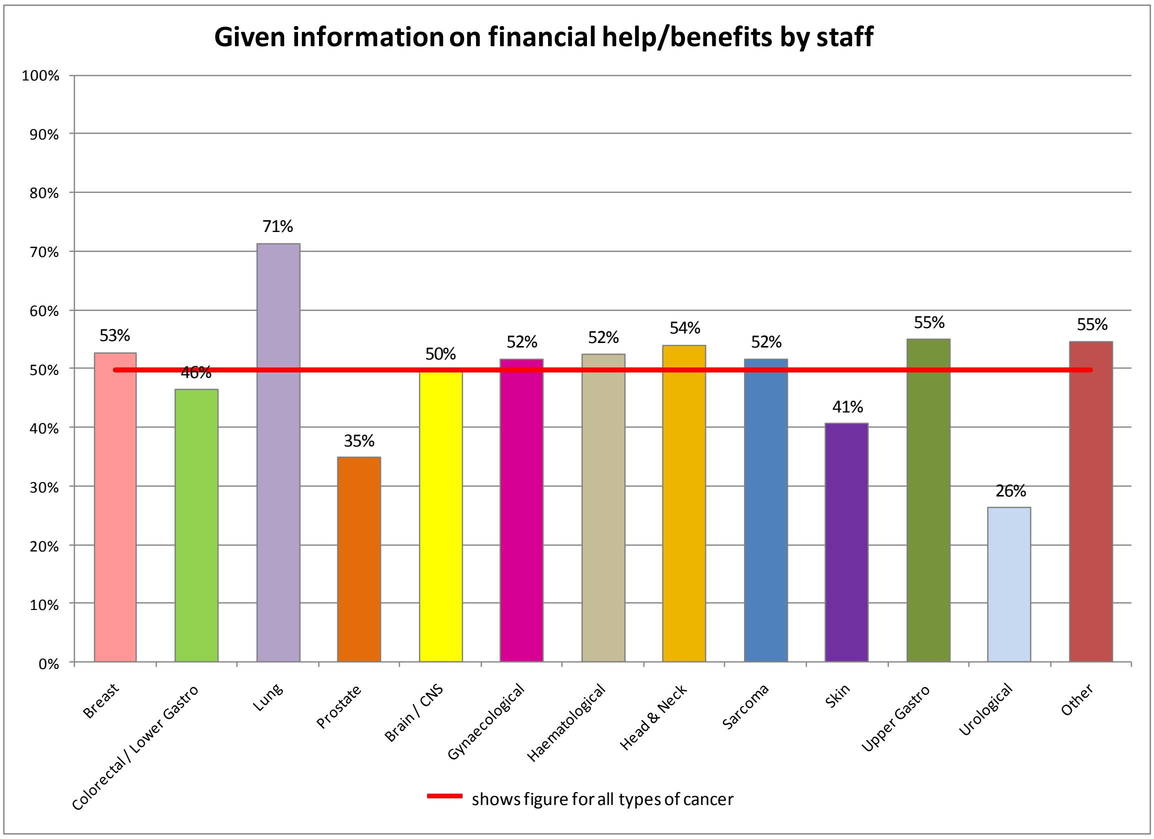

Chart 16 Given information on financial help

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had been given information about how to get financial help or benefits. Scores in Trusts ranged from 24% as the lowest score to 74% as the highest Trust score.

The 20th percentile threshold is 42%; the 80th percentile threshold is 58%.

27. Free prescriptions

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

Overall Findings

Of those patients who said it was necessary, 68% said that hospital staff had told them that they could get free prescriptions. 32% said they did not get this information but would have liked it.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying hospital staff had told them that they could get free prescriptions. Scores ranged from 80% (lung cancer) to 45% (skin cancer).

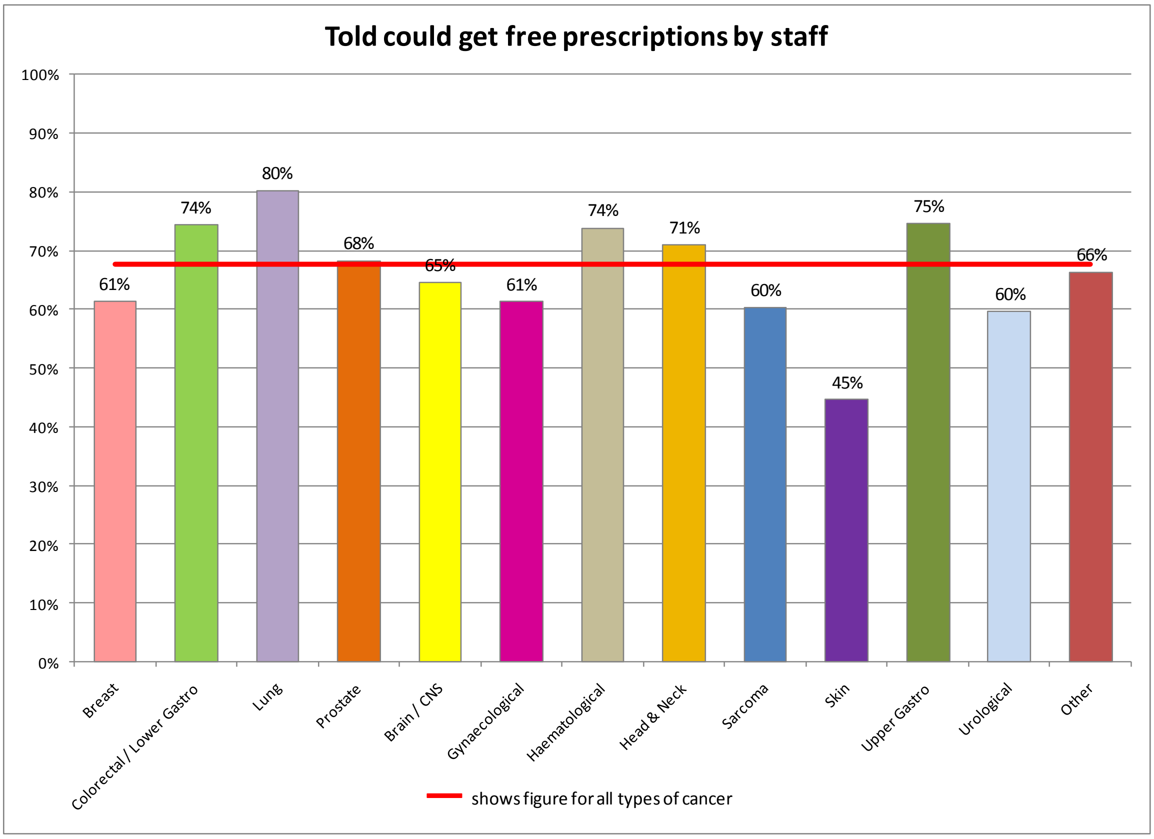

Chart 17 Told could get free prescriptions

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying hospital staff had told them that they could get free prescriptions. Scores in Trusts ranged from 30% as the lowest score to 92% as the highest Trust score.

The 20th percentile threshold is 63%; the 80th percentile threshold is 74%.

Operations

This section describes the views of patients' having operations about changes to admission dates, and the explanations and information given to them about their operation.

28. Patients having operations

During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?

Overall Findings

57% of patients said that they had had an operation such as removal of a tumour or lump during the last 12 months.

29. Changes to admission dates

The last time you went into hospital for a cancer operation, was your admission date changed to a later date by the hospital?

Overall Findings

89% of patients having an operation said that their admission date was not changed by the hospital to a later date; 9% said that it was changed once and 1% said it was changed twice or more.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying their admission date was not changed. Scores ranged from 94% (breast cancer) to 82% (prostate cancer).

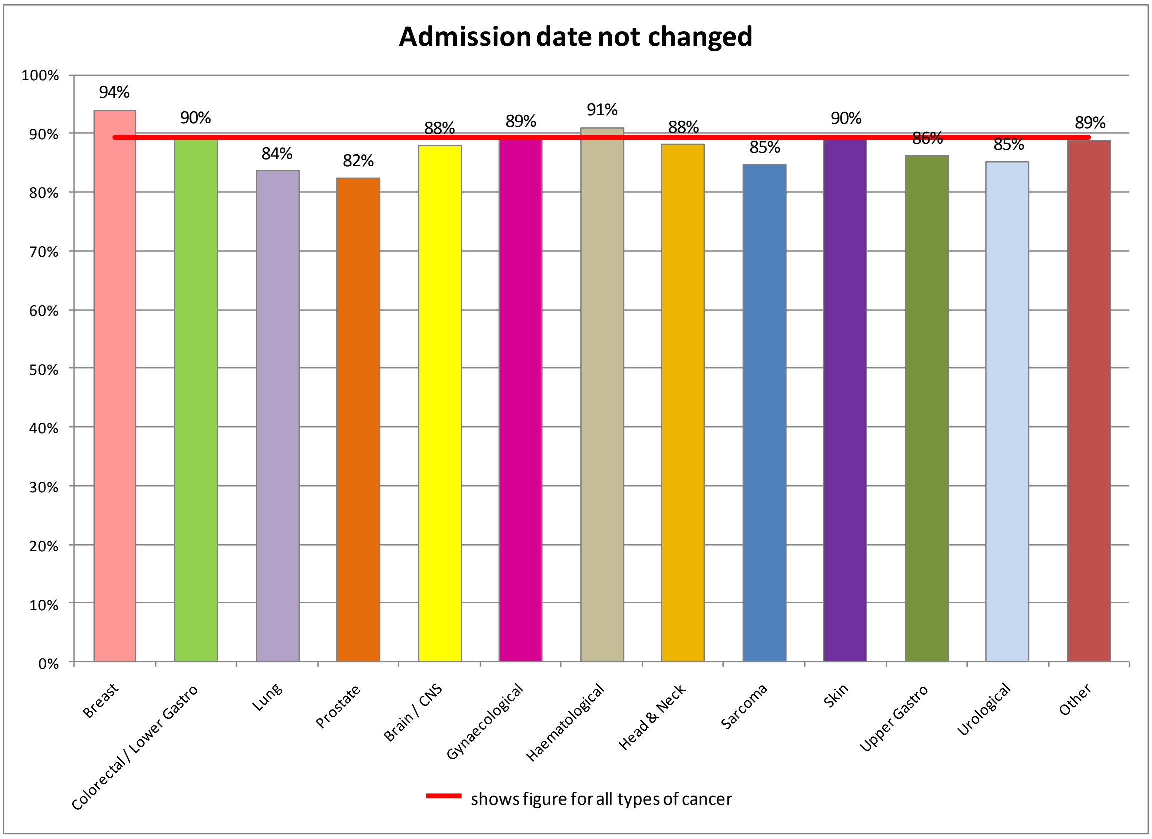

Chart 18 Admission date not changed

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying their admission date was not changed. Scores in Trusts ranged from 76% as the lowest score to 99% as the highest Trust score.

The 20th percentile threshold is 87%; the 80th percentile threshold is 92%.

30. Explanations of what would be done during the operation

Before you had your operation, did a member of staff explain what would be done during the operation?

Overall Findings

Of those patients who said they needed an explanation of what would be done during their operation, 85% said a member of staff explained completely; a further 14% said staff explained to some extent. 2% said staff did not explain but that they would have liked an explanation.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that overall the differences are not significant.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying a member of staff explained completely. Scores in Trusts ranged from 70% as the lowest score to 93% as the highest Trust score.

The 20th percentile threshold is 81%; the 80th percentile threshold is 87%.

31. Written information about the operation

Beforehand, were you given written information about your operation?

Overall Findings

68% of patients overall said they were given written information about their operation and that it was easy to understand; 3% were given written information but said it was difficult to understand. 29% said they were not given written information.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were given easy to understand written information. Scores ranged from 79% (prostate cancer) to 43% (sarcoma).

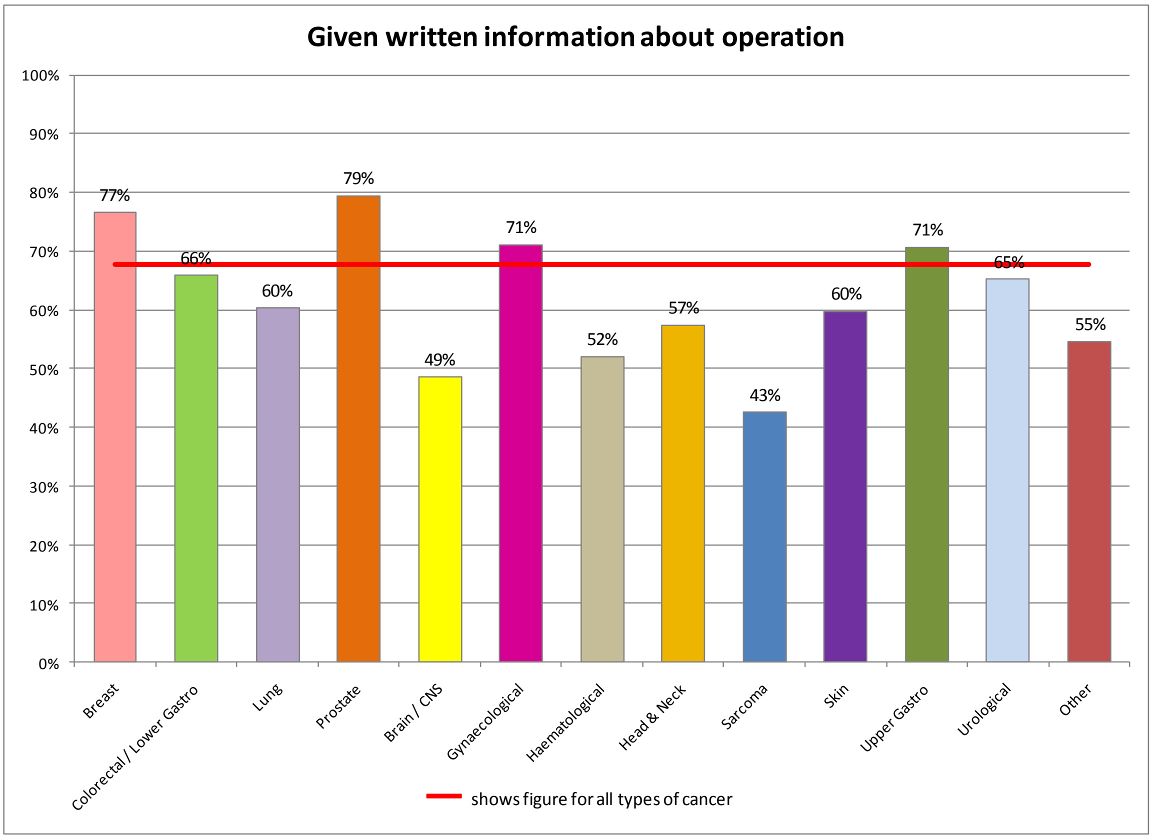

Chart 19 Given written information about operation

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were given easy to understand written information. Scores in Trusts ranged from 13% as the lowest score to 91% as the highest Trust score.

The 20th percentile threshold is 62%; the 80th percentile threshold is 73%.

32. Explanations after the operation

After the operation, did a member of staff explain how it had gone in a way you could understand?

Overall Findings

Of those patients who said they needed an explanation, 73% overall said they had received a completely understandable explanation of how the operation had gone from a member of staff; 20% said staff had explained to some extent. 7% did not get an explanation but would have liked one.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that overall the differences are not significant.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had received a completely understandable explanation of how the operation had gone. Scores in Trusts ranged from 58% as the lowest score to 89% as the highest Trust score.

The 20th percentile threshold is 69%; the 80th percentile threshold is 77%.

Hospital doctors

This section describes patients' views about information from hospital doctors, confidence and trust in them by patients, and on patients' views about doctors' knowledge and attitude.

The questions in this section were aimed at patients who had had an operation or stayed overnight in hospital for cancer care not day case or outpatients.

33. Patients having operations or staying overnight

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

Overall Findings

69% of patients said they had had an operation or stayed overnight for cancer care during the last 12 months.

34. Asking doctors important questions

When you had important questions to ask a doctor, how often did you get answers that you could understand?

Overall Findings

Of those patients who had important questions to ask doctors, 81% overall said doctors gave them answers they could understand all or most of the time; 17% said the answers were understandable only some of the time and a further 2% said they rarely or never got answers they could understand.

Findings by Tumour Group

There was some variation between cancer types in the 2010 survey data but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying doctors gave them answers they could understand. Scores in Trusts ranged from 68% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 77%; the 80th percentile threshold is 85%.

35. Confidence and trust in doctors

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

Overall Findings

84% of patients said they had confidence and trust in all of the doctors treating them; 16% said they had confidence and trust in some of them. A small number of patients said they had confidence and trust in none of them.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had confidence and trust in all of the doctors. Scores in Trusts ranged from 74% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 80%; the 80th percentile threshold is 88%.

36. Doctors knowledge of treating cancer

Do you think the doctors treating you knew enough about how to treat your cancer?

Overall Findings

89% of patients overall said that the doctor definitely did know enough; 10% said they did so to some extent. 1% said they did not think that the doctors treating them knew enough.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying that doctors definitely knew enough about treating their cancer. Scores ranged from 94% (skin cancer) to 76% (other cancers).

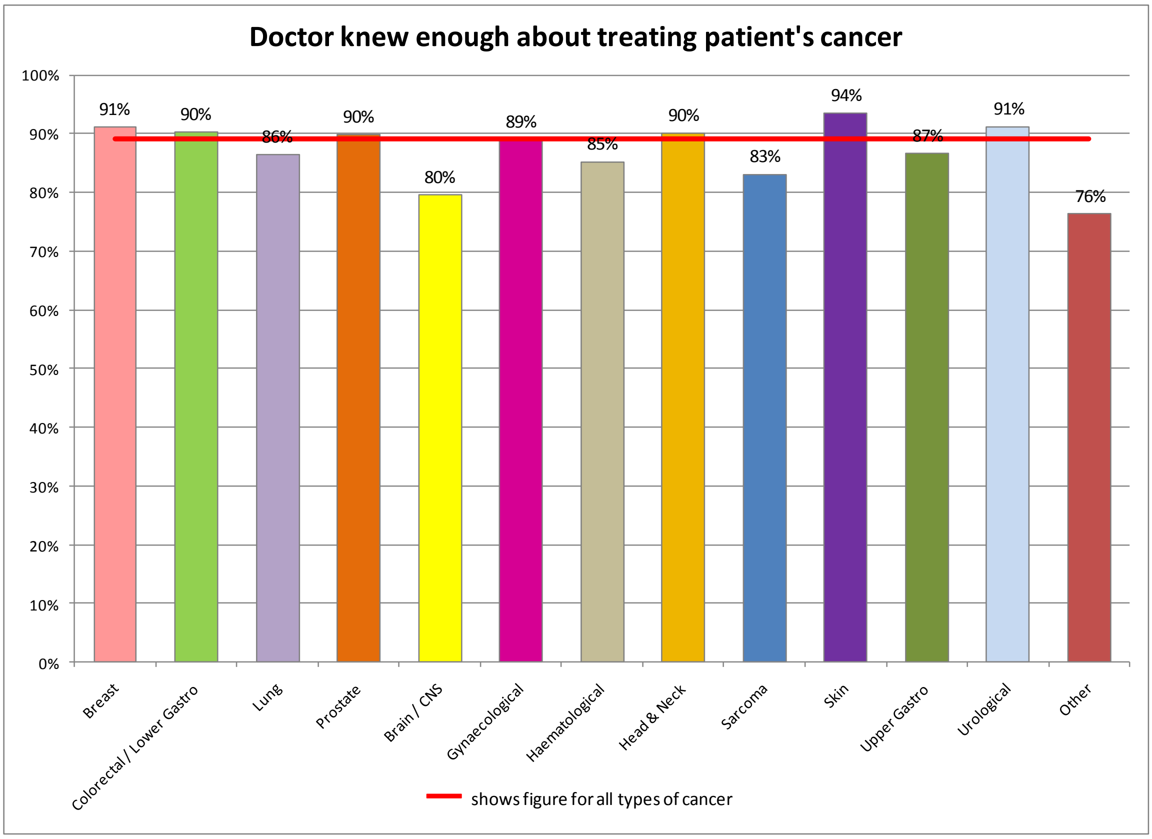

Chart 20 Doctor knew enough about patient's cancer

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying that the doctor definitely did know enough. Scores in Trusts ranged from 79% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 87%; the 80th percentile threshold is 92%.

37. Talking in front of patients

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

Overall Findings

83% of patients said doctors did not talk in front of them as if they were not there. 14% said that they sometimes did and a further 3% said that they often did.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying doctors did not talk in front of them as if they were not there. Scores ranged from 88% (breast cancer) to 78% (upper gastrointestinal cancer).

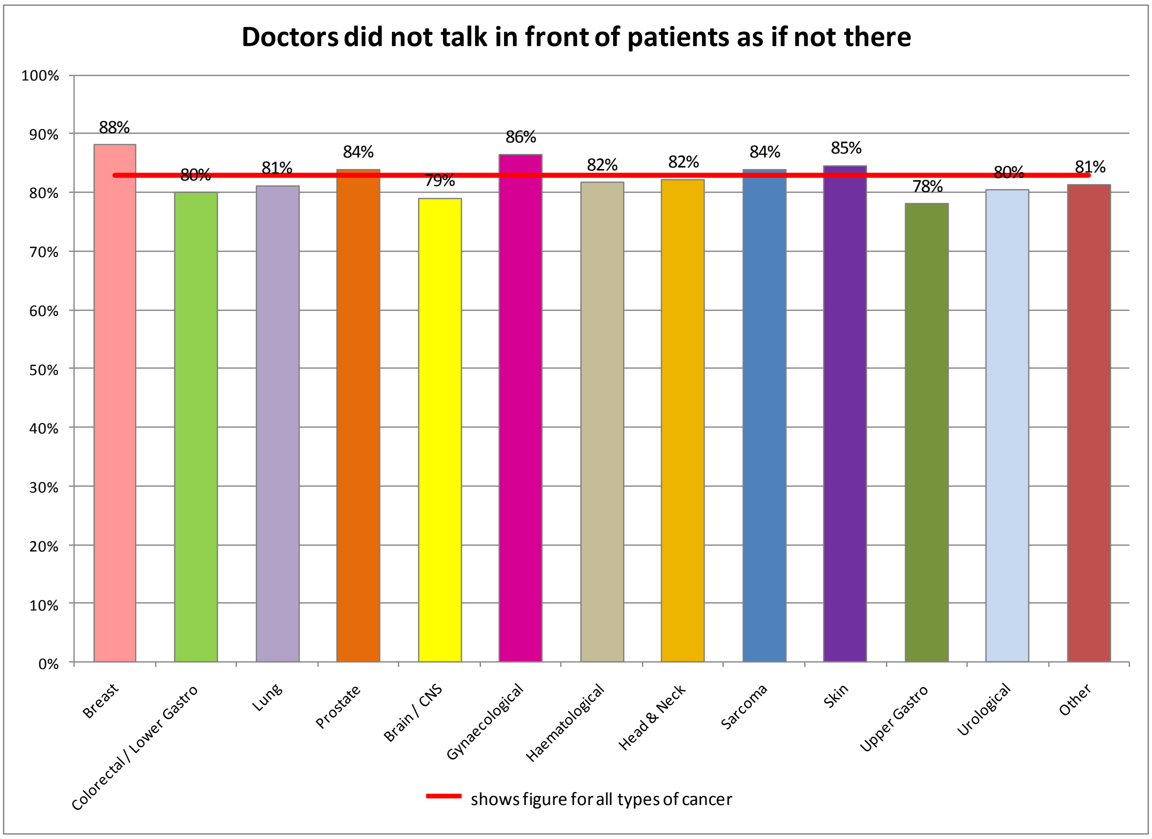

Chart 21 Doctors did not talk in front of patients as if not there

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying doctors did not talk in front of them as if they were not there. Scores in Trusts ranged from 65% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 79%; the 80th percentile threshold is 86%.

38. Family able to talk to doctor

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

Overall Findings

Of those patients saying they had family or someone close to them who might want to talk to a doctor, 66% said their family or someone close to them definitely had enough opportunity to do so; a further 27% said they did so to some extent. 7% said they did not have enough opportunity to talk to a doctor.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying their family or someone close to them definitely had enough opportunity to talk to a doctor. Scores ranged from 74% (skin cancer) to 59% (urological cancer).

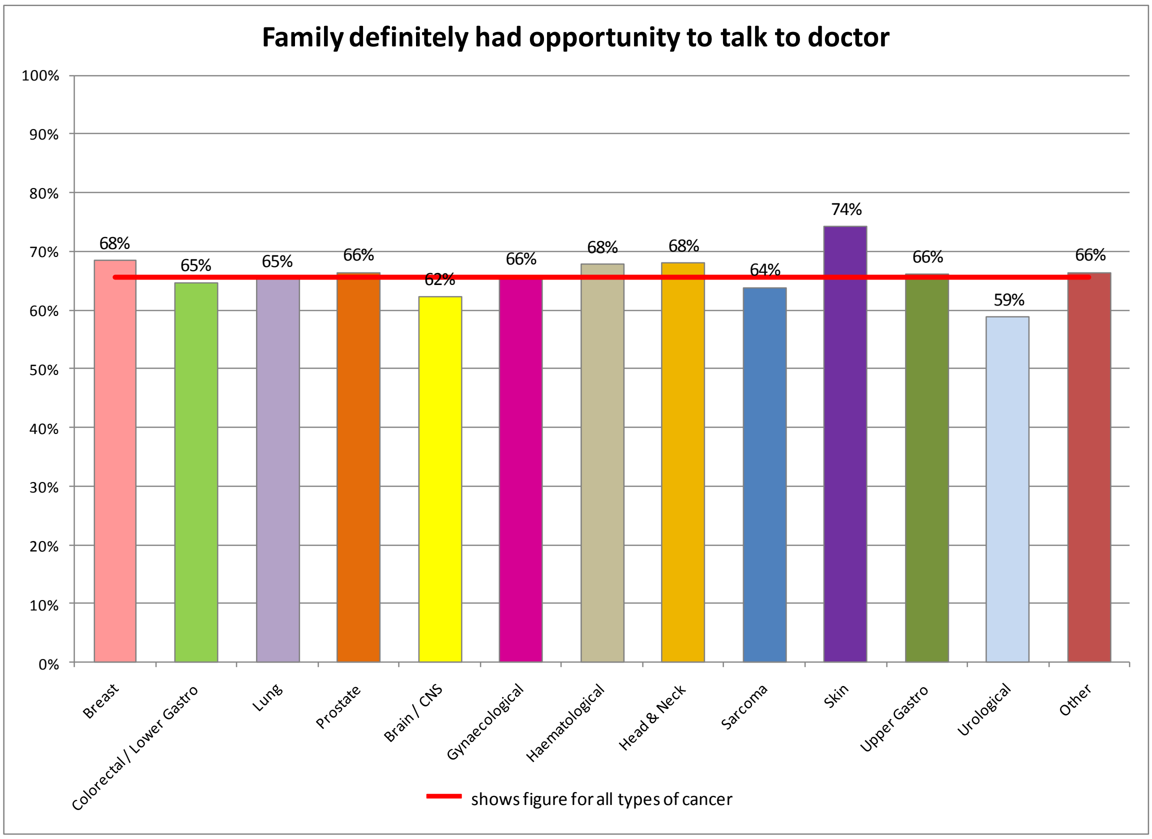

Chart 22 Family had opportunity to talk to doctor

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying their family or someone close to them definitely had enough opportunity to talk to a doctor. Scores in Trusts ranged from 53% as the lowest score to 87% as the highest Trust score.

The 20th percentile threshold is 61%; the 80th percentile threshold is 70%.

Patient views

Breast: "I felt assured that my consultant was contactable by email whenever I may have had a question. He also made sure my appointments with him were not rushed which made me feel assured that I was getting very good care."

Ward nurses

This section describes patients' views about information from ward nurses, confidence and trust in nurses, nurses' attitude, and levels of nursing care on hospital wards.

The questions in this section were targeted at patients who had had an operation or stayed overnight in hospital for cancer care and not day case or outpatients who did not stay overnight.

39. Understanding ward nurses answers to important questions

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

Overall Findings

Of those patients who had important questions to ask a ward nurse, 73% overall said nurses gave them answers they could understand all or most of the time; 23% said they gave understandable answers some of the time and a further 4% said they rarely or never got answers they could understand.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying nurses gave them answers they could understand all or most of the time. Scores in Trusts ranged from 48% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 67%; the 80th percentile threshold is 78%.

40. Confidence and trust in ward nurses

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

Overall Findings

66% of patients said they had confidence and trust in all the ward nurses treating them; 33% said they had confidence and trust in some of them and 1% said they had confidence and trust in none of them.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they had confidence and trust in all of the ward nurses. Scores ranged from 78% (skin cancer) to 62% (brain / CNS cancer).

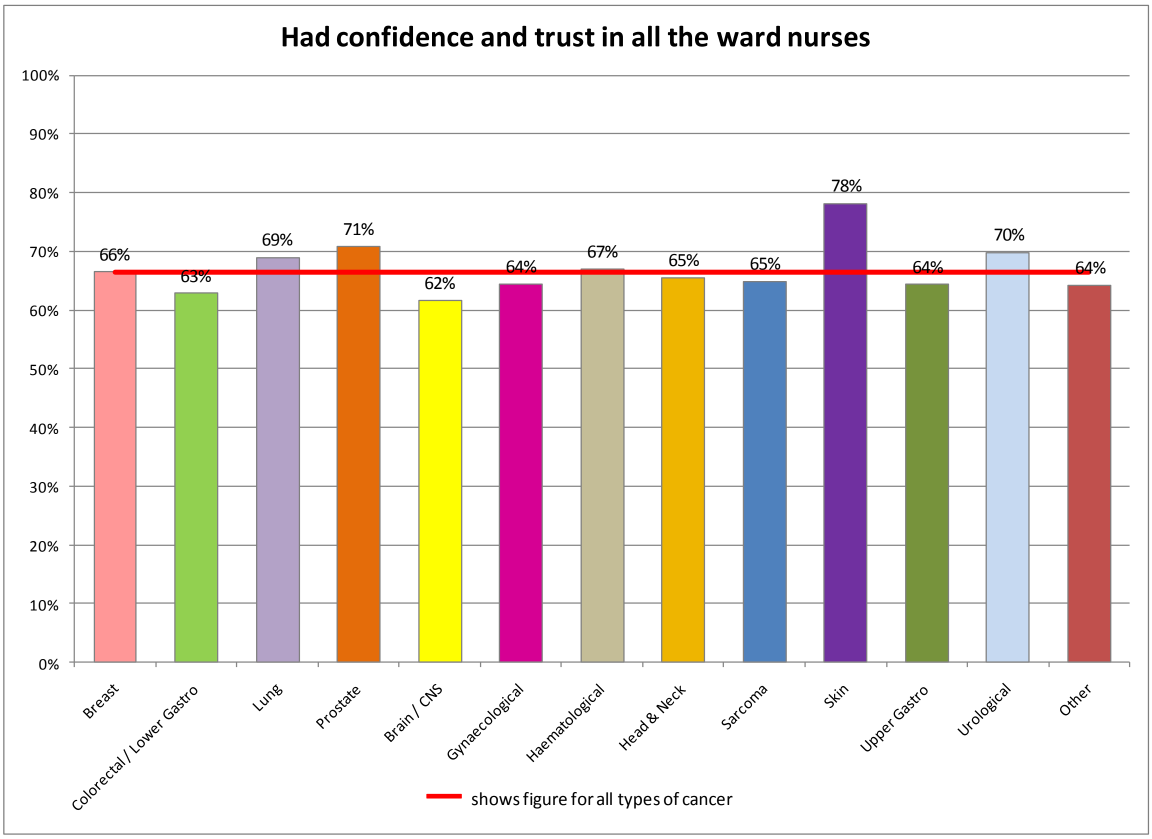

Chart 23 Had confidence and trust in ward nurses

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had confidence and trust in all of the ward nurses. Scores in Trusts ranged from 50% as the lowest score to 90% as the highest Trust score.

The 20th percentile threshold is 61%; the 80th percentile threshold is 72%.

41. Talking in front of patients

Did ward nurses talk in front of you as if you weren't there?

Overall Findings

83% of patients said nurses did not talk in front of them as if they were not there; 14% said that they sometimes did and a further 3% said they often did.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying nurses did not talk in front of them as if they were not there. Scores in Trusts ranged from 62% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 79%; the 80th percentile threshold is 87%.

42. Enough nurses on duty

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

Overall Findings

Overall, 62% of patients said there were always or nearly always enough nurses on duty to care for them in hospital; 29% said that there were sometimes enough on duty and a further 9% said there were rarely or never enough on duty.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying there were always or nearly always enough nurses on duty. Scores ranged from 78% (skin cancer) to 57% (other cancers).

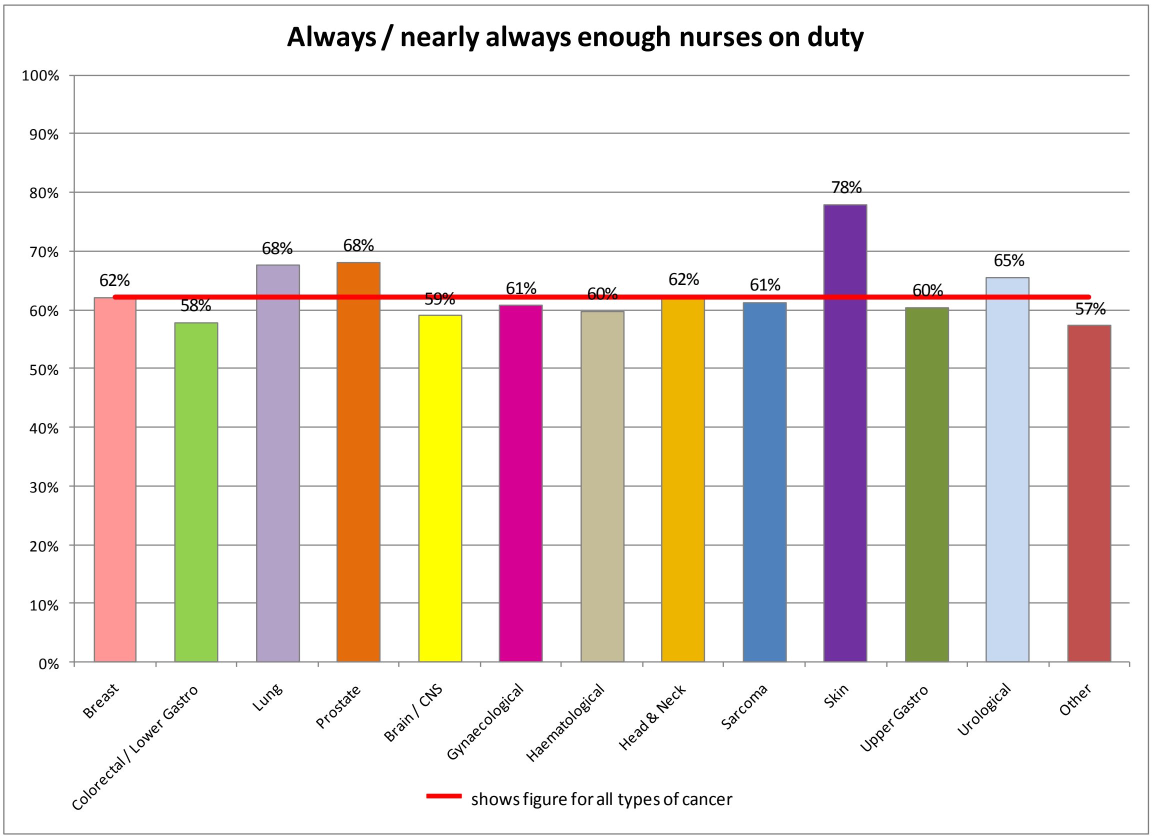

Chart 24 Enough nurses on duty

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying there were always or nearly always enough nurses on duty. Scores in Trusts ranged from 30% as the lowest score to 89% as the highest Trust score.

The 20th percentile threshold is 57%; the 80th percentile threshold is 68%.

Patient views

Gynaecological: "Staffing levels need to be improved. Some nights there was only 1 nurse on for at least 10 patients, it's not fair on the nurse or the patients."

Hospital care and treatment

This section describes patients' views about missing or conflicting information, privacy, respect and dignity, and pain control.

The questions in this section were targeted at patients who had had an operation or stayed overnight in hospital for cancer care and not day case or outpatients who did not stay overnight.

43. Not being told things

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?

Overall Findings

87% of patients said that they never thought that doctors or nurses were deliberately not telling them certain things that they wanted to know; 12% said they only once or sometimes thought they were and a further 1% said they often thought they were.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying that they never thought that doctors or nurses were deliberately not telling them certain things that they wanted to know. Scores in Trusts ranged from 71% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 84%; the 80th percentile threshold is 89%.

44. Conflicting information

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?

Overall Findings

79% of patients said that it was never the case that one doctor or nurse said one thing about their condition or treatment and another said something different; 7% said this happened only once, 12% said it happened sometimes and 2% said it happened often.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying that it was never the case that one doctor or nurse said one thing about their condition or treatment and another said something different. Scores ranged from 85% (skin cancer) to 73% (brain / CNS and sarcoma).

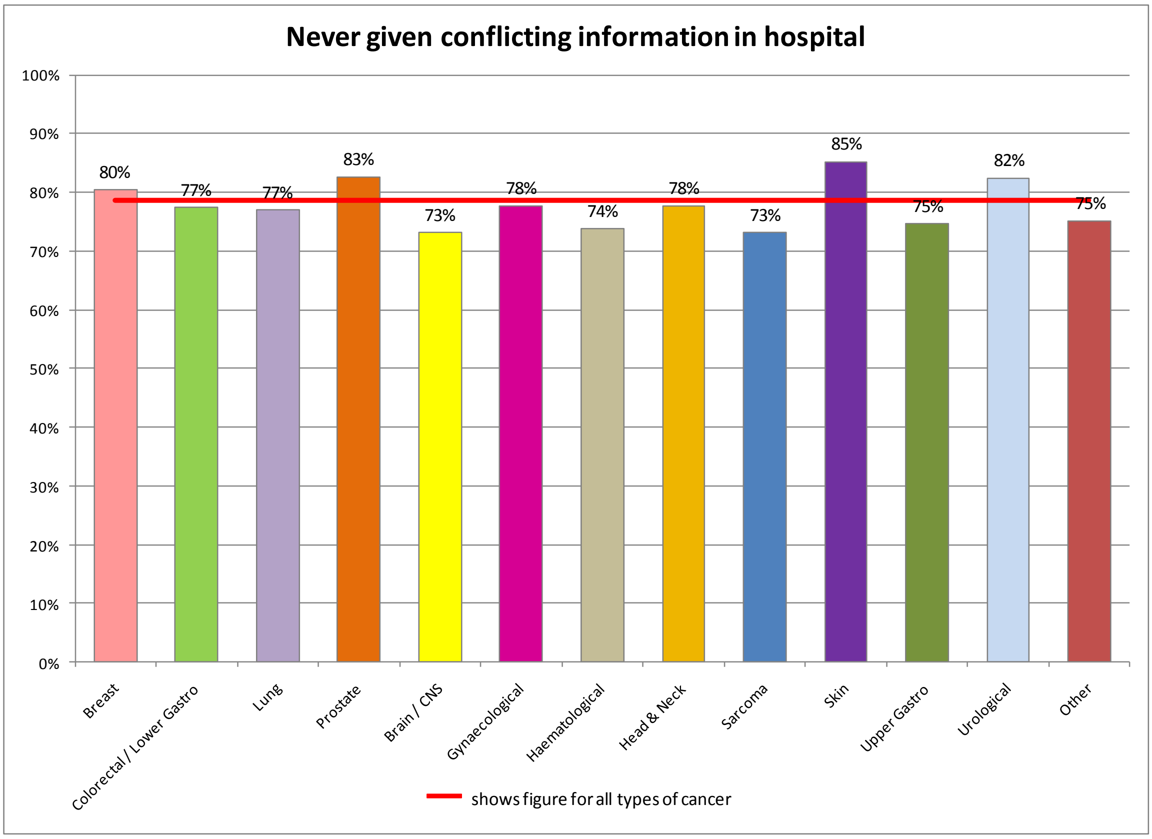

Chart 25 Never given conflicting information

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying it was never the case that one doctor or nurse said one thing about their condition or treatment and another said something different. Scores in Trusts ranged from 66% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 76%; the 80th percentile threshold is 82%.

45. Privacy discussing condition or treatment

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

Overall Findings

82% of patients overall said that they always had enough privacy when discussing their condition or treatment; a further 13% said they sometimes did. 5% said they did not have enough privacy.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they always had enough privacy. Scores in Trusts ranged from 72% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 80%; the 80th percentile threshold is 86%.

46. Privacy when being examined or treated

Were you given enough privacy when being examined or treated?

Overall Findings

93% of patients overall said that they always had enough privacy when being examined or treated; a further 6% said they sometimes did. 1% said they did not have enough privacy.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they always had enough privacy. Scores in Trusts ranged from 83% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 91%; the 80th percentile threshold is 95%.

47. Control of Pain

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

Overall Findings

85% of those patients saying they had pain said that staff did everything they could to help control it all of the time; 14% said they did so some of the time. 1% said they did not do everything they could.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying staff did everything they could to help control their pain. Scores in Trusts ranged from 71% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 82%; the 80th percentile threshold is 87%.

48. Treated with respect and dignity

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

Overall Findings

82% of patients overall said that they were always treated with respect and dignity by staff and a further 15% said they were most of the time. 3% said they were treated with respect and dignity some of the time or never were.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were always treated with respect and dignity. Scores in Trusts ranged from 65% as the lowest score to 96% as the highest Trust score.

The 20th percentile threshold is 78%; the 80th percentile threshold is 86%.

Patient views

Brain / central nervous system: "The NHS team were excellent. They answered all my questions with sympathy and expertise. At no time did I feel a nuisance or trouble. I was seen quickly and was treated professionally. I felt safe in their hands."

Brain / central nervous system: "At times pain control was very poor. The pain control nurses were good but do not work/cover weekends or out of hours."

Information before leaving and home support

This section describes the patients' views about various elements of information given to them before they left hospital and levels of home support given.

The questions in this section were targeted at patients who had had an operation or stayed overnight in hospital for cancer care and not day case or outpatients who did not stay overnight.

49. Written information about what should or should not be done

Were you given clear written information about what you should or should not do after leaving hospital?

Overall Findings

82% of patients overall said that they were given clear written information about what they should or should not do after leaving hospital; 18% said they were not given information.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were given written information about what they should or should not do. Scores ranged from 88% (breast cancer) to 74% (sarcoma).

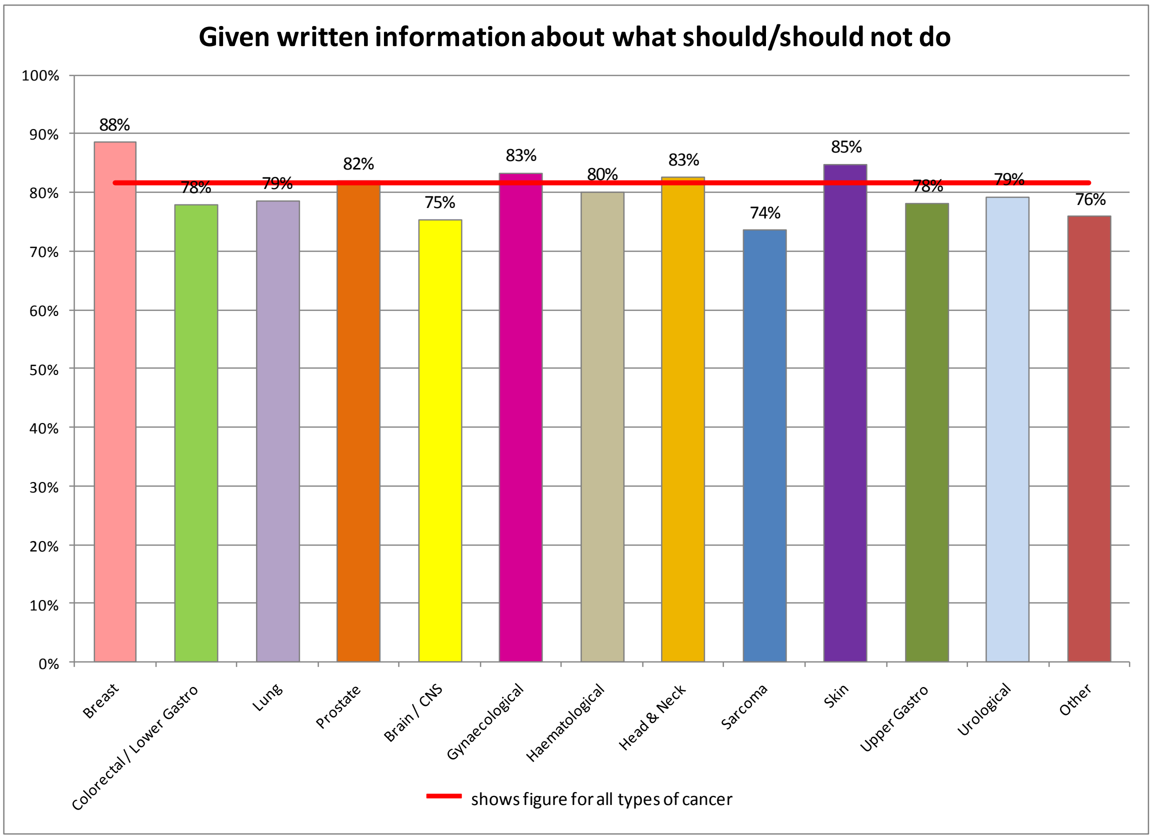

Chart 26 Given written information about what should / should not do

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were given written information about what they should or should not do. Scores in Trusts ranged from 58% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 78%; the 80th percentile threshold is 85%.

50. Told who to contact if worried

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

Overall Findings

92% of patients overall said that hospital staff told them who to contact if they felt worried about their condition or treatment after leaving hospital; 8% said they were not told.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying that hospital staff told them who to contact if they felt worried about their condition or treatment. Scores in Trusts ranged from 81% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 89%; the 80th percentile threshold is 94%.

51. Information for families

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 Findings

Of those patients with family or someone close to them wanting information, 58% said that their family or someone close to them definitely received all the information they needed to help care for them at home; 23% said they did so to some extent. 19% said their family did not get all the information they needed.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying their family or someone close to them definitely received all the information they needed to help care for them at home. Scores ranged from 65% (skin cancer) to 55% (gynaecological and urological cancers).

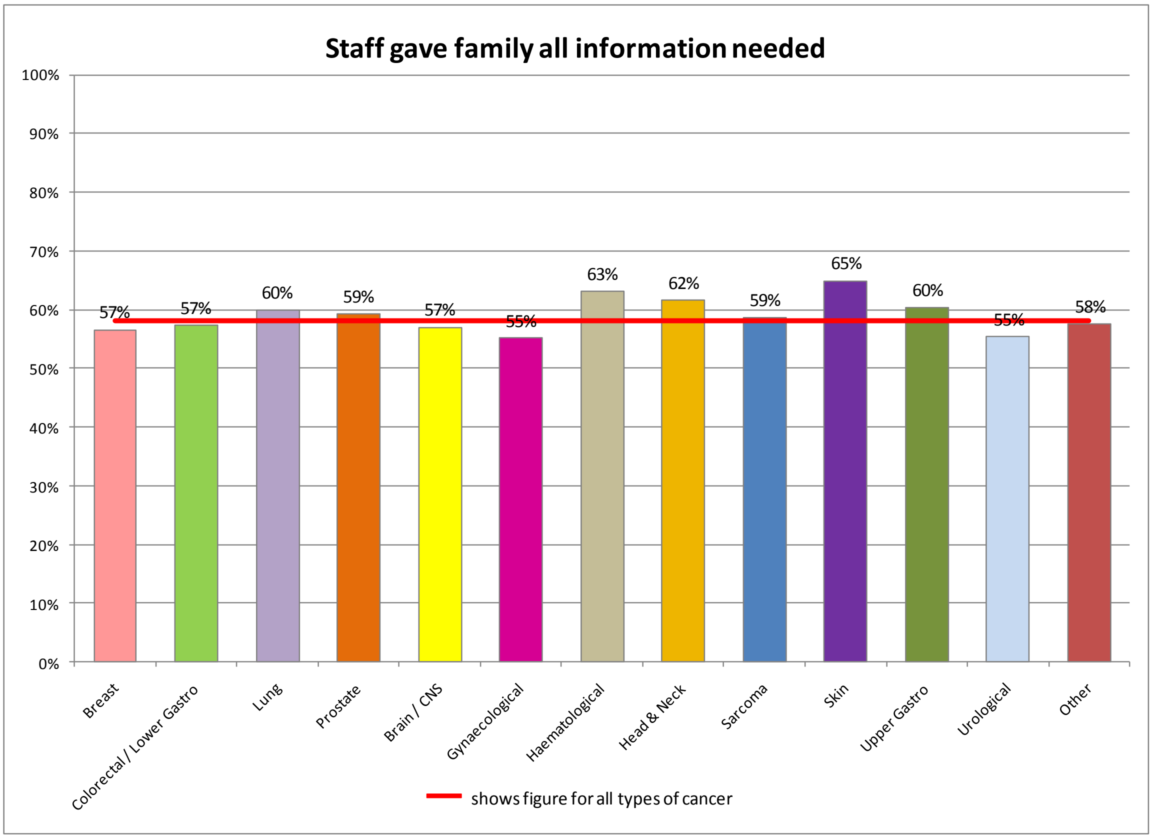

Chart 27 Family given information needed

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying that their family or someone close to them definitely received all the information they needed. Scores in Trusts ranged from 29% as the lowest score to 89% as the highest Trust score.

The 20th percentile threshold is 53%; the 80th percentile threshold is 62%.

52. Home support

After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists?

Overall Findings

Of those patients who said they needed it, 60% said they were definitely given enough care and help from health or social services after leaving hospital; 22% said they were to some extent. 19% said they did not get enough care and help.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were definitely given enough care and help from health or social services. Scores ranged from 67% (colorectal/lower gastrointestinal cancer) to 50% (urological cancer).

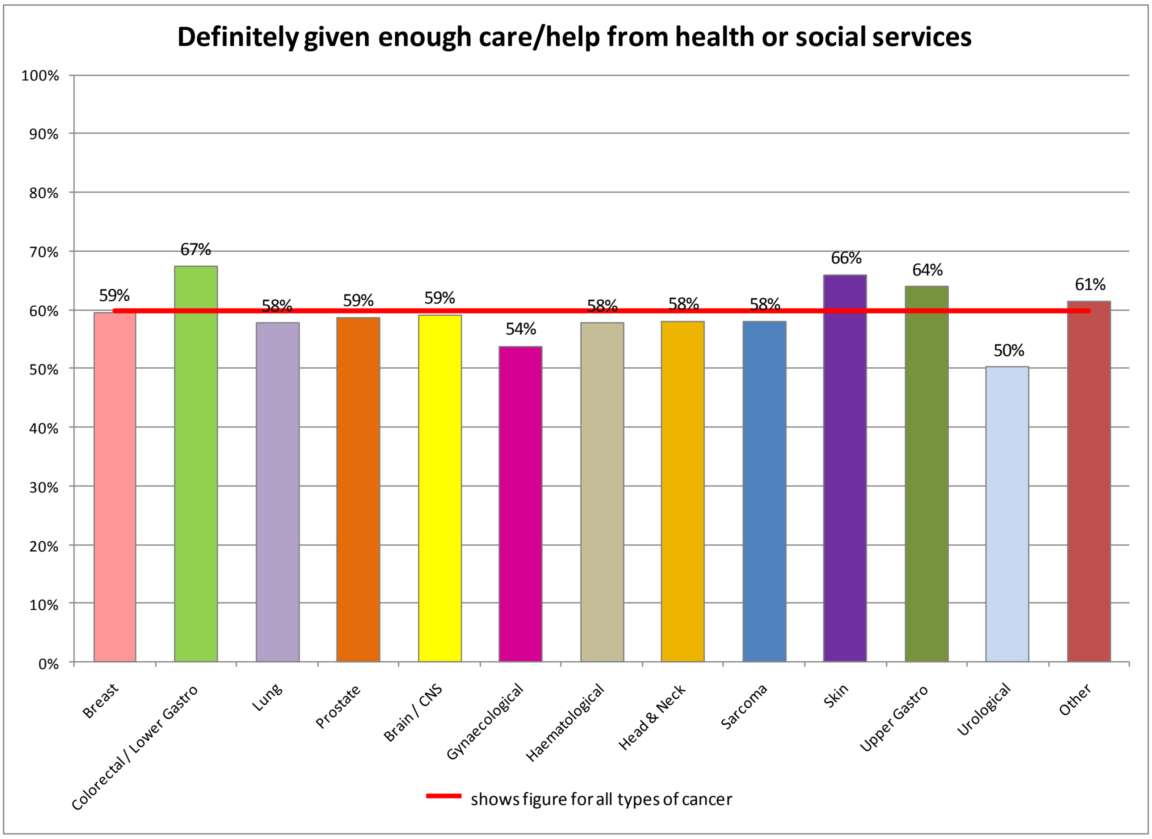

Chart 28 Given enough care from health / social services

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were definitely given enough care and help from health or social services. Scores in Trusts ranged from 27% as the lowest score to 80% as the highest Trust score.

The 20th percentile threshold is 52%; the 80th percentile threshold is 66%.

Day / outpatient care

This section describes the views of day case and outpatients about side effects of radiotherapy and chemotherapy, pain and emotional support.

53. Patients having radiotherapy

During the last 12 months, have you had radiotherapy at one of the hospitals named in the covering letter?

Overall Findings

26% of patients overall said that they had had radiotherapy during the last 12 months.

54. Side effects of radiotherapy

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

Overall Findings

82% of patients having radiotherapy who had side effects said that staff definitely did everything possible to control the side effects of the radiotherapy; 15% said they did so to some extent. 3% said they could have done more.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying staff definitely did everything possible to control the side effects of the radiotherapy. Scores in Trusts ranged from 60% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 78%; the 80th percentile threshold is 86%.

55. Patients having chemotherapy

During the last 12 months, have you had chemotherapy at one of the hospitals named in the covering letter?

Overall Findings

53% of patients overall said that they had had chemotherapy during the last 12 months.

56. Side effects of chemotherapy

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

Overall Findings

85% of patients having chemotherapy who had side effects said that staff definitely did everything possible to control the side effects of the chemotherapy; 13% said they did so to some extent. 2% said they could have done more.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying staff definitely did everything possible to control the side effects of the chemotherapy. Scores in Trusts ranged from 60% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 82%; the 80th percentile threshold is 89%.

57. Control of pain

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

Overall Findings

Of those patients experiencing pain, 83% said that hospital staff definitely did everything they could to help control the pain; 14% said they did so to some extent. 3% said they could have done more to help control the pain.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying hospital staff definitely did everything they could to help control the pain. Scores in Trusts ranged from 65% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 79%; the 80th percentile threshold is 86%.

58. Emotional support

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

Overall Findings

Of those patients needing emotional support, 71% said they were definitely given enough emotional support from hospital staff; 22% said they were to some extent. 7% said they would have liked more support.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were definitely given enough emotional support by staff. Scores ranged from 74% (lung and haematological cancers) to 61% (other cancers).

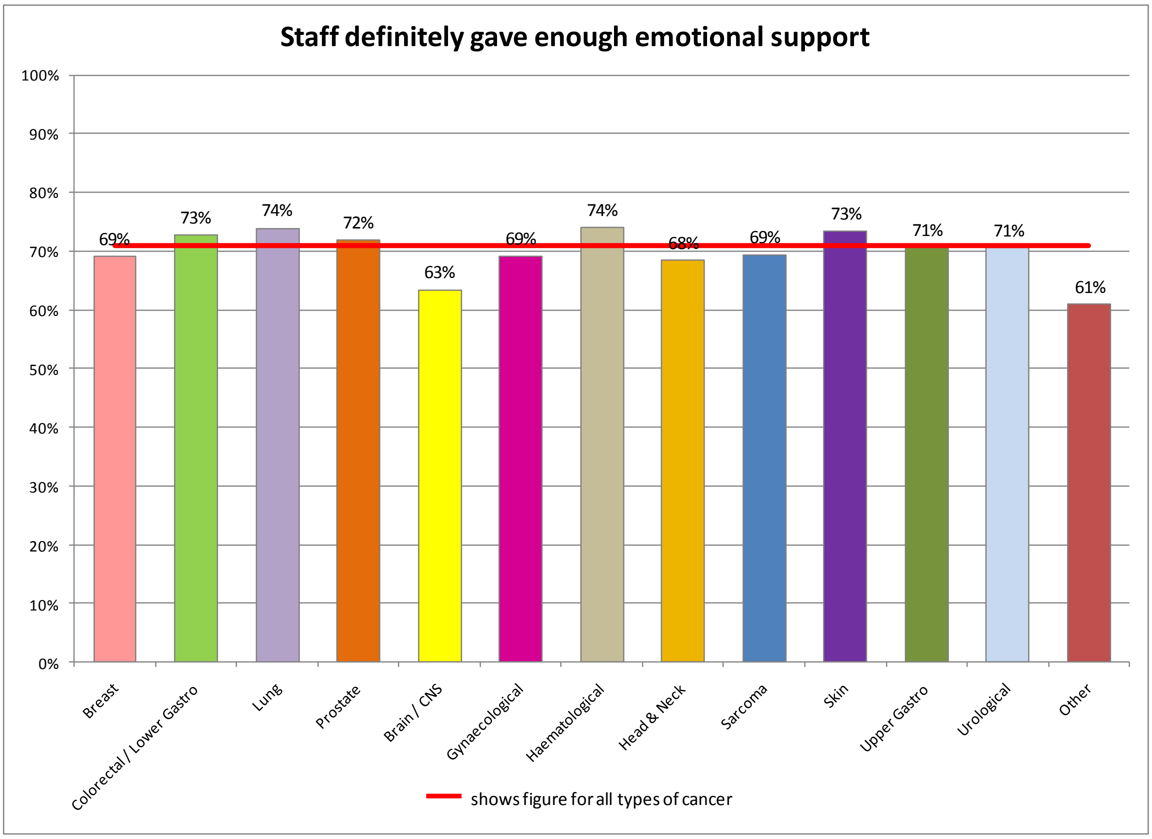

Chart 29 Given enough emotional support

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were definitely given enough emotional support from hospital staff. Scores in Trusts ranged from 56% as the lowest score to 90% as the highest Trust score.

The 20th percentile threshold is 66%; the 80th percentile threshold is 76%.

Patient views

Gynaecological: "The Macmillan nurses were always on hand to answer any questions and chase up any appointments that hadn't come through. I had six weeks of daily radiotherapy and they were superb. Just their friendly attitudes went a long way with the tiring treatment I had. They always checked how things were going and how you were feeling and always told you what they were doing."

Colorectal / lower gastrointestinal: "The emotional support available appears to be virtually non-existent. Thankfully I have now discovered "Beating Bowel Cancer," who have been marvellous and ensured that I have stayed positive."

Outpatient appointments

This section describes outpatients' views about appointments with cancer doctors.

59. Having outpatient appointments

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 Findings

93% of patients overall said that they had had an outpatients appointment with a cancer doctor in the last 12 months.

60. Appointment start times

The last time you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?

Overall Findings

68% of patients said they were seen early or within 30 minutes of their stated appointment time. Of this group, 18% were seen on time or early, 8% waited up to 5 minutes, 20% waited 6 to 15 minutes, and 22% waited 16 to 30 minutes.

19% waited 31 minutes to an hour, 11% waited 1 to 2 hours and 3% waited more than 2 hours.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they waited 30 minutes or less for their appointment to start. Scores ranged from 76% (urological cancer) to 61% (haematological cancer and sarcoma).

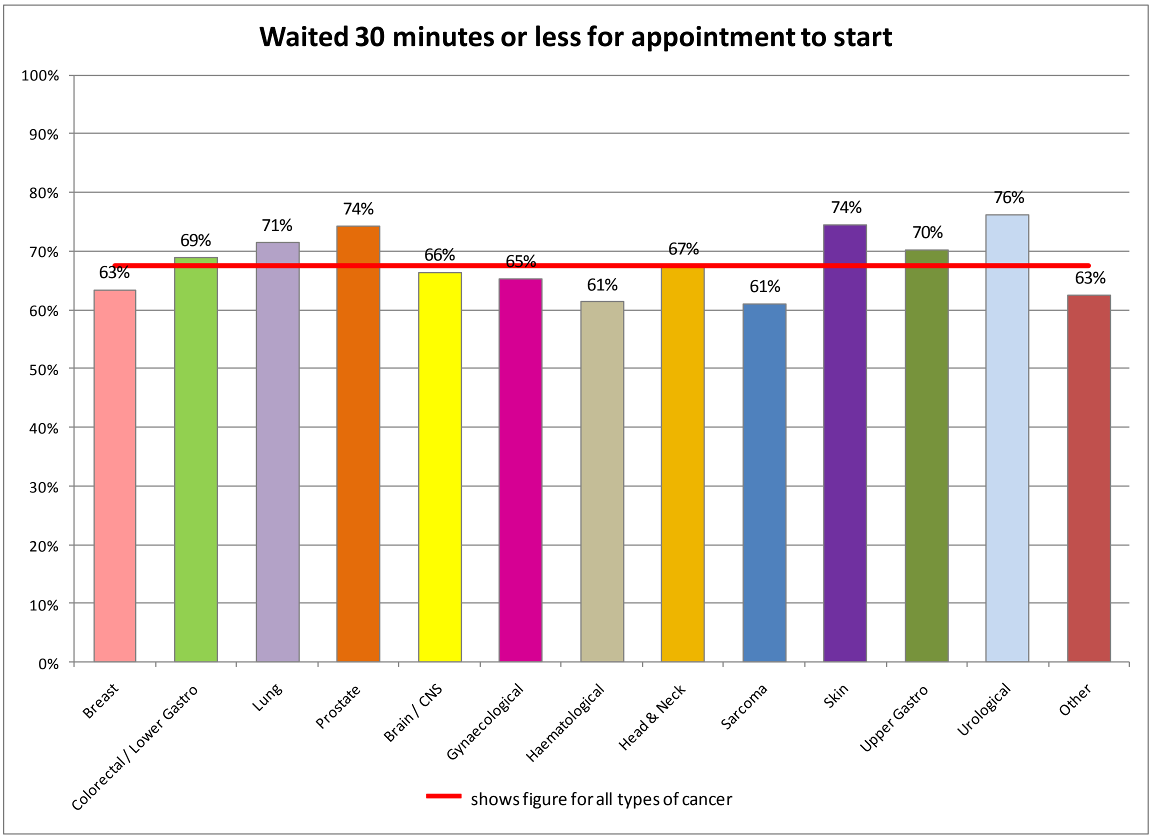

Chart 30 Waited 30 mins or less for appointment to start

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were seen early or within 30 minutes. Scores in Trusts ranged from 32% as the lowest score to 91% as the highest Trust score.

The 20th percentile threshold is 61%; the 80th percentile threshold is 77%.

61. Time spent with the doctor

The last time you had an outpatients appointment with a cancer doctor, was the time you spent with them too long, too short or about right?

Overall Findings

Patients were asked if the time spent by the cancer doctor with them was too long, too short or about right. 94% said the time spent was about right; 6% said the time was too short. A small number of patients said the time spent was too long.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying the time spent was about right. Scores in Trusts ranged from 83% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 92%; the 80th percentile threshold is 95%.

62. Doctor having right documentation

The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?

Overall Findings

95% of patients overall said that the cancer doctor had the right documents (e.g. medical notes, x-rays etc) the last time they had an appointment; 5% said that the doctor did not have the right documents.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying that the cancer doctor had the right documents. Scores in Trusts ranged from 85% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 93%; the 80th percentile threshold is 97%.

Care from general practices

This section describes the patients' views about information given to GPs and support from GPs and nurses.

63. Information given to GP by hospital

As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?

Overall Findings

93% of patients said that, as far as they knew, their GP was given enough information about their condition and treatment by the hospital; 7% said they were not given enough information.

20% of patients (who were excluded from the above calculations) said they did not know or could not remember, in answer to this question.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying their GP was given enough information. Scores in Trusts ranged from 82% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 91%; the 80th percentile threshold is 96%.

64. Support from general practice staff

Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?

Overall Findings

Of those patients who said their general practice was involved in their care, 69% said that GPs and nurses definitely did everything they could to support them whilst they were having cancer treatment; 22% said they did to some extent and 10% said they could have done more. 31% said their general practice was not involved.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying the staff at their general practice definitely did everything they could to support them. Scores ranged from 73% (prostate cancer) to 60% (other cancers).

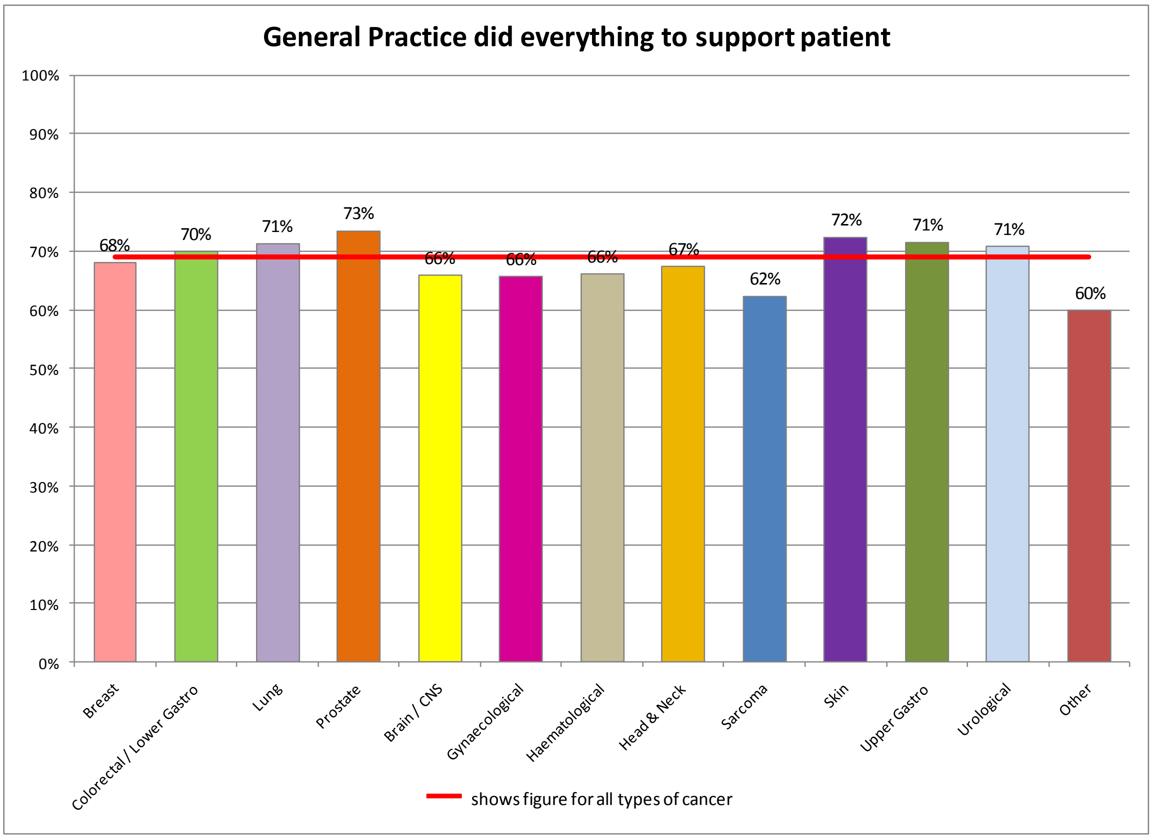

Chart 31 GP did everything to support patient

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying GPs and nurses definitely did everything they could to support them. Scores in Trusts ranged from 51% as the lowest score to 86% as the highest Trust score.

The 20th percentile threshold is 64%; the 80th percentile threshold is 74%.

Patient views

Breast: “The district nurses didn't seem to know how to treat me. In the end I had to drive to their offices for treatment - as they kept on cancelling my appointments. Sometimes I would be the only patient waiting but could wait for a while to be seen to. A bit of training in possibilities with cancer patients wouldn't go amiss.”

Overall NHS care

This section describes the patients' views about staff working well together, information given and if they felt treated as a whole person.

65. Hospital and community staff working well together

Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?

Overall Findings

61% of patients said that the different people treating and caring for them always worked well together to give the best possible care; a further 29% said they did so most of the time. 8% said they only did so some of the time and 1% said they never did.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying that the different people treating and caring for them always worked well together. Scores ranged from 68% (skin cancer) to 54% (brain / CNS and sarcoma).

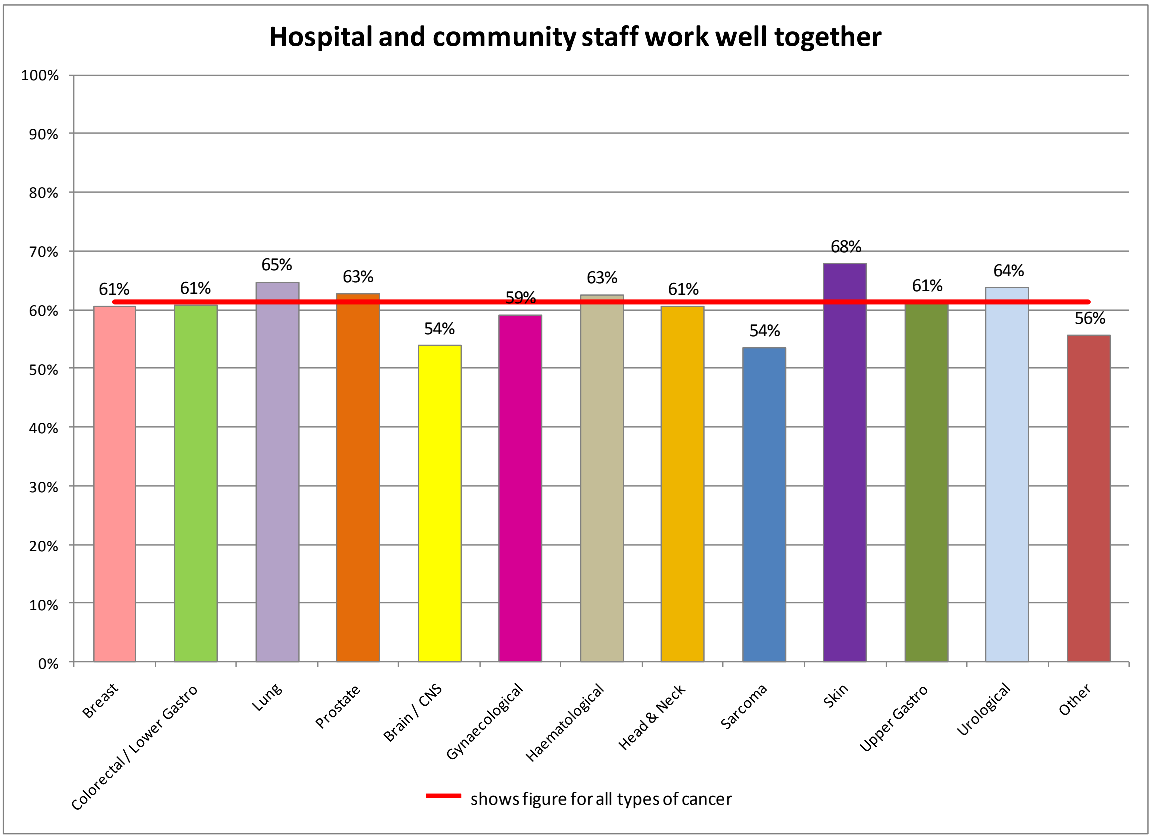

Chart 32 Staff worked well together

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying all staff always worked well together. Scores in Trusts ranged from 38% as the lowest score to 78% as the highest Trust score.

The 20th percentile threshold is 57%; the 80th percentile threshold is 67%.

66. Information about condition and treatment

How much information were you given about your condition and treatment?

Overall Findings

88% of patients overall said that they were given the right amount of information about their condition and treatment; 11% said they were not given enough and 1% said they were given too much.

Findings by Tumour Group

There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were given the right amount of information. Scores in Trusts ranged from 75% as the lowest score to 96% as the highest Trust score.

The 20th percentile threshold is 86%; the 80th percentile threshold is 90%.

67. Treated as a whole person

Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year, did you feel like that?

Overall Findings

80% of patients said that they did not feel that they were treated as ‘a set of symptoms’ rather than a whole person over the last year; 16% said they sometimes felt this and 4% said they often felt this way.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying that the different people treating and caring for them always worked well together. Scores ranged from 87% (skin cancer) to 74% (other cancers).

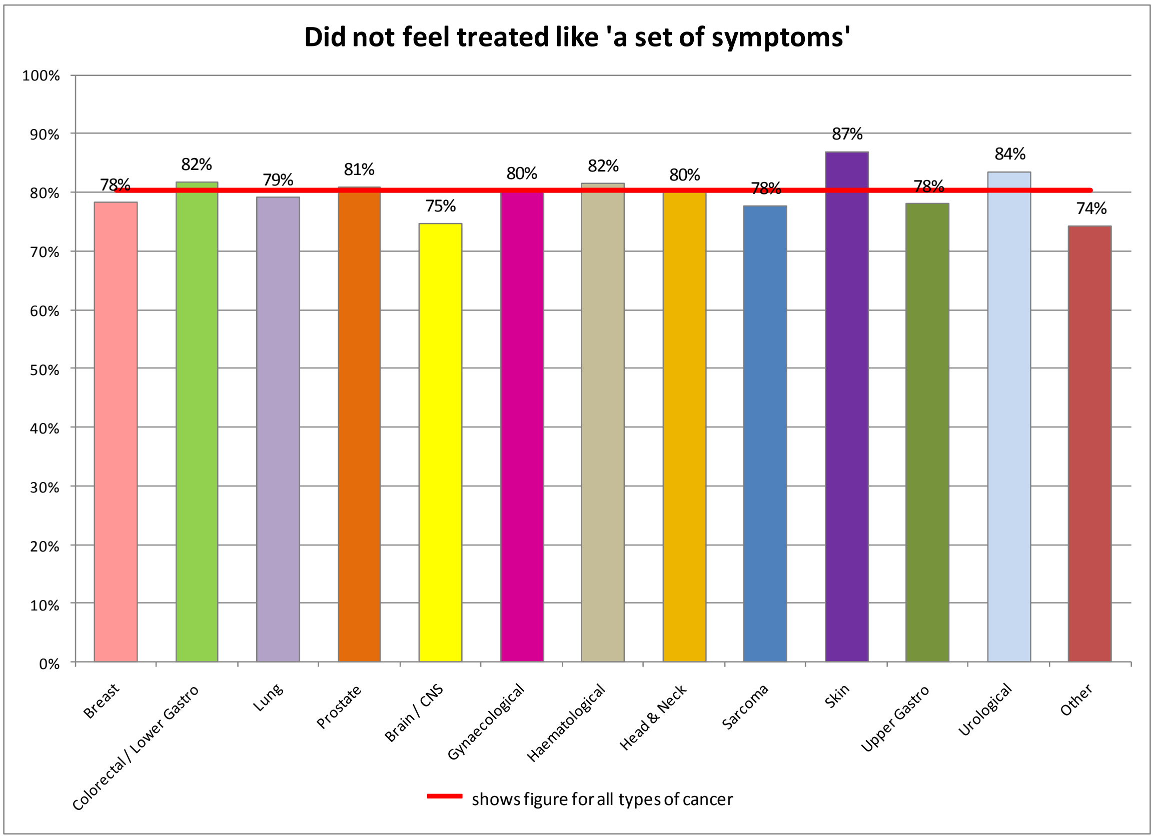

Chart 33 Did not feel treated like a set of symptoms

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they did not feel that they were treated as ‘a set of symptoms’ rather than a whole person. Scores in Trusts ranged from 54% as the lowest score to 92% as the highest Trust score.

The 20th percentile threshold is 77%; the 80th percentile threshold is 84%.

Patient views

Colorectal / lower gastrointestinal: “Clearly explaining everything in detail from the beginning of treatment to the end. Always being at the end of the telephone at any time day or evening. Staff were very helpful, caring and reassuring. The complete cancer care I received from the staff was excellent, nothing was too much for them and always ready to help. Treatment and side effects was clearly explained.”

7. Longitudinal analysis

The 2010 National Cancer Patient Experience Survey questionnaire was developed to include a number of questions which would be capable of being compared longitudinally to the baseline cancer patients survey conducted in 2000. In the results below questions from the 2010 survey have been compared to the 2000 survey, which was similar in methodology and covered all Trusts undertaking cancer treatment.

The 2000 survey did not cover all of the tumour groups that were included in the 2010 survey. Therefore for the purposes of these analyses, only those tumour groups surveyed in 2000 have been included in the 2010 longitudinal results to eliminate bias; these were colorectal (C18,19,20,21); lung (C34); breast (C50); prostate (C61); ovarian (C56) and non Hodgkin's lymphoma (C82,83,84,85). The results from all other tumour groups surveyed in 2010 are shown in a separate column for comparative purposes.

The comparison between all tumour groups surveyed in both 2000 and 2010 shows that on four questions there have been statistically significant improvements in scores between the two surveys, these are: question 43, on staff deliberately misleading patients; question 48, being treated with respect and dignity; question 49, patients receiving written information on post discharge actions; and question 61, the time that doctors in outpatients spent with patients. The most substantial improvement is in respect of patients being given post discharge information.

However, there are 3 items on which there has been a significant decline in scores between 2000 and 2010. The most substantial declines have been on question 14, patients understanding the explanation of what was wrong with them; question 42, patients saying there were enough nurses on duty; and question 44, patients receiving conflicting information. On three other questions there have been small negative movements.

There is therefore a mixed picture in terms of the longitudinal data, with some improving scores and some that have declined. When the comparable questions are analysed by cancer group they show that there have been similar patterns of movement; in particular, on questions where there have been substantial declines in scores between 2000 and 2010, all cancer groups have seen significant drops in performance.

Question		2000	2010	2010 other
Q14	Patients saying they completely understood the explanation they received of what was wrong with them	83%	76%	71%
Q34	Patients receiving understandable answers to questions posed to doctors	83%	82%	80%
Q35	Patients saying that they had confidence and trust in the doctors treating them	86%	84%	83%
Q42	Patients saying there were enough nurses on duty	75%	62%	63%
Q43	Patients saying that doctors or nurses never deliberately told them things they wanted to know	87%	87%	86%
Q44	Patients saying that they never received conflicting information	88%	79%	78%
Q48	Patients saying that they were always treated with respect and dignity	79%	82%	82%
Q49	Patients saying that they received written information on what they should or should not do after discharge	71%	83%	80%
Q61	Time the cancer doctor seen in the outpatients department spent with patient about right	92%	93%	94%
Q63	Patients saying that their GP was given enough information about their condition and treatment by the hospital	95%	94%	93%

Table 8 Longitudinal comparisons

Column 1 – 2000 Cancer Survey Results

Column 2 – 2010 Cancer Patient Experience Survey results for the same tumour groups as in the 2000 survey

Column 3 – 2010 Cancer Patient Experience Survey results for all other tumour groups surveyed in 2010 but not covered by the 2000 survey

8. Comparisons with the national inpatient survey

17 questions in the 2010 National Cancer Patient Experience Survey are the same or very similar to questions in the CQC 2009 National Inpatient Survey[6]. The table below shows a comparison between the results from inpatients responding to the National Cancer Patient Experience Survey and patients responding to the 2009 National Inpatient Survey. We display below only the results from cancer patients who had an inpatient episode in hospital in January-March 2010, as distinct from those who were treated in day case units.

All but one of the scores in the National Cancer Patient Experience Survey are significantly higher than in the national Inpatient Survey.

Question		**Cancer Survey**	**Inpatient Survey**
Q19	Patient definitely involved as much as they wanted in decisions on treatment choices	74%	52%
Q30	Patient given prior complete explanation of what would be done during their operation	85%	74%
Q32	Patient given easy to understand post operative explanation of operation outcome	74%	64%
Q34	Patient received understandable answers to questions posed to doctors all or most of the time	81%	67%
Q35	Patient had confidence and trust in all doctors treating them	85%	80%
Q37	Patient did not think that doctors talked in front of them as if they were not there	83%	72%
Q39	Patient received understandable answers to questions posed to nurses all or most of the time	73%	65%
Q40	Patient had confidence and trust in all ward nurses treating them	67%	74%
Q41	Patient did not think that nurses talked in front of them as if they were not there	83%	78%
Q42	Patient thought there were always or nearly always enough (ward)* nurses on duty to care for them	63%	59%
Q44	Patient never thought they were given conflicting information about their condition or treatment	80%	65%

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[6] CQC, National Inpatient Survey Results, May 2010, www.cqc.org.uk/publications.cfm?fde_id=15551

Q45	Patient always given enough privacy when discussing condition or treatment	83%	70%
Q46	Patient always given enough privacy when being examined or treated	93%	88%
Q48	Staff always treated patient with respect and dignity	82%	79%
Q50	Staff told patient who to contact if they were worried post discharge	91%	75%
Q51	Clinical staff definitely gave family/carer/close friend all information needed to help care for patient at home	58%	44%
Q66	Overall, patient given right amount of information about their condition and treatment	87%	78%

Table 9 Comparison with the 2009 National Inpatient Survey

In general, the above table does not display findings that are unusual or unexpected. Patients who are having major life saving or life changing interventions are more likely to be positive than patients whose contact with the NHS is more peripheral. We can clearly say that cancer inpatients are more positive than acute inpatients as a whole.

* The one question that provides a negative comparison is in respect of cancer patients' assessment of ward nurses. The question asked in the National Cancer Patient Experience Survey used the word "ward" before "nurse" to draw a distinction between the specialist nurses that cancer patients see for treatment and nurses who staff the wards where a cancer patient's bed is located. It is clear that this minor change in wording between the National Cancer Patient Experience Survey and the National Inpatient Survey has caused a different assessment to be made by patients of the trust and confidence in which they held that group of staff.

9. Demographic and specialist analyses

The impact of age

The national dataset has been analysed by using standard age bands: 16-25; 26-35; 36-50; 51-65; 66-75; and 76+. These bands were chosen in order to identify any specific age-related differences in the views of cancer patients which could illuminate the implementation of policy.

The age related analysis has identified 42 questions on which there are statistically significant differences across the age bands. Not all of these differences are of the same kind, but there are commonalities as follows:

On many questions, the youngest age group (16-25) is the least positive, with the most positive group usually being those patients in the middle years of life or early old age;

On some questions, the 26-35 age group is marginally less positive than the16-25s, and on other questions, it is older people in the 76+ age band who are least satisfied.

A clear example of the classic age distribution profile in the survey is highlighted in the chart below which shows the scores on question 14, which asked patients if they completely understood the explanation of what was wrong with them:

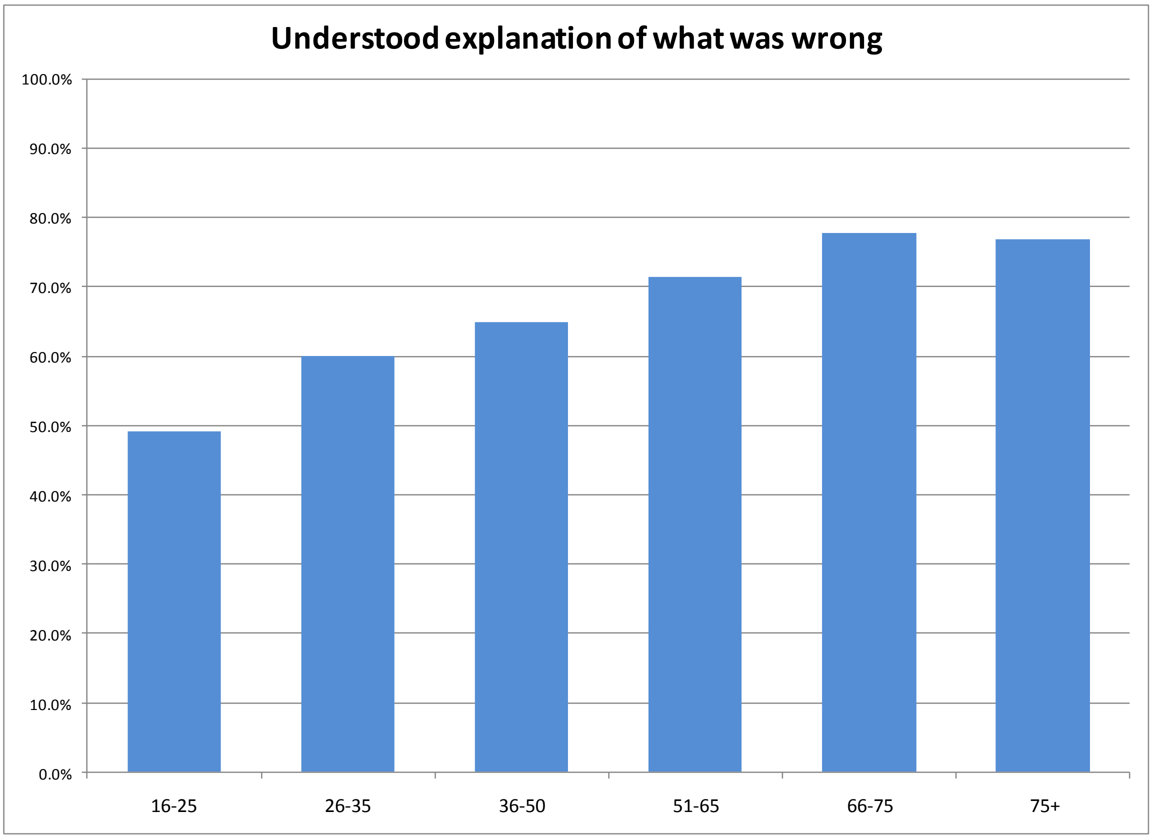

Chart 34 Patient understood completely the explanation of what was wrong with them

Younger patients, who may have less experience of being in hospital than older people, are in some cases less likely to understand medical terminology and routines. This kind of finding (as set out in the chart above), replicates other findings from the national patients surveys in different settings (i.e. primary care, hospital inpatients, and mental health). It points to the need to enhance and simplify explanations of condition and treatment to the youngest cohorts of patients.

However, it is not always younger patients who have the least positive experiences of cancer care. The most prominent example of an issue where it is older people who have least good access to support and information arises from the question on patients being given the name of a Clinical Nurse Specialist (CNS). On this question it was the oldest age group (76+) who were least likely to say they were given the name of a Clinical Nurse Specialist, as the chart below shows:

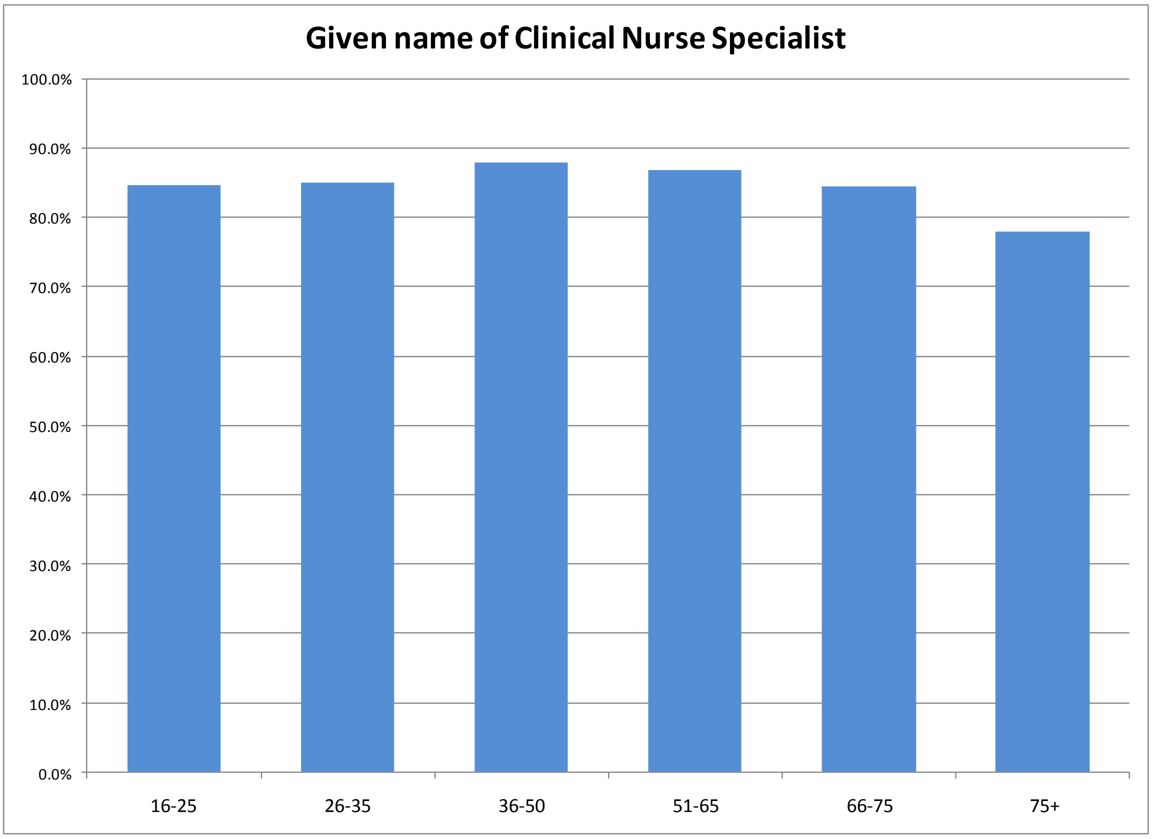

Chart 35 Patient given the name of the Clinical Nurse Specialist

A further example where younger patients are more likely to be given information is in respect of financial help or benefits. In this case, far more young people are being given information on these issues than are older people – perhaps because NHS staff believe that older people will automatically be in receipt of pensions and therefore do not need this kind of support. However, many “pensioners” do not claim all that they could by way of pension credit, housing benefit etc, and it is the case that many pensioners have very low incomes and do not claim what they could.

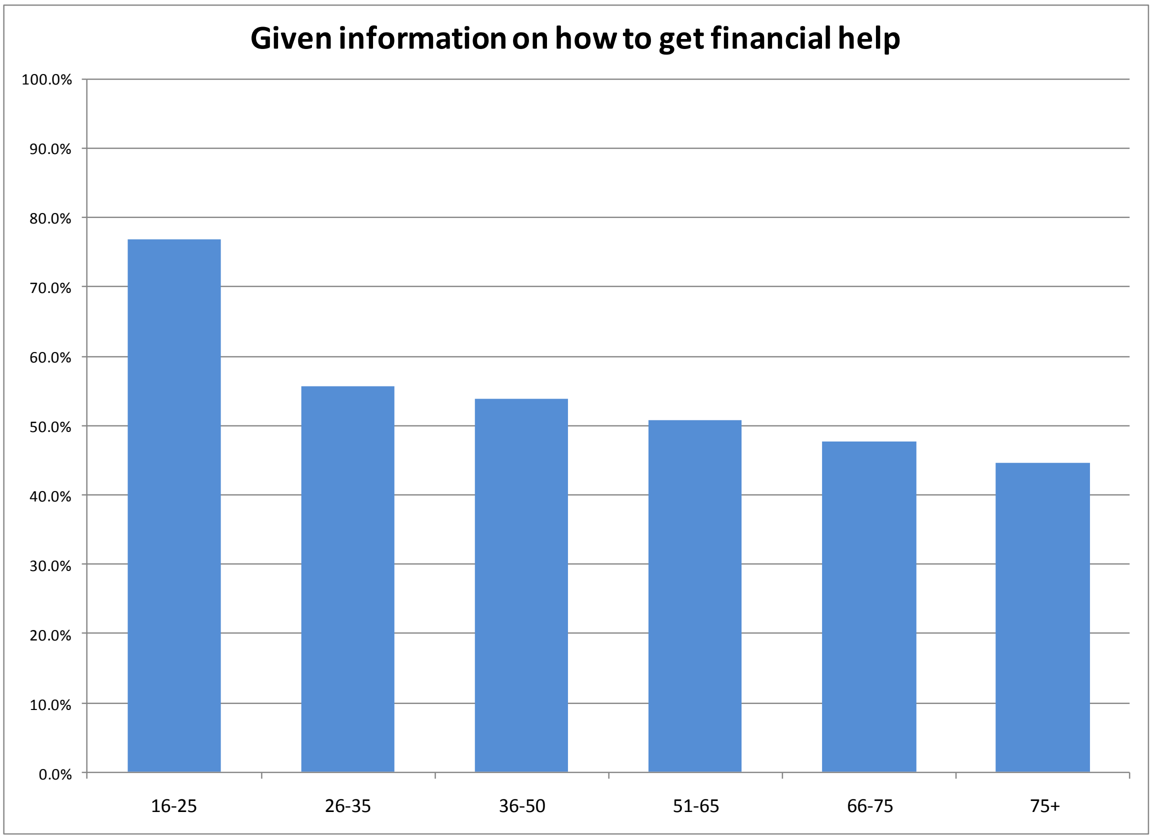

Chart 36 Patient Given Information on how to get financial help or benefits

On most issues measured in the National Cancer Patient Experience Survey, however, the normal age distribution is for the youngest age cohort to be the most critical of the services they have received. This is true not just on information questions but on broad assessment questions where the respondent has been asked to assess the quality of the service they have received. A typical example of this kind of age distribution is set out in the chart below:

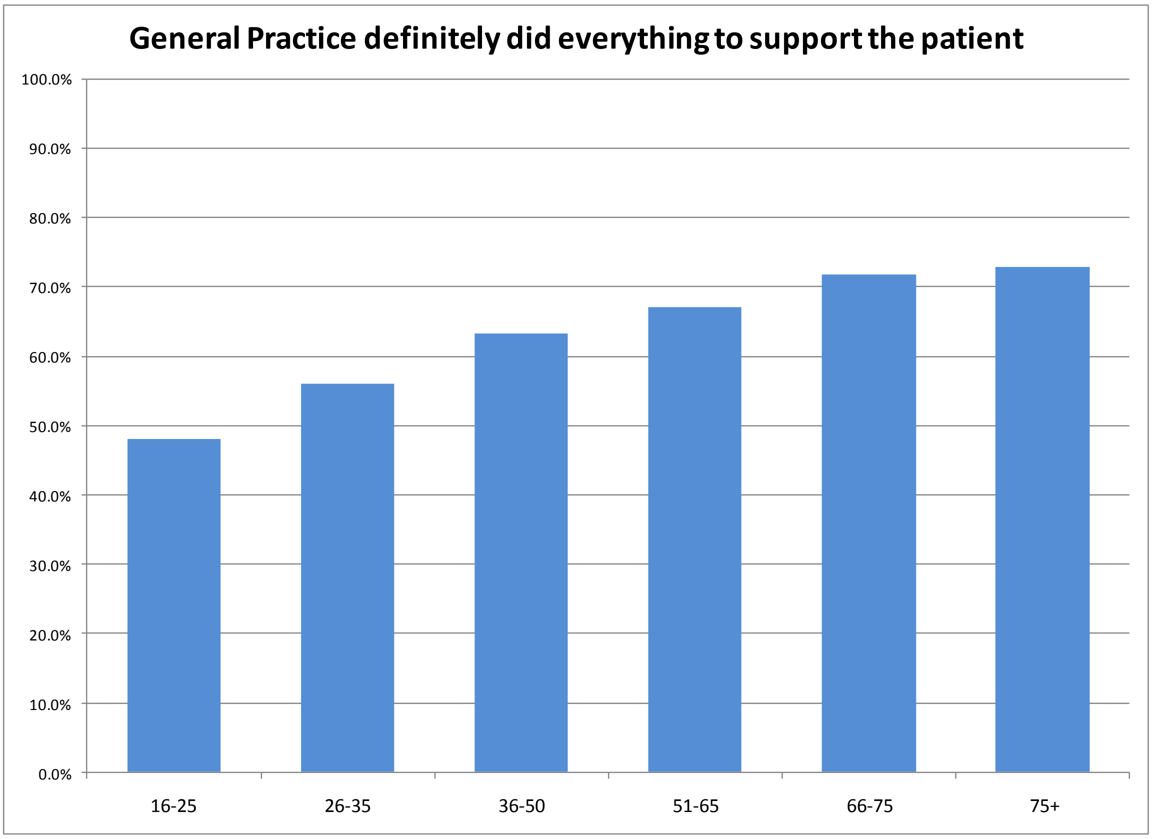

Chart 37 General Practice definitely did everything to support the patient during treatment

The age analysis shows, therefore, that both the youngest and oldest age patient groups are likely to receive different levels of information (depending on the issue concerned), which in some cases is not at optimum levels. It is also the case that younger patients take a less favourable view of the quality of services as measured by some questions.

The impact of gender

Differences in the views of patients related to their gender tend to be of smaller scale than other demographic factors, where they exist. However, there are some consistent patterns in the responses to the National Cancer Patient Experience Survey which are congruent with the kinds of responses seen in the national patient surveys of elective and emergency patients in NHS hospitals. In the National Cancer Patient Experience Survey there are 43 questions on which there are significant differences of view between men and women; in most cases men are more positive but on 12 out of 43 questions where there were significant differences, women are more positive than men.

The strategic points are:

- Men are more positive about staff and staff working well together than are women.
- Men are more positive about privacy, being given respect and dignity, being told enough about their condition and treatment, and about being treated as a person rather than as a set of symptoms.
- Men are more positive about discharge and post discharge arrangements than are women.
- A higher proportion of men also claimed that they received written information on types of cancer, and on free prescriptions.

The 12 questions where women were more positive were:

- Women were more likely to say that they saw their GP only once or twice before being referred on to hospital.
- Women were more likely to say they were seen within 4 weeks of being referred to see a hospital doctor.
- Women were more likely to say that their health stayed the same in the waiting period before seeing a hospital doctor.
- Women were more likely to say they were given written information about the side effects of their treatment.
- Women were much more likely to be given the name of a Clinical Nurse Specialist (see below).
- Women were more likely to say that their admission date to hospital for a cancer operation was NOT changed by the hospital.
- Women were more likely to say that doctors did not talk in front of them as if they were not there.

There was one issue in particular on which women were more positive – more women (87%) said they were given the name of a Clinical Nurse Specialist than did men (81%); but it is the case that in the tumour groups where women are concentrated (e.g. breast cancer) there is a slightly greater coverage of Clinical Nurse Specialists.

Three examples of the general principle that men are more positive than women are set out in the chart below:

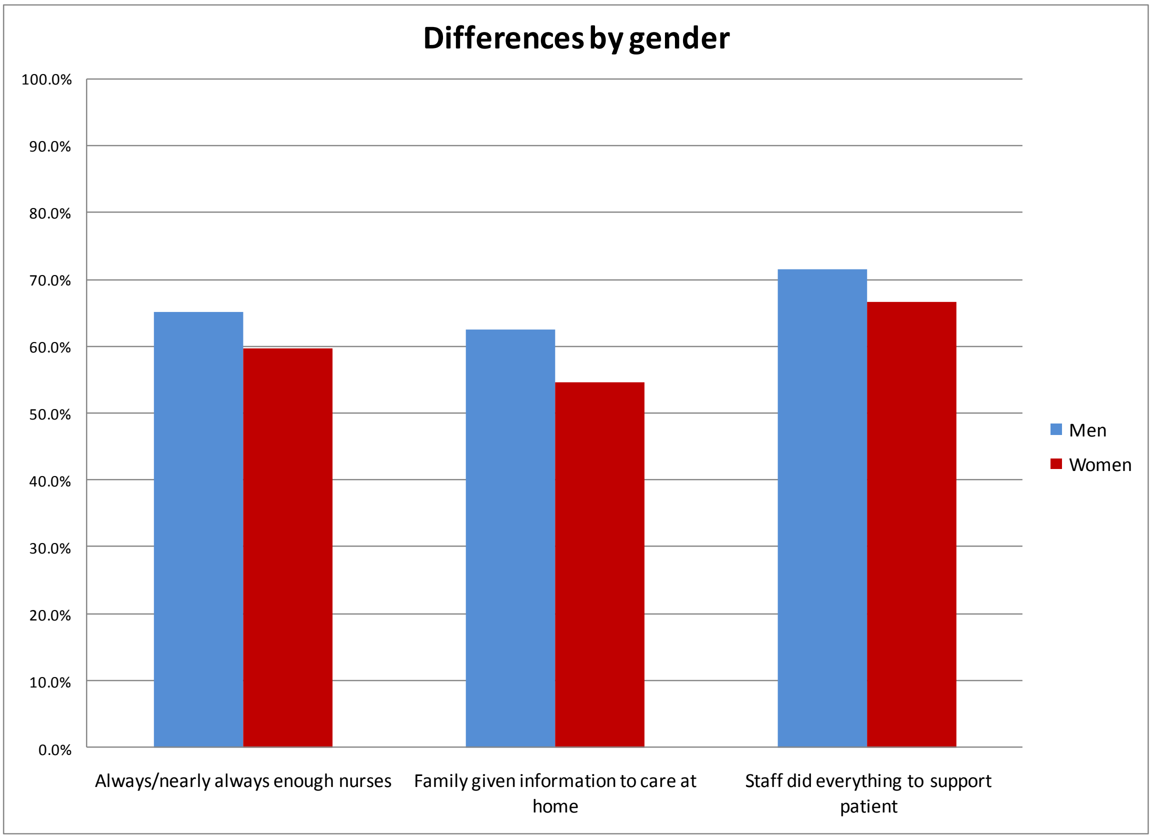

Chart 38 Examples of More Positive Views by Men

The impact of ethnicity

The full national dataset has been analysed to assess whether there are any consistent differences of opinion between cancer patients from broadly based ethnic groups.

The absolute numbers of ethnic minority respondents to the survey is quite low and is substantially less than the proportion estimated to be in the UK population generally by census returns. The lower numbers of ethnic minority respondents in the 2010 survey replicates the position in the 2000 and 2004 surveys; and in order to be able to analyse the data effectively, ethnic groups have been amalgamated into broad categories as follows:

- White (including White British, Irish, and any other White background)
- Asian (including Indian, Pakistani, Bangladeshi, Other Asian, and Asian British)
- Black (including Caribbean, African, Black British, and any other black background)
- Mixed (including White and Black Caribbean, White and Black African, White and Asian, and any other mixed background)
- Other ethnic groups (including Chinese)

The results from these five groups were then analysed to identify any differences that may exist between them on all questions in the survey. On 22 questions there were statistically significant differences between the ethnic groups, as follows:

- Saw GP once or twice only before being told needed to go to hospital Q1
- Patient felt they were seen as soon as necessary Q3
- Health stayed about the same whilst waiting for appointment with hospital doctor Q5
- Staff explained completely what would be done during test procedure Q8
- Given easy to understand written information about tests Q9
- Results of tests explained in a way that the patient could understand Q10
- Completely understood the explanation of what was wrong with them Q14
- Definitely involved as much as they wanted to be in decisions about which treatment to have Q19
- Got understandable answers all/most of the time to questions posed to doctor Q34
- Doctors talked in front of the patient as if they were not there Q37
- Patient received answers from a ward nurse that were understandable all or most of the time Q39
- Had confidence and trust in all ward nurses Q40

• Ward nurses talked in front of the patient as if they were not there	Q41
• Always/nearly always enough nurses on duty to care for patients	Q42
• Patient often thought doctors / nurses were deliberately not telling them certain things	Q43
• Give enough care and help from health and social services after discharge	Q52
• Hospital staff definitely did everything they could to control side effects of chemotherapy	Q56
• Patient definitely given enough emotional support from hospital staff when an outpatient or day case patient	Q58
• At last outpatient appointment with a cancer doctor, seen within 30 minutes	Q60
• GPs and Nurses at the practice definitely did everything they could to support patient whilst they were having cancer treatment	Q64
• GPs / other staff worked well together to give the best possible care	Q65
• Patient did not feel that they were being treated as a set of cancer symptoms rather than as a whole person	Q67

In all these cases where statistically significant differences have been found to exist between ethnic groups, the results from some ethnic minority cancer patients are more negative than those for white patients; in all but one case, white cancer patients are more positive than are patients in any other ethnic group. The one exception is in respect of Q42, “Always enough nurses on duty to care for them on the ward”, where mixed race respondents were marginally more positive than white respondents.

These questions where there are statistically significant differences cover a wide range of issues, ranging from information giving, confidence and trust in nurses and other questions about ward nurses, the control of pain, and assessment of primary care support.

The charts below show examples of the scale of differences that exist between the perceptions of some ethnic minority patients and white patients undergoing cancer treatment.

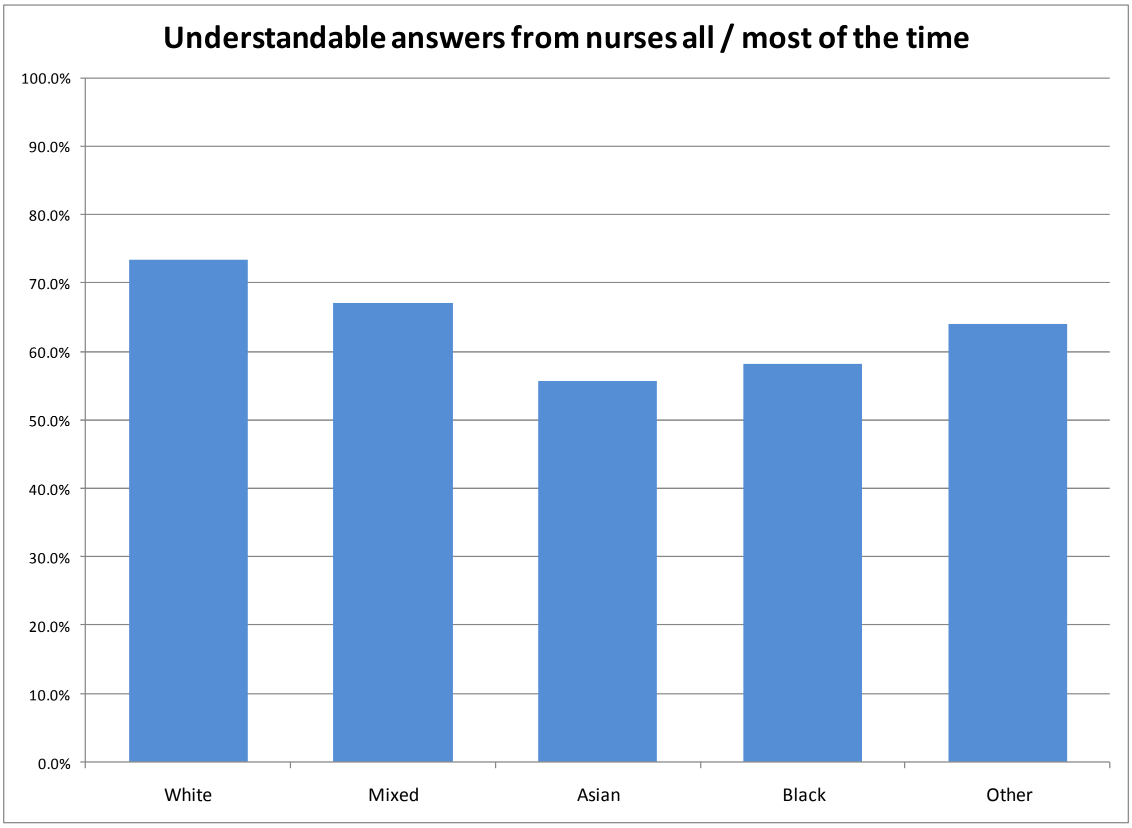

Chart 39 Patient received understandable answers from ward nurse all/most of the time

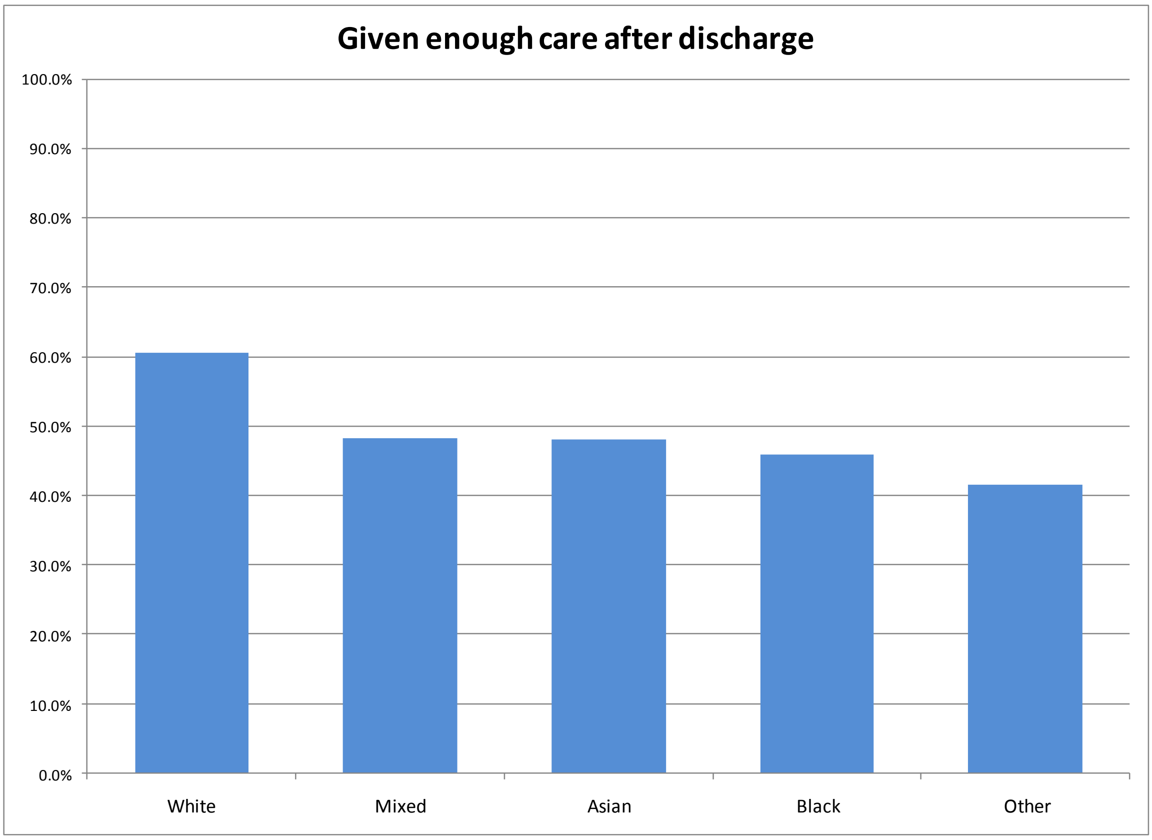

Chart 40 Given enough care from health and social services after discharge

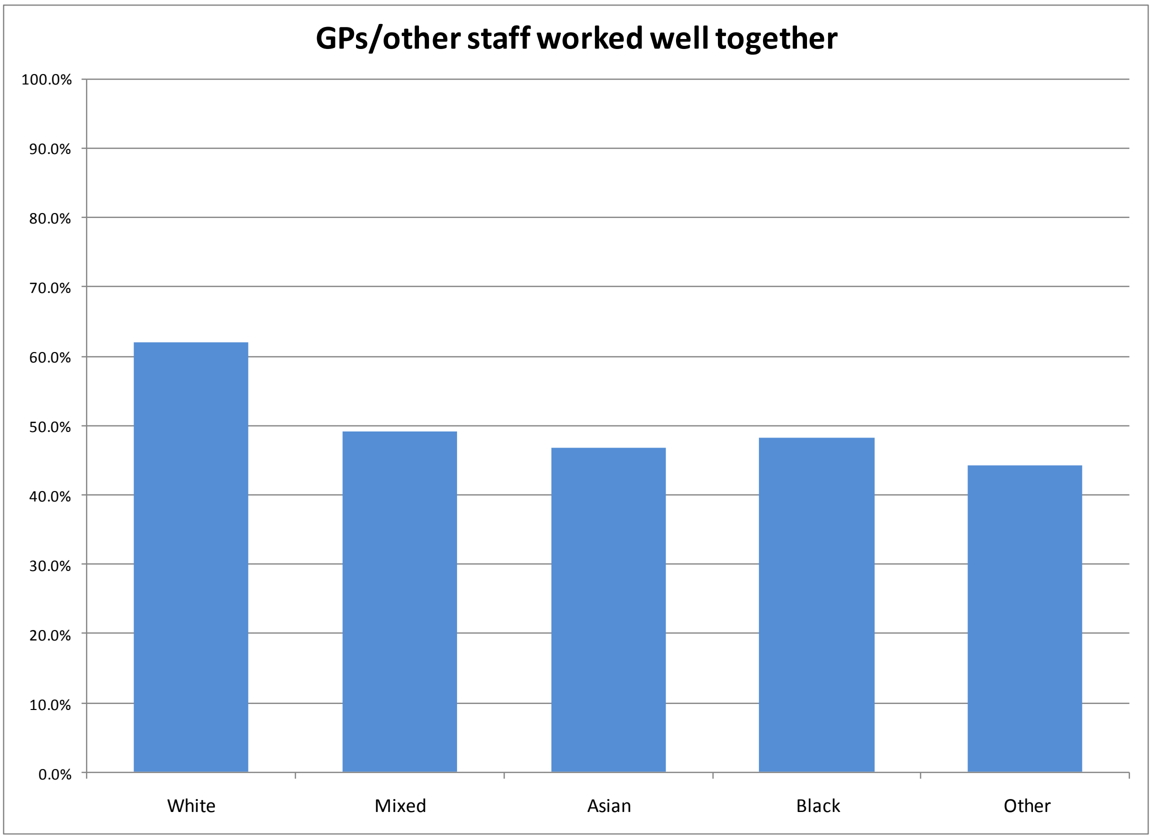

Chart 41 GPs / other staff caring for patient always worked well together

It is important to note that the scale of differences between ethnic groups identified in the National Cancer Patient Experience Survey on these questions is replicated in other official NHS national surveys of mental health service users, patients in primary care, and hospital inpatients. It is therefore not the case that there is something specific in the delivery of cancer services which is causing these differences; it appears that there may be aspects of NHS provision generally which are more heavily criticised by some ethnic minority patients. This may be because NHS provision is less well appreciated by some patients because services are generally worse in the area where they are concentrated than is the case for many areas where white people are concentrated; but there is also clear evidence from the kinds of questions on which there are differences perceived in the National Cancer Patient Experience Survey that some of these differences relate to clarity of information, and some to perceived differences of treatment of the patient as an individual. Further work needs to be undertaken by the NHS on these issues.

In respect of the National Cancer Patient Experience Survey, on the questions where there are statistically significant differences between white patients and patients from ethnic minority groups, white patients are almost always the most positive, with black patients being the least positive on 6 items; Asian patients least positive on 6 items; Chinese/other ethnic group patients being the least positive on 9 items; and mixed race patients being least positive on 1 item.

The impact of sexual orientation

Respondents were asked if they were heterosexual, bisexual, gay or lesbian, or were of other sexual orientation (Q72). Significant numbers of respondents (5%) said they preferred not to answer (a specific answer option) and a more substantial number than usual did not answer the question at all (8%); this compares to only 3.7% who failed to answer the question on gender. It is possible that significant numbers of people who were not heterosexual reacted in this way to the question, and that therefore the numbers of cancer patients who were not heterosexual is understated in the data. Only 800 patients (1.1%) overall chose one of the response options other than heterosexual.

Because the response numbers describing themselves as bisexual, gay/lesbian, or having another sexuality other than heterosexual, are small, we have aggregated the non-heterosexual groups into one response category and compared this group to the heterosexual respondent group.

This analysis shows that there are 16 questions on which there are significant differences of opinion between heterosexual cancer patients and non-heterosexual patients. In all cases these differences demonstrate less positive views by non-heterosexuals, in respect of the following items:

• Got understandable answers from the Clinical Nurse Specialist all / most of the time	Q23
• Time spent with the Clinical Nurse Specialist was about right	Q24
• Patient was given information about support / self help groups for people with cancer	Q25
• Received understandable answers from hospital doctor on important questions the patient had asked	Q34
• Doctors never talked in front of patient as if they were not there	Q37
• Received understandable answers from ward nurses on important questions the patient had asked	Q39
• Ward nurses never talked in front of patient as if they were not there	Q41
• Doctors / nurses never deliberately did not tell patient things they wanted to know	Q43
• Never received conflicting information from doctors or nurses	Q44
• Hospital staff always did everything they could to control their pain	Q47
• Always treated with respect and dignity by hospital staff	Q48
• Staff definitely did everything they could to control side effects of chemotherapy	Q56
• Staff definitely did all they could in outpatients / day case to control the patients pain	Q57
• Definitely given enough emotional support from hospital staff in outpatients / day case	Q58
• GP staff definitely did everything they could to support the patient whilst they were having cancer treatment	Q64
• Never felt treated as a set of cancer symptoms rather than as a whole person	Q67

It is possible that there is a strong association between those respondents who defined themselves as non-heterosexuals and other variables known to influence patient opinion. For example, it is the case that non-heterosexuals are significantly younger than the heterosexual respondent group and we will conduct further analyses to identify the extent to which sexual orientation explains the differences that have been described above.

Nevertheless it is important to recognise the important differences of view between heterosexuals and non-heterosexuals and to note that 11 of the 16 questions on which non-heterosexuals have less positive views on cancer treatment relate to communication and (broadly) the respect and dignity with which the patient was treated.

The impact of long term conditions

The survey sought information from patients in respect of whether they had another long term condition, or multiple conditions, other than cancer. The long term conditions (LTCs) identified in the survey were as follows:

- Deafness / severe hearing impairment
- Blindness / partially sighted
- Long standing physical condition
- Learning disability
- Mental health conditions
- Long standing illness, e.g. HIV, diabetes, chronic heart disease, or epilepsy

Responses were analysed by comparing the group of patients who had one or more of the long term conditions with the group who said they did not have a long term condition. The findings show that there are 48 questions on which there are statistically significant differences between the two groups of patients; and in 45 of these 48 cases the patients with a long term condition were less positive than the patients without such a long term condition.

The only items on which patients with long term conditions were more positive than those without long term conditions, were in respect of being told that they could bring a member of the family or a friend with them when they were first told they had cancer; on the provision of information on free prescriptions; and on length of waiting time to see a cancer doctor in outpatients.

Examples of the scale of such differences between those with and those without a long term condition are as follows:

Question		LTC	Non LTC
Q5	Health stayed the same whilst waiting for first appointment with a hospital doctor	75%	79%
Q15	Given easy to understand information about the type of cancer they had	64%	67%
Q25	Hospital staff gave information about support/self help groups for people with cancer	76%	81%
Q31	Given written information about their operation	65%	70%
Q41	Ward nurses did not talk in front of them as if they were not there	81%	85%
Q52	Given enough care/help from health and social services after discharge	57%	62%
Q67	Did not feel as if they were treated as a set of cancer symptoms rather than as a whole person	78%	82%

Table 10 Differences between those with and those without an LTC

The conclusion to be drawn from this is that patients with long term conditions are rather less likely to be positive about their cancer care than are patients without such conditions; and that this less positive assessment is present across a wide range of issues measured in the survey.

We have also analysed the data from those patients who specified that they had a particular long term condition as set out on the face of the survey. This analysis shows that in respect of long term conditions such as deafness and physical conditions, the differences between those with such a specific condition and those who did not have it are, in most cases, quite small. However, patients with mental health conditions and learning disabilities were far less likely to be positive about a wide range of issues than were patients with no long term conditions, as the chart below shows:

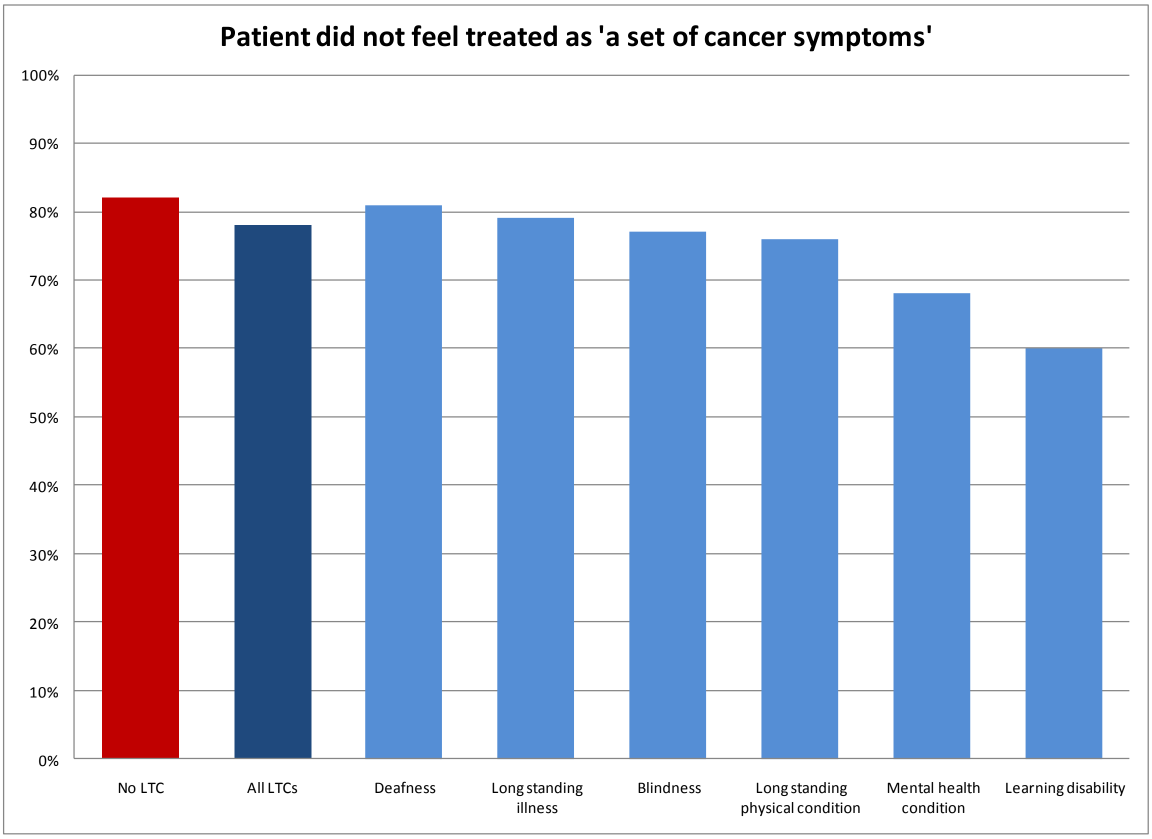

Chart 42 Patient did not feel treated as a set of symptoms by LTC

Despite the response numbers being small in the case of some of the long term conditions, in each of the cases set out in the chart above the differences between those with a specific long term condition and those without it are statistically significant.

It is clear that particular efforts need to be made to ensure that cancer patients with mental health and learning disabilities receive the kinds of information that are useful and understandable to them, and are treated in ways which are seen by them to be fair and appropriate.

There is a case, therefore, for positive action to be taken by NHS staff to address the distinct needs of people with long term conditions, especially in areas which are capable of being improved by Information Prescriptions.

Differences between tumour groups

Initiatives to improve cancer services in England over the past 15 years have generally started earlier for patients with common cancers. For example, the Improving Outcomes Guidance (IOG) reports for breast cancer, colorectal cancer and lung cancer were first published in the late 1990s. In contrast the IOG reports for brain / central nervous system tumours, skin cancers and sarcomas were only published in 2005. The assessments of services through peer review has followed the order in which the IOG reports were published.

When the data from the 2010 patient survey is analysed by cancer group, the findings show that patients in the big 4 groups (breast, colorectal / lower gastrointestinal, lung and prostate) have different and generally more positive views than do patients in other cancer groups where policy initiatives may have had a lesser impact to date.

There are 47 items on which patients in the big 4 cancer groups have significantly different views from those of patients in other cancer groups, and on 41 of these items those in the big 4 have more positive views than patients in other cancer groups.

Examples of this finding are as follows:

Question		Big 4	Others
Q5	Health stayed the same whilst waiting for first appointment with a hospital doctor	82%	74%
Q14	Completely understood the explanation of what was wrong with them	78%	69%
Q15	Given easy to understand information about the type of cancer they had	69%	63%
Q20	Given name of a Clinical Nurse Specialist	89%	79%
Q25	Hospital staff gave information about support/self help groups for people with cancer	83%	75%
Q31	Given written information about their operation	72%	62%
Q52	Given enough care/help from health and social services after discharge	62%	57%

Table 11 Differences between cancer groups

The evidence therefore supports the contention that the continued spread of active policy initiatives to cancer groups outside the big 4 is likely to improve the overall scores given by patients on a wide range of issues. We draw particular attention to the gap between the Big 4 and other cancer groups in terms of the proportion of patients given the name of a Clinical Nurse Specialist.

Differences between inpatients and day case patients

In the 2010 National Cancer Patient Experience Survey, patients eligible for the survey sample either attended hospital as a day case or as an inpatient. Many patients will have had experience of both kinds of treatment settings as a cancer patient, but we have analysed the differences between the two groups based on the last relevant spell that the patient had in January-March 2010, whether as day case or as an inpatient.

Analysis of the data by these groups shows that there is no consistent pattern of response between day cases and inpatients. On some issues, such as the patients health staying the same before being seen by a hospital doctor, understanding the explanation of what was wrong, involvement in decisions about treatment, confidence and trust in doctors, and assessment of whether there were enough nurses on duty to care for them, inpatients scored more positively. However, day case patients scored more positively on written information about the side effects of treatment, patients being given information about how to get financial help and benefits, and on free prescriptions.

These statistically significant differences between inpatients and day cases are not large in scale within questions, and the kinds of issues on which day case patients are more positive suggests that it is in the day case setting that this sort of information is more routinely given. For example, as much chemotherapy and radiotherapy is given in day case settings, it is not surprising that a rather larger group of patients is given information about the side effects of treatment in that setting. Staff may be better organised to give such information in day case settings.

We can be clear, however, that differences in perception between day case patients and inpatients are not so substantial as to be a major driver of patient opinion on cancer care.

The impact of the Clinical Nurse Specialist

One of the most striking findings of the 2010 National Cancer Patient Experience Survey is that related to the impact of the Clinical Nurse Specialist (CNS). When we analyse the data as between those who had a Clinical Nurse Specialist and those who did not, there are significant differences between the groups on every single question in the survey.

In every case, patients with a Clinical Nurse Specialist are significantly more likely to be positive about their care and treatment than are patients who did not have a Clinical Nurse Specialist. The most pronounced differences in view between those patients with a Clinical Nurse Specialist and those without one were in respect of verbal and written information, involvement, information on financial support and prescriptions, discharge information and post discharge care and emotional support.

Examples of the sizeable differences that exist between patients with Clinical Nurse Specialist support and those without such support are set out below:

Question		With CNS	No CNS
Q15	Given easy to understand information about the type of cancer they had	70%	43%
Q16	Given choice of different types of treatment	86%	65%
Q18	Given easy to understand written information about side effects of treatment	84%	58%
Q19	Involved in treatment as much as they wanted to be	74%	58%
Q25	Given information about support and self help groups	84%	48%
Q26	Given information on financial help and benefits	55%	23%
Q27	Told they could get free prescriptions	71%	49%
Q31	Given easy to understand written information about operation	71%	47%
Q52	Given enough care/help from health and social services after discharge	62%	45%

Table 12 Differences by CNS

Given the substantial impact that having a Clinical Nurse Specialist makes to patient perceptions of their care and treatment, it is important to understand if there are groups of patients who have less access to Clinical Nurse Specialists than others. Age related analysis reported earlier shows that it is the 'over 75' patient group that has least access to the support of Clinical Nurse Specialists. Further examination of the data shows that this age related effect is not uniform across all cancer groups, as the chart below shows:

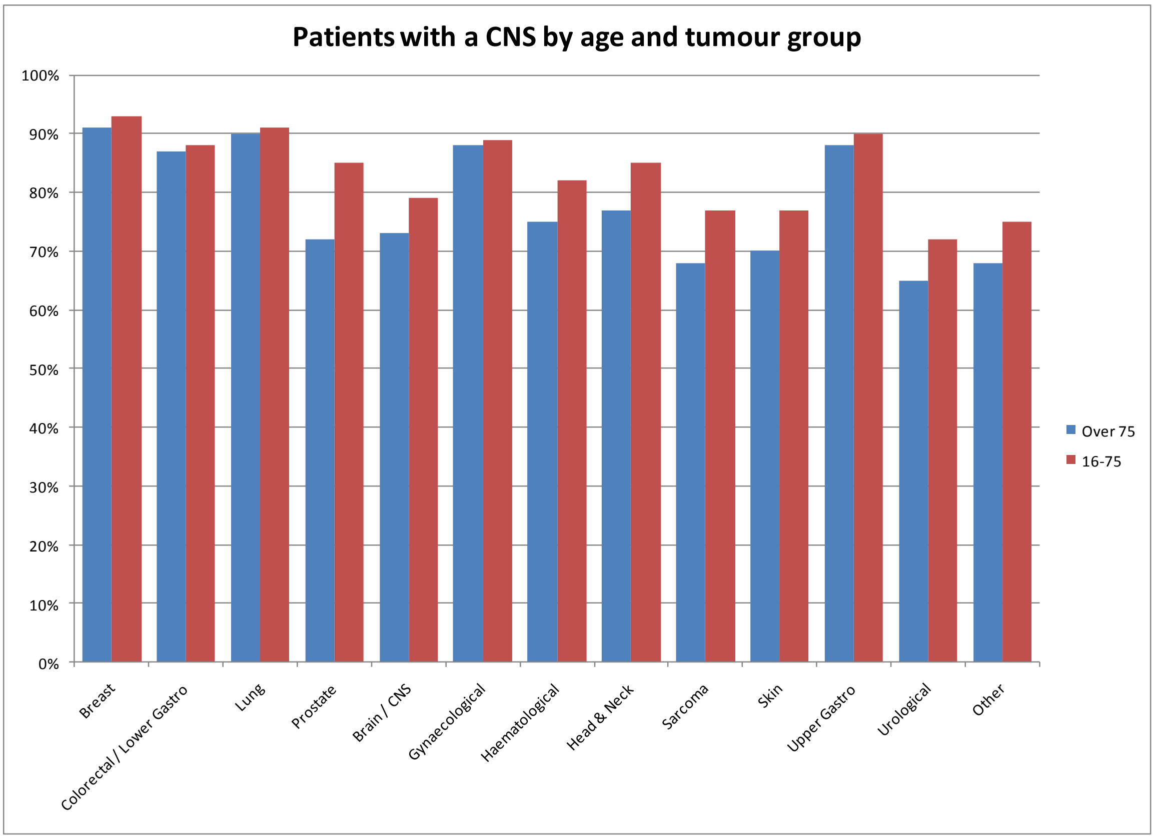

Chart 43 Patients with a CNS by age and tumour group

It is clear that this age related effect is not seen consistently across cancer groups. There is virtually no difference in the incidence of Clinical Nurse Specialist availability to patients in different age groups in 6 of the 13 cancer groups, whereas in the remaining 7 there are substantial differences in availability related to age; the cancer groups where there are the most substantial age related differences in access are haematology; head and neck; prostate; sarcoma; skin; urological and other cancers.

It is also important to identify whether there have been perceived improvements in the coverage of Clinical Nurse Specialist support to patients over time. The chart below shows that patients who started cancer treatment more than 5 years ago are considerably less likely, in every cancer group, to say that they were given the name of a Clinical Nurse Specialist than were patients who started treatment in the last year:

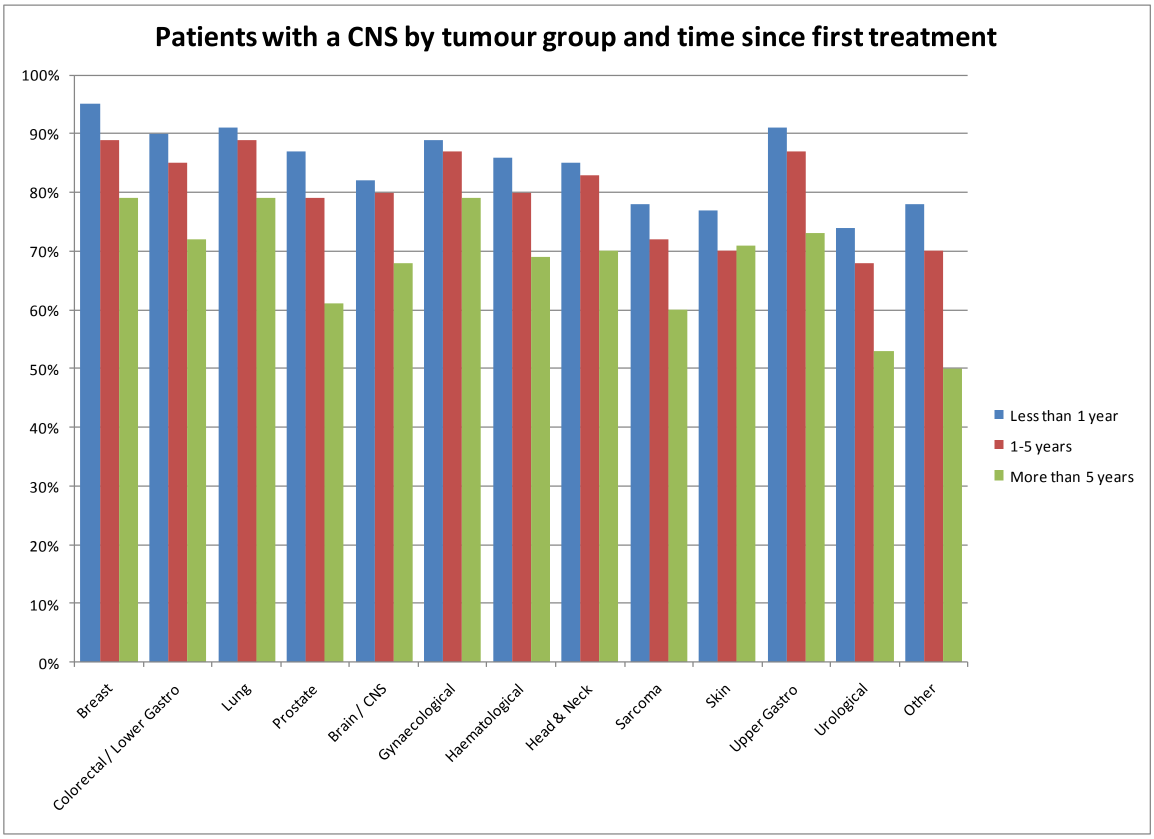

Chart 44 Patients with a CNS by tumour group and time since first treatment

The conclusions that can be drawn from this further examination of the data are that there seems to have been a considerable improvement in the coverage of Clinical Nurse Specialists in every cancer group over the last 5 years; but that there is evidence of an age related effect with fewer patients aged over 75 being given the name of a Clinical Nurse Specialist in some cancer groups, than patients who are younger. Given the profound differences in views between patients with a Clinical Nurse Specialist and those who do not have access to one, these are important findings which indicate the cancer groups and age groups in which further improvements could potentially be made.

Differences relating to length of time since first treatment

The questionnaire included a question (Q71) on the length of time that had elapsed since the patient was first treated for “this cancer”, i.e. the cancer that was being treated in the hospital episode during January-March 2010. Respondents were divided into those who had first been treated within the last year; between 1 and 5 years ago; and more than 5 years ago.

The results of the analyses on this question are some of the most important in the survey as they demonstrate clearly that on 25 separate questions there is a measurable, statistically significant difference in the number of patients expressing positive views about their treatment, with the patients who began treatment more than 5 years ago being the least positive group of respondents on each question.

There were no questions on which there was a statistically significant negative difference in patient opinion between these groups of patients who began treatment at different times and in no cases were patients who began treatment more than 5 years ago more positive than patients who began treatment in the last year.

The issues on which there are better scores from patients who started treatment recently are as follows:

• Saw GP only once / twice before being told needed to go to hospital	Q1
• Referral to hospital within 4 weeks of being told they needed to go	Q2
• Patient told they could bring a family member or friend with them when they were told about their cancer for the first time	Q12
• Received an understandable explanation of what was wrong with them	Q14
• Given written information about the type of cancer they had	Q15
• Given choice of different types of cancer treatment	Q16
• Side effects of treatment explained in a way they could understand	Q17
• Given written information on side effects of treatment	Q18
• Feeling involved in decisions about which treatments they would have	Q 19
• Being given the name of a Clinical Nurse Specialist	Q20
• Given information on support or self help groups for people with cancer	Q25
• Given information on financial help and benefits	Q26
• Given information on the availability of free prescriptions	Q27
• Being given written information on the operation they were to have	Q31
• When patient had important questions to ask a doctor received understandable answers all / most of time	Q34
• Having confidence and trust in the doctors treating them	Q35
• Doctors knew enough about how to treat the patient’s cancer	Q36
• Thinking that doctors did not talk in front of them as if they were not there	Q37
• Family / someone else close to them had enough opportunity to talk to a doctor	Q38

- When patient had important questions to ask a ward Nurse, received understandable answers all/most of time Q39
- Having confidence and trust in the ward nurses treating them Q40
- There were always/nearly always enough nurses on duty to care for them in hospital Q42
- Given enough privacy when discussing condition/treatment Q45
- Last outpatients appointment started on time or within 30 minutes Q60
- GPs and nurses at the general practice worked well together to give the patient the best possible care Q65

It is noticeable that the differences demonstrated are present across genders, as is clear from the table below. It is also clear that the improvements apparent between those who started treatment recently and those who began treatment over 5 years ago cover a wide range of topics, including information issues targeted in the Cancer Reform Strategy and also issues of general confidence and support in the pattern of treatment and the people undertaking that treatment for the patient.

It is likely that the positive change in perception between those patients who started treatment recently and those who started treatment more than 5 years ago is more than a cohort effect. For example, the proportion of patients starting treatment over 5 years ago who were given the name of a Clinical Nurse Specialist was 67%, rising to 88% amongst those starting treatment in the last year. As the numbers of Clinical Nurse Specialists has grown significantly over the last 5 years, partly funded by Macmillan and partly by the NHS, this finding could have been expected, and is confirmed by the data.

Examples of the more positive views held by patients who started treatment recently and identifiable in this longitudinal assessment are set out in the table below, which shows the figures for men and for women in each time band:

	5 years>		1-5 years		< 1 year	
Question	Men	Women	Men	Women	Men	Women
Saw hospital doctor within 4 weeks of GP referral	58%	69%	62%	71%	64%	73%
Involved in decisions about treatment	64%	67%	68%	67%	75%	73%
Given name of Clinical Nurse Specialist	63%	71%	78%	84%	86%	90%
Received information on financial help and benefits	35%	40%	47%	48%	53%	53%
Given written information on operation	61%	57%	64%	62%	67%	71%
GPs, nurses etc. caring for patient worked well together	63%	55%	61%	55%	65%	61%

Table 13 Results over time since first treatment for this cancer

The impact of social deprivation

It might be expected that social deprivation would produce differences of view between cancer patients, with those in the most deprived geographical areas being less positive about cancer care than patients in the least deprived areas. It is certainly the case that response rates vary significantly between patients with postcodes in the least deprived decile to most deprived decile based on the Index of Multiple Deprivation (IMD). Response rates on the 2010 National Cancer Patient Experience Survey ranged from 71% in the least deprived decile to 51% in the most deprived decile. This effect is not unusual and follows the general pattern of participation in public life and civil society.

The survey data was analysed by quintile (i.e. each deprivation level based on 20% groupings within the 0-100% range) and no statistically significant difference was found between the quintiles.

However, the measurable extent of social deprivation on patient’s views of their cancer care can be dependent on the way in which the analysis is undertaken. A significance test based on differences of patient views taken across all deciles (chi) shows that on only one issue (told they could bring a family member or friend with them) was there a significant difference across all deciles based on the IMD; and on that issue it was more likely that patients in the most deprived postcode decile were told they could bring a family member or friend with them than was the case for patients in the least deprived postcode decile.

The IMD deciles are intended to provide range information in respect of the differences between the most deprived decile to the least deprived. It is this range which is the most accurate description in Britain of the different socio economic circumstances of patients and it is therefore right that we should also look at the differences between the extremes of the range as distinct from test scores across the range as a whole. This analysis shows something very different: on 37 questions in the survey, there are significant differences between decile 1 (the least deprived) and decile 10 (the most deprived). However, in 16 of these 37 cases patients in the most deprived decile are more positive than patients in the least deprived decile.

The questions on which patients in the most deprived decile were ***more positive*** than patients in the least deprive decile were as follows:

- When patient first told they had cancer, told they could bring a family member or friend with them Q12
- Patient told sensitively that they had cancer Q13
- Given the name of a Clinical Nurse Specialist Q20
- Patient said it was easy to contact their Clinical Nurse Specialist Q21
- Hospital staff gave patient information about financial help or benefits Q26
- Hospital staff told patient they could get free prescriptions Q27
- Family or someone close to them definitely had enough opportunity to talk to a doctor if they wanted to Q38

Had confidence and trust in all ward nurses	Q40
Given enough privacy when discussing condition or treatment	Q45
Treated with respect and dignity by doctors, nurses and other hospital staff	Q48
Given clear written information about what they should or should not do post discharge	Q49
Doctors / nurses gave family or someone close to the patient all the information needed to care for them at home	Q51
Given enough emotional support form hospital staff when being treated as an outpatient/day case	Q58
Seen within 30 minutes at their last OPD appointment	Q60
At their last appointment the cancer doctor had the right notes etc	Q62
Different people caring for them always worked well together to give them the best possible care	Q65

The questions on which patients in the most deprived decile were ***less positive*** than patients in the least deprived decile were as follows:

Saw GP only 1-2 times before referred to hospital	Q1
Health stayed the same whilst waiting for first appointment with a hospital doctor	Q5
Staff explained completely what would be done during test procedures	Q8
Given easy to understand written information about tests beforehand	Q9
Completely understood the explanation of what was wrong with them	Q14
Given easy to understand information about the type of cancer they had	Q15
Given easy to understand information about side effects of treatment	Q18
Involved as much as they wanted to be in decisions about treatment	Q19
Got easy to understand answers from their Clinical Nurse Specialist when they had important questions to ask	Q23
Time spent with their Clinical Nurse Specialist was about right	Q24
Given easy to understand answers from a doctor all / most of the time when they had important questions to ask	Q34
Doctors did not talk in front of them as if they were not there	Q37
Given understandable answers to questions by ward nurses all / most of the time	Q39
Ward nurses did not talk in front of them as if they were not there	Q41
Hospital staff never deliberately did not tell them things they wanted to know	Q43
Definitely given enough care from health and social services after leaving hospital	Q52
Time spent with cancer doctor in OPD about right	Q61
GP given enough information about condition and treatment they had had at the hospital	Q63

- GPs / other staff definitely did everything they could to support them whilst they were having cancer treatment Q64
- Given right amount of information about their condition and treatment Q66
- Not treated as ‘a set of cancer symptoms’ rather than as a whole person Q67

There is a certain degree of consistency about the kinds of questions which are less well ranked by patients in the most deprived IMD decile. 10 of the 21 items where patients in the most deprived decile are less positive relate to information giving and understanding; and a further 4 items relate to perceived feelings that the patient is being treated in an offhand way.

This finding further emphasises the importance of the roll out of the Information Prescriptions policy and programme, and ensuring that its content is both accessible to all and is comprehensive.

A further analysis was undertaken in respect of deprivation deciles on the response rate to the survey. This demonstrated clearly that patients in the least deprived decile were significantly more likely to respond to the survey than those that were in the most deprived decile. The response rates by IMD decile are set out below[7] and show a straight line relationship between deprivation and response numbers:

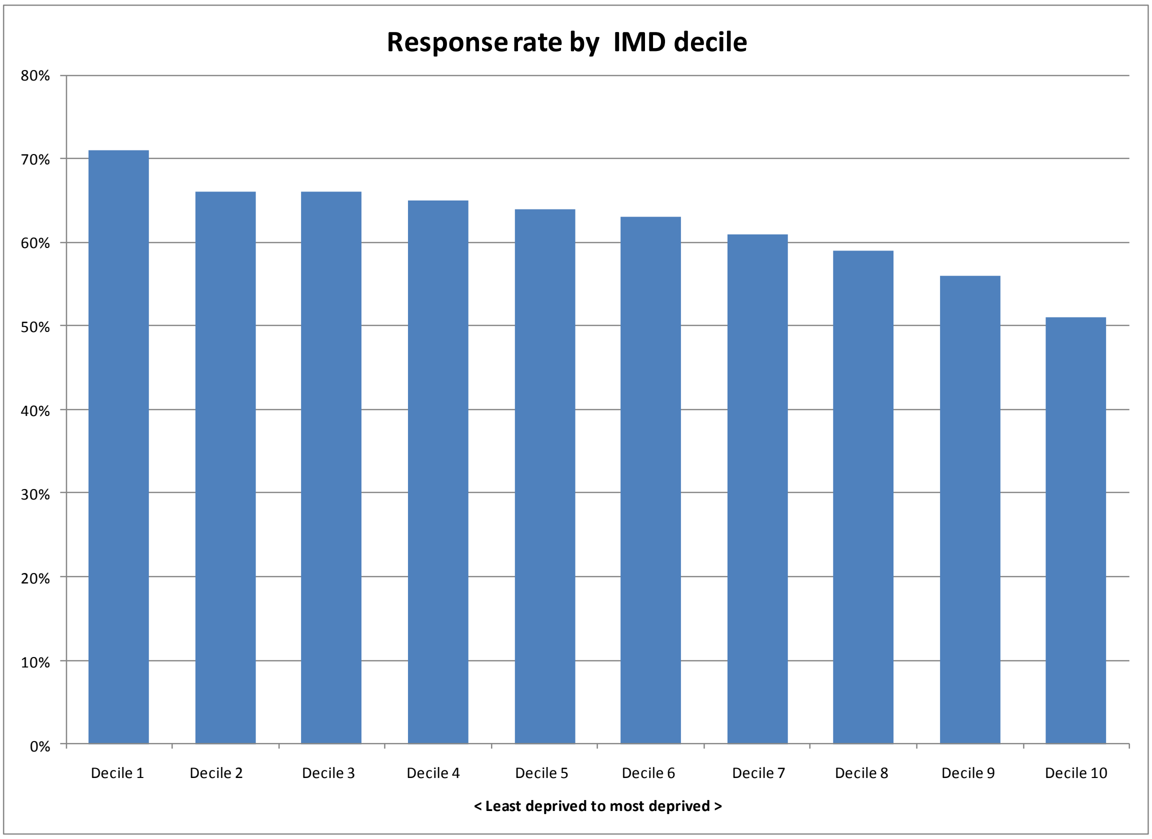

Chart 45 Response rates by IMD decile

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[7] Response rates have not been adjusted for deaths, moved etc. in this chart

It is possible that the lower response rates amongst decile 10 in particular has minimised the effect of decile 1 - decile 10 range differences in the analysis, because of the smaller quantity of data received from patients in the most deprived areas.

There is also evidence from the survey that respondents in decile 10 have different characteristics from those in decile 1.

Analysis of the ethnicity and age range composition of patients with postcodes represented in each IMD decile shows that there are heavy concentrations of ethnic minority patients and to some degree younger patients in the most deprived deciles. The chart below shows the position for deciles 1 and 10:

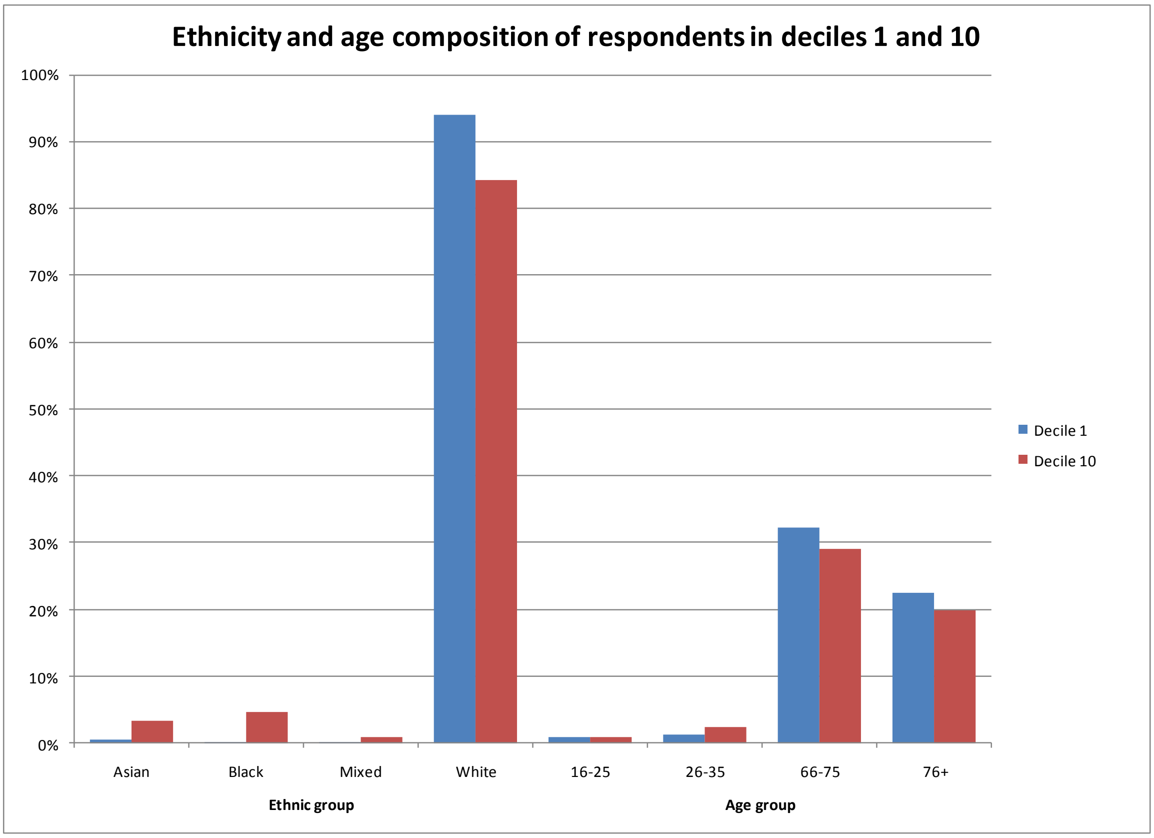

Chart 46 Ethnicity and age composition of respondents by IMD decile

None of these findings are surprising and they show that there is overlap between the analysis findings for deprivation and those for ethnicity and age.

Differences between SHA Regions and the London-non London effect

Analysis of the survey results by SHA indicates that there are some significant differences between regions, with 10 questions on which there are statistically significant differences. On 9 of these 10 questions, London is the worst performing region; and on the other question, the East Midlands is the worst performing region.

The questions on which there are statistically significant differences when the data is analysed by region are:

• Patients being told they could bring a family member or friend with them when first told they had cancer	Q12	London worst
• Easy to contact the Clinical Nurse Specialist	Q21	London worst
• Hospital staff gave information on financial help and benefits	Q26	East Midlands worst
• When had important questions to ask a ward nurse, received answers they could understand all / most of the time	Q39	London worst
• Confidence and trust in all ward nurses treating them	Q40	London worst
• Post discharge given enough help from health and social services	Q52	London worst
• Given enough emotional support by staff when treated in outpatients or as a day case patient	Q58	London worst
• Waiting time within 30 minutes at last outpatient appointment	Q60	London worst
• GPs, nurses at the Practice definitely did everything needed to support patient whilst they were having treatment	Q64	London worst
• GPs, and other staff worked well together to give best possible care	Q65	London worst

These findings replicate to some degree the findings of the previous cancer surveys in 2000 and 2004, and those of the national patient surveys. Two themes emerge: London fares worst on questions related to the general organisation of NHS services, especially those connecting primary care and hospital care; and on certain aspects of information. An area of particular concern is the significantly worse position in London in respect of patients ease of contacting the Clinical Nurse Specialist.

We will produce further analyses by the NHS London sectors to indicate where the most significant problems lie and the extent to which they are related to the composition of the patient population.

An example of the scale of differences between patients' views in London and those in other SHAs is indicated in the chart below:

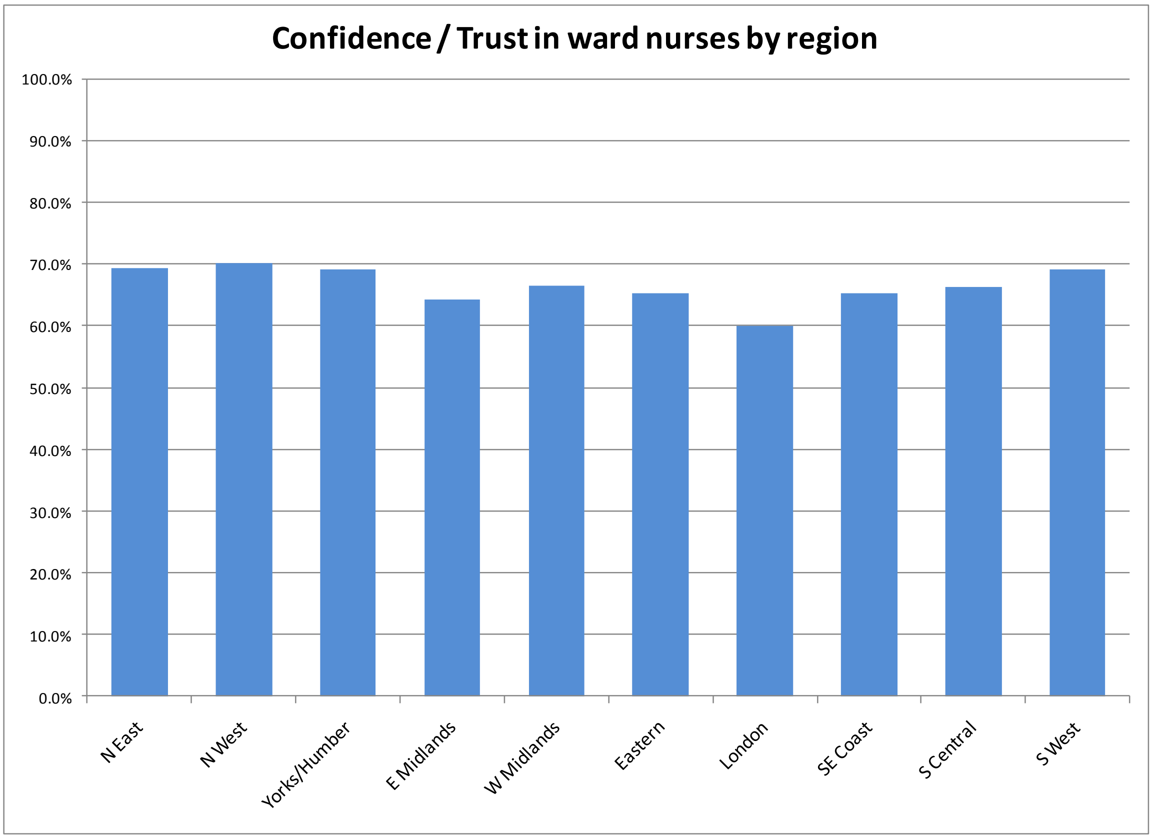

Chart 47 Had confidence and trust in all ward nurses treating them

10. Survey Development and methodology

Development of the 2010 Questionnaire

The 2010 Cancer Patient Experience Survey questionnaire drew on the 2000 and 2004 cancer survey questionnaires as the basis for many of its questions. However, many new questions were added (some taken from the National Patient Survey) or developed to meet the specific requirements of the pathways through which cancer patients received treatment.

Cognitive testing of the questionnaire was undertaken to ensure that patients would understand the questions being asked, that no important issues had been omitted and to check that the questions were, as far as possible, in the order that the patient would recognise as fitting the pathway that they had followed.

As some of the questions had been cognitively tested previously, it was decided that, although all questions in the 2010 questionnaire would be tested, greater emphasis would be placed on the structure of new questions, their place in the survey as a whole, instructions for routing, and those questions with more complex terminology or timescale assessments involved. It is known from evidence from the patient help lines run by Quality Health for the National Patient Survey system and for Patient Reported Outcome Measures (PROMs) that the issues of timescale assessment, and the meaning of NHS terminology and words which are unusual for the reader, are ones which prove difficult to understand for some patients.

A list of volunteers for the cognitive testing was provided by Macmillan Cancer Support; these patients were from a wide range of cancer types and from all over the country. A small number of additional volunteers were also recruited from the geographical area close to the Quality Health base.

Cognitive testing was undertaken in a number of phases. For each phase, the postal methodology which is used for most national patients' surveys and was to be used in the live phase for the National Cancer Patient Experience Survey was replicated. Accordingly, questionnaires were sent to participants who were asked to complete the questionnaire before the interview. This style of testing was used to help determine the participant's ability to complete the questionnaire on their own, and to follow routing instructions. Both the covering letter and language leaflet were also included in the testing.

Interviewees were talked through the questionnaire with the interviewer asking what answer was given to each question, recording the answers on screen, and then asking a number of scripted questions. If required, spontaneous follow up questions were allowed to probe further into the interviewee's reasons for giving the answer they did and their understanding of the question. Potential issues and follow up questions were listed by question on the testing template used by interviewers. The templates allowed interviewers to type in responses in real time and to record question answers given by the interviewees.

Interviewers also asked a number of general questions. These included:

- What do you think about the use of the word Cancer throughout the questionnaire?
- Was the 'lead-in text' before some of the questions clear and helpful?
- Did you understand and follow the routing instructions beside some questions?
- Are there any important things that you think are missing from the survey?
- Did you have treatment at more than one hospital site/NHS Trust, and if so which site have you been assuming you are answering about, and why did you make that decision?
- Do you have any other comments to make?

As each phase of the testing was completed discussions took place about any issues that had arisen and questions were refined, removed or moved within the questionnaire.

A detailed report on the cognitive testing of the questionnaire can be found at www.quality-health.co.uk

Methodology

The 2010 Cancer Patient Experience Survey included all adult patients (aged 16 and over) with a primary diagnosis of cancer in the first diagnosis field, who had been admitted to an NHS hospital as an inpatient or as a day case patient, and had been discharged between 1st January 2010 and 31st March 2010. Operationally used ICD10 codes of C00-C99, and D05 were used. Patients with an ICD10 code of C44 (other malignant neoplasms of the skin) were excluded from the sample by agreement.

158 hospital trusts participated in the survey. Some specialist trusts and PCTs providing cancer services were excluded from the survey as the numbers of patients being treated were very low.

Each Trust was responsible for drawing the sample of patients and checking the list of patients through the DBS system (Demographic Batch Service) for deaths. DBS checks were undertaken on three separate occasions; at the initial send out stage, and at first and second reminder stage.

A Guidance Manual was developed to guide Trust staff through the sampling process and to provide background information to the survey. The national Guidance Manual and data capture documents, and all survey materials, can be located at www.quality-health.co.uk

The survey was run using procedures very similar to those used for the national patient surveys run by the Care Quality Commission, which some Trust staff would be familiar with and which would give additional comparative data on some questions.

Data security agreements were signed between each Trust and Quality Health who undertook all fieldwork including despatch and receipt of questionnaires, data capture and analysis of the data. All personal data was held within a closed loop system and no third party contractors had any access to personal information.

The Survey Process

Samples were drawn by Trusts in accordance with the Guidance Manual provided to them and then checked through the DBS system before submission to Quality Health. Quality Health then undertook 16 further types of checks to ensure that the sample met the survey criteria and that all requested information was present.

In particular, duplicate or multiple admissions or attendances were removed from Trust samples, and also across Trusts nationwide, in order to prevent patients from being sent multiple questionnaires related to attendance at different Trusts.

The survey was conducted by post, with two reminders (to non-responders only) as is the case with the national patient surveys. A standard questionnaire, covering letter and reminder letters were used.

All covering letters were sent out on Trust headed paper and signed by a member of the Trust’s staff – often the Chief Executive; specific authorisation was obtained from each Trust for the use of the signature and headed paper. A language leaflet was also enclosed offering translation services and a pre-paid return envelope was included so that patients could respond without financial cost.

Quality Health also ran a national freephone helpline for patients, and supported completion of the survey through textphone and language translation facilities, using its own in house staff.

Questionnaires were returned to Quality Health for data capture. A log was kept of all helpline calls and correspondence detailing information about deceased patients, those who had moved or those who did not wish to participate in the survey.

At all stages of the process procedures were put in place to comply with the Data Protection Act 1998, and the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott principles.

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 1 which asks about the number of times the patient saw their GP before going to hospital. Where patients had said ‘none’, they were then asked to go to question 6. In cases such as this special rules were applied to the data in questions 2 to 5. If patients had ticked answer option 1 in question 1 and said they did not see their GP but had then gone on to answer any of questions 2 to 5, this response data was removed; if question 1 had been left blank with no answer option ticked, but patients had gone on to answer questions 2 to 5, this response data was left in and question 1 was left blank.

When calculating percentage responses to questions some patients were removed from the calculation: those who had not answered at all; those who had answered ‘don’t know / can’t remember’; and those who had said that the question was not relevant to them (e.g. I did not need an explanation).

No weighting or standardisation was applied to the data before analysis.

Reporting

Reports have been produced at both national and Trust level arising from the 2010 National Cancer Patient Experience Survey[8].

These reports are as follows:

- This National Report, covering all Trusts and all cancer types
- Reports for each participating Trust, indicating their performance against providers generally, and by cancer type

Consideration is also being given to providing further reports for Cancer Networks and Primary Care Trusts in their capacity as Commissioners of service.

The conventions used in this National 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 (for example) one tumour group and the total for all tumour groups are of real standing. The test has been applied to give results at the 95% confidence interval and in almost all cases the resulting confidence interval is +/- 1.9%. The only cases where the confidence interval is wider is where the absolute numbers of respondents falls below about 500 in a category being analysed.

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[8] These reports will be available via Quality Health at www.quality-health.co.uk and Department of Health at www.dh.gov.uk

The second statistical test used is chi squared, giving an analysis of whether the differences seen across all tumour groups (or other categories) are in fact significant taking them as a whole. In this Report we have used a standard form of words in the text to reflect instances where chi square indicates that there are no real differences in results looking at tumour groups as a whole.

Where we are analysing the results by tumour group, we only report where a particular group's results have been identified as significantly different from the results for all tumour groups. In cases where chi square tells us that the results across all groups are not significantly different, we have indicated in the text that there are no real differences between them.

Normally, when analysing results by tumour group, we have used examples from the best and worst performing tumour groups on that particular question. These examples have only been used where that tumour group itself has significantly different results from that of respondents as a whole.

In respect of each question in the survey, a "scored" answer line has been identified as the data to be reported on as the key response on that question and these key responses are also used in the charts and tables.

Appendix A – Full Survey Results

This appendix sets out the full results from the 2010 National Cancer Patient Experience 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. 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 or to remove neutral responses e.g. 'don't know' or 'can't remember'. 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 2).

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 1 is ticked and the patient goes on to answer questions 2 to 5, then any data between question 1 and question 6 (where the patient was directed) will be deleted as these questions should not have been answered by the patient.

SEEING YOUR GP

		Total	Percent
1.	**Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?**		
	None I did not see my GP before going to hospital	13224	20%
	I saw my GP once	*27600*	*54%*
	I saw my GP twice	*10733*	*21%*
	I saw my GP 3 or 4 times	*8234*	*16%*
	I saw my GP 5 or more times	*4613*	*9%*
	Don't know / Can't say	1318	2%
	Missing	1991	
2.	**After your GP first told you that you would need to see a hospital doctor, how long did you have to wait before your first appointment with a hospital doctor?**		
	I was seen the same day or next day	*4665*	*10%*
	I was seen after 2-14 days	*28240*	*58%*
	I was seen in 3 to 4 weeks	*11097*	*23%*
	Waited 1 to 4 months	*4377*	*9%*
	Waited more than 4 months	*373*	*1%*
	I did not see my GP before going into hospital	916	2%
	I chose to have a later appointment than the one I was offered	110	0%
	Don't know / Can't remember	1837	4%
	Missing	16098	
3.	**How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?**		
	I was seen as soon as I thought was necessary	41528	81%
	I should have been seen a bit sooner	6332	12%
	I should have been seen a lot sooner	3643	7%
	Missing	16210	
4.	**How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?**		
	Less than 3 months	38401	74%
	3-6 months	6787	13%
	6-12 months	2624	5%
	More than 12 months	2217	4%
	Don't know / Can't remember	1855	4%
	Missing	15829	
5.	**Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?**		
	My health got worse	11523	22%
	My health got better	348	1%
	My health stayed abou the same	40104	77%
	Missing	15738	

DIAGNOSTIC TESTS

		Total	Percent
6.	**In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?**		
	Yes	58653	90%
	No	6741	10%
	Missing	2319	
7.	**Beforehand, did a member of staff explain the purpose of the test(s)?**		
	Yes completely	*44902*	*81%*
	Yes to some extent	*9318*	*17%*
	No but I would have liked an explanation	*1229*	*2%*
	I did not need an explanation	3019	5%
	Don't know / Can't remember	653	1%
	Missing	8592	
8.	**Beforehand, did a member of staff explain what would be done during the test procedure(s)?**		
	Yes completely	*47617*	*84%*
	Yes to some extent	*8163*	*14%*
	No but I would have liked an explanation	*782*	*1%*
	I did not need an explanation	2185	4%
	Don't know / Can't remember	496	1%
	Missing	8470	
9.	**Beforehand, were you given written information about your test(s)?**		
	Yes and it was easy to understand	*37624*	*85%*
	Yes but it was difficult to understand	*1631*	*4%*
	No but I would have liked written information about the test(s)	*5030*	*11%*
	I did not need written information	11076	19%
	Don't know / Can't remember	3531	6%
	Missing	8821	
10.	**Were the results of the test(s) explained in a way you could understand?**		
	Yes completely	*44166*	*76%*
	Yes to some extent	*12152*	*21%*
	No but I would have liked an explanation	*1644*	*3%*
	I did not need an explanation	680	1%
	Don’t know / Can’t remember	466	1%
	Missing	8605	

FINDING OUT WHAT WAS WRONG WITH YOU

	Total	Percent
11. Who first told you that you had cancer?		
A hospital doctor	54739	83%
A hospital nurse	3030	5%
A GP (family doctor)	4510	7%
Another health professional	2276	3%
A friend or relative	141	0%
Nobody – I worked it out for myself	1174	2%
Missing	1843	
12. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?		
Yes	*37748*	*71%*
No	*15757*	*29%*
It was not necessary	8045	12%
I was told by phone or letter	1217	2%
Don’t know / Can’t remember	3309	5%
Missing	1637	
13. How do you feel about the way you were told you had cancer?		
It was done sensitively	54744	83%
It should have been done a bit more sensitively	7737	12%
It should have been done a lot more sensitively	3691	6%
Missing	1541	
14. Did you understand the explanation of what was wrong with you?		
Yes I completely understood it	*48688*	*74%*
Yes I understood some of it	*16134*	*24%*
No I did not understand it	*1415*	*2%*
Can’t remember	375	1%
Missing	1101	
15. When you were told you had cancer, were you given written information about the type of cancer you had?		
Yes and it was easy to understand	*37139*	*66%*
Yes but it was difficult to understand	*3783*	*7%*
No I was not given written information about the type of cancer I had	*15464*	*27%*
I did not need written information	6482	10%
Don’t know / Can’t remember	2769	4%
Missing	2076	

DECIDING THE BEST TREATMENT FOR YOU

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

	Total	Percent
Yes	*18788*	*83%*
No but I would have liked a choice	*3941*	*17%*
I was not given a choice because only one type of treatment was suitable for me	40359	62%
Not sure / Can't remember	2123	3%
Missing	2502	

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

	Total	Percent
Yes definitely	*44615*	*72%*
Yes to some extent	*14014*	*23%*
No side effects were not explained	*2953*	*5%*
I did not need an explanation	2671	4%
Not sure / Can't remember	1016	2%
Missing	2444	

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

	Total	Percent
Yes and it was easy to understand	*48088*	*79%*
Yes but it was difficult to understand	*2818*	*5%*
No I was not given written information about side effects	*9587*	*16%*
Don't know / Can't remember	3594	6%
Missing	3626	

19. Were you involved as much as you wanted to be in decisions about which treatment(s) you would have?

	Total	Percent
Yes definitely	*34584*	*71%*
Yes to some extent	*10833*	*22%*
No but I would like to have been more involved	*2979*	*6%*
Only one type of treatment was suitable for me	15805	25%
Missing	3512	

CLINICAL NURSE SPECIALIST

		Total	Percent
20.	**Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?**		
	Yes	*52738*	*84%*
	No	*9780*	*16%*
	Don’t know / Not sure	2821	4%
	Missing	2374	
21.	**How easy is it for you to contact your Clinical Nurse Specialist?**		
	Easy	*35321*	*75%*
	Sometimes easy sometimes difficult	*10517*	*22%*
	Difficult	*1558*	*3%*
	I have not tried to contact her/him	5227	10%
	Missing	15090	
22.	**The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?**		
	Yes definitely	46695	91%
	Yes to some extent	3830	7%
	No	588	1%
	Missing	16600	
23.	**When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?**		
	All or most of the time	*42429*	*91%*
	Some of the time	*3895*	*8%*
	Rarely or never	*493*	*1%*
	I do not ask any questions	4442	9%
	Missing	16454	
24.	**The last time you saw or spoke to your Clinical Nurse Specialist, do you feel that the time you spent with them was too long, too short or about right?**		
	Too short	2524	5%
	About right	47753	95%
	Too long	146	0%
	Missing	17290	

SUPPORT FOR PEOPLE WITH CANCER

	Total	Percent
25. Did hospital staff give you information about support or self-help groups for people with cancer?		
Yes	*37617*	*79%*
No but I would have liked information	*10007*	*21%*
It was not necessary	14027	22%
Don’t know / Can’t remember	3497	5%
Missing	2565	
26. Did hospital staff give you information about how to get financial help or benefits?		
Yes	*17750*	*50%*
No but I would have liked information	*17923*	*50%*
It was not necessary	26881	41%
Don’t know / Can’t remember	2454	4%
Missing	2705	
27. Did hospital staff tell you that you could get free prescriptions?		
Yes	*20540*	*68%*
No but I would have liked information	*9781*	*32%*
It was not necessary	32598	51%
Don’t know / Can’t remember	1331	2%
Missing	3463	

OPERATIONS

	Total	Percent
28. During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?		
Yes	37020	57%
No	27873	43%
Missing	2820	
29. The last time you went into hospital for a cancer operation, was your admission date changed to a later date by the hospital?		
No	33533	89%
Yes it was changed once	3532	9%
Yes it was changed 2 or 3 times	462	1%
Yes it was changed 4 times or more	33	0%
Missing	30153	
30. Before you had your operation, did a member of staff explain what would be done during the operation?		
Yes completely	*31263*	*85%*
Yes to some extent	*5115*	*14%*
No but I would have liked an explanation	*603*	*2%*
I did not need an explanation	907	2%
Don't know / Can't remember	299	1%
Missing	29526	
31. Beforehand, were you given written information about your operation?		
Yes and it was easy to understand	*23342*	*68%*
Yes but it was difficult to understand	*1061*	*3%*
No I was not given written information about my operation	*10024*	*29%*
Don’t know / Can’t remember	3342	9%
Missing	29944	
32. After the operation, did a member of staff explain how it had gone in a way you could understand?		
Yes completely	*27003*	*73%*
Yes to some extent	*7574*	*20%*
No but I would have liked an explanation	*2415*	*7%*
I did not need an explanation	1024	3%
Missing	29697	

HOSPITAL DOCTORS

		Total	Percent
33.	**During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?**		
	Yes	45276	69%
	No	19917	31%
	Missing	2520	
34.	**When you had important questions to ask a doctor, how often did you get answers that you could understand?**		
	All or most of the time	*34400*	*81%*
	Some of the time	*7164*	*17%*
	Rarely or never	*974*	*2%*
	I did not ask any questions	3627	8%
	Missing	21548	
35.	**Did you have confidence and trust in the doctors treating you?**		
	In all of them	38803	84%
	In some of them	7321	16%
	In none of them	221	0%
	Missing	21368	
36.	**Do you think the doctors treating you knew enough about how to treat your cancer?**		
	Yes definitely	*40629*	*89%*
	Yes to some extent	*4411*	*10%*
	No	*529*	*1%*
	Don’t know / Not sure	743	2%
	Missing	21401	
37.	**Did doctors talk in front of you as if you weren’t there?**		
	Yes often	1527	3%
	Yes sometimes	6356	14%
	No	38359	83%
	Missing	21471	
38.	**If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?**		
	Yes definitely	*25524*	*66%*
	Yes to some extent	*10528*	*27%*
	No	*2819*	*7%*
	No family or friends were involved	2703	6%
	My family did not want or need information	3288	7%
	I did not want my family or friends to talk to a doctor	1247	3%
	Missing	21604	

WARD NURSES

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

	Total	Percent
All or most of the time	*29284*	*73%*
Some of the time	*9452*	*23%*
Rarely or never	*1547*	*4%*
I did not ask any questions	5936	13%
Missing	21494	

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

	Total	Percent
In all of them	30709	66%
In some of them	15028	33%
In none of them	463	1%
Missing	21513	

41. Did ward nurses talk in front of you as if you weren’t there?

	Total	Percent
Yes often	1394	3%
Yes sometimes	6245	14%
No	38383	83%
Missing	21691	

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

	Total	Percent
There were always or nearly always enough on duty	28539	62%
There were sometimes enough on duty	13149	29%
There were rarely or never enough on duty	4259	9%
Missing	21766	

HOSPITAL CARE & TREATMENT

		Total	Percent
43.	**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?**		
	Often	604	1%
	Sometimes	4591	10%
	Only once	959	2%
	Never	39967	87%
	Missing	21592	
44.	**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?**		
	Often	988	2%
	Sometimes	5577	12%
	Only once	3320	7%
	Never	36163	79%
	Missing	21665	
45.	**Were you given enough privacy when discussing your condition or treatment?**		
	Yes always	38093	82%
	Yes sometimes	5900	13%
	No	2208	5%
	Missing	21512	
46.	**Were you given enough privacy when being examined or treated?**		
	Yes always	42641	93%
	Yes sometimes	2809	6%
	No	478	1%
	Missing	21785	
47.	**Do you think the hospital staff did everything they could to help control your pain?**		
	All of the time	*32741*	*85%*
	Some of the time	*5360*	*14%*
	Not at all	*523*	*1%*
	I did not have any pain	7133	16%
	Missing	21956	
48.	**Were you treated with respect and dignity by the doctors and nurses and other hospital staff?**		
	Always	37653	82%
	Most of the time	6969	15%
	Some of the time	1170	3%
	Never	107	0%
	Missing	21814	

INFORMATION GIVEN TO YOU BEFORE YOU LEFT HOSPITAL

		Total	Percent
49.	**Were you given clear written information about what you should or should not do after leaving hospital?**		
	Yes	*35435*	*82%*
	No	*7923*	*18%*
	Can't remember	2239	5%
	Missing	22116	
50.	**Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?**		
	Yes	*40781*	*92%*
	No	*3570*	*8%*
	Don’t know / Can’t remember	1455	3%
	Missing	21907	
51.	**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?**		
	Yes definitely	*21780*	*58%*
	Yes to some extent	*8539*	*23%*
	No	*7128*	*19%*
	No family or friends were involved	3409	8%
	My family or friends did not want or need information	3699	8%
	I did not want my family or friends to be given information	769	2%
	Missing	22389	

ARRANGING HOME SUPPORT

52. After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists)?

	Total	Percent
Yes definitely	*15518*	*60%*
Yes to some extent	*5602*	*22%*
No	*4830*	*19%*
I did not need help from health or social services	19359	43%
Don't know / Can't remember	169	0%
Missing	22235	

HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

		Total	Percent
53.	**During the last 12 months, have you had radiotherapy at one of the hospitals named in the covering letter?**		
	Yes	16976	26%
	No	47343	74%
	Missing	3394	
54.	**Did hospital staff do everything possible to control the side effects of radiotherapy?**		
	Yes definitely	*12521*	*82%*
	Yes to some extent	*2261*	*15%*
	No they could have done more	*419*	*3%*
	I have not had any side effects from radiotherapy	1773	10%
	Missing	50739	
55.	**During the last 12 months, have you had chemotherapy at one of the hospitals named in the covering letter?**		
	Yes	34411	53%
	No	30104	47%
	Missing	3198	
56.	**Did hospital staff do everything possible to control the side effects of chemotherapy?**		
	Yes definitely	*27808*	*85%*
	Yes to some extent	*4242*	*13%*
	No they could have done more	*694*	*2%*
	I have not had side effects from chemotherapy	1701	5%
	Missing	33268	
57.	**While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?**		
	Yes definitely	*31701*	*83%*
	Yes to some extent	*5505*	*14%*
	No they could have done more	*1071*	*3%*
	I did not have any pain	24688	39%
	Missing	4748	
58.	**While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?**		
	Yes definitely	*32850*	*71%*
	Yes to some extent	*10303*	*22%*
	No I would have liked more support	*3207*	*7%*
	I did not need emotional support from staff	16863	27%
	Missing	4490	

OUTPATIENTS APPOINTMENTS WITH DOCTORS

59. 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?

	Total	Percent
Yes	60373	93%
No	4748	7%
Missing	2592	

60. The last time you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?

	Total	Percent
Seen on time or early	*10521*	*18%*
Waited up to 5 minutes	*4416*	*8%*
Waited 6 - 15 minutes	*11774*	*20%*
Waited 16 - 30 minutes	*12832*	*22%*
Waited 31 - 60 minutes	*10848*	*19%*
Waited 1 to 2 hours	*6338*	*11%*
Waited more than 2 hours	*1795*	*3%*
Don’t know / Can’t remember	1649	3%
Missing	7540	

61. The last time you had an outpatients appointment with a cancer doctor, was the time you spent with them too long, too short or about right?

	Total	Percent
Too short	3497	6%
About right	56347	94%
Too long	286	0%
Missing	7583	

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

	Total	Percent
Yes	*54887*	*95%*
No	*2994*	*5%*
Don’t know / Can’t remember	2075	3%
Missing	7757	

CARE FROM YOUR GENERAL PRACTICE

		Total	Percent
63.	**As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?**		
	Yes	*48792*	*93%*
	No	*3485*	*7%*
	Don’t know / Can’t remember	12804	20%
	Missing	2632	
64.	**Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?**		
	Yes definitely	*30702*	*69%*
	Yes to some extent	*9593*	*22%*
	No they could have done more	*4262*	*10%*
	My general practice was not involved	19757	31%
	Missing	3399	

YOUR OVERALL NHS CARE

65. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?

	Total	Percent
Yes always	*38209*	*61%*
Yes most of the time	*18095*	*29%*
Yes some of the time	*5032*	*8%*
No never	*910*	*1%*
Don't know	2540	4%
Missing	2927	

66. How much information were you given about your condition and treatment?

Not enough	6978	11%
The right amount	56924	88%
Too much	822	1%
Missing	2989	

67. Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year, did you feel like that?

Yes often	2522	4%
Yes sometimes	10087	16%
No	51780	80%
Missing	3324	

ABOUT YOU

68. Age:

	Total	Percent
16 - 25	434	1%
26 - 35	1072	2%
36 - 50	7063	11%
51 - 65	21856	34%
66 - 75	19674	31%
76+	13299	21%
Missing	4315	

69. Are you male or female?

	Total	Percent
Male	30430	47%
Female	34744	53%
Missing	2539	

70. Do you have any of the following longstanding conditions?

	Total	Percent
Deafness or severe hearing impairment	6626	10%
Missing	61087	
Blindness or partially sighted	1684	2%
Missing	66029	
A long-standing physical condition	9168	14%
Missing	58545	
A learning disability	301	0%
Missing	67412	
A mental health condition	1184	2%
Missing	66529	
A long-standing illness such as HIV diabetes chronic heart disease or epilepsy	8695	13%
Missing	59018	
No I do not have a longstanding condition	40101	59%
Missing	27612	

71. How long is it since you were first treated for this cancer?

	Total	Percent
Less than 1 year	41386	64%
1 to 5 years	16621	26%
More than 5 years	6129	10%
Don't know / Can't remember	268	0%
Missing	3309	

ABOUT YOU

72. Which of the following best describes your sexual orientation?

	Total	Percent
Heterosexual / straight (opposite sex)	58674	94%
Bisexual (both sexes)	130	0%
Gay or Lesbian (same sex)	362	1%
Other	308	0%
Prefer not to answer	2949	5%
Missing	5290	

73. Could we send you a survey in the future to ask about your health and healthcare?

	Total	Percent
Yes and I understand that this does not mean that I would have to take part in the future survey	53104	83%
No I would prefer you not to contact me again	11014	17%
Missing	3595	

74. To which of these ethnic groups would you say you belong?

	Total	Percent
British	59530	93%
Irish	1033	2%
Any other White background	1194	2%
White and Black Caribbean	74	0%
White and Black African	43	0%
White and Asian	86	0%
Any other mixed background	57	0%
Indian	563	1%
Pakistani	235	0%
Bangladeshi	55	0%
Any other Asian background	154	0%
Caribbean	524	1%
African	342	1%
Any other Black background	13	0%
Chinese	143	0%
Any other ethnic group	72	0%
Missing	3595	

The National Cancer Patient Experience Survey was undertaken by Quality Health, which specialises in measuring patients' experiences of hospital, primary care and mental health services, using this information to improve the quality of health care and the responsiveness of health services to patients and service users' needs.

Quality Health works with all acute hospitals in England, all independent providers of hospital care, and all Health Boards in Scotland using rigorous survey methods to evaluate the quality of services to patients, the outcomes of operative procedures and health gain, and establish the views of NHS staff. Quality Health also works for healthcare system providers in the Middle East and in Wales and Northern Ireland.

Quality Health is an approved contractor for the Care Quality Commission survey programmes of patients and staff in the NHS and also undertakes data collection and survey systems for the National Patient Reported Outcomes programme on behalf of the Department of Health. Quality Health has headquarters in North Derbyshire.

Further information on the National Cancer Patient Experience Survey programme and the 2010 survey can be obtained at www.quality-health.co.uk

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