NHS

Cancer Patient Experience Survey 2011/12

National Report

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Cancer Patient Experience Survey 2011/12

National Report

Prepared by Quality Health

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1. Foreword

I am delighted to present to you the national report of the 2011/12 national cancer patient experience survey. The original large scale cancer survey was run in 2000, with a smaller National Audit Office funded survey in 2004, and another major new survey in 2010. The 2011/12 survey covered inpatient and day case cancer patients treated between 1st September and 30th November 2011.

71,793 patients completed a survey with an overall national response rate of 68%, up by 1% on the 2010 survey (and far higher than the national inpatient survey with a response rate of 53%). There was considerable variation in Trust response rates, with the highest at 79% and the lowest at 45%.

On most questions in the 2011/12 survey, scores have improved, which is a major achievement considering Trust level reports were only issued in January 2011 and this latest survey covers patients from September 2011. The most significant increases in positive scores are on information and communication issues.

Nine new questions were included in the 2011/12 survey, with interesting results. A new overarching question asking patients to rate their overall care came out very high, with 88% of patients rating their care 'excellent' or 'very good'. Although this is a high score, results from individual Trusts show there is significant variation in the proportion of patients rating their care as excellent or very good – 94% in the highest Trust to 64% in the lowest.

Three new questions were asked about research, with 33% of patients saying that taking part in research had been discussed with them. Of these, 95% were glad to have been asked. Of the patients who were not asked about research, 53% said they would have liked to have been asked.

Other new questions had less positive results, such as all staff asked patients what name they preferred to be called (56% - highest Trust 82%, lowest 24%) and patient offered written assessment and care plan (24% - highest Trust 49%, lowest 5%), but we know these are relatively new initiatives and these results provide a good baseline for future surveys.

The equality and demographic analyses broadly show similar results to 2010: women are less positive than men; younger people are less positive than older people; BME groups are less positive than whites groups; non-heterosexuals are less positive than heterosexuals; those with a long term condition are less positive than those without one; and London still has the lowest reported figures. A joint analysis of both 2010 and 2011/12 data will be made to test the significance of these results with higher numbers.

As we transition to the new health and care system, the focus on improving patient experience will increase, as it is Domain 4 of the NHS Outcomes Framework and a dedicated team in the NHS Commissioning Board will strive to help the NHS improve outcomes in patient experience. These results will help drive this improvement for cancer patients. Each of the 160 Trusts taking part in the 2011/12 survey have been provided with a bespoke Trust level report, benchmarking their results against other Trusts nationally and also between multi-disciplinary teams within Trusts where numbers allow. Variations in care reported in these results can be marked, so I would strongly urge clinicians, managers and commissioners to look carefully at their local reports to assess areas where change is needed.

We intend to use and promote the 2011/12 survey results in a variety of ways. We will make this national and all the Trust level reports widely available to drive and inform local service improvement. The reports provide a breakdown of the experience of cancer patients across a number of stages in the cancer care pathway and include analysis of improvement levels since the 2010/11 survey.

The National Cancer Action Team has worked with Cancer Networks over the last year to use the results of the 2010 survey to drive service improvements and will continue this work using the results of the 2011/12 survey. We are also encouraging stakeholders in the third sector who are planning to use the survey results to identify and share best practice in patient care and services to support service improvement activity.

Finally, all the quantitative data will be sent to the National Data Archive at Essex University and will be freely available for access by academics and researchers to undertake a series of analyses under the rules of the archive.

We will be repeating the survey in 2012/13, and I look forward to seeing if the Trusts can continue to make improvements in cancer patient experience as has been shown by the results of the 2011/12 survey.

Professor Sir Mike Richards
National Cancer Director

2. Introduction

Improving Outcomes: A Strategy for Cancer **(January 2011) committed the Department of Health to repeating the 2010 Cancer Patient Experience Survey (CPES). The surveys are designed to monitor national progress on improving outcomes in cancer patient experience and to provide information that could be used to drive local quality improvements. The surveys also help gather vital information on national initiatives, such as the Transforming Inpatient Care Programme, the National Cancer Survivorship Initiative and the National Cancer Equality Initiatives.**

The 2011/12 survey fits well with the Operating Framework (OF) for the NHS 2012/13, which defines quality as those indicators of safety, effectiveness and patient experience that indicate that standards are being maintained or improved. The OF contains requirements to monitor and act on the outcomes of patient experience surveys, and indicates that Commissioners should identify local measures of integrated care which will support improved delivery, such as patient reported experience of co-ordinated care.

The principles and objectives of the 2011/12 survey and the questionnaire development were overseen by the Cancer Patients' Experience Advisory Group, which is co-chaired by Professor Jessica Corner of Macmillan Cancer Support and Professor Sir Mike Richards, National Cancer Director. The group includes representatives from NHS Trusts, academics, the third sector, and clinicians from primary and secondary care.

The 2011/12 survey follows on from the 2010 cancer patient experience survey, which built on previous surveys undertaken in 2000 and 2004. Although the 2000 and 2004 surveys were important in enabling national benchmarking, feedback suggested they had little impact in driving improvements in the quality of services locally. The national report of the 2010 survey, published in December 2010 and outlined in *Improving Outcomes – a Strategy for Cancer* (January 2011), showed that, in many areas, patient experience was improving, but also identified areas where further progress was needed.

In January 2011, 158 bespoke Trust level reports were published, and the survey provider visited the worst performing 10% of Trusts to explain their results and offer practical help on actions to improve the experience of their patients. The 2010 survey clearly had an impact locally, unlike the 2000 and 2004 surveys. For example, the London cancer networks produced an action plan to improve experience in London hospitals, and every Trust in London produced its own action plan. Highly visual red, amber, green (RAG) ratings of Trust reports were produced to show benchmarking between Trusts and between survey questions, which were highly effective in emphasising variations in patient experience. The 2010 data was also made widely available via the National Data Archive at Essex University to allow a whole range of analysis on the data from a wide variety of groups and institutions, including analysis of the results by equality characteristic by the National Cancer Equality Initiative (NCEI).

In order to establish the impact of these actions, and to measure progress on cancer care generally, a further survey of cancer patient experience was commissioned, with data capture in Autumn 2011 and fieldwork taking place early in 2012, with the purpose of measuring progress since 2010, establishing baseline data on a number of issues, such as participation in cancer research and patients' assessments of the overall rating of care, and providing benchmarks to promote continued service improvements for patients.

The results of the 2011/12 survey demonstrate that there have been significant improvements on a wide range of scores as compared with the results from 2010.

Key developments that may have impacted on improving patient experience between the 2010 survey and the 2011/12 survey have included: the implementation of cancer Information Prescriptions across beacon sites covering fifteen acute Trusts across 34 hospital sites; the expansion of the *Connected* national advanced communications skills training programme, with over 12,000 senior clinicians now trained; supporting multi-disciplinary teams (MDTs) in provider Trusts to work more effectively; repeating the 2010 adult Clinical Nurse Specialist (CNS) census to align with the 2010 survey data to enable direct comparison between results relating to CNS presence and patient satisfaction; the publication of a practical guide for healthcare professionals undertaking holistic needs assessment for people with cancer (March 2011); and the setting up of *BME Cancer Voice* to understand the issues facing people from Black and Minority Ethnic (BME) communities who have been affected by cancer.

3. Executive Summary

The results of the 2011/12 National Cancer Patient Experience Survey (CPES) indicate that cancer inpatients report significantly better experience of care than do hospital inpatients generally, despite improvements to some scores in the general hospital inpatients survey organised by the Care Quality Commission. The 2011/12 CPES shows significant improvements have been made since 2010 to the quality of cancer services as measured by the views of patients themselves.

In 2011/12 one amendment to the data capture criteria was made by agreement with the Cancer Patient Experience Advisory Group (CPEAG) to remove a very small group of haematological patients with rare conditions (e.g. Mycosis Fungoides, and unspecified T cell Lymphomas) who may not be told by clinicians on diagnosis that they had cancer. For analysis in this report, the 2010 national dataset used for both the national and Trust level reports has therefore been adjusted to exclude this small group of respondents in C84 (123 respondents in 2010) to ensure like for like comparability with 2011/12. The 2011/12 CPES sample was 113,808 and the number of respondents was 71,793.

The 2011/12 CPES included patients who had been treated as inpatients or day cases between 1st September and 30th November 2011. The patients had relevant cancer ICD10 codes (C00-99 excluding C44 and C84, and D05) in the first diagnosis field of their patient records, and were alive at the point at which fieldwork commenced.

A small number of changes were made to the content of the survey in 2011/12, to remove or reword some questions and to introduce new questions. These covered: patients' views being taken into account by doctors and nurses when discussing treatment; patients being asked to participate in cancer research; patients being able to discuss worries and fears with staff; patients being offered a written assessment and care plan; and on their overall rating of care received.

Overall, there are 64 scored questions in the CPES 2011-12 on which analysis has been undertaken.

Response rates

The response rate to the 2011/12 CPES (68%) compares very favourably with the response rate for the 2011 National Inpatient Survey[1] organised by the Care Quality Commission (53%) and is similar to that achieved in the 2010 CPES (67%). It is encouraging that again in 2011/12 a very high proportion of responders (84%) have indicated that they would be willing to participate further in surveys designed to understand their experiences of cancer services.

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[1] CQC, National Inpatient Survey Results, May 2011 at http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/inpatient-survey-2011

The high response rate to the 2011/12 CPES means that for most Trusts there are sufficient numbers of responders to make robust comparisons between Trusts, and in many instances for all cancers and between tumour groups within Trusts. Because of the very large sample, high response rate, and high completion levels for each question, the 95% confidence interval for the data at national level for all cancers is highly robust at +/- 0.3%.

Rarer Cancers

The 2011/12 CPES has continued the principle of covering all cancer groups with some minor exceptions. The responses to both the 2010 and 2011/12 surveys 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 in both surveys indicate that patients in some of the rarer cancer groups have less positive views of their treatment. However, scores in some of these groups have improved in line with the general improvements in overall scores in 2011/12.

Positive Assessments

On many questions in the 2011/12 CPES, patients' overall responses were positive. 32 questions had positive scores of 80% or more[2], out of 64 scored questions in the survey, covering the following aspects of the service. Where questions are comparable, 2011/12 scores are compared to the score in 2010, with the 2010 score in brackets:

- 83% (81% 2010) of patients felt they were seen as soon as necessary by a hospital doctor
- 83% (81% 2010) of patients said that staff gave them a complete explanation of the purpose of test(s)
- 86% (84% 2010) of patients said that staff explained completely what would be done during test(s)
- 86% (85% 2010) of patients were given easy to understand written information about test(s)
- 83% (83% 2010) of patients felt they were told sensitively that they had cancer
- 84% (83% 2010) of patients were given a choice of different types of cancer treatment before their treatment started
- 81% of patients (80% 2010) were given easy to understand written information about the side effects of treatment
- 87% (84% 2010) of patients were given the name of the Clinical Nurse Specialist in charge of their care
- 91% (91% 2010) of patients said their Clinical Nurse Specialist definitely listened carefully to them the last time they spoke to them
- 91% (91% 2010) of patients said they got understandable answers to important questions all or most of the time from their Clinical Nurse Specialist

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

- 95% of those patients who had been asked said that they were glad to have been asked about taking part in cancer research [3]
- 90% (89% 2010) of patients reported that their admission date for their operation was not changed to a later date by the hospital
- 87% (85% 2010) of patients said staff gave a complete explanation of what would be done during their operation
- 82% (81% 2010) of patients said they got understandable answers to important questions all or most of the time from doctors
- 85% (84% 2010) of patients had confidence and trust in all of the doctors treating them
- 83% (83% 2010) of patients said doctors did not talk in front of them as if they were not there
- 84% (83% 2010) of patients said ward nurses did not talk in front of them as if they were not there
- 87% (87% 2010) of patients did not think doctors or nurses were deliberately not telling them certain things that they wanted to know
- 84% (82% 2010) of patients said they were always given enough privacy when discussing condition or treatment
- 94% (93% 2010) of patients said they were always given enough privacy when being examined or treated
- 84% (85% 2010) of patients said hospital staff did everything to help control their pain all of the time
- 83% (82% 2010) of patients were always treated with respect and dignity by the doctors, nurses and other hospital staff
- 84% (82% 2010) of patients were given clear written information about what they should or should not do after leaving hospital
- 93% (92% 2010) of patients said staff told them who to contact if they were worried about their condition or treatment after leaving hospital
- 81% of outpatients / day case patients having chemotherapy said staff definitely did everything possible to control side effects [4]
- 81% (83% 2010) of outpatients / day case patients said staff definitely did everything they could to help control their pain
- 94% (94% 2010) of patients having an outpatient appointment with a cancer Doctor said that the time spent with them was about right
- 95% (95% 2010) of patients having an outpatient appointment with a cancer Doctor said that they had the right documents (notes, x rays, test results) with them
- 94% (93% 2010) of patients said their GP was given enough information about their condition and hospital treatment

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[3] New question in 2012 so no 2010 comparator

[4] Wording of question changed in 2012 so no 2010 comparator

- 89% (88% 2010) of patients felt they were given the right amount of information about their condition and treatment
- 80% (80% 2010) of patients did not feel that they were treated as 'a set of cancer symptoms' rather than a whole person
- 88% of patients rated their care overall as Excellent or Very Good [5]

In the 2011/12 survey, the two questions on controlling the side effects of radiotherapy and chemotherapy were restructured and are not strictly comparable with the 2010 data.

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 2011, and the 2011/12 CPES, that cancer inpatients are more positive about their care and treatment on almost all the questions which are comparable between the two surveys. This finding replicates the CPES results from 2010.

Less Positive Assessments

The specific areas which scored 70% or lower[6] where patients are more critical of cancer services are:

- 69% (66% 2010) of patients were given easy to understand written information about the type of cancer they had
- 70% of patients said that their views were definitely taken into account when the team of doctors and nurses were discussing which treatment they should have [7]
- 52% (50% 2010) of patients said hospital staff gave them information about how to get any benefits they might be entitled to
- 33% of patients said they had had a discussion about whether they would like to take part in cancer research [8]
- 53% of those who had not been asked about taking part in cancer research said that they would have liked to have been asked [9] [10]
- 65% (66% 2010) of patients said their family or someone else close to them definitely had enough opportunity to talk to doctor if they wanted to
- 69% (66% 2010) of patients had confidence and trust in all the ward nurses treating them
- 61% (62% 2010) of patients felt there were always or nearly always enough nurses on duty to care for them

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[5] New question in 2012 so no 2010 comparator

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

[7] New question in 2012 so no 2010 comparator

[8] New question in 2012 so no 2010 comparator

[9] New question in 2012 so no 2010 comparator

[10] In respect of new question 29, on whether patients would have been like to be asked about taking part in cancer research, there is a relatively low score (53%) but this cannot be interpreted as a negative score in the same sense that others may be.

- 56% of patients said that in hospital all doctors and nurses asked what name they preferred to be called by [11]
- 64% of patients said that they were able to discuss any worries or fears they had with staff in hospital, as much as they wanted [12]
- 60% (58% 2010) 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
- 61% (60% 2010) of patients were definitely given enough care and help from health or social services after leaving hospital
- 70% (68% 2010) of patients said their appointment started within 30 minutes of their appointment time at their last outpatient appointment with a cancer doctor
- 67% (69% 2010) of patients said GPs and nurses at their general practice did everything they could to support them while they were having cancer treatment
- 62% (61% 2010) 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
- 24% of patients said they had been offered a written assessment and care plan [13]

6 of the 16 lower scores reported above have been registered on questions new to the survey in 2011/12. It was not anticipated that the 2011/12 survey would indicate high scores on such questions as patients being offered care plans, for example, as this is a relatively new policy.

Intermediate scores

A third group of questions fell between these two ranges:

- 74% (75% 2010) of patients said they saw their GP once / twice before being told they had to go to hospital
- 79% (74% 2010) of patients said it was less than 3 months from the time they first thought something might be wrong until first seeing a hospital doctor
- 79% (78% 2010) said their health got better or stayed about the same whilst waiting for their appointment
- 78% (76% 2010) of those patients having tests said they were given a complete explanation of test results in an understandable way
- 72% (71% 2010) of patients said they were told they could bring a friend with them when first told they had cancer
- 73% (74% 2010) of patients said they completely understood the explanation as to what was wrong with them

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[11] New question in 2012 so no 2010 comparator
[12] New question in 2012 so no 2010 comparator
[13] New question in 2012 so no 2010 comparator

- 75% (72% 2010) of patients said possible side effects were explained in an understandable way
- 72% of patients said they were definitely involved in decisions about their care and treatment [14]
- 75% (75% 2010) of patients found it easy to contact their CNS
- 73% (68% 2010) of patients said hospital staff told them about free prescriptions
- 73% (68% 2010) of those patients having operations were given written information about their operation
- 75% (73% 2010) of those patients having operations said staff explained how the operation had gone in an understandable way
- 75% (73% 2010) of patients said they got understandable answers to important questions all or most of the time
- 79% (79% 2010) of patients never thought they were given conflicting information
- 79% of outpatients / day case patients having radiotherapy said staff definitely did everything possible to control side effects [15]
- 71% (71% 2010) of patients said staff definitely gave them enough emotional support

Length of time since diagnosis

The 2011/12 CPES results display a similar pattern of findings as in the 2010 CPES in respect of different views being held by patients who entered cancer treatment more than five years ago, in comparison to those who started treatment in the last year. There are 26 questions in the 2011/12 survey where patients who began treatment more than five years ago have less positive views than more recently treated patients. These questions cover a wide range of topics and there is substantial evidence to suggest that the differences between patients who first started treatment in the last year and those who started treatment earlier is not simply a cohort effect.

Variations between Trusts

In the 2011/12 survey, there are strong indications on a wide range of questions that the range of scores has compressed due to improved performance, especially in the previously poorest performing Trusts. For example, in 2010 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. In 2011/12, on the same question, the range of scores from poorest performing Trust to highest performing Trust was 99% to 74%. However, substantial variations in performance still exist.

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[14] Wording of question changed in 2012 so no 2010 comparator

[15] Wording of question changed in 2012 so no 2010 comparator

Longitudinal comparisons

On over half the scored questions in the 2011/12 survey, there are statistically significant differences between the 2010 and 2011/12 results. Significant improvements were recorded on 37 questions and declines on eight, indicating that on most items in the 2011/12 survey care and treatment was perceived as being more positive than in 2010. These are substantial improvements overall, and on some issues the scale of improvement is very large: for example there is a five percentage point improvement on the score for patients being given information on free prescriptions between 2010 and 2011/12.

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Clinical Nurse Specialists

In 2011/12 the importance identified in 2010 of patients having the name of a Clinical Nurse Specialist (CNS) is confirmed. Perhaps the most important finding of both the 2011/12 and 2010 CPES is that on almost all questions, patients with a CNS give more positive scores than do patients without a CNS. The scale of these differences, between those with a CNS and those without one, is very substantial and has been maintained over the two surveys. The findings are the clearest possible indication of the quality of care given by specialist cancer nurses, the manifest impact that they have on the services given to cancer patients, and the substantially improved understanding of treatment options and prognosis which flow to patients from contact with their CNS.

Differences between tumour groups

There are still wide variations in perceived quality of services shown by patients with different types of cancers. There is no consistent pattern of performance, with some tumour group patients having good scores on some issues and poorer scores on others; but some types of cancer, such as brain and central nervous system and sarcoma, have scores on particular questions which are 20-30 percentage points worse than those given by patients in the best rated cancer groups. Continuing efforts need to be made to reduce the gap in information giving in particular between the best and poorest performing cancer groups.

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. The results from the 2011/12 CPES broadly replicate the results from 2010.

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 43 separate issues on which there are significant differences between age groups as a whole in this survey, with younger patients being the least positive group on 30 of these questions.

As in 2010, clear themes emerge 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 CNSs and fewer of them receive information about benefits they may be entitled to than is the case for other age groups.

Differences relating to gender

On most issues in both the 2010 and 2011/12 CPES, men are significantly more positive than are women, replicating the findings of other NHS patient surveys. In the 2011/12 CPES, there are 46 issues on which there are significant differences between the views of men and of women; men are more positive on 30 of these questions, for example on matters relating to 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 (breast, prostate and gynaecological), with men remaining more positive than women.

Differences relating to sexual orientation

In the 2010 CPES, for the first time in a national NHS survey, a question was asked about patients' sexual orientation. In 2010 there were 16 questions on which there were significant differences in reported experience between heterosexual patients and non-heterosexual patients. In the 2011/12 CPES there were 19 such questions, and in every case but two, respondents who described themselves as non- heterosexual were less positive than heterosexuals. Many less positive ratings were on communication and (broadly) on the respect and dignity with which the patient was treated. The items on which non-heterosexuals were more positive than others were on questions new to the 2011/12 survey, such as participation in cancer research and on being offered care plans.

Patients with long term conditions

In the 2010 CPES, there were statistically significant differences of reported experience between those patients with a long term condition (LTC) or conditions and those without one on 48 questions. In almost all cases the patients with long term conditions were less positive. In the 2011/12 CPES there are 52 such differences, and on almost all such questions patients with at least one LTC were less positive than those without an LTC.

Analysis of results from patients with a named LTC show that there are still differences of perception between those patients with a learning disability or mental health condition in particular and those patients without any LTC. Cancer patients with a learning disability and mental health LTC reported significantly poorer experience, although the scale of difference has been reduced from 2010.

The impact of deprivation

The impact of deprivation on the CPES has been measured using the Index of Multiple Deprivation based on postcode analysis. This shows that there are some differences in the views of patients measured between the least deprived and most deprived groups, but that these differences were not all in one direction.

The IMD analysis can be summarised in the following way, covering both the 2010 and 2011/12 results:

- Whether IMD deciles or quintiles are used, the analysis shows similar results
- Testing for difference between one decile or quintile and the next produces virtually no significant results
- However, when the extremes of the range are taken (e.g. quintile 1 - quintile 5), a large number of differences can be found
- The significant differences that exist are not uni-dimensional i.e. the most deprived quintile is more positive on some issues; and the least deprived on others.

In respect of the 2011/12 CPES there were 44 questions on which there were significant differences between IMD quintile 1 (the least deprived) and quintile 5 (the most deprived), with a reasonably even split between quintile 1 being more positive and quintile 5 being the most positive.

Differences between London and non-London patients

The differences that were revealed between London and non-London Trusts in the 2000 and 2010 national cancer surveys have been confirmed in large part by the 2011/12 CPES. In 2011/12, patients in London are significantly more critical of cancer services on 11 of the 15 questions where there are significant differences between SHA areas.

Conclusion

Overall, it is clear that significant progress has been made since the 2010 CPES in respect of improving the scores received from patients on a wide range of questions; and on improving the scores in some of the poorest performing Trusts in the 2010 survey.

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

Bespoke Trust level reports will be published alongside this national report, with performance benchmarked between Trusts and, where data allows, between multi-disciplinary teams within Trusts. Key information from these reports will be available to the public via NHS Choices and on other publicly available websites.

4. Response rate & helpline calls

A total of 113,808 patients who had received treatment for cancer during September to November 2011 were included in the sample for the National Cancer Patient Experience Survey (CPES) 2011/12. These patients fell into 13 different cancer-type groupings.

Response rate

During the survey process Quality Health undertook Demographics Batch Service (DBS) checks on patient records on three occasions to remove deceased patients from the samples: before the first questionnaire were sent, before the first reminders were sent and before the second reminders were sent. Trusts in some cases also undertook their own internal checks for deceased patients.

This procedure, undertaken centrally at Quality Health for the first time in 2011/12, had the positive effect of substantially reducing the numbers of deceased patients who were sent questionnaires. A central procedure enables tighter control on the existence and timing of DBS checks to be effected, with the positive consequence that the number of deceased patients reported through the helpline dropped by 80%.

After the initial deceased checks and deduplication of samples locally and nationally took place, a final sample of 113,808 was created.

Patients were also removed from the samples arising from calls to the helpline and via postal communications that were received during the fieldwork. These included additional deceased patients, those who had moved and could not be traced and other ineligible patients.

The response rate to the 2011/12 CPES was 68% (71,793 completed questionnaires), compared to 67% in 2010 (67,713 completed surveys). This corresponds with the response rate to the Cancer Survivorship Survey pilot (68%) in 2011; and in the response rates achieved in the 22 Cancer Early Symptoms Surveys 2011/12, which ranged from 88% to 66%. Taken together, these response rates indicate strong willingness by many cancer patients to comment on the care and treatment they received, their health status, and symptoms they experienced.

In previous national cancer patient experience surveys differences in methodology and Trust coverage make response rate comparisons difficult. 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 2011/12 varied by Trust, ranging from 79% to 45% (77% to 39% in 2010). Many of the Trusts with lower response rates were in London, as in 2010. However, response rates in almost all Trusts were higher in CPES 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 provided a dedicated survey helpline staffed by trained in-house operators. 2,707 calls were made to the helpline, which 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.

Follow-on surveys

Patients were asked if a follow-on survey could be sent to them in the future to ask about their health and healthcare. 84% of respondents said yes, a further survey could be sent.

5. Patient demographics

The survey included all patients having treatment for cancer during September to November 2011 where this treatment was recorded by Trusts as falling within the first diagnosis field. Patients were placed into one of 13 cancer-type groupings using their ICD10 code. The survey covered both inpatients and day case patients, with 36% being inpatients and 64% being day cases (52% general day cases and 12% 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 49% 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	14739	21%
Colorectal / lower gastrointestinal	9483	13%
Lung	5029	7%
Prostate	5831	8%
‘Big 4’ combined	**35082**	**49%**
Brain / central nervous system (CNS)	746	1%
Gynaecological	4202	6%
Haematological	11070	15%
Head and neck	2422	3%
Sarcoma	2451	3%
Skin	1695	2%
Upper gastrointestinal	4540	6%
Urological (excluding prostate)	8447	12%
Other cancers	1138	2%

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	32796	47%
Female	36919	53%

Table 2 Respondents by gender

Age of respondents	Number of respondents	Percentage
16-25 years of age	354	1%
26-35 years of age	944	1%
36-50 years of age	6579	10%
51-65 years of age	21904	32%
66-75 years of age	22160	33%
76+ years of age	15574	23%

Table 3 Respondents by age group

Ethnicity of respondents	Number of respondents	Percentage
White (British, Irish or other white)	66421	96%
Asian or Asian British	1146	1.7%
Black or Black British	949	1.4%
Mixed background	278	0.4%
Other	292	0.4%

Table 4 Respondents by ethnicity

Sexual orientation of respondents *	Number of respondents	Percentage
Heterosexual	64161	99%
Bisexual	130	0.2%
Gay or lesbian	439	0.7%
Other sexuality	269	0.4%

Table 5 Respondents by sexuality

* 3% of patients said they preferred not to answer this question, and a further 6% of all respondents to the survey did not answer the question at all.

Respondents with long term conditions *	Number of respondents	Percentage
Deafness or severe hearing impairment	7281	10%
Blindness or partially sighted	1856	3%
A longstanding physical condition	9347	13%
A learning disability	354	0.5%
A mental health condition	1347	2%
A long standing illness	9241	13%

Table 6 Respondents with long term conditions

* 61% of patients said they did not have a long-standing condition other than cancer. The table shows the number and then the percentage of respondents 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	44997	65%
1 to 5 years	17486	25%
More than 5 years	6212	9%

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.

Question numbers referenced in this section refer to the 2011/12 survey; a small number of questions that were in the 2010 survey were removed and replaced with new questions (for example on being asked to take part in cancer research, and on overall rating of care) and a further small number were amended or had response options changed in 2011/12.

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 in 2011/12 for all respondents (the national average) is shown as a red line; the overall key score for 2010 is shown as a dark blue 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.

Comparisons are also shown with the key scores from the 2010 survey where these are available. Patients who responded in 2010 who had an ICD 10 code of C84 were removed from the 2010 data to ensure that comparisons with 2011/12 were on a like for like basis.

Seeing your GP

The early diagnosis of cancers is seen in the *Improving Outcomes Strategy for Cancer* 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"[16]. 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, 74% said that they saw their GP either once (53%) 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.

Comparison with 2010 Survey

The proportion of patients saying they saw their GP only once or twice before being referred on to a cancer specialist was 74% in the 2011/12 survey compared to 75% in 2010.

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 62% (brain and haematological cancers and sarcoma).

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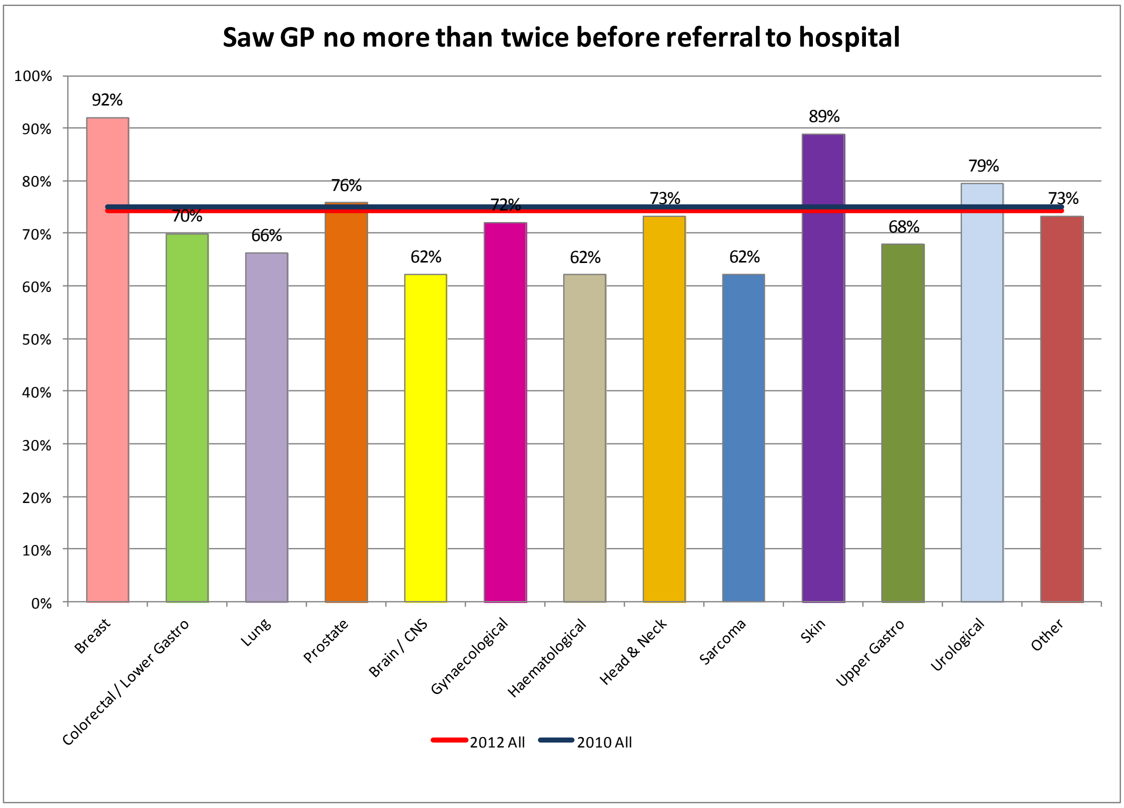

Chart 1 Saw GP no more than twice

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 40% as the lowest score to 93% as the highest Trust score.

The 20th percentile threshold is 72%; the 80th percentile threshold is 78%.

2. 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

83% of patients in all cancer groups said they felt that they were seen as soon as they thought was necessary: 10% felt they should have been seen a bit sooner and a further 7% felt they should have been seen a lot sooner.

Comparison with 2010 Survey

The proportion of patients saying they were seen as soon as they thought necessary was 83% in the 2011/12 survey compared to 81% in 2010.

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 90% (breast cancer groups) to 73% (sarcoma).

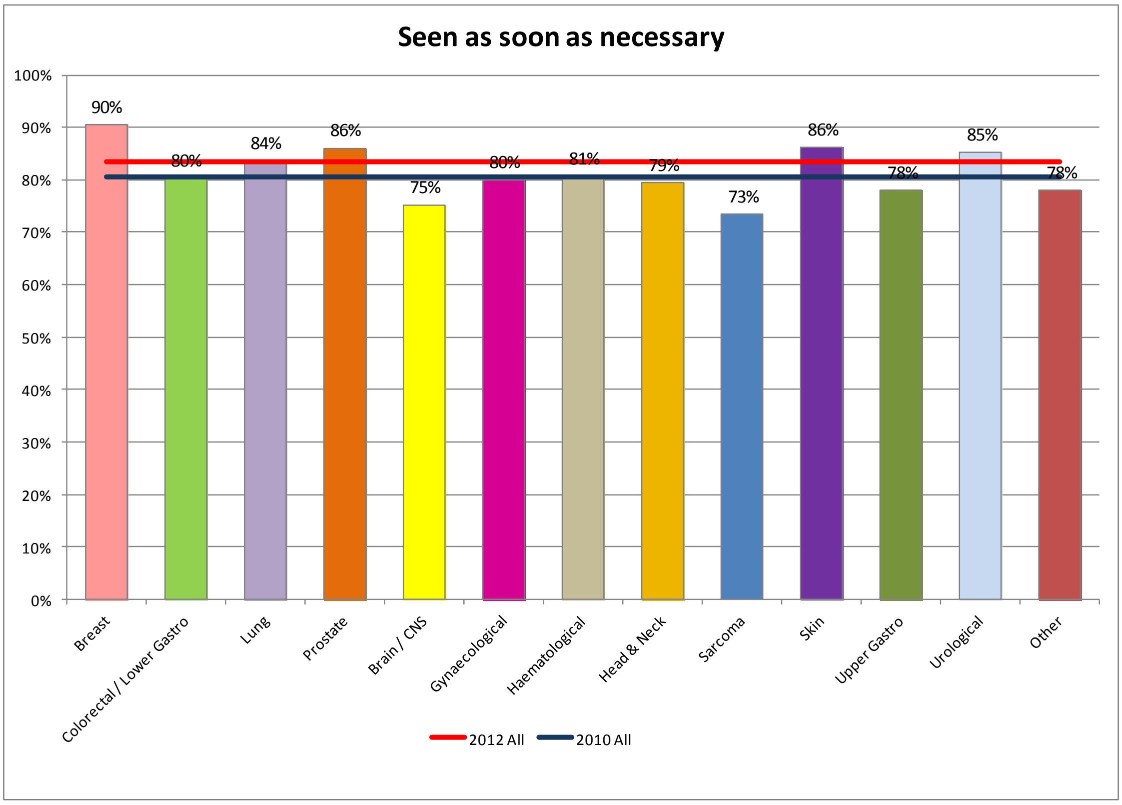

Chart 2 Seen as soon as necessary

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 66% as the lowest score to 92% as the highest Trust score.

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

3. 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

79% 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. 11% said the gap was 3-6 months; 4% said 6-12 months and 4% said more than 12 months.

Comparison with 2010 Survey

The proportion of patients saying they were seen by a hospital doctor within 3 months of thinking something might be wrong was 79% in the 2011/12 survey compared to 74% in 2010.

Findings by Tumour Group

There was some variation in the proportion of patients saying they were seen by a hospital doctor within 3 months of thinking something might be wrong, 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 seen by a hospital doctor within 3 months of thinking something might be wrong. Scores in Trusts ranged from 84% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 95%; the 80th percentile threshold is 97%.

4. 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

79% of patients in all cancer groups said that their health got better (1%) or stayed about the same (79%) during the time they were waiting for their first appointment with a hospital doctor; 21% said their health got worse.

Comparison with 2010 Survey

The proportion of patients saying their health got better or stayed about the same was 79% in the 2011/12 survey compared to 78% in 2010.

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% (brain / CNS).

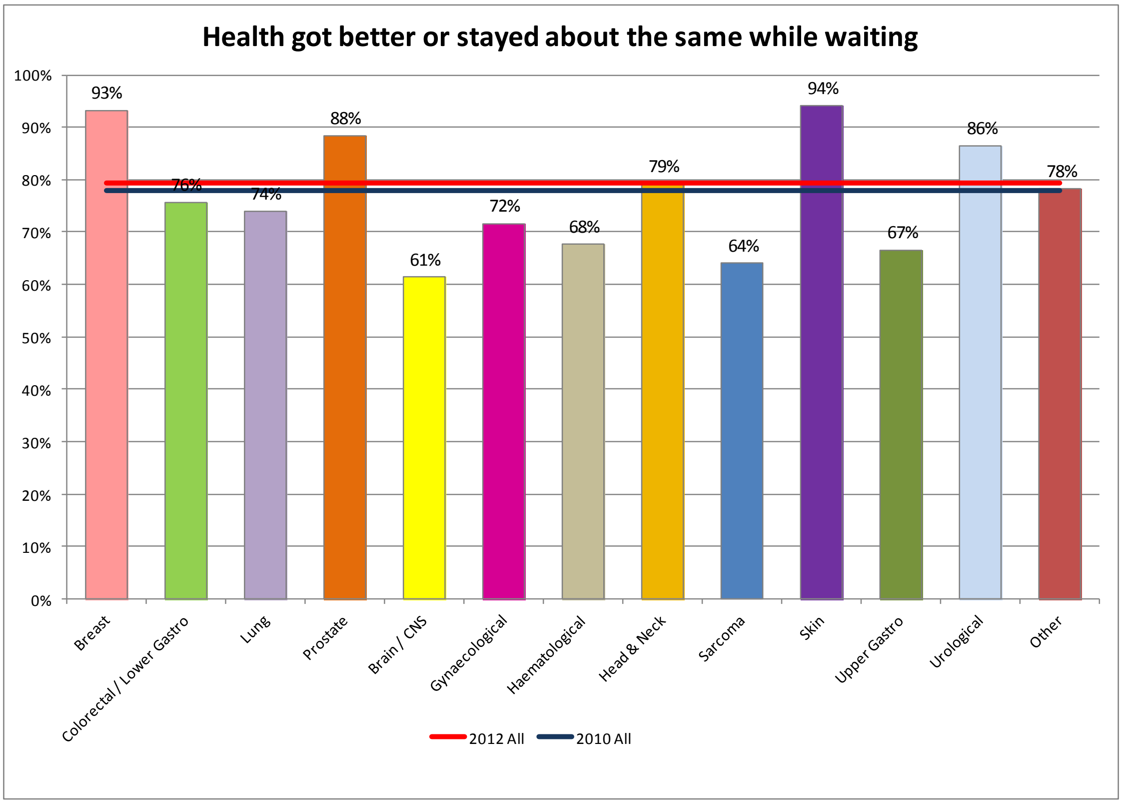

Chart 3 State of health while waiting

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 40% as the lowest score to 90% as the highest Trust score.

The 20th percentile threshold is 77%; the 80th percentile threshold is 83%.

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.

5. 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.

Comparison with 2010 Survey

The proportion of patients saying they had diagnostic tests for cancer such as an endoscopy, biopsy, mammogram or scan was 90% in the 2011/12 survey compared to 90% in 2010.

6. 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, 83% said staff explained the purpose of tests completely; a further 15% 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.

Comparison with 2010 Survey

The proportion of patients receiving explanations of tests completely was 83% in the 2011/12 survey compared to 81% in 2010.

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 87% (skin cancer) to 79% (gynaecological cancer).

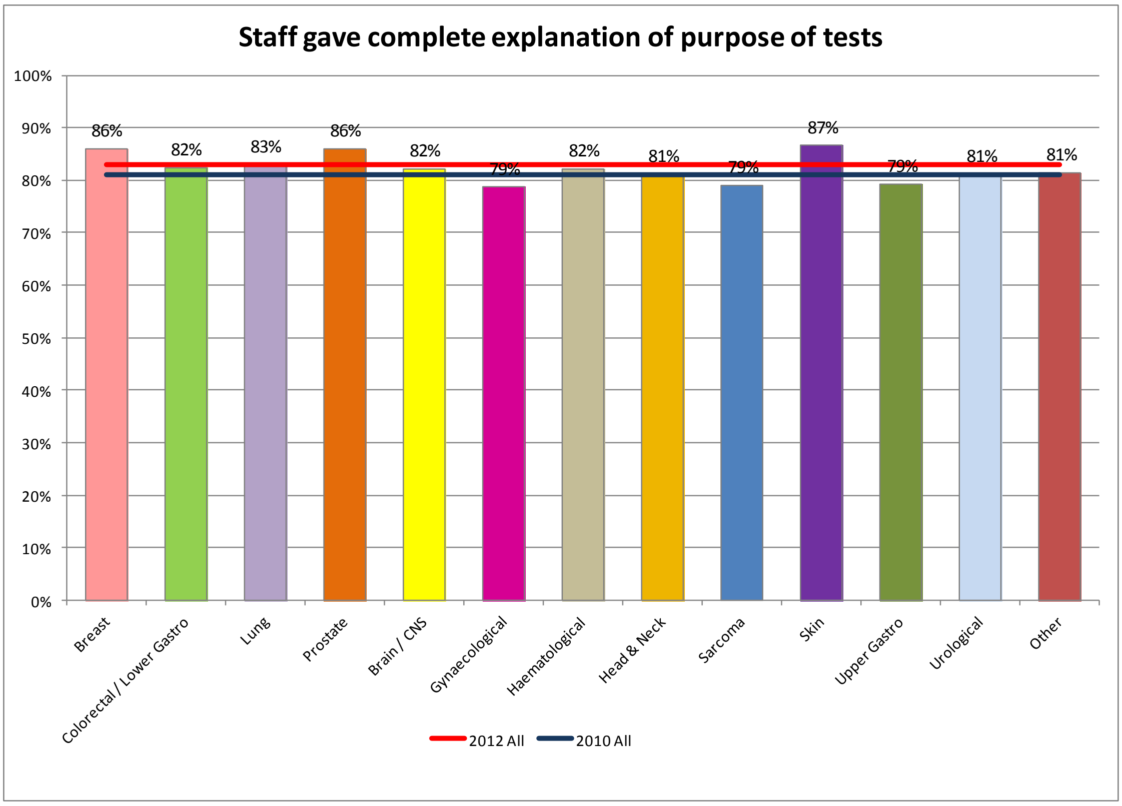

Chart 4 Explanation of purpose of tests

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 66% as the lowest score to 92% as the highest Trust score.

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

7. 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, 86% said staff explained what would be done during tests completely a further 12% said it was explained to some extent. 1% said it was not explained but that they would have liked an explanation.

Comparison with 2010 Survey

The proportion of patients receiving explanations of what would be done during such tests completely was 86% in the 2011/12 survey compared to 84% in 2010.

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 75% as the lowest score to 94% as the highest Trust score.

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

8. 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, 86% said they were given written information that was easy to understand; 4% were given information but it was difficult to understand. 10% said they were not given written information but would have liked some.

Comparison with 2010 Survey

The proportion of patients being given written information about their tests that was easy to understand was 86% in the 2011/12 survey compared to 85% in 2010.

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 67% as the lowest score to 98% as the highest Trust score.

The 20th percentile threshold is 83%; the 80th percentile threshold is 89%.

9. 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, 78% said they received a completely understandable explanation of their test results; a further 20% said the explanation was only understandable to some extent. 2% said the results were not explained but they would have liked an explanation.

Comparison with 2010 Survey

The proportion of patients saying they had a completely understandable explanation of their tests results was 78% in the 2011/12 survey compared to 76% in 2010.

Findings by Tumour Group

There was significant variation in the number of patients saying they had a completely understandable explanation of their tests results. Scores ranged from 83% (skin cancer) to 71% (brain / CNS).

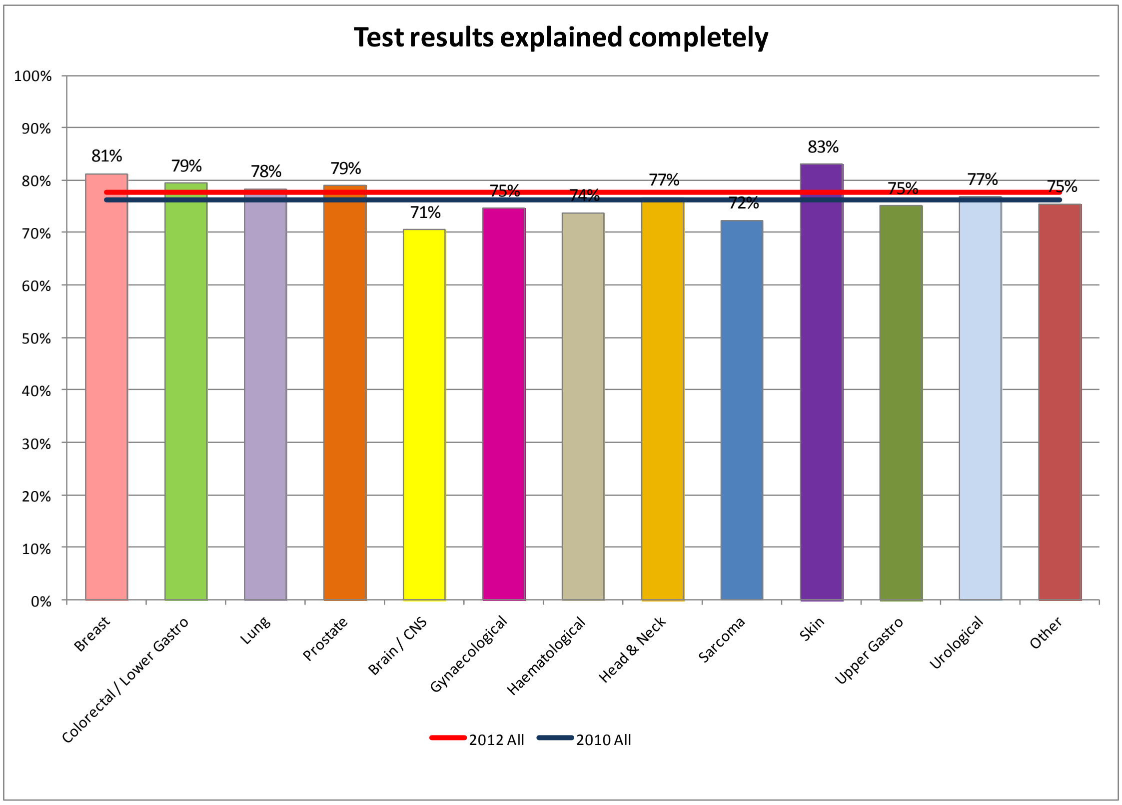

Chart 5 Test results explained

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 68% as the lowest score to 88% as the highest Trust score.

The 20th percentile threshold is 75%; the 80th percentile threshold is 81%.

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.

10. Who first told the patient they had cancer

Who first told you that you had cancer?

Overall Findings

82% 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.

Comparison with 2010 Survey

The proportion of patients saying they were first told they had cancer by a hospital doctor was 82% in the 2011/12 survey compared to 83% in 2010.

11. 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, 72% overall said they were told they could bring a family member or friend with them; 28% were not told. 2% said they were told they had cancer by phone or letter.

Comparison with 2010 Survey

The proportion of patients saying they were told they could bring a family member or friend with them was 72% in the 2011/12 survey compared to 71% in 2010.

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 80% (breast cancer and brain / CNS) to 61% (skin cancer).

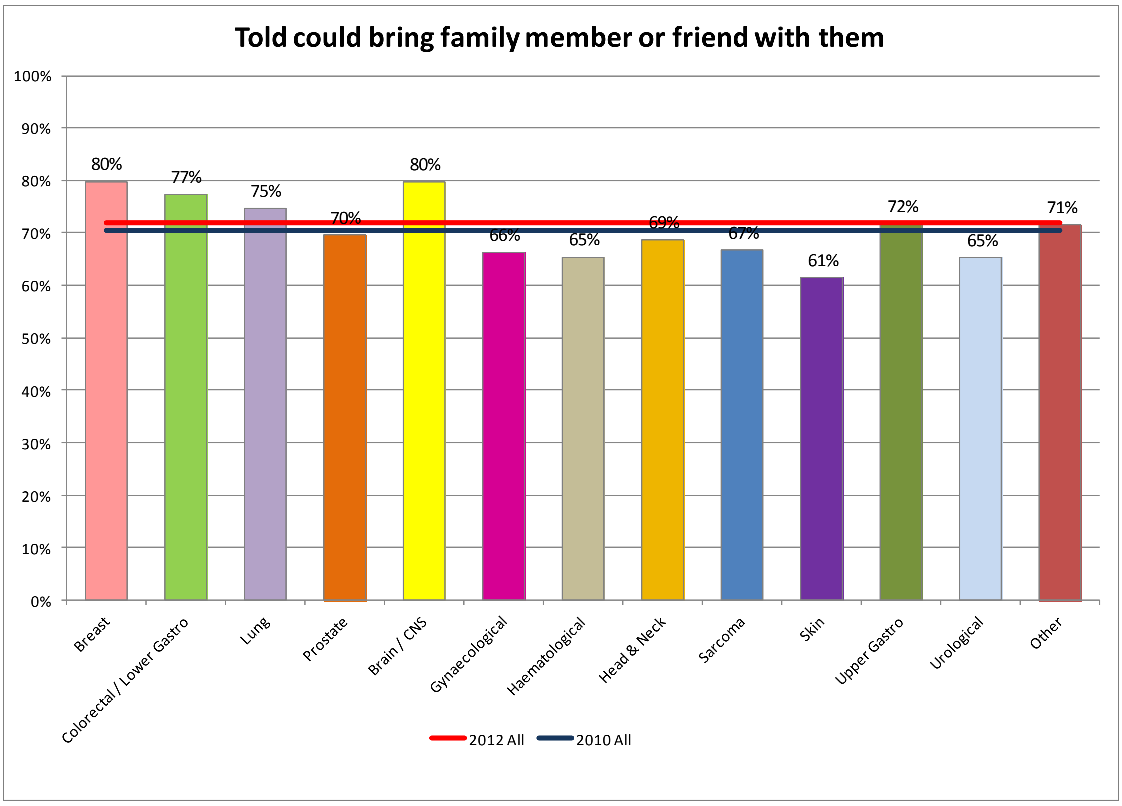

Chart 6 Told could bring family member

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 55% as the lowest score to 88% as the highest Trust score.

The 20th percentile threshold is 67%; the 80th percentile threshold is 76%.

12. 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; 11% felt it could have been done a bit more sensitively and a further 5% said it could have been done a lot more sensitively.

Comparison with 2010 Survey

The proportion of patients saying the way they were told they had cancer was done sensitively was 83% in the 2011/12 survey compared to 83% in 2010.

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 74% (brain / CNS).

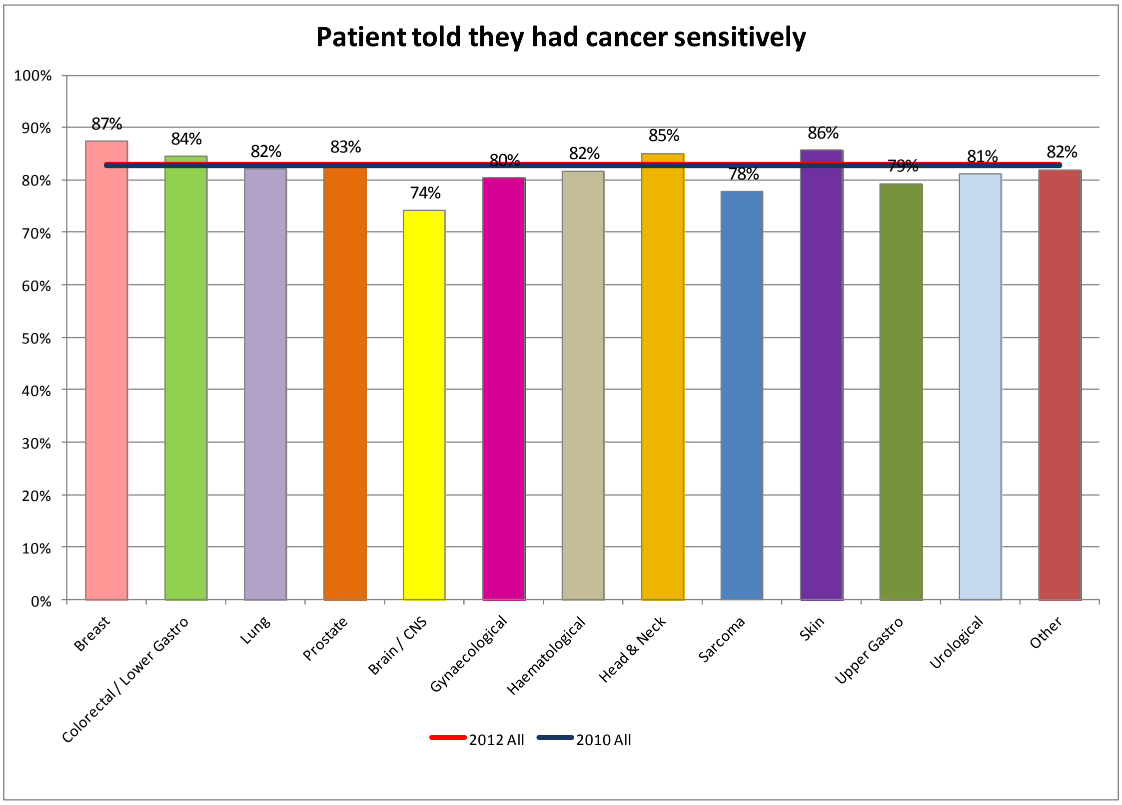

Chart 7 Patient told they had cancer sensitively

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 94% as the highest Trust score.

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

13. Patients understanding explanations of what was wrong

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

Overall Findings

73% of patients said that they completely understood the explanation of what was wrong with them; 25% said that they understood some of it. 2% said that they did not understand the explanation they were given.

Comparison with 2010 Survey

The proportion of patients saying they completely understood the explanation that they received of what was wrong with them was 73% in the 2011/12 survey compared to 74% in 2010.

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, colorectal and skin cancers) to 57% (haematological cancer).

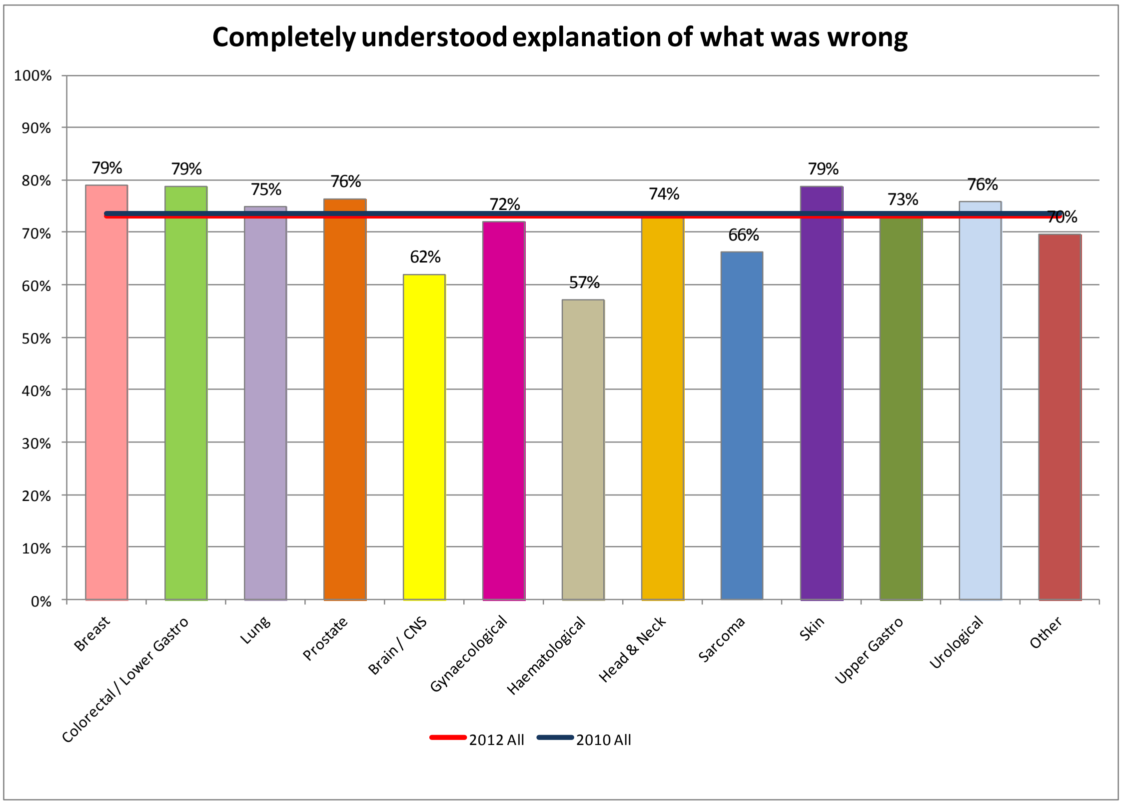

Chart 8 Completely understood what was wrong

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 60% as the lowest score to 83% as the highest Trust score.

The 20th percentile threshold is 71%; the 80th percentile threshold is 76%.

14. 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, 69% 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. 24% were not given written information.

Comparison with 2010 Survey

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 was 69% in the 2011/12 survey compared to 66% in 2010.

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 78% (prostate and skin cancers) to 50% (sarcoma).

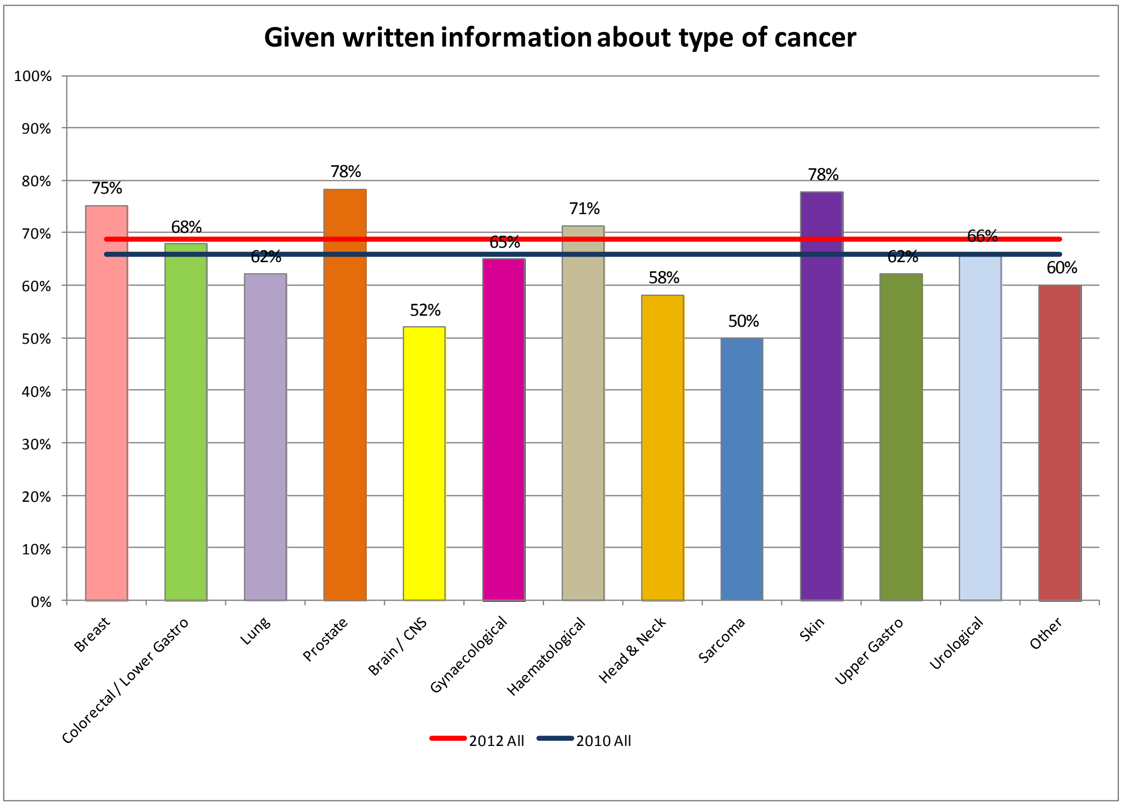

Chart 9 Given written information about type of cancer

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 45% as the lowest score to 86% as the highest Trust score.

The 20th percentile threshold is 64%; the 80th percentile threshold is 73%.

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.

15. Choice about types of treatment

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

Overall Findings

61% of patients overall said only one type of treatment was suitable for them; of the remaining patients, 84% said they were given a choice of different types of treatment; 16% said they were not given a choice but would have liked one.

Comparison with 2010 Survey

The proportion of patients saying they were given a choice of different types of treatment was 84% in the 2011/12 survey compared to 83% in 2010.

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 90% (prostate cancer) to 75% (urological cancer).

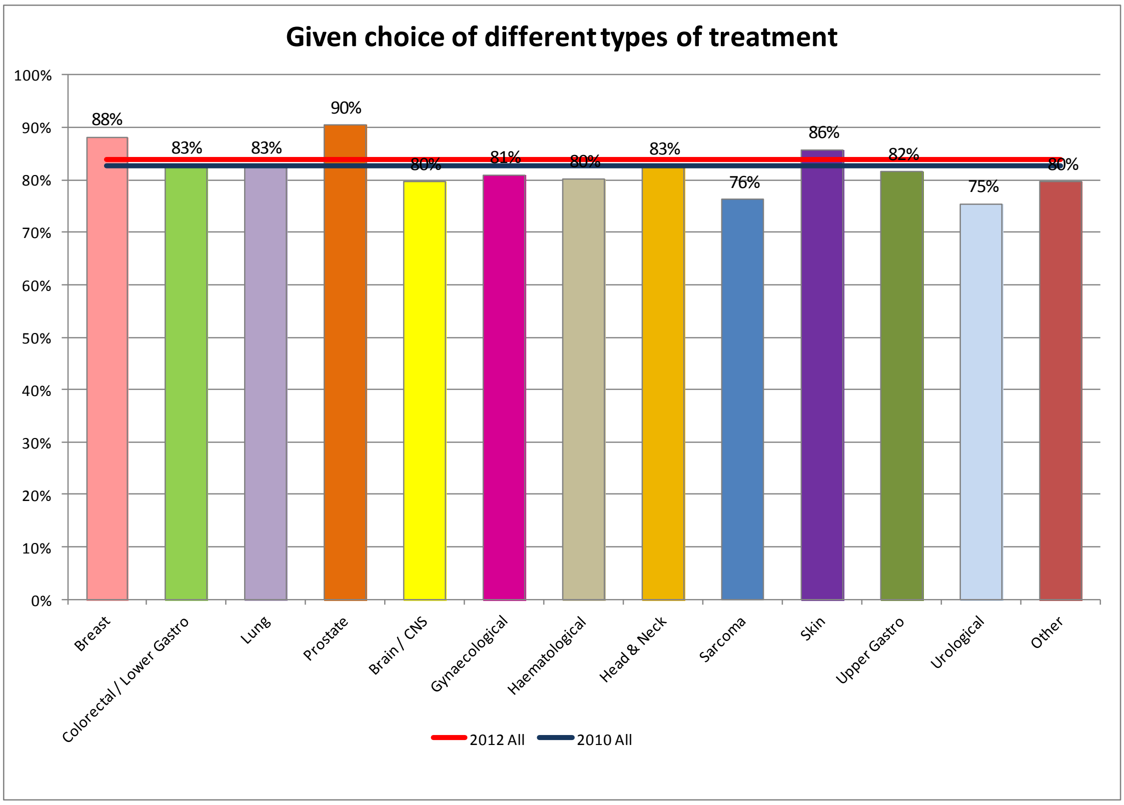

Chart 10 Given choice of treatment

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 62% as the lowest score to 100% as the highest Trust score.

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

16. Decisions about best treatment

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

Overall Findings

8% of patients said they did not know their treatment was being discussed by a team of doctors and nurses and a further 5% said they were not sure or could not remember.

70% of those patients who knew said their views were definitely taken into account; 24% said they were to some extent. 6% said their views were not taken into account.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying their views were definitely taken into account. Scores ranged from 76% (skin cancer) to 64% (brain / CNS and sarcoma).

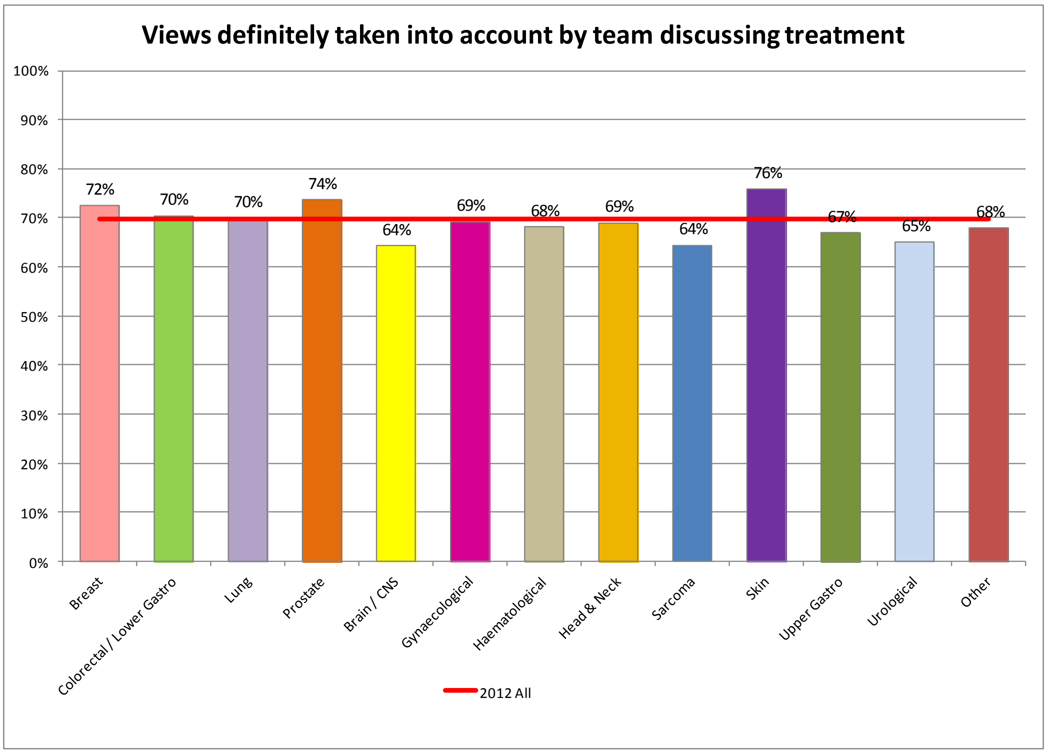

Chart 11 Views taken into account by team

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying their views were definitely taken into account. Scores in Trusts ranged from 56% as the lowest score to 83% as the highest Trust score.

The 20th percentile threshold is 66%; the 80th percentile threshold is 74%.

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, 75% said possible side effects of treatment were definitely explained to them in a way they could understand; a further 21% said the explanation was understandable to some extent. 5% said side effects were not explained to them.

Comparison with 2010 Survey

The proportion of patients saying possible side effects of treatment were definitely explained to them was 75% in the 2011/12 survey compared to 72% in 2010.

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 79% (breast cancer) to 69% (urological cancer).

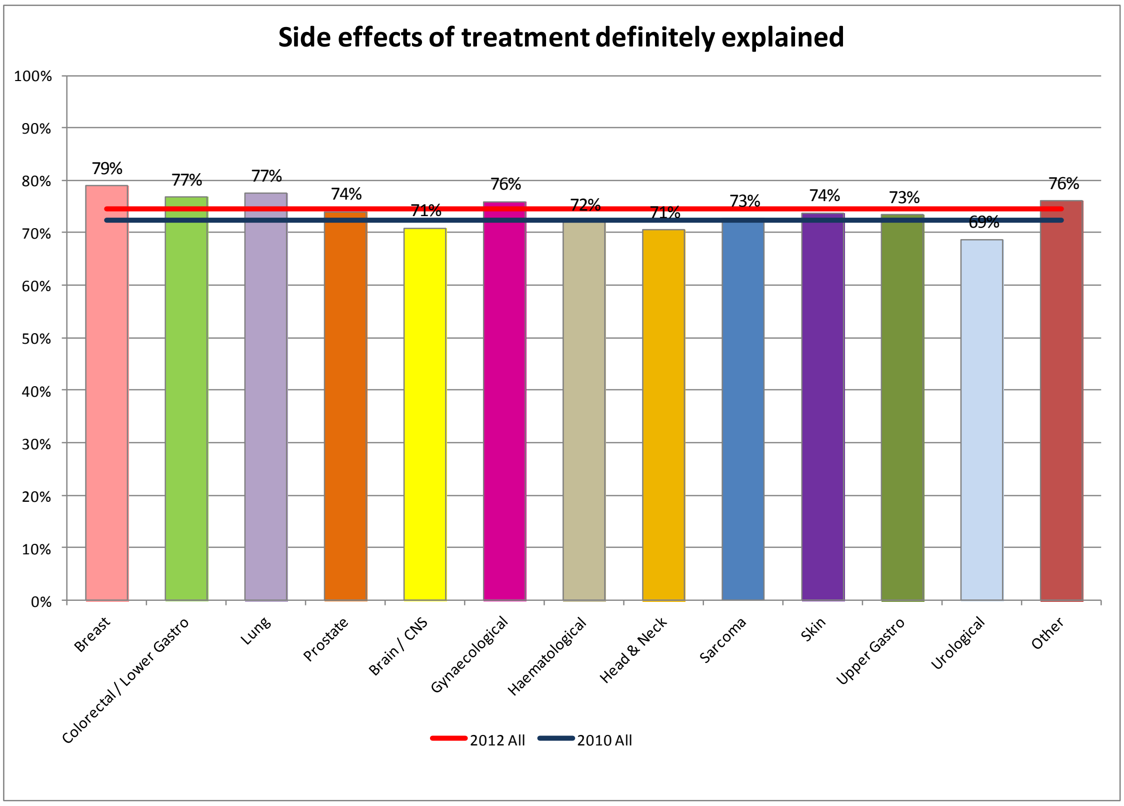

Chart 12 Side effects explained

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 61% as the lowest score to 87% as the highest Trust score.

The 20th percentile threshold is 71%; the 80th percentile threshold is 78%.

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

81% 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. 14% of patients said they were not given written information about side effects.

Comparison with 2010 Survey

The proportion of patients saying they had received written information about the side effects of treatment was 81% in the 2011/12 survey compared to 80% in 2010.

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 90% (breast cancer) to 67% (skin cancer).

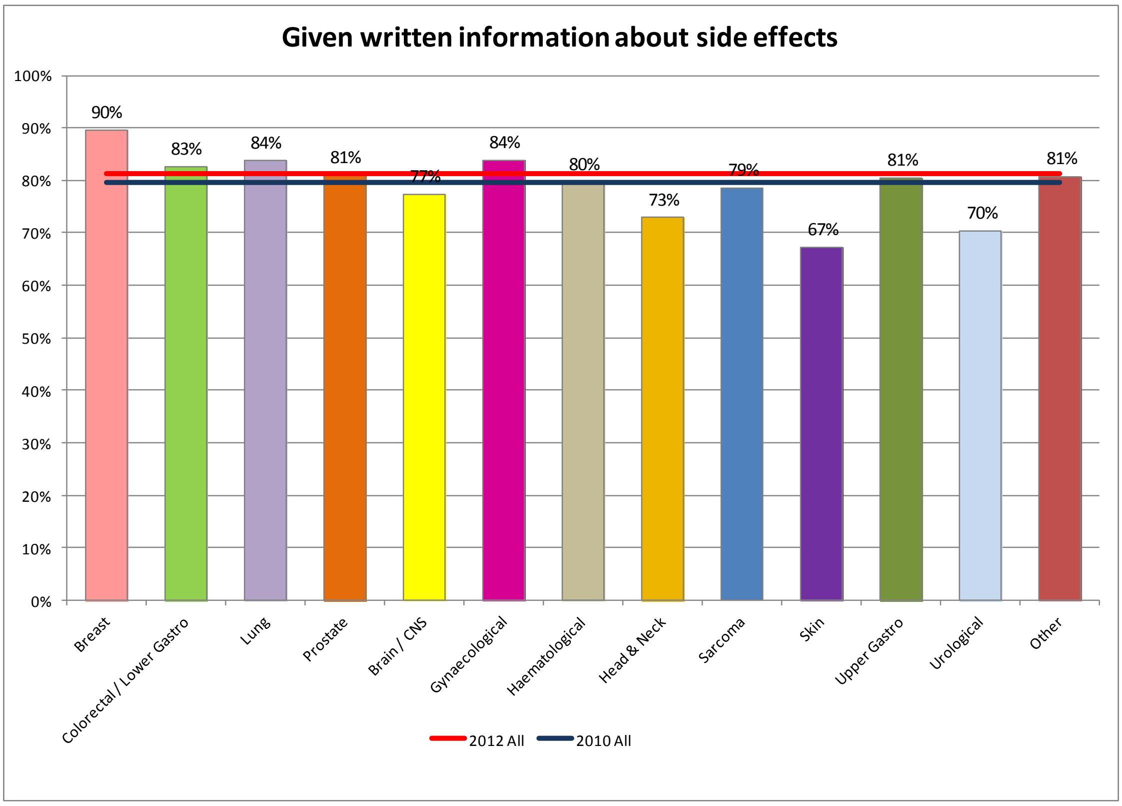

Chart 13 Given written information about side effects of treatment

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 53% as the lowest score to 89% as the highest Trust score.

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

19. Patient involvement in decisions about treatment [17]

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

Overall Findings

72% of patients said that they were definitely involved as much as they wanted to be in decisions about their treatment; 23% said they were involved to some extent. 5% said no but 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 60% as the lowest score to 83% as the highest Trust score.

The 20th percentile threshold is 68%; the 80th percentile threshold is 76%.

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[17] New question in 2012

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

87% of patients overall said that they had been given the name of a Clinical Nurse Specialist; 13% were not given the name of a Clinical Nurse Specialist.

Comparison with 2010 Survey

The proportion of patients saying they were given the name of a Clinical Nurse Specialist was 87% in the 2011/12 survey compared to 84% in 2010.

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 75% (urological cancer).

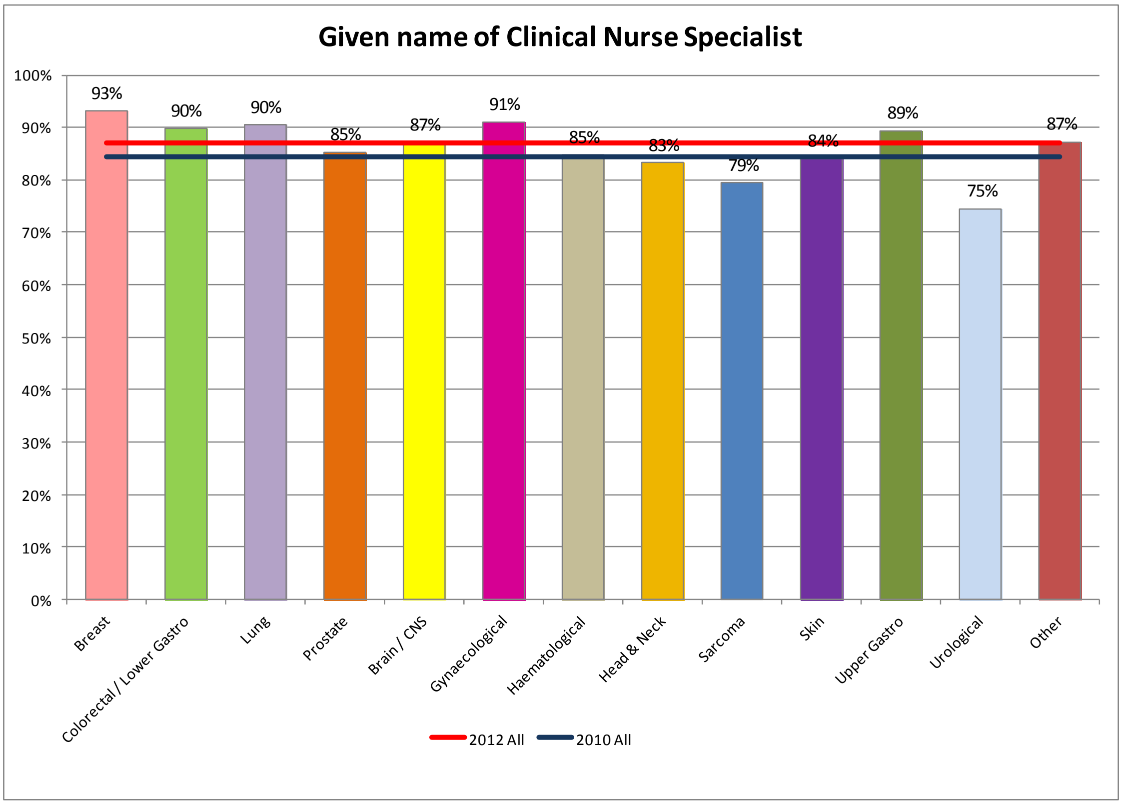

Chart 14 Given name of CNS

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 74% as the lowest score to 99% as the highest Trust score.

The 20th percentile threshold is 83%; the 80th percentile threshold is 90%.

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.

Comparison with 2010 Survey

The proportion of patients saying that it was easy to contact their Clinical Nurse Specialist was 75% in the 2011/12 survey compared to 75% in 2010.

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 59% as the lowest score to 92% as the highest Trust score.

The 20th percentile threshold is 71%; the 80th percentile threshold is 81%.

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.

Comparison with 2010 Survey

The proportion of patients saying that the Clinical Nurse Specialist definitely listened carefully was 91% in the 2011/12 survey compared to 91% in 2010.

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 82% as the lowest score to 99% as the highest Trust score.

The 20th percentile threshold is 90%; the 80th percentile threshold is 93%.

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.

Comparison with 2010 Survey

The proportion of patients saying they got understandable answers all or most of the time was 91% in the 2011/12 survey compared to 91% in 2010.

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 72% as the lowest score to 97% as the highest Trust score.

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

Support for patients

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

24. 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, 82% reported having been given information about support or self-help groups for people with cancer by hospital staff. 18% said they did not get any information but would have liked some.

Comparison with 2010 Survey

The proportion of patients saying they had been given information about support or self-help groups was 82% in the 2011/12 survey compared to 79% in 2010.

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 89% (breast cancer) to 65% (urological cancer).

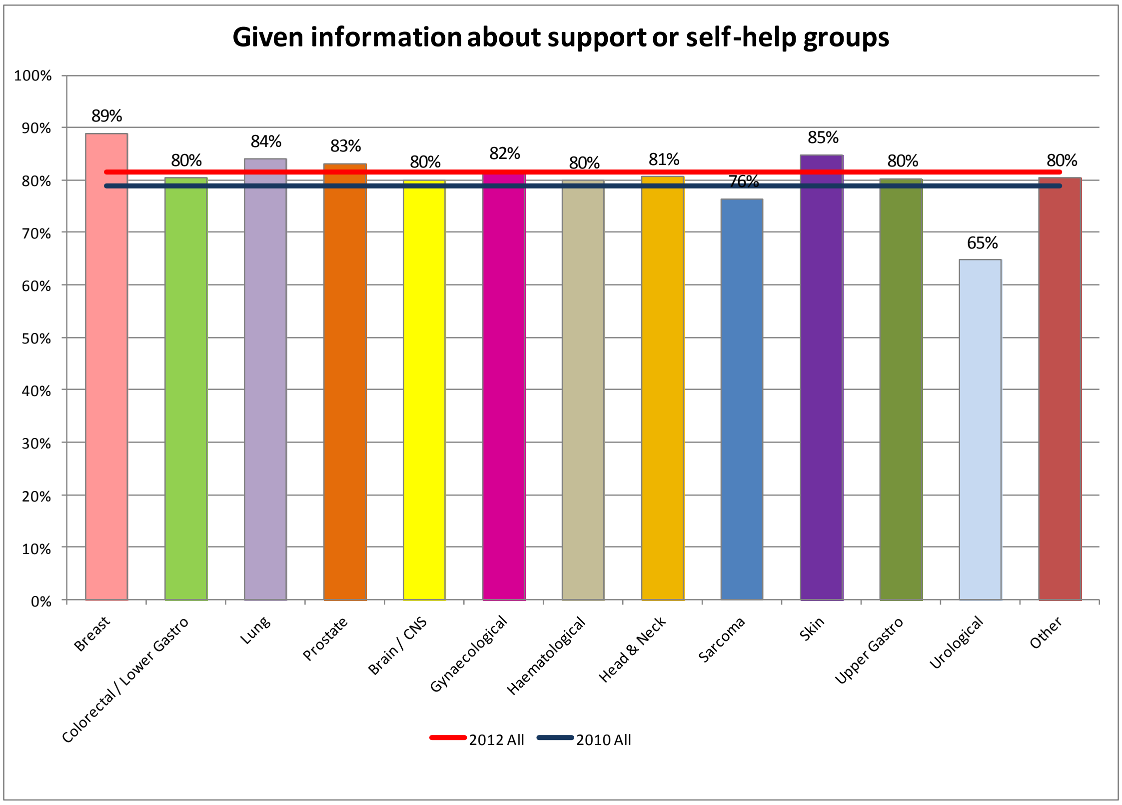

Chart 15 Given information about support groups

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 60% as the lowest score to 91% as the highest Trust score.

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

25. Information about financial help and benefits

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

Overall Findings

Of those patients who said it was necessary, 52% said they had been given information about how to get financial help or benefits they might be entitled to by hospital staff. 48% said they did not get any information but would have liked some.

Comparison with 2010 Survey [18]

The proportion of patients saying they had been given information about how to get financial help or benefits was 52% in the 2011/12 survey compared to 50% in 2010.

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 70% (lung cancer) to 29% (urological cancer).

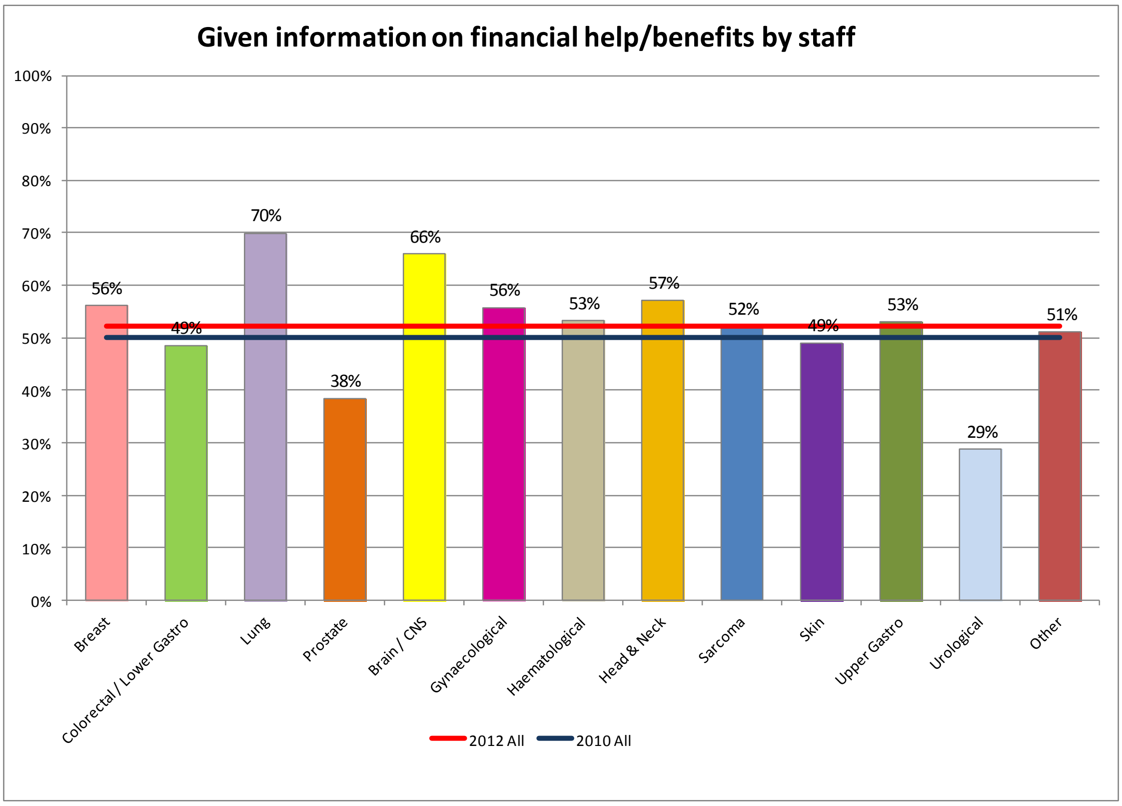

Chart 16 Given information on financial help

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 32% as the lowest score to 77% as the highest Trust score.

The 20th percentile threshold is 44%; the 80th percentile threshold is 59%.

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[18] It should be noted that the wording to question 25 was amended in 2011/12 to add at the end "you might be entitled to". This change is considered marginal so a comparison with 2010 has been given.

26. Free prescriptions

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

Overall Findings

Of those patients who said it was necessary, 73% said that hospital staff had told them that they could get free prescriptions. 27% said they did not get this information but would have liked it.

Comparison with 2010 Survey

The proportion of patients saying hospital staff had told them that they could get free prescriptions was 73% in the 2011/12 survey compared to 68% in 2010.

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 82% (lung cancer) to 50% (skin cancer).

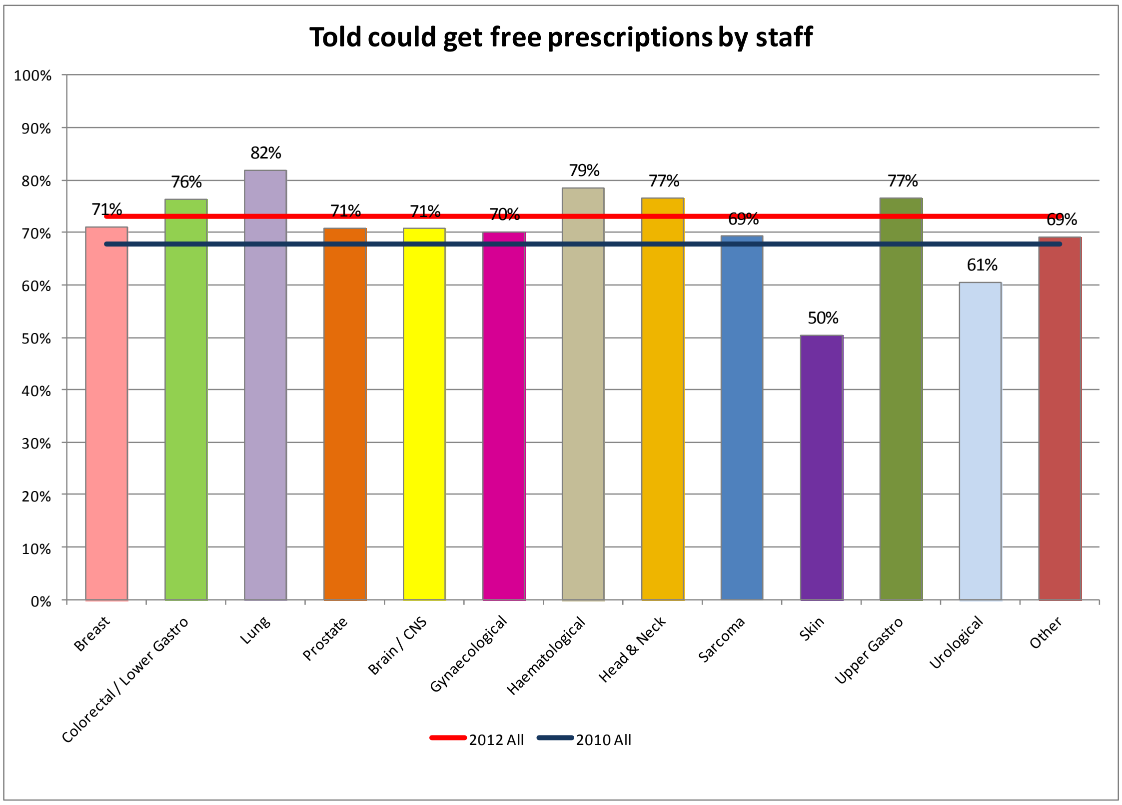

Chart 17 Told could get free prescriptions

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 52% as the lowest score to 90% as the highest Trust score.

The 20th percentile threshold is 67%; the 80th percentile threshold is 79%.

27. Taking part in cancer research [19]

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

Overall Findings

33% of patients said that taking part in research had been discussed with them; 67% said it had not.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying that taking part in research had been discussed with them. Scores ranged from 39% (breast cancer) to 15% (urological cancer).

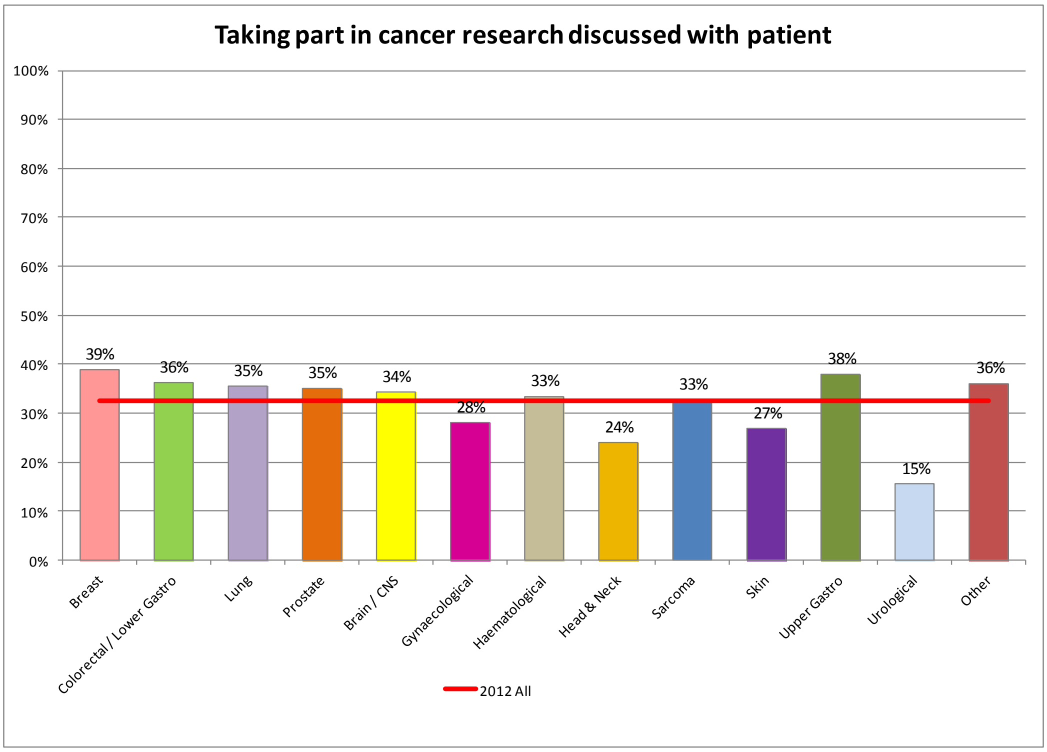

Chart 18 Taking part in research discussed with patient

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[19] New questions 27 to 29 in 2012

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying taking part in cancer research was discussed with them. Scores in Trusts ranged from 14% as the lowest score to 62% as the highest Trust score.

The 20th percentile threshold is 24%; the 80th percentile threshold is 37%.

28. Glad to be asked about cancer research

If yes, were you glad to have been asked?

Overall Findings

95% of those patients who had research discussed with them said they were glad to have been asked; 5% said they were not.

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 glad to have been asked. 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%.

29. Would have liked to have been asked about cancer research

If no, would you have liked to have been asked?

Overall Findings

53% of those patients who said they were not asked, said that they would have liked to have been asked; 47% said they would not have liked to have been asked.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying said that they would have liked to have been asked. Scores ranged from 64% (brain / CNS) to 47% (skin and urological cancers).

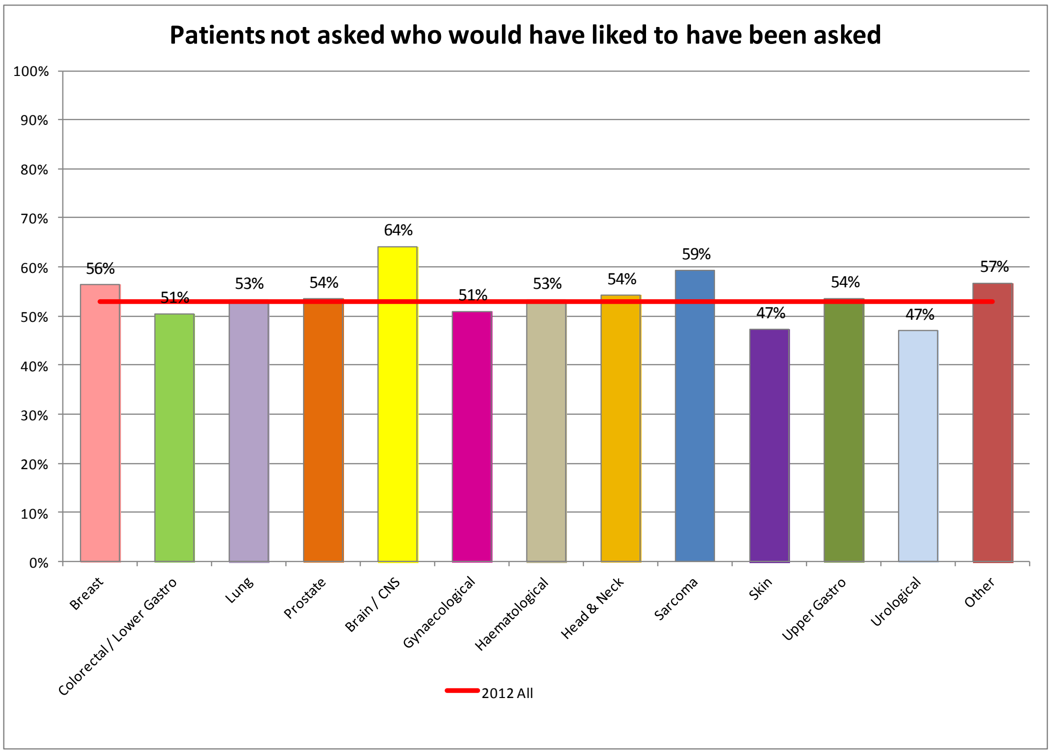

Chart 19 Patients who would have liked to have been asked about research

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying said that they would have liked to have been asked. Scores in Trusts ranged from 36% as the lowest score to 72% as the highest Trust score.

The 20th percentile threshold is 47%; the 80th percentile threshold is 55%.

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.

30. 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

56% of patients said that they had had an operation such as removal of a tumour or lump during the last 12 months.

Comparison with 2010 Survey

The proportion of patients saying they had had an operation such as removal of a tumour or lump during the last 12 months was 56% in the 2011/12 survey compared to 57% in 2010.

31. 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

90% 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.

Comparison with 2010 Survey

The proportion of patients saying their admission date was not changed was 90% in the 2011/12 survey compared to 89% in 2010.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying their admission date was not changed. Scores ranged from 95% (breast cancer) to 84% (upper gastrointestinal cancer).

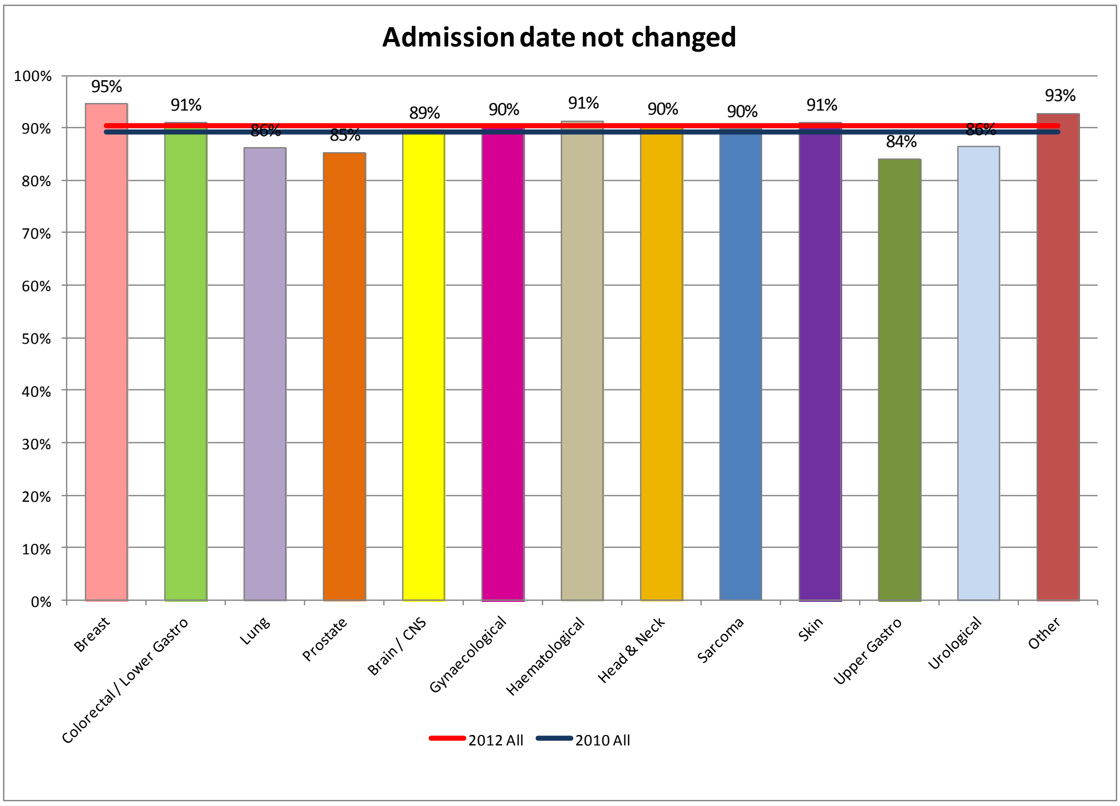

Chart 20 Admission date not changed

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 71% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 88%; the 80th percentile threshold is 94%.

32. 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, 87% said a member of staff explained completely; a further 12% said staff explained to some extent. 1% said staff did not explain but that they would have liked an explanation.

Comparison with 2010 Survey

The proportion of patients saying a member of staff explained what would be done completely was 87% in the 2011/12 survey compared to 85% in 2010.

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 73% as the lowest score to 97% as the highest Trust score.

The 20th percentile threshold is 84%; the 80th percentile threshold is 90%.

33. Written information about the operation

Beforehand, were you given written information about your operation?

Overall Findings

73% 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. 23% said they were not given written information.

Comparison with 2010 Survey

The proportion of patients saying they were given easy to understand written information was 73% in the 2011/12 survey compared to 68% in 2010.

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 83% (prostate cancer) to 55% (sarcoma).

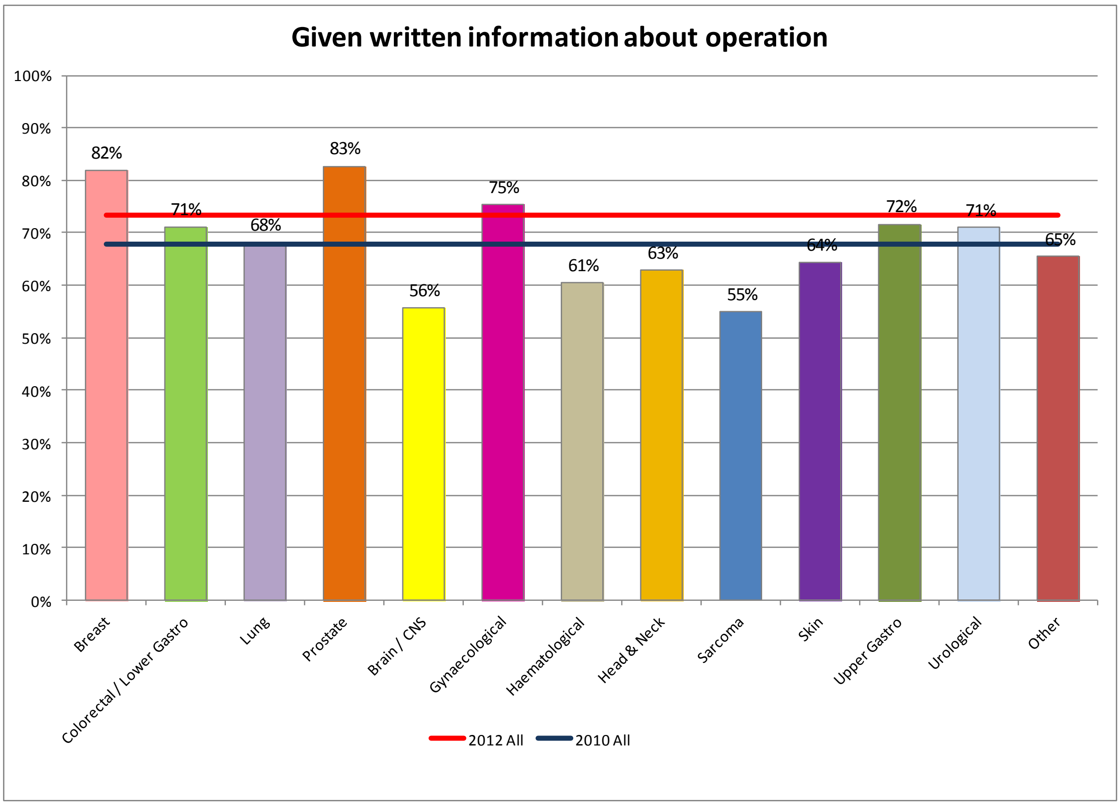

Chart 21 Given written information about operation

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 43% as the lowest score to 88% as the highest Trust score.

The 20th percentile threshold is 68%; the 80th percentile threshold is 79%.

34. 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, 75% 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. 5% did not get an explanation but would have liked one.

Comparison with 2010 Survey

The proportion of patients saying they had received a completely understandable explanation of how the operation had gone was 75% in the 2011/12 survey compared to 73% in 2010.

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 63% as the lowest score to 89% as the highest Trust score.

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

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 and not at day case or outpatients.

35. 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

68% of patients said they had had an operation or stayed overnight for cancer care during the last 12 months.

Comparison with 2010 Survey

The proportion of patients saying had had an operation or stayed overnight for cancer care during the last 12 months was 68% in the 2011/12 survey compared to 69% in 2010.

36. 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, 82% said doctors gave them answers they could understand all or most of the time; 16% said the answers were understandable only some of the time and a further 2% said they rarely or never got answers they could understand.

Comparison with 2010 Survey

The proportion of patients saying doctors gave them answers they could understand was 82% in the 2011/12 survey compared to 81% in 2010.

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 70% as the lowest score to 92% as the highest Trust score.

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

37. Confidence and trust in doctors

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

Overall Findings

85% of patients said they had confidence and trust in all of the doctors treating them; 15% 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.

Comparison with 2010 Survey

The proportion of patients saying they had confidence and trust in all of the doctors was 85% in the 2011/12 survey compared to 84% in 2010.

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 68% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 82%; the 80th percentile threshold is 88%.

38. 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 4% said that they often did.

Comparison with 2010 Survey

The proportion of patients saying doctors did not talk in front of them as if they were not there was 83% in the 2011/12 survey compared to 83% in 2010.

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 89% (breast cancer) to 76% (upper gastrointestinal cancer).

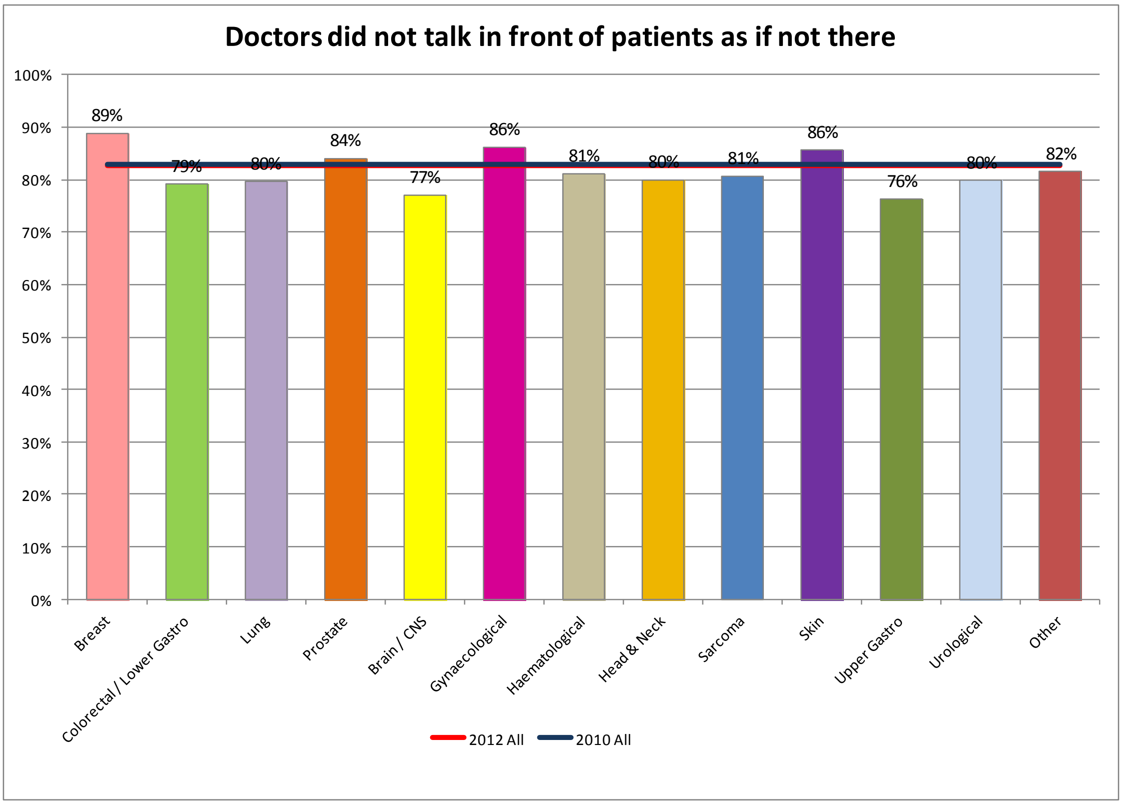

Chart 22 Doctors did not talk in front of patients as if not there

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 66% as the lowest score to 95% as the highest Trust score.

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

39. 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, 65% said their family or someone close to them definitely had enough opportunity to do so; a further 28% said they did so to some extent. 7% said they did not have enough opportunity to talk to a doctor.

Comparison with 2010 Survey

The proportion of patients saying their family or someone close to them definitely had enough opportunity to talk to a doctor was 65% in the 2011/12 survey compared to 66% in 2010.

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 73% (skin cancer) to 55% (brain / CNS).

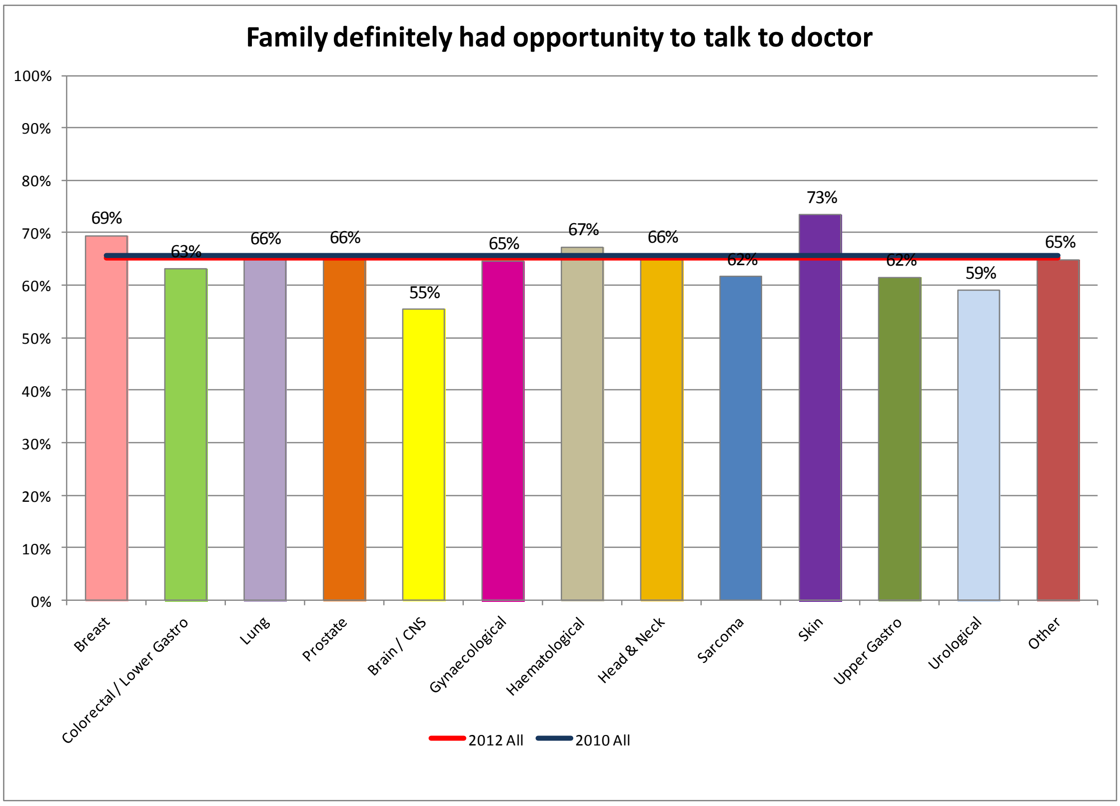

Chart 23 Family had opportunity to talk to doctor

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 49% as the lowest score to 86% as the highest Trust score.

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

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.

40. 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, 75% overall said nurses gave them answers they could understand all or most of the time; 22% said they gave understandable answers some of the time and a further 3% said they rarely or never got answers they could understand.

Comparison with 2010 Survey

The proportion of patients saying nurses gave them answers they could understand all or most of the time was 75% in the 2011/12 survey compared to 73% in 2010.

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 50% as the lowest score to 88% as the highest Trust score.

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

41. Confidence and trust in ward nurses

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

Overall Findings

69% of patients said they had confidence and trust in all the ward nurses treating them; 30% said they had confidence and trust in some of them and 1% said they had confidence and trust in none of them.

Comparison with 2010 Survey

The proportion of patients saying they had confidence and trust in all of the ward nurses was 69% in the 2011/12 survey compared to 66% in 2010.

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 81% (skin cancer) to 64% (brain / CNS and sarcoma).

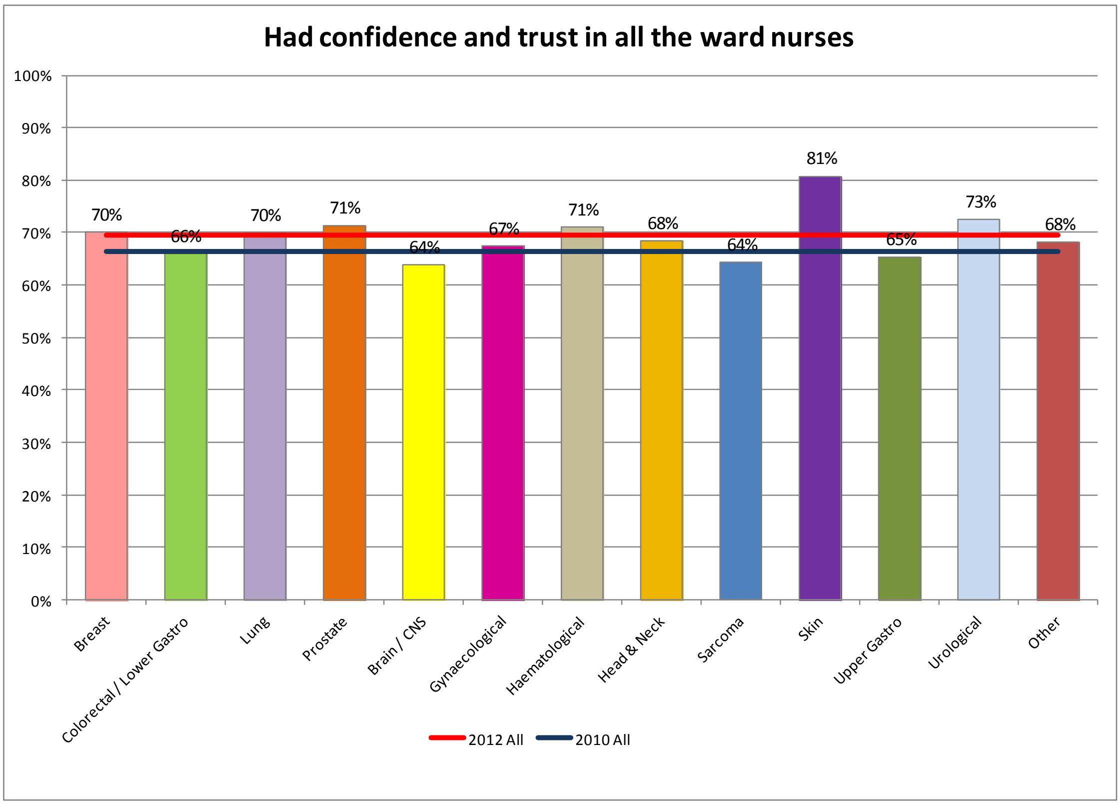

Chart 24 Had confidence and trust in ward nurses

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 41% as the lowest score to 85% as the highest Trust score.

The 20th percentile threshold is 65%; the 80th percentile threshold is 74%.

42. Talking in front of patients

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

Overall Findings

84% of patients said nurses did not talk in front of them as if they were not there; 13% said that they sometimes did and a further 3% said they often did.

Comparison with 2010 Survey

The proportion of patients saying nurses did not talk in front of them as if they were not there was 84% in the 2011/12 survey compared to 83% in 2010.

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 67% as the lowest score to 95% as the highest Trust score.

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

43. Enough nurses on duty

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

Overall Findings

Overall, 61% 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 10% said there were rarely or never enough on duty.

Comparison with 2010 Survey

The proportion of patients saying there were always or nearly always enough nurses on duty was 61% in the 2011/12 survey compared to 62% in 2010.

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 55% (upper gastrointestinal cancer).

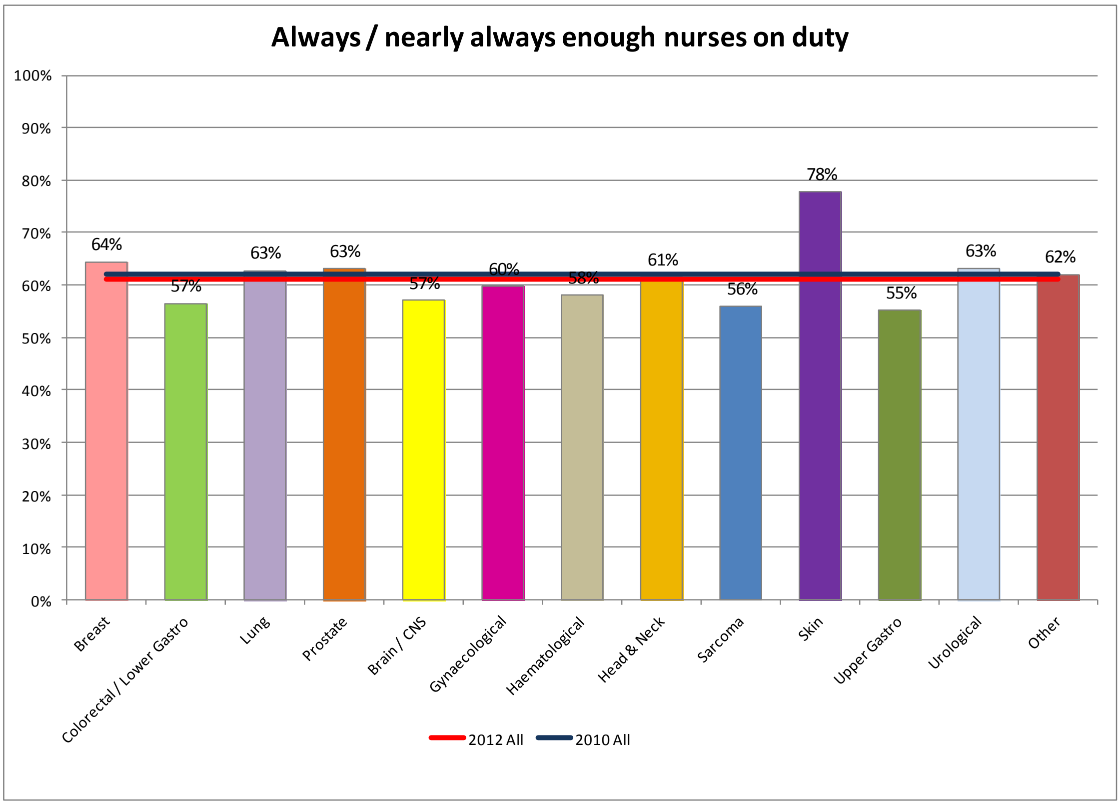

Chart 25 Enough nurses on duty

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 35% as the lowest score to 88% as the highest Trust score.

The 20th percentile threshold is 56%; the 80th percentile threshold is 67%.

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.

44. 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.

Comparison with 2010 Survey

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 was 87% in the 2011/12 survey compared to 87% in 2010.

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 74% as the lowest score to 94% as the highest Trust score.

The 20th percentile threshold is 85%; the 80th percentile threshold is 90%.

45. 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.

Comparison with 2010 Survey

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 was 79% in the 2011/12 survey compared to 79% in 2010.

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 86% (skin cancer) to 71% (brain / CNS).

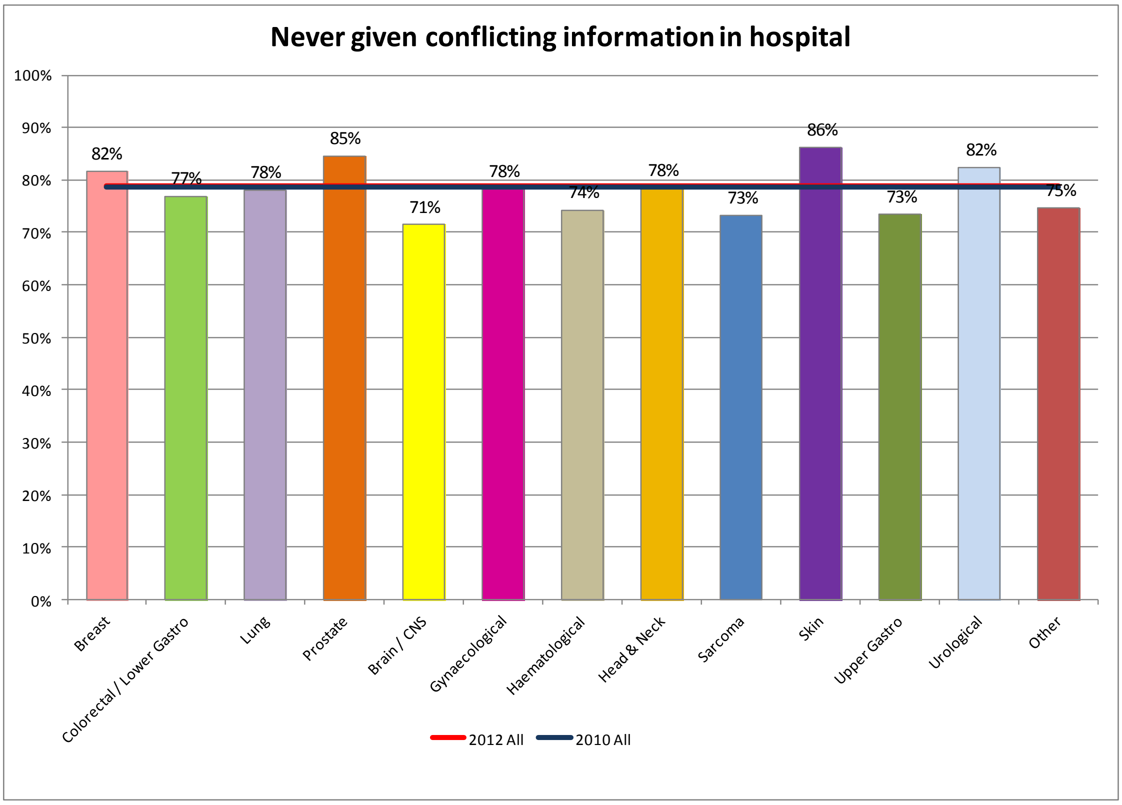

Chart 26 Never given conflicting information

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 63% as the lowest score to 93% as the highest Trust score.

The 20th percentile threshold is 76%; the 80th percentile threshold is 84%.

46. What name patients preferred to be called by [20]

While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?

Overall Findings

56% of patients said all of the doctors and nurses asked them what they wanted to be called; 23% said that only some of them did and 21% said that none of them did.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying that all of the doctors and nurses asked them what they wanted to be called. Scores ranged from 64% (lung and upper gastrointestinal cancers) to 49% (breast cancer).

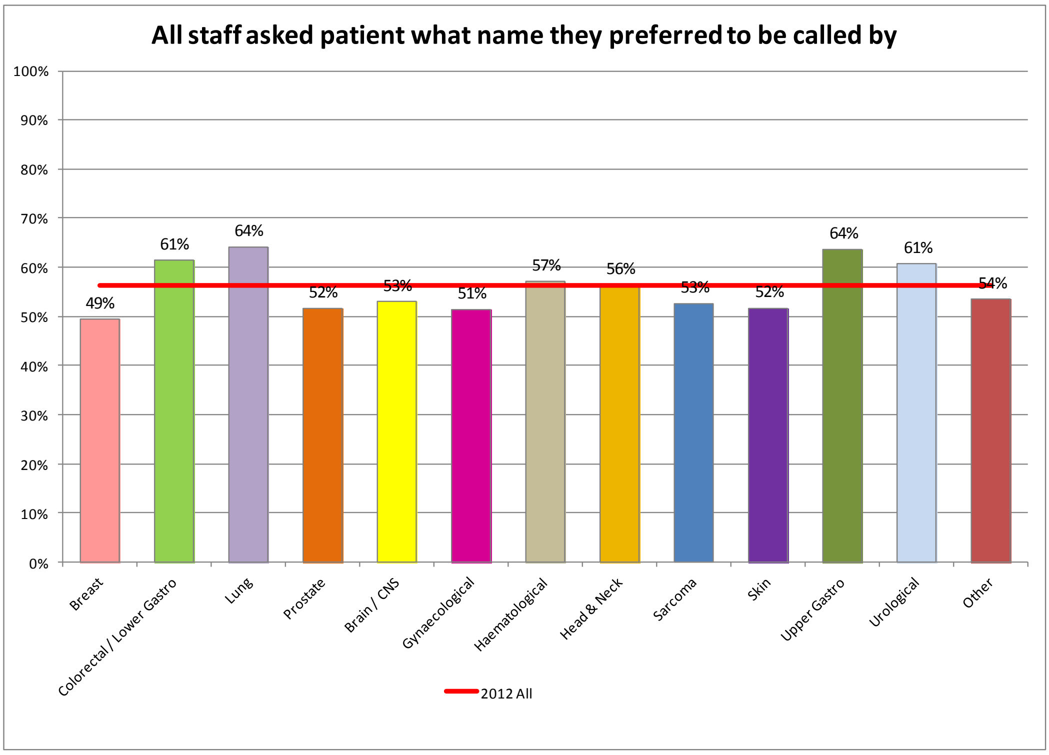

Chart 27 Staff asked patient what name they preferred

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[20] New question in 2012

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying all of the doctors and nurses asked them what they wanted to be called. Scores in Trusts ranged from 24% as the lowest score to 82% as the highest Trust score.

The 20th percentile threshold is 44%; the 80th percentile threshold is 65%.

47. Privacy discussing condition or treatment

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

Overall Findings

84% of patients overall said that they always had enough privacy when discussing their condition or treatment; a further 13% said they sometimes did. 4% said they did not have enough privacy.

Comparison with 2010 Survey

The proportion of patients saying they always had enough privacy was 84% in the 2011/12 survey compared to 82% in 2010.

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 73% as the lowest score to 93% as the highest Trust score.

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

48. Privacy when being examined or treated

Were you given enough privacy when being examined or treated?

Overall Findings

94% of patients overall said that they always had enough privacy when being examined or treated; a further 5% said they sometimes did. 1% said they did not have enough privacy.

Comparison with 2010 Survey

The proportion of patients saying they always had enough privacy was 94% in the 2011/12 survey compared to 93% in 2010.

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 85% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 93%; the 80th percentile threshold is 96%.

49. Discussing worries and fears [21]

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

Overall Findings

14% of patients said they did not have any worries or fears. Of those patients that did, 64% said they were able to discuss them as much as they wanted; 22% said they could most of the time and 10% said they could some of the time. 4% said they could not but would have liked to.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were able to discuss their worries and fears as much as they wanted. Scores ranged from 74% (skin cancer) to 54% (brain / CNS).

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[21] New question in 2012

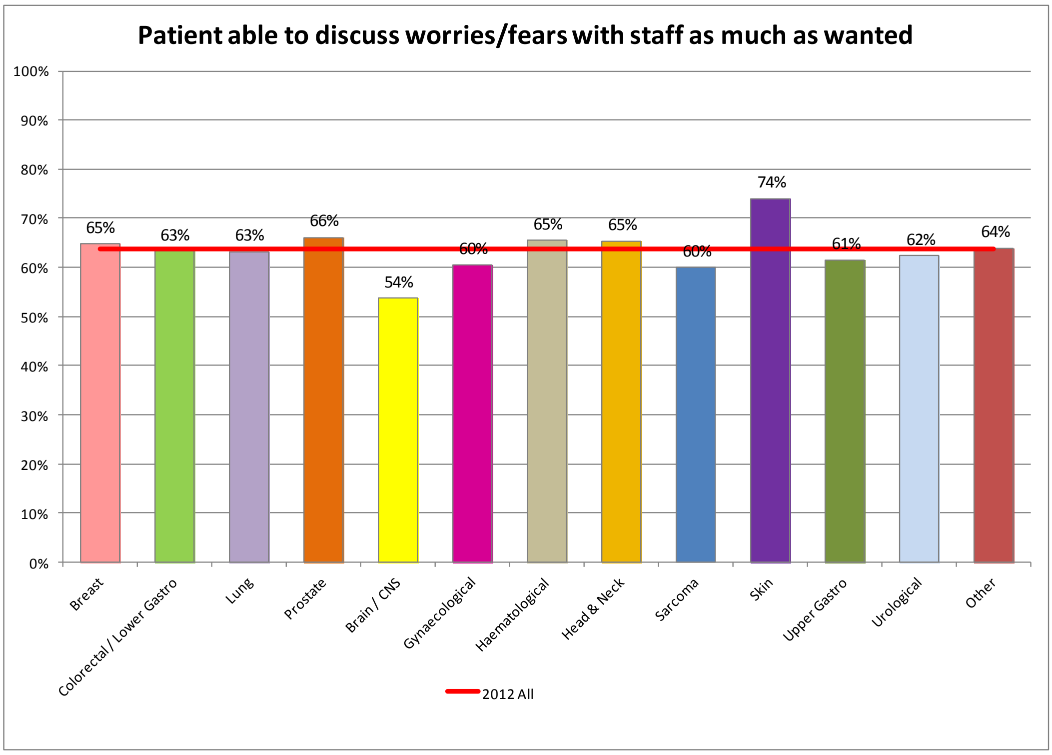

Chart 28 Patient able to discuss worries and fears

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were able to discuss worries and fears as much as they wanted. Scores in Trusts ranged from 40% as the lowest score to 81% as the highest Trust score.

The 20th percentile threshold is 59%; the 80th percentile threshold is 69%.

50. Control of Pain

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

Overall Findings

84% 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.

Comparison with 2010 Survey

The proportion of patients saying staff did everything they could to help control their pain was 84% in the 2011/12 survey compared to 85% in 2010.

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 74% as the lowest score to 93% as the highest Trust score.

The 20th percentile threshold is 82%; the 80th percentile threshold is 88%.

51. Treated with respect and dignity

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

Overall Findings

83% 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.

Comparison with 2010 Survey

The proportion of patients saying they were always treated with respect and dignity was 83% in the 2011/12 survey compared to 82% in 2010.

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 68% as the lowest score to 98% as the highest Trust score.

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

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 the levels of support given to them at home.

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

52. 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

84% of patients overall said that they were given clear written information about what they should or should not do after leaving hospital; 16% said they were not given information.

Comparison with 2010 Survey

The proportion of patients saying they were given written information about what they should or should not do was 84% in the 2011/12 survey compared to 82% in 2010.

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 90% (breast cancer) to 77% (sarcoma).

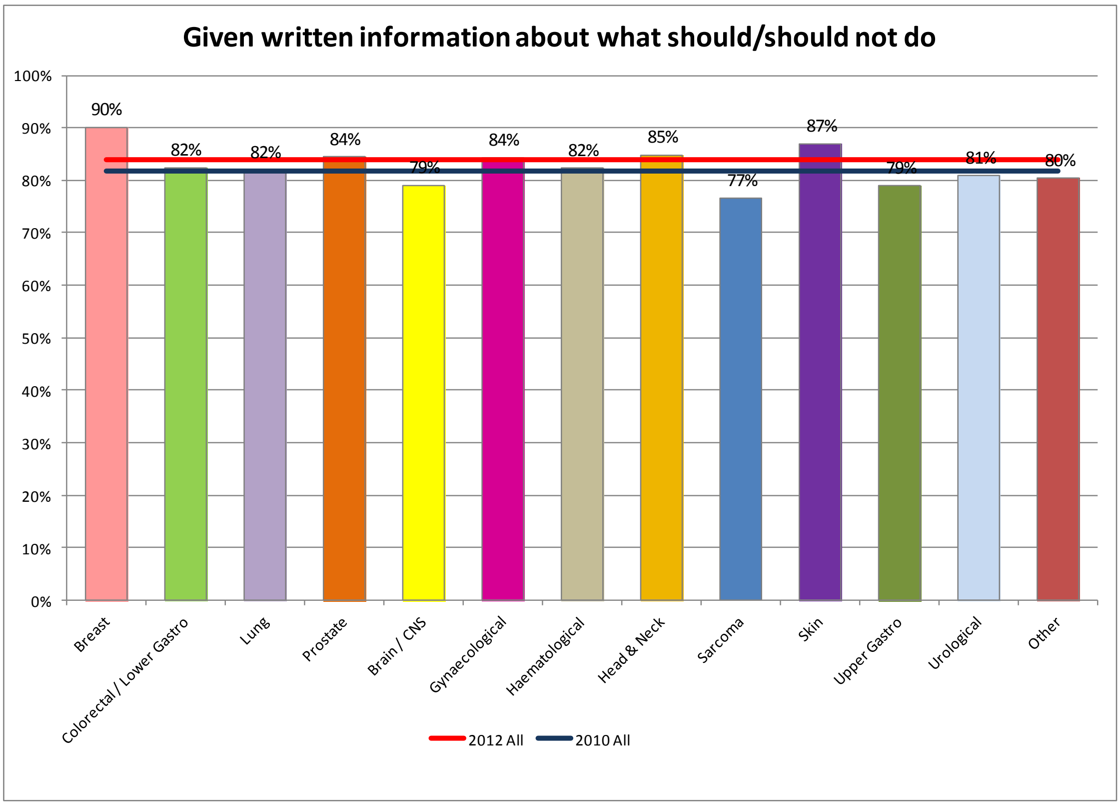

Chart 29 Given written information about what should / should not do after leaving hospital

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 68% as the lowest score to 100% as the highest Trust score.

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

53. 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

93% of patients overall said that hospital staff told them who to contact if they felt worried about their condition or treatment after leaving hospital; 7% said they were not told.

Comparison with 2010 Survey

The proportion of patients saying that hospital staff told them who to contact if they felt worried about their condition or treatment was 93% in the 2011/12 survey compared to 92% in 2010.

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 83% as the lowest score to 100% as the highest Trust score.

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

54. 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, 60% said that their family or someone close to them definitely received all the information they needed to help care for them at home; 22% said they did so to some extent. 18% said their family did not get all the information they needed.

Comparison with 2010 Survey

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 was 60% in the 2011/12 survey compared to 58% in 2010.

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% (haematological cancer) to 55% (sarcoma).

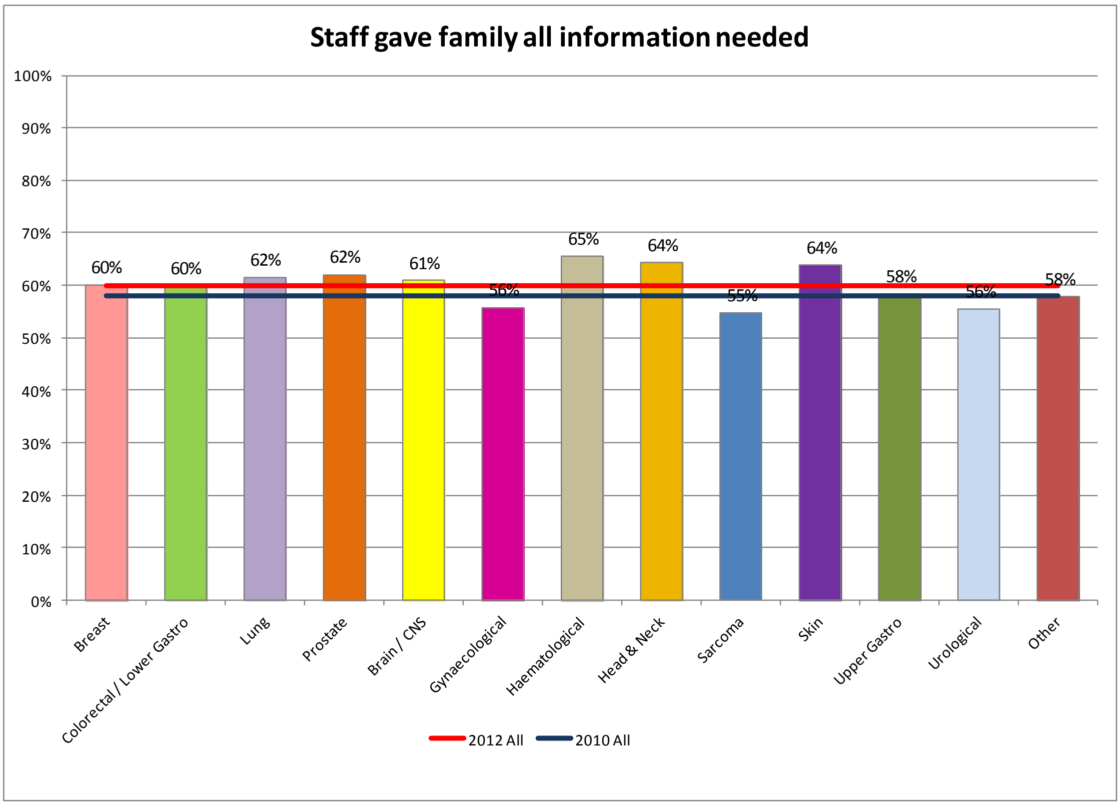

Chart 30 Family given information needed

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 45% as the lowest score to 87% as the highest Trust score.

The 20th percentile threshold is 57%; the 80th percentile threshold is 64%.

55. 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, 61% said they were definitely given enough care and help from health or social services after leaving hospital; 21% said they were to some extent. 18% said they did not get enough care and help.

Comparison with 2010 Survey

The proportion of patients saying they were definitely given enough care and help from health or social services was 61% in the 2011/12 survey compared to 60% in 2010.

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 68% (colorectal/lower gastrointestinal cancer) to 51% (urological cancer).

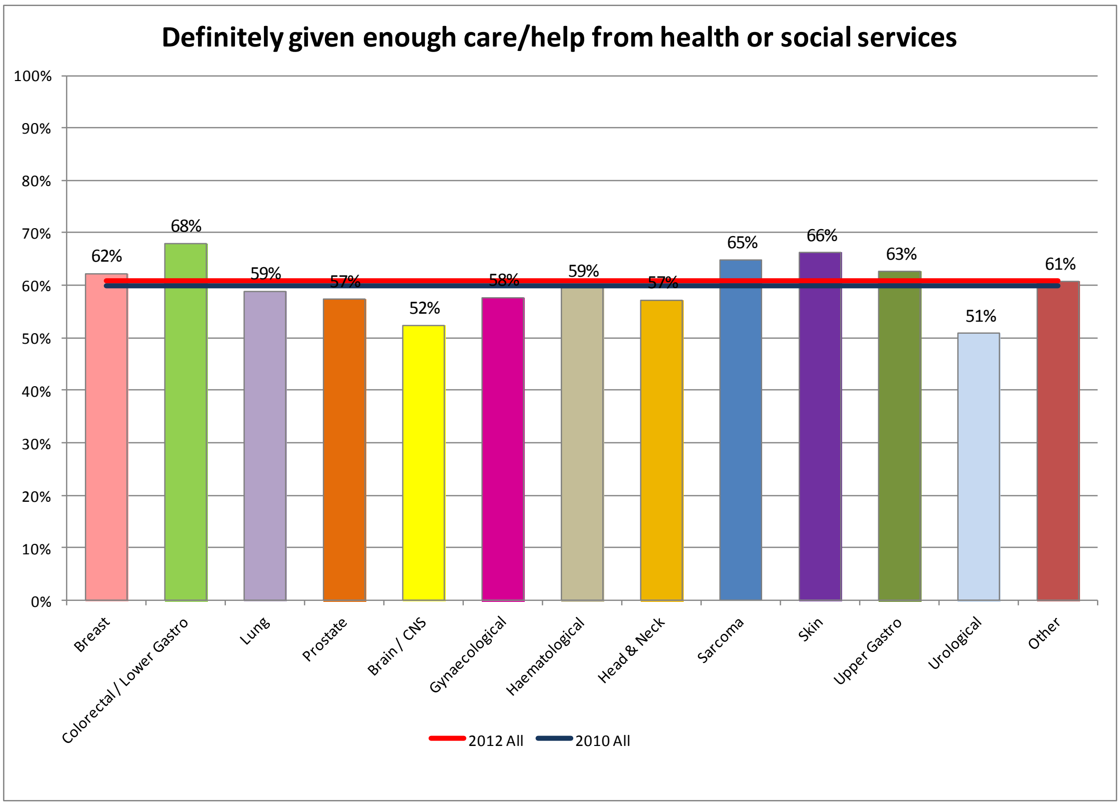

Chart 31 Given enough care from health / social services

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 32% as the lowest score to 86% as the highest Trust score.

The 20th percentile threshold is 54%; the 80th percentile threshold is 67%.

Day / outpatient care

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

56. Side effects of radiotherapy [22]

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

Overall Findings

60% of patients said they had not had any radiotherapy and 5% of patients who had radiotherapy said they had not had any side effects.

79% of patients having radiotherapy who had side effects said that staff definitely did everything possible to control the side effects of the radiotherapy; 17% said they did so to some extent. 4% 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 63% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 76%; the 80th percentile threshold is 84%.

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[22] Wording has been changed in 2012 so not comparable with 2010 question

57. Side effects of chemotherapy [23]

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

Overall Findings

36% of patients said they had not had any chemotherapy and 4% of patients who had chemotherapy said they had not had any side effects.

81% of patients having chemotherapy who had side effects said that staff definitely did everything possible to control the side effects of the chemotherapy; 16% 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 chemotherapy. Scores in Trusts ranged from 55% as the lowest score to 96% as the highest Trust score.

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

58. 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, 81% said that hospital staff definitely did everything they could to help control the pain; 16% said they did so to some extent. 3% said they could have done more to help control the pain.

Comparison with 2010 Survey

The proportion of patients saying hospital staff definitely did everything they could to help control the pain was 81% in the 2011/12 survey compared to 83% in 2010.

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[23] Wording has been changed in 2012 so not comparable with 2010 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 hospital staff definitely did everything they could to help control the pain. Scores in Trusts ranged from 67% as the lowest score to 92% as the highest Trust score.

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

59. 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; 23% said they were to some extent. 7% said they would have liked more support.

Comparison with 2010 Survey

The proportion of patients saying they were definitely given enough emotional support by staff was 71% in the 2011/12 survey compared to 71% in 2010.

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 78% (skin cancer) to 56% (brain / CNS).

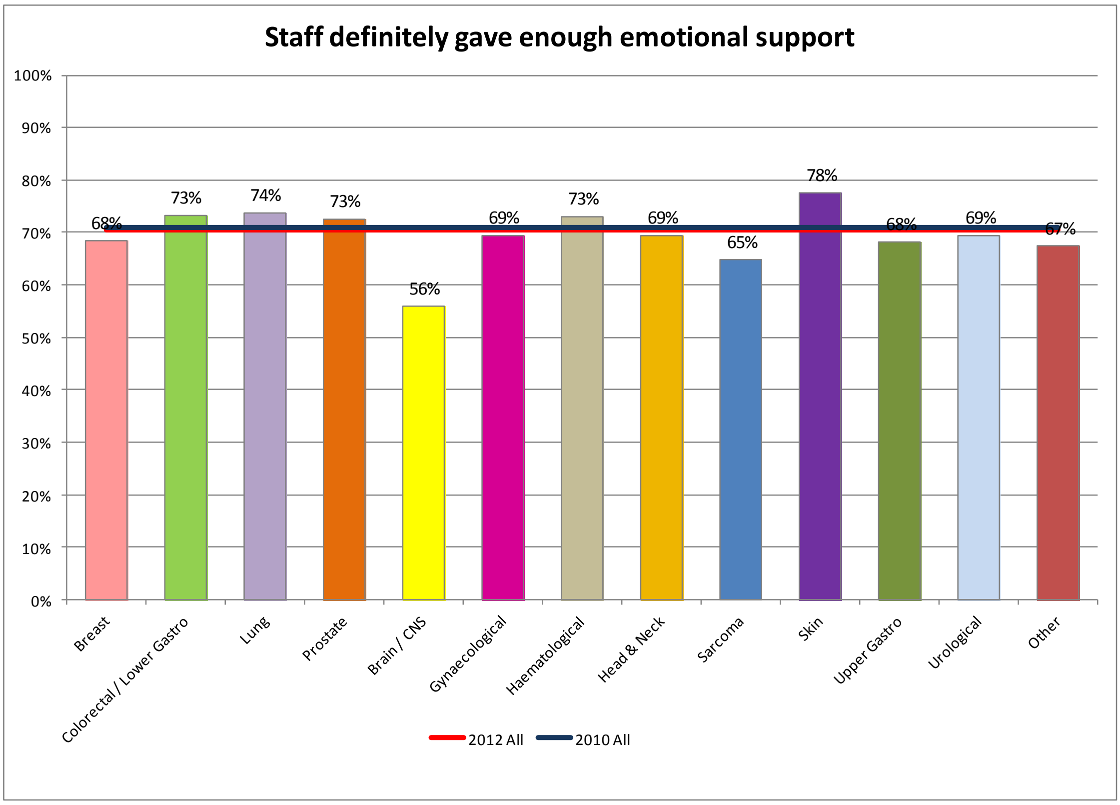

Chart 32 Given enough emotional support

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 55% as the lowest score to 93% as the highest Trust score.

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

Outpatient appointments

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

60. 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

94% of patients overall said that they had had an outpatients appointment with a cancer doctor in the last 12 months.

Comparison with 2010 Survey

The proportion of patients that they had had an outpatients appointment with a cancer doctor in the last 12 months was 94% in the 2011/12 survey compared to 93% in 2010.

61. 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

70% of patients said they were seen early or within 30 minutes of their stated appointment time. Of this group, 19% were seen on time or early, 8% waited up to 5 minutes, 21% waited 6 to 15 minutes, and 22% waited 16 to 30 minutes.

18% waited 31 minutes to an hour, 10% waited 1 to 2 hours and 3% waited more than 2 hours.

Comparison with 2010 Survey

The proportion of patients saying they waited 30 minutes or less for their appointment to start was 70% in the 2011/12 survey compared to 68% in 2010.

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 77% (urological cancer) to 65% (breast and haematological cancers and sarcoma).

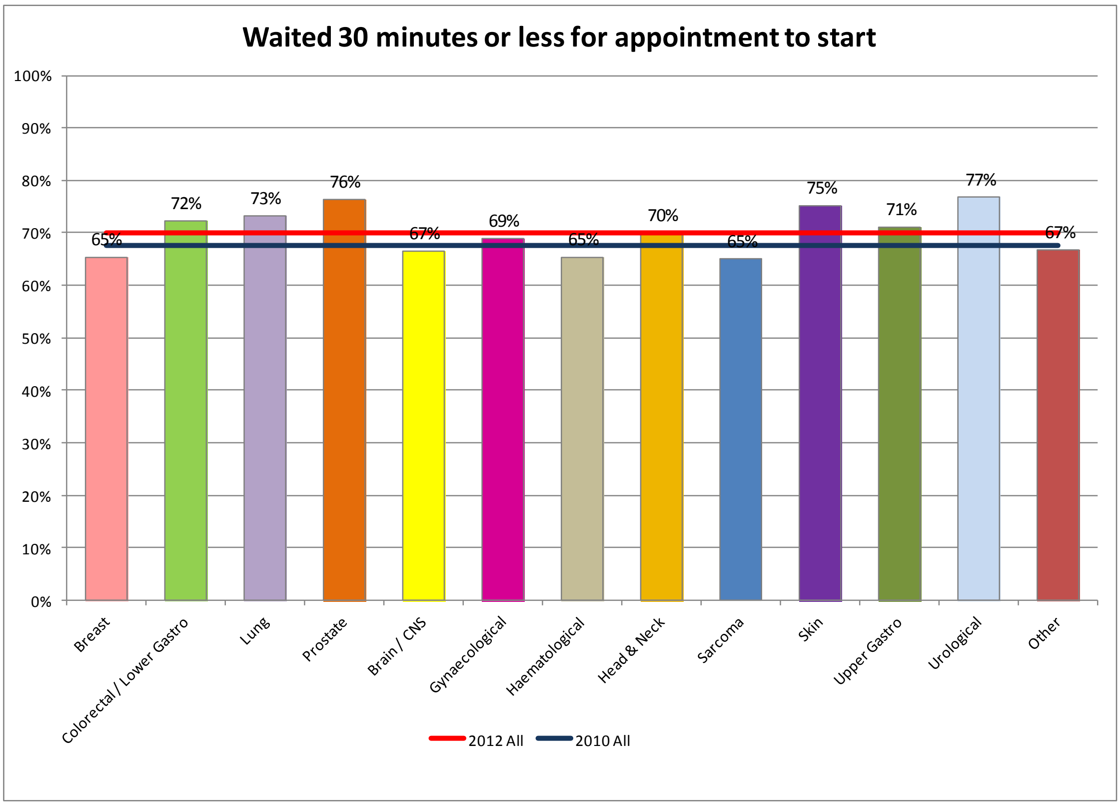

Chart 33 Waited 30 mins or less for appointment to start

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 43% as the lowest score to 89% as the highest Trust score.

The 20th percentile threshold is 62%; the 80th percentile threshold is 79%.

62. 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.

Comparison with 2010 Survey

The proportion of patients saying the time spent was about right was 94% in the 2011/12 survey compared to 94% in 2010.

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 88% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 92%; the 80th percentile threshold is 96%.

63. 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.

Comparison with 2010 Survey

The proportion of patients saying that the cancer doctor had the right documents was 95% in the 2011/12 survey compared to 95% in 2010.

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 88% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 94%; the 80th percentile threshold is 96%.

Care from general practices

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

64. 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

94% of patients said that, as far as they knew, their GP was given enough information about their condition and treatment by the hospital; 6% said they were not given enough information.

18% of patients (who were excluded from the above calculations) said they did not know or could not remember, in answer to this question.

Comparison with 2010 Survey

The proportion of patients saying their GP was given enough information was 94% in the 2011/12 survey compared to 93% in 2010.

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 87% as the lowest score to 99% as the highest Trust score.

The 20th percentile threshold is 92%; the 80th percentile threshold is 96%.

65. 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, 67% said that GPs and nurses definitely did everything they could to support them whilst they were having cancer treatment; 23% said they did to some extent and 10% said they could have done more. 30% said their general practice was not involved.

Comparison with 2010 Survey

The proportion of patients saying the staff at their general practice definitely did everything they could to support them was 67% in the 2011/12 survey compared to 69% in 2010.

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 72% (prostate and skin cancers) to 60% (brain / CNS).

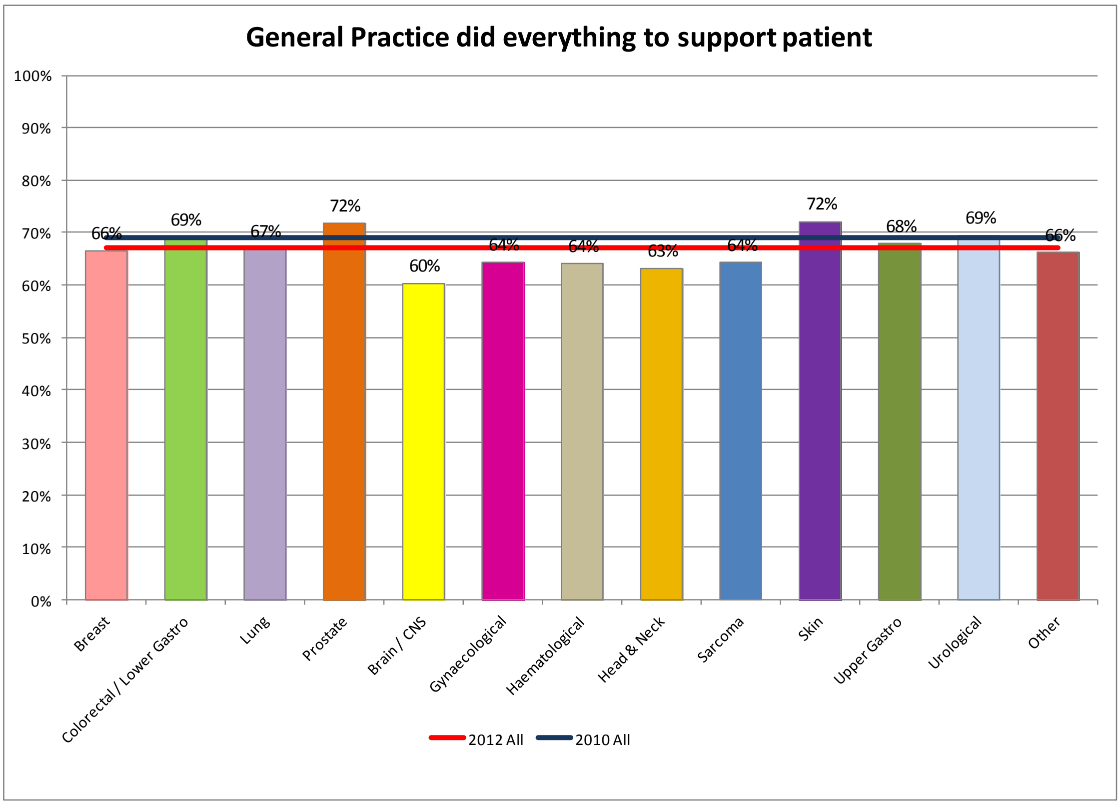

Chart 34 GP did everything to support patient

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 49% as the lowest score to 79% as the highest Trust score.

The 20th percentile threshold is 63%; the 80th percentile threshold is 71%.

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.

66. 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

62% of patients said that the different people treating and caring for them always worked well together to give the best possible care; a further 28% said they did so most of the time. 8% said they only did so some of the time and 1% said they never did.

Comparison with 2010 Survey

The proportion of patients saying that the different people treating and caring for them always worked well together was 62% in the 2011/12 survey compared to 61% in 2010.

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 67% (skin cancer) to 51% (brain / CNS).

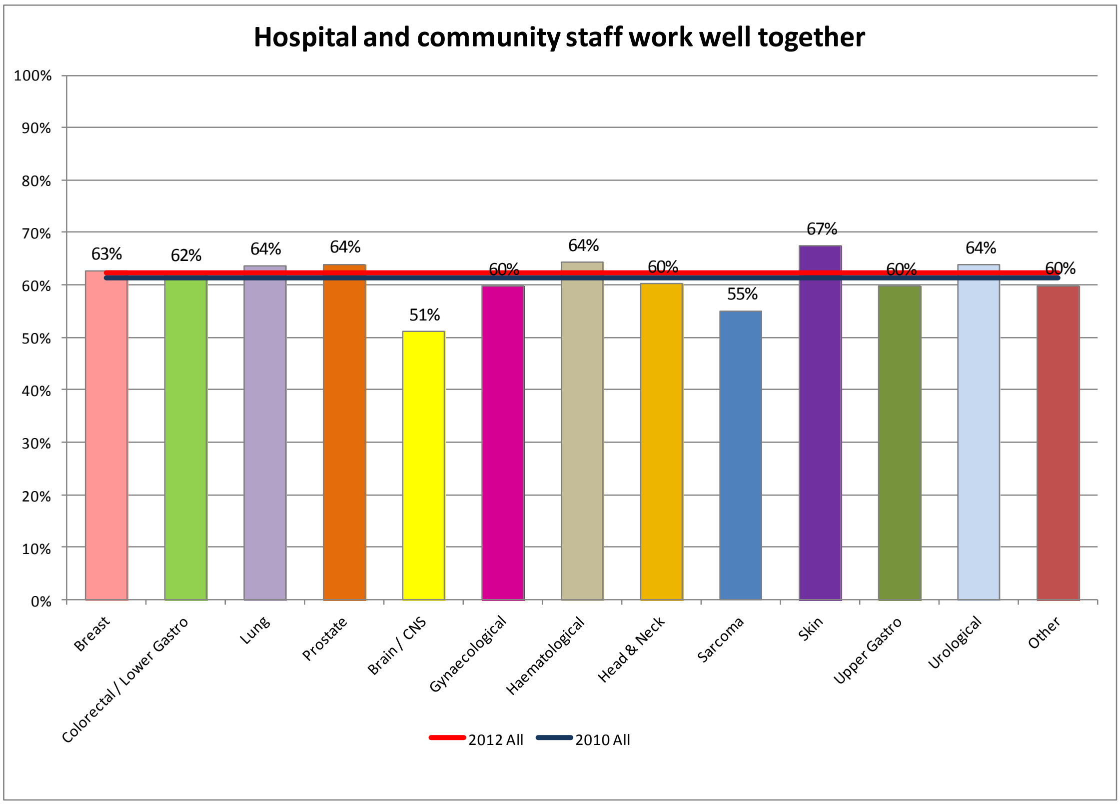

Chart 35 Staff worked well together

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 33% as the lowest score to 79% as the highest Trust score.

The 20th percentile threshold is 59%; the 80th percentile threshold is 67%.

67. Information about condition and treatment

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

Overall Findings

89% of patients overall said that they were given the right amount of information about their condition and treatment; 10% said they were not given enough and 1% said they were given too much.

Comparison with 2010 Survey

The proportion of patients saying that they were given the right amount of information about their condition and treatment was 89% in the 2011/12 survey compared to 88% in 2010.

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 78% as the lowest score to 96% as the highest Trust score.

The 20th percentile threshold is 87%; the 80th percentile threshold is 91%.

68. Written assessments and care plans [24]

Have you been offered a written assessment and care plan?

Overall Findings

24% of patients said that they had been offered a care plan; 76% said they had not and a further 13% said they didn't know or couldn't remember.

Findings by Tumour Group

There was a significant variation in the proportion of patients saying that they had been offered a care plan. Scores ranged from 27% (colorectal / lower gastro cancer) to 20% (urological cancer).

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[24] New question in 2012

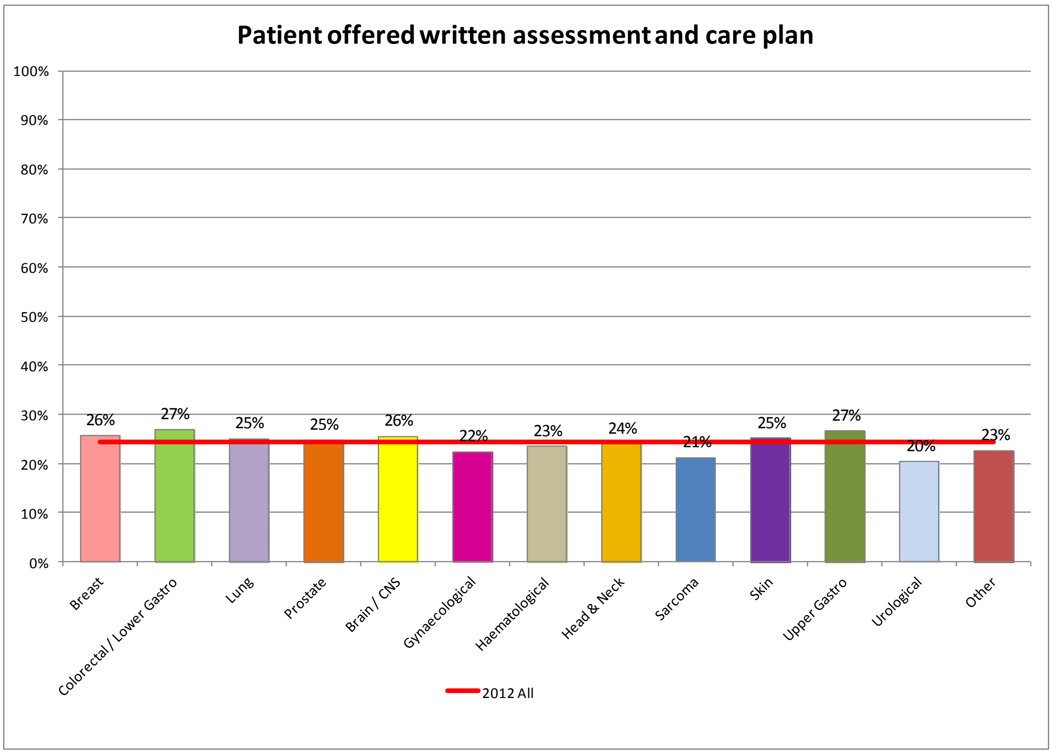

Chart 36 Offered written assessment / care plan

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were offered a care plan. Scores in Trusts ranged from 5% as the lowest score to 49% as the highest Trust score.

The 20th percentile threshold is 21%; the 80th percentile threshold is 29%.

69. 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.

Comparison with 2010 Survey

The proportion of patients saying they did not feel that they were treated as ‘a set of symptoms’ rather than a whole person was 80% in the 2011/12 survey compared to 80% in 2010.

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 89% (skin cancer) to 72% (brain / CNS).

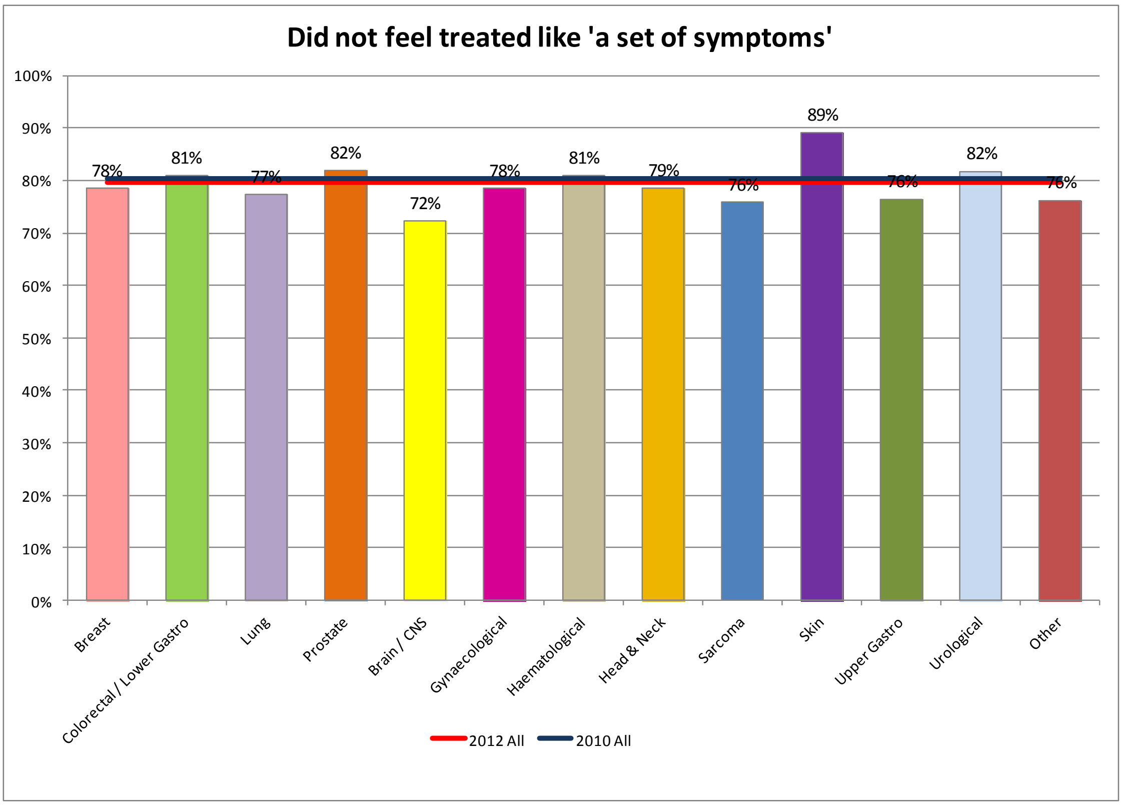

Chart 37 Did not feel treated like a set of symptoms

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 63% as the lowest score to 88% as the highest Trust score.

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

70. Patients rating of care [25]

Overall how would you rate your care?

Overall Findings

88% of patients said that their care was either excellent (54%) or very good (34%). 9% said it was good and 3% said it was either only fair (2%) or poor (1%).

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 rating their care as either excellent or very good. Scores in Trusts ranged from 68% as the lowest score to 94% as the highest Trust score.

The 20th percentile threshold is 85%; the 80th percentile threshold is 90%.

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[25] New question in 2012

7. Longitudinal analysis

There is a high degree of comparability between the 2010 and 2011/12 CPES with most questions remaining the same, and therefore a more substantial form of longitudinal analysis is now possible compared to earlier surveys.

This analysis shows that, on over half the scored questions in the 2011/12 survey, there were statistically significant differences between the 2010 and 2011/12 results. These 45 questions showed significant improvements on 37 questions and declines on eight, indicating that on most items in the 2011/12 survey care and treatment was perceived as being more positive than in 2010.

Examples of some of the biggest improvements in scores are as follows:

Question	2010	2011/12	% IMP
Q02: Patient thought they were seen as soon as necessary	81%	83%	2.7%
Q03: Time from patient first thinking something wrong to seeing hospital doctor	74%	79%	4.6%
Q06: Staff gave complete explanation of purpose of test(s)	81%	83%	1.8%
Q07: Staff explained completely what would be done during test	84%	86%	2.2%
Q09: Given complete explanation of test results in understandable way	76%	78%	1.4%
Q14: Patient given written information about the type of cancer they had	66%	69%	2.9%
Q17: Possible side effects explained in an understandable way	72%	75%	2.2%
Q20: Patient given the name of the CNS in charge of their care	84%	87%	2.6%
Q24: Hospital staff gave information about support groups	79%	82%	2.5%
Q25: Hospital staff gave information on getting financial help	50%	52%	2.1%
Q26: Hospital staff told patient they could get free prescriptions	68%	73%	5.3%
Q32: Staff gave complete explanation of what would be done	85%	87%	2.0%
Q33: Patient given written information about the operation	68%	73%	5.5%
Q34: Staff explained how operation had gone in understandable way	73%	75%	1.7%
Q40: Got understandable answers to important questions all/most of the time	73%	75%	2.2%
Q41: Patient had confidence and trust in all ward nurses	66%	69%	2.9%
Q47: Always given enough privacy when discussing condition/treatment	82%	84%	1.5%
Q52: Given clear written information about what should / should not do	82%	84%	2.3%
Q54: Family definitely given all information needed to help care at home	58%	60%	1.8%
Q61: Waited no longer than 30 minutes for OPD appointment to start	68%	70%	2.3%

Table 8 Longitudinal comparisons

The small number of questions where scores have declined are on issues such as a patient seeing their GP once or twice before being told they had to go to hospital; patients understanding completely the explanation of what was wrong; always/nearly always enough nurses on duty; staff doing everything they could to control pain; practice staff doing everything they could to support the patient; and patients feeling they were not treated as a set of cancer symptoms. However, declines in these scores were minor.

We have also controlled for the slightly different distribution of responses as between tumour groups in 2011/12 and, when this is done so that the 2011/12 data is matched to the distribution of data between tumour groups in 2010, the position changes only marginally for scored questions, with it still being the case that the largest proportion of movements are upwards (35 significant increases, eight decreases).

A further and different set of controls was also implemented in respect of the age distribution of respondents, with the 2011/12 dataset matched to the age distribution of responses in 2010. This analysis shows that again the largest proportion of significant movements are upwards (33 upward, 11 down).

It is clear therefore that the three different kinds of analysis - using raw scored data; using tumour group data standardised to 2010 levels; and using age data standardised to 2010 levels - show broadly the same results. In each case there are substantially more upward positive movements than downward negative ones.

The following charts show the three questions with the biggest positive movements:

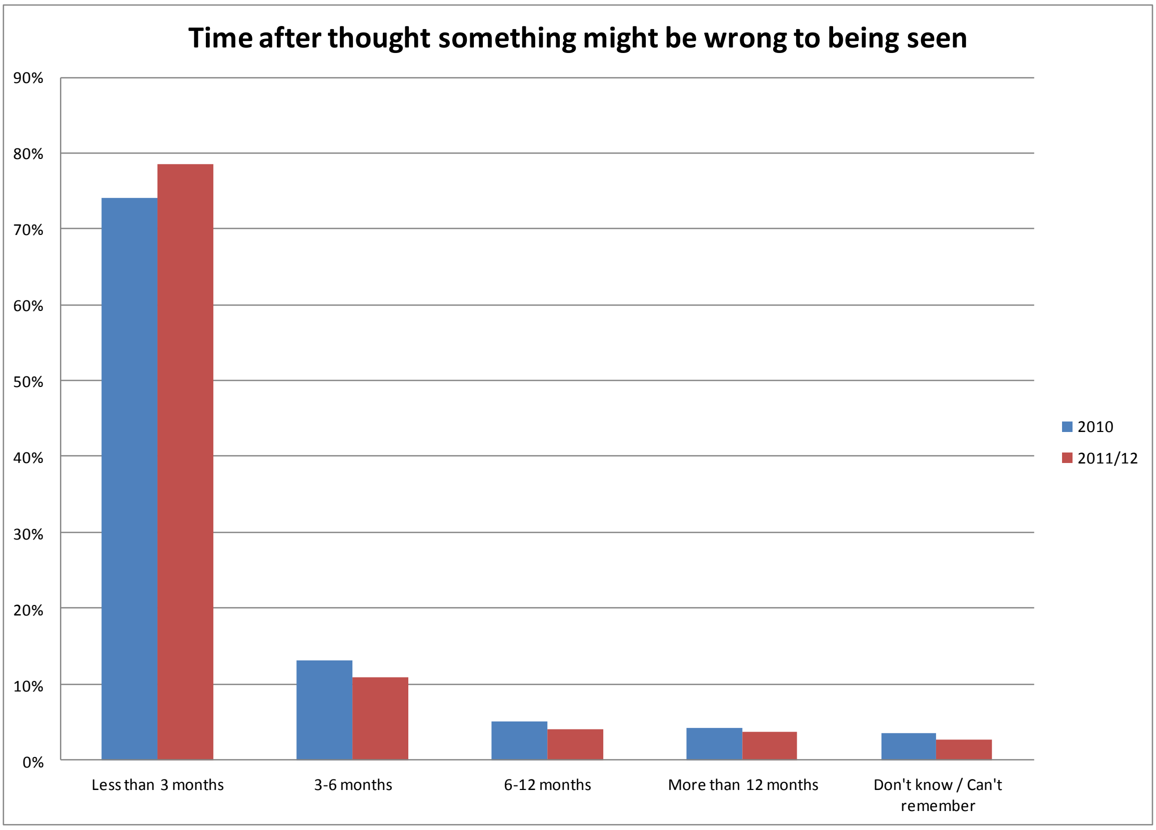

Chart 38 Time from patient first thinking something wrong to seeing hospital doctor

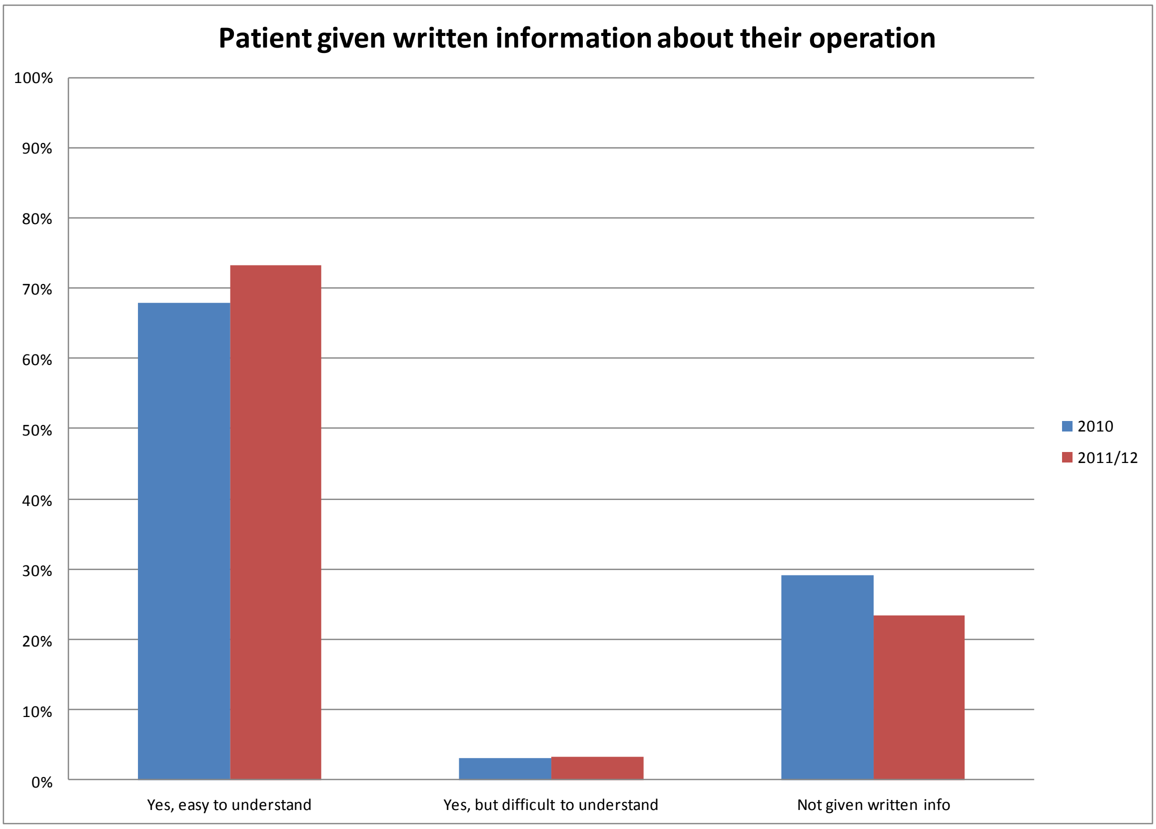

Chart 39 Patient given written information about their operation

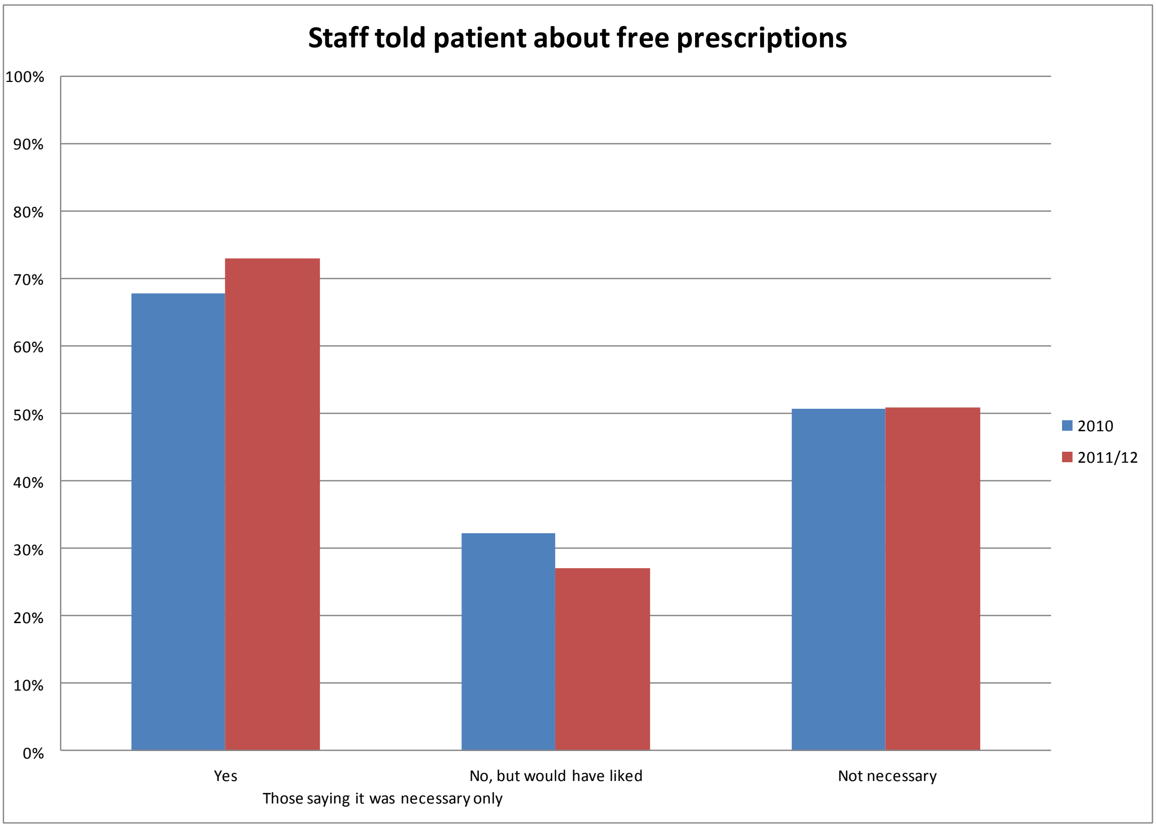

Chart 40 Staff told patient about free prescriptions

8. Differences between Trusts in 2011/12

160 NHS Trusts took part in the 2011/12 CPES, and as in 2010, there are substantial differences in ratings given by patients in different Trusts. This can be analysed in a number of ways.

Range of scores

On some questions in the 2011/12 CPES, scores in the poorest performing Trusts are considerably lower than in the best performing. The questions on which there is most variance from minimum score to maximum are as follows:

No.	Question	Range
Q1	Saw GP only once or twice before being told they needed to go to hospital	53 points
Q4	Health got better or stayed the same while waiting for first hospital appointment	50 points
Q14	Given understandable written information about the type of cancer they had	41 points
Q25	Hospital staff give information on financial help and benefits	45 points
Q27	Hospital staff discussed with you whether you would like to take part in cancer research	48 points
Q29	Wasn't asked to take part in cancer research but would have liked to have been	36 points
Q33	Given understandable written information about the operation beforehand	45 points
Q39	Family/someone else definitely had opportunity to talk to a doctor if they needed to	71 points
Q41	Had confidence and trust in the ward nurses looking after them	44 points
Q43	Always/nearly always enough nurses on duty to care for them	53 points
Q46	All Doctors/Nurses asked me what name I wanted to be called by	58 points
Q49	Able to discuss worries and fears with staff as much as they wanted	41 points
Q54	Doctors/Nurses definitely gave family all information needed to help care for you at home	42 points
Q55	Definitely given enough care and help from health/social services after leaving hospital	54 points
Q61	Waited less than 30 minutes at last outpatient appointment with a cancer Doctor	46 points
Q66	Different people treating and caring for them always worked well together	46 points
Q68	Offered written assessment and care plan	44 points

Table 9 Questions with most variance between minimum and maximum scores

The minimum and maximum thresholds, and the 10th and 90th percentile, are set out at the end of this section in respect of each question in the survey.

These ranges demonstrate that there are Trusts who have scores which are minimum outliers in the overall results, and which need considerable attention in the light of scores achieved by other similar Trusts treating similar patients.

Regional Differences

As can be seen in the analysis based on SHA, Trusts in the London SHA are less likely to have positive scores on a range of questions than is the case elsewhere.

However, within most Regions there are substantial differences between the performance of the best Trusts and those with poorer performance. Examples of these differences for some questions in three large Trusts are set out in the charts below in respect of the London SHA area:

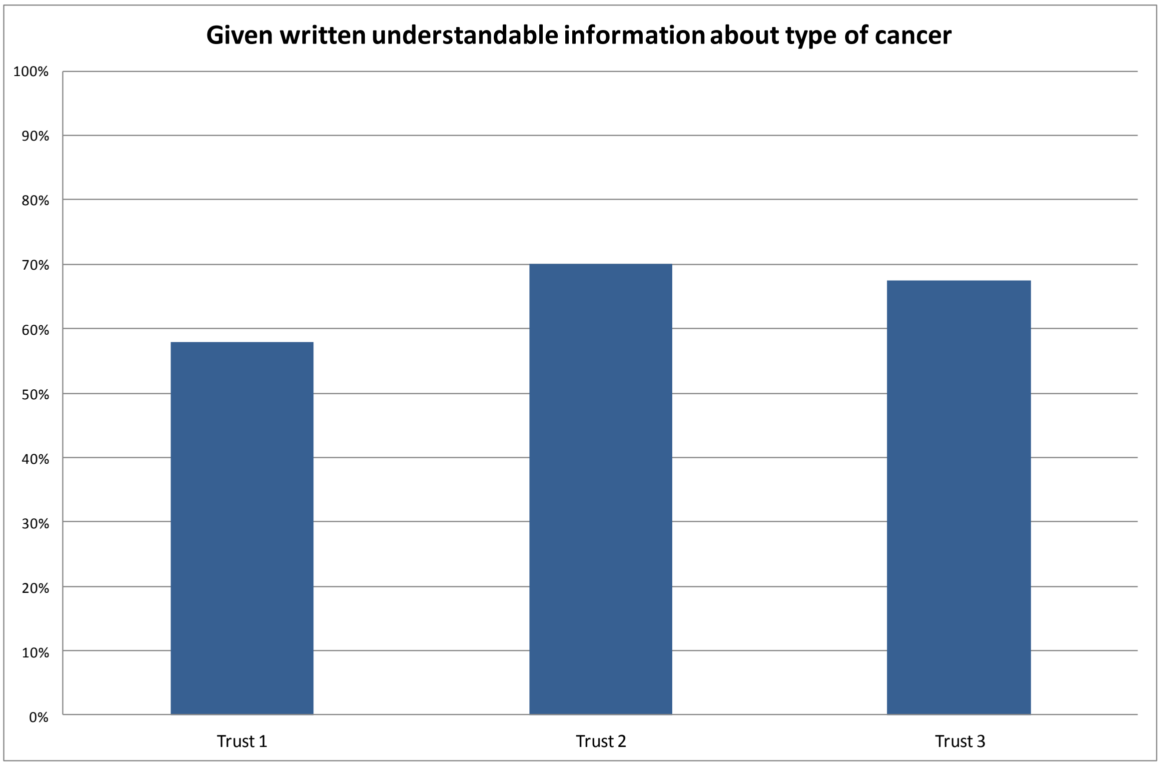

Chart 41 Range of scores on written information on type of cancer

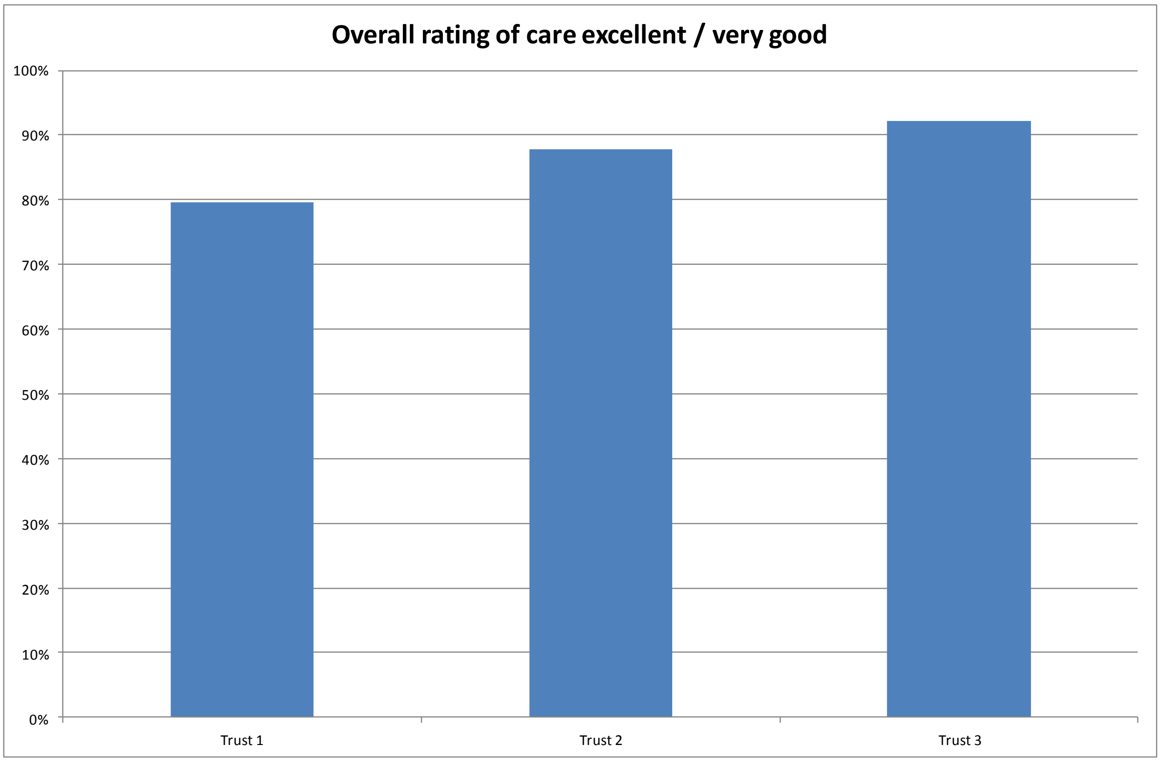

Chart 42 Range of scores on overall rating of care

Differential improvement between Trusts

In the 2011/12 CPES, a substantial number of Trusts showed improvement across a wide range of questions. There were 21 Trusts that achieved statistically significant improvements on at least 10 scored questions in the 2011/12 survey, with 3 of these being Trusts which were in the poorest performing group of 16 Trusts in 2010.

Many other Trusts achieved more modest numbers of improvements, and relatively few Trusts showed no improvements over 2010 at all. 17 Trusts showed no improving scores over 2010, with 8 of this group of 17 being in the North West SHA area.

The full picture of Trust improvement and stasis since the 2010 CPES is as follows:

- 21 Trusts had statistically significant improvements on 10 or more questions over the 2010 scores, with 7 of this group having 15 or more improvements. The top 2 Trusts showed 20 improvements each; this group is best described as "very substantial improvers";
- 26 Trusts had between 6 and 9 statistically significant improvements over the 2010 scores, with very few significant reductions in scores since 2010 registered at all; this group is best described as "substantial improvers";
- 82 Trusts had between 1 and 5 statistically significant improvements over the 2010 scores, but some of this group also had small numbers of reductions in scores since 2010. This group of Trusts is best described as "modest improvers and standstill";

- 18 Trusts have no statistically significant improvements since the 2010 survey, and almost all have modest numbers of reductions in scores since 2010. This group of Trusts is best described as "marginal decliners"
- 8 Trusts had significantly more reductions in scores than improvements since 2010. This group has no identifiable geographical pattern and contains Trusts which performed well in 2010 as well as those that were poor performers. This group of Trusts is best described as "declining score Trusts"
- 5 Trusts had very small numbers of respondents in both 2010 and 2011/12, or were not included in the 2010 CPES, making it not possible to calculate change.

On this basis, therefore, 83% of participating Trusts either improved their scores to some extent or stood still in relation to the 2010 CPES. Only 17% showed declines of some kind.

Looking at the results Trust by Trust, we can say that some Trusts with the same kinds of patients in treatment, and geographically close to one another, did substantially better than others "next door". This effect can probably be attributed to the effects of local leadership taking action immediately to improve performance.

Trust level results - Scored results, 2012 data										
	Q1	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**
Min	40%	66%	84%	40%	61%	66%	75%	67%	68%	88%
10th percentile	69%	79%	95%	75%	86%	78%	82%	80%	73%	94%
90th percentile	80%	89%	98%	86%	92%	86%	90%	90%	83%	98%
Max	93%	92%	100%	90%	98%	92%	94%	98%	88%	100%
	Q11	**Q12**	**Q13**	**Q14**	**Q15**	**Q16**	**Q17**	**Q18**	**Q19**	**Q20**
Min	55%	74%	60%	45%	62%	56%	61%	53%	60%	74%
10th percentile	64%	80%	69%	61%	77%	64%	70%	74%	66%	81%
90th percentile	78%	88%	78%	76%	90%	77%	79%	86%	77%	92%
Max	88%	94%	83%	86%	100%	83%	87%	89%	83%	99%
	Q21	**Q22**	**Q23**	**Q24**	**Q25**	**Q26**	**Q27**	**Q28**	**Q29**	**Q30**
Min	59%	82%	72%	60%	32%	52%	14%	85%	36%	28%
10th percentile	69%	88%	88%	69%	40%	64%	21%	91%	44%	49%
90th percentile	84%	94%	94%	83%	63%	81%	44%	98%	59%	72%
Max	92%	99%	97%	91%	77%	90%	62%	100%	72%	99%
	Q31	**Q32**	**Q33**	**Q34**	**Q35**	**Q36**	**Q37**	**Q38**	**Q39**	**Q40**
Min	71%	73%	43%	63%	35%	70%	68%	66%	49%	50%
10th percentile	85%	82%	64%	70%	60%	77%	80%	78%	59%	66%
90th percentile	95%	91%	81%	81%	81%	87%	90%	88%	72%	82%
Max	100%	97%	88%	89%	98%	92%	95%	95%	86%	88%
	Q41	**Q42**	**Q43**	**Q44**	**Q45**	**Q46**	**Q47**	**Q48**	**Q49**	**Q50**
Min	41%	67%	35%	74%	63%	24%	73%	85%	40%	74%
10th percentile	62%	79%	53%	83%	74%	40%	79%	92%	55%	80%
90th percentile	76%	89%	70%	91%	85%	68%	89%	97%	71%	89%
Max	85%	95%	88%	94%	93%	82%	93%	100%	81%	93%
	Q51	**Q52**	**Q53**	**Q54**	**Q55**	**Q56**	**Q57**	**Q58**	**Q59**	**Q60**
Min	68%	68%	83%	45%	32%	63%	55%	67%	55%	79%
10th percentile	77%	79%	88%	53%	50%	72%	74%	76%	63%	89%
90th percentile	88%	89%	96%	66%	69%	86%	87%	86%	78%	96%
Max	98%	100%	100%	87%	86%	100%	96%	92%	93%	98%
	Q61	**Q62**	**Q63**	**Q64**	**Q65**	**Q66**	**Q67**	**Q68**	**Q69**	**Q70**
Min	43%	88%	88%	87%	49%	33%	78%	5%	63%	68%
10th percentile	59%	91%	93%	91%	60%	55%	86%	18%	75%	84%
90th percentile	83%	97%	98%	97%	72%	69%	92%	32%	86%	92%
Max	89%	100%	100%	99%	79%	79%	96%	49%	88%	94%

Table 10 Minimum, maximum, 10th percentile and 90th percentile scores on all questions

9. Comparisons with the national inpatient survey

16 questions in the 2011/12 National Cancer Patient Experience Survey (CPES) are the same or very similar to questions in the Care Quality Commission 2011 National Inpatient Survey[26]. The table below shows a comparison between the results from inpatients responding to the 2011/12 CPES and patients responding to the 2011 National Inpatient Survey. We display below only the results from cancer patients who had an inpatient episode in hospital in September-November 2011, as distinct from those who were treated in day case units.

All but one of the scores in the 2011/12 CPES are significantly higher than in the National Inpatient Survey, as was the case in the 2010 CPES.

Question		**Cancer Survey**	**Inpatient Survey**
Q19	Patient definitely involved as much as they wanted in decisions on treatment choices	72%	52%
Q32	Patient given prior complete explanation of what would be done during their operation	87%	74%
Q34	Patient given easy to understand post operative explanation of operation outcome	75%	66%
Q37	Patient had confidence and trust in all doctors treating them	85%	80%
Q38	Patient did not think that doctors talked in front of them as if they were not there	83%	73%
Q41	Patient had confidence and trust in all ward nurses treating them	69%	74%
Q42	Patient did not think that nurses talked in front of them as if they were not there	84%	78%
Q43	Patient thought there were always or nearly always enough (ward)* nurses on duty to care for them	61%	58%
Q45	Patient never thought they were given conflicting information about their condition or treatment	79%	66%
Q47	Patient always given enough privacy when discussing condition or treatment	84%	72%

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[26] CQC, National Inpatient Survey Results, 2011, http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/inpatient-survey-2011

Q48	Patient always given enough privacy when being examined or treated	94%	89%
Q51	Staff always treated patient with respect and dignity	83%	79%
Q53	Staff told patient who to contact if they were worried post discharge	93%	77%
Q54	Clinical staff definitely gave family/carer/close friend all information needed to help care for patient at home	60%	46%
Q67	Overall, patient given right amount of information about their condition and treatment	89%	78%
Q70	Overall rating of care excellent / very good	88%	78%

Table 11 Comparison with the 2011 CQC 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 continue to be 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 (Q41). The question asked in the 2011/12 CPES 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 CPES 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.

10. 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 in 2010 identified 42 questions on which there are statistically significant differences across the age bands; in 2011/12 there are 43 such questions. Not all of these differences are of the same kind, but there are commonalities, such as:

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.

Of the 43 questions on which there are statistically significant age related differences in reported experience between the age groups, younger patients in the 16-25 and 26-35 age groups are the least positive on 30 of the 43 questions. The older age group 76+ are the least positive on nine questions. It is much less likely that patients in the middle years, very broadly defined as 35-75, will be less positive.

A clear example of the classic age distribution profile in the survey is highlighted in the chart below which shows the scores on question 13, which asked patients if they completely understood the explanation of what was wrong with them:

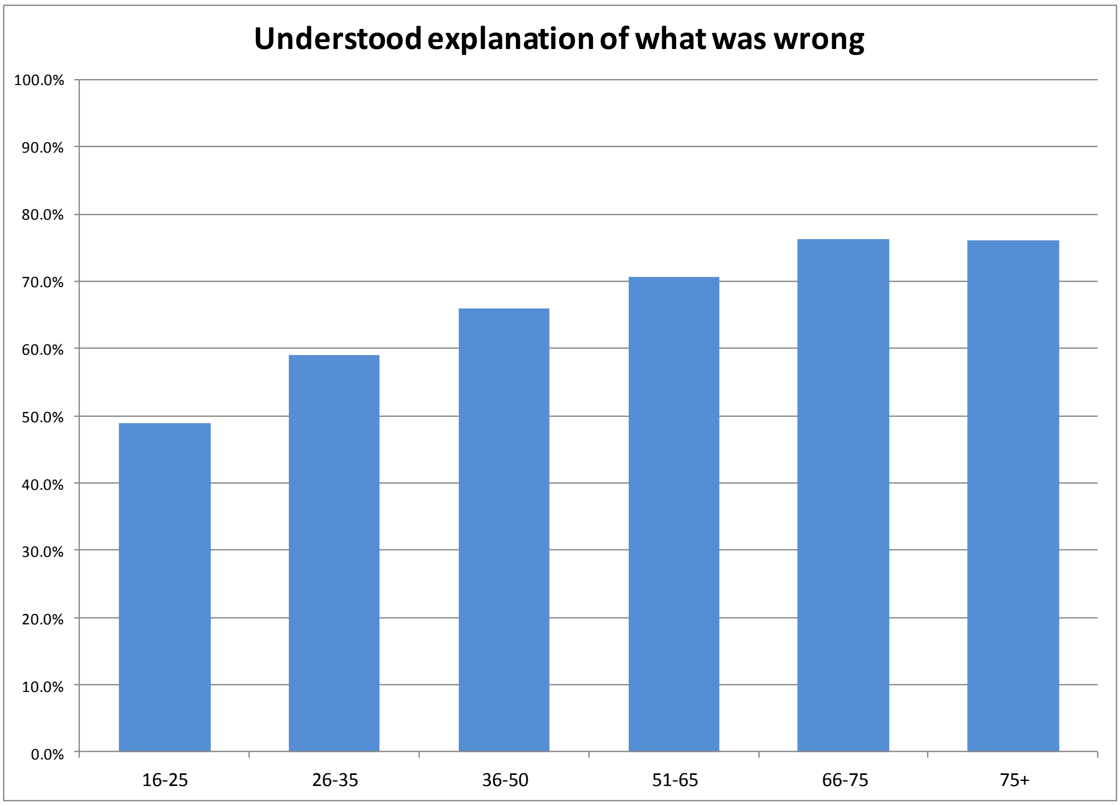

Chart 43 Patient understood completely the explanation of what was wrong with them

Younger patients, who may have less experience of being in hospital than older people and often have more complex types of cancer, 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). The fact that these findings have been replicated in two successive national cancer surveys, and that they are congruent with data from the Care Quality Commission (CQC) national surveys in all sectors of the NHS, points to the need to enhance and simplify explanations of conditions and treatment to the youngest cohorts of patients.

As in 2010, it is not always younger patients who report 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 CNS, with the proportions in each age band saying they had a CNS following very much the same profile as in 2010, but with improvements in CNS coverage recorded in almost all age bands between 2010 and 2011/12:

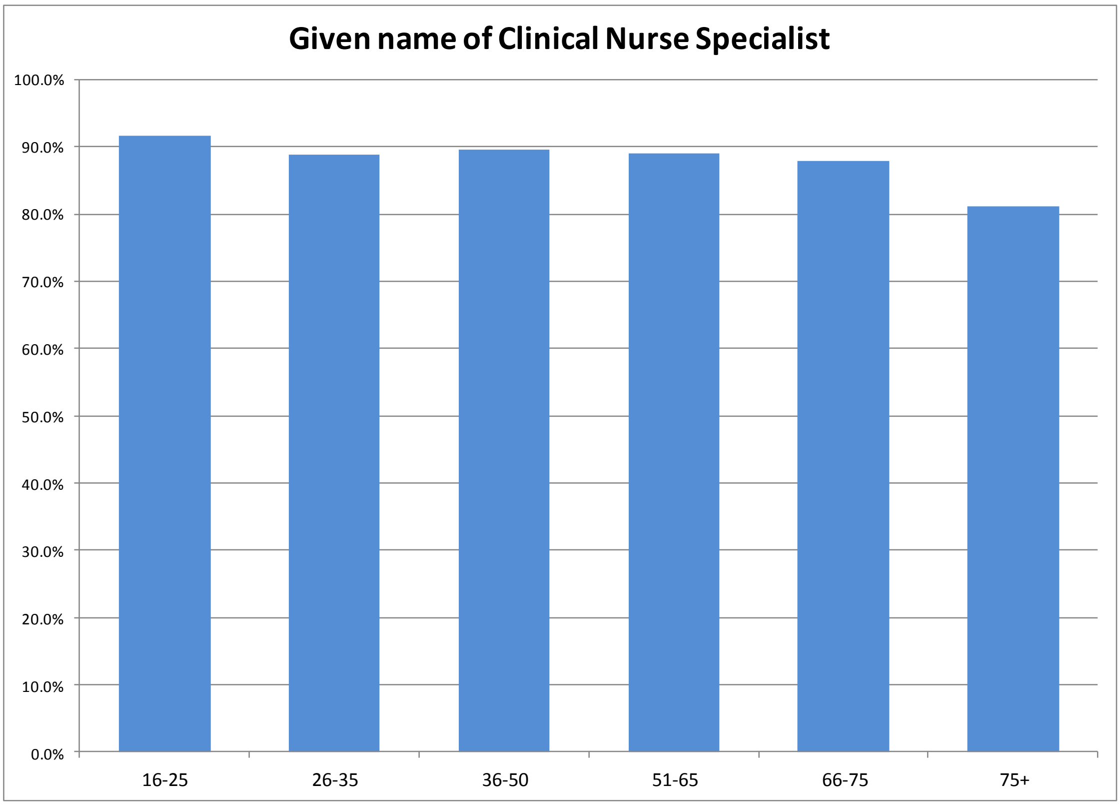

Chart 44 Patient given the name of the Clinical Nurse Specialist

A further example where younger patients are more likely to be given information is in respect of information about financial help or any benefits they may be entitled to. 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 older people do not claim all that they could by way of pension credit, housing benefit etc, and it remains the case that many pensioners have very low incomes.

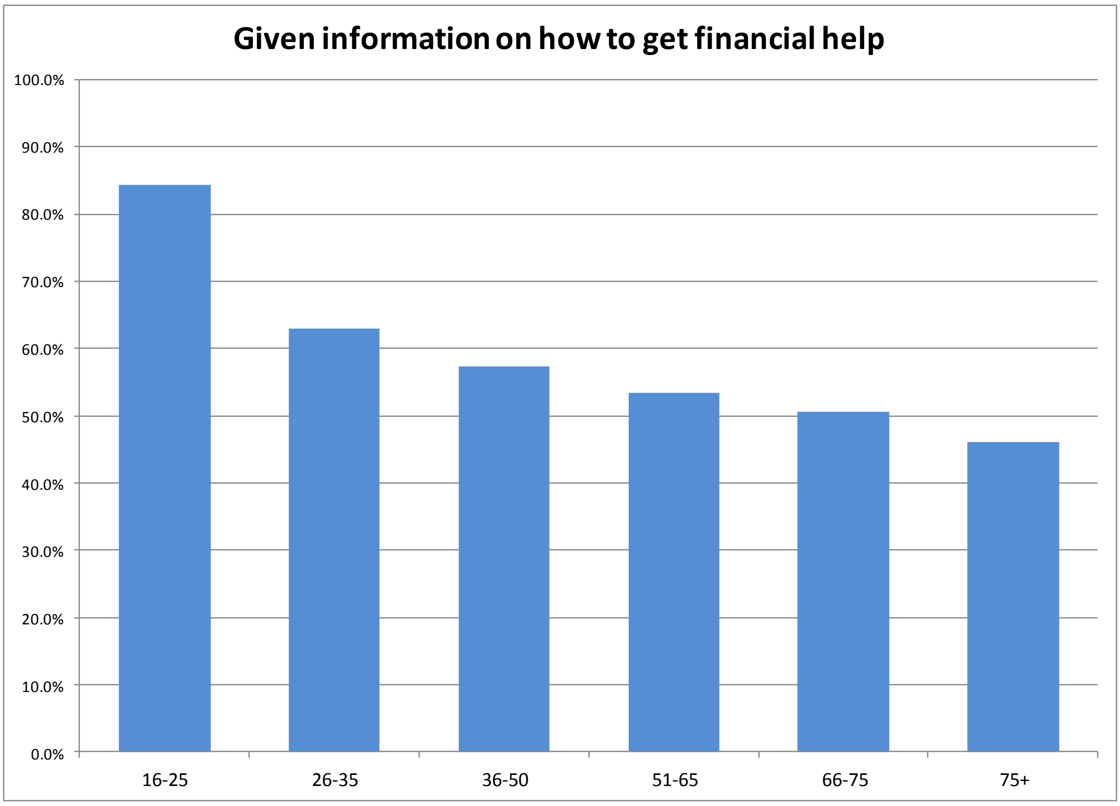

Chart 45 Patient Given Information on how to get financial help or benefits

On most issues measured in the 2011/12 CPES, 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 on whether GP staff did everything they could to support the patient while they had cancer; the age band distribution is almost identical in 2010 as in 2011/12.

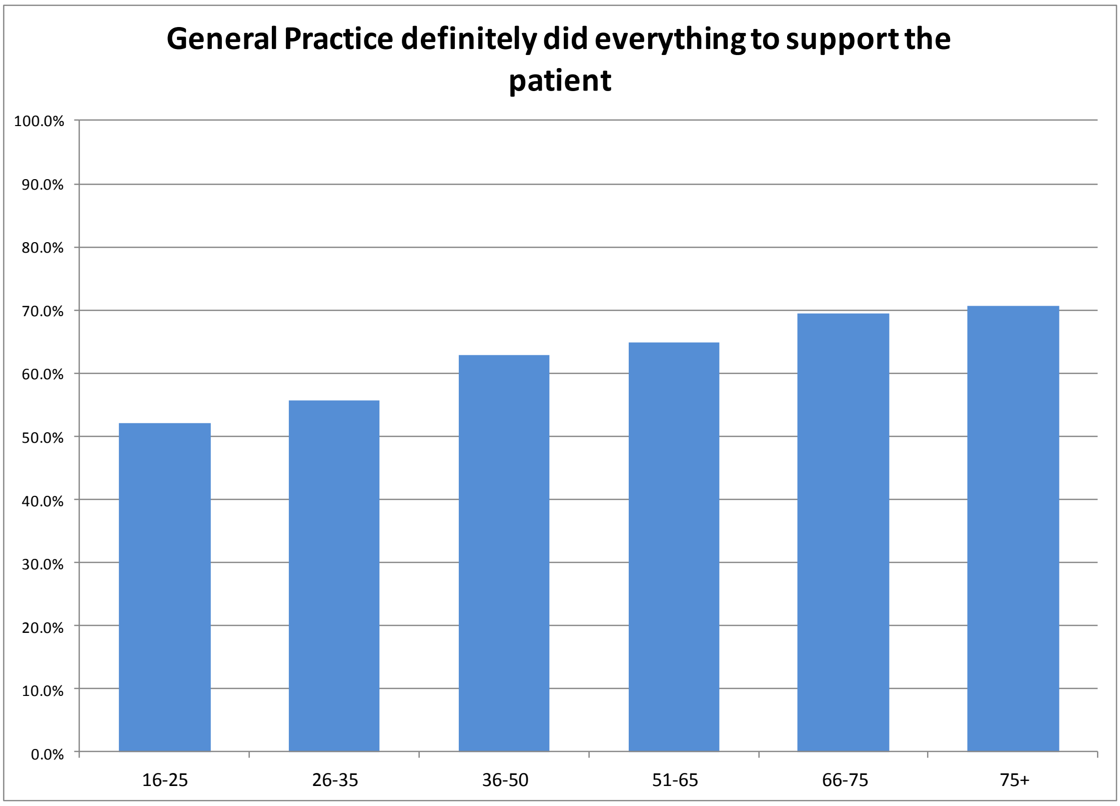

Chart 46 General Practice definitely did everything to support the patient during treatment

In 2011/12, as in 2010, 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. However, on some questions it is clear that, although there are still differences of view between the age groups, a rising tide of positive performance has affected all age groups pretty equally whilst maintaining the differentials between them.

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.

In the 2010 CPES there were some consistent patterns in responses which are congruent with the kinds of responses seen in the national patient surveys of elective and emergency patients in NHS hospitals. In the 2010 CPES there were 43 questions on which there were significant differences of view between men and women; in most cases men were more positive but on 12 out of 43 questions where there were significant differences, women were more positive than men.

In the 2011/12 CPES there were 46 questions on which there were significant differences of view between men and women, with men being more positive on 31 questions and women more positive on 11 questions.

The strategic points in 2011/12 remain the same as in 2010:

- 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.

On new questions introduced in 2011/12, men were more likely to say that they were glad to have been asked about being involved in cancer research; and were more likely to give an overall positive rating for their care and treatment as a whole.

Women were more positive on 11 questions:

- Women were more likely to say that they saw their GP only once or twice before being referred on to hospital (2010 and 2011/12)
- Women were more likely to say that their health stayed the same in the waiting period before seeing a hospital doctor (2010 and 2011/12)
- Women were more likely to say that the side effects of treatment were explained in an understandable manner (2011/12)
- Women were more likely to say they were given written information about the side effects of their treatment (2010 and 2011/12)
- Women were much more likely to be given the name of a Clinical Nurse Specialist (2010 and 2011/12 - see below)

- Women were more likely to say that they had been approached to see if they would like to take part in cancer research (new question 2011/12)
- Women were more likely to say that they were given easy to understand written information about their operation (2011/12)
- Women were more likely to say that ward nurses did not talk in front of them as if they were not there (2011/12)
- Women were more likely to say that staff did not deliberately fail to tell them things (2011/12)
- Women were more likely to say that they were given clear written information about what to do after they left hospital (2011/12)
- Women were more likely to say that doctors did not talk in front of them as if they were not there. (2010 and 2011/12)

There was one issue in particular on which women were more positive – more women (89%) said they were given the name of a CNS than did men (85%); 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 CNSs. However, the gap between CNS coverage for men and women seems to be narrowing as measured by the 2010 and 2011/12 CPES.

There is great consistency in the results between 2010 and 2011/12 in respect of gender differences in views, as can be seen by the fact that five of the questions on which women were more positive were evidenced as such in both the 2010 and 2011/12 surveys; and the questions on which men were more positive were also highly consistent between the two years.

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

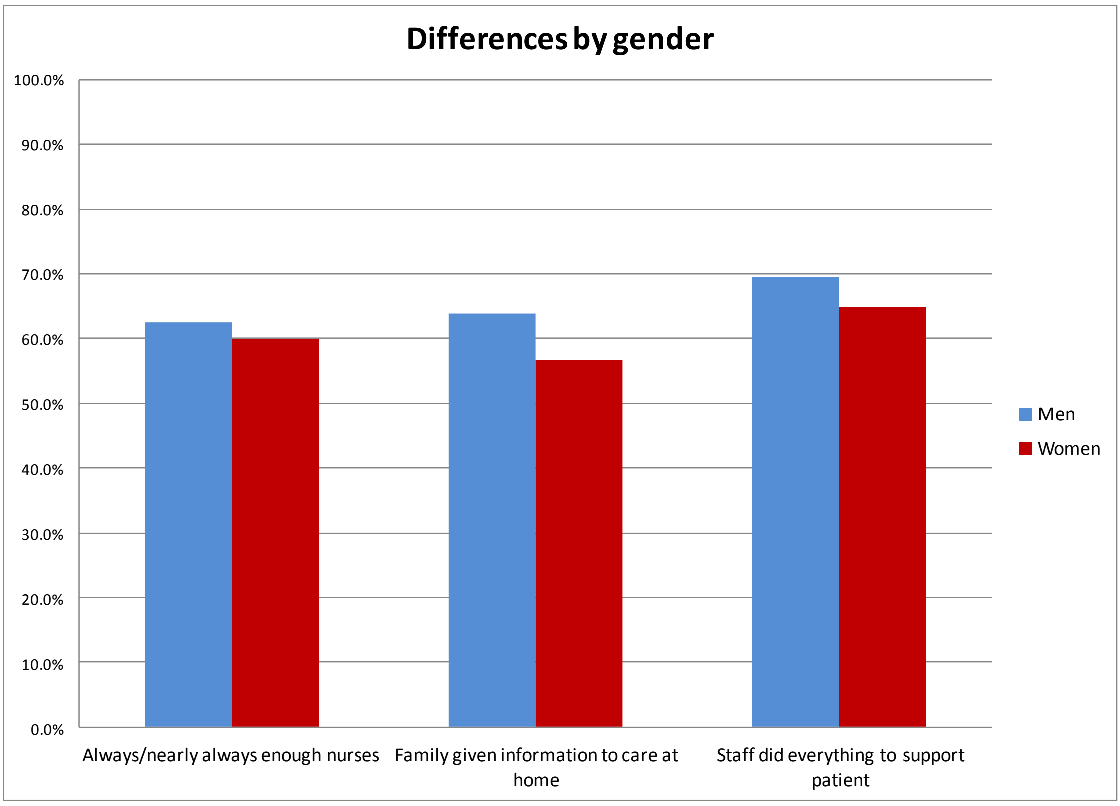

Chart 47 Examples of More Positive Views by Men

The impact of ethnicity

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

The absolute numbers of ethnic minority respondents to the survey is quite low (2,665 in 2011/12, including mixed race respondents) and is around 3.7% of the whole respondent group, 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 and 2011/12 surveys replicates the position in the 2000 and 2004 cancer 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 the 2011/12 dataset from these five groups were then analysed to identify any differences that may exist between them on any of the questions in the survey. On 25 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	Q2
• Health stayed about the same whilst waiting for appointment with hospital doctor	Q4
• Results of tests explained in a way that the patient could understand	Q9
• Completely understood the explanation of what was wrong with them	Q13
• Given easy to understand written information about their cancer	Q14
• Given written information about the side effects of treatment	Q18
• Definitely involved as much as they wanted to be in decisions about which treatment to have	Q19
• Patient asked if they wanted to take part in cancer research	Q27
• Doctors talked in front of the patient as if they were not there	Q38
• Patient received answers from a ward nurse that were understandable all or most of the time	Q40

• Had confidence and trust in all ward nurses	Q41
• Ward nurses talked in front of the patient as if they were not there	Q42
• Patient often thought doctors / nurses were deliberately not telling them certain things	Q44
• Patient asked what name they wished to be called by	Q46
• Patient able to discuss worries and fears with staff	Q49
• Give enough care and help from health and social services after discharge	Q55
• Hospital staff definitely did everything they could to control side effects of chemotherapy	Q57
• Patient definitely given enough emotional support from hospital staff when an outpatient or day case patient	Q59
• At last outpatient appointment with a cancer doctor, seen within 30 minutes	Q61
• GPs and Nurses at the practice definitely did everything they could to support patient whilst they were having cancer treatment	Q65
• GPs / other staff worked well together to give the best possible care	Q66
• Patient offered a written assessment and care plan	Q68
• Patient did not feel that they were being treated as a set of cancer symptoms rather than as a whole person	Q69
• Overall rating of care excellent / very good	Q70

As in 2010, in all cases in 2011/12 where statistically significant differences were 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 were more positive than are patients in any other ethnic group. The one exception was 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.

On all questions where there are significant differences, an ethnic minority group has the lowest scores bar two - the new questions related to being asked to participate in cancer research (Q27) and on whether the patient was offered an assessment and care plan (Q68).

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, assessment of effectiveness of primary care support, and on the overall rating of care.

The charts below show examples from the 2011/12 data in respect of the scale of differences that exist between the perceptions of some ethnic minority patients and white patients undergoing cancer treatment.

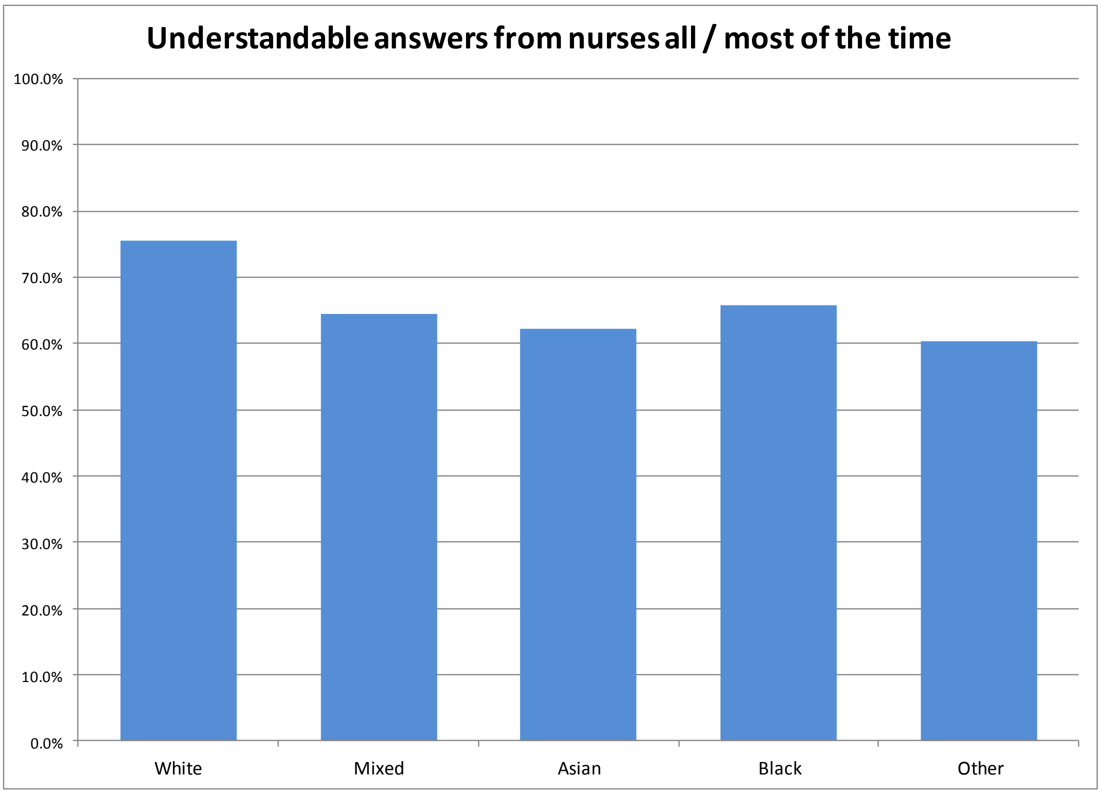

Chart 48 Patient received understandable answers from ward nurse all/most of the time

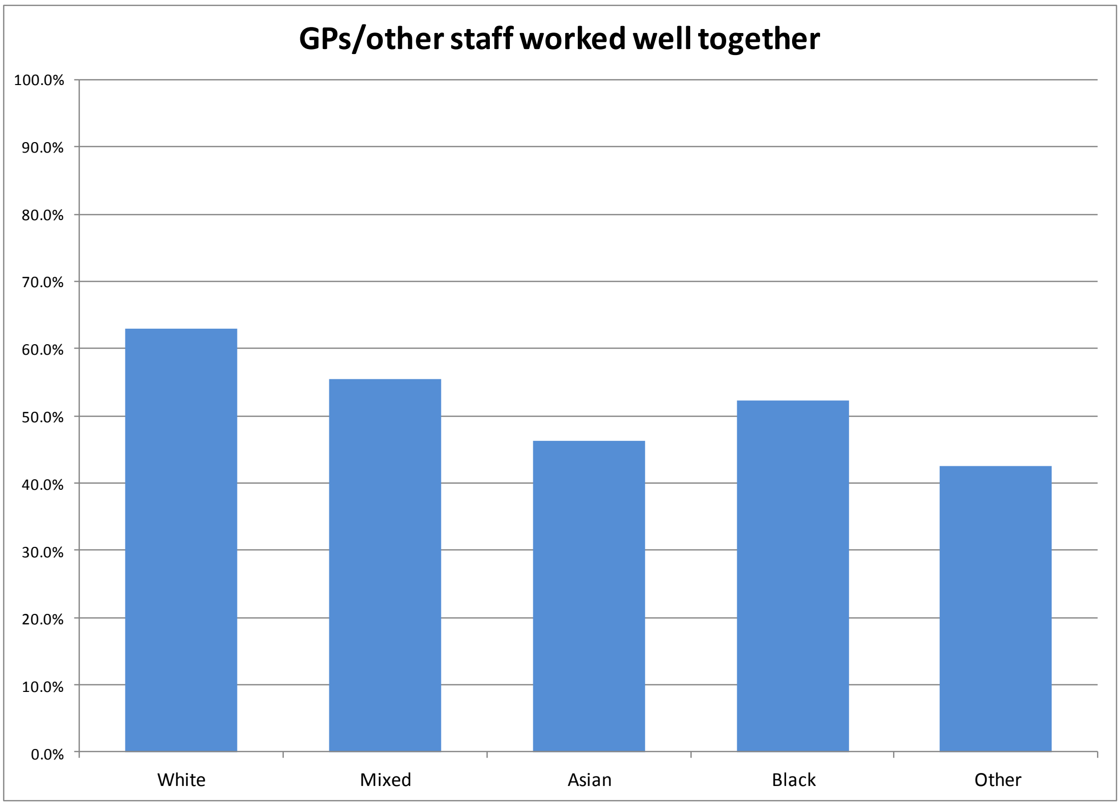

Chart 49 GPs / other staff caring for patient always worked well together

It is important to note that in both the 2010 and 2011/12 CPES surveys, the scale of differences between ethnic groups identified 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 CPES that some of these differences relate to clarity of information, and some to perceived differences of treatment of the patient as an individual.

In respect of the 2011/12 CPES, 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 three items; Asian patients least positive on eight items; Chinese/other ethnic group patients being the least positive on sixteen items; and mixed race patients being least positive on no items.

The impact of sexual orientation

In the 2011/12 CPES, as in 2010, respondents were asked if they were heterosexual, bisexual, gay or lesbian, or were of other sexual orientation (Q73). Significant numbers of respondents (3%) said they preferred not to answer (a specific answer option), although this was lower than in 2010 (5%), and a more substantial number than usual did not answer the question at all (6%), although this again was lower than in 2010 (8%). This compares to only 2.8% 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, as it probably was in 2010. Only 838 patients (1.1%) overall in 2011/12 chose one of the response options other than heterosexual. This proportion is the same as in 2010.

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 19 questions on which there are significant differences of opinion between heterosexual cancer patients and non-heterosexual patients, compared to 16 such questions in 2010. In these cases the differences demonstrate less positive views by non-heterosexuals, in respect of the following items:

- Saw GP only once or twice before being sent to hospital Q1
- Seen as soon as necessary by a hospital doctor Q2
- Patient given written information about the kind of cancer they had Q14
- Patient given the name of the CNS Q20
- Patient was given information about support / self help groups for people with cancer Q24
- Received understandable answers from hospital doctor on important questions the patient had asked Q36
- Doctors never talked in front of patient as if they were not there Q38
- Had confidence and trust in all ward nurses Q41
- Ward nurses never talked in front of patient as if they were not there Q42
- Doctors / nurses never deliberately did not tell patient things they wanted to know Q44
- Given enough privacy when discussing condition and treatment Q47

- Given enough privacy when examined or treated Q48
- Hospital staff always did everything they could to control their pain Q50
- Always treated with respect and dignity by hospital staff Q51
- Told who to contact if they were worried about their condition Q53
- Time spent with a cancer doctor in OPD last time was about right Q62
- GP given enough information about condition and treatment Q64
- Given right amount of information about treatment Q67
- Never felt treated as a set of cancer symptoms rather than as a whole person Q69

However, on three new questions respondents who described themselves as non heterosexual were more positive than heterosexuals, as follows:

- Glad to have been asked if they wanted to take part in cancer research Q28
- Would have liked to have been asked if they wanted to take part in cancer research Q29
- Offered a written assessment and care plan Q68

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.

Nevertheless, it is important to recognise the important differences of view between heterosexuals and non-heterosexuals and to note that 16 of the 19 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

As in 2010, the 2011/12 CPES 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 in 2011/12 there were 57 questions on which there are statistically significant differences between the two groups of patients, compared to 48 in 2010. In 2011/12, most such differences (52 out of 57) related to patients with a long term condition being less positive than patients without such a long term condition, compared to 45 out of 48 in 2010.

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 (both 2010 and 2011/12); on the provision of information on free prescriptions (both 2010 and 2011/12); whether they were asked which name they wished to be called by (new question 2011/12); on length of waiting time to see a cancer doctor in outpatients (both 2010 and 2011/12); and on being offered an assessment and care plan (new question 2011/12).

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

Question		LTC	Non LTC
Q4	Health stayed the same whilst waiting for first appointment with a hospital doctor	77%	81%
Q14	Given easy to understand information about the type of cancer they had	66%	70%
Q24	Hospital staff gave information about support/self help groups for people with cancer	72%	79%
Q33	Given written information about their operation	70%	75%
Q42	Ward nurses did not talk in front of them as if they were not there	82%	86%
Q55	Given enough care/help from health and social services after discharge	59%	62%
Q69	Did not feel as if they were treated as a set of cancer symptoms rather than as a whole person	78%	81%

Table 12 Differences between those with and those without an LTC

The conclusion to be drawn 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 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. 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 less likely to be positive about a wide range of issues than were patients with no long term conditions, as the chart below illustrates:

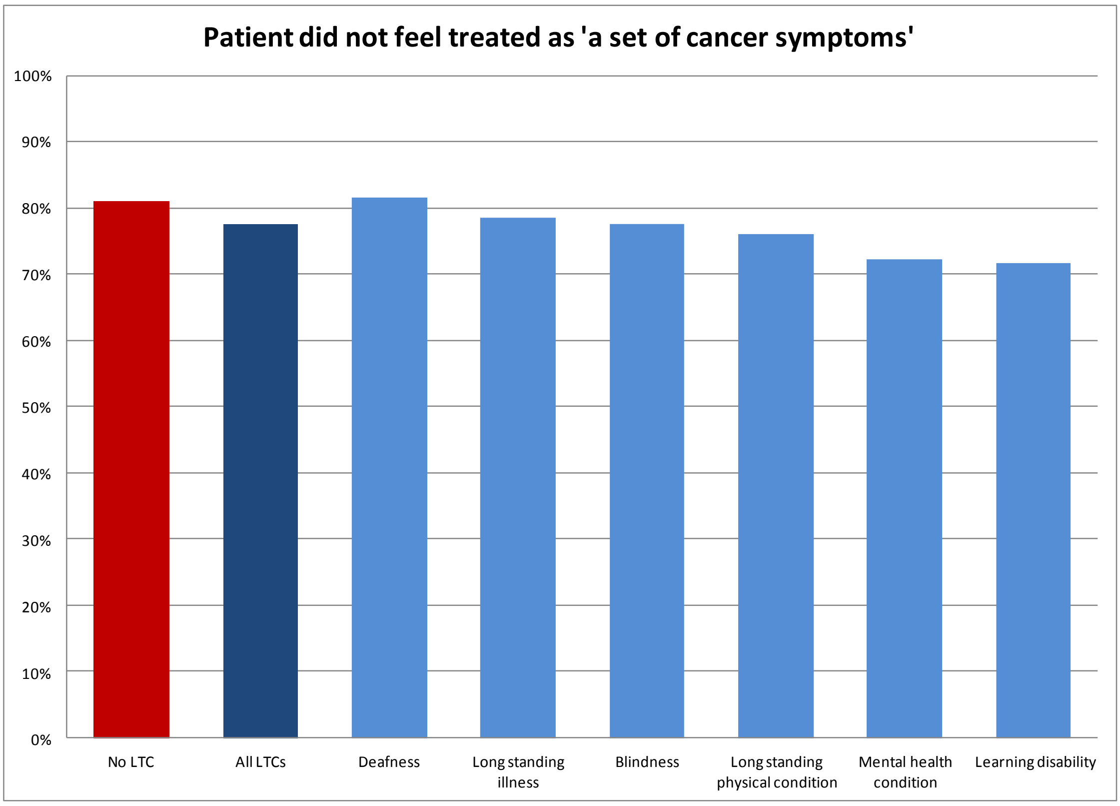

Chart 50 Patient did not feel treated as a set of symptoms by LTC

It is important to point out that the scale of the differences between those with a mental health or learning disability condition, and those who had no LTC at all, have narrowed considerably since 2010.

It continues to be the case that further 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.

The case 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 provision, appears to be clear.

Differences between tumour groups

In the 2011/12 CPES, it is clear that some of those differences between the Big 4 and other cancers identified in 2010 are still present to some degree. We have therefore looked specifically at the types of questions on which there is the widest variation in performance between tumour groups.

These differences are displayed in the main body of this report, but of the six scored questions on which there is most inter tumour group variation, three related to information giving, one to the patients health status remaining the same during the period before they saw a hospital doctor, one on families having the opportunity to talk to a doctor, and one on patients being given enough emotional support whilst being seen as a day case or outpatient.

The extreme ranges of performance are apparent on these kinds of questions, as is made clear by the following table:

Question					
Q4	Health got better or stayed the same whilst waiting for first appointment with a hospital doctor	Brain / CNS	61%	Skin	94%
Q13	Completely understood the explanation of what was wrong with them	Haematological	57%	Prostate	76%
Q14	Given easy to understand information about the type of cancer they had	Sarcoma	44%	Prostate	78%
Q33	Given written information about their operation	Sarcoma	55%	Breast	82%
Q39	Patient’s family definitely had time to talk to the doctor	Brain / CNS	55%	Skin	73%
Q59	Staff definitely gave patient enough emotional support	Brain / CNS	56%		78%

Table 13 Differences between cancer groups

It is the case that continuing efforts need to be made to reduce the "information gap" in particular between the best and poorest performing tumour groups.

Differences between inpatients and day case patients

Patients eligible for the CPES 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 between September and November 2011, whether as day case or as an inpatient.

In 2011/12, a similar picture to 2010 has emerged, as follows:

- Day case patients were more positive than inpatients on a range of questions relating to information giving, on free prescriptions, written information on the side effects of treatment, etc.
- Inpatients were in contrast more positive than day case patients on issues such as the patient’s views being taken in to account over treatment and care, there being enough nurses to care for the patient etc, in much the same pattern as in 2010 on the same questions.

On the new questions introduced into the 2011/12 CPES, a significantly higher proportion of day case patients said they had been asked if they would like to take part in cancer research; higher proportions of day cases were glad to have been asked; but more inpatients would like to have been asked about research despite the fact that they were not. On the overall rating of care question, there was no significant difference in that rating as between inpatients and day cases.

These statistically significant differences between inpatients and day cases are not large in scale on individual 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 remain clear, based on the results of two very substantial national cancer patient experience surveys, 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 CPES was that related to the impact of the Clinical Nurse Specialist (CNS). When the data was analysed as between those who had a Clinical Nurse Specialist and those who did not, there were significant differences between the groups on every single question in the survey. The same finding exists in the 2011/12 CPES except on one question (wasn't asked if they would like to take part in cancer research, but would have liked to have been). This is a powerful indication that the presence of a CNS makes a substantial positive difference to the perceived quality of cancer services seen by patients.

On every question in both 2010, and all bar one in 2011/12, patients with a CNS are more likely to be positive about their care and treatment than are patients who did not have a CNS. Even on the one question in 2011/12 where the differences between those patients who had a CNS and those who did not is not statistically significant, those with a CNS are still more positive.

The most pronounced differences in view between those patients with a CNS 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 CNS support and those without such support are set out below:

Question		With CNS	No CNS
Q14	Given easy to understand information about the type of cancer they had	72%	45%
Q15	Given choice of different types of treatment	86%	65%
Q18	Given easy to understand written information about side effects of treatment	85%	60%
Q19	Involved in treatment as much as they wanted to be	74%	56%
Q24	Given information about support and self help groups	81%	46%
Q25	Given information on financial help and benefits they might be entitled to	57%	24%
Q26	Told they could get free prescriptions	76%	53%
Q33	Given easy to understand written information about operation	76%	52%
Q55	Given enough care/help from health and social services after discharge	63%	45%
Q68	Offered written assessment and care plan	27%	11%
Q70	Overall rating of care excellent / very good	90%	77%

Table 14 Differences by CNS

The evidence from both surveys is that the impact of the CNS is overwhelmingly positive. On questions introduced in 2011/12, such as on care plans and the overall rating of care, the evidence is also very strong that having a CNS makes a measurable impact on the care that patients receive.

Given the substantial impact that having a CNS 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 CNSs than others. Age related analysis reported earlier shows that it is the ‘over 75’ patient group that has least access to the support of CNSs. Further examination of the data shows that this age related effect is not quite uniform across all cancer groups, as the chart below shows:

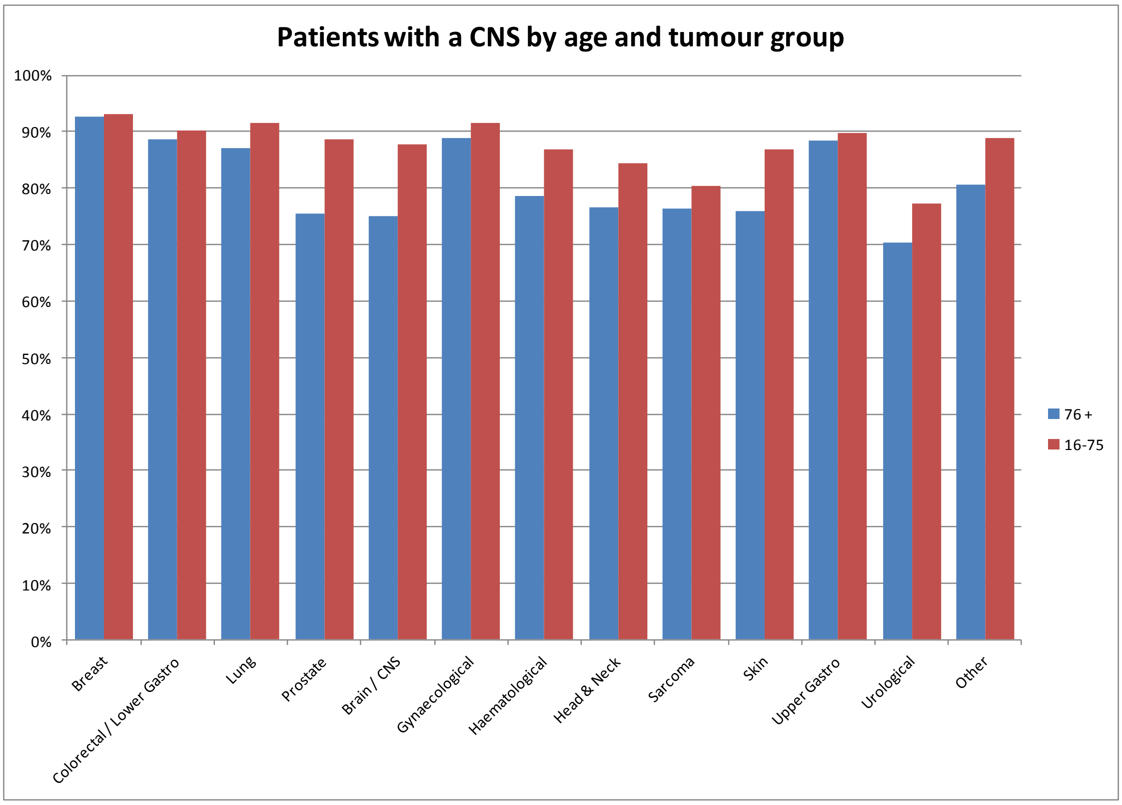

Chart 51 Patients with a CNS by age and tumour group

It is clear that this age related effect is not seen consistently across cancer groups. In 2010 we identified virtually no difference in the incidence of CNS availability to patients in different age groups in a number of tumour groups; in 2011/12 four tumour groups showed minimal differences in the availability of CNS cover. These tumour groups were breast, colorectal/lower GI, gynaecological, and Upper GI, with only the breast tumour group showing almost equal access between the age groups.

In the remaining nine tumour groups there are substantial differences in availability related to age. The cancer groups where there are the most substantial age related differences in access are brain/CNS, haematological; head and neck; lung; other cancers; prostate; sarcoma; skin; and urological. The tumour groups with the widest variation in access to a CNS by age were brain/CNS (13 points); prostate (13 points) and skin (11 points).

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

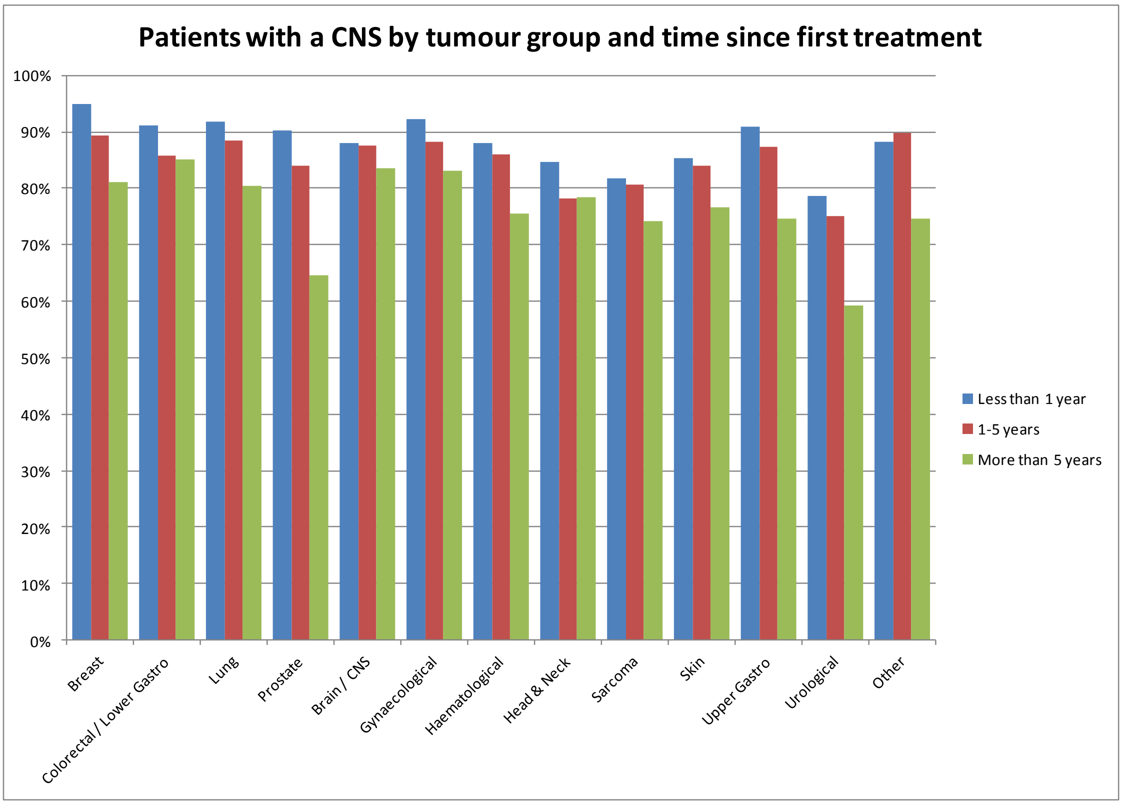

Chart 52 Patients with a CNS by tumour group and time since first treatment

The data from both 2010 and 2011/12 supports the conclusion that there seems to have been a considerable improvement in the coverage of CNSs in every cancer-type grouping over the last five years, but that there is evidence of an age related effect with fewer patients aged over 75 being given the name of a CNS in some cancer groups than patients who are younger.

Given the continued profound differences in views between patients with a CNS 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.

One action that could be taken to address the issue of patients who were diagnosed with cancer some time ago is for active measures being taken to ensure that patients who are being treated for a recurrence of cancer are re-engaged with a CNS as a matter of course, rather than assuming (as might be the case) that they have this information to hand already.

Differences relating to length of time since first treatment

In the 2011/12 CPES survey, as in 2010, the questionnaire included a question (Q75) 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 between September and November 2011. 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.

In 2011/12, analysis of the differences between patients who began their treatment for cancer within the last year as compared to more than 5 years ago shows the same kind of pattern as revealed in the 2010 data. There are 26 questions in the 2011/12 survey on which patients who began treatment more than 5 years ago have less positive views than those who began treatment in the last year; 11 questions on which patients who began treatment in the period 1-5 years ago are the least positive; and only 2 questions on which patients who began treatment in the last year had the poorest scores. The questions on which "year 1" patients were the least positive were on welcoming being asked to participate in cancer research, indicating that, as time from first treatment increases, patients are rather more likely to be positive about engagement with research.

The 2011/12 findings broadly replicate the results from 2010, where on 25 separate questions there was 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. The group of patients who first started treatment more than 5 years ago are likely, in many cases, to have been admitted to hospital for a recurrence of cancer, and their more negative feelings related to care and treatment may be associated with this unwelcome development.

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

• Staff explained test results in a way the patient could understand	Q9
• Patient told they could bring a family member or friend with them when they were told about their cancer for the first time	Q11
• Patient told sensitively that they had cancer	Q12
• Received an understandable explanation of what was wrong with them	Q13
• Given written information about the type of cancer they had	Q14
• Given choice of different types of cancer treatment	Q15
• Views taken into account by team when they discussed 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	Q24
Given information on financial help and benefits	Q25
Given information on the availability of free prescriptions	Q26
Being given written information on the operation they were to have	Q33
When patient had important questions to ask a doctor received understandable answers all / most of time	Q36
Having confidence and trust in the doctors treating them	Q37
Thinking that doctors did not talk in front of them as if they were not there	Q38
Family / someone else close to them had enough opportunity to talk to a doctor	Q39
When patient had important questions to ask a ward nurse, received understandable answers all/most of time	Q40
Having confidence and trust in the ward nurses treating them	Q41
There were always/nearly always enough nurses on duty to care for them in hospital	Q43
Able to discuss worries / fears with staff	Q49
Staff did everything they could to control pain	Q50
Patient treated with respect and dignity	Q51
Staff did everything possible to control side effects of radiotherapy	Q56
Last outpatients appointment started on time or within 30 minutes	Q61
GPs and nurses at the general practice worked well together to give the patient the best possible care	Q66
Offered a written assessment and care plan	Q68
Did not feel treated like a set of cancer symptoms	Q69
Overall rating of care excellent / very good	Q70

In 2011/12, as in 2010, it is noticeable that the differences demonstrated are present across genders. 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 and 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, in the 2011/12 data, the proportion of patients starting treatment over 5 years ago who were given the name of a CNS was 67% (67% in 2010), rising to 90% (88% in 2010) amongst those starting treatment in the last year. As the numbers of CNSs has grown significantly over the last 5 years, this finding could have been expected, and is confirmed by the data.

The impact of social deprivation

It might be expected that social deprivation would produce different responses 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). 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 only one statistically significant difference was found across the quinitiles in 2010 and 2011/12, on the same question (on bringing family and friends with them when first attending). On that issue it was more likely that patients in the most deprived postcode quintile were told they could bring a family member or friend with them than was the case for patients in the least deprived postcode quintile

The IMD quintiles and deciles are intended to provide range information in respect of the differences between the most deprived quintile to the least deprived. It is this range which is the most accurate description in the UK 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 testing results across the range as a whole. This analysis shows something very different. In 2011/12 IMD quintiles were used to look at the range of views between the least deprived and most deprived postcodes, and a similar pattern was found to that in 2010: there were significant differences on 44 questions between the least deprived quintile and the most deprived.

The IMD analysis can be summarised in the following way, covering both the 2010 and 2011/12 results:

- Whether deciles or quintiles are used, the analysis shows similar results
- Testing for difference between one decile or quintile and the next produces virtually no significant results
- However, when the extremes of the range are taken (e.g. quintile 1 - quintile 5), a large number of differences can be found
- The significant differences that exist are not uni-dimensional i.e. the most deprived quintile is more positive on some issues; and the least deprived on others.

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

• When patient first told they had cancer, told they could bring a family member or friend with them	Q11
• Patient told sensitively that they had cancer	Q12
• Patients views taken into account when clinical team discussing which treatment they should have	Q16
• Possible side effects of treatment explained in a way they could understand	Q17
• 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	Q25
• Hospital staff told patient they could get free prescriptions	Q26
• Family or someone close to them definitely had enough opportunity to talk to a doctor if they wanted to	Q39
• Had confidence and trust in all ward nurses	Q41
• Patient asked which name they preferred to be called by	Q46
• Given clear written information about what they should or should not do post discharge	Q52
• Doctors / nurses gave family or someone close to the patient all the information needed to care for them at home	Q54
• Staff did everything they could to control patient’s pain when being treated as an outpatient	Q58
• Given enough emotional support from hospital staff when being treated as an outpatient/day case	Q59
• Seen within 30 minutes at their last OPD appointment	Q61
• Different people caring for them always worked well together to give them the best possible care	Q66
• Patient offered an assessment and care plan	Q68

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

Saw GP only 1-2 times before referred to hospital	Q1
Time gap between first thinking something wrong and seeing a hospital Doctor	Q3
Health stayed the same whilst waiting for first appointment with a hospital doctor	Q4
Given easy to understand written information about tests beforehand	Q8
Completely understood the explanation of what was wrong with them	Q13
Given easy to understand information about the type of cancer they had	Q14
Given easy to understand information about side effects of treatment	Q18
Patient thought CNS listened carefully to them	Q22
Got easy to understand answers from their Clinical Nurse Specialist when they had important questions to ask	Q23
Staff gave information about self help and support groups	Q24
Patient asked if they would like to take part in cancer research	Q27
Glad to have been asked if they would like to take part in cancer research	Q28
Would have liked to have been asked if they would like to take part in cancer research	Q29
Given easy to understand answers from a doctor all / most of the time when they had important questions to ask	Q36
Doctors did not talk in front of them as if they were not there	Q38
Given understandable answers to questions by ward nurses all / most of the time	Q40
Ward nurses did not talk in front of them as if they were not there	Q42
Hospital staff never deliberately did not tell them things they wanted to know	Q44
Definitely given enough care from health and social services after leaving hospital	Q55
GP given enough information about condition and treatment they had had at the hospital	Q64
GPs / other staff definitely did everything they could to support them whilst they were having cancer treatment	Q65
Given right amount of information about their condition and treatment	Q67
Not treated as ‘a set of cancer symptoms’ rather than as a whole person	Q69
Overall rating of care excellent / very good	Q70

There is a certain degree of consistency about the kinds of questions which are less well ranked by patients in the most deprived IMD quintile, with 14 of the items relating to information giving and understanding.

This finding emphasises the importance of the concept of the “informed patient”, which aims to ensure that the content of information is both accessible to all groups and is comprehensive.

Differences between SHA Regions and the London-non London effect

Analysis of the survey results by SHA in 2010 indicated that there were some significant differences between regions, with 10 questions on which statistically significant differences existed. In 2011/12 the number of questions on which there are such significant differences has increased to 15.

Of these, London was the worst performing region on 11 questions; on 4 questions other regions were the worst performing (East Midlands 1; West Midlands 1; South Central 1; SE Coast 1).

The questions on which there are statistically significant differences when the data is analysed by region in 2011/12 are:

• Patients being told they could bring a family member or friend with them when first told they had cancer	Q11	London worst 2010 + 2012
• Easy to contact the Clinical Nurse Specialist	Q21	London worst 2010+2012
• Hospital staff gave information on any benefits	Q25	East Midlands worst 2010 + 2012
• Asked if they would like to take part in cancer research	Q 27	SE Coast worst 2012 (new question)
• When had important questions to ask a ward nurse, received answers they could understand all / most of the time	Q40	London worst 2010+2012
• Confidence and trust in all ward nurses treating them	Q41	London worst 2010+2012
• Enough nurses on duty to care for them	Q43	West Midlands worst 2012; no sig differences 2010
• Asked what name they preferred to be called by	Q46	London worst 2012 (new question)
• Able to discuss worries and fears with staff	Q49	London worst 2012
• Post discharge given enough help from health and social services	Q55	London worst 2010; no sig differences 2012

• Given enough emotional support by staff when treated in outpatients or as a day case patient	Q59	London worst 2010+2012
• Waiting time within 30 minutes at last outpatient appointment	Q61	London worst 2010+2012
• GPs, nurses at the Practice definitely did everything needed to support patient whilst they were having treatment	Q65	London worst 2010+2012
• GPs, and other staff worked well together to give best possible care	Q66	London worst 2010+2012
• Offered a written assessment and care plan	Q68	South Central worst 2012 (new question)

Patients in London hospitals are less positive than in other parts of England on a wide range of questions. This must be read in the context of individual Trust Reports for 2011/12.

These findings replicate to some degree the findings of earlier cancer surveys and those of the national patient surveys. Three themes emerge: London fares worst on questions related to the general organisation of NHS services, especially those connecting primary care and hospital care; on certain aspects of information; and that very general questions on the rating of care do not discriminate between regions in a meaningful way.

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

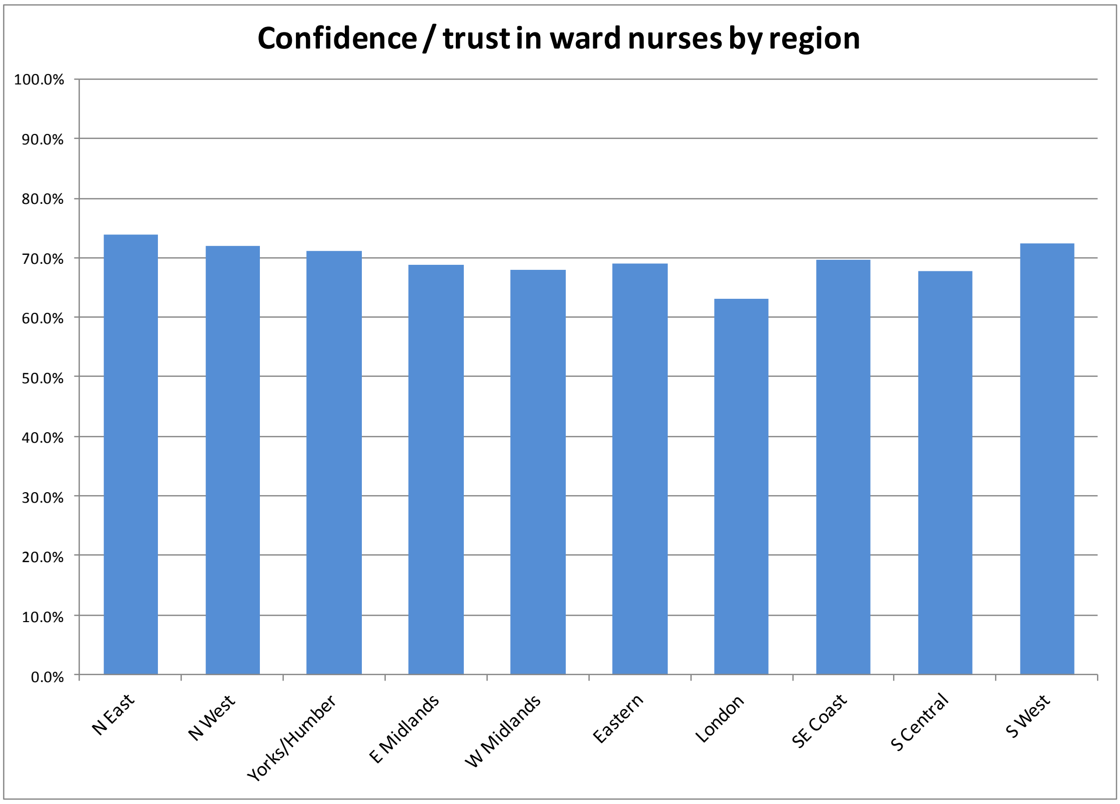

Chart 53 Had confidence and trust in all ward nurses treating them

11. Survey Development and methodology

Development of the 2011/12 Questionnaire

The 2011/12 National Cancer Patient Experience Survey (CPES) questionnaire drew on the 2000 and 2004 cancer survey questionnaires as the basis for some of its questions, but most of the questions in the 2011/12 survey replicated those in the 2010 survey. In 2011/12, some questions were removed or amended and new questions were added as follows:

Questions removed from 2010:

Q2	Wait before first appointment with hospital doctor
Q24	Time spent with Clinical Nurse Specialist
Q36	Patients thinking doctors treating them knew enough about how to treat cancer
Q53	Had patients had radiotherapy in last 12 months
Q55	Had patients had chemotherapy in last 12 months

Amendments to the following questions were made in 2011/12:

Q19	In 2010, question 19 asked if patients were involved as much as they wanted in decisions about which treatment they would have; this was amended to ask about involvement in decisions about care and treatment
Q25	In 2010, question 26 asked if staff gave information on financial help or benefits; the words ‘you might be entitled to’ were added at the end of the question.
Q56	An additional response option was added to the 2010 question 54: ‘I have not had radiotherapy’
Q57	An additional response option was added to the 2010 question 56: ‘I have not had chemotherapy’

Because of the changes to questions 19, 56 and 57 they were not comparable with 2010.

New questions were inserted into the questionnaire in 2011/12 as follows:

Q16	Patients thinking their views were taken into account when the team of doctors and nurses were discussing their treatment
Q27	Patients were asked if participation in Cancer Research had been discussed with them
Q28	If participation was discussed was the patient glad to have been asked
Q29	If the patient was not asked about cancer research would they have liked to have been asked.
Q46	Patients were asked if staff asked them what they preferred to be called
Q49	Were patients able to discuss worries and fears with staff
Q68	Were patients offered a written assessment and care plan
Q70	Patients overall rating of care

Cognitive testing of the whole questionnaire and on the new questions 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 all the questions taken from the 2010 survey had been cognitively tested previously, it was decided that, although all questions in the 2011/12 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.

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 2011/12 CPES 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.

Methodology

The 2011/12 CPES 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 September 2011 and 30th November 2011. Operationally used ICD10 codes of C00-C99, and D05 were used. Patients with an ICD10 code of C44 (other malignant neoplasms of the skin), and C84 (some Haematology codes) were excluded from the sample by agreement. The exclusion of C84 was a new development for the 2011/12 survey and followed investigation of the extent to which some of the patients with an attributed code of C84 were being told they had cancer. There were only 123 respondents with any kind of C84 code who returned completed questionnaires in 2010, so the impact on results is minimal in 2011/12.

160 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.

In a break with practice from 2010, Quality Health undertook the checking of patients through the DBS system (Demographic Batch Service) for deaths, once Trusts had selected their patients from local patient administration systems. DBS checks were undertaken on three separate occasions; at the initial send out stage, and at first and second reminder stage. Centralisation of the DBS checking system was extremely successful in removing patients from send out lists before questionnaires had been despatched, with the result that the number of patients who were reported as deceased through the helpline and correspondence fell by 80%. In this particular instance, centralisation has proved to be more efficient and has minimised distress levels for families.

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. The evidence from the 2011/12 CPES is that Trust staff had become used to the processes used by the survey, were more familiar with the rules, and the number of complex policy and procedure query telephone calls and correspondence received by Quality Health was significantly reduced in 2011/12.

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, the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott principles, the ISO 27001 and 9001 accreditations enjoyed by Quality Health, and by the requirements of IGSoCv9.

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 5 which asks about whether the patient has had diagnostic tests. Where patients said 'no', they were then asked to go to question 10. In cases such as this special rules were applied to the data in questions 6 to 10.

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 2011/12 National Cancer Patient Experience Survey[27].

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 where numbers allow
- Reports for each participating Trust on written comments received from patients

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. At whole survey level, including all cancer groups and all respondents, the confidence interval at 95% is +/- 0.3%
>
> 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.

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

Appendix A – Full Survey Results

This appendix sets out the full results from the 2011/12 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 first set of columns show the results from 2010 and the second set of columns show the results from 2011/12. Some questions do not have comparisons with 2010 as the questions were either reworded and therefore not comparable or were new in 2011/12.

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 6).

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 2 in question 5 is ticked and the patient goes on to answer questions 6 to 9, then any data between question 5 and question 10 (where the patient was directed) will be deleted as these questions should not have been answered by the patient.

SEEING YOUR GP

		Total	2010	Total	2012
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	13199	20%	13725	20%
	I saw my GP once	*27566*	*54%*	*29119*	*53%*
	I saw my GP twice	*10723*	*21%*	*11506*	*21%*
	I saw my GP 3 or 4 times	*8210*	*16%*	*8871*	*16%*
	I saw my GP 5 or more times	*4593*	*9%*	*5186*	*9%*
	Don't know / Can't say	1312	2%	1576	2%
	Missing	1987		1810	
2.	**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	41455	81%	57680	83%
	I should have been seen a bit sooner	6320	12%	6730	10%
	I should have been seen a lot sooner	3634	7%	4798	7%
	Missing	16181		2585	
3.	**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	38340	74%	54073	79%
	3-6 months	6767	13%	7506	11%
	6-12 months	2618	5%	2816	4%
	More than 12 months	2213	4%	2523	4%
	Don't know / Can't remember	1852	4%	1871	3%
	Missing	15800		3004	
4.	**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	11479	22%	14193	21%
	My health got better	348	1%	483	1%
	My health stayed about the same	40054	77%	54444	79%
	Missing	15709		2673	

DIAGNOSTIC TESTS		**Total**	**2010**	**Total**	**2012**
5.	**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	58544	90%	61481	90%
	No	6733	10%	7014	10%
	Missing	2313		3298	
6.	**Beforehand, did a member of staff explain the purpose of the test(s)?**				
	Yes, completely	*44825*	*81%*	*48661*	*83%*
	Yes, to some extent	*9289*	*17%*	*8936*	*15%*
	No, but I would have liked an explanation	*1227*	*2%*	*1139*	*2%*
	I did not need an explanation	3016	5%	3019	5%
	Don't know / Can't remember	651	1%	723	1%
	Missing	8582		9315	
7.	**Beforehand, did a member of staff explain what would be done during the test procedure(s)?**				
	Yes, completely	*47541*	*84%*	*52115*	*86%*
	Yes, to some extent	*8138*	*14%*	*7464*	*12%*
	No but I would have liked an explanation	*781*	*1%*	*723*	*1%*
	I did not need an explanation	2179	4%	1804	3%
	Don't know / Can't remember	491	1%	463	1%
	Missing	8460		9224	
8.	**Beforehand, were you given written information about your test(s)?**				
	Yes, and it was easy to understand	*37563*	*85%*	*40398*	*86%*
	Yes, but it was difficult to understand	*1627*	*4%*	*1756*	*4%*
	No, but I would have liked written information about the test(s)	*5017*	*11%*	*4570*	*10%*
	I did not need written information	11047	19%	11584	19%
	Don't know / Can't remember	3526	6%	4037	6%
	Missing	8810		9448	
9.	**Were the results of the test(s) explained in a way you could understand?**				
	Yes, completely	*44092*	*76%*	*47786*	*78%*
	Yes, to some extent	*12122*	*21%*	*12273*	*20%*
	No, but I would have liked an explanation	*1640*	*3%*	*1517*	*2%*
	I did not need an explanation	679	1%	605	1%
	Don’t know / Can’t remember	463	1%	439	1%
	Missing	8594		9173	

FINDING OUT WHAT WAS WRONG WITH YOU

		Total	2010	Total	2012
10.	**Who first told you that you had cancer?**				
	A hospital doctor	54628	83%	56982	82%
	A hospital nurse	3026	5%	3641	5%
	A GP (family doctor)	4507	7%	5148	7%
	Another health professional	2273	3%	2373	3%
	A friend or relative	140	0%	167	0%
	Nobody – I worked it out for myself	1173	2%	1258	2%
	Missing	1843		2224	
11.	**When you were first told that you had cancer, had you been told you could bring a family member or friend with you?**				
	Yes	*37691*	*71%*	*40924*	*72%*
	No	*15720*	*29%*	*16009*	*28%*
	It was not necessary	8028	12%	8239	12%
	I was told by phone or letter	1214	2%	1195	2%
	Don’t know / Can’t remember	3300	5%	3590	5%
	Missing	1637		1836	
12.	**How do you feel about the way you were told you had cancer?**				
	It was done sensitively	54639	83%	58262	83%
	It should have been done a bit more sensitively	7727	12%	8051	11%
	It should have been done a lot more sensitively	3685	6%	3819	5%
	Missing	1539		1661	
13.	**Did you understand the explanation of what was wrong with you?**				
	Yes, I completely understood it	*48632*	*74%*	*51241*	*73%*
	Yes, I understood some of it	*16077*	*24%*	*17523*	*25%*
	No, I did not understand it	*1407*	*2%*	*1414*	*2%*
	Can’t remember	374	1%	425	1%
	Missing	1100		1190	
14.	**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	*37068*	*66%*	*41667*	*69%*
	Yes, but it was difficult to understand	*3767*	*7%*	*4533*	*7%*
	No, I was not given written information about the type of cancer I had	*15443*	*27%*	*14380*	*24%*
	I did not need written information	6475	10%	6149	9%
	Don’t know / Can’t remember	2764	4%	3260	5%
	Missing	2073		1804	

DECIDING THE BEST TREATMENT FOR YOU

		Total	2010	Total	2012
15.	**Before your cancer treatment started, were you given a choice of different types of treatment?**				
	Yes	*18764*	*83%*	*20833*	*84%*
	No, but I would have liked a choice	*3935*	*17%*	*4029*	*16%*
	I was not given a choice because only one type of treatment was suitable for me	40274	62%	42489	61%
	Not sure / Can’t remember	2120	3%	2362	3%
	Missing	2497		2080	
16.	**Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?**				
	Yes, definitely	*0*	*0%*	*41678*	*70%*
	Yes, to some extent	*0*	*0%*	*14371*	*24%*
	No, my views were not taken into account	*0*	*0%*	*3789*	*6%*
	I didn't know my treatment was being discussed by a team of doctors / nurses	0	*0%*	5582	8%
	Not sure / Can't remember	0	*0%*	3617	5%
	Missing	67590		2756	
17.	**Were the possible side effects of treatment(s) explained in a way you could understand?**				
	Yes, definitely	*44536*	*72%*	*49522*	*75%*
	Yes, to some extent	*13984*	*23%*	*13808*	*21%*
	No, side effects were not explained	*2947*	*5%*	*3001*	*5%*
	I did not need an explanation	2669	4%	2517	4%
	Not sure / Can’t remember	1015	2%	905	1%
	Missing	2439		2040	
18.	**Before you started your treatment, were you given written information about the side effects of treatment(s)?**				
	Yes, and it was easy to understand	*48002*	*80%*	*52851*	*81%*
	Yes, but it was difficult to understand	*2806*	*5%*	*3080*	*5%*
	No, I was not given written information about side effects	*9569*	*16%*	*9053*	*14%*
	Don’t know / Can’t remember	3590	6%	3628	5%
	Missing	3623		3181	
19.	**Were you involved as much as you wanted to be in decisions about your care and treatment?**				
	Yes, definitely	*0*	*0%*	*48657*	*72%*
	Yes, to some extent	*0*	*0%*	*15882*	*23%*
	No, but I would like to have been more involved	*0*	*0%*	*3119*	*5%*
	Not sure / Can't remember	*0*	*0%*	1563	2%
	Missing	67590		2572	

CLINICAL NURSE SPECIALIST	Total	2010	Total	2012
20. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?				
Yes	*52647*	*84%*	*58011*	*87%*
No	*9760*	*16%*	*8703*	*13%*
Don't know / Not sure	2814	4%	3071	4%
Missing	2369		2008	
21. How easy is it for you to contact your Clinical Nurse Specialist?				
Easy	*35260*	*75%*	*38972*	*75%*
Sometimes easy, sometimes difficult	*10498*	*22%*	*11453*	*22%*
Difficult	*1556*	*3%*	*1718*	*3%*
I have not tried to contact her/him	5216	10%	5893	10%
Missing	15060		13757	
22. The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?				
Yes, definitely	46613	91%	51131	91%
Yes, to some extent	3825	7%	4186	7%
No	586	1%	719	1%
Missing	16566		15757	
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	*42359*	*91%*	*46604*	*91%*
Some of the time	*3888*	*8%*	*4025*	*8%*
Rarely or never	*491*	*1%*	*580*	*1%*
I do not ask any questions	4432	9%	5240	9%
Missing	16420		15344	

SUPPORT FOR PEOPLE WITH CANCER

		Total	**2010**	**Total**	**2012**
24.	**Did hospital staff give you information about support or self-help groups for people with cancer?**				
	Yes	*37544*	*79%*	*42280*	*82%*
	No, but I would have liked information	*9989*	*21%*	*9584*	*18%*
	It was not necessary	14007	22%	14228	20%
	Don’t know / Can’t remember	3488	5%	3581	5%
	Missing	2562		2120	
25.	**Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?**				
	Yes	*17709*	*50%*	*20833*	*52%*
	No, but I would have liked information	*17884*	*50%*	*19130*	*48%*
	It was not necessary	26849	41%	27148	39%
	Don't know / Can't remember	2447	4%	2553	4%
	Missing	2701		2129	
26.	**Did hospital staff tell you that you could get free prescriptions?**				
	Yes	*20494*	*68%*	*23915*	*73%*
	No, but I would have liked information	*9762*	*32%*	*8834*	*27%*
	It was not necessary	32549	51%	35340	51%
	Don’t know / Can’t remember	1327	2%	1252	2%
	Missing	3458		2452	
27.	**Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?**				
	Yes	*0*	*0%*	*21655*	*33%*
	No	*0*	*0%*	*44790*	*67%*
	Don't know / Can't remember	0	0%	3284	5%
	Missing	67590		2064	
28.	**If yes, were you glad to have been asked?**				
	Yes	*0*	*0%*	20444	95%
	No	0	0%	988	5%
	Missing	67590		50361	
29.	**If no, would you have liked to have been asked?**				
	Yes	*0*	*0%*	22046	53%
	No	0	0%	19701	47%
	Missing	67590		30046	

OPERATIONS	**Total**	**2010**	**Total**	**2012**
30. 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	36980	57%	39327	56%
No	27799	43%	30291	44%
Missing	2811		2175	
31. The last time you went into hospital for a cancer operation, was your admission date changed to a later date by the hospital?				
No	33494	89%	35903	90%
Yes, it was changed once	3531	9%	3388	9%
Yes, it was changed 2 or 3 times	461	1%	423	1%
Yes, it was changed 4 times or more	33	0%	35	0%
Missing	30071		32044	
32. Before you had your operation, did a member of staff explain what would be done during the operation?				
Yes, completely	*31227*	*85%*	*33723*	*87%*
Yes, to some extent	*5109*	*14%*	*4700*	*12%*
No, but I would have liked an explanation	*603*	*2%*	*548*	*1%*
I did not need an explanation	905	2%	664	2%
Don't know / Can't remember	299	1%	238	1%
Missing	29447		31920	
33. Beforehand, were you given written information about your operation?				
Yes, and it was easy to understand	*23323*	*68%*	*26454*	*73%*
Yes, but it was difficult to understand	*1058*	*3%*	*1178*	*3%*
No, I was not given written information about my operation	*10007*	*29%*	*8450*	*23%*
Don’t know / Can’t remember	3337	9%	3500	9%
Missing	29865		32211	
34. After the operation, did a member of staff explain how it had gone in a way you could understand?				
Yes, completely	*26973*	*73%*	*29125*	*75%*
Yes, to some extent	*7567*	*20%*	*7720*	*20%*
No, but I would have liked an explanation	*2413*	*7%*	*2142*	*5%*
I did not need an explanation	1020	3%	980	2%
Missing	29617		31826	

HOSPITAL DOCTORS		**Total**	**2010**	**Total**	**2012**
35.	**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	45197	69%	47449	68%
	No	19881	31%	22043	32%
	Missing	2512		2301	
36.	**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	*34337*	*81%*	*36677*	*82%*
	Some of the time	*7151*	*17%*	*7094*	*16%*
	Rarely or never	*974*	*2%*	*892*	*2%*
	I did not ask any questions	3621	8%	3524	7%
	Missing	21507		23606	
37.	**Did you have confidence and trust in the doctors treating you?**				
	In all of them	38739	84%	40893	85%
	In some of them	7304	16%	7159	15%
	In none of them	220	0%	204	0%
	Missing	21327		23537	
38.	**Did doctors talk in front of you as if you weren't there?**				
	Yes often	1525	3%	1687	4%
	Yes sometimes	6346	14%	6674	14%
	No	38293	83%	39813	83%
	Missing	21426		23619	
39.	**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	*25467*	*66%*	*26411*	*65%*
	Yes, to some extent	*10511*	*27%*	*11268*	*28%*
	No	*2817*	*7%*	*2913*	*7%*
	No family or friends were involved	2703	6%	2714	6%
	My family did not want or need information	3284	7%	3421	7%
	I did not want my family or friends to talk to a doctor	1246	3%	1276	3%
	Missing	21562		23790	

WARD NURSES

	Total	2010	Total	2012
40. When you had important questions to ask a ward nurse, how often did you get answers you could understand?				
All or most of the time	*29234*	*73%*	*31676*	*75%*
Some of the time	*9429*	*23%*	*9127*	*22%*
Rarely or never	*1546*	*4%*	*1461*	*3%*
I did not ask any questions	5929	13%	5839	12%
Missing	21452		23690	
41. Did you have confidence and trust in the ward nurses treating you?				
In all of them	30663	66%	33305	69%
In some of them	14993	33%	14192	30%
In none of them	463	1%	500	1%
Missing	21471		23796	
42. Did ward nurses talk in front of you as if you weren't there?				
Yes, often	1391	3%	1404	3%
Yes, sometimes	6233	14%	6085	13%
No	38317	83%	40522	84%
Missing	21649		23782	
43. In your opinion, were there enough nurses on duty to care for you in hospital?				
There were always or nearly always enough on duty	28492	62%	29165	61%
There were sometimes enough on duty	13126	29%	13886	29%
There were rarely or never enough on duty	4248	9%	4691	10%
Missing	21724		24051	

HOSPITAL CARE & TREATMENT

		Total	2010	Total	2012
44.	**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%	619	1%
	Sometimes	4582	10%	4622	10%
	Only once	959	2%	913	2%
	Never	39895	87%	41932	87%
	Missing	21550		23707	
45.	**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	985	2%	990	2%
	Sometimes	5559	12%	5647	12%
	Only once	3316	7%	3465	7%
	Never	36106	79%	37874	79%
	Missing	21624		23817	
46.	**While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?**				
	Yes, all of them did	0	0%	26901	56%
	Only some of them did	0	0%	10842	23%
	None of them did	0	0%	10117	21%
	Missing	67590		23933	
47.	**Were you given enough privacy when discussing your condition or treatment?**				
	Yes, always	38024	82%	40440	84%
	Yes, sometimes	5892	13%	6027	13%
	No	2206	5%	1699	4%
	Missing	21468		23627	
48.	**Were you given enough privacy when being examined or treated?**				
	Yes, always	42562	93%	45442	94%
	Yes, sometimes	2806	6%	2473	5%
	No	478	1%	412	1%
	Missing	21744		23466	
49.	**Were you able to discuss any worries or fears with staff during your hospital visit?**				
	As much as I wanted	*0*	*0%*	*26394*	*64%*
	Most of the time	*0*	*0%*	*9272*	*22%*
	Some of the time	*0*	*0%*	*4283*	*10%*
	Not at all, but would have liked to	*0*	*0%*	*1467*	*4%*
	I did not have any worries or fears	*0*	*0%*	6749	14%
	Missing	67590		23628	
50.	**Do you think the hospital staff did everything they could to help control your pain?**				
	All of the time	*32688*	*85%*	*34703*	*84%*
	Some of the time	*5351*	*14%*	*5772*	*14%*
	Not at all	*523*	*1%*	*604*	*1%*
	I did not have any pain	7114	16%	7104	15%
	Missing	21914		23610	

HOSPITAL CARE & TREATMENT

	Total	2010	Total	2012
51. Were you treated with respect and dignity by the doctors and nurses and other hospital staff?				
Always	37583	82%	39680	83%
Most of the time	6958	15%	7075	15%
Some of the time	1169	3%	1193	2%
Never	107	0%	82	0%
Missing	21773		23763	

INFORMATION GIVEN TO YOU BEFORE YOU LEFT HOSPITAL

		Total	2010	Total	2012
52.	**Were you given clear written information about what you should or should not do after leaving hospital?**				
	Yes	*35377*	*82%*	*38331*	*84%*
	No	*7908*	*18%*	*7285*	*16%*
	Can't remember	2230	5%	2220	5%
	Missing	22075		23957	
53.	**Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?**				
	Yes	*40702*	*92%*	*43251*	*93%*
	No	*3569*	*8%*	*3301*	*7%*
	Don’t know / Can’t remember	1453	3%	1372	3%
	Missing	21866		23869	
54.	**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	*21733*	*58%*	*23694*	*60%*
	Yes, to some extent	*8522*	*23%*	*8853*	*22%*
	No	*7119*	*19%*	*6974*	*18%*
	No family or friends were involved	3406	8%	3436	7%
	My family or friends did not want or need information	3694	8%	3642	8%
	I did not want my family or friends to be given information	769	2%	771	2%
	Missing	22347		24423	

ARRANGING HOME SUPPORT	Total	2010	Total	2012
55. After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists)?				
Yes, definitely	*15492*	*60%*	*16493*	*61%*
Yes, to some extent	*5594*	*22%*	*5718*	*21%*
No	*4822*	*19%*	*4864*	*18%*
I did not need help from health or social services	19321	43%	20322	43%
Don't know / Can't remember	169	0%	181	0%
Missing	22192		24215	

HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

		Total	2010	Total	2012
56.	**Did hospital staff do everything possible to control the side effects of radiotherapy?**				
	Yes, definitely	*12503*	*82%*	*18512*	*79%*
	Yes, to some extent	*2258*	*15%*	*3984*	*17%*
	No, they could have done more	*418*	*3%*	*920*	*4%*
	I have not had any side effects from radiotherapy	1769	10%	3606	5%
	I have not had radiotherapy	0	0%	39717	60%
	Missing	50642		5054	
57.	**Did hospital staff do everything possible to control the side effects of chemotherapy?**				
	Yes, definitely	*27734*	*85%*	*32798*	*81%*
	Yes, to some extent	*4230*	*13%*	*6502*	*16%*
	No, they could have done more	*692*	*2%*	*1080*	*3%*
	I have not had any side effects from chemotherapy	1698	5%	2585	4%
	I have not had chemotherapy	0	0%	24540	36%
	Missing	33596		4288	
58.	**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	*31638*	*83%*	*31972*	*81%*
	Yes, to some extent	*5493*	*14%*	*6275*	*16%*
	No, they could have done more	*1068*	*3%*	*1240*	*3%*
	I did not have any pain	24648	39%	27616	41%
	Missing	4743		4690	
59.	**While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?**				
	Yes, definitely	*32784*	*71%*	*33473*	*71%*
	Yes, to some extent	*10277*	*22%*	*10776*	*23%*
	No, I would have liked more support	*3199*	*7%*	*3218*	*7%*
	I did not need emotional support from staff	16842	27%	19772	29%
	Missing	4488		4554	

OUTPATIENTS APPOINTMENTS WITH DOCTORS	**Total**	**2010**	**Total**	**2012**
60. 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?				
Yes	60263	93%	64575	94%
No	4743	7%	4201	6%
Missing	2584		3017	
61. 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?				
Seen on time or early	*10500*	*18%*	*11909*	*19%*
Waited up to 5 minutes	*4412*	*8%*	*5174*	*8%*
Waited 6 - 15 minutes	*11758*	*20%*	*13372*	*21%*
Waited 16 - 30 minutes	*12805*	*22%*	*13700*	*22%*
Waited 31 - 60 minutes	*10827*	*19%*	*11148*	*18%*
Waited 1 to 2 hours	*6318*	*11%*	*6196*	*10%*
Waited more than 2 hours	*1794*	*3%*	*1660*	*3%*
Don’t know / Can’t remember	1646	3%	1723	3%
Missing	7530		6911	
62. 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?				
Too short	3493	6%	3666	6%
About right	56241	94%	61486	94%
Too long	284	0%	379	1%
Missing	7572		6262	
63. 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?				
Yes	*54784*	*95%*	*59967*	*95%*
No	*2986*	*5%*	*3079*	*5%*
Don’t know / Can’t remember	2073	3%	2435	4%
Missing	7747		6312	

CARE FROM YOUR GENERAL PRACTICE

		Total	2010	Total	2012
64.	**As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?**				
	Yes	*48710*	*93%*	*53726*	*94%*
	No	*3480*	*7%*	*3368*	*6%*
	Don't know / Can't remember	12774	20%	12636	18%
	Missing	2626		2063	
65.	**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	*30652*	*69%*	*32280*	*67%*
	Yes, to some extent	*9576*	*22%*	*11027*	*23%*
	No, they could have done more	*4253*	*10%*	*4803*	*10%*
	My general practice was not involved	19716	31%	20888	30%
	Missing	3393		2795	

YOUR OVERALL NHS CARE		Total	2010	Total	2012
66.	**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?**				
	Yes, always	*38151*	*61%*	*41756*	*62%*
	Yes, most of the time	*18057*	*29%*	*18988*	*28%*
	Yes, some of the time	*5019*	*8%*	*5231*	*8%*
	No, never	*909*	*1%*	*962*	*1%*
	Don't know	2533	4%	2706	4%
	Missing	2921		2150	
67.	**How much information were you given about your condition and treatment?**				
	Not enough	6965	11%	6922	10%
	The right amount	56821	88%	61373	89%
	Too much	822	1%	957	1%
	Missing	2982		2541	
68.	**Have you been offered a written assessment and care plan?**				
	Yes	*0*	*0%*	*14233*	*24%*
	No	*0*	*0%*	*44329*	*76%*
	Don't know / Can't remember	0	0%	9099	13%
	Missing	67590		4132	
69.	**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	2518	4%	2684	4%
	Yes, sometimes	10068	16%	11273	16%
	No	51689	80%	54776	80%
	Missing	3315		3060	
70.	**Overall, how would you rate your care?**				
	Excellent	0	0%	37319	54%
	Very good	0	0%	23510	34%
	Good	0	0%	6398	9%
	Fair	0	0%	1579	2%
	Poor	0	0%	470	1%
	Missing	67590		2517	

ABOUT YOU

		Total	2010	Total	2012
71.	**Age:**				
	16 - 25	431	1%	354	1%
	26 - 35	1066	2%	944	1%
	36 - 50	7044	11%	6579	10%
	51 - 65	21815	34%	21904	32%
	66 - 75	19644	31%	22160	33%
	76+	13280	21%	15574	23%
	Missing	4310		4278	
72.	**Are you male or female?**				
	Male	30360	47%	32796	47%
	Female	34695	53%	36919	53%
	Missing	2535		2078	
73	**Which of the following best describes your sexual orientation?**				
	Heterosexual / straight (opposite sex)	58569	94%	64161	95%
	Bisexual (both sexes)	130	0%	130	0%
	Gay or Lesbian (same sex)	361	1%	439	1%
	Other	308	0%	269	0%
	Prefer not to answer	2944	5%	2306	3%
	Missing	5278		4488	
74.	**Do you have any of the following longstanding conditions?**				
	Deafness or severe hearing impairment	6612	10%	7281	10%
	Missing	60978		64512	
	Blindness or partially sighted	1683	2%	1856	3%
	Missing	65907		69937	
	A long-standing physical condition	9149	14%	9347	13%
	Missing	58441		62446	
	A learning disability	300	0%	354	0%
	Missing	67290		71439	
	A mental health condition	1183	2%	1347	2%
	Missing	66407		70446	
	A long-standing illness such as HIV, diabetes, chronic heart disease or epilepsy	8684	13%	9241	13%
	Missing	58906		62552	
	No I do not have a longstanding condition	40023	59%	43724	61%
	Missing	27567		28069	
75.	**How long is it since you were first treated for this cancer?**				
	Less than 1 year	41320	64%	44997	65%
	1 to 5 years	16586	26%	17486	25%
	More than 5 years	6114	10%	6212	9%
	Don't know / Can't remember	268	0%	285	0%
	Missing	3302		2813	

ABOUT YOU

	Total	2010	Total	2012
76. Could we send you a survey in the future to ask about your health and healthcare?				
Yes, and I understand that this does not mean that I would have to take part in the future survey	53008	83%	57481	84%
No, I would prefer you not to contact me again	10992	17%	11217	16%
Missing	3590		3095	
77. To which of these ethnic groups would you say you belong?				
White British	59429	93%	63987	93%
White Irish	1029	2%	1060	2%
Any other White background	1191	2%	1374	2%
White and Black Caribbean	72	0%	71	0%
White and Black African	43	0%	41	0%
White and Asian	86	0%	88	0%
Any other mixed background	57	0%	78	0%
Indian	563	1%	573	1%
Pakistani	234	0%	241	0%
Bangladeshi	55	0%	52	0%
Any other Asian background	154	0%	280	0%
Caribbean	522	1%	565	1%
African	340	1%	340	0%
Any other Black background	13	0%	44	0%
Chinese	142	0%	150	0%
Any other ethnic group	72	0%	142	0%
Missing	3588		2707	

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 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 Outcome Measures 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 2011/12 survey can be obtained at www.quality-health.co.uk