Cancer Patient Experience Survey 2014
National Report
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• Given regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and in securing that services are provided in an integrated way where this may reduce health inequalities.”
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<tr>
<th>Publications Gateway Reference</th>
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<td>Document Purpose</td>
<td>Tools</td>
</tr>
<tr>
<td>Author</td>
<td>Quality Health</td>
</tr>
<tr>
<td>Publication Date</td>
<td>September 2014</td>
</tr>
<tr>
<td>Target Audience</td>
<td>CCG Clinical Leaders, CCG Chief Officers, CSO Managing Directors, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, NHS England Regional Directors, NHS England Area Directors, NHS Trust Board Chairs, GPs, NHS Trust CEs</td>
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**Additional Circulation List**

**Description**

This is the national report on the fourth Cancer Patient Experience Survey covering all 153 Trusts in England providing adult cancer services. It analyses results at all cancer and tumour group levels and data longitudinally, and analyses other national dataset by equalities and other variables.

**Cross Reference**


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Cancer Patient Experience Survey 2014

National Report

Version number: 1.0

First published: September 2014

Prepared by: Quality Health
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1. Foreword

I have pleasure in introducing the report on the national Cancer Patient Experience Survey 2014, undertaken in 153 NHS Trusts across England. 70,141 cancer patients responded to the survey, a response rate of 64%, giving valuable information at the level of individual cancers and at all cancers level. This level of response has been consistent through the years and shows how patients value this survey and understand the importance of their voice in driving change and improvement.

Because this is the fourth year in which the survey has been run, we can see clearly how services for cancer patients have developed over time. There have been substantial improvements on 46 questions in the 2014 survey compared to the results on those same questions in 2010, the first year in which the Cancer Patient Experience Survey (CPES) was undertaken. In addition, improved scores are seen on 27 questions between the 2013 and 2014 surveys, showing that progress is continuing to be made; and the results show that many Trusts have improved their position in the last 12 months through concerted quality improvement planning and action by cancer teams.

NHS England will be working with NHS Improving Quality and Macmillan Cancer Support to ensure that improvement work is prioritised and supported over the coming year, by spreading good practice in practical ways across hospitals providing cancer care.

This year, we have undertaken work to identify which factors are most strongly associated with high scores given by patients. It is very clear that the presence of a Clinical Nurse Specialist working with the patient to support them, is the factor most likely to be associated with high scores in every one of the 13 tumour groups that we use to analyse the data, reinforcing strongly the analysis that has been undertaken in previous years.

Two other analyses undertaken point toward areas for action in the future. First, those patients with a recurrence are less likely to think that their care and treatment had been good; and patients who said that their treatment had been effective were more likely to be positive about their care than those who said that their cancer was still present after treatment. Therefore we need a greater focus on the different needs and concerns of patients with a recurring cancer and those where treatment has not been effective as yet.

Second, new work on linking CPES results from 2010 with data from the National Cancer Intelligence Network Routes to Diagnosis project, and reported here for the first time, has shown that patients who entered treatment through an emergency route are less likely to give positive scores than others. Including this important finding means that we must redouble our efforts to ensure that as many patients as possible present at the right time if they have symptoms, and that they are diagnosed as speedily as is possible by the NHS.

The report shows us that we need to concentrate on:

- Improving care and survival for patients with rarer cancers, who in some cases report poorer quality care;
- Improving care for patients entering through the emergency treatment route, and minimising the numbers who do so;
- Improving the transition point to community care after acute treatment;
• Being sensitive to the particular needs of patients with a recurrence of cancer, or where tumours have not responded to treatment as had been hoped;
• Maximising the support available from Clinical Nurse Specialists, given the substantial evidence now available linking their presence to good care as seen by the patient;
• Supporting those Trusts whose services have not improved in line with developments in the best performing areas.

Clearly CPES provides valuable evidence which has already been used by many front line cancer teams to improve services, and I hope that this process will continue in 2014 as the process of service modernisation continues.

Sean Duffy
National Cancer Director
2. Introduction

The 2014 National Cancer Patient Experience Survey (CPES), is the fourth iteration of the survey first undertaken in 2010. It has been designed to monitor national progress on cancer care; to provide information that could be used to drive local quality improvements; and to assist Multi Disciplinary Teams, Commissioners, and NHS Trusts in improving services for patients, and to inform the work of the charities supporting cancer patients.

The 2014 Cancer Patient Experience Survey was overseen by a national Cancer Patients Experience Advisory Group co-chaired by Mr Sean Duffy, National Clinical Director for Cancer Care and Professor Jessica Corner of Macmillan Cancer Support. The Advisory Group set the principles and objectives of the survey programme and guided questionnaire development. This survey was commissioned and managed by NHS England. The survey provider Quality Health has been responsible for designing, implementing and analysing the data for each CPES.

The 2014 CPES followed the same methodology as in previous years; a detailed description of this, and supporting documentation, is available in a separate document, as are the data tables for the analyses undertaken. These are all viewable at www.quality-health.co.uk

Most questions in the CPES 2014 remained the same as in 2013, but new or revised questions on the recurrence of cancer were introduced for the first time.

In 2014 new kinds of Key Drivers analysis were undertaken, and work was performed linking responses from the 2010 CPES to the Routes to Diagnosis data developed by the National Cancer Intelligence Network, to identify differences in view between the perceptions of care held by patients who initially entered treatment through an emergency department route and those who began treatment following a planned pathway referral.
3. Executive summary

The Cancer Patient Experience Survey (CPES) 2014 is the fourth in the series of surveys begun in 2010, covering all adult patients in active treatment for cancer in England. In 2014 the number of respondents was 70,141 from 153 NHS Trusts from a sample of 109,760 (64% response rate).

The key themes from the 2014 survey are set out below:

Nationally cancer patients continue to give positive responses about their treatment and care. Scores of 80%\(^1\) and over have been achieved on questions such as: information about their cancer; treatment options; tests and operations; being seen as soon as was necessary for an initial appointment with a hospital doctor; privacy; care by doctors; pain control; and being treated with respect and dignity.

89% of respondents said that their overall care was excellent or very good.

However, some scores in the CPES suggest there may be opportunities for improvement. These include:

- Being told about side effects of treatment that might affect the patient in the future (56%)
- Being given information on financial help and benefits they might be entitled to (54%)
- Having a discussion with staff about taking part in cancer research, and then going onto take part (63%)
- Families or someone close to them having the opportunity to talk to a doctor if they wanted to (67%)
- There being enough nurses on duty to care for them in hospital (62%)
- Being asked which name they preferred to be called by (60%)
- Giving families or someone close to them all the information they needed to look after them at home (60%)
- Being given enough care and help from health and social services post discharge (59%)
- GPs and nurses at their general practice doing everything they could to support them whilst they were being treated (66%)
- Different professionals working well together to give the patient the best possible care (63%) and
- Being offered a written assessment and care plan (22%)

Concern about these lower scores is based on information from the 400,000 written comments made by cancer patients in the CPES since 2010, and the experience of national cancer charities on what matters to patients in active treatment, as well as on the quantitative data from CPES.

\(^1\) A description of scoring methodology and detailed analyses can be found in the "Methodology and Data Tables" document available at www.quality-health.co.uk
Being informed about side effects of treatment that may be delayed in onset could affect informed consent, in situations where treatment may have high impact in future years. Not being given information on financial help and benefits they may be entitled to might cause the patient difficulties in coping with the additional costs known to face cancer patients, such as any need for supplementary heating. Involvement by patients in research is not evenly spread across Trusts, and there is concern that some patients who might fit the criteria for clinical trials may miss out on opportunities that could exist for them, to the detriment of future patients. Information and support to families is regarded as crucial in situations where patients may struggle to cope emotionally or with the consequences of treatment or disease progression, and the absence of opportunities to talk to a Doctor is important in this respect for carers and families, as is the imparting of information to them on how best to care for the patient when they are discharged from hospital care.

Aspects of personal care are also regarded as important given the large number of cancer patients treated on wards which deal with a wide range of patients, with a clear need for appropriate numbers of nurses in place who are knowledgeable about the treatment that cancer patients receive, and who ask important questions which support the respect and dignity with which the patient is treated - such as addressing them by their preferred name. The absence of a written care plan may also limit the knowledge that patients have of their care pathway, and place obstacles to staff having a full understanding of treatment planned; and lack of support from primary care, social services, and community health services post discharge may have detrimental effects on both patients and carers over time.

Many of these low scores have been stable over the period 2010-14, such as those indicating low levels of discussion about cancer research, and low proportions of patients being given care plans. But some questions - for example that on patients being given information on financial help and benefits - have recorded improved scores since 2010 (up by 4.3 points between 2010-14). Some low scores also reflect points of care transition, which are crucial in ensuring that patients have seamless, organised and personal care which meets their needs.

There is an important improvement agenda for cancer care, based on the issues where there continue to be low scores; where there are Trusts with outlier scores on individual questions; and where some Trusts as a whole are performing much more poorly than others. Examples of questions on which the range from top performing to bottom performing Trusts is 40 percentage points or more are:

- Q27 Patient given information on financial help and benefits – difference between top performing Trust and bottom performing Trust 60 points
- Q30 Taking part in cancer research discussed with the patient - difference between top performing Trust and bottom performing Trust 52 points
- Q34 Given written information on the operation they were having - difference between top performing Trust and bottom performing Trust 50 points
- Q44 Always/nearly always enough nurses on the ward to look after them in hospital - difference between top performing Trust and bottom performing Trust 45 points
- Q56 Given enough care from health and social services post discharge - difference between top performing Trust and bottom performing Trust 60 points

2 The incidence of participation in research being discussed with the patient varies by the amount of cancer activity in Trusts
Key drivers analysis of the 2014 data shows that the single most important factor associated with high patient scores, in every tumour group, is the patient being given the name of a clinical nurse specialist (CNS) in charge of their care. The number of patients having a CNS has continued to increase in each year that the CPES has been undertaken (up from 84% in 2010 to 89% in 2014).

It is also the case that patients with rarer cancers were more likely to give poorer scores on a range of questions than was the case for patients with more common tumours, following the pattern of previous years’ results in the CPES.

Some patient groups were also less likely to be positive than others about their care and treatment. As has been shown in previous years in the CPES, patients with a long term condition other than cancer, or multiple long term conditions, were more likely to be critical of care - as were some ethnic minority patients; younger patients aged 16-35; patients attending London hospitals; lesbian, gay, bisexual and patients classifying themselves as ‘other’; and women. This pattern of response in 2014 is very similar to that seen in previous years.

Routes to diagnosis

In addition to these key themes from the 2014 survey, work has been undertaken using the 2010 CPES data to match with data held by the National Cancer Intelligence Network which allows us to distinguish between responses from patients who entered treatment via an emergency route and those who entered treatment from a recognised planned cancer pathway. This analysis, using the Routes to Diagnosis methodology\(^3\), shows that patients who entered through emergency routes were less likely to be positive about their care and treatment - on a wide range of questions - than were patients entering through a planned pathway.

Progress and change over time

At national level scores for some questions have changed significantly between 2010 and 2014, mainly in a positive direction. Improvements have been seen on a large number of questions (46), covering a wide variety of topics.

The range of questions on which scores have improved nationally is substantial. Six such questions have the common theme of being about verbal information given by staff to patients - such as information on tests and operations, what would be done and what the outcome was, and telling patients they could bring a friend or family member with them when they were being told they had cancer.

A further group of six questions where there has been substantial improvement relate to written information given to the patient - on the type of cancer they had; on financial help, benefits, and free prescriptions; about operations; and on what to do and not do post discharge.

There were also improvements on two questions related to ward nurses - on getting understandable answers to questions (up from 73% in 2010 to 76% in 2014), and having confidence and trust in them (up from 66% in 2010 to 71% in 2014).

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\(^3\) A description of the Routes to Diagnosis analysis and methodology can be found in the “Methodology and Data Tables” document available at www.quality-health.co.uk
Therefore, we see that better information giving has been at the core of the improved scores registered nationally by the CPES since 2010. This better information has been recognised by patients during the diagnosis phase; during testing and treatment; and at discharge.

However, there were a number of key questions on which scores have declined nationally over the period 2010-14. The single largest fall was on whether GPs and nurses at their general practice did everything they could to support patients whilst they were having cancer treatment; and a small fall was recorded on whether the patient felt they were given enough care from health and social services post discharge. Other questions on which there were small reductions in scores related to patients understanding the explanation of what was wrong with them; it being easy to contact their CNS if they had one; pain management in day case and outpatient units and in emotional support to patients there.

Looking just at the period between the last two surveys in 2013 and 2014, scores rose on 27 questions and fell on 6 questions.

At the level of the 13 tumour groups the experience of patients with different types of cancer has changed little over time: patients with a urological cancer were the most likely to give low scores, as they did in 2013, followed by patients with some of the rarer cancers such as brain and central nervous system, sarcoma and “other” cancers.

At Trust level, improved scores can be seen on a wide range of questions in 2014 when compared to the results in 2013, continuing the progress that has been made since 2010. Some Trusts have increased their scores markedly. 13 Trusts improved their scores on at least 10 questions in the survey in 2014 and just 2 Trusts showed declines in scores on at least 10 questions. 41% of Trusts improved overall, 22% showed an overall decline in scores, and 37% were in a standstill position.

Conclusion

The further improvement agenda on cancer might reflect the issues identified through the CPES. The key points are:

- To improve those Trusts which have a pattern of consistently poor scores overall;
- To focus on care in day case units and post discharge, where scores have fallen slightly over time;
- To improve scores on issues such as on financial support, provision of care plans, and participation in research, where scores are low in absolute terms;
- To improve the care and experience of patients with rarer cancers;
- To address the poorer experience of patients entering care through an emergency route and those where new cancers have been found or where cancer has returned;
- To identify methods of support for patients who may have additional needs, such as those with multiple long term conditions.
4. Benchmark Charts

The RAG (Red Amber Green) charts set out below for each scored question show the range of scores from highest to lowest for all Trusts participating in the CPES at "all cancers" level.

Percentage scores are displayed on benchmark bar charts in the following section. Each bar represents the range of results across all Trusts that took part in the survey for one question. The bar is divided into:

- a red section: scores for the lowest-scoring 20% of Trusts in 2013/14
- a green section: scores for the highest-scoring 20% of Trusts in 2013/14
- an amber section: scores for the remaining 60% of Trusts in 2013/14

Seeing your GP

![RAG Chart for Seeing your GP](chart1)

Chart 1 RAG Seeing your GP
**Diagnostic Tests**

Q6 Staff gave complete explanation of purpose of test(s)

Q7 Staff explained completely what would be done during test

Q8 Given easy to understand written information about test

Q9 Given complete explanation of test results in understandable way

Chart 2 RAG Diagnostic Tests

**Finding out what was wrong with you**

Q11 Patient told they could bring a friend when first told they had cancer

Q12 Patient felt they were told sensitively that they had cancer

Q13 Patient completely understood the explanation of what was wrong

Q14 Patient given written information about the type of cancer they had

Chart 3 RAG Finding out what was wrong with you
Deciding the best treatment for you

Chart 4 RAG Deciding the best treatment for you

Clinical nurse specialist

Chart 5 RAG Clinical Nurse Specialist
Support for people with cancer

Q25 Hospital staff gave information about support groups

Q26 Hospital staff gave information about impact cancer could have on work/education

Q27 Hospital staff gave information on getting financial help

Q28 Hospital staff told patient they could get free prescriptions

Chart 6 RAG Support for people with cancer
**Cancer research**

Q29 Patient has seen information about cancer research in the hospital

Q30 Taking part in cancer research discussed with patient

Q31 Patient has taken part in cancer research

**Operations**

Q33 Staff gave complete explanation of what would be done

Q34 Patient given written information about the operation

Q35 Staff explained how operation had gone in understandable way
Hospital doctors

Q37 Got understandable answers to important questions all/most of the time

Q38 Patient had confidence and trust in all doctors treating them

Q39 Doctors did not talk in front of patient as if they were not there

Q40 Patient’s family definitely had opportunity to talk to doctor

Ward nurses

Q41 Got understandable answers to important questions all/most of the time

Q42 Patient had confidence and trust in all ward nurses

Q43 Nurses did not talk in front of patient as if they were not there

Q44 Always / nearly always enough nurses on duty
Chart 11 RAG Hospital Care and Treatment
Information given to you before leaving hospital and home support

Chart 12 RAG Information given to you before leaving hospital

Hospital care as a day patient / outpatient

Chart 13 RAG Hospital care as a day patient / outpatient
Care from your general practice

Q63 GP given enough information about patient’s condition and treatment

Q64 Practice staff definitely did everything they could to support patient

Your overall NHS care

Q65 Hospital and community staff always worked well together

Q67 Given the right amount of information about condition and treatment

Q68 Patient offered written assessment and care plan

Q69 Patient did not feel that they were treated as a ‘set of cancer symptoms’

Q70 Patient’s rating of care ‘excellent’/ ‘very good’
5. Section by section

This section of the report describes the results for each part of the questionnaire in the order in which it was read by the patient. The survey order was designed to reflect the patient’s journey through 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 2014 survey; one new question has been added this year (Q77) about recurrence of cancer and last year’s question 77 (now Q78) has been rewritten.

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. Full survey results tables are set out in a supplementary report.

There are 7 questions (3, 5, 10, 32, 36, 61 and 66) which are not scored. These questions are information or routing questions e.g. question 5 which asks if patients have had tests.

For all other questions key scores have been calculated after removing any patients who said that the question did not apply to them, who ticked ‘don’t know / can’t remember’ or who did not answer at all.

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.

For each scored 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.

There are two types of chart in this section. Firstly longitudinal charts which show the key scores on each question for each year that that question has been. On the longitudinal charts the score above the bar appears in green where there is a positive significant difference to the prior year, and in red where there is a negative significant difference. For display purposes we have always used figures rounded to the nearest whole number, and it is possible for there to be a significant difference reported between years where the score is the same whole number. However, in these cases the underlying data and the tests carried out support the identification of a significant difference.

The tumour group charts show the key score on each question for each of the 13 cancer groups where there is a significant difference in scores between the groups. On these charts, the overall score in 2014 for all respondents (the national average) is shown as a red line; the score for 2013 is shown as a blue line (where a comparator with 2014 exists).

Comparisons are also shown with the overall key scores from the 2013 survey; on the new questions listed above there are no comparisons with 2013.
5.1. Seeing your GP

The early diagnosis of cancers is seen in the Cancer Reform Strategy as a critical issue and the second Annual Report on the CRS states that “patients in this country are diagnosed later and with more advanced disease than elsewhere in Europe”\(^4\). 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. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?

**Overall Findings**

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

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

**Longitudinal comparison 2010 to 2014**

The proportion of patients saying they saw their GP only once or twice before being referred on to a cancer specialist was 75% in 2010 compared to 75% in the 2014 survey.

![Chart 16 Saw GP no more than twice](chart16.png)

\(^4\) Page 5 Cancer Reform Strategy Second Annual Report December 2009 Gateway Ref. 12927
Findings by Tumour Group
There was a significant variation in the proportion of patients saying they saw their GP only once or twice before being referred on to a cancer specialist. Scores ranged from 92% (breast cancer) to 59% (sarcoma).

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 53% as the lowest score to 94% as the highest Trust score.

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

2. 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.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they were seen as soon as they thought necessary was 81% in 2010 compared to 83% in the 2014 survey.
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 91% (breast cancer) to 70% (sarcoma).
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 58% as the lowest score to 91% as the highest Trust score.

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

3. 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

78% 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.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they were seen by a hospital doctor within 3 months of thinking something might be wrong was 74% in 2010 compared to 78% in the 2014 survey.

Chart 20 Seen by Hospital Doctor within 3 months
Findings by Tumour Group
There was some variation in the proportion of patients seen by a hospital doctor within 3 months, 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 96%; the 80th percentile threshold is 98%.

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?

Overall Findings
80% 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; 20% said their health got worse.

Longitudinal comparison 2010 to 2014
The proportion of patients saying their health got better or stayed about the same was 78% in 2010 compared to 80% in the 2014 survey.

Chart 21 State of health while waiting
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 63% (sarcoma).

![Health got better or stayed about the same while waiting](chart)

Chart 22 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 60% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 77%; the 80th percentile threshold is 83%. 
5.2. 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. 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**

89% of patients overall said they had diagnostic tests for cancer such as an endoscopy, biopsy, mammogram or scan.

**Longitudinal comparison 2010 to 2014**

The proportion of patients saying they had diagnostic tests for cancer such as an endoscopy, biopsy, mammogram or scan was 90% in 2012 compared to 89% in the 2014 survey.

![Chart 23 Had diagnostic tests](image)

**Findings by Tumour Group**

There was a significant variation in the proportion of patients saying they had diagnostic tests for cancer such as an endoscopy, biopsy, mammogram or scan. Scores ranged from 95% (upper gastrointestinal cancer) to 76% (haematological and skin cancers).
Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had diagnostic tests for cancer such as an endoscopy, biopsy, mammogram or scan. Scores in Trusts ranged from 64% as the lowest score to 100% as the highest Trust score.

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

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

Overall Findings

Of those patients who said they needed an explanation, 84% said staff explained the purpose of tests completely; a further 14% 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.

Longitudinal comparison 2010 to 2014

The proportion of patients receiving explanations of tests completely was 81% in 2010 compared to 84% in the 2014 survey.
**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 staff explained the purpose of tests completely. Scores in Trusts ranged from 64% as the lowest score to 92% as the highest Trust score.

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

### 7. 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, 87% 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.

**Longitudinal comparison 2010 to 2014**

The proportion of patients receiving explanations of what would be done during such tests completely was 87% in 2013 compared to 87% in the 2014 survey.
**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 59% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 85%; the 80th percentile threshold is 89%.

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

**Overall Findings**

Of those patients who said they needed written information about their tests, 87% said they were given written information that was easy to understand; 4% were given information but it was difficult to understand. 9% said they were not given written information but would have liked some.
Longitudinal comparison 2010 to 2014
The proportion of patients being given written information about their tests that was easy to understand was 85% in 2010 compared to 87% in the 2014 survey.

![Chart 27 Given written information about tests]

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 65% as the lowest score to 95% as the highest Trust score.

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

9. 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 19% said the explanation was only understandable to some extent. 2% said the results were not explained but they would have liked an explanation.
**Longitudinal comparison 2010 to 2014**

The proportion of patients saying they had a completely understandable explanation of their tests results was 76% in 2010 compared to 78% in the 2014 survey.

![Chart 28 Given understandable test results](chart)

**Findings by Tumour Group**

There was significant variation in the number of patients saying they were given a complete explanation of their tests results in an understandable way. Scores ranged from 83% (skin cancer) to 73% (brain / CNS).
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 61% as the lowest score to 91% as the highest Trust score.

The 20th percentile threshold is 75%; the 80th percentile threshold is 82%.
5.3. 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 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, 8% 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.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they were first told they had cancer by a hospital doctor was 83% in 2010 compared to 82% in the 2014 survey.

Findings by Trust
Results from individual Trusts show that there are significant variations in the proportion of patients saying they were first told they had cancer by a hospital doctor. Scores in Trusts ranged from 91% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 96%; the 80th percentile threshold is 98%.
11. 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, 75% overall said they were told they could bring a family member or friend with them; 25% were not told. 2% said they were told they had cancer by phone or letter.

**Longitudinal comparison 2010 to 2014**

The proportion of patients saying they were told they could bring a family member or friend with them was 71% in 2010 compared to 75% in the 2014 survey.

<table>
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<th>Percentage</th>
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</tr>
<tr>
<td>2012</td>
<td>72%</td>
</tr>
<tr>
<td>2013</td>
<td>74%</td>
</tr>
<tr>
<td>2014</td>
<td>75%</td>
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</tbody>
</table>

*Chart 31 Told could bring family member*

**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 83% (brain / CNS) to 64% (skin cancer).
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 63% as the lowest score to 88% as the highest Trust score.

The 20th percentile threshold is 71%; the 80th percentile threshold is 79%.

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

Overall Findings

Overall, 84% 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.

Longitudinal comparison 2010 to 2014

The proportion of patients saying the way they were told they had cancer was done sensitively was 83% in 2010 compared to 84% in the 2014 survey.
Findings by Tumour Group

There was a significant variation in the proportion of patients saying the way they were told they had cancer was done sensitively. Scores ranged from 88% (breast cancer) to 79% (sarcoma).
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 70% as the lowest score to 97% as the highest Trust score.

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

13. 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.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they completely understood the explanation that they received of what was wrong with them was 74% in 2010 compared to 73% in the 2014 survey.

Chart 35 Completely understood what was wrong
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 and skin cancers) to 58% (haematological cancer).

Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they completely understood the explanation that they received of what was wrong with them. Scores in Trusts ranged from 57% as the lowest score to 86% as the highest Trust score.

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

14. 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, 72% overall said they were given written information about the type of cancer that they had and that it was easy to understand; a further 8% were given written information but said it was difficult to understand. 20% were not given written information.

Longitudinal comparison 2010 to 2014

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 66% in 2010 compared to 72% in the 2014 survey.
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 81% (skin cancer) to 58% (sarcoma).
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 48% as the lowest score to 84% as the highest Trust score.

The 20th percentile threshold is 68%; the 80th percentile threshold is 76%.
5.4. 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. Before your cancer treatment started, were you given a choice of different types of treatment?

**Overall Findings**

59% of patients overall said only one type of treatment was suitable for them; of the remaining patients, 86% said they were given a choice of different types of treatment; 14% said they were not given a choice but would have liked one.

**Longitudinal comparison 2010 to 2014**

The proportion of patients saying they were given a choice of different types of treatment was 83% in 2010 compared to 86% in the 2014 survey.

![Chart 39 Given choice of treatment](image)

**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 a choice of different types of treatment. Scores in Trusts ranged from 68% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 82%; the 80th percentile threshold is 90%.

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?

Overall Findings
7% 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.

71% of those patients who knew said their views were definitely taken into account; 23% said they were to some extent. 6% said their views were not taken into account.

Longitudinal comparison 2010 to 2014
The proportion of patients saying their views were definitely taken into account was 70% in 2012 compared to 71% in the 2014 survey.

Chart 40 Views taken into account by team
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 77% (skin cancer) to 65% (other cancers).

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 60% as the lowest score to 85% as the highest Trust score.

The 20th percentile threshold is 69%; the 80th percentile threshold is 74%.

17. 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. 4% said side effects were not explained to them.

Longitudinal comparison 2010 to 2014
The proportion of patients saying possible side effects of treatment were definitely explained to them was 72% in 2010 compared to 75% in the 2014 survey.
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 70% (urological cancer).
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 53% as the lowest score to 85% as the highest Trust score.

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

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

Overall Findings
82% 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. 12% of patients said they were not given written information about side effects.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they had received written information about the side effects of treatment was 80% in 2010 compared to 82% in the 2014 survey.
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 69% (skin cancer).

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 64% as the lowest score to 90% as the highest Trust score.

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

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

Overall Findings
56% of those patients who needed to be told said they were definitely told about longer term side effects; 26% said they were to some extent. 18% said future side effects were not explained to them. 6% said they did not need an explanation.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they were definitely told about the side effects of treatment that could affect them in the future rather than straight away was 55% in 2013 compared to 56% in the 2014 survey.
Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were definitely told about future side effects of treatment. Scores ranged from 66% (prostate cancer) to 48% (urological cancer).
Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they were definitely told about future side effects of treatment. Scores in Trusts ranged from 41% as the lowest score to 69% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 52%; the 80\textsuperscript{th} percentile threshold is 59%.

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

Overall Findings

72% of patients said that they were definitely involved as much as they wanted to be in decisions about their care and treatment; 23% said they were involved to some extent. 5% said no but they would have liked to have been more involved.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they were definitely involved as much as they wanted to be in decisions about their care was 72% in 2012 compared to 72% in the 2014 survey.

![Chart 48 Q20 Involved in decisions about care](chart)

Findings by Tumour Group

There was a significant variation in the proportion of patients saying they were definitely involved in decisions about their care and treatment. Scores ranged from 78% (skin cancer) to 68% (urological and other cancers).
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 care and treatment. Scores in Trusts ranged from 52% as the lowest score to 85% as the highest Trust score.

The 20th percentile threshold is 69%; the 80th percentile threshold is 76%.
5.5. Clinical nurse specialist

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

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

Overall Findings
89% of patients overall said that they had been given the name of a Clinical Nurse Specialist; 11% were not given the name of a Clinical Nurse Specialist.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they were given the name of a Clinical Nurse Specialist was 84% in 2010 compared to 89% in the 2014 survey.

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 and gynaecological cancers) to 79% (urological cancer).
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 72% as the lowest score to 97% as the highest Trust score.

The 20th percentile threshold is 86%; the 80th percentile threshold is 92%.

22. 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, 73% said that it was easy to contact them; 23% said it was sometimes easy, sometimes difficult; and 4% said it was difficult.

Longitudinal comparison 2010 to 2014

The proportion of patients saying that it was easy to contact their Clinical Nurse Specialist was 75% in 2010 compared to 73% in the 2014 survey.
Findings by Tumour Group

There was a significant variation in the proportion of patients saying that it was easy to contact their Clinical Nurse Specialist. Scores ranged from 80% (skin cancer) to 70% (other cancers).
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 58% as the lowest score to 92% as the highest Trust score.

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

23. 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; 8% said they listened carefully to some extent. 1% said they did not listen carefully.

Longitudinal comparison 2010 to 2014
The proportion of patients saying that the Clinical Nurse Specialist definitely listened carefully was 91% in 2010 compared to 91% in the 2014 survey.

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 85% as the lowest score to 98% as the highest Trust score.

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

24. 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.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they got understandable answers all or most of the time was 91% in 2010 compared to 91% in the 2014 survey.

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 71% as the lowest score to 97% as the highest Trust score.

The 20th percentile threshold is 88%; the 80th percentile threshold is 93%.
5.6. Support for patients

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

25. 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, 83% reported having been given information about support or self-help groups for people with cancer by hospital staff. 17% said they did not get any information but would have liked some.

**Longitudinal comparison 2010 to 2014**
The proportion of patients saying they had been given information about support or self-help groups was 79% in 2010 compared to 83% in the 2014 survey.

![Chart 56 Q25 Given information about support groups](image)

**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 69% (urological cancer).
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 63% as the lowest score to 96% as the highest Trust score.

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

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

Overall Findings

Of those patients who said it was necessary, 75% said they had discussed or been given information about the impact of cancer on work or education; 25% said no, but they would have liked this. 48% said this was not necessary or relevant to them.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they had discussed or been given information on the impact cancer could have on their work life or education was 74% in 2013 compared to 75% in the 2014 survey.
Findings by Tumour Group

There was a significant variation in the proportion of patients saying they had a discussion or were given information about the impact of cancer. Scores ranged from 78% (breast and prostate cancers) to 63% (urological cancer).

Chart 59 Impact of cancer on work or education discussed
Findings by Trust
Results from individual Trusts show that there are significant variations in the proportion of patients saying they had a discussion or were given information about the impact of cancer. Scores in Trusts ranged from 62% as the lowest score to 91% as the highest Trust score.

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

27. 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, 54% said they had been given information about how to get financial help or benefits by hospital staff. 46% said they did not get any information but would have liked some.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they had been given information about how to get financial help or benefits was 50% in 2010 compared to 54% in the 2014 survey.

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 33% (urological cancer).
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 25% as the lowest score to 84% as the highest Trust score.

The 20th percentile threshold is 48%; the 80th percentile threshold is 61%.

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

Overall Findings

Of those patients who said it was necessary, 78% said that hospital staff had told them that they could get free prescriptions. 22% said they did not get this information but would have liked it.

Longitudinal comparison 2010 to 2014

The proportion of patients saying hospital staff had told them that they could get free prescriptions was 68% in 2010 compared to 78% in the 2014 survey.
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 83% (lung cancer) to 56% (skin cancer).
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 56% as the lowest score to 93% as the highest Trust score.

The 20th percentile threshold is 73%; the 80th percentile threshold is 82%.

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

Overall Findings
86% of patients said they had seen information about research; 14% had not.

Longitudinal comparison 2010 to 2014
The proportion of patients saying that they saw cancer research information in the hospital was 85% in 2013 compared to 86% in the 2014 survey.

Findings by Tumour Group
There was a significant variation in the proportion of patients saying they had seen information about research. Scores ranged from 88% (breast, lung, haematological, head & neck, upper gastrointestinal and other cancers) to 78% (urological cancer).
Findings by Trust

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had seen information about research. Scores in Trusts ranged from 72% as the lowest score to 96% as the highest Trust score.

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

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

Overall Findings

31% of patients said that taking part in research had been discussed with them; 69% said it had not.

Longitudinal comparison 2010 to 2014

The proportion of patients saying someone discussed participation in cancer research with them was 33% in 2012 compared to 31% in the 2014 survey.
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 37% (brain / CNS and haematological cancers) to 14% (urological cancer).
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 10% as the lowest score to 61% as the highest Trust score.

The 20th percentile threshold is 21%; the 80th percentile threshold is 35%.

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

Overall Findings
63% of those patients who said they were asked, said they went on to take part in cancer research; 37% did not.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they had taken part in cancer research was 64% in 2013 compared to 63% in the 2014 survey.

Findings by Tumour Group
There was a significant variation in the proportion of patients saying they went on to take part in research. Scores ranged from 75% (brain / CNS) to 58% (lung, prostate and urological cancers).
Chart 69 Patients who went on to participate in research

**Findings by Trust**

Results from individual Trusts show that there are significant variations in the proportion of patients saying they went on to take part in research. Scores in Trusts ranged from 33% as the lowest score to 80% as the highest Trust score.

The 20th percentile threshold is 55%; the 80th percentile threshold is 68%.
5.7. 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.

32. 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
55% of patients said that they had had an operation such as removal of a tumour or lump during the last 12 months.

Longitudinal comparison 2010 to 2014
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 2012 compared to 55% in the 2014 survey.

![Chart: Q32 Had an operation during the last 12 months](image)

Findings by Tumour Group
There was a significant variation in the proportion of patients having an operation during the last 12 months. Scores ranged from 90% (skin cancer) to 15% (haematological cancer).
Findings by Trust
Results from individual Trusts show that there are significant variations in the proportion of patients having an operation during the last 12 months. Scores in Trusts ranged from 25% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 51%; the 80th percentile threshold is 63%.

33. 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, 88% said a member of staff explained completely; a further 11% said staff explained to some extent. 1% said staff did not explain but that they would have liked an explanation.

Longitudinal comparison 2010 to 2014
The proportion of patients saying a member of staff explained what would be done completely was 85% in 2010 compared to 88% in the 2014 survey.
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 68% as the lowest score to 94% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 85%; the 80\textsuperscript{th} percentile threshold is 90%.

34. Beforehand, were you given written information about your operation?

Overall Findings
76% 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. 21% said they were not given written information.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they were given easy to understand written information was 68% in 2010 compared to 76% in the 2014 survey.
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 84% (breast and prostate cancers) to 56% (sarcoma).
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 31% as the lowest score to 89% as the highest Trust score.

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

35. 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, 78% overall said they had received a completely understandable explanation of how the operation had gone from a member of staff; 18% said staff had explained to some extent. 5% did not get an explanation but would have liked one.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they had received a completely understandable explanation of how the operation had gone was 73% in 2010 compared to 78% in the 2014 survey.

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 60% as the lowest score to 92% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 74%; the 80\textsuperscript{th} percentile threshold is 81%.
5.8. Hospital doctors

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

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

36. 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

66% of patients said they had had an operation or stayed overnight for cancer care during the last 12 months.

Longitudinal comparison 2010 to 2014

The proportion of patients saying had had an operation or stayed overnight for cancer care during the last 12 months was 68% in 2012 compared to 66% in the 2014 survey.

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Chart 76 Had overnight hospital stay in last 12 months

Findings by Tumour Group

There was a significant variation in the proportion of patients that they had an operation or stayed overnight. Scores ranged from 83% (head & neck and urological cancers) to 44% (haematological cancer).
37. 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, 83% 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.

Longitudinal comparison 2010 to 2014
The proportion of patients saying doctors gave them answers they could understand was 81% in 2010 compared to 83% in the 2014 survey.
Findings by Tumour Group
There was some variation between cancer types in the 2014 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 69% as the lowest score to 95% as the highest Trust score.

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

38. 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. No patients said they did not have confidence and trust in them.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they had confidence and trust in all of the doctors was 84% in 2010 compared to 85% in the 2014 survey.
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 94% as the highest Trust score.

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

39. Did doctors talk in front of you as if you weren’t there?

Overall Findings
84% of patients said doctors did not talk in front of them as if they were not there. 13% said that they sometimes did and a further 4% said that they often did.

Longitudinal comparison 2010 to 2014
The proportion of patients saying doctors did not talk in front of them as if they were not there was 83% in 2010 compared to 84% in the 2014 survey.
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 90% (breast cancer) to 78% (upper gastrointestinal cancer).
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 64% as the lowest score to 94% as the highest Trust score.

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

40. 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, 67% said their family or someone close to them definitely had enough opportunity to do so; a further 26% said they did so to some extent. 6% said they did not have enough opportunity to talk to a doctor.

Longitudinal comparison 2010 to 2014

The proportion of patients saying their family or someone close to them definitely had enough opportunity to talk to a doctor was 66% in 2013 compared to 67% in the 2014 survey.

Chart 82 Family had opportunity to talk to doctor
Findings by Tumour Group

There was a significant variation in the proportion of patients saying their family or someone close to them definitely had enough opportunity to talk to a doctor. Scores ranged from 72% (skin cancer) to 60% (brain / CNS).

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 44% as the lowest score to 89% as the highest Trust score.

The 20th percentile threshold is 64%; the 80th percentile threshold is 71%.
5.9. 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.

41. 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, 76% overall said nurses gave them answers they could understand all or most of the time; 21% said they gave understandable answers some of the time and a further 3% said they rarely or never got answers they could understand.

Longitudinal comparison 2010 to 2014

The proportion of patients saying nurses gave them answers they could understand all or most of the time was 73% in 2010 compared to 76% in the 2014 survey.

![Chart 84 Given understandable answers](attachment:chart.png)

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

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

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

Overall Findings

71% of patients said they had confidence and trust in all the ward nurses treating them; 29% said they had confidence and trust in some of them and 1% said they had confidence and trust in none of them.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they had confidence and trust in all of the ward nurses was 66% in 2010 compared to 71% in the 2014 survey.

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 79% (skin cancer) to 66% (other cancers).
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 52% as the lowest score to 88% as the highest Trust score.

The 20th percentile threshold is 66%; the 80th percentile threshold is 75%.

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

Overall Findings

85% of patients said nurses did not talk in front of them as if they were not there; 12% said that they sometimes did and a further 3% said they often did.

Longitudinal comparison 2010 to 2014

The proportion of patients saying nurses did not talk in front of them as if they were not there was 83% in 2010 compared to 85% in the 2014 survey.
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 68% as the lowest score to 93% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 81%; the 80\textsuperscript{th} percentile threshold is 89%.

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

Overall Findings
Overall, 62\% of patients said there were always or nearly always enough nurses on duty to care for them in hospital; 29\% said that there were sometimes enough on duty and a further 10\% said there were rarely or never enough on duty.

Longitudinal comparison 2010 to 2014
The proportion of patients saying there were always or nearly always enough nurses on duty was 62\% in 2010 compared to 62\% in the 2014 survey.
**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 76% (skin cancer) to 56% (colorectal / lower gastrointestinal and other cancers).
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 44% as the lowest score to 89% as the highest Trust score.

The 20th percentile threshold is 56%; the 80th percentile threshold is 69%.
5.10. 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.

45. 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**

88% of patients said that they never thought that doctors or nurses were deliberately not telling them certain things that they wanted to know; 11% said they only once or sometimes thought they were and a further 1% said they often thought they were.

**Longitudinal comparison 2010 to 2014**

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 2010 compared to 88% in the 2014 survey.

![Chart](image)

Chart 90 Staff did not deliberately misinform them

**Findings by Tumour Group**

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

Results from individual Trusts show that there are significant variations in the proportion of patients saying 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 72% as the lowest score to 95% as the highest Trust score. The 20th percentile threshold is 86%; the 80th percentile threshold is 91%.

46. 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.

Longitudinal comparison 2010 to 2014

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 2010 compared to 79% in the 2014 survey.
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 73% (upper gastrointestinal and other cancers).

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 70% as the lowest score to 94% as the highest Trust score.

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

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

Overall Findings

60% of patients said all of the doctors and nurses asked them what they wanted to be called; 22% said that only some of them did and 18% said that none of them did.

Longitudinal comparison 2010 to 2014

The proportion of patients saying all staff asked them what they preferred to be called was 56% in 2012 compared to 60% in the 2014 survey.
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 69% (upper gastrointestinal cancer) to 53% (skin cancer).
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 33% as the lowest score to 85% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 50%; the 80\textsuperscript{th} percentile threshold is 67%.

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

Overall Findings
85\% of patients overall said that they always had enough privacy when discussing their condition or treatment; a further 12\% said they sometimes did. 3\% said they did not have enough privacy.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they always had enough privacy was 82\% in 2010 compared to 85\% in the 2014 survey.

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Chart 95 Given privacy when discussing condition

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 70% as the lowest score to 96% as the highest Trust score.

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

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

Overall Findings

95% 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.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they always had enough privacy was 93% in 2010 compared to 95% in the 2014 survey.

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%.

50. 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, 65% 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. 3% said they could not but would have liked to.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they were able to discuss worries and fears with staff was 64% in 2012 compared to 65% in the 2014 survey.

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 able to discuss worries and fears as much as they wanted. Scores in Trusts ranged from 49% as the lowest score to 80% as the highest Trust score.

The 20th percentile threshold is 60%; the 80th percentile threshold is 70%.

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

Overall Findings

86% of those patients saying they had pain said that staff did everything they could to help control it all of the time; 13% said they did so some of the time. 1% said they did not do everything they could.

Longitudinal comparison 2010 to 2014

The proportion of patients saying staff did everything they could to help control their pain was 85% in 2010 compared to 86% in the 2014 survey.

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 70% as the lowest score to 95% as the highest Trust score.

The 20th percentile threshold is 83%; the 80th percentile threshold is 88%.

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

Overall Findings

84% of patients overall said that they were always treated with respect and dignity by staff and a further 13% said they were most of the time. 2% said they were treated with respect and dignity some of the time or never were.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they were always treated with respect and dignity was 83% in 2013 compared to 84% in the 2014 survey.

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 63% as the lowest score to 94% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 81\%; the 80\textsuperscript{th} percentile threshold is 88\%. 
5.11. Information before leaving and home support

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

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

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

Overall Findings

85% of patients overall said that they were given clear written information about what they should or should not do after leaving hospital; 15% said they were not given information.

Longitudinal comparison 2010 to 2014

The proportion of patients saying they were given written information about what they should or should not do was 82% in 2010 compared to 85% in the 2014 survey.

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 91% (breast cancer) to 79% (sarcoma and upper gastrointestinal cancers).
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 62% as the lowest score to 100% as the highest Trust score.

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

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

Overall Findings

94% of patients overall said that hospital staff told them who to contact if they felt worried about their condition or treatment after leaving hospital; 6% said they were not told.

Longitudinal comparison 2010 to 2014

The proportion of patients saying that hospital staff told them who to contact if they felt worried about their condition or treatment was 92% in 2010 compared to 94% in the 2014 survey.
Q54 Staff told patient who to contact if worried post discharge

![Chart 102 Told who to contact if worried about condition](image)

**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 86% as the lowest score to 100% as the highest Trust score.

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

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

**Overall 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; 24% said they did so to some extent. 16% said their family did not get all the information they needed.

**Longitudinal comparison 2010 to 2014**

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 58% in 2010 compared to 60% in the 2014 survey.
Findings by Tumour Group

There was a significant variation in the proportion of patients saying that their family or someone close was given all the information they needed to help care for the patients at home. Scores ranged from 64% (skin cancer) to 55% (urological cancer and other cancers).
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 34% as the lowest score to 80% as the highest Trust score.

The 20th percentile threshold is 56%; the 80th percentile threshold is 65%.

56. 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, 59% said they were definitely given enough care and help from health or social services after leaving hospital; 23% said they were to some extent. 18% said they did not get enough care and help.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they were definitely given enough care and help from health or social services was 60% in 2010 compared to 59% in the 2014 survey.

Findings by Tumour Group
There was a significant variation in the proportion of patients saying they were definitely given enough care and help from health or social services. Scores ranged from 67% (colorectal / lower gastrointestinal cancer) to 51% (urological cancer).
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 23% as the lowest score to 85% as the highest Trust score.

The 20th percentile threshold is 52%; the 80th percentile threshold is 65%.
5.12. Day / outpatient care

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

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

Overall Findings
59% 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.

Longitudinal comparison 2010 to 2014
The proportion of patients saying staff definitely did everything they could to help control side effects was 82% in 2010 compared to 79% in the 2014 survey.

![Chart 107 Controlled side effects of radiotherapy](chart107.png)

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 61% as the lowest score to 91% as the highest Trust score.

The 20th percentile threshold is 75%; the 80th percentile threshold is 83%.

58. 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.

Longitudinal comparison 2010 to 2014

The proportion of patients saying staff definitely did everything they could to help control side effects was 85% in 2010 compared to 81% in the 2014 survey.

Chart 108 Controlled side effects of chemotherapy
Findings by Tumour Group
There was some variation between cancer types but statistical tests indicate that the differences between cancer groups are not significant overall.

Findings by Trust
Results from individual Trusts show that there are significant variations in the proportion of patients saying staff definitely did everything possible to control the side effects of the chemotherapy. Scores in Trusts ranged from 60% as the lowest score to 98% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 78%; the 80\textsuperscript{th} percentile threshold is 85%.

59. 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, 82% said that hospital staff definitely did everything they could to help control the pain; 15% said they did so to some extent. 3% said they could have done more to help control the pain.

Longitudinal comparison 2010 to 2014
The proportion of patients saying hospital staff definitely did everything they could to help control the pain was 83% in 2010 compared to 82% in the 2014 survey.
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 68% as the lowest score to 93% as the highest Trust score.

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

60. 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, 70% 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.

Longitudinal comparison 2010 to 2014
The proportion of patients saying they were definitely given enough emotional support by staff was 71% in 2010 compared to 70% in the 2014 survey.

Chart 110 Given enough emotional support
**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 given enough emotional support from hospital staff. Scores in Trusts ranged from 44% as the lowest score to 86% as the highest Trust score.

The 20\textsuperscript{th} percentile threshold is 66%; the 80\textsuperscript{th} percentile threshold is 76%.
5.13. Outpatient appointments

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

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

**Overall Findings**

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

**Longitudinal comparison 2010 to 2014**

The proportion of patients that they had had an outpatients appointment with a cancer doctor in the last 12 months was 94% in 2012 compared to 94% in the 2014 survey.

![Chart 111 Had an outpatients appointment in last 12 months](chart)

**Findings by Tumour Group**

There was a significant variation in the proportion of patients saying that they had an outpatients appointment in the last 12 months. Scores ranged from 97% (haematological cancer) to 88% (urological cancer).
**Findings by Trust**

Results from individual Trusts show that there are significant variations in the proportion of patients saying they had an outpatients appointment with a cancer doctor in the last 12 months. Scores in Trusts ranged from 84% as the lowest score to 98% as the highest Trust score.

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

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

**Overall Findings**

96% 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; 4% said that the doctor did not have the right documents.

**Longitudinal comparison 2010 to 2014**

The proportion of patients saying that the cancer doctor had the right documents was 95% in 2010 compared to 96% in the 2014 survey.
**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 86% as the lowest score to 100% as the highest Trust score.

The 20th percentile threshold is 95%; the 80th percentile threshold is 98%.
5.14. Care from general practices

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

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

Overall Findings
95% of patients said that, as far as they knew, their GP was given enough information about their condition and treatment by the hospital; 5% said they were not given enough information.

16% of patients (who were excluded from the above calculations) said they did not know or could not remember, in answer to this question.

Longitudinal comparison 2010 to 2014
The proportion of patients saying their GP was given enough information was 93% in 2010 compared to 95% in the 2014 survey.

<table>
<thead>
<tr>
<th>Year</th>
<th>Q63 GP given enough information about patient`s condition and treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>93%</td>
</tr>
<tr>
<td>2012</td>
<td>94%</td>
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<tr>
<td>2013</td>
<td>95%</td>
</tr>
<tr>
<td>2014</td>
<td>95%</td>
</tr>
</tbody>
</table>

Chart 114 GP given enough information about condition

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 78% as the lowest score to 100% as the highest Trust score.

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

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

Overall Findings
Of those patients who said their general practice was involved in their care, 66% 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 11% said they could have done more. 32% said their general practice was not involved.

Longitudinal comparison 2010 to 2014
The proportion of patients saying the staff at their general practice definitely did everything they could to support them was 69% in 2010 compared to 66% in the 2014 survey.

<table>
<thead>
<tr>
<th>Year</th>
<th>Q64 Practice staff definitely did everything they could to support patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>69%</td>
</tr>
<tr>
<td>2012</td>
<td>67%</td>
</tr>
<tr>
<td>2013</td>
<td>68%</td>
</tr>
<tr>
<td>2014</td>
<td>66%</td>
</tr>
</tbody>
</table>

Chart 115 GP did everything to support patient

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 cancer) to 55% (brain / CNS).
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 47% as the lowest score to 83% as the highest Trust score.

The 20th percentile threshold is 62%; the 80th percentile threshold is 71%.
5.15. Overall NHS care

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

65. 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**

63% of patients said that the different people treating and caring for them always worked well together to give the best possible care; a further 27% said they did so most of the time. 8% said they only did so some of the time and 2% said they never did.

**Longitudinal comparison 2010 to 2014**

The proportion of patients saying that the different people treating and caring for them always worked well together was 61% in 2010 compared to 63% in the 2014 survey.

![Chart 117: Staff worked well together](chart.png)

**Findings by Tumour Group**

There was a significant variation in the proportion of patients saying that the different people treating and caring for them always worked well together. Scores ranged from 68% (skin cancer) to 51% (brain / CNS).
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 39% as the lowest score to 83% as the highest Trust score.

The 20th percentile threshold is 60%; the 80th percentile threshold is 69%.

66. Have you had treatment from any of the following for your cancer?

Overall Findings

Patients were asked if they had had treatment from a range of therapists. 12% said they had treatment from a physiotherapist; 5% said they had treatment from an occupational therapist; 13% said they had treatment from a dietician; 2% said they had treatment from a speech and language therapist and 7% said they had treatment from a lymphoedema specialist.

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

Overall Findings

88% of patients overall said that they were given the right amount of information about their condition and treatment; 10% said they were not given enough and 2% said they were given too much.
Longitudinal comparison 2010 to 2014

The proportion of patients saying that they were given the right amount of information about their condition and treatment was 88% in 2010 compared to 88% in the 2014 survey.

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 70% as the lowest score to 98% as the highest Trust score.

The 20<sup>th</sup> percentile threshold is 86%; the 80<sup>th</sup> percentile threshold is 90%.

68. Have you been offered a written assessment and care plan?

Overall Findings

22% of patients said that they had been offered a written assessment or care plan; 78% said they had not and a further 15% said they didn’t know or couldn’t remember.
**Longitudinal comparison 2010 to 2014**

The proportion of patients saying they were offered a care plan was 24% in 2012 compared to 22% in the 2014 survey.

<table>
<thead>
<tr>
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<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
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<td>22%</td>
</tr>
<tr>
<td>2013</td>
<td>22%</td>
</tr>
<tr>
<td>2014</td>
<td>22%</td>
</tr>
</tbody>
</table>

Chart 120 Offered written assessment / care plan

**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 25% (colorectal / lower gastrointestinal cancer) to 18% (other cancers).
Patient offered written assessment and care plan

Chart 121 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 8% as the lowest score to 45% as the highest Trust score.

The 20th percentile threshold is 18%; the 80th percentile threshold is 27%.

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?

Overall Findings

81% 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; 15% said they sometimes felt this and 3% said they often felt this way.

Longitudinal comparison 2010 to 2014

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 2010 compared to 81% in the 2014 survey.
**Q69 Patient did not feel that they were treated as a `set of cancer symptoms`**

Chart 122 Did not feel treated like a set of symptoms

**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 76% (brain / CNS and other cancers).

Chart 123 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 69% as the lowest score to 93% as the highest Trust score.

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

70. Overall how would you rate your care?

Overall Findings

89% of patients said that their care was either excellent (57%) or very good (32%). 8% said it was good and 3% said it was either only fair (2%) or poor (1%).

Longitudinal comparison 2010 to 2014

The proportion of patients saying care was excellent or very good was 88% in 2012 compared to 89% in the 2014 survey.

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 63% as the lowest score to 97% as the highest Trust score.

The 20th percentile threshold is 86%; the 80th percentile threshold is 92%.
5.16. First treatment and recurrence

This section describes the length of time since the patient's cancer was first treated, whether it was the first treatment for cancer, a recurrence of the same cancer, or treatment for a different type of cancer; and whether the cancer has responded to treatment.

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

**Overall Findings**

65% of patients had been treated for the first time for cancer within the last year; 26% between 1 year and 5 years ago; and 8% longer than 5 years ago.

**Comparison with 2013 Survey**

The proportion of patients who had been treated for the first time for cancer within the last year was 66% in 2013 compared to 65% in 2014.

![Chart 125 How long since treated for this cancer](chart.png)

77. Is this the first time you have been treated for cancer?

**Overall Findings**

77% of patients said that this was the first time that they had been treated for cancer; 13% of patients said that they had been treated for the same type of cancer but it had now come back; 10% of patients said that they had been treated for a different type of cancer before.
78. How has your current cancer responded to treatment?

**Overall Findings**

36% of patients said that they were in the course of treatment and cannot yet tell how the cancer has responded to treatment; 32% of patients said that the treatment had been effective; 9% of patients said that they had finished their course of treatment but their cancer is still present; 6% of patients said that their cancer is being treated again because it has not responded fully to treatment; 14% of patients said that they are not in active treatment but are on “Watch and Wait”.
How has your cancer responded to treatment?

Chart 127 How has cancer responded to treatment
6. **Key Drivers**

In 2014 tree analysis (a form of factor analysis) has been undertaken to identify which variables were most strongly associated with high scores given by patients. A more detailed description is contained in the Methodology and Data Tables document published for this survey.

The analysis was undertaken at "all cancers" level and for each of the 13 tumour groups analysed in this survey, which put broad groups of cancers together.

The variables tested against each other for association with high patient scores were gender, type of patient (inpatient or day case), presence of a Clinical Nurse Specialist, ethnic group, age band, region of hospital attendance, Index of Multiple Deprivation quintile, and recurrence of cancer as measured by question 77 in the questionnaire.

At all cancers level, and for each of the 13 tumour groups, the results showed that the factor with the strongest association with high patient scores in the survey was always the presence of a Clinical Nurse Specialist. In almost all the tumour groups the second most strongly associated factor with high patient scores was age.
7. Emergency patients compared to elective patients

Work has been conducted by the Cancer Registry and the National Cancer Intelligence Network (NCIN) to create a “Routes to Diagnosis” dataset which identifies whether a patient initially presented through an emergency route or through a pathway based on screening, 2 week waits, or other kinds of referrals.

These identifiers are now available for the first time, but for patients who answered the 2010 Cancer Patient Experience Survey. We have matched the 2010 CPES data with the routes to diagnosis identifiers at individual patient level, through the good offices of NCIN.

Analysis of the 2010 dataset using these identifiers shows that there are a large number of significant differences between the views of patients who entered treatment through organised pathways as distinct from emergency routes.

On almost all questions in the 2010 survey, emergency entry patients gave less positive scores than did those who entered through the 2 week wait pathway or screening.
8. Patients with a recurring cancer

The CPES included questions in 2014 on the impact that a recurrence of cancer had on patients perceptions of care and treatment. In previous years a question on when patients were first treated for this cancer (Q76 in 2014) had been asked, with the results showing that patients who were first treated more than 5 years ago were the least likely to be positive on many questions.

New questions were introduced on whether this was the first time that the patient had been treated for cancer, whether they had been treated previously for the same type of cancer, or had been previously treated for a different type of cancer (Q77). In addition, patients were asked to complete a question on the effectiveness of treatment (Q78).

The results from all three questions on treatment patterns and outcomes showed that:

• Patients who were first treated for cancer more than 5 years ago gave the lowest scores on 23 of the 33 questions on which there were significant differences across the time periods since first treatment.

• Patients who were first treated for cancer within the last year almost always gave the highest positive scores on any question where there were significant differences across the time periods since first treatment, with the exception of the questions on research. Patients who had just started treatment for the first time were the least likely to say that they had had a discussion about taking part in cancer research, and were the least likely to say that they went on to take part in research.

• Patients who said this was the first time they had been treated for cancer were more likely to be positive on almost every question in the survey than were patients who were being treated again for the same cancer. There were 57 questions on which there were significant differences between the scores given by those being treated for the first time and those being treated for a recurrence of the same cancer, and on 55 of the questions the patients being treated for the first time were more positive.

• Patients who said this was the first time they had been treated for cancer were also more likely to be positive than patients who were being treated again but for a different cancer than the one they had been treated for before. There were 35 questions on which there were significant differences between the scores given by those being treated for the first time and those who had been treated before for a different cancer, and on 31 of these questions the patients being treated for the first time were more positive.

• Patients who were being treated for a different cancer than the one they had been initially treated for were more positive on most questions than patients who were now being treated for a recurrence of the same cancer.

• On most questions, the scale of differences in scores given by patients who were being treated for the first time and those being treated for a recurrence of cancer of any kind was small - and much smaller than in relation to some other issues (for example on the impact that a CNS has on the perceived quality of care and treatment).