

# National Cancer Patient Experience Survey 2016

## National Results Summary



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## Introduction

As in previous years, we are hugely grateful to the tens of thousands of cancer patients who responded to this survey, giving us views of their cancer care in the hope of improving services for others in the future.

The National Cancer Patient Experience Survey 2016 is the sixth iteration of the survey first undertaken in 2010. It has been designed to monitor national progress on cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting cancer patients.

The survey was overseen by a national Cancer Patient Experience Advisory Group. This Advisory Group set the principles and objectives of the survey programme and guided questionnaire development.

The survey was commissioned and managed by NHS England. The survey provider Quality Health is responsible for designing, implementing and analysing the survey.

[www.ncpes.co.uk](http://www.ncpes.co.uk)



## Executive Summary

The experience of cancer patients in England continues to be generally very positive. Asked to rate their care on a scale of zero (very poor) to 10 (very good), respondents gave an average rating of **8.7**. On nearly half of the questions in the survey, over **80%** of respondents gave positive responses<sup>1</sup>.

Compared to last year's survey<sup>2</sup>, there were significant<sup>3</sup> improvements on 13 questions; scores deteriorated significantly on 1; there was no significant difference on 35; and the remaining 3 questions changed slightly so are not possible to compare.

The following questions are also included in phase 1 of the Cancer Dashboard developed by Public Health England and NHS England<sup>4</sup>:

- **78%** of respondents said that they were definitely involved as much as they wanted to be in decisions about their care and treatment
- **90%** of respondents said that they were given the name of a Clinical Nurse Specialist who would support them through their treatment
- **86%** of respondents said that it had been 'quite easy' or 'very easy' to contact their Clinical Nurse Specialist
- **88%** of respondents said that, overall, they were always treated with respect and dignity while they were in hospital
- **94%** of respondents said that hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital.
- **62%** of respondents said that they thought the GPs and nurses at their general practice definitely did everything they could to support them while they were having cancer treatment.

However, the national picture of experience of care remains inconsistent, with some elements of care rated more positively than others. For example, patients appear to get more information on some areas (e.g. free prescriptions) than on others (e.g. benefits); information about chemotherapy/radiotherapy appears to be better before treatment than during it; and care and support from health and social services at home appears to be less positively experienced than care received in hospitals.

These differences were all evident in last year's data as well.

Detailed results for these and other questions are set out in the sections that follow.

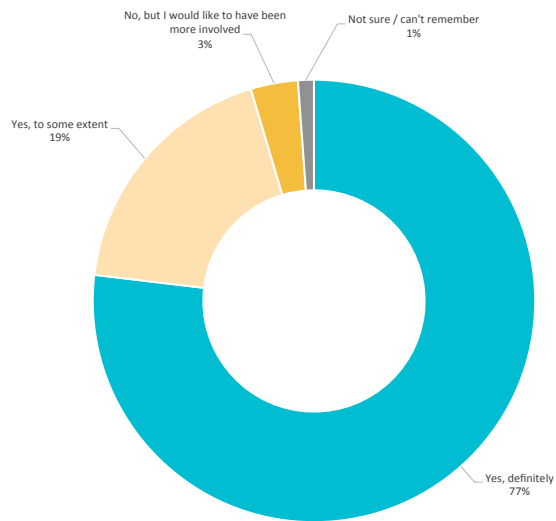
<sup>1</sup>When referring to percentages of positive responses in this report, these have been computed as the number of positive responses, divided by the number of positive and negative answers (other, non-scored responses, were excluded). The section "Understanding the results" details this aspect of the methodology.

<sup>2</sup>The detailed statistical methodology for undertaking these year-on-year significance tests is included in the Technical Documentation for this survey, which is published separately at [www.ncpes.co.uk](http://www.ncpes.co.uk).

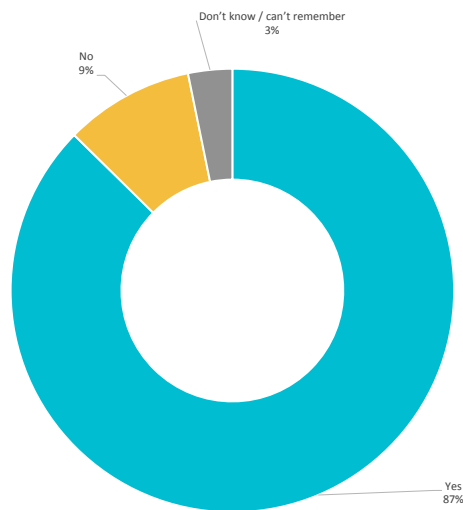
<sup>3</sup>In this report, when discussing differences in percentages or scores, we use the word "significant" to mean statistically significant differences at the 95% confidence level, unless otherwise specified.

<sup>4</sup>[www.cancerdata.nhs.uk/dashboard](http://www.cancerdata.nhs.uk/dashboard)

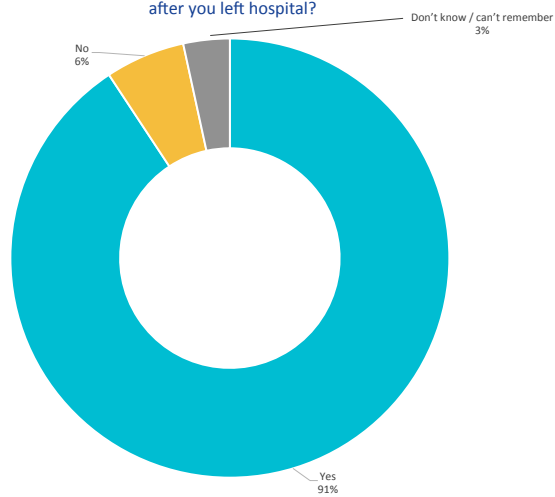
Were you involved as much as you wanted to be in decisions about your care and treatment?



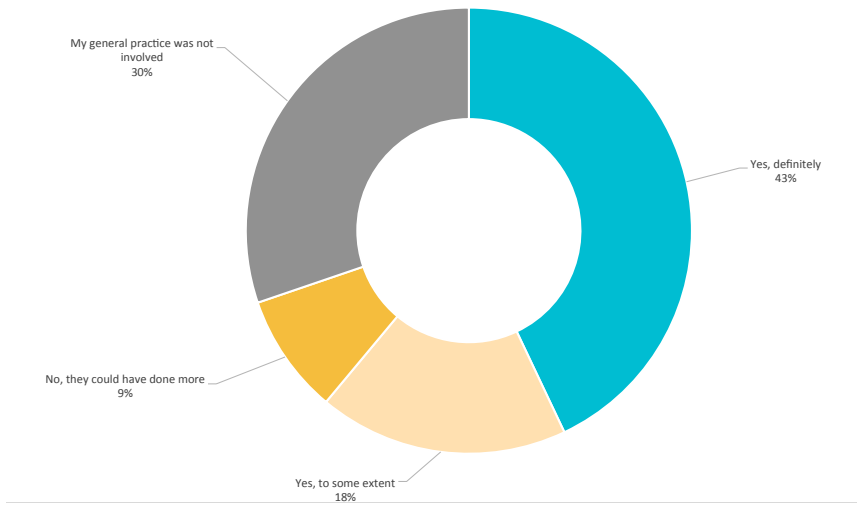
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?



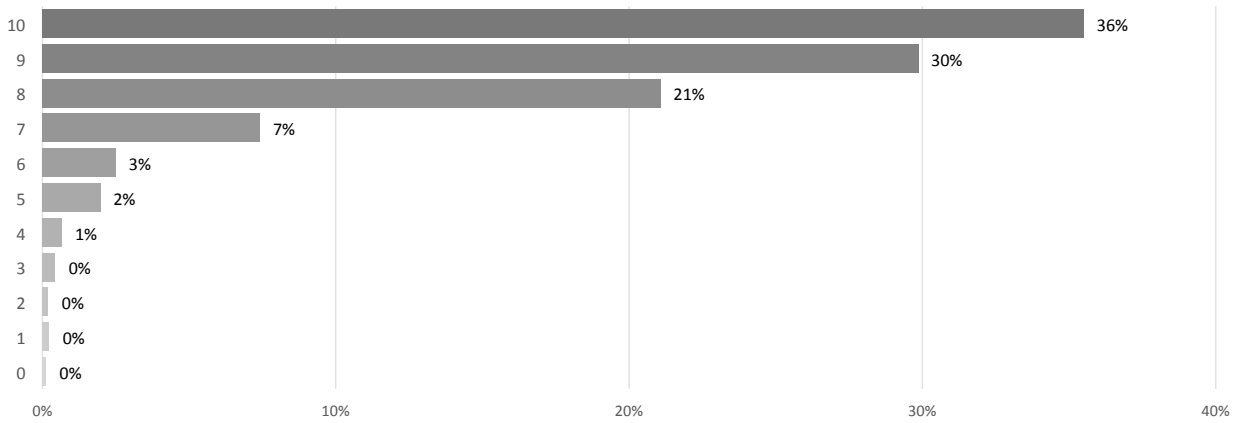
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?



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, how would you rate your care?



## Methodology

The sample for the survey included all adult (aged 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged from an NHS Trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June 2016<sup>5</sup>.

The fieldwork for the survey was undertaken between October 2016 and March 2017.

As in 2015, the survey used a mixed mode methodology. Questionnaires were sent by post, with two reminders where necessary, but also included an option to complete online. A Freephone helpline was available to respondents to ask questions about the survey, to enable them to complete their questionnaires over the phone, and to provide access to a translation and interpreting facility for those whose first language was not English.

<sup>5</sup> The patients included in the sample had relevant cancer ICD10 codes (C00-99 excluding C44 and C84, and D05) in the first diagnosis field of their patient records, applied to their patient files by the relevant NHS Trust, and were alive at the point at which fieldwork commenced. Deceased checks were undertaken on up to three occasions during fieldwork, to ensure that questionnaires were not sent to patients who had died since their treatment.





## Response rates and confidence intervals

The sample size for the survey was **118,253** cancer patients. Of these, **7,974** had died since the sample was drawn, and so their details were removed. **562** patients could not be contacted as they had moved house. In a small number of cases (**54**) patients reported that they were not eligible to receive the questionnaire. The eligible sample size was therefore calculated as **109,663** patients, of whom **72,788** responded.

Completed questionnaires were received by post from **67,037** respondents (**92.1%** of responses); and **5,714** (**7.9%**) chose to complete their questionnaires online. **30** respondents called Quality Health's Freephone helpline to give their responses over the telephone; and a further **7** used Quality Health's translation/interpreting services to give their responses.

The overall response rate of **66.4%** for the survey compares favourably with the response rate for other NHS surveys, and is in line with previous iterations of the National Cancer Patient Experience Survey (**66%** in 2015, **64%** in 2013 and 2014, **68%** in 2012, and **67%** in 2010).

A very high proportion of respondents (**82%**) said that they would be willing to participate in further surveys to ask about their health and healthcare.

As in previous years, because of the very large sample, high response rate, and high completion levels for each question, the data is highly robust from a statistical point of view.

### Survey responses

post



**92.1%**

online



**7.85%**

phone



**0.04%**

translation



**0.01%**

## Comparisons with previous years

There have been only minor changes to the questionnaire compared to 2015.

Questions 5 and 25 (relating to patients being given all the necessary information about their treatment) were not scored last year. This year, the answer options on the questionnaire were changed to enable these questions to be scored; so they appear in the detailed analysis for the first time.

The answer options for question 8 (relating to patients' experience of first being told they had cancer) have been changed slightly to allow more meaningful analysis; but this means that comparisons cannot be made with the 2015 scores.

Further details are available at [www.ncpes.co.uk](http://www.ncpes.co.uk)



## This report, and subsequent publications

This report sets out a summary of the results of the survey at the national level. It is accompanied by a separate publication of data tables giving a breakdown of the national results by various key variables: age, gender, ethnicity, deprivation, and tumour groups.

Separate publications give a breakdown of results by Clinical Commissioning Group, and by NHS Trust (in both cases, showing unadjusted and Case Mix Adjusted results, and year-on-year comparisons). Separate reports for each Clinical Commissioning Group, and each NHS Trust, give individual results, and breakdowns by tumour group at these local levels. All of these reports are available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

**Please note the percentages in this report have been rounded to the nearest percentage. Therefore, in some cases the figures do not appear to add up to 100%.**

A copy of the detailed scoring methodology for the questionnaire is available at [www.ncpes.co.uk](http://www.ncpes.co.uk)



## Understanding the results

Scores have been presented in this report for the 52 questions in the questionnaire that relate directly to patient experience.

The full detail of responses to these questions is provided in the **Detailed Data** section.

The **Survey Results** section shows the derived percentage scores for each of these questions. For most questions, these have been presented as the percentage of responses which were positive. To calculate these scores, each individual answer option to a question has been identified as either positive, negative, or neutral. The percentage score is calculated using the positive total as the numerator, and the total of positive and negative responses as the denominator. Neutral scores (e.g. "Don't know / can't remember") are excluded from the scoring calculation (i.e. not included in either the numerator or denominator).

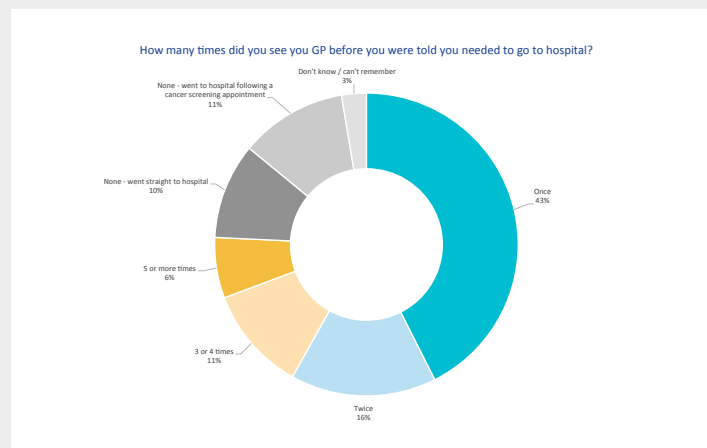
Question 59 asks respondents to rate their overall care on a scale of 0 to 10. Scores have been given as the average on this scale.

Comparisons have been calculated between this year's results and those from last year. Compared to last year's survey, there were significant improvements on 13 questions; scores deteriorated significantly on 1; there was no significant difference on 35; and the remaining 3 questions changed slightly so are not possible to compare. In the text describing the results for each question, year-on-year comparisons have only been noted where there are significant differences at the 99% confidence level. The detailed statistical methodology for undertaking these year-on-year significance tests is included in the Technical Documentation for this survey, which is published separately at [www.ncpes.co.uk](http://www.ncpes.co.uk).

Where charts have been presented for some questions, these show the full breakdown of responses across the various answer options. For example, for question 1, the text and accompanying chart from the Survey Results section are as follows:

## Seeing your GP

Respondents were asked how many times they saw their GP about the health problem caused by cancer, before they were told they needed to go to hospital about cancer. Of those who saw their GP, **77%** said that they saw their GP only once or twice. **15%** said that they saw their GP three or four times; and **9%** said that they saw their GP five or more times. **The score for this question, given by the percentage of patients seeing their GP only once or twice, is significantly higher than last year's score of 76%.**



The detailed breakdown of responses from the Detailed Data section is as follows:

	2015	2016
<b>Q1</b> 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?		
1 None - I went straight to hospital	10.0%	10.2%
2 None - I went to hospital following a cancer screening appointment	11.0%	11.4%
3 I saw my GP once	42.4%	42.6%
4 I saw my GP twice	15.7%	15.5%
5 I saw my GP 3 or 4 times	11.8%	11.2%
6 I saw my GP 5 or more times	6.7%	6.5%
7 Don't know / can't remember	2.5%	2.6%

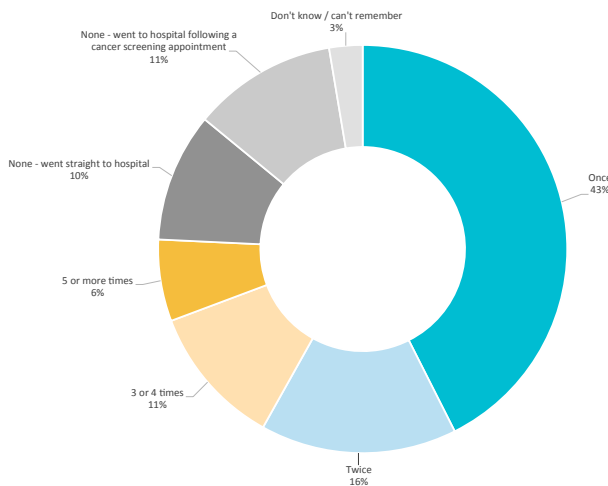
Full data tables of national and local data are available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

# Survey Results

## Seeing your GP

Respondents were asked how many times they saw their GP about the health problem caused by cancer, before they were told they needed to go to hospital about cancer. Of those who saw their GP, **77%** said that they saw their GP only once or twice. **15%** said that they saw their GP three or four times; and **9%** said that they saw their GP five or more times. **The score for this question, given by the percentage of patients seeing their GP only once or twice, is significantly higher than last year's score of 76%.**

How many times did you see you GP before you were told you needed to go to hospital?



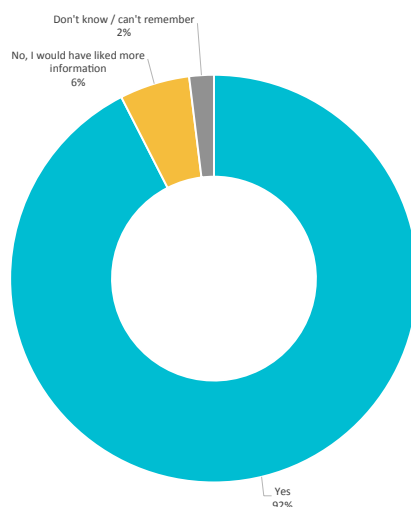
When asked how they felt about the length of time they had to wait before their first appointment with a hospital doctor, **83%** of respondents said that they were seen as soon as they thought was necessary. **This is significantly higher than last year's score of 82%.**

## Diagnostic tests

The majority of respondents (**88%**) said that they had had diagnostic tests for cancer (such as an endoscopy, biopsy, mammogram or scan) in the last 12 months.

When asked about their last diagnostic test, **94%** of these respondents said that they had all the information they needed about it beforehand.

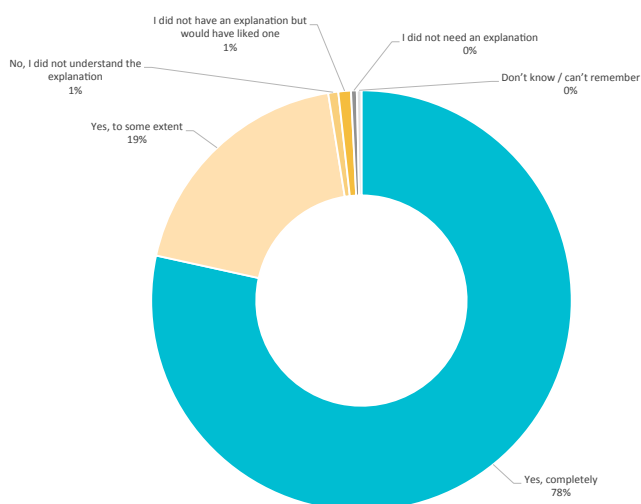
Did you have all the information you needed about your tests?



**87.5%** of respondents said that they felt the amount of time they had to wait for this (last) test to be done was about right. This is significantly higher than last year's score of 86.6%.

**79%** of respondents said that the results of their tests were explained to them in a way they could completely understand.

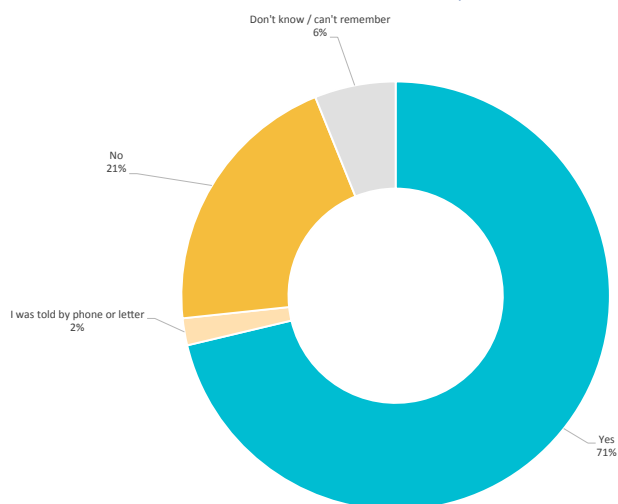
Were the results of the test explained in a way you could understand?



## Finding out what was wrong with you

**76%** of respondents said that, when they were first told they had cancer, they had been told they could bring a family member or friend with them.

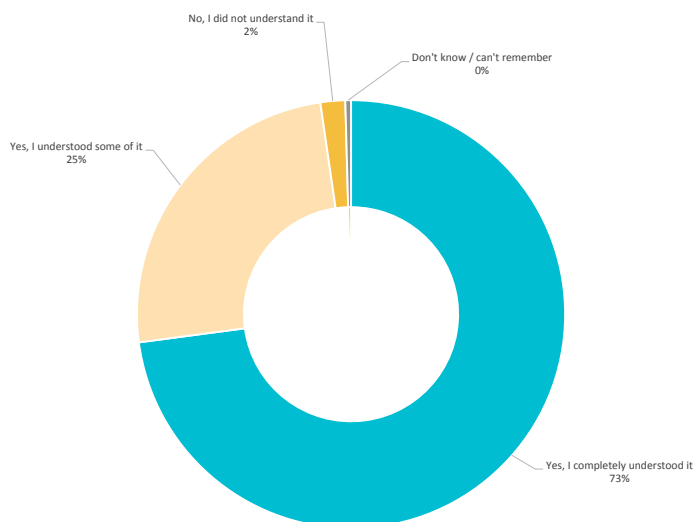
When you were first told that you had cancer, had you been told you could bring a family member or friend with you?



When asked how they felt about the way they were told they had cancer, **84%** of respondents said that it was done sensitively.

**73%** of respondents said that they completely understood the explanation of what was wrong with them.

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



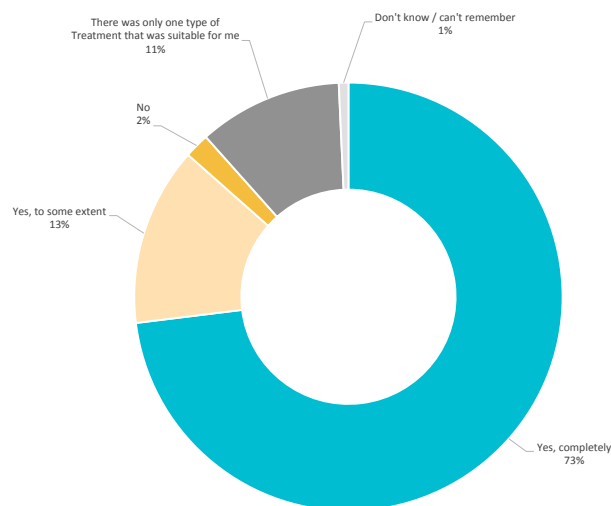


72.4% of respondents said that, when they were told they had cancer, they were given written information about the type of cancer they had, and that it was easy to understand. Of the remainder, **10%** said that they were given written information, but that it was difficult to understand; and **18%** said that they were not given written information. **The 72.4% score for this question is significantly higher than last year's score of 71.6%.**

## Deciding the best treatment for you

**83%** of respondents with more than one treatment option said that, before their cancer treatment started, the options were explained to them completely.

Before your cancer treatment started, were your treatment options explained to you?



**72%** of respondents said that the possible side effects of treatment(s) were definitely explained to them in a way they could understand.

**66%** of respondents said that they were definitely offered practical advice and support in dealing with the side effects of their treatment(s).

**54%** of respondents said that, before they started their treatment(s), they were definitely also told about any side effects of the treatment that could affect them in the future rather than straight away.

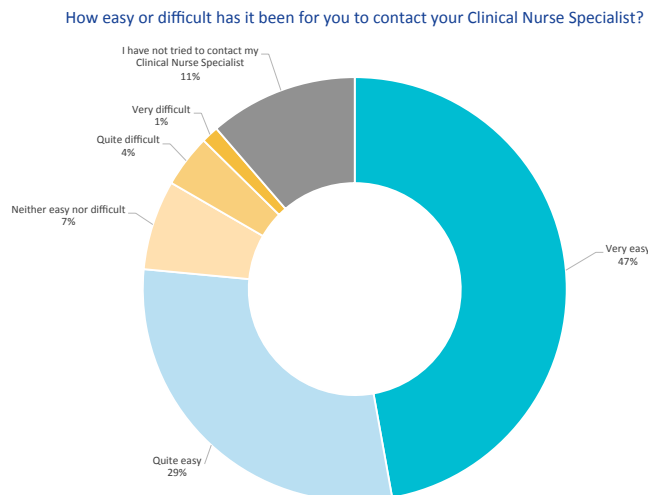
**78%** of respondents said that they were definitely involved as much as they wanted to be in decisions about their care and treatment.

## Clinical Nurse Specialist

The questionnaire described a Clinical Nurse Specialist as *"a specialist cancer nurse who makes sure you get the right care and gives you help and advice on coping with cancer"*.

**90%** of respondents said that they were given the name of a Clinical Nurse Specialist who would support them through their treatment.

When asked how easy or difficult it had been to contact their Clinical Nurse Specialist, **86%** of respondents said that it had been 'quite easy' or 'very easy'.



**88%** of respondents said that, when they had had important questions to ask their Clinical Nurse Specialist, they had got answers they could understand all or most of the time.

## Support for people with cancer

**84%** of respondents said that hospital staff gave them information about support or self-help groups for people with cancer.

**This is significantly higher than last year's score of 83%.**

**81%** of respondents said that hospital staff discussed with them, or gave them information, about the impact cancer could have on their day to day activities (*"for example, your work life or education"*).

**56%** of respondents said that hospital staff gave them information about how to get financial help or any benefits they might be entitled to. **This is significantly higher than last year's score of 55%.**

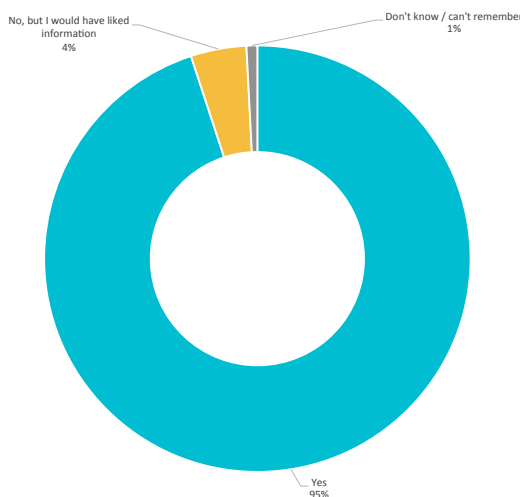
**80%** of respondents said that hospital staff told them that they could get free prescriptions.

## Operations

More than half of respondents (**55%**) said that they had had an operation (*"such as the removal of a tumour or lump"*) during the last 12 months.

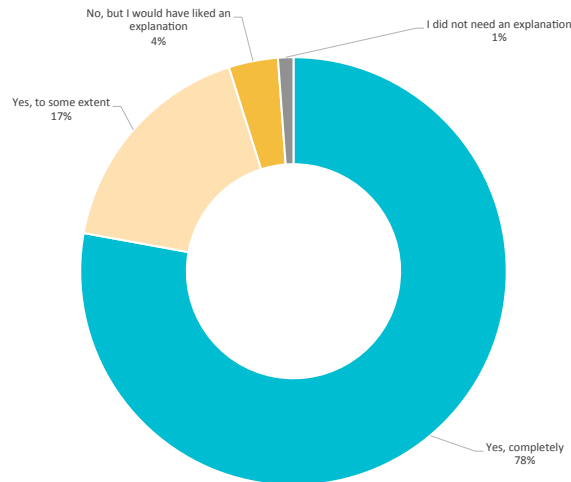
When asked about their operation, **96%** of these respondents said that they had all the information they needed about their operation before it took place.

Beforehand, did you have all the information you needed about your operation?



**79%** of respondents said that, after the operation, a member of staff explained how it had gone in a way they could completely understand. **This is significantly higher than last year's score of 78%.**

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



## Hospital care as an inpatient

**62%** of respondents said that they had had an operation or stayed overnight for cancer care during the last 12 months. The questions in this section all refer to the last such episode.

**82%** of respondents said that groups of doctors and nurses did not talk in front of them as if they weren't there. **14%** said that this sometimes happened; and **4%** said that this often happened.

**85%** of respondents said that they had confidence and trust in all of the doctors treating them.

**73%** of respondents said that, if their family or someone else close to them wanted to talk to a doctor, they were definitely able to. **This is significantly higher than last year's score of 72%.**

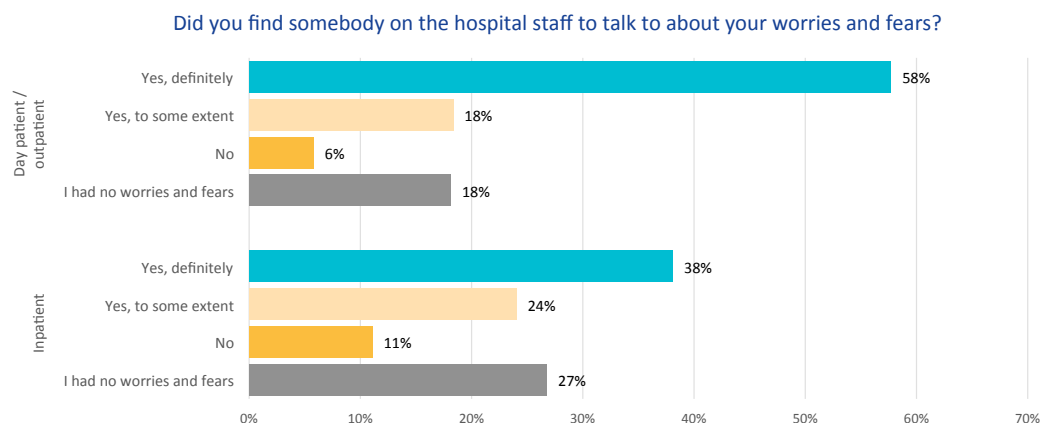
**74%** of respondents said that they had confidence and trust in all of the nurses treating them. **This is significantly higher than last year's score of 72%.**

**67%** of respondents said that, in their opinion, there were always or nearly always enough nurses on duty to care for them in hospital.

**68%** of respondents said that, while they were in hospital, all of the doctors and nurses asked them what name they prefer to be called by. **This is significantly higher than last year's score of 67%.**

**85%** of respondents said that they were always given enough privacy when discussing their condition or treatment.

**52%** of respondents said that, during their hospital visit, they definitely found someone on the hospital staff to talk to about their worries and fears.



**84%** of respondents said that hospital staff definitely did everything they could to help control their pain.

**88%** of respondents said that, overall, they were always treated with respect and dignity while they were in hospital.

**86%** of respondents said that they were given clear written information about what they should or should not do after leaving hospital. **This is significantly higher than last year's score of 84%.**

**94%** of respondents said that hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital.

## Hospital care as a day patient/outpatient

Most respondents (**91%**) said that they had been treated as an outpatient or day case for cancer care during the last 12 months.

**70%** of respondents said that, while they were being treated as an outpatient or day case, they definitely found someone on the hospital staff to talk to about their worries and fears.

**96%** of respondents said that, the last time they had an outpatients appointment with a cancer doctor, they had the right documents, such as medical notes, x-rays and test results.

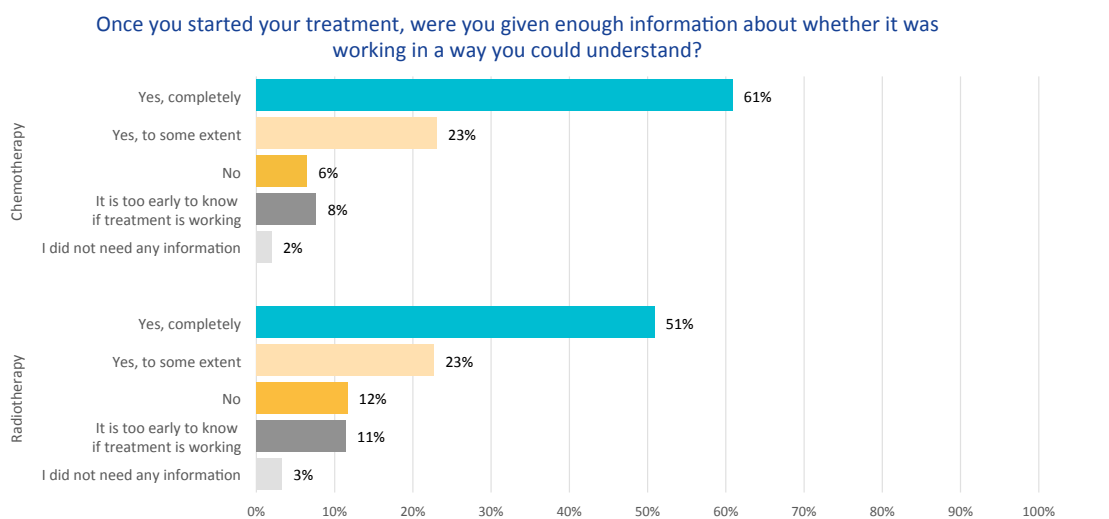
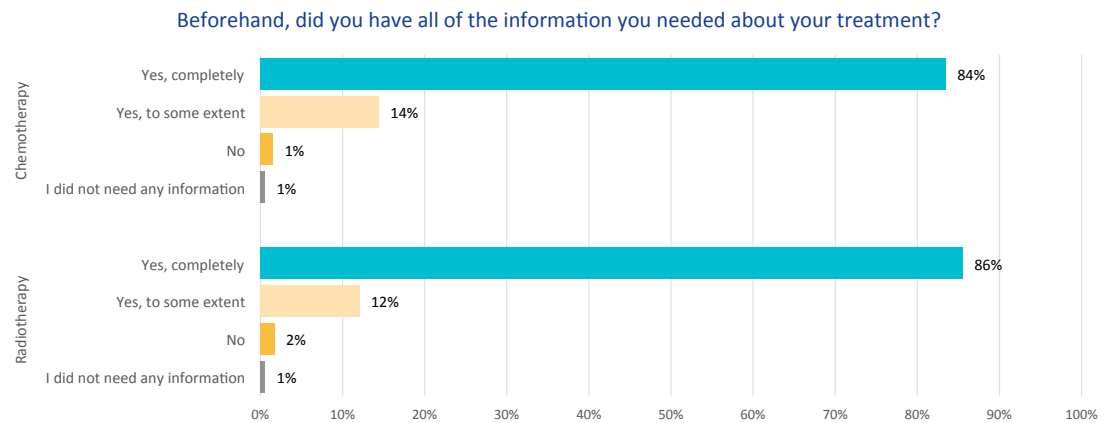
Of those respondents who said that they had had radiotherapy during the last 12 months:

- **86%** agreed completely that they had all the information they needed about their radiotherapy beforehand
- **60%** agreed completely that once they started their treatment they were given enough information about whether their radiotherapy was working, in a way they could understand.



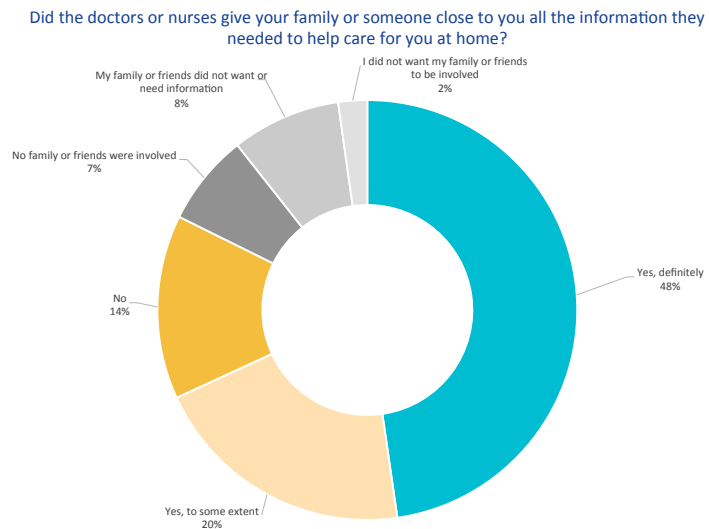
Of those respondents who said that they had had chemotherapy during the last 12 months:

- **84%** agreed completely that they had all the information they needed about their chemotherapy beforehand
- **67%** agreed completely that once they started their treatment they were given enough information about whether their chemotherapy was working, in a way they could understand.



## Home care and support

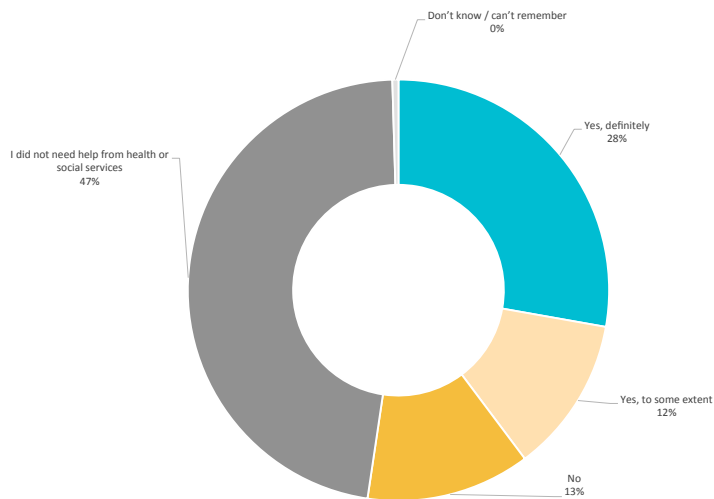
**58%** of respondents said that the doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home.



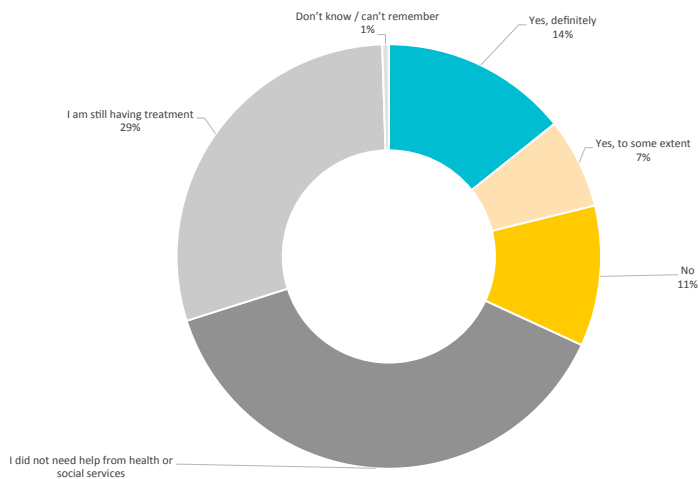


Respondents were asked whether they were given enough care and support from health or social services (*“for example, district nurses, home helps or physiotherapists”*). **53%** said that this was definitely the case during their cancer treatment; and **45%** said that this was definitely the case once their cancer treatment finished.

During your cancer treatment, were you given enough care and support from health or social services?



Once your cancer treatment finished, were you given enough care and support from health or social services?



## Care from your general practice

**95%** of respondents said that, as far as they knew, their GP was given enough information about their condition and the treatment they had at the hospital.

**62%** of respondents said that they thought the GPs and nurses at their general practice definitely did everything they could to support them while they were having cancer treatment.

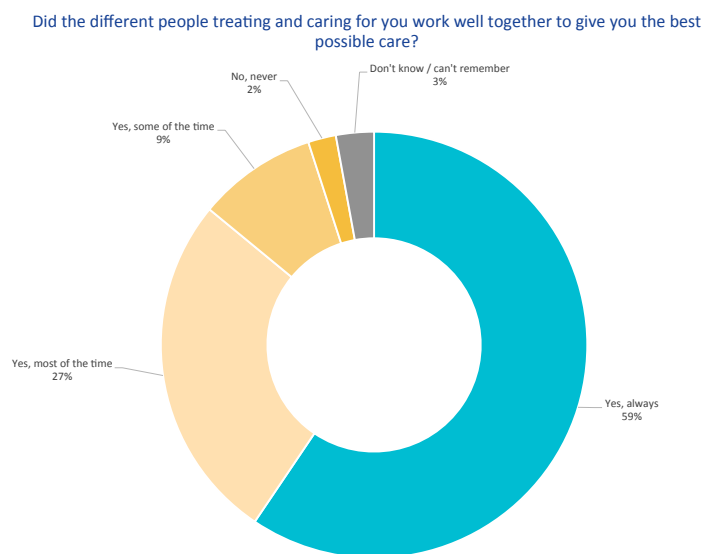
**This is significantly lower than last year's score of 63%.**



## Your overall NHS care

Respondents were asked whether the different people treating and caring for them (such as GPs, hospital doctors, hospital nurses, specialist nurses, and community nurses) worked well together to give them the best possible care.

**61%** of respondents said that this was always the case.

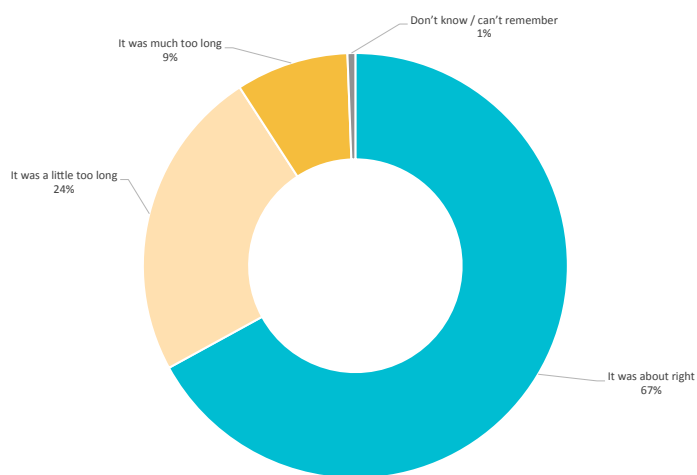


Respondents were asked whether they had been given a care plan. The questionnaire explained that this means: "A care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals". **33%** of respondents said that they had been given one.

When asked to rate the administration of their care ("getting letters at the right time, doctors having the right notes/test results, etc."), **89%** of respondents said that this was 'good' or 'very good'.

**67%** of respondents said they felt that the length of time they had to wait when attending clinics and appointments for their cancer treatment was about right. **This is significantly higher than last year's score of 66%.**

Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?



**29%** of respondents said that, since their diagnosis, someone had talked to them about whether they would like to take part in cancer research.

Asked to give an overall rating of their care on a scale of zero (very poor) to 10 (very good), **8.74** was the average rating from respondents. **This is significantly higher than last year's rating of 8.70.** **94%** of respondents who provided valid answers to this question gave a rating or 7 or higher.

## Comparisons between different groups of cancer patients

All of the national level data for the survey has been analysed across different patient groups, to establish whether there are any significant differences in their experience of cancer care. Specifically, we have looked at the impact of gender, ethnicity, age, deprivation and tumour group.

The analysis discovers statistically significant differences on very many questions in the survey, and across all of these sociodemographic factors. The full detail is available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

As a summary, we have looked in this report at the following questions:

- Q10** Did you understand the explanation of what was wrong with you?
- Q16** Were you involved as much as you wanted to be in decisions about your care and treatment?
- Q17** Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?
- Q18** How easy or difficult has it been for you to contact your Clinical Nurse Specialist?
- Q37** Overall, did you feel you were treated with respect and dignity while you were in hospital?
- Q39** Did the hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
- Q51** Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?
- Q53** Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?
- Q59** Overall, how would you rate your care?

Analysing by **gender**, there is no significant difference on question 39; but there are significant differences on all of the others. Female respondents reported a more positive experience on question 17; whilst on all of the others a more positive experience was reported by male respondents. The biggest difference is on question 51, where 48% of male respondents gave a positive response, compared to 42% of female respondents.

Analysing for significant differences by **ethnicity**, there is no significant difference on question 39; but there are significant differences on all of the others. Black respondents report the highest score on question 17; respondents who recorded their ethnicity in an "other" category report the highest score on question 37; white respondents report the highest scores on the six remaining questions. Respondents who recorded their ethnicity in an "other" category report the lowest score on question 17; respondents who recorded their ethnicity as "mixed" report the lowest score on question 37; Asian respondents report the lowest score on questions 53 and 59; black respondents report the lowest scores on the four remaining questions. The biggest difference is on question 51, where 45% of white respondents gave a positive response, compared to 30% of black respondents.

Analysing by **age**, there are significant differences on every question. Reported experience varies between age band on each question. Patients in age bands 45-54 and 55-64 have not had either the highest or the lowest score on any of the nine questions. For seven questions, the age band where patients report the lowest scores was one of the three age bands with patients under 45. Patients in the 85 and older age band reported the lowest scores on questions 17 and 39. For six questions, the age band where patients report the highest scores was one of the three age bands including only patients 65 and over. Patients in the 16-24 age band report the highest scores for questions 17, 18 and 39. The biggest difference is on question 10, where 77% of respondents aged 75 to 84 gave a positive response, compared to 52% of respondents aged 16 to 24.

Analysing by **deprivation**, there are significant differences between the least and most deprived groups of respondents on most questions (questions 17 and 18 are the exceptions), with the least deprived groups reporting the most positive experience. The biggest difference is on question 51, where 47% of respondents from the least deprived group gave a positive response, compared to 43% of respondents from the second most deprived group.

The widest range of scores is seen when analysing by different **tumour groups**, where there are significant differences with respect to the national average for one or more of the tumour groups for each of the nine questions. Patients with brain cancers report the lowest scores on five of the nine questions, including the overall quality of care question (question 59), with an average score of 8.35. Patients with melanoma report the highest scores in seven of the nine questions, including question 59, with an average score of 8.86 (the same score reported by patients with haematological cancers.)

Full data tables of these breakdowns and analyses are available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

## Detailed data

Full data tables of national and local data are available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

# Appendix

		2015	2016
<b>Q1</b>	<b>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?</b>		
	1 None - I went straight to hospital	10.0%	10.2%
	2 None - I went to hospital following a cancer screening appointment	11.0%	11.4%
	3 I saw my GP once	42.4%	42.6%
	4 I saw my GP twice	15.7%	15.5%
	5 I saw my GP 3 or 4 times	11.8%	11.2%
	6 I saw my GP 5 or more times	6.7%	6.5%
	7 Don't know / can't remember	2.5%	2.6%
<b>Q2</b>	<b>How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?</b>		
	1 I was seen as soon as I thought was necessary	82.3%	83.3%
	2 I should have been seen a bit sooner	10.6%	10.0%
	3 I should have been seen a lot sooner	7.1%	6.7%
<b>Q3</b>	<b>How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?</b>		
	1 Less than 3 months	79.5%	79.2%
	2 3-6 months	10.3%	10.1%
	3 6-12 months	3.3%	3.5%
	4 More than 12 months	2.6%	2.6%
	5 Don't know / can't remember	4.3%	4.6%
<b>Q4</b>	<b>In the last 12 months, have you had a diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?</b>		
	1 Yes	87.9%	87.8%
	2 No	12.1%	12.2%
<b>Q5</b>	<b>Beforehand, did you have all the information you needed about your test?<sup>6</sup></b>		
	1 Yes	-	92.5%
	2 No, I would have liked more information	-	5.6%
	3 Don't know / can't remember	-	1.9%
<b>Q6</b>	<b>Overall, how did you feel about the length of time you had to wait for your test to be done?</b>		
	1 It was about right	85.8%	86.6%
	2 It was a little too long	10.2%	9.6%
	3 It was much too long	3.1%	2.8%
	4 Don't know / can't remember	0.9%	1.0%

<sup>6</sup>Question 5 answer options changed for 2016 to enable the question to be scored. Comparisons cannot be made with the 2015 data.



		2015	2016
<b>Q7</b>	<b>Were the results of the test explained in a way you could understand?</b>		
	1 Yes, completely	78.1%	78.4%
	2 Yes, to some extent	19.1%	19.0%
	3 No, I did not understand the explanation	0.9%	0.8%
	4 I did not have an explanation but would have liked one	1.1%	1.0%
	5 I did not need an explanation	0.4%	0.4%
	6 Don't know / can't remember	0.4%	0.4%
<b>Q8</b>	<b>When you were first told that you had cancer, had you been told you could bring a family member or friend with you?<sup>7</sup></b>		
	1 Yes	-	71.3%
	2 No	-	20.6%
	3 I was told I had cancer by phone or letter	-	2.0%
	4 Don't know / can't remember	-	6.1%
<b>Q9</b>	<b>How do you feel about the way you were told you had cancer?</b>		
	1 It was done sensitively	84.3%	84.2%
	2 It should have been done a bit more sensitively	10.6%	10.7%
	3 It should have been done a lot more sensitively	5.1%	5.0%
<b>Q10</b>	<b>Did you understand the explanation of what was wrong with you?</b>		
	1 Yes, I completely understood it	72.7%	72.9%
	2 Yes, I understood some of it	24.9%	24.8%
	3 No, I did not understand it	1.9%	1.9%
	4 Don't know / can't remember	0.4%	0.4%
<b>Q11</b>	<b>When you were told you had cancer, were you given written information about the type of cancer you had?</b>		
	1 Yes, and it was easy to understand	63.3%	63.6%
	2 Yes, but it was difficult to understand	8.5%	8.5%
	3 No, I was not given written information about the type of cancer I had	16.6%	15.7%
	4 I did not need written information	7.1%	7.5%
	5 Don't know / can't remember	4.6%	4.8%
<b>Q12</b>	<b>Before your cancer treatment started, were your treatment options explained to you?</b>		
	1 Yes, completely	72.8%	73.0%
	2 Yes, to some extent	13.3%	13.5%
	3 No	1.9%	1.9%
	4 There was only one type of treatment that was suitable for me	11.3%	10.9%
	5 Don't know / can't remember	0.7%	0.7%

<sup>7</sup> Question 8 answer options changed slightly in 2016 to allow more meaningful analysis. Comparisons cannot be made with the 2015 data.

		2015	2016
<b>Q13</b>	<b>Were the possible side effects of treatment(s) explained in a way you could understand?</b>		
	1 Yes, definitely	70.0%	69.5%
	2 Yes, to some extent	22.3%	22.4%
	3 No, side effects were not explained	3.9%	4.0%
	4 I did not need an explanation	2.7%	2.9%
	5 Don't know / can't remember	1.1%	1.2%
<b>Q14</b>	<b>Were you offered practical advice and support in dealing with the side effects of your treatment(s)?</b>		
	1 Yes, definitely	64.1%	63.7%
	2 Yes, to some extent	26.3%	26.6%
	3 No, I was not offered any practical advice or support	6.4%	6.4%
	4 Don't know / can't remember	3.2%	3.3%
<b>Q15</b>	<b>Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?</b>		
	1 Yes, definitely	49.8%	49.7%
	2 Yes, to some extent	26.5%	26.5%
	3 No, future side effects were not explained	15.2%	15.1%
	4 I did not need an explanation	5.0%	5.2%
	5 Don't know / can't remember	3.5%	3.6%
<b>Q16</b>	<b>Were you involved as much as you wanted to be in decisions about your care and treatment?</b>		
	1 Yes, definitely	76.8%	76.9%
	2 Yes, to some extent	18.6%	18.5%
	3 No, but I would like to have been more involved	3.5%	3.4%
	4 Don't know / can't remember	1.1%	1.2%
<b>Q17</b>	<b>Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?</b>		
	1 Yes	87.2%	87.4%
	2 No	9.7%	9.4%
	3 Don't know / can't remember	3.1%	3.2%
<b>Q18</b>	<b>How easy or difficult has it been for you to contact your Clinical Nurse Specialist?</b>		
	1 Very easy	47.7%	47.2%
	2 Quite easy	29.2%	29.3%
	3 Neither easy nor difficult	6.6%	6.9%
	4 Quite difficult	4.0%	4.0%
	5 Very difficult	1.3%	1.3%
	6 I have not tried to contact my Clinical Nurse Specialist	11.2%	11.3%

		2015	2016
<b>Q19</b>	<b>When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?</b>		
	1 All or most of the time	75.5%	75.3%
	2 Some of the time	8.3%	8.3%
	3 Rarely or never	1.5%	1.6%
	4 I have not asked any questions	14.7%	14.8%
<b>Q20</b>	<b>Did hospital staff give you information about support or self-help groups for people with cancer?</b>		
	1 Yes	61.9%	62.8%
	2 No, but I would have liked information	12.7%	12.0%
	3 It was not necessary	21.0%	20.7%
	4 Don't know / can't remember	4.3%	4.4%
<b>Q21</b>	<b>Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?</b>		
	1 Yes	53.6%	53.5%
	2 No, but I would have liked a discussion or information	12.8%	12.4%
	3 It was not necessary / relevant to me	29.7%	30.3%
	4 Don't know / can't remember	3.8%	3.9%
<b>Q22</b>	<b>Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?</b>		
	1 Yes	29.1%	29.4%
	2 No, but I would have liked information	24.1%	22.7%
	3 It was not necessary	44.0%	45.1%
	4 Don't know / can't remember	2.8%	2.9%
<b>Q23</b>	<b>Did hospital staff tell you that you could get free prescriptions?</b>		
	1 Yes	38.1%	37.5%
	2 No, but I would have liked information	9.4%	9.1%
	3 It was not necessary	51.0%	51.9%
	4 Don't know / can't remember	1.5%	1.5%
<b>Q24</b>	<b>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?</b>		
	1 Yes	54.7%	55.1%
	2 No	45.3%	44.9%
<b>Q25</b>	<b>Beforehand, did you have all the information you needed about your operation?<sup>8</sup></b>	<b>8</b>	
	1 Yes	-	95.0%
	2 No, I would have liked more information	-	4.2%
	3 Don't know / can't remember	-	0.8%

<sup>8</sup> Question 25 answer options changed for 2016 to enable the question to be scored. Comparisons cannot be made with the 2015 data.

		2015	2016
<b>Q26</b>	<b>After the operation, did a member of staff explain how it had gone in a way you could understand?</b>		
	1 Yes, completely	76.8%	77.9%
	2 Yes, to some extent	18.3%	17.2%
	3 No, but I would have liked an explanation	3.8%	3.7%
	4 I did not need an explanation	1.1%	1.2%
<b>Q27</b>	<b>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?</b>		
	1 Yes	62.6%	61.6%
	2 No	37.4%	38.4%
<b>Q28</b>	<b>Did groups of doctors and nurses talk in front of you as if you weren't there?</b>		
	1 Yes, often	4.4%	4.5%
	2 Yes, sometimes	14.2%	13.7%
	3 No	81.3%	81.9%
<b>Q29</b>	<b>Did you have confidence and trust in the doctors treating you?</b>		
	1 Yes, in all of them	84.1%	84.7%
	2 Yes, in some of them	15.3%	14.7%
	3 No, in none of them	0.6%	0.6%
<b>Q30</b>	<b>If your family or someone else close to you wanted to talk to a doctor, were they able to?</b>		
	1 Yes, definitely	60.2%	61.0%
	2 Yes, to some extent	20.2%	19.5%
	3 No	3.2%	3.0%
	4 No family or friends were involved	6.4%	6.4%
	5 My family did not want to talk to a doctor	7.5%	7.7%
	6 I did not want my family or friends to talk to a doctor	2.5%	2.4%
<b>Q31</b>	<b>Did you have confidence and trust in the ward nurses treating you?</b>		
	1 Yes, in all of them	72.4%	74.1%
	2 Yes, in some of them	26.4%	24.8%
	3 No, in none of them	1.2%	1.1%
<b>Q32</b>	<b>In your opinion, were there enough nurses on duty to care for you in hospital?</b>		
	1 There were always or nearly always enough on duty	66.1%	66.7%
	2 There were sometimes enough on duty	26.9%	26.3%
	3 There were rarely or never enough on duty	7.0%	7.0%
<b>Q33</b>	<b>While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?</b>		
	1 Yes, all of them did	66.5%	67.7%
	2 Only some of them did	21.6%	21.0%
	3 None of them did	11.9%	11.4%

		2015	2016
<b>Q34</b>	<b>Were you given enough privacy when discussing your condition or treatment?</b>		
	1 Yes, always	84.8%	85.3%
	2 Yes, sometimes	12.3%	11.8%
	3 No	2.9%	2.9%
<b>Q35</b>	<b>During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?</b>		
	1 Yes, definitely	38.3%	38.1%
	2 Yes, to some extent	24.4%	24.0%
	3 No	11.1%	11.1%
	4 I had no worries or fears	26.2%	26.8%
<b>Q36</b>	<b>Do you think the hospital staff did everything they could to help control your pain?</b>		
	1 Yes, definitely	73.7%	73.4%
	2 Yes, to some extent	11.9%	11.8%
	3 No	2.3%	2.3%
	4 I did not have any pain	12.1%	12.6%
<b>Q37</b>	<b>Overall, did you feel you were treated with respect and dignity while you were in the hospital?</b>		
	1 Yes, always	87.5%	88.0%
	2 Yes, sometimes	11.2%	10.7%
	3 No	1.4%	1.3%
<b>Q38</b>	<b>Were you given clear written information about what you should or should not do after leaving hospital?</b>		
	1 Yes	79.5%	80.3%
	2 No	14.6%	13.5%
	3 Don't know / can't remember	5.9%	6.2%
<b>Q39</b>	<b>Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?</b>		
	1 Yes	90.4%	90.7%
	2 No	6.1%	5.9%
	3 Don't know / can't remember	3.5%	3.4%
<b>Q40</b>	<b>During the last 12 months, have you been treated as an outpatient or day case for cancer care at one of the hospitals named in the covering letter?</b>		
	1 Yes	91.1%	91.0%
	2 No	8.9%	9.0%
<b>Q41</b>	<b>While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?</b>		
	1 Yes, definitely	57.6%	57.7%
	2 Yes, to some extent	18.7%	18.3%
	3 No	5.9%	5.8%
	4 I did not have any worries or fears	17.8%	18.1%

		2015	2016
<b>Q42</b>	<b>The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?</b>		
	1 Yes	92.3%	92.4%
	2 No	4.3%	4.1%
	3 I didn't have an appointment with a cancer doctor	1.6%	1.6%
	4 Don't know / can't remember	1.8%	1.8%
<b>Q43</b>	<b>During the last 12 months, have you had radiotherapy at any of the hospitals named in the covering letter?</b>		
	1 Yes	28.4%	29.0%
	2 No	71.6%	71.0%
<b>Q44</b>	<b>Beforehand, did you have all of the information you needed about your radiotherapy treatment?</b>		
	1 Yes, completely	85.4%	85.6%
	2 Yes, to some extent	12.3%	12.1%
	3 No	1.6%	1.8%
	4 I did not need any information	0.6%	0.5%
<b>Q45</b>	<b>Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?</b>		
	1 Yes, completely	51.0%	50.9%
	2 Yes, to some extent	23.2%	22.7%
	3 No	11.4%	11.7%
	4 It is too early to know if my radiotherapy is working	11.4%	11.4%
	5 I did not need any information	3.1%	3.3%
<b>Q46</b>	<b>During the last 12 months, have you had chemotherapy at any of the hospitals named in the covering letter?</b>		
	1 Yes	57.3%	56.5%
	2 No	42.7%	43.5%
<b>Q47</b>	<b>Beforehand, did you have all of the information you needed about your chemotherapy treatment?</b>		
	1 Yes, completely	83.8%	83.5%
	2 Yes, to some extent	14.2%	14.5%
	3 No	1.4%	1.5%
	4 I did not need any information	0.5%	0.5%
<b>Q48</b>	<b>Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?</b>		
	1 Yes, completely	61.6%	60.9%
	2 Yes, to some extent	22.9%	23.1%
	3 No	6.3%	6.5%
	4 It is too early to know if my chemotherapy is working	7.6%	7.6%
	5 I did not need any information	1.6%	2.0%

		2015	2016
<b>Q49</b>	<b>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?</b>		
	1 Yes, definitely	47.6%	47.7%
	2 Yes, to some extent	20.9%	20.4%
	3 No	14.3%	14.2%
	4 No family or friends were involved	6.9%	7.1%
	5 My family or friends did not want or need information	8.1%	8.4%
	6 I did not want my family or friends to be involved	2.3%	2.2%
<b>Q50</b>	<b>During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?</b>		
	1 Yes, definitely	29.1%	27.8%
	2 Yes, to some extent	12.6%	12.0%
	3 No	12.5%	12.6%
	4 I did not need help from health or social services	45.3%	47.2%
	5 Don't know / can't remember	0.4%	0.5%
<b>Q51</b>	<b>Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?</b>		
	1 Yes, definitely	14.6%	14.3%
	2 Yes, to some extent	7.5%	6.9%
	3 No	10.6%	10.7%
	4 I did not need help from health or social services	37.0%	38.2%
	5 I am still having treatment	29.8%	29.4%
	6 Don't know / can't remember	0.5%	0.5%
<b>Q52</b>	<b>As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?</b>		
	1 Yes	80.1%	79.8%
	2 No	3.9%	4.0%
	3 Don't know / can't remember	16.0%	16.2%
<b>Q53</b>	<b>Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?</b>		
	1 Yes, definitely	44.5%	43.0%
	2 Yes, to some extent	18.1%	18.1%
	3 No, they could have done more	8.5%	8.7%
	4 My general practice was not involved	28.9%	30.2%
<b>Q54</b>	<b>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?</b>		
	1 Yes, always	59.0%	59.4%
	2 Yes, most of the time	26.9%	26.5%
	3 Yes, some of the time	9.3%	9.0%
	4 No, never	2.0%	2.1%
	5 Don't know / can't remember	2.8%	2.9%

		2015	2016
<b>Q55</b>	<b>Have you been given a care plan?</b>		
	1 Yes	26.4%	26.6%
	2 No	53.6%	53.3%
	3 I do not know / understand what a care plan is	12.3%	12.2%
	4 Don't know / can't remember	7.7%	8.0%
<b>Q56</b>	<b>Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?</b>		
	1 Very good	56.9%	57.5%
	2 Good	31.7%	31.4%
	3 Neither good nor bad	7.4%	7.3%
	4 Quite bad	2.5%	2.4%
	5 Very bad	1.1%	1.0%
	6 Don't know / can't remember	0.4%	0.4%
<b>Q57</b>	<b>Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?</b>		
	1 It was much too long	9.1%	8.6%
	2 It was a little too long	24.9%	23.8%
	3 It was about right	65.5%	67.0%
	4 Don't know / can't remember	0.6%	0.6%
<b>Q58</b>	<b>Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?</b>		
	1 Yes	27.3%	27.4%
	2 No	64.5%	64.0%
	3 No, but I would have liked them to	4.7%	4.8%
	4 Don't know / can't remember	3.5%	3.8%
<b>Q59</b>	<b>Overall, how would you rate your care?</b>		
	0	0.1%	0.1%
	1	0.2%	0.2%
	2	0.2%	0.2%
	3	0.5%	0.4%
	4	0.7%	0.6%
	5	2.1%	2.0%
	6	2.6%	2.5%
	7	7.6%	7.3%
	8	22.0%	20.9%
	9	29.6%	29.5%
	10	33.6%	35.1%
	not valid <sup>9</sup>	0.8%	1.1%

<sup>9</sup>“not valid” scores for Q59 are where respondents marked a range on the 0-10 scale, or more than one option. These haven't been included in the calculation for scoring.



Quality Health is a specialist health and social care survey organisation, working for public, private and not-for-profit sectors, in the UK and overseas.

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