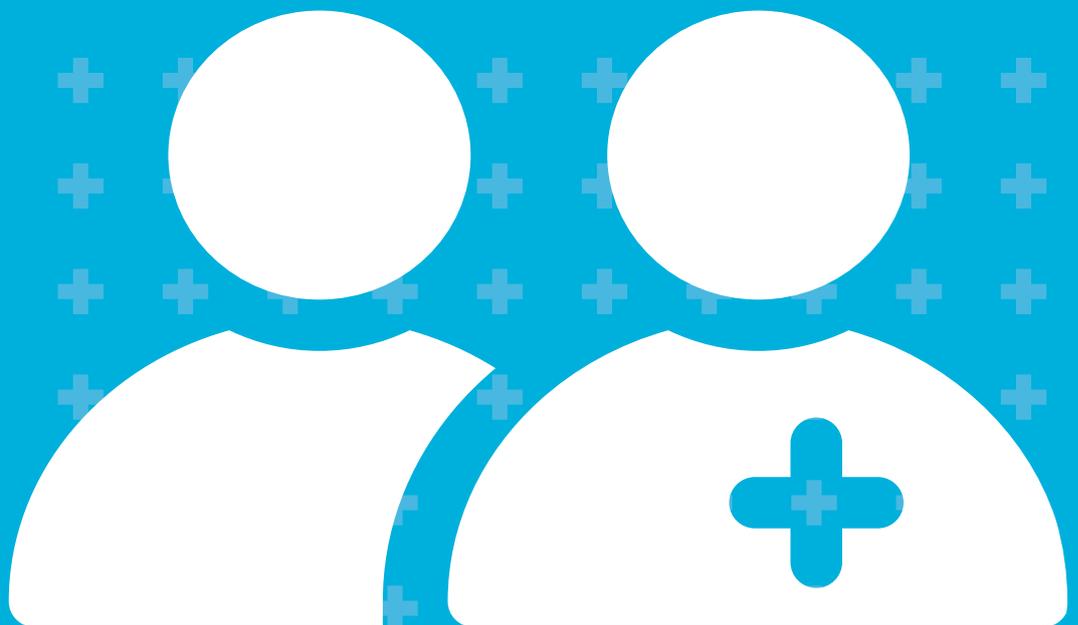


National Cancer Patient Experience Survey 2015

National Results Summary



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 2015 is the fifth 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



Executive Summary

The experience of cancer patients in England is 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.

The following questions are included in phase 1 of the Cancer Dashboard developed by Public Health England and NHS England*:

- **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
- when asked how easy or difficult it had been to contact their Clinical Nurse Specialist **87%** of respondents said that it had been 'quite easy' or 'very easy'
- **87%** of respondents said that, overall, they were always treated with dignity and respect 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
- **63%** 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 is not consistent, with some elements of care rated more positively than others. For example, patients appear to get more information on some areas (free prescriptions), than on others (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 hospital.

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

*www.cancerdata.nhs.uk/dashboard

On nearly half of questions, over
80%
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78%
were involved as much as they wanted to be in decisions about their 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 2015*.

The fieldwork for the survey was undertaken between October 2015 and March 2016.

For the first time, 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 for 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.

*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 **116,991** cancer patients. Of these, **8,086** had died since the sample was drawn, and so their details were removed. **506** patients could not be contacted as they had moved house. In a small number of cases (**127**) patients reported that they were not eligible to receive the questionnaire. The eligible sample size was therefore calculated as **108,272** patients, of whom **71,186** responded.

Completed questionnaires were received by post from **66,086** respondents (**92.8%** of responses); and **5,069** (**7.1%**) chose to complete their questionnaires online. **25** respondents called Quality Health's Freephone helpline to give their responses over the telephone; and a further **6** used Quality Health's translation/interpreting services to give their responses.

The overall response rate of **65.7%** 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 (**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



92.84%

online



7.12%

phone



0.04%

translation



0.01%

Comparisons with previous years

There have been significant changes to the questionnaire compared to previous years' surveys. Of the **50** questions that relate directly to patient experience, **15** are either new or substantially changed; **21** have been slightly amended; and only **14** remain entirely unchanged. However, even where questions remain entirely unchanged, changes in the questionnaire and its administration mean that comparisons with previous years should be treated with caution.

It is expected that there will be few, if any, changes to the questionnaire going forwards, so we expect that, in future publications, there will be full comparability over time on all questions.

Further details are available at 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 key variables: age, gender, ethnicity, deprivation, and tumour groups.

Subsequent publications will give a breakdown of results by Clinical Commissioning Group, and by NHS Trust (in both cases, showing unadjusted and Case Mix Adjusted results). Separate reports for each Clinical Commissioning Group, and each NHS Trust, will give individual results, and breakdown by tumour group at these local levels.

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



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, **76%** 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.

When asked how they felt about the length of time they had to wait before their first appointment with a hospital doctor, **82%** of respondents said that they were seen as soon as they thought was necessary.

Diagnostic tests

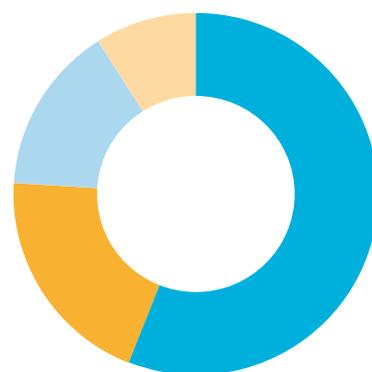
The majority of respondents (**88%**) said that they had had one or more diagnostic tests (such as an endoscopy, biopsy, mammogram, or scan) in the last 12 months.

When asked about their last diagnostic test, **89%** of those who responded said that they had all the information they needed about their test. **3%** said that they would have liked more written information; **3%** said that they would have liked more verbal information; and **1%** said they would have liked more written and more verbal information.

87% of respondents said that they felt the amount of time they had to wait for this (last) test to be done was about right.

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

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



Once	55%
Twice	20%
3/4 times	15%
5 + times	9%

Finding out what was wrong with you

70% 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. **19%** said that they were not told this and **10%** said that it was not necessary. **2%** said that they were first told they had cancer by phone or letter.

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.

72% 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 **19%** said that they were not given written information.

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.

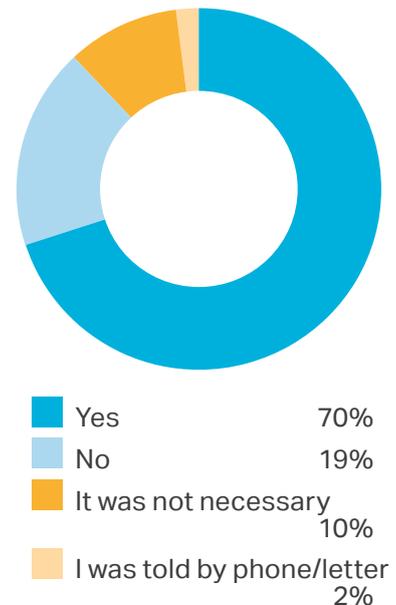
73% of respondents said that the possible side effects of treatment(s) were definitely explained to them in a way they could understand.

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

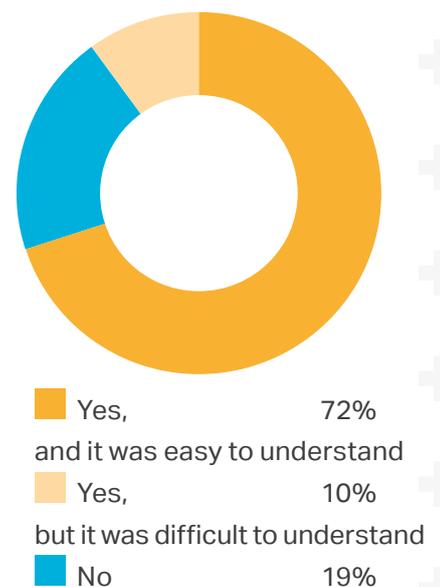
54% of respondents said that, before they started their treatment(s), they were definitely also told about any side effects of the treatment that could affect them in the future rather than straight away.

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

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



Were you given written information about the type of cancer you had?



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, **87%** 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.

90%
were given the name of
a Clinical Nurse Specialist

87%
said it was easy to contact
their Clinical Nurse Specialist

Support for people with cancer

83% of respondents said that hospital staff gave them information about support or self-help groups for people with cancer.

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"*).

55% of respondents said that hospital staff gave them information about how to get financial help or any benefits they might be entitled to.

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

Operations

Just over 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, **92%** of those who responded said that they had all the information they needed about their operation before it took place. **3%** said that they would have liked more written information; **2%** said that they would have liked more verbal information; and **1%** said they would have liked more written and more verbal information.

78% of respondents said that, after the operation, a member of staff explained how it had gone in a way they could completely understand.

Did hospital staff...

...give you information about support or self-help groups for people with cancer?

83%

...discuss with you or give you information about the impact cancer could have on your day to day activities?

81%

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

55%

...tell you that you could get free prescriptions?

80%

Hospital care as an inpatient

63% 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.

81% 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.

84% of respondents said that they had confidence and trust in all of the doctors treating them.

72% of respondents said that, if their family or someone else close to them wanted to talk to a doctor, they were definitely able to.

72% of respondents said that they had confidence and trust in all of the nurses treating them.

66% of respondents said that, in their opinion, there were always or nearly always enough nurses on duty to care for them in hospital.

67% 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.

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.

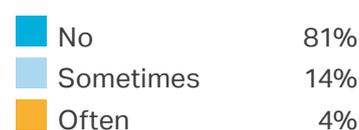
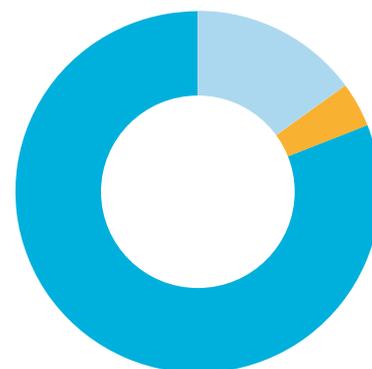
84% of respondents said that hospital staff definitely did everything they could to help control their pain.

87% of respondents said that, overall, they were always treated with dignity and respect while they were in hospital.

84% of respondents said that they were given clear written information about what they should or should not do after leaving 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.

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



87%
were always treated
with dignity and respect

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.

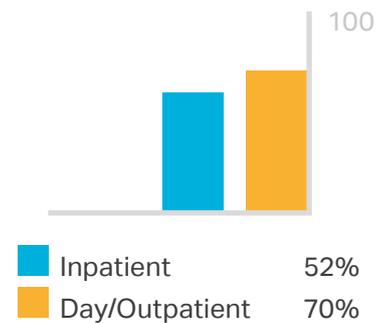
Of those respondents who said that they had had radiotherapy during the last 12 months:

- **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.

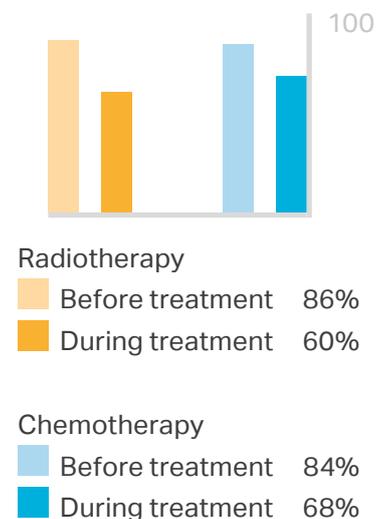
Of those respondents who said that they had had chemotherapy during the last 12 months:

- **84%** agreed completely that they had all the information they needed about their chemotherapy beforehand
- **68%** 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.

Did you find somebody on the hospital staff to talk to about your worries and fears?



Did you have all the information you needed?

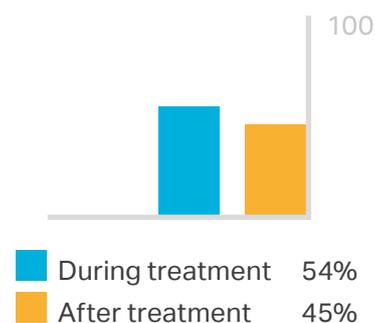


Home care and support

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”*). **54%** 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.

Were you given enough care or 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.

63% 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.



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 what 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'.

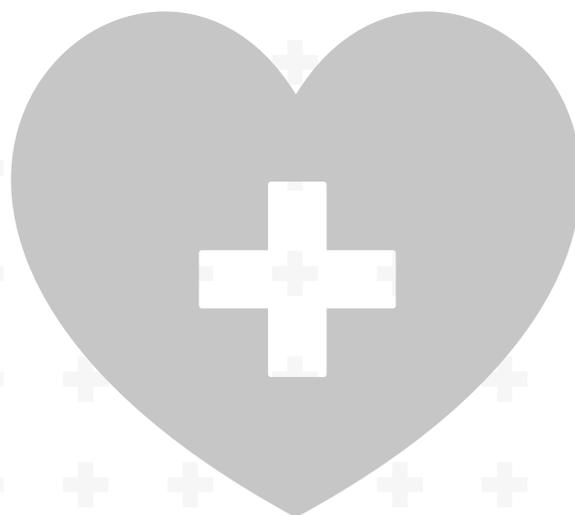
66% of respondents said they felt that the length of time they had to wait when attending clinics and appointments for their cancer treatment was about right.

28% of respondents said that, since their diagnosis, someone had talked to them about whether they would like to take part in cancer research.

When asked to give an overall rating of their care on a scale of zero (very poor) to 10 (very good), **8.7** was the average rating from respondents. **94%** of respondents gave a rating of 7 or higher.

Patients' overall rating
of their care was

8.7
out of 10



Quality Health is a specialist health and social care survey organisation,
working for public, private and non-for-profit sectors, in the UK and overseas.

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