Cancer Patient Experience Survey 2015
Summary of key national and local results
July 2016

Revised on 13 July 2016
A number of corrections have been made due to errors identified. We apologise for any inconvenience.
This section | Background
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Section 2 | National results
Section 3 | National results by demographics and tumour groups
Section 4 | Local results
The survey is based on a robust methodology with a high response rate.

**SURVEY**

Target population:
- All adult NHS patients with a primary diagnosis of cancer
- Patients in treatment in April, May and June 2015

Fieldwork: October 2015 to March 2016

Survey carried out by Quality Health on behalf of NHS England.

**RESPONSE RATE**

108,272 patients in eligible sample

71,186 patients responded

66% response rate
- This is similar to previous years and high for surveys of this nature
A number of improvements were made in 2015 including questionnaire redevelopment and …

Questionnaire redeveloped*

• Length reduced
• Response options consistent throughout survey
• Questions and/or response options in line with other patient surveys
• Topic areas capture whole patient journey

Online version of questionnaire made available

Data published as Official Statistics

*Click here for further details of CPES question changes from 2014 to 2015.
...changes to ensure greater comparability of results across local areas*.

More comparable results:

- Case-mix adjusted data presented for the first time
- Comparability charts based on expected ranges which are dependent on how many respondents a trust has and on the national score.

*Click here for further details of improvements made to the 2015 survey and their likely impact.
50 scored patient experience questions – a selection are presented in this slide pack*.

How to interpret the graphs:

The pie charts show results for each response option given in the question:
- Green = positive experience
- Red = negative experience
- Grey = options that do not provide any information on positive or negative experience i.e. don’t know/can’t remember

Overall care question on a scale of 0 to 10. Other questions assigned a score to reflect positive / negative experience.

Score presented reflects positive experience as a percentage of positive and negative experience excluding other options e.g. don’t know/can’t remember

*Full results can be found on the National Cancer Patient Experience Survey website.
Section 1  Background

This section  National results

Section 3  National results by demographics and tumour groups

Section 4  Local results
Care was generally positive across the Cancer Dashboard* indicators.

8.7 out of 10 overall rating of care

78% were involved as much as they wanted to be in decisions about their care and treatment

87% said overall they were always treated with dignity and respect while they were in hospital

90% reported being given the name of a Clinical Nurse Specialist (CNS) who would support them through treatment

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

87% who were given the name of a CNS and tried to make contact said that it had been very or quite easy to do so

63% reported they thought GPs and nurses at their general practice did everything they could to support them while they were having cancer treatment

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

*https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview

www.england.nhs.uk
Across all questions, some were rated more positively than others.

**Scored highest**

- The last time you had an outpatients appointment with a cancer doctor, did they have the right information, such as medical notes, x-rays and test results?
  - 96%

- As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?
  - 95%

- Beforehand, did you have all the information you needed about your operation?
  - 94%

- Did the hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
  - 94%

**Scored lowest**

- During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?
  - 52%

- 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)?
  - 45%

- Have you been given a care plan?
  - 33%

- Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?
  - 28%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
Three quarters of GP-referred patients saw their GP once or twice before being referred for cancer.

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?

- I saw my GP 5 or more times: 7%
- I saw my GP 3 or 4 times: 12%
- I saw my GP twice: 16%
- I saw my GP once: 42%
- Don't know / can't remember: 2%
- None - I went straight to hospital: 10%
- None - I went to hospital following a cancer screening appointment: 11%

Score: 75.8%

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

- I was seen as soon as I thought was necessary: 82%
- I should have been seen a lot sooner: 7%
- I should have been seen a bit sooner: 11%

Score: 82.3%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.
Just under 1 in 6 patients reported that the way they were told they had cancer should have been done more sensitively.

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
Patients appear to get more information on some areas (day-to-day activities) than on others (benefits).

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

- Yes, I completely understood it: 73%
- Yes, I understood some of it: 25%
- No, I did not understand it: 2%
- Don't know / can't remember: 0%

**Score 73.1%**

**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)?
  - Score 54.7%
  - Yes: 29%
  - No, but I would have liked (a discussion or) information: 24%
  - It was not necessary (/ relevant to me): 44%
  - Don't know / can't remember: 3%

- how to get financial help or any benefits you might be entitled to?
  - Score 80.7%
  - Yes: 54%
  - No, but I would have liked (a discussion or) information: 13%
  - It was not necessary (/ relevant to me): 30%
  - Don't know / can't remember: 4%

*Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.*
Three-quarters of patients felt they were definitely involved in decisions about care and treatment.

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

- Yes, completely: 73%
- Yes, to some extent: 13%
- No: 2%
- Don't know / can't remember: 1%
- There was only one type of treatment that was suitable for me: 11%

Score: 82.7%

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

- Yes, definitely: 77%
- No, but I would like to have been more involved: 4%
- Don't know / can't remember: 1%

Score: 77.6%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
Experiences with a Clinical Nurse Specialist appeared to be very positive.

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

- Yes: 87%
- No: 10%
- Don't know / can't remember: 3%

Score 89.9%

How easy or difficult has it been for you to contact your Clinical Nurse Specialist?

- Very easy: 48%
- Quite easy: 29%
- Neither easy nor difficult: 7%
- Quite difficult: 4%
- Very difficult: 1%
- I have not tried to contact my Clinical Nurse Specialist: 11%

Score 86.6%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
Confidence and trust were higher in doctors than ward nurses.

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

- Yes, in some of them: 15%
- No, in none of them: 1%
- Yes, in all of them: 84%

Score: 84.1%

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

- Yes, in some of them: 26%
- No, in none of them: 1%
- Yes, in all of them: 72%

Score: 72.4%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
A significant minority of patients did not feel they were always treated with respect and dignity.

Overall, did you feel you were treated with respect and dignity while you were in hospital?

- Yes, always: 87%
- Yes, sometimes: 11%
- No: 1%

Score: 87.5%

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

- Yes: 90%
- Don't know / can't remember: 3%
- No: 6%

Score: 93.7%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
Experience of information provision before an operation was particularly positive.

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

- Yes: 92%
- No, I would have liked more written information: 3%
- No, I would have liked more verbal information: 2%
- Both 2. and 3.: 1%

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

- Yes, completely: 77%
- Yes, to some extent: 18%
- No, but I would have liked an explanation: 4%
- I did not need an explanation: 1%

Score: 77.6%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

*Not scored. Multiple response option question.

www.england.nhs.uk
Information about radiotherapy appears to be better before treatment than during it…

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

Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
...this was also the case for chemotherapy.

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

- Yes, to some extent: 14%
- No: 1%
- I did not need any information: 1%

Score: 84.3%

Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?

- Yes, to some extent: 23%
- No: 6%
- It is too early to know if my chemotherapy is working: 8%
- I did not need any information: 2%

Score: 67.8%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
Care and support at home appears to be less positively experienced than care received in hospital.

During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?

- I did not need help from health or social services: 45%
- Yes, definitely: 29%
- Yes, to some extent: 13%
- No: 13%
- Don't know / can't remember: 1%

Score: 53.7%

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)?

- I am still having treatment: 30%
- I did not need help from health of social services: 37%
- Yes, definitely: 15%
- Yes, to some extent: 8%
- No: 11%
- Don't know / can't remember: 1%

Score: 44.8%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
Experience of transition of care was mixed.

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

- Yes, always: 59%
- Yes, most of the time: 27%
- Yes, some of the time: 9%
- No, most of the time: 2%
- No, never: 2%
- Don't know / can't remember: 3%
- My family or friends did not want or need information: 8%
- No family or friends were involved: 7%
- I did not want my family or friends to be involved: 2%
- Yes, to some extent: 21%
- Yes, definitely: 48%

Score: 57.5%

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?

Score: 60.7%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.
A significant proportion of patients were not given a care plan or did not know/understand what it is.

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

www.england.nhs.uk
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This section  National results by demographics and tumour groups

Section 4  Local results
Scores for involvement in decisions and support from GP were significantly lower for other ethnic groups.

Cancer Dashboard indicators*

Overall, how would you rate your care? (average score)***

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?

How easy or difficult has it been for you to contact your Clinical Nurse Specialist?***

Overall, did you feel you were treated with respect and dignity while you were in hospital?***

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?***

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

*https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview

** Includes other white backgrounds

*** Statistically significant differences

www.england.nhs.uk
Those aged 75 & over generally had more positive experiences than 55-64 year olds across the Cancer Dashboard indicators*. 

Cancer Dashboard indicators – selected age groups**

<table>
<thead>
<tr>
<th>Question</th>
<th>Score 55-64</th>
<th>Score 75 &amp; over</th>
<th>Score Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall, how would you rate your care? (average score)***</td>
<td>8.6</td>
<td>8.8</td>
<td>8.7</td>
</tr>
<tr>
<td>Were you involved as much as you wanted to be in decisions about your care and treatment? ***</td>
<td>76%</td>
<td>79%</td>
<td>78%</td>
</tr>
<tr>
<td>Were you given the name of a Clinical Nurse Specialist who would support you through your treatment? ***</td>
<td>92%</td>
<td>86%</td>
<td>90%</td>
</tr>
<tr>
<td>How easy or difficult has it been for you to contact your Clinical Nurse Specialist? ***</td>
<td>85%</td>
<td>89%</td>
<td>87%</td>
</tr>
<tr>
<td>Overall, did you feel you were treated with respect and dignity while you were in hospital? ***</td>
<td>85%</td>
<td>91%</td>
<td>87%</td>
</tr>
<tr>
<td>Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?</td>
<td>93%</td>
<td>93%</td>
<td>94%</td>
</tr>
<tr>
<td>Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment? ***</td>
<td>60%</td>
<td>66%</td>
<td>63%</td>
</tr>
</tbody>
</table>

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

* Results for all age groups are available at [http://www.ncpes.co.uk/index.php/reports/national-reports/2488-cpes-2015-national-results/file](http://www.ncpes.co.uk/index.php/reports/national-reports/2488-cpes-2015-national-results/file). These age groups have been selected to match age groups used by the Office for National Statistics in cancer survival analysis.

**https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview

*** Statistically significant differences

www.england.nhs.uk

25
Patients with skin and brain/CNS tumours were the most and least satisfied overall respectively.

Overall, how would you rate your care? (average score)

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

*Statistically significantly different from ‘all cancers’
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On overall experience, 21 and 27 CCGs scored better and worse than most other CCGs respectively.

**Variation across Cancer Dashboard indicators** (case-mix adjusted scores) - CCGs

| Number of CCGs that scored better/worse than most other CCGs** |
|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Better              | 21                  | 12                  | 25                  | 16                  | 12                  | 9                   | 21                  |
| Worse               | 27                  | 13                  | 26                  | 20                  | 15                  | 12                  | 25                  |

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

* [https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview](https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview)

** Based on expected range.
Across the survey, questions with the highest and lowest variation (case-mix adjusted scores) - CCGs

Based on the questions with the highest number of outliers. Outliers are defined as CCGs scoring better or worse than expected when compared with most other trusts in the survey.

<table>
<thead>
<tr>
<th>Question</th>
<th>Number of outliers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Highest variation</strong></td>
<td></td>
</tr>
<tr>
<td>Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?</td>
<td>56</td>
</tr>
<tr>
<td>When you were first told you had cancer, had you been told you could bring a family member or friend with you?</td>
<td>53</td>
</tr>
<tr>
<td>Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?</td>
<td>51</td>
</tr>
<tr>
<td><strong>Lowest variation</strong></td>
<td></td>
</tr>
<tr>
<td>Were you given enough privacy when discussing your condition or treatment?</td>
<td>11</td>
</tr>
<tr>
<td>Did you understand the explanation of what was wrong with you?</td>
<td>13</td>
</tr>
<tr>
<td>Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?</td>
<td>14</td>
</tr>
</tbody>
</table>

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.
On overall experience, 17 and 19 trusts scored better and worse than most other trusts respectively.

Variation across Cancer Dashboard indicators* (case-mix adjusted scores) - trusts

| Number of trusts that scored better/worse than most other trusts** |
|---|---|---|---|---|---|---|---|
| Better | 17 | 16 | 15 | 9 | 7 | 12 | 17 |
| Worse  | 19 | 12 | 17 | 11 | 14 | 14 | 13 |

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

* [https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview](https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview)

** Based on expected range.

[www.england.nhs.uk](http://www.england.nhs.uk)
Across the survey, the question with the lowest variation across trusts concerned provision of information and radiotherapy.

Across the survey, questions with the highest and lowest variation (case-mix adjusted scores) - trusts

Based on the questions with the highest number of outliers. Outliers are defined as trusts scoring better or worse than expected when compared with most other trusts in the survey.

<table>
<thead>
<tr>
<th>Question</th>
<th>Number of outliers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Highest variation</strong></td>
<td></td>
</tr>
<tr>
<td>When you were first told you had cancer, had you been told you could bring a family member or friend with you?</td>
<td>41</td>
</tr>
<tr>
<td>Did hospital staff give you information about support or self-help groups for people with cancer?</td>
<td>38</td>
</tr>
<tr>
<td>Did the different people treating and caring for you work well together to give you the best possible care?</td>
<td>38</td>
</tr>
<tr>
<td><strong>Lowest variation</strong></td>
<td></td>
</tr>
<tr>
<td>Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?</td>
<td>10</td>
</tr>
<tr>
<td>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?</td>
<td>14</td>
</tr>
<tr>
<td>Were the results of the test explained in a way you could understand?</td>
<td>16</td>
</tr>
<tr>
<td>How do you feel about the way you were told you had cancer?</td>
<td>16</td>
</tr>
<tr>
<td>Beforehand, did you have all the information you needed about your chemotherapy treatment?</td>
<td>16</td>
</tr>
</tbody>
</table>

Options that do not provide any information on positive or negative experience (e.g. “don't know / can't remember”) are excluded from the scores.

www.england.nhs.uk