

# **National Cancer Patient Experience Survey 2015**

## **Technical Documentation for CCG-level and Trust-level results**

**July 2016**

***Revised 17<sup>th</sup> August 2016***

<b>Report Revisions</b>
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Report Name:	National Cancer Patient Experience Survey 2015 Technical Documentation for CCG-level and Trust-level results
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Reason for revisions:	Further quality assurance conducted after initial publication. Tumour Group table found to be a working version not consistent with final mappings used for analysis. A small numbers of typos also identified.
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<b>Detail of revisions made</b>		
Report Section	Page	Revision
5. Expected Values and Comparability Charts	13	3 typos corrected where text previously said "repots", replaced with "reports"
6. Tumour Groups	16-17	Table replaced with correct version

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## 1. Introduction

This document sets out the methodology used in the analysis of the response data to the 2015 National Cancer Patient Experience Survey, and gives some guidance on how to interpret the results. This includes how percentage scores have been derived for individual questions (**section 2**); and how statistical confidence intervals around those scores have been calculated (**section 4**).

For the first time this year, a number of new statistical approaches have been used to analyse the data:

- Case-mix adjustment has been used to allow us to account for the impact that differing patient populations might have on results (looking at age, gender, ethnicity, deprivation and tumour group). This is described in **section 3**
- “Expected Ranges” have been calculated for each organisation, for each question, in order to report comparative performance between organisations and to produce the Comparability Charts that are published in the Trust- and CCG-level reports. These are based on the approach used by the Care Quality Commission for other national patient surveys, and are described in **section 5**.

These methods make comparisons between Trusts, and between CCGs, more robust. However, because of significant improvements to the survey this year, and changes to the sampling and fieldwork period, we recommend caution in making any comparison between 2015 and previous years, even on similar questions.

All of the national and local-level results, and further background material to the survey, are available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

For further information on the methodology and details of the statistical analysis, please contact [info@quality-health.co.uk](mailto:info@quality-health.co.uk).

*We acknowledge the work of Dr Gary Abel, Senior Lecturer in Statistics at the University of Exeter, in the development of the case-mix adjustment protocol and his technical advice on the implementation of the 'CQC' method for outlier identification; and input by Dr Yoryos Lyratzopoulos, Reader in Cancer Epidemiology at University College London.*

## 2. Scoring

### Introduction

Scores have been presented for the 50 questions in the questionnaire that relate directly to patient experience. For most questions, these have been presented as the percentage of responses which were positive.

### Positive, negative and neutral scores

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).

For example, for question 7 in the survey, asking about the explanation of test results, the following scoring approach is used:

Question	Answer option		Scoring key (1=positive, 0=negative, blank=neutral)
Were the results of the test explained in a way you could understand?	1	Yes, completely	1
	2	Yes, to some extent	0
	3	No, I did not understand the explanation	0
	4	I did not have an explanation but would have liked one	0
	5	I did not need an explanation	
	6	Don't know / can't remember	

In this case, answer option 1 has been identified as the only positive answer, and included in both the numerator and denominator for the scoring calculation. Answer options 2, 3 and 4 have been identified as negative answers, and are included only in the denominator for the calculation. Answer options 5 and 6 have been identified as neutral scores, and are excluded from the scoring calculation (i.e. not included in either the numerator or denominator).

Full tables showing the mapping of positive, negative and neutral scores for all questions are included within the CCG- and Trust-level data tables at [www.ncpes.co.uk](http://www.ncpes.co.uk).

A copy of the questionnaire itself, with these scores marked up in the same way for each question, is also available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

## **Alternative approaches for other questions**

### *Question 59*

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.

### *Question 5*

Question 5 asks respondents to "tick all that apply". Scores have not been calculated for this question, but a breakdown of results is given in the local reports for each organisation. The numbers shown in the reports for this question only show all of the responses given, including where respondents chose two or more options.

### 3. Case-mix Adjustment

#### Introduction and rationale

From detailed analyses of previous iterations of the National Cancer Patient Experience Survey (and from other patient surveys), we know that different demographic groups tend to report their experience of care differently. For example, previous analysis indicates: that women generally report a significantly less positive experience than men; that black and Asian patients report a less positive experience than white patients on many questions; and that there are significant differences in the experiences reported by patients with different types of cancer.

Because the mix of patients varies between organisations (for example, one Trust may serve a considerably older population than another; and one CCG might be in a more deprived area than another), this could potentially lead to the results for an organisation appearing better or worse than they would if they had a slightly different profile of patients.

Case-mix adjustment is a methodology for ‘standardising’ the data to account for these differences, to allow comparisons to be made more fairly.

#### What they should be used for

Case-mix adjusted scores, alongside the case-mix adjusted confidence intervals, should be used when comparing scores between different organisations.

#### How to interpret the results

The case-mix adjusted scores are the score we would expect a Trust or CCG to obtain had their case-mix of respondents been the same as that of the whole survey.

The following example is from the unadjusted scores for an organisation with 500 respondents to question 7 in the survey, asking about the explanation of test results.

Question	Numbers of responses	Unadjusted score	Case-mix adjusted score	National average score
Were the results of the test explained in a way you could understand?	500	79%	77%	78%

In this case, the unadjusted score is 79%, slightly higher than the national average of 78%. But once the characteristics of the organisation’s population are taken into account, the case-mix adjusted score is below the national average, at 77%. It is this second figure which should be used when making comparisons between different organisations.

## Methodology

The following variables were used in the case-mix adjustment: age, gender, ethnicity, cancer type and deprivation. In detail:

- Age was derived from the sample data provided by Trusts (year of birth), categorised into a number of age bands: “16 to 24”; “25 to 34” and similar ten-year age bands to “75 to 84”; and “85+”
- Gender was taken from the sample data provided by Trusts
- Ethnicity was derived from patient responses to question 69 in the questionnaire, categorised into the following broader groups: Asian, black, mixed, other, white, not given
- Cancer type was derived from 3-digit ICD10 codes provided in the sample data from Trusts (the mapping is shown separately in Section 6 of this document)
- Deprivation uses Index of Multiple Deprivation (IMD) quintiles, derived from mapping the postcode provided in the sample data provided by Trusts against its local super output area (LSOA) using the ONS postcode directory file of February 2016. The full 2015 Index of Multiple Deprivation (IMD) score and hence quintile for each postcode was obtained from files linking the LSOAs to IMD scores from <http://opendatacommunities.org/def/concept/general-concepts/imd>.

### *Case-mix adjustment for Trusts, and for CCGs*

The case-mix adjustment methodology chosen uses a logistic regression model to quantify the impact of each of the five variables above on each of the scored questions in the questionnaire. This produces a statistical case-mix adjustment model for each question. This is based on the 2013 paper produced by Abel, Saunders & Lyratzopoulos<sup>1</sup>.

These individual models were then run for each question to produce a case-mix adjusted score that takes account of how the demographics of an individual Trust differ from the national average (for a Trust with exactly the same demographics as the national average, the case-mix adjusted score would be the same as the unadjusted score).

A similar process was run for each CCG. Although there are 222 CCG codes represented in the overall data file, a small number of responses (396 out of 71,186) were received from patients who were resident in parts of the UK outside of England (e.g. patients resident just inside the Welsh border, but treated at a Trust in England). These records were removed from the CCG analysis (although retained for the Trust-level analysis), reducing the number of CCGs to 209.

Some questions had a zero response from a few organisations (CCGs and/or Trusts). These organisations were removed from the modelling process for these individual questions.

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<sup>1</sup> Abel, Saunders & Lyratzopoulos, *Future Oncol.* (2014) 10(9) , “Cancer patient experience, hospital performance and case mix: evidence from England”, <http://www.futuremedicine.com/doi/pdf/10.2217/fon.13.266>



*Question 59 – the overall experience question*

For question 59, which is an average score, a different approach is necessary. The same five variables are used, and a similar process, but this time the case-mix adjustment methodology chosen uses a linear (rather than logistic) regression model.

## 4. Confidence Intervals

### Introduction and rationale

The single percentage figures given as a score for each organisation for each question are an estimate of the score from that population, based on the responses received. Assuming the sample is representative of the organisation, confidence intervals are a method of describing the uncertainty around these estimates. The most common methodology, which has been used here, is to produce and report 95 per cent confidence intervals around the results. At the 95 per cent confidence level, on average, the confidence interval is expected to contain the true value 95 per cent of the time.

### What they should be used for

Confidence intervals should be used to understand and describe the accuracy of a single point score for a question.

### How to interpret the results

The following example is from the unadjusted scores for an organisation with 500 respondents to question 7 in the survey, asking about the explanation of test results.

Question	Numbers of responses	Lower 95% Confidence Interval	Unadjusted Score	Upper 95% Confidence Interval
Were the results of the test explained in a way you could understand?	500	75%	79%	82%

In this case, the unadjusted score is 79%, and the confidence interval is calculated as between 75% and 82%. In other words, we could say that “It is 95% certain that the score for this organisation lies between 75% and 82%.”

### Methodology

Confidence intervals for unadjusted scores for all questions have been calculated using Wilson’s Confidence Intervals. This particular approach has been chosen as it is more robust for small numbers (both numerators and denominators), and for results close to 0% or 100%.

For case-mix adjusted scores, confidence intervals have been calculated using a binomial approach with Wilson adjustment.

*Question 59 – the overall experience question*

For question 59, which is an average score, a different approach is necessary. For unadjusted scores, confidence intervals in this case are +/- 1.96 standard errors, which are calculated by:

$$\text{S.E.} = \frac{\sigma}{\sqrt{N}}$$

where  $\sigma$  is the standard deviation of responses for that particular organisation.

For case-mix adjusted scores, +/- 1.96 standard errors are again used, derived as a by-product of the regression routine itself.

## 5. Expected Values and Comparability Charts

### Introduction and rationale

For this year's publication, we have adopted the Care Quality Commission<sup>2</sup> standard for reporting comparative performance, based on calculation of expected ranges, adjusted for over-dispersion.

A standard technique for comparing organisations' performance to the national mean is to identify the range of scores (for a given size of organisation) outside of which there is evidence that the score is different to the national mean (i.e. it is statistically significantly different). The problem with this method is that when the sample size is large and standard errors on organisational scores are small a large number of organisations may be flagged as outliers even when their score is close to the national mean. This variation in organisational performance gives rise to over-dispersion, i.e. there is more variation in the scores than described by the binomial distribution.

By identifying and quantifying the real variation between organisations (rather than that due to chance) we can then calculate an expected range of scores. This expected range is the range of scores expected for organisations of a given sample size to lie within if their underlying performance (rather than measured performance) was within the core of the distribution of performance between organisations.

So the organisations outside this range are flagged as outliers and have scores that are not expected for most organisations. The method is a way of fairly treating organisations of different sizes in the presence of natural variation between them.

The methodology to detect over-dispersion is described in detail in the methodology section that follows. Its purpose is to allow organisations of different sizes to be judged equally.

### What they should be used for

For an individual organisation, expected values and comparability charts should be used to compare to the national distribution.

### How to interpret the results

The following example shows the scores for an organisation with 500 respondents to question 7 in the survey, asking about the explanation of test results.

Question	Numbers of responses	Case-mix adjusted scored percentage	Performance rating	Expected range (lower)	Expected range (upper)
Were the results of the test explained in a way you could understand?	500	84%	1	76%	80%

<sup>2</sup> [https://www.cqc.org.uk/sites/default/files/inpatient\\_survey\\_technical\\_document.pdf](https://www.cqc.org.uk/sites/default/files/inpatient_survey_technical_document.pdf)

In this case, the expected range calculated for this organisation is between 76% and 80%. The case-mix adjusted score is 84%, which is above the expected range. This organisation is therefore performing at a *higher* level than expected on this question. We have flagged the performance rating in such cases as dark blue (in the local CCG- and Trust-level reports, and in the Data Tables).

The following example shows how we would report the score for the same organisation if it were 75%.

Question	Numbers of responses	Case-mix adjusted scored percentage	Performance rating	Expected range (lower)	Expected range (upper)
Were the results of the test explained in a way you could understand?	500	75%	3	76%	80%

In this case, the expected range calculated for this organisation is still between 76% and 80%. The case-mix adjusted score is 75%, which is *below* the expected range. This organisation is therefore performing at a lower level than expected on this question. We have flagged the performance rating in such cases as pale blue (in the local CCG- and Trust-level reports, and in the Data Tables).

The following example shows the scores for another, smaller, organisation, with 100 respondents, to the same question.

Question	Numbers of responses	Case-mix adjusted scored percentage	Performance rating	Expected range (lower)	Expected range (upper)
Were the results of the test explained in a way you could understand?	100	75%	2	74%	82%

In this case, the expected range calculated for this organisation is wider (as the results are less certain because the sample size is smaller), between 74% and 82%. The case-mix adjusted score is 75%, which is within the expected range. This organisation is therefore performing *within* the expected range on this question. We have flagged the performance rating in such cases as grey (in the local CCG- and Trust-level reports, and in the Data Tables).

This illustrates how reducing smaller sample size will widen the expected range of results, due to the increased influence of chance. Hence a given score could be inside the expected range for one organisation and outside it for another if their sample sizes differ.

It is important to note that the second two examples show different organisations with the same case-mix adjusted scores, but different performance ratings – due to the different levels of statistical uncertainty around the scores.

## Methodology<sup>2</sup>

The calculations use three steps: (1) testing for over-dispersion; (2) adjusting for over-dispersion; and (3) identifying the expected range, and assigning a performance rating. These are described in detail below.

### *Testing for over-dispersion*

For each organisation, for each question, the standard error (S.E.<sub>ij</sub>) around the national figure (p<sub>Nj</sub>) is calculated using the number of responses (n<sub>ij</sub>), as follows:

$$S.E._{ij} = \sqrt{(p_{Nj} \times (1 - p_{Nj})) / n_{ij}}$$

Z-scores (Z<sub>ij</sub>) are calculated, as follows:

$$Z_{ij} = (p_{ij} - p_{Nj}) / S.E._{ij}$$

The z-scores are ranked within each question. The z-scores of those in the bottom 20% are set to be equal to the z-score of the 20<sup>th</sup> percentile. Similarly, the z-scores of those in the top 80% are set to be equal to the z-score of the 80<sup>th</sup> percentile (a process known as Windsorisation). These adjusted z-scores are squared and  $\phi$  is calculated for each question by summing the squares and dividing by the number of relevant organisations (CCGs or Trusts), i.e. by 209 or 148. For example, for CCGs:

$$\phi = \sum Z_{adj}^2 / N$$

From this, if

$$N \times \phi > N-1$$

then the scores are taken to be over-dispersed and need adjustment. If not, the scores are assumed to not be over-dispersed and the original z-scores can be used.

### *Adjusting for over-dispersion*

Where over-dispersion has been identified across organisations, within a question, then there is a need to estimate the expected variance between organisations. This is done by calculating the standard deviation of individual CCG or Trust scores.

First, we calculate for each organisation within the question under consideration:

$$w_i = 1 / S.E._i^2$$

Then,  $\tau^2$  is calculated from:

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<sup>2</sup> [https://www.cqc.org.uk/sites/default/files/inpatient\\_survey\\_technical\\_document.pdf](https://www.cqc.org.uk/sites/default/files/inpatient_survey_technical_document.pdf)

$$\tau^2 = ((N \times \phi) - (N - 1)) / (\sum w_i - \sum w_i^2 / \sum w_i)$$

Having calculated  $\tau^2$ , this is added to the squared standard error, and used to calculate revised z-scores for each organisation for this question using the following formula:

$$Z_{ij}(\text{rev}) = (p_{ij} - p_{Nj}) / \sqrt{(S.E._{ij} + \tau^2)}$$

*Identifying the expected range, and assigning a performance rating*

Once the appropriate z-scores have been calculated (either the original z-scores, or revised z-scores if there is over-dispersion for a particular question), then an expected range can be calculated around the national figure for each organisation for each question.

First, expected ranges are calculated by finding the scores that would have produced a revised z-score of either 1.96 or -1.96 using the formula directly above. Thus organisations with revised z-scores either great than 1.96 or less than -1.96 can be considered as lying outside of the expected range.

Organisations with scores below the lower limit are outside the expected range, performing *lower* than expected and coloured pale blue in the tables and comparability charts. Organisations with scores above the lower limit are outside the expected range, performing *higher* than expected and coloured dark blue in the tables and comparability charts. Organisations with scores between the upper and lower limits are within the expected range, and coloured grey in the tables and comparability charts.

*Question 59 – the overall experience question*

For question 59, all of the steps described above are repeated in exactly the same way as for the other questions, with the exception of the first step – calculating standard errors. In this case, the standard errors are derived as a by-product of the regression routine itself.

## 6. Tumour Groups

The table below shows the detailed mapping of 3-digit ICD codes to tumour groups. This has been used throughout the national and local-level reporting of the 2015 results, and is an identical mapping to previous years.

Tumour group	Cancer type (for case mix adjustment)	ICD code	Description
Brain / CNS	Brain	C71	Malignant neoplasm of brain
Breast	Breast	C50	Malignant neoplasm of breast
	DCIS	D05	Carcinoma in situ of breast
Colorectal / LGT	Rectal	C19, C20	Malignant neoplasm of recto-sigmoid junction (C19) and of rectum (C20)
	Colon	C18	Malignant neoplasm of colon
	Anal	C21	Malignant neoplasm of anus and anal canal (C21)
	Small Intestine	C17	Malignant neoplasm of small intestine
Gynaecological	Ovarian	C56	Malignant neoplasm of ovary
	Endometrial	C54, C55	Malignant neoplasm of corpus uteri (C54) and of uterus, part unspecified (C55)
	Cervical	C53	Malignant neoplasm of cervix uteri
	Vulva / vaginal	C51, C52	Malignant neoplasm of vulva (C51) and vagina (C52)
Haematological	Non-Hodgkins lymphoma	C82, C83, C84, C85	Follicular [nodular] non-Hodgkin's lymphoma (C82), diffuse non-Hodgkin's lymphoma (C83), Mycosis Fungoides (C84) other and unspecified types of non- Hodgkin's lymphoma (C85)
	Multiple myeloma	C90	Multiple myeloma and malignant plasma cell neoplasms
	Leukaemia	C91, C92, C93, C94, C95	Lymphoid (C91), myeloid (C92), monocytic (C93), and other leukaemia of specified (C94) and unspecified (C95) cell type
	Hodgkins lymphoma	C81	Hodgkin's disease
	Head and Neck	Thyroid	C73
	Laryngeal	C32	Malignant neoplasm of larynx
	Oropharyngeal	C01, C09, C10	Malignant neoplasm of base of tongue (C01), tonsil (C09) and oropharynx (C10)
	Oral	C02, C03, C04, C06	Malignant neoplasm of other / unspecified parts of tongue (C02), gum (C03), floor of mouth (C04) and other parts of mouth (C06)
	Parotid	C07, C08	Malignant neoplasm of parotid gland (C07) and other / unspecified major salivary gland (C08)
Lung	Lung	C33, C34	Malignant neoplasm of trachea (C33) and bronchus and lung (C34)
	Mesothelioma	C45	Mesothelioma
Prostate	Prostate	C61	Malignant neoplasm of prostate



Sarcoma	Soft Tissue Sarcoma	C46, C48, C49	Karposi's sarcoma (C46). Malignant neoplasm of retroperitoneum and peritoneum (C48) and other connective and soft tissue (C49)
	Bone Sarcoma	C40, C41	Malignant neoplasm of bone and articular cartilage of limbs (C40) and of bones and articular cartilage of other and unspecified sites (C41)
Skin	Melanoma	C43	Malignant melanoma of skin
Upper Gastro	Oesophageal	C15	Malignant neoplasm of oesophagus
	Stomach	C16	Malignant neoplasm of stomach
	Pancreatic	C25	Malignant neoplasm of pancreas
	Liver	C22	Malignant neoplasm of liver and intrahepatic bile ducts
	Gall Bladder	C23	Malignant neoplasm of gall bladder
Urological	Bladder	C67	Malignant neoplasm of bladder
	Renal	C64	Malignant neoplasm of kidney, except renal pelvis
	Penile	C60	Malignant neoplasm of penis
	Testicular	C62	Malignant neoplasm of testis
	Ureteric	C65, C66	Malignant neoplasm of renal pelvis (C65) and ureter (C66)
Other	Secondary	C77, C78, C79	Secondary and unspecified malignant neoplasm of lymph nodes (C77), of respiratory and digestive organs (C78) and of other and unspecified sites (C79)
	Any Other		All other codes C00, C05, C11, C12, C13, C14, C24, C26, C30, C31, C37, C38, C39, C47, C57, C58, C63, C68, C69, C70, C72, C74, C75, C76, C80, C86, C88, C96, C97

## **7. Further Information**

All of the national and local-level results, and further background material to the survey, are available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

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