

# National Cancer Patient Experience Survey 2019

Technical Documentation

**June 2020**

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## Introduction

This document sets out the methodology used in the analysis of the response data to the 2019 National Cancer Patient Experience Survey (CPES) and gives guidance on how to interpret the results. This includes the following:

- how percentage scores have been derived for each scored question
- how the adjusted response rate was calculated
- how scores were adjusted and details on the variables used for the adjustment
- rules on suppression and where it was applied
- methods for establishing differences between different groups of respondents
- methods for establishing changes from 2019 and 2018 and overall changes (2015 to 2019)
- how statistical confidence intervals around scores have been calculated
- methodology for expected range and how to interpret the results

All of the national and local-level results are available at <https://www.ncpes.co.uk/current-results>.

## Acknowledgments

We would like to 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 performance ratings along with input by Professor Yoryos Lyratzopoulos, Reader in Cancer Epidemiology at University College London.

## Scoring

Scores are presented for 52 questions that relate directly to patient experience. For all but one question (Q61), scores are presented as the percentage of positive responses out of all scored responses. For Q61, respondents rate their overall care on a scale of 0 to 10, of which the average was calculated for this question's presented score.

### Positive, negative and neutral scores

For each scored question, each response option has been identified as either a positive, negative or neutral response. Scores were calculated using the total number of positive responses as the numerator and the total number of positive and negative responses as the denominator. Neutral scores (e.g. 'Don't know / can't remember') were excluded from this calculation.

See [Appendix A](#) for the mapping of positive, negative and neutral scores for all questions.

## Adjusted response rate

During fieldwork for the 2019 survey, all patients were coded with an outcome code depending on their response to being sent the questionnaire. This outcome codes were as follows:

- Outcome 1 = patient completed the questionnaire
- Outcome 2 = questionnaire was returned undelivered (i.e. patient did not receive the questionnaire)
- Outcome 3 = patient deceased after the sample was drawn (i.e. patient may not have received the questionnaire)
- Outcome 4 = patient opted out of the survey (i.e. called the helpline, emailed or returned a blank questionnaire)
- Outcome 5 = patient is ineligible for the survey (i.e. patient was sampled incorrectly and does not meet the eligibility criteria for the survey)
- Outcome 6 = unknown (i.e. there has been no response from the patient)

To calculate the adjusted response rate, the numerator was the total number of patients with an outcome of '1' and the denominator was the total number of patients with an outcome of '1', '4', and '6'. Therefore, patients that may not have received a questionnaire or was not eligible to take part was excluded from this calculation.

## Case-mix Adjustment

### Introduction

From detailed analyses of previous iterations of the survey (and other 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 experiences reported by patients with different types of cancer. Thereby, Trusts with differing populations could potentially lead to results appearing better or worse than they would if they had a slightly different profile of patients.

To adjust for the different proportion of patients within sub-groups across organisations, a case-mix adjustment was done to 'standardise' the data to allow for fair comparisons.

### How to interpret the results

The case-mix adjusted scores are the scores we would expect a Trust, CCG or Cancer Alliance to obtain had their mix of respondents been the same demographically across each organisation. Therefore, to compare scores across different organisations, the case-mix adjusted scores, alongside the confidence intervals, should be used.

The following example shows two tables for the same organisation: the first has the total number of respondents to Q7, the unadjusted score, and the corresponding confidence intervals; the second has the same data for Q7 but after the case-mix adjustment has been applied. In this case, the

unadjusted score is 83%. Once the characteristics of the organisation's population are taken into account, the case-mix adjusted score is at 82%. It is this second figure (i.e. case-mix adjusted score) which should be used when making comparisons.

Question	Question text	Number of responses	Unadjusted score	95% Confidence Intervals	
				Lower	Upper
Q7	Were the results of the test explained in a way you could understand?	500	83%	79%	86%

Question	Question text	Number of responses	Adjusted score	95% Confidence Intervals	
				Lower	Upper
Q7	Were the results of the test explained in a way you could understand?	500	82%	78%	85%

## Methodology

### *Variables used in the case-mix adjustment*

Scores were adjusted based on 5 characteristics of the patients: age, ethnicity, gender, cancer type and IMD quintile. Below is a description of how these variables are derived and grouped.

- Age was derived from sample data provided from the Trust i.e. date of birth of patient. It was then grouped into eight age groups for the case-mix adjustment: 16-24; 25-34; 35-44; 45-54; 55-64; 65-74; 75-84; 85+
- Ethnicity was derived from Q72 in the questionnaire where respondents indicate which ethnic group they belong to. Ethnicity was grouped into six groups for the case-mix adjustment: White; Mixed; Asian; Black; Other; Not given
- Gender was taken from sample data provided from the Trust, unless it was unknown, in which case data from Q66 was taken. If gender was unclear from the sample and response data, a statistical process was taken to assign a gender<sup>1</sup>. Gender was grouped into two groups: Male; Female
- Cancer type was derived from clinical codes provided from the Trust i.e. ICD-10 codes. It was then grouped into 38 groups (see [Appendix B](#) for the full list)

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<sup>1</sup> Consultations with Dr Gary Abel (Senior Lecturer, University of Exeter) were undertaken to identify the best practice for randomly assigning a gender code whilst taking into account the probability of being a particular gender based on the data.

- IMD quintiles were derived using the patient's postcode data provided from the Trust and used to mail the questionnaire packets. The IMD (i.e. Index of Multiple Deprivation) quintiles were generated by mapping the postcode of referral for each patient against the most recently available published English IMD data using the ONS postcode directory file of February 2020. In some cases (415 in 2019), patients from outside England (from Wales, Scotland, Northern Ireland, the Channel Islands or the Isle of Man) are referred to English NHS Trusts for treatment. However, these patients were not included in the case-mix adjustment and are all described as 'Non-England' in the national tables<sup>2</sup>. The responses from these patients were included in the overall national analysis and in the unadjusted results for the relevant NHS Trust. However, they do not appear in any of the CCG or Cancer Alliance results as these are only presented for relevant English CCGs and Alliances.

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

A logistic regression model was used for the case-mix adjustment to quantify the impact of each of the five variables above on each of the scored questions in the questionnaire. This produced a statistical case-mix adjustment model for each question. This is based on the 2014 paper produced by Abel, Saunders & Lyratzopoulos<sup>3</sup>.

These individual models were then ran for each question (aside from Q61) to produce a case-mix adjusted score that takes account of how the demographics of an individual Trust differ from the national average. For Q61, the same five variables were used however the case-mix adjustment was created using a linear regression model.

Any questions with zero responses from a particular organisation were removed from the modelling process for these individual questions.

## Suppression

### Question-level suppression

For unadjusted and adjusted scores at national, Trust, CCG and Cancer Alliance levels, when the base size per question was < 21, the score was suppressed and replaced with an asterisk (\*). The base size included only positive and negative response options.

### Response-level suppression

Where results are presented at response option level, questions where the number of respondents selecting a given option was not 0 but less than 6 were suppressed and replaced with an asterisk (\*). This is to minimise the risk that the results could be disclosed. All other response options, which could be used to calculate the suppressed number, was also suppressed. This suppression

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<sup>2</sup> For 2015, a few respondents did not have valid postcodes to generate IMD quintiles, therefore some of the counts in the 2015 data do not match previously published results.

<sup>3</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>

rule did not apply to all neutral response options (see [Appendix A](#) for which response options were included in the suppression).

## Double suppression

Results for any sub-group breakdown adheres to the same suppression level as the question-level suppression but has an additional double suppression rule. Where any of the groups within the sub-group breakdown had < 21 respondents then the figure for this particular group was suppressed and replaced with an asterisk (\*). If there was only one group within the sub-group that had < 21 respondents and therefore suppressed, the group with the next lowest number of respondents (regardless of whether it was greater than or less than 21) was also suppressed and replaced with an asterisk (\*). This rule applies to scores and proportions.

## Comparisons between groups of respondents

### Introduction

Significance tests were carried out to identify a statistically significant difference between groups of respondents on a particular question.

### How to interpret the results

In the Excel tables, results for between groups significance tests are marked with either 'Sig.' or 'Not Sig' for statistically significant or not, respectively.

### Methodology

Four standard tests of significance were used for identifying statistically significant differences between groups. All tests were set with a confidence level of 95% ( $p < 0.05$ ).

- A z-test of proportions was used to test whether there is a significant difference between the scores of two groups for all scored questions aside from Q61:
  - gender (male vs female)
  - sexual orientation (heterosexual vs non-heterosexual)
  - deprivation (1<sup>st</sup> quintile vs 5<sup>th</sup> quintile).
  - Tumour type (Each tumour type vs. score for all tumour types combined) (brain/CNS, breast, colorectal/LGT, gynaecological, haematological, head and neck, lung, prostate, sarcoma, skin, upper gastro, urological, other) (see [Appendix B](#) for the mapping document used)
- A Pearson chi-square test was used to test whether there are significant differences in scores across multiple groups for all scored questions aside from Q61:
  - ethnicity (across White, Mixed, Asian, Blank, Other, Not given)
  - age (across 16-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)
- A two-sample t-test was used to compare the mean score from Q61 (overall experience question) in the following forms:

- gender compared mean scores for male vs female
- sexual orientation compared mean scores for heterosexual vs non-heterosexual
- deprivation compared mean scores for 1<sup>st</sup> quintile vs 5<sup>th</sup> quintile
  
- A one-sample t-test was used to compare the national mean score from Q61 (overall experience question) to the national score for the following groups:
  - each ethnicity group vs. score for all ethnicity groups combined (White, Mixed, Asian, Blank, Other, Not given)
  - each age group vs. score for all ages groups combined (16-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)
  - each tumour type vs. score for all tumour types combined (brain/CNS, breast, colorectal/LGT, gynaecological, haematological, head and neck, lung, prostate, sarcoma, skin, upper gastro, urological, other) (see [Appendix B](#) for the mapping document used)

## Comparisons between 2019 and 2018, and trend comparisons (2015-2019)

### Introduction

Where possible<sup>4</sup>, the scores for each of the scored questions from the 2019 results were compared with those from the 2018 results to see if there are any significant differences. Comparisons were also made across the last 5 iterations of the survey (2015-2019) to see if there are any trends. Comparisons were made at national, trust, CCG and Cancer Alliance level for each scored question. See [Appendix C](#) for a list of which questions were comparable to previous year's scores.

### How to interpret the results

In the Excel tables, results between 2019 and 2018 as well as trend results are marked with either '↑' or '↓' for a statistically significant increase or decrease, respectively.

### Methodology

A longitudinal logistic regression model with robust variance estimation<sup>5</sup> was used to determine whether there has been a significant change from the previous year and whether there are any trends over the last 5 years.<sup>6</sup> A linear regression was used to determine whether there are any changes to Q61 (overall experience question) from last year and for identifying any trends. Age,

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<sup>4</sup> For the 2019 survey, 37 questions were comparable to 2018. For the trend comparisons, 37 questions were comparable across 2016-2019 and 35 questions were comparable across 2015-2019.

<sup>5</sup> The regression models differ slightly from those used in previous iterations of the survey. The change was made because some respondents did not have NHS numbers and this makes it difficult to reliably identify where patients have completed the survey in successive years. The revised approach has been tested against the previous method and found to give very similar results. We therefore do not expect these to have led to different conclusions about change over time.

<sup>6</sup> In a small number of cases, data conditions (primarily small numbers of responses) did not permit the regression model to converge on an estimate of the year to year effect. In these cases, the significance test was omitted.

IMD quintile, ethnicity and tumour type are added as covariates since these variables may differ across years. Results were considered significant at the 99% ( $p < 0.01$ ) level.

## Confidence intervals

### Introduction

The single percentage figures given as a score for each organisation for each question are an estimate of the score from the 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 was been used here, is to produce and report 95 percent confidence intervals around the results. At the 95 percent confidence level the confidence intervals are expected to contain the true value 95 percent of the time (i.e. out of 100 such intervals, 95 will include the true figure).

### How to interpret the results

The following example shows the unadjusted score for an organisation with 500 respondents to Q7 in the questionnaire, which asks about the explanation of test results. In this case, the unadjusted score is 83% and the confidence interval is calculated as between 79% and 86%.

Question	Question text	Number of responses	Unadjusted score	95% Confidence Intervals	
				Lower	Upper
Q7	Were the results of the test explained in a way you could understand?	500	83%	79%	86%

### Methodology

Confidence intervals for unadjusted scores for all questions (aside from Q61) were calculated using Wilson's Confidence Intervals. This particular approach was chosen as it is more robust for small numbers (both numerators and denominators), and for results close to 0% or 100%. For Q61, confidence intervals are +/- 1.96 standard errors, which was calculated by:

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

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

For the case-mix adjusted scores for all scored questions (aside from Q61), confidence intervals were calculated using a binomial approach with Wilson adjustment. For Q61, +/- 1.96 standard errors was used again, derived as a by-product of the regression routine itself.

## Expected values and comparability charts

### Introduction

We have continued to use an adapted version of the Care Quality Commission<sup>7</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 from 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.

As such, the organisations outside this range are flagged as outliers and have scores that are not expected for most organisations. This 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.

### How to interpret the results

The following example shows the scores for an organisation with 500 respondents to Q7 in the survey, asking about the explanation of test results. In this case, the expected range calculated for this organisation is between 78% and 85%. The case-mix adjusted score is 86%, 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, Trust and Alliance-level reports, and in the data tables.

Question	Question text	Number of responses	Adjusted score	Performance rating	Expected range	
					Lower	Upper
Q7	Were the results of the test explained in a way you could understand?	500	86%	1	78%	85%

<sup>7</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)

The following example shows how we would report the score for the same organisation if it were below the expected range. In this case, the expected range calculated for this organisation is still between 78% and 85%; however 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, Trust and Alliance-level reports, and in the data tables.

Question	Question text	Number of responses	Adjusted score	Performance rating	Expected range	
					Lower	Upper
Q7	Were the results of the test explained in a way you could understand?	500	75%	3	78%	85%

The following example shows the scores for another, smaller, organisation, with 100 respondents, to the same question. 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 for this specific organisation. 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, Trust and Alliance-level reports, and in the data tables.

Question	Question text	Number of responses	Adjusted score	Performance rating	Expected range	
					Lower	Upper
Q7	Were the results of the test explained in a way you could understand?	100	75%	2	74%	82%

This above example illustrates how a 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.

## Methodology

The calculations included 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.

### 1. 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>) was 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>) were calculated, as follows:

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

The z-scores were ranked within each question. The z-scores of those in the bottom 20% were set to be equal to the z-score of the 20<sup>th</sup> percentile. Similarly, the z-scores of those in the top 20% were set to be equal to the z-score of the 80<sup>th</sup> percentile (a process known as Winsorisation). These adjusted z-scores were squared and φ was calculated for each question by summing the squares and dividing by the number of relevant organisations (CCGs, Trusts or Alliances), i.e. by 191, 143 or 20. For example, for CCGs:

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

From this, if

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

then the scores were taken to be over-dispersed and needed adjustment. If not, the scores were assumed to not be over-dispersed and the original z-scores were used.

## 2. Adjusting for over-dispersion

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

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

$$w_i = 1 / S.E._{ij}^2$$

Then, τ<sup>2</sup> was calculated from:

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

Having calculated τ<sup>2</sup>, this was added to the squared standard error, and used to calculate revised z-scores for each organisation for this question using the following formula:

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

## 3. Identifying the expected range and assigning a performance rating

Once the appropriate z-scores were calculated (either the original z-scores, or revised z-scores if there was over-dispersion for a particular question), then an expected range was calculated around the national<sup>8</sup> figure for each organisation for each question.

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<sup>8</sup> For patients residing in England.

First, expected ranges were calculated by finding the scores that would have produced a revised z-score of either 1.96 or -1.96. Thus organisations with revised z-scores either greater 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 upper 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.

To summarise, the equations used for calculating expected range were:

$$\text{Lower\_exp} = (\text{S.E.}_{ij} * (-1.96)) + p_{Nj}$$

$$\text{Higher\_exp} = (\text{S.E.}_{ij} * (1.96)) + p_{Nj}$$

Where over-dispersion was identified across organisations for this question, a revised S.E.<sub>ij</sub>, S.E.<sub>z</sub>, were substituted in the Lower\_exp and Higher\_exp equations above, where S.E.<sub>z</sub> was calculated as follows:

$$\text{S.E.}_z = (p_{ij} - p_{Nj}) / Z_{ij}(\text{rev})$$

For question 61 (overall experience question), all of the steps described above were 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 were derived as a by-product of the regression routine itself.

## Respondent burden calculation

The National Cancer Patient Experience Survey (CPES) complies with the Code of Practice for Statistics. Within the code, Practice V5.5 requires producers of statistics to monitor the burden on respondents providing their information. In order to achieve this, the following calculation is done for CPES:

Number of respondents x Average time spent completing the survey

There were 67,858 responses to the 2019 CPES. The median completion time based on online completion was 19 minutes per survey. Therefore, respondent burden calculated results for the 2019 CPES are:

67,858 respondents x 19 minutes = 21,488 hours spent completing the survey

## Further information

For further information on the methodology and details of the statistical analysis, please contact [CPES@PickerEurope.ac.uk](mailto:CPES@PickerEurope.ac.uk)

## Appendix A

This table lists all questions, excluding the last section (about you) in the questionnaire. The questions were recoded into binary variables where 1 meant positive experience and 0 meant negative experience. The proportion of positive responses to negative responses were then used to calculate unadjusted and adjusted scores. The last column of this table indicates 'Yes' for response options that were used within the response-level suppression rule an 'No' if it was excluded from this suppression rule.

Question	Question text	Answer option	Option text	Scoring	Used in suppression
Q1	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	n/a	Yes
		2	None – I went to hospital following a cancer screening appointment	n/a	Yes
		3	I saw my GP once	1	Yes
		4	I saw my GP twice	1	Yes
		5	I saw my GP 3 or 4 times	0	Yes
		6	I saw my GP 5 or more times	0	Yes
		7	Don't know / can't remember	n/a	No
Q2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	1	I was seen as soon as I thought was necessary	1	Yes
		2	I should have been seen a bit sooner	0	Yes
		3	I should have been seen a lot sooner	0	Yes
Q3	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?	1	Less than 3 months	n/a	Yes
		2	3-6 months	n/a	Yes
		3	6-12 months	n/a	Yes
		4	More than 12 months	n/a	Yes
		5	Don't know / can't remember	n/a	No
Q4	In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q5	Beforehand, did you have all the information you needed about your test?	1	Yes	1	Yes
		2	No, I would have liked more information	0	Yes
		3	No, I did not need any information	n/a	No
		4	Don't know / can't remember	n/a	No

Question	Question text	Answer option	Option text	Scoring	Used in suppression
Q6	Overall, how did you feel about the length of time you had to wait for your test to be done?	1	It was about right	1	Yes
		2	It was a little too long	0	Yes
		3	It was much too long	0	Yes
		4	Don't know / can't remember	n/a	No
Q7	Were the results of the test explained in a way you could understand?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, I did not understand the explanation	0	Yes
		4	I did not have an explanation but would have liked one	0	Yes
		5	I did not need an explanation	n/a	No
		6	Don't know / can't remember	n/a	No
Q8	How long ago were you told that you had cancer?	1	Less than 6 months ago	n/a	Yes
		2	At least 6 months ago but not more than twelve months ago	n/a	Yes
		3	More than twelve months ago	n/a	Yes
		4	Don't know / can't remember	n/a	No
Q9	Who told you that you had cancer? (Cross ALL that apply)	1	A specialist doctor or consultant at hospital	n/a	Yes
		2	My GP	n/a	Yes
		3	A Clinical Nurse Specialist (CNS)	n/a	Yes
		4	Someone else	n/a	Yes
		5	Don't know / can't remember	n/a	No
Q10	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	1	Yes	1	Yes
		2	No	0	Yes
		3	I was told I had cancer by phone or letter	0	Yes
		4	Don't know / can't remember	n/a	No
Q11	How do you feel about the way you were told you had cancer?	1	It was done sensitively	1	Yes
		2	It should have been done a bit more sensitively	0	Yes
		3	It should have been done a lot more sensitively	0	Yes
Q12	Did you understand the explanation of what was wrong with you?	1	Yes, I completely understood it	1	Yes
		2	Yes, I understood some of it	0	Yes
		3	No, I did not understand it	0	Yes
		4	Don't know / can't remember	n/a	No
Q13	When you were told you had cancer, were you given written information about the	1	Yes, and it was easy to understand	1	Yes
		2	Yes, but it was difficult to understand	0	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	type of cancer you had?	3	No, I was not given written information about the type of cancer I had	0	Yes
		4	I did not need written information	n/a	No
		5	Don't know / can't remember	n/a	No
Q14	Before your cancer treatment started, were your treatment options explained to you?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	There was only one type of treatment that was suitable for me	n/a	Yes
		5	Don't know / can't remember	n/a	No
Q15	Were the possible side effects of treatment(s) explained in a way you could understand?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, side effects were not explained	0	Yes
		4	I did not need an explanation	n/a	No
		5	Don't know / can't remember	n/a	No
Q16	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, I was not offered any practical advice or support	0	Yes
		4	Don't know / can't remember	n/a	No
Q17	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?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, future side effects were not explained	0	Yes
		4	I did not need an explanation	n/a	No
		5	Don't know / can't remember	n/a	No
Q18	Were you involved as much as you wanted to be in decisions about your care and treatment?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
Q19	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	1	Yes	1	Yes
		2	No	0	Yes
		3	Don't know / can't remember	n/a	No
Q20	How easy or difficult has it been for you to	1	Very easy	1	Yes
		2	Quite easy	1	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	contact your Clinical Nurse Specialist?	3	Neither easy nor difficult	0	Yes
		4	Quite difficult	0	Yes
		5	Very difficult	0	Yes
		6	I have not tried to contact my Clinical Nurse Specialist	n/a	No
Q21	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	1	All or most of the time	1	Yes
		2	Some of the time	0	Yes
		3	Rarely or never	0	Yes
		4	I have not asked any questions	n/a	No
Q22	Did hospital staff give you information about support or self-help groups for people with cancer?	1	Yes	1	Yes
		2	No, but I would have liked information	0	Yes
		3	It was not necessary	n/a	No
		4	Don't know / can't remember	n/a	No
Q23	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)?	1	Yes	1	Yes
		2	No, but I would have liked a discussion or information	0	Yes
		3	It was not necessary / relevant to me	n/a	No
		4	Don't know / can't remember	n/a	No
Q24	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	1	Yes	1	Yes
		2	No, but I would have liked information	0	Yes
		3	It was not necessary	n/a	No
		4	Don't know / can't remember	n/a	No
Q25	Did hospital staff tell you that you could get free prescriptions?	1	Yes	1	Yes
		2	No, but I would have liked information	0	Yes
		3	It was not necessary	n/a	No
		4	Don't know / can't remember	n/a	No
Q26	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?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q27		1	Yes	1	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	Beforehand, did you have all the information you needed about your operation?	2	No, I would have liked more information	0	Yes
		3	Don't know / can't remember	n/a	No
Q28	After the operation, did a member of staff explain how it had gone in a way you could understand?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, but I would have liked an explanation	0	Yes
		4	I did not need an explanation	n/a	No
Q29	During the last 12 months, have you stayed overnight for cancer care at one of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q30	Did hospital staff talk in front of you as if you weren't there?	1	Yes, often	0	Yes
		2	Yes, sometimes	0	Yes
		3	No	1	Yes
Q31	Did you have confidence and trust in the doctors treating you?	1	Yes, in all of them	1	Yes
		2	Yes, in some of them	0	Yes
		3	No, in none of them	0	Yes
Q32	If your family or someone else close to you wanted to talk to a doctor, were they able to?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	No family or friends were involved	n/a	No
		5	My family did not want to talk to a doctor	n/a	No
		6	I did not want my family or friends to talk to a doctor	n/a	No
Q33	Did you have confidence and trust in the ward nurses treating you?	1	Yes, in all of them	1	Yes
		2	Yes, in some of them	0	Yes
		3	No, in none of them	0	Yes
Q34	In your opinion, were there enough nurses on duty to care for you in hospital?	1	There were always or nearly always enough on duty	1	Yes
		2	There were sometimes enough on duty	0	Yes
		3	There were rarely or never enough on duty	0	Yes
Q35	While you were in hospital did hospital staff ask you what	1	Yes, all of them did	1	Yes
		2	Only some of them did	0	Yes
		3	None of them did	0	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	name you prefer to be called by?				
Q36	Were you given enough privacy when discussing your condition or treatment?	1	Yes, always	1	Yes
		2	Yes, sometimes	0	Yes
		3	No	0	Yes
Q37	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I had no worries or fears	n/a	No
Q38	Do you think the hospital staff did everything they could to help control your pain?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not have any pain	n/a	No
Q39	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	1	Yes, always	1	Yes
		2	Yes, sometimes	0	Yes
		3	No	0	Yes
Q40	Were you given clear written information about what you should or should not do after leaving hospital?	1	Yes	1	Yes
		2	No	0	Yes
		3	Don't know / can't remember	n/a	No
Q41	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	1	Yes	1	Yes
		2	No	0	Yes
		3	Don't know / can't remember	n/a	No
Q42	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?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q43	While you were being treated as an outpatient or day case, did you find someone on the	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not have any worries or fears	n/a	No

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	hospital staff to talk to about your worries and fears?				
Q44	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?	1	Yes	1	Yes
		2	No	0	Yes
		3	I didn't have an appointment with a cancer doctor	n/a	No
		4	Don't know / can't remember	n/a	No
Q45	During the last 12 months, have you had radiotherapy at any of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q46	Beforehand, did you have all of the information you needed about your radiotherapy treatment?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need any information	n/a	No
Q47	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	It is too early to know if my radiotherapy is working	n/a	Yes
		5	I did not need any information	n/a	No
Q48	During the last 12 months, have you had chemotherapy at any of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q49	Beforehand, did you have all of the information you needed about your chemotherapy treatment?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need any information	n/a	No
Q50	Once you started your treatment, were you given enough information about whether your	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	It is too early to know if my chemotherapy is working	n/a	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	chemotherapy was working in a way you could understand?	5	I did not need any information	n/a	No
Q51	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?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	No family or friends were involved	n/a	No
		5	My family or friends did not want or need information	n/a	No
		6	I did not want my family or friends to be involved	n/a	No
Q52	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need help from health or social services	n/a	No
		5	Don't know / can't remember	n/a	No
Q53	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)?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need help from health or social services	n/a	No
		5	I am still having treatment	n/a	No
		6	Don't know / can't remember	n/a	No
Q54	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	1	Yes	1	Yes
		2	No	0	Yes
		3	Don't know / can't remember	n/a	No
Q55	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, they could have done more	0	Yes
		4	My general practice was not involved	n/a	No
Q56	Did the different people treating and caring for you (such as GP, hospital	1	Yes, always	1	Yes
		2	Yes, some of the time	0	Yes
		3	No, never	0	Yes
		4	Don't know / can't remember	n/a	No

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?				
Q57	Have you been given a care plan?	1	Yes	1	Yes
		2	No	0	Yes
		3	I do not know / understand what a care plan is	n/a	No
		4	Don't know / can't remember	n/a	No
Q58	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?	1	Very good	1	Yes
		2	Good	1	Yes
		3	Neither good nor bad	0	Yes
		4	Quite bad	0	Yes
		5	Very bad	0	Yes
		6	Don't know / can't remember	n/a	No
Q59	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	1	It was much too long	0	Yes
		2	It was a little too long	0	Yes
		3	It was about right	1	Yes
		4	Don't know / can't remember	n/a	No
Q60	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	1	Yes	1	Yes
		2	Yes, but I was not eligible to take part	1	Yes
		3	No	0	Yes
		4	No, but I would have liked them to	0	Yes
		5	Don't know / can't remember	n/a	No
Q61	Overall, how would you rate your care?	0		Average score is used	Yes
		1			Yes
		2			Yes
		3			Yes
		4			Yes
		5			Yes
		6			Yes
		7			Yes
		8			Yes
		9			Yes
10		Yes			

Question	Question text	Answer option	Option text	Scoring	Used in suppression
		not valid*		n/a	No

## Appendix B

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 2019 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, C85	Follicular [nodular] non-Hodgkin's lymphoma (C82), diffuse non-Hodgkin's lymphoma (C83), 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

Tumour group	Cancer type (for case mix adjustment)	ICD code	Description
Head and Neck	Thyroid	C73	Malignant neoplasm of thyroid gland
	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)

Tumour group	Cancer type (for case mix adjustment)	ICD code	Description
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

## Appendix C

This table lists all questions, excluding the last section (about you) in the questionnaire. Those that were deemed comparable despite changes made have historic results presented in outputs. However these results should be interpreted with caution.

Question	Question text	Change(s) made	Comparable to 2018
Q1	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?		Yes
Q2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?		Yes
Q3	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?		Yes
Q4	In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?		Yes
Q5	Beforehand, did you have all the information you needed about your test?	Added a response option	No
Q6	Overall, how did you feel about the length of time you had to wait for your test to be done?		Yes
Q7	Were the results of the test explained in a way you could understand?		Yes

Question	Question text	Change(s) made	Comparable to 2018
Q8	How long ago were you told that you had cancer?	New question	No
Q9	Who told you that you had cancer? (Cross ALL that apply)	New question	No
Q10	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?		Yes
Q11	How do you feel about the way you were told you had cancer?		Yes
Q12	Did you understand the explanation of what was wrong with you?		Yes
Q13	When you were told you had cancer, were you given written information about the type of cancer you had?		Yes
Q14	Before your cancer treatment started, were your treatment options explained to you?		Yes
Q15	Were the possible side effects of treatment(s) explained in a way you could understand?		Yes
Q16	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?		Yes

Question	Question text	Change(s) made	Comparable to 2018
Q17	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?		Yes
Q18	Were you involved as much as you wanted to be in decisions about your care and treatment?	Response options changed	No
Q19	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?		Yes
Q20	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?		Yes
Q21	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?		Yes
Q22	Did hospital staff give you information about support or self-help groups for people with cancer?		Yes
Q23	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)?		Yes
Q24	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?		Yes
Q25	Did hospital staff tell you that you could get free prescriptions?		Yes
Q26	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?		Yes

Question	Question text	Change(s) made	Comparable to 2018
Q27	Beforehand, did you have all the information you needed about your operation?		Yes
Q28	After the operation, did a member of staff explain how it had gone in a way you could understand?		Yes
Q29	During the last 12 months, have you stayed overnight for cancer care at one of the hospitals named in the covering letter?	Question text changed	No
Q30	Did hospital staff talk in front of you as if you weren't there?	Question text changed. Filter question changed (Q29)	No
Q31	Did you have confidence and trust in the doctors treating you?	Filter question changed (Q29)	No
Q32	If your family or someone else close to you wanted to talk to a doctor, were they able to?	Filter question changed (Q29)	No
Q33	Did you have confidence and trust in the ward nurses treating you?	Filter question changed (Q29)	No
Q34	In your opinion, were there enough nurses on duty to care for you in hospital?	Filter question changed (Q29)	No
Q35	While you were in hospital did hospital staff ask you what name you prefer to be called by?	Question text changed. Filter question changed (Q29)	No
Q36	Were you given enough privacy when discussing your condition or treatment?	Filter question changed (Q29)	No
Q37	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	Filter question changed (Q29)	No

Question	Question text	Change(s) made	Comparable to 2018
Q38	Do you think the hospital staff did everything they could to help control your pain?	Filter question changed (Q29)	No
Q39	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Filter question changed (Q29)	No
Q40	Were you given clear written information about what you should or should not do after leaving hospital?	Filter question changed (Q29)	No
Q41	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Filter question changed (Q29)	No
Q42	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?		Yes
Q43	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?		Yes
Q44	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?		Yes
Q45	During the last 12 months, have you had radiotherapy at any of the hospitals named in the covering letter?		Yes
Q46	Beforehand, did you have all of the information you needed about your radiotherapy treatment?		Yes
Q47	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?		Yes

Question	Question text	Change(s) made	Comparable to 2018
Q48	During the last 12 months, have you had chemotherapy at any of the hospitals named in the covering letter?		Yes
Q49	Beforehand, did you have all of the information you needed about your chemotherapy treatment?		Yes
Q50	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?		Yes
Q51	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
Q52	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?		Yes
Q53	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)?		Yes
Q54	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?		Yes
Q55	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?		Yes

Question	Question text	Change(s) made	Comparable to 2018
Q56	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?	Response option removed	No
Q57	Have you been given a care plan?		Yes
Q58	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?		Yes
Q59	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?		Yes
Q60	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Added a response option	Yes
Q61	Overall, how would you rate your care?		Yes