National Cancer Patient Experience Survey 2021

Quantitative Technical Documentation

July 2022

Contents

Introduction

This document sets out the methodology used in the analysis of the response data to the 2021 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
- rules on suppression and where it was applied
- how scores were adjusted and details on the variables used for the adjustment
- methods for establishing differences between different groups of respondents
- how statistical confidence intervals around scores have been calculated
- methodology for expected range and how to interpret the results

All of the results are available at https://www.ncpes.co.uk/current-results.

Acknowledgments

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Scoring

Scores are presented for 61 questions that relate directly to patient experience. For all but one question (Q59), scores are presented as the percentage of positive responses out of all scored responses. For Q59, 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 2021 survey, all patients were coded with an outcome code depending on their response to being sent the questionnaire. The outcome codes were as follows:

- Outcome 1 = questionnaire completed
- 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'. 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 were not eligible to take part were excluded from this calculation.

Suppression

When a response to a question is low, the data is suppressed to prevent individuals and their responses being identifiable in the data. After consultation with the Cancer Patient Experience Survey Advisory Group in April 2021 a decision was made to lower the question-level suppression and double suppression from <21 to <11 for CPES20 and future iterations of the survey. Agreement was also made to remove the response level suppression rule.

Question-level suppression

For scores where the base size per question had <11 respondents, the score was suppressed and replaced with an asterisk (*). The base size did not include non-scored response options. For unscored questions, any frequencies were suppressed when the base size per question was <11.

Double suppression

Results for any sub-group breakdown adhere to the same suppression level as the question-level suppression but have an additional double suppression rule. Where any of the groups within the sub-group breakdown had <11 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 <11 respondents and was therefore suppressed, the group with the next lowest number of respondents was also supressed and replaced with an asterisk (*). This rule applies to scores and proportions. We do this so that the suppressed subgroup score cannot be worked out by subtracting the other scores from the National/England score.

Organisation-level suppression

At Trust, Integrated Care System (ICS) and Cancer Alliance level, additional suppression happens if only one Trust (or ICS or Cancer Alliance) has a score or result suppressed (for either of the reasons above). If this happens, we will suppress another Trust's results (both the Trust level and subgroup results for the question) based on the next lowest base size for the score. We do this so that the national / England score cannot be used to work out the suppressed score for the individual Trust.

In the case that two or more Trusts (or ICS or Cancer Alliance) have an equal count, we select the Trust (or ICS or Cancer Alliance) code based on alphabetical order[1].

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 females generally report a significantly less positive experience than males; 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, ICS 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 Q8, the unadjusted score, and the corresponding confidence intervals. The second has the same data for Q8 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
Q8	Diagnostic test results were explained in a way the patient could completely understand	500	83%	79%	86%

[1] Note that the double and organisation-level suppression rules can interact and result in multiple further suppressions to prevent calculation of suppressed results.

Question	Question text	Number of responses	Adjusted score	95% Confidence Intervals	
				Lower	Upper
Q8	Diagnostic test results were explained in a way the patient could completely 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 Index of Multiple Deprivation (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 Q71 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 Q64 where respondents indicate the gender they identify as. The groups used for the case-mix adjustment were Female; Male; Non-binary; Prefer to self-describe; Prefer not to say; Not given.
- Cancer type was derived from clinical codes provided from the Trust i.e., ICD-10 or ICD-11 codes. It was then grouped into 38 groups (see Appendix B for the full list)
- IMD quintiles were derived using the patient's postcode data provided from the Trust and used to mail the questionnaire packets. The IMD 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. In some cases (365 in 2021), 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. 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 ICS or Cancer Alliance results as these are only presented for NHS England.

Case-mix adjustment for Trusts, ICSs 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[2].

These individual models were then run for each question (aside from Q59) to produce a case-mix adjusted score that takes account of how the demographics of an individual Trust differ from the national average. For Q59, 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.

Comparisons with previous iterations of the survey

The questionnaire for the 2021 survey underwent significant redevelopment to reflect changes to service delivery, clinical practice and policy. Due to the number of changes made to the questionnaire (including amending questions, removing questions, adding questions, and changes to question ordering it would not be appropriate to present any trend comparisons for 2021. 2021 will be the start of a new trend series.

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

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

For the following variables a z-test of proportions for Q02 to Q58 and a one sample t-test for Q59 was used to determine whether the scores are significantly different between each breakdown and the total:

- Male/Female/Non-binary/Other
- Gender same as sex at birth indicator
- Sexual Orientation
- Ethnicity
- Age

[2] 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

- Long term condition
- Cancer spread to other organs/parts of body at time of diagnosis
- Cancer outcome
- Tumour group
- Cancer type

For IMD quintile (1 most deprived vs. 5 least deprived) a z-test of proportions for Q02 to Q58 and a two-sample t-test for Q59 was used to identify statistically significant differences.

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 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 Q8 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
Q8	Diagnostic test results were explained in a way the patient could completely understand	500	83%	79%	86%

Methodology

Confidence intervals for unadjusted scores for all questions (aside from Q59) 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 Q59, confidence intervals are +/- 1.96 standard errors, which was calculated by:

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

Where σ is the standard deviation of responses for that particular organisation.

For Q59, +/- 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[3] 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 Q8 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 ICS, Trust and Alliance-level reports, and in the data tables.

[3] https://www.cqc.org.uk/sites/default/files/inpatient_survey_technical_document.pdf

Question	Question text	Number of responses	Adjusted score	Performance rating	Expected range	
					Lower	Upper
Q8	Were the results of the test explained in a way you could understand?	500	86%	1	78%	85%

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 ICS, Trust and Alliance-level reports, and in the data tables.

Question	Question text	Number of responses	Adjusted score	Performance rating	Expected range	
					Lower	Upper
Q8	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 ICS, Trust and Alliance-level reports, and in the data tables.

Question	Question text	Number of responses	Adjusted score	Performance rating	Expected range	
					Lower	Upper
Q8	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 ($S.E._{ij}$) around the national figure (p_{Nj}) was calculated using the number of responses (n_{ij}), as follows:

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

Z-scores (Z_{ij}) 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 20th percentile. Similarly, the z-scores of those in the top 20% were set to be equal to the z-score of the 80th 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 (ICSs, Trusts or Alliances), i.e. by 191, 143 or 20. For example, for ICSs:

$$\varphi = \Sigma\ Z_{adj}^2 / N$$

From this, if

$$N \times \varphi > N-1$$

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, ICS or Alliance scores.

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

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

Then, τ^2 was calculated from:

$$\tau^2 = ((N \times \varphi) – (N -1)) / (\Sigma w_i - \Sigma w_i^2 / \Sigma wi)$$

Having calculated τ^2, 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:

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

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[4] figure for each organisation for each question.

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:

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

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

Where over-dispersion was identified across organisations for this question, a revised $S.E._{ij}$, $S.E._z$, were substituted in the Lower_exp and Higher_exp equations above, where $S.E._z$ was calculated as follows:

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

For question 59 (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 for CPES we take the total number of respondents to the survey multiplied by the average time spent completing the online survey[5].

Limiting the time frame to just those individuals who started and finished the online survey on the same date, the average completion time is 27 minutes. (This is then 98.9% of all online respondents or 12,234 respondents).

If you then take out anyone who took over 100 minutes to complete (and assume they completed in multiple sittings within one day), the average is then 24 minutes. (This is then 96.8% of all online respondents or 11,974 respondents).

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[4] For patients residing in England.
[5] Average completion time is available for the online survey only.

Therefore, respondent burden calculated results for the 2021 CPES are:

59,352 respondents x 24 minutes = 23741 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

Appendix A

This table lists all questions, excluding the last section (about you) in the questionnaire. The questions in grey were non-scored questions. For each scored question, each response option was identified as either a positive (1), negative (0) or neutral response (n/a). The proportion of positive responses to negative responses were then used to calculate unadjusted and adjusted scores.

Question	Question text	Answer option	Option text	Scoring
Q01	How long was it from the time you first thought something might be wrong with you until you first contacted your GP practice to talk about it?	1	Not applicable - I didn't contact my GP practice	n/a
		2	Not applicable - The GP first identified that something could be wrong	n/a
		3	Less than 3 months	n/a
		4	3-6 months	n/a
		5	6-12 months	n/a
		6	More than 12 months	n/a
		7	Don't know / can't remember	n/a
Q02	Before you were diagnosed, how many times did you speak to a healthcare professional at your GP practice about health problems caused by cancer?	1	Once	1
		2	Twice	1
		3	Three or four times	0
		4	Five or more times	0
		5	Don't know / can't remember	n/a
Q03	When you were referred for diagnostic tests, did staff at your GP practice explain why you were being referred in a way that you could understand?	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	I wasn't referred by my GP practice	n/a
		5	Don't know / can't remember	n/a
Q04	In the last 12 months have you had any tests that helped to diagnose your cancer at one of the hospitals named in the covering letter? This could have been an endoscopy, biopsy, blood test or a scan.	1	Yes	n/a
		2	No	n/a
Q05	Before you went for your test(s), were you given all the information you needed about the test(s) you were having, including where they would be and how long you would be waiting?	1	Yes	1
		2	No, I would have liked more information	0
		3	No, but I didn't need any information	n/a
		4	Don't know / can't remember	n/a
Q06	When you went for your test(s) did the healthcare staff that you saw appear to have all the information that they needed about you?	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a

Question	Question text	Answer option	Option text	Scoring
Q07	Overall, how did you feel about the length of time you had to wait for your test results to be shared with you?	1	It was about right	1
		2	It was a little too long	0
		3	It was much too long	0
		4	Don't know / can't remember	n/a
Q08	Were the results of the tests explained in a way you could understand?	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No, I didn't understand the explanation	0
		4	I didn't have an explanation but would have liked one	0
		5	I didn't need an explanation	n/a
		6	I haven't had the results yet	n/a
		7	Don't know / can't remember	n/a
Q09	Were you given enough privacy when receiving the results of your tests?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don't know / can't remember	n/a
Q10	How long ago were you told that you had cancer?	1	Less than 6 months ago	n/a
		2	At least 6 months ago but not more than 12 months ago	n/a
		3	At least 12 months ago but not more than 2 years ago	n/a
		4	At least 2 years ago but not more than 5 years ago	n/a
		5	At least 5 years ago	n/a
		6	Don't know / can't remember	n/a
Q11	Who told you that you had cancer?	1	A specialist doctor or consultant	n/a
		2	A specialist cancer nurse	n/a
		3	Another member of the team that looked after you at the hospital	n/a
		4	Someone at your GP practice	n/a
		5	Someone else	n/a
		6	Don't know / can't remember	n/a
Q12	When you were first told that you had cancer, had you been given the option of having a family member, carer or friend with you while being told?	1	Yes, I was told I could have someone with me	1
		2	No, I was not given the option to have someone with me	0
		3	No, I was specifically told I could not have someone with me	0
		4	No, I was told by letter or email	n/a
		5	Don't know / can't remember	n/a
Q13	Were you told in a sensitive way?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a

Question	Question text	Answer option	Option text	Scoring
Q14	Was it explained to you in a way that you could understand?	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q15	Were you told in a place that was appropriate for you?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / not applicable	n/a
Q16	Were you told that you could go back for more information after you had time to reflect on what it meant?	1	Yes	1
		2	No	0
		3	Don't know / can't remember	n/a
Q17	Did you have a main contact person within the team looking after you, such as a clinical nurse specialist, who would support you through your treatment?	1	Yes, it was a specialist nurse	1
		2	Yes, it was another member of the team	1
		3	No	0
		4	Don't know / can't remember	n/a
Q18	How easy has it been to contact your main contact person?	1	Very easy	1
		2	Quite easy	1
		3	Neither easy nor difficult	0
		4	Quite difficult	0
		5	Very difficult	0
		6	I haven't needed to contact this person	n/a
Q19	Overall, how helpful was the advice you received from your main contact person?	1	Very helpful	1
		2	Quite helpful	1
		3	Neither helpful nor unhelpful	0
		4	Quite unhelpful	0
		5	Very unhelpful	0
		6	I haven't needed to ask for advice	n/a
Q20	Before your cancer treatment started, were your treatment options explained to you in a way that you could understand?	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	There was only one type of treatment	n/a
		5	Don't know / can't remember	n/a
Q21	Were you involved as much as you wanted to be in decisions about your treatment options?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q22	Were your family and/or carers able to be involved as much as	1	Yes, definitely	1
		2	Yes, to some extent	0

Question	Question text	Answer option	Option text	Scoring
	you wanted them to be in decisions about your treatment options?	3	No, and I wanted them to be	0
		4	No, but I didn't want them to be	n/a
		5	Not applicable	n/a
		6	Don't know / can't remember	n/a
Q23	If you wanted a second opinion or further advice from a healthcare professional before making decisions, were you able to get it?	1	Yes	1
		2	No	0
		3	I didn't want this	n/a
		4	I wasn't aware I could get this	0
		5	Don't know / can't remember	n/a
Q24	Before your treatment started, did you have a discussion with a member of the team looking after you about your needs or concerns?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No, and I wanted this	0
		4	No, but I didn't want this	n/a
		5	Don't know / can't remember	n/a
Q25	Has a member of the team looking after you helped you in creating a plan to address those needs or concerns?	1	Yes	1
		2	No, and I wanted this	0
		3	No, but this was not needed	n/a
		4	Don't know / can't remember	n/a
Q26	Did a member of the team looking after you review the plan with you to make sure it continued to reflect your needs or concerns? (E.g. soon after treatment started or at a follow up appointment).	1	Yes	1
		2	No, it didn't need to be reviewed	n/a
		3	No, it should have been reviewed but it wasn't	0
		4	Don't know / can't remember	n/a
Q27	Did hospital staff give you information that was relevant to you about support or self-help groups, events or resources for people with cancer?	1	Yes	1
		2	No, but I would have liked information	0
		3	No, I did not need information	n/a
		4	Don't know / can't remember	n/a
Q28	Do you feel you got the right amount of support with your overall health and well-being from hospital staff?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / not applicable	n/a
Q29	Were you offered information about how to get financial help or any benefits you might be entitled to?	1	Yes	1
		2	No, but I would have liked information	0
		3	No, I didn't need information	n/a
		4	Don't know / can't remember	n/a
Q30	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
		2	No	n/a
Q31		1	Yes, in all of them	1
		2	Yes, in some of them	0

Question	Question text	Answer option	Option text	Scoring
	Did you have confidence and trust in the team looking after you?	3	No	0
		4	Don't know / can't remember	n/a
Q32	If a member of your family or someone close to you wanted to talk to someone in the team looking after you during your stay in hospital, were they able to?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	My family or friends were not involved	n/a
		5	My family or friends did not want to talk to a member of the team	n/a
		6	I did not want my family or friends to talk to a member of the team	n/a
		7	Don't know / can't remember	n/a
Q33	Did you feel you were involved in decisions about your care and treatment while you were in hospital?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don't know / can't remember	n/a
Q34	Could you get help from staff on the ward when you needed it?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	I didn't need any help	n/a
		5	Don't know / can't remember	n/a
Q35	During your hospital stay, could you talk with hospital staff about your worries and fears if you needed to?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don't know / can't remember	n/a
Q36	Did the hospital staff do everything you wanted to help control your pain?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	I didn't have any pain	n/a
		5	Don't know / can't remember	n/a
Q37	Were you treated with respect and dignity during your stay in the hospital?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don't know / can't remember	n/a
Q38	Did hospital staff give you information about what you should or should not do after leaving hospital?	1	Yes, and it was easy to understand	1
		2	Yes, but it was difficult to understand	0
		3	No	0
		4	Don't know / can't remember	n/a
Q39	If you were treated as an outpatient or day case, were you	1	Yes, always	1
		2	Yes, sometimes	0

Question	Question text	Answer option	Option text	Scoring
	able to talk to hospital staff about your worries or fears if you needed to?	3	No	0
		4	I didn't have an outpatient or day case appointment	n/a
		5	Don't know / can't remember	n/a
Q40	During the last 12 months, have you had...?	1	Surgery	n/a
		2	Chemotherapy	n/a
		3	Radiotherapy	n/a
		4	Hormone Therapy	n/a
		5	Immunotherapy	n/a
		6	None of these	n/a
Q41_1	Before your treatment started were you given all the information you needed about the treatment in a way that you could understand? Surgery	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q41_2	Before your treatment started were you given all the information you needed about the treatment in a way that you could understand? Chemotherapy	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q41_3	Before your treatment started were you given all the information you needed about the treatment in a way that you could understand? Radiotherapy	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q41_4	Before your treatment started were you given all the information you needed about the treatment in a way that you could understand? Hormone Therapy	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q41_5	Before your treatment started were you given all the information you needed about the treatment in a way that you could understand? Immunotherapy	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q42_1	Once your treatment started, were you given enough information about your progress in a way you could understand? Surgery	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q42_2	Once your treatment started, were you given enough information about your progress in a way you could understand? Chemotherapy	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q42_3	Once your treatment started, were you given enough	1	Yes, completely	1
		2	Yes, to some extent	0

Question	Question text	Answer option	Option text	Scoring
	information about your progress in a way you could understand? Radiotherapy	3	No	0
		4	Don't know / can't remember	n/a
Q42_4	Once your treatment started, were you given enough information about your progress in a way you could understand? Hormone Therapy	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q42_5	Once your treatment started, were you given enough information about your progress in a way you could understand? Immunotherapy	1	Yes, completely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q43	Overall, how do you feel about the length of time you generally had to wait when you arrived at the clinic or day unit for your cancer treatments?	1	It was much too long	0
		2	It was a little too long	0
		3	It was about right	1
		4	Don't know / can't remember	n/a
Q44	Before you started your treatment(s), were the possible side effects of your treatment(s) explained in a way you could understand?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	I didn't need an explanation	n/a
		5	Don't know / can't remember	n/a
Q45	Were you offered practical advice and support in dealing with the immediate side effects of your treatment(s)?	1	Yes, always	1
		2	Yes, to some extent	0
		3	No, but I needed it	0
		4	No, I didn't need it	n/a
		5	Don't know / can't remember	n/a
Q46	Were you given information about where you could access other advice and support in dealing with the immediate side effects of your treatment?	1	Yes, and I was able to access it	1
		2	Yes, but I wasn't able to access it	0
		3	No, but I needed it	0
		4	No, but I didn't need it	n/a
		5	Don't know / can't remember	n/a
Q47	Before you started your treatment(s), did hospital staff explain the possible long-term side effects, including the impact on your day-to-day activities, in a way you could understand?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	I didn't need an explanation	n/a
		5	Don't know / can't remember	n/a
Q48	Were you able to discuss options for managing the impact of those long-term side effects on your day-to-day activities?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No, but I would have liked to	0
		4	No, I didn't need to	n/a
		5	Don't know / can't remember	n/a

Question	Question text	Answer option	Option text	Scoring
Q49	Did the team looking after you give your family, or someone close to you, the information they needed to help care for you at home?	1	Yes, they were given all the information they needed	1
		2	Yes, they were given some of the information they needed	0
		3	No	0
		4	Not applicable	n/a
		5	Don't know / can't remember	n/a
Q50	During your cancer treatment, could you get enough care and support at home from community or voluntary services?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	I didn't need care and support from community or voluntary services	n/a
		5	Don't know / can't remember	n/a
Q51	Did you get the right amount of support from staff at your GP practice while you were having cancer treatment?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	My GP practice wasn't involved	n/a
		5	Don't know / can't remember	n/a
Q52	Have you had a review of your cancer care by a member of staff at your GP practice?	1	Yes	1
		2	No	0
		3	Don't know / can't remember	n/a
Q53	Once your cancer treatment had finished, could you get emotional support at home from community or voluntary services (for example, district nurses, paid carers, mental health support or physiotherapists)?	1	My treatment hasn't finished	n/a
		2	Yes, definitely	1
		3	Yes, to some extent	0
		4	No	0
		5	I didn't need care and support from community or voluntary services	n/a
		6	Don't know / can't remember	n/a
Q54	Thinking about the time between your final treatment and your first follow up appointment, did the team looking after you provide you with information and support that was right for you?	1	My treatment hasn't finished	n/a
		2	Yes, I was given enough information and support	1
		3	I was given enough information but not enough support	0
		4	I was given enough support but not enough information	0
		5	No	0
		6	Don't know / can't remember	n/a
Q55	Were you given information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if you had concerns?	1	Yes, I was given enough information	1
		2	Yes, I was given some information but I would have liked more	0
		3	No, and I think I should have been given information	0
		4	No, because this information would not be relevant to me	n/a

Question	Question text	Answer option	Option text	Scoring
		5	Don't know / can't remember	n/a
Q56	Did the whole team looking after you work well together to give you the best possible care?	1	Yes	1
		2	No	0
		3	Don't know / can't remember	n/a
Q57	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
		2	Good	1
		3	Neither good nor poor	0
		4	Poor	0
		5	Very poor	0
		6	Don't know / can't remember	n/a
Q58	Since your diagnosis, has anyone discussed with you whether there are any cancer research opportunities that you could take part in (for example: clinical trials, tissue donation, additional scans, sharing data)?	1	Yes	1
		2	No, and I would have liked them to	0
		3	No, but I didn't want them to	n/a
		4	Don't know / can't remember	n/a
Q59	Overall, how would you rate your care? (scale from 0 to 10)	0	0 Very poor	Average score is used
		1	1	
		2	2	
		3	3	
		4	4	
		5	5	
		6	6	
		7	7	
		8	8	
		9	9	
		10	10 Very good	
		not valid*		n/a

Appendix B

The table below shows the detailed mapping of 3-digit ICD codes to tumour groups. This has been used throughout the reporting of the 2021 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-Hodgkin 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
	Hodgkin 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