National Cancer Patient Experience Survey 2024

Quantitative Technical Documentation

July 2025

Contents

Introduction

This document sets out the methodology used in the analysis of the response data to the 2024 National Cancer Patient Experience Survey (NCPES) 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
- methods for establishing changes from 2024 and 2023 and overall changes (2024 to 2021)
- how statistical confidence intervals around scores have been calculated
- methodology for expected range and how to interpret the results
- information on data limitations, including coverage, gratitude bias, survivorship bias, recall bias, response rates and non-response bias

All of the results are available at www.ncpes.co.uk.

Our statistical practice is regulated by the Office for Statistics Regulation (OSR). OSR sets the standards of trustworthiness, quality, and value in the Code of Practice for Statistics that all producers of official statistics should adhere to. You are welcome to contact us directly with any comments about how we meet these standards. Alternatively, you can contact OSR by emailing regulation@statistics.gov.uk or via the OSR website.

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Helpdesk activity

A Freephone helpline and an email contact were available throughout the fieldwork period allowing respondents to do the following: opt out of the survey, ask questions, complete the questionnaire over the phone, or access translation services for those whose first language was not English. The online survey was also available to complete in three additional languages (Bengali, Punjabi and Polish) with 66 responses being completed in Polish. 2,920 calls were made to the Freephone helpline (Table 1), and 200 emails sent to the email contact address (Table 2). The nature of the calls and emails is outlined below.

Table 1: Number of helpline telephone contacts by query type for the National Cancer Patient Experience Survey (NCPES) 2024

Query type	Number
Questionnaire already returned	1054
Patient too ill/frail to take part, wishes to opt out	717
Queries about the survey/a question/the questionnaire	407
Other	221
Wants to complete (received reminder but not mailing 1)	142
Patient does not have cancer	71
Deceased individual	66
Questionnaire paper copy request	52
Needs help to complete survey	45
Not eligible for the survey	31
Patient has requested accessible survey - large print, Easy Read or Braille	18
Needs help to complete survey in other languages (linked to Language Line)	17
Technical/IT difficulties	11
Complaint about the survey itself	11
Not known at this address	11
Objection to receiving a questionnaire/data being held	3
Queries about data protection/confidentiality/GDPR/NHS data sharing etc.	3
Complaint/query about the hospital and/or treatment received	2
Total	**2882**

Table 2: Number of helpline email contacts by query type for the National Cancer Patient Experience Survey (NCPES) 2024

Query type	Number
Patient too ill/frail to take part, wishes to opt out	78
Questionnaire already returned	54
Queries about the survey/a question/the questionnaire	22
Not eligible for the survey	11
Deceased individual	10
Other	9
Patient does not have cancer (see process flow chart)	8
Wants to complete (received reminder but not mailing 1)	4
Not known at this address	2
Questionnaire paper copy request	2
Total	**200**

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.

Please note that following a review of the scoring methodology in 2022, a change was made to the scoring of Q12 such that the response option "No, I was told by letter or email" is no longer considered neutral and is now scored as negative.

Adjusted response rate

During fieldwork for the 2024 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 (outcome '2'), were deceased (outcome '3'), or were not eligible to take part (outcome '5') were excluded from this calculation.

Suppression

Data is suppressed for two reasons: to ensure unreliable results based on very small numbers of respondents are not released, and to prevent individuals being identifiable in the data.

The suppression methods for the survey follow the “NHS Information Standards Board Anonymisation Standard” which fell within NHS England’s remit during the amalgamation of organisations that took place over 2022 and 2023.

In cases where a result is based on fewer than 10 responses, the result has been suppressed. For example, where fewer than 10 people answered a question from a particular organisation, the results are not shown for that question for that organisation.

For organisations with an eligible population of 1,000 or fewer, data relating to the respondent and their condition has been suppressed where 5 people or fewer were in a particular category. In instances where only one has been suppressed, the next lowest category has been suppressed to prevent back calculation from the total number of responses.

Additional custom suppressions were applied in the following way:

- Cancer type requires custom suppression as this feeds into tumour group. Tumour group (upper level) follows the standard suppression process. Cancer type (lower level) suppresses based on the same rule but when the second suppression is applied it is done so within each tumour group.
- Long-term condition suppression is only applied where the "yes" answer code is presented, and there is no need for further suppression as this is a multiple-choice question. The binary version of the long-term condition suppression process remains standard.
- Where multiple suppressions occur within a row or column, and each suppressed count is one, an additional double suppression is applied. No further double suppressions are applied after this.
- The 2024 reports introduced the “number of long-term conditions” subgroup in addition to the existing long-term condition status subgroup. Both subgroups are derived from the same long-term condition question, and standard disclosive suppression alone may risk revealing suppressed counts. The “number of long-term conditions” subgroup is reported at national, cancer alliance, and ICB levels, but not at trust level. There are no additional suppression requirements at ICB level for this survey year; however, if suppression occurs in the future or if the subgroup is introduced at trust level, custom rules will be implemented to align suppression across both subgroups.

Population is defined as the number of patients eligible to complete the survey for each organisation. In the case where only a small number of organisations satisfy this condition, additional suppression may need to be carried out to larger organisations to prevent back calculation of suppressed results.

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, the differing populations across trusts 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, integrated care board (ICB) 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%
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 five characteristics of the patients: age, ethnicity, 'Which of the following best describes you?', 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.
- **'Which of the following best describes you?'** was taken from Q64 where respondents indicate how they identify. 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 39 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[1]. In some cases (389 in 2024), 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 single year (2024) national analysis and in the unadjusted results for the relevant NHS trust. However, they do not appear in any year-on-year comparisons, or the ICB or Cancer Alliance results as these are only presented for England.

Case-mix adjustment for trusts, ICBs 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.

Cancer Alliance and ICB results

Cancer Alliance and ICB results are derived using the postcode of each patient, rather than by mapping trust results to Cancer Alliances or ICBs. Cancer Alliance and ICB results therefore reflect the experience of people referred from within the geographical footprint. This mapping is achieved using lookup files released by the Office for National Statistics[3]. Alliance and ICB results are therefore presented at the 'England' level and exclude other UK postcodes. This is why England level data is used to compare within Cancer Alliance and ICB outputs, as opposed to National level data.

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[1] For the 2024 survey the LSOA 2021 mapping has been used to derive the IMD quintiles. All 2024 results and historic results (2023, 2022 and 2021) have been calculated using this mapping. Prior to the 2023 survey, the LSOA 2011 mapping had been used, therefore historic comparisons should not be made between the 2024 / 2023 reports and 2022 / 2021 reports for the IMD quintiles.
[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
[3] https://geoportal.statistics.gov.uk/datasets/b54177d3d7264cd6ad89e74dd9c1391d/about

Boundary changes, organisational mergers and recalculation of historic results

If geographical boundaries change over time, or if organisational mergers occur, historic results will be recalculated based on the most recent mapping to ensure comparability.

Due to geographical boundary changes in 2024, historic results have been recalculated to ensure comparability with the 2024 data. For the 2024 survey, LSOA 2021 mapping was used to derive IMD quintiles, as detailed in the section above.

To maintain consistency, this same mapping has also been applied retrospectively to results from 2023, 2022, and 2021. Prior to the 2023 survey, the LSOA 2011 mapping was used. As a result, historic comparisons of IMD quintile data should not be made between reports using different LSOA mappings (i.e. 2023/2024 vs. 2022/2021 as originally published). In the case of an organisational merger, historic results will be recalculated to include both organisations, enabling relevant comparisons over time. Examples of this include:

Survey year	New organisation	Previous organisations
NCPES 2024	East of England Cancer Alliance	East of England Cancer Alliance – North East of England Cancer Alliance – South
	Mersey and West Lancashire Teaching Hospitals NHS Trust (RBN)	St Helens and Knowsley Teaching Hospitals NHS Trust (RBN) Southport and Ormskirk Hospital NHS Trust (RVY)
NCPES 2023	Somerset NHS Foundation Trust (RH5)	Somerset NHS Foundation Trust (RH5) Yeovil District Hospital NHS Foundation Trust (RA4)

Question comparability

The questionnaire was redeveloped for the 2021 National Cancer Patient Experience Survey. Year on year comparisons between 2021, 2022, 2023 and 2024 are included for most questions.

Other comparability changes to be noted are:

- In 2023, the question text for Q23 and Q42 were amended. These questions are no longer deemed comparable to 2021 and 2022. Data is only comparable for 2023 and 2024.
- In 2023, the long-term condition question (Q67) was amended to include “Autism or autism spectrum condition” as a response option. And the “Neurological condition” answer option was updated to include an example condition changing it to “Neurological condition, such as epilepsy”. These changes see the answer option “Neurological condition, such as epilepsy” no longer being deemed comparable to 2021 and 2022. Data for this answer option is only comparable for 2023 and 2024.
- In 2023, the ethnic group question (Q71) was amended to include “Roma” as an answer option. The ethnic group question is still deemed comparable between 2021 and 2024. Data for the answer option “Roma” is only available for 2023 and 2024.
- In 2024, an additional long-term condition subgroup “number of long-term conditions” was introduced. This subgroup is not available in the outputs from previous years.
- In 2024, the binary groupings of the overall rating of care question were changed from ‘’0 to 6’’ and ‘’7 to 10’’ to ‘’0 to 7’’ and ‘’8 to 10’’. This change means the 2024 binary results of Q59 are not comparable to previous years.

Comparisons between 2023 and 2024, and trend comparisons (2021-2024)

Introduction

The scores for each of the comparable scored questions from the 2023 results were compared with those from the 2024 results to see if there are any significant differences. Comparisons were also made across the last 4 iterations of the survey (2021-2024) to see if there are any significant differences. Comparisons were made at national, trust, ICB and Cancer Alliance level for each scored question.

How to interpret the results

In the Excel tables and the national PDF report, results between 2023 and 2024 as well as trend results (between 2021 and 2024) are marked with either ‘↑’ or ‘↓’ for a statistically significant increase or decrease respectively. No arrow indicates no statistically significant change. In the National PDF report, ▼ or ▲ arrows have been used in the subgroup

section to denote whether the score for the subgroup shows a statistically significant variation (higher or lower) compared with the national average.

In the organisational PDF reports (trust, Cancer Alliance and ICB) results between 2023 and 2024 are marked with either a ▼ or ▲ for a statistically significant increase or decrease respectively. No arrow indicates no statistically significant change. In all reports, a '*' is used to indicate when a result is supressed or not available due to lack of data, and a '-' indicates that there is no data available or the data is not applicable due to an organization not having historic results. It can also be used to indicate that a significance test cannot be shown because data has been supressed.

In all reports, † is used in the excel reports to show that data is not comparable or subject to caveats.

Methodology

A longitudinal logistic regression model with robust variance estimation was used to determine whether there has been a significant change from the previous year and whether there are any trends over the last 4 years. A linear regression was used to determine whether there are any changes to Q59 (overall experience question) from last year and over the last 4 years. Age, IMD quintile, ethnicity and tumour group are added as covariates since these variables may differ across years. Results were considered significant at the 99% ($p<0.01$) level.

As the longitudinal logistic regression model utilises IMD quintile, year on year counts and scores have non-England cases excluded. This is because they do not have England IMD quintiles that are used in the model.

Mailing error and mailing one reprint

Within the first mailing for the 2024 survey there was a batch of 400 paper questionnaires (out of 135,429) which had been printed incorrectly by Picker's printing supplier. Corrected questionnaires and a letter explaining the error were sent to these individuals 10 days after the first mailing.

The error affected individuals across 17 NHS trusts. The majority of trusts had a small number of individuals affected and there was no impact on the survey results. Three trusts had a higher number of individuals affected and additional data checks were completed to assess the impact of the incorrect printing on response rates and the demographic profile of participants. No evidence of negative impact was found, and the survey results were not impacted. Therefore, there is no change to the reporting outputs, the results received by the trusts, or any historical trend data comparisons due to this issue.

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.

In the national PDF report, ▼ and ▲ are used to indicate statistically significant differences between subgroups and the national average.

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:

- Which of the following best describes you?
- Is your gender identity the same as the sex you were registered at birth?
- Sexual orientation
- Ethnicity
- Age
- 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 +/- 1.95996398454 standard errors (exact z-value), 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, +/- 1.95996398454 standard errors (exact z-value) were 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[4] 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 and '1' in the local ICB, trust and Alliance-level reports, and in the data tables.

[4] https://www.cqc.org.uk/sites/default/files/2023-09/20230912_aip22_TechnicalDocument.odt

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 and '3' in the local ICB, 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 and '2' in the local ICB, 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 (ICBs, trusts or Alliances), i.e. by 191, 143 or 20. For example, for ICBs:

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

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, ICB 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[5] 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.

[5] For patients residing in England.

Respondent burden calculation

The National Cancer Patient Experience Survey (NCPES) statistical practice is regulated by the Office for Statistics Regulation (OSR). OSR sets the standards of trustworthiness, quality, and value in the Code of Practice for Statistics that all producers of official statistics should adhere to. 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 NCPES we take the total number of respondents to the survey multiplied by the average time spent completing the online survey[6].

Limiting the time frame to just those individuals who started and finished the online survey on the same date, the average completion time is 28 minutes. (This is then 98.5% of all online respondents or 14,427 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 96.4% of all online respondents or 14,166 respondents).

Therefore, respondent burden calculated results for the 2024 NCPES are:

64,055 respondents x 24 minutes = 25,622 hours spent completing the survey.

Data limitations

As with any survey, statistical analysis of data from the NCPES has been susceptible to various types of error from different sources. Potential sources of error have been carefully controlled through development work in terms of questionnaire design and sampling strategy, which is in turn supported by extensive quality assurance at every stage of the survey.

Coverage

Patient samples submitted by the trusts include those patients who were discharged from an NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June. Patients who have only received cancer care outside of these months are not included in the sample. Therefore, survey results represent the period of April to June.

Gratitude bias

It is important to be aware that there is often goodwill towards the NHS, which can influence how people respond to questions about services. Patients who are grateful for

[6] Average completion time is available for the online survey only. Please note the respondent burden calculation is based on all people who accessed the online survey. This count may vary from the final count of online respondents due to the data cleaning process.

the treatment they have received can often be reluctant to say things that might appear to criticise the service and/or staff who helped them. This is known as ‘gratitude bias’.

This bias can be mitigated by asking about specific aspects of their experience rather than general questions about their overall experience. This approach provides a clearer understanding of areas needing improvement.

Ensuring the survey is anonymous and reassuring the participant of this (i.e., their individual responses won’t be seen by the people that provide their care) also helps to encourage honest feedback.

Survivorship bias

In the context of collecting survey data from cancer patients, survivorship bias could be present due to the time lag between patients receiving care and treatment (April-June) and receiving the survey (November-February). Patients with less survivable cancers are at a higher risk of passing away between the time they received care and the time they are surveyed. Consequently, the survey results are biased towards reflecting the experiences and outcomes of those who survived longer, which may not be representative of all patients initially treated.

The potential effects on the final results are:

- The survey data will likely overrepresent the experiences and outcomes of patients with more survivable cancers. This can lead to conclusions that may not accurately reflect the experiences of those with less survivable cancers.
- Since patients with less survivable cancers may not live long enough to respond to the survey, the data may underreport the negative experiences associated with these types of cancers. Patients with more aggressive cancers often have a higher symptom burden, which could negatively impact their overall satisfaction with care.[7,8] This underrepresentation could result in a more positive assessment of the care experiences for the overall NCPES results.

For example, analysis of survival by cancer group for adults diagnosed between 2016 and 2021 shows pancreatic cancer had the lowest survival estimate of all cancers for 1-year, for both males (27.4%) and females (28.1%)[9]. The survey data is therefore likely to

[7] Qian, C.L., Kaslow-Zieve, E.R., Azoba, C.C. et al. Associations of patient-reported care satisfaction with symptom burden and healthcare use in hospitalized patients with cancer. Support Care Cancer 30, 4527–4536 (2022). https://doi.org/10.1007/s00520-021-06764-y

[8] Lis, C.G., Rodeghier, M., Grutsch, J.F. et al. Distribution and determinants of patient satisfaction in oncology with a focus on health related quality of life. BMC Health Serv Res 9, 190 (2009). https://doi.org/10.1186/1472-6963-9-190

[9] https://digital.nhs.uk/data-and-information/publications/statistical/cancer-survival-in-england/cancers-diagnosed-2016-to-2020-followed-up-to-2021/survival-by-cancer-group

underrepresent the experiences of patients with pancreatic cancer overall, and overrepresent the experiences of those with pancreatic cancer who have survived which will not represent the whole population.

By recognising these limitations, healthcare researchers and providers can better understand the potential biases in their survey data and interpret the results with caution.

Recall bias

The NCPES 2024 used a mixed mode methodology. Questionnaires were sent by post, with two reminders where necessary, but also included an option to complete the questionnaire online. At places in the questionnaire people are asked to think about care received in the last 12 months.

Recognising the possibility of recall bias, where individuals might be unable to accurately remember their experiences, specific measures were taken to mitigate this issue. Recall bias can lead to inaccuracies in data when respondents have difficulty remembering past events or are influenced by subsequent experiences.

The following points outline steps taken to mitigate recall bias:

- **Cognitive testing:** The questions were cognitively tested with people who met the same eligibility criteria as the survey respondents to ensure that the questions could be recalled appropriately.
- **Answer codes:** Where required, “Don’t know / can’t remember” answer codes were included to provide respondents with an option that accurately reflects their memory of the events.
- **Reminders:** Reminders were included in both the covering letter and the questionnaire itself, prompting respondents to reflect on the relevant time period when answering the questions.
- **Timely mail out:** The surveys were mailed out as soon as possible after sampling. Patients received care and treatment from April to June, and the survey was conducted from November to February, demonstrating a time lag that was minimized as much as possible to reduce the risk of recall bias.

Despite these efforts, some degree of recall bias may still be present, as the accuracy of memories can vary among individuals. Factors such as the complexity of medical treatments, the emotional impact of cancer care, and the time elapsed since the care was received can all influence how well respondents remember and report their experiences.

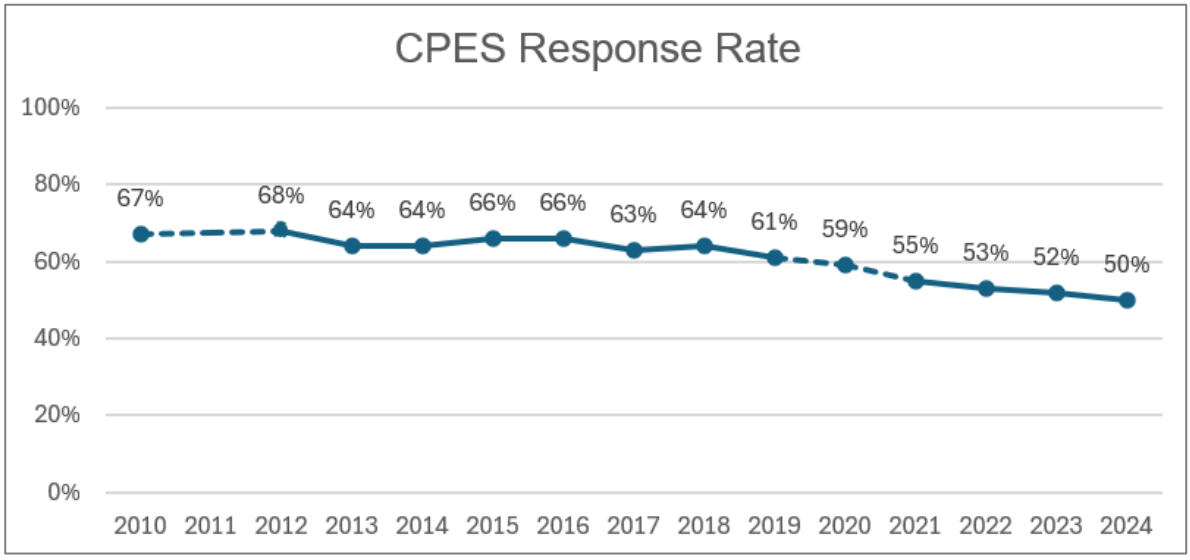
By acknowledging and addressing recall bias through these measures, the survey aims to gather more accurate and reliable data, leading to better insights into the cancer patient experience.

Response rates

The response rate for the NCPES 2024 is relatively high compared with other national patient experience surveys. However, the response rate (50% in 2024) has shown a steady decline in recent years, down from 55% in 2021. A similar decline is happening with other NHS patient surveys, as well as more widely in social and market research surveys.

Figure 1 shows the response rate trends for NCPES since first undertaken in 2010 (the year the survey was established). The survey was not conducted in 2011, and the 2020 survey was voluntary. The dotted line on the chart indicates this interruption in data collection.

Figure 1: Adjusted response rates for NCPES since 2010



A lower response rate means fewer responses are received from cancer patients which can reduce the accuracy of results. Future implications of declining response rate may mean that a larger initial sample size is required to get the same number of responses, which has cost and resource implications. For NCPES, this would mean extending the sampling period across more months in the year, for example including patients receiving cancer related treatment in March so that the window is 1st March to 30th June (rather than 1st April to 30th June used currently).

Several measures are employed to maximise response rates achieved on NCPES. This includes, but is not limited to, minimising survey length; using multiple contacts to invite patients to take part; a choice of response modes (telephone, online, paper); employing best practice design principles to invitation letters, for example personalisation and persuasive messaging; offering support to participants via a telephone and email helpline; as well as supporting with accessibility offers such as the use of a translation help sheet in mailing packs and a translated section of the website.

Non-response bias

Non-response bias refers to the risk that respondents to a survey differ systematically from non-respondents, potentially skewing the survey results. For example, if non-respondents possess different characteristics or experiences compared to respondents, it can bias the findings. While response rates for surveys do not necessarily correlate with non-response bias and are dependent on the circumstances of the survey, the risk of non-response bias typically increases with lower response rates.

When trying to achieve a representative sample, it is important to offer alternative completion methods (such as paper) in addition to online, to mitigate non-response bias[10]. NCPES continues to offer both online and paper completion options, as surveys that use an online only methodology introduce coverage bias; those who cannot or would not complete an online survey will not take part. Overall, participants in online surveys tend to be younger and have completed higher education than participants that respond by other survey methods.

There are several limitations to assessing levels of non-response bias:

- We cannot always differentiate between those who received a questionnaire but chose not to respond (non-response), versus those who did not receive a questionnaire and hence could not respond (non-contact), even though mailings returned undelivered are logged during fieldwork.
- We do not have a way of finding out how non-responders would have answered had they participated. Therefore, comparisons for demographic variables such as age and ethnicity between responders and non-responders is often used as a proxy for assessing the level of non-response bias.

Table 3 below shows the response rates by key demographic groups (taken from sample data). Please note that Table 3 is based on information from trust sample files only and will therefore differ from response rates published elsewhere which are compiled from response data, or sample data if a response is missing. We cannot use respondent-provided information to calculate response rates, as the corresponding information is unavailable for non-respondents.

Table 3 indicates that certain demographic groups, such as young people, people from minority ethnic groups, and those from deprived areas, are less likely to respond to NCPES. This aligns with research from the NHS Patient Survey Programme (NPSP),

[10] E.g. Messer, B. L. and Dillman, D. A. (2011). Surveying the general public over the Internet using address based sampling and mail contact procedures. Public Opinion Quarterly, 75, 429-457

which also found that young people, individuals from Black and other minority ethnic groups, and those from deprived areas are consistently less likely to respond.[11] [12] [13]

These groups often report more negative experiences of care, meaning that by underrepresenting these groups the results may underrepresent their experiences[14]. As shown in Table 3 and 4, similar to most large-scale surveys, there is evidence of non-response bias in NCPES 2024. For example, older patients are more likely to respond than other age groups and also more likely to report a positive overall experience. Specifically, 48% of those aged 65 and over, rated their experience as '10,' compared with 43% of those aged 35 to 64 and 33% of those aged 16 to 34. When interpreting Tables 3 and 4, please bear in mind that there are likely interrelationships between these groups.

Table 3: Response rates (adjusted) for the National Cancer Patient Experience Survey (NCPES) 2024 by demographic groups and tumour group

Group	Response rate
Age group	
16-24	19%
25-34	22%
35-44	26%
45-54	36%
55-64	45%
65-74	58%
75-84	61%
85+	53%
Ethnicity	
White	52%
Mixed	36%
Asian or Asian British	30%
Black or Black British	31%
Other ethnic groups	38%
Not stated	51%
Not known	53%

[11] nhssurveys.org/Filestore/documents/Increasing_response_rates_literature_review.pdf

[12] nhssurveys.org/Filestore/documents/Review_BMEcoverage_HCC_surveys.pdf

[13] nhssurveys.org/Filestore/documents/Increasing_response_rates_stakeholder_consultation_v6.pdf

[14] https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/

Group	Response rate
IMD quintile	
1 (most deprived)	39%
2	46%
3	52%
4	54%
5 (least deprived)	58%
Non-England	53%
Tumour group	
Brain / CNS	33%
Breast	49%
Colorectal / LGT	52%
Gynaecological	49%
Haematological	50%
Head and neck	47%
Lung	51%
Prostate	57%
Sarcoma	46%
Skin	54%
Upper gastro	48%
Urological	51%
Other	46%

Note: Some subgroups within the sample may have smaller base sizes, such as the age group 16-24, non-England records, and the Brain/CNS tumour group, each having fewer than 900 records in the sample and fewer than 400 respondents in the survey.

Table 4 shows key demographics for the overall sampled cohort for the survey (taken from sample data) versus for respondents (taken from response data).

Table 4: Sample (eligible) versus response profile for the National Cancer Patient Experience Survey (NCPES) 2024

Group	Sample profile	Response profile
Age group		
16-24	1%	0%
25-34	2%	1%
35-44	5%	3%
45-54	11%	8%
55-64	23%	21%
65-74	29%	33%
75-84	24%	29%
85+	5%	5%
Ethnicity		
White	76%	78%
Mixed	1%	0%
Asian or Asian British	3%	2%
Black or Black British	2%	2%
Other ethnic groups	2%	2%
Not stated	14%	14%
Not known	2%	2%
Tumour group		
Brain / CNS	1%	0%
Breast	22%	22%
Colorectal / LGT	11%	11%
Gynaecological	5%	4%
Haematological	14%	14%
Head and neck	3%	3%
Lung	7%	7%
Prostate	11%	12%
Sarcoma	1%	1%
Skin	4%	4%
Upper astro	5%	5%
Urological	7%	7%
Other	10%	9%

Group	Sample profile	Response profile
IMD quintile		
1 (most deprived)	16%	12%
2	19%	17%
3	21%	22%
4	22%	24%
5 (least deprived)	22%	25%
Non-England	1%	1%

Data quality statement

Purpose

This data quality statement aims to provide users with an evidence-based assessment of the quality of the data used in the National Cancer Patient Experience Survey. It reports against the European Statistical System (ESS) quality dimensions and principles appropriate to this output.

In doing so, this meets our obligation to comply with the UK Statistics Authority (UKSA) Code of Practice for Official Statistics, particularly Principle Q3 which states that 'Producers of statistics and data should explain clearly how they assure themselves that statistics and data are accurate, reliable, coherent and timely'.

Relevance

The degree to which a statistical product meets user needs in terms of content and coverage.

The survey is designed in collaboration with an Advisory Group which includes representatives from providers, Cancer Alliances, a range of charities, lived experience partners, commissioners, and survey experts. It is regularly tested with a range of users, in particular when new questions are included.

The outputs are used by a wide range of users such as:

- NHS England and Department of Health and Social Care, to monitor the experience of patients and in policy development.
- ICBs, Cancer Alliances and trusts, to understand aspects of patient experience in their area
- Charities, to inform service improvement, advocacy, and support resources for people affected by cancer
- Academic researchers, to analyse trends and contribute to the evidence base on cancer care

Accuracy and reliability

The difference between an estimated value and the true value.

The figures in this publication come from a survey which gathers information from those people from the whole population who have chosen to respond. Results from this survey are always estimates, not precise figures. This can have an impact on how differences in the estimates should be interpreted.

As the number of people available gets smaller (for example for individual trust results, rather than national) the variability of the estimates that we can make gets larger. Estimates for small groups are less reliable and tend to be more volatile than for larger aggregated groups.

In order to quantify the uncertainty around point estimates, 95% confidence intervals are presented in some outputs (see the confidence intervals section for more information). In general, attention is drawn differences between estimates only when they are significant at the 95% confidence level.

Another aspect of accuracy comes from the quality of the data collected in the survey and subsequent quality assurance, which is described in general terms elsewhere in this document.

In particular, we are reviewing the accuracy and reliability of two specific questions:

Which of the following best describes you?

- Male
- Female
- Non-binary
- Prefer to self-describe
- Prefer not to say

Is your gender identity the same as the sex you were registered at birth?

- Yes
- No
- Prefer not to say

These questions were introduced in 2021 after full testing and significant engagement. They were intended to be an inclusive way of capturing gender identity and a proxy for gender reassignment, whilst continuing to collect information on the protected characteristic of sex, since a combination of the two questions was designed to also be used to derive sex (see FAQs for more detail). However, there are indications that some responders are answering these questions in potentially unexpected ways, and we are carrying out an in-depth review before drawing conclusions and making future

recommendations. In the meantime, we have improved how we label these questions in the reporting outputs in order to improve accuracy and to help users interpret the data.

Timeliness and punctuality

Timeliness describes the time between the date of publication and the date to which the data refer. Punctuality describes the time between the actual publication and the planned publication of a statistic.

This report contains data covering a three month period and is collected annually. The complexities and cost of running an in-depth, representative, robust survey such as this mean that it is not currently possible to complete more frequently than annual.

The publication is released several months after the survey closes to allow for data processing, analysis and quality assurance. Last year some outputs were staggered and released later, however this is not the case this year and it has been possible to release all outputs at the same time which will benefit users.

The release is in line with pre-announced publication dates.

Accessibility and clarity

Accessibility describes the ease with which users can access data. Clarity describes the quality and sufficiency of metadata, illustrations and accompanying advice.

This publication is available in a bespoke website and is a combination of HTML web pages and pdfs for description, charts, and graphs, with data provided in usable formats, such as Excel spreadsheets, csv files and web-based report building dashboard tools. The publication includes many of the Government Statistical Service recommendations on improving accessibility of spreadsheets for users.

The survey questionnaires and fieldwork communication materials are shared alongside the published results. The technical document describes the methodologies used to generate the survey sample and the subsequent results.

Coherence and comparability

Coherence is the degree to which data derived from different sources or methods, but that refers to the same topic, is similar. Comparability is the degree to which data can be compared over time and domain, for example, geographic level.

There are no other nationally published sources of data measuring the experience of cancer patients with which these data could be compared.

The survey has been running for many years, however changes in questions asked, how the survey is administered, and underlying methodology mean it is not possible to compare data across the full lifetime of the survey. Comparing across different domains is

possible, taking into account the inherent uncertainty in the results and associated confidence intervals (see Accuracy and Reliability section).

Trade-offs between output quality components

The extent to which different aspects of quality are balanced against each other.

Service delivery, national policy and survey administration methods can and do change over time and therefore it is necessary to revise both the questions and how the survey is delivered. However, changes of this nature are likely to break trends and therefore they must be balanced against user requirements for time series data. In practice this usually means large scale changes across different aspects of the survey are introduced in one go, and approximately every 5 years, in order to prevent more regular disruption to the time-series.

A survey of this scale, complexity requires a relatively long time period to administer, analyse and change, and this does come somewhat at the expense of timeliness. However, this is balanced against the depth and robustness of the resulting data.

Completion of the survey and all questions within it are voluntary and self-completed. Support is provided in a variety of ways to help the responder to complete as accurately as possible.

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.

Questions 53 and 54 are currently under review by NHS England.

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	1	Yes	n/a
		2	No	n/a

Question	Question text	Answer option	Option text	Scoring
	named in the covering letter? This could have been an endoscopy, biopsy, blood test or a scan.			
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
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		1	Yes, always	1

Question	Question text	Answer option	Option text	Scoring
	Were you given enough privacy when receiving the results of your tests?	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	0
		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

Question	Question text	Answer option	Option text	Scoring
		3	No	0
		4	Don't know / can't remember	n/a
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

Question	Question text	Answer option	Option text	Scoring
		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 you wanted them to be in decisions about your treatment options?	1	Yes, definitely	1
		2	Yes, to some extent	0
		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 further advice from a different 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

Question	Question text	Answer option	Option text	Scoring
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

Question	Question text	Answer option	Option text	Scoring
Q31	Did you have confidence and trust in the team looking after you?	1	Yes, in all of them	1
		2	Yes, in some of them	0
		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	1	Yes, always	1
		2	Yes, sometimes	0

Question	Question text	Answer option	Option text	Scoring
	wanted to help control your pain?	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 able to talk to hospital staff about your worries or fears if you needed to?	1	Yes, always	1
		2	Yes, sometimes	0
		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		1	Yes, completely	1

Question	Question text	Answer option	Option text	Scoring
	Before your treatment started were you given all the information you needed about the treatment in a way that you could understand? Chemotherapy	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 had started, were you given enough information about your response to 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
Q42_2	Once your treatment had started, were you given enough information about your response to 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
Q42_3		1	Yes, completely	1

Question	Question text	Answer option	Option text	Scoring
	Once your treatment had started, were you given enough information about your response to treatment in a way that you could understand? Radiotherapy	2	Yes, to some extent	0
		3	No	0
		4	Don't know / can't remember	n/a
Q42_4	Once your treatment had started, were you given enough information about your response to 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
Q42_5	Once your treatment had started, were you given enough information about your response to 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
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	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

Question	Question text	Answer option	Option text	Scoring
	effects of your treatment(s)?	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
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	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0

Question	Question text	Answer option	Option text	Scoring
	community or voluntary services?	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

Question	Question text	Answer option	Option text	Scoring
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
		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?	0	Very poor 0	0
		1	1	1
		2	2	2
		3	3	3
		4	4	4

Question	Question text	Answer option	Option text	Scoring
		5	5	5
		6	6	6
		7	7	7
		8	8	8
		9	9	9
		10	Very good 10	10

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 2024 results. Following consultation with stakeholders in 2022, the mapping has been updated to take into account:

- Separating out Cholangiocarcinoma (CCA) from the "Liver" cancer type to form its own cancer type.
- Moving ICD codes C70 and C72 out of the "other" tumour group and into the "Brain / CNS" tumour group.
- The cancer type "Parotid" has been renamed to "Salivary glands". The cohort of patients included in the results for the salivary glands cancer type is the same as it was for parotid.

Tumour group	Cancer type	ICD code	Description
Brain / CNS	Brain / CNS	C70, C71, C72	Malignant neoplasm of meninges (C70), brain (C71) and spinal cord, cranial nerves and other parts of central nervous system (C72)
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
	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)

Tumour group	Cancer type	ICD code	Description
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
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)
	Salivary glands	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)

Tumour group	Cancer type	ICD code	Description
	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 (excluding cholangiocarcinoma)	C22.0, C22.2-C22.9	Malignant neoplasm of liver: liver cell carcinoma (C22.0), hepatoblastoma (C22.2), angiosarcoma of liver (C22.3), other sarcomas of liver (C22.4), other specified carcinomas of liver (C22.7) and liver, unspecified (C22.9)
	Cholangiocarcinoma	C22.1, C24.0, C24.8, C24.9	Malignant neoplasm of intrahepatic bile ducts and other and unspecified parts of biliary tract: intrahepatic bile duct carcinoma (C22.1), extrahepatic bile duct (C24.0), overlapping lesion of biliary tract (C24.8) and biliary tract, unspecified (C24.9)
	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	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, C24.1, C26, C30, C31, C37, C38, C39, C47, C57, C58, C63, C68, C69, C74, C75, C76, C80, C86, C88, C96, C97