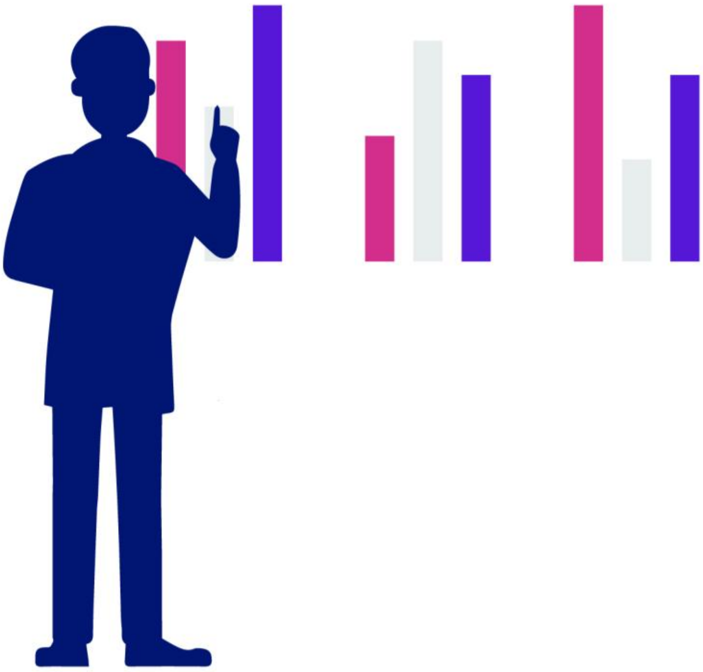
Under 16 Cancer Patient Experience Survey 2023

Technical Appendix

November 2024



Contents

Introduction

This document sets out the methodology and analysis approach used in the Under 16 Cancer Patient Experience Survey (U16 CPES) 2023 and gives guidance on how to interpret the results. This includes:

- how the adjusted response rate was calculated
- how percentage scores have been derived for each scored question
- rules on suppression and where it was applied
- how statistical confidence intervals around scores have been calculated
- how to interpret Principal Treatment Centre (PTC) results
- guidance on data limitations and how this is mitigated

All results are available at https://www.under16cancerexperiencesurvey.co.uk

Note on terminology

The term 'sample' is used throughout this document to refer to the eligible population that fulfils the established sampling criteria. Additionally, the term ‘sample’ may also refer to the respondents of the survey.

Eligibility

The sample for the survey included all patients with a confirmed tumour or cancer diagnosis who received inpatient or day case care from NHS Principal Treatment Centres (PTCs) between 1 January 2023 and 31 December 2023, and were aged under 16 at the time of their discharge.

Duplicate patient records were identified by NHS number and removed as follows:

- **Step 1: De-duplication across trust samples**: When a patient appeared on more than one NHS trust list, the records for the hospital site that was attended most frequently (i.e. with the most records for that patient) were retained. If the number of records for a given patient was identical across two or more sites, the record(s) were retained for the site that had the most recent discharge date.
- **Step 2: De-duplication within trust samples:** When patients appeared multiple times within a trust list, the record with the latest discharge date was retained.

Fieldwork

The fieldwork for the survey was undertaken between April and June 2024. One of three versions of the survey was distributed based on the patient’s age immediately prior to survey fieldwork (30 March 2024):

- The 0-7 questionnaire; sent to parents or carers of patients aged between 0 and 7 years old
- The 8-11 questionnaire, sent to parents or carers of patients aged between 8 and 11 years old
- The 12-15 questionnaire; sent to parents or carers of patients aged between 12 and 15 years old

Survey methods

Questionnaires sent to those aged 8-11 and 12-15 contained a section for the child to complete, followed by a separate section for their parent or carer to complete. Where a child was aged 0-7, the questionnaire was completed entirely by their parent or carer.

Please note that questionnaire version was assigned based on the patient’s age immediately prior to survey fieldwork (on 30 March 2024) as opposed to their age at the time they received care. This was to ensure children received a questionnaire that was age-appropriate in terms of design and wording.

Questions asked recipients about their (or their child’s) cancer care in 2023. Some patients may have been 16 or 17 years old when they received the questionnaire if they were 15 at the time of their discharge but then had a birthday or two prior to the survey being sent out.

The survey used a mixed mode methodology. Questionnaires were sent by post and addressed to the parent or carer of the child, with two reminders sent to non-responders, and also included an option to complete the questionnaire online.

Management information status update

Official statistics are statistics produced by Crown bodies and other organisations listed within an Official Statistics Order, on behalf of the UK government or devolved administrations. Up to now, U16 CPES has been published as an official statistic under the badge of ‘experimental statistics’ reflecting its status as a new survey and set of data. This terminology has recently been changed across all official statistics to ‘official statistics in development’ and is intended to be time limited.

There has been a review of the status of U16 CPES, based on the first 3 publications of the survey results (2020,2021 and 2022). There are known limitations associated with U16 CPES which have been made clear at the time of publication, namely that the small population and low response rates lead to a relatively high degree of uncertainty in the results, meaning that comparisons between organisations and demographic groups is cautioned. These limitations mean the survey cannot progress to a status of ‘official statistics’ and is instead given the label of ‘management information’. **Although we have made this change in status, in practice we have maintained the same rigorous approach to survey collection, data production, reporting and quality assurance as in previous years, using the Code of Practice for Statistics as our framework. This means there is no material difference to this year’s publication as a result of this new status and we encourage you to review and use the results to identify and drive improvement as you would do, noting the limitations shared at the time of publication.**

Helpdesk activity

Both a Freephone helpline and an email contact were available enabling 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.

Nineteen calls were made to the Freephone helpline (Table 1), and seven emails sent to the email contact address (Table 2). The nature of the calls and emails was as follows:

Table 1: Number of helpline telephone contacts by query type

Query type	Number
In call support	**9**
Call disconnected / no answer / hung up	4
General support to complete questionnaire	3
Surveys completed over the phone	2 (inc. 1 completed via Language Line in Urdu)
Request to remove from future mailings	**6**
Received reminder though had completed survey	4
Completed previous year	2
Ineligible	**4**
Total	**19**

Table 2: Number of helpline email contacts by query type

Query type	Number
Email support	**4**
General support to complete questionnaire	4
Request to remove from future mailings	**3**
Did not wish to complete the survey	3
Total	**7**

No one requested their data be deleted for U16 CPES 2023.

Question numbering

As the survey uses three separate questionnaires, a master question number was created for reporting purposes. This master question number is referenced in the data tables and final reports and differs to the question numbers used on the actual surveys. The ‘Question list’ tab in the Excel data tables (available on the survey website) indicate the question numbers in the surveys that correspond to each master question number.

Scoring

A score has been created for questions that address performance in relation to patient experience. This applies to most survey questions, excluding filter questions and demographic questions such as sex registered at birth or ethnic group. Response options that are not scored (for example, “don’t know/can’t remember”) or not applicable, are removed before the score is calculated.

All scores are presented as the percentage of positive responses out of all scored responses. For X59 ” Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)”, we also report X59 mean alongside the score, as the average of respondents' overall rating of care on a scale of 0-10.

Positive and negative responses

For each scored question, each response option has been identified as a positive, a negative response or are not scored. 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. Response options that are not included in the equation are denoted as "n/a" – see Appendix A for a full list of scored questions and their positive and negative responses.

From the example in Table 3 below, the question would be scored as follows:

> "60% of parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way"

Table 3: Example positive score calculation

Question text	Answer options	No. of responses	% of scored responses
Were you told about your child's cancer or tumour in a sensitive way?	**Yes, definitely**	**120**	**60%**
	Yes, to some extent	74	37%
	No	6	3%
	Don't know / can't remember	5	-

Scoring change

Please note the following scoring change for U16 CPES 2023:

For X32 "How easy was it for you to contact this person?", the positive score in 2022 was calculated from the response options "Very easy" and "Quite easy". For the 2023 survey, X32 scoring was aligned with the top-box scoring approach taken elsewhere in the survey, and as such only "Very easy" was used to calculate the positive score.
Historic comparability was maintained as historic scores were recalculated in line with the new scoring approach.
Scoring figures for X32 from previously published reports would not be comparable, but a caveat was added to the 2023 reports.

Adjusted response rate

During fieldwork for the 2023 survey, all patients were coded with an outcome code depending on their response to being sent the questionnaire. Please note that a response means one survey completion, which could be completed by both a parent/carer and a child.

The outcome codes were as follows[1]:

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[1] A separate outcome code of 7 was used for patients who passed away before fieldwork started. However, these are removed from the data as they were never sent the survey.

- 1 = Completed questionnaire
- 2 = Questionnaire returned undelivered (respondent did not receive the questionnaire)
- 3 = Patient deceased after first survey mailing
- 4 = Patient opted out of the survey (i.e. called the helpline to opt out, emailed to opt out, or returned a blank questionnaire)
- 5 = Patient was ineligible (i.e. was sampled incorrectly and does not meet the eligibility criteria for the survey)
- 6 = Unknown (i.e. no response received)

For those with an outcome code of 1, a response method was also assigned to indicate the mode of completion:

- 1 = patient completed paper questionnaire
- 2 = patient completed online questionnaire
- 3 = patient completed questionnaire in English by phone
- 4 = patient used Language Line to complete questionnaire with a translator in a language other than English
- 5 = mixed (respondent completed paper questionnaire and online questionnaire, e.g. a parent may have completed the paper questionnaire, and a child completed the online version)

To calculate the adjusted response rate percentage, the numerator was the number of records with an outcome code 1, and the denominator was the total number of records with an outcome of 1, 3, 4, and 6. Please note that patients who were deceased after the first survey mailing are included in the calculation since they would have received a survey and their parent or carer would have had the opportunity to complete it. Respondents that did not receive a questionnaire (outcome code 2) or were not eligible to take part (outcome code 5) were excluded from the adjusted response rate calculation.

Suppression

Data are 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. There are several steps to this suppression to prevent disclosure of information whilst also reporting on the largest volume of data possible. When a result is suppressed, it is replaced with an asterisk (*).

The suppression methods were updated for the 2022 survey in line with updates to 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. Suppression rules for U16 CPES 2023 follow those that were applied to the 2022 survey.

Disclosive purpose suppression

Quasi-identifiable data relating to the respondent and their condition has been suppressed where 5 people or fewer (excluding 0) were in a particular category. In instances where only one result has been suppressed, the next lowest result has also been suppressed to prevent back calculation from the total number of responses. If there is a tie on the next lowest result, suppression is applied by alphabetical order of the tied variables.

Robustness suppression

In cases where a result is based on fewer than 10 responses (including 0), the result has been suppressed for that question and response. 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 scored questions, the base size is based on counts of scored options, and for non-scored questions, the base size is based on counts of all options in the questionnaire.

PTC reporting - Suppression of the About the Respondents breakdown

Due to small numbers at PTC level, certain demographic response options have been aggregated, or excluded, to maximise data sharing whilst protecting patient's identities. A full demographic breakdown can be found in the National data tables.

Where it is possible, the breakdown of ”Not Givens” have been shown. An example of this is the Long-Term Condition breakdown, where “Not Givens” are shown and not suppressed. “Not Givens” have not been suppressed, as it does not disclose information.

PTC reporting – Suppression across the 2-group and 5-group ethnicity breakdowns

At PTC level, Ethnicity data have been presented at two levels of aggregation:

- 2-group (White; Mixed, Asian, Black and Other)
- 5-group (White; Mixed; Asian; Black; Other)

Where the White sub-group has been suppressed in the 2-group breakdown, it will also be suppressed in the 5-group breakdown. This is done so that the national score for that question cannot be used to work out the suppressed White score in the 2-group breakdown.

Not applicable values

Where a question is not asked in a particular survey type, for example question X02 is not asked in the 0-7 version, the values will be represented by “n.a.” (not asked). In this scenario, only the other survey type subgroups (8-11 Survey and 12-15 Survey) would count towards the disclosive suppression criteria.

Historical question comparability

The questionnaire was reviewed and tested ahead of the 2023 survey. Year on year comparisons between 2021, 2022 and 2023 are possible for most questions. The following changes to the questionnaire were made for the 2023 survey meaning that comparisons to previous years are not possible for those questions:

- A wording change to X06b was made to the 8-11 and 12-15 surveys so that it aligned with the wording of X06a in the 0-7 survey: “How did you feel about the length of time you waited between being referred by your GP to a hospital doctor until you were seen at the hospital?” (changed in tense from “How do you feel…?”). The question label was changed to X06.
- X11 was added to the 0-7 survey to align with its inclusion in the 8-11 and 12-15 surveys: “Did hospital staff give you details for who to contact if you wanted more information after you were told about your child’s cancer or tumour?”
- The wording of X44 was amended:

  - 0-7 survey: from “Was there a choice of hospital food for your child?” to “Was there a suitable choice of hospital food for your child?”
  - 8-15 surveys: from “Was there a choice of hospital food?” to “Was there a suitable choice of hospital food?”

- The long-term condition question (X65) was redesigned, changing from “Does your child have any unrelated physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more, other than their cancer or tumour?” (Yes/No options) to “Does your child have any of the following long-term conditions or illnesses? (Select ALL conditions that have lasted or are expected to last for 12 months or more)” (list of conditions).

- A follow-up question to the long-term condition question above was added to all survey versions. X66 asks: “Thinking about your child’s cancer or tumour, and other long-term conditions or illnesses, do any of these reduce your child’s ability to carry out their day-to-day activities?”

Confidence intervals

Introduction

The percentage figures given nationally and for each organisation, for each question, are an estimate of the score or proportion 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

All scores in U16 CPES are unadjusted. The following example shows the score for an organisation with 500 respondents to a question asking about whether parents or carers were told about their child’s cancer or tumour in a sensitive way. In this case (using dummy data), the score is 83% and the confidence interval is calculated as between 79% and 86%.

Table 4: Example confidence interval calculation

Reporting text	Number of responses	National Score	Lower 95% Wilson Confidence Interval	Upper 95% Wilson Confidence Interval
Parents or carers reported that they were definitely told about their child's cancer or tumour diagnosis in a sensitive way	500	83%	79%	86%

In instances where a score is calculated from a small base size, the confidence intervals will be wider.

For example, if 15 people responded to a question and 90% of these answered with a positive scored response, the confidence interval range is from 66% to 98%. However, if 1,000 people responded to the question and 90% of these answered with a positive scored response, the confidence interval range would be much smaller (88% to 92%).

This is most pertinent for scores at PTC level, and for questions that are asked to fewer people (i.e. questions asked only to children). Findings for these questions will often have especially wide confidence intervals, and so should be regarded as indicative rather than robust.

Where confidence intervals overlap, and the comparison is valid, there is not enough statistical evidence to conclude whether there is a “true” difference between the two. If confidence intervals do not overlap, and the comparison is valid, we could be confident that this is a “true” difference. It is crucial to note that **non-overlapping confidence intervals are not a substitute for statistical testing**. Confidence intervals can help visually estimate the precision of a sample's estimate, but they do not account for all factors considered in statistical testing.

Confidence intervals are included in the National report, PTC reports and online dashboard. Confidence intervals for year-on-year scores only are included in the National and PTC data tables. All of these outputs, except the online dashboard, can be found on the current results page of the website. The online dashboard will be available in early 2025.

Methodology

Confidence intervals for scores and proportions for all questions (aside from X59_mean) were calculated using Wilson’s confidence intervals. This approach was chosen as it is more robust for small numbers (both numerators and denominators), and for results close to 0% or 100%.

For X59_mean, confidence intervals are +/- the exact z score multiplied by the standard error, which was calculated by:

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

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

Interpretation of PTC results

All scored data have been calculated using unadjusted scores. Scores have not been adjusted for differences in patient profiles across PTCs (such as demographic and clinical characteristics, or what stage of care or treatment they are in). Thereby, PTCs with differing populations could potentially lead to results appearing better or worse than they would if they had a slightly different profile of patients.

In addition, the small sample sizes at PTC level mean that these scores will often have wide confidence intervals, meaning that we cannot be confident whether differences between PTC scores are reflective of true differences in patient experience, or due to random variation.

As a result, we recommend that PTCs take caution when benchmarking their results against those of other PTCs, or against results at National level.

We recommend that PTCs review their results for the 2023 survey and triangulate these with local intelligence and other data sources to identify areas for further local investigation. We recommend that this is done whilst also reviewing the information about who responded to the survey in the PTC, to understand the patient groups that make up (and do not make up) the results.

Year on year comparisons

Introduction

Scores and confidence intervals are presented at National and PTC level for each scored question for the 2023, 2022 and 2021 surveys. Results for 2020 are not reported on since:

- Feedback from cognitive interview testing with patients identified that clarification was needed on which period patients should be reporting on. Changes were made to the wording of the 2021 survey as a result, but it was possible that the 2020 and 2021 surveys reported on patients' experience of care across potentially different and overlapping time periods.
- The response rate in 2020 was notably higher than that in subsequent survey years. Coupled with a small sample size, this reduces statistical confidence in comparisons.
- The sampling period was during the pandemic during which care and services were affected. People's perceptions of their care and treatment were possibly impacted.

Diagnostic groupings

Please note that the diagnostic groupings available at the national level differ from those available at the PTC level. This is due to the greater number of groups that would be suppressed at the PTC level.

At the national level, the following groups are available:

Table 5: Diagnostic groupings at national level

Diagnostic Group – National	ICD10 Codes
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	C91-C95, D46
Lymphomas and reticuloendothelial neoplasms	C81-C90, C96
CNS and miscellaneous intracranial and intraspinal neoplasms	C70-C72, C75.1-C75.3, D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5
Retinoblastoma	C69.2
Renal tumours	C64, C65
Hepatic tumours	C22 - Exclude C22.3 and C22.4 and place in "all other"
Malignant bone tumours	C40-C41
All other	Subgroups X(c)-X(e) (gonadal): C56, C62 Subgroup XI(b) (thyroid): C73 Subgroup XI(d) (melanoma): C43 Any other ICD codes

At the PTC level, the following groups are available:

Table 6: Diagnostic groupings at PTC level

Diagnostic Group - PTC	ICD10 Codes
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	C91-C95, D46
Lymphomas and reticuloendothelial neoplasms	C81-C90, C96
CNS and miscellaneous intracranial and intraspinal neoplasms	C70-C72, C75.1-C75.3, D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5
All other	All other eligible ICD-10 codes fall under the 'Other' diagnostic group.

Data limitations

As with any survey, statistical analysis of data from the Under 16 Cancer Patient Experience Survey (U16 CPES) 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.

Proxy response bias

Surveys of children's experiences of care frequently ask the parent or carer to provide feedback on the child's behalf, with no opportunity for the child to report on their own experience. This potentially impacts the accuracy of survey results since findings reflect experiences from the perspective of the parent or carer, rather than from that of the child, and opinions may differ. It has also been shown that on some measures, children and their parents or carers report experiences across some metrics differently, with a tendency also for children to be less positive about the quality of care received[2].

To address these concerns, three age-appropriate questionnaires were designed with the age of the patient in mind. For children aged 8-15, a separate section was included for their parent or carer to complete.

Creating separate questionnaires for children to self-report their experience enables them and their parents or carers and to give their views and therefore gives a more accurate picture of the experience of children receiving cancer care.

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[2] Hargreaves, D.S., Sizmur, S.,Pitchforth, J. et al. Children and young people's versus parents' responses in an English national inpatient survey. BMJ Journals. Volume 103, issue 5. https://adc.bmj.com/content/103/5/486

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 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 type of bias was perhaps evident during the Covid pandemic, for example. This can be mitigated by asking about specific aspects of people’s experience rather than general questions about their overall experience or satisfaction. 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 and receiving the survey. 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 results are:

- The survey data will 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[3][4]. This underrepresentation could result in a more positive assessment of the care experiences.

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 survey 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

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[3] 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

[4] 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

places in the questionnaire, children and their parents or carers are asked to think about care received by the child during 2023.

Recall bias can lead to inaccuracies in data when respondents have difficulty remembering past events or are influenced by subsequent experiences. Due to sample size limitations, the sampling period for the survey needed to be longer than for the adult Cancer Patient Experience Survey (CPES), with patients eligible if they had received care or treatment during any time in 2023 and invited to complete a questionnaire during April to June 2024. This could potentially impact patients' and parents' or carers' ability to recall events.

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 ("during 2023") when answering the questions.
- **Timely mail out:** The surveys were mailed out as soon as possible after sampling to minimise any time lag between undergoing care and treatment to then receiving a questionnaire.

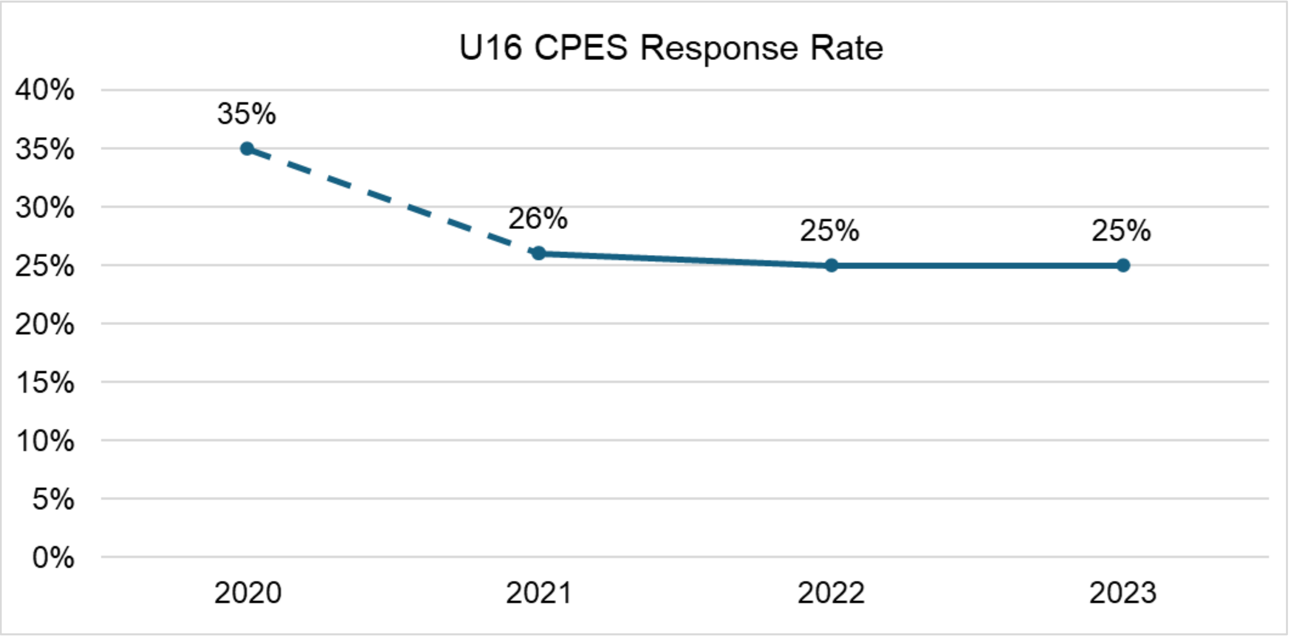
Despite these efforts, some degree of recall bias may still be present, as the accuracy of memories can vary among individuals. Factors such as the complexity of medical treatments, the emotional impact of cancer care, and the time elapsed since the care was received can all influence how well patients, and parents or carers, 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 U16 CPES 2023 is low when compared with a 52% response rate for the adult CPES 2023. Figure 1 shows the response rate trends for U16 CPES since it was first undertaken in 2020. Note the response rate was far higher in 2020 – this is likely due to the sampling period being during the Covid pandemic which may have influenced people's likelihood to respond. The dotted line indicates the break in comparability.

Figure 1: Adjusted response rates for U16 CPES



A lower response rate means fewer responses are received from cancer patients which can reduce the accuracy of results – though this is not always the case. Although 2020 saw a higher proportion of people responding, this was during the Covid pandemic and as such, care and services were affected along with people's perceptions of their care and treatment, and their views of the NHS in general. As such, this higher response rate does not necessarily translate into more 'accurate' patient experience measures.

Future implications of declining response rates may mean that a larger initial census size is required to get the same number of responses, which has cost and resource implications. For U16 CPES, the sampling window already spreads across the whole year, potentially affecting people's ability to recall. Other initiatives to improve response rates would therefore need to be investigated.

Several measures are employed to maximise response rates achieved on U16 CPES. This includes, but is not limited to, employing age-specific questionnaires; minimising survey length; using multiple invitations to take part; allowing the parent / carer, and / or the child to respond; offering a choice of response modes (telephone, online, paper); employing best practice design principles to invitation letters, for example personalisation and persuasive messaging; the inclusion of a child-friendly leaflet with age appropriate messaging encouraging children to complete the survey; 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[5]. U16 CPES 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.

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 7 below shows the response rates by key demographic groups (taken from sample data). Please note that this 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.

Note that while the response from different groups relating to the child are presented below in Tables 7 & 8, response is at least partly influenced by the parent or carer since: i) for consent reasons, survey invitations are addressed to the parent or carer, not the child; ii) a completed questionnaire return could have come from the child only, the parent only, or both. Care must be taken therefore in drawing conclusions around response biases when looking at groups that relate to information relating to the child (e.g. age group, gender, ethnicity, diagnostic group) rather than to the household (e.g. IMD quintile).

Certain groups, such as those from deprived areas, often report more negative experiences of care, meaning that by underrepresenting these groups the results may underrepresent their experiences[6]. The overall response rate for U16 CPES 2023 is 25%. Table 7 indicates that certain demographic groups, such as the 8-11 age group, more deprived groups, and those from certain diagnostic groups are less likely to respond.

Table 8 shows key demographics for the overall eligible population for the survey (taken from sample data) versus for respondents (taken from response data). It shows where different groups may be over or under-represented, for example, those within the 8-11 age group make up 22% of the sample though only 19% of respondents; those in the two most deprived groups make up 43% of the sample, but only account for 36% (rounded sum) of responses.

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[5] 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

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

When interpreting Tables 7 & 8, note that there are possible interrelationships between the groups.

Table 7: Response rates (adjusted) for the Under 16 Cancer Patient Experience Survey (U16 CPES) 2023 by demographic groups and diagnostic group

Group	2023 Response Rate
Age Group	
0-7	26%
8-11	22%
12-15	28%
Gender	
Boy / male	26%
Girl / female	25%
Ethnicity	
White	25%
Mixed	25%
Black	24%
Asian	24%
Other	24%
Not given	27%
Not known	27%
IMD Quintile	
1 (most deprived)	21%
2	21%
3	25%
4	28%
5 (least deprived)	33%
Non-England	28%
Diagnostic Group	
Retinoblastoma	30%
Lymphomas and reticuloendothelial neoplasms	28%
Malignant bone tumours	28%
Renal tumours	27%
CNS and miscellaneous intracranial and intraspinal neoplasms	24%
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	24%
Hepatic tumours	22%
All other	27%

Table 8: Sample (eligible) versus response profile for the Under 16 Cancer Patient Experience Survey (U16 CPES) 2023

Group	Sample profile	Response profile
Age Group		
0-7	51%	52%
8-11	22%	19%
12-15	27%	30%
Gender		
Boy / male	58%	58%
Girl / female	42%	42%
Ethnicity		
White	61%	61%
Asian	9%	8%
Mixed	4%	4%
Other	4%	4%
Black	2%	2%
Not given	18%	19%
Not known	1%	1%
IMD Quintile		
1 (most deprived)	23%	20%
2	20%	17%
3	19%	19%
4	18%	20%
5 (least deprived)	18%	23%
Non-England	2%	2%
Diagnostic Group		
Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	41%	39%
CNS and miscellaneous intracranial and intraspinal neoplasms	24%	23%
Lymphomas and reticuloendothelial neoplasms	10%	11%
Renal tumours	4%	5%
Malignant bone tumours	4%	4%
Retinoblastoma	2%	3%
Hepatic tumours	1%	1%
All other	14%	15%

Further information

For further information on the methodology and details of the statistical analysis, please contact under16cancersurvey@pickereurope.ac.uk

Appendix A

This table lists all questions, excluding the last section (About you) in the questionnaire. The questions in grey are the non-scored questions and those unshaded are the scored questions. For each scored question, each response option was identified as either a positive (1) or negative (0) response. Response options that do not contribute to the positive score calculation are denoted as "n/a."

Question	Question text	Answer option	Option text	Scoring
X01	Were you told about your child's cancer or tumour during 2023?	1	Yes	n/a
		2	No	n/a
X02	Were you told you had cancer or a tumour during 2023?	1	Yes	n/a
		2	No	n/a
X03	Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem(s) caused by the cancer or tumour?	1	None - they went straight to hospital	n/a
		2	They saw the GP once	1
		3	They saw the GP twice	1
		4	They saw the GP 3 or 4 times	0
		5	They saw the GP 5 or more times	0
		6	Don't know / can't remember	n/a
X04	Were you told about your child's cancer or a tumour at the hospital named in the letter that came with this questionnaire?	1	Yes	n/a
		2	No	n/a
X05	Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?	1	Yes	n/a
		2	No	n/a
X06	How did you feel about the length of time you waited between being referred by your GP to a hospital doctor until you were seen at the hospital?	1	We were seen as soon as I thought was necessary	1
		2	We should have been seen a bit sooner	0
		3	We should have been seen a lot sooner	0
		4	We were not referred by a GP	n/a

Question	Question text	Answer option	Option text	Scoring
X07	Were you told about your child's cancer or tumour 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
X08	When you were told about your child's cancer or tumour, was information given in a way that you could understand? / When you were told about your cancer or tumour, was information given in a way that you could understand?	1	Yes, definitely	1
		2	Yes, to some extent / Yes, sort of	0
		3	No	0
		4	Don’t know / can’t remember	n/a
X09	Were you able to have any questions answered by healthcare staff after you were told about your child's cancer or tumour? / Were you able to have any questions answered by healthcare staff after you were told about your cancer or tumour?	1	Yes, definitely	1
		2	Yes, to some extent / Yes, sort of	0
		3	No	0
		4	I did not have any questions	n/a
		5	Don’t know / can’t remember	n/a
X10	Have you been able to find the information that you need about your child's diagnosis?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	This was not needed	n/a
X11	Did hospital staff give you details for who to contact if you wanted more information after you were told about your child's cancer or tumour? / Did hospital staff give you details for who to contact if you wanted more information after you were told about your cancer or tumour?	1	Yes	1
		2	No	0
		3	Don't know / can't remember	n/a
X12	Do you feel that staff are friendly?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
X13		1	Yes, always	1

Question	Question text	Answer option	Option text	Scoring
	When staff speak to you, do you understand what they are saying? / Do staff speak to you in a way that you can understand?	2	Yes, sometimes	0
		3	No	0
		4	Don’t know / can’t remember	n/a
X14	Do staff talk to you, not just to your parent or carer?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
X15	Do you see the same members of staff for your treatment and care?	1	Yes, always or mostly	1
		2	Yes, sometimes	0
		3	No	0
X16	Have you had the chance to ask staff questions about your child's care and treatment?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	I have not had any questions	n/a
X17	Are you and your child treated with respect and dignity by staff?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
X18	Do you have confidence and trust in the members of staff caring for your child?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
X19	Do members of staff caring for your child treat you with empathy and understanding?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
X20	Are you ever told different things by different members of staff, which leaves you feeling confused?	1	Yes, always	0
		2	Yes, sometimes	0
		3	No	1
X21	Are staff sensitive to the information they share with you when your child is in the room?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	This is not needed	n/a
X22	Do healthcare staff share information with your child in a way that is appropriate for them?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0

Question	Question text	Answer option	Option text	Scoring
		4	This is not needed	n/a
X23	Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour? Please select all that apply.	1	Charities (such as Young Lives vs Cancer or Macmillan)	n/a
		2	A psychologist or counsellor	n/a
		3	Other children with cancer or a tumour	n/a
		4	Other	n/a
		5	No, none of the above	n/a
		6	Don’t know / can’t remember	n/a
X24	Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour? Please select all that apply.	1	Charities (such as Young Lives vs Cancer or Macmillan)	n/a
		2	A psychologist or counsellor	n/a
		3	Other parents of children with cancer or a tumour	n/a
		4	Other	n/a
		5	No, none of the above	n/a
		6	Don’t know / can’t remember	n/a
X25	Do you have enough information about how to get financial help or any benefits you might be entitled to?	1	Yes, I have enough information	1
		2	Some, but not enough information	0
		3	No, but I would like this information	0
		4	This was not needed	n/a
		5	Don’t know / can’t remember	n/a
X26	In your opinion, do different hospital staff caring for your child work well together?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don’t know	n/a
X27	Are different hospital staff caring for your child aware of your child's medical history?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	Don’t know / not applicable	n/a
X28	Do you always know what is happening with your child's cancer or tumour care? / Do you always know what is	1	Yes, definitely	1
		2	Yes, to some extent / Yes, sort of	0
		3	No	0

Question	Question text	Answer option	Option text	Scoring
	happening with your cancer or tumour care?	4	This is not needed	n/a
X29	Are you involved as much as you want to be in decisions about your child's care and treatment? / Do you have a say in deciding what happens with your care and treatment? / Are you involved in decisions about your care and treatment?	1	Yes, definitely	1
		2	Yes, to some extent / Yes, sort of	0
		3	No	0
		4	No, but this is not needed	n/a
		5	No, but this is not possible	n/a
Answer option and option text at X30 below for 0-7s				
X30	Has your child's schooling and education (including pre-school) been impacted in any of the following ways by their treatment and care? Please select all that apply. / Has your child's schooling and education been impacted in any of the following ways by their treatment and care? Please select all that apply.	1	My child is not at pre-school or has not started school	n/a
		2	My child's schooling or education has not been impacted	n/a
		3	Being too unwell to attend school, pre-school or home education	n/a
		4	Missing school, pre-school or home education due to timings of treatment and care	n/a
		5	Poor concentration due to ill health or worries	n/a
		6	Tiredness or fatigue	n/a
		7	Other	n/a
Answer option and option text at X30 below for 8-15s				
X30	Has your child's schooling and education (including pre-school) been impacted in any of the following ways by their treatment and care? Please select all that apply. / Has your child's schooling and education been impacted in any of the following ways by their treatment and care? Please select all that apply.	1	My child's schooling or education has not been impacted	n/a
		2	Being too unwell to attend school or home education	n/a
		3	Missing school or home education due to timings of treatment and care	n/a
		4	Poor concentration due to ill health or worries	n/a
		5	Tiredness or fatigue	n/a
		6	Other	n/a
X31	Did you have a main person in the team looking after your child (such as a specialist nurse or key worker)	1	Yes	1
		2	No	0

Question	Question text	Answer option	Option text	Scoring
	who you could contact about their care and treatment?			
X32	How easy was it for you to contact this person?	1	Very easy	1
		2	Quite easy	0
		3	Neither easy nor difficult	0
		4	Quite difficult	0
		5	Very difficult	0
		6	I have not tried to contact them	n/a
X33	Do you have access to reliable help and support 7 days a week from the hospital?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	This is not needed	n/a
X34	Did staff do what they could to make the timing of your child's care and treatment suitable for you and your family (e.g. to fit in with education, employment and other needs)?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No, but I would have liked this	0
		4	No, but this was not needed	n/a
		5	No, but this was not possible	n/a
X35	Has your child received treatment for their cancer or tumour during 2023?	1	Yes	n/a
		2	No	n/a
X36	Were you offered clear information about your child's treatment?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	This was not needed	n/a
X37	Did staff offer you enough time to make decisions about your child's treatment?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No, but I would have liked this	0
		4	No, but this was not needed	n/a
		5	No, but this was not possible	n/a
X38	Did staff offer support to help manage side effects	1	Yes, definitely	1
		2	Yes, to some extent	0

Question	Question text	Answer option	Option text	Scoring
	from your child's treatment?	3	No	0
		4	This was not needed	n/a
X39	If your child's treatment has finished, did you receive enough ongoing support from the hospital after it ended?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	Not applicable / this was not needed	n/a
		5	My child is still receiving treatment	n/a
X40	Has your child stayed in hospital during 2023 (receiving treatment or care in the daytime, or for an overnight stay)?	1	Yes	n/a
		2	No	n/a
X41	Have you stayed in hospital during 2023 (receiving treatment or care in the daytime, or for an overnight stay)?	1	Yes	n/a
		2	No	n/a
X42	When your child was in hospital, were they able to get help from staff on the ward when they needed it? / 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	They did not need any help / I did not need any help	n/a
		5	Don't know / can't remember	n/a
X43	Were there enough things for your child to do in the hospital? / Were there enough things for you to do in the hospital?	1	Yes, definitely	1
		2	Yes, to some extent / Yes, sort of	0
		3	No	0
		4	This was not needed	n/a
X44	Was there a suitable choice of hospital food for your child? / Was there a suitable choice of hospital food?	1	Yes, definitely	1
		2	Yes, to some extent / Yes, sort of	0
		3	No	0
		4	My child did not have hospital food / I did not have hospital food	n/a
X45	Were you given somewhere private to talk to staff when your child was in hospital? /	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0

Question	Question text	Answer option	Option text	Scoring
	Were you given somewhere private to talk to staff when you were in hospital?	4	This was not needed	n/a
X46	Was play support available in hospital when your child needed it (i.e. from a Health Play Specialist who uses play and activities to support patients and/or prepare them for treatments)?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	My child did not need this	n/a
X47	If your child stayed overnight, did you stay overnight with them?	1	Yes	n/a
		2	No	n/a
		3	My child did not stay overnight	n/a
X48	How would you rate the facilities for parents or carers staying overnight?	1	Very good	1
		2	Good	0
		3	Fair	0
		4	Poor	0
		5	Very poor	0
X49	Was it quiet enough for you to sleep in the hospital?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	I did not need to sleep in the hospital	n/a
X50	Were you able to prepare food in the hospital if you wanted to?	1	Yes, definitely	1
		2	Yes, to some extent	0
		3	No	0
		4	I did not want to prepare food	n/a
X51	Did the hospital Wi-Fi meet your and your child's needs?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	This was not needed	n/a
X52	Did your child have access to hospital school services during their stay in hospital?	1	Yes	1
		2	No	0
		3	This was not needed	n/a
X53		1	Yes	n/a

Question	Question text	Answer option	Option text	Scoring
	Has your child been visited at home or school by a nurse during 2023 for care for their cancer or tumour?/ Have you been visited at home or school by a nurse during 2023 for care for your cancer or tumour?	2	No	n/a
		3	Don’t know	n/a
X54	Were the nurses that came to your home or your child's school friendly? / Were the nurses that came to your home or school friendly?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don’t know / can’t remember	n/a
X55	When nurses speak to you, do you understand what they are saying?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don’t know / can’t remember	n/a
X56	Did the same nurses come to your home or your child's school?/ Did the same nurses come to your home or school?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	Don’t know / can’t remember	n/a
		5	My child has only been visited once / I have only been visited once / I was only visited once	n/a
X57	Do different hospitals providing your child's cancer or tumour care work well together?/ Do different hospitals providing your cancer or tumour care work well together?	1	Yes, always	1
		2	Yes, sometimes	0
		3	No	0
		4	My child does not receive care at different hospitals / I don’t receive care at different hospitals	n/a
X58	How long does it take to get to the hospital where your child receives most of their cancer or tumour care?	1	About an hour or under	1
		2	Over an hour	0
X59	Overall, please rate your child's cancer or tumour care from 0 (very poor) to 10 (very good)	0	0 - My child's cancer or tumour care is very poor	0
		1	1	0
		2	2	0

Question	Question text	Answer option	Option text	Scoring
		3	3	0
		4	4	0
		5	5	0
		6	6	0
		7	7	0
		8	8	1
		9	9	1
		10	10 - My child's cancer or tumour care is very good	1
X60	Overall, how well are you looked after for your cancer or tumour by the healthcare staff?	1	Very well	1
		2	Quite well	0
		3	OK	0
		4	Not very well	0
		5	Not at all well	0