Under 16 Cancer Patient Experience Survey 2022

Technical Appendix

November 2023

Contents

Introduction

This document sets out the methodology and analysis approach used in the Under 16 Cancer Patient Experience Survey (U16 CPES) 2022 and gives guidance on how to interpret the results. This includes the following:

- how percentage scores have been derived for each scored question
- rules on suppression and how it has been applied
- how statistical confidence intervals around scores have been calculated
- interpretation of PTC results

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

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 January 1, 2022 and December 31, 2022, and were aged under 16 at the time of their discharge. PTCs should apply local knowledge to the interpretation of their findings.

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 2023. One of three versions of the survey were distributed:

- The 0-7 questionnaire; sent to parents/carers of patients aged between 0 and 7 years old immediately prior to survey fieldwork (30th March 2023)
- The 8-11 questionnaire, sent to parents/carers of patients aged between 8 and 11 years old immediately prior to survey fieldwork (30th March 2023)
- The 12-15 questionnaire; sent to parents/carers of patients aged between 12 and 15 years old immediately prior to survey fieldwork (30th March 2023)

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 survey version was assigned based on the patient's age immediately prior to survey fieldwork (on 30th March 2023) as opposed to their age at the time they received care. This was to ensure children received a survey that was age-appropriate in terms of design and wording.

The survey asked recipients to answer about their (or their child's) cancer care in 2022. 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. A Freephone helpline and email address were available for respondents to opt-out, ask questions about the survey, enable respondents to complete their questionnaire over the phone and provide access to a translation and interpreting facility for those whose first language was not English.

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. The score shows the percentage of respondents who gave the most favourable response to a question.

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

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

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	-

The 'Question list' tab in the Excel data tables (available on the survey website) details the mapping of scores for all questions.

Adjusted response rate

During fieldwork for the 2022 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]:

- 1 = Completed questionnaire
- 2 = Questionnaire returned undelivered (respondent did not receive the questionnaire)
- 3 = Patient deceased after survey mailing 1
- 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 survey and a child completed the online survey)

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.

---

[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.

Suppression and not applicable values

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. 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 for the 2022 survey have been updated to include 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.

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 supressed, as it does not disclose information.

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

At PTC level, Ethnicity data has 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.

Confidence intervals

Introduction

The percentage figures given 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).

Methodology

Confidence intervals for unadjusted scores and proportions for all questions 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%.

How to interpret the results

The following example shows the unadjusted 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, the unadjusted score is 83% and the confidence interval is calculated as between 79% and 86%.

Reporting text	Number of responses	National Score	Lower 95% Wilson Confidence Interval	Upper 95% Wilson Confidence Interval
Parents/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 or not 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.

Confidence intervals are included in the National report, PTC reports and Tableau dashboard. Confidence intervals for year on year scores only are included in the National and PTC data tables. All of these outputs can be found on the current results page of the website.

Interpretation of PTC results

All scored data have been calculated using unadjusted scores. In larger samples, scores are ordinarily adjusted to account for the fact that different demographic groups tend to report their experience of care differently.

Due to small sample sizes, 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 (see 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 2022 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

Year-on-year comparisons are new for U16 CPES 2022 and present 2022 scores alongside 2021 scores for comparable questions. These are included in the PTC and the national reports. Full data, including how scores for each question are calculated, can be found within the National Excel Data Tables available on the survey website.

Due to the changes made to the survey, the 2020 results are not comparable to 2021 or 2022.

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:

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:

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.

Respondent burden calculation

The Under 16 Cancer Patient Experience Survey (U16 CPES) complies with the Code of Practice for Statistics. Within the code, Practice V5.5 requires producers of statistics to monitor the burden on respondents providing their information. To achieve this, the following calculation is done for online U16 CPES completions:

Number of responses x average time spent completing the online survey[2].

Limiting the time frame to just those individuals who started and finished the online survey on the same date, the average completion time is 21 minutes. (This is 96.6% of all online respondents or 257 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 16 minutes. (This is 94.7% of all online respondents or 252 respondents).

Therefore, the respondent burden for the U16's CPES is:

252 respondents x 16 minutes = 4,032 hours spent completing the survey.

Further information

For further information on the methodology and details of the statistical analysis, please contact under16cancersuvey@pickereurope.ac.uk

---

[2]Please note that online responses accounted for only around a third (30%) of responses to the survey, and so this calculation does not cover the response burden for those who responded via other survey modes. Only those who were included in the final data after cleaning were considered in the respondent burden calculation.