

Under 16 Cancer Patient Experience Survey 2021

Technical Appendix

November 2022



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Introduction

This document sets out the methodology and analysis approach used in the Under 16 Cancer Patient Experience Survey (U16 CPES) 2021 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 where it was 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, 2021 and December 31, 2021, and were aged under 16 at the time of their discharge. Principal Treatment Centres 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) will be retained for the site that has 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 2022. 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 2022)
- The 8-11 questionnaire, sent to parents/carers of patients aged between 8 and 11 years old immediately prior to survey fieldwork (30th March 2022)
- The 12-15 questionnaire; sent to parents/carers of patients aged between 12 and 15 years old immediately prior to survey fieldwork (30th March 2022)

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 2022) as opposed to their age at the time they received care. This assignment was made to better suit the needs of child participants. For instance, there were small differences in wording and the way that answer options were presented in the 8-11 and 12-15 questionnaire versions. It was also thought that sending the most age-appropriate version to child participants might increase response rates.

The survey asked recipients to answer about their (or their child's) cancer care in 2021. 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 gender or ethnic group. Response options that are not scored (for example don't know/can't remember) are removed before the score is calculated. The score shows the percentage of respondents who gave the most favourable response to a question. Any response options that are not applicable are removed before the score is calculated.

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	n/a

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 2021 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 follows¹:

- 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, 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 online survey and a child completed the paper 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

Where there have been a small number of responses to a question, suppression is applied to the results to prevent individuals and their responses being identifiable in the data.

There are several steps to this suppression² to prevent disclosure of information whilst also reporting on the largest volume of data possible. Please note that the suppression rules have been applied in the order they are presented below.

Question-level suppression

For scored questions, when the base size per question is less than 11, the score will be suppressed and replaced with an asterisk (*). The scored base size will not include non-scored response options.

For unscored questions, any response option counts are suppressed when the overall base size per question is less than 11. The overall base size includes both scored and non-scored response options.

Double suppression of sub-group data

Scored results for any sub-group breakdown adhere to the same suppression level as the question-level suppression but have an additional double suppression rule.

If any group within a sub-group breakdown (such as the diagnostic group breakdown) has between 1 and 10 responses, then the figure for this group is suppressed and replaced with an asterisk (*). If only one sub-group within a breakdown is suppressed, the group with the next lowest number of respondents is also suppressed for that question. When there is a tie for next lowest number of responses, the numerical order will be used to determine which sub-group is suppressed. This rule applies to scores and response option counts, and is done so that the so that the suppressed score cannot be worked out from the remaining unsuppressed information.

Organisation-level suppression

At Principal Treatment Centre (PTC) level, additional suppression is applied if only one PTC has a score or result suppressed for a question (for either of the reasons above). In these instances, the PTC with the next lowest base size for that question will also have its result suppressed. When there is a tie for next lowest base size, an alphabetical order will be used to determine which PTC is suppressed. This is done so that the suppressed score for the individual PTC cannot be worked out from the national score for that question.

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)

² Please see Appendix A for a worked example of the suppression steps.

- 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.

Suppression across Sub-group scores and data tabs

If a score is suppressed, the corresponding response option counts in the Sub-group data tab will also be suppressed³.

This step is applied after all the other suppression levels are evaluated, as it can be influenced by the other suppression levels.

Suppression applied to two variable analysis output

Question-level suppression is applied to the data. Double suppression is applied across each of the two variable breakdowns as many times as needed so that suppressed scores cannot be worked out from the remaining unsuppressed information. Where a sub-group has been suppressed for a question in the National Excel tables, all instances of this sub-group will be suppressed for this question in the two variable analysis.

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).

³ This scenario can occur for questions that contain non-scored options, where the base size of the scored options can be less than 11, while the base size including the non-scored options can be equal to or greater than 11.

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).

Methodology

Confidence intervals for unadjusted scores 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 tumour in a sensitive way. In this case, the unadjusted score is 83% and the confidence interval is calculated as between 79% and 86%.

Question Text	No. of responses	National Score	Lower 95% Wilson Confidence Interval	Upper 95% Wilson Confidence Interval
Parents or carers definitely told about cancer or tumour 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 66.03% to 97.66%. 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 (87.98% to 91.71%).

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.

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 the type of specialised care and treatment that might be offered). 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 statistically 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 do not benchmark their results against those of other PTCs, or against results at National level.

We recommend that PTCs review their results for the 2021 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 comparability

The Under 16 CPES is at a relatively early point in its evolution, and we continue to learn a lot about what is working well and what might need adjusting. There are differences between the 2021 and 2020 surveys which has led to the analytical and insight recommendation that comparisons should not be made between results. In line with this, comparisons between 2021 and 2020 results are not included within this report and trends are not shown. This is because:

- Feedback from cognitive interview testing with patients identified that clarification was needed on which time period patients should be reporting on. Changes have been made to the wording to accommodate this, but as these only affect this year's iteration, the 2020 and 2021 survey report on patients' experience of care across potentially different and overlapping time periods.
- Additionally, there are differences in response rates across the 2 years. Coupled with a small sample size, this reduces statistical confidence in comparisons.
- Taken together, this makes it extremely difficult to disentangle change (or lack of) in patient experience from survey change when comparing results. Work will be undertaken to enhance comparability as much as possible for future years.

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
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. In order to achieve this, the following calculation is done for online U16 CPES completions:

Number of responses x Median time spent completing the survey

There were 252 online responses to the 2021 U16 CPES. The median completion time based on online completion was 12.5 minutes per survey. Therefore, respondent burden calculated results for the 2021 U16 CPES are:

252 responses x 12.5 minutes = 52.5 hours spent completing the survey.

Please note that online responses accounted for only around a quarter of responses to the survey, and so this calculation does not cover the response burden for those who responded via other survey modes.

Appendix A – Suppression examples

This section illustrates how the suppression steps are applied to the results. **Please note that these examples are all based on fabricated data.**

Example A: Sub-group data: question-level suppression and double suppression

This example shows how question-level suppression and double suppression are applied to the sub-group data, using fabricated data for Question X03 broken down by Survey type.

- 1) The scores for each sub-group are calculated before any suppression is applied. In this example, the score for the 12-15 sub-group is based on fewer than 11 scored responses. This means that a question-level suppression is required.

Q	Scored Text	National score		Survey type					
		No. of responses	Score	0-7 Survey		8-11 Survey		12-15 Survey	
				No. of responses	Score	No. of responses	Score	No. of responses	Score
X03	Parents/carers reported that their child saw a GP once or twice before they were referred to hospital	60	50%	30	50%	20	50%	10	50%

- 2) The score for the 12-15 sub-group is suppressed and replaced with an *. At this step, this is the only suppressed score within the Survey type breakdown. This means that double suppression is required.

Q	Scored Text	National score		Survey type					
		No. of responses	Score	0-7 Survey		8-11 Survey		12-15 Survey	
				No. of responses	Score	No. of responses	Score	No. of responses	Score
X03	Parents/carers reported that their child saw a GP once or twice before they were referred to hospital	60	50%	30	50%	20	50%	10	*

- 3) The 8-11 sub-group has the next lowest number of scored responses for this question (20 scored responses). This is therefore chosen for double suppression, and its score is replaced by an *.

Q	Scored Text	National score		Survey type					
		No. of responses	Score	0-7 Survey		8-11 Survey		12-15 Survey	
				No. of responses	Score	No. of responses	Score	No. of responses	Score
X03	Parents/carers reported that their child saw a GP once or twice before they were referred to hospital	60	50%	30	50%	20	*	10	*

The scored data is now adequately suppressed, and the corresponding response-option counts will also be suppressed.

Example B: Organisation-level suppression

This example shows how organisation-level suppression is applied to the PTC results, using fabricated data for Question X23.

- 1) The scores for each PTC are calculated before any suppression is applied. In this example, the score for Sheffield Children's NHS Foundation Trust is based on fewer than 11 scored responses. This means that a question-level suppression is required:

Trust Code	PTC name	Q	Scored Text	No. of responses	PTC Score
RBS	Alder Hey Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	12	91.7%
RQ3	Birmingham Women's and Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	30	90.0%
RGT	Cambridge University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	14	78.6%
RP4_RRV	Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	28	92.9%
RR8	Leeds Teaching Hospitals NHS Trust	X23	Children feel that staff are always friendly	30	93.3%
ROA	Manchester University NHS Foundation Trust	X23	Children feel that staff are always friendly	35	94.3%
RX1_RWE	Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	X23	Children feel that staff are always friendly	17	88.2%
RTH	Oxford University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	14	92.8%
RCU	Sheffield Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	5	80.0%
RTD	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	23	91.3%
RPY_RJ7	The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	27	88.9%
RHM	University Hospital Southampton NHS Foundation Trust	X23	Children feel that staff are always friendly	30	86.7%
RA7	University Hospitals Bristol and Weston NHS Foundation Trust	X23	Children feel that staff are always friendly	19	94.7%
All	National	X23	Children feel that staff are always friendly	284	90.5%

- 2) The score for Sheffield Children's NHS Foundation Trust is suppressed and replaced with an *:

Trust Code	PTC name	Q	Scored Text	No. of responses	PTC Score
RBS	Alder Hey Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	12	91.7%
RQ3	Birmingham Women's and Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	30	90.0%
RGT	Cambridge University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	14	78.6%
RP4_RRV	Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	28	92.9%
RR8	Leeds Teaching Hospitals NHS Trust	X23	Children feel that staff are always friendly	30	93.3%
R0A	Manchester University NHS Foundation Trust	X23	Children feel that staff are always friendly	35	94.3%
RX1_RWE	Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	X23	Children feel that staff are always friendly	17	88.2%
RTH	Oxford University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	14	92.9%
RCU	Sheffield Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	5	*
RTD	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	23	91.3%
RPY_RJ7	The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	27	88.9%
RHM	University Hospital Southampton NHS Foundation Trust	X23	Children feel that staff are always friendly	30	86.7%
RA7	University Hospitals Bristol and Weston NHS Foundation Trust	X23	Children feel that staff are always friendly	19	94.7%
All	National	X23	Children feel that staff are always friendly	284	90.5%

3) At this step, Sheffield Children's NHS Foundation Trust is the only PTC with a suppressed score for this question. This means that an organisation-level suppression is required. Alder Hey Children's NHS Foundation Trust has the next lowest number of scored responses for this question (12 scored responses). This is therefore chosen for organisation-level suppression, and its score is replaced by an *:

Trust Code	PTC name	Q	Scored Text	No. of responses	PTC Score
RBS	Alder Hey Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	12	*
RQ3	Birmingham Women's and Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	30	90.0%
RGT	Cambridge University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	14	78.6%
RP4_RRV	Great Ormond Street Hospital for Children NHS Foundation Trust & University College London Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	28	92.9%
RR8	Leeds Teaching Hospitals NHS Trust	X23	Children feel that staff are always friendly	30	93.3%
R0A	Manchester University NHS Foundation Trust	X23	Children feel that staff are always friendly	35	94.3%
RX1_RWE	Nottingham University Hospitals NHS Trust & University Hospitals of Leicester NHS Trust	X23	Children feel that staff are always friendly	17	88.2%
RTH	Oxford University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	14	92.9%
RCU	Sheffield Children's NHS Foundation Trust	X23	Children feel that staff are always friendly	5	*
RTD	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	23	91.3%
RPY_RJ7	The Royal Marsden NHS Foundation Trust & St George's University Hospitals NHS Foundation Trust	X23	Children feel that staff are always friendly	27	88.9%
RHM	University Hospital Southampton NHS Foundation Trust	X23	Children feel that staff are always friendly	30	86.7%
RA7	University Hospitals Bristol and Weston NHS Foundation Trust	X23	Children feel that staff are always friendly	19	94.7%
All	National	X23	Children feel that staff are always friendly	284	90.5%

The scored data is now adequately suppressed, and the corresponding response-option counts will also be suppressed.

Further information

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