

Under 16 Cancer Patient Experience Survey 2024

Sampling Webinar

14th January 2025



About the Survey

Under 16 Cancer Patient Experience Survey



Under 16 Cancer Patient Experience Survey



- The Under 16 Cancer Patient Experience Survey (U16 CPES) was developed and is implemented by Picker on behalf of NHS England.
- **Purpose:** to understand the experiences of cancer care among children under the age of 16 and their parents/carers, in England. Results are used to understand and improve cancer care nationally and locally.
- Supported by an Advisory Group of expert stakeholders who meet quarterly to advise on methodology.
- Mixed-mode survey (paper and online options).
- Results from the 4th iteration of the survey were published in November 2024 (<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>).
- Three survey versions (0-7 years; 8-11 years; 12-15 years).
- Survey website: <https://www.under16cancerexperiencesurvey.co.uk>



U16 Cancer Patient Experience Survey

FINDING OUT ABOUT YOUR CHILD'S CANCER OR TUMOUR

Please think about the time your child's cancer or tumour was confirmed. If your child has had cancer or a tumour more than once, please think about the most recent time you were told when answering the following questions.

1 Were you told about your child's cancer or tumour during 2023?
1 Yes Go to Question 2
2 No Go to Question 9





2 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?
None - they went straight to hospital
They saw the GP once
They saw the GP twice
They saw the GP 3 or 4 times
They saw the GP 5 or more times
Don't know / can't remember

3 Were you told about your child's cancer tumour at the hospital named in the letter that came with this questionnaire?
1 Yes Go to Question 4
2 No Go to Question 9

4 How did you feel about the length of time waited between being referred by a hospital doctor until you were seen at hospital?
1 We were seen as soon as necessary
2 We should have been seen sooner
3 We should have been seen later
4 We were not referred

5 Were you told about your child's cancer or tumour in a sensitive way?
1 Yes, definitely
2 Yes, to some extent
3 No
4 Don't know / can't remember

6 When staff speak to you, do you understand what they are saying?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No
- 4  Don't know / can't remember



YOUR CARE AND TREATMENT

Please answer these questions about care and treatment received during 2023 at the hospital named in the covering letter.

7 Do staff speak to you in a way that you can understand?
1 Yes, always
2 Yes, sometimes
3 No
4 Don't know / can't remember

8 Do staff talk to you, not just to your parent or carer?
1 Yes, always
2 Yes, sometimes
3 No

9 Do you see the same members of staff for your treatment and care?
1 Yes, always or mostly
2 Yes, sometimes
3 No

10 Are you ever told different things by different members of staff, which leaves you feeling confused?
1 Yes, always
2 Yes, sometimes
3 No

11 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)
2 A psychologist or counsellor
3 Other children with cancer or a tumour
4 Other
5 No, none of the above
6 Don't know / can't remember

CARE IN HOSPITAL

Please answer the following questions about any hospital stays you have had for cancer or tumour care and treatment at the hospital named in the covering letter.


12 Do you always know what is happening with your cancer or tumour care?
1 Yes, definitely
2 Yes, sort of
3 No
4 This is not needed

13 Are you involved in decisions about your care and treatment?
1 Yes, definitely
2 Yes, sort of
3 No
4 No, but this is not needed
5 No, but this is not possible

14 Have you stayed in hospital during 2023 (receiving treatment or care in the daytime, or for an overnight stay)?
1 Yes Go to Question 15
2 No Go to Question 20

15 Could you get help from staff on the ward when you needed it?
1 Yes, always
2 Yes, sometimes
3 No
4 I did not need any help
5 Don't know / can't remember

16 Were there enough things for you to do in the hospital?
1 Yes, definitely
2 Yes, sort of
3 No
4 This was not needed



U16 Cancer Patient Experience Survey



- The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning.
- The Under 16 Cancer Patient Experience Survey is exempt from the National Data Opt-out Programme, meaning patients are not required to opt-in to taking part. All eligible patients are to be included in the patient list unless otherwise stated, and patients do not have to actively consent to the sharing of their data.

<https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/policy-considerations-for-specific-organisations-or-purposes>

<https://digital.nhs.uk/services/national-data-opt-out/programmes-to-which-the-national-data-opt-out-should-not-be-applied>



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- The survey has received Section 251 approval from the Research Authority's Confidentiality Advisory Group (**CAG**) and the Secretary of State for Health. This means that the common law duty of confidentiality has been lifted **to allow confidential patient information to be disclosed for the purpose of carrying out the survey.**
- Details on the CAG website: See approved non-research applications register here: <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/confidentiality-advisory-group-registers/>
- Approval letter is on the U16 CPES website: <https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>



- Trusts must not submit any additional data variables than those requested from Picker in the sampling instructions
- Trusts must ensure they have removed patients that have specifically opted out from this survey via the dissent posters
- Trusts should submit their patient list using Picker's secure sampling platform only



Under 16 Cancer Patient Experience Survey for children, young people and their parents or carers



Help us improve cancer care

NHS England and NHS Improvement may invite you to take part in the cancer survey for children and young people and their parents and carers. This is part of a national programme to improve care and patients' experiences.

Your views are important to us

It is your choice whether to take part in the survey, and your answers will be kept confidential.



If you are invited to take part, the hospital will send your contact details to an independent research organisation, Picker, which is carrying out the survey on behalf of NHS England and NHS Improvement.

If you do not wish to take part, or have any questions about the survey, please contact:

PLEASE INSERT A PHONE NUMBER AND EMAIL ADDRESS OF SOMEONE AT THE HOSPITAL WHO CAN BE CONTACTED TO RECORD DETAILS OF THOSE WISHING TO OPT OUT

Patients opting out please note: by opting out you are removed from the mailing list **for this survey and for this hospital only**, so you might still be included in other surveys. **If you do not wish to receive a survey from another hospital you will need to contact staff at that hospital to opt out.**

For more information about the survey, please see the survey website:
<https://www.under16cancerexperiencesurvey.co.uk/>





- Keep patient information confidential at all times and to comply with data protection legislation.
- To check for deceased patients before each mailing by submitting the list to DBS and removing patients from any future mailings
- To remove patients that opt out via the Freephone line, email or by returning a blank questionnaire
- To check all free-text comments for any safeguarding concerns and escalate as necessary
- Securely delete patient identifiable information by 12 months after publication of results

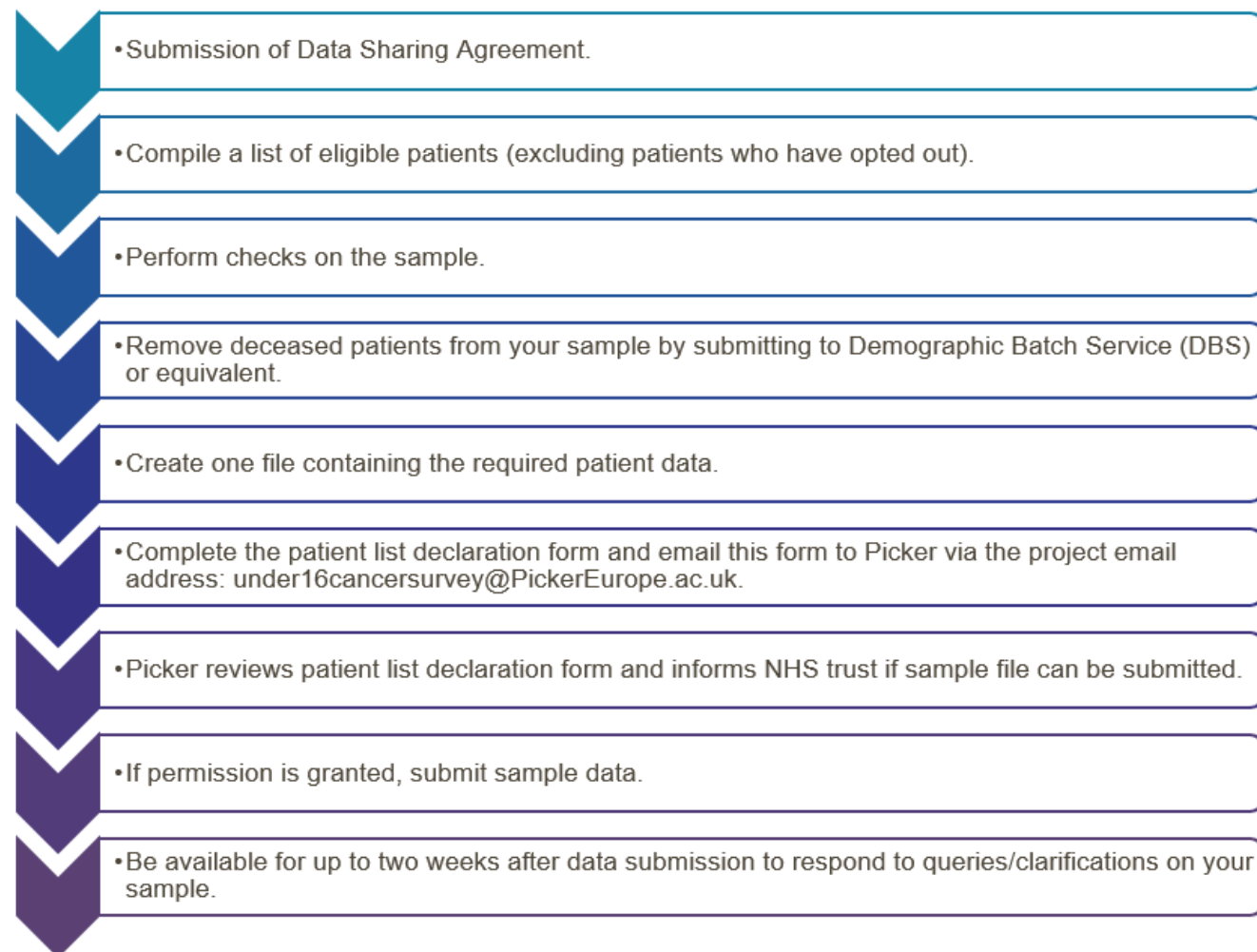
Compiling your patient sample

Under 16 Cancer Patient Experience Survey 2024



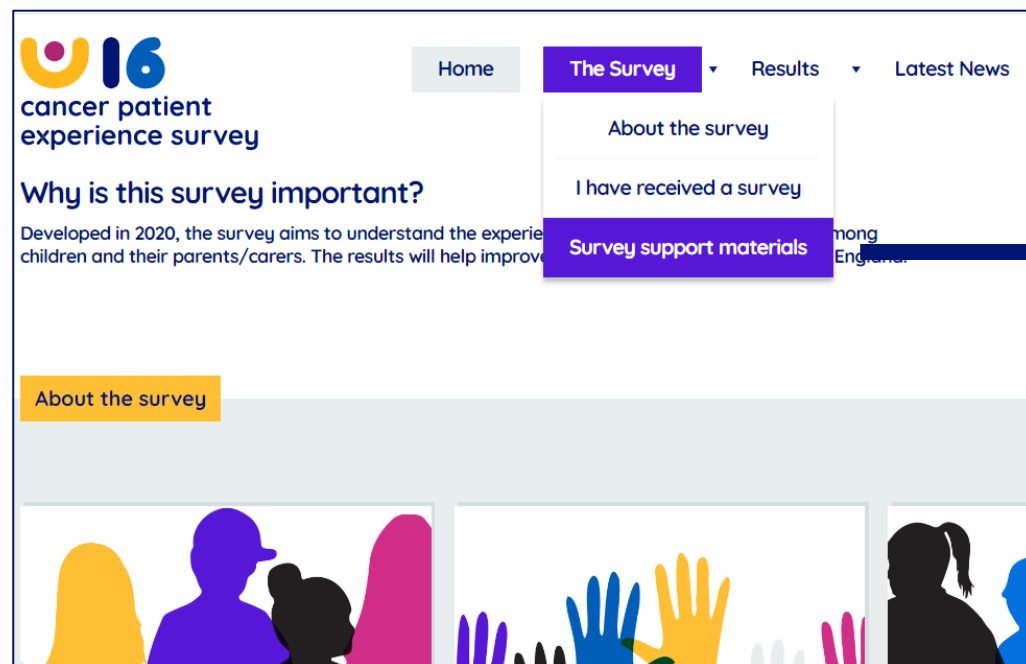
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The following flowchart shows the sequential steps that you must follow to draw your sample.



Under 16 Cancer Patient Experience Survey

- Go to <https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>



Sampling documents:

2024 U16 CPES Sampling Instructions

2024 U16 CPES Sampling Patient List Spreadsheet

2024 U16 CPES Declaration Form

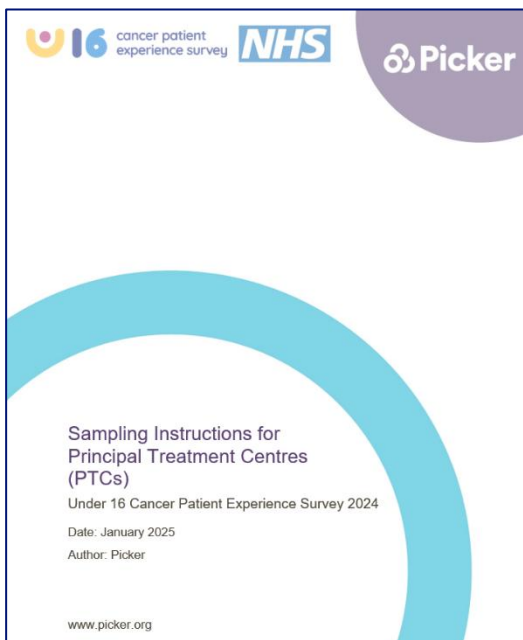
2024 U16 CPES Data Sharing Agreement

Sampling Guidance Materials

Under 16 Cancer Patient Experience Survey

<https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>

Sampling Guidance Data sharing agreement Excel template Declaration form



Under 16 Cancer Patient Experience Survey Data Sharing Agreement	
THIS AGREEMENT is made and will come into force on 13 th January 2025	
1	<p>Between: 1) Name and address (The Trust); and 2) NHS England</p> <p>For the purposes of this agreement, Picker Institute Europe is acting as the data processor under the sole instructions of the data controller, NHS England.</p> <p>Picker Institute Europe a company incorporated and registered in England and Wales under company number 3908160 and a registered charity in England with registered number 1081688 and in Scotland with registered number SC045048 and whose registered office is at Suite 6, Fountain House, 1200 Parkway Court, John Smith Drive, Oxford OX4 2JY ("Picker").</p>
2	Definitions See Annex A
3	<p>BACKGROUND</p> <p>The Trust has agreed to provide the data items (listed in section 6 of this document) with NHS England (for Picker to process) for the purposes of the Under 16 Cancer Patient Experience Survey 2024.</p> <p>The data items provided to NHS England (for Picker to process) shall only be processed in connection with the Under 16 Cancer Patient Experience Survey 2024 and will not be used for any other purposes.</p>

A	B	C	D
Note: not the NHS number. Instead create a unique code per record, in the format of 'Trust code' (3 characters) plus a unique 4 digit, starting at 1001, e.g. RTH1001. Where there are multiple rows for the same patient, then each row must have a different PRN assigned.	The 3-digit ODS code for your NHS Trust, e.g. RA7	The 5-digit ODS code for the NHS site where the patient received care	First name or initials of patient (child)
1	Patient record number (PRN)	NHS Trust Code	NHS Site Code
2			Patient First Name or Initials

Under 16 Cancer Patient Experience Survey 2024: Sample Declaration Form

This declaration is to be signed off by the member of staff responsible for drawing and checking the patient list, as set out in the Sampling Instructions.

This checklist will be used for audit purposes to ensure that the patient list conforms to the instructions. If all steps are completed it will help to avoid any breaches of confidentiality.

This survey has received Section 251 approval from the Health Research Authority to enable data to be transferred to Picker for the purposes of this survey only. In order to be operating under that approval, you must follow the steps outlined below, otherwise the approval will not apply. For more information on the approval requirements and confidentiality, please refer to the Survey Handbook.

How to complete this declaration:

Checklist: Please confirm that the checks on the 'Checklist' tab have been completed on behalf of your NHS trust by inserting a '✓' or 'NA' in the boxes adjacent to the check listed.

Entering an NA: If an 'NA' is inserted to any of the checks, a comment will be expected from the trust, explaining why this check is not applicable. This will avoid unnecessary queries during the patient list checking process, and help have your patient list approved faster.

Checks to note: For rows 33, 35 and 37, a number must be entered instead of a '✓' or 'NA' in the boxes adjacent to the check.

Declaration agreement: On the Declaration Agreement tab, enter the required information to confirm that the patient list file has been prepared and is ready to be submitted to Picker for checking. Please wait for a member of Picker staff to tell you when and how you can submit your patient list.

Confirm the following:	Check	Comments
Your patient list consists of eligible patients aged under 16 years with a confirmed primary diagnosis of cancer, and who are aware of their diagnosis, who were admitted as inpatients or seen as day case patients for cancer-related care and have been discharged between January 1, 2023 and December 31, 2023. (Patients who are currently 16 may be included if they were discharged at 15 years old).		
Please confirm that you have not removed current INPATIENTS from your sample.		
Please confirm that you did not remove patients who received most care at another trust from your sample.		
Confirm that you have included:	Check	Comments
Patients with a confirmed primary diagnosis of cancer or one of the specified tumour types. That is: they do not have a holding code and they have been told they have cancer or one of the specified tumour types.		
Patients born in 2007 or after who were aged under 16 at the time they received cancer care (at the time they were discharged as inpatients or day case patients).		
Patients with an ICD-10 code of C00-C97 or D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5, D48, D76.1 (or equivalent ICD-11 code) in the first diagnosis field of their PAS record. Except the exceptions below.		
All eligible patients who had at least one overnight stay or were seen as a day case in which they were receiving cancer-related care or treatment.		
Patients whose address is incomplete, but contains enough information to have a reasonable chance of being delivered. E.g. Keep in those with (i) address '1' and post code, (ii) complete address without a post code, (iii) address without city or county details but with post code.		
Patients with an address in the UK including addresses in the British Islands (isle of Man, the Channel Islands) and addresses for a military base, care home or prison establishment.		
Duplicate patients (i.e. the same patient that has multiple care episodes should be included on multiple rows).		
Confirm that you have excluded:	Check	Comments
Patients aged 16 years and older at the time they were discharged during an episode		

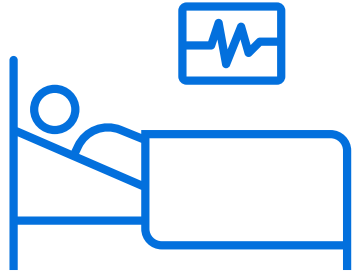
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<https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>

Declaration form

Confirm the following:	Check	Comments
Your patient list consists of eligible patients aged under 16 years with a confirmed primary diagnosis of cancer, and who are aware of their diagnosis, who were admitted as inpatients or seen as day case patients for cancer-related care and have been discharged between January 1, 2024 and December 31, 2024. (Patients who are currently age 16 or 17 may be included if they were discharged at 15 years old).		
Please confirm that you have not removed current INPATIENTS from your sample.		
Please confirm that you did not remove patients who received most care at another trust from your sample		
Confirm that you have included:	Check	Comments
Patients with a confirmed primary diagnosis of cancer or one of the specified tumour types . That is, they do not have a holding code and they have been told they have cancer or one of the specified tumour types.		
Patients born in 2008 or after who were aged under 16 at the time they they received cancer care (at the time they were discharged as inpatients or day case patients).		
Patients with an ICD-10 code of C00-C97 or D32 - D33, D35.2 - D35.4, D42 - D43, D44.3 - D44.5, D48, D76.1 (or equivalent ICD-11 code) in the first diagnosis field of their PAS record. Except the exceptions below.		
All eligible patients who had at least one overnight stay or were seen as a day case in which they were receiving cancer-related care or treatment .		

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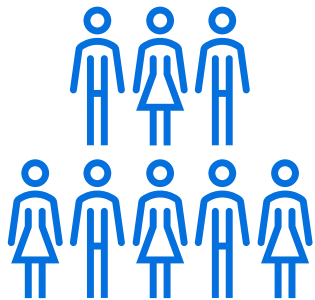
INCLUDE:

- All children aged under 16 at the time of their discharge for cancer related care or treatment between January 1, 2024 and December 31, 2024.
 - With a confirmed primary diagnosis of cancer or a non-malignant brain, other central nervous system or intracranial tumour.
 - 'Primary cancer' is defined as the main diagnosis shown on your system, regardless of how many times someone has had cancer in the past or how progressive their cancer is.
- Inpatients and day case admissions who have received NHS care and/or treatment (elective and non-elective) in England for their cancer or tumour.

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Please ensure that:

- Only patients that are seen by the cancer teams are included in the sample
 - Some patients may have been seen by non-cancer teams, such as epilepsy surgery or rheumatology patients with macrophage activation syndrome
- Patients are aware of their diagnosis
 - Will likely require a cancer team member checking the patient list
- Duplicate patients are **not** removed
 - Patient list must include all eligible instances of care, so some patients may appear more than once
- Unlike previous years, patient mobile number and email address should not be included in your sample

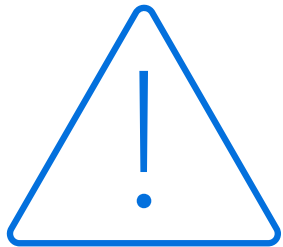


EXCLUDE:

- Deceased patients
- Patients only seen as outpatients during the sampling period
- Patients without a confirmed diagnosis of cancer or one of the specified tumours, including those given a holding diagnosis code with pending results
- Patients who are not aware of their diagnosis of cancer or one of the specified tumours (this will require a check by a member of your clinical cancer team)
- Patients aged 16 years and older at the time they were discharged from inpatient or day case care
- Private patients (non-NHS)
- Patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no postcode)
- Parents/patients that have informed your trust, in response to communications about the Under 16 Cancer Patient Experience Survey, that they (or their child) do not wish to be included in the survey.



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- Only include patients discharged during the sampling frame (1st January – 31st December 2024)
- Do **not** remove duplicates – in many instances, a patient will appear multiple times in your sample (one row/record per discharge) – Picker will remove duplicates
- Include *all* eligible patients, not just those who are newly diagnosed
- Patients who **receive one off treatment** at your NHS Trust but receive most of their care at another NHS Trust should be included. We deduplicate patients across Trust sample files based on the number of visits to a PTC.
- Patients who **do not speak English as a first language** should be included. There is a translation service available to assist patients who do not speak English.
- Patients who are **receiving follow-up care after their treatment has ended** should be included if they were discharged during the eligible time period.

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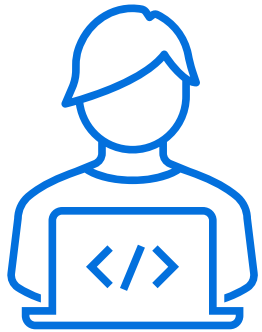
- **ICD-O-3 site code** (4 digits) as per the validation list available here: <https://seer.cancer.gov/icd-o-3/>, e.g. C488
- **ICD-O-3 morphology code (cancer type)⁵** – histology code (4 digits) plus behaviour code (1 digit) e.g. 9673/3, as per the validation list available here: <https://seer.cancer.gov/icd-o-3/> . Please see Appendix A for more details.

Your trust will have access to this data, as it is collected as part of the Cancer Outcome and Services Dataset (COSD) submission, normally managed by a cancer data management team within your Trust. **If you do not know who to contact within your Trust concerning ICD-O-3 codes, Picker or NHS England will be able to direct you to the appropriate teams.**

Submitting your patient sample

Under 16 Cancer Patient Experience Survey





- Make sure you have the relevant permissions to share the data by completing and submitting online the **Data Sharing Agreement**.
- When your sample list is ready, please complete the **Patient List Declaration Form** (to confirm the sample has been drawn following the guidance with the necessary checks), and email to under16cancersurvey@PickerEurope.ac.uk
- Once your forms have been received and checked, you will be emailed details of how to access Picker's online sample checker platform <https://samplechecker.picker.org/>

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<https://samplechecker.picker.org/>



Home

Guide & FAQs

Contact us

Welcome Test from Test org

To upload a file for a survey, please select the appropriate survey from the list below

To upload a file into the platform, please first populate the appropriate template. These templates are available for download below.

If the survey you need is not listed, please contact clientservice@pickereurope.ac.uk




U16 CPES Survey

Download the data template for submission


How to submit your patient sample

U16 Cancer Patient Experience Survey

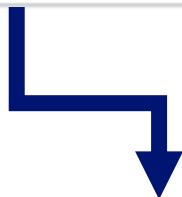
<https://samplechecker.picker.org/>

In progress files that have been uploaded are within the table below
To continue working on a file, please select the 'View upload details' button  under the Actions column for the appropriate upload.
Found 1 previously uploaded sample file.








Show entries Search:

Survey code	Status	# records	# queries	Last modified	Actions
UEC20	Upload has queries	3550	Errors 10 Checks 5 Notices 0 Historic 7 Total open queries 22	2020-10-01 10:11:00	

Showing 1 to 1 of 1 entries Previous Next

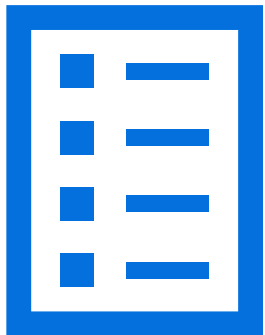


Show entries Search:

Status	Type	Data field	# Issues	Explanation	Details
Trust	Check	Ethnicity - Blank ethnicity value(s) found.	1		
Trust	Check	Firstname - Missing/blank value(s) found. This field needs to be populated for each record.	1		
Trust	Check	NHS number - Invalid value(s) found. The NHS number should be a 10 digit number.	3		
Trust	Check	NHS number - Missing/blank value(s) found. The NHS number should be a 10 digit number.	2		
Trust	Check	Postcode - Missing/blank value(s) found. This field should ideally be populated for each record to ensure a reasonable chance for delivery. Please confirm if correct OR resubmit an updated patient list.	3		
Trust	Error	Address - Missing/blank value(s) found across all address fields. Paper surveys can only be delivered when addresses are provided.	1		
Trust	Error	Date of birth - Child is too old to take this survey. Please resolve and resubmit an updated patient list.	14		

TYPES OF QUERY:

- **Error** – to resolve these issues you will need to upload a revised sample file
- **Check** – queries that may or may not be an error, to resolve you will need to provide an explanation or upload a revised file
- **Historical difference** – indicates a >5% difference in the sample file compared to the previous year. If >5% difference, please provide confirmation that this has been checked
- **Notice** – provides an overview of the information in the sample, no action needed



- Picker will share mailing dates with Trusts once they are confirmed
- Picker will conduct DBS checks within 24 hours prior to each survey mailing
- If Trusts wish to do a local check before each mailing, this is most welcomed
- If a Trust needs to inform Picker of a deceased patient, they will need to contact Picker with the unique Patient Record Number(s) so we can ensure they are removed from the mailing. This will need to be **at least 48 hours before the mailing date.**

U16 Cancer Patient Experience Survey

Dates	Task	Responsibility
14th Jan 2025	Sampling Webinar with Trusts	Picker
14th Jan 2025	Trusts to start to submit Data Sharing Agreements (DSAs), Declaration Forms, Patient Samples & Covering Letter Info	Trusts
14th Feb 2025	Deadline for Trusts submit DSAs, confirm Covering Letter Information (Signature, JPEG, title, Trust Logo if required)	Trusts
14th Feb 2025	Deadline for Trusts to submit Declaration Form and Patient Sample (with deceased patients removed).	Trusts
14th Jan – 21st Feb 2025	Picker to check samples. Trusts to respond to queries	Picker and Trusts
Late March – Early April 2025*	Mailing 1 (with DBS applied) - first survey invite	Picker
Early May 2025*	Mailing 2 (with DBS applied) - first reminder	Picker
Late May 2025*	Mailing 3 (with DBS applied) - final reminder	Picker
Late June 2025*	Fieldwork closes	Picker
July 2025	Analysis and reporting begins	Picker

* These are estimated dates – final dates will depend on the timely submission of patient samples and resolution of queries across all Trusts

Sampling Questions

Under 16 Cancer Patient Experience Survey





Within the sampling period, a patient might turn 16. Should they still be included?

- Yes – any episodes of cancer-related care and treatment that the patient received when they were under 16, during the defined sampling period of 1st Jan and 31st Dec 2024, should be included. If they turn 16 in July for example, only those episodes of care received between January and July should be included.

Do all the radiotherapy sessions have to be counted as day cases or do we count them as a whole treatment?

- Yes, the sampling process would consider each radiotherapy session an individual care episode and each eligible instance to be included in your sample, after which Picker would remove duplicate patient records. However, if this will result in a significant amount of work to re-code your patient lists, please speak to Picker in the first instance as we do not want to place unnecessary burden on trusts.

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Looking into the necessity of patients to be informed of their cancer diagnosis, is it ok if only the parents know that the child has cancer?

- Yes. The mailing is sent to the parent/carer of the child, and the parent/carer will therefore be the first to open the envelope and read the survey invite letter. It is then up to the parent to decide whether to share the survey invitation with their child which may depend on various factors such as whether they consent to their child taking part, whether their child is aware of their diagnosis, and their child's current health status.

Some people receive care which is not directly cancer-related but for symptoms relating to side effects of treatment. We log these instances as supportive care. Would these instances be included in the sample?

- As long as supportive care is provided directly by members of the cancer team, it should be included in the sample. If this care is not provided by the cancer team, then please exclude these instances.

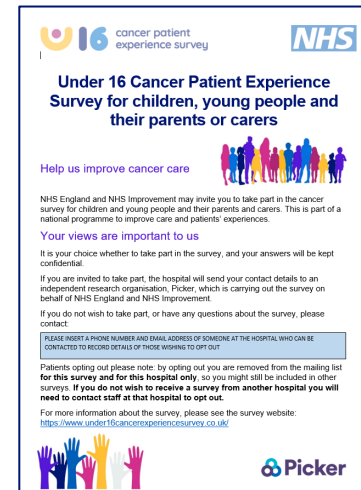


What opt-out options will patients have?

- If your trust has advertised the survey through the dissent poster provided, patients may have contacted your trust to opt out from taking part. If they did, these patients should be recorded and removed from your patient list before submitting to Picker.
- Patients can also opt out by calling the Freephone line or helpline email provided on the questionnaire and covering letters, or by sending back a blank questionnaire.

When patients appear on more than one trust list, how will you choose which trust the patient is asked about on the questionnaire?

- The trust that was attended most frequently during the sample period will be asked about.



When patients appear multiple times on a trust list, how will you choose which record to retain?

- The one with the latest discharge date. However, the questionnaire will ask patients to feedback on care during the whole of 2024.

Should Langerhans-cell histiocytosis be included?

- Yes, patients with Langerhans-cell histiocytosis (ICD-10 code C96.6) should be included in your sample, as per the sampling guidance:

Who to include in the patient list:

- **All patients aged under 16 years old at the time of their care and discharge, with a confirmed primary diagnosis of cancer and are aware of their diagnosis**, specified by an ICD-10² code of C00 – C97. Note that this includes all C codes and all sub-categories of these codes. The equivalent codes if you are using ICD-11 codes can be found in Appendix B.



Contact Details and Support

Under 16 Cancer Patient Experience Survey



Contact Details

- Bernardine Jappah, National Programme Administrator
- Róisín Atkin, National Programme Administrator
- Caroline Hancock, Research Associate

Key Contact Details

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