Sampling Instructions for Principal Treatment Centres (PTCs)

Under 16 Cancer Patient Experience Survey 2024

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Picker

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* Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
* Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people’s feedback.

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**Adherence to the procedures in this document**

It is essential that the sampling is carried out according to the instructions in this document, and it is the responsibility of NHS Trusts to ensure the guidance is carefully followed. Non-compliance could compromise the comparability of the survey and potentially result in the removal of your data from the national results.

However, if you need any support or have any queries about compiling your patient list or following the guidance, please contact us on the details above.

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# Background

These instructions explain how to compile your patient sample file for the 2024 Under 16 Cancer Patient Experience Survey. **This guidance must be followed by Principal Treatment Centres (PTCs).** For PTCs that are jointly provided by two NHS Trusts, each Trust must compile their own patient sample which can be submitted to Picker separately.

Who is excluded from the survey?

Please note that the following sites are not included as part of the current survey, and therefore will not be drawing a sample:

* Paediatric Oncology Shared Care Units (POSCUs)
* Specialist cancer treatment centres **that are not a PTC,** including those providing
	+ Stem cell transplants,
	+ Liver cancer surgery,
	+ Bone cancer surgery,
	+ Other specialist surgery,
	+ Retinoblastoma,
	+ Proton Beam Therapy for cancer.

In addition, outpatients should be excluded from the current survey.

The inclusion of the above groups of patients has been explored but we currently exclude them from the survey. Outpatients are not included due to the likely manual process that would need to be undertaken to select the correct outpatients at some trusts and subsequent burden of doing so. Meanwhile, the reason for deciding to exclude POSCUs and specialist sites was due to the burden of providing a sample in the absence of getting site-level outputs and reports due to low numbers of patients. Furthermore, we need to attribute survey responses to either a POSCU *or* a PTC (as we would not want to send multiple survey invites to the same person).

However, it is recognised that to fully understand experiences of care for children with cancer, we should aim to broaden the inclusion to POSCUs and specialist cancer treatment centres outside of PTCs. Our current approach is to continue collecting feedback via PTC patients, but we will continue to explore what options may be available outside of this survey for collecting specific feedback from outpatients and POSCUs.

**We strongly advise that you read all this document BEFORE you start to compile your patient list. It is your responsibility to ensure that the sampling processes and checks happen in the given timeframe. Please refer to the timetable below.**

# Timetable

Please make sure the survey team at your trust are aware of the key dates shown in the table below. Delays to samples being submitted will impact on the start of fieldwork. This will lead to data and reports being published later than planned.

**Table 1: Key** **Survey Dates**

|  |  |  |
| --- | --- | --- |
| Dates | Task | Responsibility |
| Early Dec 2024 | Sampling instructions available to Trusts | Picker |
| 14th Jan 2025 | Sampling Webinar with Trusts | Picker |
| 17th Jan 2025 | Trusts to start to submit Data Sharing Agreements (DSAs), Declaration Forms, Patient Samples & Covering Letter Info  | Trusts |
| 2nd 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 |
| 17th Jan – 21st Feb 2025 | Picker to check samples. Trusts to respond to queries | Picker and Trusts |
| Mid-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.

# Compiling your list of cancer patients

You compile your list of eligible cancer patients by following the procedure outlined in Figure 1. This task will need to be carried out by a member of staff at your NHS Trust (probably in the Informatics Team /IT department or Cancer Data Management Team). The sample will normally be drawn from the Patient Administration System (PAS) or equivalent. You will also need to liaise with a member of the clinical team (such as the lead cancer nurse) to check the sample after you have drawn your patient list (please see section 3.4).

Please follow the instructions in this manual carefully and allocate sufficient work time to compile and check the patient list carefully. The time that is needed to complete this will vary and depend on a number of factors, ranging from the size of the sample, how long it takes to complete the manual validation and checks, and experience of drawing similar samples. However, please ensure you have allocated enough staff time, as errors may result in the wrong people being surveyed, invalid survey data being collected, or the exclusion of your survey results from analysis and publication.

**Figure 1: sampling procedure flowchart**

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

Trusts are only required to check for deceased patients before submitting their patient list to Picker. Picker will be doing DBS checks before each mailing, however if a trust wishes to do a **local** check before the second and third mailing, then this is definitely welcomed. The mailing dates will be shared with Trusts once they are confirmed. If a Trust needs to inform Picker of a deceased patient, they will need to contact Picker (see contact details on page 3 of this document) with the unique Patient Record Number(s) so we can ensure they are removed from the mailing. This will need to be **at least 24 hours before the mailing date.**

# Eligibility Criteria

All children aged under 16 at the time of their care and discharge, **with a confirmed primary diagnosis[[1]](#footnote-2) of cancer** ora **non-malignant brain, other central nervous system or intracranial tumour** should be included in your sample. These patients must also be aware of their diagnosis and have received NHS care and/or treatment (elective and non-elective) in England for their cancer or tumour. This should include:

* Those who have been discharged from hospital as inpatients for cancer related care or treatment between 1st January 2024 and 31st December 2024.
	+ Please note that current inpatients (those who are currently in hospital for cancer related care or other care) **should not be removed.**
* Those who have been seen as day case patients for cancer related care or treatment, who have been discharged between 1st January 2024 and 31st December 2024.

Additional details on inclusion/exclusion criteria are provided below.

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-10[[2]](#footnote-3) 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.
* **All patients aged under 16 years old at the time of their care and discharge**, with a confirmed primary diagnosis of a non-malignant brain, other central nervous system or intracranial tumour, or non-cancerous blood disease, specified by an ICD-10 code of: D32 - D33, D35.2 - D35.4, D42 - D43, D44.3 - D44.5, D48, D76.1. Note that this includes all sub-categories of these codes. **Please note that if your Trust has switched to ICD-11 codes**, you may provide these instead of ICD-10 codes. The equivalent codes if you are using ICD-11 codes can be found in Appendix B.

Important - Must Read

**Please ensure you are using the most up-to-date ICD-10 Codes, currently 5th Edition.**

You must ensure that ***all patients*** have a ***confirmed diagnosis of cancer or one of the specified tumour types.*** There have been instances in the Adult National Cancer Patient Experience Survey where the patient had been given an ICD-10 code as a ***‘holding code’*** before their diagnosis was confirmed. ***This led to some patients receiving a questionnaire when they either do not have cancer or had not yet been told they had cancer.***

Extra care must be taken to select only those patients with a confirmed diagnosis of cancer to avoid causing ***unnecessary distress*** to the patients and their family/carer.

Patients should be included if they have **a confirmed diagnosis (as per the ICD-10/11 inclusion codes)**, are **aware of their diagnosis** (which may only be possible via manual checks of the sample), and if the **care and treatment is considered to be part of the cancer care pathway**. This means that patients may sometimes be under the care of someone other than an oncologist or a haematologist for their cancer (e.g. a neurosurgeon or member of a patient’s wider multi-disciplinary team). The information you obtain about each patient will be used by Picker both for administering the survey and for sending to the Demographics Batch Service to check for deceased patients.

Please note:

* Patients who receive one off treatment at your NHS Trust but receive most of their care at another NHS Trust should be included.[[3]](#footnote-4)
* 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 are discharged during the eligible time period.

Please note

For the 2024 survey, we would like to group cancers according to the International Classification of Childhood Cancer (ICCC). The ICCC definitions are based on primary site and tumour morphology coded according to ICD-O-2 or ICD-O-3. We would like to collect ICD-O-3 codes, sometimes known as morphology type and site codes. **Your trust will have access to this data, 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.**

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Duplicate patients

The patient list must include **all eligible instances of care**, rather than a list of patients, so some patients will appear on the list more than once if they have had more than one episode of care.

It is very important you **do not** remove duplicate patients at any stage, as this could bias your sample. Duplicate patients will be removed at a later stage by Picker.

Who to **exclude** from the patient list:

* **Deceased** patients.
* Patients **without** **a confirmed diagnosis of cancer** **or one of the specified tumours,** including patients who have been given a holding diagnosis code with pending results.
* Patients or parents/carers who are **not aware of the 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 (DO NOT exclude incomplete addresses that are useable, e.g. no post code).
* Parents/carers or 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.
* Patients being treated solely as an outpatient during the sampling period (i.e. were not admitted to hospital as an inpatient or day case patient).

**IMPORTANT NOTES:**

* If someone has received a diagnosis but their treatment has not yet commenced, they are still eligible and should be included in the sample (for example if they received their diagnosis during an episode of care that falls within the sampling period).
* If there are multiple episodes of care for the same patient, only remove those that meet the above exclusion criteria. It is likely that your patient list will include duplicate patients – Picker will de-duplicate any repeat patients in your file.
* If a patient is 15 at the time of their care but turns 16 during the sampling period (between 1st January 2024 and 31st December 2024) but *after* being discharged from inpatient or day case care, they should be included in the sample.
* If a patient is **discharged more than once during the sampling period** and they are 15 years old during the discharge of their earlier episodes of care but are aged 16 years and older at the time they were discharged during a later visit for an inpatient or day case care. The patient and their earlier episode(s) of care should be included in the sample, but the later episode(s) should be excluded.
* Patients who were diagnosed with cancer a long time ago and have since gone into remission will receive the survey if they have received care or treatment related to their cancer during the sampling period (e.g. if they have had check-ups).

UK General Data Protection Regulation (GDPR): National Data Opt-out Programme

The Under 16 Cancer Patient Experience Survey has received permanent exemption from the National Data Opt-out Programme. This means that the Under 16 Cancer Patient Experience Survey will continue to operate separate opt-out mechanisms. Therefore, to be included in your sample, patients do not have to actively consent to the sharing of their data, and this is for the purpose of the Under 16 Cancer Patient Experience Survey only.

# Checking your patient list

Once you have put together the patient list, **check again** that you have correctly followed each of the points in section 3.1 above. This is a very important step and will save a lot of time because Picker will likely have less queries if you are sure your patient list is correct. Errors in putting together the patient list can result in:

* Picker raising queries on the patient list which need to be resolved prior to mailing
* The wrong people being surveyed
* Invalid survey data being collected
* The exclusion of survey results from analysis, and publication

**Please check the following very carefully:**

* Patients in the list have a confirmed primary diagnosis of cancer or one of the specified tumour types (as per the ICD-10 code inclusion and exclusion criteria listed in section 3.1), and that the patient or parent/carer is aware of their diagnosis (do not include patients who have had “holding codes” assigned)
* The patient list includes all eligible patients within the sampling period and that duplicates have not been removed
* The discharges included in the list are relevant and are where the patient was seen in relation to cancer-related care (the patient list should not include patients who were seen for other treatment which was not in relation to their cancer, but it ***should*** include patients who are receiving psychological support in relation to their cancer)
* The patient list includes both elective and non-elective activity
* The patient list includes all eligible cancer patients (and is not restricted to patients who were *newly* diagnosed in the sampling period or in recent years only)
* Although patients nearing the end of their life should be included, if you feel that by sending a patient a survey will cause particular distress or harm, then they should be removed from the sample and alternative methods of seeking parent/carer feedback considered. You will need to liaise with a member of the cancer clinical team and ask them to review these specific patients to ensure that the correct patients are removed.

In addition, please check the following:

**Deceased patients**

Remove deceased patients from the sample. Check that hospital records do not have a record of a patient’s death from a subsequent admission or visit to hospital. It is strongly recommended that you conduct a DBS trace to help identify these patients.

**Patient ages**

Check that all patients are aged under 16 (i.e. up to 15 years and 364 days) at the time they were discharged (inpatients and day case patients) from that particular episode of care. If a patient is 15 at the time of their care but turns 16 during the sampling period (1st January to 31st December 2024) after receiving care, they should be included in the sample.

**Postal addresses**

Exclude any addresses that are outside the UK. Patients whose address is in the British Islands (Isle of Man, the Channel Islands) are eligible. Equally, patients whose address is a military base, care home, children’s home or prison establishment are also eligible.

**Incomplete information**

Check for any records with incomplete information on key fields (such as surname and full address) and remove those patients. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a patient if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. The more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias.

**Dissent**

Your organisation will have been asked to display a poster relating to this survey giving patients the opportunity to indicate dissent – i.e. opt out from receiving a survey. Please contact the team responsible for recording this to ensure these patients are removed from the sample. Please also check the patient records on your hospital system for patients who have indicated dissent, as that information may also be recorded there.

# Creating the patient list spreadsheet

This guidance has an associated patient list sample construction spreadsheet. Please use this for your patient list and rename it as <**NHSTrustName\_U16CPES2024**>. The sample patient list construction spreadsheet will be sent to all trust contacts via email and can also be requested by contacting: under16cancersurvey@pickereurope.ac.uk.

The spreadsheet contains all the data fields required, details of which are as follows:

* **Patient Record Number** (PRN) – Note: **not** the NHS number. Instead assign a **unique** sequential number to each row in the data, in the format of 'Trust code' (3 characters) plus a unique 4 digits, starting at 1001. E.g. RTH1001, RTH1002
	+ **Note** –where there are multiple rows for the same patient, then each row must have a different PRN assigned.
* **NHS Trust Code** – the ODS 3-digit code for your Trust, e.g. RA7. Please select ‘NHS Trusts *etr*’ on the following webpage for your trust code: <https://digital.nhs.uk/services/organisation-data-service/data-downloads/other-nhs-organisations>[[4]](#footnote-5).
* **NHS Site Code -** please record the hospital site code where the patient was treated using the five character NHS Trust Site Codes (maintained by HSCIC): <https://data.england.nhs.uk/dataset/ods-nhs-trusts-and-sites>
* **Patient (child) First name or initials**
* **Patient (child) Surname**
* **Address Fields (1 to 5)** - the address should be held as separate fields (e.g. street, town, and county). You must use the most *current* address on your system
* **Full Post code**
* **Day** of birth (1 or 2 digits; e.g. 2 or 30)
* **Month** of birth (1 or 2 digits; e.g. 4 or 12)
* **Year** of birth (4 digits; e.g. 2020)
* **NHS Number** – verified as belonging to that individual. Ensure as much as possible that this is populated as it will be used for DBS checks
* **Gender** – code as follows:
	+ 1 = male
	+ 2 = female
	+ 9 = not specified
	+ 0 = not known
* **Ethnicity** – The ethnicity of a person is specified by that person and should be coded as follows. The code “Z” (not stated) should be used if a patient was asked for their ethnic category but refused to provide it. If this code is missing for any other reason, ethnic category should be left blank in the sample information.
	+ **White**
		- * A British
			* B Irish
			* C Any other White background
	+ **Mixed**
		- * D White and Black Caribbean
			* E White and Black African
			* F White and Asian
			* G Any other mixed background
	+ **Asian or Asian British**
		- * H Indian
			* J Pakistani
			* K Bangladeshi
			* L Any other Asian background
	+ **Black or Black British**
		- * M Caribbean
			* N African
			* P Any other Black background
	+ **Other Ethnic Groups**
		- * R Chinese
			* S Any other ethnic group
			* Z Not stated
* **Day** of discharge (1 or 2 digits; e.g. 2 or 30)
* **Month** of discharge (1 or 2 digits; e.g. 4 or 12)
* **Year** of discharge (4 digits; e.g. 2024)
* **ICD-10 Code on discharge** – 4 digits, including sub-categories for these codes, i.e. C25.1.
	+ These must be coded in the ***primary diagnosis field*** and should be between C00 & C97 and D codes, of: D32 - D33, D35.2 - D35.4, D42 - D43, D44.3 - D44.5, D48, D76.1
	+ *Please note that if you provide the ICD-10 Code, you do not need to provide the ICD-11 Code.*
* **ICD-11 Code on discharge** – These must be coded in the ***primary diagnosis field*** and should match the codes provided in Appendix B.
	+ *Please note that if you provide the ICD-11 Code, you do not need to provide the ICD10 Code.*
* **ICD-O-3 site code** (4 digits)[[5]](#footnote-6) 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.
* **Main Specialty on discharge**– code in the form NNN as [Specified by NHS Digital](https://datadictionary.nhs.uk/attributes/main_specialty_code.html#ariaid-title3)
* **Patient classification** – the type of care received, as detailed here

<https://datadictionary.nhs.uk/attributes/patient_classification.html>; 1 = ordinary discharge (inpatient), 2 = day case discharge, 3 = regular day case admission & 4 = regular night admission.

**Parents’ details**

Please **do not** include parents’ name or address in the sample file.

# Checking the trust’s own records for patient deaths

One of the most reliable and up-to-date sources of information on patient deaths is your own trust’s records. Therefore, it is essential that you check your own trust’s records for patients selected for the survey having died at your trust. Relatives are likely to be particularly upset if they receive a questionnaire or reminder from the trust where their child has recently died. We will then carry out a final deceased check using DBS before sending out the questionnaires.

**Validate your list**

**Validate the patient list with your Cancer Services Team** to ensure only eligible patients have been included.

**This step is essential and must be completed** to check that patients in your list have a **confirmed diagnosis** of cancer or one of the specified tumour types, that they are **aware of their diagnosis** and that their care **was in relation to** their cancer or tumour. This is to minimise the risk of questionnaires being sent out inappropriately.

# Response to relatives of patients who have died

Tracing services are not fool proof and even after your sample has been checked for deaths, some patients may die before the questionnaire is delivered. For example, although the questionnaire mailing is immediately after the deceased patient checks, sometimes a patient may pass away between this check and receiving the questionnaire via 2nd class post. Picker will run a Freephone helpline and offer an email address to patients and relatives to handle any queries from patients during fieldwork. These contact details will be clearly advertised on the survey covering letters. However, your Trust may be contacted directly by a bereaved relative and special sensitivity will be required when responding to them. **If you do have such contact, please inform Picker immediately to ensure that no further mailings are sent to the deceased patient.**

# Data submission and data checking process

In this section we have provided an outline of the various stages involved in the data checking process. This is to provide insight into what happens to the patient list after it has been uploaded to Picker and to explain the timeframe between the point at which patient lists are uploaded and the first mailing to patients.

# Stage 1 – Patient List

The first task that needs to be completed before we are able to receive a patient list is for the person compiling the sample to complete and submit a Patient List Declaration Form. This is a requirement of the survey’s Section 251 approval and provides confirmation that the trust has completed all required checks and validation of the patient list, which is designed to minimise errors, data breaches and data queries.

The patient list declaration form will be sent to all trust contacts via email and can also be requested by contacting: under16cancersurvey@pickereurope.ac.uk.

Once the form has been received, it is checked by Picker, who will provide confirmation to the trust that they are able to proceed with securely uploading their patient list via the online sample platform [**https://samplechecker.picker.org/login.htm**](https://samplechecker.picker.org/login.htm). **Please do not send the patient list using any other method. Patient lists should NEVER be sent by email.**

If the Patient List Declaration Form is not received or if there is a need to query anything relating to the form, this can delay the sample upload and checking process.

# Stage 2 – Detailed sample checks by Picker

Once the Patient List Declaration Form has been approved and data uploaded to the sample checker platform, the sample goes through a multi-stage checking process.

This includes:

* Sample validation to ensure that all eligible patients have been included
	+ The previous wave of survey data will be used to compare key characteristics and trends in the dataset
* Checks against exclusion criteria – i.e. whether any patients are included that should not be (for example, based on the ICD codes or their age). This may require the trust to compile a new list
* Checks to ensure that information provided regarding each patient is complete and that no information is missing i.e. patient name or address information

Once the sample checks have been completed, Picker will raise any queries directly with the trust. In some cases, where sampling errors are identified, trusts will be required to compile a new patient list, which would be subject to the same checking process described above.

Once all queries and confirmation points have been resolved with the trust, the patient list can be approved for the next stage.

# Stage 3 – Batching and de-duplication

The final stage is preparing for mail out by batching trust samples together into a combined sample so we can undertake duplicate checks across all trusts. This is a necessary step, as many patients attend multiple trusts as part of their treatment pathway and, therefore, appear in multiple samples. We need to ensure that each patient only receives a survey once. We can only undertake this process when we have received and approved patient lists from all participating trusts.

It is therefore important that trusts upload their patient list to Picker as quickly as possible and keep to the dates outlined in the **timetable** (section 2)**,** and that trusts respond to any data queries swiftly.

# Stage 4 – DBS and final validation checks

Once duplicates have been removed from the amalgamated file, this is submitted to DBS for tracing to identify any patients who are deceased. Any patients identified as deceased are removed from the sample.

We also undertake further final name and address checks by cross checking the results in the DBS trace file with the original file submitted. We then complete an additional DBS trace on the updated amalgamated data to confirm that all patients in the updated file are traced successfully.

To ensure the correct questionnaire is sent to the correctly aged patient, Picker will be using the date of birth information to calculate the **current age** of the patient immediately before sending the survey invites out to patients. Based on this, Picker will assign the correct survey version to each patient[[6]](#footnote-7).

Once this has been completed, the amalgamated file is ready to be used to prepare mailing packs for send out. Surveys will be mailed within 24 hours of completion of the process for running and applying deceased checks. If the mailing process takes longer than 24 hours, deceased checks will be repeated to ensure records remain up to date.

# Appendix A: ICD-O-3 Codes

For the 2024 survey, we would like to group cancers according to the International Classification of Childhood Cancer (ICCC). The ICCC definitions are based on primary site and tumour morphology coded according to ICD-O-2 or ICD-O-3. Therefore, we would like to collect ICD-O-3 codes, sometimes known as morphology type and site codes. Your trust will have access to this data, 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.

# Appendix B: ICD-10 to ICD-11 Code Mapping

|  |  |
| --- | --- |
| ICD-10 Code | ICD-11 Code |
| C00 | 2B60.Z |
| C00.0 | 2B60.Z |
| C00.1 | 2B60.Z |
| C00.2 | 2B60.Z |
| C00.3 | 2B60.Z |
| C00.4 | 2B60.Z |
| C00.5 | 2B60.Z |
| C00.6 | 2B60.Z |
| C00.8 | 2B60.Z |
| C00.9 | 2B60.Z |
| C01 | 2B61.Z |
| C02 | 2B62.Z |
| C02.0 | 2B62.Z |
| C02.1 | 2B62.Z |
| C02.2 | 2B62.Z |
| C02.3 | 2B62.Z |
| C02.4 | 2B62.1 |
| C02.8 | 2B62.Z |
| C02.9 | 2B62.Z |
| C03 | 2B63.Z |
| C03.0 | 2B63.Z |
| C03.1 | 2B63.Z |
| C03.9 | 2B63.Z |
| C04 | 2B64.Z |
| C04.0 | 2B64.Z |
| C04.1 | 2B64.Z |
| C04.8 | 2B64.Z |
| C04.9 | 2B64.Z |
| C05 | 2B65.Z |
| C05.0 | 2B65.Z |
| C05.1 | 2B65.Z |
| C05.2 | 2B65.Z |
| C05.8 | 2B65.Z |
| C05.9 | 2B65.Z |
| C06 | 2B66.Z |
| C06.0 | 2B66.Z |
| C06.1 | 2B66.Z |
| C06.2 | 2B66.Z |
| C06.8 | 2B66.Z |
| C06.9 | 2B66.Z |
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| C08.9 | 2B68.Z |
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| C09.8 | 2B69.Z |
| C09.9 | 2B69.Z |
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| C10.1 | 2B6A.Z |
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| C10.3 | 2B6A.Z |
| C10.4 | 2B6A.Z |
| C10.8 | 2B6A.Z |
| C10.9 | 2B6A.Z |
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| C11.1 | 2B6B.Z |
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| C11.3 | 2B6B.Z |
| C11.8 | 2B6B.Z |
| C11.9 | 2B6B.Z |
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| C13.1 | 2B6D.Z |
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| C13.8 | 2B6D.Z |
| C13.9 | 2B6D.Z |
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| C14.8 | 2B6E.Z |
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| C16.4 | 2B72.Z |
| C16.5 | 2B72.Z |
| C16.6 | 2B72.Z |
| C16.8 | 2B72.Z |
| C16.9 | 2B72.Z |
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| C17.0 | 2B80.0Z |
| C17.1 | 2B80.Z |
| C17.2 | 2B80.Z |
| C17.3 | 2B80.Z |
| C17.8 | 2B80.0Z |
| C17.9 | 2B80.0Z |
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| C18.3 | 2B90.0Z |
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| C18.8 | 2B90.Z |
| C18.9 | 2B90.Z |
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| C20 | 2B92.Z |
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| C21.0 | 2C00.Z |
| C21.1 | 2C00.Z |
| C21.2 | 2C00.Z |
| C21.8 | 2C00.Z |
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| C22.2 | 2C12.01 |
| C22.3 | 2B56.3 |
| C22.4 | 2B5F.2 |
| C22.7 | 2C12.0 |
| C22.9 | 2C12.0 |
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| C24 | 2C17.Z |
| C24.0 | 2C14.Z |
| C24.1 | 2C16.Z |
| C24.8 | 2C17.Z |
| C24.9 | 2C17.Z |
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| C25.1 | 2C10.Z |
| C25.2 | 2C10.Z |
| C25.3 | 2C10.Z |
| C25.4 | 2C10.Z |
| C25.7 | 2C10.Z |
| C25.8 | 2C10.Z |
| C25.9 | 2C10.Z |
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| C26.0 | 2C11.0 |
| C26.1 | 2C11.Z |
| C26.8 | 2C11.Z |
| C26.9 | 2C11.Z |
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| C30.0 | 2C20.Z |
| C30.1 | 2C21.Z |
| C31 | 2C22.Z |
| C31.0 | 2C22.Z |
| C31.1 | 2C22.Z |
| C31.2 | 2C22.Z |
| C31.3 | 2C22.Z |
| C31.8 | 2C22.Z |
| C31.9 | 2C22.Z |
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| C32.0 | 2C23.1 |
| C32.1 | 2C23.2 |
| C32.2 | 2C23.3 |
| C32.3 | 2C23.4 |
| C32.8 | 2C23.5 |
| C32.9 | 2C23.Z |
| C33 | 2C24.Z |
| C34 | 2C25.Z |
| C34.0 | 2C25.Z |
| C34.1 | 2C25.Z |
| C34.2 | 2C25.Z |
| C34.3 | 2C25.Z |
| C34.8 | 2C25.Z |
| C34.9 | 2C25.Z |
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| C38 | 2C28.Z |
| C38.0 | 2C28.1 |
| C38.1 | 2C28.1 |
| C38.2 | 2C28.1 |
| C38.3 | 2C28.1 |
| C38.4 | 2C26.Z |
| C38.8 | 2C28.1 |
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| C39.0 | 2C29.Z |
| C39.8 | 2C29.Z |
| C39.9 | 2C29.Z |
| C40 | 2B5Z |
| C40.0 | 2B52.0 |
| C40.1 | 2B52.0 |
| C40.2 | 2B52.0 |
| C40.3 | 2B52.0 |
| C40.8 | 2B52.0 |
| C40.9 | 2B52.0 |
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| C41.0 | 2B52.Z |
| C41.1 | 2B52.Z |
| C41.2 | 2B52.Z |
| C41.3 | 2B52.Z |
| C41.4 | 2B51.2 |
| C41.8 | 2B5J |
| C41.9 | 2B5J |
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| C43.4 | 2C30.Z |
| C43.5 | 2C30.Z |
| C43.6 | 2C30.Z |
| C43.7 | 2C30.Z |
| C43.8 | 2C30.Z |
| C43.9 | 2C30.Z |
| C44 | 2C34 |
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| C44.1 | 2C3Z |
| C44.2 | 2C3Z |
| C44.3 | 2C3Z |
| C44.4 | 2C3Z |
| C44.5 | 2C3Z |
| C44.6 | 2C3Z |
| C44.7 | 2C3Z |
| C44.8 | 2C3Z |
| C44.9 | 2C3Z |
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| C45.0 | 2C26.0 |
| C45.1 | 2C51.2Z |
| C45.2 | 2C28.Z |
| C45.7 | 2C26.0 |
| C45.9 | 2C26.0 |
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| C46.1 | 2B57.Z |
| C46.2 | 2B57.Z |
| C46.3 | 2B57.Z |
| C46.7 | 2B57.Z |
| C46.8 | 2B57.Z |
| C46.9 | 2B57.Z |
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| C47.0 | 2C4Z |
| C47.1 | 2C4Z |
| C47.2 | 2C4Z |
| C47.3 | 2C4Z |
| C47.4 | 2C4Z |
| C47.5 | 2C4Z |
| C47.6 | 2C4Z |
| C47.8 | 2C4Z |
| C47.9 | 2C4Z |
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| C48.1 | 2B5F.10 |
| C48.2 | 2C51.Z |
| C48.8 | 2C53.1 |
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| C49.1 | 2B5K |
| C49.2 | 2B5K |
| C49.3 | 2B5K |
| C49.4 | 2B5K |
| C49.5 | 2B5K |
| C49.6 | 2B5K |
| C49.8 | 2B5K |
| C49.9 | 2B5K |
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| C50.0 | 2C6Z |
| C50.1 | 2C6Z |
| C50.2 | 2C6Z |
| C50.3 | 2C6Z |
| C50.4 | 2C6Z |
| C50.5 | 2C6Z |
| C50.6 | 2C6Z |
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| C50.9 | 2C6Z |
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| C51.1 | 2C70.Z |
| C51.2 | 2C70.Z |
| C51.8 | 2C70.Z |
| C51.9 | 2C70.Z |
| C52 | 2C71.Z |
| C53 | 2C77.Z |
| C53.0 | 2C77.Z |
| C53.1 | 2C77.Z |
| C53.8 | 2C77.Z |
| C53.9 | 2C77.Z |
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| C54.0 | 2C76.Z |
| C54.1 | 2C76.Z |
| C54.2 | 2C76.Z |
| C54.3 | 2C76.Z |
| C54.8 | 2C76.Z |
| C54.9 | 2C76.Z |
| C55 | 2C78 |
| C56 | 2C73.Z |
| C57 | 2C7Z |
| C57.0 | 2C74.Z |
| C57.1 | 2C72.Z |
| C57.2 | 2C72.Z |
| C57.3 | 2C72.Z |
| C57.4 | 2C72.Z |
| C57.7 | 2C7Z |
| C57.8 | 2C72.2 |
| C57.9 | 2C7Z |
| C58 | 2C75.Z |
| C60 | 2C81.Z |
| C60.0 | 2C81.Z |
| C60.1 | 2C81.Z |
| C60.2 | 2C81.Z |
| C60.8 | 2C81.Z |
| C60.9 | 2C81.Z |
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| C62 | 2C80.Z |
| C62.0 | 2C80.Z |
| C62.1 | 2C80.Z |
| C62.9 | 2C80.Z |
| C63 | 2C84 |
| C63.0 | 2C84 |
| C63.1 | 2C84 |
| C63.2 | 2C84 |
| C63.7 | 2C84 |
| C63.8 | 2C84 |
| C63.9 | 2C8Z |
| C64 | 2C90.Z |
| C65 | 2C91.Z |
| C66 | 2C92.Z |
| C67 | 2C94.Z |
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| C67.2 | 2C94.Z |
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| C67.6 | 2C94.Z |
| C67.7 | 2C94.Z |
| C67.8 | 2C94.Z |
| C67.9 | 2C94.Z |
| C68 | 2C9Z |
| C68.0 | 2C93.Z |
| C68.1 | 2C93.Z |
| C68.8 | 2C95.Z |
| C68.9 | 2C9Z |
| C69 | 2D0Z |
| C69.0 | 2D00.Z |
| C69.1 | 2D01.Z |
| C69.2 | 2D02.Z |
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| C69.4 | 2D06.Z |
| C69.5 | 2D03.Z |
| C69.6 | 2D04 |
| C69.8 | 2D0Z |
| C69.9 | 2D0Z |
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| C70.0 | 2A01.00 |
| C70.1 | 2A01.2 |
| C70.9 | 2A01.00 |
| C71 | 2A00.11 |
| C71.0 | 2A00.5 |
| C71.1 | 2A00.5 |
| C71.2 | 2A00.5 |
| C71.3 | 2A00.5 |
| C71.4 | 2A00.5 |
| C71.5 | 2A00.5 |
| C71.6 | 2A00.5 |
| C71.7 | 2A00.5 |
| C71.8 | 2A00.5 |
| C71.9 | 2A00.5 |
| C72 | 2A02 |
| C72.0 | 2A02 |
| C72.1 | 2A02 |
| C72.2 | 2A02 |
| C72.3 | 2A02 |
| C72.4 | 2A02 |
| C72.5 | 2A02.1Z |
| C72.8 | 2A02 |
| C72.9 | 2A0Z |
| C73 | 2D10.Z |
| C74 | 2D11.Z |
| C74.0 | 2D11.Z |
| C74.1 | 2D11.Z |
| C74.9 | 2D11.Z |
| C75 | 2D12.Z |
| C75.0 | 2D12.Z |
| C75.1 | 2D12.Z |
| C75.2 | 2D12.Z |
| C75.3 | 2D12.Z |
| C75.4 | 2D12.Z |
| C75.5 | 2D12.Z |
| C75.8 | 2D12.Z |
| C75.9 | 2D12.Z |
| C76 | 2D4Z |
| C76.0 | 2D4Z |
| C76.1 | 2D4Z |
| C76.2 | 2D4Z |
| C76.3 | 2D4Z |
| C76.4 | 2D4Z |
| C76.5 | 2D4Z |
| C76.7 | 2D4Z |
| C76.8 | 2D4Z |
| C77 | 2D6Z |
| C77.0 | 2D60.0 |
| C77.1 | 2D60.1 |
| C77.2 | 2D60.2 |
| C77.3 | 2D60.3 |
| C77.4 | 2D60.4 |
| C77.5 | 2D60.5 |
| C77.8 | 2D61 |
| C77.9 | 2D6Z |
| C78 | 2D7Z |
| C78.0 | 2D70 |
| C78.1 | 2D71 |
| C78.2 | 2D72 |
| C78.3 | 2D73 |
| C78.4 | 2D84 |
| C78.5 | 2D85 |
| C78.6 | no code |
| C78.7 | 2D80.Z |
| C78.8 | 2D8Z |
| C79 | 2E2Z |
| C79.0 | 2E00 |
| C79.1 | 2E01 |
| C79.2 | 2E08 |
| C79.3 | 2D51 |
| C79.4 | 2E09 |
| C79.5 | 2E03 |
| C79.6 | 2E05.0 |
| C79.7 | 2E07 |
| C79.8 | 2E2Z |
| C79.9 | 2E2Z |
| C80 | 2D4Z |
| C80.0 | 2D4Z |
| C80.9 | 2D4Z |
| C81 | 2B30.Z |
| C81.0 | 2B30.0 |
| C81.1 | 2B30.10 |
| C81.2 | 2B30.12 |
| C81.3 | 2B30.13 |
| C81.4 | 2B30.11 |
| C81.7 | 2B30.1Z |
| C81.9 | 2B30.Z |
| C82 | 2A80.Z |
| C82.0 | 2A80.0 |
| C82.1 | 2A80.1 |
| C82.2 | 2A80.2 |
| C82.3 | 2A80.2 |
| C82.4 | 2A80.2 |
| C82.5 | 2A80.Z |
| C82.6 | 2A80.3 |
| C82.7 | 2A80.Z |
| C82.9 | 2A80.Z |
| C83 | 2A8Z |
| C83.0 | 2A82.0Z |
| C83.1 | 2A85.5 |
| C83.3 | 2A81.Z |
| C83.5 | 2A8Z |
| C83.7 | 2A85.6 |
| C83.8 | 2A8Z |
| C83.9 | 2A8Z |
| C84 | 2B2Z |
| C84.0 | 2B01 |
| C84.1 | 2B02 |
| C84.4 | 2A90.C |
| C84.5 | 2B2Z |
| C84.6 | 2A90.A |
| C84.7 | 2A90.B |
| C84.8 | 2B0Z |
| C84.9 | 2B2Z |
| C85 | 2A8Z |
| C85.1 | 2A86.Z |
| C85.2 | 2A81.0 |
| C85.7 | 2A8Z |
| C85.9 | 2A8Z |
| C86 | 2A90 |
| C86.0 | 2A90.6 |
| C86.1 | 2A90.8 |
| C86.2 | 2A90.7 |
| C86.3 | 2B00 |
| C86.4 | 2A60.5 |
| C86.5 | 2A90.9 |
| C86.6 | 2B03 |
| C88 | 2A84.Z |
| C88.0 | 2A85.4 |
| C88.2 | 2A84.1 |
| C88.3 | 2A84.0 |
| C88.4 | 2A85.1 |
| C88.7 | 2A85.0 |
| C88.9 | 2A84.Z |
| C90 | 2A83.Z |
| C90.0 | 2A83.1 |
| C90.1 | 2A83.4 |
| C90.2 | 2A83.3 |
| C90.3 | 2A83.2 |
| C91 | 2B33.3 |
| C91.0 | 2A7Z |
| C91.1 | 2A82.0Z |
| C91.3 | 2A82.1Z |
| C91.4 | 2A82.2 |
| C91.5 | 2A90.5 |
| C91.6 | 2A90.0 |
| C91.7 | 2A82.3 |
| C91.8 | 2A85.6 |
| C91.9 | 2B33.3 |
| C92 | 2B33.1 |
| C92.0 | 2A60.Z |
| C92.1 | 2A20.0Z |
| C92.2 | 2A41 |
| C92.3 | 2A60.39 |
| C92.4 | 2A60.Z |
| C92.5 | 2A60.33 |
| C92.6 | 2A60.Z |
| C92.7 | XH5AH8 |
| C92.8 | 2A61 |
| C92.9 | 2A60.3Z |
| C93 | 2B33.1 |
| C93.0 | 2A60.34 |
| C93.1 | 2A40 |
| C93.3 | 2A42.Z |
| C93.7 | 2B33.1 |
| C93.9 | 2B33.1 |
| C94 | 2A61 |
| C94.0 | 2A60.35 |
| C94.2 | 2A60.36 |
| C94.3 | 2A21.00 |
| C94.4 | 2A60.38 |
| C94.6 | 2A44 |
| C94.7 | 2A61 |
| C95 | 2B33.4 |
| C95.0 | 2B33.0 |
| C95.1 | 2B33.4 |
| C95.7 | no code |
| C95.9 | 2B33.4 |
| C96 | 2B3Z |
| C96.0 | XH60Q1 |
| C96.2 | 2A21.Z |
| C96.4 | 2B31.Z |
| C96.5 | XH86U0 |
| C96.6 | 2B31.2 |
| C96.7 | XH0124 |
| C96.8 | 2B31.1 |
| C96.9 | 2B33 |
| C97 | 2D43 |
| D32 | 2A01.2 |
| D32.0 | 2A01.2 |
| D32.1 | 2A01.2 |
| D32.9 | 2A01.2 |
| D33 | 2A00 |
| D33.0 | 2A00.5 |
| D33.1 | 2A00.5 |
| D33.2 | 2A00.5 |
| D33.3 | 2A02.3 |
| D33.4 | 2A02.4 |
| D33.7 | 2A0Z |
| D33.9 | 2A0Z |
| D35.2 | 2F37.Z |
| D35.3 | 2F37.Z |
| D35.4 | 2F37.Z |
| D42 | 2A0Z |
| D42.0 | 2A01.2 |
| D42.1 | 2A01.2 |
| D42.9 | 2A01.2 |
| D43 | 2A0Z |
| D43.0 | 2A00.5 |
| D43.1 | 2A00.5 |
| D43.2 | 2A00.5 |
| D43.3 | 2A0Z |
| D43.4 | 2A0Z |
| D43.7 | 2A0Z |
| D43.9 | 2A0Z |
| D44.3 | 2F7A.Z&XA8J35 |
| D44.4 | 2F7A.Z |
| D44.5 | 2F7A.Z&XA1EU3 |
| D48 | 2F9Z |
| D48.0 | 2F9B |
| D48.1 | 2F7C |
| D48.2 | 2F9Z |
| D48.3 | 2F93 |
| D48.4 | 2F94 |
| D48.5 | 2F92 |
| D48.6 | 2F95 |
| D48.7 | no code |
| D48.9 | 2B31.Z |
| D76.1 | 4A01.23 |

1. ‘Primary cancer’ is defined as the main diagnosis shown on your system, regardless of how many times they’ve had cancer in the past or how progressive their cancer is. [↑](#footnote-ref-2)
2. The ICD codes (5th Edition which became the mandated diagnostic classification in the UK on 1 April 2016) are shorthand for the International Statistical Classification of Disease and Related Health Problems, published in the UK by Health and Social Care Information Centre. They give the diagnosis or reason for a patient episode and are mandatory codes used in the NHS [↑](#footnote-ref-3)
3. Patients that have received treatment at more than one PTC should still be included in the sample (we deduplicate patients across Trust sample files based on the number of visits to a PTC). [↑](#footnote-ref-4)
4. Important note: if there’s a date in column L, that means the trust ceased to exist (closed/merged) on that date. [↑](#footnote-ref-5)
5. Your trust will have access to this data, 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. [↑](#footnote-ref-6)
6. Patients aged 15 at the time of their care but turn 16 before receiving a survey will be sent the 12-15 survey version [↑](#footnote-ref-7)