**National Cancer Patient Experience Survey Programme**

**Pilot Sampling Instructions**

**2025**

The National Cancer Patient Experience Survey Programme Pilot is run by Picker on behalf of NHS England

If you are taking part in the pilot for NCPES 2025, which involves testing the use of text message reminders, please ensure you only use the pilot versions of sampling documentation.

**Contacts**

For information or advice about compiling and submitting your patient list, please contact the National Cancer Patient Experience Survey project team:

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**Adherence to the procedures in this document**

It is essential that the sampling is carried out according to the agreed protocol set out in this instruction manual. Non-compliance could compromise the comparability of the survey results. If you have any problems or queries about compiling your patient list or following the guidance, please contact the National Cancer Patient Experience Survey project team.

# Compiling a List of Patients

These instructions explain how to compile a list of eligible cancer patients for the NCPES pilot and mainstage. If you are taking part in the 2025 pilot, you will only need to use this pilot version of the sampling documentation and submit a single patient list.

This task will need to be carried out by a member of staff at the NHS Trust. The sample will normally be drawn from the Patient Administration System (PAS).

Please follow the instructions in this manual carefully, step-by-step and allocate sufficient work time to compile and check the patient list. It is important that the person drawing the sample is given sufficient time and support by their manager to do this properly. Errors may result in the wrong people being surveyed, invalid survey data being collected, or the exclusion of survey results from analysis, benchmarking and publication. **We strongly advise that you read all of this document BEFORE you start to compile your patient list.**

**Information about the 2025 pilot**

For the 2025 NCPES, we will be piloting the use of a new contact strategy to invite patients to take part in the survey. This will involve using text message reminders to encourage online completion. Your NHS trust has volunteered to take part in this pilot. These sampling instructions have been updated to reflect this. In summary:

* Your patient list must include patients discharged during **March 2025** (in addition to the mainstage sampling months of April to June 2025). The patient list will all be submitted in one spreadsheet.
* There are **no changes to the inclusion or exclusion criteria**.
* Where available, **providing a valid mobile number for participants is important**. For the first time in 2025, mobile number will be used to send text message reminders to patients. Please continue to include patients both with and without a mobile number.

## Compiling your list of cancer patients

**Who to include in the patient list:**

All adult patients (aged 16 and over) with a confirmed diagnosis of cancer, who have been admitted to hospital as an inpatient for cancer related treatment or who were seen as a day case patient for cancer related treatment, and have been discharged between **1st March 2025** **and 30th June 2025** should be included in the survey. Please note the change in sampling period to include March for trusts taking part in the 2025 NCPES pilot to test the use of text message reminders.

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 (DBS) to check for deceased patients.

**Important – Must read**

**Please ensure you are using the most up to date ICD10 Codes, currently 5th Edition.**

You must ensure that **all patients**have a **confirmed diagnosis of cancer**. There have been instances in previous iterations of the survey where the patient had been given an ICD10 code as a **‘holding code’** before their diagnosis of cancer was confirmed. **This led to some patients receiving a questionnaire when they either did 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 patient.

If your Trust has switched to the use of ICD11 codes, you may provide these instead of ICD10 codes but should still check that all patients have a **confirmed diagnosis of cancer**. You only need to provide either ICD10 or ICD11 codes, not both.

# ICD codes

**All** adult patients with a **confirmed diagnosis** of cancer should be specified by an ICD10 code of C00 - C97 or D05 in the first diagnosis field of their PAS record. Note that this includes all C codes and ONE D code and all sub-categories of these codes, **with the exception of those listed in the exclusions list further down**. The equivalent ICD11 codes can be found in [Appendix A](#_Appendix_A:_Valid).

# Duplicate patients

* The patient list must include **all eligible discharges**, rather than a list of patients, so some patients will appear on the list more than once.
* It is very important you **do not** remove duplicate patients at this 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 including patients who have been given a holding diagnosis code with pending results
* Children or young persons under 16 years old at the time they were discharged
* Patients with a Patient Classification (i.e., type of admission) of 5 (Mother and baby using delivery facilities only)
* Patients with an ICD10 code[[1]](#footnote-2) of C44 (other malignant neoplasms of skin) and all C44 classifications (C44.0 to C44.9). The equivalent ICD11 code (2C3Z) should also be excluded.
* Patients with an ICD10 code of C84 (Mature T/NK-cell lymphomas) and all C84 classifications (C84.0 to C84.9). The equivalent ICD11 codes (2B01, 2B02, 2A90.C, 2B2Z, 2A90.A, 2A90.B, 2B0Z and 2B2Z) should also be excluded.
* Patients who are registered as private patients (non-NHS)
* Any patients who are known to be current inpatients[[2]](#footnote-3)
* Patients being treated solely as an outpatient
* Patients without a UK postal address
* Patients with not enough address information to have a reasonable chance of the questionnaire being delivered (e.g., keep in those with address 1 and post code; complete address without a post code; address without city or county details but with post code).
* Patients who have requested their details are not used for any purpose other than their clinical care. This includes patients that have informed your trust, in response to communications about the National Cancer Patient Experience Survey, that they do not wish to be included in the survey. Trusts need to have a mechanism in place to record patients who opt out of the survey in response to seeing dissent posters.

This does not include those who have opted out of having their data used for planning and research purposes via the National Data Opt-out Programme (see box below).

**National Data Opt-out Programme**

The National Cancer Patient Experience Survey is exempt from the National Data Opt-out meaning that these **should not be applied** to your survey sample. Therefore, to be included in your sample, patients do not have to actively consent to the sharing of their data. More information on the survey’s exemption can be found [here](https://digital.nhs.uk/services/national-data-opt-out/programmes-to-which-the-national-data-opt-out-should-not-be-applied).

## Checking your patient list

Once you have compiled your patient list, **check** that you have correctly followed each of the points in section 1.1 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 having to raise 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, benchmarking and publication

**Please check the following very carefully:**

* Patients in the list have a confirmed diagnosis of cancer, and that the patient is aware of their diagnosis (do not include patients who have had “holding codes” assigned)
* The patient list includes all eligible discharges within the sampling period (March to June 2025) and that duplicates have notbeen removed
* The discharges included in the list are relevant and are where the patient was seen in relation to their cancer (the patient list should not include patients who were seen for other treatment which was not in relation to their cancer)
* The patient list includes both elective and non-elective activity
* Patient list includes emergency admissions.
* 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)

**Important Note**

It is the responsibility of trusts to ensure the patient list **only** includes eligible patients who have a **confirmed diagnosis of cancer** whose admission during the sampling period was **in relation** to their cancer diagnosis.

Any reported cases of ‘no cancer’ by patients during fieldwork will be looked into by Picker and the Trust. Where there is more than one identified case for a Trust, we will pause the survey mailings for that Trust whilst eligibility is investigated. It is therefore important that cases are investigated quickly by Trusts so that patients can be re-assured, and fieldwork can proceed on schedule.

## Creating the patient list spreadsheet

Provided alongside this guidance is a patient list template spreadsheet.

Please use this for entering data for your patient list and rename it as <NHSTrustCode\_CPES25.xlsx> where ‘NHSTrustCode’ is the code of your trust. Full instructions on how to do this and how to transfer the data securely will be sent through to you separately via email. You will submit data for the pilot sample (March) and mainstage sample (April to June) in one spreadsheet.

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

* **Trust Code** – the ODS 3-digit code for your Trust, e.g., RA0
* **Patient Record Number** (PRN) – The unique serial number allocated to each patient by the trust (e.g., CPES25RTH0001). This is composed of the survey code (CPES25), followed by your trust code (e.g., RTH), followed by a four-digit number starting with 0001 (e.g., 0001, 0002, etc.). Do not include hyphens, spaces, underscores, etc.
	+ **Note** – where there are multiple rows for the same patient, then each row must have a different PRN assigned.
* **Title** (Mr, Mrs, Ms, etc.)
* **Initials / First name**
* **Surname**
* **Address Fields** – the address should be held as separate fields (e.g., street, area, town, and county). You must use the most *current* address on your system
* **Postcode**
* **NHS Number** – verified and belonging to that individual. Ensure as much as possible that this is populated as it will be used for DBS checks
* **Date of Birth** in text format (YYYYMMDD). This needs to be the **FULL** date of birth of the patient to ensure DBS checks can be carried out on the sample before any mailings**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 using the [17-item alphabetical coding specified by NHS England](https://www.datadictionary.nhs.uk/data_elements/ethnic_category.html). 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**.** The codes are as follows:
	+ **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 Admission** (1 or 2 digits, e.g., 7 or 26)
* **Month of Admission**
	+ 1=January
	+ 2=February
	+ 3=March
	+ 4=April
	+ 5=May
	+ 6=June
	+ 7=July
	+ 8=August
	+ 9=September
	+ 10=October
	+ 11=November
	+ 12=December
* **Year of Admission** (4 digits, e.g., 2025)
* **Day** **of Discharge** (1 or 2 digits, e.g., 2 or 30) **Month of Discharge**
	+ 3=March
	+ 4=April
	+ 5=May
	+ 6=June
* **Year of Discharge** (4 digits, e.g., 2025)
* **ICD-11 Code** – Please include if these are available. 4-7 digits, include sub-categories for these codes, i.e., 2A01.2.
	+ Valid codes can be found in [Appendix A](#_Appendix_A:_Valid). **DO NOT include 2C3Z, 2B01, 2B02, 2A90.C, 2A90.A, 2A90.B, 2B0Z or 2B2Z.**
	+ Note: If your trust has not switched to ICD-11 codes, you may provide ICD-10 codes instead.
* **ICD10 Code** – Please include these if your trust has not yet switched to ICD-11 codes. 3-4 digits, include sub-categories for these codes, i.e., C25.1.
	+ These must be between C00 & C97 and D05 codes**. DO NOT include C44 codes and C84 codes.**
* **Main Specialty** – code in the form NNN as [specified by NHS England](https://datadictionary.nhs.uk/attributes/main_specialty_code.html)
* **Sub ICB Location code** – the [3-5 character code](https://digital.nhs.uk/services/organisation-data-service/data-downloads/other-nhs-organisations) which will be billed for the care of the patient
* **Patient classification** – [the type of admission](https://datadictionary.nhs.uk/data_elements/patient_classification_code.html); 1 = ordinary admission (inpatient), 2 = day case admission, 3 = regular day case admission & 4 = regular night admission
* **Site code** – record the hospital organisation code where the patient was treated, as [specified by NHS England](https://digital.nhs.uk/services/organisation-data-service/data-downloads/other-nhs-organisations). Please include codes for any [private sites](https://digital.nhs.uk/services/organisation-data-service/data-downloads/non-nhs-organisations) **as long as the patient was registered as an NHS patient**. Exclude any patients seen privately if they were not registered as NHS patients.
* **Site name** – record the hospital site name where the patient was treated if the site code is unavailable.
* **Patient email address, if available.**
	+ This will be used to explore the digital potential for the survey further. This data will not be used to make contact with patients at this stage.
	+ **Eligible patients should be included in the sample whether or not they have an email address.**
* **Patient mobile phone number, if available.**
	+ Please include the most recent valid UK mobile numbers listed on your system. These should be either an 11-digit number starting with ‘07’ or a 12-digit number starting with ‘+44 7’. Please DO NOT include landline numbers. Picker will be conducting additional checks on the sample submission to ensure only valid mobile numbers are included. If you have any questions about this, please get in touch with the Picker team.

**Mobile numbers**

Please **do not remove** patients without mobile numbers. **Eligible patients should be included in the sample whether or not they have a mobile phone number.**

We will be using patient mobile number during the 2025 pilot survey to contact patients by text to remind them to take part in the survey with the aim to improve response rate and online completion. **It is important to include this information where available**. The Section 251 approval grants “the legal basis to allow access to the specified confidential patient information without consent.” This allows for trusts to provide details like patients’ postal addresses and applies to mobile numbers too.

The only cases in which you should not provide a mobile number is if the patient has explicitly dissented to the use of their mobile number, or if there is a note specifying that the number belongs to someone other than the patient, such as a carer or family member**.**

If collating this data is causing delays in submitting your sample please contact the team for advice on how to proceed.

**Should we include mobile number where we cannot determine if it is for the patient or not?**

If the mobile number listed on your system is specified as belonging to someone other than the patient, this should **not** be included. However, if the patient has provided a “work mobile” for their records this is fine to include, and if nothing is specified alongside the number it’s fine to assume this belongs to the patient.

**For patients where we have a mobile phone number listed in the mobile telephone field, and a different mobile phone number listed in the telephone field, should we just pick one and include it?**

Please prioritise the ‘mobile’ column. If you have any records where the mobile field is blank, and the telephone number field is populated with a mobile number, please include this.

**What should we do if duplicate mobile numbers are present?**

In the case of duplicate numbers across different patients, please submit the mobile number for all of the patients. Picker will take the appropriate action depending on the most recent discharge date.

**Remember**

**Do NOT remove duplicates** for patients who have had more than one admission within the sampling period. Picker will remove duplicates before sending out 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, and that their **admission was for the treatment** of cancer. This is to minimise the risk of questionnaires being sent out inappropriately.

## 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 in your list that have died. Relatives are likely to be particularly upset if they receive a questionnaire or reminder from the trust where their relative has recently died. Picker will carry out a final deceased check using DBS before sending out the questionnaires.

## Response to relatives of patients who have died

Tracing services are not foolproof and even after your sample has been checked for deaths, some patients may die before the questionnaire is delivered. Picker will run a freephone helpline for patients and relatives and will accordingly have most contact with patients as the freephone helpline will be clearly advertised on the survey materials. 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.**

# Patient List Declaration Form

The person compiling the list of patients must complete and sign the Patient List Declaration Form. This is a requirement of the survey’s Section 251 approval and is a key element to minimise the risk of any data breaches occurring.

**It is important that you use the Patient List Declaration Form as an opportunity to make comments on any data issues or changes that have occurred at your trust in the last year.**

The form must be completed and sent to Picker prior to submitting your patient list. You will receive notification when you are permitted to submit your spreadsheet.

# 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 an 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 is sent out to patients.

## Stage 1 – Patient List Declaration Form

The first task that needs to be completed before we can receive a patient list is for the trust to submit a Patient List Declaration Form. This 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.

Once the form has been received, the information provided is checked and approved by Picker, who then provide confirmation to the trust that they are able to proceed with securely uploading their patient list.

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 data upload and checking process.

## Stage 2 – Detailed data checks

Once you have submitted your sample declaration form and this has been approved, you will be provided with access to the Picker secure online sample checking platform. The platform will conduct a number of automatic checks on the sample, some of which you will need to address before Picker can approve your sample. The data then goes through a multistage checking process.

This includes:

* Removal of duplicates (keeping the most recent admission)
* Data validation to ensure that all eligible patients have been included and no patients have been excluded
	+ This is achieved by looking at the distribution of certain characteristics of the sample against the previous year to ensure there is a consistent pattern
	+ Any variations could indicate potential errors in the sample, and this would be queried with the trust
	+ Any patients included that should not be (for example, based on the ICD10/11 codes or age) 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., valid address information (including mobile number where it is available).

Once the data checks have been completed, Picker will raise any queries and confirmation points directly with the trust. In some cases, where 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 national deduplication

To prepare for mail out, Picker will start by batching all final samples together into a combined sample to 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 can only undertake this process when we have received and approved patient lists from all participating trusts, as conducting this on smaller batches would result in inconsistencies in terms of how patients are removed. This is minimised by undertaking the national deduplication process at the point when all samples have been received, checked, and approved.

It is therefore important that trusts upload their patient list to Picker as quickly as possible **starting from Monday 18th August** and respond to any data queries **within** **2 working days** to ensure this process can begin promptly.

## 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 to ensure questionnaires are not sent out.

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 also remove any patients who could not be traced (no NHS number) and update any blank NHS numbers that have been traced successfully. We then complete an additional DBS trace on the updated amalgamated data to confirm that all patients in the updated file are traced successfully.

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.

# Frequently Asked Questions

|  |  |
| --- | --- |
| **Question** | **Answer** |
| If patients opt-out nationally (to all patient experience surveys), does this apply to this survey? | No. The NCPES is **exempt** from the National Data Opt-Out Programme. This should not be applied to the NCPES patient list.However, if someone has indicated through seeing survey communications that they do not want to take part, then please exclude them from the sample. |
| If a patient contacts Picker to opt-out, would Picker make them aware that this only opts them out of the NCPES 2025 survey and that they would need to contact the trust to be opted out of other surveys? | Yes, Picker has guidance for call and email handlers to instruct patients that they would only be opted out of this year’s NCPES survey and would need to contact the trust in order to be opted out of wider surveys. |
| Who should sign the Data Sharing Agreement (DSA)? | The DSA should be signed by whoever you consider most appropriate for it in the trust. This could be the survey lead, Caldicott Guardian or Chief Executive, for instance. |
| Will you need Caldicott Guardian clearance for the declaration form from our trust or will the Data Sharing Agreement cover this?  | No, the Caldicott Guardian is not required to sign off on the declaration form. The transfer of data from your trust to Picker will be covered from the Data Sharing Agreement. |
| Will Picker be requesting local deceased checks before each mailing? | No. You are required to do a local check for deceased patients only before submitting your initial 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 sent out once they are confirmed, alongside deadlines for local deceased checks. |
| What do we mean by cancer related treatment? | Examples include the below if delivered as an inpatient or a day case:* Treatments directly related to cancer such as all forms of chemotherapy, cryotherapy, hormone therapy, immunotherapy, laser treatment, light therapy, palliative surgery (debulking etc.), radiotherapy, radioisotope therapy, surgical resections.
* Treatments for symptoms related to cancer such as cancer related anaemia, malignant pleural effusions and ascites, infections related to the cancer site, poor nutrition caused by the cancer, urinary problems caused by cancer.

A patient should not be included if they no longer have cancer and are receiving treatment for something that occurred during their cancer treatment years ago. An example of this would be if they had breast cancer 5 years ago, they’re in remission but they’d been admitted in the sampling period for reconstruction surgery. This patient would be excluded. If you have any specific scenarios that you’re unsure of, please send us an email or give us a call and we’re happy to help with making a decision. |
| Should we exclude dementia patients? | No. Dementia patients should be included as long as they meet all other eligibility criteria. It is important to provide these patients with the opportunity to give feedback.  |
| Why are patients with C44 and C84 ICD-10 codes excluded?  | To support with the running of the survey this year, we’ve kept the sampling criteria the same as in previous years, which means excluding C44 and C84 codes. Historically, where we have had cases of patients with these ICD-10 codes being wrongly included in the survey we have found that they have not always been clear that they have cancer resulting in a high volume of freephone calls/queries being received. |
| Are outpatients included in the survey sample? | No. The survey sample does not include patients who were seen solely as outpatients for cancer related treatment. Over the last few years, we have explored ways to widen the scope of the sampling approach so that patients who solely have outpatient appointments could be included in the sample. After thoroughly exploring different approaches, such as inclusion of such patients in the list produced locally by Trusts and use of national datasets including cancer registration, we have not been able to find an approach that meets the criteria of being timely, accurate, consistent and low burden. More information about this is available on the [NCPES website](https://www.ncpes.co.uk/faqs/). |
| Should patients who were only seen for diagnostic tests be included in the sample? | No. Please exclude patients who were seen only for diagnostic tests, as there is a greater risk around these patients having not received their diagnosis yet. In addition, if the patient did receive a diagnosis, there is a greater likelihood that they will be sampled from another point in their care pathway (e.g. if they were seen for treatment later/at another Trust).  |
| Should people receiving systematic anti-cancer therapy (SACT) as an outpatient be included? | No. People receiving SACT as an outpatient should not be included. Outpatients are currently excluded from the survey sampling. People receiving SACT as a day case or inpatient should be included. |
| Can we include patients who live in Northern Ireland, Scotland, and Wales? | Yes. If patients meet all other eligibility criteria, then they should be included. However, if they are without a UK address then they should be excluded. |
| ­When patients appear on more than one trust list will they get multiple questionnaires? How will you choose which trust is on the questionnaire to the patient­? | No. Each patient will only get one questionnaire. Once we have a full list of patients, we will then remove duplicates, keeping the record with the most recent treatment discharge date. Patients will therefore be asked to think about the hospital at which they had their most recent discharge during this period. |
| Should we include patients without an NHS number?­ | Yes. As long as the patients meet all other eligibility criteria they should be included. |
| We don’t have email addresses and phone numbers for everyone, is that OK? | Yes. Please provide the data that you do have as it will help us understand the % of records in the NCPES sample that do have this information. For 2025, the mobile number information will also be used to invite some patients to take part in the survey pilot using text message reminders. |
| We collect phone numbers but don’t know if it is a mobile number or a home telephone number, should we still include this information? | We ask that you include valid mobile numbers and exclude landline numbers Valid mobile numbers should be either an 11-digit number starting with ‘07’ or a 12-digit number starting with ‘+44 7’. However, if collating this data is causing delays in submitting your sample please contact the team for advice on how to proceed. |
| Are there provisions for people whose first language isn’t English? | Yes. Patients have the option to complete the questionnaire using a translation service offered by our freephone provider. The online survey is also available in three languages (Polish, Bengali and Punjabi).The [survey website](https://www.ncpes.co.uk/) has a translated section in 14 languages communicating key survey information to patients to support survey completion. |
| Are patients sent any subsequent surveys as a result of their answers to this survey? | Yes, they can be. If a patient ticks yes to Q69 in the questionnaire (agreeing to NHS England contacting you in future to tell you about other surveys or research about your healthcare experiences) then they could be contacted with a follow up questionnaire from research organisations that have requested and been approved by NHS England to use the data for a cancer-related questionnaire. If a patient ticks no to this question, then their data would not be used for any further contact from us, NHS England nor any other research organisation. |
| When will the 2025 NCPES results be published? | Publication is expected in summer 2026. |

# Appendix A: Valid ICD Chapter Codes and Mapping

| **Valid ICD-10 codes** | **ICD-11 equivalent** |
| --- | --- |
| 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 |
| C01.0 | 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 |
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| C13.9 | 2B6D.Z |
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| C14.8 | 2B6E.Z |
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| C15.9 | 2B70.Z |
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| C17.2 | 2B80.Z |
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| C18.6 | 2B90.1Z |
| C18.7 | 2B90.3Z |
| C18.8 | 2B90.Z |
| C18.9 | 2B90.Z |
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| C21.1 | 2C00.Z |
| C21.2 | 2C00.Z |
| C21.8 | 2C00.Z |
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| C22.2 | 2C12.01 |
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| C22.7 | 2C12.0 |
| C22.9 | 2C12.0 |
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| C24.1 | 2C16.Z |
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| C24.9 | 2C17.Z |
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| C32.2 | 2C23.3 |
| C32.3 | 2C23.4 |
| C32.8 | 2C23.5 |
| C32.9 | 2C23.Z |
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| C34.1 | 2C25.Z |
| C34.2 | 2C25.Z |
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| C34.9 | 2C25.Z |
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| C38.0 | 2C28.1 |
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| C38.2 | 2C28.1 |
| C38.3 | 2C28.1 |
| C38.4 | 2C26.Z |
| C38.8 | 2C28.1 |
| C39.0 | 2C29.Z |
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| C41.2 | 2B52.Z |
| C41.3 | 2B52.Z |
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| C41.9 | 2B5J |
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| C43.8 | 2C30.Z |
| C43.9 | 2C30.Z |
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| C45.7 | 2C26.0 |
| C45.9 | 2C26.0 |
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| C46.2 | 2B57.Z |
| C46.3 | 2B57.Z |
| C46.7 | 2B57.Z |
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| C47.9 | 2C4Z |
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| C49.1 | 2B5K |
| C49.2 | 2B5K |
| C49.3 | 2B5K |
| C49.4 | 2B5K |
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| C50.3 | 2C6Z |
| C50.4 | 2C6Z |
| C50.5 | 2C6Z |
| C50.6 | 2C6Z |
| C50.8 | 2C6Z |
| C50.9 | 2C6Z |
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| C51.9 | 2C70.Z |
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| C53.8 | 2C77.Z |
| C53.9 | 2C77.Z |
| C54.0 | 2C76.Z |
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| C54.3 | 2C76.Z |
| C54.8 | 2C76.Z |
| C54.9 | 2C76.Z |
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| C55.0 | 2C78 |
| C56 | 2C73.Z |
| C56.0 | 2C73.Z |
| C57.0 | 2C74.Z |
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| C57.3 | 2C72.Z |
| C57.4 | 2C72.Z |
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| C57.8 | 2C72.2 |
| C57.9 | 2C7Z |
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| C60.2 | 2C81.Z |
| C60.8 | 2C81.Z |
| C60.9 | 2C81.Z |
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| C62.1 | 2C80.Z |
| C62.9 | 2C80.Z |
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| C63.1 | 2C84 |
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| C63.8 | 2C84 |
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| C67.7 | 2C94.Z |
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| C68.8 | 2C95.Z |
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| C69.3 | 2D05 |
| C69.4 | 2D06.Z |
| C69.5 | 2D03.Z |
| C69.6 | 2D04 |
| C69.8 | 2D0Z |
| C69.9 | 2D0Z |
| C70.0 | 2A01.00 |
| C70 | 2A01.00 |
| C70.1 | 2A01.2 |
| C70.9 | 2A01.00 |
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| C71 | 2A00.5 |
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| C71.2 | 2A00.5 |
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| C71.4 | 2A00.5 |
| C71.5 | 2A00.5 |
| C71.6 | 2A00.5 |
| C71.7 | 2A00.5 |
| C71.8 | 2A00.5 |
| C71.9 | 2A00.5 |
| C72.0 | 2A02 |
| C72 | 2A02 |
| C72.1 | 2A02 |
| C72.2 | 2A02 |
| C72.3 | 2A02 |
| C72.4 | 2A02 |
| C72.5 | 2A02.1Z |
| C72.8 | 2A02 |
| C72.9 | 2A0Z |
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| C74.1 | 2D11.Z |
| C74.9 | 2D11.Z |
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| C75.3 | 2D12.Z |
| C75.4 | 2D12.Z |
| C75.5 | 2D12.Z |
| C75.8 | 2D12.Z |
| C75.9 | 2D12.Z |
| C76.0 | 2D4Z |
| C76 | 2D4Z |
| C76.1 | 2D4Z |
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| C76.3 | 2D4Z |
| C76.4 | 2D4Z |
| C76.5 | 2D4Z |
| C76.7 | 2D4Z |
| C76.8 | 2D4Z |
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| C77 | 2D60.0 |
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| C77.3 | 2D60.3 |
| C77.4 | 2D60.4 |
| C77.5 | 2D60.5 |
| C77.8 | 2D61 |
| C77.9 | 2D6Z |
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| C78.1 | 2D71 |
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| C78.5 | 2D85 |
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| C78.7 | 2D80.Z |
| C78.8 | 2D8Z |
| C79.0 | 2E00 |
| C79 | 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 |
| C80.0 | 2D4Z |
| C80 | 2D4Z |
| C80.9 | 2D4Z |
| C81.0 | 2B30.0 |
| C81 | 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 |
| C82.0 | 2A80.0 |
| C82 | 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 |
| C83.0 | 2A82.0Z |
| C83 | 2A82.0Z |
| C83.1 | 2A85.5 |
| C83.3 | 2A81.Z |
| C83.5 | 2A8Z |
| C83.7 | 2A85.6 |
| C83.8 | 2A8Z |
| C83.9 | 2A8Z |
| C85.0 | 2A8Z |
| C85 | 2A8Z |
| C85.1 | 2A86.Z |
| C85.2 | 2A81.0 |
| C85.7 | 2A8Z |
| C85.9 | 2A8Z |
| C86.0 | 2A90.6 |
| C86 | 2A90.6 |
| C86.1 | 2A90.8 |
| C86.2 | 2A90.7 |
| C86.3 | 2B00 |
| C86.4 | 2A60.5 |
| C86.5 | 2A90.9 |
| C86.6 | 2B03 |
| C88.0 | 2A85.4 |
| C88 | 2A85.4 |
| C88.2 | 2A84.1 |
| C88.3 | 2A84.0 |
| C88.4 | 2A85.1 |
| C88.7 | 2A85.0 |
| C88.9 | 2A84.Z |
| C90.0 | 2A83.1 |
| C90 | 2A83.1 |
| C90.1 | 2A83.4 |
| C90.2 | 2A83.3 |
| C90.3 | 2A83.2 |
| C91.0 | 2A7Z |
| C91 | 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 |
| C92.0 | 2A60.Z |
| C92 | 2A60.Z |
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| 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 |
| C93.0 | 2A60.34 |
| C93 | 2A60.34 |
| C93.1 | 2A40 |
| C93.3 | 2A42.Z |
| C93.7 | 2B33.1 |
| C93.9 | 2B33.1 |
| C94.0 | 2A60.35 |
| C94 | 2A60.35 |
| C94.2 | 2A60.36 |
| C94.3 | 2A21.00 |
| C94.4 | 2A60.38 |
| C94.6 | 2A44 |
| C94.7 | 2A61 |
| C95.0 | 2B33.0 |
| C95 | 2B33.0 |
| C95.1 | 2B33.4 |
| C95.7 | no code |
| C95.9 | 2B33.4 |
| C96.0 | XH60Q1 |
| C96 | 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 |
| C97.0 | 2D43 |
| D05.0 | 2E65.0 |
| D05.1 | 2E65.2 |
| D05.7 | 2E65.Z |
| D05.9 | 2E65.Z |

1. The ICD codes are shorthand for the International Statistical Classification of Disease and Related Health Problems, published in the UK by NHS England. They give the diagnosis or reason for a patient episode and are mandatory codes used in the NHS. [↑](#footnote-ref-2)
2. **Current inpatients**: Trusts are instructed to exclude current inpatients from the sample when generated. This should be the only time current inpatients are excluded from the survey process. [↑](#footnote-ref-3)