

National Cancer Patient Experience Survey Programme

Sampling Instructions 2019

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

Contacts

Picker
Buxton Court
3 West Way
Oxford
OX2 0JB

For questions or comments about the National Cancer Patient Experience Survey Programme contact the Project Lead:

Tiffany Gooden, Senior Research Associate

Tel: 01865 208157 E-mail: Tiffany.Gooden@SurveyCoordination.com

For information or advice about compiling and submitting your patient list please contact your designated project manager in Picker's Service Delivery team. If you do not know who this is please use the contact details below:

Tel: 01865 208100 E-mail: Clientservice@Pickereurope.ac.uk

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 and potentially result in the removal of your data from the national results. If you have any problems or queries about compiling your patient list or following the guidance, please contact our Service Delivery team (details above).

1 Compiling a List of Patients

These instructions explain how to compile a list of eligible cancer patients. This task will need to be carried out by a member of staff at the NHS Trust. In hospital trusts, 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 carefully. 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 section BEFORE you start to compile your patient list.**

1.1 Compiling your list of cancer patients

Who to include in the patient list:

All adult patients (aged 16 and over), with a **confirmed primary 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 April 2019 and 30th June 2019 should be included in the survey.

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.

ICD-10 codes

All adult patients with a **confirmed primary diagnosis** of cancer should be specified by an ICD-10 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.***

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 ICD-10 code¹ of C44 (other malignant neoplasms of skin) and all C44 classifications (C44.0 to C44.9)
- Patients with an ICD-10 code of C84 (Mature T/NK-cell lymphomas) and all C84 classifications (C84.0 to C84.9)
- Private patients (non-NHS)
- Any patients who are known to be current inpatients²
- Patients being treated as only 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 that have requested their details are not used for any purpose other than their clinical care (please see text box below)
- Patients that have informed your trust, in response to communications about the National Cancer Patient Experience Survey (NCPES), that they do not wish to be included in the survey

¹ 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.

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.

National Data Opt-out Programme

The National Cancer Patient Experience Survey (CPES) is exempt from the National Data Opt-out meaning that these **should not be applied** to your survey sample.

1.2 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 primary 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 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 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
- 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 primary diagnosis of cancer whose admission during the sampling period was in relation to their cancer diagnosis.

1.3 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 <NHSTrustName_CPE19.xls> where ‘NHSTrustName’ is the name 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.

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)** – starting at 0001, assign a **unique** sequential number to each row in the data
 - **Note** –where there are multiple rows for the same patient, then each row must have a different PRN assigned.
- **Title** (Mr, Mrs, Ms, etc.)
- **First name / initials**
- **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
- **Post code**
- **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
- **Ethnicity** – The ethnicity of a person is specified by that person, and should be coded using the [17-item alphabetical coding specified by NHS Digital](#). 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 the month of admission (1 or 2 digits; e.g. 7 or 26) *
- **Month** of admission (1 or 2 digits; e.g. 9 or 10) *
- **Year** of admission (4 digits; e.g. 2019) *
- **Day** of the month of discharge (1 or 2 digits; e.g. 2 or 30) *
- **Month** of discharge (1 or 2 digits; e.g. 4 or 5) *
- **Year** of discharge (4 digits; e.g. 2019) *
- **ICD10 Code** – 4 digits, include 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 D05 codes, **with the exception of all C44 codes and all C84 codes**
- **Main Specialty** – code in the form NNN as [Specified by NHS Digital](#)
- **CCG code** – the [3-character CCG code](#) which will be billed for the care of the patient
- **Patient classification** – [the type of admission](#); 1 = ordinary admission (inpatient), 2 = day case admission, 3 = regular day case admission & 4 = regular night admission
- **Site name** – hospital name of where the patient attended

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.

1.4 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.

1.4.1 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.

2 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.

3 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.

3.1 Stage 1 – Patient List Declaration Form

The first task that needs to be completed before we are able to 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.

3.2 Stage 2 – Detailed data checks

Once the Patient List Declaration Form has been approved and data uploaded to Picker, the data goes through a multi stage 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 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.

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.

3.3 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 the 20th August** and respond to any data queries within 2 working days to ensure this process can begin.

3.4 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.