

National Cancer Patient Experience Survey Programme

Guidance Manual 2017

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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 guidance manual. Non-compliance would compromise the comparability of the survey. If you have any problems or queries about drawing your sample or following the guidance, please contact our Data Team (details above).

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1 Introduction

NHS England will repeat the annual National Cancer Patient Experience Survey (NCPES) during the autumn of 2017. This will enable us to build on progress made and target efforts to continue to improve patients' experience of NHS cancer care.

The survey supports the implementation of [Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020](#). The strategy highlights that improving people's experience across the pathway needs to be prioritised and recommends that NCPES should continue to evolve and be repeated every year.

The survey is overseen by the Cancer Patient Experience Advisory Group which consists of patients, professionals, voluntary sector representatives, academics and patient survey experts.

Aside from the national importance of this survey, there are important direct benefits for your trust in taking part:

- You will receive a bespoke report on your cancer patients' experiences, broken down by cancer type grouping and will be able to benchmark cancer services locally (within your trust) and nationally.
- The results will help you meet the requirement to measure patient experience as set out in the Peer Review Measures for Cancer.
- The results will help you to populate your Quality Accounts.
- The results will also help inform the commissioning of local services by Clinical Commissioning Groups.

2 Survey Information

2.1 Who is carrying out the survey?

The survey is being carried out by Quality Health on behalf of NHS England.

2.2 Who will be included in the survey?

The survey will cover all acute and specialist NHS Trusts in England that provide adult cancer services.

All adult patients (aged 16 and over), with a **confirmed primary diagnosis of cancer**, who have been admitted to hospital as inpatients for **cancer related treatment**, or who were seen as day case patients for **cancer related treatment**, and have been discharged between 1st April 2017 and 30th June 2017 will be included in the survey.

2.3 What is the survey method?

The 2017 survey will replicate the 2016 survey methodology. The survey will be conducted by post, with two reminders (to non-responders only) as is the case with other national patient surveys. A standard questionnaire, covering letter and reminder letters will be used. Patients will also be sent a link to complete the survey online should they prefer to do so.

Quality Health will run the national freephone helpline for patients, and will support completion of the survey through text, phone and language translation facilities.

2.4 How much will it cost?

The costs of survey development, fieldwork, and reporting are being met by NHS England under the national contract with Quality Health. Trusts do not need to appoint a survey contractor.

2.5 Has approval been received by the Burden and Advice and Assessment Service (BAAS)?

The Burden Advice and Assessment Service (BAAS) have advised that as there are no changes or additional costs involved to the previous year, the existing burden assessment for the survey still stands.

This collection is mandated for all adult acute cancer services. NHS Foundation Trusts are mandated under schedule 6 of their Terms of Authorisation.

2.6 Does the survey have Section 251 approval?

The application for Section 251 approval, which allows the common-law duty of confidentiality to be set aside and data to be transferred to Quality Health, has been approved by the Confidentiality Advisory Group at the Health Research Authority under proportionate review.

2.7 How will the survey findings be reported?

A national report will be published on the Quality Health website alongside individual trust and CCG reports in the early summer of 2018. In addition to the analysis of where the trust sits on each question in relation to other trusts for all cancers, and where individual cancer groups sit in relation to the same cancer groups nationwide, trust reports will contain an analysis of change over time. This analysis will be carried out where comparability between questions has been maintained.

The data will be used to inform the cancer dashboard, which is co-produced by NHS England and Public Health England, as a tool to help clinical leaders, commissioners and providers to quickly and easily identify priority areas for improvement in their cancer services. Please see www.cancerdata.nhs.uk/dashboard

Quality Health will assist any trust with the interpretation of its data, and will offer presentations on site, linked to management recommendations. We hope that the trust level results will be helpful to the development of cancer services at both generic and MDT level.

3 Survey Responsibilities

3.1 What do trusts need to do?

The trusts' responsibilities are to ensure that the patient sample is drawn in accordance with this Guidance Manual. The manual procedures are aligned as closely as possible to those used for the national inpatient surveys, which are already carried out by NHS Trust Information Systems staff annually

Trusts should endeavour to alert patients with whom they are in contact that they can inform the trust **if they wish not to be included in the survey**. Trusts may want to do this in different ways, e.g. leaflets, websites and other communication. Trusts should then remove these patients from the sample before it is sent to Quality Health.

For future years of the survey, we would expect trusts to pay particular attention to this during the sampling window of April, May and June.

The sampling procedure set out in *Section 6 - Compiling a list of patients* must be followed carefully. To do this, survey leads will need to work closely with the person who draws the sample, and check carefully that this guidance has been adhered to. The patient list must be signed off by the trust's nominated survey lead before it is submitted to Quality Health.

3.2 What will Quality Health do?

All other survey work will be carried out by Quality Health. This will include postage, data entry and the production of reports.

Quality Health will also undertake all deceased checks. These will be carried out through N3 access to the DBS system. The DBS checks will be undertaken at least three times during the fieldwork period: before initial send out; and before each of the two reminders. Quality Health guarantees that the send out of the initial surveys and the reminders will take place within 24 hours of the relevant DBS deceased check for your trust being received from the service. This arrangement will make the process more efficient and will ensure that the number of deceased patients in the sample will be minimised. It will also reduce the amount of work that trust staff have to perform.

4 Timetable

Response rates to your survey are likely to be higher if patients are given the maximum time to respond. It is therefore important that you send your patient list to Quality Health as soon as possible.

July/August 2017	Trusts identify key survey contacts and send forms back to Quality Health
September/October 2017	Trusts put together their patient lists, and send them to Quality Health by 6 October 2017 . Patient lists are checked by Quality Health.
October 2017	Questionnaires sent out to patients
November – February 2017/2018	Reminders sent to patients and data collated

5 Data Protection and Confidentiality

5.1 Principles of data protection

When carrying out the survey, both Quality Health and NHS trusts need to ensure that they comply with the Data Protection Act 1998. Trusts will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott Principles.

The guidelines in this manual will help to ensure that data are handled in a manner in keeping with the spirit of the Data Protection Act 1998 and the Market Research Society's Guidelines for social research (2005). It will be necessary to establish appropriate data security arrangements with Quality Health, who will send each trust a Data Security Agreement governing the transfer to them of personal data.

The websites below have further information:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253

Information about the Data Protection Act 1998 can be found at the Information Commissioner's Office (ICO; <https://ico.org.uk/>)

Further guidance can be found in the Market Research Society document at http://www.mrs.org.uk/standards/data_protection/

5.2 Internet transfer of encrypted data

Trusts may send patient lists to Quality Health over the internet using the encrypted secure upload system based on the Transport Layer Security (TLS) or Secure Sockets Layer (SSL) protocol (for example as with HTTPS or SFTP). A key size of 256 bits or greater should be used. This is to ensure a high level of security and to protect against any accidental or intentional interception during the transfer of patients' details. Quality Health will provide guidance on the use of an encrypted session to trusts. This method is recommended by the Department of Health. Over 300 NHS Trusts already use this system to send personal data to Quality Health for postal survey purposes.

The trusts are the owners of the data, so the transfer of patient data is ultimately the trust's decision, because the trust remains legally responsible for the security and processing of the information it shares.

5.3 Using an encrypted session

1. You may already have an account to access the Quality Health Upload Portal; if not then you will shortly receive an e-mail from our system with your password.
2. Go to the Quality Health Upload Portal at <https://portal.quality-health.co.uk>
3. Login to your account using the account details provided. Please note that your username is your e-mail address.
4. Full upload instructions will be sent through separately. Please follow those detailed instructions carefully.

If you have any problems, please call our Data Team on 01246 856263 or e-mail richard.gosling@quality-health.co.uk; joanne.marsden@quality-health.co.uk; grainne.gosling@quality-health.co.uk; lauren.coupe@quality-health.co.uk

5.4 Data Security Agreement

A Data Security Agreement will be sent to the designated survey lead in each trust and will need to be signed by the trust. This agreement is based on the agreement used for the National Patient Survey Programme. By signing it, Quality Health is obliged to keep the information confidential at all times, and to comply with the Data Protection Act 1998. It provides the trust with some recourse if any breach of the Data Protection Act were to occur as a result of any actions of Quality Health. The Agreement also ensures that Quality Health staff members sign and abide by the Agreement, which describes how patients' personal data will be sent to Quality Health, and how the data can be used.

5.5 Patient confidentiality

The covering letters that accompany the mailed questionnaires inform patients that their name and address will never be linked to their responses. Therefore, for the purposes of the NCPES and when presenting trust, CCG and national results at the end of the survey period, results will only be presented for groups of 20 or more responders.

6 Compiling a List of Patients

This section explains how to draw a sample of 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 below carefully and allocate sufficient work time to draw the sample and check it 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.**

Important Note

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**. Previously, there were a few instances 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 been told they had cancer. This must be avoided as much as possible and extra care must be taken to select only those patients with a confirmed diagnosis of cancer to avoid causing unnecessary distress to the patient.

6.1 Compiling your list of cancer patients

Compile a full list of all adult (**aged 16 and over**) NHS patients, with a **confirmed primary diagnosis** of cancer, discharged from the trust after an inpatient episode or day case attendance **for cancer related treatment** between April, May and June 2017.

Please note:

- Your list must be a list of **all eligible discharges**, rather than a list of patients, so some patients will appear on the list more than once at this stage.
- Duplicate patients will be removed at a later stage of the process by Quality Health, but it is very important you **do not** remove them, as this could bias your sample.

The information you obtain about each patient will be used by Quality Health both for administering the survey and for sending to the Demographics Batch Service to check for deceased patients.

The list should include:

- All adult patients with a **confirmed primary diagnosis** of cancer, specified by an ICD-10 code¹ of C00 - C99 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**.
- All eligible patients with **discharge dates** between 1 April 2017 and 30 June 2017.
- Only **admitted** patients should be included: that is, inpatients and day cases. These need to be coded 1 = ordinary admission (inpatient) or 2 = day case admission, 3 = regular day case admission or 4 = regular night admission as recorded in the Patient Classification data field.
- Only include **adult** patients (aged 16 and over on the date they were discharged).
- Only include inpatient episode or day case attendances where the patient was being seen **in relation to / for treatment of their cancer diagnosis**.
- Include **both** elective and emergency patients.
- Include **all cancer patients** who were seen / received treatment for their cancer. The list **should not** be restricted to include only patients who were newly diagnosed within the sampling period.

The list should exclude:

- Those with an ICD10 5th Edition code of **C44** (other malignant neoplasms of skin) **and all other C44 classifications** (C44.0 to C44.9).
- Those with an ICD10 5th Edition code of **C84** (Peripheral and cutaneous T-cell lymphomas) **and all other C84 classifications** (C84.0 to C84.9).
- Deceased patients
- Non-cancer patients
- Non-confirmed cancer patients
- Any inpatient admissions / day case attendances which were NOT in relation to the patient's cancer.
- Children or young persons aged under 16 years at the time of discharge
- Private patients (non-NHS)

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.

- Any patients who are known to be current inpatients²
- Patients whose “admission” was only as an outpatient
- Patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g.no postcode).
- Any patient known to have requested that their details are not used for any purpose other than their clinical care – if this information is collected by your trust you should ensure that you remove these patients from your sample list at this stage.
- Any patient who has informed your trust, in response to communications about the NCPES, that they do not wish to be included in the survey

6.2 Check again

Once you have put together the patient list, **CHECK AGAIN** that you have correctly followed each of the points above. This is a very important step and will save a lot of time because it is not uncommon for trusts to make errors when putting together a patient sample.

Please check very carefully. Validation checks are an essential part of the sampling process, to ensure that we only send out questionnaires appropriately to patients, so please check again that:

- Patients 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 sample includes all eligible discharges within the sampling period and that duplicates have not been removed
- The discharges included in the sample are relevant and are where the patient was seen in relation to their cancer (the sample should not include patients who were seen for other treatment which was not in relation to their cancer)
- The sample includes both elective and non-elective activity
- The sample includes all eligible cancer patients (and is not restricted to patients who were *newly* diagnosed in the sampling period)

Important Note

It is the responsibility of trusts to ensure the sample 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.

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.

6.3 Creating the patient list spreadsheet

Attached with this guidance is a template excel spreadsheet. Please use this for your sample and rename it as CLIENTCODE_CPES17.xls. **Once your sample has been drawn and is ready to send to us, you will need to convert the spreadsheet to a csv file.** 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 by us, details of which are as follows:

- **PatientRecordNumber** – starting at 1001, assign a **unique** sequential number to each row in the data
 - **Note** – *duplicate cancer related admissions/attendances should not be removed from your list, so where there are multiple rows for the same patient, then each row must have a different PatientRecordNumber assigned.*
- **ClientCode** – the ODS 3-digit code for your Trust, e.g. RA0
- **NHSNumber** – verified and 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**
- **Title** (Mr, Mrs, Ms, etc.)
- **Firstname**
- **Surname**
- **Address Fields:** The address should be held as separate fields (e.g. street, area, town, and county).
- **Postcode**
- **DateofBirth** 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
- **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 codes are as follows:

National Codes:

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

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 or a full-stop should be inserted in the sample information

Please see:

http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp.

- **Day** of the month of admission (1 or 2 digits; e.g. 7 or 26) *
- **Month** of admission (1 or 2 digits; e.g. 4 or 5) *
- **Year** of admission (4 digits; e.g. 2017) *
- **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. 2017) *
- **ICD10Code:** *please ensure you are using ICD10 5th Edition codes.* 4 digits; include sub-categories for these codes, i.e. C25.1. These need to be coded in the **primary diagnosis field** and should be between C00 & C99 and D05-D05.9, **with the exception of all C44 codes and all C84 codes.**
- **MainSpecialty** code is recorded in the form NNN as Specified by NHS Digital. See http://www.datadictionary.nhs.uk/data_dictionary/attributes/m/main_specialty_code_de.asp?shownav=1
- **CCG code:** please provide the 3-character CCG code. This should be the CCG which will be billed for the care of the patient. Please see: <https://digital.nhs.uk/organisation-data-service/data-downloads/other-nhs>

* Date fields must be supplied in separate columns (e.g. date, month, and year).

- **PatientClassification** should record the Type of admission; 1 = ordinary admission (inpatient), 2 = day case admission, 3 = regular day case admission & 4 = regular night admission – see http://www.datadictionary.nhs.uk/data_dictionary/attributes/p/pati/patient_classification_de.asp?shownav=1 for the description codes
- **Site** - hospital name of where the patient attended

6.4 Do not remove duplicate patients

Do NOT remove duplicates for patients who have had more than one admission. Quality Health will de-duplicate the samples of patients before sending out questionnaires.

6.5 Validate the patient list with your Cancer Services Team

Please do pass your patient list to your trust's Cancer Services Team to validate the list against your trust's cancer system. This step is essential and must be completed to check that patients in your list have a **confirmed diagnosis** of cancer, and to minimise the risk of questionnaires being sent out inappropriately.

6.6 Check 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 relative has recently died. We will then carry out a final deceased check using DBS before sending out the questionnaires.

6.7 Response to relatives of patients who have died

Tracing services are not foolproof and even after your patient list has been checked for deaths, some patients may die before the questionnaire is delivered. Quality Health 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 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 Quality Health immediately to ensure that no further mailings are sent to the deceased patient.

7 Sample Declaration Form

Once the sampling steps have been completed to compile your sample list, please carry out the following checks and initial ALL checklist boxes in the checklist table below, to sign-off that all actions and validation checks have been completed.

It is the responsibility of trusts to ensure that only eligible patients who have a confirmed diagnosis of cancer whose admission during the sampling period was in relation to their cancer diagnosis/treatment have been included in the sample uploaded to us. The consequences of not fully validating your sample at this stage could result in questionnaires being sent out inappropriately to patients without a cancer diagnosis.

Check	Initials
Your file name follows the naming convention: CLIENTCODE_CPES17	
The data is saved as a CSV (Comma delimited) file – full upload instructions will be sent through separately).	
All required data fields are included in the CSV file, as defined in the section Compiling a List of Patients.	
All data is in the correct format as described in the section ‘Creating the patient list spreadsheet’.	
Check that full date of birth information is included for each patient and, where possible, complete NHS numbers so that deceased checks can be done on the sample before any mailings take place.	
Patients known to have requested that their details are <i>not used for any purpose other than their clinical care</i> have been removed from the sample – you <u>must</u> ensure that this check is complete if this information is collected by your trust.	
Patients known to 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 have been removed.	
Check that ALL eligible patients discharged between 1 st April 2017 and 30 th June 2017 are included.	
All patients have a confirmed ICD10 Cancer code in the Primary diagnosis field (and that these are <u>not “holding” codes</u> where a diagnosis has not yet been confirmed)	
Ensure you are using the most recent ICD10 Codes – 5th Edition .	
Diagnosis codes include ALL C00-C99 – and all sub-categories are coded as such.	
Diagnosis codes include D05 – and all sub-categories are coded as such	
Diagnosis codes C44 (ALL) and C84 (ALL) have been excluded .	
All records are for either inpatient episode or day case attendances where the patient was seen in relation to / for treatment of their cancer diagnosis.	
Both elective and emergency patients have been included.	

Check that duplicate records have not been removed in error – the sample should include all eligible discharges for a patient during the three-month sampling period (the same patient can have multiple records in the file).	
CHECK AGAIN that all patients in the list have a confirmed diagnosis of cancer, ensuring that patients with “holding codes” have been removed.	
CHECK AGAIN that the discharges included in the sample are relevant and are where the patient was seen <i>in relation</i> to their cancer	
CHECK AGAIN that the sample includes all eligible cancer patients (and is not restricted to patients who were newly diagnosed in the sampling period)	
Your trust’s Cancer Services Team has checked and validated the patient list (against the trust Cancer System) to ensure that this contains only patients with a confirmed diagnosis of cancer.	
Trust’s own records have been checked for deceased patients and trust-recorded deceased patients have been removed.	
The data will be uploaded securely using the Quality Health secure Upload Portal and that no other transfer method will be used as it may not be secure.	

Declaration by trust staff drawing the sample

I confirm that the above steps have been completed and that the sample has been drawn in accordance with the survey instructions.

Trust name

Contact name

Contact signature

Contact email address and phone number

You will have been sent a separate copy of this declaration form with this Guidance. Please complete the declaration form and return to Quality Health as soon as the data has been drawn and before you transfer any data to us.

Full instructions will be sent separately explaining how to securely upload your sample declaration form and sample to us for checking.

For information or advice about this guidance or sampling contact our Data Team on 01246 856263 or email: richard.gosling@quality-health.co.uk; joanne.marsden@quality-health.co.uk; grainne.gosling@quality-health.co.uk; lauren.coupe@quality-health.co.uk