

National Cancer Patient Experience Survey Programme

Guidance Manual 2015

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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: why is this survey important?

Following the success of the 2010, 2011-2012, 2012-2013 and the 2014 surveys, NHS England has committed to repeating the survey in 2015. This will enable us to identify and build on progress that has already been made and target our efforts to continue to improve patients' experience of NHS cancer care.

This survey was initially publicised in an email in February from the National Programme Manager (Cancer), Carol Ferguson. Previous national surveys of cancer patients were carried out in the NHS in 2000, 2004, 2010, 2012 (2011/12), 2013 (2012/2013) and, most recently 2014.

The survey is being overseen by a new Cancer Patient Experience Advisory Group, chaired jointly by Sean Duffy, the National Cancer Director, and Professor Jessica Corner, of Macmillan Cancer Support and Southampton University.

The previous national surveys of cancer patients indicated that the survey results were being used extensively by clinical teams, Trust Management, national and specialist cancer charities, and front line staff such as Clinical Nurse Specialists, in order to improve the quality of care. Both of these surveys showed that very substantial improvements had been made in services to patients.

The survey results at national and Trust level, and for individual cancers and tumour groups is being used extensively for research nationally and internationally on issues of importance to particular groups of cancer patients. The survey is being replicated in Australia, New Zealand, the Middle East, Wales, Northern Ireland, as well as other jurisdictions.

The survey fulfils a key plank of cancer policy since 2007 – to listen to the experiences of cancer patients themselves as a guide to future action, alongside other important sources, such as peer review and cancer waiting times data.

2 Background

2.1 How has the survey been designed?

The 2015 survey will largely replicate the 2014, 2012-2013, 2011-2012 and the 2010 survey methodology and questionnaire which was developed by experts in patient experience surveys and cancer patients' experiences. The Cancer Patients' Experience Advisory Group (CPEAG), co-chaired by the National Clinical Cancer Director Sean Duffy and Professor Jessica Corner of Macmillan Cancer Support, has continued to provide oversight of the principles and objectives of the survey, as well as give guidance on amendments to the 2015 survey.

The 2015 survey has been thoroughly reviewed and as a result around one-third of the questions are new or have been amended; and a number of questions have been deleted. This followed feedback from patients and other stakeholders and aims to make the content of the questionnaire more relevant and user-friendly.

2.2 NHS Operating Framework

Improving patient experience remains a core principle for the NHS. The 2014 survey supports implementation of *Improving Outcomes: A Strategy for Cancer* (January 2011) and the NHS Operating Framework 2012/13 which defines quality as those indicators of safety, effectiveness and patient experience that provide an indication that standards are being maintained or improved. Para 2.28 states that the national patient experience surveys should continue to be monitored and acted upon. Para 2.29 states that commissioners should also look to identify local measures of integrated care that will support improved delivery such as patient reported experience of co-ordinated care, which is covered in the survey. Domain 4 of NHS Operating Framework includes patient experience of hospital care

The survey will gather vital information on the Transforming Inpatient Care Programme, the National Cancer Survivorship Initiative and the National Cancer Equality Initiatives.

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

2.3 SCCI and BAAS

SCCI (Standardisation Committee for Care Information) approval has been applied for and is being considered by the Burden Advice and Assessment Service (BAAS) as a Mandatory Collection.

2.4 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.

2.5 How will the survey benefit NHS trusts?

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

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

3 How is the survey being conducted?

3.1 Who is carrying out the survey?

The survey is being organised and run by Quality Health, an NHS patient survey company that already works with every acute hospital trust in the NHS. NHS England has contracted with Quality Health to run the cancer survey programme.

3.2 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 primary diagnosis of cancer who have been admitted to hospital as inpatients, or who were a day case patient, and have been discharged between 1st April 2015 and 30th June 2015 will be included in the survey.

3.3 What is the survey method?

The survey will be conducted by post, with two reminders (to non-responders only) as is the case with the National Patient Survey. A standard questionnaire, covering letter and reminder letters will be used.

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

3.4 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.

3.5 Deceased Checks

As per the 2014 survey, again Quality Health will be undertaking all deceased checks through its N3 access to the DBS system.

The DBS checks will be undertaken at least 3 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 numbers of deceased patients in the sample will be minimised. It will also reduce the amount of work that Trust staff have to perform.

3.6 What will trusts have to do?

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

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.

All other survey work, including deceased checks, postage, data entry and producing reports, will be carried out by Quality Health. Quality Health will work with NHS trusts to arrange appropriate data security agreements.

Quality Health will sign data security agreements with each Trust, undertake all fieldwork including dispatch and receipt of questionnaires, data capture and analysis of the data. Quality Health is accredited to the highest standards of Data Security and Quality Management under ISO 27001 and ISO 9001.

3.7 Reporting

As in 2014, there will be both National and local Trust Reports, and these will be placed on the Quality Health website when they are ready in the Spring of 2016. Trust reports will contain an analysis of change between 2010, 2011-2012, 2012-2013, 2014 and 2015, in addition to the analysis of where the Trust sits on each question in relation to others for all cancers, and where individual cancer groups sit in relation to the same cancer groups nationwide. This analysis will be carried out where comparability between questions has been maintained.

The 2010, 2011-2012, 2012-2013 and the 2014 data is also reported on a unified master spreadsheet on the NCIN website, and we plan to make the national and Trusts data available in this way for 2015; this means that no one has to trawl through each individual Trust report if they want to make comparisons.

Quality Health will assist any Trust with the interpretation of its data, and will offer presentations on site, linked to management recommendations developed since 2010, 2011-2012, 2012-2013 and 2014. We hope that the Trust level results will be helpful to the development of cancer services at both generic and MDT level.

4 Timetable

Response rates to your survey will 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 2015	Trusts identify key survey contacts and send forms back to Quality Health
September 2015	Trusts put together their patient lists, and send them to Quality Health by 2nd October 2015 . Patient lists are checked by Quality Health.
October 2015	Questionnaires sent out to patients
November – January 2016	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. You 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 ICO – Information Commissioner's Office (<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.

The Department of Health recommends this method. 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

You will receive an e-mail from Quality Health with your username and password.

1. You may already have an account to access the new 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 Richard Gosling, Iain Milner or Joanne Marsden on 01246 856 263 or e-mail richard.gosling@quality-health.co.uk; iain.milner@quality-health.co.uk; joanne.marsden@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 Cancer Survey, and when presenting trust 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. That person's manager must give them the necessary time and support to do this properly. Errors may result in the wrong people being surveyed, invalid survey data being collected, and in the exclusion of the 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 4th 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 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, discharged in the months of April, May and June 2015.

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 1st April 2015 and 30th June 2015.

¹ The ICD codes (4th Edition) are shorthand for the International Statistical Classification of Disease and Related Health Problems, published in the UK by Connecting for Health. They give the diagnosis or reason for a patient episode and are mandatory codes used in the NHS.

- 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).

The list should exclude:

- Those with an ICD10 4th Edition code of **C44** (Other malignant neoplasms of skin) **and all other C44 classifications** (C44.0 to C44.9).
- Those with an ICD10 4th 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
- Children or young persons aged under 16 years at the time of discharge
- Private patients (non-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 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.

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 new type of patient sample.

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_CPES15.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.

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** - *duplicates 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** – 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
- **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 Connecting for Health. The codes are as follow:

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.

- **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. 2015) *
- **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. 2015) *
- **ICD10Code:** *please ensure you are using ICD10 4th 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 outlined in the Updated National Specialty List which was implemented on the 1 April 2004. 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: <http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs>
- **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

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

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 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.

6.6 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 boxes to sign-off that all actions have been completed.

Check	Initials
Your file name follows the naming convention: CLIENTCODE_CPES15	
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 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	
Check that ALL eligible patients discharged between 1st April 2015 and 30th June 2015 are included.	
All patients have a confirmed ICD10 Cancer code in the Primary diagnosis field	
Ensure you are using the most recent ICD10 Codes – 4th 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 <i>excluded</i>	
CHECK AGAIN that all patients in the list have a <u>confirmed</u> diagnosis of cancer, ensuring that patients with “holding codes” have been removed	
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 from with this Guidance. Please complete the declaration from 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; jain.milner@quality-health.co.uk; joanne.marsden@quality-health.co.uk