

Northern Ireland Cancer Patient Experience Survey Programme

Guidance Manual 2014

The Northern Ireland Cancer Patient Experience Survey
Programme

is run by Quality Health on behalf of the Public Health Agency
(PHA) and Macmillan Cancer Support

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1 About this handbook

Following the success of the 2010, 2011-2012 and 2012-13 Surveys in England, the Macmillan Cancer Support and HSCB/PHA Cancer Commissioning Team has committed to undertaking a similar survey in Northern Ireland in 2014, with suitable amendments reflecting the position of NHS Northern Ireland. This will enable the service 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.

The survey has been designed to provide a reliable and consistent measurement of cancer patients' experiences of care in Northern Ireland to establish a baseline and allow benchmarking (as detailed in the HSCB/PHA Cancer Commissioning Plan for 2011/12).

1.1 How has the survey been designed?

The Northern Ireland CPES survey 2014 is based on the methodology and questionnaire which has been developed by experts in patient experience surveys and cancer patients' experiences.

1.2 Help and Advice

If you have any queries relating to this guidance or need help in drawing your sample please contact our Data Team:

Richard Gosling or Iain Milner on 01246 856263 or email:

richard.gosling@quality-health.co.uk

iain.milner@quality-health.co.uk

2 Data Protection and Confidentiality

2.1 Principles of data protection

When carrying out surveys, 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 the 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 (<http://www.ico.gov.uk>)

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

2.2 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.

Information Governance restrictions in Northern Ireland prevent the transfer of person identifiable information to Quality Health. For this survey, the HSCB/PHA Cancer Commissioning Team have nominated a central contact **Robert McCormac (robert.mccormac@setrust.hscni.net)** from South Eastern Trust, who will be responsible for collating the individual Health & Social Care Trust samples, de-duplicating and removing deceased patients before sending an anonymised patient list through to Quality Health.

Separate Instructions on how to upload the data securely will shortly be sent to Robert.

2.3 Data Security Agreement

A Data Security Agreement has been sent to the designated survey lead in the 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.

2.4 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, 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.

2.5 Deceased Patients

The HSCB/PHA Cancer Commissioning Team will be required to perform checks for deceased patients.

One of the most reliable and up-to-date sources of information on patient deaths is a trust's own records. It is essential that you check that your trust has no record of a patient 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 died. Clearly, patients may also have died at home or while under the care of another trust, so you still need to check with the tracing service (CSA) as well.

Checks will need to be undertaken at least 3 times during the fieldwork period: before initial send out; and before each of the two reminders.

3 Compiling a list of patients (Trust Level)

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 Health & Social Care Trust. The sample will be usually 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.

3.1 Compile a list of eligible patients

Compile a list of all adult (**aged 16 and over**) NHS patients with a **confirmed** primary diagnosis of cancer discharged from the Health & Social Care Trust after an inpatient episode or day case attendance, discharged in the months of December 2013-May 2014.

The information you obtain about each patient will be used both for administering the survey and for sending to the Northern Ireland/ CSA tracing service to check for any deaths. It saves time and effort if all the information is gathered at the same time [See section 4 for a list of the data fields that you will need to include in your sample file for the survey].

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 December 2013 and 31st May 2014
- 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 or 3 = regular day case 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
- Any patients who are known to be current inpatients at the time the sample is drawn
- Patients whose “admission” was only as an outpatient
- Patients without a valid UK Northern Ireland postal address

3.2 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 errors to be made when putting together a new type of patient sample.

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.

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.

3.3 Creating the patient list spreadsheet

Attached with this guidance is a template excel spreadsheet. Please use this for your sample and rename it as Trust ODS Code_NICPES13.xls – e.g. ZT001_NICPES13. The spreadsheet contains all the data fields required by us, details of which are as follows:

- **PatientRecordNumber** – starting at 1001, assign a sequential number to each patient
- **ClientCode** – the ODS 5 digit code for your Trust (please refer to the following table):

ZT001	Belfast Health & Social Care Trust
ZT002	Northern Heath & Social Care Trust
ZT003	Southern Health & Social Care Trust
ZT004	South Eastern Health & Social Care
ZT005	Western Health & Social Care Trust

- **HCNNumber** – the Health & Care Record Number. Ensure as much as possible that this is populated as it will be used for duplicate and deceased checking
- **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**
- **Date of Birth** in text format (YYYYMMDD). This needs to be the **FULL** date of birth of the patient to ensure deceased checks can be carried out on the sample before any mailings
- **Ethnicity** - The ethnicity of a person is specified by that person. Ethnic codes are not routinely recorded in Northern Ireland. However, where available, these codes should be provided as follows:

:

_SYSTEM_ETHN	
EthnicOriginCode	EthnicOriginDesc
B	BANGLADESHI
BA	BLACK AFRICAN
BC	BLACK CARIBBEAN
BO	BLACK OTHER
C	CHINESE
I	INDIAN
IT	IRISH TRAVELLER
M	MIXED ETHNIC GROUP
O	OTHER ETHNIC GROUP
P	PAKISTANI
RT	ROMA TRAVELLER
W	WHITE

If the code is not available, then the ethnic category should be left **blank**.

- **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. 2012) *
- **Day** of the month of discharge (1 or 2 digits; e.g. 2 or 30) *
- **Month** of discharge (1 or 2 digits; e.g. 9 or 10) *
- **Year** of discharge (4 digits; e.g. 2012) *

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

- **Length of Stay** (Units = Days)³
- **ICD10 Code:** *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.**
- **Main Specialty** 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
- **Patient Classification** should record the Type of admission; 1 = ordinary admission (inpatient), 2 = day case admission & 3 = regular day case 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

3.4 Do not remove duplicate patients

Do not remove duplicates for patients who have had more than one admission. the HSCB/PHA Cancer Commissioning Team have nominated a central contact Robert McCormac (Robert.mccormac@setrust.hscni.net) from South Eastern Trust, who will be responsible for collating the individual Health & Social Care Trust samples, and removing duplicate patients before sending the anonymised patient list through to Quality Health.

3.5 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 records. Therefore, it is essential that you check your own Board'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. The HSCB/PHA Cancer Commissioning Team nominated contact Robert McCormac will also ensure that further deceased checks (using the CSA service) are run prior to the lists being sent to Quality Health, and again prior to distributing mailing packs after they have been received from Quality Health.

³ To calculate this, subtract admission date from discharge date. For example, if discharge date = 03/09/2012 and admission date= 02/09/2012, LOS=1. Do not use any other fields to calculate Length of Stay (i.e. do not use hours/minutes/seconds). For day case/regular day case admissions, the length of stay would be 0.

3.6 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.

Mary Haughey (Mary.Haughey@hscni.net) will act as the Northern Ireland contact for this survey, and Quality Health will notify Mary of any calls. 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.

4 Finalising the Full Patient List

Once the individual Trust samples have been received, these will need to be combined to produce a single patient list covering all five Trusts.

The sample will need to be de-duplicated to ensure that it contains one record only for each unique patient, and that only the most recent attendance at Trust most recently attended is retained for each patient.

The sample will contain patients who received treatment for their cancer between the period 1st December 2013 and 31st May 2014, and is expected to generate a sample size of approximately **5500** patients.

4.1 Remove Duplicate Patients

Having combined the full patient list for all Trusts, it will be necessary to remove any duplicate patients found in the sample. The process relies on the provision of HCN numbers (any patients without HCN numbers should be excluded from the sample before running duplicate checking, to minimise the risk of a patient being contacted multiple times for this survey).

To identify and remove duplicate patients in Excel:

- First of all, check how many individual patients are duplicated if possible. The easiest way to do this is to do a pivot table on the HCN number if this is fully populated and note the number of those that appear more than once
- To remove/check for duplicates, sort the data by HCN Number, firstname, surname, discharge year (largest to smallest) discharge month (largest to smallest) and finally discharge day (largest to smallest)
- Use the duplicate button in 2007 Excel, tick NHS Number and DOB only. This should remove all but the most recent discharges who are duplicated.
- Note how many were removed
- If no duplicates – check back with the Trust(s) to see if they have already removed them and if so ask them to confirm that all but the latest discharge date have been removed.

4.2 Remove Deceased Patients

Once duplicates have been removed, perform full deceased checks using the CSA service to ensure that deceased patients are removed from the sample. Note – this is in addition to the initial checks which Trusts are being asked to perform against their local records (please see section 3.5)

5 Send out Process

This section explains the send out process for this survey programme. There are two identified roles in Northern Ireland who will be involved with this process:

- NI data contact – Robert McCormac
- NI mailing contact – Mary Haughey

The following steps explain the send out process for this survey programme.

1. The NI data contact will be responsible for drawing the final sample for this survey programme, by collating the samples provided by the Trusts (as detailed in section 3) and ensuring that all duplicate and deceased patients have been removed (as detailed in section 4 of this guidance manual).
2. The NI data contact will prepare a version of this final patient list to upload to Quality Health, having removed person identifiable data (PID). Section 6 details how to upload this initial list to Quality Health.
3. Quality Health will then collate and produce the required numbers of packages ready for send out. The packages will include: covering letter, questionnaire, language leaflet, return reply paid envelope. The unique identifier number will be clearly visible through the window in the envelope and printed on the covering letter. Quality Health will produce a mapping file which maps the patient record number (that the NI data contact assigned in their sample file) to the unique participant id which will be printed on the letters/visible through the envelope
4. These packages will then be couriered to the mailing contact in Northern Ireland. In addition, the mapping list will be emailed to both the NI data and mailing contacts.
5. The NI mailing contact will then need to print out labels with the patients' names and addresses on, as well as the unique identifier number. These labels will then be matched with the corresponding envelope and stuck over the window on the envelope.
6. Before send out, the appropriate death checks will need to be carried out by the Northern Ireland data contact to ensure that patients who have died do not receive a questionnaire. Note – it is important to ensure that this deceased check is completed as close to send out as possible
7. Any deceased patients who have been identified via this check will then need to be removed from the send out by the NI mailing contact.
8. The packages will then be mailed out by the NI mailing contact.
9. The NI data/ mailing contact will need to email a password protect excel workbook which contains the list patient record numbers of any deceased patients who were extracted before send out. Quality Health will log these details on our database to ensure that no further mailings are sent to these patients.
10. Completed questionnaires will be sent back to Quality Health via post as normal.
11. When first reminders are due, Quality Health will then produce a list of unique identifier numbers (mapped to the patient record number) who have not responded to the initial send out.

12. Quality Health will then send this mapping list to the NI data and mailing contacts.
13. Quality Health will send the first reminder letters for the appropriate number of patients by courier to the Northern Ireland mailing contact – the unique identifier number will be printed onto these letters. This is so that if a patient calls the helpline, we will be able to identify them, if necessary, if they quote the number.
14. Steps 5-9 will need to be repeated by the NI data contact and mailing contact to label the reminders appropriately (using the mapping file provided by Quality Health), to run full deceased checks prior to send out, and to notify Quality Health of any patients who we need to log as deceased.
15. The same process will be followed for second reminders. The second reminder packs will include a unique identifier as a second copy of the questionnaire is included – steps 5 to 9 should be repeated to label/removed deceased patients.
16. Quality Health’s data team will liaise with the NI data and mailing contacts to ensure that the process runs smoothly.