



# 2014 NATIONAL NHS CHILDREN'S INPATIENT AND DAY CASE SURVEY

THE CO-ORDINATION CENTRE FOR THE  
NHS PATIENT SURVEY PROGRAMME

SAMPLING HANDBOOK FOR TRUSTS USING A  
CONTRACTOR

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## Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in this guidance manual, for example, by offering financial inducements or lottery prizes to respondents. The terms of the ethical approval do not permit these types of alteration. Furthermore, such alterations might mean that the comparability of the survey would be compromised, and such results may not be acceptable for computation of the relevant measures within the Care Quality Commission assessments for that trust. If trusts want to make any adjustments to the method set out in this guidance, they will need to seek local research ethics approval, and check with the Co-ordination Centre that the proposed alteration would not compromise comparability or impact on Research Ethics Committee or Section 251 approvals.

## Updates

Before you start work on your survey, check that you have the latest version of this document, as there might be some small amendments from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will e-mail all trust contacts and contractors directly to inform them of the change.

This document is available from the Co-ordination Centre website at:  
**[www.nhssurveys.org](http://www.nhssurveys.org)**

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# 1 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). Prior to sending out questionnaires, a number of important checks must be carried out on the sample, including a check by the Demographics Batch Service (DBS) to identify deceased patients.

Please follow the instructions below carefully and allocate sufficient work time to check the sample for deceased patients with DBS before the first mailing and within the trust prior to each mailing.

## Before compiling your patient list

We strongly advise that you read all of this section BEFORE you start to compile your patient list.

### 1.1 Compile a list of eligible patients

- 1) Select the month of paediatric inpatient and day case discharges in which your survey sample will end. **NOTE: This should be August 2014.** You should start counting back from the last day of **August 2014**.
- 2) Compile a list of a **maximum** of 900 eligible patients (**aged 0-15 years old**) inpatients and day case patients consecutively discharged alive from your trust working back from the **31<sup>st</sup> August 2014**. That is, you should count back through the list of patients discharged live from the trust, including all eligible patients, until you have a maximum of 900, or until you reach 1<sup>st</sup> August 2014 (whichever occurs first). The minimum sample size for this survey is 300 patients. **With the exclusions that will be made as a result of deceased checks, removing duplicate records etc, you are advised to have a minimum pre-DBS sample size of 380 patients.** If you have sampled back from 31<sup>st</sup> August 2014 and have not reached 380 patients, you may sample back into July 2014 until you reach the minimum sample size. The reason for including a minimum of 380 patients and maximum of 900 patients at this stage is to allow for the removal of some patients following checks (for example deceased patients will need to be removed following DBS checks) to achieve to minimum sample size of 300 and maximum of 850.

#### Note

Some trusts have a much lower discharge rate than others. If necessary, a trust can include all patients discharged back as far as the **1<sup>st</sup> July 2014** to generate their sample of eligible patients submitted to DBS. The minimum sample size drawn required is 380 prior to DBS, therefore if July and August discharges does not generate a large enough sample, then the sample should include inpatients and day cases from September. If you wish to sample September please contact the Co-ordination Centre to discuss.

The information you obtain about each patient will be used both for administering the survey and for sending to the tracing service to check for deceased patients. It saves time and effort if all the information is gathered at the same time.

The list should **include**:

- **ALL** eligible inpatients and planned day cases aged 0-15 years at the time of their discharge. This should **NOT** include any patients who were aged 16 years or older at the time of discharge.

The list should **exclude**:

- deceased patients
- patients **aged 16 years or older** at the time of their discharge
- obstetrics/maternity patients, including spontaneous miscarriages
- newborn babies where the mother is the primary patient (ie: *well babies*, specialty code 424)
- patients who were **only admitted to a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU)** ie: specialty code 422.
- patients admitted for planned termination of pregnancy
- psychiatry patients, including CAMHS
- private patients (non-NHS)
- NHS patients treated at private hospitals
- any patients who are known to be current inpatients
- ward attendees- exclude those patients who visited the ward (eg: for a blood test) but were **not** admitted as a day case or did not have an overnight stay as an inpatient.
- patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no postcode).
- Any patient, parents or carers 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).

## Treatment Centres

If there are any instances where young patients stayed as an inpatient or received day case services from an NHS treatment centre at the trust, they are eligible for inclusion in the sample for the 2014 Children's survey, provided they meet the criteria above. These patients should be flagged up by inserting a '1' in the appropriate column in the sample file (see the example sample file in Table 3).

### 1.2 Checks carried out by the trust

Once you have compiled your list of 900 patients, you should carry out the following checks *before* you send the list to the DBS (who will carry out a further check for deceased patients):

- **Deceased patients.** Check hospital records do not have a record of a patient's death from a subsequent admission or visit to hospital. More information on checking for deceased patients is shown in the text box below.
- **Current inpatients.** Check that none of the patients are known to be current inpatients in your trust (or elsewhere, if possible). This should be the only time current inpatients are excluded from the survey process. When checks for deceased patients are carried out immediately prior to each mailing, do not check for, or exclude, current inpatients at these times. This improves the comparability of samples between trusts and thus reduces bias.
- **Patient ages.** Check that all patients are aged 0-15 years old at the time of their discharge in August 2014 (and July 2014 if you are also including that month in your sampling period).

- **Postal addresses.** Exclude any addresses that are outside the UK. Patients whose address is in the British Islands (Isle of Man, the Channel Islands) are eligible. Equally patients whose address is a military base, care home or prison establishment are also eligible.
- **Incomplete information.** Check for any records with incomplete information on key fields (such as surname and address) and remove those patients. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a patient if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. The more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias.
- **Duplications.** Check that the same patient has not been included more than once.
- **Community Hospitals.** As a general rule, patients who have only spent time in a community hospital should not be included in the sample. Patients who have spent time in both a community hospital and an acute hospital can be included depending on circumstance - please contact the Co-ordination Centre for further advice.
- **Obstetrics/maternity service user.** Check that the list does not include maternity service users. Please ensure that no episode of a patient's care has a maternity specialty code and that there are no route of admission codes indicating a maternity admission. You should not include patients with a Route of Admission code of 31 (ante-partum) or 32 (post-partum). There should also be no patients included who have a Main Specialty code of 501 (obstetrics) or 560 (midwife). If codes of 500 (obstetrics and gynaecology) are included, please ensure any included patients have been treated for gynaecology and not obstetrics.
- Check again that none of the patients were admitted for a **termination of pregnancy**.
- **Psychiatry patients.** Check Main Specialty codes and ensure that the list does not include psychiatry patients i.e. patients with the following Main Speciality codes should be excluded:
  - 700 learning disability
  - 710 adult mental illness
  - 711 child and adolescent psychiatry
  - 712 forensic psychiatry
  - 713 psychotherapy
- **Private patients.** Remove any private patients from the sample.
- **Patients treated at private hospitals.** Remove any patients who were treated by the trust as NHS patients in private hospitals.
- **Dissent.** Any patient known to have requested their details are not used for any purpose other than their clinical care. Your trust will have been asked to administer survey flyers on discharge to the eligible patient population during the sampling period. The flyer will have advised patients to contact the PALS team at your trust to indicate dissent. The PALS team will have been provided with a dissent log, and you should cross check your sample with this log to make sure any patients who have indicated dissent are removed.

## Checks for deceased patients

One of the most reliable and up-to-date sources of information on patient deaths is your own trust's 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 child 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 (DBS) as well.

The methodology for this survey requires three stages of checks for deceased patients before the first mailing is sent out. The checks are carried out sequentially by:

- 1) the trust
- 2) DBS
- 3) again by the trust (for patients who may have died in hospital after submission of the sample to DBS).

You are also advised to check your hospital records for any further deaths prior to posting the second and third mailings, and to ensure that approved contractors are advised immediately if any patients in the sample die during the survey period.

### 1.3 Submitting your patient list to the Demographics Batch Service (DBS)

Before sending out the questionnaires, the list of patients should be checked for any deaths by the Demographics Batch Service (DBS).

The DBS enables users to submit and receive a file containing relevant patient records electronically using dedicated client software. The patient records in the file are matched against the NHS Spine Personal Demographics Service (PDS). The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

**Please ensure that you have checked that your DBS licence is up to date and that you have updated your software (which changed as of July 2014). Please make sure that you have done this well in advance of when you need to draw your sample and submit this to the Co-ordination Centre.**

#### Create a trace request file

Using your list of patients, you need to create a correctly-formatted batch trace request file to send to DBS. You should take advice from your local trust PAS team on the correct format to submit files. Technical details on the file format are available from <http://www.hscic.gov.uk/demographics/>

For each patient you will need to include as a minimum:

- NHS number and full date of birth (yyyymmdd) – this is the recommended approach *OR*
- Surname, first name, gender, date of birth and postcode (can be wild carded e.g. LS1\*)

Although residential postcode is not mandatory it is highly recommended to include it to avoid incorrect matches. Due to the way addresses are recorded throughout the NHS, it is very difficult to get an exact match on address lines. For this reason, **do not** include address lines in the trace request file.

## Submitting the trace request file

Please note that the DBS does **not** accept the transfer of files by encrypted emails or on physical media. Instead, **request and response files must be transferred electronically using the dedicated DBS client software**. The DBS client software should have already been installed on a server within your trust. Please speak to a member of your IT department or PAS team if you do not know how to access and use the application. If your IT department cannot help, contact the DBS implementation team at: [demographics@hscic.gov.uk](mailto:demographics@hscic.gov.uk) and they should be able to advise you.

If you have been set up to use DBS, then once you have created the request file, it should be placed in the client in-box. The DBS client will then send the file to the Spine and, if you are registered, you will receive an email to say that the file was received. The DBS processes the file overnight and it should be ready the following morning. You will be notified by email when the file has been processed. During periods of high demand for DBS service, it may take 48 hours for your file to be returned.

### 1.4 Identifying deceased patients when the patient file is returned from DBS

The trace response file returned from DBS can be used to identify any patients who have died and therefore need to be deleted from the sample file (see below). This will reduce the numbers in your sample list slightly. **Please note that you should not exclude patients just because it was not possible for DBS to match them on their records. If you did this, you would bias the sample.**

#### The response file

The DBS will return a header row, response body and trailer row. The response row will be in two parts:

- The response containing all the data supplied in the request record, together with a trace outcome indicator. The main record is returned in all cases.
- An additional response column, which is returned only when there is a single unique match. It is in this additional response column that patients found to be deceased will be indicated (by a letter 'D').

For further information see: <http://nww.hscic.gov.uk/demographics/>

#### Note

Please be aware that tracing services are not fool proof and even after your patient list has been checked for deaths, some patients may die in the period between running the check and the questionnaire being delivered. You may find that some recently deceased patients remain in your sample. You need to be prepared for this. Special sensitivity is required when dealing with telephone calls from bereaved relatives. We recommend that you take all possible measures to avoid this occurring in the first instance.

### What to do if you have more than 850 patients remaining on your list

When your patient list is returned by DBS, and you have removed all deceased patients, there should still be more than 850 patients in the list. You will need to remove the **least recent** patients from your sample so that only the 850 most recent patients remain.

## What to do if you have fewer than 300 patients remaining on your list

If your patient list has fewer than 300 patients after deceased patients have been removed, you **MUST** contact the Co-ordination Centre on 01865 208127 or email [CYP.data@pickereurope.ac.uk](mailto:CYP.data@pickereurope.ac.uk). If possible, the next most recently discharged patients after the sample will need to be added to create a sample of 300 patients, although these must also be checked by DBS.

### Important note

You are aiming for a **high response rate for this survey**. You will be able to maximise your response rate by following this guidance carefully. It is **not** acceptable to try to boost the number of responses you receive by including more patients when compiling your sample for the survey as this would bias the survey. The Co-ordination Centre will only be able to accept responses from the patients in your list that have been correctly sampled and mailed.

## 1.5 Create the sample file

Information relating to your sample of patients should be entered into an Excel file which should resemble Table 3 below. A pre-designed spreadsheet including all the required column headings can be downloaded from the NHS Surveys website (<http://www.nhssurveys.org/surveys/787>) and is entitled 'Sample construction spreadsheet'. The column headings in this spreadsheet are identical to those supplied in the validated spreadsheet produced by the Co-ordination Centre for final submission of data (the 'Data entry spreadsheet') and so it will be advantageous for you to use the sample construction spreadsheet at this stage, rather than to create your own spreadsheet. Enter the required information and save this file as <NHStrustname>\_CYPInpatients2014.

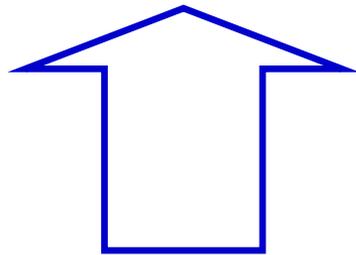
This file has three purposes:

- 1) It will be used to keep a record of which patients have not returned questionnaires so that reminders can be sent to them.
- 2) It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from **16th October 2014** until the closing date of the survey.
- 3) The anonymous data in this file (i.e. all the data **except** patient name and address information) will form part of the file that your contractor will submit to the Co-ordination Centre when the survey is completed.

More details about the information required in this file are provided below.

**Table 1 – Sample construction spreadsheet of patient details**

<i>NHS Trust Code</i>	<i>Patient record number</i>	<i>First name</i>	<i>Surname</i>	<i>Address1</i>	<i>Address5</i>	<i>Postcode</i>	<i>Month of birth</i>	<i>Year of birth</i>	<i>Gender</i>	<i>Ethnic category</i>	<i>Day of admission</i>	<i>Month of Admission</i>	<i>Year of Admission</i>	<i>Day of discharge</i>	<i>Month of discharge</i>	<i>Year of discharge</i>	<i>Length of Stay</i>	<i>Main Speciality on discharge</i>	<i>CCG code</i>	<i>Treatment centre admission</i>	<i>Route of admission</i>	<i>NHS Site code on admission</i>	<i>NHS Site code on discharge</i>	<i>Day of questionnaire being received</i>	<i>Month of questionnaire being received</i>	<i>Year of questionnaire being received</i>	<i>Outcome</i>	<i>Comments</i>
RT5	CYP14RX 10001	Annie	Shaw	-	-	AB1 1YZ	2	2005	2	A	5	6	2014	11	8	2014	6	100	12H	0		RR115	RR115				3	Informed that patient had died
RT5	CYP14RX 10002	Jatish	Ahmed	-	-	AB2 6XZ	11	2000	1	J	20	6	2014	30	8	2014	10	101	10Q	1	11	RTE03	RTE03	22	10	2014	1	
RT5	CYP14RX 10849	Katherine	Yoo	-	-	AB4 7MX	10	2000	2	R	17	6	2014	17	7	2014	0	300	09Y	0		RR115	RR115					
RT5	CYP14RX 10850	Ruby	Young	-	-	AB9 5ZX	08	2013	2	A	14	6	2014	14	8	2014	0	100	08L	0	22	RR120	RR117	6	11	2014	1	



**FIRST NAME, SURNAME, ADDRESS1...ADDRESS5 and POSTCODE columns are PATIENT IDENTIFIABLE DATA.**

**MUST NOT BE INCLUDED IN THE ANONYMISED SAMPLE FILE.**

## Important note about Table 3

The headings are in three different colours:

**Black** headings: these columns contain information on patients' names, addresses and comments that may allow them to be identified. This information must not appear in **any files** sent to the Co-ordination Centre. This mailing information, along with a copy of the patient record number should be removed from the sample file as soon as your sample is finalised and saved to a new file (your "mailing data" file). Please note that no patient identifiable data (names and addresses) should appear in the same file as the sample information when you send this to your contractor. All information **MUST** be kept separate.

*Red italic* headings: these columns should be completed during the sampling phase and submitted to your approved contractor, who will then submit the anonymised sample file to the Co-ordination Centre prior to mailing and at the conclusion of the survey.

*Green italic* headings: these columns should be completed when the patient responds to the survey (e.g. by returning a completed questionnaire), or when the approved contractor is notified the patient will not be participating (patient deceased, moved address, too ill, or called to opt out). The approved contractor will provide this information to the Co-ordination Centre.

The information that must be entered into this spreadsheet will come from a number of different sources:

## Information from hospital records

The following information can be compiled from hospital records:

- **First name** ensure that the first name is present rather than 'baby', 'boy', 'twin' etc OR **Initials:** trusts have the option of mailing to either first name or initials- please discuss this with your contractor
- **Surname**
- **Address Fields:** This should be held as separate fields (e.g. street, area, town and county)
- **Postcode**

### Note

The **Patient Record Number** (see 'Additional information' section below), **First name/ initials, Surname, Address Fields** and **Postcode** are used for printing out address labels. You (or your contractor) can use the mail merge function in a word processing package for this purpose.

- **Month of birth** should be included in the form of N or NN: eg. June=6 or November=11.
- **Year of Birth** should be included in the form NNNN, eg: 2011.
- **Gender** should be coded in numeric form: 1 = male, 2 = female.
- **Ethnic Category** is required in order to evaluate non-response from different ethnic categories. The ethnicity of a person is specified by that person and should be coded using the 17 item alphabetical coding specified by the Health and Social Care Information Centre (HSCIC). Further information is available at:  
[http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/e/end/ethnic\\_category\\_code\\_de.asp?query=ethnicity&rank=70&shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp?query=ethnicity&rank=70&shownav=1)

Please note that only patients who refuse to provide ethnic category should be coded as "Z" (not stated). If this code is missing for any other reason, ethnic category should be left blank in the sample information. Ethnic 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
<b>Other Ethnic Groups</b>	
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. June = 6 or November = 11)\*
- **Year** of admission (4 digits; e.g. 2014)\*
- **Day** of the month of discharge (1 or 2 digits; e.g. 2 or 30)\*
- **Month** of discharge (1 digit; e.g. August = 8)\*
- **Year** of discharge (4 digits; e.g. 2014)\*
- **Length of stay** (Units = Days). Calculate this by subtracting the admission date (day/month/year) from the discharge date (day/month/year). For example, if discharge date = 15/8/2014 and admission date = 14/8/2014, the length of stay = 1. Do not use any other type of unit to calculate length of stay (i.e. do not use hours/minutes/seconds).
- **Main Specialty (of consultant) code on discharge.** It is recorded in the form NNN as outlined by the Health and Social Care Information Centre (HSCIC). Please see: [http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/m/main\\_specialty\\_code\\_de.asp](http://www.datadictionary.nhs.uk/data_dictionary/attributes/m/main_specialty_code_de.asp)
- **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>
- **Treatment Centre Admission** should be coded as '1' for patients who spent any part of their inpatient stay at an NHS treatment centre within the trust, and coded as '0' if they did not.
- **Route of Admission:** Please include the two-digit descriptive code as used within the NHS Commissioning Data Sets. A blank or full-stop should be used if this information cannot be obtained for a patient. Please see: [http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/a/add/admission\\_method\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/a/add/admission_method_de.asp?shownav=1)
- **Hospital Site Code on Admission:** Please record the site of admission of the patient using the five character NHS Trust Site Codes (maintained by HSCIC). Please see: <http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs>
- **Hospital Site Code on Discharge:** Please record the site from which the patient was discharged using the five character NHS Trust Site Codes (maintained by HSCIC). Please see: <http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs>

## Additional information

A number of additional pieces of information should also be entered into this spreadsheet:

- 1) **NHS Trust Code.** Enter your 3-character Trust Code against all records in the first column.

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

- 2) **Patient record number (PRN)**. This is a unique serial number which must be allocated to each patient by the trust. It should take the following format: CYP14XXXNNNN where XXX is your trust's 3-digit trust code and NNNN is the 4-digit number relating to your sampled patients, e.g., 0001-0850. The PRN will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), the approved contractor will be able to use these numbers to monitor which patients, parents and carers have returned their questionnaires and to identify any non-responders, who will need to be sent reminders. **Please note: this number should be available in, and correctly referenced for, every patient dataset for this survey (e.g. sample file, mailing file, final data)**. Note that the PRN is a unique number assigned to each patient record and the PRN will be the same regardless of whether the survey was completed on paper or online.
- 3) **Day of questionnaire being received**. This will only be completed if and when a questionnaire is received by the approved contractor.
- 4) **Month of questionnaire being received**. This will only be completed if and when a questionnaire is received by the approved contractor.
- 5) **Year of questionnaire being received**. This will only be completed if and when a questionnaire is received by the approved contractor.
- 6) The **Outcome** field will be used to record which questionnaires are returned to the freepost address, or are returned undelivered, or which patients opt out of the survey, etc.
  - 1 = Returned useable **paper** questionnaire
  - 2 = Returned undelivered by the mail service or patient moved house
  - 3 = Patient died
  - 4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire
  - 5 = Patient was not eligible to fill in questionnaire
  - 6 = Questionnaire not returned (reason not known)
  - 7 = Returned useable **online** questionnaire
- 7) The **Comments** column is useful for recording any additional information that may be provided when someone calls the helpline – for example, to inform the contractor that the respondent has died or is no longer living at this address.

## 1.6 Checking the distribution of patient ages in your sample

You should check that patients of all ages are included in your sample. A good way to check that your sampled patients' ages cover the full range of expected ages is to examine the distribution of ages on a histogram.

## 1.7 Checking the distribution of patient gender

With the exception of hospitals specialising in one gender, your sample will probably have similar proportions of boys and girls. You should check that both boys and girls are included and that you can explain if the sample is skewed toward male or female patients.

## 1.8 Checking the distribution of patient route of admission and episode type

Please also check that the split of patients is roughly as you would expect – for example between emergency versus planned admissions, and the proportion of inpatients versus day case patients. This is essential as it help you to discover any errors that might have occurred when the sample was drawn. The split across groups is unlikely to exactly match any data you have on the proportions across all patients, as it is a sample survey. However, looking at the data this way will help you spot any apparent problems.

## 1.9 Separating mailing details from sample information

At this point you should transfer the names, address and postcode for each patient in the sample to a new file – your ‘mailing file’. The patient record number (PRN) for each patient should be copied to the new file, so that the two datasets are connected using the unique PRN. It is essential to ensure this number is correctly applied to the two datasets. Save this new file as ‘CYP1PandDC2014\_mailing data’. It should resemble Table 4 below.

This file should be used for mailing purposes: it will be used to check for deceased patients prior to reminder mailings and will be cross-referenced with the sample file (<NHStrustname>\_CYP2014) to identify patients who will need to be sent reminders.<sup>1</sup>

**As this mailing file will only be used occasionally during the survey, we recommend you keep this file encrypted. The mailing file should be destroyed when the survey is complete. This should be done by both the trust and the approved contractor, along with all other files created for the survey (aside from the survey response file).**

### Remember

For patient confidentiality reasons, **it is essential that you do not keep patient name and address details in the same file as their survey response data.**

*Table 2 – Example mailing file*

<i>NHS Trust Code</i>	<i>Patient record number</i>	<i>First name</i>	<i>Surname</i>	<i>Address1</i>	<i>Address2</i>	<i>Address3</i>	<i>Address4</i>	<i>Address5</i>	<i>Postcode</i>
RT5	CYP14RX10001	Annie	Abbot	14 Station Road	London				AB1 1YZ
RT5	CYP14RX10002	Jatish	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ

<sup>1</sup> As shown in Table 3 the ‘outcome’ field in the sample file is used to record which questionnaires are returned completed (and whether paper or online), or are returned undelivered, or which patients opt out etc...

RT5	CYP14RX10849	Katherine	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Cambs	AB4
RT5	CYP14RX10850	Ruby	Young	634 Tyne	Newcastle-Upon-Tyne	Tyne and Wear			AB9

## 1.10 Sample declaration form

For this survey, there is a sample declaration form that needs to be completed by the person preparing the sample. This form has a number of compliance statements which both the person drawing the sample and also the Caldicott Guardian must sign.

The form must be completed and sent to your approved contractor prior to submitting your separate mailing file and anonymised sample file to them. The form will be provided to the Co-ordination Centre alongside your sample file, as it will be used for assisting with sample checking for both the contractor and Co-ordination Centre.

## 1.11 Sharing the patient sample file with an approved contractor

If you have a contract in place, with your approved contractor, relating to the transfer of patient identifiable information (i.e. names and addresses) which allows the contractor to carry out the mailing of the questionnaires for you, both the sample file (<NHStrustname>\_CYP2014) **and** the mailing file (CYP2014\_mailing data) should be sent to the contractor staff in encrypted format.

You must submit your completed sample declaration form to your contractor first before you send any files to them. The contractor will then confirm they are happy to receive both the separate mailing file and anonymised sample file.

**Whilst your contractor has approval to receive patient identifiable data, this must be received by them in a separate file to the anonymised sample information. Files that contain both the sample information and mailing information will be considered a breach of the surveys Section 251 Approval. Breaches of this nature will be reported to the CQC and follow up action will be taken.**

If you are working with an approved contractor, but have chosen to mail out the questionnaires yourself, in-house, you should supply them with just the sample file (<NHStrustname>\_CYP). The contractor can use this file to record the outcome codes, but you should ensure that the contractor is kept up to date with any information that comes directly to the trust about patient deaths, etc.

Trusts which have not submitted their sample for checking by the **3rd October 2014** will be contacted by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. However, if samples are not received by the **8<sup>th</sup> October 2014**, then we are required to notify the Care Quality Commission of this and they will contact you to discuss any implications for inclusion in Care Quality Commission produced data.

## 1.12 Summary of key steps

By following the guidance in this section you should have completed all of the tasks set out below:

1. Compiled a list of eligible patients

2. Checked your patient list to make sure it meets requirements and only includes eligible patients
3. Sent the list to the DBS to check for deceased patients and removed these patients from your list
4. Created a sample file
5. Checked the distribution of patient age, gender and route of admission (planned versus emergency) in your sample file
6. Checked for other errors that may have occurred when drawing your sample.
7. Removed personal data from the sample file and created a mailing file
8. Share the sample file (and possibly the mailing file) with an approved contractor

### 1.13 Making the most of the fieldwork period

Because certain demographic groups and those from non-white ethnic backgrounds have been shown to take longer to respond to patient surveys, we strongly recommend that files are submitted within the four weeks specified for sample checking detailed above. The best way to ensure you are able to do this is to prepare before the start date of the survey (**15<sup>th</sup> September 2014**). **There are several ways you can do this:**

- 1) Check that your DBS software and licence are up to date- issues with submitting your sample to DBS will introduce delays into the sampling process meaning that you may end up delaying when your mailings are sent out and how long you have in the fieldwork period.
- 2) Allocate sufficient time to the individual who will generate your sample to allow them to generate it, dispatch it to DBS, and to respond to queries or corrections specified by your contractor or the Co-ordination Centre.
- 3) Discuss the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey.
- 4) Ensure your trust is registered with DBS and that the person who submits your sample to them understands their requirements – problems with data submitted to tracing services is one of the most significant obstacles in mailing out your survey in good time. Also, do not assume you are registered – please check this ahead of time.

**PLEASE NOTE: Your contractor only has approval to receive information relating to the patients that will be in your sample. Therefore, you are not permitted (under any circumstances) to send more than 850 records to your contractor. Your contractor will not be able to draw the sample for you from the returned list of records from DBS.**