2014 NATIONAL NHS CHILDREN’S INPATIENT AND DAY CASE SURVEY

THE CO-ORDINATION CENTRE FOR THE NHS PATIENT SURVEY PROGRAMME

SAMPLING HANDBOOK FOR IN HOUSE TRUSTS

Last updated: 15th August 2014

Contacts

The Co-ordination Centre for the Patient Survey Programme
Buxton Court
3 West Way
Oxford
OX2 0JB

Tel:	01865 208127
Fax:	01865 208101
E-mail:	CYP.data@pickereurope.ac.uk
Website:	www.nhssurveys.org

Key personnel

Chris Graham (Director of Research and Policy)

Hannah Atherton
Caroline Killpack
Susie Stevenson
Mark Waters

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

Contents

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 **31st 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 1st August 2014 (whichever occurs first). The minimum pre DBS sample size for this survey is 380 patients. If you have sampled back from 31st 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 is 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 **1st July 2014** to generate their sample of eligible patients submitted to DBS. The minimum sample size drawn required is 380, 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 and your clients have checked that DBS licences are 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 samples are drawn 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://nww.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 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 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, drawing your sample and mailing out as soon as possible, and you will need to send out two reminders. 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 of 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 you 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

NHS Trust Code	Patient record number	First name	Surname	Address1		Address5	Postcode	Month of birth	Year of birth	Survey version	Gender	Ethnic category	Day of admission	Month of Admission	Year of Admission	Day of discharge	Month of discharge	Year of discharge	Length of Stay	Main Specialty on discharge	CCG code	Treatment centre admission	Route of admission	NHS Site code on admission	NHS Site code on discharge	Day of questionnaire being received	Month of questionnaire being received	Year of questionnaire being received	Outcome	Comments
RT5	CYP14RX10001	**Annie**	**Shaw**		- -		**AB1 1YZ**	2	2005	B	2	A	5	6	2014	11	8	2014	6	100	12H	0		RR115	RR115				3	Informed that patient had died
RT5	CYP14RX10002	**Jatish**	**Ahmed**		- -		**AB2 6XZ**	11	2000	C	1	J	20	6	2014	30	8	2014	10	101	10Q	1	11	RTE03	RTE03	22	10	2014	1	
RT5	CYP14RX10849	**Katherine**	**Yoo**		- -		**AB4 7MX**	10	2000	C	2	R	17	6	2014	17	7	2014	0	300	09Y	0		RR115	RR115					
RT5	CYP14RX10850	**Ruby**	**Young**		- -		**AB9 5ZX**	08	2013	A	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 1

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.

Red italic headings: these columns should be completed during the sampling phase and submitted to the Co-ordination Centre prior to mailing (to allow for final inspection by the Co-ordination Centre) 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 trust is notified the patient will not be participating (patient deceased, moved address, too ill, or called to opt out).

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 either using first name or initials for the covering letter mailing
- **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, 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. Envelopes will be addressed: 'To the parent or carer of:'

- **Month of birth** (1 or 2 digits; e.g. June = 6 or November = 11)*
- **Year of Birth** (4 digits eg 2011)
- **Survey version:** calculate the patient's age as of **August 2014**, using the month and year of birth information above. Assign the correct questionnaire version:
    - A (0-7s) – any child with a birth date of September 2006 or later
    - B (8-11's) – any child with a birth date of September 2002 - August 2006
    - C (12-15s) – any child with a birth date of September 1998 – August 2002
- **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
  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
Other Ethnic Groups	
R	Chinese
S	Any other ethnic group
Z	Not stated

- **Day** of the month of admission (1 or 2 digits; e.g. 7 or 26)*
- **Month** of admission (1 or 2 digits; e.g. 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
- **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
- **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

---

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

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.
2) **Patient record number (PRN)**. This is a unique serial number which must be allocated to each patient by the trust (if the survey is being carried out in-house) or the contractor (if the survey is being carried out by an approved contractor). 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), you (or 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. If an approved contractor is used, you will need to agree with them on the range of serial numbers that will be used for your patients. 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 can only be completed if and when a questionnaire is received by the trust. It should be filled in as a one or two digit numerical response which will range from 1-31, **not** a date format (e.g. N or NN **not** 22/10/14).
4) **Month of questionnaire being received**. This can only be completed if and when a questionnaire is received by the trust. It should be a one or two digit numerical response, ranging between 1 and 12, **not** a date format.
5) **Year of questionnaire being received**. This can only be completed if and when a questionnaire is received by the trust. It should be a four digit numerical response (e.g. 2014), **not** a date format.
6) In the event that both a paper and an online questionnaire are received with the same PRN, the version that arrives first must be the one that is logged as completed (and the data processed). Priority must not be given to either method as this would skew the response rates by method.
7) 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

    The outcome column is left blank at first if the questionnaire has not been returned (in Table 3 you can see that Ms Yoo has not yet returned her questionnaire).

8) The **Comments** column is useful for recording any additional information that may be provided when someone calls the helpline – for example, to inform you 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 'CYPIPandDC2014_mailing data'. It should resemble Table 2 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.[1]

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 the trust, 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**.

---

[1] As shown in Table 1 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...

Table 2 – Example mailing file

NHS Trust Code	*Patient record number*	First name	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
RT5	CYP14RX10001	Annie	Abbot	14 Station Road	London				AB1 1YZ
RT5	CYP14RX10002	Jatish	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
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 is a requirement to reduce data breaches where patient identifiable data is submitted in the same file as the sample variables. The form can be downloaded from here: http://www.nhssurveys.org/surveys/787

The sample declaration form must be emailed to the Co-ordination Centre before you send the sample file to them. The Co-ordination Centre must confirm that they are happy to receive the sample file before it is sent to them. **You must not send the sample file to the Co-ordination Centre until the permission has been given.** The Co-ordination Centre will not be able to receive your anonymised sample file until they have received your sample declaration form and have confirmed that they are happy to receive the sample.

Please ensure that no patient identifiable data is sent to the Co-ordination Centre. If this happens, it will be logged as a breach of the Section 251 Approval for the survey, and follow up action taken by the CQC.

1.11 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. If required, shared the sample file (and possibly the mailing file) with an approved contractor

2 Final sampling inspection by the Co-ordination Centre

2.1 Procedure for submitting the anonymised sample file to the Co-ordination Centre

In order for the Co-ordination Centre to make final quality control checks, an anonymised sample file must be submitted to the Co-ordination Centre **prior** to the first mailing. This file will contain all columns *in red italics* in Table 3 – *Sample construction spreadsheet of patient details*, **but must not contain name, address and postcode details**.

Remember

Before submitting this data, you **must** first complete all checks described in the previous section

You must submit your sample declaration form to the Co-ordination Centre and wait for confirmation that this has been received **before** you send your anonymised sample file. **This is a requirement of the survey's Section 251 Approval and must be adhered to.**

Please ensure the sample file does not contain patient name, address or postcode details. Please ensure fields are correctly formatted and contain only the data requested in the format requested e.g. year of birth field does not contain date of birth. If name, address and similar identifiable data is transferred to the Co-ordination Centre, CQC inspectors will be notified of such data breaches and will consider if enforcement action is required.

The sample construction spreadsheets will be formatted to prevent data being entered in the wrong format. It is essential that samples are submitted using the construction spreadsheets provided.

2.2 Timetable for submitting data to the Co-ordination Centre

The Co-ordination Centre will be checking for extraordinary errors. These are more visible when viewing data from many trusts at one time. For this reason, samples will be checked as collated files (the 'anonymised' versions of files, excluding names and addresses). Table 5, below, sets out the dates of submission and the respective date trusts can expect to receive a response back from the Co-ordination Centre.

Table 3 – Sample submission dates

Date sample received	Date of response (midday)
15th September -19th September	**25th September**
22ndth- 24th September	**29th September**
25th – 29th September	**3rd October**
29th September – 3rd October	**8th October**

In cases where anomalies are discovered in the sample data submitted, trusts will be notified no later than midday of the day indicated in Table 3 above.

Samples should be submitted to the Co-ordination Centre no later than **3rd October 2014**. If they are not, there is a risk the trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may result in the data from the trust being excluded from CQC assessments and national level indicators.

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 **8th 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.

Important note

The first mailing should take place as soon as possible after the sample has been approved by the Co-ordination Centre and certainly **no later than seven days** after this. A large time lag increases the likelihood of patients having died between the sample file being received back from DBS and the questionnaire being received, increasing the risk of distress to family members and complaints to trusts.

Remember to submit your data declaration form to the Co-ordination Centre before you start mailing out, even if your sample has been approved.

2.3 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 **(15th September 2014). There are several ways you can do this:**

1) Check your DBS licence and software are up to date, ready for the sample to be submitted to check for patient deaths.

2) Allocate sufficient time to the individual who will generate the sample to allow them to generate it, dispatch it to DBS, and to respond to queries or corrections specified by the Co-ordination Centre.

3) The printing of questionnaires and assembly of mailing packs can take place before the sample is signed off. Please ensure that the envelopes are left open though so that you can check the correct label is applied to the correct questionnaire.