# SAMPLING INSTRUCTIONS

# CHILDREN AND YOUNG PEOPLE'S

# PATIENT EXPERIENCE SURVEY 2018

Last updated: 05 September 2018

## Adherence to the procedures outlined in this document

It is extremely important to follow the instructions in this manual carefully.

The Section 251 approval for this project provides a legal basis for trusts to share names and addresses with approved contractors for the purpose of sending out questionnaires. **NHS trusts must not send patient identifiable data, such as patient's names and/or addresses to the Survey Coordination Centre**. Any breach of the conditions will be reported to the CQC and the Confidentiality Advisory Group at the Health Research Authority.

It is also not permissible to offer financial inducements or lottery prizes to respondents. Similarly, producing versions of the questionnaire translated into other languages is also not permitted. The terms of the ethical approval do not permit these types of alteration. If trusts want to make any adjustments to the method or materials set out in this guidance, they will need to seek local research ethics approval and check with the Survey Coordination Centre that the proposed alteration would not compromise data comparability.

CQC use patient survey data for performance monitoring, and the data are also used by NHS England and the Department of Health and Social Care for Patient Experience Outcome Measures and the NHS Outcomes Framework. If the sampling guidance issued for the survey is not adhered to by a trust, it may be necessary to exclude their results from the survey. Lack of patient experience data will be flagged within CQC's performance monitoring tool (CQC Insight).

We request that all trust staff involved in drawing samples are made aware of the importance of checking previously written code and other historical arrangements, to minimise the risk of historic errors being repeated and the risk that your trust's survey results cannot be used.

## Updates

Before you start work on your survey, check that you have the **latest version** of this document (the date of the last update is on the front page). This document is available from the Survey Coordination Centre website: http://nhssurveys.org/surveys/1241

Sampling will need to be carried out by a member of staff at the NHS trust – very often a colleague in the trust's Informatics Team. The sample will normally be drawn from the Patient Administration System(PAS).

Trusts need to allocate sufficient work time and resources to respond quickly to any sample queries raised by the Survey Coordination Centre and approved contractors (if using one). All queries must be resolved before mailings can proceed.

Your sample may only be used for the purposes of distributing the 2018 Children and Young People's Patient Experience Survey and up to two reminder letters. Any additional use of the sample is not covered by the project's information governance or ethics approval. For example, it would neither be appropriate to send additional reminder letters to people in the sample, nor to contact them as a group before or after the survey.

## Did you know?

- o Throughout this document, there are links to detailed information on the topics covered in this manual.
- o If you are reading this on your computer, please click any of the blue underlined text for more information or visit the NHS Surveys website here: http://www.nhssurveys.org/usefullinks
- o You can also find the Survey Handbook for this survey on our website: http://nhssurveys.org/surveys/1241
- o For detailed instructions and templates that are specific to the 2018 Children and Young People's Patient Experience Survey, please go to: http://nhssurveys.org/surveys/1234
- o For definitions of terminology used in this document, please refer to our universal glossary for the NPSP.

# 1. How to draw a sample of patients

The flowchart on the following page shows the sequential steps that you must follow to draw your sample. Trusts are not permitted to submit any files to the Survey Coordination Centre with more than **1250 records**.

If trusts do this, it will be considered a breach of the Section 251 approval for the survey, resulting in follow-up action being taken.

## Sample sizes

The survey permits a sample size of **up to 1250** patients. However, your trust may not have had enough eligible patients discharged during the sampling period to meet this maximal sample size. This is permissible for the survey.

The sampling instructions and materials detailed in this manual should be followed exactly to successfully sample from an eligible population of **400 patients or greater**.

If your trust has an eligible population of **fewer than 400 patients** please contact the Survey Coordination Centre **immediately** as alternative sampling materials are required.

## National Data Opt-out Programme

The national data opt-out service, launched on the 25 May 2018, permits individuals to withhold their confidential patient information from use in research and planning (for more information see https://digital.nhs.uk/services/national-data-opt-out-programme).

The NHS Patient Survey Programme is presently **exempt** from the opt-out scheme. As such, during the sampling process, trusts should **not** exclude patients who have opted-out through the new national data opt-out service. **This means that patients do not have to consent to the sharing of their data to be sampled for the 2018 Children and Young People's Patient Experience Survey.**

# 2. Patient sample process

Compile a full list of patients using [CYP18 Sampling workbook 1](#)

Submit your patient list to the Demographics Batch Service (DBS)

Undertake checks to ensure no sampling errors have occurred (see pages 11-13)

Sort and label your eligible patient list in [CYP18 Sampling Workbook 1; Tab 1](#)

Create the sample in [CYP18 Sampling workbook 1; Tab 2](#) and save the file

Create your final sample file in [CYP18 Sampling workbook 2](#) and save the file

Referring to your saved copies of CYP18 Sampling workbook 1 and CYP18 Sampling workbook 2, complete the 'Figures' tab of the [Sample Declaration Form](#)

Complete and submit your [Sample Declaration Form](#).

**If using a contractor**

When instructed, send the sample file (mailing and sample data[) to your contractor](#) via an encrypted FTP

**If conducting the survey in-house**

Separate the mailing data (names & addresses) from the sample data (pseudonymised data including cluster codes)

When instructed, send the *pseudonymised* sample file (sample data only) [to the Survey Coordination Centre](#) via an encrypted FTP

# 3. Compiling your patient sample

The sample for this survey is selected from all patients, aged 15 days to 15 years old, who have been admitted to your trust. Details on the sampling period and who should be included and excluded are set out below.

- o  If your trust does not already have all patients on one electronic list, you will need to combine all the separate lists so that you have one single complete list.

- o  If some patients' details are not held electronically, it will be necessary to type in their details, so that all patients' details are held electronically.

- o  If you do not have an adequate list of patients or if you do not have adequate information on date of discharge, please contact the Survey Coordination Centre.

The following section details how to successfully draw your sample for the 2018 Children and Young People's Patient Experience Survey.

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

It is **vital** that you use the correct CYP18 Sampling workbooks provided at each stage of the process.

## Compile a full list of patients using **CYP18 Sampling workbook 1**

**1)** Download '**CYP18 Sampling Workbook 1**' template from here:
http://nhssurveys.org/surveys/1242

**2)** In tab '1. Full list' in that template, compile a list of all children and young people who were admitted patients, discharged from your trust in line with the eligibility criteria below.

## Who to include

**ALL** eligible **admitted patients** discharged from your trust between **1st November 2018** and **31st December 2018**, who were aged **between 15 days and 15 years** (inclusive) at the time of their **discharge**. Include all teams within your trust providing health services to children and young people.

Patients are considered eligible if they have been admitted (i.e. have an admission method code:
www.datadictionary.nhs.uk/data_dictionary/attributes/a/add/admission_method_de.asp)
and fulfil all other eligibility criteria

Eligible patients include:

o Admitted patients who did not stay overnight (e.g. emergency admissions and planned day cases)

o Admitted patients who did stay overnight.

## Who to exclude

o Patients who were not admitted (e.g. ward attendees or patients who attended an outpatient appointment, but were not admitted)

o Deceased patients

o Any duplicated patients

o Patients aged 16 years or older at the time of their discharge

o Babies aged between 0 and 14 days at the time of their discharge

o New-born babies where the mother was the primary patient (i.e. well babies, treatment function code 424)

o Patients who were **only** admitted to a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU) (Treatment Function Code 422)

o Obstetrics/maternity patients, including spontaneous miscarriages

o Patients admitted for planned termination of pregnancy

o Psychiatry patients, including CAMHS

o Private patients (non-NHS)

o NHS patients treated at private hospitals

o   Any patients who are known to be current inpatients

o   Patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no postcode)

  –   Please note: patients should be *included* if they have an address in any part of the UK, including those not in England (Wales, Scotland, Northern Ireland, Isle of Man, Channel Islands, etc.). Equally, patients whose address is a military base, care home or prison establishment are also eligible

o   Any patient, parents or carers known to have requested their details are not used for any purpose other than their clinical care. Please remember this **does not** include patients who have opted out of having their data used for planning and research purposes via the National Data Opt-Out Programme. Under the conditions of the survey's Section 251 approval from the Confidentiality Advisory Groups, **trusts must also consult their dissent logs from previous CYP surveys and exclude any patients who asked to be removed from that survey.**

**Exclusions should only be made based on the criteria listed in the sampling instructions.**

Your patient list should be a list of unique patients. If a patient has been admitted more than once during the sampling period, please remove the earlier admission(s) and leave the most recent admission for that patient.

If you are unable to remove duplicates when drawing the patient list from your patient administration system, you can include duplicate admissions at this stage, and remove them from your full list as outlined in 'Removing duplicates in **CYP18 Sampling workbook 1, Tab 1**' section.

## Include the following information:

When you put your data into '**CYP18 Sampling workbook 1**', you should **include the following information in the respective columns**:

o   **NHS number**

  –   Please note, this will be used for removing duplicates and for DBS checks - it **must not** be submitted as part of the 'mailing' or 'sample' data. If you are missing the NHS number for any patients who are otherwise eligible, please still include these patients in your list.

o   **Patient initials or first name**

o   **Patient surname**

o   **Address, including postcode**

o   **NHS Trust Code**

o   **Month of Birth** (numeric: e.g. January as 01)

o   **Year of Birth**

o   **Gender** (numeric: male coded as 1, female coded as 2, non-binary coded as 9)

- o **Ethnicity** 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: www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp?query=ethnicity&rank=70&shownav=1.

  Some trust systems no longer accept missing ethnic data, so please note that any patient whose ethnic category is unknown may be coded as "Z" or left blank; 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 or unknown

- o **Date of admission** (separate columns for day, month and year)
- o **Date of discharge** (separate columns for day, month and year)
- o **Length of stay**. (Number of days. For example, if the admission date was 15/11/2018 and the discharge date was 16/11/2018, the Length of Stay = 1. If the child did not stay overnight, Length of Stay = 0.)
- o **Main specialty (of consultant) code on discharge** (using numeric codes). Please see: https://www.datadictionary.nhs.uk/data_dictionary/attributes/m/main_specialty_code_de.asp

- o **Treatment Function Code**. Please see:
  https://www.datadictionary.nhs.uk/data_dictionary/attributes/t/tran/treatment_function_code_de.asp?shownav=1
- o **CCG code**. This should be the CCG which will be billed for the care of the patient. Please see:
  https://digital.nhs.uk/services/organisation-data-service/data-downloads/other-nhs-organisations
- o **Treatment Centre Admission.** This flags whether the patient spent time in a NHS treatment centre at the trust. If the patient spent any time as an inpatient in a treatment centre, this should be recorded as '1'; if they did not then it should be recorded as '0'.
- o **Admission Method.** Please see:
  http://www.datadictionary.nhs.uk/data_dictionary/attributes/a/add/admission_method_de.asp?shownav=1
- o **NHS Site Code on admission**
- o **NHS Site Code on discharge**

**Please note**: there is also a column for 'record number' (column K), please leave this blank at this stage as this is done later. Instructions on how to construct each patient record number are provided below.

## Removing duplicates in **CYP18 Sampling workbook 1, Tab 1**

**If you have already removed duplicate patients from your patient list, please skip to the following section, 'Checks carried out by the trust'**

The sample that you will submit must consist of a list of unique patients. Some patients may have attended hospital more than once during the sampling month; in these cases, you may have duplicate patients in the initial selected sample you have just put into tab 1. Full List. You need to remove those, so that you have only unique patients.

If you have not already removed duplicates, you should be able to use the NHS number to identify such patients. When removing duplicates, you should remove the earlier admission(s) and leave **the most recent admission** for that patient. Please ensure that you do not leave blank rows when you remove duplicate records.

The following instructions explain one of the ways you can remove duplicate patients, based on NHS number:

1) Sort your patient list by NHS number. To do this, select **all** your data starting on row 3 – please **ensure you are not selecting the two header rows**. Click on the data menu, then click 'sort'. Select to sort by column A (NHS Number), then click ok.

**Please note**: it is vital that you **select all your data (all columns and rows) except for the header rows (1 and 2) before** sorting, as otherwise the file can become miss-sorted. If the data is miss-sorted, this could result in a major sampling error, which could invalidate your sample or your survey data.

2) Now select all the values in column A 'NHS number', then click on 'conditional formatting', 'highlight cell rules' then 'duplicate values'. This will colour all duplicate values in that column.

3) Go through the list looking at the coloured values to identify duplicate patients. You can filter the records to show only highlighted cases by clicking the filter arrow on column A, then selecting 'filter by colour' then clicking the cell colour listed.

4) When removing duplicates, you should remove the earlier admission(s)s and **leave the most recent admission for that patient**.

5) When you remove duplicate records, you should also ensure that you **do not leave blank rows**.

6) If you are missing NHS number for any patients in your list, please use their name and address information to check that they appear only once in your list and remove any duplicates.

## Checks carried out by the trust

Once you have compiled your list of patients, it is important to carry out the following checks **before** sending the list for checking by the Demographic Batch Service (DBS).

### Duplications

Check that the same patient has not been included more than once. Where possible, link any alias names so that only one name per patient appears in the list.

### Incomplete information

Check for any records with incomplete information on key fields (such as surname and full address) and remove those patients. However, do not exclude anyone simply because you do not have a postcode for them. Only remove patients 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.

### 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.

### Ages

Check that all patients were aged between 15 days and 15 years old (inclusive) at the time of their discharge.  Also check that your sampled patient's ages cover the full range of expected ages.

### Current inpatients

Check that none of the patients are known to be current inpatients in your trust or elsewhere, if possible. This is because we want to avoid sending a questionnaire to a patient who is still in hospital. A patient who used to be inpatient but has now been discharged should be included.

### Deceased Patients

Check that trust records do not have a record of a patient's death. The next section provides details on how to check for deceased patients.

### Patient in sample period

Check that all patients were discharged in the sample period of 1st of November and 31st of December 2018.

### Dissent

Remove any patient known to have requested their details are not used for any purpose other than their clinical care, including requests made by patients after seeing pre-survey publicity (you must ensure that you remove these patients from your sample list at this stage).

## National Data Opt-out Programme

The NHS Patient Survey Programme is presently **exempt** from the opt-out scheme. As such, during the sampling process, trusts should **not** exclude patients who have opted-out through the new national data opt-out service. **This means that patients do not have to consent to the sharing of their data to be sampled for the 2018 Children and Young People's Patient Experience Survey.**

### 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 Survey Coordination 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 admission method codes indicating a maternity admission. You should **not** include patients with an Admission Method code of 31 (ante-partum) or 32 (post-partum). There should also be **no** patients included who have a Treatment Function 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. Please note, gynaecology patients **should** be included if their visit was unrelated to pregnancy.

Also check again that none of the patients were admitted for a **termination of pregnancy**.

### Psychiatry patients.

Check Treatment Function codes and ensure that the list does **not** include psychiatry patients (i.e. Treatment Function Codes 700 to 727).
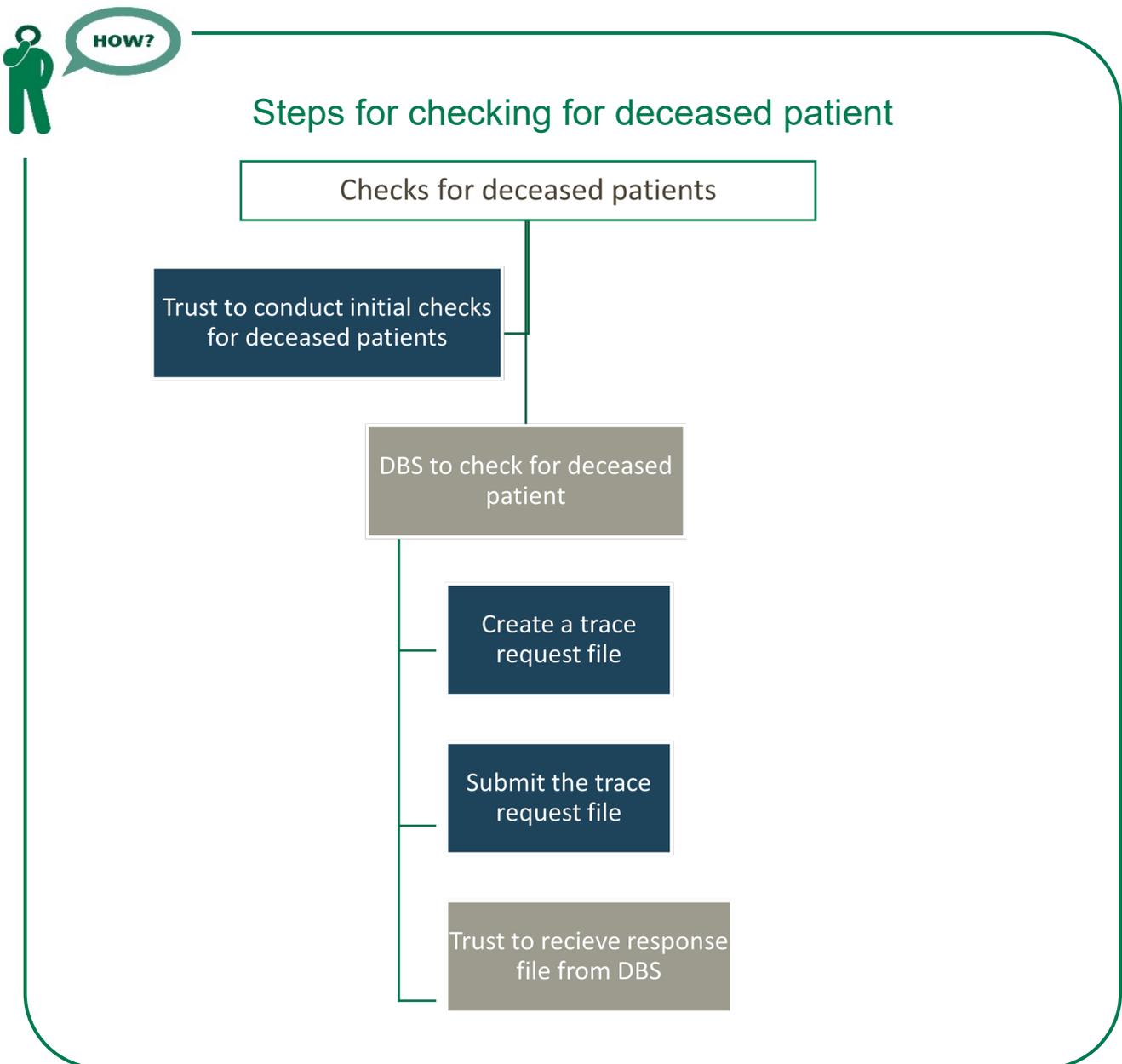
### Patients treated at private hospitals.

Remove any patients who were treated by the trust as NHS patients in private hospitals.

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

Before sending out the questionnaires, you need to have your **full list** of eligible patients checked for any deaths by the DBS.

The DBS enables users to submit and receive an electronic file containing relevant patient records, 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.

**HOW?**

### Steps for checking for deceased patient

Checks for deceased patients

Trust to conduct initial checks for deceased patients

DBS to check for deceased patient

Create a trace request file

Submit the trace request file

Trust to recieve response file from DBS

## Create the trace request file

Using your list of eligible patients, you need to create a 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. For each patient you will need to include as a minimum:

o   NHS number and full date of birth (yyyymmdd) – this is the recommended approach.

**OR**

o   Surname, first name, gender, date of birth and postcode (can be wild carded e.g. LS1*). The postcode is not mandatory but it will help avoid incorrect matches, please do not include address lines.

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

DBS requires that request and response files are transferred using the dedicated DBS client software. The DBS client software should have already been installed on a server within your trust and most trusts use this on a routine basis. 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, please contact the DBS implementation team at **demographics@nhs.net**.

If you have been set up to use DBS, then once you have created the request file, it should be placed in the client inbox. 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 or more for your file to be returned.

## The response file

The DBS will return a file with:

o   A header row

o   A response body. This will be in two parts:

o   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.

o   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').

o   A Trailer row.

## After you get the response file

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

## Do I need to do any additional checks following DBS checks?

Check your trust records for any further deaths prior to posting the second and third mailings. We strongly recommend that trusts conduct further DBS checks before the third mailing to avoid sending reminders to patients who have died between mailings.

If you are using a contractor, advise your contractor immediately if any patients in your sample die during the survey period.

Tracing services are not infallible: even after your patient list has been checked for deaths, some people may die in the period between running the check and the questionnaire being delivered.

Unfortunately, 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.

## Sorting and labelling your eligible patient list in **CYP18 Sampling workbook 1; Tab 1**

Once you have compiled and checked your full eligible patient list in 'CYP18 Sampling workbook 1', tab '1. Full List', you will need to follow the process below to sort and label your eligible patient list, prior to drawing the sample.

To sort the data in '**CYP18 Sampling workbook 1**', please complete the following steps:

1) Sort by gender (**column N**), **then** by year of birth (**column M**), and **then** by month of birth (**column L**).

To do this, select **all** your data starting on <u>row 2</u> **(second header row)**. Please **ensure you are not starting on row 1 (first header row), or row 3 (first data row).** Click on the data menu then click 'sort'. Then create three sorting levels to include column N (gender), column M (year of birth), and column L (month of birth), **in that order**. It should look like one of the images below. Click 'OK' to sort your data.
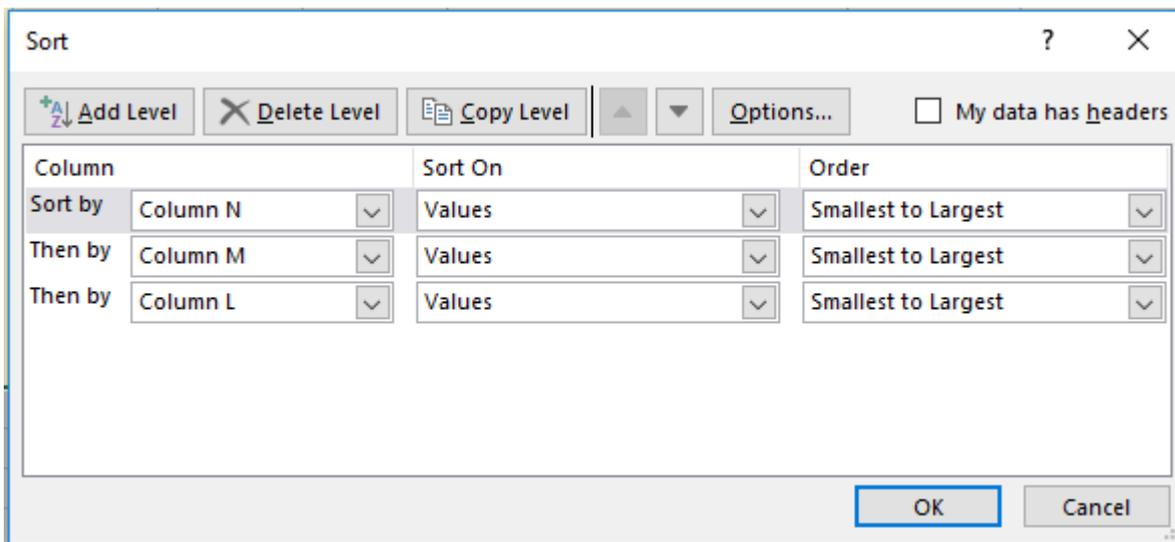
EXAMPLE
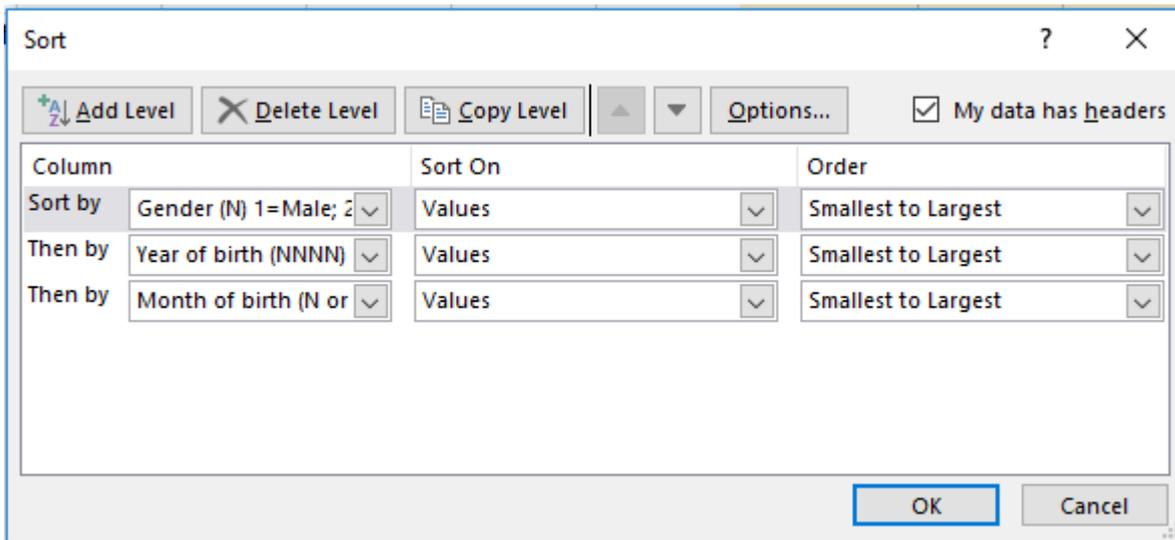
**Please note**: it is vital that you **select all your data (all columns and rows) except for the row 1 before sorting**, as otherwise the file can become miss-sorted. If the data are miss-sorted, this could result in a major sampling error, which could invalidate your sample or your survey data.

2) Now add a **record number** in the correct column. The record number should be in the following format: CYP18XXXNNNN where "CYP18" is the survey code, "XXX" is your trust code, and "NNNN" is the number.

At this stage, record numbers will run consecutively from CYP18XXX0001 to CYP18XXXNNNN, where NNNN should match the total number of records you have in your list of attendances. **Ensure you do not have any duplicate record numbers.**

3) Please check that there are no blank rows in your data.

## Creating the sample in **CYP18 Sampling workbook 1; Tab 2**

Once your data is sorted correctly and you have added record numbers, you need to use 'CYP18 Sampling workbook 1', tab '2. Sample selection' to calculate the survey versions and draw your sample, as detailed in the following instructions.

1) Please select all your data in 'CYP18 Sampling workbook 1', tab '1. Full List', **except for column A, 'NHS number',** then copy and paste this into the corresponding columns in tab '2. Sample selection' of 'CYP18 Sampling workbook 1'. (Do not copy the two header rows).

2) Check the "Number in list" section (see example image below), which is located in columns AF and AG, to see if the template has loaded your data properly. This section will show you how many records you have for each age group: double-check to be sure these figures are in line with what you know about your trust.

**Please note**: survey version is calculated automatically by the workbook based on patient month and year of birth. The survey version sent to each patient is based on their age at the very end of the sampling period, rather than their age when they were in hospital. This

is to avoid patients of the same age receiving different versions of the survey. All patients born 2011 or later will be counted as version A, all patients born between 2007 and 2010 will be counted as version B, and all patients born in 2006 or earlier will be counted as version C.

EXAMPLE



The "Ineligible dates" count should be zero, and you should **not** have any records marked 'Ineligible' in column B.

EXAMPLE



If you do have any records marked as 'Ineligible' in column B, please look at them and check the following:

o   There are no missing birth or discharge dates;

o   All birth dates are between November 2002 and December 2018;

o   All discharge dates are November or December 2018;

o   All patients were aged between 15 days old and 15 years old on the date of their discharge;

o   All the above numbers are entered as integers (whole numbers with no decimal places).

If you have checked all the above and still have records marked ineligible, please contact the **Survey Coordination Centre on 01865 208127.**

3)   Now you need to enter a random start number in the orange boxes in column AG for each of the three survey versions A, B and C. This must be a whole number (i.e. not have a decimal place). The red text will give you a number range that you can choose from – for instance, if it says "Version A: Enter random start between 1 and 2" you can put a 1 or 2 in the orange box

next to it. (If the red text says to enter a number 'between 1 and 1', you must enter the number 1 in the orange box).

| | | |
|---|---|---|
| Version A: Enter random start between 1 and 2: | | 1 |
| Version B: Enter random start between 1 and 1: | | 1 |
| Version C: Enter random start between 1 and 3: | | 3 |

Please allow time for Microsoft Excel to finish processing after you enter a number in each of the orange boxes. This may take some time.

4) After doing this, a random sample of records will be selected and column A and column B of the spreadsheet will automatically update. **Please allow time for Microsoft Excel to do this.** Records that have been randomly selected will be denoted by a '1'; those that have not been selected will be indicated by a '0'.

| A | B |
|---|---|
| In sample? (1 if included in sample, 0 if not) | Survey version |
| 1 | C |
| 0 | |
| 1 | B |
| 0 | |
| 0 | |
| 1 | B |
| 0 | |
| 0 | |

5) The "Number in sample" section in columns AE-AF will automatically update.

A total sample of 1250 will be drawn if there are enough eligible patients. The target sample sizes for each survey version are:

o  Version A: 450

o  Version B: 400

o  Version C: 400

You should check the "numbers in sample" listed in columns AE-AF are in line with the instructions below. If your numbers do not match what you would expect from the instructions below, please contact the Survey Coordination Centre for advice.

o  **If your trust has enough eligible cases for all three survey versions**:

  –  The total sample size will be 1250, made of 450 cases for version A, 400 for version B, and 400 for version C. For example:

**Number in list**

| | |
|---|---|
| Survey version A (0-7s): | 824 |
| Survey version B (8-11s): | 583 |
| Survey version C (12-15s): | 649 |
| Ineligible dates: | 0 |

**Number in sample**

| | |
|---|---|
| Survey version A (0-7s): | 450 |
| Survey version B (8-11s): | 400 |
| Survey version C (12-15s): | 400 |
| Total sample size: | 1250 |

o **If your trust has fewer than or exactly 1250 eligible cases in total**:

– All cases should be included in your sample, meaning the 'number in sample' section will match the 'number in list' section. For example:

**Number in list**

| | |
|---|---|
| Survey version A (0-7s): | 516 |
| Survey version B (8-11s): | 269 |
| Survey version C (12-15s): | 141 |
| Ineligible dates: | 0 |

**Number in sample**

| | |
|---|---|
| Survey version A (0-7s): | 516 |
| Survey version B (8-11s): | 269 |
| Survey version C (12-15s): | 141 |
| Total sample size: | 926 |

o **If your trust has more than 1250 eligible cases in total, but less than the target sample size for one or two of the survey versions**:

– All patients from the survey version(s) with less than the target number of cases will be included.

– The workbook will automatically increase the number of cases from the survey version(s) with excess patients, selecting a total sample size of 1250 cases. For example:

**Number in list**
| | |
|---|---|
| Survey version A (0-7s): | 229 |
| Survey version B (8-11s): | 285 |
| Survey version C (12-15s): | 1108 |
| Ineligible dates: | 0 |

**Number in sample**
| | |
|---|---|
| Survey version A (0-7s): | 229 |
| Survey version B (8-11s): | 285 |
| Survey version C (12-15s): | 736 |
| Total sample size: | 1250 |

6) Now **save this file** for future reference. Please note that you will **not send 'CYP18 Sampling workbook 1' to your contractor / the Survey Coordination Centre**, but you will use it to create the final sample file and may need to refer back to the file in the next few months if your contractor / the Survey Coordination Centre have any queries, so please make sure that the person that will deal with it in the next few months is aware of its location.

## Creating your final sample file in **CYP18 Sampling workbook 2**

1) Download '**CYP18 Sampling workbook 2**' from http://nhssurveys.org/surveys/1242

2) Returning to the previously completed **'CYP18 Sampling workbook 1'**, in tab '2**. Sample selection**', filter by column A so that only cases with a "1" in the column are shown. These are the cases that will be included in your sample. You can filter this column by clicking the grey arrow in cell A1 and making sure only "1" is selected, as shown below, then clicking 'OK'. Once you have applied the filter, you should only see "1" in column A, and no blanks in column B.
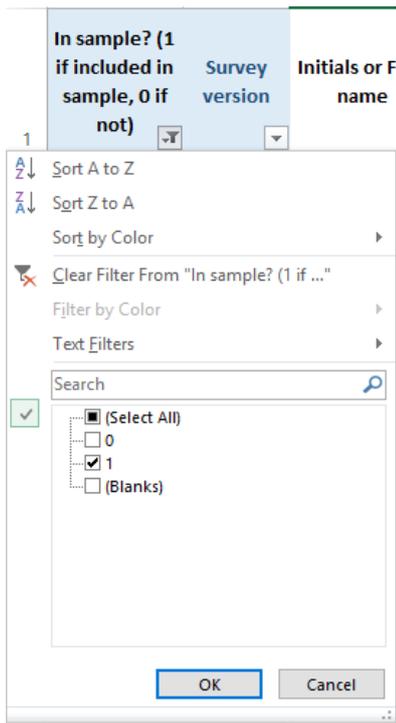
3) **With the filter still on**, select all data from **column B "Survey version"** through to column **AD "NHS Site Code on discharge"** (but do not select the header row 1), right click, and press copy. **Please ensure you select your entire sample (all records with a '1' in column A).**

4) Now paste this data into the corresponding columns (A to AC) in the tab named "Sample" of **CYP18 Sampling workbook 2**.

5) Check that the number of records you have pasted into the tab named "Sample" of **CYP18 Sampling workbook 2** matches the total number of records in your sample indicated in **CYP18 Sampling workbook 1** tab '2. Sample Selection' in the 'Number in sample' section (the total sample size is in cell AF18).

Please note: the column titles are in the first row, so the total number of records in the CYP18 Sampling workbook 2 "sample" tab will be the number of rows minus 1.

6) **Save the workbook as 'CYP18_< trust code >_sample'**

Sampling is now complete, subject to approval from the Survey Coordination Centre.

## Fieldwork information (contractors and in-house trusts only)

After questionnaires have started to be mailed out to patients, additional information regarding the progress of fieldwork should also be entered on this spreadsheet. The details of this information are indicated below:

- o **Day questionnaire returned.** This can only be completed if and when a questionnaire is returned by a respondent to the contractor/in-house trust. It should be a one or two digit numerical response not a date format, e.g. N or NN not 20/02/19.

- o **Month questionnaire returned.** This can only be completed if and when a questionnaire is returned by a respondent to the contractor/in-house trust. It should be a one or two digit numerical response, not a date format.

- o **Year questionnaire returned.** This can only be completed if and when a questionnaire is returned by a respondent to the contractor/in-house trust. It should be a four digit numerical response, not a date format.

- o **Outcome.** This 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 questionnaire

  2 = Returned undelivered by the mail service or patient moved house

  3 = Patient died (after fieldwork had commenced)

  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 = Patient deceased prior to fieldwork

  The outcome column is left blank at first if the survey has not been returned (in table 1 you can see that K Yoo has not yet returned their questionnaire).

- o **Comments.** This 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.

An example of the sample worksheet you will complete has been included below:

| Survey version | Initials or first name | Surname | Address1 | Address5 | Postcode | Trust Code | Record number | Month of Birth | Year of birth | Gender | Ethnicity | Day of admission | Month of admission | Year of admission | Day of Discharge | Month of Discharge | Year of Discharge | Length of Stay | Main Speciality on Discharge | Treatment function code | CCG code | Treatment Centre Admission | Admission Method | NHS Site code on Admission | NHS Site code on Discharge | Day questionnaire returned | Month questionnaire returned | Year questionnaire returned | Outcome | Comments |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| A | AM | Abbot | | -- | AB1 1YZ | R1X | CYP18 R1X1001 | 1 | 2008 | 2 | A | 5 | 11 | 2018 | 11 | 11 | 2018 | 6 | 120 | 220 | 10Q | 0 | 11 | RR115 | RR115 | | | | 3 | Informed that patient had died |
| A | EC | Ahmed | | -- | AB2 6XZ | R1X | CYP18 R1X0005 | 1 | 2011 | 1 | J | 1 | 11 | 2018 | 12 | 11 | 2018 | 11 | 101 | 215 | 10Q | 1 | 11 | RTE03 | RTE03 | | | | | |
| | | | | -- | | | | | | | | | | | | | | | | | | | | | | | | | | |
| A | K | Yoo | | -- | AB4 7MX | R1X | CYP18 R1X2655 | 3 | 2013 | 2 | R | 5 | 11 | 2018 | 11 | 11 | 2018 | 6 | 110 | 215 | 10Q | 1 | 22 | RR115 | RR115 | | | | | |

*Please note this table is for illustration purposes only. CYP18 workbook 2 appearance may vary from that shown above.

**Blue heading:** This column contains the survey version assigned in 'Sampling workbook 1'.

**Black headings**: these columns contain information on patients' names, addresses and comments that may allow them to be identified.

*Red italic headings*: these columns should be completed during the sampling phase and will include data relating to patients' demographic and clinical data, their unique record number and your trust code.

*Green italic headings*: these columns will be completed throughout the fieldwork period and will include the date the questionnaire was returned or whether patients have deceased or opted out

<table>
<tr><td>

**If you are using a contractor…**

You will submit **one sample file** to your contractor. In reference to Table 1 above, your sample file should **only** include data under the **blue,** **black**, and *red-italic* headings.

The data under the *green-italic* headings will be completed by your contractor during fieldwork.

</td><td>

**If you are conducting the survey in-house…**

You will submit **one sample file** to the Survey Coordination Centre.

**Your sample file should <u>not</u> include any identifiable information.**

In reference to Table 1 above, your Sample File should **only** include data from under the **blue** and *red-italic* headings

Remove the data under the **black** headings **<u>before</u>** submitting your file.

The data under the *green-italic* headings will be completed by your trust during fieldwork.

</td></tr>
</table>

## Checking for sample errors

**Distribution of patient gender**

Your sample will probably have similar proportions of boys and girls - unless your trust treats boys or girls only. You should check both of these genders are included and that you can explain if most, or a very large proportion, of your patients are either male or female.

**Distribution of patient ages**

You should check that patients of all eligible 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.

**Checking the distribution of patient admission method 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 length of stay = 0 versus length of stay = 1+ patients. This is essential as it helps 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. However, looking at the data this way will help you spot problems.

**Checking for other sample errors**

Please also ensure you have checked the following:

o   No patients aged 0-14 days at the time of discharge should be included

o   No patients aged 16 or over at the time of discharge should be included

o   Correct ethnicity coding

o   Gender coding should be numeric (male = 1, female = 2, non-binary = 9)

o   Only unique patients should be included (no duplicates)

o   The sample should have been drawn from the full sampling period (discharged patients between 1 November 2018 and 31 December 2018).

**Please also check to ensure your data has not become miss-sorted.**

Miss-sorting can occur if data has been sorted while only part of the data has been selected (e.g. if some columns were not selected).

To check this, please look at several patient records spread throughout your data and ensure the data in every column is correct for these patients.

# 4. Complete and submit the Sample Declaration Form

Once your sample has been drawn, you must complete the Sample Declaration Form, available here: http://nhssurveys.org/surveys/1242

1) Complete the 'Figures' tab by referring to your saved copy of CYP18 Sampling workbook 1, taking the requested figures from cells AF9-AF18 of tab '2. Sample Selection'. **You must ensure these figures are correct for the sample you are submitting as they will be used to as part of data analysis.**

2) Complete the 'Checklist' tab, ensuring all checks have been responded to. If a check is responded to with 'N/A', please give details of why this check is not relevant in the 'Comments' box provided next to that check.

3) Once both the 'Figures' and 'Checklist' tab has been completed, ensure the 'Declaration Agreement' tab has been completed and submit your Sample Declaration Form to your contractor or to the Survey Coordination Centre if undertaking the survey in-house. **Do not submit any data until you are instructed to do so.**

# 5. For in-house trusts only

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 for each person in your sample list must be copied to the new file, so that **the two datasets are connected using the unique record number**. It is essential to ensure this number is correctly applied to the two datasets, so that you can link them when necessary. Save this new file as **CYP18_MailingData_XXX** were XXX is your Trust code. **Do not submit this file to the Survey Coordination Centre.**

You will use this file to:

1) Check for deceased patients prior to reminder mailings.

2) Cross-reference it with the sample file (**CYP18_SampleFile_XXX**) 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. For patient confidentiality reasons, you are asked **not to keep patient name and address details in the same file as their survey response data**. The mailing file should be destroyed when the survey is complete, along with all other files created for the survey (aside from the survey response file).

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[1] The 'outcome' field in the sample file is used to record which questionnaires are returned completed, or are returned undelivered, or which patients opt out etc.