



## Sampling instructions

# 2026 Children and Young People's Patient Experience Survey

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## Picker

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## About this document

This document details the processes involved in drawing the sample for the 2026 Children and Young People's Patient Experience Survey (CYP26). **The information contained in this document supersedes all previous versions.**

These instructions are designed to be used by trusts delivering the survey in partnership with an approved contractor and trusts delivering the survey in-house.

Efforts have been made to ensure that the information provided is comprehensive. It is however necessary to supplement this document with a small number of complementary documents. These are:

- **The survey handbook**, which contains detailed information about the processes for preparing and running the survey.
- **The sampling workbooks**, which are used by Trusts to construct the sample of patients.
- **The sample declaration form**, which is used to check the sample has been drawn correctly before it is submitted by the Trust.

The most recent versions of these documents can be downloaded from the [NHS patient survey website](#).

If you have any queries about the contents of these instructions, please contact your approved contractor in the first instance (where relevant), or the Survey Coordination Centre (SCC) at Picker at [cyp@surveycoordination.com](mailto:cyp@surveycoordination.com).

## Adherence to the procedures outlined in this document

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

**NHS trusts must not send patient identifiable data, such as patients' names and/or addresses to the Survey Coordination Centre (SCC).**

The Section 251 approval for this project provides a legal basis for trusts to share names, addresses, mobile phone numbers, NHS numbers and full date of birth with approved contractors for the purpose of sending out questionnaires. Any breach of the conditions will be reported to the Care Quality Commission (CQC) and the Confidentiality Advisory Group at the Health Research Authority. Please note that patient postcodes are to be submitted with the sample and are excluded from the restriction for patient identifiable data as per Section 251 approval.

Any suspected breach of Section 251 approval by your trust should be raised with your contractor, or the SCC, immediately. Breaches will need to be reviewed, and your trust will need to decide whether the breach is to be reported through the [Data Security and Protection Toolkit](#). CQC are obligated to inform the Confidentiality Advisory Group at the Health Research Authority of any breaches and the outcomes of incident reviews.

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<sup>1</sup>. 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 check with the SCC that the proposed alteration would not compromise data comparability and, if they were permissible, would then need to be cleared with a local ethics board.

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 (DHSC) for similar purposes. 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.

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<sup>2</sup>, 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 [NHS patient surveys website](#).

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<sup>1</sup> The Survey Coordination Centre will provide an online questionnaire translated into 9 languages, and also offer a telephone assisted survey for 22 languages via the Language Line service.

<sup>2</sup> This relates to any historic code that the trust has used to draw a sample previously.

## Section 1: General information

### 1.1 Survey team

#### Sample Drawer

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 SCC 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 2026 Children and Young People’s Patient Experience Survey. This will include:

- Three invitation letters which will contain a URL, a QR code, and log-in details for the online survey.
- Two SMS text messages with a unique link to the online survey.
- A paper questionnaire will be included in the 2<sup>nd</sup> and 3<sup>rd</sup> postal mailing if a trust has <50% mobile number coverage in their sample, or a paper questionnaire will be included in the 3<sup>rd</sup> mailing only if trusts have >50% mobile number coverage in their sample.

Any additional use of the sample is not covered by the project’s Section 251 approval. For example, it would not be appropriate to send additional reminder letters to people in the sample.

#### Survey Lead

You will need to identify a survey lead(s) for the project and someone who will be responsible for drawing the sample at your trust. The person drawing the sample will need to be available to answer any queries that arise after the sample has been checked by your contractor and then by the SCC.

#### Caldicott Guardian

Ensure that your Caldicott Guardian is aware of the process and timelines for signing off the Sample Declaration Form. We will be including your trust’s Caldicott Guardian in routine communications about the survey, but we strongly recommend that this is reiterated internally at your trust. Samples cannot be processed and checked by the SCC and approved contractor (if applicable) unless the Sample Declaration Form has been signed by the Caldicott Guardian. Please discuss deadlines for submitting your Sample Declaration Form with your approved contractor, or the SCC in the case of in-house Trusts.

### 1.2 Sample months and dissent posters

The sample months for the Children and Young People’s Patient Experience Survey are **March, April and May 2026**.

This means that your sample must include all eligible discharges between 1<sup>st</sup> March and 31<sup>st</sup> May 2026 (inclusive).

It is a requirement as per [Section 251 approval](#) that your Trust advertises the upcoming survey during the sampling period. This is done by displaying [dissent posters](#) in all relevant places where Trusts deliver services. [Dissent posters](#) must be displayed at least for the entirety of March to May 2026 to maintain compliance with the Section 251 approval for this survey. The poster allows patients to be aware of the survey and provides an opportunity for them to ask questions or give dissent if they wish to be excluded from taking part.

The poster is available in English and other commonly spoken languages in England. Additional languages are provided based on individual Trust requirements, taking into account the demographic profile and linguistic needs of their local populations. Trusts should display the posters most relevant to their own patient populations.

Dissent posters must be displayed for the entirety of March, April and May to maintain compliance with the Section 251 approval for this survey, to give patients the chance to opt out of the survey.

**If for any reason your Trust has not displayed dissent posters during the sample months, please display these immediately and contact the SCC. You will need to inform your Caldicott Guardian and gain their approval to use the sample.**



### **General Data Protection Regulation (GDPR): National Data Opt-out Programme**

The NHS Patient Survey Programme has received exemption from the National Data Opt-out Programme. This means that the 2026 Children and Young People's Patient Experience Survey will continue to operate separate opt-out mechanisms. Therefore, to be included in your sample, patients **do not** have to actively consent to the sharing of their data, and this is for the purpose of the 2026 Children and Young People's Patient Experience Survey only.

## Section 2: Important information for 2026 survey

### 2.1 Safeguarding guidance

In CYP24, trusts were asked to exclude any patients that were currently known to be under safeguarding measures, i.e. any patient that the trust would exclude under their own safeguarding procedures and policies to prevent increased risk of harm.

We recognise that some teams lack visibility or access to all safeguarding information. In some trusts, safeguarding data may sit in separate systems, be held by different services, or not be accessible to all staff. This can limit the ability to check every patient for a safeguarding concern.

For CYP26, trusts should determine whether a patient should be removed from the sample in line with their own safeguarding policies and professional judgement. A patient should be excluded where the delivery of the questionnaire may increase the risk of harm to the individual.

In practice, this may include patients with known high-risk safeguarding concerns (for example, cases discussed through multi-agency safeguarding arrangements such as MARAC, or other situations where contact could pose a risk). These examples are provided as guidance only, and trusts should apply their own policies and judgement in determining exclusions.

Trusts are only expected to apply safeguarding exclusions based on the information they already hold and can reasonably access within their own systems. Trusts are **not** required to seek additional safeguarding information from external services or attempt to access systems they do not normally use if this will cause substantial delays.

Trusts should ensure that the approach taken is applied consistently across all eligible patients within the sample. The aim is to support trusts in applying their safeguarding policies appropriately when determining whether patients should be included in the sample.

If you have any queries on this, please contact your approved contractor or the SCC for further guidance.

### 2.2 Duplicate / triplicate mobile numbers in the sample

During CYP24, some patients in the sample shared the same mobile phone number. This typically occurred when a parent or carer had more than one child admitted to the hospital during the sample period, and their mobile number was recorded for each child.

This is a problem because SMS reminders do not include the patient's name. If the same parent or carer receives multiple survey links, they may not know which child the survey refers to, increasing the risk of completing the survey for the wrong patient.

#### Key principles:

- o Each mobile phone number must appear only once in the final sample.

- If the same mobile number appears for multiple patients, this must be resolved by removing and replacing records where possible.
- Only remove the mobile number (rather than the patient) if no suitable replacement is available.

For CYP26, trusts must check for duplicate / triplicate mobile numbers **after** they have drawn their sample selection. When duplicate / triplicate numbers are identified, apply the following rules.

**Duplicate mobile numbers across different age cohorts (survey versions) where the sample size has not been met:**

- Keep the patient in the survey version that has **not** met its target sample size.
- Remove the patient from the survey version that has already met (or is closest to meeting) its target.
- Replace the removed record with the next eligible patient in the sampling list. This refers to the next sequential record in the sampling list based on the original ordering in the CYP26 Sampling Workbook.
- For example, if one patient is in survey version A (0-7) which has achieved the 450 target sample size, and the other patient is in survey version C (12-15), which only has 150 records, the patient from survey version A should be removed and replaced, if possible.

**Duplicate mobile numbers within the same age cohort (survey versions), or across different age cohorts where the sample size has been met:**

- Keep the patient record with the **most recent discharge date**.
- Remove the patient(s) with older discharge dates from the sample and replace with new patient(s).
- For example, if three patients in survey version B (8-11) share the same mobile phone number, review their date of discharge and keep the record with the most recent discharge date. The other two records, with earlier discharge dates, should be removed and replaced, if possible.

How to replace a record:


1. **Return to Step 9** of the sample drawing process and open CYP26 Sampling Workbook 1, Tab 2: Sample selection.
2. Remove the filter on column A, so that cases with a “1” or a “0” in the column are shown, not just a “1”.
3. Find the next non-selected patient immediately following the removed record, and copy and paste this row into the sample following the instructions in Step 10.
  - a. If the record cannot be replaced with a new patient, as all patients have already been included in the sample, the patient should be retained and the mobile phone number removed only.

For further instruction on how to review and remove duplicates, please see step 11. If you have any queries on this, please contact your approved contractor or the SCC for further guidance.

## Section 3: Overview of the sample drawing process

The following flowchart shows the **sequential** steps that you must follow to draw your sample. Each step is further described in individual sections below.

Figure 1: Steps to draw a sample

- 
1. Compile a list of eligible patients, in Sampling workbook 1, tab 1.
  2. Add additional information to your Sampling workbook 1, tab 1, full list.
  3. Remove duplicate patients.
  4. Check that you have included the correct patients.
  5. Conduct local checks for deceased patients and send your patient list to the DBS to check for deceased patients.
  6. Remove deceased patients from your list.
  7. Note requirements for DBS and local checks during fieldwork.
  8. Sort your eligible patient list in Sampling workbook 1, tab 1.
  9. Create sample in Sampling workbook 1, tab 2.
  10. Create your final sample in Sampling workbook 2.
  11. Check for duplicate mobile phone numbers.
  12. Add additional variables if using SCC central online survey tool.
  13. Check your final sample file in Sampling workbook 2.
  14. In-house trusts and contractors to note down fieldwork requirements.
  15. Complete your sample declaration form and submit it once approval from your Caldicott Guardian has been obtained. Please send to your approved contractor, or the SCC if you are an in-house trust, for approval.
  16. When instructed, send Sampling Workbook 2 (both mailing and sample data) to your approved contactor or (if you are conducting the survey in-house) send the sample file only (not the mailing data) to the SCC via the sample upload portal.
  17. Respond to any queries from your contractor and/or the SCC.
  18. Once the sample is approved by the SCC, and your sample has been uploaded to the online survey tool, mailings for your trust can begin.

## Section 4: Drawing your sample

This section takes you through, step by step, how to draw your sample. It is important that you read this next section in full before you make a start. If, once you have read this section, you have queries then do get in touch with the SCC team.

### Important considerations

The survey permits a sample size of up to 1,250 patients. However, your trust may not have had enough eligible patients discharged during the sampling period to meet this maximum 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.

Trusts are not permitted to submit any files to the SCC with more than 1,250 records. Please note, you will first draw a list of all eligible patients and then reduce your sample to 1,250 records. If trusts submit more than 1,250 records, it will be considered a breach of the Section 251 approval for the survey, resulting in follow-up action being taken.

### **Electronically held patient records**

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.

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.

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](#).

## 4.1 Review common sampling errors

Below we have detailed the most common sampling errors to look out for while drawing your sample:

- **Age eligibility:** Patients included must be at least 15 days old up to 15 years old at the time of their discharge to be eligible for the sample.
- **Sampling months:** Ensure that all patients discharged during March, April and May 2026 are included within the initial list drawn. Your full initial list should include all discharges on and between 1<sup>st</sup> March and 31<sup>st</sup> May 2026.
- **Sub ICB Location codes:** Clinical Commissioning Group (CCG) codes were renamed to Sub ICB Location codes as of 1 July 2022, with the establishment of Integrated Care Boards (the 3 or 5-digit alphanumeric organisational codes remain the same as the CCG codes). Please make sure your sample includes these correct codes and that they are up-to-date. Please check against the list of Sub ICB Location codes detailed in the Sample Declaration Form.
- **Duplicate record numbers:** Please ensure there are no duplicate record numbers within the sample. Each patient should have a unique record number.
- **Sequential record numbers:** CYP uses a stratified random sampling approach. Due to the random selection process, record numbers must not be drawn sequentially.
- **Postal addresses:** Ensure postal addresses are complete and ensure there are no non-UK postal addresses included. Patients whose address is in the British Islands (Isle of Man, the Channel Islands) are eligible.
- **Mobile phone numbers:** Check that no landline numbers are included; check there are 11-12 digits in each number (e.g. +44); check no text is included within the mobile phone number.
- **Duplicate / triplicate mobile phone numbers:** Check for duplicate mobile phone numbers, please follow the guidance detailed in Section 2.2.
- **First name:** Check that the first name includes the patient's name.
- **Incomplete information:** Check that all variables are as complete as possible. Please make a note of any missing information as your contractor and the SCC will ask for this.

## Step 1: Compile a full list of eligible patients using **CYP26 Sampling Workbook 1**

The information you obtain about each patient will be used both for administering the survey and for conducting DBS and local checks. **It saves time and effort if all the information is gathered at the same time.**

- Download '[CYP26 Sampling Workbook 1](#)' template from NHS Surveys website
- In tab '1. Full list', compile a list of **all** children and young people who were admitted patients and were discharged from your trust in line with the eligibility criteria below.

### Eligibility criteria - who to **include** in the sample

- Admitted patients **discharged** from your trust between **1 March and 31 May 2026** (inclusive).
- **Aged between 15 days and 15 years** (inclusive) at the time of their discharge.
- Patients cared for by all service teams within your trust providing health care services to children and young people, that are not otherwise specified on the exclusions list.
- Admitted patients who did not stay overnight (e.g. emergency admissions and planned day cases).
- Admitted patients who stayed overnight.
- Include patients even if their addresses are incomplete but still useable (e.g. no postcode).

Patients are considered eligible if they have been admitted (i.e. have an admission method code) and fulfil all other eligibility criteria. Please see [the data dictionary website for a list of admission method codes](#).

### Exclude ineligible patients - who to **exclude** from your sample

- Patients who were not admitted (e.g. ward attendees or patients who attended an outpatient appointment, but were not admitted)
- Deceased patients
- Any duplicated patients
- Patients aged 16 years or older at the time of their discharge
- Babies aged between 0 and 14 days at the time of their discharge
- New-born babies where the mother was the primary patient (i.e. well babies, treatment function code 424)

- Patients who were **only** admitted to a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU) (Treatment function code 422)
- Obstetrics/maternity patients, including spontaneous miscarriages (further details in [‘Obstetrics/maternity service user’](#) section)
- Patients admitted for planned termination of pregnancy
- Psychiatry patients, including Children and Young People’s Mental Health Services
- Private patients (non-NHS)
- NHS patients treated at private hospitals
- Any patients who are known to be current inpatients
- Any patients that are currently known to be under safeguarding measures
  - The patient should only be removed from your sample where the delivery of the questionnaire itself is likely to increase the risk of harm to the individual.
  - Trusts are only expected to apply safeguarding exclusions based on the information they already hold and can reasonably access within their own systems. Trusts are **not** required to seek additional safeguarding information from external services or attempt to access systems they do not normally use if this will cause substantial delays. The intention is simply to ensure that any patient *already known* to the trust as being under safeguarding measures is not included in the final sample.
  - Please note: you will be asked to complete some information on the sample declaration form on how many safeguarding exclusions were made. If you have any questions or need guidance on safeguarding, please contact the Survey Coordination Centre.
- 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.
- 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.



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 step 3.

## Step 2: Add additional data to your full list

As part of the final sample list, there is additional information to submit. When you put your data into 'CYP26 Sampling workbook 1', tab 1 'Full list', it may be easier to collect that information now, when running the initial data extraction and setting up your initial data extraction query. This will save you having to go and find out this information later on.

If you are an in-house trust you will need to separate your mailing file containing person identifiable information (name, NHS number and address fields, excluding postcode) from your sample file so that only the sample information is sent to the SCC for checking. Please note, this separation is not required for trusts using an approved contractor, they require both your combined mailing and sample file to distribute the survey. The approved contractors operate as data processors and are therefore permitted to handle person identifiable data for the purposes of this survey.

The following information should be added to the respective columns:

Variable	Type	Notes
<b>NHS number</b>	Mailing	The patient's NHS number is used by contractors to conduct DBS checks. This variable can also be used to conduct checks on duplication of patients in the sample file. Patients may still be included in the sample even if their NHS numbers are missing, provided they meet all other eligibility criteria.
<b>Patient first name or initials</b>	Mailing	
<b>Patient surname</b>	Mailing	
<b>Address fields</b>	Mailing	This should be held as up to five separate fields (e.g. street, area, town and country). You must use the most current address on your system.
<b>Full postcode</b>	Sample and Mailing	This should be the patient's full postcode.
<b>Mobile phone number</b>	Mailing	This should be the current mobile phone number listed on your system, either an 11-digit number starting with '07' or a 12-digit number starting with '+44 7'. Do not include any home or landline phone numbers.  Please provide the mobile phone number attached to the patient's record, which could be either the child / young person's or the parent / carer's. The mobile phone number must be taken from the trust's records and be the number provided by the patient, parent / carer for clinical correspondence.

		<p>The Section 251 approval grants “the legal basis to allow access to the specified confidential patient information without consent.” This allows for trusts to provide details like patients’ postal addresses and applies to mobile numbers too. The only cases in which you should not provide this is if the patient, parent or carer has explicitly dissented to the use of their mobile number, or if there is a note specifying that the number belongs to someone other than the patient, parent or carer.</p> <p>Please ensure no duplicate/triplicate mobile numbers are included. Please see step 11 for further details on how to handle these cases.</p>
<b>Mobile phone number indicator</b>	Sample and Mailing	If a mobile number is included, this should be marked as ‘1’, if not this should be marked as ‘0’.
<b>Trust Code</b>	Sample and Mailing	This should be the three character code of your organisation e.g. RTE
<b>Patient Record Number (PRN)</b>	Sample and Mailing	<p>Please leave blank at this stage. This is a unique serial number which must be allocated to each patient by the trust. It should take the following format: 'CYP26XXXNNNN', where 'XXX' is your trust’s three-digit trust code and 'NNNN' is the 4-digit number relating to your sampled patients, e.g., 0001-1250.</p> <p>The record number will be included on invitation letters and will be the log-in username for the online survey. Later, when questionnaires are returned (whether completed or not) or completed online, these numbers will be used to monitor which patients have taken part and to identify any non-responders, who will need to be sent reminders.</p> <p>Please note: this number should be available in and correctly referenced for every patient dataset for this survey (e.g. sample file, mailing file, response data). Please note that record number is not a variable present in trust databases, it is created only to allow the monitoring of patient response.</p>
<b>Day of Birth</b>	Mailing	Numeric DD format (e.g. 28)

<b>Month of Birth</b>	Sample and Mailing	Numeric MM format (e.g. January as 01)
<b>Year of Birth</b>	Sample and Mailing	Should be included in the form of YYYY
<b>Gender</b>	Sample	Numeric (male = 1, female = 2, not known = 0, not specified = 9). For further information please see <a href="#">person gender code on data dictionary</a> .
<b>Ethnicity</b>	Sample	Required to evaluate non-response from different ethnic categories. The ethnicity of a person is specified by that person and should be coded using the <a href="#">17 item alphabetical coding specified in the NHS data dictionary</a> . Please note that any patient whose ethnic category is unknown may be coded as 'Z' or left blank.
<b>Day of admission</b>	Sample	Numeric DD format (e.g. 28)
<b>Month of admission</b>	Sample	Numeric MM format (e.g. January as 01)
<b>Year of admission</b>	Sample	Should be included in the form of YYYY
<b>Day of discharge</b>	Sample	Numeric DD format (e.g. 28)
<b>Month of discharge</b>	Sample	Numeric MM format (e.g. March as 03)
<b>Year of discharge</b>	Sample	Should be included in the form of YYYY. This should be 2026
<b>Length of stay in days</b>	Sample	Calculate this by subtracting the admission date (day/month/year) from the discharge date (day/month/year).  For example, if discharge date = 15/03/2026 and admission date = 14/03/2026, 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).
<b>Sub-ICB code</b>	Sample	This should be the billing Sub-ICB location code. The current three-or five-character Sub-ICB Location codes should be used (previously CCG codes). Please see list detailed in the sample declaration form. Note that this list includes both English and non-English codes.

<b>Main specialty (of consultant) code on discharge</b>	Sample	Using numeric codes, specified by the <a href="#">NHS data dictionary main specialty code</a> .
<b>Treatment Function Code on discharge</b>	Sample	Using numeric codes, specified by the <a href="#">NHS data dictionary treatment function codes</a> .
<b>Treatment Centre Admission</b>	Sample	This flags whether the patient spent time in an 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'.
<b>Admission Method</b>	Sample	Specified by <a href="#">NHS data dictionary admission methods</a> .
<b>NHS Site Code on admission</b>	Sample	Please record the site of admission of the patient using the <a href="#">five-character NHS Trust Site Codes (maintained by NHS Digital)</a> .
<b>NHS Site Code on discharge</b>	Sample	Please record the site from which the patient was discharged using the <a href="#">five-character NHS Trust Site Codes (maintained by NHS Digital)</a> .

## Step 3: Remove duplicates from your full list

**If you have already removed duplicates from your full list, please go to step 4.**

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 months (March, April and May 2026), 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 to ensure that you have only unique patients.

You should be able to use the **NHS number to identify duplicate patients**. If you are missing the 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 accordingly.

You can follow the instructions below to 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 4 – please **ensure you are not selecting the three header rows**.

**Please note:** it is vital that you **select all your data (all columns and rows) except for the header rows (1, 2 and 3) before** sorting, as otherwise the file can become mis-sorted. If the data is mis-sorted, this could result in a major sampling error, which could invalidate your sample or your survey data.

2. Click on the data menu, then click 'sort'. Select to sort by column A (NHS Number), then click ok. Please tick the box 'My data has headers'.
3. 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.
4. 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.
5. When removing duplicates, you should remove the **earlier admission(s) and leave the most recent admission for that patient**. To do this, compare the day and month of attendance and delete the rows with the dates which are earlier than the most recent attendance.
6. When you remove duplicate records you should ensure that you **do not leave blank rows**. To do so, make sure to delete the whole row (click right, delete row) rather than clearing values.

## Step 4: Check you have included the correct patients

Once you have compiled your list of eligible patients and removed any duplicates, it is important to carry out the following checks. Checks are required **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.

### Patient in sample months

Check that all patients were discharged in the sample months of the full months of March, April and May 2026 (admission date can be before sampling period).

### Incomplete information

Only remove patients if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. Check for any records with incomplete information on key fields (such as surname and full address) and remove those patients.

This includes checking the “Initials or First name” field for placeholder values (for example, “Baby”, “Boy”, “Girl”, “Twin”, “Triplet”). Any placeholder values should be **removed** from this field (but not necessarily the entire record at this stage).

Once placeholder values have been removed, **records should only be removed where there is insufficient name or address information overall** to reliably deliver and complete the survey for the correct patient.

**However, do not exclude anyone simply because you do not have a postcode for them.** 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 patients’ 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 an 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.

### 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). Previous indications of dissent should also be checked at this stage.

### 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 users

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.

## Step 5: Conduct local checks for deceased patients and submit your patient list to the Demographics Batch Service (DBS)

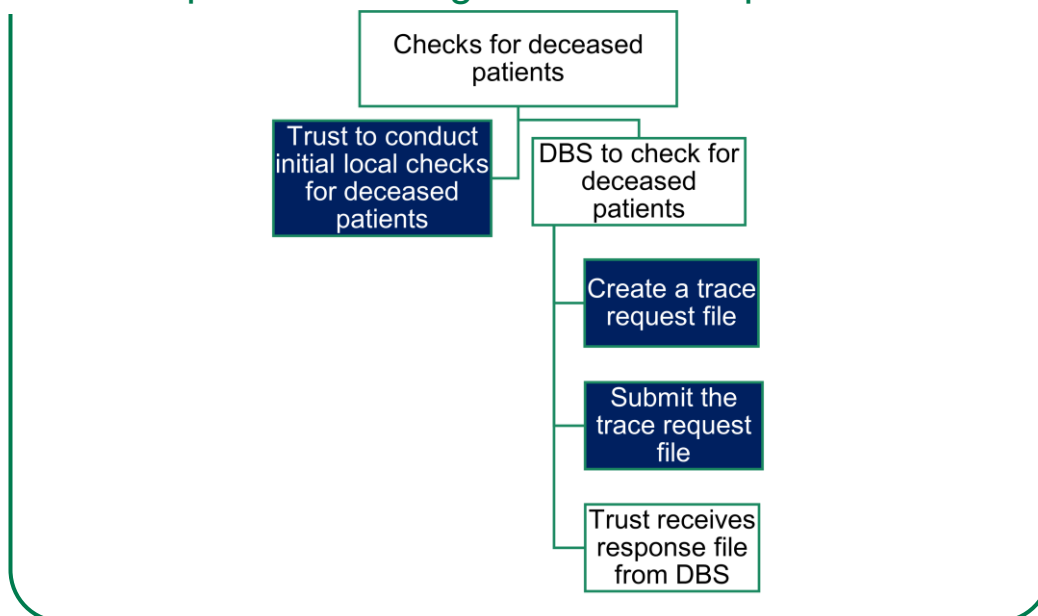
You will need to have your list of patients checked for any deaths, both internally and by the Demographic Batch Service (DBS). DBS checks can take a while (up to 5 working days is possible), so please ensure these are planned in. **This process is fundamentally important and must happen before you create the final sample file.**

Please keep in mind that additional DBS checks, as well as checks on your local trust systems, will be needed during fieldwork, in advance of the survey reminders being sent. Some contractors have access to DBS and can run DBS checks during fieldwork on trusts' behalf. Please liaise with your contractor to arrange this. **Trusts are still required to run initial first full DBS checks and local checks when drawing the sample, even if your contractor can run DBS checks during fieldwork.**

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. In the flow chart below, the activities undertaken by Trusts are highlighted in blue.



### Steps for checking for deceased patients



### Step 5.1 Local checks for deceased patients

You need to 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 for their relative who has recently died.

It is also a requirement to run further local checks prior to posting the second and third mailings 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 so that the approved contractor can ensure they are removed from any reminder mailings.

### Step 5.2 Create the 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 also available on the [Demographics Batch Service website](#).

**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, postcode** (can be wildcarded 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.

### Step 5.3 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 Patient Administration System (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](mailto:demographics@nhs.net).

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 for your file to be returned.

#### Step 5.4 The response file from DBS

The DBS will return a file with:

- A header row.
- A response body. This 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').
- A trailer row.

Further information is provided on the [DBS website](#).

## Step 6: Remove patients following DBS and local checks

Once your DBS file has been returned, you need to remove any patients identified as deceased in the DBS response file from your sample file (i.e. tab 1 of your sampling workbook 1). Make sure you cross-reference these two files carefully so you are removing the correct patients.

This will reduce the numbers in your sample list slightly. Using the response file from DBS, you should remove any patients from your sample who have died (indicated by a letter 'D'). Please do not exclude patients just because it was not possible for DBS to match them on their records, as this would bias the sample.



**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.

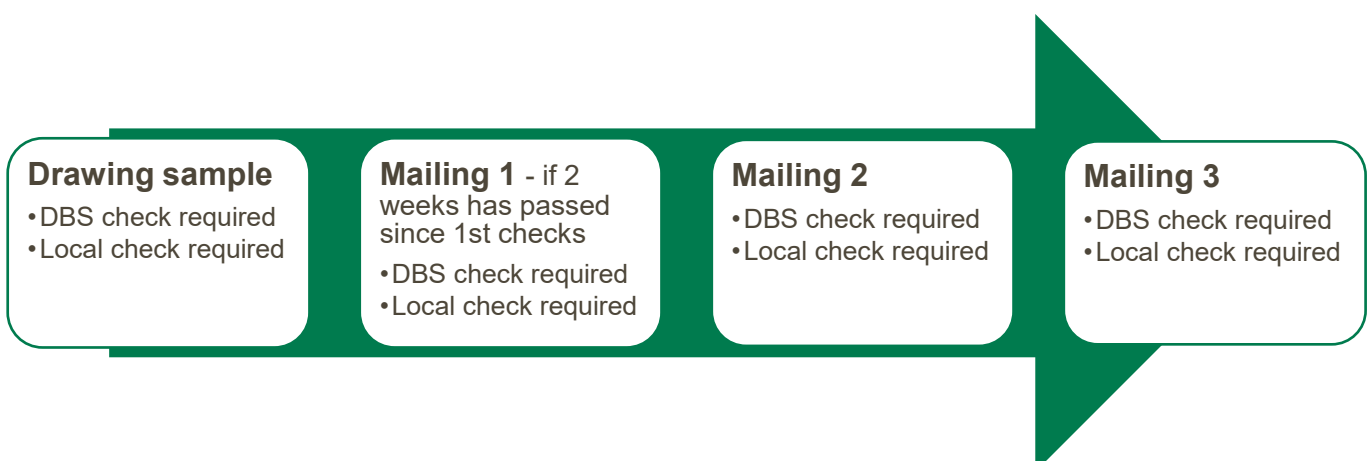
So, you may find that some recently deceased patients remain in your sample. **You need to be prepared for this.** Special sensitivity is required when dealing with telephone calls from bereaved relatives.

## Step 7: DBS and local checks during fieldwork

It is also a requirement to run further DBS and local checks prior to posting the second and third mailings to avoid sending reminders to patients who have died between mailings.

If you are using the services of an approved contractor, please notify them immediately if any patients in your sample die during the survey period and ensure they are removed from any reminder mailings.

### Protocol for conducting DBS and local checks throughout fieldwork



## **Contractors running DBS checks on behalf of trusts**

Some contractors have the capability of running DBS checks during fieldwork on the trust's behalf. This removes the requirement for trusts to run DBS checks ahead of mailing two and mailing three. Trusts can still choose to run DBS checks, this should be agreed with your approved contractor.

**Trusts are still expected to run the initial DBS checks (and local checks) when drawing the initial sample.**

**Please contact your contractor to discuss this further.**

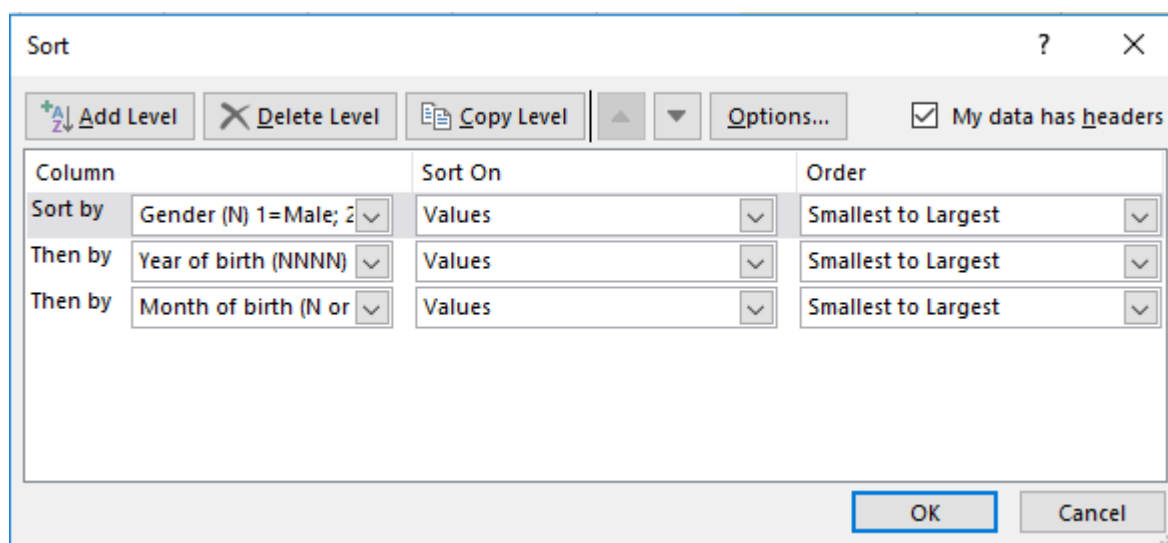
## Step 8: Sort your eligible patient list

Once you have compiled and checked your full eligible patient list in ‘**CYP26 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 ‘**CYP26 Sampling workbook 1**’, tab ‘**1. Full list**’, please complete the following steps:

- 1) Sort by gender, **then** by year of birth, and **then** by month of birth.
- 2) To do this, select **all** your data starting on **row 4 (first data row)**. Please **ensure you are not starting on row 1, row 2 (first header row) or row 3 (second header row)**.
  - a. Click on the data menu then click ‘sort’.
  - b. Then create three sorting levels to include column Q (gender), column P (year of birth), and column O (month of birth), **in that order**. It should look like in the image below. Click ‘OK’ to sort your data.
  - c. As shown in the image below – please sort on ‘**values**’ and order ‘**smallest to largest**’.
  - d. Please also ensure that the ‘**My data has headers**’ box is ticked.

### EXAMPLE



**Please note:** it is vital that you **select all your data (all columns and rows) except for the rows 1, 2 and 3 before sorting**, as otherwise the file can become mis-sorted. If the data is mis-sorted, this could result in a major sampling error, which could invalidate your sample or your survey data.

- 2) **Add a record number in column M**. The record number should be in the following format: CYP26XXXNNNN where “CYP26” is the survey code, “XXX” is your trust code, and “NNNN” is

the number in which the record appears in the spreadsheet. Please ensure you add record numbers at this point only, prior to creating your sample.

- 3) At this stage, record numbers will run consecutively from CYP26XXX0001 to CYP26XXXNNNN, 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.**
- 4) Please check that there are no blank rows in your data.

## Step 9: Create the sample in CYP26 Sampling workbook 1, Tab '2. Sample Selection'

Once your data is sorted correctly and you have added record numbers, you need to use 'CYP26 Sampling workbook 1', tab '2. Sample Selection' to calculate the survey versions and draw your sample.

**Please draw your sample by following these instructions.**

- 1) Select all your data in 'CYP26 Sampling workbook 1', tab '1. Full List', then copy and paste this into the corresponding columns in tab '2. Sample selection' of 'CYP26 Sampling workbook 1'. (Do not copy the three header rows).
- 2) Check the 'Number in list' section (see example image below), which is located in columns AI and AJ, 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.

### EXAMPLE

<b>Number in list</b>	
Survey version A (0-7s):	1788
Survey version B (8-11s):	353
Survey version C (12-15s):	451
Ineligible dates:	0
<b>Number in sample</b>	
Survey version A (0-7s):	0
Survey version B (8-11s):	0
Survey version C (12-15s):	0
Total sample size:	0

The image above displays the 'Number in list' section showing figures for 'Survey version A' (patients aged 0-7) as 1,788, 'Survey version B' (patients aged 8-11) as 353 and 'Survey version C' (patients aged 12-15) as 451.

The "Ineligible dates" count should be zero, and you should not have any records marked 'Ineligible' in column B 'Survey version' (see below).

### EXAMPLE

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

As shown in the example above, column A states 'In sample? (1 if included in sample, 0 if not)', the data entries are 0. Column B 'Survey version' and shows 'ineligible' in row 1.

**If you have records marked as 'Ineligible' in column B, please check the following:**

- There are no missing birth or discharge dates.
- All birth dates are between March 2011 and May 2026.
- All discharge dates are in March, April or May 2026.
- All patients were aged between 15 days old and 15 years old on the date of their discharge.
- 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](#).

3) Now you need to enter a random start number in the boxes in column AK for each of the three survey versions A (row 5), B (row 6) and C (row 7). This must be a whole number (i.e. not have a decimal place).

- a. The text in columns AI and AJ 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 box next to it (in column AK). (If the text says to enter a number ‘between 1 and 1’, you must enter the number 1 in the box).

**EXAMPLE**

<b>Version A: Enter random start between 1 and 3:</b>	2
<b>Version B: Enter random start between 1 and 1:</b>	1
<b>Version C: Enter random start between 1 and 2:</b>	2

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

- b. After doing this, a random sample of records will be selected, and column A and column B of the spreadsheet will automatically update.
- c. In column A, records that have been randomly selected will be denoted by a '1'; those that have not been selected will be indicated by a '0'. Sample rows with the number 1 in column A have a corresponding letter in column B (titled survey version) of A, B or C to denote the survey version.

**EXAMPLE**

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

4) The 'Number in sample' section, column AJ (rows 16-19), will now automatically update.

**A total sample of 1,250 will be drawn if there are enough eligible patients.** The target sample sizes for each survey version are:

- o Version A (0-7s): 450
- o Version B (8-11s): 400
- o Version C (12-15s): 400

You should check the figures in 'Numbers in sample' column AJ (rows 16-19) 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.

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

- o The total sample size will be 1,250, made of 450 cases for version A, 400 for version B, and 400 for version C.

If your trust has fewer than or exactly 1,250 eligible cases in total:

- o All cases should be included in your sample, meaning the 'Number in sample' section (column AJ, rows 16-18) will match the 'number in list' section (column AJ, rows 10-12).
  - For example: if the 'Number in list' section includes 516 in 'Survey version A' (column AJ, row 10), 269 'Survey version B' in (column AJ, row 11) and 141 in

'Survey version C' (column AJ, row 12) the total sample will only be 926 rather than 1250. All records will be included in the sample in this case.

**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

If your trust has more than 1,250 eligible cases in total, but less than the target sample size for one or two of the survey versions:

- o All patients from the survey version(s) with less than the target number of cases will be included.
- o The workbook will automatically increase the number of cases from the survey version(s) with excess patients, selecting a total sample size of 1,250 cases.
  - For example: if the 'Number in list' section includes 229 in 'Survey version A (0-7)' (column AJ, row 10), 285 in 'Survey version B (8-11s)' (column AJ, row 11) and 1,108 in 'Survey version C (12-15s)' (column AJ, row 11). The total number of records is 1,622, but Survey version A and Survey version B are under quota (do not meet the 450 and 400 sample size).
  - In this case, the 'Number in sample' will retain Survey version A and Survey version B (at 229 and 285 respectively), and version C figure will reduce to 736 records, so the total sample size meets 1,250 sample size.

**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
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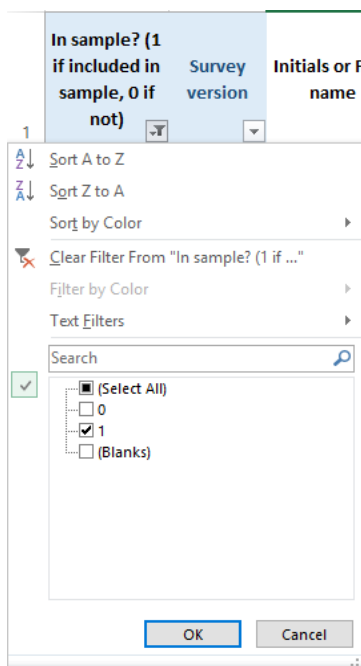
Survey version B (8-11s):	285
Survey version C (12-15s):	736
Total sample size:	1250

- 5) Now **save this file** for future use. Please note that you will **not send ‘CYP26 Sampling workbook 1’ to your contractor / the Survey Coordination Centre**, but you will use it to create the final sample file.
- a. You may also need to refer back to the file if your contractor or the Survey Coordination Centre have any queries.

## Step 10: Create your final sample file

- 1) Download '[CYP26 Sampling workbook 2](#)' from the NHS surveys website.
  - a. '**CYP26 Sampling Workbook 2 for central online survey tool**' – This workbook should be used by in-house trusts and contractors using the SCC online survey tool and includes extra information on the online survey link and password.
  - b. '**CYP26 Sampling Workbook 2**' – This workbook should be used by trusts using a contractor who are creating their own online survey tool.
  - c. If you are unsure whether your Approved Contractor is using the SCC online survey tool or their own online survey tool, please contact them for advice.
- 2) Return to the previously completed '**CYP26 Sampling workbook 1**', in tab '**2. Sample selection**'.
- 3) Filter by column A (titled 'In sample') 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 A2 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.

### EXAMPLE



- 4) **With the filter applied**, select all data from **column B 'Survey version'** through to column **AH 'NHS Site Code on discharge'** (but do not select the header rows 1 or 2), right click, and

press copy. **Please ensure you select your entire sample (all records with a '1' in column A).**

- 5) Now paste this data into the corresponding columns (A to AG) in the tab named '**Sample**' of **CYP26 Sampling workbook 2**.
- 6) Check that the number of records you have pasted into the tab named '**Sample**' matches the total number of records in your sample indicated in **CYP26 Sampling workbook 1**, tab '**2. Sample Selection**' in the 'Number in sample' section (the total sample size is in cell AJ 19).
- 7) **Save the workbook as 'CYP26\_< trust code >\_sample'**

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



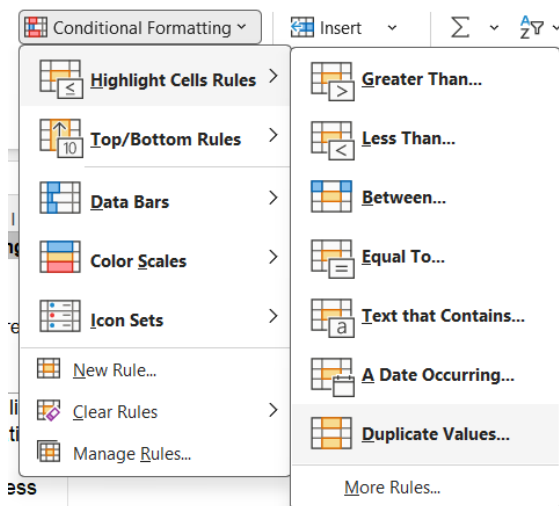
## Step 11: Check for duplicate mobile phone numbers

Trusts are asked to check for any duplicate/triplicate mobile numbers in their sample before submitting their final sample. Trusts must follow the duplicate mobile number guidance set out in Section 2.2 when identifying and resolving duplicate records. To check for duplicate/triplicate numbers, please follow the steps below.

The aim of this process is to ensure that each mobile phone number appears only once in the final sample and is linked to a single patient, in line with the guidance in Section 2.2.

1. Select all the values in column K 'Mobile phone number', then click on 'conditional formatting', then click 'highlight cell rules' then 'duplicate values'. This will colour all duplicate values in that column.

### EXAMPLE



2. Go through the list, looking at the coloured values to identify duplicate mobile phone numbers. You can filter the records to show only highlighted cases by clicking the filter arrow on column K, then selecting 'filter by colour' then clicking the cell colour listed.
3. When removing duplicates, please follow the guidance detailed below:

**Duplicate mobile numbers across different age cohorts (survey versions) where the sample size has not been met:**

- Keep the patient in the survey version that has **not** met its target sample size.
- Remove the patient from the survey version that has already met (or is closest to meeting) its target.

- Replace the removed record with the next eligible patient in the sampling list. This refers to the next sequential record in the sampling list based on the original ordering in the CYP26 Sampling Workbook.
- For example, if one patient is in survey version A (0-7) which has achieved the 450 target sample size, and the other patient is in survey version C (12-15), which only has 150 records, the patient from survey version A should be removed and replaced, if possible.

**Duplicate mobile numbers within the same age cohort (survey versions), or across different age cohorts where the sample size has been met:**

- Keep the patient record with the **most recent discharge date**.
- Remove the patient(s) with older discharge dates from the sample and replace with new patient(s).
- For example, if three patients in survey version B (8-11) share the same mobile phone number, review their date of discharge and keep the record with the most recent discharge date. The other two records, with earlier discharge dates, should be removed and replaced, if possible.

How to replace a record:

1. **Return to Step 9** of the sample drawing process and open CYP26 Sampling Workbook 1, Tab 2: Sample selection.
2. Remove the filter on column A, so that cases with a “1” or a “0” in the column are shown, not just a “1”.
3. Find the next non-selected patient immediately following the removed record, and copy and paste this row into the sample following the instructions in Step 10.
  - a. If the record cannot be replaced with a new patient, as all patients have already been included in the sample, the patient should be retained and the mobile phone number removed only.
4. When you remove duplicate records, you should also ensure that you do not leave blank rows. To do so, make sure to delete the whole row (click right, delete row) rather than clearing values.

If you have any queries on this, please contact your approved contractor or the SCC for further guidance.

## Step 12: Additional variables for contractors and in-house trusts using the SCC central online survey tool

In the 'CYP26 Sampling workbook 2 for central online survey tool', there are two additional columns in this spreadsheet for you to complete.

The two additional columns are included to provide participants with access to the online survey. These will generate:

- 1) **Online survey password:** a unique password for the online survey, which will be used in combination with the patient record number to allow patients to access the online survey
- 2) **Online survey link:** a unique link to the online survey that automatically logs the participant into the survey. This should be used (in shortened form) in the SMS reminders and QR codes

To generate these fields:

- Complete the rest of the spreadsheet, then copy the formula from the top of the spreadsheet into the first row of data.

### EXAMPLE

Online survey password	SMS link
Generate using the following formula: =VLOOKUP(RANDBETWEEN(1,31),Lookups!\$A\$1:\$C\$31,2,FALSE)&VLOOKUP(RANDBETWEEN(1,5),Lookups!\$A\$1:\$C\$31,3,FALSE)&VLOOKUP(RANDBETWEEN(1,31),Lookups!\$A\$1:\$C\$31,2,FALSE)&VLOOKUP(RANDBETWEEN(1,5),Lookups!\$A\$1:\$C\$31,3,FALSE)&VLOOKUP(RANDBETWEEN(1,31),Lookups!\$A\$1:\$C\$31,2,FALSE)	Generate using the following formula: ="Lookups!\$E\$1&\$B4"&password"&\$AF4&'Lookups!\$E\$2

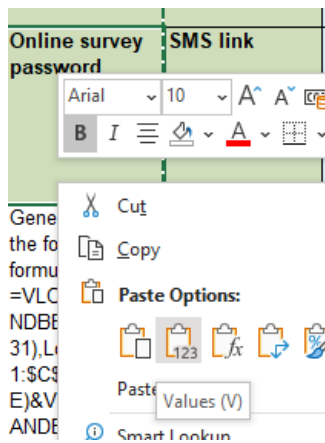
- This should give you a 5-character random password in the 'Online survey password' field and a long web link in the 'SMS link' field. Check the format of the password is correct and that the web link includes the correct **username** and **password**.
- Then drag the formula down to the final row of data.

### EXAMPLE

6VDQR	https://surveys.
2Q8Q8	
QJ7ZZ	
4ZZZQ	
JZGV8	

- Finally, copy and paste values for these columns, to make sure they will not continue to update.

**EXAMPLE**



## Step 13: Check your sample prior to submission for checking

Before you submit your sample, you are asked to carry out several checks on your sample: the distribution of age, gender and admission method.

### Checking the distribution of patient gender

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

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

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 check that the split of patients is roughly as you would expect – for example between emergency versus planned admissions, and the proportion of patients where length of stay = 0 versus length of stay = 1+. 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 the admission and discharge dates

There should be admission and discharge dates across March, April and May 2026 for CYP26.

### Checking for other sample errors

Please also ensure you have checked the following:

- No patients aged 0-14 days at the time of discharge should be included
- No patients aged 16 or over at the time of discharge should be included
- Correct ethnicity coding
- Gender coding should be numeric (male = 1, female = 2, not known = 0, not specified = 9)
- Only unique patients should be included (no duplicates)
- That the sample includes patients drawn from the full sampling period (discharged patients between 1st March 2026 and 31st May 2026). Admitted dates can be before the sampling period months.
- Inserting an incorrect Sub-ICB code (please check the codes inserted against the list provided in the sample declaration form)

If you discover errors in your sample, please get in touch with your approved contractor for further guidance.

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

Mis-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. You may wish to check this against the original data files you used to construct workbook 1.

## Step 14: 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 in the **CYP26 Sampling workbook 2**.

They will be completed by approved contractors and in-house trusts when the patient responds to the survey (e.g. by completing online or returning in the post), or when the trust is notified the patient will not be participating (e.g. patient deceased, moved address, too ill, or called to opt out).

The details of this information are indicated below:

- **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.
- **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.
- **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.
- **Hard copy accessible format requested** This can only be completed on request for an accessible format of the questionnaire. It should be completed regardless of whether a request turns into a valid survey completion. It should be a one-digit numerical response.
- **Outcome code** This field will be used to record which questionnaires are returned to the freepost address, or completed online, or are returned undelivered, or which patients opt out of the survey, etc. Please use the following codes:
  - 1 = Returned completed questionnaire (response received either online or via post, including completed accessible versions)
  - 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
- **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.

## Step 15: Complete and submit the sample declaration form

Once your sample has been drawn, you must complete the [Sample Declaration Form](#). You will need to submit the sample declaration form and wait for confirmation from the SCC (if you are an in-house trust) or your approved contractor (if you are using an approved contractor) before you submit your sample file. **This is a crucial step to reduce the risk of a confidentiality breach.**

A sample declaration form fully and accurately completed can speed up the sample approval process and therefore allow an earlier start of fieldwork.

Both the person drawing the sample and the trust's Caldicott Guardian must complete and electronically sign off the Sample Declaration Form. This is a requirement under the survey Section 251 approval and is a key element to minimise the risk of any data breaches occurring.

It is important that you use the sample declaration form as an opportunity to make comments on any data issues or changes that have occurred at your trust since the 2024 survey.

For example, if your trust has undergone a recent merger, then remember to highlight this. Or you may have moved clinical systems that means data is recorded slightly differently. This information will help your approved contractor and the SCC to check your sample, which may reduce the need for further queries.

Completing the sample declaration form:

- Complete the 'Figures' tab by referring to your saved copy of CYP26 Sampling workbook 1, taking the requested figures from cells AJ10-AJ19 of tab '2. Sample Selection'. **You must ensure these figures are correct for the sample you are submitting as they will be used as part of data analysis.**
- 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.
- 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.**

### **If you are using a contractor...**

Submit your Sample Declaration Form to your contractor.

Your contractor will let you know how and when to [submit your sample](#) to them.

Your contractor will then submit your sample to the SCC on your behalf.

### **If you are an in-house trust...**

Submit your Sample Declaration Form to the SCC.

Separate your mailing and sample data.

The SCC will let you know how and when to [submit your sample](#) information.

## Step 16: Receiving permission to submit your sample

For in-house trusts only



**This section is only relevant for in-house trusts. If you are using a contractor, please skip to the next section.**

Once you have completed your sample declaration form, you should transfer all of the variables in Sampling workbook 2, labelled 'Mailing' and 'Sample and Mailing' into a new file – called '**mailing file**'. Only the following variables should appear in both your mailing file and your sample file:

- **Record Number:** This will allow connection of the two datasets and ensure that responses and monitoring variables are recorded for the correct patients. It is essential to ensure this number is correctly applied to the two datasets.
- **The full postcode, mobile phone number indicator, trust code, month and year of birth:** The postcode is used for both mailing and analysis purposes. The postcode will be used to map each patient's location against deprivation indicators to conduct analysis of the results in terms of level of deprivation. This will allow identification of whether experience of care varies by level of deprivation. Month of birth is required for sample checking to validate age eligibility, and year of birth will be used for analysis by age groups.

The remaining 'Sample' variables and 'Sample and Mailing' variables form your '**sample file**'. This file will be shared with SCC for checking.

### Sample file

Contains sample information (columns called 'Sample' or 'Sample and Mailing' in the [Sampling Workbook 2](#)).

Save this file as **CYP26\_Sample File\_XXX**. Once your Sample Declaration Form has been approved, you upload your sample to SCC sample checking platform.

During fieldwork, you will use this file to:

- Keep a record of which patients have not returned questionnaires, so that reminders can be sent to them.
- Generate [weekly monitoring reports](#). You must send these to the SCC every Thursday from the first week of fieldwork (16 July 2026) until the closing date of the survey.
- Submit the sample information alongside patients' response data to the SCC once the survey has closed.

### Mailing file

Contains 'Record number' plus mailing information (names and addresses, including postcode – columns called 'Mailing' or 'Sample and Mailing' in the [Sampling Workbook 2](#)).

Save this new file as **CYP26\_MailingData\_XXX** where XXX is your Trust code.

**DO NOT submit this file to the SCC.**

You will use this file to:

- Check for deceased patients prior to mailings
- Identify which patients need to be sent reminders (by cross-referencing with the outcome codes in the sample file).



### Storing your mailing file (in-house trusts)

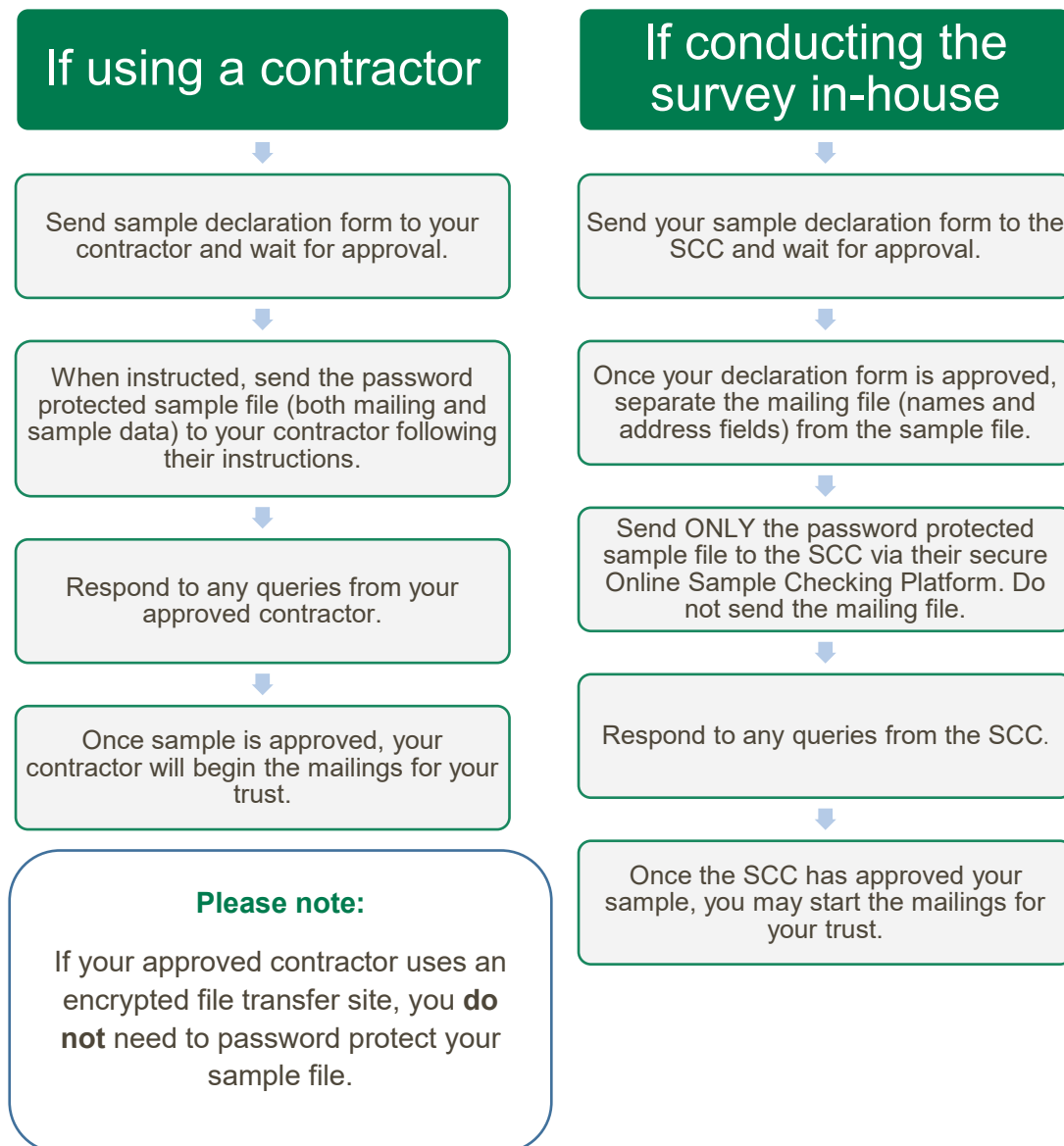
- As your mailing file will only be used occasionally during the survey, we recommend you keep this file encrypted.
- For patient confidentiality reasons, you are asked **not** to keep patients' name and address details **except the postcode** in the same file as their survey response data.
- Your mailing file should be destroyed when the survey is complete, along with other files created for the survey (except for the survey response file).

### Example of a mailing file

Record Number	NHS number	Initials or first name	Surname	Address1	Address2	Address3	Address4	Address5	Postcode	Mobile number	Trust code	Mobile number indicator	Day of birth
CYP26R TE00001	1234567 890	AM	Abbot	14 Station Road	London				E5	0781234 5634	RTE	1	01
CYP26R TE00002	1234567 890	EC	Ahmed	Flat 7	Short Street	Oxford			OX1 1SL	0781234 5698	RTE	1	02
CYP26R TE00003	123456 7890	K	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Camb	CB1 0AP	0781234 5656	RTE	1	03
CYP26R TE00339	123456 7890	F	Young	634 Tyne Road	Newcastle -Upon- Tyne	Tyne and Wear			NE7 011			0	04

## Step 17: Submit your sample – for in-house Trusts and Trusts using a contractor

After submitting your sample declaration form and **once receiving confirmation** from the SCC (for in-house trusts) or the approved contractor (for trusts using an approved contractor) you will be able to submit the sample, following the process described in the chart below.




## Section 5: Questions?

For any questions, please contact the Survey Coordination Centre based at Picker at [cyp@surveycoordination.com](mailto:cyp@surveycoordination.com)

## Appendix:

### Glossary of terms

<b>Terms</b>	<b>Definitions</b>
Central online tool	Online survey platform that allows patients to complete the questionnaire online.
Eligible patient list	List of patients that meet the survey eligibility criteria.
Final sample file	The output of CYP26 Sampling workbook 2, constructed using filtered data from CYP26 Sampling workbook 1.
In-house trusts	Trusts that do not employ a contractor and will submit the final sample file to SCC by themselves.
Sample declaration form	Workbook sent to contractor or SCC (for in-house trusts), utilised to check the sample has been drawn correctly before it is submitted by the trust.
Sample file	Initial sample file with eligible patients, compiled in Sampling workbook 1, tab 2.
Sampling workbook 1	An excel workbook which trusts use to prepare the survey sample information.
Sampling workbook 2	An excel workbook which is used by trusts to prepare the final sample to a contractor using their own online survey tool.
Sampling workbook 2 for central online survey tool	An excel workbook which is used by trusts to prepare the final sample to contractor or SCC (for in-house trusts). Used only by those using the SCC central online survey tool.
Survey version	Information calculated automatically in Sampling workbook 1, tab 2, between survey versions A (0-7s), B (8-11s) and C (12-15s). The survey version sent to each patient is based on their age at the very end of the sampling period.
Trace request file	File compiled from the list of eligible patients, to be sent for DBS check. The file includes either 'patient NHS number and full date of birth', or 'surname, first name, date of birth and postcode'.



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