SAMPLING INSTRUCTIONS

CHILDREN AND YOUNG PEOPLE'S

PATIENT EXPERIENCE SURVEY 2020

Last updated: 20th January 2021

Contents

1. 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 for Existing Methods (SCCEM).** 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 for Existing Methods 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.

2. Updates

Before you start work on your survey, check that you have the **latest version** of the sampling instructions (the date of the last update is on the front page). This document is available from the Survey Coordination Centre for Existing Methods website.

Did you know?

Throughout this document, there are links to detailed information on the topics covered in this manual.

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 to look at additional useful information.

You can also find the Survey Handbook for this survey on our website.

For detailed instructions and templates that are specific for this survey please go to the 2020 Children and Young People's Patient Experience Survey webpage.

For definitions of terminology used in this document, please refer to our universal glossary for the NPSP.

Sampling and data use

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 SCCEM 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 2020 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.

3. What's new for 2020?

Sampling period extension

Overall, the sampling procedure for the Children and Young People's Patient Experience Survey 2020 has remained the same as for the 2018 Survey. However, we are asking trusts to sample patients from January 2021, as well as December and November 2020. In addition, there are some additional sampling variables required and an attribution file to be submitted to SCCEM during fieldwork.

The 2020 Children and Young People's Patient Experience Survey sampling period has been extended to run from **November 2020 to January 2021**. This decision has been made to counteract the negative impact of drops in admissions due to COVID-19. When compiling your patient sample, **ALL TRUSTS** must include eligible patients from November, December and January.

As a result of this extension of the sampling period, we are asking **ALL TRUSTS** to **display dissent posters throughout the months of November, December <u>and</u> January**. It is important that dissent posters are displayed at your trust throughout these months, failure to do so is a breach of Section 251 approval conditions.

Full postcode

This year you will need to include the patient's full postcode within the sample file to be sent to the SCCEM. Receiving postcode information will enable the SCCEM to map respondents' postcodes to the Lower Layer Super Output Areas (LSOA). This mapping will in turn enable us to examine whether there is a link between level of deprivation (through the Index of Multiple Deprivation Index) and experiences of care.

Mobile phone indicator

Over the past few years, a number of methodological pilots undertaken across the wider NHS Patient Survey Programme (NPSP) have looked at ways of increasing response rates and encouraging feedback from those groups that tend to be 'harder to reach'. We have explored different ways of inviting people to take part and different modes for completing the survey (such as online). Sending SMS invitation and SMS reminders to patients has been identified as a factor contributing to improved response rate. Although we are not adopting this approach for the CYP survey yet, we are seeking to monitor the availability of patient phone numbers across surveys in the programme. Therefore, we are asking trusts to provide an additional sample variable this year: mobile phone indicator. This is a numeric indicator that will tell us whether a trust has a mobile number on record for the parent/carer of each sampled patient. **It is important to note that we are not asking you to provide mobile phone numbers**. More information on the format of this variable is included in section 5.

COVID-19 diagnosis

The coronavirus (COVID-19) pandemic has significantly impacted services provided by the NHS. Although research suggests that children and young people are less affected by the disease, and relatively small numbers of children and young people have been admitted to hospital due to COVID-19, children and young people's hospital services are one of many services that have been affected by the pandemic.

To understand if experiences of children and young people with confirmed or suspected COVID-19 differs from other children and young people, a COVID-19 diagnosis variable is to be added to all sample files provided by NHS trusts (or as part of a separate attribution file if the trust has clinical coding delays). Please see section 5 for more information.

Treated as a suspected or confirmed COVID-19 case

This is to be added to all sample files provided by NHS trusts (or as part of a separate attribution file if the trust is experiencing clinical coding delays). Combined with the COVID-19 diagnosis variable (above), collecting this information will allow CQC and the SCCEM to examine whether the experiences of children and young people with confirmed or suspected COVID-19 differ from other children and young people (e.g. interactions and communication with staff, parent involvement, suitability of the care environment including the availability of play facilities). This data will provide valuable information for local and national efforts to improve the experiences and outcomes of this important group during the evolving coronavirus pandemic. Please see section 5 for more information.

4. How to draw a sample of patients

Instructions on the following pages show the sequential steps that you must follow to draw your sample. Trusts are not permitted to submit any files to the SCCEM 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 for Existing Methods](#) **immediately** as alternative sampling materials are required.

National Data Opt-out Programme

The national data opt-out service, launched on the 25th 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 **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 2020 Children and Young People's Patient Experience Survey.**

Patient sample process

1. Compile a full list of patients using the CYP20 Sampling workbook 1

2. Send the list to the Demographics Batch Service (DBS) to check for deceased patients and remove deceased patients from your list.

3. Undertake checks to ensure no sampling errors have occurred.

4. Sort and label your eligible patient list in CYP20 Sampling workbook 1, Tab 1

5. Create the sample in CYP20 Sampling workbook 1, Tab 2 and save the file

6. Create your final sample file in CYP20 Sampling workbook 2 and save the file

7. Referring to your saved copies of CYP20 Sampling workbook 1 and CYP20 Sampling workbook 2, complete the 'Figures' tab of the Sample Declaration Form

8. Complete and submit your Sample Declaration Form

9. Complete and submit COVID-19 Attribution File (should the trust not be able to submit this data with the Sample Workbook)

If you are using a contractor

o When instructed, send a single sample file (mailing and sample data) to your contractor via a secure file transfer system.

o Please liaise with your contractor about the requirements for transfer and details on how to do so.

If you are conducting the survey in-house

o Separate the mailing data (names & full addresses) from the sample data (pseudonymised data including postcodes).

o When instructed, send the sample file (sample data only) to the SCCEM via a secure file transfer system. Please contact SCCEM for details.

5. 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.

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 for Existing Methods.

Compile a full list of patients using **CYP20 Sampling workbook 1**

1) From the NHS Surveys website, download '**CYP20 Sampling Workbook 1**' template

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 2020** and **31st January 2021**, 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) and fulfil all other eligibility criteria. Please see the data dictionary website for a list of admission method codes.

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 (further details in 'Obstetrics/maternity service user' section)

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 **CYP20 Sampling workbook 1, Tab 1**' section.

Include the following information:

When you put your data into '**CYP20 Sampling workbook 1', tab 1 'Full list'**, 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 = 1, female = 2, not known = 0, not specified = 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 Ethnic Category Code 2001 of the NHS Data Model and Dictionary.

    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. Ethnicity 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 15/11/2020 and the discharge date was 16/11/2020, 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) specified by the NHS data dictionary main speciality codes.

o **Treatment Function Code on discharge** specified by the NHS data dictionary treatment function codes.

o **CCG code** as found in the downloadable NHS digital organisations list. This should be the CCG which will be billed for the care of the patient. Please see:

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** specified by NHS data dictionary admission methods.

o NHS Site Code on admission

o NHS Site Code on discharge

o Mobile phone number indicator

o COVID-19 diagnosis

o Treated as a suspected or confirmed COVID-19 case (derived from trust locally held records)

Details and recommended coding strategies for the three new requirements this year — mobile phone number indicator, COVID-19 diagnosis and Treated as a suspected or confirmed COVID-19 case (derived from trust locally held records) — are provided below.

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.

Three new variables to be included in the CYP20 Sampling Workbook 1

Mobile phone number indicator

To create this variable you will need to check whether a mobile phone number is recorded for a patient and assign one of the following codes to indicate mobile phone status. This should be coded in numeric form: 0 = do not have mobile phone number of parent/carer of patient, 1 = have mobile phone number for parent/carer of patient, 9 = unsure, 99 = unable to identify whether contact details recorded are parent's/carer's or child's. If there is no mobile number, or there is a telephone number present but you suspect it is a landline, code as 0.

COVID-19 diagnosis

SCCEM and CQC recommend that the COVID-19 diagnosis is derived from ICD-10 codes. Please note that we are not requesting the transfer of ICD-10 data to either the SCCEM or approved contractors as part of the sample file. NHS Trusts will use the ICD-10 information they have on a patient's records to create the COVID-19 diagnosis variable.

The sample variable COVID-19 Diagnosis should be coded from ICD-10 codes as follows:

Category	ICD-10 codes
1 = COVID-19 positive confirmed via testing	U07.1 means COVID-19 virus identified (and treated as COVID-19).
2 = COVID-19 suspected but testing inconclusive	U07.2 means COVID-19 virus not identified (but treated as if they have COVID-19).
3 = COVID-19 testing status unknown	Trust has no record of whether patient was tested, and neither U07.1 or U07.2 is coded.
4 = COVID-19 negative confirmed via testing	Trust has a record of the patient being tested, but neither U07.1 (positive) or U07.2 (suspected) is coded.
5 = COVID-19 not suspected, not tested	Trust knows that the patient was not tested, and neither U07.1 (positive) or U07.2 (suspected) is coded.

Some trusts may have upgraded to using ICD-11 codes. The sample variable COVID-19 Diagnosis should be coded from ICD-11 codes as follows:

Category	ICD-11 codes
1 = COVID-19 positive confirmed via testing	RA01.0 means COVID-19 virus identified (and treated as COVID-19).
2 = COVID-19 suspected but testing inconclusive	RA01.1 means COVID-19 virus not identified (but treated as if they have COVID-19).
3 = COVID-19 testing status unknown	Trust has no record of whether patient was tested, and neither RA01.0 or RA01.1 is coded.
4 = COVID-19 negative confirmed via testing	Trust has a record of the patient being tested, but neither RA01.0 (positive) or RA01.1 (suspected) is coded.
5 = COVID-19 not suspected, not tested	Trust knows that the patient was not tested, and neither RA01.0 (positive) or RA01.1 (suspected) is coded.

Treated as a suspected or confirmed COVID-19 case (derived from trust locally held records)

1= Treated as confirmed or suspected COVID-19

2= Treated as non COVID-19

3= Status unknown

The 'Treated as a suspected or confirmed COVID-19 case' variable aims to capture potential scenarios in which people had a negative test (or were not tested) but were assumed to have COVID-19 and treated as such due to symptoms. Some overlap is anticipated with the COVID-19 diagnosis variable, but we hope this will also capture some cases of COVID-19 that the diagnosis variable does not. Please look into the feasibility of using locally held records. If this isn't possible, you can derive from ICD-10 codes if that's what is most appropriate. Please submit both variables.

The table on the next page provides the suggested mapping for deriving the COVID-19 treatment variable from the COVID-19 testing variable:

COVID-19 testing variable	COVID-19 treatment variable
1 = COVID-19 positive confirmed via testing	1 = Treated as confirmed or suspected COVID-19
2 = COVID-19 suspected but testing inconclusive	1 = Treated as confirmed or suspected COVID-19
3 = COVID-19 testing status unknown	3 = Status unknown
4 = COVID-19 negative confirmed via testing	The mapping of this can vary. For example, there may be a scenario in which a patient was "treated" as COVID-19 until test results were received. If this is indicated through local records, please code as "1 = Treated as confirmed or suspected COVID-19". If every patient is being tested by the NHS trust, a COVID-19 testing variable "4 = COVID-19 negative confirmed via testing" could map to COVID-19 treatment variable "2 = Treated as non-COVID-19". If it is unknown, please code as "3 = Status unknown"
5 = COVID-19 not-suspected, not tested	2 = Treated as non-COVID-19

Important: The two COVID-19 variables (COVID-19 diagnosis and Treated as a suspected or confirmed COVID-19 case) can be submitted as part of the CYP20 Sampling workbook or can be submitted separately to the SSCEM directly as a COVID-19 Attribution File. This will allow trusts to meet sample provision deadlines.

The COVID-19 Attribution file will contain the following variables:

- o Trust code
- o Patient Record Number (PRN)
- o COVID-19 diagnosis derived variable
- o COVID-19 treatment variable

The COVID-19 Attribution File should be submitted through the SCCEM secure transfer site by **9th July 2021**. Please contact the SCCEM for details on how to access the secure transfer site.

6. Removing duplicates in CYP20 **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 months; 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 4 – please **ensure you are not selecting the three header rows**. Click on the data menu, then click 'sort'. Select to sort by column A (NHS Number), then click ok.

   PLEASE ENSURE THAT YOU TICK THE BOX 'MY DATA HAS HEADERS'

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 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) 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.

7. 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.

Patient in sample period

Check that all patients were discharged in the sample period of the full months of November 2020, December 2020 and January 2021.

January included in sampling

Check that you have included eligible patients from **January 2021,** as well as November and December 2020.

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. **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 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 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).

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.

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

After you have complied a list of eligible patients from <u>November, December and January</u> discharges, the list will need to be checked for any deaths by the DBS. This is **fundamentally important** and must happen before you create the final sample file. There are several checks you need to carry out on your list of eligible patients before and after your sample has been approved:

o Once you draw your sample of eligible patients, this list must be locally checked for deceased patients, **and** it must be submitted for DBS (Demographics Batch Service) checks. This is to check for any patients who may have died during or since attending your department.

o Before mailing one, trusts should also carry out local and DBS checks if it has been 2 weeks or more since DBS checks were done prior to sample submission and the date for mailing one.

o Before mailing two and three, a local check **must** be conducted for patients. We also strongly recommend conducting an additional DBS check before mailing three.

DBS & local checks requirements	
Before mailing 1	Local AND DBS checks if it has been 2 weeks or more since DBS checks prior to sample submission and mailing 1
Before mailing 2	Local checks and optional DBS checks
Before mailing 3	Local checks AND strongly recommended DBS checks

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

Steps for checking for deceased patients

1) Trust to conduct initial checks for deceased patients (local checks).
2) DBS to check for deceased patients.
3) Trust create a trace request file.
4) Trust submit the trace request file.
5) Trust receive a response 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.

- 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.

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

9. Sorting and labelling your eligible patient list in **CYP20 Sampling workbook 1, Tab 1**

Once you have compiled and checked your full eligible patient list in 'CYP20 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 '**CYP20 Sampling workbook 1**', tab 1 **'Full list'**, 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 4 (first data row)</u>. Please **ensure you are not starting on row 1, row 2 (first header row) or row 3 (second header 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. As shown in the image below – please sort on 'values' and order 'smallest to largest'. Please also ensure that the 'My data has headers' box is ticked.

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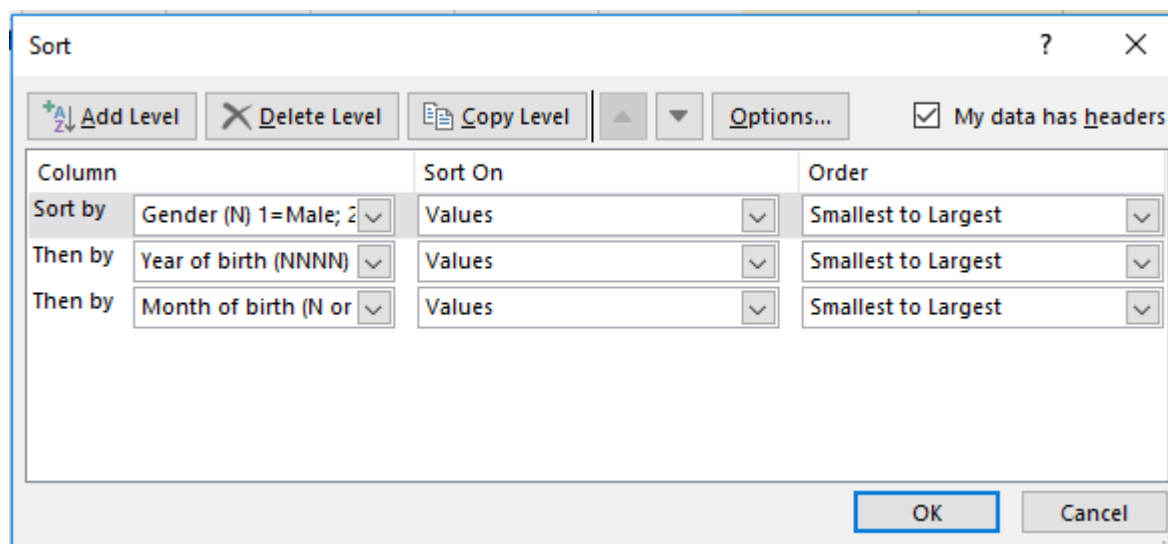
Please note: it is vital that you **select all your data (all columns and rows) except for the rows 1, 2 and 3 before sorting**, as otherwise the file can become miss-sorted. If the data are miss-sorted, this could result in a major sampling error, which could invalidate your sample or your survey data.

2) Now add a **record number** in column K. The record number should be in the following format: CYP20XXXNNNN where "CYP20" is the survey code, "XXX" is your trust code, and "NNNN" is the number. Please ensure you add record numbers at this point only, prior to creating your sample.

At this stage, record numbers will run consecutively from CYP20XXX0001 to CYP20XXXNNNN, 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.

10. Creating the sample in CYP20 **Sampling workbook 1, Tab 2**

Once your data is sorted correctly and you have added record numbers, you need to use 'CYP20 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 'CYP20 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 'CYP20 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 AH and AI, 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

Number in list	
Survey version A (0-7s):	1788
Survey version B (8-11s):	353
Survey version C (12-15s):	451
Ineligible dates:	0

Number in sample	
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 (0-7) as 1788, Survey version B (8-11's) as 353 and Survey version C (12-15s) as 451

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

EXAMPLE

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

In column A the image states 'In sample? (1 if included in sample, 0 if not)', the data entries are 0. Column B is titled as 'survey version' and shows 'ineligible' in row 1.

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 2004 and January 2021.
- o All discharge dates are in November and December 2020 or January 2021.
- 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 for Existing Methods on 01865 208127.**

3) Now you need to enter a random start number in the boxes in column AJ 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). The text in columns AH and AI 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 AJ). (If the red text says to enter a number 'between 1 and 1', you must enter the number 1 in the box).

EXAMPLE

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

Please allow time for Microsoft Excel to finish processing after you enter a number in each of the 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'.

In column A titled 'In sample? (1 if included in sample, 0 if not)' each row shows the number 1 or 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

5) The "Number in sample" section, columns AI (rows 16-19), 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 AH-AI 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: if have 824 in the 'number in list' section (column AI, row 10) rather than 450 for version A (0-7s), 583 in the 'number in list' section (column AI, row 11) rather than 400 for version B (8-11s) and 649 in the 'number in list' section (column AI, row 12) rather than 400 for version C (12-15s). In this instance do not include the total sample, only the correct numbers for each version.

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 (column AI, rows 16-18) will match the 'number in list' section (column AI, rows 10-12). For example: if you have 516 in the 'number in list' section (column AI, row 10) rather than 450 for version A (0-7s), 269 in the 'number in list' section (column AI, row 11) rather than 400 for version B (8-11s) and 141 in the 'number in list' section (column AI, row 12) rather than 400 for version C (12-15s). As the total sample is only 926 rather than 1250 – the total sample should be included.

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: if have 229 in the 'number in list' section (column AI, row 10) rather than 450 for version A (0-7s), 285 in the 'number in list' section (column AI, row 11) rather than 400 for version B (8-11s) and 1108 in the 'number in list' section (column AI, row 11) rather than 400 for version C (12-15s). As the total sample is 1622 rather than 1250 the 'number in sample' (Column AI, rows 16-20) will be automatically calculated as 229 for version A (0-7s), 285 for version B (8-11s) and 736 for version C (12-15s).

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 **'CYP20 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.

11. Creating your final sample file in **CYP20 Sampling workbook 2**

1) Download '**CYP20 Sampling workbook 2**' from the NHS surveys website.

2) Returning to the previously completed **'CYP20 Sampling workbook 1'**, in tab '2**. Sample selection**', 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.
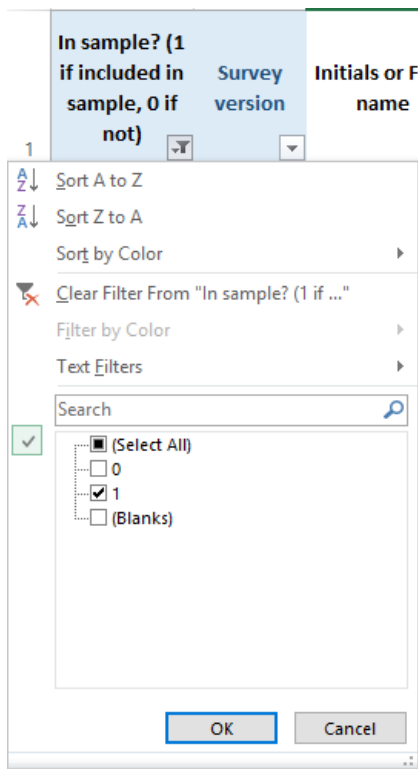
3) **With the filter still on**, select all data from **column B "Survey version"** through to column **AG "COVID-19 Suspected/Confirmed"** (but do not select the header rows 1 or 2), right click, and press copy. **Please ensure you select your entire sample (all records with a '1' in column A).**

4) Now paste this data into the corresponding columns (A to AF) in the tab named "Sample" of **CYP20 Sampling workbook 2**. There are two sample tabs. One is for trusts using a contractor and is title 'Sample for Contractor'. The second sample tab is for trusts conducting the survey in-house and is titled 'Sample In-house for SCCEM'.

5) Check that the number of records you have pasted into the tab named "Sample for Contractor" if using a contractor, or 'Sample In-house for SCCEM' if conducting survey in-house, of **CYP20 Sampling workbook 2** matches the total number of records in your sample indicated in **CYP20 Sampling workbook 1,** tab '2. Sample Selection' in the 'Number in sample' section (the total sample size is in cell AI 19).

Please note: the column titles are in the first row, so the total number of records in the CYP20 Sampling workbook 2 'sample for Contractor'/ 'Sample In-house for SCCEM' tab will be the number of rows minus 2.

6) **Save the workbook as 'CYP20_< trust code >_sample'**

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

12. 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 20/03/21.

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

8= Easy Read completed questionnaire

9= Braille completed questionnaire

10= Large print completed questionnaire

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. See sample workbook on page 31.

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 name and full address details (but it should contain patient's postcode).

In reference to Table 1 below, your Sample File should **only** include data from columns A, and I-AF.

Remove the data in columns B-H before submitting your file.

The data in columns AG-AK will be completed by your trust during fieldwork.

If you are using a contractor…

You will submit **one sample file** to your contractor. In reference to Table 1 below, your sample file should **only** include data for columns A-AF.

The data in columns AG-AK will be completed by your contractor during fieldwork.

Table 1. Sample CYP20 Workbook

A	B	C	D	E-G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z	AA	AB	AC	AD	AE	AF	AG	AH	AI	AJ	AK
Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Submit to Contractor	Completed by Contractor	Completed by Contractor	Completed by Contractor	Completed by Contractor	Submit to Contractor
Survey version	Initials or First name	Surname	Address 1	-	Address 5	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 Specialty of consultant on discharge	Treatment function code	CCG Code	Treatment centre admission	Admission method	NHS Site Code on admission	NHS Site Code on discharge	Mobile Phone Number Indicator	COVID-19 Diagnosis	COVID-19 Suspected/Confirmed	Day of questionnaire being received	Month of questionnaire being received	Year of questionnaire being received	Outcome	Comments
A	A	Smith	-	-		AB2 2XX	R1X	CYP20R1X2655	1	2019	1	A	11	11	2020	11	11	2020	0	120	220	10Q	1	11	RR115	RR115	0	5	3					
A	E	Ahmed	-	-		AB1 7IL	R1X	CYP20R1V67	1	2018	2	J	20	12	2020	22	12	2020	2	101	215	10Q	1	22	RTE03	RTE03	0	1	1					
A	K	Yoo	-	-		AB7 3VX	R1X	CYP20R1X2623	3	2016	2	R	7	1	2021	12	1	2021	5	115	220	10Q	0	11	RTE03	RTE03	99	5	3					
A																																		

*Please note this table is for illustration purposes only. CYP20 workbook 2 appearance may vary from that shown above.

Column A: This column contains the survey version assigned in 'Sampling workbook 1'.

Columns B-H, AK: these columns contain information on patients' names, addresses and comments that may allow them to be identified (note that column I is both sample and mailing data. For in-house trusts, you must include column I in your sample file to the SCCEM but not columns B-H)

Columns I-AF: 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 (note that column I is both sample and mailing data).

Columns AG-AJ: 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.*

13. 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 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.

January admission and discharge dates

You should also check that your sample contains admissions and discharge dates in January 2021. As the sample period has been extended for CYP20 there should be admission and discharge dates across November and December 2020 and January 2021.

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, not known = 0, not specified = 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 1st November 2020 and 31st January 2021).

> **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.

14. Complete and submit the Sample Declaration Form

Once your sample has been drawn, you must complete the Sample Declaration Form.

1) Complete the 'Figures' tab by referring to your saved copy of CYP20 Sampling workbook 1, taking the requested figures from cells AI10-AI19 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.**

Submit the sample declaration form

If you are using a contractor…	**If you are an in-house trust…**
Submit your Sample Declaration Form to your contractor.	Submit your Sample Declaration Form to the SCCEM.
Your contractor will let you know how and when to submit your sample to them.	Separate your mailing and sample information.
Your contractor will then submit your sample to the SCCEM on your behalf.	The SCCEM will let you know how and when to submit your sample information once the sample declaration form has been approved.

For in-house trusts only

At this point you should transfer the names, and full address (note that postcode is included in the sample file) 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 **CYP20_MailingData_XXX** were XXX is your Trust code. **Do not submit this file to the Survey Coordination Centre for Existing Methods.**

You will use this file to:

1) Check for deceased patients prior to reminder mailings.

2) Cross-reference it with the sample file (**CYP20_SampleFile_XXX**) to identify patients who will need to be sent reminders.

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 patients' name and address details in the same file as their survey response data (apart from patients' postcode which is included as part of the sample file).** 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).

15. Submit your sample

After submitting your sample declaration form and **once receiving confirmation** from the SCCEM (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.

If using a contractor

⬇

Send sample declaration form to your contractor and wait for approval.

⬇

When instructed, send the password protected sample file (both mailing and sample data) to your contractor via their secure transfer site.

⬇

Respond to any queries from your approved contractor.

⬇

Once sample is approved, your contractor will begin the mailings for your trust.

Please note:

If your approved contractor uses an encrypted file transfer site, you **do not** need to password protect your sample file.

If conducting the survey in-house

⬇

Send your sample declaration form to the SCCEM and wait for approval.

⬇

Once your declaration form is approved, separate the mailing file (names and full address fields) from the sample file. NOTE: postcode is to be included in the sample file.

⬇

Send ONLY the password protected, sample file to the SCCEM via their secure transfer site. Do not send the mailing file.

⬇

Respond to any queries from the SCCEM.

⬇

Once the SCCEM has approved your sample, you may start the mailings for your trust.

16. Submit your COVID-19 Attribution file

If you were unable to include the COVID-19 variables (COVID-19 diagnosis and Treated as a suspected or confirmed COVID-19 case) at the time of drawing your sample these can be submitted separately to the SCCEM as a COVID-19 Attribution File. This will allow trusts to meet sample provision deadlines if you are experiencing clinical coding delays needed to create the COVID-19 related variables.

The COVID-19 Attribution file contains the following fields:

- o Trust code
- o Patient Record Number (PRN)
- o COVID-19 diagnosis derived variable
- o COVID-19 treatment variable

It should be submitted through the SCCEM secure file transfer site by **9th July 2021**. Please contact the SCCEM for details on how to access the secure transfer site.