

National Neonatal Care Experience Survey

Sampling Instructions 2025

The National Neonatal Care Experience Survey is run by Picker on behalf of NHS
England

Contacts

For information or advice about compiling and submitting your patient list, please contact the National Neonatal Care Experience Survey project team:

E-mail: Neonatal.Survey@pickereurope.ac.uk

Phone: **01865 208 159** or **01865 208 152**.

Contents

1	Introduction.....	4
2	Compiling the sample list.....	4
2.1	Inclusion/exclusion criteria	4
2.2	Checking your patient list.....	6
2.3	Creating the patient list spreadsheet.....	6
2.4	Checks to carry out	10
3	Sample Declaration Form.....	10
4	Data Checking Process	11
4.1	Stage 1 – Sample Declaration Form	11
4.2	Stage 2 – Detailed data checks.....	11
4.3	Stage 3 – Batching and national deduplication	11
4.4	Stage 4 – DBS and final validation checks.....	12
5	Frequently Asked Questions	13

Adherence to the procedures in this document

It is essential that the sampling is carried out according to the agreed protocol set out in this instruction manual. Non-compliance could compromise the comparability of the survey results. If you have any problems or queries about compiling your patient list or following the guidance, please contact the National Neonatal Care Experience Survey project team at Neonatal.Survey@pickereurope.ac.uk

1 Introduction

This survey of neonatal care experience is being managed by Picker on behalf of NHS England. The purpose of collecting and analysing data via this survey is to:

- Measure perceptions, expectations, and experiences of neonatal care.
- Understand variation and inequalities in experiences of care across sub-groups, for example by age, ethnicity, or deprivation levels.
- Enable analysis and benchmarking of results.

The survey gives parents the opportunity to give feedback on their experiences of their baby's / babies' neonatal care. Note: although there are sections for the mother and other parent to complete separately in the questionnaire, we are only collecting sample information relating to the mother and the baby / babies.

2 Compiling the sample list

Please follow the instructions in this manual carefully, step-by-step and allocate sufficient work time to compile and check the patient list. It is important that the person drawing the sample is given sufficient time and support by their manager to do this properly. Errors may result in the wrong people being surveyed, invalid survey data being collected, or the exclusion of survey results from analysis, benchmarking and publication. **We strongly advise that you read all of this document BEFORE you start to compile your patient list.**

Please refer to the **Sample Spreadsheet** where there is an 'Example' tab, and to the **Sample Declaration Form** which contains a list of checks.

The information you obtain about each baby and mother will be used by Picker both for administering the survey and for sending to the Demographics Batch Service (DBS) to check for deceased babies and mothers.

Note: BadgerNet is used at all NHS trusts and may have information available that is otherwise missing on other patient administration systems. If there are any gaps once you have compiled your sample, please refer to BadgerNet to fill in any missing information as far as possible.

2.1 Inclusion/exclusion criteria

Use the **Sample Spreadsheet** to compile your sample. There are two tabs: an 'Example' tab which shows how the data should be presented, and a 'Sample' tab which should be used to compile the sample for your trust.

You will need to compile a list of all babies discharged alive from the neonatal unit(s) at your trust up to and including: **1st June 2025 to 31st August 2025**. The list will also need to include details of the baby's mother.

Duplicate babies

- The patient list must include **all eligible discharges**, rather than a list of babies, so some babies will appear on the list more than once.
- It is very important you **do not** remove duplicate babies, as this could bias your sample. Duplicate babies will be removed at a later stage by Picker.

Who to include in the list:

- All babies (and their mothers) discharged alive from a neonatal unit (to home or to a general ward) who had stayed in the unit for 24 hours or longer.
- Babies discharged from **all neonatal units** (i.e. all levels of care) in your trust, including:
 - Special Care Baby Units (SCBU), or level 1 care;
 - High Dependency Units (HDU) / Local Neonatal Unit (LNU), or level 2 care;
 - Neonatal Intensive Care Units (NICU), or level 3 care.
- Babies **transferred to a neonatal unit at a different NHS Trust**.
- For multiple births, include details of each baby who was admitted to a neonatal unit on separate rows¹ in your spreadsheet.
- A baby may have had multiple admissions to, and discharges from, neonatal units at your Trust. Please include each of them on separate rows in your Sample Spreadsheet (along with all the other associated mother / baby sample information). Use the same PRN in all rows relating to that mother and baby (refer to the 'Example' tab in the **Sample Spreadsheet**).
- Include babies even if their addresses are incomplete but still useable (e.g. no postcode).

Who to exclude from the list:

- Mothers who have requested their or their baby's / babies' details are not included in the survey. This includes those that have informed your trust, in response to communications about the National Neonatal Care Experience Survey, that they do not wish to be included in the survey. Trusts need to have a mechanism in place to record people who opt out of the survey in response to seeing dissent posters. PALS team and survey lead to check.
- Babies that stayed in the unit for **less than 1 day**.
- Babies that only received '**Transitional care**' and were not admitted to a neonatal unit (i.e. care provided for babies who need some medical treatment but who are well enough to be cared for at their mother's bedside in the maternity area of the hospital).
- Babies whose mother is aged **under 16 years old** at the time the sample is drawn.
- Babies that have died since discharge from neonatal care. Any associated babies from multiple births linked to deceased babies should also be removed.

¹ Details for each baby are required for deceased checks using the Demographic Batch Service (DBS).

- Mothers who have died since discharge.
- Where known, babies taken into care (i.e. foster care, adopted).
- Mothers / babies without a UK postal address.
- Mothers / babies with not enough address information to have a reasonable chance of the questionnaire being delivered (e.g., keep in those with address 1 and postcode; complete address without a postcode; address without city or county details but with postcode).

National Data Opt-out Programme

The National Neonatal Care Experience Survey is exempt from the National Data Opt-out meaning that these **should not be applied** to your survey sample. Therefore, to be included in your sample, mothers do not have to actively consent to the sharing of their or their baby's / babies' data. More information on the survey's exemption can be found [here](#).

2.2 Checking your patient list

Once you have compiled your list, **check** that you have correctly followed each of the points in section 2.1 above. This is a very important step and will save a lot of time because Picker will likely have fewer queries if you are sure your list is correct.

Errors in putting together the patient list can result in:

- Picker having to raise queries which need to be resolved at a rapid pace? prior to mailing.
- The wrong people being surveyed.
- Invalid survey data being collected.
- The exclusion of survey results from analysis, benchmarking and publication.

2.3 Creating the patient list spreadsheet

Provided alongside this guidance is a patient list template spreadsheet.

Please use this for entering data for your patient list and rename it as **NHSTrustCode_NEO25.xlsx** where 'NHSTrustCode' is the code of your trust. Full instructions on how to do this and how to transfer the data securely will be sent through to you separately via email.

The spreadsheet contains all the data fields required, details of which are as follows:

- **Trust code** – the ODS 3-digit code for your trust eg RTH
- **Personal Reference Number** – the unique serial number allocated to each mother by the trust for the purposes of this survey (eg NEO25RTH0001). This is comprised of the survey code (NEO25), your trust code (eg RTH), and a 4-digit number starting with 0001 (002, 0003 etc). Do not include hyphens, spaces, underscores etc. **Note: for multiple births, each baby admitted to a neonatal unit and the associated mother should be included on separate rows, but allocated the same PRN.**

- **Mother's NHS Number** – verified and belonging to that individual. Ensure as much as possible that this is populated as it will be used for DBS checks
- **Mother's Forename**
- **Mother's Surname**
- **Address Fields** – the address should be held as separate fields (e.g., street, area, town, and county). You must use the most *current* address on your system
- **Postcode**
- **Mobile phone number, if available.**
 - This should be the current mobile phone number listed on your PAS, either an 11-digit number starting with '07' or a 12-digit number starting with '+44 7'. If it is possible to check this, do not include any home or landline phone numbers.
 - **Eligible mothers should be included in the sample whether or not they have a mobile phone number.**
 - The only cases in which you should not provide a mobile number is if the mother has explicitly dissented to the use of their mobile number.
 - **If the mobile number listed on your system is specified as belonging to someone other than the mother, this should not be included.** However, if a “work mobile” is included on their records this is fine to include, and if nothing is specified alongside the number it's fine to assume this belongs to the mother.
 - Where a mobile phone is listed in the mobile telephone field and a different mobile phone number listed in the telephone field, please prioritise the 'mobile' column. If you have any records where the mobile field is blank, and the telephone number field is populated with a mobile number, please include this.
- **Mother's Date of Birth** in text format (YYYYMMDD). This needs to be the **FULL** date of birth to ensure DBS checks can be carried out on the sample before any mailings
- **Mother's Ethnic Group** – The ethnicity of a person as specified by that person, and should be coded using the [17-item alphabetical coding specified by NHS England](#). The code “Z” (not stated) should be used if a patient was asked for their ethnic category but refused to provide it. If this code is missing for **any other reason**, ethnic category should be left blank in the sample information. The 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
- **Number of babies born** from mother's recent birth experience (single = 1, twins = 2 etc)
- **Baby NHS Number** – verified and belonging to that individual. Ensure as much as possible that this is populated as it will be used for DBS checks
- **Baby Forename**
- **Baby Surname**
- **Baby Date of Birth** in text format (YYYYMMDD). This needs to be the **FULL** date of birth to ensure DBS checks can be carried out on the sample before any mailings
- **Gestational age at delivery** this should be indicated as numbers of weeks
- **Baby Day of Admission** to the Neonatal Unit (1 or 2 digits, e.g., 7 or 26)
- **Baby Month of Admission** to the Neonatal Unit
 - 1 = January
 - 2 = February
 - 3 = March
 - 4 = April
 - 5 = May
 - 6 = June
 - 7 = July
 - 8 = August
 - 9 = September
 - 10 = October
 - 11 = November
 - 12 = December
- **Baby Year of Admission** to the Neonatal Unit (4 digits, e.g., 2025)
- **Baby Day of Discharge** from the Neonatal Unit (1 or 2 digits, e.g., 2 or 30)
- **Baby Month of Discharge** from the Neonatal Unit
 - 6 = June
 - 7 = July
 - 8 = August
- **Baby Year of Discharge** from the Neonatal Unit (4 digits, i.e., 2025)
- **Baby Length of stay** in the Neonatal Unit (to the nearest whole day): Units = Days.
 - Calculate this by subtracting the admission date (day/month/year) from the discharge date (day/month/year). For example, if discharge date = 15/7/2025 and admission date = 14/7/2025, 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).
 - All babies in the sample should have a length of stay greater than or equal to 1 day.
 - A baby may have been admitted to and discharged from neonatal units multiple times within your Trust. Please record each occasion on separate rows in your sample and calculate the length of stay for each

admission / discharge pairing separately – please refer to the ‘Example’ tab in the **Sample Spreadsheet**.

- **Neonatal Unit Name** (i.e. text variable e.g. Oxford Newborn Care Unit)
- **Site code** – record the 5 character hospital organisation code where the baby was treated, as [specified by NHS England](#). Please include codes for any private sites **as long as the baby was registered as an NHS patient**. Exclude any babies seen privately if they were not registered as NHS patients.
- **Site name** – record the hospital site name where the baby was treated if the site code is unavailable.
- **Type of neonatal unit/level of care** (This is the level of care of the unit, not the baby)
 - 1 = Special care; such as special care baby units (SCBU, SCU) or low dependency units
 - 2 = High dependency units (HDU) or local neonatal units (LNU)
 - 3 = Intensive care, Neonatal intensive care units (NICU)
- **Code of where baby admitted to the unit from** should be coded as follows:
 - If the baby was admitted from another hospital, use the five character [NHS site code](#) related to that hospital
 - If the baby was born on the maternity ward at your hospital trust, then the admission site code will be that of your hospital.
 - If the baby was admitted from home, code as ‘ZZ201’
 - If the baby was admitted from other non-NHS location, code as ‘ZZ888’
 - If the baby was admitted from an unknown location, code as ‘ZZ203’
- **Transfer**
 - If a baby was transferred from your Trust to another NHS Trust, keep them in your sample, but add codes as follows:
 - Baby transferred to another trust = 1
 - Baby not transferred = 0

Remember

Do NOT remove duplicates for babies who have had more than one discharge within the sampling period. Picker will remove duplicates before sending out questionnaires.

2.4 Checks to carry out

Once you have compiled your list of babies/mothers, you should carry out the following checks before you send the list to the DBS to carry out a further check for deceased women or babies

- **Deceased mothers or babies:** Check that all women and their babies were discharged from the trust alive and that the trust does not have a record of either person's death from a subsequent admission or visit to the hospital. This is an essential step to ensure that women and/or their families are not further traumatised by receiving a questionnaire asking about their neonatal experiences. If you do find a case where either person has died, please delete this person from the sample
- **Women's ages:** Check that all women are **aged 16 or over** at the time when you draw the sample
- **Length of Stay:** Babies should have stayed on the ward for at least **1 (day)**
- **Babies taken into care:** Where possible, exclude any women who are known to have had their baby taken into care.
- **Incomplete information.** Check for any records with incomplete information on key fields (such as surname and address) and remove those women and their baby/babies. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a woman if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. The more cases that are removed at this stage, the poorer the sample coverage and the greater the risk of bias.

If you have any questions regarding the sampling process, please email the project team at Neonatal.Survey@pickereurope.ac.uk

3 Sample Declaration Form

The person compiling the list of mothers and babies must complete and sign the **Sample Declaration Form**. This is a requirement of the survey's Section 251 approval and is a key element to minimise the risk of any data breaches occurring.

The form must be completed and sent to Picker prior to submitting your sample or mothers and babies. You will receive a notification when you are permitted to submit your Sample Spreadsheet.

4 Data Checking Process

In this section we have provided an outline of the various stages involved in the data checking process. This is to provide an insight into what happens to the sample list after it has been uploaded to Picker and to explain the timeframe between the point at which patient lists are uploaded and the first mailing is sent out to patients.

4.1 Stage 1 – Sample Declaration Form

The first task that needs to be completed before we can receive your **Sample Spreadsheet** is for you to submit a **Sample Declaration Form**. This provides confirmation that the trust has completed all required checks and validation of the sample, which is designed to minimise errors, data breaches and data queries.

Once the form has been received, the information provided is checked and approved by Picker, who then provide confirmation to the trust that they are able to proceed with securely uploading their patient list.

If the **Sample Declaration Form** is not received or if there is a need to query anything relating to the form, this can delay the data upload and checking process.

4.2 Stage 2 – Detailed data checks

Once you have submitted your sample declaration form and this has been approved, you will be provided with access to the Picker secure online **Sample Checking Platform**. The platform will conduct a number of automatic checks on the sample, some of which you will need to address before Picker can approve your sample. The data then goes through a multistage checking process.

This includes:

- Data validation to ensure that all eligible babies (and their mothers) have been included and all non-eligible babies (and their mothers) have been excluded
- Checks to ensure that information provided regarding each baby and mother is complete and that no information is missing i.e., valid address information.

Once the data checks have been completed, Picker will raise any queries and confirmation points directly with the trust. In some cases, where errors are identified, trusts will be required to compile a new sample, which would be subject to the same checking process described above.

Once all queries and confirmation points have been resolved with the trust, the sample can be approved for the next stage.

4.3 Stage 3 – Batching and national deduplication

To prepare for mail out, Picker will start by batching all final samples together into a combined sample to undertake duplicate checks across all trusts. This is a necessary step, as babies may appear have been admitted to multiple trusts as part of their treatment pathway and, therefore, appear in multiple samples.

We can only undertake this process when we have received and approved samples from all participating trusts, as conducting this on smaller batches would result in inconsistencies in terms of how mothers and babies are removed. This is minimised

by undertaking the national deduplication process at the point when all samples have been received, checked, and approved.

It is therefore important that trusts upload their patient list to Picker as quickly as possible and respond to any data queries **within 2 working days** to ensure this process can begin promptly.

4.4 Stage 4 – DBS and final validation checks

Once duplicates have been removed from the amalgamated file, this is submitted to DBS for tracing to identify any babies or mothers who are deceased. Any babies or mother identified as deceased are removed from the sample to ensure questionnaires are not sent out.

We also undertake further final name and address checks by cross checking the results in the DBS trace file with the original file submitted. We also remove any babies or mothers who could not be traced (no NHS number) and update any blank NHS numbers that have been traced successfully. We then complete an additional DBS trace on the updated amalgamated data to confirm that all babies and mothers in the updated file are traced successfully.

Once this has been completed, the amalgamated file is ready to be used to prepare mailing packs for send out. Surveys will be mailed within 24 hours of completion of the process for running and applying deceased checks. If the mailing process takes longer than 24 hours, deceased checks will be repeated to ensure records remain up to date.

5 Frequently Asked Questions

Question	Answer
If mothers opt out nationally (to all patient experience surveys), does this apply to this survey?	<p>No. The National Neonatal Care Experience Survey is exempt from the National Data Opt-Out Programme. This means that even if someone has opted out via the national data opt-out, they should still be included in this survey.</p> <p>However, if someone has indicated through seeing survey communications that they do not want to take part in this particular survey, then please exclude them from the sample.</p>
If a mother contacts Picker to opt-out, would Picker make them aware that this only opts them out of the Neonatal 2025 survey and that they would need to contact the trust to be opted out of other surveys?	Yes, Picker has guidance for call and email handlers to instruct people that they would only be opted out of this year's Neonatal survey and would need to contact the trust in order to be opted out of wider surveys.
Who should sign the Data Sharing Agreement (DSA)?	The DSA should be signed by whoever you consider most appropriate for it in the trust. This could be the survey lead, Caldicott Guardian or Chief Executive, for instance.
Will you need Caldicott Guardian clearance for the declaration form from our trust or will the Data Sharing Agreement cover this?	No, the Caldicott Guardian is not required to sign off on the declaration form. The transfer of data from your trust to Picker will be covered from the Data Sharing Agreement.
Will Picker be requesting local deceased checks before each mailing?	No. You are required to do a local check for deceased patients only before submitting your initial patient list to Picker. Picker will be doing DBS checks before each mailing. However, if a trust wishes to do local checks before subsequent mailings, then this is definitely welcomed. The mailing dates will be sent out once they are confirmed, alongside deadlines for local deceased checks.
Can we include mothers who live in Northern Ireland, Scotland, and Wales?	Yes. If patients meet all other eligibility criteria, then they should be included. However, if they are without a UK address then they should be excluded.
When babies / mothers appear on more than one trust list will they get multiple questionnaires? How will you	No. Each mother will only get one questionnaire. Once we have a full list of mothers and babies, we will remove duplicates, keeping the record with the most recent discharge date.

choose which trust is on the questionnaire to the mother?	Mothers (and other parents) will therefore be asked to think about the hospital and unit from which their baby was most recently discharged (referenced in the survey invite).
Should we include mothers and babies without an NHS number?	Yes. As long as they meet all other eligibility criteria they should be included.
We don't have mobile phone numbers for everyone, is that OK?	Yes. Please provide the data that you do have as it will help us understand the % of records in the sample that do have this information. People without mobile phone numbers will still be able to take part as there will be postal invites.
We collect phone numbers but don't know if it is a mobile number or a home telephone number, should we still include this information?	Yes. If it is possible to check that numbers are mobile not landline then please do so. This should be either an 11-digit number starting with '07' or a 12-digit number starting with '+44 7'. However, please don't let this delay submission of your patient list. If you are unable to carry out this check, please send us all numbers.
Are there provisions for people whose first language isn't English?	Yes. Patients have the option to complete the questionnaire using a translation service offered by our freephone provider. The online questionnaire will be made available in nine languages other than English.
When will the Neonatal 2025 results be published?	Publication is expected in summer 2026.