

2025 Neonatal Care Experience Survey – sampling webinar for trusts

The presentation will start shortly!

Agenda

- Background
- Sampling process and support materials
- Inclusion & exclusion criteria
- Submitting your sample list
- Picker's role / your role
- FAQ
- Any questions?



Background

Overview, impact and importance

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 where possible.
- Enable analysis and benchmarking on various levels of granularity including where possible by Trust, Integrated Care System, Operational Delivery Network (ODN), region and national level.

Data from the survey will enable a greater understanding of neonatal care experience, providing data to enable quality improvements locally and nationally.

Methodology

- Trusts will be asked to submit a sample of babies who have received neonatal care, and details of their mothers to send out the survey invite, and for analysis.
- The questionnaire will be completed by the mother, with a short section at the end for the other parent to complete (though we do not ask for identifying details in the sample information or ask them any demographic questions).
- The survey is using a strong push to web approach with potential respondents initially sent a postal invite followed shortly after by a reminder SMS, this is repeated before a paper questionnaire is sent out and a final reminder SMS to any non-responders (up to six invites in total).

Section 251 requirements



We now have full approval under Section 251 for the survey from the Health Research Authority's Confidentiality Advisory Group (**CAG**) and the Secretary of State for Health.

Approval is necessary as it means that the common law duty of confidentiality has been lifted **to allow confidential patient information to be disclosed for the purpose of carrying out the survey.**

Trust Section 251 requirements



Requirements:

- Trusts must not submit any additional data variables than the ones requested from Picker.
- Trusts must ensure they have removed mothers that have specifically opted out from this survey (having seen a dissent poster).
- Trusts should submit their sample list using Picker's secure site (on the Sample Checking Platform) only.

Picker Section 251 requirements



- Keep mother and baby information confidential at all times and comply with data protection legislation.
- Check for deceased mothers and babies before each mailing by submitting the list to DBS and subsequently removing these records from any future mailings / SMS invites.
- Remove mothers that opt out via the Freephone line, by email or by returning a blank questionnaire.
- Check all free-text comments for any safeguarding concerns and escalate as necessary.
- Securely delete identifiable information 12 months after publication of all survey results.

National data opt-out programme

The National Data Opt-out Programme is a service that allows people to opt out of their confidential information being used for research and planning.

The Neonatal Care Experience Survey is **exempt** from the National Data Opt-out.

All eligible mothers, and their babies, are to be included in the list unless they have requested their details are not used following sight of survey pre-publicity (e.g. the survey's dissent posters).

Sampling process and support materials

Sampling process - trusts



- Display dissent posters. Keep a record of any mothers who dissent to participate.



- Compile a list of eligible mothers and babies



- Perform checks on the sample



- Remove deceased mothers and babies from your sample by submitting to the Demographic Batch Service (DBS) or equivalent



- Complete the Sample Declaration Form and send it to Picker via neonatal.survey@pickereurope.ac.uk



- When you receive confirmation that the declaration form is approved, submit your sample via the Sample Checking Platform



- Be available for up to two weeks after data submission to respond to any queries on your sample

Guidance materials

Dissent posters



Help us improve neonatal care for everyone

If your baby has been admitted to a neonatal unit at this NHS trust you may soon be asked to take part in NHS England's National Neonatal Care Experience Survey. The survey helps us monitor what's working well and how neonatal care services could be improved, both locally and nationally. Your feedback will help shape NHS neonatal care for others in the future.

All eligible parents or guardians of babies who were discharged from neonatal care in June, July or August 2025 will be contacted to take part in the survey.

Taking part in the survey is voluntary and all answers are confidential.

If you are invited to take part, you may be contacted by letter or SMS and sent reminders. If you are invited, we will use your personal details to send you a letter by post or a text message to your phone explaining how to take part. We will only use your details to carry out the survey. These details will be provided by this NHS trust. Your personal information will be handled securely and confidentially. We will not publish any information which might identify you.



If you do not want to take part, you do not have to give a reason. To opt out, or if you have any questions about the survey, please contact this NHS trust [space for trust to insert contact details, please include telephone number and email address]

The survey will be carried out by Picker on behalf of NHS England. We have applied to an independent oversight group which includes members of the public, to provide support for confidential patient information to be accessed to identify and invite people to respond to this survey.

NHS England will be applying to the Department of Health and Social Care for exemption from the National Data Opt Out for this survey. For further information visit <https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out>. If exemption is granted, you might be invited to take part in the survey.



Dissent posters (available in English and 24 other languages) were sent out in May 2025.

It is a Section 251 requirement to display these materials during the sampling frame of June, July & August 2025.

Mothers will also have the opportunity to opt out through calling our helpline or sending back a blank questionnaire.

Mothers who opt out should be recorded and removed from your patient list **before submitting to Picker.**

There is a space on the Sample Declaration Form to record the number of people who dissented from the survey.

Guidance materials

Sample List Spreadsheet

	A	B	C	D	E	F	G	H	I	J	K	L
1	The ODS 3-digit code for your Trust, e.g. RA0	The unique serial number allocated to each mother by the trust (e.g. NEO25RTH0001). This is composed of the survey code (NEO25), followed by your trust code (e.g. RTH), followed by a four digit number starting with 0001 (e.g. 0001, 0002, etc.). Do not include hyphens, spaces, underscores, etc.	Verified and belonging to the mother. Ensure as much as possible that this is populated as it will be used for DBS checks.	First name of mother	Last name of mother	First line of the mother's UK address	Second line of the mother's UK address	Third line of the mother's UK address	Fourth line of the mother's UK address	Fifth line of the mother's UK address	Mother's postcode	Mother's mobile phone number
2	Trust code	Personal Reference Number (PRN)	NHS number	Forename	Surname	Address 1	Address 2	Address 3	Address 4	Address 5	Postcode	Mobile phone number
3												

Sample Declaration Form

A	B	C	D
<h3>2025 Neonatal Care Experience Survey: Sample Declaration Form</h3> 			
<p>This declaration is to be signed off by the member of staff responsible for drawing and checking the patient list, as set out in the Sampling Instructions.</p> <p>This checklist will be used for audit purposes to ensure that the patient list conforms to the instructions. If all steps are completed it will help to avoid any breaches of confidentiality.</p> <p>Once your sample declaration form has been approved you will be asked to submit this to the Picker Sample Checking Platform. Instructions will be sent by email to explaining how to do this.</p>			
<p>How to complete this declaration:</p> <p>Checklist: Please confirm that the checks on the 'Checklist' tab have been completed on behalf of your NHS trust by inserting a '✓' or 'NA' in the boxes adjacent to the check listed.</p> <p>Entering an NA: If an 'NA' is inserted to any of the checks, a comment will be expected from the trust, explaining why this check is not applicable. This will avoid</p>			

Guidance materials

Sample Checking Platform User Guide

Gives instructions for uploading your sample list to the online checking platform at Picker



Online Sample Checking Platform - User Guide and FAQs for the Neonatal Care Experience Survey 2025

Contents

Online Sample Checking Platform - User Guide and FAQs for the Neonatal Care Experience Survey 2025	1
Login	1
Welcome page	2
Uploading a file	3
Query resolution page.....	5
Completing query verification.....	7
Downloading detailed historic comparison tables	8
Uploading a revised file	10

Data Sharing Agreement

Agreement between NHSE and your Trust for the sharing of patient data

THIS AGREEMENT is made on DATE 2025	
1	Between: NHS England ("NHS England") and [Insert NHS Trust name and address] ("The Trust")
2	Definitions See Appendix 1
3	Purpose and objectives of the information sharing: The National Neonatal Care Experience Survey 2025 and the National Neonatal Care Experience Survey 2026 will be carried out to help the NHS monitor and improve the quality of neonatal services so that they better meet patient needs. The Trust has agreed to provide the data items (listed in section 7 of this document) with NHS England (for Picker to process) for the purposes of the National Neonatal Care Experience Survey 2025 and the National Neonatal Care Experience Survey 2026.

Inclusion and exclusion criteria

Eligibility criteria – Who to include



- Babies - and their mothers aged 16 or above at the time of drawing the sample – who were discharged alive from neonatal care at your Trust during the period 1st June to 31st August 2025.
- The list should include all eligible discharges. Some babies may appear on the list more than once. Keep these in your list, Picker will remove these when samples from all trusts have been approved.
- Babies must have stayed on the unit for 1 day or longer.
- All types of neonatal unit are included:
 - Special Care Baby Unit (SCBU) - Level 1 care;
 - High Dependency Unit (HDU) / Local Neonatal Unit (LNU) - Level 2 care;
 - Neonatal Intensive Care Unit (NICU) - Level 3 care.
- Babies transferred to a neonatal unit at another hospital.

Eligibility criteria – Multiple births



- For multiple births, each baby who received neonatal care should be included. Each baby from a multiple birth is on a separate row in the spreadsheet and the same Personal Reference Number (PRN) is assigned to each, and to their mother.
- The mother and all babies from a multiple birth must be alive to be included.

Eligibility criteria – Contact info



- Mothers who are resident in the UK and whose address is incomplete but contains enough information to have a reasonable chance of being delivered should be included, e.g.:
 - Keep in those with address 1 and postcode;
 - ...complete address without a postcode;
 - ...address without city or county details but with a postcode.
- Eligible mothers should be included regardless of whether they have a mobile phone number on record or not.
- Mothers who have explicitly dissented to the use of their mobile phone number being used should be kept in the sample, but the mobile number should be removed.
- Where there is a mobile phone number listed but it is not the mother's, the mother should still be included in the sample, but the mobile phone number removed.

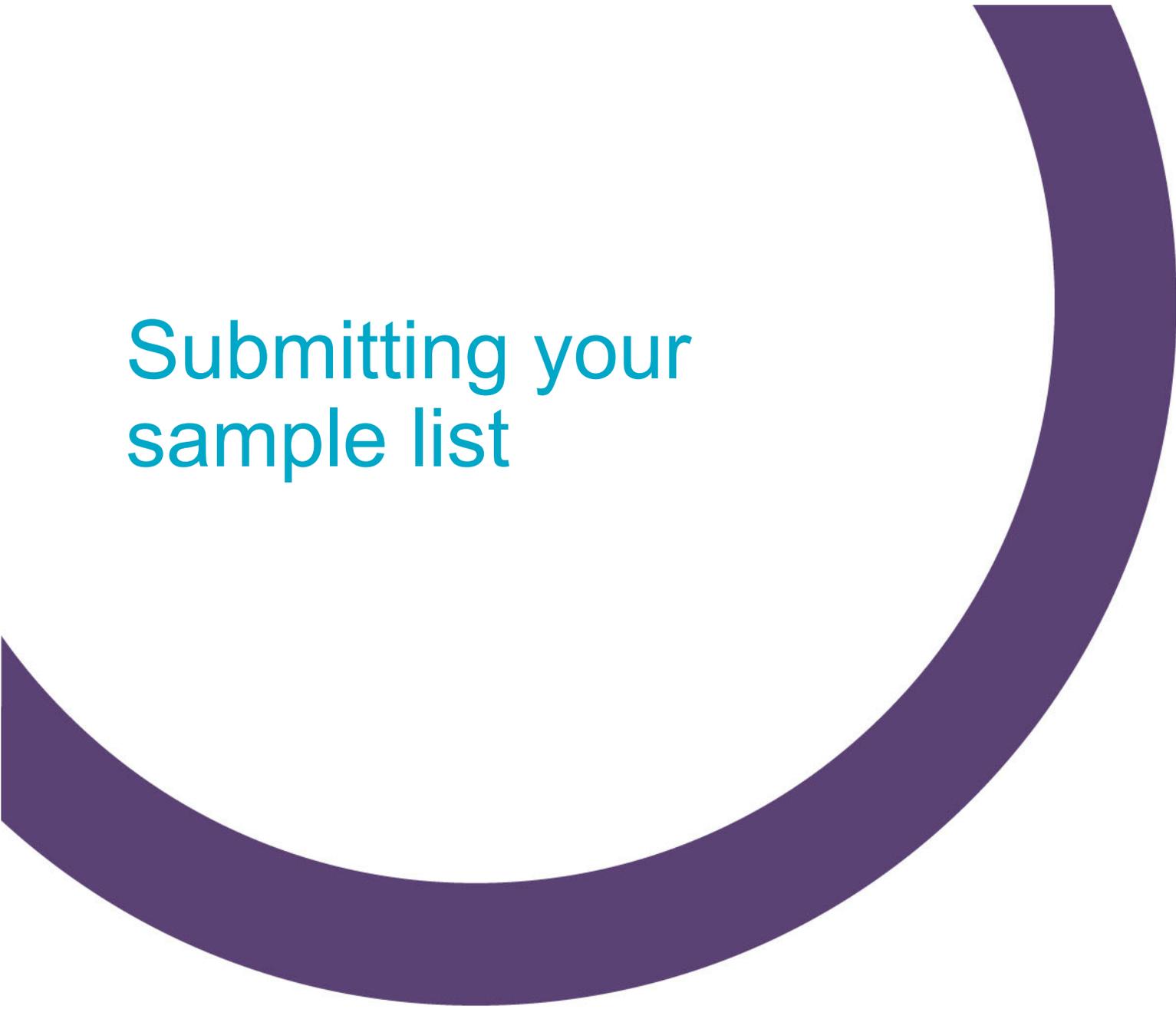
Eligibility criteria – Who to exclude



- Mothers aged under 16 – and the associated babies - at the time of drawing the sample.
- Babies that stayed on the unit for less than 1 day.
- Babies that only received transitional care (i.e. care that is administered at the mother's bedside in the maternity area of the hospital) and were not admitted to a neonatal unit.
- Babies who have since been taken into care.
- Mothers that have informed your trust, in response to communications about the survey including the dissent poster, that they do not wish to be included in the survey.

Implications of sampling errors

- The online sample checker and Picker staff check that sample lists have been drawn correctly according to the sampling criteria. This is to aid you in avoiding common errors prior to fieldwork commencing.
- They are also flagged to you in order to help you avoid errors in future iterations of the survey.
- It is important that errors are identified as they can lead to delays in the survey process and/or poor data quality.
- Depending on the nature of the error, it may not be possible to provide historical data comparisons during the reporting stage of the survey in future years.



Submitting your sample list

Submitting your Sample List

- Make sure you have the relevant permissions to share the data by completing and submitting the Data Sharing Agreement. We will email trusts with a hyperlink where they can fill in the details of the person at their Trust to sign the agreement.
- When your sample list is ready, please complete the Sample Declaration Form (to confirm the sample has been drawn following the guidance with the necessary checks), and email the form to neonatal.survey@pickereurope.ac.uk
- Once your forms have been received and checked, you will be emailed details of how to access Picker's online sample checker platform <https://samplechecker.picker.org/>

Sample Declaration Form

B

C

Declaration by trust staff compiling the patient list

I understand that any errors with the way the patient list has been compiled may limit, or prevent, the use of the survey data. Where data cannot be used, this would mean this trust's results would be excluded in 2025.

I confirm that the steps outlined within the *Checklist* tab have been completed and that the patient list has been compiled in accordance with the **Sampling Instructions**.

I will be required to amend or update the patient list if any errors or deviations are identified during the checks conducted by Picker.

I confirm that if I am unavailable or unable to submit the patient list or to respond promptly to Picker queries regarding the patient list, someone from the trust will be allocated to cover this task in my absence.

Trust name

Contact name

Contact email address

Contact phone number

Date sample signed off by sample drawer

ATTENTION! You have not completed all the fields in the 'Checklist' tab

Sample Declaration Form

Purpose – to ensure all necessary checks have been completed as per the Sampling Instructions and so Picker know who to contact for any queries.

The member of staff responsible for compiling and checking the sample list must complete the Sample Declaration Form and send to Picker before submitting their sample list.

To complete the declaration form:

- Complete each check in the checklist
- Provide an explanation for any 'NA' entered for a check
- Sign and date the declaration form

Sample Declaration Form

Dissenting patients check

How many dissenting patients were removed?

Enter a number in the check box (if none were removed, please record as 0).

This should **not** include those who have opted out of having their data used for planning and research purposes via the National Data Opt-out Programme.

1

Dissenting patients check



This should only include patients that have informed your trust, in response to communications about the survey, that they do not wish to be included.

Continue?

Yes

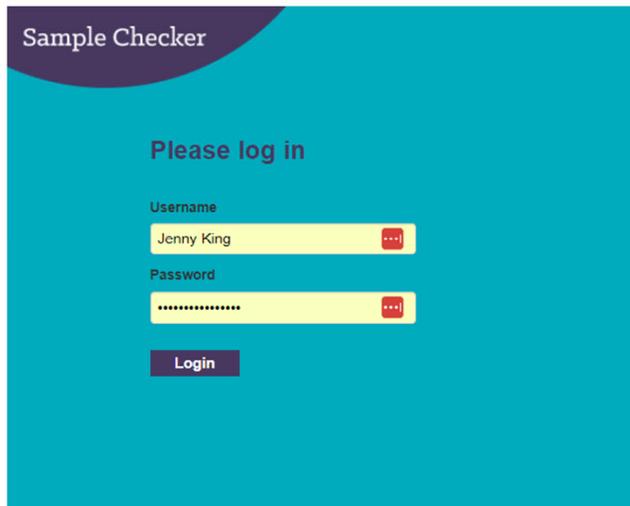
No

Cancel

Help

Submitting your patient list

<https://samplechecker.picker.org/>



Sample Checker

Please log in

Username
Jenny King

Password

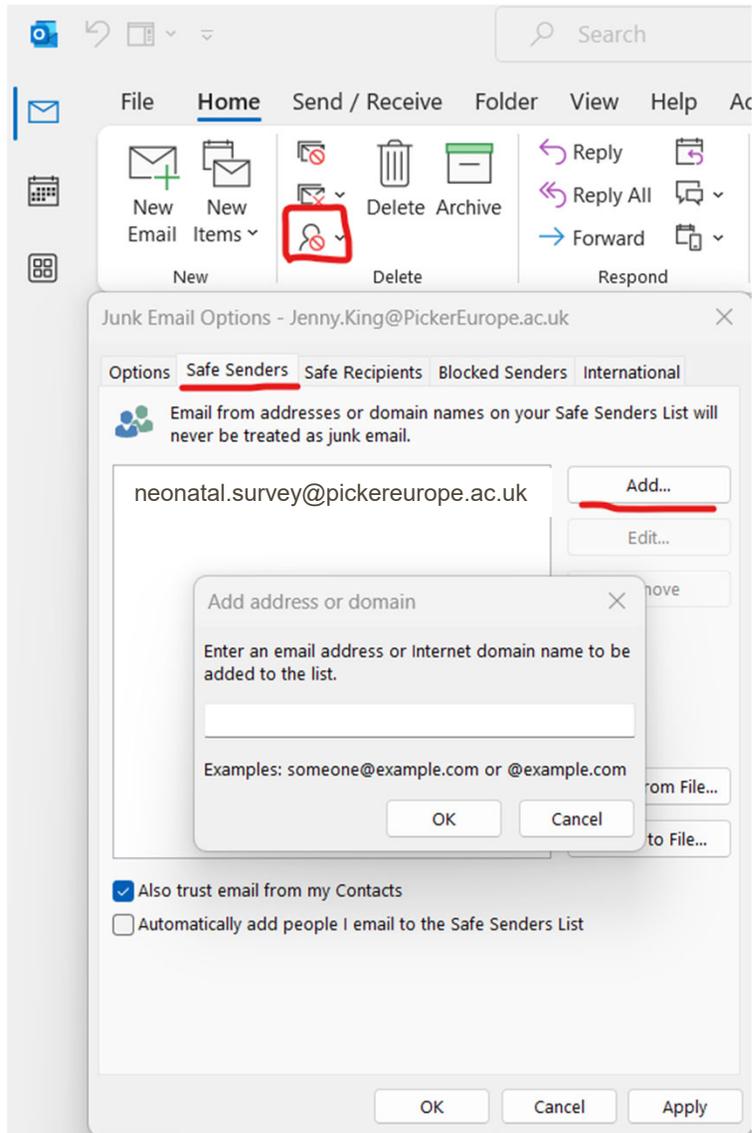
Login

Submitting your patient list

TYPES OF QUERY:

- **Error** – to resolve these issues you will need to upload a revised sample file
- **Check** – queries that may or may not be an error. To resolve you will need to provide an explanation or upload a revised file
- **Notice** – provides an overview of the information in the sample, no action needed

Safe Sender List



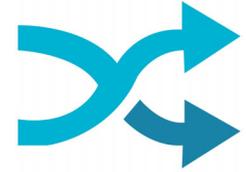
- Remember to add the Picker email address to your safe sender list!
- This is so that Picker emails don't go to junk, and you don't miss important communications regarding your sample and survey fieldwork

Neonatal.survey@pickereurope.ac.uk

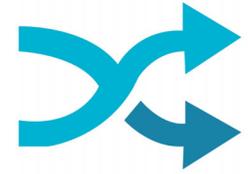


Picker's role / your role

Picker's role



- Send trusts the Data Sharing Agreement.
- Support trusts in submitting as early as possible with any queries or issues they have over the sampling criteria.
- Provide trusts with the link and log-in information for submitting their Sample List.
- Check each Sample List within 4 working days.
- Follow up on unresolved queries within 2 working days.



Picker's role

- Create a file of all trusts' records after all samples have been approved.
- Remove all duplicates, retaining the record with the latest discharge date and submit to DBS.
- Post the questionnaires/invite letters and SMS reminder mailings, and host online survey versions.
- Provide and host a Freephone helpline number and email address for potential respondents.
- Capture all data returned from respondents.
- Conduct analysis on final data and produce reports.

Your role



Survey leads:

- Ensure Data Sharing Agreement is signed.
- Ensure Picker have up-to-date contacts for your trust.
- Confirm cover letter information (signatory and logo).
- During fieldwork – inform Picker of any mothers that contact the Trust directly, wanting to opt-out of the survey.

Data team members:

- Compile your Sample List using the template spreadsheet.
- Complete the Sample Declaration Form.
- Submit your Sample List as soon as possible.
- Respond to Picker queries within 2 working days.
- Ensure Picker are given any necessary contacts for planned leave cover.

FAQ

FAQ

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 (such as from having seen the dissent poster) that they do not want to take part, 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?	<p>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.</p>

FAQ

Question	Answer
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 welcome. The mailing dates will be sent out once they are confirmed, alongside deadlines for local deceased checks.

FAQ

Question	Answer
When babies / mothers appear on more than one Trust list will they get multiple questionnaires? How will you choose which Trust is on the questionnaire to the mother?	<p>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.</p> <p>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).</p>
Should we include mothers and babies without an NHS number?	<p>Yes. As long as they meet all other eligibility criteria they should be included.</p> <p>If NHS numbers can't be found when Picker runs the DBS checks, we will remove these records from the sample.</p>
Can we include mothers who live in Northern Ireland, Scotland, and Wales?	<p>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.</p>

FAQ

Question	Answer
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 as part of our helpdesk service (available via Freephone and email). 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.

Any further questions?

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