

Newborn Blood Spot Screening

Movers-in with No Available Records

South West Best Practice Guide

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Document objective	To clarify the roles and responsibilities of all partners involved in the NBS mover in pathway (for registered and non-registered children).
Target audience	Health professionals working on this pathway including practitioners in maternity settings, CHIS, Health Visiting Teams, Newborn Bloodspot takers, and Newborn Screening labs.

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List of Abbreviations

CF	Cystic Fibrosis
CHIS	Child Health Information Service
DNA	Did Not Attend
DOB	Date of Birth
GP	General Practice / Practitioner
HV	Health Visitor
NBS	Newborn Blood Spot
NBSFS	Newborn Blood Spot Failsafe Solution
PCHR	Personal Child Health Record (Red Book)
WNB	Was Not Brought

Introduction and Aim of Guidance

The South West NHS England (NHSE) Vaccination and Screening Team is responsible for the commissioning and oversight of the Newborn Bloodspot Screening (NBS) programme. The programme pathway involves a wide range of partner agencies whose input and failsafe mechanisms are critical to safeguard children from missing screening and to ensure they are screened in a timely manner.

This guidance covers NHSE South West and aims to clarify the roles and responsibilities of all partners involved in the NBS mover in pathway (for registered and non-registered children). Local variation of practice across the region is recognised and work to address potential obstacles/delay in the pathway will need to be addressed.

All local provider practice should reflect the below guidance, which represents the best practice for this pathway and mirrors (and should be read in conjunction with) [national movers in screening babies with no available records guidance](#).

Key Principles

- All babies under a year of age should have documented NBS results/declines **for all 9 conditions** on the local Child Health Information System (CHIS).
- Only results documented in English are accepted (this includes translations).
- If a baby **under a year of age** does not have all results recorded on the CHIS, screening should be offered for the untested conditions. The offer can only be made up to the child's first birthday and the sample should be taken **no later than 14 calendar days** after the baby's first birthday. Babies are only eligible for Cystic Fibrosis (CF) screening up to 8 weeks of age.
- If a baby is not registered with a GP locally, they can still be referred for screening and should be encouraged to register as soon as possible.
- The laboratory will complete all screening processes even if the sample reaches the laboratory after the baby's first birthday or if a repeat is needed.

The national standard is that all 9 conclusive blood spot results should be recorded on the child health information system at less than or equal to 21 calendar days of the child health team being notified of the movement in.

Key Responsibilities

When results of NBS screening are not immediately available:

CHIS will:

- On the day of notification of movement in, check with previous CHIS for results.
- If a baby was born in England, check the NBS failsafe solution (NBSFS) to see if the baby has a record and which screening laboratory tested the sample.
- If no results are available, email letter / referral documentation (**see Appendix 1 for minimum data fields required**) for NBS as per local arrangements to health visitor requesting urgent follow up with family. Referral email (if sending referral documentation as an attachment) should contain the following minimum fields to ensure that screeners are aware of urgency:
 - Reason for email
 - Name of child
 - DOB / current age of child
 - Contact number / address
 - Deadline for NBS result to be recorded on the system
- Follow up as per local agreement (three times as a minimum) with health visitor that offer/referral has been made where appropriate and child has been screened (unless parent/carer declined). Ensure health visitor attempts are recorded in the child's CHIS record.
- Record outcomes of follow up/referral (NBS result, decline or no contact with family). Timely uploading of NBS results is essential.
- If a parent/carer declines an offer of bloodspot screen, send parent/carer 'decline' letter and copy in GP and health visitor (HV). [Declined newborn blood spot screening: template letters - GOV.UK \(www.gov.uk\)](#)
- Inform the lab of any declines. Please note that if the parents decline screening, the lab should also receive a completed blood spot card with 'decline' written on the card as per the national guidance found [here](#). In some areas this may be done by the HV and in other areas by CHIS.

- If no result 8 weeks after moving in, send parent/carer 'no result recorded' letter copying in the GP and HV.
- The infant should remain on a CHIS mover-in with no result list until an outcome is confirmed.
- If no result recorded at 12 months of age send GP letter notifying no NBS result recorded.

Health visitor will:

- Within 2 working days of receipt of letter from CHIS, contact the child's parent/carer to check for any NBS results (these should be in child's Personal Child Health Record (PCHR)).
- Make at least three attempts to contact the baby's parent/carer as a matter of urgency (considering the 21-day target). Up to two of these contacts can be a phone call or text, but if there is no response then face to face contact should be attempted. Ensure parents are aware of the importance of timely booking of appointments to meet the 21-day target.
- If NBS result available, inform CHIS of the date and all results of screening. If screening was done, results must be in English (translations acceptable).
- If no NBS result available or fewer conditions screened for than UK standard tests, offer screening.
- If the screening offer is accepted, refer the child to the local provider for NBS using the relevant documentation as per local arrangements. This referral should be made as quickly as possible and ideally within 2 working days.
- Learning from incidents suggests that there may be a benefit to peer review of completed blood spot cards and referral forms to ensure all information is correct to reduce possibility of avoidable repeats, being mindful of the tight 21-day turnaround target.
- Inform CHIS that the referral has been made.
- Track the referral and attendance to ensure that the child is brought to clinic and, if necessary, ensure that the provider has offered at least 2 appointments as per Trust DNA policy.
- Inform CHIS of appointment attended, or the number of appointments where child was not brought (WNB).

- If the child is not registered with a GP practice, contact CHIS to check if the previous bloodspot result is available. If no result is available, refer as per pathway and encourage the parent to register as a matter of urgency.
- If the parent/carer declines the NBS, a completed blood spot card should be sent to the lab with 'decline' written on the card as per the national guidance found [here](#). In some areas, HV also inform CHIS of decline, and this is considered best practice.
- Inform CHIS and use all opportunities up to 12 months of age to re-offer.

The newborn bloodspot screener (outpatient clinic or health visitor – depending on local area arrangements) will:

- In view of the 21-day pathway, make an urgent appointment to allow time for lab sample testing and results to be recorded on CHIS.
- Give special consideration for children under 8 weeks to ensure they can be tested for Cystic Fibrosis and for children approaching 12 months of age so that they are still eligible for screening.
- Take NBS sample, following the NBS [national sampling guidelines](#).
- Ensure that the card is within its expiry date.
- For all cards, ensure that **all the fields** are completed accurately and in BLOCK CAPITAL LETTERS.
- This includes the below fields which are essential / mandatory:
 - Child's name and address
 - Child's NHS number
 - Child's DOB
 - Parent/carer's name
 - Sample taker's details
 - GP practice (unless child is not registered)
 - Date of sample

- Check the completed blood spot card with the parents and make any necessary changes.
- Learning from incidents suggests that there may be a benefit to peer review of completed blood spot cards and referral forms to ensure all information is correct to reduce possibility of avoidable repeats being mindful of the tight 21-day turnaround target.
- Ensure a new blood spot card is used for each repeat sample.
- Send the sample on the same day to the appropriate NBS lab at Southmead Hospital, Bristol or Portsmouth lab at Queen Alexandra hospital, Portsmouth.
- Inform health visitor and CHIS of the date the sample was taken using contact details on referral form.
- If a child was not brought to a screening appointment, offer at least one further appointment for screening being mindful of the tight 21-day turnaround target.
- If the child was not brought to 2 appointments, inform CHIS and the HV using the contact details on the referral form.
- Follow guidance and resources to prevent avoidable repeats and further delays. (See resources on page 8 for links to guidance).

The newborn screening lab will:

- Test the NBS sample and report the results to the CHIS in line with national guidance and standards.

Useful Resources

<p>This guidance explains what is required of health professionals carrying out newborn blood spot (NBS) screening.</p>	<p>Newborn blood spot screening: programme handbook - GOV.UK (www.gov.uk)</p>
<p>Guidance and resources for health professionals and commissioners working in the NHS newborn blood spot (NBS) screening programme.</p>	<p>Newborn blood spot screening programme: supporting publications - GOV.UK (www.gov.uk)</p>
<p>Newborn blood spot (NBS) screening guidance for babies under a year of age with no available screening results.</p>	<p>Newborn blood spot screening: movers in with no available records - GOV.UK (www.gov.uk)</p>
<p>These documents explain how to take a newborn blood spot screening sample.</p>	<p>Newborn blood spot screening: sampling guidelines - GOV.UK (www.gov.uk)</p>
<p>Newborn blood spot screening sample quick reference guide</p>	<p>Newborn blood spot sampling guidelines: quick reference guide - GOV.UK (www.gov.uk)</p>
<p>New resources to help improve quality of samples taken in NHS newborn blood spot screening</p>	<p>New resources to help improve quality of samples taken in NHS newborn blood spot screening - PHE Screening (blog.gov.uk)</p>

Appendix 1 - Frequently Asked Questions:

1. Can patients moving in from outside of England receive screening free of charge?

Yes, when a mover-in from outside of England registers with a GP practice, from day one they are entitled to Primary Care including ANNB screening even if the procedure is carried out in Secondary Care.

2. What should happen with movers in who are less than 28 days old?

The same processes should be used for these as for infants aged 29 days and over.

3. Should generic email addresses be used for CHIS/ HV/ SIT/ SQAS/ Outpatients?

Generic emails are used by CHIS, SQAS and the Screening and Immunisation Team. Not all HV teams use generic email addresses and if this is the case, CHIS will endeavour to send notification of movers in to more than one email address. It is also essential that administrative staff monitoring generic email addresses are trained in the screening pathway to ensure they are aware of the appropriate action to take and the short timelines and need for urgent appointments to be given.

Appendix 2 - Standard Referral Form / Minimum Data Set

Reason for Referral	Recognition of 21-day deadline Ensure health visitors are aware that the sample needs to be taken with sufficient time before the deadline to allow for results to be feedback to CHIS
Date NBS result due	Dates eligible for screening / Timeframe in which to contact parents
Date moved in	Number of previous attempts to contact
Patient Name	Patient DOB
Patients age at referral	Patient NHS Number
Patient / Mother Address	
Patient / Mother Tel Number	Patient GP Practice / Code/ address
Mother's Full Name	Mother's NHS Number
Reason for repeat test	Name and contact details of health professional referring (PRINT)
Referral date	Health visitor contact
Ethnicity	Language needs
Accessibility needs	Other needs