

## Newborn Bloodspot Screening (NBBS)

This guidance does not override the individual responsibility of health professionals to make appropriate decision according to the circumstances of the individual patient in consultation with the patient and /or carer. Health care professionals must be prepared to justify any deviation from this guidance.

**Introduction**

This guideline applies to all newborn babies resident in the UK and those that move into the UK, up to the age of one year. All babies in this category should be offered blood spot screening. The screening test will be carried out at a designated laboratory, which is currently Birmingham Childrens Hospital (BCH).

**This guideline is for use by the following staff groups:**

All Maternity and neonatal staff providing counselling or undertaking the procedure for newborn blood spot test screening.

**Lead Clinician(s)**

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Lead Midwife

Approved by Maternity Governance Meeting on: 21<sup>st</sup> April 2023

Review Date: 21<sup>st</sup> April 2026

This is the most current document and should be used until a revised version is in place

**Key amendments to this guideline**

Date	Amendment	Approved by:
April 2023	Full Guideline review – addition of SCID testing	MGM

The NHS newborn blood spot (NBBS) screening programme helps identify several rare but serious diseases with a small blood sample. The UK National Screening Committee recommends that all babies in the UK are offered screening for Phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell disease (SCD), cystic fibrosis (CF), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), glutaric aciduria type 1 (GA1) homocystinuria (HCU), isovaleric acidaemia (IVA), maple syrup urine disease (MSUD).

**All babies should be screened by taking a dried blood on day 5 and only in exceptional circumstances day 5-8, regardless of milk feeding and gestation. For the purpose of screening, date of birth is day 0. Where babies are born at less than 32 weeks gestation, a repeat is required to be taken on day 28. One exception to this rule is if the baby has received a blood transfusion (red packed cells/fresh frozen plasma or platelets) then the sample must be taken 72hrs post completion of the transfusion but at the latest by day 8.**

### Objectives

The main objective of the screening programme is to ensure the early detection and referral of those babies found to be high risk. This is to improve their health and prevent severe disability or even death.

### Policy Scope

This guideline applies to all newborn babies resident in the UK and those that move into the UK, up to the age of one year. All babies in this category should be offered blood spot screening. The screening test will be carried out at a designated laboratory, which is currently Birmingham Childrens Hospital (BCH).

### SCID testing- Temporary Evaluation programme

In September 2021, Public Health England (PHE), the UK National Screening Committee (UK NSC) and NHS England and NHS Improvement (NHSEI) launched an evaluation of newborn blood spot screening for severe combined immunodeficiency (SCID) in England.

The evaluation will initially run for 2 years, covering around two-thirds of the newborn population of England. Screening will continue for a third year while the results from the evaluation are analysed. The UK NSC will then make a definitive recommendation about whether newborn screening for SCID should become part of the NHS Newborn Blood Spot (NBS) Screening Programme in England.

SCID is a group of rare conditions that affect the immune system and make it very hard for a baby to fight off common infections. Without treatment, babies with SCID usually die before they reach a year of age.

About 1 in 40,000 babies born in England has SCID (about 14 babies a year). About a third of these babies are diagnosed because another member of their family has SCID. The remainder are usually diagnosed when they become ill. This can mean they are exposed to potentially fatal infections for longer before starting treatment. Early diagnosis also means treatment for SCID (a bone marrow transplant) is more likely to be successful and the baby spends less time being ill, or in hospital having tests.

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Birmingham Children's Hospital laboratories are part of the evaluation programme. Therefore, all babies born within WAHT will be offered SCID testing alongside the 9 other conditions screened for. This will be done using the same blood spot sample. Information for parents about the additional screening is included in the leaflet 'screening tests for you and your baby'.

Babies with a higher chance screening result for SCID will be referred promptly to regional immunology services for diagnostic tests.

### **Screening process: birth registration/baby NHS number**

At birth every baby is assigned a NHS number which is a unique identifier that aids identification and tracking of babies as they progress through the screening process. In April 2010 it became mandatory that all blood spots included the babies NHS number and that these cards should have a label that includes the Information Standard Board (ISB) approved bar-coded babies' NHS number. These labels are generated at delivery and filed in the baby's personal health record (Red Book). The community midwife should check on the first home visit that the NHS bar code labels are present and correct in the baby's red book.

### **Information for parents**

It is important to offer parents an informed choice about screening for their baby, to gain consent and to prepare them for the blood spot. At least 24hrs before taking the blood spot sample the midwife should ensure that parents have a copy of the National Screening Committee leaflet 'screening tests for you and your baby'. This leaflet is available in other languages and from [www.newbornbloodspot.screening.nhs.uk](http://www.newbornbloodspot.screening.nhs.uk)



### **Procedure:**






#### **Equipment Needed for Bloodspot:**

- Copy of National Screening Committee screening booklet containing parent information leaflet
- Baby's NHS number on a bar-coded label
- Blood spot card and glassine envelope
- Maternity record and personal child health record
- Water for cleansing
- Non-sterile protective gloves
- Automated incision devise for use on the newborn (to prevent damage to the heel)
- Sharps box
- Cotton wool / gauze
- Hypoallergenic spot plaster

## Taking the sample

1. Clean the heel by washing thoroughly with plain water.
2. **Do not** use alcohol or alcohol wipes.
3. The heel should be allowed to completely air-dry before taking the sample.
4. Wash hands and apply gloves.
5. Additional pre-warming of the foot is not required.
6. Perform the test using an automated incision device designed for use on newborns.
7. Manual lancets **must not** be used.
8. Allow the heel to hang down to assist blood flow.
9. Before activation, place the automated incision device against the heel in accordance with manufacturer's instruction.
10. The aim is to fill each circle on the newborn blood spot card completely, using a single drop of blood.
11. Wait for the blood to flow. Allow one spot of blood to drop onto each of the circles on the card.
12. Do not squeeze the foot in an attempt to increase blood flow.
13. Allow the blood to fill the circle by natural flow, and seep through to the back of the card.
14. Fill the circle completely and avoid layering the blood.
15. Do not compress the blood spot.
16. Repeat the procedure for each circle. Each drop should soak through to the back of the card.
17. When the sample collection is complete, wipe excess blood from the heel and apply gentle pressure to the wound with cotton wool or gauze.
18. Apply a spot plaster if required and remind the parent to remove the plaster in a few hours.
19. Return completed card to community office for validation and collection by hospital trust courier service.
20. Inform parents that they will receive the results by 6 weeks of age, and how they will receive the results, e.g. by post or via the HV (Health Visitor).
21. Document sample taken on page 3 of the Postnatal Notes for Baby (Purple Notes) recording test card number and date of sample.
22. Complete information in Baby Personal Child Health record and on discharge file copy Midwife discharge from Red Book to Page 19 on Baby Postnatal Notes

Right	Do 
 <p>Circle filled and evenly saturated</p>	<p>Clean and dry the baby's heel before taking sample. This will avoid contamination of the sample</p> <p>Fill the circle completely with one drop of blood</p>

Wrong	Don't 
 <p>Insufficient, multiple spots</p>	<p>Take insufficient or multiple applications. This is unacceptable for testing and a repeat will be required</p>
 <p>Layering</p>	<p>Layer the blood. Too much blood can cause erroneous results</p>
 <p>Contaminated</p>	<p>Contaminate the sample (e.g. faeces, adult blood and touching the circles)</p>
 <p>Compressed</p>	<p>Compress the blood spot. Applying pressure reduces the density of blood on the sample and can lead to a 'suspected' result being missed</p>

**All details of the specimen should be validated with a second person. The second person can be a midwife, nurse, student nurse/midwife, support worker.**

If upon validation the blood spot is identified as being insufficient, the specimen should still be sent to the screening laboratory but with a note on the tracker form identifying that the sample is insufficient and a repeat sample has already been requested.

For community samples, The Newborn Blood Spot Screening Sample tracker Form must accompany the Specimens to the screening laboratory and a copy kept by the area sending the specimens. The copy must be kept for a minimum of one month.

For Delivery Suite/ postnatal ward/transitional care unit samples, these must be hand delivered to the courier bag and the tracker sheet completed on the Neonatal unit.

Blood spot screening card should be despatched to the screening laboratory within 24 hours of being taken. These are collected Monday to Friday by a designated courier to Birmingham Children's Hospital.

Neonatal screening specimens taken at a weekend or Bank Holiday should be despatched to the screening laboratory on the next working day.

**Ensure that parents know to contact their HV if results are not received within 6 weeks.**

#### **National Failsafe for Blood Spot Screening.**

National Failsafe for Blood Spot Screening is a web-based system which allows Maternity units, Child Health record departments and Laboratories to verify the location and screening status of any baby registered in England and take appropriate action.

The Failsafe system highlights those babies who have **no** Blood Spot card received by the laboratory and need investigating:

Not received by 12 days of age = **Amber** status

Not received by 17 days of age = **Red** status

The requirement for a "Repeat" sample is flagged on the system

The system makes it less likely that babies will miss screening and quickly identifies any babies who require repeat testing.

On A daily basis (working days) the Antenatal and Newborn screening team will log onto the system to:

1. Investigate babies who have gone to **AMBER** and/or **RED** status and escalate as required.
2. Ensure additional information is always kept up-to-date in the "Notes" section.
3. Amend a baby's "Failsafe Status" due to a change in circumstances –Repeats, Deceased, Out-of-Area, Declined, Mother Cannot Be Located.
4. Advise the midwife if the lab has requested a repeat sample.
5. Accept or reject babies who are "Moved in" from different areas.
6. Transfer out babies who have moved to a different area.

#### **Informing Clinicians and Parents of the Results**

All positive screening results for PKU, CHT and MCADD s will be sent to the clinical lead for newborn screening at Birmingham Children's Hospital (BCH) by 14 days of age.

In the event of screen positive results, the clinical lead for newborn screening at BCH will contact parents and initiate clinical referral within 4 working days of sample receipt by screening laboratory.

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Parents will receive normal results by 4-6 weeks following birth. Currently the Child Health Records Department send all normal results to Health Visitors who should record the screening results in the Child Health Record (Red Book)

### **If Parents Decline Screening**

Record each condition declined in the maternity records and child health record and the reason for declining.

Complete card as described above, marked as **DECLINE** to the screening laboratory

Inform GP and HV of the conditions for which the baby has not been screened.

Inform the parents that if they change their mind or would like further information they can contact Lead Newborn Screening Nurse at Birmingham Children's Hospital

### **Baby is deceased before screening**

If this occurs before the Newborn Blood spot screening has been completed then the member of staff involved in the care must inform the Newborn Screening team so that the Newborn Blood Spot Screening Failsafe system can be updated to state that the baby is deceased. The Newborn Screening Team will also update the screening laboratory.

### **Neonatal Unit (NICU) Admissions**

All babies admitted to NICU before 5 days of age must have a pre-transfusion sample consisting of 1 blood spot taken. This must be sent with the baby if transferred to another hospital before 5 days. It is important that this is carried out as if the baby should require a blood transfusion testing for SCT from the single spot can be undertaken within the laboratory. The single spot must be sent with the sample completed on day 5 if a transfusion has taken place.

If a baby is born before 32 weeks (less than or equal to 31+6 days) they will require a further sample in addition to 5 day sample. This should be completed at 28 days after birth or upon discharge from hospital whichever is soonest, as with babies born before 32 weeks gestation the day 5 sample may not detect CHT.

### **Avoidable repeat newborn blood spots**

Any blood spot cards rejected by BCH are emailed directly to the generic account for the Antenatal and Newborn Screening team. The email will include a cover letter giving the patient details, reason for repeat such as 'insufficient sample' or 'missing date of sample' as well as a copy of the card and actual blood spots taken. The email will be forwarded to the relevant team for immediate action. All details for each repeat request are recorded and monitored using a monthly spreadsheet by the Antenatal and Newborn Screening team. Team leaders are emailed by the screening coordinator informing them of any member of staff who has had 2 or more repeat requests in a month. A one to one meeting is requested with the member of staff, following which the outcomes/actions are sent back to the screening coordinator.

### **Training and audit**

Each month a detailed regional audit report is sent to the screening teams/matrons/head of midwifery. This provides a breakdown of sample data for each trust which is used to provide the quarterly KPI data for submission to Public Health/QA.

Any member of staff that is involved with taking the new born blood spot sample must ensure that the E-learning module is completed every 2 years. This is in addition to the yearly mandatory training which includes a teaching session by a member of the screening team.

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It is the responsibility of every individual to ensure this is the latest version as published on the Trust Intranet

**Monitoring**

Page/ Section of Key Document	Key control:	Checks to be carried out to confirm compliance with the Policy:	How often the check will be carried out:	Responsible for carrying out the check:	Results of check reported to: <i>(Responsible for also ensuring actions are developed to address any areas of non-compliance)</i>	Frequency of reporting:
	<b>WHAT?</b>	<b>HOW?</b>	<b>WHEN?</b>	<b>WHO?</b>	<b>WHERE?</b>	<b>WHEN?</b>
	Data Feeding into national audit	Audit collection Data	Continuously	Antenatal Screening Team	National Audit	Quarterly & Yearly



**Contribution List**

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This key document has been circulated to the following individuals for consultation;

Designation
All Maternity Staff Via Newsletter

This key document has been circulated to the chair(s) of the following committee's / groups for comments;

Committee
Maternity Governance Meeting