

NEWBORN BLOODSPOT - FULL CLINICAL GUIDELINE

Reference No.: IP/03:24/N7

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1. Introduction

Newborn blood spot screening identifies babies who may have rare but serious conditions. The UK National Screening Committee recommends that all babies are offered screening for:

- sickle cell disease (SCD)
- cystic fibrosis (CF)
- congenital hypothyroidism (CHT)
- phenylketonuria (PKU)
- medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
- maple syrup urine disease (MSUD)
- isovaleric acidaemia (IVA)
- glutaric aciduria type 1 (GA1)
- homocystinuria (pyridoxine unresponsive) (HCU)
- severe combined immunodeficiency (SCID)

2. Aims and Objectives

The aims of this guideline are to:

- Achieve early detection, referral and treatment of babies thought to be affected by the conditions
- Support midwives and nurses in gaining consent for the blood spot test
- Support midwives, MSW`s, HCA`s and nurses in obtaining good quality samples and reduce the need for repeat samples
- Support midwives MSW`s, HCA`s and nurses in obtaining a valid screening sample for all conditions
- Advise staff how to reduce pain during the heel puncture
- Encourage the uptake of newborn blood spot screening through evidence based information
- Provide a consistent approach to newborn blood spot sampling

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3. **Abbreviations**

CF	-	Cystic Fibrosis
CHT	-	Congenital Hypothyroidism
GA1	-	Glutaric Aciduria type 1
HCU	-	Homocystinuria
HCA	-	Health Care Assistant
IVA	-	Isovaleric Acidaemia
MCADD	-	Medium-Chain Acyl-CoA Dehydrogenase Deficiency
MHHR	-	Maternity Hand Held Record
MSUD	-	Maple Syrup Urine Disease
MSW	-	Maternity Support Worker
NBSFS	-	Newborn Spot Sampling Failsafe
PCHR -	-	Personal Child Health Record
PKU	-	Phenylketonuria
Proband	-	the first affected family member
SCD	-	Sickle Cell Disease
SCID	-	Severe Combined Immunodeficiency
TSH	-	Thyroid Stimulating Hormone

4. **Key Responsibilities and Duties**

Newborn screening will be co-ordinated by the UHDB screening team lead and/or deputies.

5. **Contraindications**

The parent may decline screening or referral. This must be clearly documented in the neonatal health records, the PCHR and the MHHR and the mother's obstetric health records. The screening card should be labelled and returned back to the Newborn screening laboratory, indicating "decline" in the comments section. If parents decline they should be advised that bloodspot screening can be completed up to one year of age and to discuss this with their community midwife or health visitor if needed.

6. **Process**

6.1 **Equipment Required**

To have had the opportunity to read the NHS screening programme booklet "screening tests for you and your baby" and obtain consent from parent.

- Blood spot card and glassine envelope (in date)
- Non-sterile protective gloves
- Age appropriate automated incision device designed for use on newborns
- Cotton wool/gauze
- Hypoallergenic spot plaster if required
- Sharps box
- Maternity Hand Held Record (MHHR)
- Personal Child Health Record (PCHR)
- Water for cleansing
- Glassine envelope
- Baby's NHS number – Barcoded label

6.2 **Preparation for taking the blood spot sample**

The Midwife/Maternity Support Worker/Nurse/Health Care Assistant will:

- Provide the woman with a copy/access to the booklets 'Screening tests for you and your baby' leaflet, or signpost the mother to <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby>, which is developed to enable parents to make an informed decision about blood spot screening for their baby
- Advise parents that the babies foot should be warm i.e. add a layer of socks.

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The blood spot sample should be obtained on **day 5 for all babies**, regardless of milk feeding and prematurity. For the purpose of the screening, **date of birth will be counted as day 0**. If women decline a day 5 sample this must be documented on the form when the sample is obtained.

6.3 The Midwife/Maternity Support Worker/Nurse/Health Care Assistant taking the blood spot sample will:

Explain fully to parents and then record in the Maternity Hand Held records that the newborn blood spot screening has been discussed and recommended, the leaflet read and consent sought. It is the midwives responsibility for gaining consent and documenting in the Maternity Hand Held Notes.

6.4 If the parents' consent to screening the Midwife/Maternity Support Worker/Nurse/Health Care Assistant will:

- Document this in the Maternity Hand Held records and the Personal Child Health Record (PCHR) with the card number and proceed with the test.

Parents may decline one or more of the screening tests offered – please mark which condition is “declined” in the comment section.

6.5 If the parents decline screening the Midwife/Maternity Support Worker/ Nurse/Health Care Assistant will:

- Document decline and reason for decline (if stated) in the obstetric health records and PCHR (in the 'birth details' section). Discuss the potential implications for not screening for these conditions on the baby's health.
- Mark completed card as DECLINE “all conditions” or which conditions have been declined then send to the screening laboratory
- Inform the GP and Health Visitor (HV) of the conditions of which the parents have declined screening. Inform parents who to contact if they change their mind or would like further information. See section 5. Document this in the PCHR and the Maternity Hand Held records.
- Inform NBS lead manager/midwife

6.6 Completing the Blood Spot Card

The Midwife/Maternity Support Worker/ Nurse/Health Care Assistant / will:

- Check the expiry date on the front of the card
- Complete the blood spot card at the time of sampling
- Check with the parent that all details on the label are correct and make any necessary changes
- Apply one label to each sheet of the blood spot card at the time of taking the sample
- Ensure the baby's NHS number is on the card, document legibly if no barcode label available
- Legibly complete all fields on the card even when there is a bar-coded label
- Ensure the label has a complete bar code with no sections missing
- Ensure the font size on the label is big enough to read
- Ensure the bar code and text fits on one label
- When completing the card care must be taken to avoid contamination caused by placing the card on a dirty surface
- Record any of the following in the 'comments' box on the card:
 - Baby's known medical condition
 - Relevant family history e.g. CF etc
 - Relevant antenatal screening results, e.g. haemoglobin variants etc.
 - Alternative address for family, if staying at a different address
 - Reason for sample not done on day 5-8 (Pre transfusion/preterm etc.)

6.7 Collecting the Blood Spot Sample

The Midwife/Maternity Support Worker/ Nurse/Health Care Assistant will:

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- Ensure the baby is comforted and in a secure position for taking the sample, swaddling the baby may be helpful.
- Suggest the baby is breast feeding during the heel prick; this will serve as an analgesic. An alternative to direct breastfeeding would be to encourage the mother to hand express her colostrum & give via a syringe. Sucrose/glucose water may be offered for babies within the neonatal unit.
- Breast milk or breast feeding should always be preferred and sucrose used for situations where the mother or breast milk are not available.
- Hand expressed colostrum or breast milk may be harvested before the procedure (see EBM guideline for procedure and storage)
- Clean the heel by washing thoroughly with tepid plain water. Do not use alcohol or alcohol wipes
- Allow the heel to completely air-dry prior to taking the sample
- Wash hands and apply gloves
- Additional pre-warming of the foot is not required
- Perform the test using an automated incision device no deeper than 2mm designed for use on newborns (see below)
- For full term and preterm infants, the external and internal limits of the calcaneus are the preferred puncture sites. This is marked by the shaded areas in Diagram B. Skin puncture must be no deeper than 2.0mm for term infants and 1.0mm for preterm or small for gestational age infants
- Choose the heel site with the least number of previous heel sticks. If a heel has been extensively traumatized this should be reported to the neonatologist
- Avoid the posterior curvature of the heel
- Allow the heel to hang down to increase blood flow
- Before activation place the automated incision device against the heel in accordance with manufacturers' instruction



These sites are also suitable for infants up to a year of age.

- Aim to fill each circle on the newborn blood spot card completely, using a single drop of blood
- There is no need to discard the first drop.
- Wait for the blood to flow. Allow one spot of blood to drop onto each of the circles on the card
- Do not allow the heel to make contact with the card as this can prevent blood from soaking through to the back of the card.
- Do not squeeze the foot in an attempt to increase blood flow
- Allow the blood to fill the circle by natural flow, and seep through to the back of the card
- Fill the circle completely and avoid layering the blood
- Do not compress the blood spot
- Repeat the procedure for each circle. Each drop should soak through to the back of the card. If blood is flowing well, an additional 5th 'spot' can be added onto the filter paper. Do not overlay any of the four circles

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If the blood flow ceases

- Wipe away the congealed blood firmly with cotton wool or gauze
- Gently 'massage' the foot, avoid squeezing, and drop the blood onto the card

If the baby is not bleeding a second puncture is necessary:-

- Perform the 2nd puncture on a different part of the same foot or on the other foot
- Wipe excess blood from the heel and apply gentle pressure to the wound with cotton wool or gauze
- Apply a hypoallergenic spot plaster if required and remind the parent to remove the plaster in a few hours



Expected standard of sample obtained

If unable to obtain the sample following second puncture offer visit the following day to re-bleed or access to Paediatrician to obtain a venous sample.

6.8 After taking the blood sample

The Midwife/Maternity Support Worker/ Nurse/Health Care Assistant will:

- Allow the blood spots to air-dry away from direct sunlight or heat before placing in the glassine envelope
- Complete all details on the form
- Make a record of the card serial number and date of specimen.
- Document that the test has been taken in the MHHR for mother and baby and in the PCHR
- Document and notify screening status on discharge/transfer notifications
- Inform the parents that they will receive the results via the Health Visitor
- Ensure the parents know how to contact their Health Visitor if results are not received within 6 weeks
- **BURTON SITE ONLY**-Take the sample to the team base within 24 hours. Document details of baby on NBS Sample Tracker Form and place in red courier bag for transport via the courier to the laboratory (see flow chart, appendix 2). Document date, method and site of sample dispatch in the MHHR for mother and baby.
- **DERBY SITE ONLY**-
- **Acute Setting:** The screening team should check all samples prior to sending.
- **Community Setting:** A member of staff should check the NBS sample to ensure all demographic fields are completed correctly (see appendix 3). All samples should be posted as soon as possible (ideally within 24 hours). The NBS failsafe should then be updated.

6.9 Special Circumstances

- Babies in Special Care Baby Unit/ Neonatal Intensive Care Unit
- Babies Born Preterm

The Neonatal Nurse will:

- All baby's on admission to Neonatal unit to obtain one circle blood spot sample from all babies less than 5 days of age on admission to the NNU. Mark as 'PRE-TRANSFUSION'.
- Obtain the blood spot sample on day 5 regardless of milk feeding and prematurity. For the purpose of screening, count date of birth as day 0

- Complete the blood card as described previously

Analgesia/comfort measures

The Neonatal Nurse will:

- Assess the baby's level of distress and ability to tolerate handling must be made before initiating comfort measures
 - Suggest the baby is breast feeding during the heel prick; this will serve as an analgesic. An alternative to direct breastfeeding would be to encourage the mother to hand express her colostrum & give via a syringe. If 'dummy' is declined, sucrose/glucose water may be offered via the neonatal unit
 - Breast milk or breast feeding should always be preferred and sucrose used for situations where the mother or breast milk are not available.
- Advise whilst there is no evidence that formula feed has analgesic properties, parents may comfort formula fed babies with a bottle feed during the procedure
- Co-ordinate the blood spot screening with other tests when possible as babies admitted to NNU are likely to have multiple blood samples taken
- Venepuncture or venous/arterial sampling from an existing line is an alternative. This is providing the sample is not contaminated with EDTA and the line is cleared of infusate.
- Store the 'PRE-TRANSFUSION' blood spot card with the baby's medical records in line with local protocols and send to the newborn screening lab together, with the 5 day 8 sample if the baby has received a blood transfusion in the interim
- Complete all boxes on both cards. The baby's NHS number should be handwritten on the cards if no printed labels are available. Then a bar coded label should be generated.
- Where a baby has already had a blood transfusion, either intrauterine or in the newborn period, before the screening blood sample has been taken, repeat the sample 72 hours after the blood transfusion for PKU, CHT, CF and MCADD
- For intrauterine transfusion count date of birth as date of transfusion
- Record the date of the last blood transfusion on the blood spot card and on discharge/transfer notifications
- In the event of multiple transfusions, send an initial screening sample by day 8 regardless
- **BURTON SITE ONLY**-Specimen to be taken to ANC Screening office for checking and to be collected by courier

DERBY SITE ONLY-The sample should be taken to the screening team office to be checked by a member of the screening team prior to sending to ensure that all fields are completed correctly

- **6.10 Documentation**

Record the Day 5 blood spot in the following:

- PCHR
- Babies maternity notes
- Record book kept on NNU
- Admission to Discharge pathway
- Badgernet
- V6/Lorenzo

Record the Day 28 blood spot in the following:

- Record book kept on NNU
- Admission to Discharge pathway
- Badgernet
- V6/Lorenzo

6.10.1 Preterm Infants

- Test babies born at 31 weeks + 6 days or less at day 5 and at day 28 or discharge home, whichever is the sooner
- Ensure a one week interval between repeat samples for borderline thyroid stimulating hormone (TSH) results. Mark the cards 'repeat TSH 'and make sure that gestation is recorded in weeks and days

6.10.2 Repeat Samples

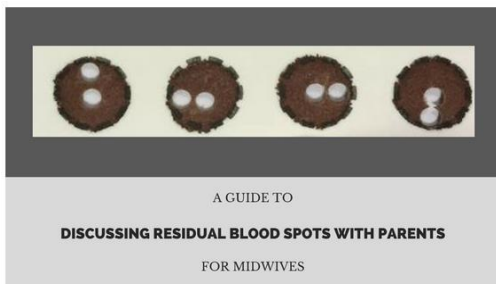
Repeat samples will be required from a few babies, due to prematurity, borderline TSH results, inconclusive CF screening or post-transfusion. These samples should be taken at the age specific for the indication

The Laboratory may request that a repeat sample is taken from a baby due to any of the following. Repeat these samples within 72 hours:

- Incorrect or incomplete labelling of the sample, i.e. wrong label on the card
- No NHS number on the card
- Bar-coded label not complete due to misalignment of label printer
- Insufficient blood on the card, i.e. has not soaked through to back of card
- Inappropriate application of the blood/damaged in transit.
- Compression of the blood spot
- Delay in laboratory receiving the sample
- Taken before day 5
- Second samples (for CHT or post-transfusion) taken at wrong time
- Contamination of the sample card, e.g. faeces, adult blood, etc.
- Expired bloodspot card used.

The Child Health Department is responsible for notifying screening status when the care of a baby is transferred. This includes babies who are transferred in the neonatal period or discharged home before screening for all tests is complete.

7. Residual Samples and Research



The originator who takes the sample must inform and discuss with the parent about residual samples.

After screening blood spot cards are stored for at least 5 years and may be used:

- to check the result or for other tests recommended by the GP
- to improve the screening programme
- for research to help improve the health of babies and their families in the UK

This research will not identify the baby and parents will not be contacted. The use of these blood spots is governed by the code of practice available from a community Midwife/Maternity Support Worker, or on the website.

There is a small chance researchers may want to invite them or their child to take part in research linked to this screening programme. Inform parents if they do not want to be invited to take part in research, please let the Midwife/Maternity Support Worker know.

8. Failsafe

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This Trust uses the Northgate Newborn Bloodspot Failsafe Solution (Appendix 3)

Correct use of the failsafe ensures that:

- all babies that are transferred have their screening status notified
- all eligible babies are identified and offered screening
- all babies whose parents accept screening are tested
- all samples arrive at the laboratory in a timely manner
- all positive babies receive timely treatment within national standards
- parents receive their results within six weeks

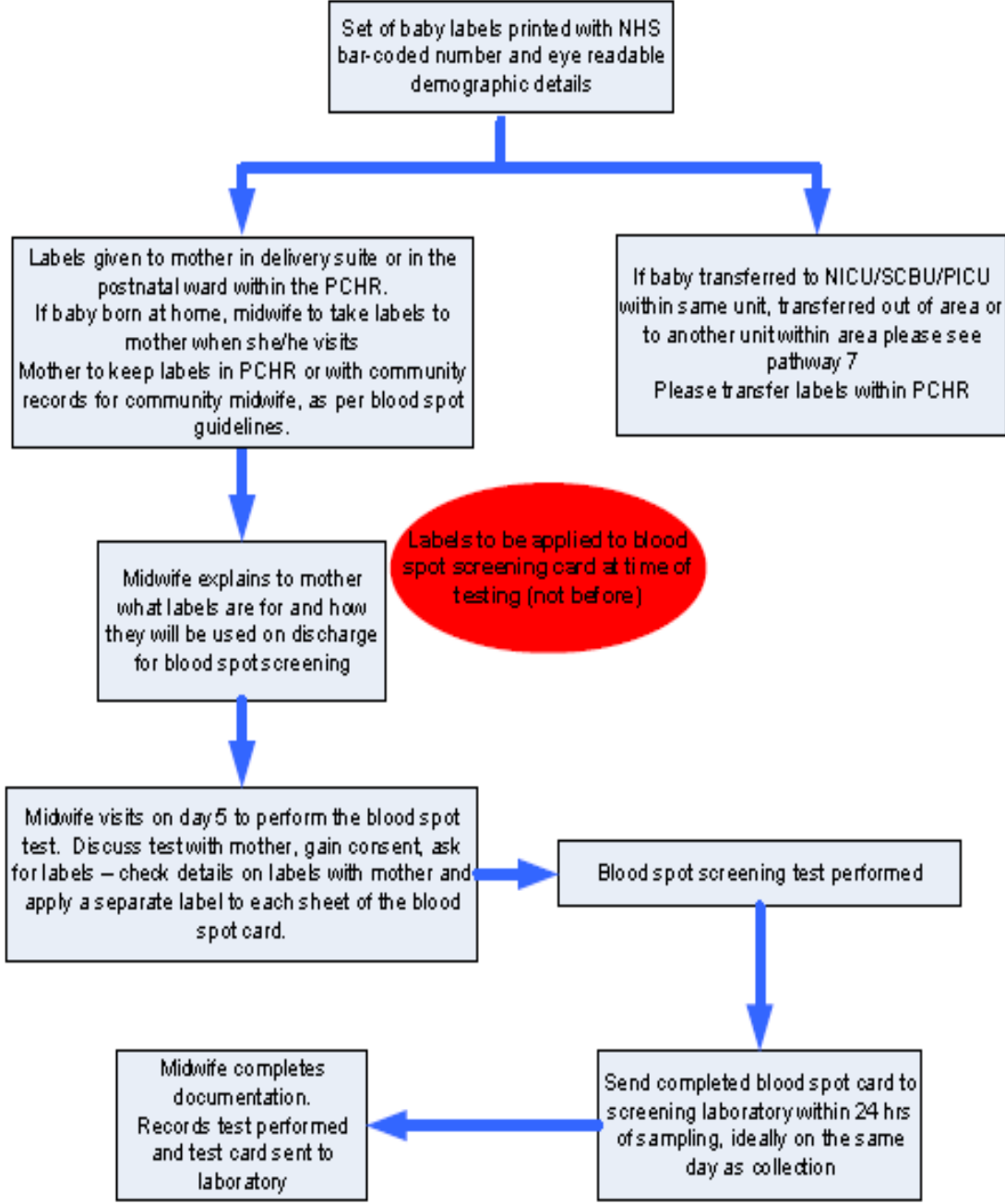
Daily checks of the Newborn Blood Spot Failsafe Solution are implemented to identify babies that might have missed NBS screening.

9. Monitoring Compliance and Effectiveness

This Guideline will be reviewed on a three yearly basis

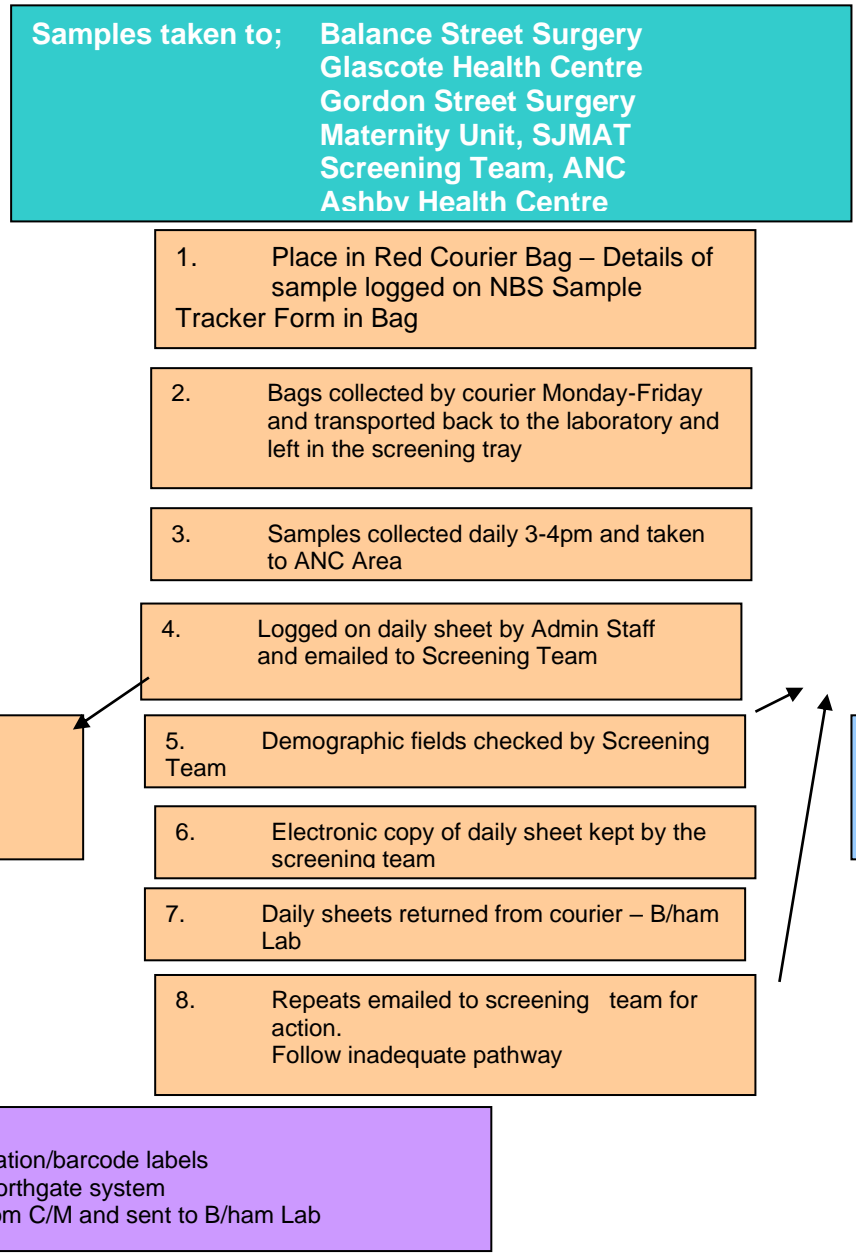
Any actions following audit/monitoring of this guideline will be reported to the Maternity Development /Governance Committee through the risk process.

Pathway 2: Midwife pathway



Labels to be applied to blood spot screening card at time of testing (not before)

Should read “Midwife completes documentation and failsafe”



Placed in red courier bay with daily sheet.
 Take to porters lodge
 Mon/Tues/Wed/Friday by 10.30pm
 Taken to Birmingham Lab by courier

Community Midwife contacted
 asked to repeat within 72 hours
If inadequate twice submit incident form

Appendix C- DERBY SITES ONLY

All NBSS samples **MUST** be checked by another staff member on the day of sample collection for correct demographics and quality of the sample.

Document the member of staff who checked the sample in the “comments box” on the NBS card.

The NBS **MUST** be posted as soon as possible using the pre-paid Regional Newborn Screening Service envelopes.

Newborn Blood Spot Failsafe Solution (NBBSFS) – SOP

The Newborn Blood Spot Failsafe (NBSSFS) system has to be checked every working day (Mon-Fri excluding bank holidays). Users are advised to refer to the handbook available on the government website: Guidance: NBSFS User guide. (2017, Updated March 2023) NHS England
<https://www.gov.uk/government/publications/newborn-bloodspot-screening-failsafe-solution-user-guide>

This procedure is to be followed each time the system is checked

1. Responsibility of NBSSFS

- Accountability for this process lies with the screening team (a specialist screening midwife and/or senior midwife will be allocated for the day as the identified NBBSFS), supported by Maternity support workers
- The NBBSFS for the day to check the Newborn blood spot failsafe system Mon – Fri to;
 - Check if any new cases have been added
 - Check if any old cases have action planned for that day (or the next 3 days for example if prior to a weekend)
- Screening team will be allocated as NBSFS for all working days Mon-Fri on a rota
- If cases were identified that need to be followed up the screening team will be responsible to login to and follow up:
 - the NBSFS system
 - generic email for newborn screening (emails from Child Health, Sheffield and Birmingham)
- Responsibility will fall to the specialist screening team on both sites.
- All actions taken need to be documented on the NBSFS system

2. Log into the newborn bloodspot failsafe system

Open the website on: <https://nww.bloodspot.northgate.thirdparty.nhs.uk/BloodspotWeb/nhsbaby> and login with user name and password.

Tick the boxes for 'not received' and 'repeat needed' and press search to view all outstanding cases.

3. Notification from the laboratory that a newborn bloodspot has not been received

For each baby listed as no sample received follow the below process.

The identified NBS FS for the day to:

- Check birth notification to establish likelihood of that baby being an inpatient on NICU. If that is the case, the coordinator is to contact NICU
- Check GP and team base caring for baby in case baby is likely to be cared for in community
- Forward the Child Health email with the birth notification (sent to the generic email) to the community team base responsible

- Add note of action taken on to the NBSFS system

The community team base:

- Community team to open email and identify details for baby, mother, birth, address and action
- Community midwife to check if there is evidence of a sample taken and sent;
 - If there is evidence, the community midwife to send an email with the date and time the sample was taken and the name of the person doing so to the generic screening email address
 - If there is no evidence that the sample was taken, the community midwife will organise for this to be done within 24 hours and email the details to the coordinator
- The screening team will add a note on the NBSFS system with:
 - Date and time a sample was taken and sent
 - If 19 days have passed since the sample was taken, the coordinator will contact the base to organise a repeat to be taken
 - Date and time a sample will be taken and sent in case of no evidence that this has already happened

4. Notification from the laboratory that a newborn bloodspot repeat is required

For each baby listed as 'sample requires repeat' follow the below process.

The screening team will:

- Check the details on the NBSFS system to check the reasons why the sample needs to be repeated
- Check the likelihood of that baby being an inpatient on NICU. If that is the case, the coordinator is to contact NICU
- Check GP and team base caring for baby in case baby is likely to be cared for in community
- Forward the email from Sheffield/Birmingham (sent to the generic email) to the community team base responsible and add the reason why the sample needs to be repeated
- Add note of action taken on to the NBSFS system

The community team base:

- Community team to open email and identify details for baby, mother, birth, address and action as below
- Community midwife to contact the parents to:
 - Explain the sample needs to be repeated and confirm the reason why
 - Plan visit or book in for a postnatal clinic appointment
 - If repeat planned to be carried out by MSW the community midwife needs to consent on the phone and document clearly
 - Send an email to the generic screening address to confirm action taken
- The NBS failsafe should be updated by the screening team and/or community team.

5. **Special actions points**

Recording baby on Neonatal Unit

- Click on the baby's name
- Scroll along and click on the column titled view
- Within the box titled failsafe status tick NICU
- Click save

Recording deceased babies

- Click on the baby's name.
- Scroll along and click on the column titled view
- A box will appear titled Failsafe Status
- Click onto drop down box titled failsafe status
- Select deceased
- Click save
- Confirm

Accepting babies in from other Trusts

- Click on the baby's name
- Scroll along to the column titled status, then click onto accept transfer
- Click, yes to accept transfer
- Write a message in text box if required
- Click save. pressing onto yes

Transferring babies out to another Trust.

- Click on the baby's name
- Scroll along to column titled transfer out, then click on the arrow
- A box will appear click, new location
- Scroll down and select the location the baby is to be transferred to
- Click save
- The baby's name will disappear off UHDB failsafe after the receiving trust has accepted the baby

6. **References**

<https://www.gov.uk/government/publications/newborn-blood-spot-screening-sampling-guidelines>

<http://sct.screening.nhs.uk/AimsObject.htm#ProgStandards>. These include the following core and development standards:

- NHS Sickle Cell and Thalassaemia Programme – Handbook for newborn screening 2021

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- UK Newborn Screening Programme Centre (2016, updated 2021) Guidelines for Newborn Blood Spot Sampling.
- Guidance: NBSFS User guide. (2017, Updated March 2023) NHS England.

Documentation Control

Reference Number: UHDB/IP/03:24/N7	Version: UHDB V2	Status: Final		
Royal Derby prior to merged document:				
Version / Amendment	Version	Date	Author	Reason
	1	Feb 2015	Rachel McLean Specialist Midwife	Updated to include new CHT screening for preterm infants.
	2	May 2017	Rachel McLean Specialist Midwife	Updated following QA visit
WC/NP/	Burton Trust prior to merged document:			
WC/NO/80N	3	April 2018	Annette Haynes Senior Midwife	Routine review and update
Version control for UHDB merged document:				
UHDB	1	Sept 2020	Rachel McLean Specialist Midwife	Review & Merge
	2	Feb 2024	Rachel McLean Specialist Midwife	Triannual review - minor changes
Intended Recipients: All staff caring for newborn infants				
Dissemination: Cascaded electronically through lead midwives/doctors; Published on Intranet Articles in Divisional newsletter				
To be read in conjunction with the following: Newborn Screening Committee guidelines:- UK Newborn Screening Programme Centre: www.newbornbloodspot.screening.nhs.uk				
Consultation with:	Neonatologists			
Business Unit sign off:	11/03/2024: (Exceptional ratification) Maternity Guidelines Group: Miss A Joshi – Chair 11/03/2024: Maternity Governance Group/CD - Mr R Deveraj			
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