

Newborn Blood Spot screening test for babies cared for in UHL Neonatal Service and Children's Hospital.



Trust Ref: C26/2005

1. Introduction and who the guideline applies to:

This guideline is aimed at all Health care professionals involved in the care of infants within the Neonatal and Children's Hospital Services.

Aim

1. All parents of babies on the Neonatal Unit and Children's Hospital will be able to make an informed choice about the Newborn Bloodspot Screening Test
2. Newborn Bloodspot Screening within the Leicester Neonatal & Children's Services will meet the national standards

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Rationale

The Newborn Blood Spot Screening Test aims to find out if babies are affected with the following conditions:

- Congenital hypothyroidism (CHT)
- Cystic fibrosis
- Phenylketonuria (PKU)
- Medium chain acyl CoA dehydrogenase deficiency (MCADD)
- Maple Syrup urine disease (MSUD)
- Isovaleric Acidaemia (IVA)
- Sickle Cell Disease(SCD)
- Glutaric Aciduria Type 1 (GA1)
- Homocystinuria (pyridoxine unresponsive) (HCU)
- Severe Combined Immune Deficiency(SCID)

<https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/severe-combined-immunodeficiency-scid/>

<https://www.nhs.uk/conditions/pregnancy-and-baby/newborn-blood-spot-test/>

Key Points

1. Treatment for PKU and MCADD should be started within 21 days of birth and as early as possible to avoid permanent damage. It is therefore imperative that the timing and collection of the Newborn Blood spot Screening Test is taken within the recommended time frame.
2. SCID screening positive, follow SCID screening Pathway (SCID)
3. All infants must have blood spot screening between day 5 and day 8
4. If the infant has the first transfusion is before day five, collect one blood spot and mark as 'pre transfusion' (if not already collected on day 0 at the time of admission).
5. Do not use Vaseline (white soft paraffin/petroleum jelly) on the heel when taking the sample.
6. New SOP - Email notification requirements and new collection and transport process for NBBS ([see appendix 5](#))

Related UHL documents

- [Severe Combined Immune deficiency \(SCID\) Newborn Screening UHL Childrens Hospital Guideline](#) Trust ref: C48/2021
- [Newborn Screening for Severe Combined Immune Deficiency \(SCID\) UHL Neonatal Guideline](#) Trust ref: C3/2022

This guideline also incorporates

[Appendix 1: Technique for filling blood spot](#)

[Appendix 2: Sample Screening Calendars](#)

[Appendix 3: Newborn blood spot failsafe system](#)

[Appendix 4: Blood Spot Screening Poster](#)

[Appendix 5: SOP for collection and transportation](#)

2. Process / Procedure

*** Date of birth equals Day 0 for sampling purposes**

On admission:

- Take a single bloodspot on admission. Retain this card with the baby's notes until the 5-8 day sample (four bloodspots) is taken - in case the baby has a blood transfusion in the interim. **Do complete the information on the card at the time that the blood sample is taken and use the bar coded label on both samples if available.**
- If the baby is transfused before the 5–8 day sample is taken, send this single bloodspot, along with the 5-8 day sample (two cards in total), providing consent is given, as detailed below.
- Only the Day 5-8 card is sent if the baby has not been transfused.
- You **MUST** record the mother's Sickle Cell and Thalassaemia screening result in the comments box on the one-spot card. This can be found on the Euroking front sheet under Hb Electrophoresis / Haemoglobinopathy screening or in the hand-held notes or on iLab / iCM.
- If a baby is transferred to another ward or hospital before the day 5 sample, ensure the 'pre-transfusion' blood spot card and barcoded labels accompany the baby.

Within 24 hours of admission:

1. Ensure the parents have been given the NHS Antenatal and Newborn Screening Programmes booklet "Screening tests for your baby"
2. Check that the parents have read and understood the information – for non-English speaking parents this will need to be through an interpreter. Leaflets in 18 different languages are available through the link: <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief>
3. Ask the parent/s with parental responsibility for consent to perform the test

– verbal consent is acceptable and this should be recorded in the baby’s notes, on Badgernet and the personal child health record – PCHR (Red Book) with the entry signed and dated

4. ‘Decline’ for screening should also be recorded in the notes and PCHR. A newborn bloodspot screening card should be completed and ‘DECLINE’ for each or all conditions clearly documented in the comments box on the card. This should be sent to the newborn screening laboratory in the normal manner
5. If screening is declined and consent is not given please ask a senior member of medical staff to explain the potential implications to the parents. The GP and Health Visitor must also be informed and screening should be reoffered at a later date.
6. Parents should be informed who to contact if they change their minds and decide that screening may be undertaken (i.e. H.V. or G.P.)

When the baby is five days old:

1. Providing consent has been obtained, complete the Newborn Bloodspot Screening Test, as per the “Blood Sampling Guidelines” and [Appendix 1](#).



2. **DO NOT use Vaseline on the baby’s heel.**
3. Documentation should be made in the baby’s notes, newborn bloodspot screening folder and in the PCHR that screening has been undertaken with consent together with the date the test was taken and by whom.
4. Screening should take place on day 5 unless exceptional circumstances such as blood transfusion – regardless of current medical condition or feeding status.
5. The sample **MUST** be taken by day 8 in all circumstances.
6. Babies born at less than 32 weeks gestation need a repeat sample taking for CHT at 28 days of age or discharge whichever is sooner.
7. Comments regarding feeding status and transfusion history should be noted on the screening card
8. Ensure the sample is dry before putting in the glassine envelope and get another person to check that the sample has been collected according to national guidance. Send the sample in accordance with the Standard Operating Procedure (SOP) [in Appendix 5](#)

Blood transfusions:

If the first transfusion is **before** day five*:

1. Collect one spot of blood and mark for 'PRE TRANSFUSION'
2. Ensure consent has been obtained
3. Send it off to Newborn Screening Laboratory in Sheffield, with the day 5 sample in the normal manner.
4. More than 72 hours must elapse before a valid screening sample can be obtained.
5. However **ALL** babies must have a sample taken by day 8 regardless of blood transfusion.
6. In case of multiple transfusions and where there is no clear 72 hour period, the sample must still be taken by day 8, with a further repeat once the infant reaches 72 hours post-transfusion.
7. For the purposes of screening red cell transfusion, platelet transfusion and fresh frozen plasma are all considered significant.

(see [Appendix 2](#): sample screening calendar)

Repeat tests:

- All babies of less than 32 weeks gestation will need a repeat test at 28 days of age or discharge whichever is sooner (Screening for Congenital hypothyroidism prior to this will not give an accurate result). This test will not be requested by the laboratory. (See [Appendix 2](#): sample screening calendar)
- *If the baby is already being treated for CHT do not repeat this test but inform the newborn screening team on ext 14860 if this is the case.
- Repeats will be requested by the newborn screening laboratory where insufficient blood has been obtained, was of poor quality, not valid for testing or as per national protocol for specific conditions
- If a repeat test is requested follow the process on the flowchart:
“Process for a request for a repeat bloodspot”

Failsafe System:

1. UHL uses the nationally recommended failsafe system provided by Northgate to ensure that all babies under the care of UHL are tested within the required timeframe.
2. This is monitored by the Community Office and Newborn Screening Team.
3. See [Appendix 3](#) for the Standard Operating Procedure (SOP) for use of the failsafe system.

Sending the test:

1. The baby's NHS number, date of birth and date sample taken must be clearly documented on the newborn bloodspot screening card and be clearly legible on all copies (the NHS number can be found on the front sheet from Euroking). Use of a bar-coded label with the baby's information and NHS number should be used if available. These are printed at the time of birth and should be transferred between departments with the baby's notes.
2. If the mother is HIV, Hepatitis B or Hepatitis C positive do not write this – put an 'infection risk' sticker on the card
Ensure the sample is dry before putting in the glassine envelope and get another person to check that the sample has been collected according to national guidance. Send the sample in accordance with the Standard Operating Procedure (SOP) in [Appendix 5](#)
3. The test must be sent within 24 hours of taking the sample.
4. You must enter the date the test was taken on BadgerNet and in the red book (PHCR).
5. The test has to be checked by a second member of staff who must enter their details on BadgerNet to confirm the test has been taken and the details have been filled in correctly.

Education and Training:

- Antenatal and newborn (ANNB) screening training is provided as part of induction training for midwives, obstetricians and midwifery care assistants.
- ANNB screening training is provided on annual mandatory training for midwives and children's nurses.

Monitoring Compliance:

- ANNB screening is monitored through the screening Key Performance Indicators (KPI's) and annual data returns the National screening committee programme centre.
- Quarterly ANNB screening programmes boards chaired by NHS England, alongside PHE QA teams monitor the annual and quarterly data returns from UHL.

References

Public Health England (PHE) Guidelines for Newborn blood spot sampling; 2016 (updated Dec 2021)

Severe Combined Immune deficiency (SCID) Newborn Screening Pathway for use on NNU : 2021

6. Key Words


Congenital hypothyroidism (CHT), Cystic fibrosis, Phenylketonuria (PKU), Medium chain acyl CoA dehydrogenase deficiency (MCADD), Maple Syrup urine disease (MSUD), Isovaleric Acidaemia (IVA), Sickle Cell Disease(SCD), Glutaric Aciduria Type 1 (GA1), Homocystinuria (pyridoxine unresponsive) (HCU), Severe Combined Immune Deficiency(SCID)





The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs. As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

Contact and review details			
Guideline Lead (Name and Title) Sumit Mittal - Consultant		Executive Lead Chief Nurse	
Original Author: Marie Hubbard & Helen Ulyett			
Details of Changes made during review:			
Date	Issue Number	Reviewed By	Description Of Changes (If Any)
2005	1		
March 2015 – April 2015	2	Neonatal Guidelines & Neonatal Governance Meeting	Editorial Changes undertaken (Neonatal lead - REM) Appendices added
July 2018 - August 2018	3	Neonatal and Maternity Guidelines and Governance Meetings	Minor changes/ratified. Added diagram page 3
Nov 2021 - January 2022	4	Neonatal Guideline Meeting Children’s Hospital Guidelines Group Neonatal Governance Meeting	Changes in line with new SCID screening

September 2022	5	Guideline group Maternity Governance	Changes to the transportation of newborn blood spot samples to the Sheffield lab from 31 st October 2022 and changes to the failsafe process as a result of the transportation process
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Appendix 1: Technique for filling blood spot

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>Layer the blood. Too much blood can cause erroneous results</p> <p>Contaminate the sample (e.g. faeces, adult blood and touching the circles)</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>
 <p>Layering</p>	
 <p>Contaminated</p>	
 <p>Compressed</p>	

Appendix 2: Sample screening calendars


Screening calendar for all babies admitted

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			Day 0: Date of birth Take pre transfusion blood spot 	Day 1	Day 2	Day 3
Day 4	Day 5 Take 4 spot sample ALL babies must have a sample sent by day 8 	Day 6	Day 7	Day 8	Day 9	Day 10
Day 11	Day 12	Day 13	Day 14	Day 15	Day 16	Day 17
Day 18	Day 19	Day 20	Day 21	Day 22	Day 23	Day 24
Day 25	Day 26	Day 27	Day 28	Day 29		

Pre-transfusion: Day 0-4 babies admitted to hospital <5 days. Mark card 'pre transfusion' in the comments box






Day 5-8: Use a separate card for pre transfusion and day 5-8 sample.




1


Screening calendar for babies born at less than 32 weeks gestation

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			Day 0: Date of birth Take pre transfusion blood spot 	Day 1	Day 2	Day 3
Day 4	Day 5 Take 4 spot sample ALL babies must have a sample sent by day 8 	Day 6	Day 7	Day 8	Day 9	Day 10
Day 11	Day 12	Day 13	Day 14	Day 15	Day 16	Day 17
Day 18	Day 19	Day 20	Day 21	Day 22	Day 23	Day 24
Day 25	Day 26	Day 27	Day 28 Take 2 spot pre term sample as born at <32 weeks gestation 	Day 29		


Pre-transfusion: Day 0-4 babies admitted to hospital <5 days. Mark card 'pre transfusion' in the comments box



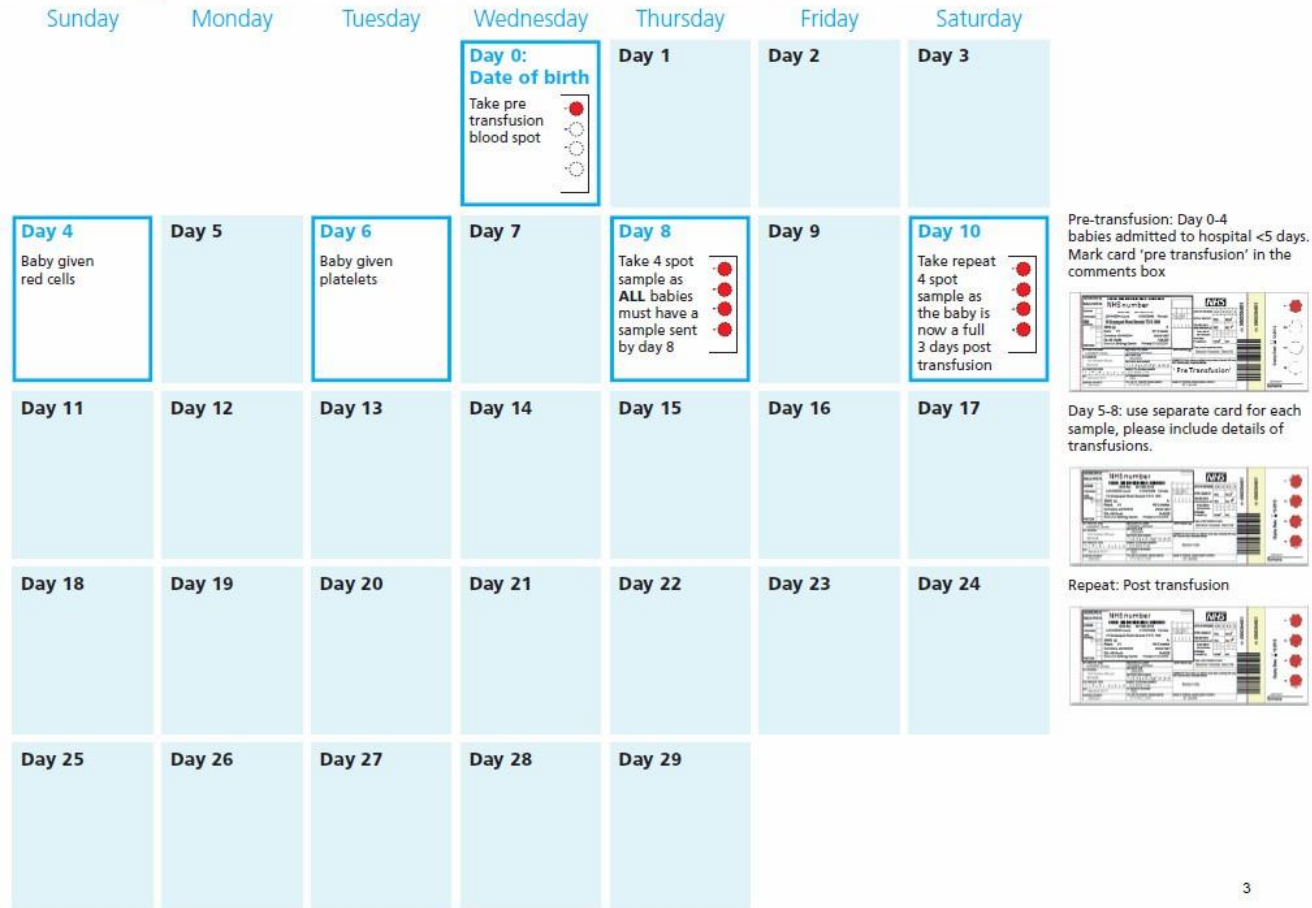
Day 5-8: Use a separate screening card for each sample



Day 28: If born <32 weeks gestation take a 2 spot sample at 28 days or day of discharge whichever is sooner and mark 'CHT preterm' in the comments box

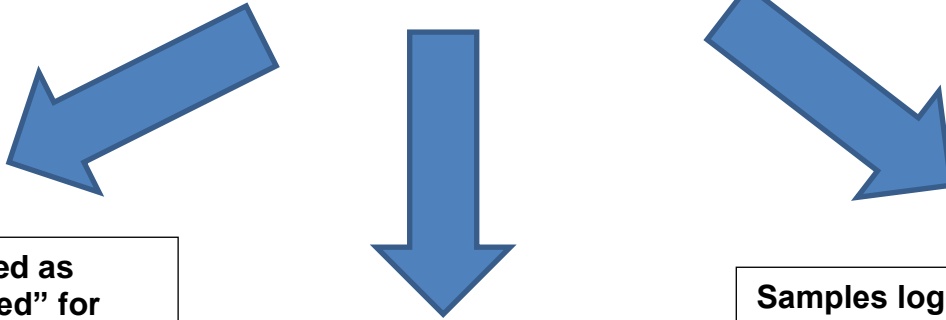


Screening calendar example for babies who have been transfused



Appendix 3: Standard Operating Procedure - for the daily review of the Newborn Blood Spot (NBBS) Failsafe system after 31st October 2022

Newborn screening team to Log in to NBBS failsafe system daily on week days



Samples logged as “repeat required” for CHT as premature baby

Make a note on the system that this is a NICU baby and the date the 28 day repeat is due. Contact the relevant NNU when the sample due date has passed to ensure the 28 day sample has been taken.

Samples logged as “repeat required” as unsuitable for testing

These requests will come via the community office and do not need action by the daily review of the NBBS failsafe system. If a sample has not been actioned contact the community office/review the local NBBS database

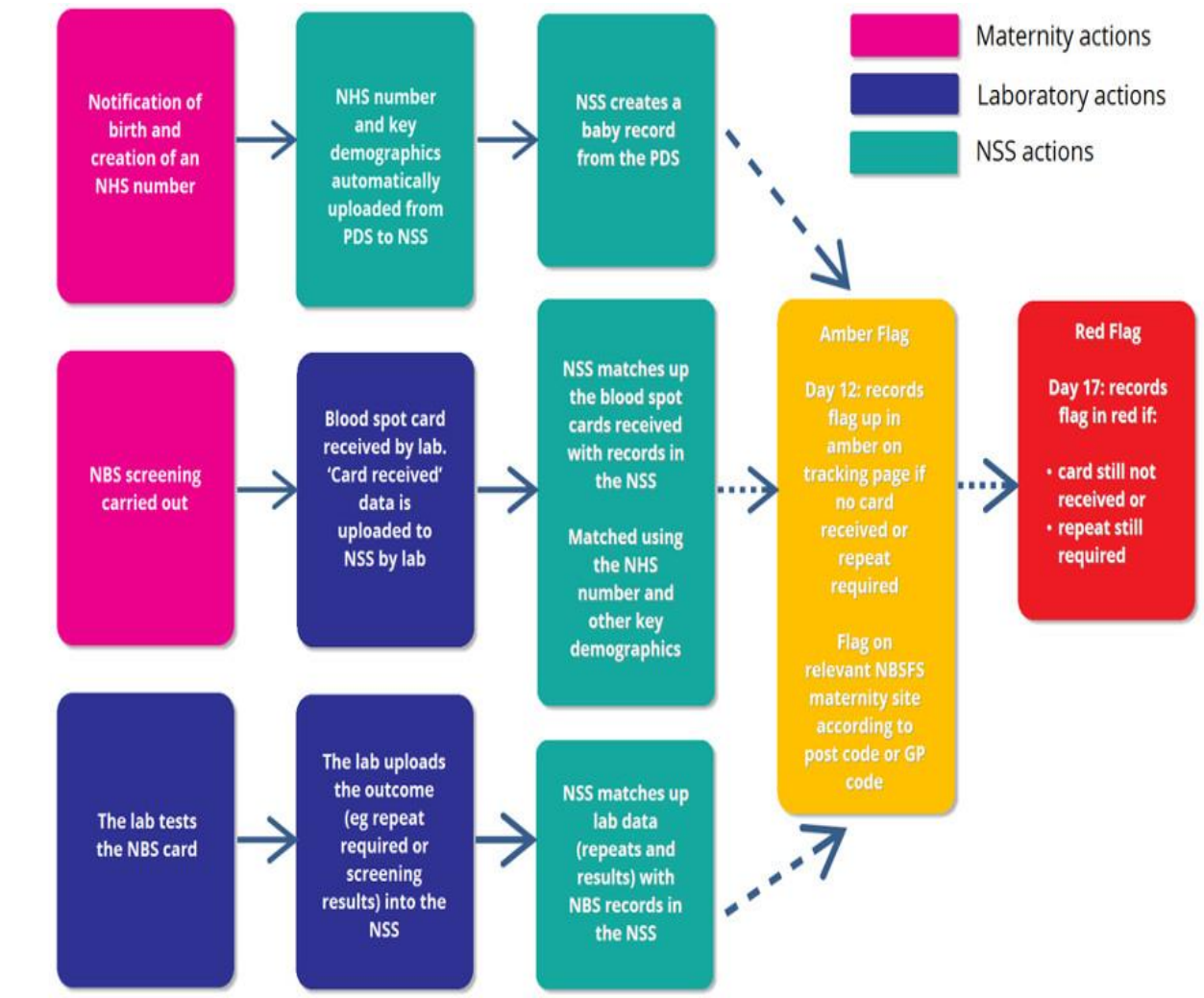
Samples logged as “not received”

Check HISS/PAS to ensure the baby is alive and well
Confirm the 5 day sample was taken:

- a. if not - arrange testing urgently.
- b. Any samples missing after 72 hours from the email from the midwife to alert the admin team that the sample has been dropped at one of the 10 LLR locations, arrange a repeat sample.
- c. If the 5 day sample was taken and has not been logged on the sample tracking system as arrived at UHL lab, arrange a repeat immediately.

Any actions must be documented in the NBBS failsafe system under “notes” and in the local NBBS database for the relevant year/month of birth of the baby.

Appendix 3a: Newborn blood spot failsafe solution flowchart



www.gov.uk/government/publications/newborn-blood-spot-screening-failsafeprocedures

Appendix 4 - Quick guide for blood spot screening on NNU

BLOOD SPOT SCREENING

What is it?

The aim of screening is to find out if babies possess the following rare, but serious conditions:

- Congenital hypothyroidism (CHT)
- Cystic fibrosis
- Phenylketonuria (PKU)
- Medium chain acyl CoA dehydrogenase deficiency (MCADD)
- Maple Syrup urine disease (MSUD)
- Isovaleric Acidemia (IVA)
- Glutaric Aciduria Type 1 (GA1)
- Homocystinuria (pyridoxine unresponsive) (HCU)
- Sickle Cell Disease
- Severe Combined Immunodeficiency (SCID)

Why is it important?

Early identification of the disorders can allow for early treatment leading to a healthy child.

ALWAYS REMEMBER

- Always gain consent
- Never use Paraffin
- Document on Badger once its been taken.
- Any issues with badger, including incorrect documentation, email a badger administrator.

By Kirsty Nicholson & Shevani Patel (Jan 2022)

When?

- All Babies between Days 5 – 8.
- Babies born less than 32 weeks gestation need a repeat blood spot sample taken at 28 days old or at discharge, whichever is sooner.
- Post transfusion wait 72hrs before obtaining sample.

How to document on Badger?

- Go to procedures/events
- Complete form
- Check the form and authorise
- Have a colleague check and authorise the form.
- Save and close

The screenshot shows a web-based form for documenting blood spot screening. At the top, there is a link 'Click to view guideline...'. Below this, the form has several sections:

- Consent obtained for screening:** Radio buttons for 'Yes' and 'No'.
- Sample taken for:** Radio buttons for 'Admission/pre transfusion sample', 'Routine blood spot screen (day 5-8)', 'Routine repeat sample in preterm (28 days)', 'Repeat sample by request from lab', and 'Other'. A text input field is next to 'Other'.
- Sample taken:** Radio buttons for 'Yes' and 'No'.
- Sample sent:** Radio buttons for 'Yes' and 'No'.
- Form checked by:** Two 'Authorise' buttons, each with a user icon.
- Notes:** A large text area for entering notes.

At the bottom of the form, there are three buttons: 'Audit trail...', 'Save & Close', and 'Cancel'.

Appendix 5 - Standard Operating Procedure for the Transportation of Newborn Blood Spot Screening samples to the Newborn Screening Laboratory in Sheffield from any location in Leicester, Leicestershire and Rutland (LLR) from 31st October 2022

All babies born in the United Kingdom should be offered Newborn blood spot (NBBS) screening on day 5 or in exceptional circumstances by day 8. At the University Hospitals of Leicester (UHL) this test is normally performed in the baby's home on day 5 and screens for 9 serious conditions that if treatment is delayed can cause severe morbidity and mortality. The national standard is that over 97% of NBBS samples will arrive in the Newborn Screening Laboratory in Sheffield within 3 working days.

Background/ Factors affecting current level of service

Currently NBBS samples taken for babies born and cared for in Leicester, Leicestershire and Rutland (LLR) are sent in dedicated pre-paid envelopes and posted in the Royal mail post boxes. This equates to approximately 1000 samples a month.

Using the current system, transportation of samples from LLR has never met the standard and **currently only 90% of samples arrive in the required timeframe**. Further to this, local audit has shown that **approximately 20 samples per month take more than a week to get to the Lab** and a handful take more than 14 days and have to be repeated as they are too old for testing. Should one of these delayed samples be from a baby affected with one of the conditions, the delay could cause permanent damage to the child if not death (NB samples delayed in the post has been part of the root cause of two SI's at UHL in the last 2 years) Further to this, repeating any sample has an immediate impact on the experience that we provide babies and their families, in addition to the cost of every repeat sample which is in excess of £100.

New process for transporting samples from LLR to the screening Laboratory in Sheffield from 31st October 2022

NBBS sample is taken in accordance with national guidance and second checked by a health professional or parent of the baby (DO NOT delay sending the sample for second checking).

For samples taken in the community:

Take a photo of the sample using your work iPhone and email to bloodspot@uhl-tr.nhs.uk with details of the location that the sample was sent from. Please only send one sample per email so it is clear for the admin team.

Sending the email using M360 emails:

1. log onto your emails on your phone through the outlook app
2. open a new email by pressing the blue plus button
3. type in the email address bloodspot@uhl-tr.nhs.uk ,
4. Subject of the email - blood spot test
5. Click on the body of the email and Write the location that the sample is being sent from of the 10 listed sites below
6. Press return, click on camera, take the photo, press done
7. Send the email
8. For samples taken in the hospital:
9. Send an email with the baby's name, DOB, NHS number and location that sample is being dropped at to bloodspot@uhl-tr.nhs.uk

10. Once the sample is completely dry place in the glassine envelope and then into the dedicated blood sample specimen bag.



11. The sample must be placed in the dedicated collection box for your area. There are 10 areas as follows: (each area also has a local “Champion” to help you with any queries about the process)

- **LRI maternity reception**
Collection point - Box at maternity reception,
Local Champion – Julie Saunders
- **LGH Maternity reception**
Collection point - Box at maternity reception – if reception is unmanned leave samples under the glass front for the porter.
Local Champion – Julie Saunders
- **Glenfield Pathology Reception**
Collection point – Green tray on the left of the pathology reception. Door code - 1479
Local Champion – Janine Fulbrook
- **Rutland Memorial hospital**
Collection point – Blue Box in Out patients department
Local Champion – Tracey Aylward
- **St. Mary’s Hospital, Melton Mowbray**
Collection point - Box in midwives office at the birth centre
Local Champion – Sam Whait
- **St. Luke’s hospital, Market Harborough**
Collection point - Box in the treatment room on level one. Code for the door is C1678X
Local Champion – Tracey Hull
- **Lutterworth Health Centre**
Collection point – Blood Box in the Wycliffe MP clean sluice
Local Champion – Su Ferrar
- **Hinckley Health Centre**
Collection point – basket in the midwives office and then MCA’s to take to the blood box behind main reception
Local Champion – Anita Wragg
- **Loughborough hospital, Epinal way**
Collection point - Box in phlebotomy room Outpatients 1 or Midwives pigeon hole in the post room where MCA’s will collect and take to OP1 when open
Local Champion – Kate Hammond

- **Coalville Hospital**

Collection point - Box behind main reception or if out of hours the porters can unlock the door for access Tel: 07960856330
Local Champion – Rachel Darling

NB – samples should be dropped at the dedicated collection point on the same day as testing unless there is no access out of hours. It is acceptable to leave samples overnight or at the weekend in the collection boxes.

- UHL van drivers collect the samples alongside all other pathology samples on a daily/twice daily basis weekdays.
- UHL pathology reception staff place all samples in the dedicated blood spot screening bags into the collection box.

The blood spot admin team will:

- Do a daily extract from the blood spot failsafe system to identify samples expected on a daily basis.
- Log all emails received to know that samples are on the way to Pathology at UHL
- Collect all samples from Pathology reception at UHL
- Remove samples from the plastic sample bag and recirculate any bags deemed as suitable or discard as required.
- Check each sample for accuracy and amend as required or escalate to the screening team if unsure of details needed
- Leave sample in the glassine envelope.
- Package all the day’s samples into an appropriate sized receptacle that can be securely fastened (large envelope or box is fine – size doesn’t matter, it is the weight that will increase the cost).

Address the package to the following:

Regional Newborn Screening Service
Sheffield Children’s NHS Foundation Trust
Western bank
Sheffield
S10 2TH

- Put the cost code in the top left corner of the package – X47.
- Place a “special delivery” sticker on the package (anywhere but not top right or over the cost code).
- Record the tracking number against the “pilot package” number on the dedicated tab on the spreadsheet.
- Take the package to the post room in basement of Windsor building.
- Any “missing samples” after 72 hours are highlighted to the newborn screening team to investigate and arrange a repeat sample if required.
- Daily monitoring of the national blood spot failsafe system by the newborn screening team will provide a third check of any samples not received by the Sheffield newborn screening lab for any babies that are 12 days of age or older.

