

1. Introduction and who the guideline applies to:

This guideline is for midwives caring for mothers and their newborn babies to describe the process of taking the newborn blood spot screening test. It is not for pre-term babies or babies who are resident on the Neonatal Unit.

Background:

Newborn blood spot screening is undertaken at UHL as per NSC guidelines. The conditions screened for in Leicestershire are:

- Cystic fibrosis
- Congenital hypothyroidism
- Sickle Cell Disease
- Phenylketonuria
- Medium Chain Acyl Co A Dehydrogenase Deficiency
- Maple syrup urine disease (MSUD)
- Isovaleric acidaemia (IVA)
- Glutaric aciduria type 1 GA1)
- Homocystinuria (pyridoxine unresponsive)(HCU)

From September 2021 UHL will be involved in a pilot to evaluate screening babies for Severe Combined Immunodeficiency (SCID)

What's new?

- New email notification and collection/transportation process ([see appendix 5](#))

Related UHL documents:

- [Hand Hygiene UHL Policy](#)
- [Severe Combined Immune deficiency \(SCID\) Newborn Screening UHL Childrens Hospital Guideline](#)
- [Bloodspot Screening UHL Neonatal Guideline](#)

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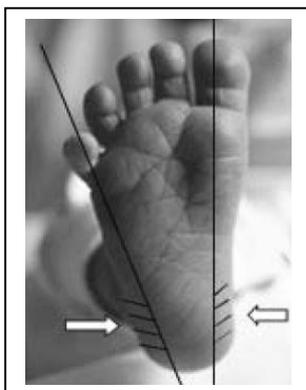
2. Guidance:

- Ensure mother received the pre-screening information leaflet at least 24 hours before the heel prick is taken (document leaflet given).
- Verbal consent is required from the mother or person with parental rights for the test.
- The blood spot screening test should be performed when the baby is 5 days old wherever possible.
- Take earlier if baby is a new sibling of a child known to have PKU or MCADD
- Repeat sample on day 5 or on exceptional circumstances by day 8, indicating on the card that a sample has already been sent for PKU / MCADD testing
- See page 2 for details of how to take the test
- The card must be complete, legible and include an adequate blood sample. Use the bar coded label with the baby's NHS number but ensure the labels are correct prior to use (see Appendix 1 and 2 for details.)
- If mother declines screening for the baby, either for specific conditions or the full programme: Refer to section on [page 4](#)

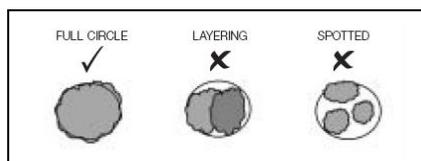
Procedure for parents who consent:

1. Check the card's expiry date
2. The baby's NHS number on the blood spot card is mandatory please use the bar code label if available and accurate. Complete all other fields on the card using block capital letters
3. Confirm baby's name, DOB and parents' contact details.

4. Explain the procedure.
5. Advise on measures to comfort the baby and reduce pain, such as feeding, sucking, engaging the baby through face-to-face contact, voice and touch.
6. Clean the heel by washing thoroughly with plain water using cotton wool/gauze. The water should not be heated and the baby's foot should not be immersed. **Do not** use alcohol or alcohol wipes. Allow the heel to dry completely.
7. Do not use any petroleum jelly/vaseline on the heel as this has shown to contaminate samples.
8. Wash hands and put on gloves.
9. Obtain the sample using an age/weight -appropriate automated incision device (manual lancets must **not** be used). An arched-shaped incision device is recommended – ideally the tenderfoot lancets which are provided.
10. Allow foot to hang to increase blood flow. Before activation, place automated device firmly against the heel. Heel puncture should be performed on the plantar surface of the heel, beyond the lateral and medial limits of the calcaneus. Marked by diagonal lines.
11. Avoid posterior curvature of the heel.



12. Wait up to 15 seconds to allow blood to flow. Apply the blood drop to one side of the card. 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 blood.



13. Repeat procedure for each circle; each drop should permeate through to the back of the card. Extra circles can be placed on the testing area of the card if required.
14. Wipe excess blood from heel and apply gentle pressure to the wound with cotton wool ball.
15. If the blood flow ceases:
 - The congealed blood should be wiped away firmly with cotton wool or gauze
 - Gently 'massage' the foot, avoid squeezing, and drop the blood onto the card
16. If the baby is not bleeding a second prick is necessary and should be taken from a different part of the same foot (within area illustrated in point 11) or the other foot.
17. Apply a spot plaster, if required.
18. Allow blood spots to air-dry before placing the card in glassine envelope.
19. An additional member of staff should check all details are correct and that the sample looks sufficient but do not delay sending the sample on the same day.
20. Transport the sample to the lab in accordance with the Standard operating procedure (SOP) in [Appendix 5](#).
21. Record taking the test in the mother's Postnatal Notes and the baby's Child Health Record ('red baby book').
22. Inform parents that they will receive a letter with the baby's results within six weeks (sooner by phone if the baby screens positive for a condition). Ensure that parents know to contact their health visitor if results are not received within six weeks.
23. Inform parents that residual blood spots will be stored securely in the laboratory for up to 5 years and are used for quality assurance.

Parents who decline screening:

1. Complete all boxes on the blood spot card, including NHS number. Use a bar code label if available and accurate.
2. Confirm baby's name, DOB and parents' contact details.
3. Parents may decline screening for any or all of the conditions:
4. If screening is declined for all conditions send completed card (without blood sample) clearly marked 'DECLINE – ALL'.

5. If declining screening for individual conditions , the blood spots should be collected as normal, and the card should be clearly marked with the condition declined e.g. 'DECLINE – XX'
6. The laboratory will inform NHS England of all mothers who have declined screening for their babies and they will create a letter for the GP and the Parents confirming their wishes.
7. Record decline, including reasons for decision, in Postnatal Notes and Child Health Record ('red baby book').
8. Confirm the parents understand the risks of baby not being screened.
9. Offer further information and who to contact if they change their minds.
10. Inform GP and HV of the conditions that the baby has not been screened for.
11. If the parents do not wish to be contacted about future research write 'NO RESEARCH CONTACT' on the blood spot card.

Repeat samples:

1. Repeats will be requested by the Community Office where insufficient blood has been obtained, was of poor quality, not valid for testing or as per national protocol for specific conditions. Repeats will also be requested when the details on the card are missing or incorrect or because a card has been used beyond its expiry date
2. If a repeat test is requested this should be performed and submitted to the laboratory within 72 hours.
3. Inform the community midwifery office when the repeat sample has been taken and sent.

Failsafe System:

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.

This is monitored by the Community Office and Newborn Screening Team.

See Appendix 4 for the Standard Operating Procedure (SOP) for use of the failsafe system.

Result reporting:

All low risk results should be sent to the family by letter from the Child Health Records Department.

It is the responsibility of the Health Visitor at the 6 week check to ensure these results have been received.

High risk results should be telephoned by the screening laboratory to the relevant consultant at UHL.

Babies suspected to be affected with one of the conditions should be seen by the relevant Consultant at UHL within the required timeframe, usually 24 hours depending on the condition.

3. Education and training:

All Midwives should attend mandatory training where there is a session on antenatal and newborn screening

4. Monitoring Compliance:

Mandatory Training is provided by the Antenatal & Newborn Screening Co-ordinator or her Deputy for all Midwives and MCA's on an annual basis at UHL. More detailed sessions are provided as a response to a high repeat rate.

Specific training on Newborn Blood spot screening as part of the induction programme at UHL for Midwives, MCA's and Doctors.

A UHL database is completed by the Community Midwifery office staff that monitors all Newborn blood spot repeat requests and the reasons for the repeat. This is reviewed regularly by the Antenatal & Newborn Screening Team and trends are fed back to Team Leaders to provide support for relevant individuals.

Team Leaders discuss performance in newborn bloodspot screening as part of their midwives annual appraisals

Performance review is undertaken if an individual fails to improve with support.

Sheffield screening Laboratory provides feedback on an annual basis of actual blood spots performed in Leicestershire and those not performed in a timely fashion.

Key Performance Indicator Data is provided to the National Screening Committee quarterly.

5. References:

Public Health England. [NHS Newborn Blood Spot Screening Programme.](http://www.gov.uk/topic/population-screening-programmes)
www.gov.uk/topic/population-screening-programmes

NHS Newborn Blood Spot Screening Programme Standards. Implementation 1 April 2017 updated 1 April 2020 <https://www.gov.uk/government/collections/newborn-blood-spot-screening-programme-supporting-publications>

Guidelines for Newborn Blood spot sampling (2016)
www.gov.uk/government/publications/newborn-blood-spot-screening-sampling-guidelines

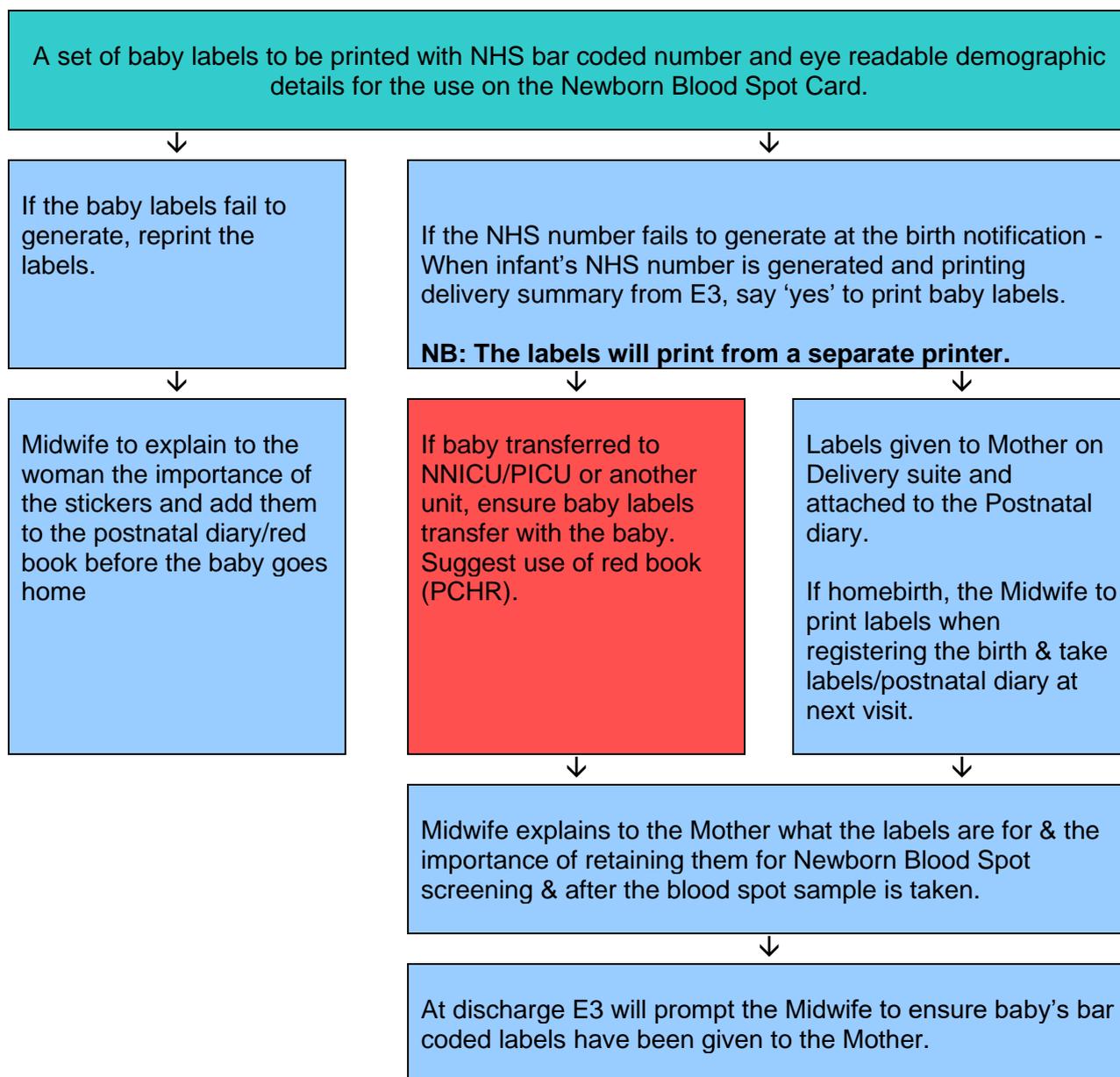
6. Keywords

Blood sample, Heal Prick,

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.

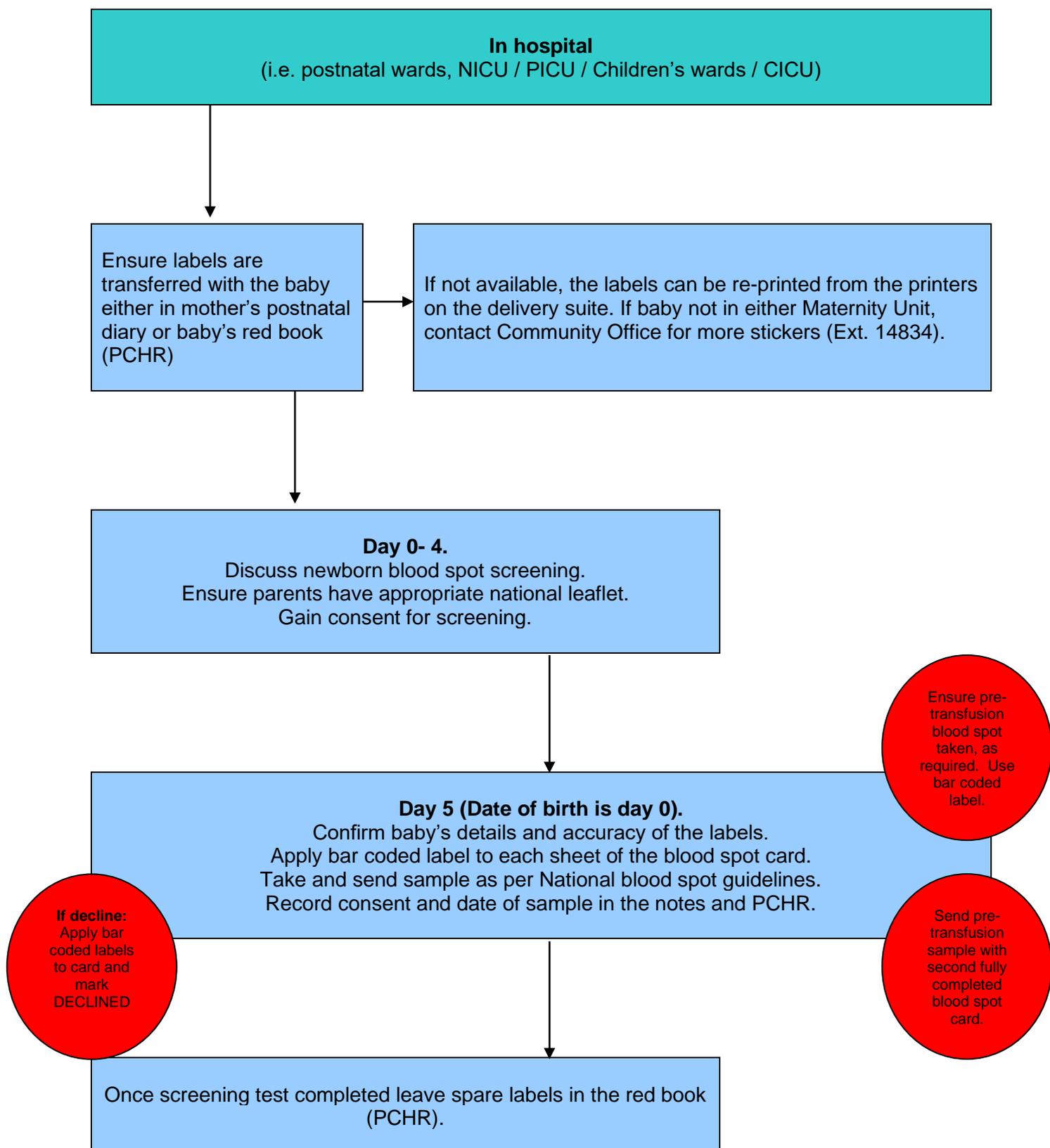
CONTACT AND REVIEW DETAILS			
Guideline Lead (Name and Title) H Ulyett - Antenatal & Newborn Screening Co-Ordinator		Executive Lead Chief Nurse	
Details of Changes made during review:			
Date	Issue Number	Reviewed By	Description Of Changes (If Any)
June 2014	V2	G Evans-Hay, Deputy Antenatal and Newborn Screening Coordinator	Regional screening lab additional conditions to be screened audit Clearer details about bar coded labels
March 2015	V3	G Evans-Hay, Deputy Antenatal and Newborn Screening Coordinator	Additional conditions now screened for as part of the national protocol Failsafe and repeat sample processes added
September 2017	V4	G Evans-Hay, Deputy Antenatal and Newborn Screening Coordinator	Change to standard 4 – take sample day 5, unless exceptional circumstances (previously day 5-8
October 2017	V4	G Evans-Hay, Deputy Antenatal and Newborn Screening Coordinator	Do not use chlorhexidine/alcohol swabs to clean the skin or petroleum jelly. Ideally use tenderfoot lancets
July 2021	V5	H Ulyett & L Payne	General update Added reference to SCID pilot screening
September 2022	V6	H. Ulyett	Changes to the transportation of samples to the lab with addition of SOP in Appendix 5.

Appendix 1: UHL pathway for the production of Newborn Blood Spot bar coded labels (Delivery Suite / Postnatal Wards).

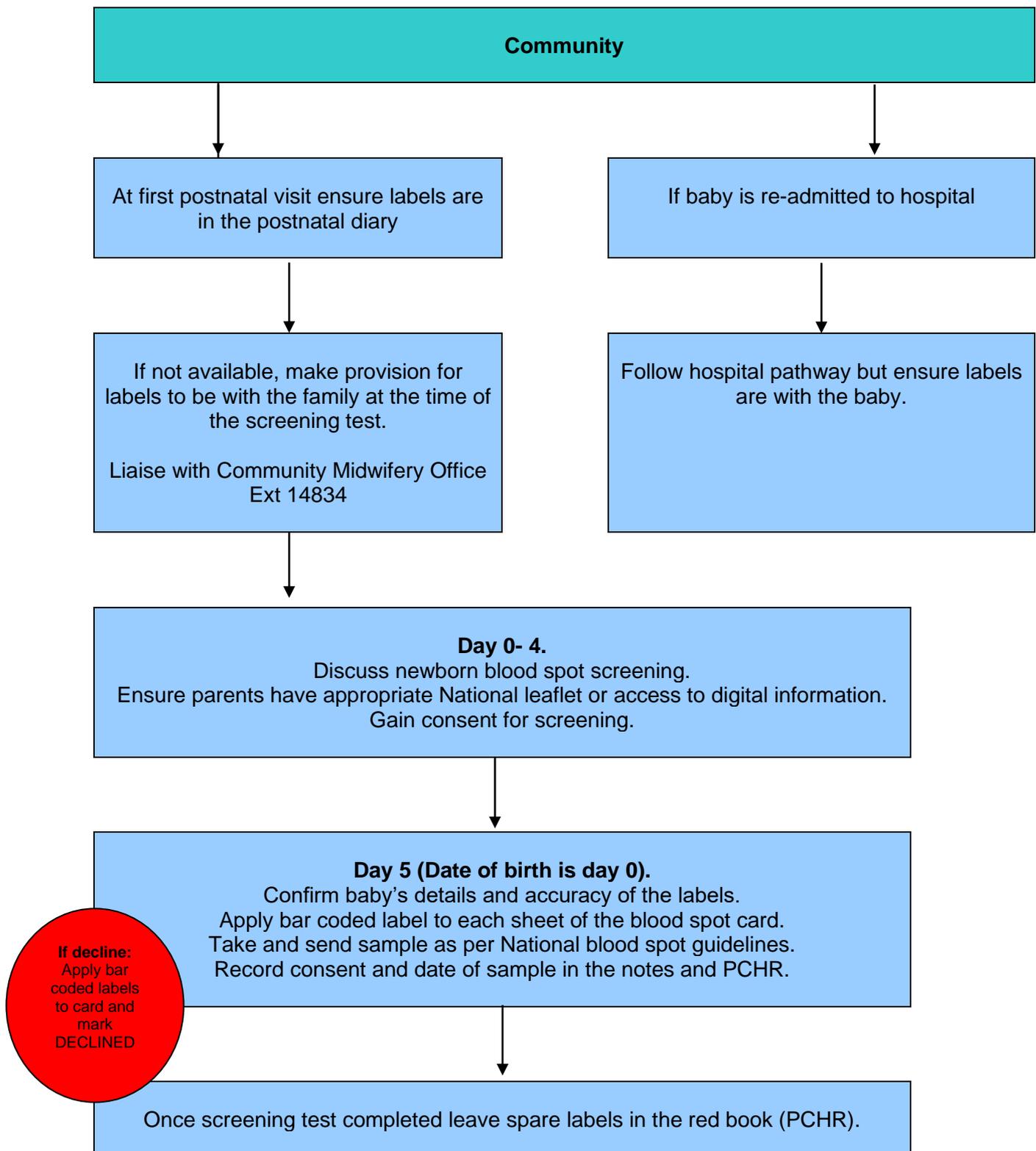


Appendix 2:

**UHL pathway for the use of the Newborn Blood Spot
Bar-coded label - HOSPITAL**

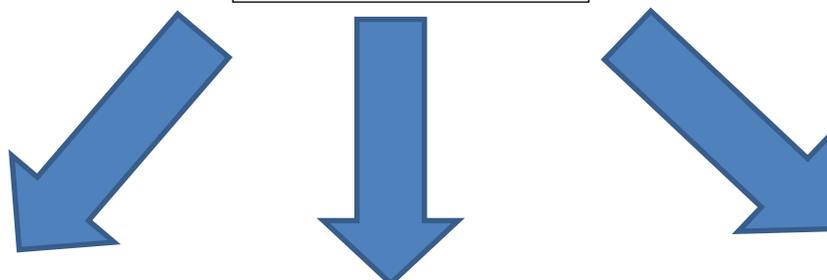


Appendix 3: UHL pathway for the use of the Newborn Blood Spot Bar-coded label - COMMUNITY



Appendix 4 - Standard Operating Procedure - for the daily review of the Newborn Blood Spot (NBBS) Failsafe system after 31st October 2022.

Log in to NBBS failsafe system daily.



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 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 Whit
- **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.

