The Northern Neonatal Network
An Operational Delivery Network
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NHS

Guideline for Newborn Blood Spot Screening

October 2017

Due for review – October 2019

Northern Neonatal Network guideline

Guideline for Newborn Blood Spot Screening

Purpose

This document offers guidance to healthcare professionals, predominantly staff on NICUs (Neonatal Intensive Care Units) and SCBUs (Special Care Baby Units) for the requirements for newborn blood spot screening. This guidance must be applied to ensure babies admitted to NICUs and SCBUs do not miss screening, especially when transfer to other hospitals and units is required. This differs from those routinely used for "well babies" that do not require admission to a baby unit.

Summary

The guideline details how and when blood spots should be taken from babies that require admission to a baby unit, including the extra steps needed when they may subsequently require transfer to other hospitals and units, including cardiac and surgical cases. It is particularly important to ensure that babies who undergo blood transfusions or are under the 32 week gestation and require further testing have the appropriate blood spots taken as highlighted below as these are the highest risk of being missed. The guideline compliments and reflects the most recent guidance issued by the nationalNHS newborn blood spot screening programme (1.). This includes guidelines for health professionals on newborn blood spot sampling (2.)

Background

Newborn blood spot screening identifies babies who may have rare but serious conditions. The national programme aims to achieve early detection, referral and treatment of babies thought to be affected by the conditions. The UK National Screening Committee (UK NSC) recommends that all babies are offered screening for phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell disease (SCD), cystic fibrosis (CF) and inherited metabolic diseases (IMDs). These are genetic diseases that affect the metabolism and include phenylketonuria (PKU),medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD) isovaleric acidaemia (IVA),glutaric aciduria type 1 (GA1),homocystinuria (HCU)

All babies are offered newborn bloodspot screen tests and it is important that parents are given appropriate information in order for them to make an informed choice and give consent if they agree based on that. The UK NSCprovides comprehensive booklets "Screening Tests for your baby" and "Screening Tests for you and your baby", these are the most suitable sources of this information and copies should be given to parents when discussing testing and seeking consent. Parents should access the NHS Choices website for further information and links for newborn blood spot screening. This includes links to documents in alternative languages. (3.)

Consent to storage of residual blood spots (4)

When taking consent for NBS screening, make sure that parents understand that

- They are consenting to processes that support the screening programme – this includes storage of residual blood spots for a minimum of 5 years
- Residual blood spots can be used to check screening results, for testing equipment or methods, and for training and audit
- Residual blood spots can also be used for health research that does not identify their baby
- They must be asked if they consent to future contact about research that could identify their baby
- If parents do not consent to future research contact, you must record this in the baby's notes and in the comments box on the blood spot card as 'no research contact'.

Responsibility for Admission Day Blood Spot Screening

The responsibility for ensuring the admission day blood spot screening test for a baby under 5 days of age is undertaken is dependent on the circumstances at birth and transfer, Both sender and receiver unit staff are responsible for communicating the status of the admission day blood spot screening.

1. Babies transferred direct from a delivery suite to same unit: **the NICU/SCBU staff are responsible for ensuring an admission day blood spot is taken.**

2. Babies transferred direct from a delivery suite to an external NICU/SCBU: **the receiver unit is responsible for ensuring the admission day blood spot.**

Method

Practical bloodspot sampling – sample collection methodology

Full details as to the methodology used in the actual bloodspot sampling, including suggested equipment, paperwork and technique are detailed in the NSC Guidelines[1] (pages 1- 10). This includes the use of the bar coded labels and what to do if consent for screening is withheld. These are for the general bloodspot screening and sampling guidelines, which is usually routinely taken on day 5 of age (the day of birth always being counted as day "0"). However, for babies admitted to NICUs and SCBUs, the additional important principles to grasp are;

1. All babies MUST have a SINGLE blood spot taken on admission if they are under 5 days of age. The blood spot card used for this should be marked "**Pre Transfusion**".
2. This "Pre Transfusion" card should be stored with the baby's notes/medical records (in line with local protocols and policies) and sent in addition to the

routine day 5 full 4-spot sample card ***if the baby has received a blood transfusion between admission and day 5 sampling.*** NB the pre-transfusion card can not be added to for the 5 day sample.

3. If the baby is transferred to another hospital/unit (***including a cardiac/surgical ward***) before the day 5 sample is taken, ensure the "Pre Transfusion" card accompanies the baby. Details of all newborn sampling should be documented and included in any transfer information – and also entered on to the Badger system. (See Appendix 1 for the correct pathway for all babies requiring transfer). If the baby is not transfused before the 5 day sample is taken the admission days sample can be appropriately discarded.
4. When a baby has had a blood transfusion (either intrauterine or in the newborn period) before the routine day 5 sample is taken, ***another*** sample (four spots) is needed at least 3 clear days after the last blood transfusion.
5. In the event of multiple blood transfusions, even if it has not been at least three clear days since the last transfusion, a routine blood spot sample should be sent by day 8 at the latest regardless. In this scenario, a repeat sample will be needed at least three clear days after the last transfusion (For intrauterine transfusions, count the date of birth as the date of transfusion)
6. The date of the last blood transfusion before the blood spot sample must be recorded on the card ***and*** on any discharge/transfer paperwork and notifications when the baby is moved to another hospital/unit.

General blood spot sampling principles;

1. Babies admitted to NICUs/SCBUs are likely to have multiple blood samples taken both at admission and throughout their stay, therefore wherever possible; blood spot screening should be co-ordinated with other sampling/tests.
2. Venepuncture or arterial/venous sampling from an existing line can be used to obtain the newborn blood spot sample but it must ***not*** be contaminated with EDTA and the lines/syringes flushed clear of any infusate from the line used in accordance with normal local policies and guidelines.
3. ***All*** details on the blood spot sample card must be completed, including the baby's NHS number in all cases before sending for testing in accordance with local policies and guidelines.
4. Parents should be informed of any outstanding screening tests, and this should be recorded in the Personal Child Health Record (PCHR). They should also be advised of which healthcare professional will be responsible for completing the blood spot screening and approximately when it will occur. In the case where newborn blood spot bar coded labels are used these should be checked with the parents before being attached to the request card.
5. Provider organisations should also ensure failsafe arrangements are in place for notifying screening status when the care of babies is transferred. This includes babies who are transferred in the neonatal period.
6. In the event that a baby dies it is the responsibility of the staff member in charge to notify both the Child Health Record Department and the Local Screening Coordinator for the Maternity Service.

Rationale

1. It is important to minimise blood sampling in sick and premature babies, particularly those of extremely low birthweight due to their low circulating blood volume and increased risk of anaemia.
2. The screening test for SCD cannot be done on samples from babies who have received a blood transfusion.
3. The single circle blood spot sample taken and marked as 'Pre transfusion' can be discarded if the baby does not receive a blood transfusion.
4. For SCD, a pre-transfusion sample is the preferred option for sickle cell screening. To ensure all babies are screened for SCD
5. Maternity units across England and Wales have implemented the Northgate national maternity failsafe IT system in order to ensure that all babies have a concluded result from screening. The system alerts maternity staff of babies where a sample has not reached the laboratory (including avoidable repeat samples) to ensure a rapid response for offer of screening or repeat testing. In the event that a baby dies the record should be marked by the Screening Coordinator to ensure no visit is made to the home to take the sample.

CHT Preterm Repeat Blood Spot Screening

1. Babies born at less than 32 weeks (equal to or less than 31 weeks + 6 days) require a second blood spot sample to be taken in addition to the day 5 sample (counting day of birth as day 0). These babies are to be tested when they reach 28 days of age (counting day of birth as day 0) or day of discharge home, whichever is the sooner.
2. To meet this requirement, a further blood spot card should be completed in the same way as outlined above on day 28, but with '**CHT preterm**' on the card. Write the gestational age on the card. Only ***two*** spots on the card should be filled with blood.
3. The responsibility for taking both samples lies with the healthcare professional that is responsible for clinical care at the time the blood spot sample is due.
4. In babies who are transferred before they reach 28 days of age, the responsibility for completing screening is transferred to healthcare professionals in the receiving unit.
5. Record all blood spot samples taken in baby's hospital records, on transfer documentation, PCHR and on the Badger system.

Rationale

1. To ensure a valid sample for congenital hypothyroidism screening as immaturity/prematurity can mask this condition.
2. The card is marked "CHT preterm" to ensure laboratory is aware of reason for second sample.
3. To ensure babies who are transferred at less than 28 days of age have all newborn blood spot tests completed.
4. To ensure screening will be completed by receiving unit.
5. To ensure all babies born at less than 32 weeks (equal to or less than 31 weeks + 6 days) are screened.

References

1. UK National Screening Committee, Newborn Blood Spot Programme Overview: https://www.gov.uk/guidance/newborn-blood-spot-screening-programme-overview

2. UK National Screening Committee (UK NSC), (2016) Guidelines for Newborn Blood Spot Sampling https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/511688/Guidelines_for_Newborn_Blood_Spot_Sampling_January_2016.pdf

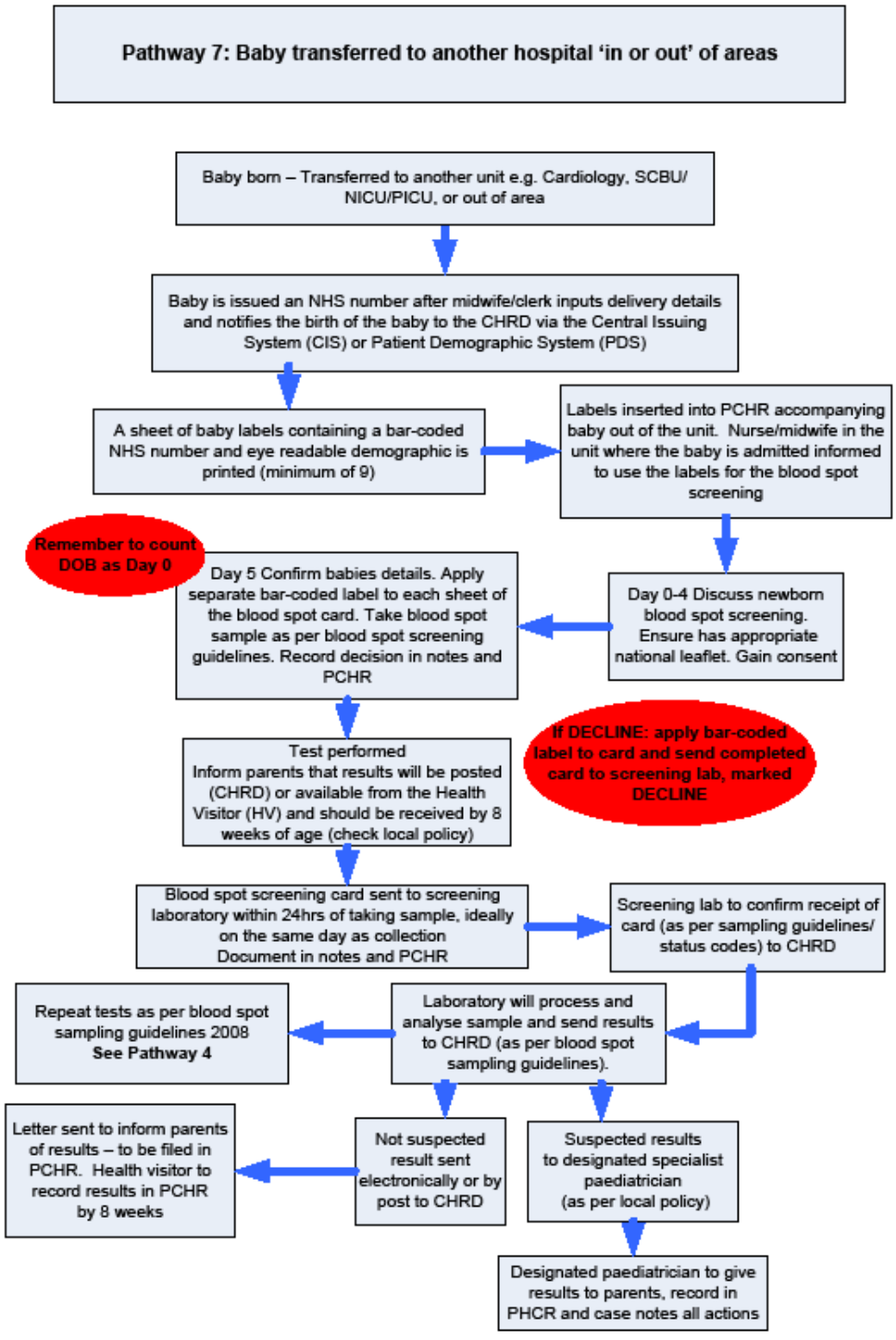
3. NHS Newborn Blood Spot Screening Programme Failsafe processes, (2011) https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-procedures

4. NHS Choices, Newborn screening, http://www.nhs.uk/Conditions/pregnancy-and-baby/Pages/newborn-screening.aspx

5. UK National Screening Committee (2015) Code of Practice for the Retention and Storage of Residual Newborn Blood Spotshttps://www.gov.uk/government/publications/newborn-blood-spot-screening-code-of-practice-for-the-retention-and-storage-of-residual-spots

Appendix 1

Pathway for babies requiring transfer to another hospital/unit, including out of area transfers.



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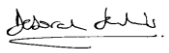
Signed off by Board	 D. Jenkins, Network Chair August 2014
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V 1.0	September 2012	Guideline Group
V 1.1	October 2012	Network Board
V 2.0	June 2014 with amendments from Kim Moonlight and Liz Robinson	Guideline Group
V3.0	October 2017 update/ amendments from Liz Robinson	Network Clinical Lead