University Hospitals Sussex
NHS Foundation Trust

Newborn Blood Spot Screening

Maternity Protocol: MP079

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Guideline Reviewer:	Alex Winstanley and Sally Burrows
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Contents

Key Principles
A protocol is a set of measurable, objective standards to determine a course of action. Professional judgement may be used in the application of a protocol.

Scope
♦ This protocol applies to: all babies born within BSUH NHS trust or resident within the catchment area within the first year of life. This includes babies who were born elsewhere but have moved into the area during the first year of life.

Responsibilities

- Midwives & Obstetricians: [include neonatal staff, and those members of staff trained to take newborn blood spot screening samples: this may include nursery nurses, maternity support workers and maternity / neonatal care assistants working under supervision of a registered professional:
    - To access, read, understand and follow this guidance
    - To use their professional judgement in application of this protocol

- Management Team:

    To ensure the protocol is reviewed as required in line with Trust and National recommendations

    To ensure the protocol is accessible to all relevant staff

Update Process

Prior to the review of this guideline a structured search and appraisal of the evidence will be undertaken by the lead author with the library services in the Trust. The most recent national guidance from the RCOG is still current at the time of this update and no additional evidence was found that added to the recommendations in this document.

1.0 Newborn Blood Spot Screening: Rationale for Screening and Conditions Screened for

1.1 Newborn blood spot screening is recommended for all babies up to one year old. Up to but not including 1st birthday. Screening for Cystic Fibrosis is unreliable after 8 weeks.

1.2 At BSUH screening is offered for the following conditions:

- phenylketonuria [PKU]
- congenital hypothyroidism (CHT)
- medium chain acyl-Co A dehydrogenase deficiency [MCADD]
- sickle cell disease [SCD]
- cystic fibrosis [CF].
- maple syrup urine disease (MSUD)
- homocystinuria (pyridoxine unresponsive) (HCU)
- isovaleric acidaemia (IVA)
- glutaric aciduria type 1 (GA1)

1.3 A summary of the national pathway for newborn screening is given in diagram 1.1 below:

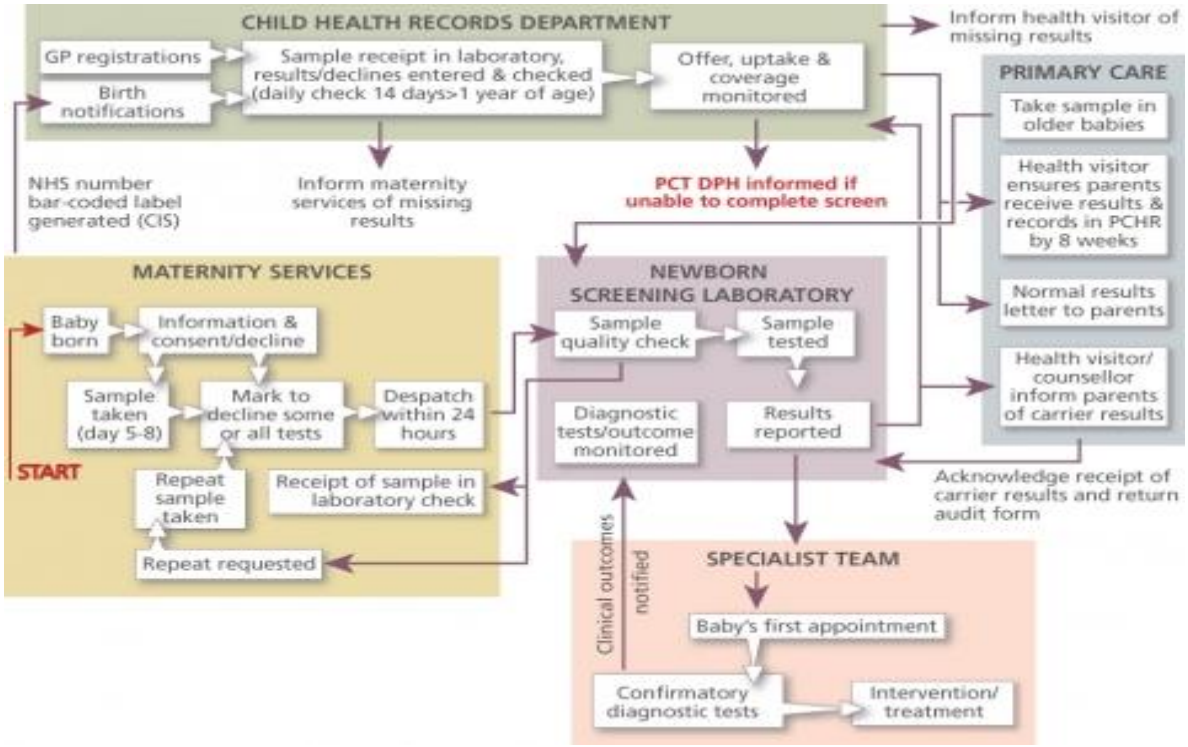


Diagram 1.1 Ref: NHS Newborn bloodspot screening programme [2013]

1.4 Aims and Objectives

1.4.1 The aims of newborn blood spot screening are:

- To achieve early detection, referral and treatment of babies thought to be affected by the conditions.

- To reduce morbidity and mortality through prompt identification and treatment of affected babies

1.4.2 The national objectives of the newborn bloodspot screening programme [NHS England 2018:

- To offer all eligible babies timely screening
- Support parents to make an informed choice about screening for their baby.
- To refer all screen positive babies to diagnostic and clinical care within an effective timeframe (in accordance with standards) remove in brackets
- Provide equal access to high quality screening across England
- To record all results on a Child Health IT system and give a copy to parents
- To ensure all those involved in the care of the child also have access to the results – remove this statement
- Minimise harmful effects of screening including anxiety, inaccurate information and unnecessary investigation.

1.5 The designated programme lead for maternity services at this trust is the antenatal screening co-ordinator.

1.6 See appendix B for contact details of the BSUH programme lead and other staff, departments and organisations relevant to the screening programme.

1.7 This screening programme is dependent on systematic specified relationships between the following stakeholders: maternity services, neonatal and paediatric services, the newborn screening laboratory, diagnostics and genetics laboratory, child health records, health visiting services, and specialist condition specific services. This protocol includes details of roles and responsibilities of external agencies where relevant.

2.0 Definition of 'sample taker'

2.1 The term 'sample taker' is used throughout this document to indicate the clinician responsible for obtaining parental consent and taking the blood spot sample.

2.2 The newborn blood spot sample may be taken by any member of staff who has undergone training for the procedure. Within BSUH NHS TRUST this may include:

2.2.1 Registered professionals:
Midwife
Nurse [neonatal / paediatric]
Doctor [paediatric]

2.2.2 Non-registered staff:
Nursery nurse
Maternity support worker
Paediatric phlebotomist

2.3 Nursery nurses and maternity support workers may take the sample only after appropriate training and only working under supervision of a registered nurse or midwife. They should only be assigned routine cases and must refer back immediately to their supervising professional in the following circumstances:

2.3.1 Where parents decline screening for some or all of the conditions.
2.3.2 [In such cases, a follow-up visit by a registered nurse or midwife, must be arranged within 24 hours of the parent declining the test]
2.3.3 Where parents have questions that the nursery nurse or maternity support worker cannot answer

2.4 A paediatric phlebotomist may take the sample following referral by a registered professional who has previously conducted pre-test discussion and obtained and documented parental consent. The referring professional is responsible for completing the sample request card [except for date of sample collection and name of sample taker which should be completed by the sample taker at time of sample collection].

2.5 Repeat samples for an inconclusive result or suspected affected baby must always be taken by a registered professional as these cases are likely to involve more detailed explanations requiring additional expertise. A registered professional may refer a baby for a repeat sample to paediatric phlebotomy after discussion with the parents.

3.0 Pre-Screening Information

3.1 The trust uses the UK National Screening Committee patient information leaflet 'Screening tests for you and your baby' which includes the section 'Blood spot screening for your newborn baby'. Available in a number of languages at gov.uk

3.2 The patient information leaflet should be given to women prior to or at booking [ideally prior to 10 weeks gestation]. Parents who have babies admitted to the neonatal unit will receive a copy of this leaflet on admission.

3.3 The midwife should document at booking in the maternal hand held notes that this information leaflet has been given.

3.4 The sample taker should ensure that parents have had access to the patient leaflet at least 24 hours before the test is due and they should document this in the maternity or paediatric notes.

3.5 Leaflet is available in English and other languages to download via the following website: https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief

3.6 Interpreting services should be used for communicating with parents who are not fluent in English at all stages of the screening pathway.

4.0 Offering screening

4.1 Newborn bloodspot screening should be offered to all babies:

4.1.1 The policy is to actively recommend screening however parents have the right to decline some or all of the tests.

4.1.2 Pathway 1 [Appendix A] summarises the pre-test information and testing process.

4.2 Pre-test discussion

Pre-test discussion with the parent[s] should ideally include the following:

- The conditions currently being screened for including rationale for screening and treatment in the case of an affected baby
- That this is a screening test and so both false-negatives and false-positives can be obtained
- How the test is taken from their baby
- The results process to include follow up in the case of a screen positive result
- Sample storage and future research [see section 4.4]

4.2.1 If parents require further information that cannot be answered by the sample taker, then referral can be made to the screening midwife team [see contacts appendix B].

4.3 Obtaining consent to screen

4.3.1 Screening should only be performed with parental consent. Verbal consent is adequate and so does not require a signature from the parent.

4.3.2 The professional gaining consent from the parents should document in the postnatal baby notes, [or neonatal/ paediatric notes if the baby is under the care of the paediatric services], that discussion has taken place and the parent's decision to accept or decline screening.

4.3.3 Consent should also be documented in the personal child health record book [PCHR] where available.

4.4 Parents must understand that they are agreeing to both testing and quality assurance processes that are an essential part of the screening program. These include:

- completing the blood spot card and taking the sample
- testing the blood spot sample in a newborn screening laboratory
- additional testing of the same sample if the initial result is positive (may involve testing in another laboratory)
- contacting parents about the screening results – positive or negative or carrier (only for CF and SCD)
- referral to a specialist clinical team if the result is positive
- recording the screening results on laboratory and child health information systems, national newborn blood spot failsafe solution and sickle cell and thalassemia newborn outcomes system
- retention and storage of residual blood spots for checking the screening results, monitoring and improving the screening program
- Residual blood spots are dried blood spots that are 'left over' after the laboratory punches (removes) several small discs from the sample to complete screening. The screening laboratory stores them for 5 years.
- Laboratories use residual blood spots to check screening results, for testing equipment or methods, and for training and audit. It is a vital part of screening that helps to maintain high standards. If parents consent to screening, they cannot opt out of storage of their baby's residual blood spots for these purposes.

5.0 When Parents Decline Screening

5.1 Although screening is recommended, parents have the option of declining some or all tests offered.

5.2 With regard metabolic disorders, parent cannot decline individual metabolic disorders. They can decline all of them or accept all of them. This is because they are processed simultaneously in the lab and it is not possible to exclude screening for individual metabolic disorders from the testing panel.

5.3 Where parents have declined screening and the member of staff involved at the point of declining is a Phlebotomist, Maternity Support Worker or Nursery Nurse, then a follow up appointment should be made with a registered midwife [or neonatal professional if the baby is on the special care unit or Health Visitor if the baby was referred by the HV] to revisit and discuss the offer of a test again within 24 hours of the decline.

5.4 Where parents have declined screening, the sample taker must complete the following actions:

5.4.1 Document the decline and reason for the decline [if stated] in the maternity postnatal baby notes or paediatric record and, if available, personal child health record book [under 'birth details' section].

5.4.2 Complete all sections of the sample card as described in section 6.2] and write the following on the card according to which tests have been declined:

If all tests are declined write: '*DECLINES ALL TESTS*'

If specific tests are declined – write the specific tests declined on the card.
E.g. if sickle cell and CF have been declined write:
'*DECLINES SICKLE CELL and CF ONLY*'

5.4.3 Send the completed sample card [without any blood spots if all tests were declined] to the laboratory as per section 8.0. The rationale being that the newborn screening laboratory receives a card for every baby born. The newborn screening laboratory will then inform the child health record department that screening has been declined.

5.4.4 Inform the following professionals in writing of the conditions for which the parents have declined screening using the template letter in appendix E as a guide:

- General practitioner
- Health visitor
- Child health record unit
- Community midwife team leader

5.4.5 A copy of this letter should be retained in the postnatal maternity records.

5.4.6 Ask the parents to sign the 'decline form' in appendix F and retain this to be inserted in the postnatal baby notes.

5.5 The registered professional discussing the implications of declining screening with parents should clearly state the following:

5.5.1 The potential complications if their baby is affected by one of the conditions being screened for and remains undiagnosed. Such complications include irreversible brain damage and death and this should be clearly stated to the parents.

5.5.2 That many of the conditions being screened for are recessively inherited and so anyone could carry these genes and not be aware of it. Hence the fact that if there is no one in their family with these conditions it does not mean that they cannot have an affected child.

5.6 Details of the discussion made between the registered professional and the parents should be clearly documented in the baby notes.

5.7 The sample taker should inform parents who to contact [and how to contact them] if they subsequently change their minds about screening or would like to discuss this further. The screening midwife team are available to speak with parents for further

discussion in such cases [see appendix B for contact details]. The parents should be given a letter that confirms their decision (for their records).

6.0 Performing the Screening Test

6.1 Timing

6.1.1 The blood spot sample should be taken on day 5 of life. For the purpose of screening, date of birth is day 0.

6.1.2 The sample should be taken on day 5 of life on all babies where parental consent has been given regardless of medical condition, prescribed drugs, milk feeding and prematurity.

6.2 Completing the blood spot card

6.2.1 Prior to completing a sample card, the sample taker should check the expiry date on the front of the card. The laboratory will be unable to process samples if the card is out of date and a repeat sample will be required, resulting in a possible delay in treatment if the baby is subsequently diagnosed with a condition.

6.2.2 A sample card should not be used if it has been damaged in any way, for example the blotting paper is folded, contaminated or has been compressed.

6.2.3 It is the responsibility of the sample taker to enter the details on the blood spot card at the time of sampling.

6.2.4 It is mandatory to enter the baby's NHS number onto the sample card. Where the NHS number is not given or is incorrect, the laboratory will issue a request for a repeat sample to be taken resulting in a possible delay in treatment if the baby is subsequently diagnosed with a condition.

6.2.5 If available, a NHS number bar-coded label should be used. When using a bar-coded label:

- Ensure no sections of the bar code or text are missing
- Ensure the printing is aligned: the laboratory may reject a card where the print is misaligned, partially missing or at an angle.
- Check all details on the label are correct with the parent and make any necessary changes
- Apply one label to each sheet of the blood spot card at the time of sampling

6.2.6 Any additional information required on the card that is not included on the bar-coded label should be completed by the sample in block capitals.

6.2.7 Where labels are not available, the sample taker should ensure that all fields on the card are completed using legible handwriting. The sample taker should then check all details entered by hand onto the sample card with the parent.

6.2.8 When completing the card, care must be taken to ensure it is placed on a clean surface to avoid contamination of the blood spot sample.

6.2.9 Care must be taken not to fold or compress the blotting paper on the card as this will result in the sample being rejected by the laboratory.

6.2.10 The sample taker should, where relevant, enter the following information in the 'comments' box on the card:

- Baby's known medical condition [if any] including any drugs received by the baby or breastfeeding mother within 24 hours of the blood test.
- State if the baby had an in-utero blood transfusion
- State if the mother has received thyroxine or anti-thyroid drugs
- Relevant family history [e.g. known history of PKU, CF, MCADD etc]
- Results of pre-natal diagnostic testing if relevant [for example CVS result where the couple was at–risk for having a baby with sickle cell disorder]
- Mother's carrier status for sickle cell of haemoglobin variant [if known]
- If the sample was not taken on day 5, state why: [eg pre-transfusion spot, preterm CHT]

6.2.11 Write the maternity code into the PCT box [bottom left hand corner of the sample card]. The maternity code alerts the screening lab as to which trust took the sample [which may of course be different to the hospital of birth]. This ensures swift follow up on any samples that may require repeating. Use the maternity code as listed in the table below according to where the sample was taken:

Maternity codes for newborn bloodspot screening cards	
CODE	**For samples taken in:**
RXH 1 M	RSCH maternity Community / hospital midwifery
RXH 1 T	RSCH TMBU Trevor Mann Baby Unit
RXH 1 A	RACH Royal Alexandra Children's Hospital
RXH 2 M	PRH maternity Community / hospital midwifery
RXH 2 S	PRH SCBU PRH special care baby unit

7.0 Collecting the Blood Spot Sample

7.1 Sample takers should gather necessary equipment prior to taking the sample and comply with the trust guidance on infection control, using universal precautions before taking any blood sample.

7.2 The sample taker should recommend comfort measures for the baby [UK Newborn Screening Programme Centre [2012] section 3 page 6]:

7.2.1 Ensure the baby is cuddled and in a secure position for taking the sample as swaddling may reduce pain and discomfort

7.2.2 Engaging the baby through face-to-face contact, voice and touch may also be beneficial

7.2.3 Breastfeeding during sample collection may have analgesic affect. Offering expressed milk, non-nutritive sucking [e.g. a pacifier] or a sucrose or glucose solution are alternatives to breastfeeding. Painful procedures are a medical indication for such measures and do not undermine the WHO/UNICEF's Baby Friendly Initiative.

7.2.4 There is no evidence that formula feed has analgesic properties, but parents may comfort formula fed babies with a feed during the procedure.

7.2.5 Containment holding or the use of a pacifier (with parental consent) may provide comfort measures for babies on the neonatal unit

7.3 Preparing the foot

7.3.1 The heel should be cleaned prior to taking the sample, with tepid plain water and cotton wool/ gauze. This is to avoid contamination of the sample which may affect results.

7.3.2 Alcohol or alcohol based wipes must NOT be used as this can cause burns and blisters.

7.3.3 Soap and detergent should not normally be used as this can be irritant to infantile skin. However if faecal matter cannot be removed with water alone, mild unperfumed soap may be used and rinsed off thoroughly after. Faecal contamination of the sample can lead to a false positive result for CF screening

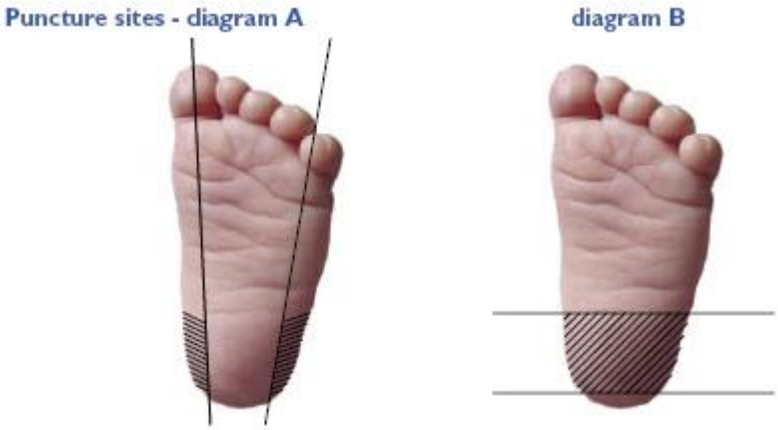
7.3.4 The heel should be completely dry before taking the sample

7.3.5 The baby should be warm and comfortable prior to taking the sample. Additional warming is not required. The foot should NOT be soaked in warm water as there is no evidence that warming the foot aids blood flow and there have been reports of babies being scalded/ burned during foot warming [UK Newborn Screening Programme Centre [2012] section 3.4 page 7]

7.3.6 The sample should be obtained using an automated incision device designed for use on newborns [eg Gentleheel lancet] in accordance with manufacturer's instructions. The device should be placed against the heel gently and not pressed into the heel, to ensure correct depth of incision is achieved. Manual lancets must not be used.

7.3.7 For full term and preterm infants, the external and internal limits of the calcaneus are the preferred puncture site. This is marked by the shaded area in diagram A below. The skin to calcaneous depth is greater in these areas and so using these areas minimises the risk of calcaneal puncture that may lead to osteomyelitis. The automated incision device should have a penetrative depth of no more than 2.0 mm.

Diagram A and B – Puncture sites [UK Newborn Screening Programme Centre 2012 page 8]



7.3.8 For infants requiring repeated heel punctures, for example babies in neonatal or paediatric care, the areas marked in diagram B may also be used. However when using the whole plantar surface, it is recommended that the automated incision device should have a penetrative depth of no more than 1.0 mm [Arena et al 2005 in UK Newborn Screening Programme Centre 2012].

7.3.9 Avoid the posterior curvature of the heel.

7.3.10 Allow the heel to hang down to assist blood flow.

7.3.11 It is acceptable for paediatric phlebotomists who are trained in venous sampling of neonates, to take a venous sample from the antecubital fossa and use this for newborn bloodspot sampling. Such samples should be obtained in accordance with phlebotomy protocols.

7.4 Filling the Circles

7.4.1 The aim is to fill each circle on the newborn blood spot sample card using a single drop of blood. The blood should reach the printed edge of the circle.

7.4.2 Wait for the blood to flow. Allow one spot to drop onto each of the circles on the card. Do not allow the heel to make contact with the card.

7.4.3 Allow the blood to fill the circle by natural flow and seep through the card.

7.4.4 Do not squeeze the foot in an attempt to increase blood flow.

7.4.5 The minimum sample requirement for day 5 screening is for four blood spots at least 7mm in diameter. Therefore aim to fill each of the four circles completely.

7.4.6 Table 7.1 summarises the number of spots required according to reason for sampling and advises which section of the policy to refer to for further information:

Table 7.1: Number of spots required for sampling **Reason for sampling**	**Baby's age at which sample should be taken**	**Minimum number of spots required**	**Section in policy to refer to for further information**
Pre-transfusion admission spot [on NICU or SCBU] to be dispatched with D5 spot	On admission to NICU/ SCBU	1	12.3
Routine for all babies	Day 5	4	6.0 and 12.4
Repeat sample requested by the lab because: - Because first sample went missing - Because first sample was insufficient or unsuitable	Within 72 hours of laboratory request for repeat	4	10.3
Repeat sample for confirmation [Usually CF]	As directed by laboratory	2	10.2
Premature babies born < 32 weeks – repeat for CHT screening	Day 28 or discharge – whichever is soonest	2	12.6
Baby has moved in to area having not previously been screened or no evidence that screened for all conditions currently offered in England	Up to 1 year of age	4	11.0

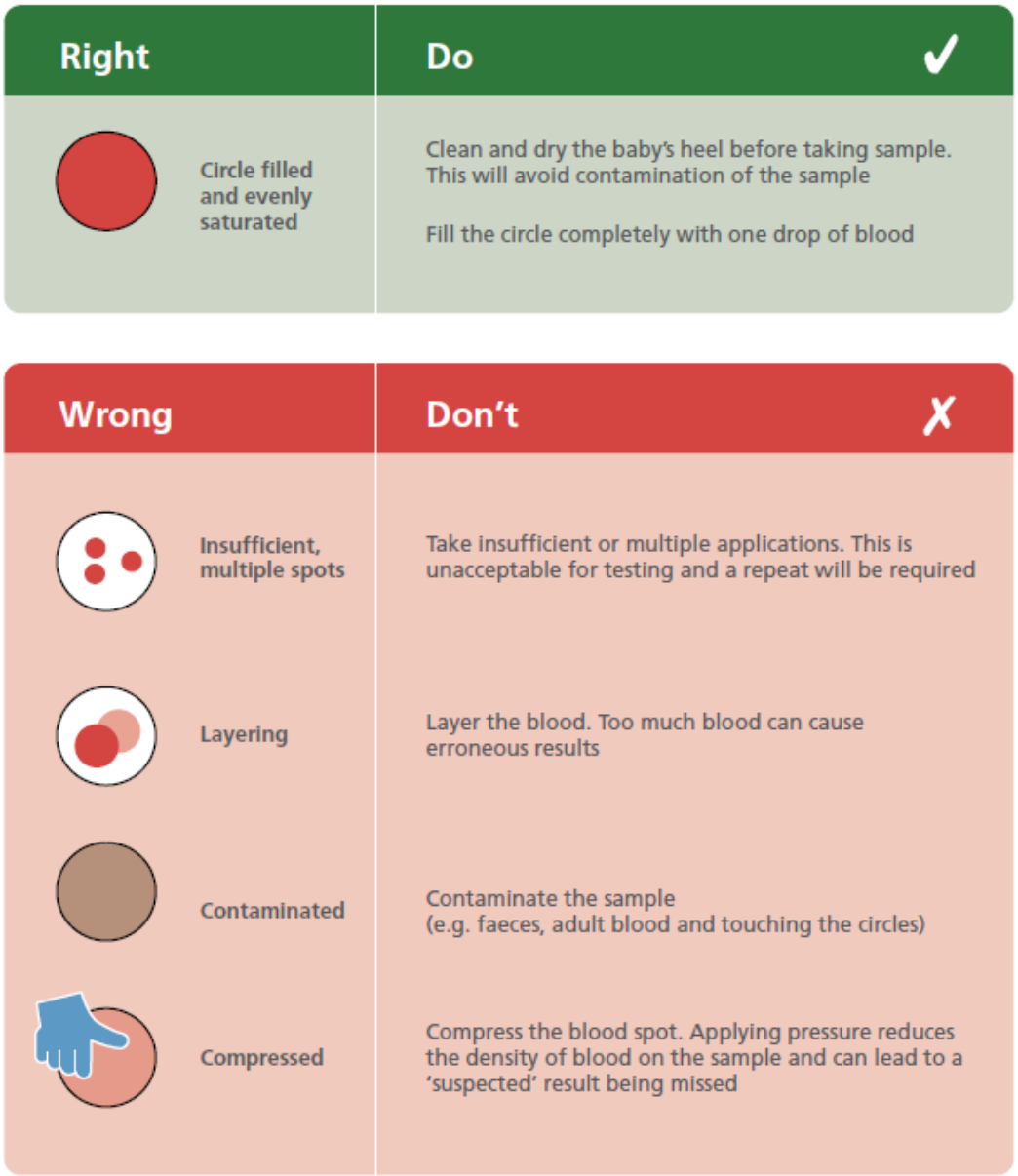
7.4.7 Do not layer the blood. Layering is where more than one drop of blood has been added on top of another blood spot to one circle from either the same side of the card or both sides of the card. Layered samples are not acceptable as they can give false positive results and the laboratory will request a repeat sample.

7.4.8 After taking the four spots of blood, ensure the blood has seeped through to the other side. If one circle is insufficient it is acceptable to add additional blood spots anywhere on the blotting paper, taking care that the blood spots don't join together.

7.4.9 Do not compress the blood spot in order to ensure that the blood has soaked through to the reverse of the card. This increases the risk of a false negative result.

7.4.10 See Diagram C for summary [UK Newborn Screening Programme Centre 2012]

Diagram C



7.4.11 If the blood ceases to flow:

- Wipe away the congealed blood with cotton wool or gauze.
- Gently massage the foot, avoid squeezing, to encourage flow and drop the blood onto the card.

7.4.12 If the baby is not bleeding, a second puncture is required. Perform the second puncture on a different part of the same foot or on the other foot.

7.5 After taking the sample:

7.5.1 Wipe excess blood from the heel and apply gentle pressure to the wound with gauze or cotton wool. This should be sufficient to stop bleeding in most babies.

7.5.2 If required, in a healthy term neonate, a hypoallergenic spot plaster may be applied, reminding the parent to remove the plaster in a few hours. However if the baby is on the neonatal unit, spot plasters are not to be used, in order to minimise the amount of adhesive that is applied to the skin [especially premature skin which is more delicate] and to avoid the risk that the plaster may come off and remain unnoticed in the incubator creating an infection risk.

7.5.3 Allow blood spots on the sample card to air-dry away from direct sunlight or heat before placing in the glassine envelope for protection.

7.6 Documentation of sample taking

7.7 The sample taker must record that the sample has been taken in the mother's maternity record and PCHR [and the child's hospital records if appropriate].

7.8 All blood spots to be double checked by another practitioner qualified to perform bloodspots before posting.

7.9 The screening status should be recorded on discharge and transfer notifications by the clinician responsible for discharging the baby.

8.0 Sample Transport

8.1 Posting routine samples [routine day 5 samples]

8.1.1 Samples are processed at the Newborn Screening Laboratory at St. Thomas's Hospital, London [see address appendix B]

8.1.2 It is the sample taker's responsibility to ensure that the sample is transported to the laboratory according to these guidelines.

8.1.3 All samples must be despatched to the newborn screening laboratory in the prepaid addressed envelope and posted within 24 hours of the sample being taken.

8.1.4 Samples are posted using first class Royal Mail either in standard post boxes or via the hospital post room.

8.1.5 Samples must NEVER be sent via hospital internal mail as this causes unacceptable delays in the cards reaching the laboratory. However, sample cards from babies that are in-patient [to include babies on postnatal wards, neonatal units, paediatric wards or out-patient paediatric phlebotomy] can be taken on a daily basis direct to the hospital post-room on each site where staff will put the samples immediately into the external post.

8.1.6 Samples must be posted on the same day that the sample was taken. Despatch should not be delayed in order to batch cards together.

8.1.7 A maximum of 5 sample cards can be put in one pre-paid envelope.

8.2 Record of samples taken by the maternity unit

8.2.1 Every sample taker should keep a record of all samples that they have taken and sent to the laboratory. This record must include the baby's name and NHS number, date taken, card serial number, reason sample was taken, date posted and location of post box used. This is for internal audit purposes. See appendix C for an example record sheet.

8.2.2 The sample taker must forward the record sheets of samples taken on a weekly basis to a central collection point where they are to be retained for audit:

- RSCH midwives – level 12 community office, RSCH
- PRH midwives – community office, PRH

8.3 Record of samples taken by the neonatal unit / SCBU

8.3.1 Babies screened on the neonatal unit [Trevor Mann Baby Unit and Special Care Baby Unit] will retain a central record of all babies screened in each area respectively. As it is necessary to record where samples were posted, it would be advisable to post all samples at either the hospital post room or post box immediately outside the hospital.

8.4 Record of samples taken by the RACH

8.4.1 Paediatric wards at the Royal Alexandra Children's hospital should maintain a record of all samples taken. As it is necessary to record where samples were posted, it would be advisable to post all samples at the hospital post room.

8.5 Sample transport in exceptional circumstances

8.5.1 Where there are exceptional circumstances that may disrupt postal services and delay sample transport to the laboratory [for example: over long bank holiday periods, prolonged bad weather or postal strikes], contingency plans will be made for alternative methods of transporting samples to the laboratory.

8.5.2 At such times the trust may revert to using a courier service during the period of disruption. Staff will be informed of changes to services accordingly and advised of sample collection points. At such times further information will be available via the Community Midwifery Matron, antenatal screening midwives or community midwife team leaders.

8.6 Transport of repeat samples

8.6.1 Where a sample requires repeating [regardless of the reason], there is already the possibility of delayed diagnosis of an affected baby. For this reason every effort must be taken to repeat and transport the sample to the laboratory as quickly as possible.

8.6.2 In all cases it is the sample taker's responsibility to ensure that the repeat sample has arrived at the laboratory within 5 working days of taking the sample. In the case of samples taken by the paediatric phlebotomy department, it is the sample requestor's responsibility to do this.

8.6.3 In certain circumstances, it is advisable to use a courier to transport the sample to the laboratory. For example:

- if the baby is unwell
- if it is suspected that the baby may be affected by one of the conditions being screened for
- if this is the second [or more] repeat sample.

8.6.4 The sample taker should exercise their judgement as to whether a courier is necessary. Advice, including information on how to arrange a courier can be obtained from the screening midwives, community midwifery matron or community midwife team leaders

8.6.5 Samples sent by courier must be inserted into a plain envelope which is then sealed with the following address clearly written on the front:

Newborn Bloodspot Screening lab
C/O Central Specimen Reception
5th Floor
North wing
St Thomas Hospital
London
SE1 7EH

8.6.6 Note that the address must be written on the envelope PRIOR to putting the sample inside. This ensures that there is no sample compression during writing which could cause the laboratory to reject the sample.

8.6.7 Courier company details are given in appendix B.

9.0 Results Processes

9.1 The sample taker should inform parents of the results process.

9.2 Results process when conditions not suspected

9.2.1 Where conditions are not suspected, the child health bureau will send parents a letter within 6-8 weeks of the test. If the baby screens positive for a condition the parents will be contacted sooner [see sections 9.3 to 9.7].

9.2.2 Parents should be advised that if they have not received their baby's results within 8 weeks, they should contact their health visitor whose responsibility it is to follow up any missing results.

9.2.3 It is the health visitor's responsibility to document screening results in the PCHR.

9.2.4 Ensure parents understand results are not 100% accurate.

9.3 Results process when conditions suspected: CF suspected

9.3.1 CF is suspected in the following cases:

- Two genetic mutations are confirmed on screening
- One genetic mutation is confirmed on screening and 2 consecutive samples show a raised IRT.

9.3.2 In these cases the newborn screening laboratory will inform the Regional Cystic Fibrosis Unit at Kings College Hospital, London. The regional team at Kings then contact the local CF team at the Royal Alexandra Children's Hospital. A local CF nurse specialist will then arrange to visit the family ideally with named HV to inform the parents of the result and arranges for a diagnostic sweat test for the following day.

9.3.3 The local CF nurse will inform the baby's GP and HV of the sweat test result.

9.3.4 The laboratory will also send a copy of the result to the child health bureau.

9.4 Results process when conditions suspected: CF carrier suspected

9.4.1 The newborn screening test is not designed to detect carriers of CF but may identify a small number of carriers during the process of screening. A CF carrier is suspected when the first sample has a raised IRT and 1 genetic mutation is identified, but the second sample has a normal IRT.

9.4.2 In such cases the newborn screening laboratory will inform the Regional Cystic Fibrosis Unit at Kings College Hospital. The regional team at Kings then contact the local CF team at the Royal Alexandra Children's Hospital. A local CF nurse specialist will then arrange to inform the parents of the result and implications

of the result [for example: regarding inheritance and options for screening parents for their carrier status]. In such cases a diagnostic sweat test may be arranged to exclude a diagnosis of CF and reassure parents.

9.4.3 The local CF nurse will inform the baby's GP and HV of the carrier result.

9.5 Results process when conditions suspected: Inherited metabolic disorders - PKU/ MCADD/ MSUD/ HCU/ IVA/ GA1

9.5.1 In these cases the newborn screening laboratory will inform the Paediatric Metabolic Consultant at the Evelina Children's Hospital, St Thomas's Hospital, London. The consultant will then contact the parents direct [by phone usually] and arrange confirmatory testing and follow-up as detailed below according to the condition suspected:

MSUD/IVA/ MCADD – should be seen the same day as the result is generated, ideally at the regional paediatric metabolic unit in London, as these babies require immediate treatment

GA1/ PKU/ HCU – should be seen the same or next working day following the result, ideally at the ideally at the regional paediatric metabolic unit in London Inform GP of the results.

9.5.2 Where parents are unable to attend the regional IMD unit in London, the consultant in London will liaise with local paediatric services with regard repeat confirmatory samples, treatment and follow up.

9.5.3 The newborn screening laboratory will send a copy of the result to the local CHB.

9.5.4 The consultant at the regional IMD unit will inform the baby's GP, HV and CMW as well as local paediatric services of the baby's diagnosis.

9.5.5 The newborn screening laboratory will send a copy of the result to the local CHB.

9.6 Results process when conditions suspected: Sickle cell disorders

9.6.1 The newborn screening laboratory will refer all suspected carrier and SCD results to King's Red Cell Lab for further testing [Contacts in appendix B]. The King's lab will then contact designated paediatrician at the Royal Alexandra Children's hospital who will arrange to see the parents and arrange follow up as appropriate. This includes informing the baby's GP and HV.

9.6.2 The newborn screening laboratory will send a copy of the result to the local CHB.

9.7 Results process when conditions suspected: Carriers of haemoglobin variants

9.7.1 In addition to detecting babies with sickle cell disorders, newborn blood spot screening may also detect carriers of haemoglobin variants. However carriers of thalassaemia are NOT detected by screening.

9.7.2 Carrier results are given to parents by a specialist link HV. The newborn screening laboratory will inform the specialist link HV who will then arrange to inform the parents and advise regarding the implications of the result. Specialist parent information leaflets, according to the type of carrier identified, are available online: http://sct.screening.nhs.uk/leaflets

9.7.3 The link HV will also inform the baby's named HV, GP and CHB of the carrier status.

9.7.4 The newborn screening laboratory will inform the BSUH antenatal screening co-ordinator of all carrier and affected babies. The ASC will ensure all women with a carrier or affected baby were screened appropriately [according to policy] during pregnancy and inform the laboratory lead at BSUH to enable the lab to link parents and baby results in the future.

10.0 Repeat Samples

10.1 The process for repeat samples is summarised in Pathway 4 [Appendix A]

10.1.1 The laboratory will contact BSUH to request repeat samples by sending an email to the trusts shared generic newborn screening email account: undefined uhsussex.newbornscreening@nhs.net

10.1.2 The community midwife team leaders at both PRH and RSCH will nominate someone on a daily basis [Monday to Friday inclusive] to check the shared email account to action any request for repeat samples.

10.1.3 When taking a repeat sample, the sample taker must tick the '**repeat sample'** box on the blood spot card.

10.1.4 Repeat samples are considered either to be unavoidable or avoidable.

10.2 Unavoidable repeat samples

10.2.1 Unavoidable repeat samples may be required from some babies due to prematurity, borderline TSH results, inconclusive CF screening or having received a blood transfusion. These samples should be taken as soon as possible [certainly within 72 hours of receipt of the request] or at the age directed by the screening laboratory.

10.2.2 A one week interval between samples is recommended for borderline TSH results. In such cases the sample taker must take 4 blood spots and mark the card **'CHT borderline'**.

10.2.3 Where repeat samples are required for inconclusive CF screen or borderline TSH results, the sample taker should inform the HV by phone so that the HV can follow up results and offer additional support to the family whilst results are awaited.

10.3 Avoidable repeat samples

10.3.1 Laboratories may also request a repeat sample due to any of the following reasons. Table 10.1 lists the reasons considered to be avoidable reasons for having to repeat a sample:

Table 10.1: Reasons for avoidable repeat samples	**Examples**
Insufficient	Insufficient blood / blood not soaked through the card or circles not filled
Unsuitable	Compression of the blood spot Overlapping, multiple layered or multiple blood spots Suspected contamination of the sample card [e.g. faeces] Sample card expired Pre-transfusion spot and day 5 spots on same card Presence of adult blood Diluted sample / squeezed heel Insufficient or incorrect data on the card [e.g. incorrect date of collection or date of birth] NHS number not given or incorrect Printed information on barcoded label misaligned Clotted / congealed sample Delay in sample reaching laboratory [> 14 days] Wet card
Too young	Sample taken too soon [e.g. before day 5]
Too soon post transfusion	Sample taken before donor blood cleared

10.3.2 When a repeat sample is requested for any of the above reasons, the sample should be taken within 72 hours of receipt of the request. The only exception to this is where a baby is receiving a blood transfusion [see section 12.5].

10.3.3 All first repeat samples should be sent to the lab in prepaid envelopes [as for first samples]. Second or subsequent repeats should be sent by courier as per section 8.5.

10.3.4 The sample taker must discuss the reason for the repeat with the parents and obtain consent as described in section 4.0.

10.3.5 The sample taker should give parents a copy of the national information leaflet:

'Your baby needs a repeat screening test –heel prick test. Information sheet for parents & carers November 2013 (v1.1)' [copy in Appendix D].

10.3.6 In such cases parents should be informed of the results process and how to follow up the results with the health visitor if they have not heard by post.

10.4 Repeat samples on babies over 28 days [this section applies to babies living at home]

10.4.1 It is the responsibility of maternity services to arrange a repeat sample on any baby up to and including 28 days of age and living at home.

10.4.2 If a baby is over 28 days and a repeat sample is required because there was an error in sample taking [e.g. due to avoidable reasons listed in section 10.3, table 10.1] then maternity services are responsible for informing parents and taking the repeat sample.

10.4.3 If a baby is over 28 days, and the reason for the repeat sample is due to an unavoidable reason, then the health visitor should be informed and it is their responsibility to arrange the repeat sample. Details on how health visitors can arrange a repeat sample are given in section 11. In rare circumstances when the midwife may continue visiting past 28 days, then it would be appropriate for the midwife to take a repeat sample.

10.4.4 If the baby, of any age, is an in-patient under the care of neonatal or paediatric services, then the team caring for the baby are responsible for arranging the repeat sample.

11.0 Special Circumstances: Babies who have moved into the area.

11.1 Responsibility for arranging and taking samples on babies who have moved into the area:

11.1.1 The process for taking samples on 'movers-in' is summarised in Pathway 5 – appendix A.

11.1.2 Newborn blood spot screening is recommended on all babies up to one year of age.

11.1.3 If a baby has moved into the area whilst still receiving routine postnatal midwifery care, then it is the responsibility of maternity services to offer screening and take the sample.

11.1.4 If a baby has moved into the area after discharge from midwife care, up to one year of age, then the responsibility for offering and arranging screening lies with the health visitor.

11.1.5 The health visitor visits the baby within 10 working days of being notified of a new family, to ascertain whether the baby has been screened elsewhere.

11.1.6 If the baby has had screening elsewhere and there is written evidence of the results then no further action is necessary.

11.1.7 In the following circumstances, it is the responsibility of the health visitor to offer and arrange screening:

- the baby has not had any screening
- the baby was screened elsewhere [either in the UK or abroad] but there are no written results
- the baby has had some screening tests but has not been tested for all nine conditions currently screened for in England [listed in section 1.0]

11.1.8 If there is any doubt about what tests a child has had or whether the child has had screening, then screening should be re-offered.

11.1.9 It is not possible to offer screening for CF over the age of 8 weeks. Parents should be advised as to whether screening for this condition has been possible or not.

11.2 Health visitor referral process for screening

11.2.1 The health visitor is responsible for pre-test discussion and documentation of acceptance or decline of screening.

11.2.2 Where parents decline screening, the HV should follow the guidance in section 5.0 and return a blank sample card to the laboratory by completing the form in appendix F.

11.2.3 Where parents accept screening, the health visitor can arrange for the baby to have a screening test as follows according to area:

11.3 How the HV organises repeats: Brighton and Hove area

11.3.1 The health visitor arranges an appointment in paediatric phlebotomy at the Royal Alexandra Children's Hospital.

11.3.2 The HV phones 01273 696955 x 62474 at the RSCH to arrange an appointment.

11.3.3 The HV must complete all sections on the request form in appendix G and faxes the request form to 01273 523120 and write: For The Attention of Phlebotomists, level 5, RACH.

11.3.4 The HV should also give parents a hard copy of the request form to take along to the appointment at phlebotomy.

11.3.5 The phlebotomy department cannot take the sample from the baby without a request form or if the request form is incomplete. In such cases the phlebotomy department will refer back to the requesting HV.

11.3.6 If the baby does not attend for blood spot sampling, the phlebotomy department will inform the HV by phone on the day that the appointment was scheduled. If the phlebotomy staffs are unable to contact the HV that day, they will inform either their manager or the HV manager by phone or email to arrange follow up with the named HV.

11.4 How the HV organises repeats: Mid Sussex area

11.4.1 The health visitor can arrange for blood spot screening at Princess Royal Hospital at Haywards Heath via the on-call paediatric nurse. The nurse can be contacted by phoning 01444 441 881 and asking switchboard to bleep the paediatric nurse on bleep 6034 to arrange a time for parents to bring their baby in and have the sample taken.

11.4.2 Within the Crawley area, the HV can refer babies to the Child Assessment Unit at East Surrey Hospital for blood spot sampling.

11.4.3 It is the HV's responsibility to ensure that all babies referred for screening attended for the test and that a result has been received and documented in the PCHR book and HV notes.

12.0 Special Circumstances: Babies born preterm or cared for in hospital specialist units [summarised in Pathways 2 and 3 in appendix A]

12.1 Babies requiring care from neonatal or paediatric services should have screening taken in accordance with the guidelines contained within this document. The following section 12.2 describes additional measures to be considered when caring for these babies.

12.2 Pre-test information and consent

12.2.1 The pre-test information and consent process should be the same as section 4.0. However in emergency situations there may be limited time to allow discussion with parents.

12.2.2 Babies admitted to neonatal units are likely to have multiple blood samples taken for medical reasons. Blood spot screening should be coordinated with other tests where possible.

12.2.3 Venepuncture or venous / arterial sampling from an existing line is an alternative method to collect the blood spot sample. This is providing the line is cleared of infusate. EDTA, heparin or citrate tubes or capillaries should not be used to collect blood as these anticoagulation reagents will affect the assay [NHS Newborn blood spot screening programme 2014].

12.2.4 Alcohol, Vaseline or any antiseptic solutions for skin preparation should **not** be used, as these can interfere with the results. Parafin solutions can increase the risk of infection, can alter results of the test and may clog the equipment used [Linger 2014].

12.2.5 Sample cards should be completed as detailed in section 6.2. It is important to include all details regarding the baby's medical condition and any blood transfusions received on the sample card as in some cases, the baby's condition and treatment may affect accuracy of screening results. In such cases the lab will advise the unit of any baby that requires a repeat test.

12.2.6 Babies cared for in hospital specialist units will usually require additional newborn blood spot screening samples in excess of the routine day 5 sample, as detailed below.

12.3 Admission spot for SCD screening

12.3.1 All babies admitted to TMBU or SCBU should have a single circle blood spot sample taken on admission or prior to transfusion to screen for SCD. The sample taker must write '**Pre-Transfusion'** on the sample card.

12.3.2 The '**Pre-Transfusion'** blood spot card should be stored on the baby's clip board in the glassine envelope, kept dry and not compressed in any way. It should be sent to the newborn screening laboratory together with the routine day 5 sample.

12.3.3 If the baby is transferred to another unit or discharged home before the day 5 sample has been taken, the 'pre-transfusion' sample accompanies the infant. Details of newborn sampling should be included in the transfer information.

12.4 Day 5 routine screening

12.4.1 On day 5 of life [remember day of birth is day 0], a further sample card of four full circles should be taken on **all** babies, regardless of the medical condition, milk feeding or prematurity. The **only** exception to this is babies who have received a blood transfusion [see section 12.5].

12.4.2 A new sample card should be used for the routine day 5 sample containing 4 sample spots. Extra blood spots must NOT be added to the existing single spot 'pre-transfusion' card taken on admission to the unit.

12.4.3 The 'pre-transfusion' card should be placed in a glassine envelope and stapled to the glassine envelope containing the day 5 card. Details must be fully completed on BOTH cards. Both cards should then be sent to the laboratory together on day 5.

12.4.4 The single circle blood spot sample taken and marked as 'Pre-transfusion' can be discarded if the baby does not receive a blood transfusion. However if there is any uncertainty, for example if it is not possible to confirm in the medical notes, then the 'pre-transfusion' spot should be sent in with the day 5 card.

12.5 Screening after blood transfusion [including intrauterine transfusion]

12.5.1 Blood transfusion should refer to the transfusion of any blood product that will affect the circulating concentration of the metabolite being measured on screening. In practice this refers to blood transfusions, exchange transfusions, platelets and fresh frozen plasma.

12.5.2 For babies who have received an intrauterine transfusion, count the date of birth as date of transfusion.

12.5.3 When a baby has had a blood transfusion, either intrauterine or in the newborn period, before the day 5 blood spot, another sample [of four spots] is required 72 hours after the last blood transfusion. There must be at least 3 days from the end of the transfusion before the blood spot is taken.

12.5.4 On reaching day 5, if 72 hours has not passed since transfusion, then wait until this number of hours has been reached, but if you reach day 8 then a full screen must be taken regardless.

12.5.5 In the event of multiple transfusions, a sample card of four spots must be sent by day 8 at the latest. This ensures *all* babies are screened by day 8 regardless of blood transfusion status

12.5.6 The sample taker should record the date of the last blood transfusion before the blood spot was taken on the sample card.

12.5.7 A pre-transfusion sample is the preferred option for sickle cell screening. When a preterm baby has not has a pre-transfusion sample taken, the laboratory may forward the routine 5-8 day sample to the DNA laboratory for analysis as a failsafe. The laboratory will advise if further specimens are required in these circumstances.

12.5.8 If a baby who has been transfused has not had a pre-transfusion sample taken, the laboratory will forward the routine day 5 sample to the DNA lab for analysis as a failsafe.

12.6 CHT screening for preterm infants

12.6.1 Babies born at less than 32 weeks [equal to or less than 31weeks and 6 days] require a second blood spot sample for CHT screening to be taken in addition to the 'pre-transfusion' and day 5 sample.

12.6.2 These babies should be re-tested when they reach 28 days of age [counting day of birth as day 0] or the day of discharge home, whichever is sooner. If baby is discharged home before 28 days, write 'discharged home' on the bloodspot form.

12.6.3 The sample taker must clearly write on the card if the baby has been discharged or remains an in-patient

12.6.4 Only two blood spots are required for this sample.

12.6.5 The sample taker should write **'CHT preterm'** and the gestational age on the blood spot card.

12.6.6 The responsibility for taking the sample lies with the healthcare professional responsible for clinical care at the time the sample is due. Where babies are transferred before they reach 28 days of age, the responsibility is transferred to the healthcare professional in the receiving unit.

13.0 Documentation

13.1 It is the sample taker's responsibility to record all blood spot samples taken in the baby's hospital records and as follows:

- On the cot card which includes space to document when the admission spot and day 5 spot have been taken.
- In the admission book held in each unit
- On Metavsion [neonatal electronic patient record] which records the dates the samples are due and when they have been taken. Repeat samples are also included on this system. [Note at time of writing policy, Metavision was not yet in place at SCBU, PRH] Therefore the sample taker should record in the baby's notes that the baby has been screened]

13.2 Any transfer documentation should include details of blood spot samples taken.

14.0 Special Circumstances: Family history of any of the conditions screened for

14.1 Where there is a family history of any of the conditions that are screened for, this should have been identified by the midwife at booking. The booking midwife should refer the woman to the screening midwife team or obstetrician for further discussion in the antenatal period. Such discussions may include options for prenatal and postnatal diagnosis, taking specialist advice from the genetics and paediatric teams where appropriate as to the risk to the baby in this pregnancy.

14.2 Where parents have opted for postnatal diagnosis, a plan should have been made and agreed with parents as to the most appropriate method of testing after birth. This should be agreed with the paediatric team and a copy of this plan should be in the hospital file and maternal hand held notes.

14.3 In certain conditions, early screening may be indicated, for example with MSUD/IVA/ MCADD, due to the potential for the baby to become symptomatic prior to screening on day 5. Where the baby is at risk of inheriting a specific condition it should be under paediatric care and not discharged before the result of screening is known or without consultant paediatric review. Advice as to the best time to screen should be sought from the paediatric team and/or newborn screening laboratory.

14.4 In all such cases, details of the family history should be written on the screening sample card. In urgent cases, the lab should be informed by phone to alert them to expect a sample card on a baby at risk or at higher risk of a condition.

15.0 Ensuring All Babies Have Been Offered Screening

15.1 The trust uses NORTHGATE Newborn Blood Spot Failsafe Solution – the national web based software programme which lists all babies born at the trust along with their blood spot screening result. Where parents have declined screening this is also recorded. Northgate identifies and highlights any babies for whom there is no record of a screening result or record of decline by day 17.

15.2 The designated Northgate lead at each site [RSCH, PRH, TMBU, SCBU and RACH] [see appendix B contacts], will check Northgate on each week day and action repeats on any baby found not to have a screening result by day 17. See appendix H for Standard Operating Procedure.

15.3 It is acceptable for the designated Northgate lead to nominate a named member of staff to check Northgate, as long as the named member of staff has had training in using the system.

15.4 The trust's shared NHS net newborn screening email account has the following address: uhsussex.newbornscreening@nhs.net

15.5 The newborn screening email account can be accessed by the key users, that is the community midwife matron, CMW team leaders and antenatal screening co-ordinator. Other members of staff may have access to this account to check emails with permission from key users.

15.6 The Newborn Screening Laboratory will send a list of all samples received from our trust direct to the trust's shared NHS net newborn screening email account on a daily basis. Therefore it will be possible to cross check that samples sent have been received. It is especially important to check that repeat or delayed samples have been received by the laboratory.

16.0 Audit, training and performance management of sampling [including Key Performance Indicators]

16.1 The newborn screening laboratory will notify the trust of the avoidable repeat rate on a quarterly basis. This forms the dataset for performance in the screening Key Performance Indicator [KPI].

16.2 The antenatal screening co-coordinator will collate and submit the data required for the KPI and disseminate performance issues within the trust.

16.3 The Community Midwife Team Leader at each site will monitor all avoidable repeats and any sample taker with a high percentage of avoidable repeats will be required to undertake additional measures such as retraining and online learning.

16.4 Staff new to an area [for example new to the trust, new to working in the community, newly qualified or new in to taking blood spot samples etc] should ideally have their first ten samples second checked before sending to the laboratory [see appendix H for information about second checking samples]. This is at the manager's discretion.

16.5 Staff involved in the newborn blood spot screening programme should ideally attend an annual update.

16.6 Staff new to the trust who will be involved in the newborn blood spot screening programme should attend an induction session covering this screening programme.

17.0 References

Arena, J., et al., *Skin to calcaneus distance in the neonate.* Arch Dis Child Fetal Neonatal Ed, 2005. 90(4): p. F328-f331.

Linger A [2014] Clinical Guidelines: neonatal capillary blood sampling. Great Ormond Street Hospital. Available at www.gosh.nhs.uk/health-professionals/clinical-guidelines/blood-sampling-neonatal-capillary/ Accessed: 13/08/2014.

NHS England [2013] Public health functions to be exercised by NHS England: Service specification No.19 NHS Newborn blood spot screening programme Available at: https://www.gov.uk/government/publications/public-health-commissioning-in-the-nhs-2014-to-2015

NHS Newborn blood spot screening programme [2014] A Laboratory Guide to Newborn Screening in the UK for cystic fibrosis. Available from: http://newbornbloodspot.screening.nhs.uk/cf-supportingdocs [accessed 13/08/2014].

NHS Newborn blood spot screening programme [2013] Newborn blood spot screening pathway. Available at: http://newbornbloodspot.screening.nhs.uk/pathways#fileid12534 [accessed 5/11/14]

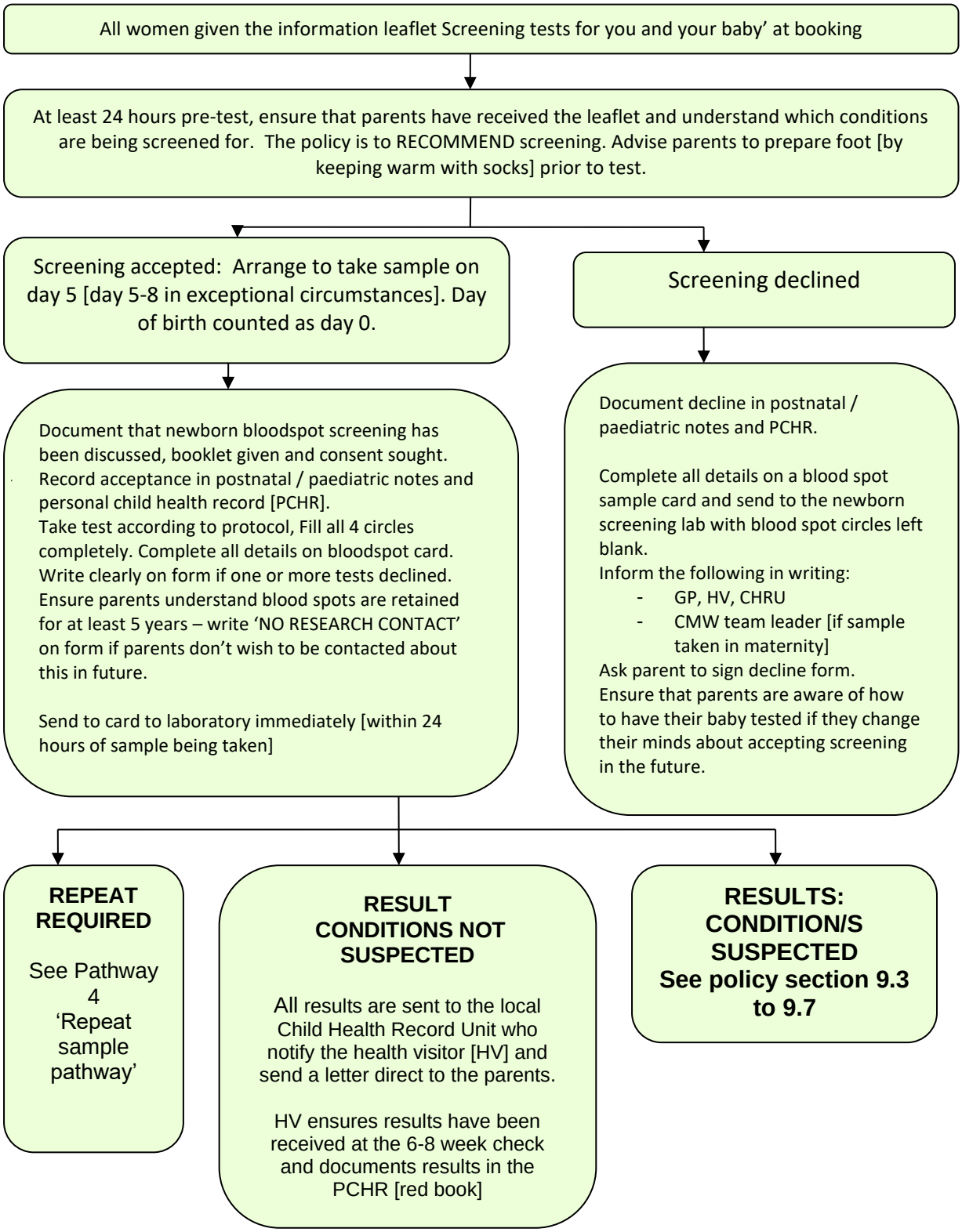
UK Newborn Screening Programme Centre [2012] Guidelines for Newborn Blood Spot Sampling. UK National Screening Committee, February 2012.

Abbreviations used within this document :

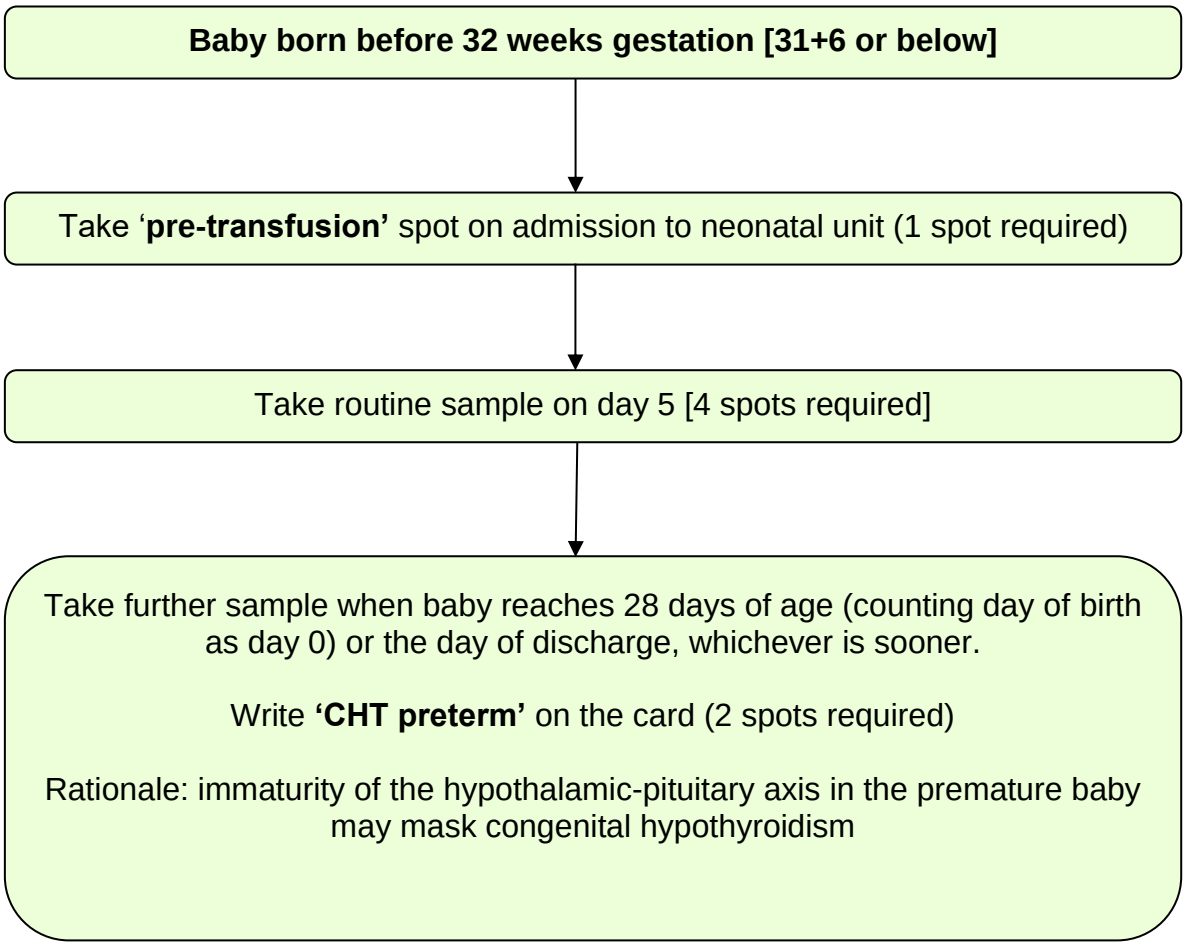
AN - anetenatal
CHRU – Child health record unit
CHT – congenital hypothyroidism
CF – cystic fibrosis
DNA – Did not attend
GA1 - Glutaric aciduria type 1
GP – general practitioner
HCU - Homocystinuria (pyridoxine unresponsive)
HV – health visitor
IMD – inherited metabolic disorder
IVA - Isovaleric acidaemia
MCADD – medium chain Acyl-CoA dehydrogenase deficiency
MSUD - Maple syrup urine disease (MSUD)
MSW – Maternity Support worker
MW – midwife
PCHR – personal child health record [red book]
PKU – Phenylketonuria
RACH – Royal Alexandra Children's Hospital
SCD – sickle cell disorders

Appendix A- Care Pathways

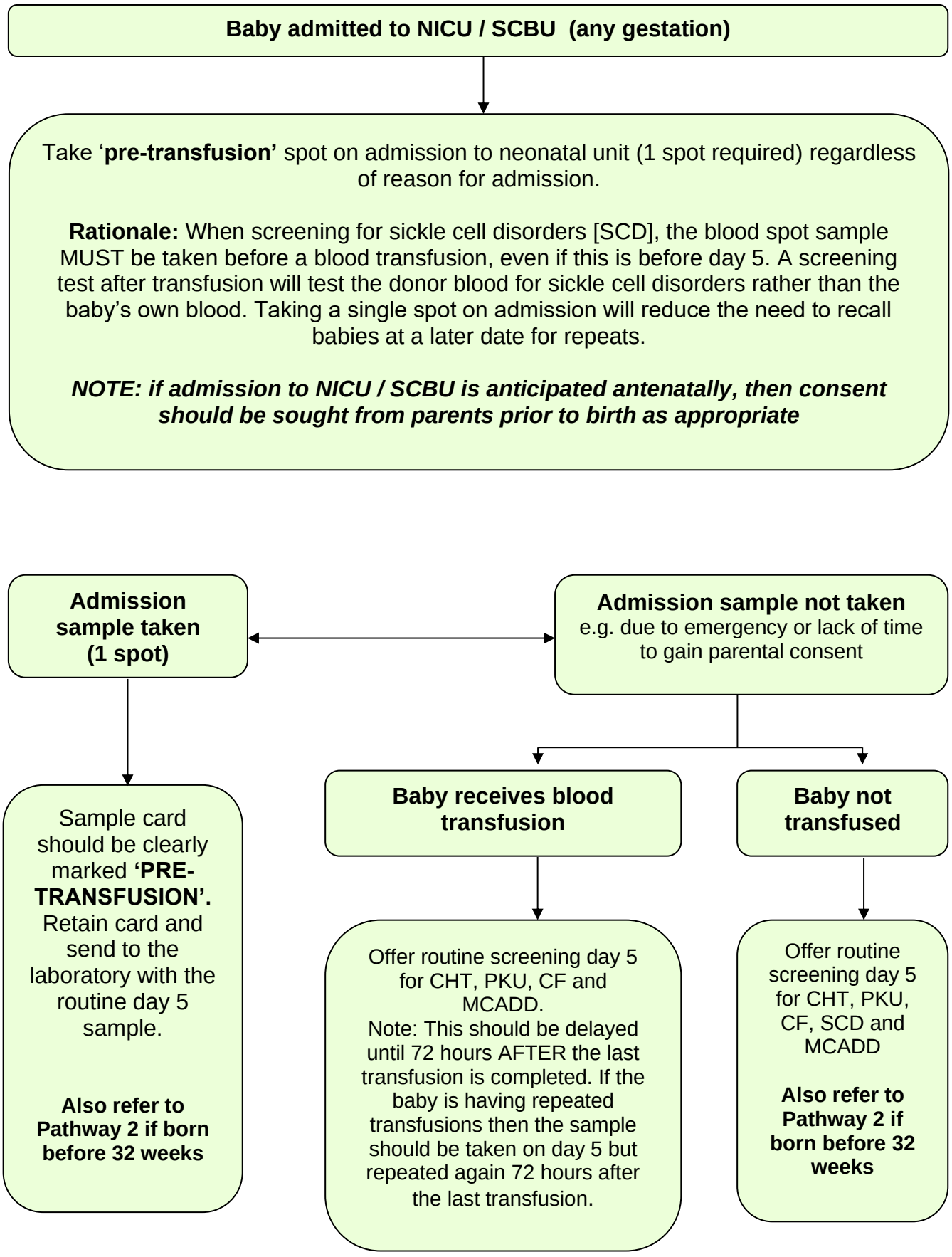
Pathway 1.1 Healthy term neonate: Information and testing process



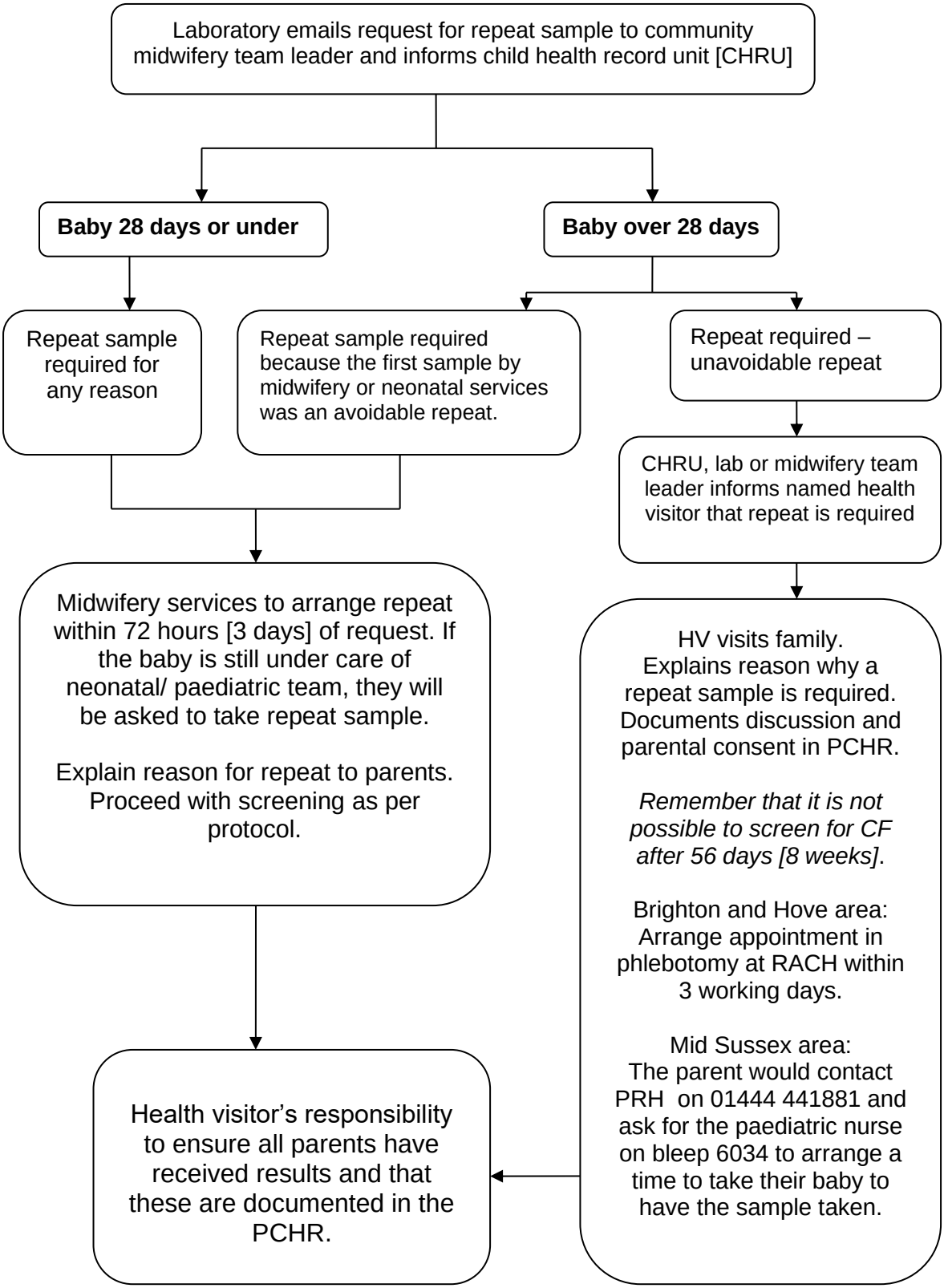
Pathway 1.2 Special considerations for premature infants and screening for CHT



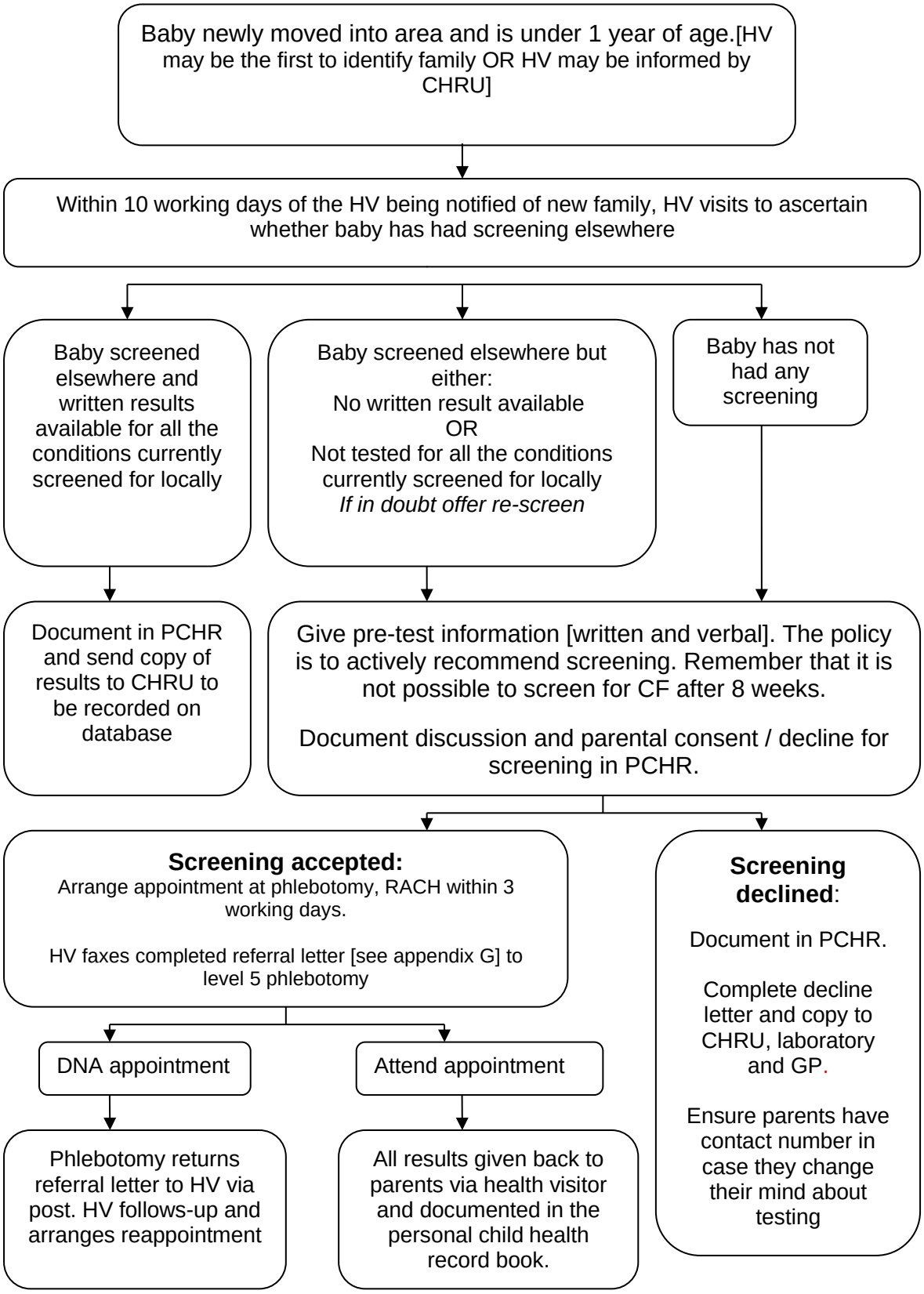
Pathway 1:3 Special considerations for newborn blood spot screening in babies admitted to SCBU/ neonatal unit



Pathway 1:4 Repeat sample pathway [RSCH/ Brighton and Hove]



Pathway 1:5 Movers-in pathway [includes arranging for sample collection at RACH phlebotomy by health visitors]



Appendix B : Contacts

Newborn Screening Laboratories [note: all sample cards are sent to St Thomas's]

LABORATORIES

Laboratory for CF/ MACDD / PKU / CHT/ Additional metabolic disorders

Newborn Screening Laboratory
GSTS Pathology, 4th Floor North Wing, St Thomas Hospital, SE1 7EH
Tel: 0207 188 1267 All queries
Service Manager: 0207 188 5472

Director: Rachel Carling
Deputy: Rachelle Garstone

Laboratory for Sickle Cell Disorders
Sickle Cell Suspected or other haemoglobin suspected cases are dealt with by :
Consultant: Dr David Rees
Laboratory Operations Manager: Chris Lambert
Red Cell Centre
Kings College Hospital
Denmark Hill
LONDON SE5 9RS

Tel 020 3299 9000 ext 32455

Address to send the sample cards to [when using courier to transport specimens]:

Newborn Bloodspot Screening lab
C/O Central Specimen Reception
5th Floor
North wing
St Thomas Hospital
London
SE1 7EH

COURIER COLLECTION COMPANY
CITY SPRINT

Telephone: 01273 818285

Newborn screening laboratory results line [for all results and queries]
Phone: 0207 188 1267

Fax number: 02071881269 Gst-tr.selonbslab@nhs.net

MATERNITY UNIT

Shared email for newborn screening enquiries:
bsu-tr.newbornscreening@nhs.net

Antenatal Screening Co-ordinator
Karen Gregory
karen.gregory12@nhs.net
Mobile: 07876 357 423
Office: 01273 696955 X7477

Antenatal Screening Support Midwives [BSUH]
RSCH: Mobile: 07876 357 423 Office: 01273 696955 X7477

PRH: Office: 01444 441881 X 65404

Midwifery Liasion

Community Midwives Office, RSCH 01273 664794 X 64361
Bolney Ward, PRH: 01444 441881 X 68478

Lead for Northgate [failsafe web programme]
Alex Winstanley, Midwifery Team Leader 01273 664794
Rebecca Elms, Midwifery Team Leader 01444 448608
TMBU : Claire Hunt, Neonatal Matron 01273 696955 x 4377

Child Health Bureau

Brighton & Hove Children & Families Services, Child Records Unit – Office 3, Basement - E Block, Brighton General Hospital , Elm Grove, Brighton, BN2 3EW

Telephone 01273 696011 Blood spot recording: X 4224 / 4227

Community Health Centre, Bicentennial Building, Terminus Road, Chichester, PO19 8EZ

Telephone 01243 793643

Blood Spot Recording: Lucy White x 65158, General ext x65160

Cystic Fibrosis

Regional CF team at Kings College Hospital:
CF nurse specialist= Jo Dignan 020 3299 9000 ext 33342, bleep 876047
Email : jo.dignan @nhs.net

CF team at Royal Alexandra Children's Hospital, Eastern Road, Brighton.
Level 4C, Cystic Fibrosis and Respiratory Nurse Specialists:
Jason Lenton 07810 550433
Phone: 01273 696955 Extension 62518

CF Paediatrician
Dr Paul Seddon [Consultant Paediatrician]:
Royal Alexandra Children's Hospital, Brighton 01273 696955
paul.seddon@nhs.net

CF – Genetics Counselling:
North East Thames Regional Genetics Service - Clinical Genetics Department, Great Ormond Street Hospital, Great Ormond Street, London, WC1N 3JH
Telephone number: 020 7762 6845/ 6831/ 6856
Fax number: 020 7813 8141 Email: gos-tr.clinicalgenetics@nhs.net

IMDs – Inherited Metabolic Disorders
[MCADD/ PKU/ MSUD/ HCU/ IVA/ GA1]

South Thames Metabolic Service is based at the Evelina Children's Hospital
Lead Consultant: Dr Mike Champion
Metabolic Nurse Specialist Tanya Gill 020 7188 0855
Email : paediatricmetaboliccns@gstt.nhs.uk

Cogenital Hypothyroidsim- CHT

Dr Shankar Kanumakala [Consultant Paediatrician – Endocrinology]
Royal Alexandra Children's Hospital, Brighton
01273 696955 ext 62341
s.kanumakala@nhs.net

Haemoglobinopathy [Sickle cell and thalassaemia]

Paediatrician
Dr Anne Davidson [Consultant Paediatrician - Haemoglobinopathy]: Royal Alexandra Children's Hospital, Brighton 01273 696955 X 62324
anne.davidson10@nhs.net

Health Visitor Specialist [RSCH babies]
Hollingdean Childrens Centre, 8 Shenfiled Way, Brighton, BN1 7DY
linda.gardner@nhs.net rachael.chatterje@nhs.net and hilda.beckford@nhs.net

Link Health Visitor Specialist [PRH - West Sussex babies]

Claire Auston
Pound Hill Children and Family Centre
Crawley Lane, Pound Hill, Crawley, RH10 7EB

c.auston@nhs.net

01293 227809
07500 097442

APPENDIX C : Newborn bloodspot screening [see following page]
Newborn bloodspot screening: Record of samples taken / sent

Name of sample taken:

Baby name /DOB / NHS no Use barcoded label where available	**Date taken** **Date posted**	**Sample card serial number** **Location of post box**
	Taken: Posted:	Card serial no: Post box:
	Taken: Posted:	Card serial no: Post box:
	Taken: Posted:	Card serial no: Post box:
	Taken: Posted:	Card serial no: Post box:
	Taken: Posted:	Card serial no: Post box:

RETURN to community midwifery office every week

Appendix C – Patient Information Leaflet – Repeat Screening Test.

UK National Screening Committee

NHS Screening Programmes

Newborn Blood Spot

Your baby needs a repeat screening test – heel prick test

Information sheet for parents & carers November 2013 (v1.1)

When your baby was about a week old, your midwife took some blood from your baby's heel. The blood was used to test for several rare disorders, which are routinely tested for in all newborn babies. Sometimes it is necessary to take another sample because either:

1. There is something wrong with the either the card or the sample obtained, e.g. there was not enough blood on the sample, not all the information required was put on the card, the card got delayed getting to the laboratory. This means that the test could not be done and so we do not have a result. It does not mean that we suspect that anything is wrong with your baby.

2. Much less commonly, the sample needs to be repeated for other reasons:
   - Your baby has had a blood transfusion or was premature, so even though the result of the tests was normal, another test is needed when they are older, so that we can be certain

     Premature babies: in babies born at less than 32 weeks of pregnancy, the routine day 5 test may not pick up congenital hypothyroidism. It is advised to have another test at either 28 days of age or immediately before the baby is discharged home, whichever comes first

   - The test result is not clearly normal. On most occasions, the repeat test result is normal

The person who is taking the repeat sample has this information and will explain the reason to you. Please feel free to ask any questions.

How will the test happen?
Once the repeat blood sample has been taken from your baby, the sample will be sent to your local screening laboratory for testing.

When will you get the result?
You can expect to receive the result within 6 – 8 weeks, either by letter or from your health visitor. If it is thought that your baby may have one of the conditions, you will be contacted sooner. If you do not receive the result by the time your baby is 6 – 8 weeks old, please contact your health visitor (details are in your Personal Child Health Record 'Red Book').

Part of Public Health England

If you are worried about your baby in any way whilst waiting for this result, you should contact your midwife, health visitor or GP.

Please keep this sheet with your baby's personal records.

Information about newborn blood spot screening is available at
www.newbornbloodspot.screening.nhs.uk/public

Appendix D – Letter to inform health professionals of screening decline: Copy to GP, HV, CHRU, Screening Lab, CMW team leader.

University Hospitals Sussex
NHS Foundation Trust

Private and Confidential

<Insert your address >
<Insert your contact number>

TO

<INSERT GP name>
<INSERT GP address>

<INSERT date>

DECLINE OF NEWBORN BLOOD SPOT SCREENING

Dear <GP name>

Re: <INSERT baby's name>
< INSERT baby's NHS number
<INSERT date of birth>
<INSERT Baby's last known address>

I am writing to inform you that the parents of the child above have declined <all> <part, name tests declined> newborn blood spot screening.

Newborn blood spot screening is offered to all babies up to one year of age and screens for the rare conditions listed below:

Phenylketonuria
Congenital hypothyroidism
Sickle cell diseases
Cystic fibrosis (can only be tested for babies up to 56 days of age)
Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
Maple syrup urine disease (MSUD)
Homocystinuria (pyridoxine unresponsive) (HCU)
Isovaleric acidaemia (IVA)
Glutaric aciduria type 1 (GA1)

We are providing this information so that a record of decline is entered onto the medical record and to make you aware should the child present with any symptoms of the conditions normally screened for.
Although not as satisfactory, screening for all conditions except cystic fibrosis would be available up to one year old, if the parents should change their minds

Yours sincerely,

<INSERT signature >
<Insert your printed name and job title >

CC: Health Visitor <INSERT HV name>
Child Health Record Unit
Copy to maternal notes

Appendix E Parental Decline Form

National Newborn Bloodspot Screening Programme

Parental Decline Form

Parent/Carer----------

Baby ----------

Baby's DOB ----------

Baby's NHS number----------

I have been informed about the National Newborn Bloodspot Screening Programme and understand why the screening is recommended and what medical conditions are screened for.

I have had the opportunity to discuss the newborn screen with

---------- **(name)**

---------- **(profession)** and all of my questions have been answered to my satisfaction.

Please confirm below:
I do not want my baby to have a blood spot test to screen for the following conditions which, if undiagnosed, could in some cases result in serious health problems, permanent disability or death: Phenylketonuria, Hypothyroidism, MCADD, Sickle Cell disease and Cystic Fibrosis (if under 8 weeks of age), maple syrup urine disease (MSUD), homocystinuria (pyridoxine unresponsive) (HCU), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1)

Signed ----------

Date ----------

C.C. G.P, H.V. records, Child record unit
SEND COMPLETED SAMPLE CARD TO LABORATORY

Appendix: F HV Referral Form to Paediatric Phlebotomy

To the Phlebotomy Department, ROYAL ALEXANDRA CHILDREN'S HOSPITAL

I would like to refer the following client for a repeat bloodspot screening due to:

☐ Transfer in under 1 year old (no evidence of previous result)
☐ Post transfusion sample
☐ Lab. Request – inconclusive result
☐ Other –please state below
☐ Repeat due to prematurity – born before 35+2 wks. .....

Health Visitor to complete this form clearly in block capitals:

NEWBORN SCREENING BLOOD SPOT TEST				**NHS**		
Baby's NHS No				DATE OF SPECIMEN	D D M M Y Y	
Surname				Is this a repeat [√]	YES	NO
Fornames						
Home address		Baby's DOB D D M M Y Y		Has the baby had a blood transfusion [√]	YES	NO
		GEST /40		If yes, date of last transfusion	D D M M Y Y	
Postcode	SEX [√] M F	Rank /	Ethnic Code	Is the baby in hospital [√]	YES	NO
GP Practice Name	Mother's full name	Birth weight [g]		If yes, current hospital and ward:		
GP address	Mother's DOB	Comments [family history e.g. Mother's carrier status [Antenatal HBO code, HBO outcome code]: Temporary address				
	Mother's NHS number					
GP practice code	Parent phone no.					
Maternity code **RXH**	Alternative surname	Name of person taking sample [PRINT]				
Hospital of birth	Tel no of person taking sample					

APPOINTMENT FOR BLOOD SPOT TEST
DATE..... TIME.....

Name of HV [PRINT] ..... HV signature.....

HV Based at .....

HV Telephone..... H.V. Fax no.....

Date of referral .....

To make appointment; Telephone 01273 696955 X 2474 and fax completed form to ***01273 523120*** **FAO Phlebotomists, Level 5, RACH**

Appendix G : Flow Chart: Performance Management Of Avoidable Repeats