Multi-professional PROTOCOL for newborn blood spot screening (CG498)

Approval and Authorisation

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<thead>
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<th>Approved by</th>
<th>Job Title</th>
<th>Date</th>
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<td>Chair, Maternity Clinical Governance Committee</td>
<td>5th February 2016</td>
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Change History

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Multi-professional protocol for newborn blood spot screening (CG498)  
February 2016

Contents

1.0 Purpose
2.0 Policy Function
3.0 Policy Content
4.0 Definitions
5.0 Consultation
6.0 Dissemination/Circulation
7.0 Monitoring of Compliance and Effectiveness
8.0 Implementation

Appendix 1 - Multiprofessional process for Newborn Blood Spot Sample - Consent and Decline

Appendix 2 – Newborn bloodspot screening form for Neonatal Unit

Appendix 3 – Screen positive results pathway for Haemoglobinopathies

Appendix 4 - Local Communication pathway of CF screening results on repeat blood spot testing and carrier status

Appendix 5 – Equality Impact Assessment Toolkit
1.0 Purpose

This protocol for the Newborn Blood Spot Screening for PKU / CH / CF/ MCADD and Haemoglobinopathies is based on the National Standards for Newborn Blood Spot Screening (UK Newborn Screening Programme Centre, August 2013 version 1.0). The document contains 12 standards on the screening programme for Midwives, Health visitors, Neonatal Nurses, Paediatricians, the Child Health Records Department and Biochemistry Laboratory at Oxford.

2.0 Protocol Function

The Aim of the screening programme is:
- The early treatment of PKU, CH, MCADD, CF IMD and Haemoglobinopathies and the prevention of complications in babies up to the age of 12 months.

3.0 Protocol Content

3.1 Objectives
- To achieve a 100% offer of the NBBS test to the eligible population for newborn babies and babies new to the area up to 1 year
- To initiate clinical referral within 3 working days (dependant on suspected condition) of timely receipt of sample in the screening laboratory of those with positive results
- To identify the "untested" newborns (including declines) within 17 days of birth (The Newborn Screening Coordinator works with CHIS to identify babies with no conclusive result by 13 days)
- To ensure that parents are offered written information about the screening both antenatally (3rd trimester) as well as prior to the testing.
- To ensure verbal consent is sought from the parents and documented in the maternity records.
- To ensure that parents are advised of all the results which are entered in the Personal Child Health Record (PCHR / Red Book).
- To ensure 100%of NBBS have the babies NHS number, 95% with ISB approved bar-coded babies NHS number sticker
- To ensure 95% of 1st samples are taken day 5-8. Ideally day 5 (DOB as day 0)
- 100%of samples are received by the screening laboratory within 4 working days of being taken.
- To ensure good quality blood spots.
3.2 Summary of Process

3.2.1 Newborn Blood Spot taking procedure - Consent and Decline (see Appendix 1)

For all newborn well babies, the responsibility to take the NBBS for babies registered to the agreed GP cohort is the midwifery team. The HV is responsible for all babies that ‘move in’ to the GP cohort area referring to the dedicated Health Visitor team for NBBS taking. For babies on the Neonatal Unit, the responsibility will be with the Neonatal Nurse caring for the baby.

- The Neonatal Biochemical Screening blood test (heel prick) is carried out on all babies between days 5-8. Ideally the sample should be taken on day 5. The baby’s date of birth is counted as day 0 irrespective of the time of birth. The test is taken regardless of mode of feeding or gestational age. The blood is collected on the Neonatal Screening Blood Test Card

- For babies admitted to the Neonatal/Paediatric Unit – see neonatal unit section

- Ideally the midwife informs parents about the newborn blood spot screening in the third trimester of pregnancy and provides a copy of the national screening committee literature- Screening tests for you and your baby

  www.screening.nhs.uk/annbpublications

- Communication with the parents and their decision must be recorded in the maternity antenatal records.

- From Sept 1st 2010 all screen positive Haemoglobinopathy neonates will have their demographic information collected on a database. This database is to ensure the correct treatment, care and follow up the affected child. Parents must be informed of this prior to screening.

- Inform the parents that blood will be stored for future research purposes within the laboratory. Should the parents not wish for this to happen, please mark the card ‘NO RESEARCH CONTACT’

- At least 24 hours before taking the heel prick, the midwife or health care professional should again discuss this test with the parents and this discussion as well as the parental decision should be recorded in the maternity notes.

- Inform the parents that repeat testing is sometimes necessary. Preterm infants, neonatal blood transfusion, borderline positive results for CH and suspected conditions and insufficient samples are some of the reasons

- Please note: samples taken after 8 weeks of age are regarded as unsuitable for testing for Cystic Fibrosis. Rationale: most babies with CF have an abnormally high concentration of IRT (immunoreactive trypsinogen) in blood only during the first few weeks of life. Thereafter IRT concentration decreases until at a few months of age it is abnormally low.

- If the parents choose to decline any or all of the tests, they should be given the full information on who to contact and how (midwife and health visitor), should they change their mind. The CMW completes the NBBS card, marked Declined, and
sends to Laboratory. The Laboratory will inform CHIS (Child Health Information Services) who in turn inform the HV of parental decision.

- Where the baby is a new sibling of a child known to have PKU or MCADD, a sample for earlier testing for these conditions should be taken on Day 1. In this case, it will still be necessary to repeat the sample between 5-8 days.

- Where both parents are known to have Haemoglobinopathy traits and who have not had prenatal diagnosis, capillary or venous blood must be taken in the immediate postnatal period into a Paediatric edta bottle and sent to the RBH Haemoglobinopathy/specials laboratory, informing them on ext. 7756 that they should expect blood. Cord blood is no longer taken for Haemoglobinopathy screening; this is to avoid possible maternal contamination. This blood is then sent on the next transport to JRH Newborn screening lab. The Screening Coordinator will have alerted the NBBS laboratory in JRH in the antenatal period, that this is a high risk pregnancy. A routine day 5 NBBS should still be carried out and any known Haemoglobinopathy results should be recorded on the NBBS card. The screening Coordinator will be informed on ext. 7292 of samples being sent to the JRH laboratory via the RBH haematology laboratory ext. 7756, and will arrange results to be reported by the CNS in Haemoglobinopathies or inform the parents of the results

- For those babies with only one parent known to have a trait no further testing is required other than routine Day 5 NBBS testing and any known Haemoglobinopathy results should be recorded on the NBBS card.

- Parents where only the mothers Haemoglobinopathy result is known (no partner test result) is offered routine Day 5 NBBS and any Haemoglobinopathy result recorded on the NBBS card. The Screening Coordinator will have alerted the NBBS laboratory in JRH in the antenatal period, that this is a high risk pregnancy.

- Completed NBBS cards should be received by the lab within 4 working days

- The completed blood cards are as a first choice sent via pathology from the community midwives office or if absolutely necessary via the surgery, on a daily basis –to the Department of Clinical Biochemistry - Neonatal Screening Laboratory, level 4, John Radcliffe Hospital, Oxford for analysis.

- Prior to placing the specimen in the envelope in the community midwives office, the sample taker should complete the form pinned to the outside of the envelope (Neonates surname/NHS NO/ DOB/DOS and sample takers name. This is to ensure NBBS forms are correctly filled out but ALSO to provide the sample taker with proof that a sample has been taken and placed for delivery to the Screening Lab)

- Second choice for delivery of sample, (this is as an absolute last choice) is at the GP surgery into the specimens for pathology drop point. The sample should be in its glassine envelope but no other envelope or it will be treated as post rather than a blood specimen. The specimen taker should make a written record of date and surgery where the specimen was dropped

### 3.2.2 Results

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<th>Jo Young</th>
<th>Date:</th>
<th>February 2016</th>
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<td>Review date:</td>
<td>February 2018</td>
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<td>Group Director Urgent Care</td>
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• The results are returned from Oxford to the Child Health Department. Any request for a repeat test, or missing details is sent directly by the Oxford Laboratory to the Newborn Screening Lead for the RBH Trust (for action) and to CHIS (for information).

• In Suspected cases of PKU, MCADD and CH the Laboratory directly notifies the Duty Consultant Paediatrician (for action) and Screening Coordinator (for monitoring and audit purposes).

• In suspected cases of CF the Laboratory informs the regional CF coordinator based at JRH Oxford, the CF coordinator then informs the Designated Paediatrician for CF (for action), the Community Specialist Nurse (for action) and Screening Coordinator (for monitoring and audit purposes).

• Suspected Cystic Fibrosis (CF), clinical referral should be made by 28 days when 2 mutations are present or by 35days when a repeat IRT level is raised.

• The Screening Coordinator informs the Haemoglobinopathy Nurse Specialist of any neonates with carrier status (see Appendix 3).

• The Screening Coordinator liaises with the Haemoglobinopathy Nurse Specialist regarding Haemoglobinopathy affected status. (see appendix 3).

• The Haemoglobinopathy Nurse Specialist is responsible for communicating positive Haemoglobinopathy results to the parents by 6 weeks. The HBO Nurse Specialist also sends these results directly to CHIS once she has informed the parents of the result (see Appendix 3).

• All repeat NBBS test should be taken within 72hrs of request or specified date.

• All results are entered by Child Health Information Services onto the RiO system; the results are then viewed by the Health Visitor electronically on RiO.

• The Health Visitor records the result in HV Records and gives the results to the General Practitioner for the neonates file.

• The Health Visitor informs the parents of the results and ensures that it is recorded in the Personal Child Health Record and the Child Health Summary.

• Results on all babies should be available by 17 days.

• If results are late, the Health Visitor is responsible for establishing the cause for the delay, including obtaining results from other areas. A request for a repeat test may be necessary.

3.2.3 Neonatal/Paediatric Unit Guidance

1. Prior to the NBBS screen parents must be given both written and verbal information www.screening.nhs.uk/languages.

2. On admission to the Neonatal Unit the admitting Nurse will complete a Newborn Bloodspot Screening form (See Appendix 2), making due assessment of any immediate NBBS screening that is necessary. All samples taken should be clearly
dated and signed for on the Newborn Bloodspot Screening Form, Day 0 samples should be sent immediately and not held in the notes

3. A specimen is sent at Day 5 for all babies, regardless of the baby’s method of feeding or gestation.

4. **For Preterm infants.** Neonates born before a gestation of 32+0 will have a Day 0 pre-transfusion admission sample, a Day 5 routine sample and a Day 28/pre-discharge sample (whichever is sooner)

5. **For Preterm Infants.** Neonates born after 32+0 will have a Day 0 pre-transfusion admission sample if admitted to the NNU and a routine Day 5 sample. NO MORE samples are required unless specifically requested by the SCO

6. **Blood Transfusions** – The test for the Haemoglobinopathies will be affected by a blood transfusion. If blood spot testing is not done before the transfusion, it will have to be repeated at 120 days post transfusion. Therefore, every effort should be made to take a single blood spot on admission and prior to blood transfusion if no day 0 sample was obtained. The tests for PKU, CH, CF and MCADD cannot be done before day 5 or for at least 72 hours post transfusion (4 full calendar days). It is the responsibility of the Screening Coordinator to organise any 120 post transfusion samples via Kempton ward or Paediatric outpatients

Hence, if a baby needs a blood transfusion before day 5, it is very important that a single blood spot be taken beforehand; the NBBS card should be clearly identified as a pre-transfusion single blood spot. Where this is not done, the baby will require the blood spot test done 120 days post transfusion for the Haemoglobinopathies screen.

The PKU/CH/CF tests should be done at least 72 hours (4 full calendar days) post transfusion. This would fall on –

Day 5 if Transfusion is on day 1

Day 6 if Transfusion is on day 2

Day 7 if Transfusion is on day 3

Day 8 if Transfusion is on day 4

If the blood transfusion is on day 5 ensure the NBBS is performed prior to transfusion then all the tests will be done with just the one sampling.

The Oxford Newborn Screening Laboratory will inform the Screening Coordinator of a necessary repeat at the time of initial sample.

When transferring neonates to another unit it is the responsibility of the nurse caring for the baby to communicate any outstanding NBBS tests required

NBBS samples will be sent via pathology on the day they are taken.
3.2.4 Child Health Guidance

The Child Health Information Service receives notification of all results from the Screening Laboratory.

The notification includes the following:

- Screen negative & screen positive results
- All screening tests declined by the parents

The Child Health Department records all results electronically on RiO and notifies the health visitors whom access RiO for the results.

Three reports are produced from the Child Health Information Service system.

1. **On a weekly basis**, a list of babies awaiting results of repeat tests 21 days post notification from Laboratory.

2. **On a daily basis**, a search to identify a list of infants aged between 14 days and 1 year, for whom no result has been received. Two lists are generated. The first list is newborns who are in the Child Health Information Services geographical area and this list is sent electronically to the Newborn Screening Coordinator on a daily basis who looks into each individual case. The second list is older babies who have moved into the area and are the responsibility of the Health Visitors who look into individual cases.

3. **On an annual basis**, an annual count to identify the percentage of babies (between 28 days and 1 year who are resident in the catchment area on the day of the count) with a recorded screening result or decline notification.

**Role of the Health Visitor**

- It is the responsibility of the Health Visitor to ensure babies who have ‘moved’ in to the area under one year have a NBBS result.
- If no result is available the Health Visitor responsible for the baby will offer a NBBS test.
- If the parents decline a NBBS card should be completed and sent to the Oxford Laboratory.
- If the parents accept a NBBS test the Health Visitor organises a test to be performed by a dedicated team of Health Visitors trained to take the NBBS test.
- It is the Health Visitors responsibility to ensure all parents receive their baby’s NBBS result.

3.2.6 Role of Oxford University Hospital Neonatal Screening Laboratory
Multi-professional protocol for newborn blood spot screening (CG498)  
February 2016

- The Neonatal Screening specimens are processed and reports leave the laboratory on the 3rd working day after receipt of the specimen.
- The Laboratory returns all results to Child Health Information Service electronically,
- The Laboratory requests second tests as necessary, e.g. borderline first test, insufficient blood, prematurity, or details needing clarification, to the Newborn Screening Coordinator for the RBH, via Lifecycle software.
- The Laboratory will discuss any concerns on a case to case basis directly with the Newborn Screening Coordinator.
- In the event of an abnormal result the Laboratory will contact the Duty Consultant Paediatrician or Lead Paediatrician for the condition at Royal Berkshire Hospital,. The Laboratory also will inform the Newborn Screening Coordinator (for audit and monitoring purposes). The Paediatrician will then have responsibility for the case and will liaise with the General Practitioner and the family. In addition, abnormal results will be reported through the usual channels but the written report will not be issued until diagnosis has been confirmed and treatment started.
- Undertakes the specified audits and quality assurance measures in line with National Standards.

The Laboratory’s responsibility ends when it has been told in writing that the child has been seen by a Paediatrician.

3.2.7 Definitions of conditions tested

Phenylketonuria (PKU) is an autosomal recessive genetic disorder with a national incidence of between 1:8,000 to 1:10,000 in Britain (incidence in area served by Oxford Radcliffe Neonatal Screening Laboratory 1:12,000). There is a deficiency of the enzyme phenylalanine hydroxylase leading to the failure of conversion of the essential amino acid phenylalanine to tyrosine. The consequence of this is an accumulation of phenylalanine in the blood which if prolonged and if sufficiently high leads to brain damage.

Congenital Hypothyroidism (CH) is one of the preventable causes of development delay in children, with a national incidence of 1:4,000 births. (Incidence in area served by Oxford Radcliffe Neonatal Screening Laboratory 1:3,000).

Cystic Fibrosis (CF) is an autosomal recessive genetic disorder with a national incidence of 1:2,500 in Britain. It affects the exocrine glands, with pancreatic insufficiency and chronic respiratory symptoms.

Medium Chain Acyl-coA Dehydrogenase Deficiency (MCADD) is an autosomal recessive genetic disorder with a projected national incidence of 1:10,000-20,000 in Britain. MCADD is caused by the lack of the enzyme required to break down long chain fat down into useable energy. When a sufferer is in ‘crisis’ (low calorie intake due to illness) and relies on fat stores for energy the partially broken down fats become toxic, added to low energy, can cause fits, coma and death. Treatment is to avoid fasting (providing dextrose supplements) and prompt response to illness.
Haemoglobinopathies are autosomal recessive genetically inherited disorders of the haemoglobin. They include Sickle Cell disease and Thalassaemia. The carrier incidence ranges from 1:6 to 1:1000 depending on ethnic origins, with a 1:4 risk of an affected child being born to parents who are both carriers of the relevant genes. Sickle cell disease affects the quality of the red blood cells and predisposes them to forming sickle shapes, which cause blockage in small blood vessels resulting in pain. The Thalassemia’s affect the quantity of haemoglobin produced. Beta Thalassaemia major is a serious condition requiring monthly blood transfusions for life and treatment to reduce iron overload. The NBBS is unable to detect carrier status of Thalassaemia.

The diagnosis of PKU, CH, CF MCADD and Haemoglobinopathies should always be considered in appropriate clinical circumstances and there should be no hesitation in repeating the investigations where there is doubt. This is particularly important in the case of CH, since for a variety of reasons, the screening procedure misses a few cases.

Maple Syrup Urine Disease is a rare disorder in which a baby or child has a problem breaking down particular amino acids known as leucine, isoleucine and valine contained within protein. For people with MSUD, eating too much protein can cause a harmful buildup of these amino acids in the blood.

IVA is a rare disorder in which a baby or child has a problem breaking down protein in particular the amino acid known as leucine. For people with IVA, eating too much protein can cause causes harmful substances to build up in the blood.

GA1 is a rare disorder in which a baby or child has a problem when breaking down the building blocks of protein, in particular the amino acids lysine and tryptophan. For people with GA1, eating too much protein can cause causes harmful substances to build up in the blood and urine.

HCU is a rare disorder that prevents the breakdown of a building block of protein, the amino acid, and homocysteine. This then builds up in the blood. In the long term, this can lead to a number of health problems.

4.0 Definitions

This protocol is for the specific use of maternity and children’s services. Departmental are those documents which are for a specific use of that department/clinical directorate e.g. neonatal protocol and maternity specific guidelines

5.0 Consultation

This protocol has been written in consultation with Midwives, Neonatal Unit, Health Visitors, Cystic Fibrosis Programme Lead, Paediatricians, Haemoglobinopathy Nurse Specialist, Child Health Records and Oxford University Neonatal Screening Laboratory.
6.0 Dissemination/Circulation

This protocol will be available on the Trust Policy hub under Clinical/ Maternity/ Postnatal. The protocol will be circulated to all leads in each ward, community and Health Visitor area location.

7.0 Monitoring of Compliance and Effectiveness

Compliance will be monitored, results reviewed and action plans made.

8.0 Implementation – See Appendices
Appendix 1 - Multiprofessional process for Newborn Blood Spot Sample - Consent and Decline

Parents must be given information both verbally and via a copy of Newborn Blood Spot Screening for your Baby leaflet. This leaflet is available from the National Screening Committee in pdf format and other languages to ensure informed consent mailto:www.screening.nhs.uk/annbpublications

NBBS CARDS MUST BE FILLED IN CONTEMPORANEOUSLY

1. Complete all boxes (names of parents, name and title of professional taking specimen, name of GP) on the blood spot card and apply baby's barcode label (when available). If unavailable, the NHS number should be handwritten on card.

100% OF NBBS CARDS SHOULD HAVE THE BABIES NHS NUMBER ON

If a baby leaves the maternity unit without an NHS number contact CHIS 020 7004 1501.

2. Confirm baby’s name, D.O. B and parents’ contact details.

Missing data means a request for repeat samples which could cause delay in treatment if a neonate is affected with one of the conditions being screened for.

3. Explain the procedure.

4. Recommend measures to comfort the baby and reduce pain. Feeding, and sucking, engaging the baby through face-to-face contact, voice and touch, are beneficial.

N.B. Pre-warming of the foot is not essential.

Topical pain relief cannot be given as this may contaminate the sample.

5. Disinfecting clean skin pre-test is unnecessary although the foot should be washed with plain water or in the absence of water disinfected with an alcohol swab for 30 seconds, and allowed to dry.

6. Wash hands and apply gloves.

7. Perform the test using a newborn automated device (Depth of incision to be < 2.0mm in full term neonates and <1.0mm in pre-term neonates)

N.B. Manual lancets must not be used.

8. 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 calcaneous. (Marked by diagonal lines) Avoid posterior curvature of the heel.
Shading represents areas from where Samples should be taken

9. 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 card. Fill the circle completely and avoid layering blood.

10. Repeat procedure for each circle; each drop should permeate through to the back of the card.

11. Wipe excess blood from heel and apply gentle pressure to the wound with cotton wool ball.

12. If the blood flow ceases:
   a. The congealed blood should be wiped away firmly with cotton wool or gauze
   b. Gently massage the foot, avoid squeezing, and drop the blood onto the card

13. If the baby is not bleeding a second prick is necessary. The second prick should be taken from a different part of the same foot (within area illustrated on photograph) or the other foot.

14. Apply spot plaster, if required.

15. Allow blood spots to air-dry before placing the card in glassine envelope. Despatch in accordance guidelines within 24 hours of taking the sample.

16. Record taking the test in the mother’s maternity record (and Personal Child Health Record - where available)

17. Inform parents how and when they will receive results.

18. **Parents may decline screening for any or all of the conditions**
   a. If screening is declined for all conditions send completed card (without blood sample) clearly marked 'DECLINE – ALL'. The card should then be returned to the laboratory in the usual manner. They will pass on decline details to CHIS
who will in turn inform the HV. The GP will then be informed by the HV in due course.

b. If declining screening for individual conditions the card, the blood spots should be collected as normal, and the card should be clearly marked with the condition declined e.g. DECLINE – XX

Record decline, including reasons for decision, in maternity record (and Personal Child Health Record book where available).

19. Confirm the parents understand the risks of baby not being screened.

20. Offer further information and who to contact if they change their mind.

21. If a parent does not wish to be contacted about future research, the health professional collecting the blood sample should write ‘NO RESEARCH CONTACT’ on the blood spot card

22. All test cards (including declined tests) to be sent within 24 hours of taking the specimen, preferably via community midwives office, and if absolutely necessary via GP surgery. The Oxford University Screening Laboratory Address is, Screening Laboratory, Department of Clinical Biochemistry, Level 4, Oxford University Hospital, Oxford OX3 9DU

23. Completion of records is as follows:
   - Maternity records
   - Personal Child Health Record (PCHR)/”Red Book” where possible
   - If on Neonatal Unit, the Neonatal Unit’s Day book, Admission book and the Newborn Bloodspot Screening Chart (see appendix 2)

If a test is identified as delayed or missed within the GP cohort the midwifery team is responsible for ensuring that the test is carried out as soon as possible, following the procedure described. The Standard of Excellence is that no tests are late for any reason. Delay due to missed visits, insufficient sample etc., are all preventable.

Reference:

Appendix 2 – Newborn bloodspot screening form for Neonatal Unit

NEWBORN BLOODSPOT SCREENING FORM FOR NEONATAL UNIT

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**BLOODSPOT SCREENING**

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<th>DATE DONE &amp; SIGNED</th>
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<tr>
<td><strong>DAY 5:</strong></td>
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<tr>
<td>(If BT administered - ensure there is a full 4 days post transfusion)</td>
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</tr>
<tr>
<td>&lt;32/40 GESTATION</td>
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<tr>
<td>28 DAY sample or DISCHARGE sample - whichever sooner</td>
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<td></td>
</tr>
<tr>
<td>&gt;32/40 GESTATION</td>
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<td></td>
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<tr>
<td>NO further sample required</td>
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<tr>
<td>120 DAY POST TRANSFUSION</td>
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<tr>
<td>Sample if no pre-trans sample taken</td>
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<td><strong>ANY OTHER REPEAT REQUESTED</strong></td>
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**RATIONALE**

**DAY 0/ADMITTANCE TO NNU UNIT:** A single spot for Haemoglobinopathy screening, to avoid 120 day post-transfusion follow-up.

**DAY 5:** A full 4 spot card for PKU (phenylketonuria) TSH (congenital hypothyroidism) CF (cystic fibrosis) MCADD (medium chain acyl-coA dehydrogenase deficiency) and 4 metabolic conditions HCU, MSUD, IVA and GA1 plus HbO (haemoglobinopathies).

<32/40 GESTATION: A 28 day sample OR discharge sample. Whichever is soonest. Mark the card ‘28 day sample’ or ‘discharge’ sample.

>32/40 GESTATION no further samples are necessary

**120 DAY POST TRANSFUSION** this is only necessary if a DAY 0/ADMITTANCE sample was not obtained. The SCO will inform if this is necessary.

**ANY OTHER REPEAT REQUESTED** Occasionally the lab will request URGENT and NECESSARY repeats.

**ALL BENEFICIAL TREATMENT DEPENDS ON TIMELY ACTION**

These are standards clearly set in the National Screening Committee’s Standards and guidelines for Newborn Blood Spot Screening (Aug 2008)

Standard 3: Timely sample collection

Standard 6: Timely receipt of a repeat/second sample

**SCREENING COORDINATOR** Jo Young (0118 322 7292)

**VITAMIN K ADDITIONAL DOSES**

Required if first dose given IV for infants <1 kg or term infants receiving oral vitamin K

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<td>Date 3rd dose due</td>
<td>Sign and date</td>
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</tbody>
</table>

February 2016
Appendix 3 – Screen positive results pathway for Haemoglobinopathies
All screen positive results will be directly notified by the JRH laboratory following those identified from High Risk Antenatal Screening (both carriers parents with NO Pre-Natal Diagnosis) leading to capillary or venous blood in the immediate postnatal period or the NBBS to the Haematology Clinical Nurse Specialist (CNS) who will initiate the one of the following processes;

<table>
<thead>
<tr>
<th>Babies diagnosed with HAEMOGLOBINOPATHY TRAIT</th>
<th>Babies diagnosed as HAEMOGLOBINOPATHY AFFECTED</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Screening Coordinator liaises with CNS</td>
<td>• Screening Coordinator and RBH lab liaise with CNS</td>
</tr>
<tr>
<td>• Parents are sent a letter by CNS explaining the condition together with contact details for further counselling should they decide it desirable</td>
<td>• CNS contacts mother to arrange a ward or home visit</td>
</tr>
<tr>
<td>• HV is notified electronically via CHRD RiO system</td>
<td>• CNS to arrange for paediatric care</td>
</tr>
<tr>
<td></td>
<td>• Babies are to be seen by paediatrician or paediatric haematologist within 3 months of assumed affected status</td>
</tr>
</tbody>
</table>

Appendix 4 - Local Communication pathway of CF screening results on repeat blood spot testing and carrier status

<table>
<thead>
<tr>
<th>CF NOT SUSPECTED on SECOND BLOOD SPOT TEST</th>
<th>LIKELY CARRIER STATUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Programme coordinator notifies Newborn Screening Coordinator of results</td>
<td>• Programme coordinator notifies CF Specialist Paediatrician and Newborn Screening Coordinator via email</td>
</tr>
<tr>
<td>• Parents informed by Screening Coordinator or Health Visitor</td>
<td>• Newborn Screening Coordinator or community midwife contacts parents with result Appropriate leaflet available on website <a href="http://www.newbornbloodspotscreening.co.uk">www.newbornbloodspotscreening.co.uk</a></td>
</tr>
<tr>
<td>• Results to CHIS/ HV and GP as part of normal process</td>
<td>• Newborn Screening Coordinator arranges further follow up testing with CF Specialist Paediatrician at parents request</td>
</tr>
</tbody>
</table>
Appendix 5 – Equality Impact Assessment Toolkit

For each of the six equality categories, ask the questions in the table below.

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Disability</th>
<th>Race</th>
<th>Gender</th>
<th>Religion or Belief</th>
<th>Sexual Orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do different groups have different needs, experiences, issues and priorities in relation to the proposed protocol?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is there potential for or evidence that the proposed protocol will not promote equality of opportunity for all and promote good relations between different groups?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is there potential for or evidence that the proposed protocol will affect different population groups differently (including possibly discriminating against certain groups)?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is there public concern (including media, academic, voluntary or sector specific interest) in potential discrimination against a particular population group or groups?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
</tbody>
</table>

Equality Impact Assessment Summary of Findings

Name of Policy: Multiprofessional Protocol for Newborn Blood Spot Screening

Write short notes to explain why you have drawn your conclusions including any evidence (of whatever type) that you have to support your assessment.

Do different groups (age, disability, race, sexual orientation, gender, religion or belief) have different needs, experiences, issues and priorities in relation to the proposed protocol?

There is currently no evidence to suggest different groups will have different needs, experiences, issues, and priorities in relation to this proposed protocol.

Is there potential for or evidence that the proposed protocol will not promote equality of opportunity for all and promote good relations between different groups (age, disability, race, sexual orientation, gender, religion or belief)?

This proposed protocol will promote equality and opportunity amongst all the different groups and does not differentiate the proposed care to any group.
Is there potential for or evidence that the proposed protocol will affect different population groups (age, disability, race, sexual orientation, gender, religion or belief) differently (including possibly discriminating against certain groups)?

There is currently no evidence to suggest the proposed protocol will affect different groups differently

Is there public concern (including media, academic, voluntary or sector specific interest) in potential discrimination against a particular population group or groups (age, disability, race, sexual orientation, gender, religion or belief)?

There is no current evidence to suggest there is any public concern in potential discrimination against a particular population group or groups

Based on the information set out above I have decided that a full equality impact assessment is not necessary.

Name, Job title and signature: Jo Young, Screening Co-ordinator

Department: Antenatal Services, Maternity

Date: January 2016