Postnatal Guidelines

No.7 Newborn Bloodspot Screening Programme

1. Introduction

Newborn blood spot screening identifies babies who may have rare but serious conditions. The National Screening Committee recommends that all babies are offered screening for 9 conditions:

- Phenylketonuria PKU
- Congenital Hypothyroidism CHT
- Sickle cell anaemia
- Cystic fibrosis
- Medium chain acyl-CoA dehydrogenase deficiency MCADD
- Maple Syrup Urine Disease (MSUD)
- Isovaleric aciduria (IVA)
- Glutaric aciduria type 1 (GA1)
- Homocystinuria

Early identification can improve the health of an infant and in certain cases can prevent serious disability.(Detail see appendix 1)

1.1 Phenylketonuria affects 1 in 10,000 infants born in the UK. Untreated an infected infant will develop serious, irreversible mental disability. The treatment is with a special diet avoiding phenylalanine.

1.2 Congenital hypothyroidism affects 1 in 4000 infants. It affects growth and development. Treatment is with thyroxine.

1.3 Sickle cell anaemia affects 1 in 2500 UK births and tends to occur in specific ethnic groups. Early identification allows early treatment of potential complications.

1.4 Cystic fibrosis affects 1 in 2500 UK births. Early identification and treatment is felt to be beneficial.

1.5 Medium chain acyl-CoA dehydrogenase deficiciency (MCADD) is an autosomal recessive condition affecting 1 in 10,000. It is an enzyme deficiency that means the body cannot effectively use fat stores in times of stress. Periods of fasting or illness can therefore be associated with hypoglycaemia, drowsiness, coma and apnoea. Early identification enables the introduction of pre-symptomatic treatment reducing the risk of acute, life threatening episodes.

1.6 Maple Syrup Urine Disease (MSUD) an autosomal recessive condition affecting 1 in 200,000. There is a metabolic block resulting in increased levels of branched chain amino acids.the name derives from sweet smelling urine likened to the smell of maple syrup. Symptoms are vomiting, difficulty feeding lethargy and progressive neurological deterioration.

1.7 Isovaleric aciduria (IVA) is an autosomal recessive enzyme deficiency disease affecting 1 in 100,000. The loss of enzyme function leads to the toxic build-up of metabolites leading to vomiting, lethargy and coma. The acute condition usualy presents in the first two weeks of life.

1.8 Glutaric aciduria (GA1) is an autosomal recessive condition caused by an enzyme deficiency that affects 1 in 100,000 live births. The symptoms of encephalopathic crisis appear most commonly between the age of 9 months and 2 years.

1.9 Homocystinuria an autosomal recessive condition affecting 1 in 100,000 live births. Diagnosis characteristically between 2-3 years of age when there is myopia, dislocation of the lens, osteoporosis and thinning and lengthening of the long bones.

The British Inherited Metabolic Diseases Group (BIMDG) provides National standards and best practice for care for newborns with a family history of MCADD Consultant paediatrician responsible for metabolic diseases should be informed antenatally, urgent testing for MCADD should be discussed, and a clear plan of care for after delivery established

http://www.bimdg.org.uk/guidelines.asp

2.The Process (see appendix 2)

The newborn screening blood spot programme includes a series of steps involving different health professionals at each stage.

2.1 Communication and Consent

It is recommended that all infants should have a newborn screening bloodspot test with parental consent, verbal consent is adequate. To enable parents to make an informed decision and maintain the high level of uptake of screening the Community Midwife should discuss the bloodspot screening with the parents during the antenatal period and document in the handheld notes.

The Newborn screening information is included in the patient information booklet ***Screening Tests for you & your Baby*** which is given to all women at booking to read.

The midwife should check that the woman has read the leaflet and understands the test and agrees to the test being performed.

The newborn bloodspot screening test can be offered any health professional until the child is one year old. Cystic Fibrosis can only be tested using the newborn bloodspot in the first eight weeks.

2.2 Parents who decline screening

If the parents decline, the health professional offering the screening should record the discussion and offer to provide more detailed information.

They should be sent a letter detailing the decline and informing them that the bloodspot can be performed up to 1 year of age with the exception of cystic fibrosis as this condition can only be screened in this way until the baby is eight weeks old.

Record Decline in maternity record, Personal Child Health Record (PCHR) and send the completed newborn bloodspot card marked as **DECLINE** to the laboratory.

All tests maybe declined; if specific condition tests are declined clearly indicate on the card. Cystic fibrosis and sicle cell tests may be declined individually but all other tests are grouped together and cannot be separated so must be declined as a whole.

The Screening Midwives use this information to monitor the levels of consents/declines and effectively communicate parent's requests to the laboratory and Child Health Information team.

The GP and Health Visitor should be informed by letter to ensure that they do not assume that the bloodspot screening has been completed and thereby should symptoms become apparent, rule out the possibility of an affected child. Appendix 4.

Decline letters can be found at:

https://www.gov.uk/government/publications/declined-newborn-blood-spot-screening-template-letters

examples can be found at the end of this guideline

2.3 Deceased Babies

Deceased babies are notified by the attending clinician to the Child Health Team. These babies are notified as deceased on the Careplus child health information system and the Northgate Newborn Failsafe.

2.4 Research Contact

In accordance with the Code of Practice for the storage and use of residual bloodspots please record **NO RESEARCH CONTACT** clearly on the card if the parents do not wish to be contacted.

Linkage of Antenatal & Newborn Sickle Cell Screening

To ensure that the screening laboratory can provide linkage between the antenatal and newborn screening results for Sickle cell the screening team will send an alert antenatally if either parent is a significant carrier of any relevant haemoglobin disorder.
When performing the bloodspot, carrier status of both parents should be documented on the card.

3 Infants admitted to NICU

All infants admitted to NNICU require a one bloodspot admission sample.

This sample should be sent to Bristol within 24hours.

By taking this sample it reduces the number of babies who require DNA for sickle cell testing if they have been transfused prior to screening. It is also a failsafe for identifying babies within NNICU who will require follow up bloodspot tests.

To minimise the number of invasive procedures, babies admitted to NNICU are likely to have multiple blood samples taken so bloodspot screening can be coordinated with other tests. Venepuncture or venous /arterial sampling from an existing line is an alternative, this is providing the sample is not contaminated with heparin and the line cleared of infusate.

When an infant has already received a transfusion, either intrauterine or in the newborn period prior to the NICU day 6 sample being taken, repeat samples are needed. To be able to complete the screening test a bloodspot must be taken at least 72 hours after the transfusion. If transfused blood is found in the bloodspot sample then the Newborn Screening Laboratory will send the sample for DNA testing to Kings College Hospital for sickle cell disorders. If no transfused blood is found in the bloodspot sample then the Newborn screening laboratory will report the result within the normal result pathway.

For intra-uterine blood transfusion, count the babies date of birth as the date of transfusion

In the event of multiple transfusions an initial screening sample should be sent on day 8 regardless to reduce the chance of the bloodspot screening being missed

The date of the last transfusion should be documented on the bloodspot cards. All details of the newborn screening need to be documented in the PHCR, the medical records. The parents need to be informed of outstanding screening required.

When a baby is discharged it is essential that the appropriate postnatal documentation - i.e. discharge summary/letter that clearly identifies the need for a repeat test and identifies when and where this should be done is copied to relevant departments (and parents) so that the arrangements are made.

When transferring to another unit it is essential that the nurse caring for the baby documents the screening status and that this is handed over both verbally and in the transfer documentation.

4 **The Procedure**

Regardless of medical condition, feeding status or prematurity it is recommended that blood spot samples should be collected on **day 5** (For the purpose of screening, **date of birth is counted as 0**)

The blood sample is collected by the health care professional using a heel prick; universal precautions are taken as when taking any blood sample.

- The health professional taking the blood sample must check with the parent that all fields of the label and blood spot card are correct and make any changes necessary.
- It is the responsibility of the health professional taking the sample to ensure that all layers of the bloodspot card have a pre-printed barcoded label attached. (A barcoded label must be attached unless there are exceptional circumstances in this case it is the health professional's responsibility to ensure the correct details are written on the form).
- Ensure that the baby is in a secure position.
- Clean the heel with plain water to prevent contamination of the sample that may affect the result of the test. Faeces contains high concentrations of IRT (IRT is measured during screening for Cystic Fibrosis).
- Perform the test holding automated lancet device firmly against the heel in the

appropriate area.

- Wait for the blood to flow, avoid squeezing and allow blood to fill each circle soaking completely through. The laboratory punch out several circles of the blood spot for analysis, the sample needs to be sufficient to screen for all of the conditions and to be retained if retesting is required to check equivocal or suspected results.
- Do not add layers of small blood spots, this will be identified in the laboratory and a repeat test will be requested.
- Allow spots to dry prior to placing in the glassine envelope, wet samples can stick to the envelope and a repeat sample will be required.
- If a second prick is necessary it should be made in a different area to prevent the sample containing excessive tissue fluid and to reduce the pain of the procedure.
- Despatch the sample within 24 hours to enable early analysis and subsequent treatment in the event of a 'condition suspected' result.
- Samples posted from a community post box must have only one sample per envelope
- Samples taken in the hospital or brought in from community will be sent by Royal Mail Special delivery service.
- All samples are sent via Royal Mail; during times of postal strikes the Screening Midwife will co-ordinate a contingency plan using a transport courier.
- Record taking the sample in maternity notes and PCHR to comply with the NMC record keeping guidelines
- Complete the record in the Community office (or book on NICU for NICU/TCW babies) for audit purposes, this provides evidence that the sample has been taken & sent. This enables the Screening Midwife to operate the failsafe & track samples.

5 Results of Screening

5.1 Inconclusive result

Results that are inconclusive require an additional sample to be obtained to complete the screening test. e.g. this may occur in cystic fibrosis and congenital hypothyroidism when the result is borderline. The laboratory will contact the midwife and provide information for the parents

5.2 Not suspected result

The term 'not suspected' is used because screening test are not 100% certain
All not suspected results are sent by letter generated from Plymouth Child Health Information team to the parents.

5.3 Carriers of Cystic Fibrosis & Sickle Cell Trait

Screening for cystic fibrosis includes testing some babies for the most common gene changes that cause cystic fibrosis. This means screening may identify some babies who are likely to be well genetic carriers of cystic fibrosis.
Carriers of a condition are usually healthy and not affected by the condition.

5.4 Giving the carrier result

The GP and Health Visitor will provide support and information, along with appropriate referral for families for genetic counselling.
The Genetic Counsellors and Genetics Haemoglobinopathy Co-ordinator Nurses are based at Exeter Genetics centre. Telephone 01392 405728

5.5 Condition Suspected results
The laboratory initiates immediate clinical referral each of the conditions has a lead Clinician who will contact the GP and arrange appointments with the parents.

The diagnosis is confirmed for each condition and the result notified to the Newborn Screening laboratory by the designated lead for that condition.

Confirmatory tests and the initial management of conditions can be found on the Newborn Bloodspot Screening website.

The Bristol Newborn Screening laboratory will report all results to the Health visitor and GP via the Child Health Information Team (CH IT).
Appendix2

6 **RepeatTesting**-seeappendix 3.

The screening team use a form to request that the Community Midwife repeats a newborn blood spot and gives the reason why the test needs to be repeated. The repeat test must be completed the day that the Community Midwife receives the form to ensure that the test results can be communicated to the relevant people within the recommended time frame and any treatment needed can be commenced. All repeat testing appointments on Children and Young Peoples Outpatient Department (CYPOD) should be appointed within 3 working days of the referral.

A repeat test WILL be requested by Bristol Newborn Screening Laboratory if the card has a documentation anomaly.

- A repeat test **may be** requested because:
  - The sample is not valid (e.g. taken too early,)
  - Sample contaminated
  - Sample card has passed its expiry date
  - Blood spots are compressed or damaged
  - Insufficient demographic detail (ie no NHS number)
  - Insufficient blood
  - Results are uncertain
  - A repeat for CHT in a baby born prematurely at 31+6 weeks gestation or less.

NB. Immaturity can mask congenital hypothyroidism hence the revised policy is based on gestational age criteria and includes babies born at less than 32 weeks gestation (less than or equal to 31+6 days) repeat testing at 28 days postnatal age, counting day of birth as day 0, or discharge home, whichever is the sooner

7 Failsafe **arrangements**

The Plymouth failsafe for newborn screening is included in this guideline it provides a process for checking that all babies have a bloodspot screening result. It is performed by the Screening Team.

All repeat tests are inputted into the Newborn Repeat database and followed up by the Screening Team.

The responsibility for sustaining the failsafe is multi-disciplinary with each professional involved with care of the baby checking that there is a conclusive screening result for every baby.

Plymouth Hospitals NHS Trust have to supply regular data to Public Health England who monitor the quality of the Screening programme, this is collected by the Screening Team

Babies identified by the failsafe with no sample received in the laboratory will need the bloodspot repeated, the request for missed or lost in the post samples will be generated by the Screening Midwife using the Newborn repeat bloodspot request form, this form is completed and returned with the appropriate documentation.

All babies under one year should have documented results for all the conditions routinely screened for in England. If results cannot be found or babies new to the area have missed the bloodspot screening they are able to have them undertaken up to 1 year of age. Health Visitors should discuss with parents at the first contact and can refer babies over 28 days for repeat testing to Children & Young Peoples Outpatients (CYPOD) using the correct referral form .Appendix 5

All health care professionals when seeing babies less than 1 year old in hospital, community and primary care should check that the newborn bloodspot screening has been completed.

8 Regional Screening team

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Plymouth Newborn Bloodspot Screening team
Alison Mackenzie Consultant Public Health 01752 315764
PHNT lead Consultant for Newborn Bloodspot Screening Julia Lilley based in NICU
Peadiatrician Georgina Selby Consultant for Endocrine disorders.0845 155 8155
Ruth Rice Screening Co-ordinator /Midwife 01752 439792 ext 39792
Jackie Craner Deputy Screening Midwife 01752 439792 ext 39792
Lead Health Visitor Denise Edgecombe 01752 434428

Operational link in laboratory -Tracey Brunsdon
Child Health Information Team MANAGER -Helen Finnie 01752 437281
Bristol Newborn Screening laboratory Director- Helena Kemp

Congenital Hypothyroidism Suspected

On the day that the result is available

1. NSL will contact the Specialist Metabolic team and inform them (both by telephone and in writing) of the result. The screening midwives are notified, for completeness, by telephone.

2. A health professional working in the Specialist Metabolic team will discuss the positive screening result with the health visitor or other appropriate health profession; and co-ordinate the first joint contact with the family. Results should be communicated face to face.

3. Parents should be provided with:

    a. A copy of the results leaflet "Congenital Hypothyroidism is suspected";

    b. Contact numbers for the designated clinician or specialist nurse;

    c. Details of the time and location of follow up appointment, which will be within 3 working days;

4. Parents should be offered an appointment with the designated Specialist Metabolic team within 3 days of giving the parents results.

5. Results should not normally be communicated to parents on a Friday, Saturday or Sunday, or just before a Bank Holiday.

6. Results should be recorded in the Personal Child Health Record and in the baby's notes.

PKU Suspected

On the day screening result available

1. NSL makes contact (both by telephone & in writing) with the Lead Metabolic disorder Consultant Georgina Selby to inform them of the result, provide contact details of the family and agree the date and time of the first review appointment(within 24 hours).
2. The Lead Consultant for metabolic disorders will discuss the positive screening result with the GP, health visitor or midwife and co-ordinate the first joint contact with the family. Results should be communicated face to face.
3. Parents should be provided with:
    a. Inform them of the result and time and location of the first review appointment.
    b. Provide contact details of the PKU team
    c. Organise provision of written information i.e. the 'PKU is suspected leaflet'
4. NSL contacts GP to inform them of the results and provide the following (fax or e-mail):
    a. PKU GP letter
    b. 'PKU is suspected' leaflet
    c. Contact details of PKU team
    d. Details of the time and location of the appointment with the Metabolic disorders Consultant.
5. . NSL contacts local screening midwife by phone

MCADD Suspected

On day screening result available

1. NSL informs the Lead Paediatrician for Metabolic disorders Georgina Selby (both by telephone and in writing) to inform them of the result and ensure that arrangements are in place for the baby to seen (within 24 hours) and for further testing to take place.
2. NSL contacts GP to inform them of the results and provide the following (fax or e-mail):
   a. MCADD GP letter and copied to HV
   b. Contact details of the relevant clinical team
   c. Details of the time and location of the appointment with the clinical team.
3. Parents should be provided with 'MCADD suspected leaflet' with links to the screening website and support groups.
4. NSL contacts local screening midwife by phone

Maple Syrup Urine Disease (MSUD) SUSPECTED

On day screening result available

1. NSL makes contact with the Lead Paediatrician for Metabolic disorders Georgina Selby to inform them of the result.
2. Baby to be seen by the specialist paediatrician within 24 hours.
3. Parents should be provided with the
4. 'MSUD suspected leaflet' with links to the screening website and support groups.
5. Specialist team to contact family and offer ambulance admission
6. NSL contacts GP to inform them of the results and provide the following (fax or e-mail):
   a. MSDU letter and copy in HV
   b. Details of the time and location of the appointment with the Metabolic disorders Consultant
   c. Relevant details of the specialist team.
7. NSL contacts local screening midwife by phone.

IVA SUSPECTED

On day screening result available

1. NSL makes contact with the Lead Paediatrician for Metabolic disorders Georgina Selby to inform them of the result and arrange urgent admission to hospital.
2. Specialist/Designated team to contact family and offer ambulance admission.
3. Parents should be provided with the 'IVA is suspected' leaflet with links to the screening website and support groups.
4. NSL contacts GP to inform them of the results and provide the following (fax or e-mail):
   a. IVA letter and copy in HV
   b. Details of the time and location of the appointment with the Metabolic disorders Consultant
   c. Relevant details of the specialist team.
5. NSL contacts local screening midwife by phone.

GAl SUSPECTED

On day screening result available

1. NSL makes contact with the Lead Paediatrician for Metabolic disorders Georgina Selby to inform them of the result and arrange urgent admission to hospital.
2. Specialist/Designated team to contact family and offer ambulance admission.
3. Parents should be provided with the 'GAl is suspected' leaflet with links to the screening website and support groups.
4. NSL contacts GP (fax or email) to inform them of the results and provide the following
   a. GA l letter and copy in HV
   b. Details of the time and location of the appointment with the Metabolic disorders Consultant
   c. Relevant details of the specialist team.
5. NSL contacts local screening midwife by phone.

HCU SUSPECTED

On day screening result available

1. NSL makes contact with the Lead Paediatrician for Metabolic disorders Georgina Selby to inform them of the result and arrange appointment within 24 hours unless result is available on a Friday.
2. Specialist/Designated team to contact family and instruct them to take the child to a specialist hospital. Parents given the 'HCU is suspected' leaflet with links to the screening website and support groups.
3. NSL contacts GP (fax or email) to inform them of the results and provide the following
   a. HCU letter and copy in HV
   b. Details of the time and location of the appointment with the Metabolic disorders Consultant
   c. Relevant details of the specialist team.
4. NSL contacts local screening midwife by phone.

Sickle Cell Suspected

On the day that the result is available

1. NSL will contact the Lead Haematologist Tim Nokes and inform them (both by telephone and in \VTiting) of the result. The screening midwives are notified, for completeness, by telephone.

2. The Lead Haematologist will discuss the positive screening result with the health visitor or other appropriate health professional, and co-ordinate the first joint contact with the family.

3. Parents should be provided with:

   a. The screening results leaflet "Parents Guide: Care and management of your child with Sickle Cell Disease"

   b. Contact numbers for the designated clinician and details of parent support groups (healthtalkonline.org)

   c. Details of the time and location of any appointments with the Lead Haematologist.

4. Results should be recorded in the Personal Child Health Record and in the baby's notes.

Cystic Fibrosis Suspected

On the day that the result is available

1. NSL will contact the Lead Paediatric Cystic Fibrosis Consultant Dr Derry and inform them (both by telephone and in writing) of the result. The screening midwives are notified, for completeness, by telephone.

2. A health professional working in the Cystic Fibrosis team will discuss the positive screening result with the GP, health visitor or midwife and co-ordinate the first joint contact with the family. Results should be communicated face to face.

3. Parents should be provided with:

   d. The screening results leaflet "Cystic Fibrosis is suspected";

   e. Contact numbers for the designated clinician or specialist nurse and details of parent support groups;

   f. Details of the time and location of any appointments at the designated Cystic Fibrosis centre, which will be within 28 days for babies with two mutations detected, and day 35 for babies who have required a second sample IRT measurement.

4. Parents should be offered an appointment with the designated local cystic fibrosis team the following day.

5. Results should be recorded in the Personal Child Health Record and in the baby's notes.

6. For quality control and audit purposes the Lead Consultant should send confirmatory results to the NSL.

Appendix 2

PLYMOUTH NEONATAL BLOODSPOT SCREENING PATHWAY

For Premature babies, information is provided in NNICU have a 1 bloodspot admission sample taken & posted within 12 hours to the Bristol newborn laboratory.

"Screening tests for you and your baby" leaflet given antenatal to mother. Information to be discussed prior to bloodspot screening test. All cards to have newborn barcoded bloodspot labels on.

https://newbornbloodspotscreening.nhs.uk/ resource to support delivery of newborn bloodspot screening test or contact screening midwives 01752 439792

Informed Choice.

Consent for screening given

Screening Declined Screening midwife to contact the parents and send out decline letter with contact details in case of change of mind

Blood sample collected and posted within 12 hours

Analysis at Bristol Newborn Screening lab. Results sent to CHIT by email

Selective tests declined – mark card, e.g. 2declined PKU screening"

All tests declined – Mark card "decline – all tests"

Repeat sample required with consent

Not suspected result

Suspected abnormal result

CHIT sends paper copy of result to HV & GP

CHIT informs parents by letter

Newborn screening lab initiates clinical referral via appropriate clinical lead.

CMW informs screening midwife, HV and GP; Still sending card to Bristol lab as essential for failsafe procedures.

HC checks PCHR at developmental check and inserts result if not filed.

GP ensures paper copy filed and results entered on child's electronic record; including read code.

Abbreviations

NICU – Neonatal Intensive Care Unit
CYPOD – Children and Young People's Outpatient Department
CHIT – Child Health Information Team TCW – Transitional care ward
HV - Health Visitor PHCHR – Parent Health Child Health Record
DHS HV- Deputy Head of Service for Health Visiting
GP – General Practitioner CMW – community midwife

FAILSAFE
ALL HCPs TO CHECK BLOODSPOT SCREENIGN STATUS OF UNDER 1 YEAR OLDS

ROUTINE FAILSAFE

CHIT checks daily for babies aged 14 days with no status code recorded. List emailed daily to Screening Midwife. Checked with Northgate Newborn Failsafe.

Need to check if baby has had NBBS screening?
Contact:
CHIT: 01752 437281
Screening Midwives: 01752 439792

Screening Midwife validates list with Bristol Laboratory list, to check that that sample has been received.

Untested babies less than 28 days old
Screening Midwife contacts CMW who arranges for screening tests to be done at home
Untested babies older than 28 days
Screening midwife contacts CMW or HV who arranges for screening tests to be done at home or CYPOD (using appropriate referral form- see appendix 2)

FAILSAFE
ALL HCPs TO CHECK BLOODSPOT SCREENIGN STATUS OF UNDER 1 YEAR OLDS

ROUTINE FAILSAFE

Babies born at less than 32 weeks gestation (less than or equal to 31+6 days) need repeat test at 28 days postnatal age, counting day of birth as day 0 or at discharge.

1. Bristol Screening Lab emails screening team with details of babies requiring repeat testing
2. Lab sends reminder letter to HV and GP
3. HV arranges for screening tests to be done at CYPOD (using appropriate referral in appendix 1)
4. If child does not attend for test, CYPOD contacts HV and GP
5. If no tests received, lab sends 2 further reminder letters to HV and GP to prompt

Screening midwife liaises with NICU to ensure tests done on inpatients (tests done by ward staff).
In cases where a repeat sample is required SM contacts Head of Service HV to arrange for tests to be done at CYPOD (using referral form in appendix 2).

ii) babies who have missed admission sample and have a blood transfusion require a pre – transfusion, send to Bristol Newborn Screening laboratory.

Transfused Blood present in Newborn Blood spot sample Newborn Lab to send sample the DNA Lab (KCH or Sheffield) for sickle cell screen

Babies who move into Plymouth area

CHIT checks daily for all babies who have moved into the area in the previous month, and who have no screening results recorded. List sent weekly to the Deputy Head of Service Screening HV c/o

Appropriate HV identified & contacted

HV checks baby's HV records from previous area to confirm if bloodspot test was done

Tested Babies
HV ensures test result recorded in new HV record and PHCHR
Untested Babies
HV arranges for screening tests to be done at CYPOD or home (see appendix 2)

Plymouth Hospitals NHS
NHS Trust

Repeat Newborn Blood Spot Screening Test Form

Date:

……

Mother's Name: …… **DOB:** …… **NHS No.** …… **Hospital No.** ……
Baby's Name: …… **DOB:** …… **NHS No.** …… **Hospital No.** ……
Home address: …… …… **Post Code:** …… **Contact No.** ……
GP **Dr.** …… **Address:** …… **Post Code:** …… **Contact No.** ……
Reason for repeat:

Message passed to:	
Date: ……	
Test performed by:	
Date: ……	
Comments:	

Please return to Screening Midwives c/o EPU level 06.

Ref: S/Com mid/2011

Plymouth Hospitals NHS
NHS Trust

URGENT

Repeat Newborn Bloodspot Request form for
Children & Young People's Outpatients Department (CYPOD)
Please arrange an appointment within 3 days of receipt of this form

Surname …….. Forename …….

Address ……
DOB …… Contact No: …….

Hospital No: …… NHS No: …….

Mothers full name ……... DOB …….

Reason for Repeat test

36 week corrected gestational age ☐

New to the area ☐

4 months post transfusion ☐

Baby's age at referral date …….

Health care professional referring ……...

Print name ……..

Date …….

Contact No: …….

GP …… Contact No: ……..

Additional needs

Language line ……..

Accessibility ……

Other ……

Comments ……

Please email this form to plh-tr.PaediatricAppointments@nhs.net.
CYPOD Tel No: 01752 430927 Screening Midwife Tel No: 01752 439792

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<INSERT parent name>
<INSERT parent address>

<Insert HCP address>
<Insert HCP telephone number>

<INSERT date>

DECLINE OF NEWBORN BLOOD SPOT SCREENING

Dear <parent name>,

Re: <INSERT baby's name>
<INSERT baby's NHS number>
<INSERT baby's date of birth>

I am writing to confirm that you have declined the offer of newborn blood spot screening for your baby for <INSERT all conditions> <INSERT some conditions – name tests declined).

Newborn blood spot screening involves taking a blood sample to find out if your baby is at risk of one of several rare but serious health conditions. If these conditions are detected early, they can be treated effectively. However, if they are not detected early, they may cause irreversible harm to your child. Screening is not compulsory, but it is strongly recommended because it could save your baby's life.

Information on the conditions screened for is available in the '*Screening tests for you and your baby*' booklet (www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief) and on NHS Choices (www.nhs.uk/Conditions/pregnancy-and-baby/Pages/newborn-blood-spot-test.aspx).

If you change your mind

You have the right to decline screening for your baby and we will record this in your baby's health records. However, if you change your mind, screening can be done up to a year of age but only for some of the conditions. In the meantime there is a risk that your child may become seriously ill and suffer irreversible harm. Please contact your midwife, health visitor or GP urgently if you would like your baby to be screened, or if you would like further information or talk about any concerns.

Yours sincerely,

<INSERT signature>

For further information visit www.gov.uk/topic/population-screening-programmes/newborn-blood-spot

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<Insert HCP address>
<Insert HCP telephone number>

<INSERT GP/HV/CHRD name>
<INSERT GP/HV/CHRD address>

<INSERT date>

DECLINE OF NEWBORN BLOOD SPOT SCREENING

Dear <GP/HV/CHRD name>,

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

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

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

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

Delete as applicable – for GP/HV: 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 is available up to one year of age, if the parents change their minds.

Delete as applicable – for CHRD: We are providing this information so that a record of decline is entered onto the child health information system.

Yours sincerely,

<INSERT signature>

For further information visit www.gov.uk/topic/population-screening-programmes/newborn-blood-spot

Monitoring & Audit

Auditable standards:

Evidence of documented discussion with parents
Evidence of patient information leaflet having been given to parents
Review of results undertaken appropriately within timescale
Please refer to audit tool, location: 'Maternity on cl2-file11', Guidelines

Reports to:

Clinical Effectiveness Committee - responsible for action plan and implementation of recommendations from audit

Clinical Governance & Risk Management Committee

Frequency of audit:

Annual

Responsible person:

Antenatal screeninQ midwife

Cross references

Antenatal Guideline 31 - Maternity Hand Held Notes, Hospital Records and Record Keeping

Antenatal Guideline 44 – Guideline Development within the Maternity Services

Training requirements

Audit of training needs compliance - please refer to TNA policy

Training needs analysis:

Please refer to 'Training Needs Analysis' guideline together with training attendance database for all staff

References

NHS Screening Programmes 2012 Guidelines for Newborn Blood Spot Sampling.
Department of Health, 2005. Policies & Standards Newborn bloodspot screening in the UK Newborn Screening Programme. London
Antenatal and Newborn Screening Programmes 2014 Regional Policy for Newborn Blood Spot Screening for inherited Metabolic disease (IMO) in the South West (Bristol Newborn ScreeningLaboratory)

Nursing and Midwifery Council 2004 Midwives rules and standards. London

Nursing and Midwifery Council 2004 Record keeping: Guidance for nurses and midwives. London.
httg://newborn bloodsQot.screening. nhs.uk

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