



Guideline for offering, performing and managing the Newborn Blood Spot Screening Test and results.

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1.0 Introduction

Newborn Blood Spot Screening (NBSS) is offered for all newborn babies up to one year of age in order that a small number with the potential to develop disease might be diagnosed and treated and their parents receive support and education. It is a complex programme delivered by a range of different organisations working together.

2.0 Objective

The main objective of the screening programme is to ensure the early detection and referral of babies found to be high risk, in order to improve their health and prevent severe disability or even death.

It is essential to minimise the adverse effects of screening, such as anxiety, inaccurate information, unnecessary investigation and to provide reassurance to the majority of parents whose babies are thought not to be affected.

This SOP outlines the processes to be followed when taking a NBBS and if parents decline screening.

3.0 Scope

This guideline applies to all staff working within the Maternity Services at BHNFT who provide care for mothers and babies.

4.0 Main body of the document

Background

The National Screening Committee (NSC) recommends that all babies in the UK are offered screening for:

- Phenylketonuria (PKU)
- Congenital Hypothyroidism (CHT)
- Sickle Cell Disease (SCD)
- Cystic Fibrosis (CF)
- Medium-chain acyl-CoA dehydrogenase Deficiency (MCADD)
- Maple syrup urine disease (MSUD)
- Isovaleric acidaemia (IVA)
- Glutaric aciduria type 1 (GA1)
- Homocystinuria (pyridoxine unresponsive) (HCU).
- Severe Combined Immunodeficiency (SCID) is a 2 year evaluative rollout from 6th September 2021. The evaluation, which launched on 6 September 2021, will help to determine whether screening for SCID works in practice as part of the [NHS Newborn Blood Spot \(NBS\) Screening Programme](#). Testing for SCID uses the same blood spot as the other [9 NBS conditions](#). No extra blood spots are needed. The evaluation will initially run for 2 years, covering around two-thirds of the newborn population of England. It will continue to run in a third year while the results are used to make a recommendation on whether or not it should be implemented nationally.



Barnsley NHSFT send the newborn bloodspot samples for analysis to the Sheffield Newborn Screening Laboratory which is part of the evaluative rollout for SCID.

Please use the link to access the most up to date Public Health England **Guidelines for newborn blood spot sampling**.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/899485/Guidelines_for_Newborn_Blood_Spot_Sampling_March_2016.pdf

See below for additional guidance that is specific to Barnsley NHSFT.

4.1 Routine Testing

Potentially infectious samples must have danger of infection stickers on the request card and be put in a biohazard bag prior to sealing it in the pre-paid envelope.

4.2 Timely Sample Despatch

Completed samples are to be placed in the Community Office. Once reviewed they will be dispatched to the reference lab via the daily hospital transport run.

4.3 Timely Receipt of a Repeat/Second Blood Spot Sample

A request for a repeat sample is made by Sheffield Laboratory to the Antenatal & Newborn Screening Coordinator. The request for a repeat sample is made electronically and clearly states why it is needed

4.4 Parents who decline screening

If the parent(s) decline screening for their baby, either for specific conditions or the full programme, the blood spot screening card **MUST** be completed and clearly marked 'DECLINE' (specify test or all tests) and **still be sent** to the laboratory. Please note that if MCADD is declined this also includes MSUD/ IVA/ GA1 & HCU. This enables the decline to be noted in the laboratory and passed on to the Child Health Information Service (CHIS) for recording.

It is the responsibility of the health professional offering the test to confirm in writing to the parents, and to inform the General Practitioner (GP) and Health Visitor (HV) of the condition(s) for which the baby has **not** been screened. Please complete the letter templates for decline of Newborn Blood Spot Screening for both parents (Appendix 1) and health professionals (Appendix 2). The community midwife should liaise with the antenatal and newborn screening coordinator.

For families who move into the area, and then decline screening, please see Appendix 3 - Decline of newborn blood spot screening: template letter to give to parents who moved in from a different area or another country (SCID offered).



5.0 Associated documents and references

Public Health England (PHE). Screening test for you and your baby (2021)

<https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief>

Public Health England (PHE). NHS Newborn blood spot (NBS) screening programme: detailed information. <http://newbornbloodspot.screening.nhs.uk>

6.0 Training and resources

Any training will be given as documented in the Maternity Training Needs Analysis. This is updated on an annual basis.

The Barnsley HNFT Competency Framework for Newborn Blood Spot ideally should be used for:

- Induction of new staff.
- The framework should be used when an individual has had to perform 3 repeat newborn blood spot samples in a 3 month time period.
- The framework should be used when an individual has had a single sample rejected due to either insufficient, multi spotted or spotted on both sides of the request form

7.0 Monitoring and audit

The screening coordinators is responsible for identifying practice issues for individuals generating an unacceptable level of avoidable repeat samples and to coordinate with their line manager the performance management of these individuals to address issues identified.

Any adverse incidents relating to performing and managing the Newborn Blood Spot Screening Test and results will be monitored via the Incident reporting system. Any problems will be actioned via the case review and Root cause analysis action plans. The action plans are monitored by the risk midwife to ensure that improvements in care are made. The trends and any root cause analysis are discussed at the monthly risk meetings to ensure that appropriate action has been taken to maintain safety.

The guideline for offering, performing and managing the newborn blood spot screening test and results will be audited in line with the annual audit programme, as agreed by the CBU. The audit action plan will be reviewed at the monthly risk management meetings on a quarterly basis and monitored by the risk midwife to ensure that improvements in care are made.

8.0 Equality and Diversity

The Trust is committed to an environment that promotes equality and embraces diversity in its performance as an employer and service provider. It will adhere to legal and performance requirements and will mainstream equality, diversity and inclusion principles through its policies, procedures and processes. This guideline should be implemented with due regard to this commitment.



To ensure that the implementation of this guideline does not have an adverse impact in response to the requirements of the Equality Act 2010 this policy has been screened for relevance during the policy development process and a full equality impact assessment is conducted where necessary prior to consultation. The Trust will take remedial action when necessary to address any unexpected or unwarranted disparities and monitor practice to ensure that this policy is fairly implemented.

This guideline can be made available in alternative formats on request including large print, Braille, moon, audio, and different languages. To arrange this please refer to the Trust translation and interpretation policy in the first instance.

The Trust will endeavor to make reasonable adjustments to accommodate any employee/patient with particular equality, diversity and inclusion requirements in implementing this guideline. This may include accessibility of meeting/appointment venues, providing translation, arranging an interpreter to attend appointments/meetings, extending policy timeframes to enable translation to be undertaken, or assistance with formulating any written statements.

8.1 Recording and Monitoring of Equality & Diversity

The Trust understands the business case for equality, diversity and inclusion and will make sure that this is translated into practice. Accordingly, all guidelines will be monitored to ensure their effectiveness.

Monitoring information will be collated, analysed and published on an annual basis as part of Equality Delivery System. The monitoring will cover the nine protected characteristics and will meet statutory employment duties under the Equality Act 2010. Where adverse impact is identified through the monitoring process the Trust will investigate and take corrective action to mitigate and prevent any negative impact.



Appendix 1 – Decline of newborn blood spot screening: template letter to give to parents to confirm their decision of decline (SCID offered)

[insert parent/carer name]

[insert parent/carer address]

Barnsley Hospital NHSFT
Gawber Road
Barnsley
South Yorkshire
S75 2EP
Tel: 01226 435369

[insert date]

Decline of newborn blood spot screening

Dear [parent/carer 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 [all conditions] / [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.

Newborn blood spot screening is offered to all babies up to one year of age and screens for the 10 rare conditions listed below:

- congenital hypothyroidism (CHT)
- cystic fibrosis (CF)
- glutaric aciduria type 1 (GA1)
- homocystinuria (pyridoxine unresponsive) (HCU)
- isovaleric acidaemia (IVA)
- maple syrup urine disease (MSUD)
- medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
- phenylketonuria (PKU)
- severe combined immunodeficiency (SCID)
- sickle cell disease (SCD)



For information on the conditions screened for, please see the 'Blood spot' section of the 'Screening tests for you and your baby' booklet (www.gov.uk/phe/pregnancy-newborn-screening) and the SCID screening leaflet (www.gov.uk/government/publications/scid-screening-helping-you-decide-if-you-want-this-for-your-baby).

Visit the NHS website for information about:

- newborn blood spot screening, at www.nhs.uk/bloodspot
- screening for sickle cell and thalassaemia, at www.nhs.uk/sct

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 to talk about any concerns.

Yours sincerely,

[insert signature]



Appendix 2 – Decline of newborn blood spot screening: template letter to inform HVs, GPs and CHIS (SCID offered)

[insert GP/child health information service/health visitor name]
[insert GP/child health information service/health visitor address]

Barnsley Hospital NHSFT
Gawber Road
Barnsley
South Yorkshire
S75 2EP
Tel: 01226 435369

[insert date]

Decline of newborn blood spot screening

Dear [GP/child health information service/health visitor 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 10 rare conditions listed below:

- congenital hypothyroidism (CHT)
- cystic fibrosis (CF)
- glutaric aciduria type 1 (GA1)
- homocystinuria (pyridoxine unresponsive) (HCU)
- isovaleric acidaemia (IVA)
- maple syrup urine disease (MSUD)
- medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
- phenylketonuria (PKU)
- severe combined immunodeficiency (SCID)
- sickle cell disease (SCD)



[Delete as applicable – for GP/health visitor] 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 child health information service] 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



Appendix 3 - Decline of newborn blood spot screening: template letter to give to parents who moved in from a different area or another country (SCID offered)

[insert parent/carer name]
[insert parent/carer address]

Barnsley Hospital NHSFT
Gawber Road
Barnsley
South Yorkshire
S75 2EP
Tel: 01226 435369

[insert healthcare professional telephone number]

[insert date]

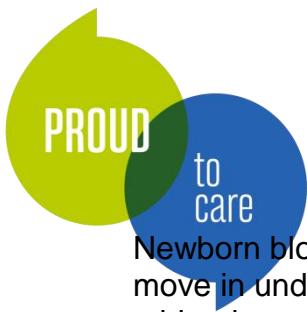
Decline of newborn blood spot screening

Dear [parent/carer name],

Re: [insert baby's name]
[insert baby's NHS number]
[insert baby's date of birth]

I am writing to confirm that we do not have a record of your baby's newborn blood spot screening results and that you have declined the offer of screening in our area.

[Delete if not applicable] This is because you believe that your child has already been screened in a different area or in another country. Please note that different countries screen for different conditions.



Newborn blood spot screening is offered to all babies born in the UK and those that move in under 12 months of age without screening results. 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.

Newborn blood spot screening is offered to all babies up to one year of age and screens for the 10 rare conditions listed below:

- congenital hypothyroidism (CHT)
- cystic fibrosis (CF)
- glutaric aciduria type 1 (GA1)
- homocystinuria (pyridoxine unresponsive) (HCU)
- isovaleric acidaemia (IVA)
- maple syrup urine disease (MSUD)
- medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
- phenylketonuria (PKU)
- severe combined immunodeficiency (SCID)
- sickle cell disease (SCD)

For information on the conditions screened for, please see the 'Blood spot' section of the 'Screening tests for you and your baby' booklet (www.gov.uk/phe/pregnancy-newborn-screening) and the SCID screening leaflet (www.gov.uk/government/publications/scid-screening-helping-you-decide-if-you-want-this-for-your-baby).

Visit the NHS website for information about:

- newborn blood spot screening, at www.nhs.uk/bloodspot
- screening for sickle cell and thalassaemia, at www.nhs.uk/sct

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 to talk about any concerns.

Yours sincerely,

[insert signature]



Appendix 4
SCID resources for blood spot takers

Health professionals making the offer of SCID screening to parents and carers can now access [SCID screening resources](#) to support the evaluation.

e-learning

Blood spot takers who offer SCID screening to parents and carers can now access the new [SCID e-learning module](#). The training resource helps health professionals to understand more about the condition and what information and support is available to parents who are offered SCID screening for their babies.

Crib sheet

We've also produced a handy [crib sheet to support conversations with carers or parents](#). Most blood spot takers will access it digitally, but it can also be printed out locally. Small quantities are orderable from the [PHE Screening print ordering portal](#) (search for 'SCID02').

SCID information leaflet

The new [parent information on SCID](#) should be provided alongside [Screening tests for you and your baby](#) (STFYAYB) as appropriate. It has been provided ahead of the evaluation start date so that health professionals can familiarise themselves with the information.

Appendix 5
Glossary of terms

List all terms/acronyms used within the document and provide a summary of what they mean.

Appendix 6 (must always be the last appendix)

Maintain a record of the document history, reviews and key changes made (including versions and dates)

Version	Date	Comments	Author

Review Process Prior to Ratification:

Name of Group/Department/Committee	Date
Maternity Guideline group	04/03/2021
Women's Business and Governance Meeting	17/12/2021
CBU 3 Overarching Governance Meeting	26/01/2022



Trust Approved Documents (policies, clinical guidelines and procedures)

Approval Form

Please complete the following information and attach to your document when submitting a policy, clinical guideline or procedure for approval.

Document type (policy, clinical guideline or procedure)	Guideline	
Document title	Guideline for offering, performing and managing the Newborn Blood Spot Screening Test and results.	
Document author (Job title and team)	Antenatal & Newborn Screening Coordinator	
New or reviewed document	New	
List staff groups/departments consulted with during document development	Consultant obstetricians Lead midwives	
Approval recommended by (meeting and dates):	Maternity Guideline group	04/03/2021
	Women's Business and Governance Meeting	17/12/2021
	CBU 3 Overarching Governance Meeting	26/01/2022
Date of next review (maximum 3 years)	26/01/2025	
Key words for search criteria on intranet (max 10 words)	Newborn blood spot, blood spot, Guthrie	
Key messages for staff (consider changes from previous versions and any impact on patient safety)		
I confirm that this is the <u>FINAL</u> version of this document	Name: Charlotte Cole Designation: Practice Educator Midwife	

FOR COMPLETION BY THE CLINICAL GOVERNANCE TEAM

<p>Approved by (group/committee): CBU3 Overarching meeting</p> <p>Date approved: 26/01/2022</p> <p>Date Clinical Governance Administrator informed of approval: 07/02/2022</p> <p>Date uploaded to Trust Approved Documents page: 08/02/2022</p>
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