



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

**Policy and Procedure for Newborn Bloodspot Screening for the
HSE Home Birth Service**

Document Reference Number	HB006	Document Developed By	Sub-group of the Clinical Governance Group for the HSE Home Birth Service, chaired by Ms Michelle Waldron
Revision Number	1	Document Approved By	Clinical Governance Group for the HSE Home Birth Service, chaired by Ms Rosemary Ryan
Approval Date	December 2016	Responsibility for Implementation	National Implementation Steering Group, HSE Home Birth Service, chaired by Ms Mary Wynne
Revision Date	December 2017	Responsibility for Review and Audit	Clinical Governance Group for the HSE Home Birth Service

Table of Contents

1. POLICY STATEMENT	3
2. PURPOSE	3
3. SCOPE	3
4. LEGISLATION, CODES OF PRACTICE, STANDARDS AND GUIDANCE	3
5. DEFINITIONS	3
6. ROLES AND RESPONSIBILITIES	4
6.1. HSE National Director of Primary Care	4
6.2. The Designated Midwifery Officer (DMO)	4
6.3. The SECM.....	4
6.4. The DPHN or delegate.....	5
7. PROCEDURE	5
8. MONITORING AND AUDIT	7
9. TRAINING	7
10. IMPLEMENTATION PLAN	7
11. APPENDIX I: INFORMATION FOR PARENTS AND GUARDIANS LEAFLET..	8
APPENDIX II: A PRACTICAL GUIDE	9
12. APPENDIX III: OPT OUT FORM	10
13. SIGNATURE PAGE	11

1. Policy Statement

This policy mandates the Self-Employed Community Midwife (SECM) to undertake the bloodspot screening test on all babies between 72 hours and 120 hours of age that have been delivered at home under the HSE Home Birth Service.

2. Purpose

- 2.1 To provide a policy and procedure to support the SECM in undertaking the Newborn Bloodspot Screening.
- 2.2 To support compliance with the National Newborn Bloodspot Screening Programme in Ireland as provided by the National Newborn Bloodspot Screening Laboratory, Children's University Hospital Temple Street, Dublin 1.

3. Scope

This policy and procedure applies to all SECMs who have responsibility for HSE home births.

4. Legislation, Codes of Practice, Standards and Guidance

- 4.1 Health Acts, 1970 to 2015 and regulations made thereunder
- 4.2 Guardianship of Infants Act, 1964
- 4.3 A Practical Guide to Newborn Bloodspot Screening in Ireland, National Newborn Bloodspot Screening Laboratory, Children's University Hospital Temple Street, Dublin, 6th Edition (HSE 2016)
- 4.4 Recording Clinical Practice (NMBI 2015)
- 4.5 Practice Standards for Midwives (NMBI 2015)
- 4.6 Newborn Bloodspot Screening Card (Revised) (HSE Memo July 2012)

This list is not exhaustive and reference should be made at all times to the guideline for reference sources or the database of legislation, codes of practice, standards and guidance (Clinical Governance Group for the HSE Home Birth Service 2016).

5. Definitions

- 5.1 **Should** indicates a strong recommendation to perform a particular action from which deviation in particular circumstances must be justified (NMBI, 2014).
- 5.2 **Must** commands the action a nurse or midwife is obliged to take, from which no deviation whatsoever is allowed (NMBI, 2014).
- 5.3 **National Newborn Bloodspot Screening Programme** is a blood test taken from a heel-prick of the newborn infant to help identify babies who may have rare but serious conditions (HSE 2016).
- 5.4 **Unique perinatal identifier (UPI)** is allocated to each baby in either the hospital or community of birth. The first three digits is the assigned hospital or community code and in the case of hospital births is

followed by the baby's health care record number. Numbers for births in the community will be assigned by the DPHN or nominee (HSE 2016).

- 5.5 **Phenylketonuria (PKU):** Approximately 1:4,500 infants born in Ireland will have phenylketonuria. It is an inherited disorder and without treatment this condition may cause severe mental handicap in some affected individuals.
- 5.6 **Maple syrup urine disease (MSUD):** Approximately 1:125,000 infants born in Ireland may have this condition and it is life-threatening if it is not detected and treated early.
- 5.7 **Homocystinuria:** Approximately 1:65,000 infants born in Ireland may have this condition; it is a difficult condition to screen for and not all infants will be detected by screening.
- 5.8 **Classical galactosaemia:** Approximately 1:1,500 infants born in Ireland may have this condition. However, infants born to Traveller parents have a higher incidence of 1:450 births. This disorder may cause damage to the liver and may occasionally be life-threatening. Because the condition is relatively common in infants born to Traveller parents, a special screening test (Beutler test) is offered to all these infants at birth.
- 5.9 **Cystic fibrosis:** Approximately 1:1,500 infants born in Ireland may have cystic fibrosis; early treatment does improve their quality of life.
- 5.10 **Congenital hypothyroidism:** Approximately 1: 3,500 infants born in Ireland may have this condition; early detection allows treatment and prevention of the onset of symptoms.

6. Roles and Responsibilities

6.1. HSE National Director of Primary Care

shall ensure:

- 6.1.1. The provision of appropriate systems and structures to support the SECM to provide newborn bloodspot screening for the HSE Home Birth Service.

6.2. The Designated Midwifery Officer (DMO)

shall ensure:

- 6.2.1. That a copy of this policy and procedure is made available to all SECMs, and record same.
- 6.2.2. That appropriate professional support is provided as required to the SECM.
- 6.2.3. That monitoring and audit of this policy and procedure is undertaken on a regular basis.

6.3. The SECM

Shall:

- 6.3.1. Demonstrate compliance with this policy and procedure.
- 6.3.2. Communicate to the woman the importance of the newborn bloodspot screening and provide the information leaflet (Appendix I).
- 6.3.3. Obtain written consent to undertake the bloodspot screening.

- 6.3.4. Obtain the required information from the woman to make available to the DPHN in order that the UPI can be issued prior to obtaining the bloodspot screening test.
- 6.3.5. Ensure that the bloodspot screening is undertaken between 72 hours and 120 hours post-delivery.
- 6.3.6. Ensure that the bloodspot screening card, when dry, is sent by registered post as soon as possible to the National Bloodspot Screening Laboratory and receipt is recorded in the midwifery notes.
- 6.3.7. Register with the Newborn Screening Laboratory in order to obtain evidence that the test was received by the national laboratory and the result has been reported.

6.4. The DPHN or delegate

Shall:

- 6.4.1. Issue the unique perinatal identifier (UPI) to the SECM on request and obtain the required data set from the SECM for the newborn screening register.
- 6.4.2. Facilitate, if requested, the provision of required information to the SECM to confirm the result of the bloodspot screening test by the national laboratory.
- 6.4.3. On receipt of information from the National Screening Laboratory, where a repeat bloodspot test is required, contact the responsible SECM or the area PHN to repeat the test.
- 6.4.4. Maintain all required records in the bloodspot screening register confirming that the screening was completed and the result is documented.

7. Procedure

- 7.1. Reference should be made to A Practical Guide to Newborn Bloodspot Screening in Ireland, HSE 2016 (Appendix II).
- 7.2. The SECM shall obtain an adequate stock of bloodspot screening cards, lancets and information leaflets.
- 7.3. The SECM shall provide the woman and her partner with the required information as provided by the National Screening Laboratory on the indications for the newborn screening test that will be undertaken in the early post-natal period (Appendix I).
- 7.4. The SECM shall obtain written consent from the mother, but both parents may sign the bloodspot form.
- 7.5. The following steps are required to complete the newborn screening card as per HSE Memorandum 2012:
 - 7.5.1 The top information sheet must be removed from the newborn screening card (NSC) by the SECM and given to the parent together with the parent/guardian copy (third sheet of NCS) at the time of sampling.
 - 7.5.2 Health area: This refers to the area whereby public health nurse services are maintaining the newborn bloodspot screening register and will be following up on the baby.
 - 7.5.3 Location of sample taken: Tick the relevant field and enter location in the field provided.

- 7.5.4 Type of feed: If the baby is being breast and artificially fed then both boxes must be ticked.
- 7.5.5 Phone number: This requires the phone number of the SECM. The parent's phone number should not be entered here.
- 7.5.6 Preferred language: This field should always be completed for English or another language, as an interpreter may be needed to communicate possible positive results and the need to attend hospital for further tests.
- 7.5.7 Each circle should be filled completely with blood through from the back.
- 7.6. The SECM shall obtain the required bloodspot screening sample as outlined in section 1.5 of A Practical Guide to Newborn Bloodspot Screening in Ireland, HSE 2016, Appendix II of which shall be undertaken by the SECM.
- 7.7. The bloodspot test card should be allowed to air-dry at room temperature for at least two hours prior to posting in an envelope (water resistant, tear-proof Tyvek® or equivalent) by registered post to the Newborn Screening Laboratory as soon as possible after collection. Transport of the sample should NOT be left to the parents.
- 7.8. The SECM shall ensure the correct disposal of all sharps used to undertake the bloodspot test.
- 7.9. The SECM shall ensure compliance with universal precautions to prevent exposure to biohazards and to ensure the safety, health and welfare of others who will have responsibility for handling the bloodspot screening card and envelope as per HSE guideline (Appendix II).
- 7.10. The SECM shall obtain evidence that the bloodspot screening card has been received and reported on by the National Bloodspot Screening Laboratory.
- 7.11. Where a request is made by the National Screening Laboratory to repeat the bloodspot screening test, the SECM shall complete this. The SECM will explain to the parents why the test is being repeated, inform the parents which condition is being investigated and reassure parents that if the repeat test should prove positive, which is unlikely, that they will be contacted immediately by the SECM. Having taken the repeat test, the sample should be allowed to air-dry before placing sample in a (water resistant, tear-proof Tyvek® or equivalent) envelope and delivered immediately to the National Newborn Bloodspot Laboratory by registered post. The SECM should indicate clearly on the newborn screening card that it is a repeat sample and why and for which test a repeat sample was requested.
- 7.12. The SECM shall notify the DPHN if a repeat screening is being carried out by the SECM.
- 7.13. In the event that an infant is transferred to hospital prior to the SECM carrying out the newborn screening test, she/he shall obtain evidence from the hospital that the bloodspot screening test has been undertaken.
- 7.14. In the event that the parents wish to opt out of the Newborn Bloodspot Screening Test on behalf of their child:
 - 7.14.1 Reference should be made to Section 5, Consent for Newborn Screening of a Practical Guide to Newborn Bloodspot Screening

in Ireland, HSE 2016 (Appendix II) and in particular section 5.2, 'Right to opt out of newborn screening'.

- 7.14.2 The SECM shall record in the maternity records a list of all relevant information provided to the woman, and the discussion prior to signing the Opt-out form.
- 7.14.3 The SECM shall ensure that appropriate time is given to the discussion and reflection of the consequences of opting out from the screening programme.
- 7.14.4 The SECM shall seek the support of the general practitioner/paediatrician to advise the woman of the consequences of opting out of the bloodspot screening programme (HSE 2016).
- 7.14.5 The Opt-out Form shall be downloaded from www.newbornscreening.ie
- 7.14.6 Following completion of the form, the SECM shall provide a copy to the following:
 - a. The Director of Midwifery
 - b. The Director of PHN
 - c. The NNBBS Laboratory
 - d. The GP
 - e. Mother
 - f. Copy to be retained in the mother's record.
- 7.14.7 Prior to the discharge of the woman from the care of the SECM to the PHN on Day 14, the consequences of opting out from the Bloodspot Screening Test should be revisited in case that the woman would like to change her mind.
- 7.14.8 The benefits of screening are explained in the Parent Information Leaflet (Appendix I) and the consequences of not detecting a case are summarised on the Opt-out Form (Appendix III).

8. Monitoring and Audit

- 8.1. Monitoring of compliance with this policy and procedure shall be undertaken by the DMO.
- 8.2. Audit of compliance with this policy and procedure shall be undertaken by nominated HSE professionals.

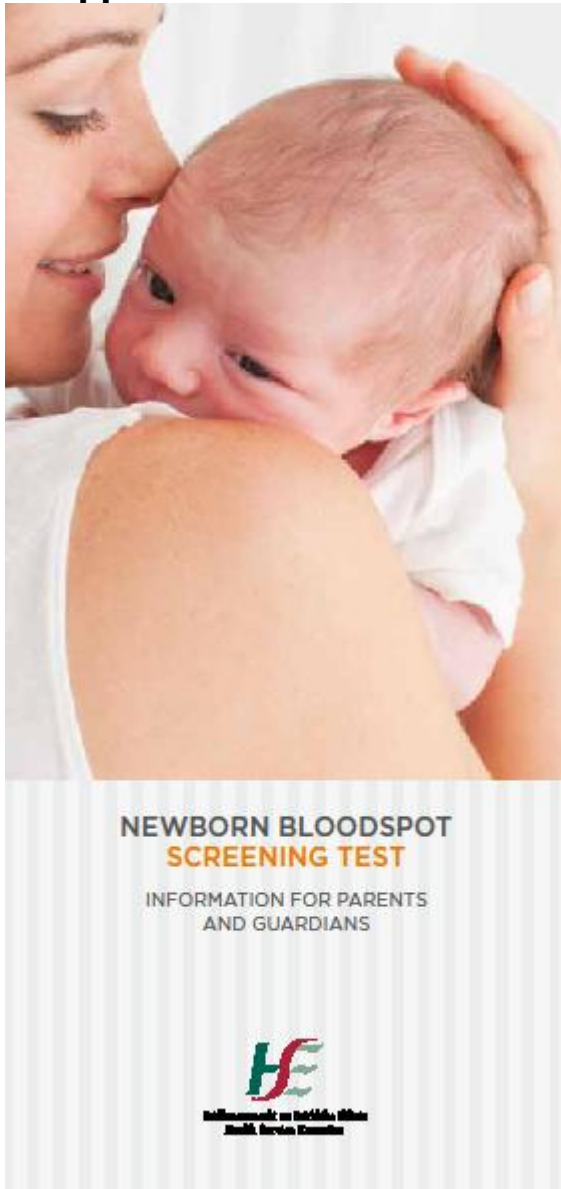
9. Training

The SECM shall ensure that she/he has sourced appropriate education and training to support the implementation of this policy and procedure.

10. Implementation Plan

The Clinical Governance Group for the HSE Home Birth Service developed this document, which has been approved for implementation by the National Implementation Steering Group for the HSE Home Birth Service. This document will be piloted for a year from the approval date. It will be disseminated by the Designated Midwifery Officers to relevant healthcare personnel and to all SECM who provide home birth services on behalf of the HSE.

11. Appendix I: Information for Parents and Guardians Leaflet



Appendix II: A Practical Guide

A Practical Guide to Newborn Bloodspot Screening in Ireland (HSE 2016) is available at

http://www.hse.ie/eng/health/child/newbornscreening/newbornbloodspot/screening/Information_for_Professionals/June%2022Practical%20Guide%20to%20Newborn%20Bloodspot%20Screening%20in%20Ireland%206th%20Edition.pdf




A Practical Guide to **Newborn Bloodspot Screening** **in Ireland**

National Newborn Bloodspot Screening Laboratory
Temple Street Children's University Hospital
Temple Street, Dublin D01 YC67

6th Edition – May 2016

© National Bloodspot Screening Laboratory, Temple Street Children's University Hospital, Temple Street, Dublin D01 YC67
No part of this *Practical Guide to Newborn Bloodspot Screening in Ireland* may be altered without permission of the HSE.

12. Appendix III: Opt-out Form



NATIONAL NEWBORN BLOODSPOT SCREENING PROGRAMME

Forfeiteannacht na Scríofaí Stáim
Health Service Executive

OPT- OUT FORM

Baby's Surname

Date of Birth

____/____/____

Hospital/Place of Birth

Local Health Office

Baby's Address

Mother's Surname

Baby's First Name

Baby's Unique Identifier

Mother's First Name

• I _____ being the parent/guardian of Baby _____, do not consent to allow the Newborn Bloodspot Screening Test (Heel-prick) to be carried out on my baby.

• I have read the information leaflet on Newborn Bloodspot Screening and the test has also been explained to me.

• I fully understand the importance of the decision that I am taking by not allowing my baby to be tested.

• I understand that not detecting or treating one of the conditions, should baby have one, may result in severe intellectual or physical disability which could require long term care or result in premature death.

Signed (Parent/Guardian): _____

Full Name (PRINT): _____ **Date:** _____

(BLOCK CAPITALS)

Signed in the presence of (Midwife/PHN): _____ **Date:** _____

Position/Job Title: _____ **Local Health Office:** _____

OFFICIAL USE ONLY

5 copies of the completed form, signed by parent/guardian and midwife/PHN should be made. A copy to be given to the parent/guardian and a copy kept by the Midwife/PHN.

Copies are to be posted to the following:

- The Director of Nursing/Midwifery • Director of Public Health Nursing • National Newborn Bloodspot Screening Laboratory
- the Baby's General Practitioner

	Director of Nursing/Midwifery	Director of Public Health Nursing	National Newborn Bloodspot Screening Laboratory	General Practitioner
Name:				
Address:			Children's University Hospital, Temple Street, Dublin 1	
Date Sent:				

Signed: (Midwife/PHN) _____ **Date:** _____

Name: (BLOCK CAPITALS) _____

NNBSP April 2011

Parents have the right to opt-out from the programme on behalf of their baby and must sign this HSE Opt-out Form; this must be witnessed and signed by all parties.

The Opt-out Form can be downloaded from:

www.newbornscreening.ie or www.hse.ie/go/newbornscreening

13. Signature Page

I have read, understand and agree to adhere to the attached:

[illegible]