National Policy ☐ National Procedure ☒ National Protocol ☐ National Guideline ☐
National Clinical Guideline ☐

HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP)

DOCUMENT GOVERNANCE	
Document Owner (post title):	Programme Manager, National Healthy Childhood Programme Screening Programmes
Document Owner name:	Paul Marsden
Document Owner email contact: *(Generic email addresses only for the Repository)*	child.screening@hse.ie
Document Commissioner(s): (Name and post holder title):	Dr Abigail Collins, National Clinical Lead Child Health Public Health
Document Approver(s): (Name and post holder title):	Dr Abigail Collins, National Clinical Lead Child Health Public Health
Document Approver Sign-off: (e-signature)	Collins
Document Approver Registration number: (where applicable)	MCRN: 404629
Development Group Name:	National Newborn Bloodspot Screening Programme PPPG Subgroup
Development Group Chairperson:	Dr Heather Burns

Additional headings can be inserted if required

DOCUMENT MANAGEMENT			
Date effective from:		11/11/2026	
Date set for next review:		11/11/2029	
Your Reference No: *(if applicable)*		Click or tap here to enter text.	
Current version no:	6	**Archived version no:**	5

Note: Original document is Version 0. First revision is Version 1. Second revision is Version 2, and so on.

Note: HSE National 3PGs should be formally reviewed every 3 years, unless new legislative/regulatory or emerging issues/research/technology/audit etc. dictates sooner.

VERSION CONTROL UPDATE		
Version No. (most recent version first)	**Date reviewed** (most recent date first)	**Comments** (1 sentence max, if required)
6	11/11/2026	Amendments made to sections 2.3; 3.1.12.3; 3.2 and Appendix 13
5	13/04/2026	All sections reviewed, minor updates, addition of details on SCID and SMA, removal of reference to Private Midwives, clarity provided around consent and changes to screening card Title change to "HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme" from previous version 4 "Procedure for all Community and Hospital Services Providing the National Newborn Bloodspot Screening Programme (NNBSP)"
4	17/05/2022	All sections reviewed and updated
3.1	23/09/2021	Amendments made to sections 2.7.15.1, 2.7.16.1, 2.7.16.6, 2.7.16.7, 2.7.16.8, 2.7.16.15, 2.7.16.15-2.7.16.18, Appendix XVII, Appendix XXVII (Archived directly with the document owner)
3.0	03/12/2018	Amendments made to sections 2.7.9.10 (new); 2.7.12.1; 2.7.14.5 (Archived directly with the document owner)
2	02/12/2018	Revision of V1 to place on a revised national template (Archived directly with the document owner)
1	Feb 2018	Original (Archived directly with the document owner)
Additional notes: If there are no amendments to the National document following a formal review, the date and detail of the review must still be recorded in the version control update box.		

PUBLICATION INFORMATION

Topic:

Newborn Bloodspot Screening

National Group:

National Healthy Childhood Programme; Public Health Nursing; National Women and Infants Health Programme

Short summary:

To provide a standardised approach for the provision of the National Newborn Bloodspot Screening Programme (NNBSP) in all relevant community and hospital settings.

Description:

This HSE national procedure, and its appendices, apply to all staff working directly and indirectly in the provision of the National Newborn Bloodspot Screening Programme (NNBSP) in all relevant hospitals and community settings. Users of this procedure include all staff working directly and indirectly in the provision of the NNBSP. The NNBSP applies to all infants in the Republic of Ireland as outlined in the procedure.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Contents

1.0 Planning 5
1.1. Purpose 5
1.2. Scope 5
1.2.1. Target users 5
1.2.2. Target population 5
1.3 Objective(s) 5
1.4 Outcome(s) 5
1.5 Disclosure of interests 6
1.6 Rationale / alignment with HSE national priorities 6
1.7 Supporting evidence 6
2.0 Methodology 7
2.1. List of key questions this national procedure will answer 7
2.2. Describe and document the evidence search 8
2.3. Describe the method of screening and evidence appraisal 8
2.4. Attach any copyright or permissions sought 11
3.0 Procedure 11
3.1. Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP) 12
3.2. Specific roles and responsibilities 50
4.0 Consultation 53
4.1. Stakeholder involvement 53
4.2. External review 53
5.0 National implementation plan 53
5.1. Describe the structure governance of the national implementation team 53
5.2. List tools and resources developed to support local implementation of the National 3PG. 54
5.3. Expected date of full implementation 54
6.0 Governance and approval 54
7.0 Communication and dissemination plan 54
8.0 Sustainability 555
8.1. Describe the plan for monitoring and audit 555
8.2. National audit tool 55
9.0 Review / update 55
9.1 Review of national document 55

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

10.0 References 56
11.0 Glossary of terms 57
12.0 Appendices 59
Appendix 1: Membership of Development Group 59
Appendix 2: Membership of Approval Governance Group 60
Appendix 3: Conflict of Interest Declaration Form 61
Appendix 4: Implementation plan template 62
Appendix 5: National Audit Tool 63
Appendix 6: Checklist 64
Appendix 7: Regional Health Areas and Integrated Healthcare Areas 65
Appendix 8: Maternity Hospital/Unit Unique Perinatal Identifier (UPI) 66
Appendix 9: DPHN/IHA Unique Perinatal Identifier (UPI 68
Appendix 10: Information for parents and guardians 69
Appendix 11: Newborn bloodspot screening card parent information 70
Appendix 12: Newborn bloodspot screening card 71
Appendix 13: Patient details amendment form 72
Appendix 14: NNBSP Opt-out form 73
Appendix 15: National Newborn Bloodspot Screening Laboratory Contact Details 74
Appendix 16: Newborn bloodspot screening card checklist 75
Appendix 17: Flow chart for newborn bloodspot screening sample takers 76
Appendix 18: Transport/drying box – procedure for transporting samples 77
Appendix 19: Waterproof and tear proof envelope for registered post 79
Appendix 20: NNBSL – newborn bloodspot screening result request form 80
Appendix 21: Informing NNBSL of reports received that do not belong to DPHN/IHA 81
Appendix 22: Individual bloodspot results – print out example 82
Appendix 23: Procedure for infants who have missed the newborn bloodspot screening for cystic fibrosis 83

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

1.0 Planning

1.1. Purpose

To provide a standardised approach for the implementation of the National Newborn Bloodspot Screening Programme (NNBSP) in all hospitals and community settings where newborn bloodspot screening samples are taken.

1.2. Scope

This procedure and its appendices apply to all staff working directly and indirectly in the provision of the NNBSP in all hospitals and community settings.

1.2.1. Target users

Target users of this procedure include all staff working directly and indirectly in the provision of the NNBSP.

1.2.2. Target population

The target population for this procedure is all infants in the Republic of Ireland to whom the NNBSP applies.

1.3 Objective(s)

1.3.1 To ensure a standardised approach in the delivery of the NNBSP to all infants in Ireland.

1.3.2 To promote the delivery of a safe and effective NNBSP by all Registered Public Health Nurses (RPHNs), Registered Midwives (RMs), Registered General Nurses (RGNs), Registered Children's Nurses (RCNs), Self Employed Community Midwives (SECMs), midwifery students, student PHNs and Nursery Nurses who work in the provision of the NNBSP in hospital or community settings.

1.3.3 To guide administrative/clerical officers who have delegated roles from the Director of Midwifery and/or Nursing (DOM/N) and Director of Public Health Nursing (DPHN) in supporting the processes of the NNBSP in maternity hospitals/units, tertiary paediatric hospitals and Public Health Nursing services within Regional Health Areas (RHAs) and Integrated Healthcare Areas (IHAs).

1.3.4 To provide information to Consultant Neonatologists, Consultant Paediatricians, Non Consultant Hospital Doctors (NCHD), Public Health Doctors, Community Medical Doctors and General Practitioners (GPs) who are working in Maternity Hospitals/Units and RHAs/IHAs on supporting best practice in relation to the delivery of the NNBSP.

1.4 Outcome(s)

Parent(s)/legal guardian(s) of all infants who are born in Ireland, or who become Irish residents in the first year of life without having been screened for the conditions in the NNBSP in their country of origin, should be offered newborn bloodspot screening as per the NNBSP.

Any infants suspected of having any of the conditions screened for should be referred to the appropriate clinical care pathway.

1.5 Disclosure of interests

None

1.6 Rationale / alignment with HSE national priorities

This procedure supports all staff who are involve in the provision of the NNBSP service in line with the National Healthy Childhood Programme (NHCP), the universal model of care provided to all children, and the National Service Plan of the HSE.

1.7 Supporting evidence

1.7.1 Relevant legislation and circulars

- Department of Health and Children (1966) Circular 27/66 District Nursing Service
- Department of Health and Children (2000) Circular 41/2000
- General Data Protection Regulation (2016), European Commission
- Government of Ireland
  - Notification of Births Act (1907)
  - Notification of Births Extension Act (1915)
  - Guardianship of the Infant Act (1964)
  - Health Acts 1947, 1953 and 1970 and Infectious Diseases Regulations 1981 as amended
  - Data Protection Acts (1988, 2003)
  - Child Care Act (1991)
  - Civil Registration Act (2004) and Civil Registration (Amendment Act (2014)
  - Nurse and Midwives Act (2011)
  - Children First Act (2015)
  - Child and Family Relationship Act (2015)
  - Patient Safety (Notifiable Incidents and Open Disclosure) Act (2023)
  - Medical Officer of Health Legislation, Health Duties of Officers order, 1949 Section 2

1.7.2 Relevant Guidelines/Policy

- Health Information and Quality Authority (2024) National Standards for

Safer Better Healthcare

- Health Information and Quality Authority (2016) Supporting Peoples Autonomy: a Guidance Document
- Health Information and Quality Authority (2017) National Standards for the Prevention and Control of Healthcare Acquired Infections
- Health Service Executive & Children's Health Ireland (2026) A Practical Guide to Newborn Bloodspot Screening in Ireland (12th Edition)
- Health Service Executive (2024) National Consent Policy
- Health Services Executive (2024) National Records Retention Policy
- Health Service Executive (2023) How to develop HSE National Policies, Procedures, Protocols and Guidelines: A Practical Guide
- Health Service Executive (2019) Personal Data Protection Policy
- Health Service Executive (2019) Child Protection and Welfare Policy
- Health Service Executive (2019) National Infant Feeding Policy for Maternity and Neonatal services
- Health Service Executive (2019) National Infant Feeding Policy for Primary Care Teams and Community Health Organisations. Health Service Executive: Dublin.
- Health Service Executive(2020) National Healthy Childhood Programme Child Health Assessment Manual for Registered Public Health Nurses
- Health Service Executive (2020) Incident Management Framework and Guidance
- Health Service Executive (2025) Open Disclosure Policy
- National Institute for Health and Clinical Excellence (2021) *Guideline postnatal care of women and infants*. National Institute for Health and Clinical Excellence, London
- Nursing and Midwifery Board of Ireland (2025) Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives

2.0 Methodology

2.1. List of key questions this national procedure will answer

This is a review of the current national procedure. This review of the national procedure will provide an updated, standardised procedure to the provision of the NNBSP by all staff across hospital and community services that participate in the NNBSP.

What is the evidence-based guidance on newborn bloodspot screening that should be included in this procedure to assist services in providing the NNBSP?

2.2. Describe and document the evidence search

The NNBSP has been operational since 1966. The National Newborn Bloodspot Screening Laboratory (NNBSL) at Children's Health Ireland at Temple Street, developed a "*Practical Guide to Newborn Bloodspot Screening in Ireland* which formed the basis for how the NNBSP operated.

This national procedure has been developed to compliment the '*Practical Guide to Newborn Bloodspot Screening in Ireland'* and offer more detailed guidance for relevant staff. Information from the relevant international screening and national guidance documents have been used to update this procedure.

2.3. Describe the method of screening and evidence appraisal

This update was informed by the *Practical Guide to Newborn Bloodspot Screening in Ireland* which is now in its 12th edition. Various national guidelines supported the development of this procedure and as such quality appraisal of those national documents did not take place.

What is Newborn Bloodspot Screening?

Newborn bloodspot screening, also known as the 'heel-prick test', screens all newborn infants for eleven rare conditions currently. More conditions may be added in the future.

A sample of blood is taken from the newborn infant's heel between 72 and 120 hours after birth and is sent to the National Newborn Bloodspot Screening Laboratory for analysis. The eleven conditions currently screened for are:

- Phenylketonuria (PKU)
- Maple syrup urine disease (MSUD)
- Homocystinuria (HCU)
- Classical galactosaemia (GAL)
- Cystic fibrosis (CF)
- Congenital hypothyroidism (CHT)
- Medium chain Acyl-CoA dehydrogenase deficiency (MCADD)
- Glutaric aciduria type 1 (GA1)
- Adenosine deaminase deficiency severe combined immunodeficiency (ADA-SCID)

- Severe combined immunodeficiency (SCID)
- Spinal muscular atrophy (SMA)

Why is it important?

The overall aim of newborn bloodspot screening is to reduce morbidity and mortality by screening newborns for rare but clinically serious conditions that benefit from early detection and intervention. All conditions that form part of the NNBSP have been selected because they all have a relatively high incidence within the Irish population and they fulfil, in part or in full, the criteria that have been set out internationally for newborn screening. These include:

- The conditions screened for are treatable
- There is a screening test available which is easily applied to large population groups
- There are few false positives and false negative results; i.e. the test is reliable
- The incidence of the conditions in the community is sufficiently high to warrant screening
- The cost of screening makes the process cost-effective

Newborn bloodspot screening commenced in Ireland in 1966 with the development of a national screening programme for phenylketonuria (PKU). Participation in the NNBSP in Ireland is high, with an uptake of 99.9% annually. This indicates considerable confidence in the screening programme amongst parents, guardians and the public. Each year, the NNBSP identifies approximately 130 infants in Ireland with one of the conditions screened for through the programme.

Other issues of note

General Data Protection Regulations (GDPR)

The HSE Data Protection Officer has produced a number of guidance documents in relation to GDPR.

- HSE Data Protection Policy (https://www.hse.ie/eng/gdpr/hse-dataprotection-policy/hse-data-protection-policy.pdf)
- HSE Privacy Notice - Patients and Service Users (https://www.hse.ie/eng/gdpr/hse-data-protection-policy/hse-privacynoticeservice-users.pdf)
- HSE GDPR Frequently Asked Questions (https://www.hse.ie/eng/gdpr/gdprfaq/hse-gdpr-faqs-public.pdf)

Sharing information within the HSE

Within the HSE, the clinical information collected by a doctor or other healthcare

professional or staff member authorised to process a service users' data is not passed on to others within the HSE, unless it is considered necessary for their health or social care needs or for one of the other reasons set out in the HSEs Data Privacy Notice.

Freedom of Information

The 2014 Freedom of information Act provides every person with the legal right to access official records held on them by the HSE. All relevant staff should ensure that information regarding the mother is documented only in the maternal postnatal record and not in the child health record. Only the mother or her designate should have access to her personal data in the maternal postnatal record.

Documentation

Professional record keeping and the documentation and interactions between the patient and healthcare professional are key features in clinical practice. The maintenance of accurate records is also essential given the professional and legal requirements on healthcare practitioners to ensure high standards of practice in this area (NHCP 2020). The Nursing and Midwifery Board of Ireland (NMBI) highlights the importance of appropriate and high-quality documentation in the Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (NMBI 2025).

The NMBI advise that the maintenance of good clinical records is essential for nurses and midwives. Refer to Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (NMBI 2025) for more detailed guidance if required.

Infection prevention and control considerations (IPC)

All staff should refer to the Health Protection Surveillance Centre website (www.hpsc.ie) for updated IPC publications. Standard Precautions and Transmission Based Precautions are detailed in the IPC guidance. They include advice regarding hand hygiene, use of Personal Protective Equipment (PPE), handling and disposing of sharps, precautions regarding droplet transmission, cleaning of equipment etc. Refer to HSE's Guidance on Infection Prevention and Control for further details.

Incident Management – National Incident Management System

All staff involved in the provision of the NNBSP must ensure that all risks and incidents relevant to the screening programme are monitored and actioned as required as per the HSE Incident Management Framework (2020) with completion of National Incident Report Forms (NIRF) as required and submission to the National Incident Management System (NIMS). All incidents assigned as Category 1 and Category 2 must be notified to the National Clinical Lead Child Health Public

Health (child.screening@hse.ie).

Any risks identified that may impact on, or threaten the delivery of the NNBSP must be escalated immediately to the National Clinical Lead Child Health Public Health(child.screening@hse.ie).

2.4. Attach any copyright or permissions sought

No copyright or permissions are required in relation to this document.

3.0 Procedure

3.1. Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP)

For simplicity of language, this guideline will use the term 'female' or 'mother' throughout, and this should be taken to include people who do not identify as female but who have given birth and also for females who have given birth but the infant may not be with them due to fostering, adoption, hospitalisation of the infant and/or mother. Similarly, where the term 'parents' is used, this should be taken to include other people who are the infant's primary caregivers and single parents (NICE 2021).

3.1.1. Maternity hospital/unit births and NNBSP

Maternity hospitals/units, both within the Republic of Ireland (ROI) and Northern Ireland, notify the relevant Integrated Healthcare Area (IHA) office of all infants born and who reside in the designated IHA. This may be notified to the Child Health Office/DPHN Office/Birth Notification Office and Primary Care Unit Management depending on local arrangements.

3.1.1.1 The maternity hospital/unit ascertains if the newborn bloodspot screening (NBS) sample is scheduled to be obtained in the hospital or the community or tertiary hospital.

3.1.1.2 The maternity hospital/unit:

- maintains a birth register for all infants born in the hospital/unit
- issues the **Unique Perinatal Identifier (UPI)** number for all infants born in the Maternity hospital/unit (Appendix 8). It is anticipated that the UPI will be replaced by the Individual Health Identifier (IHI) when implemented
- maintains a Newborn Bloodspot Screening (NBS) register for infants who have their NBS sample taken while in the maternity hospital/unit
- for all samples obtained in the maternity hospital/unit, the Newborn Bloodspot Screening (NBS) cards must be forwarded to the National Newborn Bloodspot Screening Laboratory (NNBSL)

3.1.1.3 The maternity hospital/unit is responsible for completing the NBS for all infants on the wards and in the Special Care Baby Unit (SCBU)/High Dependency Unit (HDU) Neonatal ICU between 72 and 120 hours following the birth and also for any repeat NBS samples required for in-patient infants. Frequency of sampling is referred to in the Practical Guide to Newborn Bloodspot Screening in Ireland (12th Edition).

3.1.1.4 Arrangements may be put in place for the NBS to be obtained by the maternity hospital/unit staff following discharge, for example outpatients, Community Midwifery team visiting in the home (e.g. domino, early transfer home teams).

3.1.1.5 If infants are being discharged without the NBS completed, the maternity hospital/unit is responsible for notifying the relevant designated IHA Public Health Nursing Service of the requirement to carry out the NBS.

3.1.1.6 In the case where the maternity hospital/unit wish to review the infant, the Director of Midwifery and/or Nursing (DOM/N)/designated staff member may issue an appointment for the infant to return to the hospital for follow up/review during the designated timeframe for which the NBS must be undertaken. The Public Health Nursing Service must be informed of the birth and that the NBS will be undertaken in the hospital during the review visit.

3.1.1.7 The maternity hospital/unit may request that the mother and infant return to the maternity hospital/unit at weekends/bank holidays/extended holiday periods, to facilitate early discharge and when a weekend Public Health Nursing Service is not available. The maternity hospital/unit of birth is responsible for ensuring that the NBS is taken. The Public Health Nursing Service must be informed of the birth and the plan for undertaking the NBS.

3.1.1.8 If infants are being transferred to a tertiary hospital, the transferring maternity hospital/unit is responsible for notifying the relevant tertiary hospital in their transfer referral documentation of the requirement to carry out the NBS and includes the infants UPI in all correspondence. (Refer to 3.1.3).

3.1.2 Maternity hospital/unit Notification of NBS request to PHN service

3.1.2.1 If the NBS is scheduled to be obtained by the PHN service, the DOM/N/designated staff member is responsible for ensuring that:

- the designated officer in the IHA is notified of the birth
- the DPHN/Child Health Office is informed that the infant has been discharged prior to the sample being carried out and is notified of the request for NBS to be obtained by the PHN service
- the maternity hospital/unit should provide two confirmed phone contact details of parent(s)/legal guardian(s) and the Eircode if known
- where a parent(s)/legal guardian(s) and infant are staying at a temporary address, e.g. grandparents house, this should be made clear on the NBS request to the PHN service
- the date the NBS sample is due to be taken should be indicated on the NBS request
- the following information is provided and correct:
  - infant's UPI number
  - date of birth
  - time of birth

- date of first feed
- type of feed

- the mother has been given the parent information leaflet –"*What you need to know about Newborn Bloodspot Screening – the 'heel prick' test"* (Appendix 10)
- notification to the DPHN of the infection status of the child or mother if relevant; e.g. HIV, Hepatitis B
- in the case of a family and infant relocating and/or returning to reside in ROI (from outside ROI) prior to the NBS, it is the responsibility of the maternity hospital/unit where the infant is born to inform the DPHN for the designated IHA that the infant and family is relocating/returning to the ROI, within the timeframe for the sample to be taken (72-120 hours). (See section 3.1.6.2 – 3.1.6.4)
- maternity hospitals/units can use the Health Atlas address finder facility to help check the location of the appropriate IHA for the infant https://hseareafinder.ie/

3.1.2.2 Where a request for NBS comes from a maternity hospital/unit to an incorrect IHA, the DPHN/IHA must return the NBS request to the maternity hospital/unit and provide the correct IHA details. The maternity hospital/unit must correct this information and send the request to the correct IHA/DPHN as soon as possible to avoid delays in sample taking.

To minimise the risk of delayed screening, a representative of the DPHN office should contact the correct IHA to inform them of the pending NBS request.

3.1.2.3 In addition to the above, Northern Ireland (NI) maternity hospitals/units will contact the Public Health Nursing Service/IHA and request:

- The Public Health Nursing Service Office/Child Health Office to issue the Infant's **Unique Perinatal Identifier** (UPI) number (Appendix 9). It is anticipated that the UPI will be replaced by the Individual Health Identifier (IHI) when implemented.

3.1.3 Maternity hospital/unit notification of NBS request to tertiary hospital paediatric unit

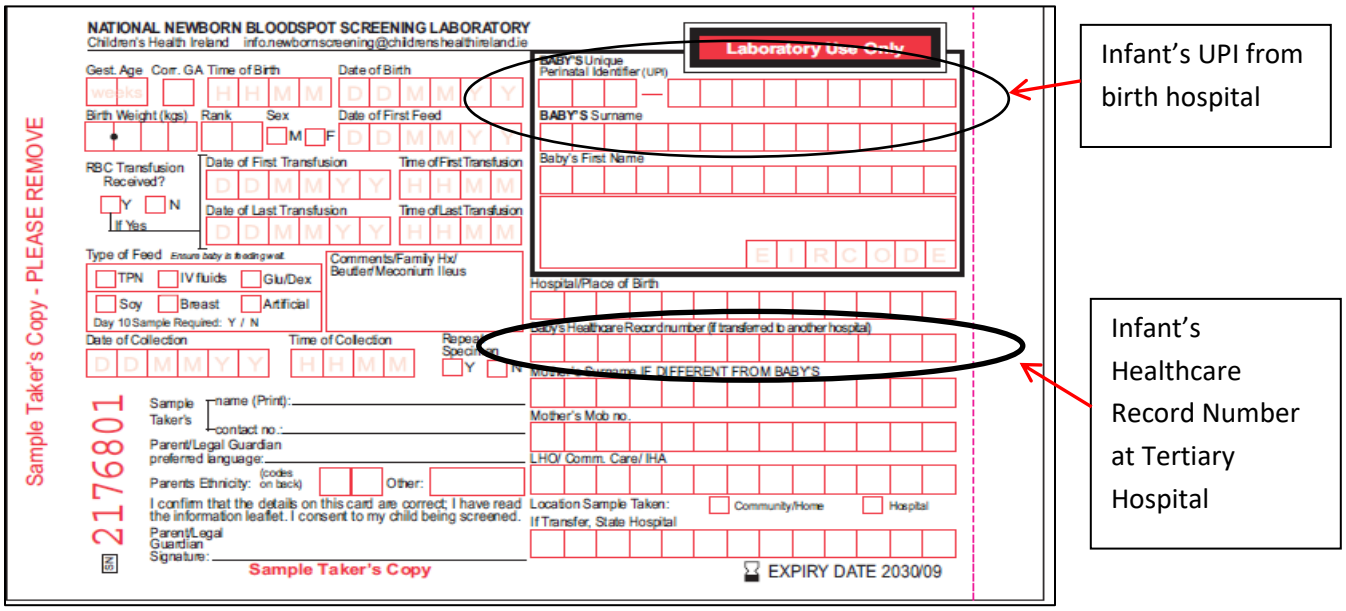
3.1.3.1 It may be necessary for an infant to be transferred to a tertiary hospital for continuing medical and/or surgical treatment before the NNBSP has been completed.

3.1.3.2 The nurse/midwife responsible for the transfer of an infant from a maternity hospital/unit to a tertiary hospital paediatric unit must inform the receiving unit that NBS is required and provide them with the infant's UPI.

- The infant's UPI issued by the maternity hospital/unit must be used on all NBS samples sent to the NNBSL even when an infant is transferred to a tertiary hospital paediatric unit.

- If an infant is transferred to a tertiary hospital paediatric unit and an NBS sample (initial and/or repeat) is required the hospital chart record number (HCRN) of the transfer hospital must be included in the appropriate space on the NBS card.
  - For example if an infant is born in Midland Regional Hospital Portlaoise (MRHP) a UPI of 201-XXXXXXX is generated for that infant. If they are transferred to a Children's Health Ireland Hospital (e.g. CHI at Crumlin) and a newborn bloodspot sample is required to be taken, the MRHP UPI is recorded at the top of the screening card and the CHI Crumlin HCRN is recorded in the 'Infant's healthcare record number (if transferred to another hospital)' field on the NBS card – See Figure 1.
  -

Figure 1: Newborn Bloodspot Screening Card Data Fields



3.1.3.3 The receiving tertiary hospital paediatric unit must have written procedures for:

- performing the test between 72 and 120 hours after birth and repeat samples as recommended in the *Practical Guide to Newborn Bloodspot Screening In Ireland* (12th edition) or as requested by the NNBSL
- sending the NBS card to the NNBSL
- receive the reports via eReports and post as applicable
- recording the results in the infant's medical record

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

3.1.4 Self-employed community midwife (SECM) notification of birth and NBS status to PHN service

3.1.4.1 The SECM will notify the relevant DPHN of the home birth and the pending discharge from SECM service. On discharge from the SECM service, the DPHN office should receive a discharge summary from the SECM detailing the newborn bloodspot screening status.

3.1.4.2 The SECM is responsible for undertaking NBS for all infants in their care. The NBS sample must be taken between 72 hours and 120 hours following the birth.

3.1.4.3 If the mother was booked with a maternity hospital/unit, the SECM will contact the maternity hospital/unit in which the mother was booked and request them to issue the Infant's **Unique Perinatal Identifier** (UPI) number. It is anticipated that the UPI will be replaced by the Individual Health Identifier (IHI) when implemented.

If the mother was not booked with a maternity hospital/unit, the SECM should contact the nearest maternity hospital/unit and request a UPI. Should there be any difficulty in obtaining a UPI this should be escalated to the relevant designated midwifery office/Director of Midwifery or deputy.

3.1.4.4 The maternity hospital/unit and the DPHN will receive the result of the NBS via eReports.

3.1.5 Public health nursing service and the NNBSP

3.1.5.1 The DPHN/Designated Officer will:

- maintain the NBS register for the IHA/DPHN area
- ensure on receipt of NBS request that all the relevant details of the NBS request are included and correct
- if required, the infection status (e.g. HIV, Hep B) of the mother and infant is highlighted to the sample taker
- issue a UPI number on request for infants born outside of ROI and home births.

3.1.5.2 The DPHN or Designated Officer will notify the relevant Primary Care Teams (PCT)/Registered Public Health Nurse (RPHN)/Registered Midwife (RM)/Registered Nurse (RGN) of the request for the NBS by email/mobile phone/other local electronic means as per local procedures.

3.1.5.3 The email will generate an automatic acknowledgement of read receipt. Where email read receipts are not used the RPHN/RM/RGN acknowledges

receipt of the request for Newborn Bloodspot Screening as per local arrangements.

3.1.5.4 The RPHN/RM/RGN contacts the parent(s)/legal guardian(s) and arranges an agreed time and place for NBS to be carried out.

- Ideally the NBS is taken in the home environment.
- In exceptional circumstances, if the mother must attend a primary care facility for the NBS, it is recommended that they are accompanied at the clinic visit.
- The clinical environment should be conducive to carrying out the NBS. Parents are also advised of the need to bring the infant in a buggy/car seat to the primary care facility for safety reasons.

3.1.5.5 At weekends/bank holidays/extended holiday periods and when there is a PHN weekend/bank holiday service available in the IHA for the NNBSP, the Designated Officer informs the weekend nurse by 12:00 midday on Friday that a NBS is requested for the infant. If there is no weekend/bank holiday PHN service please refer to 3.1.1.7.

3.1.5.6 As per local arrangements, additional special arrangements can be organised for extended holiday periods/urgent requests from the NNBSL, to ensure the NBS is delivered from the IHA to the NNBSL as soon as possible (for example a courier arrangement).

3.1.5.7 Red Weather alerts: In the event of a red weather alert due to adverse weather conditions, the sample taker, in conjunction with the ADOM/ADPHN, must assess the risk of travel of either the sample taker or the parent and infant against the risk of delayed newborn screening. Further advice on sample taking in the context of red weather alerts can be can be sought from child.screening@hse.ie

3.1.5.8 In the case of highly mobile families, the infant may have moved out of the area before the NBS has been carried out. The DPHN must be informed of the circumstances as early as possible. Every effort should be made to ensure that the NBS is taken.

3.1.6 Other situations

3.1.6.1 In the case of infants born outside the jurisdiction when the parent(s)/legal guardian(s) notify the PHN service that they have brought their infant to this jurisdiction, the PHN service is responsible for ensuring that the sample is carried out if required. For example, this may occur following international adoptions, surrogacy, emigration, persons seeking asylum etc. Screening can

be carried out up to the age of one year. The RPHN/RM may seek the advice of the NNBSL and/or their GP.

3.1.6.2 Where an infant under one year of age has moved into the IHA (temporary or permanent), evidence of NBS must be obtained. This may take the form of email or written results or a written record in the CHR. Where no proof of screening is available it should be assumed that the infant is not screened. The sample taker and/or PHN service should check with the NNBSL and/or eReports to confirm screening status.

Screening a child who has not been screened, should be discussed with the NNBSL, and where relevant, the GP, together with the parent(s)/legal guardian(s). If screening is recommended it must be arranged.

In general, all conditions are eligible for screening in unscreened children under one year except cystic fibrosis (CF) where bloodspot screening is not reliable in infants over 6 weeks of age. Please see Appendix 23 for further details regarding CF screening in children under one year who have missed the newborn bloodspot screening window.

3.1.6.3 Where an infant, up to one year of age, enters the country and has not received NBS for all the conditions screened for in the Irish NNBSP in the infant's country of origin, clarification should be sought from the NNBSL and the infant's family GP regarding the required screening for the infant.

In general, all conditions are eligible for screening in unscreened children under one year except cystic fibrosis where bloodspot screening is not reliable in infants over 6 weeks of age. Please see Appendix 23 for further details regarding CF screening in children under one year who have missed the newborn bloodspot screening window.

3.1.6.4 The decision to screen children greater than one year of age who arrive in Ireland is a local decision, made by the clinician and family GP and is dependent on the family history and the country of origin of the parents. In such circumstances the NNBSL should be contacted for advice in advance of sample taking.

3.1.7 Consent

3.1.7.1 **Who can give consent?**

Only an infant's legal guardian can provide informed consent for screening and sign the NBS card. Being clear who can give informed consent can be challenging.

The HSE has published the revised National Consent Policy (2022, revised 2024) and Part 2 specifically related to children and young People. Appendix 9 (page 107) of the National Consent Policy provides clarity as to who qualifies as a child's legal guardians and are therefore authorised to give consent.

The National Consent Policy (2022, revised 2024) notes that this is a complex legal position and the relevant provisions are set out in the *Guardianship of Infants Act 1964*, as amended by the *Child and Family Relationships Act 2015.*

If you have any cases of challenging informed consent, or where you are unclear who can consent, please contact the National Healthy Childhood Programme (NHCP) by emailing child.screening@hse.ie or phone (086)1033771.

Given the tight timeframe for sample taking (72-120 hours) early contact is advisable. If unable to get advice to allow screening within the recommended timeframe ensure that a National Incident Report Form (NIRF) is completed and entered onto the National Incident Management System (NIMS).

Non-complex informed consent

Mother and father are married: both are legal guardians and either can give consent for newborn bloodspot screening as per Section 6 of the *Guardianship of Infants Act 1964*.

Mother and father are not married: the birth mother is automatically the infant's legal guardian and can provide consent for screening and sign the NBS card. The father is not the legal guardian unless conditions in the bullet below are met and therefore, cannot provide consent for screening (see next bullet point for further info).

- If unmarried, the infant's father is an automatic legal guardian only if he has lived with the infant's mother for 12 consecutive months including at least 3 months with the mother and infant following the infant's birth. This may be relevant in situations where newborn bloodspot screening is offered to an infant older than 3 months and up to the age of one year.

Female same-sex couples: the infant's biological parent is the legal guardian. If the biological parent is not available, please contact the NHCP by emailing child.screening@hse.ie or phone (086)1033771.

Where a same-sex couple has an infant through Donor Assisted Human Reproduction (not including surrogacy) and has complied with the provisions of Part 2 of the Children and Family Relationships Act 2015 (i.e. they have used a recognised fertility clinic and have signed all the relevant consents and declarations), the spouse, civil partner or cohabitant of the mother will be the legal parent of the infant. In this situation, the spouse or civil partner of the biological parent will automatically be a legal guardian. If you are unclear whether a recognised fertility clinic was used and all the relevant consents and declarations were signed, please contact the NHCP by emailing child.screening@hse.ie or phone (086)1033771.

- A cohabitant will be a legal guardian if they fulfil the residence requirement stated above (i.e. have lived with the infant's mother for 12 consecutive months including at least 3 months with the mother and infant following the infant's birth).

Specific situations:

- If the father is unmarried to the birth mother and the birth mother is unavailable to provide informed consent and sign the NBS card, i.e. through illness or hospital transfer, the unmarried second parent cannot provide consent for screening.
  In these cases, the sample taker should make every effort to contact the birth mother to get verbal consent and should document this in the relevant clinical notes/child health record. Written consent from the birth mother must be obtained at the earliest opportunity and forwarded to the NNBSL.

- If the father is unmarried to the birth mother and the birth mother is not contactable, for example due to severe illness, then you should discuss with the NHCP by emailing child.screening@hse.ie or phone (086)1033771.
  Efforts should be made to ascertain what the birth mother's opinions/views are regarding newborn screening as well as a detailed family composition and medical history to support the discussion with the NHCP programme.

- If the father is unmarried to the birth mother and if the birth mother is well but not available at the time of the midwife/nurse's bedside visit or the PHN home visit, alternative arrangements should be made to

ensure the birthmother is present at the time of the test and can give informed consent. No other relative or friend can provide consent for screening.

- Where an interim care order is in place only the parent(s)/legal guardian(s), or the birth mother if unmarried, can provide consent.

- If there is a full care order in place, consent can be provided by the relevant health or social care provider. HSE National Consent Policy (2022, revised 2024) notes that it is good practice to seek consent from parent(s)/legal guardian(s), but it is not mandatory.

- If the parent(s)/legal guardian(s) has literacy difficulties, they can be asked to make a mark on the NBS card to indicate that they have been fully informed about the benefits and risks of newborn bloodspot screening and that they consent to screening for their infant.

- Where married parents or legal guardians disagree about consent for newborn bloodspot screening, Section 4 (p.58) of the HSE National Consent Policy (2022, revised 2024) applies. A sample must not be taken against the wishes of a legal guardian (as per a 2001 Supreme Court ruling). The sample taker should confirm both parents are legally able to consent, assess any family history suggesting increased risk for any of the conditions screened for, and consult the NHCP by emailing child.screening@hse.ie or phone (086)1033771.

  If a high risk is identified, the NHCP may need to seek legal advice.

  If no increased risk is identified, screening should not proceed, and parent(s)/legal guardian(s) should be advised to seek to resolve the dispute, with support from the NHCP or the child's GP/PHN.

Obtaining Consent in Complex Cases

There are other complex circumstances which may affect newborn screening and should be discussed with the NHCP by emailing child.screening@hse.ie or phone (086)1033771. A detailed family composition and medical history should be taken to support discussion with the programme.

Adoption: Where an infant has been jointly adopted, the adoptive parents are the infant's legal guardians and either adoptive parent can provide consent for screening. However, adoption is unlikely to have been

completed at the time that newborn bloodspot screening is due to take place (72-120 hours after birth), and the birth mother would be the legal guardian at that time. Consent must be obtained from the birth mother.

Surrogacy:

Surrogacy in Ireland:

Where a child is born through surrogacy in Ireland, the surrogate mother is the legal guardian at birth until the commissioning mother/father are appointed as legal guardians. The surrogate mother, as birth mother, has legal responsibility for the newborn until the infant is legally adopted. The commissioning parents cannot provide consent for screening until the adoption is completed.

For infants born to surrogates in Ireland it is permissible under the HSE National Consent Policy (2022, revised 2024) for consent to be obtained from the surrogate mother by the sample taker by telephone/electronic means (Part 2 Section 4.2.2) if deemed necessary.

If practicable, the surrogate mother may give consent prior to the infant being discharged from the maternity hospital/unit, but it must be made clear to the surrogate mother that she is consenting to newborn bloodspot screening for the infant. The discussion that has taken place and the consent agreement must be documented.

The commissioning mother, or a commissioning father, may apply to the Court for legal guardianship one they/she has fulfilled the relevant legal requirements (see National Consent Policy 2022, pages 140-141).

Surrogacy in another jurisdiction:

Under current Irish legislation, when an infant is born through surrogacy in another jurisdiction, only the birth mother has legal responsibility for the infant until the adoption is completed. Therefore, only the birth mother can provide consent for screening but may be resident in another jurisdiction. The commissioning parents cannot provide consent for screening until the adoption is completed.

The sample taker should discuss screening in these complex cases with the NHCP by emailing child.screening@hse.ie or phone (086)1033771.

3.1.7.2 The sample taker is responsible for ensuring that appropriate informed signed consent is obtained prior to any sample being taken, or that it has been discussed with the NHCP.

Sample takers must inform the parent(s)/legal guardian(s) that by signing the NBS card they are confirming that:

- they are the infant's legal/guardian
- they received and understood the information about the heel prick screen
- the information that is written on the screening card about their infant is correct
- they consent to having their infant screened and that this involves different laboratory tests. Screening will include a genetic test for spinal muscular atrophy only and may include a genetic test for cystic fibrosis
- they consent to how the NNBSP use and store their personal information
- they consent to the screening card being stored for 10 years
- they consent to other uses of the card and personal information as described in the parent information leaflet - *What you need to know about newborn bloodspot screening – the heel prick test'*
    - There are translated versions of the HSE Parent/Guardian Information Leaflet available on the HSE website for download (https://www2.hse.ie/conditions/heel-prick-screening/about/). Translators can be used if required.

It is important to note that the NNBSL has a duty of care to analyse all newborn bloodspot screening samples they receive, irrespective as to whether they are signed by a parent(s)/legal guardian(s) or not. It is the responsibility of the sample taker to ensure that signed consent, indicating informed consent, is obtained when taking the sample.

3.1.8 Parent(s)/legal guardian(s) right to opt out of NNBSP

3.1.8.1 The parent(s)/legal guardian(s) have the right to opt-out from the NNBSP on behalf of their infant.

3.1.8.2 The sample taker accurately documents in the clinical record the discussion with the parent(s)/legal guardian(s), including the screening procedure that has been offered, the evidence base, benefits and risks, the parent(s)/legal guardian(s) decision to decline and the fact that the implications of this decision have been fully outlined.

3.1.8.3 The sample taker informs the DPHN/DOM/N/Paediatric Consultant on Call (maternity hospital/unit only) that the parent(s)/legal guardian(s) is opting out of the NNBSP and will discuss further actions required.

3.1.8.4 The sample taker must complete and the parent/legal guardian must be requested to sign the *National Newborn Bloodspot Screening Programme Opt-out form* (Appendix 14)

The parent(s)/legal guardian(s) can be given the opportunity to consult with other healthcare professionals if required.

3.1.8.5 The parent (s)/legal guardian(s) sign the *National Newborn Bloodspot Screening Programme Opt-out form* in the presence of the sample taker and the sample taker also signs the form.

- A copy of this form is given to the parent(s)/legal guardian(s).
- The original form is filed in the CHR/maternity chart.

3.1.8.6 The sample taker will send a copy of the *National Newborn Bloodspot Screening Programme Opt-out form* to:

- The DPHN
- The NNBSL
- The infant's General Practitioner (GP)
- DOM/N/Maternity Hospital

3.1.8.7 Where the parent(s)/legal guardian(s) have opted out of the NNBSP, the parent(s)/legal guardian(s) will be informed that it is their responsibility to contact the Public Health Nursing Services and/or the infant's GP should they change their mind in the future and wish to be included in the NNBSP. The sample taker will record the discussion and decision made in the CHR.

3.1.8.8 Where parent(s)/legal guardian(s) decline to sign the *National Newborn Bloodspot Screening Programme Opt-out form*

- The opt-out form must be completed by the sample taker and documented on the opt-out form that the parent(s)/legal guardian(s) declined to sign the form.
    - For samples due to be taken in the maternity hospital/unit, the sample taker will document the discussion with the parent(s)/legal guardian(s) and the decision made on the maternity chart. The maternity hospital/unit will inform the infant's GP, DPHN and the NNBSL. The sample taker will discuss this case with their DOM/N and decide on further actions, for example completion of a National Incident Report Form (NIRF) if required.
    - For samples due to be taken in the community the sample taker will document the discussion with the parent(s)/legal guardian and record the decision made on the CHR. The sample taker will discuss this case

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

with their ADPHN and decide on further actions, for example completion of a NIRF if required.

- The Sample Taker will send a copy of the *National Newborn Bloodspot Screening Programme Opt-out form* to:
  - Parent(s)/legal Guardian(s)
  - The DPHN
  - The NNBSL
  - The infant's General Practitioner (GP)
  - DOM/N/Maternity Hospital

3.1.9 Information Giving

3.1.9.1 Parent(s)/legal guardian(s) should receive information on the NNBSP antenatally in the 3rd trimester and at the time of sample taking.

3.1.9.2 All parent(s)/legal guardian(s) will be given:

- the HSE Parent /Guardian Information Leaflet –"*What you need to know about newborn bloodspot screening – the heel prick test"*. If they have not already received this information the information leaflets can be obtained online at: https://www2.hse.ie/conditions/heel-prick-screening/about/ including information leaflets in a selection of other languages.
- the parent information sheet from the *Newborn Bloodspot Screening Card* which also contains information about the NNBSP (Appendix 11).

3.1.9.3 All parent(s)/legal guardian(s) must be provided with an opportunity to review the parent information leaflet and for any queries that they may have to be answered. They must be informed that newborn bloodspot screening is screening and not diagnostic testing. They should also be informed:

- about the conditions which are being screened for
- that screening will involve genetic testing (for SMA only and maybe for CF)
- with advice that further samples may be required
- about other possible uses of the screening card and personal data as noted on the parent information leaflet
- that the NBS card will be retained for 10 years and then disposed of

3.1.9.4 Parent(s)/legal guardian(s) may request that the NBS card be returned to them or disposed of. It is NNBSL policy to retain all samples for a minimum of six months before any return or disposal. Such requests must be made in writing to the Risk Management Department of CHI. Requestors will be asked to provide proof of identity, e.g. a copy of their passport or driving license and a recent utility bill and a copy of the infants birth certificate.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

3.1.10 Completion of the newborn bloodspot screening card

3.1.10.1 The sample taker completes the details required for the NBS card:

- infant's Unique Perinatal Identifier (UPI)
- infants demographic details: Infant's surname (as given by the parent(s)/legal guardian(s)), first name, address including postal code/Eircode
- place of birth: Hospital or Community
- infants healthcare record number/transfer to another hospital number
- mother's surname (if different from infant's)
- mother's mobile number (Note: if both parents are male, 'mother' can be crossed out and 'father' noted with their mobile number recorded)
- LHO/Comm. Care/Integrated Healthcare Area (e.g. Meath, West Cork, Dublin South West, Laois/Offaly)
- location sample taken: please tick the relevant box 'Community/Home' or 'Hospital'
- if a hospital transfer record the hospital name the infant is transferred to
- gestational age; corrected gestational age (if applicable)
- time of birth; date of birth
- birth weight (recorded to 3 decimal places, if available)
- rank (for multiple births e.g. twin 1 twin 2)
- gender
- date of first feed
- red blood cell (RBC) transfusion - date and time of first transfusion, date and time of last transfusion
- type of feed at the time of sample collection (breast, artificial, total parenteral nutrition (TPN), IV fluids, soy, glucose/dextrose (Glu/Dex)
- if a day 10 sample is required due to poor feeding
- comments: (family history, Beutler, meconium ileus, maternal history of taking medication during pregnancy (e.g. steroids, immunosuppressant medication during pregnancy)
- date and time of collection
- if it is repeat specimen/sample (yes or no)
- sample taker name and sample taker phone contact number: the phone number of the sample taker is required to enable the sample taker to be contacted directly should this be required. The parent(s)/legal guardian(s) phone number is **NOT** to be entered here.
- parent(s)/legal guardian(s) preferred language: this field should always be completed – insert the preferred language. For any language, other than English, an interpreter could be required to communicate possible suspected screen positives and the need to attend a hospital for further samples.

- Both parent(s)/legal guardian(s) ethnicity (ethnicity codes are provided on the back of the NBS card, leave blank if ethnicity is unknown)
  - The HSE LAND eLearning module '*Introduction to Guidance on Ethnic Data Collection'* provides guidance on how to sensitively and appropriately gather and record ethnicity information.
- parent(s)/legal guardian(s) signature of consent
- note: any details on the reverse side of the NBS card will be filled in by the laboratory

3.1.10.2 The sample taker when completing the NBS card, and as part of the consent process, ensures that:

- all the data recorded on the NBS card is correct and confirmed by the parent/legal guardian
- the NBS card is signed, indicating that the parent/legal guardian is consenting to their infant being screened
- the top information sheet is removed and given to the parent/legal guardian
- the parent/legal guardian copy of the NBS card is given to the parent(s)/legal guardian(s) at the time that the screening sample is taken
- the '*Sample Takers*' copy is filed in the CHR/maternity chart.

3.1.10.3 Parent(s)/legal guardian(s) will be informed that results will be issued to the maternity hospitals/units and IHAs only and that results will not be issued to parent(s)/legal guardian(s) over the telephone.

Parent(s)/legal guardian(s) will be contacted as soon as possible if the screening results show that their infant is at increased risk of having one of the conditions screened for.

Parent(s)/legal guardian(s) will not be contacted if the screening results show that their infant is not at increased risk of having one of the conditions screened for.

If the parent(s)/legal guardian(s) would like a copy of the screening results they can ask their PHN for them and they must be provided.

3.1.10.4 Further information is available on https://www2.hse.ie/heel-prick-screening/ or by e-mailing child.screening@hse.ie

3.1.11 Education and Training

3.1.11.1 The sample taker must have completed education and training in the procedure of taking an NBS sample and carry out this procedure within their scope of practice.

3.1.11.2 There is an eLearning module available on HSE LAND for all staff under the suite of modules contained in the National Healthy Childhood Training Programme called '*National Newborn Bloodspot Screening Programme*'

3.1.11.3 RPHNs, RMs, RCNs, RGNs, midwifery students, student PHNs, and nursery nurses (NN) undertake NBS under their scope of professional practice/competence:

- where a RGN undertakes NBS, the DPHN and RGN must be satisfied that additional training has been undertaken and that the nurse is working within their scope of practice
- where a NN undertakes NBS, the DOM/N/maternity hospital/units and NN must be satisfied that additional training has been undertaken and that the NN is working within their scope of practice.

3.1.12 Sample Taking Timing and Special Considerations

3.1.12.1The blood sample should be taken **not earlier than 72 hours and not later than 120 hours** after the infants birth and when feeding has been established.

Infants should be established on full lactose and protein containing feeds for at least 24 hours before the newborn bloodspot sample is taken unless at high risk for Classical Galactosaemia (refer to 3.1.12.5).

Sample takers must determine feeding status by reviewing the infant's intake over the preceding 24 hours and applying professional, clinical judgment in their decision-making.

Sample takers should use their professional clinical judgement in decision making around infants feeding intake at the time of sampling:

- for breastfed infants in the community, the Breastfeeding Observation Assessment Tool (BOAT) should be used to guide assessment of feeding and support professional decision making
- for breastfed infants the maternity hospital/unit local individual feeding records (i.e. LATCH score) are available to guide assessment of feeding and support professional decision making

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

- For infants on expressed breastmilk/formula, the sample taker can review the infant's intake over the previous 24 hours to aid assessment of feeding and support professional decision making.

3.1.12.2 Using professional clinical judgement, if an infant has not been feeding well then:

- the sample taker should arrange to take the NBS the next day if it is still within the 72 to 120 hour window and as close to 120 hours as possible
- if still not feeding well, take the initial sample within the 72 to 120 hour window, but arrange for an additional sample to be taken on or around day 10

3.1.12.3 Specific concerns for infants need to be considered and stated on the NBS card. There are further details included in '*A Practical Guide to Newborn Bloodspot Screening in Ireland*' (12th Edition). Sample takers are advised to contact the NNBSL with any queries they have in relation to these.

- **Total Parenteral Nutrition (TPN):** This should be clearly indicated on the NBS card because these infants may not be on any galactose containing feed and a Beutler test will need to be performed to rule-out classical galactosaemia. TPN is only to be recorded on the NBS card if the infant is on TPN at the time that the sample is taken.

- **Intravenous fluid (IV fluids):** Infants on IV fluids may not have adequate protein and galactose intake and may result in a false negative for some metabolic conditions, including classical galactosaemia.

- **Intravenous glucose/dextrose:** If an infant is on IV glucose or dextrose a false negative screen may be reported for MCADD. It is imperative that this is noted on the screening card and a repeat card to be collected when IV is discontinued.

  Blood transfusion: If an infant requires a red blood cell (RBC) transfusion before the routine 72-120 hour sample is taken, a pre RBC transfusion should be collected to perform a Beutler test to rule out classical galactosaemia. (Note: a RBC transfusion invalidates the Beutler test). The routine 72-120 hour sample should be collected as normal regardless if the child has a RBC transfusion and do not delay this 72-120 hour sample due to RBC transfusions.

  If the 72-120 hour screening sample is taken with 72 hours of a RBC

transfusion, then a repeat screening sample is routinely requested by the NNBSL. This is because screening results for some conditions may be affected by the transfusion. A report will be issued from the NNBSL to request the repeat screening sample. Allow 72 hours to pass after any further RBC transfusions before taking the repeat screening sample.

For any further samples to be collected on a RBC transfused infant then allow 72 hours to pass before taking any more samples.
If the infant received an intrauterine transfusion, this should be clearly noted on the screening card, as this will invalidate the result of the Beutler test and could give a false negative screen result.

- **Prematurity (<36 weeks):** All infants born at less than 36 weeks corrected gestational age should have a pre-transfusion sample taken if a RBC transfusion is planned or likely to out-rule classical galactosaemia. A routine sample should be taken between 72 hours and 120 hours after birth.

  Infants born at less than 36 weeks corrected gestational age are at risk of false negative screening results for several conditions, including metabolic conditions, CHT and SCID.

  For infants born at less than 36 weeks corrected gestational age:
  - Take a routine screening sample at 72-120 hours
  - Take further samples at weekly intervals for a maximum of 4 weeks and/or until they reach 36 weeks corrected gestational age
  - If they have had 4 weekly samples but not yet reached 36 weeks, they will require a final sample at 36 weeks corrected gestational age
  - Take a final sample when the infant reaches 36 weeks corrected gestational age.

- **Meconium ileus** is a common complication in infants with CF. Therefore, CF should be considered in all infants who present with meconium ileus and MI must be noted on the NBS card, plus the clinical team in the maternity hospital/unit should actively follow-up if MI is suspected. An ethylenediaminetetraacetic acid (EDTA) blood sample should be sent directly to the Department of Medical Genetics, Children's Health Ireland at Crumlin for CF genetic variant analysis, with full clinical information (CFTR mutational analysis is undertaken as bloodspot IRT may give a false negative result in this clinical setting). A routine NBS sample should be taken at 72-120 hours to screen for the other conditions and meconium ileus noted on the NBS card.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

- **Maternal phenylketonuria:** phenylalanine is actively transported across the placenta. As a result the blood level in the foetus is about twice that of the mother. Pregnancy should be discussed with the metabolic clinical team in the National Centre for Inherited Metabolic Diseases (NCIMD), and women who have PKU should aim to ensure that their PKU is under optimal control at the time of conception. Regular and frequent monitoring of blood levels of phenylalanine and tyrosine is required throughout pregnancy in order to safeguard the wellbeing of the foetus.

  If the 72 hours following birth falls on a Saturday, the required 2mls lithium heparin liquid sample can be taken and sent to metabolic laboratory in CHI Temple Street on the preceding Friday morning (i.e. at less than 72 hours of age) and the metabolic laboratory phoned in advance, in order to try to ensure that results are available on the Friday, thereby minimising parental anxiety over the weekend.

3.1.12.4 Families who are deemed to be high risk for any of the conditions being screened for, require careful attention and an early NBS sample may be required; e.g. Traveller families, or other ethnic groups, or a family history of any of the screened for conditions.
Screening requirements for the infant will be determined by the clinical team. In addition to specific screening testing requirements for the condition suspected, the infant will also typically require a routine NBS card in the usual timeframe of 72-120 hours following birth. Family history of the condition suspected should be noted on the NBS card(s) and clarified; for example, whether a parent or sibling has the condition and the name of the condition, e.g. MCADD. Refer to Section 4.2 in *A Practical Guide for Newborn Bloodspot Screening in Ireland* (12th Edition).

3.1.12.5 The Beutler test (for classical galactosaemia) is completed for all infants born to parents who both identify as Irish Travellers and siblings of known cases of classical galactosaemia:

- A NBS sample should be taken from the infant immediately after the infant is born and/or before any blood transfusion has been given.
- This NBS sample is immediately sent to the NNBSL for a Beutler test – the NBS card should be clearly marked ‘FOR BEUTLER TEST’.
- Samples for Beutler testing must be in the laboratory by 12pm on weekdays and by 10am on a Saturday for same day reporting. If received after these times, samples will be analysed the next working day.
- Where the mother’s expressed wish is to breastfeed the infant, all efforts must be made to ensure that the Beutler is sent to the lab as soon as

possible so that breastfeeding can be initiated in the event of a negative Beutler result.

- Reporting of Beutler results can be obtained from the laboratory between 09:00-17:00 Monday to Friday.
- On Saturdays and Bank Holidays all maternity units are phoned with results. To facilitate this phoning of results, the contact number for where results are to be phoned to should be noted on the NBS card.
- Christmas and Easter opening hours of the NNBSL will be circulated in advance to DOM/Ns and DPHNs.
- Following the NBS sample for the Beutler test, infants should be fed with a lactose/galactose free feed until the result of the Beutler test is known.
- If the result of the Beutler is negative for classical galactosaemia the parent(s)/guardian(s) should be informed as soon as possible so as to take the infant off the lactose/galactose free feeds.
- These infants should have the routine NBS sample taken between 72 and 120 hours.

3.1.12.6 Family history must be stated clearly on the NBS card and the condition indicated. High risk family history includes; siblings of known case of any of the conditions screened for and marriage of first cousins.

3.1.13 Requirements for sample procedure

3.1.13.1 All sample takers must follow current national and local guidelines regarding infection prevention and control including hand-washing and/or use of alcohol hand gel, personal protective equipment (PPE) in the taking of the sample. Latest guidance available at www.hpsc.ie

3.1.13.2 Ask parent(s)/legal guardian to keep infants feet warm prior to taking the sample by applying two sets of socks approximately an hour in advance. Do not use any active heating mechanism such as warm water or a hair dryer to warm the infant's heel prior to undertaking newborn bloodspot screening as there is a risk of thermal burns from such practice.

3.1.13.3 The following are the equipment requirements:

- Automated incision device (lancet) of penetrative depth of no more than 2.4 mm in depth. Smaller lancets should be used for premature infants (0.85mm lancets are available) (WHO 2010). A slice incision is recommended as opposed to a prick/stab incision.
- Latex free gloves (latex can interfere with the test and may give a false result)
- NBS card (Check expiry date on NBS card and do not use if this date has passed)

- Gauze
- Cool, sterile water
- Envelope for dispatch to lab, water resistant and tear-proof (Tyvek or equivalent envelope)
- Drying box if necessary
- Sharps box for safe disposal of automated incision devices.
- For community services:
  - An Post registration label (if appropriate)
  - transport and drying box

3.1.13.4 The sample taker will check the expiry date on the NBS card – this can be found on the bottom right hand corner. The NBS cards should not be used after this date. Using expired cards may result in a request for a repeat sample. Do not detach the bloodspot portion of the card from the main card, as it is bar-coded and is required for laboratory use.

3.1.13.5 Sample takers need to note that:

- Total parental nutrition (TPN) should be clearly indicated on the NBS card; because these infants may not be on any galactose containing feed and a Beutler test will need to be performed to rule-out Classical Galactosaemia.
- If the family have a history of PKU, HCU, MCADD and GA1, an additional NBS card is taken on day 10.

3.1.13.6 Infants whose mothers are known or suspected of being infected with HIV or Hepatitis B or other known infectious diseases should have newborn bloodspot screening performed as normal.

3.1.13.7 NBS cards, appropriately dried and packaged, should be sent to the NNBSL as soon as possible either by registered post or by courier. Samples should not be held or delayed to accumulate additional samples before sending to the NNBSL.

3.1.13.8 It is acceptable to send a number of samples together in the one water resistant and tear proof envelope once this does not cause a delay in sending samples to the NNBSL. When a number of samples are being sent in the one water resistant and tear proof envelope, ensure that all the samples are fully air dried and that the bloodspots are aligned at 180 degrees to each other so that the bloodspots do not rest on each other. Please ensure the checklist (Appendix 16) is enclosed with:

- The details of all the infants surnames and their UPIs
- The total number of NBS cards enclosed and the date posted
- The name of the person compiling the checklist, their location and

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

contact number
- Any additional comments

3.1.13.9 Sample takers should notify the DPHN/designated officer that the newborn bloodspot screening sample is taken and record in the CHR as per local procedures.

3.1.13.10 Sample takers in the maternity hospital/unit should record that the NBS sample is taken as per local procedures.

3.1.14 Sample Technique

3.1.14.1 The method used for obtaining the blood sample is by “heel prick”.

3.1.14.2 Obtain the sample using an automated incision device.
- Avoid posterior curvature of the heel; see Figure 2
- Allow the heel to hang down to assist blood flow
- Before activation, place the automated incision device against the heel in accordance with the manufacturer’s instruction.
- For full-term and preterm infants, skin puncture must be no deeper than 2.4mm.

Figure 2: Location on heel where sample should be taken from (shaded area)



3.1.14.3 In order to encourage blood flow to the heel area, the parent(s)/guardian(s) should be advised on the day prior to sampling (if possible) to put two pairs of socks on the infant’s feet for approximately an hour in advance of sample taking.

3.1.14.4 Do not touch bloodspot rings on the NBS card with gloves before, during or after the sample is taken. Ensure there is no contact with Vaseline or other creams.

3.1.14.5 Latex interferes with Beutler sample and may cause a false positive result. Latex free gloves are to be used when carrying out the NBS.

3.1.14.6 Preferably take the sample from the infant while the parent/legal guardian holds the infant. Encourage skin to skin contact, breastfeeding or

non-nutritive sucking to aid comfort. This assists you and helps comfort the infant, and provides an opportunity for parents to ask questions about newborn bloodspot screening.

Allowing the infant's leg to hang lower than the heart will encourage blood flow.

3.1.14.7 Place a paper towel on the lap of the individual holding the infant.

3.1.14.8 Ensure that the heel is visibly clean and warm**.** The skin may be gently rubbed for 1-2 minutes to increase blood supply if deemed necessary. Never use any external warming source (e.g. hairdryer, warm water). This introduces a risk of thermal burns and/or scalds.

3.1.14.9 Routine cleansing of the heel is not required. However, if the heel is visibly dirty or soiled it can be cleaned with gauze soaked in cool sterile water.
Ensure that the heel is completely dry before taking the sample. Do not use alcohol or infant wipes as they may interfere with sample results or cause serum rings.

3.1.14.10 Encircle the heel with finger(s) and thumb and squeeze gently until the skin looks taut and suffused/filled with blood.

3.1.14.11 Press the automated incision device (lancet) firmly against the side of the ball of the heel and activate the device.

3.1.14.12 Hold the foot downwards and gently massage the heel to encourage blood flow.

3.1.14.13 Wipe away the first drop of blood and allow another large drop to form. (The first drop may be a diluted blood drop). Allow the blood to drop onto the circles marked on the newborn bloodspot screening card by using the '*hanging droplet technique'*.

The hanging droplet technique is the recommended method for applying blood drops and uses the kinetics of blood spreading to soak blood evenly across the spot diameter, as opposed to touching the filter paper to the heel.

Do not touch the NBS card to the heel

Do not layer more than one drop of blood per circle

Ensure that the blood soaks through from the back of the card to the front:

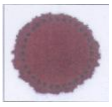
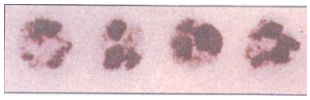
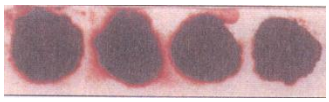
- Blood should be applied only to one side of the filter paper with the

recommended guidance that the blood is applied to the back of the card.

- Blood drops must be soaked through from the back to the front of the card, filling all circles completely
- Check that the blood has soaked completely through the circle on the front as well as the rear of the card
- When sample is turned over for final checks it will be obvious if blood has not fully soaked through and if the pre filled printed spot areas are fully filled.
- Do not press or squeeze the bloodspot to 'force' it through the NBS card.

Figure 3 outlines various types of sample quality

Figure 3: Examples of various types of sample quality

Sample Quality	Example	Comment
Valid sample		Sufficient amount of blood to completely fill all circles.
Insufficient sample		Removing card before blood has completely filled circle.
Sample not dry before posting		~~Posting sample before drying for up to 4 hours.~~ Sample sent to laboratory before completely dry
Sample appears supersaturated		Applying excess blood to card.
Sample appears diluted or contaminated		Squeezing area surrounding puncture site Allowing card to come in contact with gloved or ungloved hands Exposing blood spots to direct heat.
Sample shows serum rings.		Not wiping alcohol from puncture site before skin puncture. Squeezing area surrounding puncture site excessively. Drying specimen incorrectly.

3.1.14.14 Wipe away excess blood with sterile gauze. Press clean gauze firmly onto the wound until bleeding stops. **N.B**. It is not recommended that a plaster is used as this may be a choking hazard if swallowed.

3.1.14.15 The sample taker will ensure sufficient blood is taken to meet the requirements to completely fill the four bloodspot circles on the NBS card.

3.1.14.16 See *Flowchart for Newborn Bloodspot Screening Sample Takers* if having difficulty in obtaining a sufficient sample – Appendix 17.

3.1.14.17 It is imperative that adequate blood is supplied for analysis to reduce the incidence of repeat sample requests. Please ensure that the blood soaks through fully from the back through to the front of the card to avoid an **insufficient** sample.

3.1.14.18 Ensure the sample is **completely dry by air drying** the NBS card before putting it in the tear-proof, water resistant envelope.

- Drying time is dependent on the environment
- **Wet samples** cause the production of 'serum rings' which could result in a false negative result and ultimately increases the risk of missing a case.
- Do not dry in direct sunlight or near a heating source, e.g. a radiator, as this may invalidate the test and could lead to a false result. Failure to fully dry the sample may invalidate the screening sample result.

3.1.14.19 Ensure not to contaminate the filter paper circles. Possible reasons for contamination include spillage of liquids or lotions or allowing the card to come in contact with gloves or placing the sample wet into the envelope.

Drying bloodspots stabilises analytes, allowing longer time periods between taking the sample and sample analysis without compromising results. If the NBS sample is not dry when it is put in an envelope, blood will leach from the filter paper onto the envelope, altering the blood volume left in the filter paper and could generate an inaccurate result.

3.1.14.20 The sample taker must remove their gloves and PPE if used and perform hand hygiene.

3.1.14.21 The sample taker in the IHA will use a transport/drying box for the NBS card following the procedure to facilitate the transport of the NBS card from the infant's home to the nurse's/midwife's car in a safe manner.

3.1.14.22 Dispose of lancets as per local guidelines; never enclose the lancet in the envelope with the NBS card.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

3.1.15 Transporting the NBS card to the NNBSL

3.1.15.1 If the NBS is taken in the maternity hospital/unit, the nurse/midwife/nursery nurse transfers the NBS card to the NNBSL through hospital arrangements for blood sampling products.

3.1.15.2 If the NBS is taken in the community, the RPHN/nurse/midwife in the IHA will:

- transfer the NBS card from the drying box and package according to the NNBSL regulations
- a water resistant and tear proof envelope (e.g. Tyvek or equivalent) can be used with the yellow fluorescent address label (Appendix 19)
- it must be noted that a maximum of three NBS cards can be put into one water resistant and tear proof envelope. The samples must be fully air dried and assembled opposite ends to each other i.e. to prevent blood circles from each card touching each other
- in the community, send the NBS cards by registered post (or by courier/hand deliver in exceptional circumstances i.e. emergency situations/extended holiday periods) to the NNBSL. Evidence of posting is attached to the CHR.

3.1.15.3 In the maternity hospital/unit; details of samples sent by courier are recorded as per local procedure.

3.1.15.4 If more than a single NBS card is being dispatched together please include summary list of names/UPIs (Appendix 16).

3.1.15.5 Laboratory opening hours and requirements around weekend/bank holidays (Appendix 15):

- Laboratory opening hours are:
- 09:00 – 17:00 Monday-Friday
- 09:00 – 12:30 Saturday

- To ensure samples reach the NNBSL in a timely manner and to minimise a delay in reporting over weekends, samples due to be taken on a Thursday should be collected early Thursday morning if infant is 72 hours old, allow sample to dry fully, **and post on Thursday afternoon** to arrive in the NNBSL on Friday morning for analysis.
  - at weekends, where possible, samples taken on a Saturday are posted by 13:00 by registered post. Samples taken on Saturday afternoon/Sunday are posted on a Monday morning
  - At bank holiday weekends, where possible, samples taken on a

Saturday are posted by 12midday by registered post. Samples taken on Saturday afternoon/Sunday/Monday are posted on a Tuesday morning.

- At extended holiday periods, a courier/taxi service may be used from a designated centre to the NNBSL for the NBS card to be transported directly to NNBSL.
- A memo will issue from the NNBSL each year outlining Christmas/New Year and Easter opening arrangements

3.1.16 Record keeping

3.1.16.1 The midwife/nurse/nursery nurse in the maternity hospital/unit will record in the maternal healthcare record – child care section either:

- completion of the procedure
- or issue a request for NBS to the relevant IHA or tertiary paediatric hospital

3.1.16.2 The RPHN/midwife/nurse working in the IHA will record in the child health record the following:

- yes, no or refused (opt-out)
- location: hospital or community
- date
- evidence of posting attached and filed in the CHR
- is repeat required?
- the sample taker's copy of the NBS card should be filed in the CHR

3.1.17 Amendments to newborn bloodspot screening cards

3.1.17.1 If there are any amendments required to be made to any details recorded on the NBS card, the **Patient Details Amendment Form** should be completed (Appendix 13) and forwarded to the NNBSL by email.

3.1.17.2 Where there is an error in recording the 'type of feed' identified, the NNBSL needs to be notified immediately by emailing info.newbornscreening@childrenshealthireland.ie identifying the service e.g. maternity hospital/unit, paediatric unit, IHA; stating the infant's clinical details and the amendment to be made

3.1.18 Managing inaccessible visits

3.1.18.1 On failing to gain access to the mother's home:

- the RPHN/RM must phone the maternity hospital/unit to confirm the discharge details, discharge address and additional contact details of nominated support person
- the RPHN/RM can telephone the nominated support person to

request the mother makes contact with the RPHN/RM as soon as possible

- if the above is not productive, the RPHN/RM should phone the GP. Under article 9 (2) h of GDPR concerning the provision of health and social care services, data concerning health may be requested from the Data Controller (GP). The Data Controller determines if and what information is given.
- all of the above steps should be documented, dated, timed and signed appropriately using the child health record
- the RPHN/RM will inform the ADPHN of the above and discuss actions. An NIRF should be completed if discharging address/contact numbers are incomplete or inaccurate and this causes a delay in the sample taking.
- following confirmation that it is the correct address the RPHN/RM should leave a PHN visiting card requesting the parent(s)/legal guardian(s) to contact the RPHN/RM as soon as possible to arrange for a sample to be taken
- in the event the address cannot be confirmed (e.g. a rural address without an Eircode) then the RPHN/RM is not in a position to leave a PHN visiting card, contact should be made with the maternity hospital/unit /midwife/GP for further details and records same in the maternal postnatal record

3.1.18.2 The RPHN/RM contacts the maternity hospital/unit with notice of the inaccessible visit. Every effort must be made to ensure that the sample is taken in collaboration with appropriate services (e.g. the maternity hospital/unit, GP, Garda Síochána, other PHN Departments etc.) The RPHN/RM records this in the CHR.

3.1.18.3 If the sample is successfully taken it is the responsibility of the sample taker to ensure that the relevant services are informed that the sample has been taken.

3.1.18.4 If the sample is subsequently late or missed a NIRF should be completed. Learning from such an incident is circulated to relevant colleagues as appropriate.

3.1.19 Newborn bloodspot screening sample results

3.1.19.1 The NNBSL notifies the maternity hospital/units/ DPHN of NBS Result by eReports™ The URL to access eReports™ is: https://nnbs.childrenshealthireland.ie/eReports

- each maternity hospital/unit and DPHN Office must nominate a NBS

Management Lead and two authorised eReports™ users. This ensures eReports™ access is available at local level for authorised users.

3.1.19.2 The NNBSL provides each authorised user with:

- User Name
- User ID
- URL for eReports™ access
- Handbook for eReports™ users
- Training as needed for authorised users

3.1.19.3 Ereports™ allow:

- verification of receipt of samples before results are available
- requests for repeat samples can be made electronically
- results of samples become available 2-3 days after receipt of sample in the laboratory
- result codes are supplied which indicate interim stages of results analysis and investigations for some conditions
- a search facility which can be used to find and link results, this includes searching by infant name, date of birth (DOB), or range of birth dates, mothers name, UPI etc.
- results available online to authorised users in the IHA and the maternity hospitals/units for up to 60 days following the issuing of a result
- individual reports can be printed locally for healthcare records and for parent/guardian information requests

3.1.19.4 The NNBSL approves screening results normally within 48 hours of receipt of sample, which are made available via eReports™ to authorised users.

3.1.19.5 The NNBSL phones the DOM/N or designated officers and/or DPHN or designated officers with results requiring urgent action for example screen positives, admission to hospital, sweat test.

3.1.19.6 The NNBSL forwards a list via eReports™ indicating the results of the screening to both:

- The DOM/N/maternity hospital/unit – designated officers.
- The DPHN/IHAs – designated officers.
- Where relevant to Children's Health Ireland.

3.1.20 Checking NNBSP sample results

Maternity hospital/units checking NBS register – sample results

3.1.20.1 The DOM/N/designated officer (Outpatient Midwife Manager and/or Postnatal Midwife Manager) oversees and monitors NBS results for infants where a NBS has taken place in the maternity hospital/unit.

3.1.20.2 The Designated Officer undertakes daily monitoring of the eReports™ for initial requests for NBS and for any repeat NBS requests and arranges appropriate sampling and resampling for any infant who remains in hospital at that point.

3.1.20.3 The Designated Officer undertakes weekly monitoring procedures as follows:

- Identifying and eliminating duplication.
- Identifying infants without UPIs and ensuring all infants have a UPI issued.
- Monitoring on the newborn screening register those infants 12 days old where there are no eReport results identified. For those infants check the following:
  - that the sample has reached NNBSL (eReports™)
  - that the hospital/ward has a record of the NBSS been taken
  - or that a record of the "*National Newborn Bloodspot Screening Programme Opt-out form*" form is in the maternal chart – infant section.
- Record closure of screening episode where information received identifies:
  - confirmation that an infant has died
  - the family have refused the service and a "*National Newborn Bloodspot Screening Programme Opt-out form*" form is completed
  - if sample has not been taken for other reasons, arrange sampling and continue to follow up until screening episode is closed.
- The designated officer signs/initials the entries to indicate that he/she has undertaken the exercise (note: manual format).

3.1.20.4 Conclusive results will normally be available within 18 days of birth for most conditions screened. Cystic fibrosis results may not be available for up to 28 days after birth.

3.1.20.5 If results are not available by day 18, the designated officer should contact the NNBSL and request the result (Appendix 20).

3.1.20.6 The designated officer will continue to follow up on results that are pending until all results are made available.

3.1.20.7 The maternity hospital/unit is responsible for ensuring that omissions are notified to the DPHN where results have not been received from the NNBSL.

3.1.20.8 The maternity hospital/unit /Designated Officer:

- works with the RHA/IHA Child Health Lead, DPHN and/or their designated officers as required to ensure that all infants have a result recorded

3.1.20.9 The DPHN and their designated officers maintains an electronic/paper NBS register based on the full birth register (Immunisation/PHR/Child Health Information ICT System) and ensures all infants for the IHA have received the NNBSP and have a result recorded.

Tertiary paediatric hospitals – sample results

3.1.20.10 As per section 3.1.3.3 the tertiary hospital must have written procedures in place for:

- performing the test between 72 and 120 hours after birth and repeat samples as recommended in the *Practical Guide to Newborn Bloodspot Screening In Ireland* (12th Edition) or as requested by the NNBSL
- sending the NBS card to the NNBSL
- receive the reports via eReports and post as applicable
- recording the results in the infant's medical records

DPHN/IHA checking NBS register - sample results

3.1.20.11 DPHN Office/Designated Officer has direct access to the Immunisation/PHR/Child Health ICT system/database as an electronic full birth register for all infants in the IHA as per birth notification processes.

3.1.20.12 The DPHN Office/Designated Officer ensures homebirths and infants born outside the ROI are included in the IHA birth register.

3.1.20.13 The DPHN/Designated Officer checks all NBS results against the IHA birth register for the designated IHA to ensure that all infants residing in the designated area have an NBS outcome status recorded by day 18.

3.1.20.14 The Designated Officer undertakes a daily monitoring of the eReports™ for initial requests for NBS and for any repeat NBS requests and informs the relevant ADPHN and/or PHN who arranges appropriate sampling and resampling for any infant who has returned home.

3.1.20.15 The Designated Officer undertakes "failsafe"[1] weekly monitoring procedures as follows:

- confirmation that sample reached NNBSL through checking the eReports™ (i.e. check through "Patient Search" that the name of the infant is on eReports™ although results may not be available)
- if not reported within 4 days of sample collection (or by Day 12 if sample collection date is unknown), check that:
  - the maternity hospital/unit of birth or SECM has completed the NBS
  - the RPHN/RM/RGN has taken the NBS
  - a record of the "*National Newborn Bloodspot Screening Programme Opt-out form*" form is in the CHR
  - the infant is known to have "moved out" of the area
  - infant has died
- Record closure of screening episode where information received identifies:
  - confirmation that an infant has died
  - the family have refused the service and a "*National Newborn Bloodspot Screening Programme Opt-out form*" is completed
  - the family moved to another area, which has taken over responsibility for NBS
- If the NBS sample has not been taken for other reasons, arrange sampling and continue to follow up until screening episode is closed
- Conclusive results will normally be available within 18 days of birth for most conditions screened. Cystic fibrosis results may not be available for up to 30 days after birth.
- The designated officer signs/initials the entries to indicate that he/she has undertaken the exercise (Note: manual format).

3.1.20.16 Where confirmation is obtained through the eReports™ search that a sample has reached the NNBSL and no results or repeat request are received by Day 18, the designated officer makes a request for the results to the NNBSL (Appendix 20).

3.1.20.17 Where reports are received which do not belong to the IHA; the Designated Officer will inform the NNBSL (Appendix 21).

3.1.20.18 The NBS register should match the Immunisation/PHR/Child Health System. The designated officer will:

- Where infants have moved into the area and an eReport™ is

[1] Failsafe means in this context a system designed to ensure that if one part of the system does not work, the whole system does not become dangerous.

received, the designated officer will inform the Immunisation/PHR/Child Health ICT system and add the infant to the NBS register

- Where infants are on the NBS register which is aligned to the Immunisation/PHR/Child Health ICT system and an eReport™ is not received, the designated officer will contact the NNBSL (telephone or email) to ascertain is there a change of address or detail.
  - if the infant is residing in the area, the designated officer will request the result (Appendix 20) and notify the Immunisation/PHR/Child Health ICT system of any change in details of the child
  - if the infant is not residing in the area, the infant is ineligible for screening and the designated officer will notify the Immunisation/PHR/Child Health ICT system of any change in details of the child

3.1.20.19 Where issues are identified by the designated officer in the monitoring procedures, the designated officer will inform the relevant Nurse Manager (DPHN/ADPHN) as appropriate.

3.1.20.20 This procedure does not mandate that all reports must be issued to RPHNs for filing. If required, the RPHN can obtain the NBS results from the DPHN/designated officer. Individual results can be printed out from the eReport™ system and sent to the RPHN to be filed in the CHR.

3.1.20.21 Where results are pending, the DPHN/designated officer monitors the results which are pending via the eReports system until confirmation of final results are received.

3.1.20.22 The RPHN should discuss the results with the parent(s)/legal guardian(s) at the next child health visit (3 months PHN child health assessment) as prompted by the CHR; i.e. not suspected/in treatment.

3.1.20.23 Parent(s)/legal guardian(s) can request a written copy of the sample result from the DPHN and/or NNBSL:

- where the results are normal the DPHN can issue the results to the parent(s)/legal guardian(s) via the DPHN office.
- screen positive results will be notified as per 3.1.25. The DPHN can liaise with the NNSBL and/or relevant medical team before issuing the written copy to the parent(s)/legal guardian(s).

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

3.1.21 Repeat screening requests

3.1.21.1 Repeat samples are requested by the NNBSL and reasons for the repeat request are outlined below.

Valid repeat requests

- For borderline or equivocal results, a repeat NBS screening sample is required to ensure an accurate screening result

Avoidable repeat samples – these must be kept to a minimum

- insufficient bloodspots for all or some of the screens to be performed
- unsatisfactory sample quality due to compressed or diluted sample, serum rings formation or contamination of the sample
- sample received wet
- unlabelled or inadequately labelled samples
- samples collected before 72 hours of birth
- there is a query about the identification of the infant or infants if multiple births
- the sample was taken on an expired card
- the card was delayed, greater than 14 days and is too old for reliable analysis
- the name on the bloodspot portion does not match that on the demographic portion of the card; the identity of the infant may need clarification or a repeat sample
- sample is unsuitable for analysis if taken within 72 hours of a RBC transfusion
- the bloodspot portion of the NBS card and demographic portion were re-attached but NBS card barcodes do not match up

3.1.21.2 The NNBSL will inform the DOM/N/designated officer in hospital services and the DPHN/designated officer in community services that a repeat NBS is required by way of eReports.

3.1.22 Repeat sampling

3.1.22.1 The DOM/N/maternity hospital/unit and DPHN/IHA will establish the location of the infant:

- where the infant remains in maternity hospital/unit care, the maternity hospital/unit will complete the request
- where the infant has been discharged to the IHA, the repeat sample will be completed by Public Health Nursing service
- If the infant is in a tertiary hospital see section 3.1.3.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Repeat newborn bloodspot screening for infants who remain in the maternity hospital/unit/tertiary paediatric hospital

3.1.22.2 The DOM/N/Designated Officer in hospital services will ensure the request for the repeat NBS is forwarded to the relevant ward on the day of receipt of request for repeat NBS and ensure that it is completed as soon as possible.

3.1.22.3 The RM/Nursery Nurse in the relevant ward will inform the parent(s)/legal guardian(s) of the reason for requiring the repeat sample and obtain informed consent.

3.1.22.4 Where the infant has been discharged from hospital care, the DPHN will be requested to complete the repeat NBS screening.

3.1.22.5 In the event that the infant has been discharged from hospital care and the DPHN office cannot be contacted, for example outside of normal office hours (9-5 Mon-Fri), arrangements are made by the maternity hospital/unit for the parent(s)/legal guardian(s) and the infant to return to the hospital for sample taking.

Repeat newborn bloodspot screening for infants who have been discharged home (Public Health Nursing)

3.1.22.6 The DPHN/Designated Officer will ensure that the request for the repeat NBS is forwarded to and received by the appropriate RPHN/RM/RGN on the day of receipt of request for repeat NBS.

3.1.22.7 The RPHN/RM/RGN will contact the parent(s)/legal guardian(s) to arrange for sample taking as soon as possible either at a home visit or at a clinic visit.

3.1.22.8 The repeat NBS screening will be completed as soon as possible.

3.1.22.9 If the repeat sample is due to be taken at a weekend, the sample may need to be taken in the local, maternity hospital/unit if community services not available at the weekend – see Section 3.1.5.5

3.1.23 Procedure for repeat sampling

3.1.23.1 The sample taker must:

- explain to the parent(s)/legal guardian(s) why a repeat sample has been requested
- assure the parent(s)/legal guardian(s) that if the repeat sample should prove screen positive, that they will be contacted immediately

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

by a healthcare professional the relevant maternity hospital/unit
- be aware that the parent(s)/legal guardian(s) can decide to opt-out of the repeat sample being taken. Section 3.1.8 covers this in detail

3.1.23.2 The sample will be taken in the same way as the initial sample (Section 3.1.9 – 3.1.15).

3.1.23.3 The sample taker must clearly indicate on the NBS card that the sample is a Repeat Sample by ticking the relevant box 'Yes'.

3.1.23.4 The sample should then be sent immediately to the NNBSL either by registered post or by courier or fast track services as appropriate.

3.1.23.5 The sample taker informs the DOM/N/DPHN/designated officer and/or NNBSL where relevant that the sample is taken and gives details of how the sample is sent to the laboratory.

3.1.23.6 The sample taker will keep a record of the NBS in the infant section of the maternal chart or the neo-natal infant chart for hospital services and/or the Child Health Record (CHR) for community services.
- For community services, the sample taker documents in the CHR that a repeat was required and the date the repeat sample was taken.
- The relevant designated officer records in the newborn bloodspot screening register that a request for a repeat sample has been received and that the NBS sample has been taken and submitted to the NNBSL.

3.1.24 NBS repeat sample results

NNBSL notify maternity hospital/unit/community of repeat sample results

3.1.24.1 The NNBSL informs the DOM/N/ maternity hospital/unit and the DPHN/IHA of the repeat sample results (individual report) of the repeat screening via eReports™.

3.1.24.2 The NNBSL follows up on all children where a result is not normal and/or requires clarification and further follow up.

3.1.24.3 The NNBSL liaises with the designated liaison nurse in the relevant maternity hospital/unit who refers the infant and their parent(s)/legal guardian(s) to the appropriate pathway if required.

3.1.24.4 The Clinical Team/Clinical Nurse Specialist for the appropriate care

pathway makes contact with the family and arranges a hospital /outpatient visit for infants with a suspected screen positive result (See section 3.1.25).

3.1.24.5 The designated officer for the DOM/N/maternity hospital/unit and/or DPHN for the designated IHA continues to follow up on repeat sample results until screening is closed.

3.1.25 Procedure for management of screen positive results and repeat newborn bloodspot screening samples

Screen Positive Results

3.1.25.1 The response to a query screen positive result is immediate and direct.

3.1.25.2 The Clinical Liaison Nurse/Clinical Director of the NNBSL contacts the designated liaison midwife or paediatric registrar (depending on the condition) in the maternity hospital/unit of birth and:

- informs of the name, UPI, date of birth and address of the infant
- the condition suspected and the result of the screening
- requests the designated liaison midwife in the maternity hospital/unit to contact the parent(s)/legal guardian(s)

3.1.25.3 The designated liaison Midwife/Paediatric Registrar/Consultant Paediatrician in the maternity hospital/unit contacts the parent(s)/legal guardian(s) to:

- explain the screening result and the condition suspected
- explain why the infant has to be referred to hospital (typically for further testing to confirm/refute the diagnosis)
- explain why a further blood sample is required
- explain what further tests are needed, e.g. a blood test, another NBS sample, thyroid scan if CHT suspected, sweat test if CF suspected etc.

Arrangements are made with the parent(s)/legal guardian(s) for the infant to be brought directly to Children's Health Ireland at Temple Street or to the local Paediatric Unit as requested by the Newborn Bloodspot Screening Laboratory depending on the condition suspected

Parent(s)/legal guardian(s) should be advised that their infant might be kept in hospital for a few days, depending on the result of the repeat investigation(s). Therefore, they should bring change of clothes for the infant and themselves and be prepared for a hospital stay.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

3.1.25.4 The designated liaison midwife in the maternity hospital/unit or the Paediatric Registrar/Consultant Paediatrician may contact the Clinical Liaison Nurse or the Director of the NNBSL if further information is required.

3.1.25.5 The designated liaison midwife in the maternity hospital/unit may give the contact details of the Clinical Liaison Nurse or the Clinical Director of the NNBSL to parent(s)/legal guardian(s), and invite them to make contact for more information, if they wish to do so, before they arrive in the hospital.

3.1.25.6 Special arrangements have been put in place to contact parent(s)/legal guardian(s) with suspected CF where the Clinical Liaison Nurse in the NNBSL will contact the CF Nurse Specialists in the appropriate HSE designated paediatric CF centres to give them the full contact details, relevant information and results of the mutational screen. The CF Nurse Specialist will book a sweat test appointment if it is required and then contact the parent(s)/legal guardian(s) to arrange for the infant to attend the appropriate CF centre.

3.1.25.7 The person contacting the parent(s)/guardian(s) must impart the information in a calm and professional manner and must aim to minimise parental anxiety. They must be fully informed of all the facts and explain to the parent(s)/guardian(s) what condition the infant is suspected of having. Further information of the various follow up actions based on the relevant condition is contained in the *Practical Guide to Newborn Bloodspot Screening in Ireland* (12th Edition).

3.2. Specific roles and responsibilities

National Clinical Lead Child Health Public Health / Consultant in Public Health Medicine / Medical Officer of Health

The National Clinical Lead Child Health Public Health, Consultant in Public Health Medicine / Medical Officer of Health (MOH) has MOH responsibilities for the National Healthy Childhood Programme, as legislated for in the 1947 and 1970 Health Acts, at national level. The NNBSP is a component part of the National Healthy Childhood Programme. These responsibilities include the sign-off of this national procedure and addressing any issues nationally that arise from its implementation.

The role of the NNBSP Operational Governance Group

The NNBSP Operational Governance Group is responsible for developing and recommending this national procedure for use in the provision of the

NNBSP. On approval by the National Clinical Lead Child Health Public Health, the NNBSP Operational Governance Group will ensure that final approved copies are circulated to all DPHNs and DOM/Ns nationally. The NNBSP Operational Governance Group will agree a review date for this procedure and in the event of amendments to legislation, HSE policy or other related PPPGs, will initiate an earlier review if required.

The NNBSP Operational Governance Group will ensure:

- this document is available online in the national HSE National Central PPPG repository
- any updates, if necessary, are made to the HSE LanD Newborn Bloodspot Screening Programme eLearning module

The role of Directors of Midwifery, Directors of Public Health Nursing and Directors of Nursing of Tertiary Paediatric Hospitals

Within the maternity hospitals/units, the community services and the Tertiary Paediatric Hospitals, the DOMN/DPHN/DON will be responsible for ensuring that:

- this procedure is implemented within their area of responsibility
- nursing and midwifery staff members will be informed of this procedure
- all relevant administrative and clerical staff members will be informed of this procedure
- nursing and midwifery staff will be informed of the educational eLearning module available on HSE LAND
- it is the responsibility of relevant Line Managers to ensure that all staff members working under their remit have read and signed the policy (on paper or electronic format) in each clinical area
- this version of the document will be made available in an electronic format through the HSE PPPG repository
- all risks and incidents relevant to this procedure are monitored and actioned as required as per the HSE Incident Management Framework (2020) with completion of National Incident Report Forms (NIRF) as required and submission to the National Incident Management System (NIMS). All incidents assigned as Category 1 and Category 2 must be notified to the National Clinical Lead Child Health Public Health (child.screening@hse.ie).
- Any risks identified that may impact on, or threaten the delivery of the NNBSP must be escalated immediately to the National Clinical Lead Child Health Public Health(child.screening@hse.ie).
- For PHN services, if Priority 1 designation for immediate and time sensitive response with regards to taking NBS samples is at risk this

must be immediately escalated to the National Clinical Lead Child Health Public Health.

Designated Midwifery Officer

The Designated Midwifery Officer for Self Employed Community Midwives (SECMs) who are employed under the Memorandum of Understanding and Contractual Agreement (2014) will ensure that:

- SECMs will be informed of this revised procedure
- all relevant administrative and clerical staff members will be informed of the approval of this revised procedure
- nursing and midwifery staff will be informed of the educational eLearning module available on HSE LAND
- it is the responsibility of relevant Line Managers to ensure that all staff members working under their remit have read and signed the policy (on paper or electronic format) in each clinical area
- this version of the document will be made available in an electronic format through the HSE PPPG repository
- all risks and incidents relevant to this procedure are monitored and actioned as required as per the HSE Incident Management Framework (2020) with completion of National Incident Report Forms (NIRF) as required and submission to the National Incident Management System (NIMS). All incidents assigned as Category 1 and Category 2 must be notified to the National Clinical Lead Child Health Public Health (child.screening@hse.ie)

Role of Registered Public Health Nurses/Registered General Nurses and Midwives

It is every nurse and midwives' responsibility to ensure they are working within their "Scope of Practice" at all times and that they identify their training needs to their manager to maintain standards of care (NMBI, 2025).

- Each RPHN/RM/RGN is responsible for adhering to this procedure and to use it to guide their practice in the delivery of the service they provide.
- Each RPHN/RM/RGN is responsible for ensuring that they read and understand the procedure and have confirmed this through the electronic policy portal. When areas of concern are identified, where legislation is known to have changed or where a health and safety risk is identified, it is the responsibility of each RPHN/RM/RGN to ensure that their line manager is informed in order to ensure appropriate review and amendments are made to the guideline. RPHNs/RMs/RGNs should adhere to HIQA and NMBI guidelines regarding documentation, record

keeping and file management.

RPHNs/RMs/RGNs must ensure that all risks and incidents relevant to this procedure are monitored and actioned as required as per the HSE Incident Management Framework (2020) with completion of National Incident Report Forms (NIRF) as required and submission to the National Incident Management System (NIMS). All incidents assigned as Category 1 and Category 2 must be notified to the National Clinical Lead Child Health Public Health (child.screening@hse.ie).

4.0 Consultation

4.1. Stakeholder involvement

This is revision of the previous version of the procedure (V4, May 2022) to transfer it onto the new national template with some minor updates. A draft of this revised procedure was circulated to a small working group of key stakeholders for review. The draft was also submitted to the HSE National Clinical Lead Child Health Public Health and the members of the NNBSP Operational Governance Group. All feedback was reviewed and recommendations accepted or rejected.

4.2. External review

There was no requirement for external review of this procedure.

5.0 National implementation plan

5.1. Describe the structure governance of the national implementation team.

The NNBSP is already in operation using the previous version of this procedure (V4, May 2022) and the "*Practical Guide to Newborn Bloodspot Screening in Ireland*" (12th Edition) as a basis for its operation. Therefore there will be no requirement for an implementation plan. Clinical governance for the NNBSP is provided through the NNBSP Clinical and Quality Assurance Governance Group and the NNBSP Operational Governance Group, both chaired by the National Clinical Lead Child Health Public Health and implementation is the responsibility of the public health nursing and midwifery services. This procedure will be disseminated as per Communication and Dissemination plan (Section 7) to alert all users to the updated version of the procedure.

The HSE LAND online training module on newborn bloodspot screening has been revised and will reference this latest version of the procedure.

Education/training plans required to implement the PPPG

The NNBSP is already in operation using the previous version of this

procedure (V4, May 2022) and the "*Practical Guide to Newborn Bloodspot Screening in Ireland*" (12th Edition) as a basis for its operation. The HSE LAND online training module will be updated and will be offered to relevant staff in conjunction with the communication and dissemination of this procedure.

A copy of the procedure will be stored on the national HSE PPPG repository.

5.2. List tools and resources developed to support local implementation of the National 3PG.

This version replaces the previous version of this procedure (V4, May 2022) that is already in place. The relevant eLearning module regarding the NNBSP is available on HSE LAND.

5.3. Expected date of full implementation

This version replaces the previous version of this procedure that is already in place.

6.0 Governance and approval

This national procedure was commissioned by the National Clinical Lead Child Health Public Health on behalf of the NNBSP Operational Governance Group. Final approval of the procedure was provided by the National Clinical Lead Child Health Public Health and follow up reviews will be initiated by NNBSP Operational Governance Group as required.

Refer to Appendix 1 for the development group details. Appendix 2 details the Membership of the Approval Governance Group. This procedure will be submitted to the HSE National Central Repository Office for referencing.

7.0 Communication and dissemination plan

The approved document will be circulated to all DPHNs/DOMs/SECMs for dissemination to their respective nursing/midwifery departments and to other key stakeholders involved in the day to day operation and management of the NNBSP. A copy of the procedure is available on the HSE National PPPG Repository.

Communication in relation to this procedure will clearly identify that it supersedes the previous national procedure for the provision of the NNBSP.

8.0 Sustainability

8.1. Describe the plan for monitoring and audit

The monitoring of this procedure will be through the DPHN/DOM/DON/Designated Midwifery Officer. Any relevant findings from such monitoring must be provided to the NNBSP Governance group through the relevant representatives where the findings will be discussed and appropriate action taken.

8.2. National audit tool

Audit tool for the HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP) is located in Appendix 5

Audit

Midwifery/Nursing/Public Health Nursing management team will conduct an annual audit. The objectives of the audit will be:

- to provide evidence of compliance to the national procedure
- to ensure standardisation of application of the procedure
- to identify areas for improvement, make recommendations and prioritise actions

Evaluation

Evaluation of the procedure will be initiated by the NNBSP Programme Manager, National Healthy Childhood Programme and will occur through feedback at professional team meetings, direct patient feedback and through reviews of National Incident Report Forms (NIRFs) to monitor any Near- Misses/Adverse Incidents. Feedback from Your Service Your Say and through local formal complaints processes will be considered in any revision of the procedure.

9.0 Review / update

9.1 Review of national document

This National procedure will be reviewed and revised, if required, after three years by the date specified on the front cover of this document. The review will be triggered by the NNBSP Governance Group. If there is any new supporting evidence identified by findings from audit and evaluation, advances in technology or research, in the meantime this National procedure should be reviewed, updated and re-published as necessary.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

10.0 References

Government of Ireland (1947) & (1970) Health Act – Irish Statute Book. Available online from: www.irishstatutebook.ie/1970/en/act/pub/0001/print.html

Health Information and Quality Authority (2024) National Standards for Safer Better Healthcare

Health Information and Quality Authority (2016) Supporting Peoples Autonomy: a Guidance Document

Health Information and Quality Authority (2017) National Standards for the Prevention and Control of Healthcare Acquired Infections

Health Service Executive and Children's Health Ireland (2026) A Practical Guide to Newborn Bloodspot Screening in Ireland (12th Edition)

Health Services Executive (2024) National Records Retention Policy

Health Service Executive (2023) How to develop HSE National Policies, Procedures, Protocols and Guidelines: A Practical Guide

Health Service Executive (2022, revision 2024) National Consent Policy

Health Service Executive (2019) Personal Data Protection Policy

Health Service Executive (2019) Child Protection and Welfare Policy

Health Service Executive (2019) National Infant Feeding Policy for Maternity and Neonatal services

Health Service Executive (2019) National Infant Feeding Policy for Primary Care Teams and Community Health Organisations. Health Service Executive: Dublin.

Health Service Executive (2020) National Healthy Childhood Programme Child Health Assessment Manual for Registered Public Health Nurses

Health Service Executive (2025) Open Disclosure Policy

Health Service Executive (2020) Incident Management Framework and Guidance
National Institute for Health and Clinical Excellence (2021) *Guideline postnatal care of women and infants*. National Institute for Health and Clinical Excellence, London

Nursing and Midwifery Board of Ireland (2025) Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives

11.0 Glossary of terms

Abbreviations

ADA-SCID	Adenosine Deaminase Deficiency Severe Combined Immunodeficiency
ADOM/N	Assistant Director of Midwifery and/or Nursing
ADPHN	Assistant Director of Public Health Nursing
CF	Cystic Fibrosis
CGAL	Classical Galactosaemia
CHIS	Child Health Information System
CHO	Community Healthcare Organisation
CHR	Child Health Record
CHT	Congenital Hypothyroidism
DOM	Director of Midwifery
DON	Director of Nursing
DPHN	Director of Public Health Nursing
GA1	Glutaric Aciduria Type 1
GDPR	General Data Protection Regulations
GP	General Practitioner
HCU	Homocystinuria
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IHI	Individual Health Identifier
IHA	Integrated Healthcare Area
LHO	Local Health Office
MCADD	Medium Chain Acyl-CoA Dehydrogenase Deficiency
MSUD	Maple Syrup Urine Disease
MN-CMS	Maternal and Newborn Clinical Management System
NBS	Newborn Bloodspot Screening
NHCP	National Healthy Childhood Programme
NI	Northern Ireland
NIMS	National Incident Management System
NIRF	National Incident Report Form
NMBI	Nursing and Midwifery Board of Ireland
NN	Nursery Nurse
NNBSL	National Newborn Bloodspot Screening Laboratory
NNBSP	National Newborn Bloodspot Screening Programme
PCT	Primary Care Team
PHR	Personal Health Record
PKU	Phenylketonuria
PPPGs	Policies, Procedures, Protocols and Guidelines
RCN	Registered Children's Nurse
RGN	Registered General Nurse
RHA	Regional Health Area
RM	Registered Midwife
ROI	Republic of Ireland

RPHN	Registered Public Health Nurse
SCID	Severe Combined Immunodeficiency
SECM	Self Employed Community Midwife
SMA	Spinal Muscular Atrophy
TOR	Terms of Reference
UPI	Unique Perinatal Identifier

Definitions

Appropriate	Matching the circumstances, meeting the needs of the individual, groups or situation (NMBI, Glossary of Terms)
Consent	Consent is the giving of permission or agreement for a treatment, investigation, receipt or use of a service or participation in research or teaching. Consent involves a process of communication about the proposed intervention in which the person has received sufficient information to enable them to understand the nature, potential risks and benefits of the proposed intervention. Seeking consent should usually occur as an on-going process rather than a one-off event. (HSE National Consent Policy, 2022)
Infant	Applicable up to one year of age
Must	Commands an action a nurse of midwife is obliged to take where there is an absolute duty to comply with the principle and standard (NMBI, 2025)
Professional Judgment	A nurses professional judgment is based on the principles of responsibility, accountability and autonomy as outlined within their professional scope of practice (NMBI, 2025)
Referral	An act of referring someone for consultation, review or further action if the required intervention is outside the scope of practice of the nurse or midwife's competence to provide safe, quality care (NMBI, Glossary of Terms)
Should	Indicates the course of action that is generally best practice while acknowledging that another approach may be appropriate in certain circumstances, or that there may be factors outside their control that affect the ability to comply(NMBI, 2025)

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

12.0 Appendices

Appendix 1: Membership of Development Group

Membership for revision of HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP) Development Group	
Name	**Role and position**
Brenda Mellett	Director of Public Health Nursing, National Healthy Childhood Programme
Anne Lynott	Director of Public Health Nursing, Dublin West
Rachel McKevitt	Assistant Director of Nursing, Cavan/Monaghan
Angela Dunne	Director of Midwifery, National Women and Infants Health Programme
Margo Dunworth	Assistant Director of Nursing Neonatal, National Women and Infants Health Programme
Chairperson: Paul Marsden	Programme Manager, National Healthy Childhood Programme Screening Programmes

This revision to the HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme was formally ratified and recorded in the minutes of the NNBSP Operational Group on 27th February 2026. The national procedure was then submitted for approval and sign off.

Appendix 2: Membership of Approval Governance Group

Membership of HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP) **Approval Governance Group**	
Name	**Role and position**
Dr Abigail Collins (on behalf of the NNBSP Operational Governance Group)	National Clinical Lead Child Health Public Health

Sign-off by Chair of Approval Governance Group

Name: (print)	**Dr Abigail Collins**
Title:	**National Clinical Lead Child Health Public Health**
Signature: **(e-signatures accepted)**	
Registration number: (if applicable)	**MCRN 404629**

Appendix 3: Conflict of Interest Declaration Form

CONFLICT OF INTEREST DECLARATION FORM

This form must be completed by each member of the Development Group.

Title of National document: HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP)

Please indicate the statement that relates to you

I declare that **I DO NOT** have any conflicts of interest ☐

I declare that **I DO** have a conflict of interest ☐

Details of conflict (please refer to specific National 3PG)

(Append additional pages to this statement if required)

Signature:

Print name:

Registration number (if applicable):

Date:

The information provided will be processed in accordance with data protection principles as set out in the Data Protection Act. Data will be processed only to ensure that Development Group act in the best interests of the members. The information provided will not be used for any other purpose.

A person who is covered by this National document* is required to furnish a statement, in writing, of:
(i) The interests of the person, and

(ii) The interests, of which the person has actual knowledge, of his or her spouse or civil partner or a child of the person or of his or her spouse which could materially influence the person in, or in relation to, the performance of the person's official functions by reason of the fact that such performance could so affect those interests as to confer on, or withhold from, the person, or the spouse or civil partner or child, a substantial benefit.
*policy, procedure, protocol or guideline.

Appendix 4: Implementation plan template

National Document Title: HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP)
Expected date of full implementation:This is a revision of a national procedure that has already been implemented. Effective date: 13/04/2026

Implementation lead/role: Programme Manager, National Healthy Childhood Programme Screening Programmes

IMPLEMENTATION ACTION	Implementation barriers / enablers	List of tasks to implement the action	Lead responsibility for delivery of the action	Expected completion date	Expected outcomes
Disseminate approved revision document to all relevant staff	Electronic Policy Portal in use in all areas Will be available on HSE National PPPG Repository	Circulate to all DPHNs/DOMS/DONs and cc relevant RHA/IHA contacts	Programme Manager	After approval date for SCID and SMA from HSE Senior Leadership Team	The revised procedure will be available for use across the PHN and midwifery services nationally
		Inform DPHN and DOM forum of this revised version	Programme Manager	After approval date for SCID and SMA from HSE Senior Leadership Team	The revised procedure will be available for use across the PHN and midwifery services nationally

Education / training required to implement the National document:

This national procedure is already in place and this is a revision. The HSE LanD training module on newborn bloodspot screening will be updated to refer to this updated revision of this national procedure.

Adapted from National Clinical Effectiveness Committee (NCEC) Implementation Guide and Toolkit (Department of Health 2018)

Appendix 5: National Audit Tool

Audit tool for the HSE National Procedure for all staff providing the National Newborn Bloodspot Screening Programme (NNBSP)

Methodology:
Population: A sample of child health records to be included from each DPHN area/maternity hospital/unit
Sampling: A total of 10% or 10 target users, whichever is greater, should be selected.
Frequency: To be determined locally at least annually.
Method: Record **Y** for **Yes**, if the criteria are met. Record **N** for **No**, if criteria are not met or **N/A** for **Not applicable**.
Compliance requirement: 100%

Is standard/criteria being met for the following statements:	**Yes**	**No**	**N/A**	**Evidence**
The Development Group should identify the core statements that should be audited at least annually.				
Statement 1 Is the parent/guardian signature of consent completed on the NBS card				
Statement 2 Is there documented evidence that the bloodspot sample was taken in the record				
Statement 3 Is there documented evidence of posting of the newborn bloodspot screening in the record				
Statement 4 Has the sample taker evidence that they have completed the HSE LanD eLearning module?				

Date of Audit:
Audited by (name/title):
Compliance Rate %:

Calculation of Compliance Rate %:
The score, expressed as a percentage, is calculated by dividing the number of “yes” and “no” answers. “Not applicable” answers are excluded from the calculation of the percentage score.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Appendix 6: Checklist

[Completion of the Checklist is the responsibility of the chairperson of the Development Group]

Checklist for Best Practice in Developing HSE National 3PGs

Stage 1	**Deciding the need**	
1.	Aligned with HSE National Priorities	☒
2.	Clearly defined document type (P,P,P or G)	☒
3.	Approval obtained to develop	☒
Stage 2	**Planning**	
4.	Governance clearly established	☒
5.	Appropriate stakeholder involvement	☒
6.	Defined in-scope and out-of-scope	☒
7.	Development Group (terms of reference/conflict of interest forms)	☒
Stage 3	**Development**	
8.	Evidence methodology based	☒
9.	Creation of guidance / recommendations	☒
10.	Explicit link between the evidence to guidance / recommendations	☒
11.	Circulated for national consultation/independent expert review (as required)	☒
12.	Audit Tool developed	☒
Stage 4	**Implementation**	
13.	Implementation plan completed / Team established	☒
14.	Communication and dissemination plan developed	☒
15.	Supports: advice, tools, resources developed and where to access	☒
Stage 5	**Sustainability**	
16.	Monitoring and Audit Plan outlined	☒
17.	Audit outcomes: structure in place to link to quality improvement and risk management processes	☒
Document Control		
18.	Mandatory pages 1+2 of this template are fully completed.	☒

I confirm that all of the above key activities have been met: ☒

Chairperson name: Paul Marsden **Title: Programme Manager**

Signature: (e-signatures accepted)

Registration number:
(if applicable)

Date: 27/02/2026

Submit this Checklist with your final National document to the Document Approver.

Appendix 7: Regional Health Areas and Integrated Healthcare Areas

Region	CHO	IHA	LHO
HSE Dublin and North East	**1**	Cavan/Monaghan	Cavan/Monaghan
	8	Louth/Meath	Louth
			Meath
	9	Dublin North City and West	Dublin North West
			Dublin North Central
		Dublin North County	Dublin North
HSE Dublin and Midlands	**7**	Dublin South City and West	Dublin South City
			Dublin West
		Dublin South West	Dublin South West
		Kildare/West Wicklow	Kildare/West Wicklow
	8	Midlands	Laois/Offaly
			Longford/Westmeath
HSE Dublin and South East	**5**	Carlow Kilkenny and Tipperary South	Carlow/Kilkenny
			Tipperary South
		Waterford Wexford	Waterford
			Wexford
	6	Dublin South and Wicklow	Dublin South East
			Dun Laoghaire
			Wicklow
HSE South West	**4**	Cork North and East	North Lee
			North Cork
		Kerry	Kerry
		Cork South and West	West Cork
			South Lee
HSE Midwest	**3**	Limerick City and Tipperary North	Tipperary North/East Limerick
		Clare and Limerick County	Clare
			Limerick
HSE West and North West	**1**	Donegal	Donegal
		Sligo Leitrim	Sligo/Leitrim/West Cavan
	2	Mayo	Mayo
		Galway Roscommon	Galway
			Roscommon

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Appendix 8: Maternity Hospital/Unit Unique Perinatal Identifier (UPI)

What is the Unique Perinatal Identifier (UPI)

From 1st July 2011 each infant born in Ireland will be issued with an individual (unique) identifying number to ensure that newborn bloodspot screening samples can be traced throughout the screening process.

Why is the UPI being introduced now?

This date has been chosen to coincide with the introduction of newborn screening for Cystic Fibrosis (CF) on 1st July 2011. CF screening will be added to the conditions for which screening already takes place through the 'heel-prick' method and will be carried out on the same bloodspot sample.

How will the UPI be issued?

The UPI will be formed by the 3 digit hospital HIPE code (see list of maternity hospitals/units below) of the birth hospital followed by the healthcare record number (HCRN) of the infant.

Will an infant who is not born in an Irish Maternity Hospital/Unit receive a UPI?

Infants born either at home or in a maternity hospital/unit outside Ireland will be issued a UPI by the Director of Public Health Nursing in the area in which their birth is registered following notification of birth.

How will the UPI work?

The number will be used on all information relating to the National Newborn Bloodspot Screening Programme (NNBSP) including the following:

- On all newborn bloodspot screening cards sent to the National Newborn Screening Laboratory in the CHI Temple Street including repeat samples
- On maternity hospital/unit newborn bloodspot screening registers
- On requests from maternity hospital/unit to public health nursing services to undertake newborn bloodspot screening
- On requests from maternity hospitals/unit to a tertiary paediatric hospital to undertake newborn bloodspot screening on infants transferred prior to completion of the NNBSP
- On DPHN/IHA newborn bloodspot screening registers
- On NNBSL reports of result via eReports
- On all notifications of births from maternity hospitals/units to DPHN/IHA community health services.

The newborn bloodspot screening cards have been modified to include a space for UPI.

HIPE Code	Maternity Hospital / Unit
201	Midland Regional Hospital Portlaoise
202	Midland Regional Hospital Mullingar
301	University Maternity Hospital Limerick
402	Cavan General Hospital
500	Letterkenny University Hospital
501	Sligo University Hospital
600	University Hospital Waterford
601	St Luke's General Hospital Kilkenny
605	Wexford General Hospital
607	Tipperary University Hospital
724	Cork University Maternity Hospital
726	University Hospital Kerry
800	University Hospital Galway
802	Mayo University Hospital
919	Portiuncula University Hospital
922	Our Lady of Lourdes Hospital Drogheda
930	The Coombe Hospital
931	National Maternity Hospital Holles Street
932	Rotunda Hospital Dublin

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Appendix 9: DPHN/IHA Unique Perinatal Identifier (UPI)

Unique Perinatal Identifier (UPI) for non-Irish hospital births.

The first 3 digits of the UPI for non-Irish hospital births will be as follows:

L01	Dublin Area 1
L02	Dublin Area 2
L03	Dublin Area 3
L04	Dublin Area 4
L05	Dublin Area 5
L06	Dublin Area 6
L07	Dublin Area 7
L08	Dublin Area 8
L09	Wicklow
L10	Kildare
L11	Louth
L12	Meath
L13	Cavan
L14	Monaghan
L15	Longford/Westmeath
L16	Laois/Offaly
L17	Wexford
L18	Waterford
L19	South Tipperary
L20	Carlow/Kilkenny
L21	Cork South
L22	Cork North
L23	Cork West
L24	Kerry
L25	Limerick
L26	Clare
L27	Tipperary North/East Limerick
L28	Galway
L29	Roscommon
L30	Mayo
L31	Sligo/Leitrim
L32	Donegal

The remaining digits of the identifier will then commence with the year (i.e. 2011 followed by a unique 4 digit number given by the LHO (e.g. 0001 for the first non-Irish hospital birth notified each year, 0002 for the second).

These will be allocated by the DPHN (or her/his nominee) and recorded in a file held locally (either electronically or in a manual file).

- Therefore the third infant recorded in such a manner in Dublin Area 5 in 2012 would have the following UPI **L05 20120003**
- The third infant recorded in such a manner in Longford/Westmeath in 2012 would have the following UPI **L15 20120003**

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Appendix 10: Information for parents and guardians



The information for parents and guardians leaflet is available in a number of languages for download at:
https://www2.hse.ie/conditions/heel-prick-screening/about/

Hard copies of the information for parents and guardians leaflet are available in English only from www.healthpromotion.ie

Appendix 11: Newborn bloodspot screening card parent information

Information for Parent/Legal Guardian

Newborn bloodspot screening (heel-prick) helps identify babies who may be at high risk of having a rare but serious condition. Most babies who are screened will not have any of the conditions. But for the small number of babies who do, the benefits of screening are enormous.

Early treatment can improve health and prevent disability or early death. Unfortunately, there are limitations to screening. Not all cases are detected by newborn bloodspot screening.

You are asked to sign the newborn bloodspot screening card to confirm that:

- the information about your baby is correct, and
- you consent to the screening.

The newborn bloodspot screening card is sent for analysis to the National Newbom Bloodspot Screening Laboratory at Children's Health Ireland (CHI).

Depending on the screening result, your baby's sample may need to be sent for a further test. This test is also to check for a condition included in the newborn bloodspot screening programme. This completes the screening process.

A public health nurse or midwife may contact you about taking a second blood sample. This may be because not enough blood was collected or because the result was not clear.

After screening, the blood sample may be used:

- for checking your baby's results or for other tests that your doctor recommends – you will be asked for permission first
- for quality assurance purposes and to help improve the screening programme. In this event all samples will be completely anonymised. It will not be possible to trace any results back to an individual child.

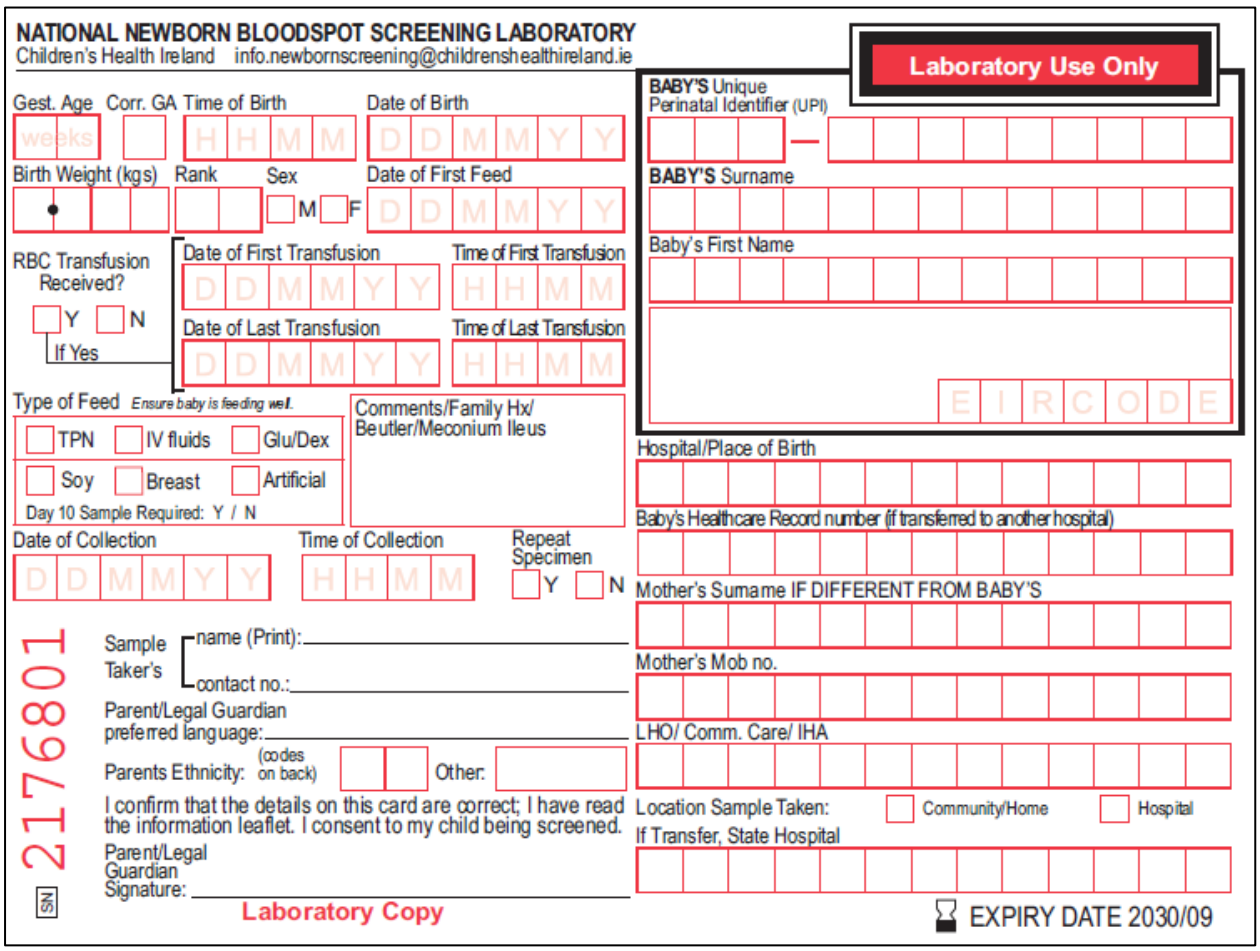
If you would like a copy of the screening results, please ask your public health nurse.

You can find more information on the newborn bloodspot screening programme in the information leaflet for parents or by visiting www2.hse.ie/conditions/heel-prick-screening

The newborn bloodspot screening card and results are stored securely as part of your baby's health record by the National Newborn Bloodspot Screening Laboratory. The card will be stored securely for at least 10 years. After this time the card will be destroyed as part of current policy.

We strongly recommend that all babies have newborn bloodspot screening. If you do not want your baby screened, you should speak with your public health nurse or midwife. You will be asked to sign a different form.

Appendix 12: Newborn bloodspot screening card



Appendix 13: Patient details amendment form

Children's Health Ireland at Temple Street, Department of Paediatric Laboratory Medicine

LF-NNS-0137 PATIENT DETAILS AMENDMENT FORM EDITION 5

This form is to amend incorrect details recorded by the laboratory or supplied by sample taker and/or to confirm information to complete babies' newborn screen details and comply with GDPR regulations gathering only minimum required demographics and sampling details

Lab sample no:

Baby's surname:

DOB:

Baby's Unique Perinatal Identifier:

Address:

Hospital of birth:

For the amendment to be accepted, it must be clearly stated below the changes to be made

Dear NNBSL please amend the following details on baby noted above:

Signed by: **PRINT NAME:**

Position: Phone no:

Please forward to secure email
info.newbornscreening@childrenshealthireland.ie

NOTE: If attaching additional documentation please ensure it only contains required information on baby, not on parent(s) e.g. birth notification as not appropriate to share outside Maternity unit. All documents received will be attached to patient record and stored permanently.

Lab use only

Source of change: Lab/LHO/Maternity unit (please circle)

Details checked on LIMS: Disclaimer added:

Sample quality checked: Results reviewed:

Amended by: PC action complete:

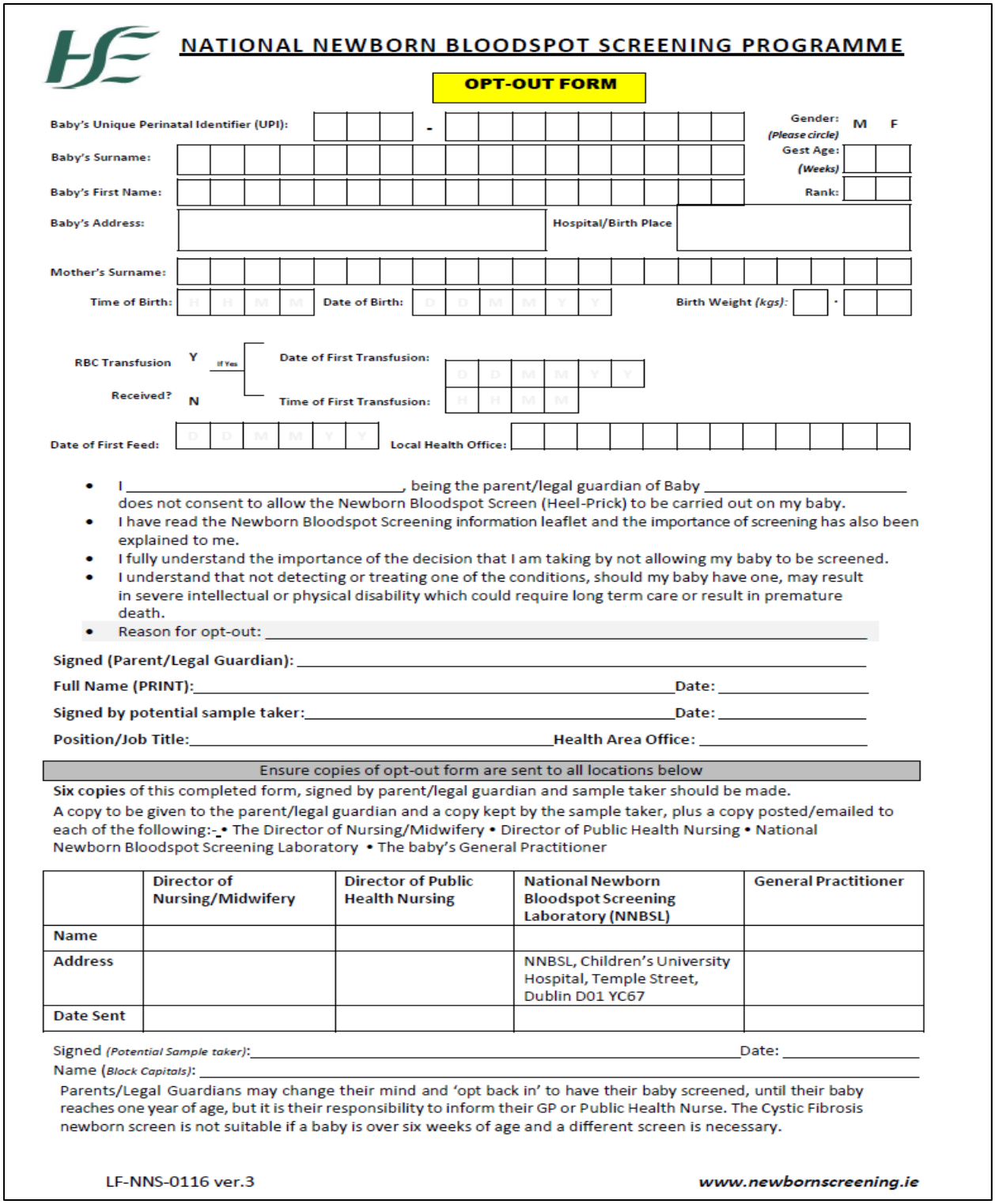
Sign:

Page 1 of 1

Author: Méabh Mac Manamon Ref: LP-NNS-0047 & NNS264 Date of issue: 13/10/2026

Authoriser: Loretta O'Grady

Appendix 14: NNBSP Opt-out form



NATIONAL NEWBORN BLOODSPOT SCREENING PROGRAMME

OPT-OUT FORM

Baby's Unique Perinatal Identifier (UPI): ___ - ___

Gender: M F *(Please circle)*

Baby's Surname:

Gest Age: *(Weeks)*

Baby's First Name:

Rank:

Baby's Address:

Hospital/Birth Place

Mother's Surname:

Time of Birth: H H M M Date of Birth: D D M M Y Y Birth Weight *(kgs)*: .

RBC Transfusion Received? Y *If Yes* N

Date of First Transfusion: D D M M Y Y

Time of First Transfusion: H H M M

Date of First Feed: D D M M Y Y Local Health Office:

- I _____, being the parent/legal guardian of Baby _____ does not consent to allow the Newborn Bloodspot Screen (Heel-Prick) to be carried out on my baby.
- I have read the Newborn Bloodspot Screening information leaflet and the importance of screening 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 screened.
- I understand that not detecting or treating one of the conditions, should my baby have one, may result in severe intellectual or physical disability which could require long term care or result in premature death.
- Reason for opt-out: _____

Signed (Parent/Legal Guardian): _____

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

Signed by potential sample taker: _____ **Date:** _____

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

Ensure copies of opt-out form are sent to all locations below

Six copies of this completed form, signed by parent/legal guardian and sample taker should be made.

A copy to be given to the parent/legal guardian and a copy kept by the sample taker, plus a copy posted/emailed to each of 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 (NNBSL)	General Practitioner
Name				
Address			NNBSL, Children's University Hospital, Temple Street, Dublin D01 YC67	
Date Sent				

Signed *(Potential Sample taker)*: _____ Date: _____

Name (*Block Capitals*): _____

Parents/Legal Guardians may change their mind and 'opt back in' to have their baby screened, until their baby reaches one year of age, but it is their responsibility to inform their GP or Public Health Nurse. The Cystic Fibrosis newborn screen is not suitable if a baby is over six weeks of age and a different screen is necessary.

LF-NNS-0116 ver.3 ***www.newbornscreening.ie***

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Appendix 15: National Newborn Bloodspot Screening Laboratory Contact Details

Laboratory: 01 878 4277 or 01 878 4610 CHI at Temple St., Dublin, DO1 YC67 The laboratory will in time move to the new paediatric hospital adjacent to St James Hospital, Dublin 8. **Email**: info.newbornscreening@childrenshealthireland.ie **Website**: https://www2.hse.ie/conditions/heel-prick-screening/
Clinical Liaison Nurses based in the NNBSL, CHI: 01 892 1804
National Centre for Inherited Metabolic Disorders (NCIMD) : 01 878 4317 CHI at Temple St., Dublin, DO1 YC67 for advice on metabolic disorders
National Healthy Childhood Programme (NHCP) contact details: Email: child.screening@hse.ie Website: www.mychild.ie

Day	Opening hours	Services provided
Monday-Friday	09.00-17:00	All screens including Beutler tests, reporting of results and Clinical Liaison Nurse (CLN) service.
Saturday and Bank Holiday Monday Sunday-closed	09:00-12:30	**Beutler test -** high risk screen for Classical Galactosaemia Beutler samples must be in laboratory before 10 am. The test takes approx. 2.5hrs and all maternity units are phoned with results. To facilitate phoning of results, please note contact number on screening cards where results are to be phoned to.
NOTE: Christmas and New Year period opening hours will be circulated in advance.		

Appendix 16: Newborn bloodspot screening card checklist

Children's Health Ireland, Department of Paediatric Laboratory Medicine
LF-NNS-0111 NNBSL Screening Card Checklist EDITION 2

IMPORTANT – Ensure Samples are Dry, Envelopes Sealed and No Lancets Enclosed

Location:		**Contact No.:**
Total number of cards:	**Date Posted:**	**Checked by:**

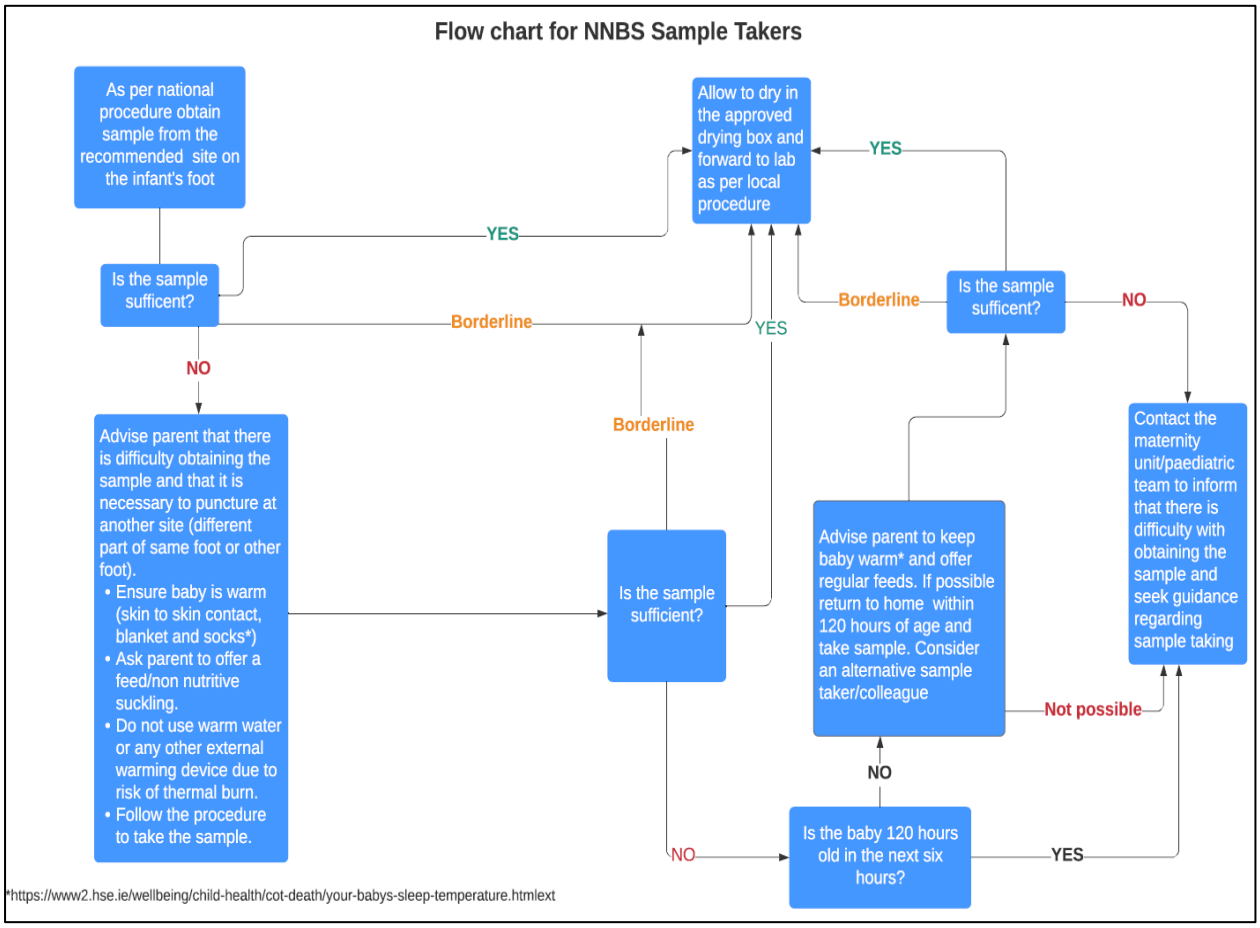
Baby's Surname (as on card)	**Baby's UPI (as on card)**	**Additional Comment** *if relevant*
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		
15.		
16.		
17.		
18.		
19.		
20.		
21.		
22.		

This form should be included in all envelopes containing more than one screening card
National Newborn Bloodspot Screening Laboratory, CHI, Temple Street, Dublin 1, D01 YC67
Ph: 01 8784610 /01 878 4277

For office use only - checked by: _____

Page 1 of 1
Author: Sophie Murphy Ref: LP-NNS-0001 Date of issue: 27/05/2025
Authoriser: Loretta O'Grady

Appendix 17: Flow chart for newborn bloodspot screening sample takers



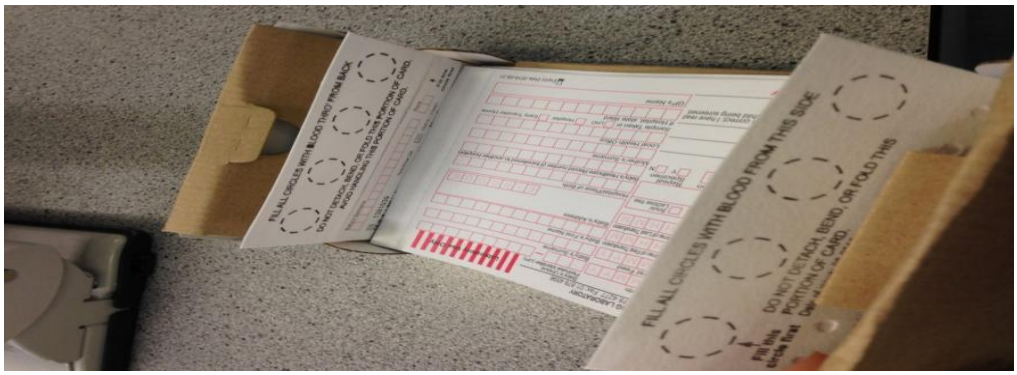
Appendix 18: Transport/drying box – procedure for transporting samples



Transport/Drying Boxes

- The National Newborn Bloodspot Screening Laboratory has designed drying/transport boxes in conjunction with Mega Pak to facilitate the transport of NBS cards from the infant's home to the PHNs car in a safe manner. Once the bloodspot has dried, the NBS card should be removed from the box and packaged according to the regulations. These drying boxes can hold two NBS cards.
- The boxes are reusable. However, if they become contaminated with blood they should be disposed of either by incineration or through the accepted procedure for disposable of hazardous waste.
- These boxes can be ordered directly from Mega Pak Ltd by the Public Health Nursing Department – order reference is TEMPLE03C. The minimum order is 1 pack of 50 boxes, flat packed, from Mega Pak Ltd (Irish Office), 16 Highfield Green, Swords, Co Dublin. Tel: 01 8402063, email vhalhedmoran@mega-pak.com, website www.mega-pak.com

Drying box for two NBS cards: top and tail samples, blood spots should not come in contact.



Procedure for transporting samples

The sender of NBS cards by registered post or by courier is responsible for ensuring that the packaging and transportation of the sample complies with current transport regulations regarding Health and Safety as laid down in the European Directive (ADR 2015) Packaging Regulations P650.

Dried bloodspots must be packaged appropriately. NNBSL recommends that once the blood has dried, the NBS card(s) should be inserted into a water-resistant, tear-proof Tyvek® envelope or equivalent. The yellow fluorescent address label should be fixed to the outer envelope.

Pre-printed registered envelopes

Pre-addressed printed registered waterproof envelopes may be purchased directly from An Post by e-mailing customer care using a locally generated HSE purchase order number.

Responsibility of sender

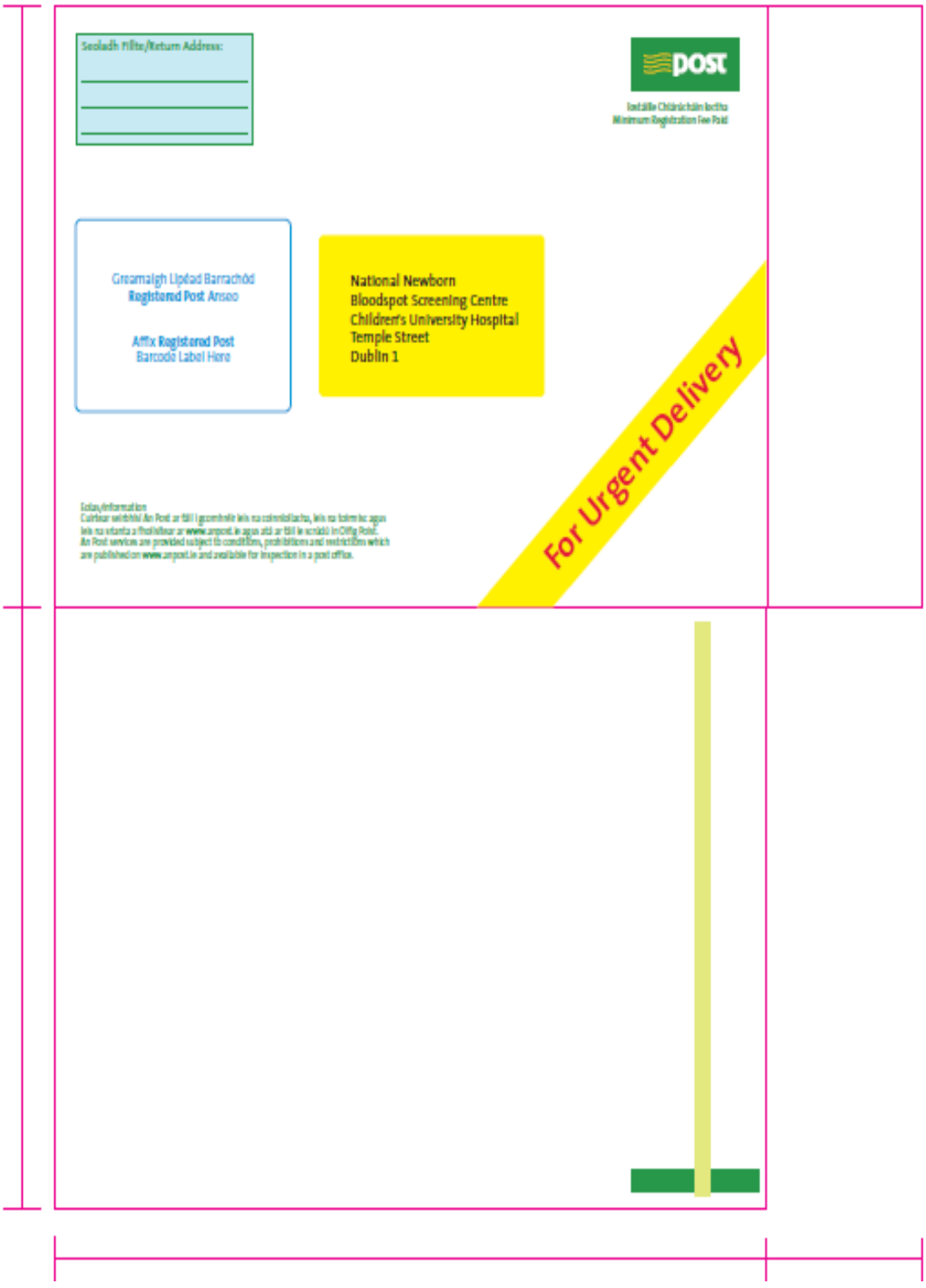
If more than one NBS card is put in an envelope, they should be placed at 180° to each other (i.e. the bloodspots should not overlap and therefore not touch). The sender should state in writing how many NBS cards are in each envelope and include a list of the names of the infants on a separate page, a sample checklist (Appendix 16) is available to download from www.newbornscreening.ie or by contacting the NNBSL or child.screening@hse.ie.

NBS cards, appropriately packaged, should be sent daily and not batched. It is the responsibility of the sender to dispatch the sample as soon as possible after collection, either by registered post or by courier. It is not appropriate to put the package into the post knowing that there may be a delay in it arriving at the NNBSL due to either a postal dispute (local or national) or over the Christmas period when the post may be delayed. Alternative arrangements should be made by maternity hospitals/units and DPHNs to ensure NBS cards are dispatched to NNBSL without delay.

Parents should never be asked to post or deliver NBS cards to the NNBSL. This is the responsibility of the sample taker.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

Appendix 19: Waterproof and tear proof envelope for registered post



Appendix 20: NNBSL – newborn bloodspot screening result request form

Children's Health Ireland, Temple Street, Department of Paediatric Laboratory Medicine

LF-NNS-0046 COPY RESULT REQUEST FORM EDITION 6

N.B.: Forms only accepted from head office locations. Email to info.newbornscreening@childrenshealthireland.ie

****ALL RESULTS REQUESTED BY THE COMMUNITY SHOULD BE DONE SO THROUGH THEIR LIAISON HEAD OFFICE & WILL BE RETURNED TO THE SAME, WE CANNOT SEND RESULTS DIRECTLY TO INDIVIDUAL PHNs OR HEALTH CENTRES.****

No.	Baby Surname	Mother Surname	Baby DOB	Baby Forename	Mother Forename	Address at Birth	Hospital of Birth	Unique Identifier (UPI)	NNBSL Office Use/Comments
1									
2									
3									
4									
5									

Ensure **e-reports have been checked** prior to sending this form.

Requested by: _____ **Address:** _____ **Tel No.:** _____

Issued by (NNBSL use only): _____ **Date** (NNBSL use only): _____

Page 1 of 1

Author: Sophie Murphy Ref: LP-NNS-0047 Date of issue: 27/05/2025

Authoriser: Loretta O'Grady

Appendix 21: Informing NNBSL of reports received that do not belong to DPHN/IHA

Please complete details of this form:
For infants on whom you have received reports who do not belong to your Area
Return the Form to NNBSL. Please indicate correct LHO (if known).
Please email or FAX (on headed paper) to NNBSL as soon as possible

Location (LHO):	**Date:**
Reported By: (Print name and provide signature)	**Position:**

UPI	Lab Number	Infant's Surname	Infant's First Name	Date of Birth	Mothers Surname	Old Address	New Address	Correct LHO (if known)

Comment:

Appendix 22: Individual bloodspot results – print out example

National Newborn Bloodspot Screening Laboratory

An INAB accredited testing Laboratory Reg. No.374MT

Children's Health Ireland at Temple Street, D01 YC67

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Tel: 01 878 4277 Fax: 01 878 4596 Email: info.newbornscreening@cuh.ie: www.newbornscreening.ie

Newborn Bloodspot Screening Report **Report date:** 11/01/2022

Location: Paediatric OPD Rotunda Hospital (RH)

Baby Details

Name:	**TEST SAMPLE, TEST SAMPLE**	**UPI:**	**932-H0000000** **Sex:** Male
Mother's Surname:			
Address:	123 TEMPLE ST, DUBLIN 1, D01 YC67		
DOB:	**01/12/2021**	**Lab number:**	22-001001
Date of collection:	05/12/2021	**Time of collection:**	14:00
Date received:	06/12/2021	**Sample type:**	Initial

Sample taker name: MARY SMYTH **Contact number:** 01 8784200

Location sample taken: Hospital place of birth

Screening results

Condition	Result	Result Codes NNBSL	HSE
GA1 (Glutaric aciduria type 1)	Not Suspected	N	2
MCADD (Medium-chain acyl-CoA dehydrogenase deficiency)	Not Suspected	N	2
PKU (Phenylketonuria)	Not Suspected	N	2
HCU (Homocystinuria)	Not Suspected	N	2
MSUD (Maple Syrup Urine Disease)	Not Suspected	N	2
GAL (Classical Galactosaemia)	Not Suspected	N	2
CHT (Congenital Hypothyroidism)	Not Suspected	N	2
CF (Cystic Fibrosis)	Not Suspected	N	2

Appendix 23: Procedure for infants who have missed the newborn bloodspot screening for cystic fibrosis

Children who have missed the 72-120 hour window for newborn bloodspot screening for logistical or other reasons (e.g. clinical condition, lost screening card, mix up in identification, etc.) can have the bloodspot repeated for immunoreactive trypsinogen (IRT) up to six weeks of age (day 42 of life). This applies to premature infants as well as term infants.

Beyond six weeks of age the IRT values are not interpretable with respect to cystic fibrosis (CF) newborn bloodspot screening (NBS) and a bloodspot screening sample should **not** be taken for the purpose of newborn bloodspot screening (NBS) for CF.

Infants and children greater than six weeks of age who were not screened, or where issues with the sample, or testing resulted in no result for CF NBS available in the correct timeframe, should have a sweat test performed. This approach is applicable up to one year of age to align it with the upper age limit for repeating newborn bloodspot screening for the other conditions (not CF) in the newborn bloodspot screening programme.

Parents who opt out of screening initially and decide to opt in at a later date, providing the child is under one year of age at the time of opt in will have a sweat test performed to complete the screening process. If the child is over one year of age at the time of opt in, no sweat test will be offered unless there are clinical suspicions to warrant same.

The sweat test should be performed in one of the six HSE designated specialist CF centres involved in accepting infants for assessment as per the CF NBS programme. The six centres are:

- Children's Health Ireland, Crumlin
- Children's Health Ireland, Temple Street
- Tallaght University Hospital
- University Hospital Galway
- University Hospital Limerick
- Cork University Hospital

The following steps should be undertaken:

1. The individual aware of, or concerned that, a child has not been screened for CF as part of the newborn bloodspot screening programme should inform the National Newborn Bloodspot Screening Laboratory (NNBSL) in the Children's Health Ireland, Temple Street, Dublin.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

2. The NNBSL should collect the relevant details of the infant involved, and the details of why screening was missed, and then contact the specialist CF centre (based on the geographic catchment areas covered by the CF NBS programme) to request a sweat test.

3. The NNBSL will contact the designated newborn bloodspot screening liaison person in the Maternity Unit/Hospital in which the infant was born to inform them that the infant has not been screened to date and that a newborn bloodspot screen is required for all other conditions on the screening programme and a sweat test should be performed to out rule CF.

   The Clinical Liaison Officer in the NNBSL will contact the newborn bloodspot liaison person in the Maternity Unit/Hospital to obtain parent and infant information and to inform them that the infant has not been screened to date.

4. PLEASE NOTE: If the infant was **NOT** born in a maternity unit in Ireland (e.g. a home birth, or an infant born outside the Republic of Ireland) then the NNBSL does **NOT** contact the newborn bloodspot screening liaison person in the Maternity Unit/Hospital, but links directly with the Assistant Director of Public Health Nursing (ADPHN) and the CF specialist centre, to make the arrangements outlined below.

5. The Clinical Liaison Officer in the NNBSL will contact the relevant ADPHN based on the family's address, to inform them that the newborn bloodspot screening is required for all the other conditions on the newborn bloodspot screening programme (if not already screened) and a sweat test should be performed to out rule CF.

6. The newborn bloodspot screening liaison person in the Maternity Unit/Hospital or ADPHN/Public Health Nurse (PHN) will inform the parents that the sweat test needs to be done and explain why. It will be made clear that the Public Health Nurse (PHN) will take the newborn bloodspot screening sample for all the other conditions on the newborn bloodspot screening programme (with the exception of CF) and the specialist CF centre will contact them to arrange the sweat test. It is also advisable that the PHN provides the parents with the contact details for the Clinical Liaison Officer in the NNBSL.

7. Contact with the specialist CF centre should use the existing lines of communication for the CF newborn bloodspot screening programme; i.e. a

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.

telephone call to the CF Clinical Nurse Specialist (CNS) followed by faxed written details.

8. The NNBSL will provide the specialist CF centre with the ADPHN contact details.

9. It is important that the parents have been informed by the PHN or Maternity Unit/Hospital that a sweat test needs to be performed PRIOR to the parents been contacted by the CF CNS.

10. The CF CNS will organise a sweat test and review by a CF Consultant as per the usual procedure for the CF NBS programme.

11. The specialist CF centre will provide the results to the NNBSL as soon as they are available.

12. The NNBSL will report the results of the CF screen via eReports once the sweat test result is available from the CF centre.

13. The NNBSL will inform the individual who highlighted the case that the infant has been assessed and will inform the Maternity Unit/Hospital and the DPHN in that area via eReports.

The procedure as described above does not apply to infants who had newborn bloodspot screening performed in another country which did not include screening for CF, and then moved to Ireland at a later date. These children should not be screened for CF, but should have a sweat test performed only if clinically indicated, such as if they develop clinical features, or have a strong family history, of CF.

This is a controlled document and must always be accessed from the HSE National Central Repository. Whilst printing is permitted, printed copies are not controlled. Controlled documents must never be saved to secondary electronic/other locations which are accessible by staff or the public.