

Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

Procedure Responsibilities and Authorisation

Department Responsible for Procedure	Neonatal Intensive Care Unit (NICU)
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Target Audience	Health care professionals caring for newborns
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Procedure Review History

Version	Updated by	Date Updated	Description of Changes
1	Nadia Cooper	October 2016	First version
2	Richard Pagdanganan	November 2019	Due for review
3	Hayley Clark	November 2022	3-yearly review
4	Hayley Clark	January 2024	Revised collection time
4.1	Karlena Best	June 2024	Preterm testing schedule changes

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Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

1. Overview

1.1 Purpose

To ensure safe and accurate collection of the newborn metabolic screening test, in the NICU environment, in compliance with the Ministry of Health.

The test screens for 20 rare but potentially serious conditions.

The current conditions screened for include:

- amino acid disorders (e.g., phenylketonuria (PKU) and maple syrup urine disease)
- fatty acid oxidation disorders (e.g., MCAD)
- congenital hypothyroidism
- cystic fibrosis
- congenital adrenal hyperplasia
- galactosaemia
- biotinidase deficiency
- severe combined immunodeficiency (SCID)

1.2 Staff group

Health care professionals caring for newborns within the hospital and community including:

- Registered Nurse (RN)
- Enrolled Nurse (EN) under the direction and delegation of an RN
- Midwife/Lead Maternity Carer (LMC)
- Neonatal Nurse Practitioner (NNP)/Doctor

Allied Health for additional roles: Department Receptionist

1.3 Patient / client group

All Newborn infants admitted to Health New Zealand facilities.

1.4 Exceptions / contraindications

Parents decline screening

If parents have been well informed and declined newborn screening, fill in the testing card with details, document on it that screening is declined and send the card without the blood. Ensure that parents are aware that testing can be completed later if they change their mind, though ideally between 24-72 hours after birth, and who to contact in this instance.

Document discussion in clinical notes and inform medical team.

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1.5 Definitions

Guthrie	Alternative name for the Newborn Metabolic Screening (preferred). Guthrie's test refers to the original inventor of the newborn metabolic screening Robert Guthrie.
Metabolic disease	A group of disorders where any of a variety of metabolic pathways can malfunction, at any point in the pathway, resulting in disrupted protein delivery and production and preventing normal body function.
National Screening Unit (NSU):	The governing and regulating body for newborn metabolic screening in New Zealand which functions under the Ministry of Health
Newborn metabolic Screening-NMS	A New Zealand health initiative to ensure early diagnosis of newborn with a range of metabolic diseases and SCID This promotes early treatment and management for rare, but treatable, diseases and prevents and/or minimises morbidities and mortality.
NTC	Newborn testing card
PKU	Alternative name for the Newborn Metabolic Screening – (preferred) Phenylketonuria is an inborn error of metabolism that results in decreased metabolism of the amino acid phenylalanine. Untreated, PKU can lead to intellectual disability, seizures, behavioural problems, and mental disorders. It was the first metabolic disorder able to be screened for.
SCID	Severe combined immune deficiency

1.6 Roles and Responsibilities

RN/EN/LMC/Midwife

- Obtain informed consent.
- Collect samples and ensure correct details are documented on the test card.
- Complete relevant documentation.

Receptionist - NICU

- Receptionist enters the details in the NICU PKU book and fills in all available details on the newborn testing card (NTC) stamp 'VAN84'
- Place stamp in patient's clinical notes for bedside nurses to complete once sample is collected.
- NTCs are given to the bedside nurse or put at the bedside on the morning the sample is due.
- Completed and dried cards are collected from the office collection bag. Details are checked including collection date in PKU book.
- Put collected cards in envelope place the purple address sticker on and **send NTC cards to the laboratory via the Lamson no later than 0900 every day** to ensure that cards are sent promptly via courier to the testing laboratory. This ensures that all samples are sent within 24 hours of being collected.

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- The date & time the sample was sent to laboratory is recorded in the PKU book next to the Baby's NHI

Laboratory process

- All envelopes with the purple label received via the Lamson, prior to 0930, are included in the once a day 'sendaway' specimen batch on the Sub-60 Courier to LabPLUS on job number #269
- Waikato laboratory 'sendaway' team receives confirmation that LabPLUS has received the 'sendaway' package. If it is not received this allows for identification of which blood spot cards were sent on that day so re-collection can be arrange.

2. Clinical Management

2.1 Competency required

- Registered Nurse/Midwife who has completed education on appropriate sample collection
- Enrolled Nurse who is under the direction and delegation of an RN and has completed education on appropriate sample collection

2.2 Equipment

- NSU screening pamphlet "Your Newborn Baby's Blood Test." (See section 2.1 Associated Documents for link).
- Blood sample collection equipment: refer to NICU service specific nursing procedure
- [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352)
- Newborn test card (NTC) (beige for postnatal, blue for NICU).
- Documentation:
- Receptionist to fill in the initial details in the NICU specific PKU book.
- Nurses to document date/time of collection in the following locations: NTC stamp in clinical notes, Neonatal Problem Sheet (green), NICU Admission Form (yellow), Well Child Book and NICU PKU Book.
- Reception staff to countercheck documentation in the NICU PKU book upon receipt of NTC card

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2.3 Procedure

2.3.1 Consent

Newborn metabolic screening requires informed verbal consent from a parent/guardian prior to testing. Nurses are responsible for consenting parents in NICU.

Generally an LMC will have discussed the test with the parents in antenatal care, unless in the case of preterm delivery. However, provide parents with the “Your Newborn Baby’s Blood Test” NSU pamphlet and clarify their understanding.

There are two parts to consent:

- a) Parents consenting for their baby to be screened for metabolic diseases
- b) Parents consenting for the screening card to be stored or requesting for residual blood samples to be returned to them.

When English is a second language, assess whether an interpreter is required to ensure consent is sufficiently informed. See [Interpreters and Translation](#) (Ref. 0137)

2.3.2 Once verbal consent has been obtained, document in the infant’s clinical notes.

Some parents will experience anxiety waiting for results or be fearful of positive results. Ensure that parents are well informed of the routine nature of this screening process and the rarity of these disorders, as well as the benefits of early recognition/treatment.

2.3.3 Parent Information

New Zealand was one of the earliest countries to implement Newborn metabolic screening in 1969. New Zealand Newborn Metabolic screening tests for a range of 28 diseases and disorders which are rare but can be well-managed if detected early and treatment begins promptly. All these conditions are life-long and many, without early recognition have extensive morbidities and can cause death.

Testing is offered to all families both in hospital and in the community and is not based on specific risk. Collection is recommended between 24-48 hours after birth, and should be before 72 hours as the newborn metabolic system takes time to reach detectable abnormal levels of substances tested for. Beyond 72 hours some metabolic diseases, if present, may have already caused consequences for the infant. Therefore, the recommended timing window allows for the earliest accurate detection to prevent morbidities and mortality.

Normal metabolic adaptation is based on the infant receiving milk feeds. If the infant has not received adequate enteral milk prior to the test being performed, this may need to be repeated when the infant reaches full feeds (e.g. Neonatal encephalopathy or surgical infants with clinical concerns).

Please see “Your Newborn Baby’s Blood Test” NSU pamphlet for more information or the NSU website.

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2.3.4 Storage or return of residual sample

Storage: With parental consent residual samples will be stored indefinitely in a secure facility. Stored blood spots may be used for:-

- Further investigation if baby develops a disorder but initially tested negative.
- To improve the screening programme.
- For research approved by an ethics committee and Ministry of Health.
- To investigate a death or illness within the family.

Return: If parents wish for the residual samples to be returned then complete a “request for return” form including parent/guardian signed consent and address for return and send this with the test card. The lab will ensure residual samples are returned.

The form for request for returned samples can be found here:

<https://www.nsu.govt.nz/system/files/resources/request-form-return-of-card-final.pdf>

2.3.5 Preterm infants

Due to functional immaturity preterm infants metabolic screening will commonly have positive screening with one or more results outside of normal parameters. This is a normal physiological occurrence. Because of this, preterm infants born <1500g or <32/40 the screening process is as follows;



*Unless there has already been a bloodspot sample collected within 2 weeks

Importantly: When consenting parents of premature infants reassure them of the normality of a positive screen in this group and why. Obtain consent for repeat screening.

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Collection

The optimal time for newborn blood spot collection is between 24 and 48 hours of baby's age and should be before 72 hours. (NOTE: This is a change from the previous timeframe for collection of 48-72 hours.)

Receptionists will place the cards at the bedside for each baby when it is due for the nurse to collect the sample. This includes repeat samples. NICU screening cards are blue.

- Please see NSU metabolic screening guidelines for details on collection (https://www.nsu.govt.nz/system/files/page/metabolic_screening_guidelines_final_february_2010.pdf) and NICU service specific nursing procedure: [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352)

See Appendix A for safe site selection for neonatal heel prick sampling.

Points to remember

- Enteral feeding is not a requirement for a valid sample, but a repeat sample may be required in an infant who is not fully fed.
- Before collecting the blood sample check all information sections are filled in, consent has been obtained and the patient identifiers on the card match those on the patient (NHI, name and date of birth).
- Take care not to touch the blood spot area before collecting the sample.
- All four spots on the test card must be filled to the edges and soak through to the back of the card. Blood must be applied only to ONE side of the testing card.
- Blood may be dropped directly onto the circles from a syringe. The use of capillary tubes is not recommended.
- DO NOT layer new blood on dried blood.
- Dry the card horizontally at the bedside for 1-3 hours (use card flap to make a stand). Blood is no longer red when dry.
- LMC details MUST be provided to ensure follow-up in the community for discharged babies.
- If parents request for return of residual samples ensure appropriate forms are completed, as per NSU website, and send with the sample.
- Send as soon as possible after drying to avoid delay in testing.
- Complete required documentation. (See Appendix B for an example of a completed NICU "blue" card).

Following up

Results come back electronically in CWS. Occasionally results will come back in paper form – in this instance check with the NTC that processes regarding registering and processing results are adhered to.

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A **negative screen** means that results are within normal parameters. This must be communicated to the parents.

An **unsuitable sample** means that there was inadequate blood or inappropriate timing to obtain accurate results. A repeat screening will be required in this situation. Parental verbal consent must be obtained prior to repeat screening. Complete repeat screening as soon as possible.

A **positive screen** is usually phoned to the neonatal unit or lead clinician. It means that one or more results are outside of normal parameters. If the infant is still admitted at Waikato hospital inform the NNP/CNS/Registrar/SMO, to review and discuss the results with the parents, document in the notes, and inform LMC. If the infant has been discharged contact the LMC with the results for communication to the parents.

2.4 Potential Complications

- False Negative results

The screening process is not diagnostic and false negative results are possible. It is essential that clinicians do not ignore clinical symptoms based on a negative result.

- Heel Prick care

Please see the NICU service specific nursing procedure [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352) to ensure correct sample collection and minimise bruising and adverse outcomes of heel prick sample collection.

3. Audit

3.1 Indicators

- All babies have Newborn Metabolic Screening within 72 hours after birth (unless declined by a parent/caregiver)
- There is evidence of informed consent for every test taken
- The sample cards and PKU book are completed in full for every infant

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4. Evidence Base

4.1 Associated Documents

- Code of Health and Disability Services Consumer' Rights Regulations. Health and Disability Commissioner. Retrieved from: <https://www.hdc.org.nz/media/2829/you-have-rights-easy-read-version.pdf>
- Link for documents and information pamphlets from NSU: www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test/information
- Ministry of Health eLearning Module; Best Practice – Newborn Metabolic Blood Spot Collection. <https://learnonline.health.nz/enrol/index.php?id=436>
- Ministry of Health eLearning Module; Newborn Metabolic Screening Programme (NMSP). <https://learnonline.health.nz/enrol/index.php?id=163>
- NSU website for national recommendations/requirements and further information: <https://www.nsu.govt.nz/health-professionals/newborn-metabolic-screening-programme/procedures-guidelines-and-reports-0-0>
- [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352)

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Appendix A – Safe sites for neonatal heel prick for sampling

Need to label safe areas where arrows are pointing



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Appendix B – Example of Blue NICU Test Card Completed

Collected sample filling each of the 4 circles to the black line

Neonatal details written DO NOT cover this area with a sticker.

Maternal and neonatal details. A full sticker can be used in this section.

Midwife/LMC details. Must be provided to ensure follow-up in the community

Neonatal delivery and test collection time details.

Note:

- Test within 48-72 hours from birth
- Infant <1500g requires repeat testing

LAB USE ONLY DO NOT COVER NHI # ABC123
BABY SURNAME Doe

LAB USE ONLY DO NOT COVER

BABY INFORMATION - FILL OUT OR USE LABEL
NHI Number ABC123
Surname DOE
First Name Baby of Jane
Sex M

MOTHER'S INFORMATION - if not on label
Surname DOE
First Name Jane

REPORT TO VAND84
Name / Unit

COPY TO (LMC OR WELL CHILD PROVIDER)
Name Julia Midwife
Address 123 Delivery Place

Hospital Waikato Ethnicity NZM
Birth time 00:23 Birth date 01/02/2021
Gestational age 29 wk Birth Wt. (g) 1400
Collection time 1330 Collection date 03/02/2021
Select 1st 2nd 3rd sample Further sample to come Y N