

Newborn Metabolic Screening - NICU

Procedure Responsibilities and Authorisation

Department Responsible for Procedure	Neonatal Intensive Care Unit (NICU)
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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

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Newborn Metabolic Screening - 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 are:

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

1.2 Scope

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/Clinical Nurse Specialist (CNS)

Allied Health for additional roles: Department Ward Clarks,

1.3 Patient / client group

Newborn infants admitted to the neonatal unit at Waikato District Health Board (DHB)

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 as per completed test. Ensure that parents are aware that testing can be completed later if they change their mind, though ideally between 48-72 hours, and who to contact in this instance.

Document discussion in clinical notes.

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1.5 Definitions

Newborn metabolic Screening	A New Zealand health initiative to ensure early diagnosis of newborn with a range of metabolic diseases. This promotes early treatment and management for rare, but treatable, diseases and prevents and/or minimises morbidities and mortality.
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.
Guthrie/PKU	Alternative names for the Newborn Metabolic Screening. Guthrie's test refers to the original inventor of the newborn metabolic screening Robert Guthrie.
PKU	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, behavioral problems, and mental disorders. It was the first metabolic disorder able to be screened for.
National Screening Unit (NSU):	The governing and regulating body for newborn metabolic screening in New Zealand which functions under the Ministry of Health

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.

Ward Clark - NICU:

- Ward Clarks enter details in the NICU PKU book and fill in all available details on the test card.
- Test cards are given to the bedside nurse or put on the cot-side 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 and cards sent by fast-post through hospital system.

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

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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 (4352)*.
- Newborn metabolic screening test card (beige for postnatal, blue for NICU).
- Documentation:
 - Ward Clerk to fill in the initial details in the NICU specific PKU book.
 - Nurses to document date/time of collection in the following documents:
 - clinical notes *Neonatal problem sheet (green)*, *NICU admission form (yellow)*, *Well Child Book* and *NICU PKU book*.

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 on 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.

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/disorders which are rare but predominantly can be well managed if detected early with prompt treatment. All of these conditions are life-long conditions

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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. The timing of testing, between 48-72 hours is very important. In the first 48 hours following birth the newborn metabolic system begins to function independently but takes time to reach normal level of function. Beyond 72 hours some metabolic diseases, if present, may have already caused damage to the infant. Therefore the required timing window allows for the earliest accurate detection to prevent morbidities and mortality.

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

2.3.4 Storage or return of residual sample:

Storage: With parental consent residual samples will be stored indefinitely in a secure facility for further investigation and/or research approved by an ethics committee.

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 <1500g require repeat screening at 2 weeks of age.
- Preterm infants <1000g require a third screening at 4 weeks of age.

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.

Collection

Collection must occur as soon as possible after 48 hours from birth but prior to 72 hours. This timing allows for the neonatal metabolism to take over and is the earliest time for accurate detection of metabolic diseases.

Ward Clerks will put out the cards onto the cot or outside the incubator for each baby when it is due for the nurse to collect the sample. This includes repeat samples. NICU screening cards are blue.

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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 (4352)

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

Points to remember:

- Feeding does not influence testing
- Enteral feeding is not a requirement for a valid sample (i.e. there is no need to repeat sample in an infant who is not fully fed).
- All four spots on the test card must be filled
- Spots must be filled to the edges and soak through to the back of the card
- DO NOT layer new blood on dried blood
- Allow to dry for 2-3 hours on the clip in the office
- ALL information sections on the card must be filled in
- 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.

2.3.6 Sending

All test cards must be sent as soon as possible once they have dried.

Ward Clerks ensure all details are filled in and post via fast-post daily through the hospital system.

All posted samples to be sent to:

Newborn Metabolic Screening Programme LabPLUS
PO Box 872
Auckland 1140

Following up

Results can come back either

*Negative screen

*Unsuitable sample

*Positive screen

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Negative screen means that results are within normal parameters. This should be communicated to the parents.

Unsuitable sample means that there was inadequate blood or timing inappropriate 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.

Positive screen means that one or more results are outside of normal parameters. If the infant is still admitted on the NICU or postnatal ward inform the NNP/CNS/Registrar, to review and discuss the results with the parents, and document in the notes. 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 (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

4. Evidence Base

4.1 Associated Documents

- 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>
- Link for documents and information pamphlets from NSU: www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test/information
- Code of Health and Disability Services Consumer' Rights Regulations. Health and Disability Commissioner. Retrieved from: <http://www.hdc.org.nz/media/123229/english.pdf>
- Waikato DHB NICU Nursing Procedure: Heel Prick for Blood Sampling (4352)

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4.2 References

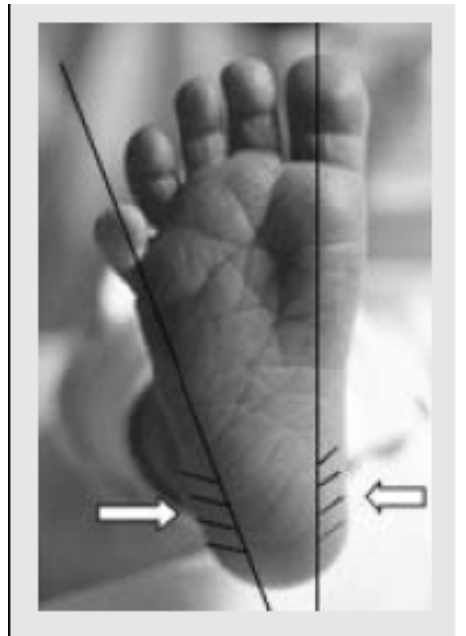
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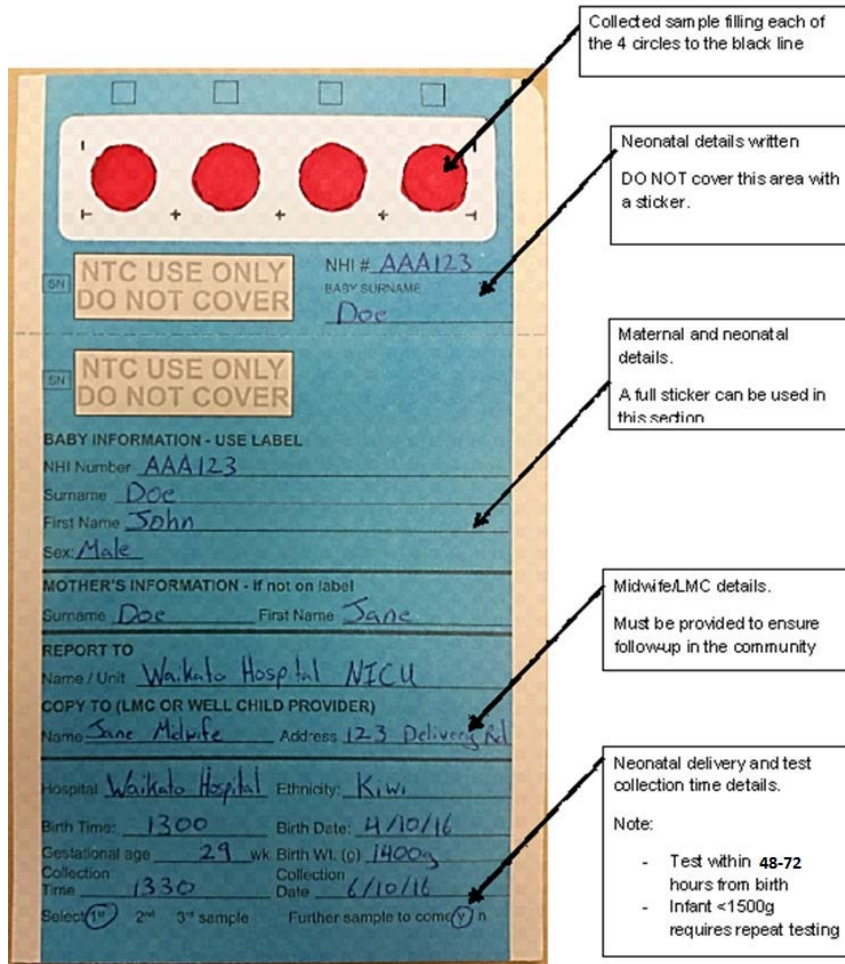
Appendix A – Safe sites for neonatal heel prick for sampling

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

NTC USE ONLY
DO NOT COVER

NHI # AAA123
BABY SURNAME
Doe

NTC USE ONLY
DO NOT COVER

BABY INFORMATION - USE LABEL
NHI Number AAA123
Surname Doe
First Name Sohn
Sex: Male

MOTHER'S INFORMATION - If not on label
Surname Doe First Name Jane

REPORT TO
Name / Unit Waikato Hospital NICU

COPY TO (LMC OR WELL CHILD PROVIDER)
Name Sue Midwife Address 123 Delivery Rd

Hospital Waikato Hospital Ethnicity: Kiwi
Birth Time: 1300 Birth Date: 4/10/16
Gestational age 29 wk Birth Wt. (g) 1400g
Collection Time 1330 Collection Date 6/10/16
Select 1st 2nd 3rd sample Further sample to come Yes No