GUIDELINE

Newborn Blood Spot Screening Test (NBST)

Scope (Staff):	Nursing and Medical Staff
Scope (Area):	NICU KEMH, NICU PCH, NETS WA

Child Safe Organisation Statement of Commitment

CAHS commits to being a child safe organisation by applying the National Principles for Child Safe Organisations. This is a commitment to a strong culture supported by robust policies and procedures to reduce the likelihood of harm to children and young people.

This document should be read in conjunction with this disclaimer

Aim

The WA Newborn Bloodspot Screening Program identifies around 25 serious medical conditions, generally before symptoms arise to enable early intervention.

Risk

Delayed identification of treatable disorders may result in irreversible physical and/or intellectual disability.

Background

Newborn screening involves testing infant to enable early detection of treatable metabolic disorders so that infants can be identified and treated before problems occur. The Newborn Bloodspot Screening Policy MP 0163/21 sets the mandatory requirements that outline roles, responsibilities and reporting requirements for Health Service Providers that provide maternity, neonatal, clinical specialist and pathology services for newborn babies in the WA health system as part of the WA Newborn Bloodspot Screening Program.

The range of diseases which are tested for are not clinically obvious at birth, but unless treated early they can cause damage. Screening is the first step in a two-step process. The first screening test indicates a problem MAY be present, and then a second diagnostic test confirms whether the problem or disease is truly present. Some of the conditions that can be tested are:

- Phenylketonuria.
- Congenital Hypothyroidism.
- Galactosaemia.
- Cystic Fibrosis.

- Amino Acid Disorders.
- Fatty Acid Oxidation and organic acid disorders.
- Severe Combined Immunodeficiency
- Spinal Muscular Atrophy

Consent

Consent is required prior to performing the NBST. Consent is often obtained antenatally. If consent is not complete, ensure the parents are provided with the <u>WA Newborn Bloodspot Screening Program Information Pamphlet</u> and consent documented on the MR216 (Information for Newborn Care).

If consent declined: Reiterate the importance of newborn bloodspot screening. Inform the parents of the risks if the baby does have one of the conditions that newborn bloodspot screening detects. Provide options for seeking further information from appropriate health professionals. If the parents continue to decline consent to NBS, record the baby's details on the bloodspot card and document the decline to consent in the medical records. The blood sample is NOT collected. Advise the family to seek medical advice if their baby is unwell. Tell them to make sure that they let the health professional know the bloodspot sample was not collected. The bloodspot card, with only the baby's details, is then sent to the screening laboratory. Write on the card the words "declined consent".

Testing

- 1. Routine testing occurs between 48-72 hours of age.
 - All infants that are discharged home prior to 48 hours of age must have followup arranged to complete a NBST prior to leaving the nursery with VNS or VMS.

2. Additional Testing

- All infants that require a blood transfusion or exchange transfusion prior to 48 hours of age are to have a NBST collected prior to commencement of the transfusion
- All deceased infants prior to death is recommended. Mark the card as 'neonatal death.'

3. Repeat testing

- VLBW infants' birthweight <1500 grams require a repeat test on D 14.
- ELBW infants' birthweight <1000 grams require a repeat test on D 14 and 28.
- All infants that receive a blood transfusion or exchange transfusion prior to 48 hours of age require a repeat NBST > 48 hours after the transfusion.

Procedure

Steps

- 1. Identify when the infant is due for the test and ensure that the timing of collection is appropriate.
- 2. Ensure parents have been provided with information about the NBST prior to collection and consent is complete. Refer to MR 216.
- 3. Clearly print ALL the required information on the NBST card
- 4. Throughout handling of the card, ensure that the collection circles are not touched or contaminated by oils, sweat, and talc from gloves, or Vaseline
- 5. Collect sample on the back of the card. Ensure all 3 circles are completely filled, and that blood has penetrated both sides of the card. This is a requirement for the analysis.
- 6. Place addressograph on the back of the NBST card and check against infant's identity band.
- 7. Check that all required information is correctly documented on NBST card

Documentation

Following sample collection, record the following **on** the card:

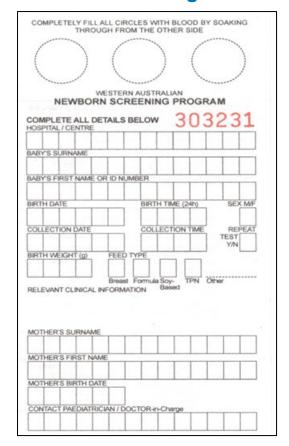
- Meconium plug / meconium ileus.
- Family history of cystic fibrosis (siblings).
- Pre/post blood/exchange transfusion.
- TPN and/or type of feed.
- Neonatal death.

Document the NBST card number and sample collection date in the following places:

- Neonatal History (MR410)
- Neonatal Observation Chart (on day of completion)
- Personal Health Record Book.
- Neonatal Discharge Assessment (MR 430).

The cards collected from drying racks and sent to QEII PathWest Clinical Biochemistry by the neonatal Ward Clerks in designated envelopes.

Newborn Screening Card





WA Newborn Bloodspot Screening Program Oversight

The WA Newborn Bloodspot Screening Program activities are overseen by the WA Newborn Bloodspot Screening Committee under the Office of Population Health Genomics. This includes that all babies are tested, necessary follow up is done and all cases found are notified to initiate recall, diagnosis and treatment identified.

References and related external legislation, policies, and guidelines

Newborn Bloodspot Screening Policy MP0163/21

Newborn Bloodspot Screening Procedure

WA Newborn Bloodspot Screening Program

Useful resources

Healthy WA Your baby's newborn bloodspot screening test

WA Newborn Bloodspot Screening Program Information Pamphlet

MyLearning - [NMHS] WNHS Newborn bloodspot screening (001) (health.wa.gov.au)

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About newborn bloodspot screening | Australian Government Department of Health and Aged Care

This document can be made available in alternative formats on request.

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