

Local Guideline and Procedure



John Hunter
Children's Hospital
CHILDREN. YOUNG PEOPLE AND FAMILIES



Health
Hunter New England
Local Health District

Newborn Screen Test in NICU

Sites where Local Guideline and Procedure applies	Neonatal Intensive Care Unit, JHCH
This Local Guideline and Procedure applies to:	
1. Neonates – less than 29 days	Yes
Target audience	NICU clinical staff, which provide care to neonatal patients. Guideline for procedure and equipment requirements for collecting a newborn screen test from an infant in NICU
Description	Guideline describing metabolic disorders, procedure for gaining parental consent, testing & documentation of collection for clinical staff in NICU

[Hyperlink to Procedure](#)

Keywords	Bloodspot, Cystic fibrosis, Galactosaemia, Hypothyroidism, Metabolic, Phenylketonuria, consent, JHCH, NICU
Document registration number	JHCH_NICU_16.02
Replaces existing document?	Yes
Registration number and dates of superseded documents	JHCH_NICU_16.02 Developed 10/06/2014
Related Legislation, Australian Standard, NSW Ministry of Health Policy Directive or Guideline, National Safety and Quality Health Service Standard (NSQHSS) and/or other, HNE Health Document, Professional Guideline, Code of Practice or Ethics:	
<ul style="list-style-type: none"> NSW Health Policy Directive 2014_036 Clinical Procedure Safety http://www0.health.nsw.gov.au/policies/pd/2014/pdf/PD2014_036.pdf NSW Health Policy Directive PD 2007_036 Infection Control Policy http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_036.pdf NSW Health Policy Directive PD 2016_015 Newborn Bloodspot Screening http://www0.health.nsw.gov.au/policies/pd/2016/pdf/PD2016_015.pdf NSW Health Newborn Bloodspot Screening Programme http://www.kidsfamilies.health.nsw.gov.au/publications/tests-to-protect-your-baby-newborn-bloodspot-screening 	
Prerequisites (if required)	N/A
Local Guideline and Procedure note	This document reflects what is currently regarded as safe and appropriate practice. The guideline section does not replace the need for the application of clinical judgment in respect to each individual patient but the procedure/s require mandatory compliance . If staff believe that the procedure/s should not apply in a particular clinical situation they must seek advice from their unit manager/delegate and document the variance in the patients health record.
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Date authorised	28/09/2016

This document contains advice on therapeutics No

Issue date 28/09/2016

Review date 26/05/2018

Note: Over time links in this document may cease working. Where this occurs please source the document in the PPG Directory at: <http://ppg.hne.health.nsw.gov.au/>

RISK STATEMENT

This local guideline has been developed to provide guidance to clinical staff in NICU about the importance of a newborn screen test and the procedure and documentation. It ensures that the risks of harm to infants and staff during the collection procedure are identified and managed. Any unplanned event resulting in, or with the potential for injury, damage or other loss to infants or staff as a result of this procedure must be reported through the Incident Information management System and managed in accordance with the Ministry of Health Policy Directive: Incident management PD2007_061. This would include unintended injury that results in disability, death or prolonged hospital stay.

Risk Category: Clinical Care & Patient Safety

ABBREVIATIONS & GLOSSARY

Abbreviation/Word	Definition
CF	Cystic Fibrosis
CNC	Clinical Nurse Consultant
DNA	Deoxyribonucleic acid
EDTA	ethylenediaminetetraacetic acid (type of blood tube)
HMS	Home Midwifery Service
MRN	Medical Record Number
NBST	Newborn screen test
NND	Neonatal Death
NSW/ACT	New South Wales/Australian Capital Territory
PAL	Peripheral Arterial Line
PN	Parenteral Nutrition
PKU	Phenylketonuria
UAC	Umbilical Arterial catheter

OUTCOMES

1	Ensure metabolic screening is undertaken for all newborns admitted to NICU as per NSW Health PD 2006_099
2	Information is given to parents and written consent received from parents and recorded on NBST card
3	NBST is to be collected between 24 and 72 hours following birth. Optimal time is 48 hours and is documented appropriately
4	Accurate documentation of administration recorded in Personal Health Record (blue book), admission book, infant's progress notes & admission page of cheat sheet
5	Observe universal precautions and safe practice with sharps and blood products

GUIDELINE

This Guideline does not replace the need for the application of clinical judgment in respect to each individual patient.

Newborn Screen Test in NICU - One Page Summary and Index

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RATIONALE

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The purpose of newborn screening is to test all newborns for early signs of treatable congenital metabolic disorders. This guideline describes these disorders and the correct procedure for John Hunter Children's Hospital. Each year the NSW Newborn Screening Program tests over 100,000 infants and detects approximately 100 that require further assessment and treatment.

SUMMARY OF DISORDERS TESTED ON THE NBST

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There is over 30 disorders tested for on the NBST and information and factsheets for some are available at: <http://www.kidsfamilies.health.nsw.gov.au/publications/tests-to-protect-your-baby-newborn-bloodspot-screening>. The main disorders tested are summarized below.

Cystic Fibrosis (CF): 1 in 2,500 live births will be detected with CF (approximately 34 infants in NSW per year). CF is a condition in which the body's secretions, especially in the lungs and gut, are much more sticky than usual. These thick secretions encourage infection in the lungs, and abnormal secretions from the pancreas frequently make food digestion and absorption incomplete. The infant may have large bulky smelly bowel actions. Without treatment infants develop chest infections and often have very serious failure to thrive. Early treatment greatly improves the health of infants with CF. Newborn bloodspot screening detects about 95% of infants with CF but also detects a few infants who may only be healthy carriers. For these infants a sweat test at about six weeks of age determines whether the infant has CF or is a healthy carrier.

Primary congenital hypothyroidism: 1 in 3,500 live births are detected with primary congenital hypothyroidism (approximately 26 infants in NSW) per year. It is caused by the absence or abnormal formation or function of the thyroid gland. A normally working thyroid gland is critical for normal growth and brain development and causes growth and intellectual disability if not treated. Medication with thyroid hormone started early, results in normal growth and development.

Phenylketonuria (PKU): 1 in 10,000 live births (approximately 10 infants in NSW) per year). PKU is an inherited condition in which the body is unable to break down one of the protein building blocks from food. These building blocks are called amino acids and one of them is phenylalanine. In PKU the phenylalanine cannot be metabolised normally and builds up in the blood and tissues. The high phenylalanine level can prevent the brain from developing as it should. Early detection and a diet low in phenylalanine, started in the first two to three weeks results in normal development.

Galactosaemia: 1 in 40,000 births (approximately 1-3 cases in NSW per year). Galactosaemia is an enzyme deficiency that occurs when both parents pass galactosaemia gene to their infant. Galactosaemia causes an accumulation in the blood of galactose, a sugar that is in milk. The enzyme deficiency prevents the galactose from being changed to another sugar, glucose. Galactose and other compounds accumulate and cause lethargy, vomiting, jaundice and sepsis. Infants with galactosaemia need treatment to avoid these problems. The treatment is a diet that completely excludes galactose. For newborn infants this means a special formula.

Less common metabolic disorders: Some fatty acid, organic acid and other amino acid defects can now be detected using Tandem Mass Spectrometry. These much less common metabolic disorders affect approximately 15–18 infants born in NSW per year. Early detection is important as diet and medications can treat most of these disorders. Without appropriate management they can cause severe disability or death.

INFORMED CONSENT/ REFUSAL OF CONSENT

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The following information is to be provided to parents/guardians prior to blood sample being collected:

- An explanation about the reasons for testing. The purpose of newborn screening is to test all newborns for a number of treatable congenital metabolic disorders such as phenylketonuria, galactosaemia, hypothyroidism, cystic fibrosis and rare metabolic disorders.

Parents/guardians:

- Must be given a copy of the brochure entitled “Newborn bloodspot screening- tests to protect your baby” <http://www.kidsfamilies.health.nsw.gov.au/publications/tests-to-protect-your-baby-newborn-bloodspot-screening>

Parents/guardians must be told:

- Information about the newborn bloodspot screening card collection-collects written information as well as 3 bloodspots. Written information is transferred to an electronic record as well as the results from the blood. The card with unused portion of 3 bloodspots is retained for a minimum of 2 years for quality assurance and audit purposes.
- An explanation of the method of collection
- Storage of the blood sample is in a secure, locked area and access is tightly controlled and protected by legislation. After 2 years parents may request card to be returned or destroyed if they do not wish it to be stored. If they are happy to have it stored it is retained by the laboratory for 18 years.

Parents/guardians are also able to consent to non-identifiable bloodspot samples being used for research purposes with ethics approval.

- Written consent is required on the reverse side of the card which includes ticking the Yes/No boxes and then signing. See below for details

Consent for Collection and Testing of Sample
 I have received and understood the information in the NSW Newborn Screening pamphlet.
 I consent to my baby having blood collected and tested Yes [] No []

Storage of screening card for greater than 2 years
 I consent to the storage of the screening card for longer than 2 years Yes [] No []
 I understand that blood from screening cards may be used for de-identified health research.
 I agree to make my baby's blood sample available for this purpose Yes [] No []
Cards without consent will not be used for research

Parents signature: _____

- An explanation that hospitals are only advised of individual results when retesting is necessary

- Samples are stored in a locked area. No tests other than the routine NBST are carried out without written permission from parents or carers.

The newborn screening program complies with the Health Records and Information Privacy Act (HRIP) 2002.

Obtain verbal consent from the parent/carer and sign the NBST sticker to place in infant's notes-see Documentation section

If parents refuse to have the test the following steps should be followed:

- Confirm that the parents have received the brochure entitled "Newborn bloodspot screening- tests to protect your baby", and that staff have discussed the test with them.
- A medical staff member must meet with the parents and clearly outline the benefits of the newborn screening test and the risk to the infant for refusal.
- Medical staff should document the refusal of consent in the progress notes and the nature of the discussion with the parents.
- The newborn screening card should be filled out with relevant baby details and 'REFUSAL' written in red across the card and sent to the Newborn Screening Laboratory.
- Document the refusal for the test in the Personal Health Record (also known as the blue book) and the NICU admission book.

Advise the parents that if the infant becomes unwell, they must inform their paediatrician or GP that their infant has not had a newborn screening test.

If parents not available for consent –may be due to ill health (in ICU) or has not been transferred to referring hospital as yet or an infant that is for 'assumption of care'

*-please **obtain NBST** sample and record **reason for no consent***

TIMING OF SAMPLING AND REPEAT TESTING

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Newborn screening tests are based on the analysis of biochemical markers that accumulate if the infant has one of the disorders screened for. The levels of these vary in the first days after birth.

The NBST may be collected from 24-72 hours following delivery and the optimal time is at 48 hours

Low Birth Weight

- Infants <1500 grams require a repeat sample at 28 days of age.
- If a twin/ multiple is <1500 grams, all their twins/multiples require a repeat sample at 1 month of age. It is possible to miss a metabolic disorder, especially Congenital Hypothyroidism, in an infant whose birth weight is <1500 grams.

Blood product transfusions

- Blood products include- red blood cells, fresh frozen plasma, cryodepleted plasma, cryoprecipitate, platelets, albumin, and immunoglobulins.
- Babies who require blood products prior to 24 hours of age require collection of a NBST before the blood product transfusion.
- A 2nd sample should be collected 48 hours after the blood product transfusion is completed.
- A 3rd sample is then collected 2 weeks post transfusion to ensure accurate results for Congenital Hypothyroidism, except if baby is <1500 grams the sample is collected at 28 days of age.
- Enzyme tests to confirm Galactosaemia will be invalidated after any blood transfusion for 3 months. DNA tests to confirm Cystic Fibrosis or other metabolic disorders will be invalidated for 6 months after a blood product transfusion.
- Document on the card in 'relevant information' the date and time of blood transfusion

Stillbirth

- In the case of a stillbirth, blood can be taken from a heel prick or from the cut end of the umbilical cord of the placenta. Write in red on the screening card that it is a 'post mortem' sample. Stillbirth is defined as being ≥ 20 weeks gestation or ≥ 400 grams birth weight who did not, at any time after delivery, breath or show any evidence of life such as heart beat.
- A blank card containing baby's details should be sent if no blood is collected

Neonatal death

- If possible collect a sample before an anticipated neonatal death as this allows testing which may benefit the family. A neonatal death is the death of a live born infant within 28 days of birth. Write in red on the screening card that it is a 'NND or Neonatal Death' sample.
- A blank card containing baby's details should be sent if no blood is collected

PROCEDURE[Top](#)**Pre sample**

- Sight that consent is given for NBST in the infant's notes-if not obtain consent.
- Obtain NBST card that is stored in the small filing box on the ward clerk's desk with the infants details partially completed. Spare cards are found at the back of this filing cabinet.
 - If possible, organise for NBST to be taken with other routine blood tests to minimise painful procedures
 - Check infants identification bands
 - Complete details on NBST card and place infants MRN sticker on back of card without covering circles for bloodspots.
 - Collect sample completely saturating all three circles with blood

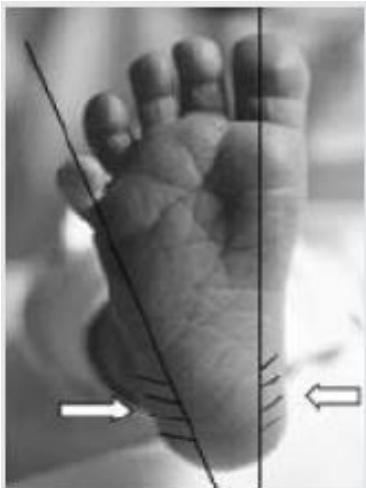
- Completed specimen cards should be dried horizontally in drying rack at room temperature away from artificial heat and direct sunlight (located near the blood gas machine)
- Do not store sample cards in plastic prior to or after sample has been taken
- Document (see documentation section)

Capillary Sampling

- Capillary sample required if no Umbilical Arterial catheter (UAC) or Peripheral Arterial Line (PAL) access.
- Wash hands and obtain non-sterile gloves, eye protection & cotton wool
- Sucrose solution (if infant weighs >1000 grams) as per Pain CPG Management of pain in the newborn” and the drug protocol for the use of “Oral sucrose solution 25%”. Or breastfeed to relieve discomfort (Shah et al., 2006).
- Feet should only be warmed with booties, warm hands, or after a warm bath. Do not use cloths moistened with hot water or apply direct heat to infant (Janes et al., 2002).
- It is important not to squeeze the infants’ heel as this causes pain, bruising, leakage of interstitial fluid and haemolysis
- Select tenderfoot™ lancet device appropriate for gestation-see table below
 - Collect sample completely saturating all three circles with blood

Case colour	Lancet depth (mm)	Lancet	Infant
Blue	0.65 mm	tenderfoot micro-preemie	infants <1000g
White	0.85 mm	tenderfoot preemie	infants 1000g – 2500g
Pink / Blue	1.0 mm	tenderfoot newborn	>2500 g

- The heel incision should be made in areas indicated by the arrows on the diagram below



http://www.wirral.nhs.uk/document_uploads/Policies_Nursing/HeelPrickProcedureJune2009.pdf

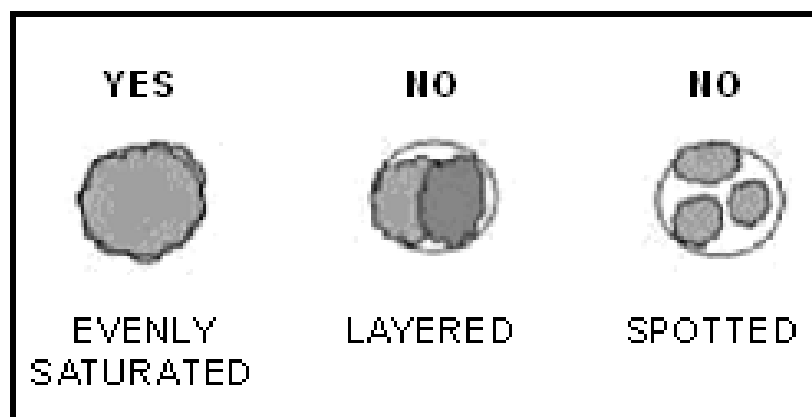
- Position the infants leg lower than the rest of the body for gravity
- Ensure sample area is clean and dry. If area needs cleaning use sterile water on gauze or cotton ball. **Do not use an alcohol swab** as this can lead to haemolysis and dilute the sample.
- Puncture heel with lancet
- Wipe away first drop of blood with sterile cotton wool
- Massage above puncture site to encourage blood flow
- **Drop free-flowing blood onto the front of NBST card**
- completely filling all three circles and soaking through to the other side, ensuring card is not rubbed on the heel
- Apply gentle pressure to puncture site with cotton wool until bleeding stops
- Dispose of sharps

Arterial line sampling

- Refer to 'Arterial Line CPG' for sampling
- Wash your hands
- Put on non-sterile gloves, and protective eyewear
- 1ml of blood should be removed from the line and saved, to clear for sample
- Do not use a lithium heparin syringe or EDTA tube as these anticoagulants interfere with the test results.

Points to consider related to the NBST card

- Capillary tubes should not be used
- Fill the circles on the newborn blood spot card completely and saturate evenly from the front. **Do not turn the card over and fill from the back**
- **Blood spots should not be pressed with fingers or gloves.**
- Avoid the card touching contaminated skin or surfaces such as milk, antiseptic solutions, skin creams or lotions, or urine as contamination adversely affects the sample and may lead to a missed diagnosis.
- Never put samples in plastic as it encourages bacterial growth and invalidates test results



(http://www.wirral.nhs.uk/document_uploads/Policies_Nursing/HeelPrickProcedureJune2009.pdf)

DOCUMENTATION[Top](#)

- Complete details on NBST card using a pen
- On the card, the gestation refers to the gestation at birth.

NBST card (front)NBST card(back)

NSW NEWBORN SCREENING PROGRAMME	
Mother's information	
Full name: _____	
Baby's information	
Last name: _____	
Date of birth: ____ / ____ / ____	Time of birth: _____
Birth weight: _____	Gestation: ____ weeks ____ days
Gender: M F Not determined	Test < 24 hours of age: Y N
Date of sample: ____ / ____ / ____	Time of sample: _____
Feeds: Breastmilk Formula Soy based TPN Other: (Circle all that apply)	
Place of birth: _____ (E.g. home or name of hospital)	
Sample collected at: _____ (E.g. home or name of hospital)	
Paediatrician/doctor/midwife in charge: _____	
Relevant clinical information: _____	
Initial test: []	Repeat test: []
COMPLETE ALL DETAILS ON BOTH SIDES OF CARD	
Eastern Business Forms 530 Old Sulphur Springs Rd. [SN] Greenville, SC 29607, USA	
Consent for Collection and Testing of Sample I have received and understood the information in the NSW Newborn Screening pamphlet. I consent to my baby having blood collected and tested Yes [] No [] Storage of screening card for greater than 2 years I consent to the storage of the screening card for longer than 2 years Yes [] No [] I understand that blood from screening cards may be used for de-identified health research. I agree to make my baby's blood sample available for this purpose Yes [] No [] Cards without consent will not be used for research	
Parents signature: _____	
Collect from ALL newborns between 48 and 72 hours 1. Warm heel before blood collection. 2. Puncture clean dry heel with a disposable lancet (Point < 2mm). 3. Wipe away first drop of blood. 4. Do NOT layer blood. Only fill spot from one side. 5. Allow spots to dry before mailing (4 hours). 6. Return completed card without delay.	
Baby's medical record number: _____ (if available)	
Do not touch sample area. Do not use card if damaged. COMPLETELY FILL EACH CIRCLE - BLOOD MUST SOAK RIGHT THROUGH PAPER	
If available apply Baby's hospital label on top of dotted box. Ensure that all of the CONSENT remains visible.	
Interpath Services	AR: Interpath Services Pty Ltd +61 (0)3 9457 6277
REF 10539639 Rev.AD	LOT 7037316/W152

- Place patient identification sticker with home address on back of card within the dotted area. ***If infant is for 'assumption of care" and being managed with DOCS please record only MRN and do not place sticker identifying mothers details.***
- The feeding status of the infants at time of sample must be stated on card. It is important to state if the infant is on TPN, formula, breast milk, or soy based milk. Also note if the mother is on thyroxine, if infant has meconium ileus, or there is a family history or sibling with a known metabolic disorder.
- Completed specimen cards should be dried horizontally in drying rack at room temperature away from artificial heat and direct sunlight (located behind the door of receptionist door in main reception area)
- **Do not** store sample cards in or near **plastic** prior to or after sample has been collected.

Record NBST Collection in

- Admission book
- Patient Health Record (Blue Book)
- Front page of tick chart
- Record in patients notes
- Flow chart

RESPONSIBILITY

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- All nursing staff regardless of time of day/night are responsible for ensuring that screening is performed or has been performed on infants in their care.
- Ensure that the newborn screening test is completed prior to transfer to another hospital.
- If the infant is being discharged or transferred before 48 hours the receiving hospital or Home Midwifery Service (HMS) can take the sample. Ensure that any receiving hospital or HMS is aware if a NBST is required or if a repeat is necessary.
- Ensure all documentation has been filled out correctly (refer to 'Documentation' section of this guideline).

RESULTS

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The disorders screened for are rare and in most cases the results are normal. Parents are contacted only if there are concerns with the test results. A few infants may require a second blood test, usually because the first test did not give a clear result or was contaminated. Most second tests will give normal results. The test will be abnormal in a small number of infants and the doctor or midwife will notify parents. These infants will require further testing and treatment if necessary.

ABNORMAL RESULTS AND REPEAT TESTING

Each unit will have a nominated newborn screening contact person for the NSW and ACT Newborn Screening Programme.

All infants at John Hunter Hospital NICU have Dr Glover as the 'Paediatrician/ Dr in charge' noted on the NBST card.

If a recall is necessary the contacts are Dr Glover or Liaison CNC NICU.

The exception to referral of recalls is for abnormal Cystic Fibrosis tests which are referred directly to the Paediatric Respiratory team.

The 'Paediatrician/ Dr in charge' stated on the newborn bloodspot screening card is notified by telephone within 2 working days of receipt of sample if abnormal.

It is the responsibility of this person to promptly ensure that the infant is recalled for repeat testing and provided with further investigations and treatment.

APPENDIX 1 NEWBORN SCREENING TEST (NBST) PROCEDURE

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New Born Screening Test (NBST) Procedure

<u>NBST for Term Infant</u>	<u>NBST for Preterm Infant Babies born < 1500grms</u>
<ul style="list-style-type: none"> • NBST can be attended 24 to 72 hours post-delivery. Preferably 48 hours • Information to be given to parents and written consent obtained • Record in <ol style="list-style-type: none"> 1. Blue Book 2. Admission Book 3. Record in patient notes 4. Front of the Tick Sheet 5. Flow Chart 	<p>1st Test</p> <ul style="list-style-type: none"> • NBST can be attended after 24 to 72 hours post-delivery. Preferably 48 hours • Information to be given to parents and written consent obtained • Record in <ol style="list-style-type: none"> 1. Blue Book 2. Admission Book 3. Record in patient notes 4. Front of the Tick sheet 5. Flow Chart <p>Repeat NBST at 28 days</p> <ul style="list-style-type: none"> • Information to be given to parents and consent obtained again • Record in <ol style="list-style-type: none"> 1. Blue Book 2. Admission Book 3. Record in patients notes 4. Front of the Tick Sheet 5. Flow Chart

Babies who require Blood Transfusions, Blood Products, FFP need:

- NBST prior to administration of blood or blood products and repeat NBST 48 hours following completion of blood transfusion
- Information to be given to parents and consent obtained
- Record in
 1. Blue Book
 2. Admission Book
 3. Record in patient notes
 4. Front of the Tick Sheet
 5. Flow Chart
- Collect another NBST at **14 Days post transfusion** of blood or blood products or if infant <1500g requires NBST at 28 days
- All babies have Dr Glover's name as paediatrician

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NSW Health Newborn Bloodspot Screening Programme
<http://www.kidsfamilies.health.nsw.gov.au/publications/tests-to-protect-your-baby-newborn-bloodspot-screening> < Accessed September 13th 2016>.

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FEEDBACK

Any feedback on this document should be sent to the Contact Officer listed on the front page.

IMPLEMENTATION PLAN

1. Awareness of this clinical practice guideline will be posted on the neonatal HUB as well as in the NICU clinical practice newsletter
2. The clinical practice guideline will be communicated via email to:
 - NICU medical and nursing staff and clerical staff
 - HNEhealth maternity service managers
3. The updated clinical practice guideline is uploaded to the HNE Policy, Procedure and Guideline directory
4. In-service education by NICU education staff as well as delivery of power point presentation from NSW health will be provided to all staff.

Clinical Audit Tool –**(National Standard 1: 1.7.2 The use of agreed clinical guidelines by the clinical workforce is monitored)**

Criterion no.	Criterion	Exceptions	Definition of terms and/or general guidance	Data source	Frequency	Position Responsible
1	<i>Clinical staff working in NICU are updated on the changes to the policy</i>	<i>None.</i>	<i>The aim is that education is provided to support clinical staff by way of in-service education and/or viewing NSW health Information power-point presentation.</i>	<i>Staff HETI record.</i>	<i>6 monthly</i>	<i>Guideline Co-Ordinator NICU</i>
2	<i>All women are provided with the consumer brochure “Newborn Bloodspot Screening”</i>	<i>None</i>	<i>The aim is for women to be informed about testing procedure for the NBST as well as providing written consent for storage of samples and possible de-identified research</i>	<i>Patient health records</i>	<i>6 monthly</i>	<i>Guideline Co-Ordinator NICU</i>
3	<i>Written consent is provided by a parent/guardian prior to collection of the blood sample</i>	<i>None</i>	<i>The aim is that parents/guardians confirm their understanding of the NBST procedure and written consent by ticking yes/no to 3 points then signing</i>	<i>Written consent recorded on the reverse side of the NBST card</i>	<i>6 monthly</i>	<i>Guideline Co-Ordinator NICU</i>
4	<i>Name and position of the hospital-nominated newborn screening liaison person is notified in writing to the NSW Newborn Screening Programme</i>	<i>None</i>	<i>The aim is to ensure hospital contact available if re-testing or other relevant clinical information required.</i>	<i>NBST card</i>	<i>6 monthly</i>	<i>Guideline Co-Ordinator NICU</i>

Reference: *Electronic audit tool - National Institute for Health and Clinical Excellence (NICE): www.nice.org.uk/nicemedia/live/10996/56372/56372.xls*