

Newborn Bloodspot Screening Policy

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Functional Sub group Clinical/ Patient Services - Baby and child
Clinical/ Patient Services - Maternity

Summary Hospitals with maternity units are to offer newborn bloodspot screening tests to all newborn babies, provide a copy of the pamphlet TESTS TO PROTECT YOUR BABY to parents and make sure they understand the contents and that they agree to the test. Newborn bloodspot screening detects serious disorders such as phenylketonuria, primary congenital hypothyroidism, cystic fibrosis and galactosaemia. Among the 92,000 babies born each year in NSW and ACT, about 90 babies are diagnosed with one of these conditions. Early diagnosis and immediate treatment by medication or diet can prevent death or serious complications including mental retardation, and can lead to significantly improved outcomes.

Replaces Doc. No. Newborn Screening Guidelines [PD2005_566]

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Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Public Hospitals

Audience Maternity units, midwives, clinical and nursing staff, administration

Distributed to Public Health System, Community Health Centres, Divisions of General Practice, Government Medical Officers, Health Professional Associations and Related Organisations, NSW Department of Health, Public Health Units, Public Hospitals, Private Hospitals and Day Procedure Centres, Tertiary Education Institutes

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Director-General

Compliance with this policy directive is mandatory.

NEWBORN BLOODSPOT SCREENING POLICY

This Policy Directive supersedes Policy Directive PD2005_566.

The Newborn Bloodspot Screening Policy provides guidance to antenatal and maternity unit staff, midwives and relevant others.

Newborn bloodspot screening detects serious disorders including phenylketonuria, primary congenital hypothyroidism, cystic fibrosis, galactosaemia and rare metabolic disorders. Among the 92,000 babies born each year in NSW and ACT, about 90 babies are diagnosed with one of these conditions. Early diagnosis and immediate treatment by medication or diet can prevent death or serious complications including intellectual disability, and can lead to significantly improved outcomes.

In newborn bloodspot screening the interests of the child are paramount. It is important that full participation occurs on the understanding of clear information about screening tests and benefits; about storage and potential uses of bloodspots and health information, appropriate consent processes, and confidence in legally enforceable privacy safeguards that protect against unauthorised use, disclosure, loss or other misuse of patient information or bloodspots.

Newborn bloodspot screening as directed by this Newborn Bloodspot Screening Policy complies with all relevant NSW laws, NSW Health policy and other relevant publications as listed in Section 10.

Objectives of this policy directive are to achieve best practice by:

- 1. Offering newborn bloodspot screening to all babies**
Pamphlet - *Tests to protect your baby*
- 2. Informing parents/guardians about the test, including:**
 - Conditions tested
 - Benefits of testing
 - Test process and heelprick
- 3. Informing parents/guardians prior to testing about collection of personal information and what happens to the bloodspot after testing, including:**
 - What personal information is collected and stored
 - That after testing the bloodspot cards are retained for 18 years by the laboratory at the NSW Newborn Screening Programme at the Children's Hospital at Westmead in accordance with privacy and human tissue legislation and policy that mandate their protection.
 - That patient records are retained for 25 years according to Health Department guidelines
 - That stored cards are potentially valuable to provide clinical information for the family where a child has become sick or died, or for future reproductive decisions and also for research.

Title: Newborn Bloodspot Screening Policy

- That stored identified bloodspots or information are not used again without first obtaining parent/guardian consent for the particular purpose, except where the use or disclosure is required or authorised under law
 - That small amounts of the bloodspots may be used in non-identifiable form without parental/guardian consent for ethics committee approved research.
 - Parents'/guardians' rights in relation to access to cards and records
4. **Obtaining and recording of informed parent/guardian consent on the basis of provision of the above information.**
 5. **Explaining to parents/guardians how bloodspot screening test results will be conveyed.**

The policy also provides **direction for maternity units** on:

6. **Implementing the NSW Newborn Screening Programme Sampling Information and Guidelines**
7. **Developing written clinical protocols**
8. **Nominating a Newborn Screening Liaison Person**
9. **Contact details and sources of further information**
10. **NSW laws, NSW Health policy and other publications relevant to newborn bloodspot screening**

Compliance with this policy is mandatory.

Robyn Kruk
Director-General

Newborn Bloodspot Screening Policy

See also Appendix 1 for checklist

1 Offering newborn bloodspot screening to all babies

- Newborn bloodspot screening for phenylketonuria, primary congenital hypothyroidism, cystic fibrosis, galactosaemia and rare metabolic disorders is to be offered to all babies.
- It is recommended that parents/guardians be told about newborn bloodspot screening during the last four to six weeks of their pregnancy to allow sufficient time for consideration, clarification and informed decision-making.
- Hospitals are required to nominate an officer/s with responsibility for ensuring newborn bloodspot screening information is provided to parents or guardians.
- Parents/guardians are to be given a copy of the pamphlet *Tests to protect your baby* in an appropriate language where possible and provided with the opportunity for discussion and questions to achieve clarification, either in a group situation, such as antenatal classes or on a one to one basis. Distribution of the pamphlets without discussion is not permissible.
- After birth, and before the bloodspot is collected, the nominated health professional/s should check that parents/guardians have received a copy of the parent information pamphlet, that they have had opportunity for discussion and clarification and that they agree to the test.
- The pamphlets are available from The Better Health Centre – Publications Warehouse or via the internet (see contact details in Section 9).
- Pamphlets in 9 languages are available from the NSW Newborn Screening Programme.

2 Informing parents/guardians about the conditions tested, the benefits of testing and the test process

2.1 Conditions tested

Phenylketonuria (PKU): 1 in 10,000 live births (about 10 babies per year). PKU causes high blood levels of phenylalanine and severe intellectual disability. A diet low in phenylalanine, started in the first two to three weeks results in normal development.

Primary congenital hypothyroidism: 1 in 3,500 live births (about 26 babies per year). It is caused by the absence or abnormal formation or function of the thyroid gland. This causes growth and intellectual disability if not treated. Medication with thyroid hormone started early, results in normal growth and development.

Cystic Fibrosis (CF): 1 in 2,500 live births (about 34 babies per year). Without treatment babies develop chest infections and often have very serious failure to

thrive. Early institution of treatment greatly improves the health of babies with CF. Newborn bloodspot screening detects about 95% of babies with CF but also detects a few babies who may only be healthy carriers. For these babies a sweat test at about six weeks of age determines whether the baby has CF or is a healthy carrier.

Galactosaemia: 1 in 40,000 births (about 1-3 cases per year). Babies cannot process galactose, a component of lactose. Life-threatening liver failure and infections can occur. A galactose-free diet instituted in the first week is life saving.

Rarer metabolic disorders: Some fatty acid, organic acid and other amino acid defects can now be detected using Tandem Mass Spectrometry. These much rarer metabolic disorders affect about 15 – 18 babies 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.

2.2 Benefits of testing

Newborn bloodspot screening is highly recommended for all babies. Among the 92,000 babies born each year in NSW and ACT, about 90 babies are diagnosed with one of these conditions. Early diagnosis and immediate treatment by medication or diet can prevent death or serious complications including intellectual disability, and lead to significantly improved outcomes.

2.3 The heel prick process

The process for collecting the bloodspot is to be explained to parents. A blood sample is obtained by heel prick when the baby is 48 to 72 hours old, and placed on special pre-printed filter paper card, provided by the NSW Newborn Screening Programme, and in accordance with the NSW Newborn Screening Programme Sampling Information and Guidelines. (See Section 9 for contact details).

Mothers/parents/guardians are encouraged to be present and hold the baby during the procedure. Breast-feeding during the test is clinically recommended as it helps to relieve discomfort for the baby^{1, 2}.

It is essential that the card has ALL INFORMATION completed. Each field has been included for a specific purpose.

¹ Guideline Statement: Management of Procedure-related Pain in Neonates, Royal Australasian College of Physicians, Paediatric and Child Health Division, 2005

² NSW Health Policy Directive PD 2006/060 http://www.health.nsw.gov.au/policies/pd/2006/pdf/PD2006_060.pdf

Title: Newborn Bloodspot Screening Policy

3 Informing parents/guardians about the collection of personal information, retention and storage, potential uses, privacy and protection of records and bloodspot cards

In addition to providing information about the conditions and benefits of testing as outlined above, it is important that BEFORE TESTING, parents/guardians are told about what information is collected, the storage and potential uses of health information and the bloodspots, and privacy and protection processes, so that consent to the test is on the basis of this understanding.

3.1 Information collected

Three bloodspots and information are collected on the newborn screening card as indicated.



NSW NEWBORN SCREENING PROGRAMME

Baby's
Last name

Mother's
Full Name

Baby's
Date of Birth..... Sex M / F
Birth Weight.....g Gestation.....weeks

Date of Sample..... Test less than 48 hr []
Feeds: Breast / Formula / Soy based / TPN / Other.....

Hospital of Birth

Hospital/Sample Source.....
Paediatrician/Doctor in Charge

Relevant Clinical Information

Initial Test [] Repeat Test []

**COMPLETE ALL DETAILS REQUESTED ABOVE.
COMPLETELY FILL EACH CIRCLE -
BLOOD MUST SOAK RIGHT THROUGH PAPER**

Title: Newborn Bloodspot Screening Policy

The newborn bloodspot screening card is sent from the maternity hospital to the laboratory at the NSW Newborn Screening Programme at The Children's Hospital at Westmead. The laboratory transfers the written information to an electronic record and the blood is tested and the card containing the unused portion of the three bloodspots is retained as a sample.

All results are recorded in the electronic record, not on the card.

3.2 Privacy, storage, security and retention periods

Privacy, storage and security

The laboratory as a NSW Health facility is the custodian of the bloodspot cards and records. Both the electronic record and the bloodspot card are subject to the privacy protection requirements of NSW privacy legislation^{3, 4, 5}. The bloodspot cards are stored in a secured locked area with appropriate safeguards to prevent unauthorised use, disclosure, loss or other misuse.

Retention of newborn bloodspot screening cards

The bloodspot cards are stored for 18 years. At the end of the retention period the bloodspot cards are shredded and then securely disposed of. The National Pathology Accreditation Advisory Council has guidelines for retention of laboratory records and diagnostic material⁶.

Retention of health records

The electronic record, containing written information from the cards, is stored for 25 years according to NSW Department of Health policy requirements for children's records^{7, 8, 9}.

There is no stored data about DNA. Newborn bloodspot screening involves biochemical testing. On this testing about 1% of the samples show an increased risk for cystic fibrosis and MCAD. As part of routine testing these samples are retested for a common change in the DNA (a mutation) associated with the two disorders. No DNA tests are done on any other samples and no other DNA records are held.

³ NSW Health Privacy Manual (Version 2) 2004:
http://www.health.nsw.gov.au/policies/pd/2005/PD2005_593.html

⁴ Privacy and Personal Information Protection Act, 1998

⁵ Health Records and Information Privacy Act, 2002

⁶ National Pathology Accreditation Advisory Council, Retention of laboratory records and diagnostic material

⁷ General Retention and Disposal Authority – Public Health Services: Patient/ Client Records (GDA 17), NSW Department of Health Information Bulletin No 2004/20, <http://www.health.nsw.gov.au/archive/cib/information-bulletins/2004/ib2004-20.pdf>

⁸ Records - Principles for Creation, Management, Storage and Disposal Health Care Records, NSW Department of Health PD2005_127 http://www.health.nsw.gov.au/policies/PD/2005/PD2005_127.html

⁹ NSW State Records Act, 1998

3.3 Potential uses of bloodspots, information and consent requirements

Stored bloodspots have a number of potential uses. Any further use must be in compliance with privacy law, NSW human tissue law¹⁰ and NSW Health policy. Potential benefits from stored bloodspots include obtaining clinical information for the child and/or the family. Whilst requests for use for this purpose are rare, the information potentially available to families is extremely valuable. Bloodspots may also be used for research to improve newborn screening techniques or develop new tests. It is likely that as yet unknown public health benefits may arise in the future as research develops. Given the privacy and security laws and policies for the protection of bloodspots, the potential benefit from secondary use is considered to outweigh any conjectured (but not experienced) risk to their security or from misuse.

Directly related clinical purposes

Bloodspots or information may be used for purposes that an individual would reasonably expect and which are directly related to collection and testing of the sample such as retesting to confirm a result or to provide information to a person or organisation providing ongoing care of the baby.

Separate consent is not required for this purpose.

Laboratory quality control

Retained bloodspot cards are used for normal quality control practices.

Separate consent is not required for this purpose.

Clinical use for the individual and family

The stored bloodspot sample may be used for further testing at the request of the parents or guardians to provide valuable new medical information for the benefit of the child or the family, eg determining if a cytomegalovirus infection was present at birth or acquired later. Other uses might be where a child has died, and no other sample is available, but there is new information suggesting a likely diagnosis, or a mutation test for a known disorder. Diagnostic information can be useful to parents for future reproductive decisions.

Separate parent/guardian consent is required for this purpose before testing.

Research using identified bloodspot samples

It is possible that new tests for treatable conditions can be developed by determining whether a disorder normally recognised during childhood, when damage has already occurred, could have been diagnosed by a newborn test. Research requires approval from the appropriate Health Research Ethics Committee.

Separate parent/guardian consent is required for this purpose before testing.

Research using non-identifiable bloodspot samples

Non-identifiable portions of bloodspots may be released for research only with approval by the appropriate Health Research Ethics Committee. Newborn bloodspot

¹⁰ Human Tissue Act, 1983

Title: Newborn Bloodspot Screening Policy

samples are an unbiased population sample and research can lead to improvements in health and well being of large populations of individuals.

Consent is not required for this purpose.

3.4 Access to bloodspots and personal information, disclosures and consent requirements

Patient access

Parents/guardians, on behalf of the child, or the patient at adulthood, have the right to access personal information held about them. See NSW Health Privacy Manual, Version 2¹¹, for further details.

Access by a third party

Access to stored samples or information by third parties such as employers, insurers, police, legal representatives, other relatives or medical practitioners is not allowable except with the written consent of the parent/guardian (or child if of age of consent) or by court order¹¹.

Separate parent/guardian consent is required for this purpose

Access for coronial purposes

Generally a bloodspot sample is only released for coronial purposes where no other identifying sample is available, and in circumstances where a person is dead, or missing believed dead, for the purpose of identifying remains and with written consent. Newborn bloodspot screening cards from individuals who are alive and not missing are not normally released. A Memorandum of Understanding between NSW Health and NSW Police, 2002¹² sets out parameters and processes for requests for access to newborn bloodspot screening cards. Since implementation of the MOU there have been 10 requests from police with only three releases.

Separate parent/guardian consent is required for this purpose before testing provided that the parents can be located.

Access for law enforcement purposes, and Access and disclosure authorised by law

It is possible that access to bloodspot samples and disclosure of information may be required by court order. To date this has not occurred.

3.5 Transfer of cards to parents/guardians

The laboratory must retain the bloodspot cards for a minimum of 2 years for quality assurance and audit purposes in accordance with National Pathology Accreditation Advisory Council requirements. As a general rule, newborn bloodspot screening

¹¹ NSW Health Privacy Manual (Version 2) 2004:
http://www.health.nsw.gov.au/policies/pd/2005/PD2005_593.html

¹² Memorandum of Understanding between the NSW Police and NSW Health (2002)
<http://www.health.nsw.gov.au/legal/pdf/mou.pdf>

cards are retained by the laboratory for 18 years and are stored securely as indicated in this policy. Any requests for destruction or transfer of cards to parents after 2 years are to be in writing from both parents or guardian and supported with identification.

4 Obtaining and recording of consent or refusal

4.1 NSW Health Policy on Consent

As with all medical procedures or treatments, offering the test and obtaining consent should comply with “Patient Information and Consent to Medical Treatment”¹³

Adequately informing patients and obtaining consent in regard to an operation, procedure or treatment is both a specific legal requirement and an accepted part of good medical practice. Failure to do this could result in legal action for assault and battery. For a patient under the age of 14 the consent of a parent or guardian is necessary. NSW Health consent policy applies to all public health organisations as well as to all people who work within these organisations and are involved in the provision of health care, including employees, contractors and other health service providers.

4.2 Processes for obtaining consent to newborn bloodspot screening

In newborn bloodspot screening, valid consent requires provision of full information about the test including information about what happens to the bloodspot sample after testing as outlined above. Each maternity hospital’s newborn bloodspot screening protocols and procedures must include instruction on provision of information and obtaining and documenting verbal consent from parents or guardians. Informing parents about the test in the last four to six weeks of pregnancy as well as postnatally is recommended. (Section 1 above). It is noted that the earlier prenatal period is the time for making decisions about prenatal testing and other tests related to pregnancy. A significant number of mothers do not present for prenatal care but only at delivery time. It is also noted that having a baby is accompanied by the provision of a great deal of information about prenatal health, the birth process and care of the infant. The perinatal period is busy with a potentially confusing number of events such as administration of oxytocin, vitamin K or hepatitis B immunisations and their information and consent requirements.

Therefore, it is recommended that after birth, and before the bloodspot is collected, the nominated health professional should check that parents/guardians have received a copy of the parent information pamphlet, that they have had opportunity for discussion and clarification and that they agree to the test. The mother’s presence during the test is recommended to soothe the baby and enhance understanding.

¹³ “Patient Information and Consent to Medical Treatment” – NSW Health Department Policy Directive PD2005_406
http://www.health.nsw.gov.au/policies/PD/2005/PD2005_406.html

Title: Newborn Bloodspot Screening Policy

There must be documentation in the mother's or baby's medical record stating there has been discussion about the newborn bloodspot screening test. The parent's/guardian's consent must be recorded in the medical record. Written consent from the parent/guardian is not necessary. However some hospitals have opted to obtain written consent for the test. In some instances this is combined with consent for other procedures such as vitamin K and hepatitis B injections.

The medical record should also indicate completion of the newborn screening test. A pre-inked stamp similar to the example below is recommended. All parts need to be completed.

Baby's name: _____	
Signature (Health Professional)	
Provision of the NBS pamphlet: _____	Date: _____
Discussion of NBS information: _____	Date: _____
Verbal/written consent: _____	Date: _____
Completion of sample collection: _____	Date: _____

It is noted that depending on local protocols, there may be a medical record in the mother's name or in the baby's name. It is important that information about newborn bloodspot screening is recorded in the baby's Personal Health Record (PHR) also known as the "Blue Book".

4.3 Refusals

The Patient Information and Consent to Medical Treatment policy also provides guidance concerning refusals and care and protection of minors based on the Children and Young Persons (Care and Protection) Act 1998¹⁴.

Parents/guardians may refuse the newborn bloodspot screening test on behalf of the baby. However, the program diagnoses about 90 babies each year for which treatment is urgently needed and refusal of the test might unnecessarily risk the baby's health. Hospitals should devise a protocol for parental/guardian refusal of a newborn bloodspot screening test for their baby consistent with NSW Health's Policy Directive on Consent and NSW Newborn Screening Programme Sampling Information and Guidelines disclaimer form. The protocol should include parents/guardians being properly informed about the test and its importance, discussion about concerns with the paediatrician or specified health professional who

¹⁴ NSW Children and Young Persons (Care and Protection) Act, 1998

Title: Newborn Bloodspot Screening Policy

is aware of all the implications of not screening, and an offer of the option of telephoning the Director of the Newborn Screening Programme to answer any further questions they may have.

Refusals must be documented and signed in the mother's/baby's record and a *newborn bloodspot screening sample card with completed demographic information, and "refusal" written on it sent to the laboratory*. This is important for future enquiries regarding the lack of testing for both the hospital and the laboratory. Reason for refusal should be documented for audit purposes and program improvement.

Parents/guardians who refuse testing should be advised to take their child for medical attention if they are at all worried or the child is unwell and tell the healthcare worker that the child has not been screened.

5 Results

The receipt of each baby's bloodspot card is confirmed with the hospital. Results are usually available within two working days after receipt of the sample. In most cases the results are normal. Hospitals are only advised of individual results when retesting is necessary.

5.1 Repeat blood test

A few babies will need to have a second blood test, usually because the first test did not give a clear result. The reason for retesting should be explained to parents/guardians. Most babies' second tests will give normal results and the hospital/doctor will be informed.

5.2 Abnormal results

The paediatrician/doctor/independent midwife shown on the newborn bloodspot screening card is notified by telephone of test results which are abnormal and could indicate any of the disorders. It is the responsibility of this person to ensure that the baby is promptly referred for further investigation and treatment. The name of the responsible person must be filled in on the test card. Where there is uncertainty regarding whose name is to be written, it is recommended that the name be that of the paediatrician of the day.

6 Sampling Information and Guidelines

The NSW Newborn Screening Programme laboratory issues Sampling Information and Guidelines detailing procedures for collecting and handling newborn bloodspot screening samples. These are updated from time to time to incorporate new procedures and are supplied to hospitals/maternity units and independent midwives. Contact details are included in section 9 below.

7 Written protocols

Hospitals are required to have written protocols that incorporate the information provided in this policy together with additional information from the NSW Newborn Screening Programme Sampling Information and Guidelines.

8 Maternity hospital nominated newborn screening liaison person

Hospitals are to nominate a liaison person (eg community liaison midwife or nurse unit manager of maternity) to be responsible for newborn bloodspot screening. The name and position of the nominated and relief person should be notified in writing to The NSW Newborn Screening Programme (see contact details). Responsibilities of the nominated newborn screening liaison person are detailed in The NSW Newborn Screening Programme Sampling Information and Guidelines.

9 Contact details and sources of further information

Tests to protect your baby - available from:

The Better Health Centre – Publications Warehouse
Locked Mail Bag 5002
GLADESVILLE NSW 5003
Telephone: (02) 9816 0452
Facsimile: (02) 9816 0492

NSW Newborn Screening Programme Sampling Guidelines – available from

The NSW Newborn Screening Programme
Locked Bag 2012
WENTWORTHVILLE NSW 2145
Telephone: (02) 9845 3255 / 3659
Facsimile: (02) 9845 3800
Website <http://www.chw.edu.au/prof/services/newborn>

10 NSW laws, NSW Health policy and other publications relevant to Newborn Bloodspot Screening

NSW Acts

Health Records and Information Privacy Act, 2002
Human Tissue Act, 1983
NSW Children and Young Persons (Care and Protection) Act, 1998
NSW State Records Act, 1998
Privacy and Personal Information Protection Act, 1998

Title: Newborn Bloodspot Screening Policy

NSW Health Policy

NSW Health Consent Policy - Consent to Medical Treatment – Patient Information, PD2005_406

http://www.health.nsw.gov.au/policies/PD/2005/PD2005_406.html

NSW Health Privacy Manual (Version 2) 2004:

http://www.health.nsw.gov.au/policies/pd/2005/PD2005_593.html

General Retention and Disposal Authority – Public Health Services: Patient/ Client Records (GDA 17), NSW Department of Health Information Bulletin No 2004/20,

<http://www.health.nsw.gov.au/archive/cib/information-bulletins/2004/ib2004-20.pdf>

Records - Principles for Creation, Management, Storage and Disposal Health Care Records, NSW Department of Health PD2005_127

http://www.health.nsw.gov.au/policies/PD/2005/PD2005_127.html

Other Guidelines

National Statement on Ethical Conduct in Research Involving Humans, National Health and Medical Research Council, 1999, currently under revision.

<http://www.nhmrc.gov.au/publications/synopses/e35syn.htm>

National Pathology Accreditation Advisory Council, Retention of laboratory records and diagnostic material.

APPENDIX 1

Newborn Bloodspot Screening

Checklist for health professionals to complete with parents

- **During pregnancy** – Give the leaflet “TESTS TO PROTECT YOUR BABY” to parents preferably in the last four weeks of pregnancy with opportunity for discussion and questions and show video.
- **After birth** – Make sure that parents/guardians have been given the leaflet “TESTS TO PROTECT YOUR BABY” with opportunity for discussion and questions and show video.

Inform parents/guardians about:

- 1 Conditions tested – phenylketonuria, galactosaemia, hypothyroidism, cystic fibrosis and rare metabolic diseases
- 2 Benefits of testing - diagnosis and treatment can prevent death or serious illness.
- 3 Heel prick process – encourage mothers to be present and breastfeed.
- 4 Information collected – name, date of birth, hospital, etc.
- 5 Bloodspots storage for 18 years – consent is not required for storage
- 6 Records storage for 25 years – standard policy
- 7 Bloodspots and record security – governed by privacy and human tissue legislation and Health Department policy
- 8 Potential uses of, and access to, stored bloodspots
 - Identified cards may be used for family benefit or research and only with separate consent obtained before testing
 - Non-identifiable cards, ie with identifiers permanently removed may be used for research approved by a Health Research Ethics Committee – consent is not required
 - Parents have a right to access their child's information. Other access requires parental consent except where there is a court order. To date this has not occurred.
- 9 Inform the parents about how results are conveyed
 - Normal results
 - Retesting
 - Abnormal results

After all the above information has been provided and discussed:

- 1 Record in the mother's/baby's medical record that information has been provided and discussed
- 2 Obtain and document parent/guardian consent in the mother's/baby's medical record
- 3 Hospital staff are required to complete the relevant section of the baby's Personal Health Record (Blue Book)
- 4 If parents refuse testing, follow hospital protocol
- 5 Conduct the test following sampling guidelines provided by the NSW Newborn Screening Programme

Title: Newborn Bloodspot Screening Policy

Contact details and sources of further information:

Tests to protect your baby - pamphlets from:

The Better Health Centre
Locked Mail Bag 5002
GLADESVILLE NSW 5003
Telephone: (02) 9816 0452
Facsimile: (02) 9816 0492

NSW Newborn Screening Programme Sampling Guidelines – available from

The NSW Newborn Screening Programme
Locked Bag 2012
WENTWORTHVILLE NSW 2145
Telephone: (02) 9845 3255 / 3659
Facsimile: (02) 9845 3800
Website <http://www.chw.edu.au/prof/services/newborn>