

Newborn screening sample collection guidelines

Detailed information about the newborn screening program, including correct sample collection techniques, can be found in the e-learning tool available at:

www.vcgs.org.au/pathology/nbs

Step 1

Informing parents about screening

Before sample collection, staff must ensure parents are properly informed about screening and its importance.

The information brochure 'Newborn Screening – for the health of your baby' should be provided to parents during the last trimester. The information must be discussed with parents and is available in a number of community languages:

www.vcgs.org.au/pathology/nbs

Step 2

Informed consent

Prior to sample collection, staff must obtain written consent. The consent form is on the front of the screening card and has two sections; consent for collection of a blood sample and permission for secondary use of the sample in de-identified research. **Both sections must be completed and signed.**

Secondary use of the sample in research is a personal choice and should not deter parents from screening.

Decline of screening

- If parents choose to decline screening, engage in further discussion to ensure they are aware of the risks. These are outlined on the newborn screening brochure.
- Fill in a screening card as normal with the baby's details and send to the laboratory.
- Have parent/s complete the decline of screening form and place in the medical record.

There may be legal implications for hospitals if appropriate records of decline are not maintained.

Step 3

Sample collection

Collection should occur between 48-72 hours after birth via a heel prick. Feeding or holding baby during collection is encouraged and reduces anxiety.



Clean the heel with an alcohol wipe

Do not add anything further to the heel – e.g. paraffin. This will contaminate the sample.

Puncture the heel at the edge of the plantar surface (see diagram) using an automated lancet.

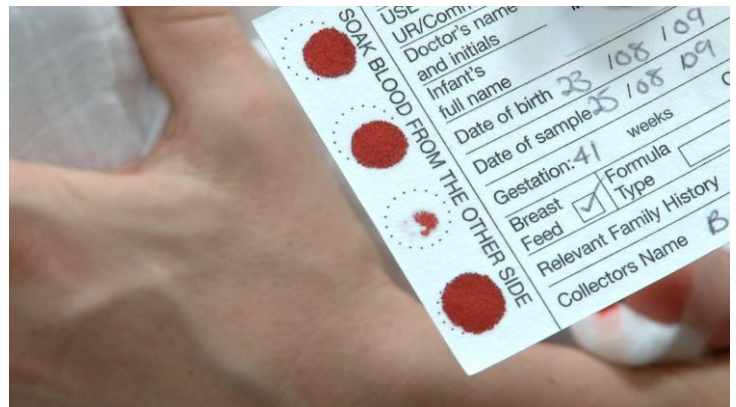
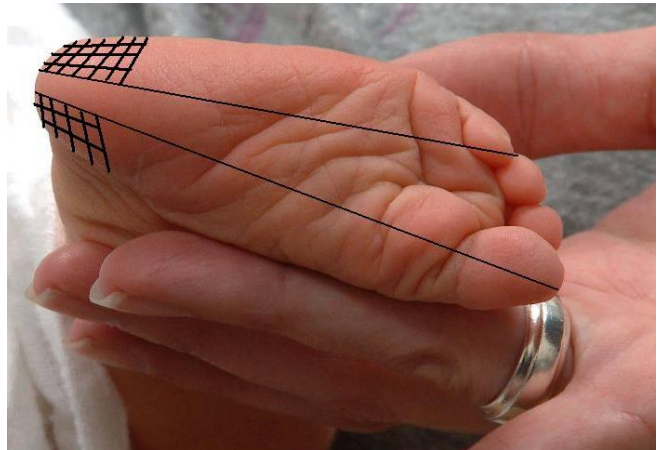
Wipe away the first drop of blood to remove any contamination.

Soak blood from one side only (screening card is labelled) and avoid layering spots – apply as a single drop.

It is not vital that all circles are full – a drop that is evenly soaked through and fills 2/3 of the circle is adequate.

If collection is difficult, 3 good circles will be sufficient.

Air dry cards away from heat, for at least 4 hrs. Send to the laboratory ASAP – do not place cards in plastic as they will sweat.





Newborn screening blood spot check

After the card has dried, check your collection against these examples. Any cards that look like the 'not acceptable' examples should be recollected.

GOOD SAMPLE



All circles filled, blood soaked from back of card, one application with no over-layering of blood, sample dried in air for 4 hours

ACCEPTABLE SAMPLE



It is not essential to fill all circles if collection is difficult or causes unnecessary trauma to the baby or parents. Three good spots are usually sufficient



Small misalignments with the circles or slight over or under filling is acceptable

NOT ACCEPTABLE



Insufficient blood: blood not soaked through card properly



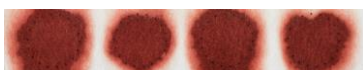
Insufficient blood: not enough circles



Contaminated sample: another liquid has been in contact with the card e.g. TPN, water, urine, tea, coffee, etc



Sample not dried properly: not air dried for 4 hours, card placed in plastic bag



Serum rings: not wiping alcohol from heel before puncture, card contaminated with alcohol, hand lotion or water, excessive squeezing to collect sample.

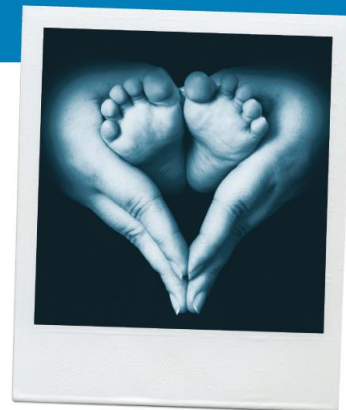


Back

Clotted or layered: filling card from both sides, touching paper to blood several times



Front



Collecting a sample—key points

Consent must be obtained prior to undertaking the heel prick—doing a procedure without consent is not permissible.

Having mum **breastfeed** (or hold the baby) is recommended to provide comfort during the procedure.

Do not apply paraffin to a clean heel and wipe away the first drop of blood remove contaminants— as this may affect results.

Avoid excessive squeezing of the heel—this can contaminate the sample with tissue fluid.

Do not overlay spots or soak from both sides—this leads to layering and too much blood being collected.

Keep the wet card **away from contaminating** surfaces or substances.

Air dry the card at room temperature for 4hrs; away from direct sunlight or heat.

Use paper envelopes to send cards to the laboratory—**not plastic**.

Avoid delays in getting the sample to the laboratory.

Express post or courier within 24hrs of collection. If mail is going to be disrupted (e.g. Easter, Christmas) a courier service should be used. Cards need to be kept cool and it is not appropriate to have cards sitting in post boxes over weekends or holidays.



Collecting a sample - other considerations

Storage of screening cards prior to use

It is best to store cards on their side, especially if storing several hundred cards. Laying cards flat 'compresses' the fibres in the card and reduces the blood holding capacity of the card. When blood is applied, it will look pale and blotchy and cannot be used by the laboratory.

Newborn screening liaison midwife

It is vitally important that a newborn screening liaison midwife be identified to assist with tracking samples and so that the laboratory has a single point of contact with regard to repeat samples and positive screening results. The laboratory only knows a baby has been born when it receives a card; the hospital only knows the newborn screening card was received and tested by the laboratory when they receive the weekly report of results. Therefore, the liaison midwife is needed to check off the results with the hospital birth register to make sure all babies are accounted for. The laboratory also needs to be informed when there is a neonatal death and when testing is declined (send a completed card to the lab).

NST's collected in the community

The biggest issue is maintaining the integrity of the sample once collected. For midwives making multiple stops, it is recommended that you take an A4 envelope to collect the cards in (easier than an esky). Lightly wrap each card in paper towel (does not have to be sterile) and place in the envelope. Carry this envelope at each stop – do not leave it sitting in a hot car. Cards will still require time to dry, but the paper towel will prevent them touching. Also avoid heavy objects sitting on the envelope. Blank cards should not be stored in cars for later use.

Repeat samples

On occasion, a repeat sample will be requested. This may occur because of an insufficient sample, contamination, sample is clotted or layered or the screening results were borderline or unclear. Reassure parents that most repeat samples will provide normal results. Research has shown some parents will avoid screening of future children because of a previous bad, anxiety provoking experience – so communicate clearly.



Why do I have to collect the sample between 48-72 hours?

This time period represents a balance between allowing enough time for baby's metabolism to establish itself (independent of mum) and avoiding a delay in diagnosis. A sample collected too early may give a false negative result, as imbalances may not yet be apparent. A sample collected too late, may lead to a delay in diagnosis and treatment of a condition. The hormone or chemical imbalances that characterize metabolic conditions can irreversibly impair development if undetected. The laboratory controls and standards are also set using these particular timeframes. If samples are collected outside 48-72hrs, make sure to note this on the card.

Is it too late to collect a sample?

In the case of PKU or hypothyroidism, the screening tests remain positive throughout life (if untreated). In both cases however, for treatment to be effective it must be initiated in the newborn period. With CF, the screening test gradually becomes negative over a period of months, which means screening is only useful during the newborn period. Any sample is better than none, so collect a sample ASAP if a baby has not been screened in the 48 – 72 hour window.

What if all the circles can't be filled?

It is not vital to have all 4 circles completely filled. Circle size is just an indicator – an evenly soaked through drop that fills 2/3 of the circle is adequate. If collection is traumatic or difficult, three circles will usually be sufficient.

Breastfeeding and blood taking

It is appropriate to collect the newborn screening sample prior to a feed; this is because we are trying to measure the baby's baseline biochemical profile. However, it is perfectly acceptable (and recommended) for mum to breastfeed baby during the heel prick procedure (and for a few minutes prior to collection) to reduce discomfort and anxiety.



Clotted and layered samples

This is one of the most common reasons for a repeat sample being requested. Several drops are being placed 'on top of each other' on the same circle with some time passing between each drop. This results in the first drop starting to dry before another is dropped on top. The second drop will be unable to penetrate the filter paper and is 'sitting' on top of the first, giving falsely increased results. Another problem is filling a circle from both sides of the card. Sometimes, a blood drop doesn't completely soak through from the back to the front of the card and another drop is then placed on the front of the card in a misguided attempt to completely fill both sides. These samples will be rejected.

Faecal contamination

Can increase many amino acids and cause a false positive for cystic fibrosis. Make sure the heel is clean before collecting the sample.

Iodine based antiseptics

Iodine is absorbed and can cause a false positive for hypothyroidism. Avoid use until after sample has been collected.

Jaundice and antibiotics

Do not affect the screening test, collect the sample as normal.

Lines

Central, peripheral or arterial lines can dilute the sample with IV fluid. Draw back 2-3mls, change syringe and collect sample; can replace first syringe to conserve blood.

Feeding

Phenylalanine in the blood of a baby with PKU comes from protein and amino acids in the diet. Babies deprived of protein will eventually breakdown tissue protein in order to obtain the essential amino acids, including phenylalanine. Thus in PKU, phenylalanine will build up in the blood even with a protein deficient diet and it is not necessary to delay the test in the case of a 'poor feeder'.



Premature and low birth weight infants

These babies will require a second sample at a time when their systems are fully functional. From the perspective of the laboratory, the WEIGHT of the baby is more important than the prematurity (gestational age); weight is a definite and gestational age is open to interpretation. Both should be recorded on the card. The recommendations below are based on low birth weight and not prematurity.

Less than 1000g – 2nd sample collected at 3 weeks
Between 1000g- 1499g – 2nd sample collected at 2 weeks

Samples collected into EDTA or citrate tubes

This is not recommended. Sample preference is heel prick, followed by samples collected by venepuncture or from a line. If sampling from a tube is unavoidable, please record the type of tube used on the NBS card.

Intravenous and total parenteral nutrition (IVN/TPN)

Collect the sample in the normal 48 – 72 hour period. IV nutrition changes the levels of many metabolites. Make sure the TPN box is ticked for any samples taken when the baby is on IVN/TPN because this information helps the laboratory interpret the profiles. Some babies on IVN/TPN may require a repeat test because of equivocal results.

Transfusions

This includes platelets, FFP, whole/packed and exchange transfusions. NICU/special care infants present many challenges with regard to interpretation of newborn screening results; there are a number of factors that may affect the metabolic status. Introducing 'foreign material' dilutes the baby's system and can lead to false negative results. Therefore, it is recommended to collect a sample before transfusion, regardless of the time. The second sample should be collected 48hrs after the transfusion is complete.

Please note

A sample will also be requested at 3 weeks in the following circumstances. If the initial sample was taken prior to the 48-72hrs, the baby was extremely premature and/or blood transfusions are involved or combinations of the above. The main purpose of this sample is to recheck the baby's TSH level because blood transfusions or prematurity can possibly mask hypothyroidism



Repeat samples -NICU/SCN

The laboratory will request a repeat sample in the following

Circumstances:

- the initial sample was taken prior to the 48-72hrs
- the baby was very low birth weight (see above)
 - the initial sample was collected less than 48 hours after a blood transfusion

The main purpose of this repeat sample is to recheck the baby's TSH level because blood transfusions or prematurity can possibly mask hypothyroidism. We recognise that some babies will still be receiving transfusions when the repeat sample should be taken. In this situation it is acceptable to delay collection of the repeat sample for a while until the baby has 48 hours clear of transfusions.

However, please do not delay the repeat collection for too long:

Birth weight <1000 g – repeat sample no later than 6 weeks

Birth weight 1000g-1499 g– repeat sample no later than 4 weeks

Please record any transfusion details on the card.



Timeliness of sampling and quality issues (key performance indicators)

Our guidelines are based on recommendations by the joint newborn screening subcommittee of the Human Genetics Society of Australasia and the Division of Paediatrics of the Royal Australasian College of Physicians. The full guidelines can be found at:

<http://www.hgsa.org.au/2011/08/newborn-blood-spot-screening/>

It is important that hospitals take steps to ensure that good quality newborn screening (NBS) samples are collected and sent promptly to the NBS lab. Any repeat samples should also be collected promptly. A delayed diagnosis could result in permanent damage or even death to the baby. We recommend that hospitals and midwives/nurses aim to achieve the following performance:

- a) <2% bad sample rate. This includes cards with inadequately completed information.
- b) >95% of first NBS samples to arrive at the NBS lab within 4 days of sample collection.
- c) >95% of repeat samples to arrive at the NBS lab within 12 days of receipt of request for the repeat.

The NBS lab can provide hospitals with a statistical breakdown of the above performance indicators and also provide advice on ways to achieve and maintain this performance. Please contact the newborn screening lab on 8341 6272 or email-screeninglab@vcgs.org.au if you would like further information or advice.

Lastly.....

If you are unsure or have a question about appropriate sample collection, contact the laboratory – they will be able to guide you.

Newborn Screening Laboratory:

Po Box 1100, PARKVILLE 3052

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