NBS Collection Guideline

Contents (clickable links)

BG-W-267 v9 05/01/2026

1. Resources via QR code

All your newborn bloodspot screening resources are now available at the bedside including important information for parents and midwives/nurses.

Using a mobile phone, scan the QR code located on the back of the NBS card.

All your NBS resources are available to download including translations of the brochure, correct sample technique and the e-learning tool or visit the website:

https://www.vcgs.org.au/tests/newborn-bloodspot-screening

Figure 1. Side 1 of screening card

2. Written informed consent

Consent

Consent is a process that ensures an individual has been provided with appropriate information that enables them to make an informed choice, considering the implications and consequences of such a decision. The amount of information required to allow an informed choice will vary amongst individuals.

Information

Before the newborn bloodspot screening sample is collected, midwives must ensure that parents or guardians are properly informed about the test and its importance. This information needs to be multi-layered to account for different individual requirements. Information available includes:

- written information in the form of a brochure, ideally given and discussed during the third trimester
- verbal information from a midwife/health professional
- the option of a consultation by phone with a newborn bloodspot screening counsellor based at Victorian Clinical Genetics Services (The Royal Children's Hospital)
- electronic information available at https://www.vcgs.org.au/newborn-bloodspot-screening

Information and discussion around newborn bloodspot screening should occur prior to delivery and again after birth, before sample collection.

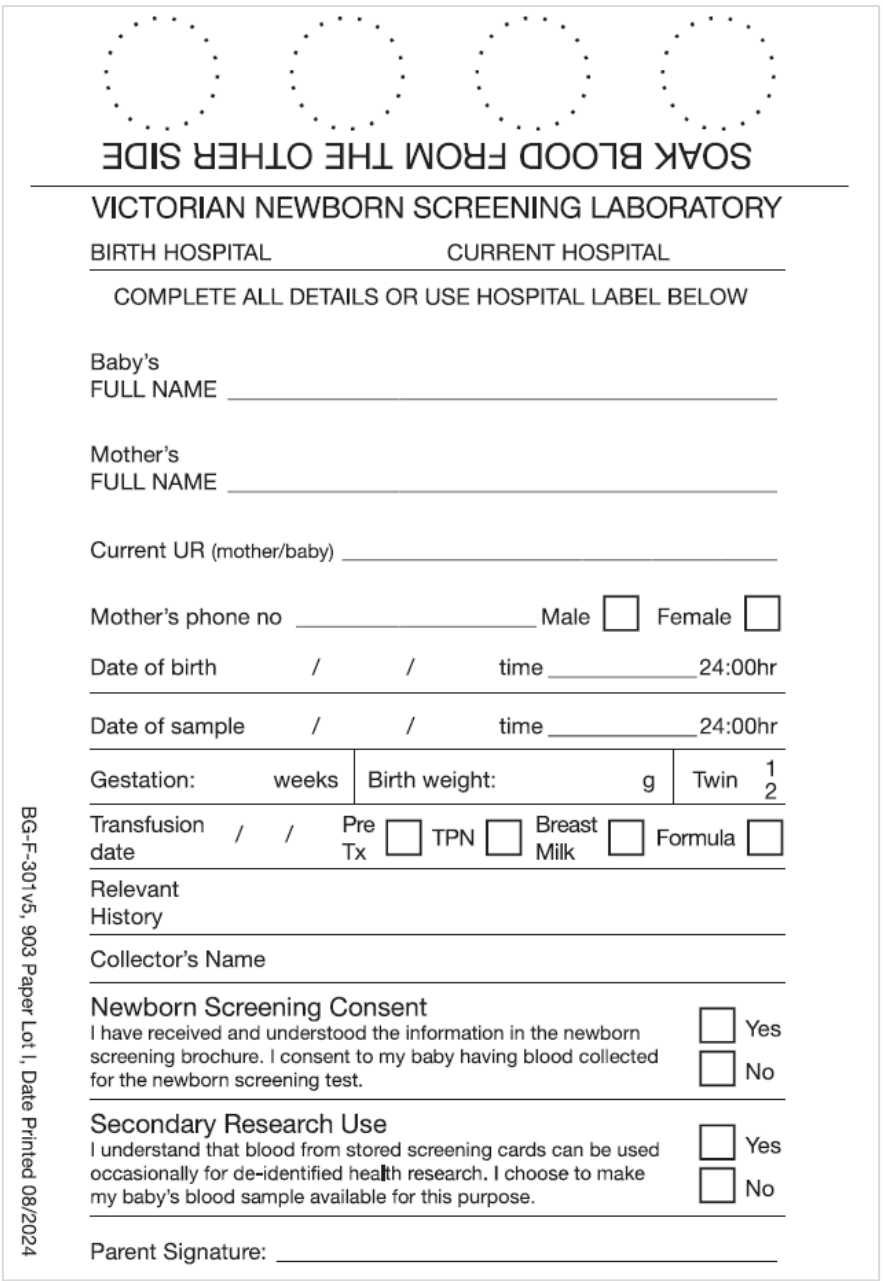
Obtaining consent

Written consent is required from a parent or guardian before collecting a sample; taking blood without consent is not permissible and is a breach of the *Human Tissue Act 1982*.

The consent section on the screening card needs to be completed and signed by a parent/guardian. Documentation should also be made in the mother's file that discussion around newborn bloodspot screening has occurred, consent provided and the date a sample was collected.

Screening card

The screening card will look like this:



SOAK BLOOD FROM THE OTHER SIDE

VICTORIAN NEWBORN SCREENING LABORATORY

BIRTH HOSPITAL CURRENT HOSPITAL

COMPLETE ALL DETAILS OR USE HOSPITAL LABEL BELOW

Baby's FULL NAME _____

Mother's FULL NAME _____

Current UR (mother/baby) _____

Mother's phone no _____ Male ☐ Female ☐

Date of birth / / time _____ 24:00hr

Date of sample / / time _____ 24:00hr

Gestation: weeks | Birth weight: g | Twin 1 2

Transfusion date / / Pre Tx ☐ TPN ☐ Breast Milk ☐ Formula ☐

Relevant History

Collector's Name

Newborn Screening Consent
I have received and understood the information in the newborn screening brochure. I consent to my baby having blood collected for the newborn screening test. ☐ Yes ☐ No

Secondary Research Use
I understand that blood from stored screening cards can be used occasionally for de-identified health research. I choose to make my baby's blood sample available for this purpose. ☐ Yes ☐ No

Parent Signature: _____

BG-F-301v5, 903 Paper Lot I, Date Printed 08/2024

Figure 2. Side 2 of screening card

Please complete all the personal details and/or attach the hospital bradma label.
If you know the father has a different surname to the baby, it is useful to list that on the card.
A parent or guardian must indicate consent for sample collection and their preference regarding secondary research use of the sample for de-identified research.
A signature at the bottom is required.

Making the card available for research use is a personal choice and should not interfere with the decision for screening.

3. Decline of screening

Hospitals and maternity service providers are responsible for ensuring that parents of all newborns are offered screening. Whilst Newborn bloodspot screening is a voluntary program in Australia and is highly recommended, parents do have the right to refuse. This decision must be informed, and midwives must take extra time to ensure parents are aware of the risks involved.

Step 1

When parent/s are unsure or choose to decline screening, engage them in further discussion to determine their concerns and any possible misinformation. If their concerns are around storage and access to screening cards, reassure them they are free to opt out of research use and are able to request their baby's card back after 2 years.

Step 2

Highlight that:

- choosing not to screen may lead to a delay in diagnosis and treatment of a serious medical condition;
- a delay in treatment could impair normal development and in rare cases, the condition may cause death;
- there are no alternatives to screening; by the time symptoms appear, development may already be affected.

Step 3

Offer to refer parent/s to a paediatrician or a newborn screening counsellor (ph. 1300 118 247), who will be able to further discuss any concerns.

Step 4

If, after discussion, parents wish to decline screening, this decision must be respected. Accurate records are required to document parental choices; there may be legal implications if such records are not kept.

If the decline scenario is not straight forward, please contact the NBS lab immediately for clarification

It is vital a decline of screening is appropriately recorded - both by the hospital/provider and by the laboratory. The following needs to be completed:

- A decline form indicating understanding of potential risks, should be signed by the parent and placed in the baby's or mother's file for future reference (see example below). Also record refusal in the baby's Maternal and Child Health Record.
- Fill in a screening card. This **should be signed by the parent indicating 'decline' of screening** and sent to the laboratory as a record of refusal.

The laboratory **does not know a baby is born** unless it receives a screening card.

You must also advise the family to seek medical attention if their baby is unwell and to tell the health care provider that the baby has not had newborn bloodspot screening.

INFORMAL DECLINE: Protecting Privacy

In the situation where parents refuse to engage with the maternity facility and have not made their intentions to consent to screening clear, this may be considered an informal decline of screening.

DH has indicated that making a card (containing baby's details) available to NBS cannot be enforced if the maternity facility believes this to be a breach of the parent's right to confidentiality, as documented in their charter.

Maternity staff should document the informal decline to screen in the mother's medical history, including all attempts to follow up with the family.

Step 5

Finally: remind parents/guardians that they can change their mind at any time regarding declining screening but, some disorders will not be detected if newborn bloodspot screening is not performed within the recommended time frame. Parents/ guardians can also be advised to speak with their MCHN or contact VCGS newborn bloodspot screening counsellor for further information.

<u>Decline of Screening Form – suggested wording</u>

- I understand the information in the newborn bloodspot screening brochure.
- I **do not** consent to blood being collected from my baby for newborn bloodspot screening.
- I understand that choosing **not** to have my baby screened could lead to a delay in diagnosis and treatment of a serious medical condition.
- I understand that a delay in treatment could affect normal development and in rare cases death, should my baby have a condition detectable by newborn bloodspot screening.
- I have discussed my decision with a midwife or health professional.

Parent signature_____
Parents Name_____
Midwife/ health professional_____
Date:_____

Figure 3. Decline of screening form.

4. Sample Collection

Collection should occur between 36-72 hours after birth via a heel prick. Feeding or holding baby during collection is encouraged and reduces anxiety.

[Heel puncture collection for Newborn Bloodspot Screening (video)]

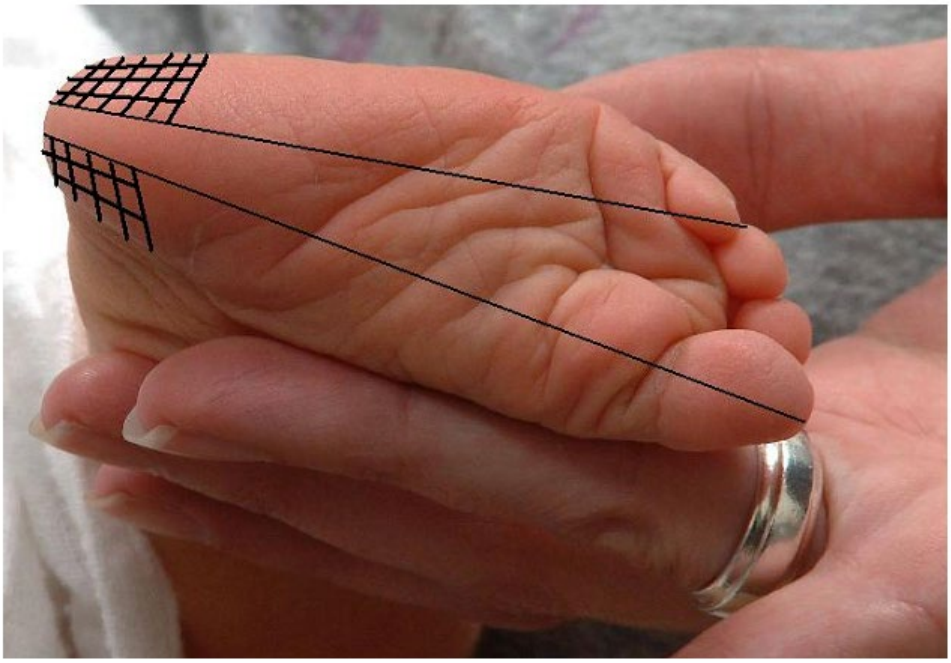


Figure 4a. Puncture heel at the edge of the planter surface

Figure 4b. Aim for all 4 circles to be filled

5. Key points

1. **Preparation**
   a) **Consent** must be obtained prior to undertaking the heel prick—doing a procedure without consent is not permissible.
   b) **Pain management -** Having mum **breastfeed** (or hold the baby) is recommended to provide comfort during the procedure.
   c) **Condition of heel – Ensure heel is warm** using your own warm hands. Do not use artificial means to warm the heal.
2. **Identify the correct side of card** on which to apply blood.
3. **Clean heel** as per local protocol. Do not apply paraffin to the heel.
4. **Puncture** heel at the edge of the planter surface (see Figure 4a) using a retractable automated lancet. **Wipe away the first drop of blood** to remove any contaminants and tissue fluid. Although not the preferred method, blood can be collected and applied using an ANTICOAGULANT-FREE capillary tube. Using blood from heparinised tubes can interfere with some NBS laboratory tests.
5. **Gently squeeze** the heel to produce a large drop of blood. **Avoid excessive squeezing** as this can contaminate the blood with tissue fluid. Place the drop of blood onto the first circle marked on the card. Complete this circle before moving on to apply blood to the next circle.
6. **Do not overlay** spots or soak from both sides—this leads to layering and too much blood being collected.
7. **Aim to fill all circles** - If the collection is difficult or traumatic, send the card to the NBS laboratory, where it will be tested, and if deemed insufficient, a recollection will be requested (see Figure 4b).
8. Keep the wet card **away from contaminating** surfaces or substances.
9. **Air dry card horizontally,** at room temperature for 3-4 hours; away from direct sunlight or heat.
10. Place dried card into a **paper envelope** to send to the laboratory. **DO NOT PLACE CARDS IN PLASTIC BAGS/SPECIMEN BAGS.**
11. **Avoid delays**, send in the sample to the laboratory ASAP. Courier or express post within 24hrs of collection (check local protocol). 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.

6. Quality 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	
	Small misalignments with the circles or slight over or under filling is acceptable
GENERALLY ACCEPTABLE	
	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
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.
	Clotted or layered: filling card from both sides, touching paper to blood several times

Figure 5. Examples of good, acceptable and not acceptable samples

7. Quality issues

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 usually affect the screening test. Collect the sample as normal and document on the card.

Lines

Central, peripheral, or arterial lines can dilute the sample with IV fluid. Draw back 2-3mls, change syringe and collect sample; replace first syringe to conserve blood (as per your institute's protocols).

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'.

8. Other considerations

Storage of screening cards prior to use

It is best to store cards vertically, ie. 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. Blank cards should not be stored in cars for later use as overheating then cooling decreases absorption.

Why do I have to collect the sample between 36-72 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 timeframes. If samples are collected outside 36-72hrs, make sure to note this on the card.

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 pain/discomfort and anxiety.

What if all the circles cannot be filled?

Due to an increased number of screening tests, adequate blood volume is essential. To avoid recollections, please aim to fill all circles. Circle size is just an indicator. If the collection is traumatic or difficult, please send all cards to the NBS lab as they will be tested. Then, if deemed insufficient, a recollection will be requested.

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 cystic fibrosis, 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 36-72 hour window.

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.

Samples 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. It is also recommended that blank cards not be stored in the cars for later use, as overheating then cooling decreases absorption.

Stillborn babies

As per the Department of Health guidelines please ensure that stillborn births are recorded, and a notification sent to the newborn bloodspot screening laboratory.

9. Newborn bloodspot screening for premature / sick neonate protocol

Each of the conditions/diseases we are screening for has an optimal screening window, the ideal window is different for preterm / low birth weight and sick baby's vs a healthy term baby.

The flow chart (figure 6) below shows the pathway for the collection of NBS samples for all neonates.

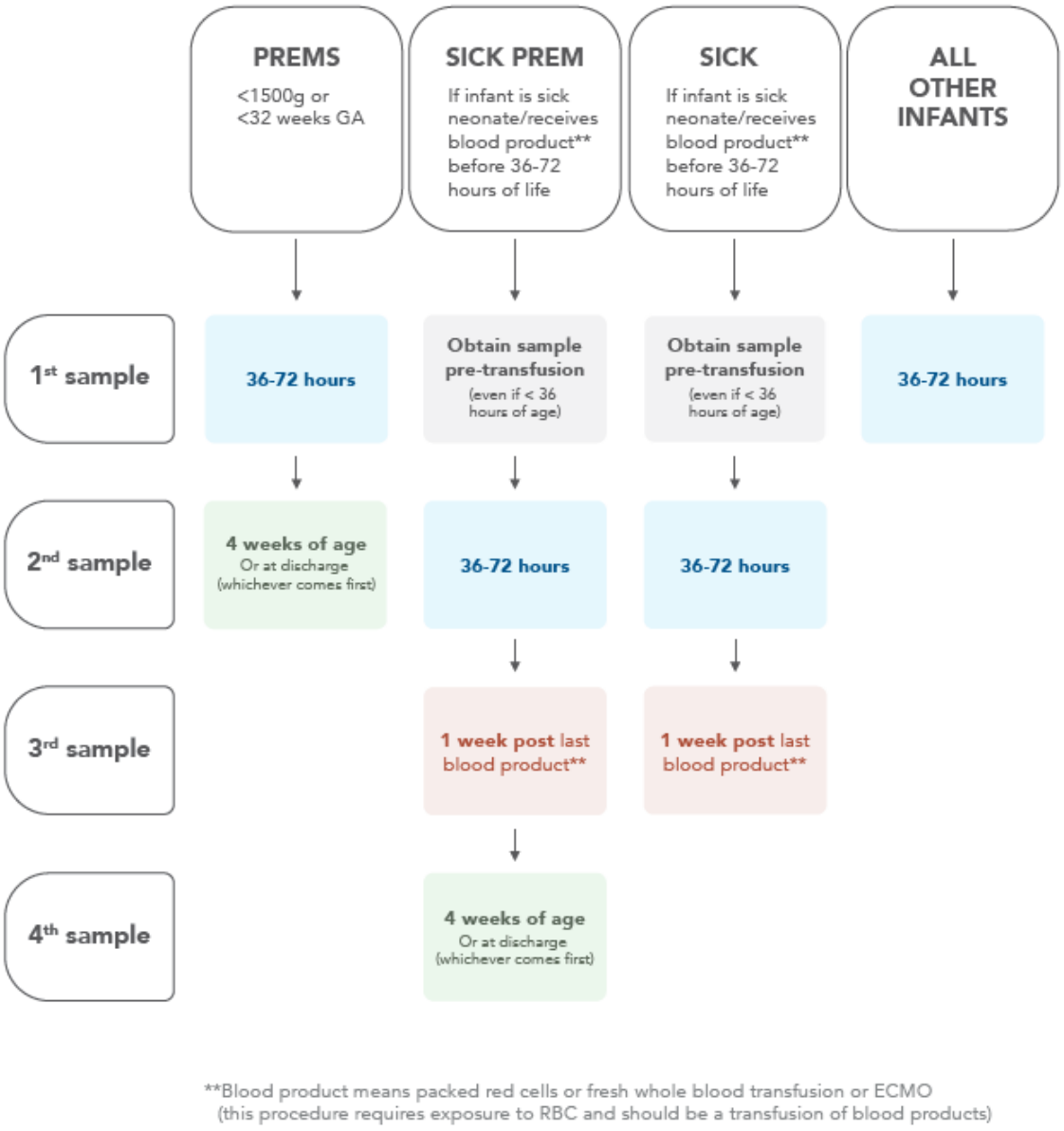
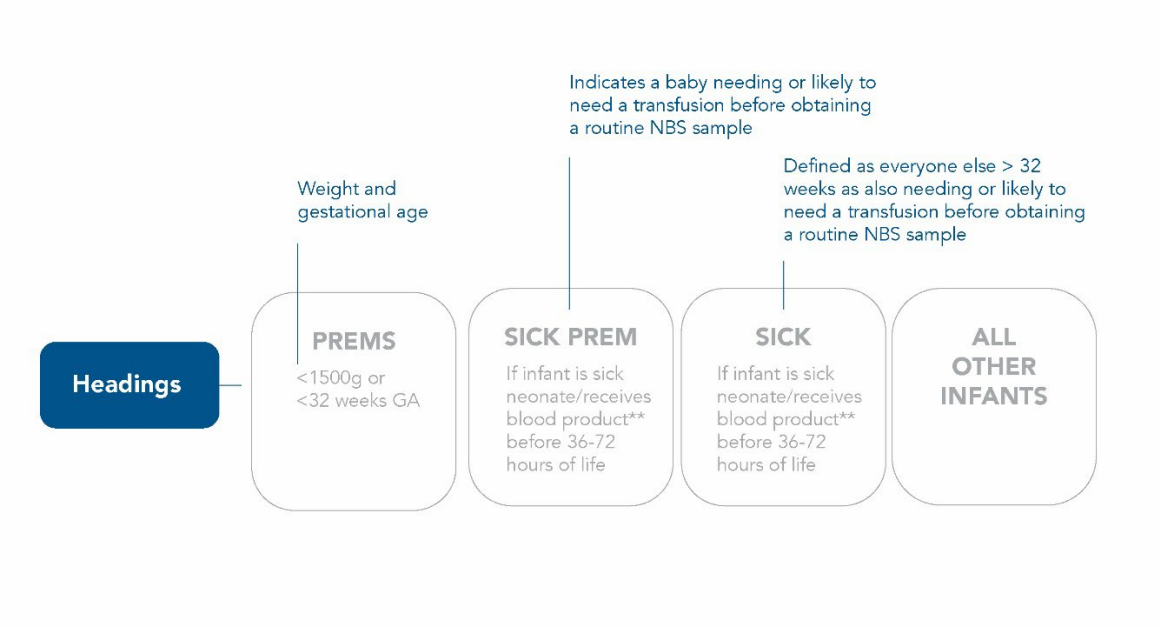


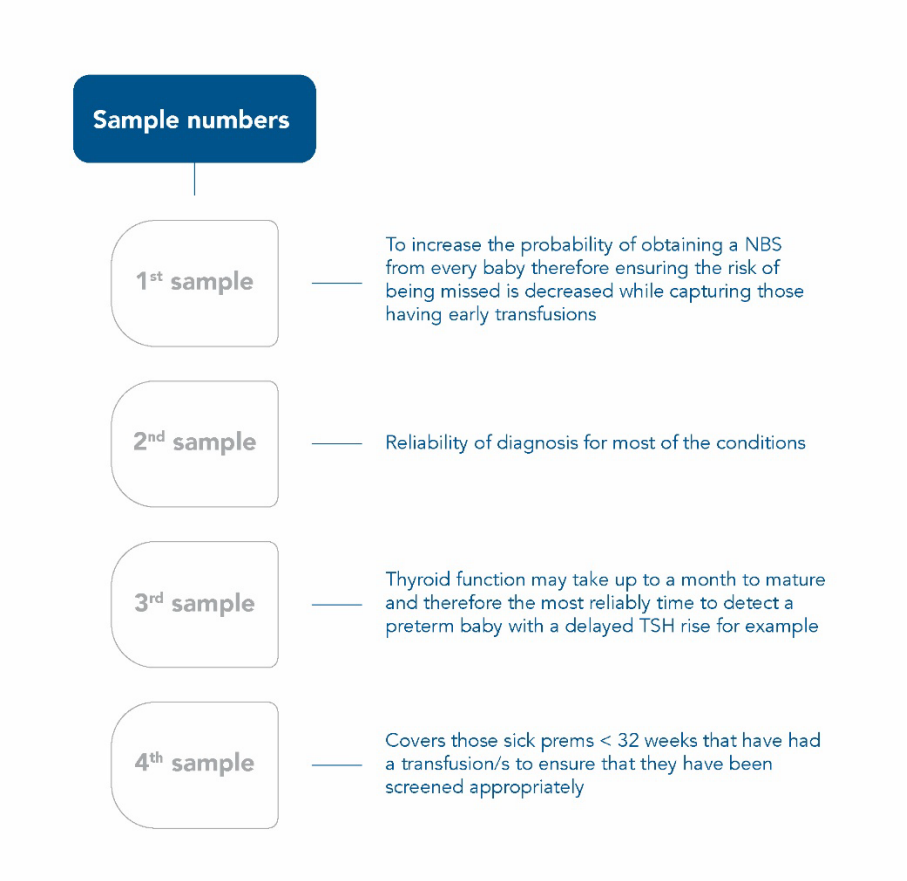
Figure 6. Premature and sick neonate collection times

Flowchart legend:

Horizontal:



Vertical:



Blood products

Blood product means packed red cells or fresh whole blood transfusion or ECMO (this procedure requires exposure to RBC and should be a transfusion of blood products).

Samples collected into EDTA or citrate tubes

This is not recommended as these anticoagulants can interfere with our immunoassays. 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 36-72 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.

10. Newborn bloodspot screening liaison midwives

It is vitally important that two newborn bloodspot screening liaison midwives be identified, and email addresses registered with the NBS lab. They will need to be available from Monday to Friday to assist with tracking samples and as a single point of contact with regard to repeat samples, recollection letters and positive screening results.

Please refer to newborn bloodspot screening recollection letter electronic delivery for full details of roles and responsibilities.

The NBS laboratory only knows a baby has been born when it receives a card; the hospital only knows the newborn bloodspot 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 or stillbirth and when testing is declined (send a completed card to the lab).

11. Sending and tracking samples

As the symptoms for some of the conditions screening for can present in the early days of life, getting the samples to the laboratory as early as possible can save lives and prevent illness or disability.

Samples should be dispatched within 24 hours, in paper envelopes not plastic, preferably by courier or express post. Check with your own health service for local protocols.

Please do not hold samples over to the next day in order to send a larger batch.

Note:

- Keep a record including time and date of courier dispatch for each sample.
- Keep the tracking label with the records if you have used Express Post, to assist in tracking.
- Please ensure all express envelopes are placed in designated yellow post boxes or hand-delivered to the postmaster to avoid creating delays.

Mailing address

Newborn Bloodspot Screening Laboratory:
PO Box 1100, PARKVILLE 3052

Courier address and details

Newborn Bloodspot Screening (NBS) Laboratory
Victorian Clinical Genetics Services
Royal Children's Hospital Campus
Specimen Reception, 4th Floor East Building
50 Flemington Road
Parkville Victoria 3052

Victorian Clinical Genetics Services Specimen Reception is open **Monday to Friday 8:30am – 6:00pm.** (Excluding all Public Holidays)

Outside of these hours please go to:

Royal Children's Hospital Core Laboratory
4th Floor East Building
50 Flemington Road
Parkville VIC 3052

They are located on the same floor just further along corridor and are open 7 days a week.

12. Timeliness of sampling and quality issues

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 and are endorsed by the Victorian Department of Health.

It is important that hospitals take steps to ensure that good quality newborn bloodspot 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.

To support timely and accurate screening, hospitals and midwives/nurses are expected to meet the Victorian Department of Health Key Performance Indicators (KPIs):

- ❑ <0.5% bad sample rate. This includes cards with inadequate completed information.
- ❑ >95% of babies born in Victoria should have a sample collected before 72 hours of age, ideally between 36 and 72 hours post birth.
- ❑ >95% of samples should be in transit for less than 96 hours
- ❑ >95% of babies born in Victoria should have an NBS result by 9 days of age.
- ❑ >95% of recollection requests should be received by the laboratory within 12 days of the request
- ❑ <0.5% no written consent

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

13. Maternity providers and private midwives

As per the Department of Health guidelines, service providers have roles and responsibilities for newborn bloodspot screening. New service providers should adhere to the DH guidelines and contact the NBS lab to register their Business details, including all contact details. This will enable the NBS lab to send the weekly report containing the NBS results, request urgent recollections and will enable providers to obtain NBS cards and brochures while being informed of any changes to NBS program.

14. Contact information

Victorian Clinical Genetics Services:

Newborn bloodspot screening webpage: VCGS Newborn bloodspot screening

DH webpage for NBS including policy and guidelines:

Health.Vic: Newborn bloodspot screening

Counselling enquiries: 1300 118 247

Ordering newborn bloodspot screening information brochures & newborn bloodspot screening cards is best by email:

Email: screeninglab@vcgs.org.au

Newborn bloodspot screening educator:

Contact Hours: Monday, Tuesday, Wednesday, Thursday and Friday

Phone: 8341 6460

Email: screeninglab@vcgs.org.au

Lastly…

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

Newborn Bloodspot Screening Laboratory:

PO Box 1100, PARKVILLE 3052

p) 1300 118 247

e) screeninglab@vcgs.org.au

Web) https://www.vcgs.org.au/tests/newborn-bloodspot-screening