

**Aneurin Bevan University
Health Board**

**Midwifery Newborn
Bloodspot Screening
Policy**



N.B. Staff should be discouraged from printing this document. This is to avoid the risk of out of date printed versions of the document. The Intranet should be referred to for the current version of the document.

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INTRODUCTION

Newborn bloodspot screening is when a small sample of blood is taken from the baby's heel, ideally on day five of the baby's life. This blood sample is screened for rare but serious diseases that can cause serious illness or even death if not treated early. This initial screening test is carried out by maternity and neonatal services.

The health visiting service will offer Newborn Bloodspot Screening for all children under one year of age that move into Aneurin Bevan University Health Board (ABUHB), from overseas or where there is no evidence of screening within the United Kingdom. In Wales, all babies are offered screening for:

- Inherited metabolic disorders (IMDs)
- Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCADD)
- Phenylketonuria (PKU)
- Maple Syrup Urine Disease (MSUD)
- Isovaleric acidaemia (IVA)
- Glutaric aciduria (HCU)
- Hypothyroidism (CHT)
- Cystic Fibrosis (CF)
- Sickle Cell Disorders (SCD)

Screening for all the conditions is recommended by the UK National Screening Committee (UK NSC 2019)

POLICY STATEMENT

Aneurin Bevan University Health Board is committed to ensuring that all babies are offered a newborn screening bloodspot test and that where accepted all babies are screened appropriately in a timely manner.

AIMS

The aim of the Newborn Bloodspot Screening Programme is to offer all eligible babies quality assured screening, for rare but serious diseases, that would benefit from early intervention to reduce mortality and or morbidity from the disease.

OBJECTIVES

The guidance aims to achieve early detection, referral and treatment of babies found to be affected by the conditions for which screening is offered. The guidance will ensure quality improvements and consistency in newborn bloodspot screening and result processing across Aneurin Bevan University Health Board (ABUHB).

SCOPE

This Policy applies to midwives, neonatal and paediatric nurses and paediatricians. All staff must adhere to this guidance in order to ensure that

Newborn Bloodspot Screening is undertaken appropriately. It is intended to support health professionals in the delivery of NBS, outlining national standards, and providing information for health professionals to support them in answering queries.

RESPONSIBILITIES

- Midwifery, Neonatal and Paediatric Service to offer and undertake the NBS screening test on all babies in ABUHB between 5-8 days of age (preferably day 5, counting the DOB as day 0) in accordance with local and national guidance.
- To continue to obtain samples when NBS samples are missed, fail to reach the lab, fail to meet the standard set by NBSW or require repeat due to prematurity or for further investigations as requested by the lab.

See Appendix A – for Newborn Bloodspot Screening Wales Guidance for Sample Takers – Quick Reference.

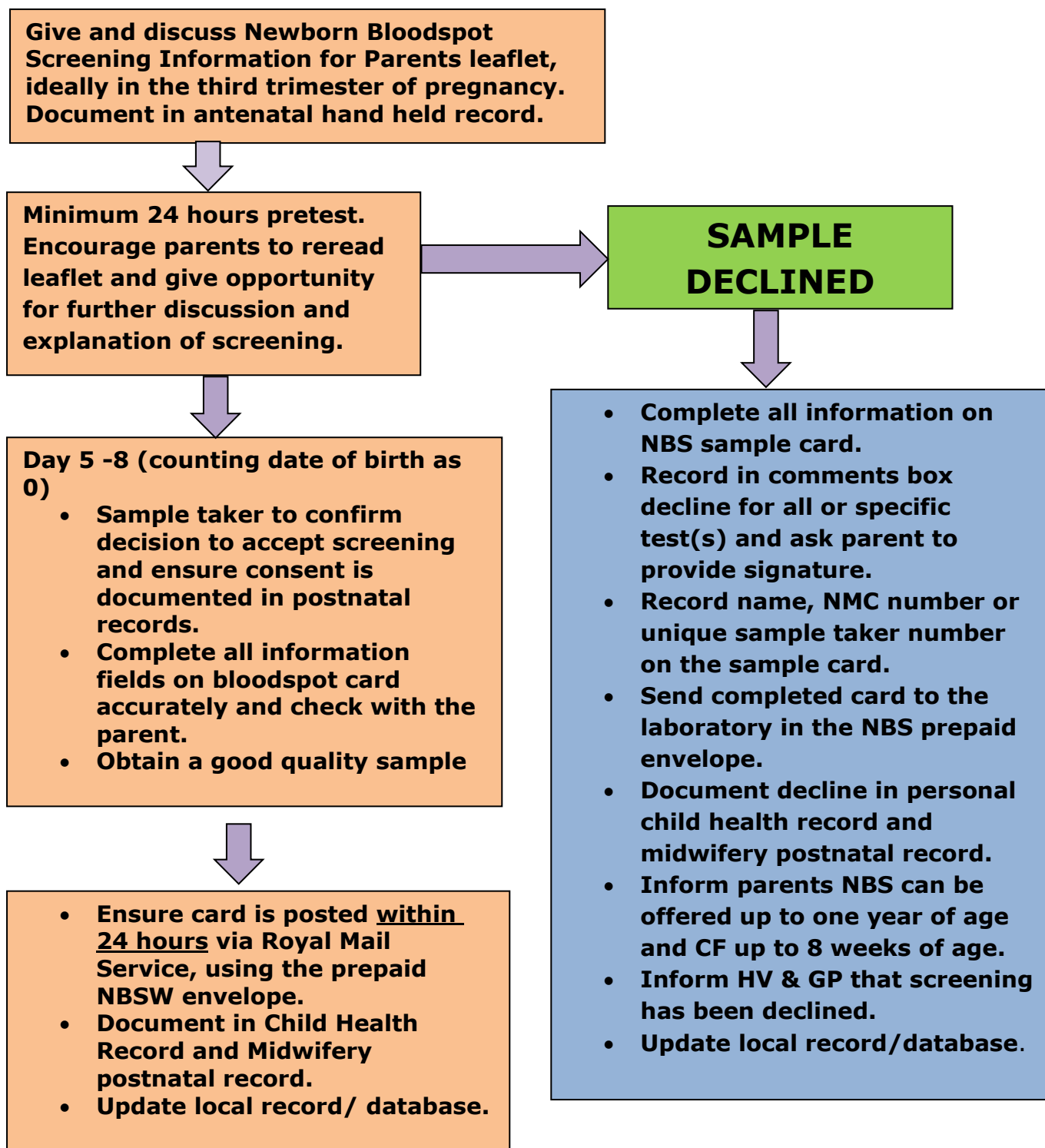
See Appendix B – for Newborn Bloodspot screening Wales Pathway A for babies born in Wales or moved into Wales from overseas aged more than or equal to one year and Pathway B for babies moved into Wales from elsewhere in the UK.

See Appendix C – for Guidance for completing Newborn Bloodspot Screening Card.

Please see Appendix D – for Newborn Bloodspot Screening Pathway for babies admitted to the neonatal Unit.

Please see Appendix E – Newborn Bloodspot Screening Wales Sample Takers Registration Form.

NEWBORN BLOODSPOT SCREENING (NBS) PATHWAY FOR SAMPLE TAKERS



PROCEDURE FOR OBTAINING A BLOODSPOT SAMPLE

- Ensure the baby is warm, comfortable and secure.
- Consider methods to maximise the comfort of the baby which may include face-to-face contact, voice and touch and feeding.
- Wash hands & use disposable plastic gloves before the procedure
- Clean the heel by washing thoroughly with plain tepid water and ensure the skin is dried to avoid sample contamination.
- The heel should be warm, however, additional warming of the foot is not advised.
-
- The blood sample should be collected from the baby's heel (see appendix 2)
- Use an automated lancet drive (incision depth<2.00mm) to obtain the blood sample, in accordance with the manufacturer's instructions.
- **Wait for the blood to flow**, wipe away the first drop of blood from the heel, **be patient** and wait for a further generous drop of blood to form, allow **one generous drop** of blood to drop onto each circle on the sample card. Squeezing of the foot is not required or advised.
- The generous drop of blood should **symmetrically soak through to the back of the sample card.**
- **Do not layer, multi spot or compress the blood spots** because this may lead to inaccurate results or repeat blood samples being required.
- If the blood flow ceases, the congealed blood should be wiped away firmly with gauze, gently massage the foot, avoid squeezing and wait for generous drop of blood to form.
- If the foot is not bleeding, a second puncture should be performed on a different part of the same foot or on the other foot.
- After obtaining a quality sample, wipe excess blood from the heel and apply gentle pressure to the wound, with gauze.
- Allow the blood spots on the card to air dry away from direct sunlight or heat before placing in the glassine sleeve, then place in envelope.
- Dispose of sharp implements in the correct manner and dispose of used materials.
- Inform the parents how & when they will receive the results
- Ensure that all demographic fields have been completed accurately on the sample card, record that the sample has been taken in the maternity records and update the local NBS data collection record/database (NMC 2019).
- Post the NBS sample using first class Royal Mail postal service within 24 hours of taking the sample.
- For any NHS number queries contact are; NBS Administration Team (Failsafe) Tel: 02920743568 or Maternal and Child Health Governance Lead for Screening (Julie Crane) 01443 802655/52655 or NBS support

Team: Katharine Wilson 01443 802429/52429 or Rhiannon Griffin 01443 802437.52437 or 01633 234009/44009.

BABIES ADMITTED TO NEONATAL INTENSIVE CARE AND PREMATURE BABIES (SEE APPENDIX D)

Babies admitted to neonatal intensive care units are likely to have multiple blood samples taken, venous or arterial sampling from an existing line is an alternative for babies **in special circumstances only, providing the sample is not contaminated with heparin or EDTA and the line is cleared of infusate.**

- Every baby admitted to a neonatal unit in Wales should have a single bloodspot sample taken on admission regardless of the length of stay on the unit or the care received
- The sample should be labelled pre transfusion sample, kept and then stapled to the routine bloodspot sample taken at day 5 of life, (counting day of birth as day 0)
- Both samples should then be sent to the Newborn Bloodspot Screening Laboratory for analysis
- If the baby does not have a blood transfusion the pre transfusion sample should still be sent to the laboratory, attached to the routine sample
- If the baby is discharged from the neonatal unit before the routine sample is due or has been taken, the pre transfusion sample should be sent separately to the Newborn Screening Laboratory

It is important to ensure that it is clearly documented in the baby's notes and the discharge/transfer summary that a pre transfusion sample has been taken and that a routine sample is due on day 5.

If the baby has a blood transfusion an interval of at least 3 clear days is required between a blood transfusion and the routine sample. In the event of a baby requiring multiple transfusions, even if it has not been 3 clear days since the last transfusion, a routine sample should be obtained and sent to the lab by day 8 at the latest for IMD's, CHT and CF. A single repeat sample (4 spots) will be required once 72 hours have passed without a blood transfusion.

BABIES BORN AT LESS THAN 32 WEEKS GESTATION

All babies born at less than 32 weeks gestation (less than or equal to 31 weeks+6 days), should be offered a second preterm CHT test at 28 days of age (counting day of birth as day 0), or on day of discharge home whichever is the sooner.

The professional caring for the baby is responsible for ensuring that the second CHT sample is offered and that the sample is obtained whilst the baby is an in-patient in neonatal or pediatric services. If a baby is moved to another hospital, the responsibility for taking the second CHT sample is transferred to the receiving hospital.

To enable the Newborn Screening Laboratory to report a valid CHT result, it is essential that the gestational age at birth is recorded on the bloodspot card.

REPEAT SAMPLES

Occasionally the laboratory may have an inconclusive result that requires a repeat sample, or an avoidable repeat sample may be required because the sample did not meet the standard required by the lab.

Avoidable repeat samples are required for the reasons that include:

- Incorrect or absent NHS number
- Insufficient sample
- Layered or multi spotted sample
- A sample that appears to have not fully dried prior putting the glassine sleeve.
- A compressed sample
- A contaminated sample
- Delay in the laboratory receiving the sample (>14 days old)
- Taken too early – before day 5
- Repeat samples taken at the wrong time
- A sample taken on an expired card

Where a request is made for an avoidable repeat sample, the repeat sample should be taken at the earliest opportunity and the acceptable standard is within 72 hours.

OUTSTANDING RESULTS

Newborn Bloodspot Screening Failsafe Team identify babies born in Wales who have not had a NBS sample received in the lab by 14 days of age. The Health Board is informed via email, which is investigated by the Maternal and Child Health Governance lead Julie Crane and NBS Support Team. Aneurin Bevan University Health Board's Child Health Web Cypris generates weekly lists of babies aged 6 weeks who do not have an NBS result and this is forwarded to the NBS Governance Lead and NBS support Katharine Wilson.

If it is identified that the sample has not been taken or taken, and failed to reach the lab, a sample will be required at the earliest opportunity and within 72 hours of the receipt of the request. It is the responsibility of the healthcare professional to inform the parents and ensure the sample is obtained.

RESOURCES

- Newborn bloodspot screening leaflets – information for parents
- Newborn bloodspot screening card glyssine sleeves and prepaid envelopes
- Newborn bloodspot screening Wales health professional information pack
- NBSW training film – how to take a good quality sample
- NBSW training presentations – how to take a good quality sample
- Access to Newborn Bloodspot Screening Wales for general queries via E-mail: nbsw@wales.nhs.uk

TRAINING

- All staff to undergo an initial training session relevant to their area of work and complete a Newborn bloodspot screening sample taker registration form, available from NBSW website or MAC Governance lead Julie Crane to forward to NBSW website (see appendix E)
- All staff should have an annual update to be incorporated into mandatory and professional study days
- Line managers to maintain records of NBS training

AUDIT

Newborn Bloodspot Screening Wales requests for repeat samples and NBS queries are emailed to ABUHB YYF ANC generic email and Maternal Child Health (MAC) Governance Lead Julie Crane.

A database is kept of registered sample takers within ABUHB, the errors made and training received.

Newborn Bloodspot Screening Wales provide monthly data to ABUHB which includes; the amount of NBS samples taken within a given month, the type of errors, the percentage of errors for the HB, for Maternity, Neonatal, Paediatric and Health Visiting services and errors made by the individual sample takers.


The MAC Governance Lead feeds back the errors made to the individual sample takers and sample takers are able to monitor their own sample taking performance by accessing NBSW website – selecting health professionals and individual sample takers report.

The password required is NB\$WReport234 and NMC Pin No.

REFERENCES

- NBSW Programme Handbook
- [http://www.newbornbloodspotscreening.wales.nhs.uk/information for heal](http://www.newbornbloodspotscreening.wales.nhs.uk/information-for-health-professionals)
- Record Keeping Guidance, The Code 2019 – www.nmc.org.uk/strandard/code/record-keeping
- UK NSC recommendations (Updated 12 August 2019) – <https://www.gov.uk/government/publications>

Appendix A (Please see Blood Spot Screening Wales website for original)



**Newborn Bloodspot
Screening Wales**
Sgrinio Smotyn Gwaed
Newydd-anedig Cymru

**Guidance for sample takers -
Quick reference guide**

**Newborn Bloodspot Screening -
Importance of taking good quality bloodspot samples**

The aim is to enable early referral of babies for diagnostic tests and treatment by:

- Taking samples at the right time
- Taking good quality samples that do not need to be repeated.

Samples should be taken on day 5 of life

- The sample should be taken on day 5 of life, but if this is not possible the sample must be taken between day 5 and day 8
- Day of birth is counted as day 0.

Newborn bloodspot samples are screened for:

- Inherited metabolic disorders:
 - Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
 - Phenylketonuria (PKU)
 - Maple syrup urine disease (MSUD)
 - Isovaleric acidemia (IVA)
 - Glutaric aciduria type 1 (GAI)
 - Homocystinuria (HCU)
- Congenital hypothyroidism
- Cystic fibrosis
- Sickle cell disorders

After taking the bloodspot sample

- Allow bloodspots to air-dry away from direct sunlight or heat before inserting card into glassine envelope.
- Record taking the sample in the maternity/professional record and the baby's Personal Child Health Record.
- Inform parents how and when they will receive the results.
- Send the bloodspot card in the NBSW prepaid/stamped addressed envelope (first class) to the Newborn Screening Laboratory on the same day. If not possible, send within 24 hours of taking the sample. Record the date posted.
- Record and notify screening status on discharge home or transfer to another unit.

What happens if parents decline screening?


- Complete information fields on bloodspot card and record in the comments box 'DECLINE' for 'ALL' or specific test(s).
- Ask parent to sign the bloodspot card confirming their decision to decline.
- Send the bloodspot card to the Newborn Screening Laboratory.
- Inform parents whom to contact if they change their mind or would like further information.
- Inform parents that newborn bloodspot screening can be offered to babies up to 1 year of age.
- Inform parents that cystic fibrosis screening is only offered up to 8 weeks of age as the test is unreliable after this time.
- Inform GP and Health Visitor of the screening test(s) declined.

Further information

The full guidelines for newborn bloodspot screening can be found in the programme handbook, accessed via our website www.newbornbloodspotsscreening.wales.nhs.uk

or contact us at:
nbsw@wales.nhs.uk

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GIG : Newborn Screening
NHS : Public Health Wales
Wales

February 2019

Appendix A cont'd (Please see Blood Spot Screening Wales website for original)

Insufficient or poor quality bloodspot samples will result in:

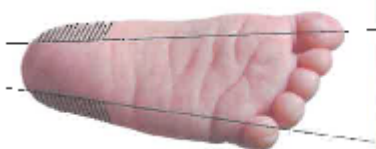
- Delays in referral of babies for diagnostic tests and treatment
- Increased anxiety/distress due to the need for repeat samples
- Increased workload for health professionals and the Newborn Screening Laboratory.

Preparation for taking bloodspot sample

- Ensure parents have the information leaflet and an opportunity to ask any questions.
- Explain procedure to parents and confirm their decision to accept screening.
- Check the **expiry date** on the front of the bloodspot card.
- Complete the details on the bloodspot card **at the time of sampling**:
 - Ensure the information is **accurate, legible and complete**
 - Check with parent that all details on the bloodspot card are correct and make any changes.
- Recording the **baby's NHS number** on the bloodspot card is **mandatory** as the sample cannot be processed without it.
- If the NHS number is not available, please contact your regional Newborn Screening Administration Failsafe Team (office hours Monday - Friday).

Skin puncture sites for full-term and preterm infants

External and Internal limits of the Calcaneus
(shaded areas indicate puncture sites)



Taking good quality bloodspot samples for newborn screening

Correct



A single, evenly saturated drop of blood that **fills the circle completely and soaks through to the back of the card.**







Good quality bloodspots are essential to obtain accurate screening results.

Do

Ensure baby is warm and comfortable.
Warming of the foot is not required.
Position baby to maximise blood flow to heel - allow foot to hang down.
Clean baby's heel with plain water (not heated) and ensure skin is dried. This avoids sample contamination.
Use an age appropriate automated incision device (incision depth $\leq 2.0\text{mm}$).
Fill each circle completely with a single drop of blood.
Ensure blood seeps through to back of card.

Incorrect

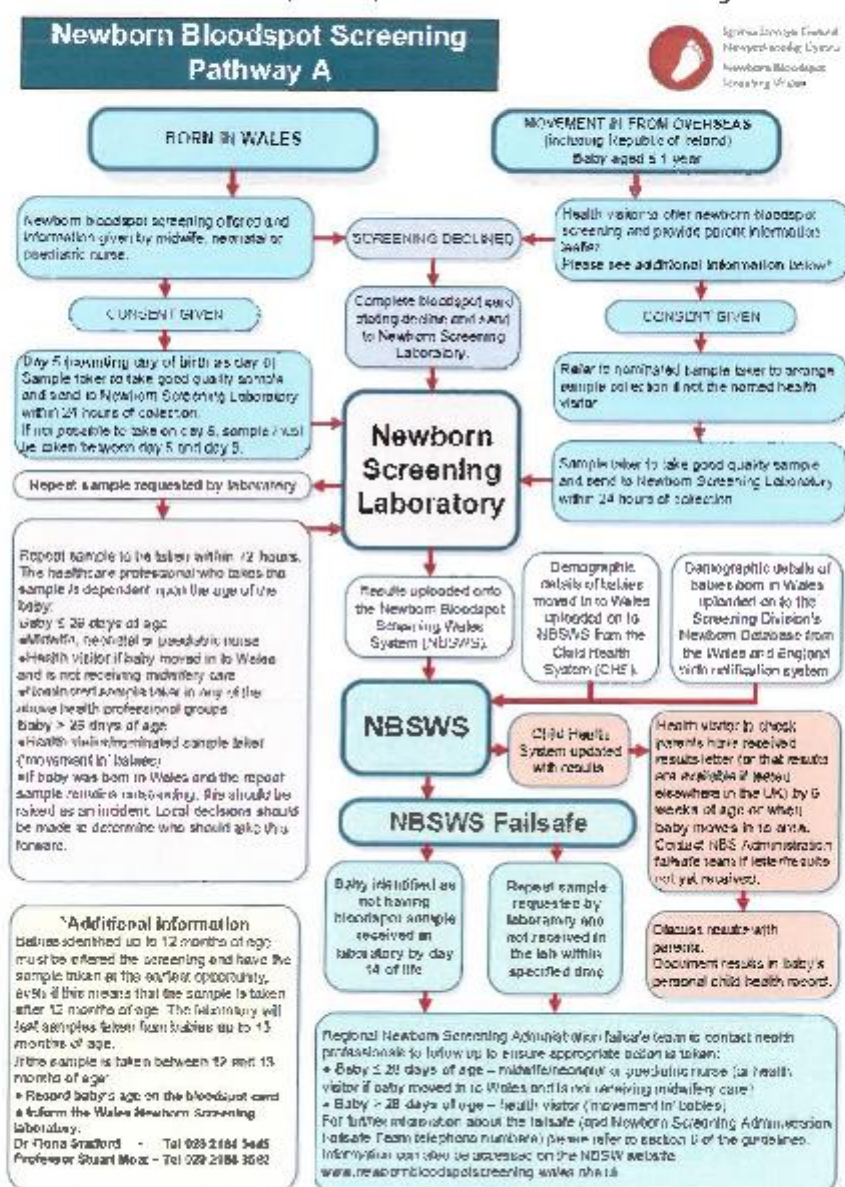
Reasoning

	Insufficient sample: small volume spots	Risk of false-negative result (babies with a condition could be missed)
	Insufficient sample: blood not soaked through to the back of the card	Risk of false-negative result
	Multispotted sample	Risk of false-negative result
	Compressed sample	Significant risk of false-negative result
	Layered sample: one spot of blood layered directly on top of another or blood applied to front and back of card	Risk of false-positive result
	Contaminated sample	Risk of inaccurate result

APPENDIX B (Please see Blood Spot Screening Wales website for original)

Appendix B: Newborn bloodspot screening pathways

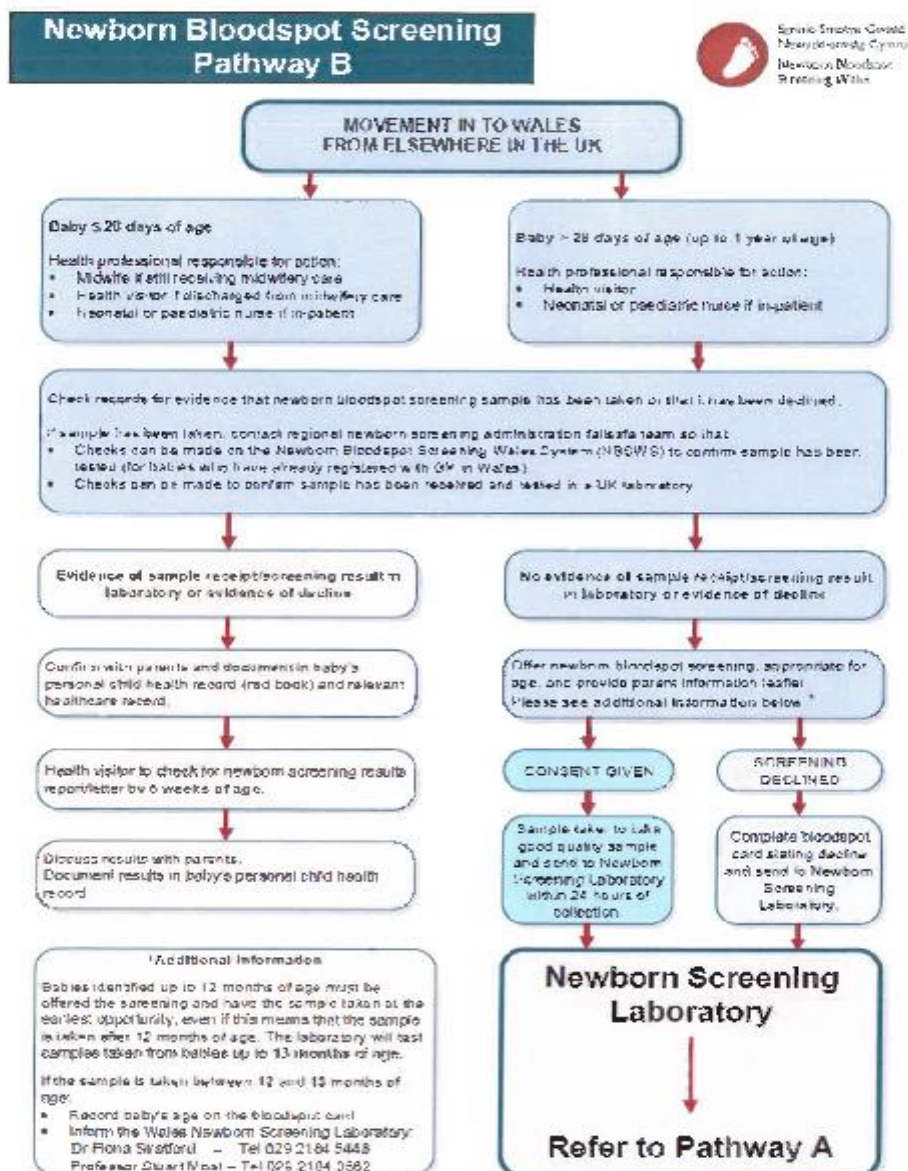
Pathway A relates to babies born in Wales and those who have moved in from outside the UK. All babies in pathway A are to be offered screening.



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APPENDIX B Cont'd (Please see Blood Spot Screening Wales website for original)

Pathway B relates to babies who have moved in to Wales from elsewhere in the UK. Babies in this pathway would need to be assessed to see if they are eligible.



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Appendix C (Please see Blood Spot Screening Wales website for original)

Appendix C: Guidance for completing the bloodspot screening card

1 NHS Number is the only unique identifier for a baby. It is essential – a repeat will be requested without it.

2 Surname by which the baby will be known.

3 Baby's alternative surname. Record surname by which the baby will be known if local policy requires mother's surname in box 2.

4 DOB is essential for the card to be processed.

5 Gestational age of baby at birth is essential for a valid CH result.

6 Rank identifies birth order. Refer to back of card.

7 Birth weight is important – can aid interpretation of results.

8 Date of sample is essential for the card to be processed.

9 Expiry date must be checked before sample collection. A repeat sample will be requested if the card has expired.

10 Is this a repeat? Record reason in the comments box.

11 Record if a blood transfusion has been given to baby either prenatally or after birth. Record date of last (most recent) transfusion, if intravenous, count day of birth as date of last transfusion.

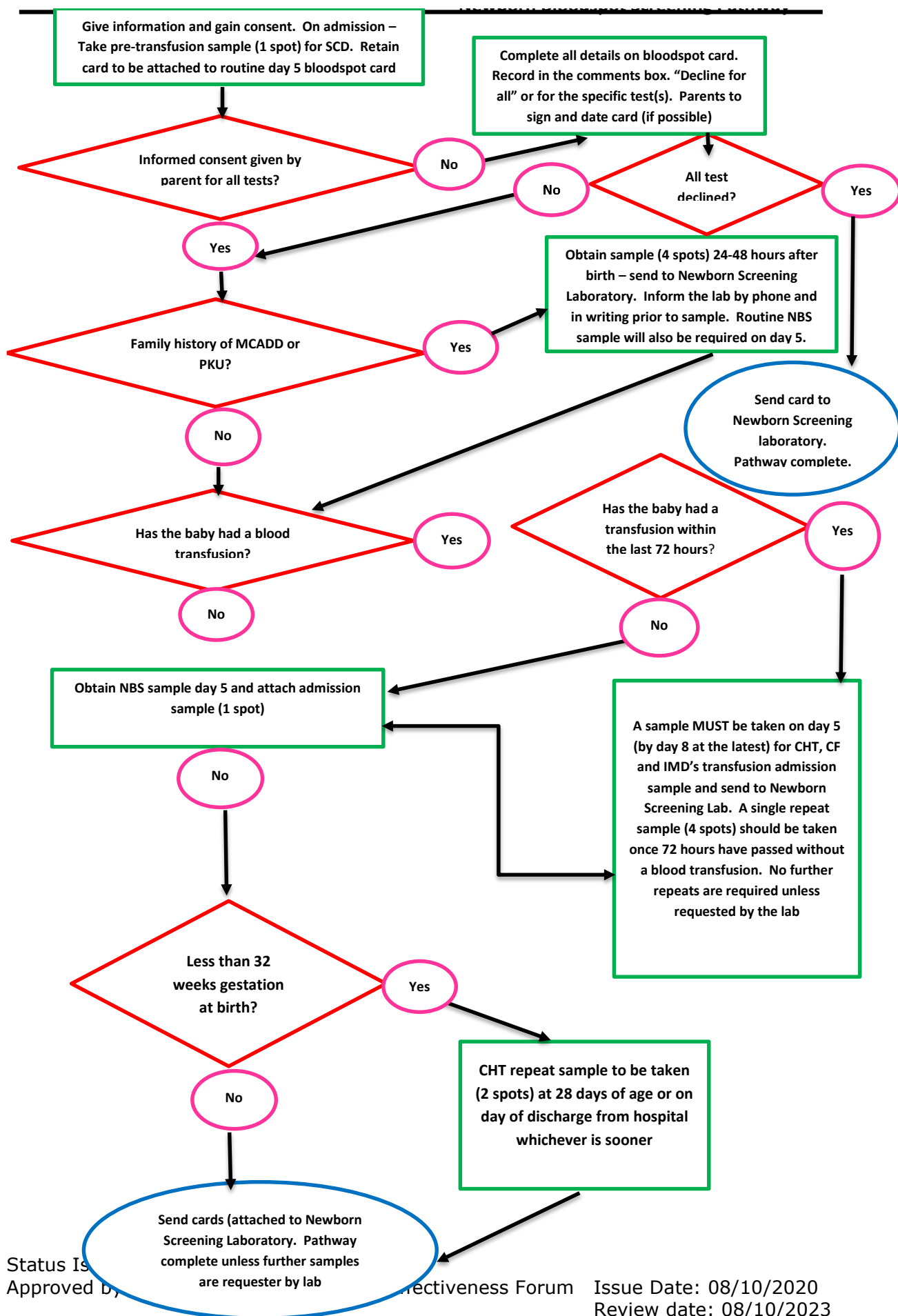
12 Type of transfusion is important information required for the screening of sickle cell disorders.

Appendix C Cont'd (Please see Blood Spot Screening Wales website for original)

Record in Comments box:

- Any screening tests declined, plus a parent's signature
- Any known medical condition in baby, or any relevant family history e.g. CF, inherited metabolic disorder (inborn error of metabolism) or thalassaemia?
- Reason for any aspect of second samples
- Reason for sample being taken at a different time from routine day 5 test e.g. pre transfusion, preterm CH1, family history of an inherited metabolic disorder (state disorder)
- Any complications in pregnancy or labour that may have affected the baby
- Name of person applying blood to card if not recorded as sample taker

The image shows a 'Wales Newborn Bloodspot Screening Test' card. It contains various fields for recording information about the baby and the screening process. Numbered callouts point to specific areas: 13 points to the 'Sample taken' section; 14 points to the 'GP practice name, telephone number, address and postcode' section; 15 points to the 'Refers to Health Board providing care at the time of the test' section; 16 points to the 'Parents should be asked if they consent to future contact about research linked to NBSW. Tick the box if they do not wish to be contacted' section; 17 points to the 'Current contact number for parents is essential to enable follow up of baby' section; 18 points to the 'Sample taker ID is their GMC number, or a number issued by NBSW' section; and 19 points to the 'Record in Comments box' section.



Appendix E (Please see Blood Spot Screening Wales website for original)



lechyd Cyhoeddus
Cymru
Public Health
Wales



Newborn Bloodspot
Screening Wales
Sgrinio Snotyn Gwaed
Newydd-anedig Cymru

Newborn Bloodspot Screening Wales Sample Taker Registration Form

Newborn Bloodspot Screening Wales (NBSW) is establishing a database of all newborn bloodspot screening sample takers in Wales as part of its quality assurance processes.

The database will be used as a mechanism to distribute information to sample takers and monitor the quality of the newborn bloodspot screening programme. The database will hold information about health professionals as sample takers, and about the newborn bloodspot screening training that they have received. Personal details will be held securely and confidentially and will not be released outside of the programme.

The Nursing and Midwifery Council have given their approval for health professionals to use their NMC number as a unique identifier and this should be recorded in the 'sample taker ID' field on the bloodspot card.

Those sample takers who do not have an NMC number will be issued with a unique identifier by NBSW, after they have completed and returned the sample taker registration form.

Please complete in block capitals:

Personal Details		Staff Group	
Title		Midwife	<input type="checkbox"/>
Surname		Health Visitor	<input type="checkbox"/>
Forename(s)		Nursery Nurse	<input type="checkbox"/>
Date of Birth	/ /	NMU nurse	<input type="checkbox"/>
NMC number		Paediatric nurse	<input type="checkbox"/>
		Other (please specify)	

Location details: please give full details of the main location where you work and NOT your home address. This address should be where you would like your NBSW correspondence and individual Sample Taker Report to be sent.

Department/Ward	
Hospital/Clinic/Surgery address	
Post Code	
Work Telephone Number	
NHS Email address	
Signature:	Date: / /

Please return the completed form to:

Newborn Bloodspot Screening Wales, Floor 4, Public Health Wales, Number 2 Capital Quarter, Tyndall Street, Cardiff CF10 4RZ. Alternatively if using an NHS email address submit to nbsw@wales.nhs.uk

Please keep us informed about changes to your details by contacting us at nbsw@wales.nhs.uk