

<b>Newborn Blood Spot Screening (UH Sussex West) SOP</b>	
<b>Summary statement: How does the document support patient care?</b>	This pathway provides information for staff with regard to the process for offering, undertaking and providing results for newborn bloodspot screening.
<b>Staff/stakeholders involved in development:</b>	Midwives, Paediatric team, Health Visitors, Joint Obstetric Guidelines Group, Community teams, Laboratory, Community Child Health Information Service
<b>Division:</b>	Women and Children's
<b>Department:</b>	Maternity
<b>Responsible Person:</b>	Chief of Service
<b>Author:</b>	Jacqueline Gregory
<b>For use by:</b>	Midwives, Obstetricians, Paediatric staff and Health Care Support workers
<b>Purpose:</b>	To provide accurate information for staff on the processes to follow with regard to newborn blood spot screening
<b>This document supports:</b>	NHS public health functions agreement 2017-18. Service specification no.19 NHS Newborn Blood Spot Screening Programme
<b>Key related documents:</b>	<b>UH Sussex West Maternity Guidelines:</b> Antenatal Care and Patient Information, Postnatal Care <b>UH Sussex West Trust Policies:</b> An organisation-wide policy for screening procedures, An organisation-wide policy for diagnostic testing <b>NHSEI publications:</b> KPI's
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<b>If you require this document in another format such as Braille, large print, audio or another language please contact the Trusts Communications Team</b>	
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1.0	March 2018	Antenatal & Newborn Screening Co-ordinator NHSP lead	Archived	Revised WSHFT Pathway
2.0	February 2019	NHSP lead - Jacqueline Gregory	Archived	
3.0	July 2020	NBS Lead - Jacqueline Gregory	Archived	See page 42 for amendments
3.1	Nov 2021	J. Collard, Clinical Effectiveness Support Midwife	Archived	Guideline expiry date extended to Feb 2022 following agreement from C. Parr, Clinical Governance Lead and J. Gregory, NHSP Lead.  Formatting and new Trust logo.
4.0	Feb 2022	Jacqueline Gregory, NBS Lead	Archived	See: <a href="#">Main additions/changes to SOP</a>
4.1	May 2022	Jacqueline Gregory, NBS Lead	LIVE	Changes to: <ul style="list-style-type: none"> <li>• Movers in and out</li> <li>• Avoidable repeats</li> <li>• Newborn Screening Outcome Solutions</li> <li>• Decline</li> <li>• Laboratories</li> <li>• Screening co-ordinators email addresses</li> </ul>

**The interpretation and application of clinical guidelines will remain the responsibility of the individual clinician.**

**If in doubt contact a senior colleague or expert.**

This SOP can be located on the trust's intranet:

[http://www.westernsussexhospitals.nhs.uk/?s=newborn+screening&resource\\_type=&post\\_type=resource](http://www.westernsussexhospitals.nhs.uk/?s=newborn+screening&resource_type=&post_type=resource)

## Contents

1.0	Background .....	5
2.0	Identifying eligible population.....	5
2.1	Antenatal notification .....	6
3.0	National Screening Pathway.....	7
4.0	Northgate Blood Spot Failsafe Solution Flow Chart .....	8
5.0	UH Sussex West screening pathways .....	9
5.1	Well baby/born after 32 weeks GA .....	9
5.2	Premature Neonate .....	10
5.3	In a Transfused Neonate .....	11
5.4	Repeat Samples Pathway .....	12
5.5	Leaflets.....	13
5.6	Exclusion Criteria .....	13
6.0	Performing a Newborn blood spot .....	14
6.1	Complete blood spot card.....	14
6.2	Preparing the foot.....	15
6.3	Lancet use/ puncture sites.....	15
6.4	Taking the sample .....	15
6.5	After taking the sample .....	17
7.0	Referrals of affected babies following the Newborn blood spot.....	17
7.1	Sickle Cell Disease (SCD) .....	17
7.2	Cystic Fibrosis (CF) .....	18
7.3	Congenital Hypothyroidism (CHT) .....	18
7.4	Inherited Metabolic Diseases (IMD's) .....	18
7.5	Carrier results.....	18
8.0	Results pathway .....	18
9.0	Governance structure and reporting .....	19
9.1	Governance structure .....	20
10.0	Movers in and out of area.....	20
11.0	Training and ongoing assessments/avoidable repeats .....	23
12.0	Newborn Outcome Solutions .....	23
	Appendix 1: Mapping and cohort checking in NBS FS .....	24
	Appendix 2: Day 5 – check all cohort is visible in NBS FS .....	26
	Appendix 3: Daily tasks.....	27
	Appendix 4: Dispatch pathways .....	28
	Appendix 5: NICU paperwork.....	30
	Appendix 6: Child death notifications .....	32
	Appendix 7: New user request for Northgate Failsafe Solution .....	33
	Appendix 8: Decline NBS screen .....	34
	Appendix 9: Northgate Newborn blood spot failsafe solution has not been populated.....	35
	Appendix 10: Deletion of record/ changes to a record in NBS FS .....	36
	Appendix 11: Repeat blood spots .....	37
	Appendix 12: Admission Day Spot/Discharge Spot Failsafe.....	38
	Appendix 14: Laboratories .....	39
	Appendix 15: Screening co-ordinators email addresses.....	40
	Appendix 16: Movers in – advised by CHIS .....	41
	Appendix 17: Checking that all Newborn screening has been completed.....	42
	Appendix 17: Examples of bloodspot samples.....	43

Contact List.....	46
Abbreviation used within this SOP .....	48
References .....	49
Main additions/changes to SOP:.....	51

# Newborn Blood Spot Screening SOP

## 1.0 Background

The NHS Newborn Blood Spot Screening Programme aims to identify babies who have rare but serious conditions so as to improve health and reduce disability or death.

These conditions comprise of newborn babies who are at high risk of being affected by or may be carriers of:

- Sickle cell disease (SCD)
- Cystic fibrosis (CF)
- Congenital hypothyroidism (CHT)

six inherited metabolic diseases:

- Phenylketonuria (PKU),
- Medium-chain acyl-CoA dehydrogenase deficiency (MCADD),
- Maple syrup urine disease (MSUD),
- Isovaleric acidaemia (IVA),
- Glutaric aciduria type 1 (GA1)
- Homocystinuria (pyridoxine unresponsive) (HCU)

And

- Severe combined immunodeficiency (SCID) – Screening for SCID is currently being offered in some parts of England as part of an evaluation. It is not yet available for all newborn babies in England

Note UH Sussex West use SW Thames lab who currently are not part of the SCID testing pilot programme. Once SCID testing commences at SW Thames lab it must be noted that bloodspot sample sizes **must not** be larger than the circle on the card.

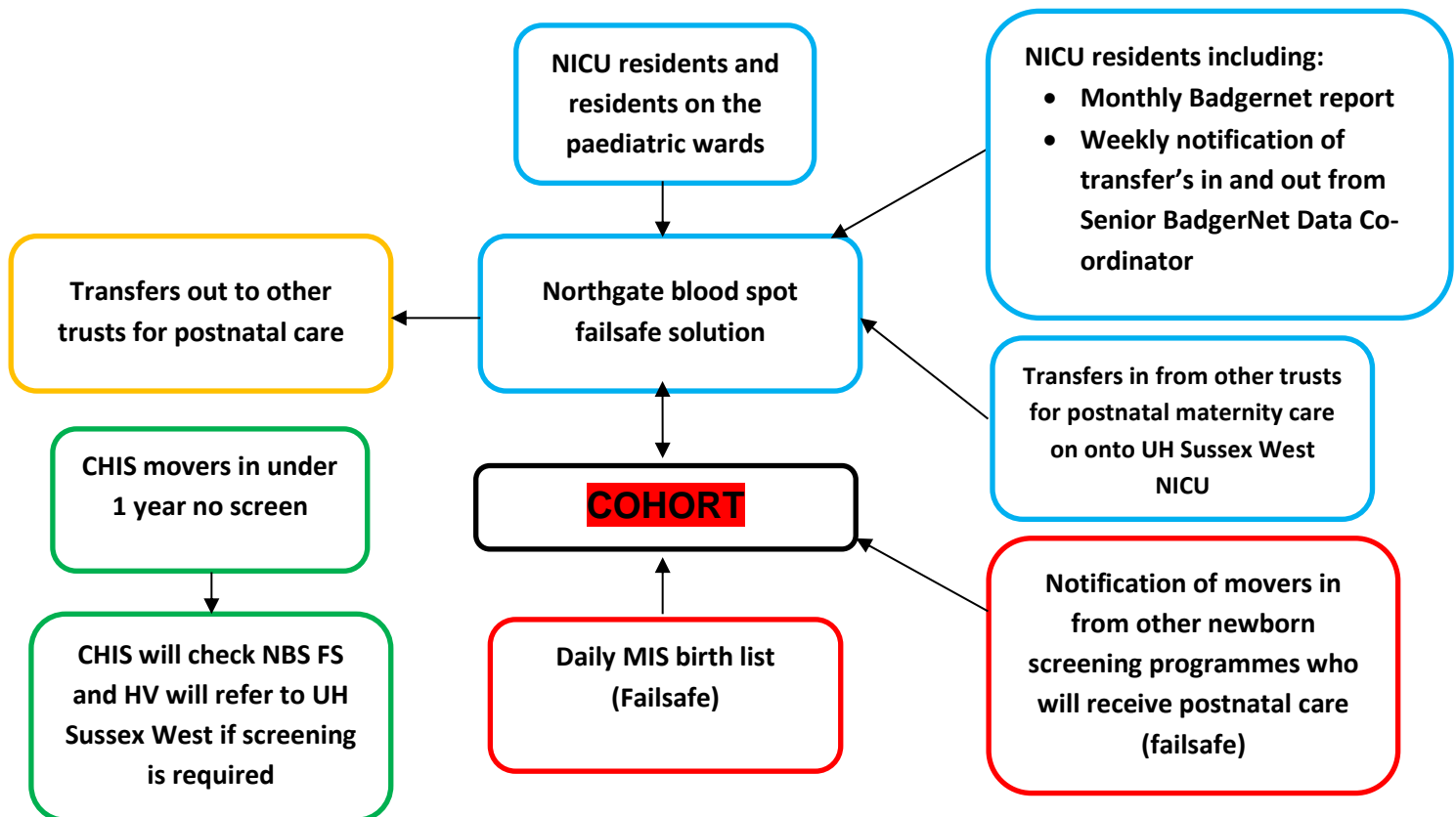
## 2.0 Identifying eligible population

The eligible population is identified through the issuing of an NHS number at birth or registration with a GP practice for babies born abroad.

Northgate Newborn Blood Spot Failsafe Solution is populated electronically via PDS (Patient demographic service) at point of birth. Movers in from abroad do not populate NBS FS so are managed manually.

NBS FS is populated based on address of the baby and the GP they reside with.

Capture of full cohort and movement of population is based on the following, and incorporates layers of fail safes to ensure no babies are missed.



The paediatric wards (Howard- SRH, Bluefin Worthing) will be checked daily for re-admissions, any baby 5 days old will require their bloodspot taking whilst resident on the ward.

## 2.1 Antenatal notification

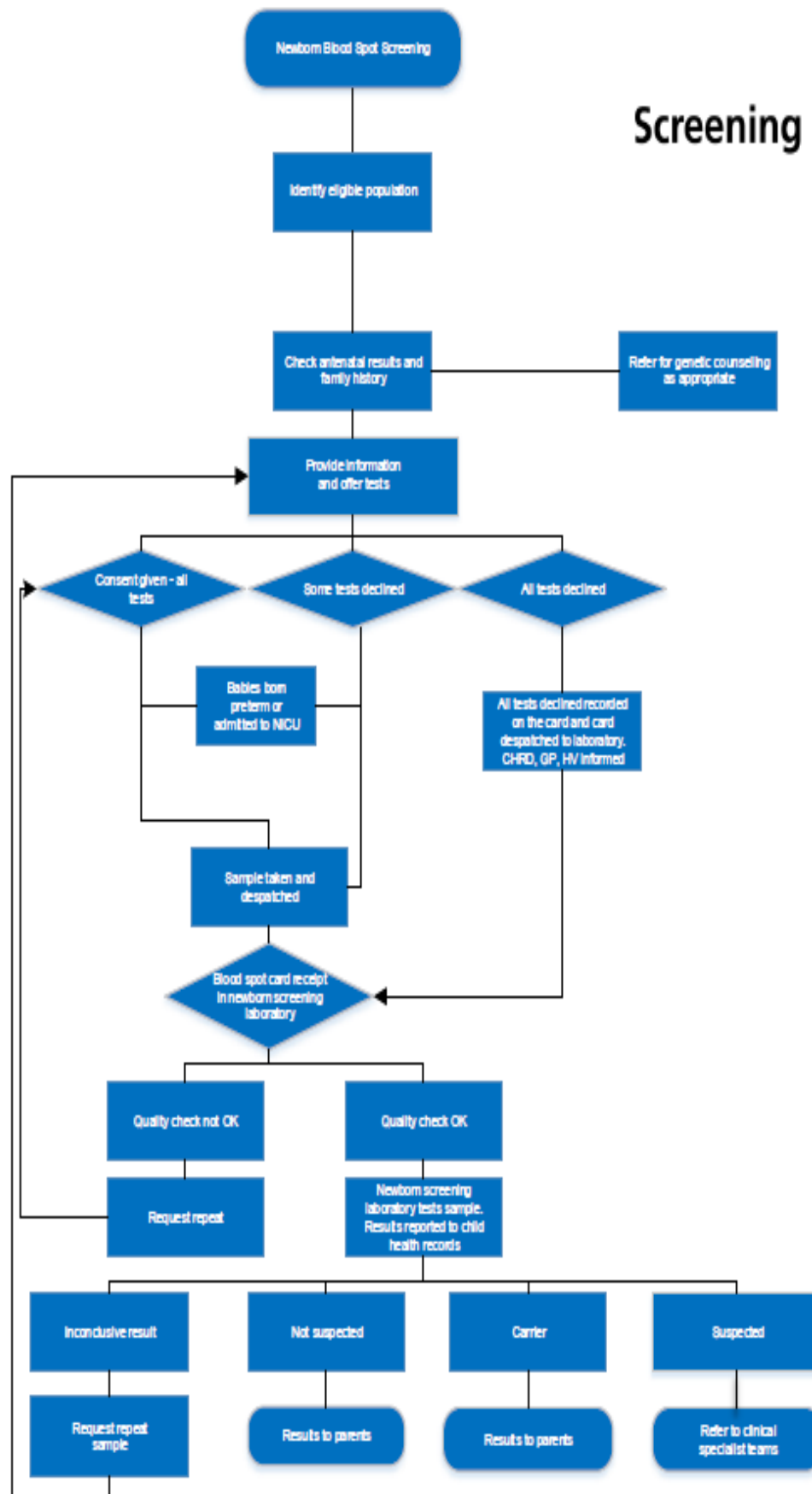
Where a family history of any metabolic condition is identified in either parent antenatally, the antenatal screening team should be notified. They should then notify the postnatal failsafe clerk so that plan can be made for early testing of the baby. SW Thames Lab should be contacted as part of the plan.

### 3.0 National Screening Pathway



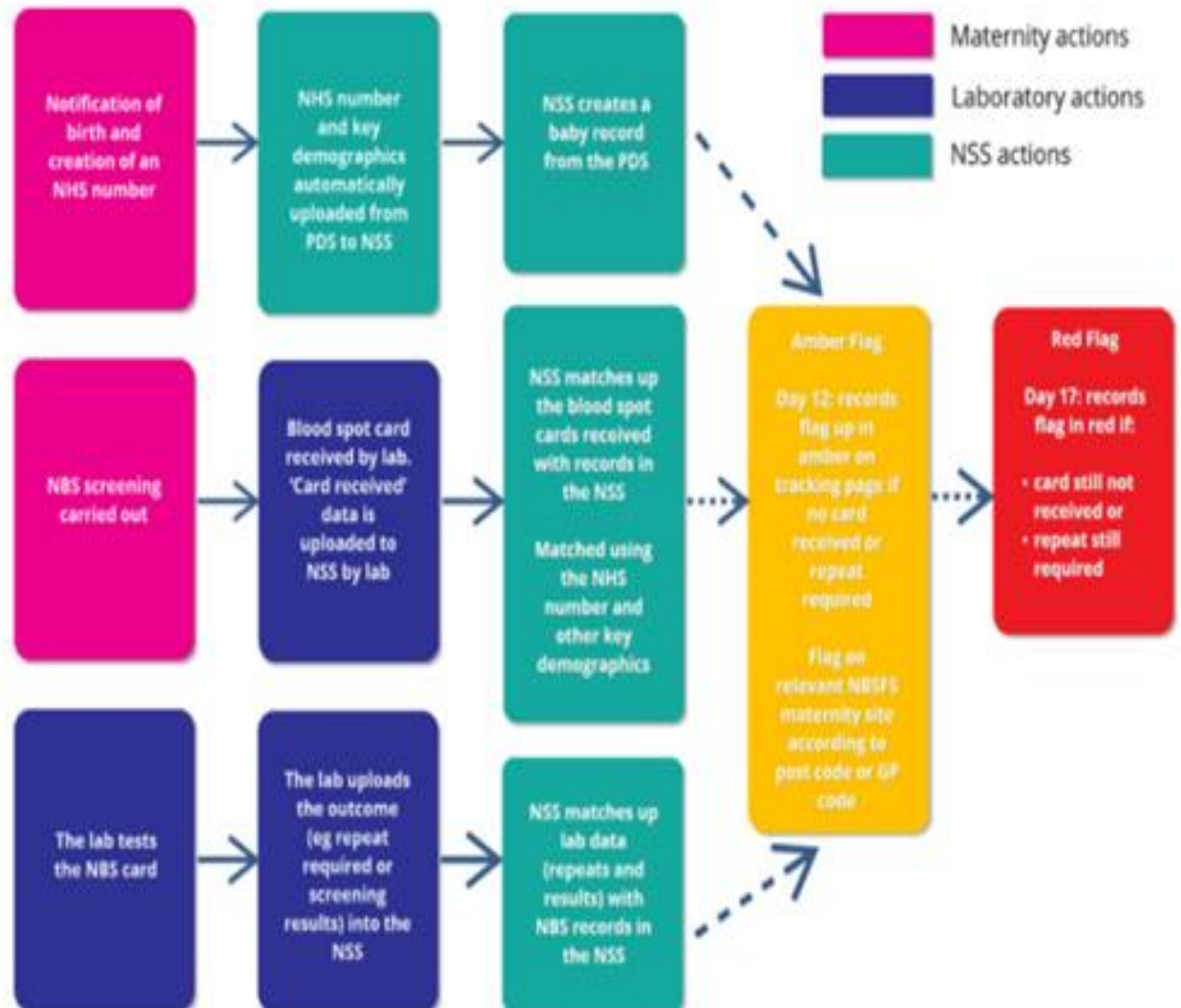
## Screening Programmes

### Newborn Blood Spot



## 4.0 Northgate Blood Spot Failsafe Solution Flow Chart

Note: NBS FS requires Internet explorer 10 to run correctly



**NBS FS web address – which can only be accessed via a secure N1 link:**

[Northgate - bloodspot](#)



## 5.0 UH Sussex West screening pathways

### 5.1 Well baby/born after 32 weeks GA

Provide all pregnant women the information leaflet 'Screening tests for you and your baby' in their preferred language where possible.

At least 24 hours prior to screening, ensure that parents have received, read and understood the 'screening tests for you and your baby' leaflet.

Ensure they understand what conditions baby is being screened for:

- sickle cell disease (SCD),
- cystic fibrosis (CF),
- congenital hypothyroidism (CHT)
- phenylketonuria (PKU),
- medium-chain acyl-CoA dehydrogenase deficiency (MCADD),
- maple syrup urine disease (MSUD),
- isovaleric acidaemia (IVA),
- glutaric aciduria type 1 (GA1)
- homocystinuria (pyridoxine unresponsive) (HCU)

Screen and data capture consented to. Ensure parents are aware the residual blood spots get retained for 5 years and can be used for research. Write 'NO RESEARCH CONTACT' on the form if parents do not want to be contacted about this in the future.

Arrange to take blood sample on day 5, with day of birth counting as day 0. Note – ideally this should be day 5 regardless of gestational age, feeding status, medical condition or medication.

Document that NBS screening has been discussed, recommended and that consent has been given, and that parents have been provided with a copy of the screening leaflet.

Record consent in maternal hand held notes and babies PCHR book. Write on the blood spot form if 1 or more tests have been declined. Fill in the card completely attaching the bar code label. **NHS number is mandatory**

Return sample to community midwives office, or post directly after adequate drying and notify screening admin for documenting.

#### **NORMAL RESULTS**

Results are sent to CHIS from the lab. CHIS will notify parents by letter

#### **REPEAT REQUIRED**

UH Sussex West notified by email from the Lab and on Northgate search

#### **ABNORMAL RESULTS**

Lab informs relevant clinician. Results are copied to CHIS. CHIS to advice parents of normal results at 6 weeks

Screen and data capture declined

Ascertain if all screening is declined. SCD, CF and CHT can be declined individually however the 6 IMD's can only be declined as a group

Document that NBS screening has been discussed, recommended and that consent has been declined, and that parents have been provided with a copy of the screening leaflet.

Record consent in maternal hand held notes and babies PCHR book.

**A blood spot card MUST still be completed with a bar code label and sent to the lab.**

Ensure parents have information on how to have their baby tested if they changed their mind.

Send letter to parents, GP, CHIS, and Antenatal & Newborn Screening Co-ordinator that screening was declined.

**See Decline pathway**

#### **Babies admitted to NICU**

All babies, regardless of GA should have an admission bloodspot taken which is sent to the lab with the day 5 bloodspot

## 5.2 Premature Neonate

Provide all pregnant women the information leaflet 'Screening tests for you and your baby' in their preferred language where possible.

Baby born before 32 weeks gestation (equal to 31+6 days). With parent consent take admission bloodspot.

Baby stays on UH Sussex West NICU and is resident on day 5. Set Northgate record to NICU.  
 Provide parents with information leaflet 'screening tests for you and your baby: babies in special care units'

**YES**

Screen offered to parents

Screen and data capture consented to ensuring parents are fully aware of all conditions baby will be screened for.

Take admission day blood spot

Take routine sample on day 5

Document that NBS screening has been discussed, recommended and that consent has been given, and that parents have been provided with a copy of the screening leaflet.  
 Record consent on Badgernet, in Hospital notes, SCBU notes, PCHR book and the Discharge summary.

Follow well baby pathway for results/repeat.  
**Additionally follow below for CHT**

**CHT NOT  
SUSPECTED**

Repeat sample (2 spots) at 28 days or day of discharge. If discharged before 28 days –write 'discharge sample' on the card.  
 NBS FS will flag the record as repeat required and date.

**SUSPECTED  
CHT**

**REFERRAL BY THE  
LABORATORY**

**CHT  
BORDERLINE -**

Laboratory will request a 4 spot repeat sample. This must be no sooner than 7 days from the previous sample.

**NO**

If baby is resident on another NICU on day 5, transfer NBS record to them and email the sites screening team

Screen and data capture declined

Ascertain if all screening is declined.  
 SCD, CF and CHT can be declined individually however the 6 IMD's can only be declined as a group.

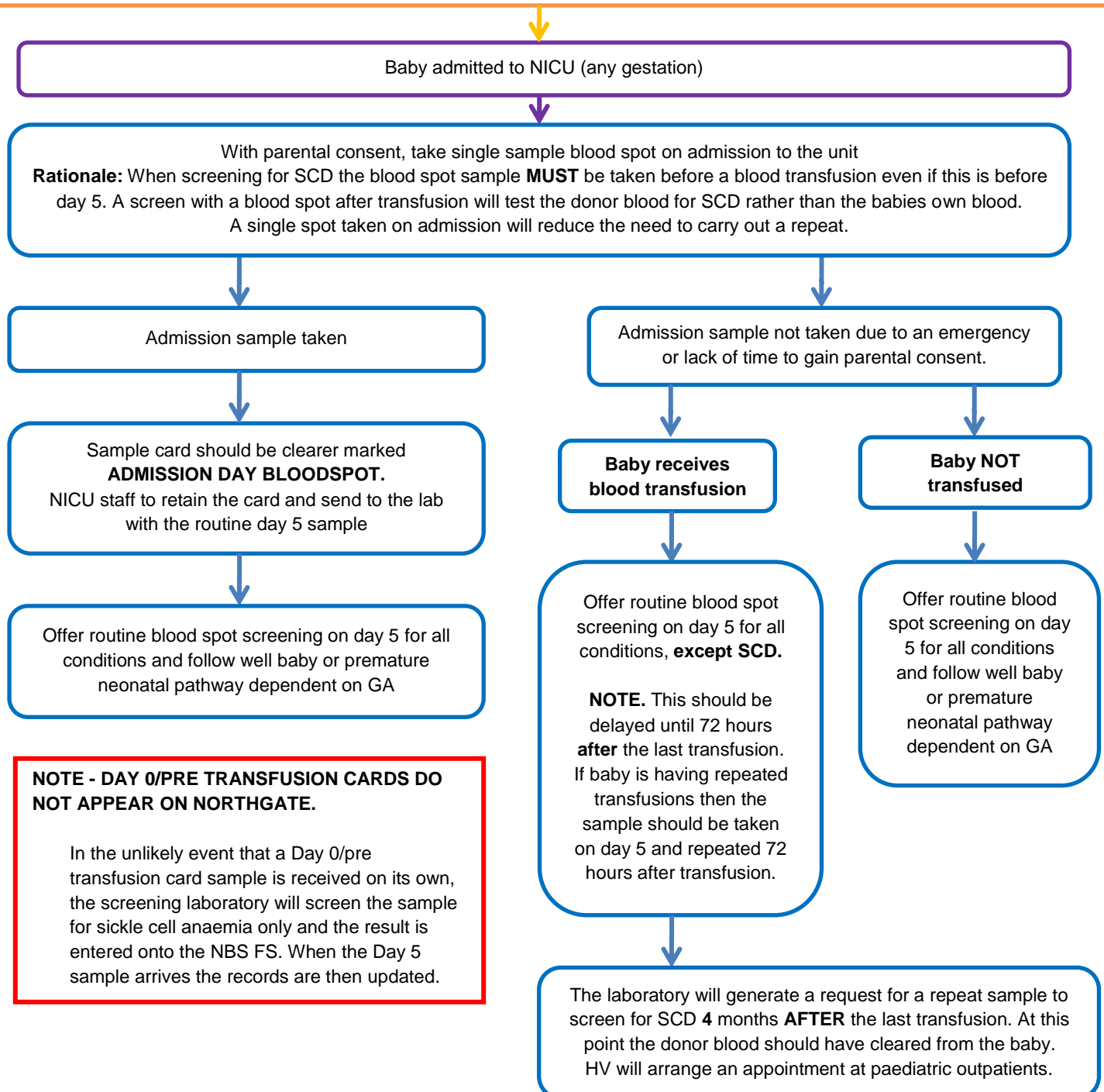
Document decline on Badgernet, in Hospital notes, SCBU notes, babies PCHR book and the discharge summary.

Send letter to parents, GP, CHIS, and Antenatal & Newborn Screening Co-ordinator that screening was declined.  
**See Decline pathway**

Admission spot should be sent to the lab if baby transfers to another NICU

### 5.3 In a Transfused Neonate

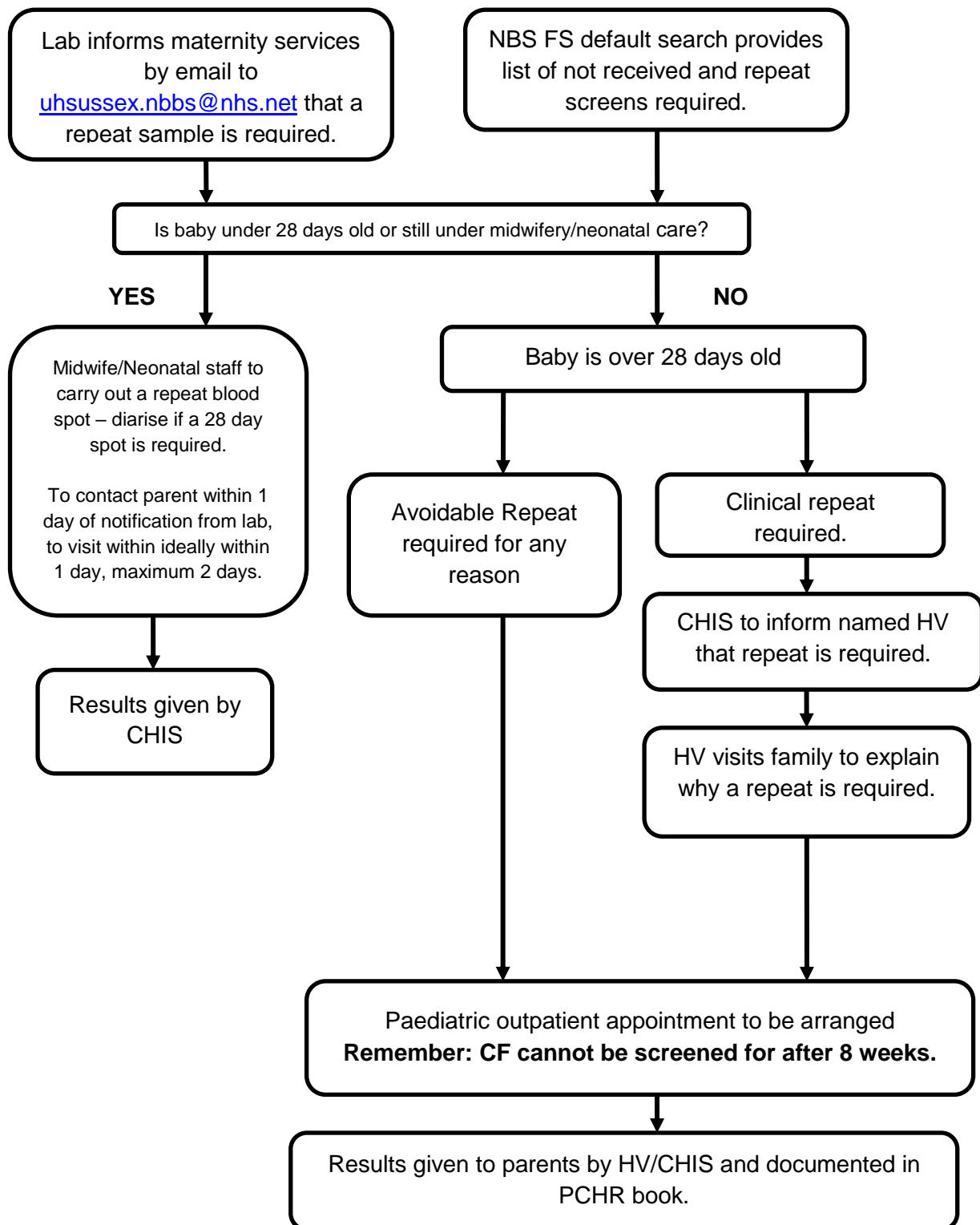
Provide all pregnant women the information leaflet 'Screening tests for you and your baby' in their preferred language where possible.



**NOTE:** If baby leaves UH Sussex West care then the NBS FS record will be case noted with where baby has moved to and transferred out. An email will be sent to the screening lead. The receiving site should transfer the NBS FS record in to gain access.

Templates for letters sent from CHIS can be found on the following link  
[newborn-blood-spot-screening-results-to-parents-template](#)

## 5.4 Repeat Samples Pathway



If a clinical repeat is required and a Health Professional requires any advice prior to seeing/contacting the parents/carers, Dr Rabbs, Consultant Paediatrician (UH Sussex West) can be emailed.

## 5.5 Leaflets

Information regarding the screening programmes is provided to all parents:

- 'Screening for you and your baby' booklet is provided via a QR card to all parents by community midwives at booking.

Screening tests for you  
and your baby



Information can also be found at:

- [screening-tests-for-you-and-your-baby-description-in-brief](#)
- Parents of babies who are resident on NICU are also given the booklet 'Screening for you and your baby – babies in special care unit's  
[screening-tests-for-you-and-your-baby-babies-in-special-care-units](#)
- An easy read version is available:  
[screening-tests-for-you-and-your-baby-easy-guides](#)
- Written information is available in different languages:  
[screening-tests-for-you-and-your-baby-description-in-brief](#)
- Information is available to watch on animations, these are subtitled for sign language and different languages:  
[screening-tests-for-you-and-your-baby](#)  
[Screening test for you and your baby - different languages, subtitled and British Sign Language](#)
- [Information on SCID screening](#)  
[scid-screening-helping-you-decide-if-you-want-this-for-your-baby](#)

Additional information for health professionals and parents/carers regarding repeats can be found at:

[repeat-blood-spot-samples-description-in-brief](#)

Information on repeat bloodspot for cystic fibrosis can be found at:

[repeat-blood-spot-test-for-cystic-fibrosis-information-sheet](#)

Information on repeat bloodspot for congenital hypothyroidism can be found at:

[congenital-hypothyroidism-cht-suspected-description-in-brief/congenital-hypothyroidism-cht-information-for-families-following-a-suspected-screening-test-result](#)

## 5.6 Exclusion Criteria

- Babies Stillborn or who died before day 8
- Babies >56 days old are ineligible for CF screening
- Children over 1 year of age

## 6.0 Performing a Newborn blood spot

Parents must verbally consent to the NBS. This consent must be documented in the maternity notes and the baby's child health record. Only those with parental responsibility can give consent. For surrogacy births the trust guideline for gaining consent will also be followed [Trust's surrogacy guideline](#)

Good quality blood spot samples are vital to ensure that babies with rare but serious conditions are identified and treated early. Poor quality samples can cause inaccurate newborn screening results.

Poor quality samples will be rejected by the laboratory at their discretion, the laboratory will request an 'avoidable repeat' sample. These repeat samples can cause anxiety for parents, distress to baby and can delay diagnosing a condition. In some cases parents might decline the repeat leaving babies screening incomplete. It is also costly to the trust.

The most significant effects of poor quality samples are:

- a. Falsely low analyte concentrations which can be caused by:
  - Small volume blood spots (under filled circles)
  - Compression of the sample
 These samples can cause false-negative results.
- b. Falsely high analyte concentrations which can be caused by:
  - Layering the blood
  - Applying the blood to the front and the back of the cards
 These samples can cause false-positive results.

Please refer to Newborn blood spot screening: sampling guidelines for full guidance on collecting the blood spot sample.

[newborn-blood-spot-screening-sampling-guidelines](#)

### 6.1 Complete blood spot card

- Ensure blood spot card has not passed its expiry date.
- Confirm babies name, date of birth and parents contact details.
- Ask parent to check what has been written on the card is correct.
- Attach babies barcode label to the card, remember babies NHS Number MUST be present.
- Fill in ALL boxes on the card. Write gestational age in weeks AND days.
- Take care to avoid contamination when filling in the card, by touch or by placing the card on a dirty surface.
- Ensure relevant A/N screening results are recorded on card e.g. Parents are known carriers of CF or haemoglobinopathy.
- Write on the blood spot form if 1 or more tests have been declined.

## 6.2 Preparing the foot

- Clean the heel by washing it in plain tepid water.
- Do not use alcohol wipes.
- Allow foot to air dry before taking the sample.
- The heel should be warm. Do not pre-warm by soaking the foot in warm water.
- Allow the foot to hang down to increase blood flow.

## 6.3 Lancet use/ puncture sites

- Follow local policy for universal precautions and infection control.
- Use automatic lancet device.
- The external and internal limits of the calcaneus are the preferred puncture site. See Figure 1.
- For term babies, skin puncture must be no deeper than 2.0mm.



- There is some evidence that the whole heel plantar surface is safe for obtaining blood in term and preterm infants. See Figure 2.
- For preterm babies and if using the whole of the plantar surface then skin puncture must not be deeper than 1.0 mm










- Always avoid the posterior curvature of the heel
- These sites are also suitable for babies up to a year in age.

## 6.4 Taking the sample

- The aim is to fill each circle on the blood spot card, using a single drop of blood for each circle.
- The lab aim to punch 3 2mm disc's from each circle.
- Puncture the heel and wait up to 15 seconds to allow the blood to flow.



- Allow one spot to fill each circle by natural flow, ensure it seeps through to the back of the card.
- **DO NOT** allow the heel to come into contact with the card.
- **DO NOT** squeeze the foot in an attempt to increase the blood flow.
- **DO NOT** layer the blood.
- When finished, wipe the excess blood from the heel and apply gentle pressure to the wound with cotton wool or gauze. Apply a spot plaster if required.
- Should 1 blood spot not be adequate or soak through, add another blood spot to the card ensuring it is of correct size.
- If the blood flow ceases, the congealed blood should be wiped away firmly with cotton wool or gauze. Gently massage the foot, avoid squeezing, and drop the blood onto the card.
- A second puncture should only be performed if the baby fails to bleed with the above technique. This should be carried on a different part of the foot or on the other foot.

	Correct	Reasoning
	A single, evenly saturated drop of blood that fills the circle completely and soaks through to the back of the blood spot card	Good quality blood spots are essential to obtain accurate screening results
	Incorrect	Reasoning
	Insufficient sample: small volume spots	Risk of false-negative result
	Insufficient sample: blood not soaked through to back of blood spot card	Risk of false-negative result
	Inappropriate application of blood: multispotted	Risk of false-negative result
	Compressed sample	Significant risk of false-negative result
	Inappropriate application of blood: layered sample (for example, one spot of blood is layered directly on top of another) or blood applied to the front and the back of the blood spot card	Risk of false-positive result
	Contaminated sample	Risk of inaccurate result

Images courtesy of Wyn Griffiths, South East Thames Screening Laboratory and Roanna George, Wales Newborn Screening Laboratory

If a midwife is unable to sufficiently bleed a baby and advises parents to take baby to hospital to be bled, a bloodspot card with stickers attached will be given to parents to take with them.



## 6.5 After taking the sample

- Allow the blood spots to dry away from direct sunlight or heat, before placing in the glassine envelope. The card should be placed in with the blood spots inserted first.
- Record any of the following in the 'comments' box on the blood spot card.
- Babies known medical history.
- Family history relevant to the conditions being screened for.
- If **NOT** day 5-8 the reason for sample being taken, e.g. pre-transfusion, CHT preterm.
- Record that blood spot was taken in maternal notes and PCHR book if available.
- Inform parents how and when they will receive results.
- Return card to collection point within 24hrs for dispatch and logging.
- Dispatch points are on the Birth Centre at St Richards and in the Community Midwives office at Worthing Hospital. Samples from NICU are also left at these dispatch points.
- Check date of birth is correct on the stickers.
- If posting the card directly, advise Community Team Leads or Screening Admin Clerk so dispatch date can be recorded.

Bloodspot cards are ordered from the trust's procurement system, these are ordered by the ward clerks.

## 7.0 Referrals of affected babies following the Newborn blood spot

The UKNSPC recommends the following timeframes to ensure babies achieve the maximum benefit from treatment.

Condition	Commence treatment from positive screening result
PKU	Within 17 days
CHT (first sample)	Within 17 days
CHT (second sample)	Within 24 days
MCADD	Within 17 days
CF (two CFTR mutations)	Within 28 days
CF (babies who required a second sample IRT measurement)	Within 35 days
SCD	Within 8 weeks

For babies whose blood spot was taken by UH Sussex West they will be referred as follows:

### 7.1 Sickle Cell Disease (SCD)

- Major Hbo disorder: Lab informs local Lead Paediatrician by fax and phone. Paediatrician contacts parents and a follow up arranged, GP informed by the lab.
- Lab sends copy of results to CHIS.

## 7.2 Cystic Fibrosis (CF)

- Lab informs the Regional Cystic Fibrosis Unit at The Royal Brompton Hospital, who contacts the local Lead Paediatrician, who will arrange to see the family. Lab sends copy of results to CHIS.

## 7.3 Congenital Hypothyroidism (CHT)

- Lab informs named local Consultant Paediatrician, Worthing Hospital – Dr E Vamvakiti, St Richards Hospital – Dr R Remorino. If neither available then the On-call Consultant Paediatrician will be contacted. They will arrange to inform parents and will organise appropriate follow up.
- Lab sends copy of results to CHIS and GP.

## 7.4 Inherited Metabolic Diseases (IMD's)

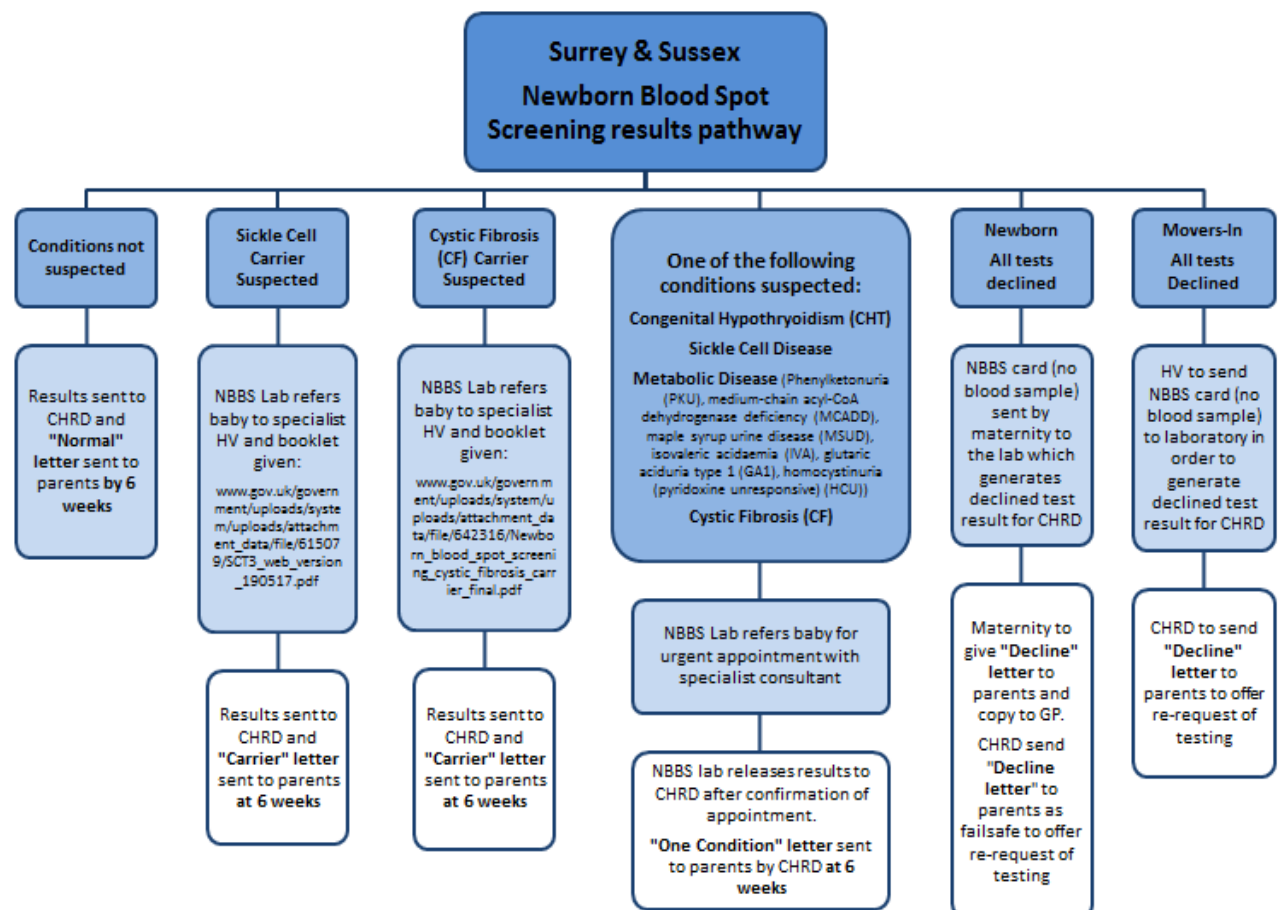
- Lab will inform Dr Mike Champion – Metabolic Consultant, Evelina Children's Hospital (St Thomas's Hospital) who arranges for parents to be informed and organises appropriate follow up.
- Lab sends copy of results to CHIS.

## 7.5 Carrier results

- CHIS will advise Link Health Visitor who contacts parents.

Exceptions to these will be on a case by case basis and will take into account parent's wishes.

## 8.0 Results pathway



### **Pathway for negative results following a repeat NBBS for a possible condition:**

CHIS will send a letter out to the Mother once the lab post their results.

The KPI for this process is 6 weeks however CHIS advise, parents should have heard within 3 weeks from the date of the repeat test.

In the event that they have not had any communication within this time frame parents can phone the Health Visitors or CHIS during business hours on 01243 793643.

### **Pathway for positive results following a repeat NBBS for a possible condition:**

The Laboratory or local Paediatric team will contact the parents with a care plan and consultation.

CHIS advise that this should be within 3 weeks from the date of the repeat test.

## **9.0 Governance structure and reporting**

KPI's are:

### **NB1 - CHIS responsible for submission**

The proportion of babies [registered](#) within the clinical commissioning group (CCG) both at birth and on the last day of the [reporting period](#) who are eligible for newborn blood spot (NBS) [screening](#) and have a conclusive [result](#) recorded on the child health information system (CHIS) at less than or equal to 17 days of age.

### **NB2 – The laboratory are responsible for submission, UH Sussex West to provide commentary.**

The proportion of 1st blood spot samples that require repeating due to an avoidable failure in the sampling process.

Monthly, Quarterly and Yearly summarised reports are saved [NEWBORN BLOOD SPOT Reports](#).

The Yearly summarised report with commentary is submitted quarterly to SIT and QA as part of the Trusts ANNB KPI submissions.

### **NB4 – CHIS responsible for submission**

The proportion of all babies [eligible](#) for newborn blood spot (NBS) [screening](#) who: Have changed responsible CCG in the first year of life or have moved in from another UK country or abroad and have a conclusive [result](#) recorded on the CHIS ≤ 21 calendar days of notifying the CHRD of movement in.

UH Sussex West NBS Lead will monitor monthly repeat reports provided by the lab for both avoidable and clinical repeats, this can be found [here](#). These will be collated and forwarded to Team Leads. When repeat rates have been over the acceptable NHSEI level they will then be investigated and reported on via the ANNB quarterly meetings along with any mitigations for screens not carried out within KPI.

Quarterly KPI reporting template can be found [here](#)

### **Screening Incidents**

Any incidents will be reported via the trusts internal system (DATIX) and escalated to the regional QA team via the Screening incident assessment form (SIAF) emailed to the regional SIT and QA teams:

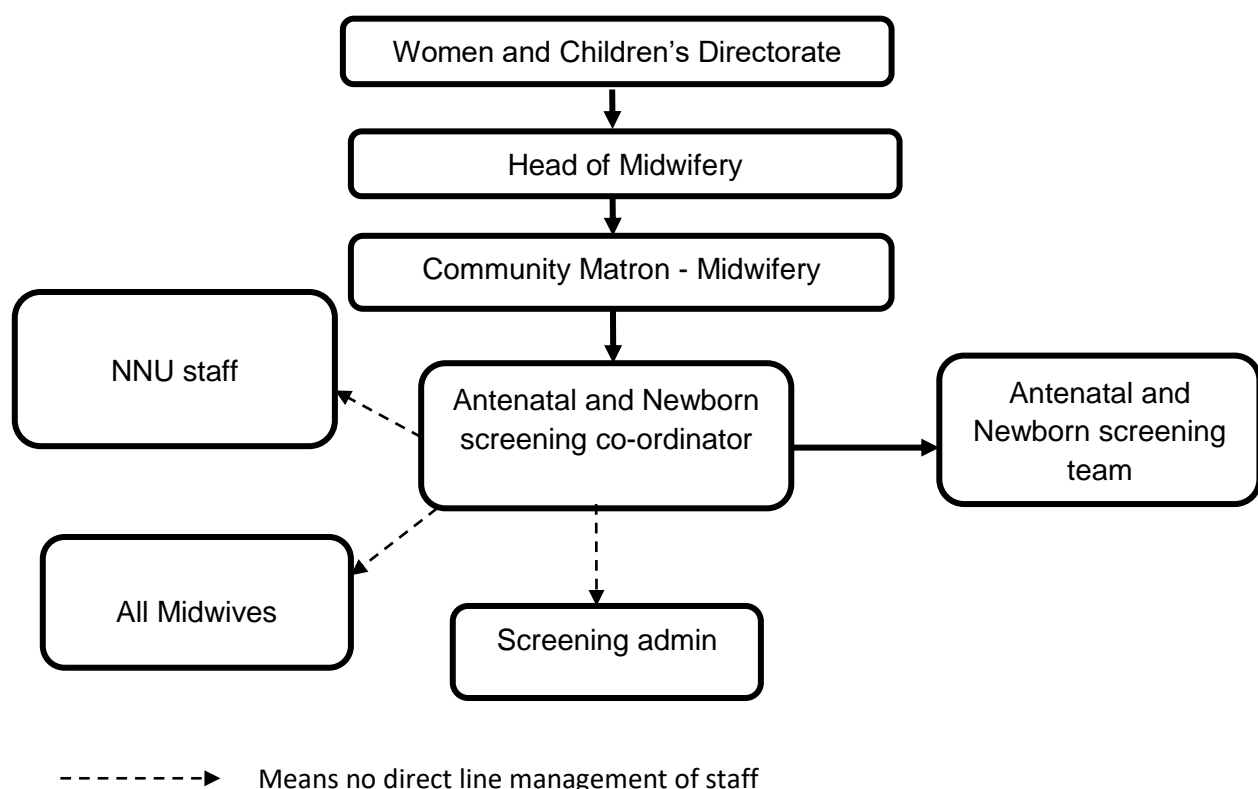
[PHE.Screening-ImmsSSAT@nhs.net](mailto:PHE.Screening-ImmsSSAT@nhs.net); [phe.southQA@nhs.net](mailto:phe.southQA@nhs.net)

[Managing safety incidents in NHS screening programmes](#) document will be adhered to and will the trust's incident policy.

Root cause analysis will be undertaken when required including a timeline of events and learning these will be signed off at trust level by the clinical governance lead (maternity). The postnatal screening log should be completed, all incidents should be saved in the Newborn screening incident folder (NBS) under the SIAF reference.

The SIAF, root cause analysis forms, screening incident log and screening programme folders can be found by clicking the link [here](#)

## 9.1 Governance structure



## 10.0 Movers in and out of area

### Movers in:

- Movers in for postnatal care are rung into the Community Midwives Office or emailed to the postnatal ward from the discharging Hospital. If seen post day 5 then blood spot screening will be checked and offered if it has not been done so already.
- The Community Team Lead will check that the NBS FS record has been transferred into our NBS FS site, if this has not been done then they will instigate this transfer.
- Blood spot screening can be undertaken up to the age of 1 year if it has not been carried out prior to moving into the area, CHIS to advise regarding these.

- Barcode labels can be printed from Northgate if parent does not have any. On babies NBS FS record click on: *View babies record, print labels, pick size of label required*

## **Movers out: Prior to a bloodspot being taken**

- The midwife responsible for the birth will ensure that details are passed onto the correct Hospital for postnatal care. See Postnatal Care Guideline.
- The Community Team Lead or postnatal screening admin will check the location of the NBS FS record and transfer out if it is not in the correct location with a case note and a comment added to the birth list for where babies PNC is being given.
- Barcode labels will be in parents postnatal notes
- For NICU babies,
  - If baby leaves UH Sussex West NICU to another NICU then the NBS FS record will be case noted with where baby has moved to and transferred out.
  - An email will be sent to the screening lead. The receiving site should transfer the NBS FS record in to gain access.
  - A note will be added to the birth list of where baby is residing
  - If baby is under 32 weeks GA details will be added to the 28 day bloodspot spreadsheet for tracking
  - Should baby return to a UH Sussex West NICU their record should be transferred back in to ensure there isn't anything outstanding regarding repeats.

## **Movers out: After a bloodspot being taken**

- If a baby is resident on any UH Sussex West ward on day 5 or is being given PNC on day 5 a bloodspot will be taken.
- Should this baby then be discharged home to another area or move area for PNC the bloodspot record on NBS FS should be case noted, transferred to new site (so a repeat can be seen should this be required) and the screening lead for the site emailed.
- The discharging midwife should notify the screening admin so the NBS FS record can be actioned as above.
- The birth list will require a comment adding to it regarding baby has moved out of area.
- Should a repeat email be received, this will be forwarded to the screening lead and the community team lead midwife/NICU matron contacted where baby now is. If the screening admin is sending this email it will be copied to UH Sussex West's community team leads.

Instructions on transferring in a bloodspot record in on Northgate records instructions can be found in the Northgate folder by clicking [here](#)



## 11.0 Training and ongoing assessments/avoidable repeats

- UH Sussex West will follow national guidance from NHSEI for training of new staff who will undertake the Newborn Blood Spot.
- UH Sussex West will ensure that for those practitioners carrying out the Newborn Blood Spot, a record is kept to show competency/when accredited study has taken place.
- UH Sussex West will provide an annual update for all those who undertake the Newborn Blood Spot. This may include practical and theoretical assessments and annual completion of the NBS e-learning module. Training logs will be kept.
- UH Sussex West will highlight when retraining is required based on avoidable repeats.
- All avoidable repeats are logged on the avoidable repeat spreadsheet found [Avoidable repeat spreadsheet](#)
- For **all** avoidable repeats the sample taker will be sent the following email from the NBS email account when the repeat is received from the lab. Community Team leads, NBS lead and NICU matrons will be copied in as required. This will be logged on the repeat spreadsheet.
- When the quarterly NBS report is received from the lab the NBS Lead will email all staff who have had a repeat with a breakdown how many on what dates. This will be logged on the repeat spreadsheet.  
When 2 repeats in a quarter have been required the [e-learning for health](#) NBS specific units will need to be undertaken within 2 weeks.  
When 2 repeats in a quarter have been required the [e-learning for health](#) NBS specific units will need to be undertaken within 2 weeks and a meeting held with their line manager to make a formal plan to improve competency.
- If 2 or 3 repeats have been taken over a 3 month period crossing 2 quarters the following emails will be sent. This will be logged on the repeat spreadsheet.  
When 2 repeats across 2 quarters have been required the [e-learning for health](#) NBS specific units will need to be undertaken within 2 weeks.  
When 3 repeats across 2 quarters have been required the [e-learning for health](#) NBS specific units will need to be undertaken within 2 weeks and a meeting held with their line manager to make a formal plan to improve competency.

Email templates can be found by clicking [here](#)

## 12.0 Newborn Outcome Solutions

Babies diagnosed with SCT must have their outcomes add to the [Newborn outcome solutions webbased database](#).

Victoria Sharp Neonatal Consultant is Lead Consultant and will input all data.

Automatic emails are received from the national team when a baby is diagnosed to initiate the data input. The lead Consultant is emailed directly and the NBS Lead is also emailed, as a failsafe, and should ensure data is inputted in a timely fashion.

[User Guide](#) can be found by clicking this link.

## Appendix 1: Mapping and cohort checking in NBS FS

Babies are mapped automatically by Northgate Blood Spot Failsafe Solution at point of the NHS number being generated.

Records are mapped by the baby's home address (post code or GP code). If the post code or GP code cannot be used, the record is mapped to the hospital of birth ('org code'). If the 'org code' cannot be used, the record is mapped to the child health unit code linked to the baby's record ('CHU code'). If the 'CHU code' cannot be used, the record moves to the 'unmapped site' and a manual process is used to place the record.

UH Sussex West's NBS FS facilities are:

- Worthing Hospital\_WSX
- Chichester St Richards \_WSX

Both facilities are checked daily against the birth list to ensure UH Sussex West's cohort is present; this is carried out on day 5, i.e. the day the blood spot should be taken by the NBS admin.

- Any missing records for which UH Sussex West will be providing postnatal care will be located via a National Record Search and transferred in. These should be transferred in at the point of notification by the community team lead and added to the birth list or by the screening admin team when the blood spot is taken and has been added to the birth list by the sender - an email should also be sent to the screening admin to advise of the transfer in.
- Any babies for which UH Sussex West are not providing postnatal care will have their NBS FS record transferred to the correct location, if this has not automatically been done so by Northgate. In each case a National Record Search should be carried out to check the location of the baby and then if required it should be transferred to the correct site with a case note added. In all cases, no matter the location of the NBS FS record, it is the responsibility of the discharging midwife to telephone/email the hospital who will be providing PNC advising of the transfer of care.
- Any babies resident on UH Sussex West's NICU's will have their NBS FS record checked to ensure it is in the correct location at the point of sending off the blood spot, the Northgate record should be marked as 'NICU' to aid tracking. The NBS FS record will change to purple italics within Northgate to highlight this easily.

Sample Taken Date

☒ NICU Baby

- Any baby resident on another NICU on day 5 whose NBS FS sits in UH Sussex West's site will have the record case noted and the record transferred, the screening lead for the site will be emailed. The birthlist will have a comment added to it regarding the location of baby and if a 28 spot required babies details will be added to this spreadsheet. The Screening admin will check the NBS record to



ensure the sample has been received and transfer the record back to UH Sussex West should baby repatriate back to UH Sussex West NICU.

- Any records transferred in from other sites should be checked and accepted by the community team lead or screening admin if UH Sussex West is providing PNC. If the screening admin accepts the record they should notify the community team lead.
- A daily search should be undertaken in NBS FS for **transfer in's** by removing the date and ticking the transfer in search box. All transfer ins should be checked and actioned accordingly.
- Any baby moving onto UH Sussex West care for PNC should be searched for on Northgate and transferred in if it is not already within the UH Sussex West site by the community team lead or screening admin. This should be carried out at the point the notification from the birth hospital is received. The hospital transferring baby should transfer the NBS FS record but it should not be presumed that this will occur. Records should be searched for even if post day 5 to check that a repeat blood spot was not required.
- Any baby being seen by an independent midwife should have the NBS record case noted with IM's name and phone number should a repeat be required.
- If a record is present on UH Sussex West NBS FS site and baby is not on the birth list then the record needs investigating.  
Check babies address and birth hospital;
  - If baby does not have a UH Sussex West address, case note and transfer baby to birth hospital.
  - If baby has UH Sussex West address, check with Community Teams Leads if we would give PNC, if we would not then transfer to birth hospital with a case note added.

Note – some border babies will have PNC delivered by birth hospital even though live in West Sussex (UH Sussex West providing area). If unsure and team leads are unsure email the screening team or ring postnatal ward of the hospital record is being transferred to so they can check

Records 'in transfer' will be visible in both sites until the transfer has been accepted.

Records are mapped to our NBS FS sites based on the following criteria:

The first "port of call" for Bloodspot mapping is the GP practice code: if a unique mapping is produced on the GP practice, then this will determine the hospital the baby is mapped to and the postcode will not be considered.

Mapped GP's and postcodes to Worthing Hospital\_WSX and Chichester St Richards\_WSX can be found by clicking [here](#)

NB. Any baby who has a Hampshire CCG GP but is having postnatal care with UH Sussex West will need to be transferred in.

## Appendix 2: Day 5 – check all cohort is visible in NBS FS

NBS admin to locate the birth list in

[Birthlist failsafe](#)

This list is populated daily with all births in UH Sussex West

Transfers in notified to NSHP or by the community midwives are also added to the lists if UH Sussex West are providing postnatal care.

This is called **the bloodspot/NIPE/NHSP list failsafe\_spreadsheet**.

Births will be highlighted for SRH.

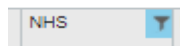
Complete the column 'Northgate checked' on the spreadsheet



In NBS FS, in both WSH and PIW facilities ensure all babies are visible if UH Sussex West are providing postnatal care. Move to correct facility if required.

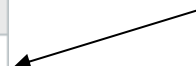
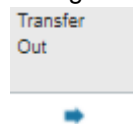


In NBS FS, in both WSH and PIW facilities, transfer in any babies who we are providing postnatal care to by carrying out a national search, if not already done so by the community team lead.  
 Choose 'receiving care in area' for the reason note, search by NHS number by clicking on



In NBS FS, in both WSH and PIW facilities, transfer out any babies who we are **not** providing postnatal care to, if not already done so by the community team lead and add a case note. Email the screening lead at the site the record is being transferred to as required.

Transfer out by clicking the transfer out arrow



Choose where to transfer the record to. The record will still be visible until the receiving site accepts the transfer. It can be cancelled by re clicking on the same icon should a mistake have been made.

### NICU BABIES

In NBS FS, in both WSH and PIW facilities, case note if a baby has moved to another NICU.

It is the responsibility of the NICU site taking the bloodspot to transfer in the NBS FS record. However it is good practice to transfer the record to them with a case note and to email the screening lead of the site.

Should a repeat or 28 day spot be required and the NBS FS record is still showing as not being accepted on a transfer, then the community team lead or screening admin should contact the NICU where baby is to ensure the repeat has been taken and case note NBS FS. The relevant lab can also be contacted.

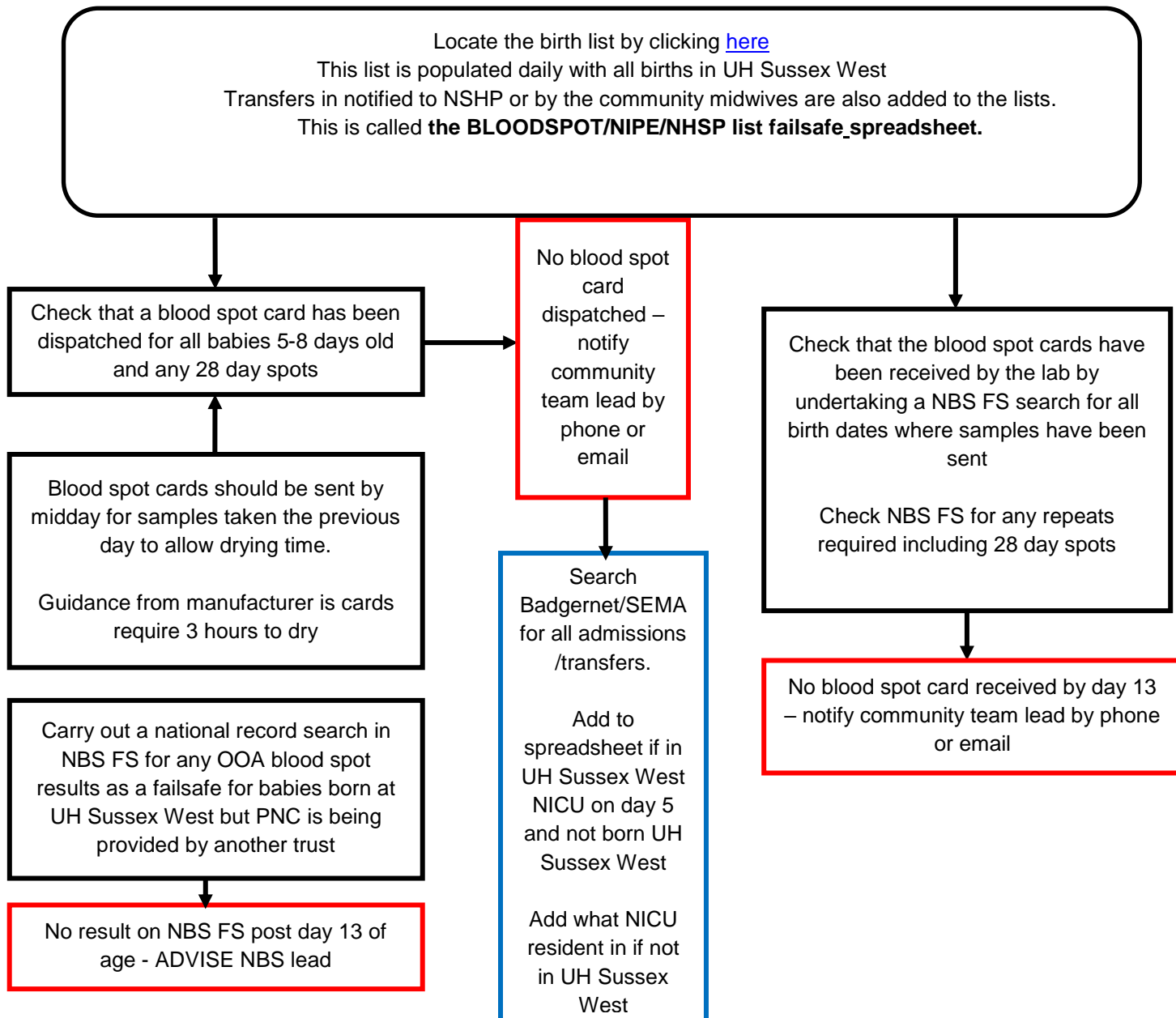
If baby is resident in UH Sussex West NICU on day 5 then it should be checked that the record is in WSH or PIW facility in NBS FS. It should be transferred in and case noted if not already visible.

Badgernet should be checked on day 5&6 for babies transferring on these days to ensure BS has been taken.

Should a repeat be required and baby is no longer resident on UH Sussex West NICU'S then the community team lead or screening admin should advise the NICU/community midwifery team where baby now resides to ensure the repeat can be taken, case note NBS FS and transfer blood spot taken

Instructions on how to check all babies have populated NBFS can be found [here](#)

### Appendix 3: Daily tasks



COLUMNS WHICH ARE COMPLETED ON THE BLOODSPOT/NIPE/NHSP LIST FAILSAFE SPREADSHEET ARE TO PROVIDE TRACKING INFORMATION:

		NHS	Hospital	Date of			Date	Date				Sent	
Last name	Postcode	Number	No	Birth	Sex	Place of birth	Taken	Sent	Admission	Repeat	Midwife	By	Received

These daily checks are carried out by:  
**Worthing Hospital – Postnatal screening admin**  
**St Richards Hospital – Postnatal screening admin**

**All repeats admission spots and 28 day spots are also recorded on this sheet for the day they are taken. These are recorded under their own headings to enable easy audit**

## Appendix 4: Dispatch pathways

### a. Worthing Hospital

Blood spot cards from community midwifery are left in the bloodspot box community midwifery office for dispatch. Blood spot cards from the wards are left in the bloodspot box on Bramber ward for collection.

All bloodspots taken by the ward should be checked by a team lead prior to being sent. If the sample has not soaked through or spots are too small this should be retaken so long as there is no delay in sending the sample

#### Check:

- Baby barcode sticker is on each page
- Date of specimen is > 5 day post birth.
- Has been signed by a midwife
- All boxes are filled in
- Date of birth is correct

Midwife posts blood spot card directly.  
 A picture of the front and back of the card should be sent to another midwife for 2<sup>nd</sup> checking

Midwife to contact team lead or NBS admin clerk to advice card has been sent if they are unable to complete the spreadsheet themselves.

Add the correct code to the card:  
 LH= well baby, LHN = NICU baby  
 Cards should be allowed to dry for 3 hours prior to posting. All cards received into the office after 1pm should be sent the following day

On BLOODSPOT/NIPE/NHSP list failsafe spreadsheet complete columns:

- date blood spot taken
- date blood spot dispatched to the lab
- who took the blood spot
- if it was a repeat
- who dispatched the blood spot

***If baby is not on the BLOODSPOT/NIPE/NHSP list failsafe spreadsheet add details and email screening admin to notify of the addition.***

If the blood spot is a repeat/ an admission spot or 28 day spot add all details to the correct title on the babies DOB list

Last post at Worthing hospital reception is  
 Weekdays 16:30 and Saturday 11:00

Blood spot cards are sent in prepaid envelopes to St Helier hospital.

No more than 3 blood spot cards can be sent in 1 envelope.

Ensure the blood spot part of the card is inserted into the envelope first to avoid damage on opening.  
 Sellotape the envelope for security.

Admission spots are not sent until the 5 day spot accompanies it unless baby has been transferred to another Hospital.

Bloodspot cards **will not & must not** be rejected by **any** member of the midwifery team for sample size/sufficiency if a repeat sample would then be delayed reaching the lab.

The lab makes the decision if a repeat is required.

## b. St Richards Hospital

Blood spot cards from midwifery and NICU are left in the blood spot box on the birth centre for dispatch

Cards are dispatched by birth centre ward clerk daily, except Sundays.

Check:

- Baby barcode sticker is on each page
- Date of specimen is > 5 day post birth.
- Has been signed by a midwife
- All boxes are filled in
- Date of birth is correct

**All bloodspots taken by the ward should be checked by a team lead prior to being sent. If the sample has not soaked through or spots are too small this should be retaken so long as there is no delay in sending the sample**

Add the correct code to the card:  
 XH= well baby, LXN = NICU baby  
 Cards should be allowed to dry for 3 hours prior to posting. All cards received into the office after 1pm should be sent the following day.

Midwife posts blood spot card directly.  
 A picture of the front and back of the card should be sent to another midwife for 2<sup>nd</sup> checking

Midwife to contact team lead or NBS admin clerk to advice card has been sent if they are unable to complete the spreadsheet

On BLOODSPOT/NIPE/NHSP list failsafe spreadsheet complete the following columns:

- Date blood spot taken
- Date blood spot dispatched to the lab
- Who took the blood spot
- If blood spot was taken whilst baby was admitted
- If it was a repeat
- Who dispatched the blood spot

***If baby is not on BLOODSPOT/NIPE/NHSP list failsafe spreadsheet add details and email screening admin to notify of the addition.***

If the blood spot is a repeat/ a 1 day spot or 28 day spot add all details to the correct title on the babies DOB list

Post is taken to the post box at the front of the Hospital

Blood spot cards are sent in prepaid envelopes to St Helier hospital.

No more than 3 blood spot cards can be sent in 1 envelope.

Ensure the blood spot part of the card is inserted into the envelope first to avoid damage on opening.  
 Sellotape the envelope for security.

Admission spots are not sent until the 5 day spot accompanies it unless baby has been transferred to another Hospital.

Bloodspot cards **will not & must not** be rejected by **any** member of the midwifery team for sample size/sufficiency if a repeat sample would then be delayed reaching the lab.

The lab makes the decision if a repeat is required.

## Appendix 5: NICU paperwork

Beeding Ward and NNU will document that a blood spot has been offered, consent to and taken on:

- Neonatal Observation Chart
- On Badgernet
- On the Discharge to Postnatal Ward Form.
- On the discharge sticker if baby is discharged home at less than 10 days old from the unit, which is stuck in the discharge book. (need to check they do this on NNU).

The following paperwork is filled out with the date of when the blood spot was taken.

### Neonatal Observation chart

Western Sussex Hospitals **WHS** Neonatal Observation Chart

Name:	DOB:	CGA:	Day:	Hospital No:	Date:
Weight: Y/N	Length: Y/N	HC: Y/N	Labels: Y/N	BM: Y/N	Parents visiting:

Consultant ward round: Y <input type="checkbox"/> N <input type="checkbox"/> Parents present on ward round: Y <input type="checkbox"/> N <input type="checkbox"/>	
Plans for the day:	
<b>MEDICATIONS</b>	Date tested: <b>BLOOD SPOT</b> Consent obtained: Yes <input type="checkbox"/> 5/7 Date completed: <32 wks, day 28 or at discharge Date due: Date completed: <b>AUDIOLOGY &gt; 48hrs:</b> Yes <input type="checkbox"/> No <input type="checkbox"/> Consent obtained: Yes <input type="checkbox"/> Date completed: <b>ROP &lt;1501/&lt;32/40:</b> Yes <input type="checkbox"/> No <input type="checkbox"/> Date due: Discharged: Yes <input type="checkbox"/> No <input type="checkbox"/>
Blood pressure due: Cot change due: Any other comments:	<input type="checkbox"/> Skin to skin (kangaroo care) <input type="checkbox"/> Containment Holding <input type="checkbox"/> Still Touch <input type="checkbox"/> Cuddle <input type="checkbox"/> Verbal Only <input type="checkbox"/> Top & Tail <input type="checkbox"/> Bathed Baby <input type="checkbox"/> Fed Baby <input type="checkbox"/> None <input type="checkbox"/> All declined by parents <input type="checkbox"/> Consent for dummy <input type="checkbox"/> Non nutritional sucking

Name \_\_\_\_\_  
 Signature \_\_\_\_\_



## Discharge to Postnatal Ward Form

Please complete or Affix Patient Label		 <b>Western Sussex Hospitals</b> NHS Foundation Trust	
Unit No: .....	Ward: .....		
NHS No: .....	<b>Discharge to Postnatal Ward Form</b>		
Surname: .....			
Forenames: .....			
Midwife informed of planned transfer to postnatal ward <input type="checkbox"/>			
Agreed date and time of transfer back to handover baby to Midwife			
Date: .....	Time: .....	Name of Midwife: .....	
Age in Days: .....			
Mothers Name: .....	ID labels x 2 <input type="checkbox"/>		
Admission Date: .....	Discharge Date: .....		
Day 5 blood Spot: <input type="checkbox"/> date/date due: .....			
Hearing Screened: <input type="checkbox"/> date: ..... Result: .....			
Reason for Admission/treatment: .....			
.....			
Medications/ next due: .....			
Feeding/Last fed: .....			
Follow up Appointment:		Yes/No	Date: .....
Rapid Access Appointment:		Yes/No	Date: .....
NIPE check completed		Yes/No	Date: .....
Care handed over to Midwife <input type="checkbox"/>			
Signature/Name/ Designation: .....			
Discharge date: .....		Time: .....	

## Discharge Sticker

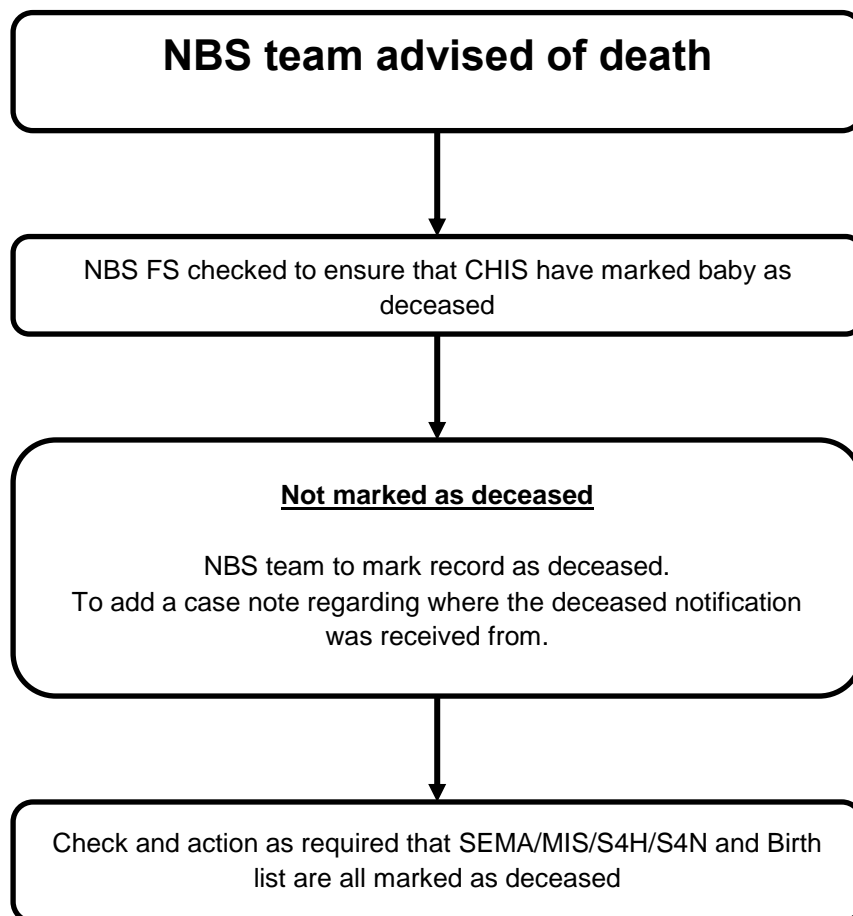
Birth & D/C Weight:  
 D/C Date:  
 NIPE Date:  
 Hearing Screen Date:  
 NBBS Date:  
 Feeding:

## Appendix 6: Child death notifications

The NBS team are advised of neonatal and child deaths from the following departments:

UH Sussex West Neonatal  
 UH Sussex West Maternity  
 UH Sussex Bereavement team  
 SCT CHIS

In all neonatal deaths, the following is carried out:





## **Appendix 7: New user request for Northgate Failsafe Solution**

The following form is required to be filled in by the NBS lead and emailed to the NBS helpdesk to request access and can be found [here](#)

## Appendix 8: Decline NBS screen

Newborn blood spot declined.  
 Record decline in maternal hand held notes and babies PCHR book if available.

Community team lead advised of decline by midwife offering the NBS.  
 Community team lead review/discuss with midwife. Advise NBS lead.

Complete baby demographics on blood spot card (barcode sticker to be used), send card to the laboratory, add decline or decline code if reason known – see below.  
 Record decline on MIS. Note decline on failsafe birth list. **Casenote decline on NBS FS**

Decline letters to be by midwife/community team lead to the following and a copy saved/uploaded onto babies evolve record under Maternity:

- Parents (asking them to confirm their decision and advising on when/how they can request screening should they change their mind)
  - GP and Health Visitor
  - CHIS - who will upload to SYSTMONE and will also task the HV team on the system
- Email letter to [SC-TR.CCHIS@NHS.NET](mailto:SC-TR.CCHIS@NHS.NET) and save to evolve

The decline letter template for parents, which should be added to trust header, and the decline screen spreadsheet can be found [here](#)

Laboratory receive card with no blood spots  
**Laboratory mark NBS FS record as declined**  
 CHIS to send decline letter to family if they have not received copy of decline letter from UH Sussex West

### Parents contact midwifery/HV team and consent for screening.

Notify GP & CHIS of contact  
 Midwifery or HV team to arrange to obtain a blood spot for screening, dependent on age of baby.

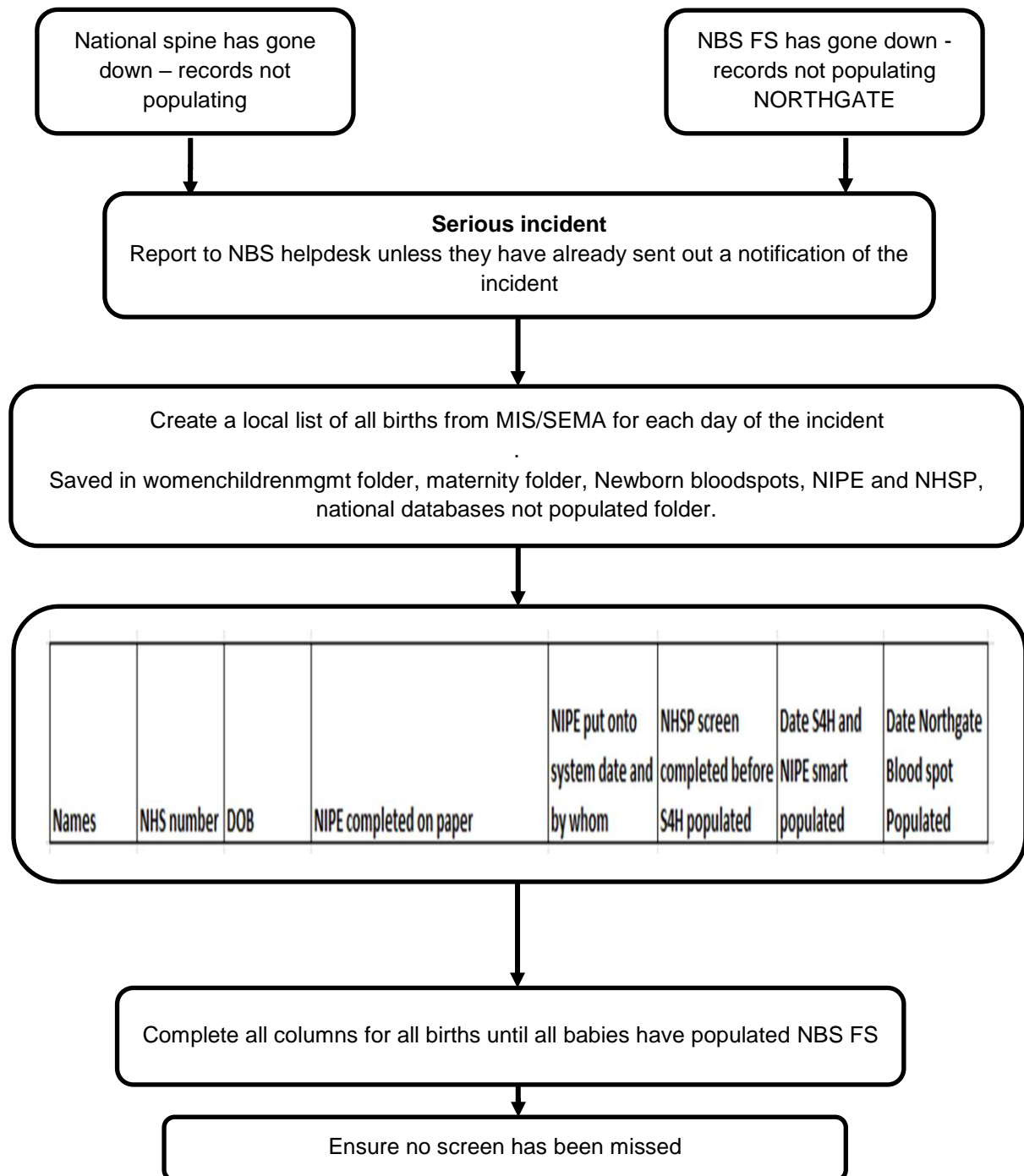
### Decline codes

**0201** – DECLINED, NO HISTORY OF BEING SCREENED  
**0202** – DECLINED, SCREENED IN UK (AS REPORTED BY PARENTS) WITH NO EVIDENCE OF RESULT  
**0203** – DECLINED, SCREENED OUTSIDE UK WITH EVIDENCE OF RESULT  
**0204** – DECLINED, SCREENED OUTSIDE UK WITH NO EVIDENCE OF RESULT

### Remember:

Ascertain if all screening is declined.  
 SCD, CF and CHT can be declined individually  
 However, the 6 IMD'S can only be declined as a group

## Appendix 9: Northgate Newborn blood spot failsafe solution has not been populated



## Appendix 10: Deletion of record/ changes to a record in NBS FS

- NBS FS is populated from the national storage system when the NHS number is generated.
- Any subsequent changes due to errors e.g. gender, time of birth, address etc will **not** change on NBS FS automatically.
- These must be manually changed or reported to Northgate.
- NOTE - date of birth can only be changed when baby is searched for in your facility, NOT via a national search.
- If a record needs removing this should also be reported to Northgate.
- Northgate should be emailed from an nhs.net account:
- [nbsfs.helpdesk@nhs.net](mailto:nbsfs.helpdesk@nhs.net)
- This request will be carried out by Community Team Leads, NBS admin or the Antenatal and Newborn Screening Co-ordinator.
- Screen shots of the NBS FS pages should be taken and saved to ensure correct changes have been made and for tracking should an incident occur.

## Appendix 11: Repeat blood spots

- All repeats will be requested by the lab, both clinical repeats and avoidable repeats via email to [uhsussex.nbbs@nhs.net](mailto:uhsussex.nbbs@nhs.net)
- For avoidable repeats the lab will send a copy of the original blood spot card
- Once actioned these emails will be saved in the SRH actioned or Worthing actioned folders under year and repeat code
- The repeat spreadsheet will be completed and an email sent to the sample taker with a picture of the card. These can be found in the [repeat bloodspot folder](#). Also see Section 11.
- Community team leads and Newborn Screening admin will check NBSFS daily for baby's requiring a repeat or a card having not been received.
- Community team leads will inform midwives and neonatal staff that a repeat is required
- If a midwife is unable to sufficiently bleed a baby and advises parents to take baby to hospital to be bled, a bloodspot card with stickers attached will be given to parents to take with them.
- All repeats will be casenoted in NBS FS with date the repeat was taken and sent, for 28 day spots a due date will be added.
- Any NBS record for babies on OOA NICU will now be transferred to the NBS site who undertook the blood spot if baby is still resident there if the record has not already been transferred out.
- Link for info to parents and professionals regarding clinical repeats: [repeat-blood-spot-samples-description-in-brief](#)

## Appendix 12: Admission Day Spot/Discharge Spot Failsafe

Badger report for NICU residents received every fortnight from Badgernet data co-ordinator



Add a column for 28 day spot  
 For any baby born 31 + 6 GA or earlier, search NBS fs to ensure a 28 day/pre discharge spot has been requested.

This can be checked in NBS FS by:

- Checking that the repeat date is on the record
- Opening the notes section and seeing

CHT	03 - Repeat Required	0315 - CHT - Pre-term
-----	----------------------	-----------------------



Check back on previous badger reports to ensure a 28 day/pre discharge spot has been taken at the correct time.

View notes in NBS FS and check that CHT no longer says repeat required.



Complete columns on the spreadsheet as per above search's (requested/completed)

**Highlight any missed baby TO NICU team and NBS lead. Raise a SIAF and Datix**  
**HIGHLIGHT ANY MISSED BABY TO NICU TEAM AND NBS LEAD**

## Appendix 14: Laboratories

Lab name	Contact number	Who uses the lab in surrounding area
St Helier (SW Thames)	02392 296 2991	UH Sussex West, East Surrey
Portsmouth Labs	02392 286 903	Portsmouth and Southampton Hospitals
South East Thames Lab	0207 149 6243	UH Sussex East

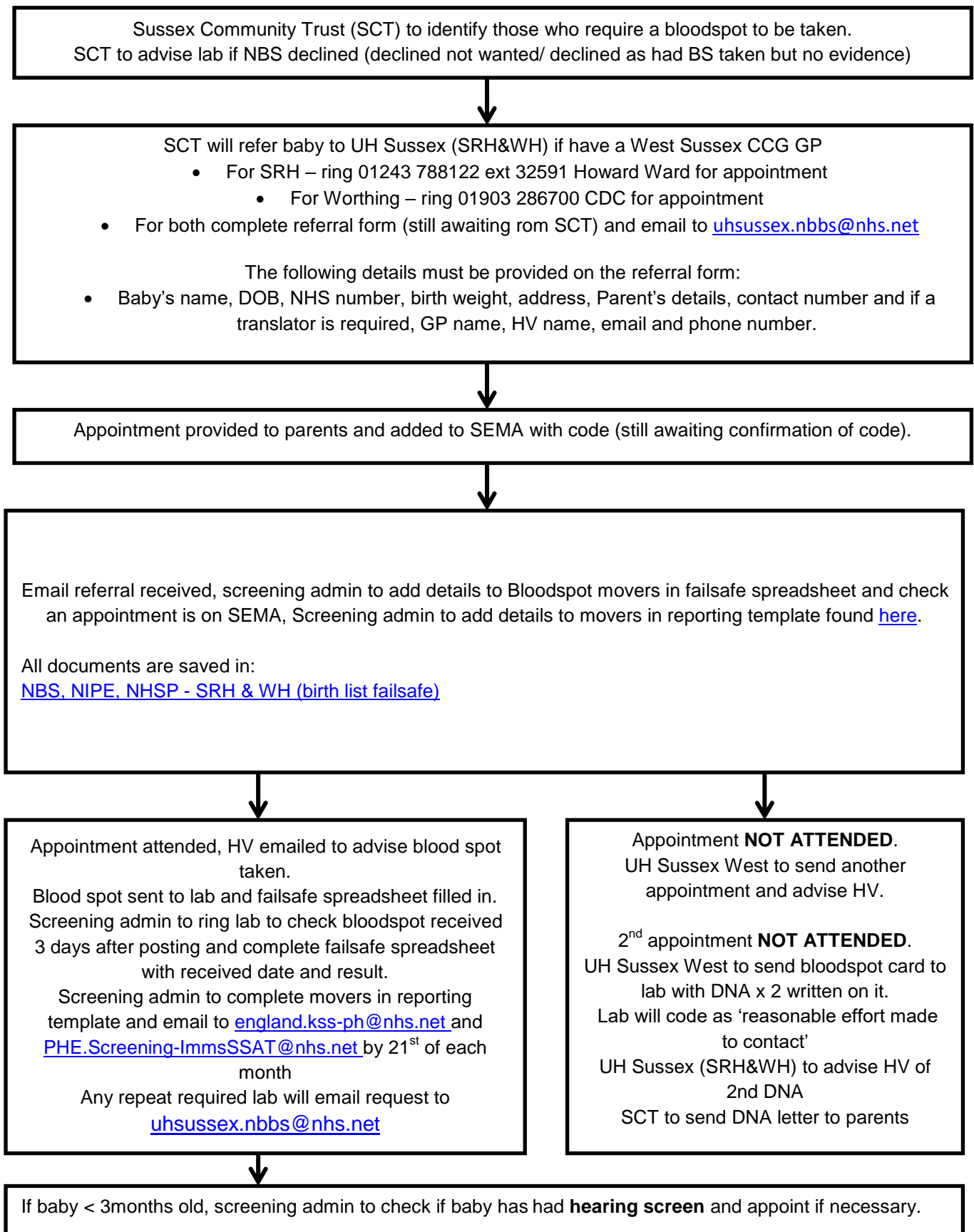
Note – some labs mark NBSFS as sample being received before it has been checked. So it must not be presumed that a received sample will not then need repeating.

## **Appendix 15: Screening co-ordinators email addresses**

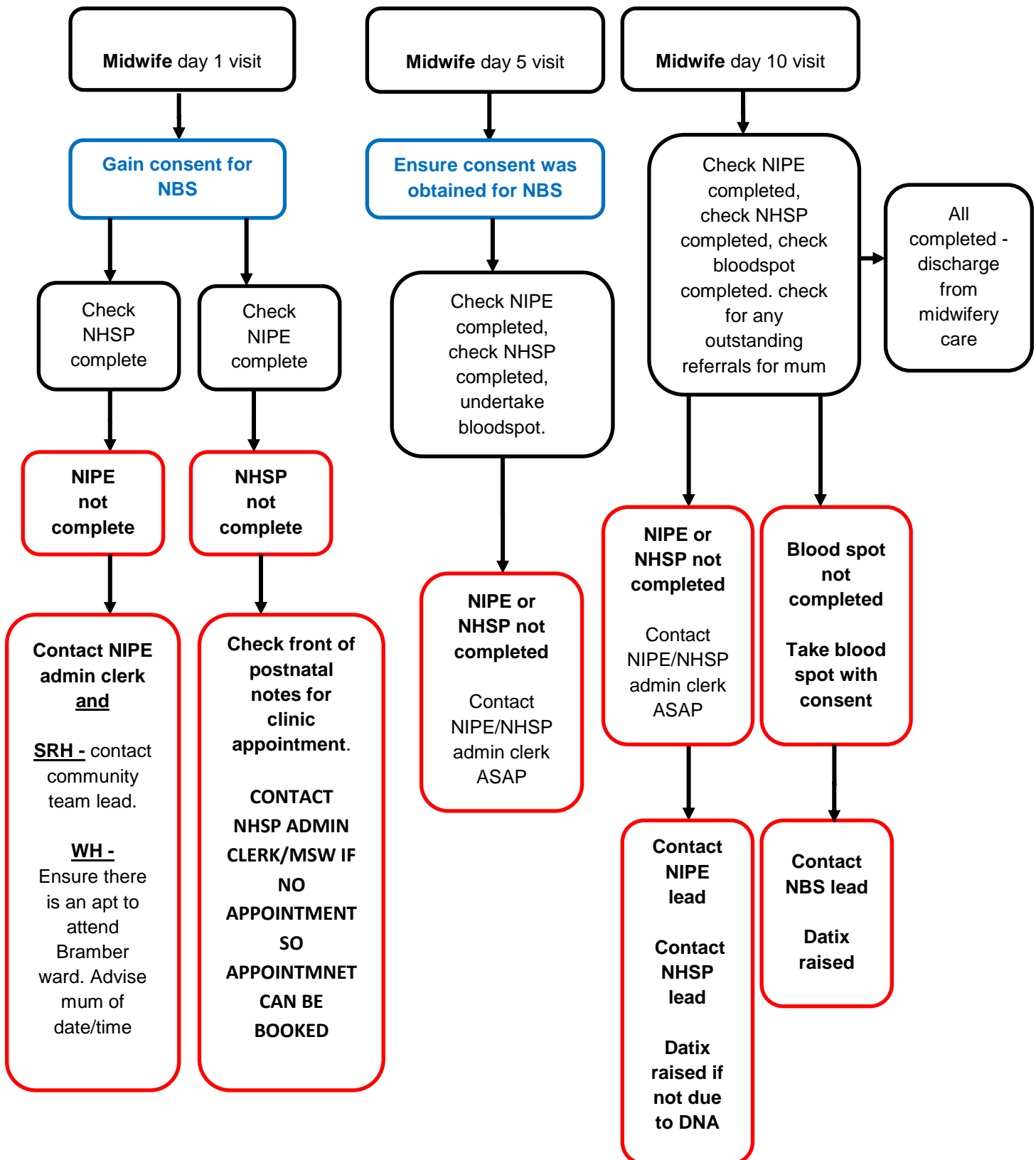
Can be found by clicking [here](#)



## Appendix 16: Movers in – advised by CHIS



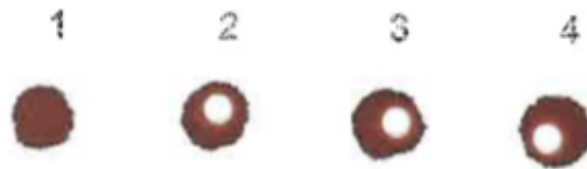
## Appendix 17: Checking that all Newborn screening has been completed



## Appendix 17: Examples of bloodspot samples

### Insufficient Samples:

The blood spots have soaked through to the back of the card but the volume of blood is too small for testing. There is a risk that a baby with a condition could be missed.



The blood spot has not soaked through adequately to the back of the card:

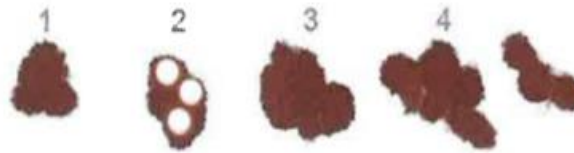


A large volume of blood was obtained but was incorrectly applied to the card meaning it did not soak through.



### Poor quality sample:

There are multiple small spots making up the larger spots and the blood spots have not soaked through to the back of the cards.



### Incomplete drying:

Staining on the glassene envelope and the ripples can be seen in the blood spots. There will be an insufficient amount of blood in the sample to obtain an accurate result. Samples should dry for at least 3 hours before sending.



### 5<sup>th</sup> spot on the card:

The lab are happy for you to add a 5<sup>th</sup> sample to the card if you are concerned about one of your spots. Do ensure this 5<sup>th</sup> spot is of correct size and has soaked through.

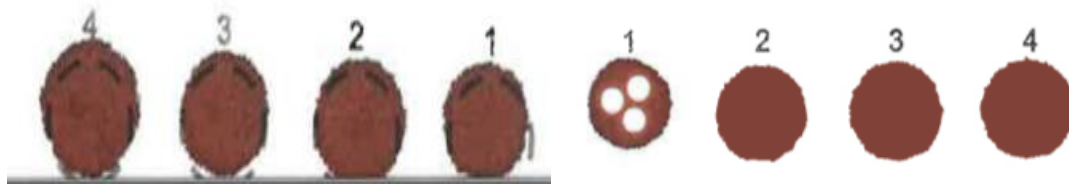


### A good quality bloodspot sample:

These blood spots are the same size and shape as seen from both sides of the card.

Each blood spot is made up of a single drop of blood.

The density of blood is consistent throughout the bloodspot which is important for obtaining accurate results and 3 samples can be taken from each bloodspot.



**Remember to check your card before it is sent for accuracy, ask parents to check the sticker and the details written on the card:**

CHECK EVERY BLOOD SPOT CARD BEFORE YOU SEND

**S**ample is sufficient, soaked through and dry.

**E**xpiry date on the card.

**N**HS number is correct.

**D**ates correct.

(Date of Specimen not Date of Birth)



### **If posting a sample yourself**

A photo of the sample and card should be to a colleague for checking

Do not send for 3 hours to ensure sample is dry

## Contact List

### **Antenatal & Newborn Screening Co-ordinator**

Karen Lundie

[karen.lundie@nhs.net](mailto:karen.lundie@nhs.net)

Mobile: 07785 996864

SRH tel: 01243 788122 ext. 32829

WH tel: 01903 205111 ext. 86077

### **NBS admin clerk**

Chrissie Thair

[Christine.thair@nhs.net](mailto:Christine.thair@nhs.net)

07808099826

### **NBS Lead**

Jacqueline Gregory

[Jacqueline.gregory1@nhs.net](mailto:Jacqueline.gregory1@nhs.net)

### **Community Midwifery – Worthing Hospital**

01903 285194

Fax: 01903 285197

### **Community Midwifery – St Richards Hospital**

(Birth Centre)

01243 788122 ext. 32811

### **Neonatal Unit, St Richards Hospital**

01243 788122 ext 32985/32986

### **Beeding Ward (SCBU), Worthing Hospital**

01903 285184

### **Paediatric Out Patients, Worthing Hospital**

01903 286700 ext. 84656

Dr Katia Vamvakiti, Consultant Paediatrician

[Ekaterini.Vamvakiti@wsht.nhs.uk](mailto:Ekaterini.Vamvakiti@wsht.nhs.uk)

### **Paediatric Out Patients, St Richards Hospital**

01243 788 122 ext. 2599. Bleep 419

Dr Rowena Remorino, Consultant Paediatrician

[Rowena.Remorino@wsht.nhs.uk](mailto:Rowena.Remorino@wsht.nhs.uk)

### **Newborn Outcome Solution UH Sussex West Contact**

Victoria Sharp Neonatal Consultant

[v.sharp@nhs.net](mailto:v.sharp@nhs.net)

**SW Thames Laboratory**

South West Thames  
3<sup>rd</sup> Floor D Block  
Regional Newborn Screening Service  
St Helier Hospital  
Wrythe Lane  
Carshalton SM5 1AA

Tel:0208 4532323

Fax:0208 4532581

[j.ssali1@nhs.net](mailto:j.ssali1@nhs.net)

**Northgate**

Newborn Blood Spot Failsafe Solution  
0845 0702778  
[nbsfs.helpdesk@nhs.net](mailto:nbsfs.helpdesk@nhs.net)

**CHIS**

Tel: 01243 812510

Fax: 01243 812590

Michelle Wright Manager  
Child Health Record Bureau,  
[Michellwright2@nhs.net](mailto:Michellwright2@nhs.net)

## Abbreviation used within this SOP

<b>NBS</b>	Newborn Blood Spot
<b>CF</b>	Cystic Fibrosis
<b>CHIS</b>	Child Health Information Services
<b>CHT</b>	Congenital Hypothyroidism
<b>GA1</b>	Glutaric Aciduria type 1
<b>GP</b>	General Practitioner
<b>HCU</b>	Homocystinuria (pyridoxine unresponsive)
<b>HV</b>	Health Visitor
<b>IM</b>	Independent Midwife
<b>IMD</b>	Inherited Metabolic Diseases
<b>IVA</b>	Isovaleric Acidemia
<b>MCADD</b>	Medium-chain acyl-CoA Dehydrogenase Deficiency
<b>MSUD</b>	Maple Syrup Urine Disease
<b>NBSFS</b>	Newborn Blood Spot Failsafe Solution
<b>NHSEI</b>	
<b>NICU</b>	Neonatal Intensive Care Unit
<b>NNU</b>	Neonatal Unit
<b>PCHR</b>	Personal Child Health Record
<b>PKU</b>	Phenylketonuria
<b>PNC</b>	Postnatal Care
<b>QA</b>	Quality Assurance
<b>SCD</b>	Sickle Cell Disease
<b>SCID</b>	Severe Combined Immunodeficiency
<b>SOP</b>	Standard Operating Procedure
<b>SRH</b>	St Richards Hospital
<b>UH Sussex</b>	University Sussex Hospital
<b>UKNSPC</b>	UK Newborn Screening Programme Centre
<b>MIS</b>	Maternity Information System



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<https://vimeo.com/phescreening/blood-spot-failsafe-videos/video/223791136>

NBS status codes and sub codes

<https://www.gov.uk/government/publications/status-codes-for-the-newborn-blood-spot-nbs-screening-programme>

Link for UH Sussex (SRH&WH)safeguarding policy

<http://www.westernsussexhospitals.nhs.uk/assets/p16007-safeguarding-children-policy-v2.pdf>

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### Main additions/changes to SOP:

[illegible]