

Newborn Screening Failsafe's	
Summary statement: How does the document support patient care?	This pathway provides information for staff with regard to the process for offering, undertaking and providing results for newborn bloodspot screening.
Staff/stakeholders involved in development:	Midwives, Paediatric team, Health Visitors, Joint Obstetric Guidelines Group, Community teams, Laboratory, Community Child Health Information Service
Division:	Women and Children's
Department:	Maternity
Responsible Person:	Chief of Service
Author:	Jacqueline Gregory
For use by:	Midwives, Obstetricians, Paediatric staff and Health Care Support workers
Purpose:	To provide accurate information for staff on the processes to follow with regard to newborn blood spot screening
This document supports:	UH Sussex West (SRH&WH) Maternity Guidelines: NHSP SOP, NIPE SOP, NBS SOP
Key related documents:	UH Sussex West (SRH&WH) Maternity Guidelines: Antenatal Care and Patient Information, Postnatal Care UH Sussex West (SRH&WH) Trust Policies: An organisation-wide policy for screening procedures, An organisation-wide policy for diagnostic testing PHE publications: KPI's
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Expiry Date:	November 2024
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If you require this document in another format such as Braille, large print, audio or another language please contact the Trusts Communications Team	
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This document pertains to the **Newborn** element of the NIPE, up to 72 hours of age for KPI and any baby up to the age of 6 weeks when the **Infant** examination occurs at age 6-8 weeks old.

Version	Date	Author	Status	Comment
1.0	May 2018	Jacqueline Gregory	Archived	
2.0	Feb 2019	Jacqueline Gregory	Archived	Pages 5, 7, 16 changed to reflect new model
3.0	September 2020	Jacqueline Gregory	Archived	See page 19 for additions
4.0	November 2021	Jacqueline Gregory, Newborn Hearing Screening Co-ordinator	LIVE	Amendments to 3.1, 3.2, 3.3 & 4.0. New sections: 3.4, 3.6, 9.0, 10.0, 11.0 & 12.0 Formatting and new Trust Logo.
4.1	June 2023	Clinical Effectiveness team	LIVE	Appendix 1 Surrogacy consent for newborn screening added.

**The interpretation and application of clinical guidelines will remain the responsibility of the individual clinician.
If in doubt contact a senior colleague or expert.**

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Newborn Screening Failsafe's

1.0 Background

The 3 NHS Newborn Screening Programmes all aim to identify babies who have serious conditions which will significantly impact on their lives if not identified early.

Each of 3 NHS Newborn Screening Programmes have national databases which are all populated electronically via PDS (Patient demographic service) at point of birth. The cohorts for all 3 programmes are independent of each other

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.

The databases for each Programme are web based and located at:

- [NIPE](#)
- [NBS](#)
- [NHSP](#)

The databases are populated based on the following criteria and UH Sussex West (SRH&WH) are responsible for the following screens:

NIPE:

Database populated based on birth hospital.

UH Sussex West (SRH&WH) RYR site responsible for screening all well babies born at Worthing and St Richards Hospital's within 72 hours, screening babies who are resident on Worthing and St Richards Hospital's NICU's once well enough to be screened and babies who move into area without a NIPE screen under the age of 6 weeks.

NBS:

Database populated based on post code and/or GP combination or birth hospital.

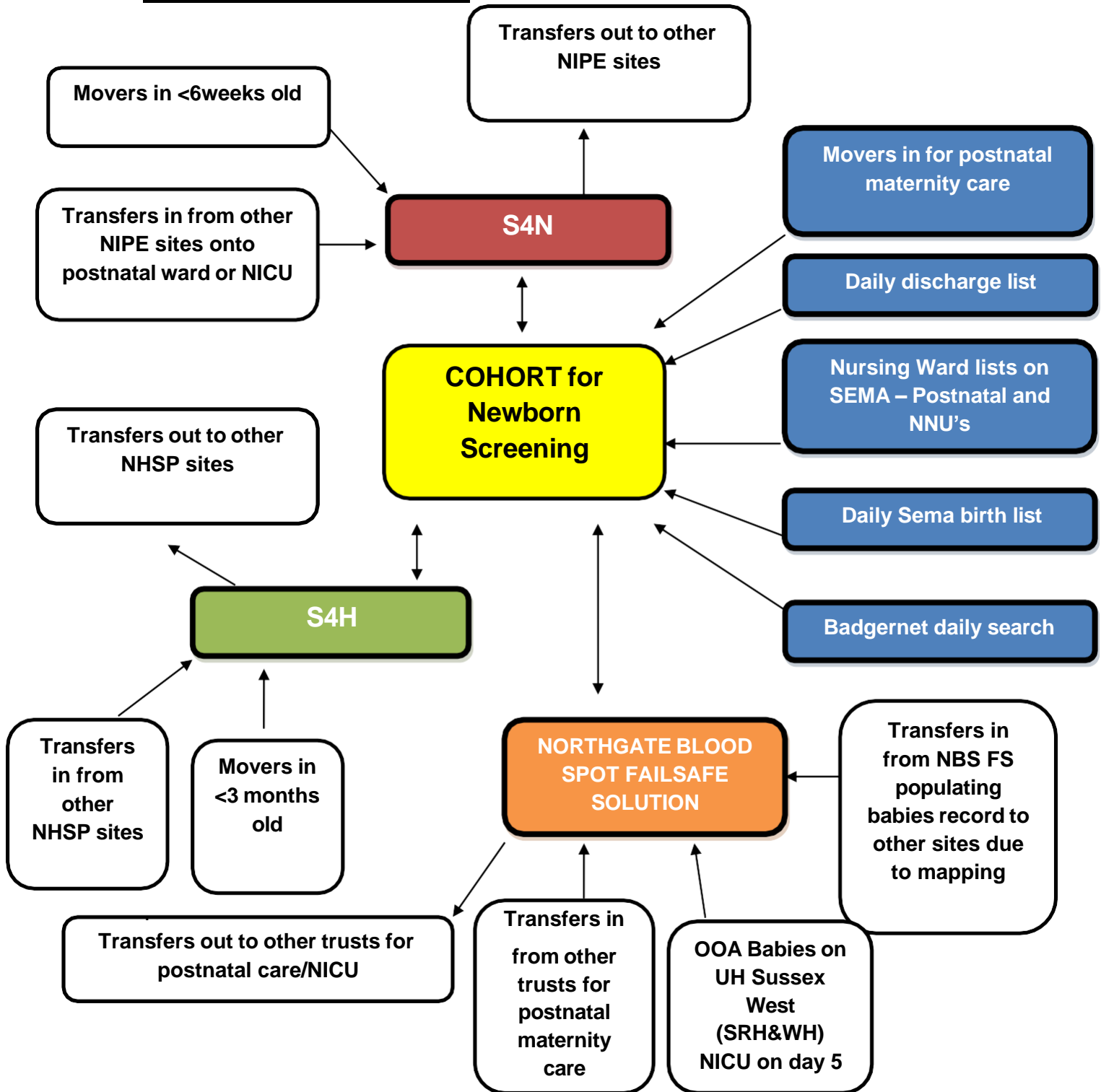
UH Sussex West (SRH&WH) Worthing Hospital _WSX site and Chichester St Richards_WSX site are responsible for screening all babies who UH Sussex West (SRH&WH) provide postnatal care to on day 5 and to babies who are resident on UH Sussex West (SRH&WH) NICU's on day 5.

NHSP:

Database populated based on GP

UH Sussex West (SRH&WH) WSH site responsible for screening all well babies with a West Sussex Coastal GP by 4 weeks old, screening babies who are resident on UH Sussex West (SRH&WH) NICU's at the point of discharge home and babies who move into area without an NHSP screen under the age of 3 months.

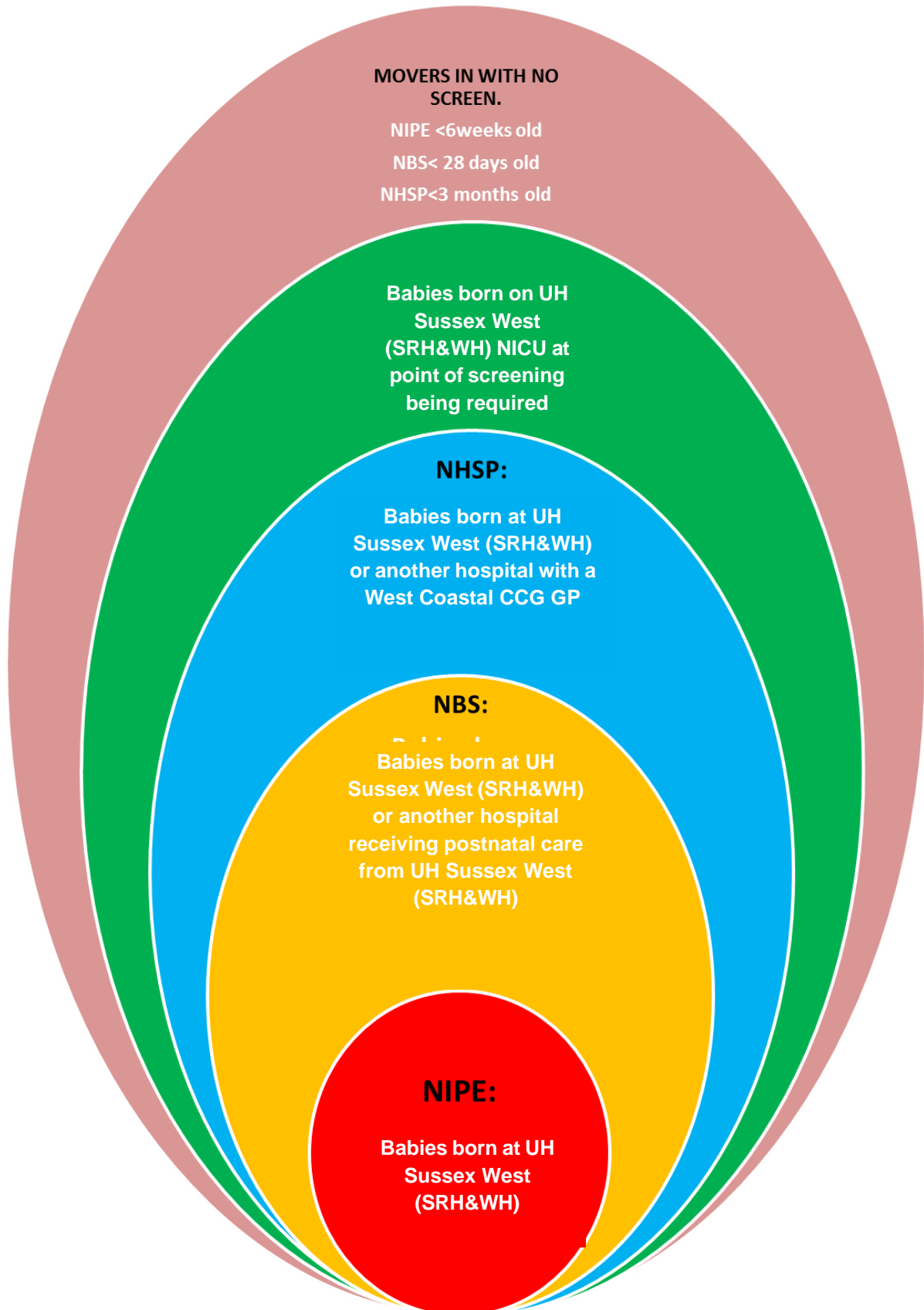
DAILY COHORT CHECKS



Movers in from abroad < 1 year old for blood spot, UH Sussex West (SRH&WH) will undertake the blood spot once notified by SCT but these do not appear on Northgate

Notification of movers in from each newborn screening programme is cross checked with the other screening programmes

COHORT LAYERS



3.0 Failsafe's

3.1 NBS, NIPE, NHSP – SRH & WH (birth list failsafe)

Located: \\rwsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn Screening\NBS, NIPE, NHSP - SRH & WH (birth list failsafe)

TO BE ACTIONED DAILY

Failsafe list populated daily with all births in UH Sussex West (SRH&WH).
 OOA transfer in's notified via S4H (NSHP) will be added to all 3 lists, community midwives to be emailed information of transfer in, if not already present on blood spot list to check regarding postnatal care.
 Community midwives to add any transfer in's to blood spot list once notified, screening admin to add to both other lists and check screen shave been completed.

NIPE

Check the cohort has populated.
 Document date NIPE completed and by whom.
 Check all NIPE screens have been completed within 72hrs.
 Chase up any NIPE screens which have been carried out but have not yet been inputted onto S4N.
 See 'RED BABY SPREADSHEET'
 Note any exceptions for babies on NICU.
 Advise NIPE lead if a baby is within 3hrs of breaching.

NBS

Check the cohort has populated NBS FS and document. Transfer records in & out as necessary. If transferring out to email the screening lead to notify them of the record.
 Document: who the bloodspot was taken by, who sent it off & when. If baby back to UH Sussex (SRH&WH) NICU day 5 or 6 check BS taken & sent.
 Check and document when bloodspot received by the lab, including those who have moved OOA.
 Document when a repeat blood spot is sent.
 Document when received by the lab.
 Advise NBS lead and team leads if a blood spot is not received by the lab by day 8 or day 10 if a weekend.

NHSP

Check the cohort has populated S4H.
 If baby discharged with no screen ensure MSW team aware to book outpatient appointment.
 Note any exceptions for babies still on NICU
 At a minimum of 14 days, no later than 21 days check and document that all babies (even those who have moved OOA) have had a hearing screen or are in the correct NHSP site to be offered a hearing screen.
 Any baby who has not had a hearing screen organise for baby to have an outpatient appointment in an AOAE2/AABR clinic.

Note. All transfer out births must have blood spot received checked and NHSP completed checked and documented on the spreadsheet.

3.2 NBS, NIPE, NHSP - Badgernet Report

Located: \\rwsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn Screening\BADGER REPORT CROSS PROGRAMME FAILSAFE

TO BE ACTIONED ON RECEIVING REPORT

Admission and discharge date/time report from BADGERNET sent to Screening admin on a rolling 4 week period.

NIPE

Add a NIPE column.

Check and document screening completed for babies resident on UH Sussex (SRH&WH) NICU.

Check and document screening completed for babies moved to OOANICU.

If not completed check on Badgernet to see if baby still resident in OOA NICU and make note on spreadsheet of where baby is.

Notify NIPE Lead of any babies discharged from any NICU without a NIPE screen.

NBS

Add a 28 day spot column.

Check and document that a day 28 spot (CHT) has been requested on NBS FS for all babies born 31+6 or earlier

Check and document that a day 28 spot (CHT) has been taken for all babies born 31+6 or earlier.

Advise NBS lead of any babies who have not had the repeat CHT bloodspot taken.

NHSP

To add 3 columns to report.

1. Duration over 48hrs yes/no i.e. is baby NICU protocol (transitional care = well baby protocol)
2. What protocol baby should be
3. What protocol is set in S4H

Check and document that all babies have the correct protocol set / have been screened in the correct protocol in S4H.

Advise NHSP lead of any babies screened as a Well Baby when they should be screened as a NICU Baby

Note. Any queries regarding discrepancies in admission/discharge times should be checked in the NICU admission/discharge book and emailed to the Badgernet lead.

Email evidence of replies will be saved

\\rwsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn Screening\BADGER REPORT CROSS PROGRAMME FAILSAFE\Badger Report Emails

3.3 NIPE – Referral/ outcome export

An export should be carried out from S4N for all conditions which would require a referral being made.

These should be run from the preset searches in S4N:

- EYE Abnormality Suspected – Failsafe awaiting outcome
- HEART– Failsafe awaiting outcome
- Hips Abnormality Suspected – Failsafe awaiting outcome
- Hips Risk Factors and No Abnormality – Failsafe awaiting outcome
- Other Hips
- NIPE other

They should re run at a minimum of twice weekly, ideally daily (Monday- Friday) with an overlap in date of 5 days to capture babies who have not had their NIPE on day of birth but within 72 hours.

Add these to the NIPE referral follow up spreadsheet, search in CRIS or ICE for appointment, add appointment date to the spreadsheet.

\\rwsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn Screening\NIPE\KPI\Current NIPE referral follow up

The following exports (see following 2 pages for search criteria) should also be set up as set searches in S4N and saved.

These should be run at a minimum of twice weekly ideally daily (Monday- Friday) with an overlap in date of 5 days and exported on a notepad file.

This search results is then then cross matched with babies who have a NIPE outstanding (by carrying out the following search in New Search with the following parameters - not started, in process, removed dates of birth).

The above is then repeated at the end of the month B for all of month A (on an ongoing basis) so as to capture any NICU babies who have had a late NIPE.

Note, There is an addition failsafe for NICU babies on the Red (Breached) baby spreadsheet with columns for checking if a Hip referral has been made, referral received/appointment made and that baby is on the referral follow up spreadsheet.

\\rwsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn Screening\NIPE\Red (Breached) Babies

All referral appointments are added to S4N for audit tracking. These are added in the screening tab, click on the relevant 'Item' and add the appointment (this appointment is also added to the hip referral spreadsheet).

In the case of Testes, Heart & Rest of Physical Examination the NIPE lead will check referrals and appointments have been made and add to S4N as required.

In all exports the following field will be exported:

- PATIENTS LAST NAME
- PATIENTS DATE OF BIRTH
- PATIENTS LOCAL NUMBER
- PATIENTS PLACE OF BIRTH
- NEWBORN SCREENING SUMMARY FOR HIPS/EYES/HEART/TESTES/REST OF PHYSICAL EXAMINATION)
- DATE AND TIME OF LAST NEWBORN SCREEN
- SCREEN PRACTITIONER – LATEST
- CONFIDENTIAL ID

Located: [Here](#)

HIPS:

IN S4N, CREATE A SEARCH FOR THE PREVIOUS WEEK.
 IN 'SCREENING STATUS TAB' CHOOSE CARE PATHWAY OF:
 Newborn Hips – Screening

INCLUDE ALL OF THE BELOW IN YOUR SEARCH:

- Newborn Hips - screening/No Abnormalities with risk factors
- Newborn Hips - screening/Unilateral Abnormality Suspected (Right) with risk factors
- Newborn Hips - screening/Unilateral Abnormality Suspected (Right) with No risk factors
- Newborn Hips - screening/Unilateral Abnormality Suspected (Left) with risk factors
- Newborn Hips - screening/Unilateral Abnormality Suspected (Left) with No risk factors
- Newborn Hips - screening/Bi-lateral Abnormality Suspected with risk factors
- Newborn Hips - screening/Bi-lateral Abnormality Suspected with no risk factors
- Other Abnormality Suspected with No Risk Factors
- Other Abnormality Suspected with Risk Factors

EYES:

IN S4N, CREATE A SEARCH FOR THE PREVIOUS MONTH.
 IN 'SCREENING STATUS TAB' CHOOSE CARE PATHWAY OF:
 Newborn Eyes – Screening

INCLUDE ALL OF THE BELOW IN YOUR SEARCH:

- Newborn Eyes - screening/Unilateral Abnormality Suspected (Right) with risk factors
- Newborn Eyes - screening/Unilateral Abnormality Suspected (Right) with No risk factors
- Newborn Eyes - screening/Unilateral Abnormality Suspected (Left) with risk factors
- Newborn Eyes - screening/Unilateral Abnormality Suspected (Left) with No risk factors
- Newborn Eyes - screening/Bi-lateral Abnormality Suspected with risk factors
- Newborn Eyes - screening/Bi-lateral Abnormality Suspected with no risk factors

TESTES:

IN S4N, CREATE A SERCH FOR THE PREVIOUS MONTH.
 IN 'SCREENING STATUS TAB' CHOOSE CARE PATHWAY OF:
 Testes– Screening

INCLUDE ALL OF THE BELOW IN YOUR SEARCH:

- Newborn Testes – Screening/Unilateral Abnormality Suspected (Right)
- Newborn Testes – Screening/Unilateral Abnormality Suspected (Left)
- Newborn Testes – Screening/Bilateral Abnormality Suspected

HEART:

IN S4N, CREATE A SERCH FOR THE PREVIOUS MONTH.
 IN 'SCREENING STATUS TAB' CHOOSE CARE PATHWAY OF:
 Newborn Heart– Screening

INCLUDE ALL OF THE BELOW IN YOUR SEARCH:

- Newborn Heart – Screening/Abnormality Suspected with Risk Factor
- Newborn Heart – Screening/Abnormality Suspected with No Risk Factor

REST OF PHYSICAL EXAMINATION:

IN S4N, CREATE A SERCH FOR THE PREVIOUS MONTH.
 IN 'SCREENING STATUS TAB' CHOOSE CARE PATHWAY OF:
 Newborn Rest of Physical Examination – Screening abnormalities

INCLUDE ALL OF THE BELOW IN YOUR SEARCH:

- Abnormality Suspected
- Referred Abnormality Suspected

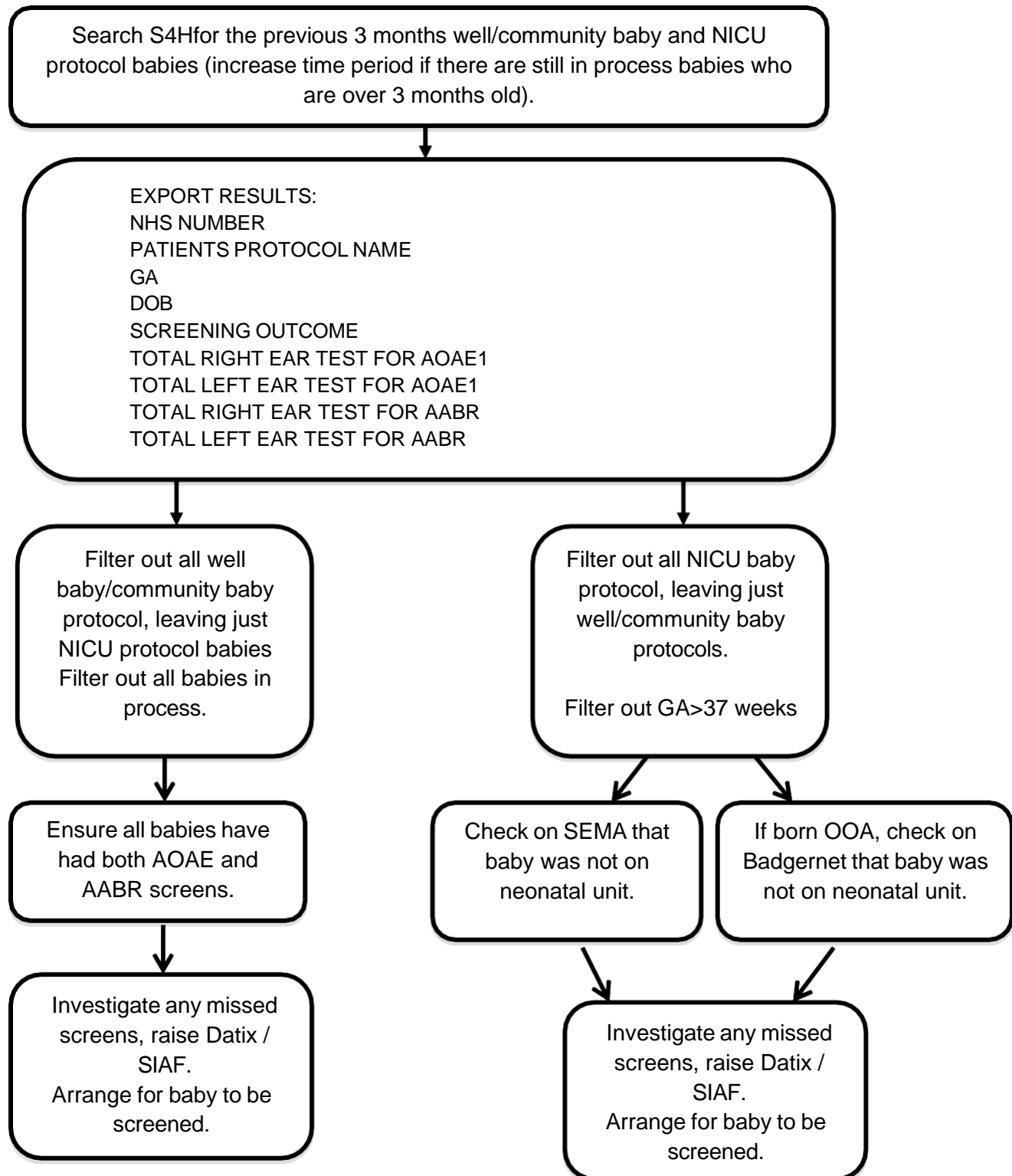
3.4 Red (Breached) baby spreadsheet

To ensure babies who are on NICU are not missed they are added to the Red (Breached) baby spreadsheet when they are admitted to NICU. This allows further tracking to occur.

[\\rwsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn Screening\WIPE\Red \(Breached\) Babies](#)

Breached well babies and babies being seen by an IM are also added to this spreadsheet for tracking.

3.5 S4H NICU Failsafe



NICU failsafe reports are saved in: [Here](#)

Standard email wording for S4H NICU check to other sites:

Dear Local Manager

As part of our monthly GA/NICU failsafe we recheck our hospital system to ensure any well baby, whose GA is 37weeks or below where only on the postnatal ward or their NICU stay was <48hrs.

I would be grateful if you check your system for this baby: who was born at GA:
And confirm that they were not a NICU protocol baby.

Many thanks

3.6 NHSP – Systmone report

CHIS have read only access to WSH NHSP S4H site.

On a monthly basis:

- I. CHIS are responsible for running a report within NHSP of all screen results and uploading the outcome codes and date/time of screen into the Child Health System (Systmone).
- II. CHIS are responsible for then running a report in Systmone to look for babies without screen results. This includes babies **born in area**, babies born **out of area but with a GP in area** and babies who **have moved in**. Any babies without a screen result in Systmone are then manually searched for in S4H using the National record search facility. The outcome code and date/time of screen are uploaded into Systmone.
- III. Any babies whose screen results could not be located are emailed in a report to the NHSP lead to ensure either they are aware of baby or if not aware of baby a screen can be offered.
- IV. CHIS run a report on **movers out of area**. Any baby **without a screen result** or with an outcome code of **C2, N1, N2, I9** (see outcome codes appendix 18) are emailed in the report to NHSP lead so the S4H record can be transferred to the correct site.

The dates for searches/reports are as follows:

During the 1st week of the month 'D' CHIS search for all results in S4H from month 'B' and upload to Systmone.

Following the upload of results CHIS search systmone for babies with no screen result based on the following parameters and S4H is manually searched. Any record with no screen result will be emailed in a report to the NHSP Lead:

Born in area	Babies born month C and 2 preceding months (month B and A) with no screen result
Born out of area with a GP in area	Babies born month C, B and A with no screen result
Moved in	Babies born month C, B and A with no screen result
Moved out	Babies up to 1 year old with no screen result or outcome code of C2, N1, N2, I9

- V. NHSP team receive the report and check that:
 - a. Babies NHSP record is in WSH S4H site and screening is pending. WSH site is already aware of baby and is tracking.
 - b. Babies NHSP record is not in WSH S4H site and screening is pending. WSH site is not aware of baby. S4H record is transferred in and baby is offered screening.

- c. Babies NHSP record is not on S4H site and was born out of the country. NHSP lead makes a request to CHIS to check the Health Visitors movers in visit notes to see if a screen was undertaken in country of birth. If no case note in Systmone the NHSP lead will contact parents by phone or a movers into are – no screen on S4H letter offering screening will be sent. If screening is accepted a manual entry of babies birth and demographic details will be added to S4H to create a record. The manual entry incident log should be completed and the NIPE lead informed of the record being created.
[\\rwsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn Screening\NHSP\Manual entry files](#)
- d. If any screening results are found for babies on the report these are emailed back to CHIs for manual entry onto Systmone.
- e. baby is now older than 3 months a letter a moved into area - too old to screen letter will be sent to parents.
- f. For movers out who have a screen pending result, outstanding Audiology referral / PCHI the demographic and GP details will be updated, a case note written and the record will be transferred to the responsible NHSP site. The NHSP Lead for this site will be emailed to advise them of the record transfer.

Systmone failsafe reports are saved in: [Here](#)

4.0 Child Death Notifications

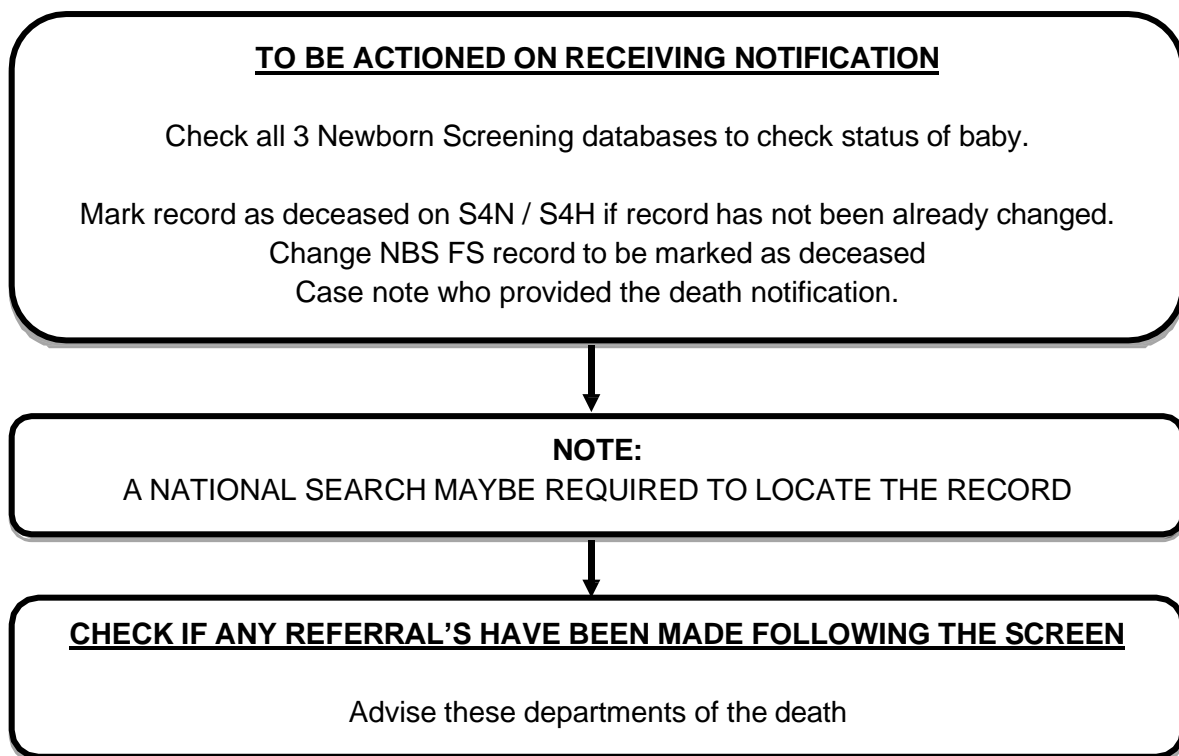
Any Still Births, Neonatal or child deaths notified to the Newborn Screening Teams will be actioned.

The Newborn Screening admin will be advised of still births, neonatal and child deaths from the following departments:

- UH Sussex West (SRH&WH) Neonatal
- UH Sussex West (SRH&WH) maternity
- SCT CHIS

The NBS are also advised of all stillbirths.

In all neonatal and child deaths, the following is to be carried out:



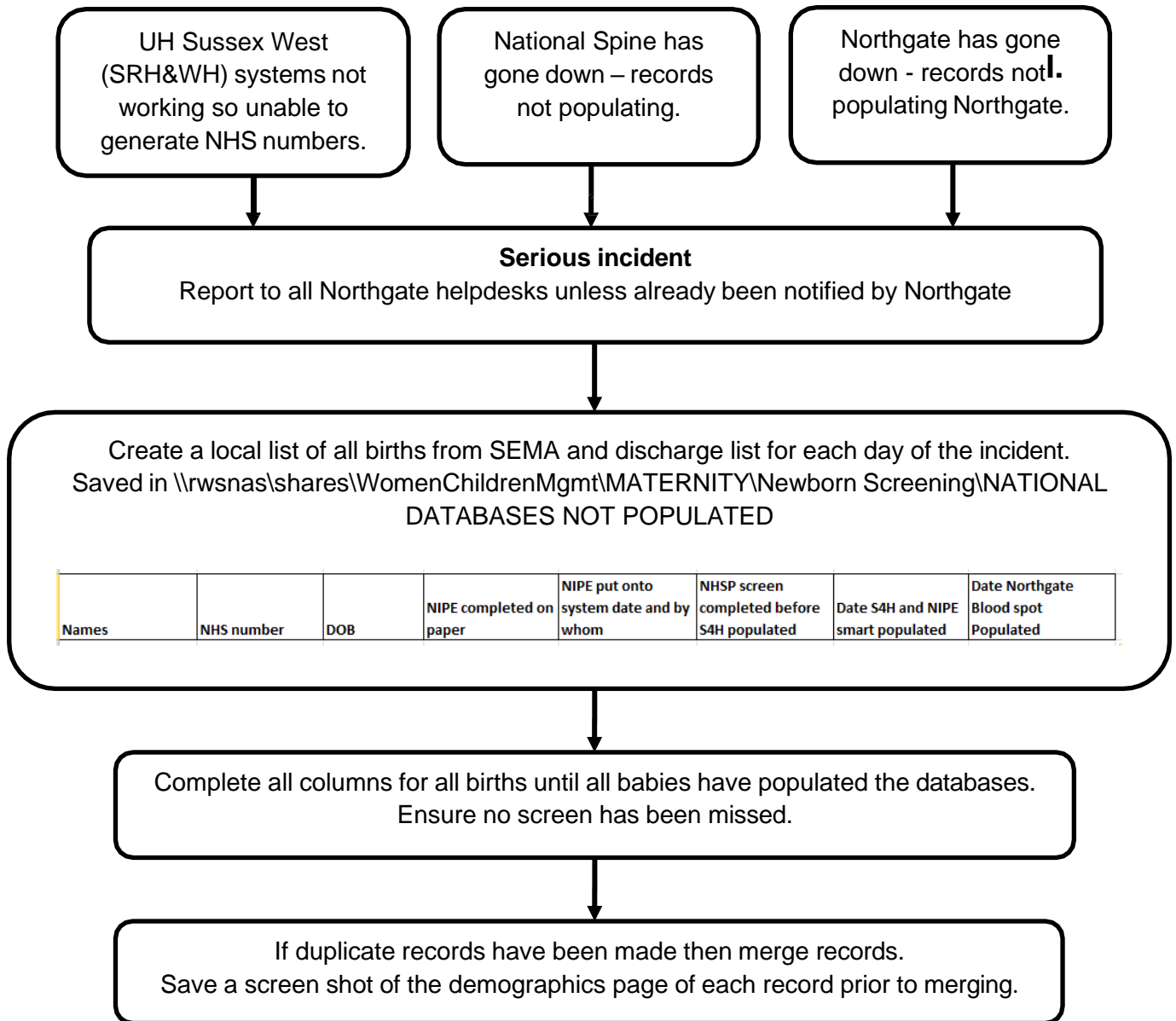
5.0 NICU transfer in's/out's

In both cases any transfer in's/outs should be documented on the NBS, NIPE, NHSP – SRH & WH (birth list failsafe).

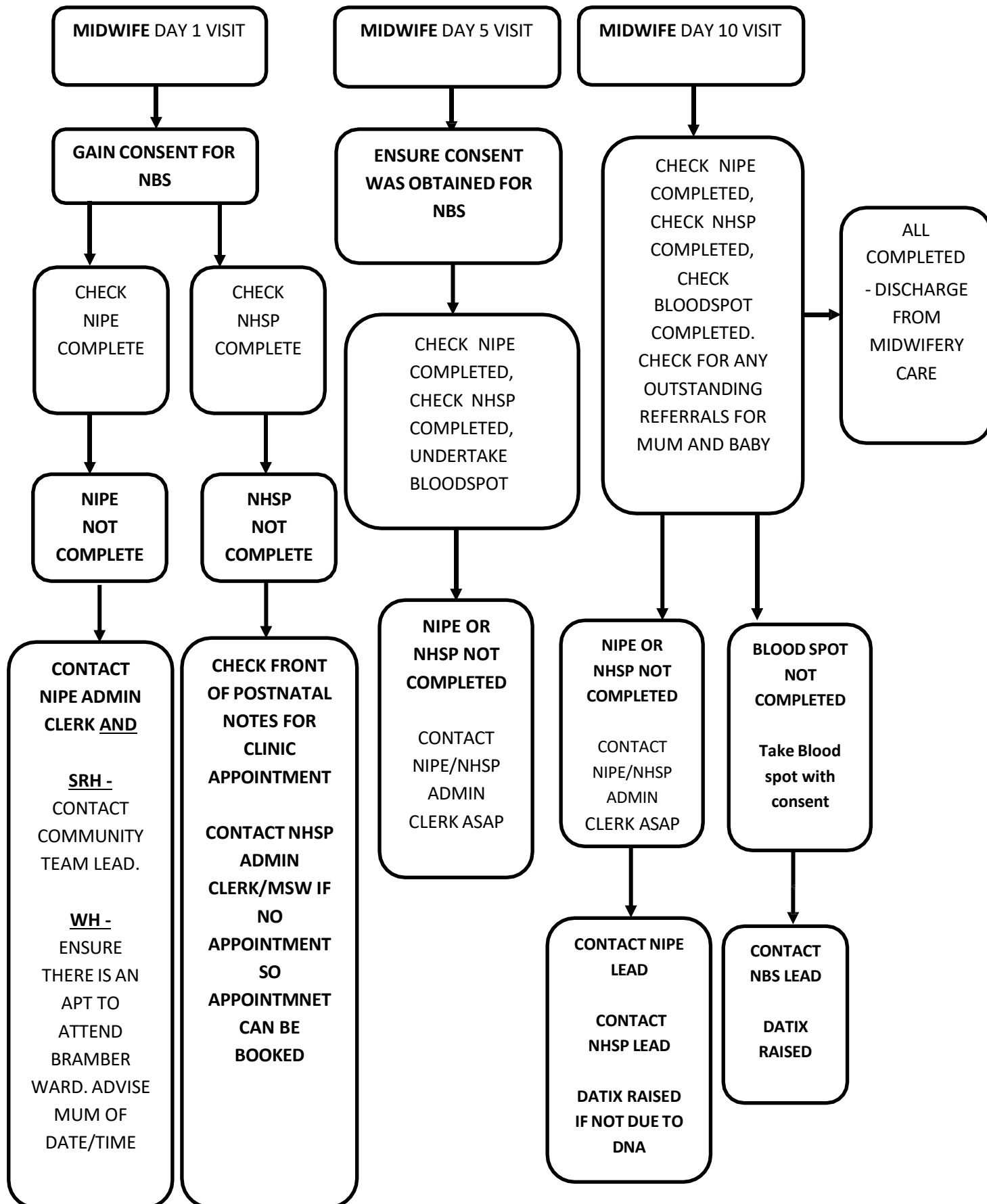
Transfer out: If a baby is discharged on Sema then the Badgernet system is to be checked to see if baby has gone to another NICU/PICU. If this is the case, the national screening databases are to be case noted and record transferred to relevant site for completion of screening.

Transfer in: Badgernet lead provides screening admin with a weekly report regarding babies who have transferred in and out of UH Sussex West (SRH&WH)'s NICU's so this can be checked against location of record on national screening databases, these records should then be transferred in or out as required.

6.0 Northgate has not been populated



7.0 Checking that all newborn screening has been completed



8.0 OOA Discharges

Discharge email from the ward postnatal ward will be copied to screening administrator.

Screening administrator to check which hospital the baby has been discharged to and double check the email address is correct.

Once checked save the email to the [Discharge OOA folder](#)

Check all screening programmes:

NIPE:

- Check the NIPE has been completed and any referrals actioned.

NBS:

- Perform a 'National Search' on Northgate Newborn Blood Spot failsafe Solution to locate the records. The record should be in the same location as the hospital in which baby's discharge has been emailed out to.
- Check baby is in the correct site, add a case note: 'baby not under UH Sussex West (SRH&WH) for PNC and emailed to On'
- If baby is in WSH site, transfer record out case noting: 'baby not under UH Sussex West (SRH&WH) for PNC and emailed to On'
- On the birth list document on baby's baby OOA and emailed to ... on
- Send an email to Screening lead to site you have transferred the record advising of transfer.

NHSP:

- UH Sussex West (SRH &WH) will attempt to complete all screening of OOA baby's on the ward.
- If the screen is not complete or it has not been started screening admin will case note S4H record, break the share and email the CI to the NHSP lead from the responsible site advising that baby requires a screen.

9.0 Home births

Home births for UH Sussex East (BRI & PRH) populate UH Sussex West (SRH&WH) postnatal screening database's (S4N, S4H, NBS FS).

If a baby is on a postnatal screening database as a home birth or other birth location but not on the birth list then this needs investigating.

This can include:

- a) Undertake a patient search and ward search (APC search) on SEMA to ensure baby is not resident on a UH Sussex West (SRH&WH) ward.
- b) Check SCR for birth hospital.
- c) If baby is not resident on UH Sussex West (SRH&WH) wards or UH Sussex West (SRH&WH) is not giving postnatal care, break the share on the record/transfer the record to the responsible site. A case note can be added 'not a UH Sussex West (SRH&WH) birth).

10.0 Independent Midwife providing postnatal care

NIPE – Case note the record that an IM undertook the NIPE and advise NIPE Lead so she can move it to the 'out of area' facility.

NBS – Case note record that an IM is undertaking the bloodspot.

NHSP – Contact parents for UH Sussex West (SRH&WH) WSH site to offer screening.

Update the NIPE and NBS tabs on the NBS, NIPE, NHSP- SRH & WH (birth list failsafe) spreadsheets to show that IM has provided screening.

11.0 Repeat bloodspots

As a failsafe, the screening administrator will email all repeat bloodspot notifications to the Community Team Leads.

- a) Forward the repeat email from the lab to the Community team leads.
- b) Highlight the repeat in red on the NBS, NIPE, NHSP- SRH & WH (birth list failsafe).
- c) Add the repeat details to the repeat section of the NBS, NIPE, NHSP- SRH & WH (birth list failsafe) on the date of birth of baby.
- d) Add a comment to say who sent to/spoke to and date.
- e) Add details of who took the sample and lab rejection reason to the repeat bloodspot spreadsheet.

\\wrsnas\shares\WomenChildrenMgmt\MATERNITY\Newborn
Screening\NEWBORN BLOOD SPOT\Repeat Blood Spot

12.0 NHSP QA checks

QA checks should be checked for the correct outcomes during assigning, they will also be checked in S4H on a daily basis (by ticking 'tests requiring action' on the QA page) for all screens carried out a week prior to ensure that any late downloads are not missed.

Any 'Fails' will be investigated via the QA page, a note written in S4H and 'override fail result' should be ticked.

Note if a screener cannot get a CR on QA3 then a NCR is considered as a pass. A NC is not a pass.

Any failed and missed QA tests will be investigated. A log sheet is kept by the NHSP team of incorrect QA checks and offered rescreens. See National Guidance Document for QA checks date Nov 2017.

Should it be found that a baby has been screened by the WSH site without the QA checks being carried out or with incorrect outcomes on that day then the member of staff will be advised and undergo re training, the NHSP lead will be notified.

To summarise for UH Sussex West (SRH&WH) WSH site:

If **QA** checks are present and the QA checks gave **expected results** in this period then babies screen result will stand.

If **QA1 or 2** gave a result of a **CR** on the day of screening (and the QA check was not repeated to give a correct result before screening) then babies screen result will **not** stand and baby **will require a re-screen**. The MSW/NHSP team will contact parents directly and the MSW will arrange a time to visit for a rescreen to take place. A datix will be raised. If a rescreen is declined/phone not answered/text/letter not responded to then a referral will be made for a follow up in Audiology at 8-10 months old. The record will be set to targeted f/up required to enable baby to be tracked.

If an **incomplete** QA check is obtained (after or instead of a correct result) a rescreen is not required but the result will be discussed with the screener and retraining given.

13.0 Contact List

Antenatal & Newborn Screening Co-ordinator

Helen Boiling
 Helenboiling @nhs.net
 01243 788122 ext. 32829
 01903 205111 ext. 86077

NIPE Lead

Caroline Thomas
Caroline.thomas2@nhs.net

NBS Lead

Helen Boiling
 Helenboiling @nhs.net
 01243 788122 ext. 32829
 01903 205111 ext. 86077

NHSP Lead

Jacqueline Gregory
Jacqueline.gregory1@nhs.net
 07808 099816

Newborn Screening admin clerk

Chrissie Thair
Christine.thair@nhs.net
 01903 205111 ext 86076
 07808099826

NIPE SmarT (Northgate). Open 7am-7pm 7 days a week

08450705902
NIPE.helpdesk@nhs.net

Northgate

Newborn Blood Spot Failsafe Solution

0845 0702778
nbsfs.helpdesk@nhs.net

SMART4Hearing (Northgate)

s4h.helpdesk@nhs.net
 08450130183

Child Health Records

Tel: 01243 812510
 Fax: 01243 812590
 Michelle Wright Manager
 Child Health Record Bureau,
Michellewright2@nhs.net

14.0 Abbreviations used in this document

AOAE	Automated Otoacoustic Emission
AABR	Automated Auditory Brainstem Response
BRI	Royal Sussex County Hospital Brighton
CR	Clear Response
CRIS	Radiology Information Solution
ICE	Pathology and Radiology system
NBS	Newborn Blood Spot
NBS FS	Northgate Newborn Bloodspot Failsafe
NC	Incomplete
NCR	No Clear Rssponse
CHIS	Child Health Information Services
CHT	Congenital Hypothyroidism
IM	Independent Midwife
HV	Health Visitor
MIS	Maternity Information System (MIS)
NHSP	Newborn Hearing Screening Programme
NIPE	Newborn Physical Examination
NICU	Neonatal Intensive Care Unit
PRH	Princess Royal Hospital
S4H	Smart 4 Hearing
S4N	NIPESmart
SCR	Summary care record
SRH	St Richards Hospital
WH	Worthing Hospital

15.0 Main additions/changes

Date	Page	Addition
22/9/20	3	Minor cohort change re movers <1yr in not on Northgate
22/9/20	7	Transfers out all must have screening databases checked
22/9/20	8	Badger report discrepancies – checking and evidencing
22/9/20	9	Link for location of system one failsafe reports
22/9/20	11	Link for location of NICU failsafe reports
22/9/20	13	Section on NICU transfer's in/out
22/9/20	16	Section on OOA discharges
12/11/21	9,10,11	Updated guidance on pre-set S4N searches for referrals
12/11/21	11	Red (Breached) Baby Spreadsheet
12/11/21	13	Standard email wording for S4H NICU check to other sites
12/11/21	14,15	Updates guidance on systmone failsafe (CHIS)
12/11/21	20	Home births
12/11/21	20	Independent Midwife giving postnatal care
12/11/21	20	Repeat bloodspot
12/11/21	21	NHSP QA Checks
27/06/23	Appendix 1	Surrogacy consent for newborn screening added.

Appendix 1: Surrogacy and newborn screening consent

NEWBORN SCREENING CONSENT

Three newborn screens are offered, all details of these screens can be found in 'Screening Tests for you are your baby' which was issued to you antenatally. This booklet can also be found by scanning this QR code:



1. Newborn & Infant Physical Examination (NIPE).

The screening elements of the NIPE programme are:

- Eyes: approximately 2 or 3 in 10,000 babies have problems with their eyes that require treatment. The prime purpose of screening is to identify congenital cataracts.
- Heart: approximately 4-10 in 1,000 babies have a heart problem.
- Hips: approximately 1 or 2 in 1,000 babies have hip problems that require treatment.
- Testes: approximately 1 in 100 baby boys have problems with their testes that require treatment.

2. Newborn Blood Spot (NBS)

The screening elements of the NBS programme are:

- 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 acidemia (IVA),
- Glutaric aciduria type 1 (GA1)
- Homocystinuria (pyridoxine unresponsive) (HCU)
- Severe combined immunodeficiency (SCID)

3. Newborn Hearing Screening (NHSP)

The screening element of the NHSP programme is:

- Permanent Hearing Loss: 2 in 1000 babies are born with a permanent hearing loss. This increases to 1 in 100 if baby has spent longer than 48hrs on a neonatal unit. No Clear Responses can be obtained from this screening due to a hearing loss, fluid/debris in the ear, baby was unsettled or it was too noisy. If a No Clear response is obtained from the AABR screen baby will be referred to Audiology for further testing. If there is a contraindication to screening, baby will be referred directly to Audiology. Contraindications are: Microtia, atresia, confirmed cCMV, bacterial meningitis, PVP shunt
- Information about your baby's visit to the audiology clinic can be found by scanning this QR code:



Consent

For each screening programme the details of baby, the screening results and, if required, any tests following the screen will be kept on the NHS screening information system used by the NHS Newborn Screening Programme. The information will be shared with babies doctor, health visitor and other health professionals directly involved with the screening and with any subsequent investigations and treatment if required.

All staff that work in or with the NHS are required as a matter of law to keep information about you and your baby confidential.

An anonymised version of this information will be used for monitoring the success and evaluating the benefits of the screening programmes. All requirements of the Data Protection Act 2018 will be met during the storage and use of the data.

You may request and receive a copy of the information held about baby at any time.

If you choose not to take up this offer of screening, we will keep a record to show that we have contacted you and that you have declined the screen, and we will let babies GP and Health Visitor know that baby has not been screened.

Please complete

Surrogate Name				
Surrogate Hospital number				
Estimated due date				
If completed postnatally				
Babies Name				
Babies Hospital number				
Babies NHS number				
	YES/NO		Signed	Date
NIPE screen consented				
NBS screen consented				
NHSP screen consented				

Midwife/doctor completing form:

Date	Printed Name	Signed	NMC/GMC Number

**If completed antenatally please email a copy of the form to the postnatal screening failsafe clerk.*