NHS
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St Richards, Worthing & Southlands Hospitals

Newborn Infant Physical Examination (NIPE) Screening Guide for Health Professionals (including referral pathways)

Summary statement: How does the document support patient care?	The NHS NIPE Programme's main aim is to identify and refer all children born with congenital abnormalities of the eyes, heart, hips, and testes, where these are detectable, within 72 hours of birth. This age is recommended based on best practice and current evidence and should facilitate a prompt referral for early clinical assessment. This document offers a guide to the examination for all NIPE practitioners and local referral pathways
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For use by:	All medical and maternity staff involved in newborn infant physical examination at UH Sussex SRH & WH
Purpose:	To provide evidence based practice for health professionals who undertake examination of the newborn
This document supports: *Standards and legislation*	Public Health England standards Public Health England (2020) Newborn & Infant Physical Examination (NIPE) Screening Programme Handbook.
Key related documents:	Newborn Screening Failsafes; NIPE SOP; Neonatal BCG Immunisation Programme
Approved by:	Joint Obstetric Guideline Group (JOGG): 15th February 2023 Maternity & Neonatal Meeting: 27th June 2023
Date uploaded:	14th July 2023
Ratified by Board of Directors/ Committee of the Board of Directors	N/A
Ratification Date:	N/A
Expiry Date:	February 2026
Review date:	August 2025
If you require this document in another format such as Braille, large print, audio or another language please contact the Trusts Communications Team	
Reference Number:	CG17003

Version	Date	Author	Status	Comment
1.0	November 2016	Claire Parr, Nick Brennan, Katia Vamvakiti	Archive	Guideline in line with NIPE Standards
2.0	June 2019	Claire Parr	Archive	Update local referrals and national standards from PHE
3.0	June 2020	Claire Parr, Nick Brennan, Victoria Clarke, Katia Vamvakiti	Archive	Update with PHE handbook and local changes
4.0	February 2021	Caroline Thomas (NIPE lead)	Archived	Public Health England guidance changes from April 2021
5.0	February 2023	Caroline Thomas (NIPE lead)	LIVE	Formatted to Trust standard to include: Responsibilities & Abbreviations used within guideline. New sections 6.0, 6.1, 9.1, 11.7.4, 25 Appendix 2: New patient information leaflet for Heart Murmur

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 Infant Physical Examination (NIPE) Screening Guide for Health Professionals (Including referral pathways)

1.0 Aim and scope

The UK National Screening Committee (UK NSC) recommends that all eligible babies should be offered the Newborn Infant Physical Examination (NIPE) screen. The screen should be undertaken and completed within 72 hours of birth and then again at 6 to 8 weeks of age (undertaken by the GP).

The NIPE screen provides a holistic head-to-toe examination of the baby. The NHS NIPE Screening Programme aims to reduce morbidity and mortality by:

- Identifying and referring all babies born with congenital abnormalities of the eyes, heart, hips, and testes, where these are detectable, within 72 hours of birth.
- Identifying those abnormalities that may become detectable by 6 to 8 weeks of age, at the second physical examination (undertaken by GP).

These ages are recommended based on best practice, national and regional historical data and current evidence and should facilitate a prompt referral for early clinical assessment.

Screening providers should use information in 'Screening tests for you and your baby' to inform parents about the newborn and 6 to 8 week physical examinations during the antenatal period and again before the newborn examination is offered. For babies in the Special Care Baby Unit (SCBU) the national information 'Babies in special care units: screening tests for your baby' should be used.

Parents should be informed of findings at the time of each examination and advised to report any concerns they have about their baby's wellbeing to a healthcare professional at any time.

2.0 Responsibilities

Midwives & paediatricians:

- To access, read, understand and follow this guidance
- To use their professional judgement in application of this guideline

Management:

- To ensure the guideline is reviewed as required in line with Trust and National recommendations.
- To ensure the guideline is accessible to all relevant staff.

3.0 Abbreviations used within this guideline

NIPE - Newborn Infant Physical Examination	**PCHR -** Personal Child Health Record
CPAP - continuous positive airway pressure	**ROP -** Retinopathy of prematurity
SCBU – Special Care Baby Unit	**GOSH -** Great Ormond Street Hospital
GBS- Group B streptococcal	**ECV -** External cephalic version
USS - Ultrasound Scan	**BP -** Blood pressure
NQM- Newly qualified Midwives	**CAH –** Congential Adrenal Hyperplasia
ECG - Electrocardiogram	**CHD -** Congenital Heart Disease
CCHD - Critical Congenital Heart Disease	**FASP -** Fetal anomaly screening programme
SLE - Systemic lupus erythematosis	**PEC -** Paediatrician with expertise in Cardiology
AVSD – atrioventricular septal defect	**NG -** Nasogastric
SALT – Speech and Language Therapy	**CXR -** Chest X-Ray
FBC - Full Blood Count	**SIAF**-Serious Incident Assessment form

4.0 Record Keeping

Verbal consent should be obtained for the screening. This may include 1 of 4 outcomes:

- Full consent (verbal consent given by the mother/birthing parent).
- Partial consent (verbal consent given by the mother/birthing parent for only certain aspects of the screen).
- Professional consent (if the mother/birthing parent is too unwell to consent for the screen and it is in the baby's best interest for the screen to be undertaken).
- Declined consent (the mother/birthing parent declines the screen completely). The mother/birthing parent should have an in-depth discussion regarding screening from either a senior paediatrician or the NIPE Lead. This should be recorded on the S4N system via case notes. The NIPE Lead will send the mother a letter detailing the discussion and who to contact should they change their mind.

Newborn Infant Physical Examination (NIPE) screening should be documented within the Screening Management and Reporting Tools system for NIPE (S4N) and Personal Child Health Record (red book). Please enter as much information as possible of your findings and print off 1 copy in the Personal Child Health Record (if the parent has not received or brought with them the PCHR then please give this to them to place in the book).

Any updates to the screen should be amended on S4N and reprinted so that the notes and PCHR have the most up-to-date copy contained within. This would include editing results following senior review for screen positive referrals where the check is

required within 24 hours (i.e. heart and bilateral undescended testes). Alternatively enter an outcome using the outcome function on S4N to document findings.

A written paper copy of the NIPE screen findings should only be carried out on the rare occasion a baby cannot be located on the S4N system. This paper copy should be scanned to the NIPE Lead and The Newborn Failsafe Administrator to ensure that the contents are put on the system as soon as possible. This will ensure that the relevant referrals are processed with minimal delay.

5.0 Process for Newborn Examination

All live babies are eligible for the NIPE examination. All babies should have their screening by 72 hours of age a by a NIPE trained midwife or paediatric doctor. It is considered safer to undertake the NIPE examination early with the potential for more false positives rather than to discharge the baby and risk missing screening altogether. It is best practice to do the NIPE in the presence of the parent so they can ask questions and have findings explained.

6.0 E-Learning Requirements & Competency Framework

All NIPE trained midwives must compete this annually. This framework ensures all midwives are regularly performing NIPE examinations and ensures competency.

All NIPE trained midwives must complete annually:

- Minimum of 10 NIPE's
- Complete the e-learning module
- Attend an annual update session

This framework needs to be signed by a confirmer (Fellow NIPE trained Midwife/NIPE lead Midwife) and the completed framework shared with to the PDT.

NQM with NIPE as part of training:

- Attend NIPE teaching session as part of their preceptorship.
- Perform 10 supervised NIPE's and 10 unsupervised NIPE's (to be checked by a NIPE practitioner)
- Final Sign off by consultant/NIPE lead midwife.
- Completion of the e-learning module and cleft palate training.

Midwives with NIPE qualification- Return to practice
For midwives who have not performed NIPE's within last 12 months they are required to:

- Complete the competency framework document
- Perform a minimum of 10 NIPE's supervised by fellow NIPE/NIPE lead/Paediatric Registrar/ Consultant and signed off as competent.
- Attend Annual NIPE update session.
- Complete NIPE e-learning for Health module
- Complete cleft palate training.

- Update from NIPE lead on use of S4N system (can be arranged on an ad hoc basis).

Records of NIPE trained midwives are held within the Practice Development team.

6.1 Criteria for Midwife/Paediatric NIPE

Midwives: are the expert in 'normal babies'. Midwives can undertake NIPE if they meet the following criteria –

Well babies on postnatal ward that are:

- Over 36 weeks gestation.
- Babies of mothers/birthing parents with GBS risk factors.
- Babies of diabetic mothers/birthing parents.
- Having routine blood sugar monitoring.
- On 48 hrs prophylactic IV antibiotics for maternal risk factors.
- Uncomplicated instrumental birth.

Midwives should use their clinical judgement when undertaking NIPE's, if they have any concerns then they can request a paediatrician to perform a NIPE.

Paediatric NIPE:

- <36 weeks Gestation
- Antenatal congenital anomalies
- Babies on treatment course of antibiotics
- Birthweight <2.2kg
- Antenatal management plan in place which requires treatment or referral.
- Complex instrumental birth.

If baby is close to breech time and paediatric team is unable to perform NIPE consultant on call needs to be aware. An individual plan on a case by case basis can be made. An experienced NIPE midwife may be able to facilitate examination.

7.0 Babies in SCBU

Babies in SCBU should be assessed at each medical handover and if well enough, the NIPE screen should take place within 72 hours of age. Any baby transferred to the Postnatal Ward should have NIPE performed prior to transfer.

Some babies on the SCBU may be too unwell or too premature for examination to be completed (e.g. fused eyes) and the NIPE screen is not appropriate at the time the examination is due. If possible, all screening elements should be carried out but it is also appropriate to examine each element of the NIPE as soon as practical once the baby's category of care is special care. If this is the case and element of the screen has not been carried out then please ensure this is clearly documented as

intentionally omitted so a record can be kept of the need to complete when appropriate.

Newborn screening may be delayed (>72 hours of age) where a clinical decision is made because the baby is 'too young' or 'too ill' for NIPE screening.

- Too young for NIPE screening' is defined as babies born <34+0 weeks gestation.
- Screening may be delayed until these babies reach 34+0 weeks corrected age.
- Screening ideally being undertaken within 72 hours of reaching this age.
- Any baby deemed 'too ill' for screen will require acceptable mitigations for delay to be submitted in the KPI data. Clinical judgement should be used when assessing suitability for NIPE screening. The list below gives circumstances NIPE can be delayed:
    - Respiratory support (other than low-flow oxygen), including the presence of chest drains for first 72hrs.
    - Any cardiovascular support, for example, inotropes, prostin.
    - Ventilated infant until extubated.
    - Baby on continuous positive airway pressure (CPAP).
    - Therapeutic hypothermia.
    - Intense phototherapy (double or more, need for immunoglobulin/exchange transfusion.
    - Chest drain in place(without additional respiratory support).
    - Umbilical lines in place/arterial lines in place.
    - Post-operative, until off analgesia.
    - Unstable hypoglycaemia until off dextrose.
    - Where active reorientation of care to comfort/palliative care is taking place.

Referral timescales should not be age adjusted for preterm babies although local arrangements have been agreed regarding routine hip scans (please see hip section).

Babies less than 32 weeks gestational age (up to 31 weeks and 6 days) or less than 1501g birthweight should be screened for retinopathy of prematurity (ROP). Please check local guidance for this pathway.

8.0 Communicating results of the screen

Following the newborn examination, the parents should be informed of the outcome of the examination with explanation of referral process if required. They should also be informed that the NIPE screen will be repeated at 6-8 weeks of age by their GP as some conditions can develop or become apparent later.

9.0 The process for full examination

- Explain purpose and limitations of the examination and gain verbal consent from the mother / birthing parent. Ideally at least one parent should be present during the examination, in order that outcomes can be communicated.
- Mother's / birthing parent's notes should be available for review.
- The infant's general condition should be assessed prior to the examination.
- Elicit any concerns or queries about the infant from the parents including detail of family history (1st degree) where relevant. (1st degree family is the relation to the baby which includes any siblings and both parents.)

9.1 History

A review of the maternity and baby medical record should be undertaken prior to the screen. This should include a review of family history as well as maternal / birthing parent antenatal, labour/ birth and perinatal histories.

Check if there are any plans made antenatally including known fetal anomalies (genetic or structurally) by checking scan results.

Details of any plans made antenatally are transferred on to the S4N system and the consultant/ team responsible informed of the birth and any referrals required as planned are made and documented.

Where notes are not available to review then the NIPE practitioner should take time to elicit as much information about pertinent family history, pregnancy and scan findings, birth outcome and initial examination and any postnatal issue.

Specific information should be gathered about the baby's family history:

- Congenital abnormality of the heart, eyes, hips and testes (if male)
- Assessment of risk for TB.

9.2 BCG immunisation Referral.

All babies should be identified at NIPE if they are at risk of TB. BCG vaccination is recommended for babies up to 1 year who:

- Has a parent or grandparent of the baby, born in country where's a high rate of TB.
- Live with or have close contracts of someone who has TB(active/latent).
- Baby will be living with local people for 3 months or longer in countries with high rates of TB.

Parents should be advised they will receive an appointment for the vaccine at around 28 days old. This is in outpatient clinic at both SRH and WH.

Referral letter is on the S4N system and should be email to:
uhsussex.bcgimmunisationprogram@nhs.net

(See BCG Immunisation Guideline.)

Action: Document on S4N. Complete and email referral letter. uhsussex.bcgimmunisationprogram@nhs.net

9.3 The newborn examination

The examination should take place in a warm, bright environment and on a firm flat surface with the baby undressed and settled. The examination should be performed in a systemic manner however many elements can be checked opportunistically. Ideally parents should be present during the examination to allow exchange of information and advice as appropriate.

9.3 General observations

- Does the baby appear well?
- Are there any obvious malformations?
- Does the baby have dysmorphic features i.e. Down Syndrome
- Does the infant have severe intrauterine growth restriction (birth weight <2nd centile)?

9.4 Colour

Is there pallor, cyanosis, plethora or jaundice present?

If cyanosis present is this peripheral or central (check tongue and buccal mucosa). Carry out pulse oximetry to check saturation levels (low threshold) if available. Acrocynosis is often seen in healthy newborns in the first few hours of life and refers to peripheral cyanosis typically the extremities. This is a normal finding.

Action: Central cyanosis(check tongue and buccal mucosa.- immediate paediatric referral. Declare neonatal emergency 2222. Carry out pulse oximetry (Appendix 1). If NIPE performed in the community then dial 999. Jaundice:< 24hrs: immediate review by paediatric team. >24hrs TCB and plotted on chart (see Jaundice guideline)

9.5 Posture and behaviour

- Tone – Assess activity, posture and response to handling and reflexes.
- Moro reflux- symmetrical?

- Abnormal movements? (Excessive jitteriness, jerking of limbs, abnormal mouth or eye movements.
- Is the baby normally active?
- Is the posture normal (flexed extremities)?
- Is the cry normal?

Action: Document on S4N refer to paediatric team if concerned.

9.5.1 Birth marks/Rashes

Note the colour and texture of the skin as well as any birthmarks or rashes. These should be documented very clearly with regards to their appearance and location on the body preferably using a body map to depict exact appearance. A body map is available in the baby's postnatal record on MIS or as a download on the S4N system.

10.1 Capillary naevi

These are "stork marks" at the nape of the neck but are also commonly seen on the upper eyelids. They fade rapidly in the early months of life though they may become more obvious with crying. They need no follow up and parents can be reassured. Occasionally they can appear elsewhere on the body, sometimes initially looking like bruises. However, naevi will blanch allowing differentiation.

Action: S4N- mark as normal observation not suspected abnormality

10.2 Dermal melanocytosis/ Slate Grey Nevi. (Mongolian/ Blue spots)

These are well-demarcated areas of increased pigmentation within the skin usually found over the lower back and buttocks at birth. The pigment is within the skin and the borders are not palpable. They are most common in children of African ethnicity but also occur in Asian and Caucasian Babies. They can be confused with bruising due to the colouration but need no follow up, if in doubt request senior review.

Action: S4N- mark as normal observation not suspected abnormality.

10.3 Strawberry naevi / Cavernous haemangiomata

These are usually not present at birth but start as minute bright red spots in the first few weeks of life. They increase in size rapidly in the first few months of life and their natural history is to then regress, disappearing by the age of 6-7 years old. They rarely bleed, although this can occur in large ones.

Action: No action is necessary unless their position is problematical involving the airway, face, genitals or anus or they become excessively large. In these cases consultant review is indicated and early referral to dermatology may be considered for treatment with propranolol or laser. Always discuss facial haemangiomata with the

consultant. Follow-up is only needed for naevi involving those areas above. Parents should seek medical advice if naevi increase dramatically.
S4N - document as suspected abnormality if they involve the concerning areas above- if not as an observation only.

10.4 Melanocytic naevi

These are rare but important. They are much darker than the surrounding skin and may have a raised edge. They often have thick hair growing within them.

Action: careful assessment needed by a consultant or dermatologist as they may warrant dermal abrasion in the first few weeks of life.

10.5 Port wine Stain

A port-wine stain is a permanent birthmark present from birth. It starts out pinkish or reddish and turns darker as the child grows. Most often, a port-wine stain appears on the face, but it can affect other areas of the body.

Action: Discuss this with a senior paediatrician, registrar/consultant. If there is eye involvement refer to ophthalmology by emailing the teams
SRH emergencyreferralssrh.ophthalmic@nhs.net
WH referralssld.ophthalmic@nhs.net
Consider the possibility of Sturge-Weber syndrome. Sturge-Weber syndrome is a condition that affects the development of certain blood vessels, causing abnormalities in the brain, skin, and eyes from birth. Sturge-Weber syndrome has three major features: a red or pink birthmark called a port-wine birthmark; a brain abnormality called a leptomeningeal angioma, and increased pressure in the eye (glaucoma). These features can vary in severity and not all individuals with Sturge-Weber syndrome have all three features. S4N - document as suspected abnormality.

10.6 Erythema toxicum of the newborn

This begins within 48 hours of birth and disappears in a few days. Blotchy erythematous macules 2-3cm in diameter with a central vesicle appear over the trunk, face or limbs. This is common and benign.

Action: S4N - mark as normal observation not suspected abnormality.

10.7 Herpes Simplex

In the presence of vesicles, herpes simplex must be suspected. This can be caused by either Herpes virus type 1 or type 2. A maternal history is often not found.

Action: requires urgent review by a registrar S4N - document as suspected abnormality.

10.8 Jaundice

If the baby appears to be jaundiced please refer to the jaundice guideline for diagnosis and treatment pathways.

11.0 Head and skull

Check the shape of the head. Palpate the anterior fontanelle, sagittal, coronal and lambdoid sutures and posterior fontanelle.

Head circumference should be measured and recorded.

Note head circumference in centimetres. If large variation between birth measurement and current measurement discuss with a senior paediatrician.

11.1 Cephalhaematoma/Caput succedaneum

A cephalhaematoma is a sub-periosteal collection of blood that develops over the first few days of life, limited by the periosteal attachments to the area of a single bone of the skull. Soft and fluctuating it feels like a fluid-filled cyst. It may last for several weeks, gradually getting smaller. These infants are at increased risk of developing jaundice.

Caput Succedaneum- swelling or oedema observable shortly after delivery. Swelling extends above the periostum and can cross suture lines.

Action: S4N - mark as observation. Add to body maps. And plan for ongoing review in relation to jaundice management if required.

11.2 Forceps / Ventouse trauma

Ventouse extraction can cause suction marks and occasionally raw areas on the scalp. Forceps marks can be seen on the face. These infants are at increased risk of developing jaundice. If severe these babies may be very unsettled and may be fractious on handling. A senior paediatric review is required and pain relief may be required for these babies.

A boggy swelling in the first few hours after ventouse birth may be subgaleal haemorrhage and requires urgent review

Action: S4N - mark as observation and plan for ongoing review in relation to jaundice management if required.

11.3 Face

Observe facial features and symmetry. Compare with other family members before deciding the baby looks ‘abnormal / dysmorphic’.

Action: Dysmorphic appearance- refer to paediatric team.. Document on S4N with plan of senior review.

11.4 Facial Palsy

Asymmetric crying may be the only clue to a unilateral facial palsy. The affected side does not move as much as the other side, with the nasolabial fold remaining flat and the corner of the mouth is drooping. These are almost all caused by pressure on the facial nerve during birth. This is sometimes due to forceps but can occur by prolonged pressure on the maternal sacral promontory. The majority of facial palsies resolve spontaneously without any permanent damage.

Action - Ensure that feeding is effective, (discuss with midwifery team to complete thorough feeding assessment). If the eye does not close then liaise with ophthalmology. WH babies email: emergencyreferralssid.opthalmology@nhs.net SRH babies email: emergencyreferralssrh.opthalmolgy@nhs.net

11.5 Ears

- Ears which are floppy and lacking in normal cartilage are of significance and may be associated with urinary tract abnormalities.
- Low set ears can be associated with various syndromes.
- Pre-auricular tags are usually benign; however they should alert the examiner in carefully assessing the form of the ear. Isolated preauricular tags in otherwise normally formed ears are not an indication for renal imaging.
- Bilateral or unilateral atresia (no ear canal). These babies cannot have their hearing screen completed in the normal manner.
- Bilateral or unilateral microtia (malformed pinna). These babies cannot have their hearing screen completed in the normal manner.

• Action: any suspected abnormality should be reviewed by a registrar. S4N - documented as suspected abnormality. • Malformed pinna or no ear canal requires a direct referral to audiometry for a diagnostic ABR. Please inform the NHSP Lead, and Newborn Screening Failsafe Administrator.

11.6 Nose

Choanal atresia is suspected if the baby is struggling to feed and there is evidence of persistent nasal congestion. If in any doubt check nasal airways with a feeding tube.

Action: Document findings. Review by paediatric team

11.7 Eyes

The prime purpose of screening is to identify congenital cataracts.

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.

11.7.1 Clinical risk factors

Risk factors for eye or visual problems include:

- A family history of bilateral congenital or hereditary cataracts affecting a first-degree relative.
- A first-degree relative with an ocular condition which was congenital or developed in early childhood, for example, aniridia (absence of the iris), colobomata (a hole in one of the structures of the eye) or retinoblastoma (a rare malignant tumour of the retina).
- Genetic syndromes, such as trisomy 21, associated with eye and vision disorders.
- Extensive port wine stain involving the eyelids, which can cause glaucoma.
- Maternal exposure to viruses during pregnancy, including rubella and cytomegalovirus.
- Neurodevelopmental conditions or sensorineural hearing loss (a type of hearing loss, or deafness, in which the root cause lies in the inner ear).
- Prematurity.

Bilateral examination covers:

- Eye opening – presence of eyes
- Position and symmetry
- Size and colour
- Presence of fundal (red) reflex

11.7.2 Screen positive

The absence of fundal (red) reflex suggests the presence of a congenital cataract. A white reflex (leukocoria) suggests a tumour of the eye (retinoblastoma).

Babies with an abnormality of the eye identified should attend an ophthalmology assessment appointment by 2 weeks of examination. S4N - document as suspected abnormality. An urgent ophthalmology referral should be made via S4N and emailed to:

- SRH emergencyreferralssrh.ophthalmic@nhs.net
- WH referralssld.ophthalmic@nhs.net

11.7.3 Other eye conditions

- Any additional risk factors or incidental findings, including the presence of aniridia, colobomata and retinoblastoma, please discuss with a Registrar.
- Sticky eyes are usually due to irritation rather than infection and washing with sterile water or saline is adequate.
- Chlamydia or Gonococcal infection should be considered if bilateral copious purulent conjunctivitis on day 1

Action: document findings on S4N refer to paediatric team.

11.7.4 Subconjunctival Haemorrhages

These are common finding in healthy new-born babies caused by mild birth injury that resolves spontaneously within the first few weeks after birth. It is caused by bleeding under the conjunctiva during vaginal delivery. The extent may be large or small but always confined to the limits of the sclera. Clear documentation can prevent future safeguarding investigations.

Action: Document on S4N findings. Mark on body maps. Reassure parents and suggest parents to take photo on their own phone for comparison in case of any future safeguarding concerns.

11.8 Mouth and Palate

The mouth should be fully inspected using palpation followed by a tongue depressor and a torch to visualise the mouth to ensure visualisation is optimal.

11.8.1 Micrognathia

Can be found with Pierre-Robin sequence which can cause possible respiratory compromise.

Action: where there is severe micrognathia (Pierre-Robin sequence), there are often airway problems and such babies should be assessed on SCBU by a registrar or consultant. S4N - document as suspected abnormality.

11.8.2 Accessory tooth

Potential to lead to parental anxiety around breastfeeding.

Action: S4N - document as an observation. Reassure parents. Ask the midwives to carry out a breastfeeding assessment. If loose, discuss with consultant paediatrician regarding removal.

11.8.3 Swelling under the tongue

Consider ranula cyst which could lead to feeding difficulty.

Action: S4N - document as a suspected abnormality and request registrar review. Ask the midwives to carry out a breastfeeding assessment.

11.8.4 Visible Frenulum/Tongue tie

A visible frenulum is not a tongue tie. A diagnosis of tongue tie can only be made after full tongue assessment including full feeding assessment by a member of the maternity team. Frenotomy is only recommended if feeding is adversely affected. (Avoid any negative connotation regarding this in relation to feeding as this can negatively impact the woman's/birthing parent's confidence with feeding. CG12033 Division of Tongue Tie (Ankyloglossia) Guideline

Action: Request a thorough feeding assessment by the midwifery team. Patient information is available online. S4N - document as for observation.

11.8.5 Bifid uvula

Denoting soft cleft palate or other midline defect, eg hypopituitarism. See actions below for cleft palate and discuss with Paediatric consultant.

11.8.6 Cleft Palate

The current national rate of cleft palates (isolated clefts) which are missed at the newborn examination is in the range of 23%. In order to improve this figure it is recommended that the palate of the newborn infant is inspected visually, using a torch with a tongue depressor, as well as digitally with the finger.

Action: where a cleft is detected or suspected, the regional Cleft Lip and Palate Team (Lead specialist nurse) should be informed, immediately. Always notify the consultant on call. The immediate practical problem with facial clefts is to establish oral feeding, liaise with nurse in charge on SCBU. S4N - document as suspected abnormality. • Worthing referrals - Evelina London Cleft Service 07548 152 738. Messages can be left on the number at any time. • St Richard's referrals - Spires Cleft Centre, Salisbury 07500 127657 (Office hours). Messages can be left on the number at any time. On call nurse 0750012657 Antenatal diagnosis - letter from cleft team in notes and sent to consultant.

12.0 Neck and Clavicles

Short neck is often significant; webbing should be looked for (present in Turner and Noonan Syndrome).

Feel for both clavicles – they may be absent or 'broken', check movement of both arms and the symmetry of the Moro reflex.

Action: any suspected abnormality, refer to paediatric registrar. S4N - document as suspected abnormality.

13.0 Chest

Asymmetry and thoracic cage defects should be noted.

13.1 Lungs

Effort, rate and auscultation:

- Listen for equal air entry and added sounds.
- Is the baby tachypnoeic?
- Are there any signs of respiratory distress i.e. nasal flaring, intercostal/subcostal recessions?

Action: refer to paediatric registrar for immediate review. S4N - document as suspected abnormality. Perform full set of observations including pulse oximetry.

13.1 Breast Development

Maternal hormones may cause transient development of breast tissue in infants of both sexes. There may even be some production of milk.

Action: this is normal and parents should be reassured. Check for signs of inflammation for the rare possibility of overlying infection.

14.0 Abdomen and umbilicus

Ensure normal bowel sounds are present, if increased or absent – consult senior for advice.

14.1 Scaphoid abdomen

Suggests possible absence of intestine from abdominal cavity, usually found with a diaphragmatic hernia.

Action: request paediatric registrar review. S4N - document suspected abnormality.

14.2 Distended abdomen

Requires more detailed examination and frequently additional investigations to determine cause, which may vary from distension of stomach and intestines as a result of resuscitation, to gross pathology such as that associated with intrauterine peritonitis, or gross neoplastic disease.

Action: Request paediatric registrar review. S4N - document suspected abnormality.

14.5 Liver and spleen

Gentle examination of the abdomen. The liver can be located approximately one finger below the ribs on the right hand side. The spleen may be palpable on left upper quadrant.

Action: Any masses felt. Refer to paediatric registrar. Document findings on S4N.

14.6 Umbilicus

Note origin of umbilical cord. Check for number of vessels.

Action: refer to paediatrician if umbilicus is inflamed with ‘flared’ or erythematous surrounding skin, for discussion about commencing IV antibiotics

14.7 Hernia

- Umbilical hernia usually resolves spontaneously by a few years of age.
- Para-umbilical hernia is an abnormal finding.

Action: Discuss with paediatric registrar and refer to surgeons. S4N - document as suspected abnormality

15.0 Upper Limbs and Hands (Digital Anomalies)

15.1 Syndactyly or Polydactyly

Action: minor hand defects are referred to Mr Pandya QA consultant, to his QA clinic. S4N - document as suspected abnormality.

15.2 Limb reduction defects

Action: if diagnosed antenatally please check paediatric plan and follow instructions. If not previous diagnosed discuss with consultant on call. S4N - document as suspected abnormality.

15.3 Contractures/Torticollis

Action: refer to physiotherapist via Bleep (WH 1148, SRH 6153) or complete orange card for Worthing babies or physio book for Chichester babies. For babies in community send email to wsht.paediatricphysio@nhs.net

15.4 Erb's Palsy

Trauma to the brachial plexus during birth is the most likely cause of congenital brachial palsy. It occurs in about 1 in 1000 births. High risk births for this injury include shoulder dystocia, large babies and difficult instrumental birth. Always consider the possibility of other trauma such as clavicular fracture.

There are three main patterns of injury:

- C5-6: Paralysis of shoulder and biceps. The arm is adducted and internally rotated at the shoulder, the elbow extended, the forearm pronated and the wrist flexed (waiter's tip position).
- C5-7: Paralysis of shoulder, biceps, forearms extensors possibly causing slight flexion of the elbow.
- C5-T1: Complete paralysis of the limb. Sometimes there is also a Horner's syndrome on the affected side.

Action: Discuss with consultant on-call and arrange an x-ray of clavicle and upper limb. Immediate referral to physiotherapy via Bleep (WH 1148, SRH 6153) or if unavailable email wsht.paediatricphysio@nhs.net.
Reassure parents that most cases resolve spontaneously within a few days or weeks. Arrange in-patient physio therapy review and Paediatric consultant follow up in outpatients clinic at 4 weeks S4N - document suspected abnormality.

16.0 Hips

The purpose of screening is to improve the early identification developmental hip dyplasia.(DDH) Approximately 1 or 2 in 1,000 babies have hip problems that require treatment. Parents should be informed that this condition can develop over time and signs should be discussed with parents.

The NHS NIPE programme national hip risk factors are:

- First degree family history of hip problems in early life. This includes baby's parents or siblings who have had a hip problem that started as a baby or young child that needed treatment with a splint, harness or operation.
- Breech presentation at or after 36 completed weeks of pregnancy, irrespective of presentation at birth or mode of birth. This includes breech babies who have had a successful external cephalic version (ECV).
- Breech birth between 28 weeks gestation and term.
- Multiple pregnancies - where any of the hip risk factors is present, all babies from that pregnancy should receive a hip ultrasound. The rationale

for this advice is that if one of the babies meets the criteria of breech presentation, as described above, it may be difficult to accurately identify which baby was affected.

- Action: For babies with any of the above risk factors, hip ultrasound examination should be arranged within 4-6 weeks of age. USS of babies born 34/40 or less will be age adjusted to term. S4N - document in risk factors
- Practitioner needs to order Hip USS via the ICE system.
- Referrals for babies with abnormal hip scans should be sent to: uhsussex.outpatientbookings@nhs.net and to uhsussex.infanthipscreening@nhs.net
- Explain to parents they should receive appointment within 2-3 weeks

Observation covers:

- Symmetry of leg length
- Level of knees when hips and knees are bilaterally flexed
- Restricted abduction of the hip in flexion

Ortolani and Barlow manoeuvres should be performed on each hip separately to assess hip stability. Ortolani manoeuvre is used to screen for a dislocated hip. Barlow manoeuvre is used to screen for dislocatable hip.

16.1 Screen negative

Following normal examination, parents should be advised to contact their midwife, GP or health visitor if they have concerns about their baby's hips. In particular they should observe if:

- One leg cannot be moved out sideways as far as the other when changing the baby's nappy
- One leg seems to be longer than the other
- A click can be felt or heard in one or both hips
- One leg drags when their baby starts crawling
- Their child walks with a limp or has a 'waddling' gait

16.2 Screen positive

Screen positive results are:

- Difference in leg length.
- Knees at different levels when hips and knees are bilaterally flexed.
- Restricted unilateral limitation of hip abduction (with a difference of 20 degrees or more between hips).
- Gross bilateral limitation of hip abduction (loss of 30 degrees abduction or more).
- Palpable 'clunk' when undertaking either the Ortolani manoeuvre.

- Action: Babies who meet screen positive threshold should undergo hip ultrasound within 4-6 weeks of age and be reviewed by a senior paediatrician.
- S4N - document suspected abnormality and make ICE request for Hip USS.

16.3 Management of 'Clicky 'Hips

Babies who have no predisposing risk factors and are found to have 'clicky hips' should NOT to be classified as screen positive and do not require any referral for ultrasound. Clicks and snaps can sometimes be heard and felt and are not normally associated with hip pathology. These noises are as a result of movement of tendons, ligaments or fluid in the hip joint.

Action: confirmation of the screening outcome by a paediatric registrar should be sought if unsure if findings After second opinion, a scan can be requested only if it meets the screen positive criteria. Isolated clicks without any other relevant clinical findings should **not** be routinely referred. S4N - document 'clicky hips' as other on hips screen and document findings including senior review in free text box.

17.0 Lower Limbs – Feet

17.1 Talipes

Feet should be examined for:

- Talipes equino varus
- Calcaneo valgus talipes

It is important to distinguish between mild, positional talipes and fixed talipes requiring intervention. Any suspicion of fixed talipes the physiotherapist should assess before discharge and will then refer for further intervention.

Action: If practitioner assess talipes to be positional or mild no referral is required. Exercises can be discussed with parents. Referral can be made to physiotherapy team if required. Exercise sheet can be downloaded from the S4N system and given to parents.
Referral to physiotherapist is indicated via email to wsht.paediatricphysio@nhs.net (Worthing) or SC-TR.chipaedsphysio@nhs.net (Chichester). Please state in referral to the physiotherapist, the type of talipes so the baby can be triaged appropriately.

Fixed talipes requires the physiotherapist to assess before discharge where possible. Bleep numbers are WH 1148, SRH 6153. For fixed talipes request a hip USS to check for any abnormal hip using the ICE system.
Referrals should be made to Orthopaedic teams at Brighton.
Uhsussex.paediatricphysio@nhs.net and Uhsussex.outpatientbookings@nhs.net
for urgent referrals please call 01273 523153
S4N - document suspected abnormality.

17.2 Major Limb Deficiencies

This is a tremendously distressing time if the problem was not expected. It will be difficult for parents to comprehend how such a problem was not found antenatally.

Action: If diagnosed antenatally please check antenatal paediatric plan and follow instructions. If not previously diagnosed contact the consultant on call and the physiotherapist on call who will visit baby. S4N - document as suspected abnormality.

REACH is a helpful charity run by parents and can offer support on www.reach.org.uk for parents with children with upper limb deformities.

STEPS is a similar charity for those with lower limb problems and can be contacted on www.steps-charity.org.uk

18.0 Genitalia

18.1 Ambiguous genitalia

Abnormality suggestive of intersex conditions should always be checked carefully and investigated. Avoid allocating a sex to the baby and do not refer to the baby as "he" or "she". Use terms such as they, the baby or use their name if they have been given one already.

Note - Posterior hypospadias particularly in the absence of palpable gonads, should be regarded as an indeterminate sex or ambiguous genitalia.

Action: Seek consultant paediatric review ASAP. S4N - document suspected abnormality.

18.2 Female babies

- Confirm normal labia majora and minora and absence of swelling (ectopic testis).
- Vaginal Tags: These are of no significance and usually disappear in a few months.
- Occasionally female infants may even have a slight vaginal bloody discharge due to maternal/birthing parent hormones, again reassure.

18.3 Male babies

Confirm the shaft of penis is 2.5 cm in length (including buried).

Action: Seek review with registrar or consultant. S4N - document suspected abnormality.

18.3.1 Hydroceles

These are common in newborns. A hydrocele is type of swelling in the scrotum that occurs when fluid collects in the sheath surrounding a testicle. Transillumination will show clear fluid surrounding the testicle. Parents can be reassured that they will usually resolve spontaneously.

Action: No follow-up is required. However a full explanation should be given to the parents. S4N - document as observation.

18.3.2 Undescended testes

Cryptorchidism affects approximately 2-6% of male babies born at term. It is associated with: a significant increase in the risk of testicular cancer (primarily seminoma); reduced fertility when compared with normally descended testes; it may also be associated with other urogenital problems such as hypospadias and testicular torsion.

The term ‘undescended’ applies for clinical findings of either ‘absence’ or ‘incorrect position’.

Associated risk factors include:

- A first degree family history of cryptorchidism (baby’s father or sibling).
- Low birth weight.
- Small for gestational age or preterm birth.

Observation: Observe scrotum for symmetry, size and colour.

18.3.3 Screen Positive

Action: S4N - document as suspected abnormality.

18.3.4 Unilateral undescended testes

These babies should be reviewed at the 6-8 week GP NIPE screen.

Action: Complete outcomes on S4N.

18.3.5 Bilateral undescended testes

May be associated with intersex or an underlying endocrine disorder such as congenital adrenal hyperplasia.

Where testes are felt bilaterally but high, this should also be managed as screen positive. The term 'undescended' applies for clinical findings of either 'absence' or 'incorrect position'.

Action: These babies should be seen for assessment by a senior paediatrician Registrar or Consultant within 24 hours of the examination to rule out metabolic and intersex conditions. Please ensure consultant is aware. Refer to Paediatric Surgeons to be seen in their outreach clinic in Chichester or Worthing. Worthing - refer to Paediatric Surgeon based at RACH, Brighton. SRH - refer to Paediatric Surgeon, based at Southampton S4N - document as suspected abnormality.

18.3.6 Torsion of the testes

This is a rare occurrence but may occur in the newborn baby. The scrotum is likely to be red and inflamed or can appear darkened; the scrotum can also be firm to touch. The baby will likely be very uncomfortable.

Action: Suspicion of torsion should be considered a medical emergency. If in doubt, ask for an urgent registrar or consultant opinion. S4N - document as suspected abnormality.

18.3.7 Hypospadias

Hypospadias is a very common congenital anomaly (1 in 200 male births).
Urethral meatal openings are generally described as being:

- Anterior – distal position, where the meatus is near the tip of the penis, 15% of these cases, the penis also curves downward slightly known as 'chordee'.
- Middle – where the meatus is along the shaft of the penis.
- Posterior – where the meatus is near the base of the penis or in the scrotum.

The baby requires a complete examination to determine whether other external abnormalities are present. However in most cases, hypospadias is the only developmental problem and doesn't imply there are other flaws in the urinary system or other organs.

Renal ultrasound is not indicated for simple *anterior or middle* hypospadias unless there are other features of concern (for example, dysmorphic features). Renal abnormalities are more common with posterior hypospadias.

Penile length should be determined, normal stretched penile length at term >2.5cm

Action: *Posterior* hypospadias particularly in the absence of palpable testes should be regarded as an indeterminate sex or ambiguous genitalia, inform the consultant. It must be explained to parents that no babies should undergo circumcision, as the skin will be needed for the repair. Worthing - refer to Paediatric Surgeon, based at RACH, Brighton, with outreach clinic at Worthing. St Richard's - refer to Paediatric Urologists at Southampton. S4N - document as suspected abnormality.

18.3.8 Inguinal hernias

These hernias can be seen bulging when the baby cries or strains and often disappears when the baby is calm.

Action: Refer baby to paediatric surgeons. S4N – document as suspected abnormality.

19.0 Anus

19.1 Anorectal malformation

Anorectal malformation is a term used to describe several types of anomalies. The anus and the rectum have not developed properly. The baby may be born with:

- No anal opening at all.
- An ectopic anus (small opening in the wrong place).
- Anal stenosis (narrowed opening of the bottom).

Confirm and note time meconium has been passed, but remember that passage of meconium does not preclude careful examination, e.g. imperforate anus with associated fistula. Careful examination of the anus is required to exclude anomaly.

Action: Anorectal malformation requires urgent surgical referral to Brighton or Southampton Paediatric surgeons. S4N - document suspected abnormality

19.2 Stools

Day 0-2- An infant's first few bowel movements consist of accumulated intestinal cells, bile and proteinaceous material formed during intestinal development. The material, termed meconium, is greenish-black. Term babies who do not pass meconium in the first 2 days of life may indicate intestinal obstruction.

Action: Ask the paediatric registrar to review. S4N - document suspected abnormality.

20.0 Urine

Day 1-2: 1-2 or more wet nappies a day. Urates may be present (dark pink / red / orange substance).

Action: If <24 hrs of age advised parents that babies should pass urine within 24hrs. If >24hrs inform paediatric team

21.0 Spine

Inspect and palpate bony structures down to sacrum including the integrity of the skin.

21.1 Sacral sinus

Most suspected sinuses are actually blind sacral pits low down on the sacrum. These are common and not usually associated with underlying spinal problems. When the bottom cannot be visualised and is >25mm from the anus or >5mm from the midline or hairy patch present then an image of the spine is required.

Action: Paedatric review Send referral for ultrasound of the spine. S4N - document suspected abnormality.

21.2 Midline spinal haemangiomas

These are vascular lesion found within the vertebral body and require investigation.

Action: Paediatric review Send referral for a spinal x-ray and ultrasound of the spine. S4N - document suspected abnormality.

21.3 Spina Bifida (Myelocoele & Meningomyelocoele)

A large blister type sac can be seen on the back covered by a thin layer of skin.

Action: Inform the Consultant on call. This needs an urgent referral to a neurosurgeon, especially where the membrane is thin or defective, as early closing of the defect may be required. S4N - document suspected abnormality.

22.0 Nervous System/Reflexes

The presence of normal activity and limb movements and normal limb tone should be checked. In addition attempts should be made to elicit normal grasp and Moro 'startle' reflex. Inability to do this strongly suggests significant abnormality of central nervous system. Remember that when the infant is crying it is sometimes not possible to elicit a normal Moro reflex.

Action: If a normal response cannot be elicited following calming the baby then this is significant and the baby will need to be reviewed by a consultant paediatrician. S4N - document as suspected abnormality.

22.1 Femoral Pulses

Palpate both femoral pulses simultaneously taking your time with the baby's legs flat not flexed at the hip. If the pulse is weak, compare the femoral pulse volume with the baby's right brachial pulse by palpating these simultaneously. Absent or weakened femoral pulses as compared to the right brachial pulse indicate a possible coarctation or narrowing of the baby's aorta.

Action: A registrar review is urgently required and would warrant careful examination of the cardiovascular system including both brachial and femoral pulse volumes, observations and considering ECG Appropriate transfer to SCBU should be considered. S4N - document suspected abnormality.

23.0 Heart

The purpose of screening is early identification of congenital heart problems.

Ranging from non-significant to major and critical lesions, the overall incidence of Congenital Heart Disease (CHD) is about 8 per 1,000 (range 6-12 per 1,000 live births). Critical Congenital Heart Disease (CCHD) accounts for 15% to 25% and these are a leading cause of morbidity and mortality.

Congenital heart abnormalities can be categorised as:

- CCHD: includes all potentially life threatening duct-dependent conditions and those conditions that require procedures within the first 28 days of life.
- major serious CHD: those defects not classified as critical but requiring invasive intervention in the first year of life.

Some critical and major cardiac lesions may be detected during pregnancy as part of the fetal anomaly screening programme (FASP) during the fetal anomaly ultrasound scan. The acceptable FASP standard target detection rate for specific cardiac abnormality is ≥50%.

The NHS NIPE programme clinical risk factors include:

- Family history of CHD (first degree relative).
- Fetal trisomy 21 or other trisomy diagnosed (these babies have high risk of cardiac defects and require continued surveillance).
- Cardiac abnormality suspected from the antenatal scan.

- Maternal exposure to viruses, for example, rubella during early pregnancy,
- Maternal/birthing parent conditions, such as diabetes (type 1), epilepsy, systemic lupus erythematosis (SLE).
- Drug-related teratogens during pregnancy, for example, antiepileptic and psychotrophic drugs.

Auscultation covers:

- Presence of a murmur, either systolic or diastolic and loudness.
- Second intercostal spaces adjacent to the sternum: left (pulmonary area).
- Second intercostal spaces adjacent to the sternum: right (aortic area).
- Lower left sternal border in the 4th intercostal space (tricuspid area).
- Apex (mitral area).
- Midscapulae (coarctation area).

23.1 Screen positive

Signs and symptoms that suggest critical or major congenital heart abnormality are:

- Tachypnoea at rest.
- Episodes of apnoea lasting longer than 20 seconds or associated with colour change.
- Intercostal, sub-costal, sternal or supra-sternal recession, nasal flaring.
- Central cyanosis.
- Visible pulsations over the precordium, heaves, thrills.
- Absent or weak femoral pulses.
- Presence of cardiac murmurs/extra heart sounds:
  - Significant murmurs are usually loud, heard over a wide area, have a harsh rather than soft quality, and are associated with other abnormal findings.
  - Benign murmurs are typically short, soft, systolic, localised to the left sternal border, have no added sounds or other clinical abnormalities associated with them.

Action: Babies with screen positive clinical findings should be seen by a registrar or consultant in the early neonatal period as required (urgency will depend on suspected condition). Heart rate, respiratory rate and pulse oximetry should be undertaken ASAP and repeated and escalated appropriately if abnormal. All babies found to have a murmur on examination should also have a 12-lead ECG performed.

Any babies with a suspected major or critical heart condition should be seen as a matter of urgency and definitely before discharge home.

Symptomatic or unwell babies

Babies with any of the following RED FLAGS are more likely to have a significant congenital cardiac defect:

- Symptoms or signs of cardiac failure or shock
- Oxygen saturations <95%
- Right arm to leg saturation difference >2%
- Absent/weak femoral pulses

These babies should be admitted to SCBU, discussed with and reviewed by the attending/on call Consultant and managed. Urgent cardiac review should take place if local expertise available. SORT guidance can be located here

Asymptomatic babies

Babies with any of the following may have acyanotic congenital heart disease:

- "Pathological murmur" (>3/6, area other than LSE, palpable thrill or heave).
- Dysmorphic features or other associated congenital abnormalities.

*those with clinically suspected or genetically confirmed Trisomy 21 should have an ECG performed.

These babies should be reviewed by the attending consultant and discussed with the local Paediatrician with expertise in Cardiology (PEC), Not all will require an inpatient echocardiogram prior to discharge, some may be appropriate for urgent outpatient review. This will be decided on a case by case basis.

Babies with no red flags who have all of the following are likely to have innocent murmurs:

- Soft systolic murmur, <3/6, located in LSE, no radiation, no thrill/heave.
- Saturations >95%.
- Right arm to leg saturation difference <2%.
- Normal 12-lead ECG.

These babies should be reassessed >24 hours of age by the Neonatal registrar. Babies should be reviewed by GP at 6-8 week check and re-referred as required.

In all cases where babies are discharged home with a murmur please do the following:

- Print GP letter to inform of patient being discharged with abnormal cardiac findings (in case the family contact them prior to their planned outpatient review). Give letter to the parents to hand in when registering their baby at the practice.
- Give safety net advice to the parents regarding signs and symptoms of

cardiac failure.

- Provide parents with the Trust patient information leaflet “Heart murmur” See appendix 2. Explain to the parents that if the baby should become unwell in the interim that they should bring the baby directly to A&E.

S4N - document as suspected abnormality.

24.0 Congenital Abnormality

- Keep the baby with mother/birthing parent (if the condition of the baby allows it). Rejection is very uncommon but there may be grief exacerbated by separation which will increase the risk of perinatal mental health concerns.
- Do not try to hide anything. Fears are usually worse than reality (but not always). Explain carefully and gently what the abnormalities are. Do no prognosticate and explain that you will ask a senior paediatrician to review, to provide a detailed explanation.
- Do not be afraid of stating when you do not know the answers and need help. Find out when that help will attend and inform parents and midwife as well as documenting it. It is always best for both parents to be present when that senior paediatrician attends for review.
- If you are in doubt as to the baby’s sex, say so and explained that it can be sometimes difficult to be sure at birth. Do not guess and do not refer to the baby by gender whatever you may think, unless you are sure. Be cautious in assigning sex to a baby with severe hypospadias (contact the consultant urgently).
- Referral to the genetics service may be appropriate at St George’s Hospital.

24.1 Down’s Syndrome

Suspected Down’s Syndrome

Are any of the following features present?

1. Low muscle tone.
2. Eyes slanting upward (up slanting palpebral fissure).
3. Small skin folds (epicanthic folds) in the inner corner of the eyes.
4. Flat nasal bridge.
5. Relatively small nose and ears.
6. Large tongue in relation to the size of the mouth.
7. Flat occiput (brachycephally).
8. Single horizontal crease across the palm of the hand (simian crease).
9. Wide gap between the large and second toe.

If yes the Consultant Paediatrician (not the SHO or Registrar) should be contacted ASAP to discuss clinical suspicions with the parents.

Check maternal/birthing parent notes to see if there is a first trimester screening result or reason not done. Review anomaly scan.

If Down's syndrome was not suspected antentally, inform NIPE lead midwife in order to inform screening team and review USS images by consultant fetal medicine team.

There are certain important principles, which apply to this and other situations where unexpected news must be broken.

- Both parents should be seen together at the outset, and unsupported mothers should be asked if they would like a supportive relative or friend with them. A consultant should see them at an appropriate time.
- The discussion should be conducted somewhere private, never on an open ward. The midwife looking after the mother should be present.
- Always refer to the baby by its given name.
- Where no mention of Down syndrome has been made it is important not to state the probable diagnosis but to examine the child, indicating features and explain that although each can be found individually in the general population, the pattern is suggestive of Down syndrome. Absolute diagnosis must wait karyotyping and a chromosome result.
- Send bloods to Guy's and St Thomas urgent PCR and next day result, (collect by 10:30 am for **Positive PCR** unless the weekend). Liaise with the antenatal screening team and the sister in charge on SCBU.

Down's Syndrome Association: http://www.downs-syndrome.org.uk/ 0845 230 0372 0333 1212300. Email: info@downs-syndrome.org.uk

Contact a Family: http://www.cafamily.org.uk / 0808 808 3555

25.0 Audit and monitoring

The NIPE programme has a defined set of standards which must be met. This is overseen by the Screening quality assurance service (SQAS).

There are 2 KPI's for NIPE screening. NP1 and NP3. This is reported on the S4N system which supports complete cohort identification, failsafe and reporting.

Data reporting is collected directly from S4N and NIPE lead provides mitigations for each baby. This is produced on a quarterly basis.

Failsafe progresses are in place to ensure the whole screening pathway is followed.

Any incidents are reported directly to the SQAS regional team and PHE screening team via a SIAF.

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Appendix 1: Pulse Oximetry screening

Pulse Oximetry Universal Screen

Mother Name / No. Address	BABY Hospital No: Name

DATE OF BIRTH: ..... TIME of BIRTH: .....

MODE: *SVD – ASSISTED – BREECH – C Section* WEIGHT: .....

SATURATION TO BE CHECKED IN RIGHT ARM & A LEG

AFTER 4 HOURS OLD AND BEFORE DISCHARGE

CONSENT FROM PARENTS: Yes / Refused – (inform Paediatrician)

DATE: .....TIME: .....SATURATION: **RIGHT** ARM: ..... LEG: .....

IF **BOTH** SATURATION ≥ **95% AND DIFFERENCE 2% OR LESS:** NEGATIVE/END

NAME HEALTH PROFESSIONAL:

IF SATURATION 90-94% OR DIFFERENCE MORE THAN 2%: REPEAT IN 1 HOUR

TIME: ..... SATURATION: **RIGHT** ARM: ..... LEG: .....

OBS: COLOUR ..... Heart Rate: ..... Resp Rate: ..... Temp: .....

IF SATURATION MORE THAN 95% + DIFFERENCE LESS THAN 2%: END

IF SATURATION STILL 90-94% OR DIFFERENCE MORE THAN 2%: INFORM PAEDS

NAME HEALTH PROFESSIONAL :

TIME PAEDIATRICAN INFORMED: .....COMMENTS:

IF SATURATION < 90% ANY TIME - CALL PAEDIATRICIAN IMMEDIATELY

PLEASE CLEAN THE PROBE AFTER EACH PATIENT

PAEDIATRIC REVIEW if PULSE OXIMETRY POSITIVE

NAME of Paediatrician: ..... Reg / Cons

Date: ..... Time: .....

1: Stable: Observe in post natal ward.

2: Concerned: Observe in Neonatal unit.

3: Needs Investigations and Treatment.

Differential diagnosis:

A:

B:

C:

Investigations:

CXR:

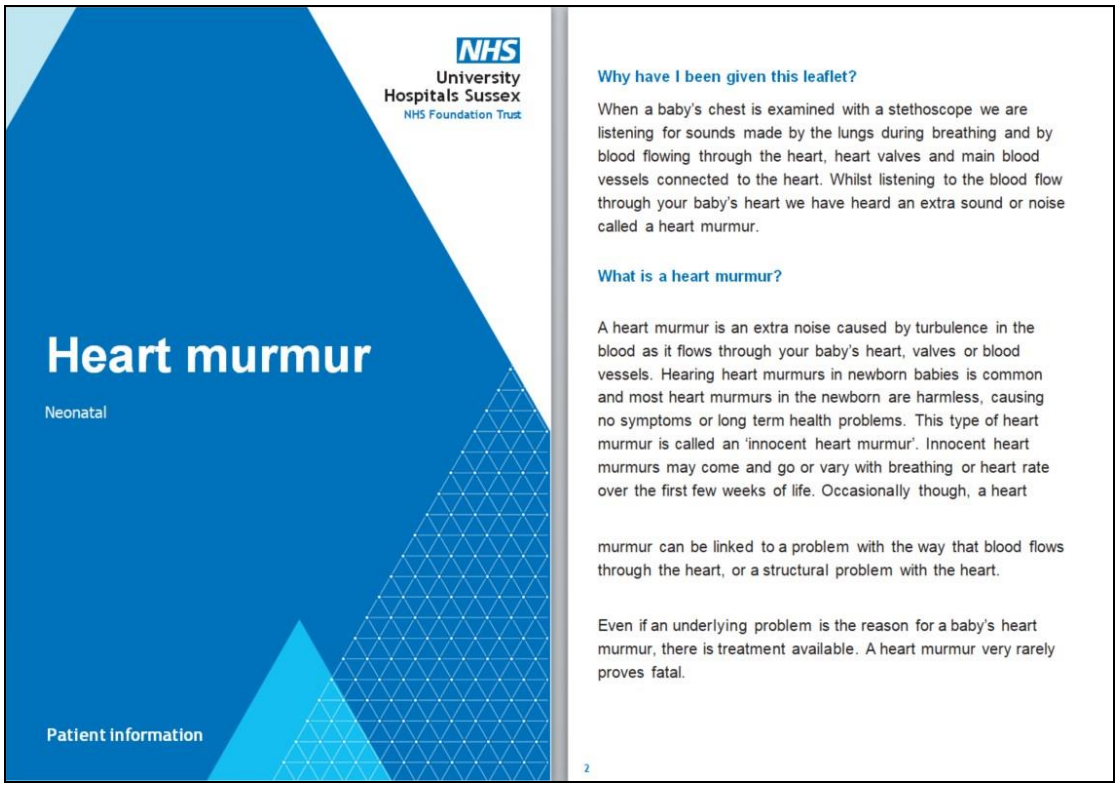
FBC:

ECG:

Discussion with Consultant: Yes / No

h:\pulse oximetry universal screen template 150120.docx

Appendix 2: Heart Murmur Patient Information Leaflet



NHS
University Hospitals Sussex
NHS Foundation Trust

Heart murmur

Neonatal

Patient information

Why have I been given this leaflet?

When a baby's chest is examined with a stethoscope we are listening for sounds made by the lungs during breathing and by blood flowing through the heart, heart valves and main blood vessels connected to the heart. Whilst listening to the blood flow through your baby's heart we have heard an extra sound or noise called a heart murmur.

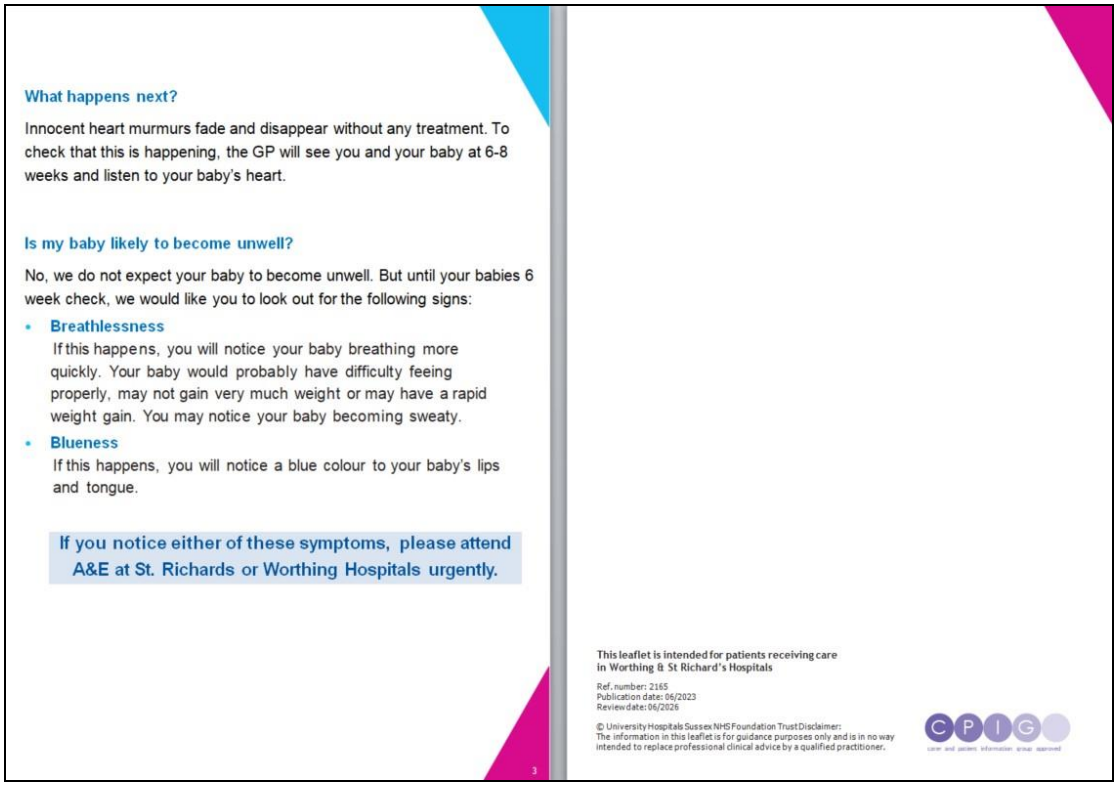
What is a heart murmur?

A heart murmur is an extra noise caused by turbulence in the blood as it flows through your baby's heart, valves or blood vessels. Hearing heart murmurs in newborn babies is common and most heart murmurs in the newborn are harmless, causing no symptoms or long term health problems. This type of heart murmur is called an 'innocent heart murmur'. Innocent heart murmurs may come and go or vary with breathing or heart rate over the first few weeks of life. Occasionally though, a heart

murmur can be linked to a problem with the way that blood flows through the heart, or a structural problem with the heart.

Even if an underlying problem is the reason for a baby's heart murmur, there is treatment available. A heart murmur very rarely proves fatal.

2



What happens next?

Innocent heart murmurs fade and disappear without any treatment. To check that this is happening, the GP will see you and your baby at 6-8 weeks and listen to your baby's heart.

Is my baby likely to become unwell?

No, we do not expect your baby to become unwell. But until your babies 6 week check, we would like you to look out for the following signs:

- **Breathlessness**
  If this happens, you will notice your baby breathing more quickly. Your baby would probably have difficulty feeing properly, may not gain very much weight or may have a rapid weight gain. You may notice your baby becoming sweaty.
- **Blueness**
  If this happens, you will notice a blue colour to your baby's lips and tongue.

If you notice either of these symptoms, please attend A&E at St. Richards or Worthing Hospitals urgently.

3

This leaflet is intended for patients receiving care in Worthing & St Richard's Hospitals

Ref. number: 2165
Publication date: 06/2023
Review date: 06/2026

CPIG
care and patient information group approved