Public Health England

NHS

NHS Newborn and Infant Physical Examination Screening Programme Handbook 2016 to 2017

Public Health England leads the NHS Screening Programmes

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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About PHE screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

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Contents

The NHS Newborn and Infant Physical Examination (NIPE) Screening Programme

The programme handbook

The purpose of this document is to inform and support best clinical practice and should be used in conjunction with the following NIPE publications:

- programme standards 2016-17 https://www.gov.uk/government/publications/newborn-and-infant-physical-examination-screening-standards
- service specification 2016-17 (No21) https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/02/serv-spec-21.pdf

The guidance in this handbook relates to the screening elements undertaken as part of an overall holistic head-to-toe examination of the baby and any reference to the newborn and infant physical examination (NIPE) in this document relates to the four screening elements only.

Although included in the earlier version of the NIPE standards and competencies (2008), the competencies and 6-8 week standards have been removed from the 2016/17 version as there is no way of systematically measuring these. Good practice guidance and recommended referral timescales are included in this document to support a high quality local 6-8 week physical examination screening service until there is a robust method of measuring and reporting these standards.

General principles of screening

Screening is a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition. Further information regarding the general principles of screening can be found online.

The policy

The UK National Screening Committee (UK NSC) policy for NIPE is that all eligible babies will be offered the NIPE screen. The screen should be offered within 72 hours of birth and then again at 6-8 weeks of age.

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; to further identify those abnormalities that may become detectable by 6-8 weeks of age, at the second physical examination, and thereby reduce morbidity and mortality. These ages are recommended based on best practice and current evidence and should facilitate a prompt referral for early clinical assessment. .

The 4 screening elements of the NHS NIPE Programme are:

1. 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.
2. Heart: approximately 4-10 in 1000 babies have a heart problem.
3. Hips: approximately 1 or 2 in 1,000 babies have hip problems that require treatment.
4. Testes: approximately 1 in 100 baby boys have problems with their testes that require treatment.

Please note that the above incidence rates are derived from best estimates of national and regional historical data. These will be revised in due course when more robust data becomes available.

Information for parents

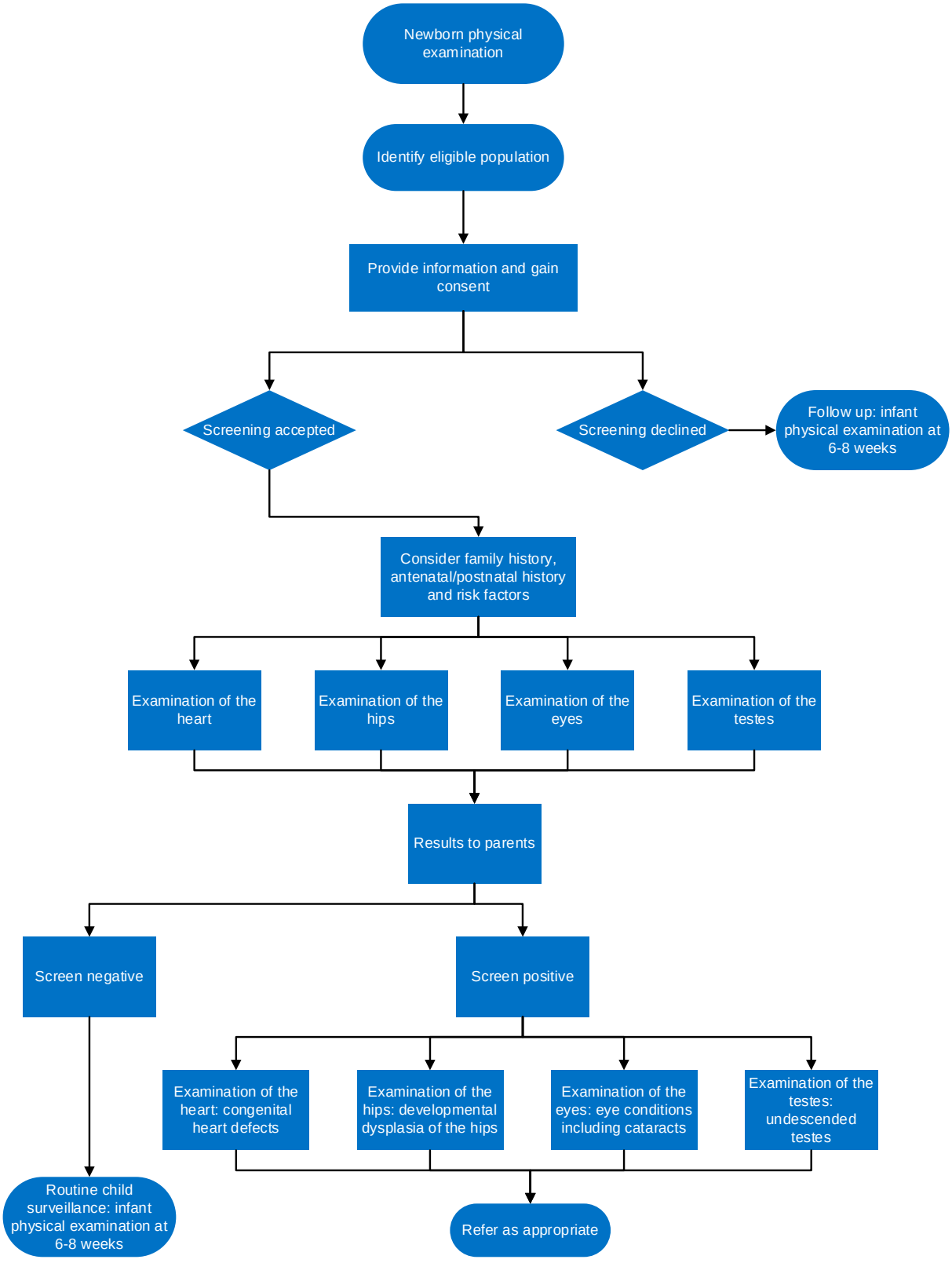
Information about the newborn and 6-8 week infant physical examinations should be given to the parents during the antenatal period and again before the newborn examination being offered. Use of the NHS Screening Programmes booklet 'Screening Tests for you and your Baby' is recommended
Parents should 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 health care professional at any time.

Record keeping

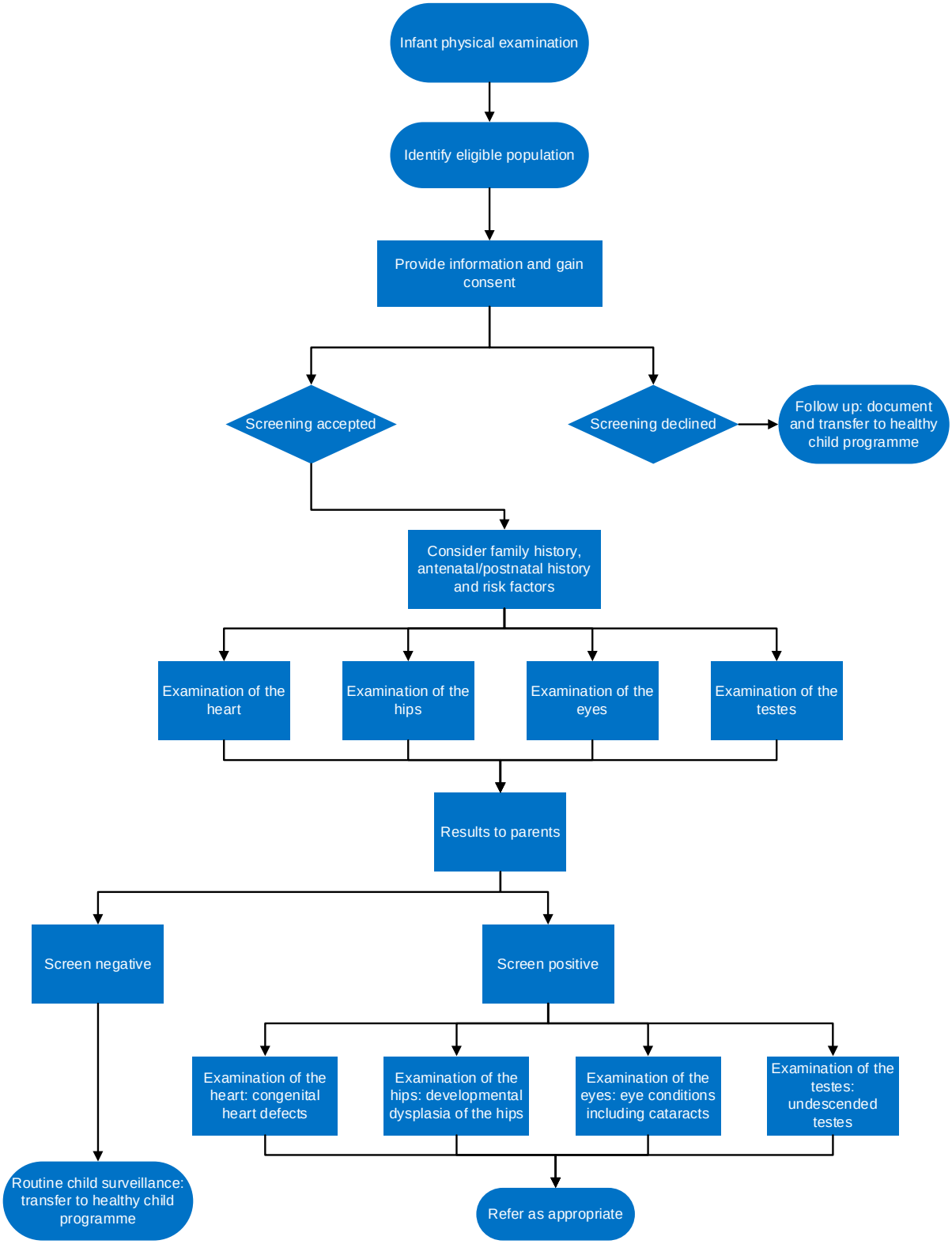
Verbal consent should be obtained.
After the examination a record of each of the screening examinations and outcomes should be made as appropriate in the following:

- baby's clinical notes
- local clinical data collection system and/or NIPE Screening Management and reporting tool SMART system (newborn examination/ GP IT system)
- Personal Child Health Record (PCHR - Red Book)

NIPE Screening Programme: Newborn Pathway



NIPE Screening Programme: Infant Pathway



The screening tests

Newborn examination

This examination should be undertaken by 72 hours of age. It is recommended that the newborn examination is undertaken before transfer home (unless a home delivery). This maximises the opportunity for the examination to be completed within 72 hours. However, local arrangements should be in place to meet national timescales when babies transfer home before undertaking the NIPE examination.

Eligibility

All newborn babies will be eligible for the NIPE examination at some point, unless the baby dies. Babies who are identified as not having a newborn physical examination should be followed up locally and the examination undertaken as soon as possible.

Key Performance Indicator (KPI) data should be counted where the provider is responsible for the baby at the time of newborn screening, including babies who have transferred out after they were screened and received a result. Babies who are transferred before screening are the responsibility of the receiving provider and should be included in their KPI coverage data. Therefore KPI data should be derived on this basis

The responsibility for identifying eligible babies remains with the birth unit until responsibility is formally passed to another maternity service or primary care.

Results

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 infant examination will be undertaken at 6-8 weeks of age as some conditions can develop or become apparent later.

Key considerations

1. It is considered safer to undertake the NIPE examination early with the potential for more false positives rather than risk missing screening altogether.
2. In the case of early transfer home, babies should still be offered a NIPE examination. If the examination is not undertaken before transfer there must be a robust local follow up pathway to ensure that it is undertaken within 72 hours of age. This could be by return to a designated NIPE clinic or arrangements being

made for the examination to be undertaken in the community/primary care setting.

3. It is the responsibility of the maternity service providing care to ensure provision is made for the examination for babies born at home
4. Screening may be delayed if a baby is too premature or too unwell to have the examination (that is, it is not the clinical priority at that given point in time).
5. Each element of the NIPE screening should be completed as and when the baby's condition allows..
6. If any particular one (or more) of the four screening elements are not undertaken for any reason, the NIPE examination's remaining screening elements should still be undertaken and the outstanding elements of the examination completed as soon as feasible. When reporting on key performance indicators, these babies should be accounted for and the reason explained in the commentary as mitigations against any performance thresholds.

Babies in neonatal units

- babies in neonatal units should be assessed and if well enough the NIPE screen should be undertaken by 72 hours of age
- it is acknowledged that some babies in neonatal units may be too ill at the time the examination is due and the NIPE screen is not appropriate
- if possible all screening elements should be undertaken but if not, the NIPE screen should be completed as soon as practicable
- some elements of the NIPE screen may need to be repeated in very preterm babies (for example, eyes) but referrals should still be made as per national standards regarding screen positive cases
- referral timescales should not be age adjusted for preterm babies
- babies less than 32 weeks gestational age (up to 31 weeks and 6 days) or less than 1500gms birthweight should be screened for retinopathy of prematurity (ROP)

6-8 week infant examination

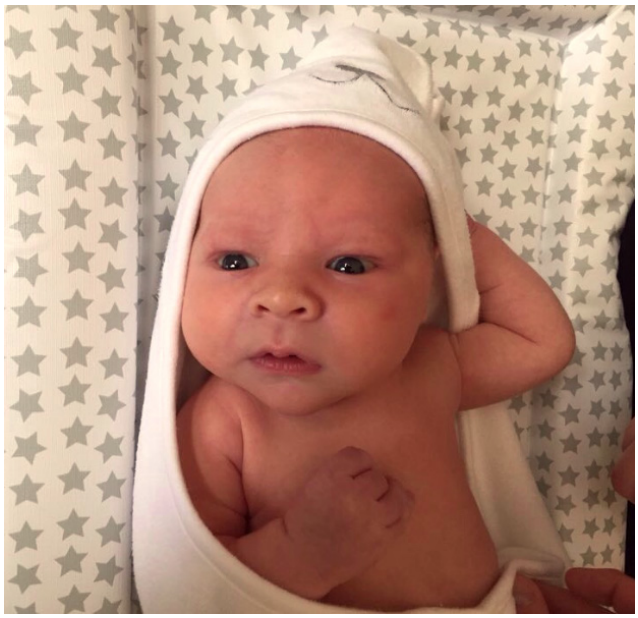
Information about the 6-8 week infant physical examination should be given to the mother during the post natal period and again before the infant examination being offered.

This examination is undertaken in the community setting (usually by the General Practitioner) between 6 and 8 weeks of age.

There should be timely checks to ensure:

1. All eligible babies are offered screening (including those who move into the area).

2. The examination is undertaken within the given timescale (between 6 and 8 weeks of age).
3. Any required referrals are made within the timescales as outlined below.
4. Follow-up of referrals is undertaken to ensure appropriate interventions have taken place as required. Therefore, if screen positive for any element of the newborn examination, the practitioner undertaking the 6-8 week examination should check the progress along the care pathway to ensure required actions are undertaken.



Examination of the eyes

Please note that the guidance below relates to both newborn and 6-8 week infant examination unless otherwise stated.

Incidence

Approximately 2 or 3 in 10,000 babies have problems with their eyes that require treatment

Associated risk factors

NHS NIPE Programme risk factor:

- family history of congenital or hereditary cataracts (1st degree relative)

Additional risk factors:

- prematurity
- children with trisomy 21 have a high risk of ophthalmological disorders and should have continued surveillance
- maternal exposure to viruses during pregnancy, including rubella and cytomegalovirus

Although the primary purpose of screening is to identify congenital cataracts, local pathways should be followed for any additional risk factors or incidental findings, including the presence of aniridia, colobomata and retinoblastoma.

Undertaking the examination

Before the examination practitioners should establish relevant history:

- mother's recent obstetric history
- baby's family history (childhood eye disorders, particularly congenital cataract)

Bilateral examination

- eye opening – presence of eyes
- position and symmetry

- size and colour
- for presence of red reflex

6-8 Week infant examination

In addition to the above, observe eye movement and fix and follow response.

Screen negative - newborn and 6-8 week infant examination

If no abnormality detected, transfer to Healthy Child Programme.

Parents should be advised to contact their midwife, GP or health visitor if they have concerns about their baby's eyes for example, if:

- their baby does not open their eyes and focus or doesn't follow small movements
- the baby's eyes look unusual
- there is a lack of 'red eye' in one eye in a photograph of their baby

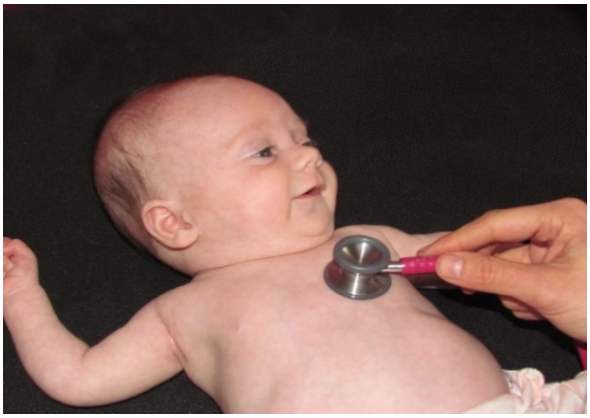
Babies with neurological/neurodevelopmental conditions or sensorineural hearing impairment and babies with chromosomal abnormalities, such as Trisomy 21 will require regular monitoring, even if the examination shows no evidence of an ocular problem.

Screen positive following newborn examination

Babies with an abnormality of the eye identified at the newborn examination should attend an assessment appointment by **2 weeks of age**. This assessment should be with a consultant ophthalmologist/paediatric ophthalmology service.

Screen positive following 6-8 week infant examination

- refer to consultant ophthalmologist/paediatric ophthalmology service for expert opinion
- to be seen by 11 weeks of age



Examination of the heart

Incidence

The overall incidence of congenital heart defects (CHD) is 4-10 per 1000 live births ranging from non-significant to major and critical lesions. Critical or major congenital cardiac malformations are found in approximately 2-3 per 1,000 live births and are a leading cause of morbidity and mortality in the neonatal period and beyond.

Congenital heart abnormalities can be categorised as follows:

- **critical CHD**: 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 require invasive intervention in the first year of life

A proportion of 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, that is, minimum FASP standard target detection rate for specific cardiac abnormality is≥ 50%.

Associated risk factors

The NHS NIPE Programme risk factors are:

- family history of congenital heart disease (1st degree relative)
- fetal trisomy 21 or other trisomy diagnosed (please note that these babies have high risk of cardiac defects and require continued surveillance)
- cardiac abnormality suspected from the antenatal scan

Other risk factors associated with CHD are:

- maternal exposure to viruses, for example, rubella during the first trimester of pregnancy,
- maternal conditions, such as diabetes (Type 1), epilepsy, systemic lupus erythematosis (SLE)
- drug related teratogens during pregnancy, for example, antiepileptic and psychotrophic drugs

Undertaking the examination

Before the examination practitioners should establish relevant information regarding:

- mother's medical and recent obstetric history including any medication
- baby's family history
- baby's immediate post natal health

Parents should be asked about the general wellbeing of the baby

- if the baby ever gets breathless or changes colour at rest or with feeding
- is the baby's feeding behaviours and energy levels normal
- is the baby ever too tired to feed, quiet, lethargic, or has poor muscle tone

Observation

- general tone
- central and peripheral colour
- size and shape of chest
- respiratory rate
- symmetry of chest movement, use of diaphragm and abdominal muscles
- signs of respiratory distress (recession / grunting)

Palpation

- femoral and brachial pulses for strength rhythm and volume.
- assess perfusion through capillary fill time
- position of cardiac apex (to exclude dextrocardia)
- palpation of liver to exclude hepatomegaly – may be present in congestive heart failure
- +/- thrill

Auscultation

- presence of a murmur – systolic / diastolic – loudness
- quality of heart sounds at the following 5 sites:
  - 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)

Screen negative

If no abnormality suspected, transfer to Healthy Child Programme.

Parents should be advised to contact their healthcare professional or emergency services if they have any concerns about their baby.

Screen positive

The following signs and symptoms can be suggestive of critical or major congenital heart abnormality:

- 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

The examining practitioner should discuss findings with a senior paediatrician or a paediatrician with expertise in cardiology and refer as appropriate. Urgency will depend on the assessment of the clinical condition of the baby.

Many babies will have cardiac murmurs in the first 24 hours of life in the absence of a cardiac defect (linked to physiological changes at birth).
Conversely cardiac murmurs may be absent in babies with a significant cardiac defect.

Cardiac standards

These will be developed at a later date and will include the findings and outcomes of the national Newborn Pulse Oximetry Pilot Study.

Examination of the hips

Please note that the guidance below relates to both newborn and 6-8 week infant examination unless otherwise stated.

Incidence

Approximately 1 or 2 in 1,000 babies have hip problems that require treatment.

Undetected developmental dysplasia of the hips (DDH) or delayed treatment may result in the need for complex surgery and/or long term complications such as:

- impaired mobility and pain
- osteoarthritis of the hip and back

Early diagnosis and intervention will improve health outcomes and reduce the need for surgical intervention.

Associated risk factors

The NHS NIPE Programme risk factors are:

- first degree family history of hip problems in early life, that is, 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 delivery or mode of delivery, or
- breech presentation at delivery
- multiple birth: if any of the babies is breech presentation, all babies in this pregnancy should have an ultrasound examination within 6 weeks of age. 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.

Undertaking the examination

Before the examination practitioners should establish relevant history:

- mother's recent obstetric history
- baby's family history
- additional relevant risk factors

The examination should be undertaken in a warm environment and on a firm flat surface with the baby undressed and settled.

Observation

- symmetry of leg length
- level of knees when hips and knees are both flexed
- symmetry of skin folds in the buttocks and posterior thighs when baby is in ventral suspension
- if legs can be fully abducted

Manipulation

Undertake both the Ortolani and Barlow manoeuvres on each hip separately.

- Ortolani manoeuvre is used to screen for a dislocated hip
- Barlow manoeuvre is used to screen for dislocatable hip

Screen negative

If no abnormality detected, transfer to Healthy Child Programme.

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 for:

- a difference in the deep skin creases of the thighs between the two legs
- 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

Adapted from the Personal Child Health Record (PCHR-Red Book).

Clicky hips

Babies who have no predisposing risk factors and are found to have 'clicky hips' on physical examination should be managed and referred as per local arrangement and should not be included in NIPE Screening Programme key performance data (KPIs)

Screen positive

- difference in leg length
- knees at different levels when hips and knees are bilaterally flexed
- difficulty in abducting the hip to 90 degrees
- palpable ‘clunk’ when undertaking either the Ortolani or Barlow manoeuvres

Hip referral

Screen positive following newborn examination

Babies who are found to have dislocated or dislocatable hips, positive Ortolani or Barlow manoeuvre on newborn physical examination (screen positive) should be referred and undergo hip ultrasound within **two weeks of age**.

Screen negative examination with risk factors

Babies who have risk factors but a normal newborn physical examination should be referred and undergo hip ultrasound within **six weeks of age**.

Screen positive following 6-8 week infant examination

- refer directly to orthopaedic surgeon for urgent expert opinion.
- to be seen by 10 weeks of age

Examination of the testes

Incidence

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

Bilateral undescended testes in the newborn may be associated with ambiguous genitalia or an underlying endocrine disorder such as congenital adrenal hyperplasia.

Early diagnosis and intervention improves fertility, reduces the risk of torsion and may aid earlier identification of testicular cancer.

Associated risk factors

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 delivery

Undertaking the examination

Before the examination practitioners should review mother's recent obstetric history and baby's family history.

Observation

- scrotum for symmetry, size and colour

Palpation

- scrotal sac to determine location of testes bilaterally
- if testes not located in the scrotal sac, palpation of the inguinal canal should be undertaken

Screen negative

If no abnormality detected, transfer to Healthy Child Programme.
Parents should be advised to contact their midwife, GP or health visitor if they have concerns about their baby's testes.

Screen positive

The absence or incorrect position of one or both testes.

Screen positive following newborn examination

Bilateral undescended testes

- to be reviewed by a senior paediatrician within 24 hours of the examination to rule out metabolic and intersex conditions

Unilateral undescended testis

- review at 6-8 week examination

Screen positive following 6-8 week infant examination

Bilateral undescended testes

- to be seen by a senior paediatrician within 2 weeks of the examination

Persistent unilateral undescended testis

- GP to review between 4 and 5 months of age
- refer to surgeon if testis still absent – to be seen no later than 6 months of age

Maintaining competency in undertaking NIPE examinations

All health care professionals have a personal professional responsibility to maintain competency. There is also an organisational responsibility to ensure a safe and competent workforce.

Those who undertake newborn and infant physical examinations are required to work in a framework of professional accountability. Each practitioner is responsible for the maintenance of their own competence to carry out the examination to the highest standard and for the identification of gaps in knowledge and training needs.

In order to provide duty of care, the examinations must be carried out by an appropriately trained health professional:

Newborn examination – a doctor (paediatrician or GP) who is competent to undertake all elements of the newborn examination or a midwife, nurse or health visitor who has successfully undertaken an accredited ‘examination of the newborn’ programme of study.

Infant examination – a doctor (paediatrician or GP) who is competent to undertake all elements of the 6-8 week NIPE examination (this may also be a health visitor with suitable competency).

Key points

The NIPE programme suggests that a local competency process is in place to ensure that examinations are undertaken encompassing best practice. The focus should not be on a minimum number of examinations but on the quality of the examination performed.

1. Consideration may be given by stakeholders and clinicians to implement local mandatory assessment of clinical competencies for all health care professionals who conduct the newborn and 6-8 week physical examination.
2. At local level, consideration should be given to provision of an annual update for those who undertake the NIPE examination. This may include practical and theoretical assessment and annual completion of the NIPE e-Learning Module (registration and a password are required to access this resource) http://cpd.screening.nhs.uk/nipe-elearning

3. Local providers may choose to determine and set minimum numbers of examinations but this is not a Programme requirement.
4. Institutes of Higher Education who provide the Examination of the Newborn Module may recommend the numbers of examinations to be performed as part of the module curriculum.

Babies who have missed NIPE screening

(Newborn and 6-8 week infant examination)

Where babies are found to have missed NIPE screening the following clinical guidance outlines the appropriate screening tests depending on age. If the missed screen is as a result of failure in screening pathway, actions should be taken in line with the NHS Screening Programmes screening incident guidance.

Movers in and out

Babies who move in or out of an area are at higher risk of missing screening and robust methods of identification and follow up should be in place.

Infants up to and including three months of age

1. If the newborn examination has not been performed, it should be undertaken as soon as possible.
2. If the 6-8 week infant examination is overdue, this should be undertaken as soon as possible.
3. If a late NIPE screening was performed at or after 6 weeks of age, it is not necessary to undertake it again.

Children older than three months of age

1. If the 6-8 week infant screening has not been performed it should be undertaken as soon as possible.
2. However examination for developmental dysplasia of the hip (DDH) using the Barlow and Ortolani manoeuvres are no longer accurate at this age.
3. Any asymmetry of leg length or hip abduction should be sought and the child's gait should be observed.

4. In line with advice in the personal child health record (“red book”) parents should be advised to contact their GP or health visitor if they have any concerns regarding their child’s wellbeing.

Undertaking a missed the NIPE examination?

The relevant examination or observation must be undertaken by a suitably qualified practitioner:

Quality Assurance (QA)

Each NHS screening programme has a defined set of standards that providers must meet to ensure that local programmes are safe and effective. Quality assurance (QA) is the process of checking that these standards are met and encouraging continuous improvement and includes:

1. Advising on the development of national quality standards
2. Monitoring how services meet (or fail to meet) standards
3. Providing expert screening advice for incident management
4. Facilitating quality review of services, including peer advice supporting, those involved in commissioning or providing screening services
5. QA covers the entire screening pathway; from identifying who is eligible to be invited to screening, through to referral where required.
6. The aim of QA is to maintain minimum standards and drive continuous improvement in the performance of all aspects of screening to ensure that all women and their babies have access to high quality screening wherever they live.
7. QA is essential in order to minimise harm and maximise benefits of screening.
8. Formal QA visits to local screening programmes provide the forum for a peer review of the whole multidisciplinary screening pathway, and an assessment of the effectiveness of team working within the local screening programme regional QA teams advise providers and commissioners about reducing risks in local screening programmes. They assess the robustness of local arrangements through audit, as part of peer review and in the investigation of any incidents as they occur they act as a conduit for information and dialogue at national, regional and local levels, additionally sharing good practice.
9. Participation in a formal process of QA is the responsibility of each local screening programme.
10. The performance of the local programmes is monitored in a variety of ways such as review of statistics, regional meetings or informal visits, all of which offer a valuable insight into the activity of a local programme.

Key performance indicators (KPIs)

Key performance indicators (KPIs) for the NHS screening programmes were introduced to provide a way of measuring screening programmes performance in specific areas. They contribute to the overall quality assurance of screening programmes but are not, sufficient to fully quality assure or performance manage screening services. KPIs assist local screening services in identify potential or actual problems so remedial actions can be taken and have led to changes in practice and implementation of measures to prevent errors occurring in the screening pathway.

There are currently two KPIs for the NIPE screening programme NP1 and NP2.

Screening coverage data and failsafe

To ensure safe and inclusive local delivery of the NIPE Programme population coverage performance data is required.

eligible babies (denominator) is the total number of babies born (within the reporting period) under the care of the maternity service at the time of the NIPE screening examination
the numerator is the number of these babies in the eligible population who are examined within 72 hours of birth

These data can be reported using NIPE SMART and should be calculated in line with NHS screening programmes guidance.

NIPE key performance indicator for coverage (NP1)

PHE screening publish key performance indicators (KPI) data quarterly. In addition PHE screening shares an extended KPI data set with NHS England.
PHE screening started collecting and publishing NIPE coverage KPI data in 2015/16. Data is currently submitted by maternity units but is patchy (99 returns in Q2) and comprises of returns from:

- maternity services that have implemented NIPE SMART
- maternity services that have not implemented NIPE SMART (33% of returns equating to ~33,000 babies)
- 47 maternity services did not submit Q2 2015/16 data

It is not possible from the above returns to provide robust coverage data for England as the complete cohort cannot be assured particularly for babies that move from one provider to another. Use of the national NIPE SMART IT or with future use of automated

feeds from provider systems will enable complete cohort identification, failsafe and robust reporting.

After extensive discussions changes were made to the NIPE coverage standard (NIPE standard 1) and KPI (NP1). The changes were made to enable population coverage data to be reported at a national level whilst being cognisant that providers and commissioners also require maternity service coverage data to ensure local systems are working. The following reporting processes are designed to meet both needs as an interim solution for 2016/17. It is envisaged that from 2017/18 we will move to reporting and publishing NP1 data derived solely via NIPE SMART.

Report 1

PHE screening will extract and publish coverage data by CCG on a quarterly basis, these data will be derived from NIPE SMART in areas where this is implemented. This report will be published at https://www.gov.uk/government/collections/nhs-screening-programmes-national-data-reporting

Report 2

In addition to report 1 PHE screening will share maternity unit level data with NHS England on a quarterly basis where these are available. These data will be derived from:

1. NIPE SMART (maternity services will have a two week period to validate their data)
2. Maternity services KPI submission (for those services that have not yet implemented NIPE SMART).

This report is for internal use only and will not be published on gov.uk webpages.

Screening safety incidents

Information about managing screening safety incidents is available at:

https://www.gov.uk/government/publications/managing-safety-incidents-in-nhs-screening-programmes

http://cpd.screening.nhs.uk/incident-resource

Summary of standards and guidance (with referral timescales)

Treatment standards: although included in earlier versions of the NIPE standards, they are outside the screening pathway and therefore excluded. The screening programme would refer to treatment standards, clinical guidance and treatment pathways published by other professional bodies.
Cardiac standards: will be developed at a later date and will include the findings and outcomes of the newborn pulse oximetry pilot study currently in progress.

Newborn (72 hour examination) Standards / Guidance			
	Rationale	**Descriptor**	**Performance thresholds**
NIPE Standard 1 Report 1	Identifying population and coverage	Percentage of eligible babies for whom a decision about referral (including a decision that no referral is necessary as a result of the newborn physical clinical examination) for each of the four conditions screened has been made within 72 hours of birth **Report 1** eligible babies (denominator) is the total number of babies born within the reporting period whose mother was registered with a GP practice within the CCG, or (if not registered with any practice) resident within the CCG area, excluding any baby who died before an offer of screening could be made.. **Report 2** eligible babies (denominator) is the total number of babies born (within the reporting period) undergoing the care of the maternity service at the time of the	Acceptable: ≥ 95.0% of babies are tested within 72 hours of birth Achievable: ≥ 99.5% of babies are tested within 72 hours of birth

		NIPE screening examination.	
NIPE Standard 2	Timeliness of intervention (abnormality of the eye)	Percentage of babies with an abnormality of the eye attending an assessment appointment by **2 weeks of age**. This first assessment should be with a consultant ophthalmologist/paediatric ophthalmology service.	Acceptable: ≥95% of babies are seen by 2 weeks of age Achievable: 100% of babies are seen by 2 weeks of age
NIPE Standard 3	Timeliness of intervention (Developmental Dysplasia of Hips-DDH)	Percentage of babies who have a positive screening test on newborn physical examination and undergo assessment by specialist hip ultrasound within **2 weeks of age**	Acceptable: ≥ 95.0% of babies have their hip ultrasound completed by 2 weeks of age Achievable: 100% of babies have their hip ultrasound completed by 2 weeks of age
NIPE Standard 4	Timeliness of intervention (Developmental Dysplasia of Hips-DDH- risk factors)	Percentage of babies who have a negative screening test on newborn physical examination but have identified risk factors and undergo assessment by specialist hip ultrasound within **six weeks of age**	Acceptable: ≥90% by 6 weeks of age Achievable: ≥95% by 6 weeks of age
NIPE Standard 5	Timeliness of intervention (bilateral undescended testes)	Percentage of babies with bilateral undescended testes who attend for assessment by a consultant paediatrician/ associate specialist within **24 hours of the newborn examination**	100% of babies seen by a consultant paediatrician/ associate specialist within 24 hours of the newborn examination. One threshold is set for this standard.
Infant (6-8 week examination) guidance			
Eye examination Screen positive	Timeliness of first appointment for expert consultation	Percentage of babies with abnormal findings on 6-8 week examination who are seen by consultant ophthalmologist/paediatric ophthalmology service) by 11 weeks of age	Acceptable 95% of babies seen by 11 weeks of age Achievable : 100% of babies by 11 weeks of age
Testes examination Screen positive	Timeliness of review by GP for babies with unilateral undescended testes	Percentage of babies with abnormal findings on 6-8 week examination who have GP review by 5 months of age	Acceptable 95% babies reviewed by 5 months of age Achievable 100% babies reviewed by 5 months of age

Testes examination Screen positive	Timeliness of review by Consultant for babies with unilateral undescended testes at GP review	Percentage of babies with abnormal findings on 4-5 month GP review who seen by Consultant by 6 months	Acceptable 95% babies seen by 6 months of age Achievable 100% babies seen by 6 months of age
Hip examination Screen positive	Timeliness of appointment with orthopaedic surgeon	Percentage of babies seen by orthopaedic surgeon by 10 weeks of age	Acceptable 95% babies seen by 10 weeks of age Achievable 100% babies seen by 10 weeks of age

Appendix 1- definitions of denominator and numerator for reports

Denominator	Numerator
Report 1	
eligible babies (denominator) is the total number of babies born within the reporting period whose mother was registered with a GP practice within the CCG, or (if not registered with any practice) resident within the CCG area, excluding any baby who died before an offer of screening could be made.	tested babies (numerator) is the total number of eligible babies for whom a decision about referral (including a decision that no referral is necessary as a result of the newborn physical examination) for each of the four conditions screened was made within an effective timeframe. The effective timeframe for the newborn physical examination is that a conclusive screening result should be available within 72 hours of birth.
Report 2	
eligible babies (denominator) is the total number of babies born (within the reporting period) under the care of the maternity service at the time of the NIPE screening examination NB: All newborn babies will be eligible for the NIPE examination at some point, unless the baby dies The maternity service responsible for the baby at the time of the NIPE screening examination should count the baby in their KPI data. This includes babies who subsequently transfer out after completion of screening. Babies who are transferred out before 72 hours of age and were not screened are the responsibility of the receiving provider and should be included in their KPI coverage data. The number of babies in this category should be small as the NIPE programme recommends babies should be offered a newborn examination before early transfer home. It is acknowledged that some babies transfer out to tertiary centres and they may be too unwell to have screening completed, this is accommodated in the KPI threshold. The responsibility for identifying eligible babies remains with the birth unit until responsibility is formally passed to another maternity service or primary care.	tested babies (numerator) is the total number of babies in the eligible population who are examined within 72 hours of birth

Glossary

The glossary defines terms that are consistent across NHS screening programmes. The scope of each defined term as it applies to a particular screening programme is detailed separately for each screening programme as required .

A broken underline indicates that a term is used according to its definition in this glossary. Where terms from the glossary are used without a broken underline, their common English meaning can be assumed; except where context determines otherwise. Definitions include all forms of the defined term; so 'tested' and 'testing' refer to the definition of 'test'.

Term	Definition
communication	An interchange that the subject is capable of understanding and acting upon. This may be in a variety of formats including verbal and/or written.
coverage	The proportion of those eligible for screening who are tested and receive a result. Coverage is a measure of timely screening to an eligible population. Low coverage might indicate that: i) not all eligible people have been offered screening ii) those offered screening are not accepting the test iii) those accepting the test are not being tested
effective timeframe	The period of time within which a screening test can be delivered such that a result is most likely to be obtained. The effective timeframe for a test is usually specified by the relevant screening programme.
eligible	The population that is entitled to an offer of screening. The criteria for eligibility may be administrative, demographic, clinical, or any combination of these, and may take into account individual circumstances such as time of presentation to the screening service.
population	The overall population for which a screening service is responsible.
maternity service	A co-ordinated network of healthcare professionals contracted to or working under the policies and

Term	Definition
	procedures agreed with a single acute trust, with collective responsibility for the provision of antenatal, intrapartum and postpartum care. A single maternity service may include: obstetric-led maternity units midwifery-led maternity units units responsible for the management of home births newborn intensive care units (NICU) special care baby units (SCBU)
offer	A formal communication made by the screening service, giving a specific subject a realisable opportunity to be tested within an effective timeframe. An offer or invitation will only count as an offer if: i) it reaches the subject ii) the subject is capable of understanding and acting upon it iii) the screening service has the capacity to realise it iv) it offers an opportunity of testing within an effective timeframe In the case of newborn screening programmes, the offer of screening is made to a responsible parent/guardian rather than the subject baby.
refer	The process of securing further diagnosis/specialist assessment following a screen positive test. The date of referral is when the request for further assessment is made to the appropriate specialist.
reporting period	The defined time period over which activities should be included in an aggregate audit or performance return. A reporting period can relate to any specified period but for routine reports is usually quarterly or annual. Most screening processes occur over a period of days or weeks, to allow a scan or sample to be assessed. In such

Term	Definition
	cases, a single point in the process (such as the screening encounter/event) should be used to determine whether the process falls within a particular reporting period.
result	A formal and completed assessment of the risk of a condition being screened for in a subject. A result will be screen positive or screen negative. Insufficient or inconclusive tests indicate a failure to obtain a result, and are **not counted** within coverage. In these cases the subject may be offered a repeat screening test.
screen positive	An indication following a test that the condition being screened is high-risk/suspected in a subject.
screening	Testing people who do not have or have not recognised the signs or symptoms of the condition being tested for, either with the aim of reducing risk of an adverse outcome, or with the aim of giving information about risk.
test	A screening encounter/event leading to the determination of an outcome. Test outcomes can be screen positive, screen negative, insufficient or inconclusive.
uptake	The proportion of those offered screening who are tested and receive a result. Uptake is a measure of the delivery of screening in the population to which it is offered. Low uptake might indicate that: i) those offered screening are not accepting the test ii) those accepting the test are not being tested

Additional terms used in NIPE handbook

Term	Definition
aniridia	The absence of the iris, usually involving both eyes. It can be congenital or caused by a penetrant injury. Isolated **aniridia** is a congenital disorder which is not limited to a defect in iris development, but is a panocular condition with macular and optic nerve hypoplasia, cataract, and corneal changes.
colobomata	A hole in one of the structures of the eye, such as the iris, retina, choroid, or optic disc.
pschotrophic	Relating to or denoting drugs that affect a person's mental state
red reflex	The red reflex is a reflection from the back of the eye that's similar to the red eye effect sometimes seen in flash photography. If no red reflex, or a weak one, is seen, it may mean there's cloudiness in the lens
retinoblastoma	A rare malignant tumour of the retina, affecting young children
seminoma	A germ cell tumour of the testicle or, more rarely, the mediastinum or other extra-gonadal locations. It is a malignant neoplasm and is one of the most treatable and curable cancers, with a survival rate above 95% if discovered in early stages
sensorineural	A type of **hearing loss**, or deafness, in which the root cause lies in the inner ear (cochlea and associated structures), vestibulocochlear nerve (cranial nerve VIII), or central auditory processing centres of the brain
ventral suspension	In ventral suspension the baby is draped over the supporting hand

Resources

Department of Healthwww.gov.uk/government/organisations/department-of-health
Down's Syndrome Medical Interest Group (DSMIG 2007 -Basic medical surveillance- essentials for people with Down's syndrome. Cardiac Disease: congenital and acquired)
Down's Syndrome Medical Interest Group (DSMIG 2012-Basic medical surveillance- essentials for people with Down's syndrome. Ophthalmic problems
NHS Screening Programmes
www.gov.uk/guidance/nhs-population-screening-explained
NHS newborn and infant physical examination (NIPE) screening programme
https://www.gov.uk/topic/population-screening-programmes/newborn-infant-physical-examination
Royal College of Midwives (RCM) www.rcm.org.uk
Royal College of Nursing (RCN) www.rcn.org.uk
Royal College of Paediatrics www.rcpch.ac.uk
Royal College of Radiologists www.rcr.ac.uk
Society and College of Radiographers (SCoR) www.sor.org