



Public Health
England



NHS public health functions agreement 2019-20

Service specification No.21
NHS Newborn and Infant Physical Examination Screening Programme

NHS England and NHS Improvement



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Promoting equality and addressing health inequalities are at the heart of NHS England and NHS Improvement values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

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Service specification No.21

This is a service specification to accompany the 'NHS public health functions agreement 2019-20 (the '2019-20 agreement').

This service specification is to be applied by NHS England in accordance with the 2018-19 agreement. This service specification is not intended to replicate, duplicate or supersede any other legislative provisions that may apply.

Where a specification refers to any other published document or standard, it refers to the document or standard as it existed at the date when the 2019-20 agreement was made between the Secretary of State and NHS England Board, unless otherwise specified. Any changes in other published documents or standards may have effect for the purposes of the 2019-20 agreement in accordance with the procedures described in Chapter 3 of the 2019-20 agreement

Service specifications should be downloaded in order to ensure that commissioners and providers refer to the latest document that is in effect.

The 2019-2020 agreement is available at www.gov.uk (search for 'commissioning public health').

All current service specifications are available at www.england.nhs.uk (search for 'commissioning public health').

Section 1: Purpose of the Screening Programme

1.1 Purpose of the Specification

To ensure a consistent and equitable approach across England a common national service specification must be used to govern the provision and monitoring of Newborn and Infant Physical Examination (NIPE) screening services.

The purpose of the service specification for the NHS Newborn and Infant Physical Examination (NIPE) Screening Programme is to outline the service and quality indicators expected by NHS England and NHS Improvement (NHS E) for the population for whom it is responsible and which meets the policies, recommendations and standards of NHS Screening Programmes

The service specification is not designed to replicate, duplicate or supersede any relevant legislative provisions which may apply, e.g. the Health and Social Care Act 2012 or the work undertaken by the Care Quality Commission. The specification will be reviewed and amended in line with any new guidance as quickly as possible.

This specification should be read in conjunction with:

- [Newborn and Infant Physical Examination Programme Standards](#)
- [Newborn and Infant Physical Examination Programme Handbook](#)
- [NHS screening programmes: national data reporting](#)
- [Managing Safety Incidents in NHS National Screening Programmes](#)
- [National Institute for Health and Clinical Excellence \(NICE\) Clinical guideline 37 Routine and postnatal care of women and their babies 2006](#)

The role of PHE Screening

The national screening team in Public Health England (PHE Screening) provides expert advice and support to the NHS Screening Programme. It does those things which make sense to do once rather than by each individual screening service. This includes:

- developing and monitoring standards
- producing public information leaflets
- quality assurance of local screening services
- enabling accessible training and education
- providers should subscribe to the PHE Screening blog for the latest national news and updates. National documentation and guidance is published on GOV.UK

1.2 Aims

The NHS NIPE Screening Programme aims 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;

- 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

1.3 Objectives

In order to reduce morbidity and mortality, to facilitate early identification and intervention and appropriate neonatal or paediatric referral and management:

- to offer the first physical examination to every newborn baby and complete within 72 hours of age
- for infant examination complete by 6-8 weeks of age

1.4 Expected Health Outcomes

The overall health outcomes are to reduce mortality and morbidity for the screened conditions through the identification of congenital abnormalities and early assessment and intervention for

- congenital cardiac defects
- developmental dysplasia of the hip (DDH)
- congenital cataracts
- undescended testes

1.5 Principles

- all individuals will be treated with courtesy, respect and an understanding of their needs,
- all those participating in the NIPE Screening Programme will have adequate information on the benefits and risks to allow an informed decision to be made before participation
- the target population will have equitable access to screening
- screening will be effectively integrated across a pathway with clear lines of communication between different providers of services in screening centres, primary care and secondary care

1.6 Addressing inequalities and ensuring equal access to screening

Screening is inherently equitable because it is offered to all individuals within the eligible population. One of the objectives of the NHS Screening Programmes is to help reduce health inequalities. The [PHE Screening inequalities strategy](#) has more information.

1.7 Equality

Delivery of the screening programme contributes to reducing health inequalities and should include the following deliverables:

- screening should be delivered in a way which addresses local health inequalities, tailoring and targeting interventions when necessary
- a Health Equity Audit should be undertaken as part of both the commissioning and review of this screening programme, including equality characteristics, socio-economic factors and local vulnerable populations
- the service should be delivered in a culturally sensitive way to meet the needs of local diverse populations
- user involvement should include representation from service users with equality characteristics reflecting the local community including those with protected characteristics
- providers should exercise high levels of diligence when considering excluding people with protected characteristics in their population from the programme and follow equality, health inequality and screening guidance when making such decisions

The provider will demonstrate they have systems in place to address health inequalities and make sure there is equity of access to screening, subsequent diagnostic testing and outcomes. This will include, for example, how the services are designed to make sure that there are no obstacles to access on the grounds of the nine protected characteristics as defined in the Equality Act 2010.

The provider will have procedures in place to identify and support those persons who are considered vulnerable/ hard-to-reach, including but not exclusive to, those who are not registered with a GP; homeless people and rough sleepers, asylum seekers, gypsy traveller groups and sex workers; those in prison; those with mental health problems; those with drug or alcohol harm issues; those with learning disabilities, physical disabilities or communications difficulties. The provider will comply with safeguarding policies and good practice recommendations for such persons.

Providers are expected to meet the public sector Equality Duty which means that public bodies have to consider all individuals when carrying out their day-to-day work – in shaping policy, in delivering services and in relation to their own employees <https://www.gov.uk/equality-act-2010-guidance>

It also requires that public bodies:

- have due regard to the need to eliminate discrimination
- advance equality of opportunity
- foster good relations between different people when carrying out their activities

Personal informed choice

All screening is an individual choice. The UK NSC has published [guidance](#) for screening programmes in the 4 UK countries to follow. Everyone must be given the opportunity to make an informed choice about whether or not to be screened. The decision should be based on an understanding of:

- why they are being offered screening
- what happens during the test
- the benefits and risks of screening
- the potential outcomes (including types of result, further tests and treatment)
- what happens to their screening records

If someone is provided with the above information about the programme and chooses not to have screening, then this is a valid choice and must be respected.

Sharing personal information

Under the [2010 Equality Act](#), screening services are required to anticipate and prevent discrimination against people with learning disabilities.

The duty of care to share information can be as important as the duty to protect patient confidentiality. GPs and other health professionals should have the confidence to share relevant information with screening services in the best interests of their patients. For example, a GP may know that an individual with a learning disability requires accessible information about screening in easy read format or needs a longer than normal appointment slot.

See [NHS England's information sharing policy](#) for more detailed guidance.

PHE Screening's [privacy notice](#) has more information about how screening data is shared within the legal requirements, including those of the General Data Protection Regulation (GDPR).

Reasonable adjustments

Under the [2010 Equality Act](#), screening providers have a legal duty to make [reasonable adjustments](#) to make sure services are accessible to disabled people as well as everybody else.

Screening providers must follow the [Accessible Information Standard](#) by law. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information they can easily read or understand with support, so they can communicate effectively with health and social care services.

As part of the Accessible Information Standard, screening providers must do 5 things.

1. Ask people if they have any information or communication needs, and find out how to meet their needs.
2. Record those needs clearly and in a set way.
3. Highlight or flag the person's file or notes so it is clear that they have information or communication needs and how to meet those needs.
4. Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
5. Take steps to ensure that people receive information which they can access and understand, and receive communication support if they need it.

National accessible information materials

PHE Screening has published national easy read versions of screening information leaflets and screening appointment letter templates.

Local screening providers should use these national materials when inviting individuals for screening who have been identified as needing information in an easy read format.

Large print and audio (MP3) versions of standard information leaflets are also available to download from GOV.UK for people with sight loss.

Local screening providers should send any individual requests for hard copy Braille versions of PHE Screening leaflets to the [screening helpdesk](#).

Section 2: Scope of Screening Programme

2.1 Description of screening programme

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 universal offer of screening facilitates early detection of congenital defects and problems with the eyes, heart, hips and testes. Any abnormalities suspected or detected and any clinical concerns identified will lead to a prompt referral for early clinical assessment by the relevant clinical expert.

In delivering a national screening programme and to ensure national consistency the local provider is expected to fulfil the following, in conjunction with guidance from the national screening programme.

- work to nationally agreed programme standards, recommended guidance and pathways
- be required to implement and support national IT developments
- work with the screening programme to further embed the use of the NIPE national IT system to support accurate data collection and management of local screening pathways and checks and audit processes.
- be required to respond to national actions such as change of IT software, equipment supplier and techniques
- ensure appropriate governance structures are in place
- implement and monitor checks and audit procedures and continuously ensure quality and safety
- work with bordering providers to ensure that handover of results for patients is smooth and robust
- provide data and reports mapped against programme standards, key performance indicators, and quality indicators as required
- take part in quality assurance (QA) processes and implement changes recommended by QA including urgent suspension of services if required
- work with stakeholders in reporting, investigating and resolving screening safety incidents and implement agreed actions
- provide evidence as required that all health care professionals access and complete appropriate training to maintain continuous professional development and competency
- use materials provided by the national screening programme, e.g. information leaflets, e-learning and other training resources to support local service delivery
- participate in evaluation of the screening programme

2.2 Screening pathway

There are two stages of the NIPE screening pathway:

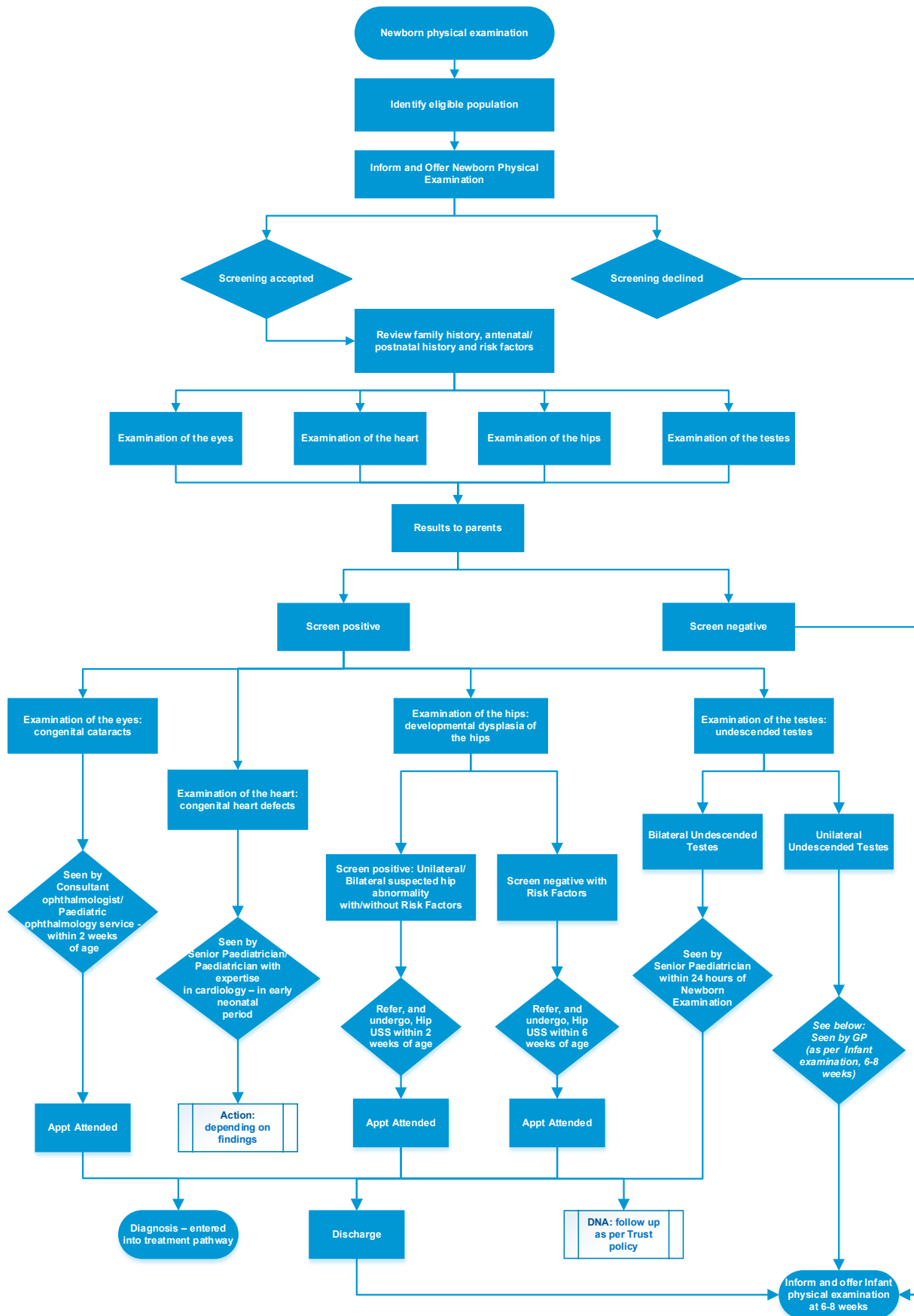
1. **Newborn** examination within 72 hours of birth (or as soon as possible after this time up to 6 weeks of age)
2. **Infant** examination between 6-8 weeks of age

The NIPE newborn screening pathway consists of the following:

- all newborn babies are eligible for the NIPE newborn screening examination unless the baby dies. The optimum time for screening is within 72 hours of age (or as soon as possible after this time)
- eligible cohort - please see the definition as outlined in KPI guidance document (NP1) Key Performance Indicators for NHS screening programmes <https://www.gov.uk/government/publications/nhs-population-screening-reporting-data-definitions> and additional information in [NIPE Programme handbook https://www.gov.uk/government/publications/newborn-and-infant-physical-examination-programme-handbook](https://www.gov.uk/government/publications/newborn-and-infant-physical-examination-programme-handbook)
- all eligible babies, born or resident in England, should be offered a NIPE screen within 72 hours of birth (see section 3.14 for details of exclusion criteria)
- it is recommended that the newborn examination is completed prior to discharge from hospital (unless home birth). This maximises the opportunity for the examination to be completed within the 72 hour target.
- the eligible population of 'new births' or 'new registrations' is identified through a birth notification and automatic transfer to the NIPE national IT system (SMaRT4NIPE) or notification to the screening team by the local Child Health Records Department (CHRD)
- the local maternity services, or in exceptional cases the Child Health Department, is responsible for entering high quality, timely data into the NHS number registration system (Patient Demographic System/ Birth Notification Application) to enable electronic identification of babies eligible for screening within the NIPE national IT system. This should be completed as soon as possible after birth and prior to any newborn screening being performed (i.e. NIPE/ NHSP/NBS)
- where a NHS number has not been generated for any reason the provider should have systems in place to identify these eligible babies and undertake screening without delay
- providers must use the NIPE national IT system to manage the local screening process and link into the national failsafe system. If the provider is not using the NIPE national IT system then the failsafe element of the programme is compromised.
- babies who are identified as not having a newborn physical examination should be followed up locally and the examination completed as soon as possible.

- babies who are receiving neonatal intensive care and are too ill to be screened should be managed as exceptions to the KPI threshold but these babies remain eligible for NIPE newborn examination until 6 weeks of age and the examination should be completed as soon as the baby's condition allows .
- it is expected that all reasonable efforts will be made to ensure that babies have their screen completed before they move area from the one in which they were born
- the responsibility for identifying eligible babies remains with the birth unit until responsibility is formally passed to another maternity service or primary care. This should be managed through utilisation of the NIPE national IT system (transfer function)
- eligible babies who move into the area who have not been screened should be offered a screen by the responsible service provider in their new area of residence. These babies remain eligible for NIPE newborn examination until 6 weeks of age.
- receiving maternity or primary care services are responsible for ensuring that NIPE screening is completed
- local systems should be in place (or be in the process of being developed) to maximise the input of data into the NIPE national IT system to reflect accurate coverage and support robust checks and audit processes (in particular where newborn examination is undertaken in neonatal units and in the primary care setting)
- the offer of screening and subsequent acceptance or decline should be recorded electronically (on the NIPE national IT system) and documented in the personal child health record (PCHR) 'red book'
- it is the responsibility of the local Child Health Records Department to ensure NIPE screening results are recorded on the child health system. For newborn screening this can be achieved by a NIPE national IT system report being sent to CHRD by Trusts or by CHRD being given Trust (s) permission for read only (with reporting capabilities) access to the relevant Trust NIPE national IT system
- there should be a local process (or a plan should be in place for this to be developed) to record all outcomes after screen positive referrals electronically, (on the NIPE national IT system) in the health records and in the personal child health record (PCHR) 'red book'. Outcomes should also be recorded on CHIS and followed up by CHRD staff as an additional failsafe measure
- written information about the NIPE screen is provided to parents using the NHS Screening Programmes booklet 'Screening Tests for You and Your Baby'

A diagram of the NIPE Programme Newborn Screening Pathway is given below



The NIPE infant screening pathway consists of the following:

- all babies resident in England , between 6 and 8 weeks of age should be offered NIPE infant screening examination (see section 3.14 for details of exclusion criteria)
- the offer of screening and subsequent acceptance or decline should be documented in the primary care health records and in the personal child health record (PCHR) 'red book'
- all aspects of the screening pathway should be completed in line with NIPE programme guidance (as outlined in the NIPE handbook)

Management of results (newborn and infant pathways)

- the outcome of the NIPE newborn screening examination should be recorded electronically , in the hospital health records/ case notes, in the personal child health record (PCHR) 'red book' and on the NIPE national IT system
- the outcome of the NIPE infant screening examination should be recorded in the personal child health record (PCHR) 'red book' and the GP IT system
- those babies with screen negative results return to the care pathway of the 'Healthy Child Programme'
- for those babies with screen positive results, appropriate and timely referrals should be made in line with NIPE screening standards and guidance. Referral to internal or to external tertiary services will be arranged locally as is clinically appropriate.
- providers must ensure that there are adequate, appropriate and linked clinical referral pathways in place across services
- local arrangements should be made to ensure robust and regular feedback of results from screening referrals (to ensure that newborn babies with a positive screen are seen by a specialist within the required referral timeframe)
- in line with the NIPE screening pathway, there should be a local systematic process (or a plan should in place for this to be developed) to ensure that each screening referral has a known outcome which is recorded electronically and is auditable (managed on the NIPE national IT system for newborn screening results)
- it is the responsibility of the service that receives the referral to follow up all non-attendance of appointments after referral in line with the local 'did not attend (DNA) policy
- a robust process should be in place to ensure that all NIPE results and outcomes of screening are recorded and communicated to the relevant Child Health Record Department (CHRD)

All providers are expected to review and risk assess local pathways in the light of national NIPE Programme guidance and work with the Quality Assurance teams, and NHS England and NHS Improvement Screening and Immunisation Leads and Teams to develop, implement and maintain appropriate risk reduction measures.

2.3 Roles and accountabilities through the screening pathway

The NIPE Programme is dependent on effective working relationships between stakeholders. Stakeholders include maternity, neonatal and paediatric services and related clinicians, ultrasound services, orthopaedic, cardiology, ophthalmology, urology and surgical services, primary care (General Practitioners, Health Visitors and Child Health Records Departments).

In order to support safe and effective delivery of the local newborn NIPE screening programme all providers should have:

- a designated co-ordinator (and deputy) in place in an oversight role. This may be a designated neonatal nurse, advanced neonatal nurse practitioner or midwife.
- a clinical paediatric or neonatal lead to provide support supervision, clinical responsibility and oversight

NHS England and NHS Improvement will be expected to ensure that the whole pathway is robust. The provider will be expected to fully contribute to ensuring that systems are in place to maintain the quality of the whole screening pathway in their organisation. This will include, but is not limited to:

- provision of robust screening coordination which links with all elements of the screening pathway
- ensuring that responsibilities relating to all elements of the screening pathway across organisations and organisational boundaries are identified
- developing joint audit and monitoring processes
- agreeing joint checks and audit mechanisms where required to ensure safe and timely processes across the whole screening pathway
- contributing to any NHS England and NHS Improvement and public health screening lead initiatives in screening pathway development in line with NHS screening programmes expectations
- providing robust electronic links for screening services across the screening pathway
- links with primary care

2.4 Commissioning Arrangements

NIPE screening services will be commissioned by NHS England and NHS Improvement alongside specialised services where appropriate. Commissioning the screening pathway involves commissioning at different levels which may include NHS England and NHS Improvement, Clinical Commissioning Groups (CCGs), and directly by maternity services.

2.5 Links between screening programme and national programme expertise

Public Health England (PHE), through the national screening programmes, is responsible for leading high-quality, uniform screening, providing accessible information to both the public and health care professionals, and developing and monitoring standards. It is also

responsible for the delivery of national quality assurance and for ensuring training and education for all those providing screening is developed, commissioned and delivered through appropriate partner organisations.

PHE will be responsible for delivery of the essential elements of screening programmes which are best done once at national level.

These include:

- setting clear specifications for screening equipment, IT and data;
- procurement of screening equipment and IT where appropriate; (procurement may be undertaken by NHS England and NHS Improvement but will need advice from PHE screening expertise and related clinical experts)
- evaluation and modification of changes to screening policies

Section 3: Delivery of the NIPE Screening Programme

3.1 Service model summary

- The model of delivery for the NIPE newborn screening examination is predominantly through maternity and neonatal services but can be undertaken in primary care or paediatric services
- The model of delivery for the NIPE infant screening examination is predominantly through primary care services

3.2 Programme co-ordination

The provider will:

- be responsible for ensuring that the part of the programme they deliver is coordinated and interfaces seamlessly with other parts of the programme with which they collaborate, in relation to timeliness and data sharing.
- have in place one or more named individuals responsible for the coordination of the delivery of the programme and provide contribution to planning supported by appropriate administrative support to ensure timely reporting and response to requests for information. Where there is only one named coordinator, the provider will ensure that there are adequate cover arrangements in place to ensure sustainability, safety and consistency of the programme including out of office hours.

3.3 Governance and leadership

The provider will:

- cooperate with and have representation on local oversight arrangements as agreed with NHS England and NHS Improvement commissioners
- identify a trust director who is responsible for the screening programme
- ensure internal clinical oversight and governance by an identified clinical lead and a programme manager. The clinical lead has overall clinical responsibility for the programme across the pathway.
- provide documented evidence of clinical governance that includes:
 - compliance with NHS Trust and NHS England and NHS Improvement information governance/records management
 - user involvement, experience and complaints
 - checks and audit procedures
 - risks and mitigation plans

- ensure that there is regular monitoring and audit of the screening programme, and as part of the organisation's clinical governance arrangements, the board is assured of the quality and integrity of the screening programme
- produce an annual report of screening services, which is signed off by the board
- ensure the programme is delivered by trained workforce that meet national requirements

3.4 Definition, identification and invitation of cohort/eligibility

The eligible population is:

- for the NIPE newborn screening examination – all live babies from birth to 6 weeks of age. Babies are eligible for newborn examination until 6 weeks of age but the examination should be completed as close to 72 hours of age as possible. Please also see the definition as outlined in KPI guidance document (NP1) Key Performance Indicators for NHS screening programmes <https://www.gov.uk/government/publications/nhs-population-screening-reporting-data-definitions> and information in the [NIPE Handbook](#)
- for the NIPE infant screening examination - all live babies at 6-8 weeks of age

The provider must ensure that maternity services complete the birth registration process on the Patient Demographic System/Birth Notification Application without delay. This enables automatic transfer of demographic information into the national NIPE IT system to allow accurate and timely identification of the population eligible for screening. This should be completed as soon as possible after birth and ideally prior to any newborn screening being performed (i.e. NIPE/NHSP/NBS)

Where a NHS number has not been generated for any reason the provider should have systems in place to identify these eligible babies and undertake screening without delay.

Where a NHS number has not been generated and a delay in screening has occurred it should be reported as a screening incident as per PHE Screening 'Managing safety incidents in screening programmes' guidance

See section 3.14 for details of exclusion criteria.

3.5 Location(s) of programme delivery

The provider will ensure appropriate accessible service provision for the population to be screened while assuring that all locations fully comply with the policies, standards and guidance referenced in this service specification and where used have the necessary capability for electronic access to the national NIPE IT system

3.6 Days/Hours of operation

The days and hours of operation are to be determined locally and must ensure sufficient resources are in place to meet screening demand within required timescales without compromising relevant standards and guidelines. However, timeliness is essential and is a key criteria of quality in all parts of the screening pathway.

3.7 Entry into the screening programme

See section 2.2: Care pathway and section 3.4 Definition, identification and invitation of cohort eligibility.

Providers will ensure timely access to all aspects of the screening programme as defined in screening programme guidance.

3.8 Working across interfaces between departments and organisations

The screening programme is dependent on strong working relationships (both formal and informal) between the screening programmes and midwifery services, paediatric services, ultrasound, cardiology, ophthalmology, orthopaedic, urology and surgical services, general practitioners, child health records departments, health visitors and other primary care and specialist professionals.

Accurate and timely communication and handover across these interfaces are essential to reduce the potential for errors and ensure a seamless pathway for service users. It is essential that the responsible care provider is identified at all times including during and after handover of care

The provider will be expected to fully contribute to ensuring that cross organisational systems are in place to maintain the quality and safety of the entire screening pathway. This will include, but is not limited to:

- work to nationally agreed programme policies, standards and guidance
- provide strong clinical leadership and clear lines of accountability
- agree and document roles and responsibilities relating to all elements of the screening pathway across organisations to ensure robust handover arrangements between services
- develop joint audit and monitoring processes
- agree collaboratively on the checks and audit mechanisms required to ensure safe and timely processes across the whole screening pathway
- develop an escalation process for screening safety incidents
- contribute to any NHS England and NHS Improvement initiatives in screening pathway development in line with NHS screening programmes guidance
- facilitate education and training both inside and outside the provider organisation (e.g. Higher Education Institutes) and maintain records of training outcomes

3.9 Information on test / screening programme

The provider will ensure that during pregnancy, after birth, and at other relevant points throughout the screening pathway, parents/ carers are provided with approved information utilising the NHS screening programmes booklet 'Screening Tests for You and Your Baby' as a guide for discussion and 'Screening tests for you and your baby: babies in special care units' as appropriate. Where there are specific communication requirements (e.g. English is not the mother's first language, visual/hearing impairment), appropriate

interpretation services should be used and appropriate information provided. Easy read versions of 'Screening Tests for You and Your Baby' are also available.

3.10 Testing (performance of test by individuals)

Providers will ensure that the NIPE examination is performed by a health professional who is appropriately trained in line with national guidance and provide evidence of training if required.

See section 3.15 Staffing and NIPE Programme Handbook

3.11 Results giving, reporting and recording

Screening results should be explained to parents by appropriately trained staff. Results are given verbally at the time of the examination and documented on the physical examination screening page within the PCHR (Personal Child Health Record - 'Red Book')

The clinician undertaking the examination is responsible for ensuring screening results are recorded. For the newborn examination, this should be undertaken by entering results on the nationally recommended the NIPE national IT system.

All results should also be recorded on the Child Health Information System (CHIS) and infant results also recorded in the GP records. It is the responsibility of the local Child Health Records Department to ensure NIPE screening results are recorded on the child health system. For newborn screening this can be achieved by a NIPE national IT system report being sent to CHRD by Trusts or by CHRD being given Trust (s) permission for read only access to the NIPE national IT system.

Screening providers are responsible for ensuring referral and outcome data from screened babies is recorded electronically (in the NIPE national IT system) to allow screening outcomes to be effectively monitored and managed

Note: there is not currently a national NIPE IT system in place to record screening results of the NIPE 6-8 week examination but there is requirement for GPs undertaking NIPE newborn examination, to communicate the screening results to the maternity service or ideally record the results directly onto the NIPE national IT system

See section 2.2 for further detail

3.12 Transfer of and discharge from care obligations

Babies with screen negative NIPE examinations are discharged from the responsibility of the screening programme.

Babies who require referral are discharged from the screening programme once they have been reviewed for further assessment (in line with national standards and guidance).

The provider will retain care obligations throughout the NIPE care pathway, unless a formal transfer of care is agreed and made to another care provider and this is accounted for within a failsafe system (via use of the NIPE national IT system)

It is the responsibility of both the transferor and receiver to be clear about the status of the newborn examination and for the receiver to undertake actions as required e.g. undertake the newborn physical examination if not done prior to transfer or follow up outcomes after screen positive referral.

3.13 Public information:

PHE Screening uses published best practice processes to develop public information leaflets. It also works with NHS Digital to ensure that information on the [NHS.UK](https://www.nhs.uk) website for the public is accurate.

Providers must:

1. use the public information leaflets from PHE Screening at all stages of the screening pathway
2. involve PHE in the development of any local awareness campaigns
3. not duplicate clinical information on local websites
4. involve PHE if they want to move from providing printed leaflets to online sources of information

Using the leaflets provided by PHE ensures accurate messages about the risks and benefits of screening and any subsequent surveillance or treatment are provided. PHE Screening must be consulted and involved before developing any other supporting materials.

Providers must involve PHE in the development of local publicity campaigns to ensure accurate and consistent messaging, particularly around informed choice, and to access nationally- developed resources. For local awareness campaigns, local contact details must be used so that the national screening helpdesk is not over.

Local provider websites must not duplicate clinical information about screening but should be restricted to contact and logistical information. Links should be provided to the national information on NHS.UK (<http://www.nhs.uk/Livewell/Screening/Pages/screening.aspx> or the relevant programme page) and GOV.UK (<https://www.gov.uk/topic/population-screening-programmes> or the relevant programme page).

To support PHE Screening to carry out regular reviews of the national screening public information leaflets and online content, providers are encouraged to send PHE Screening the results of any local patient surveys which contain feedback on these national resources.

Ordering leaflets

Providers can order [leaflets developed by PHE Screening](#) for free for core screening purposes.

Leaflets are regularly updated so providers should not order more than 3 months' supply, or stockpile leaflets, as they could become out of date and need to be destroyed. Leaflets for non-core activities, such as local health promotion purposes, can be bought from the national print provider.

PHE can only provide one leaflet per person per screening episode. A screening episode is defined as an invitation (with any subsequent reminders) for a particular screening test. People who are referred for further assessment following a screen should get a single copy of the appropriate follow-up leaflet.

Antenatal and newborn screening is treated as a single episode, so women should get a single copy of [Screening Tests For You and Your Baby](#) to last the entire antenatal and newborn period. (include this text for the ANNB programmes)

This means that duplicate copies should not be provided with reminder letters or if people lose or forget their leaflet. They should be signposted to electronic sources of information instead.

3.14 Exclusion criteria

Screening may be delayed if a baby is too premature for examination or they are too unwell to have the examination (i.e. it is not the clinical priority at that given point in time) However please note that the NIPE examination should be performed as soon as the baby's condition allows (this examination should not be viewed as a 'discharge examination' and should be performed as outlined in NIPE standards and handbook). The screening outcome should be recorded on the NIPE national IT system and other relevant local IT systems.

Please note - guidance and eligibility criteria for NIPE newborn screening in pre term babies is currently being reviewed by the NIPE programme

3.15 Education and training

PHE screening makes available a variety of education and training for NHS screening staff. Evidence based, up-to-date e-learning resources, study days and courses can be accessed here <https://www.gov.uk/guidance/nhs-population-screening-education-and-training>

In addition each screening programme will have specific guidance for the initial training and ongoing learning for screeners. This learning should be facilitated, supported and monitored by local screening providers. In line with professional regulations individuals have a responsibility to ensure their practice is up-to-date and evidence based. Local programmes can use the national programme training guidance and resources to support this.

Providers will have in place one or more named individuals (who may be the clinical lead, or designated NIPE lead) responsible for the coordination of the delivery of the programme. The designated person or persons will contribute to planning, with appropriate administrative support, to ensure timely reporting and response to requests for information. Where there is only one named coordinator, the provider will ensure that there are adequate cover arrangements in place to ensure sustainability, safety and consistency of the programme (including out of office hours). The designated person or persons are also responsible for ensuring that there is an on-going educational programme for health professionals involved in NIPE screening.

In order to undertake NIPE examination, all practitioners should be a doctor (neonatologist, paediatrician or GP) who is competent to undertake all elements of the examination or a midwife, nurse or health visitor who has successfully undertaken a university accredited 'examination of the newborn' programme of study.

It is recommended that the NIPE on line e learning resource be completed on an annual basis by all NIPE practitioners

Providers (including those providers undertaking NIPE newborn examination in primary care) must facilitate screener annual updates in line with programme guidance and should ensure:

- training has been completed satisfactorily and recorded and that there is a system in place to assess on-going competency in undertaking the NIPE examination.

- there are adequate numbers of appropriately trained staff in place to deliver the NIPE screening programme.
- appropriate annual CPD in line with programme and requirements, for example a screening study day or completion of national NHS Screening Programme e-learning for all professionals involved in the NIPE screening pathway.

3.16 User involvement

The provider(s) should:

- demonstrate that they regularly seek out the views of service users, families and others in respect of planning, implementing and delivering services
- demonstrate how those views will influence service delivery for the purposes of raising standards
- make results of any user surveys/questionnaires available to NHS England and NHS Improvement on request

3.17 Premises and equipment

The provider will ensure that:

- suitable premises and equipment are provided for the screening programme and will have appropriate policies in place for equipment maintenance and replacement to ensure programme sustainability.
- the NIPE national IT system is used to manage the local screening process and link into the national failsafe system. If the provider is not using the NIPE national IT system then the failsafe element of the programme is compromised.
- ensure that the current versions of software are installed on all and Trust IT systems

3.18 Safety & Safeguarding

The provider should refer to and comply with the safety and safeguarding requirements as set out in the NHS Standard Contract. As an example, please see the 2015-16 NHS [Standard Contract](#).

Section 4: National Standards, Risks and Quality Assurance

The provider will:

- meet the acceptable national programme standards and work towards attaining and maintaining the achievable standards
- adhere to specific professional standards and guidance

Newborn and Infant Physical Examination Programme newborn screening standards are available at <https://www.gov.uk/government/publications/newborn-and-infant-physical-examination-screening-standards> Providers will meet the acceptable and work towards the achievable programme standards.

the NIPE programme handbook outlines clinical guidance in relation to both newborn and 6-8 week examination and is available at <https://www.gov.uk/government/publications/newborn-and-infant-physical-examination-programme-handbook>

The provider will:

- maintain a register of risks, working with NHS England and NHS Improvement and quality assurance teams within Public Health England to identify key areas of risk in the screening pathway, and make sure these points are reviewed in contracting and peer review process
- participate fully in national quality assurance (QA) processes which includes:
 - submitting agreed minimum data sets and reports from external quality assurance schemes
 - undertaking ad-hoc audits and reviews as requested
 - completing self-assessment questionnaires / tools and associated evidence
 - responding to SQAS recommendations within agreed timescales providing specified evidence
 - producing with agreement of commissioners of the service an action plan to address areas for improvement that are identified in recommendations
- operate and evidence
 - check points that track individuals through the screening pathway
 - identify, as early as possible, individuals that may have missed screening, where screening results are incomplete or where referral has not happened
 - have process in place to mitigate against weakness in the pathway
 - implement and fully utilise the NIPE national IT system
- have arrangements in place to refer individuals to appropriate treatment services in a timely manner and these should meet national screening standards
- demonstrate that there are audited procedures, policies and protocols in place to ensure the screening programme consistently meets programme requirements

- comply with guidance on managing safety incidents in national screening programmes and NHS England and NHS Improvement serious incident framework
- make sure business continuity plans are in place where required
- ensure sub-contracts and/or service level agreements with other providers meet national standards and guidance

Service improvement:

The provider will develop and agree with commissioners a CSIP (continual service improvement plan) in cases where national recommendations and/or screening standards are not fully met. The CSIP will include the following:

- action plans specifying changes and improvements that will be made during the contracting period
- defined timescales for actions
- roles and responsibilities for actions
- performance issues highlighted by the commissioners
- concerns raised by service users

New technologies:

New technologies should not be used for screening unless approved by the UK National Screening Committee.

Section 5: Data and Intelligence

The collection, analysis and comparison of good quality data are critical for the all NHS screening programmes in England.

PHE Screening aims to develop a consistent approach to data collection and reporting across all screening programmes and is committed to making sure that stakeholders have access to:

- reliable and timely information about the quality of the screening programme
- data at local, regional and national level
- quality measures across the screening pathway without gaps or duplications

Performance thresholds are selected to align with existing screening standards and service objectives; 1 or 2 thresholds are specified.

The acceptable threshold is the lowest level of performance which screening services are expected to attain to assure patient safety and service effectiveness. All screening services should exceed the acceptable threshold and agree service improvement plans to meet the achievable threshold. Screening services not meeting the acceptable threshold are expected to put in place recovery plans to deliver rapid and sustained improvement.

The achievable threshold represents the level at which the screening service is likely to be running optimally. All screening services should aspire to attain and maintain performance at or above this level.

5.1 Key performance indicators (KPIs) and screening standards

The provider should adhere to the requirements as specified on following web pages:

KPIs: “Reporting data definitions” at <https://www.gov.uk/topic/population-screening-programmes/population-screening-data-key-performance-indicators>

Screening standards: <https://www.gov.uk/government/collections/nhs-population-screening-programme-standards>

Please note that indicator definitions are updated regularly and you should always obtain the most recent version available.

5.2 Data collection and monitoring

Providers should ensure:

- appropriate systems are in place to support programme delivery including audit and monitoring functions
- timely and accurate completion of data for all stages of the care pathway. This should be through use of the nationally recommended NIPE national IT system. Providers must use the NIPE national IT system to manage the local screening process and link into the national failsafe system. If the provider is not using the NIPE national IT system then the failsafe element of the programme is compromised.
- continuous monitoring and collection of data regarding delivery of the service

- compliance with the timely data requirements of the National Screening programmes and Quality Assurance teams.
- information and audit data recorded on the NIPE national IT system is available to the National Screening programme and the provider as part of the IT system functions.
- local systems should be in place to maximise the input of data into the NIPE national IT system to reflect accurate coverage and support robust checks and audit processes (in particular where newborn examination is completed in neonatal units and in the primary care setting)

The National Screening programme will produce regular performance reports for NHS England and NHS Improvement and providers of the screening programme

For quality and monitoring congenital anomaly information should be shared with the National Congenital Anomaly and Rare Disease Registration Service

5.3 Public Health Outcomes Framework (PHOF)

PHE Screening contributes to “PHOF indicator 2.20 – National Screening Programmes”. Each screening programme reports on one or more sub-indicators.

NIPE screening contributes to PHOF with [Newborn and infant physical examination screening – coverage](#)

Key deliverable: The acceptable level should be achieved as a minimum by all services

Acceptable ≥ 95.0%

Achievable ≥ 99.5%