# Newborn Blood Spot (NBS) Screening Programme: checks and audits to improve quality and reduce risks

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| WhatThis is what we recommend you do | WhyThese are the reasons why we are recommending this | HowThis is how you might do this | WhenThis is how often we recommend you undertake the action/check | Additional checks and audits |
| **1. Identify the eligible population (new births):** Have systems in place to identify the **new birth** population that you have responsibility for, including babies on the neonatal unit and paediatric wardsMaternity units must generate an accurate NHS number for all new births prior to screening, to populate child health information service (CHIS) systems and the Newborn Blood Spot Failsafe Solution (NBSFS) | To make sure the eligible population is offered screening in the correct timeframe. Screening on day 5 is vital for early diagnosis and prompt treatment  We have evidence from key performance indicators (KPIs) and screening safety incidents of:* babies who were not offered screening
* screening not completed
* screening delayed
* babies with serious conditions entering late into care
* babies who are not screened for cystic fibrosis (CF), as they were too old for screening when a suitable sample was received by the laboratory
 | Have a mechanism in place to check birth registers/ward lists/home births to identify eligible cohort Local process for sharing information on babies between neonatal and paediatric wards and maternity services CHIS to interrogate their system for any babies who are aged 14 to 365 days without a valid screening result, or, recorded decline for all 9 conditions (or 8 conditions if too old for CF screening)Maternity users to check Newborn Blood Spot Failsafe Solution (NBSFS) tracking screen and take appropriate action in line with [operational level agreement](https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-procedures)Maternity unit to develop local process for matching new births, for whom the unit is responsible, with NBSFS, and take action to make sure babies’ records appear on the correct siteHealth Visitors (HVs) must check that screening was completed and parents receive results within 6 weeks of birth | On every day the service operates | Maternity providers must take action on monthly exception report from NBSFS - - **monthly** CHIS must submit data on [KPI NB1 –coverage (CCG responsibility at birth)](https://www.gov.uk/government/publications/nhs-population-screening-reporting-data-definitions) to the NHS screening programmes - **quarterly** |
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| **2. Identify the eligible population (movers in):** Have systems in place to identify the **movers in** population that you have responsibility for Have mechanisms in place to notify the Child Health Information Services (CHIS) of any baby under one year of age moving to the area | To make sure eligible population is offered screening in the correct timeframe. Earlier diagnosis leads to improved outcomes. Screening should be completed and a result recorded on the CHIS system at less than, or equal to, 21 calendar days of notifying the CHIS of movement in  We have evidence from KPIs and screening safety incidents of:* babies who move in and are not identified for screening
* babies who are not offered screening
* unnecessary delays in completing screening
* babies with serious conditions entering late into care
* babies who were not screened for CF as they were too old for screening when a suitable sample was received by the laboratory
 | CHIS to interrogate their system for any babies who are aged 14 to 365 days without a valid screening result, or, recorded decline for all 9 conditions (or 8 conditions if too old for CF screening)CHIS can also check the NBSFS tracking screen and take appropriate action in line with [operational level agreement](https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-procedures) (with the exception of movers in from abroad – NBSFS only holds records of babies born in England) Health Visitors must check that screening was completed and parents receive results within 6 weeks of notification of movement in | On every day the service operates | Maternity providers must take action on the monthly exception report from NBSFS -**monthly** CHIS must submit data on [KPI NB4 – coverage (movers in)](https://www.gov.uk/government/publications/nhs-population-screening-reporting-data-definitions) to the NHS screening programmes - **quarterly** |
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| **3. All deceased babies are identified:**Have systems in place to identify any deceased baby and to inform other relevant screening/clinical services without delay  | To ensure that a deceased baby’s records are updated on NBSFS and the CHIS systemWe have evidence from screening safety incidents of:* families of deceased babies contacted to be offered screening
 | NBSFS and CHIS should be included in the routine list of contacts informed of a baby’s deathA contact list is maintained and regularly updated by all pathway providers | Contacts list is updated following each baby’s death | Stakeholders complete 6 monthly check to confirm that all deceased babies were identified and deaths communicated in a timely manner |
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| **4. Provide information and offer screening test:**Have systems in place to:* check that parent/carer has received a copy of ‘Screening tests for you and your baby’ and the information (including storage of the card) was discussed prior to the offer of screening
* check that a registered health professional has verbally checked that there is an informed choice to accept screening
 | Parents are aware that screening test is available for their baby and the standard national timescales, therefore, prompting requests if not offered/performedThere is an expectation that if screening is accepted the screening pathway is completedScreening cannot be carried out without parental (or appropriate) informed choice to accept screening To make sure the limitations of screening are understood | Check that ‘Screening tests for you and your baby’ was given Sample taker to check that an informed choice to accept screening was obtained and recorded | At least 24 hours before taking the sampleCheck an informed choice to accept screening is recorded before sample is taken | Audit that the booklet was given and consent recorded (evidenced by records in the maternity notes/system)**- annually** |
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| **5. Informed choice to decline screening:**Have mechanisms for recording declined screening in order to:make sure parents make an informed choice monitor declinessend timely notification letters to relevant providersmake sure there is an outcome from the offer of screening  | To make sure that the limitations of the screen are communicated and understoodParents should have information to be able to decline the screen based on personal choice To ensure parents understand that whilst screening is not compulsory, it is strongly recommended because it could save their baby’s life  | The healthcare professional responsible for offering screening should:* record the decline in the personal child health record (PCHR) and maternity/ professional record
* complete the details on the blood spot card and send to the laboratory marked ‘decline’
* send [notification letters](https://www.gov.uk/government/publications/declined-newborn-blood-spot-screening-template-letters) to health visitor, GP and child health records department
* give parents a [decline letter](https://www.gov.uk/government/publications/declined-newborn-blood-spot-screening-template-letters)
* inform NBS lead midwife/manager
* inform parents who to contact if they change their mind – record information in PCHR
 | When screening is declined | Review and monitor rate of declines as detailed in the annual data report, and investigate any inequalities that may exist and any significant changes |
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| **6. Identify babies where screening is incomplete:**Have systems in place to track from offer to receipt of a valid screening result, or, decline and take timely remedial action when neededMake sure screening pathway is complete where consent is given | Earlier diagnosis leads to improved outcomesWe have evidence of:* screening being accepted but not completed
* delayed screening
* babies with serious conditions entering late into care
* babies who are not screened for CF as they were too old for screening when a suitable sample was received by the laboratory
 | CHIS to interrogate their system for any babies who are aged 14 to 365 days without a valid screening result, or, recorded decline for all 9 conditions (or 8 conditions if too old for CF screening)Maternity and CHIS users to check NBSFS tracking screen and take appropriate action in line with [operational level agreements](https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-procedures) (NBSFS only holds records of babies born in England)Health Visitors must check that screening has been performed and parents receive results within 6 weeks of birth for new birth population/ within 6 weeks of notification of movement in, for movers in population | On every day the service operates | Site leads must check and take action on weekly NBSFS reports **- weekly** Maternity providers must take action on monthly exception report from NBSFS- **monthly** CHIS must submit data on [KPI NB1 –coverage (CCG responsibility at birth) and KPI NB4 –coverage (movers in)](https://www.gov.uk/government/publications/nhs-population-screening-reporting-data-definitions) to the NHS screening programmes - **quarterly** |
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| **7. Take a good quality blood spot sample at the right time:**Have systems in place to make sure:* the sample is taken at the right time
* the baby’s details are correct on the blood spot card
* the sample is sent to the laboratory without delay
* the sample meets the national quality consensus
 | Earlier diagnosis leads to improved outcomesIncorrect details could lead to misidentification of a baby. Use of a barcoded label will reduce the risk of an inaccurate NHS number on the cardPoor quality spots can lead to a condition being missedTimely dispatch of the sample is vital for early identification and treatment of affected babiesWe have evidence of:* receipt of blood spot cards with documentation errors and/or poor quality blood spots leading to incidents
* sample dispatch being delayed due to additional checking in the maternity unit / batching of cards for posting
 | Maternity service to make sure adequate postnatal services/processes are in place to take sample on day 5Maternity service to make sure baby is discharged home with accurate and complete barcoded labelsSample taker to check the completed blood spot card with the parents and make any necessary changesSample taker to record date, method, blood spot card serial number, and location of sample dispatch, as per local protocol. If a post box is used, record its post code (visible on each box)Laboratory to assess blood spot quality against national quality consensus guidelinesLaboratory to request avoidable repeat if not certain about identity of baby or there is a poor quality sample | Regular review of service provisionDocumentation:* on baby’s discharge home (labels)
* each time a sample is taken

Laboratory quality checks:* as samples are processed
 | Screening laboratory must submit data on [standard 4 – timely sample collection](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening)**- annually**Screening laboratory must submit, (presenting the data by maternity unit), on [standard 3 – (barcoded NHS number label is included on the blood spot card](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening))**- annually**Maternity unit must submit data on [KPI NB2 – avoidable repeat tests](https://www.gov.uk/government/publications/nhs-population-screening-reporting-data-definitions)**- quarterly**Screening laboratory must submit data on [standard 6 – quality of the blood spot sample](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening)**- annually**  |
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| **8. All samples are received in the screening laboratory:**Have systems in place to identify samples that are delayed or lost in transport  | Earlier diagnosis leads to improved outcomes. Laboratories will reject samples if received more than 14 days after the sample was takenWe have evidence of:* sample dispatch being delayed due to additional checking in the maternity unit/batching of cards for posting
* samples being dispatched but then lost
* samples delivered to Trust but lost before reaching laboratory
 | Laboratory user to upload screening data into NBSFS in line with [operational level agreement](https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-procedures)Maternity user to check NBSFS tracking screen for babies without a sample received and take appropriate action in line with [operational level agreement](https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-procedures)If already in place, maintain local processes whereby laboratories confirm receipt of identified samples | On every day the service operates | Screening laboratory must submit data, (presenting the data by maternity unit), on [standard 5 – timely receipt of a sample in the newborn screening laboratory](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening)**- annually**Maternity service and newborn screening laboratory must check their contingency plans for any possible exceptional circumstances that may delay receipt of sample, for example; postal strikes, severe weather disruptions, IT failure**- annually** |
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| **9. Take repeat sample as soon as is practical or within the timeframe directed by the laboratory (see** [**standards 7a, 7b and 7c**](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening)**):** Respond promptly to requests for repeat or second samples | Baby may have missed or delayed screening due to failure to take a repeat/second blood spot sample as requested by the laboratoryTimely taking of a second blood spot sample for CF and CHT screening is vital to maximise accuracy of the screening test, and to make sure that clinical referral and treatment targets are metWe have evidence of:* delays in taking repeat samples
* repeat samples not being taken (especially for CF and CHT screening)
 | Maternity service to use generic email account for repeat requests that can be accessed by all staff Maternity and CHIS users to check NBSFS tracking screen and take appropriate action in line with [operational level agreements](https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-procedures) | Daily check of generic email accountOn every day the service operates | When available, NBS programme to generate reports on [standards 7a, 7b and 7c](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening) from NBSFSAudit maternity notes and generic email account to ensure compliance with standards |
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| **10. Results letter sent to parent within 6 weeks:**Have systems in place to make sure accurate letters, for ‘all conditions not suspected’ and ‘one condition suspected’, are generated and sent to parents within 6 weeksHealth Visitors have a responsibility to make sure that parents have received the NBS results by 6 weeks | Parents are entitled to their baby’s screening resultsWe have evidence of:* errors made when transcribing results into the CHIS system
* incorrect results letters sent to parents
* families not informed of the results
 | CHIS operates a 2 person check when transcribing results into the CHIS system to minimise human errorsCHIS has a process to make sure that the correct results letter is sent to the parents if laboratory issues a revised result Health visitor/GP to check parents have received results by 6 weeks  | On every day the service operates  | CHIS submits data on [standards 12a and 12b – timeliness of results to parents](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening)**- annually**Health Visitors/GP to audit results in PCHR by baby’s 6 to 8 week NIPE check - **6 monthly** |
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| **11. All screen positive babies attend first clinical appointment within national standards:**Have systems in place to make sure baby attends first clinical appointment within national standards  | To make sure all screen positive babies enter diagnostic and clinical care within an effective timeframe. This is vital to realise health benefits and reduce risk of morbidity/mortalityWe have evidence from screening safety incidents of babies entering into clinical care late (especially for congenital hypothyroidism (CHT)) | Screening laboratory requests confirmation that:* clinical team has received referral
* parents are contacted and given screen-positive result and appointment
* family attends first appointment with clinical team
 | For each referral  | NBS screening programme collects data against [standard 11 – timely entry into care](https://www.gov.uk/government/publications/standards-for-nhs-newborn-blood-spot-screening)**annually** |
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| **12. All parents receive carrier results:**Have systems in place to make sure trained healthcare professional communicates CF or sickle cell disease (SCD) carrier result to family  | To reduce anxiety; as baby has had a second blood spot sample taken (for CF screening)To inform parents of genetic implications of the carrier result, and the impact of this if they plan to have more children in the future | Screening laboratory requests confirmation that:* carrier result has been communicated to the family
 | For each referral  | Audit that there is a standard operating procedure for communicating carrier results to parents**- annually** |
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