NHS Newborn Blood Spot Screening Programme
A review of Child Health Records Departments
leading improvements in health and wellbeing across cheshire and merseyside
Acknowledgements

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Thanks are also extended to Diane Cross, project administrator at ChaMPs, and to all members of the Child Health Records Departments (CHRD) in Halton & St Helens and Western Cheshire PCTs for their participation.
Endorsement
The project aims were developed through consultation with various stakeholders and have received full support from the North West regional screening team and national Newborn Blood Spot Screening Programme Centre.

ChaMPs
ChaMPs works collaboratively across Cheshire & Merseyside with PCTs, Acute Trusts, Local Authorities and wider organisations to promote and protect public health and wellbeing, and to reduce health inequalities. For more information on ChaMPs visit: www.champspublichealth.com

QIPP
Quality, Innovation, Prevention and Productivity (QIPP) is a framework for looking at how the NHS can deliver efficiency savings whilst maintaining or improving quality. It sets out the need to deliver improved services under tighter budget constraints, ever more important due to the current pressures on public sector budgets. QIPP isn’t an add-on, it encompasses the whole process of how the NHS can ensure sustainability in the way that care is funded. NHS organisations at regional and local level all have QIPP plans in place to address the quality and productivity challenge. This project is a contribution to the QIPP agenda in Cheshire & Merseyside.

Context
Supported by the ChaMPs screening lead, the eight PCT public health screening leads in Cheshire & Merseyside collaborate on a range of screening priorities. An agreed objective this year was to undertake service improvement within one of the screening pathways, as this had been highlighted as an area of need at a recent Cheshire & Merseyside screening event, where extended members of the screening community had come together.
Further conversations with screening stakeholders, including the North West regional screening team and national Programme Centre then followed in order to determine which of the screening programmes to focus on. It was through these conversations that the NHS Newborn Blood Spot Screening Programme was identified, as the regional screening team advised that a higher number of serious incidents involving the Newborn Blood Spot pathway had been declared in the North West in the past year than in any other programme.

Questions then followed as to whether the whole pathway should be reviewed or just part of it. Some stakeholders felt that the whole pathway should be reviewed as this would give the best returns, however others felt that it would be difficult to review the full pathway due to the complexities of how the programme is organised. As such, agreement was reached to focus attention on part of the pathway. It was acknowledged by the regional screening team that the possibility of commissioning a review of the full pathway could be considered at a later date and that this project would be used to inform those decisions.

All stages of the Newborn Blood Spot Screening pathway are important as they require different professional disciplines and organisations working together. Underpinning the entire pathway (in conjunction with the laboratory) is the Child Health Records Department (CHRD) function, as all Newborn Blood Spot activities in one way or another, lead back to this point. Consequently it was agreed to concentrate project efforts here.

Rather than undertaking a review of all CHRDs in Cheshire & Merseyside it was agreed to work with two CHRDs; one within the Merseyside Cluster and another in Cheshire, Warrington & Wirral Cluster. The screening leads in Halton & St Helens and Western Cheshire PCTs kindly offered their support and so the CHRDs in those PCTs were invited to participate.
**Project aims**

The aims of the project were to undertake a review of CHRDs and to benchmark performance against the relevant national standards (see appendix 1 for full details of standards) below as recommended by the regional screening team and national Programme Centre:

- **Standard 1** – Completeness of offer
- **Standard 6** – Timely receipt of a repeat/second blood spot sample
- **Standard 8** – Timely identification of babies aged 17-365 days with no results
- **Standard 9** – Completeness of uptake

750,000 babies born in the UK each year.
NHS Newborn Blood Spot Screening Programme

There are on average over 750,000 babies born in the UK each year. Funded by the Department of Health, the UK Newborn Screening Programme Centre was established in 2002 with an overall objective of assuring high quality screening services for babies and their parents, and they aim to achieve this through the development of a quality assurance programme and performance management frameworks.

The NHS Newborn Blood Spot Screening Programme offers screening for phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell disorders (SCD), cystic fibrosis (CF) and medium-chain acyl-CoA dehydrogenase deficiency (MCADD), as recommended by UK National Screening Committee (UKNSC). In the UK, approximately: one in 10,000 babies born has PKU; one in 4,000 babies born has CHT; one in 2,500 babies born has CF; one in 2,000 babies born has a SCD; and one in 10,000 babies born in the UK has MCADD.

Newborn Blood Spot Screening is a complex programme, crossing multi-professional and organisational boundaries with an overarching objective of early detection. Standards for Newborn Blood Spot Screening were developed in 2005 in order to underpin the performance management framework and to ensure a timely and effective screening programme. The standards were revised in 2008 and are currently under review. A quality assurance programme is also under development with Key Performance Indicators (KPIs) being tested this year (see appendix 2 for Newborn Blood Spot KPIs).

The UKNSC oversees this screening programme and their work is supported by the 10 regional antenatal & newborn screening teams in England and works in a collaborative manner with the other 3 UK countries (note: programmes in Wales and Scotland screen for different conditions). Newborn Blood Spot Screening is undertaken as part of the routine maternity/newborn pathway with most Hospital Trusts and identified laboratories providing services for this.
Newborn Blood Spot Pathway

**Child health records department**
- GP registrations
  - Sample receipt in laboratory, results/declines entered & checked (daily check 14 days>1 year of age)
  - Offer, uptake & coverage monitored
- Birth notifications
  - NHS number bar-coded label generated (CIS)
  - Inform maternity services of missing results
  - PCT DPH informed if unable to complete screen

**Primary Care**
- Take sample in older babies
- Health visitor ensures parents receive results & records in PCHR by 8 weeks
- Normal results letter to parents
- Health visitor/counsellor inform parents of carrier results

**Maternity services**
- Baby born
  - Information & consent/decline
  - Sample taken (day 5-8)
  - Mark to decline some or all tests
  - Repeat sample taken
  - Receipt of sample in laboratory check

**Newborn Screening Laboratory**
- Sample quality check
  - Despatch within 24 hours
  - Sample tested
  - Results reported
  - Diagnostic tests/outcome monitored

**Specialist team**
- Baby’s first appointment
  - Confirmatory diagnostic tests
  - Intervention/treatment

Acknowledgment receipt of carrier results and return audit form
CHRDs have an important part to play in healthcare as they have functioning roles within Newborn Blood Spot Screening, Newborn Hearing Screening, Newborn & Infant Physical Examination Screening, Infectious Diseases in Pregnancy Screening and Childhood Immunisations.

For the purpose of this project we focused only on their role within Newborn Blood Spot Screening. Within this programme, the CHRDs have an overarching responsibility of ensuring that all babies eligible for screening age one year and under are recorded on a child health information system along with their Newborn Blood Spot Screening status.
Child Health Records Departments pathway

The information below was gathered during the service review days and shows the main functions undertaken within the CHRDs.

- **Birth notification received**
- **Key in data – link baby to Mum onto PARIS – create NHS number**
- **Make up birth pack and print labels (Western Cheshire only)**
- **Photocopy birth notification (Halton & St Helens only)**
- **Birth notification sent to Health Visitor**
- **12 days onwards – Results spreadsheet received from laboratory**
- **Input Blood Spot results onto PARIS**
- **Full results received from laboratory and input onto PARIS**
- **Full reports sent to Health Visitor**
- **Conduct daily check of babies 17 to 365 days old – contact laboratory or previous CHRD for missing information**
- **Inform designated Health Visitor of babies identified from daily sweep**
- **Receive movers in form from Health Visitor or other source**
- **Trace baby’s history to locate Blood Spot results – inform Health Visitors of outcome**
- **Run weekly report to identify babies up to 1 year old – telephone relevant departments for missing results**
- **Inform designated Health Visitor of babies identified from weekly report**
A one day service review was conducted at each CHRD in one phase with each review implemented and completed in a single day of activity. Both reviews were conducted to understand the current systems and processes in place and to make recommendations for future redesign opportunities.
The review days were split into three phases:

**Phase 1**
- Background and context for the review.
- Understanding the sponsor requirements and intended benefits.
- Baseline of current service provision.
- Developing the vision for change.
- Activities and outputs: Data collection including organisational structure, volume flows, workforce activity, KPIs, stakeholder mapping and engagement, financial data collection, and high level review of interfaces including any Information Management & Technology requirements, key suppliers and partnerships.

**Phase 2**
- Visioning and creative thinking.
- Peak chart action plan.

**Phase 3**
- A final report detailing recommendations and suggested next steps.
- Establishing leadership for the change initiatives identified through the review.
### Table 1: CHRDs performance against national standards and Key Performance Indicators (KPIs) as at Q2 2011/12

<table>
<thead>
<tr>
<th>Standard/KPI</th>
<th>Core Standard</th>
<th>Halton &amp; St Helens CHRD</th>
<th>Western Cheshire CHRD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Standard 1: Completeness of Offer</strong></td>
<td>100% of resident PCT babies to have screening code status on child health system</td>
<td>Data unavailable</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Standard 6: Timely receipt of repeat/second blood spot sample</strong></td>
<td>95% of repeat samples should be taken within 72 hours</td>
<td>Reported by laboratory, not CHRD</td>
<td>Reported by laboratory, not CHRD</td>
</tr>
<tr>
<td><strong>Standard 8: Timely identification of babies aged 17-365 days with no result</strong></td>
<td>100% of untested babies identified by 17 days of age</td>
<td>Data unavailable</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Standard 9: Completeness of Uptake</strong></td>
<td>Screening test result recorded on child health system for 100% of resident babies in whom screening has been accepted</td>
<td>Data unavailable</td>
<td>100%</td>
</tr>
<tr>
<td><strong>NB1: Newborn Blood Spot Screening - Coverage</strong></td>
<td>Acceptable = &gt;95.0%</td>
<td>Data unavailable</td>
<td>98.36%</td>
</tr>
<tr>
<td></td>
<td>Achievable = &gt;99.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NB3: Newborn Blood Spot Screening – Timeliness of results availability</strong></td>
<td>Acceptable = 95.0%</td>
<td>Data unavailable</td>
<td>97.96%</td>
</tr>
<tr>
<td></td>
<td>Achievable = 98.0%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Evidence of good practice

During the reviews there were many examples of good practice identified:

Halton & St Helens CHRD

- Clear lines of leadership.
- Knowledgeable and dedicated team.
- Timely and efficient processes for the majority of referrals.
- Full records of daily checks undertaken.
- Standard operating procedures and policy documents evident.

Western Cheshire CHRD

- Clear lines of leadership.
- Knowledgeable and dedicated team.
- Timely and efficient processes for the majority of referrals.
- Full records of daily checks undertaken.
- Achievement of national targets for all KPIs & Standards.
Issues Highlighted

In addition to the areas of good practice identified, several areas of concern were also noted:

Halton & St Helens CHRD
- Improvements recommended by the national Programme Centre often required changes to the I.T. system. Because recommendations were sent informally rather than via a dataset change notices notification (DSCN), CHRDs found it increasingly difficult to make changes to I.T. systems at local level, especially where a cost was involved.

- When missing Blood Spot results appeared via the daily sweep, CHRD teams did inform the necessary clinicians however often the query came back to them and as such, they felt that the lines of accountability were blurred.

- Depending on the referring organisation, some birth notifications were posted. The CHRD team had kept a manual log of these referrals and records showed that some referrals were taking up to a week before being received by the team.

- Not all birth notifications included the mother’s NHS number thus causing additional work to then locate the number.

- Largely due to distance and impact on the workplace, members of the team were not always able to attend the CHRD sessions facilitated by the regional screening team.

- The team kept photocopies of birth notification and were unsure as to how long copies should be retained.

- The same storage query also applied to daily checks records.

- An increasing number of babies are born abroad, particularly from Poland, and this was causing additional work for the team.

- Notification letters to parents of a normal result were not yet in place due to delays in adapting local I.T. systems, mostly due to cost.

- The team were not always informed of changes to local health visitor contact lists.
Issues Highlighted

Western Cheshire CHRD
• Three GP practices in the Neston area currently use CHRD in Wirral; this caused practicality issues at times.

• Babies registered with local GP practices but resident in Wales caused some problems as Wales do not follow the same guidelines for Blood Spot Screening.

• Birth notifications received by post could take up to three days to be received.

• Not all birth notifications included the mother’s NHS number thus causing additional work to then locate the number.

• Individual reports from the laboratory were sent by post (taking 2-3 days) rather than by the preferred method of email.

• Additional work was required for movers in and it could often take extra time to resolve if the baby was from outside of the North West area as currently there is no availability of a national directory of CHRDs and laboratories in England.

• The current flows of information did not match the local IT system and therefore staff were experiencing duplication when inputting information.
Summary

CHRDs are responsible for recording and communicating important Blood Spot information to and from a range of health professionals. Both CHRDs in recent months have taken steps toward local improvements and this was evident during the reviews. In the main they operated as efficiently as they could, within the constraints of ongoing I.T. issues and receiving timely and complete information from screening stakeholders.

The teams however, were not always aware of the important role they had within the Newborn Blood Spot pathway and at times felt overlooked. They welcomed the opportunity of taking part in the project as they believed it would help boost their profile.

In terms of benchmarking against national standards, both CHRDs were working well. Although they did have concerns about standard 6 (timely receipt of a repeat/second bloodspot sample) as they believed this standard to ‘belong’ to the laboratory. After raising this point with the national Programme Centre via the regional screening team, it appeared that this standard is not yet reported on.

In keeping with the standards, both teams aired concerns about some of the wording used and that it was not always clear as to who was responsible for the various elements within the standards.

From a KPI perspective, Western Cheshire CHRD had made vast improvements over recent months and data reports were easily accessible. Halton & St Helens CHRD were experiencing difficulties in extracting the data and at the time of the review had no statistical evidence of performance, although informally they believed they were achieving the national KPI standards.

Both teams were experiencing delays due to some birth notifications and all individual laboratory results being posted. This issue was to be addressed as a matter of urgency as posted correspondence also had implications for the performance targets of other health professionals. The intention was to request that all correspondence be received electronically with the option of fax as the only alternative.
Action plans for CHRDs

Areas for local improvement were identified by both teams. The following action plans were agreed and will be delivered by the CHRD teams over the next 2-3 months.

Halton & St Helens CHRD

- Review the movers in form with a view to adding further information fields.
- Initiate internal discussions with PCT colleagues to ensure the list of designated health visitors is accurate and kept up-to-date.
- Approach referring organisations to request that all birth notifications are received by email or fax.
- Continue with internal plans in adapting the I.T. system to allow notifications of negative results to parents.
- Request feedback and reports from I.T. department within the organisation to review performance.

Western Cheshire CHRD

- Review the movers in form with a view to adding further information fields.
- Upon receipt of a movers in form, ring for blood spot results at time of inputting onto system as opposed to completing at a later date.
- Approach the laboratory to discuss the possibility of receiving individual blood spot results by email rather than by post.
- Contact the regional screening team to enquire about a directory of all laboratories and CHRDs in England as an addition to the present North West directory.
- Explore the possibility of adapting the I.T. system to prevent duplication of inputting.
**Recommendations**

In addition to action plans agreed, further recommendations for CHRDs are:

- Halton & St Helens to ensure that activity is monitored with performance reports reviewed regularly. Consideration should be given to a substitute form of monitoring until local I.T. issues are resolved.

- Western Cheshire to ensure documentary evidence of policies and pathways are in place to support practice.

- Both CHRDs to make contact with other CHRDs with a view to developing a network of support across Cheshire & Merseyside.

**Recommendations for Cheshire & Merseyside screening leads are to:**

- Celebrate the good work happening locally.

- Support the participating CHRDs in achieving their action plans.

- Share results of the project with other CHRDs in Cheshire & Merseyside and support those teams with any improvements they may require.

- Consider undertaking a service review of another stage, or the remaining stages of, the Blood Spot pathway.

- Consider awareness training for CHRDs to enable a fuller understanding of their important role within Newborn Blood Spot Screening and an awareness of other stages of the Programme.

**Further considerations**

Given their support for the project, the following considerations are listed for the regional screening team and the national Programme Centre:

- If necessary, provide clarification of the standards applicable to CHRDs, and of the elements within other standards, applicable to CHRDs.

- Consider implementing future I.T. changes via dataset change notices notification (DSCN).

- If necessary, provide clarification of where the CHRDs responsibility ends regarding missing Blood Spot results.

- Consider the production of a national directory of CHRDs and laboratories.

- Explore the notion of developing sub-regional CHRD networks.

- Consider awareness training for CHRDs to enable a fuller understanding of their important role within Newborn Blood Spot Screening and an awareness of other stages of the programme.

- Consider the option of undertaking a service review of the entire Newborn Blood Spot pathway.
Appendix 1

Standard 1 – Completeness of offer

The Purpose
A key objective of the programme is to ensure that the eligible population is offered screening. Every newborn baby resident in the UK, and those that move into the UK, up to the age of one year, should be offered blood spot screening.

Core Standard
Notification of receipt of sample in the laboratory or result or decline of screening, recorded on the child health system, for each of the five conditions, for 100% of babies who were resident in the PCT at birth and are still resident in the PCT at the time of count.

Developmental Standard
Notification of receipt of sample in the laboratory or result or decline of screening, recorded on the child health system, for each of the five conditions, for 100% of babies resident within the PCT at the time of the count. This standard includes babies who have moved into the PCT since birth as well as those who were born and are still resident at the time of count.

Guidelines
Screening test results should be communicated to the child health records departments using the screening status codes, including notification of receipt of sample in the laboratory using status code 01. Status codes should be implemented by March 2010 (see appendix 1 for screening status codes).

1. For ‘offer’ any of the status codes and definitions below apply:
   - 01 Specimen received in laboratory
   - 02 (Condition screened for) declined
   - 03 (Condition Screened for) repeat/further sample required
   - 04 (Condition screened for) not suspected
   - 05 (Condition screened for) carrier
   - 06 Carrier of other Haemoglobin
   - 07 (Condition screened for) not suspected other disorders follow up
   - 08 (Condition screened for) suspected
   - 09 (Condition screened for) not screened/screening incomplete

2. Each PCT must have a system in place that ensures that all eligible babies are offered screening.

3. Although 5-8 days of age is the recommended sampling period newborn blood spot screening should be carried out for untested babies up to 1 year of age for PKU, CHT, SCD and MCADD. The screening test for cystic fibrosis is not valid for babies who are tested when they are more than 8 weeks old.

4. The details of babies who move into the PCT should be entered onto the child health records department systems and that any outstanding results are tracked.

5. For babies under 1 year of age who have moved into the area and are reported to have been screened, evidence of testing is required. This may take the form of a faxed or written confirmation of the result or written record in the PCHR. Where no proof of testing is available it should be assumed that the baby is untested and re-testing discussed with the parents and if accepted, arranged.
Standard 6 – Timely receipt of a repeat/second blood spot sample

Purpose: This standard covers repeat/second samples that are requested by the laboratory because the first sample was of poor quality, not valid for testing or as required by the national protocol for specific conditions. In order that treatment and clinical referral targets are met the timely receipt of a repeat/second blood spot sample is imperative.

Core standard
95% of repeat samples should be taken within 72 hours of the laboratory request or specified date of sample.

For CHT this is within 72 hours after the baby reaches the equivalent of 36 weeks gestation (35 weeks + 7 days).

For SCD this is within 72 hours plus 4 months after the last blood transfusion.

For CF the second sample must be taken between day 21 and day 28.

Developmental standard
95% of repeat samples should be taken within 48 hours of the laboratory request or specified date of sample.

For CHT this is within 48 hours after the baby reaches the equivalent of 36 weeks gestation (35 weeks + 7 days).

For SCD this is within 48 hours plus 4 months after the last blood transfusion.

Guidelines
1. PCTs must have systems in place to ensure that responsibility for obtaining repeat and second samples, up to the age of one year, is clearly identified within local screening pathways.

2. The request for a repeat sample should be made in writing and clearly state why it is needed. It should be sent to the nominated health professional in accordance with local pathways. Local pathways must ensure urgent action. If e-mail or fax is used, acknowledgement of receipt of request must be provided.

3. The reason for the repeat should be explained to the parents along with an indication of how and when they will receive the results. The reason for the repeat should be recorded on the blood spot card.

4. It is recognised that in some instances it is difficult to locate families or achieve contact and it is recommended that the professional responsible records attempts to contact the family as part of routine record keeping.
Standard 8 – Timely identification of babies for whom the child health records department has not received notification of specimen received in laboratory, screening test result or decline

The Purpose
It is essential that laboratories notify receipt of sample (specimen received in laboratory, status code 01) as soon as possible to child health records departments so that untested babies are identified promptly. This will enable samples to be obtained, analysed and appropriate action taken. Identification of untested babies will require locally agreed ‘fast-track’ procedures to ensure that screening is offered at the earliest opportunity.

Core Standard
100% of untested babies identified by 17 days of age.

Developmental Standard
100% of untested babies identified by 14 days of age.

Guidelines
1. Untested babies are defined as those babies who do not have notification of specimen received in laboratory, screening result or a decline notification.

2. Child health records departments should perform a daily search to identify babies aged 17 days old and up to one year for whom notification of specimen received in laboratory, screening test result or decline has not yet been received.

3. On identification of babies for whom notification of specimen received in laboratory, screening test result or decline has not yet been received the child health records department should contact the nominated person (in accordance with local pathways) so that the screening process is ‘fast-tracked’, and the sample taken within 48-72 hours of the request and transferred to the laboratory.
Standard 9 – Completeness of uptake

The Purpose
A Key objective of the programme is to ensure that uptake is maximised in those babies for whom the offer of screening has been accepted.

Completeness of uptake will be measured annually, on every newborn baby resident in the PCT, in whom the offer for screening has been accepted, and for each of the five conditions: PKU, CHT, MCADD, CF and SCD.

Core Standard
Screening test result recorded on the child health system, for each of the five conditions, for 100% of babies, in whom screening has been accepted, who were resident in the PCT at birth and are still resident in the PCT at the time of count.

Developmental Standard
Screening test result recorded on the child health system, for each of the five conditions, for 100% of babies, in whom screening has been accepted, resident within the PCT at the time of the count. This standard includes babies who have moved into the PCT since birth as well as those who were born and are still resident at the time of count.

Guidelines
1. Screening test results should be communicated to the child health records departments using the screening status codes, with a view to moving to electronic messaging of results between the screening laboratory and the child health records department.

For uptake any of the status codes and definitions below apply:

- 04 (Condition screened for) not suspected
- 05 (Condition screened for) carrier
- 06 Carrier of other Haemoglobin
- 07 (Condition screened for) not suspected other disorders follow up
- 08 (Condition screened for) suspected
- 09 (Condition screened for) not screened/screening incomplete

2. It is the responsibility of the child health records department to ensure there is a process for notifying normal results to parents and to health visitors. Best practice is for the child health records department to inform parents of normal results by letter.

3. It is an absolute requirement that the screening result is documented in the PCHR by 8 weeks. The health visitor receiving the results from the child health records department should ensure that this is completed.

4. Although 5-8 days of age is the recommended sampling period newborn blood spot screening should be carried out for untested babies up to 1 year of age for PKU, CHT, SCD and MCADD. The screening test for cystic fibrosis is not valid for babies who are tested when they are more than 8 weeks old.

5. For babies under 1 year of age who have moved into the area and are reported to have been screened, evidence of testing is required. This may take the form of a faxed or written confirmation of the result or written record in the PCHR. Where no proof of testing is available, it should be assumed that the baby is untested and re-testing discussed with the parents and if accepted, arranged.
### KPI: Newborn blood spot screening – coverage (PCT responsibility at birth)

**Description**

The proportion of babies registered within the PCT both at birth and at the time of report who are eligible for newborn blood spot screening and have a conclusive result recorded on the Child Health Information System within an effective timeframe. For this KPI, PKU is used as a proxy for all tests and the test must be completed by 17 days of age.

**Rationale**

One of the main objectives of newborn blood spot screening is to ensure that eligible babies whose parents accept an offer of screening are tested within an effective timeframe. Timely information on screening coverage is key in order to identify trends and to monitor the effectiveness of service improvements.

Coverage is a measure of the delivery of timely screening to an eligible population. Low coverage might indicate that:

- i) not all eligible babies have been offered screening;
- ii) those offered screening are not accepting the test; and/or
- iii) those accepting the test are not being tested within an effective timeframe.

This indicator relates to UKNSPC Standards 1, 8 and 9.

**Definition**

\[
\text{tested babies (numerator)} = \frac{\text{tested babies}}{\text{eligible babies (denominator)}} \times 100
\]

- **tested babies** (numerator) is the total number of eligible babies for whom a conclusive screening result for PKU was available within an effective timeframe.
- **eligible babies** (denominator) is the total number of babies born within the reporting period, excluding any baby who died before the age of 8 days. For the purposes of this KPI, the cohort includes only babies for whom the PCT were responsible at birth and are still responsible on the day of report.

The effective timeframe is that a conclusive result for phenylketonuria (PKU) is recorded within the appropriate Child Health Information System by 17 days of age.

A conclusive result for PKU is one of the following newborn screening status codes:
- 04 (not suspected)
- 07 (not suspected - other disorders follow up)
- 08 (suspected)

For other definitions specific to the newborn blood spot screening programme please see [http://newbornbloodspot.screening.nhs.uk](http://newbornbloodspot.screening.nhs.uk)

**Performance thresholds**

- Acceptable level: ≥ 95.0%
- Achievable level: ≥ 99.9%

**Mitigations / qualifications**

For the purpose of this KPI, a conclusive screening result for phenylketonuria (PKU) will serve as a proxy indicator for a conclusive result for each of the conditions screened for.

This KPI does not measure babies born within the reporting period who have become the responsibility of the PCT since birth (movers-in), even though these babies are eligible for screening and will continue to be monitored through data collection by the NBS programme centre, along with coverage for all five tests.

**Reporting arrangements**

KPI to be reported from Q4, 2010-11 (i.e. first return by 30 June 2011).

- Reporting focus: PCT
- Data source: Child Health Information System

**Reporting period**

- Quarterly; data to be collated between two and three months after each quarter end. Deadlines: 30 September (Q1), 31 December (Q2), 31 March (Q3), 30 June (Q4).
- Annually; data to be collated between two and three months after fiscal year end. Deadline: 30 June
<table>
<thead>
<tr>
<th>KPI</th>
<th>NB3: Newborn blood spot screening – timeliness of result availability</th>
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</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>The proportion of newborn blood spot screening results which are screen negative for all five conditions, available for communication to parents within six weeks of birth.</td>
</tr>
</tbody>
</table>
| **Rationale**                                                    | Following a screening encounter, the prompt communication of screening results ensures that parents are appropriately informed, helps to minimise anxiety and minimises delay to follow up actions or interventions. 
Late receipt of screening results could indicate: 
• a backlog or failure in administration or sample processing. 

It is the responsibility of the PCT to ensure that the Child Health Records Department has a process for notifying screening results to health visitors. Best practice is for the Child Health Records Department to inform parents of screen negative results by letter. All results should be communicated to the parents of newborn babies within 6 weeks of birth. 

Note: It is an absolute requirement that the screening result is documented in the Personal Child Health Record (red book) by 8 weeks. The health visitor receiving the screening results from the Child Health Records Department should ensure that this is completed but there are no reliable data collection methods to assess this. This relates to SCT (Newborn) Standard P2; blood spot status codes are detailed at [http://newbornbloodspot.screening.nhs.uk/statuscodes](http://newbornbloodspot.screening.nhs.uk/statuscodes). |
| **Definition**                                                    | 

| results available for communication by 6 weeks | expressed as a percentage, where: |

| babies screen negative for all 5 conditions |  |

results available for communication by 6 weeks (numerator) is the number of babies screen negative for all five conditions for whom screening results are available on the Child Health Information System (CHIS) for access by health visitors within 6 weeks (42 days) of birth. 

babies screen negative for all 5 conditions (denominator) is the total number of babies born within the reporting period: 

• for whom the PCT were responsible at birth and still responsible on the last day of the reporting period. 

• for whom a conclusive screen negative status code 04 (condition not suspected) result is available on all five conditions on the day of report. 

This KPI does not count babies born within the reporting period who have become the responsibility of the PCT since birth (movers-in); nor does it count babies with a screen positive (condition suspected) or ‘carrier’ result for any of the conditions tested or requests for repeat tests. |
| **Performance thresholds**                                        | Acceptable level: 95.0% 
Achievable level: 98.0% |
| **Mitigations / qualifications**                                  | Screen negative for all five conditions is a prerequisite for the CHIS to automatically produce letters for parents. Where result letters are not sent directly to parents it is necessary for the PCT to ensure that results communicated to the health visitor are conveyed to parents. |
| **Reporting arrangements**                                        | KPI to be reported from Q4, 2010-11 (i.e. first return by 30 June 2011). 
Reporting focus: PCT 
Data source: Child Health Information System |
| **Reporting period**                                              | Quarterly; data to be collated between two and three months after each quarter end. 
Deadlines: 30 September (Q1), 31 December (Q2), 31 March (Q3), 30 June (Q4). 
Annually; data to be collated between two and three months after fiscal end. 
Deadline: 30 June |