

## IND66: Timeliness of results for newborn blood spot testing to parents for CCG responsibility at birth

*The proportion of babies with a “not suspected” result for all the conditions tested for by newborn blood spot testing who have a results letter sent to their parents directly from the child health information service (CHIS) ≤ 6 weeks of birth.*

Data currently collected by the child health information service. This proposal assesses the potential as a NICE CCG level indicator.

### Importance

Considerations	Assessment
<p><a href="#">Newborn blood spot screening</a> is one of 11 <a href="#">NHS national population screening programmes</a> available in England.</p> <p>This indicator would facilitate local areas to include specific and measurable goals in local improvement plans.</p>	<p>The indicator reflects a specific priority area identified by Public Health England.</p>
<p>The <a href="#">NHS Long Term Plan</a> identifies “A strong start in life for children and young people”, including maternity and neonatal services, as a priority for care quality and outcomes improvement.</p>	<p>The indicator reflects a specific priority area identified by NHS England.</p>
<p><a href="#">Newborn blood spot screening data collection and performance analysis report</a> (2018/19) reports performance of 99% in England for timeliness of results to parents. This ranged from 98.5% to 99.4% at regional level.</p> <p>Completeness for this standard can be improved in some local areas.</p>	<p>The indicator relates to an area where there is known variation in practice.</p>
<p>The NBS screening programme enables early identification, referral and treatment of babies with 9 rare but serious conditions. Conveying newborn blood spot (NBS) screening results in a timely manner to parents will minimise anxiety.</p>	<p>The indicator will lead to a meaningful improvement in patient outcomes.</p>

### Evidence base

Considerations	Assessment
<p>Newborn blood spot testing is supported by:</p> <p><a href="#">NICE’s guideline on Postnatal care</a> recommendation 1.3.8</p> <p>And the recommendations of the <a href="#">UK National Screening Committee</a></p>	<p>The indicator is derived from a high-quality evidence base.</p> <p>The indicator aligns with the evidence base.</p>

## Specification

Considerations	Assessment
<p>Numerator: number of babies in the denominator who have a results letter sent to their parents directly from the CHIS ≤ 6 weeks of birth.</p> <p>Denominator: number of babies with a “not suspected” result for all the conditions tested for by newborn blood spot testing recorded on CHISS ≤ 6 weeks of birth.</p> <p>Performance calculated by dividing numerator by denominator and multiplying by 100 to give a percentage.</p> <p>“Not suspected” result – status code 04 and 10. Further information is available on the status codes.</p> <p>This standard only includes babies who:</p> <ul style="list-style-type: none"> <li>• have a “not suspected” result for all the conditions tested for</li> </ul> <p>This standard excludes babies who:</p> <ul style="list-style-type: none"> <li>• have a condition suspected or carrier result for any of the conditions tested for</li> <li>• have a status code that denotes a declined condition, a repeat required or screening incomplete</li> <li>• are covered by a CHIS that does not send results letters directly to parents (for example the results are communicated by health visitors instead).</li> </ul> <p>Where “not suspected” results letters are not sent directly to parents by CHIS, screening and immunisation teams should provide evidence that health visitors have given the results to parents and documented this in the personal child health record (‘red book’). This could be achieved through local audit with stakeholders.</p>	<p>The indicator has defined components necessary to construct the indicator, including numerator, denominator and exclusions.</p>
<p>NICE CCG level indicators are intended for use where there is an average of 50 patients or more per CCG. Data presented by PHE as part of the <a href="#">Newborn blood spot screening data collection and performance analysis reports</a> indicate an average number of 3112 patients per CCG. (Note: The Newborn blood spot screening data collection and performance analysis report table has a denominator of 544,545 for this standard, and reports that there were 175 complete data returns in England: <math>544,545/175=3112</math>).</p>	<p>The indicator outlines minimum numbers of patients needed to be confident in the assessment of variation.</p>

## Feasibility

Considerations	Assessment
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Data is collected as part of the <a href="#">NHS Newborn blood spot screening programme</a> in the Child Health Information System.	The indicator is repeatable.
A <a href="#">data collection template</a> and <a href="#">screening standards</a> are available from gov.uk	The indicator is measuring what it is designed to measure.  The indicator uses existing data fields.

## Acceptability

Considerations	Assessment
The commissioning of the NHS NBS pathway involves commissioning at different levels which may include NHS England and NHS Improvement public health commissioning, CCGs, and directly by maternity services.  Child Health Record Departments send screen negative results letter to health visiting services (or agreed alternative) and to parents.	The indicator assesses performance that is attributable to or within the control of the audience
Data at regional and national level is published as part of the <a href="#">Newborn blood spot screening data collection and performance analysis reports</a> . CCG level data could be published as part of the <a href="#">NHS Screening programme KPI reports</a> to compare practice and assist in <a href="#">quality assurance procedures</a> .	The results of the indicator can be used to improve practice

## Risk

Considerations	Assessment
The NHS newborn blood spot screening programme operates under published standards and quality assurance frameworks.	The indicator has an acceptable risk of unintended consequences.