



Public Health
England



NHS Newborn Blood Spot Screening Programme

Programme handbook review: consultation report

Public Health England leads the NHS Screening Programmes

About Public Health England

Public Health England (PHE) exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

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About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the 4 UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

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Background

Newborn blood spot (NBS) screening enables early identification, referral and treatment of babies with rare but serious conditions. The programme helps to improve their health and prevent severe disability or even death. For each condition, the benefits of screening outweigh the risks.

NBS screening tests use a blood sample taken from a baby's heel and spotted onto a special card containing the baby's and mother's details. The sample taker sends the blood spot card to a regional newborn screening laboratory for testing.

The current NBS screening health professionals handbook was published in 2012. It informs and supports health professionals who deliver the NHS Newborn Blood Spot Screening Programme in England.

In 2017, the NHS Newborn Blood Spot Screening Programme established a review of the current handbook. This was followed by a targeted consultation.

Aims

This report is in response to the 2017 targeted consultation on the newborn blood spot screening programme handbook.

The consultation opened in December 2017 for 6 weeks. The consultation was an opportunity for stakeholders to influence the future of and share their views on the content and usefulness of the programme handbook.

The revised handbook aims to:

- provide an overview of the whole screening pathway
- make it easier for health professionals to access information
- direct users to relevant policies and guidelines
- make sure the format is user and web friendly

This document contains a summary of the responses received and identifies and responds to the main themes that emerged.

It sets out the actions agreed with the Blood Spot Advisory Group following consideration of the consultation responses.

All feedback has been presented anonymously.

Design

The handbook draws on evidence, healthcare professional enquiries to the programme, lessons from patient safety incidents, data collection, assessment of performance against standards, and evaluation of the programme's e-learning resources.

The content of the programme handbook was reviewed and updated by key stakeholders including members of the newborn blood spot screening advisory boards.

We invited comments from health care professionals including midwives, health visitors, neonatal nurses and screening coordinators on the proposed new handbook.

Feedback was sought via an online survey. A link to the survey was cascaded by the Screening Quality Assurance Service teams to antenatal and newborn screening coordinators, heads of midwifery, screening and immunisation leads, members of the UK Newborn Screening Laboratory Network and NBS screening advisory boards.

To aid stakeholders in completing their responses, the survey asked about the level of detail, accessibility and usefulness of the handbook.

The responses were considered by the newborn blood spot screening programme team.

Consultation responses

Survey responses were received from 16 health professionals including midwives, health visitors, screening co-ordinators and screening quality assurance advisors.

In addition, 3 email responses to the survey were received.

Common themes and conclusions

Detail

We asked respondents to rate the level of detail in each section of the handbook.

98% of respondents considered the level of detail in all sections was about right. One respondent felt that the section about the conditions was too detailed; one respondent felt that there was not enough detail about the screening quality assurance service and one respondent felt that there was not enough details about how to contact us.

Conclusion: More detail has been added about contacting us and the screening quality assurance service.

Accessibility

We asked respondents how accessible is the programme handbook.

All respondents felt the handbook was accessible. 53% responded very accessible and 47% fairly accessible.

Respondents identified repetition and terminology that needed clarification. They suggested format changes, more specific hyperlinks and reordering the sections to improve accessibility.

Conclusion: The programme handbook has been reworked in line with Public Health England guidance to make the handbook more accessible and user friendly when accessed on GOV.UK.

Usefulness

We asked respondents how useful the handbook is to their role within the newborn blood spot screening pathway.

All respondents felt the handbook was useful. 63% of respondents considered it very useful, 25% fairly useful and 12% somewhat useful.

We asked respondents how they will use the handbook. 56% of respondents felt that they will use the handbook for education and training and 53% will use it as a reference document.

Conclusion: The handbook has been revised to support education and training as well as meeting the user needs.

Missing topics

We asked respondents if there were any topics or chapters that they would like included in the handbook.

One respondent requested a section about screening tests that may be introduced in the future.

Conclusion: The handbook is about the current screening programme. It will be updated if there are changes to screening tests in the future.

Errors

One respondent highlighted some wording errors and another respondent identified the incorrect use of external quality assurance in a section.

Conclusion: These changes have been made to the handbook.

Additional comments

We asked responders if they had any further comments about the programme handbook.

One respondent asked for specific guidance for independent midwives. Several respondents asked for clarification about specific aspects as the screening pathway.

Conclusion: Based on the additional comments received, we have made clear:

- screening for all 9 conditions should be offered to movers in (except for cystic fibrosis after 8 weeks of age)
- parents should not be told 'no news is good news'
- when blood spot sample should arrive at the laboratory
- when parents should receive results
- 'more than 5 working days' relates to laboratories
- results translated into English are acceptable
- what to write in the newborn blood spot card comments box

Specific guidance for independent midwives is not considered necessary. The handbook content applies to all health care professionals involved in the screening pathway.

Next steps

Following the survey all comments and feedback were taken into consideration and a revised version drafted. The revised handbook was reviewed in detail by the programme team and subject experts for accuracy.

The final draft was signed off by blood spot advisory group.

The newborn blood spot screening programme handbook was published in August 2018.

Feedback

We welcome feedback about the handbook. Please email us at phe.screeninghelpdesk@nhs.net