



Public Health  
England



# **NHS Newborn Blood Spot Screening Programme**

**Newborn blood spot card review:  
consultation report**

**Public Health England leads the NHS Screening Programmes**

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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 blood spot card has been in production since September 2009. The card is produced as both a multi-part card and a single-part card, to meet the needs of the screening laboratories in England.

In early 2017, the NHS Newborn Blood Spot Screening Programme established a time-limited Blood Spot Card Review Project Group to review the current design and consult on proposed changes.

Scotland and Wales produce their own blood spot card, but contributed to this review.

## Aims

This report is in response to the 2017 consultation on the design of the newborn blood spot card.

The consultation opened on 14 July 2017 for 6 weeks. The consultation was an opportunity for stakeholders to influence the future of the card's design and share their views on the proposed changes.

The proposed new design aimed to:

- make it easier for sample takers to complete the card
- make it easier for screening laboratories to process cards
- reduce errors that lead to avoidable repeat requests
- make it easier to identify and contact the sample taker if a repeat is needed
- make sure the design of the card allows for completeness of reporting

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 Card Review Project Group and the Blood Spot Advisory Group following consideration of the consultation responses.

All feedback has been presented anonymously.

Some changes to the card remain outstanding pending further discussion with the designers. They have been documented within the report.

# Design

We invited comments from blood spot sample takers and newborn screening laboratories on the proposed new blood spot card design.

Feedback was sought via an online survey. Two different versions of the survey were developed – one for sample takers and the other for newborn screening laboratories. A link to the survey was cascaded by the Screening Quality Assurance Service (SQAS) teams to newborn screening coordinators, heads of midwifery, screening and immunisation leads, and members of the UK Newborn Screening Laboratory Network and NBS screening advisory boards.

To aid stakeholders in completing their responses, the survey provided images of the front and back of the proposed new blood spot card and the card currently in use.

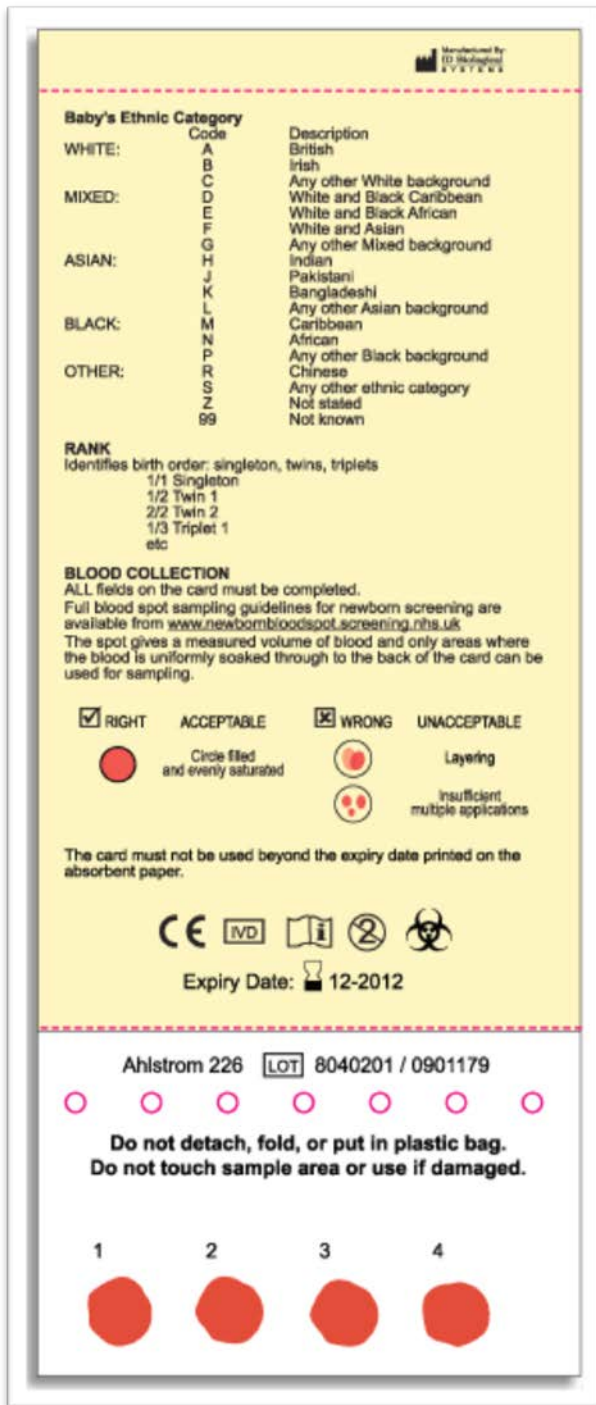
The responses were grouped into themes and presented to the Blood Spot Card Review Project Group on 18 September 2017, where changes were discussed and agreed.

Front of current card

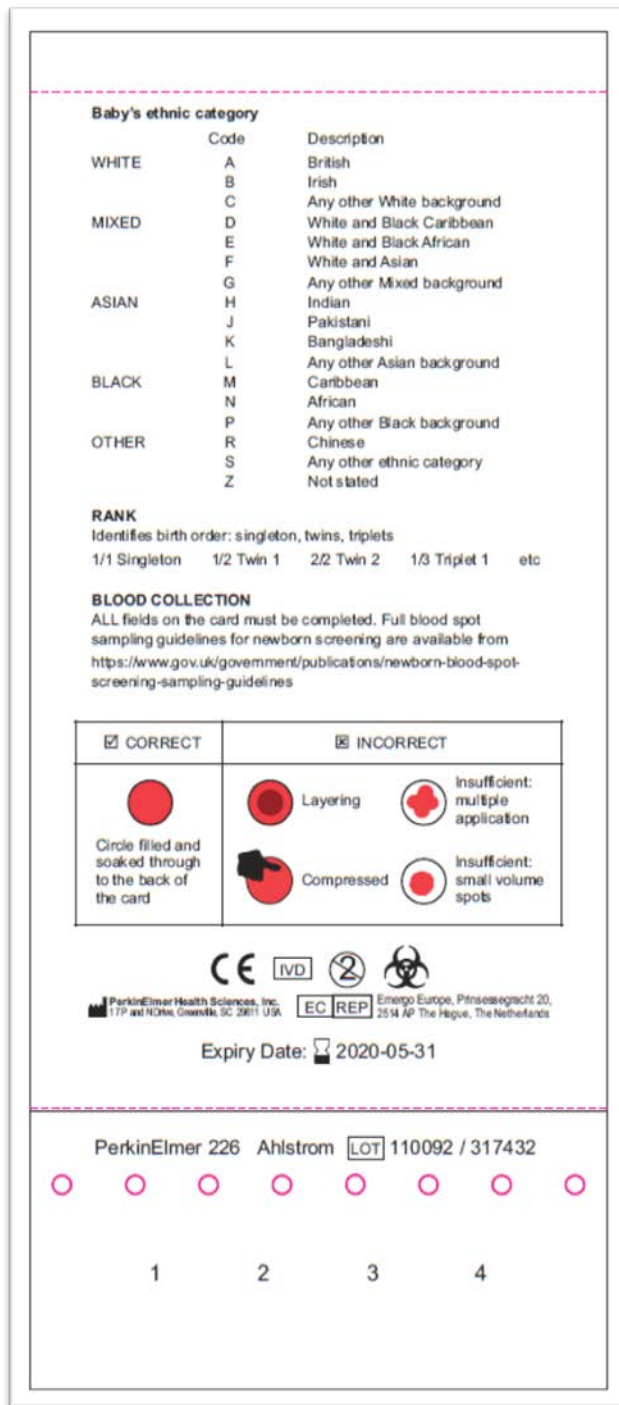
Total Form Height (all parts): 3 2/3" (93.1mm)

Total Form Length: 8 3/4" (222.3mm)

Front of proposed new design



Back of current card



Back of proposed new design

## Consultation responses

Responses were received from 98 trusts and 11 out of 16 UK screening laboratories (including 9 out of 13 English laboratories).

517 people completed the survey. Of those, 80 were excluded because they gave name and trust information only. Of the remaining 437 responses, 426 were from sample takers and 11 from newborn screening laboratories.



# Common themes and conclusions

## Shaded fields on front of card

On the new blood spot card, the shaded fields correspond to the fields that are printed on the barcoded label. If a barcoded label is used, the shaded fields do not need to be completed by hand.

We asked responders if these shaded fields were helpful. 92% of responders replied 'yes'.

**Conclusion:** Shading to be retained with the exception of the mother's NHS number and mother's DOB fields as only one or the other should be on the label. Only the field that is not on the label needs to be completed. If a label is not used then both fields will need to be completed.

## Sample taker's ID / NMC number

The new blood spot card design includes a field for the sample taker's Nursing and Midwifery Council (NMC) number.

We asked respondents if they thought it was reasonable to add this field to the card.

55% of responders replied that it was reasonable, 26% of responders replied that it was not reasonable and 19% of responders were unsure or had no preference.

**Conclusion:** NMC number field will be included on the new blood spot card, as endorsed by the Royal College of Midwives. This will make it easier for laboratories to identify and contact the sample taker if a repeat sample is required. The NBS programme advises that providers issue alternative ID numbers for non-NMC registered sample takers.

## Comments box

The current blood spot card has prompts in the comments box. One of these is 'mother's carrier status (antenatal HBO code, HBO Outcome code)'. This was changed to 'mother's antenatal sickle/thal (SCD) status if positive/carrier'.

We invited feedback from responders on the new wording.

**Conclusion:** In line with feedback, an additional prompt on in utero transfusions will be added to the 'Has baby had a blood transfusion?' field. The wording '(SCD)' will be removed.

## Research contact field

The new card design proposed a field for 'allow research contact' (with yes/no tick boxes). This field would act as a prompt for sample takers to ask parents for their consent to future contact about research that could identify their baby. Currently, sample takers record this information in the comments box if parents do not consent.

We asked responders what information would help them to complete this field.

Concerns were raised around gaining consent and approaching this subject with parents. Many responders felt unable to answer common questions asked by parents (for example who has access to the card, what type of research would be done and would another blood spot sample be needed).

**Conclusion:** To enable further consideration of its impact, the 'allow research contact' field will not be included at this stage. The NBS programme will continue to raise awareness about the principles of 'no research contact' and how to communicate with parents and record their decision in the comments box. This will enable further analysis of the benefits of the field and if necessary prepare laboratories for any changes to their laboratory information management systems. The responses from the consultation will help us to develop education and training resources.

## Back of the card

The following changes were proposed to the back of the card:

- removal of ethnic code 99 for 'not known' to comply with 2001 UK Census ethnic category codes
- rank information presented horizontally to save space
- new images of unacceptable samples (compressed and small volume spots)
- a link to the Guidelines for newborn blood spot sampling

We asked responders if they thought these changes would be helpful. 93% replied that they would be.

**Conclusion:** Proposed new design approved.

## Laboratory specific themes

Information on these proposed changes were included in the survey for newborn screening laboratories only.

### Pink paper layer

The current blood spot card has a pink paper layer which was not included in the new design. We asked laboratories if they found this layer useful and if there would be an impact on sampling processes if it was removed.

Around half (45%) of responding laboratories said they used the pink paper layer and around half (45%) said they did not. The comments indicated that the potential impacts of removing this layer vary widely across laboratories.

**Conclusion:** A designated member of the Blood Spot Card Review Project Group will liaise with newborn screening laboratories to gain a greater understanding of the potential impact of removing this layer before a final decision is made. If retained, the colour will be changed from pink to green.

### Barcode / filter paper

Blood spot cards have a barcode printed next to the 4 circles. We asked laboratory responders if they used this barcode.

5 of the 11 responding laboratories use the barcode and told us that it is an essential component of their sampling processes. Concerns were raised that the size of the filter paper on the new card did not leave enough room to attach a laboratory-issued barcoded label. This could create problems identifying the sample, particularly once the filter card is detached from the demographic details on the card.

**Conclusion:** The new card will include the barcode and the size of the filter paper will be changed to its original size, providing adequate space for laboratories to attach their barcoded labels.

### Lab use only field

We asked laboratory responders if they found the 'lab use only' box useful.

91% of responders found this field useful or very useful, providing room for additional information such as time stamps and laboratory barcodes. There were concerns about its size and the possibility of having to attach barcoded labels over parts of the card that may contain information.

**Conclusion:** The lab use only field will be increased in size to allow more space for laboratories to add additional information.

## Additional comments

We asked responders if they had any further comments or suggestions about the design of the card.

**Conclusion:** Based on the additional comments received, we have:

- made the GP practice name field bigger and changed the wording to 'GP practice name / code'
- changed the wording from 'Sample taker's Trust / Organisation' to 'Sample taker's trust / organisation name or maternity code'
- increased the size of the expiry date with bold font, and changed the date to the English format
- made the comments box bigger
- swapped the places of the 'Mother's D.O.B' and 'Mother's NHS number' and added to both '(insert below if not on label)'
- changed the birth weight from 5 boxes to 4
- changed the gestation field to weeks and days
- inserted a bold outline around the baby's NHS number field
- inserted bold separators in the mother's NHS number field to denote the XXX-XXX-XXXX format
- changed 'date of specimen' to 'date of sample' (in line with NBS standards and other documents)

## Next steps

### Glassine envelope

The size of the glassine envelope will be determined by the final version of the blood spot card. At this point the possibility of moving or removing the seam on the back of the envelope will be explored. We will consider enlarging the seam on the back of the envelope or removing it completely to avoid potential damage to blood spot samples.

### E-learning

An e-learning module on the new blood spot card (including an updated interactive blood spot card) is in development. Training tailored specifically for laboratories will be considered.