The Royal College of Pathologists
Pathology: the science behind the cure

NHS Newborn Blood Spot Screening Programme Standards 2017 to 2018 Consultation

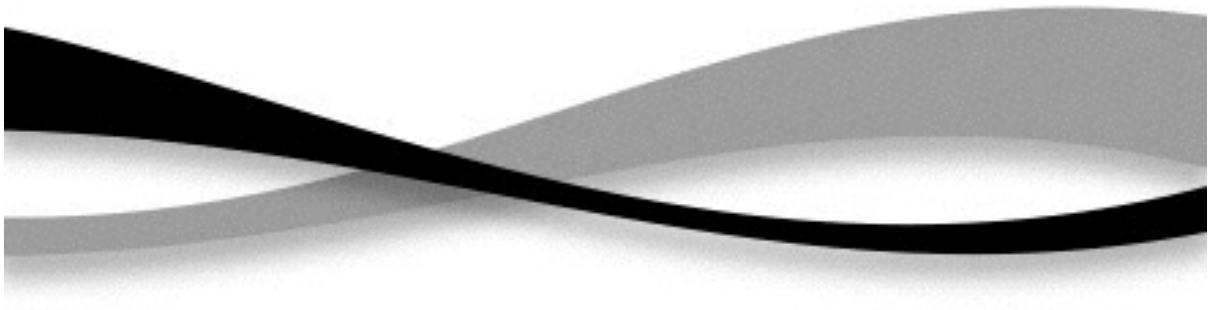
The Royal College of Pathologists' written submission

September 2016

For more information please contact:
Rachael Liebmann
Registrar

The Royal College of Pathologists
4th Floor
21 Prescot Street
London
E1 8BB

Phone: 020 7451 6700
Email: registrar@rcpath.org
Website: www.rcpath



1 About the Royal College of Pathologists

1.1 The Royal College of Pathologists (RCPath) is a professional membership organisation with charitable status. It is committed to setting and maintaining professional standards and to promoting excellence in the teaching and practice of pathology. Pathology is the science at the heart of modern medicine and is involved in 70 per cent of all diagnoses made within the National Health Service. The College aims to advance the science and practice of pathology, to provide public education, to promote research in pathology and to disseminate the results. We have over 10,000 members across 19 specialties working in hospital laboratories, universities and industry worldwide to diagnose, treat and prevent illness.

1.2 The Royal College of Pathologists comments on the NHS Newborn Blood Spot Screening Programme Standards 2017 to 2018 draft document for consultation. The following comments were made by members of the Paediatric and Perinatal Standing Advisory Committee during September 2016 and collated by Dr Rachael Liebmann, Registrar.

2 Consultation responses

2.1

2.1.1 The changes in the draft for consultation were considered to essentially be driving improvements with regard to the timely collection of samples (day 5 and not anytime between day 5 and day 8), to reflect the urgency with which healthcare professionals need to act, particularly with the introduction of the expanded screening. Early diagnosis of these conditions is even more necessary because of the speed with which children can decompensate and decline rapidly.

2.1.2 There is also a focus in the draft document on data integrity with the use of barcodes. This has been ongoing for some time however not all centres use barcodes currently and so there is a risk of misidentification.

2.1.3 The comments was made that the rationale for the exclusion of pre-transfusion samples from the numerators and denominators was not clear. It was considered that a baby should be tested pre-transfusion.

2.1.4 In the draft document Page 29 states that the standard of reporting does not apply to carriers of a condition. However College respondents could not find in the draft document anywhere a statement on the sharing of information with carriers. Is it proposed that carriers are all routinely informed, or not? The comment was made that it is also not clear in the draft document when and whether cascade screening is then offered?