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UK National Screening Committee PHE Screening Floor 5 Wellington House 133-155 Waterloo Road London SE1 8UG

08 August 2019

Dear UKNSC,

Re: Public consultation on the UKNSC's decision not to include pulse oximetry screening in the newborn and infant physical exam screening programme

The British Association of Perinatal Medicine (BAPM) is a professional organisation helping to improve standards of perinatal care by supporting all those involved in perinatal care to optimise their skills and knowledge, deliver and share high quality safe and innovative practice, undertake research, and promote the needs of babies and their families. With almost 1000 members including neonatologists, paediatricians, nurses, midwives, trainees, network managers and other healthcare professionals dedicated to shaping the delivery and improving the standard of perinatal care in the UK, BAPM leads on standards of care in perinatal practice through its Frameworks for Practice.

The BAPM invited comments from its members about UKNSC's recommendation. We have received individual comments from our members, a combined response on behalf of the National Neonatal Grid trainees, Paediatricians with Expertise in Cardiology Special Interest Group (PECSIG) and the British Congenital Cardiac Association (BCCA). These responses uniformly disagreed with the current recommendation and urged UKNSC to reconsider its recommendation. Many of these respondents have experience of having implemented routine pulse oximetry screening locally typically coupled with Newborn Infant Physical Examination (NIPE) for years and they shared their experiences of both detection of serious CHD as well as the management of 'false positives'.

1. Identification of babies with Congenital Heart diseases (CHD)

The limitations of both antenatal fetal ultrasound scanning (which detects only 43% of CHD) and Newborn Infant Physical Examination (NIPE) (which fails to detect 45% of infants with CHD) are well known. Research has shown that

adding pulseox screening as adjunct to the antenatal screening and NIPE can identify 75-92% of critical CHD^{1,2}.

Routine pulseox screening has been successfully and effectively implemented in a number of countries in the developed world including USA and recent reports from USA demonstrated decreased rates of deaths from critical CHD in states that have implemented routine pulseox screening³.

Our members shared a number of anecdotal stories of infants with critical CHD detected early through pulseox screening who might have otherwise been discharged home with the condition undiagnosed.

2. A positive result from pulse oximetry will generate some harms including: parental anxiety, a longer stay in hospital, possible transfer to the neonatal unit, further tests to assess for non-symptomatic conditions

BAPM was represented at the Expert Working Group convened by the UKNSC in June 2018 to consider the harms and benefits of the 'false positives' detected by pulseox screening. Using the data from the NSC UK PulseOx Pilot Study, of the 114 babies with positive test (from a cohort of 32,597 screened babies, 0.35%) who were admitted to the neonatal units, 82 (72% of admitted infants with screen positive) had one of eight distinct significant non-cardiac illnesses. In 6 of these conditions (persistent pulmonary hypertension of the newborn, congenital pneumonia, sepsis, meconium aspiration syndrome, transient tachypnoea of newborn and respiratory distress syndrome), the benefits of earlier detection and hence targeted treatment far outweigh any possible harms. It was only for 23 babies (22 with transient circulation and 1 with minor pneumothorax) that there was any inconvenience of delayed discharge and overtreatment, accounting for 0.07% of all screened infants. Putting it in perspective, 0.27% of screened infants were found to have a condition requiring urgent treatment which has serious implications if left undetected or detected late.

Our members have also shared instances of early detection of non-cardiac illnesses in their real life practice through pulseox screening, particularly pulmonary hypertension and sepsis.

Parental anxiety

Studies of anxiety scores among mothers of babies with false-positive results and those with true-negative results have not shown any significant differences. Our members who have implemented routine pulseox screening have not experienced parental anxiety. Instead, members have highlighted the need to balance the possible increased parental anxiety for a very small number of screened infants against the parental reassurance for vast majority of screened infants that their baby has normal oxygen saturations.

Longer Stay in hospital and unnecessary investigations

The maximum stay for babies with false-positive tests (in the absence of any significant non-cardiac illness) was 12 hours and the unnecessary investigations, which were with hindsight unnecessary, typically consisted of blood cultures and x-rays. Viewed against the huge benefits of earlier and pre-collapse detection of critical CHD through pulseox screening and timely intervention for those babies with significant non-cardiac illnesses, we do not believe that these considerations should deter the NSC from recommending a potentially lifesaving screening test.

Our members have shared their experience of a repeat pulse oximetry being the most common step following the initial positive screen test. In majority of cases, this simple step was all that was required and the families were reassured by a normal oxygen saturation before their baby being discharged home.

In summary, the current screening strategies fail to identify over half of the babies with critical CHD. The ease and high specificity of pulseox screening affords a simple yet effective and well accepted tool for earlier detection and timely intervention for babies with this potentially life-threatening health condition. Based on interpretation of the evidence and our members' shared experiences of screening thousands of babies over many years, BAPM urges the UKNSC to reconsider its recommendation against offering routine pulseox screening in the UK.

Yours sincerely,

-Helen Matter A

Dr Helen Mactier Acting President

Dr Stephen Wardle Hon Secretary

Dr Sanjeev Deshpande Hon Treasurer

- 1. Ewer AK, Middleton LJ, Furmston AT, et al. Pulse oximetry screening for congenital heart defects in newborn infants (PulseOx): a test accuracy study. Lancet 2011; 378: 785–94.
- 2. Zhao Q-m, Ma X-j, Ge X-l, et al. Pulse oximetry with clinical assessment to screen for congenital heart disease in neonates in China: a prospective study. Lancet 2014; 384: 747–54.
- Abouk R, Grosse SD, Ailes EC, Oster ME. Association of US state implementation of newborn screening policies for critical congenital heart disease with early infant cardiac deaths. JAMA 2017; 318: 2111–18.