BRITISH CONGENITAL CARDIAC ASSOCIATION

UK National Screening Committee
PHE Screening
Floor 5
Wellington House
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17th July 2019

Dear UKNSC,
Re: Pulse-oximetry screening for critical congenital heart defects NSC Consultation

On behalf of the council of the British Congenital Cardiac Association, I would like to respond to the UK National Screening Committee Consultation on the use of pulse oximetry as an additional test in the Newborn & Infant Physical Exam. The BCCA is the only body that represents the interests of everyone looking after children and adults with congenital heart disease including physicians, surgeons, nurses and cardiac physiologists. As such we are determined to improve outcomes for congenital heart disease and one of the major ways to achieve this is by early detection.

We understand that earlier this year the NSC reviewed pulse oximetry and decided not to introduce routine pulse oximetry for the detection of critical congenital heart disease (CCHD) in the newborn the reasons for which are given in the Consultation cover note. I would like to respond to each reason you gave in turn:

1) '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'

Data from the NSC UK pilot in reporting from 2015 showed that the positive test rate was between 0.7 and 0.8%. Of those who turn out not to have a cardiac condition up to 80% have a significant illness requiring treatment such as sepsis or pneumonia. Therefore for the vast majority of babies testing positive will require admission to the neonatal unit and further investigations purely on clinical grounds. In addition, the measured anxiety scores in mothers were not significantly higher in mothers of neonates with false positive results compared with mothers of those with true negative results.

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2) ‘For many of these babies, further investigations will not be necessary and the baby will be identified as healthy. This is a false positive result.’

This statement is not supported by the evidence. In the pilot study, only a minority 23 out of the 32597 screened had minor respiratory conditions which delayed discharge to a maximum of 12 hours and had unnecessary investigations in the form of blood tests and X-rays. In addition positive testing has not led to an increase in the demand for echocardiography.

3) ‘For babies with CHD or other non-cardiac condition it is not clear that investigations and identification of these conditions will lead to any better outcome than a diagnosis at the time the baby becomes symptomatic.’

This is clearly not true. Neonates are still presenting acutely unwell due to CCHD which has not been detected on antenatal scans. Although ante-natal detection is improving, it still only detects around 53.5% of CCHD in the UK with wide regional variation (National CHD Audit 2017-18, NICOR). An argument which has been advanced is that with improved prenatal detection, pulse oximetry screening is unnecessary but recent Dutch data with a 73% prenatal detection data refutes this both on accuracy (1) and cost effectiveness, particularly when both cardiac and non-cardiac morbidity is considered. A large study in the US clearly (2) demonstrated that those states who implemented routine newborn screening using pulse oximetry was associated with a significant decrease in infant cardiac deaths of 33% between 2007 and 2013 when compared to states without these policies. Pulse oximetry screening is now mandatory practice for all babies born in the US.

Therefore we would strongly urge the NSC to review their decision not to recommend routine screening for Critical Congenital heart Disease.

Yours sincerely

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References:

1. Narayan IC *et al*. Accuracy of Pulse Oximetry Screening for Critical Congenital Heart Defects after Home Birth and Early Postnatal Discharge. J Pediatr. 2018;197:29-35.

2. Abouk R, Grosse SD, Ailes EC, Oster ME. Association of US State Implementation of Newborn Screening Policies for Critical Congenital Heart Disease. JAMA 2017;381:2111-2118