# UK NATIONAL SCREENING COMMITTEE

## Newborn Screening for Kernicterus Policy Position Statement

## 13 November 2012

### Aim

1. This note provides background to the agenda item addressing the review of newborn screening for kernicterus.

### Current policy

2. The current policy is that screening should not be offered.

3. The UK National Screening Committee (UK NSC) last reviewed the case for screening in 2006. More recently the US Preventive Services Task Force considered the condition in 2009 and concluded that there was insufficient evidence on the benefits and harms of screening to recommend its introduction.

4. The reasons for this centred on:

### The natural history

5. There is an uncertain correlation between hyperbilirubinaemia and bilirubin encephalopathy. The association is often mediated by underlying problems such as blood group / rhesus incompatibility, infection, G6PD deficiency. More generally the progression from raised bilirubin levels to kernicterus is not well understood. Some babies develop bilirubin encephalopathy without having hyperbilirubinaemia and some with severe hyperbilirubunaemia do not develop bilirubin encephalopathy.

6. In the UK a recent British Paediatric Surveillance Unit study (2007) estimated an incidence of ~7/100,000 cases of severe hyperbilirubinaemia and an incidence of ~1/100,000 cases of bilirubin encephalopathy.

### The test

7. There appears to be some good evidence that babies at risk of developing hyperbilirubinaemia can be reliably detected using risk factors and / or bilirubin measurement. But as a marker of risk these appear insufficient in predicting bilirubin encephalopathy.

8. In the UK, the National Institute for Health and Clinical Excellence have published guidance on the management of jaundice and this recommends an approach to testing babies' bilirubin levels based on risk factors. These being: prematurity (<38 weeks), sibling with jaundice requiring phototherapy, maternal intention to breastfeed exclusively, jaundice in first 24 hours of life.

**The treatment**

9. There was insufficient evidence that phototherapy was effective in treating hyperbilirubinaemia with the aim of preventing severe hyperbilirubinaemia.

10. Bazian were asked to consider these issues and the review is enclosed.

**Review process**

11. The review addresses literature produced between 2006 and January 2011.

12. The document was considered by the Fetal, Maternal and Child Health Co-ordinating Group in March 2012. A three month consultation was hosted on the UK NSC website and this closed in June 2012. The following stakeholders were contacted directly: Royal College of Midwives, Royal College of Pathology (RCPath) and the Royal College of Paediatrics and Child Health (RCPCH).

13. Comments were received from RCPCH and RCPath and these raised no concerns with the documents conclusions. Both sets of comments are attached at Annex A

**Recommendation**

14. The UK NSC is asked to agree the policy position on newborn screening for kernicterus as follows:-

*A national newborn screening programme for kernicterus is not recommended*

15. The UK NSC is asked to agree that the policy should be reviewed in three years' time unless there is significant new peer reviewed evidence in the meantime.

**Annex A**

**Consultation Responses**

***Please note: We have redacted information to ensure compliance with the Freedom of Information Act***

From: UK NSC Enquiries [mailto:enquiries@uknsc.org]
Sent: 21 June 2012 10:16

Subject: Neonatal screening for kenicterus

UK Screening Portal website contact enquiry
From: [redacted]
Role: **Consultant Paediatric Chemical Pathologist, Member SAC RCPath Chem Path**
Email address: [redacted]
Message:

I think this is a good, pragmatic report.

If had decided to implement using specific laboratory bilirubin cut-offs, then many NHS labs would struggle with high levels to give accurate results. They are precise, but can be a fair way of a specific point.

**UK National Screening Committee**
**Kernicterus - an evidence review**

**Consultation comments pro-forma**

| | | | |
|---|---|---|---|
| **Organisation:** | Royal College of Paediatrics and Child Health | | |
| **Name:** | [redacted] | **Email address:** | [redacted] |
| **Section and / or page number** | **Text or issue to which comments relate** | **Comment** *Please use a new row for each comment and add extra rows as required.* | |
| Pages 34-35 | Conclusion | We agree with the conclusion that uncertainties prohibit the recommendation of a screening programme for kernicterus | |
| Page 18 | Line 22 | This should read specificity was 96.2% and not sensitivity was 96.2% | |
| Page 24 | Line 2 | DAT = Direct Antiglobulin Test (Coombs' test) | |
| Page 25 | Line 20 | Ductus arteriosus | |
| Page 29 | Line 25 | 'Suggests that that universal'. The blue that needs deleting | |

| | | |
|---|---|---|
| Page 33 | Line 26 | Should be criteria 20 and not 17 |
| Page 34 | Top of page | There is no comment about criteria 21 being met or not. Was it partially met? |
| General | | Over all this was a good review but difficult to read. There were 22 screening criteria reviewed. We wondered if a summary of the review outcome could have been included in this document for ease of recall. 3 criteria were met and 3 or possibly 4 were partially met. 3 were not clear/ uncertain/unknown. 7 criteria were not met and 5 were not applicable. Is there equipoise here? |
| General | | The conclusion is accepted that screening for kernicterus is not appropriate as part of the UK screening programme, although it is regrettable that universal screening does not appear to be feasible for this disabling condition. |
| General | | The recommendation for screening for kernicterus is still ahead of its time. The screening criteria are not met and the potential for over-medicalising normal babies as well as putting too much pressure on limited resources is too great.<br><br>We are led to believe that the NICE guideline for jaundice is still not implemented in most boroughs. Not all babies are having their bilirubin measured if they seem jaundiced, not all parents are being warned about the dangers of jaundice and the need to alert a healthcare provider to its presence within 6 hours.<br>The aim of the NICE guideline is to reduce the number of |

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| | | kernicterus cases. We would strongly suggest that we wait until it has been properly implemented and community midwifery services properly resourced before considering screening for kernicterus. Indeed, we would hope that there would then be no need for the screen anyway. |
| Page 3 | Introduction | The basic criteria on p.3 – which are sensible – have still not been met and therefore we agree that screening is premature. |
| | General | We are led to believe that money would be better spent on bilirubinometers for community midwives, further publicity for the NICE guideline, and a register to audit extreme hyperbilirubinaemia. |
| Page 5 | Appraisal against UK NSC Criteria | Bilirirubin is not yellow. It absorbs light energy from a certain part of the spectrum. |

Please return to Esther Rose, UK NSC Team Administrator (on behalf of John Marshall, Projects and Programmes Manager): esther.rose2@imperial.nhs.uk **by 23rd June 2012.**