



# Faculty of Public Health

of the Royal Colleges of Physicians of the United Kingdom

Working to improve the public's health

## Policy & Communications Department

Tel: 020 7935 3115

Fax: 020 7224 6973

13 August 2004

UK Newborn Screening Programme Centre  
Level 2  
55 Great Ormond Street  
London  
WC1N 3JH

Dear Sir/Madam,

### Re: UK Newborn Screening Programme Centre

The Faculty of Public Health welcomes the opportunity to provide comments on the *Proposed standards and policies for newborn blood spot screening*. Please find below comments which have been put together by public health colleagues with expertise in child health.

### Specific comments:

#### Framework

1. Three levels of standard is complicated. Two are used in other programmes: minimum and achievable by top quartile. This fits in better with recent Department of Health quality of healthcare framework.
2. There is a fundamental inconsistency between the targets for completeness of coverage in Standard 3 and the move to informed consent. Achievement of complete coverage will be outside the control of the programme – we do not know what an achievable target will be. Standards could be modified to completed cards [with either sample or marked decline] for 99.9% of babies be sent to laboratory.
3. Following on from this, Standard 7a should say 'no card has been received' rather than 'no sample'.
4. Timeframes for dispatch and transfer of completed cards are too slow – give no time for laboratory to identify and chase up untested babies. More than two weeks old can be too late for CHT by the time diagnosis is confirmed. Standard 11 is crucial but does not tie in with Standard 2 – the latter should be modified, as laboratory have to test all within this timescale to find the odd few positive ones. No chance of laboratory achieving ideal standard if their collecting service can achieve local ideal with no time for laboratory to process.
5. Standard 8 regarding laboratory processing: ideal should surely be within 24 hrs/one working day, down to within three working days as a minimum – sickle and CF can be a bit longer as treatment is not so urgent.
6. Standard 10 regarding routine feedback to parents at 6 week check is very welcome- long overdue.
7. Note 4: transfused babies: whilst the priority is to identify PKU and CHT babies within a few days of birth, transfusion makes sickle screening impossible. Blood spots could be taken when a sample is cross-matched prior to transfusion in many cases. This would avoid the need for repeat liquid sampling some time later – which is likely to cause a disproportionate amount of anxiety in areas with low prevalence of haemoglobinopathies.

8. Although this consultation document mentions close working with the haemoglobinopathy and CF programmes, it focuses on the 'traditional' Guthrie spot diseases, PKU and CHT. Future documents should include the standards for all disease screened through NN blood spots to enable access at one point and to ensure an integrated process.
9. This paper suggests that if a baby under 1 year has not been tested as they were not born in the UK, then a blood spot should be taken. In practice, this causes problems for health visitors, especially in parts of the country where there are new immigrants and asylum seekers. No evidence is given in the paper as to why children should be screened at age when, if affected, clinical symptoms should have appeared. This appears contrary to good screening policy. For haemoglobinopathies, where symptoms may appear later in childhood, the best way to screen the child may be to offer to screen the mother initially for carrier status. This will avoid the need to take blood from the child and give information for use in any future pregnancy in the mother.

### **Parental choice and professional communication**

10. Both leaflets are good and clear.
11. Support need informed consent for screening, and agree that this should just be recorded in notes – actually asking parents to sign makes very formal and could put some parents off.
12. However the option of allowing parents to opt out of screening for certain conditions can be very complicated and is not supported. It may make the whole consent process more fraught, as parents effectively have to make up to 4 decisions [cf MMR or single vaccines – better not to go there!]. Also it makes life very difficult for laboratories, which would then have to sort all requests manually to ascertain which babies should be screened for which conditions. This is likely to introduce delay to the process for all babies. Programming automated analysers will be unnecessarily complicated. Temptation for labs to do all and not report- until a test for which permission was not given comes up positive and then what?

### **Initial clinical referral**

13. An agreed national cut-off for screen positive PKU is essential, though may be hard to achieve.

I hope you find our comments useful. If you have any queries, please do not hesitate to contact me.

Yours sincerely,

Lindsey Stewart