



Dear Colleague

Pregnancy and Newborn Screening Programmes

I am writing to update on the implementation progress in relation to CEL 31 (2008) - Changes to the Pregnancy and Newborn Screening Programmes.

In summary these changes are:

1. The enhancement of existing pregnancy screening programmes:
 - by introducing first trimester screening for Down's Syndrome in which measurement of biochemical markers in the mother's blood is combined with the ultrasound measurement of nuchal translucency in the fetus (Combined Ultrasound and Biochemical Screening (CUBS)).
 - offering second trimester quadruple serum screening for women who book too late for first trimester Down's Syndrome screening
 - offering a second trimester fetal anomaly ultrasound scan between 18 weeks, 0 days and 20 weeks, 6 days
2. The introduction of haemoglobinopathy screening for pregnant women.
3. The extension of the Newborn Blood Spot Screening Programme to test for Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD) Sickle Cell Disorders.

Implementation schedule

The first deadline in the CEL, for all NHS Boards to offer second trimester fetal anomaly screening by 31 December 2009, has been achieved. As you are aware, the requirement is for all NHS Boards to have implemented the full range of developments no later than 31 March 2011.

**From the Chief Medical Officer
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Addresses

For action

Chief Executives, NHS Boards
Directors of Public Health, NHS
Boards

For information

Medical Directors, NHS Boards
(to cascade to Practice Managers)
Nurse Directors, NHS Boards
Chairs, NHS Boards
Royal College of General
Practitioners
Royal College of Nursing, Scottish
Division
Royal College of Midwives
Heads of Midwifery
General Medical Council
BMA

Further Enquiries

The introduction of changes to the Newborn Blood Spot Screening Programme for MCADD and Sickle Cell Disorders requires careful planning as it has to be introduced across Scotland on the same date. This has been subject to wide discussion and the following schedule has been agreed with NHS Board Implementation Groups for the remaining developments:

- From **Monday 27 September 2010** all NHS Boards must have in place systems to ensure that appropriate consent is obtained for the full range of newborn screening tests and is recorded on the revised consent form and all newborn blood spot samples are collected using the revised newborn blood spot card. NHS Boards must also ensure that referral pathways are agreed and in place.
- From **Monday 4 October 2010** the Scottish Newborn Screening Laboratory will report tests for Sickle Cell Disorders and Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD).

For pregnancy screening, NHS Boards are asked to plan to introduce the revised Down's Syndrome and haemoglobinopathies screening no later than **Tuesday 1 March 2011** to ensure that all women can access the revised programme by the deadline of the end of March. These changes will be rolled out in a phased manner once each NHS Board confirms that they have all associated requirements in place.

Annex A includes a summary of additional important operational information for health professionals involved in pregnancy and newborn screening. Further details are available on the Pregnancy and Newborn Screening Developments [website](#).

Yours sincerely

HARRY BURNS

Annex A

1. Communications

All information and guidance for professionals to support the developments to the pregnancy and newborn screening programmes continues to be published on the Pregnancy and Newborn Screening Developments [website](#) as it becomes available.

A Pregnancy and Newborn Screening Developments Bulletin will be issued and distributed regularly through existing communication channels to provide healthcare professionals with the latest information on the developments. Support from NHS Health Scotland is available to NHS Board communications teams to meet local communication requirements.

2. Resources for professionals and the public

Information resources to support informed choice

Two new information leaflets have been developed and published by NHS Health Scotland:

- *Your guide to screening tests during pregnancy (2010)*
- *Your guide to newborn screening tests (2010)*

They integrate the changes to the screening programmes and are designed to be used as a tool to support the health professional in a discussion about screening and the taking of informed consent from the parent.

Distribution of these public information materials has already begun, according to individual NHS Board requirements. The required quantities of the leaflets can be ordered from your local health promotion department. Any general questions in relation to distribution should be directed to the Publications Team at NHS Health Scotland on 0131 536 5500 or nhs.healthscotland-publications@nhs.net

All the public information materials are available to view on the Health Scotland [website](#).

Further information for the public about the screening programmes is also included on the Ready Steady Baby [website](#).

Translations and alternative formats

Translations are being developed by NHS Health Scotland in Chinese, Polish, and Urdu and will be available from the Health Scotland website later in the year. NHS Health Scotland is happy to consider requests for other languages or formats. Please call 0131 536 5500 or email nhs.healthscotland-alternativeformats@nhs.net

Provision to support parents with learning disabilities

The CHANGE resource, *My Pregnancy, My Choice*, is currently being updated to include information about all of the pregnancy and newborn screening programmes. The [Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities](#) (2009) recommend that this resource should be used to support parents with learning disabilities (in place of *Ready Steady Baby*).

The updated version of *My Pregnancy, My Choice* will be made available over the summer. To order copies or for more information contact Laura Martin, on 0131 313 7522 or laura.martin3@nhs.net.

3. Education and training

Education and training for health professionals is being coordinated by NHS Education for Scotland and is being organised at a local level through NHS Board screening coordinators and screening leads/practice development midwives.

A range of updates have been circulated through a variety of networks describing the developments and giving details of how to access support for training.

A range of resources are available to support education and training and includes:

- Pocket-sized resource cards
- Pregnancy and newborn screening developments training folders containing timeline and new information leaflets
- Support for local training
- Pregnancy and newborn screening network shared space
- Pregnancy and newborn screening resource portfolio to facilitate local cascade training which will include PowerPoint presentations covering all the screening developments (available from August 2010)

Anyone wishing to access any of the above resources or to discuss training requirements should contact Mrs Lucy Powls, Project Lead, Pregnancy & Newborn Screening Developments, lucy.powls@nes.scot.nhs.uk

4. Role of GPs for managing carriers of Sickle Cell Disorders

In line with what is currently in place to manage carriers of Cystic Fibrosis, GPs will manage carriers of Sickle Cell Disorders identified through the Newborn Screening Programme.

On detection of a Sickle Cell carrier screening result, the Scottish Newborn Screening Laboratory will notify the relevant GP Practice of the baby's carrier status, copying the notification to the local genetic service.

In line with current practice, GPs will make arrangements to meet with the family to inform them of the screening result, provide information and offer referral to the local genetic service for counselling and appropriate follow up. The Scottish Newborn Screening Laboratory will provide the GP with an information leaflet on Sickle Cell Disorder carrier status for parents and details of the process for referral.