1. Background

The National Services Division (NSD) commissions a number of screening programmes in Scotland including pregnancy and newborn screening (PNBS). The PNBS programme identifies pregnant women and babies who may have rare but serious conditions. Early treatment can improve their health and prevent severe disability or even death.

Healthcare Improvement Scotland supports NHSScotland’s screening programmes through developing new or, where appropriate, revising existing standards or indicators. For the PNBS programme, Healthcare Improvement Scotland has published *Clinical Standards for Pregnancy and Newborn Screening* (2005) and *Pregnancy and Newborn Screening Indicators* (2013).

Healthcare Improvement Scotland received a request from NSD and Scottish Government to review the clinical standards for PNBS. The project was accepted onto the Standards and Indicators work programme in August 2016.

2. The scope of the standards

2.1 Population that will be covered

- Pregnant women and newborn babies are eligible to access the PNBS programme.

2.2 Health and/or social care setting

- All PNBS services in Scotland, where directly provided by an NHS board or secured on behalf of an NHS board. This will include, but not limited to, hospitals, laboratories, prisons and long-stay institutions.
2.3 Areas for standards development

a. Areas that will be covered:

*Pregnancy screening:*
- Communicable diseases (HIV, hepatitis B, syphilis)
- Haemoglobinopathies (sickle cell disease and thalassaemia)
- Down’s syndrome and fetal anomaly

*Newborn screening:*
- Newborn hearing
- Newborn bloodspot test for maple syrup urine disease (MSUD), homocystinuria (HCU), isovaleric acidaemia (IVA) and glutaric aciduria type 1 (GA1)

b. Areas that will not be covered:

- Newborn and infant physical examination
- Diabetic retinopathy screening

These areas for exclusion are supported by other national workstreams.

A revision of the Healthcare Improvement Scotland *Pregnancy and Newborn Screening Indicators* (2013) is outwith the remit of this project. The PNBS indicators remain current and will be monitored to ensure their currency.

3. Related development sources

3.1 Key documents, policies, standards, guidelines and work programmes relating to the pregnancy and newborn screening standards.

a. Key sources (not exhaustive):

b. Related Healthcare Improvement Scotland standards or indicators:


4. Timelines

The PNBS standards project began in August 2016, with completion expected by winter 2017.

5. Proposed development group specialists

The proposed specialists to be represented during the PNBS standards development process are:

- Virologist
- Haematologist
- Obstetric sonographer
- Obstetrician
- Genetic counsellor
- Neonatalogist
- Neonatal nurse specialist
- Paediatrician
- Community midwife and hospital midwife
- Public health consultant
- Consultant specialist in immunisation
- PNBS board co-ordinator
- Representatives from the Down’s syndrome and pregnancy and newborn laboratories
- Newborn hearing service manager
- NSD representative*
- Patient/public partner
- Third sector representative
- Scottish Government – senior policy manager for screening*

* already recruited

6. Contact us

For any enquiries please contact:

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For more information about Healthcare Improvement Scotland, visit our website:
www.healthcareimprovementscotland.org