

## SCREENING OVERSIGHT AND ASSURANCE SCOTLAND BOARD: PROGRAMME INFORMATION ANNOUNCEMENT

**Subject:** Implementation of Newborn Screening for Spinal Muscular Atrophy (SMA) as part of an in-service evaluation (ISE)

**Date:** 02-03-2026

### Purpose of communication

We are writing to inform you about an upcoming change to the Scottish Newborn Bloodspot Screening Programme. **All babies who have a newborn bloodspot test taken on or after 23 March 2026 should be offered screening for spinal muscular atrophy (SMA) in addition to the existing ten conditions\*.**

### Background

SMA is being added to the programme for an 18-24 month period as part of an In-service evaluation (ISE). The UK National Screening Committee (UK NSC) has advised that important evidence gaps need to be addressed before a recommendation can be made to implement it permanently and have therefore recommended an ISE. The Scottish ISE will look at the feasibility and acceptability of SMA screening in a real-world NHS setting and will feed data into the ISE taking place in NHS England, the timescale for which has not yet been announced.

SMA is a rare, neuromuscular condition. It causes progressive muscle wasting (atrophy) and weakness. There are four main types of SMA (Types 1-4) and the severity and impact of SMA varies from person to person, both within and between the different types.

Approximately three babies every year are born with SMA in Scotland. Pre-symptomatic treatment has the potential to greatly reduce symptoms and prolong life.

### Advice for Newborn Bloodspot Sample-Takers

- Healthcare professionals taking newborn bloodspot samples should **ensure that parents are aware that SMA has been added to list of conditions screened for on a temporary, in-service evaluation basis** (this information has now been added to the information leaflet [Your baby! Tests offered - Publications - Public Health Scotland](#)) and NHS inform.
- Parents should be made aware that, as with all the screening tests, **they can choose to have SMA screening or decline it. If declined they can still have screening for the other conditions.**

\*The test currently screens for sickle cell disease (SCD), cystic fibrosis (CF), congenital hypothyroidism (CHT), phenylketonuria (PKU), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1), homocystinuria (HCU) and hereditary tyrosinaemia 1 (HT1).

- **If SMA screening is declined this must be recorded clearly on the bloodspot card.**
- No additional blood needs to be taken for SMA screening, the standard bloodspot sample is sufficient

### **Results and Referral**

As with the other screened-for conditions, the Scottish Newborn Screening Laboratory will immediately notify any positive samples to the relevant clinical service. In the case of SMA this will be the paediatric neuromuscular service in Glasgow regardless of the baby's health board of residence. Clinicians will then contact the parent and arrange urgent clinical care.

As has always been the case for the NBBS programme, no formal results letters for negative samples are routinely issued to parents; negative results are communicated verbally by the health visitor at the 6 week check using information recorded on the Child Health Records System. Since SMA screening has not been confirmed as a permanent addition to the programme, **SMA results will not be added to the Child Health Records System.** Health visitors should advise parents at the six week check that if a positive test result has not already been communicated to them then it should be assumed that the result is negative. They should be reassured that the lab has very strict processes in place to ensure that all positive tests are managed immediately. If the parent requests formal confirmation of this then the health visitor should contact the Scottish Newborn Screening Lab on 0141 354 9277 or using [gqc.newbornscreeninglaboratory@nhs.scot](mailto:gqc.newbornscreeninglaboratory@nhs.scot)

### **Professional information**

Training materials have been developed for health professionals involved in the newborn bloodspot screening programme and can be accessed here [Training Resources - Home](#)

All standard programme documentation (e.g. Newborn Bloodspot Programme Specifications) will also be updated to include the required condition specific information. We will email Heads of Midwifery and Consultant in Public Health leads for screening in each health board when this is complete and ask them to cascade links to the updated material to all midwives and neonatology units.

### **Implications for babies transferring between UK Nations and moving out of the UK**

Screening is aligned to the conditions offered within the UK nation/other country where the screening test was performed. From 23 March 2026 for the duration of the ISE, the following will apply:

#### **1.1. Babies screened in the other UK Nations or from outside the UK who transfer to Scotland:**

- Transfer records will show screening status, i.e. screening complete.
- If transferring in from another UK nation and screening is complete participation in the SMA ISE will not be offered.

- If a repeat test is required, the baby will be offered all of the screening tests that are available within Scotland, including the opportunity to participate in the SMA ISE.
- If a child under 1 year of age has transferred in from abroad and has no verifiable documented screening results available in English, screening should be offered for all conditions including the opportunity to participate in the SMA ISE, as per current guidance.

### **1.2. Babies screened in Scotland who move out of Scotland to another UK nation or abroad**

- Screening results transferred as per current protocols
- The SMA result will not be included in the “condition not suspected” results that are transferred, as the SMA result will not be recorded in the Child Health Records System.
- If the baby tests positive for SMA, the clinical team in Scotland will make a direct referral to the relevant clinical service in the new area of residence. This currently happens with babies diagnosed symptomatically or through sibling testing.
- If a repeat sample is required for any reason, the baby/family will be offered the screening programme offered in the nation they move to.

#### **Action Required**

- **Note the information above regarding the implementation of SMA screening in the PNB Programme in Scotland**
- **Cascade to all relevant staff – see distribution list below.**

Contact for queries: [NSS.SOASPandNscreening@nhs.scot](mailto:NSS.SOASPandNscreening@nhs.scot)

#### **DISTRIBUTION LIST**

	<b>Direct email</b>	<b>Cascaded via:</b>	<b>Cascade to:</b>
<b>CPH Leads for P&amp;NB Screening in all health boards</b>	X		<ul style="list-style-type: none"> <li>• Cascade to local P&amp;NB Steering group and other relevant staff within health board</li> </ul>
<b>All NHS Board hospital and community Midwives</b>		<ul style="list-style-type: none"> <li>• HoM</li> <li>• CPH leads</li> </ul>	Cascade to local teams
<b>All NHS Board Health Visitors</b>		<ul style="list-style-type: none"> <li>• DoN</li> <li>• CPH leads</li> </ul>	Cascade to local teams
<b>Child Health Administration teams</b>		<ul style="list-style-type: none"> <li>• CPH leads</li> </ul>	Cascade to local teams
<b>SNSL Director</b>	X		SNSL lab staff NHS GGC Diagnostics
<b>Clinical Lead for SMA Screening</b>	X		Paediatric NM Clinical teams Clinical Genetics teams

	<b>Direct email</b>	<b>Cascaded via:</b>	<b>Cascade to:</b>
<b>Scottish Muscle Network</b>	X		Cascade to <b>all</b> members
<b>Scottish Perinatal Network</b>	X		Cascade to <b>all</b> members
<b>SMA Implementation Group members</b>	X		Cascade to relevant stakeholders
<b>P&amp;NB Programme Board members</b>	X		Cascade to relevant staff
<b>NHS Board Directors of Public Health</b>	X		Cascade to relevant NHS board members
<b>NHS Board Heads of Midwifery</b>	X		Cascade to all hospital and community midwives
<b>NHS Board Directors of Nursing</b>	X		Cascade to all health visitors, neonatal nurses, midwives
<b>NSD Director, NSS</b>	X		Cascade to relevant staff
<b>NHS Board Medical Directors</b>	X		Cascade to Neonatologists, Paediatricians, Obstetricians, Clinical Geneticists and other relevant staff
<b>Scottish Government Screening Policy</b>	X		Cascade to CMO, SG Maternal and Child Health, SG Genetics
<b>NHS Healthcare Improvement Scotland</b>	X		Cascade to relevant staff
<b>NHS Education for Scotland</b>	X		Cascade to relevant staff
<b>Newborn Bloodspot Screening leads England, Wales, Northern Ireland</b>	X		Cascade to relevant staff
<b>Royal College of Midwives</b>	X		Cascade to relevant staff
<b>Royal College of Paediatrics and Child Health</b>	X		Cascade to relevant staff

	<b>Direct email</b>	<b>Cascaded via:</b>	<b>Cascade to:</b>
<b>Royal College of Nursing</b>	X		Cascade to relevant staff
<b>Edinburgh University Napier University Robert Gordon University University of the West of Scotland</b>	X		Cascade to relevant staff