

# Pregnancy and Newborn Screening:

## Newborn Hearing Standards

January 2019

We are committed to equality and diversity. These standards are intended to support improvements in healthcare for everyone, regardless of their age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation, socio-economic status or any other status. Suggested aspects to consider and recommended practice throughout the standards should be interpreted as being inclusive of everyone living in Scotland. We have assessed these standards for likely impact on the nine equality protected characteristics as stated in the Equality Act 2010. A copy of the impact assessment is available on request from the Healthcare Improvement Scotland Equality and Diversity Advisor.

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## Introduction

### Background to the pregnancy and newborn screening standards

Screening is offered to groups of the population to identify people who may be at an increased chance of a particular condition. Pregnancy screening is offered to help women make informed choices about their health and the health of their unborn baby during pregnancy. Newborn screening is offered to facilitate parents and carers to make informed choices about the health of their newborn baby. It is important that informed decisions are made in partnership with healthcare professionals at the respective stage of the screening programme.<sup>1</sup> Information on pregnancy and newborn screening, including national information produced by NHS Health Scotland, is provided to women throughout their pregnancy and following the birth of the baby.

### Newborn hearing screening

The newborn hearing test is a simple test undertaken in the first few weeks after a baby is born; sometimes it takes place before the baby leaves the maternity unit. A trained healthcare professional undertakes the hearing screen, which can be done in one of two ways:

- a small, soft earpiece will be placed in the outer part of the baby's ear, or
- three small sensors will be placed on the baby's head and neck. A small, soft earpiece or headphone will be placed in or over the baby's ear.<sup>2, 3</sup>

A complete screen includes:

- babies who had a conclusive screening result, and
- babies who were referred to an audiology department because a newborn hearing screening result was inconclusive or contraindicated.

### Policy context

National Services Division (NSD) has an ongoing role in the national multidisciplinary groups which monitor and evaluate the pregnancy and newborn screening programmes. Healthcare Improvement Scotland (HIS) supports NHSScotland's screening programmes through developing new and, where appropriate, revising existing standards. A request to revise the *Clinical Standards for Pregnancy and Newborn Screening* (October 2005) was received from the Scottish Government and NSD in summer 2016.

NSD has developed and published a set of Key Performance Indicators (KPIs)<sup>4</sup> to document progress in areas that have been identified within the pregnancy and newborn screening programme as requiring additional support.

These standards should be read alongside other relevant legislation, standards and guidance such as the KPIs mentioned above.

## **Scope of the standards**

These standards apply to newborn hearing screening and cover:

- coverage
- test performance and referral for diagnostic audiology assessment, and
- timeliness of diagnostic audiological assessment.

**These newborn hearing screening standards should be read alongside the general standards for pregnancy and newborn screening:**

- **Standard 1: Leadership and governance**
- **Standard 2: Information and support**

Information relating to the development of the pregnancy and newborn screening standards can be found in Appendix 1 of the general standards.

The full suite of pregnancy and newborn screening standards is available on the Healthcare Improvement Scotland website ([www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)).

## **Format of the standards**

All our standards follow the same format. Each standard includes:

- a statement of the level of performance to be achieved
- a rationale providing reasons why the standard is considered important
- a list of criteria describing the required structures, processes and outcomes
- what to expect if you are a person receiving care
- what to expect if you are a member of staff, and
- what the standards mean for organisations, including examples of evidence of achievement.

Within the standards, all criteria are considered 'essential' or 'required' in order to demonstrate the standard has been met.

## **Terminology**

Wherever possible, we have incorporated generic terminology which can be applied across all health and social care settings.

The terms 'woman', 'women' and 'individual' are used within the standards to refer to all individuals with a female Community Health Index (CHI) number.

The term 'eligible women' refers to women who are invited for pregnancy screening.

The term 'parents and carers' is used within the standards to refer to the parent, caregiver or guardian who assumes legal parental responsibility for the newborn.

## **Quality of care approach**

The pregnancy and newborn screening standards are a key component in supporting the pregnancy and newborn screening programme in quality assurance of its services. Monitoring and improving performance against these standards, at a local and national level, aims to improve the quality of the pregnancy and newborn screening programme.

External quality assurance (EQA) of screening programmes is delivered using Healthcare Improvement Scotland's quality of care approach and the Quality Framework.<sup>5</sup> This approach specifies how Healthcare Improvement Scotland will design and deliver EQA activity to support improvement in healthcare.

The quality of care approach emphasises the importance of regular open and honest self-evaluation using the Quality Framework as a basis, combined with other relevant data and intelligence including the performance against these standards. Any outcomes from the quality assurance activity will be risk based and set in the context of the programme capacity for improvement. Further information on this approach is available on the Healthcare Improvement Scotland website ([www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)).

## **Implementation**

Healthcare Improvement Scotland develops and publishes national standards to support organisations and health professionals in providing a high quality pregnancy and newborn screening programme. The implementation of these standards is for local determination.

## **Summary of standards**

**Standard 1:** All newborn babies are offered newborn hearing screening.

**Standard 2:** All stages of the newborn hearing screening process are safe and effective.

**Standard 3:** All babies requiring diagnostic audiological assessments are referred and seen in a timely manner.

# Pregnancy and newborn screening: newborn hearing standards

## Standard 1: Coverage

### Standard statement

All newborn babies are offered newborn hearing screening.

### Rationale

Newborn hearing screening is offered to all newborn babies to identify bilateral permanent moderate, severe and profound deafness. Early identification followed by appropriate and responsive support and management can give babies the best chance to develop their language skills.<sup>2, 3, 6-8</sup>

Providing parents and carers with the most up-to-date and accurate information allows them an opportunity to make an informed decision about screening for their baby.<sup>6, 7, 9, 10</sup> Information should be in a format that is accessible and understandable for individuals.<sup>6</sup> Before testing, parents and carers should have a discussion with healthcare professionals, this should include the purpose, process and benefits of testing.<sup>6</sup> When making decisions and informed choices, parents and carers should be fully involved and supported. The decisions and choices made about screening should be respected by healthcare professionals.<sup>6, 7, 9</sup> If parents and carers agree to newborn hearing screening, consent should be obtained before the screening test is carried out.<sup>6</sup>

In the event that newborn hearing screening is declined this should be recorded.<sup>6</sup>

**Please note:** Corrected age should be used for all babies born before 40 weeks gestation. This is actual age in weeks minus the number of weeks the baby was preterm.

### Criteria

- 1.1 NHS boards have systems and protocols in place for newborn hearing screening, which includes:
  - offering screening at the most appropriate time, including for babies who are ill or born prematurely
  - timescales and methods for communication of the result
  - providing opportunities to discuss with parents and carers the results, further management and/or further testing, and
  - processes for follow-up diagnostic audiological assessment.
- 1.2 NHS boards have systems and protocols in place to ensure all newborn babies:
  - are registered within the NHS board of residence



- are recorded on the Child Health Information System (CHIS) and the Newborn Hearing Screening Information Systems, and
- have processes in place with the child health or screening department to identify and follow up children with no recorded screening outcome.

**1.3** Prior to the test, parents and carers have:

- a pre-test discussion covering the purpose, process and benefits of the test (with the healthcare professional carrying out the test), and
- provided consent.

**1.4** All babies, whose parents and carers accept the offer, complete newborn hearing screening by 4 weeks corrected age.

**1.5** NHS boards have systems and protocols in place to identify and ensure appropriate management for:

- all babies who do not attend for screening, and
- all resident babies who were born outwith their NHS board area.

**What does the standard mean for parents and carers of the screened baby?**

- Parents and carers will:
  - be offered newborn hearing screening for their baby at the appropriate time
  - be advised of the newborn hearing screening options
  - receive information in a language and format appropriate to their needs, for example British Sign Language or large print, and in sufficient time to allow for informed choice
  - be offered the opportunity to discuss newborn hearing screening and results with an appropriate healthcare professional and all decisions will be respected, and
  - have their baby's newborn hearing screen completed within the agreed timescales.

**What does the standard mean for staff?**

- Staff can demonstrate knowledge of the:
  - importance of the newborn hearing screening programme
  - eligibility criteria for newborn hearing screening
  - patient pathway
  - how parents and carers can opt in and opt out of the newborn hearing screening, and
  - benefits and limitations of screening.
- Staff will:
  - provide information and support to parents and carers that is sensitive and respects their choices, and

- ensure decisions to accept or decline screening and/or referral for appropriate assessment is recorded and shared appropriately.

**What does the standard mean for the NHS board?**

- The NHS board will:
  - have an effective system in place to ensure all babies are offered newborn hearing screening within 4 weeks corrected age
  - regularly check the newborn hearing screening information systems and the Child Health Information System (CHIS) to identify babies with no screening outcome recorded, and
  - monitor the newborn hearing screening pathway to ensure it is timely.

**Practical examples of evidence of achievement** (NOTE: this list is not exhaustive)

- Monitoring reports detailing completion of the newborn hearing screening pathway within an agreed defined reporting period.
- Protocols for eligibility and invitation to the newborn screening service.
- Evidence that a baby undergoes screening if the parents and carers wish their baby to have screening.
- Audit of attendance and uptake rates of newborn hearing screening.

## Standard 2: Test performance and referral for diagnostic audiology assessment

### Standard statement

All stages of the newborn hearing screening process are safe and effective.

### Rationale

To identify newborns with bilateral permanent moderate, severe and profound deafness, a hearing screen should be carried out by 4 weeks corrected age.<sup>2, 3, 6, 7, 10</sup>

There are two different screening protocols in operation in Scotland: Automated Otoacoustic Emission (AOAE) and Automated Auditory Brainstem Response (AABR). Both of these can be offered in hospital or a community setting.

The AOAE and AABR screening protocols can have up to three stages.

- Stage 1 – the AOAE1 tests both ears and, if the result is a “no clear response” in one or both ears, the next protocol stage of the screen is AOAE2.
- Stage 2 – the AOAE2 tests the ear or ears that have not shown a “clear response” on the AOAE1. If the test result is a “no clear response”, the next stage of the protocol is the AABR.
- Stage 3 – the AABR test is carried out.<sup>2, 3, 6</sup>

The AABR screening protocol can have up to two stages.

- Stage 1 – a first AABR is carried out and if a result other than “clear response” in both ears’ is obtained then a further AABR should be carried out.
- Stage 2 – a second AABR is carried out.<sup>2, 6</sup>

Before testing, parents and carers should have a discussion with healthcare professionals about the purpose, process and benefits of testing.<sup>6</sup> This is to minimise parental and carer anxiety that may be caused by the screening process.

If a “no clear response” final outcome is recorded, a referral to audiology services for further diagnostic audiological assessment should be made.<sup>6</sup>

### Criteria

- 2.1** NHS boards ensure the proportion of babies with a “no clear response” in one or both ears at each stage of the screen is in line with national guidance.<sup>11</sup>
- 2.2** The provision of newborn hearing screening is timely, accurate and of high quality.

**What does the standard mean for parents and carers of the screened baby?**

- Parents and carers will:
  - be confident that their baby's newborn hearing screening is of high quality
  - receive information in a language and format appropriate to their needs, for example British Sign Language or large print
  - be fully informed and involved in all aspects of the screening process and given a full explanation if further assessments are required, and
  - be offered the opportunity to discuss the newborn hearing screening result with an appropriate healthcare professional to allow them to make an informed choice that will be respected.

**What does the standard mean for staff?**

- Staff can demonstrate:
  - the patient pathway, and
  - what is needed to undertake high quality hearing screening.

**What does the standard mean for the NHS board?**

- The NHS board will:
  - monitor the performance of the newborn hearing screening test, and
  - ensure continued professional development relevant to staff roles is monitored and access is provided to approved training.

**Practical examples of evidence of achievement** *(NOTE: this list is not exhaustive)*

- Reports from the screening management systems detailing referrals from each stage of the screen.
- Exception reports.

## Standard 3: Timeliness of diagnostic audiological assessment

### Standard statement

All babies requiring diagnostic audiological assessments are referred and seen in a timely manner.

### Rationale

Timely referral and assessment is essential to ensure that any babies with bilateral permanent moderate, severe and profound deafness are identified at the earliest possible age enabling appropriate support and management for the child and family and to give babies the best chance of reaching their full developmental potential.<sup>2, 3, 6-8</sup>

Babies who have a “no clear response” final outcome response in one or both ears or an “incomplete” result will be offered an immediate referral for diagnostic audiological assessment.<sup>2, 3, 7, 10</sup> A list of possible outcomes to the screening tests can be found in Appendix 1.

Following the diagnostic audiological assessment, the audiology team will explain the results to parents and carers.<sup>2</sup>

Staff are trained according to national guidance and professional competency frameworks relevant to their role.

### Criteria

- 3.1 Babies who require diagnostic audiological assessment are offered an appointment that is within 4 weeks of screen completion. This can be extended to ensure that babies have reached 0 weeks corrected age at time of assessment if required.
- 3.2 Babies who require diagnostic audiological assessment attend an appointment that is within 4 weeks of screen completion. This can be extended to ensure that babies have reached 0 weeks corrected age at time of assessment if required.

### What does the standard mean for parents and carers of the screened baby?

- Parents and carers will be offered:
  - diagnostic audiological assessment at the appropriate time, and
  - the most appropriate care and support during the diagnostic audiological assessment process.

**What does the standard mean for staff?**

- Staff can demonstrate knowledge of the:
  - referral pathways and processes in the event of the screening being incomplete, and
  - skills to undertake auditory assessment in line with professional competency frameworks.

**What does the standard mean for the NHS board?**

- The NHS board will ensure that:
  - audiology departments have the capacity to provide timely appointments to all babies referred from the newborn hearing screen, and
  - there is appropriate capacity to assess and treat within appropriate timescales.

**Practical examples of evidence of achievement** *(NOTE: this list is not exhaustive)*

- Audit of timescales of appointment offered and attendance at audiology department recorded.
- Exception reports.

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## Appendix 1: Possible screening outcomes

The screening outcomes for a complete screen within the newborn hearing screening information systems are as follows.

Screening result	Screening outcome
• clear response	no follow-up required
	targeted follow-up required
• no clear response	bilateral referral
	unilateral referral
• incomplete	baby/equipment reason
	equipment malfunction
	equipment not available
	lack of service capacity
	screening contraindicated
	baby unsettled

The screening outcomes indicating that a referral to audiology department is required are as follows.

Screening result	Screening outcome
• no clear response	bilateral referral
	unilateral referral
• incomplete	baby/equipment reason
	equipment malfunction
	equipment not available
	lack of service capacity
	screening contraindicated
	baby unsettled



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