# **Consultation on the draft standards for Pregnancy and Newborn Screening: Newborn Hearing**

**Background**

The National Services Division (NSD) commissions a number of screening programmes in Scotland including pregnancy and newborn screening (PNBS). The pregnancy and newborn screening services programme identifies pregnant women and babies who may have rare but serious conditions, where early treatment can improve their health outcomes. Healthcare Improvement Scotland supports NHSScotland’s screening programmes through developing new or, where appropriate, revising existing standards or indicators. Following a request from the NSD and Scottish Government, Healthcare Improvement Scotland are revising the pregnancy and newborn screening standards.

The standards will specify a minimum level of performance for pregnancy and newborn screening services and will apply to all screening services in Scotland, where directly provided by an NHS board or secured on behalf of an NHS board. This will include but is not limited to hospitals, laboratories, prisons and long-stay institutions. A scoping report has been developed outlining the areas for inclusion and exclusion, population and settings the standards will apply to.

* + - Fetal Anomaly
		- Haemoglobinopathies in Pregnancy
		- Infectious Diseases in Pregnancy
		- Newborn Blood spot
		- Newborn Hearing
		- General standards

There is no requirement to complete all 6 surveys relating to the draft suite of standards; please complete survey for General Standards 1&2 and then select and complete your preference from the list above. Healthcare Improvement Scotland is currently developing national standards for Pregnancy and Newborn Screening. A key element of our standards development process is public and staff consultation and we would like to hear your views and comments.

We would particularly appreciate your comments on the following aspects of each standard and please note all comments are welcome:

* Standard statement
* Rationale
* Criteria

To help you complete this survey, we have included text from all the standard statements, rationales and criteria throughout. This survey should take approximately 15 minutes.

**Information you provide:**

Healthcare Improvement Scotland (HIS) is data controller for any personal information you provide when responding. The purpose of this public consultation is to formally seek views from those with an interest in pregnancy and newborn screening services in Scotland and to use the responses in the development of these suite of standards. We will process personal data under our public task.

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The information you provide will be stored securely by Smartline Ltd on behalf of HIS, and will only be used for the reasons that have been specified in the consultation. We will only share your personal data with another organisation where this is permitted or required by law. Once the purpose of the consultation has been met, we will erase the names and contact details of private individuals.

We will publish responses or selected quotes but responses from both organisations and private individuals will be given a reference number only. Care will be taken not to reveal other information that could identify private individuals.

Further information on how we handle personal information can be found in our privacy notice online. This includes details of your information rights, such as that to receive your personal data, and who you can complain to. You can speak to our data protection officer on: 0131 623 4605.

**When you have completed this questionnaire to your satisfaction, please click "Finish Survey" at the bottom of the final page.**

**Sharing your feedback**

You can share your feedback with us by completing the survey or completing the word version and sending either:

1. An attachment to hcis.standardsandindicators@nhs.net
2. Posting it to:

Wendy McDougall
Project Officer
Healthcare Improvement Scotland
Delta House
50 West Nile Street
Glasgow
G1 2NP

This survey should take approximately 15 minutes.

The consultation will close on **Thursday 2nd August 2018** all comments submitted will be anonymised. A full consultation report will be available from Healthcare Improvement Scotland in winter 2018.

Thank you for taking part.

**STANDARD 1: ELIGIBILITY AND COVERAGE**

**Standard Statement:**All eligible newborn babies are offered newborn hearing screening.

### **Do you agree with the standard statement?**

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| --- | --- |
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| --- | --- |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

Do you have any comments about the standard statement?

|  |
| --- |
| We welcome the offer of Universal Newborn Hearing Screening to all eligible newborn babies in Scotland. The identification of childhood deafness at an earlier age has been a welcome step forward in improving Scotland’s public health and creating a fit for purpose Scottish audiology service.Following screening and identification of deafness, it is vital that coordinated follow up support services are in place to ensure that early detection is beneficial to the child’s language and communication development. This is especially important given data from an upcoming report shows that over the last seven years there has been an increase of 26% in children being identified as deaf in education and a reduction of Teacher of the Deaf support by 24%. |

**Rationale:**Babies are offered newborn hearing screening and, with written consent from a parent(s) of the baby, are tested within an agreed timeframe.5

Coverage can be defined as a measure of the delivery of screening to an eligible population.5

**Note:** Corrected age is the calculation of the baby’s actual age in weeks minus the number of weeks the baby was preterm.

 **Do you agree with the rationale?**

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**Do you have any comments about the rationale?**

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**Criterion 1.1:**NHS boards have systems and protocols in place to ensure all newborn babies:

* are registered within the NHS board of residence
* this is recorded on the Child Health Information System (CHIS), and
* have processes in place with child health/screening department to identify and follow-up children with no recorded screening outcome.

### **Do you agree with criterion 1.1?**

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| --- | --- |
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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about this criterion?**

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**Criterion 1.2:**NHS boards have systems and protocols in place for newborn hearing screening, which includes:

* offering screening at the most appropriate time
* timescales and methods for communication of the result
* providing opportunities to discuss with parents/carers the results, further management and/or further testing, and
* processes for follow-up diagnostic assessment.

**Do you agree with criterion 1.2?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about this criterion?**

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| It is important that information is made available in the appropriate format for all parents, including British Sign Language, where this is the parents preferred method of communication.We recommend this criterion refers to timescales and what is appropriate in terms of the communication of results. |

**Criterion 1.3:**Protocols are in place to undertake delayed screening for babies who are:

● ill, or

● born prematurely.

**Do you agree with criterion 1.3?**

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**Do you have any comments about this criterion?**

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**Criterion 1.4:**For pre-term babies, a minimum of 97% of babies will complete newborn hearing screening by 4 weeks corrected age.

### **Do you agree with criterion 1.4?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about this criterion?**

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| --- |
| We recommend this criterion includes all babies, not just pre-term. |

**Criterion 1.5**Each NHS board has 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.

**Do you agree with criterion 1.5?**

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| **https://app.smartsurvey.co.uk/images/ico/print/checkbox.png** | **No** |

**Do you have any comments about this criterion?**

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**Criterion 1.6:**Each NHS board has a failsafe protocol for all resident babies to ensure that follow-up action is taken where newborn hearing screening has been accepted but no result has been recorded.

**Do you agree with criterion 1.6?**

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|  https://app.smartsurvey.co.uk/images/ico/print/checkbox.png  | Yes |

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| **https://app.smartsurvey.co.uk/images/ico/print/checkbox.png** | **No** |

**Do you have any comments about this criterion?**

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| It is essential that Health Boards have processes in place to ensure that all babies whose parents accept hearing screening do actually receive it. This requires to be monitored on an ongoing basis. |

**Do you have any general comments about standard 1?**

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| --- |
| In the introduction to the standards it states that “all criteria are considered ‘essential’ or ‘required’ in order to demonstrate the standard has been met.” However it is not clear what the difference between essential and required is. Within the criteria there is no indication as to whether they are essential or required. We view all to be both essential and required.Apart from criterion 1.4 there is no indication of what is considered an acceptable level or acceptable actions that would demonstrate that the required standard has been met. |

**STANDARD 2: TEST PERFORMANCE AND REFERRAL FOR DIAGNOSTIC AUDIOLOGY ASSESSMENT**

**Standard statement:**

All newborn hearing screening is high quality, maximising effectiveness at each stage of the screening process and minimising harm.

**Do you agree with the standard statement?**

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|  https://app.smartsurvey.co.uk/images/ico/print/checkbox.png  | Yes |

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about the standard statement?**

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| It is important that the performance of the screen is monitored at each stage by all the Health Boards allowing comparisons of performance across Boards. In particular it is important to compare the numbers of babies referred from the screen to audiology with those that are found to have a confirmed permanent hearing loss (the positive predictive value). This information can be used to monitor the sensitivity and specificity of the screening process. |

**Rationale:**

Newborn hearing screening is a process which may involve up to three screening stages.

There are two different screening protocols in operation in Scotland.

* One protocol uses only Automated Auditory Brainstem Response (AABR) testing and can have up to two stages: a first AABR followed by a second if clear responses are not obtained on the initial test.
* The second protocol uses Automated Otoacoustic Emission (AOAE) testing followed by AABR if required. It can have up to three stages: a first AOAE followed by a second if clear responses are not obtained on the initial test, with an AABR being performed if clear responses are not obtained on the second AOAE.

A hearing screening record should be updated for every baby at each stage of the screen.

Complete screens are the total number of eligible babies for whom a decision about referral or discharge from the screening programme is made.

 **Do you agree with the rationale?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about the rationale?**

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| We view the above as description of the different screening protocols used, not a rationale.The rationale should be in terms of monitoring screen performance at each stage of the screening process to ensure optimal performance and that harm is minimised. |

**Criterion 2.1:**The proportion of babies who have a “no clear response” in one or both ears during the first otoacoustic emissions (AOAE1) hearing test is in line with national guidance.

### **Do you agree with criterion 2.1?**

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**Do you have any comments about this criterion?**

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| It is unclear what the national guidance is. We recommend it is stated here what the maximum percentage of babies is that we would expect to be referred at this stage. |

**Criterion 2.2:**The proportion of “well babies” who have a “no clear response” in one or both ears during the second otoacoustic emissions (AOAE2) hearing test is in line with national guidance.

**Do you agree with criterion 2.2?**

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**Do you have any comments about this criterion?**

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| --- |
| Again, it is unclear what the national guidance is here. The maximum percentage of babies expected to be referred at this stage should be stated. |

**Criterion 2.3:**The proportion of “well babies” who have a “no clear response” in one or both ears during the first automated auditory brainstem response (AABR1) hearing test is in line with national guidance.

### **Do you agree with criterion 2.3?**

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**Do you have any comments about this criterion?**

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| --- |
| Again, it is unclear what the national guidance is here. The maximum percentage of babies expected to be referred at this stage should be stated. |

**Criterion 2.4:**All babies with a screen identified as “no clear response” in one or both ears are referred for diagnostic assessment in line with national guidance.

### **Do you agree with criterion 2.4?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about this criterion?**

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| We recommend is it made clear where the national guidance can be found. This criterion may be unnecessary as Standard 3 covers the referral to audiology, or should possibly read “All babies with a screen identified as “no clear response” in one or both ears *at the end* *of the screening process* are referred for diagnostic assessment in line with national guidance.” |

**Criterion 2.5:**On completion of the screening process, the proportion of babies requiring referral for diagnostic audiology assessment is in line with national guidance.

 **Do you agree with criterion 2.5?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about this criterion?**

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| --- |
| Again, it is unclear what the national guidance is here. Percentage referral expected at this stage of screening should also be stated. |

**Do you have any general comments about standard 2?**

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| --- |
| As previously mentioned, it is not clear what the difference between essential and required is. There is no indication within the standards about what is actually required to demonstrate that a criterion has been met. For example, what is an acceptable level of referral at each stage of the screen? Should there be identified ‘targets’ to be met? Could / should there be 2 levels, acceptable and achievable as in the English standards? |

**STANDARD 3: TIMELINESS OF DIAGNOSTIC AUDIOLOGICAL ASSESSMENT**

**Standard statement:**

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

**Do you agree with the standard statement?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Yes |

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| --- | --- |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about the standard statement?**

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| --- |
| Agree with this criterion. Diagnostic follow-up has been an area of significant variation in range and quality of follow-up provided to diagnosed children across health boards in Scotland since the introduction of UNHS. Timely diagnostic assessment is essential to ensure any hearing loss is identified as early as possible. This allows for timely assessment and interventions which are crucial in ensuring improved outcomes in the child’s language and communication development, social and emotional development, readiness for mainstream education and level of educational achievements.In terms of maximising the effectiveness of UNHS there is scope for utilising UNHS data to inform service delivery for deaf children and young people across Scotland. In 2011 we commissioned two pilot projects exploring how local records of deaf children could be maintained to collate information about deaf children and ensure this data was shared effectively with relevant local partners in health, social care and education. These pilots were successful. The Scottish government have recognised this system of data collection as the best way forward and we are currently in talks on rolling out these initiatives nationally. |

**Rationale:**

Babies with a “no clear response” result in one or both ears, or “incomplete” result (see Appendix 3) are referred for immediate onward referral for audiological assessment.5 Audiological assessment and follow-up of babies is in line with national guidance.6

Timely referral and assessment is essential in order to ensure that any babies with a permanent significant hearing loss or impairment 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.

**Do you agree with the rationale?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about the rationale?**

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| --- |
| This standard is critical. Early confirmation of hearing loss is essential to allow appropriate early support for babies and their families. An integrated early years framework for a deaf child following initial diagnosis should bring together the services of paediatric audiologists, qualified Teachers of the Deaf, educational audiologists, speech and language therapists, social workers, health visitors and third sector organisations such as the National Deaf Children’s Society. In the absence of statutory or government-endorsed guidance on the supports that should be available to deaf children following diagnosis, there is inconsistent practice across Scotland which results in some areas of effective practice and some where families feel less supported.We recommend the words “or impairment” are removed. These are not necessary where screening is seeking to identify babies with a hearing loss or not. The word “impairment” is not liked by parents of deaf children or deaf children themselves who do not view themselves as being impaired. Removing any negative language from professional documents helps to stop use of the language with service users.  |

**Criterion 3.1:**Babies who require diagnostic assessment are offered an appointment that is within 4 weeks of screen completion or by 44 weeks gestational age.

### **Do you agree with criterion 3.1?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about this criterion?**

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| --- |
| It is important that audiology departments have the capacity to offer families diagnostic appointments as early as is clinically appropriate following referral from the screen.How is this to be measured to demonstrate that the standard has been met? Is it expected that 100% of babies referred are offered appointments in this timescale? That should be possible. |

**Criterion 3.2:**Babies who require diagnostic assessment attend for assessment within
4 weeks of screen completion or by 44 weeks gestational age.

**Do you agree with criterion 3.2?**

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| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |

**Do you have any comments about this criterion?**

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| --- |
| While audiology departments do not necessarily have any control over families attendance at appointments it is important that they take all reasonable action to encourage and enable families to attend, by offer appointments on different days and at variable times.How is this to be measured to demonstrate that the standard has been met? Is it expected that 100% of babies attend appointments in this timescale? That is very unlikely to happen. What is an acceptable percentage? |

**Do you have any general comments about standard 3?**

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| --- |
| Again, it is not clear what the difference between essential and required is. There is no indication within the standards about what is actually required to demonstrate that a criterion has been met. What is an acceptable level? Should there be identified ‘targets’ to be met? Could / should there be 2 levels, acceptable and achievable as in the English standards? |

**GENERAL COMMENTS**

### **If you have identified any gaps within the standards, criteria or evidence, please provide further information below:**

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| --- |
|   |

### **Is there anything which the project group should consider when finalising these standards?**

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### **Any other comments?**

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**RESPONDENT INFORMATION**

I am responding to this consultation\*

On behalf of an organisation. If yes, go to A.

As a private individual. If yes, go to B.

The organisation agrees to the inclusion of the response in the published report to illustrate points being made or to provide context. The organisation name will be replaced with a number:

Yes   No

It should be noted that a response, including its corporate source, may need to be disclosed in answer to a request under the Freedom of Information (Scotland) Act 2002.

I agree to the inclusion of my response in the published report to illustrate points being made or to provide context. My name will be replaced with a number:

Yes   No

It should be noted that a response may need to be disclosed in answer to a request under the Freedom of Information (Scotland) Act 2002. We do not disclose the names of those responding as private individuals. Names of senior employees responding on behalf of organisations may be disclosed.