

Paediatric Hearing Services Improvement Programme: Communications toolkit



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This communications toolkit has been developed to support communications teams within NHS trusts, integrated care boards (ICBs) and NHS England regions when asked about the National Paediatric Hearing Services Improvement (PHSI) Programme. The toolkit includes national key messages and media lines, advice for trusts, ICBs and NHSE regions if approached by the media, and template letters for use by trusts when contacting families and or stakeholders. We will update this toolkit every 3 months to reflect updated figures and messaging.

If you have any questions about this comms toolkit or the PHSI Programme, please contact: england.csohearingprogramme@nhs.net.

Background

In response to a report into audiology care at NHS Lothian, NHS England's Newborn Hearing Screening Programme completed an analysis of data for every baby born in England from 2018-2023. This identified four trusts (five services) with significantly fewer babies with permanent childhood hearing impairment than would be expected compared to national averages. Peer reviews, led by the Newborn Hearing Screening Programme, focused on the five initial services and highlighted systemic issues in paediatric audiology services. The National PHSI Programme was set-up in response to the peer reviews by the Office of the Chief Scientific Officer, NHS England.

The primary focus of the Programme is to undertake a nationally coordinated review of all paediatric audiology services in the NHS in England, to develop a review, recall and reassess model to identify babies and children at risk and mitigate harm caused by mis- or delayed diagnosis, and to assist services in delivering quality improvement interventions.

Current programme position – September 2024

Over the past year, the national PHSI Programme, has been working to understand the scale of challenges within paediatric audiology services and the interventions needed to support providers to make improvements.

In collaboration with ICBs, providers, NHS regions, CQC, and professional bodies, NHS England are working to ensure that these services deliver safe, high-quality, and timely care for all children.

NHS England regions have conducted desktop reviews of all 140 paediatric audiology services across England. Of these, 90 services were found to have either low or partial levels of quality assurance and will now require further, in-depth reviews to determine if babies and children need to be recalled for reassessment.

23 September 2024 - [NHS England sent a letter to ICBs](#) outlining their responsibility to carry out these in-depth reviews and the recall and reassessment process. The letter includes details of the nationally funded provision of subject matter experts who will provide support at the system level. NHS England will provide further support through a series of webinars and operational guidance.

23 September 2024 – [NHS England published operational guidance](#) outlining the national review and recall process, data requirements and governance structure.

The national ambition is to complete all patient reassessments by March 2025, ensuring that patients are either discharged or placed on an appropriate treatment pathway by September 2025.

Key messages

- The National Paediatric Hearing Services Improvement Programme was set up by NHS England in response to issues found in paediatric audiology services.
- [Since the last communication](#), the programme has been working to understand the scale of challenges within paediatric audiology services and the interventions needed to support providers to make improvements.
- NHS England regions have made substantial progress, conducting desktop reviews of all 140 paediatric audiology services across England.
- The desktop reviews have identified 90 services¹ with either low or partial levels of quality assurance and those services now require further, in-depth reviews by clinical experts to determine if babies and children need to be recalled for reassessment.
- [The in-depth review process will be led by ICBs](#). NHS England will fund subject matter experts - a group of senior scientists trained in technical reviews - to provide support at a local level.
- Where children need to be reassessed, trusts are contacting families, via their local hospital.
- The national ambition is to complete all patient reassessments by March 2025, ensuring that patients are either discharged or placed on an appropriate treatment pathway by September 2025.
- NHS England are committed to providing ongoing support to local systems as we work together on the review, recall and reassess process. [Operational guidance is available](#), outlining the national review and recall process, data requirements and governance structure.

¹ This figure is subject to change. Please check with the Paediatric Hearing Services Improvement Programme team if you are planning to use.

- A series of webinars for ICB leads and regional colleagues will take place throughout October and November 2024 to provide information and guidance on the review and recall process.
- NHS England are working with ICBs, providers, NHS regions, CQC, professional bodies, and patient groups to ensure that services operate safely and that every child receives the high-quality and timely care they deserve.
- For further information, please contact the national Paediatric Hearing Services Improvement Programme inbox england.csohearingprogramme@nhs.net.

Secondary lines/background

- Alongside the desktop reviews of 140 paediatric audiology services, the programme has hosted regional workshops on auditory brainstem response (ABR). Further workshops are planned, covering ABR and other methodologies. A webinar series covering good scientific practice is underway and lessons learnt are being collated to be shared with NHS colleagues.

Media advice

Guidance for ICBs and regions

We expect ICBs and regions to be contacted by journalists asking for information on a local level. It is the responsibility and decision of the ICB and regional comms leads to decide whether to respond.

NHS England will respond when asked, and if appropriate, about the status of paediatric audiology services across England. NHS England will not provide information about individual services, trusts or ICBs.

When approached by a journalist, this should be flagged with nhsengland.media@nhs.net and england.csohearingprogramme@nhs.net for the attention of the communications manager so that the national team is aware of media interest and activity. This provides an opportunity for the national team to advise on a coordinated response if other, or all, ICBs are approached. Your drafted responses should also be shared.

Guidance for trusts

It is the responsibility of the trust to respond to journalists as they see fit but the main angle / point of interest for journalists is likely to be about the number of patients affected within a trust.

We would avoid providing commentary relating to number of patients, whether that be recall of patients or levels of harm. We would recommend that responses are high level and focus on improvement measures that a trust is implementing.

NHS England will respond when asked, and if appropriate, about the status of paediatric audiology services across England. NHS England will not provide information about individual services, trusts or ICBs.

The national PHSI comms team can review proposed media responses where helpful. However, this is not mandatory, and we do not need to sign off your responses. Any approach by journalists should be flagged with your regional/ICB comms lead, along with england.csohearingprogramme@nhs.net. This provides an opportunity to share advice and co-ordinate responses if other services are approached. Once you have formed your response, this should also be shared.

National lines – last reviewed 20/09/2024

“Having identified issues locally, the NHS established a national programme last year to review data at all paediatric audiology services in England to assess the scale of challenges facing services and the action needed to ensure any children at risk of misdiagnosis are identified.

“This analysis has identified local services that require further, in-depth reviews by clinical experts to determine if babies and children need to be recalled for reassessment. Families affected are being kept closely informed. The review process will be led by local ICBs and the number of children affected will not be known until these expert reviews have been completed – the NHS is fully committed to being transparent about the outcomes of this comprehensive national review.”

Freedom of Information requests

If you receive a Freedom of Information (Fol) request, this should be flagged with your local Fol team with a request to liaise with the national Fol team as needed. This provides an opportunity to share advice and co-ordinate responses if other services are approached. Once you have formed your response, this should also be shared.

Resources to support ICB, subject matter experts and other staff

- [Operational guidance](#) detailing the national service assurance framework, data requirements and governance structure.
- Further technical guidance including frameworks and templates for the ABR small cohort review, on-site review, full cohort review and recall, prioritisation and harm review. Plus, example clinical testing mitigation and triage criteria for paediatric audiology referrals and reviews.
- A series of webinars for ICB leads and regional colleagues will take place throughout October and November 2024 to provide information and guidance on the review and recall process.

- Workshops targeted for audiologists have been delivered across all the regions on upholding 'good scientific practice'. These workshops will continue throughout 2024.
- The programme is working to support services to become UKAS IQIPs accredited, and an interim benchmarking offer is available to support early assessment of the quality of their paediatric hearing services.
- A wellbeing offer has been developed. More information on this is available below.

Wellbeing offer for staff

Trusts should identify a named health and wellbeing lead for the paediatric audiology workforce. This person should be able to identify immediate support for staff health and wellbeing as well as training programmes for resilience and handling difficult situations.

There are a range of national programmes that aim to support organisations and leaders to look after the health and wellbeing of their colleagues. We encourage you to also seek your local health and wellbeing support offers within your own organisations. Find out more about the national support available here: [NHS England » Supporting our NHS people and how to access support](#) see [NHS England » Staff mental health and wellbeing hubs](#).

FAQs - staff and services

How do I identify if my service may have a problem?

ICBs executive leads, trust leads and paediatric audiology services need to review all their services. The national programme has outlined the key sources of evidence that should be considered.

What if I'm aware of a service that has a problem?

Please follow the local processes at your trust for raising a concern. This may be to talk to service leads first before taking it to an appropriate executive director, such as your medical director or chief nurse.

What is the financial support available for services to support the quality improvement and resources required?

Service providers should work with their ICBs and their provider executive teams such as the medical and nurse directorate to develop the appropriate business cases for funding requests. It is important that the ICBs ensure the appropriate funding for the services that they commission.

How do I report a problem if I think there are problems with my hearing service?

Staff should follow local reporting processes to raise and or escalate a concern.

NHS England fully advocates a just culture with strong, supportive, and compassionate leadership to enable staff to speak up about their experiences and concerns. This can be raised here: [NHS England » The national speak up policy](#).

How do I find out if my patients have been affected, need re-testing or a check-up?

If your trust identifies a service in need of assurance and improvement, they should follow the National Service Assurance Framework, detailed in the [operational guidance document](#).

What should a service do if they recognise that they have identified issues related to poor quality services?

Paediatric audiology services should report their status to their trust and ICB. ICBs will then work with trusts to review available data on service quality and identify appropriate action.

All trusts – even those who have not identified issues – should ensure adequate service provision to a high standard of quality, including operating within UKAS IQIPS accreditation to ensure best possible provision of service for patients. Trusts may need to notify UKAS and CQC to update on the service status.

I work within a primary care setting – what do I need to do?

Staff who work within primary care should make themselves aware of the programme in case that they are asked by patients. Families of newborn babies should be encouraged to engage with the newborn hearing screening programme to identify whether their baby requires further testing. Staff should continue to refer children into the audiology services for their hearing needs to be assessed.

Guidance to support communicating to families

Patient letters

Once a trust has reviewed which patients require reassessment, families should be contacted with the outcome of this review. Families should be contacted whether their child requires a reassessment, or not, and they should be informed as soon as possible.

According to best practice [duty of candour processes](#), it is important that if a child needs reassessing, parents are contacted first with a telephone call explaining what has happened and what the next steps are. This should be followed up with a letter outlining what was covered in the telephone conversation. Template letters are available in the appendix.

- [Appendix A](#) - template letter for parents when their child requires reassessing.
- [Appendix B](#) - template letter for families of a child who does not require a follow up appointment, but their hearing test has been part of the review.
- [Appendix C](#) - template letter if parents have contacted a trust to enquire if their child is involved in a review.

- [Appendix D](#) - template letter for stakeholders, such as local councils and authorities, informing them of the improvement activity.
- [Appendix E](#) - template email for stakeholders updating them on the local programme/notifying them of the serious incident report being sent shortly
- [Appendix F](#) - call centre script
- [Appendix G](#) - template note to GPs with details of where to direct concerned families
- [Appendix H](#) - example local reactive media statement

FAQs - families

National FAQs

I have heard that the hearing service that assessed my child's hearing is under review. What do I need to do?

Please be assured that if your child has been part of this review, you will be contacted to either arrange a reassessment if it's required, or to let you know that your child's hearing does not require reassessment. If you are concerned, please contact the hearing team that assessed your child.

If you would like further information about hearing and hearing tests, as well as information about hearing loss and how it is managed, we recommend the following as sources of reliable information:

Information about the different types of hearing tests for children can be found on the NHS website: <https://www.nhs.uk/conditions/hearing-tests-children/>

The National Deaf Children's Society: <https://www.ndcs.org.uk/>. The Society also run a helpline which is open Monday to Thursday, 9am to 5pm and Friday, 9am to 12.30pm. Call 0808 800 8880 or email helpline@ndcs.org.uk. For Live Chat or BSL video relay visit www.ndcs.org.uk/our-services/services-for-families/helpline/

My child has a hearing test at a service which is currently under review. Should I attend?

Parents are advised to continue to attend any scheduled assessments. You will be contacted if a hearing test needs to be rescheduled.

Local FAQs

Which hospitals has this happened at?

[insert hospitals]

How did you find out you had a problem?

As part of a national review of audiology services across England, carried out by NHS England, we were identified as an outlier for the numbers of babies being identified as deaf or hard of hearing.

What is an ABR test?

The ABR (auditory brainstem response) test is used to detect hearing loss in children. It checks a child's brain's response to sound. The test is mostly done on infants and children who may not be able to respond to behavioral hearing tests because of their age. It shows whether the inner ear, called the cochlea, and the brain pathways for hearing are working. The test is used with babies who do not obtain clear responses from newborn hearing screening. The audiologist places three small sensors and a set of headphones on the child's head. For an accurate result, the child must be very still and quiet throughout the test. In young babies the test can be carried out while they are sleeping. In slightly older children, a light sedative or an anaesthetic may be offered.

When did you find out there was problem?

The initial review was done in **[insert month and year]**. The decision was taken to suspend ABR service on **[insert date]**. We are continuing to offer the ABR test, which is being done by staff from other hospitals **[insert hospital(s)]**. The work we have done with external specialists since then also identified possible issues with our paediatric audiology assessments within community paediatric clinics in both **[insert community clinics]**. As a result of this these types of community clinics were stopped on **[insert date]**.

How many children does this involve? And what is the impact on them?

Please contact the NHSE National Media team, nhsengland.media@nhs.net if you are asked to provide numbers of children involved – this will help us coordinate a responses if other services are approached.

How do you know your newborn screening service is ok?

In the UK, each newborn hearing screening service at trusts is expected to meet a set of quality standards that record how many babies are tested and how many are referred to audiology for further testing. **[insert trust]** has been meeting these standards.

Why has it taken so long to contact families/do anything?

We have been working with experts to review all cases, this will take some time.

How and when will you be contacting the families?

We have been contacting families by letter and phone. We have spoken to all those families where we have identified harm and have been in contact with them to let them know the outcome of our investigation.

Any child which needs retesting is being prioritising and we are contacting families, by letter or phone, to agree a mutually convenient time for the child to be retested.

How far back does this problem go?

It's likely that problems have existed for several years.

Next steps if child is found to have a level of deafness?

Children in this situation need two things. First treatment to be able to do everything possible to improve their hearing. Secondly support from specialists to improve their speech and language skills. We have been working with experts and specialist organisations – locally, regionally and nationally – to ensure that treatment and that specialist support is available for each child and family.

Appendix A: Template letter for parents of a child who needs their hearing reassessed

This is a template only, please amend to your local service/area as needed.

<insert date>

Dear Parent or Guardian,

Re: <insert child's details>

I am writing to you following the conversation you had with **[insert name and job title]** today about your child needing a further hearing assessment. Again – I'd like to reiterate that we are very sorry that this has happened.

As we discussed earlier, soon after your child was born, a hearing screening test was performed, which did not give a clear response. Therefore, your child was referred for a different type of test, auditory brainstem response (ABR) testing, to accurately measure your child's hearing levels.

ABR tests help to identify hearing loss in children as early as possible, so they can receive the right support to develop the language and communication skills that are critical to their development.

During a review of our ABR testing, it was found that the assessment for your child may not have been performed and reported to current guidelines, and that may have affected the results reported to you.

We are recommending that your child has further testing with an audiologist from **[insert name of hospital]** to measure your child's hearing levels. It is very important that your child is retested at the earliest opportunity. Please make sure that you and your child attend. Please be aware that this does not necessarily mean that your child has hearing problems, but it is important that we re-test your child to see if they do.

I will arrange for the team at **[insert hospital name]** to call you to arrange an appointment. However, if you want to contact the team yourself then please telephone **[insert contact number]** to get through to the children's booking team.

OR

As discussed, I have booked an appointment for your child to be retested on **[insert date]**, at **[insert time]**.

The test takes about **[insert number of minutes]** so please allow plenty of time. This will take place at:

[insert name and full address]

The service's website is: **[insert website]**

If you would like further information about hearing and hearing tests, as well as information about hearing loss and how it is managed, we recommend the following as sources of reliable information:

- Information about the different types of hearing tests for children can be found on the NHS website: <https://www.nhs.uk/conditions/hearing-tests-children/>
- The National Deaf Children's Society: <https://www.ndcs.org.uk/>. The Society also run a helpline which is open Monday to Thursday, 9am to 5pm and Friday, 9am to 12.30pm. Call 0808 800 8880 or email helpline@ndcs.org.uk. For Live Chat or BSL video relay visit www.ndcs.org.uk/our-services/services-for-families/helpline/

Please do not hesitate to contact us on **[insert telephone number, and available dates and times]**, if you have any questions and would like to speak to a member of our staff. Or you can email: **[insert email]**. Alternatively, you can contact **[insert name of person sending the letter]** directly on **[insert phone number]** or by email **[insert email]**.

Yours sincerely,

[insert name and job title]

Appendix B: Template letter for parents of a child who does not require a reassessment

This is a template only, please amend to your local service/area as needed.

<insert date>

Dear Parent or Guardian,

Re: <insert child's details>

I am writing to you about a review of hearing test results which involved reviewing your child's records. We have undertaken a review because some tests were not completed to the standards that we expect. **Our review has shown that your child was tested accurately, and no hearing loss was identified. You do not need to take any further action unless you have a concern.**

You may remember, soon after your child was born, a hearing screening test was performed which did not give a clear response. Therefore, your child was referred for a different type of test, an auditory brainstem response test, to accurately measure your child's hearing levels. As you may know, these tests are done to identify hearing loss in children as early as possible, so that they can get the right support to develop the language and communication skills that are critical to their future.

Although your child does not require any further follow up, we wanted to write to you to let you know that the review of your child's records has taken place.

If you have any concerns about your child and would like to speak to a member of our staff, please do not hesitate to contact us on **[insert number]**. Or you can email: **[insert email]**

Yours sincerely,

[insert name]

Appendix C: Template letter if parents have contacted a trust to enquire if their child is involved in a review

This is a template only, please amend to your local service/area as needed.

Dear Parent or Guardian,

I am writing to confirm that our paediatric hearing service at **[insert trust]** is under national review, to make sure that all national guidelines and standards are being followed. If your child has been part of this review, you will be contacted to either arrange a reassessment if it's required, or to let you know that your child's hearing does not require reassessment.

If you have any concerns about your child and would like to speak to a member of our staff, please do not hesitate to contact us on **[insert number]**. Or you can email: **[insert email]**

If you would like further information about hearing and hearing tests, as well as information about hearing loss and how it is managed, we recommend the following as sources of reliable information:

- Information about the different types of hearing tests for children can be found on the NHS website: <https://www.nhs.uk/conditions/hearing-tests-children/>
- The National Deaf Children's Society: <https://www.ndcs.org.uk/>. The Society also run a helpline which is open Monday to Thursday, 9am to 5pm and Friday, 9am to 12.30pm. Call 0808 800 8880 or email helpline@ndcs.org.uk. For Live Chat or BSL video relay visit www.ndcs.org.uk/our-services/services-for-families/helpline/

Yours sincerely,

[Insert name]

Appendix D: Trust stakeholder letter

This is a template only, please amend to your local service/area as needed.

Dear colleague,

I am writing to you on behalf of **[insert trust]** to inform you that we are currently reviewing our paediatric audiology services as part of a national improvement programme led by NHS England.

In response to a report into audiology care at NHS Lothian, NHS England completed an analysis of data for every baby born in England from 2018-2023. This identified four trusts (five services) with significantly fewer babies with permanent childhood hearing impairment than would be expected compared to national averages. Peer reviews of these services highlighted systemic issues in paediatric audiology services that had led to some infants and children experiencing significant delays in formal diagnosis and therapeutic management, resulting in lifelong consequences for patients and their families.

The National Paediatric Hearing Services Improvement Programme was set-up in response to the peer reviews. The primary focus of the Programme is to undertake a nationally coordinated review of all paediatric audiology services in the NHS in England, to develop a review, recall and reassess model to identify babies and children at risk and mitigate harm caused by mis- or delayed diagnosis, and to assist services in delivering quality improvement interventions.

[insert trust] is working with **[insert ICB]** to carry out an in-depth review of our paediatric audiology service. Where patients need to be recalled for reassessment, we will contact families to arrange an appointment. An improvement plan is also in place to rectify any issues within the paediatric audiology service.

We will provide more updates as we work through this process.

Many thanks for your continued support,

[Insert service lead / medical director/ CEO]

Appendix E: Template email for stakeholders updating them on the local programme/notifying them of the serious incident report being sent shortly

This is a template only, please amend to your local service/area as needed.

Email Title: Update on **[insert trust]** paediatric audiology services

Dear colleague,

Further to the Trust's previous emails on this, I am writing to let you know our investigation into the issues in our paediatric audiology services has been completed and we will be sharing the report with the affected families in the next week.

As a brief **reminder [insert hospital(s)]** – were identified as outliers following a review of data by NHS England's Paediatric Hearing Services Improvement Programme. Following this identification a team of expert peer reviewers undertook a review of a sample of the results held by **[insert trust]** for the auditory brainstem response (ABR) tests it has done since 1 April 2018.

Since we were made aware of the issues with the services, we have done work in many areas to improve what we do so we can reopen our suspended services. This includes

- Reviewing and prioritising nearly **[insert number]** patients:
 - All the original cohort of **[insert number]** patients who were identified in our initial review
 - **[insert number]** patients on paediatric audiology waiting lists
 - **[insert number]** patients who have been referred to the service within the relevant time period

These patients have been reviewed and prioritised with the most urgent scheduled to be seen first. New referrals into our services continue to be seen by specialists from other hospitals **[insert hospital(s)]**.

- Ensuring all our audiologists who undertake paediatric work are undergoing training with external providers and are undertaking a thorough assessment of their competence before they can begin running testing again.
- Ensuring our technical testing equipment has been appropriately serviced and calibrated to ensure they meet the relevant best practice standards. The equipment is also checked on a regular basis.
- Changing the assessment and treatment route for children needing the service to make sure they follow national best practice.
- Working with our colleagues at **[insert hospital]** to align our audiology service oversight and governance arrangements.

We have also been helped by, and are continuing to get help from, colleagues from NHS England and **[insert other organisations]** who have been overseeing and assuring our improvement activities.

I hope this provides reassurance that we are working hard to ensure we can reopen our services as quickly as possible with the assurance they will meet national guidelines. If you would like any more information, then please contact me.

Yours sincerely

[insert name]

Appendix F: Example call centre script

This is an example only, please amend to your local service/area as needed.

- Thank you for contacting the call centre
- Can you give me your child's name and DOB please?
- Why do you have any concerns regarding your child's hearing? [Only offer the suggestions in the list below if they ask for them – for example what type of thing should I be looking for?]
- Listen out for some or all of the following:
 - Inattentiveness or poor concentration
 - Not responding when their name is called
 - Talking loudly and listening to the television at a high volume
 - Difficulty pinpointing where a sound is coming from
 - Mispronouncing words
 - A change in their progress at school
- Advise the best option is to take a number and say someone will call them back to discuss their child further and to possibly arrange a retest.

Appendix G: Template note to GPs with details of where to direct concerned families

This is a template only, please amend to your local service/area as needed.

Dear colleague,

I am writing to update you on the paediatric audiology issue we are managing at [insert trust]. The issue arose when [insert hospital(s)] were identified as outliers following a review of data by NHS England's Paediatric Hearing Services Improvement Programme. Following this identification a team of expert peer reviewers undertook a review of a sample of the results held by [insert trust] for the auditory brainstem response (ABR) tests it has done since 1 April 2018.

Further to the Trust's previous emails on this, I am writing to let you know our investigation into the issues in our paediatric audiology services has been completed and we will be sharing the Serious Incident report with the affected families in the next week.

To help families support the affected children with their development, an urgent referral should be made to a speech and language therapy team with experience in dealing with children with hearing loss, to review and assess all patients as required, and work with those who need help and support.

Sharing the report with families may lead to other concerned families and parents trying to contact the Trust, or you. It may also lead to media coverage which may prompt calls to your practice. Could I ask that:

- if any parents call your practice you ask them to contact the Trust's contact centre. [insert number and opening times]
- if any media call you to ask them to contact the trust's communications team [insert email]

Yours sincerely

[insert name]

Appendix H: Example local reactive media statement

This is an example only, please amend to your local service/area as needed.

[insert name and job title] [insert trust], said: “We are sorry to each and every family which has a child who has not been diagnosed properly. We have seen all the children identified through our review now and we are making sure they are getting the treatment and support they need.

“We have been working solidly to improve our services and get them back up and running. We have invested in new equipment and are about to start work on building a new room in **[insert location]**. We are making sure all our audiologists are undergoing training with external providers and are undertaking a thorough assessment of their competence before they can begin running testing again. We are also changing the assessment and treatment route for children needing the service to make sure they follow national best practice.

“Making these changes will take time, but we are determined to get this right so that patients receive a good quality standard of care going forward.”

“I’d like to reassure everyone there are no issues with our newborn hearing screening programme or our adult audiology service and they are running as they always have been.”