

Introduction

The National Deaf Children's Society is represented on the NHS England Paediatric Hearing Services Improvement Programme (PHSIP). PHSIP are working on the review and recall process in paediatric audiology clinics across England. We are leading the parent lived experience work (including parents and carers who have had their child's hearing retested as part of this review). We feed back to NHS England through the Task and Finish Group, Regional Serious Incident Management meetings and directly with services to improve the review and recall process for families.

The aim of this work is to embed lived experiences into the design of parent and carer feedback questions and methodology, to capture meaningful insights to improve the review and recall process and inform support provision.

Methodology

Phase 1: Co-designed parent feedback questions and methodology

We worked alongside one audiology service to build an understanding of the review and recall process. Following this, we worked with parents with lived experience to design the feedback questions and methodology.

Phase 2: Piloting the questions, approach and refinement

The audiology service contacted parents and carers involved in the review and recall process directly via letter. The survey was promoted along with the letter using a National Deaf Children's Society flyer with a QR code, which led to an online survey. Other options to give feedback were also promoted to ensure the opportunity was accessible, including the option of a one-to-one interview or telephone call.

Phase 3: Roll-out of feedback opportunity

The National Deaf Children's Society contacted sites that had completed the review and recall process to disseminate the parent feedback opportunity. Five sites disseminated the feedback opportunity to parents and carers involved in the review and recall process.

Phase 4: Gathering actionable insights centering lived experience

We've taken a qualitative, reflexive, thematic analysis approach to explore and interpret patterns and meaning from the data collected across the different involvement activities. This has generated actionable insights to inform practical guidance for sites starting the review and recall process. These insights are also informing information and support provision and recommendations to improve routine feedback mechanisms for future service improvements. We have established a lived experience group to co-create and inform the development of this guidance for services and to identify the support families need.

Participants

- Local services promoted the opportunity to families who had completed the review and recall process to feed back on their experience.
- Phase 1: Four parents and carers took part in the co-design from one local service.
 - Phase 2: Eight parents and carers participated in the pilot feedback survey from one local service.
 - Phase 3: Eight parents and carers completed the feedback survey from across five services, and one requested to take part in a one-to-one conversation.
 - Phase 4: Three parents are taking part in the parent experience group.

Theme 1: Clear, transparent information

"They should have told us from the start there was an incident. We did receive a phone call, but they weren't sure if [the hearing test] was his or not, so they needed to retest him."

ID 5, pilot survey

Theme 2: Personalised information

"[We wanted] a guide to explain, step-by-step, what is going to happen... Stages on what is going to happen during the recall process."

ID 6, pilot survey

Theme 3: Being listened to

"I felt like I was being heard so it was brilliant."

ID 11, pilot survey

Theme 4: Empathic guidance navigating health system

"The first appointment was fine as it came as an online letter. Follow-up appointments were supposed to come within 3 months, but we have had to chase every appointment as they had not been scheduled. We are now a year overdue for our next appointment."

ID 13, main survey

Impact

- The involvement of parents and carers with lived experience at each stage had a significant impact on our work within the PHSIP.
- We were able to make immediate alterations to designed questions and methodology to reach parents and carers. Those who participated provided useful insights to deepen our understanding of the review and recall process and highlight what families need.
 - We worked with NHS England to develop a practical communications toolkit that contains the review and recall process timeline, advice for services, letter templates, phone call scripts and information and support for signposting families to early intervention advice and guidance officers at the National Deaf Children's Society.
 - Our early intervention advice and guidance officers provide specialist one-to-one support for families of newly identified deaf children. We were better able to prepare our officers to support families affected by the review and recall process or who have experienced delays in identification or treatment.

Key findings and themes

Due to the small number of participants involved, all qualitative responses gathered through the involvement activities were combined and analysed collectively. This approach allowed for a more holistic understanding of the feedback, ensuring insights were drawn from a range of participant contributions rather than from individual activities in isolation.

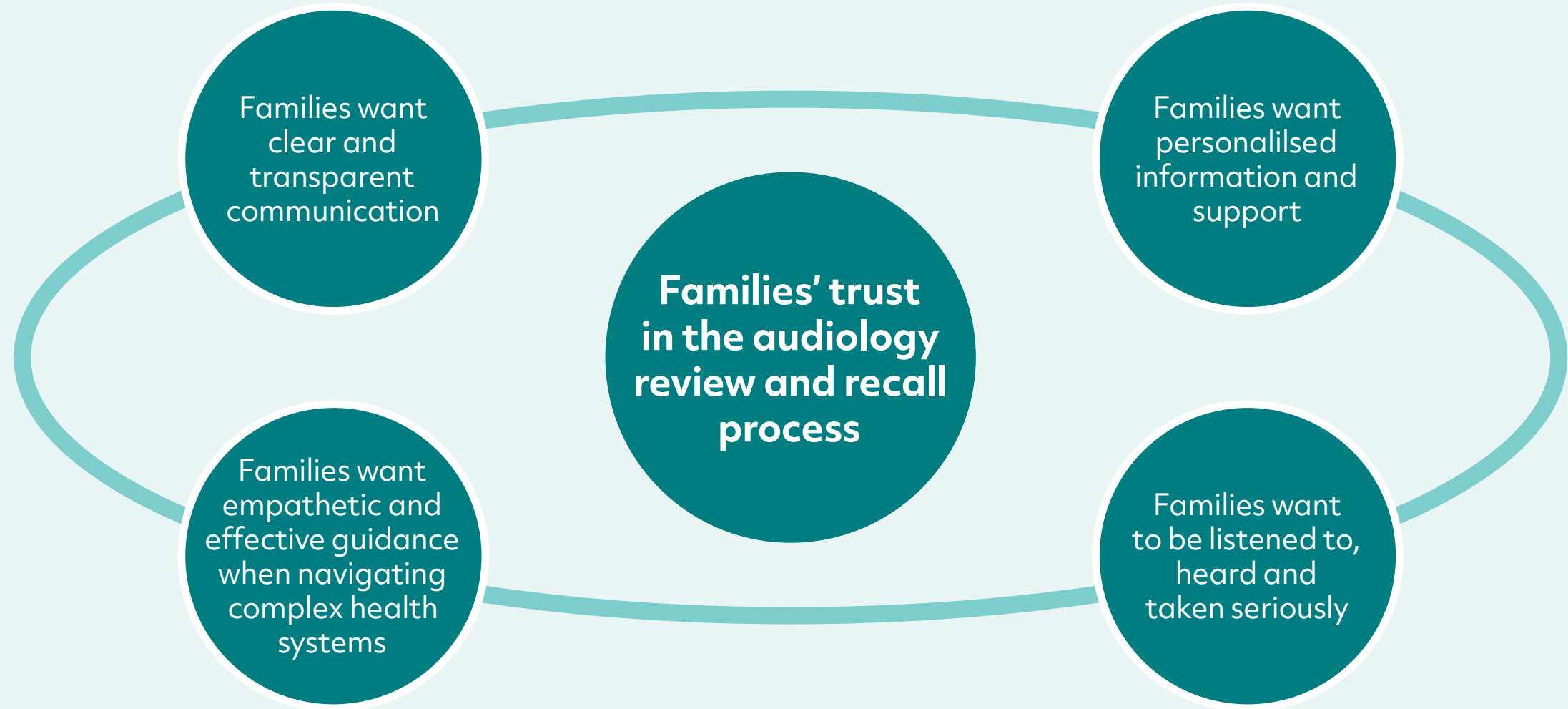
Across the different involvement activities, trust in the audiology review and recall process was identified as a central concept in families' experiences (Fig. 1).

The building of trust appeared to be shaped by four interlinked themes, which influenced how confident and supported parents felt in making decisions about their child's care. Families consistently valued:

- Clear, transparent information** – Parents wanted clear, honest information that helped them understand what was happening and why.
- Personalised information** – Parents wanted personalised support that reflected their child's situation, provided by someone with relevant knowledge and expertise.
- Being listened to** – Parents wanted to feel listened to and taken seriously, with their concerns acknowledged and respected.
- Empathic guidance navigating the health system** – Parents wanted empathetic and effective guidance through complex systems, especially when services were constrained by wider challenges.

Together, these elements helped to build trust in the process and the professionals delivering and supporting their child's care.

Fig 1. Themes identified



Challenges and learning

There were challenges involved in gathering feedback from parents and carers with lived experience of the review and recall process.

Most services routinely communicate with families by post, rather than electronically. To complement this communication approach, we provided a flyer with a QR code leading to the survey. This flyer was to be included with the letters sent by the local service. Our intention was to enable services to share the feedback opportunity with as many families as possible, in a time- and cost-effective way. However, the flyer proved to generate low engagement.

As a benchmark, we would typically expect a flyer to generate an engagement rate of between 1 to 3%. However, in this instance, the flyer generated a lower level of engagement. There may be numerous factors that contributed to the low level of engagement which we are unable to evidence at this stage. These factors may include delayed or lost post; lost flyers; unclear messaging leading to low understanding of terms used; low levels of language and literacy, and of digital literacy, amongst families who received the flyers; limited capacity of parents and carers to share feedback before the closing date; requesting feedback over the summer holiday period; and the length of time elapsed between a child being recalled and their family receiving the feedback flyer.

Conclusion

The insights and learning gained from the project have highlighted the importance of embedding lived experience feedback from the start of any project aimed at service improvements. The work has highlighted the need to further explore the mechanisms by which families are made aware of opportunities to provide feedback; to make feedback opportunities accessible to families with varying levels of medical and digital literacy; and to ensure services communicate what difference feedback has made. These efforts would help to improve services and build trust with families.

Discussion topics

- How do you routinely seek feedback from families receiving care from your service? What's worked well?
- What challenges have you experienced when asking families for feedback?
- What ways have you found helpful to share improvements made by the services because of feedback gathered?
- What support or guidance do services need to improve routine feedback mechanisms?