

Draft NICE decision aid on making a decision about glue ear when your child has hearing loss
Deadline for comments 5pm on Thursday 7 December 2023. Submission by email to: PDA@nice.org.uk

Please read the [checklist](#) for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.

We would like to hear your views on these questions:

1. How helpful do you think this decision aid will be in supporting discussions between healthcare professionals and parents/carers?
2. Is there anything you would add, delete or change about each of the sections?
3. What is your overall impression of the decision aid (for example, was it easy to navigate around the PDA; was the order of information logical)?

Organisation name	British Association of Teachers of Deaf Children and Young People (BATOD)
Name of person completing form:	Teresa Quail

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<p>1. How helpful do you think this decision aid will be in supporting discussions between healthcare professionals and parents/carers?</p>	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>BATOD feels this resource has potential to support discussions between healthcare professionals and parents/carers. However, the current version is written for those parents/families that have a level of education and understanding that supports the use of this standard of material.</p> <p>Have specialists inputted regarding readability by individuals with dyslexia? Will it be available in other languages including British Sign Language?</p>
<p>2a. Is there anything you would add, delete or change about the following section: What is this document?</p>	<p>The document may require clarification of why it is to be used for aged 12 and under.</p> <p>The current version is written for those parents/families that have a level of education and understanding that supports the use of this standard of material.</p> <p>In this document how will NICE consider the assistance that some families will need in understanding the content and making best use of it to come to a decision?</p> <p>It would be useful to include at this stage some signposts to help those making the decision e.g. Does your child have speech that is difficult to hear? Do you have concerns about how your child interacts with friend? etc</p>
<p>2b. Is there anything you would add, delete or change about the following section: What is glue ear?</p>	<p>The current image is useful. However, it would be helpful to clearly indicate where the glue ear is on the diagram. To support the accessibility of the information for all readers, two diagrams could be included. One image showing a healthy ear and a second image showing the location of the fluid.</p> <p>To support the knowledge development of readers with no prior knowledge, additional detail about how the fluid affects the passage of sound would be relevant, perhaps emphasising that cochlea and auditory nerve function are not affected. In addition, inclusion of specific wording or hyperlinks about glue ear as a conductive type of deafness which is usually not permanent, as opposed to other types of deafness such as those in the cochlea (sensori-neural deafness) which are permanent, may be helpful for some readers.</p>

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	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>The use of capitals in the image is not consistent with the use of the terms throughout the aid.</p>
<p>2c. Is there anything you would add, delete or change about the following section: What is hearing loss?</p>	<p>BATOD recognises the rationale of the use of hearing loss for the cohort of children experiencing glue ear. However, BATOD would recommend the terms ‘deaf/deafness’ are recognised too. This could perhaps be achieved with a footnote disclaimer for the rationale behind the term ‘hearing loss’ in this publication.</p> <p>In order to support the knowledge development of readers with no prior knowledge, BATOD would recommend the impact of hearing loss on speech in this part, particularly the addition of some speech sounds to the image on page 3. Currently the aid does not show that some speech sounds impacted by mild and moderate levels of deafness.</p> <p>The current image is potentially misleading with the ‘listening to speech’ illustrated in only the moderate level of deafness section. Research indicates a mild level of deafness can impact upon a child's speech discrimination. This is not explicit in the current image.</p> <p>For parents with no prior knowledge of the impact of deafness, a list of risk factors for mild and moderate levels of deafness would be useful.</p> <p>Explaining hearing is about loudness of the sound and the pitch of the sound eg high pitch sounds like door bells or low pitched sounds like rumble of lorries may be useful to include for parents with no prior knowledge.</p> <p>If parents of children with known sensori-neural deafness are given the document because the child is experiencing glue ear, specific signposting for their needs would be useful.</p> <p>A summary that is explicit about the temporary not usually permanent aspect of the conductive type of deafness would be useful.</p> <p>For readers who may find the information in an image difficult to interpret, can a description also be added?</p>

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<p>2d. Is there anything you would add, delete or change about the following section:</p> <p>How hearing loss may affect your child</p>	<p>Will the document be made accessible for individuals with vision impairment?</p> <p>The information boxes are generally clear and useful. BATOD would recommend the term ‘development’ is used instead of ‘skills’, ‘changes in behaviour’ instead of behaviour, and less negative terms such as ‘challenges’ instead of ‘problems’ and ‘difficulties.</p> <p>BATOD would suggest including recognition that social relationships involve good communication skills of listening and speaking.</p> <p>The hover boxes might not be helpful for all readers.</p>
<p>2e. Is there anything you would add, delete or change about the following section:</p> <p>Thinking about how it affects your child</p>	<p>BATOD would recommend that a question about age is included before the list of questions on page 5 and 6. The questions should include a speech specific question eg ‘is your child's speech difficult to understand?’</p> <p>BATOD feels the developmental impact at key points in a child's life eg 0 -2; 2.5 – 4 etc is not clear enough to support true decision making. For example parental decision making for an 11 year old child could be different for a 2 year old child.</p> <p>As a behaviour may not be due to hearing loss, it would be beneficial to consider as a change in the child's behaviour.</p> <p>The space for the parent/family to record notes is good as it will allow them to capture notes and/or questions for appointments with the relevant professionals.</p>

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<p>2f. Is there anything you would add, delete or change about the following section:</p> <p>Your child's options</p>	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>The Venn Diagram is useful. However, not all these choices are appropriate depending on the age of the child. The document may benefit from a chart showing which options should be considered depending on their age and language skills.</p> <p>Some readers may benefit from a hyperlink/hover box to descriptors for the unfamiliar words eg grommets, adenoids, auto-inflation, air/bone conduction.</p> <p>In order to support an informed decision by the parents/families, the document should indicate that access to surgical interventions and interventions from professionals such as speech and language therapists (SALT) and Qualified Teachers of Deaf Children and Young People (QToD) will vary in different geographical regions.</p>

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<p>2g. Is there anything you would add, delete or change about the following section:</p> <p>Things you and other carers can do</p>	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>The pop-out boxes are useful. However for some readers their devices may not enable the feature. Therefore, a hyperlink option may be more explicit that further information is available or include the list within the content.</p> <p>The inclusion of video links to demonstrate the parent /carer actions that make a difference may support some readers.</p> <p>In the ‘everyone can help by’ list it would be helpful to state the need to be patient, to rephrases not just repeat.</p> <p>Some Sensory Support Services do offer a level of support to children with glue ear either directly or via training provision to an educational setting. Therefore, it would be helpful for parents/families to understand if there is QToD input in their area.</p> <p>Regarding nursery placement advice, consider recommending the child is well placed as a location on the carpet very close to the teacher they may not have a clear enough view of the teachers face for speech reading.</p> <p>Encouraging a child to let people know if they have not heard what is said does not acknowledge the child can ask someone about something they haven't heard, and this advice assumes the child have the necessary language skills or confidence or opportunity too.</p> <p>The advice should reflect the need for effective monitoring of listening and understanding by the adult, probably by either monitoring response or by checking understanding by using content specific questions.</p> <p>As a hearing aid with support is an option noted on the previous page, this section should include content to relate to that option too.</p>

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<p>2h. Is there anything you would add, delete or change about the following section: Things you and your care team can do: Regular monitoring and support</p>	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>Is the term ‘regular’ required? Or is it possible to actually define ‘what is regular?’</p> <p>Some parents/families are not able to access ‘regular monitoring and support’ due to the ENT waiting lists.</p>
<p>2i. Is there anything you would add, delete or change about the following section: Things you and your care team can do: Using auto-inflation</p>	<p>A picture, demo video or animation of the device would be helpful.</p> <p>The image in the pop out box may be confusing for some readers.</p> <p>The devices used by some readers to access the electronic resource may prevent them from accessing the information about disadvantages and ‘other things to think about’. Therefore, this may prevent them for accessing information to make information decisions.</p>
<p>2j. Is there anything you would add, delete or change about the following section: Things your health & care team can do: Using a hearing aid</p>	<p>Some readers would benefit from a picture of each type of hearing aid that could be included. Pictures will make the resource more visual and aid understanding for a range of readers.</p> <p>Pictures of hearing aids should reflect the range of options to prevent manufacture bias.</p> <p>Clarification of the non-invasive aspect may support some readers who may assume “using vibration through bones of the head” will cause pain/discomfort to their child.</p> <p>There should be reference to the safety alert issued in 2019 that all under 5's and those with under 5's in the household should have lockable battery compartments. The decision aid should also highlight storage and disposal should still be carefully considered.</p>

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<p>2k. Is there anything you would add, delete or change about the following section:</p> <p>Things your health & care team can do:</p> <p>Having surgery</p>	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>BATOD is pleased to see a reference to the idea that waiting times vary from area to area. A child has a right to a language, therefore, to support informed decision making by parents, this section should reflect other options may need to be considered whilst waiting for surgery.</p> <p>Readers would benefit from visual aids of a grommet. There is a need to emphasise the misconception that fluid drains out of the grommet.</p> <p>To enable parents/ families to make a true informed decision, can the resource guide parents on how to find out about the real time waiting list times in their area?</p>
<p>2l. Is there anything you would add, delete or change about the following section:</p> <p>Thinking about hearing aids or surgery</p>	<p>As noted above, some readers may benefit from images.</p>
<p>2m. Is there anything you would add, delete or change about the following section:</p> <p>Thinking about types of hearing aids</p>	<p>It should be acknowledged that the type of aid is often a clinical decision.</p> <p>As noted above, some readers may benefit from images of what air conduction aids and bone conduction aids look like on a child.</p>
<p>2n. Is there anything you would add, delete or change about the following section:</p> <p>Treatments that are not recommended</p>	<p>BATOD is pleased to see a section on Treatments that are not recommended is included. It would be recommended to put the print in a bold text format against a brighter red background to indicate not preferred as a more visual representation of the message</p> <p>It should be noted that some treatments mentioned on page 7 (q5) are not appropriate for all children.</p> <p>Should 'hopi' candles be specifically referenced so as some families are advised by alternative practitioners to use them as a treatment.</p>

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<p>2o. Is there anything you would add, delete or change about the following section:</p> <p>Making a decision</p>	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>Lead the section with ‘where can my child go for information’ to retain the patient-centred approach. This may help frame decision focus on what might be best for the child ie not what is best for the parent or professional.</p> <p>Include other resources such as MESHGuide (Glue ear) Glue Ear (https://www.meshguides.org/guides/node/1096?n=1098)</p> <p>In the second box on page 14, replace ‘help’ with ‘support to make an informed choice’ and parent ownership.</p>
<p>2p. Is there anything you would add, delete or change about the following section:</p> <p>How this decision aid was produced</p>	<p>Good Resource to help with decision making but also to help parents inform wider family and other significant adults in their child's care - nursery etc.</p>
<p>3. What is your overall impression of the decision aid?</p>	<p>The decision aid is easy to navigate, laid out well.</p> <p>For confident readers who can work through the whole document it will be helpful.</p> <p>The decision aid is bright and colourful. However, some section needs more pictures to support the knowledge development for readers with no prior knowledge. A media version (YouTube) where someone is talking through the options may support access to a wider range of readers.</p> <p>It has the potential to empower parents and professionals to come to common understanding and offer the desired pathway.</p> <p>Recognising few ENT consultants may have the time capacity in the appointment, the aid will be helpful to some parents to read independently to develop a better understanding of what glue ear is and to know all the available options, plus the associated pros and cons. With access to the aid as a source of reference, it may therefore empower parents/families to raise their queries with ENT consultations, audiologists and/or sensory support services in the proceeding appointments.</p>

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	<p>Do not paste other tables into this table because your comments could get lost – type directly into this table.</p> <p>The aid needs to separate the client group a little more. For instance a pre-schooler with glue ear is a bigger issue than an 8 year old. Some of the options would not be suitable for a pre-school child.</p> <p>Will it be in electronic form only or paper based as well?</p>

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Checklist for submitting comments:

- Use this comment form and submit it as a Word document (**not a PDF**).
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Do not include any confidential information or any medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use.
- For copyright reasons, comment forms must not include attachments such as research articles, letters or leaflets. Any comment forms that include such attachments will be deleted without being read.
- We are seeking comments on the draft decision aid only; we are not able to accept any comments about the published NICE guideline on otitis media with effusion in under 12s (NG233, 2023). The decision aid does not amend or update the NICE guideline in any way.
- We do not intend to provide formal responses to comments received but we will take all comments you provide carefully into account.