

**Tinnitus stakeholder scoping workshop: notes from breakout group discussions**  
**Date: 31/10/17**

Scope details	Questions for discussion	Stakeholder responses
<p>Groups that will be covered</p> <ul style="list-style-type: none"> <li>• Adults (18 and older), young people and children with suspected or confirmed tinnitus.</li> <li>• No specific subgroups of people have been identified as needing specific consideration.</li> </ul> <p>Groups that will not be covered</p> <ul style="list-style-type: none"> <li>• None</li> </ul>	<ul style="list-style-type: none"> <li>• Should children be included in the Guideline?</li> <li>• Are there any specific subgroups that have not been mentioned (in either list)?</li> </ul>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>• Important to include children in the guideline but they should be considered as a separate group when reviewing the evidence as there are distinct differences between tinnitus in adults and tinnitus in children. For example, there is a strong link between tinnitus and hearing loss, and the causes of hearing loss are different in children. Also, there is a strong link between tinnitus and psychosocial problems. This is another area that differs significantly between children and adults.</li> <li>• Noted that there are existing BSA guidelines on tinnitus in children, which are well regarded in the field. However, commissioners noted the importance of having NICE guidance and therefore feel it is important that children are included in this scope.</li> <li>• The following subgroup should be considered: the profoundly deaf, Deaf and hard of hearing. The management tools that can be used with these groups differ significantly.</li> <li>• The following subgroups should be considered: <ul style="list-style-type: none"> <li>○ Those with hyperacusis and tinnitus. Again, management strategies differ for this group.</li> <li>○ The profoundly deaf. Some tools can't be used in this group, and accessing counselling in a format that works for them is very challenging.</li> </ul> </li> <li>• The following equality issue was noted: It is important that guidance for this topic area is available in BSL format. It should be available for all NHS literature but currently is not and this is an area where it is particularly important to have this. Signing videos would also be very useful.</li> <li>• The following equality issue was noted: Healthcare professionals</li> </ul>

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		<p>struggle to use existing management tools with people who don't have written English or BSL, for example those for whom English is a second or other language and those with autism.</p> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>• Tinnitus with hyperacusis should be included, due to different considerations for treatment (sound therapy).</li> <li>• Hyperacusis alone should not be covered as it is a separate condition. Tinnitus does not cause hyperacusis.</li> <li>• Children and young people should be included.</li> <li>• Subgroups should be identified in scope section 3.1: people with tinnitus who are profoundly deaf; people with tinnitus and hyperacusis.</li> <li>• Equalities considerations should include: people with learning difficulties, accessibility of written information (e.g. availability in different languages, should meet accessible information standards; lower numbers of black and Asian people presenting with Tinnitus and the reasons for this are unclear</li> </ul> <p><b>Group 3</b></p> <ul style="list-style-type: none"> <li>• Children aged 5 years and over should be included.</li> </ul> <p><b>Group 4</b></p> <ul style="list-style-type: none"> <li>• Group felt that children should be included, mentioned that there are recently published guidelines for paediatric tinnitus from the British Society of Audiology (best practice guidance by Veronica Kennedy) and British Tinnitus Association. Also the British Association of Audiovestibular Physicians has guidance.</li> <li>• The group raised issues around age of consent and safeguarding for children. Also, noted that the devices used for tinnitus have been/are only tested in adults</li> </ul>

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		<ul style="list-style-type: none"> <li>• Consistency is needed for tinnitus where healthcare professionals need to be trained in providing paediatric services.</li> <li>• Including paediatrics in the guideline may also combat commissioning issues – CCGs will recognise that paediatric services for tinnitus are needed and more likely to provide funding</li> <li>• Specific subgroups that were mentioned by the group were:               <ul style="list-style-type: none"> <li>– Profoundly deaf with tinnitus</li> <li>– People with learning difficulties</li> <li>– Visually impaired</li> <li>– People with dementia (unable to provide consent and assistance is needed to maintain treatment regime)</li> </ul> </li> </ul>
<p>Settings that will be covered</p> <ul style="list-style-type: none"> <li>• All settings where NHS care is commissioned.</li> </ul> <p>Settings that will not be covered</p> <ul style="list-style-type: none"> <li>• None.</li> </ul>	<ul style="list-style-type: none"> <li>• Are the listed settings appropriate?</li> <li>• Are there other settings that should be considered?</li> </ul>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>• The listed settings are appropriate. No further comments.</li> </ul> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>• Some care for Tinnitus is provided outside of the NHS by independent providers, for example audiology, hearing aid fitting. The groups asked whether independent settings could also be included.</li> </ul> <p><b>Group 3</b></p> <ul style="list-style-type: none"> <li>• No comments</li> </ul> <p><b>Group 4</b></p> <ul style="list-style-type: none"> <li>• Group suggested that setting description is changed to ‘All settings where NHS-commissioned care is provided’</li> </ul>

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<p>Key areas that will be covered:</p> <p>1 Assessment of tinnitus</p> <ul style="list-style-type: none"> <li>• Baseline audiological assessment</li> <li>• Assessment of psychological impact</li> <li>• Assessment of quality of life</li> <li>• Objective tests of tinnitus for example tinnitus matching</li> <li>• Referral to Specialists</li> <li>• Ultrasound, Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) scans</li> </ul>	<p>These are the key clinical areas that have been prioritised for inclusion in the guideline.</p> <ul style="list-style-type: none"> <li>• Do you think that these prioritised areas are appropriate for the topic?</li> <li>• Have any areas not been mentioned?</li> <li>• Should computerised tomography (CT) and Magnetic Resonance Imaging (MRI) be separate or compared to one another?</li> </ul>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>• This appears to miss a step in the process. Clinical assessment should be the first step. This includes a full examination and health check, importantly for example examining the ear, to exclude medical causes. This is included in the current BTA guidance.</li> <li>• CT and MRI should be looked at in the context of all imaging tests (for example, could also include PET scanning). The question should therefore look at what are the indications for different radiological investigations and who should and shouldn't be scanned.</li> </ul> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>• Baseline should be removed from 'baseline audiological assessment'.</li> <li>• The types of tinnitus should be categorised (e.g., subjective and objective) as choice of test depends on type of tinnitus.</li> <li>• Guidance for primary care healthcare professionals is desired.</li> <li>• Sleep is an important issue for people with Tinnitus and should be included. The scope should clarify whether this falls under physical or psychological impact in the clinical questions.</li> <li>• Terminology for objective tests was questioned, as these tests are not truly objective. There is a reproducibility issue with some of the tests that should be taken into consideration.</li> <li>• The tests should be separated out in the clinical questions (Q1.1)</li> <li>• Identification of 'red flags' to assist triage for medical and surgical care should be included.</li> </ul>

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		<p><b>Group 3</b></p> <ul style="list-style-type: none"> <li>• Treatment is different for different types of tinnitus (subjective and objective tinnitus).</li> <li>• Transitional care between paediatric and adults services can be an issue. There is regional variation in children’s services. Group were keen to address issue of service provision.</li> <li>• Important to get referral pathway right early. It is preferable to refer to ENT directly if required.</li> <li>• Clinical psychologists only see adults over 18 year olds – can be a gap in clinical psychology provision.</li> <li>• Potential need for one-stop shop for tinnitus services. Suggestion to add a clinical question on this issue.</li> <li>• Presentations can be accompanied by spectrum considerations.</li> <li>• For children there is a team approach to caring for the child, including education and mental health. Management is different and tailored to the child.</li> <li>• The group were interested in looking at the best triage system to determine the pathway -MRI compared to audiological assessment.</li> <li>• Suggestion to combine questions 1.5-1.7 about which people should be referred for a scan.</li> <li>• Need to think about families when considering quality of life.</li> <li>• Suggestion to include otoacoustic omissions (OAEs)</li> <li>• Suggestion for a question: how long should someone have unilateral tinnitus before recall for MRI?</li> <li>• Medications which can cause tinnitus should be included as part of history taking</li> <li>• There is a need for guidance/ recommendations on triage</li> <li>• What qualifications and training should healthcare professional scaring for people with Tinnitus have?</li> </ul>

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		<ul style="list-style-type: none"> <li>• The group were broadly happy with clinical questions.</li> <li>• Wax removal and relationship between wax and tinnitus needs to be part of assessment</li> <li>• Identification of urgency, particularly in respect to risk of self-harm/suicide, is important</li> <li>• Issue for people on medication for other conditions e.g. cancer</li> <li>• Suggestion for a question about how long should tinnitus be present before the referral</li> <li>• There is a need to address the person’s psychological profile and ability to handle the information to help decide what treatment will best for the person.</li> </ul> <p><b>Group 4</b></p> <ul style="list-style-type: none"> <li>• The statistic that 10 million people have tinnitus was proposed, small proportion of these people need additional support</li> <li>• There is some DoH best practice guidance on assessment of tinnitus however this is now archived.</li> <li>• Group discussed that there are various healthcare pathways associated with tinnitus, depending on the type of tinnitus. The main pathway being: <ul style="list-style-type: none"> <li>○ GP -&gt; specialist (audiologist)</li> <li>○ Specialist -&gt; ENT</li> </ul> <i>(unilateral tinnitus referred to ENT straightaway)</i> </li> <li>• Research by Derek Hoare (2010) was mentioned looking at referral patterns in UK.</li> <li>• In some parts of the country people can self-refer straight to an audiologist (Coventry, Rugby)</li> <li>• The group felt that the questions should be based around “How? Who? When?” For example, who should do the initial</li> </ul>

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		<p>assessment: primary care or specialist care?</p> <ul style="list-style-type: none"> <li>• The importance of reassurance at the initial appointment/diagnosis was emphasised. They noted that some patients can be reassured and kept within primary care, not requiring further referral.</li> <li>• When should patients be referred to a specialist?</li> <li>• Who should be referred? The '8 Red Flags highlighted by the British Academy of Audiology' indicates symptoms that would initiate direct referral to open-access referral centres.</li> <li>• In the paediatric population this direct referral can be made by a school nurse, health worker or community nursery nurse.</li> <li>• Group suggested change of 'baseline audiological assessment' to 'initial assessment'. Medical assessment by the GP will identify if there any other reasons for the symptoms</li> <li>• Methods of assessing tinnitus include: pure tone audiometry (including very high frequency hearing tests? &gt;8,000), tympanometry and OAEs (otoacoustic emissions).</li> <li>• Tests of tinnitus, although referred to as 'objective' tests, these are generally subjective. They include pitch matching and questionnaires such as TFI and THI – need to be validated in other languages to reflect multiple languages spoken in England</li> <li>• There is an unclear referral system for patients requiring mental/psychological support. Particularly from audiology to mental health services.</li> <li>• Psychological questionnaires are used such as HADS.</li> <li>• The group felt that CT and MRI should not be compared to each other. Each imaging type is used to investigate distinct anatomical areas: <ul style="list-style-type: none"> <li>– US = neck veins</li> <li>– CT = bone</li> <li>– MRI = soft tissue such as the brain</li> </ul> </li> </ul>

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		<ul style="list-style-type: none"> <li>• There was a suggestion of looking at what information should be provided to patients about tinnitus</li> </ul>
<p>2 Management of tinnitus</p> <ul style="list-style-type: none"> <li>• Self-management</li> <li>• Hearing aids</li> <li>• Sound therapy (sound generators or combination devices [sound generator and hearing aid], tinnitus re-programming devices)</li> <li>• Psychological therapy</li> <li>• Counselling</li> <li>• Combined sound therapy and counselling therapy</li> <li>• Betahistines</li> <li>• Gingko biloba</li> <li>• Antidepressants</li> <li>• Anxiolytics</li> </ul>	<p>These are the key clinical areas that have been prioritised for inclusion in the guideline.</p> <ul style="list-style-type: none"> <li>• Do you think that these prioritised areas are appropriate for the topic?</li> <li>• Have any areas not been mentioned?</li> <li>• For the question ‘what are the most clinical and cost effective self-management strategies?’ could we have a list of the strategies for the protocol?</li> <li>• Are the excluded areas appropriate?</li> <li>• Have any areas not been mentioned?</li> </ul>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>• Add earwax removal and methods of earwax removal. There is uncertainty about whether earwax can contribute to tinnitus and also whether earwax removal methods can contribute to tinnitus.</li> <li>• As well as hearing aids vs no hearing aids, different types of hearing aids (for example, those that are moulded) should also be considered.</li> <li>• Add surgical interventions that are used to treat tinnitus rather than hearing loss, for example cochlear implantation, middle ear surgery.</li> <li>• Sleep management was considered an important area to be added.</li> <li>• CBT, as distinct from counselling, has been considered useful for tinnitus and should be included within psychological therapy. Mindfulness which is also used and is another area to include within psychological therapies.</li> <li>• Support groups should be noted under self-management. This category should look at online manuals, educational classes such as relaxation, and education about anxiety.</li> <li>• Tinnitus retraining therapy (TRT) was raised; however this is a very distinct protocol of training (education and sound therapy) and is not provided currently within the NHS. Studies that state they are on TRT rarely are as it is a very specific protocol.</li> <li>• Education for people with tinnitus is important to include, distinct to self-management.</li> </ul>

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<p>Areas that will not be covered</p> <ol style="list-style-type: none"> <li>1. Management of hearing loss without tinnitus</li> <li>2. Management of the underlying health conditions causing tinnitus</li> </ol>		<ul style="list-style-type: none"> <li>• Noted the importance of the BTA and their self-management resources and support groups which have a very wide influence.</li> <li>• Suggested that this section could be grouped under sub-headers e.g. 'Self-help' 'Drugs' 'Psychological therapies' and 'Devices'. Although it was noted that some items fall within more than one sub-header.</li> <li>• Add management of hyperacusis without tinnitus.</li> <li>• Add management of dysacusis or misophonia</li> </ul> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>• Implantation devices should be added to hearing aids, as these devices, including cochlear implants can ameliorate Tinnitus.</li> <li>• Self-management strategies should include relaxation and sleep strategies.</li> <li>• Audiologists deliver 'psycho-education' rather than true counselling or psychological approaches to therapy. Psycho-education should be added. Complementary therapies could be expanded to include other therapies (e.g., magnesium, zinc, vitamin B12). Complimentary therapies were identified within the James Lind Alliance top 10 priorities.</li> <li>• Fitting of devices is an important consideration for question 2.2. Devices have different settings and the way they are programmed affects how effective they are.</li> </ul> <p><b>Group 3</b></p> <ul style="list-style-type: none"> <li>• The group wanted to include questions on: <ul style="list-style-type: none"> <li>– follow-up protocol</li> <li>– effectiveness of hearing aids</li> <li>– diet and nutrition (these are related to sleep)</li> </ul> </li> <li>• Intra-tympanic steroids, topical treatments, skin patches, grommet insertion</li> </ul>

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<p>3. Management of co-morbid conditions (depression, anxiety)</p> <p>Is there anything not on the list that is a higher priority than the items listed?</p>		<p><b>Group 4</b></p> <ul style="list-style-type: none"> <li>• The group discussed the different methods of management for tinnitus and noted that there is acute and chronic tinnitus <ul style="list-style-type: none"> <li>– Acute tinnitus - symptoms last for approximately 3 months</li> <li>– Chronic tinnitus – symptoms last for longer than approximately 3 months</li> </ul> </li> <li>• Management during the acute phase of tinnitus is very important as evidence from the British Tinnitus Association shows that symptoms subside over this time if they are managed appropriately (mainly self-management)</li> <li>• Self-management includes managing dietary intake (e.g. amount of caffeine), avoiding use of recreational drugs, reducing stress and anxiety. Directed counselling – websites and education</li> <li>• Hearing aids – low numbers of patients with tinnitus are prescribed hearing aids as management</li> <li>• Sound therapy – including ‘sound balls’, sound ‘oasis’, phone apps, speakers. Members of the group mentioned that funding is not always available for tinnitus re-programming devices</li> <li>• Combined sound therapy – pure tinnitus retraining therapy (TRT) is not delivered in the NHS. Important that evidence for all types of TRT included in a review, not exclusively ‘pure’ versions of it.</li> <li>• Psychological therapy – can include group therapy/sessions and active CBT (6 weeks long) - there was a discussion about the lack of clarity for who would deliver this program. Mindfulness/Active mindfulness should be added to list of interventions.</li> </ul>

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<p><b>Health economics</b></p> <p>An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.</p>	<ul style="list-style-type: none"> <li>• Which practices will have the most marked/<b>biggest cost</b> implications for the NHS?</li> <li>• Are there any <b>new practices</b> that might <b>save the NHS money</b> compared to existing practice?</li> <li>• Do you have any further comments on economics?</li> </ul>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>• The main issue currently is variation in clinical practice across the country. Clear guidance would be cost-saving.</li> <li>• There is uncertainty about who should refer and any improvement in this would be cost saving as it would speed up appropriate referrals.</li> <li>• Availability of psychological support is very variable and any recommendation on this is likely to have an initial cost impact but a long-term cost saving. Currently, less than 1 in 5 audiology departments have access to psychological support.</li> <li>• MRI is very expensive and this is currently huge variation in which tinnitus patients are scanned.</li> <li>• There are no new save practices that would save money, but better implementation of the existing strategies is likely to be cost-saving.</li> </ul> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>• No comments</li> </ul> <p><b>Group 3</b></p> <ul style="list-style-type: none"> <li>• Suggestion for a question on cost effectiveness of direct referral to ENT (as opposed to going through audiology)</li> </ul> <p><b>Group 4</b></p> <ul style="list-style-type: none"> <li>• Group therapy sessions (e.g. CBT) can be effective compared to individual sessions – cost-saving</li> <li>• Risk segmentation needs to be considered</li> <li>• Prevalence is hard to obtain</li> <li>• Routine audiology for tinnitus with hearing loss</li> <li>• Different health pathways are used including community-</li> </ul>

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		hospital model
<p><b>Main outcomes</b></p> <ol style="list-style-type: none"> <li>1 Change in subjective tinnitus loudness and severity</li> <li>2 Change in tinnitus-related depressive symptoms or depression scores</li> <li>3 Change in tinnitus-related anxiety symptoms or anxiety scores</li> <li>4 Change in tinnitus-related health-related quality of life</li> <li>5 Adverse effects</li> </ol>	<ul style="list-style-type: none"> <li>• Is the list of outcomes appropriate?</li> <li>• Are any key outcomes missing?</li> </ul>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>• Add sleep to outcomes (improvement in quality of sleep/sleep patterns).</li> <li>• Outcomes in tinnitus are controversial in the field and will be very varied in the literature. There is debate about whether certain domains are useful for tinnitus. For example, change in subjective tinnitus loudness is generally accepted but change in tinnitus severity is not.</li> <li>• Noted that changes that are important to patients may not be clinically measureable. All of the outcomes are subjective which brings additional challenges in interpretation of results of research.</li> <li>• Lack of validation of questionnaires is an issue in this clinical area.</li> <li>• There are around 30 tinnitus questionnaires that have been developed as diagnostic tools, but are becoming increasingly used as outcome measures. Meta-analyses have pooled these in the past.</li> <li>• Noted the tinnitus handicap inventory is becoming quite widely used and is known to be fairly sensitive to change. The tinnitus functional index which has 8 sub-domains is also reasonably sensitive to change and treatment.</li> </ul> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>• Suggestion to change Tinnitus loudness and severity to tinnitus intrusiveness.</li> <li>• Agreed that adverse events are important, especially for medicines (there is a perception that antidepressants can worsen tinnitus).</li> </ul>

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		<ul style="list-style-type: none"> <li>• Suggestion to replace anxiety / depression with psychological distress, as this term would capture more than anxiety and depression.</li> <li>• ‘Tinnitus-related’ should be removed from the outcomes as some evidence might be missed. Using the generic measures (e.g.HRQoL) will be fine as the studies will be in a tinnitus population.</li> </ul> <p><b>Group 3</b></p> <ul style="list-style-type: none"> <li>• The group flagged the importance of patients being aware of the full range of treatments available.</li> </ul> <p><b>Group 4</b></p> <ul style="list-style-type: none"> <li>• Suggested change for outcome 1 - change to intrusive tinnitus</li> <li>• Suggested change for outcome 4 – removal of tinnitus-related</li> <li>• Suggested change for outcome 5 – adverse effects of management</li> </ul>
<p><b>GC membership</b></p> <p>Full committee members:</p> <ul style="list-style-type: none"> <li>• Chair x1 (appointed)</li> <li>• Clinical Lead x1 (appointed)</li> <li>• Audiovestibular physician x1</li> <li>• ENT surgeon x2</li> <li>• Audiologist/audiological scientist x2</li> <li>• Psychologist x2 (1 each of adult and paediatric)</li> </ul>	<ul style="list-style-type: none"> <li>• Do you have any comments on the proposed membership of the committee?</li> </ul>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>• Particularly important to have paediatric audiology input alongside the adult input.</li> <li>• Consider separating audiologist and audiological scientist so that they are seen as separate and not competing positions.</li> <li>• Include a parent within the lay members but it is important that lay members understand the variability in tinnitus care across the country as this a key clinical issue.</li> <li>• Input from the BTA would be very useful for the lay member position as they are very influential and represent up to 100 groups. There was a concern about bias if the lay member does not have knowledge of tinnitus groups as they may not appreciate the variability in practice across the country.</li> </ul>

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<ul style="list-style-type: none"> <li>• GP x1</li> <li>• Hearing therapist (adult) x1</li> <li>• Lay members x2</li> </ul> <p><i>(advertise adult and paediatric for all posts)</i></p> <p>Co-opted members:</p> <ul style="list-style-type: none"> <li>• Teacher of the deaf (paediatric) x1</li> </ul>		<ul style="list-style-type: none"> <li>• A teacher of the deaf may not necessarily have experience in tinnitus. Add that they should have a special interest in tinnitus. It may be useful to contact the National Children’s Deaf Society in this regard.</li> <li>• Queried whether there should be someone with a research specialism in tinnitus on the group.</li> </ul> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>• 1 ENT surgeon is enough (2 not necessary)</li> <li>• Suggestion to add hearing aid dispenser</li> <li>• Suggestion to add research expert</li> <li>• Suggestion to add an additional lay member position for a representative of a patient organisation</li> </ul> <p><b>Group 3</b></p> <ul style="list-style-type: none"> <li>• Helpful to have a primary care audiologist as well as a hospital based audiologist</li> <li>• An additional GP should be included (2 in total)</li> <li>• Query whether 2 ENT surgeons are needed</li> <li>• Suggestion to add: <ul style="list-style-type: none"> <li>– Audiologist and a separate scientist</li> <li>– Educational audiologist</li> <li>– Community based hearing aid dispenser who practices in tinnitus</li> </ul> </li> </ul> <p><b>Group 4</b></p> <ul style="list-style-type: none"> <li>• Group felt that GC membership was too medically focused</li> <li>• Suggested:</li> </ul>

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		<ul style="list-style-type: none"><li>○ Removal of audiovestibular physician</li><li>○ Removal of an ENT surgeon</li><li>○ Audiologist AND audiological scientist (hospital based and community based). Possibly 2 adults and 1 paediatric. Noted that clinical scientists have a protected title.</li><li>○ Additional GP, possibly GP with a tinnitus specialist interest?</li></ul>