Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**

1.1 Who is the focus:
 	
Groups that will be covered:
• Adults aged 18 and over, including those with pre-18 onset but who present in adulthood
• Deaf-blind people
• Adolescents (aged 18–25)
• People with unilateral hearing loss
 	
Special consideration will be given to:
• People with disabilities, including:
  ○ physical disabilities
  ○ learning disabilities
  ○ dementia
 	
Groups that will not be covered:
• Adults with congenital hearing loss
	Groups that will be covered
	• The guideline should make a distinction between permanent and temporary hearing loss.
	• It is important to include age related hearing loss as most evidence will probably be in older adults.
	• Adult clinics see patients with congenital or childhood-onset hearing loss who request a change in treatment. There is investment from adult services into this population, and their treatment would not be covered in any future childhood guideline. This group should be included within scope.
	• The transition from paediatric to adult services is an issue that should be covered.
	• To treat people aged 18-19, providers need to be CQC registered (not just IQIPS accredited).
	• There is great diversity in the population of people with hearing loss. How will the full range of patients be reached and represented through consultation? People with mild to moderate sensorineural hearing loss aged 65 and over are not likely to be represented by stakeholder organisations as they do not consider themselves patients with hearing loss.
	• PPI groups linked to biomedical research units may be a way of reaching those less likely to engage with patient organisations.
	
	Special consideration
	• Deaf-blind people should be moved to the special consideration group.
	• The military is increasingly interested in hearing loss as it affects young soldiers. Young soldiers would however fall in the category of young people with noise-induced hearing loss, so would not need to be a separate subgroup.
	• Hearing loss is more common in some ethnic minorities, and different assessment tools may be needed if English is not the patient's first language.
	
	Groups that will not be covered
	• Explicitly exclude people with hearing loss that started in childhood but is not congenital (ie. acquired hearing loss)
	• The scope could exclude anyone who had an interaction with paediatric NHS services.

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
1.2. Settings • Primary, secondary and tertiary care • Community settings where NHS care is provided	• It should be explicitly specified that NHS-commissioned services are included. Change to 'where NHS care is commissioned or provided'. • The scope could be clearer about being for NHS settings only. Many hearing aids are sold through high street shops, not via NHS-commissioned services. The lines between independent and NHS-commissioned providers can be blurred, and not always clear to patients. • It was clarified that the guideline will cover care paid for by the NHS, regardless of provider, but private healthcare outside of the NHS is not considered in or subject to the guidance (although they may choose to follow it) • Does primary care include health and social care settings, for example domiciliary care settings and nursing homes? Should the terms primary care and community settings be defined? • There are relevant standards for service providers covering, for example, the location of where services are provided. Are these standards going to be looked at within the guideline?
1.3 Activities, services or aspects of care: **Key areas that will be covered:** **1 Assessment and treatment in primary care** – Clinical assessment that can be carried out in primary care – Identifying treatable causes of hearing loss and management in primary care – Early recognition of hearing loss that requires urgent referral to a specialist **2 Appropriate referral and assessment** – Who should be referred for specialist assessment (audiovestibular medicine or ENT) – Assessment in audiology (community or secondary care settings)	**Key areas that will be covered** **Assessment and treatment in primary care** • It was felt that the section heading should reflect the full range of assessment of hearing, listening and communication needs. • Include a question on whether patients should access hearing loss services first via the GP, or go direct to a hearing centre? Most people go to a GP because they don't know there is another option. • GPs do not do assessment other than history and examination, and treatments such as the removal of ear wax and treating infections. There is no evidence to make recommendations for further clinical assessment in primary care. • History, otoscopy and hearing screening checks are appropriate in primary care. The current quality of otoscopy is low, but there are standards covering its use. • Assessment carried out by high street providers is simpler than GP tests. • GPs need guidance on what they should do/tell patients presenting with hearing loss. They should signpost people to hearing loss services. • More detail could be added on assessment in audiology. Are imaging services going

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
and secondary medical care **3 Management** – What are the appropriate management strategies for individuals with hearing loss. For example: ⇒ Medical management for treatable or preventable causes of hearing loss ⇒ Surgical management for treatable causes of hearing loss ⇒ Patient-centred decision aids to give guidance on different management options ⇒ Hearing and listening strategies and tactics ⇒ Communication training and tactics, for example lip reading ⇒ Assistive devices (For example, flashing light fire alarms, vibrating alarms, induction loops and FM systems). These may be provided by audiology departments or by other agencies, for example social services. ⇒ Hearing aids (and training on how to use them) – Treatment and management of sudden onset sensorineural hearing loss – When should people with hearing loss be given two hearing aids rather than one – How and when to monitor/follow up patients given hearing aids – Clinical and cost-effectiveness of different types of hearing aids – Continuing appropriate use of devices – Information, support and initial management advice for patients, families and carers	to be used, and if so which and when? Many patients are referred for imaging unnecessarily. • The Royal College of Radiology has good guidelines on making use of radiology – this might be helpful when considering red flags. • Some stakeholders expressed concern that the organisation of audiology services may be missed by diagnostic services guideline. • The type of hearing loss is identified with an audiogram, but the cause of hearing loss is not always identified. The guideline should make clear the difference between identifying hearing loss and diagnosing the cause of the hearing loss. • Consider looking at assessing when people are ready for hearing aids. There is improved use and compliance if hearing aids are given when the patient is ready, not before. Some work around identifying candidates for interventions would be helpful. This could fall under the assessment area. • Training and education of medical and nursing staff is not mentioned. This is usually the remit of the Royal Colleges. Hearing loss is not adequately covered in current medical training programmes. This is not usually dealt with in NICE guidelines, but the guideline's recommendations should highlight the actions that staff will need to be competent in. • There is no mention of prevention of hearing loss, which is an issue often raised by GPs. There is particular concern about use of MP3 players. Should this be explicitly excluded if not being covered? • Syringing for wax overlaps with nursing care but nursing teams often refuse to do this. There is an additional cost to GP practices of referring to ENT for suction, which is usually unnecessary and also introduces unnecessary delay for the patient. • The terms community settings and primary should be clarified because community settings often provide primary care. Providers under the AQP scheme sometimes provide direct access to audiology with no GP referral. • Screening is used to validate problems before a GP appointment is given. This can be by use of phone and web assessment tools but it is not clear how widely these are used or known about in primary care. The guideline could look at this area. • There is a difference between audiometry and hearing screening checks. • Tools that provide hearing tests include apps. There is no standardised and clinically validated tool. They are usually aimed at consumers.

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
Areas that will not be covered: 1 Organisation and delivery of diagnostic services for hearing loss 2 Tinnitus (without hearing loss) 3 Vertigo (without hearing loss) 4 Acute temporary hearing loss caused by traumatic head injuries, for example perforated tympanic membranes or middle ear effusions 5 Management of disease processes underlying hearing loss	• GPs often ask private providers to do screening as they have time limited appointments. • There is a need for guidance on treating infections, for example what to do after ear drops, when to refer. • Early recognition of hearing loss that requires urgent referral to a specialist – this should be 'medical specialist'. **Appropriate referral and assessment** • Referral should be separated from assessment. • What is the best way in primary care to differentiate from sudden conductive and sudden sensorineural hearing loss? Patients are often misdiagnosed and end up in ENT when it is too late to treat them. • The tuning fork test can help differentiate sudden conductive and sudden sensorineural hearing loss, but are they of value in primary care? GP training does cover this, but could be asking too much to ask GPs to investigate, as it is more important to refer urgently to ENT. • Delayed referral is the main problem so the guideline should not encourage excessive interest in looking for the cause of sensorineural hearing loss. • It is critical to know if a patient has sudden sensorineural hearing loss as it can be treated with steroids immediately, which leads to better outcomes for the patient. Sudden conductive hearing loss does not need to be treated so urgently. • Sudden unilateral hearing loss needs urgent referral. • Guidelines from the British Academy of Audiology are commonly used to guide referrals. Will the guideline look at this guidance? • If audiology departments could directly order MRI, this would cut out some unnecessary referrals to ENT surgeons. There is a need for guidance on who can refer directly for MRI scans. • Assessment in audiology includes history, audiometry, assessment of communication needs and otoscopy. • There is debate about whether speech and noise clinics are useful. • How to best measure outcome and benefit? Need an explicit section on this in the scope. • Unsure about appropriateness of speech and noise measures.

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
	• Puretone audiometry is an antiquated test. Better forms of measurement are needed to get better outcomes for the patient. This is currently being researched, but the guideline can only look at what has been published. • Client and carers should be involved in the proactive identification of hearing loss at start of assessment and treatment. • It was noted that the proposal for an adult hearing screening programme has been turned down again. There needs to be a high index of suspicion for identifying patients. **Management** **Decision aids** • Decision aids are currently being developed. • At least one is in the process of being validated, so studies may be/shortly become available. Decision aids is an emerging research topic; they are not yet routinely used. But it is important to include this area as this is the direction the field is going. **Hearing aids** • Whether patients should receive 1 or 2 hearing aids is an important issue. • Should there be a question on whether people should be given hearing aids at all? Consider 0 as well as 1 or 2. Most people are now given 2, but there is high variation in current practice, ranging from 7% to 95% of hospitals giving 2 hearing aids. • 'When should people with hearing loss be given two hearing aids rather than one' – 'given' should be changed to 'offered'. • Cost effectiveness of different types of hearing aids – the QALY impact is very uncertain, so may be unable to come to a conclusion as a result. • Patient training on how to use hearing aids is an important issue. • Another issue is the selection and verification of hearing aid prescriptions, and use of an appropriate measure to verify the prescription target. • The standards of hearing aids provided in NHS are quite high. The main issue is not the hearing aid itself, but how it is provided and how the whole treatment is formulated. The question is what is appropriate for whom? • Comparing hearing aids within the same groups does not help clinicians; comparing

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
	hearing aids with 'watchful waiting' is more meaningful. • Hearing aids should be compared with other devices, for example implantable devices, assistive devices, bone anchored hearing aids, or even counselling and no device at all. **Other management strategies** • There is more uncertainty around the evidence and cost effectiveness of treatments other than hearing aids. • It would be beneficial to look at management strategies other than hearing aids. Change terminology to cover other hearing technologies. It would be helpful if some examples were added to the scope. • People want a range of options, not just always a hearing aid. More technologies are emerging. NIHR is doing some horizon scanning work over the next 6 months on emerging technologies. • Auditory training, communication strategies, alternative listening devices (wireless devices, iPhone hearing aids, wearables) – these are emerging fields. • Implantable devices may fall under specialised commissioning. This technology is still very much in development so could sit more with Technology Appraisal process, but on the other hand, bone anchored hearing aids have been around for 25 years. Wide variation in practice and commissioning is suspected. This may be a small area affecting a small number of patients, but still need to include it. • Semi-implantable devices is a developing area. Might these be commissioned by NHS? • Not yet aware of a systematic review on implantable devices. • Management strategies that could be added as examples: Counselling (with no intervention), 'watchful waiting', best form of integrated care, individual management plans. • It was noted that there is a significant cost associated with surgical treatment for hearing loss. Follow up • Many people using hearing devices would prefer walk in aftercare - much more

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
	convenient for patients. Monitor emphasised access to aftercare as being important for compliance and ongoing use. • Follow up and aftercare can be demonstrated to be very effective - there may be evidence. • Many people are not followed up. Compliance is correlated with follow-up, and therefore this improves the cost effectiveness of giving the devices. • Follow up requirements for AQPs are stringent – need to follow up hearing aid use at 1, 2 and 3 years. • It is more difficult to follow up patients in rural settings. • 'Fit and forget' leads to hearing aids not being used. • Follow up is lost in order to reduce waiting times for new patients. It is important to consider patient flow in the cost-effectiveness analysis. • The approach should be tailored to the needs of the individual – can this be highlighted? • Information and support for patients should be moved up the list as it is so important. • The guideline should stress the importance of how people access information, informing patients what their options are, and the ability for people to reconsider their options as their needs change. • The DNA rate for audiology is 48%. • Communication with patients needs to be planned sensibly – for example not trying to fix appointments over the phone. • There is debate around the use of steroids and how these are delivered for sensorineural hearing loss. **Continuing appropriate use of devices** • There are few studies on the continuing appropriate use of devices. There is often a split between assessment and provision of hearing devices versus ongoing management and follow up, which can be carried out by a separate entity. • It is unclear who is responsible for which tasks and there is overlap with issues around service provision. An example is that the GP contract says hearing aid provider will provide batteries. This can prove difficult for patients if the NHS refuses

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
	to provide batteries because the patient has seen an AQP. • Data collected by AQPs on use of hearing aids is shared with CCGs. It shows value for money and is useful to ensure the maximum benefit is being received. However this would be more of an issue for a quality standard than a clinical guideline. • NHS England is producing a specification for CCGs report. • 'Continuing appropriate use of devices' should be changed to 'Continuing benefit of devices'. **Information support and initial management advice** • Remove 'initial' from 'initial management advice'. • Sign posting and linking to other services is important. **Areas that will not be covered** • Stakeholders agreed with the areas not covered and felt they are not controversial. • Regarding management of disease processes, it was clarified that systemic (not local) diseases that also affect the ear are what is meant. • It may in some cases be appropriate for the hearing aid provider to liaise with medical professionals treating disease processes associated with hearing loss. However communication is bad and the audiologist is often not aware why hearing loss is deteriorating. • Surgical care for hearing loss was felt to be a large and complex issue that should be covered within this guideline or excluded. • If service provision in general is not covered, 'diagnostic' should be removed from point 1.
1.4 Economic Aspects 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.	• Cost effectiveness of aftercare (hearing aids maintenance). For example the majority of visits to audiology are for hearing aid repairs. • NHS pays less for hearing pathways than other countries around the world. But there may be broader international work that is relevant, for example around the cost of not treating hearing loss. • There is an association between hearing loss and dementia, with some evidence that providing hearing aids slows down progress of dementia (but it could be possible

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
	there is a common cause). This is a motivator for clinicians to refer, with cost implications for treatment of dementia. There have been instances where false diagnoses of dementia have been made when the patient actually has hearing loss. • Memory clinics do not regularly check hearing, but this could make a difference to quality of life. There are at least 2 reviews currently going on into this area. • Over-referral from primary to secondary care is not a major issue. Under-referral is a more major issue. • Patients are often referred to ENT when they should be referred to audiology. There is potential to reduce the number of patients who do not need ENT care. This would be a huge cost saving. • There is not much high quality evidence on the economic costs of hearing aids. • If was felt that open access to community providers for screening would work better for patients as they would get treated earlier. This would affect the capitation fee for GPs. However perhaps some things that GPs do could be better done in community settings so GP appointments can be used for something else. • The guideline could look at the economic implications of cognitive impairments due to hearing loss.
1.6 Main Outcomes • Health-related quality of life • Positive predictive value of symptoms • Diagnostic accuracy of tests • Adverse events • Hours of hearing aid use	• The outcome on hearing aid use should not just be limited to duration as it will vary according to patient needs. The more important factor is the time spent using hearing aids when it is important to do so and the patient will benefit – this may not be all the time and could be as little as 1 hour per day. • Appropriate use, ongoing use is a better term • Hearing-related quality of life. HUI3 picks this up. EQ5D is not sensitive enough to be a good measure on hearing. There are hearing-specific measures that should be used – see Cochrane protocol for terminology. • The Glasgow hearing aid benefit profile, COSI and IOIHA were highlighted as measures. • More 'holistic approach' outcomes were requested to be added. • There are relevant communication measures, mental health measures, and validated hearing loss measures.

Hearing Loss: scope workshop discussions Date: 04/03/16	
Scope details	**Stakeholder responses**
Committee Membership **Core GC members** • 1 Audiovestibular physician • 2 healthcare practitioners or technicians with expertise in the assessment and management of hearing loss in adults. Could include hearing therapist/audiologist and clinical scientist (audiological) • 1 ENT surgeon • 2 GPs • 1 Physician in elderly care/Geriatrician • 2 lay members **Cooptees** • Social worker • Nurse • Health psychologist	• There is no scientist representation yet there is lots of research underway – this input could be helpful. • Instead of 2 GPs, it was suggested that 1 GP and 1 practice nurse would be an alternative. • Social services professional with expertise in hearing (assistive listening devices). • The therapeutic/psychological aspect is important so hearing therapist and/or a counsellor would be good to include.

Further questions:	**Stakeholder responses**
5. If you had to **delete (or de-prioritise) 2 areas** from the Scope what would they be?	• Comparing the effectiveness of different types of hearing aids.