

Practice Guidance

Common Principles of Rehabilitation for Adults in Audiology Services

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General foreword

This document presents Practice Guidance by the British Society of Audiology (BSA). This Practice Guidance represents, to the best knowledge of the BSA, the evidence-base and consensus on good practice, given the stated methodology and scope of the document and at the time of publication.

Although care has been taken in preparing this information, with reviews by national and international experts, the BSA does not and cannot guarantee the interpretation and application of it. The BSA cannot be held responsible for any errors or omissions, and the BSA accepts no liability whatsoever for any loss or damage howsoever arising. This document supersedes any previous statement on adult rehabilitation by the BSA and stands until superseded or withdrawn by the BSA. This document deals specifically with evidence pertaining to rehabilitation for hearing disorders while previous versions have covered tinnitus and balance also. This is to allow for a greater range of evidence to be included.

An electronic copy of the anonymised comments received during consultation and the responses to these by the authors is available from BSA on request.

Comments on this document are welcomed and should be sent to:

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Contents

1.	Introduction		4
2.	Background and Context		5
3.	Guiding Principles		8
4.	Implica	tions for Practice	10
	4.1 Idei	ntifying Individual Needs	11
	4.2 Set	ting Joint Goals	12
	4.3 Making Shared Informed Decisions		
	4.4 Sup	porting Self-Management	15
5. Outcomes Measures			20
6. Summary			22
References			23
Append	dix A:	WHO International Classification of Functioning, Disability	
		and Health (WHO, 2001)	31
Append	dix B:	Resources for Identifying Individual difficulties, needs and expectations and	
		for measuring functional outcomes	33





1. Introduction

Hearing problems are often long-term conditions, which can be managed but not always cured. Effective rehabilitation is best achieved through a process that goes beyond addressing the sensory impairment by also providing support to the person experiencing the hearing problem (the 'patient') and to the patient's significant other(s)¹. The purpose of this document is to promote these aspects of care, which address patients within their social context. The document is not intended to provide specific management strategies for hearing loss. Rather, it aims to recommend a common set of principles for promoting a patient-centred, collaborative and reflective approach to rehabilitation where the audiology professional² plays the role of the 'facilitator', not the 'fixer'. This general approach is in keeping with current trends seen across other clinical disciplines in the rehabilitation of long-term conditions. Although the focus of this document is on hearing, similar principles apply to other services within audiology including tinnitus and balance rehabilitation.

Despite the crucial importance of evidence-based healthcare, one common criticism of it in recent years has been the risk of clinical guidance becoming algorithmic and prescriptive (Greenhalgh et al. 2014). There is also a concern that care has tended to be informed by effectiveness at a population level without adequate recognition of the need to individualise decisions made about patients (Greenhalgh et al. 2014). This document reflects best available evidence and is intended to support audiology professionals in identifying patient preferences for their care, especially for those who have long-term hearing conditions.



¹In rehabilitation for people with hearing loss, the patient's 'significant other' is usually referred to as the 'communication partner' (CP) as this incorporates not just the spouse but also others with whom the person with hearing loss communicates on a frequent basis, such as partners, family members, friends and caregivers.

²The term 'audiology professional' refers to all professionals working in audiology services, including audiologists, hearing therapists, clinical scientists, hearing aid dispensers, and audiological physicians.

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The document is primarily intended to inform the practice of audiology professionals directly involved in the rehabilitation process. It is also intended to be a guide for commissioners, policy makers and other stakeholders as to what best practice in rehabilitation should comprise. It applies to both public and private services in England, Scotland, Wales and Northern Ireland.

This is a revised and updated version of BSA guidance produced in 2012. It was produced by the Professional Guidance Group in collaboration with members of BSA Adult Rehabilitation Interest Group.

2. Background and Context

The International Classification of Functioning, Disability and Health (ICF) was officially endorsed by the World Health Organisation in 2001 as the framework for disability and health sectors worldwide (WHO 2001). This biopsychosocial approach highlights individual health rather than disability, with the focus on impact rather than cause (see appendix A for further details). This approach underpins the UK Action Plan on Hearing Loss (NHS England 2015) that emphasises the responsibility for the health sector to provide care with individual level activity limitations (previously known as disability) and participation restrictions (previously known as handicap) as the focus of assessment, diagnosis and management of the hearing impairment (i.e. function). Functional domains for potential activity limitations and participation restrictions include understanding spoken information, conversation, recreation and leisure, education and employment. The Action Plan, like the ICF, also highlights the influence of contextual factors on sensory impairment, activity limitations and participation restrictions. Contextual factors make up the physical, social and attitudinal setting in which people live and conduct their lives. They can be either external (e.g. lifestyle, social attitudes) or internal (e.g. age, education, coping style, personal expectations). By addressing how these issues relate to the psychological, social and emotional impacts of the hearing problem, the audiology professional can facilitate improvement of the client's activity, participation, and quality of life (Boothroyd 2007).



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Using the ICF as an intervention framework directs clinicians towards using a patient-centred approach to audiological rehabilitation. The main goal for rehabilitation is to improve quality of life by eliminating or reducing activity limitations and participation restrictions. The approach to rehabilitation should therefore be based on identifying individual needs, setting specific goals, making shared, informed decisions and supporting self-management. These steps are important for helping patients to overcome difficulties in daily life.

Hearing aid fitting is an important part of adult rehabilitation in audiology services. The use of hearing aids has been shown to improve health-related quality of life by reducing psychological, social and emotional effects of hearing loss (see Chisolm et al. 2007, for review). There is also evidence that fitting hearing aids when people first begin to experience hearing loss results in better long-term outcomes than when getting hearing aid fittings are delayed (Davis et al. 2007). It is important to note that decisions about whether and when to fit hearing aids should not be based primarily on the degree of hearing loss. A systematic review by Knudsen et al. (2010) found that hearing sensitivity of pure-tone audiometry is a poor predictor of hearing aid use and that self-perceived activity limitations are better predictors.

The purpose of rehabilitation goes far beyond giving advice in terms of instruction to use technology and manipulate the listening and communication environment (Boothroyd 2007; Grenness et al. 2014; Grenness et al. 2015). Managing hearing loss involves changing behaviour, and extensive research in the field of health psychology suggests that most people do not change their behaviour in response to simple advice-giving (Mason and Butler 2010). Rather, people's motivation, capability and opportunity for change all need to be considered (Michie et al. 2011). Within audiology, there has been an increasing use of health behaviour change theories to improve understanding of help-seeking, decision-making and intervention uptake and adherence in adults with hearing loss (Ferguson et al. 2016a; see Coulson et al. 2016, for critique of health behaviour theories).



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Helping people to confront a range of psychological, social and emotional concerns as they relate to hearing means that audiology professionals typically find themselves in a counselling role. In this document, counselling refers to the use of counselling skills by audiology professionals with patients and their communication partners as they recognise hearing-related problems and attempt to acknowledge and understand the realities of living with those (Clark and English 2014). This process of adjustment should naturally evolve as part of the dialogue that arises within the clinic visits. Adjustment counselling is distinguished from psychological counselling, which explores a reinterpretation of the personal conflicts or emotions that a person might have. Research examining how audiologists and patients interact has identified that audiologists tend to focus on solving problems rather than attending to the emotional content of patient narrative (Ekberg et al. 2014; Grenness et al. 2015). This may result in patients not feeling fully understood, and they may see their encounters and interactions with audiologists as isolated events rather than stages in the rehabilitative process (Laplante-Levesque et al. 2012).

The UK National Health Service embraces a client-centred model of health care (DH 2011) which is based on the Picker principles of patient-centred care (www.pickereurope.org.). In keeping with this, we suggest that our guiding principles should be central to all forms of audiological practice:

- 1. Identifying individual needs
- 2. Setting joint goals
- 3. Making shared, informed decisions
- 4. Supporting self-management strategies.

These principles are outlined in Section 3 of this document, and section 4 provides some examples of how these guiding principles can be applied at different phases of care. Such skills are learned, not innate, and so they should be continuously developed and evaluated through reflective practice.





3. Guiding Principles

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Effective audiological rehabilitation places importance on the successful development of a positive, interactive relationship between the audiology professional and the patient and their communication partners (Preminger and Meeks 2010; Poost-Foroosh et al. 2011; Ekberg et al. 2015; Eckberg et al. 2016). Establishing a rapport is important because it is known to improve listening, information gathering and motivation, which are all factors that influence treatment outcomes (Roberts and Bouchard 1989). The audiology professional's mastery of these counselling skills enables him/her to know when to listen and when to offer a comment that might permit exploration of feelings and thoughts that can aid the rehabilitation process. In the context of this positive audiology professional-patient relationship, the following principles will facilitate the rehabilitation process. These principles should be fully integrated with technological and/or biomedical management as part of a patient-centred approach so that these elements do not form an additional, separate component to routine practice such as hearing aid assessment and fitting (Laplante-Levesque et al. 2010; Grenness et al. 2014).

Identifying individual needs

Rehabilitation is a process that addresses the needs of each individual. Biological, psychological and social perspectives are used to define the individual's unique experience of her/his hearing difficulty. The aim is to facilitate the development of self-management strategies through the identification and response to an individual's needs in terms of impaired function, activity limitation and participation restriction, and associated environmental factors. This may also involve consideration of third-party disability experienced by the individual's partner or family members. Note that for the purposes of this document, the identification of needs is considered to be an integral part of, but practically separate, from goal-setting.





Setting joint goals

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Rehabilitation occurs through a problem-solving and goal-setting partnership. McKenna (1987) was among the first to describe the use of goal setting by audiology professionals. He described several notable features for its successful implementation, including the importance of involving patients, communication partners and all relevant clinical professionals in the goal planning process. It requires a relationship based on trust, respect and empathy that enables the individual to develop a sense of ownership of the rehabilitation programme.

Making shared, informed decisions

Rehabilitation requires a shared understanding between the audiology professional, the patient, and communication partner(s) of (i) effects of the hearing problem, (ii) agreed strategies intended to reduce these effects and (iii) how to effectively implement these strategies.

Shared decision-making offers an intermediate alternative between the patient accepting full decision-making control, and having no say at all. Intervention strategies might include, but are not limited to, technological or biomedical options, and it is important that intervention options are offered (Laplante-Levesque et al. 2012). Shared decision making has become an important feature of contemporary healthcare and is an ethical imperative to ensure patient benefit, autonomy and justice. Where clinicians focus on alleviating impairments but do not personalise or individualise the decisions made, patients report dissatisfaction with the encounter and lose trust in the clinician (Pryce and Wainwright 2008). The identification of and discussion about the harms and limitations as well as the benefits of routine audiological interventions such as hearing aids need to be included in clinical appointments (Pryce and Hall 2014). Audiology professionals should be aware that uptake of interventions may depend on factors that are non-audiological (e.g. support from significant others, perception of benefits of interventions, motivation, self-efficacy, expectations) as well as audiological (Meyer al. 2014; Ridgway et al. 2015; Ferguson et al. 2016b, c).





Supporting self-management

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A patient-centred approach can help people develop effective ways to help themselves. As is characteristic of people with a long-term health condition, individuals with hearing loss spend relatively little time in clinical settings and the vast majority of their time managing their condition themselves as they go about their everyday lives. Lorig and Holman (2003) identify two factors that are essential to successful self-management of any long-term condition: knowledge of the condition and its effects, and the ability to adapt behaviour appropriately. The audiology professional has a role to play in providing knowledge and facilitating behaviour change so that individuals can eventually live well with their hearing loss with minimal ongoing professional support.

Exactly how clinicians can best support self-management of hearing loss has yet to be firmly established. Barker et al. (2015) conducted a Delphi review in which they posed this question to a panel made up of experienced audiologists, researchers in auditory rehabilitation and people with hearing loss. Consensus was reached on a number of items that included giving clear information on hearing loss and hearing aids but also giving people choices and making joint decisions.

4. Implications for Practice

The four guiding principles described in Section 3 can help audiology professionals to engage the patient and their communication partner in all key aspects of rehabilitation, thus enhancing their motivation and developing a sense of personal control over the problem. Here, we provide a few examples of opportunities to apply those guiding principles in routine practice. This is not intended to be an exhaustive list nor a replacement of good practice guidelines and quality standards on service provision for people with hearing, tinnitus and/or balance problems.



4.1 Identifying Individual Needs

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The clinician should aim to understand the patient's experience of hearing loss within the ICF framework (this is also true of balance and tinnitus problems). The experience of hearing cannot be separated from the broader circumstances of the individual's life and health (Tjornhoj-Thomsen 2009). Careful listening to patient experience will enhance the helping relationship (Midwinter and Dickson 2015). This involves use of open questions, paraphrasing and reflection to explore a patient's perspective fully (Midwinter and Dickson 2015) finding out as much as possible about what situations are relavant and important to them. Patients place significant value on their relationship with the clinician and demonstrating an understanding and appreciation of their individual experience results in improved coping ability (Mattingly 2006).

Promoting discussion of patient perspectives of their individual experience and being genuinely interested is essential to patient-centredness (Michie et al. 2003). Equally important is being able to engage patients in actively taking control of their health condition, and this can be done by encouraging them to ask questions, as well as involving them in decision-making (Laplante-Lévesque et al. 2010). It is important for audiology professionals to:

- 1. Consider individuals' needs and desires, as well as their perspective and individual experiences
- 2. Offer opportunities to patients to provide input into and participate in their care
- 3. Enhance partnership and understanding in their relationship with the patient (Epstein et al. 2005).



4.2 Setting Joint Goals

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Goal planning refers to a way of structuring and evaluating a rehabilitation programme which is individually designed for a particular patient and her/his communication partner(s). The NHS Scotland (2009) Quality Standards for Adult Hearing Rehabilitation Services recommend the use of an Individual Management Plan (IMP) for agreeing needs and actions that seek to improve a person's participation in life, and using an IMP is part of the service specification detailed in the Any Qualified Provider scheme in England. The NHS Commissioning Framework in England (NHS England 2016) also includes the need for completing an IMP. The IMP includes the subheadings: (i) agreed needs; (ii) planned actions; (iii) completed actions; and (iv) outcomes. It is also useful to document the decision-making process and proposed time scales in the IMP. The Quality Standards reinforce the viewpoint that an effective IMP relies on consultation between the audiology professional, the patient and her/his communication partner(s). Only when all parties are committed to the joint goals can an optimal outcome likely to be achieved, and it is important to review goals at subsequent appointments. The Quality Standards also support the notion that an IMP is most effective if it takes into account a range of factors, in addition to the type and level of sensory impairment. Goals should be explicit, realistic and achievable.

A Cochrane review by Coulter et al. (2015) investigated whether involving patients with a range of long-term health conditions in goal planning yielded better results than a traditional, clinician-led approach. It arrived at the conclusion that "personalised care planning is a promising approach that offers the potential to provide effective help to patients, leading to better health outcomes. More research is needed to work out which aspects are most effective for specific patient groups." (p3).

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4.3 Making Shared, Informed Decisions

Decisions about how to proceed when a hearing loss is identified are heavily influenced by individual lifestyle and preferences. Although hearing aids are often prescribed routinely, there is evidence that, when asked, some patients may prefer social interventions or information gathering before hearing aid prescription (Claesen and Pryce 2012; Laplante-Levesque et al. 2012). In order for patients to make decisions it is necessary to get a full picture of their situation, to recognise that they have a decision to make, and to be informed of the options (Laplante-Lévesque et al. 2010). A survey of cochlear implant users (Athalye et al. 2015) found that they would like to be more involved in decision-making.

Decision aids can be helpful in informing patients of likely options ahead of the clinical encounter. Decision aids can take a variety of formats, such as paper, DVD, audio or internet tools³. Short versions have been developed for use in clinical encounters as well as more extensive versions with detailed information. There are a set of international standards⁴ for development of new aids and to assess the quality of published decision aids (Elwyn et al. 2006). These quality standards specify there should be a systematic development process, use of up to date cited evidence, use of plain language and information presented in a balanced way. Further information on the development process for decision aids is described by Coulter et al. (2013).



³ A database of decision aids is at: http://decisionaid.ohri.ca/index.html

⁴http://ipdas.ohri.ca

⁵https://www.sanfordhealth.org/HealthInformation/Healthwise/Topic/za1122

⁶www.optiongrid.org

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Examples of decision aids that have been published for use with adults with acquired hearing loss are a paper based tool that presents the options of trying a hearing aid, participating in a communication group program, taking part in a written communication program or no intervention (Laplante-Lévesque, Hickson et al. 2010), a web-based tool that allows patients to compare the options of trying a hearing aid versus living without hearing aids⁵ and the Hearing Loss Option Grid⁶, developed to international decision aid development standards.

Decision aids facilitate conversations between clinicians and patients but are not designed to replace detailed discussion. Such discussion has three phases: choice talk – to examine the choice to be made, to make patients fully aware that they have a choice; option talk – to examine the pros and cons of different options, and decision talk - to weigh up the individual circumstances and preferences of the patient in making a decision (Elwyn et al. 2012). Goal-setting may be part of the decision-making process but the discussion should not only be focussed on goals.

Shared decision making (SDM) requires excellent counselling and communication skills to provide health coaching, which involves conversations geared at encouraging the patient to make and be involved in decisions with open and closed questioning and support for reasoning and deliberation (Coulter and Collins 2011). Barriers to patient use of SDM were reviewed by Joseph-Williams et al. (2014). Within audiology, barriers include organisation of clinics and in particular having inadequate time to make decisions (Pryce and Hall 2014).



⁵<u>https://www.sanfordhealth.org/HealthInformation/Healthwise/Topic/za1122</u>

⁶www.optiongrid.org

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Professional training routes need to include skills in assessing patient preferences as much as diagnosing impairments (Mulley et al. 2012). UK commissioners of hearing services are frequently unaware of patient preferences, prioritising clinicians' report on hearing healthcare needs (Mulley et al. 2012)

4.4 Supporting Self-Management

Self-management occurs when the individual takes responsibility for their own behaviour and wellbeing. For long-term conditions, this refers to management of symptoms, interventions or treatment, and physical and psychosocial consequences alongside life-style changes (Barlow et al. 2002). In other health domains it is recognised that individuals who are motivated and actively participate in their care are more likely to adopt health behaviours that then lead to better patient outcomes (Mosen et al. 2006). This is particularly the case in patients with long-term conditions who are required to play a role in their day-to-day management (Hibbard et al. 2004). A systematic review of self-management systems that combine health information and at least one of the following: informed decision-making, promotion of health behaviour, peer information exchange, and promotion of self-care, found that these strategies result in improved knowledge, self-efficacy, social support and clinical and behavioural outcomes (Murray et al. 2005).

For hearing loss, self-management support might include assessment of hearing loss and difficulties, shared decision making with audiologists, patient education on hearing aids and communication, self-management resources and tools, and practice of behaviour change (Barker et al. 2014). A summary of some interventions that support the self-management of hearing loss, and in some case hearing aids, are discussed below.





Information delivery and patient education

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Providing written information is probably the most common way in which audiologists try to support self-management. Research in other fields of healthcare has demonstrated that well-designed patient information leaflets can be effective in improving knowledge and understanding of one's condition when used in combination with information given orally but are less helpful when distributed without discussion (Coulter and Ellins 2007). The same review found that personalised information is more effective in improving knowledge than more general information. Furthermore, it is important to recognise that one-way delivery of information is not the same as educating individuals (Boothroyd 2007), which requires taking an interactive role in the learning, resulting in greater learning, knowledge and education (Zhang et al. 2006). Provision of written information alone is rarely adequate.

An increasingly popular and simple way of supporting self-management in healthcare is through multimedia which can be used in the client's home and shared by significant others. A Cochrane review (Ciciriello et al. 2013) found that multimedia education (mostly DVDs or computer programs) about medication was more effective than 'traditional' education alone (oral or written instructions) at increasing knowledge and skills around medication use. A study that provided people with hearing loss and their communication partners with a series of DVDs showing ideas for effective communication in different scenarios reported improved use of communication strategies and better interaction with communication partners compared to a control group who received no intervention (Kramer et al. 2005).

More recently, an educational programme was developed for first-time hearing aid users ("C2Hear")⁷ on practical and psychosocial issues related to hearing aids and communication that uses animations, cartoons and video clips to illustrate concepts and processes and includes activity, engagement and self-assessment (Ferguson et al. 2015a). C2Hear is available on DVD for television and PC, and online via the internet and mobile technologies⁷. A randomised controlled trial showed that benefits included greater knowledge, better practical hearing aid handling skills and greater



2016



hearing aid use in suboptimal users, alongside greater confidence, reassurance and preference for this interactive material compared to written information (Ferguson et al. 2016d). It is suggested that C2Hear and other similar programmes should be an adjunct to audiology services rather than a replacement of audiologist input. This advice is consistent with that from other health domains (Ciciriello et al. 2013).

Studies in Sweden have looked at provision of written information supplemented with clinician support via telephone or email to help people with hearing loss develop self-management strategies (Lundberg et al. 2011; Thorén et al. 2011). Improvements were reported in emotional and participation difficulties related to hearing loss. Further delivery of online materials showed similar results and longer term retention (Thorén et al. 2013).

Computer-based auditory training

Auditory training traditionally aims to improve speech perception and listening skills. A number of computer-based and online auditory training programmes exist, which are designed for use in the individual's home without clinician support, such as LACE- Listening and Communication Enhancement (Sweetow and Sabes 2007). A systematic review of such programmes suggested that improvements in speech perception are small and not robust, and that published evidence is of very low-moderate quality (Henshaw and Ferguson 2013). There is, however, emerging high-quality evidence to suggest that auditory training may improve cognitive abilities (Anderson et al. 2013), particularly those that tap into executive processes (i.e. attention monitoring and switching, memory updating) that are important for challenging listening situations such as speech in background noise (Ferguson et al. 2014; Ferguson and Henshaw 2015).

Rehabilitation Groups

Although aural rehabilitation groups may be led by clinicians, their explicit aim is usually to support self-management and equip participants to live well with their hearing loss within their own





communities. A review of 13 aural rehab groups (Hawkins 2005) concluded that they are effective in increasing participation and improving quality of life, at least in the short term. Since this review, an Active Communication Education group programme for older adults has been developed and manualised (Hickson et al. 2007)⁸ that has also shown positive effects on participation and wellbeing (Hickson et al. 2007; Oberg et al. 2014). Importantly, Hickson et al. found that improvements were largely maintained 6 months after the end of the group programme, suggesting that successful self-management is occurring.

Peer-led support groups also exist, with the UK charity Hearing Link⁹ being the largest provider of these. User feedback tends to be very positive and they are seen as a valuable source of support.

Motivational engagement and patient readiness

Motivational engagement has been successfully applied to health behaviour changes such as smoking cessation (Lindson-Hawley et al. 2015) and reducing alcohol intake (DiClemente et al. 1999). More recently, there has been an increasing awareness of the role that health behaviour change plays in audiology and the role of non-audiological factors (e.g. self-efficacy, positive visual abilities and communication partners), as well as audiological factors (e.g. advanced hearing aid handling, greater hearing aid gain) in the uptake and use of hearing aids (Hickson al. 2014; Ekberg et al. 2015; Ferguson et al. 2016b, c).



⁷for online version: https://www.youtube.com/channel/UC_CO85ih5H68q5YSxMziidw and DVD http://www.hearing.nihr.ac.uk/research/ordering-c2hearDVD

⁸The ACE manual is available online at http://www.shrs.ug.edu.au/active-communication

^{9.} <u>www.hearinglink.org</u>.



Examination of motivation to use hearing aids and other interventions (e.g. auditory training) suggests intrinsic motivations influence uptake and use (Ridgway et al. 2015).

A range of motivational tools have been developed by the Ida Institute⁹ with the aim of increasing self-efficacy and improving engagement with the audiologist at hearing assessment and fitting appointments. By using the tools, audiologists can work collaboratively with patients on matters that are important and relevant to them¹¹ (Ferguson et al. 2016b). Furthermore, readiness to take action is associated with improved hearing aid outcomes (Laplante-Levesque et al. 2012; Grenness et al. 2014; Ferguson et al. 2016b, c).

In conclusion, there is some emerging evidence within Audiology to suggest there are a range of tools and resources to support the patient, whether a hearing aid user or not, in the self-management of their hearing loss and communication.

¹¹see ethnographic video <u>http://www.hearing.nihr.ac.uk/public/evaluation-of-benefits-of-motivational-engagement-in-first-time-hearing-aid</u>



¹⁰ http://idainstitute.com/toolbox/motivation_tools/



5. Outcome Measures

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In order to assess the effectiveness of interventions for patients and their communication partners, appropriate and sensitive outcome measures are required. These are helpful both in measuring an individual's progress towards desired goals and in evaluating the overall effectiveness of audiology services. Careful consideration needs to be given to which outcome measure is most fit for purpose. A measure that enquires only about pre-determined situations, for example, may not be compatible with an individual, goal-setting approach to rehabilitation. A systematic review has shown an enormous range of outcome measures (objective and subjective) have been used in hearing-related studies, and currently there is no consensus on which outcome measures are most appropriate (Granberg et al. 2014). Even for a specific measure, such as hearing aid use, there is no consensus (Perez and Edmonds 2012). The majority of outcome measures are used in the short-term (<6 weeks) and there is a paucity of studies that have used outcome measures in the long-term (e.g. 1 year or longer; Barker et al. 2014). Measuring longer term outcomes routinely would help to fill in some important shortfalls in the current evidence base.

While measures pertaining to the outcome of hearing aid fitting are perhaps the most commonly used in the UK, alternative measures might be considered when the intervention is not confined to amplification. Similarly, the majority of measures address activity limitations, such as speech perception or communication, with relatively few measuring psychosocial aspects that include identity and emotion (Heffernan et al. 2016).

Assessment of health-related quality of life (HRQoL) measures may be useful when considering the effect of hearing-related interventions on patients' overall health and well-being. Assessment of HRQoL can be measured using generic and/or disease-specific health-related quality of life (HRQoL) outcome measures. The benefit of generic-HRQoL measures (e.g. EQ-5D, Short Form-36) is that they allow for comparison across different health conditions, populations and interventions, which can be used subsequently to assess relative cost-effectiveness across different health conditions and interventions. The disadvantage of generic-HRQoL measures is that they are generally not sensitive



2016



to hearing-related populations and interventions. Those measures that have a hearing or communication domain (WHO-Disability Assessment Schedule II, Health Utilities Index Mk-3) are more sensitive than those that do not mention hearing (e.g. EQ-5D, SF-36; Barton et al. 2005; Chisolm et al. 2007; Davis et al. 2007). Disease-specific outcome measures are designed to measure the effectiveness of both the specific intervention (e.g. hearing aid) in a specific population (e.g. adults with mild to moderate hearing loss). The advantage of hearing-specific measures is that they are more sensitive and subsequently show greater effect sizes (see Chisolm et al. 2007). In terms of selecting outcome measures for use in clinic, it is important that outcome measures tap into individual needs and are sensitive and appropriate to the intended mechanism of benefit (Ferguson and Henshaw. 2015). See Appendix B for examples of outcome measures.

There is an increasing need to demonstrate the clinical and cost-effectiveness of hearing services against a backdrop of cuts to audiological services. Commissioners are looking for outcomes that provide evidence of efficiency and value for money, thus there is an imperative to provide relevant evidence. The framework for clinical commissioning groups (NHS England 2016) includes standard clinical patient reported outcome measures (PROMS e.g. Glasgow Hearing Aid Benefit Profile) and patient reported experience outcomes (PREMS e.g. satisfaction with service), as well as measures of how hearing rehabilitation has an impact across the lifespan (e.g. reducing loneliness, increasing social function and reducing risks of dementia, frailty and falls). The use and analysis of PROMS needs to be robust to avoid providing a false picture of patient outcomes and value for money. Just as important as the type of PROM tool that is used is i) how the tool is used, and ii) how outcomes are analysed/reported for cohorts of patients. In order to judge comparative performance of service provision it is important that robust (objective) benchmarking is conducted to ensure like-for-like comparison. As a guide, such processes should be at least as well defined as use of outcome measurement tools reported in research studies. The BSA will be providing further guidance based on these important principles to help ensure optimum use of outcome measurement in clinical practice and their use to guide commissioning of effective Audiological Rehabilitation services.

A future Cochrane review will assess high-quality evidence for the clinical effectiveness of hearing aids for mild-moderate hearing loss in adults (see Ferguson et al. 2015b, for protocol). Both clinical





and cost-effectiveness of management of hearing loss will be considered in the future recommendations of the National Institute for Health and Care Excellence (NICE) guidelines for hearing loss (adult presentation) (NICE 2016).

6. Summary

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Whilst audiology services have benefitted from significant technological advances in recent years, achieving beneficial outcomes for patients is also heavily reliant on an approach to rehabilitation that goes beyond the sensory impairment, considers patients within their social context and addresses the most important needs of the individual. This document describes those aspects of rehabilitation that have also been shown to be effective in other chronic health domains and makes suggestions for how outcomes of rehabilitation can be measured. The major goal for rehabilitation is to improve quality of life by focusing on ameliorating activity limitations and participation restrictions. It is recommended that this is achieved by adopting four key principles:

- 1. Identifying individual needs
- 2. Setting joint goals
- 3. Making shared, informed decisions
- 4. Supporting self-management

This approach represents a shift away from a traditional medical approach in which something is 'done to' a patient towards an empowerment approach in which people are encouraged to become active participants in the management of their own health and wellbeing (Department of Health, 2011; NHS Scotland, 2009). This document fully supports those legislative changes such that the operating principles become central to all audiology services, both public and private providers across the UK.





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2016

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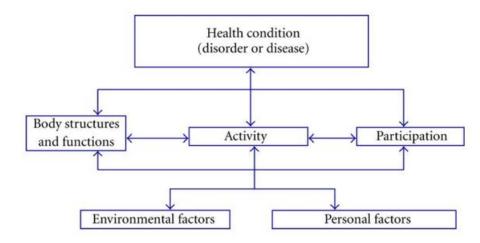
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2016



Appendix A. WHO International Classification of Functioning, Disability and Health (WHO, 2001)



Based on the biopsychosocial model, the ICF provides different perspectives of health (biological, individual and social) and has been expanded to address specific health conditions by the development of ICF Core Sets. A comprehensive ICF Core Set for Hearing Loss has been rigorously developed, that consists of 117 ICF categories and a briefer subset of 27 categories (Danermark et al. 2013). These provide a means to measure the outcome of an intervention in terms of the functioning of a person with hearing loss, as follows:

Body functions are the physiological function of body systems. Hearing functions relate to the presence of sounds and discriminating the location, pitch, loudness and quality of sound. Other functions include cognition (attention, memory) emotion, vision and personality.

Body structures are the anatomical parts of the body including structures of the external ear, middle ear, inner ear and brain. Activities and participation are the execution of a task or action by an individual and involvement in a life situation. These include listening, conversation, family relationships and community life. Environmental factors make up the physical, social and attitudinal





environment in which people live and conduct their lives. These include immediate family, health professionals, education and work, societal attitudes and health services, systems and policies.

2016



Appendix B. Resources for identifying individual difficulties, needs and expectations and for measuring functional outcomes

This section summarises tools that may be useful to audiology professionals. Within UK adult rehabilitation services, the most commonly used self-report outcomes are the COSI, GHABP and Glasgow Hearing Aid Difference Profile (Ferguson et al. 2015). Reasons given are for patient benefit (help future appointments, enhance individual care, monitor individual outcomes) and service evaluation (monitor service, justify resources). The framework for clinical commissioning groups provides recommended outcomes and key performance indicators (NHS England, Appendix 7).

These are given as examples rather than to attempt to provide an exhaustive list; no implication that they are specifically recommended is intended. Note that some of these tools are suitable as functional outcome measures only if they are administered twice (before and after rehabilitation). The outcome is represented by the difference between those two scores.

B.01 Client-Oriented Scale of Improvement (COSI)

The COSI promotes a focus on the client's individual needs and can be helpful to facilitate joint goal setting for a range of audiological interventions. Clients nominate up to five rehabilitation goals and evaluate the changes at the end of the rehabilitation process. Hence, the COSI is useful for evaluating functional outcomes too. Developed in Australia, the questionnaire can be downloaded from: www.nal.gov.au/outcome-measures tab cosi.shtml.

 Dillon H, James A, Ginis J (1997) Client Oriented Scale of Improvement (COSI) and its relationship to several other measures of benefit and satisfaction provided by hearing aids.
 Journal of the American Academy of Audiology, 8, 27-43.

B.02 Expected Consequences of Hearing aid Ownership (ECHO) questionnaire



2016



The ECHO has been designed to measure pre-fit expectations of hearing-aid use. It can be used to examine unrealistic expectations that a potential hearing aid user might have, so that counselling can be directed to address these areas before the hearing aid is issued. This may prevent unnecessary disappointment with the experience of hearing-aid use. This tool is recommended at the assessment stage of the IMP (NHS Scotland, 2009). The ECHO has four subscales; Positive Effect, Service and Cost, Negative Feature and Personal Image. Developed in USA, the questionnaire can be downloaded from: www.memphis.edu/csd/harl/echo.htm.

A sister questionnaire, the Satisfaction with Amplification in Daily Life is designed to evaluate the satisfaction that individuals feel about their hearing aids. The subscales are the same as for the ECHO. The SADL can be downloaded from: http://www.harlmemphis.org/index.php/clinical-applications/sadl/

- Cox RM, Alexander GC (2000) "Expectations about hearing aids and their relationship to fitting outcome". *Journal of the American Academy of Audiology*, 11, 368-382.
- Cox, RM and Alexander, GC. "Measuring satisfaction with amplification in daily life: The SADL Scale", *Ear and Hearing*, 20: 306-320 (1999).

B.03 Glasgow Hearing Aid Benefit Profile (GHABP)

The Glasgow Hearing Aid Benefit Profile (GHABP) is a situation-specific questionnaire designed to be used in conversation with the client. It assesses aspects of auditory disability, auditory handicap, and hearing-aid benefit through the use of up to four standard situations, as relevant to the patient, and up to four patient-determined situations. Each situation has six questions, two for before the hearing-aid fitting and four for follow-up. GHABP was the functional measure used as part of the NHS Modernising Hearing Aid Services (MHAS) programme and remains the primary validated hearing-related questionnaire in use across the UK. Its standard scoring system makes local and national comparisons possible. Norms for the GHABP are available (see Whitmer et al. 2014).





The Glasgow Hearing Aid Difference Profile (GHADP) is designed for existing users who have received replacement hearing aid(s), and looks at the direct difference between new and previous hearing aids.

MHAS Protocols are available:

2016

GHABP: http://www.mhas.info/documents/Combinedsitepack/GHABP%20protocol.pdf

GHADP: http://www.mhas.info/documents/Combinedsitepack/GHADiffP%20protocol.pdf

- Gatehouse S (1999) Glasgow Hearing Aid Benefit Profile: Derivation and validation of a client-centered outcome measure for hearing aid services. *Journal of the American Academy of Audiology* 10, 80-103.
 - Whitmer WM, Howell P, Akeroyd MA. Proposed norms for the Glasgow hearing-aid benefit profile (GHABP) questionnaire. *International Journal of Audiology*. 2014;53(5):345-351.
 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4067542/

B.04 International Outcomes Inventory – Hearing Aids (IOI-HA)

The IOI-HA covers a set of seven core outcomes, which includes use, benefit, residual activity limitations, satisfaction, residual participation restrictions, importance to others, quality of life. The IOI-HA is scored on a five point Likert scale. It was developed as an addendum to other outcome measures, to facilitate co-operation across different countries (it has been translated into over 30 languages). The questionnaire can be downloaded from:

http://www.harlmemphis.org/files/4113/4625/3392/IOIHA-EnglishNormsVersion.pdf

Cox, R., Hyde, M., Gatehouse, S., Noble, W., Dillon, H., Bentler, R., Stephens, D., Arlinger, S., Beck, L., Wilkerson, D., Kramer, S., Kricos, P., Gagne, J., Bess, F., and Hallberg, L. "Optimal outcome measures, research priorities, and international cooperation." *Ear & Hearing*, 21 (4): 106S-115S (2000).



2016



There are two extensions to the IOI-HA; one for alternative interventions other than hearing aids (IOI-AI) and another which includes items about how hearing loss affects significant others (IOI-HA-SO.)

• Noble, W. "Extending the IOI to significant others and to non-hearing-aid-based interventions." *International Journal of Audiology*, 41(1), 27-29 (2002).

B.05 Speech Spatial and Qualities of Hearing Scales (SSQ)

The SSQ was developed to measure self-reported auditory disability across a wide variety of domains, reflecting the reality of hearing in the everyday world. It has 49 questions that cover hearing speech, spatial hearing, segregation of sounds, ease of listening, quality of sound, and is measured on a 10-point scale. There are three versions; in addition to the original version, there is a 'benefit' version intended for first-time hearing aid users, and a 'comparative' version intended for comparing two different hearing aids.

Questionnaires can be downloaded from:

https://www.ihr.mrc.ac.uk/pages/products/ssq

• Gatehouse, S., and Noble, W. (2004). "The Speech, Spatial and Qualities of Hearing Scale (SSQ)," *International Journal of Audiology*, 43, 85-9.

B.06. Other hearing specific self-report questionnaires that are frequently used (see Granberg et al. 2014).

Abbreviated Profile of Hearing Aid Benefit Profile (APHAB)

Cox RM, Alexander GC. The abbreviated profile of hearing aid benefit. Ear and hearing.
 1995;16(2):176-186.

Communication Profile for the Hearing Impaired (CPHI)



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2016



• Demorest ME, Erdman SA. Development of the communication profile for the hearing impaired. *Journal of Speech and Hearing Disorders*. 1987;52(2):129-143.

Communication Scale for Older Adults (CSOA)

• Kaplan H, Bally S, Brandt F, Busacco D, Pray J. Communication scale for older adults (CSOA). Journal of the American Academy of Audiology 1997;8:203-217.

Hearing Handicap Inventory for the Elderly (HHIE) or Adults (HHIA)

• Ventry IM, Weinstein BE. The Hearing Handicap Inventory for the Elderly: A New Tool. *Ear & Hearing*. 1982;3(3):128-134.

B.07 Ida Institute tools

This independent, non-profit educational institute based in Denmark has generated a suite
of practical tools to assist audiological professionals in using non-technological based
techniques for achieving better client outcomes. These tools have been designed
collaboratively with audiology professionals, but to the best of our knowledge there is not
yet any published research evidence on their efficacy in routine clinical practice. Any of the
tools can be downloaded from: http://idainstitute.com.

B.08. Measures of health-related quality of life

EQ-5D

• Rabin R, Charro Fd. EQ-SD: a measure of health status from the EuroQol Group. *Annals of medicine*. 2001;33(5):337-343.





Glasgow Benefit Inventory (GBI)

2016

 Robinson K, Gatehouse S, Browning GG. Measuring patient benefit from otorhinolaryngological surgery and therapy. *Annals of Otology, Rhinology & Laryngology*. 1996;105(6):415-422.

Health Utilities Index Mark 3 (HUI-3)

• Furlong W, Feeny D, Torrance G, et al. *Multiplicative multi-attribute utility function for the Health Utilities Index Mark 3 (HUI3) system: a technical report.* Centre for Health Economics and Policy Analysis (CHEPA), McMaster University, Hamilton, Canada;1998.

Short-Form 36 (SF-36)

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