

Quality Standards for (Re)habilitation



HEARRING Group
2012

HEARRING is a **learning network of collaborative experts** in the field of hearing implants. It is an association of preeminent international centers offering comprehensive hearing implant solutions for the treatment of hearing loss.

HEARRING members are committed to leading the exploration of new avenues of research in hearing implant science, to advancing clinical procedures and to developing and perfecting surgical techniques. Membership in the HEARRING network is founded on the belief that research, and any subsequent advancement in the field of hearing implants, is possible only through **international collaboration** and the pooling of collective experience from leading clinical centers around the world.

In order to provide each patient with the best possible hearing implant solution for the treatment of her/his individual hearing loss, the HEARRING network is committed to the **highest standards of quality**.

HEARRING surgeons are worldwide **leading experts** in restoration AND preservation of hearing.

Because the field is developing quickly and encompasses an ever-growing knowledge base which includes new scientific insights, technologies and materials, HEARRING members' **collaborative research** initiatives are extremely important to the success of each individual member clinic. To meet the challenges of the future, HEARRING will continue to not only develop and advance standards in the field but will also make these standards transparent.

... network with the experts

Index

1 Introduction	4
2 Structure	4
3 Accommodation (where applicable)	7
4 Pre-operative Assessment and Counselling	8
5 Post-operative (Re)habilitation and Assessment	11
6 Transfer of Care	15
7 Device Failure	16

1 Introduction

Cochlear implantation is a multidisciplinary therapy that involves, as a key element, the surgical implantation of an electrode array into the cochlea to provide direct electrical stimulation of the auditory nerve. Cochlear implants (CIs) are designed for individuals with hearing impairment to compensate for a moderate to profound sensorineural hearing loss, if there is little or no benefit from hearing aids. CIs bypass the non-functioning part of the auditory system in order to deliver electrical signals directly to the auditory nerve. They can be used effectively by both prelingually and postlingually deafened children and adults.

Studies have shown that cochlear implantation is recognised as a safe and effective procedure.

(Re)habilitation support helps CI recipients obtain the maximum possible benefit from their implants. Both recipients and their families, friends, and, particularly in the case of children, their local professionals should be involved in the process. It is strongly recommended that each centre provide a set-up for habilitation for children and rehabilitation for adults to maximise the benefit they could obtain from their cochlear implants. Whilst it is recommended that protocols for support should be in place, a flexible approach to rehabilitation should be adopted which can respond to the individual adult's or child's needs, for example a very young congenitally deaf child will need very different support to that of a teenager who has experienced a sudden or progressive loss.

(Re)habilitation support can be provided on an individual basis and through group work. This can be enhanced by the provision of training events and workshops for adults and children and their families and for the relevant local professionals that are involved.

2 Structure

2.1 Structure of the (re)habilitation team

The (re)habilitation team may function independently or as part of a wider service within a hearing or hearing implant centre, including paediatric, teen and adult cochlear implant services. It is a multidisciplinary team made up of the following key personnel:

a. **Team Coordinator**

The Coordinator is responsible for the day-to-day management of the programme and will ensure that appropriate services are provided for each child and adult through the cochlear implant patient pathway. They will be a core team member, with further specialist training in cochlear implantation and clinical management of the hearing impaired. The Coordinator will have a high degree of clinical, organisational, leadership and professional skills.

b. **Rehabilitation Therapists, Hearing Therapists, Speech and Language Therapists, Educators, Teacher of the Deaf**

The job titles mentioned here may vary in different countries. These personnel must be qualified to a post-graduate level, and hold an accredited MSc or a qualification according to national standards. In addition, two years of practical experience, a qualification in approved hearing therapy modalities and an adequate knowledge of cochlear implants and (re)habilitation are mandatory.

The team must be skilled in the field of cochlear implantation, including having knowledge of the multidisciplinary areas and research responsibilities within the programme.

c. **The Key Worker or Family Liaison Worker**

Each family must be assigned a key worker or family liaison worker who will act as a facilitator and contact person. The key worker or family liaison worker may be any one of the cochlear implant rehabilitation team members.

d. (Re)habilitation team personnel should be members of the relevant national and / or international cochlear implant professional groups.

e. Clinical team members should attend regular training in developments within the field of cochlear implantation. Attendance at relevant courses, conferences and meetings at national and international levels is desirable. Regular attendance at national meetings should be available for all team members. All team members should have a plan for their continuing professional development.

f. All team members should be trained in awareness of Deaf culture and in practical aspects of communicating with people with hearing loss, as part of their induction.

g. Parents / Caregivers

Parents and caregivers play a crucial role in influencing and assessing their child's needs and progress. The implant team has a duty to work in partnership with them in order to provide the support they need to carry out this role of care and responsibility.

2.2 (Re)habilitation team: additional support

The (re)habilitation team should have access to the following support professionals, when necessary. Personnel with these skills can vary from country to country but may include:

- a. Audiologists
- b. Hearing aid acoustician services
- c. Tinnitus professionals
- d. Balance professionals
- e. Clinical scientists
- f. Engineers
- g. Genetic counselling
- h. Audiovestibular physician / paediatrician
- i. Psychiatry / Psychology
- j. Interpreter services
- k. Social services for the deaf
- l. Advocate for the deaf

The (re)habilitation team may cooperate with local services where appropriate. Such partnership services must have appropriate training and expertise.

2.3 Cooperation of the (re)habilitation team with other services and agencies

All members of the (re)habilitation team should meet on a regular basis to ensure effective internal communication, thereby ensuring quality service for each patient. Contact must be maintained with the cochlear implant team, the referring agent, the general practitioner and local professionals.

The (re)habilitation team should cooperate with other services including the following:

- a. Other hospital departments
- b. Audiology, radiology, medical physics, wards, ambulatory care, etc.
- c. Newborn hearing screening
- d. Local / national support groups
- e. Social services
- f. Community services
- g. Educational services

Contact with support services should only be made with the permission of the parents / caregivers and at the discretion of the cochlear implant team.

3 Accommodation (where applicable)

- 3.1 To ensure ease of communication there should be suitable telecommunication access for patients and their relatives. This should include the necessary facilities for the patient to contact the clinic through a variety of modes (e.g. speech-to-text, text-to-text, fax, or e-mail).
- 3.2 All patient areas should be appropriate to the needs of persons with hearing impairment. This should include consideration of visual alerts (e.g. patient appointment information), visual alarms (e.g. fire alarms) and appropriate auxiliary devices for communication.
- 3.3 Proper accommodation for the patient and family members should be offered, and rooms for clinical examinations and counselling interviews (by clinician, observer, and / or interpreter) must be appropriate, and must have the necessary technical equipment.
- 3.4 Common rooms for group work including patient activities and team meetings / trainings should be available.
- 3.5 Waiting areas should be easily accessible and offer proper facilities for all patients and accompanying persons. This should include a separate area suitable for children.
- 3.6 Examination rooms should be sufficiently separated from waiting areas so that noise from the waiting areas does not disturb counselling and treatment, and privacy is guaranteed.

- 3.7 All facilities and rooms must comply with current relevant health and safety regulations and guidelines.

4 Pre-operative Assessment and Counselling

4.1 General

- a. Whenever possible, information should be given in a language or medium that is appropriate to the family's preferred method of communication. If necessary, interpreters should be offered. Verbal information should be supported by a written summary for patients / parents / caregivers whenever required.
- b. The (re)habilitation team should continuously monitor, review and update the quality and quantity of the information they provide, and should have a written protocol to determine what information is given at which time.
- c. Throughout the assessment period, patients or their parents / caregivers should have a clear understanding of the main benefits and limitations of implantation. For children, parents / caregivers should be counselled about the need to avoid unrealistic expectations regarding auditory perception, speech and language development, as well as educational progress. For older children, teenagers and adults, a questionnaire for reviewing their expectations should be included in the general assessment protocol.
- d. Where a child is considered to be old enough to make an informed choice, their assent should be obtained and their views should be respected.
- e. Device selection should be incorporated into the counselling process. There are different cochlear implant manufacturers currently supplying CI centres. Information regarding the technical specifications of these different devices should be made available. Their advantages and disadvantages should be discussed. Patients or parents / caregivers should be given an explanation as to why they have been offered a particular device, or choice of devices. Written information on the device(s) offered should also be made available. HEARRING centres only use and implant devices that are legally approved by national authorities.

4.2 Children

a. **Family support and education**

It is very important to establish the family's / care-giver's commitment to supporting the child and to ensure that they have a clear understanding of the whole process. Involvement of external agencies, typically educational services, is also pivotal to making sure the correct support for long term success is in place.

b. **Goals**

Goals of pre-operative education and counselling may include:

- (1) Guidance and education
- (2) Expectations
- (3) Language outcomes
- (4) Options for post-cochlear implantation habilitation
- (5) Techniques for facilitating language development prior to receiving a cochlear implant

c. **Assessment**

Assessment of the child and their family should provide the team with the following information:

- (1) Family expectations
- (2) Information needed for the candidacy decision-making process. This should form part of a holistic view of the child and their family and should consider communication, behavioural, social, cognitive, motoric and medical aspects
- (3) Information about the child's baseline performance
- (4) Information for counselling the family about the child's prognosis

d. **Pre-operative habilitation programme**

Children and their parents / caregivers should be enrolled in a pre-operative habilitation programme that would include, among other things, counselling, introducing sound and language, and preparation for wearing a cochlear implant.

e. **Associated organisations**

Parents/caregivers should be given information about cochlear implantation organisations, national and local charities and self-help organisations, and equipment and services for deaf and people with hearing impairment.

f. **Final outcome**

A final discussion between the parents / caregivers and key team members should be scheduled for the end of the assessment period, at which agreement is reached about whether or not to proceed. If the outcome of the assessment is that cochlear implantation is not recommended for a patient, an exit clinic appointment should be offered to explain and discuss this recommendation and provide patient support. The discussion should address recommendations for future patient management, including communication modalities, education and connecting the parents / caregivers with appropriate professionals for further follow-up, together with the opportunity for re-referral in the future. These issues must be communicated in a written report to the referring clinician or agency.

4.3 Adults

a. **Communication**

Pre-operative assessment may include a full assessment of the patient's communication and social strategies. These assessments may take the form of observation, subjective description or evaluation using formal test procedures. The assessment procedure will take into account the patient's age and hearing status and will normally include a detailed case history, and an assessment of the patient's receptive and expressive skills. The following areas may be assessed:

- (1) Auditory perception skills
- (2) Voice
- (3) Speech production
- (4) Receptive language skills
- (5) Expressive language skills
- (6) Bilingual issues (sign versus spoken, spoken versus spoken)
- (7) Pragmatics
- (8) Lip-reading skills
- (9) Telephone use
- (10) Music appreciation
- (11) Communication strategies in e.g. the workplace, at home, at social gatherings
- (12) Quality of life
- (13) Social situation and support at home and opportunities for training

Details should be collated about the environments in which each adult typically communicates and where they find the most difficulty.

b. Psychological status

Some patients will require a psychological assessment. A referral to a qualified psychologist or psychiatrist should be initiated when there are concerns regarding the candidate's mental health, learning ability, personality and motivation, adaptation to their deafness, or unrealistic expectations about cochlear implantation that cannot be addressed through counselling by the cochlear implant programme team.

c. Associated organisations

Patients should be given information about cochlear implantation organisations, national and local charities and self-help organisations, and equipment and services for deaf and hearing impaired people.

d. Final outcome

A final discussion between the patient and key team members should be scheduled for the end of the assessment period, at which agreement is reached about whether or not to proceed. If the outcome of the assessment is that cochlear implantation is not recommended for a patient, an exit clinic appointment should be offered to explain and discuss this recommendation and provide patient support. The discussion should include recommendations for future patient management, and referral for other equipment and / or services for hearing impaired adults if appropriate, together with the opportunity for re-referral in the future. These issues must be communicated in a written report to the referring clinician or agency.

5 Post-operative (Re)habilitation and Assessment

5.1 General

Post-operative (re)habilitation should begin immediately after initial fitting, according to the individual needs of the patient, to:

- a. Provide opportunities to ensure the patient adjusts to the new sensation of sound

- b. Reassure patients and / or their parents / caregivers
- c. Outline the (re)habilitation programme

The (re)habilitation programme should be tailored to each individual's needs. Counselling should support patients and their parents / caregivers regarding expectations, (re)habilitation procedures, and continuing commitment to the (re)habilitation programme.

For adults, appropriate standardised audiological, speech perception and quality of life measures should be performed pre-implant and at regular intervals post implant to allow progress to be monitored. For children, appropriate evaluation should be performed at regular intervals to monitor progress in audiological, educational and communication outcomes. Standardised assessments should be used for comparisons.

It is recommended that local involved professionals receive written reports on patient progress.

The patient must have open access to the cochlear implant centre (or a designated local partner-service) for rehabilitation and counselling as required.

5.2 Children

a. **Assessment**

The habilitation team should conduct ongoing assessment of children with respect to:

- (1) Auditory development
- (2) Speech and language development
- (3) Habilitation services
- (4) Educational needs and placement
- (5) Additional needs

This allows the team to update the child's progress on a regular basis and assists them in patient management, as well as in ongoing counselling with the parents / caregivers.

b. **Habilitation**

Habilitation support may be provided within the cochlear implant centre and/or in the child's home and educational setting with local staff working

in partnership. If services are conducted at a local centre, the habilitation team should work in close liaison with local professionals and there should be regular consultations between the two.

The following aspects should be considered within the habilitation programme:

- (1) Mode of communication
- (2) Auditory skills, within the auditory hierarchy of detection, discrimination, identification, and comprehension
- (3) Voice
- (4) Speech production skills, including articulation, phonology and overall intelligibility
- (5) Language development, including vocabulary, receptive and expressive language, pragmatic skills, and meta-language skills
- (6) Bilingual issues (oral-sign and / or two oral languages)
- (7) Telephone use
- (8) Music
- (9) Literacy
- (10) Localisation and spatial listening skills
- (11) Listening in noise
- (12) Assistive listening technology

There are a number of therapeutic approaches available for the habilitation of young children. The most appropriate approach should be chosen for the needs of the individual child and their parents / caregivers.

The habilitation programme should begin prior to cochlear implantation, and continue according to team protocols and in consideration of individual need, at the centre and/or in the child's local environment. During the first year following implantation the rehabilitation requirement will be higher than in subsequent years with regular input being the norm but habilitation should be considered as a life-long process. Support can be provided either individually or on a group basis. The implant team should work alongside parents and/or local professionals. As it is important that rehabilitation is integrated into daily life and, for school aged children, into the curriculum to ensure that listening is encouraged in a real and meaningful way throughout the day.

5.3 Adults

a. **Goals**

Goals for rehabilitation may include:

- (1) Development of realistic expectations
- (2) Systematic auditory and auditory-visual training
- (3) Communication skills training

b. **Therapy programmes**

Therapy programmes may include some or all of the following components:

- (1) Counselling
- (2) Auditory training, including analytic skill development
- (3) Speech reading
- (4) Communication skills training, which may include:
 - a. Conversational techniques
 - b. Repair strategies
 - c. Assertiveness training
 - d. Interpersonal skills
 - e. Coping mechanisms
- (5) Voice therapy, which may include:
 - a. Articulation - Voice and resonance
 - b. Rhythm - Timing
 - c. Speech production training
- (6) Guidance, which may include:
 - a. Information on the auditory system and hearing loss
 - b. The effects of hearing loss on communication
 - c. The impact of background noise and poor listening conditions
 - d. The importance of visual input, audio-visual integration and attending behaviour
 - e. The impact of speaker differences and social conditions
 - f. Benefits and limitations of speech reading
 - g. Benefits and limitations of assistive devices
 - h. The use of community resources
 - i. Self-help groups
- (7) Assistive listening devices

Rehabilitation may occur individually and / or in group sessions.

Rehabilitation programmes should consider using the "significant other" principle in

therapy, where a partner, spouse, family member or friend is considered an active participant in the rehabilitation process.

Rehabilitation should begin prior to cochlear implantation, and should be provided as a regular option in the year following implantation, and afterwards as needed.

6 Transfer of Care

- 6.1 A protocol must be in place to transfer the on-going care of adolescent cochlear implant users to the adult section or programme at an appropriate age. The protocol must take into account their educational needs and must be agreed upon by the cochlear implant team.
- 6.2 A protocol must be in place for the transfer of care of a child, an adolescent, or an adult to an alternative programme or the acceptance of care of a child, adolescent or adult from an alternative programme, if requested.
- 6.3 Patients will usually be referred to the nearest cochlear implant centre, unless the patient or family request to be transferred to a particular centre.
- 6.4 The referring centre must confirm that they can support the type of device used by the patient before the referral is made.
- 6.5 All the relevant documentation will be sent to the receiving centre. This will include: full details of the patient's address, telephone number, and email address, information on the internal device and external processor used, recent programmes, neural response telemetry data, aided audiograms, speech perception results, (re)habilitation reports and results, medical details of surgery and any complications, and contact details for the GP.
- 6.6 The receiving cochlear implant programme will acknowledge the referral in writing and confirm that the funding has been agreed on for continued support of the patient.
- 6.7 Generally, patients will not be referred to another centre less than one year after implantation. This is to allow for post-operative medical follow-up, the establishment of a suitable device programming, and the provision of initial rehabilitation.

7 Device Failure

- 7.1 If an internal device failure is suspected, the patient and / or their parents / caregivers should be offered an appointment promptly to check the device's internal and external components.
- 7.2 The implant manufacturer should be contacted promptly regarding investigation of the device failure. If required, a clinical / engineering representative from the company should be available at the patient appointment to provide support.
- 7.3 Upon confirmation of internal device failure, the clinical personnel must inform the Otologist Surgeon and the Coordinator and an appointment with the implant surgeon should be offered to the patient and / or their parents / caregivers, to discuss re-implantation or other options.
- 7.4 The device failure should be reported to the relevant national authorities.
- 7.5 If re-implantation is agreed upon with the patient and their parents / caregivers, it should be carried out as soon as medically possible and appropriate, to minimise auditory deprivation.
- 7.6 Re-implantation and programming should be carried out as detailed above. Further rehabilitation needs should be assessed and provided for as appropriate.

Acknowledgement

The "Quality Standards for (Re)habilitation" were developed by Jane Martin (YCIS, Bradford, U.K.) and the HEARRING Group.