

follow-up services and indeed life-long care for cochlear implant users of all ages. In the UK we are fortunate to have newborn hearing screening and funded bilateral cochlear implants for children, but our adults cannot routinely have the funded bilateral cochlear implants which are available in other countries. Wouldn't it be wonderful if access to bilateral cochlear implants and the very best standards in cochlear implantation were available globally for deaf people of all ages?



Following on from the previous article about CIICA's recently launched 'Cochlear implants for deaf children' we are now going to hear from their Acting Chair, Leo De Raeve who is an expert on social functioning and well-being in children who use cochlear implants, and wears many hats: Scientific Advisor of EURO-CIU, a member of the World Hearing Forum of the WHO (World Health Organisation), and Lecturer at University College Leuven-Limburg (Belgium), but it is as Director of ONICI (Independent Information Centre on Cochlear Implants) Zonhoven, Belgium, that he brings us this article on a research project which has come to fruition relating to

YOUNG DEAF CHILDREN RECEIVING COCHLEAR IMPLANTS: QUALITY STANDARDS FOR THEIR REHABILITATION



1. Introduction

With the introduction of universal neonatal hearing screening in many countries, hearing loss in children is being identified earlier in life than ever before. Also more and more children with severe to profound hearing loss are receiving cochlear implants (CI) to improve their hearing abilities. Research provides strong evidence of the benefits of early identification, early intervention and early implantation on the development of expressive and receptive language, on auditory and reading skills and on social emotional development, which results in an increase of deaf children in mainstream education.

There are many variables which can influence the outcomes: age at implantation, additional needs, parental support, surgery, fitting of the device, etc, and the quality of the support and rehabilitation (Percy-Smith et al, 2012). Because of the huge differences in service delivery models and intervention between countries, and even within the same country between CI-teams, quality standards for rehabilitation of young deaf children receiving CI's have been created as part of 'the European KA202 Erasmus+ - project 'VOICE' - Vocational education and training for speech and language therapists and parents on rehabilitation of young deaf children with CI's, Ref. no.: 2020-1-RO01-KA202-080059'. Seven partners from four European countries are involved in this project (Note A) which began in December 2020 and will end on 31 May 2023.

2. Interviewing local experts

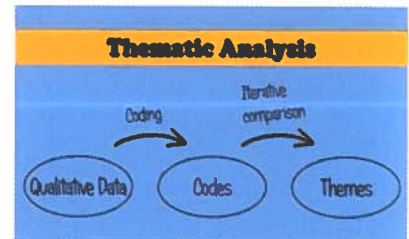
To develop quality standards on rehab of young CI-children, the first step was interviewing 12 local experts in rehabilitation of young CI-children. Each of the six partners interviewed two local experts, in person or online, resulting in 12 experts from four countries (Belgium, the Netherlands, Portugal, and Romania) (Note B). Sadly we lost one expert because of personal reasons. To have a standardised interview across the partners, we created eight open questions :



- What is your experience in rehabilitation of young deaf children with CI's learning to speak and to develop spoken language?
- Who (what kind of professionals/parents) should be involved in the (re)habilitation process after CI in young deaf children?
- What should be the role for the CI-team and what should we expect from local professionals? Who is doing what?

- What are important domains to focus on during the rehabilitation process?
- Should we involve the parents/family in the rehabilitation process? If so, why, how and how often?
- Do you prefer a specific rehabilitation program or approach for therapy? Which resources (books, publications, etc) do you suggest for other therapists to increase their competences?
- Do we have to monitor the listening, speech and spoken language development of these young CI-children? If so, why and how often?
- What frequency of therapy sessions do you suggest for these young CI-children and their families? How often? For how many minutes? For how many months/years?

We used a thematic analysis to analyse and structure the content and focused on common answers between the local experts. The group of local experts consisted of 10 speech and language therapists (SLT) and 1 otolaryngologist, with an average experience of 13 years in the field of paediatric cochlear implantation. All mentioned that the CI-team should be a multidisciplinary team, which consists of a minimum of an otolaryngologist, audiologist and SLT, and preferably there should also be a psychologist, social worker, teacher of the deaf and a physical or occupational therapist included in the team or working in liaison with the CI-team. Parents should be seen as equal partners, and nearly all experts (8/11) suggested using a family-centred approach.



The local experts also suggested that the CI-team should be the coordinator of the child's rehabilitation/after care and that there should be good liaison with the local support team. The most important domains to focus on during the rehabilitation process are: audition/hearing/wearing devices, communication/speech/spoken language (11/11); parent (care) support/coaching (8/11); cognitive development (7/11); social-emotional development (6/11); reading/school performance (4/11); motor skills/planning (4/11) and self-advocacy/identity (3/11).

Auditory Verbal Therapy (AVT) was mentioned by 7 out of 11 experts as the approach best suited to most of the children and their families, but on the other hand the same experts also stated there is not one approach that fits all.



Most local experts (9/11) also mentioned that during the rehabilitation process all steps in the development of the child should be monitored regularly, especially hearing, speech and spoken language development. There was huge variability between the experts regarding the frequency of therapy, but ideally most of the experts (6/11) suggested one session of one hour on a weekly basis and that parents should be involved. The progress of the child will determine for how long these sessions should continue post-CI. It was also mentioned that the frequency of rehabilitation will depend on the child, the family, the distance from the implant centre (although rehabilitation can also take place online) and the availability of support services.

3. Systematic review

To have input from latest scientific research, we also did a systematic review on rehabilitation of young children receiving CI's. All studies at all levels of evidence were included, from randomized controlled studies to descriptions of good practise and case-studies. The articles had to have been published in peer-reviewed journals or books, in the English language, between 2000 and 31 May 2021. They should also focus on CI-children under the age of six with a bilateral hearing loss. The literature search was conducted between 31 May and 31 August 2021 by using a four-word search (cochlear implant + children + rehabilitation + education) through six databases: PubMed, Eric, Cochrane, CINAHL, Scopus, Psych info. The quality of the studies was evaluated using the classification of the levels of evidence by Lebowhl and colleagues (2010): level A, double blind study; level B, clinical trial > 20 subjects; level C, clinical trial < 20 subjects; level D, Series > 5 subjects; level E, case reports.



In total 848 publications were identified, but after removing the duplicates and those which didn't fall within the inclusion criteria only 150 publications were included in the qualitative synthesis. Most of the 150 publications had a poor level of evidence (C, D or E-score). Only two publications received an A-score and 64 a B-score, which illustrates how weak the level of evidence is in general on studies related to rehabilitation of young children receiving CI's.

4. Delphi study consulting international experts

The further development of the quality standards involved a modified Delphi consensus process that was informed by outcome of the interviews of the local experts and the systematic review of the literature. Based on all this information, we created a list of 32 quality standards over four domains related to rehabilitation: (1) general quality standards, (2) quality standards on fitting, (3) quality standards on rehabilitation, (4) quality standards for professionals.



An international group of clinical experts in the field of rehabilitation of young children with CI's and a lot of scientific experience on paediatric cochlear implantation was brought together to form a Delphi consensus panel. All six partners suggested a top three of international experts (see Note C) in the field of rehabilitation of young CI-children, to contact to review the quality standards.

Further on, we carried out a two-step Delphi consensus method, which was modified to include two rounds of email questionnaires. In the first round we asked the 18 international experts to give their comments and suggestions concerning the 32 quality standards. After adapting the quality standards following their comments and suggestions, we went back to the experts asking them to agree or not agree with each quality standard.

The final list of quality standards will propose the optimal level of experience and expertise necessary for their staff and describe important facilities and resources that CI-teams should possess or have access to. Based on the comments of the international experts during the first round, we updated the quality standards and came to a new list of 29 quality standards. We then asked the same international experts to agree or not agree on these quality standards. Finally, above 90% of the international experts agreed on 28 quality standards over four domains: (1) general quality standards, (2) quality standards on fitting, (3) quality standards on (re)habilitation, (4) quality standards for staff, of which most of them contain several subcategories.

This set of quality standards for rehabilitation of young children receiving CI's can help healthcare systems and more specifically the CI-teams and everyone involved in rehabilitation of young CI-children to provide comprehensive and state-of-the-art post-operative care for these children. We're absolutely convinced that by using these quality standards, CI teams and local professionals will be able to improve their quality service provision, which will result in better outcomes.



5. Quality standards for rehabilitation of young children receiving CI's

These quality standards for rehabilitation of young deaf children receiving CI's can be downloaded as a pdf-file from the project website:

<https://voice-erasmus.eu/ci-standards/>

or go straight to the quality standards document at:

<https://bit.ly/3EhQYZm>



6. Conclusion

More and more children with severe to profound hearing loss are receiving CI's at an early age to improve their hearing and listening abilities, speech recognition, speech intelligibility and other aspects of spoken language development. Despite this, the rehabilitation outcomes can be very

heterogeneous in this population not only because of issues related to surgery, fitting or specific characteristics of the child with his/her additional disabilities, but also because of huge differences in the quality of the support and rehabilitation offered by the therapist and the family.

To develop quality standards for rehabilitation of deaf children receiving CI's, we used the input from the interviews of 11 local rehabilitation experts on CI's from the four partner countries involved in the VOICE-project and the outcomes of a systematic review of 848 publications related to the theme and retrieved from six databases. The Delphi method approach was used by 18 international rehabilitation specialists in CI intervention to discuss and agree on these quality standards. Finally, over 90% of the international experts agreed on 28 quality standards, most of which contain some sub-categories.



Further research is needed to address the issue of rehabilitation of young deaf children receiving CI's. Studies involving larger samples, matched groups and well controlled interventions are essential to isolate the intervention factor and be able to generalize findings. Meanwhile we have to focus on good practice which takes into consideration the specific needs of child, family and their environment.

We believe that the guidelines for good practices presented here can act as a lever for the necessary studies as they already indicate the conceptual field where future studies should take place, and therefore help in the creation of evidence-informed approaches.

Note A

Spitalul Clinic de Recuperare Iasi, Romania; Societatea de Otologie Si Implant Cochlear (SOIC), Romania; Universitatea Alexandru Ioan Cuza din Iasi, Romania; Fundatia EuroEd, Romania; Independent Information & Research Centre on Cochlear Implants (ONICI), Belgium; Universidade de Aveiro, Portugal and Zuyd University of Applied Sciences, the Netherlands.

Note B:

Local experts: Martine de Smit (Belgium); Marlies Oyen (Belgium); Kirsten Gennotte (the Netherlands); Pedro Brás da Silva (Portugal); João Eloi Moura (Portugal); Camelia Oana Radu (Romania); Ady Cristian Mihailov (Romania); Crăescu Adina (Romania); Elena Macovei (Romania); Mariana Pop (Romania); Theodor Sirbuletu (Romania)

Note C:

International experts: Cheryl Dickson (Australia); Diana Zegg (Austria); Mila de Melo (Canada); Uwe Martin (Germany); Shirlly Kaplan (Israel); Anneke Vermeulen (the Netherlands); Camelia Rusu (Romania); Mihaela Alexandru (Romania); Gal Katalina (Romania); Ion Mihaela (Romania); Theodor Sirbuletu (Romania); Mariana Pop (Romania); Luciana Frumos (Romania); Mihaela Fotescu Zamfir (Romania); Louise Ashton (South Africa); Manuel Manrique (Spain); Teresa Amat (Spain); Tricia Kemp (UK)

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We thank Leo for his thorough article and welcome the guidelines for good practices presented. We can see from the above article just how much evidence is needed for research to eventually lead to quality standards.

We will now turn to the topic of guidance and policies in the UK, but first a little background to set the scene. In our July, 2020, edition, Tracey Twomey reported on the possibility of the British Cochlear Implant Group (BCIG) developing a mission statement or guideline on lost and damaged beyond repair sound processors. She told us that the cost of replacing lost processors in 2018/19 alone was estimated to be nearly £3.5m.