

Foundations for Health and Empowerment (F4HE)
Application Form for Expression of Interest

(Please use Calibri Font Size 11)

Application number : _____
(For office use only)

**1. Principal Investigator and team
(Name, designation, affiliation, address and email)**

Principal Investigator's Details

Title Dipl.-Psych. Given Name Dennis Family Name Metzeld

Institution Hör- und Sprachförderung Rhein-Main gGmbH
Friedberg - Germany
www.cic-rheinmain.de

Email dmetzeld@cic-rheinmain.de

Department Research

CO- Principal Investigator 1 Details

Title Given Name Shirin Family Name ZHUMABAEVA

Institution National Center of Maternity and Childhood
Care (NZOMID)

Email chishiko2@gmail.com

Department ENT, Research

CO- Principal Investigator 2 Details

Title Dr. Given Name Michael Family Name Goriany

Institution Lehnhardt Foundation, Germany

Email michael.goriany@lehnhardt-stiftung.org

Department Telehealth

*Insert more rows for additional Investigators as required

**Affiliation with F4HE Four components
(for any member of the team, please specify member (e.g. PI / co PI)**

Advancing Gender Equality through Civil Society (AGECS) [] _____

Foundations for Health (F4H) [1]

Shirin Zhumabaeva

Foundations for Children (F4C) [2]

Dennis Metzeld, Michael Goriany

2. Project title (Maximum 50 words)

Create a comprehensive databasis on which to build a professional intervention program for deaf children in Kyrgyzstan

3. Project Summary (Maximum 250 words)

Lehnhardt Foundation, Germany has been working in Kyrgyzstan since 2016 to establish a cochlear implant program. In 2016, a cooperation agreement was signed with the National Center of Maternity and Childhood Care (NZOMID), approved by the Kyrgyz Ministry of Health. Recently, the International Association of Hearing Rehabilitation Therapists has been established in Bishkek. In 2019 and 2020 grant support was given from the Hospital Partnership Program of the GIZ German Gesellschaft für Internationale Zusammenarbeit.

CIC is a leading rehabilitation center in Germany and contributes substantially in the field of rehabilitation and early intervention ([Recording March 2021](#) - en translation in progress). In the German center approx. 350 families with children wearing a CI are serviced, 15 % with Arab immigration background.

In Kyrgyzstan approximately 150 children are born deaf annually (1 of 1.000 newborns is deaf - this applies worldwide, except for risk babies where the incidence is much higher). The electrode array of the cochlear implant is inserted into the inner ear. The CI opens the way into the world of hearing and enables these children to acquire speech and spoken language. Therefore, they are fully integrated into the hearing society, can attend mainstream school and choose the job they prefer. However, this can be achieved only if adequate speech therapy and full support from parents is provided.

The price for the implant system is € 12.000 (much lower than in Western countries, but still exorbitant for the families). The Kyrgyzs Government does not provide any financing for hearing aids, cochlear implantation (the device and costs for surgery), or rehabilitation. Cochlear implantation is therefore fully dependent on sponsors and contributions from the families.

Within the framework of our project 51 children have so far been provided with a CI (in total some 200 children have been implanted - some of them outside Kyrgyzstan). Surgeons, physicians and therapists have received support and training online and locally as a part of our project. Recently, two ENT doctors were trained in Germany and Austria

The aim of this research project is twofold:

Aim 1: Collect and make accessible hard data on the macro level and soft data concerning hearing impaired children and their families, attendance in kindergarten and schools. The method to achieve soft data will be a specific Evaluation Program, which is in use in the CIC, Germany. It also enables self- and peer group evaluation. From the conceptual framework of self-determination theory, responses can be categorized with respect to psychological needs for autonomy, competence, and relatedness. Part of this project will be to explore how to implement this method under Kyrgyzs cultural and organizational conditions.

Aim 2: Explore how to make use of digital technologies, recently upgraded due to the Corona pandemic challenges and of data management technologies, providing for Telehealth solutions (remote training, remote coaching, remote intervention), also enabling patients to access Big Data on a broad basis and benefit from Artificial Intelligence solutions (e.g. automatic transcription and translation).

Both aims will significantly contribute to further develop the CI program on a higher level of

sustainability, based on advanced technologies.

This project includes capacity building opportunities for the research department and the Telehealth dept. of our local clinic partner NCMCC. The Telehealth department was equipped with support of AKN.

4. Significance

**(In this section please briefly give the important contextual problem or a critical barrier to progress in the field that you are addressing. Detail a rationale with appropriate citations of prior work. Once you achieve your aims how will prevailing knowledge, concepts or practice or policy be advanced?)
(Maximum 350 words)**

It is of crucial importance for the auditory language development of prelingually severely hearing impaired children that implantation takes place as early as possible. Therefore, it is necessary to build capacity to identify severely hearing impaired children at an early stage and to be able to provide them with care. Every year, an estimated 160 children are born in Kyrgyzstan whose hearing impairment is so severe that they can only learn to hear and speak with a CI.

Implantation must be accompanied by audiological and auditory speech therapy support for the parents and children. In the latter, the parents are supported in dealing with their child in a way that promotes hearing and speech.

The collection and analysis of data is a necessary tool in the process, showing therapists as well as patient parents where the child is currently in its development and in which aspects support can be improved.

In the field of data collection/data management a critical barrier to progress often is lack of readiness to share and data protection fears. This is to overcome by establishing trust, which is much easier once a project is AKU funded and supervised.

Advance of concepts and practice:

- availability of data (aim 1) will enable a new dimension for creating strategic and operational planning for a further development of the Cochlear Implant program towards sustainability and comprehensiveness. It will significantly increase the chances for fundraising and will increase awareness within society, institutions and Government about the relevance of Cochlear Implantation and the positive impact not only to individual life but society as well
- the introduction of new Cloud services, such as the upgraded Google Workspace tools for hybrid working, will enhance the concepts and practice of remote services (such as e.g. Remote fitting of Speech Processors) and of collaboration, networking, social learning. A substantial driver is availability of tools via mobile apps. A study of UNICEF showed, that almost 80% of people in Kyrgyzstan is using a smartphone.

5. Specific Aims

**(Delineate in point form your study aims, objectives and associated hypotheses (as applicable).
(Maximum 150 words)**

Study aim 1: Collection of hearing related data

Data to be collected are:

- general data from clinics, ministry, parents association - by field research in cooperation with UNICEF, parents' associations, with whom we are already cooperating in the field of neonatal hearing screening and early intervention.
- children/families related data by interviews, questionnaires
- services related data, by evaluation processes. Interviews and video sequences to improve the counseling of parents will be implemented in a model project.

Objectives:

- necessary for planning

Study aim 2: Exploring how to make use of recent digital technologies and data management.

Obviously, it is most relevant for all to be "digital fit", which is even more important for the disabled and those who are caring for them. Much additional progress has been made since the Corona challenge as to easy access and cloud solutions. The project will enable all participants to keep up with the recent developments.

6. Approach/Methodology

(Describe the methods you will use to execute each specific aim. 1000 words only).

Referring to aim 1: Collection of hearing related data

In order to assess current and future needs, the number and results of hearing screenings carried out will be compared with results from other countries in order to be able to make a dark field estimate. Based on the severity of the hearing disorders detected, the total need for CI fittings will be estimated and put in relation to the current annual number of implantations. Based on the trajectory of previous care measures, it is possible to calculate how great the need for CI care is and how many additional resources would be necessary to ensure comprehensive care. Given the scarcity of resources for implantation, the analysis also focuses in particular on the establishment of and compliance with the selection criteria for implantation. In addition, there is currently no information on the provision of CI-supplied children and their parents with fitting and therapy services that are essential for language development. An analysis will also be conducted on existing and future needs.

At CIC Friedberg a test concept has been developed which standardizes recommended test times. If the child's development does not yet allow the respective test to be performed, this is noted separately and the test can be performed at a later time. Test periods have been defined at which hearing tests, and age-appropriate tests for listening comprehension in everyday life, vocabulary, morphology, syntax, sentence comprehension and working memory, and, from the age of 7, also written language are carried out. The time periods are based on listening age up to the second year of life, and on age from the second year of

life onwards. This serves to observe developmental progressions in order to be able to intervene promptly and in a targeted manner. At specified times, interactions between parent and child are recorded and evaluated by the therapists using set criteria. Based on this, the parents are given specific advice, using concrete examples, on the areas in which they are already succeeding in promoting their child's hearing and how they can improve their child's promotion. In order to assess the effectiveness of treatment, questionnaires are used to measure health-related quality of life. These measurements have the advantage over audiological measurement data or language development tests in that they can capture the patient's subjective hearing language-related quality of life in everyday situations that are typical for him or her.

The satisfaction of patient parents with support services is not only a possible indicator of the quality of treatment. It can also help to improve the quality of treatment at the same time: Especially in CI therapy, therapeutic approaches rely heavily on the motivation and active cooperation of patients and/or their parents. Based on this, questionnaires will be developed that both meet the theoretical recommendations and are adapted to the conditions and offers on site, providing the professionals on site with information for the further development of the offer from the patient's point of view. Questionnaires developed for this purpose will be used to evaluate and compare both on-site and remote counseling services.

Questionnaires will also be developed for the experts in order to ensure the effectiveness of the on-site training provided by the Lehnhardt Foundation on the one hand, and to obtain information on factors that promote and hinder the implementation of the concepts in everyday therapeutic practice on the other. These questionnaires will be based on the same criteria as the surveys on the quality of care planned for the parents.

Referring to aim 2: Explore how to make use of recently further developed digital technologies, recently upgraded due to the Corona pandemic challenges and of data management technologies.

The technologies providing for Telehealth solutions (remote training, remote coaching, remote intervention - such as remote fitting) are also enabling patients to access Big Data on a broad basis and benefit from Artificial Intelligence solutions (e.g. automatic transcription and translation).

This project aim is also part of aim 1. All of the above data can be collected and analyzed remotely/online. Feedback on results for parents and experts can also be provided online. Video recordings are a way of directly observing behavior without being on site.

This project investigates to what extent results from this and the technologies for easy access (eg. personal digital patients folder, dig. "Experience Book" for documentation and Evaluation of children's progress - Link Webseminar A.Kendrick), which have been strongly further developed in the course of the Corona pandemic, can be made accessible on a broad basis in Kyrgyzstan.

The method to execute aim 2 will primarily be a specific Workshop platform to host pilot projects for the introduction of "Telehealth Lite" applications in the everyday life of clinics and hearing related institutions and private homes of children wearing a CI and their families.

Telehealth Lite means easy accessible and low cost or even free Apps, such as the latest version of Google Workspace (link <https://earbook.online/giz2020telehealth/>) It was previously developed for internal use and now is upgraded. Pre Launch is planned for January 2022. This project could provide for a co-financing in 2022 to stay free of charge for the CI related people in Kyrgyzstan.

7. Ethical considerations

Provide a list of the ethical considerations for the project (maximum 350 words).

Provide details on where ethical clearance will be sought. Ethical clearance must be obtained from Ethics Review Committee of Aga Khan University, and where appropriate from a registered National Health and or Institutional Human Research Ethics Committee.

Institution AKU

Institution

Institution

Aside our joint ethnical values there are specific ethnical considerations as follows:

- children have a basic humanitarian right for any defect to be compensated
- The impact of deafness does not only mean no hearing. It has a significant negative on the development of the child
- all children - regardless of where they live in Kyrgyzstan - need to have access to early intervention. For children in the countryside this is only possible by providing online support for local therapists and parents
- it needs to provide information and online support in Kyrgyz language as many therapists and parents do not speak any other language

It is our motivation for delivering this EoI to gain additional insights and further experience in multicultural and ethical questions related to the situation for children and families in Kyrgyzstan (and in Germany) and so better being able to contribute to the development of pluralistic, inclusive and tolerant mind-sets.

8. Data governance

Names and contacts of all people who will have access to the raw data for analysis.

Title Dipl.-Psych. Given Name Dennis Family Name Metzeld

Institution Hör- und Sprachförderung

Rhein-Main gGmbH

Email dmetzeld@cic-rheinmain.de

Title Given Name Yvonne Family Name Seebens

Institution Hör- und Sprachförderung

Rhein-Main gGmbH

Email yseebens@cic-rheinmain.de

Title Dr.Dr.h.c

Given Name Monika

Family Name Lehnhardt-Goriany

Institution Lehnhardt Foundation, Germany	Email ml@lehnhardt-stiftung.com
Title Dipl.-Ing. Given Name Peter	Family Name Zoth
Institution Lehnhardt Foundation, Germany	Email zothpeter1@gmail.com
Title Dr. Given Name Michael	Family Name Goriany
Institution Lehnhardt Foundation	Email michael.goriany@lehnhardt-stiftung.org

9. Overview of Research Expertise

Provide details on who will provide statistical and/ or qualitative expertise and input (if any)

Title Dipl.-Psych. Given Name Dennis Family Name Metzeld

Institution Hör- und Sprachförderung
Rhein-Main gGmbH Friedberg - Germany

Email dmetzeld@cic-rheinmain.de

The research department of the Hör- und Sprachförderung Rhein-Main gGmbH - CIC Friedberg was established by the former director Prof. Dr. Gottfried Diller, Dean and Professor at the Pedagogical University Heidelberg, Germany (cv: <http://www.monsana.ch/who-is-who/prof-dr-gottfried-diller-cic-rhein-main-friedberg/info/curriculum-vitae.html>)

10. F4HE Resources (if planning to utilize)

Provide information and indicate timeframes for the facilities and/or resources to be accessed (may include clinic facilities, clinic database, clinic files, student contact, alumni contacts, staff contacts, classroom facilities, laboratory facilities, internal databases [you must nominate which databases and which variables from those databases]).

In the case that no better solution is existing, we will provide for a project blog.
Rooms are available in our partner clinic and Co-Principal Investigator National Center of Maternity and Childhood Care (NZOMID), Bishkek

As to the research team: we would be very interested in a collaboration with AKU faculty either as principal investigator or as co-principal investigator.

The problem of Cochlear Implantation for deaf born children not being supported by the government at all or not sufficiently is not only relevant in Kyrgyzstan but in the other countries of F4HE as well.

Unfortunately, we received the information of the call only short before the deadline and so could not address AKU before.

11. Inclusivity/Diversity

(Reflect on diversity in participants and study team as appropriate)
(Maximum 250 words)

Diversity in participants: Currently, opportunities to receive CI care and long-term support are very limited in Kyrgyzstan. It will therefore need to be clarified to what extent the criteria by which those to be provided for are selected will result in the children and families provided for not differing systematically from those without provision in terms of urban vs. rural, Russian vs. Kyrgyz-speaking, gender, educational level and socioeconomic status.

At least in Germany, the majority of hearing and speech therapists are women. Since many children come from families with non-German speaking backgrounds, multilingual therapists are of great benefit to the centers. In our experience, it is mainly the mothers who participate in the therapies and video analyses. The data collected in this study make it possible to compare the situation in Kyrgyzstan with that in Germany against this background as well.

Diversity in the study team: The study team is composed on the one hand of the participating employees of the Lehnhardt Foundation, on the other hand of the Russian and Kyrgyz speaking employees on site.

12. Impact of research

(Describe the anticipated impact of the proposed work on Public health/clinical/social/educational/arts and humanities research as applicable)
(Maximum 250 words)

Sufficient data are elemental for proper planning of the further steps towards a sustainable Cochlear Implant program (Aim 1). Obviously hearing and speaking is one the most substantial components of early childhood development and child health (Aim 2).

CI implantation is the only way for profoundly prelingually deaf children to achieve the hearing and language development of a normal-hearing child, and thus to achieve full participation in the hearing society. This includes especially the educational area.

For this, audiological and therapeutic care is necessary in addition to implantation.

The planned project will make a decisive contribution to this by evaluating the measures taken so far to achieve the most comprehensive possible diagnosis and care of profound hearing impairment, in order to create the basis for improving this and developing ways of dissemination to the wider community.

First and foremost, data are collected for the affected persons (parents and children, therapists, physicians, audiologists) themselves, who are thus empowered for independent self-evaluation.

Only secondarily (and more highly aggregated) do data at all other (political, administrative, etc.) levels provide action- and control-relevant information for dissemination of such a project to the wider community.

Similar concepts could also be applied in other countries and in other settings.

13. Strategy for dissemination of results

(describe your specific approaches to disseminating the results of your research) (Maximum 350 words)

Aim 1 - Collection of data: aside possible legal rules we will follow the principles of AKU. First and foremost, data is collected for the affected persons (parents and children, therapists, physicians, audiologists) themselves, who are thus empowered to act independently and in a goal-oriented manner. In order to achieve a further impact in Kyrgyzstan, close cooperation with the local specialists will be established.

Aim 2 - digital technologies: outcome of pilot workshops will be under a Creative Commons NonCommercial license.

Concepts and results of the study will be presented by the authors on scientific events according to international customs.

All results can thus be models for establishing effective needs assessment, data management and evaluation concepts from the outset in other countries where CI care is not yet widespread.

14. Departmental Research Committee (DRC) peer review

or equivalent has peer reviewed the Project

(If a DRC/ equivalent does not exist in your dept./entity please mark NA):


Yes No

NA

N/A

15. Name and signature of the Principal Investigator

Friedberg, den 30.11.2021


D. Metzger