

Information about the current status of the database

This document is the result of the 2nd COST TINNET Database Workgroup Meeting, that took place January 29-30, 2015 in Klagenfurt, Austria. Goal of this document is to inform the other TINNET workgroups about the current status and the historical development.

The document will be updated and distributed after each work group meeting.

Timeline

- 2006 Consensus paper for a standardized assessment of tinnitus cases ([Consensus for Patient Assessment](#)).

- 2007-2010 Database workgroup funded by TRI and University of Regensburg for the establishment of an international tinnitus database.

- 2007 First implementation of the tinnitus database. Patient information was collected via case report reforms. The case report forms are structured based on the consensus paper from 2006. Examples of the case report form can be found here [Case Report Forms in different languages](#)

- 2010 Publication of the organizational structure and the purpose of the tinnitus database ([Landgrebe 2010: The Tinnitus Research Initiative database](#)).

- 2007-2014 Collection of about 3000 cross-sectional and longitudinal data sets from 9 different centres. Case report forms are available in eight different languages.

- 2014 Start of the TINNET action
- 2014 Start of the implementation of a new technical structure of the database (together with the Institute of databases and information systems, University Ulm) to meet the requirements for further developments in the context of the TINNET action.
- 2013 Cross-validation of the database questionnaires in different languages
- Dec 2014 Transfer of the already 3000 data sets to the new established data structure.

- current status
- Implementation of the new graphical user interface
 - Update of the legal framework (e.g. scientific agreement) and cooperation policy (e.g. data sharing, author ship rules)
 - Mutual interaction and regular information from work groups 1,3,4,5 to guide further developments of the database

- planned
- Definition of the interface for neuroimaging and genetics data
 - Establishing means to ensure high data quality (e.g. consistency and plausibility checks)
 - Implementing a presentation mode of the database

Major tasks:

- legal framework for data sharing and cooperation policy
- how to store neuroimaging data efficiently? (work with WG III)

- what genetics data can be integrated in the database? (work with WG IV)

Contact to other workgroups

contact person to WG I: Berthold Langguth

contact person to WG III: Agnes Szczepek

contact person to WG III: Martin Schecklmann, Winfried Schlee

contact person to WG IV: Birgit Mazurek, Yossi Arzouan

Scientific cooperation agreement

A discussion about the existing agreement revealed the following open questions:

- Who owns the collected data?
- Is it possible for a centre to withdraw its data?
- Is it possible to "embargo" special analyses?

Suggestions:

- Ownership has to be regulated within a special license right. The patient remains the owner, but he/she can assign the right to the hospital and the database. The informed consent has to be updated accordingly.
- Each centre who wants to analyse its data or the whole data set has to write a proposal / Statistical Analysis Plan SAP, that has to follow certain rules
- The SAP has to be approved by the Steering Committee (at the moment Berthold Langguth (University Hospital Regensburg), Michael Landgrebe (Hospital Agatharied), Michael Koller (Center for clinical trials, Regensburg))
- After approval, contributing centres will be informed about the decision. Within a certain timeframe they have the possibility to agree, disagree or suggest changes.

Rules about publications need to be discussed in more detail in the next meeting.

Time schedule and Working plan

- Update of the Scientific Cooperation Agreement (Regensburg)

- Contact to programmers in Ulm in order to inform about necessary implementations (e.g. test-surrounding, presentation mode)
- Contact to other workgroups (see above)

Next Meeting of the TINNET Database Workgroup: Friday, September 25, 2015
Cologne