WORKING GROUPS SUPPORTED BY JPND



Longitudinal Cohorts

Body fluid biobanking of longitudinal cohorts in neurodegenerative diseases

There is a strong need for collaboration to study neurodegenerative disease markers in body fluids such as blood and cerebrospinal fluid. These body fluids are commonly stored for many years in biobanks to be able to collect information on disease evolution of patients over the years.

Historically, such biobanks have been established under different laboratory conditions, which can influence the results of research performed on the samples. Furthermore, when researchers want to collaborate and share the biological fluids and data, they are confronted with differences in legal and ethical requirements between countries. Moreover, the databases that contain the patient information present the data in different ways.

The aim of this Working Group is therefore to develop guidelines to enable international collaboration between biobanks for neurological patients. This will be accomplished by

- 1) developing evaluation programs to test the quality of biobanks
- 2) to develop guidelines for exchange of biomaterial
- 3) develop guidelines on how information from the biobanks should be presented

The activities will provide practical guidelines and useful tools to improve and assess the quality of biobanks. Implementation of these guidelines will make existing and future biobanks of patients with neurological diseases more visible, more accessible and more usable.

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