

Protocol number 3.1

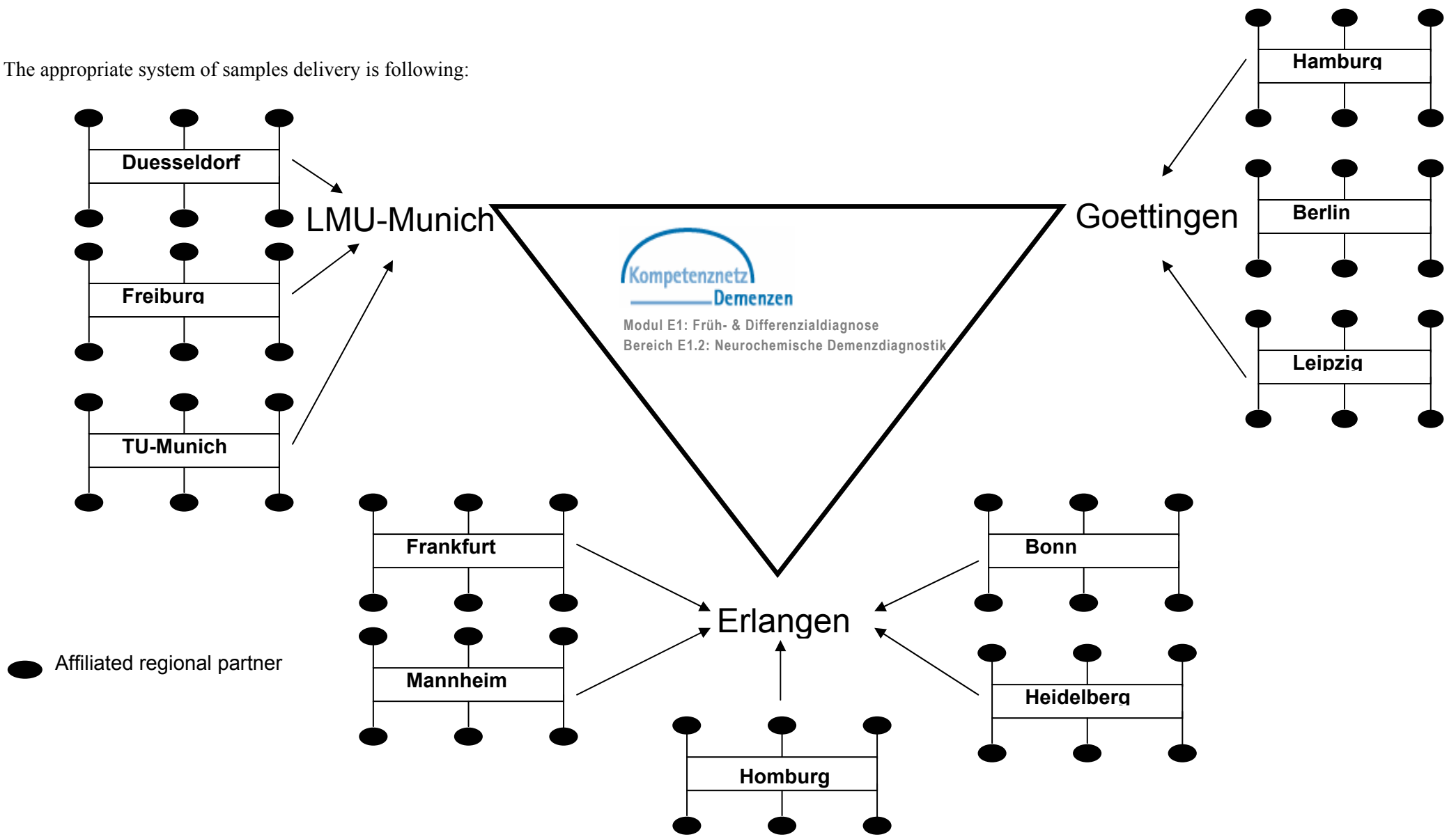
Storage and shipment of samples

GENERAL NOTE: Within this project, several hundreds of thousands of samples will be collected, stored and evaluated by Neurochemistry Diagnosis Centers. This is only possible if one consequent system is used by all participants. Therefore, it is mandatory to collect, store and send all material exclusively within one system consisting of barcoded Matrix-vials systematically arranged within plastic Matrix-boxes. Material submitted in other vials **CANNOT** be accepted.

Please note that one Matrix-box is designed for samples of exactly two patients (see protocols 1 and 2). Never add any samples of a third patient into any Matrix-box. It is strongly suggested that all participants evaluate their own internal system of vials marking.

1. Since the material (CSF, blood, plasma, serum) has been frozen once, it should be kept arranged in Matrix-boxes (see protocols 1 and 2) in -80°C freezer, and it should **never** be thawed.
2. The material should be shipped when appropriate amount of Matrix-box has been collected, not more frequently than once in two weeks. The Matrix-boxes should be sent in styrofoam boxes filled with appropriate amount of dry ice (minimum, 4 kg) by an express delivery system (like e.g. FedEx). The delivery should be performed on Monday or Tuesday, and only if the following days are not business holidays in either the Federal State of the origin or the state of the appropriate center (Bavaria or Lower Saxony).
3. The samples should be accompanied by **all** of the following items:
 - 3a. floppy disk with CRF as an Excel file, one file for each patient,
 - 3b. check list, one for each patient,
 - 3c. a complete routine blood, urine and CSF work out of each patient.

4. The appropriate system of samples delivery is following:



5. The protocol to collect blood for genetic analysis will be prepared and provided by the Module E3 of the Network.

6. The current shipment addresses are:

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7. Currently, this protocol is devised for horizontal network (14 university centers), however, a very similar version will be extended to the forthcoming regional network partners.