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Establishing a Neurological-Psychiatric Biobank: Banking, informatics, ethics

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Abstract

The recent development of genetic databases and biobanks in a number of countries reflects scientist's beliefs in the future health benefits to be derived from genetic research. The NEPSYBANK is a national program of the Hungarian Clinical Neurogenetic Society with comprehensive participation of the Neurology and Psychiatry Departments of Medical Universities and the National Institute of Psychiatry and Neurology. The NEPSYBANK forms a part of the national biobank project (www.biobank.hu). The goal is to establish nationwide collaboration and common biobanking standards on quality, access, and protection of integrity in the field of neurology and psychiatry. Biological materials and databases are already collected in stroke, epilepsy, multiple sclerosis, motoneuron diseases, dementia, movement disorders, schizophrenia, and alcohol addiction. In peripheral neuropathies, neuropathic pain syndromes, muscle diseases, migraine, myasthenia gravis, depression, panic disease, anxiety, autism, and software development is in progress. The resources have been expanded by continued prospective collection of samples and data and important bottlenecks in sample purification, sample retrieval, in protection of the integrity of the research participants, as well as in guaranteeing the security and confidentiality of the participant's information have been harmonized. The development of uniform consent management, comprehensive sample overview and quality standards for health care-related biobanking may provide a unique opportunity for Hungary in molecular clinically oriented research. The program is a diseased-based research biobank with comprehensive collection of phenotypic and environmental information as well as biobanking of DNA, RNA or buffy coat, plasma, and erythrocytes stored at −80 °C. The biobank has a neuropathological part as well: storing conventional pathology and biopsy specimens. The analytical and informational demands being created by biobanking requires a "connectivity of community" that has not traditionally been present in the life sciences. As you put more resources into something, your silos tend to become taller, and we need to avoid this. The life science and healthcare community should be ignored working in individual "silos."

Keywords: Neurology; Psychiatry; Biobanking; Database

1. Introduction

The necessity of establishing a biobank in the field of the neurology and psychiatry came from the fast moving area of the complex genomial–postgenomial research. The research of the pathogenesis of the complex multifactorial polygenic diseases such as stroke, schizophrenia, and dementia cannot avoid this type of genomial research. The complex genetic studies require two main items. One is the biobanks, having large sample numbers, relative homogenous material, redefined phenotypes and well constructed endophenotypes [1]. The other key item is the availability of new technologies, such as expression profiling, whole genome analysis, bioinformatics technologies etc. [8]. These items may lead us to the construction of new disease pathways [6]. A good biobank system has a well structured clinical, laboratory and genomic database [7]. The processing of the data by the use of proper bioinformatics,

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data management and artificial intelligence with the integration of the literature data makes possible the development of new diagnostics, and therapeutics [5]. For this purpose the Hungarian Society of Clinical Neurogenetics established a nationwide collaboration for prospective collection of human biological materials and databases from patient with neurological and psychiatric diseases. The basic triangle of the NEPSYBANK is the sample, the information and the study management. In the following we will introduce the NEPSYBANK, its role in the medical care, its organization and management, the disease collection, the way of sampling, the data management, the access to the service, quality assurance and ethical regards.

2. The Hungarian Neurological-Psychiatric Biobank—NEPSYBANK

2.1. Organization and management

NEPSYBANK is managed by the Board of the Hungarian Clinical Neurogenetics Society. The biobank is led by a steering committee; the president of it's the society president. The members of the steering group represent clinical researchers at participating institutes. The management group has the operative responsibility for all activities (data management, QA, and financial management). NEPSYBANK is ready to collaborate with leading national and international biobank consortia.

2.2. The NEPSYBANK's role in patient care

In the medical care usually biobanking enhance the clinical diagnostics, in some cases helps to make the best treatment possible by comparing different samples from the same patient or samples from other patients with similar diseases and performs additional analyses on old samples when new questions arise or new methods are available. It is important from the responsibility point of view, because if complaints are raised on correctness of an analysis, a re-analysis of a stored sample may be performed. Furthermore medical research and quality follow up of medical care has a big impact as well, because the samples are a valuable source for epidemiological and genetic studies on the aetiology of human diseases.

2.3. NEPSYBANK participants

The present participants of the NEPSYBANK are the Department of Neurology and Psychiatry of the four Medical Universities (in Budapest, Debrecen, Pécs, Szeged) and the National Institute of Psychiatry and Neurology in Budapest.

2.4. Sampling and disease collection

The NEPSYBANK is a disease based biobank collecting both phenotypical and environmental data and biological materials such as DNA/RNA, whole blood, plasma, cerebral spinal fluid, muscle/nerve/ skin biopsy, brain, and fibroblast. The target of the diseases is presently (Phase I): stroke syndromes, dementias, movement disorders, motoneuron diseases, epilepsy, multiple sclerosis, schizophrenia, and alcohol addiction. In the near future (Phase II) it is planned to enlarge the scale with headaches, disorders of the peripheral nerves, disorders of neuromuscular transmission, disorders of skeletal muscle, depression, and anxiety. DNA/RNA is usually extracted from whole blood, but occasionally different tissues such as muscle, brain, etc., can be used as well. The extracting procedures differ among the institutes, but in all cases the concentration and the quality of the DNA/RNA must be registered in the database. Samples are stored in freezers or liquid nitrogen tanks at the place of the sample collection. We have to use strict precautionary measures to avoid specimens being destroyed or mixed up, or of unauthorized persons gaining access to the material. The temperature control is essential during the processing of samples and the long-term storage (it determines the usefulness of samples in future analyses) is needed. Freezers must be placed in rooms with backup power and cooling systems. The freezer rooms are connected to an alarm-system. All samples stored in NEPSYBANK must be registered and labelled in a way that permits tracing to the donors and linkage to the personal identification numbers. When the samples are received in the labs of NEPSYBANK, they are registered in the local registration system. The registration procedure may include transfer of samples into appropriately coded tubes. Bar coding is in progress. After registering the patient in the NEPSYBANK database a new registration code is generated, which provides reversible anonymization and easy lab identification.

2.5. Data management

In every case the following data are registered. (1) General data: main bank categories, age, sex, ethnicity, body height, body weight, economic stats, education, type of place of living, marital status, birth complications, alcohol, drugs, and smoking. (2) Sample properties (sample ID, type of sample, date of extraction, concentration, and level of purity). General patient data as blood pressure, heart rate, internal medical status, ECG, and additional diseases. Disease specific question e.g. in schizophrenia the diagnosis after DSMIV and ICD 10, detailed diagnostic questions after both classification, detailed psychiatric and neurological status, laboratory findings, rating scales, data of neuroimaging, genetic tests, applied medication (with generic name, dose, duration), adverse drug effects and other treatments. The identification code of the patient is recorded only at the local laboratory registry. The security and confidentiality of data are ensured by the use of data systems conforming to established standards, such as: backup procedures of the databases, restricted access, logs for all data entry and corrections performed. The registration of