W04.02
ETHICAL PROBLEMS WITH A HEALTH DATABASE LEGISLATION

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Epidemiological research is based on access to data and freedom to analyze available data for scientific purposes. In epidemiological research the ethical principles such as informed consent from the participants have to be respected. Under exceptional circumstances when that cannot be obtained for some reasons, an exemption should be approved by an independent ethical review committee. Modern biotechnology and information technology make it possible to link various personal records generating information about indiduals which they may not be aware of themselves. This makes it more imperative than ever to adhere to ethical principles.

Public concern as to the protection of privacy was aroused by increasing use of computerized records for administrative purposes as these might be misused for covert activities. Despite the danger being much greater today than before many seem to have forgotten this concern and yielded to the pressure of multinational companies to get access to personal information for the profit of their shareholders.

In accordance with a legislation passed in 1998 an American company has been given exclusive license to establish and run a health database in Iceland and to get access to the medical records of all Icelanders, dead or alive, without procuring informed consent. The company has already access to genetic and genealogical data. The legislation violates ethical principles and the exclusive license precludes fair competition in ensuring that science is seeking the truth for the benefit of the people.

W04.03
ETHICAL REVIEW OF PSYCHIATRIC RESEARCH PROTOCOLS

M. Lader

No abstract was available at the time of printing.

W04.04
ETHICAL QUESTIONS IN GENETIC PSYCHIATRIC STUDIES

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Family, twin and adoption studies allow insight in the genetics of psychiatric disorders. In order to detect the vulnerability genes, linkage studies in extended families with multiple affected family-members are most promising. The process of gathering information in genetic studies however, is considerably more complex from the ethical standpoint than would appear at first: especially in mentally ill patients appropriate procedures for obtaining informed consent are necessary to ensure that subjects understand the study and the inherent risks and to ensure that they are able to handle this information. As communications of risk can be misleading, appropriate genetic counselling has to be provided for the participating family members. On the other hand, privacy of the participants with respect to clinical and sensitive biological information (e.g. non-paternity) has strictly to be kept. In order to validate diagnoses subjects are asked for information on other family members. Hereby, information of family members who did not consent to participate in the study may be gathered and they may even been characterised as persons at risk (e.g. clinically as "obligate carrier" or by interpreting genetic results). Ethical problems may also emerge when relatives from distant branches of the families who did not know of their potential risk, learn about it when being approached for participation in the study. When stored samples are used in successive phases of research, implications for the use of samples may exist at the later stage that were not thought of when the sample was originally taken (e.g. data exchange with other groups, patent application, commercial gain). How different has the work to be that the researcher has to seek new consent? Detection of vulnerability genes can raise further problems, e.g. emotional distress and stigmatisation on account of genetic findings, identification of genetic predispositions in children, protection of confidentiality.

W04.05
ETHICS OF PSYCHIATRIC POST-MORTEM BRAIN RESEARCH

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The HUBIN brain bank at Karolinska Institutet is aimed to collect human brain tissue to meet the increasing interest in post mortem human brain research. General ethical rules for post-mortem tissue banking are currently under work by an EU ethics group to provide material for a future convention. The Swedish Medical Research Council gives guidelines based on the Council of Europe's "Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: Convention on human rights and biomedicine" from 1997.

Collection and conditions for use of the brain material are based on informed consent and ethical approval of prioritized research projects. The collection criteria and storage of the brain material is made according to protocols assuring good tissue quality. All information about and resulting from the brain material is kept in a coded database.

Setting up a brain bank requires enthusiasm, hard work, and determination as well as coordination between ethical committees, researchers, pathologists, treatment unit staff and relatives.

The ultimate aim is networking of brain banks keeping high legal and quality standards, monitored by local research ethics committees opening up for new collaborations with researchers and biomedical companies.

W11. Clinical hypnosis – an exploratory workshop

Chair: V.M. Mathew (UK)

W11.01
Clinical application of hypnotherapy

V.M. Mathew

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W11.02
VARIOUS HYPNOTIC TECHNIQUES

M. Joseph

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