



PRESS RELEASE

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German National Ethics Council publishes Opinion on biobanks for research

The National Ethics Council issues its Opinion on biobanks for research purposes this Wednesday.

The National Ethics Council has examined the scientific status of biobanks by reference to concrete examples, established ethical principles for their evaluation, put forward a framework of legal conditions to govern their operation, and formulated conclusions on how they should be regulated. The Opinion is preceded by 30 regulatory proposals.

For the purposes of this Opinion, biobanks are defined as collections of specimens of human bodily substances associated, or associatable, with personal data and information on their donors. The Opinion deals exclusively with biobanks intended for medical research.

Biobanks are an important resource for identifying the causes and mechanisms of a large number of diseases, and in that respect could lead to significant breakthroughs in medical and pharmaceutical research. However, they also arouse anxiety and distrust. The main concern is donor protection. What is feared is the uncontrolled use of specimens and data, together with the possibility that potential donors might be pressurized into assuming unreasonable risks or imprudently divulging personal information.

The National Ethics Council therefore considers it essential for explicit information to be given to those concerned and regards their consent as being of central importance. At the same time the Ethics Council is aware that the full scientific potential of biobank specimens and data can often be exploited only if their use is not restricted to individual, predetermined research projects. For this reason, it must be also possible for donors to consent to the use of their specimens and data for medical research in general and for an indefinite period. The risks to donors presented by the greater flexibility thus afforded to research must, however, be offset by a legal requirement of confidentiality on the part of the researchers.

This is the third Opinion to be issued by the National Ethics Council since its formation in June 2001; the subjects of the first two were “The import of human embryonic stem cells” and “Genetic diagnosis before and during pregnancy” respectively.

The German National Ethics Council

The German National Ethics Council's task is to provide a forum for interdisciplinary discourse between the natural sciences, medicine, theology and philosophy, and the social and legal sciences.

It expresses views on ethical issues relating to new developments in the field of the life sciences and on their consequences for the individual and society.

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