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Data access and international transfer of biobanks samples – Ethical and societal perspective

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Background: Biobanks are a new scientific tool for biomedical research and currently it can be observed the rapid development of biobanking entities. One of the most common problems associated with biobanking for research purpose is ensuring the right to privacy which is connected with the effective protection of the stored samples, ensuring data confidentiality and creating appropriate procedures of data access and transfer of biological material. The aim of the research was to examine social attitudes towards biobanking, access and sharing of data and samples stored in biobanks.

Material and Method: The survey was conducted on a representative group of 600 Polish respondents through direct interviews (PAPI).

Results and conclusions: The knowledge on the biobanks for research purposes is relatively low, but social attitudes are not negative. The level of trust depends on the type of the biobanking institution, and the lower trust is given to commercial biobanks. Majority of the respondents do not accept transfer data and samples to foreign and commercial entities as well as using them for non-scientific purposes. Respondents who were willing to donate samples to biobanks present a more liberal attitude towards data access and international transfer of human tissues samples (in comparison to general population). It is important to develop a model of data/samples transfer agreement and a model of informed consent for data access and transfer of samples in order to protect the donors' rights and responsible sharing of data and samples.

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