

Genetic privacy versus genetic solidarity: In the field of donation, and expectation of benefits in research biobanks

Angeliki Barmpagalou

National and Kapodistrian University of Athens, School of Law, Economics and Political Sciences, Faculty of Law, Athens, Greece

The last two decades we are witnesses of a massive development in the field of biotechnology, genetics and medical research. Several issues have been arisen and they are related to the use of biological material for the scope of the research and the protection of the donor's rights.

People who participate in a research project, such as donors, face their donation either as an action which is a result of personal generosity and altruism or as an action which is going to result in personal benefit. On the other hand it is widely believed that every single member of our society has benefited from medical research which is based on donations of biological material. Thus, each of us has a moral obligation to take part to this type of research.

The issue of protecting privacy is directly connected to the type of consent provided prior to the conduction of research projects. It is claimed that participants are suspicious in granting broad consent as they take into account that in this case they will not have the possibility to approve every single research step, considering that research is not limited to a single moment, but constitutes a continuous process. Informed consent may balance donor's right to privacy and people's profits and expectations, which are related to scientific research, assuming that genetic information is used for a superior purpose, such as the health care and treatment improvement. For the above reasons, donors should be more tolerate with the idea of their privacy breach for the sake of solidarity, thus a broader consent seems to be appropriate.