

Publication

Collaborative projects involving research biobanks – ethical and legal aspects of data protection

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Collaborative projects involving research biobanks raise various ethical and legal issues as insufficient data protection and/or inappropriate data management may have harmful effects for sample donors. The idea of data protection follows from the principle of non-maleficence and from the respect for autonomy of donors. The idea of patient (or donor) protection, by contrast, is based on the concept of beneficence and can be in conflict with those autonomy rights. In the present article we focus on this often tense relationship between data protection and patient (or donor) well-being. For this purpose, we first address the different levels of anonymity and data protection. Next we identify the advantages and disadvantages and examine the ethical acceptability of the various possible solutions to this problem. Our main aim is to raise awareness about the ethical issues related to data protection in biobanking, including knowledge about the different levels of anonymity, the careful use of appropriate terminology, and the identification and acknowledgement of various and possibly conflicting interests.

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