Data Protection in Germany

Historical Overview, its Legal Interest and the Brisance of Biobanking

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Abstract  Data protection law has a comparatively long history in Germany. To understand its meaning for biobanking, it seems important to present the history of data protection from its beginnings in 1970 and its connection with the Population Census Act in 1983 up to the existing legal framework. With reference to the Federal Data Protection Act (FDPA) of 1977 the European influence on the law and the legal status of personal data are discussed. The paper will then look at the current aims of and legal interest in data protection law, including today’s question as to how a gradually developed protective standard can fulfill the requirements of a rapidly developing technology and its participants. It will also discuss the distinction between biobanks that have specific research objectives and those projects that, at least initially, do not. Furthermore, a presentation of the legislative status quo in biobanking draws attention to the distinction between aliased data and data rendered anonymous as well as to the legal and practical consequences of such a distinction. The remaining question is whether there is a need for specific statutory legislation in the domain of biobanking or whether the principles of anonymity and coding of dating imposed by general data protection law are sufficient for future major biobanking projects.

1 Why we Have to Protect our Data

Big Brother is Watching You! Anybody who hears this sentence is instantly reminded of George Orwell’s book „1984“, in which the author describes his nightmare of a perfect autarchy achieved by the excessive use of technical devices. But it is no longer repression by human despots that needs to be feared. Today’s threat comes from the “political authority of technology itself, which will certainly find its beneficiaries“ (Benda et al 1994, translation by the author). In the mid-18th century, the British philosopher Francis Bacon stated: “Knowledge is power“. Knowledge in terms of information about others is an important economic good and thus displays a competitive factor of high economic value (Tinnefeld et al 2005). A modern example of this might be store cards, which are offered widely in
order to bind customers to the company and collect information on their personal habits and other data useful for marketing purposes. The danger that these personal data might be handled in a frivolous way is generally underestimated and most of the times accepted unconsciously (Simitis 2007). Thus, we have developed into an information society which is preoccupied with collecting personal data all the time and in all places, making them available through new (mobility-) technology and sharing them with miscellaneous parties even over great distances. This development has an enormous potential, especially for the private sector: while initially fear pointed towards the state as the Big Brother (Simitis 2007), the threat today has shifted to private industry, which now dictates the development of modern data protection law (Bizer 2001).

Over the last couple of years the responsible handling of data in the field of genetic engineering has gained much attention in the area of data protection law: there are only a few debates that are as intense and controversial. With the use of biobanks and the consequent possibility of studying multiple human bodily substances, researchers expect important insights into widespread diseases and the development of effective medication. But among the population there is heavy skepticism concerning the benefits of biobanking. Prospective participants worry that their data may be used for non-medical purposes or for purposes they did not agree to. It is thus not surprising that in a European survey only 42% of German respondents would allow the banking of their genetic information for research. Across Europe, only Austria had lower support (37%) regarding the setup of biobanks (Gaskell et al 2006). What is the cause of this restraint? Is it a lack of trust in the present legal protection of the donor and his donation? So far, there are no specific statutory provisions in Germany that regulate the operation of biobanks for research. In order to protect samples and associated information linked to the donor, it is necessary to investigate whether general data protection in the existing legal framework satisfies both the interests of researchers and the demands of donors.

2 Aims and Legal Interest of Data Protection

A glance at the Federal Data Protection Act (FDPA) suffices to locate the aims of the national German data protection law in section 1 [1] of the FDPA. That provision says: “The purpose of this Act is to protect the individual against the impairment of his right to privacy through the handling of his personal data”. The question is how, the “right to privacy” – the object of legal protection –, is to be defined.