Property and Personality Rights with Regard to Biobanks: A Layered System with Germany as an Example

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ABSTRACT

In the field of genetic research and the subsequent rise of biobanks an intensive discussion is taking place on national and international levels about property and personality rights to one's own body and body parts. The authors attempt to develop on the basis of the current controversially discussed law a concept of property, which can solve the legal and bioethical problems of the multiple use of human samples. Therefore, the question will be discussed whether a person is eligible to claim property rights to the tissue, which was separated from him. The authors’ opinion is that this person only loses his property rights when all data are completely anonymised. Also the trustee model could be an efficient model, in which the tissue is safeguarded and pseudonymised by a trustee, to preserve the interests of the former owner of the human samples, but concurrently support the interests of the users.

Keywords: Anonymized Data, Biobanks, Human Biological Material, Layered System, Personality Rights, Property Rights, Pseudonymized Data

1. INTRODUCTION

Human body materials have been gathered and evaluated either for diagnostic or scientific-medical research purposes; due to this fact, until today there have been established a multitude of human biological material and data collections, some of them are very large (Freier, 2005; German Ethics Council (2010), p.10). Collecting human biological materials has been carried out mostly on the basis of an existing diagnosis and treatment contract or post mortem due to a proper donor declaration of the deceased, or today, more and more, from voluntary donors. However, independent of the manner in which physicians or researchers receive the materials, whether it is with or without consent, any further use was to the benefit of others, which means for medical research purposes; otherwise the material was destroyed.

Biotechnological and biomedical research continues to increase enormously, more than fivefold since 2004, in particular as the biotechnological industry shows an increasing interest

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in scientific and commercial research as well as in any commercial utilization which may follow (Keller, 2008; Zech, 2007). Therefore, the number of biobanks and the activities connected are growing both nationally and internationally. For a couple of years some biobanks merged to large centralized biobanks. A lot of research projects, especially in the emerging field of personalized medicine, system medicine and epigenetics requires a large number of well characterized donor materials and the possibility to change the purposes of research freely. This requires national and international networking between biobanks and their results also (German Ethics Council, 2010). A broad discussion is taking place on all levels about the question of access to or collecting the needed body materials. In addition to ethical also legal and economic aspects are intensively discussed.

In this respect, the legal position of man is being discussed as a person who is, as either patient or donor, “providing” his human biological material (Laurie, 2005).

In this discussion process, there has been increasing criticism to the effect that the institutional parties involved in this process, i.e., science, the market (biotechnological and biomedical industry) and the law, keep reducing human biological resources to a concept of mere biological information. This allows them to come up with the opinion that anonymisation, pseudonymisation and “informed consent” are sufficient to properly honour the rights and interests of individual donors or patients (Laurie, 2005),- in particular the right to informed self-determination and the dignity of the individual. In this case the existence of further reaching rights, derived from the position of the owner, particular participatory rights, are usually negated (Laurie, 2005).

This is best shown in the “Moore-case”, known worldwide, in which the Californian Supreme Court held that any claims made by the plaintiff Moore were not to be considered, because individual property rights regarding body materials would hinder medical research by means of limiting access to necessary raw material and because a decision in a different direction would destroy the economical drive to do important medical research (Moore v. Regents of University of California, Cal. App. 2 Dist. (1988), e 51 Cal. 3D (1990). The question whether the individual donor has property rights to his body materials and, thus, consequential rights, is being answered and justified actually not on the basis of legal-dogmatic ideas, but rather exclusively on the basis of interest-governed, economical considerations.

The significance of this discussion in society varies greatly among countries. While countries in the southern hemisphere and strongly religious countries have more of a public discussion, this discussion process in Germany seems to take place mostly on an academic level.

Although the German Ethic Council published a revised opinion in 2010 and also in 2010 a Law on Gene Diagnosis (Gesetz über genetische Untersuchungen beim Menschen: BGBl. I S. 2529, 3672) has been set into force by the German government the general population does not or hardly take part in this discussion. Here is one example:

In fall of 2003, the project “Chromosoma” was initiated under the direction of the Federal Centre for Political Education. In the center of the northern German city of Bremen, among the best shops in the area, a store opened with the identical name. It offered potential customers a multitude of gene technological services such as “genetic horoscope”, wish-embryo or performance increase through gene maximisation. The interest was great. Particularly the welcome action was appreciated. Passersby were given a little package with some chewable mass along with the promise of a gift if the used chewing gum was returned. Upon its return one received one apple and one egg, a German phrase or synonym for giving something away for almost nothing. Many people followed the request and voluntarily provided their personal data like the name, address, birth date etc., although an information leaflet informed that “Chromosoma” wanted the saliva and, thus, the genetic material.

Person-identifiable genetic material was given literally for the proverbial ‘an apple and an egg’. On the first day, only one passerby
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