

Chapter 17

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

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ABSTRACT

This chapter is a discussion and analysis of the concept of property in the context of genetic research and biobanking. The authors are proposing a novel way of conceptualizing the concept of property, one which could unravel many difficulties that beset bioethical and legal debates on this issue. Once a certain part of the body is taken out, to what extent could the person from whom the tissue has been separated claim property right over the tissue? If the tissue is completely anonymized, then the person loses her right to claim the tissue to be her property. The linking could then be done by way of pseudonymization. Furthermore, the trustee model where the tissue is safeguarded and pseudonymized by a trustee could act as the middle path between complete retention of personal and property rights of the alienated tissue on the one hand, and complete disregard of the property or ownership rights to the tissue on the other

INTRODUCTION

Human body materials have been gathered and evaluated either for diagnostic or scientific-medical research purposes; due to this fact, until today there are a multitude of human biological material and data collections, some of them very

large (Freier, 2005; Stellungnahme der Zentralen Ethikkommission, 2003, A-1632). Collecting human biological materials has been mostly done 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 free donors. However, independent of the manner in which physicians or researchers

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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.

As options of biotechnological research continue to increase, in particular as the biotechnological industry is showing an increasing interest in scientific and commercial research as well as in any commercial utilization which may follow, a broad discussion is taking place at all levels on the questions of access to or collecting the needed body materials.

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 have been increasing criticisms to the effect that the institutional parties involved in this process, i.e., science, the market (biotechnological industry) and the law, keep reducing human biological resources to mere biological information. This allows them to come up with the opinion that anonymization on the one hand and “informed consent” on the other are sufficient to properly honor the rights and interests of individual donors or patients, in particular the right to informed self-determination and the dignity of the individual (Laurie, 2005). In this case the existence of further reaching rights, derived from the position of owner, in particular participatory rights, is 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.¹

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 thoughts.

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

The general population does not, or hardly, take part in this discussion. Here is a new example. In fall of 2003, the project “Chromosoma” was initiated under the direction of the Federal Center 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 same name. It offered potential customers a multitude of gene technological services such as “genetic horoscope,” wish-embryo or performance increase through gene maximization. The interest was great. Particularly the welcome action was appreciated. Passersby were given a little package with some chewable mass in connection with the promise of a gift if the used chewing gum was returned. Upon its return one received an apple and an egg, a German picture or synonym for giving something away particularly cheaply. Many people followed the request and voluntarily provided their personal data like the name, address, birth date etc., although an information leaflet informed that “Cromosoma” wanted the saliva and, thus, the genetic material.

Person-identifiable genetic material was given for an apple and an egg. On the first day, only one passer by complained after she had thought about the matter and the meaning of her action at home (Zinkant, 2003, p. 65).

Particularly because the general public is not sufficiently sensitized with regard to the problem of use and continued use of genetic materials and its economical consequences, further explanations

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