

New bio bank to resolve legal and ethical issues

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When researchers collect human tissue in a so-called bio bank, the purpose is usually to learn about various diseases and improve curing of them. But at the University of Copenhagen a group of researchers are in the process of creating a bio bank, which will generate knowledge about the legal and ethical aspects of bio banking as well as contributing to medical research. The project has been selected as one of the University of Copenhagen's interdisciplinary star programmes.

A group of researchers across different disciplines within natural sciences, health sciences, humanities and law have come together in a common gene project. '[Global genes, local concerns](#)' is an interdisciplinary research project in which researchers create a bio bank

and also map out the legal and ethical aspects of bio banks, which operate across cultural and national borders.

"When we uncover the ethical and legal dilemmas related to bio banking in the research project 'Global genes, local concerns', we do so in order to develop new guidelines for the work of the bio banks," says head of project and Professor of Law Jens Schovsbo.

The consequence will be that the work of the bio banks will flow more easily, and that the involved parties' rights will be respected, while the people will gain as much as possible from the work of the bio banks.

"In the research project we are working to ensure that we get the optimal output of the modern international bio banks - without it being at the expense of the people, who ultimately make research possible," says Jens Schovsbo.

Modern research creates dilemmas

The [tissue](#), which the bio bank consists of, will be used to research diseases as in any other bio bank, but at the same time we use the creation of the bio bank to study all the issues relating to creation and operation of a bio bank.

"Tissue samples in bio banks often come from donors around the world. It creates a lot of legal and ethical issues, which we need to relate to," says Jens Schovsbo.

The ethical implications could be questions like: How to ensure that a tissue donor from Pakistan, where a large part of the population cannot read and write, is informed of his rights? How to handle the demand for donor anonymity? How to handle the different hospitals' patients' rights? And how do you distribute any revenue from the use of the information

in the bio bank?

Medicine of the future

While these questions will occupy researchers within humanities and jurisprudence, the bio bank [tissue samples](#) will form the basis for research into how diseases arise. Professor Niels Tommerup, Department of Cellular and Molecular Medicine and Associate Professor Søren Tvorup Christensen from Department of Biological Sciences, are participating in the project with this in the offing:

"By mapping the genetic defects, which can cause severe malformations in the foetus and life-threatening diseases in the adult, we learn how the diseases occur in detail in the body's cells. And it is this knowledge, which will form the basis for the fact that in the future we can diagnose and treat patients with defects in the genes," says Søren Tvorup Christensen.

Solutions for the future bio banks

Over time, collaboration across disciplines will be an advantage for [disease](#) research of the future. Bio banks represent a huge potential in the quest to crack the code of life-threatening diseases such as cancer, but it is a recurring problem for the bio banks that the parties involved from donors, researchers and pharmaceutical companies often have conflicting interests. It may ultimately jeopardise the good research results. All parties' rights must be respected, but it is often a dilemma to establish where the major considerations should be.

One example is the Danish Cancer Registry, which is one of the world's best and which has generated good research results within cancer treatment. The register has only been possible to build because citizens

automatically have had their blood and tissue registered. If the registration of tissue and blood is made optional, it will be detrimental to research. It should therefore be considered carefully, whether the interests of the individual citizen may outweigh the risk of poorer research in the future.

More information: globalgenes.ku.dk/

Provided by University of Copenhagen

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