

TAIWAN BIOBANK PROJECT AND THE ETHICAL AND LEGAL CONTROVERSIES IT AROUSED

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Taiwan's government has recently decided to sponsor a biobank project conducted by the Institute of Biomedical Sciences, Academia Sinica. This project is expected to develop a national-level biomedical database that will store blood samples, genetic information derived from them, and personal lifestyle information, with linkage to health data and medical records, collected from 200,000 people in Taiwan. Many ethical and legal controversies have been aroused by this project, and some of them are unique because of the social/cultural contexts and past biomedical research practices in Taiwan. For example, self-regulation of medical professionals and researchers are still underdeveloped, and concepts like privacy, confidentiality, and conflict of interest are not taken as seriously as they are in many Western societies. Moreover, most IRBs in Taiwan are unsound, and the process of informed consent in many biomedical studies is problematic. To put the author's discussion in Taiwanese contexts, and because the Academia Sinica still plans to follow some of its past research practices to establish the Taiwan Biobank, this article first identifies and examines the common problematic research practices that involve collection and utilization of human tissue samples in Taiwan. Next, by demonstrating some points from the research proposal and public statements of the Academia Sinica, this article argues that its researchers are still not fully aware of the problems of past research practices, and they seem to disregard the importance of legal and institutional frameworks for the biobank project. Furthermore, this article argues that before public consultation and debate are held and a sound governance framework is designed, the Taiwan Biobank project should not start its promotion to the public, not to mention collecting blood samples. Finally, this article make some suggestions, such as establishing an independent and multidisciplinary committee, for the future governance framework of the Taiwan Biobank project.