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[Sci-tech Policy][Biotech] Incomplete BioBank Regulations Put People at Danger of Privacy Infringement, Calls the Lawmaker

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[Sci-tech Policy][Biotech] Incomplete BioBank Regulations Put People at Danger of Privacy Infringement, Calls the Lawmaker (Chinese Version)

Many transnational pharmaceutical companies are collecting and exporting blood and bio-samlpes in Taiwan, causing the concerns with privacy infringement and the further ethical issues. Lawmaker Sue-ying HUANG thus urges Department of Health to keep strict check on this and to complete the BioBank regulations as soon as possible.

Bio-sample collection and BioBank establishment are significant moments in the research and development of new science and technology. However there is no complete relevant regulations yet in Taiwan. Sue-ying HUANG has recently received the states from people that many international pharmaceutical companies, using intricate and obscure authorization letters that are not only difficult to understand for the non-specialist people but even unclear about the sample's utility scope and the retention period, are collecting and exporting gene samples. She criticizes that these companies are taking advantage over the government's undue delay of lawmaking and blames these companies for taking Taiwan for their bio-sample acquisition farms. She urges the related departments in the government to complete the relevant reguations to protect people's rights.

According to Merit Times (2009/07/03), Li-Ling LIU (Deputy Director General of Bureau of Pharmaceutical Affairs, DOH) points out that DOH has set up a standard form of gene research authorization letter and its drafting guidelines, requiring that the letter should write down clearly the purpose and plan of the research, the retention location and the volume number of samples etc.; that the authorization letter must be reviewd by DOH and Committee of Human Body Research Execution; and that the director general of the research plan has to explain to the public about the plan. She suggests that if any worry occurs, people should not sign the letter. Awakening News Network (2009/07/02) reports, Committee Member of Academia Sinica's Human Subject Research Ethics Committee Wen-tsong CHIOU says that there must be a reconfirmation mechanism when the purpose of sample collection is not well identified and the sample reference is not cut off. If the sample is refferred abroad, he continues, it becomes more difficult for the control, and people's health data are put at danger of exposing. He emphasizes that it is necessary to grant the subject of the sample the right of "reconfirm" when the sample is to be used again. Mr. Yen-qing LUO from Science and Technology Unit, DOH, says that before the lawmaking people have to reassure their own will about the sample collection and try to get better understanding about the research plan, the privacy policy, the purpose of the sample and its destination before signing the authorization letter, so that they can protect their own rights.

## Related History Message:

[Bio-medical][Sci-tech Policy] Bio-data Collecting Program Allures Ethical Controversy 2009/05/12

## Further Information:

<u>Yahoo! News /BCC News 2009/07/02</u> (Chinese) <u>Awakening News Network 2009/07/02</u> (Chinese) <u>Merit Times 2009/07/03</u> (Chinese)

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