

# 論我國原住民族群基因研究 之群體同意機制

林瑞珠\*、梁宗憲\*\*

## 要 目

- |                    |                                       |
|--------------------|---------------------------------------|
| 壹、前 言              | 伍、特殊同意機制之芻議                           |
| 貳、噶瑪蘭族異議事件之探討      | 一、透過焦點團體、深入訪談<br>及問卷收集，找出適當的<br>研究方式  |
| 一、背景事實             | 二、籌備原住民族教育機制，<br>以培養在地之溝通、監督<br>及宣導人才 |
| 二、問題之提出            | 三、結合現有部落健康公約機<br>制，建構原住民族之群體<br>同意機制  |
| 參、族群基因研究之風險        | 四、建立跨部落參與監督的機<br>制                    |
| 一、外部風險             | 陸、代結論                                 |
| 二、內部風險             |                                       |
| 肆、群體同意機制之問題與策<br>略 |                                       |
| 一、與研究族群溝通之問題       |                                       |
| 二、同意之取得問題          |                                       |
| 三、利益分享之問題          |                                       |

---

\* 台灣科技大學專任教授。

\*\* 台灣大學法學碩士／律師。

投稿日期：97年5月5日；接受刊登日期：97年5月26日

## 摘 要

生物科技的突破性發展，使過去被棄之如敝屣，或是當成廢棄物處置的人體組織，成為炙手可熱的研究素材。雖然相關研究的推展，將是科技進步的動力，此研究自由並為憲法所保障之基本權；然而，當研究的素材涉及另一個基本權主體，並以其人體組織為研究對象時，如何確保參與者權利並兼顧研究自由保障，正形成法律價值判斷之難題。以族群基因研究為例，在透過採集人體組織供研究使用時，由於基因本身在遺傳屬性上具有非個人專屬特殊性，其可能引發侵害隱私，或對原住民、移民等少數族裔，帶來污名化、種族歧視等隱憂之問題。

2007年4月，台灣學術研究史上便發生首次因參與者提出異議，要求研究者銷毀生物樣本之事件，其在噶瑪蘭族巫師主持祭告祖靈儀式後，公開銷毀由有「台灣血液之母」之稱的研究者所採集之唾液；此一事件充分顯示原住民族人權意識的抬頭，也讓研究者驚覺，應以更審慎的態度面對族群基因研究倫理問題。本文以為，台灣未來可在憲法與原住民基本法的規範架構下，參考UNESCO的人類基因資訊國際宣言、美國及澳洲對原住民族政策上的精神、以及「部落健康營造」、太魯閣族推動自治法的經驗，以作為族群基因研究在原住民族部落間取得群體同意之特殊模式的基礎。

**關鍵詞：**群體同意、原住民、族群研究、基因資訊、基因隱私、告知後同意、利益分享

# **Broadband Regulation – Network Neutrality**

Jui-Chu LIN, Tsung-Hsien LIANG

## **Abstract**

The breakthrough in biotechnology has transformed human tissues, traditionally deemed as unwanted waste and were discarded like worn shoes, into valuable research materials which have been dubbed “Gold Mine” by scientists. It is true that biotechnology can be the momentum for the development of science & technology in the 21st century and scientific researches deserve the constitutional protection for freedom to express as a fundamental right. Yet human rights of research participants/subjects should also be taken into consideration when it comes to experiments using human tissues. Given the rapid growth of biotechnology, finding out a balance between rights and interests on the two sides is urgent for jurists. Biomedical researches, for instance, are capable of uncovering sensitive genetic information of participants from whom the research materials are collected. This, in case of misuse of genetic information, can raise risks such as privacy infringement to the subjects; when the research participants are selected as a group, the risks may escalate to humiliation and discrimination against certain ethnical characteristics, particularly that of minority groups like aborigines and migrants.

In April 2007, an unprecedented event happened in the bio-research history of Taiwan. After the tissue collection procedure was denounced as violation of the principle of informed consent, the aboriginal research participants required the researchers to destroy their biological samples in a sacrifice ceremony. After the sacrificial rites for memorizing the ancestors presided by the sorcerer of Kavalan people, the participants destroyed the saliva samples collected by the researcher who was recognized as “The Mother of Taiwan Blood.” The case sufficiently revealed the trend that indigenous peoples’ awareness of human rights has been strengthened, and the researchers should be aware of the ethical issues of biomedicine research, and with more cautiousness and carefulness as well. In this paper, the authors would like to argue that the balance between the freedom of speech and expression through scientific researches and the protection of participant/subjects’ fundamental rights might be achieved progressively subject to the ROC’s Constitution and the Indigenous Peoples Basic Law, and by taking into consideration “The Universal Declaration on the Human Genome and Human Rights” adopted by the UNESCO, the U.S and Australian policies concerning indigenous people, and Taiwan’s domestic experiences in tribal health management and promoting self-governance rules in the Taroko tribes. Bearing in mind these experiences, Taiwan is now developing its own special mode of group consent in researches relating to indigenous tribes, which can be taken further as the mode for future biomedicine research purposes.

*June/2008*

論我國原住民族群基因研究之群體同意機制 91

**Keywords:** Group Consent, Indigenous Peoples, Population-Based Research, Genetic Information, Gene Privacy, Informed Consent, Benefit Sharing