

# 消失的多元公眾：Taiwan Biobank 的建置、爭議與科學治理

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本文以「科學的公眾想像」概念出發，分析 Taiwan Biobank 發展過程的倫理、社會與法律爭議、公眾溝通與科學治理。首先，全文指出 Taiwan Biobank 科學團隊所進行的招募說明會、官方網站與文宣、社會意向調查、科學演講與教育等公眾溝通，呈現科學徵召下可被教育的單一公眾想像。科學家倚賴人文社會科學學者協助制定 Taiwan Biobank 倫理治理架構，但相關規劃大多停留在論述層次，並未發展出符合公眾諮詢的多元參與機制，因此無法針對 Taiwan Biobank 議題提出不同公民認識論的反省。其次，Taiwan Biobank 爭議呈現出一個「消失的多元公眾」的圖像。少數人權團體代表、特定人文法律學者做為公眾代言人，並沒有納入一般民眾的聲音與建立實質參與機制，使得 Taiwan Biobank 爭議反映的是少數行動者所代表的公民社會監督。法律賦予倫理治理委員會代表公眾監督的合法地位，但倫理治理委員會實作上缺乏獨立性與社會正當性，引發民主治理的難題。最後，本文分析指出 Taiwan Biobank 科學計畫缺乏「上游式公眾參與」想像，無法建立容納不同行動者多元價值辯論、進行實質審議的合理溝通情境。不同意見的行動者訴諸媒體發聲，擴大彼此之間的對立，也限縮相互理解、深度對話的可能，走向以法制化解決爭議尋求共識，成為台灣獨特的科學治理模式。

論文關鍵字：基因、台灣人體生物資料庫、公眾溝通、治理、想像

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## Genetic Technology and Public Communication: Taiwan Biobank, Controversy, and Democratic Governance

The aim of this study is to analyze the controversy, public communication, and scientific governance in the establishment of Taiwan Biobank in terms of the concept of “scientific imaginaries of publics”. First, this article examines Taiwan Biobank’s implementation of public communication, which was mainly aiming for scientific recruitment. This reflected the imaginary of a singular public to be educated and informed in order to support Taiwan Biobank. Scientists relied on social scientists to tackle public communication, but the participation mechanisms were not developed to include multiple publics and to further reflect on different civic epistemologies against Taiwan Biobank. Second, the public controversy over the ethics and governance problems of Taiwan Biobank reveals a picture of “missing publics”. Some social scientists and the human rights group have represented the public, but their interventions were not based on general-public perspectives or intended to initiate genuine public engagement. Although the Ethics and Governance Committee of Taiwan Biobank is legally responsible for monitoring Taiwan Biobank on the public’s behalf, the independence and social legitimacy of its operation have been questioned, causing problems for its democratic governance. Third, Taiwan Biobank lacked the “upstream public engagement” imaginary. Because actors with different opinions were unable to create an ideal communicative situation, they resorted to the media, which did not resolve conflicts or enhance mutual understandings. The legalization of ethics and governance became the approach for settling controversy and seeking social consensus; this approach has subsequently shaped the specificity of scientific governance in Taiwan.

Keywords: gene, biobank, public communication, governance, imaginary