

# How do researcher duties conflict with Aboriginal rights?: Genetics research and biobank problems in Taiwan

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## ¿Cómo entran en conflicto las responsabilidades de un investigador con los derechos de los aborígenes? Problemas en investigación genética y biobancos en Taiwán

**ABSTRACT:** Taiwan has a population of 23 million, of which some 500,000 are Aborigines. Recent conflicts over a national biobank as part of Taiwan's biotechnological industrial development, genetic research on Aboriginal origins, and commercialization of research findings involving Aborigines have raised a number of important ethical conflicts. These ethical conflicts involve on one hand, the importance of researchers' duties, and on the other hand, Aboriginal rights. This paper will go in three steps. First, this paper describes the three cases of ethical violations of Aboriginal rights committed by Taiwanese researchers in the course of their scientific duties. After having given an account of ethical conflicts between research duties and Aboriginal rights, the paper addresses larger ethical issues underlying this Taiwanese research context. Finally, the paper considers if stronger ethical regulation could reconcile Aboriginal rights and research duties.

**RESUMEN:** Taiwán tiene una población de 23 millones, de los cuales 500,000 son aborígenes. Recientemente se han dado conflictos éticos sobre los biobancos nacionales, parte del desarrollo biotecnológico industrial Taiwanés, en el contexto de la investigación genética sobre los aborígenes y sobre la comercialización de los resultados de investigación. Estos conflictos éticos se relacionan en parte con la importancia de las responsabilidades de los investigadores y por otra parte con los derechos de los aborígenes. Este artículo se desarrolla en tres etapas. Primero, describe tres casos de violación ética de los derechos de aborígenes por parte de investigadores Taiwaneses en el curso de sus investigaciones científicas. Después da cuenta de conflictos éticos entre las responsabilidades de los investigadores y los derechos de aborígenes. El artículo aborda conflictos centrales en el contexto de investigación en Taiwán. Finalmente, el artículo considera si una regulación ética fuerte podría reconciliar los derechos aborígenes y las responsabilidades de investigación.

**KEYWORDS:** Aboriginal rights, autonomy, informed consent, paternalism, researcher duties.

**PALABRAS-CLAVE:** Derechos de los aborígenes, autonomía, consentimiento informado, paternalismo, obligaciones de la investigación.

### Introduction

Article Six of the World Medical Association's *Declaration of Helsinki* on ethical principles for medical research emphasizes the fundamental requirement that the welfare of subjects involved in medical research projects must always take precedence over the interests of science (World Medical Association, 2008). This fundamental requirement underlines the possible tension between patient rights and researchers' scientific duties. Genetic databases and biobanks pose new challenges to this ethical and fundamental requirement. These challenges are further complicated in settler dominated countries where systemic racist discrimination against Aboriginal peoples has been the norm, and serious conflicts of interest are emerging in biotechnology

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oriented development (Harry, Howard, and Shelton, 2000; Harry and Kanehe, 2006). Dealing with such situations requires use of grounded critical bioethics which consider not only bioethics' traditional topics of patient autonomy, informed consent, paternalism, and researcher duties but also larger more overtly historical, sociological, and political considerations (Dickenson, 2005; Hedgecoe, 2004). Indeed, the conception of autonomy takes on significant additional meanings since political autonomy have been a major goal of modern Aboriginal rights movements. The need to consider such a broad set of concerns becomes particularly salient in dealing with how Aboriginal worldviews and interests have been dismissed or marginalized in racialized and paternalistic relations between genetic researchers and Aboriginal peoples (Mead and Ratuva, 2007:12; Harry and Kanehe, 2006).

The collection and procurement of human biological samples from Aboriginal peoples has been a subject of intense research ethics debate since the disputes of the early 1990s such as the Human Genome Diversity Project and US patent applications on Indigenous peoples from Panama, the Solomon Islands, and Papua New Guinea. Taiwan has a population of 23 million people, of which some 500,000 are Aborigines. Recent conflicts over a national biobank as part of Taiwan's biotechnological industrial development, genetic research on Aboriginal origins, and commercialization of research findings involving Aborigines have raised a number of important ethical conflicts. These ethical conflicts involve on one hand, the importance of researcher's duties, and on the other hand, (in)alienable Aboriginal rights. Collection of human material can give potential benefits to society and underlines the importance of researcher duties to bring these potential benefits. However, research on human genetics can also cause economic or psychosocial harms to material donors, their families and their community (Ashburn, Wilson, and Eisenstein, 2000).

The purpose of the paper is to, first, describe three cases of ethics violations where researchers purporting to carry out their duties have violated Taiwanese Aboriginal rights during genetic collection procedures; second, to examine the ethical requirement of giving priority to participant interests over scientific duty through the consideration of paternalistic attitudes of involved Taiwanese researchers; and third, the paper considers if stronger legal regulation could help ethics to reconcile Aboriginal rights and research duties, and then gives recommendation to avoid future Taiwanese research misconduct involving human material.

## Three cases of ethical violation during the collection of human material

**2.0 Aboriginal rights background:** Strategically located about 100 miles off the southeast coast of China, the island of Taiwan has been gradually colonized by Chinese settlers under a succession of external powers: the Dutch East Indies Company (1624-62), the Spanish Empire (1626-41); Koxinga, a Ming dynasty loyalist and pirate (1662-1683); the Ching dynasty (1683-1895), the Japanese empire (1895-1945) and the Kuomintang (KMT) Chinese Nationalist dictatorship (1945-1987).<sup>1</sup> During the late 1800s, Western demand for tea and camphor began to drive the invasion of Aboriginal territories by Chinese settlers. Despite these incursions, a little over a century ago Aboriginal peoples still controlled half the island. However, the Japanese and their successors, the KMT Chinese Nationalists under Chiang Kai-shek, colonized and transformed these remaining Aboriginal territories into a resource periphery displacing Aboriginal peoples from their territories. Their territories were heavily exploited for logging, hydroelectric development, cement production, mining and agriculture during Taiwan's so-called "economic miracle." It was only during Taiwan's democratization of the 1970s and 1980s that the contemporary Aboriginal rights movement began.<sup>2</sup> With the lifting of martial law in 1987, Aboriginal rights and political autonomy issues have gained further in public prominence and legal stature. In 1994, Aboriginal rights were recognized in Taiwan's constitution albeit rather vaguely and paternalistically (Shih, 1999). In 1996, the Council of Indigenous Peoples, a cabinet level Aboriginal affairs ministry was established. However, issues of Aboriginal political autonomy have been constrained by Aborigines' lack of political economic clout relative to settlers, including resistance from big business and settler interests in Aboriginal areas. A significant step forward came in 2005 when the Taiwan Parliament passed the *Indigenous Peoples Basic Law*, which came into effect on February 5 2005.

### 2.1 Case 1: Taiwan Biobank: Health, wealth, duties and rights

If we consider that applied ethics involves considering how action is informed by moral judgements, these often conflict in Taiwan: economic development, health of populations, human rights, and Aboriginal rights. Beginning in the mid-1990s, Taiwan state industrial planning has promoted biotechnologies as a strategic new area of economic development, hoping to emulate the earlier successes in computer manufacturing and information technologies of the 1980s and 1990s (Chou, 2007; Wong: 2005). These development efforts have included signifi-

cant state investments in biotech start-ups, changes in regulations to attract foreign and Taiwan investments, joint ventures between Taiwan research institutes and investors ("Incentives," 2006; Wong, 2005). This integration involves government scientific policy planners and scientists enacting a set of norms and values which consider that health care can be integrated into economic development which must serve Taiwan's population by transforming Taiwan's population into strategic resource for economic development. For example, competition with other East Asian countries was cited by a senior Taiwan government official as a reason for the Taiwan Biobank in a 2005 *Taipei Times* article on the "Taiwan Biomedtech Island":

*'We have to build the genetic database in the very near future because we are competing with others in Asia, such as Singapore. However, the health records collected over the last decade through our single national insurance system are an advantage,'* said Chen Tzay-jinn (陳再晉), deputy minister of the Department of Health (Chiu Yu-tzu, 2005).

However, this integration of the Biobank, National Health Insurance system (which covers 99 percent of the population) and economic development, involves a set of relations and goals with some very important contradictions and conflicts that raise various ethical dilemmas. In particular, how do issues of consent affect Aboriginal peoples?

The Taiwan Biobank has been pitched as a cornerstone of Taiwan's state biotechnology development. Taiwan Biobank promoters have popularly portrayed it as following the UK Biobank and it is supposed to be a 200,000 person sample representative of Taiwan's population that will be followed in a prospective cohort study covering life style, diet, environment, medical factors, and genetics (Chen Yuan-Tsong, 2007). Implementation was to begin in 2006; however, a dispute broke out in early 2006 after human rights organizations criticized privacy problems and Aboriginal rights activists charged that the Biobank violated *Section 21* of the *Indigenous Peoples Basic Law* that had been passed by Taiwan's Parliament in 2005 (Chou, 2007; Tai and Chiou, 2008). *Section 21* states:

*The government or private party shall consult indigenous peoples and obtain their consent or participation, and share with indigenous peoples benefits generated from land development, resource utilization, ecology conservation and academic researches in indigenous people's regions.*

This section posits an equitable reciprocal sets of relationships in which outside parties have a legal duty to engage in an ongoing dialogue with involved Aboriginal peoples through all phases of research. The *Indigenous Peoples Basic Law* has significant implications for bioethics as it requires an expanded conception of autonomy from a conventional

bioethics focus on the individual patient to that of the political autonomy of Aboriginal peoples.

The Biobank involves serious contradictions between economic development, privacy concerns in a new democracy, and Aboriginal rights. Indeed it was this combination of privacy concerns with Aboriginal rights that was critical to disputes over the Biobank. The use of Biobank participants' information from Taiwan National Health Insurance system has raised ethical confidentiality questions. The importance of protecting individual data to avoid confidentiality issues has been stressed, for instance, by Swedish guidelines, which define biobanks as any collection storing biological samples or information that may be linked to an individual (Abbott, 1999:3). The potential risks to patient confidentiality raised by using Biobank participants' National Health Insurance system medical records were challenged by both Aboriginal rights and privacy advocates who viewed the attitudes of involved scientific elites and planners towards these risks as the paternalistic and authoritarian (Chou, 2007; Tai and Chiou, 2008).

### **2.1.1 How to justify research duties: 'Trust us, we're experts'**

After the Biobank dispute began in early 2006, Taiwan scientists attempted to quickly re-establish their authority with a series of opinion pieces in newspapers and press conferences. These opinion articles framed the Biobank as a vital duty to the economic future of Taiwan. For example, two senior members of Academia Sinica, Taiwan leading research institute, Chen Yuan-Tsong and Shen Chen-Yang in a *China Times* article argued that if Taiwan failed to push forward with the Biobank it would risk economic marginalization because other Asian countries such as "China, Japan, Korea, Malaysia, Singapore and India" are pursuing biotechnology development (Chen and Shen, 2006a). In another article, Chen and Shen explained the Biobank project as bringing health benefits because "The genetic inheritance of the Taiwanese people is unique, and lifestyles and disease-causing risk factors differ from country to country" and concluded "We hope that every sector in society will be able to discuss the matter in a rational manner, based on facts" (Chen and Shen, 2006b). Furthermore, in effect ethics, privacy, and related concerns were dismissed as unfounded and based on irrational fears—trust us we're experts. However, the strength of resistance to the Biobank forced its proponents to delay its implementation and various meetings and public consultations were held.

Despite public consultations, ethical problems persist. The first sampling done for the Biobank in 2009 involved charges of poor imple-

mentation of informed consent. This first sampling trial occurred in the Minnan-speaking majority cities of Chiayi and Tainan in which 1000 samples were gathered. Critics of this trial considered that informed consent processes were still badly carried out with Academia Sinica's (the main implementing institution) own figures revealing that 53 percent of participants did not understand they were contributing to the Biobank, and instead thought they were only getting a health checkup (Loa, 2009). This trial sets a troubling precedent particularly since informed consent abuses involving Aborigines have historically been pervasive (Chou, 2007; Liu, 2000).

Explicit informed consent procedures are an object of increased international ethical inquiry. Problems with informed consent are not uncommon, even when effective informed consent procedures are followed, in general, the participants are not necessarily well informed (Hoeyer, Olofsson, Mjörndal and Lynöe, 2005). As we will see later in the following two cases, effective informed consent remains a major concern in Taiwan due to senior researchers' failures to carry it out properly.

Even if informed consent issues are remedied, there may be deeper ethical problems with the Biobank's organization and approaches because Biobank planners have configured it along existing racial and ethnic divisions: Hoklo, Hakka, Aborigines, and "Mainlanders." These divisions are reflected in areas of the country chosen for initial sampling. Chiayi and Tainan were chosen to allow sampling of the South Minnan language speaking Hoklo majority who comprise 65-70 percent of the country's population (often called "Taiwanese"). Miaoli was chosen since it has a large Hakka population. The Hakka (*kejia* or "guest" in Mandarin) are a Chinese minority, who number some 15-20 percent of the population, and have their own language and culture. Hualien was chosen as it has a large Aboriginal population. The fourth ethnic category, "Mainlanders" (a catchall phrase for post-WWII immigrants and refugees who fled China after Chiang Kai-shek's defeat by the Communists) are spread throughout these areas, and account for some 14 percent of the population (Tai and Chiou, 2008; Chen, 2007). Advocates of the Biobank plan have justified this use of racial difference for example by citing the differentials between Europeans and Chinese in metabolism of warfarin that can lead to adverse reactions (e.g. Chen Yuan-Tsong, 2007).<sup>3</sup> However, such a racially organized effort has significant risks for Taiwan Aborigines, who have already been stigmatized by earlier research on alcoholism during the 1990s.

Writing in 1999, a Taiwan academic shows how genetics had already been incorporated into negative stereotypes of Aborigines: "...the po-

pular perception of Indigenous peoples is invariably, in one form or another, of social pathology in need of social relief at best, or to be condemned to their own miserable destiny resulting from genetic defects at worst" (Shih, 1999). Researchers were central figures in propagating conceptions of Aborigines as genetically predisposed to alcoholism, despite the fact that alcoholism has only emerged as a social problem among Aborigines since the 1950s (Munsterhjelm, 2005).<sup>4</sup> In Taiwan's mass media, researchers have stated Aborigines are genetically predisposed to develop diabetes (Central News Agency, 2004), gout (Chen Qing-Fang, 2004), and alcoholism (Hsu, 1998), all of which are supposedly factors which contribute to mortality rates 3 to 5 times the national average thereby reducing life expectancy (Central News Agency, 2004). Such geneticization of disease is a serious risk because it marginalizes or reifies the critical social contexts of the widespread poverty, cultural loss, and systemic racism that affect Aborigines, even blaming them (Harry, 2009; Harry and Kaneka, 2006; ten Have, 2001; World Health Organization, 2007). Critically, as well, geneticization could then readily lead to regimes of social control rather than individual autonomy (Hoedemaekers and ten Have, 1998) which would also undermine Aboriginal political autonomy. There is a significant risk this sort of discrimination will be repeated in the Biobank because scientists configure their duties to further public health through use of existing racially configured categories which carry with them all manner of connotations including common negative stereotypes. Therefore, issues of autonomy understood broadly in individual, group, and political senses that inform collective informed consent and consultations for Aborigines are very important (Tai and Chiou, 2008) because they have already been most adversely affected by past genetic research abuses and would face the most serious potential future impacts—genetic research has persistent and strong intergenerational impacts.

## **Case 2: Austronesian origins research**

Curing disease and knowing the origins of humanity are two powerful duties claimed by genetic researchers. Scientists assert they have duties to know the origin of the population so they can both contribute to knowledge of genetic aspects of pathologies and knowledge of where we are from. However, in Taiwan mythic aspects become important in the competing claims of Chinese nationalists and Taiwan nationalists over the island. Therefore in Taiwan, research into Taiwan Aborigines relationships to prehistoric migrations in the Pacific has both nationalistic and scientific intonations (Rudolph, 2004; Sleeboom-Faulkner, 2006; Stainton, 1999; Tai and Chiou, 2008). Beginning the early 1990s, the

scientific theory that Taiwan is the homeland of the Austronesian peoples whose languages are spoken in a broad band across the Pacific through Southeast Asian to Madagascar, was popularized in Taiwan. Taiwan researchers integrated advancing transnational scientific knowledge with their responsibilities to advance the Taiwan-centred identity project begun under Taiwan President Lee Teng-hui's administration in the early 1990s to replace One-China ideologies (Sleeboom-Faulkner, 2006).

Yet the paternalistic manner in which genetic researchers have considered that they can go into Aboriginal territories to obtain genetic samples and related information without proper informed consent, has been an escalating source of conflict because it violates Aborigines' individual and political autonomy. Aborigines had publicly complained about such abuses since the late 1990s ("Aborigines in Test Tubes," 1999; Chou, 2007; Liu, 2000; Tai and Chiou, 2008). Furthermore, researchers' statements on Aboriginal origins can have negative impacts on Aboriginal peoples. These two aspects came together in the following case. In the early 2000s, Lin Ma-li, a famous genetic researcher in Taiwan, publicly stated that the Taiwan Ping-pu ("Plains") Aborigines, which includes the Kavalan, were extinct (Lin, 2001).<sup>5</sup> Lin's statements upset Kavalan and other Ping-pu Aboriginal activists who were trying to rebuild their cultural identity (Shu Jing-ru, 2007). Lin later changed her views and began to argue that many if not most Taiwanese settlers had some Aboriginal ancestry. Later in January 2007, a team of researchers led by Lin Ma-li went to the Kavalan Aboriginal village of Xinshe in Hualien County to obtain samples for an Austronesian origins related research project (Tai and Chiou, 2008; Zhang, 2007). Lin said she obtained permission from a village elder to do the research and chose to sample saliva, not blood which is considered more sacred and therefore more contentious (Tai and Chiou, 2008:113). However, as news of the saliva sampling spread, concerns about informed consent violations grew, so shortly thereafter the Kavalan Development Association (a community NGO) held a public meeting in Xinshe (Chen and Zhang, 2007; Tai and Chiou, 2008). At the meeting it was decided to file a complaint with the Taiwan National Science Council arguing that Lin had violated *Section 21* of the *Indigenous Peoples Basic Law* by not consulting with the community as a whole before taking the samples (Chen and Zhang, 2007; Tai and Chiou, 2008). The Association met with some success, for on April 2 2007 the 29 saliva samples were returned to the village and dumped in a ditch in a brief 15 minute ceremony (Zhang, 2007). In press coverage, Lin Ma-li expressed her surprise and confusion, saying she had never encountered anything like this in all her years of research (Zhang, 2007; Chen Hui-hui, 2007).

The Xinshe case reveals a major ethical challenge in terms of the interests of Aborigines as research participants and the general population. Both the individuals and the Aboriginal population being studied were, in fact, "subjects" of the research (Greely, 2001). The Xinshe case shows that not only collective but also individual informed consent can be rendered ineffective through lack of concern by researchers (Tai and Chiou, 2008). For instance, the cursory nature of individual informed consent in practice was evident in the account given by a Xinshe elder named Pan A-Yu (Tai and Chiou, 2008; Zhang, 2007). Pan told *United Daily News* that she was riding her motorcycle when a researcher waved her over and asked her to participate in the project (Zhang, 2007). Pan agreed and went into a local restaurant where the sampling was taking place. At first, she said her mouth was too dry to give a saliva sample, so the researchers gave her water and waited for her to be able to give a sample (Zhang, 2007). However, the informed consent form contained only one sentence on the purpose of the study and researchers did not make any sort of any effort to further explain to her about the purposes of the research project (Tai and Chiou, 2008; Zhang, 2007). She said she simply signed the consent forms because she saw other people from her village that she trusted sign their consent forms (Zhang, 2007).

Despite such accounts, when the censure arrived, the Taiwan National Science Council's public statement sought to minimize the magnitude of the ethical violations. The statement outlined the project's purpose as Austronesian research but then abruptly concluded that there was accidental "miscommunication" thereby absolving Lin of the more severe ethical charges of research misconduct ("Tracing Austronesian," 2007). The NSC did not proceed with any further inquiries into the violations, in effect denying full consideration of Aboriginal rights. This wording reduced the violation to a procedural issue, which contradicts the evidence that Lin's research team had not only failed to properly consult with the community of Xinshe but as the account given by Pan A-Yu indicates, that individual informed consent also was carried out in a haphazard cursory manner.

In a 2008 newspaper article, Lin reasserted her duty to study Taiwan Aborigines but this time in order to help Aborigines' health. Lin argued that the provisions of the *Indigenous Peoples Basic Law* requiring collective informed consent were vague (Lin, 2008). More disparagingly, she argued such provisions were a threat to Aborigines' health as they would reduce research on Aborigines and even undermine individual privacy of medical information (Lin, 2008). Lin's rendering of collective consent as a threat to Aborigines' health is misleading (something of a

red-herring) because her research involving Aborigines has primarily been on their origins, not any specific health issues.

The Xinshe community case is significant as it involved the first censure, albeit minor, of a senior genetic researcher for ethics violations involving Taiwan Aborigines. International guidelines discuss that some kind of consent or at least consultation with a population as a whole should be required, in addition to individual informed consent (Greely, 2001). The case shows how Aboriginal rights and autonomy can affect researchers' ethical conduct but that violating these still has minimal long term repercussions for researchers.

### 2.3 Case 3: "My blood, your patent"

Scientists conducting research into Aboriginal health can run into conflicts between their ethical and moral duties to advance biotechnology development and to respect Aboriginal rights. The case of Ko Ying-chin applying for patents based on gout research involving over 1500 Atayal Aborigines involves the integration of Taiwan's national health care system and government science council funding with state biotechnology development efforts. This case has not yet been discussed anywhere in the bioethics literature. It shows how respect for Aboriginal rights is clearly restricted by the conversion of national populations into strategic resources for biotechnology development. The central figure, Dr. Ko Ying-chin has been conducting research on Taiwan Aborigines for about 20 years. Ko is arguably Taiwan's most influential Aboriginal health researcher, receiving awards for his work from the Taiwan President's Office and the Taiwan government's Council of Indigenous Peoples ("Vice-President: Ko Ying-chin," 2008).

Increasingly, researchers are encouraged to commercialize research through changes in legislation that allow government funded research to be commercialized. According to the *Fundamental Science and Technology Act*:

*For the purpose of promoting the research and development results of applied scientific and technological projects funded by the government, the government shall supervise or assist the research organizations and units mentioned in the preceding Paragraph to industrialize or commercialize their research results (Article 5).*

Implicit in such legislation are expectations that researchers will take on duties and obligations to commercialize their research to advance economic development. Such duties are further encouraged and reinforced through significant financial and organizational resources dedicated to

the development of biotechnology as discussed earlier.

An initial gout related health research project involving 154 Atayal Aborigines led to Ko and Cheng Li Shu-Chuan filing patent applications in the US and Taiwan for a "gout related genetic locus" in 2003 (Ko and Chuang, 2005a, 2005b). Ko and another colleague Tsai Shih-feng subsequently ramped up this line of gout related research (which focuses on an area of chromosome four) with a new series of grants totalling over \$11 million Taiwan dollars (over US\$300,000) from the Taiwan National Science Council and increased the number of research subjects nearly tenfold to over 1500 Atayal Aborigines (Ko and Tsai, 2009a, 2009b; Ko 2010a, 2010b; "Genetic Polymorphism of Chromosome 4q22-25": 2006, 2007, 2008). This multiyear project has thus far led to another two US patent applications and two Taiwan patent applications (Ko and Tsai, 2009a, 2009b; Ko 2010a, 2010b).<sup>6</sup> The US patent applications indicate Ko gained individual informed consent and he claims to have collective informed consent for the research (Taiwan Indigenous Television, 2009). Critically, however, he publicly stated in a Taiwan Indigenous Television report entitled "My blood, your patent," that he did not gain consent for the commercial patent applications because it was not legally required (Taiwan Indigenous Television, 2009). However, clearly Ko has violated *Section 21* which articulates a set of equitable and reciprocal relationships between researchers and involved Aboriginal communities. Though *Section 21* is still without any sort of enforceable legal statues, one could still say ethically researchers have a duty to try to accord with *Section 21*. Certainly *Section 24* of the *Declaration of Helsinki* (World Medical Association, 2008) already sets a clear precedent with the requirement that researchers reveal any conflicts of interest. Indeed, Ko might be expected to abide by a higher set of ethical standards in the absence of enforceable laws since he has received awards for his research on Aboriginal health and given lectures on bioethics to the Taiwan Biobank and to students at Kaohsiung Medical University ("Bioethics/Biomedical Research," 2006; "Course Schedule," 2007). However, Ko has adopted a long-term minimal interpretation of his potential duties to inform research subjects. He has not considered it necessary to abide by the *Declaration of Helsinki's* principle of full disclosure of his intentions including conflicts of interest, which involves a sustained denial of Aboriginal participants' rights. Furthermore, we have a situation in which Ko fully exploits the legal void surrounding implementation of *Section 21* in order to pursue the patent applications.

### 2.3.1 "Catch me if you can" ethics

Why did Ko adopt a minimal interpretation of his potential duties to inform research subjects? It appears what is good for business is bad for ethics and vice-versa. Aboriginal collective informed consent is a complex set of negotiations that would require extensive organizing efforts spread over a long period of time with consultations and follow-ups in an ongoing relationship. It is easier and cheaper just to ignore it and say that it is not legally required. Without any penalties for non-compliance and with many costs involved in compliance, researchers like Ko have no incentive to fulfil the spirit of *Section 21*. Ko and the Taiwan National Health Research Institutes only withdrew the second US patent application following an investigation by the international NGO on social justice and technology, the ETC Group in 2009 which subsequently led to national media coverage and a major controversy including public criticism by Taiwan human rights and Aboriginal organizations (*Taiwan Today*, 2010a, 2010b).<sup>7</sup> Ko has not withdrawn the third US patent application nor withdrawn any of the three Taiwan patent applications since these have not yet been publicized, so he has not faced any pressure over them. Ko's actions indicate he is only willing to move under strong public pressure and if that pressure is not there, he will follow the minimal interpretation of Aboriginal rights that fits readily with commercialization. Ko's abilities to engage in these violations of Aboriginal rights are furthered by the conflicts of interest in which institutional duties to commercialize research override their obligations to respect Aboriginal rights. The involved main institutions have contradictory roles in providing ethical oversight for research in which they have commercial interests, which violates *Article 15* of the *Declaration of Helsinki* that mandates that institutional review boards "...must be independent of the researcher, the sponsor and any other undue influence" (World Medical Association, 2008). In the first patent, Ko Ying-chin and Cheng Li Shu-chuan were the assignees (Ko and Cheng, 2005b). In the second US patent application, the assignee was the Taiwan National Health Research Institutes which also provided IRB approval for the research project, and where Ko Ying-chin is also a research fellow (Ko and Tsai, 2009b). In the third US patent application, the assignee is Kaohsiung Medical University which also provided IRB approval and where Ko Ying-chin is a vice-president (Ko, 2010a, 2010b). In this situation, researcher duties conflict within a set of institutional relationships so oversight procedures become severely skewed toward commercial considerations including maintaining secrecy of the invention until the patent application is filed.

## Research paternalism and Aboriginal autonomy

Will a proper understanding of the respect for autonomy principle involve drawing a line between justified and unjustified paternalism? (Scoccia, 1990). Generally, paternalistic actions are justified by claiming that more good than harm is produced. In other words, paternalistic decisions are justified to promote the bioethical principles of beneficence and nonmaleficence. The underlying reasoning behind the dilemma of scientific duty and Aboriginal rights is the difficulty to compare the importance of paternalism, the principle of beneficence and nonmaleficence and the principle of respecting Aboriginal autonomy as individuals and politically as a people. If the concept of paternalism is analysed with reference to the necessity of truth telling, in our three reported cases, researcher's paternalism has seemed to undermine Aborigines' autonomy even if no direct harm was involved. Even if the principle of beneficence and nonmaleficence shapes the ethical frame of the researcher's paternalism, arguably, the three previous cases show that researcher duties cannot be a reason to override Aborigines' autonomy and their rights to make a fully informed decision to participate based on clear understanding, and if desired later, to withdraw from the research.

Although it is still argued by some that the regulatory system for human research is justifiably paternalistic (Miller and Wertheimer, 2007), the dominant philosophical view has privileged respect for autonomy as a guiding principle over the paternalistic one. But this common philosophical view does not rule out all forms of paternalism. In our three previous cases, the disrespect of autonomy of Aboriginal right brings a threat to Aboriginal capacity for self-determination as a group, but on an individual level, where Aboriginal need assistance, a soft paternalism could have been defended. Being an autonomous population, however, is not the same as a soft paternalistic respect for an autonomous Aboriginal individual. To acknowledge Aboriginal persons' rights is to respect them as autonomous agents, a respect involving not only researchers refraining from interfering with Aborigines' individual choices, but providing Aborigines with the necessary conditions and opportunities for exercising autonomy as a group. In the three cases, researchers have seemed to extend their soft paternalism from individuals to a strong paternalism on the whole Aboriginal population. There is a paternalistic ethical disjuncture, for instance, in how the Biobank planners initially failed to consult with Aboriginal peoples or in how Ko considers he is advancing Aboriginal interests by engaging in gout research project and filing patent applications yet he did not tell Aborigines about such commercialization. Ko did not consider it necessary to

engage in an open dialogue including explaining the conflicts of interest with Aborigines as part of the informed consent process which is mandated by the *Declaration of Helsinki* (article 24) and we would argue is strongly implied in *Section 21* of the *Taiwan Indigenous Peoples Basic Law*.

The paternalistic attitude shown by scientists in these three cases towards Aborigines at collective level may derive from fundamental conflicts between researchers' various duties including commercializing genetic research findings and improving the health of the population backed by numerous government resources and legal rights versus recognition and respect for Aboriginal rights and political autonomy. In these cases, researchers' paternalism interferes with their recognition of Aboriginal autonomy. Therefore, if researchers are to engage in beneficence toward Aborigines collectively, they should follow the sort of open, dialogical, and extended relationships sketched out in *Section 21* in which Aboriginal peoples' rights and autonomy have priority over the researchers' duties.

### **Reconciling Aboriginal rights and researcher duties: Using law to establish ethics?**

Proponents of the Taiwan Biobank initially rejected Aboriginal concerns as unfounded, while Lin Ma-li and Ko Ying-chin have publicly complained and challenged informed consent requirements in various ways as infringements on their prerogatives as researchers and interfering with research on Aboriginal health, with Lin asserting it was a threat to Aborigines' privacy and health. Such criticism of Aboriginal rights is typical of the paternalistic culture among some genetic researchers. Could a stronger ethical regulation reconcile Aboriginal rights and research duties?

In short, reconciling these may only occur if ethics is transformed into practice backed by the force of law and other penalties. According to *Article 10* of the *Declaration of Helsinki*, ethical considerations must always take precedence over laws and regulations (World Medical Association, 2008). Nevertheless, these examples of genetic research violations reflect the deeply rooted and pervasive anti-Aboriginal discrimination in settler society, discrimination which backed by powerful economic and social forces. Therefore, these examples point towards the need to use critical bioethical approaches that consider such larger contexts (Hedgecoe, 2005; Twine, 2005: 287). Right now despite having some laws on the books, there are no professional or legal penalties as disincentives to researchers. This lack of strong punitive legal

disincentives when combined with competitive pressures to publish and patent, means that researchers who do respect Aboriginal rights are actually penalized in a market for knowledge. Why should researchers bother with Aboriginal rights when they do not have to, particularly in the highly competitive national and transnational markets for scientific information? Consideration of Aboriginal rights is costly for genetic researchers, requiring extended negotiations and allowing Aborigines the potential to veto research projects that may already represent considerable investments of resources and effort by researchers. Furthermore, Aboriginal consultations may risk prematurely publicizing research intentions which would undermine secrecy required for patent application processes. Marginalizing and violating Aboriginal rights concerns therefore makes sense (and cents) both academically in terms of maximizing available research resources, and commercializing research findings.

The extensive resources accorded by the Taiwan government to biotechnology stand in sharp contrast to the attention given to relevant sections of the *Indigenous Peoples Basic Law* which has no appropriate regulations to enforce them. Though *Section 34* of the *Basic Law* states "The relevant authority shall amend, make or repeal relevant regulations in accordance with the principles of this law within three years from it" taking effect in 2005, over five years after the *Basic Law* was passed, there is still no legislation that puts *Section 21* or other relevant sections into practice. Therefore, there is no significant legal pressure and no incentives for researchers to respect Aboriginal rights and negotiate with Aboriginal peoples in accordance with broad and sustained equitable relations set out in *Section 21*, unless Aborigines are able to mobilize significant coalitions to enforce such a set of relationships as they were able to in the Taiwan Biobank and the Lin Ma-li cases.

In order to counter such pressures, we recommend that there should be a set of positive incentives but also punitive disincentives in order to have Taiwanese researchers to thoroughly integrate respect for Aboriginal rights into their research practices. Ethical regulation backed by substantial and significant disincentives and penalties including professional condemnation and legal penalties including funding bans and bans on any use of findings from unethical research would be major steps in the right direction. In the past, colonial governments disregarded Aboriginal rights, dignity and lives in their colonization practices. If Taiwan purports to be a democratic state with full respect for human rights and equality before the law, then Aboriginal rights must be accorded something more than nominal attention among its scientific policy forming elites, funding agencies, and senior scientists. For instance, Ko's actions are all the more reprehensible since he also sets

a poor example to other researchers on how to do research involving Aboriginal peoples. The closest that Taiwan science establishment has come to professional condemnation in the censure of Lin Ma-li which was phrased as involving "miscommunication" and failed to more fully consider the violations. As well, the US Patent and Trademark Office and national patent offices elsewhere, must have a stronger set of rules over whether informed consent has been obtained for patent applications based on genetic research involving Aboriginal peoples. Setting such morally high ethical and legal standards throughout the research processes from initiation to any end-uses would pressure researchers to ensure informed consent is carried out properly.

Ethical regulation requiring a more inclusive and ultimately precautionary principle in dealing with Aboriginal peoples would in the final assessment place priority on Aboriginal rights over other concerns. This ethical regulation is needed to counter any utilitarian calculus of greatest good for the greatest number, which invariably favours settler majorities in national development agendas. In effect, Aboriginal peoples at collective *and* individual levels must be able to exercise effective veto power over any research involving them. This veto then places an incentive on researchers to negotiate and reach a mutually agreeable consensus, one that takes Aboriginal concerns and worldviews into respectful consideration (Varelius, 2008). As well, both individual and collective informed consent must be practiced, an important aspect of the latter being consensual understanding so that Aboriginal peoples can debate within their communities over the impacts of research (Tai and Chiou, 2008). Individual informed consent is still important in that it respects individual rights and acts as check on the potential problem of unrepresentative or unaccountable authorities (including local leaders) approving research projects on behalf of Aboriginal communities without first conducting community level consultations (Andanda, 2005:26; UNESCO, 2005, Article 6 Section 3).

Involved Aboriginal peoples are collectively subject to possible benefits and harms from the research and have interests, somewhat different from those of the individuals. In particular, because genes are considered as units of inheritance that link generations, it is critical to consider issues of intergenerational justice. Research inscribes genes with particular traits and meanings, so genetic research that attributes alcoholism and disease to genetic factors while ignoring larger social contexts of poverty and social upheaval affects not only living individual subjects but also the group as whole including past, present, and future generations. Such research can unjustly misattribute to genetic causes high rates of morbidity and mortality, thereby absolving settler states

of responsibilities for systemic racism imposed upon past, present, and future generations of Aboriginal peoples. Therefore, it is imperative that Aboriginal communities have a central role in research involving them, something which is also consistent with concepts of the sacredness of blood among many Taiwan Aborigines (Liu, 2000) and the concepts of guardianship in which living generations must show care of the land (Lin, Chang, and Tsai et al, 2005:13). These concepts view genetics in terms of a sacred responsibility inherited from the ancestors and managed for the well-being of future generations (Reynolds, 2004:16, 212).

Substantially stronger regulations with significant legal penalties might be one possible means to install this ethical frame. Yet without an effective enforcement mechanism we cannot ascribe any hope to this. For instance, Ko Ying-chin blatantly violated what can be called the spirit of *Section 21*. When caught, Ko even tried to deflect criticism and in effect buy-off Aborigines with a vague promise of revenue sharing of any patent proceeds with Aboriginal organizations (Taiwan Indigenous Television, 2009). Though he and the Taiwan National Health Research Institutes were criticized and pressured enough to drop the second US patent application, Ko has not faced any formal censure or any legal repercussions, he has not even apologized. Though the case received some press coverage in late March 2010, it rapidly dropped off the radar. Ko still has over 1500 Atayal samples plus the others he has collected over the years to do with as he sees fit. As well, Ko still has the third US patent application and all three Taiwan patent applications pending. Ko is an example of how the convergence of genetic research and national biotechnology development readily takes precedence over Aboriginal rights. Ko and his colleagues decided what rights Atayal Aboriginal research subjects had without consultation with involved Atayal Aboriginal communities or participants. It is this power of senior scientists to unilaterally decide to a large extent what rights Aborigines have that severely weakens the apparent advances of the *Indigenous Peoples Basic Law*.

In June 2010, a number of Taiwan mass media stories credited the earlier March 2010 national controversy over the Ko Ying-chin patent application case with pushing the Taiwan government to approve new draft legislation on ethical treatment of human research subjects (for e.g. "Unauthorized human research," 2010; Taiwan Today, 2010b). The draft legislation contains fines of NT\$100,000(US\$3,125) and NT\$1 million (US\$31250) (Taiwan Today, 2010b). However, the Taiwan government has to date been lax in enforcing settlements in favour of Aborigines against powerful business interests.<sup>8</sup> There are a powerful

array of actors and political-economic forces involved in genetic research. Therefore, even if these draft laws are passed, they will likely only be effective provided involved Aboriginal communities are able to organize strong enough networks to pressure researchers. Such Aboriginal networks would likely have to span not only the Taiwan state institutions like the courts and Council of Indigenous Peoples but also some combination of national human rights organizations, international NGOs, and transnational Aboriginal rights forums. The enforcement of Aboriginal rights is therefore politically contingent, and fraught with inequities since senior scientists and science policy planners have virtually unlimited resources to engage in violations of Aboriginal rights but Aboriginal peoples have only limited resources to counter such violations.

There is an important caveat about collective informed consent. It is not a panacea. What it means and should incur are still very much issues of debate, which would have to be negotiated on a case by case basis, including what communities need, want, and even who communities are (Schüklenk and Kleinsmidt, 2006, 131-2). Though it would increase costs and complexity of research, requiring such communal knowledge and decision making through dialogues between researchers and involved Aboriginal communities are necessary to prevent abuses. In general, demanding such high requirements will pressure researchers to act with sincerity and respect towards Aboriginal participants and communities.

## Conclusion

The three cases analysed in this paper indicate major conflicts between researcher duties and Aboriginal rights remain a problem in Taiwan. The *Declaration of Helsinki* and *Section 21* of the *Indigenous Peoples Basic Law* set out the ideal of full disclosure and informed consent, premised upon equitable relationships between researchers and research subjects that are mutually respectful. In particular, there is a strong implication that researchers should err on the side of caution rather than unilaterally act in such a way as to restrict Aboriginal peoples' rights through often cavalier disregard of consultation in planning major research project, violations of informed consent, and failure to fully disclose research projects' commercial interests. In the three cases, Taiwan researchers show a strong resistance to more fully consider Aboriginal peoples rights in their research. It appears that full consideration of Aboriginal rights and autonomy is viewed by scientists involved in these three cases as impediments to research and in the third case as

impediments to commercialization of research. This view is typical of the larger problems in the implementation of Aboriginal rights' legislation. Laws are only effective when enforced and to date there is no legal disincentive for researchers to comply and plenty of incentives to disregard Aboriginal rights. It is this view of Aboriginal rights as impediments to research that must be replaced by equitable reciprocal relations.

Conflicts of interest: Mark Munsterhjelm found the US patent applications filed by Ko Ying-chin and his colleagues. He passed this information to the ETC Group and provided some assistance to Taiwan Indigenous Television and United Daily News in their reporting on this case. Fredrick Gilbert has no conflicts of interest.

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## Notes:

1. The Dutch colonization began in the south-west near present day Tainan in 1624. The Spanish established a colony at Keelung in the north tip of the island in 1626. In 1642, the Dutch defeated the Spanish.
2. The KMT military regime murdered and imprisoned a number of Aboriginal leaders and intellectuals during the period of political repression called the "White Terror" that began in the late 1940s and lasted until the 1980s.
3. Malinowski cites these Academia Sinica warfarin findings in his advocacy of using racial categories in genetic research (Malinowski, 2009:1489-1490).
4. Lin and Rin (1962:138) found rates of 0.0% to 0.16% in fieldwork done between 1949-1953 among the Paiwan, Atayal, Saisiat, and Ami (Pangcah).
5. For example, Lin wrote, "由於其他平埔族現在差不多已消失, 無法追蹤檢驗..." which translates as "Because Pingpu peoples have nearly disappeared we cannot trace them..." (Lin, 2001:243).

6. This first application was eventually rejected by the US Patent and Trademark Office for being too vague and conflicting with existing patents (Kapushoc, 2006, 2007).
7. One of Taiwan's major daily newspapers, the *United Daily News* did a feature report on March 22 2010 with 5 articles on various aspects of the Ko Ying-chin case. This coverage led to sharp criticism and the withdrawal of the patent application on March 23 2010 (Ko and Tsai, 2009a; Taiwan Today, 2010a).
8. A particularly glaring example is an August 2000 Taiwan court decision that returned to a small amount of land to Truku Aboriginal land owners that had been illegally occupied by the Asia Cement Company since the early 1970s (Shiban, 1997; Chuang Chi-ting, 2001). Despite a number of Aboriginal protests and some international attention the Asia Cement Company, which is owned by the powerful and politically well connected Far Eastern Group, has continued to defy the court decision (Shiban, 1997; Chuang Chi-ting, 2001).