

# Equality and Community in Public Deliberation: Genetic Democracy in Taiwan

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## 1 Introduction

In 2004, the Science and Technology Advisory Group in the Executive Branch of Taiwan's government made a policy recommendation, which was subsequently adopted, that Taiwan should strive to become an "island of biomedical technology" if it is to seek a better prospect for economic growth in the near future. Three infrastructure objectives were put forward together with this national goal: (1) to digitalize all health records kept by the Bureau of National Health Insurance in Taiwan, (2) to institute a sound regulatory framework for clinical research, and (3) to establish a Taiwan Biobank.<sup>1</sup> These are interconnected and definitely challenging tasks. In order to pave the way for accomplishing the third objective in particular, the National Science Council of Taiwan requested the Institute of Biomedical Sciences (IBMS) at Academia Sinica, the highest-ranking academic institution for basic research in the nation, to draft a blueprint of the envisaged large-scale human genetic repository and to conduct pilot study on its feasibility. Well aware of the ethical, legal and social issues (ELSI) that might be involved in this endeavor, the IBMS invited a team of scholars, who had been conducting ELSI-related research funded by the National Science Council, to collaborate with biomedical experts in order to work out a regulatory framework for the Taiwan Biobank. Such a framework has been duly recognized as essential to the success of the Taiwan Biobank Project, which, once officially launched, is obviously in need of long-term public trust and support.

However, the pilot project undertaken by the IBMS since 2005 has repeatedly encountered stern criticisms in the national news media. It is noteworthy that not only are these criticisms directed to issues about protection of genetic privacy, but they also call for public deliberation on the acceptability of such a large-scale genetic database. During the last decade, Taiwan has been undergoing a rapid process of democratization, and nowadays a strong conviction can easily be detected in

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public discourse that such basic values in a pluralistic democratic society as personal autonomy and social justice should be accorded moral weight to be balanced against the familiar appeal to national prosperity or general welfare. This prevailing ethos in Taiwan has added attractiveness to the claim that the Taiwan Biobank Project should be scrutinized through public deliberation, especially in view of the fact that the Project will consume a large amount of public funds and require the willingness and long-term participation of a great number of ordinary citizens. How such deliberation is supposed to be carried out and, more importantly, how the requisite deliberative process is to be organized in the first place are admittedly difficult questions (the solution to which may itself require consensus). Nevertheless, it seems safe to say beforehand that since indigenous peoples are one of the four populations targeted by the Taiwan Biobank, whether or not they, as a social group or community that has long suffered various sorts of inequalities, can *really* (not only formally) have an equal representation in the deliberative process in question may serve as a litmus test for the adequacy and trustworthiness of such a process.

As will be explained later in this chapter, a recent event in which members of an aboriginal tribe jointly requested withdrawal from a genetic research highlights the urgency of this question, and makes it even more complicated: representatives of the tribe argued not only that the procedure for individual informed consent had been poorly conducted, but also that, according to the Basic Laws of Indigenous Peoples promulgated just recently in 2005, researchers should have consulted the tribe so as to obtain tribal consent. This event made national headline news with a full-page report, and so far the tribe's claim about the necessity of prior tribal consent has not been questioned. Thus, it seems, a similar claim can also be made, by appealing to the Basic Law, that community consent of the indigenous peoples in Taiwan should be obtained through *some* form of public deliberation among them if the Taiwan Biobank Project is to include them as one of its target populations. If this is an acceptable claim, then in case the indigenous peoples decide through public deliberation to give their *dissent* to the Taiwan Biobank Project, this will amount to a veto over the right of their individual members to decide for themselves whether or not to participate in the Project. Such a consequence may sound unsettling to anyone who takes individual rights to be fundamental.

In this chapter, we will first describe how Taiwan has endeavored to move ahead toward establishing a large human genetic repository, the Taiwan Biobank, for research in the post-genomic era, and what ethical, legal and social issues have been raised by this project. Against this background, we will argue that, while it is necessary for the democratic legitimacy of the Taiwan Biobank that its ethics and governance framework be subjected to the scrutiny of a (suitably designed) public deliberative process, the requirement that community consent of indigenous peoples be obtained before their individual members can exercise their right to decide whether or not to participate does not have to vitiate the fundamental status of individual rights. On the contrary, such community consent may empower members of the indigenous communities, enabling individuals to exercise their rights more substantively than without prior consent of the long exploited, disadvantaged and vulnerable communities to which they belong.

But we will argue against the need for indiscriminate prior public consent concerning (what we call) internal arrangements of a biobanking project at the national level over individual consent. In our view, while public deliberation at this level must proceed against the background of certain institutions and public policies that must be accountably determined and put in place to regulate the Taiwan Biobank “from the outside,” the deliberation on internal arrangements needs only to yield reasoned judgments, pros and cons, that may be taken into account by individual citizens when they come to make their own decision as to whether the Taiwan Biobank Project is worthy of their trust and participation.

## 2 Design of the Taiwan Biobank

Taiwan Biobank is intended primarily to be a population-based human genetic repository for prospective cohort studies on the interaction between environmental and genetic factors in the etiology of various chronic diseases common in Taiwan such as cancers, cardiovascular diseases, diabetes, hepatitis, hepatocirrhosis, etc. It aims to collect and store blood samples and lifestyle information from 200,000 participants aged 40–70, with linkage to their health records kept by the Bureau of National Health Insurance. The target populations include: (1) people of Fu-kien, or Hoklo, descent (immigrants of the 19th century or earlier from mainland China); (2) people of Hakka descent (immigrants of the 19th century or earlier from the mainland); (3) the so-called “mainlanders,” a group name coined in the mid-20th century to refer to people who came to Taiwan when the nationalist government took refuge in the island in 1949 after its defeat by the Chinese communists; and finally, (4) indigenous peoples, the earliest inhabitants of Taiwan who were forced by later settlers over the last four centuries or so to retreat to mountainous areas and less developed eastern shores.

A survey conducted by the Council of Hakka Affairs in 2004 shows that when asked about one’s ethnic identity, with multiple choices allowed, 80 % of those interviewed regarded themselves as Hoklos, 22.4 % as Hakkas, 13.1 % as “mainlanders,” and 5.3 % as indigenes. While this may give a good idea of the relative sizes of different populations in Taiwan today, it also shows considerable intermixing among them. In order to establish a repository that is recognizably population-based, the plan for the Taiwan Biobank is to recruit participants in the following three locations: Miao-li county in northern Taiwan, where the majority residents are of Hakka descent; Jia-yi city in the south, a typical Hoklo area; and the Hua-lien county at the east coast, where the indigenous population is much larger than elsewhere in Taiwan. The mainlanders, though a minority in all three locations, are of a sufficient size in each location to be included as a target population in the Taiwan Biobank.

In view of the highly controversial nature of such a large-scale genetic database, Taiwan’s government decided in 2005 to explore its feasibility through an NSC-funded pilot project, to be carried out by the IBMS of Academia Sinica. The pilot project was aimed at recruiting 1,000 participants (in Jia-yi city) to evaluate the

rationality and reasonableness of protocol procedures to be used when the Taiwan Biobank Project gets officially under way. After the proposal of the pilot project went to the Research Ethics Committee of Academia Sinica for review, a conspicuous commentary appeared in a national newspaper *China Times* in January 2006, raising several important questions about confidentiality, informed consent and benefit sharing.<sup>2</sup> The author of the commentary demanded that the entire plan for Taiwan Biobank be made public and subjected to open debate. The commentary accused the IBMS of having been secretly taking some ethically dubious first steps toward establishing the Taiwan Biobank by collecting as many as 3,000 blood samples in the east coast. Such accusation proves to stem from misinformation, for, strictly speaking, no blood sample has ever been collected so far under the name of the Taiwan Biobank Project. While the commentary may have mistaken another, less-noticed genetic database project of the IBMS (which is equally in need of public scrutiny) for the Taiwan Biobank Project, it attests to the widespread distrust of genetic research enterprises.

### 3 Unfavorable Circumstances

It is unfortunate that the plan for a Taiwan Biobank was proposed under circumstances that made public trust difficult to attain. First of all, there have been high-profile incidents in which supposedly confidential personal information of credit-card holders was leaked to people who used the information to commit fraud. These incidents gave rise to heightened awareness on the part of the general public about the importance of privacy protection. At the same time, dissatisfaction with the government's capacities to protect personal privacy has also been on the rise. Failing to appreciate the extent of public distrust and scepticism, the Department of Health once intended to issue an all-embracing IC version of the national health insurance cards that carry both personal health records and other personal information, but eventually settled for a much truncated version because of strong opposition.<sup>3</sup> More recently, a newly passed law authorizing the Ministry of Internal Affairs to require citizens to leave fingerprints before getting their renewed national ID cards was soon declared unconstitutional by the Constitutional Court on the ground that the law infringed upon informational privacy.<sup>4</sup>

In the last two years, the Department of Health has begun to review and improve its regulations of research involving human subjects. Though never too late to make, this move is long overdue. The indigenes, in particular, have been persistent victims of a long history of exploitation in which researchers often went to tribal villages to covertly collect blood samples under the guise of "free health checks." A news report even quoted a villager as saying that in just one year he gave blood "eight" times—meaning, perhaps, "several" times in his native tongue—for "free health checks."<sup>5</sup> Moreover, the Bureau of Health Promotion has been offering indigenous elderly two physical examinations per year for free, but, lacking a sound monitoring procedure, this well-intentioned health policy has unfortunately made the examinees

vulnerable to surreptitious, unconsented extraction of more blood from them than is necessary for the proclaimed purpose.<sup>6</sup> Worse still, even today one still finds that the registration form of a major hospital in an east-coast county<sup>7</sup> requires indigenous patients to fill in tribal origins of their parents and grandparents—something that is absolutely unnecessary for diagnostic or therapeutic purposes.

City folks in Taiwan have not been free from worries about similar abuses befalling them. In 2005 the Consumers' Foundation of Taiwan pointed out in a press conference that "[p]atients have no obligation to act like 'mice in the lab' for physicians and researchers." According to the Foundation, a physician at a prestigious military hospital in the capital city Taipei collected blood samples for research use without going through the informed consent procedure properly. It was alleged, with good reason we think, that the physician had failed to discern possible conflict between the role of a physician and that of a medical researcher, so that his (or her) patients might have signed what was actually the consent form for donating their blood samples, thinking that this was only for treatment of their illness.

Given such an atmosphere of distrust and suspicion, it seems safe to assume that the public tend to be concerned more with the protection of their basic rights than with the promotion of general welfare in health care through medical research. Thus, in January 2006, the *China Times* was keen enough to issue a full-page special report on ethical issues over the Taiwan Biobank Project shortly after the appearance of the critical commentary mentioned above. The *China Times* ran a provocative headline on the front page that day: "Academia Sinica Plans to Pry into People's Privacy."<sup>8</sup> The special report led to follow-up coverage by major TV news channels. Deliberating under this climate of public distrust, the Research Ethics Committee of Academia Sinica finally approved the pilot project on the feasibility of Taiwan Biobank, but only on the condition that there should be *no actual collection of blood samples* taking place at this early stage.

## 4 Individual Consent is Not Enough

Critics of the Taiwan Biobank Project argue that individual consent to participation ought to be obtained by appeal to altruism, and through forthright account of possible risks and benefits not only to individual participants but also to family members and different social groups. Moreover, they argue for benefit sharing, and for some form of collective or social consent that is to be obtained through an appropriate deliberative process if the Taiwan Biobank Project is to proceed in any legitimate way.

This appeal to social consent raises important questions. Inevitably, public deliberation can only involve a *limited* number of (suitably selected) representatives. Suppose that the outcome of such deliberation is that the Taiwan Biobank Project is in the opinion of the deliberators *not* worthy of public trust, or even ethically flawed, and should therefore be rejected. This outcome will very likely influence public opinion and bring about strong opposition to the Project. But why should this outcome

be binding on those who did not participate in the deliberative process? Suppose that there are still some individuals in the society who disagree with the outcome of public deliberation and whose considered judgment is that they should, despite the outcome, be left free to decide on their own whether or not to participate in the Project—just as they should be left free to do so even if public deliberation results in unanimous consent to the Project. Can't these people give their individual consent to participate in the Taiwan Biobank Project *in spite of* the dissent, if any, arrived at through public deliberation? Does public deliberation carry enough moral weight to make an individual's decision to act contrary to its conclusion morally *unjustified*? If, after considering the case in an unobjectionably informed way, one decides to participate, then isn't it morally permissible for one to do so? What grounds can there be for conferring upon public deliberation a moral veto power over individual consent?

An answer to these questions seems to be suggested by Onora O'Neill's criticisms of individual informed consent as it has been traditionally understood. O'Neill first points out a problem—a "philosophical weakness," as she puts it—that she thinks is inherent in individual informed consent. Consent is a "propositional attitude" that is "referentially opaque": a propositional attitude is a mental state with propositional content, and it is "referentially opaque" just in case its content cannot be replaced by its logical equivalent or any of its implications without falsely attributing the resultant attitude to the subject of the original attitude.<sup>9</sup> For example, *belief* is a propositional attitude with referentially opaque content, for supposing that I believe Mark Twain is the author of *The Adventures of Huckleberry Finn*, then even though Mark Twain is actually the pseudonym of someone known as Samuel Clemens, you cannot validly infer that I also believe Samuel Clemens is the author of *The Adventures of Huckleberry Finn* (for I may be unaware that Mark Twain *is* Samuel Clemens). *Consent* is like *belief* in this respect. Even if I give my consent to a medical treatment on the basis of what is explicitly written in a consent form, I may be unable to comprehend all that is implied by the actual contents of the consent form, and it is possible that I would have, instead, *dissented* if I had known some of their implications.

The upshot is that it is hard to tell whether the consent I give to a medical treatment or research amounts to *informed* consent. Thus, even granted that informed consent is *sufficient* to justify administering a medical treatment to a patient or enlisting a human subject in a medical research, and that it is not necessary to inform an individual of *everything* about a medical treatment or clinical trial in order for his or her consent to participating in it to be valid, it is still hard to draw a clear line between when this sufficient condition is satisfied and when it is not. The situation may be further complicated when we move away from the clinical setting. As traditionally conceived, informed consent is given by an individual, and the consent procedure has been applied typically in the clinical setting. Many writers and international guidelines have now come to conclude that individual informed consent *alone* is not sufficient to justify the collection, storage and use of human biological samples in the setting of large-scale biobanking, targeted at populations. While *individual* informed consent may well be indispensable in this new context nonetheless, serving as what may be called "the lowest common denominator,"<sup>10</sup> it is now believed by some to be by itself *insufficient*: the so-called "public consent,"

at least in the increasingly important setting of large-scale biobanking, seems to be a necessary supplement.

Advocates of this idea include O'Neill, who introduces it when distinguishing between "seeking *public consent to systems* for collecting, storing, using and disclosing [personal genetic] data" and "seeking (a necessarily limited degree of) *individual consent to particular acts* of collecting, storing or disclosing data about individuals."<sup>11</sup> The difficulty caused by "referential opacity" in telling when an individual has really made an *informed* consent is aggravated by recent technological developments: "the merger of genetic and information technologies make it possible to assemble massive quantities of complex information *that defeat individuals' best efforts to grasp what is at stake*, or to give or withhold informed consent."<sup>12</sup> In O'Neill's view, a feasible way to overcome this difficulty is not to provide *more information* but, instead, to introduce "public consent" procedures aimed at examining the adequacy and trustworthiness of systems or institutions for the protection of personal genetic data from misuse or improper disclosure.

Before delving further into O'Neill's proposal, we need, first of all, to clarify two types of regulatory schemes and their decision-making mechanisms. On the one hand, there are existing regulatory arrangements related but *external* to a particular biobanking project. These may include, among others, governmental policies concerning the development of science and technology, regulations of research involving human subjects, legal protection of personal data in general, laws that ensure free public access to governmental information, and even the budgeting mechanism. On the other hand, there are regulatory arrangements *internal* to a particular biobanking project that include at least an ethics and governance framework congruent with the *external* arrangements and specific to the design of the proposed biobank. Since the *external* arrangements specify the minimal setting for the *internal* arrangements of a particular biobanking project, they may in some cases entirely foreclose a proposed biobanking project. For example, a law prohibiting data linkage among different databases would prohibit the establishment of any biobank that intends to link personal health records with genetic repository, and a governmental policy that disallows public money to be used to fund biobanking would make a costly project extremely difficult to carry out. While those *external* arrangements have long been the focal points of struggle among different stake-holder groups in the traditional political arena, and policy deliberation is especially needed for a publicly-funded biobanking project, we take it that by "seeking public consent to *systems* for collecting, storing, using and disclosing data" O'Neill means the latter, internal arrangements. For her, public consent to these arrangements is *prior* to individual informed consent to participation in the project that is to be internally regulated by them; in other words, only after a (suitably composed) deliberative body has given its public consent to arrangements internal to a biobanking project can the project be allowed to go about seeking individual informed consent from potential participants. To take issue with O'Neill's proposal, our following discussion will focus primarily on the role that different communities may play concerning the *internal* arrangements of a biobanking project.

## 5 Other Grounds for the Priority of Public Consent

O'Neill's claim for the priority of public consent is chiefly grounded on the fact that genetic and information technologies are working together to introduce new and ever-growing powers for processing "massive quantities of complex information" in ways that far surpass the cognitive capacities of ordinary people to comprehend what personal information is actually at stake and, for that matter, what can serve as trustworthy protection of their privacy. O'Neill is concerned, at bottom, about the adequacy of the protective means used by systems of information processing for research purposes to ensure an important value presumably held by all, i.e., *individual privacy*. So grounded, the claim does not seem to imply that the requisite deliberative process for the formation of public consent must incorporate equal representation of especially vulnerable communities in such a process. That is, *one possible way* to alleviate O'Neill's specific worries under discussion here seems to be for the deliberative process to involve no more than experts in the relevant fields together with some lay persons acting as representatives of the "general public" (rather than members of particular social groups). Moreover, if public deliberation grounded in this way results in *dissent* to a biobanking project, it seems likely to be considered *improperly* paternalistic by those who do not think that issues about the protection of privacy matter much: they may well insist that even if such deliberation can legitimately provide recommendations that tend to influence people's decision to give or withhold consent, it ought to refrain from pronouncing public dissent that deprives people of the opportunity to make such decision for themselves.

However, there may be grounds other than O'Neill's for the priority of "*public consent to systems* for collecting, storing, using and disclosing [genetic] data." For one thing, in the context of large-scale biobanking, interests involved and values concerned may pertain neither to *individual* citizens nor to their *privacy*. A variety of important interests of the communities implicated may be at stake. Thus, although samples collected and stored in a biobank will be encrypted, with personal identifiers removed, subsequent research using the samples and genetic information derived from them will often depend on the availability of group identities—such as ethnic, gender, and occupational identities—of sample sources. While such research holds promise for enormous improvements in medicine and public health, it also raises serious concern that publicized research results and their implications about the genetic and environmental factors in the etiology of diseases might foster stigmatization and unjust discrimination against vulnerable communities as a whole. In order to protect these communities from such unjust disadvantages, we cannot rely solely on individual informed consent, for interests of an individual (and their priorities) do not necessarily coincide with those of the community to which he or she belongs. As a matter of justice, public deliberation is needed to safeguard the latter interests. Grounded in this way, the relevant deliberative process will have to include representatives from communities whose interests are foreseeably put at risk by a biobanking project. But can this deliberative process be allowed to issue in



public consent or dissent that is not amenable to the kind of objection raised against O'Neill's proposal?

Before addressing this question, we will now consider an actual case to illustrate how seriously the Taiwanese indigenous peoples are vulnerable to various harms in current genetic research on them, and in which they finally find a legal basis for their insistence that prior public consent be obtained from their community if they are to be approached for recruitment by any academic research.

## 6 The Case of Kavalan Tribe

A research funded by the National Science Council was launched in 2005 by a group of anthropologists, archaeologists, linguists and geneticists from several prestigious academic institutions to investigate the migratory routes and the likely Austronesian origins of indigenous peoples in Taiwan. Such an academic research is regarded by some to be of great significance as Taiwan is eager to confirm its own distinct identity from China, whose studies tend to suggest that indigenous peoples in the island migrated from the mainland. On the other hand, this kind of research project is regarded by some as highly debatable, or in need of unbiased scrutiny, since those who claim themselves to be a distinct indigenous people have been frustrated by alleged scientific findings that some indigenous peoples in Taiwan are either at the verge of extinction or no longer in possession of enough genetic distinctness to be recognized as a *separate* indigenous people.

The interdisciplinary research in question went under way rather inconspicuously. During recruitment, the ethnic origin of parents was asked for along with the name, gender and genetic sample of every participant. Unlike what the Taiwan Biobank proposes to do, however, there was no acquisition of medical or other phenotypic or lifestyle data, and no follow-up investigation will be undertaken. Nor does the study intend to link the information derived from the data collected with other, more fertile databases, such as the participants' health records kept by the Bureau of National Health Insurance. There is apparently no intention whatsoever on the part of the researchers to mine any further information about the participants and their tribes. The alleged purpose of the study is straightforward, and the limited data-collection plan seems hardly to enable the researchers to engage in any investigation other than the one avowed. All these factors may help explain why the research did not initially encounter as much distrust, or even draw as much public attention, as did the proposal for the Taiwan Biobank Project.

Despite the seemingly modest nature of the research, however, indigenous peoples targeted by the research did not agree wholeheartedly to its apparent innocence. When an investigator contacted a tribe elder of *Kavalan* (also known as *Kavarawan* or *Cavalan*), an indigenous people with a total population of three thousand or so, and asked him for assistance in recruiting sample donors from his scattered tribespeople in early 2007, the elder expressed concern about collection of blood samples.

Aware of the growing uneasiness about blood sampling among indigenous peoples, the project's principal investigator settled on the more costly option of collecting saliva, in the hope that collecting something of a supposedly less sacred nature would leave the already hostile nerves undisturbed. Twenty-nine samples of saliva were at last collected in a small Kavalanian village.

The dispute came up when the Kavalanian Development Association, a non-governmental organization devoted to promoting community development of the Kavalan tribe and their fundamental rights, later objected that the research project should have been reviewed and approved by the tribe as a whole. Without such a public or community consent process, argued the Association, the project violated Article 21 of the "Basic Law of Indigenous Peoples" promulgated just recently in 2005, which provides that "[t]he government or any private party shall consult indigenous peoples and obtain their consent or participation when undertaking land development, resource utilization, ecological conservation, or academic research in the lands of indigenous peoples, and shall share with indigenous people benefits generated therefrom." In addition to this procedural issue, the Association also argued, among other things, that the Kavalan people do not need outsiders to narrate their tribal history. From their past experiences, they came to believe that genetic research projects aiming to tell the origins of indigenous peoples tend to do more harm than good to the peoples they study.

Leaving aside these objections, the research also suffered from flaws during recruitment in failing to abide by familiar ethical principles endorsed by international organizations for research involving human subjects. It turns out that the individual consent given by the twenty-nine sample donors was obtained through a poorly conducted process: the informed consent form is brief and meager in content (just one short sentence in each of the entries for research purpose, method, and possible risks and benefits), and far from meeting the ethical standards for research practice (such as requirement of informed consent, protection from undue risks, guarantee of the right to withdrawal, and equity in the selection of participants) that have been followed by academic communities worldwide in keeping with basic democratic values (such as personal autonomy, beneficence/non-maleficence, and justice). Moreover, according to news report, an elderly woman pointed out that she was not even asked to read the consent form before she signed it and allowed her saliva to be taken. Still worse, the sample donors did not even receive a copy of the signed consent form (where their pertinent rights as subjects are to be stated and explained). These flaws, together with the aforementioned provision by Article 21 of the Basic Law, gave the Kavalanian Development Association good reasons to file, with signed endorsement by the sample donors, a formal request that they be withdrawn from the study and that their biological samples be returned or destroyed.

In April 2007 the Kavalanian participants of the research had their saliva samples returned, which were then flushed away in a ditch publicly in a ceremony held in their village. Like the controversy over the Taiwan Biobank Project, this event also found its way to become a headline with a full-page coverage in a national newspaper.<sup>13</sup> And it was hailed in the news as a "leap forward" for human-rights protection in Taiwan.

## 7 A “Leap Forward”?

Whether this is a genuine “leap forward” for human-rights protection in Taiwan depends, in our view, on whether concrete measures for reform will be taken to ensure that when indigenous people are approached for individual informed consent to participate in research projects, they will be treated, to say the least, with no less respect than has been enjoyed by members of better-off populations.

There are two importantly different arguments for such “egalitarian” measures. One argument is equality-based in an abstract way: appealing to the ideal of *equal citizenship*, to the equal status of everyone *qua* citizen in abstraction from the social group(s) he or she belongs to, it insists that all citizens should be treated as “free and equal” in a Rawlsian sense. But such an argument can by itself shed little light on how precisely to protect legitimate interests of indigenous peoples, in particular, and their members in the age of genetic research. The other argument is also equality-based, but with weighted consideration of *de facto* inequalities that have drastically disadvantaged minority groups: it draws special attention to long-entrenched political, economic and educational *inequalities suffered by indigenous peoples*, and calls for special arrangements to enable their members to make effective use of the right to equal respect and concern.<sup>14</sup> The legal requirement in Taiwan that prior community consent to academic research on indigenous peoples be obtained in the first place may be seen as an indispensable part of such special arrangements.

This requirement is ethically justified not only in the context of genetic (or medical) research whose expected potential for the development of new drugs or treatments raises issues about benefit-sharing that have to be discussed and settled through communal deliberation. It is also ethically justified in the context of genetic research of a kind that does not have such potential, as the Kavalan case described above sufficiently demonstrates.

The Kavalan case is reminiscent of the Genographic Project, an international collaboration to study human origins and migratory history. In 2005, the National Geographic Society, together with the IBM and the Waitt Family Foundation, launched this five-year endeavor to amass at least 100,000 indigenous and traditional genetic samples from around the world.<sup>15</sup> The goal is simply to identify genetic markers for genealogical relationships among different populations and to chart human migratory routes thereby. This modest study-design was approved by the Institutional Review Board (IRB) at the University of Pennsylvania, and the Genographic Project managed to recruit some 18,000 donors from around the world in its first 18 months. Nevertheless, the Indigenous Peoples Council on Biocolonialism (IPCB), whose mission is to “assist indigenous peoples in the protection of their genetic resources, indigenous knowledge, cultural and human rights from the negative effects of biotechnology,” has strongly opposed this project.<sup>16</sup> Although it is unclear whether any of the Taiwanese indigenous peoples have been recruited under the Genographic Project, several indigenous organizations in Taiwan have participated in IPCB’s petition against it. It is argued that the actual risks of the study outweigh the benefits it could bring to the sampled populations. Scientific evidence may point to the conclusion that indigenous peoples came from elsewhere; and

this could threaten not only indigenous peoples' long-held beliefs that shape their self-understanding, but also their moral basis for sovereignty and collective legal claims, such as land rights and other benefits (the moral basis being that their ancestors have lived in the territory since time immemorial). As one indigenous leader puts it, "We don't need genetic testing to tell us who we are or where we come from. Our creation stories and language inform us of our genealogy and ancestors." The Genographic Project was accused of underselling the risks to individual participants. Eventually, in response both to pressure from indigenous groups and to the recommendations of the United Nations Permanent Forum on Indigenous Issues, the IRB at the University of Pennsylvania suspended its previous approval of the project in December 2006.

Unless the kind of genetic research involved in the Kavalan case and in the Genographic Project can proceed without relying on samples collected from members of the relevant indigenous communities, it must try to overcome the present gridlock by negotiating with these communities, through deliberative procedure, about the ends and acceptable ways of undertaking the research and publishing its results while paying due respect to their already disadvantaged cultures. Moreover, the outcome of such negotiation cannot fall short of community consent insofar as the research is to comply with basic values in a pluralistic democracy. This may look to be a rather controversial claim, for, as indicated earlier in this chapter, in case no community consent was arrived at, individual members of an indigenous community would be deprived of the opportunity to decide for themselves whether or not to participate in the research in question.

However, as Allen Buchanan has argued, liberalism, which places fundamental importance on individual rights, "can accommodate the legitimate concerns about groups and their role in the good life which communitarians and advocates of group rights for indigenous peoples rightly emphasize."<sup>17</sup> In supporting ascription of a collective right to consent to indigenous peoples in Taiwan, we do not have to assume that cultural identity somehow constitute individual identity. Rather, we only need to assume that cultural membership plays an essential role of providing meaningful choices with which individuals can shape their own identity and pursue their own conception of the good life. Thus, given that participation in a genetic research will give rise to significant risks to the already vulnerable indigenous groups in Taiwan, and given that only if these groups are possessed of a collective right to consent (or dissent) can they find adequate protection, it should not be considered detrimental to democratic values if they are ascribed a veto power over individual consent by their members.

The foregoing justification of the indigenous peoples' right to community consent may nonetheless leave room for worries about the tendency of this right to be wielded *paternalistically* in an objectionable way. Aware of this lingering problem, Buchanan suggests that group rights be "embedded in a framework of appropriate individual rights."<sup>18</sup> Matters may be made simpler, though perhaps not easier, in the Taiwanese context if we assume that the right to community consent is to be wielded by a deliberative body composed mainly of indigenous representatives, rather than through some majoritarian decision procedure. This is a reasonable assumption if

it turns out that the Taiwan Biobank Project can reasonably be taken, especially in view of Article 21 of the Basic Law invoked by the Kavalan tribe, to require a similar deliberative process to be incorporated into its regulatory framework for specific research projects that apply for usage of data gleaned from the indigenous population. If so, then what needs to be done is to ensure that representatives of the deliberative body in question be selected through democratic means, and that they follow a procedure which is sensitive to diverse opinions held by individual members of the indigenous population, and which is properly designed to meet necessary conditions for informed and fair-minded public deliberation. Although it is as yet unclear how this is to be done in the Taiwanese context, it seems plausible to say that this is the kind of approach that is worth trying out if the collective interests of Taiwanese indigenous peoples are to be safeguarded and promoted in the age of genetic research.

## 8 Public Deliberation at the National Level

Focusing on the Taiwan Biobank Project, we find that the justification suggested above for conferring a right to community consent upon the indigenous peoples does not seem to apply in the case of other target populations without a long-lasting history of subordination: the indigenous peoples are the least-advantaged population in Taiwan, and no other target population's interests are similarly put at significant risk. Nevertheless, at least public deliberation at the national level is called for if such a national project is to secure public trust and support. The question is whether O'Neill's thesis we saw earlier about the *priority* of public over individual consent holds in the Taiwanese context, or, in other words, whether public consent, to be acquired through public deliberation at the national level, is morally required before the Taiwan Biobank Project can go ahead with its recruitment process.

O'Neill is primarily concerned about the complexity of "*systems* for collecting, storing, using and disclosing data" that large-scale biobanking projects aim to establish. Indeed, such systems, or internal arrangements as we call them, go well beyond an unsophisticated lay person's ability to comprehend so that he or she is cognitively in a poor position to determine whether such arrangements are adequate for the purpose of privacy protection. This makes it doubtful whether individual *informed* consent is really possible in this case. And there are other often-discussed problems that also make this doubtful. For example, data stored in a biobank will be used for a variety of research purposes which cannot be exhaustively specified in the consent form; consequently, potential participants in the biobank cannot be guaranteed at the time of recruitment that their conception of the good life will be fully respected by future usage of the data they contribute to the biobank. Although different proposals are made to tackle this indeterminacy in data usage, the problem itself may be taken to show that individual consent in the context of large-scale biobanking cannot amount to *informed* consent.

Solution to problems like these seems to lie in the internal arrangements of a large biobank, rather than in the contents of the individual consent form. O'Neill is definitely right about this. And provided that the internal arrangements are beyond ordinary lay people's comprehension, it seems also reasonable to require that they be subjected to the scrutiny and deliberation of a public forum to make sure that the biobank in question will operate in ways that do not betray or exploit the good will or altruistic motivation that is supposed to lead the (less than adequately informed) individuals to participate. However, as we noted earlier in connection with O'Neill's priority thesis about public consent, there may be people who consider the biobanking endeavor so important for the well-being of future generations that they are willing to participate regardless of whether their personal privacy has been adequately protected, or their conception of the good life fully respected. Call these "overwhelmingly altruistic people." It may not be difficult to find these people in the Taiwanese society: a recent finding by the Center for Survey Research at Academia Sinica shows that out of 1,089 interviewed in a nationwide telephone survey conducted in 2005, 76.7 % stated that they would be inclined to donate blood samples to a biobanking project if privacy protection is assured, and 51.3 % were still willing to do so after they were alerted that leakage of personal genetic information might be a serious concern. Now suppose public consent at the national level is required but turns out to be withheld after the Taiwan Biobank Project has been examined by a public forum. Then, *unless* overwhelmingly altruistic people belong to especially vulnerable minority groups such as the indigenous population, there doesn't seem to be any good moral reason compatible with the liberal stance on the importance of individual rights to discredit their complaint that the forum's decision to withhold public consent is objectionably paternalistic.

However, as noted earlier, there are concerns other than the adequacy of means to ensuring the single end of privacy protection, and there is a distinction between external and internal regulatory arrangements. People who challenge the justice of spending substantial amount of public money on the search for some magic cure of illness at the genetic level rather than on more familiar toxic-control programs may legitimately bring their concern to the national level and seek to change *externally* the current allocation of public resources. People who are worried that their samples and data might be used in ways that conflict with their conception of the good life may push for an *external* policy or legislation prohibiting medical research on certain topics.<sup>19</sup> After these issues have been settled *externally*, public deliberation on relevant *internal* arrangements need only to yield reasoned judgments, pros and cons, that may enable individuals to decide for themselves as to whether the Taiwan Biobank Project is worthy of their trust and participation. However, the institutional capacities of public deliberation on arrangements *internal* to a biobanking project are limited in scope: they can only be exercised when the kind of *external* arrangements described above have already been put in place. That is to say, as far as (what we hold to be non-binding) deliberative outcome at the national level is concerned, a minimum set of settled external arrangements are a necessary background against which public deliberation on the *internal* arrangements of a biobanking project can meaningfully proceed.

## 9 Conclusion: A “Two-Tiered, Double-Standard” Scheme

What we are suggesting in outline above may be called a “two-tiered, double-standard” scheme for public deliberation in the context of the Taiwan Biobank Project. Public deliberation at the *national* level is indeed necessary if the project is to attain public trust and support, but we think it should *not* be put in a position to yield an outcome taken so strongly as to amount to public consent or dissent. For taking the deliberative outcome at the national level so strongly may usher in dangers of paternalism *incompatible* with respect for individual rights, contrary to the increasing importance placed by the Taiwanese society on such rights.

However, whereas it has been duly recognized in Taiwan that individual rights should be equally respected for all citizens, the *equal value* of these rights for all citizens has yet to be ensured in practice. The Taiwanese government has tried to adopt policies of various sorts to rectify the long-entrenched inequalities befalling the indigenous population, but effects of these inequalities are inevitably still causing the population familiar undeserved disadvantages besieging other indigenous peoples elsewhere in the world. Under such circumstances, members of the population may very likely be unable to wield their (legally recognized) individual rights as effectively as members of other, better-off populations in Taiwan. Thus, in the context of the Taiwan Biobank Project, it is far from enough merely to guarantee “equality of opportunity” for every citizen to participate in the public deliberative process at the national level or at least have an indirect influence over its outcome.

As the Kavalan case has brought to the attention of human-rights advocates and concerned scholars in Taiwan these days, it is arguable that the indigenous population is in fact legally entitled, according to the Basic Laws promulgated in 2005, to demand that collective consent be obtained from local indigenous communities before the Taiwan Biobank Project begins recruitment in them. In this chapter, we have tried to make a moral case for this claim to community consent, namely, that demand for such consent, to be obtained through public deliberation at the *local* level, is in any case *morally* justifiable if the indigenous population is to safeguard its legitimate interests against significant risks it will be particularly exposed to by the kind of genetic and medical research that will utilize the Taiwan Biobank. As far as we can see, no other population targeted by the project deserves a similarly strong moral claim to such community consent.

Accordingly, a kind of public deliberation at the local level on the Taiwan Biobank Project needs to be arranged specifically for the purpose of protecting the indigenous population. How this is to be arranged, and whether it should engage only the local, tribal communities where recruitment will be conducted, or the indigenous population at large, are matters to be worked out by the relevant indigenous stakeholders, who must face up to the unprecedented challenge of deciding how the collective right conferred by the Basic Law is to be wielded in democratic ways. Nevertheless, it seems reasonable to say here that, in the order of time, this local deliberative process for reaching community consent or dissent should be arranged to start off prior to public deliberation at the national level on the Taiwan Biobank Project. For not only will this provide members of the indigenous population with an

opportunity, welcomed by indigenous non-governmental organizations, to generate (and then accumulate) their own distinctive resources for public discourse and rationation on the ethical aspects of research involving them as subjects, but it will also help heighten the general public's sensitivity to issues of distributive and restorative justice that should be taken into account by the pursuit of common good in a society like Taiwan determined to oppose exploitation and manipulation of minority groups. Hopefully, with additional positive actions taken by the government to assist them in building up capacities for initiating their own issues and concerns and communicating with citizens from other social groups in public deliberation, members of the Taiwanese indigenous population will then be empowered to participate in deliberative forums at the national level more effectively as free and equal citizens.

## Notes

<sup>1</sup> Science and Technology Advisory Group of Executive Yuan, *Policy Statement on Constructing an Island of Biomedical Technology*, April 6, 2005, [http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=&grpId=5&vroot=&cntgrp\\_ordinal=00060004&cnt\\_id=400](http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=&grpId=5&vroot=&cntgrp_ordinal=00060004&cnt_id=400).

<sup>2</sup> *China Times*, Jan. 7, 2006, at A5.

<sup>3</sup> More information on the topic can be obtained from the website of the Popular Alliance Against the National IC Card System, [http://www.tahr.org.tw/noidcard/analysis\\_paper/fact\\_sheet.html](http://www.tahr.org.tw/noidcard/analysis_paper/fact_sheet.html).

<sup>4</sup> J. Y. Interpretation No. 603 (2005).

<sup>5</sup> S. J. Chen, "Indigenous Peoples in the Test Tube," *Medical Look* 23 (1998), pp. 45–47.

<sup>6</sup> Allegations along this line were made in a (videotaped) panel discussion by an indigenous health professional.

<sup>7</sup> Registration form on file with the authors.

<sup>8</sup> *China Times*, Jan. 23, 2006, at A10, and Jan. 24, 2006, at A8.

<sup>9</sup> See Onora O'Neill, "Informed Consent and Genetic Information," *Studies in History and Philosophy of Biological and Biomedical Sciences* 32 (2001), pp. 689–704; and *Autonomy and Trust in Bioethics*, Cambridge University Press, 2002.

<sup>10</sup> See Donna Dickenson, "Consent, Commodification and Benefit-Sharing in Genetic Research," *Developing World Bioethics* 4 (2004), pp. 109–124.

<sup>11</sup> O'Neill, "Informed Consent and Genetic Information," p. 701, original emphases.

<sup>12</sup> *Ibid.*, p. 689, emphasis added.

<sup>13</sup> *United Daily*, April 2, 2007, at A1 and A3.

<sup>14</sup> For the second kind of equality-based argument, see James Bohman, *Public Deliberation: Pluralism, Complexity, and Democracy*, The MIT Press, 1996, esp. Chapter 3.

<sup>15</sup> For more detailed information on the Genographic Project, see <https://www3.nationalgeographic.com/genographic/index.html>.

<sup>16</sup> For more information on IPCB's position on genetic research, see [http://www.ipcb.org/issues/human\\_genetics/index.html](http://www.ipcb.org/issues/human_genetics/index.html).

<sup>17</sup> Allen Buchanan, "Liberalism and Group Rights," in Jules L. Coleman and Allen Buchanan, eds., *In Harm's Way: Essays in Honor of Joel Feinberg*, Cambridge University Press, 1994, pp. 1–15; quotation from p. 11. For similar defenses of liberalism as compatible with attribution of group rights, see, e.g., William Kymlicka, *Liberalism, Community, and Culture*, Oxford University Press, 1989, and more recently, Steven Wall, "Collective Rights and Individual Autonomy," *Ethics* 117 (2007), pp. 234–264.

<sup>18</sup> *Ibid.*, p. 13.

<sup>19</sup> Of course, people who weigh informational privacy more heavily than research may well think it imperative to promote an external legislation that prohibits any unauthorized data linkage among different databases.