Governance through scientism: Taiwan Biobank and public controversy

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Based on the concept of “governance through scientism”, this article aims to reveal the tacit practices of the institutional culture of scientism among Taiwan Biobank’s elite scientists, whose imaginaries have shaped the dominance of a deficit model of the public in dealing with public controversy and establishing regulatory mechanisms. Examining three periods of ELSI controversies from 2000 to 2021, we identify three types of scientific imaginaries of publics, namely the silent public (2000–2004), the anti-science public (2005–2010), and the EGC as the lawful public supervisory body (2010–2021). In 2010, the Human Biobank Management Act (HBMA) was passed in Taiwan as a solution to public controversy and as a strategy to bypass public engagement. However, the overemphasis on formative legislation caused actors to overlook the processual approach in which ongoing critical reflections are required for the changing operations of TBB

Keywords: National biobank; governance; scientism

Introduction

The completion of the Human Genome Project in 2003 heralded a new post-genomic age where national biobanks supported by the state have flourished, including UK Biobank, Biobank Japan Project, Korean Biobank, and so forth. Research has shown that gaining public trust and citizens’ voluntary participation for the collection of specimens is important for the success of national biobanks (Petersen 2005; Hawkins and O’Doherty 2010).

In East Asia, states dominate biomedical research and policy using the discourse of nationalism to win the scientific competition in the global knowledge economy and to rebuild national identity (Ong and Chen 2010). National biobanks in Japan, Korea, and China, were developed with strong nationalist imaginaries and used

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governance models that involved low levels of public engagement (Sung 2009; Triendl and Gottweis 2008; Kim et al. 2017; Yoshizawa et al. 2014). Similarly, when Taiwan Biobank (TBB) was proposed in 2000, its founders emphasized that national prosperity could be achieved through identifying the unique genetic profile of the national population to promote national health and the knowledge economy. Nevertheless, TBB generated a public controversy that led to calls for public engagement which delayed its scientific progress; thus, TBB was not established until 2012.

In this article, building on literature on national biobanks and public engagement, we develop the concept of “governance through scientism” to analyze how the culture and institution of scientism has shaped how TBB scientists deal with public controversy and establish regulatory mechanisms. The term scientism is critically employed to describe the complete belief in science as the fundamental method and value to solve social problems. With this normative assumption, elite scientists and technocrats have been granted authority to define the meaning of public policy (Blue 2018). We take on the perspective of Welsh and Wynne (2013) to argue that scientism is practiced and reinforced as an institutional culture by actors who share specific values regarding scientific development.

Paying attention to how an institutional culture of scientism has shaped the model of biobank governance in Taiwan, we explore the following questions: how did TBB scientists design the governance mechanism and frame the issues of public engagement? What kind of controversies has Taiwan Biobank generated since 2000? What kind of scientific imaginaries of publics are reflected in the controversies? Why did TBB choose legislation as a solution to governance? To answer these questions, we examine public controversies over TBB from 2000 to 2021. Our analysis reveals how the institutional culture of scientism among the biobank’s elite scientists presents a barrier to implementing democratic governance. We argue that the tacit practices of the institutional culture of scientism among the elite scientists have shaped the dominance of a deficit model in dealing with public controversy. In 2010, Human Biobank Management Act (HBMA) was enacted as a solution to public controversy. This Act stipulated formal regulatory procedures for TBB, but it also limited the development of democratic governance that could constantly consider the relationship between science and publics.

**Biobank governance and controversy**

National biobanks are a globalized phenomenon associated with biomedicalization (Clarke et al. 2010) that have raised new challenges. Scientists and biobank organizers need to adopt new approaches to scientific governance of national biobanks in response to the ELSI debate at national and international levels.

Numerous studies of biobanks have focused on ELSI issues, such as privacy protection and anonymization (Elger and Caplan 2006), informed consent (Chadwick and Berg 2001), benefit sharing (Ganguli-Mitra 2012), and regulations
(Cambon-Thomsen et al. 2003; Cutter, Wilson, and Chadwick 2004). Nevertheless, in the above-mentioned research, the top-down regulatory approach to biobank governance is still based on the tradition of bioethical regulations, in which the primary aim is to protect the human rights of biobank participants as passive objects of research. In contrast to these top-down approaches to scientific governance with an emphasis on the role of the state, research in Sociology and Science and Technology Studies (STS) has advocated a bottom-up approach to scientific governance that incorporates wide-ranging engagement with multiple publics, such as scientific organizations, industries, general publics, patient groups, and ethics committees (Weldon 2004; Cañada, Tupaselab, and Snell 2015).

According to Corrigan and Petersen (2008, 145), a lack of public trust can jeopardize a biobank. For example, the Icelandic government passed the Health Sector Database Act in 1998 to allow deCode Genetics access to national medical records without the informed consent of individual citizens. After an outburst of public criticism, the Supreme Court of Iceland repealed this act and ended IHSD (Winickoff 2006). The Australian company Autogen also had to cancel its biobank project in Tonga because it failed to hold public consultations and ignored the cultural and religious meanings of genetic information for local community members (Burton 2002). The above cases demonstrate that public controversy, as a battleground that reflects conflicts of perspectives and values from different stakeholders, might lead to the failure of a biobank.

In the field of national biobanks, top-down biobank governance emphasizing state-based regulation continues to be crucial, but bottom-up democratic governance is also necessary to explicitly make a role for diverse publics. Gottweis and Petersen (2008) suggest that biobank governance can be seen in two ways at once: “governance of biobanks” and “governance through biobanks”. Governance of biobanks is seeing biobanks as an object of regulation, funding, ethical guidelines, etc. Governance through biobanks captures the way that biobanks become a form of governance themselves by creating new information about citizens and new forms of interaction between the state, scientists, and citizens. In other words, each national biobank is both an object and a tool of governance. This complex interplay means that biobanks necessarily vary between countries and thus must be governed through a dynamic process of negotiation between scientists and local stakeholders. In our opinion, biobank governance should include a balanced mixture of top-down and bottom-up governance in which legitimacy, public interests, transparency, and accountability can thus be ensured.

Science, scientism and publics

Since the 1990s, the deficit model of public understanding of science (PUS) has been strongly criticized. Scientific institutions or governments assumed that enhancing the public’s scientific literacy could increase support for scientific policies (Bucchi and Neresini 2008). The assumption behind this PUS framework is
that public rejection of new developments in science and technology results from ignorance and that the public is a homogeneous mass without local differences (Irwin and Wynne 1996). However, Einsiedel (2008) reminds us that publics are products of contexts changing with time, place, and issue. Different practices of public engagement may construct different categories of publics (Braun and Schultz 2010; Wynne 2007). In turn, examining what kind of publics were imagined and constructed by particular institutional arrangements helps us explore the inherent institutional culture of governance and tacit assumptions about science–public relationships among scientific and political elites.

Welsh and Wynne (2013) explored post-WWII science-publics relations in the UK to demonstrate the neglected institutional culture of scientism in Britain. First, publics were primarily imagined as “passive non-entities” between 1950 and 1990, when scientific rationality was celebrated. Second, between 1990 and 2000, publics were imagined as “incipient threats” because public mistrust and resistance to science and technologies were simply attributed to ignorance. Third, as technological innovations became crucial to the economy and national security after 2000, controversial publics were imagined as “ politicized threats” requiring state control. Welsh and Wynne proposed that there should be bilateral engagement between scientific imaginaries of publics and public imaginaries of science in modern democratic governance. However, the heterogeneous public imaginaries are easily overlooked due to the institutional culture of scientism, which influences how experts deal with public attitudes toward science. To help improve this situation, Wynne (1993, 2011) suggested institutional reflexivity to invite actors affected by the institutional culture of scientism to reflect on their normative commitments about science and publics.

In this article, through reflecting on what is regarded as good governance at TBB, we develop the idea “governance through scientism” to demonstrate that governance of Taiwan biobank has evolved between national imaginaries of elite scientists, the institutional culture of scientism, and public controversy. The common definition of the term “scientism” is a complete belief in scientific methods, or in the truth of scientific knowledge to solve problems of human society. Especially in East Asia, science has been employed as the fundamental method, value, and idea that drives social change and reform of nation states. Scientism has become “a new orthodoxy” (Williams and Robinson 2015) that has granted science authority to define the meaning of public policy and predict the future direction of national development. When others question the normative commitments justified by science, they are then deemed to be anti-science. As Gwendolyn Blue (2018) argues, current manifestations of scientism result in a disproportionate emphasis on fixing public knowledge and attitude deficits and a concomitant lack of scrutiny of the values and assumptions at play in the framing of public policy issues. Taiwan, as a “developmental state” (Wang 2010), has employed its national biobank to catch up with the global competition in bio-science and rebuild national pride and identity. TBB has relied on elite scientists’
judgements and imaginaries to set the agenda and direction (Tsai and Lee 2021). We point out governance through scientism at TBB to reveal the tacit practices of the institutional culture of scientism among the elite scientists, whose imaginaries have shaped the dominance of a deficit model of the public in dealing with public controversy.

**Research method and data collection**

This article employs a multi-method qualitative approach, primarily using in-depth interviews and archival research.

First, we interviewed significant actors involved in the development of TBB and its controversies, including (1) government officials and elite scientists who initiated, planned and promoted TBB; (2) ELSI scholars who helped establish the ethical and governance framework and engaged in related ELSI debates; (3) ELSI scholars and NGO representatives who have criticized the ELSI problems of TBB; (4) members of the TBB Ethics and Governance Committee (EGC) and members of the Institutional Review Board (IRB) on Biomedical Research of Academia Sinica.

Second, we collected the original TBB proposals; official reports and websites for each stage of TBB’s development; videos and brochures used for recruitment, some of which were collected at recruitment orientations; and the minutes of meetings held by the Institutional Review Board (IRB) on Biomedical Research of Academia Sinica and the EGC. We also employed secondary documents such as newspapers, magazines, media reports, and journal articles regarding TBB development and public controversies from 2000 to 2021. In addition, we referenced quantitative public surveys, such as Genetic Research and Public Opinion: Survey Interview and Database in Taiwan (GRPO) conducted by Academia Sinica.

**Boundary-making between science and nonscience: the role of ELSI in TBB projects.**

The proposal to establish a Taiwanese genetic database was first made by Academician Ming T. Tsuang in 2000. Elite scientists at Academia Sinica then conducted a feasibility study and pilot project with funding from the Ministry of Science and Technology and the Ministry of Health and Welfare, respectively¹, before TBB’s official establishment in 2012. TBB reflects the cooperation of leading scientists and the state to develop the Island of Biomedical Technology Project, based on scientists’ imaginaries of “catching up with the global competition”, “advancing the biomedical industry in Taiwan”, and “a healthier future generation” (Tsai and Lee 2021).

Under these national imaginaries, the planners of TBB had to establish its governance framework. During its initial stage, TBB scientists appointed several
jurists and ethicists to establish an in-house ELSI team responsible for developing this framework. A TBB scientist explained that “ELSI, after all, is not our expertise. Therefore, I invited jurists and ethicists to establish the ELSI framework; by outsourcing the ELSI project to them, we could focus on the scientific aspects, such as scientific recruitment” (2017-05-C). Outsourcing ELSI issues to ELSI scholars has been a common practice in biomedical research in Taiwan based on the boundary-making between science and nonscience (Gieryn 1995).

ELSI research began to be included in state-led biomedical projects in Taiwan starting in 1998, following the Human Genome Project’s allocation of 3% to 5% of its annual budget to ELSI during the 1990s. Nonetheless, a division remained between ELSI and other aspects of biomedical research. A former lead ethicist of the ELSI team of TBB observed that

most of the advisors of the state-led biomedical projects were Taiwanese scientists in the US. Their experience in the US suggested the ELSI issues were important; ELSI projects were thus initiated. But scientists in Taiwan think that these (ELSI) problems belong to the expertise of the fields of humanities and social science. For scientists, gaps do exist between the sciences and the humanities. (2017-01-I4)

A jurist from the in-house ELSI team at TBB explained its function and role as a “boundary organization” (Kelly 2003) as follows: “The ELSI team invited scientists, lawyers, and ethicists to evaluate every stage of the sample collection and scientific research against the governance frameworks of other national biobanks”.

In their report on the feasibility study, the in-house ELSI team proposed “enhancing public education and developing diverse strategies for public consultation with different stakeholders to avoid elite decision-making in TBB” (Chen et al. 2007, 56–60). However, this approach was difficult to implement. On one hand, the in-house ELSI team was led by jurists who lacked experience in public engagement. They paid more attention to the regulatory framework of biobank governance and guidelines for scientific recruitment.

On the other hand, in 2007, TBB commissioned another ELSI team, the Foundation of Medical Professionals Alliance in Taiwan (FMPAT), to develop a mechanism to build public trust. The FMPAT proposed a public communication plan emphasizing democratic governance; however, in practice, the FMPAT strategy was based on public education and failed to develop an institutional mechanism to substantially include publics in biobank governance. A medical ethicist who participated in the preliminary planning of TBB commented that the FMPAT “did not facilitate real public consultation. The FMPAT only held conferences, filed paperwork … How could the scholars be convinced? How could people be involved? They needed to listen to local publics’ voices, like those of indigenous people … ” (2010-09-M1). In May 2009, the FMPAT terminated its 3-year involvement with TBB (Chen et al. 2009, 175–176)

While the in-house ELSI team focused on regulation and an outside ELSI team failed to initiate real public consultation, the public communication strategy
adopted by TBB came to focus on recruitment (e.g. brochures, television and radio advertisements, and recruitment orientations) and scientific education (e.g. scientific lectures on genetic databases and relevant issues) to increase public understanding of TBB and therefore encourage voluntary recruitment. In other words, scientists’ imaginary of public communication focused their attention on scientific recruitment at TBB. An ethicist who participated in the preliminary planning of TBB noted that “for scientists, the public is ignorant and needs to be educated; however, from my perspective, scientists should take education as offering information and initiate public debate to let the publics discuss ethical and legal problems … based on the information …” (2017-1-I4) However, from the view of scientists, the reason to communicate with the society is to convince the public to participate in TBB to contribute to the next generation as good citizens. A former TBB scientist argued that

we organized public lectures to show Taiwanese people the need for developing personalized medicine and to tell them that their participation is an act of public good, that is, to enhance the health of the next generation … By using the local language (Taiwanese) to explain the purpose of TBB, we aimed to obtain their trust and support. (2016-08-C)

Another former TBB scientist commented that “the success of TBB depends on the support of Taiwanese, without whom we cannot collect data. We need to let the public know that TBB is beneficial to our understanding of illness and genes” (2017-08-R).

These TBB scientists assumed that once they had described the purpose of TBB in terms of preventive medicine improving the health of future generations, the public would voluntarily commit to working together for the national health (Tsai and Lee 2021). In other words, TBB scientists’ imaginary of the public as being either ignorant or altruistic influenced their focus on science education and recruitment rather than including the publics as deliberative actors in the biobank’s democratic governance.

Legislation then became the sole focus of the ELSI team. In the early 2000s, the Guidelines for Collection and Use of Human Specimens for Research was the only government regulation for biomedical research on human subjects in Taiwan. Due to the lack of regulation, from the start of TBB, the Ministry of Health and Welfare asked the ELSI team to evaluate and establish TBB’s regulatory framework. Meanwhile, human rights groups, jurists, and legislators also requested legislation to regulate TBB. There was also evidence that the general public believed that “having a law to protect privacy would encourage the public to participate,” as shown by The Genetic Research and Public Opinion (GRPO) survey conducted by Academia Sinica (2004). Given the government’s request and public opinion, the in-house ELSI team concentrated their governance strategy on legislation. A jurist on the in-house ELSI team argued that “TBB is publicly funded, so we should accept the supervision of the people. We need to make a new law
because the national biobank does not have any supervisory mechanism…” (2017-03-I8). A TBB scientist also showed that “social scientists argued that TBB was like … [a road with] no traffic laws; how could the cars be on the roads? … So, we promoted the law and then started recruitment” (2012-10-C).

In summary, scientific imaginaries of publics based on the demarcation of science and nonscience (ELSI) led to TBB scientists being unaware of the challenges of democratic governance. We argue that, under the institutional culture of scientism in Taiwan, the public was regarded by scientists and other ELSI experts as participants to be educated and recruited rather than as a deliberative public. With the lack of an institutional mechanism to build public participation, the social legitimacy of TBB was, therefore, open to challenge and public controversy was inevitable.

Scientific imaginaries of publics in TBB: three periods of public controversy

Since 2000, TBB has caused numerous ELSI controversies that brought governance issues into the public eye. In the following analysis, we divide these controversies into three periods reflecting three imaginaries of publics held by TBB scientists

Period 1 (2000–2004): dominant elite scientists vs. the silent public

On July 3, 2000, Taiwan’s leading research institute, Academia Sinica, convened its 24th academicians’ meeting. One of the academicians, a scientist named Ming T. Tsuang, proposed the establishment of a “genetic database for Taiwan” based on the new concept of Taiwan’s “four great ethnic groups”, including Hoklo, Hakka, Mainlanders, and Indigenous Peoples. In the beginning, concern was raised about the classification of the four great ethnic groups and the potential dangers of classifying people by race/ethnicity. The concept of the “four great ethnic groups” first appeared in a proposal made by a legislator, Ye Ju-lan, in 1993. In the context of democratization in the 1990s, Taiwan shifted from human classification based on Chinese “Provincial Background” (1945–1994) to classification based on Taiwan’s “Four Great Ethnic Groups” (1994–). Thus, the human classification of “four great ethnic groups” is a 1990s political construct (Tsai 2010). When the concept of human classification was proposed in 2000, some academicians worried that genetic research might be used to argue that one racial group is superior to another. The academicians Jacqueline Whang-Peng and Wu Kun-Yu emphasized that the concept of race/ethnicity is itself contentious and a genetic database should be used only for disease research, not for ethnic studies.

The next day after that meeting, Taiwan’s major newspapers published many prominent headlines, such as “Whose Genes Are Representative of the Taiwanese People?” and “The Genetic Database of Taiwan is Controversial”. Some
newspapers discussed the potential danger of applying ethnic categories to the study of Taiwan’s genetic profile (Zhang 2000).

Despite the criticism about the sample’s representativeness of Taiwanese and the concept of the four great ethnic groups, the proposed national biobank did not trigger further public discussion. Then in 2010, a member of EGC questioned TBB scientists:

Taiwan is an immigrant society where interethnic marriages have been common. What we today call four great ethnic groups are socially/culturally/historically constructed. In addition, genetic variation can be greater within a racial/ethnic group than between racial/ethnic groups. I am just wondering why TBB uses this concept?3

A biomedical scientist from TBB responded that “based on research into Stevens-Johnson syndrome, the genetic marker HLA-B*1502 differs between Han and Caucasian patients. Moreover, TBB will recruit volunteer participants … participants can decide whether they would like to write down the ethnic category”. There were no further dialogues between scientists and EGC members.

During the drafting of TBB in period 1, only a few academicians engaged in scientific debates around human classification. Despite the media reports, there was very little public discussion. The public was imagined by elite scientists as silent, passive, lacking scientific knowledge, and unable to respond to scientific projects.

Period 2 (2005–2010): the emergence of the anti-science public (informed consent, confidentiality and privacy protection, and lack of public engagement)

When the government initiated the feasibility study and pilot project for TBB in 2005, criticisms were voiced mainly through the media by ELSI scholars and NGO groups, such as The Association for Human Rights (TAHR). Public controversy reached a peak during this period, as ELSI issues related to TBB were openly debated in Taiwanese society.

First, an article on “informed consent” appeared in the media with the title “Taking Blood Without Clearly Informing the Indigenous People in a Certain Tribe” (Wang 2006). Although this news was later confirmed to be misinformation and not related to TBB, it forced leading TBB scientist Yuan-Tsong Chen and the National Science Council to clarify that “TBB will not start recruitment before the governance framework is established” (Lee, Huang, and Jiang 2006). This controversy reflected anxiety resulting from previous neglect of informed consent procedures and the long-term absence of legal regulations for biomedical research. Thus, protecting publics from being forced to participate in TBB through unethical incentives came under formal scrutiny.

Second, Taiwan Biobank was initiated as part of the Island of Biomedical Technology Project in which various Taiwanese cohort records on health, disease, and
migration (e.g. the National Health Insurance system and the cancer registry) were regarded as essential infrastructure for TBB (Tsai and Lee 2021). Several news articles expressed concerns about “the lack of regulation for genetic privacy protection” (Cheng 2006; Wang 2006). Moreover, in 2005, disputes over the proposal to establish the national fingerprint database raised criticisms about the state having too much power as the “Big Brother”, which resulted in further public mistrust of Taiwan Biobank. All these concerns about the absence of regulations to protect personal genetic privacy during the pilot stage of TBB led to subsequent calls for legislation.

Third, a lack of transparency and minimal public engagement were also criticized. In particular, the development of TBB illustrates a top-down model of decision-making and governance by the state, elite scientists, and ELSI experts. Due to related controversies, in 2007, the IRB of Academia Sinica, which was responsible for TBB’s project review during the early stage, asked TBB scientists to “enhance transparency and public communication to gain public trust,” and suggested that TBB should “publish proposals, reports, and decisions to obtain feedback from the public.” During an interpellation session of the Legislative Yuan, legislator SueYing Huang requested that TBB obtain social consensus from “relevant public groups including human rights organizations and representatives of indigenous people and women.” The vice Director of TAHR, Ching-Yi Liu, argued in a letter to the media that “TBB is a national project related to citizens’ health, privacy, and property rights, but most of us know no details about this project” (Liu 2006).

Because TBB failed to initiate public engagement with different stakeholders – human rights groups, ELSI scholars, and legislators – media became the platform for these actors to represent the general public’s criticisms of TBB. They wrote letters to the media and TBB scientists also responded to the criticisms in the media. In a press release, leading TBB scientists emphasized that “the difficulties TBB encountered were not scientific issues but ELSI challenges. Suspicions about the purpose of TBB were raised due to long-term distrust of public policies. We need a rational discussion about TBB rather than trivial criticisms” (Chen and Shen 2006). TBB scientists imagined these actors as “anti-science and irrational publics” who did not understand TBB. The way that TBB scientists framed dissent and controversy as “trivial” and “irrational” reflects the inherent “institutional culture of scientism” shared by scientists and experts in scientific policymaking. This culture of scientism has ignored the diverse public interests and values revealed in public controversy and also influenced how TBB subsequently excluded these dissenters from TBB’s development and governance (see the section Period 3 (2010–2017)).

After encountering these controversies and criticisms, a TBB scientist realized that the scientific community should acknowledge the importance of public viewpoints and values to ensure the success and longevity of the biobank. He admitted the following:
Scientists know very little. After being involved in TBB, I have realized that a full understanding of the Taiwanese society is fundamental to the success of the project. Blinded by arrogance, we [scientists] often belittle challenges that come from outside our field, such as those from civic organizations and jurists. We are inclined to view people with different viewpoints as troublemakers without seriously considering their motivations. From the very start, we did not respect their theoretical frameworks or thoughts; the impact [from the neglect of their criticism] was inevitable.

(2017-05-C)

However, this personal reflection by a scientist did not lead to the development of a more democratic governance of TBB. Instead, to appease critics and build consensus, actors with different opinions – including TBB scientists, ELSI scholars, and human rights organizations – all appealed to legislation to protect participants’ legal rights, resulting in the passing of the HBMA in 2010.

**Period 3 (2010–2017): EGC as the public supervisory body and problems with its democratic governance**

In response to public controversy between 2005 and 2010, legislation was considered the only solution. In 2010, the HBMA was passed. Based on the HBMA, the Ethics and Governance Committee (EGC) was established to represent the public and supervise TBB. However, in 2016, a news article showed a conflict between the EGC and the IRB of Academia Sinica which revealed a lack of clarity regarding the supervisory role and mandate of the EGC (Lo 2016).

Because the initial feasibility study and pilot project for TBB were organized by Academia Sinica, the biobank was originally reviewed by Academia Sinica’s IRB. Given the difference between research oversight and biobank governance, the in-house ELSI team of TBB proposed the establishment of an independent EGC based on the UK Ethics and Governance Council (UK-EGC). This proposal was supported by the IRB of Academia Sinica. An IRB member recalled that “because the IRB did not have the capacity to confirm the social legitimacy of the project, an inclusive organization with social representativeness was required to discuss the purpose of TBB” (2010-09-I3). In other words, the EGC was established as an inclusive supervisory body to act as “a surrogate for voicing the views of Taiwanese publics.”

In 2016, conflict occurred between the IRB of Academia Sinica and the EGC because the IRB still regarded itself as a supervisory committee of TBB after the establishment of the EGC in 2012. Due to its mistrust of the EGC, the IRB argued it should maintain its power of review over TBB and forced TBB to pause participant recruitment until it had reviewed and approved changes in TBB operations. This controversy was intensified by remarks of TBB scientists, the chair of the EGC, and an IRB member, who personally wrote letters to the media (Chen 2016; Chiou 2016) to debate operational problems at the EGC in terms of public accountability, independence, and governance culture.
First, these critics questioned the ability of the EGC to fulfill its remit of “public accountability”, without which it lacked legitimacy. Because national biobanks are publicly funded, public trust is a crucial criterion for evaluating not just national biobanks per se, but also their governance bodies. A jurist stated that “TBB is a national policy which has to fulfill public interests. In comparison to institutional review boards, the EGC should take a more significant responsibility for public communication” (2018-05-M2). However, the EGC restricted itself to reviewing data releases for biomedical research projects and to supervising TBB operations instead of fulfilling its original mandate to enhance public engagement.

Based on the Act, the EGC is a lawful representative of diverse publics; therefore, further public communication is not needed. The EGC did not establish an independent website and only limited information on its members and summaries of meeting minutes were published on the TBB website. The EGC thus exhibited a lack of transparency. Two EGC members made the following comments:

EGC governance must maintain openness and transparency by creating complaint procedures and even by including the Ministry of Health and Welfare as an external reviewer. Currently, the EGC is not subject to external review. (2018-05-I9)

The social legitimacy of the EGC depends on the openness of meetings and the interactions with the public. We must show the public what has been done and achieved and create ways to receive public feedback. (2017-03-I8)

Moreover, the EGC did not have transparent regulations for member selection. The HBMA only stipulated the ratio of experts from certain professional categories that should be included on the committee. Since 2012, the selection of EGC members has been through invitation by EGC conveners rather than open recruitment. Some EGC members criticized the closed governance model: “Instead of relying on the conveners’ choices, rules for membership selection should be established … some EGC members have not participated for a long time … they should step down…” (2018-05-I9)

The closed-door member selection process excluded candidates with critical viewpoints, who were originally invited as members of the preliminary committee of EGC but wrote a letter to the media to criticize the operation of EGC in 2009 (Liu and Liu 2009). This leads to the second problem with the EGC: its lack of an independent governance culture. A jurist criticized this selection process by commenting that “the EGC is supposed to be an independent organization but choosing members from EGC members’ circle weakens its supervisory power” (2018-05-M2). Moreover, despite the mandate for a wide range of representatives in the HBMA, the conveners and the deputy conveners have so far all been from medical backgrounds, which demonstrates the predominant role of medical scientists in the EGC.

A type of “friendly governance culture” was thus formed. For example, an EGC member argued that
the biggest problem of the EGC is that it has not fulfilled its supervisory role and is closely associated with TBB. The convener was an elite bio-medical scientist. Because other members respected him due to his prestige, no one dared to offer different opinions. (2017-08-15)

Another member stated that “instead of defending TBB, we must be proactive. If we fail to be proactive, the EGC may be regarded by the public as a ‘shield’ for TBB” (2015-02-I11).

Graeme Laurie, the second chairman of the UK-EGC, argued that, as a critical friend of UK Biobank, UK-EGC needs to continually reassess its rationale, role, and governance by reviewing principles and carrying out consultations with diverse actors and publics (Laurie 2011). Instead of being a critical friend, the EGC was a friendly supervisory body with legitimacy as a public representative based on legislation rather than on practices of democratic governance. As an intermediary governance mechanism between TBB and the public, the EGC deliberately excluded critical actors and did not effectively represent diverse public interests. The EGC thus maintained a mode of top-down governance based on experts and scientism.

**Governance through scientism and top-down regulation**

The scientific imaginaries of publics manifested during the aforementioned three periods, namely the silent public (2000–2004), the anti-science public (2005–2010), and the lawful public supervisory body (2010–2021), reflect a model of governance through scientism in Taiwan. This model demonstrates that in Taiwan science and technology are afforded superiority over other fields and only the risk management and scientific governance of experts are valued. As mentioned above, Taiwan has employed its national biobank to catch up with the global competition in bioscience and rebuild national pride and identity. On one hand, the policy-making process of Taiwan Biobank was made top-down under the national vision of transforming Taiwan into an Island of Biomedical Technology and funded by the government as a high-priority project. On the other hand, biobank governance was institutionalized based on the authority of the scientists and experts. The focus on top-down legislation in TBB governance limited innovation and flexibility for future governance, despite persistent criticisms by ELSI scholars and human rights organizations.

TBB scientists and the ELSI teams failed to develop mechanisms for upstream public engagement, resulting in the dominance of scientific imaginaries of publics over public imaginaries of science and the neglect of the diverse values underlying public controversy. A jurist commented that “the policy making of TBB takes a top-down approach; the legitimacy of TBB and inherent political and economic assumptions had not yet been fully discussed.” (2017-01-I3). Another jurist also argued in a news article that: “Whether TBB is a “have-to-
do” project, this was supposed to be a debatable question. But we did not get any explanation” (Liu 2006)

Legislation was the easiest method to achieve social consensus during ELSI controversies, but it also brought up new governance problems. Thus, legislation is a “double-edged sword’. According to an ELSI scholar, legislation was “a leap in the development of TBB governance taken without successfully negotiating with the diverse social values; from legislation, stakeholders’ interests were reconfigured from the top down … or scientists, [so] the problem was solved, no need for public communication” (2012-03-I8). In other words, legislation was a strategy for TBB to bypass public communication.

Relying on legal frameworks to govern biobanking practices is neither effective nor necessary protection for the interests at stake. In a comparative research on UK Biobank and TBB, Laurie (2017, 292–293) noted that the legal governance culture in Taiwan tends to reduce matters of governance to a narrow focus on procedural compliance. We argue that the overemphasis on formative legislation caused actors to overlook the processual approach in which ongoing critical reflections are required for the changing operations of TBB. Legal regulations could not meet the diversifying functions and management of the TBB as it developed; furthermore, an overreliance on formative regulatory procedures limits the development of more reflexive governance approaches and puts up barriers to possible paths towards democratic governance. For TBB, achieving democratic and reflexive governance would require TBB scientists, ELSI experts, and government officials to reflect on the institutional culture of scientism and strive to establish a friendly institutional environment that welcomes conversations, negotiations, and consultations with all stakeholders.

Conclusion

By drawing on “governance through scientism”, this article examined the ELSI controversies, institutional culture of scientism, and TBB governance practices that caused the invisibility of multiple publics in Taiwan.

First, due to the demarcation of a boundary between science and non-science, TBB scientists were not involved in the design of the ELSI framework and outsourced ELSI issues to an in-house ELSI team and the FMPAT team. Although the idea of bottom-up participation was raised, substantial public participation was never properly implemented by the in-house ELSI team. This reflected scientists’ and ELSI experts’ imaginaries of the publics in terms of the deficit model and led to a formalist approach to public communication based mostly on education and scientific recruitment. The recruitment strategy for TBB constructs the public as being altruistic and dedicated to the health of the next generation rather than empowered and able to debate diverse values in policy making.

Second, the three periods of public controversy illustrate the invisibility of multiple publics from 2000 to the present. In Period 1 (2000–2005), the scientific
debates regarding the representativeness of the sample of Taiwanese and the human classification of four great ethnic groups did not trigger a further discussion with the general public. The public was imagined by scientists as silent and unable to respond to the TBB proposal. In Period 2 (2005–2010), TBB scientists imagined an irrational and anti-science public based on the criticisms made by human rights NGOs and ELSI scholars, thus marginalizing the diverse values revealed in these public challenges. In Period 3 (2010–2021), the EGC obtained legitimacy as the representative of diverse publics through top-down legislation rather than more participatory practices of democratic governance. Through all three periods, the scientific imaginaries reflected in the institutional responses to public controversy revealed the exclusion of diverse publics from the scientific governance of TBB. Thus, following the calls for democratic governance made by various actors and scientists in interviews and public statements, as well as the explicit statements in TBB’s own original planning documents, we argue that TBB still needs to figure out how to establish partnerships with its participants and engage in substantive deliberation with the aim of achieving democratic governance.

Finally, by unpacking the institutional culture of scientism in Taiwan, this article reveals that the TBB scientists lacked the imaginary of “upstream public engagement”, resulting in an overreliance on top-down governance. Despite some attempts to communicate through the media, TBB failed to fully engage with multiple publics and finally relied on a formalistic law as a foundation for governance. In fact, truly democratic biobank governance would entail a process of establishing partnerships with stakeholders and diverse publics to openly debate emerging ELSI issues, thus providing balanced two-way interaction between “scientific imaginaries of publics” and “public imaginaries of science”. However, the governance through scientism practiced by TBB as well as its supervisory body, the EGC, led TBB scientists to dismiss reflection on the science-publics relationship.

To overcome the TBB’s current assumption of a “phantom public” (Gottweis, Chen, and Starkbaum 2011) and “governance through scientism”, we argue that institutional reflexivity is essential to ensure democratic governance; this includes reflecting on the deficit in the imaginaries of publics, acknowledging diverse public values, and enacting substantial public participation among scientists, stakeholders and participants.

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Notes
1. The development of TBB went through four stages before its official establishment in 2012: Stage 1: prefeasibility study (September to December 2003); Stage 2: feasibility study (August 2005 to July 2007); Stage 3: preparatory phase (pilot study, December 2005 to October 2010); Stage 4: extension of the pilot study (December 2010 to December 2011).
2. This report suggested taking Canada as a reference model to emphasize public engagement and transparency (Chen et al. 2007, 56–57).
3. See the fourth meeting minutes of the EGC on 20th August, 2009.
4. A government plan to force citizens to undergo fingerprint-scanning for new identity cards was terminated following a public petition.
5. The relationships between the IRB of Academia Sinica and the TBB-EGC are further elaborated in the analysis of Period 3.
6. See the meeting minutes of the IRB in January, 2006
7. Published in Gazette of the Legislative Yuan (2007, 385–386).
8. The first-term EGC was formed in 2009 as the preliminary committee and then legalized in 2012.
9. See Article V of the HBMA.
10. See the eighth meeting minutes of IRB in 2007.
11. Finally, the IRB and EGC cogoverned TBB. The EGC was mainly responsible for TBB operations and the release of data, whereas the IRB reviewed the research projects from Academia Sinica that applied for data from TBB.
12. This article takes the view that initiating public consultation in the early stages of biobank establishment is the normative method of “upstream public engagement”.

References
Academia Sinica. 2004. “Survey Interview and Database of Genetic Research and Public Opinion in Taiwan: Telephone Interview Wave 2 of Medical Genetics Group.” Available from Survey Research Data Archive, Academia Sinica.
Blue, Gwendolyn. 2018. “Scientism: A Problem at the Heart of Formal Public Engagement with Climate Change.” ACME: An International Journal for Critical Geographies 17 (2): 544–560.
Braun, Kathrin, and Susanne Schultz. 2010. “‘… A Certain Amount of Engineering Involved’: Constructing the Public in Participatory Governance Arrangements.” Public Understanding of Science 19 (4): 403–419.
Bucchi, Massimiano, and Federico Neresini. 2008. “Science and Public Participation.” In The Handbook of Science and Technology Studies. 3rd ed., edited by Edward J. Hackett et al., Olga Amsterdamska, Michael E. Lynch, and Judy Wajcman, 449–472. London: The MIT Press.
Burton, Bob. 2002. “Proposed Genetic Database on Tongans Opposed.” BMJ: British Medical Journal 324 (7335): 443.
Cambon-Thomsen, Anne, Pascal Ducournau, Pierre-Antoine Gourraud, and David Pontille. 2003. “Biobanks for Genomics and Genomics for Biobanks.” Comparative and Functional Genomics 4 (6): 628–634.
Cañada, Jose A, Aaro Tupaselab, and Karoliina Snell. 2015. “Beyond and Within Public Engagement a Broadened Approach to Engagement in Biobanking.” New Genetics and Society 34 (4): 355–376.

Chadwick, Ruth, and Kåre Berg. 2001. “Solidarity and Equity: New Ethical Frameworks for Genetic Databases.” Nature Reviews Genetics 2 (4): 318–321.

Chen, Ting-Hsin. 2016. “Statement of the Ethical Governing Committee (EGC) of Taiwan Biobank.” The Liberty Times, November 25. (in Chinese).

Chen, Yuan-Chong, Chien-Te Fan, Hwang Der-Tsai Lee, Kung-Yee Liang Ming-Jing, Wen-Harn Pan, and Chen-Hsin Chen. 2007. The Report of the Establishment of Taiwan Biobank and the Follow-Up Research of Multiple Risk Factors of Multiple Diseases (The Feasibility Project). Taipei: National Science Council.

Chen, Yuan-Chong, and Chen-Yang Shen. 2006. “Planning Taiwan Biobank Carefully.” China Times, April 2. (in Chinese).

Chen, Yuan-Chong, Chen-Yang Shen, Shu-Ming Wu, Belinda Chen, and Chi-Chiang Chen. 2009. The Preparatory Phase of the Establishment of Taiwan Biobank (The Third Year of the Pilot Project). Taipei: Ministry of Health, Project Report of the Ministry of Health, Executive Yuan: DOH96-TD-M-113-B001. (in Chinese).

Cheng, Hsueh-Yung. 2006. “Lack of Legislation. Who Will Be Accountable for the Supervision of These Data?” The Liberty Times, June 25. (in Chinese).

Chiou, Wen-Tsung. 2016. “The Governing difficulties of Taiwan Biobank.” The Liberty Times, November 23. (in Chinese).

Clarke, Adele E., Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, and Janet K. Shim. 2010. Biomedicalization: Technoscience, Health, and Illness in the U.S. Durham and London: Duke University Press.

Corrigan, Oonagh, and Alan Petersen. 2008. “UK Biobank: Bioethics as a Technology of Governance.” In Biobanks: Governance in Comparative Perspective, edited by Herbert Gottweis and Alan Petersen, 143–158. London and New York: Routledge.

Cutter, Anthony Mark, Sarah Wilson, and Ruth Chadwick. 2004. “Balancing Powers: Examining Models of Biobank Governance.” Journal of International Biotechnology Law 1 (5): 187–192.

Einsiedel, Edna F. 2008. “Public Participation and Dialogue.” In Handbook of Public Communication of Science and Technology, edited by Massimiano Bucchi and Brian Trench, 173–184. New York: Routledge.

Elger, Bernice S, and Arthur L Caplan. 2006. “Consent and Anonymization in Research Involving Biobanks: Differing Terms and Norms Present Serious Barriers to an International Framework.” EMBO Reports 7 (7): 661–666.

Ganguli-Mitra, Agomoni. 2012. “Benefit-sharing, Biobanks and Vulnerable Populations.” In Trust in Biobanking, edited by Peter Dabrock, Jochen Taupitz, and Jens Ried, 257–266. Berlin, Heidelberg: Springer.

Gieryn, Thomas. F. 1995. “Boundaries of Science.” In Science and the Quest for Reality, edited by Alfred I. Tauber, 293–332. London: Palgrave Macmillan.

Gottweis, Herbert, Haidan Chen, and Johannes Starkbaum. 2011. “Biobanks and the Phantom Public.” Human Genetics 130 (3): 433.

Gottweis, Herbert, and Alan Petersen. 2008. Biobanks: Governance in Comparative Perspective. London and New York: Routledge.

Hawkins, Alice K., and K. O’Doherty. 2010. “Biobank Governance: A Lesson in Trust.” New Genetics and Society 29 (3): 311–327.

Irwin, Alan, and Brian Wynne. 1996. Misunderstanding Science?: The Public Reconstruction of Science and Technology. Cambridge and New York: Cambridge University Press.

Kelly, Susan E. 2003. “Public Bioethics and Publics: Consensus, Boundaries, and Participation in Biomedical Science Policy.” Science, Technology, & Human Values 28 (3): 339–364. Sage Publications.
Kim, Hannah, Sumin Kim, Soo Jin Hong, and So Yoon Kim. 2017. “Ethical and Regulatory Considerations on Biobanking in the Republic of Korea.” *Asian Bioethics Review* 9: 367–378.

Laurie, Graeme. 2011. “Reflexive Governance in Biobanking: On the Value of Policy Led Approaches and the Need to Recognise the Limits of Law.” *Human Genetics* 130 (3): 347–356.

Laurie, Graeme. 2017. “What Does It Mean to Take an Ethics+ Approach to Global Biobank Governance?” *Asian Bioethics Review* 9: 285–300.

Lee, Zong-You, Ting-Yu Huang, and Zhao-Qing Jiang. 2006. “Before ELSI Isn’t Fully Developed and TBB Hasn’t Passed the IRB Review. National Science Council: Would Never Rush to Collect Blood Sample.” *China Times*, January 23. (in Chinese).

Liu, Jing Yi. 2006. “What Is Biobank for?” *China Times*, page A15, January 7. (in Chinese).

Liu, Jing Yi, and Hung En Liu. 2009. “Taiwan Biobank Deviated from the Script”. *Apple Daily*, May 7th.

Lo, Yu-Heng. 2016. “Taiwan Biobank Collects Samples Illegally. Conflicts within Academia Sinica Come to the Surface.” *The Liberty Times*, November 16. (in Chinese).

Ong, Aihwa, and Nancy N. Chen. 2010. *Asian Biotech: Ethics and Communities of Fate*. Durham and London: Duke University Press.

Petersen, Alan. 2005. “Securing Our Genetic Health: Engendering Trust in UK Biobank.” *Sociology of Health & Illness* 27 (2): 271–292.

Sung, Wen-Ching. 2009. “Within Borders: Risks and the Development of Biobanking in China.” In *Human Genetic Biobanks in Asia: Politics of Trust and Scientific Advancement*, edited by Margaret Sleeboom-Faulkner, 168–188. London and New York: Routledge.

Tsai, Yu-Yueh. 2010. “Geneticizing Ethnicity: A Study on the ‘Taiwan Bio-Bank’.” *East Asian Science, Technology and Society: An International Journal* 4: 433–455.

Tsai, Yu-Yueh, and Wan-Ju Lee. 2021. “An Imagined Future Community: Taiwan Biobank, Taiwanese Genome, and Nation-Building.” *BioSocieties* 16: 88–115.

Wang, Chao-Qun. 2006. “No One in the Tribe Knew What the Blood Test Was For.” *China Times*, page A10, January 23. (in Chinese).

Wang, Jenn-Hwan 2010. *The Limits of Fast Follower: Taiwan’s Economic Transition and Innovation*. Taipei: Chuliu Book Company. (in Chinese).

Weldon, Sue. 2004. “Public Consent’ or ‘Scientific Citizenship’? What Counts as Public Participation in Population Based DNA Collections?” In *Genetic Databases: Socio-Ethical Issues in the Collection and Use of DNA*, edited by R. Tutton and O. Corrigan, 161–180. London: Routledge.

Welsh, Ian, and Brian Wynne. 2013. “Science, Scientism and Imaginaries of Publics in the UK: Passive Objects, Incipient Threats.” *Science as Culture* 22 (4): 540–566.

Williams, Richard, and Daniel Robinson, eds. 2015. *Scientism: The New Orthodoxy*. London: Bloomsbury Academic.

Winicoff, David E. 2006. “Genome and Nation: Iceland’s Health Sector Database and its Legacy.” *Innovations: Technology, Governance, Globalization* 1 (2): 80–105.

Wynne, Brian. 1993. “Public Uptake of Science: A Case for Institutional Reflexivity.” *Public Understanding of Science* 2 (4): 321.

Wynne, Brian. 2007. “Public Participation in Science and Technology: Performing and Obscuring a Political–Conceptual Category Mistake.” *East Asian Science, Technology and Society: An International Journal* 1: 99–110.

Wynne, Brian. 2011. “Lab Work Goes Social, and Vice Versa: Strategising Public Engagement Process.” *Science and Engineering Ethics* 17 (4): 791–800.
Appendix. Interview List

| Code | Interviewee          | Date                  | Code | Interviewee          | Date                  |
|------|----------------------|-----------------------|------|----------------------|-----------------------|
| A    | Scientist            | November 2012         | I1   | EGC Member           | January 2011          |
|      |                      | October 2015          |      |                      | April 2012            |
| B    | Scientist            | October 2015          | I2   | EGC Member           | March 2011            |
| C    | Scientist            | October 2012          | I3   | EGC Member           | December 2012         |
|      |                      | September 2015        |      |                      | September 2010        |
|      |                      | August 2016           |      |                      | March 2011            |
|      |                      | May 2017              |      |                      | January 2017          |
|      |                      | September 2017        |      |                      |                       |
| D    | Scientist            | August 2017           | I4   | EGC Member           | January 2011          |
|      |                      |                       |      | The IRB Member,      | January 2017          |
|      |                      |                       |      | Academia Sinica      |                       |
| E    | Scientist            | July 2020             | I5   | EGC Member           | February 2011         |
|      |                      | September 2021        |      |                      | October 2012          |
|      |                      |                       |      |                      | March 2017            |
|      |                      |                       |      |                      | May 2018              |
| G    | Scientist            | November 2016         | I6   | EGC Member           | October 2012          |
|      | EGC Member           | May 2018              |      |                      |                       |
| R    | Scientist            | September 2017        | I7   | EGC Member           | March 2011            |
|      |                      | August 2020           |      |                      | April 2012            |
| J1   | Government           | January 2013          | I8   | EGC Member           | March 2012            |
|      | Official             | October 2015          |      |                      | October 2012          |
|      |                      |                       |      |                      | March 2017            |
|      |                      |                       |      |                      | August 2017           |
|      |                      |                       |      |                      | February 2020         |
| J2   | Government           | March 2011            | I9   | EGC Member           | December 2016         |
|      | Official             | September 2015        |      |                      | December 2016         |
|      |                      | January 2015          |      |                      | May 2018              |
| M1   | ELSI Scholar         | September 2010        | I10  | EGC Member           | November 2012         |
| M2   | ELSI Scholar         | May 2018              | I11  | EGC Member           | February 2015         |
| M3   | ELSI Scholar         | April 2012            | I11  | EGC Member           | November 2016         |
|      |                      | May 2018              |      |                      | May 2018              |
| R1   | ELSI Scholar         | May 2017              | I     | EGC Member           | September 2021        |
|      |                      | March 2020            |      |                      |                       |
| N5   | NGO Representative   | May 2018              | L    | EGC Member           | February 2020         |