Bioethical Governance in South Korea: Tensions between Bottom-Up Movement and Professionalization, and Scientific Citizenship

Seyoung Hwang and Margaret Sleeboom-Faulkner

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Abstract In South Korea, bottom-up campaigns played a significant role in legislating the Bioethics and Biosafety Act. Formed of alliances between civic activists, NGOs, religious groups, and some individual experts, they shared the goal of bioethical legislation and also demanded the democratic control of new biotechnologies. However, the Hwang Woo-suk scandal and the increased bureaucratic control of research that followed have challenged the development of a more democratic mode of governance.

Through ethnographic methods, this article seeks to understand how three groups—activists, bioethics experts, and scientists—viewed their roles in formulating bioethical governance. It does so by observing the manner in which public representation was framed and reframed by the state and different social actors. We aim to contribute to ideas of scientific citizenship by outlining the complex and contradictory relationship between democracy and the logic of bioethical regulation, and between the roles and identities of campaigners and expert groups and the larger public needs. We argue that the professionalization of bioethics in South Korea has missed opportunities regarding the inclusion of the public in debate, and it has preempted the formation of new alliances and negotiation between scientists, other expert groups, and civic groups.

Keywords Bioethics · human embryonic stem cell research · governance · professionalization · scientific citizenship

S. Hwang (✉)
Science Education Research Center, Building 10–1, #411, 599, Gwanak-ro, Gwanak-gu, Seoul 151–748, South Korea
e-mail: ecophil@snu.ac.kr

M. Sleeboom-Faulkner (✉)
ARTS C209, Department of Anthropology, Centre for Bionetworking, School of Global Studies, University of Sussex, Falmer BN1 9SJ, UK
e-mail: M.Sleeboom-Faulkner@sussex.ac.uk
1 Introduction: Bioethical Governance and Scientific Citizenship

Bioethics is an important device in reconciling sociopolitical and ethical issues arising from developments in life sciences. Its potential for implementation in the long run may depend on the representation of the civic voices of the social and political groups concerned. Although many references exist regarding the robust nature of bioethics of human embryonic stem cell research in the United Kingdom, the civic nature of bioethics in pre-Hwang Korea is much less widely known. Long before Hwang was accused of scientific data fabrication and unethical conduct, a fragile civic basis for bioethics had come about in South Korea. This article is mainly about how this forum was sidelined.

In Europe there have been debates on how to improve public consultation beyond mere sloganizing of science and democracy (Irwin 2001), and various forms of scientific citizenship have been discussed in the light of science communication (Elam and Bertilsson 2003). The notion of scientific citizenship is aimed at restoring public trust in the application of new science technologies and to bridge the gap between science and the society that it serves (CEC 2001; Davies and Wolf-Phillips 2006; Nowotny, Scott, and Gibbons 2001). Nevertheless, bioethical governance could mean the foregoing of chances for public engagement and bottom-up campaigns involving, for instance, alliances between bioethics activists and scientists. This possibility, in our view, has not received adequate attention. This study investigates how new forms of “governance” in bioethics policy making in South Korea both create and lose forms of public engagement on issues raised by new scientific developments. State governments invest substantially in bioethics institutions and bioethics capacity building and regulation. Here we show how this form of institutionalizing bioethics governance in the case of South Korea has led to missed opportunities to include the public in debate and therefore can be seen as a missed chance of the further democratization of “good governance.”

While the debate and research on democratic governance of new science and technologies are still conducted mainly in Western political and cultural contexts, public participation initiatives have also been experimented with and discussed in non-Western countries (Chen and Wu 2007). However, little attention has been paid to the complex relationship between democracy and bioethical regulation in these different cultural and national contexts, nor the gaps between the democratic ideals presupposed in these initiatives and the actual social changes (Wynne 2007). For example, how do different political infrastructures, traditions of public debate, the social status of experts, and public attitude toward science and technology become the positive or negative factors in increasing democratic decision-making structure, and importantly, from whose perspectives?

Furthermore, the shaping of the governance of biotechnology in some fast-growing Asian countries is particularly complex to understand because of the nationalistic drive to biomedical technologies on the one hand, and the growing recognition of the pressing need to fill the “bioethical vacuum” to become a credible member of the international scientific community on the other (Salter 2008; Sleeboom-Faulkner 2007; Sleeboom-Faulkner 2008). This article, then, asks how global bioethical discourses produce logics of regulation in a particular local context, in conjunction with the political and bureaucratic systems and expert cultures in which they are embedded.
This study adopted ethnographic methods in fieldwork conducted from April to December 2009. Interviews were held with more than thirty individuals from a variety of political and professional backgrounds, with a focus on their views on the values of public representation in policy decision making, and the implication of bioethics policy on the nature of their campaign or work. Later, they were grouped into activists (six), stem cell scientists (fourteen), and bioethics experts (fourteen) for analysis. The interviewees’ individual characteristics are worth mentioning in order to explain carefully how they were “representative” of the groups. All six activists were deeply involved in the early bioethical movement. All scientists were based in universities, five of them specializing in embryonic stem cell research and twelve of them possessing more than ten years’ experience. Bioethics experts held backgrounds of medicine, law, or religious studies, many of them having been members of the National Bioethics Advisory Committee (NBAC) or the National Bioethics Committee (NBC). The first author also tried to enter the expert culture, which is not easily accessible. This included sitting in on weekly meetings in one university-based biology laboratory, attending scientific conferences, and actually participating in a five-day ethical committee training course, organized in cooperation with The Forum for Ethical Review Committees in the Asian and Western Pacific Region (FERCAP), at Seoul National University Hospital in May 2009.

Interview data were interpreted by triangulation with documentary sources already available, such as self-reflective accounts on bioethical campaigns written by interviewees; academic papers and media articles that directly addressed the activities in which interviewees were engaged; Internet Web sites of nongovernmental organizations (NGOs), campaigners, and research institutes; and bioethics policy documents. Importantly, by using such a variety of data sources to identify the interpretations by the three groups of their roles, beliefs, and identities, with the critical stance to their mutual views of the other groups or particular individuals, we strived to reconstruct the stories of bioethical campaigns and policy-making process in ways that reveal the gaps between the ideals of public representation in pursuing democratic governance of science and technology (S&T), that is, bottom-up approaches, and the actual process of bioethical legislation and subsequent regulatory arrangements.

Firstly, the study captures and critically examines the messy processes involved in turning bioethical issues into a policy concern and object for democratic governance by focusing on the manner in which public representation was framed and reframed by the state and different social actors. In part, we also tell a story of successes and struggles in the bottom-up campaigns for bioethical legislation, which was formed by the various preregulatory groups in their hope of filling the regulatory and participatory gap in Korean biotechnology policy. Secondly, the study investigates an inevitable consequence of the legislation—the emergence of professionalization and bureaucracy—by addressing the views of expert groups, such as scientists and bioethics experts, on their roles in establishing ethical research practice.

2 Bioethical Legislation in South Korea

Unlike some Western societies, where various interest groups, experts, and institutions were active participants of the politics of biotechnology, the initial agenda
setting for bioethical legislation in South Korea was restricted to parliamentary discourse. This situation suggests at least two problems in the policy mechanism. Firstly, the policy-making mechanism, especially in the areas of science and technology, was a top-down process in the aftermath of the state-driven developmental system in existence since the 1960s. Without much effort on the part of the state to seek public consultation, the public acceptance of new science and technologies was taken for granted and was, in turn, used to justify the state’s ideology. Secondly, the authority of experts—scientists and bioethicists in this case—was not yet established. In fact, scientific professionalism and organizational voice only began to emerge as late as the early 1990s, when there was a dramatic political regime change from the old dictatorship to a democratic state (Bak 2007; Park 2006). The lack of scientists’ collective voices was especially obstructive in the process of bioethical legislation, in that Hwang Woo-suk was able to form liaisons with politicians, purportedly through their mutual interests, without the existence of authoritative objections by scientific professional organizations (Kim 2007).

Ever since bioethical issues entered the policy arena in the late 1990s, large-scale campaigns and negotiations among actors of differing interests and values. Appendix 1 shows the main bill proposals supported by these groups. The Bioethics and Biosafety Act, announced in 2004, aimed to achieve a dual function, namely, the promotion of reproductive medicine and the establishment of a biotechnology research regimen. The law declares that it follows principles of bioethics in order to “protect human dignity and to prevent harm to human beings by ensuring that these life sciences and biotechnologies are developed safely” (Article 1).

The regulation and research oversight was structured around three main domains: establishment of the National Bioethics Committee, the requirement of research institutions to create institutional review boards, and the direction of the Ministry of Health and Welfare to perform oversight of research institutions. The areas under supervision include embryo storage and research, DNA testing, protection of genetic information, and gene therapy. However, from the point of view of bottom-up campaigners, such as scientists, bioethics experts, and NGO activists, the strong drive for biotechnological advance itself should be a question of debate, which would have to be addressed through wider public engagement. They criticized a framing of bioethical regulation that presupposed the law as the sole instrument for ethically appraising controversial research, such as human embryonic stem cell research. For example, the law took a more permissive approach compared to other countries, such as the United States and Germany, by permitting a method of somatic cell nuclear transfer (SCNT) in humans that involved destroying human embryos. In fact, human embryonic stem cell research was one of the few areas in which South Korea was thought to be more internationally competitive in the biosciences. The field was strongly promoted in Bio-Vision 2016 (2007–16)—the new science and technology policy initiative aimed at positioning South Korea as a world-leading bio-economy. Included in this state vision is the “establishment of bioethics and research integrity” (MOST et al. 2006).

Although criticism of the legislative processes is already abundant in terms of the content of regulatory approaches in the making (Han, Yoo, and Rho 2003; Harmon and Kim 2008a, 2008b), no work has shown how fragile the actual practice of bioethical governance was when the scandal around Hwang Woo-suk occurred. Dr. Hwang published two papers in the highly respected journal Science, in which
he made (false) claims of deriving the world’s first human embryonic stem cells through SCNT and the world’s first patient-specific embryonic stem cells in 2004 and 2005, respectively (Hwang et al. 2004, 2005, both later withdrawn). In fact, the studies were conducted in a legislative vacuum at the time (Gottweis and Triendl 2006; Han 2007).

The first work was conducted without any regulatory oversight. Immediately after the Bioethics and Biosafety Act took effect, Hwang’s team applied to the health ministry for permission for a new project on patient-specific somatic embryo cloning. Although Articles 22 and 23 stated the strict conditions under which SCNT research was permitted, the interim measures on embryonic stem cell research did create a loophole by allowing qualified SCNT researchers to continue the same research with ministerial approval. Hwang’s team alone met the criteria at the time in South Korea; this is why many critics dismissed the law as the “Hwang Woo-suk Law.” Hwang was very adept at forming alliances with politicians and bureaucrats, and it is well known that the role of Park Ki-young, then science advisor to the president, was instrumental in the manipulation of the legislative process.

In terms of bioethical governance, not only did the bureaucratic control of research oversight fail but so did democracy in the policy decision-making process (Kim L. 2008; Kim T. H. 2008; Leem and Park 2008; Song 2006). The former has been key to the ensuing measures in response to the Hwang affair, in order to “turn the misfortune into blossom” (Hwang 2009; also see appendix 1: table 6). However, focused on only clearing up deficiencies in the oversight concerning the Hwang scandal, the post-Hwang policy is seemingly geared mainly toward promoting biotechnology rather than defining guidelines on a solid sociopolitical basis. For example, rules were specified for egg donations for stem cell research, whereas these rules do not apply in other cases, such as infertility treatment.

To tackle such discrepancies, this study asks, Who represents the public under different conditions, and what sociopolitical processes are involved? The analysis that follows does not pursue an exhaustive description of the history of bioethical legislation in South Korea. Instead, we try to develop a more nuanced account of the role of three major social actors and their views of public representation in bioethical governance. We present analysis in two sections according to the historical periods characterized by the bottom-up movement and top-down bureaucracy.

3 The Bottom-Up Movement for Bioethical Legislation

This section analyzes how bioethical issues became a policy concern and the object of democratic governance of science and technology in South Korea from the perspectives of bottom-up campaigners. It shows how bioethical legislation became a goal shared by campaigners with disparate interests. Then, with regard to the narratives of activists, scientists, and bioethics experts, we discuss how their shared desire for an informed public debate was thwarted.
A Bioethical Legislation: The Goal Shared by the Campaigners

Although the genesis of bioethical regulation in South Korea dates back as early as the Genetic Engineering Promotion Act (1983)—later renamed the Biotechnology Promotion Act—moves toward the ethical governance of science and technology did not begin until the mid-1990s. Nevertheless, the ensuing success of cloning technology, notably, the announcement of the birth of Dolly the sheep in 1997 and the cloning experiments by Korean researchers thereafter, provoked a good deal of social debate.

Initially, the interest of the public and the media was mainly focused on the possibility of the birth of a cloned human being. Legislation campaigns were mobilized by certain religious groups and environmental NGOs. Their concern lay in how to represent public opinion. They demanded the installing of a national bioethics committee as a formal public body that would produce a social consensus on emerging bioethical issues. These efforts were not successfully reflected in the policy-making process, since bills proposed by the National Assembly concerned the controversy over human cloning alone. Moreover, the scope of participation was restricted to individual legislators and their scientific advisors (Kim 2004). Therefore, the scope of bioethical legislation was also narrow, including only a partial revision of the Biotechnology Promotion Act (see appendix 1: table 1).

In Korean NGOs of the early 1990s, feminism and environmentalism were newly emergent. They diversified the old antidictatorship movement, whose socialist paradigm underpinned the antigovernment movements of the 1970s and 1980s. The Centre for Democracy in Science and Technology (CDST), which originated from a network of scholars and activists, was formed in 1997. Within this progressive NGO, the People’s Solidarity for Participatory Democracy was the first civic group that addressed political issues in the areas of science and technology. (See appendix 2 for examples of their public engagement.) Importantly, it played a crucial role as the key mediator of civil-voice groups by facilitating the setting up of the Alliance for Biosafety and Ethics in 1998. The alliance constituted a network of campaigner groups, and it aimed to alert the public about biotechnology issues and increase public involvement in the policy-making process. Since 1998, the alliance campaigned to replace the Biotechnology Promotion Act with the Biosafety and Bioethics Bill, which adopted more comprehensive and strict regulatory approaches.

Significant to such bottom-up movements was the way in which these early NGO campaigns developed into larger-scale, organized action. In fact, the main motive and initiative came from a small network of civic activists based mainly in the CDST. Participation of members from professional groups, such as scientists, medical professionals, and bioethicists, followed, consequently forming a bioethical knowledge network. Of course, one must not undervalue the pioneering work by the experts in the development of bioethics in South Korea, such as the establishment of the Korean Bioethics Association in 1998. However, its constituents, mainly academics, were less motivated to organize bioethical campaigns compared to civic campaigners. The elements involved in bioethics included the Roman Catholic faith, environmentalism, feminism, leftism, and professional ethics, but they shared a common goal: the legislation of preregulatory approaches. However, having a common goal did not prevent the activists from prioritizing some concerns over others. For example, the “civic” concerns over genetically modified (GM) food and bio-patenting issues were priori-
itized over religious concerns about the use of human embryos for stem cell research. This heterogeneity, in effect, suggests how barren the bioethics field in South Korea was, but it allowed the activists to set the agenda regarding the range of regulatory concerns and to get actively involved in public debate.

By 2000, bioethical regulation had become a more important policy concern as Hwang’s SCNT research, more popularly termed “therapeutic cloning,” attracted media attention, but with the accent on its scientific and economic promises, ethical problems were overlooked by the mainstream media. The Ministry of Science and Technology (MOST) and the Ministry of Health and Welfare (MOHW) were two primary actors within the government that had a large stake in biotechnology policy, MOST for the promotion of science and technology, and the MOHW for the assurance of safety and oversight. The scope in which human embryonic stem cell research was permitted became the central policy issue.

In 2000, the MOHW tried to seize the initiative by developing a legal framework, namely, the Bioscience, Health, Safety, and Ethics Bill. In fact, in terms of its comprehensiveness and preregulatory approach, this bill was similar to the Biosafety and Bioethics Bill espoused by the campaigners. Spurred by its rival’s action, MOST asked the Office for Government Policy Coordination (OGPC) to initiate legislation through coordination across ministries. As the legislation became a turf war between the two ministries, the OGPC decided to set up the National Bioethics Advisory Committee (NBAC). The committee ran under MOST from November 2000 to August 2001, its aim being “to identify ethical issues related to biotechnological advances” (Park 2001). Its twenty members were from a wide range of professional fields and interest groups, including human and social scientists (five), NGOs (two), religious leaders (three), bio-scientists (five), and medical scientists (five). Such a democratic climate was not merely tokenistic from the participants’ point of view (Chin 2001; Hong 2001). The framework identified “respect for human embryos” as the principle in covering regulations on cloning, human embryo research, genetic treatments, genetic mutation of animals, and the use of information from the human genome.

Regarding the thorny issue of human embryo research, the NBAC adopted a middle-ground, cautious approach: it prohibited nuclear transfer embryo cloning (which in the actual legislation was permitted), but it permitted, under strict regulative conditions, the use of spare embryos created for in-vitro fertilization purposes. However, the decision that limited the scope of human embryonic stem cell research sparked a strong backlash from medical and industrial fields. In this process, the mainstream media played an important role in increasing public support for somatic cell cloning and representing more of the position of the Ministry of Science and Technology. For example, the conflict between science and ethics was given prominence in biased ways, amplified by the voices of scientists and industrial groups who often characterized the conflict as scientific advance fettered by ethics (Kim 2003). Regardless of the ongoing debate over the legislation of bioethics at the time, governmental support for stem cell research continued. Moreover, funding for Hwang’s research was exceptionally generous: between September 1999 and August 2000, the Ministry of Science and Technology awarded him US$1.6 million to support research into cattle cloning through the SCNT technique. Despite the failure to produce cloned
cows and the absence of scientific research papers, governmental funding poured in (a total of US$15 million between 1998 and 2006) (Kang, Kim, and Han 2006).

The bioethics bill was prepared through the coordination of the Ministry of Science and Technology and the Ministry of Health and Welfare, and eventually the Bioethics and Biosafety Act was passed in December 2003. By permitting somatic cell cloning, the bill was a step backward from the original draft of the MOHW and preregulatory campaign groups, whose positions were represented in two other bills submitted by legislators (appendix 1: table 4). During this period, the controversy over therapeutic cloning or somatic nuclear transfer technique dominated the public debate with the rise of Hwang Woo-suk as a star scientist. Even so, to bottom-up campaigners, the fruition of the initial consensus by the National Bioethics Advisory Committee into an actual policy and law was an accomplishment that filled both regulative and participatory vacuums. Of course, dissent among the campaigners did exist, and the NBAC framework was not perfect for different reasons, for different interested groups. For example, it was less satisfactory to the interests of Roman Catholic and feminist groups, whose views framed biotechnology very differently: objection to any human embryo use and women’s rights in the reproductive technologies, respectively. In short, bottom-up campaigns were successful in turning bioethical issues into comprehensive legislation by mobilizing the participation of experts and activists. In terms of the actual policy-making process, however, opportunities for consulting wider public interests were compromised as a result of the blind support for human embryonic research by the government, politicians, and the mainstream media.

B “Informing the Public” as the Concern Shared by Activists and Experts

Frustration with the pro-Hwang policy united civic-rights activists with experts in their aim of informing the public to get involved in rational public debates that went beyond naive support for human embryonic stem cell research.

The CDST’s participatory framework of the early bioethics campaign was derived from theories of science, technology, and society (STS) studies, which had just arisen in South Korea (CDST 1999). Their utmost concern was to control the regulation of science and technology through deliberation and informed decision making by the lay public. The Consensus Conference was one of the major experiments and models that represented their ideal of participatory democracy. In 2000, the CDST proposed the Bioethics and Biosafety Bill (appendix 1: table 4) in the form of a petition. For the CDST, the tension between pursuing participatory means to science governance and developing policy alternatives framed by its own ideological goal—as specified by its human rights concern—was evident.

A debate regarding their identity was raised among members, relating to their ideologically charged agenda, on the one hand, and their assumed neutral standing as coordinator of the public debate, on the other. Self-reflective accounts by some members revealed their wish to channel their energies into the former, if only there had been more active involvement by other NGOs in biotechnological issues, which had been the very motivation for the CDST to form the Alliance for Biosafety and Ethics (Kim and Kang 2007). One of the ideals of the CDST was the up-streaming of bioethical decision making from public debate to actual policy, for example, by enabling
the consensus made in a consensus conference to actually be represented in the policy-making processes and in the outcome of decision making (Kim 2000).

The sluggish progression in the policy-making process drove the CDST to take the lead in the legislation campaign from 2001 onward, through the Cooperative Campaign for Urgent Bioethical Legislation. So blind was the support for Hwang’s stem cell research that even criticism of the abuse of the regulatory vacuum by a professional organization such as the Korean Bioethics Association did not receive attention (KBA 2004), let alone the more sustained criticism from minority journalists and activists.

In 2005, the Biotechnology Watch Alliance was formed by a small number of activists, core members of the earlier two alliances. In August 2005, it held a public debate entitled “What Went Wrong with Human Embryo Research?” to attract more public attention (Kim and Kang 2007), but the scandal that exploded over charges of scientific fabrication diverted the campaign’s focus to the Hwang affair. The initial, long-term vision to spread critical social discourses of biotechnological issues did not have a chance to come to fruition.

The multiple roles that the CDST took on board—human rights campaigner, public debate coordinator, and researcher—were rather a poor fit, owing to the limited pool of expertise and the gap between their own goals and social reality. This threatened its aim of generating legislation issues as a public discourse. A critical relationship with science and technology experts was the key component for the CDST’s identity as a “boundary-blurring” organization connecting science and the public (Kim 1999). Nevertheless, the interviews with both parties revealed slightly different interpretations of the reasons for collaboration between scientists and other experts. For example, an activist member of the CDST felt that science-, medicine-, and law-based expert knowledge functioned as some kind of basic “grounding” in the bioethical debate. The expectation was that more radical, or polarized, views could be brought into the spectrum of the public debate, opening it up to more issue-based, pro/con discourses. In his view, the initial collaborative efforts with the experts’ community actually meant a discovery of the role of experts.

In fact, the experts’ interest in participating in the bioethical debate outside their own community varied. For example, a biologist who was actively involved in the design of the gene therapy and GMO regulations framed his role as that of a “concerned scientist.” Therefore, the reason he became involved in the public debate was because his work as a researcher would directly generate social and ethical issues and become influenced by policy decisions. However, his initiative was more personal—a “sense of duty” that “made things happen”—and was not shared by all his colleagues in the research institute where he worked. From this expert’s point of view, the boundary between activism and expertise should be kept, but this was hard when the stakes were high.

Also, accounts by a handful of pioneers of medical ethics and bioethics suggest that boosting public interest in the bioethical legislation was not only the activists’ agenda but also that of the elites. During an interview, one senior scholar reflected that his participation of over twenty years could be characterized as being more of advocacy than of expertise, driven by his mixed identity as a Roman Catholic doctor. As he stated, it is not just coincidental that many professional pioneers of bioethics in South Korea possessed a religious faith, explaining partly why their motivation was well
matched with the politically motivated activist campaign, such as that of the CDST in the early period of the legislative campaign. In other interviews, some senior figures went one step further by condemning widespread “ignorance” in antiregulatory voices, including the lay public. Despite the varied identity positions and attitudes, what stands out in the recounting by both individual activists and experts of their often painful memories is the shared sense of isolation they felt as their voices were muffled in society.

These campaigners’ narratives reveal that their concerns were about making bioethics policy through the means of public representation. The frustration that the campaigners felt during the massive fanaticism over Hwang Woo-suk suggests that there was a significant gap between what they imagined to be “scientific citizenship” and the actual understanding of the meanings of human embryonic stem cell research by the majority of the public. Indeed, when the fabrication of Hwang’s research data was exposed, it meant to ordinary people that there were no world-first human embryonic stem cells.

At a media conference on December 16, 2005, Dr. Hwang pleaded for public support by arguing, “I still have the ‘original technology’ (woncheon-gisul).” “No stem cells exist, but the original technology does” was a powerful rhetoric that made some groups of people cling to the staunch belief in their hero (Kim 2009). To the campaigners, activists, and experts alike, at stake was the fight against the “wrongful” support for Hwang’s research, as the mainstream politics and media abandoned chances of experimenting with scientific citizenship. In consequence, tensions between different views were overlooked rather than carefully negotiated, and the boundaries between the groups’ tasks became blurred, as was their utmost goal of informing the public to get involved in more genuine public debates.

4 The Post-Hwang Bioethics, Research Culture, and Bureaucracy

In telling the story of bioethical regulation so far, the role of bioethical and legal experts has not been given much attention. From the perspective of campaigning activists, the legal experts were seen as not being motivated enough to commit to the bottom-up campaign. For example, activists heavily criticized the Korean Bioethics Association for its silence during the slow policy-making process. In this section, we explore the roles of the views of scientists and bioethics experts in restoring public trust with regard to the ethical conduct of research. We argue that the current logic of bioethical regulation is restraining democratic governance by shaping the bioethics expert culture to serve bureaucratic demands.

A Bioethics as Professional Behavior

As shown in recent surveys, the enforcement of the Bioethics and Biosafety Act in the aftermath of the Hwang affair has alerted Korean stem cell researchers to the need for external regulation of scientific research (Choi, Kim, and Kim 2008; Kim et al. 2006). In interviews, scientists claim that evading ethical issues has increasingly become a risky business; but for most scientists, bioethics is an externally defined and imposed
form of rule, and some expressed discontent about the authoritative attitude of ethicists, saying, “We are not criminals!” More predominantly, scientists express a sense of imbalance in agency between regulators who are rule makers and practitioners who are rule followers. The scientists’ ethical strategy seemed individualistic and passive, as revealed, for example, in saying, “I mind my own business.” Even though the scientists were able to reflect on the Hwang affair and stressed that they should be sensitive to ethical issues, the reflexivity was confined to the personal level (Hwang and Sleeboom-Faulkner 2011).

To some extent, scientists had been alienated from formal ethics for some years. Since the inception of the Stem Cell Research Centre in 2002—the largest research project in this area with a budget of US$152 million for a decade funded by the Ministry of Science, Technology, and Education—the center has run an ethical review committee composed of scientists and nonscientists, and its introduction was expected to set an example in research oversight. Without legally binding regulations, due to the earlier delay of bioethical legislation, the committee’s main tasks included the development of research and ethical guidelines. As for human embryonic stem cell research, the committee adopted a cautious approach by not permitting SCNT, given the ongoing social controversy at the time. Its task also included a review of research protocols for which, owing to a lack of administrative power and the researchers’ lack of awareness about ethical issues, the compliance rate was low.

In 2004, the committee was taken aback by the announcement of the world’s first derivation of human embryonic stem cells by Hwang’s team, more so because Hwang was a member of the ethical committee. Although Hwang claimed that the research was conducted without the benefit of the center’s funding, many members felt that the committee’s trust had been compromised, especially since they were unable to formally demand an explanation from him because of the committee’s own lack of power and the social atmosphere wherein he was regarded as a national hero (MOST 2008: 36).

The Korean scientific community never enjoyed the independence and authority required for autonomous control. Nonscientific members on the committee, as revealed during interviews, felt that the committee held only a “peripheral” status and was not the “main agent” of the organization. Without any support from the head of the research center, their tasks were narrowly focused on the procedural and practical issues, rather than the bigger questions such as the role of an ethics committee within the research center. They were intended to bolster the authority of the scientific community and to augment the trust of the wider public in science, releasing the scientific community from the task of questioning itself.

In the aftermath of the Hwang scandal, the Korean scientists’ community was much criticized for its lack of self-discipline. Furthermore, the scientific community failed to speak with one voice during the bioethical legislation. Although scientists’ support of research using embryos was often quoted by the media, the fact that scientific and medical members of the National Bioethics Advisory Committee showed various views concerning the extent to which embryo research should be permitted suggests that scientists are not a one-voice group, as was suggested by representations of scientists in the media campaign (Kim 2003). In one interview, a scientific member of the National Bioethics Advisory Committee supported this, arguing strongly that
scientific members supported the prohibition of SCNT, too, and that resistance was not shared by all but a handful of scientists who supported embryo research.

B Emerging Technocracy?

Since the early stages of the bioethical legislation process, the bioethical experts’ role was essential in developing the contents of regulation, mainly introducing the existing global consensus and legal and regulatory framework of other countries and making them relevant to the policy environment and the scientific culture in South Korea. Also, through their participation in public debate and the policy-making process, bioethical experts have now seen that reflexive, mutual learning and motive for collaboration should be the essential ingredients of bioethical expertise.

The Bioethics Policy Research Centre—an academic institute established in 2006 and funded by the Ministry of Health, Welfare, and Family Affairs—assists bioethics expert groups involved in regulatory practice. The center’s focus on academic and professional work relates greatly to policy coordination and development, with efforts for establishing bioethics policy as a new interdisciplinary study (Choi 2007). Communication is one of its primary concerns, through developing collaborative relationships among different actor groups, including scientists, bioethicists, policy makers, the public, and the international community. Since the center’s inception, its political neutrality has been a crucial issue due to ministerial sponsorship. Members claim to take a nonpartisan approach so as to strike a balance between collaboration with researchers and bioethicists, and policy implementation.

Xenotransplantation is one of the cases that show the center’s current role and challenges as policy coordinator. Since the launch of the Xenotransplantation Research Centre (2004–13), a large-scale national research consortium similar to the Stem Cell Research Centre, the experts in the Bioethics Policy Research Centre have taken part in the ethical committee and coordinated with policy makers and experts to develop a regulatory framework for new technologies, including clinical applications of biological materials. The bioethics expert has now become a professional and academic category, nourished by the pioneers’ legacy and an increase in policy demand. During interviews, experts emphasized the need for providing expertise in many regulatory bodies, such as institutional review boards and the National Bioethics Committee, in order to achieve further quality assurance in clinical and research practice (e.g., Lee 2006). However, from the campaigner’s point of view, there was now a gulf between the small circle of experts working under the bureaucracy and the others outside this circle. A scientist-cum-environmental activist remarks, “They [academics] were energetic and open-minded, but seem to now be swamped by [a] heavy workload,” suggesting the space for activist-expert collaboration has shrunk.

Increasingly, bureaucratic methods match well with international science and bioethics standards, so that the need for consulting wider public opinion becomes unnecessary. For example, scientific journals’ requirement for ethical approval by an institutional review board (IRB) is now a much more pressing concern for the Korean scientists who believe that a Korean scientists are viewed with doubt. Also, the fact that securing international collaboration for research and clinical trials requires meet-
ing global standards proves that researchers, industries, and regulators have an interest in ethical behavior. By 2010, thirteen IRBs in South Korea, mostly large, reputable hospitals, gained SIDCER (Strategic Initiative for Developing Capacity in Ethical Review) recognition for quality ethical review—a recognition program facilitated by WHO (World Health Organization).

A recent decision by the National Bioethical Committee to pass a proposal on the somatic nuclear transfer technique—the same technique used by Hwang—suggests that Hwang’s disgrace has been forgotten. The review process for this proposal took more than two years, the research being the first case after three years’ suspension in the aftermath of the Hwang scandal, and the final decision in early 2009 mandated further revision. This included omitting “treating diseases” from the research title to avoid raising people’s expectations too high, minimizing the use of human embryos, and reorganizing the institutional review board for ensuring quality ethical review. Already being so public, the research by the Cha Medical Centre—one of the most renowned expert groups in infertility treatment and human embryonic stem cell research in the country—is under stronger scrutiny. To the scientists interviewed, the review was necessary to restore public trust. The issue now concerns the practicability of scientific methodology, rather than the destruction of human embryos and research oversight. SCNT research is now receiving much more sober assessment compared to the time when Hwang took it forward with grand promises.

Nevertheless, it is still unclear to what extent the ethical decision about the Cha application actually reflects people’s concern. Earlier on, in 2008, the NBC rejected a license application by the Suam Biotech Research Foundation, currently headed by Hwang Woo-suk. Stated reasons were the fact that Hwang’s case was still in litigation and the gravity of the ethical misconduct. This decision contrasted with public opinion: a media poll by SBS (Seoul Broadcasting System) and Matrix in July 2008 showed that more than 80 percent of the public supported Hwang’s human embryo research. Such widespread approval might simply be an expression of sympathy for their disgraced hero, Hwang Woo-suk. When asked during interviews for their views on the gap between expert knowledge and public opinion, all scientists and experts showed great concern about the persistent occurrence of hype in the mass media, and they all demanded more accurate representation of science in the press, querying the role of the media in educating the public.

More reflective scientists and experts expressed the view that a one-direction mode of communication would never be able to address adequately the dissent and controversies that exist among the public. Nevertheless, experts insist on the importance of “rational” thinking and decision making in scientific communication. This aspect of scientific citizenship is reflected by the Bioethics Policy Research Centre in its public representation methods, including the Consensus Conference on Xenotransplantation (BPRC and UNESCO 2007).

5 Conclusion

This study has highlighted the way in which current bioethics policy has been shaped through a different approach to public representation—bottom-up campaigns, intergovernmental politics, and expert-led bureaucracy. Through ethnographic methods,
the study tried to understand how three groups—activists, bioethics experts, and scientists—viewed their roles in formulating bioethical governance. Firstly, bottom-up approaches, once considerably beneficial to the formalization of bioethical governance, are now being replaced by professionalization and bureaucracy. In this process, the critical frames of biotechnology and bioethics, as public science and democracy, have also been replaced by policy regulation, which focuses on the quality assurance of research oversight defined by the experts’ knowledge. The consequence is an increase in public alienation from the bioethical debate and policy decision-making process.

Secondly, under the current regulatory arrangement, the relationship between regulators and bioethics experts and the scientific community, in their role of establishing an ethical research culture, has been uneasy, and discontent and mistrust still exist on all sides owing to their differing opinions about regulatory methods. Even so, policy makers, bioethics experts, and scientists share one voice in terms of embracing globalization of competition in the field of science, in their view, as a result of the hard lesson from the Hwang scandal. However, it remains questionable whether the Korean scientific community is now taking a more substantial role in the public communication of science. The current science policy, based on short-term interests, is clearly restrained in generating social discourse about the meanings of scientific advance and biotechnology from a wider perspective of social responsibility.

Finally, as bioethics has been narrowly defined in the post-Hwang era, one may question whether the bioethics “debate” has excluded the larger public. In the expert discourse, lay perception was often regarded as unscientific; hence, it must be corrected through sound scientific knowledge and rational thinking. Yet, when it comes to the question of the lay perception of biotechnology, it seems naive to read the layperson’s “blind” support for Hwang as meaning that Korean people were merely uncritical of the hype regarding its innovative potential. Instead, it should be pointed out that over the years, the dramatic story of Hwang Woo-suk hijacked the way in which stem cell research, and more widely, biotechnology, are defined, most notably in terms of desire for national pride and desire for a wealthy nation, motifs that dominated the story. Thus, although many critiques of public support for Hwang Woo-suk provided insight into the understanding of Korean society itself (Song 2007), there is a real lacuna in the discussion regarding how to define public concerns and the public domain of issues, not as separable from those of experts and campaigners, without taking the risk of viewing them as a somewhat “softer” domain of values, emotions, and opinions (Irwin 2008: 597).

Korean experiences show dynamic sociopolitical processes that shape institutional modes of addressing public concerns about biotechnology and in anticipating scientific citizenship. The Korean public’s “blind” support for human embryonic stem cell research and their hero Hwang Woo-suk may present a “wrong” case of scientific citizenship, but in this article we have shown that the Korean case suggests a very complex and contradictory relationship between democracy and the logic of bioethical regulation, and between the roles and identities of campaigners and expert groups. In our view, the sociopolitical processes that shape the roles of various voice groups in policy making deserve more attention in order to extend social science’s insight into the elusive idea of public representation. In this study, our analysis addressed this concern through the campaigners’ struggle for informing the public and the experts’
views of lay people and science communication. Future studies need to address how to bridge the gap between public representation methods and the lay repertoires of biotechnology.

**Appendix 1. A Summary of Key Legislative Points in Different Bills and the Actual Law**

**Table 1** Bills Proposed between 1997 and 1999 in the National Assembly

<table>
<thead>
<tr>
<th>Bills</th>
<th>Jurisdiction</th>
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<tbody>
<tr>
<td>Biotechnology Promotion (1997)</td>
<td>Prohibition of human cloning</td>
</tr>
<tr>
<td></td>
<td>National Bioethics Advisory Commission</td>
</tr>
<tr>
<td></td>
<td>NBAC under the Ministry of Science and Technology</td>
</tr>
<tr>
<td></td>
<td>Bioethics Commission under the Prime Minister</td>
</tr>
</tbody>
</table>

**Table 2** Main Contents in CDST’s Bioscience, Human Right, and Ethics Bill Petition (2000)

- Prohibition or regulation of a range of bioscience research that entails ethical problems, such as human cloning
- Prohibition of a range of gene therapy, e.g., gamete cell therapy and eugenics, and regulation for safety and informed consent in gene therapy
- Prohibition or regulation of bio-patent that entails ethical problems
- Protection of genetic information and prohibition of discrimination
- Establishment of national bioethics committee

**Table 3** Main Contents in the MOHW’s Bioscience, Health, Safety, and Ethics Bill (2000)

- Strict ban on human cloning
- Restriction of usage on a 14–day embryo for medical applications
- Ban on embryo research except the use of spare embryos
- Strict ban on fertilization, fusions, or transplantation between humans and animals
- Informed consent for embryo research
Table 4  Examples of Other Bills Proposed between 2002 and 2003

<table>
<thead>
<tr>
<th>Supporting group</th>
<th>Civic groups</th>
<th>Roman Catholic Church</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic cloning</td>
<td>Prohibition, but exceptionally allowed if the president allows or if the minister of health and welfare approves the currently proceeding research. (Civic groups insisted on prohibition without exceptions.)</td>
<td>Prohibition without any exceptional provisions</td>
</tr>
<tr>
<td>The usage of embryos for research</td>
<td>Allowance in using remaining embryos after five years</td>
<td>Prohibition</td>
</tr>
</tbody>
</table>

Table 5  The Administrative Focus of the Bioethics and Biosafety Act (Announced in 2004)

- Establishment of a national bioethics committee
- Requirement of research institutions to create institutional review boards
- Direction of the Ministry to perform oversight of research institutions

Table 6  Main Revisions Made in 2008

- Oversight of IRB
  - It is necessary to stipulate requirements for the evaluation of IRB, of evaluation results, and education.
  - Minister shall evaluate the capability and organization of IRB and consider the result to be used to review the funding scheme. The educational institutions shall submit annual plans to the Ministry until one month before they commence, and also report the results after they end.
  - It is expected that the enhancement of IRB can assure ethics and safety regarding biotechnology research.

- Conditions for egg donation for embryo research
  - Donor must be over 20 years old, must be independent, and must be both physically and psychologically healthy.
  - If independence of donors is in question, the extraction must be considered and confirmed by the relevant IRB.
  - Super-ovulation relies on the requirement set by the Ministry.
<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
</tr>
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</table>
| Compensation for egg donation                | • It is necessary to stipulate compensation for egg donation, considering the real expense that occurs during surgery and recovery, including transportation.  
• Neither the use nor offer of reproductive cells or embryos shall be induced by commercial dealings.  
• The institutions which generate embryos shall provide compensation that includes transportation, meals, and accommodation, under IRB’s oversight.  
• It is expected that stipulation of the compensation can prevent illegal transaction of eggs, and provide the compensation at minimum requirement. |
| Registration and use of stem cell lines      | • Newly established stem cell lines shall be registered in the Ministry.  
• Use of stem cell lines for research shall be reported by the provider, and free of charge, except the actual expense for maintenance as set by the Ministry.  
• Stem cell lines shall only be used for research that is aimed at (1) diagnosis, prevention, and cure of disease; (2) basic understanding about characteristics and differentiation of stem cells; and (3) other research set by the Presidential order after NBC’s review.  
• Research proposal or revision of research proposal shall be reviewed by IRB and permitted by the head of the research institution.  
• The head of the research institution who permits research shall oversee the research to be conducted in accordance with the proposal. |
| Personal information protection in gene bank  | • It is necessary to stipulate the requirements regarding the work of staff responsible for the management and security of information at the gene bank.  
• The head of the gene bank shall (1) establish and implement to protect personal information; (2) prepare and implement the standard for work manual; and (3) implement education regarding these.  
• The security staff shall anonymize the personal content of genetic information, and maintain it separately from other information, unless consent to open the personal information is given.  
• Security including restriction on entrance to the room where genetic information is maintained can be considered.  
• Detailed criteria can be stipulated by the Minister. |
Appendix 2. Public Events Organized by the Centre for Democracy in Science and Technology (Source: http://blog.peoplepower21.org)

<table>
<thead>
<tr>
<th>Date</th>
<th>Activity</th>
</tr>
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<tbody>
<tr>
<td>18–01–1999</td>
<td>[debate] Legal responses on human cloning</td>
</tr>
<tr>
<td>20–08–1999</td>
<td>[workshop] Environmental justice and biotechnology watch movement</td>
</tr>
<tr>
<td>28–08–1999</td>
<td>[debate] Technological background and social implications of information age</td>
</tr>
<tr>
<td>01–10–1999</td>
<td>[lecture] Science and technology policy and citizens’ movement</td>
</tr>
<tr>
<td>23–10–1999</td>
<td>[debate] Evaluation and prospect of the movement on medical industry</td>
</tr>
<tr>
<td>26–02–2000</td>
<td>[debate] Science, technology, and human rights</td>
</tr>
<tr>
<td>01–06–2000</td>
<td>[workshop] Making biotechnology safety and ethics into law</td>
</tr>
<tr>
<td>29–06–2000</td>
<td>[debate] Biotechnology special 1: human embryo cloning and “14th day”</td>
</tr>
<tr>
<td>28–04–2001</td>
<td>[debate] NMD/TMD and East Asian military competition: focus on China and Russia</td>
</tr>
<tr>
<td>02–06–2001</td>
<td>[workshop] Science, technology, and human rights</td>
</tr>
<tr>
<td>08–06–2001</td>
<td>[debate] Regulating gene test and genetic information use</td>
</tr>
<tr>
<td>30–06–2001</td>
<td>[debate] Open-source movement and NGOs</td>
</tr>
<tr>
<td>01–08–2001</td>
<td>[debate] Public symposium on social and ethical issues of the usage of human genetic information</td>
</tr>
<tr>
<td>13–10–2001</td>
<td>[debate] Biotechnology and gender in Korea</td>
</tr>
<tr>
<td>18–10–2001</td>
<td>[debate] Symposium on the prospects, limits, and alternatives of human embryonic stem cell research</td>
</tr>
<tr>
<td>08–01–2002</td>
<td>[debate] Glivec, a medicine for life or profit?</td>
</tr>
<tr>
<td>07–02–2002</td>
<td>[debate] Bioethical legislation</td>
</tr>
<tr>
<td>25–07–2002</td>
<td>[debate] Responding to Industrial Education Promotion Act Amendment</td>
</tr>
</tbody>
</table>

References


Seyoung Hwang is senior research fellow at the Center for Educational Research, Seoul National University. Her interests include public participation in science and technology issues and the role of science and scientists.

Margaret Sleeboom-Faulkner is professor of anthropology at the University of Sussex (Brighton, UK). She leads the Centre for Bionetworking and two projects on science collaboration in innovative stem cell therapies (ESRC, 2011–2014) and stem cell banking (ERC, 2012–2017).