

# Biomedtech Island Project and Risk Governance

—Paradigm conflicts within a hidden and delayed high-tech risk society

*Chou, Kuei-Tien*

Associate professor, National Taiwan University, Taiwan

## **Abstract**

Among global fierce competitions of biotechnological R&D, as a junior technology learning country and a burgeoning IT power in East Asia, the Taiwanese government declared to boost the project— “Island of Bio-medical Technology” in 2005. This project contains three programs: Taiwan Biobank, NHII (National Health Information Infrastructure), and clinical medical treatment industry. It attempts to combine niches of local IT industry superiority to construct electronic bio-medical industry thus become the gene research center of global Chinese and develop corresponsive systems of clinical medical treatment industry simultaneously. However, these beaming techno-industrial policy decisions are encountering highly suspicions in terms of human right, ethics, and society development. They not only rouse continuous paradigm war of risk but also bring challenges to the government’s capacity on risk governance in its technological policy decision-making.

Within local social context, recent-launched human right and social movements such as “Anti-National IC Card”, “Anti-Health Insurance IC Card”, and “Anti-Citizen Fingerprint Database” arouse paradigm conflicts of risk such as discourses on “efficiency vs. safety” and “progress vs. human right”. These problems will directly impact on policy promotions of Biobank and electronic bio-medical industry. Meanwhile, since such techno-industrial policy involves both ethical restricts of Universal Declaration of Human Rights and risk governance construction of disputable technology. Thus, new governance challenges emerged under local technological decision-making model of an economic logic which gets used to monopolistic technocracy and “values technological/scientific R&D, ignores risk”.

Based on current technological policy decision and governance relation, this article mainly discusses how local risk dispute movements deal with paradigm conflicts with existing government policies. In addition, this article aims to explore new governance moments in a so-called “double risk society” with distinctive local

risk governance and structural culture such as allocative technocracy with unilateral risk assessment, unilateral risk communication, transparency-lacked policy decision, integrity-lacked responsibility, lack of public participation, lack of public learning and trust construction, and problem outbreaks of hidden and delayed risks. Relatively, in recent years, the special resolution mechanism of “democratization of expertise and extended peer communities” in EU technological governance mechanism emphasizes multilateral and participative risk assessment and risk communication, and transparency and responsibility of policy decision. As to speak, this gradually develops as a new model of global risk governance. Even so, what deserves deliberation is— as a link in the chain of East Asian society; does such social risk culture of “institutional hidden and delayed risk” in Taiwan reveal similar social structure as that of South Korea, which is now clouded with the scandal of stem cell research? Therefore, we need to debate whether the newly-developed EU risk governance model can easily be applied in various distinctive local risk societies? Or, is there a need to take chronic distinctive risk culture and society communication structure into consideration while implementing these governance strategies?

From another aspect, under fierce global competition in techno-industry, for East Asian countries those seem in lack of severe risk governance, whether local risks raised would reversely impact on world countries then develop into even blindly globalizational risks is still worth investigating.

**Key words:** Paradigm war, contested issues, social movement, risk governance, double risk society, delayed high-tech risk society

# Biomedtech Island Project and Risk Governance

—Paradigm conflicts within a hidden and delayed high-tech risk society

*Chou, Kuei-Tien*

Associate professor, National Taiwan University, Taiwan

## **I. Problem identification**

For developmental states, technocrats and science elites are usually monopolizing formulations of technological and industrial policies. From the 1980s, these policies successfully create development in machinery, electronics, information, optoelectronics and communication in newly industrial countries such as Taiwan, South Korea and Singapore. Accordingly, in the 1990s, these technological latercomer countries are able to hold their stance in related technological industries and R&D, even to catch up from behind in 2000 and after<sup>1</sup>.

As we observing development of global techno-industry and technological R&D competition from the point of view of industry division and information economy, these electronics and information industry based techno-industry and R&D competition are enjoying gains from global information economy and the oncoming of “post-industrial society” and “network society”. Meantime, basic infrastructures of closely interacted globalizational politics, economy, culture and society are founded. Even some technological latercomer countries have been lagging behind; gradually, they are still able to catch up with global trend of information economy. However, along with the rapid development of knowledge economy and technological R&D competition, some newly developed technologies (such as genetically modified foods, genetic medicine, nanomedicine, nanofoods, and electronicalized technology system and genetic nanomedicine that combine information and digital technology) bring highly uncertainty to human beings in terms of health, ecology, society and ethics. Consequently, “world risk society” or “globalizational risk” formed. In other words, such occurring future-oriented technological development is disarranging social trust and interactions within local societies. Meanwhile, risk governance capacity of

---

<sup>1</sup> Semi-conductor, information and optoelectronics industries in Taiwan and South Korea hold considerable production proportion in global markets. For instance, in 2005, the distribution of LG electronic plasma TV outnumbered those of Sony in global market. (The statements were concluded from the reference news.) (2006.4.14 Yahoo Kimo Stock Market News. Samsung back to electrics market of Taiwan. Entering the war of plasma TV sales. <http://tw.stock.yahoo.com/xp/20060414/50/2084959412.html>)

governments in the world and transnational governmental organizations are being tested.

Followed the viewpoints of risk governance, risks of health, ecology, society, and life ethics caused along with development of newly technology has reached its limitation in terms of global technological policy and traditional operation of technological R&D, and being pressed to propose a risk governance model in respond to these newly future-oriented technology for reaching a balance between technology and society and to maintain an advantageous position. Hence, such phenomenon becomes not only a great challenge for advanced industrial countries, but also for newly industrial countries. The problem is that traditionally, newly industrializing developmental states tend to apply the logic of “valuing technological R&D, ignoring risks” to undergo direction of technological industry and formulation of technological policy. Also, technocrats and science elites still attempt to duplicate the previously successful example of information industry – the state as the fundamental role to integrate investment and R&D in order to lead development of these sensitive technologies and to pursue learning and chasing for high-tech industrial development. Consequently, such operation model makes the society unable to react to risk governance of sensitive technology system.

From this, two problems can be identified. First, developments of sensitive technologies may help newly industrial countries hold superior stances. However, since technocrat-monopolized technological policy decision-making is in lack of bilateral and democratic risk communication, tensions between technological development and the society therein aroused, even creates serious social distrust. Second, for take advantages in global technological R&D competition, developmental states tend to apply loose risk governance model. Also, technocrats and science elites are accustomed to apply traditional positivist risk assessment for technological policy decision-making. Also, they intentionally and institutionally ignore the existence of social risks, so as to result in disconnection with global risk governance trend. Such circumstance may reflexively stimulate and influence risk governance models of other countries and cause vicious technology competition and policy relaxation. Scandal of South Korean scientist Hwang Woo-suk can be the example of the latter statement. Dr. Hwang claimed a series of remarkable breakthroughs in stem cell research. This caused great pressure of global technological R&D competition. However, the story supervened scandal outbreak of research ethics break for he fraudulently reported to have succeeded in creating human embryonic stem cells by cloning in November

2005<sup>2</sup>.

In East Asia, as a junior learner in terms of technology, or, say, emerging power in terms of information industry in the environment of fierce global competition in biotechnology R&D and various industries, the Taiwan government announced to further “The Taiwan Biomedtech Island Project”. It includes three subprojects: Taiwan Biobank, National Health Information Infrastructure (NHII)<sup>3</sup>, and a clinical trials research system. The Taiwan government attempts to combine superior niches of local information industry in order to construct electronicalized biomedtech industry for building the country as the “Global Chinese Genetic Research Center” and developing related clinical trials research system. However, these glary techno-industrial policies are under suspicion in terms of human right, social trust, and ethic. They not only arouse continuous risk paradigm conflicts, but also bring challenges to the government’s risk governance capacity in its technological policy decision-making.

Correspondingly, dual risk paradigm conflicts between the government and social movement groups formed in the Taiwanese society. Technological policy confrontation on issues of “Anti-National IC Card”, “Anti-NHI IC Card<sup>4</sup>”, “Anti-National Fingerprint Database” forms dual arguments below: “effectiveness vs. risk”, “centralized management vs. human right protection”, and “control to be safe vs. possible malfunction control”. These problems subsequently pose direct impact on policy implementation of Taiwan Biobank and electronicalization of medical records. Meanwhile, because these two subprojects involve not only restriction of global ethical norms (such as International Declaration on Human Genetic Data<sup>5</sup>), but relate to risk governance construction of disputable technology. Thus, new governance problems emerged for developmental states that chronically accustomed to technocrat-monopolized technological policy decision-making.

The foremost purpose of this article is to critically discuss decision-making problems of developmental states in dealing with disputable and sensitive technological policy. Also, this article attempts to analyze – as Taiwan follows the tradition of technocrat and science elite dominated technological policy for learning and chasing newly developed technology, what kinds of risk governance paradigm conflicts will be formed? What kinds of model and culture will be created due to

---

<sup>2</sup> (2006.1.12 The Guardian newspaper “Disgraced stem cell scientist blames researchers” <http://education.guardian.co.uk/higher/research/story/0,,1684954,00.html> )

<sup>3</sup> For this part we focus on discussions on “electronicalization of medical records” in this article.

<sup>4</sup> NHI IC Card = National Health Insurance IC Card.

<sup>5</sup> UNESCO (2003). International Declaration on Human Genetic Data <http://unesdoc.unesco.org/images/0013/001331/133171e.pdf#page=45>

confrontation between disputable technology policy decision-making and the society? Especially, main focus of analysis is on discussing how technocrats undergo risk governance deliberations on disputable technological policy, including exploring what kind of governance paradigm they apply for doing risk assessment, risk communication and solving the problems of diminishing public trust? What kinds of corresponsive special and local risk structure and risk culture will be developed? These are all dilemmas for sensitive technological policy operation in development states.

Secondly, discussions on the Taiwanese society will be emphasized to further deliberate the pull-and-push tension behind such special risk governance structure and risk culture. Phenomena observed from discussions will be examined if they are general dilemmas and features for newly industrializing countries in terms of technological development; or, if they cause a hidden and delayed high-tech risk society that is weaker than those of western advanced industrial countries and with double risks, and possibly pose influence on global risk governance.

## **II. Theoretical framework of glocalizational risk governance**

### **2.1 Genetic and medical information risks**

Contemporary newly sensitive technologies are usually with the attributes of being large-scale, centralized, and involving group subjects. At the same time, within basic structure of global information, these large-scale and centralized group data turn to be trans-regional and quickly circulated. Therefore, such kind of technological R&D is with the innate effect to be globally circulated. Especially, along with the combination of information economy and commercial application, once there is careless in dealing with group data, risk effect caused will be transmitted globally. To be detailed, information collection, research and application of electronic data are themselves involving highly uncertainty of data storage and circulation security. At any moment, it is very possible that they will be invaded, duplicated and modified. Once these data are stolen, it could cause globalizational risk effect.

Establishments of large-scale genetic database and implementation of electronicalization medical records are all with the threats listed in above paragraph. Regarding Biobank establishment, along with the breakthrough of “the cloning of Dolly” in 1997 and “human genome sequencing” in 2000, scientists in world countries are gradually conceiving large-scale human genetic sample collection (Petersen 2005).

However, in 1998, disputes caused by the Icelandic biopharmaceutical company deCODE pushed world countries start to value legal, social and ethical risks caused by establishment of large-scale genetic database (Greely 2000, 2005; Arnason 2004; Wendler 2002), especially implications of genetic privacy and social discrimination (Rothstein 2005; Noble 2006; Tavani 2004), genetic database research and ethics of commercial application (Rothstein, 2002; Terry 2006), genetic research responsibility and social participation (Malinowski 2005; Racine 2003), mass disasters caused by genetic information divulgence (Knoppers 2005), and ethical problems of personal medical records and genetic information (Regidor 2004). Besides, regarding global risk governance, from the perspective of group and individual genetic rights protection in scientific R&D, ethical concerns of genetic data/samples collection and biobanks establishment are included in the Universal Declaration on the Human Genome and Human Rights announced by the United Nations Educational, Scientific and Cultural Organization (UNESCO) in 1997. Suchlike ethical concerns are being more concretely expressed in International Declaration on Human Genetic Data<sup>6</sup> announced by UNESCO in 2003. The declaration indicated that the specialties of human genetic information are protection of privacy and confidentiality, access to data, and free from discrimination in the process of data collection, handling, usage, and preservation. Possible exploitation during data collection process by transnational companies and R&D sectors in developing countries are discussed as well. Above discussed viewpoints and values involve generality of human right. Although these viewpoints do not directly infer that technological R&D and commercial application of genetic database will gradually enter development of global networks; in fact, they imply genetic research would cause ethical risks in global societies.

Even, in two documents from WHO<sup>7</sup> and Council of Europe<sup>8</sup>, to agree by mere coincidence, principles of privacy, confidentiality, rights of and control, free from discrimination are considered, so do ethical doubts and breach of large-scale biological sample collection are considered. These two documents also clearly point out that it is possible global ethical and social uncertainties will be caused (Chou 2005a). It is thus evident that because collection and establishment of large-scale genetic database

---

<sup>6</sup> UNESCO (2003) – International Declaration on Human Genetic Data. <http://unesdoc.unesco.org/images/0013/001331/133171e.pdf#page=45>

<sup>7</sup> WHO (2004) – Genetic Databases – Assessing the Benefits and the Impact on Human & Patient Rights. European Journal of Health Law, p. 79-84. <http://www.law.ed.ac.uk/ahrb/publications/online/whofinalreport.pdf#search='Genetic%20Databases%20%E2%80%93%20Assessing%20the%20Benefits%20and%20the%20Impact%20on%20Human%20%26%20Patient%20Rights'>

<sup>8</sup> Council of Europe – Convention on Human Rights and Biomedicine. <http://www.oup.co.uk/pdf/bt/cassese/cases/part3/ch16/1121.pdf#search='Convention%20on%20Human%20Rights%20and%20Biomedicine'>

involves sensitive social and ethical concerns for individuals, clans, and ethnic groups in the process of data storage, research and application, it is therefore considered that genetic research must be regulated within global framework instead of being merely a legal issue in one single country. Especially, as genetic data are being collected, stored and managed by computers, it is yet more possible to be divulged, duplicated and modified, even being transmitted cross boundaries, consequently to cause global risks of information divulgence and illegal transmission. Just like the subproject of electronicalization of medical records, what disputable is the possible breach to human rights and privacy, much less to compare, research, develop and apply electronicalized genetic data and medical records.

As basic structure of information networks being developed and employed, medical record electronicalization is sure to bring risks and impacts. Already, the situation of information divulgence liability caused by mal-management of medical records was quite complicated (Andrew 1992), medical record electronicalization makes the problem even troublesome. The issue reached its peak when the US Congress passed the Health Insurance Portability and Accountability Act<sup>9</sup> (HIPAA) in 1996 (Buckman 2004). While dense global information networks stimulate quick transmission, exchange, duplication and production of various kinds of knowledge, information and records, electronicalization of medical records also brings convenience in information exchange and management, such as reduced management cost and quicker information exchange speed. However, relatively, electronicalization of medial records does cause considerable social risks, especially in the aspects of privacy protection (Gilbert 1997; Petersen 1995; Rackett 1997; Steward 2005), social discrimination and privacy breach due to information divulgence, privacy and ethical jeopardy resulted from commercial application of EMR (Graham 1987). Particularly, with respect to transnational pharmaceutical R&D, EMR are most favored by pharmaceutical companies for they are easily to be transmitted, advantageous for inventing new medication, and can be the crucial reference for opening new markets. However, possible risks of privacy breach and social discrimination will be amplified and reproduced within global information networks without end. In other words, social and ethical risks caused by storage, management, circulation and application of EMR are not only national and regional, but also global.

The Taiwan government attempts to combine competition niches of information industry with the Taiwan Biomedtech Island Project, which including genetic database

---

<sup>9</sup> Health Insurance Portability and Accountability Act (1996). <http://thomas.loc.gov/cgi-bin/query/z?c104:H.R.3103.ENR>:



establishment, electronicalization of medical records and Bioinformatics. To such an extent that the society has to face risk challenges cause by sensitive technologies.

## **2.2 Technological policy and risk governance**

R&D competition of science and technology essentially attracted attentions of world countries. Nevertheless, as breakthroughs of information and communication technology push forward development of global information economy, science and technology therefore face more intense global competition (Stein 2002; Gibbons 1994). From 1990s, world governments cooperate to formulate competition and benefit oriented technological policies for winning superiority, even the leading role, in global scientific and technological R&D competition. In other words, globalization of science stimulates yet fiercer technological R&D competition internationally. Even, with the attitude to learn and catch-up with global techno-industrial trend, newly industrializing countries attempt to dig out techno-industrial policies beneficial for national niches (ibid).

Yet, though fierce competition in global techno-industry brings more intense development in global economy; it does create serious ecological and environmental destruction and result in “globalization of risk” (Giddens 2002) and the effect of “world risk society” (Beck 1999). With spring up of all kinds of criticisms, from “small is beautiful” (Schumacher 1989) in the 1970s to the paradigm of sustainable development in the 1990s, more and more people are expecting that the state can be transformed from a economy development oriented “technological regime” aiming at technological R&D competition and innovation to a regime that concerning sustainable living and development (Smith 2001). To consider from another aspect, the technological policy decision-making model that valuing economic and technological R&D competition and national superiority in innovation is being challenged severely. Traditional technocrat and science elite dominated technological policy ever tried to discourse upon national benefit oriented techno-industrial policy, and it did cause positive effects (Gottweis 1998). However, since risks on global ecology, health, society, and ethics are involved, governance dilemmas therein roused. On the one hand, technocrat-dominated regime is facing crises in public trust on policy decision-making quality; on the other hand, they are being challenged with trans-regional risk governance. Hence, nationally, legitimacy of technological policy which lacks democratic decision-making process is being critically debated (Irwin 1995; Fischer 1989; Jasanoff 1990). Globally, technocrat-dominated regime is being examined to see if it has the capacity of global risk governance.

When doing risk assessment and risk management, technocrat and science elite dominated regime tends to apply positivist scientific evidences as the fundamental authority for decision-making and deem that technological assessment should be done in accordance with objective and neutral scientific rationality to affirm the existence and effect of “fact” and to exclude political intervention and social value of non-scientific rationality (Wynne 1980; Rutgers & Mentzel 1999). Such positivism based risk assessment paradigm has been the main stream for world technocrats’ technological policy decision-making chronically. It deems national technological policy and social engineering as parts of scientification and considers that all political and policy affairs must be evaluated and implemented according to positivism and scientific rationality. However, such say-so scientific decision-making ideology encountered governance dilemma because disasters and risks are emerging in an endless stream. Hence, people started to criticize politicization of science (Hoppe 1999). It can be seen that scientific affairs and policy must be dealt with together with impacts on political and social values.

Traditional practice by technocrat-dominated regime to divide facts and values has been unable to handle more and more risks resulted from scientific uncertainties. In fact, development and assessment of many scientific affairs should be based on social values and contexts. They are being mutually influenced simultaneously. For example, when developing a certain techno-industry or evaluating a certain risk affair, degree of social acceptance and social value are the main basis for constructing further judgments on risk assessment and policy decision. However, as contemporary newly globalizational risk issues and sensitive technological industry involve more and more uncertainties (such as across-boundary technological impacts are uncontrollable, uncountable, irrecoverable and noncompensable) (Beck 1993; Ravetz 1999; Chou 2003), unilateral scientific positivism centered risk assessment turns to lose effectiveness and is in need of a new set of risk governance paradigm.

Besides, technological innovation and R&D being emphasized in world technological policies are bottlenecked as well. Usually, traditional technocrat-dominated technological innovation and R&D tends to emphasize linear economic growth. However, when encountering sensitive high-tech risks; market, competition, and effectiveness oriented development ideology embraced by such paradigm would subject to fierce suspicions and challenges on its legitimacy. Hence, technological innovation systems of the EU are required to draw into more democratic governance procedures. For example: public involvement and participation are applied

to examine risks resulted from innovation of national technological policies (Gonçalves 2005). That is, in the environment of fierce global technology competition, innovation, and R&D policies valued by world countries can no more be promoted by the development logic of cost-saving, benefit-driving, and effectiveness-oriented. Still, great risks being posed on ecology, health, society and ethics cannot be ignored. To think from another perspective, when promoting these disputable and sensitive high-tech technologies, risk is no more a by-product of industrial society (Beck 1986), but the co-evolution of technological development, which then derives various social risks and uncertainties as these newly technologies evolved (Gibbons 1994). Especially, in modern society, knowledge-based innovation and R&D is no more an independent action or a simple behavior in social division, but involves more and more complicated, overlapping, and cross-checking challenges. Therefore, in managing socially distributed knowledge (Nowotny & Scott & Gibbons 2001), especially under the trend of globalizational knowledge economy competition, new risk governance paradigm should be formed.

In recent years, technocrats have had experienced the bitterness of public distrust on related technological and risk policies in many countries. Thus, three fundamental directions are decided: to enhance transparency of decision-making process, to construct models of public participation and decision-making, and to differentiate scientific risk assessment and risk governance (Marchi & Ravetz 1999; Löfstedt 2002). From the perspective of post-normal science, when considering various kinds of trans-regional risks and threats caused by rapid development of new technology, many scholars indicated “*traditional authoritative and centralized technological policy decision-making becomes unable to react to rapid social changes and dilemmas after risk outbreak*” (Healy 1999; Luks 1999; Marchi & Ravetz 1999; Ravetz 2002). More, positivist scientific risk assessment model becomes unable to respond to various kinds of uncertain ecological, healthy, social and ethical risks. Accordingly, it is quite essential to develop decentralized, transparent, diversified and open risk assessment and technological policy decision-making process (Gerold 2001; IRGC 2005). To be detailed, regarding expertise monopoly and authoritative malpractice in technological policy decision-making process, principles of “democratizing expertise” and “extended peer communities” become worthy of deliberation<sup>10</sup>. Based on these two principles, risk assessment should include enhanced diversity and be early warning. Hence, participants in risk assessment include academics, risk takers, and the civil society (Gerold 2001). Risk assessment and investigation should be based on not

---

<sup>10</sup> Report of the working group “democratizing expertise and establishing scientific reference systems” (2001). [http://ec.europa.eu/research/science-society/pdf/governance\\_questionnaire\\_01.pdf](http://ec.europa.eu/research/science-society/pdf/governance_questionnaire_01.pdf)

merely scientific considerations; viewpoints in terms of policy, society, economy, gender, environment, law, and culture should be taken into consideration as well (ibid.). Also, experts from various fields will participate into risk assessment including those from the government, industries and the opposition. Also, professionals in various fields should be invited as well for carrying out cross layer participation (ibid.)<sup>11</sup>. Still, besides expert and cross layer examination, participations of lay persons are even more crucial for this will bring into lay knowledge and mutual supervision (ibid.).

While facing more and more complicated technological uncertainties, in order to reduce drawbacks of technocrat-dominated regime, to enhance quality of technological and risk policy decision-making, and to recover public trust on risk policy, the European Union (EU) and the International Risk Governance Council (Renn 2005) proposed new risk governance paradigms respectively. Science and Society Action Plan<sup>12</sup> (EU 2002) proposed by the EU affirmed that risk governance including risk identification, risk assessment, risk management and risk communication. Since risk issues involve scientific uncertainty, risk assessment and management strategies are differentiated for developing independent and transparent risk assessment as the foundation of risk identification. On the other hand, risk communication and public participation are applied as the guidelines of risk governance. Similarly, in the IRGC document – IRGC White Paper No.1: Risk Governance – Towards an Integrative Approach (IRGC 2005)<sup>13</sup>, it stressed that risk governance including risk contexts and related risk policy decision-making process such as reactions to risk outbreak and related regulations. In addition, collection, analysis, and communication of risk information are important as well. It is because these diversified political and social contextual factors often influence the overall final risk governance policy decisions. In other words, political culture and risk perception formed in local societies are crucial factors in risk assessment and risk governance.

Under this meaning, risk governance operation becomes an integrated strategy – risk identification, risk assessment, risk perception and risk communication are links in the chain of risk governance (Gerrard, Simon, & Petts 1998; Chou 2005a). Namely, when making technological policy decisions, professional but narrow results of positivist scientific assessment cannot be the only accordance for making

---

<sup>11</sup> Governance in the UE – White Paper on Governance Work area 1: Broadening and enriching the public debate on European matters. [http://ec.europa.eu/governance/areas/group1/report\\_en.pdf](http://ec.europa.eu/governance/areas/group1/report_en.pdf)

<sup>12</sup> European Commission – Science and Society Action Plan. [http://ec.europa.eu/research/science-society/pdf/ss\\_ap\\_en.pdf](http://ec.europa.eu/research/science-society/pdf/ss_ap_en.pdf)

<sup>13</sup> IRGC White Paper No.1: Risk Governance - Towards an Integrative Approach (2005) [http://www.irgc.org/irgc/projects/risk\\_characterisation/\\_b/contentFiles/IRGC\\_WP\\_No\\_1\\_Risk\\_Governance\\_\(reprinted\\_version\).pdf](http://www.irgc.org/irgc/projects/risk_characterisation/_b/contentFiles/IRGC_WP_No_1_Risk_Governance_(reprinted_version).pdf)

technological policy decisions. Social and ethical uncertainties derived from scientific development and the responsive public risk perception and risk communication all are important references for the overall risk governance and risk assessment, especially political, social and institutional contexts embedded. Therefore, in the process of technological policy decision-making, public risk communication and risk perception must be yet more valued. Moreover, public participation should be promoted to stabilize the foundation of risk policy decision-making.

Heading on requests for new risk governance paradigm, the EU (Science and Society Action Plan 2002) proposed four democratic procedures as basic principles for making technological policy decisions: 1) accountability – social responsibility should be respected; 2) accessibility – openness and control of stakeholder participation should be maintained; 3) transparency - transparency and information openness should be emphasized to ensure stakeholders' rights of acknowledgment; 4) participation – participations of the public and social groups should be promoted to increase legitimacy of risk governance (Chou 2005a).

In short, technological policy decision-making faces challenges and requests of new risk governance paradigm. Especially, with the development of globalization, various kinds of technological risks are emerging in different fields and posing impacts on ecology, human health, society and ethics. However, developments of above risks are often beyond risk governance capacity of technocrats and science elites who adhere to traditional positivist risk assessment. More, communication, perception and judgment of considerably complicated political, social and ethical uncertainties are involved. Hence, for ensuring quality and legitimacy of technological policy decision-making, public participation should be promoted in order to create a more democratic, transparent and diversified risk governance process. This could also be the fundamental basis for the public to learn, to accept and to judge impacts caused by collisions between technological development and consequent risks.

### **2.3 Glocalizational risk governance**

One crucial problem that risk governance encountered is that as different kinds of newly-developed risks become cross-boundary, uncontrollable and unpredictable, they cause serious impacts on ecology, health, society and ethics worldwide. In other words, this is the general phenomenon of “globalization of risks” (Giddens 2002; Bekkers & Thaens 2005) or “world risk society” (Beck 1999). These risks develop into globalizational risks with the intense interactions and exchanges among actors and

networking nodes<sup>14</sup> in global society. That is, regarding development and dialectics of globalization, “risk” becomes the general phenomenon of globalization and develops into the so-called “globalizational risk” (Chou 2003). To be detailed, although risk formation is under the influence of globalization, what important are the distinct features, definitions and connotations embedded in the diversified political, social, psychological, cultural and institutional contexts in local societies (Beck 1986; Slovic 2001; IRGC 2005; Kasperson, Jhaveri, & Kasperson 2005). From the perspective of cultural anthropology, such contextualistic local risks bring about echoes, dialectics, influences and stimulation in respond to globalization, so as to create glocalizational risks<sup>15</sup> (Robertson 1992; Appadurai 1998).

There are unique patterns and operational logics in different societies and systems. They are embedded in cultures, events and historical traditions in local societies, so as to form politics and governance models within. As globalizational risks entering local societies, they are sure to experience the distinct political, institutional and cultural conflicts within, thereby contextual and Glocalizational risks are developed. According to this logic, there are two interesting points in analysis of Glocalizational risk governance. First, technological policy decision-making models, stakeholders, systems, politics and conflicts in local societies are main points for observation. More, glocalizational risk governance structures and problems will be evolved from issue contexts and history of conflicts. Second, what deserves further deliberation is how glocalizational risk governance structure and culture would stimulate, feedback, and poses influence on globalizational risk governance then to bring about dialectics in respond to general globalization<sup>16</sup>.

Under such contexts, risk governance in newly industrializing countries is worthy observation. From the perspective of “systemic risks” proposed by the OECD (2003),

---

<sup>14</sup> Here, Castells’ (1996) sagacious ideas of “network nodes” represent the relationships between globalizational and glocalizational risks. Basically, they are mutually mobilized and stimulated. And, the dialectics raised would pose influences on both of them. No matter a risk stem from which node (regional or country), it will be spread to local societies worldwide according to its (cause capacity), thus develop into mutually affected dialectical relationships among local societies. For instance, after the outbreak of 9/11 Attack; political, economic, social and cultural dimensions have been under immeasurable threats. Thus, globalizational terrorism, cultural confrontation, economic depression, and new political cold war were caused.

<sup>15</sup> Basic theses including the following: 1) features of globalizational risk formation and relationships between them and globalization; 2) how will political, institutional and cultural contexts in local societies shape glocalizational risks? 3) how to analyze the dialectical and mutual influence processes resulted from globalization and glocalization.

<sup>16</sup> In fact, risk governance models of the EU, IRGC, and UN were proposed in the beginning. To certain degree, they are general models that in accordance with global risk governance trend and regional features. However, we still need to further discuss risk governance structures and cultures in different countries/social contexts in order to examine influences of globalization.

problems and structures derived from political, social, cultural and scientific systems in newly industrializing countries have their specialties. On the one hand, internal political, economic, cultural, scientific and technological developments in these countries have been chronically dominated and influenced by advanced industrial countries, such as to expressing the attitudes of eager to learn and catch up with advanced industrial countries. However, due to compression of industrialization and globalizational technological R&D and economic competition; various aspects in local societies, such as institutional, scientific, cultural and social dimensions, are under serious compression by the log of economic competition. Thus, unbalance formed. On the other hand, in these newly industrializing societies of developmental states; decision-making, formulation and implementation of technological policy are chronically being dominated by technocrats and science elites. Although the patriarch's role of a "leader" in past society has been transformed into the role of an "instructor" (Evans 1995; Hsu 2002), there is still pronounced culture of centralized policy decision-making and authoritative domination. By the same token, even though the "instructor" had been successfully performed the role of promoting developments of information and communication industries within the historical structure of global OEM<sup>17</sup>, many problems are left behind as well, such as ecological destruction and social inequity. Still more, with the development of highly sensitive and disputable technologies; more transparent, open and diversified risk communication and policy assessment are needed as traditional technological policy decision-making models in developmental states encountered challenges in terms of legitimacy.

More, for junior industrial countries, whether in dimensions of political, social, cultural, scientific or technological policy decision, they tend to follow the operational model of traditional developmental states in dealing with risks; on the other hand, they are under great pressure of globalizational technological R&D and economic competition. Thus, the society itself becomes seriously in lack of the capacity to criticize and introspect, thus system gaps formed (Chou 2002, 2004). Consequently, lagging developments in terms of construction of regulation and institution, supervision of the civil society, risk communication of media, and public risk perception make the society becomes relatively insensitive in respond to risks. This is "systemic risks" proposed by the Organization of Economic Cooperation and Development (OECD); or, we can say, "double risk society"<sup>18</sup> – a hidden and delayed

---

<sup>17</sup> OEM (original equipment manufacture).

<sup>18</sup> In Chou (2000, 2002, 2004) successive researches on Taiwan's technological policies, such the risk "time bomb" (Beck 1993) formed by "system gaps" will seriously accumulate the society's risk governance, especially the highly public distrust on disputable technologies. Meanwhile, public trust on the government's risk governance capacity failed.

high-tech risk society. From observations to risk governance of such a society with “system gaps”, technocrat-dominated technological policy decision-making model plays the key role. In developmental states, technocrat and science elite dominated regimes often direct the development trend of all industries. Similarly, as those in western societies, technocrat and science elite dominated regimes in developmental states strongly embraces the paradigm of positivist scientific risk assessment. Concerning technological development of sensitive and disputable risks, they subjectively argue that risk assessment and risk governance should be done through a neutral and objective scheme in accordance with scientific rationality. Thus, technocrat and science elite dominated regimes in both Taiwanese society and western societies (ex: UK) are on a par. To be detailed, in newly industrializing countries, technocrat and science elite dominated regimes seemed to have great power in controlling and operating official and mainstream policy discourses. On the one hand, they are able to operate official and mainstream technological discourses of policy making decision; on the other hand, they are able to suppress objections through dominating academic networks. Thus, it reveals that the guiding patten of integrated technological policy formulation and development becomes top-to-bottom and lacks criticism and objections. Let along emphasis on risk and diversified, open and democratic decision-making procedures<sup>19</sup>. Based on such research foundation, policy decision-making process of the Taiwan Biomedtech Island Project will be examined to see if such authoritative and centralized policy decision-making model is able to respond to sensitive and highly-disputable technological risks and to react to challenges of consequent social movements and criticisms, so do the paradigm conflicts of risk assessment and risk discourses emerged afterwards. From cross discussion of above arguments, the following paragraphs intend to explore the special structural problems of risk governance culture in local society and their meanings to global society.

### **III. Technological policy decision-making and risk governance of the Taiwan Biomedtech Island Project**

#### **3.1 Technological policy decision-making contexts**

As a newly industrializing country with the attitudes of eager learning and to

---

<sup>19</sup> Chou (2004)’s technological policy analyses on Taiwan’s GMO agriculture showed a phenomenon – regarding science counseling and policy decision-making of mainstream science elites, there is a situation that the player is also the referee. Objections to mainstream science discourses were compressed through the scheme of administrative resource distribution. Hence, what we can see is that in related policies, there was no open criticism and opinions from academics. Policy decision-making process thus became unilateral.



catch up with advanced technology, the Taiwan government devoted to promoting techno-industrial policies in information, electronics, chemistry, and biotechnology industries. Taiwan attempts to seize its niche in the environment of fierce global competition and industrial division (Chou 2000). Within the background of cold war in global society and national authoritative politics, technocrat and science elite dominated technological policy decision-making model becomes the pronounced feature of developmental states (Evans 1995). In 1980s, as the policy decision-making scientific-consultation-based and technocrat-dominated mechanism in western industrial countries was under the challenge of democratic procedures (Jasanoff 1990; Dryzek 1997), technocrats still enjoyed its authoritative and instructive role, even until the 1990s when the role of developmental state had already faded away (Hsu 2002). At that time, in directing technological and industrial policies, technocrats and science elites still possessed their top-to-bottom directive way. Such kind of authoritative and centralized technological policy decision-making model has been continued until now, and then becomes the tradition of scientific policy operation in government sectors. It is not until the year of 2000 it started to face oncoming social challenges.

In the mid-1990s, world countries valued biotechnological breakthroughs in pharmaceuticals and agriculture. At the same time, genetically modified organisms (GMO) brought about social concerns<sup>20</sup>. In the 1980s, the Taiwan government devotedly promoted pharmaceutical industries. However, due to the distinctions of pharmaceutical industry, the government failed to make it a link in the chain of global OEM. Therefore, in confronting global competition in biotechnological R&D, following efforts were accomplished. In 1995, technocrats and science elites remade development strategies for biotechnology. In 1997, three pioneering technological project in the fields of genetic medicine, bio-pharmaceuticals and bio-agriculture were launched to foster the development of biotech industry. In 1998s, deCODE Genetics attempted to build large-scale genetic database in Iceland. This raised global disputes in terms of ethics, society and human right. Meanwhile, technological R&D cat-up in several countries was stimulated<sup>21</sup>. Within such international environment, technocrats and science elites proposed to establish Taiwan Biobank in 2000<sup>22</sup>. In 2003, initial Biobank researches of 3,312 samples were done. In 2004, it is proposed to launch Taiwan Biobank, a large-scale genetic database of 500,000 samples, just like the UK Biobank (Liu, Ching-yi 2004; Chou 2005a). Under such contexts, the Taiwan

---

<sup>20</sup> OECD (2003) deemed biotechnological industry as a newly-developed crucial knowledge-based industry, which would greatly influence the development of global economy.

<sup>21</sup> In around 2000, UK, Singapore, Estonia, Japan and Taiwan successively announced the establishments of large-scale genetic databases as the essential foundation of genetic medicine research.

<sup>22</sup> In July 2000, conference resolution of Academia Sinica academicians decided to fully support "Taiwan Biobank" establishment (Chou 2005a).

government announced the idea of the Taiwan Biomedtech Island Project in December 2004 and to formally initiate this project by investing 15 billions NTD (est. 375 million euros)<sup>23</sup>.

Such significant national technological policy includes three subprojects: National Health Information Infrastructure (NHII), Taiwan Biobank and a clinical trials research system. They are instructed by the Science and Technology Advisory Group of Executive Yuan, an organization with science elites who supervising policy formulation and information communication. Main focus is to make connection between genetic-pharmaceutics and information industry by combining Taiwan's existing niches in information engineering with subprojects of NHII, electronicalization of medical records, and Taiwan Biobank. At the same time, the government planed to develop biomedical technology research that matches up "Bio-IT" development in order to expand potential but crucial markets of genetic-pharmaceutics and genetic therapy. The government aims to build Taiwan as the "Research Centre for Genetic Medicine and Clinical Studies" in Asia (Science and Technology Advisory Group of Executive Yuan 2005). Regarding Taiwan Biobank project, technocrats was thinking to use systemic EMR and household register records as the bases for tracing associations and connections between illness and environment, then to facilitate the integrated cohort study. Besides, through construction of Bio-IT, millions of genetic data in Taiwan Biobank could be analyzed, decoded and studied. Eventually, through industrial application and R&D of EMR, Taiwan Biobank and Bio-IT, Taiwan is keen to win the niche in genetic illness and therapy markets that are characteristic of Chinese (Hsie 2004a; Hsie 2004b; Science and Technology Advisory Group of Executive Yuan 2005; Lie 2005)

Combining cooperation and planning of different governmental, academic and industrial sectors, the Taiwan Biomedtech Island Project actually involves two great risks. The first one relates to establishment of large-scale genetic database; the second relates to the circulation, calculation, delivery and duplication of electronicalized information. Both of them involves uncontrollable risks such as information divulgence, social discrimination and breaches in ethics and human right. However,

---

<sup>23</sup> Minister without portfolio Lin, Fon-chin proposed the projects of "Taiwan Biobank" and "Bio-IT" in the hope to win the genetic therapy market of 3 billion (est. 75 million euros). Taiwan Biobank, combining the Bio-IT project and inputs of the NSC, Academic Sinica, Industrial Technology Research Institute, DOH, and Vita Genetics, is the continuation of "Taiwan Genetic Database" proposed in February 2004. (2004a.12.4 Commercial Times. Hsie, Bo-hon. "MOI directs the establishment of the Taiwan Biomedtech Island Project." [http://grad.ncku.edu.tw/news/insur\\_dtl.asp?sno=869](http://grad.ncku.edu.tw/news/insur_dtl.asp?sno=869)) (2004b.12.4 Commercial Times. Hsie, Bo-hon. "To win global genetic medicine market, MOI is prepared." [www.tcoc.com.tw/newslist/700/878.htm](http://www.tcoc.com.tw/newslist/700/878.htm))

power to policy decision-making lay in science elites in Institute of Biomedical Sciences (IBMS), Academia Sinica. They dominate the overall process of scientific counseling and policy decision-making. With the intense top-to-bottom network combining technocrats in Science and Technology Advisory Group of Executive Yuan, National Science Council (NSC) and Department of Health (DOH), national science resources were mobilized to fully support this official techno-industrial R&D project (Lie 2005). Within this background, technological policy decision-making network formed by technocrats and science elites in developmental states still plays crucial role in confronting fierce global competition in genetic medicine and technological R&D. The network attempts to promote a high-tech industry, which is characteristic of national distinctiveness and is capable to win its niche in global arena. This will be achieved by studying Taiwanese ethnic groups, combining Bio-IT development, then eventually to accomplish the establishment of “Chinese genetic database”<sup>24</sup> for winning the leading role in world genetic medical research in terms of Chinese illness therapy (Chang 2003). To certain degree, this discourse expressed the voice that newly industrializing countries are keen in exploring their niches in global market for creating breakthroughs and winning the leading role in genetic medical research arena. However, obviously, this discourse agrees to the logic of valuing technological R&D competition and economic development by duplicating and promoting previous development model of information industry. Such ideology is similar as Chou’s analyses about technological policy of Taiwan’s GMO agriculture<sup>25</sup> (Chou 2000). Yet, formulation of the Taiwan Biomedtech Island Project involves highly sensitive and highly disputable technological risks; it cannot be accomplished by past policy decision-making and assessment models. Therefore, what we need to deliberate is what kinds models of risk assessment, risk communication and risk governance would technocrats apply for dealing with and resolving difficulties that the Taiwan Biomedtech Island Project may encounter.

Basically, risk assessment and risk governance of the Taiwan Biomedtech Island Project involve problems in different dimensions. So do all genetic research projects.

---

<sup>24</sup> Prof. Chen, Yuan-chon, director of the Institute of Biomedical Sciences, Academia Sinica indicated that “the Chinese genetic database established by Taiwan can be applied by Chinese in China, Hong Kong, Singapore, and other overseas Chinese.” (2003.7.22 Taiwan Today News Network. “Taiwan Biobank, consider one of the best.” <http://www.tnn.com/cna/news.cfm/030722/101>)

<sup>25</sup> In comparing development models and strategies Taiwan used for promoting bio-agricultural and IT industries, Chou (2000) indicated “for catching up with the trend of global bio-agricultural competition in the mid-1990s, technocrats attempted to quickly duplicating the model being used for past IT industry development. The government built agricultural science parks around the island. There were also large amount government investments into biotech companies. Under such a development strategy of “valuing technological R&D but ignoring risk”, the state does not have to deliberate too many biotech risks. Just like the phenomenon revealed in for anti-GMO movement.

In the initial process of Taiwan Biobank formulation, ELSI (ethical, legal, and social issues in science) evaluation was suggested, especially problem analysis and amendment suggestion relating to large-scale genetic database establishment and possible breach to Computer-Processed Personal Data Protection Law<sup>26</sup>. On the other hand, Taiwan Biobank was initially launched as “pioneering project”; meanwhile, “practicability assessment<sup>27</sup>” was required to be done (Hsei 2004b). The former is social risk assessment for Taiwan Biobank; the latter is about policy assessment. These two are all included in the framework of the Taiwan Biobank project conducted by Institute of Biomedical Sciences, Academia Sinica. That is to say, their independence and objection are under suspicion.

For policy assessment, there is a situation that the player is also the referee. In the beginning of 2004, as the Science and Technology Advisory Group of Executive Yuan announced Taiwan Biobank establishment, practicability assessment was authorized to be done by the Institute of Biomedical Sciences, Academia Sinica, which is also the organization be responsible for Taiwan Biobank establishment. That is to say, science elites play both the roles of counselor and promoter of national technological policy simultaneously. This makes the public confused. However, it also reveals that technocrats and science elites are powerful in making national technological policy decisions. There are also close relationships between science elites and national technology policy.

The ELSI risk assessment performs the function to resolve social, legal and ethical problems emerged due to Taiwan Biobank establishment. However, its structure and members are designed under the framework of Taiwan Biobank project (DOH 2005), which is an ironically endorsement. Formalism and instrumentalism shown from such arrangement makes science elites become over confident that they objectively assuming that by studying Taiwanese’ distinct genes, they will be able to build the “World Chinese Genetic Research Center”. Even, they attempted to the complete national health insurance system and household register records to facilitate

---

<sup>26</sup> Computer-Processed Personal Data Protection Law. <http://db.lawbank.com.tw/Eng/FLAW/FLAWDAT0201.asp>

<sup>27</sup> From August 2003, the Institute of Biomedical Sciences, Academic Sinica has been mandated to undergo “practicability assessment” for Taiwan Biobank establishment. (2004.3.31 Chen, Yuan-chon. “To undergo practicability assessment of Taiwan Biobank.” A result report of National Science Council sponsored research project. ) The results of practicability assessment indicated that Taiwan has its own special ethnic groups, which is able to develop into the supply center of the Chinese Racial Database. Plus, since there is complete health insurance and household register system, it is to form a complete family disease database. (2004.2.25 Chao, Pei-ju & He, Pei-ju. “Taiwan is going to build disease and genetic database.” Commercial Times. <http://www.cyberbees.org/blog/archives/002764.html> )

<sup>27</sup> ibid.

Taiwan Biobank establishment. They totally disregard potential risks<sup>28</sup> (Science and Technology Advisory Group of Executive Yuan 2005; Chao & He 2004).

After knowing the whole process, local scholars criticized that there is no complete privacy protection mechanism to ensure human rights of genetic sample donors. In addition, the whole policy decision-making process appears to be some kind of black box operation (Chen 2003). Concerning governance of sensitive technological policies, Taiwan Biobank establishment fails to fulfill the four principles proposed by UNESCO's Universal Declaration on the Human Genome and Human Rights. Risks involving ethics, human right and the whole society are not regulated through public determination (Liu, Ching-yi 2004; Chou 2005a). More, comparing with risk governance mechanism of the UK Biobank, which of Taiwan Biobank is relatively in lack of critical introspections on professional and public consultation (Petersen 2005). Backing to real situation, as the government attempting to establish large-scale genetic database, they did not clarify potential risks and undergo bottom-up and open risk assessment and risk communication. Research units too were hurrying collecting blood plasma samples at the outset of 2006. Thus, hidden risks emerged and caused public distrust. Consequently, yet higher tension between the society and technological development raised (Chou 2005a).

Although technocrat-dominated risk assessment of Taiwan Biobank was acknowledged of ethical and social disputes involved; in fact, it still follows the ideology of positivist scientific risk assessment. As Wynne (1996) indicated, the government was trying to develop mainstream discourses such as "World Chinese Genetic Research Center", "utilizing the complete national health insurance system and household register records" to facilitate the construction of racial genetic database and to strengthen the importance of national technological R&D<sup>29</sup>. Also, it is believed that risk disputes involving ethics, human right and the society can be resolved by regulations. Even, they devalued social scrutiny as "reckless critics" can also be resolved by modifying guiding policies<sup>30</sup>. In other words, technocrats and science elites hold a simplistic view of risk assessment in dealing with great social risks involved in genetic database establishment. They did not really examine possible privacy breach, information divulgence, social discrimination and ethical harms in the

---

<sup>28</sup> Refer to footnote 26.

<sup>29</sup> On many occasions, science elites have been continued to falsely stress that world countries are trying to establish national genetic databases. Thus, Taiwan has to establish its own one. Scholars who advocated this idea including Prof. Lie, Min-hsao (vice president of the Academia Sinica) (Lie 2005) and Prof. Chen, Yuan-hon (director of the Institute of Biomedical Sciences) (Chen & Shen 2006). They are two major promoters and science counselors of national major genetic medical policies.

<sup>30</sup> Prof. Chen and Prof. Lie's replies in respond to criticisms from the society. (Chen & Shen 2006)

processes of saving, preserving and managing data. Instead, they considered that strengthening policy regulation and risk governance could reduce these risks. This means that they do not truly realized the importance of discreteness in the processes of gene collection and genetic database construction (UNESCO 1997; UNESCO 2003). Thus, under such contexts, in SWOT analysis of project report of “Taiwanese Disease and Genetic Database Establishment”, technocrats and science elites again proposed – the fundamental superiority of Taiwan Biobank research is that we can combine the complete health insurance system and household register records. Meantime, one weakness they observed and eager to solve is – the public often reject to trust in new technology.

The “simplistic view of risk assessment” also appeared in the informed consent designed by researchers. According to past analyses of Liu (2005), informed consent of Taiwan Biobank emphasized the purpose of health check-up for inducing blood donation. A new wave of social criticism thus raised. For instance, it is criticized that they ever “cheated” blood from aboriginals by the same scheme. Aboriginal groups started to pay attention on this issue<sup>31</sup>. Such kind of simple and instrumental risk assessment was under fierce assault by human right groups. It is because there are no backup measures and complete risk assessment and risk communication mechanisms to ensure privacy concerns of utilization of national health insurance system and household register records. Even more, blood plasma collection was done in the name of health check-up instead of telling the truth to donors. Such deeds not only serious breach privacy right, but results in great risks of social and ethical discrimination. It also violates the research ethics of “principle of voluntary un-paid blood donation”<sup>32</sup>.

The Taiwan Biomedtech Island project is another plan involving related social risk disputes. For Taiwan Biobank establishment, there are potential risks in personal and group genetic information divulgence. For NHII, there are potential risks in EMR circulation and possible divulgence of EMR. In facing challenges of new technological risks, if technocrats and science elites keep on applying old risk assessment and risk communication models and to ignore the existence of risks, they would be trapped in

---

<sup>31</sup> Journalist Chang, Li-wen had interviewed with aboriginals in Hwa-lien. She found that some aboriginals had been drawn bloods by different medical agencies for 8 times in 1 year. Most of them were done in the name of health check-up. Such scheme ignored donors’ right to know. Related discussions on this issue had caught aboriginal groups’ attention. (2006.1.23 China Times. Chang, Li-wen. “War of gene decode. Pain of the aboriginals.” <http://www.bio.idv.tw/data/data13/2001031901.htm>

<sup>32</sup> Prof. Liu, Ching-yi, vice president of Taiwan Association for Human Rights, publicly criticized the legitimacy of Taiwan Biobank establishment. Especially the point that the government naively attempted to combine Taiwan Biobank with national health insurance and household register information (Liu 2005; Liu 2006).

paradigm conflicts of risk governance.

### 3.2 Technological policy and information risk dispute

Taiwan Biobank, NHII and Bio-IT in the Taiwan Biomedtech Island Project all involve computer calculation and information circulation systems. Therefore, it is quite sensitive that there are risks exposed in the process of managing, exchanging, duplicating and using related information. More, for promoting development of medical industry and reducing costs, governmental sectors started to encourage exchange and delivery of EMR and electronicalized medical images in order to enhance the effectiveness of medical system. Thus, in 2005, National Health Information Infrastructure was launched<sup>33</sup>. The original idea of utilizing medical information can be traced back to the National Information Infrastructure introduced in 1994; combine with the National Health Insurance IC Card policy promoted by DOH in 1998, policy of electronicalization of medical records was able launched<sup>34</sup> (Graduate Institute of Building and Planning, National Taiwan University 2000). The first main idea of NHII is to strengthen the control and utilization of medical information through electronicalization of medical records. The second one is build intranet among hospitals in the country. This would strengthen the connection between medical industry and information system and to enable mutual delivery and exchange of EMR and related medical images. These two ideas are being promoted as national medical technological policies<sup>35</sup> together with the Taiwan Biomedtech Island Project and other bio-IT research projects.

Policies of electronicalization of medical records and intra-hospital medical information exchange and circulation included in NHII are similar with Taiwan Biobank project; they all face risk challenges of information security. In the past

---

<sup>33</sup> (2005.4.6 Science and Technology Advisory Group of Executive Yuan “Official launch of the Taiwan Biomedtech Island Project.” [http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=7&grpid=5&vroot=&cntgrp\\_ordinal=00060004&cnt\\_id=400](http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=7&grpid=5&vroot=&cntgrp_ordinal=00060004&cnt_id=400)) (2005.4.20 Department of Investment Services, Ministry of Economic Affairs. “Taiwan Biomedtech Island Project. 40 billion investment (est. 1 billion euros) in 5 year.” <http://investintaiwan.nat.gov.tw/zh-tw/news/200504/2005042001.html>)

<sup>34</sup> According to one research report “Mobilization Project of Kaohsiung as a Globalizational IT City” of Graduate Institute of Building and Planning (of National Taiwan University), regarding NHII launched by Executive Yuan in 2004, its application on medical and insurance management including distant treatment, electronicalization of medical records, health education, and medical affairs. <http://www.bp.ntu.edu.tw/bpresults/khc/project/seminar2.htm>

<sup>35</sup> On November 14<sup>th</sup> 2001, Electronic Signatures Act was passed. In June 2003, the DOH built “Healthcare Certification Authority” (HCA) as the preparation for EMR exchange. On March 3<sup>rd</sup> 2004, the DOH announced “Guidelines of Electronicalized Medical Record Application in Medical Sectors”. In August 2005, the DOH drafted “Policy on Electronicalization of Medical Records”. In November 2005, the DOH announced “Draft on Medical Information Security and Privacy Protection Guidelines” for gradually implementing electronicalization of medical records.

decade, besides connections among information, human right, social and gender scholars and the frequent outbreaks of information divulgence cases, a set of information risk discourse different from that of government thus formed. In 1994, the Taiwan government planned to combine the functions of National ID, NHI Card and personal fingerprints on one electronicalized National IC Card. In 1998, comprehensive social movement started. In the same year, the Personal Information Protection Alliance of Taiwan successfully mobilized Anti-National Card movement, this policy thus faded away silently. In light of the failure of National IC Card policy, the DOH decided to formulate electronicalized NHI IC Card separately. Together with the adoption of Electronic Signatures Act<sup>36</sup>, electronicalization of medical records enables us to save medical records in one NHI IC Card. However, this idea resulted in serious assault from human right and patient groups. In August 2002, Personal Information Protection Alliance of Taiwan, which connects tens of social movement groups, was founded. It was objected to the idea of combining EMR in NHI IC Card. Regardless of objections, NHI IC Card policy started on July 1<sup>st</sup> 2003. However, only limited information was recorded, such as doctor diagnosis, description and examination items. In 2003, the policy “Fingerprint Collection with New ID Card Issuance” came to its birth. Social movement groups gathered again. Two years of social protests continued. In September 2005, through the scheme of “constitutional release by grand justices” in the Constitutional Court, the policy that intended to falsely collecting biological features of nationals in the name of ensuring social security was stopped. These issues raised international concerns and criticisms. For example, the Identity Cards Bill<sup>37</sup> passed by the United Kingdom Parliament in 2004. Then, in mid-2005, the Executive Yuan launched Taiwan Biobank. Again, due to possible violations to social ethics and genetic privacy, serious criticisms from human right groups and scholars raised. The whole project thus discontinued.

In the past decade, for criticisms on “Anti-National IC Card”, “Anti NHI IC Card”, “Anti-Fingerprint Collection with New ID Card Issuance”, and Taiwan Biobank, main appeals of these social movements focused on security, management, circulation and utilization of information. Information risk movements developed in local society are directly relating to the main idea of the Taiwan Biomedtech Island Project – to exchange and delivery genetic and medical information. Therefore, dilemmas cause including not only those resulted from technological policy decision-making of Taiwan Biobank; but also those from NHII – electronicalization of

---

<sup>36</sup> Electronic Signatures Act. 2001.11.14. <http://db.lawbank.com.tw/Eng/FLAW/FLAWDAT0202.asp>  
<sup>37</sup> Identity Cards Bill (2004).  
<http://www.publications.parliament.uk/pa/cm200506/cmbills/009/2006009.htm>



medical records (NHI IC Card policy).

In light of the failures of electronicalized National IC Card, the DOH reformulated policies of electronicalization of medical records and NHI IC Card in 1999 (18.06.1999). For reducing social objections, the DOH stressed that detailed medical records will not be included in NHI IC Card. Only the time and reason of visiting hospital, prescription, examination items, and expenses will be recorded. However, the possibility of including medical records in NHI IC Card is still under negotiation. Simultaneously, the government is also gradually undergoing various kinds of measures to promote electronicalization of medical records<sup>38</sup>. From the perspective risk assessment of technological policy, it is sure that technocrats would stress effectiveness and development. Instead, they consider that as long as there is good risk governance, problems of privacy divulgence can be resolved. In other words, technocrat-dominated decision-making was limited in the model of traditional positivist scientific risk assessment. They consider the risk of possible privacy divulgence is controllable. However, such simplistic view of risk assessment can not clear public doubts, especially criticisms from health reform, human right, patient, and sex-worker groups. Thus, we can see, although NHI IC cards were formally issued in July 2003, social movement group still held highly suspicion on promotion of electronicalization of medical records. In the meantime, technocrats continued to promote electronicalization of medical records and its inclusion to NHI IC Card through the scheme of continuous negotiation<sup>39</sup>. Moreover, in 2005, NHII policy was proposed to promote intra-hospital exchange and circulation of medical information. This is also a policy connecting all ideas (electronicalization of medical records, NHI IC Card, and NHII).

In analyzing policy promotion of above projects, it is observed that there are

---

<sup>38</sup> In consideration of objection of “National IC Card” (a policy which combines the function of NHI IC Card and National ID Card) due to possible privacy divulgence, MOI decided to separately the functions of NHI IC Card and National ID Card. Jen, Chi-shen, the ministry of DOH, stressed that due to privacy consideration, NHI IC Card will only include the time of visiting hospital, prescription, and medical expenses; medical records will not be included. However, BNHI indicated that the space for recording patients’ medical information had already been saved. Yet, how much information can be saved in the IC card is still under research. (1999.6.18 Lu, Bing-yuan. “NHI IC Card will be issued at the end of the year.” Liberty Times.) (1999.12.16 Chang, Yao-mao. “Hope to protect medical records and personal privacy.” Min Shen Pao.)

<sup>39</sup> Press releases from BNHI of the second stage of NHI IC Card policy declared “for continuously promoting NHI IC Card policy and achieving the goal of the policy, BNHI had finished the details and timeline of the second stage of NHI IC Card policy after negotiated with the medical society and human right groups. There are 4 programs included in the second stage of NHI IC Card policy implementation. The timeline are as below: organ donation (November 1<sup>st</sup> 2004); serious illness and injury code (December 1<sup>st</sup> 2004); important medical information (ex: computed tomography, nuclear magnetic resonance, and positron emission tomography) (January 1<sup>st</sup> 2005), and continuous prescription of chronic disease (January 1<sup>st</sup> 2005).

structural problems in corresponsive risk assessment and risk communication procedures. Basically, technocrats and science elites held fairly positive attitudes towards policy formulation of below issues: “National IC Card”, “NHI IC Card”, “electronicalization of medical records”, and “Fingerprint Collection with New ID Card Issuance”, and “National Health Information Infrastructure”. Table 1 is the comparison of the following aspects of issue development: “decision-making unit”, “main discourse”, “official risk assessment”, “social movement”, and “risk communication and results”. Regarding risk assessment, technocrats and science elites embraced viewpoints of traditional scientific positivism. They considered risk control and damage prevention are possible. As long as information management and circulation security is confirmed, damages will be reduced to the least. Regarding risk communication, they deemed that continuous communication with social movement groups and public education are needed for smooth policy promotion. Hence, the overall governance strategy inclined to formalistic social assessment and instrumental regulation amendment for policy promotion. Such kind of operation represented the top-to-bottom and authoritative decision-making process. With positivist scientific risk assessment model, actually, the government does not really comprehend problems (such as information and social uncertainties) caused by sensitive technologies. Thus risk assessment and risk communication were operated in cost-saving formalistic scheme. For example, it is observed that technological projects and policies relating to information of individuals, clans, and ethnic groups were not perfectly evaluated before implementation. As a result, fierce criticism from social movement groups generated. It is not until then the government started to take precaution after suffering a loss in public trust.



**Table 1: Comparison of Risk Issue Development**

<b>Technological Policy</b>	<b>Decision-making Unit</b>	<b>Main Discourse</b>	<b>Official Risk Assessment</b>	<b>Social Movement</b>	<b>Risk Communication and Results</b>
<b>National IC Card (1998)</b>	Ministry of the Interior	To include information of household register, banking, health insurance and fingerprint.	Involving risks of privacy and information divulgence, social discrimination and crime commitment. Formally, legal institutions should be amended.	Popular Alliance against the National IC Card System – academics-based social movement of “against expert” argument.	The government was forced to stop the project and to start risk communication.
<b>NHI IC Card and Electronicalization of Medical Records (1999 to present)</b>	DOH	To include medical records in NHI IC Card	Involving risks of privacy and information divulgence, social discrimination and crime commitment. Formally, legal institutions should be amended.	Personal Information Protection Alliance of Taiwan – academics-based social movement of “against expert”.	The government was forced to communicate with patient and human right groups. However, NHI IC Card policy and EMR are still being promoted.
<b>Fingerprint Collection with New ID Card Issuance (2002-2005)</b>	Ministry of the Interior	To record and store biological features of nationals by computer systems.	Involving risks of privacy and information divulgence, social discrimination and crime commitment. Formally, legal institutions should be amended.	Taiwan Association for Human Rights –Anti-Fingerprint Collection – academics-based social movement of “against	Paradigm conflicts among the government and human right groups. Policy was stopped due to violation of the Constitution. However, after release of Constitution,

				expert”.	up to 68.5% of the participants supported the state to collect fingerprints of nationals <sup>40</sup> .
<b>Taiwan Biobank (2003 to present)</b>	Science and Technology Advisory Group of Executive Yuan, DOH and NSC.	To establish a genetic database including 200,000 samples recorded by computer system.	Involving risks of privacy and information divulgence, social discrimination and crime commitment. Formally, ELSI research should be done. “Protocol of Personal Data Protection Law” should be amended for policy untrap.	Supervision and criticisms of Taiwan Association for Human Rights and aboriginal groups – academics-based social movement of “against expert”.	Science elites were forced to converse with the public. Original blood collection plan in 2006 stopped.
<b>NHII (2005 to present)</b>	Science and Technology Advisory Group of Executive Yuan and DOH.	To promote intra-hospital exchange and circulation of medical information.	Involving risks of privacy and information divulgence, social discrimination and crime commitment. Formally, ELSI research should be done. “Protocol of Personal Data Protection Law” should be amended for policy untrap.	Developing...	Developing...

<sup>40</sup> Chou, Kuei-tien had done a national telephone survey after the Council of Grand Justice announced that “fingerprint collection policy” is a breach to the Constitution on September 28<sup>th</sup> 2005. The survey was done during November 2<sup>nd</sup> 2005 to November 17<sup>th</sup> 2005. High as 68.5% of the respondents agreed that “the state can collect citizens’ fingerprints and to establish Citizen Fingerprint Database”, where 28% disagreed. The question being asked was “Do you agree the MOI to collect citizen fingerprints and to establish Citizen Fingerprint Database?” The sample collection included all of the national field. Subjects over the age of 18 were selected by the Computer-Assisted Telephone Interviewing system. 924 valid samples were collected with the standard error of ±3.29%.

In fact, in developmental states, technocrats and science elites continuously to apply logics of technological R&D, industrial development, information security and management application for policy promotion. Aside from serious criticisms from social, gender, human right and patient groups, they also have to deal with numerous dupery crimes and related disputes happened in the Taiwanese society. They all resulted from information and medical records divulgence. Since 2000, information divulgence cases emerged in an endless stream. For instance: citizen information sale to detective agencies and tabloid magazines from policemen in Miao-li County<sup>41</sup>, customer information sale to fraud groups from Chunghwa Telecom<sup>42</sup>, student information divulgence to insurance companies from National Ping-tung University of Science and Technology<sup>43</sup>, and malpractice of medical information (unsupervised outdated paper medical records discards of Chang Gung Memorial Hospital – Lin-co Branch and Mackey Memorial Hospital – Hsin-chu Branch)<sup>44</sup>. Outbreaks of these risk

---

<sup>41</sup> On August 23<sup>rd</sup> 2002, policemen in Miao-li County stole information from computer system in police stations then sold to detective agencies and tabloid magazine companies. One aftermath was that nearly 3,000 families were illegally wiretapped by detective agencies. The number was far higher than legal wiretaps of judiciary agencies. More, on October 23<sup>rd</sup> 2002, policemen in Taiwan city sold telecommunication records of family use phone numbers to detective agencies. In sum, sine 2002, there has been hundreds of data divulged from policemen. (2002 Taiwan Association for Human Rights. "Personal information divulgence cases of 2002." <http://www.tahr.org.tw/site/PDPA/2002case.htm>)

<sup>42</sup> On May 18<sup>th</sup> 2003, fraud groups who used the same tricks to cheat people's money in Kao-hsiung were caught by policemen in Tainan County. Through this clue, two contractors of Chunghwa Telecom were arrested. They were accused of selling falsified ID Card and fake telephone number accounts to fraud groups. They already got millions of money. (2004.5.28, 93.5.18 ETtoday. Huang, Zon-hsin. "Sell customer information. 2 Chunghwa Telecom contractors arrested." <http://gb.ettoday.com.tw/2004/05/18/545-1631826.htm> )

Recently, many people reported to the Kao-hsiung District Prosecutors Office (KDPO) of personal information divulgence. People said there were unidentified calls and the caller attempted to sell products to them. Also, people got calls called from fraud groups. After investigation, the KDPO found that these victims are all customers of Chunghwa Telecom. It is very possible that employees of Chunghwa Telecom were involved in the case. Next, investigations to related personnel of Chunghwa Telecom were done. Suspects included contractors and employees of Chunghwa Telecom. Since Chunghwa Telecom owns the greatest number of customers in Taiwan's telecommunication industry, which holds the greatest number of customer data, the KFPO worried that the situation may be even worse. Chunghwa Telecom's branches around Taiwan were searched on May 25<sup>th</sup> 2004. Clues evidenced that contractors of Chunghwa Telecom sold customer information to fraud groups. The number of data being sold was great. (2004.5.25 ETtoday "Chunghwa Telecom sell its customer data? KDPO searched its branches." <http://www.ettoday.com/2004/05/25/331-1634957.htm>)

<sup>43</sup> Without the approvals of 8,000 students and teachers in the school, National Ping-tung University of Science and Technology announced new Student Card use, which combines the functions of banking and student ID. Students were forced to apply new Student Card. In the past, Yuan Ze university and National Chengchi University ever attempted to launch IC Card use. However, it was under suspicion of possible information divulgence. Thus, the plan stopped. (2002 Taiwan Association for Human Rights. "Personal Information Divulgence Cases of 2002". <http://www.tahr.org.tw/site/PDPA/2002case.htm>) Without the approval of students, National Ping-tung University of Science and Technology provide student records to banks for credit card application. (2004.8.28 Lihpao Daily. Zeng, Wen-jin "To defend civil rights. Against electronicalization of privacy." <http://publish.lihpao.com/Education/2004/08/28/04d08271/> )

<sup>44</sup> On February 8<sup>th</sup> 2006, outdated paper medical records discarded by the Chang Gung Memorial Hospital – Lin-co Branch were flown away without notice. They were supposed to be carried from Chang Gung University to a incinerator in central Taiwan by a transportation company. It is because the

issues resulted in a great deal of dupery and information crimes and caused great social cost. Ironically, this is the result of valuing techno-industrial competition superiority rather than information security. Paradoxically, these serious risk issues were not cautiously deliberated in national technological policy assessment. Therefore, the authoritative and top-to-bottom policy decision-making model dominated by technocrats and science elites tends to ignore social contexts. Without a second thought, technocrats and science elites were too confident that they considered regulation modification would serve to problem resolution<sup>45</sup>. Consequently, serious information divulgence and related crimes become criticism handles for social movement groups in commenting on national technological policies<sup>46</sup>. From surveys on public trust and risk perception of Taiwan Biobank, we can tell that public attitudes towards related technological policies.

In November 2005, survey on public trust and risk perception of Taiwan Biobank was done<sup>47</sup>. Questions examining public trust and their attitudes towards Taiwan

---

transportation was late. Thus, in the process of moving the documents, some of them were flown away by the winds and unable to be got back. The whole process was captured by the hospital. Mr. Pan (spokesman of the hospital) and Mr. Lie (manager of Medical Record Unit) indicated: according to regulations of the Medical Treatment Law, there are legal processes for medical record preservation, management and destroy, which should all be done by trained personnel. For patients did not visit a certain medical institute for more than 7 years, their medical records can be destroyed. The hospital authority indicated that students saw these records on campus. The hospital authority said they would investigate on this issue and proposed improvement measures. They decided to box all outdated medical records before shipping. Also, the DOH said it will investigate see if there was malpractice in terms of medical record management. (2006.2.11 United Daily. Zeng, Zen-hsin. "Outdated medical records of Chung Gung everywhere. DOH: is there management malpractice?" <http://www.udn.com/2006/2/11/NEWS/LIFE/LIF2/3158111.shtml> )

One scavenger picked up medical records of the Mackey Memorial Hospital – Hsin-chu Branch on street. There were 20 documents with general patients records written, including time of visiting the hospital, surgery taken, prescription, blood test records, hospitalization certificate,...etc. they are all original records in these two years. Even one document was dated March 3<sup>rd</sup> 2006. At the scene, the journalist found that these medical records were discarded at one vacant land at Gong-fu Road in Hsin-chu City. The place is less than 100 meters far from the Mackey Memorial Hospital. Mr. Lin (manager of Medical Record Unit) said that four branches of the Mackey Memorial Hospital never happened the incident of patient/personal record divulgence. There may be problems in medical record management process. The hospital will investigate where these records go afterwards and take the consequent responsibilities. These discarded medical records were all bought by Mr. Wu. (2006.3.5.TTV. Chen, Jia-chi. "Hsin-hsu Mackery Hospital. Medical records everywhere." <http://www.ttv.com.tw/news/html/095/03/0950305/09503054791003I.htm> )

<sup>45</sup> From all accessible policy reports and assessment reports, including reports of "To undergo practicability assessment of Taiwan Biobank" and "Establishment of Taiwan Biobank Proposals for Preparatory Phase", there is no related risk assessment about the serious situation of information divulgence and information risks in local society.

<sup>46</sup> In Chou & Chang's (2006) article discussing anti-fingerprint policy, it is found that sociologists, information and human right scholars apply the numbers evidencing the serious condition of information divulgence in Taiwan to assault the threats to personal privacy due to policy implementations of "NHI IC Card" and "Fingerprint Collection with New ID Card Issuance".

<sup>47</sup> The national telephone survey was done during the period from November 2<sup>nd</sup> 2005 to November 16<sup>th</sup> 2005 by Center for Survey Research, Academia Sinica. Subjects included citizens aged over 18. Sample collection included all of the national fields. The sampling method was stratified systematic sampling.

Biobank establishment in such social environment with serious information divulgence were designed. First, regarding confidentiality of genetic information, this question was asked: *“Generally speaking, if you draw blood for genetic testing or screening (whether passively or actively), do you trust related personnel will keep your testing records confidential?”* 34.8% of the respondents said they trusted related personal will keep their testing records confidential while 59.4% distrusted. It implies that the public held conservative attitudes towards confidentiality of genetic information preservation. One question asked: *“Will you agree to donate 15 cc. of blood for Biobank establishment? (Do not cue for academic research if not asking)”* 48.7% of the respondents agreed to donate 15 cc. of blood for Biobank establishment while 46.7% disagreed. Then, conditional questions were designed as the following. *“People are worrying about possible personal privacy divulgence due to Biobank establishment. Under such circumstance, do you still agree to donate 15 cc. of blood?”* 31.4% of the respondents agreed to donate 15 cc. of blood under the circumstance of possible personal privacy divulgence while the percentage of disagreed raise up to 64.4%. This means that as long as “possible personal privacy divulgence” is mentioned, the rate of disagree to donate bloods obviously raised. Another question: *“If there are laws to protect personal gene information from divulgence, will you agree to donate 15 cc. of blood for Biobank construction under such circumstance?”* It showed that under legal protection, the rate of agree to donate bloods rebounded, even higher than results of questions without conditional design (58.8%). Yet, the percentage of respondents disagreed to donate bloods even there is legal protection maintained as 37.9%<sup>48</sup>.

Since the situation of information divulgence and related crimes was quite serious in local society<sup>49</sup>, survey results evidenced that the respondents were still worried about risk governance of Biobank. One question concerning risk perception asked: *“Even though there are laws to prevent personal gene information from divulgence, do you think it is possible that personal genetic information will be divulged?”* High as 81.9% of the respondents agreed it is possible that personal genetic information will be divulged while 14.3 % disagreed with this statement. This means that most of the public showed no confidence in the government’s risk governance capacity in terms of policy implementation. With the prerequisite of the former

---

Totally 924 valid samples were collected with confidence level of 95%. The standard error was  $\pm 3.29\%$ .

<sup>48</sup> Survey results reflected that the public held suspicions towards the possibility of genetic privacy divulgence. However, as long as there is complete legal regulation, people who support Biobank implementation will increase. In other words, the key point is to build a complete set of protection mechanism including legal regulations, information protection programs, and communication system. Or, it will be difficult to win social trust.

<sup>49</sup> 2004.6.3. United Daily. Liu, Ching-yi. “If, information divulgence plus fingerprint policy.... ” <http://intermargins.net/Forum/2001%20July-Dec/privacy/nation/na07.htm> )



question, one question followed: “If, under the protection of laws, personal gene information may be divulged still. Under such circumstance, do you agree to donate 15 cc. of blood for Biobank establishment?” 28.8% of the respondents still agreed to donate bloods under this circumstance. However, the rate of respondents who disagreed to donate bloods suddenly rebounded to 68.3%. This result was quite similar to that of the question first mentioned about possible personal privacy divulgence (31.4% agreed to donate bloods; 64.4% disagreed to donate bloods). Thus, we can conclude, ***stable public opinions on possible genetic information / privacy divulgence were formed. The public deem whether there is legal protection or not, even under the circumstance of high information divulgence possibility, percentages of agree and disagree to donate bloods for Biobank establishment are fixed.*** In other words, survey results indicate – once the public realize there is serious condition of information divulgence in local society, the percentage of agreeing to donate bloods for Biobank establishment dropped.

Information divulgence and related crimes of local society already influenced public risk perception towards technological policies and projects, especially those involving collection, management, exchange, application and circulation of large amount of information. Current situation is no more controllable by positivist information security assessment. Structurally speaking, with fierce global technological R&D and economic competitions, technocrats and science elites in developmental states tend to apply the ideology of “valuing technological R&D, ignoring risks” in dealing with direction and decision-making of national technological policies. In facing newly-developed sensitive risk disputes resulted from genetic engineering and info-tech industry, just like western industrial countries, they tend to apply traditional positivist scientific risk assessment<sup>50</sup>. On the other hand, the intense network composed of technocrats and science elites dominates technological policies. They get used to apply authoritative and top-to-bottom guidelines of policy decision-making, so as to ignore risk movements on information divulgence and related crimes in local society over a long period of time. Hence, ***in analyzing such dual policy decision-making structure, we can see there are risk governance problems in such a decontextual developmental state that ignores technological risks.*** This risk governance model gets used to instrumentalize legal and institutional designs through formalistic scheme to untrap problems and to delay its reactions to

---

<sup>50</sup> As previous discussion, technocrats in western industrial countries are accustomed to the narrow and positivist risk assessment model in dealing with technological policy decision-making and risk disputes. However, such scheme, which believes that scientific rationality is the only standard for policy decision-making risk assessment, has been under great challenge. Obviously, public trust on risk governance is decreasing and under great criticism (Wynne 1996; Jansanoff 1990; Revatz 2002).

social movement groups' criticism and objections. However, such tension is under challenge while social movement groups are proposing new discourses on information risk. They attempted to initiate paradigm shift. Nevertheless, the war is not as perfect as they expected.

### **3.3 Paradigm conflicts of risk discourses**

Although the policy decision-making system in developmental states has been gradually degenerated from the its authoritative domination to the role of formulator (Evans 1995; Hsu 2002), the intense network formed by technocrats and science elites still remain its legitimacy in the environment of fierce global technological R&D and economic competitions. Hence, such top-to-bottom and centralized technological policy decision-making model is one central feature of Taiwan. In other words, such decision-making model is with closedness itself. Plus the guarantee of traditional positivist scientific rationality, it is possible that social movements and objections to risk issues are excluded from policy decision-making. It is also because of the existence of such decision-making model, policy decision makers in Taiwan are still trapped in old paradigm while many western industrial countries have been modifying their technological policies and risk governance models.

This kind of contradictory phenomenon happened in a series of disputable technological issues, such as genetic medicine and information technology. Moreover, since subprojects of NHII and Taiwan Biobank are still under implementation. It is necessary to systematically analyze and conclude paradigm conflicts between policy decision makers and social movement initiators. Especially, through comparative discussions, it would be helpful for us to deliberate what kinds of effect and national technological policy decision makers and their risk governance scheme will result in social condition. Two paradigms can be divided from discourses on above technological policy disputes. They are not only risk discourses of different technological policies; the systemic debates within these two paradigms are even crucial. It is also important to know what kinds of influences risk governance will cause in terms of technological policy in local society.

Discourse Group (I) emphasizes *technological certainty* of biofeature and electronicalized medical information system. Issues to be examined to evidence this paradigm including the followings: Ministry of the Interior promoted the policy of "Fingerprint Collection with New ID Card Issuance" through computer recording systems (1995); inclusion of information of household register, banking, health

insurance and fingerprint in “National IC Card” (1998); NHI IC Card and electronicalization of medical records (2000 to present), “Citizen Fingerprint Database” (2001); Taiwan Biobank (2003); and the Taiwan Biomedtech Island Project (including Bio-IT and NHII) (2005). Discourse Group (I) emphasizes public security effectiveness, reducing health insurance cost, valuing technological R&D and economic development. The fundamental base of Discourse Group (I) is certainty of technological risks. In other words, it is quite instrumentalistic.

Discourse Group (II) emphasizes the highly *technological uncertainty* in terms information storage, management, exchange and circulation of biofeature and electronicalized medical information system. These technological risks include social and ethical impacts resulted from information divulgence. From past issue contexts, it is studied that many discourses from by sociologists, human right scholars, and social movement groups emerged. From the issue of National IC Card in 1998, sociologists, human right scholars, and social movement groups proposed some critical points, such as privacy breach, information divulgence, commercial crime, and social discrimination (please refer to Table 2). Then, from policies of NHI IC Card and electronicalization of medical records (2000), social movements on “Anti-Fingerprint Collection” (2005), criticisms on Taiwan Biobank (2005), to supervision of NHII (2006), Discourse Group (II) has been chronically fight against the discourses of Discourse Group (I). This is a war between paradigms of advocating positivist scientific certainty and scientific uncertainty.

The special policy decision-making model and culture in local society formed paradigm conflicts of the two discourse groups. We can call it the confrontation between “security/effectiveness” and “human right / uncertainty of technological risks”. Take the Taiwan Biomedtech Island Project as an example, there is confrontation between “technological R&D/economic development” and “information divulgence/social and ethical impacts” In terms of risk society theory, discourses of this two paradigms stemmed from the production logic of “simple modern” and “reflexive modern” (Beck 1986; Chou & Chang 2006). The ideology of “simple modern” lies in the logics of positivism, scientific certainty, countability and Controlability. Based on the ideologies “progress” from the Enlightenment, industrial revolution, to modern-day techno-industrial society, the paradigm of “simple modern” evolves into the foundation and features of modern society. Accordingly, as modern human face great technological, ecological and social risks and disasters, this paradigm will be employed continuously. However, by only believing that by-products of industrial civilization are controllable (thus constantly pursuing technological

breakthroughs) can no more be enough to respond to great risks generated in dimensions of technological, industrial, economic, social and ethical developments. Referring to Beck's arguments in the book – World Risk Society (Beck 1999), with the development of globalization, impacts of information divulgence may be pervaded across boundaries of state, family and ethnical groups, even to the field of economy, society and ethics. The “reflexive modern” paradigm was deduced from contradictory and uncertainty of technological civilization. Thus, various kinds of logics of scientific development should be cautiously and preventively reconsidered in terms of spreading network, spreading speed, and spreading fields of risk because the problem of “risk” is now across-boundary and across academic disciplines (Ravetz 2002). In other words, risks and impacts posed to human society by scientific and technological developments can be evidenced by reexamining and criticizing the logic of positivist scientific certainty (main argument of Discourse Group (I)).

Basically, discourses of these two groups raised a phenomenon – positivist technological policy decision-making model of technocrats and science elites had encountered the challenge of social movement elites' argument of technological uncertainty. It reflects the impact of paradigm shift and the tension caused in a local society which chronically holding the ideology of “valuing technological R&D, ignoring risks”. Also, between paradigm conflicts of the two discourse groups, legitimacy of such a centralized and top-to-bottom technological policy decision-making model is under serious provocation. The following policies will be analyzed: of National IC Card, NHI IC Card, electronicization of medical records, Citizen Fingerprint Database, to Taiwan Biobank, Bio-IT and NHII (subprojects of the Taiwan Biomedtech Island Project). Arguments of Discourse Group (I) on above risk issues expresses firm belief in technological security and linear causality. Also, they believe in the controllability (able to preserve confidentiality and information security), amendability (worthy to sacrifice a bit of human rights for public security/effectiveness/technological R&D/economic development), and recoverability (able to rebuild personal reputation even suffer from information divulgence) of technological system. Advocates of Discourse Group (I) include technocrats (successive ministers of Ministry of the Interior and police affair scholars) and science elites. Although the centre of this paradigm is to operate risk issue analysis by applying the logic of positivist scientific certainty, another feature is that it utilizes the scheme of risk governance and technological R&D competition of promoting functional national tasks. Details of the scheme include improving effectiveness of handling interior affairs, promotion developments of medical and information industries join fierce technological R&D and economic competition, and scientific and industrial

competition brought by genetic engineering.

Based on the logic of “reflexive modern”, Discourse Group (II) criticizes the highly uncertainty and complexity of modern technological systems. Especially, technological systems of National IC Card, NHI IC Card, electronicalization of medical records, Taiwan Biobank, and NHII involve cross-check, storage, duplication, preservation and management of information. Since these processes involve scientific uncertainty, it is possible that information cannot be preserved safely. Basically, advocates of Discourse Group (II) appear through the form of “against expert”, including sociologists, human right and information scholars, and related social movement groups. The emphases of this paradigm are the uncontrollability (it is possible to duplicate, falsify and steal computerized data), unamendability (sacrificed human rights cannot be made up); and irrecoverability (unable to rebuild personal reputation when suffering from information divulgence). Even, the whole society would suffer from uncontrollability resulted from privacy divulgence, social discrimination, and increasing crime rate. These breaches of rights are unamendable and irrecoverable. Such centralized computer system includes personal information, medical records and genetic information that can be circulated and utilized by the state. Besides some imaginable governance leaks mentioned above, state monitoring is another thesis which can not be ignored.

**Table 2: Paradigm Conflicts of Risk Discourses**

	<b>Discourse Group (I) “simple modern”</b>	<b>Discourse Group (II) “reflexive modern”</b>
<b>Main Discourse</b>	Public security, effectiveness, technological R&D and economic development.	Human right breach, technological risks, information divulgence, social and ethical impacts.
<b>Logic</b>	Simple modern	Reflexive modern
<b>Epistemology</b>	Scientific certainty	Scientific uncertainty
<b>Foundation</b>	Based on certainty of biofeature and electronicalized medical information system. Emphasized on information security control.	Arguing there is high uncertainty for preservation, management, exchange and circulation of biofeature and electronicalized medical information system.
<b>Actors</b>	Technocrats and science elites who possess counseling resources.	“Against expert” groups including sociologists, human right and information scholars, and related social movement groups.
<b>Main Issues</b>	<ul style="list-style-type: none"> <li>➤ 1995 – “Fingerprint Collection with New ID Card Issuance” policy by the Ministry of the Interior – preserved by computer systems.</li> <li>➤ 1998 – “National IC Card” – combining information of household register, banking, health insurance and fingerprints.</li> <li>➤ 2000 to present – “NHI IC Card” and “electronicalization of medical records”.</li> <li>➤ 2002 – “Citizen Fingerprint Database”</li> <li>➤ 2004 – “Taiwan Biobank”</li> <li>➤ 2006 – “National Health Information Infrastructure”</li> </ul>	<ul style="list-style-type: none"> <li>➤ 1998 – “Anti-National IC Card Movement” – risk discourses on privacy breach, information divulgence, commercial crimes, and social discrimination resulted from scientific uncertainty.</li> <li>➤ 2002 – Social movements against “NHI IC Card” and “electronicalization of medical records” policies.</li> <li>➤ 2005 – Social movements against “Fingerprint Collection”. Suggestions on release of the Constitution.</li> <li>➤ 2005 – “Taiwan Biobank” project was under criticism of possible human right breach and social / ethical risks.</li> </ul>
<b>Features</b>	Utilizing the scheme of risk governance and technological R&D competition	Any large-scale genetic, medical and bio-IT system cannot be perfect for

	to promote functional national tasks, including information management systems of genetic database, biofeature, electronicalized medical information, and biometric verification.	preservation, storage, management and utilization of information. Besides social risks caused by information divulgence, state monitoring would cause human right breach as well.
<b>Impacts on technological System</b>	Trust in controllability (able to preserve confidentiality and information security), amendability (worthy to sacrifice a bit of human rights for public security/effectiveness/technological R&D/economic development), and recoverability (able to rebuild personal reputation even suffer from information divulgence) of biofeature and electronicalized medical information systems.	Thinking there are uncontrollability (it is possible to duplicate, falsify and steal computerized data), unamendability (sacrificed human rights cannot be made up); and irrecoverability (unable to rebuild personal reputation when suffering from information divulgence) in using computer system for preserving biofeature, genetic information, and electronicalized medical records.
<b>Social Impacts</b>	Technological instruments should be utilized to improve social security and administrative effectiveness, and to strengthen abilities of technological R&D and economic development in order to respond to globalizational competitions.	Once information divulged, uncountability, unamendability and irrecoverability caused. Such as privacy divulgence, social discrimination of individuals, clans, or a certain ethnical group, and related crimes. The society thus become under the threat of globalizational risks.

Paradigm conflicts of these two discourse groups actually involve risk assessment on related technological policies. First, concerning “National IC Card” policy proposed by Ministry of the Interior, technocrats attempted to include information of household register, fingerprint, health insurance and banking. They thought that exchange and circulation of electronicalized information can improve administrative effectiveness and reduce costs as long as PKI (personal key infrastructure) management is guaranteed. Relatively, “Anti-National IC Card Movement” argued that centralized management of information system is the testimony of totalitarian state. Also, information security management may be put in the hands of foreign experts. Monopoly in national security and certification management market may be caused as well<sup>51</sup>. Moreover, *“information security mechanism may be broken in two or three years..... The design of National IC Card requires including the function of “Smart Card Reader”. This made only directive governmental units have the rights to access information in the IC card. Essentially, this means that 21 million locks can be unlocked by only one key.”*<sup>52</sup> Obviously, this is unsafe. Even, this can be the potential strategic target. Therefore, Popular Alliance against the National IC Card System appealed that as *“privacy right enlightenment in Taiwan is in the initial stage”*, the government should not abuse information technological in such a careless way so as to result in irrecoverable risks<sup>53</sup>.

Concerning policies of NHI IC Card and electronicalization of medical records, main idea of the DOH is that the utilization of NHI IC Card will enhance administrative effectiveness through the schemes of recording the time of visiting hospital, division visited, prescription details, and medical expenses. Also, avoiding repetitive prescription of doctors and to supervise patients not to go to see a doctor for trivial illness can reduce medical resource waste<sup>54</sup>. Regarding security protection mechanism, the Bureau of National Health Insurance (BNHI) stressed that NHI IC Card has the function to ensure confidentiality. Each card holder has a PIN number to

---

<sup>51</sup> Refer to opinions of information scholars. (1998.8.12 Popular Alliance against the National IC Card System . Chen, Zhen-zan, Huang, Shi-kun, Ho, Jen-min, Liu, Ching-yi, Wang, Da-wie, & Zhuang, Ting-zuei. “Conscience can be awakened: Our common appeals to National IC Card policy .” <http://www.iis.sinica.edu.tw/~hoho/bookmarks/ccard/6pccard.html> )

<sup>52</sup> Refer to opinions of professors of Department of Computer Science and Information Engineering, National Taiwan University. (1998.11.4 Popular Alliance against the National IC Card System. Hsan Jai, Hsu, Hsen-chin, Lee, Xue-yan, O-Yang, Min, & Tang, Yuao-Jon. “Conference of National IC Card and Its Social Impacts.” [http://www.tahr.org.tw/noidcard/analysis\\_paper/a029.html](http://www.tahr.org.tw/noidcard/analysis_paper/a029.html) )

<sup>53</sup> Refer to opinions of information and legal scholars. (1998.8.12 Popular Alliance against the National IC Card System . David Wong, Prof. Huang, His-kuen & Jang-Tin-zuei. “Conscience can be awakened: Our common appeals to National IC Card policy .” <http://www.iis.sinica.edu.tw/~hoho/bookmarks/ccard/6pccard.html> )

<sup>54</sup> Mr. Jen (president of the DOH) stressed that through the implementing NHI IC Card policy, the Bureau of National Health Insurance will be able to enhance administrative effectiveness and reduce health insurance expenses. (1999.6.18 Liberty Times. “NHI IC Card issuance at the end of the year.”)



lock information in his/her NHI IC Card, unless upon each individual's approval, there is low possibility of information divulgence<sup>55</sup>. At this point, Discourse Group (II) proposed its criticisms from the perspective of scientific uncertainty of information system. Prof. Lee of Institute of Information Science, Academia Sinica indicated, "*the biggest news relating to security of information science in 2004 was that one system with PKI protection was cracked by a professor in Zhejiang University, China.*"<sup>56</sup> Therefore, we can say, there is no perfect information security system. Prof. Ho, a information scholar, once publicly criticized that NHI IC Card policy can not reduce administrative costs. More, concerning information security control, "*to avoid including sensitive information in paper NHI cards, why we put them in NHI IC cards, which requires higher security standards and is more expensive?*"<sup>57</sup>. Persons with HIV/AIDS Rights Advocacy Association of Taiwan (PRAA) indicated: "*In the initial stage of NHI IC Card policy implementation, serious illness and injury code is included. Next, records of visiting hospitals will be recorded. Doctors who have smart card readers can access these information simply by slip your NHI IN Card. This design may result in hospital-visiting record divulgence of HIV patients, and to cause privacy breach and rejection when they revisit a hospital. In addition, as internet code stealing and card copying skills are renovating, HIV patients become more worry about that other people may access their information in NHI IC cards, thus violate their right to work, right to study, and right to see a doctor*"<sup>58</sup>. In the press release of "Anti-NHI IC Card Movement", the Taiwan Association for Human Rights argued that "*The Taiwanese Society is seriously in lack of respects to personal privacy. Everywhere, at any time, there are harms done by tabloid news. Thus, personal information protection becomes rather significant in Taiwan. Before obtaining approvals of individuals, it is a breach to human right that the Bureau of National Health Insurance presumably to include hospital-visiting records in NHI IC Card*"<sup>59</sup>.

Regarding establishment of "Citizen Fingerprint Database", main discourses of MOI officials focused on to enhance the speed of dead body identification, to improve

---

<sup>55</sup> (2002.4.17. Christian Health Care Alliance. "Data in NHI IC Card can be locked. Low possibility of NHI IC Card information divulgence." <http://www.mmh.org.tw/chca/newspaper/54/%B9q%A4l%B3%F854.htm> )

<sup>56</sup> (2005.4.27 Lee, Der-zsai. "Suspicious towards new ID card issuance with Citizen Fingerprint Database." Yam Digital Technology. <http://news.yam.com/yam/politics/200505/20050525168243.html> )

<sup>57</sup> Refer to opinions of information scholar. (2000.9.18 Taiwan Association for Human Rights. Ho, Jen-min (researcher of the Institute of Information Science, Academic Sinica. "NHI IC Card policy should not be implemented." <http://www.tahr.org.tw/site/PDPA/her.htm> )

<sup>58</sup> (2005.5.17 Christian Health Care Alliance. "NHI IC Card would divulge medical history. "HIV patient face difficulties in revisiting hospitals." <http://www.mmh.org.tw/chca/newspaper/54/%B9q%A4l%B3%F854.htm> )

<sup>59</sup> (2002.7.26 Taiwan Association for Human Rights – press release. "Protests on the lavish NHI IC Card. Civil rights under deprivation." <http://www.yccc.com.tw/hope/news5.htm> )

social security, and to facilitate missing elderly search<sup>60</sup>. Although MOI officials' discourses sound there is possible privacy breach, as long as there is good data management/control, "Citizen Fingerprint Database" is practicable<sup>61</sup>. While the "simple modern" paradigm emphasizes on social security and effectiveness, the "reflexive modern" paradigm stresses scientific uncertainty of technological risks. Information experts ever mentioned *"A computer system which is able to record millions of fingerprint data of all nationals and to facilitate to make comparisons with 'unknown' fingerprints collected at scene of crime must be designed with high specifications. However, the result may turn to be – a computer system with high cost but low rate of verification."* Also, what we are worrying about is that *"since fingerprints are unchangeable biofeature, modern science proved that fingerprints could be duplicated easily. Duplicated fingerprints cheated many fingerprint verification products. That is to say, under the condition of information inequality, people can misuse or even abuse other people's fingerprints, let innocent common people suffer the consequences."* In recent years, *"there are frequent cases of computer crimes and information divulgence, the public become distrust on the government's crisis management and handling abilities. Thus, if Citizen Fingerprint Database policy is to be managed by the government, we cannot say for sure that the fingerprint database will not be stolen and indulged. If so, disputes will raise and there will be social costs even higher than the expected cost for promoting effectiveness"*<sup>62</sup>. Establishment of fingerprint database cannot be evaluated from only the dimension of data management/control. Possible fallacies in fingerprint verification process must be pay attention to as well. More, since there is possibility of invasion to computer system, discourses of controllability, countability and amendability of the "simple modern" paradigm thus failed. Advocates of the "reflexive modern" paradigm are worrying about that the oncoming "slippery slope effect" would cause great social uncertainty to these newly-developed technological risks. Prof. Lee ever indicated, *"In the future, it is possible that governmental units and banking agencies will apply biofeature (ex: fingerprint) as identity verification instrument. Also, they anticipate including such biofeature in general business and civil practices. Thus, the public will be require to submit fingerprint for identify verification. For now, it is very common that we have to submit IC Card copies for business/civil practices. Once there is malpractice of document/information preservation, there must be incidents of information stealing and duplication. Even, fraud groups may 'cut one's*

---

<sup>60</sup> (2002.5.28 Central Daily News. Wang, Jon-hwa. "Fingerprint database is helpful for dead body verification." <http://www.cdn.com.tw/daily/2002/05/28/text/910528ac.htm> )

<sup>61</sup> (2002.8.9 Liberty Times.)

<sup>62</sup> (2005.11.27 Taiwan Association for Human Rights. Jang, Chi-tin. "Taiwan will be the "BIG" to collectively monitor its citizens." <http://www.tahr.org.tw/site/PDPA/Chiting.htm> )

*fingers' for stealing 'fingerprint'.*" These are all conditions that the MOI cannot image while they compelled the public to provide fingerprints. Are there other worse behaviors? No one would tell. However, risks let the public fail victim to harms do exist. How will the government abide by the consequences?<sup>63</sup>. (Chou & Chang 2006).

The "simple modern" paradigm of technocrats and science elites is also shown in risk assessment and policy formulation of the Taiwan Biomedtech Island Project. As mentioned above, the project will combine the complete household register and health insurance records, the distinct genes of Taiwanese, intra-hospital information circulation and exchange, and Bio-IT industry for upgrading genetic medicine and bio-IT industries in Taiwan. However, complicated problem are involved, such as personal autonomy, privacy rights, information confidentiality, social ethics, benefit share of research results, and the appointment of directive agent. Plus, there is insufficient legal regulation. At this point, the government is under serious criticism by the Taiwan Association for Human Rights. However, in fact, technocrats and science elites adhered to the paradigm of "simple modern" were quite hostile to criticisms of social movement groups and supervision of related scholars. They continuously emphasized the importance of global technological R&D competition (Chen & Shen 2006)<sup>64</sup>. They thought "*a great project involves national welfare and the people's livelihood should not be a decision made recklessly*"(ibid). Also, technocrats and science elites argued, "*In-depth rational communication on substantial issues is even more necessary*" (ibid). With all these ideologies, they revealed unable to realize the social and ethical impacts caused during formulation process of Taiwan Biobank. "*Yet, in fact, as we started to promote Biobank project, problems we face are not scientific but ethical and legal disputes in local society.*" These disputes stemmed from the prevailing public distrust on public affairs, so as to be suspicious of the motives of policy implementation. For instance, there are accusations that disregard human right: 1) blood plasma collection should not be done in the name of health check-up instead of telling the truth to donors; 2) the contents of informed consent letter may not be fully practiced even they are signed by donors because research personnel may fail to explain the fundamental meanings to donors and the donor may also have misunderstandings about the contents; 3) personal privacy information may be abused; 4) supervisory mechanisms of technological policies are in lack of credibility (ibid). Under these contexts, technocrats and science elites of the "simple modern" paradigm

---

<sup>63</sup> Refer to opinion of information scholars. (2005.4.57 Yam Digital Technology. Lee, Der-tzai. (President of the Institute of Information Science. "Suspicious towards new ID card issuance with Citizen Fingerprint Database." <http://news.yam.com/yam/politics/200505/20050525168243.html> )

<sup>64</sup> (2006.4.2 China Times. Chen, Chon-yuan & Hsen, Chi-yon. "Be cautious for Biobank formulation." <http://www.ibms.sinica.edu.tw/biobank/950402.pdf> )

trusted in scientific certainty of large-scale genetic database control and security. They compare “Biobank” to “bank” and argued “*although there will be possible risks when we deposit in banks, even the bank might go bankruptcy, we will still deposit. The management team thus realizes that the point is we have to build a set of practicable controlling mechanism to make the public willing to confide their property to us*” (ibid).

However, in fact, such logic cannot fully comprehend the great risk genetic engineering would bring to individuals, clans, or ethnical groups. As Liu, Hung-en (2005) questioned the Setting of Taiwan Biobank that ignoring “*risk governance of such large-scale genetic database would bring the public impacts on personal autonomy and privacy breach. For the whole society, racial labeling and discrimination may be generated*”. For instance, for recruiting enough subjects for Biobank establishment, “*sample collection team told the public that the public can have free health check-up by drawing bloods*” (ibid). This action seemed infringed international research ethics. What the “reflexive modern” emphasizes are not merely the importance of “sensitivity and confidentiality involved in large-scale genetic database establishment” mentioned in two documents of UNESCO<sup>65</sup> and WHO<sup>66</sup>. Especially, since operation of this project would involve household register data of donors and their medical records in the following years; many legal, social and ethical problems are involved, the foundation of public participation and risk communication should be expanded. In other words, Discourse Group (II) had acknowledged that Taiwan Biobank establishment will result in other social risks besides scientific uncertainty. Thus, related problems should be assessed based on social rationality. Therefore, the range and definition of risk assessment should not be limited within the field of science. Instead, transparent and participative risk communication is more important to understand risk perception and trust resulted from different values and judgments (Chou 2005a). Liu, Ching-yi (Liu 2005; Liu 2006), vice president of the Taiwan Association for Human Rights, indicated that “*it is because this project involves great national resources input and it relates to rights and welfare of all nationals*”<sup>67</sup> (ibid), but not only a “*simple scientific theses*”. Hence, “*it is essential to*

---

<sup>65</sup> UNESCO (1997) – Universal Declaration on the Human Genome and Human Rights. <http://unesdoc.unesco.org/images/0011/001102/110220e.pdf#page=47>

<sup>66</sup> WHO (2004) – Genetic Databases – Assessing the Benefits and the Impact on Human & Patient Rights. European Journal of Health Law, p. 79-84. <http://www.law.ed.ac.uk/ahrb/publications/online/whofinalreport.pdf#search='Genetic%20Databases%20%E2%80%93%20Assessing%20the%20Benefits%20and%20the%20Impact%20on%20Human%20%26%20Patient%20Rights>

<sup>67</sup> 92005.9.25 iThome online. Liu, Ching-yi. “While IT meets biomedtech: are you ready?” <http://www.ithome.com.tw/itadm/news/news.php?c=33299> ) (2006.2.15 The Judicial Reform Foundation. Liu, Ching-yi. “How come there is Taiwan Biobank?”

*build an operational model in accordance with life ethics and principle of justice*” (ibid). Also, she strongly criticized technocrats and science elites for *“ignoring human right and research ethics”* (ibid), because with the support from DOH, NSC, MOI, and other related organization, establishment of Taiwan Biobank was undergo through an intransparent scheme. *“While the Taiwan Biomedtech Island Project has been undergone, projects of NHI IC Card, electronicalization of medical record, and Taiwan Biobank are all major national projects which are in lack of supervision”* (ibid). The paradigm of Discourse Group (II) attempts to outline the social, ethical and human right risks stemmed from the Taiwan Biomedtech Island Project. It also requires a more transparent policy decision-making model, diversified communication schemes, and democratic participation. Arguments of Discourse Group (II) also shows challenged the legitimacy of arguments of Discourse Group (I) by pointing out that technological policy decision-making model of the traditional positivist risk assessment is unable to respond to newly-developed technological risks.

In brief, paradigm conflicts on risk assessment and risk discourses over the past decade revealed that the two groups held different opinions about definition, range, decision-making and resolution of technological risks. It is the competition of different risk governance models and paradigms. Discourse Group (I) argues that as long as we follow the positivist scientific view – to control, calculate and manage risks, combine technological R&D of biofeature and genetic medicine, it is possible to successfully utilizing modern information and digital technological systems. Thus, within the limited boundary and definition of risk, following traditional decision-making model can do risk governance. Discourse Group (II) argues that technological systems of biofeature and electronicalized medical information system involve highly uncertainty during the processes of managing, controlling and using these data. Also, these technological risks may be disseminated from the field of science to the local society then to create unpredictable harms to individual, clans and ethnical groups. It is because the field and definition of risk are highly socialized, risk governance must not be underground operation. On the contrary, it must be an open model with responsibility, transparency, participation and accessibility in order to review social impacts posed by these newly-developed sensitive technologies. These are also the basic principles promoted by the EU (2002). However, new risk governance paradigm proposed by social movement elites and that of the government have been often under fierce confrontation. In developmental states, under discourse propaganda of promoting technological R&D and economic development, paradigm shift encountered dilemmas to some extent.

#### **IV. Discussion and comparison: Glocalizational risk governance of a delayed and hidden high-tech society**

As the major instructor and actor of national technological policies, technocrats and science elites continue to duplicate and generate institutional and positivist mainstream discourses (Wynne 1996). Also, within the environment of fierce global technological R&D and economic development, technocrats and science elites attempt to strengthen the legitimacy of national interest competition by improving biofeature and medical information systems. Under such situation, the Taiwan Biomedtech Island Project thus becomes the crucial target for catching up with the developments of genetic engineering and IT industry. That is, just like other advanced industrial societies, developmental states simply want to win their niches in the arenas of biotechnology, information, and knowledge-based economy (OECD 2003). In fact, some developmental states do keep abreast of the global. That is why the public were convinced by this mainstream technological discourse and showed supportive attitudes towards these policies (even being strengthened as to win the niches of national industries). In other words, if we temporarily ignore conflicts among political, social, ethical, ecological, and industrial systems in newly industrializing countries, such top-to-bottom and authoritative policy decision-making model will be rather effective. It can also be the paradigm for risk governance of global technological policies.

The dual decision-making structures in developmental states discussed in this article including: 1) influences of globalizational risk governance; 2) public, social and national trust on traditional positivist risk paradigm. Influences caused by the global society can be traced back to worldwide anti-GMO movements in the mid-1990s. Then, in around 2000, there were paradigm shifts on risk control and risk governance of genetic engineering, IT industry, nanotechnology, and other related risks. For example, import bans on GMO, labeling regulations of GMO, and the announcement of Convention on Biological Diversity, International Declaration on Human Genetic Data (UNESCO 2003); and regulations on research, collection, storage and management of genetic data proposed by WHO<sup>68</sup> and the EU<sup>69</sup>. A new risk governance model, which

---

<sup>68</sup> WHO (2004) – Genetic Databases – Assessing the Benefits and the Impact on Human & Patient Rights. European Journal of Health Law, p. 79-84. <http://www.law.ed.ac.uk/ahrb/publications/online/whofinalreport.pdf#search='Genetic%20Databases%20%E2%80%93%20Assessing%20the%20Benefits%20and%20the%20Impact%20on%20Human%20%26%20Patient%20Rights>

<sup>69</sup> European Commission – Science and Society Action Plan. 2002. [http://ec.europa.eu/research/science-society/pdf/ss\\_ap\\_en.pdf](http://ec.europa.eu/research/science-society/pdf/ss_ap_en.pdf)

emphasizes openness, diversity, transparency, participation and responsibility, emerged in world countries. EU proposed technological and social governance is an example. So do the International Risk Governance Council founded in Switzerland in 2003. Whether in regulation of species, industries and technological R&D, establishments of risk governance paradigms and models do caused impacts and pressures to some extent. For example, Taiwan and South Korea successively emulated the EU to formulate labeling policies and regulations on GMO products. Related GMO products for expert have to past risk assessment procedure as well. The ethical scandal broke out in South Korea unmasked international research ethics because one female personnel donated her eggs for stem cell research directed by Dr. Hwang Woo-suk<sup>70</sup>.

The traditional technological policy decision-making model and risk governance paradigm were being challenged by national political and social environment. Thus, glocalizational special risk culture and structural problems emerged. With respect to the chronic research on GMO risk perception and public trust, Chou (2000, 2002 2004) indicated decision-making and risk governance models in newly industrializing countries are the main factors that cause the “system gaps” among risk perception, information communication and social learning. Based on positivist risk assessment viewpoints, technological policy decision makers and risk governors ignored the existence of risks. From survey results of 2003, 2004 and 2005, regarding the great amount of imported GMO, over half of the Taiwanese did not know why GMO is risky. Also, they did not know the government ever propagated and communicated health and risk problems to the public and did not know there is GMO labeling policies in Taiwan<sup>71</sup>. Most of the people are in the state of unawareness due to knowledge gap and information gap. Namely, such system gaps resulted in the reality that the local society

---

<sup>70</sup> This means that globalizational risk governance paradigm will gradually influence worldwide local societies, then to stimulate general interactions. Most important, when different societies are under the prevailing influence of risk governance paradigm, with their distinct political, social and cultural contexts, special risk governance models and risk cultures will form. Thus, impacts raised will reflect to the whole global society. Refer to the reference followed for background story. (2006.1.12 The Guardian newspaper “Disgraced stem cell scientist blames researchers” <http://education.guardian.co.uk/higher/research/story/0,,1684954,00.html> )

<sup>71</sup> From past researches, it is observed that there are structural defects in risk communication and risk governance dominated by technocrats of DOH. Chou (2003, 2004 & 2005a) had done surveys in the past three years. When respondents who have heard of GMO were asked about questions regarding risk communication of health authority, averagely, there were more than 80% of the respondents considered the DOH did not explain and propagandize GMO risk and safety concerns (2003—80.5%; 2004—83.3%; 2005—83.8%). Around 90% of the respondents thought that the public had not enough information to judge the safety of GMO products (2003—90.9%; 2004—88.9%; 2005—88.9%). Concerning GMO labeling policy, great number of respondents never heard of DOH’s propaganda on GMO labeling policy (2003—78.9%; 2004—92.5%; 2005—76.8%) Last, especially for risk communication, risk decision-making, and interaction between the public and the government, when the respondents were asked about “if the public have the opportunity to participate technological policy decision-making”, nearly 70% of the respondents thought that the public did not have the access to participate technological policy decision-making (2003—65.7%; 2004—67.6%; 2005—73.3%)

has been seriously delayed in dealing with risks and it hides the existence of risks. Thus, the special risk culture and structure formed dialectically. Meanwhile, system gaps in risk decision-making, governance model, and culture resulted in highly public distrust on technocrats and science elites<sup>72</sup>. Under the background that national policy decision makers were full-heartedly propagating and puffing the benefits of new technologies, delayed perception gap and judgment gap to technological risks formed (Chou 2005a). This is the “systemic risks” accumulated within such special social, political and cultural contexts. (OECD 2003).

Such “system gaps” appeared in paradigm conflicts of biofeature and electronicalized medical information system. Even though there were not many social movements to stand against GMO import, national technological projects in different years did proposed some diversified criticisms and objections. Arguments of these risk movement, such as movements of against policies of National IC Card, NHI IC Card, electronicalization of medical records, and Taiwan Biobank, are quite similar as the arguments presented in Chou & Chang (2006)’s article concerning the establishment of Citizen Fingerprint Database. Basically, these risk movement groups composed of experts, with also the participation of patient, woman and environmental groups. To be frank, risk movement participation was restricted to experts and a few minority groups. Thus, less public mobilizations were launched. Even though social movements were launched to boycott the implementation of technological policies with high-tech risks, the phenomenon that the public tend to blindly accept technocrats’ discourses (valuing benefits of technological development) can not be changed. This means, to some degree, even elite-dominated “against-expert” social movements cannot shake the impacts caused by existing decision-making models and ideologies dominated by technocrats and science elites. Thus; new risk governance paradigms were still trapped.

Two examples can evidence above arguments. This first one is establishment of Citizen Fingerprint Database. Technocrats and science elites have been applying positivist risk assessment models to form discourse on Citizen Fingerprint Database establishment. This made the public held over optimistic attitudes towards development of new technologies. Even there were a large number of social movements and media discourses to warn the risks of Citizen Fingerprint Database establishment. Also the Constitution Court had announced that Citizen Fingerprint Database establishment is a

---

<sup>72</sup> When the respondents were asked “do you trust in DOH’s statement – currently, GMO pose no harm to human health”, 73.2%(2003) 63.6%(2004) 74.1%(2005) of the respondents distrusted. When the respondents were asked “do you trust that some scientists alleged ecological and health risks resulted from GMO can be controlled”, 53.7%(2003) 52.3%(2004) 52.3%(2005) of the respondents distrusted. In other words, the public was distrusted in GMO safety assessment done by technocrats and scientists.



violation to the Constitution and should be terminated. However, there were still 68.5% of the respondents held supportive attitudes towards Citizen Fingerprint Database establishment<sup>73</sup>. This kind of contradictory and paradoxical phenomenon indicates that the traditional closed and authoritative paradigm in developmental; stated holds its legitimacy. Similarly, regarding Taiwan Biobank establishment, even under the suspicion of social movement groups, science elites still attempted to instrumentalize the interpretation of public opinion surveys by differentiating survey results. They also continued puffing up that there were 70% of the respondents supported Biobank establishment (according to survey results of Academia Sinica). On the contrary, they intentionally conceal the low public support rate (41 %) once Biobank establishment involves privacy divulgence<sup>74</sup>. In other words, science elites still followed the old model and attempted to instrumentalize scientific certainty to hide great risk resulted from Biobank research and to delay risk governance of it.

It is unknown if there are similar decision-making model and risk governance culture of technological policies in South Korea. After the scandal outbreak of Dr. Hwang Woo-suk's research ethics breach and fraud scientific breakthrough in stem cell research in November 2005, the rate of supporting stem cell research was higher than before (Cho 2005)<sup>75</sup>. Meanwhile, under the appeal of nationalism, there were nearly one hundred Korean women volunteering to donate their eggs to Dr. Hwang's research team, regardless global criticisms<sup>76</sup>. Relatively, we see similar dilemmas due to risk governance paradigm shift in Taiwan. What similar in these two country is that they all face the pressure of fierce global technological R&D and economic competition. Also, they all enjoyed the fruits of successful technological and economic development in past decades. Together, in the new wave of global competition, they all face challenges in terms of risk governance paradigm of new technologies. In analyzing risk issues in Taiwan, whether for disputes on GMO or the Biomedtech Island Project, the special

---

<sup>73</sup> Refer to footnote 40.

<sup>74</sup> At that time, there were two surveys analyzing public opinions on Taiwan Biobank establishment. One is done by Chou, Kuei-tien in November 2005 (refer to footnote 47); one was done by Institute of Biomedical Science, Academia Sinica. The one done by IBMS in 2005 included 1,089 samples. (2006 Fu, su-tan. &Hu, Ko-wei "Public Attitudes toward Biobank in Taiwan" Conference of Survey Research and the Bioethics Studies of Genomic Research in Taiwan. Academia Sinica. Taipei.)

<sup>75</sup> According to a public opinion survey done by South Korean scholar Cho (2006) after scandal outbreak of Hwang, Woo-suk's stem cell research. It is observed that in July 2005, there was 64.2% of the respondents supported stem cell research for strengthening national competitiveness. Instead, after scandal outbreak, the rate to support stem cell research for strengthening national competitiveness mounted to 83% in February 2006. (2006 Cho, Sung-Kyum. "Public opinion of the biotechnology in Korea" A dissertation for Taiwan Genetic Intention Survey and Research Conference. Center for Survey Research, Academia Sinica. Taipei.) This phenomenon revealed South Korean society still held optimistic attitudes towards genetic engineering. However, similarly, it lacks the ability of self-reflection and to criticize, just like Taiwan society.

<sup>76</sup> See Kim Rahn report: women rush to donate ova to back Hwang, The Korea Times, 06. December 2005.

technological policy decision-making models within a hidden and delayed high-tech risk society were formed. Articles of Chou and Chang indicated (Chou 2005a, b; Chou & Chang 2006), such a culture/structure with hidden risk and delayed risk governance caused dilemmas of risk governance paradigm shift in the local society. Thus, what we need to think is – as a junior industrial country with the attitudes of eager to learn and to catch up with advanced industrial country, do we face similar problem? Are there different risk decision-making cultures formed? As there are loose policies and legal regulations, many newly-developed sensitive technological risks must be dealt with, thus to pose impacts on global risk governance paradigm.

What certain are that such hidden and delayed risk governance culture and decision-making model have their globalizational and glocalizational meanings. On the one hand, these distinct risk governance dilemmas formed in local society face the challenge of global fierce technological R&D and economic competition. On the other hand, since there is weak risk governance of technological policy, system gaps and risks are generated cyclically. Thus, newly industrializing societies become rather weak in respond to technological risks. That is, junior industrial countries face more serious system gaps than advanced industrial countries. The fragility of the society in reaction to risks in newly industrializing countries is far behind that in western countries (Bijker 2005)<sup>77</sup>. Second, problems of decision-making and risk governance in developmental states are not merely stay regionally; they could be internationally with the globalization. Thus, such phenomenon would reflect risk governance relaxation in world countries and form dilemmas in the next wave of risk governance.

## **V. Conclusion**

New technologies such as genetic engineering, IT industry, and nanotechnology are continuously combining biofeature and electronicalized medical information systems to respond to the global trend of fierce technological R&D, economic development, and anti-terrorism. On the one hand, high-tech industrial competition is undergoing. On the other hand, systemic tools for global anti-terrorism and national security are under development. For both directions, serious globalizational risks

---

<sup>77</sup> By comparing “Eurobarometer – Risk Issues 2006” done by European Commission (2006) and Chou’s successive survey results of the past three years (2003, 2004, & 2005) (Chou 2005a), it is observed that the rates to trust in risk governance capacity of the government in major industrial country (ex: UK, Germany, France, and Finland) were about 60%, which is higher than that of Taiwan. On the contrary, the distrust rate of risk governance capacity of the Taiwan government was around 70% in the past three years (refer to footnote 71). One of the reasons is there are strict regulations (ex: GMO) in European Union, which let the public has more confidence on risk governance.

formed in the process of dialectics. In confronting these challenges, world countries are gradually clarifying world crises stemmed from globalization and technological competition. Also, they are integrating diversified and democratic new risk governance paradigm in respond to the disputable, sensitive, and innovative systemic risks. From analyses in this article, we see conflicts and dilemmas of risk governance paradigm shift. They are all embedded in the distinct political, cultural, social and historical contexts in local societies worldwide.

In analyzing risk discourses and decision-making disputes of national technological policies, we know that structural dilemmas of paradigm shift were stemmed from serious collision between the top-to-bottom/authoritative decision-making model and positivist risk assessment culture. On the one hand, in the process of rapid techno-industrial development, the ability to introspect and criticize current situations in political, social, cultural and technological developments are compressed. On the other hand, with the drive of global technological R&D and economic competitions, discourses of system security and scientific certainty were at the disposal of technocrats and scientific experts. Also, they held pessimistic attitudes towards risk control, thus resulted in the problem of hidden and delayed risk culture in local society. Concerning technological risk disputes discussed in this article, sociologists, information and human right scholars, and social movement groups launched protests. Also, over a long period of time, there were paradigm conflicts on risk discourses. However, as the government continuously puffing up the benefits of new technologies simultaneously, the society became one with delayed and hidden risk culture. The possibility of successful risk governance paradigm shift seemed not so optimistic.

The special risk governance structure in newly industrializing countries, which valuing technological R&D and industrial competition, has been systemically ignoring threats of technological risks. This is the prevailing problem worldwide. Accordingly, many newly industrial countries, especially those highly reply on technocrat and science elite dominated decision-making model, all face similar problems. The point is that the technological systems developed by modern human beings are usually highly sensitive and disputable, such as genetic engineering, IT industry and biofeature. In addition, they may result in generate unpredictable globalizational risks and unamendable consequence. In sum, risk governance dilemmas and structures in various local societies in the world would cause bring about great influences.

Furthermore, what deserves deliberation is that whether if these risk governance

dilemmas and the special risk society structures are the distinct phenomenon in newly industrial countries. Or, this is the common phenomenon in world countries, including advanced industrial countries. Traditionally, from past research findings, we concluded that western industrial countries pay more attention to environmental risk governance; on the contrary, developing countries are weak in environmental governance and regulation (Kasperson, Jhaveri, & Kasperson 2005). However, as we examine new technological, especially those involving high risk and scientific uncertainty, past research findings therein should be reviewed. In analyzing international risk governance of global climate change and GMO, on the one hand, there are disputes on scientific uncertainty; on the other hand, there are system gaps of governance due to the special political and social contexts in various countries/regions. For example, by following the risk governance paradigm of the EU, Taiwan and South Korea set different standards for its GMO labeling policy. More, as a leading country for GMO production, although there are voices advocating GMO regulation, GMO labeling policy was not set until now. Concerning CO<sub>2</sub> emission regulation of the Kyoto Protocol, many developing countries are under the pressure of international governance and started to formulate related policies. However, the US as the great producer of 1/4 of world CO<sub>2</sub> emission, they disagreed to comply with the Kyoto Protocol due to political and economic concerns. With the development of risk issues, the fence between risk governance models of developing and developed countries are no more clear. What is important is that the distinct risk governance models and structures in various local societies will be formed according to their political, economic and cultural contexts. This raises the importance of globalizational risk governance. Based on such contexts, it is worthy observation whether such phenomenon would reflect to global risk governance paradigm then to cause problems in the new wave of risk governance.

## Reference

- Andrew, B. W. (1992, Summer). Medical records liability. *Health Law: Health Lawyer*, 11. American Bar Association.
- Appadurai, A. (1998). Globale ethnische räume. In Beck, U, *Perspektiven der Weltgesellschaft*. Suhrkamp.
- Árnason, V. (2004). Coding and consent: Moral challenges of the database project in Iceland. *Bioethics*, 18(1), 27-49.
- Beck, U. (1986). Risikogesellschaft. *Auf dem Weg in einen andere Moderne*. Suhrkamp.
- Beck, U. (1993). Die Erfindung des Politischen. *Zu einer Theorie reflexiver Modernisierung*. Frankfurt a.M: Suhrkamp.
- Beck, Ulrich. (1999). *World Risk Society*. Cambridge: Polity Press.
- Bekkers, V., & Thaens, M. (2005). Interconnected networks and the governance of risk and trust. *Information Polity*, 10, 37-48.
- Bijker, W. E. (2006, March). The vulnerability of technological culture. In Nowotny (ed.) *Cultures of Technology and the Quest for Innovation* (pp. ???). Berghahn Books.
- Buckman, D. F. (2004). Validity, construction, and application of Health Insurance Portability and Accountability Act of 1996 (HIPAA) and regulations promulgated thereunder. *American Law Reports ALR Federal*, 133. The ALR databases.
- Castells, M. (1996). *The Rise of the network Society*. Blackwell Publishers.
- Chang & Chou. (2006). Paradigm Conflict within hidden and delayed high-tech risk society – with special focus on the case of “New ID card application with fingerprint submission. *Societas : a journal for philosophical study of public affairs*, 17, 127-215.
- Chang, Li-wen. (2003, July 22<sup>nd</sup>). Chinese Biobank establishment – “blood” thirst. China Times. <http://www.ttnn.com/cna/news.cfm/030722/100>
- Chang, Li-wen. (2006, January 23<sup>rd</sup>). War of gene decode; pain of the aboriginals. China Times. <http://www.bio.idv.tw/data/data13/2001031901.htm>
- Chang, Yao-mao. (1999, December 16<sup>th</sup>) Hope to protect medical records and personal privacy. Min Shen Pao.
- Chao, Pei-ju & He, Pei-ju. (2004, February 25<sup>th</sup>). Taiwan is going to build disease and genetic database. Commercial Times. <http://www.cyberbees.org/blog/archives/002764.html>
- Chen, Jia-chi. (2006, march 5<sup>th</sup>). Hsin-hsu Mackery Hospital. Medical records everywhere. TTV.

- <http://www.ttv.com.tw/news/html/095/03/0950305/09503054791003I.htm>
- Chen, Yao-hwa. (2003, December 5th). Ethical problems on Taiwan Biobank establishment. Academic Conference on Ethical Problem and Technological Regulation of Genetic Engineering. School of Law, Soochow University. Taipei.
- <http://www.scu.edu.tw/law/news/news40.htm>
- Chen, Yuan-chon. (2004, March 31). To undergo practicability assessment of Taiwan Biobank. A result report of National Science Council sponsored research project.
- Chen, Yuan-chon. (2003, July 22<sup>nd</sup>). National genetic database is one of the best. Taiwan Today News Network. <http://www.ttn.com/cna/news.cfm/030722/101>
- Chen, Yuan-chon, & Shen, Chi-yang. (2006, February 27<sup>th</sup>). Biobank establishment. Turning point for nationals' illness. ndn.com. <http://www.udn.com/2006/2/27/NEWS/LIFE/LIF2/3185510.shtml>
- Chen, Zhen-zan, Huang, Shi-kun, Ho, Jen-min, Liu, Ching-yi, Wang, Da-wie, & Zhuang, Ting-zuei. (1998, August 18<sup>th</sup>). Conscience can be awakened: Our common appeals to National IC Card policy. Popular Alliance against the National IC Card System. [http://www.tahr.org.tw/noidcard/analysis\\_paper/a013.html](http://www.tahr.org.tw/noidcard/analysis_paper/a013.html)
- Cho, Sung-Kyum. (2006). Public opinion of the biotechnology in Korea. A dissertation for Taiwan Genetic Intention Survey and Research Conference. Center for Survey Research, Academic Sinica. Taipei.
- Chou, Kuei-tien. (2000). Bio-industry and Social Risk - Delayed High-tech Risk Society. *Taiwan: A Radical Quarterly in Social Studies*, 39, 239-283.
- Chou, Kuei-tien. (2002). The Theoretical and Practical Gap of Glocalizational Risk Delayed High-tech Risk Society. *Taiwan: A Radical Quarterly in Social Studies*, 45, 69-122.
- Chou, Kuei-tien. (2003). From Globalizational Risk to Glocalizational Risk: Critical Rethinking of Beck's Theory of Risk Society. *Taiwanese Journal of Sociology*, 31, 153-188.
- Chou, Kuei-tien. (2004). Dialogue' between monopolistic scientific rationality and tacit (submerged) social rationality: a discussion of risk culture between local public, scientists, and the state. *Taiwan: A Radical Quarterly in Social Science*, 56, 1-63.
- Chou, Kuei-tien. (2005a). How is social trust of Biobank possible? Presented on SWISS/TAIWAN Scientific Seminar 2005 - Biotechnology and Public Health in the Gene-Era: Ethical, Legal, Social and Political Aspects. Universität Zürich, Institut für Politikwissenschaft. August 17, 2005. Swiss
- Chou, Kuei-tien. (2005b). How is risk governance possible in a double risk society?

- Presented on 14<sup>th</sup> SRA Europe Annual Meeting 2005 – Major risks challenging publics, scientists and governments. Society of Risk Analysis. September 12, 2005. Italy.
- Chunghwa Telecom sell its customer data? KDPO searched its branches. (2005, May 25<sup>th</sup>). Etoday. <http://gb.ettoday.com.tw/2004/05/25/331-1634957.htm>
- Council of Europe. (2005). *Convention on Human Rights and Biomedicine*. Strasbourg.
- Data in NHI IC Card can be locked. Low possibility of NHI IC Card information divulgence. (2002, April 17<sup>th</sup>). *Christian Health Care Alliance Newsletter*, 54. “.” <http://www.mmh.org.tw/chca/newspaper/54/%B9q%A4%B3%F854.htm>
- de Marchi, B., & Ravetz, J. R. (1999). Risk management and governance: a post-normal science approach. *Futures* 31, 743-757.
- Dryzek, J. S. (1997). Leave it to the experts: Administrative rationalism. In: *The Politics of the Earth – Environmental Discourses* (pp. 63-83). Oxford University Press.
- Electronic Signatures Act. (2001, November 14<sup>th</sup>). <http://db.lawbank.com.tw/Eng/FLAW/FLAWDAT0202.asp>
- Emerging systemic risks in the 21st century: **An agenda for action**.
- Chapter 2 Risk Assessment. (2003). <http://www.unisdr.org/unisdr/eng/library/Literature/7754.pdf#search='Emerging%20Systemic%20Risks%20in%20the%2021st%20Century%3A%20An%20Agenda%20for%20Action.'>
- Establishment of Taiwan Biobank Proposals for Preparatory Phase 2005 and Phase I Project 2006-2009 . (2005, June). Department of Health. [http://www.doh.gov.tw/ufile/Doc/200506\\_Biobank-2005-RFP-DOH-scyclo.pdf#search='%E5%BB%BA%E7%BD%AE%E5%8F%B0%E7%81%A3%E5%9F%BA%E5%9B%A0%E8%B3%87%E6%96%99%E5%BA%AB%E5%85%88%E6%9C%9F%E8%A6%8F%E5%8A%83'](http://www.doh.gov.tw/ufile/Doc/200506_Biobank-2005-RFP-DOH-scyclo.pdf#search='%E5%BB%BA%E7%BD%AE%E5%8F%B0%E7%81%A3%E5%9F%BA%E5%9B%A0%E8%B3%87%E6%96%99%E5%BA%AB%E5%85%88%E6%9C%9F%E8%A6%8F%E5%8A%83')
- European Commission. (2006). Eurobarometer 2006 – Risk Issues . [http://ec.europa.eu/public\\_opinion/archives/ebs/ebs\\_238\\_en.pdf](http://ec.europa.eu/public_opinion/archives/ebs/ebs_238_en.pdf)
- Evans, P. (1995). *Embedded autonomy: states and industrial transformation*. New Jersey: Princeton University Press.
- Fischer, F. (1989). Technocracy and expertise: The basic political question, In Fischer, *Technocracy and the Politics of Expertise* (pp.13-39). Sage Publications.
- Fu, su-tan. &Hu, Ko-wei. (2006). Public Attitudes toward Biobank in Taiwan. Conference of Survey Research and the Bioethics Studies of Genomic Research in Taiwan. Academia Sinica. Taipei.
- Genetic databases – Assessing the benefits and the impact on human & patient rights. (2004). *European Journal of Health Law*, 79-84.

- Gerold, R. & Liberatore, A. (2001). Report of the working group “Democratising expertise and establishing scientific reference systems”. European Union.
- Gerrard, Simon, & Petts. (1998). Isolation or integration? The relationship between risk assessment and risk management. In Hester & Harrison (Eds.) *Risk Assessment and Risk Management* (pp. 1-20). The Royal Society of Chemistry Information Services.
- Giddens, A. (2002). *Runaway world: How globalization is reshaping our lives*. New York, NY: Routledge.
- Gibbons, M. (1994). Competitiveness, collaboration and globalisation. In M. Gibbons, C. Limoges, H. Nowotny, S. Schwartzman, P. Scott, & M. Trow, *The new production of knowledge – the dynamics of science and research in contemporary societies* (pp. 111-136). London: Sage Publications.
- Gilbert, F. (1997). Privacy of medical records? The Health Insurance Portability and Accountability Act of 1996 creates a framework for the establishment of security standards and the protection of individually identifiable health information. *North Dakota Law Review*, 93. North Dakota Law Review.
- Gonçalves, M. E. (2005). Risk and the governance of innovation in Europe: an introduction. *Technological Forecasting & Social Change*, 73, 1-12.
- Gottweis, H. (1998, December 25<sup>th</sup>). What is poststructuralist science and technology policy Analysis? In Gottweis, *Governing molecules – the discursive politics of genetic engineering in Europe and the United States* (pp. 11-38). The MIT Press.
- Governance in the UE – White Paper on Governance Work area 1: Broadening and enriching the public debate on European matters. [http://ec.europa.eu/governance/areas/group1/report\\_en.pdf](http://ec.europa.eu/governance/areas/group1/report_en.pdf)
- Graham, J. P. (1987, June). Privacy, computers, and commercial dissemination of personal information. *Texas Law Review: Note*, 1395. Texas Law Review Association.
- Greely, H. T. (2000, Winter). Iceland’s plan for genomics research: Facts and implications. *Jurimetrics Journal*, 153. American Bar Association.
- Greely, H. T. (2005, December). Population participation and other factors that impact the compilation and the utility of resulting database. *Louisiana Law Review*, 79. Louisiana Law Review
- Guidelines of Electronicalized Medical Record Application in Medical Sectors. (2004, March 3<sup>rd</sup>). Department of Health. <http://jj.tmu.edu.tw/issue2.pdf#search='%E9%86%AB%E7%99%82%E6%A9%9F%E6%A7%8B%E5%AF%A6%E6%96%BD%E9%9B%BB%E5%AD%90%E7%97%85%E6%AD%B7%E4%BD%9C%E6%A5%AD%E8%A6%81%E9%BB%9E'>



- Health Insurance Portability and Accountability Act (1996).  
<http://thomas.loc.gov/cgi-bin/query/z?c104:H.R.3103.ENR>:
- Healy, S. (1999). Extended peer communities and the ascendance of post-normal politics. *Futures*, 31, 655-669.
- Ho, Jen-min. (2000, September 18<sup>th</sup>). Appealing: do not promote “NHI IC Card policy”. Taiwan Association for Human Rights.  
<http://www.tahr.org.tw/site/PDPA/her.htm>
- Hoppe, R. (1999). Policy analysis, science and politics: from “speaking truth to power” to “making sense together”. *Science and Public Policy*, 26(3), 201-210.
- Hsie, Bo-hon. (2004c, December 4<sup>th</sup>). MOI leads to integrate resources for Biobank and Bio-IT projects. Commercial Times.  
[http://grad.ncku.edu.tw/news/insur\\_dtl.asp?sno=869](http://grad.ncku.edu.tw/news/insur_dtl.asp?sno=869)
- Hsei, Bo-hon. (2004b, February 25<sup>th</sup>). Tasi, Chin-yen: MOI promoting Taiwan Biobank establishment. Commercial Times.
- Hsu, K-L. (2002). The rise and fall of the Taiwanese development state, 1949-1999, Ph.D. Thesis. Department of Sociology, Lancaster University.
- Hsu, Kuo-ziang. (2005, November 4<sup>th</sup>). Don't let medical regulations die without voices. *Information Security Newsletter*, 150.  
<http://www.informationsecurity.com.tw/newsletter/20050704.htm>
- Huang, Zon-hsin. (2004, May 28<sup>th</sup>). Sell customer information. 2 Chunghwa Telecom contractors arrested. ET today.  
<http://gb.ettoday.com.tw/2004/05/18/545-1631826.htm>
- International Risk Governance Council (IRGC). (2005). White paper on risk governance towards an integrative approach, Geneva.  
[http://www.irgc.org/irgc/projects/risk\\_characterisation/\\_b/contentFiles/IRGC\\_W\\_P\\_No\\_1\\_Risk\\_Governance\\_\(reprinted\\_version\).pdf](http://www.irgc.org/irgc/projects/risk_characterisation/_b/contentFiles/IRGC_W_P_No_1_Risk_Governance_(reprinted_version).pdf)
- Irwin, A. (1995). *Citizen science A study of people, expertise and sustainable development*. London: Routledge.
- Jang, Chi-tin. (2005, November 27<sup>th</sup>). Taiwan will be the “BIG” to collectively monitor its citizens. Taiwan Association for Human Rights.  
<http://www.tahr.org.tw/site/PDPA/Chiting.htm>
- Jasanoff, S. (1990). *The fifth branch – science adviser as policymakers*. Harvard University Press.
- Kasperson, E. R., Jhaveri, N., & Kasperson, X. J. (2005). Stigma and the social amplification of risk: towards a framework of analysis. In Kasperson, J. X. & Kasperson, R. E., *The social contours of risk – volume I: publics, risk communication & the social amplification of risk* (pp. 161-180). Earthscan, London.
- Knoppers, N. M. (2005, Spring). Biobanking: International norms. *Journal of Law, Medicine and Ethics*, 15. American Society of Law, Medicine & Ethics, Inc.

- Lee, Der-zsai. (2005, April 27<sup>th</sup>). Suspicions towards new ID card issuance with Citizen Fingerprint Database. Yam Digital Technology. <http://news.yam.com/yam/politics/200505/20050525168243.html>
- Lie, Min-hsao. (2005). Taiwan Biobank establishment and related ethical regulation and laws. The 7<sup>th</sup> National Science and Technology Conference. Taipei. <http://www.nsc.gov.tw/pla/tc/Files/9401briefing-8-4.pdf#search='%E5%BB%BA%E7%AB%8B%E5%8F%B0%E7%81%A3%E5%9F%BA%E5%9B%A0%E8%B3%87%E6%96%99%E5%BA%AB%E5%8F%8A%E7%9B%B8%E9%97%9C%E4%B9%8B%E5%80%AB%E7%90%86%E8%A6%8F%E7%AF%84%E5%8F%8A%E6%B3%95%E4%BB%A4'>
- Liu, Ching-yi. (2004, June 3<sup>rd</sup>). If, information divulgence plus fingerprint policy.... United Daily. <http://intermargins.net/Forum/2001%20July-Dec/privacy/nation/na07.htm>
- Liu, Ching-yi. (2005, September 25<sup>th</sup>). While IT meets biotechnology: are you ready? iThome online. <http://www.ithome.com.tw/itadm/news/news.php?c=33299>
- Liu, Ching-yi. (2006, January 7<sup>th</sup>). How come there is Taiwan Biobank? The Judicial Reform Foundation. [http://www.jrf.org.tw/mag/mag\\_02s.asp?SN=1561](http://www.jrf.org.tw/mag/mag_02s.asp?SN=1561)
- Liu, Hung-en (2005). Public trust, commercialization, and benefit sharing in Biobanking, *NTPU Law Review*, 57. National Taiwan University, Taipei.
- Löfstedt R. (2002). The precautionary principle: risk, regulation and politics. (Introduction paper). United Kingdom, Oxford: Merton College.
- Luks, F. (1999). Post-normal science and the rhetoric of inquiry: deconstructing normal science? *Futures*, 31, p.705-719.
- Malinowski, M. J. (2005, December). Taking genomics to the biobanks: Access to human biological samples and medical information. *Louisiana Law Review*, 43. Louisiana Law Review.
- Mobilization Project of Kaohsiung as a Globalizational IT City. (2005). Graduate Institute of Building and Planning, National Taiwan University. <http://www.bp.ntu.edu.tw/bpresults/khc/project/seminar2.htm>
- Noble, A. A. (2006, Summer). DNA fingerprinting and civil liberties. *Journal of Law, Medicine and Ethics*, 149. American Society of Law, Medicine & Ethics, Inc.
- Nowotny, H., Scott, P., & Gibbons, M. (2001). The co-evolution of society and science. In: *Re-Thinking Science: Knowledge and the public in an age of uncertainty* (pp.30-49). Cambridge: Polity Press.
- OECD: Emerging systemic risks. (2003). Organization of Economic Co-operation and Development. Final report to the OECD Futures Project. <http://www.oecd.org/dataoecd/23/56/19134071.pdf>
- Personal information divulgence cases of 2002. (2002). Taiwan Association for Human Rights. <http://www.tahr.org.tw/site/PDPA/2002case.htm>

- Petersen, S. B. (1995, December). Your life as an open book: Has technology rendered personal privacy virtually obsolete? *Federal Communications Law Journal: Note*, 163. Federal Communications Bar Association.
- Petersen, A. (2005). Securing our genetic health: Engendering trust in UK Biobank, *Sociology of Health & Illness*, 7(2), 71-292.
- Protests on the lavish NHI IC Card. Civil rights under deprivation. (2002, July 26<sup>th</sup>). Taiwan Association for Human Rights – press release. <http://www.yccc.com.tw/hope/news5.htm>
- Racine, E. (2003, Fall). Discourse ethics as an ethics of responsibility: Comparison and evaluation of citizen involvement in population genomic. *Journal of Law, Medicine and Ethics*, 390. American Society of Law, Medicine & Ethics, Inc.
- Rackett, C. M. (1997, Fall) Telemedicine today and tomorrow: Why “virtual” privacy is not enough. *Fordham Urban Law Journal: Note*, 167. Fordham University School of Law.
- Ravetz, J. R. (1999). What is post normal science?, *Futures*, 31(7), 647-653.
- Ravetz, J. R. (2002). The post-normal science of precaution. PNS-P, 1-13.
- Regidor, E. (2004). The use of personal data from medical records and biological materials: Ethical perspectives and the basis for legal restrictions in health research. *Social Science & Medicine*, 59, 1975-1984.
- Renn, O. (2005). “Before assessment starts” to “risk appraisal”. In *IRGC White Paper No.1: Risk Governance - Towards an Integrative Approach* (pp. 23-35). International Risk Governance Council. [http://www.irgc.org/irgc/projects/risk\\_characterisation/\\_b/contentFiles/IRGC\\_WP\\_No\\_1\\_Risk\\_Governance\\_\(reprinted\\_version\).pdf](http://www.irgc.org/irgc/projects/risk_characterisation/_b/contentFiles/IRGC_WP_No_1_Risk_Governance_(reprinted_version).pdf)
- Report of the working group “democratizing expertise and establishing scientific reference systems” (2001). [http://ec.europa.eu/research/science-society/pdf/governance\\_questionnaire\\_01.pdf](http://ec.europa.eu/research/science-society/pdf/governance_questionnaire_01.pdf)
- Robertson, R. (1992). *Globalization*. London.
- Rothstein, M. A. (2002, Spring). The role of IRBS in research involving commercial biobanks. *Journal of Law, Medicine and Ethics*, 105. American Society of Law, Medicine & Ethics, Inc.
- Rothstein, M. S. (2005, Spring). Expanding the ethical analysis of biobanks. *Journal of Law, Medicine and Ethics*, 89. American Society of Law, Medicine & Ethics, Inc
- Robertson, R. (1992). *Globalization*. London.
- Rutgers, M R & Mentzel, M A (1999). Scientific expertise and public policy: resolving paradoxes? *Science and Public Policy*, 26(3), 146-150.

- Schumacher, E. F. (1989). *Small is beautiful: Economics as if people mattered*. London: Harper Perennial.
- Science and Society Action Plan. (2002). EUROPA – Research – Science and Society in Europe: Science and Society Action Plan. [http://europa.eu.int/comm/research/science-society/pdf/ss\\_ap\\_en.pdf](http://europa.eu.int/comm/research/science-society/pdf/ss_ap_en.pdf).
- Science and Technology Advisory Group of Executive Yuan. (2005). Official launch “Taiwan Biomedtech Island Project”. [http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=7&grp\\_id=5&vroot=&cntgrp\\_ordinal=00060004&cnt\\_id=400](http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=7&grp_id=5&vroot=&cntgrp_ordinal=00060004&cnt_id=400)
- Slovic, P. (2001). The risk game. *Journal of Hazardous Materials*, 86, 17-24.
- Smith, M. J. (2001, December). Population-based genetic studies: Informed consent and confidentiality. *Santa Clara Computer and High Technology Law Journal: Comment*, 57. Santa Clara Computer & High Technology Law Journal.
- Stein, J. A. (2002). Introduction: Globalization, science, technology and policy. *Science and Public Policy*, 29(6), 402-408.
- Steward, M. (2005, December). Electronic medical records. *Journal of Legal Medicine: Commentary*, 491. Taylor & Francis.
- Taiwan Biomedtech Island Project will bring in 40 billions (est. 1 billion euros) in 5 years. (2005, April 20<sup>th</sup>). Department of investment Services, Ministry of Economic Affairs. <http://investintaiwan.nat.gov.tw/zh-tw/news/200504/2005042001.html>
- Tavani, H. T. (2004). Genomic research and data-mining technology: Implications for personal privacy and informed consent. *Ethics and Information Tchnology*, 6, 15-28.
- Terry, S. F. & Terry, P. F. (2006, Summer). A consumer perspective on forensic DNA banking. *Journal of Law, Medicine and Ethics*, 408. American Society of Law, Medicine & Ethics, Inc.
- The Guardian newspaper. (2006, January 12<sup>th</sup>). Disgraced stem cell scientist blames researchers”. <http://education.guardian.co.uk/higher/research/story/0,,1684954,00.html>
- United Nations Educational, Scientific and Cultural Organization. (1997). Universal Declaration on the Human Genome and Human Rights, <http://unesdoc.unesco.org/images/0011/001102/110220e.pdf#page=47>.
- United Nations Educational, Scientific and Cultural Organization. (2003). International Declaration on Human Genetic Data, <http://unesdoc.unesco.org/images/0013/001331/133171e.pdf#page=45>.
- Wendler, D. (2002). What research with stored samples teaches us about research with human subjects. *Bioethics*, 16(1), 33-54.
- Wang, Jon-hwa. (2002, May 28<sup>th</sup>). Fingerprint database is helpful for dead body

- verification. Central Daily News.  
<http://www.cdn.com.tw/daily/2002/05/28/text/910528ac.htm>
- World Health Organization. (2004). Genetic databases – Assessing the benefits and the impact on human & patient rights. *European Journal of Health Law*, 79-84.  
<http://www.law.ed.ac.uk/ahrb/publications/online/whofinalreport.pdf#search='Genetic%20Databases%20%E2%80%93%20Assessing%20the%20Benefits%20and%20the%20Impact%20on%20Human%20%26%20Patient%20Rights>
- Wynne, B. (1980). Technology, risk and participation: On the social treatment of uncertainty. In Conrad, J. (Ed.), *Society, technology and risk assessment* (pp. 173-208). New York: Academic Press,
- Wynne, B. (1996). May the sheep safely graze? A reflexive view of the expert-lay knowledge divide. In Lash, S. & Szerszynski B. (Eds.), *Risk, Environment & Modernity* (pp.45-83). London: Sage Publications Ltd.
- Zeng, Wen-jin. (2004, August 28<sup>th</sup>). To defend civil rights. Against electronicalization of privacy. Lihpao Daily. <http://publish.lihpao.com/Education/2004/08/28/04d08271/>
- Zeng, Zen-hsin. (2006, February 11<sup>th</sup>). Outdated medical records of Chung Gung everywhere. DOH: is there management malpractice? United Daily.