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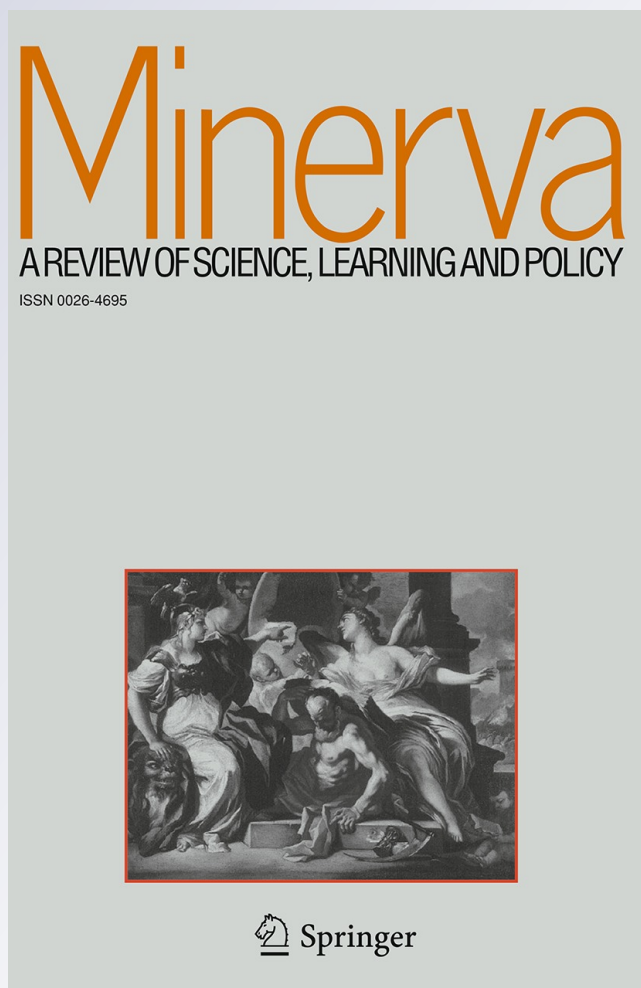
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# Commercial Genetic Testing and its Governance in Chinese Society

Suli Sui<sup>1</sup> · Margaret Sleeboom-Faulkner<sup>2</sup>

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**Abstract** This paper provides an empirical account of commercial genetic testing in China. Commercial predictive genetic testing has emerged and is developing rapidly in China, but there is no strict and effective governance. This raises a number of serious social and ethical issues as a consequence of the enormous potential market for such tests. The paper demonstrates that the commercialization of genetic testing and the lack of adequate regulation have created an environment in which dubious advertising practices and misleading and unprofessional medical advice are commonplace. The consequences of these ethically problematic activities for the users of predictive tests are unknown. The paper concludes with a bioethical and social science perspective on the ethical governance issues raised by the dissemination and utilization of commercial genetic testing in Chinese society.

**Keywords** Commercial genetic testing · Bio-company · Commercialization · Governance · Chinese society

## Introduction

Commercial genetic testing (CGT) is usually offered to individuals with a positive family history, who are either pre-symptomatic of a late-onset disease or have an increased genetic susceptibility conferring a predisposition to future disease

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symptoms (Marteau and Richards 1996; Fulda and Lyknes 2006; Mand et al. 2012). It is used to determine whether the person has a genetic mutation that will lead to a late-onset disorder. In China, the application of predictive genetic testing and its commercialization are becoming increasingly popular. There are some biotech companies providing services for predictive genetic testing, such as Shanghai Fudan Bio-Technologies Co., Ltd.; Beijing Anmanli Health Technology Co., Ltd.; Nanjing Nanbo Bio-Technologies Co., Ltd.; Wenzhou Huada Bio-Technologies Co., Ltd.; Henan Yujing Bio-Technologies Co., Ltd., and Chongqing Xiehe Genomics Center. Companies such as these offer genetic testing directly to individual customers or to the organizations that desire their employees have a clean bill of genetic health. Customers buy tests directly from the company, through company agents, or online. The number of such biotech companies has been growing rapidly, although the precise number throughout the country is not known. Additionally, the scope of testing services has become wider, and the modes of business operation simpler, some companies solely selling tests online, such as is the case with Genetic Testing Net and Zhong Ren Gene Net.<sup>1</sup>

This paper provides an account of CGT offered by biotech companies and its implications in Chinese contexts. It analyzes the commercialization of predictive genetic testing and illustrates social and ethical issues related to its governance. We argue that, in the Chinese contexts, individuals are not well prepared for CGT. Even though research indicates that the influence of CGT on the public and society might be limited in the context of the USA (Bloss et al. 2011), we argue that in the context of China it has caused, and might continue to cause, serious social and ethical problems. Examples include the violation of confidentiality and privacy, genetic discrimination, and preventable anxiety. We suggest that these issues need to be addressed by the public and regulated through administration modes appropriate to Chinese society.

## Assumed Choice, Individual Responsibility and Privacy of CGT

Currently, the management and operation of CGT profiling is outside the supervision of the Ministry of Health (MOH).<sup>2</sup> The application of genetic testing relates to the medical domain and genetic information of individuals, so the practice of CGT should be under supervision to avoid harm to individuals. For that reason, many societies guard the field through regulation and social networks such as professional codes.

Our considerations proceed from a general question relating to the adoption of potentially intrusive biotechnologies in society. As Nikolas Rose argued, the rise of new “advanced liberal” governmental technologies involves the devolution of many responsibilities for the management of human health and reproduction from

<sup>1</sup> The website of Genetic Testing Net is: [www.jiyinjiancewang.org](http://www.jiyinjiancewang.org); the website of Zhong Ren Gene Net is: <http://yiyawang.org/index.html>.

<sup>2</sup> From March 17, 2013, the Ministry of Health has changed its name to National Health and Family Planning Commission. For easier understanding, this paper still uses MOH.

the state to quasi-autonomous regulatory bodies (e.g., institutional review boards, national ethics committees, local councils and NGOs, private corporations such as biotech companies selling products such as genetic tests directly to consumers) and to professional groups (e.g., medical associations). According to Rose, this process is regulated “at a distance” by powerful mechanisms of audits, standards, benchmarks, and budgets. These modifications involve an emphasis on the responsibility of individuals to manage their own affairs and to manage their own security with an eye on the future. This complex of marketization, autonomization, and responsabilization gives a particular character to the contemporary politics of life in advanced liberal democracies (Rose 2007). However, the influence of these mechanisms and modifications are not felt where such processes of governance do not reach. For instance, the control of the US FDA (Food and Drug Administration) over “23andMe” has been limited (Seife 2013). In China, however, the notion of such mechanisms of governance is only gradually spreading, and, as we show below, plays out quite differently if at all.

But what happens when CGT is offered in a society where individuals do not have a similar experience of making free and autonomous decisions about medical matters, where citizens have not been taking part in a relatively open or critical debate about government policies, including those of science and technology, and individuals have not been “trained” in taking responsibility for their own health. In advanced liberal democracies, citizens are conceptualized as having become consumers who actively choose and use medicine, bioscience, pharmaceuticals, and “alternative medicine” in order to maximize and enhance their own vitality (Rose 2007: 23). The research done by Scripps Translational Science Institute (La Jolla, California), surveying the reactions of over 2,000 consumers of genetic tests five months after receiving test results, has to be understood within this context. This form of genome-wide profiling examined the psychological, behavioral, and clinical effects of risk scanning with a commercially available test of uncertain clinical validity, called Navigenics Health Compass. The test was offered to cover genetic predispositions for 22 conditions, including Alzheimer’s disease, diabetes, glaucoma, obesity, and cancers of the lung, breast and prostate. Companies have offered CGT for several years, taking saliva samples from customers, analyzing the DNA, and delivering a risk report for a series of diseases. According to the findings of the Scripps study, only about half of the participants reported that they would seek medical testing in the future because of their DNA results, and on average there was no increase in anxiety. Without genetic counseling, apparently, the participants regarded the test results merely as fragmentary information. Thus, clients usually are laypersons of genomics, might not understand test results well, and hardly change their eating and exercising behavior. One can interpret these results in various ways: first, the consumers who were educated could handle the volume of information, and therefore did not become anxious; second, the consumers did not understand the information, and so there was no reason for them to change their behavior. This was an interpretation favored by some professionals, who think that consumers without the guidance of a genetic counselor cannot interpret the results from a DNA test, and so it is difficult for laypersons to act upon the information. Third, consumers did understand the information but were still not very much

concerned. This conclusion was reached by Eric Topol, director of Scripps Translational Science Institute in La Jolla, California. Both Eric Topol and Lotre Greenspan concluded that people need a shock to change their health habits, usually that of a close friend or family member dying suddenly (CBC News 2011).

This example illustrates how, in an ideal-typical advanced liberal society, the uptake, interpretation, and influence of genetic tests are socially mediated. In the US context, Bloss et al. mention only the role of a genetic counselor, the motivation of the consumer, and the pressure of family and friends as determining factors of the way tests are interpreted. The underlying implicit assumptions of the research are that the consumers have bought the tests for themselves, and that they themselves decided what to do with the test results. Furthermore, the research presumes that there are no other institutions involved that might discriminate consumers on the basis of the test results, and that information is presumed to be protected and private. Hence, it is up to the individual to decide to act upon and to deal with the information, with or without invoking the help of other sources.

Although this “liberal” model has been criticized in the context of the USA (Duncan 2004; Duncan and Delatycki 2006; Robertson and Savelescu 2001), this paper illustrates how a society short of the effective means to mobilize and channel criticism of CGT lacks the capacity to regulate it. In the following, we argue that when justifying CGT in the context of China, the presumptions of free choice and the availability of the information to make those choices are carried over from the USA. Below, we argue, however, that the significance of genetic information to individuals, institutions, and Chinese society requires a mode of governance suitable to Chinese contexts.

What follows explains how commercial genetic testing operates and how it is institutionally situated in China, shows how Chinese experts critically review potential benefits of genetic testing, and discusses why the presumptions underlying commercial genetic testing and its governance in advanced neoliberal societies should be put into perspective when examining its governance in Chinese society.

## **The Rise of Commercial Genetic Testing in China**

### *Believing in Science*

Since the nineteenth century, “science” has underpinned various ideologies, including enlightenment, communism, anarchism, capitalism, modernization, the Dengist reforms, and the current social ideology of socialism with Chinese characteristics. For instance, in the late 1970s, the most important element of the four reforms was the development of science and technology (Deng 1978; Hua 1978; Perrole 1982; Saich 1985). The widely appreciated success of the post-1978 reforms, the “socialist market economy,” and the application of high-end technology, all of which are formulated in scientific terms, have contributed to the belief in science and technology as saviors of society (Suttmeier 1980; Saich 1985; Bowers et al. 1988; Simon and Goldman 1989; Bakken 1994; Sleeboom-Faulkner 2006). This general belief in the efficacy of scientific knowledge has made

it easy for people to put their faith in the technologies developed on its basis, such as genetic testing.

Advertising agencies make use of scientific gullibility when describing the predictive power of genetic testing, exaggerating the number of predictable conditions, the certainty of these predications, the pertinence of solutions, and the suitability of advice. Some companies adopt a particular strategy by asking clients for personal health information and then returning the given information as “results” by using “scientific” terms. Furthermore, the authority of scientific jargon enforces the general lifestyle advice, which is then “explained” in everyday language.

Such belief in science and technology does not prepare clients or parents for the quality of the genetic tests and advice they are given. This phenomenon has little to do with their educational background, as it is often the better off and educated parents who use the tests. In fact, parents with little financial means in need of genetic tests often cannot afford them, and those who can afford them try to enhance their already strong position by strategizing the family future around knowledge of their child’s possession of a “beauty gene” or a “talent gene.” Invalid and “positive” test results, however, might lead to much distress, as in many cases there are no cures or solutions available for the detected conditions, or the client develops not unrealistic anxieties of becoming an outcast or subject to discrimination. The consequences of the absence or low quality of genetic counseling in the context of commercial genetic testing in China does not so much lead to an incapacity of consumers to act on information, but to an overinterpretation of test results with the capacity to harm the person tested.

### *Commercial Genetic Testing Companies*

As with other commercial companies in China, biotech companies planning to set up a genetic testing business have only to apply for a business license from the local Industrial and Commercial Bureau. They are neither limited in the way they market their testing products, nor do they need any special medical qualifications or permissions from the Ministry of Health (MOH) and the Ministry of Science and Technology, nor do the staff of these companies need any medical qualification. In 2007, the MOH issued *The List of Clinical Testing Items for Medical Institutions*,<sup>3</sup> and in 2010 the MOH enacted *The Guidelines for Gene Chip Diagnosis Technology*.<sup>4</sup> The list and the guidelines, however, only regulate the clinical activities of medical institutions, and are not applicable to the business activities of companies.

CGT in China was incentivized by the availability of genetic testing technologies and a large pool of potential customers. Currently, the testing price varies from 4,000 to 10,000 RMB (Euro 498 to 1,245), depending on the number of testing

<sup>3</sup> <http://www.moh.gov.cn/publicfiles/business/htmlfiles/mohbgt/pw10710/200804/19045.htm> (official website of MOH).

<sup>4</sup> [http://www.moh.gov.cn/sofpro/cms/previewjspfile/mohyzs/cms\\_00000000000000073\\_tpl.jsp?requestCode=44624&CategoryID=3585](http://www.moh.gov.cn/sofpro/cms/previewjspfile/mohyzs/cms_00000000000000073_tpl.jsp?requestCode=44624&CategoryID=3585) (Official website of MOH).



items. The tests yield considerable profit. A marketing agent of one company stated that the selling price of one set of its tests services was introduced at 3,650 RMB (Euro 454), while the cost declared to the Price Bureau was 1,799 RMB (Euro 224) (Huang 2006). Such profit margins are not unusual.

On the websites of biotech companies<sup>5</sup> and in newspapers such as *Beijing Daily*, *South Weekend*, and *Beijing Keji Daily*, one can easily find commercial advertisements and those disguised as scholarly articles, introducing the merits of genetic tests in a speculative manner. Some biotech companies declare on their websites that they collaborate with a state university or research institution, even when only one or two technical advisers are researchers/professors there. The proclamation of cooperation with state-supported research institutions aims to obtain the trust of the public, as people are presumed to trust state educational institutions more than they do commercial enterprises. In the advertisements, the companies offer genetic testing services for a wide range of multifactorial diseases. For example, Chongqing Xiehe Gene Center declares that it offers genetic tests for the genetic predisposition to 110 diseases. One principal member of staff said that technically their genetic testing could test for more than one thousand diseases, but most are rare diseases. Thus, considering low detection efficiency and high testing cost, 110 tests (related to the three main kinds of human diseases, namely cardiovascular diseases, cellular immunity, and cancer) were finally selected for their testing services portfolio (Chen and Liu 2009). A test only requires one or several drops of blood or a few mucous membrane cells from the client to test whether a person is a carrier of genes associated with certain diseases, and thus his or her predisposition status.

In order to gain market share, some biotech companies have agents in more than one large city. For instance, Shanghai Fuda Genetic Testing Distribution Co., Limited has an office in Beijing with a special agent, who needs to remain anonymous. The first author met the agent in Beijing, and the agent explained the procedure in detail. Potential customers in Beijing can contact the agent and the agent arranges for her or him to be sampled, and mails the sample to the company. If the customer wishes, he or she can receive “door-to-door” services and be sampled at home. Some online selling of genetic testing services does not even involve any intermediary agent. The client buys a testing service online through Internet banking or by transferring money to the company. The sample equipment is sent to clients by express mail for the collection of oral mucosa membrane cells, and then returned, which is paid by the company. After the tests are analyzed, the client receives the testing report of her or his predisposition status. Usually, the results are stratified into three categories of risk referred to as “high,” “medium,” and “low,” but no exact percentage is attached to these. The probability of contracting a disease is explained in terms of likelihood in comparison with the “average” individual without such a predisposition. If, for instance, the results identify a medium-level risk of developing Alzheimer’s disease, it is explained by the additional information

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<sup>5</sup> For instance: <http://www.yiyaowang.org/index.html>; <http://www.genecore.com/>; <http://www.fudanjm.com/>; <http://www.rjgne.com/>; <http://www.newkang.com/>; <http://www.zkjmh.com/>; <http://www.sangon.com/>.



that the client has a five-times increased probability of developing the disease compared to an “average” person. Furthermore, the report usually provides advice on a healthy diet and lifestyle, allegedly to prevent or avoid the disease in question. The implications of such advice will be discussed below.

In practice, biotech companies, in their advertisements and in their public relations leaflets, seek to reach the public by using attractive and striking concepts, such as “decode the mystery of life, predict your future health,”<sup>6</sup> “genetic testing—the most fashionable healthy lifestyle in the twenty-first century,”<sup>7</sup> “personal treatment, decode health,”<sup>8</sup> and “create a healthy life based on genetic technology.”<sup>9</sup> These sensationalist headings aim to persuade potential customers to believe that genetic testing can provide predictable health and a healthy future. These images have a great power to attract laypersons, given the increased popularity of genetic testing in China, especially in big cities, and especially in the comparatively wealthy parts of society. Some companies point out that genetic tests are suitable for anyone, and encourage healthy people to purchase tests for themselves, their partner, their children, and their parents. They also encourage employers to purchase tests for their employees. To deal with commercial competition, some of the companies offer sets of services at discount prices, exemplified by the test price of Chongqing Xiehe Genomics Center being 3,995 RMB (Euro 497) for 33 diseases, 6,995 RMB (Euro 871) for 60 diseases and 9,995 RMB (Euro 1,244) for 110 diseases (Chen and Liu 2009).

Besides genetic testing for susceptibility genes, some companies, such as Chongqing Xiehe Genomics Center, Beijing, Zhong Ren Gene, and Henan Yujing Bio-Technology Company, offer new kinds of genetic testing, such as for “talent genes,” “rational drug use,” and “safe drug use.” These kinds of testing mainly target children, usually between 4 and 13 years of age, a huge group of potential customers in China. “Talent genes” divide into several major items, including personality, emotion, art, sport, and IQ, and 40 to 50 sub-items, including genes for optimism, shyness, passion, depression, puppy love, and alcohol addiction. The various gene items all include numerous potential abilities and imperfections. The price of testing for one “talent gene” item is approximately 600 RMB (Euro 75), and 4,000 RMB (Euro 498) for a set. Additionally, some companies sell a test for the “beauty gene,” targeting women longing for beauty, a large group of consumers. For example, Henan Yujing Company sells genetic tests for the genes of “skin color,” “no-wrinkles,” “antioxidation,” and “cell renewal.” It declares that such tests can assess the most suitable nutrients and beauty determinants for skin.<sup>10</sup>

<sup>6</sup> Available at: <http://www.qiji.cn/scinews/detailed/2330.html>.

<sup>7</sup> Available on the website of Fudan Biotechnologies Co, Ltd. <http://www.fudan.com/>.

<sup>8</sup> From a leaflet of Shanghai Gene Core Biotechnologies Co, Ltd.

<sup>9</sup> From a name card of an agent of a Biotech Company.

<sup>10</sup> Information can be found on: <http://www.genegov.com/jyj/jyjcxm/200811/8804.html>.

### *Business Operation and Agent Recruitment*

The popularity and applications of the new technology is in need of regulatory supervision, as this technology exploits existing business models, and allows for further mishandling of what is sold as scientific genetic information. To boost business volume, some biotech companies use controversial methods to attract investment and recruit sales agents. In general, the recruitment of agents is a legal commercial method, but some systems of agent recruitment are regarded as problematic. In 2006, a journalist published a report in *Shanghai Dongfang-Zaobao* (Eastern Morning Post), based on his personal investigation, showing how the Shanghai Fuda Genetic Testing Distribution Co., Limited (Fuda Company) recruits agents throughout the country. The company is suspected of a recruitment and sales practice called multilevel marketing, which is illegal in China. It works as follows. First, to become qualified as a primary-level agent of Fuda, an individual is required to pay the company 35,200 RMB (Euro 4,382). The money is used to fund 14 sales units that sell genetic tests, of which the new agent takes on three units. Second, the agent has to then recruit three other agents as daughter agents. Each of these three newly recruited agents also pays 35,200 RMB (Euro 4,382) to the company for her or his agent qualification and also takes on three units, totaling twelve units taken on by the four agents themselves. Finally, the two remaining units are left for the agent to sell to interested customers. The income of the agent constitutes 1 percent of the company's profit, which increases with the number of agents he or she recruits. According to the new revision of "Corporation Law," which was enacted on January 1, 2006, ordinary persons can apply for a "One-Person Company."<sup>11</sup> Fuda requires its agents to register as such one-person companies, so that it can declare that its agents are not "natural persons" (*ziranren*) but corporations, and that the relationship between the agents is a business relationship between companies. In fact, these so-called companies are only "bag companies" (*pibao gongsi*). A *pibao* company runs its business with only a company name, an official business stamp, and only one or a few members of personnel without an office and business staff.<sup>12</sup> The agents are mainly interested in how to develop new agencies, encouraging their friends and relatives to take part in the business and inducing them to become their new agents (Zhou 2006). The structure of this business model very much resembles "pyramid schemes" (*jinsita pianju; feifachuanxiao*). But this illegal form of business operation and agent recruitment has not drawn much public attention. One can still find the advertisements of Fuda and the introduction of its so-called "synergic distribution" business operation on the Internet.<sup>13</sup> Additionally, other companies, such as Shanghai Youyuan Bio-company, have started operating their business using the same method as Fuda (Jing 2011). As a result of using this method, the livelihood of agents and their investments depends on the sale of as many tests as possible. Thus, agents are under pressure to sell testing kits by any

<sup>11</sup> Article 59, 60 of Chinese Corporation Law.

<sup>12</sup> They are called 'bag companies' because everything of the company can be easily gathered and moved to an unknown place at any time. The practice resembles "post-box number companies."

<sup>13</sup> For example: <http://www.jobui.com/company/175199/>.

means, without being held liable for the products they sell or held responsible for the consequences to the lives of the users.

In summary, commercial genetic service companies in China often use exaggerated and misleading advertisements to attract customers with a veneer of expertise, and the pretense of trustworthiness and scientific value. They target those with health worries, ambitions, and money, and they provide tests that are of little reliability: the interpretation of genetic data is tendentious or too general to be of predictive value. These tests are expensive, and the test results might contain misleading and life-changing suggestions with unintended consequences. The marketing techniques used to sell commercial tests vary from advertising through the Internet, using express mail, to door-to-door sales, and agents are under great pressure to make lucrative sales for which they are not held accountable.

### **Predictive Genetic Testing and its Responsible Use**

The activities of genetic testing companies have been increasing, and some of their practices have been criticized as harmful. According to some critics, genetic tests are often inaccurate, irrelevant, and misleading, and should not be offered without medical advice by experts in the field. It was reported that the genetic test results were possibly unreliable and incomplete. This might lead to panic, and to the taking of further tests unnecessarily. The quality and use of the ‘individualized diagnosis,’ organized on a commercial basis, has been much exaggerated (Ray 2014; Yuan 2014). Zhang pointed out that the results of these genetic tests are only predictions, not across-the-board panacea. Therefore, the tests providers should not provide a misleading picture to the public (Zhang 2014).

Genetic testing is usually advertised as a powerful technological tool that enables the prediction of future health status. Some companies suggest that potential benefits of an early identification of susceptibility include the opportunity to have regular medical check-ups and to make behavioral changes such as seeking a healthier lifestyle, even if, in multicausal diseases, many factors remain unclear. Pointing out the importance of a “healthy lifestyle” has, in modernistic, capitalistic-driven sectors of society, a particular psychological attractiveness, as many people are already aware of their unhealthy, often stressful urban lifestyle.

Another point is the benefit for public healthcare. Some multifactorial diseases such as heart disease and some forms of cancer have a higher incidence among certain population groups, and these populations are more easily identified by genetic testing. The hope is that, once the genetic basis of serious and common multifactorial diseases such as heart failure or cancer have been identified, early diagnosis of predisposition to certain disorders will become increasingly important in an effort to increase the effectiveness of preventive health policies and economically reduce healthcare costs as well as loss of working days (Martean and Richards 1996).

Some medical experts and officials in the Chinese MOH, such as Professor Zhu Ping, director of the Clinical Gene Center, Beijing University No.1 Hospital, Liang Qianjin, professor of Beijing Normal University, and Wu Chaoqiu, professor of

Fudan University's Bioscience and Genetics Institute, recommend that the public use predictive genetic tests with caution. Professor Wu reasons that the genetic tests the companies provide all belong to the realm of clinical diagnosis, and should not be performed by commercial companies (Zhou 2006). According to Professor Zhu Ping, predictive genetic testing has some value but not as much as companies claim in their "advertisements" and he considers the pathogenesis of many kinds of diseases as too complex to predict (Fu 2006). Because many environmental factors can also affect the development of a disease, test results cannot resolve health problems. Long Guifang, professor and chief physician of Guangxi Medical University, holds the opinion that, considering the complicated pathogenesis of polygenic diseases, it is difficult to get effective information for prevention from genetic testing. Huang Ribo, the president of Guangxi Academy of Sciences, considers it is too early to do genetic testing on polygenic diseases if there is no verifiable pathogenesis of the disease (Tan et al. 2008).

Overall, medical experts in China have criticized biotech companies for paying more attention to their own financial profits than to public health and the benefits to the individual. The companies are accused of promising the provision of services they cannot deliver, as the multifactorial diseases they claim to test for are too complex to predict. Even if they could predict them, they do not provide the clinical services that accompany clinical genetic testing. Moreover, the test results might not just lighten wallets, but provide false certainties and needless worries to clients. In this sense, the raised concerns are perhaps justified.

## Commercial Predictive Genetic Testing in Chinese Society

The critique of Chinese experts that Chinese clients are not yet sufficiently equipped to deal with genetic tests of dubious quality can be expanded from the cognitive and material realm into the social and political one. In the following, we will outline how the social effects of genetic testing depend on a critical awareness and certain public understanding concerning the circumstances under which genetic tests can benefit individuals. This includes the availability of medical counseling, health checks, and access to medical healthcare provision.

### *Exaggerated Advertisements*

The enormity of the Internet makes advertisements difficult to regulate (Frosst and Wattendore 2006). In China, the Internet is widely used. Usually, biotech companies publish their advertisements on their own websites, as this is an efficient way of spreading information. Currently, it is difficult for the state to regulate this practice. According to a technical newspaper, *Beijing Keji Bao*, genetic testing is a form of "genetic fortune-telling" (Tong 2005). In this respect, the scientific technology is treated as divination (Lock 2005; Konrad 2003). The genetic companies use tempting phrases to sell their test product, as exemplified by the advert for susceptibility testing for breast cancer. The test is called "Pink Angel," and the

advertising slogan for the “Pink Angel” is “angel decoding for endless love.”<sup>14</sup> The companies also encourage young people to obtain genetic information relating to their partner before deciding to get married.

In fact, many people do not understand clearly what genetic testing is about. Faced with advice from so-called genetic experts, senior physicians, and other professionals engaged by the companies, many people are easily led to believe their advice. As shown below, these kinds of advice might create problems and increase existing social tensions.

### *Public Need or “Luxury” for the Wealthy*

Although predictive genetic testing has not been developed only for people with a family history of a genetic disorder, it is especially significant for them. Often, people with a family history of a genetic disorder are among the financially disadvantaged and cannot afford to undergo testing. In China, some rural areas have retained traditional consanguineous marriage institutions and sometimes have a high incidence of genetic disorders (Jiang 2004). Genetic testing technologies are often not accessible to the poor. For instance, one poor rural family with a quadruplet pregnancy could not afford a prenatal genetic examination and the four newborn babies all had birth defects (Chen 2012). On the other hand, those with a higher income might be attracted by the advertisements and take the tests for fun, such as is the case with the tests for the so-called “beauty gene” and “talent gene.” This might be of little consequence to their medical health, and tends to be a luxury. However, such luxury does not always bring benefit for the wealthy either, as unwelcome test results in China’s current socioeconomic and political context might form an unnecessary psychological burden for them.

### *Reliability of Test Result and Advice*

As mentioned above, the results of genetic tests offered by companies are usually expressed in terms of “high,” “medium,” and “low” susceptibility, indicating qualitative categories of likelihoods of developing a certain genetic disorder. Several samples of the test reports available on websites and on leaflets are similarly vague in most cases, partly because predictive genetic testing is not formally regulated, and there is still no universal standard for describing genetic risk. Companies claim that the test report criteria are based on academic papers recently published in the fields of medicine, genetics, biology, and epidemiology.<sup>15</sup> To the present, regulatory bodies have not decided which institutions should have the authority to approve and control such criteria. It is not surprising then that laypersons taking the tests do not understand the criteria and risk evaluations either. And, as indicated above, the indication of the probability in the test results might be subject to bias due to environmental and lifestyle factors, such as radiation, drug use, and chemical pollution. In fact, the positive result of a test might have a

<sup>14</sup> Information from: <http://www.genegov.com/jyjc/jyjcxm/200810/8795.html>.

<sup>15</sup> Available at: <http://www.rjgene.com>.

negative effect on the behavior of the person concerned. For instance, Mr. Chen, a Beijing citizen in his forties, now feels free to smoke more after taking a predictive test that did not detect any gene that predisposes him to developing lung cancer (Zhou 2006).

Several biotech companies ask their clients to answer a questionnaire about their everyday lifestyle. For instance, Shanghai Rongjian Bio-Technologies Co., Ltd. tell their clients that precision and honesty in answering such questionnaires will help the company to confirm the relationship between the client's genetic heredity and his or her lifestyle. The company also asks for reports from recent check-ups and declares that these would help the company in providing the client with a suitable health report on health advice.<sup>16</sup> To some extent, then, the clients themselves provide the testing results.

Usually, the advice in the companies' results reports contain both a section on the actual predictive result of the test and a section on prophylactic measures, a feeble attempt to enhance the significance of the outcome. The advice usually concerns the lifestyle, diet, and intake of vitamins and minerals. For example, the Beijing Huada Gene Research Centre gives the following lifestyle advice to prevent senile dementia in a sample report of the genetic test results: "take physical exercise for half an hour each day; do mental exercises at least for two hours a day, by for instance playing chess, playing cards and reading; do not smoke; eat five pieces of fresh fruit and vegetables every day; drink eight cups of water a day; and, take enough rest and sleep."<sup>17</sup> These pieces of advice belong to the realm of general knowledge of health, though they are certainly helpful for leading a healthy lifestyle. However, one need not take a genetic test to obtain such knowledge and, as one geneticist who was interviewed pointed out, there are insufficient experimental data to prove the efficacy of the intake of vitamins and mineral substances as a prophylactic measure against developing senile dementia.

As for the so-called "talent gene," doubts arise about the existence of such genetic items and whether they can be standardized for genetic testing and diagnosis. Without reliable proof of the existence of such genes, the genetic tests for "talents" might mislead the direction of education for children with or without a certain "talent gene." Currently, the genetic test for talent has already become popular in some cities. In 2009, the city of Chongqing carried out the "talented baby project," which was based on the genetic testing of a selection of children with special talents. The city used 'advanced' genetic testing to help single out fifty children with special talents, and cultivate them according to their talent gene (Li 2009). These tests may impact the children's sense of an open future, and their ability to develop a sense of autonomy. There exists an unavoidable tension between the goal of maximizing children's talents and nurturing their self-determination (Camporesi 2013). However, as the reliability of such tests is unknown, an emphasis on the "talent gene" might create an impression in the children and their parents that inborn intelligence is more important than postnatal education and diligence. This might unduly influence the children's motivation and the parents' willingness

<sup>16</sup> For more details, see: <http://www.rjgene.com>.

<sup>17</sup> The template concerned is downloaded from: <http://south.genomics.org.cn/genetest/template.doc>.

to invest in the future of the children. In addition, parents' high expectation of their talented children might lead to disappointment if it is not realized. This might undermine the relationship between parents and children.

### *No Genetic Counseling Available*

According to Article 11 of the UNESCO *International Declaration of Human Genetic Data*, it is an ethical imperative that in cases of genetic testing having likely significant implications for a person's health, appropriate genetic counseling should be made available. Genetic counseling should be nondirective, culturally adapted, and consistent with the interest of the person (UNESCO 2003). However, questions arise as to who is the appropriate expert to counsel the patient and/or the family, and how to counsel them (Fulda and Lykens 2006). Although biotech companies in China offer predictive genetic testing services, they do not provide any professional genetic counseling. While companies do claim in their advertisements that they offer counseling, our research revealed that "counseling" covered a session to introduce the price of the test, the test procedure, and the benefits of the tests on offer, while providing an opportunity to encourage people to buy tests. Such "genetic counseling" resembles the work of a salesperson or receptionist.

The perceived risk of developing a hereditary disease, especially those for which there are no cures or for those that are severe, is usually accompanied by considerable psychological distress (Friedrich 2002). Yet, it remains an unresolved problem in China that, without appropriate support from professional genetic counselors, invalid test results will remain undetected, and no responsible provisions can thus be made for the potential patient.

## **Ethical Governance of Genetic Testing in China**

The way in which genetic testing is adopted in China resonates with cultural, socioeconomic, and political developments in Chinese society. Genetic testing is thought to operate in an advanced liberal democracy thanks to cultural notions that regard individuals as autonomous decision-makers capable of taking responsibility for their health, and the existence of institutions that protect the privacy and confidentiality of genetic information (Marteau and Richards 1996).

Genetic information is different from other personal information because it concerns the privacy of family members who usually share the same or similar genetic information (O'Neill 2002). The confidentiality of genetic information is regarded as highly important. Both the rights of the individual who undertakes tests and the rights of those who might be affected by the information regarding the test results, in this view, deserve to be respected. The failure to protect privacy and confidentiality could also lead to genetic discrimination. Thus, the biotech companies having access to the genetic information on their clients and their families should have the duty not to sell or to reveal the data to third parties. This is particularly crucial, as such information is of potential interest to employers, insurance companies, and even governmental agencies. Apart from in the most



exceptional circumstances, the privacy of the individual should be regarded as more important than the interests of third parties and those of the public. Particularly, genetic information of children or other vulnerable persons should be carefully protected, as such people are dependent, and not fully competent or able to make free and informed decisions. For example, the sale of predictive genetic tests for talent or potential might harm these children. If such a child is branded for carrying, say, a gene for “puppy love,” “prone to violence,” or “prone to depression,” it might have a deep psychological impact on the child, and could result in social stigma and genetic discrimination. Similarly, if a child is regarded as a “genius” on the basis of a genetic test, the high expectations of parents and society regarding gifted children might also put a heavy burden on the child, especially if the child fails to meet the expectations.<sup>18</sup> Moreover, in China, the enormous pressure on “genius” children has started to receive more attention (Huang 2009; Zhou 2010). These trends have to be seen in a context of a population policy and educational discourse that emphasizes the quality of the population (Kipnis 2011; MoE 2010).

### *Personal Autonomy and Free Decision-Making*

Personal autonomy is regarded as a basic ethical principle, and refers to the individual's capacity for self-determination (Beauchamp and Childress 1989; Qiu and Zhai 2003). For instance, in relation to the decision whether to take a genetic test, people should have a right to make the decision themselves, independent from the views of others.

Advising young people to take a genetic test is in line with the policy of premarital testing, which was compulsory from 1994 until 2002, when, after protest against its invasive nature, it became recommended on a voluntary basis. Nevertheless, it is still of widespread influence in Chinese society (Sleeboom-Faulkner 2010). In the context of the “one-child policy” and “family planning” this policy aimed to “raise the quality of the population,” which entailed premarital testing and counseling. Today, young adults are still advised to scrutinize the “quality” of potential partners, including their “genetic quality” (Sleeboom-Faulkner 2010).

The situation in which parents buy genetic tests for their child is just as complex. If a child's adverse test results are received at a very early age, the child might have to live for a long period with the prospect of a later onset of the disease in question. Thus, in such a situation, perhaps the parents failed to achieve their original well-meaning intention. The children, in turn, might regret knowing about the diagnosis, the consequences of which might continually worry them. To some, not knowing might mean a less worrisome life. The decision to take a “talent gene” test is made by the parents who usually ignore the personal feelings of their children about the matter. Parents in China are especially concerned with the education of their children, something that parents and the broader family is willing to invest in heavily (Kipnis 2011). The association between talent, education, and the future of

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<sup>18</sup> Alice Miller has described the situation of genius children's life in her book *The Drama of the Gifted Child* (Miller 2008).

the family household is an important one, and leads to decisions in which the children themselves sometimes have little say.

In fact, a similar situation as when parents buy tests for young children will obtain when adult children buy tests for parents or when a spouse buys a test for his or her partner. For example, one company offers a special set of tests for elderly people, named “filial piety”<sup>19</sup>. It encourages people to buy their set of tests as a gift to express their filial piety to their parents. Since it is in the nature of genetic test companies to attract potential buyers in manipulative ways, and since there is lack of the regulation and supervision on commercial genetic testing, these issues, concerning personal autonomy and free decision-making, should be taken into account and should be part of any attempt to regulate commercial genetic testing and enhance its supervision.

### *Privacy, Confidentiality, and Genetic Discrimination*

Although predictive genetic testing is rapidly becoming more popular, the problems in relation to autonomous decision-making have not yet occurred on a large scale. These are bound to appear, since the main concern for the biotech companies is to attract more customers, and young people take seriously the advice they receive about obtaining genetic information regarding their partner before formal marriage, some employers and insurance companies consider arranging genetic tests for their employees, and parents desire to obtain genetic information on their offspring’s talent. Such practices entail serious issues of privacy and confidentiality.

Genetic information differs from other personal information because it concerns the privacy of genetically related family members. Therefore, the confidentiality of genetic information is of great importance for the client as well as his or her relatives. Both the rights of the individual who undertakes tests and the rights of those affected by the information of the test results deserve to be respected. The dramatic explosion of information brought about by the use of genetic technology raises complex and troubling issues concerning privacy and confidentiality (Rothstein 1997). The failure to protect privacy and confidentiality could, in practice, lead to genetic discrimination. Similar problems might exist in the USA before, but, the USA have passed a Genetic Information Non-discrimination Act (GINA) in 2008, which protects Americans against discrimination based on their genetic information when it comes to health insurance and employment.<sup>20</sup> Actually, the lack of governmental oversight in the market of genetic testing is particularly troublesome in light of the fact that a handful of companies have started marketing test kits directly to the public and making dubious claims (Sateesh 2008). In practice, a large number of employers and insurance companies are expected to turn to genetic tests as a requirement for employment and insurance. A potential drawback of genetic testing is the perception that individuals with predisposition to syndromes can be unjustly discriminated against in employment and in applications

<sup>19</sup> Information from leaflet of Shanghai Gene Core Biotechnologies Co, Ltd.

<sup>20</sup> Information can be found on the official website of National Human Genome Research Institute: <http://www.genome.gov/24519851/>.

for health and life insurance (Fulda and Lykens 2006; Harris et al. 2005). Genetic discrimination arises when individuals with no symptoms or signs receive less favorable or adverse treatment because of their genotype (Knoppers and Godard 2003). In China, a country with a large labor market and labor resource, underdeveloped public healthcare system, and a high demand for employees, these are issues with far-reaching implications. A recent example of genetic discrimination had been widely referred to as “the first genetic discrimination lawsuit case in China.” Mr. Xie, 22 years old, participated in the civil service examinations in April 2009 in Foshan city, Guangdong Province. He passed the written examination and job interview against hard competition, and prepared to work in an official department of the Foshan government for which he had applied. The Foshan government required its employees to provide evidence of their genetic and general medical health. Such evidence could only be provided through a medical examination and by engaging the services of a commercial genetic company, paid for by the prospective employees themselves. Thus, in June, during the required routine medical examination, Mr. Xie was told that he needed to have a genetic and blood test. The genetic testing result showed him to be a thalassemia gene carrier.<sup>21</sup> Subsequently, he was refused the job because of this reason. Mr. Xie protested that he was in perfect health, and that his blood donated to clinics had been accepted. He lamented that even the physical check for entrance to the army did not require thalassemia carrier genetic testing. Why could he not work for the civil service? He felt he was unfairly treated simply because of his genes. There were several other people who had had a similar experience. Three of them, including Mr. Xie, started a lawsuit on genetic discrimination on November 29, 2009. In China, this was the first lawsuit with genetic discrimination as the cause of action. On January 2, 2010, the case was heard in the local People’s Court of Chancheng District in Foshan city. This case was reported by the media, and was called “the first genetic discrimination case in China.” After Mr. Xie lost this case, he appealed. On August 11, 2010, the court of appeal, Foshan intermediate court, heard the case and affirmed the original judgment as final. This meant that on the basis of current law and regulations Mr. Xie had lost the case, as the law says that blood diseases are within the range of health checks for candidates for civil service positions. Thus, the court accepted the opinion that thalassemia should be regarded as a kind of blood disease, and did not pronounce a judgment on the requirement of a genetic test to be purchased by candidates. This means that the availability of commercial genetic testing in China allows local councils to make requirements that enable them to appoint candidates on the basis of the genetic make-up of individuals. Although this case was called “the first,” in fact, before this case received media attention and became known to the public there had been many similar cases in the south of China, where a high incidence of thalassemia exists. Because this case received public attention, the stories of other people with similar experience were revealed,

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<sup>21</sup> Thalassemia is a genetic blood disorder. The carriers of thalassemia have 20 percent possibility of having a child with thalassemia, but they are physically and mentally as healthy as unaffected persons.

and many Chinese experts in law, ethics, and sociology also appealed for nondiscrimination on the basis of genetic information.<sup>22</sup>

It has been more than two years since the final judgment on the Xie case, but there has not been any progress regarding the change of the regulations on pre-employment medical examination to reduce or prevent genetic discrimination. It is plausible, therefore, that, accompanying the indiscriminate application of genetic testing, genetic discrimination was already widespread, but had not received much attention.

We assume that, in China, the development of genetic testing will have great potential to lead to genetic discrimination, as individual privacy is not sufficiently protected, and because the activities of biotech companies have not been officially regulated. Due to widespread advertising of predictive genetic testing for employees, and the acceptability of using genetic tests on employees, individuals with a genetic predisposition for developing cancer, for example, will most probably lose the chance to find employment.

## Conclusion

In China, the selling of genetic tests by biotech companies has developed rapidly. Partly due to the lack of regulation and supervision of commercial genetic testing, socioeconomic and ethical governance issues have emerged. In this paper, we argue that these problems, though to a certain extent existing in most societies with direct-to-consumer genetic testing, take on a particular shape in China. This we explain by referring to the discrepancy between the advanced liberal society in which we imagine commercial genetic testing to operate and the host of societies that diverge socioeconomically and politically from this ideal-typical image, among which China is one. We have identified several such differences in the case of China: (1) the institutional forms through which tests are sold take on different forms, including that of 'bag companies'; (2) the meaning of genetic testing, which is socially constituted, in China has close associations with the blueprint of a human being; (3) the belief in the power of science and technology imbues genetic testing with power; (4) although it is often presumed that higher education leads to less anxiety about test results, in China it is especially the educated and the rich that use the tests and use them in designing life; and, (5) predictive testing in China is in line with widely implemented policies of health check-ups, preventative public health, predictive testing and increasing the quality of the population. This political context encourages giving legitimation and authority to any form of genetic testing.

The investment Chinese parents are prepared to make in their child's education is not just related to China's "one-child policy" and attempt to increase the "quality of the population." More directly driving factors are related to continuing the family line, increasing its wealth and status, and the belief that education is a form of self-cultivation necessary to any full human being. Science plays a crucial role in both

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<sup>22</sup> Relevant reports can be found in newspapers and online. For example: Legal Daily (February 3, 2010); Legal Weekend (February 4, 2010); Chinese Youth News (January 13, 2010).

education and the idea of self-improvement. Only the empirical study of such socioeconomic and political factors can adequately elucidate the practices of commercial genetic testing in society, including the effects of misleading advertising practices, the suitability of the groups targeted for potential customers, the reliability of test results, and the unavailability of genetic counseling to clients. The ethical issues brought about by the application of genetic testing in China, such as genetic discrimination and the lack of privacy and confidentiality of genetic information, deserve more attention from the public and the authorities, and need to find solutions particularly to Chinese society.

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