

## **The Harvard case of Xu Xiping: exploitation of the people, scientific advance, or genetic theft?**

MARGARET SLEEBOOM

*Amsterdam School of Social Science Research, University of Amsterdam and International Institute for Asian Studies, University of Leiden, The Netherlands*

**ABSTRACT** *A unique genetic history and make-up of a population may make it an attractive research target for population geneticists and pharmaco-genomic investors. The promise of pharmaceutical profits and advances in medical knowledge attracted Harvard researchers and the company Millennium Pharmaceuticals to remote areas in Anhui Province, Central China, leading to international diplomatic disagreements about issues such as the ownership of genetic material and informed consent (IC). This article discusses the role of genomics and genetic sampling in China, the way it is related to population policies (the new eugenics), the national importance of genetic materials and the conflicts it led to between the Chinese government and Harvard University. Here many consider the Xu Xiping case as a textbook example of ruthless Western exploitation of development countries, illustrating the cold rationality of science in the process of globalisation. Ten perspectives on this case show that this view is simplistic and contributes little to an understanding of bioethical issues important to the population actually donating the samples. Viewing the Xu Xiping case as the nexus of the intertwining of international, transnational, national, and local interest groups shows how different interest groups make use of different units of analysis. It also clarifies why the same practice of genetic sampling continues under a different regime, and why the discussion about genetic sampling has shifted from a concern with health care of the poor to an issue of international exploitation, terrorism and development.*

### **Introduction**

In my research on the application of new genetics and vulnerable groupings in Asia, the concept of vulnerability is problematic. In many respects, views on vulnerability depend either on who is speaking or on what risks particular groups are exposed to. In general, however, agreements exist on the criteria by which groups are regarded as vulnerable. Thus, it is generally agreed that impoverished illiterate peoples may be too easily persuaded to donate blood samples against a small fee or service. Nevertheless, diverging views exist about the practice of such genetic sampling, largely reflecting the multiple social and economic contexts of the persons in relation to the practice. In other words, multiple actors with diffuse and blurred interests and identities articulate their views through multiple

---

Correspondence to: Margaret Sleeboom, Beatrixstraat 2, 2202 NR Noordwijk, The Netherlands.  
Email: m.sleeboom@wanadoo.nl

frames of references and interests. The complexity of their interaction, partly due to the very diversity of the sampling practices themselves, show that discussions on genetic sampling and the requirement of informed consent are fragmented and diffuse. Moreover, the views of the stakeholders involved are far more sophisticated and context-dependant than discussions on the bioethical correctness of Xu Xiping's projects suggest.

This paper emphasises the importance of delineating the divergence of interests groups, their self-definitions, and their institutional settings in the study of genetics and society. I examine the stated aims of various groups of actors in the constellation of conflicts that resulted from genetic research led by Harvard researcher Xu Xiping in Anhui Province. The 10 perspectives examined here include those of nation-states (the USA and the PRC) in defence of the interest of the people, pharmaceutical companies in defence of the interests of clients, university researchers that claim to work in the interest of science, and patients that want to get better. It is important to note here that the 10 perspectives described are the views of people who have the will and ability to write and publish about the case of Xu Xiping. I grouped these perspectives according to the kinds of interests and ideals they defend in their writing, i.e. national interests, scientific knowledge, human health, developing medicine, human rights, academic interests and money. Such interests appear to be linked to the daily activities and ideals adopted by these groups, although, as will be shown, social institutions and ideologies limit the way in which these interests are defined and expressed. This also has implications for the way students of society link their research problems and analyse their units of research. The concluding part of this article discusses this issue with relation to 'informed consent' in genetic sampling.

Central in this paper is the analysis of conflicts between groups as expressed in the ways in which they define themselves and one another in their institutional context. Without taking the specific institutional contexts and histories into account, and without examining the processes in which the various institutional rules and interests are accommodated, the dynamics of the Xu Xiping case and the practice of genetic sampling in China remains underexposed. For, the conflicts result from the coinciding accumulative effects of personal and institutional actions with, mainly, unintended socio-economic consequences of historical processes.

In short, instead of just concentrating on a surface of simple conflicts between opposite groups at a national level, a deeper understanding of the debate around Xu Xiping must proceed from a multi-sited and multi-level approach. It should take into account the open-endedness and complexity of ongoing clashes and frictions of interests. These interests are expressions of a continuously changing discourse, whose expression in this article are only momentary and aspectual glimpses of ideals, goals and drives of groups that develop in close relation with other institutional concerns.

#### *The Human Genome Diversity Project (HGD project) in China*

As the Human Genome Project (HGP) is completing the 'map' of the 'average' human genome, the interest in sampling populations to study human group

and individual genetic diversity has grown. The HGD project, initiated in 1991, engages in the collection of genetic material from select populations to identify differences in genetic sequences between populations.

In China, the HGP began in November 1993. It is especially interested in determining the types and incidences of genetic diseases and to preserve each ethnic group's genetic materials. Because of an increase in intermarriage and the perceived dilution of the unique genetic material of China's minority ethnic groups, the Chinese HGD project proposed to collect the DNA samples of indigenous peoples and store the collections in gene banks. China is interesting to geneticists because some of its rural populations and ethnic groups are thought to have remained static for centuries, making each region different in its pattern of genes and diseases. The Chinese HGD project is particularly interested in the 'national minorities' (*xiaoshu minzu*) of Central and Southwest China.

Because the HGD project collects blood samples, various protest groups have called it the 'Vampire Project' (Lock, 1994), while others object to its lack of communication and negotiation with community representatives (Macer, 1998). For these and other reasons, the HGD project came to a halt in the US. The Chinese HGD project, however, is still going on strong. A large gene bank for ethnic minorities in Yunnan Province aims to study the diversification of inheritance and inherited diseases of the ethnic minorities. It stores 1,250 men's DNA from 25 ethnic groups in the province. The men who gave samples have no history for marrying other ethnic peoples, and every man has the same ethnic origin for at least three generations in succession. As they live in remote areas, they are thought to have high purity and separation degrees. The gene bank, according to the radio broadcast *People's Daily* (2000) is so far the largest of its kind in the world that has adopted the standard of the international human genome programme.

One aim of the gene bank is to reconstruct the history of populations by studying genetic variation to determine patterns of human migration. These new findings can be used to make claims on disputed territory, resources, and self-determination. Of course, many factors contribute to population differences, such as culture, language, environment, and lived experience. Nevertheless, the identification of genetic difference between ethnic groups (such as a different gene sequence that causes immunity to a disease) is expected to have human (medical, cultural or historical) and economic value. This perceived value has led universities, governments, corporations, and private researchers to invest immense efforts into identifying human genetic variation.

#### *Worries about the Eugenic Law and about genetic theft*

New genetic technologies play a major role in the political issues of the new eugenics, improving the quality of the population and the one-child birth policy (Mao, 1998; Nie, 1999; Wang, 2004). As genetic technologies have become available to the state in policies aimed at raising the quality of the population, concerns have been voiced that genetics may entail compulsory sterilisation

or abortion of those found to possess 'undesirable' genetic sequences.<sup>1</sup> The introduction of the *Law of the PRC on Maternal and Infant Health Care* (Ministry of Public Health, 1994) supports the systematic 'implementation of premarital medical check-ups' on hereditary, venereal or reproductive disorder as well as mental disorder so as to prevent 'inferior births'. Affected groups are rendered socially marginal due to the make-up of their DNA (Dikötter, 1997).

In 1996, the Paris-based company Genset, signed a letter of intent with the Chinese Academy of Medical Sciences (CAMS). Genset, working with the French trading company Tang Frère International, planned to employ some twenty researchers to collect the DNA and diagnose diseases. Samples were to be analysed in Paris using gene-sequencing machines with the aim of developing diagnostic tests and new drugs. When Genset and the CAMS worked out the details of the agreement, Genset President Pascal Brandys announced their intention to have clauses related to ethics, and CAMS Vice President Lu Shendong and President Ba Denian declared:

We view gene research as extremely important for Chinese health care in the 21st Century and we are convinced that our joint effort will lead to fundamental discoveries which will benefit not just China but the rest of the world.

However, in 1996 experts warned that China faces the prospect that the genes of hundreds of millions of its people may become the priceless resources of foreign pharmaceutical companies. A drug company-supported research program involving Harvard University researchers and six Chinese medical centres were going to sample the blood and genes of 200 million Chinese people. Unless measures were taken, these resources would be incorporated into foreign products without bringing any benefit to the Chinese people who furnish the genetic resources.

In early 1997, financial details about a Millennium-Harvard deal in Anhui leaked to the Chinese press and caused a storm of criticism. The idea of US capitalists profiting from China's genetic heritage sparked such a fury that foreign genetic research was stalled for a year. At the same time, the State Science and Technology Commission (SSTC) organised the regulation of the collection, handling, and export of genetic material in the *Interim Measures for the Administration of Human Genetic Resources*, promulgated by the General Office of the State Council upon its approval on 10 June 1998 (Ministry of Science and Technology & the Ministry of Public Health, 1998). It made very clear that genetic resources were not to be taken abroad without permission and observing due procedures as defined in the *Interim Measures*.

Bioethical issues concerning the actually sample population, such as that of IC, were emphasised in the press more than in the *Interim Measures*, which focuses on issues of national interests. Newspaper discussions referred to human experiments on POWs, undertaken by Japanese and German scientists during WWII, the various treaties with relation to human experimentation, such as the

Nuremberg Treaty of 1947, the Helsinki Treaties of 1964 and 2000, the UN 1998 Declaration on the HGP and Human Rights, and the 1996 and 2000 declarations of the WHO. *Southern Weekend (Nanfang Zhoumo)* even mentioned that on 18 April 1979, the US government declared the ethical policy against ‘lure by promise of gain’, meaning that IC cannot be obtained under pressure or by means of promises of rewards (Xiong, 2002).

### *The Washington Post watershed*

In December 2000, the Harvard investigator Xu Xiping became subject of an investigative article written by Washington Post reporters John Pomfret and Deborah Nelson. Xu’s research, carried out in a poor region of Anhui Province in central China, supported by US government grants along with money from Millennium Pharmaceuticals Inc., of Cambridge (Mass.) started to cause diplomatic upheaval (Pomfret & Nelson, 2000).

The project had been conceived by Geoffrey Duyk, a Harvard geneticist connected with pharmaceutical industry. He found research collaborators in Scott Weis, a prominent Harvard respiratory epidemiologist, who had an interesting cell line on 62 million people in Anhui province, and a postdoctoral researcher, Xu Xiping, with hometown connections in Anhui Province, who was to recruit thousands of volunteers. A pilot study began in 1994, and within a year, Millennium agreed to pay US\$3 million for the DNA of thousands of Anhui residents to be collected through a collaborative effort among Harvard, Brigham and Women’s Hospital (a Harvard affiliate) and Xu’s alma mater, Anhui Medical University. Millennium announced the deal in July 1995, just after the controversial eugenics law had taken effect, and many deals were to follow (Pomfret & Nelson, 2000).

After the December 2000 *Washington Post* report, Xu’s work became the subject of US government investigation. Early 2001, the Chinese government investigated Xu’s projects following an article by Xiong & Yan (2001) in *Outlook*, a popular Chinese weekly, which repeated and expanded on some of the allegations in the *Washington Post* report. In August 2001, Harvard University strongly criticised Xu Xiping for writing letters to Chinese government officials that urged Beijing to censor news reports on genetic experiments and to take action against critics of his research (Pomfret, 2001). Xu was warned against independently campaigning against his critics, and several of his projects were brought to a halt early 2002 (Shan & Ma, 2002).

### **Ten perspectives on the Xu Xiping case**

The Xu Xiping case shows a complex intertwinement of financial and bioethical interests between researchers, pharmaceutical companies, multinational companies, national governments, academic leaders and institutions and local populations. The case is known also as the story of how an American exploited the vulnerability and gullibility of a backward population in the desolation of mountainous Anhui province.

A look at the different parts of people in and reactions to the Xu Xiping case may bring more nuance into this view and shed light onto the question of how to best approach the issue of IC in genetic sampling. I here discuss 10 different perspectives that represent the views and ideals of different interest groups. Different group perspectives from people affiliated with different institutions, as will become clear, also tend to make use of different units of research. This makes it difficult to decide with whom responsibility for the way IC is acquired should reside, and what value should be attached to it.

### *1. Xu Xiping: scientific research to improve universal health care*

Xu Xiping is Associate Professor of Occupational Epidemiology with the Department of Environmental Health, heads the Programme for Population Genetics at the Harvard School of Public Health, is Associate Professor of Medicine at Harvard Medical School, and co-chairs the China project of the Harvard University Committee on Environment. In the early 1970s, Xu started out his career in Anhui Province as a 'barefoot doctor', but in 1982 he acquired a Medical Degree from Anhui Medical University. He continued his studies at the University of Tsukuba, where he was awarded a PhD in 1988, after which he moved to Harvard University, where he earned a Master's Degree in biostatistics in 1993 (see <http://www.hsph.harvard.edu/facres/xu.html>). Xu is particularly interested in understanding the interaction between genetic and environmental factors in the occurrence of complex diseases in human populations. In 1994, he received encouragement in this field from Song Jian, chairman of the State Science and Technology, and in 2002 from Xie Zhenghua, the head of the Chinese Environmental Protection Agency (Gewertz, 2000).

To acquire an idea of how Xu obtained financial support and of the value attached to population research, a look at the arguments he used in his March 1997 project application to the National Institute of Health (NIH) may be instructive (Xiong, 2001). In it he states that Anqing is ideal as a research target for the following reasons:

1. The type of asthma prevalent is the same type as in the West;
2. Anhui chronic sufferers of asthma, compared to Western ones, hardly ever receive medicine, enabling researchers to trace distortions in the medical syndrome;
3. Divorce is rare in China, households are stable and villages are usually closed off. This facilitates the collection of harmonious data;
4. The Chinese household is bigger in scale compared to the Western home;
5. The population of Anqing has been stable over the last 1,000 years;
6. The current production expenses for are very low, so Xu would have no problem to have millions of samples taken from experimentees at low costs;
7. In Anqing Xu found a phenomenal co-operation rate of 95%;
8. There was no comparative research based on Asians, especially on Chinese, even though the Chinese constitute one/fifth of the world population.

9. Finally, Xu refers to his wide experience in China, the quality of his research team and the ability to collect high quality data.

Important to note is that the arguments for his research are structured to convince the NIH board of the project's merits to patients in wealthy countries, not to those in China. Even though the arguments may not be very persuasive, as evidence for population stability is not reliable, the general conditions of a co-operative population, scientific promise, and low production costs must have been tempting.

But, in 1997, Xu was accused of smuggling Chinese DNA. Xu denied this, saying that he had received permission to take DNA out of China with the help of Anhui officials. However, in 1998, Xu had set up a company in Boston to co-ordinate private research ventures with the newly set up Meizhong Institute, which shifted activities to China. Furthermore, criticism of Xu's work in Huaining County led a team of social scientists to interview asthma volunteers for a UN-funded public health study. Several of them refused to co-operate, because of their experiences with Xu's project: they had been promised free medical treatment but never received it. After learning of the issue from *The Washington Post*, Xu said he wasn't aware of any complaints from asthma families (Pomfret, 2001).

Xu's hospital projects were also criticized for the use they made of Communist Party officials to find volunteers by doing thought work. Co-operation was exerted by relying on people's dependence on the Communist Party and local government for favors involving taxes and the division of land. However, Xu's Harvard spokeswoman Robin Herman denied that Xu or other Harvard researchers had ever been involved in such an effort (Pomfret & Nelson, 2000).

Xu regards himself as an enlightened scientist who unselfishly helps people by mobilising his resources and using his skills to provide healthcare data to medicine producers and by teaching indigenous researchers about genetics. Despite the criticism of smuggling data, breaking promises of free health care, unethical data collection and accomplice to forcing co-operation from patients, Xu showed no sense of responsibility for any of these allegations. Instead, he blamed less enlightened people, such as local physicians and executors.

## *2. Xiong Lei: science must serve the people*

Xiong Lei, a top journalist for the state-run New China News Agency (Xinhuashe), spent a long time on the Xu Xiping case trying to stand up for 'the people' of China. Her reports became so influential that Xu Xiping saw Xiong as a threat to his research; he asked the ministry of education to censure her reports.

An article by Xiong & Wang (2001), published in the Chinese magazine *Outlook*, had prompted the Chinese government to investigate Xu's projects in early 2001. The article repeated and expanded on some of the allegations in *The Post's* report. Following the *Outlook* article, Xu Xiping wrote a letter to Wei Yu, China's deputy education minister, urging the suppression of a report by Xiong Lei, arguing that its details should not be given to 'foreigners'. He also

wrote a letter to Bai Chunlin, vice-president of the Chinese Academy of Sciences, urging him to take action against Yang Huanming, a leading Chinese geneticist (discussed below), who had criticised Xu's work (Shan & Ma, 2002).

In 1999, Xiong Lei conducted investigative research in Toutuo, an impoverished village in Yuexi district with an average yearly wage of less than €200, and whose people became well-known as the victims of Xu's projects. In 1996, a new form of co-operative medical centre was set up in Yuexi district under Xu's auspices, for which more than 1,400 samples were taken. A second time, in 1997, the selection was much stricter and only three-generation households with at least two generations of asthma patients were selected: four households in Toutuo; and 50 households in Yuexi district, counting a population of 400,000.

Xiong Lei went up to Toutuo in the remote countryside. There she interviewed one of the in the asthma project participating households, that of the 60-year-old Chu Mianzhai. The first time, on 5 November 1996, the family gave a little blood for which they were given 10 Yuan as compensation each. The second time, on 10 March 1997, they gave a little more and were given 20 Yuan each. Old Chu also received a bottle of medicine against his high blood pressure. The family insists that no one had given them an overall check-up. They had read the IC form, but they had not known about any co-operation with Harvard University. They showed Xiong the IC form, which clearly indicated the co-operation and explained the purpose of the project. It also promised free check-ups, treatment and possibly preventative medicine in future. The Chus had not received them. Neither did they know where the samples were to be stored. Chu had signed the form, but mainly for the compensation (Xiong & Wang, 2001).

According to Xiong, their poverty had driven the Chus to give blood in exchange for medical check-ups. Due to the high illiteracy rate, Xiong argues, many people did not know what was going to happen to their samples and that their samples was going to go into the DNA bank of Harvard University. Xiong regards it as her task to stimulate discussion, and her articles can be very provocative. Some researchers, according to Xiong, subconsciously look down upon the people they study as mere research objects. But if you don't respect them as people, how could you go all the way to visit them and draw their blood? Just for genetic experiments? 'How is this different from the behaviour of fascist researchers?' she asks provokingly (Xiong, 2002a, 2000b).

Because human experiments have to be transparent in their own countries and because the costs are high, researchers increasingly look for participants in developing countries. To make this point clear, Xiong turns up at international conferences on genetic research, introducing old Chu as an example of exploitation and mismanagement by foreign scientists (Tao & Li, 2001). Until today she approaches organisers of international conferences with offers to bring Chu Mianzhai and health workers along to promote international bioethical understanding, promising that farmer Chu is an understanding and rational being who will not embarrass conference participants. Will she be treated as a serious partner in discussion or as a campaigner against foreign exploiters of Chinese blood?

*3. Local scientists: science advances academic research*

According to Liu Jianhui, the vice-director of science research management of Anhui Medical University, in 1993 his institute had started working together with Xu Xiping. Xu set up the Sino-American research institute for the biomedical study of the environment and hygiene. Liu co-operated in conducting physical examination and blood draws. In 1998, the institute started to co-operate with Harvard formally, establishing the Meizhong research institute for biomedicine of Anhui Medical University. In both Hefei and Anqing laboratories for molecular genetics were set up.

Among the Chinese counterparts of the Harvard research projects were Beijing Medical University (at present the Beijing University Department of Medicine), Anhui University and Anqing City Hospital. Liu emphasises that, since 1998, one needs state permission to apply for research and also permission to take samples abroad. For this reason, Liu claims, Xu Xiping built a laboratory in Anhui. But no one knows how much material Xu has taken abroad in the past. Xu himself admits that he has taken to America 164,000 samples; and according to his 1993 article, for his Anqing research on high blood pressure he needed samples from over 200,000 people (Xiong & Wang, 2001).

Liu, who effectively accused Xu of dodging the 1998 law on export of blood samples, seems to be disappointed in the small part played by his institute in the research. Liu feels that the co-operation was not very balanced. The Chinese, he complained, should receive more information on the outcome of the research and on the IC procedure that had been used. Thus Liu feels that Chinese academic interests have been frustrated.

In the more positive view of Fang Zhi-an, Chinese academic interests are satisfied. Fang, head of the committee for health and education of the Anqing City's Peoples Congress' Standing Committee, explains that Xu started his unofficial research in 1993, when he was interested in the relationship between environment and female fertility. To this end, he conducted research into the subject in Anqing City's textile factory. People accepted it as such, but found it strange that they were asked so many questions about genetic diseases. In his account, Fang makes out that Xu Xiping is a serious scientist with a healthy sense of curiosity (Xiong & Wang, 2001).

Fang explains that through Xu's co-operation the study of Anqing District epidemiology has received a boost. Even though Anqing City could not directly co-operate with Harvard, Fang dispatched personnel to be trained at the Sino-American research centre. Fang, who is also a professor at Anqing Medical University, believes that the Harvard co-operation has initiated the development of local hygiene work, and has trained both Chinese talents locally, in Anqing and nationally. Relevant here probably is the fact that Fang and Xu have co-authored more than 10 articles in international academic journals. Xu has already invested 6 million dollars in Anqing, used to cover the centre's expenses, travel, research and personnel (Xiong & Wang, 2001).

It seems that local scientists have much to gain and much to lose by participating in experiments, as apart from learning about the usage of modern technologies and methods, large sums of financial investment and academic status are involved. These interests can, at least partly, explain some of the frustrations and satisfaction of local scientists and leaders with the projects, disregards of the bioethical question of IC.

*4. Harvard University, the National Institute of Health (NIH) and the Office of Health and Research Project (OHRP): the need for high profile research*

Only after 1998, the reputations of Harvard University and the NIH were in danger. In late 1999, the Department of Health and Human Services launched an investigation of Harvard's genetic research in China, based on a complaint of Gwendolyn Zahner, a former School of Public Health faculty member. Zahner claimed that reviews of genetic studies hadn't adequately weighed the risks of the Chinese government misusing sensitive genetic information and showed that some of Xu's research appeared to have started ahead of any ethics review. On her four investigative visits to Anhui, the police questioned her twice: they knew her exact whereabouts and all the Chinese to whom she had spoken (Pomfret & Nelson, 2000).

Harvard officials said they took cultural differences into consideration and built protective measures into the studies to prevent the Chinese government from obtaining participants' genetic information. Harvard spokeswoman Robin Herman reasoned that as Xu was principal investigator, his studies fell under the purview of their institutional review processes. However, records show thousands of DNA vials were being shipped from Anhui to Harvard for analysis and storage under informal arrangements. Herman said Harvard officials now—in the year 2000—realise that under US rules ethics approval was needed, after reviewing regulations and a recent NIH advisory that clarified the rules. But Frank E. Speizer, co-director of Brigham and Women's Channing Laboratory, who oversaw the asthma research, challenged the notion that residents from Anhui needed special protection. Speizer believed China to be a 'very sophisticated country' (Pomfret & Nelson, 2000). And at Millennium, chief business officer Steven H. Holtzman, a presidential appointee to the National Bioethics Advisory Commission, said he had no reason to believe that Harvard broke any rules in carrying out company-sponsored research in China.

It seems that the main concern of Harvard, the NIH and Brigham's Women's Hospital is the reputation of their institutes and the clarification of procedures (c.f. Herman, 2003). These interests are not inherent to the personal objectives of leaders and researchers, but are related to the history of the regulatory structures of research institutions. Scientists do not research ethics, they observe regularities, create theories, and try out. Mistakes are related to professional damage, rather than to moral failure. Thus, it was only in 2001 Xu was reprimanded. Barry Bloom, dean of the Harvard School of Public Health, wrote to Xu that he had to officially disassociate himself and the School from any

actions he had taken to interfere with, or seek reprisals against, anyone who has taken legitimate steps to raise issues about his research in China. If Xu continued his campaign against journalists and others that questioned his research, he would face 'appropriate sanction' (Pomfret, 2001).

This reprimand came as a result of the investigation by the Office of Human Research Protections (OHRP), after a complaint lodged in September 1999. In letters to two Harvard units, the Federal Office underscored the ethical pitfalls of working with impoverished people in developing countries. Consent forms often include complex language and researchers in one study recruited thousands more volunteers than were authorised. Federal officials had particular concerns about how researchers dealt with China's eugenics law that limits most couples to having a single child. In an asthma study, supervised by the Harvard-affiliated Brigham and Women's Hospital, researchers sought out families that on average had more than four children. Identifying these families could have placed them at risk with the Chinese government for violating the one-child law (Office of Public Health and Science, 2002).

The Harvard School of Public Health said it supported the thrust of the federal letter, but at the same time the school noted that federal officials 'found no instances of harm to any participants in our studies' (Zitner, 2002). The School said that Xu was now required to submit to a review of his research involving human subjects every three to six months, instead of the usual twelve. In a March 2002 letter to Brigham and Women's Hospitals, federal officials said some of Xu's research was conducted without the necessary review by an Institutional Review Board (IRB). The investigation concluded that the continuing review of research by the Harvard ethics committee regularly failed to be substantive and meaningful (Stephens, 2002; c.f. Office for Human Research Protection, 2002).

Whether the Chinese population needs protection against researchers or not has been a bone of contention, but most disputes over the Xu Xiping case were related to institutional proceedings rather than to the bioethical rights and wrongs done to the sampled population in Anhui. Even though the OHRP investigation led to a critical assessment of Xu's research, it was the smell of diplomatic trouble and accusations of interference with China's internal politics for which Bloom reprimand Xu, not for unethical research. In fact, Xu could continue his research albeit under additional supervision. It was recognised that the problem did not just concern IC and blood collection, but also the internal politics of China, which combination could endanger the reproduction of participating families.

##### *5. Chu Jiayou: Chinese science serves national minorities*

Chu Jiayou is the director of the Institute of Medical Biology, Chinese Academy of Medical Sciences (CAMS), Kunming, and also heads the Chinese HGD project and the Nationalities Gene Bank. The Chinese HGD project has become central to the Chinese HGP, which was inaugurated in 1993. The collection and

preservation of the population samples were considered to be a top priority in its first phase that extended from 1993 to 1998 (Chu, 2000), which, interestingly, is the same period in which Xu did his Anhui research.

At a UNESCO conference on 'Genomics of the South', held in 2001, Chu spoke about 'Informed Consent in the Chinese HGD project' (Chu, 2001). There are 56 populations in China, each with their own designated area. Some of them are genetically isolated. But as intermarriage among different populations is on the increase, Chu points out, the preservation of the genome of different populations' has become an urgent matter. Chu explains that blood samples of different populations were collected from healthy individuals, through consultation with nationality scholars. Three generations were traced. By providing medical consult to local people, Chu claims to have succeeded in collecting a sufficient number of samples. Up until now, the cell bank and gene bank of 22 different Chinese populations, including 2,000 DNA samples and 1,200 immortalised cell strains, have been established successfully. These, Chu believes, are an important source of medical and genetic research in Chinese populations. Meanwhile, the Chinese HGD project, including the correlation of SNPs<sup>2</sup>, Y-chromosome, mtDNA polymorphisms<sup>3</sup>, and genetic polymorphism with certain diseases, have attained significant achievements (Chu, 2001).

Chu has personally conducted researched among 28 national minorities, applying strict criteria of IC for sampling. In an interview in June 2002, Chu explained that he had been working as a physician among various minorities for many years. He has even learnt four of their languages. Chu provided them with polio vaccines and with vaccination for hepatitis A. As the people knew him well and trusted him, they consented in donating blood for research. They knew that blood samples were used for scientific research. This exchange of vaccine for samples, according to Chu, amounted to IC used in the collection of blood samples between 1993 through 1998. Though Chu claims that 'Proper informed consent was obtained from each participating subject', Xu's critics have pointed out on many occasions that procedures of IC in the collection of blood samples among the minorities were not an issue then. It must be concluded, therefore, that at the time Chu's ethical correctness was outstanding and advanced.

#### 6. *Qiu Renzong: protect the human genome and safeguard human rights*

Qiu Renzong is one of China's leading medical ethicists, a member of the Human Genome Organization (HUGO), the international organisation of scientists involved in the HGP, and a senior government adviser. Qiu has called for a joint US-Chinese review of the Xu Xiping case and the Harvard experiments. According to Qiu, Xu Xiping as principal investigator makes him responsible for everything that happened.

At the 2001 UNESCO conference on 'Genomics in the South', Qiu argued that advances in high-tech including new genetics will bring great benefits to human kind (Qiu Renzong, 2001). At the same time, however, he warned that they

increase the possibility of violating human rights. High-tech may increase human vulnerability to possible harm and the autonomy and privacy of people may be more easily infringed upon, if they are treated as objects. For this reason, Qiu argues, we must carefully review what kinds of positive and negative impacts on human rights and interests that each important step of technological advance may bring about. This statement is quite bold in a country that officially regards the development of science and technology as its main area of modernization and defines it as the 'first productive force'.

With the advances of new genetics the tendency to reduce the person to his genome or 'genetic essentialism' could intensify. The growth and development of a person or the shaping of a person is the product of long-time and complicated interaction between his multiple genes and his natural/social environment that is not merely determined by his genes. Genetic essentialism and genetic determinism, Qiu believes, may lead to the violation of human rights and interests.

Despite his human insights, Qiu's political and biological views sometimes seem to be at odds. For instance, Qiu (Qiu, 2001) opines that:

The results of human genome research should be applied to the treatment and prevention of diseases. It is not ethically justifiable to use them for eugenics or any attempt to 'improve human races' or make 'superman'. It is not permissible to follow the disastrous road of Nazi's 'race hygiene'.

From these views it follows that somehow human genome research could facilitate a politic of 'improving a particular race', even though, in fact, genetics has shown that the concept of race is scientifically not tenable (Qiu, 2001). Even though Qiu's view is a humanist one, it is important to note this erroneous interpretation of the capacity of new genetics, as the notion of race plays an important role in some Chinese discussions on the safety of new genetics research. Moreover, a miscalculation of the possibilities of the new genetics, may also lead to a misreading of the consequences of the 1995 maternal and infant healthcare law in China, whose eugenic nature Qiu rejects (c.f. Chen *et al.*, 1999).

Qiu also has warned that in China, IC faces many difficulties: first, 25% of the population is illiterate or semi-literate; second, Chinese physician-researchers have not paid much attention to developing skills of conveying information about procedures, risks, and consequences for the patient; and, third, Chinese culture contains a deep element of collective-oriented, holistic, socio-political philosophy (Qiu, 1993). This presumably, would go against the grain of an individualistic approach to IC.

Most importantly, Qiu expressed his concern about the societal and state influences that limit the reproductive lives of families. He argued that marriage or reproduction is a choice made by the individual, other people and the state have no right to intervene. For protecting the rights and interests of subjects in genome research, Qiu argued, it is necessary to uphold the principle of IC embodied in Nuremberg Code and Helsinki Declaration. Here, Qiu seems to hit two

birds with one stone, arguing against genetic sampling without IC and against Chinese state-intervention in the area of human reproduction.

*7. Yang Huanming: science in aid of developing countries!*

In China, Xu's critics have attempted to stop or at least slow his expanding genetic research empire. Yang Huanming, the director of sequencing work for the Chinese Human Genome Project, is one of them. Yang sits on the national board appointed to review international collaborations. The board in 1999 rejected two of Xu's research applications and held up a third as they could not meet China's newly enacted patient protection standards (Pomfret & Nelson, 2000). Yang claimed that Xu had appealed to Chinese leaders and forced a compromise that would allow him to proceed with the projects if they received approval from the US government. Yang, who has worked with the United Nations on genetic research ethics did not hide his criticism of Harvard: 'I hope that Harvard and the School of Public Health will understand that the [recruiting] methods they used in China are unacceptable to the Chinese' (Pomfret & Nelson, 2000).

At the 2001 conference on Sino-American co-operation, Yang showed his criticism of Xu just as much as did Xiong Lei, who was present too (Tao & Li, 2001). Xiong Lei related her Toutuo story, accusing Xu and his researchers of exploiting poor farmers (Xiong & Xin, 2001). Chen Changzhong, from Anhui Medical University, defended Xu, claiming that their research acquired a 100% IC. Yang sneered at him, promising that he would take lessons from him, if that were really the case. Yang also asserted that Xu's taking abroad of genetic samples meant an immense problem for China: 'for who would profit from the knowledge gained from these samples?' (Tao & Li, 2001).

One year later, in a paper at the 'Third International DNA Sampling Conference' in Montreal in September 2002, Yang Huanming declared that Human Rights demand international validity and solidarity. In other words: co-operation between the two worlds of developed and developing countries. Yang explained the problematic nature of foreign research in China:

- It takes place in a non-intact legal framework;
- It lacks bioethical awareness;
- It shows ignorance of the views and needs of the public;
- Transactions with the local population are characterised by unfair benefit sharing; and
- There is no situation of faire and free exchange as scientific knowledge (accrued from the large-scale collection of patient or family materials) benefits companies abroad.

Yang Huanming discussed the case of Xu Xiping, the poverty of his research population, the way they had been cheated out of their DNA, and the backdating of IC forms. Many of the papers of Chinese IRB were forged, he argues, for the

first Chinese IRB was only set up in 1998 (two years after the start of Xu's research in 1996), and only three of Xu's projects had been approved.

Yang's criticism targets rich Western countries, taking advantage of a poor developing country, such as China. As such his views have been applauded as brave and faire-minded. It is no less fair, however, to point out that Yang also runs his own laboratory in Beijing, called the 'Huada Gene Research Centre' (Huada Jiyin Yanjiu Zhongxin). According to Fang (2000), who visited the lab, one of its project applications concerns the 'Chinese Genetic Multiple Condition Plan' for which the lab asks the government 800 million RMB (approximately €1 million) in 2000. Its explanation included references to foreign military attacks on the Chinese race by using biological weapons. Though geneticists should now better and realise that the concept of 'Chinese race' can only be of social or cultural meaning, the applicants then stick to military formulations as they sought to solicit the support of the military.

8. *China Production Daily, Beijing Youth: science makes China target of biological weapons*

Yang Huanming's concern with Chinese science and its possibilities, and his institute's racial and militarist formulations feed into nationalistic and racist interpretations of the new genetics. One article in *China Production Daily* (*Zhongguo Chanjing Xinwenbao*), 12 April 2002 entitled, 'For the sake of our national security: carefully preserve our genetic code' (*Weile guojia anquan kanguanhao women de yichuan mima*), claimed that genetic engineering is used to make ethnic specific biological weapons. For this reason, it argues, China must very fast develop this technology by joint research, and at the same time to alert people to preserve state and ethnic security. The article makes out that Sino-American joint research projects in the 1990s used students and joint-research to steal Chinese blood and to decode the DNA of the Chinese race. This code would provide information on the Chinese immune system, which could be used to create genetic weapons.

The *China Production Daily* article claims that all Zhonghua Chinese, who stem from the Yellow River and Changjiang, share the same genes. According to the paper, the Americans thought that Anqing district, where the mobility of the population is low, the blood relations relatively stable, and the dispense of medicine relatively low, is not polluted yet. This facilitates genetic experiment on Orientals. Not only were human experiments done on the DNA of the Han and the Tibetans, but research was also done into the differences between the Eastern and Western genetic codes.

The paper maintains that China's experience with two biological wars (with Japan and the Korean defence war against the US), enabled it to work on its biological immunity against biological warfare. Since the 1950s, it has been built up its medical, immunological, and nuclear defence, which has kept China safe for 50 years. But China's weak nuclear deterrence and its policy of non-aggression renders it vulnerable to high-tech genetic warfare. The solution, the paper claims, lies in deterrence and vigilance.

Another article in *Beijing Youth* (*Beijing Qingnian Bao*, 28 October 2000) entitled, ‘We will start to research the characteristics of the national/ethnic disease gene’ (*Women jiang kaishi yanjiu minzu zhi bing jiyin de tedian*), foresees that foreign companies will steal Chinese genetic blueprints to produce medicine and sell it dearly to the Chinese. For the different sequence in amino acids between, say, Germans and Chinese could mean that medicine would be effective to the one and not the other. A German scientist that realises this, *Beijing Youth* claims, could adjust the medicine to target the Chinese. Foreigners could even alter Chinese herbal medicine to tally with the Chinese genetic makeup and sell it to the Chinese with large profit.

It is not hard to see that such articles in serious newspapers could lead to misunderstanding about the nature of genetic research and to an atmosphere of international hostility. The nationalist hue of such language, unfortunately, is not just to blame on the language used by non-scientists.

#### 9. *Fang Zhouzi: genes have no nationality*

Fang, *nom de plume* of San Diego-based biochemist Dr Fang Shiming, criticises both Yang Huanming and scientific nonsense, arguing that people have a right to hear the truth (Fang, 2001). Fang believes that it is, of course, nonsense and unscientific to think that Americans are trying to destroy the Chinese by unravelling their genetic code and making biological weapons. Why should they do it even if they could? They would kill Chinese Americans, such as Xu Xiping, at the same time. How can we speak of the existence of a *Zhonghua Minzu* gene as a gene that all Chinese share? And what about the Chinese who marry into other ‘races’?

Fang reminds the reader that the author and the editors of the first journal that wrote about the ethical problems with Xu’s research, *The Washington Post*, is an American newspaper, not Chinese. Fang laments that it is ridiculous and harmful to even think of the US-administration spying on researchers at Harvard to pass on secrets about Chinese DNA to the American military. For ‘This kind of talk hampers proper criticism of Xu Xiping’s behaviour, takes the Chinese people for fools, and uses libel as a source of patriotic rubbish’ (Fang, 2000).

#### 10. *Chinese official policies: American science is good for China*

Despite the ups and downs in political relations between China and the United States, China can be a good place to pursue co-operative research projects. This is what the Chinese government seems to say to American scientists (of which many are of Chinese origin).

In mid-July 1999, a delegation from the PRC, including Vice Minister of Health Peng Yu, attended a meeting in Lexington, Massachusetts, organised by the Association of Chinese Professionals in Biomedicine USA (ACPB). The ACPB is composed predominantly of American scientists who came to the

United States from China for advanced study and remained there to become researchers and professors.

Peng's goal in attending the conference (and subsequent meetings at the NIH) was to 'find a mechanism...to promote international co-operation [in scientific research] between China and the USA' (Watanabe, 1999). At the meeting joint projects with China were encouraged, as China has well-trained scientists, a large population whose people potentially could be enrolled in clinical studies. For an American scientist who initially came to the United States from China for advanced study and remained to become a professor or researcher, there are added advantages to working with Chinese colleagues. The American scientists speak the Chinese language, know the culture, may know the institution, and may be friends or former classmates of their Chinese counterparts. This description seems to fit Xu Xiping's exactly. Maybe not coincidentally, as the person presiding over this institute was Xu Xiping.

### **Discussion: the unit of analysis and the issue of informed consent**

A main problem in understanding genetic sampling is the definition of the groups of people we want to examine. In other words, what criteria we use for including people in a group we want to examine and how do we delineate their bioethical interests from those of others. The suitability of the criteria we use for group delineation depends on their relevance to the research problem at hand:

- Defining a research population on the basis of genetic particularity seems to be a problem in that we cannot apply the criteria until we have sampled the population. Even if we find a shared genetic trait shared, we don't know if groups elsewhere share the same traits until we have sampled all people. Neither do we know whether the trait is relevant as a criterion of distinction in the case concerned. Xu Xiping's research experience shows that this is a problem also for scientists: Xu himself had to change the focus of his research from asthma to blood pressure as he had overestimated the genetic homogeneity of the population of Anqing and underestimated its complexities vis-à-vis the environment, which of course is of central concern of genetic epidemiology;
- Some geneticists use language for defining a research population, others use genealogical records. These cultural criteria lead to, to historians and social scientists, familiar research problems. For languages are not static: they migrate and change; and genealogical records are often faulty, or manipulated for religious, personal and political ends. As the 'family' is not just a biological concept, but also a phenomenon understood through changing cultural meanings, it is difficult to define a stable research population. In other words, the tools with which we define cultural change tend to correlate with cultural change, though we are not sure how;
- Lifestyle is another criteria used for defining cultural minority groups, such as mountain peoples, slash-and-burning communities, and isolated sedentary

communities. Similar problems occur here as exactly these groups tend to have no historical records and often do their best to define themselves strategically as different from other peoples as a form of self-preservation against the 'modern' world (Barth, 1969);

- Political criteria are used to define national minority groups in China: officially recognised national minorities have special administrative status. Other groups are categorised politically as a part of public health care policy-making, such as in the application of eugenic criteria to groups of mentally handicapped. Furthermore, in the official press, links are made between genetic make-up, having a criminal record, and being a country bumpkin (Dikötter, 1998). In defining the bioethical interests of vulnerable groups of people, we need to know whether we are going to group them against foreign geneticists, Chinese geneticists or the Chinese state;
- A distinction between local population and the national population may give us insights into the difference between the organisation of local health care and administrative interest groups more directly related to the sample-population. In the Xu Xiping case, it became clear that Party ideology, political pressure, local corruption by officials and health workers, bribes of free health-care and money all can have influence over the individual- or group- decision to co-operate with researchers at a local level. We cannot automatically assume that local is a reflection of the national situation. The question at a local level is whether we do define the local bioethical interests of the sample population against local Party cadres, local power monger or the career interests of local physicians, or against state policies, governmental decisions, provincial laws, and so on;
- We could also make a distinction between privileged and disadvantaged population groups by looking at which groups have access to health care. The crumbling of the health care system in the Chinese countryside since the 1980s, is a good indication of where to look for vulnerable groupings (Qiu, 1999). On the other hand, private and collective health care organisations have been set up in the country, too, so we cannot generalise about the health care access of the entire rural population. It is obvious that those with little or no money or no access to health care cannot be expected to stand up for their bioethical interests as they are in no position to give 'free' consent;
- The criterion of education is of importance to institutes responsible for research as IC forms are supposed to be understood by sample donators. If the research population is regarded as backward and illiterate, this ethically excludes them from giving IC. This criterion is interesting as it is also used strategically by researchers to incapacitate other rivalling researchers. The IC-forms of the actual researchers always seem to be in good order, according to the researchers themselves;
- Examining the interest of people that co-operated with Xu Xiping, economic criteria can be used to define those who have access to science and technology and investment capital, and those who have not. Chinese researchers,

practitioners, and officials had a lot to gain from foreign investment and foreign knowledge. Some had a better catch than others, which made, for instance, Liu Jianhui more positive about Xu Xiping than Fang Zhi-an. Yang Huanming's views are an example of the defence of the intrinsic Chinese nature of knowledge deduced from Chinese samples, despite his long and rich scientific experience abroad and despite his optimism about the rose future of humanity made possible by the new genetics;

- The criterion of nationality seems to be crucial in discussions on genetic sampling and IC. Particularly the extrapolation of Chinese and American/Western interests has coloured the discussion to such an extent that the nationality of the researchers has become of greater importance than the bioethical fate of the sample donators. The familiar nationalistic image of Americans targeting poor Chinese people and the allegation of preparing biological warfare against Orientals has been played upon by both gutter press and academics of reputation;
- The distinction between the wealthy nations and the developing world population has also been important in the discussion, and of course rightly so: a poor population incapable of affording health care is an easy target for exploitation. Moreover, the lack of health care access makes such populations more attractive to genetic researchers as the want of medication avoids distortions of the medical picture. This fact by itself is a cruel irony, but not necessarily the result of a global plot. On the other hand, the 'Third World' card has been played out over and over again by members of the educated elite that have the interest of their own research at heart.

What does this all mean for the issue of IC? First of all, the different criteria for defining research groups lead to more questions: Are uneducated and underprivileged individuals capable of giving IC? Do they know what it is about? Do they understand the language? Are they too poor to refuse? Are they under pressure from others (relatives, the community, political parties, and the state)? Are they lured into giving IC by rewards?

Multiple aspects of groups and group definition at different levels are important if we want to weigh the bioethical interests of donating groups against those of other groups. Discussions have suggested to consider Group Consent (GC) as an alternative for IC. Considering the many ways in which we can define groups indicates that we need to make a political decision about who defines and represent the groups involved. Can we be sure that village leaders or the heads of households or governments represent the views of the groups involved fairly? How can we make sure that national and local IRBs are impartial if nationalist interest play a part in decisions that transcend borders? Some governments, such as those of Iceland and Estonia have been willing to sell out their population's genome. In these decisions the national unit of research was of overriding importance. What is in the PRC?

In this paper I have argued for the need to view new genetics practices and society as an interaction of groups and their histories at different levels of

abstraction so that we can take into account the unintended consequences of historical processes. I did this by examining the use of materials expressing the self-justification of behaviour and action by the groups of people I believed to have a stake in, and, therefore, to be relevant to, understanding the Harvard case of Xu Xiping. These interests of these groups tend to be related to the aims and set-up of the institutional context relevant to the problem at hand.

Thus, when discussing the Xu Xiping case, civil servants or party cadres tend to use patriotic jargon, claiming to defend the nation against terrorism and the exploitation of the motherland; population-policy makers speak in terms of eugenic laws and improving the quality of the population; academics refer to the institutional context (foreign company, hospital, university) to which their scientific achievements are related; company leaders refer to the rules of international capital and economic development; and local power brokers speak of caring for the community. Here qualitative social-science methods have an important part to play in relating research regulation to actual practice. For they enable the researcher to move back and forth between different levels of abstraction and analysis: from the point of view of local and personal interests to the regional, national and transnational factors in processes of globalisation.

## Notes

1. Provincial regulations require one spouse to be sterilised if one or both partners suffer from a 'serious hereditary' disease. For example, the Henan Eugenics Law requires sterilisation of at least one spouse if a married couple suffers from 'chronic mental disorders' such as schizophrenia and manic depression. In addition, provincial regulations, such as those of Gansu Province, require the sterilisation of married 'mentally retarded' persons.
2. Though humans differ very little among themselves, the differences explain genetic proclivity. Usually they are limited to differences in one base, called single nucleotide polymorphisms [SNPs]. They refer to the locations in which one letter of the genetic code is different from other persons. Nearly three million SNPs have been charted.
3. Mt DNA refers to the DNA in the mitochondrial chromosomes, organised structures in the cell's cytoplasm involved in the process, by which cells transform foodstuffs to generate energy. Mitochondria contain their own complement of DNA that mutates slowly over the generations, thus producing variation (Mt DNA polymorphism).

## References

- Barth, F. (1969) Introduction. In Barth, F. (ed.) *Ethnic Groups and Boundaries: The Social Organization of Cultural Difference* (London: Allen and Unwin).
- Beijing Qingnian Bao [Beijing Youth] (2000) We will start to research the characteristics of the national/ethnic disease gene, 28 October 2000.
- Chen Z., Chen R., Qiu R., Du R. & Lo W. (1999) Chinese geneticists are far from eugenic movement, *American Journal of Human Genetics*, 64, p. 1199.
- China Production Daily (2002) For the sake of our national security: carefully preserve our genetic code, 12 April 2002.
- Chu, J. (2000) Chinese Human Genome Diversity Project: a synopsis. In Li Jin, Seielstad, M. & Xiao Chunjie (eds) *Genetic, Linguistic and Archaeological Perspectives on Human Diversity in Southeast Asia*, pp. 95–105 (Hong Kong: World Scientific).

- Chu, J. (2001) *Zhongguo butong minzu jiyinzu yichuan duoyangxing yanjiuzhong de 'zhiqing tongyi' wenti* ['Informed consent' in Chinese human genome diversity research], <<http://south.genomics.org.cn/unsceo/referen.htm>>.
- Dikötter, F. (1997) Reading the body: genetic knowledge and social marginalization in the People's Republic of China, *China Information*, pp. 1–13.
- Dikötter, F. (1998) *Imperfect Conceptions. Medical Knowledge, Birth Defects and Eugenics in China* (London: C. Hurst & Co.).
- Fang, Z. (2000) *Fangwen Beijing huada jiyin yanjiu zhongxin xiaoji* [A short report on my visit to Beijing Huada Genetic Research Centre], <<http://www.xys.org/xys/netteres/Fang-Zhouzi/evolution/huada.txt>>.
- Fang, Z. (2001) *Zai qing 'jiyin zhuanjia' bu yao zhizao jiyin de shenhua* [Repeat: 'genetic experts' should not produce genetic fairy-tales], <<http://www.xys.org/xys/netters/Fang-Zhouzi/science/HGP6txt>>.
- Gewertz, K. (2000) Interfaculty initiative helps clear the air, *Harvard Gazette*, Harvard Gazette Archives, Harvard University, 4 May, <<http://www.news.harvard.edu/gazette/2000/05.04/interfac.html>>.
- Herman, R. (2003) Conclusion of US government's inquiry into HSPH genetic research in China, 30 May, <<http://www.hsph.harvard.edu/press/releases/press05302003.html>>.
- Lock, M. (1994) Interrogating the human diversity genome project, *Social Science & Medicine*, 39, pp. 603–6.
- Macer, D.R.J. (1998) UNESCO IBC report and an ethical oversight committee on population genetics. In Fujiki, N. & Macer, D.R.J. (eds) *Bioethics in Asia* (Tsukuba, Japan: Eubios Ethics Institute).
- Mao, X. (1998) Chinese geneticists' view of ethical issues in genetic testing and screening: evidence for eugenics in China, *American Journal of Human Genetics*, 63, pp. 688–95.
- Ministry of Public Health (1994) *Zhonghua Renmin Ghongheguo Muying Baodianfa* [Law of the People's Republic of China on Maternal and Infant Health Care] (Beijing: Ministry of Public Health of the PRC).
- Ministry of Science and Technology & the Ministry of Public Health (*Zhonghua Renmin Gongheguo kexue jishubu, weishengbu*) (1998) *Renlei yichuan ziyuan guanli zhanxing banfa* [Interim Measures for the Administration of Human Genetic Resources] (Beijing, PRC: Ministry of Science and Technology and the Ministry of Public Health).
- Nie, J.-B. (1999) Voices behind the silence: Chinese moral views and experiences of abortion, PhD dissertation, University of Texas Medical Branch, USA.
- Office for Human Research Protection (2002) Letter to John A. Lichten, Dean for Administration and Finance, Harvard School for Public Health, <[http://ohrp.osophs.dhhs.gov/detrm\\_lettrs/YR02/mar02b.pdf](http://ohrp.osophs.dhhs.gov/detrm_lettrs/YR02/mar02b.pdf)>.
- Office of Public Health and Science (2002) Letter to Keith Marcotte, Science Department of Health and Human Services, <[http://ohrp.osophs.dhhs.gov/detrm\\_lettrs/YR02/mar02a.pdf](http://ohrp.osophs.dhhs.gov/detrm_lettrs/YR02/mar02a.pdf)>.
- People's Daily (2000) World's largest gene bank for ethnic people set up in Yunnan, 28 November.
- Pomfret, J. (2001) Harvard rebukes head of China gene study, *Washington Post*, 9 August, p. A14.
- Pomfret, J. & Nelson, D. (2000) An isolated region's genetic mother lode. Chinese Human Genome Project Millennium Pharmaceuticals Harvard School of Public Health, *Washington Post*, 20 December, p. A01.
- Qiu, R. (1993) Asian perspectives: tension between modern values and Chinese culture. In Bankowski, Z. & Levine, R.J. (eds) *Ethics and Research on Human Subjects. International Guidelines. Proceedings of the XXVIth CIOMS Conference Geneva, Switzerland (5–7 February 1992)*, pp. 188–97 (Geneva: The Council for International Organisations of Medical Sciences [CIOMS]).
- Qiu, R. (1999) Medical ethics in China: status quo and main issues. In Döring, O. (ed) *Chinese Scientists and Responsibility. Ethical Issues of Human Genetics in Chinese and International Contexts*, pp. 24–32 (Hamburg: Mitteilungen des Instituts für Asienkunde).

- Qiu, R. (2001) Protecting human genome and safeguarding human rights, UNESCO'S Workshop Related to Ethical Issues on Biotechnology and Biosafety, Hangzhou, PRC (2–3 April), <<http://south.genomics.org.cn/unsceo/referen.htm>>.
- Shan, J. & Ma, N. (2002) Harvard research halted, *Beijing Today*, 48, 12 April.
- Stephens, J. (2002) Harvard research in China is faulted. Safety, ethics problems of tests noted, *Washington Post*, 29 March.
- Tao, P. & Li, H. (2001) *Zhong-Mei hezuo yinfu ganran dabao. Hangzhou Huiyi jibian jiyin lunli* [Sino-American co-operation evokes a big dispute. Hangzhou conference catalyses argument on the ethics of genetics] (9 April), <[http://technology.china.com/zh\\_cn/science/zhuanti/jiyinzu/2917/20010409/161451.html](http://technology.china.com/zh_cn/science/zhuanti/jiyinzu/2917/20010409/161451.html)>.
- Wang, Y. (2004) Chinese 'eugenics': definition, practice and cultural values. In Sleeboom, M. (ed) *Genomics in Asia: A Clash of Bioethical Interests?* (London: Kegan Paul).
- Watanabe, Myrna E. (1999) Science overrules politics in US-China collaborations, *The Scientist*, 13(16), 16 August.
- Xiong, L. (2001) *Meiguo Hafei Daxue zai Anhui de jiyin yanjiu xiangmu* [Harvard University's genetic research project in Anhui Province], <[http://www.xys.org/xys/ebooks/others/science/dajia2/xuxiping\\_finding4.txt](http://www.xys.org/xys/ebooks/others/science/dajia2/xuxiping_finding4.txt)>.
- Xiong, L. (2002a) *Nanfang Zhoumo* [Southern Weekend], 24 January.
- Xiong, L. (2002b) More work needed in Harvard case, *China Daily*, 22 May.
- Xiong, L. & Wang, Y. (2001) *Ling rensheng yi de guoji jiyin hezuo yanjiu xiangmu* [Suspicious international collaboration in joint genetic research projects], *Liaowang* [Outlook], 13, 26 March.
- Xiong, L. & Xin, H. (2001) *Women youquan zhidao—lai zi dabiesshan de ge'an* [We have the right to know—a case form Dabie Mountain], <<http://south.genomics.org.cn/unsceo/referen.htm>>.
- Zitner, A. (2002) Harvard gene study in China is questioned, *Los Angeles Times*, 30 March.