

Research Ethics in Health and Social Sciences: Unpacking Key Issues and Controversies from Field Study Experience in South China

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Principles and ethical rules in the humanities and social sciences are basically drawn from research ethics in biomedical sciences¹ and from a North-American globalized approach of good practices.² Unsurprisingly this genealogy raises epistemological and practical issues in actual local situations. For instance, obtaining informed consent from research participants is a vital procedure covered in all good practices guidelines. However, applying them in specific contexts may prove difficult.

In China and in the Mekong region, when shifting from collective principles of behavior to actual practice, the individual may not be able to make a health-related decision when family members play an *active* role in the decision-making process, whether it is to prevent or treat an ailment. These collective principles may contradict international research ethics guidelines, which are based on supposed individual rights, drawn from the individual's legal status. Collective ethical principles, termed ethno-ethics or local ethics when related to the local culture and society, are rooted, both implicitly and explicitly, in local social norms, thought, and lifeworld: these have to be taken into account in the complex negotiation of health care decisions.^{3,4}

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1. Desclaux, A. (2008). L'éthique médicale appliquée aux sciences humaines et sociales : pertinence, limites, enjeux, et ajustements nécessaires. *Bull Soc Pathol Exot*, 101(2), 77–84.
2. Fassin, D. (2008). L'éthique, au-delà de la règle. Réflexions autour d'une enquête ethnographique sur les pratiques de soins en Afrique du Sud. *Sociétés contemporaines*, 71, 117–136.
3. Micollier, É. (2012). Réflexion transculturelle en bioéthique à partir d'une expérience en Chine : construire un cadre théorique et méthodologique pour de futures coopérations de recherche. *Journal international de bioéthique*, 23 (2), 105–116.
4. Desclaux, A., & Sarradon-Eck, A. (2009). Introduction au dossier "L'éthique en anthropologie de la santé : conflits, pratiques, valeur heuristique."

In the Chinese context, these sets of principles are grounded in either scientific, lay, or inherited scholarly knowledge.^{5,6}

In 2000s' China, issues related to research ethics first arose in biology and medicine, followed by social sciences and policy research at the institutional level and were openly discussed mainly in academic circles and the news media. Ethics committees designed to review biomedical research on humans and animals that met international recommendations, regulations, and norms insofar as possible, were created in a short period. Although less so than in health research, research ethics issues have also been addressed in the social sciences and in policy research, two closely related fields in China and in most low- and middle-income countries.

Drawn on case studies investigating HIV, reproductive health, gender, and sexuality in multi-ethnic, low income, and mobile living conditions, my experience in China shows that people's vulnerability, culture, and development are closely linked. These links are also acknowledged in Southeast Asia's bordering regions, which share cultural, social, and environmental features with Southwest China. Today, these links are even more salient in times of intensifying cultural and material exchanges and circulation in the Greater Mekong Subregion (GMS). The GMS draws its name from a development project initiated by the Asian Development Bank (ADB) in 1992 to promote closer economic regional integration; approximately 326 million people live across this natural area bound together by the Mekong River. China's Guangxi (bordering Vietnam) and Yunnan (bordering Lao PDR and Myanmar) provinces are part of the GMS.

In Southwest China, the two GMS provinces, along with Hainan Island province, share many cultural, linguistic, and economic features with Southeast Asian countries. For example, the social dynamics specific to trans-border exchanges and inter-ethnic relations demonstrate one reason why linking China and the Association of Southeast Asian Nations (ASEAN) in the GSM project produces a consistent regional perspective. Based on self-declared ethnic affiliation, some 55 "official" ethnic groups account for approximately 8.49% of Mainland China's total population (over 1.3 billion).⁷ Yunnan is the most diverse province in terms of ethnic identities, with at least 25 registered groups. Its ecosystem diversity boasts landscapes

Ethnographiques 17. <http://www.ethnographiques.org/2008/Desclaux-Sarradon-Eck>

5. Micollier, É. (2015). Medical ethics and therapeutic knowledge from China: contested knowledge in times of globalization? *Chiang Mai University Journal of Humanities and Social Sciences*, 2(2), 91–101.
6. Micollier, É. (2015). (Ethno-)medical ethics in globalizing China: tracing local knowledge and adaptation of biomedicine. *Journal internationale de bioéthique*, 26(4), 101–116.
7. National Bureau of Statistics of China. (2010) The Sixth National Population Census of the People's Republic of China, 第六次全国人口普查. Beijing.

ranging from tropical plains to the high mountains near Tibet, the source of the Mekong River. In the two GMS provinces, the Zhuang, a large Thai group from Guangxi, account for 16 million, currently the most numerous minority group in China, while the Miao (called Hmong in Southeast Asia,) account for 9 million. The Thai people, all groups included, and the Hmong people are well represented in the Mekong region; and the Dai, another Thai group (called Tai Lue in Southeast Asia) account for one million. Guangxi and Yunnan are still poor Chinese provinces with socio-demographic data showing living standards below the national average. These specificities partly explain transnational mobilities; migrations are a key factor for macro- and micro-social analysis of living conditions and social dynamics in this region, considered as a highly diverse though relatively integrated territory sharing common features including its diversity and spreading beyond the borders of nation-states. This region reveals an ethnic mosaic and a natural heritage including various ecosystems.

Medical research ethics in China: issues and controversies⁸

Current Chinese guidelines and regulations show similarities and differences with international regulations in terms of principles.⁹ However, when implementing studies, the situation must be investigated case by case, and the situation may diverge from one research site to another.

The early 2000s saw a surge in the establishment of ethics committees, primarily to promote international-level research in partnership with foreign research institutes. These committees were designed to provide research ethics clearance at local, provincial, and national levels for scientific research projects. However, some key guidelines were not followed. For instance, many committee members did not grasp the concept that independent expertise must exclude conflicts of interest. For example, hospital directors were often the presidents of the newly created committees. Issues related to the ethical governance of national ethics committees, specifically the management of interactions between committees at various administrative levels such as universities or hospitals, were neglected. Accordingly, the committees' legitimacy and authority were problematic: Qiu Renzong, an ethicist and philosopher of science, referred to them as "cosmetic committees."

In the context of *biomedical research with human subjects*, patients hardly differentiate between clinical treatment and clinical research trials.

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8. Project on Ethics in Research, Treatment and Care, Center for Bioethics, Department of Humanities and Social Sciences, IRD UMI 233/PUMC (Peking Union Medical College)-CAMS (Chinese Academy of Medical Sciences), Tsinghua University, Beijing, 2009–2011, Micollier, É., & Zhai, X. M., Principal Investigators.
 9. See the main Chinese Guidelines and Regulations (translated from Chinese) (2009). *China-UK CURE Committee Report*. Appendix I, 45–51.

The risks and benefits of participating in a trial have not been properly explained to them. In most observed situations, the patient cannot provide genuine “informed consent”: he or she usually lacks consistent information about the associated risks while “choosing” to participate in a trial involving an innovative treatment instead of one that has already been tested and approved. Hence, actors working in research and health institutions compromise on the issue of *therapeutic misconception* since they are aware of their failure to provide sufficient information to the patient. They frequently claim that some patients cannot understand their explanations about available treatments. This jeopardizes the funding principle in research ethics, which depends on the patient’s correct assessment of the risk/benefit balance.

There is no clear line between adapting a well-known clinical treatment and testing an innovative one. This poses a confusion for the patient at the cognitive level. Furthermore, it may serve the interests of various actors, particularly those in low-income countries, who are more specialized and skilled than most patients, namely academic researchers, clinicians, officials, and actors from private laboratories and pharmaceutical companies.¹⁰

Poor training of health personnel was also part of the problem. However, there has been greater discussion on the necessity for research planning to respond more appropriately to local needs. The debate surrounding public health policies when choosing between policies that genuinely benefit patients and those that reflect positively on a State that is engaged in international research unveils diverging voices among healthcare providers, research staff, and officials.¹¹ Choosing between a study on the development of an HIV vaccine versus increasing the quality of and access to HIV treatment and care is a paradigmatic example of such ongoing controversies.¹² Basic research development for innovative treatments could be detrimental to clinical research that aims to optimize adaptation of current treatments.¹³

The issue of *biomedical research with animals* was raised in the late 2000s with some questions addressed in international conferences and in the context of booming research cooperation between China and foreign countries in biology and medicine. Did the research questions and therapeutic perspectives justify developing the experimental process with animals? From an ethical lens, this is the key question: it should be clearly

10. Micollier, É. (2012). *Op. cit.*

11. Micollier, É. (2012). *Op. cit.*

12. Micollier, É. (2009). Management of the AIDS epidemic and local/global use of Chinese medicine: treatment and research issues. *China Perspectives*, 77, 67–78.

13. Micollier, É. (2009). Experimenting on innovative scientific vs traditional treatments: the case of AIDS medical research in China. In C. Glymour & Wei Wang, D. Westerstahl (Eds.), *Logic, methodology and philosophy of science* (pp. 639–644). University of London, King’s College.

raised before implementing any research protocol including experimenting with animals.

The debate on the relevant social and cultural factors influences the ethics of animal research. This debate addresses the local lifeworld underlying the concept of animal, life, and of its position in the universe, and has far-reaching consequences for knowledge production in ethno-sciences and in life sciences. Moreover, it also focuses on changing perceptions of relations and inter-relations between animals, humans, and the environment; the transition from rural to urban societies; social movements for animal welfare and environmental protection; and the overall ethical governance process involving a whole range of stakeholders.

Reproductive and sexual health in Southwest China

In the 1990s, long before the HIV and AIDS National Program was launched in 2004, the Yunnan provincial government¹⁴ designed and implemented specific policies, such as targeting vulnerable groups that were either socially or ethnically marginalized. Health personnel, students, and volunteers were trained in Thailand; academic exchanges and exchanges between civilian and official actors were encouraged. Research projects brought together officials, academic institutions, local social organizations, international non-governmental organizations, and foundations. The Yunnan provincial government, Kunming Medical University, and the Ford Foundation became partners in a long-term comprehensive research program in reproductive health. Teams conducted research about family planning issues, contraception and childbirth methods in a multi-ethnic context, youth vulnerability to sexually transmitted infections (STIs), access to health facilities, and treatment acceptance. Based on the results, several policies were redesigned to better consider local specificities.

Following the gradual implementation of the national HIV program, national policies to improve access to family planning services were revised at the central level. The former policy scheme only covered people who were engaged or already married and registered in their municipalities and therefore excluded teen-agers, unmarried individuals, and mobile populations. According to field studies¹⁵ in Beihai, a coastal town in Guangxi province, “beach girls” who provide erotic and sexual services on the beach, including many Vietnamese women, could not receive family planning and STI/HIV-related services. The same situation occurred in the central

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14. In the 1990s, Yunnan province went through a dramatic HIV epidemic outbreak. The majority of people living with HIV in China were reported as living in this province, with most of them in poor, rural, and border districts.
 15. Studies on STIs (including HIV) and gendered youth vulnerability in Guangxi and Hainan province, Social Sciences Program (2006–2011), IRD UMI 233-PUMC-CAMS, Tsinghua University, Beijing, Micollier, E. & Liao, S. S., Principal investigators.

province of Hainan Island in mountainous multi-ethnic districts populated by Li (an ethnic Thai group), Miao-Yao, and ethnic Chinese people. The same study acknowledged the HIV vulnerability of teen-aged and unmarried young Li women. Premarital sexual relations and sex work are widespread. Premarital sex among teenagers or young adults from neighboring villages is practiced as a ritualized prelude to courtship in order to select an appropriate marriage partner. In this cultural context coupled with booming economic development, a new social condition emerged for many young women and their families seeking economic opportunities. Hainan Island became a province in 1988 and was granted the privileged status of “Special Economic Zone.” Consequently, numerous young women migrated to beach towns or the capital city, Haikou, and entered the sex industry.

Concluding remarks: a quiz on ethical issues

a) What are the main ethical issues in medical research?

Our experience in the South of China highlights the following points: independent expertise is in demand, ethics committees have not established legitimacy, and patients are easily confused about the difference between clinical treatment and research trials. Higher quality and widespread access to common treatment for more patients may be a better option than the development of cutting-edge research.

In medical research development, a *pragmatic adaptation* of research and administrative institutions has been observed over the years: ethics committees to review protocols designed to comply with international recommendations emerged in a *short time* and with *insufficient human resources and poorly trained staff*. Within the framework of the *research context* in China, civilian voices are rarely heard and their agency is very limited. Subsequent tensions are related to conflicting national and global economic interests, either public, private, or mixed. These include economic constraints, such as the case of vulnerable individuals who have no other choice than to register as research subjects. These people are usually excluded from local regular health care services due to poverty and/or mobile living conditions.

b) What ethical issues are related to biomedical research with animals?

Firstly, the main issue concerns the relevance of the research question and therapeutic prospects: do they warrant experimenting on animals?

Secondly, the animal's suffering and living conditions in the laboratory context should be taken into account in all phases of the experimental process.

c) What are the main ethical issues regarding policy and governance?

Reproductive and sexual health in South-China was detailed as an example.

Local cultural and socio-economic conditions need to be accounted for as a whole. Policy changes ignite tensions and invite negotiations at the local, national, or international levels, unveiling ethical implications that must be tackled. As we observed, the implementation of these changes was very uneven. Moreover, it should be monitored in context at each administrative level. In some cases, health officials and personnel were not even informed that an ethical review was required. As pointed out in this article, social, ethnic, or age-related vulnerabilities—involving both cultural context and socio-economic conditions—need to be unpacked in order to frame an appropriate project, along with a policy designed to monitor the intervention phase.

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Health, Environment, Societies

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