



Ethical Governance of Biological and Biomedical Research: Chinese-European Co-operation

CONFERENCE REPORT



Ethical governance of reproductive technologies, therapeutic stem cells and stem cell banks

Institute of Reproduction and Stem Cell Engineering,
Central South University & Reproductive and Genetic Hospital
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Introduction

Following two BIONET workshops held in Beijing (April 2007) and Shanghai (October 2007), a number of key issues related to ethical governance in the fields of Assisted Reproductive Technologies (ART) and Stem Cell Research were identified. These issues set the context for BIONET's first international conference held in Changsha from 1 to 3 April 2008 which rounded off BIONET's work on reproductive and regenerative medicine. It was also an opportunity to discuss the BIONET's findings to date in the greater context of our project's mission

The key questions addressed at the conference included:

- how can effective *systems of science governance* be put in place to ensure scientific and ethical oversight of reproductive and stem cell research?
- how should agreement or consensus on *ethical principles* be reached and how can adherence to them be ensured?
- how should *conflicts of interests* between clinicians, researchers, hospital administrators and patients be managed at a time when healthcare and biomedical research are becoming increasingly commercialised in both Europe and China?
- how can *vulnerable patients* who are in a desperate situation (as is often the case with both ART and stem cell therapy patients) be safeguarded against risks of inducement and exploitation?
- how to *govern* the related medical services and research activities when they involve the crossing of national borders, challenging the established national spheres of jurisdiction and oversight?

These questions which were specifically related to reproductive and regenerative medicine research were then placed in a context of growing international scientific collaboration where scientists, biological materials from human subjects, scientific equipment, technical expertise and/or information databases are exchanged across continents and countries. When it comes to Chinese-European research collaborations in the fields of stem cell and reproductive science, participants debated and discussed:

- what are the resources to build sufficient conditions for better ethical governance and practice in Europe and China?
- which concepts, debates, institutional approaches can benefit good governance?
- what models can be used for governance of research collaborations between Chinese and European scientists?

The following report describes some of the main lines of discussion with particular significance for these guiding questions, without attempting to summarize the entire discussion, and leaving out several valuable contributions in the interest of being concise.

Systems of science governance

Ensuring quality in scientific research has long relied on a system of peer review, which aims to ensure that results have been obtained according to strict criteria of scientific rigour. In the fields of biological and biomedical research, where human subjects are involved, quality assurance has also come to rely on systems of ethical review, which aim to ensure that any procedures that derive data using human subjects have respected their dignity and rights. And so when it comes to stem cell research (both basic and clinical), integrity concerns not only rigour but also ethical propriety in the conduct of scientific research, which challenges the scientific community and even the meaning of science itself. As the Hwang scandal demonstrated, ‘tainted data’ is not just that which has been fraudulently manipulated, but also that which has been obtained without regard for the dignity and rights of involved individuals (whether as donors of biological materials or as patients undergoing treatment linked to clinical research). As a result, ethical review has emerged as a parallel mechanism of quality control with informed consent procedures, ethical guidelines, codes of conduct and ethical review boards used to ensure that scientific research is carried out in an ethically appropriate and approved manner. Moreover, such governance instruments need to be embedded in an accommodating context that depends not only on law but on characteristics such as transparency and sincerity among stake holders.

At the same time, it has also been shown that peer review and ethical review alone cannot prevent misconduct, perhaps especially so in fields such as stem cell research where there is national (and regional) competition and prestige at stake. What then, are the elements of ‘good science governance’ in stem cell research? This question was touched upon in a number of presentations.

Entering the dialogue, Nikolas ROSE described ways of “Regulating the practice of biomedical research - problems of governance”, with a European view on the development in China. Good governance systems were in general characterised by an orchestrated interplay of top-down and bottom-up approaches, with efficiency, transparency, and accountability. He reported that literature has been accounting for an ongoing course of decentralisation and the building of law in China’s governance system, which now raises the question of how to govern fragmentation. At present, there seemed to be a wide area of overlapping challenges, in Europe and in China, with shared (infra-) structural problems, such as how to deal with regulatory diversity, or with policy-making lagging behind science and technology development; public distrust in science and a growing demand for public participation were also widely seen. For all the differences, Europe and China were still engaged in building their regulatory systems. Establishing a joint governance regime for collaborative quality research was an effort in which culture mattered as much as good law.

In her scientific presentation, on “Cross-species somatic cell nuclear transfer: scientific, ethical and regulatory issues”, SHENG Huizhen introduced an oocyte engineering project and reflected upon her experiences in collaborative international research projects. She acknowledged the extremely different religious and cultural backgrounds for researchers

in Europe and China, and in different regions within the PRC. In an attempt at a systematic governance model for China-European collaborations, she suggested a model for China that would distinguish China's research into two development zones, which were unified by the same goal but different in pace. Those partaking in international projects should immediately be subject to the highest international standards of best practice and straightforwardly be enabled to facilitate collaboration. They would accumulate experience on the basis of which to inform regulatory bodies about their feasibility under Chinese conditions, and leave room with special support for those lagging behind and who would then be gradually enabled to follow suit. Thus a comprehensive governance system could be established, while different development stages would be respected and double standards could be avoided.

Concerns about governance issues owing to uncertainty about the legal situation of scientists collaborating from different countries were also addressed in LU Guangxiu's presentation about "The establishment of Embryonic Stem Cell bank and preliminary study on its ethical governance". She explained that, in engagements with the International Stem Cell Initiative in Germany, questions about legal or ethical repercussions remained open regarding the heavy limitations for embryo research in Germany, and their potential impact upon collaboration. Governance would hence require clarification about the scientist's legal position in different contexts.

Stephen MINGER explored the "Therapeutic and Research Potential of Human Stem Cells", with a view on research targeted at Parkinson's disease. As he explained, "no one has ever taken HESC's into the clinic yet", as the main scientific work is done on rat models. Mindful of sometimes misleading public representation of actual scientific work, namely exaggerated fears or expectations associated with the advancement of the life sciences, he argued for a rational discussion of fundamental research towards innovative biomedical technologies, such as cybrids and HESC.

There seemed to be a consensus among European and Chinese presenting scientists who emphasized that, owing to huge difficulties in obtaining human eggs and the current inefficiency of somatic cell nucleus transfer, research will need to be based upon other resources, such as stem cells of varied origin.

Herbert GOTTSWEIS discussed, "how best to govern human embryonic stem cell science?" Using the examples of case studies from three contrasting HESC governance systems: the United Kingdom, Italy, and South Korea, he argued that openness, accountability, transparency and the avoidance of hype in research policy and regulation were key for creating sustainable and internationally legitimate stem cell governance. He pointed out that national domestic governance and international best practice needed to be rooted in and interconnected according to these principles.

Margaret SLEEBOOM-FAULKNER presented findings from her field research on "China and the regulation of stem cell research: Risk perception at global, national and local levels". In her comparative analysis, she observed different priorities on the policy agenda. When comparing China with the "World Risk Society model" with its concerns

about global governance of ethics and “kosher production”, China showed primary concern with distribution of resources in society and concern about global competition. As a result from differences in these macro-agendas, topics of relevance for governance and cooperation would be weighed and treated quite differently, such as encouraging public debate, representation of bioethics, or criteria for funding. Thus there are challenges and concrete starting points for the EU-China collaborative governance debate to refer to.

LI Jianhua presented insights from “Ethical education in ART practice”, from a Chinese ethicists view. He explained that, when using teaching as a way to balance science and moral interests with “standardised ethics”, cultural peculiarities should be recognised, such as in ART, where, for many Chinese, “blood ties” sometimes stand in tension with “social ties”. “Western bioethics” could not just be copied for the conditions of China.

WANG Yifei observed the great variability of ethical questions related to ART. In his paper on “Bioethical Guidelines for ART and their Implications in China” he argued for a sustained development of ethics that would neither alienate society from science nor turn ethics against science. What was needed was rather a supportive cultural environment for policy making than top-down hard law ordinance. The challenge was in establishing governance in such a way that the universally applicable fundamental principles of bioethics were translated into norms and regulations that were practical according to given working conditions, societal and moral requirements.

Athar Hussain noted that, in China, the oversight of the health care system and policy-making are dispersed across a wide range of government departments and agencies, which raises the problem of coordination when it comes to organizing governance. He also emphasized pressures from the economic situation. Over the reform period the cost of medical treatment has risen faster than that of household income. By international standards, the percentage of the total cost borne by patients is very high; 61% compared to the international average of 43%. A substantial percentage of the population has no health insurance and the reimbursement rate is low. The leadership is acutely aware of the deficiencies in the health care system and is making efforts to reform the system and increase expenditure on health care. This situation has implications for China’s engagement in international governance collaboration, in terms of priority order and proportions of issues on the agenda.

Moral plurality and efforts to agree on ethical principles

As is well known, recent international efforts to achieve consensus on ethical issues in human embryonic stem cell research have ended with agreement only on this issue: that “reproductive cloning” should be prohibited. On all other issues – whether research on embryos should be permitted, whether human-animal hybrids/cybrids should be created, whether “therapeutic cloning” should be permitted, etc. – there has not been consensus, neither internationally, nor within Europe or China. Yet while it has proved difficult and

often impossible to agree on common international policies, the attempt to establish a regime of ordered practice is itself significant. While many shortcomings in these efforts are noted – for example insufficient inclusiveness in deliberation processes or insufficient enforceability of ethical guidelines – in both China and Europe, it is nevertheless evident that these efforts are under way.

QIU Renzong elaborated on “Common grounds and differences in ethics and governance of reproductive technologies and stem cell research in China and Europe”. While he found that some basic values in relation to reproductive technologies and stem cell research are shared by China and Europe, differences exist between them as well as pluralism among European countries due to different philosophical, legal and socio-cultural background. Challenges have to accommodate both sides, in pursuing good governance, to strike a balance between facilitating scientific progress and providing ethical and practical safeguards in face of these rapidly advancing scientific areas with uncertainty of the impact on humanity and slow regulation or legislation. Steps should be taken to develop consensus on ethics and governance of reproductive technologies and stem cell research to further bilateral collaboration between China and Europe, including how to handle inconsistency and conflict of their laws or regulations.

Christoph REHMANN-SUTTER explored an ethical discourse across moral and cultural plurality of that kind that starts practically, with concerns, cases, experiences and narrations rather than principles. In his talk about “Coping with moral plurality: Political and ethical challenges of international governance of stem cell research (from an European perspective)”, he observed that moral principles and ethical concerns have a different grammar, a fact that needs to be captured by the ways that bioethical discourse is organised. He recommended a model of a reflective and critical bioethics, as the philosophical basis for both, a strong partnership with the social sciences and a communication across “local“ and “cultural“ contexts, that takes the local and the cultural seriously. Rehmman-Sutter defended a non-essentialist, justificatory universalism, which acknowledges the communicative freedom of the other, namely, “the right of the other to accept as legitimate only those rules of action of whose validity she has been convinced with reasons.” He noted that this applies to the embryo issue in a much different way than to the informed consent issue.

Conflicts of interest

LI Yongguo introduced cases from the clinic that raised typical “Ethical dilemmas in clinical cases and their resolution”. He analysed the different interests that contribute to a triangle of varied individual concerns, medical views and social stakes. Within this field, adequate informed consent is difficult to achieve, given the complexity of problems and lack of experience with the imported “Western” models. He argued towards advanced legislation and regulation of this area, which should consider the relevant economic and health system factors and be based upon improved scholarship.

Moustapha KASSEM, in his presentation about “Stem cells – from basic biology to the challenges of clinical applications”, explained the experiences with the Danish system of

combined research and public education and communication, as an example for a sustainable science-and-society strategy. This background would be supportive of dealing with sensitive issues in the work on integrating basic research and therapy-application

Ayo WAHLBERG addressed “Conflicts of interest and defining ‘spareness’ in embryo donation”. From the anthropologists’ and sociologists’ perspectives, he discussed different ways in which ‘spareness’ has been defined and negotiated in a European context when it comes to the donation of embryos for stem cell research. Experiences from Europe have shown that it can be interpreted in many different ways, for example, in terms of embryo quality, therapeutic outlook for an IVF couple, stem cell research requirements or legal stipulations. Negotiating clinician-researcher conflicts of interests and ensuring compliance with national regulations (which are very different throughout Europe) are at the heart of efforts to define what a ‘spare embryo’ is. He explained concerns about close alliances between research laboratories and IVF clinics that might negatively affect vulnerable IVF patients.

TU Ling explored “on ethical governance of donated oocyte and embryos for ES cell research”. She started with the observation of problems related to the sourcing of human egg cells and embryos, which are increasingly difficult to obtain. She saw a conflict between overly ambitious domestic and international research and the protection of donors. She identified orderly regulation and strict enforcement as being in the shared interest between health and research, and emphasised the non-commercialisation or ban on organised harvesting of eggs/embryos as characteristics of a research/clinical environment that would accommodate trust between the patient/donor and the doctor/researcher. This description was supported by another presentation from ZHU Guijin and HUANG Guoning on “Ethical challenges in clinical work”.

In a joint presentation, GUO Hui and BAI Ting offered a “Discussion on the different attitudes of IVF-ET patients to donate spare embryos for scientific research”. From the practitioners’ point of view, they reported that the reasoning behind embryo donation is often that couples believe that they should give something back to the medicine that had helped them; especially as it is assumed that the stored embryo would have no other value than for science. Concern is mostly focused on trust-related matters, such as whether an embryo could be used for non-therapy-research purposes, for example be illegally implanted for procreation into another woman. Guo and Bai summarized that, after due explanation, most couples would agree to donate their leftover embryos for therapeutic or fundamental research.

Anika MITZKAT supplemented with findings from her own ongoing clinical fieldwork in China. Her “Decision-making in the IVF-process - themes emerging in patient reports” focused on patients’ views in a Hospital for Genetics and Reproductive Medicine. Asking patients undergoing IVF about their own perception of this decision is a method to provide empirical evidence for an ethically meaningful conceptual analysis of “How do ‘couples’ become embryo donors’?” She reported a shift in the perception of the process. Starting with the sense that “the embryo is a baby” there follows reasoning that donation would be morally preferable to waste of the embryo, so that donation can be seen as an “affordable contribution to society”. In the process after IVF, the conception of the

embryo might change, as a result from emotions and reflections, as can be accounted for in patients' narratives: "The embryo" can become "an embryo", and finally, "our embryo". Thus the knowledge, attitudes and values expressed by couples in their reflection about embryo donation for ES and their perspective on donation can become a valuable indicator of cultural characteristics in the society, informing governance.

Vulnerability and informed consent

ZHAI Xiaomei presented an outline of "Informed consent in ART treatment" in China. She explained that the concept of informed consent in the combined sense of "co-decision-making", "faithful disclosure of information" and "avoiding negative consequences for the patient" is still at the stage of being introduced. For ordinary clinical situations, informed consent would not be required in the written form, but for risky procedures it would. In China, the concept of paternalistic medicine is still widely spread; however, sometimes doctors use the legal form of an informed consent in order to avoid being held responsible. A special feature of China's situation is that "Family Assisted Consent" could be accepted.

XIAO Shuiyuan introduced an innovative approach of ART as a complex process, following a holistic bio-psycho-social model of health. In "Suffering with assisted reproduction: a clinical and ethical concern", he explained that assisted reproduction has been widely practiced in China in the past two decades. While it had become one of the most important biomedical advancements of the time, it would be of increasing importance to discuss the possible resulting psychological conflicts and sufferings of those who are receiving help from ART, such as conflicts in decision-making, socio-cultural originated stress, possible failures, uncertainty in the future, etc. Social pressure, for example, would be from the definition of the purpose of marriage to produce a child, with the associated stigmatisation of couples who fail to deliver. This background explains the importance of dealing with suffering even after successful treatment. For many couples, the situation is further complicated by the absence of financial support from health insurance. Xiao asked, who should define the condition of an infertile couple and suggested that this should be the discretion of the couple itself, sometimes the parents.

Communication and understanding with regard to the vulnerable situation of reproductive uncertainty were further highlighted by Renata SALECL. In her contribution, "New reproductive techniques and the psychological dimensions of people's reproductive desires", she systematically probed into related psychological dilemmas that are part of people's desire to reproduce. She argued, science needs to be aware of the fact that people's desire to have a child is not simple a matter of rational choice. Of particular concern is also the future child, who might react in an unpredictable way to the knowledge that his or her life came into being as a result of a special scientific intervention. Salecl noted that, for Europeans, criticism as a bioethical concept is very much a European self-criticism and intrinsic to the related discourse.

International research collaborations

In the core of ethical governance stands the question, how to assess the legal status of a researcher from one country in another country, with a significantly different system of law, ethics and governance, and the related “legal risks” in collaborative research projects.

Hans-Georg KOCH took up the “Legal status of researchers in bi- and multinational research projects”, from a European and in particular a German law perspective. He explained the existing general options of regulation on the different levels of law-making. Legal accountability can be constituted in two major ways, first through a country’s citizenship, and second, through actions within a country’s borders. In cross-national collaborations, e.g. advisory engagement can be criminally liable even when the research is not forbidden under the hosting country’s law, but because a scientist contributed from within a country where it is prosecuted (e.g. phone or email consultation). In such situations, in practice and at present, there is a high degree of legal uncertainty, but no high feasibility of actual legal consequence, as there are as yet no effectively established forms of collaborative international legal enforcement in this area. Another governance tool is control by funding. Funding contracts require conformity with national law, and often include specified ethical codes, whereas ethical standards can be more restrictive in their requirements than law. Currently, this instrument might be the most effective means to ensure best practice. With a hint towards the difficulties in the relevant inner-European efforts, Koch concluded that it was not realistic to expect, in the near future, a EU-China harmonisation on the level of laws. However, significant progress could be reached in governance standards that refrain from judging outcomes, but focus on procedures and professional codes of practice.

Amanda DICKINS, while pondering “Global science, global governance?”, discussed the creation of international space in relation to different approaches to bioethics regulation through both, expert authority and public deliberation, regarding HESC and how these approaches are deployed in different regulatory contexts. She enquired, whether the presently accepted approach to regulating international collaboration will need to change as HESC research moves from ‘basic science’ to ‘translational research’, specifically research involving human subjects. How can international collaboration be well governed, maintaining public confidence and support for research? Dickins argued for the creation of a particular ‘international space’ in bioethics regulation, wherein bilateral and regional coordination could provide important tools and add to global governance instruments.

CONG Yali shared “Some thoughts on China-European biomedical research collaboration”. In general, she acknowledged a promising background for EU-China collaborations, notwithstanding the underdevelopment of joint governance institutions, and the small number of actual collaborations in the stem cell field to date. Major activities were rather to be found in the areas of TCM and industry research. Cong called for taking the BIONET’s cooperative agenda serious and make greater efforts to establish “Ethical guidelines for China-EU biomedical cooperation”. She identified governance-developmental issues on all sides as major problems in this endeavour, such as poor

understanding of the relevant governance institutions, the complexity on relevant levels of the systems, infrastructures and the cultural differences, but not so much the fact that some countries have stricter or more permissive law.

Ole DOERING, speaking about “Governing best practices of reproductive and stem cell medicine and research between Europe and China”, offered comments on the BIONET’s work. Summarising that, not only are there considerable disparities in the governance policies in China and European countries, he observed that it also makes a substantial difference, in cultural terms, what it means to implement law, in the focus areas of the life sciences, in both regions. Referring to related theory-discussions in business ethics in China, he proposed a definition of good governance that can integrate diversity under an umbrella of accepted ethical standards in the field of medicine research. He discussed the challenge of avoiding twofold standards when doing research involving European and Chinese partners. Doering highlighted the importance of “middle level” and “soft law” mechanisms of governance and identified cultural invariant qualitative denominators as compatible with EU and China’s governance requirements, such as social sustainability, transparency, responsibility and participation. In terms of practicality of specific governance instruments, however, it was noted that institutional and procedural cornerstones, such as subsidiarity and informed consent, could not be easily adapted, as they depend upon reliable adherence of key actors and supportive framing conditions.

Programme

31 March 2008

Arrivals and registration, PREESS Resort & Hotel

Meetings for BIONET members: Expert Group (4 – 6 pm), Steering Committee (over dinner)

1 April 2008

<p>Opening ceremony (8.30 – 9.45)</p> <p>GUO Kailang, Vice Governor of Hunan Province, People’s Republic of China David CONCAR, Science & Innovation Counsellor, British Embassy, Beijing YU Xiucheng, Department of Medical Science, Technology and Education Ministry of Public Health LU Guangxiu, Institute of Reproduction & Stem Cell Engineering Central South University LI Guiyuan: Vice President of Central South University Nikolas ROSE, BIONET Consortium</p> <p>Media briefing chaired by: Christoph REHMANN-SUTTER, BIONET Expert Group QIU Renzong, BIONET Expert Group</p>	
<p>Chairs: LI Benfu & Wolfgang HENNIG</p>	
<p>Plenary 1A (9.45 – 10.45)</p> <p>Differences and common ground in ethical governance of reproductive technologies and stem cell research in China and Europe</p> <p>QIU Renzong: Common grounds and differences in ethics and governance of reproductive technologies and stem cell research in China and Europe Nikolas ROSE: Regulating the practice of biomedical research - problems of governance Discussion (10.45 – 11.00)</p> <p>Plenary 1B (11.00 – 12.00):</p> <p>Ethical Governance of ART and stem cell research: Institutional perspectives</p> <p>LU Guangxiu: The establishment of Embryonic Stem Cell bank and preliminary study on its ethical governance Stephen MINGER: Therapeutic and Research Potential of Human Stem Cells Discussion (12.00 – 12.15)</p>	
<p>Lunch (12.15 – 2.00)</p>	
<p>Sessions 1 (2.00 – 3.00)</p>	
<p>Session 1A: <i>Clinical ethics committees – functions, composition, training of members and experiences</i></p> <p>Chairs: ZHOU Canquan & SLEEBOOM-FAULKNER Rapporteur: Joy ZHANG</p>	<p>Session 1B: <i>Informed consent – best practices and challenges in ART</i></p> <p>Chairs: LI Jianhua & Alicja LASKA-FORMEJSTER Rapporteur : HU Linying</p>

<p>LI Benfu: The organization and management of ethics committees in China Peter PROPPING: How is the genetic structure of the population influenced by reproductive medicine? CHEN Zhenwen: Ethical Principles for Human Sperm Banks</p> <p>Discussion (15 min)</p>	<p>FENG Yun: Thoughts on ethics concerning human gametes and embryos Renata SALECL: New reproductive techniques and the psychological dimensions of people's reproductive desires WANG Yifei: Bioethical Guidelines for ART and their Implications in China</p> <p>Discussion (15 min)</p>
Tea/coffee break (3.00 – 3.30)	
Sessions 2 (3.30 – 4.30)	
<p>Session 2A: <i>Application of ethics in reproductive and regenerative research</i></p> <p>Chairs: FAN Liqing & Athar HUSSAIN Rapporteur: Thomas STREITFELLNER</p> <p>SUN Yingpu: Exploration on informed consents in ART Herbert GOTTWEIS: Governing Stem Cell Research: Models-Options-Strategies LI Jianhua: Ethical education in ART practice</p> <p>Discussion (15 min)</p>	<p>Session 2B: <i>What is a 'spare embryo'? – patient perspectives</i></p> <p>Chairs: CHEN Pei & Amanda DICKINS Rapporteur : ZHU Wei</p> <p>Ayo WAHLBERG: Conflicts of interest and defining 'spareness' in embryo donation GUO Hui & BAI Ting: Discussion on the different attitudes of IVF-ET patients to donate spare embryos for scientific research Anika MITZKAT: Decision-making in the IVF-process - themes emerging in patient reports</p> <p>Discussion (15 min)</p>
Break (10 min)	
Reports from 4 sessions (4x5 min) (4.40 – 5.00) General Discussion (5.00 – 5.30) Closing of the day	
Welcome dinner at 6.30 Optional Spa evening	

2 April 2008

Chairs: QIU Renzong & Christoph REHMANN-SUTTER
Plenary 2A (9.00 – 10.00) Ethical Governance of stem cell research: International/national perspectives
SHENG Huizhen: Cross-species somatic cell nuclear transfer scientific, ethical and regulatory issues Hans-Georg KOCH: The legal status of researchers in bi- and multinational research projects Discussion (10.00 – 10.15)
Plenary 2B (10.15 – 11.15) Application of ethics in stem cell research

LI Yongguo: Ethical puzzle in clinical case and its decipher Moustapha KASSEM: Stem cells – from basic biology to the challenges of clinical applications Discussion (11.15 – 11.30)	
Interim Report from BIONET Expert Group (11.30 – 11.40) Discussion (11.40 – 11.50) General Discussion (11.50 – 12.15)	
Lunch (12.15 – 2.00)	
Sessions 3 (2.00 – 3.00)	
<p>Session 3A: <i>Research ethics committees – functions, composition, training of members and experiences</i></p> <p>Chairs: LEI Ruipeng & Ole DOERING Rapporteur: Ayo WAHLBERG</p> <p>HUANG Hefeng: Ethical Problems from Stem Cell Research and Reproductive Cloning Megan ALLYSE: Research Ethics Review in the United Kingdom XIAO Shuiyuan: Suffering with assisted reproduction: a clinical and ethical concern</p> <p>Discussion (15 min.)</p>	<p>Session 3B: <i>Ethical governance of stem cell research – global and local perspectives</i></p> <p>Chairs: CONG Yali & Michael BARR Rapporteur: ZHAO Mingjie</p> <p>Amanda DICKINS: Global science, global governance? Creating “international space” for collaboration in hESC research TU Ling: Exploration on ethical governance of donated oocyte and embryos for ES cell research Margaret SLEEBOOM-FAULKNER: China and the regulation of stem cell research: Risk perception at global, national and local levels</p> <p>Discussion (15 min.)</p>
Tea/coffee break (3.00 – 3.30)	
Sessions 4 (3.30 – 4.30)	
<p>Session 4A: <i>Commercialization, standardization, patenting</i></p> <p>Chairs: ZHAI Xiaomei & Peter PROPPING Rapporteur: Michael BARR</p> <p>Athar HUSSAIN: Health Care of the Chinese Population - Current Pattern and Future Trend YANG Huanming: Definition of human life and its relevance to bioethical discussion Leo KIM: Governing Stem Cell Discourse: Actors-Strategies-Knowledges in UK and Korea</p> <p>Discussion (15 min)</p>	<p>Session 4B: <i>Regenerative medicine: challenges in moving “from bench to bedside”</i></p> <p>Chairs: FAN Minsheng & Ayo WAHLBERG Rapporteur: SU Yeyang</p> <p>Lotte HUNICHE: Challenges in regenerative medicine – from bench to bedside CHEN Fangping: Ethics of Cell and Gene Therapy ZHU Guijin and HUANG Guoning: Ethical challenges in clinical work</p> <p>Discussion (15 min.)</p>
Break (10 min)	
Reports from 4 sessions (4x5 min) (4.40 – 5.00) General Discussion (5.00 – 5.30) Closing of the day	

Cultural activity / dinner at Xihulou (West Lake Tower) (6.30 – 9.00)

3 April 2008

Chairs: LU Guangxiu & Herbert GOTTWEIS

Plenary 3A (9.00 – 10.00)

Informed consent in ART treatment and stem cell research

ZHAI Xiaomei: Informed consent in ART treatment

Christoph REHMANN-SUTTER: Coping with moral plurality: Political and ethical challenges of international governance of stem cell research (from an European perspective)

Discussion (10.00 – 10.15)

Plenary 3B (10.15 – 11.15)

Common understandings – ways forward in research collaborations

CONG Yali: Some thoughts on China-European biomedical research collaboration

Ole DOERING: Governing best practices of reproductive and stem cell medicine and research between Europe and China

Discussion (11.15 – 11.30)

Tea/coffee break (11.30 – 11.45)

Chairs: CONG Yali & Ole DOERING

Final Plenary Discussion (11.45 – 12.15)

Summary and closing ceremony (12.15 – 12.30)

BIONET Expert group meeting (1.30 – 4.30)

Afternoon cultural / tourist activities (optional)

Dinner at PREESS Resort & Hotel

4 April 2008

Optional site visit to the XIANGYA clinic

BIONET Steering Group meeting, XIANGYA clinic (9.00 – 11.00)

Press Meeting at XIANGYA clinic (11.30 – 12.30)

Media coverage

“捐精像献血，而不是来做父亲”

中欧专家共同讨论生命伦理



昨日，中欧“生殖技术、治疗性干细胞和干细胞库的伦理管理”国际研讨会在长沙召开，“中国‘试管婴儿’之母”卢光琇教授(左一)在会议中与中外专家交流。图/记者秦楼

本报记者沈颖 实习生张楠长沙报道

“人的生殖性克隆涉及的伦理问题是对人类尊严的亵渎和侵犯。发展下去，有可能建立生产人的流水线作业线，婴儿像产品一样被制造和处理，与之相关的供卵和代孕妇女将被工具化和客体化(物化)。”浙江大学教授黄荷凤旗帜鲜明地表示。

昨日，来自中国和欧洲的100多名从事干细胞研究的科学家、医务工作者、伦理学家、社会科学家齐聚长沙，参加中欧“生殖技术、治疗性干细胞和干细胞库的伦理管理”国际研讨会。世界各国的伦理界定、法律条文都不尽相同，“中国‘试管婴儿’之母”卢光琇教授表示希望求大同存小异，将科学技术共同运用到造福人类之上。

“代孕”是否应该商业化

“现在不孕夫妇占总数的10%—15%，仅仅我们研究所，去年就做了5000个周期的试管婴儿，可见人类辅助生育研究有着非常重要的意义。”中南大学生殖与干细胞工程研究所的卢光琇教授提出，中国与欧洲各国在胚胎、干细胞研究技术上的差异不见得有多大，但在伦理道德上的认识就

有着很大的分歧。比方说，在德国，捐精和捐卵都是不允许的，而在中国捐精捐卵都被认可，但是不允许“代孕”行为，在美国不仅允许捐精捐卵，代孕也是可以的，甚至还将“代孕”商业化，有专职“代孕者”。

卢光琇教授介绍，卫生部《人类辅助生育技术和精子库的伦理指导原则》实施以来，我国的辅助生育治疗市场得到了一定的规范。然而，一些医疗机构受商业利益的诱惑，违规从事辅助生育服务。临床上也出现了越来越多的具有伦理挑战的病例，如患者利用其对辅助生育技术的认识来寻求“不孕症”的治疗，而实际上是试图进行性别选择胚胎，甚至是希望获得多胎妊娠。

“捐精只是像献血一样的捐助”

卢光琇教授曾建立了我国第一个冷冻精子库，诞生了第一例冷冻精液人工授精婴儿。捐精者在捐精前就必须签署《知情同意书》，“我们首先会告诉捐精者，他们只是在从事一项像献血一样崇高的人道捐助。捐献的只是一些细胞，而不是来做父亲。我们也曾遇到过抱着多繁衍后代的心态来捐精的人，但都被我们婉言谢绝。”

而瑞士巴塞尔大学教授 Christoph

Rehmann-Sutter 认为知情同意原则和胚胎或胚胎细胞的道德问题之间存在显著差别，知情同意原则认为当事人(患者，参加者，家庭成员等)有权享有权利。“我将捍卫一个非主流的，鲜明正当的承认其他人交流自由的普遍主义。”

克隆人是对人类尊严的亵渎

“不管是胚胎干细胞、治疗性克隆、还是生殖性克隆都存在伦理上的争论和问题。”浙江大学教授黄荷凤首先解释了什么是克隆人。克隆人是一种人工诱导的人无性繁殖方式和过程，对以医疗为目的、创建人胚胎干细胞的克隆人技术称为治疗性克隆，而对以复制生命个体为目的的克隆人技术特称为生殖性克隆。

“基于尊重人类尊严的考虑，生殖性克隆涉及的伦理问题是对人类尊严的亵渎和侵犯。”黄荷凤旗帜鲜明地表示，人被“制造”本身就是对人类尊严的一种亵渎和侵犯。人的生殖性克隆发展下去，有可能建立生产人的流水线作业线，婴儿像产品一样被制造和处理，与之相关的供卵和代孕妇女将被工具化和客体化(物化)。如此，会增加对人权和人类尊严损害的风险，甚至导致新的社会问题和不平等。

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Changsha Morning Herald, 2 April 2008



China Hunan Television News, 2 April 2008



CHINA IS POISED TO BECOME THE WORLD'S NEXT SUPERPOWER, LEADING THE WAY IN SCIENCE AND TECHNOLOGY. SO WHY IS THE WEST SO WORRIED?

The US has demanded the world's economy for the past 50 years, but now another country is emerging to claim the role of chief driver of global wealth. A recent study of 23 countries shows that China will overtake the US in the ability to develop those science and technology products and services.

The Irish Tech Industries study prepared every third year for the Central Bank of Ireland in Dublin, shows China leading ahead of the competition over the past 20 years in the number of high-tech patents filed.

The data points to a steady increase in China's capacity to do science and commerce in the West.

While economic sea and space into the decades since the West first recognised Chinese capabilities in research and development, and not just in a competitive sense.

Concerns are being expressed about differences in how science is conducted in the East. There are claims of ethical standards poorer than those in the West.

Research, particularly life-science research, looks over the nations' responsibility ethics committees, which have been set up in many countries.

These raising concerns prior to state jobs in the regulatory control and oversight functions in the East compared to those in the West.

However, there is a strong view of substantial progress with some of the claims, as if China and the Asian Tiger economies have no right to make scientific discoveries faster than the West.

There is also the claim that China enjoys a strong competitive advantage in life-science research, given its less restrictive approach to the use of embryonic stem cells, compared to those in the West.

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要闻 CHANGSHA EVENING A3

精子是否能成商品？代孕如何才能被允许？
百余中外专家
长沙探讨生命伦理

本报讯（记者 唐江澎 实习生 袁婧）精子是否应该是商品？判断精子质量的标准是指供精人的智力、社会地位或是精子活动力？代孕在什么情况下能被允许？昨日，带着生殖技术、治疗性干细胞和干细胞库方面的诸多伦理管理上的问题和挑战，来自中国和欧洲的100多名从事干细胞研究的科学家、医务工作者、伦理学家等齐聚长沙，开展为期3天的国际研讨。

“一对不能生育的夫妇寻求卵子，理想卵子捐赠者年龄在20-29岁之间，至少大学文凭，没有家庭病史、相貌好……报酬在1万元以上。”专家们从这则张贴在北京某大学校园里的广告展开了讨论。专家们表示，捐赠被看作是无私的行为，任何补偿仅仅是基于有关捐赠行为所带来的特殊不适。如果配子捐赠开放于市场，将会使许多人，特别是女性利益受损。然而，在我国，是否对代孕立法提议的问题还没有定论。

在我国，尚未有覆盖辅助生育技术治疗的医保系统，但接受该技术治疗的开销并不小。据介绍，人工受精（采用供精者精液）一般要花费3000-5000元人民币，而体外受精要高出4-5倍，达到2万-3万元人民币。

“然而，一些医疗机构受到不断增长的辅助生育服务需求和潜在的巨大商业利润的诱惑，甘愿冒着被惩罚的危险，在未获得审批的情况下继续提供辅助生育服务。”卫生部科教司副司长于修成表示。临床上也出现了越来越多的具有伦理挑战的病例。

中南大学生殖与干细胞研究工程研究所卢光绣教授表示，仅仅有卫生部制定的关于辅助生育的制度和指导方针还不够，因为它们不仅需要贯彻审核程序，还要强制执行、普及教育和提高公众意识。

湖南自考6个专业
变更主考学校

本报讯（记者 徐媛）昨日，记者从省教育考试院获悉，从今年起，湖南省高等教育自学考试计算机及应用（专科）等6个专业的的主考学校已变更，考生在报考时应注意。

从2008年起，国防科技大学不再担任湖南省高等教育自学考试计算机及应用（专科）、计算机及应用（独立本科段）、计算机信息管理（专科）、计算机信息管理（独立本科段）、计算机网络（独立本科段）和数学（本科）等6个专业的的主考学校。

中南大学担任计算机信息管理（专科）专业、计算机信息管理（独立本科段）专业和数学（本科）专业主考学校；湘潭大学担任计算机及应用（专科）专业、计算机及应用（独立本科段）专业和计算机网络（独立本科段）专业主考学校。从今年起，以上专业的实践环节课程考核均由新的主考学校组织进行。

2008年符合上述专业毕业条件的考生，国防科技大学认可其新的主考学校获得的实践环节课程考核成绩，仍颁发由国防科技大学副署的毕业证书；持有国防科技大学副署的2008年12月31日前颁发的计算机及应用（独立本科段）专业、计算机信息管理（独立本科段）专业、计算机网络（独立本科段）专业、数学（本科）专业本科毕业证书的毕业生，符合申报学位条件者，仍可按相关规定在国防科技大学申办学士学位。2008年12月31日前尚未毕业的的考生将颁发新的主考学校副署的毕业证书。

Innovation section, Irish Times, March 2008 2008

Changsha Evening Newspaper, 2 April

新闻导航

- ▶ 设计院:举行优秀共产党员、优秀共产党员座谈会[05-06]
- ▶ 一亩梅之改革开放巨变三十年 [05-06]
- ▶ “让班级成为学生成长的家园”——记校研建设团辅导工作开展的[05-06]
- ▶ 新闻院:“步步高”党委书记陈志斌莅临新闻院进行实习培训专题讲座[05-06]
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- ▶ 民革湖南大学主委唐元洪蒞临校农副委员长报见[05-05]
- ▶ 重温“五一”号[05-05]
- ▶ 党委统战部开展“五个一”活动纪念“五一”口号60周年[05-05]

2008医学与生命伦理报道研修班在我校举行

来源:宣传部 作者:蒋晶丽 责任编辑:胡琼08
发表时间:2008-04-03 点击数:669

“韩国《朝鲜日报》曾经每天都刊出专版，报道黄禹锡的起居和生活，就象报道一个帝王一样……正是媒体的力量，使黄禹锡成为公众眼中的‘干细胞研究之王’和韩国的‘国家英雄’。”3月31日，在我校举行的“2008医学与生命伦理报道研修班”首场学术报告上，维也纳大学生命伦理学教授哈伯特·戈特维兹（Herbert Gottweis）强调，需科学界的韩国黄禹锡教授造假事件的警示在于：医学与生命伦理报道需慎重！

在由我校科技新闻与科技传播研究所等单位主办的“2008医学与生命伦理报道研修班”上，来自国内外的医学与生命伦理领域的专家、新闻媒体记者聚集一堂，共同研讨医学与生命伦理科学报道的相关问题。同时，包括部分高校宣传部门负责人和我校新闻与传播学院研究生在内共80余人参加了研修。

我校党委副书记梁永玉教授出席开幕式并致词，他首先代表学校对国内外专家以及新闻界朋友的到来表示欢迎，并希望通过此次研修活动，促进不同文化与学术背景的医学与生命伦理学专家和新闻媒体之间的沟通与交流。湖南大学科技新闻与传播研究所所长李浩鸣教授主持研修班开幕式。

本次研修班采用了学术会议的形式，5位专家、教授先后作主题报告，研讨的主要议题包括：生物医学研究与临床实践中典型的伦理问题，中国生命科学伦理研究及实践的法律体系，医疗实践中的伦理问题、生命伦理报道的若干问题等。



HNU News, 3 April 2008

媒体让黄禹锡变“英雄” 医学与生命伦理报道需慎重

<http://news.qq.com> 2008年04月01日14:03 红网 张树忠



(在湖南大学举行的2008医学与生命伦理报道研修班着重关注了医学与生命伦理新闻报道)



April 1, 2008

Ethics of stem cell research brings Chinese and European scientists together

Around 100 Chinese and European stem cell scientists, reproductive medicine practitioners, ethicists, social scientists and legal experts are meeting at a conference from 1-3 April 2008 in Changsha, the capital of the People's Republic of China's Hunan Province. The three-day conference marks the halfway point for BIONET, a Chinese-European Collaboration on the ethics of biological and biomedical research, which is funded by the European Commission. Participants will hear talks from among many others Prof. Lu Guangxiu (Institute of Reproduction and Stem Cell Engineering, Central South University, Changsha), Dr. Stephen Minger (Stem Cell Biology Laboratory, King's College London), Prof. Sheng Huizhen, and Prof. Moustapha Kassem (Medical Biotechnology Centre, University of Southern Denmark).

“We look forward to the future of biomedical technology. People live on the same earth and share in all biomedical outcomes. We need more mutual understanding and respect to seek Great Harmony and to reserve our differences on minor points for the progress of all human beings,” said conference host Prof. Lu Guangxiu, Director of the Hunan Institute of Reproduction and Stem Cell Engineering & Reproductive and Genetic Hospital CITIC-Xiangya.

Stem cell research holds great promise in an ongoing and increasingly global quest for treatments for a number of debilitating degenerative diseases – from muscular dystrophy to Alzheimer's disease and spinal cord injuries. It is hoped that once scientists have understood the self-renewing and ‘pluri-potent’ powers of stem cells (to form into any kind of human cell), they will be able to harness and direct them to treat human diseases which currently have no cure.

Stem cells can be sourced from embryos (human embryonic stem cells), foetuses (e.g. neural stem cells) or adults (e.g. cord blood stem cells); they are manipulated and cultivated in laboratories; with the hope that they can then be transplanted back into human patients in the treatment of degenerative diseases. Each of these stages of research and treatment (sourcing, manipulation and transplantation) embodies ethical challenges, and different countries have responded in different ways. Some countries allow embryonic stem cell research and/or the creation of human-animal hybrids to further research, while others have banned these practices. One of the key tasks for participants at the BIONET conference in Changsha, which has also received financial support from the United Kingdom's Medical Research Council (MRC), will be to examine how international collaboration between

Chinese and European stem cell scientists should be ethically monitored when there are different legal frameworks, ethical norms and cultural understandings involved.

One of the concrete outcomes from the conference will be an interim report from BIONET's Expert Group who are currently working on a set of "guidelines for best practice in the Ethical Governance of Europe-China Research Collaborations in the Life Sciences and Biomedicine". The BIONET Expert Group, which is chaired by Prof. Christoph Rehmann-Sutter, University of Basel (Switzerland) and co-chaired by Prof. Qiu Renzong, Chinese Academy of Social Sciences (Beijing), consists of ten Chinese and European members.

"Collaborations between East and West in biomedicine and biotechnology need collaboration also in bioethics. In sensitive questions of stem cell and embryo research, differences in law and culture exist. But the ethical concerns are not so far from each other," said Prof. Christoph Rehmann-Sutter, Professor of Philosophy and Head of the Unit for Ethics in the Biosciences, University of Basel.

For more information on BIONET please visit: www.bionet-china.org

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Appendixes

List of members of Expert Group:

- Professor Lu Guangxiu, Institute of Human Reproduction and Stem Cell Engineering, Changsha
- Professor Qiu Renzong, Chinese Academy of Social Sciences, Beijing (co-Chair)
- Professor Cong Yali, Peking University Health Science Centre, Beijing
- Professor Zhai Xiaomei, Peking Union Medical College, Research Centre for Bioethics, Beijing
- Dr. Ole Döring, GIGA-Institute of Asian Studies, Hamburg, Germany
- Professor Herbert Gottweis, Department of Political Science, University of Vienna, Austria
- Professor Wolfgang Hennig, Institute of Genetics, University of Mainz, Germany & CAS-MPG Partner Institute for Computational Biology, Shanghai, China
- Professor Genevra Richardson, School of Law, King's College, United Kingdom
- Professor Christoph Rehmann-Sutter, Unit for Ethics in the Biosciences, University of Basel, Switzerland (Chair)

Short description of BIONET:

BIONET is a network of European and Chinese researchers which will work to undertake research, training, workshops and conferences, together with the production of relevant materials and documentation, on the ethical governance of research in the life sciences and biomedicine within and between China and European countries. The project will run from October 2006 to September 2009 and is funded by the European Commission's Sixth Framework Programme (FP6). Website: www.bionet-china.org

Reporting Science – a Satellite Workshop

As a satellite to this conference, the Institute of Sci-Tech Journalism at Hunan National University, Changsha, the BIONET and the SciDev.Net's China Science Reporting Network, together with the Chinese National Research & Engineering Center of Human Stem Cells in Central South University, co-organised a workshop on "Reporting Bioethics" (March 31-April 1, 2008). The event received funding from Bertelsmann Stiftung (Germany) and assistance from China Science Reporting Network.

A total of 53 science and health journalists from seven Chinese provinces, science communicators and journalism graduate students, attended to hear lectures by seven speakers and the corresponding discussions, about reporting medical science and bioethics, with relation to civil society and capacity building.

BIONET had supported this workshop in an attempt to engage in dissemination and capacity building. One of the major findings was that in the area of reporting medical issues, including medical ethics, journalists are enthusiastic, but sometimes they do not get enough information and rely too much on single or doubtful sources. It was stressed that when looking at ethical issues in medical treatment, journalists need to assess the real situation and restraints faced by individual doctors and patients while considering the general ethical principles.

It is obvious, considering the vital role of the public for good governance, that advancing science reporting and understanding between science, the media and the public, is going to require proper attention in the future.



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