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

4th WORKSHOP REPORT

Biobanking & Personal Genomics: Challenges and Futures for EU-China Collaborations

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Introduction and background

Ever since the completion of the first working draft of the human genome was announced in June 2000 by the international Human Genome Project and Celera Genomics Corporation, expectations have been high that novel ways to prevent, diagnose, treat and cure disease would emerge out of 21st century genomic research. While this achievement was a milestone in itself, with China contributing 1% of the total sequencing work as the only developing country involved, a number of developments have since led to a 'step change' in genetic research:

- Sequencing technology has improved drastically – making it faster, cheaper and more accurate.
- Genome-wide association studies (GWAS) have been made possible, relocating genetic inquiry into disease origins from single genes to the entire genome.
- A consensus has emerged that 'single gene' approaches are not appropriate for the study of common complex diseases, (such as cancer, diabetes or heart disease), which are most likely caused by multiple genes interacting with environmental factors.

In the midst of these developments, biobanks have become a crucial resource for geneticists as they seek to translate basic knowledge into preventive, diagnostic and therapeutic applications. At the same time, these developments have also inevitably raised a number of ethical challenges around issues of privacy, informed consent, traceability and feedback of participating research subjects and issues of international collaboration.

It was against this background that around 60 Chinese and European experts gathered in Shenzhen for the BIONET's 4th workshop, for discussions on the topic of 'Biobanks and personal genomics - challenges and futures for EU-China collaborations'. The workshop was hosted by the Beijing Genomics Institute at Shenzhen which has been at the centre of recent breakthroughs in genomic sequencing.

In this report, some of the key discussions held at the workshop in Shenzhen have been summarised, with a particular emphasis on how identified ethical challenges relate to international scientific collaborations.

Banks, repositories or registers?

In many ways, biobanks are nothing new since archives of human biological materials have been compiled and maintained for many years and even decades, for the purposes of teaching, diagnosis, therapy or research. They have differed in terms of the population included (e.g. family, cohort, population or disease-based), the nature and size of the biological specimens (e.g. blood, tissue, urine), context of the collection, form of storage, underlying scientific purpose (e.g. forensics, therapy, research), funding (public, commercial, both), etc. When it comes to 21st century genomics research, biobanks are not just collections

of biological samples (genetic data), but also of related medical records, health data, lifestyle information (gleaned from questionnaires) and sometimes also genealogical information (family history) for whole populations. The commercial implications of the term “bank” have become abundant with the reappraisal of many types of human tissue as a potential powerful resource of knowledge, health and wealth rather than disposable “waste” owing to the advances of the life sciences.

One of the discussions held at the workshop concerned the use of the term ‘bank’ for such collections of biological samples and related information about the sample donors. The term of course has a long history of use in a medical context – tissue banks, organ banks, blood banks, sperm banks, etc., with “bank” being the English term for an institution with a combined portfolio of storing, processing and trading of valuable material, rendering a particular cultural distinction to such establishments. However, some participants argued that this terminology could be confusing and misleading if potential donors were given the impression that they were literally depositing something into a bank which they would later get a return on. Whereas the expectation of serious and effective governance should apply, many participants pointed out that individual benefit from participating in biobank research was likely to be limited at this point in time and would not even be intended by donors or researchers in many cases according to the traditional attitude of altruistic donation for an idealistic or charitable purpose. Moreover, the legal and philosophical matter of ownership itself is disputed in the context of human biological samples. Alternative terms such as ‘biospecimen repositories’ or ‘tissue registries’ were proposed. Julie Schneider from the National Cancer Institute in the US shared the NCI’s working definition:

“a biospecimen resource is a collection of human biospecimens and associated data for research purposes, the physical entity where the collection is stored, and all relevant processes and policies.”

This definition was helpful as it highlighted the different components of biobanks:

- the biospecimens themselves
- associated data (usually stored in the form of databases)

- physical storage site for biospecimens and data
- processes and policies governing their administration, use and maintenance

A point was also made about distinguishing between biobanks according to whether their primary purposes were forensic (e.g. DNA registers for identification in criminal investigations), therapeutic (e.g. organ banks or blood banks) or research. Indeed, Detlef Niese of Novartis argued for the importance of ensuring that potential donors were fully aware of which purposes their biological samples and associated data were to be used for as there had been an exemplary case in Sweden in which a research biobank had been accessed for forensic purposes. Similar cases were reported from other European countries and China. Discussions at the Shenzhen workshop mainly focussed on biobanks, which had been designed and used for genomic-research related purposes.

Samples, samples, samples

In his presentation, workshop host Yang Huanming proclaimed that "we have to sequence more and more individuals! 10,000 in 3 years, 1 million in 5-10 years". A number of projects have been nationally and internationally launched to do just this, such as the 1,000 genomes project which would be a "deep catalogue of human genetic variation" and the 100,000 genome project which is led by George Church with support from Google. The idea is that more statistical power is required to uncover correspondence between complex diseases, genetic variations and environmental factors. As put by Bill Ollier, "access to sufficient numbers of samples with appropriate phenotype is now identified as a major bottleneck in research". Peter Propping reminded of the importance of the phenotype in biobanking as both, a collection of samples and data and "a permanent resource for upcoming (medical / scientific) questions".

Li Jin of Fudan University explained how a baseline investigation in the context of the Taizhou Longitudinal cohort study had been designed and put into practice involving the collection of samples, medical history and lifestyle information from 100,000 donors in Taizhou province. The goal of the baseline investigation was fourfold:

- To describe the mortality and morbidity characteristics of common chronic diseases
- To determine environmental risk factors and life course causes of the common chronic diseases
- To determine genetic risk factors underlying common chronic diseases.
- To determine the contribution by gene-environment interactions underlying common chronic diseases.

Catherine Elliot of the United Kingdom's Medical Research Council described how the UK biobank had over the last years collected 300,000 (out of 500,000) samples and associated

data. Also a cohort study, the project targets 40-69 year olds and consenting participants agree to:

- provide information about health, lifestyle, memory, work and family history
- undergo some physical measurements (including blood pressure, pulse rate, height and weight)
- provide biological samples (including blood and urine)
- allow UK Biobank to access information from individual NHS medical records
- grant consent for researchers to access data samples for uses that meet the purposes of the project ("improving the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses – including cancer, heart diseases, diabetes, arthritis and forms of dementia")

In short, as put by Jan Helge Solbakk, "research needs access to extensive, well-characterized and high quality collections of human biological material and health information: Size matters". In such a context it can only be expected that the number of samples (and associated health-related data) procured for storage in biobanks will continue to increase in the coming years as high power multivariate analyses are required to capture genetic variation. Participants agreed on a cautionary approach to the promises of benefits that should not overlook the speculative grounds of such promises, as to date achievements have been made in the areas of building institutions, infrastructures and cooperation agendas, with hopes for fundamental sciences rather than health for the near future.

These institution building developments raise questions about how biological samples are collected from voluntary donors, what donors are consenting to when providing a sample and medical information, what forms of safeguards should be in place to protect their privacy as well as how any benefits arising from biobank research can be fed back to research participants.

Trust, feedback and consent

In recent years, issues of informed consent and privacy have been considered by many as the key ethical challenges surrounding biobank research. However, there was broad agreement among workshop participants that informed consent procedures, especially when presented in their established forms, were not sufficient tools to ensure ethical research and not the most important ethical issue in biobank research. Some suggested that they could be used as a legalistic 'red herring' and that the "language of informed consent" was simply not appropriate in the context of biobanks (which were by definition collectivising rather than individualising projects), especially not in order to achieve the ethical purposes it intends to serve. Others suggested (especially those referring to empirical social scientific research among donors) that these consent and privacy were not often seen as critical issues by donors. And still others pointed out that regardless of whether individuals took notice of these procedures, they were a mark of minimum respect that was always required of researchers in their contact with research participants.

Some more important ethical issues, it was suggested, concerned: 1) public and the public's trust and support for biobank research, 2) what kinds of risks participants faced, and 3) how

feedback (benefits) to research participants should be conceptualised, communicated and organised.

Christoph Rehmann-Sutter (drawing on work by Haimes & Whong-Barr in the UK as well as Høyer & Linnoe in Sweden) in a presentation on lay reasoning about the ethics of donation, argued for a distinction at least between so-called active participants, cost-benefit participants, passive participants and reluctant participants. Similarly Pascal Ducournau had found in his study of donors to a biobank research project in southern France that one could distinguish between donors with whom trust pre-exists informed consent procedures ("If they do this, they must have a reason"), donors who are not too concerned about the research being carried out ("Not knowing what this research is for, I don't really care… these are doctors, that's what they are there for"), donors who distrusted doctors ("she makes you sign a paper… it's a discharge form!") as well as an 'in-between' group. While 90% of those contacted through hospital services to be part of a case group agreed to participate in the biobank research by providing a blood sample and medical information, 20% of the people didn't read the consent form they were given and 60% didn't ask any questions from their doctor about the study. As a result, he concluded that "trust in biobank activities is not generated by information and consent procedures themselves: trust can be spontaneous, it can be impaired by procedures, or embedded in a more general social trust".

With so much investment going into biobank research, Cong Yali argued that it was time for scientists to make their cases for these investments as a way to ensure public trust and support for this research and also to ensure that these were scientifically worthy projects. Jin Li of Fudan University described how such trust building measures were built into the Taizhou biobank project as "efforts were made to explain the purposes and process of the study to the subjects individually and at community level". He described their 4 step trust-building strategy to mobilise 100,000 research subjects:

More on Informed Consent

- **Step I**: Hit the mass media city-wide (TV, radio, newspapers, internet, etc.)
- **Step II**: Reach the community 3 days before entering
  - Posters on all entrances of each building
  - A manned-booth for questions at community center
- **Step III**: Obtain informed consents at individual level
- **Step IV**: Call back for more questions and a hot line was established.

Reaching the Public

In his presentation on informed consent procedures in scientific efforts to establish immortalized cell lines from different ethnic groups in China, Chu Jiayou explained how they used local national minority languages to communicate with potential research participants

with the support of local minority doctors, village teachers, cadres and sometimes also local religious leaders. This led to a discussion about the context in which research subject recruitment and consenting procedures took place. Margaret Sleeboom-Faulkner in her presentation argued that in some cases "instead of empowering, informed consent can be disempowering if donors do not have the ability to nurture, sustain and develop themselves". For example, a case was cited whereby the setting up of a register for the DNA of tribal communities in India with a view to investigating sickle cell disease was surrounded by "fear of information leaks" as well as a possible "loss of face in the community" (e.g. what if it became known that a family declined to participate?). It was important to always keep scientific objectives of obtaining biological samples within the social and cultural context in which these samples are being procured and obtained. John Telford summarised: "Informed consent is possible but complicated, especially internationally."

In the genomic diversity project among ethnic minorities in China, participants were informed that "If you agree to participate in the study you will be asked to donate a 10 ml blood sample. There are no known risks involved with this study. The collection of blood may cause a small amount of pain." This was similar to the French case where participants were also informed: "Your participation in the study does not involve any particular risk. The blood test corresponds only to the taking of standard blood test." These statements from the informed consent forms generated discussion among participants about risks and benefits of participating in biobank projects. A point was raised that it was wrong to focus simply on the risks related to giving a blood sample, as this did not take account of longer term risks of having DNA samples analysed and stored on file or of risks arising from the information and knowledge arising out of the research and whether or not this would be fed back to participants. It also did not take into consideration possibilities of stigmatisation, discrimination or 'loss of face' if certain details became public (despite assurances of privacy). Here lies a huge task for the ethical governance of biobanks and the related sampling, as there appears to be a close link between the perceived credibility of the institution and the readiness among potential donors to trust.

The questions of trust and risk also came up in Renata Salecl's presentation about forensic DNA databases in which she argued that the cultural capital of DNA had become such that there was perhaps too much faith in DNA as a form of evidence among professional experts. She reminded that DNA evidence in forensic investigation (especially because low quality samples were often used for sequencing) was open to interpretation. And also, as pointed out by a number of participants, it was always possible that medical biobanks could become used in forensic investigations, despite assurances that biological samples would only be used for research purposes. If these assurances were ignored, then trust would be affected. This might have serious impact on the acceptance of biobanks, without appropriate protocols and institutional designs that would regulate the relation between biomedical research and forensic banks in an effective and transparent manner. And finally, Prof. Guo Sunwei pointed out that a certain amount of caution should be maintained regarding the therapeutic prospects of genomic research as trust would be affected if overly high expectations were generated.

On the question of benefits, in the ethnic minorities' project participants confirmed through informed consent forms that they were aware that "you will not benefit directly from participating in this study. However, your participation will benefit the general population by increasing knowledge related to genome diversity and its significance in diseases". And in the biobank research project from southern France, participants were informed that "the participant could not obtain individual results concerning his genome". This resulted in a

vivid discussion about benefits and feedback – what should research participants rightfully and reasonably expect to get out of participating? Jan Helge Solbakk argued that too much emphasis was placed on immediate health benefits. The benefits of the basic knowledge that would emerge through biobank research were often overlooked and, at this stage, were much more pertinent. Moreover, many donors would still claim altruistic motives for their contributing and would expect a governance system that organises the work fairly.

It was also debated whether it was realistic to expect that individualised feedback and benefit sharing was feasible, bearing in mind that larger and larger sample populations were required. Zhang Xiaoyong pointed out that, from a Chinese view, 'benefit sharing' and 'informed consent' belong among the 'missing essentials' for a desirable regulatory and conceptual governance framework; he called for special provisions to target benefit sharing. Some argued that clinically meaningful and significant results should be communicated to research participants through an anonymous automated process, while others questioned whether genomic research had come far enough (when it came to common chronic diseases) to be able to provide clinically relevant information to patients. Another point was made that since donated biological samples are often screened against a number of standard analytic tests, what kinds of clinically meaningful results should be communicated to patients.

Others proposed that biobanks, in the spirit of a "cooperative economic community", should be obligated to make public and accessible all knowledge arising from research carried out using the data and samples from a specific biobank. This could be done in the form of an annual report or a website which was updated regularly. This would mean that any research participant who was interested in receiving this information could find it easily, albeit not specifically addressing the individual case. For example, Catherine Elliot explained how broad benefit-sharing was ensured at the UK biobank by making it obligatory to publish findings and ensure the accessible archiving of data and findings for future use. As she mentioned, this practice is culturally supported in the UK as it relates to the well established Freedom of Information Act. Here lies another significant area for cross-cultural diversities.

In his presentation Jasper Bovenberg explored the possibility that participants might at a later point sue the biobank if they develop the disease under study, by arguing that they were not provided with critical information that would have perhaps helped them prevent developing the disease. This generated a heated debate about what biobanks should be obliged to feedback to individual research participants. Some argued that biobank research was neither diagnostic nor therapeutic, but rather was research and that it was crucial to maintain this distinction. Others questioned whether the legal situation would be similar in other countries, as the UK and the Netherlands would be quite different from legal cultures such as in China or in Germany.

'Sequencing, sequencing, sequencing'

Once samples and data have been collected and stored, the task of analysis begins, whereas storing requires continued data protection and sample quality assurance measures. With genomic research, a first step will be to sequence the collected biological samples as it is correlations between diseases, lifestyle factors and variations in DNA sequences that are the target of genomic studies. Sequencing was the speciality of workshop hosts BGI Shenzhen who are considered among the world's best when it comes to sequencing and bioinformatics capacity. In his presentation titled 'Sequencing, sequencing, sequencing' Wang Jun of BGI

Shenzhen argued that sequencing technology was revolutionising the possibilities for studying the place of genes in disease. Up to now it had been common to carry out single gene studies, but since these lacked genome breadth they were not so useful for common complex diseases. A number of individual genomes had also been sequenced already (e.g. BGI Shenzhen had sequenced and published an Asian individual's genome). Yet while these examples might act as good 'reference genomes' they lacked any kind of explanatory power when it came to disease. In the future, it would be possible to combine the full genome sequences from hundreds of thousands of human subjects with their medical data, making it possible to carry out far more complex calculations. However it was still early days, as for example, 11 validated type 2 diabetes relevant genes only explained 7% of the genetic contribution to type 2 diabetes, so the predictive value remains modest.

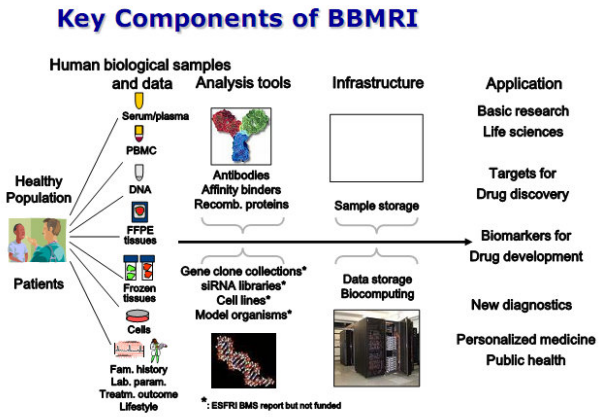
This led to a discussion about the value of genome wide association studies in complex diseases research, as questions were raised as to whether the knowledge made possible by new sequencing technologies would ever be translatable into therapeutic or diagnostic possibilities. Would there ever be health benefits or would it rather be benefits in the form of basic knowledge? The point was made that just because we *can* (sequence) doesn't mean we *should* (prioritise it and use scarce resources to fund it). Guo Sunwei argued that epigenetics was making it clear that one genotype can lead to multiple outcomes depending on life history and that there is a complex system of interaction at stake, which renders many traditional forms of genetic school wisdom obsolete or even misleading. Referring to the current fashion to do GWAS studies, Guo invoked a Confucian saying "When everybody says it's bad, be careful. When everybody says it's good, also be careful."

The falling cost and increasing speed of sequencing technology also meant that the possibility for many people to have their entire genomes sequenced at their own expense was becoming more and more realistic, with a considerable market-potential. This raised a number of ethical questions as it was clear that a market for personal genomics was emerging where individuals could send in a DNA sample and then have their genome sequenced and interpreted by experts who would provide them with health advice. This was a completely unregulated area and questions were raised about how responsible it was to provide people with clinically irrelevant knowledge in a fashion which seemed to present it as clinically relevant. On the other hand, these developments can be anticipated prior to onset, which would allow ethicists and scientists to jointly work towards sound and perhaps innovative ethical governance models.

Databases and harmonisation

A key theme through many of the presentations and discussions was that of how to ensure good quality data as well as how to ensure harmonisation of data recording practices and standards. This latter objective was important since larger and larger populations were required to ensure sufficient statistical power. Moreover, comparable quality standards and an effective infrastructure are crucial for cross-institutional and international collaborations. In a presentation on the European research infrastructure for Biobanking and Biomolecular Resources (BBMRI), Kurt Zatloukal highlighted some of the many related challenges of harmonising biobank research in a European context, pointing out that Europe is about to overcome the stage of isolated and fragmented small and middle sized institutions, building an integrated system of "research infrastructures":

- How should harmonized processes (evidence-based standards) be ensured?
- What incentives were there to contribute to European-scale biobank infrastructures?
- Access rules?
- How to deal with heterogeneous European ethical and legal landscape?
- Data protection in biobanking
- Sustainable funding



Kurt Zatloukal's presentation generated a discussion about harmonisation and standardisation with many workshop participants agreeing with his 'adapter model' as a more appropriate way of thinking about harmonisation. Standardisation in the sense of a 'uniformisation' of data collection methods, of data recording methods as well as of data storage methods on a European scale was impractical and not necessary, therefore it was more useful to agree on standards which samples and data can be combined pragmatically and according to the particular project in question. Notably, this refers to dealing with technical and legal standards rather than with standards of science and ethics.

The challenges of harmonisation and data sharing were especially relevant also for international collaborations beyond Europe. How should such collaborations be monitored and how should access to samples and data be managed if they were shared across borders and continents?

Access – governance and use of biobanks

In his presentation, Bill Ollier of the Centre for Integrated Genomic Medical Research at the University of Manchester spoke of the importance of solid foundations for good biobanks. These included quality assurance systems, access policies and ethical frameworks/ consent. He suggested that as we move away from "primary biobanks" which were small local collections held at different institutes the world over, towards "secondary

biobanks", it was important to view biobanking in terms of a centralised infrastructure. In other words, it was best if those who ran and operated the biobank did not carry out the research but instead had access policies on who would be able to access the samples and data and for what purposes.

For example, UK's biobank was just such a case where the biobank itself was the steward of the resource and legal owner of the database and the sample collection. A Governance and Ethics council decided which research projects would be granted access to the biobank based on criteria of original consent, scientific merit, prioritisation, IP rights, an obligation to return samples / data and also an obligation to acknowledge the biobank.

(Bill Ollier)

In her presentation, Margaret Sleeboom-Faulkner argued that with so many biobanks emerging throughout Asia and Europe, it was important to clarify what governance procedures they were under, which was an arduous task given the poorly developed registration situation in many countries. Her studies indicated that some biobanks were commercially owned, others were public and it was difficult for donors to know what biobanks were doing with their samples. Transparent governance procedures and structures might be a good way to provide some kind of clarity.

Sun Zhongsheng of the Wenzhou Medical College described some of the many challenges his college faced when they recently started to set up a biobank:

- Some consent forms did not strictly follow international standards
- The situation of national standards for China was unclear
- No quality control for some sample collection and processing
- No facilities with the well-controlled environmental conditions to store samples permanently

They also sought to establish standards for operation procedures, including sample collection and preservation, as well as clinical information management. Sun Zhongsheng expressed his hopes, that collaboration with foreign partners would support his institute's efforts towards good governance, especially while domestic regulatory guidance remained weak.

When it came to international collaboration and sharing of samples across borders Guo Sunwei reminded participants of the so-called 'Gene War' where a Harvard scientist was accused of stealing approximately 500,000 DNA samples from China and taking it to the

USA ultimately to profit from it (the "Harvard-Anhui" case from the 1990s, involving Xu Xiping). Guo pointed out that a lot of important information was left out of the debates about 'stealing national DNA'. The assumption was that genes=patents=money. However, in the controversy a few points were conspicuously unmentioned, namely, that the realization of the commercial value can only be in the form of marketable commodities (which has not happened for the most part in genomics research). Also, companies are not the only beneficiaries, patients are too and hunting down disease genes for the benefit of mankind is among the noblest missions that scientists of the world should undertake. He argued that "from a patient's perspective, it really does not matter which country finds the gene and comes up with the therapeutics, as long as he can access it at a reasonable cost and within a reasonable timeframe". Jan Helge Solbakk reminded the discussion of the greater international picture when he recalled that, when discussing the UNESCO's Universal Declaration on the Bioethics and Human Rights in 2005 (Article 21), the US delegates substitute "bio-terrorism" for "bio-piracy", which changed the entire focus and ethical logic significantly, away from the concerns about exploitative research towards certain political stakes.

Hu Yihong described how China had since the 'Gene Wars' put in a place a system in 1998 to manage the human genetic resources of China, which emphasised equality and mutual benefit of international cooperation and exchanges. The Chinese Human Genetic Resources Management Office was responsible for administrative approval of international cooperation projects on human genetic resources and for the acceptance of applications for the export of human genetic resources to other countries. In the period 1999 to 2009, 303 applications had been received and of these 59 had been rejected. Of the 224 approved, 73 projects involved collaboration with European partners. It was recognised in the discussion that the number and quality of EU-Chinese collaboration that will need to undergo this approval procedure would be increasing significantly with the establishing of more powerful biobanks.

Considerations for international collaborations in biobank research

China and Europe, with their internal regional diversities, share the challenges emerging from a new generation of 'secondary biobanks', among other issues raised by life sciences research and social-economic transformations in our globalised and progressively modernising world. At the same time, biobanks present us with an opportunity to anticipate and think ahead, on how ethical governance of biobanks and biobanking-related activities should be organised, within and between the regions. Europe has begun with an ambitious project to install institutional research infrastructures from the vast diversity of small and medium sized individual entities (BBMRI), as a response to requirements for systematic technical collaboration. In China, the current development is twofold: from scattered small and medium-sized facilities on the one hand to infrastructures that are about to be built, in a technologically advanced fashion, basically from scratch. This is the complex institutional structure that needs to be scrutinised when discussing bioethical governance of biobanks in general.

Whereas it was acknowledged that China, and in particular the Pearl River Delta (as highlighted by Stephen Lam from the Hong Kong Science Park and illustrated by Stephen T.S. Lam for clinical genetics in Hong Kong and Ch'ang Lan-yang for the case of Taiwan),

should be seen as an emerging hub in the area of biobanks and the related sciences, the region still faces considerable challenges. Even basic efforts to combine scientific and technological growth with ELSI-related capacity building were felt to be largely absent. There is no orchestrated development plan, no funding scheme and no concept for how to establish good governance; neither within the region nor between the region and Europe. However, notwithstanding the obvious opportunities – the complex administrative situation between special zones such as Hong Kong, Shenzhen and Shanghai (according to the somewhat simplistic slogan, "one country, two systems") require particular efforts of coordination, e.g. when it comes to overarching funding or governance. No concrete steps have been taken from the European side to seek coordinated action to prepare for the future. The initiative is largely left in the hands of scientists with a vision of ethical governance and an understanding about the future of biobanks, which is going to be entirely globalised as Herbert Gottweis suggested.

A major focus in this regard is the possibility of an integrated approach to capacity building, as it was mentioned in the debate: the continued education and training of staff in ELSI matters and the qualification of IRB members in China could be complemented by measures for a better understanding about the differences within and between the regions of China and Europe, to add human skills and good governance mechanisms to technological, economic and scientific capability.

Europe and China share in particular the task to find appropriate ways to develop legal cultures and social cultures of trust that can sustain good science in healthy societies. This will depend substantially on dialogic interaction and the ability to understand and overcome potential conflicts that may result from hard factors such as systemic differences and soft factors, such as different cultures, with their particular languages, world views and morals. Bill Ollier raised the issue of internationally and culturally different ontologies and methodologies of describing the nature of disease, quality and ethical diversity. This constitutes, in Jan Helge Solbakk's terms, a "Babylonic" situation when it comes to combining and building of networks. Though no material answers could be offered as a remedy, the problem itself was identified and placed prominently on the agenda.

In this workshop, basic ethical challenges where brought up again, such as how to maintain human diversity while ensuring fundamental protection of universal ethical standards, how to prevent strong relativism and exploitation of vulnerable populations, how to ensure medical progress without interfering with cultures and lifestyles. Once again, informed consent was disputed, as to whether it was suited to serve its original ethical purpose and how it should be modified. Informed consent symbolises, among others, the communicative practice ingrained in the life sciences, as they involve scientists, physicians, patients, donors, administrations, populations and the public (and other constituencies).

A recurring thread in this final BIONET workshop was to bring special attention to the intricacies of 'translation' and communication in the widest sense, to indicate the nature of

the project of working towards bioethical governance in an international setting. Translation as the process of conversion of text and meaning from one language to another brings together mother tongues, cultures and disciplines; it always requires interpretation of text and context, which may well be sensitive in matters that affect the lives, well-being, existential orientation within our dynamic world of complex markets, basic needs and exciting challenges for the sciences. How to conceptualise this interaction?

In the area of technologies and technical questions “adaptor” metaphors (Kurt Zatloukal, Jan Helge Solbakk) that indicate the need to create interfaces would apply that can combine different systems with their special standards, structures and language, respectively, to interact effectively towards a certain shared task. This would be more feasible than attempting to harmonise the systems themselves, as illustrated by the European developments. Another conceptual approach to “translation” is to distinguish it from forcing the more powerful language system onto a less developed or weaker system, namely “transplantational” approaches, which penetrate and alienate one culture by implanting standards and practices without attempts to accommodate structures and as a result might harm the receiving party or provoke unnecessary conflicts. Translation as an interactive communication process leaves room for gradual changes and sharing of the experiences of working together towards an adaptable and a viable system to sustain biobanks as part of medical science for society. This would be a powerful tool to strengthen social, legal and cultural framing conditions for bioethical governance between the regions.

The topic of biobanks left the workshop with the hope that this debate provides an opportunity to stimulate fresh approaches to the ways in which we discuss and organise bioethical governance.

Media Release

April 30, 2009

Ethical challenges surrounding collection and storage of biological samples for genomic research bring Chinese and European scientists together

Doctors and scientists have for many years kept collections of biological samples. In recent years, developments in genomic research and have led to renewed interest in building up collections of human biological samples – or 'biobanks' as they are known – together with personal information (such as medical history and lifestyle details) about the individuals providing these samples. It is hoped that research made possible by such biobanks will provide valuable knowledge in the fights against cancer, diabetes, and other debilitating diseases.

At the same time, practices of biobanking raise a number of ethical challenges concerning, for example, participating individuals' trust, confidentiality regarding their personal information and the question of who should benefit from commercial gains arising from genomic research.

From 27-30 April 2009, around 60 scientists, social scientists, ethicists and clinicians from Europe and China gathered in Shenzhen for a workshop on the ethics of genomic research and biobanking. Speakers discussed ways to establish best practice to ensure biological sample donors' informed consent, quality control of samples when collected and good storage practices of the samples as well as way to protect privacy of personal information on electronic databases.

"In the future, genomic studies will require many more biological samples and this raises a number of ethical challenges. It is only through international collaboration that we can, not only work more efficiently, but also address ethical issues more effectively," says host of the BIONET workshop, Dr. Yang Huanming from the Beijing Genomics Institute – Shenzhen.

One of the key tasks of BIONET, which is financed by the European Commission's Sixth Framework Programme with support from the United Kingdom's Medical Research Council (MRC), is to examine how international collaboration between Chinese and European life scientists should be ethically monitored when there are different legal frameworks, ethical norms and cultural understandings involved.

"With biobanking, we have the opportunity to organise issues of ethical governance while this new technology is developing, rather than after", says Dr. Ole Doering, BIONET partner and co-organiser of the Shenzhen workshop.

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. One of the concrete outcomes of the network will be a set of "guidelines for best practice in the Ethical

Governance of Europe-China Research Collaborations in the Life Sciences and Biomedicine".

For more information on BIONET please visit:

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生物学和生物医学研究的伦理管理研讨会在深圳召开

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应深圳华大基因研究院的邀请，生物中心组队赴深圳参加了由欧盟第六框架合作研究计划支持的“BIONET”项目关于生物学和生物医学研究的伦理管理研讨会。生物中心副主任贾丰出席开幕式并讲话。

该项目是由21位来自中欧各国的科学家、伦理学家、法学家、社会学家、政治学家、人类学家和哲学家等共同参与的国际合作交流项目。来自英国、德国、法国、美国、丹麦等16个国家和地区的30多位外国专家及国内相关研究机构共60多位专家学者就生命科学和生物医学方面的伦理管理进行了研讨和交流。生物中心相关工作人员应邀在研讨会上就中国的人类遗传资源管理向与会代表作了报告。

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华大基因研究院成功承办BIONET第4届研讨会

2009年 04月 30日 18:18 盐田网

盐田讯（深圳报业集团特派记者 匡文）由深圳华大基因研究院承办的BIONET第四届研讨会于2009年4月27日至30日成功举行。来自60余位中欧各国的科学家以“生物样品库和个体基因组学研究的伦理管理”为主题，展开了积极讨论，并共同探讨中欧合作的前景和面临的挑战。

最新新闻

由深圳华大基因研究院承办的BIONET第四届研讨会在深圳举行

2009年04月30号

2009年4月27日到2009年4月30日由深圳华大基因研究院承办的BIONET第四届研讨会：“Biobank和个体基因组学——中欧合作的前景和挑战”在深圳举行。

BIONET，“生物学和生物医学研究的伦理管理：中欧合作”(Ethical Governance of Biological and Biomedical Research: Chinese-European Co-operation)项目，是由欧盟第六框架计划资助的、由21位来自中欧各国的科学家、伦理学家、法学家、社会学家、政治学家、人类学家和哲学家等共同参与的国际合作交流项目。近60余位国内外专家参加了BIONET第四届研讨会，与会者就生物样品库和个体基因组学研究的伦理管理展开讨论，并共同探讨中欧合作的前景和面临的挑战。2009年4月28日下午，BIONET第四届研讨会会长专访了深圳华大基因研究院。

2009年4月30日下午，BIONET第四届研讨会举行了新闻发布会。发布会上，BIONET研讨会中方主席杨焕明院士、BIONET伙伴及深圳研讨会欧方主席Ole Doering博士等就媒体提出的伦理管理相关问题进行了解答。

盐田新闻 多媒体数字版

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中欧科学家聚深研讨生物伦理

贾少强

【本报讯】(记者 贾少强)4月27日至30日，来自中欧的60余名科学家、社会学家、伦理学家及临床医生聚集在深圳大梅沙，就个体化基因组研究及“Biobank”的伦理问题召开研讨会。与会者就保证生物样品信息捐献者在捐赠样品之前得到充分信息、知情同意过程完整，样品质量能够保证“利人而不损己”，实验室中样品存贮和个体化数字档案得到足够的重视等问题进行探讨。

Biobank，是指生物资料库、生物信息库，包括收集生物样本(细胞、组织、器官等)，以及与个人健康相关的信息。

研讨会的中方主席、中科院院士、深圳华大基因研究院的杨焕明博士认为，基因组研究需要更多的民众支持和更多的生物样品及信息，通过与欧盟建立国际性合作，将更好地促进基因研究与发展。

BIONET是由欧盟第六框架及英国医学研究委员会(Medical Research Council)资助的跨国、跨学科合作研究项目，其关键任务之一是解答当法律体制、伦理标准、文化理解存在差异时，如何从伦理上对中欧科学合作予以更好的监督的问题。

深圳仙湖植物园 Fairylake Botanical Garden

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仙湖通讯

BIONET“生物学和生物医学研究的伦理管理——中欧合作”项目第四届研讨会在我园召开

[返回]

4月28日下午，BIONET“生物学和生物医学研究的伦理管理：中欧合作”项目第四届研讨会“生物样品库和个体基因组学——中欧合作的前景和挑战”在我园召开，来自我国和欧盟的60余位专家参加了此次会议。

该项目由欧盟第六框架计划资助、为期三年，计划通过两次大会及四次研讨会，在中国和欧盟的生命科学和生物医学合作领域建立对话与交流的共同伦理框架。项目自2006 年启动以来，已分别在北京、上海和西安召开了三次研讨会，第四次研讨会于2009年4月28日至30日在深圳举行，我园是本次会议会场之一。

会上，上海交通大学医学院妇产科研究所所长郭养林和法国J.F Chanpollion与Toulouse大学高级讲师、社会学家Pascal Ducournau分别作了题为《本世纪的基因故事和一些经验体会》、《信任、伙伴与联合生产：研究生物样本库和捐献者之间的关系》的会议报告，并与与会人员进行了深入交流。

在我园科普负责人金红博士的带领下，与会人员参观了我园苏铁种质资源保护中心、原生植物区和古生物博物馆。（撰稿人：杜杰；摄影：林才，编辑：何晓银）

Programme

Monday April 27, 2009

Day 1: Working Towards the Good Governance of Biobanking and Genomics

Session1: Opening Ceremony **Chair: YANG Huanming**	
8:30 - 8:40	**Welcome Speech** Representatives from MOST and China National Centre for Biotechnology Development ***Ole Doering*** Introduction of BIONET
8:40 - 9:00	***Nikolas Rose*** Ethical Governance of Biobanks and Genomic Research - An Introduction
Session 2: Governance of Good Practice in the European Biobanking Sphere **Chair: Herbert Gottweis, SHEN Jianlei**	
9:00 - 9:20	***Catherine Elliott*** Governance of Biobanks - Some Models from the UK
9:20 - 9:40	***Kurt Zatloukal*** The Pan-european Research Infrastructure for Biobanking and Biomolecular Resources (bbmri)
9:40 - 10:00	***Bill Ollier*** The Role and Future of Human Biobanks in Post-genome Research
10:00 - 10:20	**Discussion**
10:20 –10:40	**Tea Break**
Session 3: Governance of Good Practice in the Chinese Biobanking Sphere **Chair: JIA Feng, Peter Propping**	
10:40 - 11:00	***ZHAN Qiming / 詹启敏*** The Development of Biobank for Cancer Research in China
11:00 - 11:20	***Stephen T.S. Lam / 林德森*** Prospects of Biobanks in Hong Kong
11:20 - 11:40	***Lan-yang Ch'ang / 常兰阳*** Biobank in Taiwan
11:40 - 12:00	**Discussion**
12:00 - 13:30	**Lunch in Coast Cafe**

Session 4: Governance of Good Practice in the International Scientific Research Biobanking Sphere **Chair: Genevra Richardson, ZHANG Zhibin**	
13:30 - 13:50	***Howard Cann*** The Foundation Jean Dausset-CEPH: Research Resources and Research.
13:50 - 14:10	***Julie A. Schneider*** Ethical, Legal, and Policy Recommendations for Biospecimen Resources: Experience from the U.S. National Cancer Institute Best Practices
14:10 - 14:30	***LV Youyong / 吕有勇*** Current Status and Prospect of Cancer Genomics and Biology in China
14:30 - 14:50	Discussion
14:50 - 15:10	**Tea Break**
Session 5: Governance of the Bioscience Industry **Chair: QIANG Boqin, Wolfgang Hennig**	
15:10 - 15:30	***Detlef Niese*** Biobanks in Globalized Drug Development
15:30 - 15:50	***Frederick C. Dubee*** Biotechnology and the Global Crisis: challenge and responsibility
15:50 - 16:10	**Discussion**
16:10 - 16.30	**Tea Break**
Session 6:The State-of-the-art Biobanking and Genomic / Genetic Research **Chair: WANG Zhen, Margaret Sleeboom-Faulkner**	
16:30 – 16:45	***WU Fan / 吴 凡*** 生物样品库和流行病学研究 / Biobank and Epidemiology Research
16:45 – 17:00	***SUN Zhongsheng / 孙中生*** Establishment of Biobank at Wenzhou Medical College.
17:00 - 17:15	***LI Shengbin / 李生斌*** Construction and Management of Biologic Bank for Forensic Research and Individual Identification
17:15 - 17:30	***WANG Jun / 王 俊*** Sequencing, Sequencing and Sequencing

17:30 - 17:45	***John L. Telford*** Molecular Epidemiology of Infectious Diseases
17:45 - 18:10	**Discussion**
18:30 - 20:00	**Welcome Dinner** **Welcome Speech by *Dr. WANG Jian***

TUESDAY April 28, 2009

Day 2: Challenges Raised by Biobanking and Genomic / Genetic Research

Session 7: Scientific and Ethical Challenges
Chair: Ayo Wahlberg, LU Guangxiu

9:00 - 9:20	***QIU Renzong / 邱仁宗*** Any Difference? Ethical Concerns Arisen From BioBanks
9:20 - 9:40	***Christoph Rehmann-Sutter*** Lay Reasoning About the Ethics of 'Donation' for Gene- and Biobanks
9:40 - 10:00	***Peter Propping*** Biobanks for Genetic Research: Chances, Needs, Responsibilities
10:00 - 10:20	***CHU Jiayou / 褚嘉佑*** "Informed Consent" and Establishment of Chinese Different Ethnic Groups' Immortalized Cell Line Bank
10:20 - 10:40	**Discussion**
10:40 - 11:00	**Tea Break**

Session 8: Social Challenges Raised by Biobank and by Its Applications
Chair: QIU Renzong, Renata Salecl

11:00 - 11:20	***Jan Helge Solbakk*** Should Biobank Regulation Be Harmonized?
11:20 - 11:40	***Pascal Ducournau*** Trust, Distrust and Co-Production: The Relationship Between Research Biobanks and Donors
11:40 - 12:00	***Renata Salecl*** Case Study : The Use of Biobank in Forensics
12:00 - 12:20	**Discussion**
12:20 - 13:30	**Lunch in Coast Cafe**

13:30 – 14:00	**Drive to Fairylake Botanical Garden**
Session 9: Social Challenges Raised by Genomic / Genetic Research **Chair: Lars Bolund, WU Fan**	
14:00 - 14:10	***YANG Huanming / 杨焕明*** Introduction and Appreciation of the Afternoon Host
14:10 - 14:30	***GUO Sunwei / 郭孙伟*** The "Gene War of the Century" and A Few Lessons Learned
14:30 - 14:50	***Margaret Sleeboom-Faulkner*** Biobanking in Transnational Perspective
14:50 - 15:10	***WANG Zhen / 王 震*** 基因专利与惠益分享 / Genetic Patenting and Benefit Sharing
15:10 – 15:30	**Discussion**
15:30 - 17:00	**Site Sight & Tea Break & Pictures**
18:00 - 19:30	**Dinner in Fairylake Botanical Garden**

WEDNESDAY April 29, 2009

Day 3: Translational Bioscience and Its Future

Session 10: Legal / Regulation Challenges **Chair: Ole Doering, CONG Yali**	
9:00 - 9:20	***ZHANG Xiaoyong / 张小勇*** 人类遗传资源研究中的惠益分享：国际经验与中国的立法选择 / Benefit Sharing in the Human Genetic Resources Research: International Experiences and Chinese Legal Choices
9:20 - 9:40	***Jasper Bovenberg*** Biobank Research: Towards An Obligation to Offer Results to Individual Participants?
9:40 - 10:00	***HU Yihong / 胡忆虹*** 中国人类遗传资源的管理 / The Management of Human Genetic Resource in China
10:00 - 10:20	**Discussion**
10:20 – 10:40	**Tea Break**
Session 11: Application and Translation of Bioscience Research **Chair: Howard Cann, ZHAI Xiaomei**	

10:40 - 11:00	***Lars Bolund*** Integrative Medicine - a Sino-Danish Perspective on Data Driven Research, Biobanks and Personalized Medicine.
11:00 - 11:20	***Wolfgang Hennig*** General Implications of Genome Research for Society and Governance in Sino-EU collaborations
11:20 - 11:40	***Stephen Lam / 林 挺*** Hong Kong Science Park – Where Research Gets Connected to Application
11:40 - 12:00	**Discussion**
12:00 - 13:30	**Lunch in Coast Cafe**
Session 12: Visions and Perspectives for Biobanking and Genomic Research Chair: Christoph Rehmann-Sutter, SU Yeyang	
13:30 - 13:50	***Andrew T. Chen*** Biobank: Present and Future
13:50 - 14:10	***JIN Li / 金 力*** 泰州队列：建立一个可共享的前瞻性队列资源 / Taizhou Study: a Prospective Cohort for Sharing
14:10 - 14:30	***Herbert Gottwets*** Biobanks: Success or Failure?
14:30 - 14:50	***YANG Huanming / 杨焕明*** Personal Genomics: New Medical Era and New Bioethical Challenges
14:50 - 15:10	**Discussion**
15:10 - 15:30	**Tea Break**
Session 13: Advance the EU-China Biomedical / Biological Co-operative Research Chair: YANG Huanming, Nikolas Rose	
15:30 - 15:50	***Ole Doering*** Summarizing the Interdisciplinary Discussions in this Workshop
15:50 - 16:10	***SU Yeyang / 苏夜阳 (Monitory)*** Brainstorming for Extra Inputs for Later Discussion
16:10 - 16:40	**Discussion 1: Challenges and Opportunities of Biobanking & Personal Genomics Research in General**
16:40 - 17:20	**Discussion 2: Challenges and Opportunities of EU-China Bioscience Collaborations**

Session 14: Closing Ceremony	
17:20 - 17:40	Closing Remarks from representatives from NASF, CAS, YANG Huanming and Nikolas Rose
17:40 –18:00	Certificate of Participation
18:30- 20:00	**Closing Dinner at the Moon Light Bar on the Dameisha Beach**

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