Media Release

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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".

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BIONET Expert Group

DNA-Sequencing and biobanks: a hot topic for the ethics of European-Chinese research collaborations

The Expert Group, an interdisciplinary body of 10 members set up under BIONET, is about to develop recommendations for ethical governance of Chinese-European research collaborations. It will treat different cutting-edge biomedical research fields including biobanks, clinical trials, reproductive medicine and stem cell research. It works on the basis of the information gathered in a series of workshops and conferences that have been organized by BIONET in different cities of China.

The BIONET Expert Group was constituted at a meeting in Beijing in Spring 2007 and works until September 2009. It is composed of scholars from the fields of medicine, ethics, law, political science and social science. The group works towards guidelines for best practice in governance of collaborative research between China and Europe. It also fosters mutual understanding and, in the course of its work, provides opportunities to learn from each other. Results will be made public in draft form at the final conference of the BIONET project that will take place in September 2009 in London. There they shall be openly discussed. The draft will then be revised and the recommendations will be published in an easily accessible form soon thereafter.

In international research collaborations between European countries and China different laws and regulations come together and can create regulatory discrepancies or unclarities. The main goal of the BIONET Expert Group is to ensure that patients and participants or other affected persons in China and elsewhere are not put under undue risks or burdens due to such international research collaborations. The protection of the rights and the well-being of all research participants in research is the first concern of the group.

A second goal is to encourage research integrity. This means that only reliable and accurate research practice can be acceptable ethically.

A third goal is to contribute to a good regulatory environment of international research in China and Europe. In the age of huge international drug trials, exchange of biomaterials like stem cells or tissues over the national boarders, huge linked data and DNA banks etc., collaborative international research is becoming more and more crucial, not just for scientific progress but above all for developing medicine for yet untreatable diseases and for improving general health care.

In biobanking and genomics research – the topic of the Shenzhen workshop – those concerns unique to this type of research were identified and reflected upon. It is generally agreed that informed consent by participants is a necessary prerequisite. But what does this consent include? Is it a simple procedure, essentially signing a consent form? Or does it include more substantial and ongoing participation? Should participants be re-contacted and re-informed if the samples they have given earlier will be used for another research purpose? Should participants receive feedback of data about their own genes, even if the findings are still under research? Which are the essential elements that build justified trust? And which are the treats that would undermine this trust? How should international collaborative biobanking be regulated? These and other questions have been tackled at the workshop.

The Expert Group is chaired by Christoph Rehmann-Sutter, a Professor of bioethics at the University of Lübeck, Germany. 2001-2009 he was President of the Swiss National Advisory Commission on Biomedical Ethics. It is co-chaired by prominent Chinese bioethicist Professor Qiu Renzong of the Chinese Academy of Social Sciences (Beijing) and includes Professor Lu Guangxiu, director of the Institute of Reproductive & Genetic Engineering (Changsha), Professor Zhai Xiaomei, Research Centre for Bioethics at Peking Union Medical College, and Professor Cong Yali, Peking University Health Science Center, Professor Herbert Gottweis, a political scientist of University of Vienna (Austria) Professor Wolfgang Hennig, a geneticist at University of Mainz (Germany), Professor Genevra Richardson, a lawyer at King's College, London, Dr. Ole Döring, a philosopher at the German Institute of Global and Asia Studies, Hamburg and Professor Margaret Sleeboom-Faulkner, an anthropologist at Sussex University (UK).