



GFBR9 AUCKLAND, NEW ZEALAND, 3-5 DECEMBER 2008

ETHICS OF RESEARCH INVOLVING INDIGENOUS PEOPLES AND VULNERABLE POPULATIONS

The GFBR9 scientific programme was developed with the metaphor of the *Pōwhiri*. It is a Māori ceremony of welcoming visitors to the land, which sequence encapsulates the sharing and exchange of various experiences and information, and in the process forging peace and friendship. The three day programme is intended to progress as follows:

Day 1 is guided by the *Pōwhiri*—the rituals of encounter—and will be keynoted by a discussion of issues for Indigenous Peoples and vulnerable populations in research in New Zealand and an introduction of the *Pōwhiri* framework as a metaphor for the process of research.

Day 2 is guided by the *Whaikorero*

and *Koha*—speech making and reciprocity. It will open with a plenary discussion on the interface of traditional knowledge system with ‘western’ science; a concept that will be discussed by various case presentations from all over the world.

Day 3 is guided by the *Hongi* and *Kai*—becoming one breath, one mind, one spirit, moving from darkness into light, feeding the spirit of future generations. This, being the last day, is intended to be the coming together of lessons learned in this meeting and at the same time a preparation for future collaborations.

Details about the GFBR9 programme and case presentations are available at <http://gfbr9.hrc.govt.nz/index.php/programme>.



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Hongi is the tradition of nose pressing, embodying the exchange of the *ha* (breath of life). In this portion of the *Pōwhiri*, and with this exchange, one is no longer considered *manuhiri* (visitor) but rather *tangata whenua*, one of the people of the land.

Photos, video, and information from Tourism New Zealand at <http://www.newzealand.com/travel/about-nz/culture/powhiri/powhiri-introduction.cfm> More information on *Pōwhiri* at <http://www.maori.org.nz/hikanga/default.asp?pid=sp41&parent=39>

VULNERABLE POPULATIONS IN RESEARCH



Vulnerable people cannot protect their own interests. Justice requires that “research be responsive to the health conditions or needs of vulnerable subjects.” (CIOMS, 2002)

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The protection of vulnerable communities and individuals against exploitation and harm in research is a responsibility borne by the various stakeholders of research and required by most national and international normative instruments. Since its incorporation in many international and national guidelines worldwide, much has been written about its definition and coverage. However, there is no evidence that this protection is in place or how specific infrastructures, networks, or setting can actually contribute to or enable its fulfilment.

The term ‘vulnerable population’ is broad and can apply to a large number of groups who find themselves marginalised, different to the majority and under-represented in discussions about matters that concern them. GFBR9 focuses on those groups who are ‘vulnerable’ because they are migrants or refugees, and will attempt to formulate ways to enhance representation of these groups in research and research ethics.

For references or reading materials, please consult the GFBR9 homepage at <http://gfbr9.hrc.govt.nz/index.php/home>

FORUM UPDATES

- ❖ **GFBR8** Photo gallery http://www.gfbronline.com/eighth_Photo_Gallery/1%20Opening%20Page.htm CD is available upon request to realpe@cohred.org
- ❖ **GFBR9**: An overwhelming number of applications were received, notably from countries that have not participated in previous GFBR meetings. Successful applicants are now being contacted.
- ❖ **GFBR10** will be held in September 2009 in Santiago, Chile

GFBR9 SATELLITE MEETINGS

1-2 December 2008, Auckland, New Zealand
- for confirmation -

UNESCO Ethics Education Workshop

Contact: Darryl Macer at rushsap@unescoibkk.org

WHO/IVR & UNAIDS AAVP Ethics, Law, & Human Rights

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GFBR-SECRETARIAT NEWSLETTER

2008 - 02

GFBR10: ETHICAL ISSUES ON CONFLICTS OF INTEREST IN HEALTH RESEARCH

GFBR10 will be held in Santiago, Chile in September 2009. This marks a special milestone since the event will be hosted by the Ministry of Health Chile, which played a pivotal role in the development of research ethics in the country. GFBR10 will be held in collaboration with two important stakeholders: Centro de Investigación en Bioética y Salud Pública (CIBISAP), Universidad de Santiago and the Centro de Estudios de Ética Aplicada (CEDEA), Universidad de Chile.

The theme chosen for GFBR10, conflict of interest in research involving human beings, promises to generate intense and productive debates. The forum intends to go beyond simple discussions and definitions denouncing conflicts that are already recognized by all. Instead, GFBR10 aspires to arrive at constructive points that would contribute to the improvement of bioethical governance of research around the world, particularly from the perspective of developing countries and transition societies. To ensure a comprehensive and in-depth discussion, stakeholders all over the world are invited to prepare and submit case studies on all aspects of conflict of interest in health research.



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The city of Santiago in Chile welcomes the 10th Global Forum on Bioethics in Research meeting to discuss conflict of interest in health research

Details for case submissions will be in the call for applications to attend GFBR10.

SECRETARIAT TEAM UPDATES

Xiuqin Wang left Geneva in mid-March 2008 and resumed her position as member and secretary of the Ethics Review Committee (ERC) in her home institution in Nanjing. In June 2008 she completed her Doctorate Degree in Clinical Pharmacology from the Nanjing University of Traditional Chinese Medicine, and has been involved in both national and provincial health research ethics initiatives. For Xiuqin, the fellowship at the GFBR-Secretariat enabled her to better participate in regional and national activities in health research ethics, and the networking experience in Geneva positively impacted her home institution in international academic exchange.

Sandra Realpe attended the 10th Annual Workshop on Ethical Issues in International Health Research at the Harvard School of Public Health in June 2008. Sandra is a member of the scientific committee of the *First Meeting for the Eastern Mediterranean and Arab Forum on Bioethics in Research* to be held in Cairo from 12 to 14 August 2008. More information regarding this meeting is available at <http://www.emro.who.int/bioethics/>.



Sajida Perveen provides administrative support to the GFBR website. Sajida has been a Software Designer at Aga Khan University (AKU) since 1998, involved in developing and maintaining customized automated internet/intranet solutions. She holds a Bachelor of Engineering (BE) Computer Systems degree.

Danny Edwards is now working as a policy officer at the Human Fertilisation and Embryology Authority (HFEA) in the United Kingdom. In this capacity he feels extremely lucky to be using his academic background in bioethics, and the experiences gained at the GFBR-Secretariat in a role which feeds directly into policy, and hopefully makes a positive impact both for people seeking fertility treatment, and for scientists conducting research into disease. The skills he learned in applying the theory of bioethics to practical situations have proven invaluable, as have the enhanced skills for presentation, research and networking during his time as a Fellow.

Edlyn Jimenez-Santos has been assisting in the work of the GFBR-Secretariat since her arrival in April 2008. On occasion, she has been invited to participate in WHO/TDR informal consultation workshops on various areas of bioethics. She was also given the chance to be an observer in a WHO/ERC meeting. Edlyn will visit GFBR partners in September 2008 to visit bioethics centres of excellence in Europe.

Our GFBR Web Team



Muhammad Sajid Khan created and now maintains the GFBR Website. He has been a Senior Programmer Analyst at Aga Khan University (AKU) since 2002, responsible for managing AKU internet and intranet websites. Sajid has a bachelor's degree in Computer Science and a master's degree in Business Administration.

GFBR PARTNERS AND CONTACT INFORMATION

GFBR Current Partners: Aga Khan University, Pakistan; Canadian Institutes of Health Research (CIHR-IRSC); European and Developing Countries Clinical Trials Partnership (EDCTP), Netherlands; Facultad Latinoamericana de Ciencias Sociales (FLACSO), Argentina; Health Research Council of New Zealand (HRC); Institut National de la Santé et de la Recherche Médicale (INSERM), France; Medical Research Council, United Kingdom (MRC-UK); National Institutes of Health-Fogarty International Center (NIH-FIC), USA; Vilnius University, Lithuania; Wellcome Trust, United Kingdom; World Health Organisation (WHO); and the Council on Health Research for Development (COHRED), Switzerland—which acts as host for the Secretariat of the GFBR.

For further information please contact: Sandra Realpe, Ethics Officer, GFBR-Secretariat realpe@cohred.org tel +41 22 591 89 00 fax +41 22 591 89 10 www.gfbronline.com c/o the Council on Health Research for Development (COHRED) 1 - 5 Route des Morillons P.O. Box 2100 1211 Geneva 2 Switzerland. The secretariat is funded by the European Commission within its FP6 Programme.