

# Ethics of Research Involving Indigenous Peoples and Vulnerable Populations



**GLOBAL FORUM**  
On Bioethics in Research



**Report of the Global Forum  
on Bioethics in Research**  
Ninth Annual Meeting

Auckland, 2008



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This report was integrated by Joseph Millum (NIH/FIC) from reports on sessions on Day 1 written by Nicole Mamotte, Day 2 by Jennifer Koen, and Day 3 by Zaynab Essack. The report was finalised by Edlyn Jimenez-Santos (GFBR Ethics Fellow).

## **PREPARED BY THE GLOBAL FORUM ON BIOETHICS IN RESEARCH SECRETARIAT**

Joseph Millum  
Fellow  
Department of Bioethics  
National Institutes of Health

Nicole Mamotte  
WHO/UNAIDS African AIDS Vaccine Programme's Ethics, Law and Human Rights  
Collaborating Centre  
University of Kwa-Zulu Natal

Jennifer Koen  
South African AIDS Vaccine Initiative's (SAAVI) HIV/AIDS Vaccine Ethics Group (HAVEG)  
University of Kwa-Zulu Natal

Zaynab Essack  
South African AIDS Vaccine Initiative's (SAAVI) HIV/AIDS Vaccine Ethics Group (HAVEG)  
University of Kwa-Zulu Natal

Edlyn Jimenez-Santos  
Fellow  
Global Forum on Bioethics in Research

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## Day 1 3 December 2008

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<b>Chair</b>	Clive Aspin
<b>Rapporteur</b>	Nicole Mamotte

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### Mihi Whakatay/Welcome

<b>Speakers</b>	Professor Graeme Fraser – Aotearoa/New Zealand His Excellency, The Hon. Anand Satyanand - Aotearoa/New Zealand
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During the opening ceremony representatives from local Māori Iwi / tribe Ngati Whatua performed a Whakatau (Māori Greeting Ceremony). Naida Glavish explained that the various elements of the Whakatau serve to unite both guests and host in an environment of friendship and peace and to protect them during their meeting. Professor Graeme Fraser introduced the Governor General of New Zealand, His Excellency, The Honorable Anand Satyanand.

The forum was officially opened by The Honorable Anand Satyanand. He stated that research can be successfully conducted between researchers and Indigenous People, and research using western technologies can enhance indigenous knowledge. For example, Māori researchers have used GPS technology to map sacred sites; this was beneficial to the wider community as it ensured that location was appropriately considered in decision making. However it was noted that successful collaboration between researchers and Indigenous People requires active involvement and extensive consultation. The Honourable Anand Satyanand stated that the promotion and maintenance of the highest ethical standards is a high priority for the Health Research Council of New Zealand and that a major conference addressing ethics in Indigenous and vulnerable populations is timely and relevant.

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### Plenary Presentations

Clive Aspin welcomed and introduced the plenary speakers

<b>Plenary Speaker</b>	<b>Bioethics, Indigeneity, and Māori Experience</b> Mason Durie - Aotearoa/New Zealand
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Mason Durie's presentation highlighted the areas in which ethical understandings are challenged by differing world views and approaches to research. He noted that Indigenous world views do not always fit with Western science and scientific research protocols. He emphasized the need for recognition of Indigenous vulnerability and of the positive contributions made by Indigenous knowledge systems.

Durie introduced three characteristics of indigeneity: ecological ties, human encounters, and autonomy and self determination; he outlined three corresponding areas of ethical understanding. First, the ethics of eco-connectedness explores the relationships between people and their natural environment. Researchers should consider how research can balance human and environmental needs, human adaptation to the environment, and species survival. Second, the ethics of engagement considers the significance of boundaries and reciprocity as guides to ethical behaviour. In the Māori case, this should include consideration of the reasons for engagement with Māori, whether trusting relationships can be built as opposed to one-off encounters, and the ownership and management of data. Third, the ethics of empowerment includes an obligation to shift Indigenous participation

in research from passive participatory roles to active leadership. This requires informed consent, active participation of Indigenous People, and guardianship of research integrity, research data and indigenous environmental interests. Durie concluded that promoting the ethics of indigeneity requires shifting researchers' attitudes and indigenising ethical standards and protocols.

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**Plenary**                      **Research Issues for Indigenous populations**  
**Speaker**                      Karina Walters – United States of America

Karina Walters detailed the historical and contemporary bioethical research concerns facing indigenous communities. Indigenous researchers and communities have much to contribute, she argued, but face barriers to scientific success and to having their ethical concerns recognised. In order to move forward Karina Walters stressed the importance of decolonising and indigenising the research process. To guide the development of mutually beneficial research partnerships with indigenous communities, she suggested eight principles for decolonizing and indigenizing research: reflection, respect, relevance, resilience, reciprocity, responsibility, retraditionalization and revolution.

Reflection involves an ongoing process of self-awareness of research partners' privileged status in society and of emotional reactions to the misery that native peoples have endured since colonization and that many continue to confront every day. Respect requires that research partners value indigenous epistemologies, knowledge, cultural protocols, and healing practices. Indigenous "scientists" and expert knowledge already exist within Indigenous communities and should be involved throughout the research partnership. For research to be relevant, researchers must actively engage the community from the earliest conception of the aims of the project. In terms of the principle of resilience, research with Indigenous communities should acknowledge the community's resilience in the face of multiple assaults on tribal autonomy and integrity. The principle of reciprocity should govern the research partnership, which should be collaborative and mutually respectful, with knowledge exchanged in both directions. Responsibility requires that researchers acknowledge their privileged status vis-à-vis community members (e.g., educational and socioeconomic privileges). Research partners have the responsibility of disseminating research findings in culturally meaningful ways and must anticipate the implications of their findings. The principle of retraditionalization involves incorporating traditional knowledge and methods into the formulation, implementation, dissemination and evaluation of research projects. Lastly, truly indigenized research collaborations involve revolution. Research partners and community members, by actively seeking to decolonize and indigenize the research process, can transform the structure and nature of knowledge production.

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**Plenary**                      **Vulnerability in Research**  
**Speaker**                      Bebe Loff - Australia

Bebe Loff examined the research carried out by Jewish doctors during the Second World War while incarcerated in the Warsaw Ghetto and in Vapnicarca, a concentration camp in what is now the Ukraine. Both the doctors and their research participants were denied all basic human rights and shared conditions in which their lives were at daily risk. In her examples of research, the ethical standards and nature of practice we have constructed are

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unlikely to have been observed by those researchers. Informed consent, as we understand it, might not have been obtained. While confidentiality was probably respected, a significant reason for doing so would have been the fear of being murdered, should the work be discovered. In addition, the research was conducted when it was unlikely that the results would be published or disseminated. The research was carried out amongst populations who would not ordinarily be considered to be suitable populations for research. According to Loff, this research, which today would be considered to breach many ethical guidelines, was ethical and, indeed, heroic. The researchers demonstrated deep solidarity with the communities in which the research was undertaken; today we need to find ways in which it might be possible to understand and operationalise a requirement for solidarity. Loff noted that failure to understand differences in values and cultures compromises research. Loff concluded that we may need to move away from the unambitious model of research ethics created as a response to Nazi atrocities and explore the research conduct exhibited by the Jewish doctors who may direct us towards ethical debate of a more aspirational and fulfilling character.

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**Presentation**     **History of the Global Forum on Bioethics in Research**

**Speaker**             Carel IJsselmuiden - Switzerland

Carel IJsselmuiden's address recounted the history of the Global Forum on Bioethics in Research (GFBR) and plans for its future. He explained that the goal of the GFBR is to strengthen the protection of human participants in international collaborative health research. It works towards this goal by bringing together researchers, ethicists and other relevant stakeholders from low, middle and high income countries for dialogue on key ethical and related social, legal and public policy issues resulting from health research in international settings. The increasing volume, complexity and global nature of health research with human participants often surpasses the capacity of stakeholders to keep up. Consequently the GFBR provides a space for discussion of how to apply or adapt existing guidelines to new realities, and to explore and resolve difference of opinions. The GFBR aims to create an environment where conflicting or unresolved ethical problems can be explored without expectation of immediate resolution. IJsselmuiden emphasized that the GFBR's purpose is not to draft new guidelines, nor to arrive at post-conference statements, nor to provide training.

The Forum's Secretariat is hosted by the Council on Health Research for Development (COHRED) and works to ensure continuity between meetings, collaboration among partners and fund raising for GFBR activities. In the future, the GFBR plans to conduct an evaluation of the Secretariat function with the goal of improving its impact. The GFBR may also extend its functions from dialogue to a 'platform' for unheard voices, from annual meetings to capacity building and follow-up action, and from global meetings to global and regional meetings. Furthermore, the GFBR wishes to deepen the representativeness of partners, consider private sector inclusion, and solidify future income.

# Day 1: Case Studies

Stream 1

## Kaitiakitanga - Protection and Guardianship

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The Local Media and Tenofovir trial in Cameroon, 2005

**Speaker** Martin Anu Nkematabong - Cameroon

A trial plan of pre-exposure prophylaxis Tenofovir to prevent HIV infections was introduced in Douala, Cameroon in February 2005. 400 sex workers volunteered as participants. The trial was short-lived, as reports in the local media alleged Tenofovir was designed to reduce the population of prostitutes in Cameroon. As a consequence, the Ministry of Public Health suspended the trial and set up a commission of inquiry claiming that the research design was flawed.

Martin Anu Nkematabong, the case study presenter, was unable to attend at short notice and so this case was not formally discussed. However, Cheryl Overs highlighted some differences between the Tenofovir trial in Cameroon and the Trovan trial in Cambodia (detailed below). She explained that in the Cameroon trial the ethical issues were raised by members of the media and activists external to the trial. Whereas in the case of the trial conducted in Cambodia the sex workers enrolled in the trial voiced concerns and defended their rights themselves.

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Sex Workers Reject an HIV Prevention Trial in Cambodia

**Speaker** Cheryl Overs – United Kingdom

In 2004 a randomised trial by investigators from the United States and Australia was planned to assess the safety and efficacy of Tenofovir as pre-exposure prophylaxis for HIV. The trial was to recruit 960 HIV negative female sex workers in Cambodia but in July 2004 protests led by sex workers in Cambodia and activists at the XV International AIDS Society conference in Bangkok, brought worldwide media attention to claims that the trial was unethical. As a result of the protests the Cambodian Prime Minister closed the trial early. The trial broke down because no constructive dialogue about ethical issues was established between the community and the researchers, because sex workers were given false and conflicting information, and because no guarantees were given about ongoing care for sex workers adversely affected by the trial.

In Cheryl Overs' noted that trial volunteers who are recruited because they engage in risky behaviours should receive the best proven measures to help them reduce their risk of acquiring HIV infection from those behaviours. Discussion raised the following key questions: If the preventive measures were already in place in Cambodia does it mean

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the researchers don't have to provide anything extra? If people become HIV infected while enrolled in a trial as a result of risky behaviour or exposures that they could not avoid, should HIV treatment be provided and if so, at what level, and for how long? If trial participants are physically harmed by the product being tested should they receive care and compensation and through what process? Finally, if the product is proved effective should trial participants or their communities receive that product even if their government or health insurer will not pay for it?

Several recommendations emerged from the discussion. Better coordination between the disparate trials, their multiple sponsors, trial participants and their communities is required. There should be protections and benefits for trial participants at all trial sites that include treatment for HIV infection, high quality prevention interventions, and compensation for physical harm caused by participation in research. Moreover, there needs to be continuing capacity building to allow the evaluation and monitoring of trials, and to build understanding of ethical issues among researchers, trial sponsors and sex worker communities.

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## Stream 2

### Partial disclosure of Information Versus Potential Benefits of Health Research

**Speaker** Aceme Nyika – Tanzania (for Francis Masiye – Malawi)

An international collaborative study on the pathogenesis of cerebral malaria involving institutions in the USA and Malawi planned to remove the eyes of children who had died and replace them with artificial ones, but not to inform their parents about this procedure. The Institutional Review Board (IRB) in the USA did not approve the consent process, whereas the Research Ethics Committee (REC) in Malawi, where the study participants were to be recruited, were satisfied with the justifications for partial disclosure and approved the study. The US IRB argued that a study with such partial disclosure would not be allowed in the USA, hence the committee could not approve it to be conducted in Malawi. On the other hand, the Malawian REC considered potential benefits of the study to outweigh the requirement for full explicit disclosure to the parents.

Several issues emerged in the discussion of this case. First, it was agreed that explicit disclosure of the research procedures is necessary for consent to be properly informed and therefore for the research to be ethical. Second, given the context in which consent was obtained, it was questioned whether consent was truly voluntary in this case. Mothers with sick children who had travelled a long way to the referral hospital might not be in a position to refuse participation. Furthermore, there was some concern that the researchers' offer to provide coffins, transport of bodies and burial constituted an undue inducement. Third, questions were raised about the ethical approval process, such as whether the REC in the host country has the mandate to approve or disapprove the research, regardless of the sponsor country REC's decision. Finally, some concerns were raised about whether local RECs are really well placed to speak for communities; the absence of community representatives and community advisory boards in this case was noted.

## Research on orphans

**Speaker** Aceme Nyika - Tanzania

This case study highlighted the vulnerability of HIV-positive, institutionalised children. Some HIV-positive orphans in a Kenyan orphanage seemed to survive longer without any medication than is normal for HIV positive-children of the same age. It was hypothesised that genetic factors may play a major role in this natural immunity. Researchers therefore began genetic studies on the orphans. In 2001, however, Dr. Moses Otsyula, the local principal investigator, alleged that his collaborator's team from Oxford had stolen blood samples from his laboratory and collected more samples without ethical approval. Papers based on these samples were published. The collaborator, Dr. Sarah Rowland-Jones, claimed that the Oxford team had been invited by Dr Otsyula and had been led to believe that the study had ethical approval. She added that the Oxford team had been given permission to conduct the research by the head of the orphanage. He had allegedly told them that Nyumbani Home had all the necessary documents authorising the research.

Five key questions were considered in the discussion of this case. First, were the children vulnerable? It was agreed that the children were vulnerable because they were minors, orphans, HIV-positive and institutionalised. There was some debate about whether the term 'vulnerable' or 'marginalised' was applicable. While it was decided that both terms applied, it was noted that the two terms have different implications and so are not interchangeable. The second question reflected on whether research on vulnerable groups should ever be conducted? In general it was agreed that if the research questions can only be answered through research on particular vulnerable groups and the potential benefits of the research outweigh potential risks, then the research should be conducted. However, it was stressed that research on vulnerable groups requires extra caution in order to safeguard the wellbeing and welfare of the research participants. It was felt by some that in this case the research was not justified as alternatives to genetic research might have been equally appropriate. Third, participants considered how the protection of orphans was compromised. Not only was ethical approval not obtained but the head of the Orphanage gave proxy consent for the orphans. Whether he had the legal right to do so was questioned and his potential conflict of interest was debated—he appeared as a co-author when the study was published, yet as the head of the orphanage he had the responsibility to act in the children's best interests. Fourth, participants discussed the allegations of data theft. It was felt that this was a result of the roles of collaborators and data sharing agreements between collaborators not being explicitly defined. REC and regulatory approval would have ensured this was considered. Lastly, participants addressed Dr Rowland-Jones' claim that she did not know that ethical approval had not been obtained. It was agreed that if she should have requested REC approval and would have been required to do so by her institution.

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## Stream 3

Ethical Considerations in a Study About HIV and Syphilis in Native Communities in Peru

**Speaker** Carol Zavaleta Cortijo - Peru

In 2006 - 2007 Dr Zavaleta Cortijo conducted research on HIV and Syphilis in Native communities in the Peruvian Amazon region. The study objectives were to estimate the

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prevalence of HIV and Syphilis, to determine knowledge, attitudes and practices (KAP) regarding these infections and, to explore KAP on sexual practices. Qualitative methods were used in the KAP studies.

Several ethical issues emerged during the study. First, a significant number of people refused to participate in the study. For example, from the more distant community only one family out of 50 agreed to participate. This community attached great significance to their blood—“taking my blood is taking my spirit”—a fact of which the researchers were initially unaware. Second, it was normal for men in these communities to make decisions on their family’s behalf, which meant that when her husband was absent a woman was generally not in a position to talk with foreign people, and the researchers risked disturbing a family if they tried to include women without their husbands’ approval. A third ethical issue emerged regarding publication of the results. A 2004 article mentioned the name of the ethnic group studied and its location. There were two responses to this. The first was immediate action from the Ministry of Health to try to find out about the AIDS situation among this and other ethnic groups in Perú. The other was press reports mentioning that this ethnic group had high HIV rates and MSM behavior.

One important lesson the researchers learned for future studies is that protecting group identity can be as important as protecting individual identity. Authors’ should discuss the best way to publish the results with the community and their IRB. Discussants debated the issue of spousal consent at some length. Concern was raised about people being excluded from research because their husbands were not available or willing to give consent to their inclusion. It was generally agreed that no one should be enrolled in research without his or her individual informed consent.

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#### Domiciliary Consent in a Community Based Tuberculosis Prevalence Study: A South African Perspective

**Speaker** Keymanthri Moodley – South Africa

The Zamstar project is a five-year community based collaborative Tuberculosis (TB) prevalence study, which has been conducted in South Africa and Zambia since 2005. This five-year study is community based. It involves field workers going out to the homes of indigent people to test them for TB and to discuss issues around TB transmission. An empirical informed consent study was conducted in 2006 to assess how Zamstar project participants had perceived the informed consent process with the intention of improving the consent process in the future. An 86 percent response rate was obtained for the informed consent study.

The results were as follows. Participants had a clear understanding of the TB prevalence study as a result of the consent process. A third of the sample perceived that not getting their TB test results returned to their homes was a loss of an important potential benefit from study participation. 65% had other family members present during the consent process, sample taking and return of results and were comfortable with the lack of privacy. Privacy and confidentiality issues may therefore be perceived differently in different communal settings. Keymanthri Moodley concluded that domiciliary community-based research is associated with unique ethical concerns; research teams and Ethics Review Committees should be sensitised to them.

## Stream 4

Is it Really ‘Too Hard’? The Serious and Continuing Illness Policy and Practice Study (SCIPPS) Experience of Conducting Research with Vulnerable Groups in Western Sydney, Australia

Beverly Essue, Masoud Mirzaei, Elaine Gordon, Joyce Davison, Kate Corcoran and the the SCIPPS team - Australia

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) was designed to develop policy and practice solutions to improve chronic illness management, and care for those affected by illness and the people involved in their care. One arm of the study is being conducted in the western suburbs of Sydney, Australia, which has large Aboriginal communities and a high proportion of people from culturally and linguistically diverse backgrounds (CALD). Aboriginal and CALD individuals affected by chronic illness may have unique experiences that impact on their care, self-management and outcomes. It was necessary to develop targeted recruitment strategies in order to maximise their representation in this study. As part of SCIPPS, semi-structured interviews were used to explore the experiences of patients and family carers in the management of Chronic Obstructive Pulmonary Disease, Type 2 Diabetes, Chronic Heart Failure and associated comorbidities. A total of 34 patients and family carers were interviewed in Western Sydney: five identified as Indigenous (15 per cent) and 12 as CALD (35 per cent). Reference groups were established to provide feedback on the results of the qualitative research and to give insights on the policy implications of the findings.

The SCIPPS team noted in their commentary that it was part of SCIPPS’ original proposal to include vulnerable populations in the study in order to reflect their needs and wants to policy makers. The relevant vulnerable populations were defined as those with poorer overall health outcomes who may have worse access to care because of language and cultural differences. Several key issues were raised during the research including: How do you know who represents the community? Who are the appropriate leaders to talk to? Who owns the data? What will the information be used for and what has been consented to? And how should data be published? Difficulties were also experienced with informed consent and information dissemination given language diversity and translation requirements and with the management of expectations. The project highlighted important lessons for working with vulnerable populations, including: the need to ensure sufficient time for consultation with the relevant communities; the need to ensure ethical approval has been obtained from relevant bodies; the importance of fostering and maintaining relationships with indigenous health professionals; securing funding for interpretation services; learning how to work effectively with interpreters and managing the expectations of research participants. These lessons are applicable to the development of health policies that are intended to be relevant to all sub-groups in the population.

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**Panel Plenary** Justice and the Colonised  
**Speaker** Moana Jackson – Aotearoa/New Zealand

Moana Jackson reflected on how to discuss ethics within the unethical construct of colonization itself. He stated that colonization is not a finite process, it is ongoing. If research is conducted on Indigenous People within this colonizing structure, we must be sure to act

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in non-colonizing or decolonizing ways. Moreover, responsibility must be taken for the harm of colonization before research can begin ethically. Jackson stressed that science is not pure, it is a product of enlightenment and colonization and it is therefore unhelpful to separate the notion of scientific method from that history, specifically in the way it relates to Indigenous People.

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### Asserting Self-Determination in an Age of Biocolonialism

**Speaker** Debra Harry – United States of America

In her presentation Debra Harry examined Indigenous Peoples' experiences with human and non-human genetic research, and the misappropriation of Indigenous knowledge and resources. Previous experience with medical, behavioural and anthropological genetic research on Indigenous People indicates some common problems and concerns. These include: the assumption of open access for research; Indigenous People bearing the risks of research without benefits or with false promises of benefit sharing; lack of appropriate informed consent; the widespread secondary use of samples; the potential for coercion; the alienation of genetic materials; and the unwillingness of researchers to repatriate misappropriated genetic material. Furthermore, current laws and policies privilege scientific, academic, and corporate interests, resulting in the misappropriation and alienation of the collective heritage of Indigenous Peoples.

Harry discussed strategies to protect Indigenous Peoples' rights and interests in an age of "biocolonialism." First, the research paradigm should be changed—Indigenous People need to be seen as rights holders and not stakeholders. Their human rights, including the right to self-determination, need to be recognized. Second, the research agenda for research involving Indigenous Peoples should involve culturally based decision making and explicitly consider who decides what research should occur and who will conduct the research, own the data, and benefit. Harry stated that Indigenous centered research should protect cultural heritage and values, protect individuals and communities, and respect protocols. She concluded that equitable partnerships in research promotes, respects, and protects tribal sovereignty, respects Indigenous methodologies, accurately speaks to the intended audience, recognizes and values indigenous contributions, is based on trust, respect, and transparency, and centers Indigenous researchers in the research process.

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## Concluding presentation

**Speaker** Doris Schroeder - Australia

Day one was closed by Doris Schroeder. She identified the common theme running through the plenary presentations as 'human encounters'. She described the honour of the 'human encounters' as experienced through the Whakatau / Māori Greeting Ceremony, the encounter of the conference participants with one another, the encounter of research participants and researchers, and the encounter with indigenous ideas. She pointed out that the most difficult encounters between research participants and researchers take place when one or both are carrying unresolved historical baggage of previous, exploitative encounters with them.

## Day 2: Case Studies

4 December 2008

### Te Ao Marama – Current developments and challenges

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**Chair** Esther Cowley-Malcolm  
**Rapporteur** Jennifer Koen

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**Plenary Session** **Reducing Vulnerability Through Indigenising Research Methodologies with Gender and Sexual Minorities**

**Speaker** Vic Muñoz – United States of America

Vic Muñoz's plenary described how, in psychology, Western paradigms of pathology and the abnormal have historically led to the marginalization of gender and sexual minorities across cultures. She argued for the need to reframe Western views of pathology and wellbeing to Indigenous and minority perspectives, in order to reduce the vulnerability of gender and sexual minorities in research. These groups may be empowered (rather than oppressed) by research when it is acknowledged that they may know themselves better than outside scientists, and when they themselves are allowed to become the researchers.

Adopting Indigenous perspectives was advocated as a means of avoiding the negative 'colonial' aspects of traditional approaches to research. Muñoz discussed several studies of gender and sexual minorities which had adopted Indigenous perspectives, highlighting some of the research challenges faced in these studies and the lessons learned. These included:

- Working with Indigenous Populations means facing linguistic complexities; there is a need to ensure accurate and meaningful translation so that people's representations of themselves are accurately reproduced.
- Language is an important aspect of many people's identities and should be acknowledged as such.
- Many of the most developed and best models of understanding gender and sexual minorities were developed from a western perspective. However, importing terms such as 'transgenderism' from such perspectives is frequently incongruent with the perspectives of those being researched. Centring the worldviews of those being studied is therefore essential to ensuring that research is productive rather than damaging.
- Certain concepts often do not exist in non-Western cultures or are interpreted differently. Researchers should be aware of this, should respect this, and where appropriate, should attempt to understand differing viewpoints.

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## Plenary Session

## Values and Ethics: Guidelines for Research in Aboriginal and Torres Strait Islander Health Contexts

**Speaker** Ian Anderson – Australia

Ian Anderson discussed the process of developing guidelines for health research with Aboriginal and Torres Strait Islander populations in Australia. Value and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research was finalised in 2003 by the National Health and Medical Research Council (NHMRC) of Australia. The explicit intention of these guidelines was that they be grounded in the values and principles of ethical relationships in Indigenous and Aboriginal populations. Some of the key concepts underpinning such relationships and upon which the guidelines are based include:

- i. Mutual recognition – the idea that engagement with Indigenous populations recognises and respects the social and political processes of these populations.
- ii. Mutual comprehension – the idea that engagement with Indigenous populations recognises, respects and seeks to understand the values of these populations.
- iii. Reconciliation and/or decolonisation – the idea that ethical relationships with Indigenous populations are essentially trust-based, incorporating mutual recognition and comprehension and seeking to promote and uphold equity and partnership, rather than furthering oppression/colonisation and alienation.

These guidelines are also grounded in the movement for civil and health rights for Indigenous People, including the right to self-determination. The impetus for their development emerged from an NHMRC conference aimed at setting research priorities to improve aboriginal health. While the intended focus of the conference was primarily biomedical research and health priority setting the discussion moved it towards the ethical basis for engagement. Key points of contention and discussion included the ownership of data and community control of the research process. While Indigenous populations' history of experiencing exploitation in research was a key driver behind the development of these guidelines, Anderson highlighted the fact that Aboriginal populations were not requesting protection from exploitation, but rather ethical engagement.

Anderson highlighted reciprocity, respect and equality as key requirements for ethical relationships. Mutual comprehension does not require complete submersion of researchers' own culture or uniformity in world-view, but rather respectful engagement and openness to understanding the perspectives of all involved parties. It is also an important basis for a collaborative reciprocal relationship.

Anderson pointed out that one of the problems of having Indigenous specific guidelines, of which researchers should be aware, is the risk that all Indigenous people can be shifted into a 'high-risk' category, when all are not vulnerable – simply being aboriginal or indigenous does not make you vulnerable. He advocated for a shift from a protective paradigm to one of equality, partnership and mutuality, particularly with respect to research with Indigenous populations.

### Session 2

## Te Ao Marama – Current developments and challenges

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**Case Study**      **San Peoples of Southern Africa and Their Traditional Knowledge Relating to the Hoodia**

**Speaker**          Roger Chennells - South Africa

Roger Chennells presented a case study focusing on the issue of ownership of traditional knowledge and intellectual property rights. The case described the commercialisation of the San people's traditional knowledge of the Hoodia plant, an indigenous succulent used as an appetite and thirst suppressant. The South African Council for Scientific and Industrial Research (CSIR) started researching the appetite suppressant properties of the Hoodia, without informing the San, and registered a patent in 1996. The case study examined the San challenge to CSIR regarding the "theft" of their traditional knowledge, resulting in various negotiated agreements. During this process, the San have developed their capacity to appreciate the value of their traditional knowledge, and to engage in the related current debates about research ethics, benefit sharing, and morality relating to communal traditional knowledge.

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**Case Study**      **Access and Benefit Sharing Issues in the Pacific: The Fable of the Mamala Tree**

**Speaker**          Clark Peteru – Samoa

Clark Peteru described the case of the Mamala plant, which has been acclaimed as a potential AIDS cure and as an economic god-send to Samoan villages. Following leads provided by Samoan traditional healers, researchers from the United States isolated prostratin (known to have certain anti-viral properties) as the active component of the Mamala plant. In the mid-1990s patents relating to prostratin were filed in the US without the ostensible approval of any Samoan authority. The case raised questions about fully informed consent concerning the use of plant samples and associated traditional knowledge by outsiders; intellectual property rights; and the fair allocation of benefits to eligible beneficiaries. The paper also suggested the need for enforceable ethical standards or guidelines for those conducting the research.

#### Discussion

Participants discussed issues relating to ownership of data and research knowledge; the most appropriate mechanisms of engaging with Indigenous populations; creating and

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sustaining partnerships with indigenous populations in research; defining the roles of stakeholders in the research; access to and fair distribution of the benefits of research; and the means of making such benefits available to host communities. A collaborative, participatory approach to research with Indigenous populations was advocated as a means of overcoming cross-cultural complexities, of acknowledging 'different ways of knowing' and for empowering and developing the capacity of indigenous populations to engage in research as partners to researchers. The importance of accessing participant perspectives in the research process was emphasized.

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## Stream 2

**Case Study**     **A Case for Iterative Informed Consent in Research with Indigenous Peoples**

**Presenter**     Fatima Alvarez Castillo - Philippines

Fatima Alvarez Castillo presented her experience of seeking informed consent from a marginalised Indigenous group in the Philippines, the Mangyan. She described this group as being particularly vulnerable to exploitation in research, because of their social and political marginalisation, because they are impoverished and because they generally lack formal education. Research focussing on these people has largely failed to benefit them. Alvarez Castillo argued that the commonly-used once-off method of obtaining participant informed consent is problematic, as understanding may be inadequate and autonomous decision-making may be limited. She described the iterative informed consent process she undertook in working with the Mangyan. This involved obtaining the consent of potential participants through a step wise process including a series of dialogues before the start of the research and continuing during the research itself. The objective of these dialogues was not only to obtain consent, but also to involve participants in finalising the design and objectives of the study, and in the validation of the study findings. Castillo argued that this iterative process is more congruent with indigenous people's dialogic, consensual and process-oriented approach to decision making, as opposed to the once-off, outcome focussed, researcher-driven conventional approach to informed consent.

### Discussion

Iterative informed consent not only promotes changes in understanding among potential participants but among researchers too. Ongoing dialogue and mutually respectful discussion were argued to promote mutual understanding of the perspectives and values of all stakeholders in the research process, to enhance trust and to be valuable in creating partnership-based researcher-community relationships. Furthermore, iterative processes of obtaining informed consent recognise and are sensitive to the multiple levels at which decisions are made (e.g. community and individual levels). It was suggested that iterative processes assist in accessing the often unheard voices of marginalised community members, and also provide a means for understanding and being sensitive to decision-making processes in indigenous and vulnerable communities. Iterative informed consent processes provide a foundation for ethical research. But engaging in an iterative process of informed consent with communities requires a shift away from traditional, paternalistic, researcher-driven, outcomes-based approaches to research towards more collaborative, participatory, process-focused approaches.

**Case Study**      **Anthropology and Mining in the Philippines: Ethical Issues in Conducting Social Impact Studies Among Indigenous Peoples**

**Speaker**          Rosa Cordillera A. Castillo - Philippines

Rosa Castillo discussed the situation of conducting social impact studies and getting social acceptability for mining projects (which is required by law) in the Philippines. Many of these projects are proposed in regions of the country which are the homes of Indigenous populations. Conducting these social assessments has become a lucrative venture for some Filipino anthropologists and other social scientists. Castillo argued that problems in relation to this have arisen because legal provisions in pertinent laws are not adequate to protect the rights of communities affected by mining. This results in the potential for unethical practice by social scientists in mining-commissioned research. In many of these studies there was a lack of clarity concerning the research questions being addressed – even for the researcher. Furthermore, there was a potential for conflicts of interest as the researchers were frequently contracted to the mining companies and so might represent the communities as pro-mining.

**Discussion**

During the discussion, provisions in the American Anthropological Association (AAA) guidelines, which should be followed by all researchers conducting social and anthropological research, were described. Castillo confirmed that the professional organization of anthropologists in the Philippines, the Ugnayang Pang-Agham Tao, also has ethical guidelines, but is in the process of strengthening it. The researcher's responsibility was argued to be to the study participants, particularly when there is a conflict of interest. The rights and welfare of the participants in studies should be safeguarded and protected, and their dignity and privacy honored. Participants must be made fully aware of the potential risks, benefits and implications of study participation. It was proposed that there should be transparency in terms of researcher motivations and agendas and in terms of the reporting of data emerging from the study. Results should be made equally available to the sponsors, general public, and to the community being studied. Furthermore there should be a fair distribution of the benefits of research.

Questions were raised about compensation for the use of potentially sacred space for commercial interest, and about conserving indigenous knowledge. It was recommended that explicit procedural processes, which detail the mechanisms for accessing communities, for monitoring research and for reporting and dealing with ethical violations, be developed and implemented. Furthermore, the need for building research and research ethics capacity in indigenous contexts was highlighted. This would help Indigenous populations become more aware of their rights, allow them to challenge unethical research, and give them the ability to conduct their own research on self-defined issues.

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## Stream 3

**The Trovan Trials Case Study: After Profits or to Save Lives?**

**Speaker**          Aceme Nyika – Tanzania

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Aceme Nyika described the case of the Trovan trials. In response to an epidemic outbreak of bacterial (meningococcal) meningitis in Kano Nigeria, Pfizer researchers recruited at least 200 children into a trial to test a drug called Trovan (or Trovafloxacin) at a local government hospital. The scientific rationale for the study was that other similar drugs in the same antibiotic class as Trovan had been previously successfully tested in children. Despite the fact that the government hospital, assisted by Medecins Sans Frontiers, treated children with chloramphenicol (an approved antibiotic for treatment of bacterial meningitis), the control group in the trial received lower than recommended doses of chloramphenicol. Pfizer collaborated with a local Nigerian team of health personnel led by a local physician who, according to Pfizer, oversaw the trial.

Subsequently, Pfizer were accused of several ethical transgressions including conducting a trial without approval from regulatory authorities or ethics committees, and not getting informed consent from the parents or legal guardians of the enrolled children. Pfizer countered that they received ethical approval from the Kano Hospital (although there was no ethics committee at the time of the trial) and that they could not obtain informed consent as parents and guardians were illiterate. Pfizer was also accused of leaving Kano at the completion of the trial, even though meningitis still ravaged the community. Families of the children who were allegedly killed or permanently disabled as a result of participation in the trial attempted to sue Pfizer in a US federal court. However, the lawsuit was dismissed because what happened in Nigeria was outside the jurisdiction of the US. Appeals have been lodged and the lawsuit is currently continuing in both the USA and Nigeria.

Aceme discussed different schools of thought around the trial and asked the group to unpack some of the key ethical issues. Several ethical concerns were identified including a below par standard of care, exploitation of a vulnerable community, a researcher-driven rather than community-driven agenda, and poor informed consent and review processes. There was concern that children in the control group died or were disabled due to the provision of an inadequate standard of care. There was some concern that Pfizer exploited a poor, desperate and vulnerable community where an emergency situation facilitated recruitment. The trial highlights the importance of collaborative partnerships between host countries and sponsors and the fact that the role of co-investigators in developing countries is ill-defined and often token. Benefits to communities (including the standard of care, ancillary care and post-trial benefits) also need to be clearly articulated. Stakeholders/gatekeepers including ethics committees, regulatory authorities, government and community advisory boards have complementary roles in ensuring that unethical research is not conducted in developing countries and their respective roles should be outlined and clarified.

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For more information on the Trovan trials see:

Ahmad, K. (2001). Drug company sued over research trial in Nigeria. *The Lancet*, 358(9284), 815.

Amanet website: <http://www.amanet-trust.org/discuss/viewtopic.php?t=2>.

Loewenberg, S. (2008). Drug company trials come under increasing scrutiny. *The Lancet*, 371(9608), 191-192.

## Stream 4

### Regaining the Centre – The Ethics of Researching by, with and for Māori

**Speaker** Fiona Cram – Aotearoa/New Zealand

In her presentation, Fiona Cram explored Kaupapa Māori (by Māori, for Māori, with Māori) as the theoretical underpinnings of an indigenous relationship ethic for research. This relationship ethic seeks to have Indigenous knowledge, culture and values re-centred, and issues of inequality and social justice foregrounded. Cram observed that there are 7 values which arise out of seeking parallel processes. These are: 1) Aroha ki te tangata (a respect for people); 2) Kānohi kitea (the seen face, that is present yourself to people face to face); 3) Titiro, whakarongo...korero (look, listen...speak); 4) Manaaki ki te tangata (share and host people, be generous); 5) Kia tupato (be cautious); 6) Kāua e takahia te mana o te tangata (do not trample over the mana of the people); and 7) Kia mahaki (don't flaunt your knowledge).

Cram examined the research protocols developed by both mainstream groups about Indigenous research, and by indigenous groups themselves about how they wish to be researched. The aim was to provide insights into the meaning of values and their applicability beyond the context of research and evaluation with Māori people. It was noted that it is not sufficient to say that communities should not be worse off as a result of research: research should always leave communities better off.

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### **Tikanga Māori in the Laboratory: Shaping Culturally Safe, Respectful and Dignified Scientific Practices**

**Speaker** Melanie Cheung – Aotearoa/New Zealand

Melanie Cheung discussed the tensions that arise as an Indigenous researcher working in a spiritually, culturally and ethically sensitive area that is also of great medical significance. She is engaged in post-mortem brain studies aimed at understanding how and why the defective Huntington's Disease gene causes the death of specific brain cells in the striatum and cortex. Without this data, a treatment for Huntington's disease will be difficult to find. The dilemmas emerge from the Māori belief that the head and brain are extremely tapu, that is, sacred or with restrictions. Researchers conducting studies with human brain tissue therefore need to be constantly respectful towards the human tissue. In addition, there are tapu restrictions on what can be done with the human body at death.

Another tension arises because the scientific worldview does not account for spirituality while the indigenous worldview perceives physical and spiritual worlds as continuous. To resolve this tension, tribal elders have recommended the development of Tikanga Māori for use in the laboratory when working with human tissue. Tikanga Māori is generally referred to as Māori protocol and provides general guidelines for work in the laboratory. This process involves prayer, song and water (karakia, waiata and wai) to acknowledge and bid farewell to the person who has died and to acknowledge the family's grief and the gift that they have given the research. In this way, indigenous researchers are able to uphold their own identities while maintaining scientific integrity in the laboratory.

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## Case Studies - 3

### Te Whai Matauranga – Gathering knowledge

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#### **Bioethical Regulation of Biomedical Research Involving Vulnerable Populations In Kenya**

**Speaker** Moses Limo – Kenya

#### Stream 1 (Afternoon Session)

Unable to attend.

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#### **Ethical Issues on Indigenous Communities' Reproductive Health and Gender Violence: The Experience of Casa de la Mujer Indígena**

**Speaker** Blanca Pelcastre-Villafuerte – Mexico

Blanca Pelcastre-Villafuerte described the experiences of setting up 'health houses' to address the health concerns of indigenous Mexican women affected by domestic violence. Most of these women live in very remote areas and lack access to formal health services. Furthermore, Indigenous women in Mexico are rendered particularly vulnerable by the convergence of three conditions leading to discrimination: ethnicity, gender and social class. Indigenous women in Mexico have been shown to have poorer health outcomes. Concerns about this led to the development of 'health houses' and to research into the conditions affecting these women. The aim of the research is to develop a culturally appropriate model to attend to their health problems.

The first 'health house' was set up in 2003 and each is coordinated by 6 – 8 Indigenous women volunteers. These 'houses' attend to the psychological, legal and medical issues experienced by women. Some of the women volunteers who are responsible for the running of the 'houses' have formal training but many do not. The 'houses' have been set up to have contact with health services, municipal authorities, and local institutions. They assist in the referral of women to the appropriate services when necessary, they support women through the organisational requirements of these services, and they provide translation services. Part of their funding agreement requires the 'health houses' to conduct research; however, lack of time and training make this problematic. Tensions in the relationships between local authorities and Indigenous populations, and gender inequities in Indigenous communities were highlighted as factors that complicate the functioning of these houses. Ethical issues identified in this case included: how to continue with the Indigenous women's empowerment process, given funding constraints; how to obtain consent and involve men in the project; and whether protection of women's health or the traditional social values of Indigenous populations (which are often used to justify domestic violence) should take priority.

## Discussion

It was emphasized that Indigenous groups in Mexico are not vulnerable because they are Indigenous but because of the context they are living in, in which they do not share the same rights (such as the right to health) as the majority or dominant population.

It was argued that if traditional values lead to threats to women's health, then changing traditional values and beliefs is legitimate. Questions were raised about how exactly traditional values were defined. Could domestic violence constitute a traditional value or is it a product of colonization? It was suggested that a potential solution to the problem of domestic violence facing women in these contexts, and a way to obtain support for the project by Indigenous men, would be to get men to re-evaluate what constituted their traditional values and to consider the possibility that violence may not be a part of their culture. It was also suggested that through making use of de-colonising and participatory approaches the research might provide a successful means of developing a culturally appropriate model for dealing with women's health issues and for addressing the issues of gender inequity.

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## Stream 2 (Afternoon Session)

### **Different Protocol Review Outcomes Between Developed and Developing Countries Ethics Committees**

**Speaker** Francis Masiye – Malawi

Unable to attend.

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### **Genetic Screening in Meso-American People with Psychiatric Disorders**

**Speaker** Virginia Rodriguez – El Salvador

Rodrigues discussed a study of the genetics of psychiatric disorders (PD) in Meso-Americans. Enrolment criteria for participants were that they must have two Latino grandparents from the Meso-American region. It was hypothesized that Meso-Americans are genetically homogenous and would therefore be useful in trying to remove the problem of genetic heterogeneity in trying to identify the genes related to PD. The rationale for the selection of Meso-Americans includes that they are the largest ethnic group in the USA, they have been largely unrepresented in previous genetic studies of PD and they may have a higher probability of having family members with PD. While there are no direct benefits for participants, participants are said to benefit from the study indirectly, as Meso-American samples will now be included in genetic studies of PD.

The discussion covered issues around the scientific reasons for selecting the population and whether these studies could be conducted with less vulnerable populations. There was also concern that the samples were going to be stored and analysed outside the country of

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origin. First, this might lead to the patenting and commercialisation of genetic sequences. Second, it neglected an important opportunity for building scientific capacity in the Meso-American countries from which the samples would come. Participants therefore highlighted the need for improved collaborative partnerships. In addition, it was questioned whether it is ethical for participants to provide blanket permission for future unspecified uses of their biological samples or waive their rights over the samples. It was noted that researchers should be cognisant of the diversity of cultural perspectives around the meaning of tissues and samples. In addition, while the informed consent document did not identify any risks associated with participating in this study the potential for stigmatization of Meso-American populations should be identified as a potential study risk.

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### Stream 3: (Afternoon session)

#### **Negotiating Ethical Spaces for Indigenous Knowledge Production**

**Speakers** Maui Hudson and Karlo Mila-Schaaf – Aoteroa/New Zealand

Maui Hudson and Karlo Mila-Schaff described the ‘Te Hau Mihi Ata’ project in New Zealand which is exploring ways to connect traditional knowledge and science through a process of progressive dialogue. They argued that in contexts, such as New Zealand, where research policies are encouraging a deeper level of interaction between Indigenous knowledge and science, the development of means of exploring knowledge gaps between the two systems of knowledge and the promotion of innovative and progressive ideas is important.

The ‘Te Hau Mihi Ata’ project brings together scientists with indigenous heritage and experts in indigenous knowledge, with the aim of facilitating knowledge exchange and Indigenous theorising. The project focuses on “negotiated space”, a conceptual model which allows for productive negotiation between cultural paradigms, for the exchange of concepts and ideas, and for the development of new insights and perspectives on knowledge. In contexts in which science and traditional knowledge both have relevance, developing ethical guidelines that source Indigenous worldviews with integrity and can meaningfully govern contemporary research settings is complex. The HRC Pacific Health Research Guidelines, which aim to uphold Pacific Indigenous ethics, knowledge paradigms and concepts are grounded in negotiation between different and often incongruent perspectives on ethics (Indigenous and Western). The “negotiated space” model has resonance in explaining the process of deliberating on, negotiating, and balancing values and ideas from divergent paradigms.

#### **Comment/ Discussion**

The implications of, and concerns about, privileging one system of knowledge over another was a focus of the discussion. Doing so may result of neglecting valuable concepts and ideas in the subordinated paradigm. The ‘negotiated space’ between traditional/Indigenous and Western ethical principles was argued to provide the conceptual room for epistemic and cultural exchange, expansion and the development of new philosophies. Within a neutral but purposeful space (negotiated space), shared ideas and ethical values can be located, and conflicts can be identified and confronted.

## **The Indigenous Research Protection Act: A Model Tribal Code to Change the Research Paradigm**

**Speakers** Le'a Malia Kanehe – Hawai'i (USA)

Le'a Malia Kanehe discussed the need for Indigenous Peoples to regulate research in their own terms in the exercise of their right of self-determination. Kanehe presented The Indigenous Research Protection Act (IRPA), which aims to assist Native American Tribes with recognised jurisdiction to assert sovereignty in the research process from conception to completion. It provides the legal basis for tribes to protect their peoples and resources from unauthorised research, to reduce the adverse affects of research on the tribal community, to ensure that researchers recognize tribal control and ownership of information generated by the research, and establishes a statutory basis for the governance of research within their jurisdictions. The IRPA sets out a number guiding principles for the conduct of research with Indigenous populations, including the review and monitoring of proposed research by a tribally established Research Review Committee (RRC).

### **Discussion/Comment**

When communities are fully involved in the review, design, and implementation of research that meets their needs the research is likely to result in greater benefits.

The IRPA model and its founding principles have much broader application – it is not only relevant to Native American Contexts. Some of the principles were discussed. They include: inherent rights; self-determination; free prior informed consent; benefits to the community; transparency and full disclosure; confidentiality; empowerment; mutual respect. For details see The Indigenous Research Protection Act (available at [www.ipcb.org](http://www.ipcb.org)).

Tribes/Nations were argued to have proprietary rights to all forms of their cultural and natural resources within their territories. It was argued that the requirement for informed consent applies to groups too, when the research or other proposed activity has potential implications for the collective. In no case should consent be presumed or implied; and new consent must be sought for uses other than that for which the original consent was granted.

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## Stream 4

### **Canadian Efforts in Addressing the Ethics of Research Involving Aboriginal Peoples**

**Speaker** Doris. M Cook – Canada

Doris Cook presented on the Canadian Institute for Health Research's Ethical Guidelines for Health Research Involving Aboriginal People, and on the process through which they were developed. The guidelines are intended to facilitate the ethical conduct of research involving aboriginal peoples. They promote health through research that is in keeping with indigenous values and traditions; provide protections for aboriginal research participants; address the needs of researchers for clear guidance for research involving aboriginal people; and emphasise respect for aboriginal culture, values and traditions in the conduct of health research. The guidelines also promote culturally competent, community-based participatory research and research partnerships.

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The impetus for these guidelines emerged from widely documented health disparities between Canadian Aboriginal people and non-Aboriginals. Concurrent with the recognition that interventions based on research results will ameliorate health disparities, there has been an increasing awareness of the history of harmful and unethical research with aboriginal communities. The result has been intense suspicion of research and reluctance of aboriginal people to participate, even when the research is expected to be beneficial. In developing the guidelines, representatives of aboriginal communities were actively engaged in discussions about their concerns.

Cook discussed some of the concerns raised by community representatives and possible recommendations for addressing them. These included:

- Community benefits – there should be mutual benefit from research for both researcher and community. Capacity building in terms of research and research ethics was noted to be mutually beneficial as it enables communities to protect their interests and facilitates future research interactions.
- Secondary use of data – All uses of collected information and biological samples require fully informed and explicit consent. Such materials might be considered as ‘on loan’ to researchers. Issues of confidentiality must be respected but where communities so desire they should be acknowledged publically for their contributions.
- Cultural appropriateness of research – Research conducted in cross-cultural settings should acknowledge and respect differences between researchers and community. Cultural norms need to be respected and information needs to be accurately translated into understandable language.
- Research interactions – Ongoing dialogue and open communication are important.

There should be opportunities for community input in the planning and conduct of research as well as in the interpretation of results. The importance of feedback of results to the community was also emphasised.

Cook concluded that research should protect the safety and rights of Indigenous communities while also maintaining and preserving community values.

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## **Ethical Space**

**Speaker** Willie Ermine – Canada

Willie Ermine discussed a philosophical perspective on the development and negotiation of ethical relationships in research, arguing for consideration of “the Ethical Space”. “Ethical Space”, a concept proposed by Roger Poole, is formed when people from different contexts, with disparate worldviews, encounter one another. Ethics is about boundaries and sensitivities to the violation of these boundaries by others. Ethical boundaries are determined by individuals, families, histories, culture, religion and collective principles. These ethical boundaries, in part contribute to defining the ethical space between people. Ermine argued that the space between people of differing worldviews, is important to

consider, because it is here that differences between paradigms are highlighted and the potential for mutual understanding is created. Ermine argued that the ethical space is an important component of interaction and warrants consideration in order to create conditions that would open channels of dialogue between disparate human communities. He argued for the adoption of a collaborative, partnership-based approach to interactions in order to facilitate this dialogue and to create the potential for new ways of thinking and understanding.

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### **Plenary Session                      The Ethics of Researching the Unstated in Pacific Contexts**

**Speaker**                      Kabini Sanga – Solomon Islands

Kabini Sanga discussed the challenges of conducting research in Pacific Contexts. He argued that conventional approaches to research and for considering the ethics of research are aimed at accessing and considering what he termed 'stated' or explicit knowledge. However, in indigenous Pacific contexts, much meaning, identity and understanding lies in what he called 'unstated' knowledge. This knowledge is inextricably linked to context and is implicit, experiential and relational.

Sanga argued that researchers and ethics committees working from a conventional, western paradigm often fail to understand the metaphors and the intricacies of the relationships in indigenous contexts and do not deal adequately with 'unstated' knowledge, focusing instead on what is stated or written down. He contended that owing to a lack of understanding of the way in which communities work, and an inability to read the 'silences' or 'unstated' knowledge, researchers approaching research from a conventional perspective may make false assumptions about the ways in which knowledge is constructed in Indigenous communities. This may lead to miscommunication and misunderstandings between researchers and communities which may undermine the validity of the research and may result in a misrepresentation of the communities. Furthermore despite a researcher's knowledge of and attempts to uphold research ethics, he may still fail to understand or connect with participants.

Sanga criticised conventional research methodologies and approaches to research ethics for ignoring the societies of certain Indigenous contexts and for privileging certain values which are assumed to be universal. He argued that connotations and implicit meanings in indigenous contexts might not be accessible to outsiders without extensive background knowledge, and so there is a need for input from the community on approaches to research and research ethics.

## He Anga Whakamua – Future Directions

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### KEY ISSUES

- Indigenous well-being
- Need for community empowerment
- Respect for indigenous perspectives
- Changing the culture of research

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**Chair**                      Robin Olds

**Rapporteur**              Zaynab Essack

**Plenary session**              **Strategies to Help Future Generations to Make a Positive Difference**

**Speaker**                      Ngiare Brown – Australia

Ngiare Brown discussed human rights and bioethics principles and practices for research with Aboriginal and Torres Strait Islander people. She argued that biomedical research is generally unpopular among these Indigenous communities due to historical practices of disempowerment and exploitation. Biomedical research is often poorly explained, presents an unacceptable risk-benefit ratio to participants and communities, and is predominantly researcher-driven.

She observed that biomedical sciences and Indigenous well-being are not, and should not, be mutually exclusive. Ngiare used four case studies/vignettes to demonstrate this point and argued that science should be used as a tool to shift the research paradigm and address power imbalances in the researcher-community relationship. Communities should be empowered to: 1) say “no” to research participation, 2) determine research priorities and the research agenda, 3) own the data and the intellectual property associated with research, and 4) make decisions on the dissemination of the research findings.

Brown noted the value of free and informed consent and outlined three levels of consent: community, organizational and individual. While community and organizational consent permit researchers to access individual participants, individual consent is essential for research participation. She asserted that the challenge is to change the culture of research by becoming outcomes-focused rather than individually-driven, ensuring accountability and providing ongoing feedback to communities. Ngiare concluded the session by advocating that research and researchers should protect and promote cultural integrity, build capacity through community partnerships, and yet still maintain scientific rigour. She also highlighted the value of being cognizant of Indigenous perspectives given that research cannot be conducted with Indigenous people without Indigenous people.

**Plenary session****Perspectives of the Chair of the International Union for the Conservation of Nature (IUCN) Commission on Environmental, Economic and Social Policy****Speaker** Aroha Mead – Aotearoa/New Zealand

Aroha Mead was unable to attend.

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## Closing Session

**Summary of the Ninth Global Forum on Bioethics in Research GFBR9****Speaker** Clive Aspin

Clive Aspin provided a summary of the forum. He noted that the forum demonstrated that there is diversity concerning what it means to be Indigenous and what it means to be vulnerable. He reflected that the importance of the role of women was aptly highlighted during the forum. Aspin reiterated that research is about human encounters and should lead to autonomy and self determination. Brief summaries of select plenary sessions were provided.

Aspin reflected on some of the important questions raised during the meeting. These included: 1) Who makes decisions? 2) Who determines what should be researched? 3) Who conducts the research? 4) What are researcher's responsibilities? 5) Who benefits from research? and 6) What is research? He ended with a quotation from Linda Tuhiwai Smith that "research is the dirtiest word in the world".

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**Thank you from partners, hand over to Chile for GFBR10****Speaker** Florencia Luna

Florencia Luna of FLACSO and member of the Steering Committee of Partners of the Global Forum on Bioethics in Research provided the thank you on behalf of the partners and handed over to the representatives from Chile for the Global Forum on Bioethics in Research 10 (GFBR10).

**Presentation: GFBR10****Speaker** Representatives from Chile

Dr M. Navarrete provided an overview of GFBR10 to be held in Chile in 2009. She gave a brief overview of Chile and noted that the theme for GFBR10 would be conflicts of interest in health research.

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## **Closing**

**Speaker** Eru Thompson - Aotearoa/New Zealand

Eru Thompson reflected on the experiences of the past days at the forum and thanked delegates for traveling from different corners of the world to attend the conference.

Delegates were invited to reflect on their experiences at the forum and of Aotearoa/New Zealand.

## Programme

## Day One - Wednesday 3 December 2008

9:00am – 10:00am	Mihi Whakatau/Welcome Hon Anand Satyanand - Governor General of Aotearoa/New Zealand
10:00am – 10:30am	Morning Tea
10:30am – 10:40am	Introduction of plenary speakers - Clive Aspin (Aotearoa/New Zealand)
10:40am – 11:10am	Plenary speaker Mason Durie (Aotearoa/New Zealand) <i>Bioethics, Indigeneity, and Maori Experience</i>
11:10am – 11:40am	Plenary speaker Karina Walters (United States of America) <i>Research Issues for Indigenous Populations</i>
11:40am – 12:10pm	Plenary speaker Bebe Loff (Australia) <i>Vulnerability in Research</i>
12:10pm – 12:30pm	Presentation Partners History of GFBR
12:30pm – 1:15pm	Lunch
1:15pm – 2:45pm	<p><b>Case Studies</b></p> <p><b>Stream 1</b> Francis Masiye (Malawi) <i>Partial Disclosure of Information versus Potential Benefits of Health Research</i></p> <p><b>Stream 2</b> Aceme Nyika (Tanzania) <i>Research on Orphans</i> Carol Zavaleta Cortijo (Peru) <i>Ethics Considerations in a Study about HIV and Syphilis in Native Communities in Peru</i></p> <p><b>Stream 3</b> Keymanthri Moodley (South Africa) <i>Domiciliary Consent in a Community-Based Tuberculosis Prevalence Study: A South African Perspective</i> Beverley Essue, Masoud Mirzaei, Kate Corcoran, Joyce Davison and Elaine Gordon (Australia) <i>Is it Really 'Too Hard'? : The Serious and Continuing Illness Policy and Practice Study (SCIPPS) Experience of Conducting Research with Vulnerable Groups in Western Sydney, Australia</i> Martin Anu Nkematabong (Cameroon) <i>The Local Media and Tenofovir Trial in Cameroon, 2005</i></p>

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	<p><b>Stream 4</b>  Cheryl Overs (United Kingdom)  <i>Sex workers Reject an HIV Prevention Trial in Cambodia</i></p>
2:45pm – 3:15pm	Afternoon tea
3:15pm – 3:45pm	Feedback from streams
3:45pm – 4:45pm	Panel Plenary <i>Justice and the colonised</i> Moana Jackson (Aotearoa/New Zealand) Debra Harry (United States of America) Naida Glavish (Aotearoa/New Zealand)
4:45pm – 5:00pm	Concluding presentation/summary of day's discussion Doris Schroeder (Australia)
7:00pm - Dinne	Plenary Pita Sharples (Aotearoa/New Zealand)

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**Day Two - Thursday 4 December 2008**

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9:00am – 9:15am	Welcome to Day Two/Summary of Day One Esther Cowley Malcolm (Aotearoa/New Zealand)
9:15am – 9:45am	Plenary speaker Vic Muñoz (United States of America) <i>Reducing Vulnerability Through Indigenizing Research Methodologies with Gender and Sexual Minorities</i>
9:45am – 10:15am	Plenary speaker Ian Anderson (Australia) Values and Ethics: Guidelines for Research in Aboriginal and Torres Strait Islander Health Contexts
10:15am – 10:45am	Morning Tea
10:45am – 12:15pm	<b>Case Studies</b> <b>Stream 1</b> Fatima Castillo (Philippines) <i>A Case for Iterative Informed Consent in Research with Indigenous Peoples</i>  <b>Stream 2</b> Rosa Castillo (Philippines) <i>Anthropology and Mining in the Philippines: Ethical Issues in Conducting Social Impact Studies Among Indigenous Peoples</i>  Roger Chennells (South Africa) <i>San Peoples of Southern Africa and Their Traditional Knowledge Relating to the Hoodia</i>

	<p><b>Stream 3</b> Clark Peteru (Samoa) <i>Access and Benefit Sharing issues in the Pacific: The Fable of the Mamala Tree Aceme Nyika (Tanzania) - The Trovan Trial Case Study: After Profits or to Save Lives?</i></p> <p>Fiona Cram (Aotearoa/New Zealand) <i>Regaining the Centre - The Ethics of Researching by, with and for Maori</i></p> <p><b>Stream 4</b> Melanie Cheung (Aotearoa/New Zealand) <i>Tikanga Maori in the Laboratory: Shaping Culturally Safe, Respectful and Dignified Scientific Practices</i></p>
12:15pm – 1:00pm	Lunch
1:00pm – 1:45pm	Feedback from streams
1:45pm – 3:15pm	<p><b>Case Studies</b></p> <p><b>Stream 1</b> Francis Masiye (Malawi) <i>Different Protocol Review Outcomes Between Developed and Developing Countries Ethics Committees</i></p> <p><b>Stream 2</b> Virginia Rodriguez (El Salvador) <i>Genetic Screening of Meso-American People with Psychiatric Disorders</i></p> <p>Moses Limo (Kenya) <i>Bioethics Regulation of Biomedical Research Involving Vulnerable Populations in Kenya</i></p> <p><b>Stream 3</b> Blanca Pelcastre-Villafuerte (Mexico) <i>Ethical Issues on Indigenous Communities' Reproductive Health and Gender Violence: Health Houses' Experience.</i> <i>Consideraciones éticas sobre salud reproductiva y violencia de género en comunidades indígenas: la experiencia de las casas de salud</i></p> <p>Maui Hudson and Karlo Mila-Schaaf (Aotearoa/New Zealand) <i>Negotiating Ethical Spaces for Indigenous Knowledge Production</i></p> <p><b>Stream 4</b> Le'a Malia Kanehe (Hawaii, USA) - The Indigenous Research Protection Act: A Model Tribal Code to Change the Research Paradigm</p> <p>Jeff Reading, Willie Ermine and Doris Cook (Canada) <i>Canadian Efforts in Addressing Ethics of Research Involving Aboriginal Peoples</i></p>
3:15pm – 3:45pm	Afternoon tea

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3:45pm – 4:30pm	Feed back from streams
4:30pm – 5:00pm	Plenary Kabini Sanga (Solomon Islands) The ethics of researching the unstated in Pacific contexts
5:00pm – 5:15pm	Concluding presentation/summary of day's discussion Donna Gardiner (Aotearoa/New Zealand)
7:00pm - Dinner	Plenary speaker Colin Tukuitonga (Aotearoa/New Zealand)

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### Day Three - Friday 5 December 2008

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9:00am – 9:15am	Welcome/Summary of proceedings so far/Introduce plenary speaker Robin Olds (Aotearoa/New Zealand)
9:15am – 9:45am	Plenary speaker Ngiare Brown (Australia) <i>Strategies to help future generations to make a positive difference</i>
9:45am – 10:15am	Plenary speaker Aroha Mead (Aotearoa/New Zealand) Perspectives of the Chair of the International Union for the Conservation of Nature (IUCN) Commission on Environmental, Economic and Social Policy
10:15am – 10:45am	Morning Tea
10:45am – 11:45am	Closing session Clive Aspin and representatives from the Scientific Programme Committee Summary of GFBR9  Florencia Luna Thank you from the Partners, hand over to Chile for GFBR10
11:45am – 12:15pm	Presentation Marisol Navarrete GFBR10
12:15pm – 12:30pm	Closing HRC Kaumatua, Ngarau Tupaea (Aotearoa/New Zealand)
12:30pm – 1:30pm	Lunch

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The Ninth Global Forum on Bioethics in Research concludes

### Access to Powerpoint Presentations

<b>Mason Durie</b>	<b>Bioethics, Indigeneity, and Māori Experience</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Mason%20Durie.ppt">http://gfbr9.hrc.govt.nz/presentations/Mason%20Durie.ppt</a> <a href="http://gfbr9.hrc.govt.nz/presentations/Mason%20Durie%20-%20The%20Ethics%20of%20Indigeneity.doc">http://gfbr9.hrc.govt.nz/presentations/Mason Durie - The Ethics of Indigeneity.doc</a>
<b>Karina Walters</b>	<b>Research Issues for Indigenous Populations</b>
<b>Bebe Loff</b>	<b>Vulnerability in Research</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Bebe%20Loff.ppt">http://gfbr9.hrc.govt.nz/presentations/Bebe%20Loff.ppt</a>
<b>Carel IJsselmuiden</b>	<b>History of the Global Forum on Bioethics in Research</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Partners%20of%20GFBR9.ppt">http://gfbr9.hrc.govt.nz/presentations/Partners%20of%20GFBR9.ppt</a>
<b>Cheryl Overs</b>	<b>Sex Workers Reject an HIV Prevention Trial</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Cheryl%20Overs.ppt">http://gfbr9.hrc.govt.nz/presentations/Cheryl%20Overs.ppt</a>
<b>Aceme Nyika</b>	<b>Research on Orphans</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Aceme%20Nyika%20-%20Orphans.ppt">http://gfbr9.hrc.govt.nz/presentations/Aceme%20Nyika%20-%20Orphans.ppt</a>
<b>Carol Zavaleta Cortijo</b>	<b>Ethical Considerations in a Study about HIV and Syphilis in Native Communities in Peru</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Carol%20Zavaleta%20Cortijo.ppt">http://gfbr9.hrc.govt.nz/presentations/Carol%20Zavaleta%20Cortijo.ppt</a>
<b>Keymanthri Moodley</b>	<b>Domiciliary Consent in a community-Based Study: A South African Perspective</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Keymanthri%20Moodley.ppt">http://gfbr9.hrc.govt.nz/presentations/Keymanthri%20Moodley.ppt</a>
<b>Elaine Gordon and Joyce Davidson</b>	<b>SCIPPS: Aboriginal Community Based Research</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Joyce%20Davidson%20and%20Elaine%20Gordon%20-%20slides%201-6.ppt">http://gfbr9.hrc.govt.nz/presentations/Joyce%20Davidson%20and%20Elaine%20Gordon%20-%20slides%201-6.ppt</a> <a href="http://gfbr9.hrc.govt.nz/presentations/Joyce%20Davidson%20and%20Elaine%20Gordon%20-%20slides%207%20-%202013.ppt">http://gfbr9.hrc.govt.nz/presentations/Joyce%20Davidson%20and%20Elaine%20Gordon%20-%20slides%207%20-%202013.ppt</a>
<b>Masoud Mirzaei</b>	<b>Overview of SCIPPS: the process of inclusion of vulnerable populations</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Masoud%20Mizraei.ppt">http://gfbr9.hrc.govt.nz/presentations/Masoud%20Mizraei.ppt</a>
<b>Kate Corcoran</b>	<b>SCIPSS: Strengths and Weaknesses</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Kate%20Corcoran.ppt">http://gfbr9.hrc.govt.nz/presentations/Kate%20Corcoran.ppt</a>
<b>Clive Aspin</b>	<b>Policy implications of SCIPPS: Making a difference for ATSI and CALD communities</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Clive%20Aspin%20-%20SCIPPS.ppt">http://gfbr9.hrc.govt.nz/presentations/Clive%20Aspin%20-%20SCIPPS.ppt</a>
<b>Debra Harry</b>	<b>Asserting Self-Determination in an Age of Biocolonialism</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Debra%20Harry.ppt">http://gfbr9.hrc.govt.nz/presentations/Debra%20Harry.ppt</a>
<b>Vic Muñoz</b>	<b>Reducing Vulnerability Through Indigenizing Research Methodologies With Gender And Sexual Minorities</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Vic%20Munoz.ppt">http://gfbr9.hrc.govt.nz/presentations/Vic%20Munoz.ppt</a>

<b>Ian Anderson</b>	<b>Regulating ethics and Aboriginal Health Research - An Indigenous Paradigm</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Ian%20Anderson.ppt">http://gfbr9.hrc.govt.nz/presentations/Ian%20Anderson.ppt</a>
<b>Roger Chennells</b>	<b>Indigenous Knowledge: The San and the Hoodia</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Roger%20Chennells.pp">http://gfbr9.hrc.govt.nz/presentations/Roger%20Chennells.pp</a>
<b>Clark Peteru</b>	<b>Access and Benefit Sharing Issues in the Pacific: The Fable of the Mamala Tree</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Clark%20Peteru.ppt">http://gfbr9.hrc.govt.nz/presentations/Clark%20Peteru.ppt</a> <a href="http://gfbr9.hrc.govt.nz/presentations/Clark%20Peteru.doc">http://gfbr9.hrc.govt.nz/presentations/Clark%20Peteru.doc</a>
<b>Fatima Castillo</b>	<b>A Case for Iterative Informed Consent in Research with Indigenous Peoples</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Fatima%20Castillo.ppt">http://gfbr9.hrc.govt.nz/presentations/Fatima%20Castillo.ppt</a>
<b>Rosa Castillo</b>	<b>Anthropology and Mining in the Philippines: Ethical Issues in Conducting Social Impact Studies Among Indigenous Peoples</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Rosa%20Castillo.ppt">http://gfbr9.hrc.govt.nz/presentations/Rosa%20Castillo.ppt</a>
<b>Aceme Nyika</b>	<b>The Trovan Trial Case Study: After Profits of to Save Lives?</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Aceme%20Nyika%20-%20Trovan.ppt">http://gfbr9.hrc.govt.nz/presentations/Aceme%20Nyika%20-%20Trovan.ppt</a>
<b>Ngiare Brown</b>	<b>Strategies to Help Future Generations to Make a Positive Difference</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Ngiare%20Brown.ppt">http://gfbr9.hrc.govt.nz/presentations/Ngiare%20Brown.ppt</a>
<b>Melanie Cheung</b>	<b>Tikanga Māori in the Laboratory: Shaping Culturally Safe, Respectful and Dignified Scientific Practices</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Melanie%20Cheung.ppt">http://gfbr9.hrc.govt.nz/presentations/Melanie%20Cheung.ppt</a>
<b>Blanca Pelcastre-Villafuerte</b>	<b>Ethical Issues on Indigenous Communities' Reproductive Health and Gender Violence: The Experience of Casa de la Mujer Indígena</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Blanca%20Pelcastre-Villafuerte.ppt">http://gfbr9.hrc.govt.nz/presentations/Blanca%20Pelcastre-Villafuerte.ppt</a>
<b>Virginia Rodriguez</b>	<b>Genetic Screening in Meso-American people with Psychiatric Disorders</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Virginia%20Rodriguez.ppt">http://gfbr9.hrc.govt.nz/presentations/Virginia%20Rodriguez.ppt</a>
<b>Maui Hudson and Mila-Schaaf</b>	<b>Negotiating Ethical Spaces for Indigenous Knowledge Karlo Production</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Maui%20Hudson%20and%20Karlo%20Mila-Schaaf.ppt">http://gfbr9.hrc.govt.nz/presentations/Maui%20Hudson%20and%20Karlo%20Mila-Schaaf.ppt</a>
<b>Le'a Malia Kanehe</b>	<b>The Indigenous Research Protection Act: A Model Tribal Code to Change the Research Paradigm</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Le'a%20Malia%20Kanehe.ppt">http://gfbr9.hrc.govt.nz/presentations/Le'a%20Malia%20Kanehe.ppt</a>
<b>Doris Cook</b>	<b>Research Involving Aboriginal Peoples: Canadian Policy Experience</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Doris%20Cook.ppt">http://gfbr9.hrc.govt.nz/presentations/Doris%20Cook.ppt</a>
<b>Willie Ermine</b>	<b>Ethical Space</b> <a href="http://gfbr9.hrc.govt.nz/presentations/Willie%20Ermine.ppt">http://gfbr9.hrc.govt.nz/presentations/Willie%20Ermine.ppt</a>

## List of Participants

Name	E-mail	Country
Eduardo Duro	eduro@unimoron.edu.ar	Argentina
Florencia Luna	florluna@pccp.com.ar	Argentina
Clive Aspin	caspin@med.usyd.edu.au	Australia
Ian Anderson	i.anderson@unimelb.edu.au	Australia
Jennifer Brown	JenniferSBrown@gmail.com	Australia
Ngjare Brown	n.brown@usyd.edu.au	Australia
Kate Corcoran	kcorcoran@med.usyd.edu.au	Australia
Joyce Davison	Joyce@amsws.org.au	Australia
Terry Dunbar	terry.dunbar@cdu.edu.au	Australia
Gillian Fletcher	gcfletcher@students.latrobe.edu.au	Australia
Elaine Gordon	Elaine@amsws.org.au	Australia
Bebe Loff	Bebe.Loff@med.monash.edu.au	Australia
Masoud Mirzaei	mirzaeim@med.usyd.edu.au	Australia
Jan Ritchie	J.Ritchie@unsw.edu.au	Australia
Matt Sammels	matthew.sammels@nhmrc.gov.au	Australia
Doris Schroeder	dschroeder@uclan.ac.uk	Australia
Paul Stewart	paul.stewart@unimelb.edu.au	Australia
Nariman Safarli	“azerma@hotmail.com / nariman@box.az”	Azerbaijan
Sanchoy Chanda	sanchoychanda@yahoo.com	Bangladesh
Ahmad Neaz	aneaz@aiub.edu	Bangladesh
Jose Edwin Soto Perez	edwinsop@yahoo.es	Bolivia
Leandro Loguercio	loguercl@lincoln.ac.nz	Brazil
Bocar Kouyate	bocar.crsn@fasonet.bf	Burkina Faso
Doris Cook	kanestenhawi@yahoo.com	Canada
Willie Ermine	wermine@firstnationsuniversity.ca	Canada
Phyllis Kinoshameg	pkinoshameg@explornet.com	Canada
Jeff Reading	jreading@uvic.ca	Canada
Maria Navarrete	mnavarrete@conicyt.cl	Chile
Rodrigo Salinas	rsalinas@minal.gov.cl	Chile
Linying Hu	hulinying@hsc.pku.edu.cn	China
Yuankun Wang	kmwyk@21cn.com	China
Sandra Realpe	REALPE@cohed.org	Colombia
Virginia Rodríguez	rodriguezvir_cirug@yahoo.com.mx	El Salvador
Kaia Kastepöld-Tõrs	kaia.kastepold-tors@ut.ee	Estonia
Kristi Lõuk	kristi.louk@ut.ee	Estonia
Shareen Ali	shareen.ali@health.gov.fj	Fiji
Eugénia Lamas	eugenia.lamas@inserm.fr	France
Anant Bhan	anantbhan@gmail.com	India
Prabha Chandra	prabhasch@gmail.com	India
Suriadi Gunawan	suriadig@cbn.net.id	Indonesia
Bakhyt Sarymsakova	bakhyts@yandex.ru	Kazakhstan
Victoria Marsh	vmarsh@kilifi.kemri-wellcome.org	Kenya
Indra Giraite	igiraite@gmail.com	Lithuania
Sharon Kaur	kaursh@um.edu.my	Malaysia
Blanca Pelcastre-Villafuerte	bpelcast@correo.insp.mx	Mexico
Giovanni Armaneo	giovanni.armaneo@waitematadhb.govt.nz	New Zealand
Rosemary Beresford	beresford@stonebow.otago.ac.nz	New Zealand
Joy Bickley Asher	bickleyasher@clear.net.nz	New Zealand
Amohia Boulton	A.F.Boulton@massey.ac.nz	New Zealand
Melanie Cheung	m.cheung@auckland.ac.nz	New Zealand
Esther Cowley-Malcolm	Es.Cowley-Malcolm@vuw.ac.nz	New Zealand
Fiona Cram	fionac@katoa.net.nz	New Zealand
Mason Durie	m.h.durie@massey.ac.nz	New Zealand
Lorna Dyal	l.dyal@auckland.ac.nz	New Zealand
Peggy Fairbairn-Dunlop	peggy.fairbairn-dunlop@vuw.ac.nz	New Zealand
Annette Finlay	annettef@nursemaude.org.nz	New Zealand
Eljon Fitzgerald	E.D.H.Fitzgerald@massey.ac.nz	New Zealand
Geoff Fougere	geoff.fougere@otago.ac.nz	New Zealand
Willem Fourie	willem.fourie@manukau.ac.nz	New Zealand
Graeme Fraser	g.s.fraser@massey.ac.nz	New Zealand
Donna Gardiner	dn.gardiner@auckland.ac.nz	New Zealand
Naida Glavish	NGlavish@adhb.govt.nz	New Zealand

Andrew Hall	AndrewH@burwood.org.nz	New Zealand
Maui Hudson	maui.hudson@esr.cri.nz	New Zealand
Moana Jackson	moanajac@paradise.net.nz	New Zealand
Huia Jahnke	T.Blake-Ponga@massey.ac.nz	New Zealand
Vanya Kovach	v.kovach@auckland.ac.nz	New Zealand
Kahu McClintock	waka@orcon.net.nz	New Zealand
Karlo Mila-Schaaf	karlodavid@xtra.co.nz	New Zealand
Helen Moewaka Barnes	h.moewakabarnes@massey.ac.nz	New Zealand
Helen Moriarty	helen.moriarty@otago.ac.nz	New Zealand
Emma Ngawhere	engawhare@adn.org.nz	New Zealand
Robin Olds	rolds@hrc.govt.nz	New Zealand
Neil Pickering	neil.pickering@stonebow.otago.ac.nz	New Zealand
Leonie Pihama	leonie@maia.maori.nz	New Zealand
Paul Reynolds	p_reynolds@xtra.co.nz	New Zealand
Paul Robertson	paul.robertson@otago.ac.nz	New Zealand
Kabini Sanga	kabini.sanga@vuw.ac.nz	New Zealand
Bruce Scoggins	bscoggins@vodafone.net.nz	New Zealand
Pita Sharples		New Zealand
Jane Sherard	jane.sherard@rodney.govt.nz	New Zealand
Barry Smith	poata_smith@xtra.co.nz	New Zealand
Armon Tamatea	armon.tamatea@corrections.govt.nz	New Zealand
Eru Thompson	eru.dot@xtra.co.nz	New Zealand
Colin Tukuitonga	Rebecca.Tufuga@minpac.govt.nz	New Zealand
Hope Tupara	H.Tupara@massey.ac.nz	New Zealand
Denise Wilson	D.L.Wilson@massey.ac.nz	New Zealand
Emma Wyeth	emma.wyeth@otago.ac.nz	New Zealand
Harun Ar-Rashid	bmrc@citechco.net	Pakistan
Arshi Farooqui	arshi.farooqui@aku.edu	Pakistan
Carlos Walter Sanabria Ortega	tesapea@gmail.com	Paraguay
Melvy Ormaeche Macassi	mormaeche@hotmail.com	Peru
Carol Zavaleta Cortijo	carol_zavaleta@yahoo.com	Peru
Fatima Alvarez Castillo	fatima.castillo@up.edu.ph	Philippines
Rosa Castillo	rosacordillera@yahoo.com	Philippines
Godofreda (Jody) Dalmacion	jrvd2003@yahoo.com	Philippines
Carel Ijsselmuiden	Carel@cohred.org	Philippines
Emerson Sanchez	em.sanchez@gmail.com	Philippines
Mohammed Khan	mmurtaz@hmc.org.qa	Qatar
Clark Peteru	clarkp@sprep.org	Samoa
Roger Chennells	scarlin@iafrica.com	South Africa
Zaynab Essack	essack@ukzn.ac.za	South Africa
Jennifer Koen	koenj@ukzn.ac.za	South Africa
Nicole Mamotte	Corbella@ukzn.ac.za	South Africa
Keymanthri Moodley	km@sun.ac.za	South Africa
Douglas Wassenaar	wassenaar@ukzn.ac.za	South Africa
Vajira Dissanayake	vajirahwd@hotmail.com	Sri Lanka
Anoja Fernando	anojaf@yahoo.com	Sri Lanka
Rajendra Surethirakumaraqn	srajendra@yahoo.com	Sri Lanka
Marie-Charlotte Bouésseau	bouesseaum@who.int	Switzerland
Edlyn Jimenez-Santos	jimenezsantos@cohred.org	Philippines
Aceme Nyika	anyika@amanet-trust.org	Tanzania
Darryl Macer	d.macer@unesco.org	Thailand
Sunia Foliaki	s.foliaki@massey.ac.nz	Tonga
Betty Kwagala	elkwagala@yahoo.com	Uganda
Catherine Elliott	Catherine.Elliott@headoffice.mrc.ac.uk	United Kingdom
Jacob Leveridge	j.leveridge@wellcome.ac.uk	United Kingdom
Cheryl Overs	cherylovers@gmail.com	United Kingdom
Elizabeth Shaw	e.shaw@wellcome.ac.uk	United Kingdom
Bob Simpson	Robert.simpson@durham.ac.uk	United Kingdom
Neil Small	n.a.small@bradford.ac.uk	United Kingdom
Angela Ballantyne	angela.ballantyne@yale.edu	USA
Debra Harry	dharry@ipcb.org	USA
Le'a Kanehe	lkanehe@ipcb.org	USA
Ruth Macklin	Macklin@aecom.yu.edu	USA
Joseph Millum	millumj@cc.nih.gov	USA
Victoria Muñoz	vm89@cornell.edu	USA
Barbara Sina	sinab@mail.nih.gov	USA
Karina Walters	kw5@u.washington.edu	USA
Thanh Hoa Le	imibtvn@gmail.com	Vietnam





