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## **Editorial: Bioethics and Ideas**

There are seven papers in this issue from authors around the world. First is my report of the AUSN Conference on Bioethics, Public Health and Peace for Indigenous Peoples, which was held in Mexico City as a Satellite event of the 12<sup>th</sup> World Congress of Bioethics, which I also attended, spoke at and chaired several sessions at. The theme of bioethics for indigenous peoples is stimulating and there is a variety of views that affect both medical ethics and environmental ethics. Since the American University of Sovereign Nations (AUSN) launched our MPH and Masters in Bioethics and Global Public Health (MBGPH) degrees we have also started to see a number of students from around the world start the first MBGPH in the world. The curriculum is on the last pages of this issue. There are many students and a lot of discussion between people across the world.

The paper by the Boyd's is stimulated by the discussions at ABC14 in India in 2013, and explores lessons which shape the future of who we want to become. Dr. Simonstein explores the ethics of autism and how our ideas of what it means to be a human in the current society shape diagnoses of health and wholeness. The broad meaning of health includes physical, mental and spiritual elements. The papers of Rafique and Muktamiroh examine definitions of what is ethical and unethical, against a milieu of what current "Bioethics" judges to be ethical and what is not. Aggarwal discusses abuses of ethics across borders, when the perpetrators knew what they were doing.

The final paper by Lajaunie et al. reports on meetings in Asia to discuss the ethics of cataloging infectious diseases and the agents that cause it. We will expect to see greater attention on ethics of public health with the emergence of Ebola as a disease affecting thousands not just tens or hundreds as in the past known epidemics. We hope more readers will submit papers for publication.

- Darryl Macer

## AUSN Conference on Bioethics, Public Health and Peace for Indigenous Peoples

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### Summary

This Conference was held all day on Saturday, 28 June 2014, at the **UNAM University Cultural Center in Tlatelolco**, Mexico City, Mexico. It was an official post-Congress side event of the 12<sup>th</sup> World Congress of Bioethics, and joined by 50 persons from around the world. The speakers came from many different nations, and stimulated discussion for all the participants to participate.

Bioethics is present in every community of the world in the relationships between people, plants and animals and nature. Indigenous Peoples are starting to rediscover their identities and philosophies. One part of this Conference was to examine the articulation of different ethical world views of nature, life and ethics, a second was how these are being applied to bioethical decision-making. A third part was to explore how these have, and could further contribute to, lessening the devastating public health divides inside and between many countries. There is a need to preserve the culture, traditions, health, welfare, and rights of Indigenous Populations throughout the globe. Indeed, health and public health are undisputedly foundational pillars of any sustainable community, society or nation and serve as positive attributes of peace. Finally we will explore the links between public health and peace for Indigenous Peoples.

It is hoped to publish the papers as a book. A yahoo network on bioethics and indigenous people was established, and further meetings of the network will be held. Those interested should send their interest in participation through Email to Darryl Macer.

### The Proceedings

After the Welcome, and Blessing of Participants and Thanks to the Ancestral Owners of the Land, and self-introductions, there were presentations.

Professor Darryl Macer, American University of Sovereign Nations (AUSN), and Director, Eubios Ethics Institute, Thailand, New Zealand and Japan, spoke on **Bioethics and Peace for Indigenous Peoples**. The AUSN represents a monumental historic development: this project represents the development of the First-ever US Medical School and First-ever Master of Public Health (MPH) program to be located on Native American Sovereign Land.

AUSN has an expressed and dedicated commitment toward academic excellence, the pursuit of truth and

social justice, the discovery of new knowledge through the attainment of the highest level of academia, scholarship, research, critical-thinking and analysis. AUSN is strongly based in the promotion of respect for human rights, fundamental freedoms, peace, the sense of human dignity, and the promotion of understanding, tolerance and friendship amongst all nations and all peoples.

AUSN is deeply committed to offering excellence of education, academia and scholarship, through which we will, provide our students the intellectual freedoms and ability to rejoice in the discovery of critical thought and the pursuit of excellence; Provide our students the knowledge and the commitment required for full participation and service as future members and leaders of the learned professions; properly prepare future leaders of our communities who will be committed and vigorously engaged in helping those who suffer, are burdened by social injustices, or who are stricken by disease, and do so for the benefit of all peoples and populations; Help our students understand the sense of obligation of citizenship, and need for a requisite commitment to the promotion of human tolerance and understanding, human respect, integrity, and human dignity.

AUSN has an expressed and dedicated commitment toward academic excellence, the pursuit of truth and social justice, the discovery of new knowledge through the attainment of the highest level of academia, scholarship, research, critical-thinking and analysis. Our research includes clinical, public health and social science research. The Institute of Indigenous Peoples and Global Studies, directed by Professor Darryl Macer, Provost of AUSN, undertakes innovative trans-disciplinary research. In this regard, while many wise people have tried to improve life and health outcomes for Native American Nations since the colonization, we believe we can greatly enhance health outcomes through integrating the wisdom, traditions, and latest scientific knowledge of Peoples from around the world, thereby enhancing the space for dialogue and learning between Peoples for a more sustainable world.

There are many types of research, as noted in the American Association for the Advancement of Science (AAAS) resolution on *Native American Science and Technology*: "Be it resolved that the Council of the Association (a) formally recognize the contributions made by Native Americans in their own traditions of inquiry to the various fields of science, engineering, and medicine, and (b) encourage and support the development and growth of natural and social science programs in which traditional Native American approaches and contributions to science, engineering, and medicine are the subject of serious study and research." [Adopted by the AAAS Council, January 31, 1975.]

AUSN shall promote community based participatory research, and the dissemination of the results of research to promote the health and well-being of all Peoples, while recognizing the sacred nature of knowledge, and international ethical standards at every stage of the research endeavor to protect the dignity of

individuals and groups associated with the research. This is supported by the U.S. National Institute of Health,<sup>1</sup> *“Community-based participatory research (CBPR) is an applied collaborative approach that enables community residents to more actively participate in the full spectrum of research (from conception – design – conduct – analysis – interpretation – conclusions – communication of results) with a goal of influencing change in community health, systems, programs or policies. Community members and researchers partner to combine knowledge and action for social change to improve community health and often reduce health disparities.” ...*

*“Advantages of community-based participatory research include:*

- *Joining partners with diverse expertise to address complex public health problems*
- *Improving intervention design and implementation by facilitating participant recruitment and retention*
- *Increasing the quality and validity of research*
- *Enhancing the relevance and use of data*
- *Increasing trust and bridging cultural gaps between partners*
- *Providing resources for the communities involved*
- *Benefiting the community and researchers alike through the knowledge gained and actions taken*
- *The potential to translate research findings to guide the development of further interventions and policy change.*

*The National Institutes of Health (NIH) continues supporting this collaborative approach”*

The Institute will be supporting students in all graduate programs offered by AUSN, as well as AUSN Research Fellows, and we shall encourage every graduate student to publish the results of their thesis in peer reviewed publications. Some of the projects of the Institute of Indigenous Peoples and Global Studies will include: Creation of a Repository of Ethical Worldviews of Nature; International Bioethics Survey; Attitudes to Life and Nature; Interventions to Improve Youth Motivation and Healthy Lifestyles; Integration of Research Methodologies and Paradigms for Indigenous Research; Decision-making processes for Community Engagement in Technology Decision-making; and the Integration of Values from Tradition and Modernity in Different Ethnic Communities.

Freedom of research, which is necessary for the progress of knowledge, is part of freedom of thought, and has been used to develop the crops that we depend on for food, the irrigation systems to provide water to agricultural land, medicines, housing, fire and all technology. Research is also conducted to describe the relationships between people, and their behavior. The applications of research shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole. Accordingly, AUSN and the

Institute shall promote a range of research methodologies that will be conducted in compliance with the highest ethical and scientific standards, consistent with millennia of research that has been conducted by inquiring human beings in every culture of the world.

Recognizing that research and the resulting applications open up vast prospects for progress in improving the health of individuals and of humankind as a whole, but emphasizing that such research should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of negative discrimination, AUSN and the Institute of Indigenous Peoples and Global Studies will promote research and its application to clinical medicine, environmental and public health and social and human sciences. AUSN was developed in close cooperation with the Fulbright Academy of Law, Peace and Public Health which has conducted clinical research on the relation of global health indicators and peace and has presented its findings throughout the world.

Both AUSN and the Fulbright Academy also have academic collaborative agreements with the Eubios Ethics Institute and other well established international institutions, to encourage joint community action, research, academic and educational activities. The Eubios Ethics Institute, founded and directed by Dr. Darryl R. Macer, Provost, AUSN, has been a repository and mainstay of research in bioethics for more than two decades and has wide international recognition and worldwide acclaim.

In addition to the research being conducted by AUSN and the Institute of Indigenous Peoples and Global Studies Faculty Members, graduate students, and Junior and Senior Research Fellows are engaged in research. We have brought together large networks of the persons globally, and invite further colleagues to join our projects. AUSN is a registered research institution with the US Federal Government. We have a growing number of collaborative agreements with other research and academic institutions around the world and have already co-organized and conducted a number of international conferences.

AUSN and the Institute of Indigenous Peoples and Global Studies adhere to the well recognized international standards for research which govern clinical and social research. No research or research applications shall prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or groups of people. Benefits from advances in medicine and research in general should be made available to all, with due regard for the dignity and human rights of each individual.

The second AUSN research institute is the **AUSN Institute for Sustainability Science and Knowledge Systems**. The Institute conducts research on integrating latest scientific knowledge and traditional wisdom and epistemology from cultures across the Americas and around the world. Our research combines theories and methods from the social sciences with relevant physical and life sciences and is aimed at advancing knowledge on various domains of

<sup>1</sup> [http://obssr.od.nih.gov/scientific\\_areas/methodology/community\\_based\\_participatory\\_research/index.aspx](http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/index.aspx)

sustainability science for building sustainable communities and societies.

The Institute's mission includes research, networking, and graduate education and capacity development, both in-house and in co-operation with an interactive network of academic institutions and international organizations. The current research agenda focuses on sustainability science, traditional knowledge systems, sustainable development, bio-cultural diversity, climate change, earth system and environmental governance, education for sustainable development, urban ecosystems, and science and technology policy for sustainability.

Possible Research Topics include: Traditional knowledge, ecosystems and preservation of biodiversity; Traditional knowledge and natural resource management; Traditional knowledge and climate change adaptation; Traditional ecological knowledge and sustainability; Integrating traditional knowledge and modern science for sustainability; Traditional knowledge and environmental ethics. For additional information contact: Prof. Govindan Parayil, PhD, Professor of Science, Society and Sustainability, Director, Institute for Sustainability Science and Knowledge Systems, E-mail: gpmash@gmail.com.

AUSN is registered as an official "Public Charity" by the United States Internal Revenue Service (IRS), under section 501(c)(3) of the Internal Revenue Code, which means that AUSN is able to receive tax deductible bequests, devises, transfers or gifts. AUSN welcomes all donations of any size, named or anonymous, as the donor chooses. AUSN is providing scholarships and other funding to empower people who are making the world better.

Professors Augusto Rojas-Martínez, M.D., D.Sc. and Jorge Aguirre, Ph.D., Universidad de Monterrey, and Instituto de Investigaciones en Bioética, Monterrey, Mexico, spoke on **The reifying grievances towards the "Indians" as bioethical problem and the philosophy of understanding**. They called for the need for historic reification of the Native Americans, and a hermeneutical approach to understanding the concepts of to know the "Indio" versus to recognize and understand the "Indio". The Conquest of America is the starting-point for the reification of their natives coined as "Indians". This may be motivated by the "universal" conception of the European conquerors. The "indio" word is currently and commonly used as a pejorative adjective in several Spanish-speaking countries. Latin American scholars are still struggling about the uniqueness of the Latin-American identity, largely based on the effort to "know" the roots. A hermeneutic vision may help, not just to understand, but to the appropriate recognition and comprehension of the Native Americans.

The Conquest led to unprecedented Interactions. Their proposal is that the philosophy of understanding applied to the plurality of the American natives brings their recognition and the appreciation of their values, not just the knowledge of them. This was followed by later subjugation (Colonization and Evangelization)

How this Reification was Constructed? The efforts of the conquerors (under the prejudice of superiority) to classify the natives as barbarous and idolatrous people that should be civilized founded on a perception of ethnic superiority produced a false recognition of the native. This false recognition produced a deformation of the aborigines affecting natives, mestizos, and ruling conquerors. Isabeline's "Encomienda" was a legal system used by the Spanish Crown in which a colonizer was granted a specific number of "indios" as obedient labor force in exchange for their services to provide instruction in the Spanish language and the evangelization. The neglected use of this system ended in abuse and torture in several instances. The reification was useful to dominate, humiliate, rape, dispossess, torture and enslave the natives, particularly to those unwilling to obey to their new masters.

The Philosophical and Ruling Dogmas included: Lord and servants → intellectual entity (close to God) and obedient inferior creatures (based on Aristotelian and Thomism grounds). Civilian and Catholic laws are imposed in these terms. These conceptions still survive, complicating the efforts of several institutions and nations to afford their native components, affecting public policies, programs and even, the environment.

The Hermeneutical Approach is that we don't need knowledge and tolerance, we need understanding. "The philosophy of understanding is recognized as the process by which a foreign culture can be understood" (Taylor). Hermeneutics may solve the Indian reification allowing a real recognition that provides political, legal, psychological, and social answers. We need a "Fusion of horizons" (Gadamer). Recognition will pave the road for an multi-ethnic and plural civilized society.

How to get started? Stage 1: Interpreting the foreign from the own and its assimilation

Step 1: The study of the prejudices (self-vision). Understanding the semantic horizons preserved in their original language. Prejudices anticipate the comprehensive thinking and facilitate self-awareness. Prejudices help to create semantic horizons that may change depending on individual experiences and help to construct the awareness of personal change → Fusion of Horizons

Step 2. The Semantic Horizons. Based on: Traditions (culture), Historic background, and Language and socialization. All these play intermingled roles in the construction of individual and communitarian horizons. Their manipulated or wrong interpretation may drive to reification. Huichol Cosmovisions and Art.

Step 3. Interpretation and Self-Awareness. All human subjects are interpreters: we project our prejudices, but we also self-expose them. We should be aware of our prejudices, they don't necessarily represent the "ultimate true". We should learn how to manage them to clarify between the own and the foreign

Stage 4. Stimulate the Historical Perspective. What means the understanding of the "Indoamerican" plurality in addition to the single knowledge? Two dynamics: Dynamics of tradition and the Dynamics of the interpreter.

Fusion of Horizons can be achieved by using the Epokhē (Bracketing). Ability to keep a distance to make sense of the observations (to find the “true” and “false” prejudices) and to show respect for the other identities and traditions. This involves the recognition of time distances and a positive probability to understand → abandon own prejudices while allowing the prejudices of the counterpart. Both parties realize different semantic horizons → Both are able to understand the “other” and avoids the clash of cosmovisions.

They talked about the Colloquium of the 12: The Meeting of Tlamantines & the 12 Franciscans in 1524. Assuming the Identity from the Differences: The Dialogue. **The** differences result after clearing the identities. False identities generate damaging deformities. Differences help to find the other’s horizon and to reinforce the own horizon. Then, it merges an opportunity to expand everyone’s horizon (avoiding unilaterality). Instead of pursuing the “true”, Differences help to find the other’s horizon and to reinforce the own horizon. Then, it merges an opportunity to expand everyone’s horizon (avoiding unilaterality). It eases comprehension and adaptation to a new situation for both parties. Thus Identification precedes Recognition. There is a need to balance Knowing the other (pretending control over other’s intellectuality) vs Understanding the other (realize the “other” through the dialogue).

Contemporary Realities include the Challenge of Understanding a New Multicultural World. The “indio” and the “mestizo” confront a new world dominated by the Free-Market economy and uncontrollable migrations. The hermeneutical approach may be relevant in present times. Still, several American native nations resist or aren’t interested in any Eurocentrist or Western-type model of life.

They also made note that not all colonial actions were reifying (e.g. Jesuit missions in Paraná). Aboriginal and colonial worlds weren’t homogeneous in terms of geography and time, Spaniards took advantage of the Tlaxcaltecs to colonize Arid-America under a sedentary style. In some instances, Spaniard liberated some tribes from brutal and anthropophagic domination.

Hermeneutics today may be conceived as a deconstructive and decentralizing thinking. This philosophy strives for an understanding above the pretension of the “Universal True”: This is the **Fusion of the Semantic Horizons**. Neither, Eurocentrism nor the hermeneutical approach should be considered simply as “right attitudes”. In Mexico 2010 among the overall population of 112,336,538, there are 62 Aboriginal languages (roots: Nahuatl, Maya, Zoque), and the population speaking indigenous languages is 6,011,202. In addition much of the population as Native Ancestry in Mexico.

In conclusion a hermeneutical approach to the process of interculturization in Latin America may teach us to respect the “horizons” of natives and conquerors, despite any justification. This approach may be relevant for recognizing other cultures. It has limitations. It can provide a “single” method for understanding. For each

intercultural confrontation, new horizons should be consider. Recognition of the prevailing native communities and admission of cultural differences is crucial for gaining others respect and for opening new ways to responsible interactions.

Professor Jason Robert, Ph.D. and Ms Mary Drago, Lincoln Center for Applied Ethics, Arizona State University, Phoenix, Arizona, USA, spoke on **How the research imperative in biomedicine can drive health inequities. There are hazards of the research imperative (Callahan 2003) including** the drive to gain scientific knowledge for its own sake, a felt moral obligation to relieve pain and suffering, a rationale for pursuing research goals that are of doubtful human value or potentially harmful, a public relations tool to justify the chase after profit, the pursuit of worthy goals even at the risk of compromising important moral and social values. These combine together in the cultural belief that we are morally obligated to undertake research.

In the extreme there are claims that “the blood of those who will die if biomedical research is not pursued...will be upon the hands of those who don’t do it”. But not all research is equally valuable in terms of method, nor ethically in individual or social terms. The type of research matters; so too does the rationale, the social value, and the justification. Credibility – science produced with integrity: good technical data, sound methods, reasonable analysis, responsible argument, and acknowledgement of study limitations. Legitimacy – sensitivity to divergent values among stakeholders, unbiased and fair analysis (especially of opposing views); applies to research agenda setting and knowledge production. Saliency – usefulness to a range of stakeholders, achieved through asking and answering meaningful, significant questions in a way that may inform a range of processes.

“The questionable social value of today’s biomedical research enterprise is the elephant in the room of research ethics. It’s time for research ethics to acknowledge this elephant, and to give it the kind of ethical scrutiny that other less important topics receive. Research ethics needs a robust analysis of research value” (Dresser 2012). Our contention is that the social value of research must include attention to health inequities. “We’ll publish, you perish” is not the kind of science with impact that we should be doing.

Mary Drago presented her case study on the Akimel O’odham (The River People), “Researched to Death: Diabetes and the Akimel O’odham. What were the expectations of the study for NIDDK and the Akimel O’odham and did the outcomes meet those expectations? Was there a burden of participation experienced by the Akimel O’odham in relation to the study objectives? What paradigm is clinical research among American Indian/Alaskan Native communities likely to follow in the future?

There were ideas for researchers of a “Thrifty Genotype” being found in a “natural population”, a homogeneous community, obese, inbred. They were seen as stable population-but a sense of urgency. A

longitudinal epidemiological study, with the observation of genetics and natural history of Diabetes Mellitus (DM). From the community there were also expectations that there would be a Holistic approach to care, so Research physicians should be given direct care privileges. Indian Health Service (HIS) physicians should be allowed to conduct research. Computerized health records were established. There were two beds in a comprehensive health center assigned for research personnel to conduct inpatient investigations. In 1968 the tribe wrote a white paper, called "It Must Happen", gave a yellow arrow to proceed.

A longitudinal epidemiological study including a biannual exam of the tribal members aged 5 and over. The focus was on observation first, to describe the prevalence and distribution of diabetes in the community, to determine the occurrence and distribution of the diabetes-related sequelae, especially the vascular complications, to attempt to identify the factors leading to the development of glucose intolerance, to identify factors associated with the development of the complications of diabetes and explore a genetic link.

Every two years there were tests of all over 30 years of age (but after 1100 persons were included they increased scope to all those over 15 years of age. The tests included a modified Glucose Tolerance Test, Tests of renal function, Retinal exams, EKG, Serum creatinine and cholesterol, X-Rays of chest, thighs & calf, and a variety of other diabetes-related tests. Simultaneous studies were made on Gallbladder Disease – cholecystogram; Arthritis Study – X-Rays; Muscle Biopsies; Stays in PIMC inside respiratory chamber; Type I diabetes; Racial Admixture and Migration patterns. The research outcomes included classification, criteria and best testing practice for diagnosis for Type I and Type II diabetes; Association between obesity and Type II diabetes; Early intervention of renal disease extends life; Diabetes and the fetus; Higher perinatal loss; Congenital anomalies; Increased risk of obesity in adolescence; Increased risk of diabetes before age 20; Gestational diabetes may decompensate to NIDDM later in life. The outcomes to the tribe were direct, such as, NIH/NIDDK contributed to Tx, a hemodialysis machine at PIMC, advocacy that laser surgery for diabetic retinopathy should be made available at PIMC, paid for a part-time podiatrist at GRIC. Indirect benefits were publicity may have led to federally funded educational and prevention programs through the HIS. There was also adverse publicity that the Disease was characterized by some as "the Pima Plague", and the subjects were identified in all journal articles published by the researchers and described as "inbred" and "obese". The tribe has a Diabetes prevalence > 50 % over age 35 years. The Diabetes incidence (from 1967-2007) increased in ages 5-14, but decreased in ages 25-34. No significant changes were seen in other ages.

As a result there were some other outcomes such as the develop of Gila River Health Care, a Medical Health Care and Research Code, and Tribally Driven Participatory Research. In conclusion the Akimel

O'odham were a convenient population to study. There was then a discordance of expectations which left the Akimel O'odham feeling as if they had been "researched to death".

Professor Manuel H Ruiz de Chávez, Chairman of the National Bioethics Commission of Mexico and President of the local organizing committee for the 12<sup>th</sup> World Congress of Bioethics, congratulated the organisers and participants for the conference.

Professor Octaviano Dominguez Marquez, Mexico; Chair of the IberoAmerican Bioethics Network spoke on **Bioethics and Diabetes Prevention Efforts**. Public health without bioethics is like rabbit stew without the rabbit. Bioethics needs to be emphasized more. 15 years ago he was coordinator of a program to study diabetes in 6 border states of Mexico and 4 states of USA. The Pima plaque denotes the importance of diabetes to the Pima tribe. Diabetes is very important for Native Americans and Hispanics, and we need to give it high importance.

Local efforts to control diabetes are really inefficient, and we have had so many deaths. We need national efforts, but most of these are insufficient at present. Mexico is leading in the number of amputees and eye surgery, and these are very costly. The impacts of diabetes go on to affect the whole family. How to solve a problem if it is so engrained with the patient's lives, and has multiple causes. We have to ask bioethicists to solve these challenges, because patients do not change their diet. They are competent individuals and even understand the physiology, they do not easily control their disease.

It is ironic that the leading cause of death in physicians is type II diabetes and the second is heart disease. Doctors are not the appropriate model for people to follow. Even nurses are the same, so why don't we do something to control these diseases? Diabetes is a biological fact, and genetic, and familial...it is problematic. No one is doing the necessary things to stop it. These social concerns need to be addressed by bioethicists. How can we operationalise ourselves for bioethical concerns in public health. Bioethics is everywhere and we have to reflect on this.

The 80% of people do not have positive outcome, they face a mountain. As Muhammad said, we need to go to the mountain. It is sad that patients just expect a simple pill to cure the disease, and this is not how diabetes works. How can we reach these states with highest rates of diabetes with bioethics to overcome this. Bioethics has a commitment to responsibility for health and if we can teach this to people, families and companies, we may move in the right direction. Bioethics principles are the central point, but justice is most important to inculcate values into people. Sociologists like Max Weber have said that the learned fabric is important.

Dr. Chamu Kuppaswamy, Senior Lecturer, School of Law, University of Hertfordshire, UK, talked on **The challenges faced in articulating a traditional**

**worldview.** Traditional and indigenous cultures are rediscovering their identities and philosophies, yet this is not a smooth or an easy process. It is wrought with challenges and is a perilous journey, which might ultimately be a wasted one. This paper will list and analyse some of the key challenges facing researchers both from within the aforesaid communities and from without. The success and failures in such journeys have an impact on the development of alternative ethical views and worldviews, affecting the development of legal, social and political agendas around indigenous knowledge and bioethics.

Traditional systems are under attack from various interests including from Feminists and so-called Progressives. Some of the objections are right, but the new models are usually not holistic, and also come from their own agenda, which is not conducive to traditional systems. Globalisation of technology is an exciting development. It is great for many things but yet it's characteristic features are non-traditional. But technology easily transmits – not necessarily holistically. The TKDL database may not be always good because disclosure is exposure.

The challenge is to make tradition as 'evolving' and as living. Tradition is not just for the museum, tourism or for entertainment. But we buy into it one way or the other as this is prevalent in our system. So we should rediscover tradition, make space for rediscovering tradition, then make it living. Great initiatives – recognition of living heritage.

Law should be a facilitator to make space for tradition. Law has been used to facilitate, but currently predominantly legal means are not aligned to tradition. Traditional legal systems often have too much emphasis on some systems over others – and most traditional or indigenous systems are ignored.

Law can also be seen as performance – an exciting traditional practice. The appropriation of tradition is an important issue as she is an IP lawyer. Ideas are important and are the basis of an innovation economy. We are standing on the shoulders of giants – what if these giants are from traditional and indigenous communities? They are not recognised. There are still further questions to discuss such as What is traditional? What is not? What is indigenous? Most danger comes from destruction of identity through appropriation. These questions are not a concern of IP law - we are not equipped to deal with it. Understanding is that there are other means of recourse. There aren't! Law is intimately related to exercise of power, and Tradition is bygone power. Attempts such as the Traditional origin certificate (WIPO) do not appear to be progressing, and TCE and TK documents are still struggling.

Contributions to property and ownership should be recognised – probably the biggest contribution comes from traditional societies, since property distribution underpins a lot of what modern society is (e.g. Rich lists!) Traditional notions of ownership and property are diverse, more suited to modern times than they have been credited for.

Professor Héctor Ochoa, PhD with Gerardo

González, MD and Rosario García, MA, Department of Health, El Colegio de la Frontera Sur, San Cristóbal de Las Casas, Chiapas, México, spoke on **Interculturality in health and community-managed Primary Health Care in indigenous Chiapas: the cases of the Casa Materna and the Zapatista health system.** They presented two experiences of health in a context of cultural dialogue. They analyzed the involvement of communities and indigenous people in health care, and presented the experience of the *Casa Materna* in the Hospital of San Andrés Larráinzar within the maternal and child health care model proposed by the Ministry of Health. In this model, traditional midwives attend indigenous women's pregnancy under the specificities and characteristics of their ancient culture. We also present the Zapatista health system; which is based on the training of health promoters, infrastructure and joint participation of Zapatista supporters and international civil society to build clinics and hospitals.

In the presentation, they talked from the perspective of cultural dialogue about health care, the importance of autonomy and bioethics of health care in intercultural contexts. The maternal mortality rate in indigenous populations is ten times higher than national average. The Mexican constitution recognizes the use of traditional med as a right; and in theory the secretary of health has an obligation to recognise, respect and promote the use of traditional medicine and adapt services to the needs and traditions of indigenous populations. Traditional birth attendants (TBA) are indigenous women who learned their skills in specific cultural ways, usually by dreams or revelations. Casa maternal is a place where women can come to give birth with their TBA. The consent of women was in their own homes.

Dr. Rekha A. Kumar, PhD., IRB Member, Office of Research and Development; Senior Lecturer, Department of Law, University of Botswana, Gaborone, Botswana, spoke on **Challenges of the application of genetic research in Africa: the case study of Botswana.** She said that WHO emphasized that States should promote, as appropriate, the establishment of Ethics Committees at national, institutional and local levels that are independent, multidisciplinary, multi-sectoral and pluralistic in nature (WHO/UNAIDS Guidelines (2000)). The value of medical developments for helping to treat and/or eliminate life-threatening illnesses was also recognized. In line with the advancement of technologies, there has been intensification in international research in studies involving human genome. Rapid growths globally in collection of biological samples, millions of samples are exchanged across the world. Thousands exported from Africa to overseas destinations, however for some justified reasons such as inadequate local capabilities to undertake certain investigations e.g. gene sequencing and genotyping, more experienced and specialized labs are overseas; lack of reliable storage facilities in most African countries; no reagents in African countries or too expensive; investigators have limited budgets to stay in the country and so forth. On

the other hand, it is also perceived that Africa sets as a good source of cheap samples, due to its numbers, lax regulations and no or almost not so strong monitoring of research activities. The fears of exploitation and justice issues are inherent.

The presentation focuses on the collaborative studies with institutions/ researchers in/ from Botswana more specifically researches involving genetic and human specimens initiated in recent past. Botswana does have its regulatory framework which includes international (e.g. The Nuremberg Code (scientific merit and value); WMA Declaration of Helsinki; Good Clinical Practice (GCP); CIOMS; ICH and the US CFR 45 Part D) and local documents ( e.g. Standard Operating Procedures (draft); Botswana Clinical Trials Guidelines ( 2008); the National Health Research Bill (draft). Botswana in addition to its domestic laws and policies, and also is one of five of the 31 countries in the sub-Saharan region, to have a National Ethics Committee, research-institute and university based committees.

International ethical guidelines infer a presumption that there are common values between different countries and different cultures or there are universal values in bioethics all over the world. However, the presumption is challenged in Botswana as has been in some other countries in the continent in recent past. The arguments for and against universal values are examined in the presentation. The present effort probes that compliance with research regulations is only one of a number of important factors in an institution's ethical culture of research. Equally important are a clear articulation of the ethical reasoning that underlies the regulations, and efforts to redress power imbalances by encouraging open communication among international collaborators and other stakeholders in genetic research studies.

There is a great deal of pressure between International Guidelines and traditional Culture in Bioethics. Ethical considerations are crucial throughout these research studies. Nevertheless, what is most important here is that research ethics needs are met with more specific focus into community/cultural setups (African settings/context) – as is the case of Botswana- a strong culturally bound society.

The challenges in genetic research are manifold and at different levels in the country. To begin with, the role played by external and internal researchers at various stages from research idea initiation, protocol writing, study conduct, data entry and analysis, to publication of manuscripts or dissemination of results remains ambiguous. It continues to include but not limited to inadequacy of resources (human and financial), limited expertise both ethics committee members/reviewers at national and institutional levels to review complex protocols, training needs (scientific design, risk assessment, understanding of trial phases, monitoring/audits, issues of after trial benefits).

The presentation further raises serious concerns with regard to protection of individual rights, dignity of tissue/samples sources e.g. against stigma and social discrimination; uncertain implications of findings; for individuals and families, groups and general public and

overall national interests of local/nationals (here Botswana). The paper also highlights that issues like technology transfer; access to research results and products, sharing intellectual property and maintaining control and ownership of human tissues/samples among others requires clear and careful consideration of what/how to be regulated are crucial for such collaborative research's goals and its sustainability.

Ms. Carmela M. Roybal, Tewa Nation; RWJF Doctoral Fellow in Sociology, University of New Mexico, USA; Senior Research Fellow, Fulbright Academy of Law, Peace and Public Health, spoke on **Bridging Knowledge Systems to Rebuilding Healthy Communities: Reflections on the social and cultural determinants of health for Indigenous Populations in the United States**. She gave examples and talked on Colonization, Policy, and Racial Projects. She gave examples of Lokota "Mitakuye Oyasin", Dine' ( Navajo) "Walk in Beauty" and Tewa "Wi dat". She said that family is first, We are all family, and we leave no one behind. She also talked on Unconditional Love; We are Love; Land is Sacred; Water is Life; Honor is Everything.

Ms. Natalie Despot Belmonte, Bolivia, and currently a PhD student in Universidad Nacional Autónoma de México, spoke on **Exploring the homo-communitas and its relationship with Pachamama**. The human race faces an ecological imbalance which has strong implications for the social, economic, political, and even ontological fields. This imbalance risks not only the survival of our species, but the entire biosphere. Faced with these challenges, Latin America shows that it is a place which seeks to establish a balance with nature, with a vision that is independent of the market's technopractical aims. I believe this is why Latin America protects and maintains its own cultural, religious and natural heritage.

Humans are disconnected from nature: they do not seem to know their place in the universe and the value of natural processes any more (Goodin,1992; Lee,2003; Mumford,1971). While it seems that human beings are aware of the need to protect the biosphere, they have not re-constructed a sustainable relationship with nature. The reason may be due to the technological and pragmatic rationality that prevails nowadays. Humanity may regain ecological balance by assimilating a renewed spirituality that recognises human dignity, a sense of community, and the value of nature. She believes this kind of spirituality is still alive in the Latin America cultures.

Some examples of the Andean cultures, specifically the Aymara and Quechua and their relationship with nature were shared, in order not only to recognise their ancestral cultural heritage, but also to be able to understand their socio-political structure and interpretation of the meaning of divinities and their relationship with nature. In Bolivia for example the diverse indigenous population remain deeply connected to their land for social, political, economical and spiritual reasons. Their belief is that within their territories, the



divinities and mother earth complement each other to create life (Montenegro, 2008: 38). When asked to define progress three similar concepts in three different ethnic languages helped to clarify what the Bolivian Indigenous population understood as progress. Suma qamaña in Aymara, qesumaj kausay in Quechua and ñadereco in Guarany – translated to “Living Well” (Bolivian Ministry of Planning and Development, 2010). The concept of “Living Well” indicates a sustainable balanced life between man, woman, and nature. The word encompasses the inseparable interconnection between the material life of production and reproduction with the social and spiritual life (ibid).

The indigenous socio-political structures of the Aymara and Quechua remain organised in ayllus (tribal agricultural communities (Morales, 1992: 14-15). Prior the Spanish colonisation within the ayllu land was communally owned and work was equally divided. Each ayllu was divided into two with one half in the valleys and the other half in the mountains. In this way the whole ayllu could trade and benefit from goods from the different ecological zones (Klein, 1993: pp 22-25). The Aymara and Quechua are connected to their ayllu not only for socio-political and economical reasons but also because of the belief that within the ayllu the divinities and pachamama (mother earth) complement each other to create life (Montenegro: 2008:38). The key principles within the ayllu are complementarity, equality and reciprocity. The ayllu could be described as a direct- democratic structure, where authorities are elected by complete communal consensus. The authorities are not permanent as the ayllu holds a rotating system. Rivera notes that “through this combination of consensus and compulsory rotation, in the long run all the families of the ayllu end up holding the principal positions of authority, in ascending order” (Rivera, 1990: p 100). These communities were, and some of them still are, agricultural, decentralised communities, organised in bioregions and deeply connected to their land for spiritual reasons.

In this manner they display all the characteristics of what would be considered a sustainable society according to political ecology. A new kind of civilisation and individual is required to make this transition possible.

Eckersley, refers to this new type of person as “homo communitas”. She reviewed this concept from the perspective of the indigenous culture (Albo, 1998) and phenomenological philosophy (Heidegger, 1985; Jonas, 1979). This will contribute to the rediscovery of a Latin American tradition, mostly ignored by the Western perspective. Understanding how Indigenous societies were, and are still structured, will provide us with a solid base to create the programme required to trigger a radical anthropological and socio-political transformation as well as to bridge the gap between green theory and practice.

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Dr. Daniel Piedra Herrera, MD PhD, Academy of Sciences of Cuba spoke on **Peace, health and bioethics**. He outlined several UNESCO Bioethics Declaration and national statements. In the real world these principles are violated regularly, for example in Iraq, Colombia, Afghanistan. We need efforts to ensure bioethics is not to remain a dead letter.

There was **General Discussion** led by the Darryl Macer and Professor Marcela Martha Rodriguez Alanis, Director, Instituto de Investigaciones en Bioética, Monterrey, Mexico. Marcela said that we should treat indigenous peoples as ways of life, inspirations, not just sources of knowledge.

Participants agreed to share emails and establish a yahoo listserve. A yahoo list serve is open for anyone interested in these issues please email to [indigenusbioethics-subscribe@yahoogroups.com](mailto:indigenusbioethics-subscribe@yahoogroups.com).

The participants said that they would circulate papers, and a book was planned when enough papers were prepared. Future meetings would be held. Everyone was asked to share their lessons of the day, and there was much positive feedback. There was suggestion for joint research activities. There should not just be reflection on theory but on real problems and population problems. Materials such as a poster and information could also be prepared.

Darryl Macer thanked again the Instituto de Investigaciones en Bioética, Monterrey, Mexico for support, and the organisers of the World Congress for provision of the room in the **UNAM University Cultural Center in Tlatelolco**, which is in the grounds of an Aztec temple. Plaza de las Tres Culturas, is so called because in one city square you can see three different time periods of Mexico City's development mixed together: the pre-hispanic Aztec temple grounds of Tlatelolco, the 16th-century Spanish Church of Santiago, and a modern 20th-century skyscraper, the University Cultural Center Tlatelolco for UNAM.

## Thinking and Technology

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The 2013 Asian Bioethics Association conference in Chennai India addressed technology, its impact and significance in contemporary bioethics. One of us (AB) attended and heard many interesting presentations at the conference. It was an interesting juxtaposition reading a paper written as part of a graduate course on Heidegger (JB). Heidegger's essay, "The Question Concerning Technology" has an Aristotelian philosophical approach to technology and what technology reveals about thinking.

Our main concern will mirror Heidegger's – which is more essential to technology: *poiesis* or *praxis*? The answer to this question will aid in our attempt to re-establish the fundamental relationship between thinking and technology, and will lead us to examine the ethical concerns of our society, which has become increasingly integrated with various forms of technology. In the end we will bring up the idea of human knowledge as it relates to purpose and point out how we believe it differs from the role of technology.

### Essence and Aristotelian Causality

Heidegger, in the tradition of Aristotle, is interested in the essence of a thing to help us understand what a thing is. When considering the essence of a thing, we are looking for what is common between all things that are named the same. Taking the essence of a thing to help us understand what a thing is raises an important philosophical question: does a "thing" that is a living organism have essence in the same way technology does?

When we merely make use of technology and consider it a tool in the hand of the user, we may ignore the essence of technology. It matters in order to separate what technology is from what human agents do with it. What is technology? Is it a human activity, and/or a means to an end? Heidegger suggests it is both. The creation of the technology and the end to which a technology is put are both human activities. How we use a machine and how we might seek to use a person or living organism are different moral questions. We may find the ethical meaning buried in the way we design an instrument and the ends to which that design are aimed, whereas, it would be ontologically problematic to use humans as a mere means. Manipulating a machine to perform a desired function may be justified as a means to an end, an end we can reasonably justify as good. Technology is usually understood as good or not in direct proportion to its teleology: how human agents use it. Living things, trees, dogs, and other humans may be subject to human agency, but the essence of a living thing has its own ontology.

The use of technology and the creation of technology then are human actions whose intent is

subject to moral judgment. However, if uncovering the essence reveals what is true about anything, it logically follows that the essence of technology should be more helpful in the case of understanding so that its usages are not abused. Heidegger is especially concerned with the origin of technology, in order to further understand its uses. We must ask, "What is the instrument?" but also, "Why was the instrument created?" The end(s) sought and the means used by any technology shape causality.

Considering technology as a means, Heidegger encourages the consideration of the 4-fold Aristotelian causes – material, formal, final and efficient. In order to express the four causes more clearly, Heidegger describes a silver chalice. A silver chalice is indebted<sup>2</sup>, says Heidegger, to its material cause, silver, it is indebted to its formal cause, chaliceness, and it is indebted to its final cause, the circumscribing (or giving bounds to) that identifies chalice as a "sacrificial vessel." In a rough sense, human beings are the embodiment of the fourth cause; the efficient cause.<sup>3</sup> Man essentially combines the three other causes when he considers the creation (the creation aspect being the efficient cause) of a thing, and also gives rise to the circumstances in which a chalice shall be used.

In terms of Heidegger's example of the chalice, the Silversmith (man in general) is "that which bounds" and is taking part in *telos*<sup>4</sup>, combining the three previous causes in order to give rise to the possibility of a chalice, being what it is. Again, causes or origins can guide the meaning or use of an object, so it is helpful to consider if one wishes to use the object in a practical way. It is because origins point to uses, that Heidegger considers *poiesis* or creation, to be more essential to technology than its *praxis* or process/development. Creation is a generative form of revealing that is physically established. When one creates, one reveals a truth<sup>5</sup>. Creation, in this way, is always related to *alethia* (revealing).

### Technology Reveals

What has the essence of technology to do with revealing? Heidegger would answer; Everything. It is the instrument, the functioning thing that is the fundamental characteristic of technology. What the instrument/technology can possibly do reveals a

<sup>2</sup> Being responsible for its primary characteristic. This starts something on its way into "arrival," says Heidegger, which I take to mean something along the lines of fruition.

<sup>3</sup> This is really more of a point to be made in what technology discloses about thinking, but I included this sentence because it logically seemed to follow. I will bring it up again in the next section.

<sup>4</sup> Often misinterpreted as aim/purpose. Heidegger broadens this term to also include the idea that circumstance arises before purpose. In fact, he means to say that the creation of the chalice is also dependent on the formation of Christianity and the need for such an instrument.

<sup>5</sup> It is important – but perhaps the subject of another paper – to keep in mind that Heidegger believes everything revealing also discloses a form of concealing. Nothing is ever wholly clear.

creators' intent<sup>6</sup>. However, original intent is not always the way technology is later used - this again points to the distinction between poesis and praxis. Technology reveals truth because it is an extension of the purpose in the mind of the creative author. In a similar fashion, poetry reveals the artful mind and creativity of the human agent.

Up until the times of Plato the word *techne* was associated with *epistino*, and both were associated with knowledge in the broadest sense. Aristotle distinguished the terms with respect to what and how they reveal. *Techne* is a mode of revealing that is hidden before the instrument is used. *Epistino* reveals the ways the instrument is put to use, the means to achieve an end which is determined by the user or moral agent.

Consider the creation of the telescope and the microscope. Through a high powered telescope we gain an appreciation of the cosmos – the universe containing our island home. The microscope magnifies things too small to be observed with the human eye. Both instruments allow the human mind to understand things hidden, to reveal something true about natural processes of the cosmos and the subcellular world.

Technology, for Heidegger, is especially concerned with creative revealing<sup>7</sup> that orders or keeps things at standing-reserve<sup>8</sup>. This means we create things, which can harness, or eventually harness, the energy of certain natural resources. In this way, we now “challenge” the Earth as Heidegger says, instead of maintaining it like we used to as farmers who cultivated and cared for the land. Now we mine, drilling large holes in the Earth, to locate resources like coal, in order to use them in specific ways. In the case of coal, we burn it to fuel other machines or to keep ourselves warm. The process of creative revealing that orders or keeps things at standing-reserve is the essence of technology (for Heidegger), otherwise known as *Gell-stell* or enframing. The enframing process allows man to pursue all physical revealing, which is called by Heidegger, destining.

Regarding destining, it is important to understand that man cannot control revealing. Although technology has made us think we are, in some ways, the source of things, we still lack certain abilities. In a sense man plays a role, when he comes to identify what can be revealed, but he cannot determine revealing independently.<sup>9</sup> In Heidegger's terms, we are the ‘considerer.’ Technology helps us realize that revealing

is secondary to natural process or physics. Heidegger here gives the example of the flower blooming, revealing itself on its own, without man, compared to the silver chalice, whose formation is dependent on man. Here again we see man as the efficient cause in the formation of the chalice.

### What Technology Reveals About Thinking

Technology appears to guide our thinking, convincing us that we possess great power, and the essence of technology, enframing, leads us to seek out what is most primary. Heidegger says, “...in the realm of thinking, a painstaking effort to think through still more primally what was primally thought is not the absurd wish to revive what is past, but rather the sober readiness to be astounded before the coming dawn,” (Heidegger and Krell, p 327). This quote captures our attachment to technology and the concept of destining. Our future is caught up in revealing new truths, as if we were solving a mystery. Through technology we are put into a position to reveal the actual, in the mode of ordering, as standing-reserve. We find the actual everywhere and reveal it.

However, this idea for Heidegger is problematic. As we take on the role of enframing, which positions the real everywhere in standing-reserve, we fail to seek other ways of revealing or unconcealment. Enframing creates an epistemological paradigm that cancels out other ways of revealing truth. Revealing is altogether threatened by the consumption of ordering. Not only do we seek truth for the sheer sake of making it useful, but also we fail to allow for mystery. We fail to consider the power of not-knowing. But Heidegger maintains hope for change.

Quoting Holderlin: “But where danger is, grows/the saving power also,” Heidegger uses the medium of poetry juxtaposed to technology as two creative activities (Heidegger and Krell, p333). The choice is not a coincidence, as Heidegger has already pointed out that poesis is essential to understanding technology. Heidegger considers the idea expressed in Holderlin's poetry to be the answer to the problem of enframing. While enframing is the essence of technology, and has influenced our thinking and relationship toward the world, Heidegger makes the distinction that enframing, as an essence, is not the same type of essence we refer to as genus.<sup>10</sup> Rather, essence, in regards to enframing, means to “essentially unfold;” where something shows how it administers itself, develops, decays, holds sway, etc.<sup>11</sup> Where something unfolds, it reveals, but does not necessarily endure. What endures has long been referred to as what is essence, according to the ideas of Plato and Socrates.<sup>12</sup>

<sup>6</sup> Meaning, technology is not merely a means.

<sup>7</sup> I combined the terms ‘creative’ and ‘revealing’ after I read Heidegger's explanation of *techne*, which he says is often, only translated as meaning “skill” but also applies to the arts and what is poetic. What is poetic requires skill, but also, it seems, reveals or uncovers some truth. Therefore I rendered that technology, with its root *techne*, must be a combination of the two – creating and revealing.

<sup>8</sup> Ready to order into action.

<sup>9</sup> Furthermore, enframing leads us to seek out the practicality of things – what is *only useful*. We begin to categorize the world based on what is most useful, and fail to appreciate any other value of things.

<sup>10</sup> Heidegger uses examples of trees - oak, cedar, cherry, pine, to point out how all trees within the genus of tree maintain a treeness that make them what they are.

<sup>11</sup> Heidegger references Goethe here & *die Weserei* which basically means “city hall” or “where the city unfolds.”

<sup>12</sup> Known as *eidōs*.

### Does the Essence of Technology Endure Permanently?

We think, to this question, Heidegger would respond, "no". Again, we must be reminded of what technology discloses about thinking, and our limitations in the role of revealing as considerer, but not the source of all revealing. "Only what is granted endures. What endures primarily out of the earliest beginnings is what grants," (Heidegger and Krell, p336). Heidegger wishes to remind us of the roots of technology and allow our thinking to return to these roots. Heidegger points out that revealing, in *techne*, was once considered one-in-the-same with *poiesis* (Heidegger and Krell, p 339). Heidegger says the solution to overcoming enframing is to seek out other ways of revealing truth. Forms of art such as poetry play a role in revealing truth, but at the aesthetic level, and not for the sake of use and efficiency. Art also can maintain an air of mystery that technology cannot. Art leaves the world open. Art reveals possibility – not is use, but in meaning. It challenges our thinking, forcing us to at least consider a variety of answers to life's questions. In this way, art is especially conducive to Heidegger's idea of "meditative thinking," which stands in opposition to "analytic thinking" that he believes plagues philosophy and diminishes Being. By equating art with technology, our thinking can realign itself with the original meaning of seeking out the actual, and can perhaps prevent further damage to the Earth, and our relationship to the world.

### Technology in the Hands of Moral Agents

Does a computer sitting in an office reveal its meaning by what it is or by what it represents as potential utility? The importance or danger of the instrument is related to the capacity of the instrument and the thinking of the person using it. It also represents the thinking and creativity of the designer who constructed the instrument and what intentional use it was designed to do. The design and intent of the original instrument may lie quite distant from the use to which it is later put and herein is a link between technology and thinking.

The technology used to create a clone of a DNA molecule is useful in making it possible to diagnose some diseases. If diagnosis leads to treatment and improved quantity and quality of life, the use of the cloning technology is good, because it is used for a good end. The same technology essentially makes it conceivable to clone an animal. Efforts to do so have revealed unanticipated harms due to complex genetic circuits. In cases of endangered species, increasing traits that help the species survive might appear to be a good end so long as the balance of predator-prey relationships is understood. If cloning a species would re-establish an ecosystem to the benefit of all, would it be a good use of the technology? Genetically modified food advocates claim that it is the answer to feeding the world's population, whereas critics warn that genetically homogenous plants would be subject to widespread destruction should a biothreat (such as a fungus) emerge that kills the entire homogenous crop.

Can art be compared to the creation of a computer, or genetic cloning? The admonition to seek out other ways of revealing truth is important. Art offers a vision, be it bright or dark, of the possibilities. Technology posits possibilities through human creativity. Creating art and designing an instrument reveal a thinking process; one can cause a reader or observer to see things differently, and both can empower a new possibility. The moral axis with which poetry is written, and the technology is designed reveals the end or potential of the designer, but not necessarily the utility or means to alternative ends another user may employ.

It is the thinking behind the creation, and the utility of the technology by those using it that is morally accountable. A poem and a computer may be designed to communicate. What is communicated can be morally open to judgment. It is beyond the reach of this paper to explore whether the moral judgment made is relative or absolute.

### Knowledge

Knowledge is belief accompanied by explanation (*logos*). We give reasoned accounts of thought, motive, and intent through speech. To differentiate between two things, we need to identify each thing's characteristics. What separates a tree from a person is not life in general but a form of life, human life vs. tree life. One can only make the separation when each thing is known and understood clearly. Herein lays the moral challenge with thought and technology: our use of technology evolves and changes depending on how diverse users differ in their intent. The machine cannot account for itself, but the user of it is subject to giving an account of its utility and *telos*.

The human thinks creatively in both constructing the technology and in putting it to diverse functions. The human essence is not the same as the technology's essence. The essence of a human is grounded in dignity, in freedom to choose actions for specific purposes, as moral agents. Technology has essence of a different type, one based on *telos*, function and it is important not to confuse these purposes – functionality should not be our greatest human concern.

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## Differential Perception of Human Life Value and Bioethics

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The objective of this paper is to reflect on the potential of perception of different intrinsic value of human life in influencing ethics violations particularly in health and medical research. It is opined here that sometimes the members of research community and business entities perceive their own life to be more precious than other lives. The factor discussed for bioethical violations is the perception of different importance of human lives of people of different races, cultures, regions, countries or ethnic origins in the minds of fellow humans. The learned medical scientists know what morally sound medical research is; however sometimes they are influenced by their perception of value of other human's life. The researchers for clinical or experimental trials are drawn to inhabitants of underdeveloped or developing nations as they perceive that if in case there is any harm to the clinical subjects' health, there won't be any big payouts; as the worth of those subjects is less than clinical subjects in a developed country. In some of the unethical human experimentations, the effected populations were vulnerable due to their social or economic conditions, being a war personnel, mentally depressed or being inmates in prisons. This vulnerability of the subjects makes the researcher throw away the concept of 'equality in the value of human life'. As long as this mentality of different values of human life persists, it will feed into ethical violations in spite of regulations or laws.

Undertaking research to find the cures for diseases has been going on since time immemorial. Sometimes, the researchers resort to unethical practices in the zeal to find the cures. This has been brought up by unearthing the research carried out by various entities and research personnel during the last number of years. A summary of some of the known bioethics violations from 1845 to 2007 has been compiled by Adams<sup>1</sup>.

Recently, an atrocity against medical science perpetrated by United States Public Health Service physician John Charles Cutler, in Guatemala over 60 years ago has come to light and US Presidential Commission concluded that ethical standards of the time were disregarded but was silent on the reason that why they were disregarded<sup>2</sup>. This bioethics violation was uncovered by Professor Susan Mokotoff Reverby of Wellesley College. Reverby found the documents in 2005 while researching the Tuskegee syphilis study, in Cutler's archived papers<sup>3</sup>. The then U.S. Secretary of State Hillary Clinton and U.S. Secretary of Health and Human Services Kathleen Sebelius issued a formal apology<sup>4</sup> to the Guatemalan government for the experiments in which Guatemalan prisoners were intentionally infected with syphilis and then treated with antibiotics.

Is life of a human being precious? What is the intrinsic value of humans? It is opined here that sometimes the political and business setup and the research community only thinks 'their own life' to be precious enough and not of others. Here 'their own life' sometimes includes being in same race, same ethnicity, same community, same region, same religion, same country or similar economic status country. All 'other lives' are perceived to have minimal value. The value with which you weigh the other individual modifies your behavior and actions towards them. The experiments carried out on Jews in Nazi camps, on African-American people in Tuskegee experiment, and on Guatemalans in Guatemala Syphilis experiment point to this perception. Not only is this true in clinical medicine research but also in today's political setup. A life lost in Bhopal accident is no less precious than the livelihood loss due to BP oil spill. Although the environmental toll in BP oil spill was huge, the cost in human lives, compared to Bhopal, was minimal. Would have BP or any American company committed \$20 billion if the same incident would have occurred on the shores of a third world country – is a multimillion question? The value of life or the earnings value of those in the third world countries (India's in case of Bhopal accident) or other ethnicities (Jews in case of Nazi Experiments) were thought to be irrelevant. On 18<sup>th</sup> October, 2011 first stage of swapping of 1,027 Palestine prisoners took place for return of one Israeli citizen pointing to the different perceptions of human lives of two communities.

The economic principles and economic perceptions have also fueled the exploitation of the vulnerable in disease research. A few medical scientists want to achieve fame and economic power, even if it is at the cost of life of humans or harm to humans. The medical research community and the pharmaceutical industry clamor for new disease cures and want to have financial gains. It tries to have the least costs for clinical trials and sometimes resorts to non-ethical studies<sup>5</sup>. This leads them to countries where the cohort is relatively poor and uneducated, and the scientific labor is cheap. It gives them access to naive people who are suffering from the disease being investigated but are not taking medicines for other diseases. This population which is uneducated, socially backward and having meager resources of livelihood are targeted as the researchers and the pharmaceutical companies know that neither these guinea pigs nor their families have the resources to fight in local courts, leave alone International courts or courts in the countries where the principal investigator (if international) or the main headquarters of the pharmaceutical company is. Even if these guinea pigs die supposedly from the drug's adverse effects and if there is a hue and cry in the local media, it will seldom be picked up by international media. Further as the research has a local CEO, Co-Principal-Investigator or local clinical trial manager in the country, all or most of the onus of the disaster will be put on his/her shoulders as was done in case of Bhopal industrial accident.

It is not that the learned and powerful medical scientists do not know what morally sound medical research is. This is also true in presence or absence of bioethical codes and Acts. Several international codes provide guidance on the ethical conduct of clinical research including the Declaration of Helsinki, Council for International Organizations of Medical Sciences (CIOMS), International Guidelines for Biomedical Research, and the UNAIDS Guidance Document on Ethical Considerations in HIV Vaccine Research. All the research proposals go through IRB or equivalent committees. Even if there are violations these codes are recommendations, not legal imperatives nor any documentation is provided to the subjects if they have any legal course in case something happens.

The main factor for bioethical violations is the perception of different importance of human lives of people of different races, cultures, regions, countries or ethnic origins in the minds of fellow humans. This was probably a reason that the Guatemala Syphilis experiment was not conducted in North East America but in Guatemala and that too at the behest of US government's department. Dr. John C. Cutler of United States Public Health Service, the main Principal-Investigator for Guatemala experiment knew that the study was not morally sound. "As you can imagine," Cutler reported to his colleague, "We are holding our breaths, and we are explaining to the patients and others concerned with but a few key exceptions, that the treatment is a new one utilizing serum followed by penicillin. This double talk keeps me hopping at time." In a second letter he repeated his concerns that "a few words to the wrong person here, or even at home, might wreck it or parts of it...." PHS physician R.C. Arnold, who supervised Cutler from afar, was more troubled than was Cutler about the ethics of the project. Eight months after the "Doctors' Trials" at Nuremberg had ended, he confided to Cutler, "I am a bit, in fact more than a bit, leery of the experiment with the insane people. They cannot give consent, do not know what is going on, and if some goody organization got wind of the work, they would raise a lot of smoke. I think the soldiers would be best or the prisoners for they can give consent. Maybe I'm too conservative....Also, how many knew what was going on. I realize that a pt [patient] or a dozen could be infected, develop the disease and be cured before anything could be suspected...In the report, I see no reason to say where the work was done and the type of volunteer."<sup>3</sup>

This shows that the United States Public Health Service doctor/s and official/s were well aware of the lack of bioethics in the experiment, turned a blind eye to the immorality and went ahead with the experiment nevertheless. In official communication (in 2010) on the atrocity committed on Guatemalan subjects it was stated that adequate human subject safeguards were not in place<sup>4</sup>.

It is well known that at Auschwitz and Buchenwald the Nazis engaged in human experimentation. Dr. Josef Mengele is remembered for experimenting on around 1,500 sets of twins (only 100 survived)<sup>6</sup>. The Guatemala Syphilis medical experiments took place in

1948, about the time that U.S. officials were prosecuting Nazi officials for subjecting human beings to gruesome medical experimentation<sup>7</sup>. The irony is that this was going on during and just after the Doctor's trials at Nuremberg (United States of America vs. Karl Brandt, et al.) in which the U.S. put Nazi doctors on trial for experimenting on prisoners without consent.

Further, in 1945 Project Paper clip was initiated. The U.S. State Department, Army intelligence, and the CIA recruited Nazi scientists and offered them immunity and secret identities in exchange for work on top secret government projects in the United States<sup>8</sup>. This shows that how serious the powers to be were concerned about medical ethics in that time period. The US government which was actively pursuing cases against Nazis for conducting medical experiments on an ethnic population thought that it is fine if they carry out similar experiments in Guatemala as long as the world does not know about them and efforts are made to keep these shrouded in the veil of secrecy. It was basically a different set of rules for you; a different one for me; a different life value for Americans and a different life value for Guatemalans.

The Guatemala experiments surpassed Nazi experiments in the sense that these were carried out on citizens of another country after taking permission from Guatemala's government in exchange for money and aid. In Nazi experiments, Jews were their own citizens. If the international pharmaceutical companies or their public health authorities don't go directly to citizens of underdeveloped/developing countries for "not so ethical" clinical trials, their governments act as a conduit for these trials. This is primarily done through direct or indirect black mailing by providing aid to the governments or corrupting the politicians of those countries. In lieu of aid from the US government, the Guatemalan's authorities at that time turned a blind eye to the details and protocols of the trials.

Another fundamental reason for most of these unethical human experimentations as it comes out is that the effected populations are vulnerable. They might be vulnerable due to their social or economic conditions, unwilling or willing partners to fight a stronger enemy, war personnel, and mental and other inmates in prisons. This vulnerability makes the researcher throw away the concept of 'equality in the value of human life'.

So let us go back to the basic question of perception of value of life and start to evaluate answers to some questions. Is the 'value of life' of a Caucasian of one country different from the value of life of a Caucasian from another country? Is the value of life of a Caucasian different than the value of life of an African-American (Tuskegee experiment); or value of life of a citizen of developed country equal to value of life of a citizen of an underdeveloped country? Was the value of life of a Jew less than that of a German in 1940's or is the value of life of a Jew more than the value of a life of a Palestinian in 21<sup>st</sup> century? Is the value of life of a person of one religion equal to value of life of a person having other religion? Is the value of life of a rich CEO of a multinational company equal to the value of a life of

a spiritual person in a third world country? Is the value of life of a medical researcher more than the value of life of an experimental human subject in an underdeveloped nation? As long as the answers to these and similar questions provide an unequal life value in the minds of the people even though outwardly they may exclaim- all humans are equal; the bioethics violations will be hard to be curtailed in spite of any regulations or laws. One of the basic human values that drives bioethical violations is the perception that 'my life' has more intrinsic value than other human's life.

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## Autistic Syndrome Disorders (ASDs) and forgotten mine-fields: What should parents do?

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In a recent paper, Patricia Walsh<sup>1</sup> has argued that there might be advantages alongside the disadvantages in some forms of disability; for instance in Asperger Syndrome (AS), she tells, which is a form of autism. I am fully committed, to the rights and equal worth of disable people; and (with Pat Walsh) I am

equally glad and thankful that the acceptance and support for AS is increasing. However, some difficult questions about reproductive ethics regarding disabilities remain. For AS may be better than the alternatives in the 'autistic spectrum' disorders (ASDs); however, according to health advisers, autism is a serious condition; even in its milder form. Parents may 'just' wish to have a healthy child; why should this be morally wrong? Moreover, supposing there is a genetic test for AS, should parents 'hide' from ethicists while trying to avoid having another child with autism? (Personal communication). This question, I believe, deserves a separate paper. The present paper will ask whether parents trying to prevent autism, including AS (if they could), and curing autism (if they could) would be morally wrong. The first part of this paper describes AS according to Walsh and the Centers for Disease Control (as part of the ASDs). The second part of the paper shall look at ASDs in Israel. Finally, we will ask whether parents trying to prevent having children with autism including AS (if there were such a test) would be wrong.

## Introduction

To better understand the issues involved, I shall recall Patricia Walsh<sup>1</sup> claims about Asperger Syndrome (AS):

- AS is a form of autism; which is a disabling condition; but AS might also involve an unusual ability.
- AS has a strong genetic component, so it may be common in some 'gifted' populations.
- The gene for unusual ability in AS seems to be coupled with the disabling gene(s).
- Curing the disability *in utero* (if we could) might diminish the unusual ability.
- Screening out embryos or terminating pregnancies with diagnosed AS could prevent the birth of geniuses.

Walsh claims also that the unusual ability that (might) appear in AS alongside the autistic features may 'compensate for the disabling condition.'<sup>1</sup> This may sound reassuring for the parents who have to decide whether or not to terminate a pregnancy. However, other remarks such as 'grieving', 'mourning', 'desperation' and 'guilt' appear often along with the diagnosis of autism,<sup>4</sup> as parents try to 'adjust' or 'accommodate' to the 'new' situation.<sup>1</sup> It seems that the 'autistic features' Walsh refers to, may cause considerable suffering to the persons involved.<sup>5,11</sup>

## I. Autistic spectrum disorders (ASDs)

According to the Centers for Disease Control and Prevention (CDC), autism is a group of [developmental disabilities](#) that can cause 'significant social, communication and behavioral challenges.'<sup>6</sup> The CDC observes that people with ASDs share some similar symptoms, such as problems with social interaction, but there are differences in when the symptoms appear, how severe they are, and the exact nature of the symptoms. Further, the CDC notes that autism typically appears during the first three years of a child's life, occurs approximately in one out of every 250 births and is four times more prevalent in males than females.

There are some indications that the prevalence of Autism might be as high as 1 in 150<sup>7</sup> or even 1 in 100.<sup>8</sup> Unarguably, trying to take an informed decision about aborting (or not) a fetus diagnosed with ASDs, prospective parents may want to look at the website of the CDC. The CDC defines ASDs in three categories as follows:

- **Autistic Disorder** (also called 'classic' autism) is characterized usually by significant language delays, social and communication challenges and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability.

- **Asperger Syndrome** is usually characterized by some milder symptoms of autistic disorder. People with AS might have social challenges and unusual behaviors and interests. However, they typically do not have problems with language or intellectual disability.

- **Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS;** also called 'atypical autism') characterized with some of the criteria for autistic disorder or Asperger syndrome, but not always. People with PDD-NOS usually have fewer and milder symptoms than those with autistic disorder.<sup>9</sup>

The CDC notes that autistic children may become obsessive and even hurt themselves. Further, about 40% of children with an ASD do not talk at all. Another 25%–30% of children with autism have some words at 12 to 18 months of age and then lose them. Others may speak, but not until later in childhood.<sup>11</sup> Moreover, according to Johnson (2004), while autism may affect each person differently, from very mild to severe, even in its milder form, autism is considered as a serious condition.<sup>10</sup>

## Causes and cures

The cause(s) of autism remain unknown.<sup>9</sup> The MMR vaccine was 'blamed' as the cause of autism, a decade ago; but this has been overruled.<sup>12</sup> Prenatal high levels of testosterone have been found correlated with some autistic characteristics,<sup>13</sup> but this does not necessarily prove that high levels of testosterone do cause autism.<sup>14</sup> Currently, the view is that autism is the result of a conglomeration of genes for individual traits that come together in any given person and are modified, or turned on/off, early in development, by the presence or absence of environmental factors.<sup>15</sup> At the time of writing there is no 'cure' for autism. However, in response to desperate parents trying to find a cure for their newly diagnosed autistic child, treatments that include gluten-free diets, forced hugs, massage, hyperbaric chambers, and others, have been suggested, and are on the market. None of them cure autism.<sup>16</sup> Early intervention with Applied Behavioral Treatment (ABA), may positively affect the communication and daily skills of about half of the children with ASDs symptoms;<sup>17-19</sup> But really 'early' is a key factor for ABA treatment.

## II. Autism in Israel

Until quite recently, the only 'treatment' available to autistic children and adults was admission to psychiatric hospitals. In 1974 the Israeli Society for

Autistic Children (ALUT), was established. ALUT aimed at better serving the needs of autistic children and their families. ALUT did start individualized educational programs and special education services in ALUT nurseries and treatment centers for toddlers ('Alutaf'). ALUT has also established rehabilitation and occupational centers for adults and has created residential 'Homes for Life' for autistic people.<sup>20</sup> Currently, children diagnosed on the Autistic spectrum are entitled to a 'special needs' monthly allowance from the Israeli Social Security Institution. Beyond the monthly allowance, if the child is under the age of three, his/her integration in a special communication day-care center is conditioned on recognition by the Israeli Social Security Institution.<sup>21</sup> If the child is aged 3-21 years old, there is the option of registering the child to a special education framework.<sup>III</sup>

The creation of ALUT in Israel, has undoubtedly improved the lives and the welfare of autistic children and their families. Nevertheless, even with such an impressive educational care (almost one to one), prospective parents Israelis would try to avoid having a child with autism (personal communication. According to Remennick,<sup>22</sup> Israeli women would take genetic tests to avoid any disability in their child). The genetic source(s) for autism remain mostly unknown up to date (although some forms of autism are related to the condition known as Fragile X<sup>23</sup>); although when and if a screening test for autism were developed, it is most likely that Israeli women would avail themselves of this test. Abortion in Israel is illegal; unless the pregnancy threatens the woman's life; results from rape or adultery; the mother is underage, or over 40; or the fetus has a major malformation or illness.<sup>24</sup> It is plausible, that since Autism is a serious condition, abortion on the grounds of any of the ASDs (including AS), would be permitted in Israel.

## III. Should parents try to avoid AS?

Walsh persuasively argues against avoiding actions such as genetic screening and abortion of a fetus because of AS.<sup>1</sup> However, let us suppose there was through prenatal care a way to avoid or prevent 'autistic like behavior' (autism), with a daily intake of, say, raw onions; Would we then argue that parents would be wrong if they took this measure to prevent autism? Prospective mothers take folic acid while planning a pregnancy; expectant mothers, avoid drinking alcohol or smoking. None of these 'avoiding' acts seem to be controversial. On the contrary, these prenatal practices are generally perceived as good examples of responsible parenthood. Now, suppose that the *postnatal* 'environmental' factor(s) for autism were known, what avoiding actions would parents be morally obliged to take then? Suppose the genetic 'unusual ability' is dormant; and it could not develop unless the environmental factor – which may also cause autism – is at work. Would we then advise parents to 'produce' AS? Moreover, would it be ethical that parents do not avoid the environmental factor(s) which may cause AS so that the child could get an 'unusual ability'? Further, should society 'expect' that parents set off the



environmental cause(s) for autism in AS in order to 'cultivate' the 'human genius'? Obviously, neither the prenatal nor the postnatal *environmental* actions to avoid or prevent AS are controversial; which suggests that the real 'avoiding acts' towards AS remain genetic screening and abortion (PGD pre-implantation diagnosis; and PND prenatal diagnosis correspondingly).

#### **A note about Stephen Hawking and minefields**

Patricia Walsh<sup>1</sup> notes that Stephen Hawking is a famous theoretical physicist *because* he suffered from a disabling disease (Motor-Neuron Disease). Indeed, Hawking did select well how to conduct his life; and he has had, undoubtedly, a worthwhile and productive life. However, had Hawking been able to *really* select his future, would he have chosen to become ill in the first place? Obviously, his choice was constrained by a disease he did not ask for. Further, with a diagnosis of MND he knew he could neither become a football player; nor an astronaut (as Hawking himself remarks in his many interviews). Hawking, most probably, would have preferred to stay away from MND.<sup>IV</sup> However, after ineffectual medical intervention, a rational person would try to make the best of her disabling condition. Hawking was rational; he took the better option available for him, after a harsh prognosis. He also has proven it was the right decision for he has been amazingly successful. Yet great achievements in spite of, or because a disabling condition, must 'invite' further disabling events? Hawkins's case is well known. Let's see now a much less known case of achievement in spite of, or because, an 'environmental' accident. Daniel Yuval was an eleven years old child when a forgotten landmine went off while he was playing on the snow during a family trip in the Golan Heights in Israel. The blast amputated Daniel's leg below the knee.<sup>25</sup> But a year later, Daniel was seen on TV walking, and even playing football, with the aid of a prosthetic limb. Daniel did also embark on an international campaign to remove from the Golan Heights all the landmines, forgotten there for decades. He has spoken at the Israeli Knesset; and at the UN. Undoubtedly, this child has achieved a great deal since the accident; and undoubtedly he is conducting a worthwhile life. Further, without the unfortunate accident he could never had accomplished so much in such a short period of life. Nevertheless Daniel is not campaigning to keep in place the minefield, which was the reason of his present achievements. On the contrary, he is campaigning, and rightly so, to remove the cause of his disability so no-one else gets hurt again. The point here is that while Daniel has precociously become a serious and determined child *because* of an unmarked minefield, no-one would want other children going through Yuval's ordeal in order to becoming such a wonderful child.

#### **The social context of a disability**

Inevitably, there is a social context to 'disabilities'. These are the social limitations of disabled persons that *can* and *should* be addressed by society. For instance,

autistic children (and their families) because of the ALUT project are clearly better off. However, if we return to Yuval's case above, having a leg amputated at the age of eleven (or at any age) can be significantly disabling; and this is a fact that also *cannot* and *should not* be ignored either. NMD is also significantly disabling. The causes of these disabling conditions are very different; i.e a mine is an 'environmental' blast; while NMD is a genetic disease. ASDs seem to have a mixed origin. ASDs are developmental disorders, for which there are no prosthesis and no wheelchairs. Yet why should we want prostheses and/or wheelchairs if we could avoid these conditions in the first place? It is my view that the cause of many ASDs may not be genetic. However, if it were genetic, we should remember that the genetic lottery -similarly of a forgotten minefield - can be relentlessly cruel. There is no doubt that we shall remove the minefields better sooner than later. By the same coin, could be ethical, that to get a 'genius' – which may be correlated with AS - we leave the 'autistic minefield' (either genetic or environmental), in place? Perhaps to test the social context of a disability we should ask this question: supposing that the 'best-possible' social care for a certain disability is available. Would there *still* be a rational interest for a parent not to have a disabled child? Or, in the case of AS, having the best possible caring-educational efforts, would prospective parents still want to have an autistic child? Seemingly even with the best social and educational support parents would still try to prevent AS. Why? Simply because parents would normally want 'the best' for their child, even without knowing what the best might be (children may often disapprove of parental choices). Bluntly, it is unlikely that parents would include ASDs' (of any kind) in the list of a godmother's gifts.

#### **Some conclusions**

It is a noble cause trying to help disabled people to have equal worth, rights, support, and the social integration they deserve. However, we also should be realistic. ASDs (including AS) are serious condition; the unusual 'gift' that may accompany AS is very costly. Not just monetarily; but also in emotionally. Children in the ASDs need (and deserve) appropriate education; however, they are left in societal disadvantage; and generally, they do suffer from poor quality of life involving the individuals and the family. Plausibly, given the chance to choosing for themselves, parents may forgo the talent that might appear with AS; parents may prefer to have a 'normal', socially-able child, rather than an autistic 'genius'. Moreover, it would be morally dubious if parents select a child with AS so that she could become a savant 'wonder'. Conducting a worthwhile and productive life after a disabling accident (genetic or environmental) does not necessarily invite further accidents; nor it mean that the avoidance or the prevention, of further accidents is unethical. On the contrary, it would rather be unethical to leave landmines (genetic and/or environmental) in place. Certainly more funding should be allocated for the research and the treatment of autism. However, this should not be

achieved at the cost of not avoiding ASDs with PGD or PND, when, and if, this is made possible. Society should invest and learn more about the ASDs to improve the lives of autistic children and their families. This may by and large pay society back.

### Acknowledgements

The author is the grandmother of a child recently diagnosed with PDD-NOS. So far she does not believe that all forms of the ASDs are of genetic origin.

### Notes

<sup>I</sup> As the father of an autistic child did put it, 'if you get lemons, make a lemonade' (personal communication).

<sup>II</sup> We may think of a solitary confinement cell in a prison. Isolation is regarded as further punishment. Non-voluntary imprisonment inside the brain may be excruciating. Parents may struggle with a child who does not comprehend the world in which he/she has (unwillingly) arrived; these parents do not comprehend their child either. On another front, parents may struggle with a society that does comprehend neither the child nor them.

<sup>III</sup> A social worker is attached to the Social Services Bureau of the Welfare Department working for the Service for Handling People with Autism, where parents open a file for their child (with the diagnostic reports).<sup>20</sup>

<sup>IV</sup> There is incoherence in some of the arguments. In a session on disabilities in Cambridge, UK, one of the panelists argued that a pregnant woman faced with a brain damaged fetus should carry on with the pregnancy. He claimed that disabled people have the right to be born. During the Q/A session, I asked this panelist if he would take a pill against Alzheimer's, if there were a pill available. Surprised, he responded immediately 'of course'. I asked him why. Unhesitatingly, he answered, 'why, because I am terrified of [getting] Alzheimer's'. From the rumor coming from the audience the panelist recognized the incongruence between what he had just wished for himself and what he had defended for others. While he had just advocated giving birth to a mentally disabled person, he himself, faced with the possibility of getting a mental disability, was terrified.

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## Pharmaceutical Bribing: A Global Challenge

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### Introduction

Much has been written about the influence of the pharmaceutical industry marketing on decisions of the healthcare providers. Marketing from industry comes in many forms. Advertisements on radio and television, advertisements in the professional journals, product detailing by medical representatives, and industry-sponsored CME (Continuing Medical Education) are only some of the ways these pharmaceutical companies market their products (1). The relationships between doctors/physicians and pharmaceutical companies are controversial and have been scrutinized by researchers, professional bodies, ethicists and legislators. In recent time, growing concerns regarding these ties, and the allegations of some corrupt practices, have generated a large amount of coverage in professional journals and media (2). In last few years at least four different medical organizations in Canada and United States have released policy statements and discussion papers, including the guidelines for physicians, on relationship between the pharmaceutical industry and the medical profession. The purpose is to ensure that the interactions do not lead to inappropriate prescribing behavior. About 85% to 90% of physicians/doctors in Canada, Britain, New Zealand and United States see pharmaceutical detailers (3). Regardless of whether the physician is actually influenced, the perception of the drug company interference damages the doctor-patient relationship.

In the contemporary era when building rapport with the patients is made even more difficult by time constraints, then why make it harder by giving the patients impression that the physician/doctor has an established relationship with some drug company. Studies have shown that the receipt of money, gifts even of small value can have an impact on the physicians prescribing decisions. The relationship between doctors and the representatives of the drug company has been under intense scrutiny and lot of criticism during last several years within Pakistan as well as globally (4). In this article I will discuss how this issue of pharmaceutical bribing is increasing day by day and it is now a global issue and challenge to health care community across the world.

### Discussion

The field of health care is becoming more corporative nowadays and maximum profit is current theme today and pharmaceutical companies are at front in this regard (5). In one study the majority (70%) of the general practitioners thought that pharmaceutical sales representatives are an appropriate means of

acquiring and processing drug information and also keeping up to date with the new products (6). In another study 76% of the doctors were of the view that pharmaceutical sales representatives often intended to influence their prescribing behavior (7).

According to another study, majority of residents found the gifts very useful and believed that prescribing practices were not influenced. They believe that pharmaceutical representatives use various marketing techniques and there is some question mark on validity of the information they provide but even then they should not be banned (8).

According to one self-report of GPs their prescribing patters were highly influenced when they were visited by sales representatives frequently (9). According to one author, all respondents indicated accepting gifts from corporates for student's related activities. They were in the form of grants, money, scholarships and meals (10). In one study the majority of physicians interviewed were of the view that elaborate enticements, such as an all-expenses-paid trip to a luxury resort to learn about a new drug, would in no way influence their prescribing decisions. They appeared to believe that any decision to prescribe a drug is based on the scientific data, patient needs and clinical experience, rather than on promotion by pharmaceutical companies. A few physicians thought that such enticements can make them think of the drug when they might not have otherwise or that the symposium might convince them that the drug had benefits for their patients which they had not previously considered. No physician felt that he or she would prescribe the medication as thanks for the drug company trip (11).

The provision of practical prescribing advice by representatives and gifts were seen as desirable activities by many respondents. However, gifts of value greater than acceptable in recent guidelines for GPs were highly favored by some practitioner (12). Preclinical and clinical students had same thoughts regarding their responses. Finally, students who reported feeling more educated about the pharmaceutical industry interactions tends to be less skeptical about them and likely to view the interactions with drug industry as appropriate (13). One author finds that only 24% of faculty and 18% of trainees were of the view that pharmaceutical representatives provide useful information on new drugs. Forty-one percent of faculty and 53% of trainees agreed that medical reps should be restricted from making presentations on campus (14). The representatives of the drug company frequently visited the GPs and used a wide variety of techniques, including the promotional gifts, drug samples, and different types of educational material. It is notable that medical representatives continued their promotion of the drugs even after they had been cleared and approved for sale. At more than fifty percent of the visits a drug sample was offered, and the probability of handing out drug samples declined slowly and gradually with increasing drug age (15). Unethical drug practices are common phenomenon around the world, but it is more severe in the developing countries.

Most of the physicians don't consider it unethical to accept the gifts in the shape of household gadgets, pens, pen stands, calendars, pads, drug samples and free drug camps. According to them, lunch and dinners of recreational value at which the company's products are favorably mentioned are unethical. They have accused the internet and electronic media for spreading biased and unreliable information regarding this issue (16).

### Conclusion

The relationship between pharmaceutical industry and medical practitioners should be strictly based on professionalism. A medical practitioner must prescribe a particular pharmaceutical agent to his/her patient based on his/her own clinical judgment and without any influence from the drug industry. Emphasis should be made on the clear common interest of an ethical nature and it must be expressed by both pharmaceutical companies and the medical profession. The common interests are, the patient satisfaction; the source of information related to the drugs must be from the authentic journals; and samples for the patients' welfare (17). It is not difficult to be convinced that the pharmaceutical companies have subtle tools to influence the prescribing patterns. But ultimately physicians/doctors must review their own actions - conscious and unconscious - to ensure that their practices reflect best available information that is scientifically valid and also objective, and not merely the persuasive powers of a commercial institution (18). Hence it is concluded that pharmaceutical bribing is a global challenge and guidelines should be made to combat this issue.

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## Academic Integrity Perception, Behavior, and Intention of Medical School Students

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### Abstract

Educational institutions must promote the learning of professional behavior and conduct as early as possible and evaluate its implementation including the evaluation of academic integrity. Academic integrity regarding the students professional behavior should receive serious attention in the field of medicine. In this study, we aimed to know the perceptions of academic integrity, as well as attitudes and intentions among medical students in Jakarta, Indonesia. This study provides a descriptive analysis and a quantitative survey (non experimental research) on a private medical school in Indonesia by using a questionnaire about academic integrity. The sample population was 209 students from level 1, 2 and 3. This study obtained a picture of perceptions, attitudes and intentions of

academic integrity, as well as the relationship between perceptions, attitudes and intentions of academic integrity. Details of the result will be presented and discussed.

**Keywords:** professional behavior, academic integrity, perceptions, behaviours, intentions

**Background**

Doctors are required to be capable of acting as professionals, capable of giving prevention services which are qualified, and capable of giving further therapeutic services. These have to be started at the educational stage. Petersdorf and Swick stated that medical education is not only preparing student to become practitioner by developing knowledge and skill, but also high ethical standards and morals including integrity.<sup>(1, 2)</sup> Van Lwijk stated that ethics attitude and behaviour were part of professionalism.<sup>(3)</sup> Some behaviour that is expected to be showed from medical students are *honesty, respect, fairness, responsibility, trust.*<sup>(4)</sup> Those behaviours corresponding to behaviour which is expected by *The Center of Academic Integrity*, who defined academic integrity as commitment (even when facing difficulty) are based on 5 basic values: honesty, trust, fairness, respect, and responsibility.<sup>(5)</sup> Based on that, it is important for an educational institution to know about student's academic integrity. Academic integrity is something that had to have serious concern. Concerns over academic integrity behaviour should be taken seriously, because academic integrity corresponds with the validity of graduate qualification.<sup>(6)</sup>

**Objectives**

To determine the perception, behaviour and intention of student's academic integrity and linkages between perception, behaviour and intention of academic integrity.

**Methodology**

This study was done by descriptive analysis of a non experimental survey at a medical faculty in Indonesia, from June – November 2011. The survey population was 209 students from first, second and third degree. The tool used to study academic integrity was the academic integrity questionnaire from Roff<sup>(7)</sup> in which validity and reliability test has been done. Inclusion criteria on this study were registered as active student of medical faculty who were willing to respond. Exclusion criteria were: a) academic integrity questionnaire is not completed and or; b) resign from study. This study got approval from students through informed consent done before collecting data and approved by Ethic Committee of Medical Faculty (*ethical clearance*).

**Results and Discussion**

To facilitate observation on perception, behaviour and intention of students relating to academic integrity, in this study most tables of answers are related to perception, behavior and intention on every questionnaire item that was made, that is: 1) The largest percentage of items which they considered violates academic integrity; 2) The largest percentage of items which respondents were not sure it is an item violating academic integrity; 3) The largest percentage of items where an item/action is not considered an item violating academic integrity; 4) The largest percentage of perceptions regarding academic integrity of fellow student; 5) The largest percentage of items in which respondents had ever violated academic integrity; 6) The largest percentage of item in which respondent intend to violate academic integrity; 7) The largest percentage of items in which respondents were not sure whether he or she will violate academic integrity in the future.

The actual questions/items that were tested and the code numbers are in Table 4 for reference for all the preceding tables.

In Table 1, "Assesing old paper or coursework, which is not published for the whole class, to help study" (item 8) was the item with the highest percentage of respondents saying that they were not sure if violated ethics. 38% (79 persons from 209 respondents) had the perception that this item violates academic integrity. Among the top 15 items that respondents were not sure violates academic integrity, the score ranged from being seen as unsure between 6 - 31%. Among the 15 items of items related to academic integrity between fellow students, the score ranged from 75% having seen this to 18%.

Table 1. The largest percentage of perceptions are not sure, perception to a friend, behaviour and intention and pattern of interrelations its items

Perception			Perception to a friend's behaviour			Behaviour			Intention						
Is this wrong?			According to you, your fellow friends to this to?			For becoming medical faculty student, do you ever done this?			For becoming medical faculty student, in the future will you do this?						
Not sure			Yes			Yes			Yes			Not sure			
Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent	
1	8	31,1	1	1	74,6	1	1	65,6	1	8	13,9	1	1	51,7	
2	5	28,7		17	74,6	2	16	56,5	2	1	8,1	2	16	43,1	
3	6	27,3	2	16	69,4		4	45,5	3	16	6,7	3	8	38,8	
4	1	26,8	3	24	63,2	3	5	45,5		11	5,3		5	37,3	
5	3	23,4	4	4	59,8	4	24	45	4	17	5,3	4	6	37,3	
6	11	19,6	5	5	59,3	5	17	42,6	5	4	3,8	5	11	33,5	
7	4	18,2	6	6	51,7	6	6	38,3		3	3,3	6	3	30,1	
8	17	15,3	7	10	50,7	7	10	29,7	6	5	3,3		4	28,7	
9	16	12,9	8	8	39,2	8	8	29,2		10	2,9	7	17	28,7	
10	20	12,4	9	7	36,4	9	7	22,5	7	24	2,9		24	28,7	
11	2	11,5	10	11	33,5	10	11	20,1	8	6	1,9	8	10	24,9	
12	14	9,6	11	26	28,7	11	3	19,1	9	2	1,4	9	7	20,6	
13	24	8,6	12	3	27,8	12	26	14,6	10	7	1		25	12,4	
14	10	6,7	13	2	22,5	13	12	3,3	11	9	0,5		26	12,4	
15	7	6,2	14	9	20,1	14	9	2,9				11	20	10,5	
			15	14	18,2	15	14	1,9					12	2	7,7
													12	7,7	
													14	6,7	
													13	19	6,7
													14	9	5,7
													15	18	4,8

Table 2. The largest percentage of wrong perception (no answer), and pattern of interrelations of its items with perception to a friend, behaviour and intention

Perception			Perception to a friend's behaviour			Behaviour			Intention		
Is this wrong?			According to you, your fellow friends to this to?			For becoming medical faculty student, do you ever done this?			For becoming medical faculty student, in the future will you do this?		
Not sure			Yes			Yes			Yes		
Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent
1	8	31,1	1	1	74,6	1	1	65,6	1	8	13,9
2	1	15,8		17	74,6	2	16	56,5	2	1	8,1
3	3	14,8	2	16	69,4	3	4	45,5	3	16	6,7
4	11	12,9	3	24	63,2		5	45,5	4	11	5,3
5	17	10	4	4	59,8	4	24	45	4	17	5,3
6	5	6,7	5	5	59,3	5	17	42,6	5	4	3,8
7	2	4,8	6	6	51,7	6	6	38,3	6	3	3,3
	6	4,8	7	10	50,7	7	10	29,7		5	3,3
8	10	4,3	8	8	39,2	8	8	29,2	7	10	2,9
9	24	2,9	9	7	36,4	9	7	22,5		24	2,9
10	7	1,9	10	11	33,5	10	11	20,1	8	5	1,9
	16	1,9	11	26	28,7	11	3	19,1	9	2	1,2
11	14	1,4	12	3	27,8	12	26	14,8	10	7	1
	20	1,4	13	2	22,5	13	12	3,3	11	9	0,5
12	4	1	14	9	20,1	14	9	2,9			
	12	1	15	14	18,2	15	14	1,9			
13	18	0,5									
	19	0,5									
	22	0,5									

behaviour that is intended to be done by the student. Item behaviour that ever been done by student, was item that student not sure will do behaviour violating academic integrity, in example item 12, 14 and 26.

Based on Table 2, it is found that the item which got the highest percentage as an item not violating academic integrity was "Accessing old paper or coursework, which is not published for the whole class, to help study" which is 32%. Item 1, 3, 11 and 17 were items that had percentages ≤ 10%. Based on Table 2, it is found that items considered not violating academic integrity, were: 1) behaviour done by fellow students; 2) behaviour that had been done by the student; 3) behaviour intended to be done by student. It is shown in example on item 1, item 8 and item 3.

Based on Table 3, it is shown among the 15 most agreed to items considered violating academic integrity, the score was on the range

81% (item 18). Item 21, which is, "Falsifying health workers signature on work result, patient graph, ranking sheet or arrival sheet", was stated to be a wrong behaviour by all respondents. Even on the few items that the majority considered as violating academic integrity there was confession that he or she has done this and there is intention to do it in the future.

The most frequent item that respondents intend to violate academic integrity was to "access old paper or coursework, which is not published for the whole class, to help study", over 10%. "Getting or giving help on courework, violate teacher's rule (for example lend his or her work to another student)" was on the first rank doubted in intent to violate academic integrity by students (52%).

Table 1 shows that the items which students are not sure that those items were violating academic integrity, were actually: 1) behaviour which is mostly done by fellow students; 2) behaviour that has been done by the student; 3) behaviour which is intended to be done by students; 4) Item behaviour which students are not sure will actually violate academic integrity, for example items 4, 5, 10, 11, 16, 17, 24.

The behaviour which is mostly done by fellow friends, was: 1) behaviour that has been done by student; 2) behaviour that is intended to be done by the student. This is shown in example of item 9 and 26. It is also found that almost all behaviours that ever been done by student, was item

Table 3. The largest percentage of right perception (yes answer), and pattern of interrelations of its items with perception to a friend, behaviour and intention

Perception			Perception to a			Behaviour			Intention					
Is this wrong?			According to you, your fellow friends to this to?			For becoming medical faculty student, do you ever done this?			For becoming medical faculty student, in the future will you do this?					
Not sure			Yes			Yes			Yes			Not sure		
Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent	Rank*	Item number	Percent
1	21	100	1	1	74.6	1	1	65.6	1	8	13.9	1	1	51.7
2	23	99.5		17	74.6	2	16	56.5	2	1	8.1	2	16	43.1
3	13	99	2	16	69.4	3	4	45.5	3	16	6.7	3	8	38.8
4	9	98.6	3	24	63.2		5	45.5	4	11	5.3	4	5	37.3
	15	98.6	4	4	59.8	4	24	45.0	4	17	5.3	4	6	37.3
5	22	98.6	5	5	59.3	5	17	42.6	5	4	3.8	5	11	33.5
6	18	98.1	6	6	51.7	6	6	38.3	6	3	3.3	6	3	30.1
7	25	97.1	7	10	50.7	7	10	29.7		5	3	3.3	6	4
	26	97.1	8	8	39.2	8	8	29.2	7	10	2.9	7	17	28.7
8	12	96.7	9	7	36.4	9	7	22.5	7	24	2.9	7	24	28.7
	19	96.7	10	11	33.5	10	11	20.1	8	6	1.9	8	10	24.9
9	7	91.9	11	26	28.7	11	3	19.1	9	2	1.4	9	7	20.6
10	10	89.0	12	3	27.8	12	26	14.8	10	7	1	10	25	12.4
	14	89.0	13	2	22.5	13	12	3.3	11	9	0.5		10	26
11	24	88.5	14	9	20.1	14	9	2.9				11	20	10.5
12	20	86.1	15	14	18.2	15	14	1.9				12	2	7.7
13	16	85.2											12	12
14	2	83.7										13	14	6.7
15	4	80.9											13	19
												14	9	5.7
												15	18	4.8

Table 4. The largest option percentage of sanction of violation academic integrity by student

Item	Statement	The largest option sanction		
		No	%	Sanction
1	Getting or giving help on couerwork, violate teacher's rule (for example lend his or her work to another student)	112	53,6	2
2	Paying fellow friend or getting paid by friend to complete the task	67	32,1	2
3	Collecting task that has been collected before for another task or another lecturing duties	83	39,7	2
4	Deliberately paraphrasea text on a task, or copy a text directly without quoting the source	125	59,8	2
5	Not quoting source of information correctly (i.e. copy a text directly but only quote the source from reference)	117	56	2
6	Quoting a source that in reality is not red completely	117	56	2
7	Changing or manipulating data (example adjust data to get significant result)	75	35,9	2
8	Assesing old paper or coursework, which is not published for the whole class, to help study	75	35,9	1
9	Sabotage the work of another student	53	25,4	5
10	Cheating answer from your next friend or allowing your next friend to cheat on your answer during exam	101	48,3	2
11	Having information from your fellow student about paper that has been tested, or providing information about paper for friend who has not been exam	74	35,4	2
12	Bringing material which is forbidden when exam	61	29,2	6
13	Doing exam on behalf of another person or exam is done by another person on your behalf	64	30,6	6
14	Looking excuses to put off the exam	57	27,3	2
15	Arranging a way to get passed from exam by using private connection or bribery	62	29,7	6
16	Signature list of attendees for a friend who is absent or asking classmate to signature list of attendees in a laboratory or lecture	111	53,1	2
17	Absent from lecture multiple time	90	43,1	2
18	Intentionally falsifying test result or treatment record (patient) to hide the mistakes	40	19,1	6
19	Not following infection control procedure correctly	42	20,1	2
20	Checking patient without knowledge or approval from supervisor who is supervise	57	27,3	2
21	Falsifying health workers signature on work result, patient graph, ranking sheet or arrival sheet	40	19,1	6
22	Changing rank on official data sheet	33	15,8	4
23	Threatening or harassing university employees or fellow student verbaly	49	23,4	5
24	Often present late in class	129	61,7	2
25	Not doing part of the taask that has been divided by his or her group	62	29,7	2
26	Damaging public property such as doodling table or chair	102	48,8	2

Sanction 1: No sanction

Sanction 5: Warning, counseling and extra work

Sanction 2: Oral warning

Sanction 6: Failed on certain courses/block/stase

Sanction 3: Written warning

Sanction 7: Failed on certain years (allowed to repeat)

Sanction 4: Warning and get counseling

Sanction 8: Expelled from university (allowed to take the test after one year)

Sanction 9: Expelled from university (no opportunity to take entrance test again)

Sanction 10: Reported to professional regulatory committe

Furthermore Table 4 relates with the student perception on most options of violating academic integrity and sanctions for the first time was made. This table showed that the most common item, sanction 2 which is "written warning" was the most common choice of a sanction for violating academic integrity by students (item 17). The next common option, was sanction 6, "failed on certain courses/block/stase" chosen for 12, 13, 18 and 21. Another sanction which become respondent option was sanction 1, which is "no sanction" for item 8; sanction 4 which is "warning and get counseling", for item 22; and sanction 5, which is "warning, counseling, extra work" for item 9 and 23.

According the largest option, no sanctions should given on the first violation item 8 which is "accessing old paper or coursework, which is not published for the whole class, to help study". Item "not following infection control procedure correctly" and item "checking patient without knowledge or approval from supervisor who is supervise, student perception about sanction that has to be given on the first time was sanction 1, which is a oral warning. This sanction, is lower than the sanction chosen for item, "threatening or harassing university

employees or fellow students verbally"; item "Falsifying health workers signature on work results, patient graph, ranking sheet or arrival sheet" and item "intentionally falsifying test result or treatment record (patient) to hide the mistakes". sanction 6, which is failed on certain courses/block/stase. On item "threatening or harassing university employees or fellow student verbaly" student perception about sanction that should be given on the first violation was sanction 5, which is, warning, counseling, extra work.

## Discussion

Among the fifteen most common items that student assuming vthet he or her friend violated academic integrity on, they ranged from a frequency of 18% - 75% students. All the percentages showed wide variation on

perception, behaviour and intention of academic integrity.

This study showed that almost all behaviour considered not violating academic integrity, were behaviour that is mostly done by students, and had been done by student once in the past, and they intended to do it again. The pattern of relatedness findings on the perception, behaviour and intention of academic integrity, should make educators more vigilant over the design of courses to help education and development of professional behaviour. Evidence of varied perception, behaviour and intention of academic integrity among students shows the need of the study to form a coaching, increasing and developing academic integrity concept among student. Those concepts are expected to result in the increase in commitment or enlightenment internal motivation which can raise awareness that: 1) The creation and implementation of academic integrity was part of dynamic educational institution culture; 2) Educational institutions integrity, teacher integrity and employees integrity is manifested in institusional policy, teacher and employees professional behaviour is a hidden curriculum for the development of student academic

integrity; and 3) Educational institution and institutional policy and teacher and employees professional behaviour is a role model for student.

The patterns of relatedness in this study is in line with previous studies and in line with planned behaviour theory by Ajzen<sup>(6)</sup>. According to those theory, behaviour is affected by the intention to behave; and intention to behave is affected by behavioural attitudes, subjective norms and behaviour control among those who lived; and attitude on behaviour affected by behaviour perception and outcome evaluation; subjective norms affected by norms of perception and motivation to obey; behaviour control who are more subject to behaviour control. It also in line with Nimran's<sup>(9)</sup> opinion which stated that human behaviour is often guided by his or her perception on reality. Jordan and Lim and See cited by Hrabak<sup>(10)</sup> stated that academic integrity behaviour affected by academic integrity perception. Furthermore Musharyanti found that behaviour considered not violating academic integrity was behaviour that is mostly done by students and by fellow etudent.<sup>(7)</sup>

Based on student perception percentage order on item behaviour considered not violating academic integrity, it is found that non ethical educational practices such as plagiarism seen as less serious compare with another aspects about educational misconduct, such as abuse of power. This finding is in line with Elzubair & Rizk.<sup>(11)</sup> findings.

In this study is also found that unethical educational practices such as plagiarism are seen as less serious compared with another aspects about educational misconduct, such as abuse of power. This is not surprising, because Ryan *et al.*<sup>(7)</sup> stated that a lot of pharmaceutical students showed ignorance about behaviour including plagiarism and *academic dishonesty*, even when his or her institution has applied rules related to *academic dishonesty*. They considered behaviour such as plagiarsm is a problem which is not important and not popular.

In this sudy it is also find that for most of the items, sanction 2, which is "written warning" was the most common suggestion. The next most common sanction was Sanction 6 which is "failed on certain courses/block/stase" chosen for items 12, 13, 18 and 21. Sanction 1, which is "no sanction" was suggested most for item 8; sanction 4 which is "warning and get counseling", for item 22; and sanction 5, which is "warning, counseling, extra work" for items 9 and 23. Revamping consequences of supporting systems incurred in connection with: 1) Those sanctions is a relevant sanction enacted in a certain violation of academic integrity which is agreed in order for the rules to be enforced; 2) Not all medical faculty has a counseling unit for students, a counseling for the student in more perfect fore than academic supervisor.

The method that cut the chain of violating academic integrity which is suggested by a former researcher, is rules enforcement and sanction to promote academic integrity.

## Conclusion

A lot of violation behaviour is not considered a violation of academic integrity by students in this study. Unethical educational practices such as plagiarism are not seen as serious. Some is because that behaviour is done by fellow students. Items of behaviour not seen to violate academic integrity were items mostly done by fellow student, behaviour that has been conducted by the student, behaviour that intends to be done by the student. It is also found among a few behaviour perceived as violating academic integrity, there was still a confession that there is a violation by fellow students and there is intention to do this themselves. On the items violating academic integrity, a mild level of sanction is the sanction level chosen by students of medical faculty.

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# Barcoding, biobanking, ebanking for “One Health” projects in South-East Asia: considering ethics and international law

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## Abstract

A first workshop held within the framework of the PathodivSEA project has been the occasion to identify the major research challenges regarding the emergence of zoonotic infectious diseases in South East Asia and the spread of pathogens responsible from those diseases. Based on supporting evidences indicating the zoonotic origins of those diseases, it appeared urgent to investigate the factors controlling the pathogens-human interface by addressing the “One Health” concept which integrates the study of human and animal health with conservation medicine. The necessity of pathogen, vector and reservoir identification (barcoding), pathogens and other tissues' preservation (biobanking) and open databases creation (ebanking) has been recognized, along with the importance of ethical and legal considerations.

## Introduction

The project PathodivSEA (“Pathogen diversity in Southeast Asia”, AFD-CNRS) aims to develop a research network in South East-Asia to measure the diversity of zoonotic agents (virus, bacteria, parasites) and their vectors and reservoirs, allowing sharing tools and concepts in relation to their identification (barcoding), the preservation of tissues and living organisms (biobanking) and open databases (ebanking) in order to better understand their ecology (transmission) and evolutionary dynamics facing the ongoing environmental changes that affect South-East Asia<sup>1-2</sup>. Southeast Asia is a hotspot for emerging infectious diseases<sup>3</sup>, and the major explanatory factor of the increase of outbreaks of those diseases is thought to be biodiversity loss<sup>4</sup>.

The first workshop held within the framework of the PathodivSEA project has been the occasion to identify the major research challenges regarding the emergence of zoonotic infectious diseases in South-East Asia and the spread of pathogens responsible of those diseases. This paper aims to present a short synthesis of the main observations done during the workshop through the various presentations in different disciplines, results to be taken into account in order to tackle the pressing research issues identified.

The first findings can be summarized by a variation at different scales (global, regional, local) following a geographical axis from West to East (Europe to Asia) and a decreasing gradient of integration of results from human health to medicine conservation. We will discuss those differences through examples concerning barcoding and biobanking as well as microbiology and parasitology.

The questions raised in the areas of ethics or law and policy by those scientific studies are important to highlight as in one hand researchers might not be aware of the need to incorporate some ethical or legal rules into their studies and in the other hand their findings could benefit the whole community if they were taken into consideration by policy-makers to design an appropriate decision framework.

## Material and Methods

During the workshop held in Singapore in August 2013, oral presentations from regional participants (Cambodia, Indonesia, Lao PDR, Malaysia, Singapore and Thailand) dealt with several topics related to epidemiology of infectious diseases and emerging diseases, wildlife conservation and diseases (conservation medicine), pathogens, vectors and reservoirs identification (screening and barcoding), tissues (wildlife) and pathogen preservation (biobanking), database (ebanking), ethics and regulations.

Based on these presentations, we proposed a schema of the advances of barcoding / biobanking / ebanking / ethics and law in relation to the different fields that are to some degree concerned with infectious diseases: public health (medicine), animal health (veterinary medicine) and wildlife health (conservatory medicine).

## Results

Table 1 summarizes the advancements of each following subjects: barcoding, biobanking, ebanking, ethics and law in relation to public and animal (domestic and wildlife health).

## Discussion

*Barcoding in medicine, veterinary medicine and conservation biology*

Efforts to control infectious diseases depend upon our ability to identify pathogens, parasites, vectors and reservoirs. In medicine, there is a perpetual quest for a gold standard test, which refers to a diagnostic test or benchmark that is the best available under reasonable conditions<sup>5</sup>. In the field of veterinary medicine, development and validation of diagnostic tools are under the head of the OIE (World Organization for Animal Health), which recognizes and gives label to national reference centers (usually specialized in one or several infectious diseases). As a matter of fact, this procedure is modeled on the process used by the WHO (World Health Organization) and its collaborative centers.

Table 1. Comparisons of the advancements of each following subjects barcoding, biobanking, ebanking, ethics and law and regulation in relation to public health, animal health and wildlife conservation.

	Public Health (Medicine)	Animal Health (Veterinary Medicine)	Wildlife Conservation (Conservation Medicine)
Screening/barcoding	Gold standard test, reference laboratory WHO	OIE, reference laboratory OIE	Barcoding (BoL, Barcoding of Life)
Biobanking	Reference centers (international, national)	Institution initiatives	Natural History Museum, Institution initiatives
Ebanking	Reference centers	OIE, FAO	GBIF, BOLD, ...
Ethics	WHO/CIOMS International Ethical Guidelines for Biomedical Research Involving Human Subjects	OIE Collaborating Centre for Animal Welfare Science and Bioethical Analysis National rules	National rules
International law and regulation	WHO International Health Regulations	OIE, WHO (zoonoses)	CDB, CITES*, CMS**

\*CITES: Convention on International Trade in Endangered Species of Wild Fauna and Flora

\*\*CMS: Convention on the Conservation of Migratory Species of Wild Animals

In the field of biodiversity, less than 10% of the all species have been described. As few taxonomists can identify species on a morphologically-basis, it has been proposed to develop an international consortium, the Barcoding of Life (BOL), which aims at promoting and developing molecular identification of living organisms<sup>6</sup>. DNA barcoding systems employ a short, standardized gene region to identify species (usually the mitochondrial COI gen). Hence, it appears that screening and identification although using similar genetic methodologies, may not use similar words (barcoding is rarely used in veterinary medicine, or in parasitology). Moreover, they rely on different protocols, and distinct data base systems (see below).

#### Biobanking

This discrepancy in screening and identification in pathogens, parasites, vectors, reservoirs can be also observed in the way practitioners from the different fields preserve tissues, parasites and pathogens.

Human medicine early recognized the necessity to cryopreserve human tissues and pathogens. Preservation of materials allows improvement of screening, genetic studies and treatments.

Storage of voucher specimens from wildlife are usually realized in internationally recognized institutions like national natural history museums<sup>6</sup>. This also concerns parasites but more rarely microbes, which might be conserved in medical institutions when they are of zoonotic concerns.

Finally, parasites and pathogens of domestic animals seem not to be preserved in official and recognized institutions, apart from OIE collaborative centers (although their primary missions are diagnostic and control).

#### Ebanking and open databases

Several international and national databases are available (WHO, OIE, FAO, Gideon data base, etc) with some geo-referencing. Most of them concern reports of disease outbreaks and few give access to information

on tissues/pathogens/parasites preserved in specific institutions. This is once more particularly true for veterinary medicine and conservation medicine.

In the field of biodiversity, an informatics workbench, The Barcode of Life Data System (BOLD) has been developed to aid in the acquisition, storage, analysis and publication of DNA barcode records<sup>7</sup>. The project CERoPath ("Community Ecology of Rodents and their Pathogens in Southeast Asia", ([www.ceropath.org](http://www.ceropath.org)) for reservoirs of rodent-borne diseases in South-East Asia is one example. By assembling molecular, morphological and distributional data, it bridges a traditional bioinformatics chasm<sup>8</sup>.

#### Pathogens research confronted with Ethics and Law

The ethical issues linked to research in infectious diseases are diverse and depend notably on: the source of material studied (animal, human), the storage of sample for future uses such as in the case of predictive medicine, or the activity of research itself.

The constitution of biobanks implies the notion of consent of the persons concerned. As stated in the Universal Declaration on Bioethics and Human Rights (2005) "*scientific research should only be carried out with the prior, free, express and informed consent of the person concerned*". The need of prior informed consent for a future storage and use of any removed part of a human body challenged the idea of the absence of proprietary rights over our body or body parts<sup>9</sup>. The notion of consent is assumed in Material Transfer Agreements (MTAs) signed in the case of transfer of research material in order to precise the use of the material and to define the rights over material and any derivatives. The example of the UK biobank, a long-term research resource, shows that the consent encompasses many aspects including the use of sensitive information, a possible link to the medical record, the confidentiality with anonymisation but giving a possibility to re-contact the participant in the future. It illustrates the necessity to clearly inform the

participants about the actual or potential uses of samples and to give him the right to withdraw.

Regarding animal health, ethics concerns should comprehend animal welfare and take into consideration animal suffering by enacting good laboratory practices and ultimately addressing the legal issues of animal rights.

In addition, the activity of research should respond to the ethical concerns of solidarity and mutual assistance<sup>10</sup> and include the necessity for researchers to return benefits to providers.

Some ethical issues such as the prior informed consent or mutual agreement are integrated into the Convention on Biodiversity (CBD, 1992) in the article providing the access to genetic resources. The Convention also regulates the issue of benefit sharing and solidarity with a particular concern for the respect of traditional knowledge. In order to implement those provisions of the Convention, the Nagoya Protocol (2010) detailed the access obligations to be implemented at the national level insisting on the need to promote and encourage research contributing to biodiversity conservation and sustainable use. Concerning the benefit sharing obligations, the non-monetary part relates to the sharing of research results, transfer of technology or training and education. ASEAN urges the States to adopt national measures regarding the access to genetic resources and benefit sharing and to ensure its enforcement through institutionalized arrangements.

The monetary benefits should be shared with the provider and there should be a necessary trade-off between the legal protection of Intellectual Property Rights and the respect of benefit sharing, traditional knowledge and cultural biodiversity.

The "One Health" approach could help to turn those ethical and legal considerations into practical policies integrating the notions of equity and justice.

## Conclusion

Based on supporting evidences indicating the zoonotic origins of those diseases, it appeared urgent to investigate the factors controlling the pathogens-human interface by addressing the "One Health" concept which integrates the study of human and animal health with conservation medicine as well as other disciplines that might influence those factors such as policy, law or ethics.

Moreover, important achievements should be accomplished in terms of barcoding (sharing protocols and concepts), biobanking (particularly for parasites/pathogens of animals and wildlife) and ebanking (access and sharing of geo-referenced data, collections and tissues).

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## Some Moral Questions on Genetic Science

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According to many the most promising frontier in modern medicine is genetic research. Genetic science finds its modern origin in Gregor Mendel, who in 1866 discovered the laws of heredity. The heart of this hard science comes from the secret of the nucleus. The nucleus of an organism possesses the chromosomes, which has the DNA (deoxyribonucleic acid) that serves as the very building blocks of life. The study of the DNA has propelled the advances made in genetic research. These advances have opened doors to many possibilities in medicine and patient care. But there are moral issues to consider.

## Ethics and Genetics

According to John Harris, "ethical issues are raised by the use of embryonic cells, tissues, or other products and indeed the use of neonates and aborted fetuses as sources of therapeutic or experimental material".<sup>13</sup> Scientists say that genetic research is vital. Today, it is modern medicine's most promising weapon in the battle against certain types of cancer, Parkinson's disease, Alzheimer's disease, diabetes and other degenerative genetic malignancies.

<sup>13</sup> John Harris, *Clones, Genes and Immortality* (Oxford: Oxford University Press), 43.

Harris writes that *"the treatment of diabetes using pancreatic cells, and embryonic myocardial tissue could be obtained from embryos and used by cardiologists to repair the major vessels of the heart"*.<sup>14</sup> But the issue is that the good of the patient, the possibility of finding the treatment for difficult diseases, are set against the background of manipulating and using the human embryo for experimental purposes. On the basis of universally accepted norms, the expected good outcomes from these experiments need to be evaluated and measured over the real possibility of reducing the embryo into a mere instrument.

Genetics can be seen as something that has been made possible by means of the gift of the human intellect. Science is a product of the human mind, and as such, science should serve the very purpose that will enable humans to enhance their over-all well-being. Still, human as we are, there is that clear danger in the possibility of doctors and scientists playing "God", or being masters of human destiny if and when they so decide to design or re-design the biological structure of the human being.

At the outset, it must be noted that bioethics was coined by Fritz Jahr in 1927 in Germany, and Van Rensselaer Potter in 1970 in an endeavor to draw attention to the fact that the rapid advances in science had proceeded without due attention being paid to values.<sup>15</sup> In this regard, Darryl Macer writes: *"It is important to examine the direction of bioethics and how this might enable people to question scientific endeavors and use of technology and what impact their moral decisions will have on them and their societies."*<sup>16</sup>

During the Second World War, Nazi doctors did some experiments on human subjects. Pseudo-scientists like Joseph Mengele put many into brutal and inhuman conditions for the sake of malicious reasons bereft of any real scientific value. The evil work of these pseudo-scientists became associated with the manipulation of human beings without due regard for their basic moral worth. Such horrific experiments are clear and blatant manifestations of disrespecting the dignity of the person. These manipulations are instances of dehumanization and a rapacious display of prejudice against others. Thus, the illusion of creating a pure breed put eugenics into a bad light.<sup>17</sup>

<sup>14</sup> Ibid., 60

<sup>15</sup> Bioethics Core Curriculum (Bangkok: UNESCO, 2008), 14.

<sup>16</sup> Darryl Macer, *Moral Games for Teaching Bioethics* (Haifa: UNESCO Chair in Bioethics, 2008), 12.

<sup>17</sup> However, Darryl Macer makes a distinction between positive and negative eugenics. He writes that "positive eugenics refers to the achievement of a systematic and planned genetic change to improve individuals and their offspring. This includes selection of healthy genes and use of gametes from people thought to be superior in intelligence and physical characteristics." On the other hand, he adds that, "negative eugenics concerns policies and programs intended to reduce the occurrence of genetically determined disease. Eugenics is negative when it results to the sacrifice of human life, for instance, in the sterilization of some adults thought to be inferior and Macer notes that some countries "sterilized persons to stop them from having children". Darryl

With the development of moral norms and universal agreements on the protection and promotion of the human subject in the field medical research, advances have been made to ensure that the previous instances of abuses are not repeated. But while the intellectual efforts of scientists to find cure for diseases that have been very difficult to treat using conventional methods is commendable, there are moral issues that need to be settled.

The decisions that doctors and clinicians make especially in the use of human embryos requires moral examination. The reason being is that humans are not guinea pigs. Harris says that, *"the moral justification that surrounds you and me, in virtue of which we cannot simply be used or experimented upon without our consent, derive from the moral differences between us and other creatures"*.<sup>18</sup>

Harris continues, *"if it would be wrong to experiment on normal adults without their consent or to use them simply as tissue and organ banks, then it would be wrong to treat embryos likewise."* The question is, he adds, when if at all, and in virtue of what does the human embryo begin to matter morally? Harris reminds us that *"at the heart of human biotechnology has been the embryo. Of course, it was the study of the embryo and the ability to fertilize the human embryo in a glass dish in a laboratory that led to the birth of the first test tube baby, Louis Brown"*.<sup>19</sup>

Whenever researchers use human embryos, the moral question regarding the sanctity of human life arises. For instance, how are human embryos to be morally regarded? Is an embryo a human person? Or are they less than human and could thus be subjected to genetic manipulation?

One can speak, for instance, of an embryo's potential to become human. But according to Harris, there is a difference between the potential of the individual and the potential to become an individual.<sup>20</sup> There is of course a distinction between actuality and potentiality. "Like an acorn", says Gregory Pence, it can be said, "the value of an embryo is all potential, little actual".<sup>21</sup> But saying that it is "little actual" implies that it can be violated since it seems that it is of little value or no value at all. From a moral point of view, such judgment is problematic. Embryos possess the capacity to become full human beings. Stones, on the other hand, do not. So to say that embryos have little value, because they are still and only potentially human, is to deprive the embryo of the right to full human development.

### Parthenogenesis: Is it a Way Out?

So, is there a way out from the moral ramifications of using a human embryo? Biologically, Harris says, the

Macer, *A Cross-Cultural Introduction to Bioethics* (Christchurch: Eubios Ethics Institute, 2006), 121.

<sup>18</sup> Harris, *Clones, Genes and Immortality*, 44

<sup>19</sup> Ibid. 43

<sup>20</sup> Ibid., 50

<sup>21</sup> Gregory Pence, *Will cloning harm people?*, in James Rachels, *The right thing to do* (Boston: McGraw-Hill, 2007), 121.

eggs of most species including humans can be stimulated to grow without fertilization.<sup>22</sup> This process, called somatic cell nuclear transfer, begins by using a female oocyte which is without any genetic contribution from a male sperm. Some consider these embryos as less morally problematic because they do not fully mature. Evidence shows that while these parthenogenetically stimulated human egg cells can develop normally until the heart-beat is discernible, they will then usually die. The reason for such is the absence of *“the male chromosomes which provide the important activity in the placenta. This absence is the cause of the short life of parthenogenic embryos”*. The embryos produced through parthenogenesis are less morally problematic because they do not actually develop into actual adults.

In this process, the female egg's nucleus is taken and then the DNA of a patient is inserted into the egg. The resulting embryo that grows becomes the source of stem cells which can be cultured in order to create tissues that would be matched with that of a donor, allowing for the possibility of a successful organ transplant. Macer explains that *“somatic cell gene therapy involves injection of healthy genes into the bloodstream or another target tissue of a patient to cure or treat a hereditary disease or similar illness”*.<sup>23</sup> Harris also notes that based on researches in genetics there are very good indications that that embryo or fetal cells, tissue and organs can be used for repair and transplants in adults.<sup>24</sup>

### The Argument from Utility

Is it morally right to destroy human embryos for the benefit of others? The argument from utility emphasizes on the extensive use of genetic science in order to find cure for some diseases. It suggests that we should use all available human resource and talent in order to find the solution to diseases which have put many people in great pain. The inner drive to pursue certain things in life includes as a fundamental principle the pursuit of scientific knowledge. Although the fact of the matter with regard to biomedical research is that it entails huge investments and many risks on the part of researchers and human subjects who take part in these experiments, the possibility of discovering new cures is justifiable.

It can be said, for instance, that *“without some risk, there is no progress, no advance. Without risks, pioneers don't cross prairies, astronauts don't walk on the moon...The past critics of assisted reproduction demonstrated a psychologically normal but nevertheless unreasonable tendency to magnify the risk of a harmful but unlikely result”*.<sup>25</sup> Based on this argument, it can be argued that the notion of risk is baseless. It is more prudent, based on this point of view, to consider first and foremost the beneficial value

of the researches made in the field of genetic science to patients.

According to Pence, *“an embryo cannot be harmed by being brought into existence and then being taken out into existence. An embryo is generally considered such until nine weeks after conception, when it is called a fetus. Embryos are not sentient and cannot experience pain. They are thus not the kind of subjects that can be harmed or benefitted”*.<sup>26</sup> Embryos do not possess a consciousness that can experience or feel pain. Since they cannot experience pain, according to Pence, it is pointless to talk about harming the embryo because it cannot be harmed.

### The Christian Position

What sort of dangers are there in genetic science? Take, for instance, the cloning of the first animal, Dolly the sheep. Here is the summary of that experiment: *“Ian Wilmut's work needed 277 embryos to produce one live lamb. In fact, Wilmut started with 277 eggs, fused nuclei with them to create embryos, which were then allowed to become the best 29 embryos, which were allowed to gestate further. He had three lambs, almost live, with one true success, Dolly”*.<sup>27</sup> Based on this claim, 26 embryos have been discarded to produce one true success.

It becomes controversial if human embryos will be used in such experiments. A big moral problem arises if human embryos are simply discarded like any piece of trash. Experimenting on the human embryo, whether for a good or bad motive, is a way of using the embryo into an instrument. For a Christian, what makes this wrong is the point that the human embryo possesses an inherent value. All instrumentation implies some kind of manipulation. One can for instance manipulate a computer program with a virus. The computer program is destroyed. It is rendered useless. But the computer does not possess an inherent value. Its value is derived from the tasks it performs.

The Christian tradition strongly argues that life begins from the moment of conception. As such, the development of that life, for instance the embryonic stage, cannot be manipulated. Since the embryo, from a Christian point of view is human and fully human, the use of this embryo is a violation of the dignity of the human person. Persons, precisely as persons, cannot be reduced to a mere function in order to benefit others. Objects have the character of having a function. Their meaning comes from their usefulness. Reducing a human embryo to a particular function, therefore, is reducing it to an object.

To manipulate means that one sees the entity as a mere object without any inherent value whatsoever. The Christian position is that if a human embryo is discarded in any experiment then one has shown disregard for the very essence and dignity of an inherent value – the sanctity of human life.

<sup>22</sup> Harris, *Clones, Genes and Immortality*, 51

<sup>23</sup> Macer, *A Cross-cultural Introduction to Bioethics*, 124.

<sup>24</sup> Harris, *Clones, Genes and Immortality*, 60

<sup>25</sup> Pence, *Will Cloning Harm People?*, 114

<sup>26</sup> *Ibid.*, 121

<sup>27</sup> *Ibid.*, 120

### Questions of Equitable Distribution

One recent source of moral debate is the assertion that genetic medicine is expensive and will therefore only benefit the rich. Tremendous amount of money is required as an investment in the arena of genetic research. This means the need to develop human resources in third world countries, one that entails financial burden on their governments.

Stem cell therapy, for example, is not available in most third world countries because most of them lack the resources and the medical equipment. For such method of treatment, patients need to go to advanced economies where competent doctors practice. In this regard, some pundits strongly argue that genetic medicine only favors the rich. While the poor are also entitled to advanced patient care, the reality of global inequity destroys any notion of equitable distribution.

However, I argue that questions of science are separate from questions of just distribution. Problems of policy are not issues that researchers need to tackle. The above are matters of political justice that governments must decide. The role of genetic research is to secure the development of treatments that should benefit humanity as a whole. The task is to develop means that are respectful of non-negotiable human values, e.g. human dignity, in order to secure and promote the well-being of patients who are otherwise hopeless.

### Conclusion

Depriving people of access to genetic medicine is also a form of denial of their basic rights. It is morally right and justifiable that scientists and researchers proceed with their investigations in genetic medicine given the proper moral norms and parameters. The argument here is that we can begin with the notion of respect for human rights and the sanctity of human life, which is non-negotiable. If genetic science aims at the enhancement of human welfare and ultimately, the good of human life, then governments should provide the resources to secure for the whole of humanity, without sacrificing universal human values, the most effective ways of treating degenerative diseases.

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We welcome applications and the MPH and program is intended to provide academically qualified individuals who are dedicated to enhancing the status and quality of life of all global communities, the basic competent knowledge and creative and critical-thinking ability to improve public health all over the world. The Director of the MPH Program is Professor Thomas Gionis, President of AUSN.

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**Curriculum for MBGPH**

Residential program	Combination hybrid program
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<p>(All courses are mandatory):</p> <p>Bioethics and Genetics (3 credit hours)</p>	<p>Complete three of the following four Courses (3 are Mandatory):</p> <p>Bioethics and Genetics (3 credit hours)</p> <p>Molecular Biology and Bioethics (3 credit hours)</p> <p>Biosystematics and Biosphere (3 credit hours)</p> <p>Biological Structures and Functions/Life Studies (3 credit hours)</p>

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**Email to Professor Darryl Macer, [dmacer@au-sn.com](mailto:dmacer@au-sn.com)**

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**Let's meet the world and our own identities and histories in AUSN**

**Let's mold the future for equity, sustainability and justice together!**

## ASIAN BIOETHICS ASSOCIATION MEMBERSHIP 2015

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