

**11<sup>th</sup> Global Summit of National Ethics/Bioethics Committees**  
**Berlin, 16-18 March 2016**  
**Meeting Report<sup>1</sup>**

## **Introduction**

The 11<sup>th</sup> Global Summit of National Ethics/Bioethics Committees was opened by Dr. Joachim Gauck, Federal President of Germany. Participants were welcomed by Prof. Christiane Woopen, Chair of the German Ethics Council and President of the 11<sup>th</sup> Global Summit of National Ethics/Bioethics Committees, Dr. Marie-Paule Kieny, Assistant Director-General of the World Health Organization (WHO), and Thomas Rachel, Secretary of the Federal Ministry of Education and Research. Prof. Manuel H. Ruiz de Chávez then looked back at the 10<sup>th</sup> Global Summit that took place in Mexico in 2014. Dr. Abha Saxena from the WHO Global Health Ethics Unit, which hosts the Permanent Secretariat of the Global Summit at WHO, reported on the organizing process for the 11th Global Summit<sup>2</sup>.

The 11th Global Summit was structured around four themes: emerging and converging technologies, epidemics and outbreaks, bioethical policies and bioethical law, and raising social awareness. Through previous Regional Summits, the 2014 Global Summit in Mexico, electronic consultations with the National Ethics/Bioethics Committees, and deliberations within the Steering Committee of the Global Summit, these four topics were identified as important and timely areas of work for the National Ethics/Bioethics Committees (NECs). For each of the themes, a background paper from experts in the field was commissioned. Each paper was circulated prior to the Summit and presented by the authors at the event itself. The presentations were followed by two country perspectives which described work that is already ongoing, and outlined present and future challenges and opportunities<sup>3</sup>.

## **Theme 1: New Technologies: Rules for the Human Park**

The first session was concerned with emerging and converging technologies. These technologies in the biomedical field challenge NECs to anticipate, identify, and find ways of responding to the ethical issues that arise from complex technological innovations and convergences, many of which have implications for human rights and human dignity. In a plenary presentation, Prof. Rinie van Est from the Rathenau Instituut, Netherlands, discussed his co-authored paper “Rules for the digital human park”. It was inspired by a lecture given by the philosopher Peter Sloterdijk at the end of the 20th century which was called “Rules for the human zoo”. Sloterdijk’s lecture caused a fierce media debate in Germany. Sloterdijk claimed that “the domestication of man is the great unthinkable, from which humanism from antiquity to the present has averted its eyes”. Actually he said it is taboo to think about the domestication of man. But his claim was that we should think about that topic, and have a debate about it. He also signalled that in the context of human reproduction, technology plays an increasingly important role. In fact, we are developing the technical means to genetically engineer our offspring. Van Est asked: What is the role of technology? What kind of choices should we make? What kind of rules should we have for the human zoo?

Inspired by Sloterdijk’s wakeup call, van Est reflected on “the rules for the maintenance of the human zoo”. Since digitization plays a central role in our current society, his presentation discussed rule-

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<sup>1</sup> Prepared on behalf of the Steering Committee of the 11<sup>th</sup> Global summit by Patrik Hummel [pah20@st-andrews.ac.uk](mailto:pah20@st-andrews.ac.uk). This is a shortened and edited version of the Conference Report of the 11<sup>th</sup> Global Summit of National Ethics/Bioethics Committees.

<sup>2</sup> The full text of the speeches of the opening session are available in the Full Conference report.

<sup>3</sup> The full text of the background papers and the discussions can be found at [\(provide link here\)](#)

making in the digital human park by looking at two technologies: human germline editing as core example of a “breeding” technology and persuasive technology, as a core example of an electronic “taming” technology. He noted that on the global level, a rather fragmented patchwork of policy instruments and governance structures emerges. As a result, the rules that exist on a national or even regional level have limited enforceability in a global political economy.

Van Est suggested that if we consider values as drivers of a certain socio-technical development, some values may be denoted as accelerator values that legitimize a certain development, while other values act more like brake values. With regards to human germline editing, relevant values like safety, individual right to procreate and the parent’s right to reproductive freedom act as accelerator values, while risk, human genome as common heritage of mankind and a child’s right to self-determination or an open future act as brake values. In the short term the fact that human germline editing is not safe eases the discussion. But it is highly conceivable that it will one day be possible to safely genetically engineer embryos. Such a situation will really bring the conflict between the brake and accelerator values to a head.

Van Est further argued that the rise of smart persuasive environments asks for a new balance between privacy and economic development. This requires us to rethink and conceptualize anew what we mean by privacy and how it can be safeguarded. The fair information principles, which stem from a period with manual collection and automatic processing of personal data, are no longer sufficient to deal with the real-time collection of data via sensors and smart environments. The agency and opacity of smart environments force us to move beyond informational privacy, and look for ways to control how these environments not only collect data, but also profile us and steer our behaviour.

### **Country Perspective from Iran: Capacity Building, Equity, and Cooperation**

Dr. Ehsan Shamsi Gooshki from the National Committee for Ethics in Biomedical Research of Iran pointed out that making rules for new technologies requires capacity building on the national level. Because of the complex nature of new emerging and converging technologies, national ethics authorities need to be enabled to assess their usage in research and in practice. He highlighted the role of international documents, issued by WHO, UNESCO, WMA, CIOMS, but also requested more specified guidelines to explicitly explore the application of human rights standards. Moreover, he argued that such guidelines need to enjoy an acceptable level of authoritativeness on the international level. To this end, the involvement and cooperation of relevant functional units across different UN agencies is crucial. Dr. Gooshki further highlighted that the main promoters of new technologies are almost always companies residing in developed and rich countries where benefits will be enjoyed, while the risks are often imposed on citizens of developing countries. The risks and benefits that arise from the activities of IT companies who collect and analyse data and pharmaceutical companies who do clinical trials are not usually distributed in a fair and justified way. Finally, given that the use of new technologies has already changed our societies profoundly, Dr. Gooshki requested a paradigm change in biomedical research away from a paternalistic framework in which research is being carried out *on* human subjects, towards conducting research *in cooperation with* human participants. Our societies’ members want to be our research partners, not our research instruments.

### **Country Perspective from New Zealand: Degradation of Privacy and Technology for the Elites**

Dr. Barry Smith from the Health Research Council of New Zealand framed his comments in terms of the ethical tensions faced by countries like Australia, Canada and New Zealand, whose populations contain indigenous peoples that have experienced the process of colonization at the hands of British political and economic interests beginning in the mid to late 18th century. He noted that there is a

temptation for researchers to indulge in data ‘hunting’, ‘snooping’ and ‘fishing’. The key implication and concern is that analysis is not being generated out of an intervention logic by which we define important health questions. Here, ethical issues emerge out of the potential misuse and waste of scarce resources for health research. Dr. Smith expressed concern that new technologies will contribute towards a ‘degradation of privacy’. He also pointed to the implications of the obvious potential in the big data space to be able to build a more complete picture of an individual citizen, simply because data is able to be extracted from a variety of sources, each relating to a different social function within the nation-state.

Moving onto the area of germ line editing, Dr. Smith noted that there has been much concern over the potential use of CRISPR-Cas9 technologies and other such approaches. He emphasized that there are uncertainties about these technologies, but identified the ultimate ethical tension as the possibility that the control of technology could rest with elites. This would likely exacerbate the extent to which benefits from, and access to, new health interventions will be distributed in a way that ignores the tenets of social justice while potentially increasing the amount of health disparity. In closing, he argued that all conversations regarding ethical matters emerging from this rapidly changing technological landscape need to give much greater recognition to the importance of socio-cultural diversity. Only then can we strive for a more just distribution of access to healthcare and the health benefits we all hope will accrue from this.

#### **Q&A: Human Germline, Future Generations, and Bioethical Literacy**

After the presentations on emerging and converging technologies, questions and statements from the audience were discussed. China suggested that international bodies like the UN, UNESCO and WHO should introduce rules on CRISPR/Cas9 that prevent modification of the human genome. As Cuba pointed out, such modifications could have drastic consequences. Jordan remarked that considerations of future generations are notably absent from the discussion, and that tampering with the human genome might be against their interests. Prof. van Est noted that as the range of safe and feasible interventions quickly increases, perceptions of the moral constraints on these technologies will change as well. Making use of new technologies in a pragmatic and emancipatory way will likely lead us to push borders which later seem ideological. Dr. Smith agreed that balancing the value and benefits of human beings against potential harms through research and germline modification is challenging, but emphasized that participation in this process of balancing must be equitable and reflect the attitudes of all people affected.

Portugal suggested that new communication technologies provide opportunities to strengthen bioethical literacy and participation of citizens. Dr. Smith stressed that increasing such literacy is a two-way process, and that we should not only think about increasing it in the general public. It is overlooked too often that researchers and clinicians too must acquire an understand of the language and values of the human beings they work with.

## **Theme 2: Epidemics and Outbreaks: WHO Ethical Guidance for Managing Epidemic Outbreaks**

The second session of the program focused on epidemics and outbreaks. Dr. Aissatou Touré from the Pasteur Institute in Dakar, Senegal, spoke on behalf of the group which developed the new WHO Ethical Guidance for Managing Epidemic Outbreaks. Dr. Touré explained how the document grew out of discussions at the WHO about ethical issues raised by the Ebola outbreak. The WHO Global Health Ethics Unit’s work on Ebola began in August 2014, immediately after Ebola was declared a “public health emergency of international concern” pursuant to the International Health Regulations (IHR). That declaration led to the formation of an Ethics Panel, and later an Ethics Working Group, which was charged with developing ethics guidance on issues and concerns as they arose in the course of

the epidemic. Throughout these discussions, it became apparent that the ethical issues raised by Ebola mirrored concerns in other global disease outbreaks, including SARS, pandemic influenza, and MDR-TB. Previous WHO ethical guidance has focused on each of these outbreaks in isolation, without considering ethical issues that might have arisen if the epidemiological circumstances had been different. The purpose of this document is to look beyond the specific issues related to a particular epidemic pathogen, and to focus on the cross-cutting ethical issues that apply to epidemic outbreaks in general. In addition to setting forth general principles, it examines how these principles can be adapted to different epidemiological and social circumstances. Dr. Touré highlighted the role of Prof. Carl Coleman from Seton Hall University who reviewed existing guidance, and played a key role in designing and drafting a guidance document that is specific enough to be helpful and at the same time general enough to enable its user to adapt it to her respective situation.

Dr. Touré reflected on how transformative the case of Ebola was. Many things that people had taken for granted suddenly appeared not to be applicable any more, and this raised a number of questions. In light of uncertainties and difficult decisions, the group found it most important to have a structured approach for developing recommendations. It thus decided that the first guideline should be on adequate public health and health system response in line with ethical principles. The group then addressed a second very important issue for epidemics management: research during epidemics. It collected a number of comprehensive questions that were related to the healthcare system and to research. It also addressed the topic of communicating with local communities, given that Ebola showed that an epidemic cannot be contained if one fails to engage communities and to communicate transparently. One thing that became clear throughout the process was the importance of solidarity. Epidemics do not stop at country borders. There is thus a need to act in unison. In the guidance document, the reader finds a list of obligations and responsibilities, especially towards response and healthcare workers. The guidelines clearly state that this is not just about doctors, physicians, and nurses, but about all people taking an active role in combating the disease, including aid workers, cleaning staff, or the people involved in organizing the funerals of the deceased. In times of epidemics, there is very often increased pressure, for example, on women. In Ebola-affected countries and beyond, it is mainly women who look after ill people. Accordingly, the guidance document lays down some principles concerning women.

### **Country Perspective from South Korea: The Importance of Risk Communication**

Prof. Sangeun Park discussed the 2015 MERS epidemic in South Korea by reference to three guidelines from the document presented by Dr. Touré: guideline no. 1 on the “Obligations of National Governments and the International Community”; guideline no. 2 concerning “Community Engagement and Communication Plans; and guideline no. 13 which deals with “Rapid Data Sharing”. First, Prof. Park gave an overview on the outbreak: only two or three weeks after the first case of MERS was reported in South Korea, MERS had spread intensely. There had been 186 MERS infection cases. Of these people infected, 38 patients died, and more than 16,000 people were released from quarantine. Prof. Park then reflected on the reasons why authorities in South Korea missed the opportunity to successfully control the spread of MERS in its early stages. First, they overlooked the importance of a proactive public communication regarding risk, which is key to the effective management of an infectious disease. According to the IHRs, one of the core capacities for protecting against the spread of a disease is risk communication. The term risk communication is defined by the WHO as the real-time exchange of information, advice, and opinions between experts, or officials, and the people who face the threat to their survival, health, economy, or social wellbeing. Second, in the face of this emergency, the public had been disappointed by relevant authorities’ behaviour which had downplayed the risk of MERS after the first confirmed case. As the disease continued to spread, authorities lost the public’s trust and had a difficult time not only controlling the outbreak but also mending their relationship with the public. Rumours about infected patients resulted in public panic.

Prof. Park described the lessons learned. After receiving recommendations from the ninth meeting of the Emergency Committee regarding MERS corona virus, convened by the WHO Director General under the IHRs, the Korean government reformed the 'National Infection Prevention and Control System'. It established a new organization, an office of communication, under the Centres for Disease Control and Prevention, and set up an immediate response team. The emergency operations centre should communicate with the office of communication about the management of risk through public expert media communication. It thereby reformed the system, planned the coordination and official communication, and placed several departments under the office of communication, including those concerned with risk assessment, international cooperation, resource management, and other topics. These efforts are promising steps in South Korea's journey to join the ranks of advanced countries regarding public health.

### **Country Perspective from Saudi Arabia: MERS-CoV and the Role of Patents in Vaccine Development**

Dr. Imad Aljahdali went on to discuss Saudi Arabia's experience with MERS-CoV. In the Middle East, MERS-CoV was first detected in 2012, and the outbreak reached its peak in April 2014. Just imagine that during that period, the Hajj was ongoing. The risk at that time was not that people bring viruses from their home countries, but instead that they get infected while visiting Saudi Arabia. According to Saudi Arabia's surveillance system, 1338 cases were recorded; 42% of these patients died. The challenges at the time included people's perception and belief systems. It became apparent that dromedary camels play a role in the transmission of the virus. Just as people in Western countries love dogs, people in Saudi Arabia love their camels. As they are so passionate about their camels, one must be sensitive and make clear suggestions on which things they can do, how they can prevent the cycle of transmission, what they need to know about the new virus, which preventive methods they can use, and what the risks are. Authorities became convinced that if they make sure to be very transparent from the start by giving comprehensive information to the public, people would understand more about the virus, and would know better how to protect themselves and not panic. Dr. Aljahdali mentioned how learning how to talk to the media and the local press about this sensitive issue of MERS-CoV was a new experience for physicians and officials, and required dedicated classes and training.

Dr. Aljahdali then explained how patents stood in the way of vaccine developments. On 13 June, 2012, a patient was admitted in a private hospital in Jeddah. The patient suffered from pneumonia and renal failure and died without an identified cause. The consulting physician at the time sent samples out of the Kingdom of Saudi Arabia, without an MTA (material transfer agreement), to a medical centre in Europe, which then identified the new corona virus. Saudi-Arabia was unaware of this until September 2012. Soon, the European lab started sharing the corona virus sample under a material transfer agreement with other laboratories across the world. It also applied for a patent on the corona virus gene sequence. This severely complicated and delayed Saudi Arabia's plans to develop vaccines. The restrictions preserved ownership of the virus samples and hindered the obtaining of intellectual property rights on research. Saudi Arabia thus challenged the patent even at the WHO level. Dr. Aljahdali cited WHO Director-General Dr. Chan who questioned why scientists would send specimens out to laboratories and allow others to have international patent rights regarding a new disease, rather than sharing it through the WHO. Dr. Chan went on to say that no intellectual property should stand in the way of the countries of the world to protect your people, and called upon the delegates of the World Health Assembly to stand against international patents blocking epidemical response. In this spirit, Dr. Aljahdali closed by demanding a clear international stand on patenting genome-related diseases.

### **Q&A: Anti-Vaccine Movements and the Demand for Further Ethics Guidance**

In the Q&A, Spain reported its difficulties with anti-vaccine movements, and demanded a new vaccination-friendly culture based on transparency and autonomy. Austria described the paradox that because in Europe, vaccines prevented outbreaks so effectively, a certain sloppiness is developing along with the upholding of personal freedoms – in a way, successful vaccination has become its own enemy. Dr. Touré added that one surprisingly widespread belief is that vaccines from northern countries can have harmful consequences in populations of other regions. Transparent communication and gaining trust are key to overcome such views.

Ivory Coast expressed interest in further guidance documents that could be used by NECs to reinforce bioethics in their countries. In response, Dr. Touré pointed at documents from the WHO<sup>4</sup>, CIOMS<sup>5</sup>, and UNESCO<sup>6</sup>. Echoing Saudi-Arabia's reports, Rwanda expressed its concern about human tissue transfers. Samples often go from the third world to the first world, but any results of research carried out there is too expensive for the ones who provided the raw material. Rwanda urged WHO and UNESCO to establish guidance that governs such transfers and the resulting patents. Dr. Touré maintained that these issues should be addressed in a close and continuous international dialogue.

### **Theme 3: Bioethical Policies and Bioethical Law: Pluralism**

The third session of the program was concerned with bioethical policies and bioethical law. Prof. Laura Palazzani raised and discussed the question: which kind of regulations should we have in bioethics? An answer is needed because we experience not only a bioethical pluralism, but also a bio-juridical or bio-legal pluralism. Prof. Palazzani distinguished four models for addressing the question.

First, the libertarian model is focused on the affirmation of individual freedom. In this model the absence of law or regulation is preferable in bioethics. There is an exclusion of the public intervention of law in order to defend the freedom and private choice of individuals. This is why this model calls bioethics a “space free from regulation”. It means that all that is neither prescribed nor forbidden is, or may be, allowed. Instead of laws, the model favours deontological codes, codes of conduct, self-discipline of researchers, and self-control of, for example, the scientific community. The implications of this model are the privatization of choices of scientists and citizens about life, death, pain, suffering, and so on.

Second, the liberal model is in favour of interventions of law in bioethics that guarantee individual self-determination. According to the liberal model, the law should protect freedom both in the negative and in the positive sense. In the negative sense, it should not be an obstacle to freedom, and in the positive sense it should multiply options that are technologically possible. According to the liberal model, law intervenes to guarantee self-determination and freedom. The model favors so-called neutral rules, which means minimal legislation, procedural rules, and above all, case law. The idea is not to intervene heavily with laws in bioethics. This implies the acceptance of temporary rules that limit freedom to deal with social emergencies. In this liberal model, for example, legitimate claims include those related to reproductive rights, genetic selection rights, the right to die, and so on.

Third, the utilitarian model proposes the need for interventions of law to maximize benefits and pleasure and to minimize costs and suffering for the greatest number of individuals. It is the so-called utilitarian, collectivistic perspective, that balances the best pragmatic results with social efficiency, productivity, quality of life, and well-being of individuals. Preferred are norms that ensure quality of

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<sup>4</sup> <http://www.who.int/ethics/research/en/>

<sup>5</sup> <http://www.cioms.ch/>

<sup>6</sup> [http://portal.unesco.org/en/ev.php-URL\\_ID=12027&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=-471.html](http://portal.unesco.org/en/ev.php-URL_ID=12027&URL_DO=DO_TOPIC&URL_SECTION=-471.html)

life. Examples of implications are, for instance, animal rights or claiming the right to euthanasia. Here, the subjects are considered to have interests because of the balance of pleasure versus pain.

Fourth, the dignitarian or personalist model emphasizes the need of interventions of law to defend the intrinsic and objective dignity of each human being, considered as a person. If a human being is an end and not just a means, as Kant said, then norms that ensure human equality are preferred. The model recognizes each human being as a subject and not the object of law.

Prof. Palazzani maintained that in view of these four individually plausible models, we should speak of pluralism not only the bioethical but also in the bio-juridical domain. Because of these pluralisms and the corresponding approaches about the role of politics, bioethics committees play an important role for scientific updating activities, the discussion of ethical pluralistic analyses, and for guiding governments regarding bio-law and bio-politics.

### **Country Perspective from Australia: The Force of Guidelines that are not Law**

Dr. Nik Zeps, Global Summit Steering Committee Member for the WHO Western Pacific Region, provided a country perspective from Australia. In Australia, there has been some controversy surrounding sex selection. While there are opportunities for sex selection on the basis of pre-implantation genetic diagnosis of sex-linked disorders or diseases, sex selection which is not motivated in this way is prohibited. The sex selection ban results from guidelines issued by the Australian Health Ethics Committee (AHEC), one of the Principal Committees established under the National Health and Medical Research Council (NHMRC) Act. The guidelines are not legally binding in the sense that they are not law. But they have the equivalent function, because you cannot get a license to practice unless you abide by the guidelines, and therefore, they effectively have the function of law. Dr. Zeps explained that a similar mechanism governs consent to the collection of medical data. The national statement is issued by the NHMRC, the Australian Research Council and the Universities Australia. Again, the statement is not law, but one cannot get funding without abiding by it. The statement allows opt-out consent procedures for data collection when it is feasible to contact patients, but the scale is so significant that using explicit consent is neither practical nor feasible. Essentially, the ethics committees are charged with the job of evaluating whether or to have opt-out procedures is reasonable. They consider whether the person had a reasonable amount of time to evaluate the information, and whether is there a mechanism to obtain further information – aspects that are not always easy to evaluate without direct conversations with the patients.

Dr. Zeps also highlighted the diversity of regulations amongst countries. If we follow the libertarian view, then people should have a choice to do what they want. And in fact, they do. People in Australia go to America, where sex selection is permitted. Twelve Australian couples become pregnant every week in America, where they had a sex selection done. This calls into question the idea about the role of NECs and the discourse that we are having there. How do we ensure uniformity? If we outlaw and make it functionally impossible to do sex selection in Australia, but people can go to Thailand, the US, wherever else and it is permitted there, then is there actually a point of a NEC having a stance?

### **Country Perspective from Malawi: The Importance of Moral Capital**

Prof. Joseph Mfutso-Bengo, Chair of the National Advisory Committee on Bioethics in Malawi, provided reflections on the relation between law and bioethics. He admitted that it is tempting to think that not ethics but only the law can bind individuals. It is the fear of the law which makes people respect the law, whereby bioethics has the power to move hearts and to strive for excellence and perfection. The law can facilitate the enforcement of bioethical theories, policies, principles, and guidelines. For example, in Malawi informed consent for research is part of the Constitution. Prof.

Mfutso-Bengo pointed out that while sometimes pressure is what brings about changes in people, ethics too can be an agent of change. Especially in countries with weak external control and governance, ethics matters most. Changing behaviours can be based on the fear of the law. But law alone as a means of social or professional control is not sustainable without investment in the right attitude and the moral character of persons. In the last 22 years, Malawi has invested a lot in knowledge and skills development, but Prof. Mfutso-Bengo pointed out that the importance of moral capital was largely overlooked. This led to corruption, fraud, moral hazards and professional misconduct. The government of Malawi eventually realised that technical competence has to be complemented with moral competence, and now propagates three ethical pillars for national development: patriotism, integrity, and hard work. The agenda for increased integrity is not only based on legal control but also transformative ethics.

The relation between law and ethics can be complicated. By referring to the example of Nelson Mandela's struggle against Apartheid, Prof. Mfutso-Bengo illustrated that it is sometimes ethical to disobey unjust law. Even today, discrepancies between law and bioethics remain. Sometimes inequity, unfair trade, other practices may be legally acceptable, but can never be moral. Politics can undermine ethical principles of respect of persons, beneficence and justice. The Malawian National Committee on Bioethics (NACOB) thus decided in its first meeting that its mandate goes beyond mere medical and research ethics, and instead covers all social determinants of human life.

#### **Q&A: Should International Guidelines Aim at Cross-Border Uniformity?**

Hungary requested further clarification on how ethics committees should assess the worry that pre-implantation genetic diagnosis can lead to sex selection. Dr. Zeps explained that public consultations are helpful to explore and discuss potential harms as well as the exact extent of pre-implantation diagnostics. Austria agreed with Dr. Zeps that while legislators can set limits, people might simply seek services abroad. Pakistan suggested that sex selection to identify chromosomal abnormalities that lead to a miserable death is one thing, but using sex selection to discriminate between chromosomal configurations is another. In certain parts of the world people want boys because they are considered to be more useful. Beyond the law and policy issues, we need bioethics, bioethicists, policy makers and governments to actually change this mindset.

Given the presence of pluralism in the legal, ethical, and policy sphere, Prof. Woopen proposed that the Global Summit issues a convention or treaty that calls for an implementation of UNESCO's Universal Declaration on the Human Genome and Human Rights<sup>7</sup> which is considered an authoritative reference point for the promotion of human rights. While Prof. Palazzani seconded this proposal, France pointed at the Oviedo Convention<sup>8</sup> which has already been ratified. Prof. Mfutso-Bengo agreed that thinking globally is important, but further reiterated that the NECs remain systematic places where local initiatives can gain international recognition and inform international discourse – a role that should not be underestimated. The Netherlands questioned whether having uniform laws amongst countries is desirable. Countries differ with respect to ethical values and the role and understanding of evidence. The international community should aim at keeping the option of having these differences reflected in the respective national laws. Dr. Zeps suggested that there are at least some domains where robust evidence is available that should guide medical practice anywhere, independently of whether there is value pluralism across borders.

#### **Theme 4: Raising Social Awareness of Bioethical Issues: Fostering Public Participation Through Education**

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<sup>7</sup> <http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/human-genome-and-human-rights/>

<sup>8</sup> <http://www.coe.int/en/web/bioethics/oviedo-convention>

The fourth session of the program was concerned with raising social awareness of bioethical issues. Biomedical issues raise complex ethical concerns that are not always immediately obvious to those not deeply engaged in understanding and analysing those issues. Prof. Jorge E. Linares from the National Autonomous University of Mexico presented his paper “Raising social awareness of bioethical issues including education, media, and communications”. According to the Universal Declaration of Bioethics and Human Rights of UNESCO, the member states of the United Nations have the obligation to promote reflection on bioethical issues in educational structure and public communication as well as to encourage international cooperation to achieve more extensive dissemination. Linares demanded that NECs should promote a pluralistic debate based on scientific knowledge, contemporary ethical theories, and a multicultural and pluri-ethnic dialogue.

Within all societies, different moral conceptions and practices coexist. None of them should arbitrarily be imposed on other communities through influence on customs, or through being more dominant or hegemonic in a given society. It is the duty of the NECs to shape public debates in which the doctrinal moralities do not prevail and are not imposed as an official public morality over all citizens. This is why pluralistic bioethical debate is needed in every society. All moral decisions should be expressed in public debates and in the media, but each has to offer rational arguments and ethical values that are acceptable and shared by all moral communities. The NECs must encourage pluralism that expands the individual and social rights to free decision-making, equal opportunities of human development, and universal access to healthcare and the benefits of science and technology.

Prof. Linares emphasized the importance of different forms of education. Education regarding bioethics should supply tools to develop autonomous deliberation about our own bodies and personal decisions in life. There should be particular attention to the bioethical rights of vulnerable groups, especially women. Moreover, dedicated training needs to be provided in higher education, particularly in postgraduate programmes that provide multidisciplinary, theoretical and practical perspectives. Bioethicists also need to be prepared to inform and guide deliberation in committees of hospitals and research centres as well as public debates. Non-formal education should be offered in all possible modalities of media and promotional campaigns targeting the main subjects related to bioethical issues. Science museums are good locations to exchange and expand exhibits on main bioethical issues, for instance the beginning and end of life, diseases and epidemics, genetics and genomic techno-sciences, health systems, neuro-ethics, environmental ethics, ecology, conservation of biodiversity, sustainability issues and social and economic development. This will enable NECs to foster the social assessment of scientific and biotechnological innovations and discuss the risks of biotechnologies as well as the fair distribution of the technological and scientific benefits – debates that might contribute to the reduction of social economic inequalities.

Prof. Linares’ presentation was followed by a panel discussion with representatives from four countries.

### **Country Perspectives from the United States: Bioethics at all Levels of Education**

Prof. Anita Allen provided insights into the work of the United States Presidential Commission for the Study of Bioethical Issues. For the Commission, public awareness and public participation go hand in hand. One way it encourages public participation is by hearing from a wide variety of stakeholders through publicly transparent and accountable mechanisms. The meetings are public, and often feature international and national experts. For example, during the 2014, 2015 Ebola outbreak in West Africa, the commission met publicly and heard from experts on public health, public health workers returning from deployment abroad and from advocates from the affected communities in the United States and Sierra Leone. Prof. Allen explained that in the future, the Commission aims at ensuring not only that the public has an opportunity to learn to know, engage and inform experts

and the government, but also hopes to develop some metrics about when impact, outreach, and inclusion efforts have been successful.

Six of the Commissions' nine written reports directly address the importance of public and professional ethics education. These reports reflect the Commission's view that public engagement and education are essential. Over fifty sets of educational materials for the public are provided. These are available on the Commission's website, [bioethics.gov](http://bioethics.gov), and are designed for a variety of learners. In contrast to Prof. Linares, Prof. Allen and the Commission do not think that the postgraduate level is the central place for bioethics education. According to the Commission, it needs to start at the beginning. Elementary school children need to be exposed to bioethics. High school students, college students, graduate and students in professional training need to have access to bioethics education. Not everybody will get to that postgraduate level, and yet everybody needs to have an opportunity to know about bioethics. At least in the United States, bioethics came to exist because of the mistreatment of ordinary people who were research subjects or patients. And since bioethics arose to make the lives of those ordinary people more full of dignity, more autonomy, more freedom, more respect, more privacy, it stands to reason that those ordinary people need to understand when their interests are at risk. Therefore, we need to start bioethics training in our societies and at the beginning of education, as soon as possible.

### **Country Perspective from Singapore: Innovative Formats for Raising Awareness**

Prof. Chin Jing Jih shared examples of how Singapore raises awareness of bioethical issues. The Bioethics Advisory Committee (BAC) was formed in the year 2000 by the Singapore Cabinet. One of the key objectives for the committee is public education and being a source of information on bioethical issues in a multiethnic, multicultural and multireligious country. In order to bring its message to the masses, the BAC realized that it needed to engage with agencies that reach out to the public. One of the key partners of the BAC is the Singapore Science Centre, an institution that promotes interest in science and technology through a blend of exhibitions, events and educational programmes. In the Science Centre, a Bioethics Exhibition has been set up and is frequented by tourists, students, and other members of the public. The exhibition is not meant to impose certain views on young minds, but to let them see things from a different perspective. For example, the main exhibit is a display on commercial aspects of organ transplantation, but it is presented in stories which are told from the perspective of the patient, the family and the community at large. It tries to get students to look at the issue in a way that allows them to establish their own views. Similar objectives are pursued through symposia, public forums, and other events. Some of the formats implemented by the BAC are quite innovative. It hosts movie screenings which are followed by discussions on some of the bioethical themes raised in the movie. Another initiative involves a popular drama group in Singapore that has been open to experimentation with bioethical issues. The Centre for Biomedical Ethics commissioned The Necessary Stage to produce a play called "Future Perfect", which dealt with the theme of human enhancement through three stories about designer babies, stem cell products and a "Youth Fountain Serum". The play was able to draw in the crowd. After the play, scholars from the Centre for Biomedical Ethics, the dramatist, and the director engaged in a conversation on human enhancement with the students and the public who came to watch the play.

Prof. Chin Jing Jih highlighted that the way the media frames topics can influence the perception of the public. Engagement with the media is thus crucial. Here, the new frontier certainly is social media. The BAC may have to consider starting a Facebook account, or develop a website that appeals to the younger generation. There is a need to think about how bioethical issues can be packed in a format that is appropriate and can be communicated effectively across social media.

## **Country Perspective from the United Kingdom: Promoting Bioethics Literacy through a Variety of Channels**

Hugh Whittall from the Nuffield Council on Bioethics captured points of agreement that were implicit in the foregoing discussions. NECs advise policy, but if we see this as a public enterprise that engages public interests, then this obviously requires public involvement in a pluralistic fashion, engaging a national and international discourse. He pointed at four aspects of this insight. First, NECs are in agreement that people's input into their work and deliberative activities is needed. Mr Whittall argued that NECs should not try to claim that they are the experts who make decisions on behalf of everybody, but try to engage people to contribute. Second, these contributions shall not only be sought and channelled through NECs themselves. Instead, a public discourse shall be stimulated in which those contributions can be made in other ways. Third, in dissemination of published opinions, reports and recommendations, NECs will of course target policy makers and decision makers, but should also promote an understanding of what they have done in a wider public context. Fourth, the objective is to promote critical thinking in general, not necessarily specific to a particular problem or a particular issue. One phrase that is often used is "promoting bioethics literacy" – the capability of people to recognise, to contemplate, to think and to engage in these types of discussions.

Regarding the ways in which public discourse is facilitated, Mr Whittall distinguished three different approaches. The first is to engage with people directly. The Nuffield Council carries out public consultations where it seeks as many views as it can, puts information out widely, targets particular interest groups who have a particular stake in an issue, or uses focus groups with representative of wider publics. The second way to facilitate public discourse is via the media. Mr Whittall highlighted the need to foster relationships with the media so that when they do see an issue relevant to the Council's field of work, they are ready to discuss, to understand and to work through it. With regards to social media, Mr Whittall described the risk that no effective attempt is being made to actually increase the range of recipients beyond those followers and Facebook friends who are already interested in bioethical issues. The third way to facilitate public discourse is through partnerships. The Nuffield Council is doing this in a number of ways. It worked with an online radio station that produced a number of two-minute radio clips directed at children aged six to twelve. These had about 370 000 listeners. The Council works with science museums, and partners with theatre groups, such as Theatre of Debate in the UK who taken out some of the plays into schools. Moreover, the Council works with spoken word groups. For example, in 2015 it developed a project around naturalness with a poetry group called Apples and Snakes. These are examples of ways the Council cooperates with others who are well placed to take our work out to audiences that we might not otherwise reach.

## **Country Perspectives from Turkey: Including Bioethics in Higher Education Curricula**

Prof. Meral Özgüc from the Bioethics Committee of Turkish National Commission for UNESCO reported that raising public awareness is not very common in Turkey as most of the biomedical issues are dealt with in a top-down approach. Medical ethics is an established discipline, but bioethics is a rather new field of enquiry. The Commission decided to focus on education, and approached faculty members and deans of universities. Especially in science faculties and medical schools with new technologies in genetics and genomics, the Commission realized that curricula were in need of being updated with bioethical contents. The Commission was instrumental in establishing a bioethics centre in Ankara in 2013. Moreover, there are two science faculties in Ankara that are now teaching bioethics and use UNESCO's materials.

The Commission recognized that bringing about changes in higher education is an important first step, but that the general public, especially young people, need to be approached as well. The Committee of Education within the UNESCO Commission facilitated meetings with secondary school

teachers who shared ideas on how topics in bioethics can be integrated in textbooks. These topics included discrimination, solidarity, stigmatization, and other issues the Commission thought should be looked at an early age, if we are hoping for a better world for all of us. Moreover, Prof. Özguc agreed that the media plays an important role in conveying bioethical issues. After several meetings with members of the media, the Commission suggested that within faculties of communication, training in science journalism should be strengthened further, and courses on bioethical issues be included in communication degree programmes.

### **Q&A:**

Pakistan opened the Q&A by highlighting how useful social media could be for awareness raising on bioethical issues, especially in order to reach younger generations. The delegate commended the US Presidential Commission on teaching materials it distributed through its Twitter feed. The materials are freely accessible and can easily be adapted.

New Zealand pointed out that many indigenous populations are not sufficiently included into bioethical conversations and have a sense that nobody, including this very Global Summit, is properly listening to their perspectives. Prof. Allen reported on how the US Bioethics Commission includes minority voices in its discourses. For example, it reached out to the Havasupai tribe and spoke with representatives about what it means when local university researchers analyse a tribe member's genome. The finding that members' roots can be traced back to regions beyond the Americas offends their worldview. Prof. Allen emphasized the importance of taking into account and respecting these perspectives.

Prof. Linares and Prof. Jing Jih were in agreement that NECs should not impose top-down approaches on their people, but should build on feedback from communities and a variety of stakeholders. Prof. Allen added that NECs' legitimacy depends upon the infusion of from the public perspectives. This is precisely what makes them worth listening to, accountable, and transparent. Mr Whittall agreed that principles of inclusion apply to all bioethical topics, from deep brain stimulation, advanced technologies, to access to basic healthcare. Given Kenya's worry that only the loudest and most powerful stakeholders will be heard in the deliberative process that informs NECs, Mr Whittall suggested that channelling voices through a committee like the Nuffield Council is more effective than raising voices directly, because government decision makers are much more responsive to loud noises.

Jamaica and several other countries reported a lack of resources and training to effectively raise awareness on bioethical issues. Mozambique explained that establishing trust in the population is key. Gambia pointed out that it is difficult to raise awareness of more advanced technologies in contexts where much more basic issues like the lack of portable water, lack of sanitation, and dysfunctional health systems fuel epidemics. Mr Whittall agreed that different priorities should be set in different circumstances – whether they concern capacity building of one's committee, developing the committee's network, or strengthening its relationship with policy makers.

## **Regional Meetings**

These presentations concluded the four thematic plenary sessions. Afterwards, participants of the respective WHO-regions – African Region (AFRO), Eastern Mediterranean Region (EMRO), European Region (EURO), Region of the Americas (PAHO: Pan American Health Organization), South-East Asia Region (SEARO) and Western Pacific Region (WPRO) – came together for the Regional Meetings in different rooms of the venue. SEARO and WPRO held their meeting together. The meetings were led by the respective members of the Steering Committee in accordance with their regional affiliation. A plenary session gave each region the opportunity to present the outcome of their discussions and to

nominate new Steering Committee members. Each group was requested to treat the following items during the presentation of the regional report: topics for the next Global Summit, regional meeting plans, recommendations for future Global Summits, representatives and suggestions for the next Steering Committee.

AFRO's meeting was summarized by Prof. Mfutso-Bengo from Malawi. AFRO suggested a number of topics for the next Global Summit: funding and maintaining of NECs; political and socio-economic aspects of Bioethics on the local, regional, and global level; Bioethics vis-à-vis democracy, sustainable development, and access to health care; capacity building for NECs; bio-banking, tissue and data trade as well as data sharing and access; the relation between bioethics and religion. Malawi's offer to host the 2017 regional meeting of AFRO's NECs was accepted. Delegates suggested that in future Global Summits, more time should be allocated to the Marketplace presentations. To this end, the programme should be prolonged by at least one day. More parallel sessions shall be introduced to cater for specific interests and needs of the regions. Prof. Mfutso-Bengo and Dr. Aissatou Touré (Senegal) were elected as AFRO's representatives in the Steering Committee of the Global Summit.

Prof. Michel Daher from Lebanon reported that EMRO suggested four topics: solidarity, international collaboration and benefit sharing; resilience of health systems in responding to migration; avoiding stigmatization and discrimination in public health issues; effective approaches for public awareness and education. EMRO's next regional meeting will be hosted by Oman in spring 2017. Moreover, EMRO suggested that WHO and UNESCO could prepare a survey to explore the interest in partnerships and twinnings between countries. Delegates from Oman and Jordan will represent the region in the Steering Committee.

EURO's suggestions were summarized by Dr. Jonathan Montgomery from the United Kingdom. Several topics were suggested: health issues (harmonization of experimental therapy; personalized or stratified medicine; dementia; expensive drugs and the patenting of genes); migration and health; pollution and global resources; bioethics and the youth (education). Austria offered to host a regional meeting in Vienna. EURO suggested that the Global Summit should be extended to two and a half or three days, and includes parallel sessions. The very good background papers should be followed directly by a plenary discussion. The marketplace location should be closer to the break area and include posters rather than PowerPoint presentations. Moreover, EURO demanded that the former and the future host country should not count as members of a region with regards to the composition of the Steering Committee. Future venues should be decided by electronic vote of all NECs, and the selection process should begin about one year before the next Global Summit.

Prof. Tunde Bewaji from Jamaica spoke on behalf of PAHO. Three topics were suggested: ethical implications of local, national, regional and global responses to public health emergencies and infectious diseases if resources are limited; ethics of genetics and stem-cell research; the relation between ethics and public health policy as well as policy more generally. A regional meeting is planned, but the host is yet to be determined. Dr. Lobos Lazzeri (Ecuador) and Prof. Bewaji will represent PAHO within the Steering Committee.

SEARO and WPRO held their regional meeting together. Suggested topics included: responding to natural disasters and managing of newly emergent diseases; definitions of vulnerability and payments for organ donors; new technologies including stem-cell therapy, CRISPR-Cas9, bio-banking, international transfer, benefit sharing as well as sequencing and data release; the relation between NECs and governments, including legal status and empowerment of NECs. The regional meeting 2017 will take place in South Korea. SEARO and WPRO remarked that the presentations at the Global Summit shall be shorter in order to allow for more discussion. Parallel sessions would help to accommodate topics that are more specific to NECs' interests. It was also suggested that a mentor-

mentee system could be established. No delegates for the Steering Committee have been determined yet. Sri Lanka and Singapore showed interest in representing SEARO.

## **Concluding Remarks**

In further parts of the programme of the Global Summit, several parallel Marketplace sessions provided opportunities for PowerPoint and poster presentations of country experiences. Through these formats, the Global Summit 2016 accomplished its mission to serve as a platform for all countries to share experiences and perspectives on bioethical topics, to foster cooperation and exchange amongst NECs, and to inform and harmonize efforts to address bioethical challenges around the world.