Global Network of WHO Collaborating Centres for

BIOETHICS

PROGRESS REPORT
2017–2018
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This report was compiled by Elly Ganakas (HEG intern) under the coordination of Dr Andreas Reis (HEG) with the support of Lee-Anne Pascoe (HEG).

Thanks go to the Collaborating Centres for their input.
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BACKGROUND

The Global Network of WHO Collaborating Centres for Bioethics (hereafter referred to as the “Network”) was established in 2009 to “support the WHO-HQ Global Health Ethics Unit (Geneva) to implement its mandated work in the field of ethics and health, including:

- “articulating ethical and evidence-based policy options' (WHO core function);
- advancing ethics- and rights-based approaches to health promoted within WHO and at national and global levels; and
- increasing capacity to assess and act upon ethical issues in public health at country, regional and global levels and within the Organization.”

The Network augments the contributions of individual WHO collaborating centres for bioethics by fostering “connections and synergies ... to achieve enhanced results, to facilitate resource mobilization, and to strengthen (institutional) capacity, in particular at regional level” with respect to public health ethics, research ethics, and clinical ethics.¹

As of December 2018, the Network comprised of 11 WHO collaborating centres in five regions.

During the reporting period, the members of the Network collaborated multilaterally on a number of major projects initiated by the WHO Health Ethics and Governance team (HEG). In the past years, these collaborative projects have focused on public health surveillance, infectious disease outbreak, vector-borne diseases and big data.

Many additional projects were undertaken by single institutions at the request of HEG.

This report of activities covers both Network projects as well as individual collaborations between collaborating centres and HEG.

**NETWORK DEVELOPMENT**

**NEW MEMBERS**

Over the past year, one new collaborating centre for bioethics was added to the Network:

- The Asian Institute of Bioethics and Health Law (AIBHL), Seoul, was designated on 20 February 2018.

This brings the total number of member institutions in the Network to 11.

The Centre of Biomedical Ethics and Culture (CBEC), Sindh Institute of Urology and Transplantation, Karachi, Pakistan was designated a collaborating centre in 2017. The inaugural ceremony for the designation of the centre was held on 25 April 2018 in Karachi.

**NETWORK BROCHURE**

UM has continued to be responsible for updating the network brochure to reflect current membership and activities.

**NINTH ANNUAL MEETING**

The 9th annual meeting of the Network was hosted by the University of Miami on 11 October 2017. Topics discussed included transparency in clinical research and data sharing, managing epidemic outbreaks, vector-borne diseases, big data and AI, ageing, antimicrobial resistance, and biobanking.

The 10th annual meeting is scheduled for 8 December 2018, Bangalore. This coincides with the 14th IAB World Congress of Bioethics.

**OTHER MEETINGS**

UM, JCB, FLACSO, NUS and HEG collaborated in developing a panel session for the forthcoming 14th World Congress of Bioethics in Bengaluru, India. The theme of the congress is ‘Health for all in an unequal world: Obligations of global bioethics’.

The 13th International Conference on Clinical Ethics and Consultation was hosted by NUS from the 24–27 May 2017. This was attended by several network members.

NUS (Prof Roy Joseph) served as an expert consultant at the Asia-Pacific Regional Meeting of National Ethics/Bioethics Committees, which was held in Seoul, Republic of Korea, 24–25 October 2017.

Dr Johann Roduit (IBME) presented his research ‘Digitalization of Homo Sapiens – Ethical Reflections’ at a WHO lunchtime seminar in April 2018.

CAS-UDD organized a meeting of the five Chilean PAHO and seven WHO collaborating centres to establish a regional network in April 2018.

SU in collaboration with the Centre for Bioethics, University of North Carolina, hosted the 7th annual ARESA research ethics seminar, 24–25 May 2018.

AIBHL participated in the 10th and 11th meeting of the Alliance of WHO Collaborating Centres in Korea, held on 28 June 2017 and 1 November 2018, respectively.
CAS-UDD visited PAHO in Washington DC, 10–13 September 2018, to increase the centre’s relationship with regional bioethics platforms in Latin America and the Caribbean. During this visit Dr Juan Pablo Beca and Dr Carmen Astete held meetings at George Washington University, Kennedy Institute of Ethics, the Clinical Bioethics Centre of Georgetown University, and the NIH, to inform about the collaborating centre’s work.

IBME (Dr Valerie Luyckx and Dr Corine Mouton-Dorey) and UM (Prof Ken Goodman) co-facilitated a training of the WHO Research Ethics Review Committee and the WHO Public Health Ethics Consultation Group, which was held on 28 September 2018 in Geneva.

HEG hosted the workshop ‘Update in Research and Public Health Ethics’ on 28 September 2018. Dr Corine Mouton-Dorey (IBME) delivered a presentation entitled ‘On Biobanking’, and Prof Ken Goodman (UM) delivered a presentation entitled ‘Big and Small Data, Artificial Intelligence’. Both speakers also facilitated group case discussions.

SU hosted the ‘Information Regulator of South Africa’ at a workshop on data privacy in research entitled ‘What does the POPI Act mean for research and clinical medicine?’, 11 October 2018.

FLACSO participated in the 13\textsuperscript{th} Global Forum on Bioethics in Research, held in South Africa from the 13–14 November 2018. The theme of the forum was ‘The Ethics of Data Sharing and Biobanking in Research’, and Dr Florencia Luna was awarded the 2018 Global Forum Award for Contribution to Progress in International Research Ethics.

### ACTIVITIES

#### AGEING

**Topics addressed:**
- Guideline development
- Revision of projects

A WHO meeting on ‘Developing an ethical framework for healthy ageing’ was hosted in Germany on 18 March 2017 by the Institute for Ethics and History of Medicine of the University of Tübingen. The meeting was attended by Prof Jennifer Gibson (JCB), Dr Ross Upshur (JCB), and Dr Kavita Sivaramakrishnan (CU). A subsequent meeting report was published in 2017. Then, Dr Florencia Luna (FLACSO) reviewed related plans for research and quality assurance and evaluated projects on ageing, in collaboration with the WHO Centre For Health Development, Kobe, Japan.

#### BIOBANKING

**Topics addressed:**
- Online training
- Consultations

A PhD student from SU is developing an online course under the supervision of Prof Keymanthri Moodley (SU) and Prof Jean Cadigan from University of North Carolina. A total of nine modules will be developed for an entire training course in biobanking.

Dr Calvin Ho (NUS) served as a presenter, resource person and discussant in the ‘WHO third consultation on biobanking: Access to, storage and use of samples during a public health emergency’, held in Geneva 24–25 October 2017. The meeting was led by Dr Vasee Moorthy (WHO).
CLINICAL ETHICS

Topics addressed:
- Euthanasia
- Ethics training
- Revision of guidelines
- Medical dispute resolution

As a PAHO/WHO CC representative, Dr Juan Pablo Beca (CAS-UDD) delivered a series of presentations on clinical ethics throughout 2017–2018. These included a presentation on Euthanasia and Palliative Sedation at the 2nd Uruguayan Congress of Medicine and Palliative Care, organized by the Uruguayan Society of Palliative Care, 16–17 November 2017; as well as four presentations at the 8th Provincial Bioethics Seminar in Córdoba, Argentina, 16–17 August 2018; a training lecture to medical students at the Instituto Universitario de Ciencias Biomédicas, Córdoba, on the issues they will face in their professional lives; and a clinical case discussion on ‘dignified death’ for a bioethics training program organized by the Regional Ministerial Secretariat, La Serena, Chile from 30–31 August 2018.

CAS-UDD in coordination with PAHO supported the 14th Intensive International Course in Bioethics (CIIB), 28 May – 2 June 2018. This was attended by participants from the region.

CAS-UDD has hosted clinicians selected by PAHO for training stays at the Centro de Bioetica. The centre is also assessing the feasibility of the creation of a Clinical Bioethics Network with the purpose of strengthening the deliberation competencies of members of clinical ethics committees of the Region.

CAS-UDD revised WHO Guidelines for both primary health care and pediatrics, on ‘Integrating Palliative Care and Symptom Relief: A WHO guide for planners, implementers, and managers’, in January 2018.

From November to December 2017, CAS-UDD in collaboration with the Instituto Catalán de Oncologia (ICO), drafted a project for an online course on advanced care directives for Latin America and the Caribbean.

In order to establish a prevention system for medical disputes and patient safety against malpractice, and to provide country guidance, AIBHL has published three books on quantitative and qualitative analyses of selected cases of medical malpractice for emergency medicine, anesthesia and plastic surgery.

EMERGING TECHNOLOGIES IN HEALTHCARE

Topics addressed:
- Big Data expert consultation
- Artificial Intelligence
- Value sensitive humanitarian innovation

UM hosted an international consultation on Big Data and Artificial Intelligence (AI) in health, in Miami, October 2017. The purpose of the consultation was to inform the work of WHO and provide guidance for stakeholders by identifying the scope and range of the ethical issues related to these topics. Approximately thirty participants attended including members of the Network, representatives from international organizations, academia, industry and government. A subsequent meeting report was published in 2018.

JCB hosted a conference on ‘Ethics and AI for Good Health’, held on 11 June 2018, to which UM, CU and HEG contributed. Dr Amy Fairchild (CU) delivered a paper entitled ‘Utopias and Dystopias: Big Data, AI and the Promise and Specter of Public Health Surveillance’.

Ning Wang (IBME) launched a new research project, in collaboration with Dr Andreas Reis (HEG), and Dr
Ali Okhowat and Dr Caroline Clarinval (Health Emergencies), investigating the notion of ‘value-sensitive humanitarian innovation’, with a focus on the ethics of emerging technologies applied in health emergencies and humanitarian action. In November 2018, HEG represented WHO to attend the project kickoff meeting in Zurich. Dr Andreas Reis gave a keynote talk on ‘The Importance of Ethics of New Technologies in WHO’s Global Program of Work’, among other academics and organizational partners. The project is funded by two Swiss foundations for 2.5 years. The results of the research will be translated into policy outcomes and toolkits.

**HEALTH SYSTEMS AND IMPLEMENTATION RESEARCH**

*Topics addressed:*
- Teaching tools
- Innovation for health systems

The ‘Ethics in Implementation Research’ teaching tool co-developed between IBME and the Special Programme for Research and Training in Tropical Diseases, HEG and the Alliance for Health Policy and Systems Research is due to be launched in January 2019. IBME will continue to support the roll-out of this tool.

Dr Ignacio Mastroleo and Ms Felicitas Holzer (FLACSO) presented their current conceptual work on innovation as a new non-validated practice to Dr Marie-Charlotte Bouësseau (WHO) and discussed future collaborations. FLACSO has committed to read the first draft of WHO’s document on innovation for health systems when available.

Dr Ignacio Mastroleo and Ms Felicitas Holzer (FLACSO) also presented their current research to Dr Andreas Reis (HEG), where Dr Reis noted the WHO ethical framework on Monitored Emergency Use of Unregistered and Investigational Interventions (MEURI). The prospect of a collaboration with the Program of Bioethics at FLACSO Argentina was discussed.

Dr Calvin Ho (NUS) supported WHO in the technical review of a survey tool in relation to the 12th Global Summit of National Bioethics Bodies, that was held from the 22–24 March 2018 in Dakar, Senegal.

**HEALTH LAW AND BIOETHICS**

*Topics addressed:*
- Development of a Public Health Law Database
- Achieving Universal Health Coverage and the Sustainable Development Goals

Researchers from AIBHL have been working on a Public Health Law Database at WPRO, classifying country data into the categories of health service and administration, infectious disease and public health, health workforce regulations, medicines regulations and food safety regulation. AIBHL have also been working on the development of an Online Country Report System on Public Health Law. These platforms are intended to help respond to information requirements of the Regional Office.

**INFECTIOUS DISEASES**

*Topics addressed:*
- Guidelines on outbreaks
- Vector-borne diseases
- Teaching tools

At the request of WHO and HEG, some members of the Network provided rapid feedback on an ethical framework for the Monitored Emergency Use of Unregistered and Investigational Interventions, for use in the August 2018 Ebola outbreak in the Democratic Republic of the Congo.

During the Ebola outbreak, Dr Corine Mouton-Dorey (IBME) revised the French translation of WHO ‘Guidance for Managing Ethical Issues in Infectious Disease Outbreaks’.

Since 2017, HEG has been carrying out a project to develop guidance on ethical issues that arise in the management of vector-borne diseases. This work has been greatly supported by MU (Dr Michael Selgelid and Dr Zeb Jamrozik), along with CBEC (Dr Aamir Jafarey) and FLACSO (Dr Florenzia Luna).

Dr Juan Pablo Beca and Dr Luis Miguel Noriega (CAS-UDD) revised the Spanish translation of WHO ‘Guidance for Managing Ethical Issues in Infectious Disease Outbreaks’ in December 2017.

At the request of HEG, Dr Juan Pablo Beca and Dr Carmen Astete (CAS-UDD) participated in an ethics consultation about the use of NYDA© in Tungiasis treatment in Washington DC, 12 September 2018.

At the request of the WHO Special Programme for Research and Training in Tropical Diseases, FLACSO is reviewing the toolkit ‘Incorporating intersectional gender analysis into research on infectious diseases of poverty’.

HEG established an interactive ‘Integrating Ethics in Infectious Disease Outbreaks’ [online platform](#) in May 2018, conceptualised by former coordinator of the HEG, Dr Abha Saxena. This received generous financial support from the Wellcome Trust.

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**NONCOMMUNICABLE DISEASES**

*Topic addressed:*
- Concept paper

Dr Valerie Luyckx (IBME), Dr Florenzia Luna (FLACSO) and HEG have begun working on a concept paper on ethics related to non-communicable diseases (NCDs). The plan is to develop a full-length manuscript for publication as well as an infographic flyer for distribution summarizing the ethical issues relevant to NCDs. Constructive feedback has been received from some of the other collaborating centres, and it is hoped that this can be taken forward in a more substantive way.

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**RESEARCH ETHICS**

*Topics addressed:*
- Public health research in disaster-struck areas
- Strengthening capacity through ethics teaching and training
- EMRO Research Ethics Committee
CBEC has produced a teaching video ‘Between Hope and Despair’ as a collaborative venture. The video addresses the ethical issue of public health research in disaster-struck areas (published on YouTube 26 December 2017).

CBEC is running a Masters in Bioethics and Postgraduate Diploma in Biomedical Ethics. From 25–28 April 2018, Dr Andreas Reis (HEG) was involved in teaching sessions on ‘Surveillance vs Research’ and ‘Ebola and Zika - Emerging Ethical Challenges’. These were based on guidelines and documents developed by WHO. WHO training manual ‘Ethics in Epidemics, Emergencies and Disasters’ was also used as a teaching template.

FLACSO provided in-depth research ethics training to a delegate from Guatemala: Dorian Ramirez, President of National Research Ethics Committee, who was selected by PAHO.


FLACSO provided support to the revision and selection of indicators of the research ethics component of PAHO’s Bioethics Strategy and Plan of Action.

At the request of PAHO, both CAS-UDD and FLACSO conducted a technical revision of the Spanish translation of the 2016 CIOMS ‘International Ethical Guidelines for Health-related Research Involving Humans’, published 2017. FLACSO co-hosted two virtual training sessions with PAHO in English and Spanish to present and discuss the new guidelines.

PAHO also requested FLACSO’s comments and review of a technical guide for research ethics committees for the evaluation of clinical trials from Peru, as well as a bill regulating use and access to human assisted reproduction treatments.

Dr Aamir Jafarey (CBEC) has been a member of the EMRO Research Ethics Committee since 2017. In the November meeting of the EMRO REC, committee members discussed the composition of the Steering Committee which will assume responsibility for next year’s Regional NEC Summit.

An article by Dr George Rugare Chingarande and Prof Keymanthri Moodley (SU), entitled ‘Disparate compensation policies for research related injury in an era of multinational trials: a case study of Brazil, India, China and South Africa’, was published in BMC Medical Ethics, February 2018.

**Surveillance**

**Topics addressed:**

- WHO Guidelines on Ethical Issues in Public Health Surveillance
- Translation and dissemination

CAS-UDD revised the Spanish translation of the 2017 WHO Guidelines on Ethics and Public Health Surveillance. FLACSO supported the dissemination of these guidelines by hosting virtual training sessions in English (November 2017) and Spanish (July 2018).

Two articles written by Dr Amy Fairchild (CU) announcing the publication of WHO Guidelines were published in 2017 in Lancet Public Health and the American Journal of Public Health.

Dr Calvin Ho (NUS) contributed as an instructor in a full-day WHO training workshop entitled ‘Ethics of Epidemics and Surveillance’, 6 August 2017, which was attended by over 20 field epidemiologists. The
workshop was led by Dr Abha Saxena (HEG) and was organized as a pre-conference session to the 9th TEPHINET Global Conference in Chiang Mai, Thailand, 7–11 August. A report of the workshop was subsequently published in September 2018, in the Asian Bioethics Review.

**Transplantation**

Topics addressed:
- Deceased organ donation
- Transplant coordinators

Dr Farhat Moazam (CBEC) is a member of the WHO Task Force for Donation and Transplantation of Human Organs and Tissues, constituted May 2018.

CBEC in collaboration with WHO will organize and host a 2-day conference and workshop in Karachi in June 2019. The theme of the conference will be deceased organ donation programs in the region (EMRO) and the key role of transplant coordinators.

Dr Juan Pablo Beca and Dr Carmen Astete (CAS-UDD) participated in an online meeting on the Ethics of Organ Transplants, organized by PAHO Medicines and Health Technologies Unit.

**Universal Health Coverage**

Topics addressed:
- Consultations and expert meetings
- Regional Action Framework

At the invitation of WHO and the Asian Development Bank, Dr Calvin Ho (NUS) served as expert consultant at the UHC Forum on Sustaining Universal Health Coverage, organized by the World Bank, WHO, Government of Japan, Japan International Cooperation Agency and UNICEF, from 12–15 December 2017, in Tokyo, Japan.

Prof Roy Joseph and Dr Calvin Ho (NUS) served as reviewers of a WHO draft document on stunting, anaemia, low birth weight, childhood overweight, breastfeeding and wasting, together with paediatricians from the Paediatric Ethics and Advocacy Centre (PEACe), National University Hospital. Joint feedback was provided to WHO on 11 April 2017.

NUS organized a research meeting, under the auspices of the Asian Bioethics Review, on the ethics of universal health coverage with a focus on high-cost medicines, in Singapore from 5–7 February 2018. Presentations were delivered by Dr Andreas Reis and Dr Abha Saxena (HEG), and Dr Socorro Escalante (WPRO). Input was also received from colleagues in SEARO. This meeting served in part as a follow-up meeting to a special session on the ethics of high-cost medicines under UHC at the Health Systems Global Symposium that was held in Vancouver in November 2016, which involved PAHO (Dr Carla Saenz), JCB and IBME.

Dr Calvin Ho (NUS) served as an expert consultant in a consultation organized by WPRO on ‘Law for Health in the Sustainable Development Goals’, 9–10 April 2018, Manila, the Philippines, and contributed to the development of meeting materials before that. The outcome of this meeting is an action framework on law for health in the SDGs, which has been endorsed at the 69th session of the Regional Committee for the Western Pacific in October 2018.
CONCLUSION

The Network has been strengthened by new members and all members have participated in important work on the global health agenda. As outlined by the Director-General in the 13th Global Programme of Work: “WHO will work to ensure that all policies, public health interventions and research are grounded in ethics, and will continue to develop ethical guidance in emerging health fields.” The breadth of expertise, responsiveness of members and collegiality of the Network are greatly valued and continue to be an important resource for WHO.

Image 4: Collaborating Centre members, 9th annual meeting, Miami 2017
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