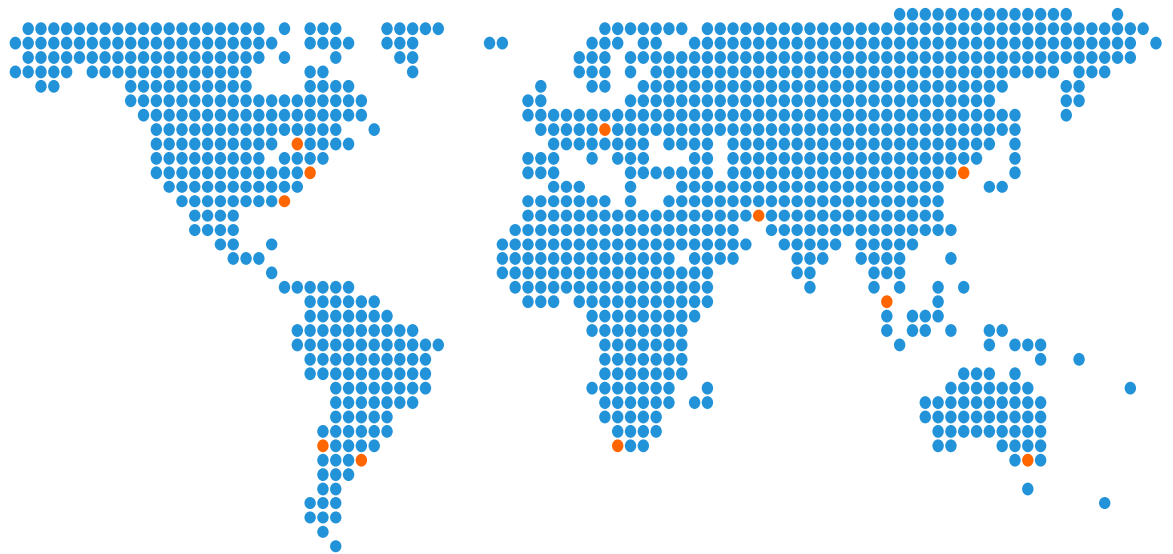




World Health
Organization

Global Network of WHO Collaborating Centres for

BIOETHICS



PROGRESS REPORT

2017 – 2018

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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.”¹

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

Collaborating Centre	Acronym	Region	Co-director(s)
Centre for Medical Ethics and Law, Faculty of Medicine and Health Sciences, Stellenbosch University, South Africa	SU	African	Keymanthri Moodley
Mailman School of Public Health, Center for the History and Ethics of Public Health, Columbia University, USA	CU	Americas	Ronald Bayer, Amy Fairchild
Programa de Bioética, Área Ética, Derechos y Bienes Públicos Globales, Facultad Latinoamericana de Ciencias Sociales, Sede Argentina, Buenos Aires, Argentina	FLACSO	Americas	Florencia Luna
Centro de Bioética, Facultad de Medicina Clínica Alemana Universidad del Desarrollo, Santiago de Chile	CAS-UDD	Americas	Juan Pablo Beca, Carmen Astete
Joint Centre for Bioethics, University of Toronto, Canada	JCB	Americas	Jennifer Gibson
Institute for Bioethics and Health Policy, Miller School of Medicine, University of Miami, USA	UM	Americas	Kenneth Goodman
Centre of Biomedical Ethics and Culture, Sindh Institute of Urology and Transplantation, Karachi, Pakistan	CBEC	Eastern Mediterranean	Farhat Moazam, Aamir Jafarey
Institute for Biomedical Ethics and the History of Medicine, University of Zürich, Switzerland	IBME	European	Nikola Biller-Andorno
Monash Bioethics Centre, Monash University, Melbourne, Australia	MU	Western Pacific	Michael Selgelid
Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore	NUS	Western Pacific	Roy Joseph, Calvin Ho
The Asian Institute of Bioethics and Health Law, Department of Medical Law and Ethics, Yonsei University, Seoul, South Korea	AIBHL	Western Pacific	So Yoon Kim

¹ Global Network of WHO Collaborating Centres for Bioethics Terms of Reference (May 2010). Geneva: World Health Organization. Available at: www.who.int/ethics/partnerships/global_network_terms_of_reference.pdf

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 WHO Global Health Ethics team (GHE). 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 GHE.

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

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** and GHE 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'.

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 in Georgetown University, and the NIH, to inform about the collaborating centre's work.

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

The 13th International Conference on Clinical Ethics and Consultation was hosted by the Centre for Biomedical Ethics, National University of Singapore from the 24–27 May 2017. This was attended by several network members.

In April 2018, **CAS-UDD** organized a meeting of the five Chilean PAHO and seven WHO collaborating centers to establish a regional network.

AIBHL participated in the 10th and 11th meeting of the Alliance of WHO Collaborating Centres in Korea, held on 28 June and 1 November, respectively.

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 in Geneva.

GHE 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.

Activities

Ageing

Topic addressed

- Guideline development

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 Dr Florencia Luna (**FLACSO**), Prof Jennifer Gibson (**JCB**), Dr Ross Upshur (**JCB**), and Dr Kavita

Sivaramakrishnan (**CU**). A subsequent report was published in 2017.

Big Data

Topics addressed

- Expert consultation
- Artificial intelligence

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.

JCB hosted a conference on ‘Ethics and AI for Good Health’ held in June 2018, to which **UM** participated, **CU** and GHE contributed.

Biobanking

Topic addressed

- Online training

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.

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 Bioética. 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’ January 2018.

From November to December 2017, **CAS-UDD** in collaboration with the Instituto Catalán de Oncología (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.

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.

AIBHL hosted a workshop entitled ‘Bioethics and Law – Changing Role of Government in Achieving UCH and the SDGs’ at the 49th Asia-Pacific

Academic Consortium for Public Health Conference, 16 September 2017. Discussions focused on communicable disease, non-communicable disease, regulation of health services and systems, health sector administration and governance, and process of legislative review.

Health Systems and Implementation Research

Topic addressed

- Teaching tools

The 'Ethics in Implementation Research' teaching tool co-developed between **IBME** and the Special Programme for Research and Training in Tropical Diseases, GHE 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.

Infectious Diseases

Topics addressed

- Guidelines on outbreaks
- Vector-borne diseases

At the request of WHO and GHE, some members of the CC 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, GHE 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 Florencia 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 GHE, 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.

GHE established an interactive 'Integrating Ethics in Infectious Disease Outbreaks' online platform in May 2018, conceptualised by former coordinator of the GHE, Dr Abha Saxena. This received generous financial support from the Wellcome Trust.

Noncommunicable Diseases

Topic addressed

- Concept paper

Dr Valerie Luyckx (**IBME**), Dr Florencia Luna (**FLACSO**) and GHE 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 CCs, and it is hoped that this can be taken forward in a more substantive way.

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 (GHE) was involved in teaching sessions on ‘Surveillance vs Research’ and ‘Ebola and Zika - Emerging Ethical Challenges’. These were based on WHO developed guidelines and documents. 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.

An article co-authored by Dr Florencia Luna (**FLACSO**) entitled, ‘La ética de los diseños y métodos alternativos de ensayos clínicos. Una reflexión sobre el Foro Global de Bioética en Investigación del 2017’ [The ethics of designs and alternative methods of clinical trials. A reflection on the Global Bioethics Forum in Research 2017] was published in January 2018 in the Pan American Journal of Public Health.

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, Dr Juan Pablo Beca and Dr Gonzalo López (**CAS-USS**) revised the Spanish translation of the 2016 CIOMS ‘International Ethical Guidelines for Health-related Research Involving Humans’, published 2017.

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.

Surveillance

Topics addressed

- 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 delivering training sessions organized by PAHO 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.

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.

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.

Acknowledgement

This report was compiled by Elly Ganakas (intern, GHE), under the coordination of Andreas Reis (GHE).

Secretariat



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