Global Network of WHO Collaborating Centres for Bioethics

University of Toronto
Joint Centre for Bioethics

Universität Zürich

Columbia University
Mailman School of Public Health

University of Miami

National University of Singapore

Facultad de Medicina
Clínica Alemana - Universidad del Desarrollo

FLACSO Argentina

Universiteit Stellenbosch University

Global Network of WHO Collaborating Centres for Bioethics • Progress Report 2016 - 2017
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Background

The Global Network of WHO Collaborating Centres for Bioethics (hereafter referred to as the “Network”) was established 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 As of September 2017, the Network comprised 10 WHO collaborating centres in five regions (Table 1).

Table 1. Collaborating centres

<table>
<thead>
<tr>
<th>Collaborating centre</th>
<th>Acronym</th>
<th>Region</th>
<th>Co-director(s)</th>
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<tr>
<td>Centre for Medical Ethics and Law, Faculty of Medicine and Health Sciences, Stellenbosch University, South Africa</td>
<td>SU</td>
<td>African</td>
<td>Keymanthri Moodley</td>
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<td>Mailman School of Public Health, Center for the History and Ethics of Public Health, Columbia University, USA</td>
<td>CU</td>
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<td>Ronald Bayer, Amy Fairchild</td>
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<td>Programa de Bioética, Área Ética, Derechos y Bienes Públicos Globales, Facultad Latinoamericana de Ciencias Sociales, Sede Argentina</td>
<td>FLACSO</td>
<td>Americas</td>
<td>Florencia Luna</td>
</tr>
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<td>CAS-UDD</td>
<td>Americas</td>
<td>Juan Pablo Beca</td>
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<td>JCB</td>
<td>Americas</td>
<td>Jennifer Gibson</td>
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<td>UM</td>
<td>Americas</td>
<td>Kenneth Goodman, Sergio Litewka</td>
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<tr>
<td>Centre of Biomedical Ethics and Culture, Sindh Institute of Urology and Transplantation, Pakistan</td>
<td>CBEC</td>
<td>Eastern Mediterranean</td>
<td>Farhat Moazam, Aamir Jafarey</td>
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<tr>
<td>Institute for Biomedical Ethics and the History of Medicine, University of Zürich, Switzerland</td>
<td>IBME</td>
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<td>Nikola Biller-Andorno</td>
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<td>Western Pacific</td>
<td>Michael Selgelid</td>
</tr>
<tr>
<td>Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore</td>
<td>NUS</td>
<td>Western Pacific</td>
<td>Roy Joseph, Calvin Ho</td>
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During the year, the members of the Network collaborated multilaterally in a number of major projects initiated by WHO. In the past years, these collaborative projects have focused on public health surveillance, infectious disease outbreaks and tuberculosis (TB).

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

This report of activities covers both Network projects as well as individual collaborations between collaborating centres and WHO, in alphabetical order.

**Network development**

**New members**

Over the past year, three new collaborating centres for bioethics were designated by WHO and added to the Network:

- The Facultad Latinoamericana de Ciencias Sociales – Argentina (FLACSO-Argentina), led by Dr Florencia Luna, was designated in July 2016.
- The Centre for Biomedical Ethics and Culture, Karachi (Pakistan), was designated in August 2017. It is headed by Dr Farhat Moazam and Dr Aamir Jafarey.
- The Centro de Bioética, Santiago (Chile), led by Dr Juan Pablo Beca, was officially designated on 27 September 2017.

This brings the total number of member institutions in the Network to 10. As the centres in Argentina and Pakistan were designated towards the end of the current reporting period, their activities are not yet fully reflected in the following pages.

**Network brochure**

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

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**Activities**

**Big data**

**Topics addressed**

- Ethical challenges of big data in public health
- E-courses

**UM** has developed health data policy and prepared a concept note on a future data protection policy for the WHO Department of Information, Evidence and Research. This is part of new WHO data-sharing policies for emergencies and non-emergency settings, which were published in 2017.

A WHO expert consultation on ethics, big data and artificial intelligence was hosted by **UM** in Miami (Florida, USA) in October 2017. The purpose of the consultation was to identify the scope and range of ethical issues and questions related to big data and artificial intelligence in health to inform the work of WHO and principles and guidance for stakeholders. The approximately 30 participants included members of the Network, experts and representatives from international organizations, academia, industry and governments.

Although it is not yet a project with direct bearing on the joint work of the Bioethics Collaborating Centres, **CU** has been working with **UM** to launch a project on ethics in big data, which is modelled on the surveillance guidelines project. The ethics of big data was raised as a critical issue during development of the ethical guidelines for public health surveillance. **CU** and **UM** will therefore continue to seek opportunities to fund the work by collaboration within the Network.
Biobanking

**Topics addressed**

- Biobanking in low- and middle-income countries
- Training in online biobanking
- Education on biobanking
- Biobanking subcommittees

**NUS** is collaborating with **SU** on an online training course in biobanking for researchers, members of research ethics committees, students of law and philosophy, as well as funders and policy-makers.

They have submitted a concept document on biobanking in low- and middle-income countries to WHO and engaged consultants: Dr Christian Simon (University of Iowa, USA) and Dr Johann Schneider (SU). The module has been outlined, and a meeting held to discuss the project took place on 25–27 May 2017 in Singapore.

A video on biobanking has been made by **SU** with funding from the US National Institutes of Health and is available to the public on YouTube ([https://youtu.be/QjSflA6_bfc](https://youtu.be/QjSflA6_bfc)). Five educational pamphlets on genetics, genomics and biobanking have been prepared by **SU** and are being used in **SA** for community engagement.

Furthermore, **CU** worked on a project to assess the extent to which various international debates have begun to use either public health ethics or human rights for judging practice and guiding policy. This work began several years ago with a grant to Dr Amy Fairchild from the US National Institutes of Health. While this project will not necessarily be part of the centre’s work as a WHO collaborating centre, it will inform the work of WHO. Public health ethics often contrast with a human rights perspective, leading to different conclusions for policy. This was apparent, for example, during development of ethical guidelines for public health surveillance. Understanding the circumstances in which frameworks have been used and the issues that create conflict over time could shed light on the best use of different normative frameworks.

**Infectious diseases**

**Topics addressed**

- Guidelines on outbreaks
- Vector-borne diseases
- Symposium at World Congress in 2016

Support for development of WHO guidance on managing infectious disease outbreaks was a major collaborative activity in 2016. Dr Michael Selgelid (MU), Dr Ronald Bayer and Dr Amy Fairchild (CU) served on the WHO expert group for the guidelines, and **UM** also contributed.

Another important collaborative activity was on the ethical issues raised by Zika virus and other vector-borne diseases. **FLACSO** chaired and **MU** participated in a consultation organized by the WHO Regional Office for the Americas (PAHO). **FLACSO** participated in preparing material for the consultation, and both centres contributed to the resulting guidance, which was published by PAHO, endorsed by *The Lancet* and incorporated into WHO’s technical cooperation with Member States. **FLACSO** disseminated the guidance through various channels, including in a keynote address at a conference of the International Association of Bioethics in Edinburgh, Scotland, in 2016. They worked collaboratively with PAHO on further projects related to Zika virus disease, such as vaccine development (led by Georgetown University, Washington DC, and Johns Hopkins University, Baltimore, USA), and practical discussion of cases.

In March 2016, **UM** hosted a half-day workshop on the ethical issues raised by the then-newly emergent Zika virus disease epidemic in the Americas, before a broader university forum. Dr Jennifer Gibson (JCB) attended the workshop in
person, while Dr Ronald Bayer (CU), Dr Amy Fairchild (CU) and Dr Ross Upshur (JCB) participated virtually. In October 2016, Dr Adriane Gelpi (UM) organized a panel presentation on the ethics of managing Zika virus disease at the annual conference of the American Association of Bioethics and Humanities in Washington DC, USA. Dr Ken Goodman (UM) and Dr Jennifer Gibson (JCB) spoke as panelists (the fourth panelist was Dr Lisa M. Lee, then the Executive Director of the Obama Presidential Commission for the Study of Bioethical Issues.)

In April 2017, UM hosted a full-day forum on questions raised by the Zika virus disease outbreak on the role of public deliberation and ethics in policy-making. Both Dr Jennifer Gibson (JCB) and Dr Amy Fairchild (CU) spoke at the event.

In February 2017, WHO organized an international consultation on ethics in vector-borne diseases in Geneva, Switzerland, with the special support of Dr Michael Selgelid and Dr Zeb Jamrozik of MU. FLACSO participated in the preparatory meeting, and MU worked with WHO in raising funds for the project (e.g. from the Wellcome Trust). After the preparatory meeting, SU co-hosted a regional expert consultation with WHO on the ethics of vector-borne diseases in Cape Town, South Africa, in May 2017.

Dr Michael Selgelid (MU) served as a member of the WHO International Health Regulations (2005) Emergency Committee on Zika virus and the observed increase in neurological disorders and neonatal malformations between June and November 2016.

SU participated in a SAGE working group on vaccines and vaccination for Ebola virus disease in March 2017. Comments were provided on the advisory document to be sent to the SAGE group.

NUS and SU worked with WHO in organizing a symposium on the ethics of biobanking in the context of infectious diseases at the World Congress of Bioethics, held in Edinburgh, Scotland, on 14–18 June 2016. The symposium was entitled “After Ebola: challenges facing infectious diseases biobanking”. Dr Alastair Campbell and Dr Calvin Ho (NUS), Dr Keymanthri Moodley (SU), Dr Abha Saxena (WHO), Dr Ciara Staunton (SU), Dr Wayne Towers, Dr Paulina Tindana and Ms Katherine Littler made presentations. The purpose of the symposium was to obtain feedback from the broader bioethics community on topics of interest to WHO, particularly with regard to the outbreaks of Ebola and Zika virus diseases.

Noncommunicable diseases

- Use of radiation in screening

Dr Owen Schaefer, a NUS faculty member, was invited to contribute to a WHO workshop on justification for use of computed tomography (CT) for individual health assessment in asymptomatic people (26–28 September 2016). Subsequently, Dr Schaefer was invited to join the WHO working group to prepare a framework of good governance for individual health assessment.
Research ethics

Topics addressed

- Vaccine research
- Research during emergencies and epidemics
- Strengthening research ethics capacity in the Region of the Americas
- Strengthening national research ethics systems in the Region of the Americas
- Research on sexual and reproductive health
- Health Policy and Systems Research

IBME received funding from the Swiss National Science Foundation to work in a focus group study on a malaria vaccine. The goal of the project, led by doctoral student, Machteld van den Berg, is to create a public health ethics framework that would provide policy guidance on critical ethical issues in vaccine development. Discussions have been held with WHO on preparing guidelines on the ethics of vaccination programmes.

SU held the 5th Annual Research Ethics Seminar on 20 May 2016, and Dr Michael Selgelid from MU presented a paper entitled "Zika & Ebola: what research is permissible during emergencies and epidemics?" The seminar was attended by 110 delegates from various African countries, who included about 20 graduates of the Advancing Research Ethics training in Southern Africa (ARESA) programme, who will develop capacity in their own countries. The seminar was reported in the ARESA Newsletter.

Dr Andreas Reis of WHO participated in the Sixth Annual ARESA Research Ethics Seminar in May 2017 at SU, where he chaired the session on international research collaboration and presented an update of the WHO guidance on ethics in outbreaks.

FLACSO co-hosted two virtual training sessions, in English and in Spanish, to discuss the new research ethics guidelines of the Council for International Organizations of Medical Sciences (CIOMS), including support for planning and disseminating the sessions.

FLACSO provided in-depth research training to the Director of the office that oversees research at the Peruvian National Institute of Health within the Ministry of Health, who was selected from among candidates (including from Panama and Nicaragua) provided by PAHO. FLACSO also trained a PAHO officer based in Nicaragua, who has become the bioethics focal point in the country, and proposed more comprehensive training of people from the three countries.

At PAHO’s request, FLACSO conducted a technical revision of a translation of the new CIOMS guidelines that are being published by PAHO, involving various experts and internal and external groups. Three FLACSO members co-authored a regional statement on the ethical duty to involve pregnant women in research, based on a consensus reached by participants from Latin America. The manuscript was published in English and Spanish in the Pan American Journal of Public Health.

NUS faculty member Dr Anita Ho served as a peer reviewer of WHO’s guidance on ethical considerations in planning and reviewing research on sexual and reproductive health in adolescents.

IBME collaborated with the Special Programme for Research and Training in Tropical Diseases (TDR), the WHO Ethics Unit and Dr Vijay Gopichandran (ESIC Medical College and Postgraduate Institute of Medical Sciences and Research, Chennai) on the development of a training tool on “Ethics in Implementation Research”. The tool was developed after a consultation workshop held in Geneva in 2015 with participation from CU, IBME, FLACSO, MU and other global experts as acknowledged in the tool manual. Pilot workshops were conducted in Indonesia and in Ghana. The tool is planned for launch end of 2018. A joint summary paper was published in Implementation Science in December 2016, entitled “Developing the ethics of
implementation research in health” (*Implementation Science* 2016 11:161). After a consultation on the ethics of Health Policy and Systems Research (HPSR) in 2015, hosted by IBME, the WHO Alliance for HPSR and the WHO Ethics Unit, an open access paper entitled “Health policy and systems research: towards a better understanding and review of ethical issues” was published in 2017 (*BMJ Glob Health* 2017;2:e000314).

### Surveillance

**Topic addressed**

- WHO Guidelines on Ethics in Public Health Surveillance

Preparation of the WHO guidelines on ethical issues in public health surveillance has been one of the Network’s most important collaborative projects and successes during the past 3 years. Dr Amy Fairchild (CU) was Co-Chair of the international guidelines committee, with Dr Ali Akbar Haghdoost (Kerman, Islamic Republic of Iran).

The Network sponsored a symposium entitled “Closing the Ethics Gap: WHO Guidance on Public Health Surveillance” at the World Congress of Bioethics in Edinburgh on 17 June 2016. The goal was to obtain feedback from the broader bioethics community on WHO’s prospective guidance on the topic and to publicize the project.

The session was chaired by Dr Ron Bayer (CU), and the presenters included Dr Amy Fairchild (CU), Dr Angus Dawson (Sydney) and Dr Andreas Reis (WHO).

The WHO Guidelines on Ethics of Public Health Surveillance were launched in June by Dr Marie-Paule Kieny, Assistant Director-General of WHO.

### Tuberculosis

**Topic addressed**

- WHO guidance on ethics in tuberculosis

Dr Ron Bayer and Dr Amy Fairchild (CU), Dr Michael Selgelid (MU) and Dr Ken Goodman (UM) were involved in updating the WHO guidance document on ethics in TB. The issues included failure to fund adequate research for treatment; failure to provide appropriate drugs for treatment and to prevent drug resistance; ensuring the adequacy of social support for people whose treatment may impose an unacceptably high burden; care for people who can no longer respond to the available drugs; and TB in vulnerable populations such as children, prisoners and migrants.

The revised document was launched on 23 March by Dr Ren Minghui, WHO Assistant Director-General for infectious diseases. The launch of the document by WHO on World TB Day 2017 emphasized the importance given to ethical issues in TB. The inter-ministerial meeting on TB held in November in Moscow, Russian Federation, also included an unprecedented ministerial discussion of ethics, human rights and equity in TB.
Eighth annual meeting

The eighth annual meeting of the Global Network of WHO Collaborating Centres for Bioethics was held on Monday, 13 June 2016 at the Edinburgh International Conference Centre.

The collaborating centres reported on their work. The meeting noted that funding of work on ethics remains a challenge for WHO, apart from work on topics in which technical partners request and support ethics guidance. Institutions and collaborating centres may be better placed to apply for funding, and letters indicating that the prospective work would (or might) contribute to WHO guidance would support the funding applications of those institutions.

The meeting discussed the appointment of lead institutions for possible areas of collaboration and drew up a matrix (Table 2) to reflect the interest and expertise of institutions.

Dr Michael Selgelid (MU) was elected new Chair of the Network by general acclamation, until 2018.

Regional meetings

NUS participated in the second regional forum of WHO collaborating centres in the Western Pacific Region, held on 28–29 November 2016, in Manila, Philippines, at the invitation of the Regional Office.

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<th>Vaccines</th>
<th>Antimicrobial resistance</th>
<th>Big data</th>
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<th>Healthy ageing and dementia</th>
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Table 2. Interest and expertise in proposed projects

FLACSO participated in a meeting organized by PAHO involving all collaborating centres in Argentina, where the work of the collaborating centre was presented, and collaboration among centres in Argentina was sought.

At PAHO’s request, UM contributed to the sixth international workshop on design and management of clinical trials held at the national centre for coordination of clinical trials in Havana, Cuba, in November 2016.

The goals included possible collaboration on data-sharing and related issues.

SU held the fifth annual seminar on research ethics on 20 May 2016 and the sixth annual
ARESA research ethics seminar in May 2017. (See Research.)

Dr Michael Selgelid (MU) supported the WHO and SAFETYNET (South East Asia Field Epidemiology and Technology Network) workshop on ethics in epidemics, research and surveillance’ in Siem Reap, Cambodia, in November 2016 as facilitator and instructor. He gave presentations on module 1, public health surveillance and research; module 4, obligations in interventions for the diagnosis, treatment and prevention of infectious disease; monitored emergency use of unregistered and experimental interventions; and restrictions on freedom of movement.

A one-day workshop on ethical issues related to outbreak response organized by WHO and the Training Programs in Epidemiology and Public Health Interventions Network (TEPHINET) was held on 4–8 August 2017 in Chiangmai, Thailand, with the support of Dr Calvin Ho (NUS). TEPHINET is a network for training field epidemiologists, who are professionals involved in both surveillance and outbreak response. TEPHINET meetings are therefore useful for raising awareness and building capacity on ethical issues related to outbreak response. Fifteen people attended the four sessions of the workshop, which covered six vital ethical areas in outbreak response, based on the recently published guidance on ethical response to infectious disease outbreaks.

**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 Johannes Köhler (intern, Global Health Ethics), under the coordination of Abha Saxena and Andreas Reis (Global Health Ethics) and guidance of Michael Selgelid, Chair of the Global Network of WHO Collaborating Centres for Bioethics.
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