

Summary report on the

Eastern Mediterranean/ Arab States regional summit of national ethics and bioethics committees

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Muscat, Oman
5–6 April 2017



**World Health
Organization**

Regional Office for the Eastern Mediterranean

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1. Introduction

The WHO Regional Office for the Eastern Mediterranean, in collaboration with The United Nations Organization for Education, Science and Culture (UNESCO) and Sultan Qaboos University, organized the first regional bioethics summit for Eastern Mediterranean/Arab States in Muscat, Oman, on 5–6 April 2017.

The Regional Summit was held in response to the recommendation of the last Global Summit of national ethics committees, held from 16 to 18 March 2016 in Berlin, Germany. The Global Summit, held once every two years, brings together national ethics committees from around the world. WHO serves as the Permanent Secretariat of the Global Summit, while UNESCO is a permanent member of its steering committee.

The main goal of the first Eastern Mediterranean/Arab States regional summit of national ethics and bioethics committees was to foster the development of national ethics/bioethics committees in the Region and establish effective mechanisms of regional harmonization and cooperation to address emerging issues related to bioethics. Specifically, its objectives were to discuss the best methods for regional collaboration, with special focus on development and the work of national ethics/bioethics committees; develop strategies to raise public awareness on bioethics in Member States in line with the outcomes and recommendations of related surveys and workshops conducted by both WHO and UNESCO in the Region; and share experiences on ethics during disasters and emergencies, with a focus on humanitarian ethics (e.g. resilience/response of health systems to migration, ethics of supplies, research ethics).

The meeting was inaugurated by Professor Ali Al-Bemani, Vice-Chancellor of Sultan Qaboos University, who emphasized the

importance of the meeting as a platform for sharing experiences, lessons learnt and working together as partners to take bioethics forward in the Region. Participants included members of the Omani National Bioethics Committee; regional representatives of national ethics and bioethics committees; speakers from Canada and Senegal and representatives from WHO and UNESCO.

2. Summary of discussions

The Global Summit of national ethics/bioethics committees was introduced; this was an international forum for exchange of views and debates on bioethics, contributing to common understanding and consensus-building between nations as well as assisting in developing national bioethical frameworks and guidelines. The preparations for the next Global Summit planned to convene in Dakar, Senegal, in 2018, were discussed, including its overall theme (bioethics, sustainable development and societies) and subthemes (bioethics in the electronic data era; bioethics, social justice and civil society; bioethics, health emergencies and resilience; and bioethics and vulnerable populations).

Representatives from UNESCO provided a general overview on the Universal Declaration on Bioethics and Human Rights guidelines, national bioethics committees (NBCs) in the Region and the outcomes of two regional surveys (2014 national ethics committees (NECs) survey, 2009 UNESCO regional legal survey) as well as the steps of the “Assisting Bioethics Committees” (ABC) project and recent workshops. Representatives from WHO presented information about the 2015 regional bioethics survey, including its main objectives, methodology and main outcomes. The identified gaps and challenges included limitations in: trained capacity, resources, transparency, autonomy and control over institutional ethical committees; gaps between policies and practice; lack of databases, reporting

mechanisms and coordination between different ethical bodies; the need for institutionalization of bioethics education within health institutions; and the lack of laws/regulations governing sensitive topics in Member States.

A number of case studies were presented and discussed, including:

- national bioethics committees: Jordan model;
- Omani NEC;
- the dilemma of premarital genetic screening and women's social rights in Bahrain;
- Oman Ministry of Health guidelines for responsible conduct of clinical studies;
- end of life care in Lebanon;
- academic collaboration with national advisory bodies in Sudan;
- integration of bioethics in health sciences curricula in the Islamic Republic of Iran.

The participants also discussed bioethics during emergency and disaster situations. This included the process of generating evidence in humanitarian emergencies, which attempts to respond to the following questions.

- What priority should be given to research and other knowledge-generating activities in humanitarian emergencies?
- What are the distinctive ethical features/challenges?
- How should these be accounted for?
- What constitutes an effective and high quality ethics review of protocols to be conducted in humanitarian crises?
- What attributes characterize a research ethics committee that is well suited to reviewing crisis research?

The key elements for creating an ethical infrastructure for humanitarian organizations from a sociopolitical perspective were presented, including organizational climate (formal and informal systems for communication, surveillance and sanctioning), ethics and justice. Types of research to be considered for enhanced include: emergency context requirements, independent ethical review, community involvement, community versus individual benefit and informed consent. The WHO guidance and training manual on “ethics in epidemics, emergencies and disasters: research, surveillance, patient care” was presented and discussed. Examples were given on issues left open in previous guidance documents, e.g. the role of informed consent in public health surveillance, the legitimacy of imposing medical interventions on an infectious patient who does not want to be treated, the process for ethics review of research in outbreak situations, the use of experimental interventions outside of research and ethical issues related to the deployment of foreign humanitarian aid workers. In addition, the WHO guidance on ethical issues in tuberculosis (TB) among migrants, launched on 24th March 2017 on World TB Day, was presented, including guiding policies and services for TB diagnosis, treatment and care among migrants.

During the panel discussion on “legal regional harmonization” emphasized making use of the experience of the Gulf Cooperation Council countries in premarital genetic counselling, starting with making it voluntarily for one year then developing/applying policies and legislation based on lesson learnt; the importance of developing and ethically using data and biobanks; role of WHO and UNESCO in developing frameworks/techniques for writing bylaws and sharing previous experiences from other countries.

In the panel discussion on “national and regional cooperation among national ethics and bioethics committees” participants emphasized the

need for networking among bioethics/ethics bodies in the Region through similar fora or webinars; the importance of priority-setting for the rational use of resources; building capacity of policy-makers to take informed decisions that rely on a bottom-up approach; developing communication skills among NBCs involving civil society and media to raise the relevant issues and create public demand; revisiting the bylaws every 4–5 years so they are updated according to public needs and demand; and considering expanding the UNESCO ABC project to other countries of the Region.

Discussion among the participants highlighted the role of UNESCO and WHO in facilitating regional collaboration, multidisciplinary cooperation between NBCs, the need for a bottom-up approach in setting priorities, applying SWOT (strengths, weaknesses, opportunities, threats) analysis to NECs to identify strengths and opportunities and overcome weaknesses and threats/challenges, misuse of technology without enough evidence, establishing WHO collaborating centres on bioethics in the WHO Eastern Mediterranean Region. In addition, the discussion covered the possible replication of the experience of Lebanon in terminal/palliative care and; integrating palliative care in undergraduate health sciences curricula. The participants also emphasized the importance of applying specific principles for research during emergencies; possible political influence on such research; the importance of distinguishing research ethics from general medical ethics during crises; the importance of neutrality of data; and the need to share experiences and lessons learnt from both inside and outside the Region.

3. Recommendations

The participants in the regional summit agreed on a list of recommendations to take bioethics in the Region forward.

To Member States, in coordination with WHO/UNESCO

1. Allocate sufficient resources for bioethics related community protection/interventions.
2. Establish/enhance the work and roles of NBCs/NECs in the Region, in coordination with UNESCO/WHO, linking with the International Bioethics Committee as needed.
3. Develop/enforce bylaws/regulations for ethical issues important to society (e.g. premarital genetic testing, organ donation/trafficking, end-of-life care, assisted reproductive technologies).
4. Promote consistency between regulations and practices within different institutions dealing with bioethics and research.
5. Raise public awareness, especially among patients, on bioethics-related matters, e.g. the informed consent process and the importance of bioethics in health care.
6. Foster bioethics principles within the health sciences curricula of academic institutions and in-service training of health care providers (using regional/international expertise).
7. Build the capacity of health care providers on medical/research ethics, priority setting, impact assessment, ethics/research/oversight during humanitarian emergencies and outbreaks, TB using available Council for International Organizations of Medical Sciences (CIOMS), UNESCO, WHO guidelines, etc.

To WHO/UNESCO

8. Strengthen national/regional coordination between NECs and NBCs, as well as among the various bodies dealing with misconduct or claims, applying research ethics and monitoring ongoing research.
9. Enhance multisectoral involvement within NEC/NBC work, including media/civil society as key stakeholders to ensure compliance of concerned bodies.



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