

Summary report on the

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

WHO-EM/RPC/047/E

Cairo, Egypt
15–16 December 2019



REGIONAL OFFICE FOR THE

**World Health
Organization**

Eastern Mediterranean

Summary report on the

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

Cairo, Egypt
15–16 December 2019

© World Health Organization 2020

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; <https://creativecommons.org/licenses/by-nc-sa/3.0/igo>).

Under the terms of this licence, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited. In any use of this work, there should be no suggestion that WHO endorses any specific organization, products or services. The use of the WHO logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: “This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition”.

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization.

Suggested citation. Summary report on the second Eastern Mediterranean/Arab States regional summit of national ethics and bioethics committees. Cairo: WHO Regional Office for the Eastern Mediterranean; 2020. Licence: CC BY-NC-SA 3.0 IGO.

Sales, rights and licensing. To purchase WHO publications, see <http://apps.who.int/bookorders>. To submit requests for commercial use and queries on rights and licensing, see <http://www.who.int/about/licensing>.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

General disclaimers. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use.

Contents

1.	Introduction.....	1
2.	Summary of discussions	2
3.	Working groups.....	8
4.	Conclusion	8
5.	Recommendations.....	9

1. Introduction

At the 11th Global Summit of National Ethics/Bioethics Committees, held in Berlin, Germany, in March 2016, it was proposed to hold regional summits between global summits to discuss bioethical issues relevant to particular regions. The first Eastern Mediterranean/Arab States regional summit was held by UNESCO and WHO in Muscat, Oman, on 5–6 April 2017, in collaboration with the Omani national bioethics committee and Sultan Qaboos University. Two years later, the second summit, jointly organized by the UNESCO Regional Bureau for Sciences in the Arab States and WHO Regional Office for the Eastern Mediterranean, was held at the WHO Regional Office in Cairo, Egypt, on 15–16 December 2019. The summit was followed by a workshop on ethics in implementation research on 17 December.

The overall aims of the second regional summit were to explore a regional approach to ethics policy processes and share experiences in promoting ethics, prior to the 13th global summit to be held in Portugal in 2020.

The specific objectives of the summit were to:

- follow up on outcomes of the first regional bioethics summit;
- discuss outcomes of the last global bioethics summit held in 2018 and plan for the upcoming summit in 2020;
- outline and discuss methods of regional collaboration, with a special focus on fostering national ethics/bioethics committees;
- develop strategies to strengthen linkages between bioethics committees and policy-makers (ministries of health, education, science and technology); and
- share experiences and deliberate on current ethical issues, such as migration ethics and artificial intelligence.

Participants of the regional summit included representatives of national ethics and bioethics committees, ministries of health and higher education, academic and research institutions, and the League of Arab States, as well as international experts and staff from WHO and UNESCO.

The summit was expected to review past progress, current actions and future goals, in order to generate a list of prioritized recommendations for a short- to medium-term operational strategy. This will allow the WHO Regional Office and UNESCO Regional Bureau for Sciences in the Arab States to develop guidance and capacity-building activities based on the inputs provided during the meeting.

The meeting was inaugurated by Dr Ahmed Al-Mandhari, WHO Regional Director for the Eastern Mediterranean, and Dr Ghaith Fariz, Director, UNESCO Regional Bureau for Sciences in the Arab States. They emphasized the significant and fruitful collaboration between WHO and UNESCO, from both a health and educational perspective, towards achieving the Sustainable Development Goals (SDGs). The two sister United Nations (UN) agencies aim to work synergistically to strengthen bioethics in the Region and support the development and fostering of national ethics committees.

Professor Samir Boubakir (Tunisia) was selected as the meeting's rapporteur, aided by Professor Dina Shoukry (Egypt).

2. Summary of discussions

During the first session, the recommendations of the first regional bioethics summit in Oman were discussed, including: establishing and enhancing the roles of national bioethics committees in the Region; enhancing multisectoral involvement within national ethics/bioethics committees; developing by-laws and regulations for important ethical issues; fostering bioethics within health sciences' curricula; and

building the capacities of health care providers in medical and research ethics. This was followed by a presentation on UNESCO's multi-dimensional approach to bioethics, focusing on the role of scientific and technological progress for human and social well-being and the equitable distribution of the benefits arising from research.

The Charter of Ethics of Science and Technology in the Arab Region was introduced, including the inclusive process followed for its development. Work on the Charter was initiated in July 2017 in Beirut, Lebanon, as a joint initiative of the UNESCO Regional Bureau for Sciences in the Arab States and a number of regional stakeholders, and the Charter was approved by the League of Arab States in 2019 as a guidance document for Arab countries. The Charter was subsequently published by UNESCO.¹

This was followed by a presentation and discussion on the main themes of the 13th Global Summit of National Ethics/Bioethics Committees, planned to be held in Lisbon, Portugal, in March 2020, but now postponed to September 2020. These included: building better health environments for future generations; ensuring access to innovation in science and technology; education, engagement and empowerment for health care decisions; and migrants and refugees – a public health challenge.

The participants discussed the implementation of the recommendations of the Oman summit, highlighting the need to start a discussion on bioethics within society and the need to focus on current bioethical problems in the Region. There were suggestions to establish regional/national “ethics days” on specialized themes, such as medical ethics, engineering ethics and social ethics, and to strengthen ethics training (especially at the undergraduate level). The need to extend the

¹ The document may be accessed through UNESDOC at: <https://unesdoc.unesco.org/ark:/48223/pf0000372170b>.

discussion of ethics to health care delivery (rather than only regarding academic research) was raised, as was the need to integrate the Charter of Ethics of Science and Technology in the Arab Region with the Universal Declaration on Bioethics and Human Rights.

Case studies on strengthening linkages between policy-makers and national ethics/bioethics committees in countries of the Region were presented and discussed. These included case studies on higher studies in ethics in Islamic Republic of Iran, implementing the national registry of clinical trials in Lebanon (a joint project between the Lebanese national committee for ethics and WHO), and the Tunisian experience in developing a national bioethics committee, which involved the organization of public conferences and debates, and its contribution to undergraduate and post-graduate bioethics education.

A case study was presented on the Omani experience in patients' rights and safety, and the role of the Omani national bioethics committee in implementing bioethical regulations through formulating national bioethics committee codes and establishing guidelines on various ethical issues. The regulations and governance for genetic testing in Bahrain were presented, including for premarital, prenatal and newborn genetic screening, as well as cancer screening. A presentation was made on Iranian research ethics governance mechanisms, including the structure of the Biomedical Ethics Council, the research ethics system, standards and guidelines, research ethics committee strengthening and a disciplinary system to combat scientific fraud.

In discussion, participants emphasized the need to improve the ethics review systems involved in research, treatment and public health systems. It was felt that accreditation of ethics committees would enhance their visibility.

During the second day, ethical issues in humanitarian settings and current ethics issues were discussed. The UNESCO report on the bioethical response to the situation of refugees, with a specific focus on the inherent right of refugee populations to health care, was presented and discussed. The ethical issues raised included discrimination and stigmatization, the high population density in refugee camps which favours the spread of infectious diseases, and the vulnerability of refugees to noncommunicable diseases, malnutrition, insecurity, acts of violence and organ trafficking.

Participants highlighted that an ethics-based approach to the situation of refugees would include: the right of refugees to health care services; the provision of health care services in a non-discriminatory manner; that special health care services be provided to the most vulnerable groups, such as women and children; the right of refugees to make their own medical decisions; no mandatory testing of refugees for diseases, unless for clear and valid epidemiological reasons; and taking protective measures to prevent exploitation of refugees as organ providers.

Case studies were presented on ethics in humanitarian emergencies. This included a presentation on the response to Syrian refugees in Jordan, which involved adopting the “one refugee” approach (where all refugees, regardless of nationality, have access to equitable protection, assistance and services) and the UNHCR Jordan refugee response, developed in 2019 as part of a regional refugee resilience plan.

Another case study was presented on the April 2019 HIV outbreak in Ratodero, Sindh, Pakistan, which illustrated the lack of public education on HIV transmission, the stigma faced by patients and their families, and the double-edged role of media.

Participants noted that while the ever-increasing number of refugees is a major source of concern worldwide, refugee issues have been largely neglected by the international community, and the required action plans are absent or deficient. Moreover, host countries often face additional problems, such as environmental issues. It was noted that the living conditions of refugees can lead to discrimination, such as in access to health care, and that most refugees do not live in refugee camps. It was felt that ethics should be considered when planning refugee responses, and the status and ethics of dealing with internally displaced persons (IDPs) should also taken into account.

The expanded access policy (EPA) was presented, including access to medicines for compassionate reasons in some countries of the Region, such as Jordan, Lebanon and Saudi Arabia. Several parties are involved in expanded access requests, including patients, licensed physicians, pharmaceutical companies, food and drug administrations, and institutional review boards. Bioethical issues related to compassionate use programmes include having a fair process to evaluate the needs of parties. National regulations on this are therefore essential for EPA.

The Charter of Ethics of Science and Technology in the Arab Region was presented. The Charter covers ethical principles related to scientific production, science and technology transfer, localization, and the use and application of science and technology. It defines the ethical responsibilities of governments, researchers, funders and research institutions, among others. The role of intellectual property in the field of innovation and technology transfer is also addressed. The 30th Ordinary Session of the Council of the League of Arab States at Summit Level approved the Charter in resolution 722 on 31 March 2019. The member states of the League are called upon to disseminate its principles to research institutions.

The participants noted that while the Charter has been approved, it is not yet binding and has not been disseminated to research institutions in the Region. They discussed the need to develop specific charters for the different domains of research, such as social research, economic research, and so on.

The ethics of artificial intelligence (AI) were also discussed. The development of AI raises ethical issues in many fields, including culture (language, cultural diversity), communication (disinformation, automated journalism), development (agenda-setting, capacity-building), peace and the environment. Although there remains no global ethics framework for AI, governments and other stakeholders need to address these issues.

The preliminary study of the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST) Extended Working Group on the Ethics of AI was presented. It recommends that ethical principles for AI should be based on: human rights, inclusiveness, flourishing (enhancing quality of life), awareness and literacy (to empower citizens), explainability, transparency, responsibility (of developers and companies), accountability (for AI-driven decisions and the behaviour of AI systems), good governance (governments should report on use of AI in policing, intelligence, and security), democracy (developed, implemented and used in line with democratic principles), sustainability (benefits balanced against environmental impact) and human autonomy (human control at all times).

The participants noted that the benefits and potential of AI for health care needs to be better identified, and that dialogue between patients and doctors should be promoted on the subject. They felt that attention should be paid to the accountability of AI systems regarding the risk of digital errors. The huge potential for the use of mobile technology for health promotion (mHealth) applications was highlighted.

3. Working groups

Participants were formed into working groups to discuss:

- national and regional cooperation among ethics and bioethics committees: policy-making, capacity-building, public awareness, advice to policy-makers, and communication with media and public.
- challenges, priorities and upcoming events (national/regional): political will and support, multiple stakeholders, human resources, social/political conflicts, cultural diversity, complexity of the convergence of decisions concerning controversial matters, and financial support.

The working groups proposed actions related to global/regional bioethics summits, networking among national ethics committees and experience exchange, and research (evidence generation and knowledge translation). Countries were asked to propose presentations for the Lisbon global bioethics summit in 2020 to the Steering Committee.

4. Conclusion

During the meeting, linkages were established between bioethics committees and policy-makers, who were provided with evidence-based advice. The high quality of exchange between organizations was fruitful, as illustrated by WHO/UNESCO collaborative activities and League of Arab States/UNESCO cooperation on the Charter of Ethics of Science and Technology in the Arab Region.

It was stressed that at the political level, proposals are usually welcomed, adopted and supported during the meetings of ministers of health, showing real political will. It was also noted that WHO can help to assist national ethics/bioethics committee teams in their accreditation process.

5. Recommendations

The participants reaffirmed the need to continue the actions launched following the recommendations of the Oman summit to improve the role of national bioethics committees in the Region, including:

- enhancing multisectoral involvement in national ethics/bioethics committees, including the media and civil society;
- developing bylaws and regulations addressing the main ethical issues;
- fostering bioethics principles within health sciences' curricula and beyond; and
- building the capacities of health care providers in medical and research ethics.

Furthermore, the participants proposed the following recommendations to Member States to improve national capacity in bioethics, in coordination with WHO and UNESCO:

1. Promote the use of new tools, such as virtual training, rather than face-to-face training, although blended models can be used.
2. Strengthen training-of-trainers courses in bioethics.
3. Extend networking to national ethics/bioethics committees beyond the Region.
4. Develop a roadmap on improving national capacity in bioethics and an action plan for implementation.

The image features a minimalist, abstract design composed of several rectangular blocks of color. A large teal block occupies the top right and bottom right portions. A grey block is positioned at the top left. A horizontal grey band runs across the middle. A dark grey block is located in the bottom left. The bottom of the image is a solid grey bar containing white text.

World Health Organization
Regional Office for the Eastern Mediterranean
P.O. Box 7608, Nasr City 11371
Cairo, Egypt
www.emro.who.int