Eastern Mediterranean/Arab States
Regional Summit of National Ethics & Bioethics Committees
(Muscat, 5-6 April 2017)

Meeting Report

November 2017
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## List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABC</td>
<td>Assisting Bioethics Committees</td>
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<tr>
<td>ASR</td>
<td>Arab State Region</td>
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<tr>
<td>CBEC</td>
<td>Sindh Institute of Urology and Transplantation – Center of Biomedical Ethics and Culture</td>
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<tr>
<td>CIOMS</td>
<td>Council for International Organizations of Medical Sciences</td>
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<td>COMEST</td>
<td>World Commission on the Ethics of Scientific Knowledge and Technology</td>
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<tr>
<td>EM</td>
<td>Eastern Mediterranean</td>
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<tr>
<td>EMR</td>
<td>Eastern Mediterranean Region</td>
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<tr>
<td>EMRO</td>
<td>Eastern Mediterranean Regional Office</td>
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<tr>
<td>IBC</td>
<td>International Bioethics Committee</td>
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<tr>
<td>NBC</td>
<td>National Bioethics Committee</td>
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<tr>
<td>NEC</td>
<td>National Ethics Committee</td>
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<tr>
<td>SWOT</td>
<td>Strengths, Weaknesses, Opportunities, Threats</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>UNESCO</td>
<td>United Nations Educational, Scientific, and Cultural Organization</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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I. Background

The Global Summit of National Ethics Committees (NEC) held once every two years, brings together national ethics committees, i.e. bodies with a recognised national role in providing bioethics advice or decision regardless of their names, such as Ethics/Bioethics Committees/Commissions/Advisory Bodies, from around the world to share their thoughts and experiences in relation to bioethical issues. It serves as an international forum for exchange of views and debate on bioethical issues of common global interest, therefore contributing both to common understanding and consensus building between nations as well as assisting those nations developing their national bioethical framework and guidelines. It is an independent initiative by and for the NECs. WHO serves as the Permanent Secretariat of the Global Summit, while UNESCO is as a permanent member of the Steering Committee.

At the last Global Summit held from 16 to 18 March 2016 in Berlin, Germany, the participants proposed holding Regional Summits between the Global Summits (i.e. years which do not include global summits) to discuss bioethical issues that are of priorities for each region. Representatives of the Sultanate of Oman offered to host the regional summit in 2017, provisionally during the Global Summit, then officially afterwards during a May 2016 meeting which was held in Muscat between members of the Omani National Bioethics Committee and WHO representatives (from regional/country offices).

II. Aims and expected outcomes of the Regional Summit

The regional summit was organized jointly by UNESCO and WHO in cooperation with Omani National Bioethics Committee (NBC) and was hosted at the Sultan Qaboos University, Muscat, Sultanate of Oman, during the period 5-6 April, 2017.

The regional summit aimed at fostering development of national ethics committees in the Eastern Mediterranean/Arab States region and establishing an effective mechanism of regional harmonization and cooperation to address emerging issues related to bioethics.

The specific objectives of the Regional summit were to:

1. **Explore and discuss methods of regional collaboration**, with special focus on development and work of national ethics/bioethics committees

2. **Develop strategies to raise public awareness and education** on bioethics in Member States, in line with findings and recommendations of related surveys and workshops held by both WHO/EMRO and UNESCO in the Region
3. **Develop strategies to strengthen linkages** between the bioethics committees and policy makers (Ministry of Health and Ministry of Education and Science & Technology)

The main outcomes of the Regional Summit were review of progress, current actions and future goals of each NBC and generation of a list of prioritized recommendations for a short to medium-term operational strategy with a view of regional coordination.

This strategy will allow EMRO and UNESCO to proactively develop guidance and potential capacity building activities on the inputs provided during the meeting.

**III. Summary of discussions**

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.

In the beginning of the session, the Global Summit (GS) of national ethics/bioethics committees was introduced. The GS represents 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 GS 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).

Then representatives from UNESCO provided a general overview of UNESCO’s program to support the capacity building of National Bioethics Committees called Assisting Bioethics Committees project (ABC) that provides technical assistance to establish national bioethics committees and enhance their work through trainings and publications of guides for national bioethics committees. UNESCO also presented universally agreed principles stipulated in the Universal Declaration on Bioethics and Human Rights (2005) and its work in supporting Member States to implement these principles into their national regulations. In order to support NBCs in this regard, the outcomes of two surveys of UNESCO (2014 national ethics
committees (NECs) survey, and 2009 regional legal survey on 10 selected bioethical issues) were presented. Representatives from WHO presented information about the 2015 regional bioethics survey, including its main objectives, methodology and main outcomes.

The three surveys presented during this session identified gaps and challenges of addressing bioethical issues in the region included limitations in: training 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.

Subsequently, a number of case studies were presented and discussed, including:

- national bioethics committees: Jordan and Omani models;
- the dilemma of premarital genetic screening and prevention of social stigma 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 for 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 this session, a draft report of the International Bioethics Committee of UNESCO (IBC) on the Bioethical Response to the Situation of Refugees was presented by two IBC members from the region followed by discussion. The report identifies a number of ethical challenges addressing health care of refugees and recommendations. The IBC report was planned to be finalized during the IBC session in September 2017 in Paris.

During the panel discussion on “legal regional harmonization” participants identified urgent issues need to be regulated in the region as follows:

- Premarital genetic testing using the experience of the Gulf Cooperation Council countries. The suggestion is to implement genetic testing and counseling voluntarily for 1 year then compulsory; then developing/applying policies and legislations based on lesson learnt.
- Biobanks: the importance of ethical management of data
- Role of WHO and UNESCO in supporting establishing regional or national regulations 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 public engagement strategies and actions for NBCs involving civil society and media for awareness raising;
- revisiting the bylaws every 4–5 years so they are updated according to public needs and demand; and
- considering the UNESCO ABC project to establish a new or enhance existing NBC in the region.
Discussion among the participants highlighted the need for;
- further cooperation between UNESCO and WHO in facilitating regional collaboration,
- promoting multidisciplinary cooperation between NBCs,
- fostering 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,
- monitoring misuse of technology without enough evidence,
- establishing WHO collaborating centres on bioethics in the WHO Eastern Mediterranean Region and UNESCO chairs on bioethics. ¹

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.

IV. Conclusion and the Way Forward

The participants of the regional summit came out with a list of recommendations to advance bioethics in the region including.

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.

¹ In the Arab Mediterranean Region, there is a UNESCO chair on bioethics first established under the University of Khartoum in Sudan in 2010; renewed in 2015. In July 2017, the Sindh Institute of Urology and Transplantation – Center of Biomedical Ethics and Culture (SIUT-CEBC), Karachi, Pakistan was designated as a bioethics WHO-Collaborating Center.
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 resources of the Council for International Organizations of Medical Sciences (CIOMS), UNESCO, WHO guidelines, etc.

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.
# Annex

## 1. Agenda of the regional summit

### Day 1: Wednesday 5 April 2017

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tr>
<td>08:00 – 09:00</td>
<td><strong>Registration</strong></td>
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<tr>
<td>09:00 – 09:30</td>
<td><strong>Opening Remarks</strong></td>
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<tr>
<td></td>
<td>● Dr Ali Al-Bemani, SQU Vice Chancellor (ONBC)</td>
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<td>● Dr Seiko Sugita (UNESCO)</td>
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<td>● Dr Ahmed Mandil (WHO)</td>
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<tr>
<td>09:30 – 10:00</td>
<td><strong>Meeting Objectives &amp; Introduction of Participants</strong></td>
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<tr>
<td></td>
<td>Mr Ahmed Khitami (ONBC Secretary)</td>
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<td></td>
<td>Dr A. Mandil; Dr S. Sugita</td>
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<td>10:00 – 10:30</td>
<td><strong>Coffee break</strong></td>
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<tr>
<td>10:30 – 12:00</td>
<td><strong>Session I: NBCs: International, Regional and National perspectives</strong></td>
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<td><strong>Chairpersons:</strong> Dr Bagher Larijani; Dr Adnan Mroueh</td>
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<td>Dr Jassim Al-Shamsi</td>
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<td>10:30 – 11:30</td>
<td><strong>Report from Global Summit (10 minutes), Dr Abha Saxena, WHO/HQ</strong></td>
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<td>General overview on National Bioethics Committees in the Region – UNESCO (10 minutes), Dr S. Sugita, UNESCO; Dr Manal Bouhaimed, Kuwait</td>
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<td>Towards Global Summit in Dakar 2018 (10 minutes), Dr Aissatou Toure, Senegal</td>
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<td>WHO Regional Bioethics Survey &amp; enhanced mechanisms of NBCs (15 minutes), Dr Mohamed Salah Ben Ammar, Tunisia</td>
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<td>Dr A. Mandil &amp; Dr Samar ElFeky, WHO/EMRO</td>
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<td>11:30 – 12:00</td>
<td><strong>Case study – Jordan, Dr Mohamed Ahmed Hamdan</strong></td>
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<td><strong>Case study - Oman, Mr A. Khitami / Dr Ahmed Al Shukaily</strong></td>
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<td>12:00 – 13:00</td>
<td><strong>Lunch break</strong></td>
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<tr>
<td>13:00 – 14:30</td>
<td><strong>Session (II): NBCs: Policies and Advice</strong></td>
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<td><strong>Chairpersons:</strong> Dr Shaikha Al Arrayed; Dr Matthew Hunt; Dr Hend Bouacha</td>
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<td>13:00 – 13:30</td>
<td><strong>Regional Legal survey results, Dr Orio Ikebe, UNESCO</strong></td>
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<td>13:30 – 14:00</td>
<td><strong>Case study: Non-discrimination / Genetics, Dr Mariam Dashti, Bahrain</strong></td>
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14:00 – 14:30  Case study: Oman MOH guideline for responsible conduct of clinical studies and trials: ethics and etiquette, Dr Adhra Al Mawali, MoH Oman

14:30 – 15:00  Coffee break

15:00 – 16:30  Session III: Public awareness and Education
Chairpersons: Dr M. S. Ben Ammar; Dr Thikra Mustafa; Dr Mary Medhat

15:00 – 15:30  Case study: Terminal care in Lebanon
Dr Michel Daher, Lebanese National Consultative Committee for Ethics

15:30 – 16:00  Case study: Academic collaboration with national advisory bodies to raise awareness on bioethics, Prof Mohamed El Sheikh, UNESCO Chair on Bioethics, Sudan

16:00 – 16:30  Case study: Integration of bioethics in health sciences’ curricula in Iran
Dr B. Larijani, IR of Iran
Day 2: Thursday, 6 April 2017

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<tr>
<th>Time</th>
<th>Event</th>
<th>Chairpersons</th>
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<tr>
<td>08:30 – 09:00</td>
<td>Recap of Day 1, Dr S. El-Feky, WHO/EMRO; Dr Manal Al-Saadoun, ONBC</td>
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<tr>
<td>09:00-10:30</td>
<td>Session (IV): Ethics in Humanitarian Settings (a)</td>
<td>Dr Hasan Al Jabah; Dr Ali Assabri; Dr A. Mandil, WHO/EMRO</td>
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<tr>
<td>09:00 – 09:30</td>
<td>Generating evidence in humanitarian emergencies: ethics of research and research ethics oversight</td>
<td>Dr Matthew Hunt, Director of Research, School of Physical and Occupational Therapy, McGill University &amp; Researcher, Centre for Interdisciplinary Research in Rehabilitation</td>
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<tr>
<td>09:30 – 10:00</td>
<td>Creating an ethical infrastructure for humanitarian organizations: Socio-political perspective, Dr Caroline Clarinval &amp; Dr Ali Okhowat, WHO / EMRO</td>
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<tr>
<td>10:00 – 10:30</td>
<td>Discussion</td>
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<td>10:30 – 11:00</td>
<td>Coffee Break</td>
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<tr>
<td>11:00-13:00</td>
<td>Session (V): Ethics in Humanitarian Settings (b)</td>
<td>Dr Khalid Al Ali; Mr Mohammed Saeed Alghamdi; Dr Ali El-Buni</td>
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<tr>
<td>11:00 – 11:30</td>
<td>IBC report on Bioethical response to the situation of refugees</td>
<td>Dr M. Bouhaimed, Kuwait; Dr Roland Tomb, Lebanon</td>
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<tr>
<td>11:30 – 12:00</td>
<td>WHO’s guidance on ethical issues in infectious diseases: Case of TB among migrants, Dr Andreas Reis, WHO/HQ</td>
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<tr>
<td>12:00 – 12:30</td>
<td>Case study - Pakistan, Dr Aasim Ahmad, Pakistan</td>
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<tr>
<td>12:30 – 13:00</td>
<td>WHO’s guidance and Training Manual on ethics in emergencies and disasters: An Overview, Dr A. Saxena, WHO/HQ</td>
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<tr>
<td>13:00 – 14:00</td>
<td>Lunch break</td>
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<tr>
<td>14:30 – 15:15</td>
<td>Panel Discussion (1): Legal regional harmonization: Challenges and priorities</td>
<td>Dr O. Ikebe, UNESCO (Moderator); Mr A. Khitami &amp; Dr A. Shukaily, ONBC; Dr A. Saxena, &amp; Dr A. Reis, WHO/HQ</td>
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<tr>
<td>15:15 – 16:00</td>
<td>Panel Discussion (2): National and Regional Cooperation among Ethics and Bioethics Committees: Challenges and support</td>
<td>Dr A. Saxena, WHO/HQ (Moderator); Dr Aissatou Toure, Senegal; Dr A. Mandil &amp; Dr S. El-Feky, WHO/EMRO; Mr A. Khitami &amp; Dr Ahmed Busaidi, ONBC; Dr S. Sugita, UNESCO</td>
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<tr>
<td>16:00 – 16:30</td>
<td>Conclusion &amp; Next Steps, Mr A. Khitami, ONBC; Dr A. Saxena &amp; Dr A. Mandil, WHO; Dr S. Sugita, &amp; Dr O. Ikebe, UNESCO</td>
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</tbody>
</table>
2. List of participants

BAHRAIN
Dr Mariam Dashti, Assistant Professor, Arabian Gulf University, Manama

CANADA
Dr Matthew Hunt, Director of Research, School of Physical and Occupational Therapy, McGill University, Montreal

EGYPT
Dr Mary Medhat, Associate Professor, Faculty of Dentistry, Ain Shams University, President of the Bioethics & Scientific Research National Committee, Cairo

ISLAMIC REPUBLIC OF IRAN
Dr Bagher Larijani, Director-General, Chief Scientific Officer Endocrinology and Metabolism Deputy, Minister of Education, Tehran

IRAQ
Dr Thikra Abdul-Wahab Mustafa, Acting General Secretary of the Ethics Commission; Professor at the Kurkok University, Kurkok

JORDAN
Dr Mohammad Hamdan, Secretary General, National committee for Sciences and Technology, Amman

KUWAIT
Dr Manal Bouhaimed, Assistant Professor of Medical Ethics & Ophthalmology, College of Medicine, Kuwait

LEBANON
Dr Michel Daher, Secretary General, Lebanese National Consultative Committee for Ethics, Beirut
Dr Adnan Mroueh, President, Lebanese National Consultative Committee for Ethics, Beirut
Dr Roland Tomb, Dean, Faculty of Medicine, Saint Joseph University, Beirut

LIBYA
Dr Abdulaziz El Buni, Chairman, Libya National Committee for Biosafety and Bioethics, Tripoli
(unable to participate)
**MOROCCO**
Dr Farid Hakkou *(unable to attend)*, Founder of Ethics committee, Medical School of Casablanca, Casablanca (unable to participate)

**OMAN**
Dr Adhra Al-Mawali, Director of Studies and Research, Centre Directorate General of Planning & Studies, Ministry of Health, Muscat
Dr Ahmad Khitamy, Sultan Qaboos University, Secretary
Dr Muna Sadoonm, Sultan Qaboos University
Dr Ahmed Al Busaidy, Ministry of Health
Dr Ahmed Al Shukaily, Nizwa University
Prof Taher Ba Omar, Sultan Qaboos University
Ms Amna Al Balushi, Sultan Qaboos University
Ms Ridha al-Hinai, Sultan Qaboos University

**PALESTINE**
Dr Asad Ramlawi *(unable to attend)*, Deputy Minister, Ministry of Health, Ramallah (unable to participate)

**PAKISTAN**
Dr Aasim Ahmed, The Kidney Centre, Aga Khan University, Karachi

**QATAR**
Dr Khalid A. Alali, Associate Vice President for Faculty Affairs, Qatar University, Doha, Qatar

**SAUDI ARABIA**
Mr Mohammed Saeed Alghamdi, General Secretary, National Committee of Bioethics, King Abdulaziz City of Science & Technology (KACST), Riyadh

**SENEGAL**
Dr Aissatou Toure, Institut Pasteur Dakar, Unité d'Immunologie, Dakar

**SOMALIA**
Dr Faisal Ahmed Ibrahim, Ministry of Health, Hargeisa (unable to participate)

**SUDAN**
Dr Mohamed El Sheikh, Faculty of Medicine, University of Khartoum, National Ethics Committee, Khartoum
SYRIA
Dr Hasan Al Jabah, Deputy Minister, Higher Education for Health Affairs, Damascus

TUNISIA
Dr Mohamed Ben Ammar, Former Minister of Public Health, Tunis
Dr Hend Bouacha, Secretary General, National Ethics Committee, Tunis

UNITED ARAB EMIRATES
Dr Jassim Ali Salem Al-Shamsi, Dean, Faculty of Law, United Arab Emirates University, Abu Dhabi
(unable to participate)

YEMEN
Dr Ali Assabri, College of Medicine, University of Sana’a, Sana’a
3. Regional Bioethics Summit Secretariat

**Oman National Bioethics Committee Secretariat**
Dr Ali Al-Bemani, Vice Chancellor, Sultan Qaboos University,
Mr Ahmad Khitamy (focal point) Secretary, National Committee for Bioethics, Sultan Qaboos University
Dr Ahmed AlShukaily, Sultan Qaboos University

**UNESCO Secretariat**
Dr Hamed Al Hammami, Regional Director, UNESCO Beirut
Dr Dafna Feinholz, Chief, Bioethics and Ethics of Science Section, Social and Human Sciences Sector, UNESCO/HQ (support from Paris)
Dr Orio Ikebe, Programme Specialist, Bioethics and Ethics of Science Section, Social and Human Sciences Sector, UNESCO/HQ
Dr Seiko Sugita, SHS Programme Specialist, UNESCO/Beirut (focal point)
Ms Jana El Baba, SHS Programme Specialist, UNESCO/Cairo (support from Cairo)
Mr Phinith Chanthalangsy, SHS Programme Specialist, UNESCO Rabat (support from Rabat)
Ms Carol Donabedian, Programme Assistant, UNESCO/Beirut (support from Cairo)

**WHO Secretariat**
Dr Arash Rashidian, Director of Information, Evidence and Research, WHO/EMRO (from Cairo)
Dr Abha Saxena, Coordinator, Global Health Ethics, WHO/HQ
Dr Ahmed Mandil, Coordinator, Research, Development and Innovation, WHO/EMRO (focal point)
Dr Caroline Clarinval, Team Leader, WHO/EMRO (unable to participate)
Dr Samar El Feky, Technical Officer, Research Promotion and Development WHO/EMRO
Dr Ali Okhowat, Health Emergency Officer, WHE, WHO/EMRO
Dr Andreas Reis, Technical Officer, Global Health Ethics, WHO/HQ
Dr Ruth Mabry, National Professional Officer, WHO/Oman (unable to participate)
Ms Marwa El Saghir, Programme Assistant, Research Promotion and Development WHO/EMRO (support from Cairo)
Ms Sema Mahfouz, Assistant to WR, WHO/Oman
Ms Suha Battash, Clerk, WHO/Oman
Ms Dalya Mostafa, Secretary, WHO/EMRO (support from Cairo)
4. Photo Gallery