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Fostering national bioethics committees: first regional summit in the Eastern Mediterranean Region/Arab States Region [1]

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Bioethics may be defined as the application of ethics to the field of medicine and healthcare, as a joint and reflective inspection in health science, healthcare policy and delivery, based on established ethical standards within each profession (1). Bioethics is multidisciplinary and pluralistically draws on science, life technology, laws, traditions, and human values (2), and thus has a significant impact on standards for disease management and conduct of research (3).

On 9 May 2016, the United Nations Education, Scientific and Cultural Organization (UNESCO) and World Health Organization (WHO) Regional Directors, met at the WHO Regional Office for the Eastern Mediterranean (EMRO) in Cairo to pursue and enhance collaboration between the two organizations in the field of bioethics in the Region (4). During the meeting, the Directors acknowledged fruitful collaboration in the past. This included jointly organizing regional meetings; for example in 2007 the “First Regional Meeting on National Bioethics Committees”, and the international seminar “Dilemma of Stem Cell: Research, Future and Ethical Challenges”; and during 2008 the “First meeting for the Eastern Mediterranean Region (EMR) and Arab Forum on Bioethics in Research”, and the “Expert Meeting on Ethical and Legal Issues in Human Embryo Research”. Recently, a Memorandum of Understanding (MoU) was signed between the Directors General of UNESCO and WHO on 26 April 2017, fostering bilateral cooperation in bioethics and related fields between both agencies at the global level.

The Global Health Ethics Unit at WHO hosts the permanent secretariat for the Global Summit of National Ethics/Bioethics Committees, which held its latest biennial meeting in February 2016, and recommended holding regional bioethics summits. As a result, WHO/EMRO in collaboration with UNESCO/Arab States and the Omani National Bioethics Committee organized the first “Eastern Mediterranean/Arab States Regional Summit of National Ethics and Bioethics Committees” in Muscat, Oman, 5–6 April 2017, hosted at the Sultan Qaboos University.

The main goal of the Regional Summit was to foster development of national ethics committees (NECs) and establish effective mechanisms of regional harmonization and cooperation to address emerging issues related to bioethics. The objectives were to explore methods of regional collaboration (with special focus on development and work of national ethics/bioethics committees), develop strategies to strengthen linkages between the bioethics committees and policy-makers, and share experiences and deliberate on relevant bioethics-related issues such as ethics during disasters and emergencies.

Meeting developments and deliberations

The Regional Summit was inaugurated by Prof Ali Al-Bemani, President of the Omani National Bioethics Committee, and Vice-Chancellor Sultan Qaboos University, as well as WHO and UNESCO representatives who emphasized the importance of the Summit as a platform for sharing experiences and lessons learnt to forward bioethics in the countries of the Region.

The first day of the Summit was dedicated to discussion of development, activities, and networking between national bioethics committees (NBCs), as well as challenges facing them from international, regional and national perspectives. On an international level, the participants were acquainted with the Global Summit of National Ethics/Bioethics Committees, which acts as an international forum for exchange of views and debates on bioethics, contributes to common

understanding and consensus building between nations, as well as assisting in developing national bioethical frameworks and guidelines (5). The latest Global Summit was held in Berlin, Germany, during March 2016, and 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 sub-themes (bioethics in electronic data era; bioethics, social justice and civil society; bioethics, health emergencies and resilience and bioethics and vulnerable populations).

In addition, UNESCO representatives presented a general overview on NBCs in the Region, Universal Declaration on Bioethics and Human Rights (6), and UNESCO Assisting Bioethics Committees Project (ABC) (7). UNESCO also reflected on recent surveys, including the 2014 NEC survey, and the 2009 UNESCO regional Legal survey, which covered 10 issues related to medical and genetic research in the Arab States, as follows:

human reproductive and therapeutic cloning;

embryonic stem cell research;

genetic testing;

human genome and gene analysis;

research involving human subjects;

organ transplantation;

assisted reproductive technologies;

pharmaceutical research;

medical practice; and

abortion in the Arab States.

The survey illustrated gaps in legal provision across the Region on advanced technologies, treatments and research. In addition, WHO representatives shared the methodology and main outcomes of the 2015 WHO Regional Bioethics Survey, which identified the main challenges facing NECs in the Region including: resources, transparency and autonomy, noncompliance, limited control over institutional ethical committees, gaps between policies and practice, reporting mechanisms and coordination between different ethical bodies, bioethics education and lack of legal stipulations governing sensitive topics of public health importance.

The experiences of NBCs were presented as case studies from representatives of Jordan, Oman and Pakistan. In addition, specific topical experiences were presented by representatives of Bahrain (premarital genetic screening and women's social rights); Oman (Ministry of Health guidelines for responsible conduct of clinical studies and trials); Lebanon (end of life care), and the Islamic Republic of Iran (integration of bioethics in health sciences curricula).

UNESCO, WHO, and NBC presentations were followed by important discussions that emphasized the role of UNESCO and WHO in facilitating regional collaboration, multidisciplinary cooperation between members NBCs, the need for a “bottom up” approach in setting priorities, applying strengths, weaknesses, opportunities, threats (SWOT) analysis to NECs to identify advantages and challenges, and establishing WHO collaborating centres on bioethics in the EMR. In addition, discussion covered the possible replication of Lebanon’s experience in terminal / palliative care and the integration of palliative care into graduate health sciences curricula.

The second day of the meeting was dedicated to bioethics during emergency and disaster situations, covering the process of generating evidence in humanitarian emergencies, and how the following questions should be addressed when planning for research in such circumstances, namely: what priority should research and other knowledge generation activities be given in humanitarian emergencies? What are the distinctive ethical features / challenges? How should these be accounted for? What constitutes effective and high-quality ethics review of protocols conducted in humanitarian crises? And what attributes characterize a research ethics committee that is well suited to review crisis research? Discussion also took place about creating an ethical infrastructure for humanitarian organizations from a socio-political perspective in relation to organizational climate (formal and informal systems for communication, surveillance and sanctioning), ethics and justice.

In addition, the International Bioethics Committee report on bioethical response to the situation of refugees, with special focus on Article 23 which provides for equality of treatment between refugees and citizens, was presented and discussed (8). The International Bioethics Committee was created in 1993 as a body of 36 independent experts to follow progress in the life sciences, and cooperate with international governmental and non-governmental organizations working in the field of bioethics.

WHO's guidance on ethical issues in infectious diseases (9) and ethics in emergencies and disasters (10) was examined in detail in order to create a conceptual framework for enhancing the role of NBCs during emergencies and disasters. There also followed discussions on the specific principles for research during emergencies; possible political influence on such research; importance of distinguishing research ethics from general medical ethics during crises; importance of neutrality of data; and the need to share experiences and lessons learnt from inside and outside the Region.

The second day of the meeting ended with two panel discussions: "legal regional harmonization" (challenges and priorities), and "national and regional cooperation among national ethics and bioethics committees" (challenges and support). The first panel discussion emphasized the adoption of the experience of the Gulf Cooperation Council (GCC) countries in premarital genetic counselling; firstly by making it voluntarily for one year followed by developing/applying polices based on the year's assessment; developing and ethically using data and biobanks; exploiting the role of WHO and UNESCO in developing frameworks for legal implementation; and the sharing of regional experiences.

The second panel discussion on "national and regional cooperation among National Ethics and Bioethics Committees" emphasized the need for networking among bioethics/ethics bodies in the Region through similar fora or webinars; importance of priority-setting for 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 awareness of the relevant issues and create public demand; revisiting legal stipulations every 4 to 5 years; and expanding the UNESCO ABC project into other countries of the Region.

Conclusion and way forward

The following recommendations resulted from the meeting in order to progress bioethics in the Region:

I. Strengthening NBC/NECs through establishing/enhancing work and roles of national ethics/bioethics committees in the Region, in coordination with UNESCO/WHO, and linking with the International Bioethics Committee (IBC) and World Commission on the Ethics of Scientific Knowledge and Technology (COMEST), as needed. This would involve multi-sectoral involvement within NEC/NBC work (including the role of media/civil society as key stakeholders to ensure compliance of concerned bodies) and allocating sufficient resources for bioethics-related community protection/interventions.

2. Enhancing the role of NBC/NECs in promoting bioethics, health and research ethics through developing/enforcing legal stipulations for common ethical issues and ethical issues with significant impact on the society (e.g., premarital genetic testing, organ donation/trafficking, end-of-life care, assisted reproductive technologies); promoting consistency between regulations and practices within different institutions working on bioethical issues; raising public awareness including patients, vulnerable populations, women and youth, on bioethics related matters (e.g., informed consent process and the importance of bioethics in health care, collection, usage and storage of genetic data, etc.); promoting collaboration on education on bioethics and health ethics; fostering bioethics principles within the scientific community and other disciplines such as laws and journalism, health sciences curricula of academic institutions and in-service training of healthcare providers (using regional/international expertise); building capacity of healthcare providers on medical/research ethics; and priority setting, impact assessment, ethics/research/oversight during humanitarian emergencies and outbreaks (using the “Council for International Organizations of Medical Sciences” [CIOMS], UNESCO, WHO guidelines, etc.)

3. Coordination and cooperation among NBC/NECs by establishing a follow-up committee of recommendations to identify priority actions, and organizing regional consultation/coordination meetings during and between the biannual Global Summits (Dakar 2018 and beyond).

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