

Islamic Ethics and Genomics: The intersection of science, religion and law

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Background

A number of countries in the Gulf region, led by Qatar and Saudi Arabia, have launched ambitious scientific ventures with the aim of gaining significant traction in the fields of genomics and personalized medicine. For a couple of years now, significant financial and manpower investments have been made in these ventures in order to achieve healthcare goals in accordance with the National Vision 2030. Thus, these recent and also prospective investments will sooner or later transform the debate within Islamic countries from simple technology-focused conversations to difficult ethical decisions to be made about complex issues related to genomic medicine and personalized healthcare.

In their inevitable engagement with genomics, most self-identified Muslims in health care or academia, e.g. physicians, biomedical scientists, and public health policy makers, will be faced with complex questions and ethical dilemmas. The general Muslim public will also be in need of more knowledge about genomics, especially with the recently announced Qatar Genome Program's ambitious goals to provide genomic testing to a large proportion of the population. Thus, there will be a significant need for genomics discourse that enhances the overall understanding of this field and the Islamic religio-ethical perspectives towards this emerging science, both as part of people's "local moral world" in the Gulf region and the Muslim world in general, and in more philosophical terms of how ethical positions concerning genomics are developed within the Islamic tradition. Together, these ethical positions will need to eventually be translated into policy guidelines, regulations and binding laws, and therefore need to be fully discussed and thoroughly understood.

Many of these issues are now under scrutiny within the research project "Indigenizing Genomics in the Gulf Region (IGGR): The Missing Islamic Bioethical Discourse" which is awarded the Qatar National Research Fund (QNRF) grant no. NPRP8-1620-6-057. The project started officially on 10 September 2016 and continues for three years. The convener of this panel is the Lead Principal Investigator (LPI) of the IGGR project.

The Panel

Based on, among other sources, the material and information available from the abovementioned IGGR project, the panel will address "Islamic Ethics & Genomics" from three main perspectives:

One part of the panel will be dedicated to presenting basic scientific information about genomics in a way accessible to the general public. The aim here is to make a contribution to nurturing and promoting Public

Understanding of Science (PUS) and Public Engagement with Science (PES). Besides presenting the scientific aspects of genomics, reference will be made to the ongoing debates within the scientific community about the strengths and limitations of genomics and personalized medicine and the anticipated future directions to solve the over-arching scientific challenges within the field. In other words, the attempt here is to solicit a well-balanced and systematic overview that takes into account the different voices on genomics. The main ongoing genomic initiatives in some Gulf Countries, with main focus on Qatar and Saudi Arabia, will be presented as well.

Another part of the panel will give an overview of the Islamic religio-ethical deliberations on genomics, which date back to the late 1990s when discussions started on the ethical implications of the then still in-progress Human Genome Project. Focus here will be on the expert meetings held by institutions like the International Islamic Fiqh Academy (IIFA) in Saudi Arabia and the Islamic Organization for Medical Sciences (IOMS) in Kuwait. During these meetings both Muslim religious scholars and biomedical scientists deliberated on these issues through an interdisciplinary approach which combines between specialists from different fields; known in Islamic studies as collective *ijtihad* (independent legal reasoning). The main conclusions made by the participants in these meeting will be analyzed and we will examine how these conclusions produced a mixture of “open embracement” of genomics and “deep concerns” about its possible negative repercussions.

A third part of the panel will explore the policy and legal regulations related to genomics and how far they are in tune with the above-mentioned scientific and religio-ethical deliberations. The main focus here will be on the efforts made by the Qatar Ministry of Public Health to develop policy guidelines and law drafts. As examples, one can refer to the ongoing process of drafting Health Research Law and the Policy for Accessing Qatar Biobank Data and Biological Samples. The latter is a joint labor between the Ministry of Public Health and Qatar Biobank. Finally, it is to be noted that the Guidelines for the Use of Stored Data and Biological Samples issued in 2009 are now under revision for the sake of producing an updated version.

Key Questions for Further Discussions

By highlighting specific aspects of genomics & ethics through these three interdisciplinary perspectives, the door will be open to tackle key and complex questions with the audience of the panel. These questions will not necessarily have clear answers during the panel but they will surely produce good stuff for future critical thinking and research. As examples, one can think of the following questions which can be shared with the audience of the panel:

- How far the groundbreaking scientific advancements of genomics are shaping the relationship between science and religion? Which field is influencing the other and in which way? Are the religious/scientific boundaries getting blurred or actually getting clearer and the distance separating between the two fields are getting longer and longer?
- Will the advanced techniques of genomics and the resulting personalized/precision medicine redefine people’s identity and status? For instance, will the structure of one’s genome be more important than one’s affiliation with a certain group of people, e.g. dynasty or tribe?

- With the huge and uncontrollable amount of personal information revealed by genomic tests, how one's privacy and information confidentiality be understood and regulated in the near future?
- Eventually, who will have the authority to define, speak for and defend individuals' or people's interests in this complex world? Will the experts in a specific field (science, religion or law) have the final word? How would/should these experts relate to the general public and how influential should be the voice of the general public?