



A fair access policy for the Saudi Biobank

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In recent times, an increasing number of research biobanks have been established in many parts of the world, and medical research has increased as well [1]. Getting access to large numbers of samples and data is a key factor in the development of successful research, which requires collaboration between researchers and biobanks and among biobanks themselves and pharmaceutical companies [2]. However, this is fraught with logistical difficulties and ethical challenges, especially those related to medical confidentiality. A good balance between allowing access to samples and data and conducting medical research on one hand, and preserving the rights of the participants—especially protecting the confidentiality and privacy of donors and not harming them—are key factors in the success of biobanks [3].

In this section we'll explain the provisions under which researchers are allowed access to samples and data in a biobank in Saudi Arabia.

In 2011 King Abdul Aziz Medical City in the National Guard, in cooperation with the King Abdul Aziz City for Science and Technology, decided to establish a biobank, which currently

contains 200,000 participants, as a base to conduct basic medical research in Saudi Arabia. Half of the participants were patients with certain common diseases, and the other half were healthy participants [4].

The samples are collected on the basis that ownership is given to the biobank, with the possibility of allowing researchers to have access to the samples and the data they need to do their research. Samples and data will be managed by the biobank as a part of the King Abdullah International Medical Research. Access policy has been approved by the Steering Committee for the Saudi Biobank [5].

Saudi biobank regulates access to samples and data, using a system of clear rules and procedures, including the use of double coding to ensure the anonymity and limiting access to anonymized samples and data only. According to Saudi biobank, individual researchers and institutions can get access after obtaining an approval from the Institutional Review Board (IRB). Access is limited to samples and data needed by the researcher, and with previous approval by the IRB. Saudi biobank intends to encourage medical research while

preserving confidentiality and protecting participants [5].

Full implementation of the Saudi biobank is still underway, with an expected start in 2014. The program will give access to both local and foreign researchers, similarly to other biobanks such as UK, Icelandic, Estonian, and other biobanks [6,7]. Previous study discovered widespread agreement to giving access to researchers inside and outside the country. Saudi biobanks as well as other biobanks require that information be coded or anonymized to allow access [1,6-8].

Giving access to samples and data to local and foreign researchers is vital to the conduct and development of research in Saudi, especially because it offers the use of a large number of samples and data in research, which will increase the credibility of research results. On other side and from an economic point of view, giving access to researchers will save financial costs of establishing other biobanks requiring expensive buildings and equipment. Usually, research institutes and researchers are interested in investing in conducting research directly rather than spending money on building and costly tools. Giving access to researchers is important and acceptable, especially if done according to correct conditions and with appropriate safeguards for confidentiality and privacy through using anonymized samples and data.

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