BIOBANKS

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1. The Consent Form delivered by Biobank to potential participants, is a statement of approval on seven general and brief questions that all but one (the right of withdrawal) protect rights of UK Biobank and could be defined as a kind of broad consent. However , first question refers to the Information Leaflet which is available to participants ,which I believe thoroughly describes both, their ,obligations and rights (provided that is adequately explained and understood) .In this Information Leaflet (and Further information Leaflet) indispensible elements of information that a potential participant should be aware of are adequately addressed . Some of these issues are : the purpose of the UK Biobank and the project, the type of information (personal ,health status) and biological samples that are going to be gathered also information about management and use of these resources as well as precaution actions and aspects of securing confidentiality along with clear wording of withdrawal options .If the Information Leaflet has a binding effect(for Biobank) and this could be stated also to Consent Form, then I would agree that the Informed Consent is adequately addressed . Otherwise ,will be considered as inadequate since a lot of information is lacking (ex explicit statement that privacy of genetic information cannot completely protected &all the aforementioned)
2. Based on the information included in Information Leaflet , Further Information Leaflet , and UK Biobank Ethics and Governance ,I assume that Biobank takes up strict measures to ensure data privacy and confidentiality .In order to minimize risk, UK Biobank computers are protected with a "firewall" software , genetic data are encrypted and access to personal information is restricted within UK Biobank only to authorized stuff .It is also stated that no personal information, samples or test results will be given to insurance companies and employers .Samples doesn't include personal identifiers and each participant is related to a project-specific ID-code which is distributed only to entitled researchers working on the project .In case the same sample is used in another project the ID-code is re-identified so that no link between two data sets could be revealed . Nevertheless linkage of data is permitted under specific research needs. Individuals' information (personal data) is kept in separate databases from other information of the participants (samples).As aforesaid I believe that UK Biobank has a satisfying level of securing data privacy and confidentiality even though samples are not fully anonymized for reasons of research utility .
3. Return of results to participants isn't in policy and aim of participation which is explained in first assessment visit and clearly stated in the Consent Form. Health information will only be given in case of abnormal measurements or accidental findings that staff consider of having a clinical meaning and encourage participants to consult a health professor. In my opinion this issue is adequately addressed.

4. In, Biobank Ethics and Governance Framework, the ownership of samples and data is adequately defined .UK Biobank is the legal and exclusive owner and steward of database and sample collection after participants sign the consent form who afterwards quit ownership. Biobank will exercises all rights concerning protection, sharing of resources, careful management and transfer and also legal action against unauthorized use or abuse. There is also a statement of no intention in exercising the right to sell recourses to third parties .Participants have the right to withdraw at any time and those who decide the level of " no further use" will have their samples destroyed. Additionally, all participants who are interested to know the uses of their resources' will be adequately informed. So this issue is adequately addressed.
5. UK Biobank , as the legal owner of all study data and sample collection is entitled of sharing this information to specific recipients which are defined and refuse access to others such insurance companies, employers ,relatives ,lawyers ,security services ,police (except courts).Access to data (assay, analysis, derived ,researcher analysis ,researcher results) will be permitted to researchers who have relevant scientific and ethics approval for their planned research, encrypted so that data privacy and confidentiality is ensured , but also will be available to other approved researchers ,pharmaceutical and health based companies for approved research .Researchers are obliged to return results from their research and also to have them published so that could be used for other research projects and ultimately all people can benefit from it. Development and use of resources is monitored by the Independent Ethics & Governance Committee. The issue of data sharing is adequately addressed because availability is ensured only to authorized recipients with scientific interests under strict conditions protecting confidentiality.
6. Duration of storage isn't adequately addressed because the only information we get, from Further Information Leaflet ,is that biological samples (saliva, blood ,urine) will be kept for several decades or by the time they reach the end of their natural life which then will be destroyed . Samples will also be destroyed in case of consent withdrawal in the level of 'no further use'.
7. There is no specific information available concerning transfer of assets or closure of the Biobank, only a general intention of protecting the rights of the participants is expressed and a statement of consultation of the Ethics Committee .The issue is not adequately addressed.
8. As mentioned before, participants signing Consent Form will have no property rights in the samples and they will not be offered any material financial or other incentive for their contribution to UK Biobank.

   Benefit sharing is expected to arise from the knowledge derived from studies based on UK Biobank resources, which will published and enrich medical literature or even be applied to the development of new drugs, medical technologies, in terms of proper use aligned with Biobank's objectives and ethics requirements. The role of Biobank is defined as valuable common resource for research and it is not expected to lead research or patentable inventions. The issue is adequately addressed.