

**Summary of decisions, actions and recommendations from
the Tenth Meeting of the UK Biobank Ethics and Governance Council
(16 January 2007)**

1. It has been the practice of the Council to date to produce both a minute of each meeting and a public report (the latter being more succinct, less formal and excluded confidential items). The Council agreed that a single document – a minute – should be produced and published on the website along with a summary of decisions, actions and recommendations. The Secretary will write a policy on the publication of EGC meeting minutes. [AH]
2. The Council agreed to invite Sir Alan Langlands (Chair, UK Biobank Board of Directors) to attend part of its March meeting. [AH]
3. The Council agreed that a policy should be drafted, describing how proposals to provide consultancy services will be judged. [AH]
4. The Council agreed to develop an Invitation to Tender (ITT) for a research study to survey opinions regarding access, intellectual property, benefit sharing and commercialisation. The study will focus on the opinions of two groups, a 40 - 69 age group and an 18 - 28 age group. Members were invited to send research questions to the Secretary, who will develop the ITT. [AH]
5. Member discussed a variety of potential research areas in which consultations could be commissioned. The Secretary will write a list of these areas for future reference of the Council. [AH]
6. The Council, which currently meets in private, discussed the possibility of changing this policy and permitting observers to attend its normal committee meetings. In light of the support for the principle, a specific proposal will be presented to the Council at its next meeting. [GTL]
7. Permitting observers to attend its normal committee meeting represents one element of a broader communications strategy which the Council needs to develop. Ms Cook agreed to take forward the development of this strategy. [AC]
8. The Council agreed to hold a public event in Manchester on the evening of 11 June 2007. This event will be organised by the Secretary. [AH]
9. The Council agreed that it should have a policy which describes to interested parties how complaints about the EGC's activities will be managed. This policy will be developed by the Secretary. [AH]
10. The Council agreed to establish an EGC sub-group on Access and IP to assist UK Biobank. A subgroup, comprising Graeme Laurie, Hilary Newiss, Chris Wild and Heather Widdows will take forward this aspect of the Council's work.

Recommendations to UK Biobank

11. The Council reviewed UK Biobank's Standard Operating Procedures (SOPs) for enquiries and complaints handling (in the assessment centre, call centre and in general). The Council suggested that:
 - a. UK Biobank might write a script for its employees to use when responding to complaints in order to manage and promote consistency in the handling of complaints.
 - b. In addition to the draft SOPs intended as a staff guide, there is a clear need for UK Biobank to develop a complaints policy to be published on the UK Biobank website. The Council suggested that the websites of various public bodies could be used as a point of reference for such policies.
 - c. UK Biobank might separate out procedures for handling complaints from those for dealing with enquiries.
12. The Council and Professor Collins discussed the range of legal and ethical input available to UK Biobank. The Council agreed to recommend that an internal mechanism

could be developed by UK Biobank to seek input from legal and ethics experts who can respond directly to developments in the project and help UK Biobank in the formulation of its responses or, for example, the development of SOPs or policies. This may include legal review of various aspects of the project design as a whole (which is not to suggest that certain aspects have not already been subject to such review). The Chair, on behalf of the Council, agreed to write to Sir Alan Langlands and Professor Rory Collins to offer this recommendation. [GTL]