

**Summary of decisions and recommendations from
the Thirteenth Meeting of the UK Biobank Ethics and Governance Council
(1 November 2007)**

1. The Council approved the circulated minutes of its twelfth meeting.
2. The Secretary will establish and maintain a database listing the EGC's main achievements.
3. A series of Frequently Asked Questions (FAQs) has been developed. The Secretary will post the FAQs on the EGC website having taken account of members' comments.
4. A commentary on the commissioned report 'Concepts of the public interest and the public good' has been prepared by the EGC Chair. The Council agreed to send the commentary to the authors of the report for their comment and to develop its understanding of the concepts the 'public interest' and 'public good' further, e.g. through the development of the commentary paper.
5. The EGC has commissioned an exploratory project to study opinions regarding the terms of 'third party' access to UK Biobank. An interim report will be distributed to the Council for comment in December. The Secretary will send the compiled comments to the project team in January 2008.
6. New appointments will be made to the Council in 2008. Members interested in serving on the Appointment Panel should contact the Secretary.
7. A consultation with a British Heart Foundation (BHF) nurse is being piloted at the Manchester assessment centre. Professor Collins offered to supply the EGC with the BHF information leaflet and to check whether any participants had gone back to UK Biobank staff to ask questions after their BHF consultation.
8. The definition of the 'No further use' option of withdrawal has been revised in both the Ethics and Governance Framework and the participant information leaflet. The Council agreed that information regarding the revisions should be posted on the EGC website.
9. A strategy for ongoing communication with participants will be essential if UK Biobank is to effectively inform participants of changes in policy or process and in the project's progress in general (e.g. via regular newsletters). Professor Collins proposed to provide the Council with a report regarding the progress being made in the development of an 'ongoing communication' strategy.
10. The Council agreed to request biannual updates on UK Biobank's information technology and information management strategy, but with the proviso for exception reports from Professor Collins as and when necessary.
11. The Council agreed that it would be beneficial to have an information technology (IT) expert on the EGC. This need will be addressed during the recruitment of new members in 2008 (by specifying in the advert that an expert in IT is sought).
12. The Council reviewed UK Biobank's biannual complaints and enquiries report:
 - Reflecting on the EGC's remit, the Council agreed to request, for future reports, more information on ethics-related issues. Examples of these issues might be enquiries and complaints relating to commercial use or the reasons why a participant withdraws.
 - The Council requested that any queries received by UK Biobank relating to the EGC should be sent to the EGC for information and/or action (providing the enquirer gives permission).

13. A new EGC leaflet will be developed by the communications subgroup describing the Council's role in accessible terms while being true to its formal remit.
14. The Chair attended the UK Biobank Board of Directors meeting on 26/10/07 at which the Council's recently commissioned public attitude survey was discussed. The Secretary will send a briefing note to the Board explaining the process by which the research was commissioned and the expected reporting dates.

Recommendations to UK Biobank

15. UK Biobank could consider using a telephone translation service in its assessment centres (if no translator is available on site).
16. A UK Biobank newsletter would be an appropriate means of conveying the project's progress to participants and informing them of any changes in policy (e.g. the revised wording for the 'No Further Use' withdrawal option). This may involve occasional joint publications between UK Biobank and the EGC.
17. In relation to the revised wording of the 'No Further Use' withdrawal option in the EGF and PIL, UK Biobank might also consider posting information about the revision on its website.
18. UK Biobank might consider producing a lay summary of data security measures to post on its website.