

**Summary of decisions and recommendations from  
the Eleventh Meeting of the UK Biobank Ethics and Governance Council  
(12 March 2007)**

1. The Council approved the new style of minutes and agreed that the current text-based summary document should be re-formatted to a bullet point list. The Secretary will re-format the summary document.
2. The Council approved the circulated minutes.
3. Professor Collins invited EGC members to visit the UK Biobank co-ordinating centre in Cheadle and the Manchester assessment centre. The Secretary will co-ordinate the visits to UK Biobank.
4. The EGC public event will take place on Monday the 11 June 2007 between 16.30 and 19.00. There will be a few short presentations, a question and answer session and a drinks reception. The Secretary will organise the event.
5. The Council agreed to invite Andrew Trehearne, UK Biobank's new Head of Communications, to attend and present at its 12 June 2007 meeting. The Secretary will contact Andrew Trehearne.
6. The EGC subgroup on Access and Intellectual Property (A&IP) has reviewed and commented on UK Biobank's draft A&IP policy (November 2006). Professor Collins will review these comments along with those submitted by the Funders of UK Biobank, before bringing the policy back to the Council.
7. The EGC policy on complaints handling was approved with minor changes. The Secretary will revise and publish the policy on the EGC's website.
8. The EGC policy on judging proposals to provide consultancy services was approved with minor changes. The Secretary will revise and publish the policy on the EGC's website.
9. The Council discussed a proposal to hold its normal committee meetings in public. The Council agreed that it was not appropriate to adopt the practice at the present time. The communications subgroup will consider the proposal to hold EGC meetings in public alongside the broader communications strategy.
10. UK Biobank recently held a meeting to discuss possible enhancements to the study protocol and to increase communication between the Regional Collaborating Centres (RCC) and non-RCC researchers. The Council noted that the meeting attendees seemed to be predominantly from a scientific background. Inviting input on enhancement more broadly (e.g. from social scientists on the inclusion of more detailed social data) might be advantageous and increase the public good potential of the project. The Council encourages a strategy of broad engagement with researchers. The Secretary will ask UK Biobank whether attendance at the meeting was by invite only or if the meeting was advertised to a broad research community.
11. The Council agreed to ask Professor Sarah Cunningham-Burley (University of Edinburgh) to provide comment on the draft specification of requirements and invitation to tender (ITT) for: 'Access, commercialisation, intellectual property and benefit sharing: An exploratory project to study opinions regarding the terms of 'third party' access to UK Biobank'. Subject to comments from Professor Cunningham-Burley, the Council approved the draft ITT. The Secretary will contact Sarah Cunningham-Burley, revise the ITT accordingly, finalise the timetable for the tender process and disseminate the final ITT.

12. A draft of the recently commissioned paper on the concepts of the public interest and the public good was brought to the Council's attention for comment. The Chair will provide the researcher with the Council's feedback.
13. Council members were asked to consider future work packages which the EGC might address in the coming years and to send their ideas to the Secretary.

#### **Recommendations to UK Biobank**

14. *Protocol describing the assessment of capacity (at the assessment centre)*. The Council suggested that the Standard Operating Procedure (SOP) should be revised to reflect the fact that there is different legislation in England and Wales (the Mental Capacity Act 2005) and Scotland (the Adults with Incapacity (Scotland) Act 2000). The Council also recommended that the SOP should follow the legal test for incapacity which refers to a person's ability to understand, retain and believe the information (as described, inter alia, in the Mental Capacity Act 2005). The Council will provide UK Biobank with a proposed wording for the legal test for incapacity.