

**Summary of decisions and recommendations from  
the Fourteenth Meeting of the UK Biobank Ethics and Governance Council  
(17 March 2008)**

1. The Council approved the circulated minutes and the summary of decisions and recommendations of its thirteenth meeting.
2. The Council agreed to produce a statement, to be published on the EGC website, regarding the process of revision of the 'No further use' option of withdrawal.
3. Regarding the British Heart Foundation (BHF) consultation offered to participants at the end of their assessment centre visit:
  - The Council had been concerned that the consultation might be considered part of participating in UK Biobank. Having had sight of the BHF leaflet members were assured that the leaflets design was sufficiently different from the project's participant materials to convey the 'separateness' of the BHF from UK Biobank.
  - Professor Collins informed the Council that there have been very few cases of a participant going back to a UK Biobank nurse after their BHF consultation and that UK Biobank staff are trained not to provide health advice.
4. UK Biobank is developing a proposal for enhancement of its protocol to be submitted to the Funders for approval later in the year. Professor Collins and the EGC agreed that the Council's advice should be sought in plenty of time for it to provide effective input into the proposal.
5. The EGC Chair has written a summary paper of the commissioned report 'Access to the UK Biobank resource: Concepts of the public interest and the public good': The summary is a living document and will be revised over time to take account of new thinking by the Council on its interpretations of 'public interest' and 'public good' (e.g. in response to other commissioned work or future experiences). A modified version of the summary paper will be published on the EGC website along with a link to the original, prefaced report. It will be made clear that the report is not an instrument of the Council but rather a piece of independent commissioned work. The website will invite comments on the report's findings to be submitted to the EGC.
6. The Council reviewed the first draft of the commissioned report 'UK Biobank: public attitudes to third party access and benefit sharing'. Feedback will be provided to the research team to inform the revision of the report.
7. An EGC recruitment process will take place in Autumn 2008 with the aim of recruiting at least two members. The Council clarified that through this process it will seek an expert in information security, rather than information technology as discussed at its last meeting. The advert might usefully be sent to the British Computing Society.
8. Members agreed to support the appointment of Professor Martin Richards as EGC Vice Chair. It was agreed that another Vice Chair may be appointed in due course if this was thought to be necessary and appropriate.
9. A public meeting will be held in Edinburgh at the Hub on 1 July 2008. The Council agreed to hold a further public meeting in Wales in either Cardiff - where recruitment is ongoing but will cease at the end of May 2008 - or a future recruitment location. The Secretary will ask UK Biobank for its plans to open new assessment centres in Wales.<sup>1</sup>

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<sup>1</sup> Subsequent to this meeting the public meeting date in Wales has been confirmed as 12 February 2009.

10. The Council agreed to explore opportunities for raising awareness about its activities, for example through presentations at Science Festivals and other external events.
11. Members should submit to the Secretary the names of individuals or organisation who might be interested in receiving a copy of the Annual Review 2007.
12. 2009 Council meeting dates were agreed: 16 March, 8 June, 7 September<sup>2</sup>, 7 December.

### **Recommendations to UK Biobank**

#### 13. *UK Biobank's long term communication strategy:*

- The strategy favours electronic means of communication including the project's website, text and email. News media and advertising are also included in the strategy and a participants' panel remains to be an area for possible further discussion. While not underestimating the difficulty of the task, given the size of the cohort and the likely attrition over time, the Council cautioned that a strategy focused on electronic communications may disenfranchise older and lower economic groups. Other outlets could be used to supplement these communications e.g. posting information in GP and hospital waiting rooms and libraries. Local council free newspapers and intermediary organisations might also be used to communicate messages about UK Biobank.
- At Professor Collins' request, Ms Cook agreed to liaise with Mr Andrew Trehearne over these issues.

14. When recruiting in ethnic minority rich areas UK Biobank might consider using established local housing agencies, tenants associations and law and advice centres who already have good local links into the community and also often possess language and translation skills which they would be prepared to offer on a sessional or peripatetic basis.

15. The Council discussed a paper prepared by Mr Jonathan Sellors describing UK Biobank's current thinking with regards to its access and intellectual property (A&IP) policies and:

- Recommended maintaining a broad definition of 'health' when considering access requests.
- Recommended that it might be beneficial for UK Biobank to provide case studies for participants of different access scenarios e.g. to demonstrate when UK Biobank might and might not seek to share some profits resulting from research conducted on the resource. This could be extended/used as a deliberative exercise by posting the case studies on UK Biobank's website and inviting comments from participants and the public.
- Stressed the importance of developing a clear timetable for the development of the policy in the near future.
- Agreed to send Mr Sellors the EGC A&IP subgroup's previous comments on earlier drafts of the policy (including comments in relation to the Access Committee and more articulation of principle than found in the EGF) for re-consideration during the further development of the policy. The subgroup's comments will also be re-sent to Council members.

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<sup>2</sup> Subsequent to this meeting it has been decided that the 7 September 2009 will be reserved for a public meeting and the 8 September 2009 will be reserved for a Council meeting.