

**Summary of decisions and recommendations from  
the Sixteenth Meeting of the UK Biobank Ethics and Governance Council  
(15 September 2008)**

1. The Council approved the circulated minutes and the summary of decisions and recommendations of its fifteenth meeting.
2. The EGC vacancies have been publicly advertised with a closing date of 24 September. Members were asked to distribute the EGC advert to their contacts. [All]
3. Commissioned report: *'Public attitudes to third party access and benefit sharing: their application to UK Biobank'*. The Council:
  - Discussed the report's recommendations and identified the key implications for the work of the EGC.
  - Agreed to publish the final report on the EGC website, accompanied by a preface containing a description of why the report was commissioned, a statement that the report does not express the Council's views but is a stand-alone document and a summary of the key implications for the EGC's work. [AH]
  - Agreed to update the Council's living document, 'Advising on the public interest and the public good', based on the key implications. [AH]
  - Agreed a policy that there is an expectation that all EGC commissioned research will result in a public document, except in exceptional circumstances.
  - Re-iterated the importance of continuing to manage the process by which the work is prepared for publication, including providing feedback to the authors on the development of the final report.
4. At its last meeting the Council proposed that UK Biobank should develop a paper on the legal and ethical implications of its enhancement proposal on the project's feedback policy. The Chair is in the process of commenting on a first draft of a paper from UK Biobank which will be brought to the full Council in due course.
5. The Council reviewed UK Biobank's paper reporting the % of participants who chose the 'prefer not to answer' or 'do not know' options when completing the assessment centre touch-screen and interviewer questionnaires. This information had been requested in order for the Council to ascertain whether certain questions were being routinely omitted by participants, possibly indicating that the question is either too ambiguous or difficult to answer or too intrusive. The Council learnt that a very small proportion of people decline to answer questions and no single question had a particularly high 'non response' rate.
6. The EGC communications sub-group will consider the question of the location and number of Science Festivals that the EGC should seek to have a presence at in 2009. [EGC communications sub-group]
7. The Secretary has developed a paper outlining the EGC's work since its creation in November 2004 as part of the EGC's review by the Funders. Members discussed the paper and suggested amendments to be included in the final report. [AH]
8. It was agreed that EGC members who choose to accept an invitation to participate in UK Biobank do so in their own individual capacity and that any

feedback provided to UK Biobank is given in their individual capacity and not as a representative of the EGC.

9. It was agreed that members' titles should be removed from future meeting name plates.
10. In light of his resignation, the Chair thanked Professor Chris Wild on behalf of the Council for his work and dedication to the EGC over the last four years and gave the Council's best wishes for his new position in Lyon, France.

### **Recommendations and requests to UK Biobank**

#### **11. *UK Biobank's access and intellectual property (AIP) policy and procedures***

- The Council agreed to request further clarification regarding what will be made public (draft headings of procedures, draft procedures?) and when.
- The Council agreed to compile a list of specific questions that it recommends UK Biobank could usefully seek to answer during the next stage of development of its AIP procedures. For example, How will the Access Committee (AC) be constituted? What will be the remit of the AC? What will be the basis for the AC's decisions? How will UK Biobank define 'health-related research' in the access decision making process? [AH]
- The National Cancer Research Institute's consultation on the development of a standard 'template' which could be used to guide the development of access policies for cancer sample collections and datasets will be distributed to members of the EGC and to Jonathan Sellors, UK Biobank's Company Secretary, for information. [AH]

#### **12. *UK Biobank's proposals for longitudinal follow up of participants***

The Council reviewed a paper prepared by UK Biobank which outlined the project's plan to undertake three exemplar follow up pilots for around 10 000 participants from each country, Scotland, Wales and England.

- The Council discussed the breadth of records that could potentially be included under the broad description of 'health-related' and agreed that the onus should be on UK Biobank to justify why a particular record is 'health-related' and how use of the information by researchers might fit the purpose of the resource. The Council recommended that UK Biobank be prepared to justify access to and use of all records in such terms.
- Professor Collins confirmed that UK Biobank will publish a list of 'health-related' record systems which it uses as part of the project's strategy for longitudinal follow up of participants. The Council recommended that this list should also include those systems from which UK Biobank has been denied access.
- The Council agreed that it will need to be kept fully informed about which 'health-related' records UK Biobank proposes to access in order to fulfil its monitoring and advisory role.<sup>1</sup>

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<sup>1</sup> Subsequent to the meeting the Chair and Secretary agreed to request at least biannual updates on this subject from UK Biobank, for example at the Council's September and March meetings.

### 13. *UK Biobank's post-visit participant questionnaire*

UK Biobank has recently undertaken a revised version of the post-visit survey that was initially conducted during its pilot phase. The survey aimed to explore participants' opinions on the assessment centre visit, the information leaflet and consent process and to test their understandings of the elements of their consent. The Council reviewed the interim results of this survey. Professor Collins indicated that UK Biobank does not intend to repeat the current post-visit survey on a wider set of participants but instead intends to focus on other aspects, including participants' understandings and expectations regarding the project. This could be achieved through a more detailed, systematic survey.

- The Council recommended that UK Biobank pursues its proposal to conduct a further post-visit survey to investigate in more detail the participants' assessment experience, their understandings and expectations of future involvement with the project and the reasons they hold these understandings and expectations. The Council agreed to provide UK Biobank with a list of specific questions that it might address in such a survey and also agreed to provide a recommendation on the type of research methodology that might be used. [AH]
- The Council suggested that UK Biobank gives further consideration to the possibility of forming a participant panel as envisaged in the EGF (akin to the Human Genetics Commission's consultative panel).