

**Report: Public meeting of the UK Biobank Ethics and Governance Council  
1st July 2007  
The Hub, Edinburgh**

The independent Chair of the meeting, Professor Sarah Cunningham-Burley (Professor of Medical and Family Sociology, Edinburgh University) opened the session by welcoming everyone. She explained that the meeting was organised by the UK Biobank Ethics and Governance Council (EGC), a monitoring and advisory body, independent of UK Biobank. The EGC is charged to advise UK Biobank on the interests of research participants and the general public in relation to the project. The Council hosts regular public meetings as one method of informing itself of these interests.

UK Biobank began recruitment in April 2007 with its first assessment centre opening in Manchester. Since then recruitment centres have operated in several cities including Oxford, Glasgow, Edinburgh, Cardiff and Bury. New centres will be opening this year in Bristol, Nottingham and London. To date approximately 140 000 people have agreed to participate in the project – at least 35 000 of which were recruited through the Scottish assessment centres. The Council held a public meeting in Edinburgh because recruitment to UK Biobank was currently occurring in the city and because the Council is committed to engaging with the public around the United Kingdom, this being its first visit to Scotland.

The purpose of the meeting was:

- To raise awareness and encourage debate among attendees about biobanking broadly, and more specifically regarding UK Biobank and the role of the EGC.
- To invite comments and questions in relation to the ethics and governance aspects of UK Biobank. These comments and questions will be used to inform the EGC's advice to UK Biobank.

The format of the meeting involved three presentations<sup>1</sup> followed by a Question and Answer session and a drinks reception. The presentations addressed the following subjects:

- An introduction to biobanking (Anneke Lucassen, EGC member and Professor of Clinical Genetics at the University of Southampton);
- An overview of the EGC and its work (Graeme Laurie, EGC Chair and Professor of Medical Jurisprudence at the University of Edinburgh);
- Background and progress regarding the UK Biobank project (Rory Collins, Chief Executive Officer and Principal Investigator of UK Biobank and Professor of Medicine and Epidemiology at the University of Oxford).

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<sup>1</sup> The presentations were broadly similar to previous public meetings and so have not been reported here. Please refer to the December 2007 public meeting report for a description of the presentations (available at: [www.egcukbiobank.org.uk/meetingsandreports](http://www.egcukbiobank.org.uk/meetingsandreports))

## Question and answer session

**Q1 Can you provide some information about the specific uses of the data and the types of diseases that will be researched. Was UK Biobank designed to answer certain scientific questions?**

A1 (RC) UK Biobank is being established as a resource of information and samples for use by researchers. UK Biobank will not conduct research itself on the data and samples it holds. Use by researchers will change over time but, as an example, you can imagine that in 2015 10 000 people in the cohort will have had a heart attack. These people can be compared to 10 000 people who have not had a heart attack but are matched in terms of their age and sex. By comparing these two sets of people researchers can investigate why some people develop the disease while others do not. For example, in the last year, the Wellcome Trust Case Control Consortium compared a few thousand people who had had heart attacks and a similar numbers of people who had not. They identified an area of DNA where a specific variant leads to higher rates of heart attack. Now researchers around the world are trying to find out why this variant leads to disease.

The content of the touch-screen questionnaire was chosen to address a varied number of diseases. The collection of DNA is relevant to the study of many diseases in the future.

**Q2 I understand that participants are not expected to benefit from their participation in UK Biobank but can you confirm whether or not baseline measurements are fed back to an individual's general practitioner (GP)?**

A2 (RC) Participants receive feedback on a number of measurements made during their assessment centre visit (including blood pressure, body mass index, height, weight and lung function). These measures are reported against population standard ranges to give the individual an indication of whether or not they fall outside of the normal range. If an abnormal measurement is found individuals are advised to visit their GP, but results are not fed-back to an individual's GP directly.

(AL) If a researcher finds something of huge significance for an individual this raises difficult questions about whether to provide that individual with feedback when they have previously been told that they would not receive individualised feedback. This needs careful deliberation on a case by case basis. However, it is unlikely that UK Biobank will find something that has clinical relevance for an individual.

(GL) When the Council was first established it had in-depth discussions on the question of feedback. It is important to note that UK Biobank does not perform assays at baseline, except for some haematology assays, and that where data and samples are provided to researchers these will be in an anonymised form for greater privacy.

UK Biobank aims to provide a resource of data and sample for research that will benefit future generations, rather than benefit individual participants. We need to be clear about this expectation and not to blur the distinction between

a research setting (in which generalisable knowledge is created) and a clinical setting (in which information of significance to an individual is created in the hope of benefiting them directly).

**Q3 You mention that UK Biobank will link to “other health-relevant records”. Which records might this include?**

A3 (RC) There are two ways to think about these linkages: First, information on health outcomes may be accessible through linkages, in particular, with primary care records. Second, information on exposures may be available by linking information about where people live to information about whether there are, for example, radio masts nearby or other environmental aspects. It might also be useful to link into other personal information, for example databases that describe a participant’s past occupation. Previous research has shown that certain occupations are associated with the development of certain diseases, for example, the occupation of carpentry has been linked to cancer of the lining of the lung.

**Q4 These linkages present interesting possibilities but raise privacy consideration.**

A4 (AL) It is important to note that, just because a link is possible it does not mean it will automatically happen. Database controllers may not allow linkages to their data (for many reasons including privacy issues).

(GL) The issue of linkages and how UK Biobank intends to follow-up participants was raised this morning in a meeting I had with the Vice Chair and Secretary of the Council. We agreed to ask UK Biobank to report to the next Council meeting on the records it hopes to access. At this meeting we might ask what privacy risk, if any, is associated with the new linkages? It is possible that the Council may advise UK Biobank that a privacy impact assessment should be carried out, that is, that UK Biobank carry out an exercise to determine the privacy implications for participants and others of making certain kinds of linkage to certain kinds of records.

It is also important to note that UK Biobank is subject to a broader regulatory framework, including being monitored by other bodies, and it must comply fully with privacy protection laws, such as the Data Protection Act.

**Q5 Quantum computing could render many computer security and encryption systems obsolete. How robust are UK Biobank’s data security protocols going to be?**

**Q6 How will you store data without it becoming corrupted over 15 years or more?**

A 5&6 (RC) UK Biobank reviews its IT security on an ongoing basis. We have been working with commercial companies to ensure that our systems are robust and are in conformance with international standards. For example, the project’s systems were recently subject to penetration testing by an external third party which was looking for weaknesses. The third party was unable to break into the systems but did make recommendation to further enhance security.

A range of data are held by UK Biobank including some that are not very sensitive and some that are very sensitive. There are accordingly different levels of confidentiality afforded to the data in the system and many corresponding identifiers used for these many levels. This makes it very difficult to trace data back to an individual.

We should bear in mind that participants are free to withdraw at any time. It is in UK Biobank's interest to have a system that means participants will not want to withdraw. Therefore UK Biobank must keep the systems robust.

(GL) An advert will be posted in the national press later this year announcing three vacancies on the Council. Recognising the importance of this field we are seeking applications from individuals with an expertise in data security to ensure that the Council is fully apprised of the issues and challenges associated with protecting privacy in the context of UK Biobank.

**Q7 There is a wealth of information that can be collected legitimately in terms of the Data Protection Act, for example Tesco Club Card data. Would UK Biobank purchase this kind of data?**

A7 (RC) We have looked at what information we might get from other sources, for example, Tesco Club Cards, but UK Biobank gets its information from participants themselves through their answers to the touch-screen questionnaire. There is nothing out there at present that UK Biobank would want to use.

(AL) There may be different sensitivities surrounding different sets of data, so having one rule for all types of data will not work. For example, an individual may feel differently about their Tesco Club Card details being used rather than information about the number of children they have; one is seen as more personal than the other. We need to keep in mind what records are being accessed and how sensitive these records are.

(GL) The Council would want to consider the privacy impact of UK Biobank's policy on linkage. The EGC has a subgroup which considers issues around access and intellectual property. The subgroup has recommended that if a UK Biobank policy has a knock-on effect in relation to participant privacy the Council should be consulted as an additional safeguard.

**Q8 Will there be any differences in the way a participant's data will be used once they have passed away?**

A8 (AL) The law does distinguish between access to data of living and deceased individuals, for example the Data Protection Act does not cover access to the records of deceased individuals. However, in the research setting such access is determined by research governance and ethical review processes. In the context of UK Biobank, it makes little difference to the project if a participant dies, the same protections are afforded to participants when they are alive and after their death.

**Q9 The assessment centre touch-screen questionnaire asks if members of a participant's family have suffered from 'severe depression'. Unsure**

**how to answer this, I asked UK Biobank employees what the phrase 'severe depression' means (e.g. diagnosis, hospitalisation etc). They were unable to provide me with a clarification and instead said it was my perception of the disease. Is more clarification needed to help people answer this question?**

A9 (RC) By asking this question we aim to ascertain which participants have a family history of the disease. It is a difficult question to be specific about and is not as simple as ascertaining whether there is a family history of certain other diseases, for example 'severe heart disease' would be indicated by a heart attack. We are very much asking about an individual's own perception of the condition.

**Q10 Regarding linkage, it is likely that some commercial organisations or the government will not want you to link to certain types of data e.g. making correlations between health and exposure to electromagnetic radiation. Are there any safeguards to check that the project is using a wide range of data and that the use is not biased? How will the Council regulate information not being hidden because it does not suit a wider purpose?**

A10 (RC) UK Biobank is trying to build a resource for anyone to use, providing their research has been scientifically and ethically reviewed, fits the purpose of UK Biobank and the consent of participants. The more the resource is used the more successful it is. The more we can link to, for example, environmental exposures the more we will. Alternatively, we may work with researchers that have a specific idea about how to incorporate environmental data into UK Biobank. Also, one important tenet of UK Biobank's access policy is that all data resulting from use of the resource should be returned to UK Biobank so it can be made available to other researchers.

(GL) UK Biobank is subject to research ethics regulation which should catch this kind of mechanism. The EGC will monitor the reasons given for allowing, or not allowing, access to the resource. We should note that the research results that are fed back into the resource will include those with negative findings.

(AL) It may happen that UK Biobank is unable to access some databases in the future if the information they contain is deemed by the database holder/owner to be too sensitive (including the example you cite of the government). UK Biobank cannot claim to be getting access to all data. Where there are obstacles, public engagement activities, such as this evening, may be able to help by highlighting the issues in a public forum and in so doing putting pressure on database holders to take certain action (for example in this case to release the data).

**Q11 Where are the blood samples stored?**

A11 (RC) The samples from each participant are halved and each half stored in 2 separate geographical locations. The back-up set is stored in liquid nitrogen at -200 degrees C. The second set is stored in an automated storage facility that has been specifically designed for the project. The facility is cooled by liquid nitrogen and maintains a temperature of -80 degrees C. Within this facility is a

picking robot running at -20 degree C, the use of which means that each sample can be tracked accurately and accessed rapidly.

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Professor Sarah Cunningham-Burley concluded the session by thanking the participants for attending and by inviting everyone to continue the discussion over a post meeting drink.

Further questions were raised by attendees during the drinks reception both with speakers and other members of the Council. Questions were also raised on the meeting feedback forms, including the topics listed below.

- Data security and confidentiality of data and samples.
- The terms under which researchers will be permitted access to UK Biobank, including the questions:
  - Will researchers have to pay a fee to access data and sample?
  - Will researchers who use UK Biobank be able to commercialise the results of their research?
  - Will researcher be obliged to publish their findings?
- The possible uses of the data and samples held by UK Biobank, including the questions:
  - Are early cross-sectional studies envisaged?
  - Will researcher be able to create cloned human or animal-human embryos for research purposes?
  - Will the police be able to access UK Biobank?
- UK Biobank's policy on providing feedback of health information to participants.
- UK Biobank's recruitment strategy: Is the project successfully recruiting individuals from a range of socio-economic groups?
- How many people have withdrawn from participation?