

## **UK Biobank Ethics and Governance Council: Communications strategy**

The UK Biobank Ethics and Governance Council's (EGC) Communications strategy has undergone a number of revisions since its initial development in 2007. This paper reports on the revision that took place in November 2010 in response to the outcomes of an independent review of the Council's activities. The EGC communications subgroup undertook the revisions and its reasoning is given below.

### **1. The EGC Communications strategy**

#### **1.1. Aims**

The aims of the communications strategy are to:

- inspire trust and confidence;
- inform and shape the EGC's decision-making;
- promote good practice (in relation to good ethics and governance);
- shape public debate.

The first two aims are of equal, high priority, while the following two are of a lesser priority. The previous strategy placed a greater emphasis on shaping public debate, however, the subgroup decided that this aim should no longer be a priority as the Council's work may inform public debate but it does not actively seek to shape it.

The above aims will be achieved in part by the EGC providing information to, and gathering information from, its key audiences. Information gathering may serve two particular functions: to inform the EGC regarding issues related to UK Biobank and the Ethics and Governance Framework (e.g. feedback policies, access policies etc.) or to inform the EGC about its own operations (e.g. by comparing operational aspects with other, similar committees).

It will be important to maintain clarity about UK Biobank and the EGC's roles and responsibilities with respect to communications about the project. As the Ethics and Governance Framework states 'The Council will not speak "on behalf of" UK Biobank, as this will be the responsibility of the Board; instead it will speak "about" UK Biobank.'

#### **1.2. Audiences**

The key audiences of the communications strategy are (in order of priority for the EGC):

- the participants of UK Biobank;
- other biobanks and biobank initiatives;
- interested parties and the EGC's peer group (including researchers, charities, other advisory committees);
- the broader public.

The EGC is charged to advise on the interests of research participants and the general public in relation to UK Biobank. Such interests may be ascertained through queries to the EGC website, via feedback at its public meetings or through its

commissioned work. The EGC welcomes this input while recognising that it is not an advocate for individual participants or members of the public but instead works to safeguard the collective interest for the common good.

The subgroup recognised that opportunities for providing information to the broader public may be limited. As such, it might be useful to work through intermediary agencies (e.g. charities, patient groups etc). In any event, the responsibility for communicating with the broader public (for example in relation to access to the resource) was felt to fall more to UK Biobank than to the EGC. The 2010 Review supports the view that the broader public should no longer be a key audience for the EGC (e.g. in relation to holding public meetings). However, the EGC should keep the provision for communicating with, and drawing on, public opinion as and when required.

The 2010 Review identified other biobanks and biobank initiatives as a new key audience for the EGC's Communication strategy.

The Council is charged to advise on the interests of the public and this can be considered to include the interests of researchers. Recognising that the Council has not to date communicated with researchers, the subgroup discussed the possible purpose of such communications. The responsibility for communicating with researchers was considered to fall to UK Biobank, including the articulation of the 'access timetable' and the content of the resource to both the national and international scientific community.

The EGC's role in relation to communicating with researchers was seen to involve the broad issues regarding the fairness and equitable nature of the access process. For example, if a researcher put forward a case that UK Biobank is allowing access for the study of certain diseases (e.g. cardiovascular) at the expense of other diseases, this question might be considered by the EGC. However, if a researcher has a grievance because their particular application was rejected, this would be processed through UK Biobank's internal complaints procedure.

## **2. Outcomes of the EGC Review 2010**

The EGC Review Panel made the following Communications-related recommendations:

- The role of the EGC in public and participant engagement activities should be clarified in relation to the expectations of the funders. Specifically, it was agreed that the EGC did not need to place as much emphasis on public engagement in future.
- The EGC might like to consider setting up a standing panel of participants to help gauge view on, for example, the proposed enhancements.
- The EGC to develop a policy on how to handle evidence or opinions from the public.
- A crisis management plan identifying responsibilities for resolution of controversial issues should be developed jointly with UK Biobank.
- The funders should consider how best to enable the experience of EGC to be shared with other cohort initiatives.

- The EGC to establish links with other advisory groups on an international level.

The EGC communications subgroup agreed the following in relation to the recommendations:

- The responsibility to establish a participant panel rests with UK Biobank, rather than with the EGC. The Ethics and Governance Framework states that UK Biobank may establish a participant panel, and this idea is mentioned more recently in the project's 2010 – 2015 application for renewed funding (in relation to virtual panels). The Council should play an active part in encouraging UK Biobank to develop its participant involvement strategy.
- The Secretary will draft an EGC policy on how to handle evidence or opinions from the public and will work with UK Biobank to develop a crisis management plan.
- The Secretary has recently joined a biobank discussion group which aims to become a chapter of the International Society for Biological and Environmental Repositories. Other similar initiatives will be sought as a way of sharing the EGC's experience with other biobanks.
- Several of the review panel's recommendations will require further consideration from the EGC once the funders have clarified and communicated their thinking (e.g. in terms of their expectation of the role of the EGC with regard to engaging with participants and the public; how best the experience and advice of the EGC should be shared with other cohort initiatives and how the EGC should go about commissioning research in the future).

### 3. EGC Communications in 2011

The subgroup recommended that the following communications aspects should be continued in 2011:

- **EGC website**
- **EGC Annual Review.** Hard copies should be available in the enhancement and/or re-assessment centres (if UK Biobank's proposal is funded).
- **EGC leaflet**
- **Provision for a public meeting,** although there is no presumption that the EGC will continue with its fixed series of annual public meetings. Instead the need for a public meeting will be considered as and when issues arise. Rather than gathering public and participant opinions through its public meetings the Council will instead keep alert to the issues being raised by participants and the public with UK Biobank (for example through reporting in the biannual enquiries and complaints report). Also, the Council will horizon-scan for potential issues by keeping abreast of the research ethics literature.
- **Provision for a consultation on UK Biobank's Access and IP procedures,** depending on the nature and outcomes of UK Biobank's own consultation.
- **Attending and/or presenting at meetings and conferences.**
- **The option to write and publish papers** that draw together the Council's discussions e.g. the paper on incidental findings and feedback for MRI.

- For the **EGC to keep alert to the various elements of UK Biobank's communications strategy** and to seek to be represented as appropriate.

UK Biobank has outlined its plans to re-contact a significant proportion of the cohort over the next few years (e.g. for the MRI enhancement, to fill-in a diet questionnaire, to repeat the baseline assessment etc). The subgroup was of the opinion that such re-contact reflects the ongoing immediateness required of the EGC's communications. That is, if UK Biobank was simply following participants' health through their medical and health-related records, and not actively re-contacting them with requests for further information, it might have been reasonable for the EGC to revise its communications activities. However, given that UK Biobank plans to actively re-contact participants over the years ahead it will be important for the EGC to have a continuing communications presence so that participants remain aware of the EGC and its activities.

#### **Annex A    The communications strategy table (4 November 2010)**

Why (aims)?	To whom?	How?									Comments from the subgroup on 'Why (aims)?'
		Website	Annual report and other publications	Conferences, workshops, one-to-one meetings etc	UK Biobank communications (e.g. website, newsletter)	Crisis management plan	Consultations	Public event	Participant Representation on EGC	Participant Panel	
<b>Trust</b>	Participants	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	This aim was considered a priority and overarching aim of the communications strategy and Council's work.
	Public	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
	Interested parties	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
<b>Inform and shape the EGC's decision-making</b>	Participants	Yes <sup>1</sup>	No	Yes	Yes	Possible (see below)	Yes	Yes	Yes	Yes	This aim was considered as a functional necessity required for the EGC to successfully fulfil its remit.
	Public	Yes	No	Yes	Yes	Possible (see below)	Yes	Yes	N/A	N/A	
	Interested parties	Yes	No	Yes	Yes	Possible (see below)	Yes	Yes	N/A	N/A	
<b>Promoting best practice (in relation to good ethics and governance)</b>	Interested parties	Yes	Yes	Yes	Yes	No (may be an example of, but does not promote, best practice)	No (may inform but does not directly promote best practice)	Yes	No (may be an example of, but does not directly promote best practice)	No (may be an example of, but does not directly promote best practice)	This aim was not considered to be essential but would be a useful role for the Council to engage with.
<b>Comment from the subgroup on 'To whom?' and 'How?'</b>	Order of priority: first participants; second, interested parties (e.g. biobank users, other biobankers, bioethics communities etc.); third, the public.	A good method for providing information (although limited if some people have no internet access).	A good method for providing information. Also informs parties about best practice. Includes leaflets, academic papers etc.	A good method for achieving all aims.	A good method for raising awareness of the EGC through UK Biobank's communications initiatives and drawing notice to the EGC's own website etc.	This method should engender trust by providing a transparent and efficient plan through which crisis is handled. Depending on its nature, a crisis may inform and shape the EGC's decision-making.	A good method for addressing an issue directly. e.g. via deliberative research or by posting consultations on the EGC website. However, there is a question over the EGC commissioning research in light of the 2010 Review.	A good method for achieving all aims. However, a regular schedule of meetings is not a priority in light of the 2010 Review.	The Council would hope that some of its members are participants of UK Biobank but this is not a requirement for appointment to the EGC.	UK Biobank has indicated that it will create a virtual panel acting via the project's website. The subgroup considers it appropriate that such a panel is the responsibility of UK Biobank and not the EGC.	

<sup>1</sup> For the given communications method this aim is a secondary spin-off to the other listed aims. For example, the primary aims of the website are to promote trust and best practice but, given that the EGC receives a number of enquiries and comments through the website, the aim of informing the EGC is also met.