

UK Biobank Ethics and Governance Council

Terms of Reference

The UK Biobank Ethics and Governance Council (EGC) is an independent committee established by the Medical Research Council and the Wellcome Trust.

Remit

- To act as an independent guardian of the UK Biobank Ethics and Governance Framework (EGF) and advise on its revision;
- To monitor and report publicly on the conformity of the UK Biobank project (“UK Biobank”) with the EGF;
- To advise more generally on the interests of research participants and the general public in relation to UK Biobank.

Functions

1. To keep the creation, maintenance and use of the resource under review in order to advise and report publicly on the conformity of UK Biobank’s activities with the EGF;
2. To consider and advise on revisions to the EGF that may be required to respond to changes in the legislative or regulatory context, developments in ethics or advances in science or technology;
3. To advise on UK Biobank policies that relate to or flow from the EGF (such as those on recruitment, access, or complaints handling);
4. To keep under review applications for access to the resource with regard to the interests of research participants and in accordance with the Intellectual Property and Access Policy;
5. To approve any transfer of the resource (or substantial parts of it) to a third party, for example, in the event of a liquidation, as set out in the Memorandum and Articles of Association of UK Biobank Limited.

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Appointment and composition

Appointments will be made by the Medical Research Council and the Wellcome Trust (“the Funders”) according to a process in keeping with the Nolan Principles of Public Life and taking into account the views of the EGC Chair where appropriate.

A broad range of experience and expertise will be sought across the membership. This may include the following: bioethics, philosophy, law, biomedical science, medical research, social science, health care, public health, public involvement, corporate social responsibility and public policy. The Council may, in due course, choose to include up to two UK Biobank participants in its membership.

Terms of Membership

Members participate in their personal capacity and work collectively to achieve Council goals rather than act as representatives of any group or interest. Initial appointments are for 2 – 4 years with a possible further three-year term.

Chair: The Chair has particular responsibility for the calling, agenda and conduct of EGC meetings, the accuracy of record keeping, and liaison with the Secretariat. The Chair is responsible for the management of EGC activity within the budget agreed with the Funders. The Chair also has responsibility for representing the Council in communications with UK Biobank, the Funders, research participants, the public, the media and external bodies. The Chair may delegate aspects of these functions to other Members or the Secretariat as he or she considers appropriate.

A time commitment of no more than 2.5 days per month is anticipated. The Chair will receive remuneration of £7000 per annum in light of these duties.

Members: There will be between 9 and 11 members, including the Chair. In addition to attending Council meetings, Members can be called upon from time to time to represent the Council in communications with UK Biobank, the Funders, research participants, the public, the media and external bodies. A time commitment of no more than 1 day per month is anticipated. Members’ expenses will be payable as set out in the EGC Expenses Policy. In addition, a meeting attendance allowance (currently £200 per diem) will be payable to all Members other than the Chair.

Declaration of interests and management of conflicts

All Members of the Council are required to declare any relevant personal or business interests on an ongoing basis in accordance with the EGC Conflicts Policy. A register

of discloseable interests is maintained, a summary of which will be made available to the public on demand and may in due course be published on the internet. The proceedings of the Council are subject to the Conflicts Policy.

Meetings

The Council will meet approximately four times a year. The Chair has particular responsibility for the calling, agenda and conduct of EGC meetings and the accuracy of record keeping, working with the support of the Secretariat. Meetings are called by the Chair on a minimum of 28 calendar days notice; they are minuted and, once approved, reports of the proceedings are published. No business will be conducted at a meeting of the Council unless a majority of the Members are present. Decisions of the Council will be made by simple majority of those present in a meeting or, outside of meetings, by consensus.

If the Council chooses to meet in public, it will retain the right to reserve matters for consideration in closed session as it sees fit. It will also publish procedures relating to such meetings (such as notice requirements). The Council may invite observers to attend all or part of its meetings.

Relationships

The Council will advise and provide information to UK Biobank Limited, the Funders or other bodies, as it thinks appropriate or as called upon to do so by the Funders.

In order to advise UK Biobank on operating in accordance with the interests of participants and the public, the Council will develop appropriate ways of engaging with participants and the public.

Secretariat

The Secretariat to the Council is provided by arrangement with the Funders. At the current time, the Secretariat is being provided by the Wellcome Trust. The Secretariat provides executive and administrative support to the Council and its Chair, services regular Council meetings and procures consultancy and other services and goods within the EGC budget as required. The Secretariat maintains records of the Council's expenditure against budget with supporting evidence.

Secretary

The Council Secretary supports the meetings of the Council, in particular by supporting the Chair in carrying out his/her responsibility for calling and conducting

EGC meetings and setting meeting agendas, record keeping in relation to meetings, managing the EGC budget and representing the EGC in communications with other bodies.

Accountability

As a committee established by the MRC and the Wellcome Trust, the Council is accountable to the Funders for acting within its remit, carrying out its functions and acting in accordance with these modus operandi. The Council may be required by the Funders to provide information to demonstrate this.

Confidentiality

All Members have a duty of confidence in relation to information to which they have access by virtue of being Members of the Council. They are only entitled to disclose such information in the proper performance of their duties as Members of the Council.

Funding

The activities of the Council are funded by the Wellcome Trust and the MRC. Financial commitments and expenditure by the Council must fall within the Council's budget and be approved by the Chair of the Council (or, with delegated authority, a Member or the Secretary) in accordance with the EGC's financial procedures.

Reporting

The Council reports publicly as it sees fit. This is likely to include the publication of an annual report on the conformance of UK Biobank with the EGF, and on the Council's activities in general.