

## Access to the UK Biobank resource: open, transparent, fair

UK Biobank was established as a resource to allow scientists to carry out research into a wide range of diseases. The resource is available for researchers to use without preferential or exclusive access and all researchers, academic and commercial, are subject to the same application criteria, approval procedures and follow-up process. This short note sets out the steps that UK Biobank takes to ensure that the end-to-end access process is open, transparent and fair.

### 1. Registration and application

1.1 UK Biobank's registration process, which is run by UK Biobank's Access Team, confirms the bona fides of scientists wishing to use the resource. It checks that the researcher is indeed who they say they are, that they are indeed affiliated to the institution they name and that they have a credible history of academic publication (allowances are made for student applications in this regard);

1.2 Each application is reviewed by UK Biobank Scientific Team who confirm that the proposed research is indeed health-related and in the public interest. Each application is also reviewed from an ethical perspective by Ethox <https://www.ethox.ox.ac.uk/> and made visible to UK Biobank's Access Sub-Committee <http://www.ukbiobank.ac.uk/access-to-the-resource/>, the body ultimately responsible for the access process.

1.3 UK Biobank's independent Ethics and Governance Committee <https://egcukbiobank.org.uk/> also monitors the access process on a periodic basis.

### 2. The MTA

2.1 Every researcher has to enter into an MTA <http://www.ukbiobank.ac.uk/wp-content/uploads/2012/09/Material-Transfer-Agreement.pdf> with UK Biobank, the terms of which are essentially identical for each and every researcher;

2.2 This legally binding document sets out a series of obligations incumbent on the researcher, such as using the UK Biobank data for the approved purpose, paying the access fees, keeping the data secure, returning their findings to UK Biobank and not trying to re-identify any participants.

### 3. Follow-up during research

3.1 The Access Team then keep abreast of the research by reviewing the annual report that the researcher is obliged to submit.

3.2 As and when the research is coming to completion, the Access Team are in touch with the researcher to:

3.2.1 Ensure that the key results are returned or made available to UK Biobank; and

3.2.2 The findings of the researcher are published in a peer-reviewed journal, which publication UK Biobank can then link to the relevant application, or are made publicly available in some other way (e.g. by posting them on the internet or providing them for UK Biobank to put on its website);

4. **Enforcement**

4.1 UK Biobank has a number of legal remedies available if it transpires that researcher transgress, including inspections, fines and preventing the researcher from ever using the resource again.

4.2 However, UK Biobank considers that such legalistic steps should only be needed in very limited circumstances as in other areas the process is to a large extent self-policing as:

4.2.1 It is clearly in the researcher's interest to play by the rules. If they don't, this will become apparent to their colleagues, institutions and funders;

4.2.2 It is almost always in the researcher's interest to publish their findings or make them publicly available in some other way, as that is how research is assessed;

4.2.3 It is not in the researcher's interest to hide or fail to disclose key findings as this could well have the effect of invalidating any intellectual property findings that the researcher may wish to make.