

FAQs on accessing UK Biobank data

This document contains answers to FAQs from researchers about the registration and application process.

Examples of the type of most frequently asked questions include:

Registrations:

- I have not received an automatic email – what do I do?
- When I log in I get an ‘Already logged in’ error – what do I do?
- What do I do if I am affiliated with more than one institute?

Applications:

- How much does it cost to access UK Biobank Resource?
- Who do I need to name as a collaborator?
- I am changing institute – do you need to know?
- How long will it take to receive data/samples?
- The Applicant PI needs to change – what do we do?
- Can I expand the scope of the approved research project?

Please read our [UK Biobank Access Policy and Procedures](#) before registering via the UK Biobank [Access Management System](#) (AMS).

For assistance please email access@ukbiobank.ac.uk or telephone 0800-0276-276 (8am and 7pm Monday to Saturday).

Registration

- **I have not received an automatic email – what do I do?**
Please check your ‘junk/spam’ email folders before contacting the [Access Team](#).
- **When I log in I get an ‘Already logged in’ error – what do I do?**
This usually happens when your cache and browsing history holds a record of an earlier login. Try clearing your cache and browsing history then log in again.
- **What do I do if I am affiliated with more than one institute?**
Please create a separate registration for each institution with your work email address for each institute.
- **Who can register for access to the UK Biobank Resource?**
The Resource is available to all bona fide researchers for all types of health-related research which is in the public interest.
- **What is the cost of Registration?**
There is no cost to register.
- **I am trying to register but the system will not let me progress. What should I do?**
If the following mandatory fields have been completed please contact the Access Team for assistance: - Institute Name, Department, 1st address line, postcode, web address and confirmation statement.
- **Can I register on behalf of someone else?**
No. The Email address used to register must be your individual business Email address (not a group or non-business Email address).
- **I have attached the wrong document (e.g. CV) to my Registration. Can I remove it?**
No. If you attach a document in error please Email the [Access Team](#) who will be happy to remove/replace it.
- **I have submitted my Registration. What happens next?**
Registrations are considered within 10 working days of submission, which may be prolonged if extra information is required. Once approved, you will receive an automatic Email.
- **Can I withdraw my Registration?**
Yes. Please email the [Access Team](#) so your registration can be archived.
- **My account is locked, what do I do?**
Follow the process for “What happens if I forget my password?” below.
- **What happens if I forget my password?**
Click the ‘Forgotten Password’ link on the [AMS Sign In Page](#) on the right hand side below ‘Password’. The system will unlock your account, generate a new password and send an automatic Email (check your spam folder if it does not appear).
- **Can I change my password?**
Yes. Use the ‘User Settings’ tab after logging into [AMS](#).
- **Can I print a copy of my Registration?**
This function is not currently available.
- **My Registration was declined. Do I have the right to appeal?**
You can request reconsideration of the decision within 30 days of your Registration being declined. Appeals will be adjudicated within 4-6 weeks of receipt.
- **My Registration was declined. Can I re-apply using the same Email address?**
No. You cannot submit another Registration using the same Email address.

- **Do I need to re-register if I change email address and/or move to a different Institute?**
Yes. You cannot change your registered Email address. Please email the [Access Team](#) to confirm that you are moving Institute, so your previous registration can be archived.
- **My institutes address has changed - how do I update my contact details?**
Contact details (except your email address) can be updated in the 'User Settings' tab on your [AMS Home Page](#). Your Email address has been set as your user name. If you have changed Institute you will be required to re-register using your new Institute Email address.

Applications

- **Will UK Biobank respond to questions regarding the Resource before submission of an application?**
UK Biobank is happy to respond to any general questions that you may have, although in the majority of cases an application is required to answer complex queries.
- **Am I required to collaborate with UK Biobank in order to access the Resource?**
No.
- **Do I need to be based in the UK to access the Resource?**
No. The Resource is available to all bona fide researchers regardless of their location.
- **Can I apply on behalf of another researcher?**
No. Researchers need to apply on their own behalf. If you apply you automatically become the Applicant PI and are required to sign the Material Transfer Agreement (MTA).
- **Who do I need to include as a collaborator?**
You need to list registered researchers who will have direct access to the UK Biobank data (quoting their registered Email). Researchers who are involved in the project (e.g., as coauthors on publications) but who are not handling the data, do not need to be named.
- **Can I remove collaborators from my Application?**
Yes. Please Email the [Access Team](#) quoting your Application ID number.
- **Why can my collaborator not see the application invite on their AMS Home Page?**
Collaborator invites are not visible until an application is submitted. The invitation will not be visible if a) the collaborator email address is not the one used to register, or b) until their registration is approved.
- **I am changing institute – do you need to know?**
Yes. Please email the [Access Team](#) to confirm that you are moving Institute with the date you intend to move. The Team will advise you how to proceed.
- **Can I transfer my Application to a new Applicant Principal Investigator (PI)?**
Yes. A request to transfer Applicant PI should be made in writing to the Access Team. The proposed new Applicant PI must be successfully registered with UK Biobank and a new MTA needs to be executed before the transfer takes place.
- **What information is required to submit an Application?**
The Application process is currently in two stages: Preliminary and Main. The information required for each stage is as follows:-
 - **Preliminary Application** -
 - A brief lay summary of the proposed research project indicating how it meets UK Biobank's stated purpose (i.e. health-related research in the public interest)
 - Methodology and timetable.
 - Up to 6 keywords to describe the proposed research project
 - Names and institute Email addresses of all collaborators.

- Main Application -
 - Lay summary (updated, if necessary, from the preliminary application)
 - Scientific rationale of the project (background of any pilot data, experimental details and design, power calculations, expected values of results and relevant references)
 - Feasibility
 - Security protocols for the storage of data and/or samples
 - Details of funding, if applicable
 - Required data and/or quantity and type of samples, and any need for re-contact, with a brief justification
 - The timeframe for the project
 - Details of any peer review of the proposed research project, if applicable
 - Other supporting documents that may be useful, if applicable
- **Is there a word limit to the information that I provide?**
The lay summary has a limit of 100 words per section. Applications must be written in English and the lay summary needs to be understandable by a member of the public.
- **Is there a limit to the amount of data and/or samples that I can request access to?**
No, although it must be relevant to your application.
- **How do I make a request to re-contacting participants?**
Researchers are able to request re-contact of participants as part of their Application. Proposals for re-contact are subject to careful review to ensure that the re-contact is justifiable and will not over-burden participants or reveal health information.
- **Why does the AMS have an Application listed but I have not completed an Application?**
Each time you click the 'New Application' button, a new blank Preliminary Application is created (with assigned ID number). This is automatically saved on your Home Page.
- **I submitted a Preliminary Application but have not received a response. Why is this?**
The Access Team aims to complete all checks within 4 weeks once payment is received. If you have not received a response, please check the 'Stage' on your AMS Home Page.
- **I cannot enter Power Calculations in my Main Application Form. What should I do?**
Please upload a document including full details of your power calculations as part of your supporting documentation. Please refer to the attachment in the text box for question 4.
- **Can I remove an uploaded document to my Application?**
No. Please email the [Access Team](#) quoting the application number, who will be happy to remove it.
- **Can I withdraw my Application?**
Yes. Please email the [Access Team](#) quoting the application number.
- **My Preliminary/Main Application has been declined. Can I appeal?**
You have the right to request reconsideration of such decisions. Requests must be submitted within 3 months of the Application being declined, and will be placed before the Access Sub-Committee (ASC), which aims to adjudicate such requests within 4-6 weeks.
- **Can I (or my collaborators) print a copy of my Application?**
Applications in the AMS can be printed by clicking the 'Print to PDF' button on your AMS Home Page.

Payment

- **How much does it cost?**
Access to the Resource is on a cost-recovery basis. Please see [Charges & using the resource](#) for more information.
- **Can I have a quote before submitting a Preliminary Application?**
The purpose of a preliminary application is to provide researchers with an indicative quote for data and/or samples.
- **Does everyone pay the same amount to access the Resource?**
Charges are the same, regardless of the type of Institution (i.e. whether from academia or commercial organizations).
- **What is meant by 'variable' charges?**
The 'variable charge' is dependent on what data are being requested and is charged on a cost recovery basis, plus any third party costs incurred.
- **How do I make payment?**
The Preliminary Application fee can be paid online or you can request an invoice. After approval of you Main Application an invoice is sent, which can be paid by BACS or cheque.
- **Can I make payment in stages?**
Payment is required in full before UK Biobank will release samples/data. Please refer to [UK Biobank Access Procedures](#) for information regarding the fees and payment schedule.
- **Do I have to pay VAT?**
UK Biobank is a limited company and is registered for VAT. UK Biobank is obliged to charge VAT on its access charges. See our [VAT note](#) for further information.
- **Do you accept payment in any currency (e.g. Euro)?**
Not currently. All invoices and payments to UK Biobank must be paid in pounds sterling (£GBP), taking bank charges into account.
- **Why can't I enter my full purchase order number?**
The on-line payment system will only accept Purchase Order numbers of up to 20 characters.

Approval, Licensing and Ethics

- **Do I need to obtain ethics approval?**
No. UK Biobank has obtained Research Tissue Bank (RTB) approval from its ethics committee that covers the majority of proposed uses of the Resource, so researchers do not typically need to obtain separate ethics approval. Please refer to the [UK Biobank Access Policy and Procedures](#).
- **What is the UK Biobank Research Ethics Committee (REC) approval number?**
The REC reference for UK Biobank is 11/NW/0382.
- **Do I need to obtain ethics approval to re-contact participants?**
Yes. Requests for re-contact require separate approval from a Research Ethics Committee.
- **Do I require a Human Tissue Authority (HTA) Licence?**
UK Biobank possesses a HTA Licence, so a separate licence is not required by researchers who receive samples from the Resource, provided that:
 - *Residual samples are destroyed or returned at the end of the project; and*
 - *Applicants do not transfer samples to a third party without UK Biobank approval.*

Property Rights

- **Who owns UK Biobank data and samples?**

UK Biobank is the owner of the Intellectual Property Rights of the data and samples contained in the Resource. Successful applicants are granted a limited, revocable, worldwide, royalty-free, non-exclusive licence (but not ownership rights) to use samples for a permitted purpose only.

Subject to the licence-back provisions set out in the Access Procedures, the Intellectual Property Rights in the Results Data deriving from use of the Resource for the permitted purpose will belong to the Applicant.

- **Does UK Biobank have any financial claim over any inventions developed by researchers using the Resource?**

UK Biobank will remain the owner of the data and samples, but will have no financial claim over any inventions that are developed by researchers as a result of accessing the Resource (unless they are used to restrict health-related research or access to healthcare unreasonably).

UK Biobank will require a copy of any patents whose claims cover, or are intended to cover, an Applicant Generated Invention within two months of their publication.*

** Applicant-Generated Invention: an invention developed by the Applicant as a result of carrying out the Approved Research Project.*

- **Is UK Biobank a research institute?**

UK Biobank is a research resource not a research institute. UK Biobank's purpose is described in the [Ethics and Governance Framework](#) as to: "build a major resource that can support a diverse range of research intended to improve the prevention, diagnosis and treatment of illness and the promotion of health throughout society".

Data and/or Sample release and additional requests

- **When will I have access to data and/or samples?**

Access will be granted when:

- *The UK Biobank Access Sub-Committee has formally approved the Main Application.*
- *All collaborators have registered with UK Biobank and responded to their invite.*
- *All charges have been paid in full.*
- *The Applicant PI, their Institution, and all lead collaborators and collaborating Institutions have signed and returned the Material Transfer Agreement.*
- *If researchers are generating new assay data, then assay details (e.g. assay method; quality control, results) must be returned to UK Biobank before UK Biobank will release the full analytical dataset. Residual samples must be destroyed or returned at the end of the project and confirmation sent to UK Biobank.*

- **Can I amend the Material Transfer Agreement (MTA)?**

No. The MTA is non-negotiable. It has been designed and written by UK Biobank in collaboration with funders, stakeholders and the independent UK Biobank Ethics & Governance Council. It does not seek to apply punitive restrictions on researchers but must safeguard the Resource and the data participants have provided.

- **Why did UK Biobank terminate my Material Transfer Agreement (MTA)?**

UK Biobank is entitled to terminate a MTA by written notice to the Applicant if:

- *The Applicant commits a breach of a material provision of the MTA and, in the case of a breach capable of remedy, fails to remedy the same within 10 days after receipt of a written notice giving particulars of the breach and requiring it to be remedied;*
- *The Applicant PI ceases to be employed (or otherwise engaged by) the Applicant Institution; or*

- *The Applicant Institution ceases, is likely to cease, or threatens to cease carrying on business.*
- **How long would I have access to the data/samples?**
Data/sample use is granted for a limited period of time. This timescale will be set by UK Biobank. Usage is for the duration of the project, which will in most cases be expressed to be for renewable periods (1 year) from the date of execution of the MTA. The licence to use will terminate on completion of the research.

Reasonable extension requests made in writing by the Applicant PI will be considered by UK Biobank.
- **I cannot download my dataset, who should I contact?**
Please log into AMS and click the 'data download' hyperlink, rather than clicking the link in the email with your MD5 checksum and password. Email the [Access Team](#) for assistance.
- **What are 'bulk' data items?**
Some data items that are particularly large and/or complex are available to download as separate data files (e.g. imaging files (MRI, OCT scans), ECG data, accelerometer data, and hospital in-patient data). For some of these files (e.g., OCT data), in-situ access is also available.
- **How do I request additional data items that were not included in my original dataset?**
Please email the [Access Team](#) quoting your application number, listing the data-fields you would like and a brief reason as to why they are needed for your project.
- **Can I expand the scope of the approved research project?**
Please email the [Access Team](#) quoting your application number and how you wish to extend the project.
- **Is it possible to conduct additional research on the dataset?**
A dataset should only be used to conduct research for which it has been given approval. Further research requires a separate application to the Resource. It is fine to use an existing dataset to undertake a new research project, but approval for this via a separate application must be sought.
- **Can you tell me how many UK Biobank participants are enrolled in other studies?**
UK Biobank is currently drafting a policy and will publish guidelines shortly. UK Biobank has already issued some linkage guidance - <http://www.ukbiobank.ac.uk/wp-content/uploads/2013/10/UK-Biobank-data-linkage.pdf> which is currently being revised to include a mechanism for linkage across different study datasets.
- **How does UK Biobank ensure participant anonymity?**
Each dataset is provided with a unique participant identifier so that researchers cannot link their datasets. Researchers are also obliged to NOT seek to identify participants, as stipulated in the signed MTA. Penalties may be imposed on researchers and / or their institutes who seek to do this.

Publications and return of results

- **Do I need to publish my findings?**
Yes. You are obliged to publish your findings in a peer-reviewed journal or on an open source publication site within 6 months after your project end date.
- **Do I need to acknowledge UK Biobank in my publication?**
Yes. Publications should include the acknowledgement "This research has been conducted using the UK Biobank Resource" and linked, if possible, to reference search tools (e.g. PubMed).

- **Is it acceptable to use UK Biobank images in a journal manuscript?**
Publishing UKB images is acceptable if the © UK Biobank credit is included.
- **Do I need to provide UK Biobank with conference abstracts and publications?**
Please send all written reports (e.g. meeting abstracts, on-line reports, publications) to UK Biobank at least 2 weeks before their expected public release date. This is solely for tracking how results are being disseminated (you do not require our approval) and to provide general information to participants who have provided samples and data.
- **Does UKBiobank need to know about potentially controversial results?**
Yes. Please let us know if you think a report is likely to provoke controversy or attract significant public attention, so we can be prepared for possible media enquiries and, when necessary, inform participants.
- **How do I return my results?**
You must return your results to UK Biobank within 6 months of publication or 12 months of completing the project (i.e. the final analytical dataset plus statistical methods and tools used to create any derived data-fields). Please also tell us which, if any, derived data might be useful to share with other researchers so we can incorporate them into the Resource.
- **Will participants and the public be kept informed about how the Resource is used?**
Yes. The UK Biobank website provides information about all approved Applications in the [‘Approved research’](#) tab and remains in touch with participants via its newsletter.

Complaints

- **How do I register a complaint?**
A complaints form is available from UK Biobank. Researchers can also complete a [feedback](#) form via the UK Biobank website. UK Biobank aims to respond within 3 working days.

Feedback

- **How do I provide feedback?**
UK Biobank welcomes feedback from researchers. The Access Team seeks feedback after Registration and Preliminary/Main Application. Researchers can also submit feedback via the [feedback](#) form or by emailing access@ukbiobank.ac.uk.

Useful Information

- **What are the contact details for UK Biobank?**
The contact number for any enquiries relating to the Access Procedures or system is 0800 0 276 276. The Email address for the Access Team is access@ukbiobank.ac.uk. The postal address for UK Biobank is: UK Biobank Coordinating Centre, Access Team, Units 1 & 2 Spectrum Way, Adswold, Stockport, Cheshire SK3 0SA.
- **I have applied to access the Resource. Do I have the right to see what information UK Biobank holds about me?**
Yes, you have the right to request a copy of the information UK Biobank holds about you and can request to have any inaccuracies in the information corrected. Any such requests should be made in writing to UK Biobank or Email to dataprotection@ukbiobank.ac.uk.