

FAQs on applying and accessing UK Biobank data

This document contains answers to FAQs from researchers. Please read our [UK Biobank Access Policy and Procedures](#) before registering via the UK Biobank Access Management System (AMS).

For assistance you can send us a Message via AMS after you have signed up. For queries pre-registration you can email access@ukbiobank.ac.uk.

Registration

- **What do I do if I am affiliated with more than one institute?**
You can add all your current affiliations to a single registration in AMS, listing your personal institute email address for each of them.
- **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 mandatory fields have been completed please contact the Access Management Team for assistance.
- **Can I register on behalf of someone else?**
No. The email address used to register must be your personal institute email address.
- **I have submitted my Registration. What happens next?**
We aim to review all registrations within 10 working days, but this may be longer if additional information is required.
- **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 'Forgot your password?' link on the AMS Log in Page. Enter your username and the system will send you an email with a reset password link.
- **Can I change my password?**
Yes. You can use the 'Human Icon'  button at the top right corner of the Home Page after logging into AMS – select 'Change password'.
- **Do I need to re-register if I change email address and/or move to a different Institute?**
No. You can click Profile after logging in to AMS to change the details in your registration. You can add, edit and remove institute details.
- **My institutes address has changed - how do I update my contact details?**
Contact details can be updated via the 'Profile' tab on your AMS Home Page. Your email address is set as your User Name by default. If you change institute you can add details of your new institute (including your personal institute email address) in your Profile tab.

Applications

- **Will UK Biobank respond to questions regarding the Resource before application?**
Yes but please be aware that we prioritise queries from registered researchers. However, UK Biobank is happy to respond to general questions, although in the majority of cases an application is required to answer specific 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 submit an application you automatically become the Applicant PI and are required to sign the Material Transfer Agreement (MTA).
- **Who do I need to include as collaborators?**
You need to list all researchers who will have direct access to the UK Biobank data. Researchers who are involved in a project (e.g., as coauthors on publications) who are not handling the data, do not need to be named on the application but they need to be registered.
- **Can I remove collaborators from my Application?**
Yes. Collaborators listed in an application can be added or removed by the Applicant PI.
- **I am changing institute – do you need to know?**
Yes. Please add the new Institute to the Profile tab on your AMS Home Page. The Access Management Team will need to verify any new Institute added.
- **Can I transfer my Application to a new Applicant Principal Investigator (PI)?**
Yes. Please send a Message to the Access Management Team for guidance. The proposed new Applicant PI must be registered with UK Biobank, named on the application and a new MTA will need to be executed.
- **What information is required to submit an Application?**
 - **Application Form tab:**
 - A1: Project title (200 characters).
 - A2: Research question(s) and aim(s) (up to 200 words).
 - Background and scientific rationale of the proposed research project (up to 300 words).
 - A3: A brief description of the method(s) to be used (up to 300 words).
 - A4: The type and size of dataset required (e.g., men only) (up to 100 words).
 - A5: The expected value of the research (taking into account the public interest requirement) (up to 100 words).
 - A6: The expected value of the research (taking into account the public interest requirement) (up to 100 words).
 - A7: Up to 6 keywords which best summarise your proposed research project.
 - A8: A lay summary of your research project in plain English, stating the aims, scientific rationale, project duration and public health impact (up to 400 words).
 - A9: Will the research project result in the generation of any new data fields derived from existing complex datasets, which might be of significant utility to other researchers? Yes/No
 - A10: The estimated duration of your project, in months (we are prepared to consider a rolling 3-year period during which annual updates are required).
 - B1: Would you like to access an existing copy of the genotyping dataset held at your institute?
 - B2: Would you like to access an existing copy of other bulk data files (e.g., imaging and eye scans) held at your institute?

- *B3. Would you like to re-use an existing dataset already held at your institute to conduct your research (i.e. that contains all the data you need for this new project)?*
 - *Selection of data-fields - use the 'Create application basket' button to transfer to our Data Showcase where you can create/edit/view a Basket of data items you wish to receive. Click the "AMS" button (at top right) to return to the application.*
 - *Consult the guidance on our website relating to sample access:*
 - *C1: What are the sample type(s), volume(s) and number(s) of samples required? Please refer to the online help for guidance including, for example, information on how DNA was extracted.*
 - *C2: If you are intending that an external lab (i.e. not UK Biobank) will conduct the assay, please provide brief details of the proposed lab, the proposed assay and the related quality control protocol (up to 150 words).*
 - *Consult the guidance on our website relating to re-contact applications:*
 - *D1: Provide scientific justification for and details of the nature of the re-contact (up to 300 words).*
 - *D2: Upload further documentation to support your request for re-contact.*
 - **Collaborators tab:**
 - *Please select Institute where you will be conducting the project.*
 - *Add collaborators at your institute - only researchers who are already registered and approved can be added.*
 - *Add collaborators at another institute.*
 - *Materials Transfer Agreement information:*
 - *Institute name to appear on legal document.*
 - *Select contact at this Institute.*
 - **Payments tab** (to be completed after application submission):
 - *Enter a payment address, make online payment or request an invoice.*
- **Is there a limit to the amount of data and/or samples that I can request access to?**
No. Although the request must be appropriate to your application.
 - **How do I make a request to re-contact participants?**
Researchers are able to request re-contact of participants as part of an Application. Proposals for re-contact are subject to careful review.
 - **I submitted an Application but have not received a response. Why is this?**
The Access Management Team aims to complete all checks within 4 weeks after the initial payment was received. Please check the 'Status' of your application in AMS before contacting the Access Management Team.
 - **My Application has been declined. Can I appeal?**
Yes. You have the right to request reconsideration. Requests must be submitted in writing within 3 months of the Application being declined, and will be placed before the Access Sub-Committee (ASC) which aims to review appeals within 4-6 weeks.

Payment

- **How much does it cost?**
Please see our [Costs](#) section for more information.
- **How do I make payment?**
The Application fee can be paid online by the Applicant PI or you can request an invoice and arrange to pay by BACS.
- **Do I have to pay VAT?**
UK Biobank is obliged to charge VAT on access charges. See our [VAT note](#) for information.
- **Do you accept payment in any currency (e.g. Euro)?**
Not currently. Payments must be in pounds sterling (£GBP) taking bank charges into account.

Approval, Licensing and Ethics

- **Do I need to obtain ethics approval?**

Not usually. 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 Procedures](#).

- **What is the UK Biobank Research Ethics Committee (REC) approval number?**

The REC reference for UK Biobank is 16/NW/0274.

- **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 prior 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:

- *UK Biobank has formally approved the Application;*
- *All charges have been paid in full;*
- *A Material Transfer Agreement has been signed and returned then executed by 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.
- **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. 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?**
Message the Access Management Team via AMS 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).
- **How do I request additional data items that were not included in my original dataset?**
Please see the User Guide for advice on how to apply via the 'Projects' area in AMS.
- **Can I expand the scope of the approved research project?**
Please see the User Guide for advice on how to apply via the 'Projects' area in AMS.
- **Is it possible to conduct additional research on the dataset?**
A dataset must only be used to conduct research which has been approved. Further research may require a separate application to the Resource. Please send a Message to the Access Management Team for guidance.
- **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 must include the acknowledgement "[This research has been conducted using the UK Biobank Resource under Application Number xxxxxx](#)" and linked, if possible, to reference search tools (e.g. PubMed). If possible, include "UK Biobank" in the title or as a keyword.
- **Do I need to provide UK Biobank with conference abstracts and publications?**
Yes. Please provide all written reports (e.g. meeting abstracts, on-line reports, publications) to UK Biobank via AMS or email at least 2 weeks before their expected public release date. This is solely for tracking how results are being disseminated (our approval is not required) and to provide general information to participants who have provided samples and data.
- **Does UK Biobank 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.
- **Is it acceptable to use UK Biobank images in a journal manuscript?**
Yes. Publishing UK Biobank images is acceptable if the © UK Biobank credit is included.

- **How do I return my results?**
You must return your results to UK Biobank within 6 months of any 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. Please see our [Guidance on the return of results data](#) for further information.
- **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 make 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 Management Team seeks feedback after registration approval and data release. 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?**
If you have registered with UK Biobank please Message via AMS. If you are not currently registered the email address for the Access Management Team is access@ukbiobank.ac.uk. Our postal address is: UK Biobank Coordinating Centre, Access Management Team, Units 1 & 2 Spectrum Way, Adswold, Stockport, Cheshire SK3 0SA, United Kingdom.
- **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 access@ukbiobank.ac.uk.