

Privacy notice

UK Biobank

The types of data UK Biobank processes

What personal information does UK Biobank collect?

UK Biobank collects personal information about you from three sources (1) directly from you (including via the Participant Resource Centre), (2) through linkage to your health records and other records, and (3) through data generation. These are explained in more detail below:

Data collected directly from you

Initial Collection

When you were recruited to join UK Biobank you will have visited a UK Biobank baseline assessment centre and provided a wide variety of data about yourself - this will have included measures such as your weight, height and blood pressure and biological samples such as blood and urine.

You will also have been asked to complete a detailed questionnaire which asked for information about a wide variety of topics such as where you were born, your early life and education, the employment you had undertaken, your marital status, how many children you have had and history relating to past illness and diseases.

For more details about the initial data collection please see: [Baseline Assessment](#)

Ongoing collection

Following the original recruitment UK Biobank has continued to collect more data directly from you on a periodic basis, such as:

- data collected through the imaging project where participants attend a clinic and undergo a number of scans (brain, heart and abdomen, carotid artery and bones);
- data collected through participants wearing both cardiac monitors to measure heart rhythm and accelerometers to measure movement;
- data collected through participants completing online questionnaires;
- data collected through the involvement of participants in particular studies: such as the coronavirus serology study and the coronavirus self-test antibody study.

For more details about the ongoing data collection please see: [About our data](#)

Participant Resource Centre

The Participant Resource Centre ("PRC") (which is an internal department within UK Biobank), is UK Biobank's primary contact point for our participants. The PRC acts as a call centre: handling inbound and outbound phone calls and participant email queries about UK Biobank. It deals with queries from participants about participation in new UK Biobank studies (such as the imaging assessment visit).

Data collected from linked healthcare data providers and other data providers

UK Biobank is a prospective resource and links to your primary and secondary healthcare records. This linkage of health-record data enables UK Biobank to meet the objective for which it was established, namely to study (a wide number of different) disease and the causes of such disease. This would not be possible without the health linkage records.

UK Biobank also uses the records provided by health linkage data providers and other organisations such as Royal Mail (via Experian) to ensure that we have accurate and up to date contact details for you (in accordance with the requirements set out in the UK GDPR).

Data generation

With the data and samples that you provide us we are able to generate further data to enhance our database, particularly from undertaking assays of the samples. This includes, by way of example, biomarkers - which include common biomarkers, such as cholesterol, infectious disease markers, proteomic and metabolomic markers - and genetic data (ranging from genotype to exome sequence to whole genome sequence). All assay work is conducted in a manner whereby the participant remains de-identified.

Who does UK Biobank share my data with?

Access to your data is strictly limited to:

- the Clinical Trials Service Unit ("CTSU") - part of Nuffield Department of Population Health ("NDPH") at the University of Oxford, who we have appointed as a data processor in order to store the UK Biobank resource data;
- our third party services providers and partners who provide data processing services to us, or who otherwise process information for purposes that are described in this Privacy Notice; and
- Approved researchers whose research project has been approved under our Access Procedures, which means that the researcher has to be a bona fide researcher and has to undertake health research that is in the public good. If you would like more information about the approved research projects which have access to UK Biobank data, please click the link below.

UK Biobank's lawful basis for processing your data

A legal requirement of the UK GDPR is that we tell you about the legal basis on which UK Biobank will process your personal data.

As UK Biobank is a research project, consent was sought from all participants for their participation in UK Biobank. Through the [information materials](#) and [consent form](#) UK Biobank set out to explain the basis of such participation and a summary of the scope to which participant data would be used by UK Biobank and the research community.

Although you needed to provide your "consent" in order to participate in the UK Biobank research project, and UK Biobank would not act in a way which was in any manner inconsistent with that consent, "consent" for data protection purposes is a distinct concept.

One of the – perhaps unintended – consequences of the GDPR was that using "consent" for GDPR purposes has become less appropriate for medical research resources and UK Biobank uses "legitimate interests" as the primary lawful basis on which to process your personal data under the UK GDPR as follows:

- basic data (such as your name and address) is processed for UK Biobank's legitimate interests to improve health care (as detailed below);
- processing of health data (such as health records) is processed by UK Biobank for necessary reasons of public interest in the area of public health and for scientific research purposes.

Consent

As mentioned above, each person who joined UK Biobank provided their explicit consent to take part in the UK Biobank project. To re-iterate UK Biobank's approach on consent, which is that notwithstanding UK Biobank's reliance (for data protection purposes) on legitimate interests and for reasons of public interest as its lawful basis for processing your data, UK Biobank acts at all times in full accordance and compliance with this consent: for example it does not affect the ability of a participant to withdraw from UK Biobank for any reason at any time.

Your Data Protection Rights

Pursuant to the GDPR individuals have a number of rights:

Rights of access, correction, restriction and to object: UK Biobank participants have limited rights in this regard. This is for the following reasons. Firstly, all participants joined UK Biobank on the explicit understanding (as described in the information leaflet and consent form) that there would be no feedback of any information that was discovered

about them from using their data. The reason for taking this “no feedback” approach was that it was considered likely that providing feedback would prevent or impair the research purposes of UK Biobank. Secondly, as set out above, UK Biobank processes personal data for the purpose of enabling scientific (health) related research that is in the public good. In accordance with schedule 2, Part 6, para 27 of the Data Protection Act 2018 this means that UK Biobank is exempt from certain provisions of the UK GDPR, including the requirement to respond to data subject access requests ("DSARs"), require corrections, restrictions or facilitate objections. This was explained to participants when they joined UK Biobank and re-iterated in the above mentioned [2018 GDPR note](#).

Rights to be forgotten, erasure and withdrawal: these rights are covered by your ability to withdraw from UK Biobank at any time for any reason (although we should add that we very much hope that you choose not to exercise that right so that your data can continue to be used to help researchers study the causes, prevention and treatment of many different diseases).

Protecting your data

UK Biobank and its appointed data processors store your data securely and to the highest industry and professional standards. It undertakes regular testing of its IT systems to ensure that they are robust. UK Biobank also commissions external experts to test the security of its systems.

Before UK Biobank provides data to researchers, we first remove all the personal identifiers so that individual participants cannot easily be identified. In addition, your data are only provided to researchers on the execution of a legal agreement prohibiting the researcher from trying to identify a participant.

Only a limited number of people working for UK Biobank or its appointed processors have access to participants' data with the personal identifiers (which is necessary in order to allow us to interact with you and add more information about each participant as it becomes available). These individuals are subject to strict confidentiality provisions and are required to undertake regular data security training.

Withdrawal from UK Biobank

You are free to withdraw at any time from the study without giving us a reason. You are welcome to discuss concerns with us at any time, and the various options you have for withdrawal.

Participants can withdraw at one of three levels:

No further contact

This means that UK Biobank would no longer contact the participant directly but would have permission to retain and use information and samples provided previously and to obtain and use further information from health records. This level of withdrawal leaves the resource intact and will allow researchers to study disease with the goal of improving the health of future generations. If you wish 'No further contact', please speak to the UK Biobank Participant Resource Centre on 0800 0 276 276 (freephone number) since there are a number of options available (for instance, you could request that UK Biobank does not contact you to ask for further help, but that you still receive the annual newsletter).

No further access

This means that UK Biobank would no longer contact the participant or obtain further information from health records in the future, but still has permission to use the information and samples provided previously. You need to contact UK Biobank by phoning the Participant Resource Centre on 0800 0276 276, email us at ukbiobank@ukbiobank.ac.uk, or you can send us a letter at the address on this page to request a Withdrawal Form.

No further use

In addition to no longer contacting the participant or obtaining further information, any information and samples collected previously would no longer be available to researchers. UK Biobank would destroy samples (although it may not be possible to trace all distributed sample remnants) and would only hold information for archival audit purposes. Such a withdrawal would prevent information about the participant from contributing to further research, but it would not be possible to remove data from research that had already taken place. You need to contact UK Biobank by phoning the Participant Resource Centre on 0800 0276 276, email us at ukbiobank@ukbiobank.ac.uk, or you can send us a letter at the address on this page to request a Withdrawal Form.