

Frequently Asked Questions

Answers to questions about UK Biobank's request for coded primary care data of participants who have given explicit consent

[The current version of this note with embedded links is available at <http://www.ukbiobank.ac.uk/extract-faq>]

What is UK Biobank?

UK Biobank is a prominent research resource which is supported by the NHS and funded primarily by the Medical Research Council and Wellcome Trust, along with the British Heart Foundation and Cancer Research UK.

UK Biobank is following the health of 500,000 adults from England, Wales and Scotland who agreed to join the project between 2006 and 2010. It is being used for a wide range of health research that is in the public interest (for example, polygenic risk predictors for heart disease, cancer and other conditions; causes of cognitive decline and dementia).

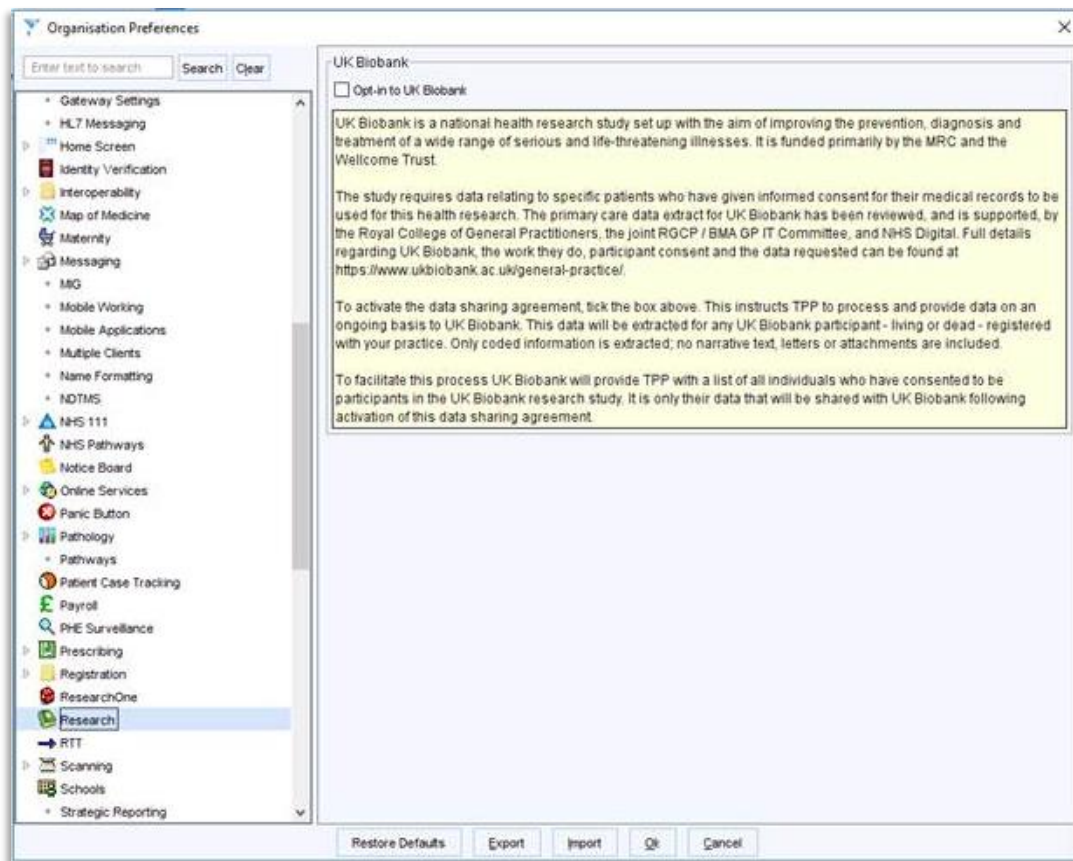
Further information about the ways in which UK Biobank is increasing knowledge about the causes of many different conditions, and of ways to prevent and treat them, is available at: <https://www.ukbiobank.ac.uk>

How do I allow the data extraction to take place?


This is easily done by accessing the data sharing agreement section of your practice management system and agreeing to the UK Biobank Data Sharing Agreement. The screenshots below show how this works for practices that use TPP and EMIS Practice Management systems.

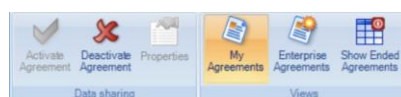
For TPP:



- The "Data Sharing Agreement" is located under the "Research" element of the "Organisation Preferences" panel within SystemOne, and is available to the GP practice administrator.
- To activate the Agreement, a GP practice simply needs to read the brief summary and then tick the checkbox marked "Opt-in to UK Biobank" (as shown in the screen capture below).

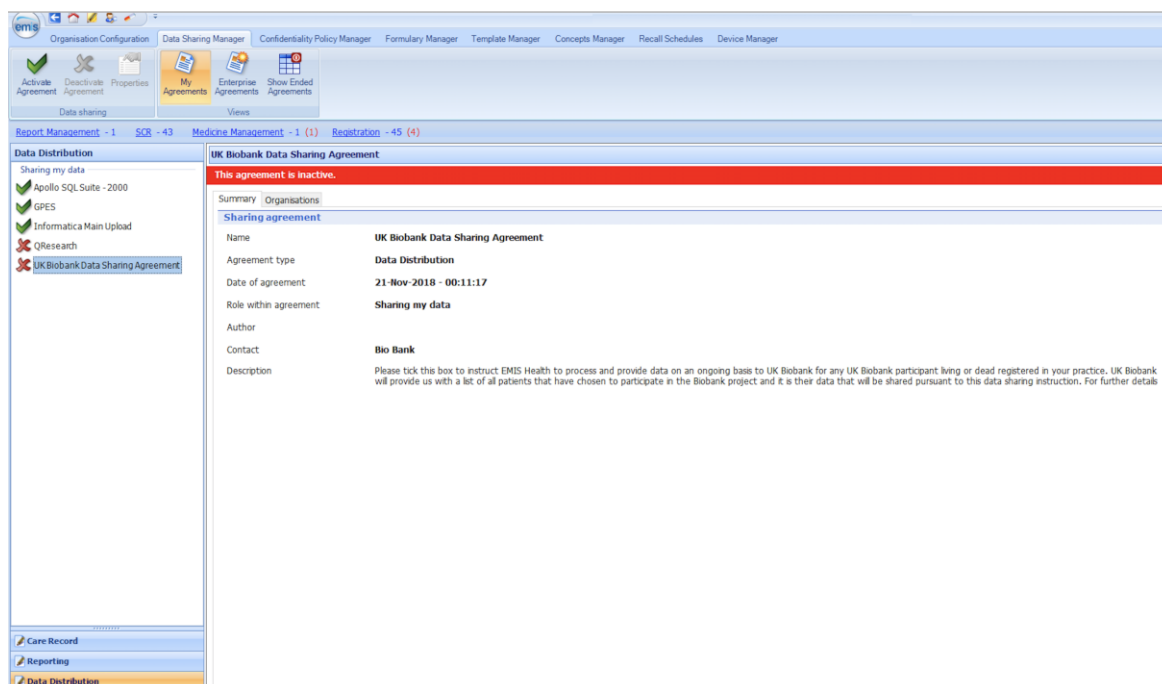


For EMIS:

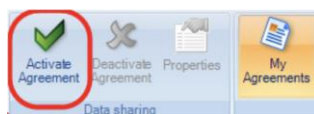
- The "Data Sharing Agreement" is located under the "Data Sharing Manager" and is available to a GP practice administrator with RBAC activity B0109 in their role profile.
- Click on , point to "Configuration" and then select "Data Sharing Manager". On the ribbon, if not already selected, click on "My Agreements" (as shown below).



- In the "My Agreements" panel, click on the "Data Distribution" tab (as shown below).
- Active agreements are displayed with a green tick  and those that have not yet been activated are displayed with a red cross . Select the "UK Biobank Data Sharing Agreement".



- To activate the Agreement, a GP practice simply needs to read the brief summary and then click on "Activate Agreement" in the ribbon (as shown below).



How do I know which of my patients are UK Biobank participants?

Unless a patient has mentioned their participation in UK Biobank to you directly, it is unlikely that you would know which of them joined it. Consequently, enclosed with this letter is a list of UK Biobank participants who NHS Digital has told us are registered with your practice. We can guarantee that all the individuals on this list are consented UK Biobank participants (and have enclosed copies of their electronic signed consent forms), although the practice registration may not be completely up-to-date (e.g. if a patient has moved quite recently to another practice).

Do I need to contact each patient to confirm their consent before agreeing to a practice extract?

Prior to beginning this primary care data linkage project, we spoke with the Information Commissioner, Elizabeth Denham, and the ICO's Legal Counsel subsequently confirmed that UK Biobank's consent is compliant with all relevant legislation (<https://www.ukbiobank.ac.uk/ico>):

"The consents given by the participants to UK Biobank provide the GPs with comfort that their disclosure of these patient records to UK Biobank is in accordance with the current and incoming law."

It not necessary to check with each UK Biobank participant registered at your practice as we have their explicit written consent, and health-related data are already being provided on that basis by NHS Digital. Moreover, providing these data to UK Biobank will have no impact on the participant (by contrast, for example, with health insurance requests where it is standard practice to contact patients before releasing their data) because there is no feedback of individual information to participants.

How do I know the consent is still valid?

As indicated in the information materials provided to potential participants before they agreed to join UK Biobank, consent was provided for the lifetime of the project:

<https://www.ukbiobank.ac.uk/participant-information-leaflet>

We wrote (in May 2018) to all of the UK Biobank participants to let them know UK Biobank's legal basis for holding their data under the new GDPR data protection legislation:

<https://www.ukbiobank.ac.uk/gdpr>

We remain in regular contact with the participants via annual newsletters that inform them about what is being done with their data:

<https://www.ukbiobank.ac.uk/newsletters>

In addition, we regularly invite participants to take part in enhancement projects (e.g. web-based questionnaires; wearing activity monitors; attending imaging assessments), and to attend meetings held all over the country in order to hear about progress with the project:

<https://www.ukbiobank.ac.uk/participant-events>

Participants can withdraw from UK Biobank at any time, without giving any reason, although only about 1000 participants have so far chosen to do so. The options for withdrawal are shown at:

<https://www.ukbiobank.ac.uk/withdrawal>

How is the extraction being undertaken and is it secure?

UK Biobank is working closely with the GP systems suppliers – including EMIS Health (EMIS Web) and TPP (SystmOne) – to manage the extract in a secure, scalable and sustainable way. UK Biobank is writing directly to each of the 8,000 GP practices across England that are covered by these system suppliers to set out the purpose of the data extract, to provide evidence of the consent from participants, and to give assurances that the extract only involves patients registered at a practice that have explicitly consented to participate in the UK Biobank study.

UK Biobank is able to ensure that only data relating to consented UK Biobank participants are extracted by the GP system supplier by providing the participants' identifiers (NHS number, date of birth and gender) in an encrypted format via secure transfer for precise matching to relevant records. Only matched participant records will be extracted and provided to UK Biobank in an encrypted format via secure transfer. Approved researchers undertaking health-related research that is in the public interest are provided with information that does not identify participants.

What information would be extracted from our GP practice records if we give our agreement?

The information extracted from the health records of consented participants would comprise coded data only about the patient's health and well-being, and interactions with the practice, including:

- Coded diagnoses, symptoms, referrals and associated dates
- Prescriptions and dates prescribed
- Lab test results and date of test
- Immunisation records

The data extraction is not focussed on any particular condition as UK Biobank is a resource for a wide variety of research into all types of health outcomes. No identifiable information about any person who works in the practice or sees the patient would be extracted. Further information on the data fields to be extracted is available at:

<http://www.ukbiobank.ac.uk/general-practice-extract>

In the event that the Practice considers it appropriate to conduct a Data Privacy Impact Assessment (DPIA), then for ease of completion we have provided an exemplar that a Practice may wish to adapt at:

<http://www.ukbiobank.ac.uk/general-practice-dpia>.