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Request to release coded primary care data for consented UK Biobank participants

(for practices running TPP and EMIS systems)

An earlier draft of this message was sent in error. Please use this version. Apologies for any inconvenience.

29 September 2023

Dear Colleagues,

We are writing to ask for your help with the world-leading UK Biobank biomedical database and research resource (more information below).

503,000 UK adults have given explicit written consent for all their medical and other health-related records to be provided to UK Biobank for all types of health-related research.

We saw the value of this resource during the COVID-19 pandemic, when special regulations permitted UK Biobank to obtain participants' coded primary care records held by GPs for research. This resulted in 200 peer-reviewed studies on the lifestyle, genetic and clinical determinants of severe COVID-19.

However, since the extraordinary provisions for COVID-19 ended, each GP practice must now take action as the 'data controller' to approve release of the coded primary care data to UK Biobank. Releasing these data to UK Biobank will allow consenting patients to participate in this important research.

This letter is to ask you to make these data available to UK Biobank.

To do this, you simply need to click a box within your GP system administration panel to enable data sharing with UK Biobank (see pages 3 and 4 of this letter for instructions on how to do so).

This can be done by you or by your practice manager.

GPs are rightly cautious in sharing their patients' data. UK Biobank has investigated this carefully:

- The Information Commissioner has confirmed that the participants' existing explicit written consent is compliant with current data protection legislation, and supports this approach.
- UK Biobank has already been making de-identified NHS health outcome data (eg deaths, cancers, and hospitalisations) available to approved researchers for the past 10 years.
- The same strict data protection and information governance processes would be applied for access to the primary care data, which would be restricted to coded information.
- This request is endorsed by the Royal College of GPs and NHS England.


Further information about UK Biobank, its research, and the detailed advice from the Information Commissioner is available at www.ukbiobank.ac.uk. If you would like to discuss any aspect of this request with the UK Biobank team, call 0161 475 5360 or email adminteam@ukbiobank.ac.uk.

We very much appreciate your support of research that will improve the lives of people around the world, as well as honouring your patients' wishes to contribute to this important initiative.

Yours sincerely,



**Professor Sir Rory
Collins**
Chief Executive
UK Biobank



**Professor Kamila
Hawthorne**
Chair
Royal College of GPs



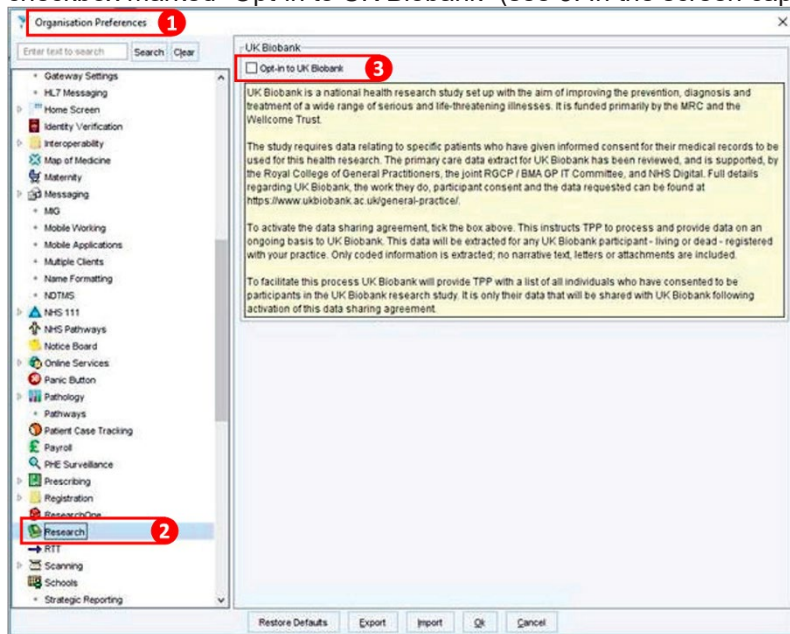
Professor Sir Stephen Powis
National Medical Director and Caldicott
Guardian
NHS England

How to enable data sharing with UK Biobank

For GP practices running TPP:

The data sharing agreement is located within the “Organisation Preferences” panel in SystmOne (see 1. below) under the “Research” element (see 2. below) and is available to the GP practice administrator.

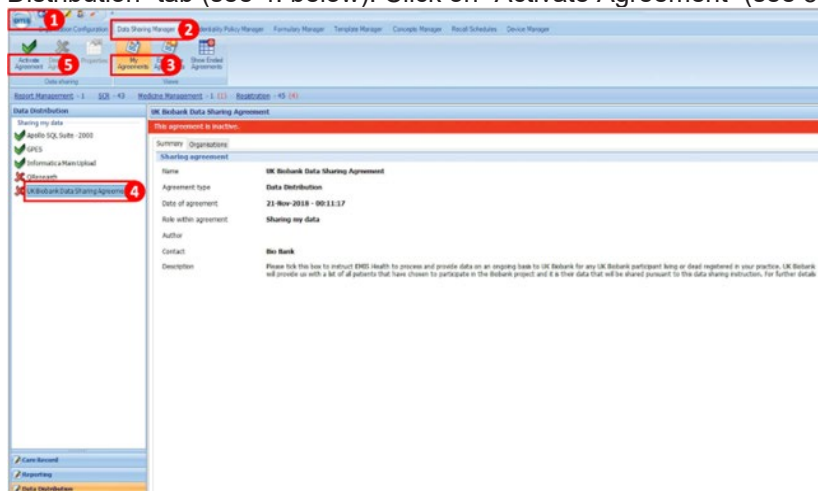
To activate the agreement, a GP practice simply needs to read the brief summary and then to tick the checkbox marked “Opt-in to UK Biobank” (see 3. In the screen capture below)



For GP practices running EMIS:

The data sharing agreement is located under the “Configuration” panel (see 1. below) and within the “Data Sharing Manager” (see 2. below) and is available to the GP practice administrator.

Click on “My Agreements” (see 3. below) and select the UK Biobank agreement within the “Data Distribution” tab (see 4. below). Click on “Activate Agreement” (see 5. in the screen capture below)



About UK Biobank

UK Biobank is a large-scale biomedical database and research resource containing genetic, lifestyle and health information from half a million UK participants. This includes blood samples, heart and brain scans and genetic data of the 500,000 volunteer participants and is globally accessible to approved researchers who are undertaking health-related research that is in the public interest.

UK Biobank recruited 500,000 people aged between 40-69 years in 2006-2010 from across the UK. With their consent, they provided detailed information about their lifestyle, physical measures and had blood, urine and saliva samples collected and stored for future analysis.

UK Biobank's research resource is a major contributor in the advancement of modern medicine and treatment, enabling better understanding of the prevention, diagnosis, and treatment of a wide range of serious and life-threatening illnesses – including cancer, heart diseases and stroke. Over 30,000 researchers from more than 90 countries are registered to use UK Biobank and more than 7,000 peer-reviewed papers have been published as a result.

UK Biobank is supported by Wellcome and the Medical Research Council, as well as the British Heart Foundation, Cancer Research UK and NIHR. Find out more here: <http://www.ukbiobank.ac.uk>

Creating a new NHS England: NHS England and NHS Digital merged on 1 February 2023. All references to NHS Digital now, or in the future, relate to NHS England. [Learn more.](#)