

October 2018

Dear Practice Manager and GP Partners

We are writing to inform you about a request that will be coming from your practice management system EMIS Health in the next few weeks relating to a data extract for UK Biobank, a leading international research cohort.

UK Biobank is a prominent resource for health research and a registered charity supported by the NHS, and funded by the Medical Research Council and Wellcome Trust. UK Biobank is following the health of 500,000 adults from throughout England, Wales and Scotland who joined the project voluntarily between 2006 and 2010. UK Biobank has been the resource used in a number of important recent research projects, including identification of genetic variants that predict glaucoma risk, links between air pollution and cognitive function, development of a simple eye test to predict dementia, validation of polygenic risk predictors in clinical care, and many more besides.

Each participant gave their express informed consent for UK Biobank to link to their medical and other health-related records for research purposes (www.ukbiobank.ac.uk/consent), and the UK Biobank participants could not have taken part in UK Biobank without completing the sign-up process and the consent form. Their consent was provided on the basis that it is for the lifetime of the UK Biobank project.

Further, UK Biobank remains in regular contact with its participants via its website, annual newsletters and requests to take part in enhancement projects. Participants can withdraw from UK Biobank at any time, without giving a reason. The withdrawal options are set out on the UK Biobank website (www.ukbiobank.ac.uk/withdrawal) although to date very few participants have chosen to withdraw.

UK Biobank has provided access to bona fide research scientists since 2012, as it contains a wide range of anonymised phenotypic and genotypic data such that researchers can study the interaction of genes, lifestyle and environment in causing a wide range of diseases (such as cancer, heart disease, dementia, diabetes, depression and arthritis). In terms of health-linkage data, UK Biobank has routinely linked to national death and cancer registries and to national hospital data electronic record systems for all its participants since 2012.

In 2016 linked primary care data for a subset of UK Biobank participants was obtained from GP practices using the TPP and Vision (InPractice Systems) practice management systems. UK Biobank is now proposing to expand this linkage across the entire cohort, including all relevant GP practices - whether they are using TPP, Vision or EMIS Health practice management systems.

Following careful review of UK Biobank's operating practices, approach and documentation (including UK Biobank's information governance, ethical approvals, and data security), both the Royal College of General Practitioners and the Chief Medical Officer for EMIS Health have agreed to endorse and support this linkage. Facilitating UK Biobank's linkage to primary care data will transform the scientific value and clinical relevance of the research questions that can be addressed using the UK Biobank resource, particularly for diseases that can only feasibly be followed using the primary care records (such as diabetes and many mental health conditions).

We would like to reassure you that:

- this process will only involve patients registered in your practice if they have consented to participate in the UK Biobank study. UK Biobank is able to ensure that only data, which relates to UK Biobank participants, will be extracted;
- this is achieved by UK Biobank providing its participants' identifiers (NHS number, date of birth and gender) to EMIS Health in an encrypted format and via secure transfer for the purpose of precisely matching to relevant records only. Extracted data will be returned to UK Biobank in a similarly encrypted format and via secure transfer;
- UK Biobank only releases anonymised data to approved registered researchers for the purpose of health-related research for the benefit of the public;
- the linkage extract process will be undertaken by EMIS Health centrally and does not require any action on your part.

You can read more information about UK Biobank at: www.ukbiobank.ac.uk/general-practice.

You should receive the request to agree to this data extract via an email from EMIS Health in a few weeks and we hope that you will agree. It will only require a moment of your time to activate the Data Distribution Agreement within the Data Sharing Manager module of EMIS Web.

However, if you have any questions or concerns about the proposed linkage then please do contact us at UK Biobank either by telephone on 0800 0 276 276, or by email to ukbiobank@ukbiobank.ac.uk.

Yours sincerely,



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