Dear Practice Manager and Data Protection Officer

Extraction of coded primary care data for consented UK Biobank participants

UK Biobank is a research charity, set up by the Wellcome Trust and the Medical Research Council, which recruited 500,000 men and women aged 40-69 during 2006-10 who agreed to be followed long-term through their medical and other health-related records. The UK Biobank resource is being used increasingly widely by scientists from around the world to help understand better the causes of many different conditions, and find better ways to prevent and treat them (https://www.ukbiobank.ac.uk).

We wrote to you at the end of last year (letter attached) seeking your agreement for the extraction of primary care data for UK Biobank participants. In response to some helpful suggestions from the Joint IT Committee of the RCGP/BMA, we have now put the following additional measures in place:

- Enclosed with this letter is a list of UK Biobank participants who are believed to be registered with your practice (although it may be the case that some have moved to another practice);
- If you wish, you can receive electronic copies of the signed consent forms for these UK Biobank participants by requesting them via an online service (https://www.ukbiobank.ac.uk/gp-request);
- Your system supplier is providing a facility that will allow you to audit the extraction process for patients registered at your practice after each data extraction (intended to be annual);
- If you wish, you can add one of the following “Participant in United Kingdom Biobank” codes [Read v2 / CTV3 code (9Q3) or SNOMED CT code (372051000000107)] to the records of these patients.

The Joint IT Committee has recommended that you conduct a Data Privacy Impact Assessment (DPIA), so we have attached a draft template. Additional guidance is provided in the attached Q&A note.

The Information Commissioner previously confirmed that UK Biobank’s approach to obtaining these data for consented UK Biobank participants complies with the General Data Protection Regulation (https://www.ukbiobank.ac.uk/ico). The Joint IT Committee has endorsed our amended process. In addition, the RCGP Chair, Chief Medical Officer, and NHS Digital CEO all strongly support UK Biobank’s approach to obtaining primary care data (see overleaf).

Consequently, if you have not already done so, I would be most grateful if you would provide your agreement for release of coded primary care data for UK Biobank participants registered at your practice. Agreeing to the UK Biobank Data Sharing Agreement is easy to do through the data sharing agreement section of your practice management system.

I recognise that you are already very busy. However, I would urge you to help us to access the primary care records for the 500,000 individuals who generously agreed to contribute to this extraordinary resource for improving patient care and public health. If you would like to discuss my request, please do not hesitate to give me a call (office: 0161 475 5360) or send me an email (rory.collins@ukbiobank.ac.uk) and I shall get back in touch. Many thanks for your consideration.

Yours sincerely

Professor Sir Rory Collins, FRS FMedSci FRCP
UK Biobank Chief Executive & Principal Investigator
"The College has supported this initiative from the outset. It has the potential to change the way in which we diagnose and treat serious illnesses – and, crucially, prevent them happening in the first place. General practice is under unprecedented pressures and, as a practising GP myself, I fully understand what life on the frontline is really like – but UK Biobank is a trusted and bona fide resource, and I would encourage GP practices to participate wherever possible.”

Professor Helen Stokes-Lampard, Chair of the Royal College of GPs

"Linkage to primary care data will enable UK Biobank to support research studies that could transform the outcomes of a broad range of conditions (including dementia and diabetes) that are primarily diagnosed and managed in primary care. UK Biobank needs your help to achieve this linkage for all of its consented participants, who are registered in thousands of general practices around the UK. I strongly urge you to agree for your system supplier to undertake this data extraction for UK Biobank.”

Professor Dame Sally Davies, Chief Medical Officer for England

"The benefits for patients that will be generated by research through the ability to integrate primary care data into UK Biobank are likely to be very substantial. Consequently, given that patients have given their explicit consent to UK Biobank for access to all of their medical records, NHS Digital is strongly supportive of its approach to accessing those data through the primary care system suppliers. I would, therefore, encourage all GPs to agree to this data extraction for the UK Biobank participants who are registered at their practices.”

Sarah Wilkinson, CEO NHS Digital

"GPs already receive so many requests to do things outside their standard clinical practice. But this is important and vital for future patient care. I would urge GPs to help the UK Biobank project access primary care records for the 500,000 individuals who have joined the study and given their explicit consent. UK Biobank is already generating findings that will help us to improve the care that we give our patients. Inclusion of the rich data from the records in primary care – where most health care is provided – will allow even more improvements to emerge.”

Clare Gerada, Clinical Chair of the NHS Assembly & GP Partner for the Hurley Group