

By email to:-
Jonathan Sellors
UK Biobank
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23 April 2018

Dear Jonathan,

Further to the telephone call you had with Elizabeth Denham on 7 November and the call with myself and Stacey Egerton on 24 November we agreed to write to you setting out the key points of advice from our discussion.

Firstly we confirmed that the General Practitioners (GPs) are the data controllers for the primary care data required by UK Biobank and are therefore responsible for ensuring they comply with their data protection obligations. The GP system suppliers (TPP, InPractice Systems, and EMIS) process the primary care information on behalf of the GPs and are therefore data processors. The data processors should act upon the instructions of the data controllers in processing the information they hold.

During our discussion you outlined that all participants in UK Biobank have provided their explicit consent for all of their medical and other health-related records to be made available to the project. UK Biobank is already obtaining health record data on deaths, cancer and hospital episodes for its study participants through NHS Digital in England (and equivalent sources in Scotland and Wales). Currently, since there is no central source of primary care data in England, UK Biobank has been working with the GP system suppliers to obtain the primary care data for its consented participants. .

You clarified that this approach has already been used with 2 out of the 3 system suppliers. However, EMIS has highlighted some concerns from their National User Group (based on previous ICO input). For the avoidance of doubt, this present and updated advice applies to all three GP system suppliers.

Our understanding is that the process that UK Biobank has been using to obtain primary care data through the system suppliers is as follows:

- A standard letter is sent to each GP practice from the relevant system supplier and UK Biobank explaining the proposed data extraction for consented participants and the basis on which it is to be made (namely explicit consent);
- UK Biobank provides an explicit assurance that its system ensures that each participant is matched with their primary care records and that no extraction will occur for anyone who is not a consented participant;

- The GP practice has the opportunity to ask questions of UK Biobank and, if it wishes, can request confidential access to the signed consent forms for participants who are registered at that practice; and
- If a GP practice decides not to allow access to the primary care data of consented participants then the extraction does not proceed (you informed us that, with TPP and InPractice System's data extractions for about 200,000 participants, only one practice took this step).

We advised that:

- The reference to the GP practices opting-out/opting-in or consenting is unhelpful in this context. Ultimately it is about whether the GPs as data controllers have given an appropriate instruction to the GP system supplier to provide the data to UK Biobank in this situation. This could be a general or a specific instruction, and may be set out in the contracts between the GPs and the GP system suppliers (the provisions of which are presumably governed by the main framework agreement between the Secretary of State and the GP system suppliers).
- If there is general wording within the contract between the GPs and the GP system suppliers that provides this instruction – or for a means by which such instruction can be made and such instruction has been given, then specific explicit agreement from each GP practice is not required.
- Notifying the GPs and providing them with the opportunity to ask questions, as UK Biobank has done, would be considered good practice and reduce the risk of any complaint from those GPs in the future. It may help to explain to GPs the process UK Biobank has used to obtain and maintain the consent of the individual participants, and that if an individual participant did ever withdraw this consent in the future, his/her personal information could be withdrawn.
- The consents given by the participants to UK Biobank, provides the GPs with comfort that their disclosure of these patient records to UK Biobank is in accordance with the current and incoming law.
- It is worth highlighting that if any of the GPs express (either verbally or in writing) that they do not want any of their patient information to be shared with UK Biobank then the GP system suppliers, as data processors, should not override this decision. UK Biobank should engage with these GPs and no information for their patients should be provided until a solution has been reached.

We are happy for UK Biobank to share this note with all interested parties, such as the system suppliers, the Royal College of General Practitioners, and NHS Digital. Please get back in touch if further guidance is required.



Information Commissioner's Office

Yours sincerely

Emma Bate
General Legal Council
Information Commissioners Office