

## Access matters / Collaborations

1. When researchers apply to access UK Biobank samples and/or data, the research application and the subsequent conduct of the research does not involve collaboration with UK Biobank. In summary, the researcher determines what research they wish to conduct, UK Biobank assesses its feasibility and the researcher then conducts the research, publishes a paper and returns the results to UK Biobank.
2. However, there are instances when researchers have collaborated with UK Biobank to produce certain derived data variables that UK Biobank considers would be useful for the entire research community. The purpose of this note is to re-state how these collaborations work.
  - 2.1 The collaborator is provided with UK Biobank data and agrees to generate a particular derived variable(s) for UK Biobank;
  - 2.2 UK Biobank does not generally pay the collaborator for this work, although there is no inherent reason why it should not do so if it was considered appropriate by both parties;
  - 2.3 The derived variables are then returned to UK Biobank, summarised in the Data Showcase, and made available for all researchers from a particular prospective date (so that no one researcher, including the group that has derived the variables, gains an unfair head start);
  - 2.4 The collaborator is entitled to publish on their research methods but not to conduct research<sup>1</sup> on the data that have been provided by UK Biobank, which requires a separate application to UK Biobank under its access procedures.
  - 2.5 For example, when additional genetic markers were imputed from the raw genotype data for UK Biobank by a statistical genetics group in Oxford, these markers were made available at the same time to all researchers. The Oxford group was entitled to publish on its methods (without making a research application) on the development of its imputation algorithms. However, they had to make an application to UK Biobank to use the imputed data for research purposes like any other researcher.
3. There is no doubt that collaborators may well gain a certain advantage in terms of their familiarity with the data that they have helped to generate, but they have no head start in terms of their ability to access the data for the purposes of conducting a research project.

## UK Biobank's Access Sub-Committee / June 2016

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<sup>1</sup> As in research into the determinants of disease.