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UKBiobank Eye & Vision Consortium : November 2012

Moorfields Eye Hospital Special Trustees Grant [\(Back to Top\)](#)

MEH-ST's have awarded funding to underpin activities of the consortium, including the annual consortium meeting, contribution toward the some working group meetings, publication costs and development of pilot image grading with some crowd-source grading.

Annual Meeting [\(Back to Top\)](#)

Tuesday 19th February 2013 at the Wellcome Collection, Euston Road, London, probably starting with coffee at 9.30am and opening the meeting at 10am, running till 4pm. I will be inviting each group with registered data requests to present, and arranging presentations on activities to develop the resource. If anyone has any suggestions for items to include on the programme, please circulate on the listserver, or direct to me (p.foster@ucl.ac.uk).

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Together with the Network of Ophthalmic Image Reading Centres, we have begun planning the grading of the colour digital images for AMD, diabetic retinopathy and glaucoma. Abstract applications for funding have been submitted to Macular Disease Society and Fight for Sight. We will continue to explore all possible avenues for funding this activity in due course. Usha Chakravarthy, Simong Harding, Jayashree Sahni and Tunde Peto and their teams have given their valuable time to develop this project.

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Data Access Requests [\(Back to Top\)](#)

The first thing to say is that this process is taking somewhat longer than we all envisaged. As of today, 7/41 groups have had their requests for data access approved. The second thing to note is that estimated costs seem to have been under-estimated. One group have found their costs increased by 30%, which has caused an issue with budget shortfall. In addition, be aware that VAT is payable on these requests. University/charitable VAT exemption covers medical equipment, but not research services.

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Outcome adjudication

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Outcomes Adjudication Group

AIMS:

To advise UKBB on methods of identifying incident disease, other relevant clinical/health outcomes and other significant episodes in the care pathway (eg service episodes) using record linkage of routinely collected data eg HES, GPRD. We propose to focus initially primarily on cataract, glaucoma, AMD and diabetes in terms of diseases-specific outcomes. We should try to include some "patient/participant related" measures, although these may be more challenging to identify as they are not necessarily routinely captured.

APPROACH:

Working group members to consider in advance and then meet to map options for identifying outcomes, specifically examining

- Which sources of routinely collected data / existing databases could be used

- Which events/ people may not be captured at all in such data sources and which events/people maybe differentially captured
- Which patient identifiers will need to be used to ensure robust record linkage
- How clinical events/outcomes are coded- OPCS/HES/Read codes etc.
- Which other Biobank outcomes groups we should liaise with e.g. Diabetes, Cardiovascular
- Patient specific outcomes?

Contact Details

As you are all aware, one of the great strengths on UKBB is the development of systems to identify incident health outcomes through a variety of systems. We have been asked to advise on this process, and to date, Jugnoo Rahi and Parul Desai have given some input. We need to give a short outline of what may be of interest on 23/11/12, so any additional comments by then please. Anyone with interest and expertise in this field, please feel free to volunteer your services! Some outline information on the approach is given to the right.

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