

Procedure of Applying for ELSA Genetics Data via the DNA Repository (EDNAR)

This document clarifies the procedure of how the ELSA genetics data was collected and analysed, and how analysts can apply to use it.

Data collection and analysis

During the ELSA Wave 2 nurse visit, respondents were asked for consent to have their genetic information analysed and stored. Blood samples were taken for analyses of levels of various compounds (such as lipids), and those who had consented had an extra blood sample taken from which their DNA was later extracted.

All of the blood samples were sent to a laboratory in Newcastle, where a separate 'blood' identifier number was assigned and most of the blood analyses were carried out. Also, 10% of the samples were split in two, and each part will be analysed separately in future for quality control purposes. Applicants who receive genotyping data will not be given these duplicate results, but they will be informed of the error rate that was found when analysing them. The samples that are to be used for genetics analysis will be stored for the foreseeable future at the MRC Geneservice in Cambridge.

Applications for data

Applicants can obtain an EDNAR (ELSA DNA Repository) application form from Dr Meena Kumari at UCL (see below for contact details). This form, when completed and signed, should be returned to Dr Kumari who will pass the form onto the Genetics Sub-Committee (GSC) for evaluation. Completed forms should contain as much information as possible, both with regards to the genotyping that is necessary and the ELSA variables that are required.

The GSC comprises members of the ELSA Research Team and members of the UCL Department of Epidemiology and Public Health, and its role is to provide an initial point of contact for prospective users of EDNAR, to liaise with applicants and to provide preliminary approval or rejection of applications. They meet monthly, although decisions can be made between meetings in special circumstances. Once the GSC has evaluated each application, it will be passed to the NatCen Data Release Panel, but only if any non-archived or disclosive variables have been requested. The Data Release Panel meets monthly, but as with the GSC, decisions can be made between meetings in special circumstances.

Applications, along with feedback from the GSC and the NatCen Data Release Panel, will then be passed to the Steering Group for final approval. Applications do not need to be approved by the GSC in order to be passed to the Steering Group. The Steering Group comprises more senior advisors from a variety of institutions such as the NIA (US National Institute on Aging), and the Universities of Cambridge, London (UCL), Newcastle, Exeter and Washington School of Medicine. Its role is to give final approval or rejection to each application, and they meet every three months, although again decisions can be made between meetings in special circumstances.

All parties (i.e. the applicant and one or more of the evaluatory panels) will agree any amendments that are necessary to the application before approval is given and work begins on preparing the data for that application.

Applicants should be aware that the maximum time for the evaluation of application (by the GSC, NatCen Data Release Panel and the Steering Group) is three months, and that another three months should be allowed if genotyping is to be carried out by the Geneservice. Additional time after this would then be needed for checking and creation of the data to be sent out.

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