**English Longitudinal Study for Ageing (ELSA)**

**Genetic Data Access Procedures**

The English Longitudinal Study of Ageing (ELSA) is a panel study of a representative cohort of men and women living in England aged 50 or over. It is a collaboration between the Department of Epidemiology and Public Health at University College London (UCL), the Institute for Fiscal Studies (IFS), the National Centre for Social Research (NatCen) and the University of Manchester, with additional input from the University of East Anglia. It is multidisciplinary in orientation, involving the collection of economic, social, psychological, cognitive, health, biological and genetic data. The study commenced in 2002 and the cohort is followed up every two years, with periodic refreshment to maintain the age profile. Data are collected using computer assisted personal interviews and self-completion questionnaires, with additional nurse visits for the assessment of biomarkers every four years. The original sample was 11,391, ranging in age from 50 to over 90 years. ELSA is managed by a management board made up of representatives from the participating institutions (see appendix for list of members). It was designed as a sister study to the Health and Retirement Study (HRS) in the USA, so is harmonised with ageing studies in other countries to facilitate international comparisons. It is also linked to financial and health registry data. The dataset is openly available to researchers and analysts soon after collection, and is available from the UK Data Service (<http://www.esds.ac.uk/longitudinal/access/elsa/l5050.asp>). A profile of the cohort was published in 2013 (<http://www.ncbi.nlm.nih.gov/pubmed/23143611>).

ELSA encourages and facilitates data sharing with all *bona fide* researchers. For a definition of *bona fide* research, please see <http://www.nshd.mrc.ac.uk/data/bona_fide_researchers.aspx>.

1. **Genetic Resources in ELSA: the ELSA DNA Repository (EDNAR)**

There are two main sets of genetic data in ELSA. First, a genome wide microarray assay (GWAS study) was carried out in 2013/14 with funding from the ESRC. This involved genotyping of around 8,000 ELSA participants with the Illumina Omni 2.5-8 chip. The same chip has been used in the HRS, allowing for direct comparisons. This provides information on 2.5 million single nucleotide polymorphisms (SNPs), which is expanded to over 4 million SNPs by imputation.

Second, genetic data has accumulated through genotyping in a number of specific candidate SNPs and variable number tandem repeats (VNTRs) on 6,000 participants. These include an Illumina bundle of 1,536 SNPs in 3,300 participants, which has contributed data and become part of a number of national and international consortia including the UCL-Edinburgh–Bristol consortium (UCLEB), and the International consortium of Blood pressure (ICBP). The 6,000 DNAs previously extracted have contributed to a number of study designs including replication for findings in genome wide association studies, large scale investigations of gene by environment interactions, analyses using the Mendelian randomisation paradigm, and targeted candidate pathway analyses. A list of research publications that include EDNAR data can be found on the ELSA website at the following address http://www.elsa-project.ac.uk/publications/case/related.

DNA from ELSA is stored at Source BioScience. The GWAS was carried out by UCL Genomics, and working samples of extracted DNA are held by LGC Genomics so that they can carry out genotyping on specified SNPs. THE GWAS has been deposited in the European Genome-phenome Archive (EGA).

1. **Genetic Data Access**

The over-riding aim of our data access procedure is to facilitate access to genetic data in a transparent and streamlined manner. We will not consider the issue of potential overlap between research projects.

We expect that two types of applications will be made:

Type a: Applications for the ELSA GWAS data without additional phenotypic information, in order to provide genotyped control data.

Type b: Applications linking the ELSA GWAS or existing candidate gene polymorphisms with ELSA phenotypic data.

1. **Evaluation of applications**

Applications will be evaluated by the METADAC. This committee meets monthly, but decisions can be made between meetings. Evaluation of applications is based on the following:

Type a: These are relatively straightforward, access to data will be provided to *bona fide* researchers.

Type b: Favourable decisions about these applications depend on the suitability of the ELSA phenotypic data for the topic under investigation and the potential for identification of the participant despite de-identification of the data.

Applicants should allow three months for this process, though most should be completed within one to two months.

1. **Conditions for the use of ELSA genetic material**
2. The samples and related data and intellectual property rights belong to the universities (UCL, Institute of Fiscal Studies, the University of Manchester and NatCen Social Research).
3. If any commercial revenues result from the Recipient's use of the materials, UCL shall be entitled to a fair and reasonable share of any such revenues that accrue to the Institution or the Recipient.
4. The applicant will acknowledge the ESRC, NIA, UCL Genomics, LGC Genomics and Source BioScience where appropriate. The following language should be used 'Samples from the English Longitudinal Study of Ageing DNA Repository (EDNAR), which receives support from the National Institute on Aging (NIA) and the Economic and Social Research Council (ESRC), were used in this study. We thank contributors and the ELSA participants’.
5. Data provided to the applicants can only be used for the purposes originally stated and must not be used in any other way without re-application to the steering committee.
6. No data should be passed on to any third party unless they were specified in the original application.
7. No applications that request sole access to a specific phenotype will be accepted.
8. Any grant applications based on the genotyping data should include a covering letter from the Chair of METADAC stating that the project has been approved by the committee or will be considered on a specific date.
9. **Grant applications**

Applicants who require agreement before submitting grants should bear in mind that the METADAC must receive the completed research proposal form at least one month before the submission deadline. It is the responsibility of the researcher to ensure compliance with their funder’s terms and conditions with respect to their use of EDNAR data.

Supervisors are ultimately responsible for their PhD students in the same way that PIs are responsible for their researchers. We therefore request that any proposals for PhD projects are submitted jointly with the supervisor rather than the student themselves.

1. **Charges for access to genetic data**

ELSA receives funding from the National Institute on Aging and a consortium of Government Departments coordinated by the ESRC to support data collection and basic data management. This does not extend to providing support for individual projects, and researchers will be expected to meet the additional costs for data access and provision. There is no charges for access to the ELSA GWAS data when linkage to ELSA phenotypic variables is not requested. Applicants requesting linkage of ELSA GWAS data to a set of selected non-disclosive ELSA phenotypic variables will be charged a cost of £500 for the linkage. Please note, we cannot give discounts to PhD students or for any other reason.

Once a proposal has been approved by the METADAC, applicants are expected to submit a complete dataset of phenotypes they are requesting to be linked. These will be checked by the ELSA team to ensure they are specific to the project specified in the data access application and then approved for linkage. .

Data will **not** be provided until an invoice has been settled or a purchase order number is received by our finance department.

**Access to data**

1. No application can request to have sole access to a specific phenotype.
2. Any grant applications based on the data should include a covering letter from the Chair of METADAC stating that the project has been approved by the committee or will be considered on a specific date.
3. Data provided to the collaborators can only be used for the purposes originally stated and must not be used in any other way without re-application to the steering committee.
4. The applicants must notify the committee of any potential errors discovered with using the data.