

For office use…

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**Application** **for Access to Understanding Society Genotype, Epigenetic and Phenotype Data**

This form should be used to apply for requests that require links between genotype, epigenetic and other data

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| **1. Details of all applicants** |

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| **Principal Applicant Details** |
| Principal Applicant Name |  |  |
| Position Held |  |  |
| Affiliation |  |  |
| Address line 1 |  |  |
| Address line 2 |  |  |
| Email |  |  |
| Telephone |  |  |

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| **Contact Person Details** |
| Name of Contact Person |  |  |
| Position Held |  |  |
| Affiliation |  |  |
| Address line 1 |  |  |
| Address line 2 |  |  |
| Email |  |  |
| Telephone |  |  |

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| **Co-applicant Details** |
| Co-applicant 1 Name |  |  |
| Co-applicant 1 Affiliation |  |  |
| Co-applicant 2 Name |  |  |
| Co-applicant 2 Affiliation |  |  |
| Co-applicant 3 Name |  |  |
| Co-applicant 3 Affiliation |  |  |
| Co-applicant 4 Name |  |  |
| Co-applicant 4 Affiliation |  |  |
| Co-applicant 5 Name |  |  |
| Co-applicant 5 Affiliation |  |  |

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| **2. Project Details** |
| Title of the project  [less than 30 words] |  |  |
| Proposed Project start Date |  | DD/MM/YYYY: // |
| Project finish Date |  | DD/MM/YYYY: // |
| Key words for application |  |  |

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| **3. Brief description of project** |
| [10 key references maximum] |
| 1-2 sides of A4 Guidance |
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| **Please include a lay summary of your project** (150 words max.) | | |
| We plan to include this project description on the Understanding Society website. Please confirm you are happy for us to do this. |  | YES / NO  If No please explain why not. |

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| **4. Funding Details** |
| Has the project been peer reviewed? |  | YES / NO |
| When was the project reviewed |  | DD/MM/YYYY: // |
| Has the project been funded? |  | YES / NO |
| Name of funding organisation |  |  |
| Final Decision of the funders |  |  |
| Funding start date |  | DD/MM/YYYY: // |
| Funding end date |  | DD/MM/YYYY: // |

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| **5. Genome wide genotype and epigenetic data** |
| Data Required |  | **Genetic only  Epigenetic only Genetic and epigenetic** |
| *Notes* |  | *Understanding Society genotype data are derived from the Illumina human core exome array. The datafile has a sex indicator and age band variable.*  *Understanding Society epigenetic data are derived from the illumine methylation EPIC Beadchip. The data file is normalised and QC’d data using Bigmelon.*  *See https://bioconductor.org/packages/release/bioc/html/bigmelon.html*  *See* [*https://www.understandingsociety.ac.uk/documentation*](https://www.understandingsociety.ac.uk/documentation) *for information on the data available.*  *If you have any queries please contact the Understanding Society genetics team:* [*genetics@understandingsociety.ac.uk*](mailto:genetics@understandingsociety.ac.uk) |
| 5.a: Does your project require access to the full data file from the available genome wide and epigenetic scan(s)? |  | Given the extent of rare variants available in the exome part of the array, the range of other information that it will be possible to link to this file is limited. Limiting your application to the core part of the array will allow for a wider range of phenotype data to be linked.  Data required  Full human core exome array YES/NO  Common core variants of the array YES?NO |
| 5. b Please justify your request for the full genome scan |  |  |
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| 5.c: If No, does your project require access to specific SNPs and/or gene regions from the Illumina array(s)? |  | Please list the SNPs with their Rs number, their chromosome base position Hapmap build, and any potential proxy SNPs in an excel spreadsheet  Please list specific gene name and chromosome number for specific regions from the epigenetic array in an excel spreadsheet. |
| 5.d: Do you have a bioinformatician/statistician who can assist in the analysis of the data requested? |  | YES / NO |

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| **6. Other genotype data (none currently available):** |
| Do you want any other genotype data generated from Understanding Society?  i.e. individuals SNPs (see website ref for available list) |  | YES / NO |
| If YES, please specify the data you require. |  |  |

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| **7. Other data:** |
| *Notes* |  | *Although data are an infinite resource, they may be sensitive and are potentially disclosive. Careful attention is therefore paid to ensuring that data are not released in unjustifiably large amounts. Any requests for specific variables must be carefully justified.*  *See* [*https://www.understandingsociety.ac.uk/documentation*](https://www.understandingsociety.ac.uk/documentation) *for information on other data in Understanding Society* |
| Please detail the variables required and explain why they are necessary: |  | Please outline the kinds of variables you require here. Please attach an excel spreadsheet that includes the variable name and specific wave(s) for all variables that you require. |
| *Notes* |  | *Your intentions should be consistent with the project description in Section 3.*  It is important to note that once an award has been made, any future additions to the dataset (for example, if an additional linked phenotype variable is required) will have to be processed by the Understanding Society Data Access Committee (Technical Review Team) and must comply with the original application. If you do need additional variables to be added, you should therefore inform the Secretariat of the Access Committee. |

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| **8. New variables created by you** |
| Will any new variables be derived or produced by you or your project team as a result of any data obtained from the Understanding Society? |  | YES / NO / unsure  If no, you do not need to complete this section. Please proceed directly to question 9. |
| *Notes* |  | *This information is important, please read the Understanding Society Data Access Policy Annex 4 (weblink).* |
| If YES, please describe what variables you expect will be generated by your study |  |  |
| If yes, in order to obtain the data requested in this application, you should return these variables to enhance the Understanding Society resource within 3 months of the end of the agreement and we will then deposit them within 6 months. |  | Please confirm you agree to this.  YES / NO |

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| 9. information on genetic variants |
| Is it likely that your study will produce incidental information on genetic variants that could potentially meet three criteria:  (i) scientific validity (the genotyping is of adequate quality);  (ii) clinical significance (the disease or condition caused by the genetic variant is potentially serious) , and  (iii) potential benefit i.e. a valid approach exists to prevent or cure the condition/disease of concern and that early knowledge of the genetic risk to which an individual is exposed could enhance the efficacy of that prevention/cure). |  | YES / NO / unsure  If no, you do not need to complete this section. Please proceed directly to question 10. |
| *Notes* |  | *This information is important, please read the Understanding Society Data Access Policy Annex 4 (weblink).* |
| If YES, please describe what incidental information you believe might be generated by your study |  |  |
| If yes, in order to obtain this data requested in this application, you should return these data to Understanding Society within 3 months of the end of the agreement. |  | Please confirm you agree to this.  YES / NO |

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| **10.** Data Security |
| Every effort should be made to ensure the data are kept securely and only accessible to the named applicants. |  | Please confirm you agree to this  YES / NO |
| **Data Security Requirements**  Data should only be accessible to named users. Files should either have only user Unix read/write access, not group or world access, or project-specific Unix groups should be used for group access that contain only those names authorised to access the data. User IDs within groups should be reviewed at 6 monthly intervals by the applicant. Data kept on laptops or desktop computers should be encrypted when not in active use, either in individual encrypted files or in encrypted directories/partitions. Data should not be held on USB keys or other portable hard drives. Users may be asked to sign an agreement addressing their responsibilities with respect to access to such data. We maintain the right to audit IT security arrangements. | | |

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| **11. Agreement** |
| **To be completed by the Principal Applicant:** | |
| Can you confirm that you have read the above application and the information contained in it is true to the best of your knowledge? | | YES / NO |
| Do you agree to protect the confidentiality of Research Participants in any research papers, publications or other dissemination activities that you prepare by taking all reasonable care to limit the possibility of identification. | | YES / NO |
| Do you agree not to link or combine the data to other information or archived data available in a way that could re-identify the Research Participants, even if access to that data has been formally granted to you or is freely available without restriction. | | YES / NO |
| Do you understand that data and samples from the Understanding Society resource cannot be used for commercial purposes? | | YES / NO |
| Are you aware that if you, a member of your group, or your institution were to use these data for such a purpose *without* obtaining prior approval from the Understanding Society Data Access Committee, you will be in breach of the data transfer agreements, and that this might result in you being excluded from using the Understanding Society resource in the future? | | YES / NO |
| Do you understand that you must not pass on any data or any derived variables or genotypes generated by this application to a third party (i.e. to anybody that is not included in this list of applicants on this project, nor is a direct employee of one of these applicants)?  (This would include any sharing of individual level data with a publically accessible archive). | | YES / NO |
| Are you aware that any third party seeking to use data, samples, or derived variables or genotypes arising from this application must approach the Understanding Society Data Access Committee to obtain access permission of their own? | | YES / NO |
| Any publications resulting from the use of these data must include an acknowledgment to the study, and a copy of publication must be provided to the Understanding Society. Do you agree to this condition  ***Acknowledgment to be included in any publication based on these data***  *These data are from Understanding Society: The UK Household Longitudinal Study, which is led by the Institute for Social and Economic Research at the University of Essex and funded by the Economic and Social Research Council (Grant Number: ES/M008592/1). The data were collected by NatCen and the genome wide scan data were analysed by the Wellcome Trust Sanger Institute. Information on how to access the data can be found on the Understanding Society website* [*https://www.understandingsociety.ac.uk/*](https://www.understandingsociety.ac.uk/)  *Please ensure the study is acknowledged in any publications that arise using the data including the grant number.* | | YES / NO |
| Do you understand that if a problem arises involving any misuse of the Understanding Society data provided for this project - that violates any of the terms and conditions specified by this agreement that you have signed (as the principal applicant) - this will mean that you will be held responsible, and that this might result in you being excluded from using the Understanding Society resource in the future? | | YES / NO |
| Signature:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Print Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |

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| **Please send completed forms to:** |
| Dr Stephanie Roberts  METADAC Committee Secretariat  D2K Group, PEALS  Newcastle University  Email: [metadac@newcastle.ac.uk](mailto:metadac@newcastle.ac.uk) | |

**For Understanding Society office use only:**

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| METADAC reference number: |  |
| Date approved by METADAC: |  |
| Date data released: |  |
| Understanding Society Director (signature): |  |