

# WTCCC Data Access Agreement:

*Consortium* means the Wellcome Trust Case-Control Consortium, a group of Wellcome Trust-funded investigators, a list of which can be found on the study website [www.wtccc.org.uk](http://www.wtccc.org.uk).

Data means all and any human genetic data obtained from the Consortium.

Data Subject means a person, who has been informed of the purpose for which the Data is held and has given his/her informed consent thereto.

User means a researcher whose User Institution has previously completed this Data Access Agreement and has received acknowledgement of its acceptance.

Publications means, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

User Institution means the organisation at which the User is employed, affiliated or enrolled.

## Terms and Conditions

In signing this Agreement:

1. You agree to use the Data only for the advancement of medical research, according to the consent obtained from sample donors.
2. You agree not to use the data from the 1958 British Birth Cohort or any part thereof for the creation of products for sale or for any commercial purpose.
3. You agree to preserve, at all times, the confidentiality of information and Data pertaining to Data Subjects. In particular, You undertake not to use, or attempt to use the Data to compromise or otherwise infringe the confidentiality of information on Data Subjects and their right to privacy.
4. You agree not to attempt to link the data provided under this agreement to other information or archive data available for the data sets provided, even if access to that data has been formally granted to you, or it is freely available without restriction, without specific permission being sought from the relevant access committees.
5. You agree not to transfer or disclose the Data, in whole or part, or any identifiable material derived from the Data, to others, except as necessary for data/safety monitoring or programme management. Should You wish to share the Data with a collaborator outwith the same Institution, a revised application to include the collaborator must be submitted and the third party must sign the Data Access Agreement.
6. You agree to use the data for the approved purpose and project described in your application; use of the data for a new purpose or project will require a new application and approval.
7. In the exceptional circumstance that we establish a Data access account using a non-institutional email address, You will inform the EGA if you move or change User Institution.
8. You accept that Data will be reissued from time to time, with suitable versioning. If the reissue is at the request of sample donors and/or other ethical scrutiny, You will destroy earlier versions of the Data.
9. You agree to abide by the terms outlined in the 'Publications Policy' as set out in Schedule 1.

10. You agree to acknowledge in any work based in whole or part on the Data, the published paper from which the Data derives, the version of the data, the role of the Consortium (if any), the relevant primary collectors and their funders. Suitable wording is provided in the Publications Policy given in Schedule 1.

11. You accept that the Consortium, the original data creators, depositors or copyright holders, or the funders of the Data or any part of the Data supplied:

a) bear no legal responsibility for the accuracy or comprehensiveness of the Data; and b) accept no liability for indirect, consequential, or incidental, damages or losses arising from use of the Data, or from the unavailability of, or break in access to, the Data for whatever reason.

12. You understand and acknowledge that the Data is protected by copyright and other intellectual property rights, and that duplication, except as reasonably required to carry out Your research with the Data, or sale of all or part of the Data on any media is not permitted.

13. You recognise that nothing in this agreement shall operate to transfer to the User Institution any intellectual property rights relating to the Data. The User Institution has the right to develop intellectual property based on comparisons with their own data.

14. You accept that this agreement will terminate immediately upon any breach of this agreement by You and You will be required to destroy any Data held.

15. You accept that it may be necessary for the Consortium, or their appointed agents to alter the terms of this agreement from time to time in order to address new concerns. In this event, You will be contacted and informed of any changes and Your continued use of the Data shall be dependent on all parties entering into a new version of the Agreement.

16. You agree that you will submit a report to the Consortium Data Access Committee, if requested, on completion of the agreed purpose. The Consortium Data Access Committee agrees to treat the report and all information, data, results, and conclusions contained within such report as confidential information belonging to the User Institution.

17. You accept that the Data is protected by and subject to international laws, including but not limited to the UK Data Protection Act 1998, and that You are responsible for ensuring compliance with any such applicable law. The Consortium Data Access Committee reserves the right to request and inspect data security and management documentation to ensure the adequacy of data protection measures in countries that have no national laws comparable to that which pertain in the EEA.

18. This agreement shall be interpreted and construed in accordance with the laws of the country of the defending party, in cases where your Institution is the defending party, or the laws of England and Wales, in cases where the Wellcome Trust is the defending party. Unless specified otherwise, reference in this agreement to a statute refers to that statute as it may be amended, or to any restated or successor legislation of comparable effect.

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## Publications Policy

The release of pre-publication data from large resource-generating scientific projects was the subject of a meeting held in January 2003, the "Fort Lauderdale meeting", sponsored by the Wellcome Trust. The report from that meeting can be viewed at [http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy\\_communications/documents/web\\_document/wtd003207.pdf](http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtd003207.pdf).

The recommendations of the Fort Lauderdale meeting address the roles and responsibilities of data producers, data users, and funders of 'community resource

projects', with the aim of establishing and maintaining an appropriate balance between the interests of data users in rapid access to data and the needs of data producers to receive recognition for their work.

The WTCCC has agreed to follow these data-release principles and as such, these data are being released as a 'community resource project' as defined in the report of the Fort Lauderdale meeting. The WTCCC, as a data producer, reserves the right to publish the initial global analyses of the data. In so doing, it will also ensure that the data generated are fully described.

## Purpose of WTCCC

The primary purpose of the Wellcome Trust Case-Control Consortium (WTCCC) is to accelerate efforts to identify genome sequence variants influencing major causes of human morbidity and mortality, through implementation and analysis of large-scale genome-wide association studies. Additional objectives include the development and validation of informatics and analytical solutions appropriate to the scale and nature of the project, as well as use of the data generated to answer important methodological and biological questions relevant to association studies in general, and in the UK in particular.

The Consortium anticipates that data generated from the project will be used by others, such as required for developing new analytical methods, in understanding patterns of polymorphism and in guiding selection of markers to map genes involved in specific diseases. A detailed list of the projects carried out by the WTCCC can be found at [www.wtccc.org.uk](http://www.wtccc.org.uk). Briefly, the aims of the projects are as follows:

### WTCCC1

Analysis of genetic data (single SNPs, CNV probes and multi-marker analyses) for association with the following phenotypes and closely related phenotypes, analysed singly and jointly:

Bipolar Disorder, Coronary Artery Disease, Crohn's Disease, Hypertension, Rheumatoid Arthritis, Type 1 Diabetes, Type 2 Diabetes, Ankylosing Spondylitis, Autoimmune Thyroid Disease, Breast Cancer, Multiple Sclerosis, Tuberculosis and Malaria.

Samples from the 1958 British Birth Cohort and the UK National Blood Service will also be analysed as control groups.

### WTCCC2

Analysis of genetic data (single and multi-marker), including imputation of SNPs and classical HLA types, for association with the following phenotypes, and closely related phenotypes, analysed singly and jointly:

Ankylosing Spondylitis; Barrett's Oesophagus and Oesophageal Adenocarcinoma and subtypes; Bacteraemia Susceptibility and subtypes; Multiple Sclerosis; Parkinson's Disease; Pharmacogenomics of Statin Response; Pre-eclampsia and subtypes; Psoriasis; Psychosis endophenotypes; Reading and Mathematical abilities; Schizophrenia (broad and narrow definition phenotypes); Ulcerative Colitis; Visceral Leishmaniasis.

Development and application of methods and identification of markers informative for population structure, natural selection and sample relatedness.

Association testing, detection and typing and method development using CNV data.

### WTCCC3

Analysis of genetic data (single SNPs, CNV probes and multi-marker analyses), including imputation of SNPs and classical HLA types, for association with the following phenotypes, and closely related phenotypes, analysed singly and jointly:

Anorexia Nervosa; End stage renal failure; HIV host control; Intracerebral haemorrhage; Pre-eclampsia; Primary Biliary Cirrhosis; Renal Transplant Dysfunction.

## Acknowledgement

Authors who use data from the Wellcome Trust Case-Control project must acknowledge the WTCCC using the following wording "*This study makes use of data generated by the Wellcome Trust Case-Control Consortium. A full list of the investigators who contributed to the generation of the data is available from [www.wtccc.org.uk](http://www.wtccc.org.uk). Funding for the project was provided by the Wellcome Trust under award 076113, 085475 and 090355*" and cite the relevant primary WTCCC publication (details of which can be found on the WTCCC website).

Users should note that the Consortium and/or Individual Investigators bear no responsibility for the further analysis or interpretation of these data, over and above that published by the Consortium.

## Agreement

I have read and agree to abide by the terms and conditions outlined in the Data Access Agreement

Name:

Institution:

Signature :

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