

# WTCCC: Access to Genotype Data

## 1. General principles

The Wellcome Trust case-control Consortium Data Access Committee will consider applications for access to anonymised genotype data generated as a result of the Consortium activities. Access to data will be granted to qualified researchers for appropriate use. A qualified researcher refers to a scientist who is employed, or a student enrolled at, or legitimately affiliated with an academic, non-profit or government institution, or a commercial company.

The data will be deposited in the European Genotype Archive (EGA) and access will be by application to the Consortium Data Access Committee (CDAC). Access to data will be granted to researchers for appropriate use and will be governed by the provisions laid out in the associated informed consent for each cohort or collection, and the terms contained in the Data Access Agreement.

The Consortium Data Access Committee is concerned only with access to the core, anonymised, genotype data generated by this study. The only phenotypic information held by the Consortium is that which is implied by membership of a particular case or control group. Data will be accompanied by information on the sex, age and broad geographical region of collection/residence. The Committee will not consider requests for more detailed phenotypic information which is held by the principal investigators for the individual case collections. Access to this data would be by arrangement with the relevant principal investigator.

In 2008, the 1958 Birth Cohort Interim Access Committee agreed that all anonymised genotype data generated from 1958BC samples should be accessed through the CDAC. Any request for additional phenotype information beyond that which is normally supplied with the anonymised genotype data will be referred to the 1958 Birth Cohorts Access Committee for consideration.

Access is conditional upon availability of samples and/or data and signed agreement by the researcher(s) and the responsible employing Institution to abide by policies related to publication, data disposal, ethical approval and confidentiality.

## 2. Application procedure

Applicants requesting access to data from the WTCCC will be asked to complete a basic application form and to agree to the terms and conditions laid out in the Data Access Agreement (DAA). The DAA must be signed by both the applicant and the relevant Head of Department, Head of Institute, or equivalent.

Successful applicants who have access to data will be designated "Registered Users" and will be issued with a username and password by the EGA to enable access to the database.

The Committee will consider applications that include named collaborators, but each Institution must sign a separate Data Access Agreement. Should you wish to share the data with additional collaborators not previously approved, they must make a separate application for access to the Data.

Applicants agree to use the data for the approved purpose and project described in the application; use of the data for a new purpose or project will require a new application and approval.

Details of the application procedure, along with the relevant forms, can be found at [www.wtccc.org.uk](http://www.wtccc.org.uk) under the 'Access to Data' tab.

## 3. Membership of Consortium Data Access Committee

**Professor Martin Bobrow**, Chair

**Professor Michael Parker**, Ethox Centre, University of Oxford

**Professor Ousman Nyan**, MRC Laboratories, The Gambia

**Professor D Timothy Bishop**, Epidemiology and Biostatistics, University of Leeds

**Professor Paul Burton**, Department of Genetic Epidemiology, University of Leicester (*ex officio*)

#### 4. Assessment Criteria

Each application will be assessed to determine if:

- it has been submitted by a qualified researcher or researchers, embedded in a recognised research institution that can provide institutional responsibility for appropriate research governance
- the project described constitutes 'biomedical research' in the context of the consent process, and is likely to be understood as such by the sample donors
- it breaches any of the ethical permissions or restrictions in the consent forms for any component cohort or collection
- it has the potential to produce information that will enable identification of individual participants
- that PhD students include details of their research supervisors
- the research breaches the Fort Lauderdale terms of data sharing for "Community Resource Projects", the WTCCC being considered to be such a project.

In considering applications, the CDAC have clarified their policies in regard to specific data access requests. The Committee has agreed that:

- CDAC does NOT attempt to peer review the scientific quality of proposals. However, it does ask for a brief summary of the research to be undertaken, in order to judge whether it falls within the scope of the consents. It also considers that grossly inadequate research is ethically questionable, and reserves the right to refer back for clarification those requests that do not appear to attain even a minimal standard of competence
- unless specifically restricted in the consent documents for a particular collection or cohort, the use of data by commercial companies for commercial purposes is permissible. A current exception to this relates to data generated from the 1958 British Birth Cohort, as the consent documents exclude the use of data or samples for any commercial purpose
- research in the genetics of learning ability has been considered 'biomedical research'
- use of anonymised data in teaching is permissible, with the proviso that datasets for specific disease collections are not identified by name of disease, and that the data must not be removed from the teaching laboratory, in order to protect the confidentiality of the participants

#### 5. Data Available

Please visit [www.wtccc.org.uk](http://www.wtccc.org.uk) to view the datasets available. Individual-level genotypes for all SNPs typed in the course of this study will be accompanied by:

- Chromosome position and strand information
- age at onset or collection (in 10 year age bands)
- broad geographical region of residence
- sex

The ethnicity of the participants in the 1958 British Birth Cohort was recorded by a school medical officer at ages 11 and 16, and self-declared by cohort members at age 33 and 43. The DNA samples issued to the WTCCC were restricted to those 97% of the cohort who are Caucasian. The samples tested are therefore estimated to be 99.8% Caucasoid.

The ethnicity of the UK Blood Service control group was self-declared as 99% Caucasian.

#### 6. Availability of DNA samples

DNA samples from the 1500 UK Blood Service Control group are available by request from Dr Willem Ouwehand, Department of Haematology, University of Cambridge by emailing: [ukbscc\\_info@bloodomics.org](mailto:ukbscc_info@bloodomics.org)

DNA samples from the 1958 British Birth Cohort can be obtained by application to the 1958 British Birth Cohorts Committee which can be found at: [www.b58cgene.sgul.ac.uk/application.php](http://www.b58cgene.sgul.ac.uk/application.php)

Note that the disease collection DNA samples used in the WTCCC are not available through the Data Access Committee. Some samples may be available through the specific disease investigators and/or their research sponsors, and you should contact them directly to explore the options. The contact details for principal investigators can be found at: [www.wtccc.org.uk](http://www.wtccc.org.uk)