

# DATA ACCESS AGREEMENT FOR TELETHON KIDS INSTITUTE ABORIGINAL GENETICS AND HEALTH GENOME-WIDE ASSOCIATION AND SEQUENCING STUDIES

This agreement governs the terms on which access will be granted to Beadchip- or Sequence-derived DNA variant data generated by Aboriginal Genetics and Health Studies based at the Telethon Kids Institute, Perth, Western Australia, including studies carried out in collaboration with the Menzies School of Health Research, Darwin, Northern Territory.

In signing this agreement, You are agreeing to be bound by the terms and conditions of access set out in this agreement.

For the sake of clarity, the terms of access set out in this agreement apply both to the User and the User's Institution (as defined below). User Institution and User are referred to within the agreement as "You" and "Your" shall be construed accordingly.

## Definitions:

*AGHS* means the Aboriginal Genetics and Health Studies based at the Telethon Kids Institute, as listed on the EGA website <https://www.ebi.ac.uk/ega/dacs/EGAC00001000261>

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

*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.

*EGA* means the European Genome-phenome Archive, which distributes *AGHS* genotype data.

## 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 or any part thereof for the creation of products for sale or for any commercial purpose other than as baseline data for diagnostic services for rare diseases in Australian Aboriginal people.
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 data access committee.

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, the third party must make a separate application for access to the Data.
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 *AGHS* (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 *AGHS*, 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 which are the property of Telethon Kids Institute or the Menzies School of Health Research and the relevant local Aboriginal Health Services where the studies took place, 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 *AGHS*, 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 *AGHS* Data Access Committee, if requested, on completion of the agreed purpose. The *AGHS* 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 Australian Government Privacy Act of 1988, and that You are responsible for ensuring compliance with any such applicable law. The *AGHS* 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 Australia.

18. Without prejudice to any right of a party to institute proceedings in a court of competent jurisdiction, any dispute between the parties shall, in good faith, first be sought to be resolved by negotiation between each party's nominated representative. If the dispute is not resolved within 20 days, the parties will explore alternative dispute resolution methods.
19. This agreement shall be construed, interpreted and governed by the laws of Australia and shall be subject to the non-exclusive jurisdiction of the Australian courts.

## SCHEDULE 1

### 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/assets/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 Telethon Kids Institute and the Menzies School of Health Research have 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 Telethon Kids Institute and the Menzies School of Health Research, as data producers, reserve 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 Telethon Kids Institute Aboriginal Genetics and Health Studies**

The primary purpose of the Telethon Kids Institute Aboriginal Genetics and Health Studies is to accelerate efforts to identify genomic sequence variants influencing major causes of morbidity and mortality in Aboriginal Australians, through implementation and analysis of genome-wide studies. Additional objectives include the development of culturally appropriate practices, as well as use of the data generated to answer important methodological and biological questions relevant to genome-wide studies in general, and in Aboriginal Australians in particular.

The Telethon Kids Institute and the Menzies School of Health Research anticipate that data generated from the projects will be used by others, such as required for developing new analytical methods, in understanding patterns of polymorphism and in informing techniques to map and identify genes/genetic variation involved in specific diseases. A list of the projects carried out by the Telethon Kids Institute can be found at <http://bioinformatics.childhealthresearch.org.au/AGHS>.

### Acknowledgement

Authors who use data from the Telethon Kids Institute Aboriginal Genetics and Health projects must acknowledge the source using the following wording "*This study makes use of data generated by the Telethon Kids Institute. A full list of the investigators who contributed to the generation of the data is available from the publications listed at <http://bioinformatics.childhealthresearch.org.au/AGHS>. Funding for the projects was provided by the National Health and Medical Research Council of Australia (NHMRC) under award 634301 or 1023462 (as appropriate)*" and cite the relevant primary publication (details of which can be found on the AGHS website).

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

**For and on behalf of User:**

Name of applicant(s):

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Signature of applicant(s):

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**For and on behalf of the User Institution:**

Signature of institutional or  
administrative authority:

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Print name:

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Position within institute:

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User institution:

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Date:

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