

NIDDK IBD Genetics Consortium

Data Use Agreement

Preamble

The NIDDK Inflammatory Bowel Disease Genetics Consortium (hereafter “IBDGC”) distributes data products for use by Consortium members and by the research community. The IBDGC also distributes data products on behalf of the International IBD Genetics Consortium (hereafter “IIBDGC”). Much of these data are distributed through NIH data repositories such as the NIDDK Central Repository and dbGaP. Any data obtained through one of those repositories are subject to the Data Use Agreement required by that repository, and are not addressed here. This document addresses data products accessed through the IBDGC Data Commons or otherwise distributed directly by the IBDGC Data Coordinating Center (hereafter “DCC”). This agreement does not cover the transfer or use of biological samples.

Three types of data products are covered here. Open and unrestricted data (hereafter “open data”) may be downloaded or used without review or approval. Restricted data (hereafter “restricted data”) require approval by the DCC to verify that the data are being used for scientific research purposes only and that adequate plans for protecting the confidentiality of research participants are in place. Internal data products (hereafter “internal data”) are for use by members of the IBDGC or IIBDGC and their collaborators and require prior approval by the IBDGC Steering Committee or IIBDGC Management Committee; such approval typically requires submission of a Project Proposal Form (hereafter “PPF”). *All data products distributed by the IBDGC are subject to the terms of this agreement.*

Members of the IBDGC or IIBDGC who submit data for Consortium projects are permitted to access their own data, or data products derived from their data only, at any time without restriction.

This DUA may include one or more appendices depending on the data being requested. Terms and conditions specified in those appendices are considered part of the DUA.

Terms and Conditions

The following terms and conditions apply to all data distributed by the IBDGC or its DCC:

1. *Any attempt to re-identify or contact individual study participants for any reason, including for obtaining or linking additional information for analytic purposes, is strictly forbidden.* Users who wish to augment a dataset with external information must contact the DCC first to discuss their desired objective and, if permissible, to determine an appropriate mechanism for accomplishing it.
2. Data users alone are responsible for obtaining IRB approval from their local institution for their activities, if necessary, prior to accessing the data; in most cases, this should be available via an expedited request. In some cases, the DCC may ask you to supply certification of IRB approval before granting access. Data users are also responsible for complying with any other governmental or institutional requirements that may pertain to their possession or use of the data.
3. Use of these data in publications or presentations must acknowledge the source of the data. A suggested acknowledgement is provided along with the data product and is also available on the IBDGC website (<https://ibdgc.org>, for IBDGC data) or IIBDGC website (<https://www.ibdgenetics.org>, for IIBDGC data).

4. Redistribution of the data by posting them on a website or submitting them to a data or code repository is not permitted. Users wishing to share their work so that others may reproduce it should *post their code only to a code repository* (e.g., GitHub) and include instructions for accessing or requesting access to the data directly from the IBDGC Data Commons or DCC, making sure to include information on the version of the data product used in the analysis. Redistribution may be permitted in certain cases (e.g., including summary statistics as part of a larger collection or reference dataset); please contact the DCC for permission.
5. Your authorization credentials (e.g., your username and password or API key) are for your use only and must not be shared with others for the purpose of accessing data. If someone you know is having trouble accessing a data resource or has not yet been authorized to do so, that person should contact the DCC.
6. All data are provided as-is and without any assurances either explicit or implied. Neither the IBDGC nor the IIBDGC assumes any responsibility for results obtained from the data.
7. You are strongly encouraged to notify the DCC after a paper using the data has been accepted for publication, so that it may be added to the list of publications that have used the data. In some cases, this may be required as specified in an appendix to this DUA.

By signing this document, I hereby certify that:

- a. I have read and understand all of the terms and conditions specified in this DUA including those specified in any attached appendices, and agree to abide by them.
- b. I understand that unless explicitly prohibited by this DUA, I may make these data available to individuals working directly under my supervision, and if I do it is my responsibility to make sure that they adhere to the terms and conditions of this DUA at all times.
- c. I understand that failure to comply with these terms and conditions may result in immediate termination of data access privileges.

Name

Institution

Signature

Date

Email address

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Appendix: IIBDGC Internal Use Only**

Certain preliminary, pre-publication or customized data products are intended for internal use by IIBDGC members only. These are subject to the following additional terms and conditions:

1. All internal data are to be treated as strictly confidential unless otherwise noted, and must not be redistributed or shared with anyone outside the IIBDGC without prior permission from the IIBDGC Management Committee (hereafter “MC”).
2. Internal, individual-level genotype or phenotype data are to be used for Consortium-approved projects only. Any other use (including personal projects of any kind) requires submission of a project proposal to the MC, and work cannot begin until you have received approval. *Preliminary or pre-publication summary statistics may be used by IIBDGC members on a limited basis for exploratory and planning purposes without prior approval by the MC, with the understanding that members will not use this access to pre-empt approved Consortium projects or to attempt to avoid submitting a project proposal form.*