

Acknowledgement of Memo of Understanding

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Graham Radford-Smith, G. L.
Mary Radford-Smith

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Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

ANZ IBD CONSORTIUM

Name of local/regional/national group that you are representing or indicate "not applicable" ***

G. L. RADFORD-SMITH, Mary Radford-Smith

Name and Signature ***

31/3/19

Date

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"

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Lynnette R. Ferguson
L.R. Ferguson

Name and Signature

The University of Auckland

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Email

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20/03/2019

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Version_28.January.2019

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Mark J. Daly



Name and Signature

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Name and Signature

The Broad Institute

Institutional Affiliation

75 Ames St, Cambridge MA USA

Institutional Address

+1 (617) 643-3297

Telephone

hhuang@broadinstitute.org

Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)? Y

I will be representing for a group of Chinese clinicians who aim to build a large-scale IBD cohort of Chinese ancestry

Name of local/regional/national group that you are representing or indicate “not applicable” ***

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Name and Signature : Caren Heller, MD, MBA

Crohn's & Colitis Foundation

Institutional Affiliation

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Institutional Address

212.943.7505
Telephone

grant@crohnscolitisfoundation.org
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

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Version_28.January.2019

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Name and Signature

CEDARS-SINAI MEDICAL CENTER

Institutional Affiliation

8730 ADEN DRIVE, LOS ANGELES, CA 90025, USA

Institutional Address

001 310 423 1485

Telephone

mcgovern.d@cshs.org

Email

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CEDARS-SINAI IBD GROUP, UNIVERSITY OF PUERTO RICO

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Institutional Affiliation

Institutional Address

267 426 0088

Telephone

HAKONARSON@CHOP.EDU

Email

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CHOP STIC (Pediatric Consenting or IBD)

Name of local/regional/national group that you are representing or indicate "not applicable" ***

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Acknowledgement of Memo of Understanding

I understand and accept all of the requirements and responsibilities outlined above. I understand that failure to comply with this MOU may result in loss of access to IIBDGC-managed data as well as a notification being sent to my institutional representative.

Judith Kelsen
Name and Signature



Children's Hospital of Philadelphia
Institutional Affiliation

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Institutional Address

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Telephone

kelsen@email.chop.edu
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

no

Name of local/regional/national group that you are representing or indicate "not applicable" N/A

Judith Kelsen
Name and Signature ***



3/22/19
Date

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"

APPENDIX - III

Genome-Wide Association Study 2019 - Requirements & Data Use

Primary objective of this IIBDGC Project

- Identification of genomic regions, genes, genetic variants, haplotypes associated with CD, UC, IBD and associated clinical phenotypes

Details of Genome-Wide Association Study

This collaborative project aims to assemble the largest number of IBD cases (and controls) from the broadest set of worldwide populations to advance our understanding of the genetic basis of IBD and associated phenotypes.

In order to participate in the above-mentioned study, I agree to the following:

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RICHARD GEARY

Name and Signature

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Institutional Affiliation

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Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

N/A

Name of local/regional/national group that you are representing or indicate "not applicable" ***

RICHARD GEARY

Name and Signature ***

20/3/2019

Date

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JEAN-PAUL ACHKAR
Name and Signature

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Institutional Affiliation

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Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

Name of local/regional/national group that you are representing or indicate "not applicable" ***

JP Achkar
Name and Signature ***

3/23/2019
Date

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International IBD Genetics Consortium (IIBDGC)

Version_28 January 2019

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- Submit individual-level genotype, sequence, and/or other genomic data; if that is not possible, the MC may approve submission of summary data on a case-by-case basis. Genetic/genomic data should be submitted in accordance with the requirements of the specific project(s) for which they are intended. These project-specific requirements are outlined in Appendices to this document.
- Provide a letter stating that you have authority from your Institutional Review Board (IRB) or equivalent to share the data with the IIBDGC *and* in a public repository such as dbGaP or EMBL-EBI; if you do not have authority to share individual-level genotype data, the MC will consider permitting you to share summary data instead. Those who have already submitted their data to a public repository need only affirm this below and indicate how the data may be accessed from that location.
- Adherence to the principles outlined in the current document.

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VIBEKE ANDERSEN

Name and Signature

UNIVERSITY H. OF

Institutional Affiliation SOUTHERN DENMAR

KRESTEN PHILIPSENS VEJ 15

Institutional Address

+45 21 15 77 90

Telephone

va@rsyd.dk

Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

Y: The Danish IBD Genetics Working Group
Name of local/regional/national group that you are representing or indicate "not applicable" ***

VIBEKE ANDERSEN

Name and Signature ***

ORCID 0000-0002-

0127-2863,

26-02-2019

Date

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"

To share our data, we need a signed data processor agreement
with all data processors/consortium members who want to use our data.

This is signed with prejudice of approval from the Danish Ethics Committee and the Danish Data Protection Agency.

APPENDIX - III

Genome-Wide Association Study 2019 - Requirements & Data Use

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Version_28.January.2019

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Sobra KUGATHASAN
Name and Signature

EMORY UNIVERSITY
Institutional Affiliation

1760, Haygood Drive, HSRB, ATLANTA, GA 30322
Institutional Address

(404) 727 1316
Telephone

SKugath@Emory.EDU
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

Name of local/regional/national group that you are representing or indicate "not applicable" ***

African American IBD - Emory group

Name and Signature ***

SKugath

Date

MARCH 25th 2019

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"



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Version_28 January 2019

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Name and Signature


Institutional Affiliation

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Version_28.January.2019

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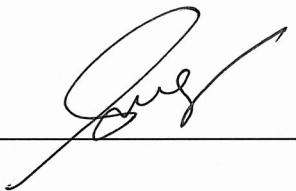
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Name and Signature



The Chinese University of Hong Kong
Institutional Affiliation

Department of Medicine & Therapeutics, 9/F, Lui Che Woo Clinical Sciences Building, Prince of Wales Hospital, Shatin
Institutional Address

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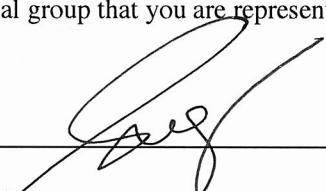
siewchiennng@cuhk.edu.hk
Email

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Not applicable

Name of local/regional/national group that you are representing or indicate "not applicable" ***

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Date 1/4/19

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Llore Franke

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Institutional Affiliation

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German IBD and PSC Genetics Study group
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Name and Signature ***

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Date

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Institut für Klinische Molekularbiologie
Direktorium
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T.L. ORCHARD *TL. Orchard*

Name and Signature

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Imperial College London

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Severine Vermeire
Name and Signature

University Hospitals Leuven and KU Leuven
Institutional Affiliation

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Institutional Address

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Telephone

Severine.Vermeire@uzleuven.be
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

N
Name of local/regional/national group that you are representing or indicate “not applicable” ***

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Name and Signature ***

March 11, 2019
Date

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Version_28.January.2019

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Name and Signature

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Lithuanian University of Health Sciences
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LTIBDGC

Name of local/regional/national group that you are representing or indicate "not applicable" ***

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11/04/19
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Name and Signature

Mass General Hospital for Children
Institutional Affiliation

175 Cambridge St Suite 567, Boston, MA 02114
Institutional Address

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Telephone

CJMORAN@MGH.HARVARD.EDU
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

N/A
Name of local/regional/national group that you are representing or indicate "not applicable" ***

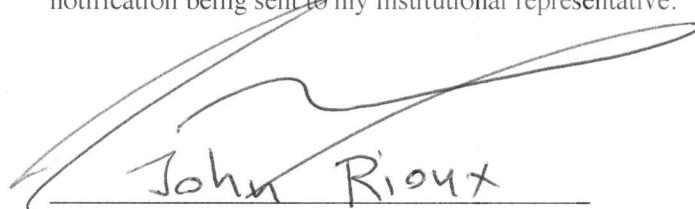
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Name and Signature

Montreal Heart Institute

Institutional Affiliation

500 rue Belanger, Montreal, QUE

Institutional Address

(514) 376-3330 x2181

Telephone

john.david.rioux@umontreal.ca

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JUDY CHO
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JCAHN SCHOOL OF MED
Institutional Affiliation @ MOUNT SINAI

ONE GUSTAVE LEVY PLACE
Institutional Address

203-506-1707
212-820-8000
Telephone

judy.cho@mssm.edu
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

NIDDC IBDGC CPI's to also sign)
Name of local/regional/national group that you are representing or indicate "not applicable" ***

JUDY CHO
Name and Signature ***

3.52.19
Date

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"



International IBD Genetics Consortium (IIBDGC)

Version_28.January.2019

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Acknowledgement of Memo of Understanding

I understand and accept all of the requirements and responsibilities outlined above. I understand that failure to comply with this MOU may result in loss of access to IIBDGC-managed data as well as a notification being sent to my institutional representative.

Prof. Dr. Weerma, MD, PhD
Name and Signature

University Medical Center Groningen
Institutional Affiliation

Hanzeplein 1, P.O.Box 30001 Groningen NETHERLANDS
Institutional Address

+31 (0) 50 3616161
Telephone

D.U. WEERMA @ UNGO.NL
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

INITIATIVE ON CROHN AND COLITIS

Name of local/regional/national group that you are representing or indicate "not applicable" ***

DU Weerma
Name and Signature ***

20 March 2019
Date

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Version_28.January.2019

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Richard H. Duerr

Name and Signature

University of Pittsburgh

Institutional Affiliation

Room: BSTWR-S704, 200 Lothrop Street, Pittsburgh, PA 15261

Institutional Address

412-648-9497

Telephone

duerr@pitt.edu

Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

Name of local/regional/national group that you are representing or indicate "not applicable" ***

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<u>Steven Brant</u>	<u>Rutgers University</u>
Name and Signature	Institutional Affiliation
<u>1 RWJ Place, MEB 478, New Brunswick, NJ 08901, USA</u>	
Institutional Address	
<u>732-235-6994</u>	<u>steven.brant@rutgers.edu</u>
Telephone (732-890-9752)	Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

Rutgers-Hopkins Genetics Research Center of the NIDDK-IBDGC
Name of local/regional/national group that you are representing or indicate "not applicable" ***

<u>Steven Brant</u>	<u>3/26/19</u>
Name and Signature ***	Date

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APPENDIX - III

Genome-Wide Association Study 2019 - Requirements & Data Use

Primary objective of this IIBDGC Project

- Identification of genomic regions, genes, genetic variants, haplotypes associated with CD, UC, IBD and associated clinical phenotypes

Details of Genome-Wide Association Study

This collaborative project aims to assemble the largest number of IBD cases (and controls) from the broadest set of worldwide populations to advance our understanding of the genetic basis of IBD and associated phenotypes.

In order to participate in the above-mentioned study, I agree to the following:

- *Submit genotype data according to the “IIBDGC Instructions for GWAS Data Submission”*
- *Submit phenotype data according to the “International IBD Genetics Consortium Core Sub-Phenotype Submission Guidelines”*
- *Genotype data should be submitted no later than 2019-02-28; complete phenotype data are due by 2019-05-10*
- Certify that I am not aware of any other group that is also submitting this data in whole or part

Data Use - Please check one of the following:

- I am including a letter authorizing me to share individual-level data in a public repository such as dbGaP, and have indicated which (if any) restrictions must be placed their use
- I have already deposited my data with a public repository such as dbGaP or EMBL-EBI, and am including instructions on how to access them
- I am not permitted to share individual-level data beyond the IIBDGC, but understand that my summary data will be deposited in a public repository
- I have permission from the MC to submit only summary data to the IIBGC, and understand that these summary data will be deposited in a public repository

APPENDIX - IV

Whole Exome Sequencing Study 2019 - Requirements & Data Use

Primary objective of this IIBDGC Project

- Identification of genomic regions, genes, genetic variants, haplotypes associated with CD, UC, IBD and associated clinical phenotypes

Description of Whole Exome Sequencing Study

Please refer to APPENDIX V (entitled “Overview of Broad IBD Exome Sequencing Program) for an overview of the project that has been led by Mark Daly. Additional data (WES and/or WES data extracted from WGS) is welcome. VCF files generated as part of this project will be mirrored on the IIBDGC Data Commons described in the MOU.

In order to participate in the above-mentioned study, I agree to the following:

- *Submit sequence data according to the “IIBDGC Instructions for Sequence Data Submission”*
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- I am including a letter authorizing me to share individual-level data in a public repository such as dbGaP, and have indicated which (if any) restrictions must be placed their use
- I have already deposited my data with a public repository such as dbGaP or EMBL-EBI, and am including instructions on how to access them
- I am not permitted to share individual-level data beyond the IIBDGC, but understand that my summary data will be deposited in a public repository
- I have permission from the MC to submit only summary data to the IIBGC, and understand that these summary data will be deposited in a public repository



International IBD Genetics Consortium (IIBDGC)

Version_28.January.2019

Memorandum of Understanding

This Memorandum of Understanding (MOU) describes the arrangement by which members of the International IBD Genetics Consortium (IIBDGC) will submit data for the purpose of group projects, and in return have the opportunity to participate in those projects and propose projects of their own. Such data will be referred to below as “IIBDGC-managed data.” This MOU has been approved by the IIBDGC Management Committee (MC)—any changes will require approval of the MC.

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The mission of the IIBDGC is to (1) identify the genetic risk factors for the inflammatory bowel diseases (IBD), Crohn’s disease (CD), ulcerative colitis (UC), and related clinical phenotypes, (2) to determine how these risk factors interact with non-genetic risk factors impact on an individual’s risk to develop IBD, CD, UC and related phenotypes, (3) perform these studies in a collaborative fashion and to broadly share the results with the international scientific community in a responsible fashion. While the original projects were limited to genomic DNA genotype data, the IIBDGC will incorporate all different data types generated on different sample types that are necessary to achieve its mission.

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The Management Committee (MC) is responsible for (1) guiding the scientific direction of the IIBDGC, (2) providing oversight of IIBDGC projects, (3) communication with IIBDGC members, (4) conflict resolution, (5) outreach to the broader IBD and general scientific communities.

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Investigators wishing to participate in IIBDGC projects must comply with the following requirements:

- Submit data from a minimum of 500 research participants; exceptions to permit submitting fewer samples (at least 100) for cohorts of particular interest (e.g., rare phenotypes) will require approval by the MC and will be considered on a case-by-case basis.
- Submit corresponding core phenotype data as described in Cleynen et al. (PMID: 26490195), formatted according to the IIBDGC’s Core Sub-Phenotype Submission Guidelines (*see Appendix-II*); specific projects may have additional phenotype requirements.
- Submit individual-level genotype, sequence, and/or other genomic data; if that is not possible, the MC may approve submission of summary data on a case-by-case basis. Genetic/genomic data should be submitted in accordance with the requirements of the specific project(s) for which they are intended. These project-specific requirements are outlined in Appendices to this document.
- Provide a letter stating that you have authority from your Institutional Review Board (IRB) or equivalent to share the data with the IIBDGC *and* in a public repository such as dbGaP or EMBL-EBI; if you do not have authority to share individual-level genotype data, the MC will consider permitting you to share summary data instead. Those who have already submitted their data to a public repository need only affirm this below and indicate how the data may be accessed from that location.
- Adherence to the principles outlined in the current document.

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Access and use of IIBDGC-managed data is limited to projects that have obtained MC approval. Any IIBDGC member (or group of members) wishing to initiate a project must complete a Project Proposal form. All approved Project Proposals are made available to the full IIBDGC membership. Project Leaders are required to (1) form a Working group that ensures the successful completion of the project, (2) make Working Group activities open to all IIBDGC members, (3) report progress to the MC on a regular basis as defined by the MC, (4) ensure that all communications of research results (abstracts, manuscripts, etc.) obtain prior MC approval.

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IIBDGC Working Groups are responsible for drafting communication of research results (abstracts, manuscripts, etc.). IIBDGC Working Groups are responsible for drafting author lists. Author lists will reflect the contributions of IIBDGC members and IIBDGC Working Groups. Author lists should include the IIBDGC banner author. Working Groups must obtain MC approval of documents (e.g. manuscripts) and author lists prior to submission.

6. Intellectual Property

The IIBDGC aims to make all of its results and findings publicly available in a timely and responsible manner. The IIBDGC will not pursue the protection/filings of any intellectual property that it generates. IIBDGC members are free to pursue intellectual property protection of their own data at any time, but such IP-related activities can't prevent or delay the public release or publication of IBDGC results and findings. Other than the members own data, use of IIBDGC-managed data or results in intellectual property filings is allowed only after public release.

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All IIBDGC-managed data (e.g. genotype, phenotype, demographic, etc.) will be securely stored and managed by the NIDDK IBD Genetics Consortium (IBDGC) Data Coordinating Center (DCC) on behalf of the IIBDGC members (see below for details regarding Data Commons). All data should be submitted with a local participant or sample ID containing no identifying information (identifying information such as names, medical record numbers, or other will not be accepted). Upon receipt of new data, the DCC will assign a unique ID that will be used for all subsequent distribution and analysis.

The DCC will submit data to dbGaP on behalf of the IIBDGC, under the direction of the IIBDGC MC, unless those data have already been deposited elsewhere (see section below on Data Sharing).

It is possible that for specific projects some data types (e.g. large-scale sequence data) may be stored on another data platform at the request of the IIBDGC MC. In such circumstances, equivalent Data Management Requirements will be respected and will be made transparent to IIBDGC members via Project description included as an Appendix to the current MOU.

8. Data Access

Data access will be provided through the NIDDK IBDGC Data Commons (<https://ibdgc.datacommons.io/>) that uses the resources of the University of Chicago's Data Commons (<https://ctds.uchicago.edu/datacommons/>). Specific projects may also request access to compute resources within the commons. Before accessing the commons, users are required to provide proof that they have completed the required Human Subjects training at their local institution (e.g., a copy of their certificate) as well as complete the NIH Secure Remote Computing training course (<https://irtsectraining.nih.gov/publicuser.aspx>). Certificates of completion should be sent to Sondra Birch

(sbirch@uchicago.edu), together with your Gmail address (authentication to the commons is through Google's OAuth).

Investigators who have submitted data as well as other researchers and students working directly under their supervision may access IIBDGC-managed data for two purposes:

- Investigators may access and download their own data at any time without explicit permission from the MC. This MOU shall in no way limit an investigator's ability to use and publish his or her own data.
- Shared data may be accessed ONLY as part of an MC-approved project. Project proposals must be submitted to the MC for approval *before* data are accessed. In some cases, a project may also require completion of one or more additional Data Use Agreements (DUAs). Data accessed for a specific project must be used solely for completing the objectives of that project as described in the project proposal. The project leader(s) are responsible for ensuring that data are being used for this purpose, and that they are being handled securely (including that any additional special restrictions attaching to a particular dataset are being followed). No sharing or use of IIBDGC-managed data outside of MC-approved projects is permitted. No publications of results obtained from IIBDGC-managed data is allowed without MC approval of the manuscript.

Investigators who have not submitted data but wish to use IIBDGC-managed data may also submit a project proposal to the MC.

IMPORTANT: Absolutely no redistribution of IIBDGC-managed data is permitted with the exception of an investigator's own data. Any data downloaded for local analysis must be handled and stored securely.

In the event that other/additional data management/data access infrastructure is required in the future, such a modification would require IIBDGC MC approval. It is possible that for specific projects some data types (e.g. large-scale sequence data) may be stored on another data platform at the request of the IIBDGC MC. In such circumstances, equivalent Data Access procedures will be respected and will be made transparent to IIBDGC members via Project description included as an Appendix to the current MOU.

9. Data Sharing

Individual-level genetic and/or genomic data (or in cases where that is not possible, summary data) will be submitted to dbGaP by the DCC within one year of the date on which the data became available for analysis. Data that have already been deposited in a public repository will not be submitted to dbGaP, but instead instructions will be included on how the data may be accessed.

10. Use of the IIBDGC name

No Participant shall use the name or logo of the IIBDGC for any commercial purposes (e.g. promotional material or other public announcement or disclosure) without the prior written consent of the MC.

11. Conflict Resolution

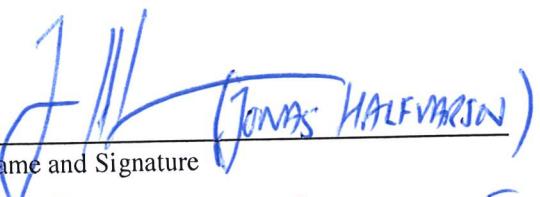
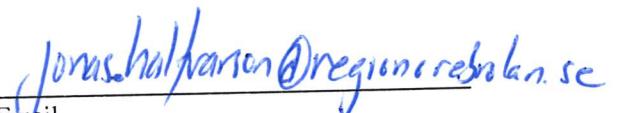
If any unresolved conflicts arise, the MC must be informed. MC decisions will be final.

12. Electronic Execution

Each Member intends that an electronic copy of its signature stored in a PDF software application format shall be regarded as an original signature and agrees that this MOU may be executed in any number of counterparts, each of which shall be effective upon delivery and thereafter shall be deemed an original, and all of which shall be taken to be one and the same instrument.

Acknowledgement of Memo of Understanding

I understand and accept all of the requirements and responsibilities outlined above. I understand that failure to comply with this MOU may result in loss of access to IIBDGC-managed data as well as a notification being sent to my institutional representative.

	<u>DEPT. OF GASTROENTEROLOGY, FACULTY OF MEDICINE AND HEALTH, ÖREBRO UNIVERSITY</u>
Name and Signature	Institutional Affiliation
<u>Campus USÖ, SE 70182 ÖREBRO, SWEDEN</u>	
Institutional Address	
<u>+46 738 082361</u>	
Telephone	Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

YES

SWEDISH NATIONAL PROGRAM ON GENETICS IN IBD (SNP IBD)

Name of local/regional/national group that you are representing or indicate "not applicable" ***

SNP IBD / J. HALVERSON

Name and Signature ***

12 FEB 2019

Date

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"

APPENDIX - III

Genome-Wide Association Study 2019 - Requirements & Data Use

Primary objective of this IIBDGC Project

- Identification of genomic regions, genes, genetic variants, haplotypes associated with CD, UC, IBD and associated clinical phenotypes

Details of Genome-Wide Association Study

This collaborative project aims to assemble the largest number of IBD cases (and controls) from the broadest set of worldwide populations to advance our understanding of the genetic basis of IBD and associated phenotypes.

In order to participate in the above-mentioned study, I agree to the following:

- Submit genotype data according to the "IIBDGC Instructions for GWAS Data Submission"
- Submit phenotype data according to the "International IBD Genetics Consortium Core Sub-Pheotype Submission Guidelines"
- Genotype data should be submitted no later than 2019-02-28; complete phenotype data are due by 2019-05-10
- Certify that I am not aware of any other group that is also submitting this data in whole or part

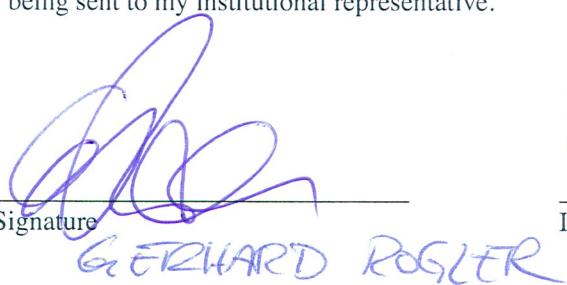
Data Use - Please check one of the following:

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Name and Signature



UniversitätsSpital Zürich
Prof. Dr. med. Dr. phil. Gerhard Rogler
Klinikdirektor
Klinik für Gastroenterologie und Hepatologie
Rämistrasse 100
8091 Zürich

Institutional Affiliation

Institutional Address

Telephone

0041 44 255 2401

Email

gerhard.rogler@usz.ch

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)? Y

Name of local/regional/national group that you are representing or indicate "not applicable" ***

Name and Signature ***

Date

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"

IIBDGC MOU 2019-01-28

UniversitätsSpital Zürich
Prof. Dr. med. Dr. phil. Gerhard Rogler
Klinikdirektor
Klinik für Gastroenterologie und Hepatologie
Rämistrasse 100
8091 Zürich

APPENDIX - IV

Whole Exome Sequencing Study 2019 - Requirements & Data Use

Primary objective of this IIBDGC Project

- Identification of genomic regions, genes, genetic variants, haplotypes associated with CD, UC, IBD and associated clinical phenotypes

Description of Whole Exome Sequencing Study

Please refer to APPENDIX V (entitled “Overview of Broad IBD Exome Sequencing Program) for an overview of the project that has been led by Mark Daly. Additional data (WES and/or WES data extracted from WGS) is welcome. VCF files generated as part of this project will be mirrored on the IIBDGC Data Commons described in the MOU.

In order to participate in the above-mentioned study, I agree to the following:

- *Submit sequence data according to the “IIBDGC Instructions for Sequence Data Submission”*
- *Submit phenotype data according to the “International IBD Genetics Consortium Core Sub-Phenotype Submission Guidelines”*
- *Genotype data should be submitted no later than 2019-02-28; complete phenotype data are due by 2019-05-10*
- Certify that I am not aware of any other group that is also submitting this data in whole or part

Data Use - Please check one of the following:

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International IBD Genetics Consortium (IIBDGC)

Version_28.January.2019

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- Submit corresponding core phenotype data as described in Cleynen et al. (PMID: 26490195), formatted according to the IIBDGC’s Core Sub-Phenotype Submission Guidelines (*see Appendix-II*); specific projects may have additional phenotype requirements.
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- Provide a letter stating that you have authority from your Institutional Review Board (IRB) or equivalent to share the data with the IIBDGC *and* in a public repository such as dbGaP or EMBL-EBI; if you do not have authority to share individual-level genotype data, the MC will consider permitting you to share summary data instead. Those who have already submitted their data to a public repository need only affirm this below and indicate how the data may be accessed from that location.
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All IIBDGC-managed data (e.g. genotype, phenotype, demographic, etc.) will be securely stored and managed by the NIDDK IBD Genetics Consortium (IBDGC) Data Coordinating Center (DCC) on behalf of the IIBDGC members (see below for details regarding Data Commons). All data should be submitted with a local participant or sample ID containing no identifying information (identifying information such as names, medical record numbers, or other will not be accepted). Upon receipt of new data, the DCC will assign a unique ID that will be used for all subsequent distribution and analysis.

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Data access will be provided through the NIDDK IBDGC Data Commons (<https://ibdgc.datacommons.io/>) that uses the resources of the University of Chicago's Data Commons (<https://ctds.uchicago.edu/datacommons/>). Specific projects may also request access to compute resources within the commons. Before accessing the commons, users are required to provide proof that they have completed the required Human Subjects training at their local institution (e.g., a copy of their certificate) as well as complete the NIH Secure Remote Computing training course (<https://irtsectraining.nih.gov/publicuser.aspx>). Certificates of completion should be sent to Sondra Birch

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Uroš Potočnik

Name and Signature

University of maribor, Faculty of Medicine,
Center for Human Molecular Genetics and Pharmacogenomics

Institutional Affiliation

Taborska 8, 2000 Maribor, Slovenia

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+386 2 2345854

Telephone

uros.potocnik@um.si

Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)? **Y**

NA

Name of local/regional/national group that you are representing or indicate “not applicable” ***

Prof. dr. Uroš Potočnik



Name and Signature ***

February 20, 2019

Date

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APPENDIX - III

Genome-Wide Association Study 2019 - Requirements & Data Use

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- Identification of genomic regions, genes, genetic variants, haplotypes associated with CD, UC, IBD and associated clinical phenotypes

Details of Genome-Wide Association Study

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International IBD Genetics Consortium (IIBDGC)

Version_28 January, 2019

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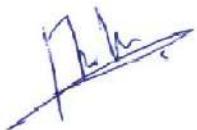
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Antonio Julià
Name and Signature



Vall Hebron Research Institute
Institutional Affiliation

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Institutional Address

+34 934029082
Telephone

toni.julia@vhir.org
Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

YES
Name of local/regional/national group that you are representing or indicate "not applicable" ***

IMID Consortium
Name and Signature ***

29th March 2019
Date

*** Please complete and return the "MOU list of contributors and Key Personnel.xlsx"



International IBD Genetics Consortium (IIBDGC)

Version_28.January.2019

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Harry SOKOL



Name and Signature

Saint Antoine Hospital, APHP

Institutional Affiliation

184 rue du Fg St Antoine, 75012, Paris, FRANCE

Institutional Address

+33 1 49 28 31 62

Telephone

harry.sokol@aphp.fr

Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)? Yes

St Antoine IBD Network (Network in St Antoine Hospital)

Name of local/regional/national group that you are representing or indicate “not applicable” ***

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Name and Signature ***

02/05/2019

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Version_28.January.2019

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Dr. Mark Silverberg



Name and Signature

Sinai Health System

Institutional Affiliation

600 University Ave., Toronto, ON, Canada M5G 1X5

Institutional Address

416-586-4800 x 8236

Telephone

mark.silverberg@sinahealth.ca

Email

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

Y NIDDK Toronto GRC

Name of local/regional/national group that you are representing or indicate "not applicable" ***

Dr. Mark Silverberg



Name and Signature ***

June 3, 2020

Date

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<u>Miles Parker</u>	<u>Jac</u>	<u>UK IBD Genetics Consortium</u>
Name and Signature		Institutional Affiliation
<u>Dept of Gastroenterology, Cambridge University Hospital</u>		
Institutional Address		
Telephone	Email	

Are you representing a group a local/regional/national group of researchers/clinicians (Y/N)?

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12 FEB 2019.

Date

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