



Dr. ___ Mr. ___ Ms. ___ _____
Last name, First name

WU-Minn HCP Terms for Access to Restricted Data

The WU-Minn HCP Consortium requires that the following Data Use Terms be signed, submitted and approved for investigators to receive access to Restricted Data generated by HCP. Given the distinctive family structure of the HCP population under study (twins and their non-twin siblings), these special precautions are essential in order to protect the privacy of our subjects and to prevent any inappropriate disclosure of subject identity.

A. Definitions of Restricted Data Elements covered by these terms:

- 1. Family structure.** Family structure (e.g., relationships as twins or non-twin siblings, but excluding birth order) is a core type of information that will be used for heritability analyses.
- 2. Additional Restricted Data Elements:** Given the population from which HCP subjects are drawn, some data elements in the Restricted Data, if used in combination with one another or with family structure information, could increase the risk that individual research subjects could be identified. Alternatively, some data elements might harm or embarrass individuals if they were inadvertently disclosed. These data elements are:
 - Handedness
 - Subject age by any finer granularity than the 5-year age ranges included in the Open Access Data
 - Birth order
 - Ethnicity and/or race
 - Body weight, height, and BMI
 - Color vision and visual correction measures
 - All data from the SSAGA telephone diagnostic interview
 - Drug test results
 - HbA1c and TSH results
 - Information on endocrine disorders and age of onset
 - Any psychiatric and neurologic illnesses of subjects' parents

Important: See section C for information on how these data elements may and may not be used in publications

B. Who Can Obtain Access:

Investigators are expected to meet one of the following criteria to be qualified to receive access to HCP Restricted Data:

1. You are a Principal Investigator (PI) of scientific research at a university, a research organization (including commercial entities) or a government agency who is the leader of a laboratory or research team or who is working independently; or
2. You provide the name of the PI who is overseeing your research and is approved for access under #1.
3. If you do not meet either of the above criteria you may be considered qualified based on a track record of scientific publications or on the basis of a written reference from someone who meets qualification #1, verifying that the data will be used only for the purpose of legitimate scientific research.

C. Obligations of Investigators

I request access to restricted data collected by the Washington University - University of Minnesota – University of Oxford Consortium of the Human Connectome Project (WU-Minn-Ox HCP).

IN ADDITION TO the rules I have accepted in the [Open Access Data Use Terms](#), to protect the privacy of HCP subjects I agree to abide by the following terms. Example scenarios illustrating these terms can be found at: <http://www.humanconnectome.org/restricted-access/>

_____ 1. I am a Principal Investigator (PI) as defined above in B.1.

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OR

I am not a PI.

We must receive an application from your PI before we can process your application.

Please complete and submit this application.

Name of PI (please print legibly) _____

_____ 2. **I will not redistribute or share Restricted Data** with others, including individuals in my laboratory, unless they have independently applied and been granted access to the Restricted Data by the HCP.

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_____ 3. I will **keep the Restricted Data secure (password protected)**, such the data are only accessible to individuals who have already been granted access).

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_____ 4. **Restrictions on publishing Restricted Data elements for individual subjects.** It is imperative that individual subjects not be recognizable to their family members or others through publication of combinations of restricted access data elements, either within or across publications. Therefore, I will abide by the following:

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a. **No reporting of HCP Subject ID numbers when publishing or publicly reporting analyses that use Restricted Data.** I will not include any HCP-assigned subject IDs in any publication or public presentation that makes use of Restricted Data from individual subjects. I will instead assign my own study-specific subject IDs to each individual, e.g. subjects A, B, C, etc.

b. **Family structure is the ONLY Restricted Data Element that can be reported for individual subjects in a publication or public presentation. As stipulated in 4a, when reporting family structure of subjects, individuals must be assigned study-specific subject IDs.**

c. If I publish data analyzed using Additional Restricted Data Elements (including handedness, exact age, ethnicity, race, body weight, and all other types listed in section A.2), each reported analysis must be based on at least 3 subjects, and the presentation of the data must not reveal the study-specific subject ID associated with any particular data point or value.

_____ 5. **Sharing of investigator-assigned subject ID numbers with other users of the Restricted Data.** Upon acceptance of each publication in which individual HCP data is reported, I will submit to HCP a key or legend that maps my investigator-assigned subject IDs to the corresponding HCP subject IDs, by following instructions given at <http://www.humanconnectome.org/data/key/>. This study-specific information will be made available to the community of HCP Restricted Data users, so that other investigators can better interpret my published findings. I will not publish this code or make it available independent of the HCP's distribution mechanism.

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_____ 6. I will comply with all relevant rules and regulations imposed by my institution. This may mean that I need my research to be approved by a committee that oversees research on human subjects, e.g. my IRB or Ethics Committee. The released HCP data are not considered de-identified, insofar as certain combinations of HCP Restricted Data might allow identification of individuals. Different committees operate under different national, state and local laws and may interpret regulations differently, so it is important to ask about this. If needed and upon request, the HCP will provide a certificate stating that you have accepted the HCP Restricted Data Use Terms.

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_____ 7. I affirm that I will use the Restricted Data exclusively for the purpose of scientific research, technology development, or education under the auspices of an academic, research, government or commercial entity.

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- _____ hand-initial 8. I agree to provide additional specific justification if requested before being granted access to any Restricted Data Elements judged by the HCP to warrant special handling (e.g., drug test results).
- _____ hand-initial 9. I also understand and have accepted the provisions in the [Open Access Data Use Terms](#).
- _____ hand-initial 10. I agree to delete specific HCP datasets if requested to do so by HCP Principal Investigator David Van Essen, e.g., if certain released datasets are found to have identifying information inadvertently included.
- _____ hand-initial 11. I understand that failure to abide by these rules may result in termination of my privileges to access WU-Minn HCP data. In addition, inappropriate use, redistribution or publication of restricted access data, including any actions that may violate the privacy of HCP subjects, may lead to HCP taking other actions against me, including informing my institution, relevant journal(s), and relevant funding agencies.

Applicant Information (required for all applicants):

Name: _____

Appointment or title: _____
(e.g. Professor, Postdoc, Graduate Student)

Institutional affiliation: _____

Highest academic degree: _____

Email address: _____

Daytime telephone number: _____

For PIs only: Names of non-PI applicants in your group who have applied or will be applying for access, to the extent known. All users of HCP Restricted Data **MUST** apply independently for access.

Applicant Signature Date

⇒ **NOTE: Applications with typed or computer-inserted initials and signatures will NOT be accepted. These must be done by hand.**

Additional Applicant Information

Investigators who wish to qualify for access to Restricted Data under the provisions of section B.3 (above) should send citations of selected scientific publications and/or the name of the PI who will be providing a letter of reference as outlined in B.3 to Ms. Erin Reid at erin@wustl.edu.

⇒ **Saving and submitting this application:** see next page

Applicants should save this completed, signed and hand-initialed form; **name it using your last name and first initial (example: Smith_S)**; and send it as a scanned pdf file to neuroscience-hcprda@email.wustl.edu or by fax to:

Erin Reid
Neuroscience Department
Washington University School of Medicine
Fax: 314-747-4370

⇒ Please note, it may take up to a week before your application is acknowledged.

Questions about this document and its provisions should be sent to Dr. Jennifer Elam elam@wustl.edu.