



GSP Restricted Access Data Use Terms

Last updated: Jan 28, 2015.

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

The following Data Use Terms must be signed, submitted and approved for investigators to receive access to Restricted Data generated by the Brain Genomics Superstruct Project (GSP). These special precautions are essential in order to protect the privacy of our subjects and to prevent any inappropriate disclosure of subject identity.

A. **Restricted Data Elements covered by these terms:** Given the population from which the GSP subjects are drawn, some data elements in the Restricted Data, if used in combination with one another 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:

- Health rating and satisfaction
- State-trait anxiety inventory for adults scores
- Neuroticism extraversion openness to experience, NEO five-factor model of personality scores
- Behavioral inhibition (BIS) and behavioral activation (BAS) scores
- Imaginal process inventory scores
- Barratt impulsivity scale scores
- Domain-specific, risk-taking scale scores
- Profile of mood states scores
- Temperament and character inventory scores
- Shipley vocabulary score
- Matrix reasoning scores
- Shipley and matrix reasoning estimated IQ

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 the GSP 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 as part of the Brain Genomics Superstruct Project (GSP) of Harvard University and the Massachusetts General Hospital. IN ADDITION TO the rules I have accepted in the GSP Open Access Data Use Terms, to protect the privacy of GSP subjects I agree to abide by the following terms. Example scenarios illustrating these terms can be found at: <http://www.humanconnectome.org/restricted-access/>

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

OR

I am not a PI.

Please complete and submit this application. **We must receive an application from your PI before we can process your application.**

Name of PI (please print legibly) _____

initial **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 GSP Restricted Data.

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

initial **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:

- a. **No reporting of GSP subject ID strings when publishing or publicly reporting analyses that use Restricted Data.** I will not include any

GSP-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. If I publish data analyzed using Restricted Data Elements (see section A above), 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.

initial 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 GSP data are not considered de-identified, insofar as certain combinations of GSP 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 GSP will provide a certificate stating that you have accepted the GSP Restricted Data Use Terms.

initial 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.

initial I agree to provide additional specific justification if requested before being granted access to any Restricted Data Elements judged by the GSP to warrant special handling.

initial I also understand and have accepted the provisions in the GSP Open Access Data Use Terms.

initial I agree to delete specific GSP datasets if requested to do so by GSP Principal Investigator Randy L. Buckner, e.g., if certain released datasets are found to have identifying information inadvertently included.

initial I understand that failure to abide by these rules may result in termination of my privileges to access GSP data. In addition, inappropriate use, redistribution or publication of restricted access data, including any actions that may violate the privacy of GSP subjects, may lead to GSP 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

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 GSP Restricted Data **MUST** apply independently for access.

Applicant Signature

Date

NOTE: Applications with typed initials and signatures will NOT be accepted.

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 the Neuroinformatics Research Group at gspdata@neuroinfo.org.

Saving and submitting this application

Applicants should save this completed, signed and initialed form; **name it using your last name and first initial (example: Smith_S)**; and send it as a scanned pdf file to gspdata@neuroinfo.org or by mail or fax to:

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Harvard University
52 Oxford St., Room 295.10
Cambridge, MA 02138

Fax: +1.617.496.9385

Questions about this document and its provisions should be sent to the Neuroinformatics Research Group at gspdata@neuroinfo.org.