



## **PPMI Data Use Agreement**

I request access to data collected by the Parkinson's Progression Markers Initiative (PPMI) for the purpose of scientific investigation, teaching, or the planning of clinical research studies and agree to the following terms:

1. I will receive de-identified data and will not attempt to establish the identity of or attempt to contact any of the PPMI subjects.
2. I will not further disclose these data beyond the uses outlined in this agreement and my data use application.
3. I will require anyone on my team who utilizes these data or anyone with whom I share these data to comply with this Data Use Agreement by registering with the PPMI database and agreeing to these terms.
4. I will accurately provide the requested information for persons who will use these data and the analyses that are planned using these data.
5. I will respond promptly and accurately to annual requests to update this information.
6. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.
7. I will comply with the PPMI Intellectual Property (IP) Policy that states:
  - a. Rights to any non-PPMI IP ("Background IP") that a researcher uses in analyzing or manipulating PPMI data, information, biospecimens, materials, or results ("Study Materials") may not be claimed by any other researcher or institution;
  - b. No researcher or institution may claim any IP rights to any Study Materials or inventions arising out of the Study Materials; and,
  - c. Researchers who publish or present analyses of Study Materials will make these freely available without charge to the research community through the PPMI website, when not prohibited by journal copyright terms and conditions.

In certain extraordinary situations, PPMI may grant a PPMI database user an exception to the PPMI IP Policy. All requests for exceptions to the PPMI IP Policy are reviewed by the PPMI IP Policy Exception Review Committee. This committee will meet every other month to review all applications received in time for the meeting. All applications submitted to this committee will be treated confidentially. [Click here to read the Conflict of Interest statement.](#) To read more about which situations may be eligible to receive an exception to the PPMI IP Policy or to submit a request for an exception to the PPMI IP Policy Exception Review Committee, click [here](#).

Please note that interested applicants must have an active PPMI database account to be able to submit a request for an exception to the PPMI IP Policy. If you do not have an active PPMI database account, you may apply for one by completing the online application form here: <https://ida.loni.usc.edu/collaboration/access/appLicense.jsp>.

8. If I seek to publish manuscripts using data from PPMI, I agree to follow the guidelines established and written out in the [PPMI Publications Policy](#), including sending manuscripts

to the PPMI Data and Publications Committee (DPC) for administrative review.

9. In manuscripts utilizing PPMI data, I will acknowledge the work by PPMI personnel that went into accumulating the data, as well as funding of the study, and will include language in manuscripts similar to the following:

"Data used in the preparation of this article were obtained from the Parkinson's Progression Markers Initiative (PPMI) database (<https://www.ppmi-info.org/access-data-specimens/download-data>). For up-to-date information on the study, visit [www.ppmi-info.org](http://www.ppmi-info.org)."

"PPMI – a public-private partnership – is funded by The Michael J. Fox Foundation for Parkinson's Research and funding partners, including [list the full names of all of the PPMI funding partners found at <https://www.ppmi-info.org/about-ppmi/who-we-are/study-sponsors>]."

10. To promote further scholarly productivity, I acknowledge that PPMI study leadership may request that I submit data generated from analyses of PPMI data upon completion of my analyses. I understand that PPMI study leadership may choose to incorporate raw data into the PPMI database.
11. In an effort to support and promote work utilizing PPMI data, I will endeavor to upload abstracts of publications to the PPMI website.
12. I will do my best to ensure that Investigators who utilize PPMI data use appropriate administrative, physical, and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement and will promptly report any use or disclosure of data that does not comply with the guidelines established by this Agreement.

*IMPORTANT NOTE: It is the policy of the Parkinson's Progression Markers Initiative to make data available to investigators as quickly as possible. These data are not locked and therefore may change. Furthermore, some data elements within PPMI may change with disease progression or as new methods of analysis are implemented. I am aware of the limitations of these data prior to using them for scientific purposes and that future results may change as additional data become available.*

*Finally, because "preliminary data" will be posted on the database, in the event that I download data from the PPMI data base for the purposes of analysis and future publication in the form of abstracts and/or publications, I will note the version of the data I download within the publication.*

I understand that failure to abide by these guidelines may result in termination of my privileges to access PPMI data.

The Michael J. Fox Foundation maintains the right to modify terms of this agreement, and may do so by posting notice of such modifications on this page. Any modification made is effective immediately upon posting the modification (unless otherwise stated). You should visit [this page](#) periodically to review the current use agreement terms.

[Investigators will be asked to sign this agreement electronically at <https://ida.loni.usc.edu/collaboration/access/appLicense.jsp>]