



PPMI Publications Policy

Introduction

Publication of PPMI data is a major goal of the PPMI Steering Committee (SC), the Industry Scientific Advisory Board and the study sponsor, The Michael J. Fox Foundation for Parkinson's Research. This document outlines both PPMI's policies for publication and publication credits for all publications utilizing PPMI subject data or biospecimens as well as abstracts and posters presenting analyses of PPMI data and biospecimens.

Publications Policy

The intent of this policy is to ensure that:

- PPMI data is published fully, accurately and expeditiously
- PPMI study members are recognized for their effort in study design, acquisition and analysis of data and collection of biospecimens
- PPMI publications may be tracked to develop a complete record of the findings resulting from PPMI efforts

As per the PPMI Data Use and Biospecimen Use Agreements, investigators are reminded that they should submit publications to the PPMI Data & Publication Committee (DPC) for administrative review *prior* to the publication's submission to a journal. Review of submitted publications is guaranteed within one week of submission.

It is anticipated that there will be two categories of PPMI publications as defined below:

Primary Publications: Publications authored by the PPMI Steering Committee, Investigators, Study Cores and Working Groups

Key Primary Publications are defined as those reports, analyses and publications identified by the PPMI Steering Committee as fulfilling the primary objectives of the study. Examples of these reports include publications detailing the baseline and longitudinal PPMI data, establishing and/or comparing clinical/imaging/biologic markers of Parkinson's disease progression. A list of planned Primary publications is listed in the PPMI Publications Plan.

The SC will be primarily responsible for completion of all Key Primary Publications. Key Primary publications will be authored by the Steering Committee, Investigators, Study Cores and Working Groups reflecting the contribution of those authors. "And The Parkinson's Progression Markers Initiative*" will be written on the author line of the manuscript with an asterisk referring to the list of names of individuals identified on the PPMI author list. The author list must be included as an appendix to ensure that all authors may be cited. The complete list of PPMI Study Investigators can be found at <http://www.ppmi-info.org/authorslist/>.

Primary publications are defined as reports, analyses and publications that are initiated by PPMI study members that utilize PPMI data, but which do not address the primary objectives of the study. Examples of these studies include a focus on specific biomarkers of





disease progression, study infrastructure or recruitment. It is anticipated that these publications will be developed by study investigators, cores, working groups and authorship will reflect the contribution of those authors. In addition to the authors, "And The Parkinson's Progression Markers Initiative*" will be written on the author line of the manuscript with an asterisk referring to the list of names of individuals identified on the PPMI author list. The author list must be included as an appendix to ensure that all authors may be cited. The complete list of PPMI Study Investigators can be found at www.ppmi-info.org/Authorlist.

Note that all primary publications must use the PPMI data repository at LONI as the exclusive source of study data and must collaborate with the PPMI Statistics Core. All primary publications must be sent to both the PPMI Steering Committee and the PPMI DPC for review prior to journal submission. To submit to the Steering Committee, please email Shirley Lasch (slasch@indd.org); to submit to the DPC, please upload the publication for review via the [PPMI website](#).

All Other Publications Utilizing PPMI Data

It is expected that investigators outside of the study will conduct research and seek to publish analyses using PPMI data and specimens. These individuals are encouraged to publish novel scientific findings that result from their research using PPMI. Authorship of such a publication will not include PPMI in the author line, but will acknowledge PPMI personnel and PPMI funding support by including the following within the manuscript:

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

All other publications must be sent to the PPMI DPC for administrative review prior to journal submission. To submit to the DPC, please upload the publication for review via the [PPMI website](#).

Abstracts and Posters

Abstracts and posters must be sent to the PPMI DPC for administrative review prior to submission. PPMI can only be listed as an author on an abstract and/or poster if authorship is approved by the PPMI Steering Committee. Abstracts and posters which have not been approved by the Steering Committee should acknowledge PPMI as the source of data within the body of the abstract or poster. To submit an abstract and/or poster to the DPC, please upload the document for review via the [PPMI website](#).

Data and Publications Committee (DPC) Structure





The PPMI Data and Publications Committee (DPC) was formed by the PPMI Steering Committee and established to conduct administrative review of all publications. The DPC will not review manuscripts for scientific quality, trusting that the peer-review process is the best way to judge the objective quality of a proposal or publication. Data and publications issues will be adjudicated by the DPC, however, if investigators disagree with the decisions of the DPC, they can appeal to the Steering Committee for final arbitration.

Unusual Situations

It is expected that the aforementioned policies will cover the majority of users of PPMI data and specimens. We anticipate that investigators will follow these guidelines in good faith and that most analyses will be of reasonable quality. However, we do anticipate the possibility of some unusual circumstances.

1. Egregiously Poor Manuscripts. If a review of a proposed manuscript reveals that it is egregiously poor in terms of language, writing or sensible substance, the DPC can recommend to the authors that it not be submitted without significant revision. If the authors choose to submit the manuscript anyway, the DPC will have three options: 1) request that the group authorship credit be withheld; 2) request that the authors publish a statement to the effect that while PPMI data were used, but that the PPMI study did not find this manuscript of sufficient merit to warrant submission for publication, or; 3) revocation of privileges to use PPMI data in the future.
2. Failure to Follow PPMI Data and Biospecimen Use Agreements. If users inadvertently violate the Data or Biospecimen Use Agreements, it is likely that they will self-correct as infractions are discovered. If users willfully violate these Agreements, the sole sanction available to PPMI will be to revoke access to the PPMI data.
3. Fraudulent Use of Data or Specimens. Open access using only online registration raises the possibility that individuals could obtain access to data under false pretenses. It is possible that even the closely vetted samples could be used inappropriately. Should the DPC discover an attempt to publish using PPMI data or samples obtained fraudulently, the user will be sanctioned through PPMI Steering Committee communication with them or their academic supervisors. As soon as the DPC becomes aware of any breach of either Use Agreements, immediate steps will be taken to cure the breach or end the violation. This may include discontinuing the user's data access and/or reporting the violation.
4. Journal Objections. It is possible that journal editors may object to the group authorship format with the caveat that those PPMI names credited have gathered data but not participated in the analysis and writing of the paper. In these situations the primary author of the paper should inform the DPC of the issue. The DPC will work with the author to resolve this problem in a way that is acceptable to the DPC.

