



Parkinson's
Progression
Markers
Initiative

PPMI Publications Policy

Introduction

This document outlines study policies for review, authorship credit and data citation for manuscripts, abstracts, and posters utilizing PPMI subject data or specimens.

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 specimens.
- PPMI publications may be tracked to develop a complete record of the findings resulting from PPMI efforts.
- PPMI data used in publications are cited accurately.
- Publications authored by PPMI investigators comply with PPMI's adopted [Open Access Policy](#) which stipulates publications must be accessible online and free of cost or other access barriers.

Publication Categories

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

(1) Primary Publications

Primary Publications are reports, analyses, and publications authored or directly supported by the PPMI Steering Committee (SC) that fulfill the study's primary objectives as stated in the PPMI protocol. Examples of these reports include publications detailing the baseline and longitudinal PPMI data and publications establishing and/or comparing clinical/imaging/biologic markers of Parkinson's disease (PD) progression. Sub-categories include 1) Primary data manuscripts; 2) Exploratory manuscripts; 3) Partnership manuscripts; and 4) Methods manuscripts.

All Primary Publications must use the PPMI Bioinformatics Core data repository at the Laboratory of Neuroimaging (LONI) as the exclusive study data source and must collaborate with the PPMI Statistics Core for the data analyses. All Primary Publications must be sent to both the PPMI SC and the PPMI Data Use and Publications Committee (DPC) for review prior to journal submission. To submit to the Steering Committee, email PPMI.Publications@indd.org; to submit to the DPC, please upload the publication for review via the [PPMI Website](#).

(2) Member-Initiated Publications by Investigators, Study Cores, or Working Groups

Investigators, Study Cores, and Working Groups may author publications that do not meet the criteria to be Primary Publications. These publications will typically require significantly fewer resources from both the Steering Committee and PPMI Statistics Core. Examples include sub-group analyses and analyses of ancillary biomarkers. The Executive Steering Committee (ESC) can assist in determining whether a planned analysis is primary or member-initiated as needed.

In the case of member-initiated manuscripts, Investigators, Study Cores, and Working Groups may perform their own analyses, rather than using the PPMI Statistics Core. In these cases, the authors should:

- Early in the planning process, share the aims of the analysis with the ESC in the early stage of the process and indicate that they will conduct the analysis independently.
- Prior to submission, share the analysis with the PPMI Statistics Core. At this point, the PPMI Statistics Core may provide feedback and may suggest a greater level of engagement in the analysis based on their review.
- Prior to submission, submit analytic datasets and statistical codes to the PPMI Bioinformatics Core data repository at LONI for review by the PPMI Statistics Core. The Statistics Core will verify key elements of the statistical approach and may provide feedback to the authors at this point. Authors of member-initiated manuscripts should not submit if the Statistics Core has provided feedback that there are concerns raised by their review of the statistical codes.

(3) All Other Publications Utilizing PPMI Data

Since PPMI data is free and publicly available, authors outside of the study are expected to conduct and publish analyses using PPMI data and specimens. Unlike those in categories (1) and (2), external users of PPMI data are strongly encouraged, but not required, to follow the guidance of PPMI's adopted [Open Access Policy](#). However, all manuscripts by external authors must be submitted to the PPMI DPC for administrative review prior to journal submission. The purpose of this review is to help track external publications and to identify cases of improper use of PPMI data. To submit to the DPC, please upload the publication for review via the [PPMI Website](#) by selecting "Submit a Manuscript or Abstract".

Guidelines for Manuscript Review

Authors must submit all manuscripts and abstracts to the PPMI DPC for review prior to submission to a journal or conference. The DPC will have a period of two weeks to review submitted manuscripts and abstracts and provide feedback. After that time, authors may submit manuscripts and abstracts to journals or meetings. Exceptions to this timeline may be considered for meeting abstracts. To submit to the DPC, please upload the publication for review via the [PPMI Website](#) by selecting "Submit a Manuscript or Abstract".

Please note that manuscripts using PPMI biospecimens or cell lines may have additional requirements for publications. These guidelines can be found in the [PPMI Biospecimen Use](#) and [Cell Lines Use Agreements](#), respectively.

Authors are required to provide the full citation of all published manuscripts and an electronic copy of the manuscript to the PPMI DPC upon publication of the manuscript so that it may be listed on the PPMI website.

Authorship and Acknowledgments

Authorship should be determined based on contribution to the project. For Primary and Member-Initiated Publications, the phrase, "and The Parkinson's Progression Markers Initiative*" will be written at the end of the author line with an asterisk referring to the PPMI author list, which must be cited by including the listed names found in the [PPMI Authorship List](#).

Manuscripts produced by external authors are not expected to include "and The Parkinson Progression Marker Initiative" in the author line. All publications using PPMI data, regardless of authorship, must acknowledge data source and funders within the manuscript or acknowledgements:

Data used in the preparation of this article were obtained [on Month, Day Year] from the Parkinson's Progression Markers Initiative (PPMI) database (www.ppmi-info.org/access-data-specimens/download-data), RRID:SCR 006431. 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 on the [PPMI Website](#)].”

Citing PPMI Data

While PPMI is an open access dataset, some components are subject to restrictions. As described in the [PPMI Data Access Guidelines](#), there are four tiers of PPMI data.

- Tier 1 is publicly available and refreshed daily.
- Tier 2 is publicly available, pending either a pre-defined embargo (e.g., 45 days for biospecimen results) or investigator submission of an associated cloud transfer request form (e.g., raw WGS or digital sensor data).
- Tier 3 is available to external investigators upon request, with approval of the PPMI Data Access Committee.
- Tier 4 data is restricted to the PPMI ESC and Statistics Core, and cannot be made available to external investigators. The majority of Tier 4 data is information that could reasonably identify individual participants.

To cite the PPMI dataset, authors should indicate whether restricted data was used in their analysis and the process for obtaining the restricted data. Examples of correct PPMI data attribution are given below. Bolded text emphasizes best practices for indicating access restrictions.

Use of Tier 1 data: This analysis used data **openly available from PPMI**.

Use of a mix of Tier 1 and Tier 2 data: This analysis used data openly available from PPMI and also whole exome sequencing data, **obtained from PPMI upon request**.

Use of Tier 3 Data: This analysis used DaTscan and α Syn-SAA results for prodromal participants, **obtained from PPMI upon request after approval by the PPMI Data Access Committee**.

Use of Tier 4 Data (applies only to certain papers published by the PPMI Statistics Core): This analysis was conducted by the PPMI Statistics Core and used actual dates of activity for participants, **a restricted data element not available to public users of PPMI data**.

Free Public Access to PPMI Publications

The intent of the PPMI Publications Policy is to provide for open, free, public access to analyses of PPMI data. All publications that are produced by PPMI funded investigators are required to publish in an open-access journal or in a hybrid open access journal as a fully open access article.

Open Access consists of the following principles:

- *Public access of submitted manuscripts at the time of submission.* Manuscripts prepared by PPMI-funded authors must be posted on a publicly accessible platform (eg. BioRxiv/MedRxiv) at the time of submission to a journal.
- *Immediate free access:* Peer-reviewed, author accepted research must be made freely available immediately upon publication, without any embargo period (zero embargo).
- *Unrestricted reuse rights:* Articles must be published under the Creative Commons Attribution license CC BY 4.0, The license ensures that you receive attribution for the work (intellectual ownership) but allows your work to be freely shared (redistributed in any medium or format or adapted for future purposes). You can also select the CC0 license (applied to authors employed by the government) which does not require attribution for the work when being re-used.

Consistent with PPMI partners, we follow guidelines as outlined in PPMI’s adopted [Open Access Policy](#) and require publications by PPMI investigators acting in their PPMI role and/or investigators funded by PPMI to follow the guidelines. In addition to public access to submitted and published manuscripts, all research outputs (data, protocols, code) should be deposited in publicly accessible repositories and cited in the publication. Details on how to meet these requirements are given in the [Open Access Policy](#). Any questions related to PPMI’s Open Access guidance should be directed to: PPMI.Publications@indd.org.

Abstracts and Posters

Abstracts and posters must be sent to the PPMI DPC for administrative review at the time of submission to a conference. PPMI may only be listed on the author line of an abstract and/or poster if authorship is approved by the PPMI DPC. Abstracts and posters which have not been approved by the DPC 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](#) by selecting “Submit a Manuscript or Abstract”. Authors of abstracts and posters will notify the DPC after abstracts or posters are presented so that they may be posted to the PPMI website.

Data Use and Publications Committee (DPC) Structure

The PPMI Data Use and Publications Committee (DPC) was formed by the PPMI SC and established to conduct administrative review of all publications. The DPC is comprised of a chair and additional members, drawn from PPMI leadership and site investigators/coordinators. The DPC will not review manuscripts for scientific quality, except to insure that PPMI data are represented in an accurate and appropriate fashion, 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 SC for final arbitration by sending an email detailing the reason for appeal to PPMI.Publications@indd.org.

Related or Ancillary Protocols

Protocols and studies related to PPMI, such as therapeutic trials associated with the P2P Platform Trial, may be subject to additional policies. Please consult the relevant study addenda before publication and reach out to PPMI.Publications@indd.org if you have any questions.

Unusual Situations

It is expected that these 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.

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, 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.

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, their access to PPMI data may be revoked.

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.

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.

Modifications

The Michael J. Fox Foundation and the PPMI Steering Committee 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 policy periodically to review the current use agreement terms.