



PPMI Publication Policy

The Parkinson's Progression Markers Initiative (PPMI) study encourages the wide use and publication of PPMI data to increase our knowledge and understanding of the underlying biology and progression of disease, and to accelerate therapeutic development for Parkinson's Disease and related synucleinopathies. This document outlines study policies for review, authorship credit, and data citation for publications utilizing PPMI subject data or specimens.

The intent of this policy is to ensure that:

- PPMI data is published fully, accurately, and expeditiously.
- PPMI study members are recognized for their efforts in study design, acquisition and analysis of data, and collection of specimens.
- PPMI publications can be tracked to develop a complete record of the findings resulting from PPMI.
- PPMI data is cited accurately in publications.
- Publications using PPMI data comply with PPMI's [Open Science Policy](#) (required for PPMI-Authored Publications and strongly encouraged for External Publications).

PPMI Data Use and Publications Committee (DPC)

The PPMI Data Use and Publications Committee (DPC) was formed by the PPMI Steering Committee (SC) and was established to conduct administrative compliance reviews of all publications using PPMI data. The DPC is comprised of members drawn from PPMI leadership and site investigators or coordinators.

The DPC **does not** review manuscripts for scientific quality. Their review is only to ensure PPMI data is referenced accurately and appropriately and that the study sponsor and partners have been appropriately acknowledged. PPMI believes that the peer-review process is the best way to judge the objective quality of a publication.

Data and publications issues will be adjudicated by the DPC. However, if authors or 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.

PPMI Publication Categories

The DPC identifies PPMI Publications in two categories, (A) PPMI Authored Publications and (B) Non-PPMI Authored (External) Publications, as defined below.

Category A: PPMI Authored Publications

PPMI Authored Publications are reports, analyses, and publications authored or directly supported by PPMI investigators. This includes the PPMI Executive Steering Committee (ESC), SC, site investigators, study core investigators, members of PPMI working groups, and industry partners.

PPMI Authored Publications are to use the PPMI Bioinformatics Core data repository at the Laboratory of Neuroimaging (LONI) as the exclusive study data source for PPMI data and will most often collaborate with the PPMI Statistics Core for data analyses. PPMI Authored Publications may utilize local statistical input, but generally the data analysis will also be reviewed by the PPMI Statistics Core.

PPMI Authored Publications are to include the phrase “and The Parkinson’s Progression Markers Initiative*” at the end of the author line as directed by the ESC or DPC. The asterisk included refers to the [PPMI Author List](#), which is to be included in the appendix of the manuscript.

PPMI Authored Publications are to be sent to both the SC and the DPC for review prior to journal submission. To submit to the SC, email PPMI.Publications@indd.org. To submit to the DPC, upload the publication via the [PPMI Website](#) by selecting “Submit a Manuscript or Abstract.” The Committees will have four weeks to review the materials and provide feedback.

Category B: Non-PPMI Authored (External) Publications

Non-PPMI Authored Publications (referred to in this policy as External Publications) are publications authored by investigators not involved with the PPMI Study or, in rare cases, are authored by PPMI Investigators working outside of their PPMI role for the purposes of a given publication.

As PPMI data is freely and publicly available, authors outside of the PPMI study are encouraged and expected to conduct and publish analyses using PPMI data and specimens.

External Publications are to be submitted to the DPC for administrative review prior to journal submission. The purpose of this review is to track External Publications and ensure appropriate attribution of the study and study sponsor and partners. The DPC *does not* review content.

To submit to the DPC, upload the publication via the [PPMI Website](#) by selecting “Submit a Manuscript or Abstract.” The DPC will have two weeks to review the materials and provide feedback. After this period, authors may submit their manuscript to a journal or conference.

PPMI Publication Requirements

1. All Publications, PPMI Authored and External, must acknowledge PPMI’s Data Source and Funding. To do so, include the following two statements with the bracketed information updated.

Data used in the preparation of this article was obtained on [YYY-MM-DD] 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 [insert full list of all PPMI funding partners found on the [PPMI Website](#)].

2. All Publications, PPMI Authored and External, are to notify the DPC upon publication of a submitted manuscript. To do so, email PPMI.Publication@indd.org with the subject "Upcoming Publication from PPMI Analysis" with a link to the publication for inclusion on our website.

PPMI Open Science Policy

PPMI Authored Publications are required to comply with PPMI's [Open Science Policy](#). External Publications are strongly encouraged, but not required, to follow the guidance of PPMI's [Open Science Policy](#).

Publications must adhere to the following standards to be compliant with our Open Science Policy:

- Public access to submitted manuscripts at the time of submission.
 - Manuscripts prepared by PPMI-funded authors must be posted on a publicly accessible preprint platform (e.g., BioRxiv/MedRxiv) at the time of journal submission.
- Immediate free access at the time of publication.
 - All manuscripts must be made freely available immediately upon publication, without any embargo period (zero embargo).
- Unrestricted reuse rights – all manuscripts must be published under the Creative Commons Attribution license CC BY 4.0.
 - This license ensures that authors receive attribution for the work (intellectual ownership) but allows their work to be freely shared (redistributed in any medium or format or adapted for future purposes).
- In addition to manuscripts, all research outputs (data, protocols, code) must be deposited in publicly accessible repositories and cited in the publication. Details on how to meet these requirements are given in the [Open Science Policy](#).

PPMI Open Science Policy Requirements for Manuscripts:

1. Recognition of Protocols

PPMI Authored Publications are to identify and include the appropriate protocol (e.g., the PPMI Parent Protocol) citation in the references section of their manuscript. Protocols and citation instructions can be found on the [PPMI website](#).

2. Recognition of PPMI Data Tier

PPMI Authored Publications are to acknowledge the tier of data used in their analysis and the process in which the data was obtained. This should be included after the Data Source recognition in the manuscript. Correct PPMI Data tier citations are as follows:

Tier 1 Data: This analysis used data openly available from PPMI.

Tier 2 Data: This analysis used data from PPMI made available after either a pre-defined embargo or investigator submission of an associated cloud transfer request to the PPMI Data Access Committee.

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

Tier 4 Data (applies only to previously identified publications 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.

For tier breakdown and further information, refer to the [PPMI Data Access Guidelines](#).

3. Recognitions of PPMI Biospecimens

PPMI Authored Publications performing new assays of PPMI biospecimens, and using this novel data in a publication, are to cite the corresponding biospecimen RRID number in the data acknowledgement section of the publication.

The biospecimen RRID number can be found in the sample manifest provided at time of sample shipment, if shipped after May 1, 2024. If shipped before May 1, 2024, the IU PPMI Biorepository Team can provide RRIDs upon request. Email IU at ppmibio@iu.edu to request this information.

4. Recognition of Statistical Analysis

PPMI Authored Publications are to deposit all statistical analysis in publicly accessible repositories. The location of these repositories (URL and/or DOI) are to be given in the publication. Authors are required to work with the PPMI Statistics Core to share codes and the corresponding README file on Zenodo. Each code should document the date that it was created.

A template of the README file format will be provided by the PPMI Statistics Core and will include relevant details from the manuscript's Data Availability statement (including RRID number for the PPMI database and the date of data download used in the analysis), as well as descriptions and instructions for each statistical code.

The README will also include the following disclaimer: "As the PPMI database is always evolving, it is possible that the code may not work if the database has changed since the date the code was created."

Contact PPMI.Publications@indd.org with any further questions regarding PPMI's Open Science guidance.

Abstracts and Posters

All abstracts and posters that utilize PPMI data are to be sent to the DPC for administrative compliance review. To submit an abstract or poster to the DPC, upload the materials via the [PPMI Website](#) by selecting "Submit a Manuscript or Abstract." Due to the short turnaround time required of abstracts and posters, approval/response from the DPC is not required prior to submission.

- PPMI Authored abstracts and posters are to include "and the Parkinson Progression Marker Initiative" in the author list where group authorship is possible. External abstracts and posters are NOT to include the former statement in their author list.
- PPMI Authored and External abstracts and posters are to acknowledge PPMI as the source of data within the body of the abstract or poster by referencing the PPMI website: <https://www.ppmi-info.org>.
- PPMI Authored and External abstracts and posters are to acknowledge PPMI study sponsor and partners by including; PPMI – a public-private partnership – is funded by the Michael J. Fox Foundation for Parkinson's Research, and funding partners; including [insert full list of all PPMI funding partners found on the [PPMI Website](#)].
- PPMI Authored and External abstracts and posters are to notify the DPC after they are accepted or presented so they may be included on the PPMI website. To do so, email PPMI.Publications@indd.org with details.

Additional Considerations

Related or Ancillary Protocols

Protocols and studies related to PPMI, such as the P2P Platform Trial, may be subject to additional policies. We advise consulting the relevant study addenda before publication and reach out to PPMI.Publications@indd.org with any questions.

Unusual Situations

The PPMI Publication Policy anticipates that investigators will follow these guidelines in good faith and that most analyses will be of reasonable quality. However, it does acknowledge the possibility of some unusual circumstances, detailed but not limited to the following.

- **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.** 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 corresponding author of the paper must inform the DPC of the issue. The DPC will correspond with the author to resolve this problem in a way that is acceptable to the policy.

Modifications

The Michael J. Fox Foundation and the PPMI Steering Committee maintain the right to modify the 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). We advise visiting this policy periodically to review the current use agreement terms.