



PPMI Publication Policy

Introduction

Publication of Parkinson's Progression Markers Initiative (PPMI) data is a major goal of the PPMI Steering Committee (SC), the Industry Scientific Advisory Board (ISAB), and the study sponsor, The Michael J. Fox Foundation for Parkinson's Research (MJFF). This document outlines PPMI's policies for publication and publication credits for all manuscripts, abstracts, and posters utilizing PPMI subject data or 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

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.

Guidelines for all Manuscripts

As per the PPMI Data Use and Biospecimen Use Agreements, investigators are reminded that they must submit all manuscripts and abstracts to the PPMI Data & Publications Committee (DPC) for administrative review *prior* to submission to a journal or conference. Review of submitted manuscripts and abstracts is guaranteed within two weeks of submission. To submit to the DPC, please upload the publication for review via the [PPMI website](#).

All publications using PPMI data must acknowledge PPMI personnel and funding support by including the following within the manuscript or acknowledgements:

"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]."





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.

Full citation of all published manuscripts will be provided to the PPMI DPC upon acceptance of manuscripts. A copy of the manuscript will be provided to the PPMI DPC upon publication of the manuscript so that it may be listed on the PPMI website.

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

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

Primary Publications are defined as those reports, analyses, and publications identified by the PPMI SC as fulfilling the primary objectives of the study 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. A list of planned Primary publications is listed in the PPMI Publications Plan.

The SC will be primarily responsible for completion of all Primary Publications. Primary Publications will be authored by the SC, Investigators, and Study Cores, and Working Groups reflecting the contribution of those authors. In addition, "and The Parkinson's Progression Markers Initiative*" will be written on the author line of the manuscript with an asterisk referring to the PPMI author list, which 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/>.

Note that all Primary Publications must use the PPMI Bioinformatics Core data repository at the Laboratory of Neuroimaging (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 SC and the PPMI DPC for review *prior to* journal submission. To submit to the SC, email Nichole Daegele (ndaegele@invicro.org); to submit to the DPC, please upload the publication for review via the [PPMI website](#).

2. 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 data. Authorship of such a publication will not include PPMI in the author line, either as a reference to the study as a whole or in reference to a group or committee which has not been approved by the SC.

Abstracts and Posters

Abstracts and posters must be sent to the PPMI DPC for administrative review *prior to* 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 SC. Abstracts and posters which have not been approved by the SC 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](#).

Authors of abstracts will notify the DPC after abstracts or posters are presented so that they may be posted to the MJFF website.

Data and Publications Committee (DPC) Structure

The PPMI Data and Publications Committee (DPC) was formed by the PPMI SC 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 SC 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 author 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.
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





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Play a Part in Parkinson's Research

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.

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