



## **LRRK2 Cohort Consortium Publication Policy**

Publications Utilizing LRRK2 Cohort Consortium Data and Biospecimens

### **Introduction**

Publication of LRRK2 Cohort Consortium (LCC) data is a major goal of the LCC Data Steering Committee (SC) and The Michael J. Fox Foundation for Parkinson's Research (MJFF). This document outlines both LCC's policies for publication and publication credits for all publications utilizing LCC subject data and/or biospecimens as well as abstracts and posters presenting analyses of LCC data and/or biospecimens.

### **Publications Policy**

The intent of this policy is to ensure that:

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

All manuscripts, abstracts, and posters should adhere to the following guidelines:

#### **1. All Manuscripts and Abstracts/Posters**

- a. All manuscripts and abstracts/posters using LCC data and/or biospecimens shall be made freely available to the scientific research community without charge, including, at MJFF's election, through a website maintained by MJFF, unless accepted for publication by a journal of established reputation in the scientific community not controlled by Recipient whose publication policies conflict with this Section 1, in which case such publication may be in accordance with the policies of the journal.
- b. All manuscripts and abstracts/posters using LCC data and/or biospecimens, as part of the Data Use and Biospecimen Use Agreements, will acknowledge the LCC and MJFF in the following ways:

- i. All manuscripts using LCC data will acknowledge the methods of LCC data gathering using the following language recommended by the LCC (see Data Use Agreement):

“Data used in preparation of this article were obtained from the MJFF-sponsored LRRK2 Cohort Consortium (LCC). For up-to-date information on the study, visit [www.michaeljfox.org/lcc](http://www.michaeljfox.org/lcc).”

- ii. All manuscripts and abstracts/posters using LCC biospecimens will acknowledge the LCC and MJFF using language similar to the following (see Biospecimen Use Agreement):

“Biospecimens used in the analyses presented in this article were obtained from the MJFF-sponsored LRRK2 Cohort Consortium (LCC). For up-to-date information on the study, visit [www.michaeljfox.org/lcc](http://www.michaeljfox.org/lcc).”

- iii. All manuscripts will acknowledge the support of MJFF using language similar to the following (see Data Use Agreement):

“The LRRK2 Cohort Consortium is coordinated and funded by The Michael J. Fox Foundation for Parkinson’s Research.”

- c. All manuscripts and abstracts/posters will be submitted to the Data and Publications Committee (DPC) for administrative review two weeks prior to submission to a journal of conference by emailing the manuscript or abstract/poster to [resources@michaeljfox.org](mailto:resources@michaeljfox.org) with subject “LRRK2 CC Publication”. The purpose of this review will be to make sure that all of the above administrative requirements are met. MJFF may share the manuscripts or abstract/poster with the SC. MJFF and the SC will maintain confidentiality of the manuscript or abstract/poster and will complete its review within one week of submission.
- d. Full citation of all published manuscripts and abstracts/posters will be provided to MJFF and the LCC upon acceptance to a journal or conference by emailing a copy of the manuscript or abstract/poster to [resources@michaeljfox.org](mailto:resources@michaeljfox.org).

## 2. Primary Publications

LCC Primary Publications are defined as those reports, analyses, and subsequent publications on studies identified by MJFF and the LCC as fulfilling the primary objectives of the study:

- rationale for LCC and impact on PD
- differences between idiopathic PD and LRRK2 PD
- characterization of premotor LRRK2 PD

All Primary Publications will be authored by MJFF and LCC investigators. In addition to



the requirements for all manuscripts and abstracts/posters detailed in the above Section 1, confirmed Primary Publications should adhere to the following guidelines:

**a. Primary Manuscripts**

The author line of the manuscript will report primary and secondary authors (as defined by the writing committee) and no more than two representatives from LRRK2 Cohort Consortium contributing sites. In addition, the LCC will be recognized in the following manner:

- i. The phrase “and the LRRK2 Cohort Consortium\*” will be written on the author line
- ii. The asterisk following “and the LRRK2 Cohort Consortium” on the author line should refer to the following sentence:

“The investigators within the LCC contributed to the design and implementation of the LCC and/or provided data and/or collected biospecimens, but did not necessarily participate in the analysis or writing of this report. The full list of LCC investigators can be found at [www.michaeljfox.org/lccinvestigators](http://www.michaeljfox.org/lccinvestigators).”

**b. Primary Abstracts/Posters**

All confirmed primary abstracts and posters should include the phrase “and the LRRK2 Cohort Consortium” on the author line.

**3. Secondary Publications**

Secondary publications will be written by independent investigators with access to LRRK2 data and /or biospecimens. In addition to the requirements for all manuscripts and abstracts/posters detailed in the above Section 1, Secondary Publications should adhere to the following guidelines:

**a. Secondary Manuscripts**

As secondary publications will be authored by independent third party researchers, the LCC will be recognized in the following manner:

- i. The phrase “and the LRRK2 Cohort Consortium” **may not** be written on the author line
- ii. The manuscript must contain an acknowledgement of the LCC members using the following language:

“The investigators within the LCC contributed to the design and

implementation of the LCC and/or provided data and/or collected biospecimens, but did not necessarily participate in the analysis or writing of this report. The full list of LCC investigators can be found at [www.michaeljfox.org/lccinvestigators](http://www.michaeljfox.org/lccinvestigators).”

**b. Secondary Abstracts/Posters**

All secondary abstracts and posters should not include the phrase “and the LRRK2 Cohort Consortium” on the author line.

**4. Unusual Situations**

It is expected that users of LCC data will follow these guidelines in good faith and that most analyses will be of reasonable quality. The DPC does not intend to review manuscripts for scientific quality, preferring to let the peer-review process sort out quality. It is recognized that LCC data may even be used to support publications with conflicting results. 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:
  - i. Request that the group authorship credit be withheld
  - ii. Request that the authors publish a statement to the effect that while LCC data were used, the DPC did not find this manuscript of sufficient merit to warrant submission for publication
  - iii. Revocation of privileges to use LCC data in the future
2. Failure to Follow LCC Data User Agreement. If users inadvertently violate the Data Use Agreement, it is likely that they will self-correct as infractions are discovered. If users willfully violate the Data Use Agreement, the sole sanction available to LCC will be to revoke access to the LCC data.
3. Fraudulent Use of Data. Open access using only email registration raises the possibility that individuals could obtain access to data under false pretenses. Should the DPC discover an attempt to publish data obtained fraudulently, the data user will be sanctioned through DPC communication with them or their institutional supervisors. As soon as the DPC becomes aware of any breach of the Data Use Agreement, 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 LCC names credited have gathered data, but not participated in the analysis and writing of the paper. The LCC can authorize exceptions to the authorship policy or can negotiate with journal editors as needed on a case by case basis.